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Retirement of Professor Terry Feest, the first Registry Chairman

Terry Feest was appointed first chairman of the UK Renal Registry when the Registry Subcommittee was established in 1990, by the then President of the Renal Association, Professor, Sir Netar Mallick. He initiated extensive negotiations with the Department of Health and pharmaceutical companies to secure the funding for the pilot project which commenced in 1995. In 1997 that pilot, based on Terry Feest's original concept of a fully electronic Registry with quarterly patient data returns including clinical and laboratory data, was shown to be a viable concept. The UK Renal Registry produced its first report in 1998 and has continued to report annually.

From the outset it was acknowledged that the whole of the UK may never make returns to the Registry. But through the tireless commitment of Terry, the Registry became a success both for commissioners and providers, and an indispensable element in the monitoring of renal service provision in the UK. This is reflected in the mandatory requirement in the NSF for all renal units to make Registry returns. The European Renal Association is now exploring ways to encourage other countries to follow the UK lead.

The renal community and the environment in which it operates have changed radically since the Renal Registry started. Public and professional interest has never been higher and as a result of the work of Terry and others we are now moving into a new period of dialogue and debate with the Department of Health, the Healthcare Commission, and many other parts of the NHS.

Terry Feest's achievement is remarkable. His determination and persistence have turned an idea, thought by some to be too ambitious, into a solidly financed registry with robust governance delivering audit and quality improvement opportunities to the entire renal community. On behalf of the Renal Association and the whole UK renal community, we offer Terry our gratitude and respect.

John Feehally
President

Past and present Registry staff wish to acknowledge all the help Terry Feest has provided to us, both professionally and personally. His knowledge, perception and understanding within the nephrology community has been invaluable in establishing the role of the Registry. We all wish Terry a very happy future and thank him for his tireless support.

Message from Incoming Chairman, Dr Charlie Tomson

I am deeply privileged to follow Terry Feest as incoming Chair of the Registry. His will be an extremely difficult act to follow; but he leaves the Registry with many exciting opportunities for its future. Through his determination, supported by the Registry Committee and staff, we are now on the verge of being able to report data from 100% of RRT patients in the UK. The scene is set for expanding the three major functions of the Registry: driving up the quality of care of patients receiving RRT by demonstrating and exploring variations; providing data for policy-makers on the epidemiology and management of kidney failure; and doing research on the outcomes of RRT. My first priority will be to learn from all users of the Registry data how we may better achieve these aims, and what we can do to improve the completeness, and ease of collection, of the data.

Charlie Tomson

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Chapter 1: Summary

Included in this Report is the first UK wide survey on vascular access (Chapter 6).

Only 6 renal units in the UK have not started submitting their data to the Registry. It is hoped all units will participate within 2 years.

In 2004, the total estimated acceptance rate for RRT in adults in the UK was 103 pmp. In addition, 104 children started RRT giving a total incidence of 105 pmp. The real incidence may be 107 pmp as the English rate is probably an underestimate by about 3 pmp.

In the mainland UK, for adults in 2004, the crude acceptance rates in Local Authorities varied from 29 to 232 pmp; the standardised rate ratios for acceptance varied from 0.27 to 2.30.

In the 38 UK renal units submitting data since 2000, there was a 7% rise in the acceptance numbers: there was a 3% rise in Scotland, a 6% rise in Wales and an 8% rise in England.

The median age of patients starting RRT in England has increased from 63.3 in 1998 to 64.7 in 2004 and in Wales from 62.5 in 1998 to 68.7 years in 2004. Over the same time the percentage of incident patients aged >75 years has risen from 18% to 25%.

The increase in the overall acceptance rate of incident patients with diabetic renal disease in the 2000–2004 period was from 17 to 20 pmp.

HD was the very first modality of RRT in 71.0% of patients, PD in 26.5% and pre-emptive transplant in 2.3%, which compares with 58% starting HD in 1998.

The estimated prevalence of RRT in the UK at the end of 2004 was 638 pmp. The maximal prevalence rate occurred in the age band 80–85 years (2,065 pmp) in men and in the 65–74 year age band in women (1,073 pmp).

The annual increase in prevalence in the 38 renal units participating in the Registry since 2000 was 5.9%.

17% of 18–44 year old patients are pre-emptively listed for transplantation. Within one year of starting dialysis, 45% of patients under the age of 65 years are listed for transplantation. Within two years this proportion has increased to 57% and by five years to 66%.

The differences between centres in the proportion of diabetic patients less than 65 years with established renal failure that have a renal transplant varies from 5–62% of patients: this may indicate differences in the policy of listing diabetic patients.

One and five year death censored allograft survival is no different for patients with diabetes mellitus than for patients with glomerulonephritis. However, there is an increased risk of death one year after transplantation. By five years the increased risk of death is more than double that of patients with glomerulonephritis.

Transplanted patients are less socially deprived than both new registrants to the waiting list and prevalent patients on the waiting list. Social deprivation is also lower in recipients of living donor transplants than deceased donor transplants.

There is no significant variation between centres in attained Hb when post transplant eGFR is >30, but when eGFR is <30 some renal units fail to maintain adequate Hb in many patients.

Including PD patients, 77% of prevalent patients were having dialysis therapy delivered by definitive access. For HD patients only, definitive access was used in 69%.

45% of all patients commenced RRT using definitive access. Of patients commencing on HD, only 31% commenced with definitive access. Of those known to the renal units for more than 1 year, only half started HD with definitive access.

5% of HD patients were in-patients, which suggests that over 320,000 bed days are utilised by HD patients per annum across the UK. Of these episodes, 29% were considered to be related to vascular access.

The number of Staphylococcal systemic infections was 13/100 patients per annum. The figures for MRSA alone were 4/100 patients per annum which suggests that HD patients contribute 8–10% of all UK cases of MRSA bacteraemia.

Improvements in Hb continued in 2004. At the end of 2004, 85% of HD patients and 90% of PD patients had a Hb >10 g/dl. This compares with 84% of HD and 88% of PD patients in 2003. 68% of HD patients and 75% of PD patients achieve a Hb above the European guideline minimum of 11 g/dl.

Compared to 2003, the percentage of patients treated with EPO in 2004 was unchanged for HD (91% vs. 91%) and higher for PD (80% vs. 77%). EPO doses were higher in patients on HD (mean 9,500 units/wk; median 8,000 units/wk) than in PD (mean 6,000 units/wk; median 4,000 units/wk).

There is a continuing year-on-year trend towards improvement in phosphate control in dialysis patients. The target of <1.8 mmol/L was achieved in 63% of patients overall, (69% on PD and 61% on HD).

Older dialysis patients are more likely to achieve target serum phosphate than younger ones. This effect was linear with age.

Achievement of the parathyroid hormone target of <32 pmol/L in dialysis patients was poor at 63%.

Analysis of aluminium monitoring practices in renal units suggests that compliance with the RA monitoring standard (all HD patients 3 monthly) is poor, with some centres possibly having abandoned routine monitoring of aluminium in dialysis patients or doing it annually. It is suggested that the role of aluminium monitoring in dialysis patients needs re-evaluation.

During the last 7 years there has been no significant improvement in systolic or diastolic BP.

Cholesterol levels have fallen progressively over the last 7 years with 81% of HD patients, 65% of PD patients and 57% of transplant patients achieving a serum cholesterol <5 mmol/L.

The 2003 one-year incident patient survival, adjusted to age 60, on HD and PD was 85.7% and 92.5% respectively, compared with 83.8% and 89.6% for 2002.

5-year survival of incident patients in the UK on RRT is 42.6%: 64% for those under 65 and 14.5% for older patients.

The one year after 90 day survival for all renal units falls within 3 standard deviations from the national mean: 2 units have survival more than 2 standard deviations above the mean and 2 units lower than 2 standard deviations from the mean.

There was no excess of co-morbidity amongst patients referred for RRT within 3 months compared to those referred earlier. Estimated GFR at start of RRT tended to be higher amongst those with co-morbidity compared to those with no co-morbidity.

20% of patients with diabetic nephropathy were referred <3 months before starting RRT and 46% within a year. Patients with diabetic nephropathy from socially deprived areas were referred later than those from more affluent areas.

19% of patients with diabetic nephropathy were recorded as smokers at the start of RRT.

Patients with diabetic nephropathy had lower serum cholesterol values than other patients on PD and HD.

The paediatric Registry reported that a greater proportion of the paediatric population are on dialysis than in previous years.

There remains a high incidence and prevalence of ERF in South Asian children, partly accounted for by an increased incidence of genetic diseases in this group.

22% of children have one or more paediatric specific co-morbidities at presentation with ERF; most common of these is developmental delay affecting 8.7%. Intellectual disability affects 17% of the paediatric ERF population with 7% having moderate or severe impairment.

28% of paediatric dialysis patients have been on dialysis for 2 or more consecutive years and 7% have had 5 or more consecutive years of dialysis.

Chapter 2: Introduction to the 2005 Report

The UK Renal Registry is part of the Renal Association and provides independent audit and analysis of renal care in the UK. The Registry is funded directly by participating renal units through an annual fee per patient registered.

Geographical areas covered by the UK Renal Registry

The areas covered by the UK Renal Registry and the completeness of such cover, are illustrated in Figure 2.1. All the participating centres are shown in Table 2.1.

The Scottish Renal Registry provided demographic data from the whole of Scotland. Summary data from Northern Ireland on incidence and prevalence were also obtained.

Centres in the 2005 Registry Report

All the renal units in England & Wales and also the Scottish Registry run the CCL Proton software, except:

Ipswich and Bangor (Baxter system), Aberdeen, Brighton & Newcastle (CCL clinical vision), Kings & The London (Renalware), Airdrie, Basildon, Chelmsford, Dorset, Dundee & Norwich (Mediqal eMed), Shrewsbury & Stevenage (Renalplus) and Birmingham QEH, Hammersmith & Hope Hospital (own systems).

Future coverage by the Registry

From the data presented here, it can be seen that the report on the 2004 data covers nearly 90% of the UK for some items and that by the end of 2005 some 94% of the UK will be covered by the Registry. With the recommendation in the Renal National Service Framework (NSF) that all renal units should participate in audit through the Registry, coverage is almost complete. The Health Care Commission (HCC) wishes to use the Registry as one vehicle for monitoring implementation of the NSF. Commissioners of renal services will thus be encouraged to enable the provision of adequate data systems for all renal units to join the Registry.

There have recently been 3 new renal units created:

1. Cheshire (previously a satellite of the Wirral renal unit) will be submitting data via Liverpool.
2. Aintree (previously a satellite of the Liverpool renal unit) will be submitting data via Liverpool.
3. Colchester.

Dialysis and transplant patients in Northamptonshire were previously under the Oxford renal unit and have been transferred to the Leicester renal unit.

Centres submitting 2005 data

The renal units shown in Table 2.2(a) plan to have their IT systems set up and running in time to submit 2005 data.

Progress of other centres

It is hoped to include the Middlesex/UCH and St George's in 2006 (Table 2.2(b)).

The two remaining renal units in England without renal IT systems are Manchester Royal Infirmary and the Kent and Canterbury Hospital (Table 2.2(c)).

Completeness of returns for four important data items

This year the Registry has included a table of completeness for 4 important data items that it has been trying to improve returns upon. Centres have been ranked on their average score

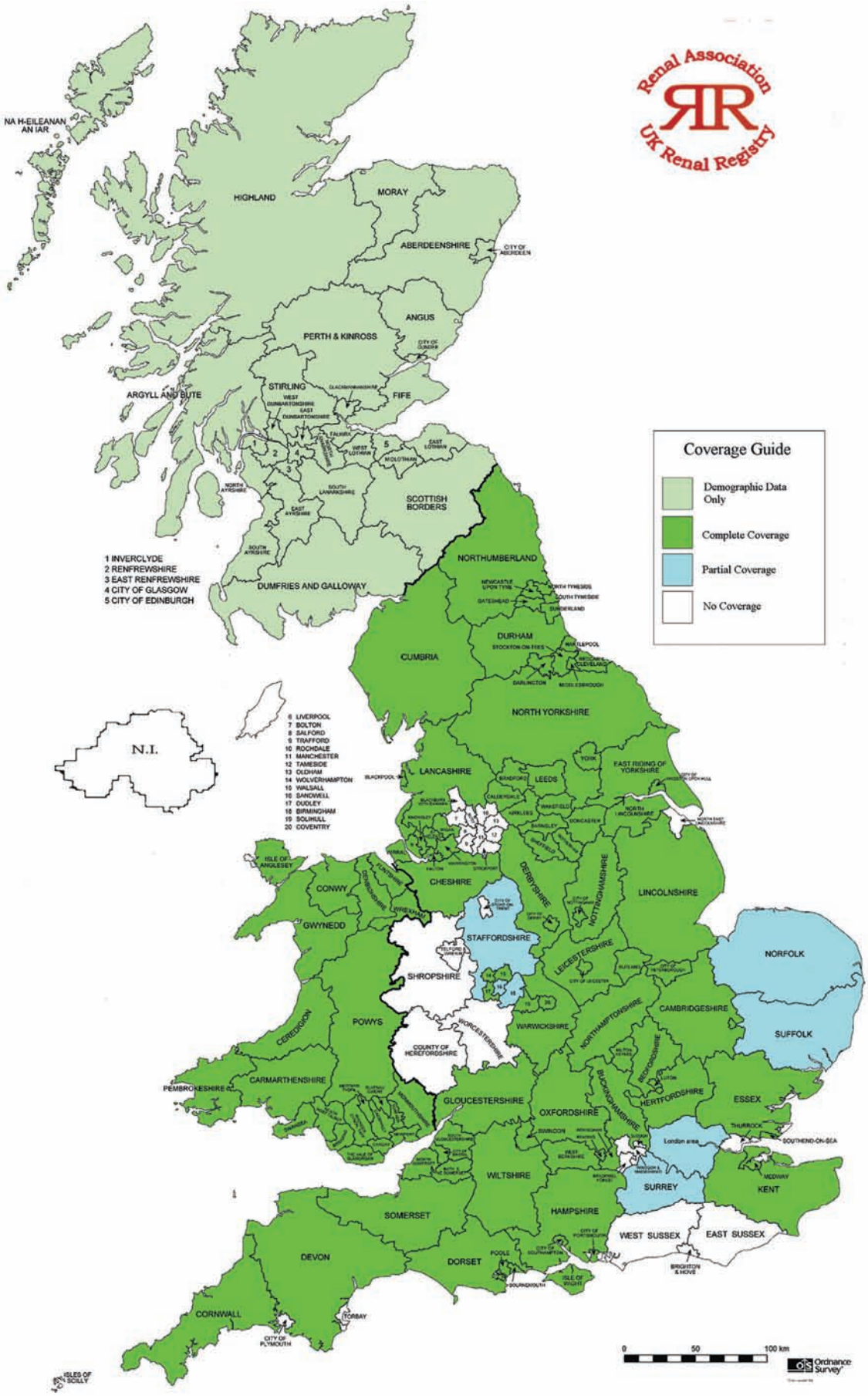

Figure 2.1: Geographical areas covered by the Renal Association UK Renal Registry

Table 2.1: Centres in the 2005 Registry Report

		Estimated population (Millions)
England & Wales		**46.55**
Bangor	Ysbyty Gwynedd	0.18
*Basildon	Basildon Hospital	0.50
Birmingham	Heartlands Hospital	0.60
*Birmingham	Queen Elizabeth Hospital	1.82
Bradford	St Luke's Hospital	0.60
*Brighton	Royal Sussex County Hospital	0.98
Bristol	Southmead Hospital	1.50
Cambridge	Addenbrookes Hospital	1.42
Cardiff	University of Wales Hospital	1.30
Carlisle	Cumberland Infirmary	0.36
Carshalton	St Helier Hospital	1.80
*Chelmsford	Broomfield Hospital	0.50
Clwyd	Ysbyty Clwyd	0.15
Coventry	Walsgrave Hospital	0.85
Derby	Derby City General Hospital	0.48
*Dorset	Dorchester Hospital	0.71
Dudley	Russells Hall Hospital (previously Wordsley)	0.42
Exeter	Royal Devon and Exeter Hospital	0.75
Gloucester	Gloucester Royal Hospital	0.55
Hull	Hull Royal Infirmary	1.04
Ipswich	Ipswich Hospital	0.33
Leeds	St James's Hospital & Leeds General Infirmary	2.20
Leicester	Leicester General Hospital	1.80
Liverpool	Royal Liverpool University Hospital	1.35
*London	Barts and The London Hospital	1.79
London	Guy's and St Thomas's Hospital	1.70
London	Hammersmith & Charing Cross Hospitals	1.30
London	Kings College Hospital	1.01
Manchester	Hope Hospital	0.94
Middlesbrough	James Cook University Hospital	1.00
Newcastle	Freeman Hospital	1.31
*Norwich	Norfolk and Norwich University Hospital	0.84
Nottingham	Nottingham City Hospital	1.16
Oxford	Oxford Radcliffe Hospital (previously reported as Churchill Hospital)	1.80
Plymouth	Derriford Hospital	0.55
Portsmouth	Queen Alexandra Hospital	2.00
Preston	Royal Preston Hospital	1.48
Reading	Royal Berkshire Hospital	0.60
Sheffield	Northern General Hospital	1.75
*Shrewsbury	Royal Shrewsbury Hospital	0.40
Southend	Southend Hospital	0.35
Stevenage	Lister Hospital	1.25
Sunderland	Sunderland Royal Hospital	0.34
Swansea	Morriston Hospital	0.70
Truro	Royal Cornwall Hospital	0.36
Wirral	Arrowe Park Hospital	0.53
Wolverhampton	New Cross Hospital	0.49
Wrexham	Wrexham Maelor Hospital	0.32
York	York District Hospital	0.39

Table 2.1: (continued)

		Estimated population (Millions)
Scotland	(via the Scottish Registry)	**5.10**
Aberdeen	Aberdeen Royal Infirmary	
Airdrie	Monklands District General Hospital	
Dumfries	Dumfries & Galloway Royal Infirmary	
Dundee	Ninewells Hospital	
Dunfermline	Queen Margaret Hospital	
Edinburgh	Royal Infirmary	
Glasgow	Glasgow Royal Infirmary & Stobhill General Hospital	
Glasgow	Western Infirmary	
Inverness	Raigmore Hospital	
Kilmarnock	Crosshouse Hospital	
Northern Ireland	Summary demographic data from all centres	**1.69**

*Renal unit included in the report for the first time.

Table 2.2: Progress in centres not included in this report

	(Indicates IT system used by hospital)	Estimated population (millions)
(a) Centres submitting data for 2005		
London	Royal Free (King's system)	0.67
Northern Ireland	Belfast + all 4 NI renal units (Mediqal system)	1.69
	Total	**2.36**
(b) Centres hoping to submit data for 2006		
London	Middlesex/UCLH – amalgamating with Royal Free in 2005 (Kings system)	0.75
London	St George's (own system)	
London	St Mary's Paddington (Proton)	0.81
Manchester	Royal Infirmary (CCL clinical vision)	2.51
Stoke	North Staffs (Cybernius system)	0.70
(c) Centre in discussion with the Registry		
Canterbury	Kent & Canterbury – buying new IT system	0.91

(Table 2.3). Ethnicity, date first seen by nephrologist and co-morbidity are not mandatory items in the Scottish Renal Registry returns so these centres have been listed separately.

Software and links to the Registry

From the above information, it is evident that there are now 11 systems in use by renal units, some of these are commercial and some in-house systems. The Registry has worked with the relevant companies to provide appropriate software links to the Registry. Ongoing development of new data items for the national spine (eg vascular access) requires a continual commitment from these companies to support and evolve their renal IT systems and also the Registry interface.

Paediatric Renal Registry links

In the UK there are 780 patients under 18 years of age who are on renal replacement therapy. As most of the 13 UK paediatric renal units are small, the British Association of Paediatric Nephrology (BAPN) was able to set up its own database to collect data on a partially manual

Table 2.3: Completeness of data returns

Centre	Ethnicity	Primary diagnosis	Date 1st seen	Co-morbidity	Average completeness	Country
H&CX	100.0	99.8	99.4	100.0	99.8	England
Basildon	98.9	98.9	99.5	93.4	97.7	England
Wolverhampton	99.6	99.8	100.0	73.5	93.2	England
Dorset	81.0	99.7	99.5	78.2	89.6	England
Nottingham	96.1	99.2	98.8	40.1	83.6	England
Sheffield	98.1	99.8	99.2	36.9	83.5	England
York	89.1	88.5	75.4	76.0	82.2	England
Norwich	44.7	100.0	85.5	97.6	82.0	England
Middlesbrough	92.0	99.3	85.6	21.4	74.6	England
Bradford	76.6	94.1	76.0	51.6	74.6	England
Newcastle	98.8	99.9	98.1	1.3	74.5	England
Stevenage	100.0	98.3	97.6	1.6	74.4	England
Leicester	97.0	97.2	52.6	50.3	74.3	England
St James, Leeds	78.4	93.1	82.1	43.3	74.2	England
Chelmsford	32.4	96.6	78.4	86.5	73.5	England
Bristol	98.5	98.0	44.0	50.8	72.8	England
Swansea	98.3	88.8	0.8	96.9	71.2	Wales
Bangor	61.5	100.0	45.2	66.4	68.3	Wales
Portsmouth	96.5	98.8	53.6	19.3	67.0	England
Derby	84.2	90.8	17.5	72.0	66.1	England
Gloucester	100.0	97.8	9.2	50.9	64.5	England
LGI	46.5	89.1	62.8	59.5	64.5	England
ManWst	93.4	100.0	0.9	54.2	62.1	England
Sunderland	93.9	99.6	11.1	35.1	59.9	England
Truro	49.0	91.7	44.1	48.6	58.3	England
Exeter	68.3	87.9	43.1	33.8	58.3	England
Liverpool	93.1	98.5	1.0	38.3	57.7	England
Barts & London	82.9	96.1	1.8	35.7	54.1	England
Carlisle	95.7	100.0	10.6	8.0	53.6	England
Hull	72.5	99.7	12.8	27.3	53.1	England
Preston	95.7	98.7	16.2	1.1	53.0	England
QEH, Birmingham	99.8	98.5	1.9	1.4	50.4	England
Heartlands	100.0	99.8	0.6	0.4	50.2	England
Dudley	100.0	99.6	0.7	0.0	50.1	England
Ipswich	5.9	100.0	31.4	60.7	49.5	England
Reading	99.2	95.3	1.6	1.3	49.4	England
Dundee	97.0	99.1	0.0	0.0	49.0	Scotland
Kings	6.2	99.2	11.1	78.6	48.8	England
Plymouth	90.2	95.3	2.9	3.7	48.0	England
Shrewsbury	90.3	99.2	0.0	0.0	47.4	England
Coventry	87.5	99.2	0.8	0.7	47.1	England
Guy's & St Thomas's	85.0	99.9	0.8	0.7	46.6	England
Southend	55.1	100.0	1.1	28.4	46.2	England
Carshalton	66.0	99.8	0.9	10.0	44.2	England
Wirral	66.5	99.5	1.0	4.9	43.0	England
Cambridge	38.4	98.8	9.7	5.7	38.1	England
Clwyd	38.3	100.0	0.0	2.5	35.2	Wales
Oxford	38.9	99.3	1.2	1.1	35.1	England
Wrexham	51.0	77.1	0.5	1.0	32.4	Wales
Cardiff	27.7	93.9	0.3	7.4	32.3	Wales
Brighton	22.3	12.0	1.5	1.3	9.3	England

Table 2.3: (continued)

Centre	Ethnicity	Primary diagnosis	Date 1st seen	Co-morbidity	Average completeness	Country
Airdrie	92.0	99.5				Scotland
Aberdeen	89.7	93.0				Scotland
Inverness	83.7	97.3				Scotland
Dunfermline	51.1	95.0				Scotland
Dumfries & Galloway	18.8	98.4				Scotland
Glasgow RI	12.1	96.1				Scotland
Edinburgh	8.5	99.9				Scotland
Stobhill	10.1	97.8				Scotland
Glasgow WI	10.3	96.0				Scotland
Kilmarnock	3.7	100.0				Scotland

basis. As in previous years, this report includes a chapter of analyses from these data (Chapter 18). In order to integrate with the adult Registry and also provide funded resources for data management, the BAPN has asked the adult Registry to develop ways of collecting the paediatric data. This process of integration of paediatric data is proceeding slowly.

Links with other organisations

The UK Renal Registry has been active in supporting the Renal Association Standards Sub-committee in the production of the Standards document. It now participates in the Renal Association Clinical Affairs Board to support activity in all clinical areas and in informing new standards.

Close collaboration has developed with UK Transplant (UKT), in conjunction with the British Transplantation Society, to produce analyses utilising the strengths of both the UKT and Renal Registry databases. New analyses include access to the transplant waiting list and patient survival on the waiting list compared to patients having received a transplant: these can be found in Chapter 5 of this report.

Support has been given to the Department of Health (DoH) in acquiring the basic data necessary for the future planning of renal services. The Registry participated in providing data to formulate the advice to ministers for the Renal NSF. It is also working with the DoH Data Standards Board developing a Renal Dataset for the national IT spine. The Registry is part of the Kidney Alliance.

Healthcare Wales funded a data validation exercise and this has highlighted some important issues (see Chapter 17). A collaboration between the Renal Association and the Registry, the British Renal Society, the British Transplantation Society, the National Kidney Federation, and others, was selected and funded by the Health Care Commission to write the scope for audit of implementation of the Renal National Service Framework and of renal care in the UK.

The UK Registry sends fully anonymised data to the European Renal Association Registry. Several representatives have participated in discussions regarding the ERA QUEST programme for European countries to initiate quality initiatives, similar to many of those that are already undertaken by the UK Renal Registry.

The Registry has links with the new Swiss Renal Registry and while this is in the process of being established, Dr Dorothea Nitsch has been seconded to work in the UK and collaborates closely with the UK Registry. Collaborative work is also being undertaken with the German and Canadian Renal Registries.

Commissioning of renal services and PCTs

In April 2002, the 95 existing Health Authorities in England were reformed as 28 Strategic Health Authorities (SHAs). Established renal failure was designated by the government as a service for specialist commissioning. In the

Renal NSF the Strategic Health Authorities have been given a clear role in monitoring the performance of the specialised commissioning consortia. The Registry is assisting specialised commissioning consortia and individual Primary Care Trusts by providing appropriate data and analyses. The Registry has reported some demographic analyses by Local Authority and also by PCT.

Only some of the boundaries of PCTs and Local Authorities in England are similar. The Office for National Statistics is in the process of re-aligning the PCT boundaries with those of Local Authorities and hopes to complete this process by 2007.

The Registry and clinical governance

There has been considerable debate within the Renal Association Trustee and Executive Committees, the Clinical Affairs Board, the Registry Board and Registry Committee, about the Registry's responsibilities under the principles of clinical governance, particularly if an individual renal unit appears to be under-performing in some areas of activity.

The Registry Report is also sent to the Chief Executive of all Trusts in which a renal unit is situated, since responsibility for clinical governance within the Trust lies formally with the Chief Executive. For the anonymised parts of the report, the Chief Executive is informed of the code of the relevant renal unit.

In the event of Registry analyses of data from a renal unit giving rise to professional concern (eg mortality, or transplantation rates, etc), these data will first be validated internally in the Registry, and then the source data checked for validity with the reporting renal unit.

If the findings/analyses are robust and concern is warranted, the Registry Director will notify the President of the Renal Association who will write to explain these matters to the Clinical Director of the relevant unit, asking that this information be passed to the Chief Executive of the trust concerned, and also to the Clinical Governance lead for that Trust. Written evidence of the internal hospital transfer of information should be received back to the Renal Association within 8 weeks. If this evidence is not forthcoming the President will then write to the Medical Director and Chief Executive of the Trust. The Renal Association can offer support (in terms of senior members providing advice) if requested by the Medical Director.

Anonymity and confidentiality

There has been pressure for the Renal Registry to cease the anonymous reporting of results and analyses and to identify the individual renal centres. The removal of anonymity aids the development of comparative audit and may assist learning from best practice, as well as allowing public accountability. In 2002, anonymity was removed from all the adult data except for the survival figures in individual renal units.

Progress has been slow in improving the co-morbidity and ethnicity returns essential to producing a meaningful comparison of patient survival between renal units correcting for case mix. Discussions are ongoing on the timescale to remove anonymity on survival data; an email survey of the stakeholders through the Renal Clinical Directors Forum has shown overwhelming support for removing anonymity even if co-morbidity returns remain poor. It is hoped this may happen for the next report.

Where anonymity has been retained in the report, neither the Chairman of the Registry nor the sub-committee members are aware of the identity of the centres within the analyses; only the Renal Registry director, data managers and statisticians are able to identify the centres. This identification is necessary so that the Registry can discuss with the relevant centres any discrepancies in the data or analyses.

The 'Health and Social Care Act 2001': section 60 exemption

The Registry has been granted temporary exemption by the Secretary of State to hold patient identifiable data under section 60 of the Health and Social Care Act. This exemption allows the registration of identifiable patient information from renal units without first

asking the consent of each individual patient, avoiding a breach of the common law on confidentiality.

This exemption is temporary and is reviewed annually. The progress towards collection of anonymised data or obtaining permission of the individual patient is monitored by the Patient Information Advisory Group (PIAG). The Registry is progressing towards anonymisation of data. There are concerns about the alternative of trying to get individual patient permission to hold patient identifiable data. Two recent medical studies of patient consent, albeit in more acute circumstances than ERF, showed considerable difficulties in establishing systems to obtain consent. Although refusals were uncommon, failure to initiate or complete the consent process was very common such that consent was obtained in only 33–50% of patients[1,2]. It was also shown that outcomes in the consented group were different from those in the non-consented group. Such problems would render many of the Registry analyses invalid.

The first annual report on progress by the Registry towards anonymisation has been submitted to the Patient Information Advisory Group and the second review is due in June 2006.

Support for renal services in Connecting for Health – the National Programme for IT

Many renal units are concerned about support for existing IT systems under the National IT Programme. In addition, there is also concern about retaining existing functionality in any new IT system. Support for the National Renal Dataset and existing renal systems has been included in the Output Based Specification (OBS) contract for renal services and the full text is provided in Appendix F. Section 167 within the contract deals with provision of IT for renal services and has been signed by all the regionally based Local Service Providers (LSPs) as a component of the National IT Programme.

As mentioned earlier, the Registry is working with the DoH Data Standards Board, Connecting for Health and BT (who provide the national spine), in the specification of the national Renal Dataset that all LSP systems will be expected to support.

Support for renal systems managers

In 2005, the Registry provided a forum for a renal informatics meeting supporting development of renal IS & IT staff. Topics included; a discussion on current informatics, health informatics professionalism (eg UKCHIP), Agenda for Change and informatics related job profiles. A detailed report on these presentations is available on the Registry web site and a further meeting is being planned for 2006.

Interpretation of the data within the report

It is important to re-emphasise that for the reasons outlined below, caution must be used in interpretation of any apparent differences between centres.

As in previous reports, the 95% confidence interval is shown for compliance with a Standard. The calculation of this confidence interval (based on the Poisson distribution) and the width of the confidence interval depends on the number of patients within the Standard and the number of patients with reported data.

To assess whether there is an overall significant difference in the percentage reaching the Standard between centres, a Chi-squared test has been used. Caution should be used when interpreting 'no overlap' of 95% confidence intervals between centres in these presentations. When comparing data between many centres, it is not necessarily correct to conclude that two centres are significantly different if their 95% confidence intervals do not overlap. In this process, the eye compares centre X with the other 47 centres and then centre Y with the other 46 centres. Thus, 93 comparisons have been made, and at the commonly accepted 1 in 20 level at least 5 are likely to appear 'statistically significant' by chance. If 48 centres were compared with each other, 1,176 such individual comparisons would be made and one would expect to find 60 apparently 'statistically

significant' differences at the $p = 0.05$ level. Thus, if the renal units with the highest and lowest achievement of a standard are selected and compared, it is probable that an apparently 'statistically significant result' will be obtained. Such comparisons of renal units selected after reviewing the data are statistically invalid. The Registry has therefore not tested for 'significant difference' between the highest achiever of a standard and the lowest achiever, as these centres were not identified in advance of looking at the data.

The most appropriate way of testing for significance between individual centres, to see where the differences lie, is not clear. The commonly used Bonferroni test is not applicable to this kind of data as the individual comparisons are not independent. In several chapters, funnel plots are used to identify significant outliers outside 2 and 3 standard deviations (see Chapters 3, 4 and 14). The Registry is investigating further methods of performing such comparisons.

In Chapters 3 and 4, charts are presented to allow PCTs and other organisations representing relatively small populations to assess whether their incidence and prevalence rates for renal failure are significantly different from the average UK performance.

Future potential

Support for Renal Specialist Registrars undertaking a non-clinical secondment

Through links with the Universities of Southampton and Bristol, some training is available in both epidemiology and statistics. The Renal Registry now has the funding for 3 registrar positions. Dr Raman Rao has worked as a Registry registrar for nearly two years and Dr Alex Hodsman and Dr Uday Udayaraj started in February 2006. Dr Az Ahmad, Dr Alison Armitage, and Dr Catherine Byrne and Dr J Rajamahesh have completed two years working as a Registry registrar. It is hoped that their positive experiences will encourage other registrars who are also interested in undertaking epidemiological work to consider working with the Registry.

Dr Fergus Caskey organised a secondment in Berlin with the German Renal Registry and undertook a detailed comparative analysis between the UK and Germany on the factors underlying the large differences in incidence of renal replacement therapy in the two countries (AJKD, March 2006).

New data collection and analysis

The survey on vascular access

The preliminary results from the Vascular Access Survey are reported in Chapter 6. The 6 month and 1 year follow up of these patients is ongoing.

This is the first report available of detailed UK data on vascular access provision and will be invaluable as a base line for monitoring implementation of the Renal NSF and in identifying the obstructions to improvements in the provision of vascular access services. It has highlighted the wide variations between renal units with some units managing to start 95% of renal replacement therapy patients with definitive access and others less than 50%. MRSA rates from HD lines were shown to account for 10% of all MRSA bacteraemia in the UK.

The Renal Association would like to thank everyone involved in the collection of these data and appreciate the effort required to supply it.

Surveys of facilities

After consultation with the Clinical Affairs Board and the Renal Clinical Directors Forum, the Registry has carried out a fourth national facilities survey. The Registry is collaborating with the British Renal Society to collect data on non-medical staffing.

Chronic kidney disease

Last year the Registry published a national survey of CKD patients under the care of nephrologists (see Report 2004); this is shortly to be published in the Quarterly Journal of Medicine. There is considerable interest in collecting further data on cohorts of renal patients with chronic renal impairment: many renal units already hold such data in their systems. The members of the Renal Association will be consulted on these and other possible future projects.

The challenge

With the presentation of these Registry data to the renal community, the challenge to UK nephrology is to find effective and creative ways of using the data to improve clinical practice. As yet, not all the necessary formal structures are in place to allow full value to be derived from the opportunities provided by the Registry data. The Renal Association has set up the Clinical Affairs Board partly to promote the use of Registry data to facilitate closing the audit loops of nephrological practice. In some cases, the Registry itself has also been able to conduct enquiries to understand the factors underlying good performance.

Other insights are also possible and quantifiable. For example, this year sees a new analysis on;

- variation in achievement of the Renal Association Standards by age band and modality (Chapter 13)
- the frequency of serum aluminium measurement and incidence of toxicity (Chapter 10)
- variability in blood pressure in patients dialysing at satellite units versus main units (Chapter 11)
- a report on a data validation exercise at 5 renal units (Chapter 17).

Recent UK Renal Registry peer reviewed publications

1. Burton C, Ansell D, Taylor H, Dunn E, Feest TG; Management of anaemia in United Kingdom renal units: a report from the UK Renal Registry. Nephrology, Dialysis, Transplantation 2000;15:1022–1028.
2. Roderick P, Davies R, Jones C, Feest T, Smith S, Farrington K; Simulation model of renal replacement therapy: predicting future demand in England. Nephrol Dial Transplant. 2004;19(3):692–701.
3. Roderick P, Nicholson T, Mehta R, Gerard K, Mullee M, Drey N, Armitage A, Feest T, Greenwood R, Lamping D, Townsend J; A clinical and cost evaluation of hemodialysis in renal satellite units in England and Wales. Am J Kidney Dis. 2004;44(1): 121–31.
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The following have been submitted for publication:

13. van Manen JG, van Dijk PCW, Stel VS, Dekker FW, Clèries M, Conte F, Feest T, Kramar R, Leivestad T, Briggs JD, Stengel B, Jager KJ; Confounding effect of comorbidity in survival studies in patients on renal replacement therapy.
14. Caskey FJ, Roderick P, Steenkamp R, Thomas K, Ansell D, Feest T; Social deprivation and survival on renal replacement therapy in England.
15. Byrne C, Roderick P, Steenkamp R, Ansell D, Roderick P, Feest TG; Ethnic factors in Renal Replacement Therapy.
16. Nitsch D, Burden R, Steenkamp R, Ansell D, Roderick P, Feest TG; Diabetes in patients with established renal failure: demographics, survival and biochemical parameters.

Commissioned research and reports

1. Feest T, Rajamahesh J, Taylor H, Roderick P; The Provision of Renal Replacement Therapy for adults in the UK 1998. 1998 National Renal Survey, Report for Department of Health.

2. Roderick P, Armitage A, Feest TG, et al.; An evaluation of the effectiveness, acceptability, accessibility and costs of renal replacement therapy in renal satellite units in England and Wales. Report for Department of Health, 2003.
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Distribution of the Registry Report

The report will also be distributed to Strategic Health Authorities and all PCTs in England and Commissioners throughout the UK.

Further copies of the report will be sent to individuals or organisations on request: a donation of £15 towards the cost of printing and postage will be requested. CDs will also available. The full report may be seen on the Registry website – *www.renalreg.com*

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Chapter 3: New Adult Patients Starting Renal Replacement Therapy in the UK in 2004

Summary

- In 2004, the total estimated acceptance rate for RRT in adults in the UK was 103 pmp. This was compiled from complete data for adults from Northern Ireland, Scotland and Wales and an extrapolation from the 83% of the English population covered. In addition, 104 children started RRT (see Chapter 18) giving a total incidence of 105 pmp.

- The English rate is probably an underestimate by about 3 pmp.

- In the mainland UK, for adults in 2004, the crude acceptance rates in Local Authorities varied from 29 to 232 pmp; the standardised rate ratios for acceptance varied from 0.27 to 2.30.

- In the 38 UK renal units submitting data since 2000, there was a 7% rise in the acceptance numbers: there was a 3% rise in Scotland, a 6% rise in Wales and an 8% rise in England. The rise had occurred by 2003 with no rise in 2004: there were wide variations between different units.

- All 14 areas with significantly low standardised acceptance rate ratios have ethnic minority populations less than 5.5%. Some, eg Hertfordshire and Wiltshire are areas with lower social deprivation but this is not a consistent finding.

- Of the 22 areas with a significantly high standardised acceptance rate, three were in Scotland where the ethnic mix was not available. Of the 19 in England and Wales, the ethnic minority population was greater than 20% in 16 and 13% in one other, leaving only two with small ethnic minorities.

- The median age of patients starting renal replacement therapy in England has increased from 63.3 in 1998 to 64.7 in 2004 and this compares with a much greater increase in Wales from 62.5 in 1998 to 68.7 years in 2004. Over the same time the percentage of incident patients aged over 75 years has risen from 18–25%.

- The proportion of incident patients with diabetic renal disease as the cause of established renal failure has remained unchanged between 1999 and 2004 (19.0% in 2000 and 2004), but with the increase in the overall acceptance rate in this period there has been an increase in the acceptance rate of patients with diabetic renal disease from 17 to 20 pmp.

- Haemodialysis was the very first modality of RRT in 71.0% of patients, peritoneal dialysis in 26.5% and pre-emptive transplant in 2.3%. This represents a significant change from 1998 when the very first treatment modality was haemodialysis in 57.7%.

- Of the 90% of the 2004 incident patient cohort alive on day 90 of treatment, 70% were on HD, 27% on PD and 3% had received a transplant. This too represents a significant change from 1998 when haemodialysis was the established mode at 90 days in 59% of dialysis patients.

Introduction

In 2004, the UK Renal Registry received complete returns from an estimated 83% of England and 100% of Wales. Data on incident patients in Scotland were obtained from the Scottish Renal Registry and summary data for Northern Ireland from the renal unit in the Royal Belfast Hospital, which coordinates renal service provision in Northern Ireland. Extrapolating from Registry data to derive information relating to the whole UK must still be viewed with caution, although estimates become more reliable as coverage increases.

The proportion of the population aged over 65 years was similar in the fully covered

Table 3.1: Number of new adult patients accepted in the UK in 2004

	England	Wales	Scotland	N. Ireland	UK
No of adult renal units	44/53	5	10	5	**73**
Patient numbers	4,094* (4,929)**	367	565	227	**6088**
Population (millions)	49.6	2.9	5.1	1.7	**59.2**
Acceptance rate pmp	99*	127	111	134	**103***
(95% CI)	(96–101)	(113–138)	(103–121)	(116–151)	**(101–105)**

*Patient number returned only from fully covered Local Authority areas.
**Calculated number for the whole of England.

population (defined below, ie based on Local Authority (LA) areas whose population was thought to be fully covered by participating renal units) compared with the general population of England and Wales. The proportion from ethnic minority groups was lower in the covered population at 8.1% compared with 9.0% in the total population, because some areas not reporting to the Registry have catchments with high ethnic minority populations. Extrapolating from Registry data will therefore tend to underestimate the acceptance rate of new patients for the whole UK, as the incidence of renal failure is high in South Asian and African–Caribbean ethnic minority populations. If renal failure is 3–4 times more common in these populations this would increase the national take on rate by about 3 per million per year above the figure quoted.

Data on children and young adults can be found in Chapter 18.

Adult patients accepted for renal replacement therapy in the UK, 2004

For 2004, individual new patient data were returned from 44 of the 53 renal units in England, all 5 units in Wales and all 10 units in Scotland. Of the patients in England 4,094 were from geographical areas completely covered by the Registry, with an estimated population of 41.2 million, representing 83% of the population. There were estimated to be just over 6,000 adult patients accepted for RRT in the whole of the UK for the year 2004. This equates to a total population acceptance rate of 103 pmp for adults and 105 pmp including children (Table 3.1) which is unchanged from 2003. The annual acceptance was 127 (CI 123–133) pmp in males and 74 (CI 71–78) pmp in females. The progressive rise in incident rate seen since 1982 seems to have slowed or stopped in the last two or three years (Figure 3.1).

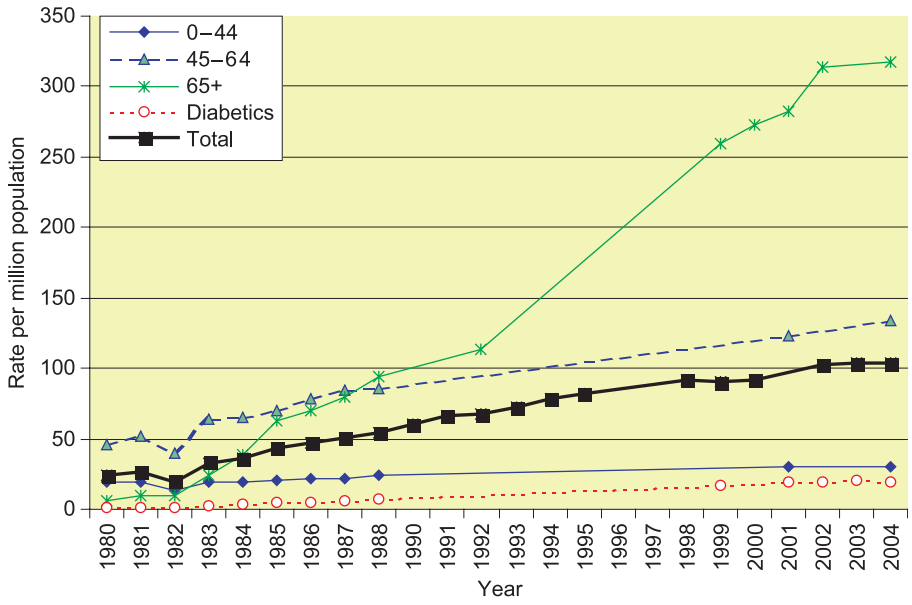


Figure 3.1: Incident rates for RRT in the UK; 1980–2004

The annual acceptance rates pmp in 2004 were 99 in England, 111 in Scotland, 127 in Wales and 134 in Northern Ireland. The trends for different age groups are shown in Figure 3.1 and for each country in Figure 3.2.

With the addition of the new paediatric patients the total incident rate was nearly 104 pmp; allowing for the under-representation of ethnic minorities in the covered areas this gives a possible total incident rate in the UK of 106–107 pmp.

The numbers accepted by individual renal units are shown in Table 3.2. Acceptance rates of individual renal units have not been calculated, as their catchment populations are not precisely defined.

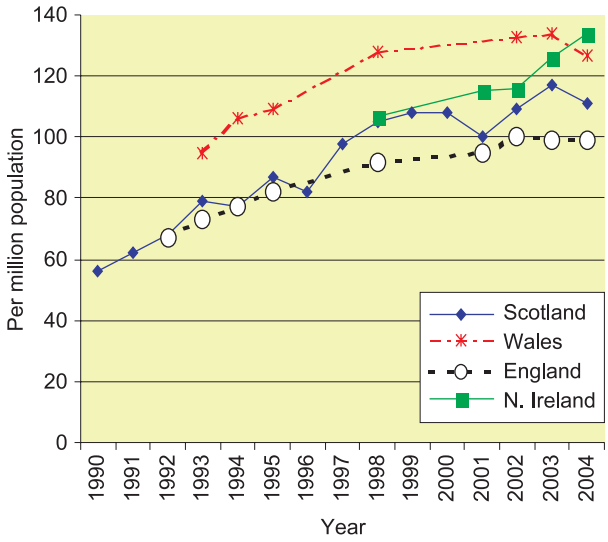


Figure 3.2: Incident rates in the countries of the UK; 1990–2004

Table 3.2: Number of new patients accepted by individual renal units reporting to the UK Renal Registry 2000–2004

Country	Centre	Year					% change since 2000
		2000	2001	2002	2003	2004	
England	Bristol	151	158	125	165	168	11.3
	Carlisle	28	28	27	31	29	3.6
	Carshalton	119	119	172	200	172	44.5
	Coventry	88	104	95	76	77	−12.5
	Derby	55	60		61	67	21.8
	Dudley	40	34	25	41	55	37.5
	Exeter	72	98	82	98	117	62.5
	Gloucester	50	50	57	57	55	10.0
	Guys	126	111	140	93	104	−17.5
	Heartlands	86	86	61	104	99	15.1
	Hull	81	74	105	80	109	34.6
	Leeds – combined	161	162	147	169	175	8.7
	Leicester	175	185	152	168	165	−5.7
	Middlesbrough	88	86	113	104	102	15.9
	Nottingham	117	123	87	116	109	−6.8
	Oxford	159	169	167	181	159	0.0
	Plymouth	59	64	79	64	61	3.4
	Preston	117	138	112	98	86	−26.5
	Reading	50	63	40	68	67	34.0
	Sheffield	137	153	156	159	169	23.4
	Stevenage	115	126	95	115	79	−31.3
	Southend	39	35	34	44	41	5.1
	Sunderland	48	38	56	56	51	6.3
	Wolverhampton	78	77	99	92	101	29.5
	York	40	37	68	57	48	20.0
	Bradford		61	62	75	62	
	Cambridge		95	74	95	103	
	Liverpool		197	156	116	131	
	Portsmouth		143	141	139	119	
	Truro		39	59	53	67	

Table 3.2: (continued)

Country	Centre	Year					% change since 2000
		2000	2001	2002	2003	2004	
England	Hammersmith&CX			176	152	196	
	Ipswich			42	35	46	
	Kings			117	108	114	
	Newcastle			106	100	101	
	Wirral			43	53	68	
	Basildon				53	43	
	Dorset				67	58	
	ManWst				141	106	
	Barts & London					187	
	Brighton					113	
	Chelmsford					52	
	Norwich					99	
	QEH, Birmingham					197	
	Shrewsbury					54	
Wales	Cardiff	142	155	182	164	181	27.5
	Swansea	92	112	113	131	95	3.3
	Wrexham	54	37	42	33	30	−44.4
	Bangor		31	29	33	36	
	Clwyd*			20	28	25*	
Scotland	Aberdeen	57	44	61	52	67	17.5
	Airdrie	57	58	60	52	51	−10.5
	Dumfries	20	23	21	21	7	−65.0
	Dundee	48	50	68	60	62	29.2
	Dunfermline	46	37	28	26	29	−37.0
	Edinburgh	101	59	81	90	99	−2.0
	Glasgow RI	56	73	58	77	79	41.1
	Glasgow WI	76	100	100	122	98	28.9
	Inverness	29	29	29	34	33	13.8
	Kilmarnock	38	27	32	40	23	−39.5
	Stobhill**	22	7	17	21	17	−22.7
England		2,279	2,913	3,270	3,684	4,381	
Wales		288	335	386	389	367	
Scotland		550	507	555	595	565	
UK		3,117	3,755	4,211	4,668	5,313	
Including only units reporting continuously 2000–2004							
England		2,279	2,378	2,294	2,497	2,465	**8.2**
Wales		288	304	337	328	306	**6.3**
Scotland		550	507	555	595	565	**2.7**
Total		3,117	3,189	3,186	3,420	3,336	**7.0**

Blank cells – no data returned to the Registry for that year.
*Clwyd might be under-reported by approximately 10 patients.
**Stobhill renal unit is part of the renal unit at Glasgow Royal Infirmary.

Geographical variation in acceptance rates in England, Scotland and Wales

Introduction

Equity of access to RRT is an important goal of service provision. The need for RRT depends on demographic factors including age, gender, social deprivation and ethnic minority status, so comparison of crude acceptance rates by geographical area alone can be misleading. This section, as in previous reports, uses age and gender standardisation and ethnic minority profile to compare RRT incident rates. The impact of social deprivation was recorded in the 2002 report. The population used for standardisation is the sum of all Local Authority areas for which the Registry had full coverage in 2004.

Methods

Standardised acceptance rate ratios were calculated as detailed in Appendix D. Briefly, age and gender specific acceptance numbers were first calculated using the available registry data on the number of incident patients for the covered areas of England, Wales and Scotland. The age and gender breakdown of the population of each Local Authority area was obtained from the 2001 Census data from the Office for National Statistics (ONS), and used to calculate the expected age and gender specific acceptance numbers for each LA area. The age and gender standardised acceptance rate ratio is the observed acceptance numbers/expected acceptance numbers. A ratio below 1 indicates that the observed rate is less than expected given the LA area's population structure. This is statistically significant at the 5% level, if the upper confidence limit is less than 1.

Results

Local Authority acceptance rates

Acceptance rates in Local Authorities with complete coverage by the Registry are shown in Table 3.3.

Acceptance rates for RRT in relatively small populations such as those covered by individual Primary Care Trusts, incur wide confidence intervals for any observed frequency. To enable assessment of whether an observed acceptance rate differs significantly from the national average, Figure 3.3 has been included.

For any population size (X-axis), the upper and lower 95% confidence intervals around the national average acceptance rate (dotted lines) can be read from the Y-axis. An observed acceptance rate outside these limits is significantly different from the national average. Thus for a population of 50,000 the observed take-on would have to be outside the limits of 10 to 180 per million population per year in order to be judged significantly different from national norms, whilst for a population of 1 million, the limits are from 80 to 120 per million population per year.

In the 2004 data there was wide variation in the standardised acceptance rate ratios, which ranged from 0.25 (in Blackpool) to 2.30 (in Merthyr Tydfil). In Table 3.3 the trends over 4 years are shown, illustrating the wide variations in small populations which are also greater in areas with habitually low take-on rates.

In general, areas with significantly high standardised acceptance rate ratios are those with a high ethnic minority population and/or a socially deprived population, as shown in previous reports (Figure 3.4). All 14 areas with significantly low standardised acceptance rate ratios have ethnic minority populations less than 5.5%. Some eg Hertfordshire and Wiltshire are areas with lower social deprivation but this is not a consistent finding.

Of the 22 areas with significantly high standardised acceptance rate ratios in 2004, 3 were in Scotland where the ethnic mix was not available. Of the 19 in England and Wales the ethnic minority population was greater than 20% in 16 and 13% in one other, leaving only 2 with small ethnic minorities.

Some analysis was also performed using combined acceptance rates over 2–4 years which confirms these findings. Of the 37 areas with significantly high standardised acceptance rate ratios, 9 were in Scotland where the ethnic mix was not available. Of the 28 in England and Wales the ethnic minority population was greater than 20% in 15, and 10–20% in 2.

Table 3.3: Crude adult annual acceptance rates and standardised rate ratios 2001–2004

Areas with significantly low acceptance ratios over 3 years are italicised in greyed areas, those with significantly high ratios are bold in greyed areas.
Ratio = observed/expected acceptance rate adjusted for age of local population.
Ethnicity = % South Asian and African–Caribbean from 2001 Census.

UK Area	Local Authority	Name	Total pop	2001		2002		2003		2004					% non White
				O/E	pmp	O/E	pmp	O/E	pmp	Total obs	O/E	L 95% CI	U 95% CI	pmp	
North East	County Durham and Tees Valley	Darlington	97,838	**0.9**	82	**1.0**	102	**1.0**	102	7	**0.68**	0.33	1.43	**72**	2.1
		Durham	493,469	**0.6**	57	**1.1**	107	**0.8**	83	46	**0.89**	0.67	1.19	**93**	1.0
		Hartlepool	88,610	**1.1**	102	**0.6**	56	**1.3**	135	10	**1.11**	0.60	2.06	**113**	1.2
		Middlesbrough	134,855	**1.2**	104	**1.1**	104	**1.2**	119	13	**1.01**	0.59	1.74	**96**	6.3
		Redcar & Cleveland	139,132	**0.9**	86	**1.8**	187	**1.0**	108	15	**1.02**	0.61	1.69	**108**	1.1
		Stockton-on-Tees	178,408	**0.9**	78	**1.1**	101	**1.0**	101	19	**1.08**	0.69	1.70	**106**	2.8
	Northumberland, Tyne & Wear	Gateshead	191,151			**1.2**	126	**0.9**	99	17	**0.83**	0.52	1.34	**89**	1.6
		Newcastle upon Tyne	259,536			**1.0**	92	**0.9**	85	28	**1.10**	0.76	1.60	**108**	6.9
		North Tyneside	191,658			**0.9**	94	**0.7**	73	19	**0.92**	0.59	1.44	**99**	1.9
		Northumberland	307,190			**0.8**	81	**0.9**	104	28	**0.82**	0.57	1.19	**91**	1.0
		South Tyneside	152,785			**0.9**	92	**0.7**	72	16	**0.98**	0.60	1.60	**105**	2.7
		Sunderland	280,807	**0.7**	68	**1.0**	96	**1.2**	121	19	**0.68**	0.43	1.06	**68**	1.9
North West	Cheshire & Merseyside	Halton	118,209	**1.8**	152	**0.8**	76	**1.3**	118	16	**1.44**	0.88	2.35	**135**	1.2
		Knowsley	150,459	**0.5**	47	**1.0**	93	**1.3**	120	13	**0.91**	0.53	1.57	**86**	1.6
		Liverpool	439,471	**1.9**	168	**1.0**	96	**0.8**	75	45	**1.07**	0.80	1.43	**102**	5.7
		Sefton	*282,958*	*0.9*	*95*	*1.0*	*106*	*0.7*	*81*	*16*	*0.52*	*0.32*	*0.84*	*57*	*1.6*
		St. Helens	*176,843*	*1.0*	*96*	*1.0*	*96*	*0.6*	*57*	*8*	*0.45*	*0.22*	*0.89*	*45*	*1.2*
		Warrington	191,080	**0.8**	73	**1.0**	94	**0.6**	63	18	**0.97**	0.61	1.53	**94**	2.1
		Wirral	312,293	**0.4**	42	**0.8**	83	**1.0**	109	40	**1.20**	0.88	1.63	**128**	1.7
	Cumbria and Lancashire	Blackburn with Darwen	137,470	**0.9**	73	**1.5**	124	**1.3**	116	14	**1.15**	0.68	1.95	**102**	22.1
		Blackpool	*142,283*	*0.9*	*91*	*1.0*	*112*	*0.3*	*35*	*5*	*0.31*	*0.13*	*0.74*	*35*	*1.6*
		Cumbria	*487,607*	*0.9*	*94*	*0.8*	*84*	*0.8*	*88*	*34*	*0.63*	*0.45*	*0.88*	*70*	*0.7*
		Lancashire	*1,134,975*	*1.0*	*91*	*0.7*	*66*	*0.6*	*63*	*69*	*0.59*	*0.46*	*0.74*	*61*	*5.3*
	Greater Manchester	Bolton	261,037					**0.9**	92	18	**0.71**	0.45	1.12	**69**	11.0
		Bury	180,607					**0.6**	55	11	**0.63**	0.35	1.13	**61**	6.1
		Oldham	217,276					**0.7**	69	13	**0.63**	0.37	1.09	**60**	13.9
		Rochdale	205,357					**1.0**	97	16	**0.83**	0.51	1.35	**78**	11.4
		Salford	*216,105*					*1.2*	*125*	*11*	*0.51*	*0.28*	*0.92*	*51*	*3.9*
		Wigan	301,415					**0.9**	86	25	**0.84**	0.57	1.24	**83**	1.3
Yorkshire and the Humber	North and East Yorkshire and Northern Lincolnshire	East Riding of Yorkshire	314,113	**0.9**	89	**0.9**	96	**1.0**	115	28	**0.79**	0.55	1.15	**89**	1.2
		Kingston upon Hull	243,588	**1.0**	86	**1.1**	99	**1.0**	99	30	**1.28**	0.90	1.84	**123**	2.3
		North East Lincolnshire	157,981	**0.3**	25	**1.2**	120	**0.7**	70	18	**1.12**	0.70	1.77	**114**	1.4
		North Lincolnshire	152,848	**0.8**	79	**1.0**	98	**0.6**	65	20	**1.23**	0.79	1.91	**131**	2.5
		North Yorkshire	569,660	**0.9**	88	**1.2**	128	**1.0**	111	65	**1.03**	0.81	1.32	**114**	1.1
		York	181,096	**0.9**	83	**1.6**	155	**1.5**	160	18	**0.96**	0.60	1.52	**99**	2.2
	South Yorkshire	Barnsley	218,063	**0.8**	73	**1.1**	110	**0.7**	73	21	**0.93**	0.61	1.43	**96**	0.9
		Doncaster	286,865	**1.0**	94	**0.9**	91	**0.9**	98	28	**0.94**	0.65	1.37	**98**	2.3
		Rotherham	248,175	**1.6**	153	**0.9**	85	**1.0**	101	30	**1.19**	0.83	1.71	**121**	3.1
		Sheffield	513,234	**1.0**	94	**1.0**	97	**1.0**	97	61	**1.18**	0.92	1.51	**119**	8.8
	West Yorkshire	**Bradford**	**467,664**	**1.5**	**128**	**1.4**	**124**	**1.5**	**141**	**61**	**1.42**	**1.10**	**1.82**	**130**	**21.7**
		Calderdale	192,405	**1.2**	114	**0.7**	62	**0.9**	94	19	**0.99**	0.63	1.55	**99**	7.0
		Kirklees	388,567	**1.0**	85	**1.2**	111	**1.2**	113	47	**1.26**	0.95	1.68	**121**	14.4
		Leeds	715,403	**1.1**	95	**0.8**	78	**1.0**	101	68	**0.98**	0.78	1.25	**95**	8.2
		Wakefield	315,172	**0.8**	76	**0.8**	79	**0.8**	82	31	**0.98**	0.69	1.39	**98**	2.3

Table 3.3: (continued)

UK Area	Local Authority	Name	Total pop	2001		2002		2003		2004					% non White
				O/E	pmp	O/E	pmp	O/E	pmp	Total obs	O/E	L 95% CI	U 95% CI	pmp	
East Midlands	Leicestershire, Northamptonshire and Rutland	Leicester	279,920	**1.3**	104	**1.6**	132	**1.7**	154	34	**1.38**	0.99	1.94	**121**	36.1
		Leicestershire	609,578	**1.2**	116	**0.8**	84	**0.8**	84	47	**0.75**	0.56	1.00	**77**	5.3
		Northamptonshire	*629,676*	*0.9*	*84*	*1.0*	*89*	*0.8*	*73*	*44*	*0.72*	*0.54*	*0.97*	*70*	*4.9*
		Rutland	34,563	**0.6**	58	**0.3**	29	**1.4**	145	1	**0.27**	0.04	1.92	**29**	1.9
	Trent	Derby	221,709					**0.9**	95	26	**1.17**	0.80	1.72	**117**	12.6
		Derbyshire	*734,585*	*0.9*	*87*	*0.4*	*44*	*0.8*	*88*	*56*	*0.72*	*0.55*	*0.93*	*76*	*1.5*
		Lincolnshire	646,644	**0.7**	73	**0.6**	70	**0.6**	70	57	**0.77**	0.60	1.00	**88**	1.3
		Nottingham	266,988	**1.7**	146	**0.7**	60	**0.9**	86	27	**1.11**	0.76	1.62	**101**	15.1
		Nottinghamshire	748,508	**1.0**	92	**0.8**	84	**1.1**	114	77	**0.98**	0.78	1.22	**103**	2.6
West Midlands	Birmingham and the Black Country	**Birmingham**	**977,085**							**151**	**1.69**	**1.44**	**1.98**	**155**	**29.6**
		Dudley	305,153	**0.6**	56	**0.6**	62	**0.8**	85	37	**1.15**	0.83	1.58	**121**	6.3
		Sandwell	**282,904**							**55**	**1.93**	**1.48**	**2.51**	**194**	**20.3**
		Solihull	199,515	**1.2**	115	**0.7**	70	**1.6**	170	26	**1.23**	0.84	1.81	**130**	5.4
		Walsall	**253,498**	**1.1**	**107**	**1.3**	**126**	**1.3**	**134**	**39**	**1.51**	**1.10**	**2.06**	**154**	**13.6**
		Wolverhampton	**236,582**	**1.3**	**127**	**1.7**	**169**	**1.8**	**182**	**40**	**1.64**	**1.21**	**2.24**	**169**	**22.2**
	Coventry, Warwickshire, Herefordshire and Worcestershire	Coventry	300,849	**1.7**	150	**1.4**	133	**1.1**	110	25	**0.86**	0.58	1.28	**83**	16.0
		Herefordshire, County of	174,871							21	**1.05**	0.68	1.61	**120**	0.9
		Warwickshire	505,858	**1.1**	105	**1.0**	101	**0.8**	81	48	**0.90**	0.68	1.20	**95**	4.4
		Worcestershire	542,105							54	**0.94**	0.72	1.23	**100**	2.5
	Shropshire and Staffordshire	Shropshire	283,173							35	**1.11**	0.80	1.55	**124**	1.2
		Telford & Wrekin	158,325							19	**1.33**	0.85	2.08	**120**	5.2
East of England	Bedfordshire and Hertfordshire	Bedfordshire	381,572	**0.9**	81	**0.9**	81	**0.9**	92	33	**0.90**	0.64	1.26	**86**	6.7
		Hertfordshire	*1,033,978*	*0.9*	*81*	*0.6*	*53*	*0.6*	*62*	*52*	*0.51*	*0.39*	*0.67*	*50*	*6.3*
		Luton	184,373	**1.4**	114	**0.9**	71	**1.7**	152	12	**0.75**	0.43	1.33	**65**	28.1
	Essex	Essex	1,310,837							134	**0.97**	0.82	1.15	**102**	2.9
		Southend-on-Sea	160,259	**1.0**	100	**1.3**	131	**1.4**	150	17	**0.99**	0.61	1.59	**106**	4.2
		Thurrock	**143,128**							**22**	**1.69**	**1.11**	**2.57**	**154**	**4.7**
	Norfolk, Suffolk and Cambridgeshire	Cambridgeshire	552,659	**1.0**	87	**0.7**	62	**0.8**	83	55	**1.01**	0.77	1.31	**100**	4.1
		Norfolk	796,728							95	**1.02**	0.84	1.25	**119**	1.5
		Peterborough	156,061	**1.0**	90	**1.2**	109	**1.2**	109	13	**0.88**	0.51	1.52	**83**	10.3
		Suffolk	668,555							64	**0.87**	0.68	1.11	**96**	2.8
London	North East London	Barking & Dagenham	163,942							18	**1.21**	0.76	1.92	**110**	14.8
		Hackney	**202,824**							**24**	**1.60**	**1.07**	**2.39**	**118**	**40.6**
		Newham	**243,889**							**35**	**2.02**	**1.45**	**2.81**	**144**	**60.6**
		Redbridge	238,634							28	**1.27**	0.88	1.84	**117**	36.5
		Tower Hamlets	196,105							20	**1.40**	0.90	2.17	**102**	48.6
	North West London	**Ealing**	**300,948**			**1.7**	**140**	**1.5**	**133**	**48**	**1.87**	**1.41**	**2.48**	**159**	**41.3**
		Hammersmith & Fulham	**165,244**			**1.8**	**139**	**2.0**	**163**	**24**	**1.80**	**1.20**	**2.68**	**145**	**22.2**
		Hillingdon	**243,006**							**32**	**1.43**	**1.01**	**2.02**	**132**	**20.9**
		Hounslow	**212,342**							**40**	**2.23**	**1.63**	**3.04**	**188**	**35.1**
	South East London	Bexley	218,307	**0.8**	73	**1.3**	124	**1.0**	96	20	**0.91**	0.59	1.42	**92**	8.6
		Bromley	295,532	**0.6**	61	**0.9**	91	**1.0**	108	30	**0.98**	0.69	1.41	**102**	8.4
		Greenwich	214,404			**1.5**	126	**1.3**	117	14	**0.75**	0.45	1.27	**65**	22.9
		Lambeth	**266,169**	**0.8**	53	**1.7**	**120**	**1.3**	**98**	**30**	**1.50**	**1.05**	**2.14**	**113**	**37.6**
		Lewisham	**248,923**	**1.0**	72	**1.9**	**145**	**1.0**	**84**	**38**	**1.90**	**1.38**	**2.61**	**153**	**34.1**
		Southwark	244,866			**1.7**	127	**1.6**	127	27	**1.40**	0.96	2.05	**110**	37.0
	South West London	Croydon	330,588	**0.7**	60	**1.5**	130	**1.3**	118	36	**1.21**	0.88	1.68	**109**	29.8

Table 3.3: (continued)

UK Area	Local Authority	Name	Total pop	2001		2002		2003		2004					% non White
				O/E	pmp	O/E	pmp	O/E	pmp	Total obs	O/E	L 95% CI	U 95% CI	pmp	
South East	Hampshire and Isle of Wight	*Hampshire*	*1,240,102*	*0.7*	*62*	*0.7*	*73*	*0.7*	*77*	*81*	*0.63*	*0.51*	*0.79*	*65*	*2.2*
		Isle of Wight	132,731	**0.6**	68	**0.7**	83	**0.6**	75	11	**0.67**	0.37	1.22	**83**	1.3
		Portsmouth	186,700	**1.2**	102	**0.7**	64	**1.0**	96	11	**0.62**	0.34	1.11	**59**	5.3
		Southampton	217,444	**0.8**	64	**0.8**	69	**0.8**	74	14	**0.69**	0.41	1.17	**64**	7.6
	Surrey and Sussex	Brighton & Hove	247,817							21	**0.86**	0.56	1.32	**85**	5.7
		East Sussex	492,326							65	**1.09**	0.86	1.39	**132**	2.3
		Surrey	*1,059,017*							*86*	*0.79*	*0.64*	*0.97*	*81*	*5.0*
		West Sussex	*753,612*							*47*	*0.55*	*0.41*	*0.73*	*62*	*3.4*
	Thames Valley	Bracknell Forest	109,616							11	**1.20**	0.66	2.17	**100**	4.9
		Buckinghamshire	479,026	**1.0**	90	**0.8**	71	**0.7**	71	35	**0.74**	0.53	1.03	**73**	7.9
		Milton Keynes	207,057	**0.9**	68	**0.9**	72	**1.4**	116	20	**1.17**	0.76	1.82	**97**	9.3
		Oxfordshire	605,489	**1.0**	92	**0.9**	83	**1.1**	111	47	**0.80**	0.60	1.07	**78**	4.9
		Reading	143,096	**1.0**	77	**0.8**	70	**1.1**	98	9	**0.73**	0.38	1.39	**63**	13.2
		Slough	**119,064**	**1.4**	**109**	**1.1**	**92**	**1.7**	**143**	**20**	**2.00**	**1.29**	**3.10**	**168**	**36.3**
		West Berkshire	144,485	**0.9**	76	**0.6**	55	**0.8**	76	17	**1.24**	0.77	2.00	**118**	2.6
		Wokingham	150,231	**1.0**	87	**0.5**	47	**1.1**	100	12	**0.88**	0.50	1.54	**80**	6.1
South West	Avon, Gloucestershire and Wiltshire	Bath & North East Somerset	169,040	**0.7**	71	**0.6**	59	**0.7**	77	23	**1.27**	0.84	1.91	**136**	2.8
		Bristol, City of	380,616	**1.7**	145	**1.0**	87	**1.4**	131	46	**1.28**	0.96	1.71	**121**	8.2
		Gloucestershire	564,559	**0.9**	85	**0.9**	89	**0.9**	97	55	**0.91**	0.70	1.19	**97**	2.8
		North Somerset	188,564	**1.1**	111	**0.9**	101	**1.3**	148	26	**1.21**	0.82	1.78	**138**	1.4
		South Gloucestershire	245,641	**1.0**	90	**1.3**	118	**1.2**	114	25	**1.04**	0.70	1.53	**102**	2.4
		Swindon	180,051	**0.7**	61	**1.0**	94	**1.0**	94	21	**1.24**	0.81	1.90	**117**	4.8
		Wiltshire	*432,972*	*0.8*	*72*	*0.5*	*46*	*0.6*	*62*	*27*	*0.60*	*0.41*	*0.87*	*62*	*1.6*
	Dorset and Somerset	Bournemouth	163,444							10	**0.54**	0.29	1.01	**61**	3.3
		Dorset	390,980							37	**0.75**	0.54	1.03	**95**	1.3
		Poole	138,288							13	**0.82**	0.48	1.41	**94**	1.8
		Somerset	498,095	**0.9**	90	**0.9**	100	**0.8**	92	48	**0.85**	0.64	1.13	**96**	1.2
	South West Peninsula	**Cornwall & Isles of Scilly**	**501,267**	**1.0**	**110**	**1.5**	**170**	**1.3**	**148**	**82**	**1.39**	**1.12**	**1.73**	**164**	**1.0**
		Devon	704,491	**0.9**	97	**0.8**	95	**0.9**	102	93	**1.11**	0.91	1.37	**132**	1.1
		Plymouth	240,722	**1.5**	141	**1.5**	141	**1.4**	137	25	**1.04**	0.70	1.54	**104**	1.6
		Torbay	129,706	**1.3**	139	**0.5**	54	**1.1**	131	22	**1.40**	0.92	2.12	**170**	1.2
Wales	Bro Taf	Cardiff	305,353	**1.0**	85	**1.7**	151	**1.6**	147	37	**1.31**	0.95	1.81	**121**	8.4
		Merthyr Tydfil	**55,979**	**1.0**	**89**	**2.0**	**197**	**1.8**	**179**	**13**	**2.28**	**1.33**	**3.93**	**232**	**1.0**
		Rhondda, Cynon, Taff	**231,947**	**1.1**	**108**	**1.5**	**151**	**1.1**	**112**	**36**	**1.52**	**1.10**	**2.11**	**155**	**1.2**
		Vale of Glamorgan	119,292	**1.0**	92	**1.2**	117	**1.0**	101	16	**1.28**	0.78	2.09	**134**	2.2
	Dyfed Powys	Carmarthenshire	172,842	**1.1**	116	**1.1**	121	**1.4**	162	23	**1.16**	0.77	1.75	**133**	0.9
		Ceredigion	74,941	**1.4**	147	**1.2**	133	**0.6**	67	10	**1.19**	0.64	2.21	**133**	1.4
		Pembrokeshire	114,131	**1.3**	131	**0.9**	96	**1.2**	140	10	**0.77**	0.41	1.42	**88**	0.9
		Powys	126,353	**0.7**	79	**0.7**	79	**0.3**	32	14	**0.94**	0.56	1.58	**111**	0.9
	Gwent	Blaenau Gwent	70,064	**1.3**	128	**1.3**	128	**0.1**	14	8	**1.09**	0.55	2.19	**114**	0.8
		Caerphilly	169,519	**1.0**	88	**1.5**	142	**1.1**	106	17	**1.01**	0.63	1.62	**100**	0.9
		Monmouthshire	84,885	**2.0**	200	**1.2**	130	**0.7**	82	12	**1.27**	0.72	2.24	**141**	1.1
		Newport	137,012	**1.3**	117	**1.1**	102	**1.4**	146	13	**0.94**	0.55	1.63	**95**	4.8
		Torfaen	90,949	**1.4**	132	**1.4**	143	**1.2**	121	8	**0.84**	0.42	1.69	**88**	0.9
	Morgannwg	Bridgend	128,645	**1.2**	117	**1.2**	124	**1.7**	179	17	**1.27**	0.79	2.04	**132**	1.4
		Neath Port Talbot	134,468	**1.3**	134	**1.4**	149	**1.6**	171	19	**1.29**	0.82	2.02	**141**	1.1
		Swansea	223,300	**2.0**	197	**1.4**	148	**1.7**	188	30	**1.24**	0.86	1.77	**134**	2.2

Table 3.3: (continued)

UK Area	Local Authority	Name	Total pop	2001		2002		2003		2004					% non White
				O/E	pmp	O/E	pmp	O/E	pmp	Total obs	O/E	L 95% CI	U 95% CI	pmp	
Wales (continued)	North Wales	Conwy	109,596			**1.2**	146	**1.0**	128	14	**1.04**	0.61	1.75	**128**	1.1
		Denbighshire	93,065	**0.3**	32	**0.6**	64	**1.0**	118	10	**0.94**	0.51	1.75	**107**	1.2
		Flintshire	148,594			**1.4**	135	**1.2**	121	19	**1.28**	0.81	2.00	**128**	0.8
		Gwynedd	116,843			**1.7**	180	**1.5**	163	16	**1.24**	0.76	2.02	**137**	1.2
		Isle of Anglesey	66,829			**1.0**	105	**1.3**	150	9	**1.19**	0.62	2.28	**135**	0.7
		Wrexham	128,476	**1.3**	125	**1.0**	101	**1.3**	132	10	**0.76**	0.41	1.42	**78**	1.1
Scotland		**Aberdeen City**	**212,125**	**0.8**	**75**	**1.2**	**108**	**1.0**	**99**	**35**	**1.69**	**1.21**	**2.35**	**165**	
		Aberdeenshire	226,871	**1.0**	93	**1.1**	106	**0.7**	71	19	**0.85**	0.54	1.33	**84**	
		Angus	108,400	**1.5**	148	**2.1**	221	**0.9**	101	16	**1.35**	0.83	2.20	**148**	
		Argyll & Bute	91,306	**1.0**	99	**0.8**	88	**1.3**	142	11	**1.08**	0.60	1.94	**120**	
		Scottish Borders	106,764	**0.4**	37	**0.9**	103	**0.7**	84	18	**1.49**	0.94	2.36	**169**	
		Clackmannanshire	48,077	**0.9**	83	**1.3**	125	**1.5**	146	5	**1.06**	0.44	2.55	**104**	
		West Dunbartonshire	93,378	**1.8**	161	**0.4**	43	**0.6**	64	12	**1.29**	0.73	2.28	**129**	
		Dumfries & Galloway	147,765	**1.5**	162	**1.3**	149	**1.3**	156	10	**0.59**	0.32	1.09	**68**	
		Dundee City	145,663	**1.4**	137	**1.3**	130	**1.9**	199	21	**1.37**	0.89	2.11	**144**	
		East Ayrshire	120,235	**1.2**	116	**0.8**	75	**1.1**	116	7	**0.57**	0.27	1.19	**58**	
		East Dunbartonshire	108,243	**0.7**	65	**0.8**	74	**1.3**	139	7	**0.63**	0.30	1.33	**65**	
		East Lothian	90,088	**0.9**	89	**1.0**	100	**0.3**	33	7	**0.73**	0.35	1.54	**78**	
		East Renfrewshire	89,311	**0.6**	56	**0.5**	45	**1.1**	112	7	**0.78**	0.37	1.64	**78**	
		Edinburgh, City of	448,624	**0.8**	76	**0.8**	76	**1.0**	103	47	**1.08**	0.81	1.44	**105**	
		Falkirk	145,191	**1.0**	90	**0.6**	55	**0.7**	69	11	**0.75**	0.42	1.36	**76**	
		Fife	349,429	**1.2**	114	**1.1**	106	**0.9**	92	38	**1.06**	0.77	1.46	**109**	
		Glasgow City	**577,869**	**1.2**	**107**	**1.3**	**119**	**1.7**	**166**	**78**	**1.40**	**1.12**	**1.75**	**135**	
		Highland	208,914	**1.4**	134	**1.3**	134	**1.4**	153	27	**1.21**	0.83	1.77	**129**	
		Inverclyde	84,203	**1.6**	154	**2.2**	214	**1.1**	119	9	**1.04**	0.54	1.99	**107**	
		Midlothian	**80,941**	**0.9**	**86**	**1.0**	**99**	**1.8**	**185**	**15**	**1.85**	**1.12**	**3.08**	**185**	
		Moray	86,940	**0.7**	69	**0.9**	92	**1.3**	138	10	**1.11**	0.60	2.07	**115**	
		North Ayrshire	135,817	**0.5**	44	**1.4**	140	**1.1**	118	16	**1.15**	0.70	1.87	**118**	
		North Lanarkshire	321,067	**1.4**	118	**1.2**	112	**1.3**	125	30	**0.99**	0.69	1.41	**93**	
		Orkney Islands	19,245	**1.0**	104	**1.5**	156	**1.9**	208	1	**0.48**	0.07	3.42	**52**	
		Perth & Kinross	134,949	**0.8**	82	**1.3**	141	**1.1**	126	19	**1.26**	0.81	1.98	**141**	
		Renfrewshire	172,867	**1.1**	98	**1.8**	174	**1.1**	116	19	**1.09**	0.70	1.72	**110**	
		Shetland Islands	21,988	**0.0**	0	**0.0**	0	**0.5**	45	3	**1.42**	0.46	4.39	**136**	
		South Ayrshire	112,097	**0.9**	89	**0.7**	71	**1.2**	134	6	**0.47**	0.21	1.05	**54**	
		South Lanarkshire	302,216	**1.4**	126	**1.2**	116	**0.9**	93	31	**1.03**	0.72	1.46	**103**	
		Stirling	86,212	**0.8**	70	**0.7**	70	**0.7**	70	6	**0.69**	0.31	1.54	**70**	
		West Lothian	158,714	**0.5**	44	**1.0**	82	**0.6**	50	10	**0.72**	0.39	1.33	**63**	
		Eilean Siar	26,502	**0.4**	38	**0.7**	75	**1.0**	113	5	**1.64**	0.68	3.93	**189**	

Social deprivation did not appear to be a consistent factor in the remaining 11 with ethnic minority populations less than 10%. It is noticeable that 6 of these were in Wales and 3 in the South West. These regional differences require investigation. These standardised rates are all relative to an overall acceptance rate that may not meet population need for RRT.

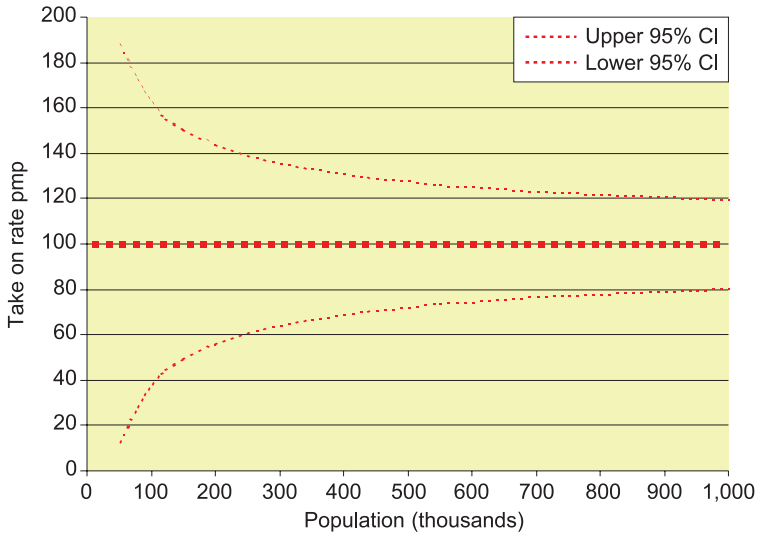


Figure 3.3: 95% confidence limits for take on rate of 100 pmp for population size 50,000–1 million

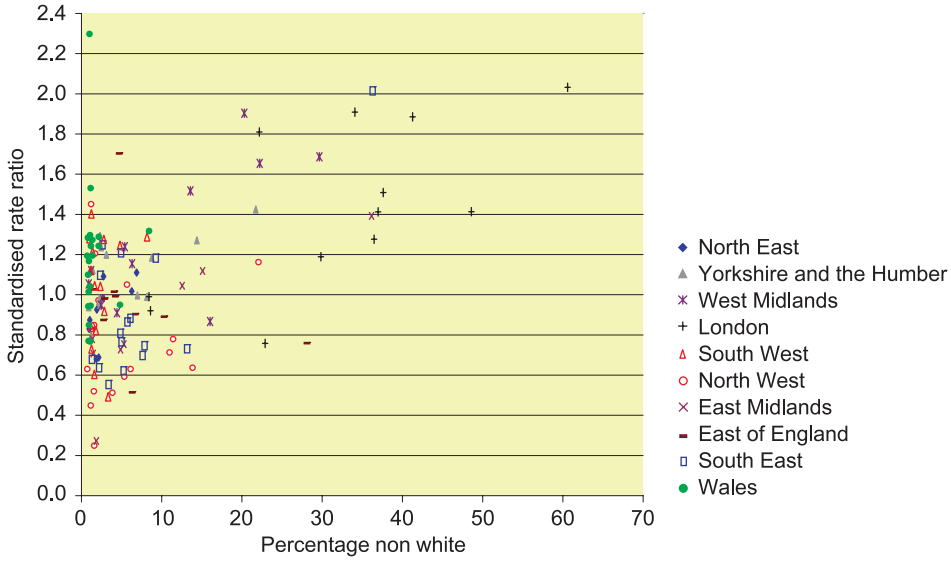


Figure 3.4: Relationship between ethnic mix and acceptance ratio

Local changes in acceptance rate

Changes in acceptance by renal units

The number of patients accepted by each renal unit is shown in Table 3.2. There is variation in time trends between renal units, which may reflect chance fluctuation, completeness of reporting, rising incidence of ERF, changes in referral patterns or catchment populations and areas, and the introduction of conservative care teams.

In the 38 UK renal units submitting data since 2000, there has been a 9.8% rise in the acceptance numbers: there was little change in Scotland, a 19.5% rise in Wales and an 11.3% rise in England. The rise had occurred by 2003 with no change in 2004. There are wide variations between different renal units ranging from an increase of 63% since 2000 (Exeter) to a decrease of 48% (Wrexham).

Ethnicity

Only 23 renal units (41%) provide over 90% complete ethnicity data (Table 3.4). In contrast, 20 (36%) provide less than 50%. This degree of incompleteness makes analysis of ethnicity data unreliable. The proportion of patients from ethnic minority populations in the returned

Table 3.4: Percentage of patients in different ethnic groups by centre

	Centre	Total pts	Completion %	Percentage in each ethnic group				
				White	Black	Asian	Chinese	Other
England	Dudley	55	100	93	4	4		
	Gloucester	55	100	100				
	H&CX	196	100	52	10	19		20
	Heartlands	99	100	74	6	18		1
	Nottingham	109	100	96	3			1
	Stevenage	79	100	86	1	13		
	Wolverhampton	101	100	85	3	11	1	
	QEH	197	99	76	7	14	1	2
	York	48	98	100				
	Basildon	43	98	95		2	2	
	Reading	67	97	82		15		3
	Leicester	165	97	84	1	14		1
	Middlesbrough	102	96	99			1	
	Bristol	168	96	92	4	3		1
	Preston	86	95	80		19		1
	Newcastle	101	94	98		2		
	Carlisle	29	93	100				
	Bradford	62	92	58	5	37		
	ManWst	106	91	79	1	18		2
	Portsmouth	119	90	98	1	1		
	Sheffield	169	87	90	3	5		2
	Sunderland	51	86	100				
	Oxford	159	85	87	4	5	1	2
	Dorset	58	84	96		4		
	Wirral	68	84	100				
	Liverpool	131	83	97			1	2
	Barts	187	80	45	15	23	2	15
	Coventry	77	73	84		11	5	
	Plymouth	61	61	97			3	
	Shrewsbury	54	57	97		3		
	Derby	67	54	100				
	Guys	104	52	70	22	6	2	
	Truro	67	47					
	Leeds	175	42					
	Norwich	99	40					
	Chelmsford	52	25					
	Exeter	117	18					
	Brighton	113	16					
	Hull	109	16					
	Southend	41	15					
	Carshalton	172	7					
	Cambridge	103	2					
	Kings	114	2					
	Ipswich	46	0					
Wales	Swansea	95	97	100				
	Bangor	36	22					
	Clwyd	25	4					
	Wrexham	30	7					
	Cardiff	181	2					

Table 3.4: (continued)

	Centre	Total pts	Completion %	Percentage in each ethnic group				
				White	Black	Asian	Chinese	Other
Scotland	Aberdeen	67	99					
	Airdrie	51	98					
	Dumfries	7	0					
	Dundee	62	97					
	Dunfermline	29	7					
	Edinburgh	99	1					
	Glasgow RI	79	6					
	Glasgow WI	98	1					
	Inverness	33	42					
	Kilmarnock	23	0					
	Stobhill	17	0					
England		4,381	**70**	**84**	**4**	**9**	**1**	**3**
Wales		367	**30**					
Scotland		565	**36**					
UK		5,313	**64**					

Details of centres with less than 50% returns are not shown.
Data on ethnicity is not mandatory in the Scottish Registry.

registry data now appears similar to that found in the National Renal Review 2002 (see Registry Report 2003).

Within the renal units with over 90% returns there is significant variation in the percentages of new patients from the ethnic minorities ranging from 0% (Carlisle, Gloucester and York) to 49% (Hammersmith & Charing Cross). The units with the highest proportion of new patients from the ethnic minorities known to have high rates of ERF (South Asian and African–Caribbean) were Bradford (42%) and Hammersmith and Charing Cross (29%).

Age

The median ages of patients starting renal replacement therapy are 64.7 England, 65.1 Scotland, 68.7 Wales and 65.1 UK. Since 1998 the median age of a patient starting RRT has increased by 1.5 years in England, compared to the largest increase being seen in Wales of 6.2 years (Table 3.5). In Scotland, results and trends are similar although more volatile in a smaller population. Over the same time the percentage of incident patients aged over 75 has risen from approximately 18% to 23% in England and from 20% to 29% in Wales. The

Table 3.5: Median age of patients starting renal replacement therapy 1998–2004

	Median age			% over 75		
Year	England	Wales	Scotland	England	Wales	Scotland
1998	63.3	62.5	63.9	17.5	19.7	15.7
1999	63.2	64.5	65.7	17.8	20.7	21.8
2000	63.8	66.2	64.4	20.9	25.3	17.4
2001	64.5	65.1	66.4	21.3	23.0	25.6
2002	65.3	66.8	65.2	23.3	26.8	24.6
2003	64.6	66.4	66.4	21.9	26.5	24.5
2004	64.7	68.7	65.1	23.4	29.4	25.5

Median age for N. Ireland for 2004 was 71 years

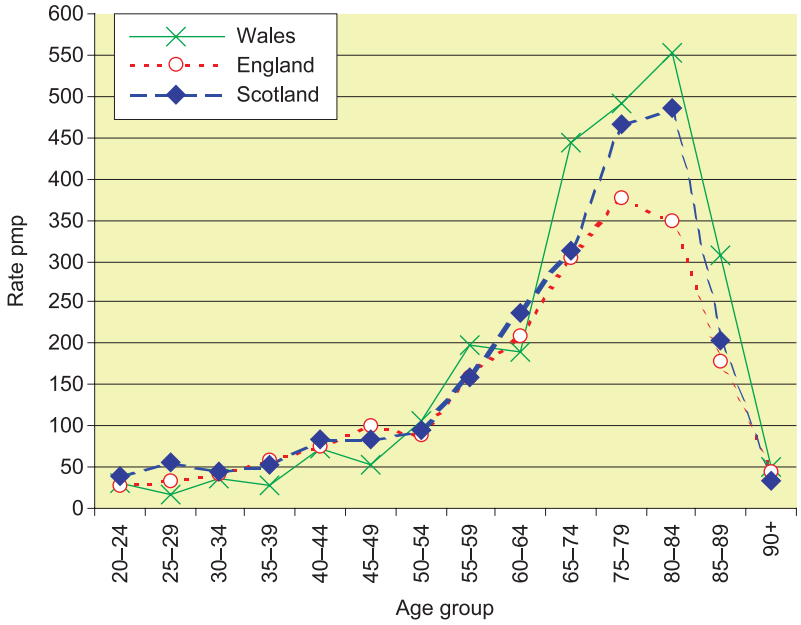


Figure 3.5: Age distribution of incident patients in 3 countries

median age of incident non-white patients in 2004 was considerably lower at 57.5.

The age distribution of incident patients in the three countries is shown in Figure 3.5. There is a large variation by centre in median age of new patients (Figure 3.6).

A few renal units have a median age under age 60; in contrast some have a median age well over 70. There are many possible reasons for these differences relating to local population demographics and the proportion of ethnic minorities in the catchment area. There may be differences in the prevalence, nature and management of renal disease and in approaches to conservative management.

Gender

As in previous years there was an excess of males starting RRT (Table 3.6). This excess is a feature of all age groups (Figure 3.7) and of all reporting centres except Stobhill and Chelmsford in the 2004 cohort (Figure 3.8).

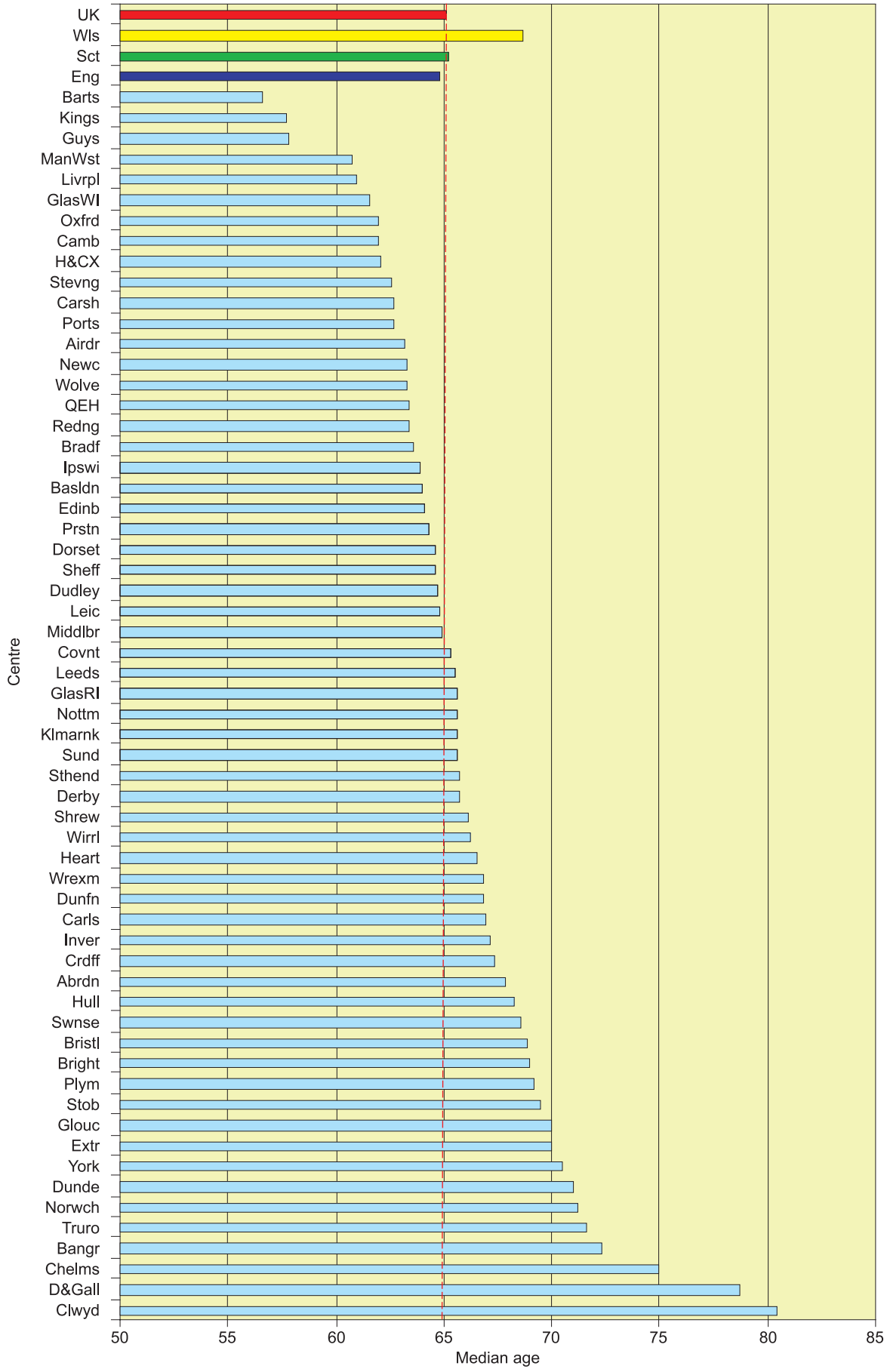


Figure 3.6: Median age of new patients in each centre

Table 3.6: Percentage starting RRT who are male, 1998–2004

	1998	1999	2000	2001	2002	2003	2004
England	63.7	62.2	59.5	63.0	61.1	61.5	62.2
Wales	53.3	63.3	59.6	63.2	63.1	64.1	62.0
Scotland	59.1	59.9	56.5	56.9	56.9	55.0	55.6
UK	62.0	61.8	59.0	62.2	60.7	60.9	61.4

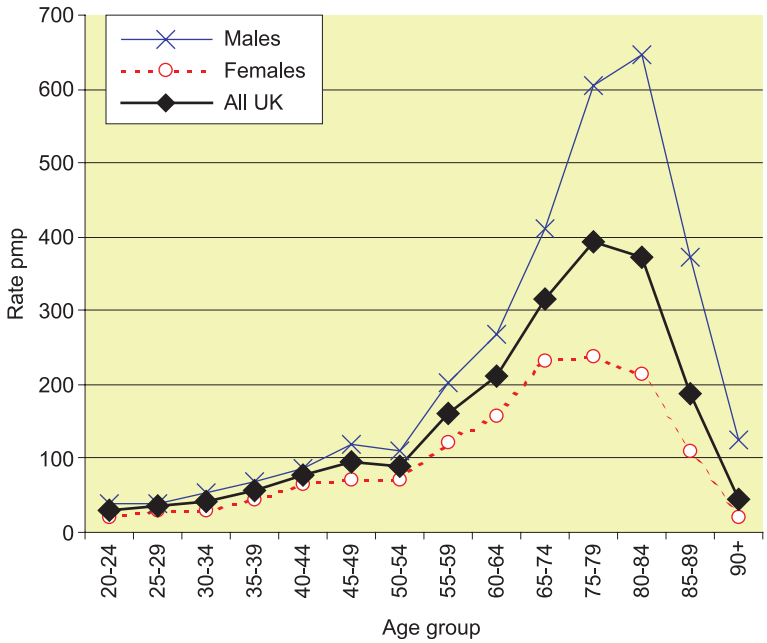


Figure 3.7: Incident rates by age and gender

Primary renal diagnosis

The distribution of new patients by age, gender and cause of ERF is shown in Tables 3.7 and 3.8. The male to female ratio is over one, as expected for most types of kidney disease. The exception is Adult Polycystic Disease (APKD) for which the ratio is, as expected, exactly 1, though this was not a feature in the previous three annual cohorts in which the ratio was 1.3 to 1.4. The gender imbalance in other disease settings such as in patients with diabetic nephropathy may relate to the presence of factors, such as hypertension and reno-vascular disease, which are more common in males and which may influence the rate of progression of renal failure. As in previous cohorts the diagnoses of aetiology uncertain/glomerulonephritis unproven and reno-vascular disease are more common in patients over the age of 65. The proportion of null returns for primary renal diagnosis is also higher in this group.

For those centres with a high percentage of missing primary diagnoses, the percentage in the other diagnostic categories has not been calculated. The percentage by each category has been calculated after excluding those patients with a missing diagnosis.

The aetiology uncertain/glomerulonephritis not proven group remains the most common group overall and there is wide variation between centres in respect of the renal units to suggest that the diagnosis is being used as a surrogate for a null return.

Some centre variation with respect to this diagnosis is likely to reflect the lack of clear definition of certain diagnostic categories eg hypertensive disease and reno-vascular disease. In addition some variation seems to result from differences between centres in the degree of certainty required to record diagnoses such as glomerulonephritis and reno-vascular disease.

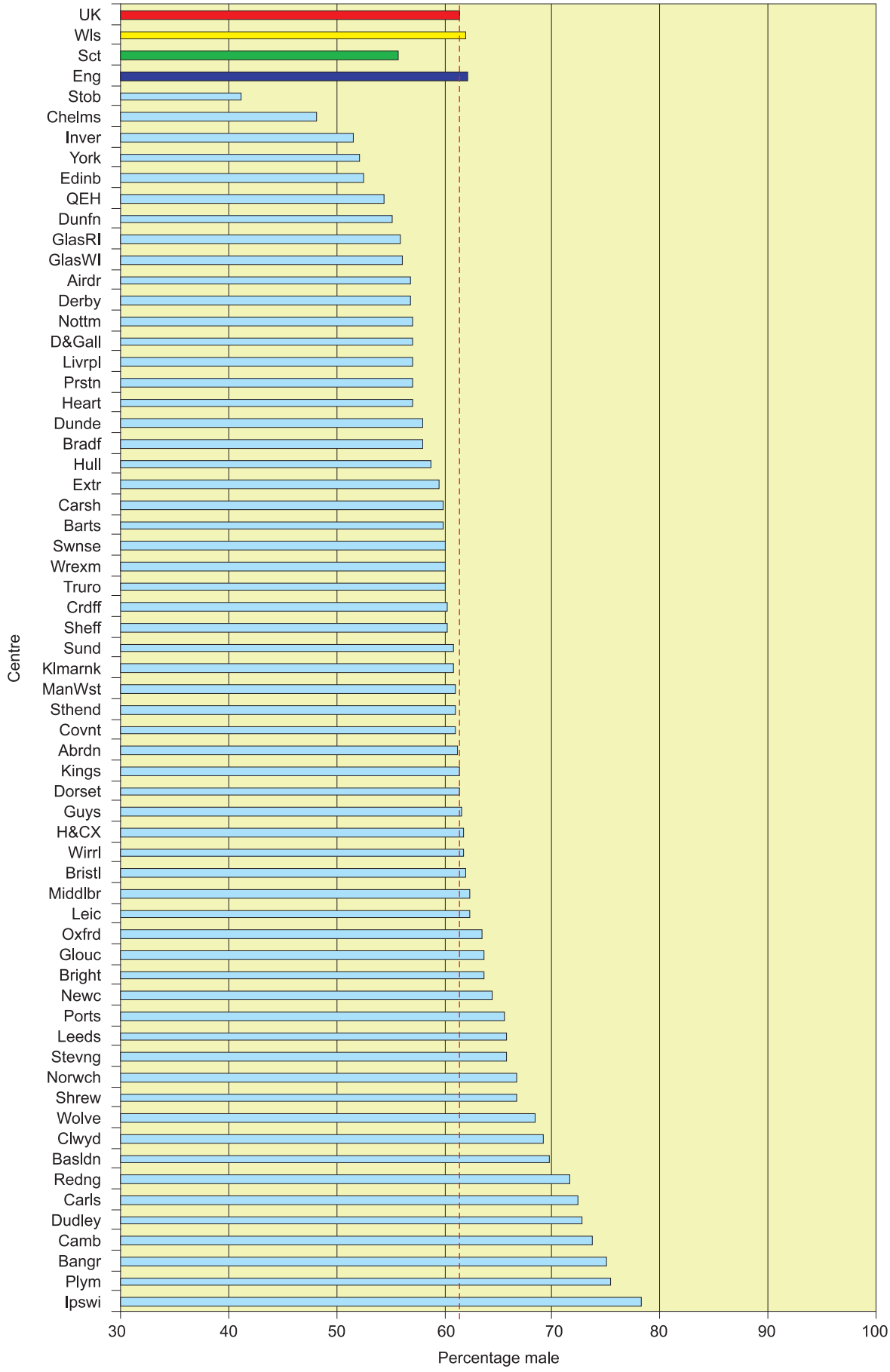


Figure 3.8: Percentage of new patients who are male in renal units reporting to UK Registry in 2004

Table 3.7: Percentage distribution of primary renal diagnosis by age and gender ratio in 2004 incident cohort

Diagnosis	UK <65	UK >65	UK All	M:F
Aetiology unc./GN NP*	18.5	27.6	23.0	1.6
Glomerulonephritis	13.3	7.7	10.4	2.4
Pyelonephritis	7.5	6.4	7.0	1.2
Diabetes	21.4	14.7	18.0	1.7
Reno-vascular disease	2.7	12.2	7.5	2.0
Hypertension	5.7	5.3	5.5	2.1
Polycystic kidney disease	8.0	2.8	5.4	1.0
Other	15.3	12.5	13.9	1.3
Not sent	7.7	10.7	9.2	1.5
No of patients	2,603	2,653	5,256	

*GN NP, glomerulonephritis not proven

Table 3.8: Percentage distribution of primary renal diagnosis by centre in 2004 incident cohort

Country	Treatment centre	*Not sent*	Aetiology unc./GN Not Proven	Diabetes	Glomerulo-nephritis	Hyper-tension	Other	Polycystic kidney	Pyelo-nephritis	Reno-vascular disease
England	Barts	***5.3***	16.4	28.8	11.3	10.7	14.7	6.8	6.8	4.5
	Basildon	***0.0***	14.0	23.3	14.0	2.3	23.3	4.7	4.7	14.0
	Bradford	***8.1***	22.8	24.6	12.3	12.3	8.8	7.0	1.8	10.5
	Brighton	***97.3***							33.3	0.0
	Bristol	***12.0***	20.5	24.7	13.0	1.4	19.9	6.2	8.9	5.5
	Cambridge	***2.9***	32.0	12.0	13.0	7.0	20.0	5.0	4.0	7.0
	Carlisle	***0.0***	0.0	13.8	13.8	13.8	24.1	6.9	10.3	17.2
	Carshalton	***0.6***	15.7	25.9	13.3	7.8	17.5	4.8	4.8	10.2
	Chelmsford	***7.7***	39.6	18.8	2.1	12.5	4.2	2.1	10.4	10.4
	Coventry	***1.3***	19.7	11.8	11.8	1.3	17.1	9.2	14.5	14.5
	Derby	***26.2***								
	Dorset	***0.0***	31.6	24.6	5.3	1.8	15.8	7.0	7.0	7.0
	Dudley	***0.0***	27.3	23.6	12.7	5.5	7.3	5.5	10.9	7.3
	Exeter	***37.1***								
	Gloucester	***0.0***	30.9	25.5	5.5	1.8	16.4	5.5	5.5	9.1
	Guys	***0.0***	7.7	20.2	15.4	12.5	22.1	6.7	2.9	12.5
	H&CX	***0.5***	12.3	31.3	6.2	15.4	20.0	5.1	7.7	2.1
	Heartlands	***0.0***	25.5	28.6	3.1	2.0	14.3	7.1	6.1	13.3
	Hull	***6.4***	28.4	19.6	9.8	3.9	15.7	5.9	11.8	4.9
	Ipswich	***0.0***	47.8	13.0	4.3	4.3	4.3	15.2	8.7	2.2
	Kings	***0.0***	16.7	30.7	10.5	12.3	16.7	0.9	5.3	7.0
	Leeds	***30.3***								5.7
	Leicester	***4.2***	30.4	17.7	9.5	1.9	15.2	7.6	8.9	8.9
	Liverpool	***4.0***	68.6	5.0	3.3	9.1	8.3	2.5	3.3	0.0
	ManWst	***0.0***	76.2	8.6	3.8	1.0	2.9	3.8	3.8	0.0
	Middlesbrough	***1.0***	35.0	14.0	12.0	13.0	12.0	4.0	3.0	7.0
	Newcastle	***1.0***	23.0	9.0	16.0	6.0	19.0	8.0	8.0	11.0
	Norwich	***1.0***	31.6	17.3	13.3	4.1	9.2	7.1	12.2	5.1
	Nottingham	***0.9***	21.7	17.9	7.5	4.7	25.5	9.4	6.6	6.6
	Oxford	***2.5***	23.9	24.5	11.6	2.6	18.1	5.2	9.7	4.5

Table 3.8: (continued)

Country	Treatment centre	*Not sent*	Aetiology unc./GN Not Proven	Diabetes	Glomerulo-nephritis	Hyper-tension	Other	Polycystic kidney	Pyelo-nephritis	Renal vascular disease
England	Plymouth	***31.1***								
	Portsmouth	***7.6***	17.3	13.6	14.5	7.3	19.1	12.7	6.4	9.1
	Preston	***3.6***	12.3	21.0	17.3	7.4	21.0	9.9	6.2	4.9
	QEH	***4.6***	17.2	25.3	7.5	1.6	19.4	7.5	9.1	12.4
	Reading	***0.0***	13.4	20.9	13.4	1.5	19.4	4.5	20.9	6.0
	Sheffield	***0.6***	32.7	20.2	12.5	6.5	10.7	3.6	4.8	8.9
	Shrewsbury	***1.9***	26.4	15.1	11.3	5.7	28.3	1.9	5.7	5.7
	Stevenage	***1.3***	50.0	12.8	6.4	2.6	15.4	3.8	3.8	5.1
	Southend	***2.4***	15.0	25.0	17.5	2.5	15.0	5.0	5.0	15.0
	Sunderland	***0.0***	3.9	19.6	17.6	29.4	5.9	9.8	5.9	7.8
	Truro	***15.0***	15.7	19.6	29.4	2.0	5.9	3.9	13.7	9.8
	Wirral	***0.0***	98.5	0.0	1.5	0.0	0.0	0.0	0.0	0.0
	Wolverhampton	***0.0***	6.9	20.8	18.8	4.0	14.9	5.0	16.8	12.9
	York	***12.5***	11.9	7.1	11.9	4.8	21.4	7.1	16.7	19.0
Scotland	Aberdeen	***37.3***								4.8
	Airdrie	***3.9***	16.3	14.3	16.3	8.2	18.4	8.2	12.2	6.1
	Dumfries	***14.3***	33.3	0.0	0.0	0.0	33.3	0.0	33.3	0.0
	Dundee	***3.2***	8.3	21.7	6.7	3.3	15.0	1.7	16.7	26.7
	Dunfermline	***24.1***	22.7	18.2	9.1	9.1	18.2	4.5	9.1	9.1
	Edinburgh	***1.0***	20.8	8.3	14.6	9.4	16.7	7.3	4.2	18.8
	Glasgow RI	***13.2***	11.9	28.8	15.3	0.0	13.6	6.8	5.1	18.6
	Glasgow WI	***40.8***								
	Inverness	***12.1***	13.8	17.2	13.8	17.2	6.9	10.3	13.8	6.9
	Kilmarnock	***0.0***	21.7	17.4	21.7	0.0	13.0	4.3	8.7	13.0
	Stobhill	***5.9***	12.5	6.3	31.3	0.0	25.0	0.0	18.8	6.3
Wales	Bangor	***0.0***	19.4	22.2	8.3	19.4	30.6	0.0	0.0	0.0
	Clwyd	***0.0***	76.9	23.1	0.0	0.0	0.0	0.0	0.0	0.0
	Cardiff	***16.0***	40.1	24.3	7.2	5.9	7.9	5.9	5.3	3.3
	Swansea	***1.1***	11.7	20.2	20.2	3.2	14.9	3.2	7.4	19.1
	Wrexham	***30.0***								4.8
England		***8.1***	**25.9**	**19.8**	**11.2**	**6.2**	**15.6**	**6.0**	**7.6**	**7.7**
Wales		***11.0***	**29.4**	**24.1**	**11.4**	**6.0**	**12.3**	**4.1**	**5.1**	**7.6**
Scotland		***16.7***	**18.7**	**17.0**	**14.3**	**5.4**	**14.1**	**6.7**	**10.0**	**13.7**
UK		***9.2***	**25.4**	**19.8**	**11.5**	**6.1**	**15.3**	**5.9**	**7.7**	**8.2**

This is suggested by the strong inverse correlations across centres between the frequency of the aetiology uncertain diagnosis and those of glomerulonephritis and reno-vascular disease. To overcome any inaccuracies introduced by low returns, Table 3.9 shows the effect on percentage primary diagnoses of excluding renal units in England and Wales with more than 25% no return, and more than 10% no return; the latter is the figure quoted as representative. Calculations could not be made for Scotland where the rate of return was lower.

Diabetic renal disease remains the most common specific primary renal diagnosis. There is a significant variation between renal units in the percentage of patients starting RRT with diabetic kidney disease, which generally follows the pattern of population distribution of ethnic minorities. Five of the 32 centres with sufficient returns (80% primary renal diagnosis and 50% ethnicity) had non-white populations above 25%. The mean incidence of diabetic renal disease in these centres was significantly higher than in those centres with

Table 3.9: Effect on percentage primary diagnosis of excluding units with low returns – England & Wales

	Percentage primary diagnosis								
	Diabetes	GN	Hypertension	Missing	Other	Polycystic kidney	Pyelonephritis	RVD	Uncert
All	18.3	10.2	5.6	8.8	14.0	5.3	6.8	7.0	24.0
>75% return	19.0	10.7	6.0	3.8	14.9	5.6	7.3	7.9	24.8
>90% return	19.0	10.6	6.4	2.2	15.4	5.6	7.2	8.0	25.5

lower non-white populations (25.9 vs 16.5: $p = 0.008$).

Excluding patients with a missing diagnosis in each year, the proportion of patients with diabetic nephropathy as the cause of ERF has remained unchanged between 1999 and 2004 (19.0% in 1999 and 2004). The increase in overall acceptance rate implies an increase in the acceptance rate of patients with diabetic renal disease from 17 pmp to 20 pmp over the same time.

First established treatment modality

In 2004 haemodialysis was the very first modality of RRT in 71% of patients, peritoneal dialysis in 26.5% and pre-emptive transplant in 2.3%. This represents a significant change from 1998 when the very first treatment modality was haemodialysis in 57.7%.

Many patients, especially those being referred late to renal units, undergo a brief period of haemodialysis before being established on peritoneal dialysis. As an indication of the elective treatment modality, the established modality at 90 days is a more clearly defined and representative figure. Of the 91.3% of the patient cohort 01/10/2003 to 30/09/2004 alive on day 90 of treatment, 70% were on HD, 27% on PD and 3% had received a transplant (Table 3.10 and Figure 3.9). This pattern is significantly different from 1998 when haemodialysis was the established mode at 90 days in 59% of dialysis patients.

Table 3.10: Treatment modality at day 90

		Percentage of patients on each modality						
Country	Centre	HD	PD	Tx	Transferred	Stopped	Died	Lost
England	Barts	51	33	7	1	0	8	1
	Basildon	60	18	0	0	8	15	0
	Bradford	74	22	0	0	0	5	0
	Brighton	67	27	0	0	0	6	0
	Bristol	72	11	4	0	0	13	0
	Cambridge	61	27	4	0	0	8	0
	Carlisle	83	14	3	0	0	0	0
	Carshalton	66	22	2	2	0	9	0
	Chelmsford	59	30	0	0	0	11	0
	Coventry	42	40	9	0	0	10	0
	Derby	68	18	0	3	0	11	0
	Dorset	33	46	0	0	13	8	0
	Dudley	54	30	0	0	0	15	0
	Exeter	71	21	0	0	1	7	0
	Gloucester	70	16	6	0	0	8	0
	Guys	53	30	13	1	0	3	0
	H&CX	69	24	0	0	1	7	0
	Heartlands	79	14	1	0	1	5	0

Table 3.10: (continued)

		Percentage of patients on each modality						
Country	**Centre**	**HD**	**PD**	**Tx**	**Transferred**	**Stopped**	**Died**	**Lost**
England	Hull	62	19	0	0	1	18	0
	Ipswich	49	41	0	0	0	10	0
	Kings	62	26	4	3	1	5	0
	Leeds	60	21	5	0	0	13	0
	Leicester	53	32	10	0	0	6	0
	Liverpool	68	19	3	0	1	9	0
	ManWst	53	43	0	0	0	4	0
	Middlesbrough	75	13	0	1	0	11	0
	Newcastle	57	17	14	0	0	12	0
	Norwich	63	13	0	15	3	6	0
	Nottingham	57	30	3	1	0	9	0
	Oxford	57	27	7	2	1	7	0
	Plymouth	54	21	0	0	1	24	0
	Portsmouth	58	33	4	0	0	4	0
	Preston	56	35	4	0	0	4	0
	QEH	72	14	4	0	0	10	0
	Reading	50	44	1	0	0	4	0
	Sheffield	55	35	3	0	0	7	0
	Shrewsbury	50	36	0	2	0	12	0
	Stevenage	66	25	2	0	0	7	0
	Southend	78	10	0	2	0	10	0
	Sunderland	86	9	0	0	0	5	0
	Truro	61	38	0	0	2	0	0
	Wirral	71	16	0	0	0	13	0
	Wolverhampton	65	22	1	0	0	12	0
	York	55	32	0	0	0	13	0
Wales	Bangor	54	18	0	3	3	23	0
	Clwyd	89	0	0	0	0	11	0
	Cardiff	70	16	6	0	0	9	0
	Swansea	71	19	0	0	0	10	0
	Wrexham	70	19	4	4	0	4	0
Scotland	Aberdeen	67	23	0	0	0	10	0
	Airdrie	73	18	0	0	2	6	0
	Dumfries	60	20	0	0	0	20	0
	Dundee	67	22	1	0	0	9	0
	Dunfermline	81	12	0	0	0	8	0
	Edinburgh	73	15	1	0	1	9	0
	Glasgow RI	75	18	0	0	0	7	0
	Glasgow WI	59	27	3	0	0	11	0
	Inverness	43	46	0	0	0	11	0
	Kilmarnock	68	32	0	0	0	0	0
	Stobhill	86	0	0	0	0	14	0
England		**62**	**25**	**3**	**1**	**1**	**9**	**0**
Wales		**69**	**17**	**3**	**1**	**0**	**10**	**0**
Scotland		**68**	**22**	**1**	**0**	**0**	**9**	**0**
UK		**63**	**24**	**3**	**1**	**0**	**9**	**0**

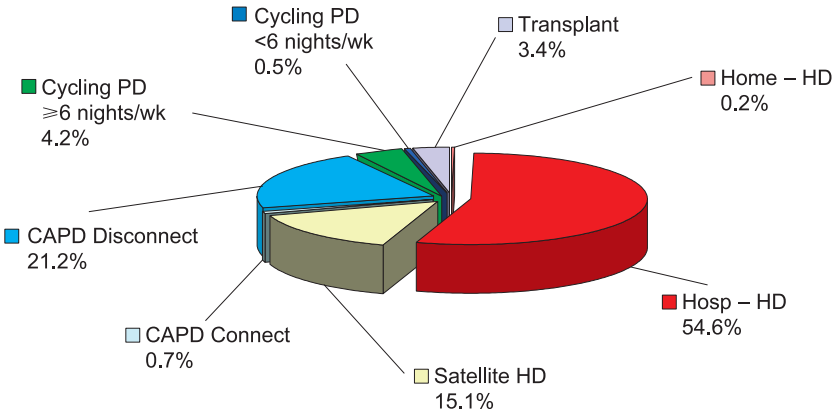


Figure 3.9: RRT modality at day 90

There were significant differences between individual renal units in the percentage of new patients established on haemodialysis ($p < 0.0001$). The wide variation between renal units in the percentage of incident dialysis patients receiving HD at day 90 persists ranging from 42 to 100% (Figure 3.10). There were no renal units with less than 40% and 17 units with over 80%. Haemodialysis was more frequently the first treatment in Wales and Scotland than in England.

A significantly higher proportion of incident dialysis patients over the age of 65 (80.0%) were on HD at 90 days compared with their younger counterparts (64.3%) (Figure 3.11). This difference is reflected in the vast majority of renal units though in 5 the proportions were similar or even reversed (Dorset, Barts, Bangor, Basildon and Derby). The median age of HD patients was significantly higher than that of PD patients (67 years and 58 years respectively, $p < 0.0001$).

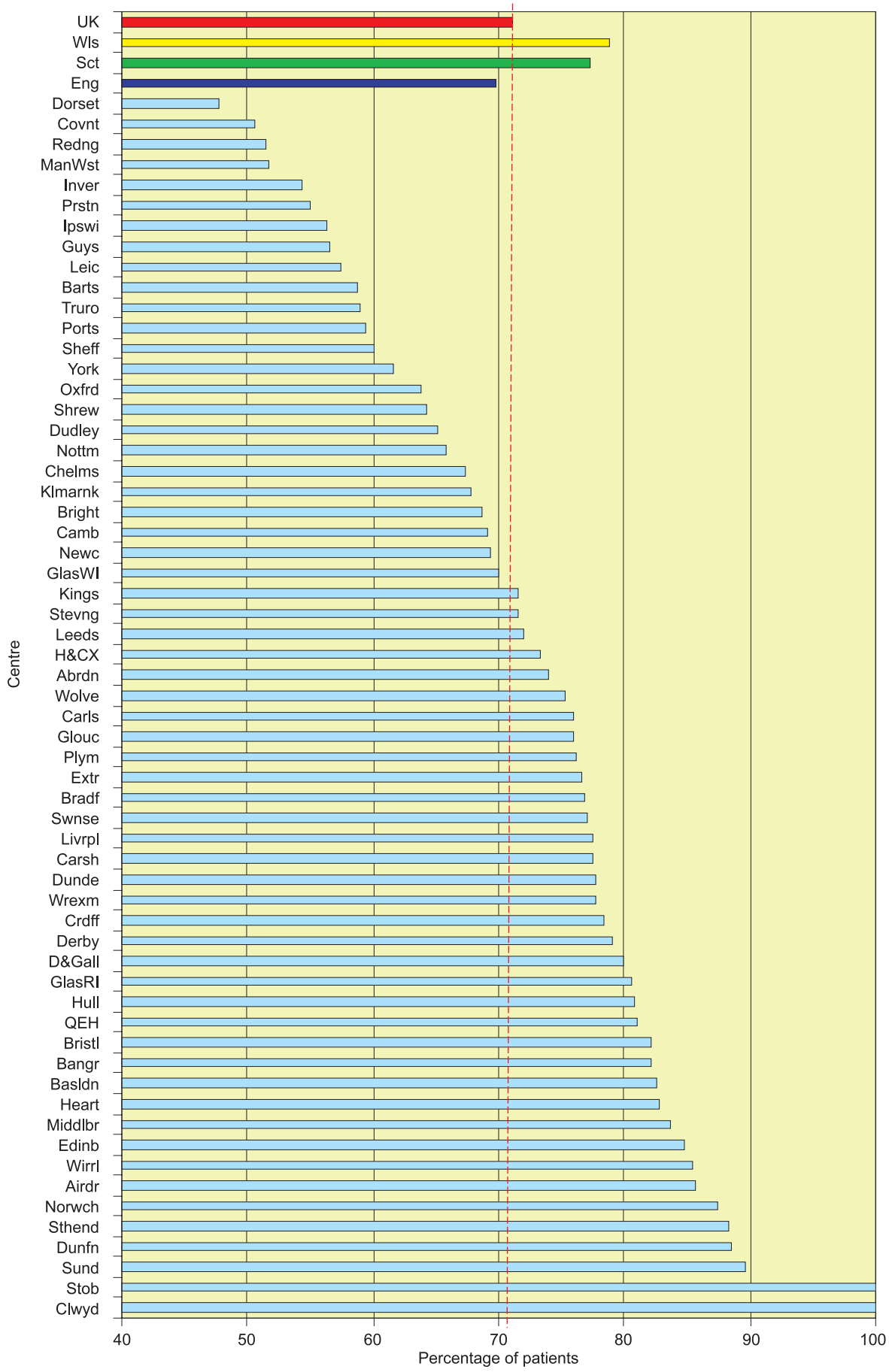


Figure 3.10: Percentage of incident dialysis patients in each centre on HD on day 90

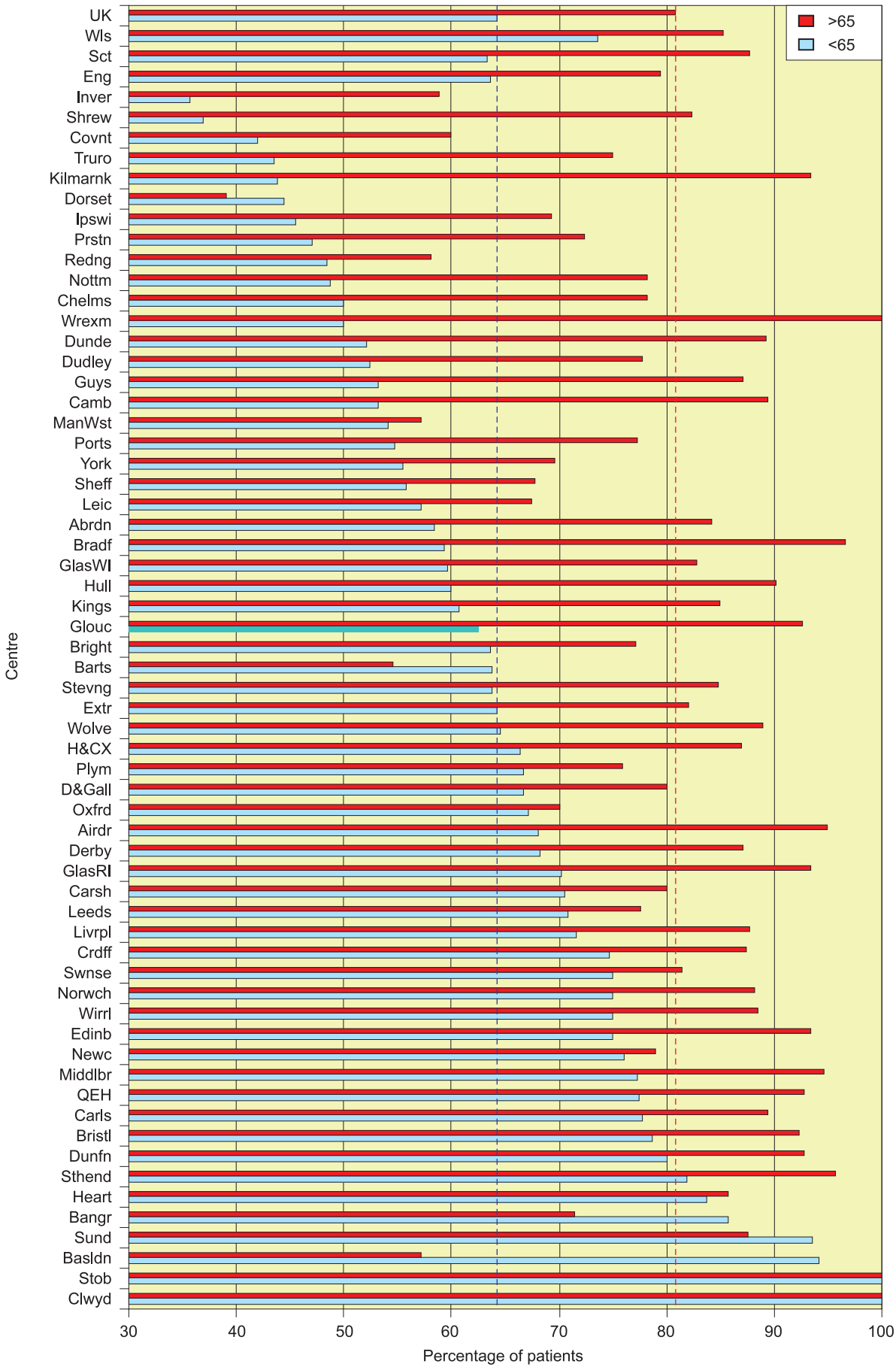


Figure 3.11: Percentage of incident dialysis patients on HD in each centre on day 90, by age

Changes in treatment modality in the first four years

Those established on haemodialysis

The modality changes in the first four years of those patients starting RRT in 1997–2000 were analysed for those patients established on haemodialysis on day 90 (n = 4,870 patients). The sequential modality changes are shown in Table 3.11. These are changes subsequent to the first 90 days after starting dialysis. Transfer to PD is negligible after the first year. This is an older group of patients than those established on PD, and the patients have more co-morbidity, explaining the relatively higher death rate and lower transplant rate compared with PD patients.

Those established on peritoneal dialysis

The sequential modality changes in the first 4 years of those patients starting RRT in 1997–2000 who were on peritoneal dialysis on day 90 are shown in Table 3.12.

After 4 years only 17% are still alive on peritoneal dialysis, and 27% have changed to haemodialysis (defined as changing to haemodialysis for at least 3 months). The rate of change is constant with about 65% of those on PD at the beginning of each year remaining on it at the end, and 11% at the beginning of each year changing to HD within the year.

Survival of incident patients

This is considered in Chapter 14.

Table 3.11: Four-year sequential modality changes in patients established on HD 1997–2000: UK

N = 4,870	End of yr 1 %	End of yr 2 %	End of yr 3 %	End of yr 4 %
Remained on HD	71	53	40	31
Changed to PD	3	3	4	4
Had a transplant	5	9	12	14
Stopped treatment	0	0	0	0
Unknown	0	1	1	1
Recovered	1	1	1	1
Died	20	32	41	49

Table 3.12: Four-year sequential modality changes in patients established on PD 1997–2000: UK

N = 3,098	End of yr 1 %	End of yr 2 %	End of yr 3 %	End of yr 4 %
Remained on PD	67	43	27	17
Changed to HD	11	19	24	27
Had a transplant	10	18	22	24
Stopped treatment	0	0	0	0
Unknown	0	1	1	1
Recovered	1	1	1	1
Died	11	19	26	31

Chapter 4: All Patients Receiving Renal Replacement Therapy in the United Kingdom in 2004

Summary

- The estimated prevalence of RRT in the UK at the end of 2004 was 638 pmp.
- The detailed analysis includes 33,511 patients in England, Scotland and Wales.
- The annual increase in prevalence in the 38 renal units participating in the Registry since 2000 was 5.9%. The overall increase over the last 4 years was 23%.
- There is substantial variation in the crude Local Authority area prevalence from 322 pmp to 1,108 pmp.
- Median vintage of the whole RRT population was 5.0 years. That of transplanted patients was 9.6 years, HD patients 2.7 years and PD patients 2.1 years.
- In numerical terms, prevalence of RRT was maximal in the age range 55–65 years, the maximal prevalence rate occurred in the 80–85 year age band (2,065 pmp) in men and in the 65–74 year age band in women (1,073 pmp).
- 61% of prevalent RRT patients were male. This male preponderance was evident across all age groups.
- In the 36 centres with ethnicity returns of 70% or more in each RRT modality, the proportion of Whites was slightly but significantly higher in the transplant cohort (88%) than in the HD (83%: $p = 0.001$) and PD (83%: $p = 0.009$) cohorts.
- The most common identifiable diagnosis was glomerulonephritis (22.3%) for those under 65 and diabetes (13.4%) in those over 65.
- Of RRT patients in the UK, 45% had a functioning transplant, 42% were on HD and 13% on PD.
- In England and Wales hospital based HD accounted for 47% of the whole dialysis program. The proportion receiving HD in satellite units was 27%. Only 2% were on home HD.
- The proportion of prevalent dialysis patients on PD varies widely across the Registry units ranging from 0% to over 40%.

Introduction

In 2004, the UK Renal Registry received complete returns from an estimated 83% of England and 100% of Wales. Data on prevalent patients in Scotland were obtained from the Scottish Renal Registry and summary data for Northern Ireland from the renal unit in the Royal Belfast Hospital, which coordinates renal service provision in Northern Ireland. Extrapolating from Registry data to derive information relating to the whole UK must still be viewed with caution, although estimates become more reliable as coverage increases. For comparisons between renal units and between local areas fully covered by the Renal Registry, the data from the Registry are fully valid.

The proportion of the population aged over 65 years covered by the Registry in England was similar to the fully covered population (defined below, ie based on Local Authority areas whose population was thought to be fully covered by participating renal units) when compared with the general population of England. The proportion from ethnic minority groups was lower in the covered population at 8.1% compared with 9.0% in the total population, as some areas not reporting to the Registry have catchment populations with a high ethnic minority. Extrapolating from Registry data will therefore tend to underestimate the prevalence of new patients for the whole UK, as the prevalence of renal failure is high in South Asian and African–Caribbean ethnic minority populations.

Paediatric data can be found in Chapter 18.

Table 4.1: Prevalence of renal replacement therapy in UK, 31/12/2004

	England	Wales	Scotland	N. Ireland	UK
No of adult renal units	44/53	5	10	5	**73**
Patient numbers	25,553* (30,762)**	2,214	3,588	1,284	**37,848**
Population (millions)	49.6	2.9	5.1	1.7	**59.2**
Prevalence pmp	620	763	709	755	**638**
(95% CI)	(612–628)	(731–794)	(686–732)	(714–797)	**(101–105)**

*Patient number returned only from fully covered Local Authority areas.
**Calculated number for the whole of England.

All adult patients receiving Renal Replacement Therapy in the UK, 31/12/2004

There were estimated to be over 37,800 adult patients receiving RRT in the UK at the end of 2004. This equates to a total population prevalence of 638 pmp (Table 4.1). The prevalence was calculated using an overall total for England extrapolated from the data for those renal units in England participating in the Registry's activity, which cover an estimated 41.2 million people. As indicated above this may be an underestimate.

The calculated prevalence in England does not show the expected rise from 2003, as many of the new renal units joining the Registry in 2004 had a prevalence rate below the previous Registry average. However as shown below, in those renal units continuously reporting for the last 5 years there is an average rise in prevalence of between 4% and 5%.

Prevalent patients on 31/12/2004

For 2004, detailed data on prevalent patients were returned from 44 of the 53 renal units in England, all 5 units in Wales and all 10 units in Scotland (the Stobhill renal unit is part of Glasgow Royal Infirmary), a total of 33,511 patients. Of the 27,853 patients in England 25,553 were from geographical areas completely covered by the Registry, with an estimated population of 41.2 million, representing 83% of the population. The number of prevalent patients in each renal unit and the distribution of their treatment modalities are shown in Table 4.2 and Figure 4.1.

The numbers of patients calculated for each country quoted above by adding the patient numbers in each renal unit differ marginally from those quoted elsewhere when patients are allocated to areas by their individual post codes, as some units treat patients from across national boundaries.

The wide variation in the proportion of transplanted patients in each renal unit is partly the result of different policies for follow up of patients at transplant centres; some transplant centres continue to follow up the patients they transplant for other renal units, others transfer them back to their parent unit but at variable times post transplant, and some renal units do not follow up any transplanted patients. Thus the 22 renal units with a transplant centre tend to have a higher proportion of transplant patients under follow up compared with the 38 units without a transplant centre, and are also the units with the largest number of prevalent RRT patients overall (Figure 4.1). Transplant centres are also significantly larger, with on average twice as many prevalent dialysis patients as other centres (approximately 500 vs. 220: $p < 0.001$).

Table 4.2: Distribution of prevalent patients and modalities 31/12/2004

Treatment centre	Total	% on HD	% on PD	% with transplant
Barts	1,306	33	17	50
Basildon	160	68	16	16
Bradford	329	48	15	37
Brighton	601	47	15	38
Bristol	1,093	37	6	57
Cambridge	790	31	12	57
Carlisle	182	41	9	50
Carshalton	956	44	19	37
Chelmsford	139	72	24	4
Coventry	604	41	13	47
Derby	290	75	23	2
Dorset	369	32	22	46
Dudley	255	42	22	35
Exeter	582	43	16	41
Gloucester	262	52	11	36
Guys	1,220	30	8	61
H&CX	1,148	48	15	37
Heartlands	503	62	5	32
Hull	557	54	8	38
Ipswich	283	37	27	36
Kings	602	44	14	42
Leeds	1,308	35	9	56
Leicester	1,335	33	16	51
Liverpool	1,268	32	9	59
ManWst	629	35	22	44
Middlesbrough	582	43	4	53
Newcastle	798	27	6	67
Norwich	362	60	12	28
Nottingham	824	36	16	48
Oxford	1,205	30	12	59
Plymouth	346	34	12	53
Portsmouth	1,055	30	9	60
Preston	771	41	13	46
QEH	1,334	50	10	40
Reading	375	42	24	34
Sheffield	1,148	46	14	39
Shrewsbury	227	54	17	29
Stevenage	551	58	11	31
Southend	173	71	13	16
Sunderland	269	50	5	45
Truro	279	53	20	27
Wirral	186	87	13	0
Wolverhampton	419	66	13	21
York	178	58	15	28
England	**27,853**	**42**	**13**	**45**
Aberdeen	389	42	11	47
Airdrie	180	81	19	0
Dumfries & Galloway	60	70	20	10
Dundee	324	41	13	46
Dunfermline	137	66	15	18
Edinburgh	649	37	9	54
Glasgow RI	193	82	17	1
Glasgow WI	1,197	21	7	72
Inverness	179	41	21	38
Kilmarnock	161	57	29	15
Stobhill*	133	100	0	0
Scotland	**3,602**	**42**	**11**	**46**
Bangor	99	75	25	0
Clwyd	74	82	8	9
Cardiff	1,225	34	11	55
Swansea	460	55	18	27
Wrexham	198	56	25	19
Wales	**2,056**	**44**	**15**	**41**
England	27,853	42	13	45
Scotland	3,602	42	11	46
Wales	2,056	44	15	41
UK	**33,511**	**42**	**13**	**45**

*Stobhill renal unit is part of the Glasgow Royal Infirmary renal unit.

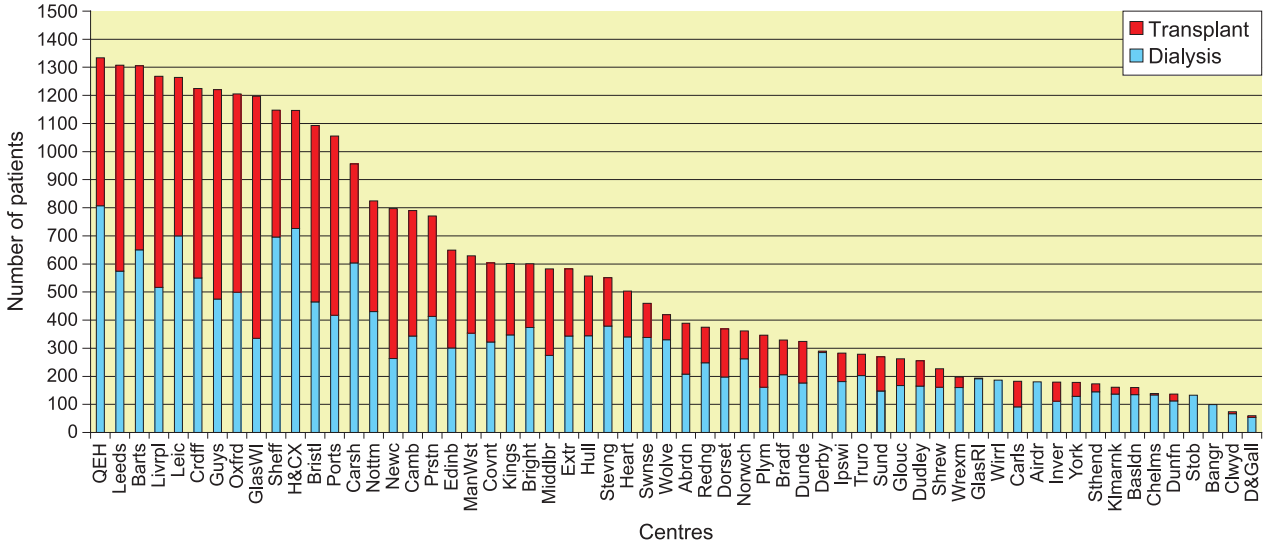


Figure 4.1: Distribution of dialysis and transplant patients in renal units, 31/12/04

Changes in prevalence 2000–2004

The total percentage increase in the number of patients in the 37 renal units who have returned data continuously over the 5 years 2000–2004 followed a fairly linear pattern at 23% and averaging 5.9% per annum (Table 4.3). This varied between UK countries from 21% in Scotland, 27% in Wales and 24% in England. There were wide variations between centres, partly due to redistribution of patients, particularly with changes in pattern of follow-up of transplant patients who are now more frequently transferred from the transplanting centre back to the referring renal centre for long-term follow-up. There was also a major redistribution of both dialysis and transplant patients from Oxford to Leicester and Reading in 2004 accounting for the 3% reduction at the Oxford renal unit. This interpretation of the data is supported through analysis of prevalence rates by postcode (according to Local Authority (LA) allocation) with Oxfordshire LA showing a continual rise from 604 pmp in 2001 to 684 pmp in 2004. Reading LA also shows a very similar increase from 587 pmp in 2001 to 678 pmp in 2004. Other renal units affected by redistribution of patients include Ipswich, Leicester, Truro, Wirral, Plymouth and Southend.

Consistent with these data, the increase was 5.1% in all 59 centres contributing to the Registry from 2003 to 2004. For individual centres, the changes in total numbers are shown in Table 4.4.

Local Authority prevalence

The prevalence of RRT and standardised prevalence ratios in those Local Authorities with complete coverage in 2004 are shown in Table 4.5.

Table 4.3: Prevalent patient numbers in renal units reporting continuously 2000–2004

Centre	31.12.2000	31.12.2001	31.12.2002	31.12.2003	31.12.2004	% change
Bristol	908	951	991	1,055	1,093	20
Carlisle	156	159	161	173	182	17
Carshalton	671	696	786	884	956	42
Coventry	515	548	565	577	604	17
Derby	132	174	n/a	274	290	120
Dudley	249	239	232	241	255	2
Exeter	423	455	514	528	582	38
Gloucester	236	195	211	245	262	11
Guys	1,124	1,142	1,185	1,186	1,220	9
Heartlands	426	458	449	495	503	18
Hull	424	450	512	523	557	31
Leeds	1,129	1,153	1,190	1,229	1,308	16
Leicester	976	1,030	1,071	1,104	1,335	37
Middlesbrough	433	436	519	550	582	34
Nottingham	750	802	788	804	824	10
Oxford	1,241	1,317	1,362	1,403	1,205	−3
Plymouth	410	394	379	341	346	−16
Preston	493	541	588	734	771	56
Reading	178	205	198	226	375	111
Sheffield	866	943	1,021	1,084	1,148	33
Stevenage	454	460	524	571	551	21
Southend	132	133	145	154	173	31
Sunderland	236	216	237	236	269	14
Wolverhampton	318	336	367	396	419	32
York	116	136	170	195	178	53
England	**12,996**	**13,569**	**14,165**	**15,208**	**16,059**	**24**
Aberdeen	311	326	354	349	389	25
Airdrie	104	148	169	171	180	73
Dumfries	55	71	72	78	60	9
Dundee	245	253	288	300	324	32
Dunfermline	90	112	119	127	137	52
Edinburgh	550	575	595	617	649	18
Glasgow RI	176	180	181	194	193	10
Glasgow WI	1,049	1,093	1,111	1,166	1,197	14
Inverness	99	127	147	160	179	81
Kilmarnock	140	147	157	168	161	15
Stobhill*	153	137	137	131	133	−13
Scotland	**2,972**	**3,169**	**3,330**	**3,461**	**3,602**	**21**
Cardiff	1,029	1,050	1,088	1,158	1,225	19
Swansea	232	390	388	426	460	98
Wrexham	227	205	207	213	198	−13
Wales	**1,488**	**1,645**	**1,683**	**1,797**	**1,883**	**27**
England	12,996	13,569	14,165	15,208	15,917	22
Scotland	2,972	3,169	3,330	3,461	3,602	21
Wales	1,488	1,645	1,683	1,797	1,883	27
Grand Total	**17,456**	**18,383**	**19,178**	**20,466**	**21,544**	**23**

*Stobhill renal unit is part of the Glasgow Royal Infirmary renal unit.

Table 4.4: Number of patients on RRT in each participating centre 2000–2004

Treatment centre	31/12/2000	31/12/2001	31/12/2002	31/12/2003	31/12/2004
Barts	n/a	n/a	n/a	n/a	1,306
Basildon	n/a	n/a	n/a	166	160
Bradford	n/a	251	279	313	329
Brighton	n/a	n/a	n/a	n/a	601
Bristol	908	951	991	1,055	1,093
Cambridge	n/a	651	711	741	790
Carlisle	156	159	161	173	182
Carshalton	671	696	786	884	956
Chelmsford	n/a	n/a	n/a	n/a	139
Coventry	515	548	565	577	604
Derby	132	174	n/a	274	290
Dorset	n/a	n/a	n/a	354	369
Dudley	249	239	232	241	255
Exeter	423	455	514	528	582
Gloucester	236	195	211	245	262
Guys	1,124	1,142	1,185	1,186	1,220
H&CX	n/a	n/a	1,090	1,089	1,148
Heartlands	426	458	449	495	503
Hull	424	450	512	523	557
Ipswich	n/a	n/a	236	244	283
Kings	n/a	n/a	561	578	602
Leeds	1,129	1,153	1,190	1,229	1,308
Leicester	976	1,030	1,071	1,104	1,335
Liverpool	n/a	1,031	1,142	1,227	1,268
ManWst	n/a	n/a	n/a	602	629
Middlesbrough	433	436	519	550	582
Newcastle	n/a	n/a	788	802	798
Norwich	n/a	n/a	n/a	n/a	362
Nottingham	750	802	788	804	824
Oxford	1,241	1,317	1,362	1,403	1,205
Plymouth	410	394	379	341	346
Portsmouth	n/a	998	1,014	1,031	1,055
Preston	493	541	588	734	771
QEH	n/a	n/a	n/a	n/a	1,334
Reading	178	205	198	226	375
Sheffield	866	943	1,021	1,084	1,148
Shrewsbury	n/a	n/a	n/a	n/a	227
Stevenage	454	460	524	571	551
Southend	132	133	145	154	173
Sunderland	236	216	237	236	269
Truro	n/a	181	210	231	279
Wirral	n/a	n/a	140	157	186
Wolverhampton	318	336	367	396	419
York	116	136	170	195	178
England	**12,996**	**16,681**	**20,336**	**22,743**	**27,853**

Table 4.4: (continued)

Treatment centre	31/12/2000	31/12/2001	31/12/2002	31/12/2003	31/12/2004
Aberdeen	311	326	354	349	389
Airdrie	104	148	169	171	180
Dumfries	55	71	72	78	60
Dundee	245	253	288	300	324
Dunfermline	90	112	119	127	137
Edinburgh	550	575	595	617	649
Glasgow RI	176	180	181	194	193
Glasgow WI	1,049	1,093	1,111	1,166	1,197
Inverness	99	127	147	160	179
Kilmarnock	140	147	157	168	161
Stobhill**	153	137	137	131	133
Scotland	**2,972**	**3,169**	**3,330**	**3,461**	**3,602**
Bangor	n/a	81	95	102	99
Clwyd	n/a	n/a	86	66	74*
Cardiff	1,029	1,050	1,088	1,158	1,225
Swansea	232	390	388	426	460
Wrexham	227	205	207	213	198
Wales	**1,488**	**1,726**	**1,864**	**1,965**	**2,056**
England	12,996	16,681	20,336	22,743	27,853
Scotland	2,972	3,169	3,330	3,461	3,602
Wales	1,488	1,726	1,864	1,965	2,056
UK	**17,456**	**21,576**	**25,530**	**28,169**	**33,511**

*Clwyd numbers might be underestimated.
**Stobhill renal unit is part of the Glasgow Royal Infirmary renal unit.

Table 4.5: Prevalence of RRT and standardised prevalence ratios in Local Authorities with complete coverage by the Registry

Areas with significantly high prevalence ratios are bold, those with significantly low prevalence ratios are italicised.

UK Area	LA	Name	Total Pop	Total	RRT rate pmp	Ratio	L 95% CI	U 95% CI	HD rate pmp	PD rate pmp	Dialysis rate pmp	Tx rate pmp	% ethnicity
North East	County Durham & Tees Valley	Darlington	97,838	59	603	0.93	0.72	1.20	286	20	307	296	2.1
		Durham	493,469	314	636	0.97	0.87	1.08	253	28	282	355	1.0
		Hartlepool	88,610	59	666	1.04	0.81	1.35	214	45	260	406	1.2
		Middlesbrough	134,855	89	660	1.10	0.89	1.35	245	22	267	393	6.3
		Redcar & Cleveland	139,132	91	654	0.99	0.81	1.22	208	14	223	431	1.1
		Stockton-on-Tees	178,408	104	583	0.93	0.77	1.12	247	22	269	314	2.8
	Northumberland, Tyne & Wear	Gateshead	191,151	129	675	1.02	0.86	1.21	220	42	262	413	1.6
		Newcastle upon Tyne	259,536	145	559	0.92	0.78	1.08	193	31	223	335	6.9
		North Tyneside	191,658	121	631	0.95	0.79	1.13	203	21	224	407	1.9
		Northumberland	307,190	195	635	0.93	0.80	1.06	182	75	257	378	1.0
		South Tyneside	152,785	92	602	0.92	0.75	1.13	223	26	249	353	2.7
		Sunderland	280,807	182	648	1.02	0.89	1.18	228	36	264	385	1.9

Table 4.5: (continued)

UK Area	LA	Name	Total Pop	Total	RRT rate pmp	Ratio	L 95% CI	U 95% CI	HD rate pmp	PD rate pmp	Dialysis rate pmp	Tx rate pmp	% ethnicity
North West	Cheshire & Merseyside	Halton	118,209	73	618	1.01	0.80	1.27	245	85	330	288	1.2
		Knowsley	150,459	109	724	1.20	0.99	1.45	306	106	412	312	1.6
		Liverpool	**439,471**	**309**	**703**	**1.17**	**1.04**	**1.30**	332	73	405	298	**5.7**
		Sefton	*282,958*	*156*	*551*	*0.83*	*0.71*	*0.97*	237	71	307	244	*1.6*
		St. Helens	*176,843*	*87*	*492*	*0.77*	*0.62*	*0.94*	198	74	271	221	*1.2*
		Warrington	191,080	108	565	0.90	0.74	1.08	215	73	288	277	2.1
		Wirral	312,293	216	692	1.06	0.92	1.21	327	58	384	307	1.7
	Cumbria & Lancashire	Blackburn with Darwen	137,470	86	626	1.10	0.89	1.36	386	51	436	189	22.1
		Blackpool	*142,283*	*71*	*499*	*0.73*	*0.58*	*0.92*	190	49	239	260	*1.6*
		Cumbria	*487,607*	*270*	*554*	*0.81*	*0.72*	*0.91*	199	68	267	287	*0.7*
		Lancashire	*1,134,975*	*624*	*550*	*0.85*	*0.79*	*0.92*	205	69	274	276	*5.3*
	Greater Manchester	*Bolton*	*261,037*	*128*	*490*	*0.79*	*0.67*	*0.94*	142	111	253	238	*11.0*
		Bury	*180,607*	*49*	*271*	*0.43*	*0.33*	*0.57*	111	61	172	100	*6.1*
		Oldham	*217,276*	*70*	*322*	*0.53*	*0.42*	*0.67*	110	92	203	120	*13.9*
		Rochdale	*205,357*	*74*	*360*	*0.60*	*0.47*	*0.75*	166	68	234	127	*11.4*
		Salford	*216,105*	*90*	*416*	*0.67*	*0.55*	*0.82*	153	74	227	190	*3.9*
		Wigan	*301,415*	*129*	*428*	*0.67*	*0.57*	*0.80*	153	96	249	179	*1.3*
Yorkshire & the Humber	North & East Yorkshire & Northern Lincolnshire	*East Riding of Yorkshire*	*314,113*	*186*	*592*	*0.86*	*0.74*	*0.99*	283	67	350	242	*1.2*
		Kingston upon Hull, City of	243,588	152	624	1.04	0.88	1.22	328	45	374	250	2.3
		North East Lincolnshire	157,981	104	658	1.04	0.86	1.26	348	51	399	260	1.4
		North Lincolnshire	152,848	94	615	0.93	0.76	1.13	334	52	386	229	2.5
		North Yorkshire	*569,660*	*323*	*567*	*0.83*	*0.75*	*0.93*	249	46	295	272	*1.1*
		York	181,096	111	613	0.96	0.79	1.15	276	66	342	271	2.2
	South Yorkshire	Barnsley	218,063	171	784	1.21	1.04	1.41	339	96	436	349	0.9
		Doncaster	286,865	200	697	1.08	0.94	1.24	307	119	425	272	2.3
		Rotherham	**248,175**	**194**	**782**	**1.22**	**1.06**	**1.41**	359	137	496	286	**3.1**
		Sheffield	513,234	347	676	1.08	0.97	1.20	351	76	427	249	8.8
	West Yorkshire	**Bradford**	**467,664**	**365**	**780**	**1.34**	**1.21**	**1.48**	340	92	432	349	**21.7**
		Calderdale	192,405	139	722	1.14	0.97	1.35	260	73	333	390	7.0
		Kirklees	**388,567**	**290**	**746**	**1.22**	**1.09**	**1.37**	288	69	358	389	**14.4**
		Leeds	715,403	442	618	1.02	0.93	1.12	259	66	324	294	8.2
		Wakefield	315,172	175	555	0.87	0.75	1.01	203	70	273	282	2.3
East Midlands	Leicestershire, Northamptonshire & Rutland	**Leicester**	**279,920**	**280**	**1000**	**1.79**	**1.59**	**2.01**	414	161	575	425	**36.1**
		Leicestershire	609,578	387	635	0.97	0.88	1.08	213	98	312	323	5.3
		Northamptonshire	629,676	359	570	0.91	0.82	1.01	199	73	272	299	4.9
		Rutland	34,563	22	637	0.95	0.63	1.45	58	87	145	492	1.9
	Trent	**Derby**	**221,709**	**176**	**794**	**1.29**	**1.11**	**1.49**	465	135	600	194	**12.6**
		Derbyshire	*734,585*	*396*	*539*	*0.81*	*0.73*	*0.89*	245	87	332	207	*1.5*
		Lincolnshire	*646,644*	*356*	*551*	*0.80*	*0.72*	*0.89*	189	88	277	274	*1.3*
		Nottingham	**266,988**	**197**	**738**	**1.30**	**1.13**	**1.49**	356	101	457	281	**15.1**
		Nottinghamshire	748,508	490	655	0.99	0.91	1.08	259	124	383	271	2.6
West Midlands	Birmingham & the Black Country	**Birmingham**	**977,085**	**894**	**915**	**1.60**	**1.50**	**1.71**	550	69	618	297	**29.6**
		Dudley	305,153	186	610	0.92	0.80	1.07	256	121	377	233	6.3
		Sandwell	**282,904**	**247**	**873**	**1.40**	**1.24**	**1.59**	477	106	583	290	**20.3**
		Solihull	199,515	133	667	1.01	0.85	1.20	391	55	446	221	5.4
		Walsall	**253,498**	**202**	**797**	**1.25**	**1.09**	**1.44**	442	87	529	268	**13.6**
		Wolverhampton	**236,582**	**200**	**845**	**1.34**	**1.17**	**1.54**	499	89	588	258	**22.2**
	Coventry, Warwickshire, Herefordshire & Worcestershire	**Coventry**	**300,849**	**223**	**741**	**1.24**	**1.09**	**1.41**	346	93	439	302	**16.0**
		Herefordshire, County of	174,871	105	600	0.87	0.71	1.05	286	86	372	229	0.9
		Warwickshire	505,858	368	727	1.10	0.99	1.22	283	93	376	352	4.4
		Worcestershire	*542,105*	*299*	*552*	*0.83*	*0.74*	*0.93*	247	92	339	212	*2.5*
	Shropshire & Staffordshire	*Shropshire*	*283,173*	*161*	*569*	*0.83*	*0.72*	*0.97*	279	92	371	198	*1.2*
		Telford & Wrekin	158,325	85	537	0.90	0.73	1.11	316	95	411	126	5.2

Table 4.5: (continued)

UK Area	LA	Name	Total Pop	Total	RRT rate pmp	Ratio	L 95% CI	U 95% CI	HD rate pmp	PD rate pmp	Dialysis rate pmp	Tx rate pmp	% ethnicity
East of England	Bedfordshire & Hertfordshire	Bedfordshire	381,572	227	595	0.95	0.84	1.08	244	89	333	262	6.7
		Hertfordshire	*1,033,978*	*391*	*378*	*0.60*	*0.54*	*0.66*	185	45	230	148	*6.3*
		Luton	**184,373**	**124**	**673**	**1.19**	**1.00**	**1.42**	396	22	418	255	**28.1**
	Essex	*Essex*	*1,310,837*	*689*	*526*	*0.80*	*0.75*	*0.87*	207	101	308	217	*2.9*
		Southend-on-Sea	160,259	108	674	1.04	0.86	1.26	424	94	518	156	4.2
		Thurrock	143,128	79	552	0.93	0.74	1.16	279	70	349	203	4.7
	Norfolk, Suffolk & Cambridgeshire	Cambridgeshire	552,659	314	568	0.90	0.81	1.01	226	92	318	250	4.1
		Norfolk	*796,728*	*479*	*601*	*0.86*	*0.79*	*0.94*	313	60	373	228	*1.5*
		Peterborough	156,061	95	609	1.01	0.83	1.24	243	135	378	231	10.3
		Suffolk	*668,555*	*338*	*506*	*0.76*	*0.68*	*0.84*	187	96	283	223	*2.8*
London	North East London	Barking & Dagenham	163,942	93	567	0.99	0.81	1.22	244	91	335	232	14.8
		Hackney	**202,824**	**127**	**626**	**1.22**	**1.03**	**1.45**	320	79	399	227	**40.6**
		Newham	**243,889**	**176**	**722**	**1.48**	**1.27**	**1.71**	336	152	488	234	**60.6**
		Redbridge	238,634	162	679	1.14	0.98	1.33	272	134	406	272	36.5
		Tower Hamlets	**196,105**	**121**	**617**	**1.26**	**1.05**	**1.50**	311	102	413	204	**48.6**
	North West London	**Ealing**	**300,948**	**265**	**881**	**1.55**	**1.37**	**1.74**	475	126	601	279	**41.3**
		Hammersmith & Fulham	**165,244**	**144**	**871**	**1.58**	**1.34**	**1.86**	533	85	617	254	**22.2**
		Hillingdon	243,006	137	564	0.95	0.80	1.12	235	111	346	218	20.9
		Hounslow	**212,342**	**210**	**989**	**1.75**	**1.52**	**2.00**	560	165	725	264	**35.1**
	South East London	Bexley	218,307	155	710	1.13	0.96	1.32	206	110	316	394	8.6
		Bromley	295,532	181	612	0.95	0.82	1.10	220	98	318	294	8.4
		Greenwich	214,404	116	541	0.96	0.80	1.15	210	103	312	229	22.9
		Lambeth	**266,169**	**196**	**736**	**1.40**	**1.22**	**1.61**	410	101	511	225	**37.6**
		Lewisham	**248,923**	**236**	**948**	**1.74**	**1.53**	**1.97**	490	68	558	390	**34.1**
		Southwark	**244,866**	**225**	**919**	**1.71**	**1.50**	**1.95**	412	90	502	417	**37.0**
	South West London	**Croydon**	**330,588**	**225**	**681**	**1.16**	**1.01**	**1.32**	330	130	460	221	**29.8**
South East	Hampshire & Isle of Wight	*Hampshire*	*1,240,102*	*629*	**507**	*0.78*	*0.72*	*0.84*	141	68	209	298	*2.2*
		Isle of Wight	*132,731*	*68*	**512**	*0.71*	*0.56*	*0.91*	173	30	203	309	*1.3*
		Portsmouth	**186,700**	**132**	**707**	**1.19**	**1.00**	**1.41**	268	43	311	396	**5.3**
		Southampton	217,444	118	543	0.93	0.78	1.12	189	46	235	308	7.6
	Surrey & Sussex	*Brighton & Hove*	*247,817*	*126*	**508**	*0.82*	*0.69*	*0.98*	238	61	299	210	*5.7*
		East Sussex	*492,326*	*299*	**607**	*0.87*	*0.77*	*0.97*	258	97	355	252	*2.3*
		Surrey	*1,059,017*	*522*	**493**	*0.76*	*0.70*	*0.83*	179	79	259	234	*5.0*
		West Sussex	*753,612*	*390*	**518**	*0.76*	*0.69*	*0.84*	211	64	275	243	*3.4*
	Thames Valley	Bracknell Forest	109,616	58	529	0.92	0.71	1.19	182	64	246	283	4.9
		Buckinghamshire	479,026	300	626	0.99	0.88	1.10	200	88	288	338	7.9
		Milton Keynes	207,057	122	589	1.04	0.87	1.24	232	77	309	280	9.3
		Oxfordshire	**605,489**	**414**	**684**	**1.11**	**1.00**	**1.22**	221	94	315	368	**4.9**
		Reading	143,096	97	678	1.20	0.98	1.46	252	70	321	356	13.2
		Slough	**119,064**	**114**	**957**	**1.71**	**1.43**	**2.06**	378	227	605	353	**36.3**
		West Berkshire	144,485	90	623	1.00	0.81	1.22	145	125	270	353	2.6
		Wokingham	150,231	87	579	0.94	0.76	1.16	200	100	300	280	6.1
South West	Avon, Gloucestershire & Wiltshire	Bath & North East Somerset	169,040	95	562	0.86	0.70	1.05	237	47	284	278	2.8
		Bristol, City of	**380,616**	**314**	**825**	**1.39**	**1.24**	**1.55**	352	58	410	415	**8.2**
		Gloucestershire	564,559	337	597	0.91	0.81	1.01	241	41	282	315	2.8
		North Somerset	188,564	144	764	1.11	0.94	1.30	302	37	339	424	1.4
		South Gloucestershire	245,641	174	708	1.12	0.96	1.29	277	49	326	383	2.4
		Swindon	180,051	109	605	0.99	0.82	1.19	211	100	311	294	4.8
		Wiltshire	*432,972*	*193*	**446**	**0.69**	*0.59*	*0.79*	136	51	187	259	*1.6*

Table 4.5: (continued)

UK Area	LA	Name	Total Pop	Total	RRT rate pmp	Ratio	L 95% CI	U 95% CI	HD rate pmp	PD rate pmp	Dialysis rate pmp	Tx rate pmp	% ethnicity
South West (continued)	Dorset & Somerset	Bournemouth	163,444	87	532	0.81	0.65	1.00	171	86	257	275	3.3
		Dorset	*390,980*	*239*	**611**	*0.84*	*0.74*	*0.95*	166	128	294	317	*1.3*
		Poole	138,288	77	557	0.82	0.65	1.02	181	101	282	275	1.8
		Somerset	498,095	302	606	0.89	0.79	1.00	235	70	305	301	1.2
	South West Peninsula	**Cornwall & Isles of Scilly**	**501,267**	**404**	**806**	**1.14**	**1.04**	**1.26**	357	150	507	299	**1.0**
		Devon	*704,491*	*433*	**615**	*0.88*	*0.80*	*0.96*	248	97	345	270	*1.1*
		Plymouth	240,722	153	636	1.02	0.87	1.19	253	46	299	336	1.6
		Torbay	129,706	96	740	1.05	0.86	1.28	332	100	432	308	1.2
Wales	Bro Taf	Cardiff	305,353	**224**	**734**	**1.26**	1.11	1.44	305	75	380	354	**8.4**
		Merthyr Tydfil	55,979	**62**	**1108**	**1.74**	1.36	2.24	518	107	625	482	**1.0**
		Rhondda, Cynon, Taff	231,947	**194**	**836**	**1.32**	1.15	1.52	319	129	448	388	**1.2**
		The Vale of Glamorgan	119,292	87	729	1.12	0.91	1.39	251	117	369	360	2.2
	Dyfed Powys	Carmarthenshire	172,842	136	787	1.15	0.97	1.36	376	87	463	324	0.9
		Ceredigion	74,941	49	654	0.97	0.73	1.28	254	40	294	360	1.4
		Pembrokeshire	114,131	69	605	0.88	0.69	1.11	219	105	324	280	0.9
		Powys	126,353	76	601	0.85	0.68	1.07	293	95	388	214	0.9
	Gwent	Blaenau Gwent	70,064	52	742	1.15	0.88	1.51	271	71	343	400	0.8
		Caerphilly	169,519	121	714	1.14	0.95	1.36	248	112	360	354	0.9
		Monmouthshire	84,885	71	836	1.22	0.97	1.54	224	141	365	471	1.1
		Newport	**137,012**	**106**	**774**	**1.24**	**1.02**	**1.50**	321	95	416	358	**4.8**
		Torfaen	90,949	72	792	1.23	0.97	1.54	242	99	341	451	0.9
	Morgannwg	**Bridgend**	**128,645**	**103**	**801**	**1.23**	**1.01**	**1.49**	342	101	443	358	**1.4**
		Neath Port Talbot	134,468	108	803	1.20	0.99	1.45	335	126	461	342	1.1
		Swansea	**223,300**	**198**	**887**	**1.35**	**1.17**	**1.55**	363	116	479	408	**2.2**
	North Wales	Conwy	109,596	75	684	0.96	0.77	1.21	301	55	356	328	1.1
		Denbighshire	93,065	59	634	0.93	0.72	1.20	301	75	376	258	1.2
		Flintshire	148,594	110	740	1.16	0.96	1.39	357	101	458	283	0.8
		Gwynedd	116,843	88	753	1.13	0.92	1.39	377	103	479	274	1.2
		Isle of Anglesey	66,829	46	688	1.00	0.75	1.34	359	120	479	209	0.7
		Wrexham	**128,476**	**108**	**841**	**1.31**	**1.09**	**1.58**	444	86	529	311	**1.1**
Scotland		**Aberdeen City**	**212,125**	**160**	**754**	**1.21**	**1.03**	**1.41**	354	90	443	311	
		Aberdeenshire	226,871	140	617	0.96	0.81	1.13	264	62	326	291	
		Angus	**108,400**	**91**	**839**	**1.24**	**1.01**	**1.52**	286	74	360	480	
		Argyll & Bute	91,306	64	701	1.02	0.80	1.30	285	142	427	274	
		Scottish Borders	106,764	58	543	0.78	0.61	1.01	215	94	309	234	
		Clackmannanshire	48,077	26	541	0.85	0.58	1.25	229	62	291	250	
		West Dunbartonshire	93,378	54	578	0.92	0.70	1.20	214	96	311	268	
		Dumfries & Galloway	147,765	108	731	1.04	0.86	1.26	345	95	440	291	
		Dundee City	**145,663**	**125**	**858**	**1.34**	**1.12**	**1.59**	378	89	467	391	
		East Ayrshire	120,235	75	624	0.96	0.77	1.20	258	116	374	250	
		East Dunbartonshire	108,243	83	767	1.17	0.95	1.46	286	65	351	416	
		East Lothian	90,088	61	677	1.03	0.80	1.32	311	33	344	333	
		East Renfrewshire	89,311	59	661	1.03	0.80	1.33	235	34	269	392	
		Edinburgh, City of	448,624	286	638	1.03	0.92	1.16	279	49	328	310	
		Falkirk	145,191	93	641	1.00	0.81	1.22	296	28	324	317	
		Fife	349,429	219	627	0.97	0.85	1.11	283	77	361	266	
		Glasgow City	**577,869**	**477**	**825**	**1.36**	**1.24**	**1.48**	374	55	429	396	
		Highland	208,914	160	766	1.14	0.98	1.33	330	153	483	282	
		Inverclyde	**84,203**	**70**	**831**	**1.28**	**1.01**	**1.62**	380	119	499	333	
		Midlothian	80,941	65	803	1.25	0.98	1.60	408	99	507	297	
		Moray	86,940	58	667	1.03	0.79	1.33	242	92	334	334	
		North Ayrshire	**135,817**	**110**	**810**	**1.25**	**1.04**	**1.50**	339	140	479	331	
		North Lanarkshire	**321,067**	**238**	**741**	**1.20**	**1.06**	**1.36**	330	75	405	336	
		Orkney Islands	19,245	15	779	1.15	0.69	1.91	156	104	260	520	
		Perth & Kinross	134,949	94	697	1.02	0.83	1.25	289	119	408	289	

Table 4.5: (continued)

UK Area	LA	Name	Total Pop	Total	RRT rate pmp	Ratio	L 95% CI	U 95% CI	HD rate pmp	PD rate pmp	Dialysis rate pmp	Tx rate pmp	% ethnicity
Scotland		Renfrewshire	172,867	134	**775**	**1.20**	1.02	1.43	336	75	411	364	
		Shetland Islands	21,988	11	500	0.80	0.44	1.44	136	45	182	318	
		South Ayrshire	112,097	74	660	0.95	0.76	1.20	187	152	339	321	
		South Lanarkshire	**302,216**	**224**	**741**	**1.16**	**1.02**	**1.32**	291	79	371	371	
		Stirling	86,212	47	545	0.85	0.64	1.14	267	35	302	244	
		West Lothian	158,714	94	592	0.99	0.81	1.21	189	76	265	328	
		Eilean Siar	26,502	15	566	0.81	0.49	1.34	113	264	377	189	

Standardised prevalence ratios

Methods

The methods of calculating the standardised rate ratio are described in detail in Appendix D. In summary, age and gender specific prevalences were first calculated using the available registry data on the number of prevalent patients for the covered area in England, Wales and Scotland and the data on the age and gender breakdown of the population of each Local Authority area obtained from the 2001 census data from the Office of National Statistics (ONS). These age and gender prevalences were then used to calculate the expected prevalence for each LA area. The age and gender standardised ratio is therefore equal to (observed prevalence)/(expected prevalence).

A ratio of 1 indicates that the LA area's prevalence was as expected if the age/gender rates found in the total covered population applied to the LA area's population structure; a level above 1 indicates that the observed prevalence is greater than expected given the LA area's population structure; if the lower confidence limit was above 1 this is statistically significant at the 5% level. The converse applies to standardised prevalence rate ratios under one.

Results

The mean LA prevalence rate in 2004 was 638 pmp.

In 2004, there is substantial variation in the crude LA area prevalence from 322 (Oldham) to 1,108 pmp (Methyr Tydfil). Local Authorities with small populations have wide confidence limits for the prevalence rate, such that the interpretation of an individual year may be difficult. The confidence limits are often such that the limits for standardised prevalence ratios (SPR) include one. Nevertheless some areas have significantly high ratios: these are often areas with a high ethnic minority population and/or a socially deprived population, factors which have been shown to influence the prevalence of RRT (see 2003 Registry Report).

There was a close relationship between the ethnic composition of a LA area and its SPR. Of the 42 LA areas with significantly high SPRs, 9 were in Scotland where acceptance rates have been higher for some years and from where ethnicity data are not available, although the ethnic minority populations are known to be smaller than England. Of the 33 areas in England and Wales with a significantly high SPR, 22 (66%) had a non-white population of over 10%, and these were mostly in excess of 20%. By comparison only 3 of 29 (7%) of those areas with significantly low SPRs had ethnic minority populations of more than 10%, and these were all below 15% ($p < 0.001$) and were all in Lancashire. Similarly twenty-six of the 33 (79%) LA areas with non-white population proportions of >10% had high SPRs (69%) compared with 13 of the 110 (12%) of those with non-white populations of less than 10% ($p < 0.001$).

Thus ethnicity is a major factor underlying high SPR in some areas but not in others, such as Merthyr Tydfil and Liverpool where social deprivation may play a significant role. Neither ethnicity nor deprivation explain all these variations; local referral patterns, acceptance policies and resource availability may play a role. None of the LA areas in Wales and only 3 in south-west England (8%) had low SPRs compared

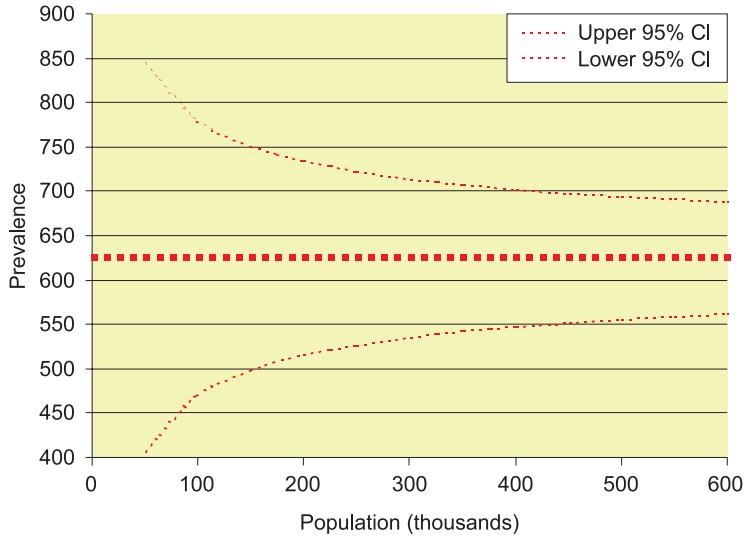


Figure 4.2: 95% confidence limits for prevalence of 630 pmp for population sizes 50,000–600,000

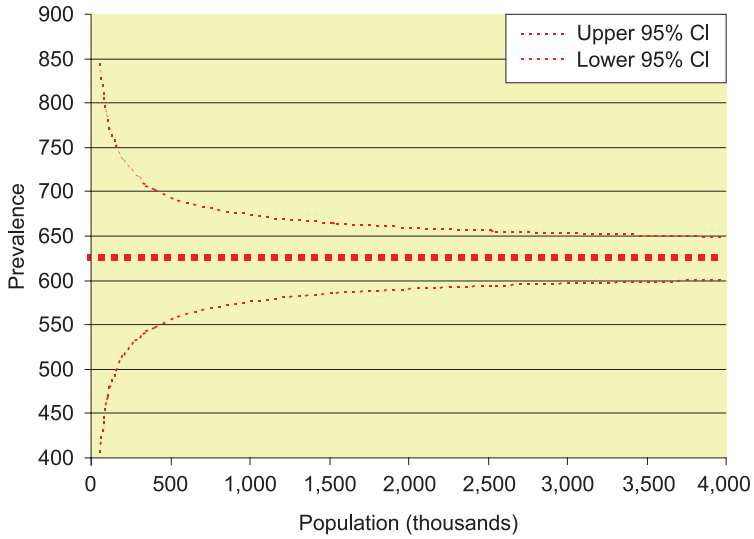


Figure 4.3: 95% confidence limits for prevalence of 630 pmp for population sizes 50,000–4 million

with 26 of 108 elsewhere in England ($p = 0.001$), and prevalences in Lancashire around Manchester seem low despite high ethnic minority populations (24%).

Prevalence rates for RRT in relatively small populations such as those covered by individual Primary Care Trusts, incur wide confidence intervals for any observed frequency. To enable assessment of whether an observed prevalence rate differs significantly from the national average, Figures 4.2 and 4.3 have been included. For any size of population (X axis), the upper and lower 1 in 20 confidence intervals around the national average prevalence can be read from the Y axis (dotted lines). Any observed prevalence for renal failure outside these limits is significantly different from the national average. Thus for a population of 50,000, an observed prevalence outside the limits of 400 to 850 pmp is significantly different, whilst for a population of 500,000 the limits are 560 to 690 pmp.

Vintage of prevalent patients

Table 4.6 shows the median vintage (years since starting renal replacement therapy) of prevalent RRT patients in 2004. Median vintage of the whole RRT population was 5.0 years. Patients with functioning transplants had survived a median 9.6 years on RRT whilst the median vintage of HD and PD patients was much less (2.7 and 2.1 years respectively).

Table 4.6: Median vintage of prevalent RRT patients on 31.12.04

Modality	N	Median time on RRT (years)
Haemodialysis	13,606	2.7
Peritoneal dialysis	4,191	2.1
Transplant	14,237	9.6
RRT	32,034	5.0

Age

The overall age profile for prevalent patients is shown in Figure 4.4.

In terms of numbers of patients, prevalence of RRT was maximal in the age range 55–65 years (Figure 4.4). Figure 4.5 shows the maximal prevalence rate (calculated from Local Authority populations covered by the Registry using 2001 Census data) occurred in the age band 65–74 (1,460 pmp) overall, but was different in men (80–85 year age band; 2,065 pmp) from women (65–74 year age band; 1,073 pmp). This pattern is also similar for dialysis patients (Figure 4.6).

Figure 4.7 shows the changes in RRT prevalence rates during the period 2001–2004.

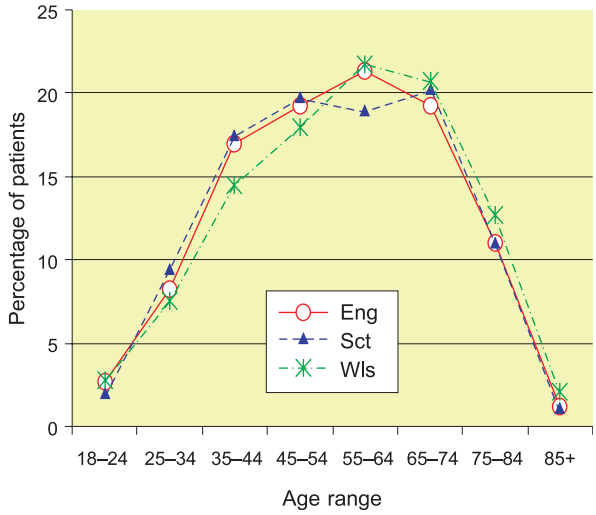


Figure 4.4: Age profile of prevalent adult patients* by country, 31/12/2004

*excludes data on those aged <18 which is reported in Chapter 18

Prevalence rates are increasing annually in all age bands over the age of 30 with the largest increases in patient prevalence rates in the 55–85 year bands.

Transplant prevalence was maximal between the ages of 40 and 60 years, whilst for dialysis treatment maximum prevalence was almost 20 years later (Figure 4.8).

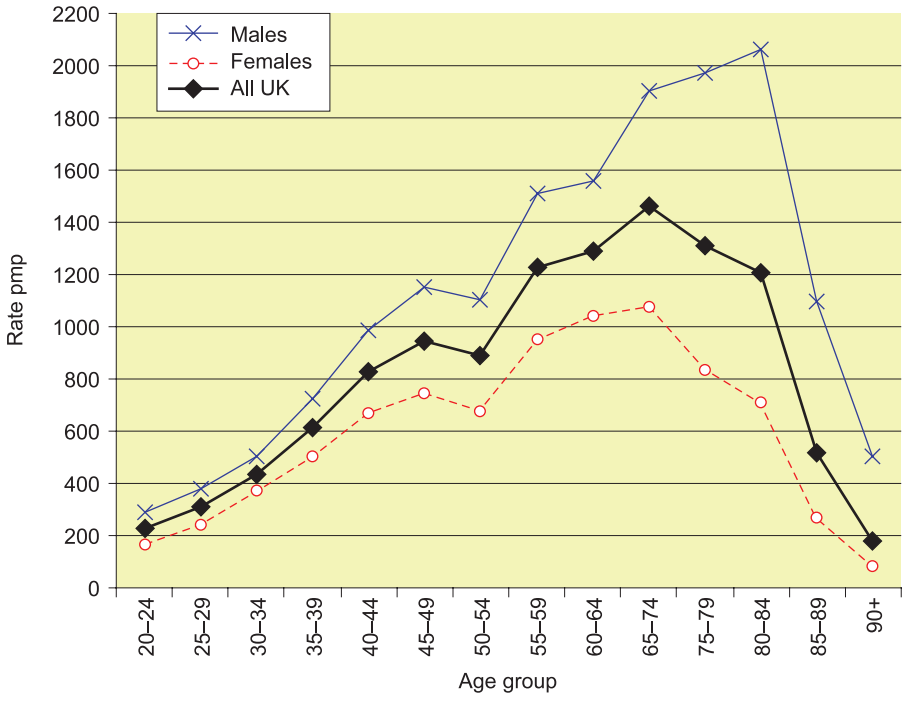


Figure 4.5: Crude prevalence rate of RRT patients per million population by age and gender on 31/12/04

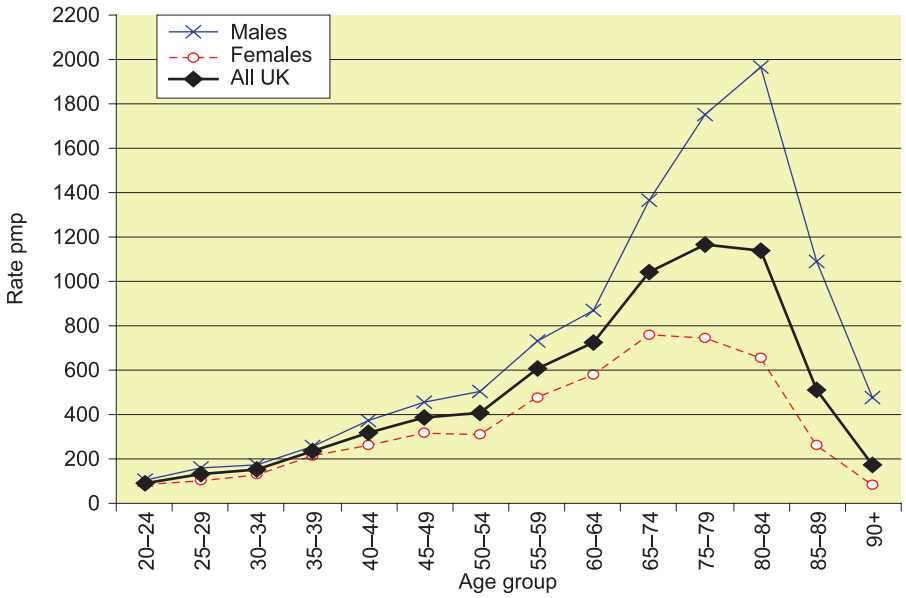


Figure 4.6: Crude prevalence rate of dialysis patients per million population by age and gender on 31/12/04

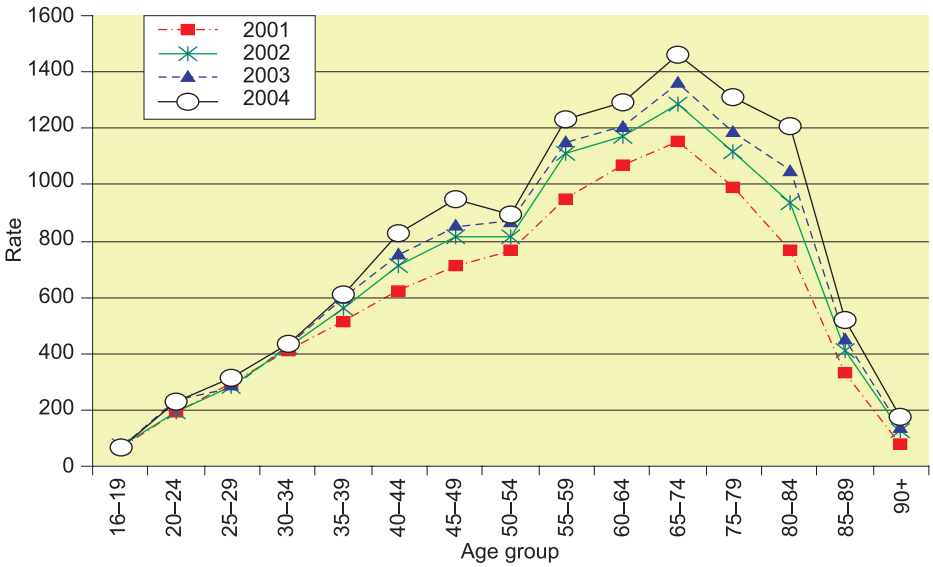


Figure 4.7: Crude prevalence rate of RRT per million population by age band, 2001–2004

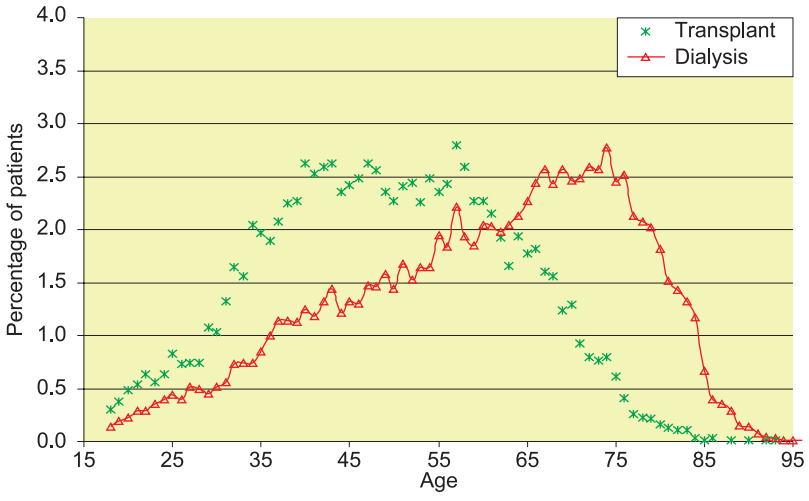


Figure 4.8: Age profile of prevalent dialysis and transplant patients 31/12/04

Gender

Of the prevalent patients 61% were male. Both England and Wales showed over 60% preponderance of males across all age groups. This contrasts with Scotland where this dropped to below 60% in the 55–64, 65–74, 75–84 and 85+ age groups where it was 59%, 58%, 54%, and 56% respectively.

Ethnicity

There has been no improvement in the provision of ethnicity data since 2002 with only 27 of 60 centres (45%) returning at least 90% complete ethnicity data (Table 4.7). This is disappointing and means that the available data are unlikely to be truly representative. Ethnicity distributions were not calculated for Wales due to the poor returns, or for centres with less than 50% of data returned. The Scottish Renal Registry does not collect ethnicity as a mandatory data item so returns have also not been calculated for Scotland.

These data demonstrate wide variation across the UK. In the 36 centres with returns of 70% or more in each RRT modality, the proportion of Whites was slightly but significantly higher in

Table 4.7: Ethnicity of prevalent patients by centre 2004

Treatment centre	% White	% Black	% South Asian	% Chinese	% Other	% return
Dudley	90	2	7	0	0	100
Gloucester	100	0	0	0	0	100
H&CX	41	11	20	1	27	100
Heartlands	71	6	20	1	2	100
Stevenage	82	4	13	0	1	100
QEH	70	10	19	1	1	100
Wolverhampton	78	6	15	1	0	100
Reading	76	7	14	1	3	99
Basildon	92	1	4	1	1	99
Newcastle	97	0	2	1	0	99
Bristol	93	3	2	0	1	99
Sheffield	93	2	3	1	1	98
Leicester	81	2	16	0	1	97
Portsmouth	97	0	2	0	0	97
Carlisle	99	0	1	0	0	96
Nottingham	89	5	5	0	1	96
Preston	85	1	13	0	1	96
Sunderland	99	0	0	0	0	94
Liverpool	97	1	1	1	1	93
Middlesbrough	96	0	3	1	0	92
Plymouth	96	2	1	1	1	92
Shrewsbury	94	2	3	0	0	92
ManWst	86	1	11	0	1	91
York	99	0	1	0	1	89
Coventry	82	3	14	1	0	88
Guys	73	22	4	1	0	86
Derby	88	3	7	1	2	85
Barts	50	12	21	2	16	83
Dorset	97	1	1	1	0	80
Bradford	62	3	34	0	1	77
Hull	98	0	0	0	1	73
Exeter	99	1	0	0	0	69
Leeds	83	4	12	0	1	69
Wirral	98	1	0	0	2	68

Table 4.7: (continued)

Treatment centre	% White	% Black	% South Asian	% Chinese	% Other	% return
Carshalton	71	10	10	1	9	67
Southend	92	4	4	0	0	56
Truro	99	1	0	0	0	50
Norwich						44
Oxford						39
Cambridge						38
Chelmsford						31
Brighton						22
Kings						6
Ipswich						6
England	**83**	**5**	**9**	**1**	**3**	**81**
Dundee	100	0	0	0	0	97
Airdrie	99	0	1	0	0	92
Aberdeen	99	0	0	1	0	90
Inverness	100	0	0	0	0	83
Dunfermline	97	0	1	1	0	51
Dumfries & Galloway						20
Glasgow RI						12
Stobhill*						11
Glasgow WI						10
Edinburgh						9
Kilmarnock						4
Scotland						**n/a**
Swansea	99	0	1	0	0	98
Bangor	100	0	0	0	0	63
Wrexham	99	0	0	1	0	53
Clwyd						36
Cardiff						28
Wales						**48**

*Stobhill renal unit is part of the Glasgow Royal Infirmary renal unit

the transplant cohort (88%) than in the HD (83%: $p = 0.001$) and PD (83%: $p = 0.009$) cohorts. Presumably, this was due to differences in blood group and HLA antigen profiles in donors and potential recipient populations, associated with differences in ethnic composition. For most centres, the proportion of Whites in the transplant and dialysis cohorts is similar. In two centres (Guy's/St Thomas' and Barts/The London), the proportion of Whites in the transplant cohort was markedly higher than the proportion in the HD and PD cohorts and in a third centre (Bradford) than in the PD cohort only. All these centres have a high proportion of non-White prevalent patients.

Primary renal disease

There has been no major difference in the pattern of diagnoses compared with last year, though there were slightly fewer patients in the aetiology uncertain/Glomerulonephritis – not biopsy proven category (19.1% vs 23.1%) and a corresponding increase (19.5% vs 15.5%) in the Glomerulonephritis – biopsy proven category (Table 4.8). The most common identifiable diagnosis remains glomerulonephritis (22.3%) for those under 65 and diabetes (13.4%) in those over 65. Overall 12.1% of the prevalent patients had a primary diagnosis of diabetic nephropathy in contrast to the 21.4% of the incident patients, although a significant proportion of patients also

Table 4.8: Primary renal disease in prevalent RRT patients by age and gender in 2004

Primary diagnosis	% all patients	Inter unit range %	% age <65	% age >65	M : F ratio
Aetiology unc./Glomer. NP*	19.1	2.2–76.3	16.4	24.8	1.5
Glomerulonephritis**	19.5	1.8–27.0	22.3	13.4	2.2
Pyelonephritis	12.8	1.7–19.4	14.5	9.1	1.0
Diabetes	12.1	1.0–24.6	11.6	13.2	1.6
Polycystic kidney	9.1	1.0–15.5	9.6	8.1	1.1
Hypertension	5.8	0.3–15.5	5.1	7.4	2.4
Reno-vascular disease	3.7	0.5–10.8	1.4	8.7	1.9
Other	13.9	2.2–25.0	15.5	10.3	1.3
Not sent	4.0	0.1–87.7	3.5	5.0	1.6

*Glomerulonephritis not proven.
**Glomerulonephritis biopsy proven.

Table 4.9: Primary renal disease in prevalent dialysis and transplant patients

Primary diagnosis	% transplant	% dialysis
Aetiology unc./Glomer. NP*	39	61
Glomerulonephritis**	57	43
Pyelonephritis	56	44
Diabetes	27	73
Polycystic Kidney	58	42
Hypertension	40	60
Reno-vascular disease	14	86
Other	48	52
Not sent	35	65

*Glomerulonephritis not proven.
**Glomerulonephritis biopsy proven.

have diabetes mellitus as a co-morbid disease. The male : female ratio was 1.6 overall, and was greater than unity for all primary renal diseases, though only marginally for polycystic kidney disease and pyelonephritis.

The transplant cohort contained a greater proportion of patients with glomerulonephritis, pyelonephritis, and polycystic kidney disease than the dialysis cohort whilst diabetes and reno-vascular disease were markedly less frequent (Table 4.9).

Diabetes

The median age of all prevalent diabetic RRT patients (58 years) is similar to that of non diabetics (56 years), though those with Type 1 disease are considerably younger (52 years) and those with Type 2 disease considerably older at 66 years (Table 4.10). The RRT vintage of prevalent diabetics (2.7 years) is significantly less than that of non-diabetics (5.6 years), particularly Type 2 diabetics (2.2 years). Fewer diabetics have a functioning transplant (26%) compared with non-diabetics (48%). Of prevalent patients with Type 1 diabetes, 35% have a functioning transplant, rising to 42% in those under 65 years of age. Only 11% of prevalent Type 2 have a functioning transplant, falling to only 7% in those over 65 (Table 4.11).

Table 4.10: Type of diabetes, median age, gender ratio, and treatment modality in prevalent RRT patients 31/12/2004

	Type 1	Type 2	All diabetes	Non-diabetics
Number of patients	**2,566**	**1,492**	**4,058**	**28,045**
M : F Ratio	1.50	1.72	1.58	1.53
Median age on 31.12.04	52	66	58	56
Median age started RRT	47	63	54	47
Median years on RRT	3.2	2.2	2.7	5.7
Percentage HD	47	69	55	40
Percentage PD	17	20	18	12
Percentage Tx	36	11	27	48

Table 4.11: Age relationships of type of diabetes and modality in prevalent RRT patients 31/12/2004

	Age less than 65			Age 65 or more		
	Type 1	Type 2	Non-diabetics	Type 1	Type 2	Non-diabetics
Total	**1,990**	**662**	**19,340**	**576**	**830**	**8,703**
Percentage HD	38	62	29	76	75	63
Percentage PD	18	22	11	15	18	14
Percentage TX	44	16	59	8	7	24

Modalities of treatment

The most common treatment modality overall is transplantation (44.9%), closely followed by HD (42.1%) (Figure 4.9). The proportion of patients on home HD remains very small in spite of the recent NICE guidelines[1]. Analysing the use of home HD by individual renal unit shows that the overall fall in patient numbers on this modality has stopped and numbers were stable. Preston is the only renal unit showing an increase in the size of its home HD programme. No new home HD programmes appear to have been started by renal units.

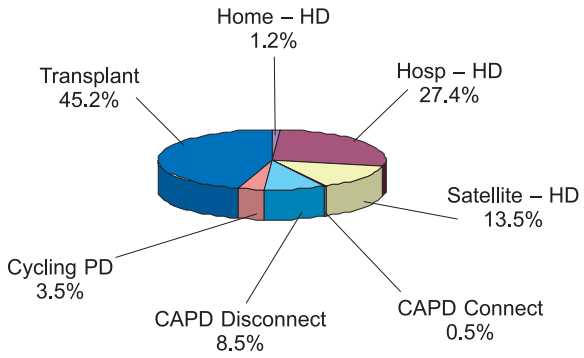


Figure 4.9: Treatment modality in prevalent RRT patients 2004

Transplantation is the predominant treatment modality in patients less than 65 years old, whilst haemodialysis is in those 65 or older (Table 4.12). The proportion of RRT patients on PD (12.5%) continues to fall. The proportion of patients on PD remains fairly stable across the whole age spectrum with respect to the whole RRT population (Figure 4.10) but diminishes with increasing age when analysed as a proportion of the dialysis population.

In some centres local coding of renal replacement therapy modality is such that the Registry could not differentiate between CAPD and cycling PD. In these centres all PD patients are included as CAPD Disconnect. Thus the proportion of PD patients on Cycling PD is a slight underestimate. These centres are: Reading, Sheffield, Stevenage, Southend, Dudley and Coventry.

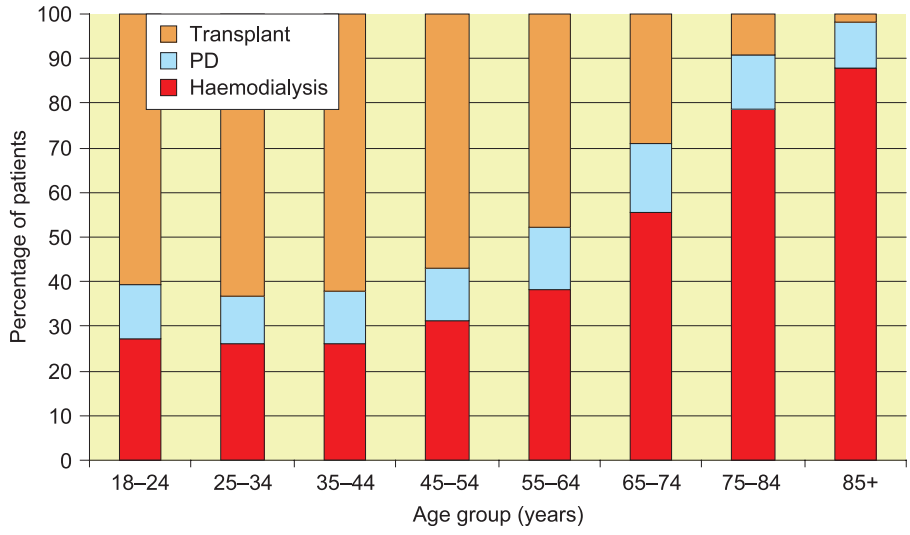


Figure 4.10: Treatment modality distribution by age in prevalent RRT patients

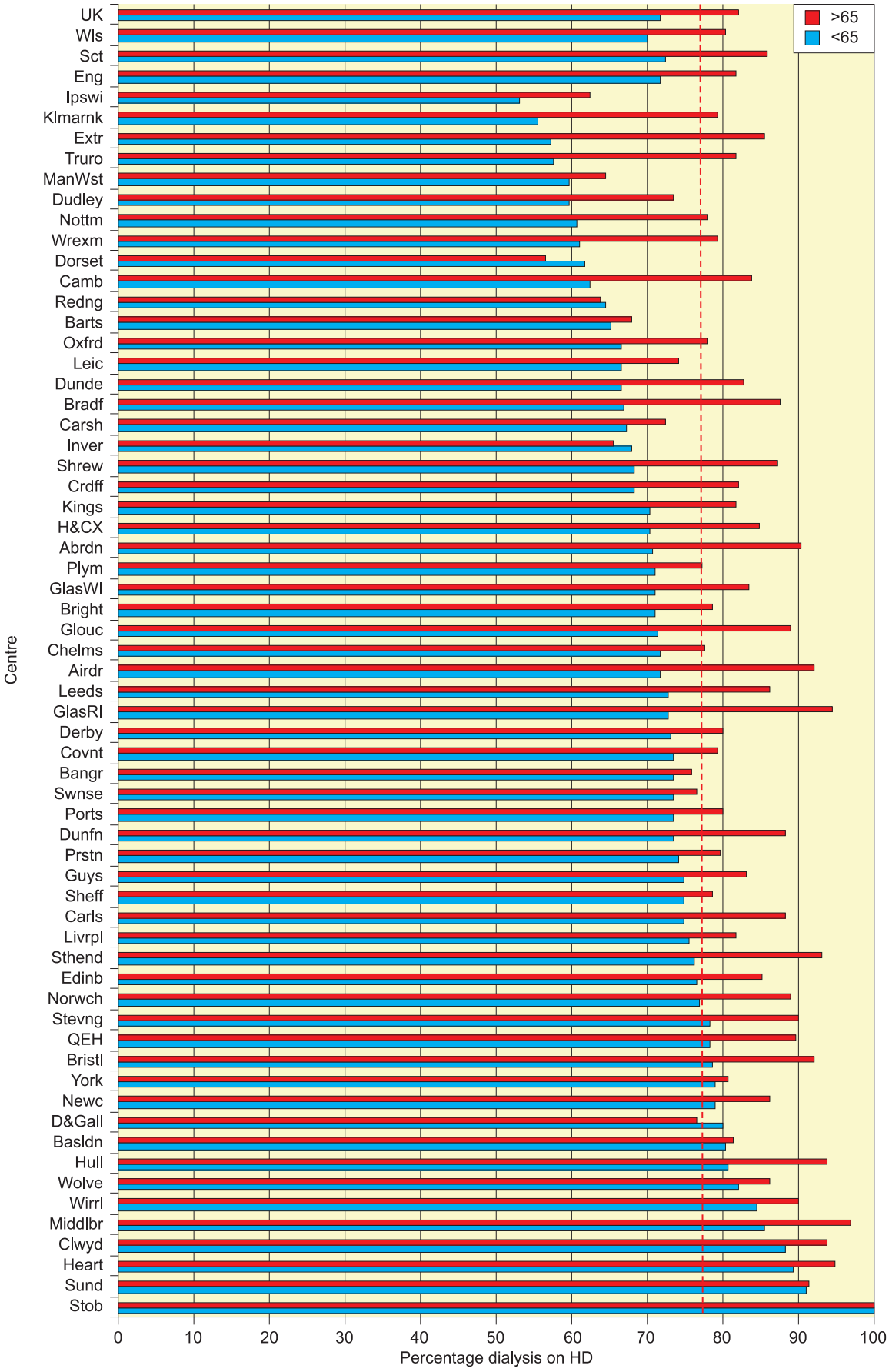


Figure 4.11: Proportion of older and younger prevalent dialysis patients on haemodialysis in each centre in 2004

Haemodialysis

The proportion of dialysis patients on HD varied widely between renal units and in all but four (Dorset, Reading, Inverness, Dumfries & Galloway) was higher in those over 65 years than in younger patients (Figure 4.11). Of the male dialysis population, 77.5% were on HD compared with 75.7% of the female dialysis population ($p = 0.005$).

In England and Wales hospital based HD accounted for 47% of the whole dialysis program. (Scottish centres were excluded from this analysis as there is no information from Scotland on whether HD patients are dialysed in main centres or satellite units.)

The proportion receiving HD in satellite units was 27% (Figure 4.12) with wide variations between centres. Only 2% were on home HD. Only 4 renal units (Brighton, Bristol, Heartlands and Sheffield) had home HD programmes amounting to more than 5% of total dialysis activity (Figure 4.12).

Peritoneal dialysis

The proportion of prevalent dialysis patients on PD varies widely ranging from 8% at Heartlands to over 40% in Ipswich and Dorset (Figure 4.13). Stobhill has no patients on PD although this centre is now incorporated with Glasgow Royal Infirmary which does have 17% of patients on PD.

Overall 23.7% of the female dialysis population were on PD compared with 22.0% of the male dialysis population ($p = 0.013$). However the Male : Female ratio varied widely between renal units from over 2 in Basildon and Sunderland to 0.66 and 0.64 in Bristol and Stevenage respectively (Figure 4.14).

Automated PD now comprises 29% of all PD, but there are huge variations between renal units from 0% of all PD patients to 98% of PD patients in Wrexham (Figure 4.15). Use of connect systems now seems to have disappeared.

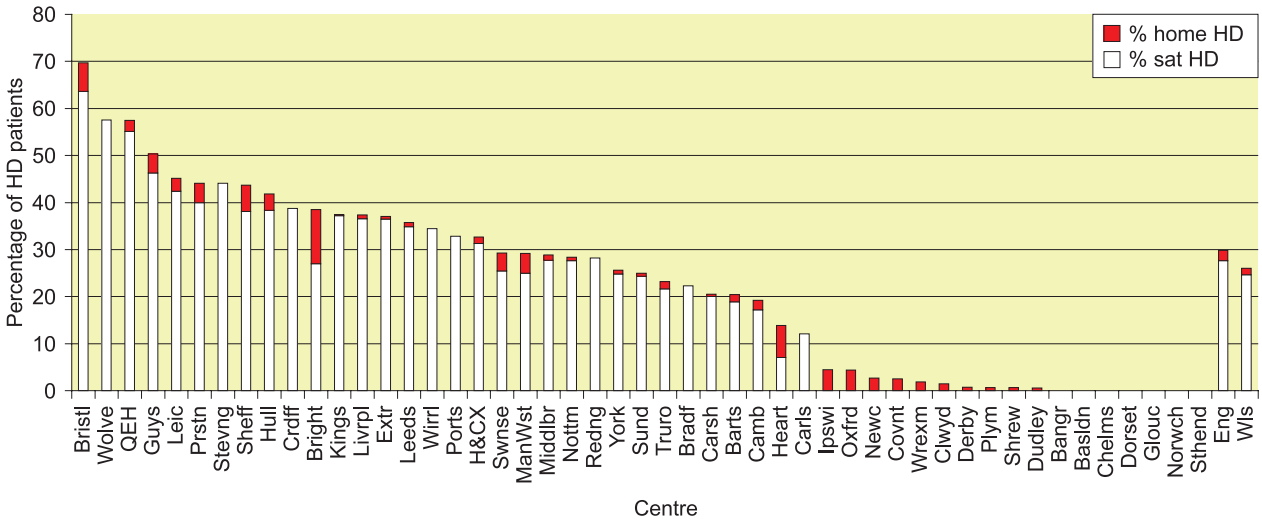


Figure 4.12: Percentage of prevalent HD patients treated at home and in satellite units in 2004

Scottish centres are excluded from analysis as there is no information on whether HD patients are dialysed in main centres or satellite units

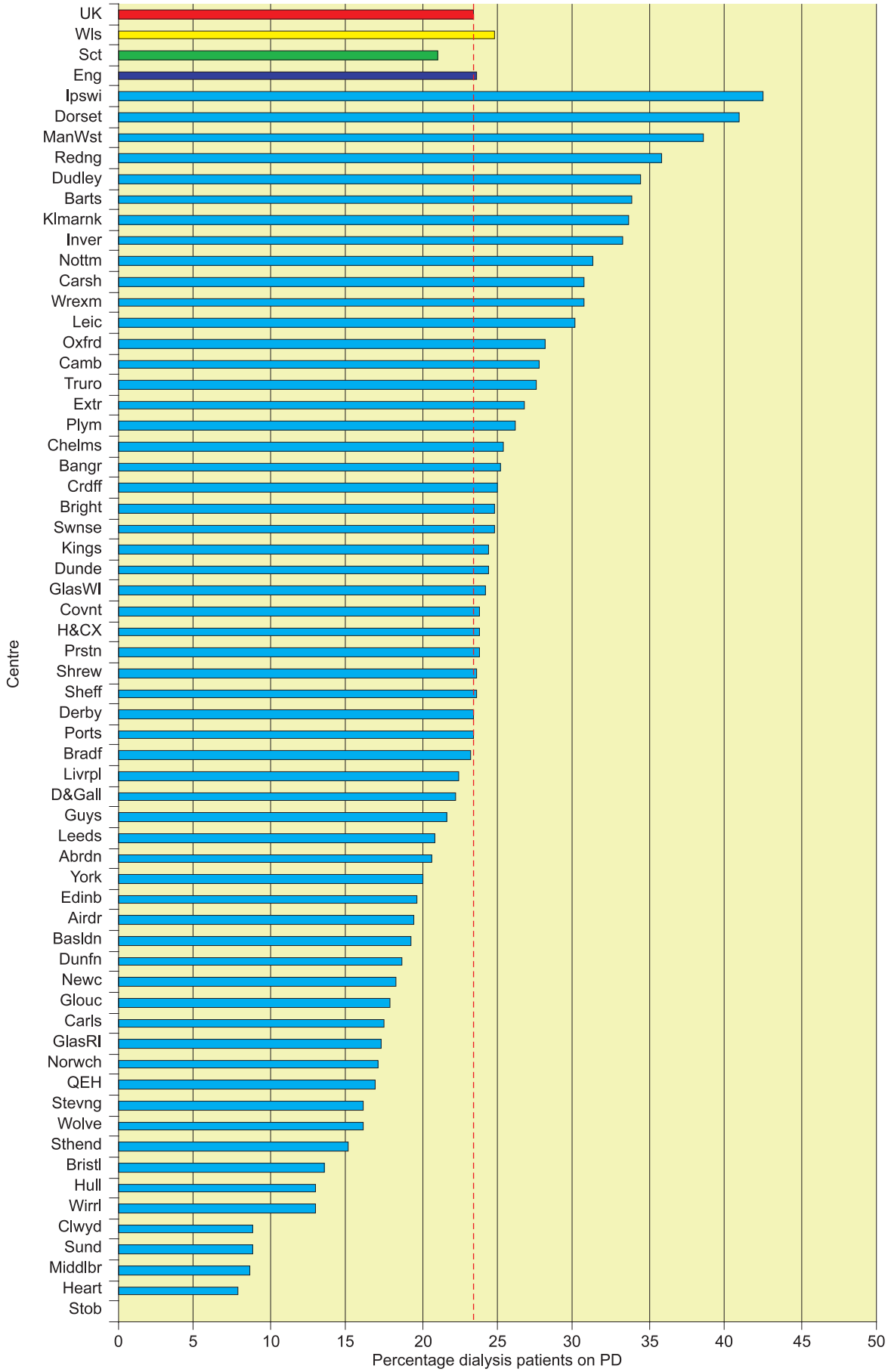


Figure 4.13: Proportion of prevalent dialysis patients on PD at each centre 2004

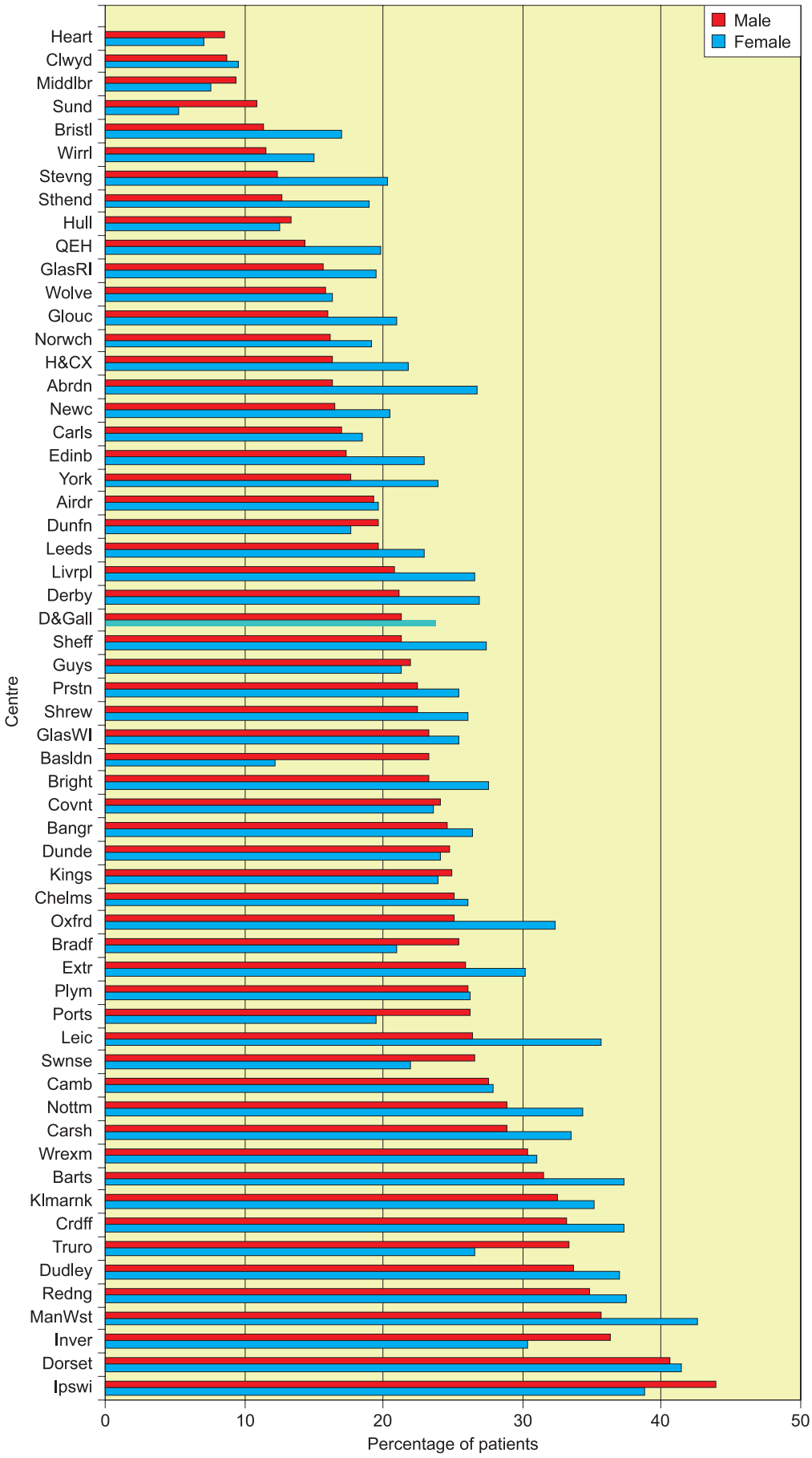


Figure 4.14: Proportion of dialysis patients on PD by gender

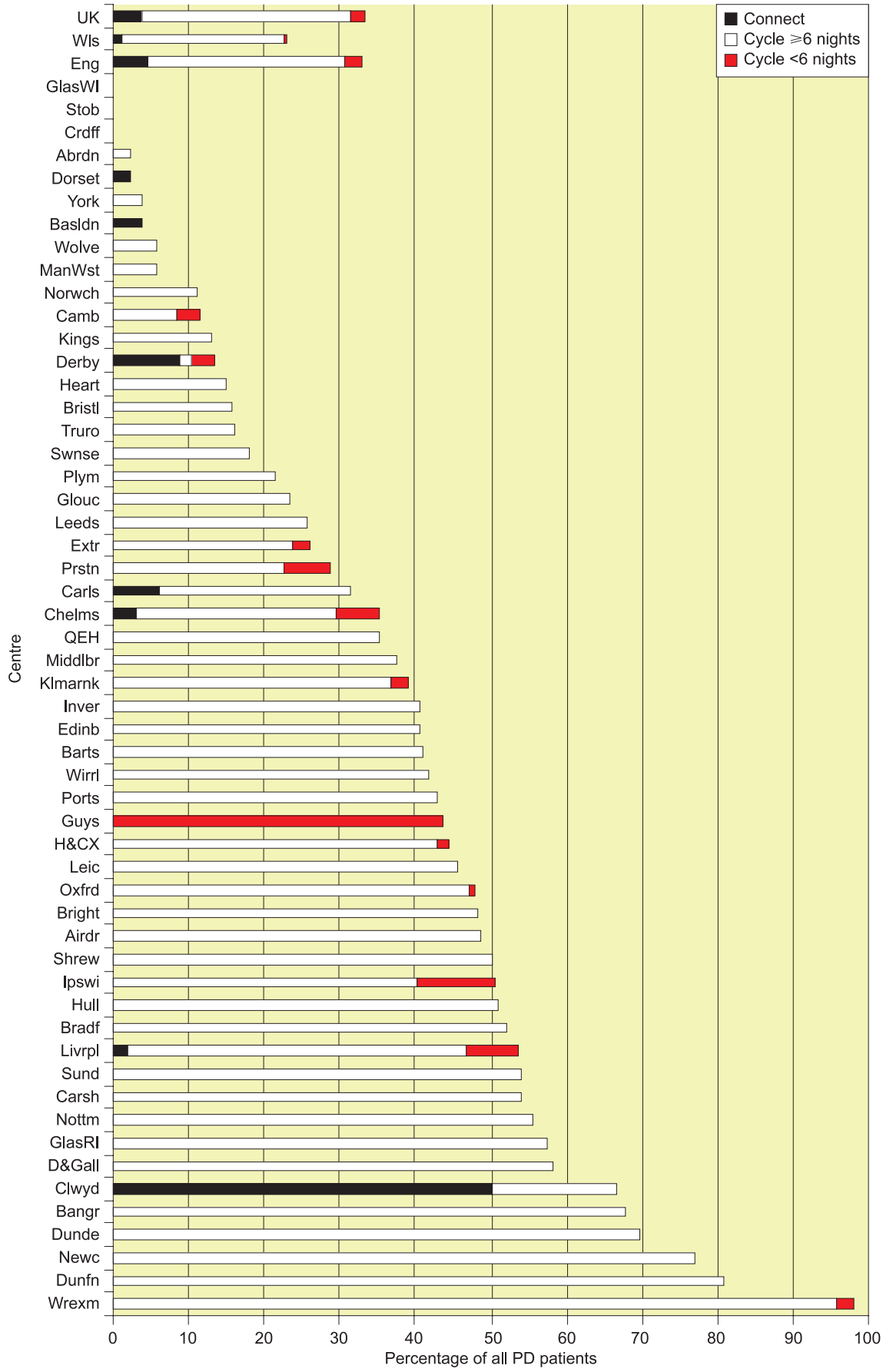


Figure 4.15: Use of connect and automated PD as a percentage of total PD

Reading, Sheffield, Stevenage, Southend, Dudley and Coventry were not able to give the number of patients on cyclical PD

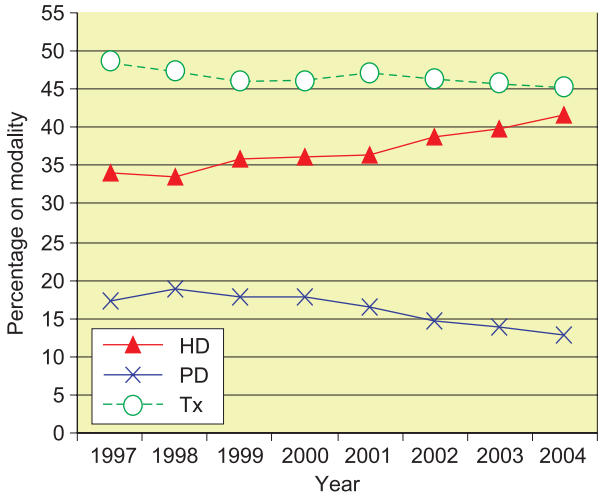


Figure 4.16: Modality changes in prevalent RRT patients 1997–2004

Change in treatment modality 1997–2004

Although the figures from each year are not strictly comparable as the number of renal units contributing to the Registry have increased successively, Figure 4.16 suggests that the proportion of prevalent RRT patients on haemodialysis is increasing. There is a decreasing proportion of peritoneal dialysis and transplant patients.

The proportion of patients using home haemodialysis remains very low despite the NICE guidance (Table 4.12), whilst the proportion on satellite HD continues to rise. The proportion on automated PD is rising very slowly.

Survival of patients established on RRT

This section analyses the one year survival of all patients who had been established on RRT for at least 90 days on 1 January 2004. The patients in the transplant cohort have all been established with a transplant for at least 6 months.

As discussed in previous Reports, comparison of survival of prevalent dialysis patients between centres is complex. Survival of prevalent dialysis patients can be studied with or without censoring at transplant. When a patient is censored at transplantation, the patient is considered as alive up to the point of transplantation, but the patient's status post-transplant is not considered. Therefore a death following transplantation is not taken into account in calculating the survival figure. It could induce differences between those renal units with a high transplant rate and those with a low transplant rate, especially in younger patients where the transplant rate is highest. The differences are likely to be small due to the low post-transplantation mortality rate and the relatively small proportion of patients being transplanted in a given year compared to the whole dialysis population (usually less than 15% of the total dialysis population). To estimate the potential differences the results for individual renal units were compared with or without censoring at transplant. The results are shown in Table 4.13. There is never more than a 0.6% difference in one year survival and overall there is a 0.2% higher survival in the censored data. With such small differences only

Table 4.12: Proportion of prevalent patients on different modalities of RRT 1998–2004, England and Wales

	% home HD	% hosp HD	% satellite HD	% CAPD connect	% CAPD disconnect	% cycling PD ⩾6 nights/wk	% cycling PD <6 nights/wk	% transplant
1998	2.59	24.02	6.97	0.70	16.83	1.26	0.16	47.46
1999	2.23	22.55	11.11	0.33	15.70	1.78	0.13	46.17
2000	1.81	25.08	9.25	0.14	15.03	2.01	0.64	46.03
2001	1.42	24.37	10.54	0.02	13.79	2.20	0.42	47.25
2002	1.23	25.32	12.17	0.03	10.99	3.37	0.35	46.52
2003	1.12	25.72	13.10	0.00	10.26	3.37	0.37	46.04
2004	1.21	25.44	15.11	0.61	8.65	3.34	0.30	45.32

This table does not contain data from Scotland as main unit and satellite unit patients in Scotland could not be differentiated.

Table 4.13: One year Kaplan-Meier survival of dialysis patients with and without censoring at transplantation (adjusted for age = 60)

	Censoring transplant			Not censoring transplant		
Centre	Adjusted 1 year survival	Lower 95% CI	Upper 95% CI	Adjusted 1 year survival	Lower 95% CI	Upper 95% CI
SA	86.1	81.3	91.2	86.4	81.7	91.4
SB	84.3	79.1	89.8	84.6	79.6	90.0
SC	82.8	75.1	91.4	83.6	76.1	91.8
SD	83.1	79.2	87.3	83.5	79.6	87.6
SE	85.4	80.4	90.7	85.9	81.0	91.1
SF	88.6	83.5	94.0	88.8	83.8	94.1
SG	91.4	87.1	96.0	91.6	87.3	96.0
SH	85.7	81.7	89.9	85.6	81.6	89.8
SI	88.9	83.7	94.6	89.0	83.8	94.6
SJ	84.9	80.1	89.8	85.1	80.5	90.0
SK	87.5	81.8	93.6	87.7	82.1	93.7
T0	86.0	83.1	88.9	86.1	83.2	89.0
T1	87.2	84.4	90.0	87.8	85.2	90.4
T2	90.1	86.8	93.6	90.3	87.0	93.7
T3	82.0	77.4	86.8	82.5	78.0	87.2
T4	87.2	84.7	89.7	87.3	84.9	89.8
T5	89.2	87.1	91.4	89.4	87.3	91.6
T6	87.1	82.2	92.3	87.4	82.7	92.5
T7	86.0	82.7	89.5	86.1	82.8	89.5
T8	88.8	86.0	91.6	89.1	86.4	91.8
U0	82.0	78.0	86.2	82.4	78.5	86.5
U1	86.2	83.2	89.4	86.2	83.2	89.3
U2	86.5	83.4	89.6	86.7	83.7	89.8
U3	91.1	85.9	96.5	91.1	86.1	96.5
U4	88.5	84.2	93.0	88.7	84.4	93.1
U5	90.3	87.6	93.2	90.5	87.8	93.3
U6	86.2	82.2	90.4	86.4	82.5	90.5
U7	90.8	88.7	93.0	91.0	88.9	93.1
U8	90.2	86.3	94.4	90.3	86.4	94.5
U9	84.6	79.4	90.1	84.3	79.1	89.8
V0	89.1	86.1	92.2	88.9	85.9	91.9
V1	83.6	80.7	86.7	83.7	80.8	86.8
V2	90.4	86.1	94.8	90.4	86.2	94.9
V3	85.8	83.2	88.5	86.0	83.5	88.7
V4	86.7	83.4	90.2	86.8	83.5	90.3
V5	81.7	73.8	90.5	81.8	74.0	90.5
V6	92.1	89.9	94.3	92.1	90.0	94.2
V7	85.3	82.5	88.2	85.6	82.9	88.5
V8	86.2	82.6	90.0	86.4	82.9	90.1
V9	88.0	85.6	90.5	88.1	85.7	90.5
W0	84.2	77.9	90.9	84.4	78.2	91.1
W1	87.4	82.6	92.5	87.7	83.1	92.7
W2	90.3	86.4	94.3	90.5	86.7	94.4
W3	91.4	88.4	94.4	91.2	88.3	94.2
W4	86.5	83.0	90.1	86.8	83.4	90.3
W6	88.0	83.0	93.4	88.2	83.2	93.4
W7	82.5	75.5	90.2	82.9	76.1	90.4

Table 4.13: (continued)

Centre	Censoring transplant			Not censoring transplant		
	Adjusted 1 year survival	Lower 95% CI	Upper 95% CI	Adjusted 1 year survival	Lower 95% CI	Upper 95% CI
W8	88.7	85.5	92.0	88.6	85.5	91.9
W9	87.1	82.2	92.3	87.5	82.8	92.5
X0	89.1	84.4	94.1	89.3	84.6	94.2
X1	87.0	82.0	92.4	87.1	82.1	92.4
X2	87.4	83.5	91.5	87.5	83.6	91.5
X3	87.1	81.0	93.6	87.2	81.3	93.7
X4	82.1	76.5	88.2	82.3	76.7	88.3
X5	83.6	79.8	87.7	83.7	79.9	87.7
X6	90.1	86.1	94.3	89.8	85.8	94.0
X8	86.5	83.6	89.5	87.0	84.2	89.9
X9	88.0	83.6	92.6	88.2	83.9	92.7
Y0	85.1	81.2	89.3	85.6	81.8	89.5
Y1	87.4	84.0	90.9	87.1	83.8	90.6
England	87.2	86.6	87.8	87.4	86.8	88.0
Scotland	85.8	84.3	87.4	86.1	84.5	87.6
Wales	87.6	85.8	89.4	87.8	86.0	89.5
UK	87.1	86.5	87.7	87.3	86.7	87.8

the censored results have been quoted throughout the rest of this chapter.

Another potential source of error in comparing survival in different renal centres of dialysis patients, especially younger patients is the differing transplant rates between centres. Those with a high transplant rate have removed more of the fitter patients from dialysis and are left with a higher risk population on dialysis.

The one year death rate for prevalent UK dialysis patients is 17.1 per 100 patient years (95% CI 16.5–17.8) and 16.9, 19.1, 17.6 per 100 patient years in England, Scotland and Wales respectively. In Figure 4.17 the survival of prevalent dialysis patients for each age band is shown.

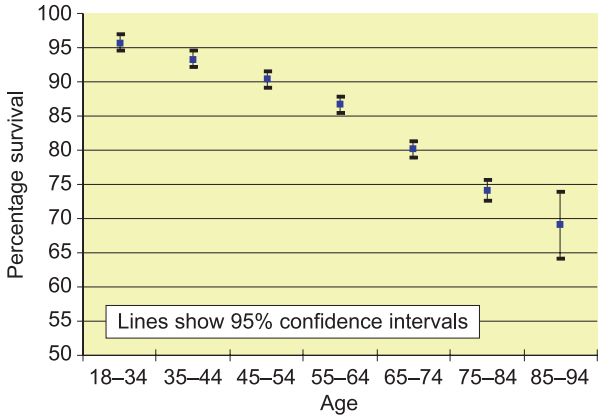


Figure 4.17: 1 year survival of prevalent dialysis patients in different age groups – 2004

The one year survival of prevalent dialysis patients in each centre

The one year survival of dialysis patients in each centre is shown in Table 4.13 and is illustrated in Figures 4.18 and 4.19. There appeared to be a significant difference in the survival rate between the centres ($p = 0.0003$), after adjusting for the difference in median age of patients at each centre (Figure 4.20). The Registry has published a paper on neural network analysis of survival in UK prevalent patients[2] which indicates that the difference in survival between centres is related to differences in patient characteristics, rather than a true centre effect. There was no significant difference in survival between England, Scotland and Wales ($p = 0.40$).

Further survival analysis is presented in Table 4.14.

Table 4.14: One-year survival of established prevalent RRT patients in England, Scotland and Wales (unadjusted unless stated otherwise)

Patient group	Patients	Deaths	KM survival	KM 95% CI
Transplant patients 2004				
Censored at dialysis	13,256	286	**97.8**	97.6–98.1
Not censored at dialysis	13,263	314	**97.6**	97.4–97.9
Dialysis patients 2004				
All 2004	14,583	2,144	**85.1**	84.5–85.7
All 2004 adjusted age = 60	14,583	2,144	**87.4**	86.8–88.0
2 year survival – dialysis patients 2003				
All 1/1/2002 (2 year)	13,359	3,182	**74.7**	74.0–75.5
Dialysis patients 2004				
All age <65	9,087	797	**90.3**	89.7–91.0
All age 65+	7,341	1,646	**77.2**	76.3–78.2
Non-diabetic <55	4,345	253	**94.1**	93.4–94.8
Non-diabetic 55–64	2,403	282	**88.2**	86.9–89.5
Non-diabetic 65–74	3,225	585	**81.8**	80.5–83.1
Non-diabetic 75+	2,896	752	**73.9**	72.3–75.5
Non-diabetic <65	6,748	535	**92.0**	91.3–92.6
Diabetic <65	1,480	242	**83.5**	81.6–85.4
Non-diabetic 65+	6,121	1,337	**78.1**	77.0–79.1
Diabetic 65+	1,137	301	**73.4**	70.9–76.0

KM = Kaplan-Meier survival.
Cohorts of patients alive 1/1/2004 unless indicated otherwise.

The one year survival of prevalent dialysis patients in England, Wales and Scotland from 1997–2004

The one-year survival of prevalent dialysis patients (Table 4.15, Figure 4.21) increased significantly from 1998 to 2004 in England (84.2% to 87.5% $p = 0.0001$ for linear trend), Scotland (84.0% to 86.1% $p = 0.023$ for linear trend), and Wales (78.2% to 87.8% $p = 0.027$ for linear trend). The test for non-linearity in this trend (indicating that there has been a large increase which is now tailing off) was significant for England and Wales.

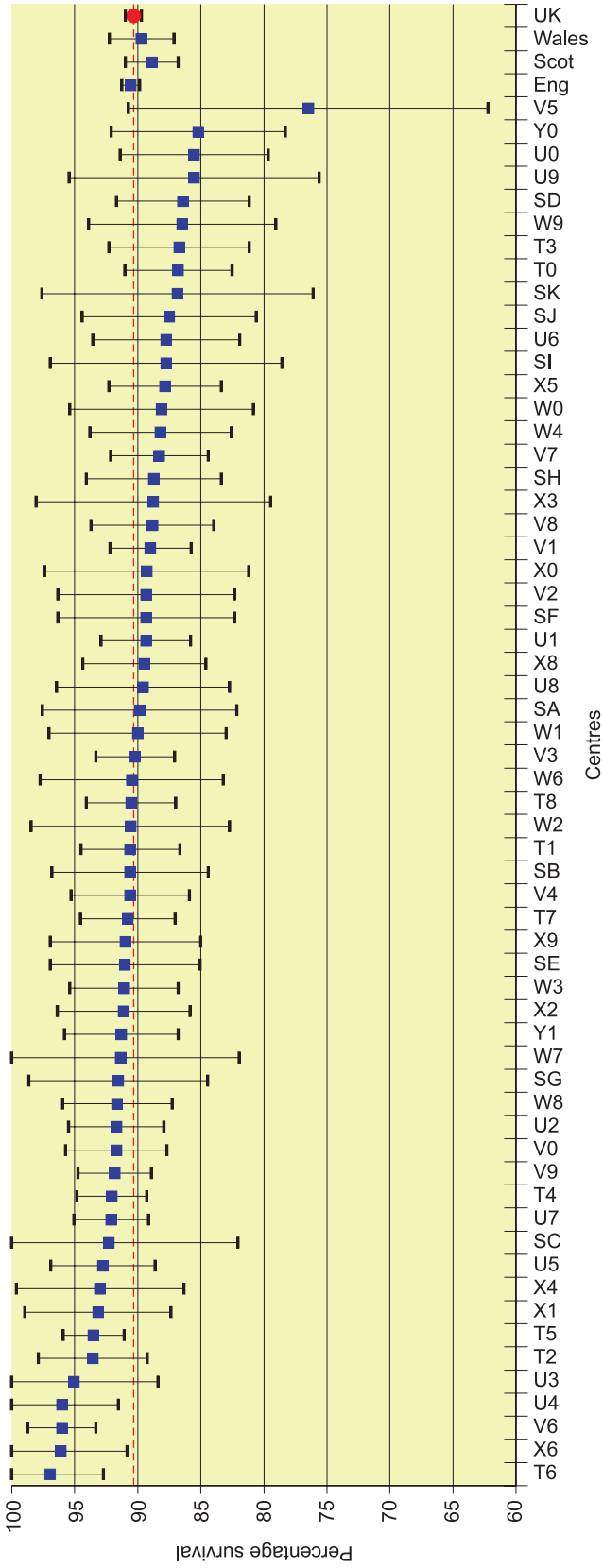


Figure 4.18: One year survival of prevalent dialysis patients aged under 65 in each centre

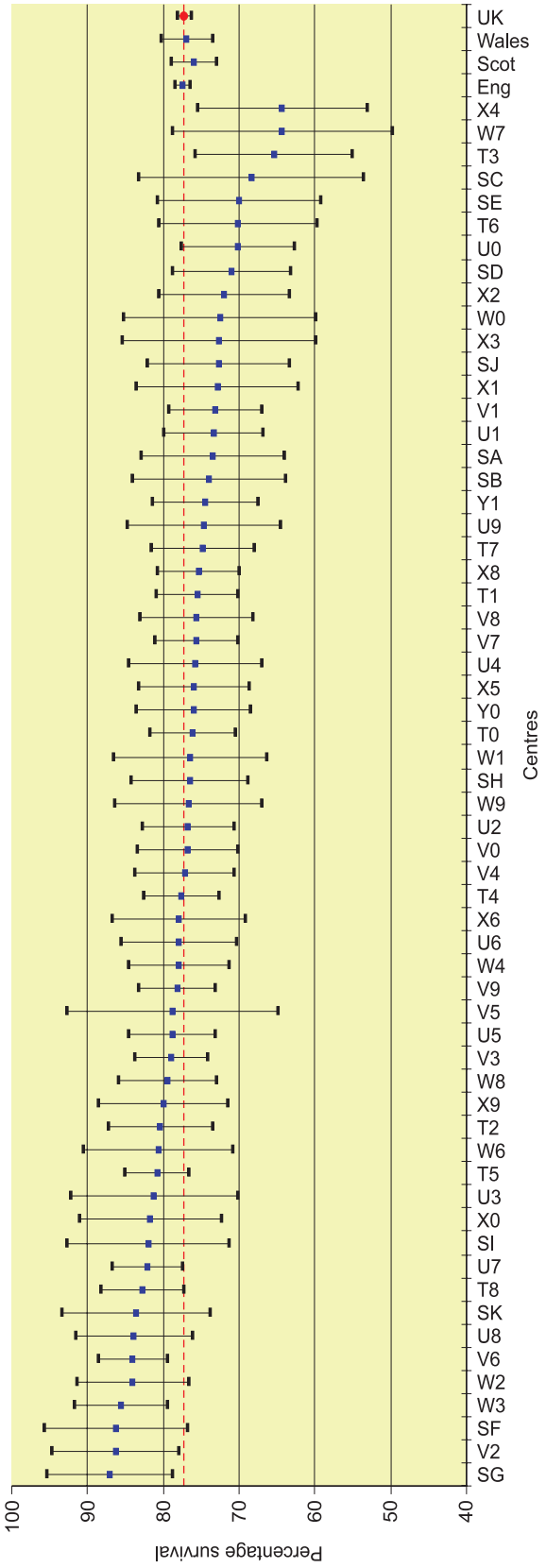


Figure 4.19: One year survival of prevalent dialysis patients aged 65 and over in each centre

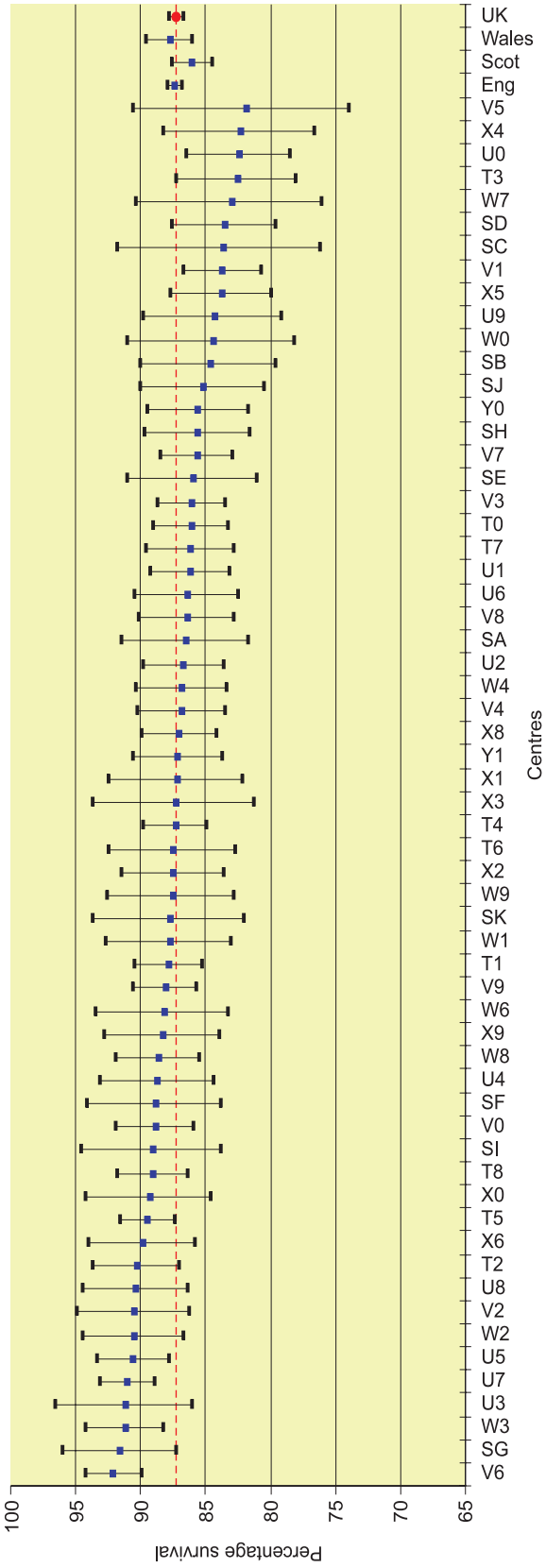


Figure 4.20: One year survival of prevalent dialysis patients in each centre adjusted to age 60

Table 4.15: Serial one year survival for dialysis patients in England, Wales and Scotland from 1997–2004 adjusted to age 60

	England		Wales		Scotland	
Year	1 year survival %	95% CI	1 year survival %	95% CI	1 year survival %	95% CI
1997	83.3	81.7–84.8	n/a		n/a	
1998	84.2	83.0–85.5	78.2	73.4–83.2	84.0	81.9–86.1
1999	84.1	83.0–85.2	83.4	80.5–86.3	82.3	80.3–84.3
2000	85.3	84.4–86.3	85.4	82.9–88.0	83.4	81.6–85.3
2001	86.1	85.3–86.9	88.0	85.9–90.2	83.6	81.8–85.4
2002	87.5	86.9–88.1	87.4	85.5–89.3	85.0	83.3–86.7
2003	86.1	85.4–86.8	84.2	82.1–86.3	83.7	82.0–85.4
2004	87.5	86.9–88.2	87.8	86.0–89.5	86.1	84.5–87.6

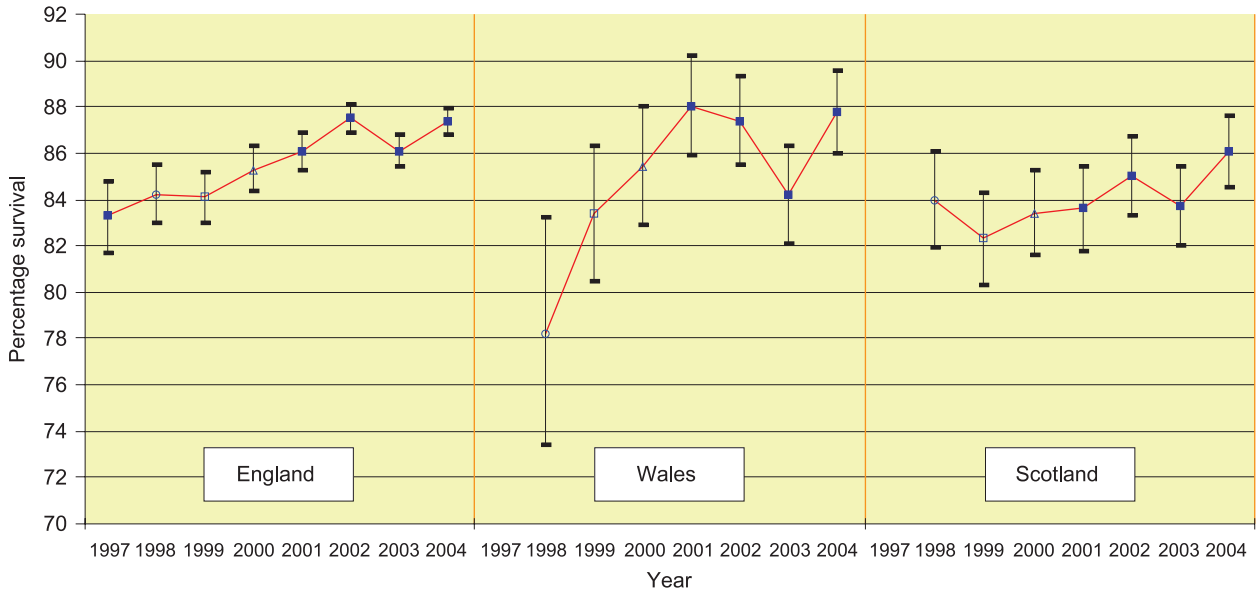


Figure 4.21: Serial one year survival for dialysis patients in the UK from 1997–2004 adjusted to age 60

References

1. National Institute of Clinical Excellence. Full guidance on home compared with hospital haemodialysis for patients with end-stage renal failure. October 2002. www.nice.org.uk

2. Tangri N, Ansell D, Naimark D. Lack of a centre effect in UK renal units: application of an artificial neural network model. *Nephrol Dial Transplant*. 2006 Mar;21(3):743–8

Chapter 5: Joint Analyses with UK Transplant in England and Wales; Access to the Renal Transplant Waiting List, Time to Listing, Diabetic Access to Transplantation and the Influence of Social Deprivation

Summary

- This chapter reports on new collaborative analyses carried out with UK Transplant (UKT).

- There is significant variation between renal units in the proportion of dialysis patients listed for renal transplantation.

- Patient specific factors that influence the probability of a patient being listed for renal transplantation include primary renal disease, age, regrafting, ethnicity and social deprivation but not gender. After correcting for co-morbidity, ethnicity is no longer significant.

- Centre specific factors that influence the probability of a patient being listed include size of the renal unit, size of the living donor programme and the listing practice for living donor recipients. Whether the renal unit is also a transplant centre is not important.

- There is no agreed "standard" proportion of dialysis patients that renal units should list for transplantation. However, renal units with a higher proportion of listed patients do not have a higher "refusal rate" or lower one year transplant or patient survival than units listing a lower proportion of patients.

- There are unexplained differences in listing practice between centres that may reflect a selection bias by healthcare professionals.

- 17% of 18–44 year old patients are pre-emptively listed.

- Within one year of starting dialysis, 45% of patients under the age of 65 years are listed for transplantation. Within two years this proportion has increased to 57% and by five years is 66%.

- Time to transplant listing is dependent on age and primary renal disease. Older patients and those with diabetes mellitus and reno-vascular disease are least likely to be listed and are listed more slowly than other patient groups.

- In 2003, 9.1% of all prevalent transplant patients had diabetes mellitus listed as their primary renal disease. This proportion has increased progressively from 2.1% in 1988.

- Patients with diabetes mellitus are less likely to be listed pre-emptively for renal transplantation.

- The differences between centres in the proportion of diabetic patients less than 65 years with established renal failure that have a renal transplant varies from 5–62% of patients and this may indicate differences in the policy of listing diabetic patients.

- One and five year death censored allograft survival is no different for patients with diabetes mellitus than for patients with glomerulonephritis, however, there is an increased risk of death one year after transplantation. By five years, the increased risk of death is more than double that of patients with glomerulonephritis.

- The Townsend index, a measure of social deprivation, is lower (less social deprivation) in transplanted patients across all age groups under 65 years compared with patients receiving either peritoneal or haemodialysis.

- Transplanted patients have a lower social deprivation score than both new registrants to the waiting list and prevalent patients on the waiting list.

- The social deprivation score is also lower in recipients of living donor transplants than deceased donor transplants.

The analyses in this chapter are part of the extensive collaborative work being undertaken between the UK Renal Registry and UK Transplant.

Access to the renal transplant waiting list

Introduction

Patients with established renal failure should have equitable access to renal transplantation. UK Transplant coordinates deceased-donor kidney allocation according to a nationally agreed algorithm based largely on blood group identity and HLA matching. However, for patients to have an opportunity of receiving a kidney transplant there needs to be equity of access to the transplant waiting list between and within renal units.

Data from the UK Renal Registry on date of starting of renal replacement therapy and the number of patients at each centre on RRT were combined with date of listing for transplantation from UK Transplant. Differences between individual renal units in the proportion of dialysis patients listed for renal transplantation were investigated and possible reasons for any differences analysed.

These analyses were undertaken before individual patient data from the Scottish Registry became available and therefore only include England and Wales.

Methodology

All adult patients receiving dialysis treatment on 31 December 2003 were included as the dialysis denominator.

Since the proportion of patients listed for a kidney transplant will depend on the renal unit's case-mix, logistic regression was used to investigate which patient variables influenced the probability of a patient being placed on the waiting list. These variables included;

1. Primary renal disease (9 categories).
2. Age.
3. Gender.
4. Ethnicity (White, non-White, not reported).
5. Whether a previous renal transplant had been performed (first transplant vs second or subsequent transplant).
6. Social deprivation was assessed with the Townsend score, a combination of four variables (unemployment, car ownership, home ownership, and overcrowding) derived from the census and calculated for each postcode. A high Townsend score indicates greater social deprivation.

Renal unit specific variables were also investigated and these included;

1. The size of the renal unit (less than 200, 200–350, 350–500, and more than 500 patients receiving dialysis on 31 December 2003).
2. Whether the renal unit also performed renal transplantation.
3. The size of the adult living kidney donor transplant programme at the transplant centre (up to 7 per million population (pmp) per year and more than 7 pmp per year).
4. The centre's practice with respect to listing living kidney transplant recipients on the deceased donor waiting list prior to transplant.

Centres that perform a large number of living donor transplants and do not list these patients on the deceased donor waiting list may appear to have proportionally fewer of their dialysis patients on the list. It was important to adjust for this in the analysis. Renal units, which do not perform renal transplantation, were considered to have the living kidney transplant programme characteristics of the transplantation centre to which their patients would usually be referred.

Results

On 31 December 2003 the UK Renal Registry held records on 12,175 adult patients who were on dialysis in 41 renal units across England and Wales, of whom 23.3% were on the active transplant waiting list. Between individual renal units there was variation in the proportion of patients on the active transplant list from 5.9% to 40.1% (Figure 5.1). Part of this variation may be due to the variation in the practice of suspension of patients and that some renal units do not list patients being worked up to receive a live donation. Figure 5.2 shows that in England & Wales 20% of wait-listed patients were suspended. Carshalton has 56%

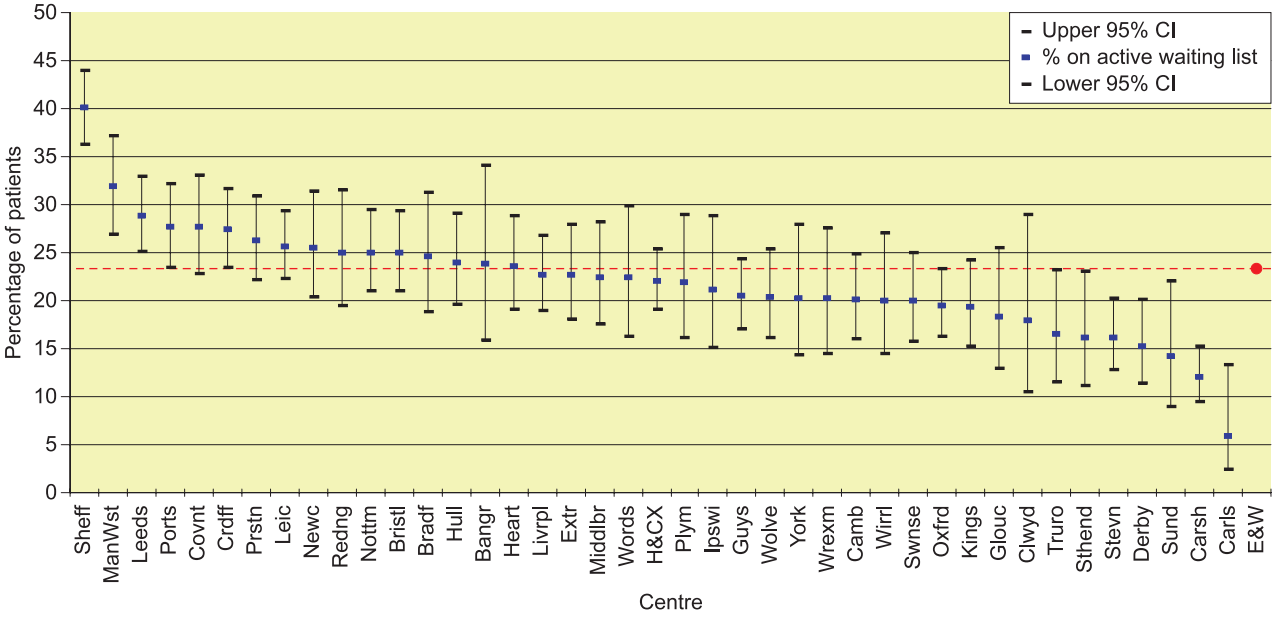


Figure 5.1: Percentage of all dialysis patients by centre on the active transplant waiting list on 31 December 2003

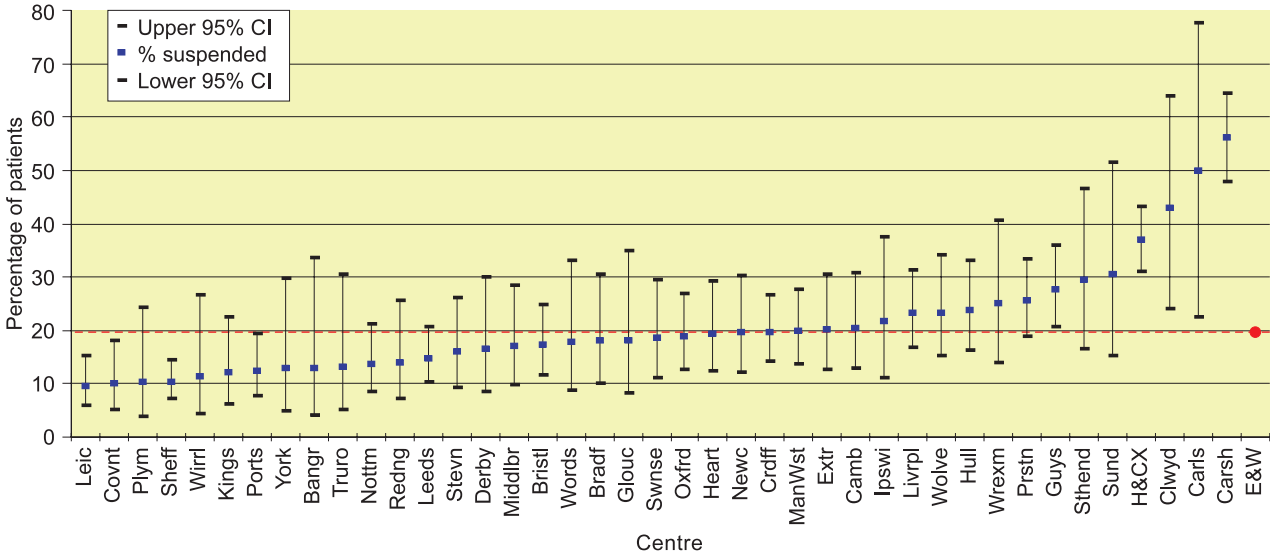


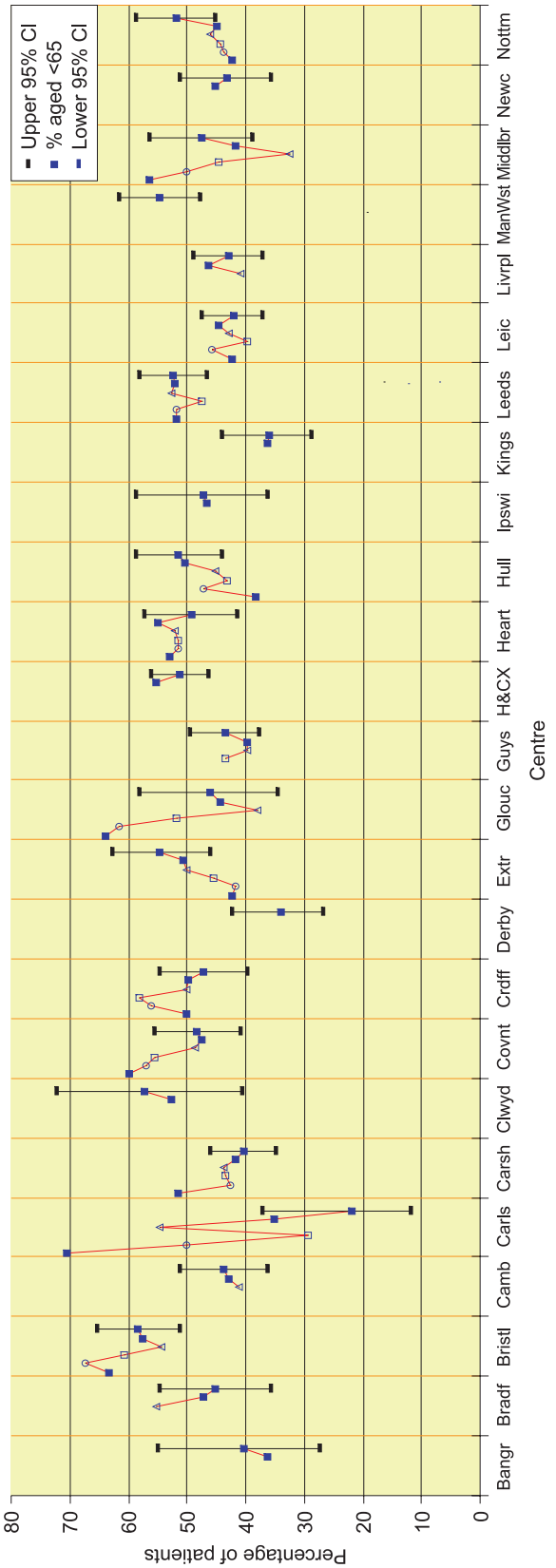
Figure 5.2: Percentage of all dialysis patients by centre who are suspended on the transplant waiting list on 31 December 2003

of wait-listed patients suspended which is due to the practice of listing all patients being worked up and then suspending them till they are worked up. This practice has changed since this analysis. The low rate of actively listed patients at this centre (6%) has also improved dramatically since being highlighted in this audit.

The change in listing practice over time from 1998 to January 2004 is shown in Figure 5.3. In England & Wales this has changed only slightly from 49.3% to 46.6% over this period.

An unadjusted funnel plot shows the percentage of patients on the active waiting list according to renal unit size (number of patients receiving renal replacement therapy) scattered around the national average (Figure 5.4). A number of renal units fall outside the 99.8% confidence interval both above and below the national average.

Patient variables that were found to be significant at the 5% level in explaining the variation observed included age, primary renal disease,



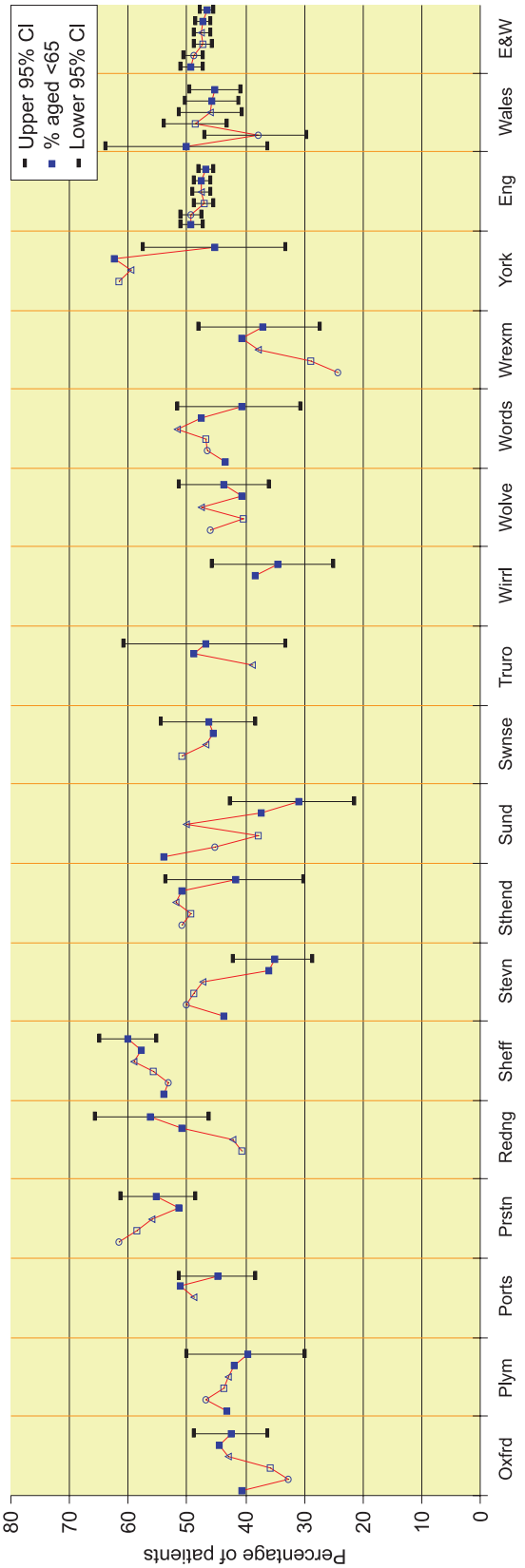


Figure 5.3: Change in percent of dialysis patients aged <65 on waiting list 1998–2003 (inc suspended)

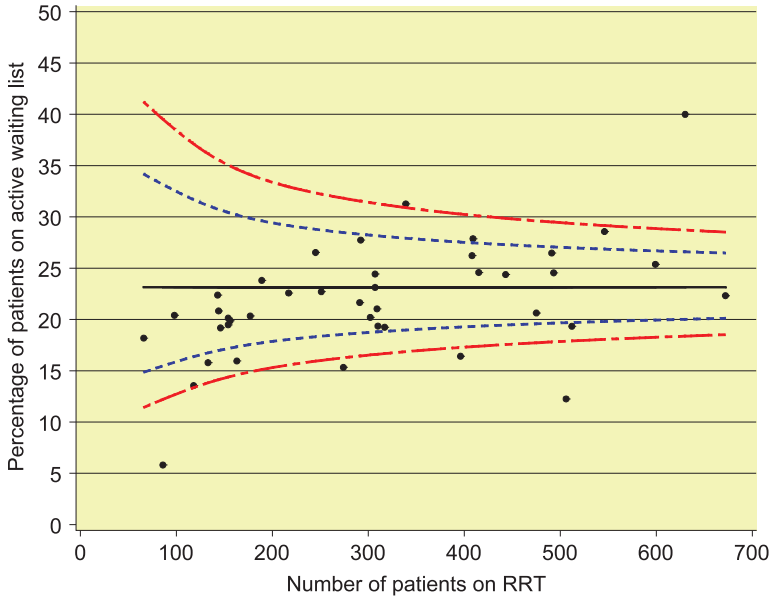


Figure 5.4: Unadjusted funnel plot showing the variation in listing rates according to renal unit size

Table 5.1: Significance of patient specific variables on the probability of a dialysis patient being listed for transplant

Factor	p-value
Primary renal disease	$p < 0.0001$
Age	$p < 0.0001$
Gender	$p = 0.80$
Regraft	$p < 0.0001$
Ethnicity	$p < 0.001$
Townsend index	$p < 0.001$

graft number, ethnicity and deprivation score but not gender (Table 5.1).

Figure 5.5 shows the percentage of adult patients on the active waiting list across England and Wales according to their age. The highest proportion of patients on the active waiting list was 63% at age 23 years. For patients aged less than 65 years, only those with autosomal dominant polycystic kidney disease were more likely to be on the waiting list than the reference group (glomerulonephritis) (Table 5.2). In contrast, patients with a primary renal diagnosis of diabetes mellitus were the least likely to be on the active waiting list. Non-White patients were more likely to be listed than White patients, although patients without ethnicity recorded were less likely to be listed. Patients in the most deprived Townsend quintile were least likely to be listed compared with the other quintiles although there was a step-wise reduction in likelihood of listing from the first to fifth quintile.

A funnel plot adjusted for these patient variables is shown in Figure 5.6 and the inclusion of a random effects term in the model for unexplained centre effects was highly significant ($p < 0.0001$), demonstrating that there is still significant variation between centres in the proportion of patients listed for transplant after adjusting for patient case-mix.

Centre-specific variables that were significant at the 5% level were size of the renal unit, size

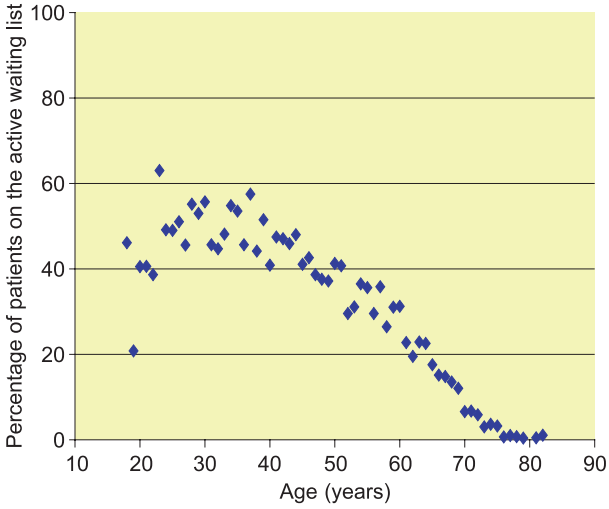


Figure 5.5: Proportion of dialysis patients on the active waiting list across England and Wales, by age

Table 5.2: The effect of primary renal disease on the odds of listing for patients aged less than 65 years

Primary disease	N	Odds ratio of listing	95% CI
Polycystic kidney disease	597	1.4*	1.1–1.7
Glomerulonephritis	1,119	Ref	Ref
Aetiology uncertain	1,481	0.7*	0.6–0.9
Hypertension	441	0.7*	0.6–0.9
Pyelonephritis	798	0.7*	0.6–0.8
Other	1,024	0.6*	0.5–0.8
Renal vascular disease	157	0.5*	0.4–0.8
Not reported	325	0.4*	0.3–0.6
Diabetes	1,223	0.3*	0.2–0.4

*$p < 0.0001$

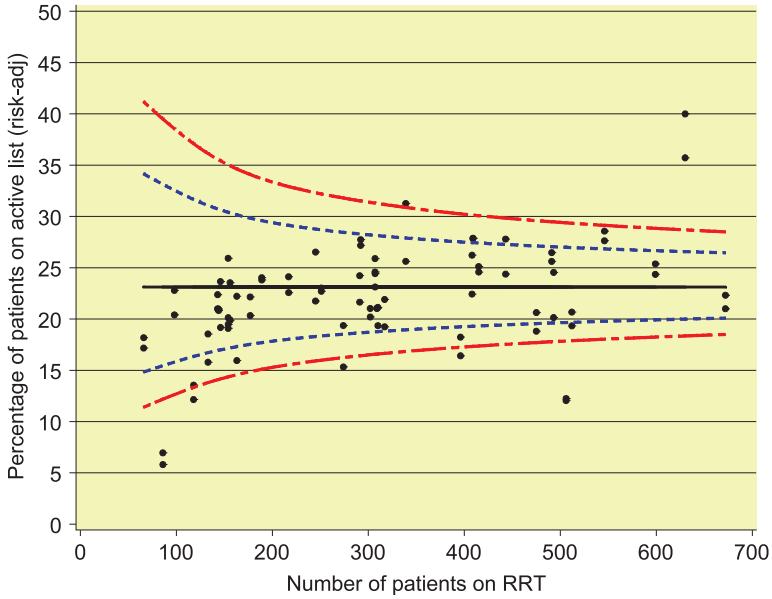


Figure 5.6: Funnel plot adjusted for significant patient variables (age, diagnosis and graft number)

of the living donor programme and the listing practice for living donor transplants, but not whether the renal unit was also a transplant centre (Table 5.3).

A funnel plot adjusted for both patient and centre-specific significant variables is shown in Figure 5.7.

Table 5.3: Significance of centre-specific variables on the probability of a dialysis patient being listed for transplant, after adjusting for patient-specific factors

Factor	p-value
Size of the renal unit	$p = 0.023$
Renal unit also a transplant centre	$p = 0.671$
Size of living donor programme	$p = 0.002$
Listing practice for living donor transplants	$p < 0.0001$

Even after taking these patient and centre-specific factors into account, there is still significant unexplained variation between renal units in the proportion of dialysis patients on the transplant waiting list ($p < 0.0001$).

Discussion

Both patient and centre-specific factors influence the probability of a patient being listed for renal transplantation. Not surprisingly, age was an important factor with few dialysis patients older than 65 years old being listed. In contrast with many other studies however, gender was not a significant determinant of access to the waiting list suggesting that in England and Wales disparities have been eliminated that in other countries have led to a gender bias.

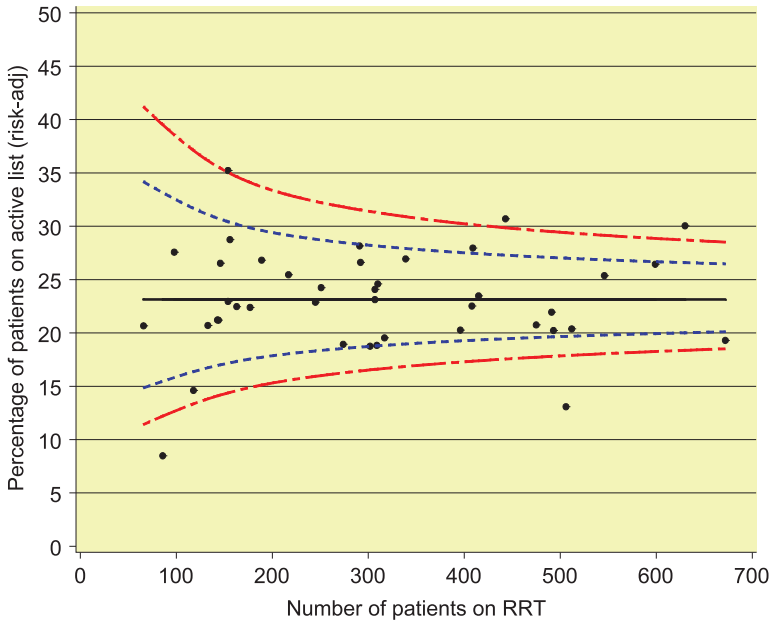


Figure 5.7: Funnel plot adjusted for significant patient and centre-specific variables*

*Age, diagnosis, graft number, centre size, size of centre's living donor programme and centre's listing practice for living donor kidney recipients

Patients whose underlying renal disease was polycystic kidney disease were most likely to be listed whilst those with diabetes mellitus were least likely. The most obvious explanation for this observation is the well recognized difference in co-morbidity associated with each condition. Surprisingly, patients with a previously failed renal transplant were more likely to be listed. Again in contrast with other reports, non-Whites were more likely to be listed than White patients. However, after correcting for differences in co-morbidity (in a subset of patients for whom these data are available) this racial difference became insignificant (although patients without reported ethnicity were still less likely to be listed).

The likelihood of placement on the waiting list declined with increasing socio-economic deprivation. Although patients who are socially disadvantaged may have more co-morbidity, socio-economic deprivation remained an independent predictive factor after correction for differences in co-morbidity. Possible explanations include inadequate patient education and understanding of the benefits of transplantation and a lack of self-advocacy. A selection bias by healthcare workers cannot be excluded.

Reassuringly for both patients and providers, whether a renal unit that was also a transplant centre cared for the patient did not influence access to the transplant waiting list. However, patients in larger renal units, linked with transplant centres with active living donor transplant programmes whose practice was not to list living kidney transplant recipients prior to transplantation were less likely to access the national deceased donor transplant waiting list.

Could the maturity of the renal unit explain these observed centre differences? That is, older renal units who have been transplanting for longer may have transplanted the majority of appropriate patients thereby leaving a smaller proportion of suitable dialysis patients on the transplant list. However, all UK transplant centres have been established for over 25 years so maturity of the renal unit cannot explain this difference. Another possible explanation is that a centre may have had a less selective policy on tissue match grade resulting in a higher proportion of highly sensitised patients on the waiting list which are unlikely to be offered a transplant. Analysis of the percentage of highly sensitised patients by centre shows no significant difference between centres. Analysis of dialysis prevalence pmp by Local Authority (LA), for those LAs close to transplant centres shows a similar prevalence of dialysis to the UK average. Some LAs have lower rates but this correlates with their lower renal replacement therapy acceptance rates. These observations suggest that a concept of 'maturity' has

no basis and cannot be the explanation for the difference demonstrated in listing practice between centres.

There is no consensus either in the UK or the rest of the developed world, on what constitutes the ''standard'' proportion of dialysis patients that a renal unit should list. It might be that some UK renal units with a high proportion of listed patients are selecting inappropriate patients that may be considered medically unsuitable by other units. If this was true then a higher ''refusal rate'' of organs might be observed in these renal units together with a higher one year transplant mortality. Analysis of the data showed no relationship between the proportion of listed patients and the proportion of offers declined, or accepted and then not used due to the recipient being unfit (data not shown). Additionally, for the period from 2002 to 2004, there was no significant difference in one year patient or transplant survival between centres (UKT data).

In conclusion, this analysis showed that there are differences in listing practice between centres that cannot be explained by either differences in patient case-mix or centre characteristics and are most likely to reflect a selection bias by healthcare professionals.

Time to listing in renal transplantation

Introduction

Waiting time spent on dialysis has been shown to be an important factor in determining mortality (Meier-Krische Transplantation 2002; 74:1377). Median waiting time after activation onto the transplant waiting list varies significantly between transplant centres. A recent analysis by UKT has identified those variables that govern how long a patient is likely to spend on the national transplant waiting list before receiving a kidney allograft. These factors include patient age, gender, ethnicity, blood group, matchability score, degree of HLA sensitisation, HLA-DR homozygosity and number of previous grafts. Centre specific factors include balance of exchange and number of deceased adult donors (greater chance of transplant if these are higher), offer refusal rate and size of waiting list (lower chance of transplant if these are higher). Recently, changes have been made to the national organ allocation scheme to take into account these variables to try and make organ allocation more equitable. However, the time it takes for patients to be placed on the national transplant waiting list is also important in ensuring equity of access to renal transplantation but has been much less well studied.

Methodology

By combining data from the UK Renal Registry and UK Transplant, the time from the start of dialysis to activation on to the national transplant waiting list was determined for each patient from a cohort of 4,951 patients (53% aged less than 65 years old) who commenced RRT in 1998/1999 in the centres covered by the Registry. Patients who died or were not listed by the time of analysis (October 2004) were included with censored times. Patients listed before the need for dialysis were given a time to listing of zero days. Time to listing was analysed by age band and primary renal disease. The two year time to listing was repeated for the 2000/2001 cohort of 5,513 patients starting RRT.

Results

Overall, 45% of patients under the age of 65 years were activated on the national transplant waiting list within one year of starting dialysis and 66% were activated within five years. The time to listing according to the patient's age is shown in Figure 5.8 as Kaplan-Meier survival curves and in Table 5.4.

For patients aged between 18–34 years at the start of RRT, 70% were activated on UKT's waiting list within one year and 87% by five years. The proportion of patients listed fell with each increasing age group such that for patients over the age of 65 years only 7% were listed within five years. The effect of age on time to listing is not surprising and reflects the increasing co-morbidity associated with increasing age. However, an additional selection bias in favour of younger patients cannot be excluded. Between one and five years of commencing RRT, an additional 21% of patients under 65 years of age were added to the list with the

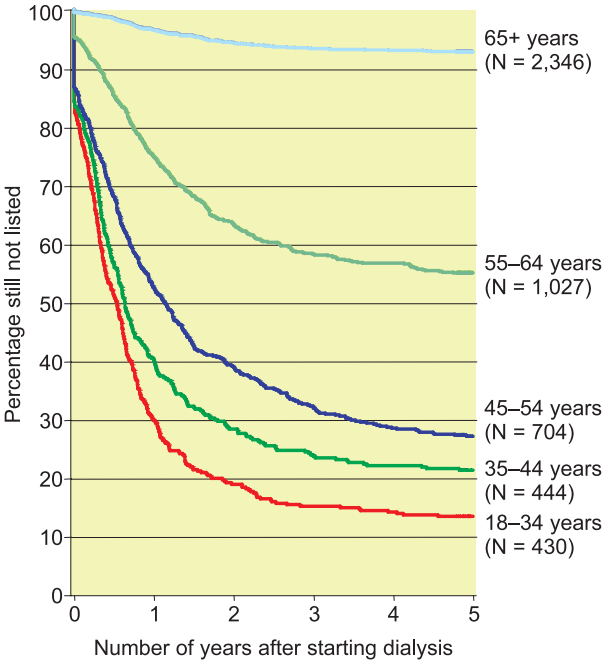


Figure 5.8: Kaplan-Meier curves showing time to listing by patient age

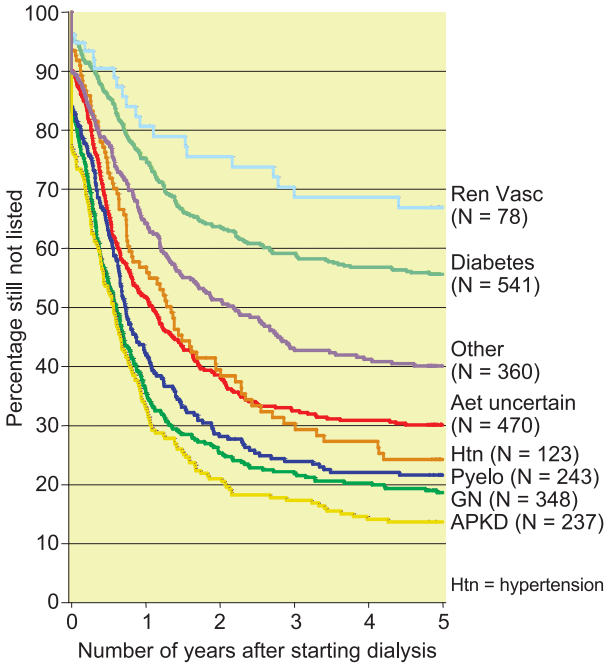


Figure 5.9: Kaplan-Meier curves showing time to listing by primary renal disease

greatest proportion (25%) observed in the 45–54 year old group.

Listing rates also vary significantly according to the primary renal disease as shown by the Kaplan-Meier curves in Figure 5.9.

79% of patients with adult polycystic kidney disease were listed within 2 years of starting RRT in contrast to 25% of patients with renovascular disease and 36% with diabetes mellitus. Once again these differences in listing rates can be explained by the well-recognised increased co-morbidity (especially cardiovascular) and early death associated with renovascular disease and diabetes mellitus.

Figures 5.10 and 5.11 show the time of listing by patient age and primary renal disease.

Table 5.4: One, two and five year listing rates according to patient age (1998/1999)

	Percentage of patients listed within			
Age (years)	Pre-emptive	1 year	2 years	5 years
18–34	17	70	81	87
35–44	16	60	72	79
45–54	13	48	61	73
55–64	5	25	37	45
65+	<1	4	6	7
All <65	11	45	57	66

Younger patients and patients with APKD, pyelonephritis and glomerulonephritis were more likely to be listed before starting dialysis.

Late listing of patients between two and five years after starting RRT was uncommon (8%) in patients aged 55–64 years and rare (1%) in those aged over 65 years (Figure 5.10). It was also least common in patients with renovascular disease and diabetes mellitus as their primary renal disease (Figure 5.11).

Comparison was made with a cohort of 5,513 patients who started RRT in 2000/2001. Table 5.5 shows that the one and two year listing rates according to different age groups were no different from those in 1998/1999 (Table 5.4).

Discussion

The renal NSF part one, Standard 2 (preparation and choice) recommends that as a marker of good practice suitable patients be wait listed prior to start of RRT.

Patients for whom transplantation is an option should be assessed before being placed on the national transplant list. Currently fewer than 40% of dialysis patients are on the national transplant list, and the proportion varies widely from unit to unit. UK Transplant has consulted with the

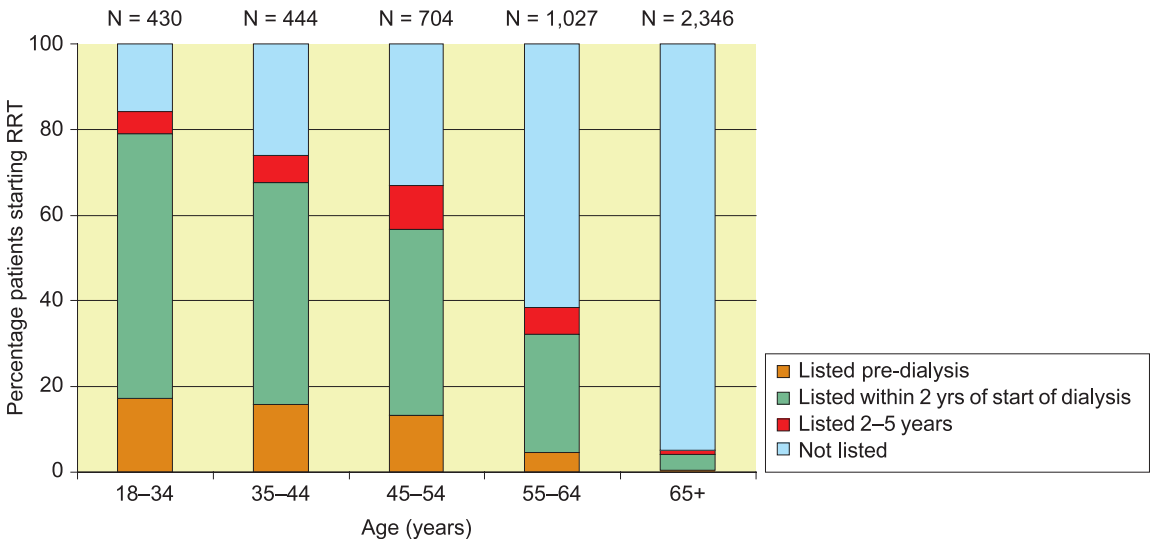


Figure 5.10: Listing time by patient age

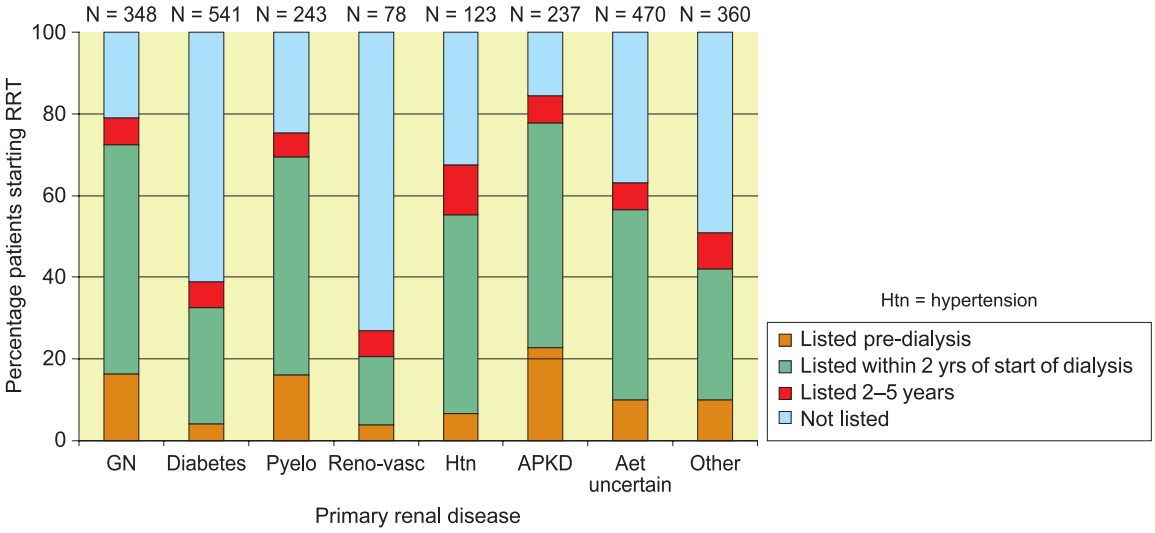


Figure 5.11: Listing time by primary renal disease

British Transplantation Society and the Renal Association to develop protocols for the assessment of adults, and with the British Association for Paediatric Nephrology to do the same for children. These will ensure that all patients are assessed to uniform standards.

Suitable people close to ERF may benefit most if they have a transplant before they need to start dialysis. This is known as a 'pre-emptive' transplant. The guideline published by UK Transplant is that people should be eligible for the national transplant list if dialysis is predicted to start within six months – typically with a GFR <15 mls/min.

Table 5.5: One and two year listing rates according to patient age (2000/2001)

	Percentage of patients listed within	
Age (years)	**1 year**	**2 years**
18–34	67	81
35–44	60	73
45–54	45	57
55–64	23	38
65+	4	6
All <65	44	57

Younger patients were more likely to be pre-emptively listed, with 25% being listed in the 18–34 age group.

In patients aged under 65 years at the start of RRT, 57% are activated on the national transplant waiting list within two years of

starting dialysis. This was identical for both the 1998/9 and the 2000/1 cohorts indicating that the 1998/9 data is representative and that practice has not changed. The rate at which patients are listed and the proportion that are listed, are determined by the patient's age and primary renal disease. Older patients and those with reno-vascular disease and diabetes mellitus are less likely to be listed and are also listed more slowly. Concomitant co-morbidity and its investigation (eg by coronary angiography) is the likeliest explanation for this observation.

The reason why 13% of patients in younger age groups take between one and two years to be activated on the transplant waiting list is unknown, but is less likely to be due to co-morbid conditions. Some renal units do not list patients who are being worked up for live donor transplant. If the donor was found not suitable this may account for a delay in listing. A few younger dialysis patients opt to remain off the waiting list (personal communication from renal units). An additional 6% of young patients take up to five years to be activated on the waiting list.

Transplantation in patients with diabetes mellitus

The most common identifiable cause of established renal failure in the United Kingdom is diabetic nephropathy accounting for 17.9% of all patients starting renal replacement therapy on 31 December 2003 (Table 5.6). Patients with diabetes mellitus also have more co-morbidity and an increased risk of death than patients

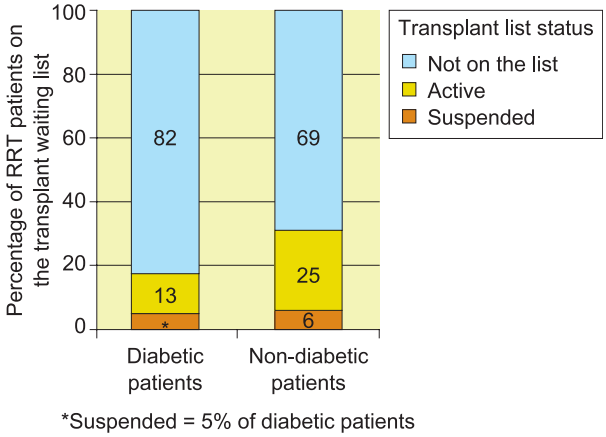


Figure 5.12: Status of diabetic and non-diabetic RRT patients on the transplant list on 31 December 2003

with other primary renal diagnoses. Data from the UK Renal Registry and UK Transplant were combined to evaluate access to renal transplantation in this important diagnostic group and to assess transplant outcome compared with other patient groups.

Figure 5.12 shows that diabetic patients with ERF were less likely to be listed for renal transplantation than non-diabetic patients. This was observed across all age groups (Figure 5.13). Once listed, diabetic patients were more likely to be temporarily suspended from the waiting list (28% vs 20%, $p < 0.005$).

The time to activation on the national transplant waiting list was compared between diabetic and non-diabetic patients who started RRT in 1998/1999 (Figure 5.13). The most striking difference was seen in the proportion of patients activated before starting dialysis.

Table 5.6: Percentage of new patients starting RRT in 2003 according to primary renal diagnosis and age

Diagnosis	Age ⩽65 years (N = 1,992)	Age >65 years (N = 1,942)	All ages (N = 3,934)
Aetiology uncertain	19.7	29.6	24.6
Glomerulonephritis	12.9	5.9	9.4
Pyelonephritis	7.8	7.4	7.6
Diabetes	**20.9**	**14.9**	**17.9**
Reno-vascular disease	2.4	13.2	7.7
Hypertension	4.7	5.6	5.1
Polycystic kidney disease	9.4	2.7	6.1
Other	15.7	13.4	14.6
Not recorded	6.6	7.3	6.9

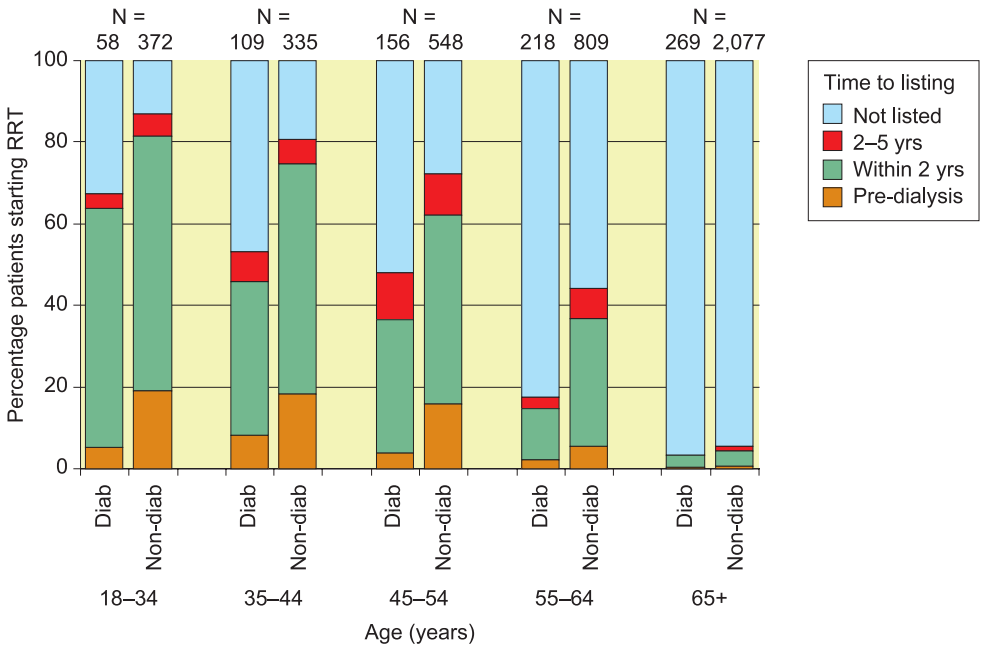


Figure 5.13: Time to transplant listing for patients starting RRT in 1998/1999 according to diabetic status and age group

Patients under the age of 65 years without diabetes mellitus were twice as likely to be listed pre-emptively for a renal transplant.

Over time an increasing number of diabetic patients have received a renal transplant (Figure 5.14). The proportion of diabetic transplant recipients has increased from 2.1% of the total in 1988 to 9.1% in 2003. Furthermore, Renal Registry data show that an additional 2.6% of transplant recipients have diabetes mellitus but not recorded as the primary cause of ERF. Combined kidney/pancreas transplantation has also increased from 4 in 1988 to 42 in 2003.

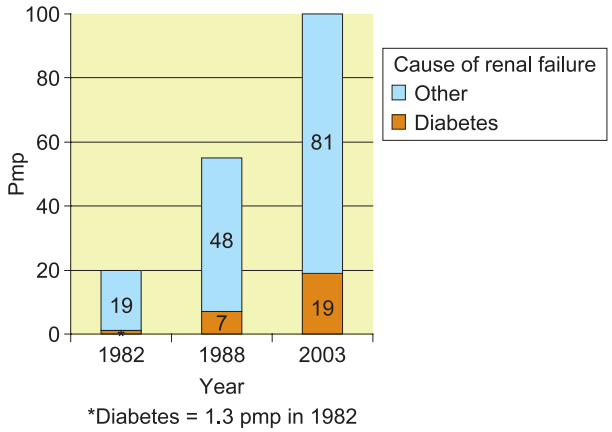


Figure 5.14: Number of adult patients receiving a renal transplant by year according to diabetic status

The percentage of diabetic ERF patients less than 65 years old with a transplant was examined by renal units to explore whether there was a difference between centres in their approach to transplanting patients with this diagnosis (Figure 5.15). There is a very wide variation (3–62%) between centres in the proportion of diabetic patients less than 65 years old with established renal failure that have a transplant (35% overall mean for England and Wales). Adjustment for patient mix (eg age, ethnicity) only partially explains these differences and may indicate variation between centres in their policy of listing diabetic patients.

Outcome after transplantation

For diabetic patients remaining on dialysis, there is a significant increased risk of death at one year of 1.87 (95% CI 1.58–2.22) compared to patients with glomerulonephritis ($p < 0.001$). Although there is an increased risk of death one year after transplantation for diabetic patients, this does not reach statistical significance. However, the risk of death five years after transplantation is more than twice that observed in the reference group with glomerulonephritis, a highly significant statistical difference ($p < 0.001$). After renal transplantation, one and five year allograft survival is no different for patients with diabetes mellitus than for patients with glomerulonephritis (Table 5.7).

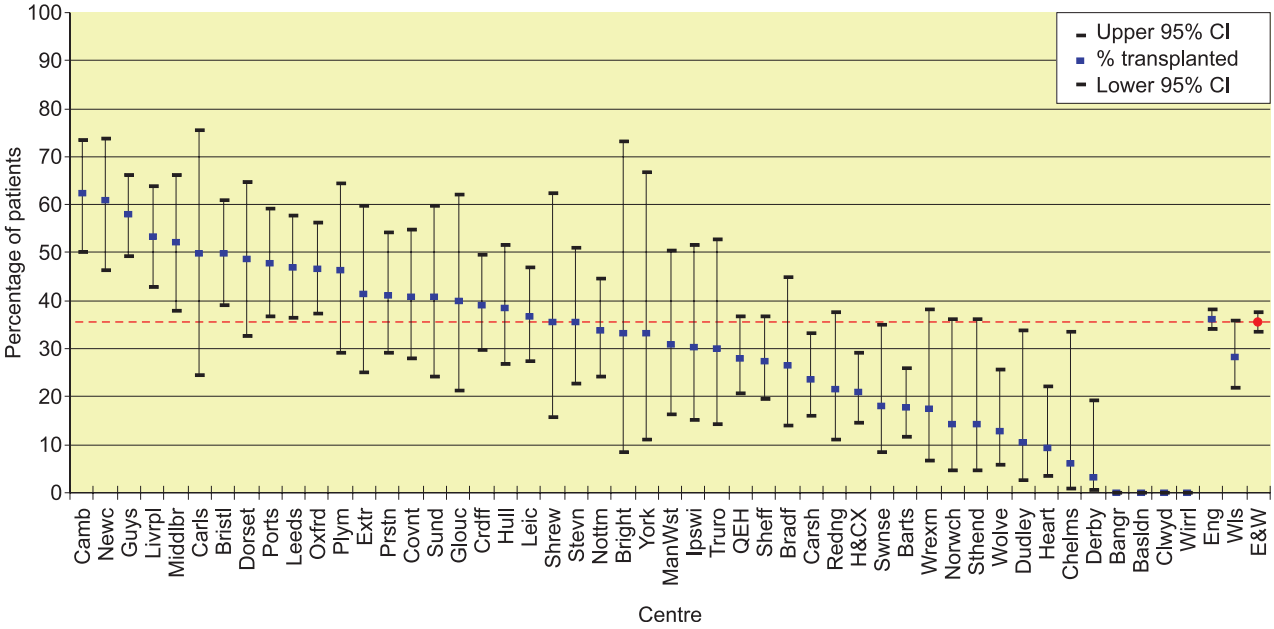


Figure 5.15: Proportion of diabetic patients with ERF aged less than 65 years with a functioning renal transplant by renal centre

Table 5.7: Outcome after renal transplantation comparing diabetic patients with patients with glomerulonephritis

Outcome		Relative Risk	95% CI	p value
Graft survival	1 year	0.72	0.37–1.39	$p = 0.33$
(death with function censored)	5 year	1.02	0.78–1.32	$p = 0.91$
Patient survival	1 year	1.85	0.99–3.46	$p = 0.06$
	5 year	2.22	1.71–2.87	$p \leqslant 0.001$

Conclusion

An increasing proportion of patients with ERF due to diabetic nephropathy are receiving renal transplants compared with previous years. Diabetic patients are less likely to be listed for a transplant than non-diabetic patients and when listed are more likely to be temporarily suspended from the transplant waiting list. Pre-emptive listing before the start of dialysis is much less common in diabetic patients.

There is centre variation in the proportion of diabetic patients with a functioning transplant that can only partially be accounted for by differences in case-mix across centres and may indicate differences in the policy of listing diabetic patients.

The short and medium term graft outcome after transplantation for diabetic recipients is similar to other patient groups although there is an increased risk of death that at 5 years is more than double that for patients with glomerulonephritis.

The influence of socio-economic deprivation on renal transplantation

The influence of socio-economic deprivation on renal transplantation has not been well studied in the UK. In the Registry Report 2000 the first analysis was reported on a prevalent cohort of renal replacement therapy patients using deprivation data from the 1991 Census. The Registry had been waiting for the new 2001 Census data before repeating these analyses on the much larger incident cohort now available. Further analyses on dialysis patients using the 2001 Census data were included in Report 2003 (Chapter 17).

Table 5.8: Townsend scores by postcode quintile

Townsend quintile	1 Least deprived	2	3	4	5 Most deprived
Townsend score range	⩽−3.35	−3.34 to −1.97	−1.96 to −0.16	−0.15 to 2.59	>2.60

Calculating the Townsend deprivation score

The Townsend index was used as the scoring system for social deprivation, which was derived from the patient's postcode. The Townsend index (calculated for the Registry from the 2001 Census data, by Hannah Jordan of Southampton University) is a composite measure of deprivation based on total unemployment rate, no car households, overcrowded households and not owner occupier households based on the electoral ward as at the 2001 Census. The higher the Townsend index, the greater the deprivation.

Using 2001 Census data, a profile was created for all 1.25 million postcodes in England and Wales. The postcodes were ordered by Townsend score from lowest to highest and then divided into quintiles of Townsend scores (Table 5.8). For those postcodes with more than one Townsend score (5% of postcode areas cross a census boundary), the mean Townsend score was calculated.

For all patients with a recorded postcode it was therefore possible to allocate;

1. A Townsend score for the postcode area in which they lived; and
2. A national Townsend quintile, the lowest quintile representing the least deprived one fifth of postcodes.

This approach was based on the assumption that each area with a postcode covers approximately the same number of residents.

Results

The distribution of Townsend deprivation scores in prevalent patients is shown in Figure 5.16 for each RRT modality and compared with that in the general population for England and Wales. Transplant recipients and PD patients appear to have a similar distribution of social deprivation to that of the non-RRT general population. Patients on HD are from the more socially deprived group. This may relate to higher rates of co-morbidity (especially diabetes) in this population. The prevalent transplant patients also largely reflect a more 'historical' dialysis population than the current one.

The Townsend index for each RRT modality across age groups is shown in Figure 5.17. At

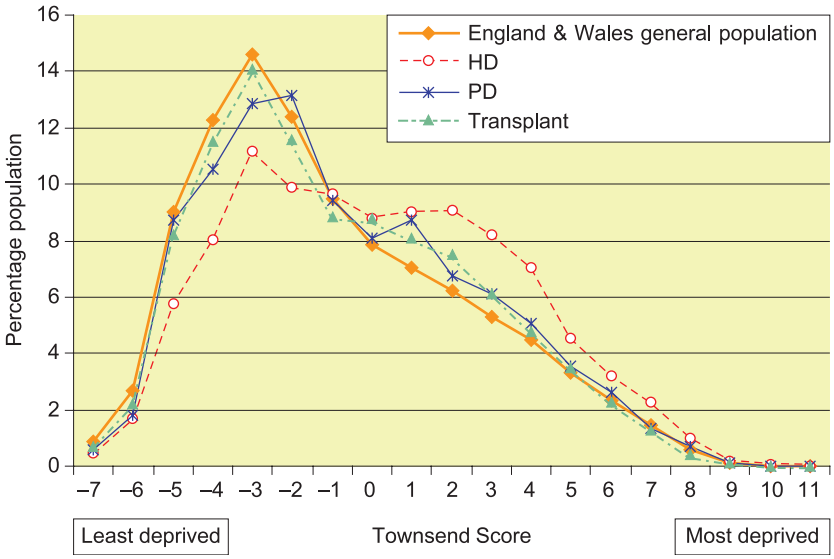


Figure 5.16: Population distribution of Townsend deprivation scores in prevalent RRT patients by modality

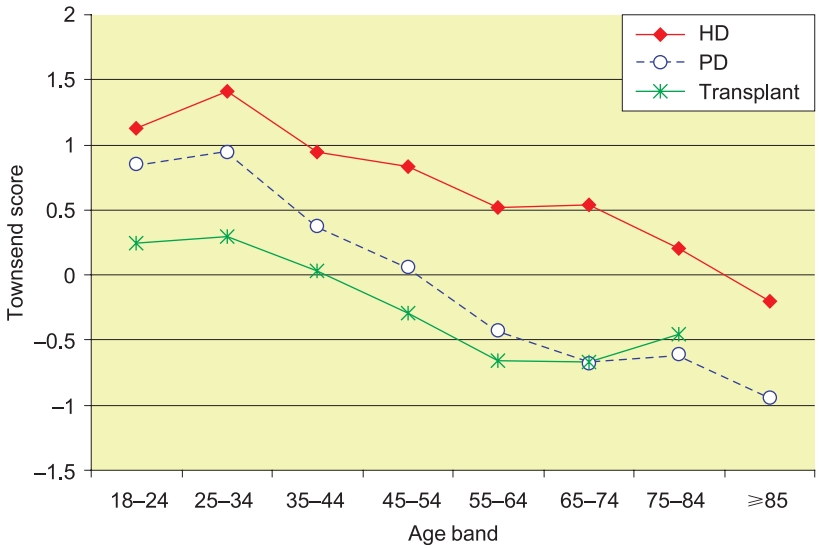


Figure 5.17: The Townsend index for each RRT modality across age groups

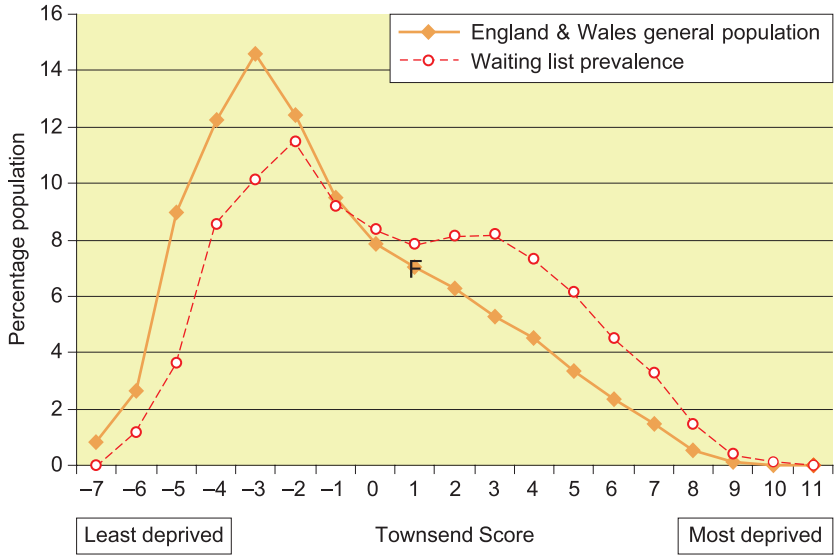


Figure 5.18: Population distribution of Townsend deprivation scores in wait listed dialysis patients

almost every age band, the Townsend index for transplanted patients is lower than for patients treated by peritoneal or haemodialysis. In addition, the index falls with increasing age in all modalities. The observed differences may be accounted for by a number of factors including differences in co-morbidity and ethnicity.

Figure 5.18 illustrates that the current waiting list population more closely resembles the prevalent dialysis population than the prevalent transplant population. Part of this difference will be related to the longer waiting time for patients from an ethnic minority background (who also live in more socially deprived areas) and the lower donor rates with a matching blood group and tissue type.

Figure 5.19 shows that transplanted patients have lower social deprivation than new registrants to the transplant waiting list (incident patients) and prevalent patients already on the waiting list. Ethnicity and also increased employment opportunities and hence income in transplanted patients may account for these observations.

For transplanted patients, the recipients of living donor transplants are less socially deprived than deceased donor transplants across all age groups (Figures 5.20 and 5.21).

Table 5.9 shows the influence of ethnicity on the deprivation scores for prevalent patients on the transplant waiting list. African-Caribbean

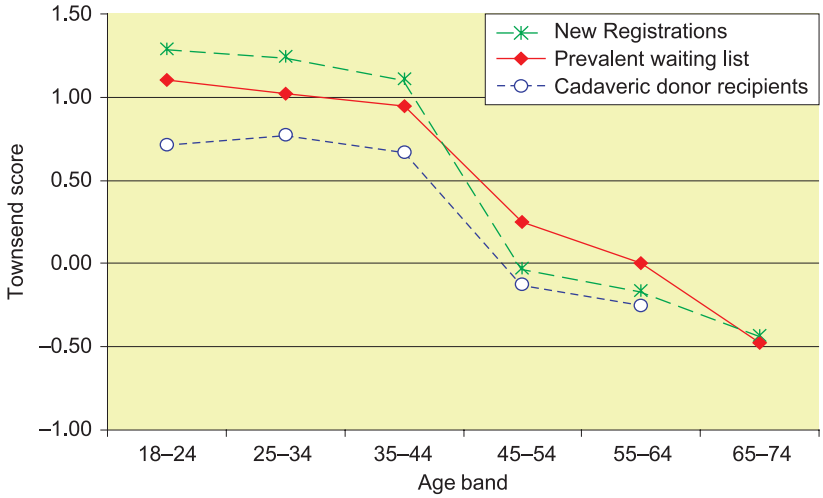


Figure 5.19: Townsend index for new registrants to the transplant waiting list, prevalent patients on the waiting list and transplanted patients (deceased donor)

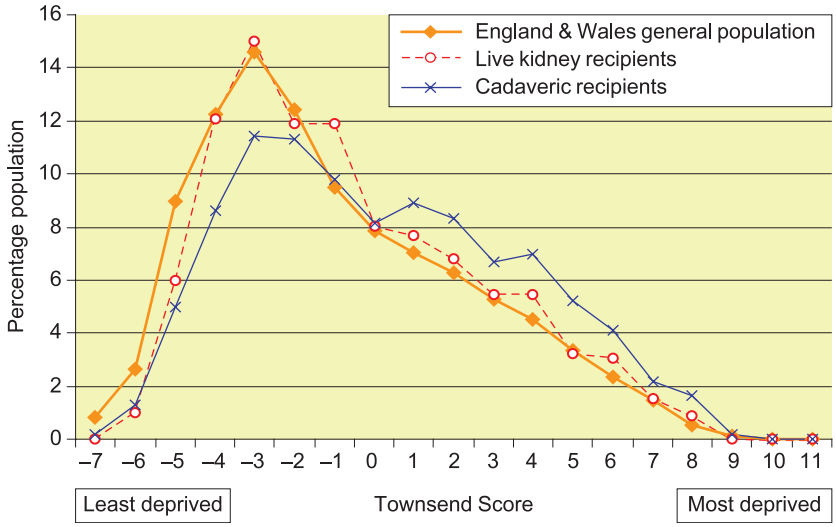


Figure 5.20: Population distribution of Townsend deprivation scores in cadaveric and live transplant recipients

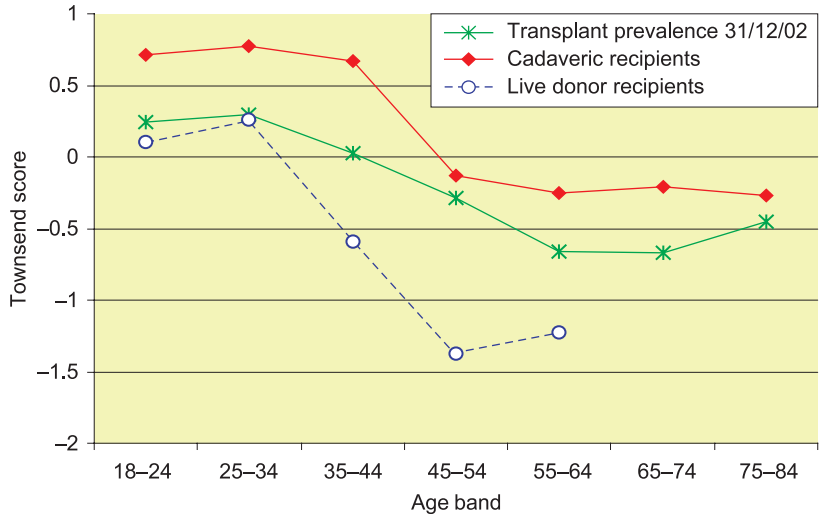


Figure 5.21: Social deprivation scores for transplant type by age groups for prevalent patients on 31 December 2002

Table 5.9: Mean Townsend index of waiting list patients by ethnicity

Ethnicity	N	Townsend index (mean)
White	2,583	−0.17
Chinese	40	1.00
Other	53	2.18
South Asian	553	2.19
African–Caribbean	306	3.69
Unknown	52	1.34

Table 5.10: Mean Townsend index by time spent on waiting list

Time on list (days)	N	Townsend index (mean)
1–1,000	2,583	−0.17
1,001–2,000	908	1.00
2,001–3,000	303	2.18
>3,000	253	2.19

patients had the highest social deprivation score.

There was also a relationship between the length of time spent on the transplant waiting list and deprivation (Table 5.10). This probably reflects the effect of ethnicity in that patients from ethnic minorities are likely to wait longer for a transplant because of their less common blood group and tissue type.

Conclusions

Combining data with UK Transplant provides important insights into patient and centre specific factors that influence patients' access to the transplant waiting list. The time it takes to list patients for transplantation can also be studied. The variation observed between centres may be explained by differences in policy and organisational arrangements. The reasons for the differences in social deprivation between live related recipients and deceased donor recipients, requires further investigation.

Acknowledgement

We would like to acknowledge the significant contribution made to this chapter by Helen Thomas, Samantha Armstrong, Rachel Johnson and Dave Collett of UK Transplant.

Chapter 6: The National Dialysis Access Survey – preliminary results

Summary

This preliminary report is based on returns from 62 of 72 renal centres, covering 62 main centres and 119 satellite haemodialysis renal units.

- Including PD patients, 13,343 (77%) of prevalent patients were having dialysis therapy delivered by definitive access, variation between centres from 52–95%. For HD patients only, definitive access was used in 69%, range from 44–94%.
- 55% had been referred to the renal centre more than 12 months before initiation of RRT, 35% less than 6 months before RRT and 30% less than 3 months.
- 45% of all patients commenced renal replacement therapy using definitive access. Of patients commencing on HD, only 31% commenced with definitive access.
- Of those known to the renal units for a year or more, only half started HD with definitive access.
- Of the patients known to the renal units more than 6 months before starting RRT, only 13% are not referred for access within 6 months of first RRT.
- Dialysis programme size did not affect rates of definitive access.
- 5% of patients currently receiving haemodialysis were in-patients (between centre range 0–14%), of which 29% of episodes were considered to be related to vascular access issues (range 0% of HD patients to 7%).
- The data presented suggest that over 320,000 bed days are utilised by HD patients per annum across the UK.
- Per hundred patients in a centre, the number of Staphylococcal systemic infections per annum varies from 2.3 to 33.8, average 13; the figures for MRSA alone being from 0 to 21.5, average 4. This is likely to be an underestimate.
- These data suggest that patients on haemodialysis may contribute 8–10% of all cases of MRSA bacteraemia in the UK.

Introduction

Despite recognition of the need for high quality access in the treatment of patients with established renal failure, haemodialysis patients often receive their therapy via access associated with a higher morbidity and mortality[1]. The Renal National Service framework recognises the importance of vascular access in the preparation of patients with established renal failure in Standard 3 from the 1st part:

> ***All children, young people and adults with established renal failure are to have timely and appropriate surgery for permanent vascular or peritoneal dialysis access, which is monitored and maintained to achieve its maximum longevity***[2].

Two pilots have been commissioned from Queen Elizabeth Hospital, Birmingham and the Royal Devon and Exeter Hospital: within these sets the vascular access pathway was analysed and an attempt made to redesign the process[3]. Despite this focus there is a widespread belief that renal units and commissioners across the United Kingdom are not able to achieve the standard and do not fully understand the areas of difficulty. In recognition of this the Renal Association, in conjunction with Kidney Research UK (formerly National Kidney Research Fund), commissioned and developed a survey to examine the provision and attainment of dialysis related access across the United Kingdom. This was intended to be a survey of all renal units and all patients receiving dialysis. This preliminary report is based on returns from 62 of 72 renal centres, covering 62 main centres and 119 satellite haemodialysis units (Table 6.1).

Table 6.1: Units contributing to the dataset
62 centres included in analysis

Country	Hospital name	Abbreviation
England	Addenbrookes Hospital, Cambridge	Camb
	Arrowe Park Hospital, Wirral	Wirrl
	Barts and the London Hospital	Barts
	Basildon Hospital	Basldn
	Birmingham Childrens Hospital	BirmCh
	Broomfield Hospital, Chelmsford	Chelms
	Cumberland Infirmary, Carlisle	Carls
	Derby City General Hospital	Derby
	Derriford Hospital, Plymouth	Plym
	Freeman Hospital, Newcastle	Newc
	Gloucester Royal Hospital	Glouc
	Guy's and St Thomas's Hospital, London	Guys
	Heartlands Hospital, Birmingham	Heart
	Hope Hospital, Manchester	ManWst
	Hull Royal Infirmary	Hull
	Ipswich Hospital	Ipswi
	James Cook University Hospital, Middlesbrough	Middlbr
	Kent & Canterbury Hospital	Kent
	Kings College Hospital, London	Kings
	Leeds General Infirmary	LGI
	Leicester General Hospital	Leic
	Lister Hospital, Stevenage	Stevn
	New Cross Hospital, Wolverhampton	Wolve
	Norfolk & Norwich University Hospital	Norwch
	Northern General Hospital, Sheffield	Sheff
	Nottingham City Hospital	Nottm
	Oxford Radcliffe Hospital	Oxfrd
	Queen Elizabeth Hospital, Birmingham	QEH
	Royal Berkshire Hospital, Reading	Redng
	Royal Cornwall Hospital, Truro	Truro
	Royal Liverpool University Hospital	Livrpl
	Royal Preston Hospital	Prstn
	Royal Sussex County Hospital, Brighton	Bright
	Russells Hall Hospital, Dudley	Dudley
	Southend Hospital	Sthend
	Southmead Hospital, Bristol	Bristl
	St George's Hospital, London	StGrge
	St Helier Hospital, Carshalton	Carsh
	St James's University Hospital, Leeds	StJms
	St Lukes Hospital, Bradford	Bradf
	University Hospital Aintree	Aintre
	University Hospital of North Staffordshire	Stoke
	Walsgrave Hospital, Coventry	Covnt
	Wrexham Maelor Hospital	Wrexm
	York District General Hospital	York
Wales	Morriston Hospital, Swansea	Swnse
	Ysbyty Glan Clwyd	Clwyd
	Ysbyty Gwynedd	Bangr

Table 6.1: (continued)
62 centres included in analysis

Country	Hospital name	Abbreviation
Scotland	Aberdeen Royal Infirmary	Abrdn
	Crosshouse Hospital, Kilmarnock	Klmarnk
	Dumfries & Galloway Royal Infirmary	D&Gall
	Edinburgh Royal Infirmary	Edinb
	Glasgow Royal Infirmary including Stobhill	GlasRI
	Glasgow Western Infirmary	GlasWI
	Monklands District General Hospital, Airdrie	Airdr
	Ninewells Hospital & Medical School, Dundee	Dunde
	Queen Margaret Hospital, Dunfermline	Dunfn
	Raigmore Hospital, Inverness	Inver
N Ireland	Antrim Hospital	Antrim
	Belfast City Hospital	Belfast
	Tyrone County Hospital	Tyrone
	Ulster Hospital	Ulster

Methodology

The 'vascular access survey' was developed by the Clinical Affairs Board of the Renal Association, under the chairmanship of the President and Clinical Vice President. Kidney Research UK provided input and assisted with the construction of the organisational question set. Initial drafts of the survey were then presented to the Renal Clinical Directors' Forum for further feedback and agreement for circulation and completion. The initial survey was then mailed to all renal unit Clinical Directors in March 2005. Table 6.1 details returns.

It was clear from early discussion with Clinical Directors that this was a major undertaking, as in many renal units many of the data had to be extracted from paper records: the Renal Association is grateful for the efforts made by participating renal units.

The survey questionnaire is in Appendix G, it was divided into 4 sections: Prevalent patients, Incident patients, Incident 6 month follow up and Organisational data.

Prevalent data

The initial section was a simple census count of all patients undergoing dialysis therapy on 31st March 2005 with details of their access.

In addition, it was felt useful to look at markers of morbidity within the ERF population which may be related to access problems. These markers had to be easily defined, and accessible to data collection: two markers were chosen.

1. Infection is considered to be a major consequence of venous catheters used for haemodialysis. Staph. aureus species bacteraemias are associated with considerable morbidity within the dialysis programme, resulting in important complications such as endocarditis or spinal abscess. National coverage of methicillin resistant Staphylococcal aureus (MRSA) rates within acute trusts has received considerable public interest. MRSA bacteraemia rates are a matter of public record and are reported centrally (Department of Health: MRSA surveillance system: Results, 2005, available at www.doh.gov.uk). Renal units are widely considered to be a major determinant of MRSA bacteraemia rates within a Trust.

   Data on Staph. aureus bacteraemia should have been available to renal units. A return on absolute numbers of MRSA and total Staph. aureus bacteraemia for 2004 was requested. This will probably be an underestimate, since it was not felt possible to collate data on haemodialysis patients either admitted or diagnosed in acute trusts outside the main renal unit trust.

2. The second morbidity marker requested was targeted at bed utilisation. Renal units were requested to report the number of chronic patients receiving haemodialysis who were an in-patient at 9 a.m., 1st April 2005, and to estimate the number deemed to be related to vascular access. The definition of the subgroup was left to the discretion of the Clinical Director, but included infection, placement of access and failure of access. Again this marker will be an underestimate of the total in patient burden for patients with established renal failure. It did not always include patients under the care of teams outside nephrology within the same trust, nor include patients in other trusts.

Incident data

Key within the Renal NSF are quality standards around patient preparation for renal replacement therapy. The consistent impression is that many patients commence renal replacement therapy poorly prepared for treatment. Many factors are felt to influence preparation, but key considerations are late referral to nephrology units, inadequate appreciation of rate of progression of renal impairment, delayed referral for vascular access formation and transplantation, and service shortfalls (eg lack of diagnostics, surgeons or operating capacity). The key components and problems of this patient pathway cross health care boundaries, and problems may differ between health care communities. Much work has been done via the Vascular Access (VA) pilots in Exeter and Birmingham subsequent to the design of the VA survey in identifying key components of this pathway. The survey does measure current performance and was designed to dissect out key areas of service shortfall.

Data were requested on new starters to renal replacement therapy, plus patients reaching established renal failure following renal transplant failure. Renal units were asked to record all such patients during April 2005. Requested data included age, gender, ethnicity and cause of renal failure. To understand the management of the patient, data were also requested on the date of referral to the renal service, when referred to a vascular surgeon and whether the patient was listed for renal transplantation. Finally, the date of first renal replacement therapy and the type of access used at first renal replacement therapy were recorded.

Transplantation listing was also useful as a marker of general preparation of the patient, and covered standard 5 of the Renal NSF. In renal units with large living donor transplant programmes this may be slightly misleading, as the majority of these patients are never listed for transplantation.

Six month follow up

To further assess the organisation of the vascular access pathway follow up, data on the patients from the April cohort will be sought. No analysis from this information is available at the time of writing, but will be included in further reports. One-year follow up data will also be requested. The data include access type at census date, mortality information and transplant status.

Organisational data set

In conjunction with Kidney Research UK (formerly the NKRF), a series of questions were devised to look at work force issues, organisation and service capacity. Again, data will not be presented within this report, pending further analysis and discussion with Kidney Research UK.

Overall, the survey was targeted at vascular access provision. However the data set yielded information relevant to several other areas of the Renal NSF. Table 6.2 summarises these.

Table 6.2: Data relevant to other areas of the Renal NSF

Survey Section	Data set	Renal NSF (Standard*)	Other areas
Prevalent data set	Prevalent census	Choice (two)	National measure
	Infection	Clinical Standards (four)	Emergency bed day target
	Bed days		
Incident	Late referral	CKD care	
	Preparation	Choice (two)	
	Access at 1st RRT	Access (three)	
	Transplant listing	Transplant (five)	
6 and 12 month follow up	Access	Standard (three and four)	High level process measure
	Transplant listing	Transplant (five)	
Organisational data			Workload
			Organisation (pilot site data)

*The number in brackets relates to the NSF Standard number.

Results

Prevalent data

Modality and access data

A total of 17,409 prevalent dialysis patients are included in this report, 11,999 patients in main renal units and 5,338 in satellite HD units, from 62 main renal units and 119 satellite HD units throughout the UK. Peritoneal dialysis comprised 24% of reported dialysis patients – only 2 renal units (Oxford and LGI) reported PD patients outside the main unit. The detailed data are shown in Table 6.3 and Figure 6.1. For comparison, the 2004 Renal Registry report is based on 32,000 patients: 45% with a transplant, 42% on haemodialysis, and 13% on peritoneal dialysis, with peritoneal dialysis patients comprising 24% of the total dialysis patients.

Including PD patients, 13,343 (77%) of prevalent patients were having dialysis therapy delivered by definitive access (HD definitive access defined as AVF or AVG). Raw data are given in Table 6.4. Of all HD patients, 66% had an arteriovenous fistula (AVF) and 4% an arteriovenous graft (AVG); 28% used tunnelled and 2% venous catheters. Not surprisingly satellite units, which tend to treat more stable patients, had a lower proportion of haemodialysis patients using catheters (22%) than main units (35%).

PD utilisation varied from 4–40% between centres (excluding Paediatric units). Including PD patients, definitive access (PD, AVF and AVG) was achieved in a range from 52–95% of patients in different centres, median 78%. For HD patients only, definitive access was present in a range from 44–94%. Usage of AVG was the most variable, varying from 0–21% of HD

Table 6.3: Prevalent patients; summary

Main renal units	N	%	Range (N)
Total main units	62		
Total dialysis pts	12,071		
Total PD	4,105	34.0	2–214
Total HD	7,966	66.0	14–303
HD (AVF)	4,800	60.8	9–202
HD (Graft)	331	4.2	0–42
HD (Tunnel)	2,535	32.1	2–119
HD (Non Tunnel)	201	2.5	0–28
HD (Other)	27	0.3	0–8
Satellite renal units	**N**	**%**	**Range (N)**
Total satellite units	119		
Total HD pts	5,294		2–131
HD (AVF)	3,831	72.8	1–102
HD (Graft)	241	4.6	0–15
HD (Tunnel)	1,078	20.5	0–46
HD (Non Tunnel)	57	1.1	0–8
HD (Other)	53	1.0	0–22
Total	**N**	**%**	
Total pts	17,365		
Total PD pts	4,105	23.6	
Total HD pts	13,260	76.4	
HD (AVF)	8,631	65.6	
HD (Graft)	572	4.3	
HD (Tunnel)	3,613	27.5	
HD (Non Tunnel)	258	2.0	
HD (Other)	80	0.6	

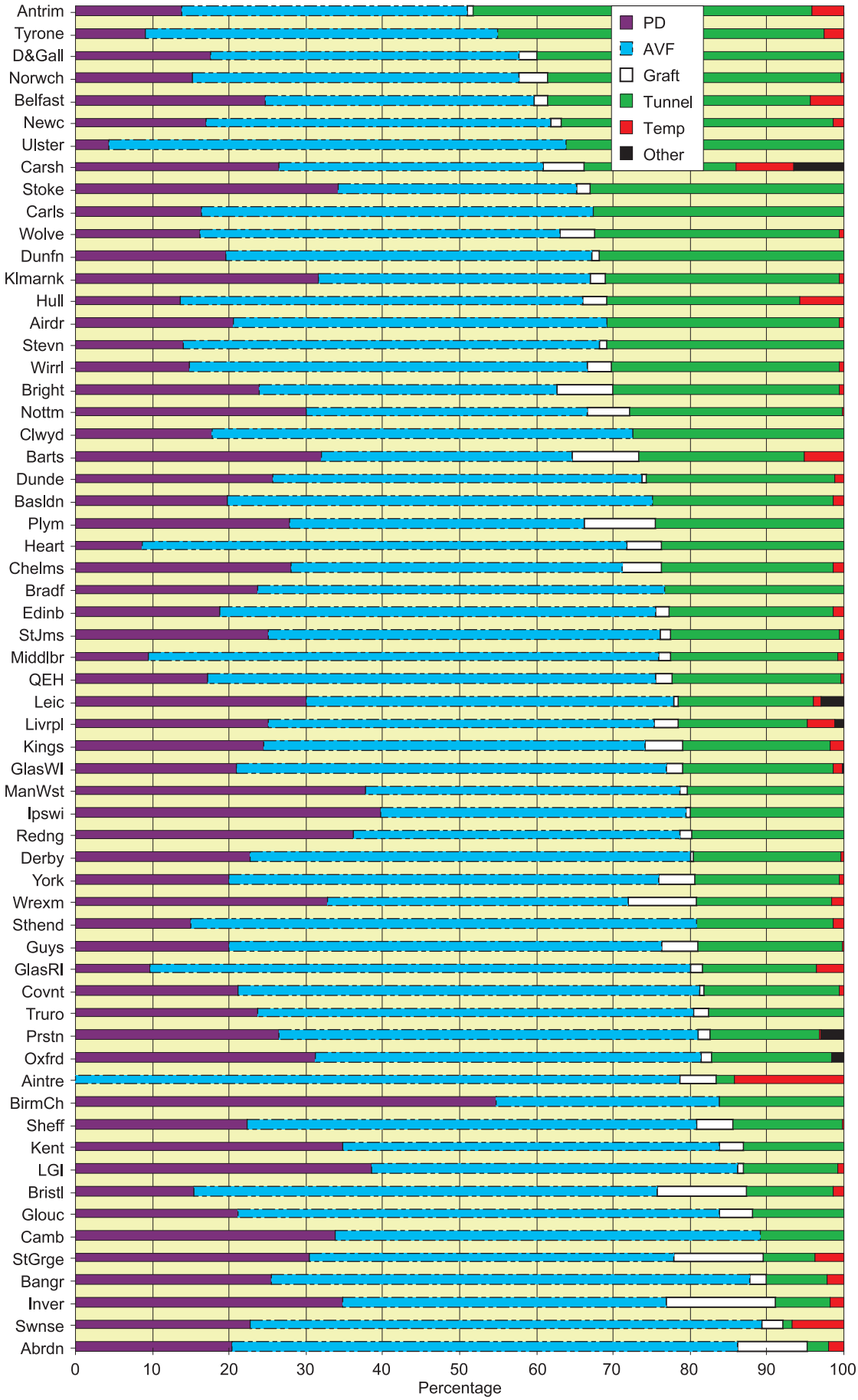


Figure 6.1: Distribution of patients by access by centre (main unit + satellite)

Table 6.4: Prevalent dialysis patient numbers, by centre and access type (1st April 2005)

Hospital name	Total PD	Total HD	Total HD (native AVF)	Total HD (graft)	Total HD (tunnelled line)	Total HD (temporary line)	Total HD (other access)	% PD	% HD	% definitive access	% HD definitive access
Aberdeen	43	168	139	19	6	4	0	20.4	79.6	95.3	94.05
Swansea	77	262	226	9	4	23	0	22.7	77.3	92.0	89.69
Inverness	39	73	47	16	8	2	0	34.8	65.2	91.1	86.30
Bangor	23	67	56	2	7	2	0	25.6	74.4	90.0	86.57
St Georges	58	132	90	22	13	7	0	30.5	69.5	89.5	84.85
Cambridge	75	147	123	0	24	0	0	33.8	66.2	89.2	83.67
Gloucester	34	127	101	7	19	0	0	21.1	78.9	88.2	85.04
Bristol	70	382	272	53	51	6	0	15.5	84.5	87.4	85.08
LGI	98	156	121	2	31	2	0	38.6	61.4	87.0	78.85
Kent	101	189	142	9	38	0	0	34.8	65.2	86.9	79.89
Sheffield	158	547	412	33	100	2	0	22.4	77.6	85.5	81.35
Birmingham Childrens	17	14	9	0	5	0	0	54.8	45.2	83.9	64.29
Aintree	0	42	33	2	1	6	0	0.0	100.0	83.3	83.33
Oxford	142	312	228	6	71	0	7	31.3	68.7	82.8	75.00
Preston	111	307	228	6	60	1	12	26.6	73.4	82.5	76.22
Truro	46	148	110	4	34	0	0	23.7	76.3	82.5	77.03
Coventry	65	243	185	2	54	2	0	21.1	78.9	81.8	76.95
Glasgow RI	31	286	223	5	47	11	0	9.8	90.2	81.7	79.72
Guys	99	399	281	24	93	1	0	19.9	80.1	81.1	76.44
Southend	22	124	96	0	26	2	0	15.1	84.9	80.8	77.42
Wrexham	41	84	49	11	22	2	0	32.8	67.2	80.8	71.43
York	29	116	81	7	27	1	0	20.0	80.0	80.7	75.86
Derby	58	198	147	1	49	1	0	22.7	77.3	80.5	74.75
Reading	95	168	112	4	52	0	0	36.1	63.9	80.2	69.05
Ipswich	68	103	68	1	34	0	0	39.8	60.2	80.1	66.99
ManWst	150	248	163	4	81	0	0	37.7	62.3	79.6	67.34
Glasgow WI	73	277	196	8	68	4	1	20.9	79.1	79.1	73.65
Kings	85	262	172	17	67	6	0	24.5	75.5	79.0	72.14
Liverpool	112	335	225	14	75	16	5	25.1	74.9	78.5	71.34
Leicester	210	487	333	4	122	7	21	30.1	69.9	78.5	69.20
QEH	140	674	475	17	178	4	0	17.2	82.8	77.6	73.00
Middlesbrough	25	237	174	4	57	2	0	9.5	90.5	77.5	75.11
St James	146	435	296	8	127	4	0	25.1	74.9	77.5	69.89
Edinburgh	51	222	155	5	58	4	0	18.7	81.3	77.3	72.07
Bradford	49	157	109	0	48	0	0	23.8	76.2	76.7	69.43
Chelmsford	38	97	58	7	30	2	0	28.1	71.9	76.3	67.01
Heartlands	29	308	213	15	80	0	0	8.6	91.4	76.3	74.03
Plymouth	42	109	58	14	37	0	0	27.8	72.2	75.5	66.06
Basildon	30	122	84	0	36	2	0	19.7	80.3	75.0	68.85
Dundee	45	130	84	1	43	2	0	25.7	74.3	74.3	65.38
Barts	214	455	218	58	144	35	0	32.0	68.0	73.2	60.66
Clwyd	13	60	40	0	20	0	0	17.8	82.2	72.6	66.67
Nottingham	132	307	160	25	121	1	0	30.1	69.9	72.2	60.26
Brighton	91	289	147	28	112	2	0	23.9	76.1	70.0	60.55
Wirral	28	161	98	6	56	1	0	14.8	85.2	69.8	64.60
Stevenage	53	324	204	4	116	0	0	14.1	85.9	69.2	64.20
Airdrie	36	139	85	0	53	1	0	20.6	79.4	69.1	61.15
Hull	43	274	166	10	80	18	0	13.6	86.4	69.1	64.23
Kilmarnock	50	108	56	3	48	1	0	31.6	68.4	69.0	54.63
Dunfermline	21	86	51	1	34	0	0	19.6	80.4	68.2	60.47
Wolverhampton	54	279	156	15	106	2	0	16.2	83.8	67.6	61.29

Table 6.4: (continued)

Hospital name	Total PD	Total HD	Total HD (native AVF)	Total HD (graft)	Total HD (tunnelled line)	Total HD (temporary line)	Total HD (other access)	% PD	% HD	% definitive access	% HD definitive access
Carlisle	15	77	47	0	30	0	0	16.3	83.7	67.4	61.04
Stoke	107	206	97	6	103	0	0	34.2	65.8	67.1	50.00
Carshalton	139	386	181	28	103	40	34	26.5	73.5	66.3	54.15
Ulster	2	45	28	0	17	0	0	4.3	95.7	63.8	62.22
Newcastle	46	226	122	4	96	4	0	16.9	83.1	63.2	55.75
Belfast	86	262	122	6	119	15	0	24.7	75.3	61.5	48.85
Norwich	49	272	136	12	123	1	0	15.3	84.7	61.4	54.41
Dumfries	15	70	34	2	34	0	0	17.6	82.4	60.0	51.43
Tyrone	11	109	55	0	51	3	0	9.2	90.8	55.0	50.46
Antrim	20	125	54	1	64	6	0	13.8	86.2	51.7	44.00

Renal units are listed in order of percentage of patients with definitive access.

patients between centres. Adult centre sizes ranged from 42–814 prevalent dialysis patients. Dialysis programme size did not affect rates of definitive access – the four renal units with total dialysis populations over 600 achieved rates of 73–86% of all dialysis patients with PD rates from 17–32%. The three renal units which achieved 90% or more of all dialysis patients with definitive access – Aberdeen, Bangor, Swansea and Inverness – had dialysis populations of 211, 90, 339 and 112 respectively.

Morbidity data

Two items of data were returned for this section – number of haemodialysis patients who were in-patients on 31st March 2005, and Staph. aureus bacteraemias reported during 2004.

In-patient census data

On 31st March 2005, 673 (5%) patients currently receiving haemodialysis were in-patients, of which 166 episodes (29%) were considered to be related to vascular access issues (Table 6.5). Individual unit numbers ranged from 0–48 HD as in-patients, ranging from 0–14% of the haemodialysis populations, average 5%. Access related admissions ranged from 0–19 patients, range from 0–7% of the HD populations, average 1.7% of patients.

During 2004, 1,576 episodes of Staph. aureus bacteraemia were recorded in haemodialysis patients from the 54 centres with available data, with a wide range between centres from 1–103 episodes: of these, 462 (29%) were MRSA bacteraemias, range 0–32 (Table 6.5).

Not surprisingly there was a correlation between centre haemodialysis patient numbers and Staph. aureus bacteraemias (Figure 6.2, $R^2 = 0.42$), but not with MRSA (Figure 6.3, $R^2 = 0.18$). The weak correlations suggest that other factors are also important in determining bacteraemia in haemodialysis patients: in the case of MRSA nearly 80% of the variation is due to factors other than centre size. Local practice may influence infection rates, but the data source may also have varied between renal units. It is possible that renal units who reported the number of infections from their own records rather than from those of the microbiology department under-reported the number of bacteraemias. Thus the true incidence may be higher than suggested here. This will be investigated for the final report. Similar considerations apply to the relationship between the number of venous catheters in a renal unit and the absolute number of Staphylococcal bacteraemias (Figure 6.4).

Table 6.5 shows a calculation for each renal unit of the number of Staphylococcal bacteraemias per annum per hundred patients in the renal unit – this varies from 2.3 to 33.8, average 13, the figures for MRSA alone being from 0 to 21.5, average 4.

Many centres of necessity excluded episodes diagnosed and treated outside the main

Table 6.5: Bacteraemias and admissions in prevalent HD patients

Renal unit	Total HD (main + satl)	HD (main unit)	HD (satl unit)	Staph. aureus	No. MRSA Bacte-raemia	Staph. aureus per 100 pats	MRSA per 100 pats	% MRSA	No. in-pats	In-pats for VA reasons	% of HD pats in-pats	% HD access admiss
Aberdeen	168	129	39	8	5	4.8	3.0	63	7	0	4	0
Aintree	42	17	25	5	2	11.9	4.8	40	5	0	12	0
Airdrie	139	139	0	32	9	23.0	6.5	28	2	0	1	0
Antrim	125	125	0	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Bangor	67	67	0	3	2	4.5	3.0	67	1	0	1	0
Barts	455	303	152	78	8	17.1	1.8	10	30	11	7	2
Basildon	122	122	0	14	3	11.5	2.5	21	n/a	n/a	n/a	n/a
Belfast	262	262	0	28	11	10.7	4.2	39	25	12	10	5
Birmingham Childrens	14	14	0	1	0	7.1	0.0	0	0	0	0	0
Bradford	157	123	34	11	4	7.0	2.5	36	5	1	3	1
Brighton	289	191	98	27	10	9.3	3.5	37	7	1	2	0
Bristol	382	84	298	57	18	14.9	4.7	32	19	4	5	1
Cambridge	147	147	0	n/a	n/a	n/a	n/a	n/a	4	0	3	0
Carlisle	77	67	10	9	5	11.7	6.5	56	6	4	8	5
Carshalton	386	223	163	103	32	26.7	8.3	31	48	14	12	4
Chelmsford	97	97	0	18	7	18.6	7.2	39	10	3	10	3
Clwyd	60	60	0	20	3	33.3	5.0	15	4	0	7	0
Coventry	243	141	102	24	2	9.9	0.8	8	5	2	2	1
Dumfries	70	70	0	15	2	21.4	2.9	13	2	1	3	1
Derby	198	198	0	23	5	11.6	2.5	22	8	0	4	0
Dudley	106	72	34	n/a	n/a	n/a	n/a	n/a	7	1	7	1
Dundee	130	130	0	44	28	33.8	21.5	64	8	1	6	1
Dunfermline	86	54	32	8	3	9.3	3.5	38	3	1	3	1
Edinburgh	222	155	67	n/a	n/a	n/a	n/a	n/a	16	3	7	1
Glasgow RI	286	101	185	46	15	16.1	5.2	33	19	3	7	1
Glasgow WI	277	198	79	79	32	28.5	11.6	41	n/a	n/a	n/a	n/a
Gloucester	127	127	0	19	7	15.0	5.5	37	9	0	7	0
Guys	399	89	310	16	10	4.0	2.5	63	17	6	4	2
Heartlands	308	123	185	24	7	7.8	2.3	29	17	3	6	1
Hull	274	140	134	46	4	16.8	1.5	9	9	3	3	1
Inverness	73	65	8	10	1	13.7	1.4	10	1	0	1	0
Ipswich	103	103	0	6	4	5.8	3.9	67	7	0	7	0
Kent	189	82	107	9	3	4.8	1.6	33	9	2	5	1
Kilmarnock	108	108	0	4	1	3.7	0.9	25	10	2	9	2
Kings	262	128	134	n/a	17	n/a	6.5	n/a	14	8	5	3
Leicester	487	176	311	50	12	10.3	2.5	24	13	5	3	1
LGI	156	93	63	4	1	2.6	0.6	25	3	2	2	1
Liverpool	335	188	147	15	n/a	4.5	n/a	n/a	36	17	11	5
ManWst	248	130	118	49	25	19.8	10.1	51	19	3	8	1
Middlesbrough	237	103	134	30	12	12.7	5.1	40	9	3	4	1
Newcastle	226	226	0	48	16	21.2	7.1	33	15	4	7	2
Norwich	272	217	55	54	12	19.9	4.4	22	37	19	14	7
Nottingham	307	182	125	19	2	6.2	0.7	11	20	4	7	1
Oxford	312	163	149	29	8	9.3	2.6	28	6	0	2	0
Plymouth	109	109	0	22	8	20.2	7.3	36	7	3	6	3
Preston	307	131	176	24	10	7.8	3.3	42	25	0	8	0
QEH	674	213	461	49	16	7.3	2.4	33	30	5	4	1
Reading	168	85	83	6	2	3.6	1.2	33	7	1	4	1
Sheffield	547	286	261	70	15	27.6	2.7	10	10	4	2	1
Stevenage	324	106	218	55	6	17.0	1.9	11	18	4	6	1
St Georges	132	119	13	3	1	2.3	0.8	33	5	2	4	2
Southend	124	124	0	13	3	10.5	2.4	23	5	1	4	1

Table 6.5: (continued)

Renal unit	Total HD (main + satl)	HD (main unit)	HD (satl unit)	Staph. aureus	No. MRSA Bacte-raemia	Staph. aureus per 100 pats	MRSA per 100 pats	% MRSA	No. in-pats	In-pats for VA reasons	% of HD pats in-pats	% HD access admiss
St James	435	218	217	19	1	4.4	0.2	5	11	3	3	1
Stoke	206	134	72	n/a	16	n/a	7.8	n/a	20	9	10	4
Swansea	262	158	104	73	11	27.9	4.2	15	12	2	5	1
Truro	148	76	72	n/a	n/a	n/a	n/a	n/a	5	0	3	0
Tyrone	109	109	0	11	5	10.1	4.6	45	3	1	3	1
Ulster	45	45	0	3	0	6.7	0.0	0	0	n/a	0	n/a
Wirral	161	86	75	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Wolverhampton	279	94	185	43	11	15.4	3.9	26	16	10	6	4
Wrexham	84	84	0	7	6	8.3	7.1	86	2	1	2	1
York	116	57	59	12	3	10.3	2.6	25	5	4	4	3

N/A = not available.

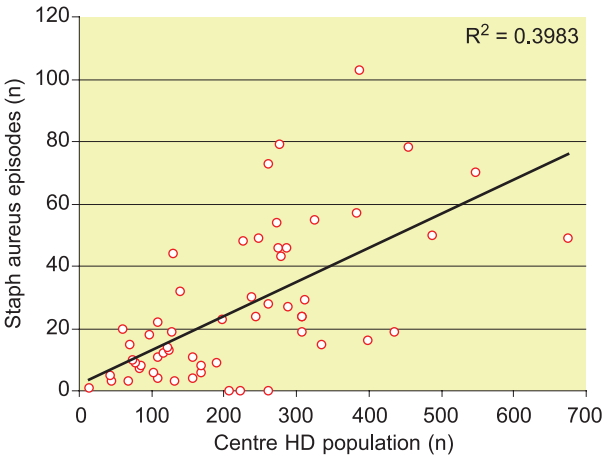


Figure 6.2: Relationship between numbers of haemodialysis patients in a centre and Staph. aureus bacteraemias

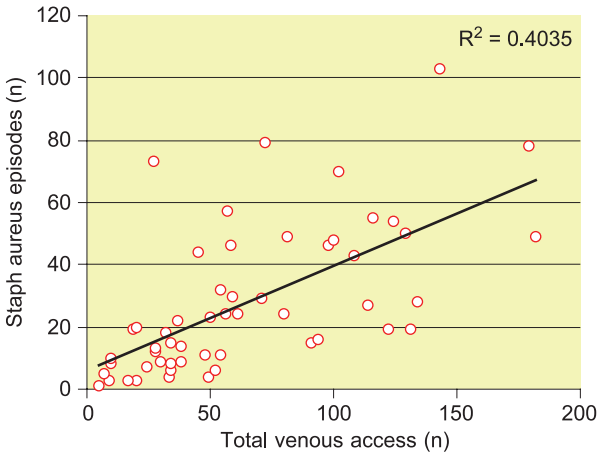


Figure 6.4: Relationship between number of venous catheters in a centre and number Staph. aureus bacteraemias

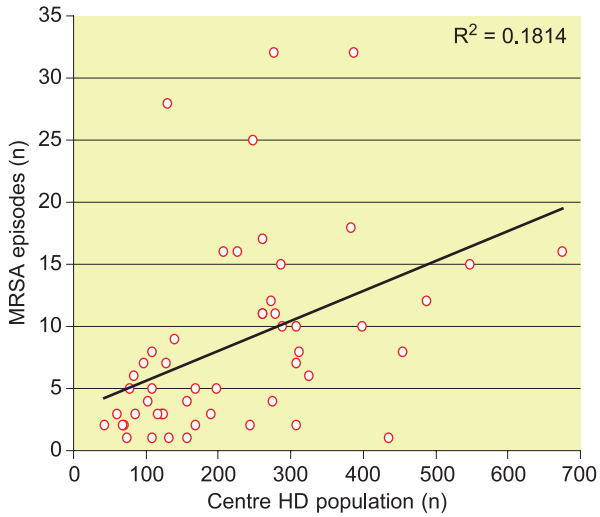


Figure 6.3: Relationship between number of haemodialysis patients in a centre and number MRSA bacteraemias

centre. This is another potential source of under-reporting of infection rates.

Incident data

Modality and access data

During April 2005, 457 incident patients from 62 renal units were reported. Renal units reported between 1 and 25 patients, which generally related to the size of the catchment population (Figure 6.5). Primary renal disease is detailed in Figure 6.6, and is similar to the data for the whole registry, although diabetic nephropathy is rather low. There is a disappointingly high rate of late referral in the diabetics (vide infra), a group under continuing medical surveillance. Gender ratio was 1.5 : 1 male to female (275 : 181). Ethnicity was

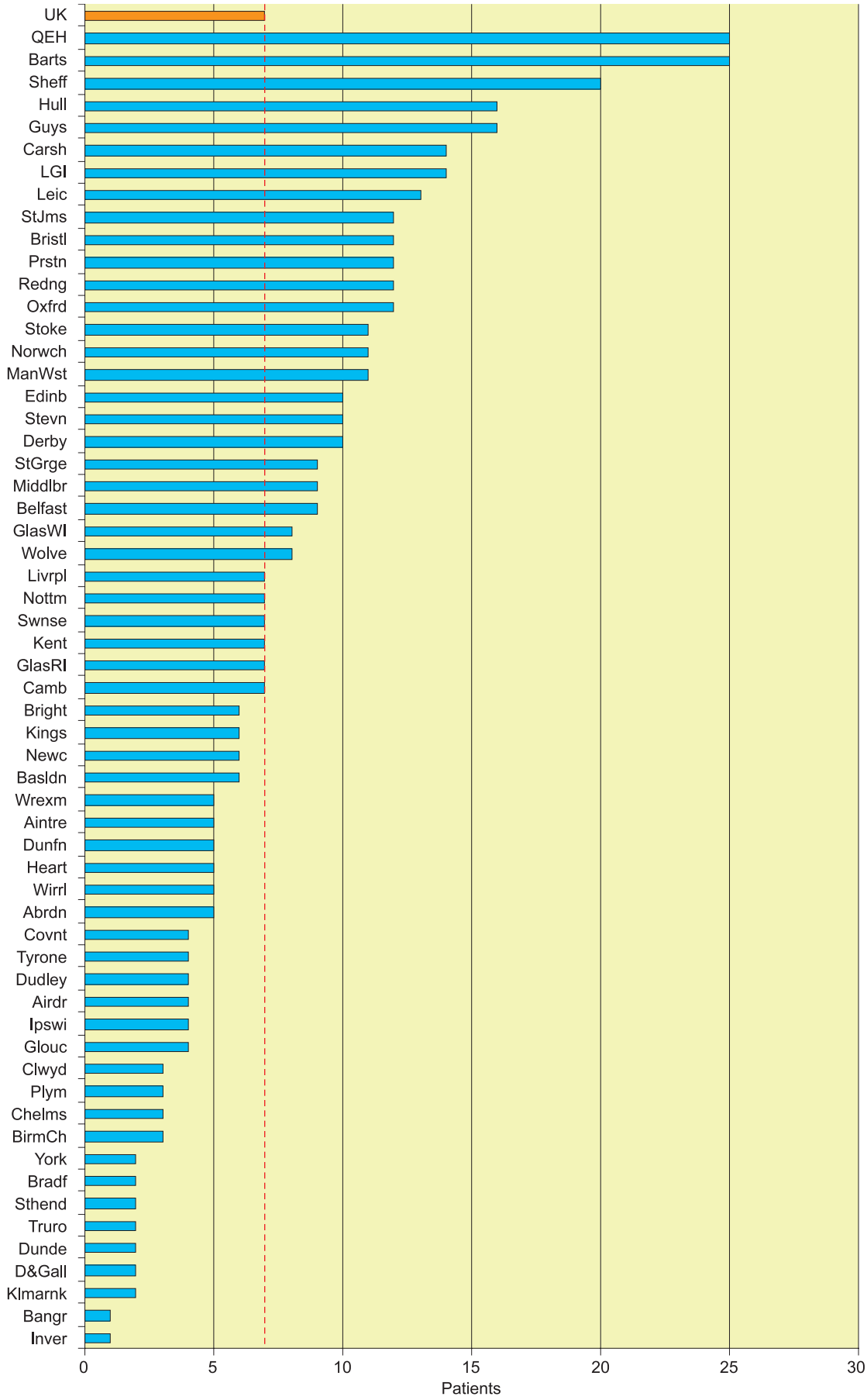


Figure 6.5: Number of incident patients per unit, April 2005

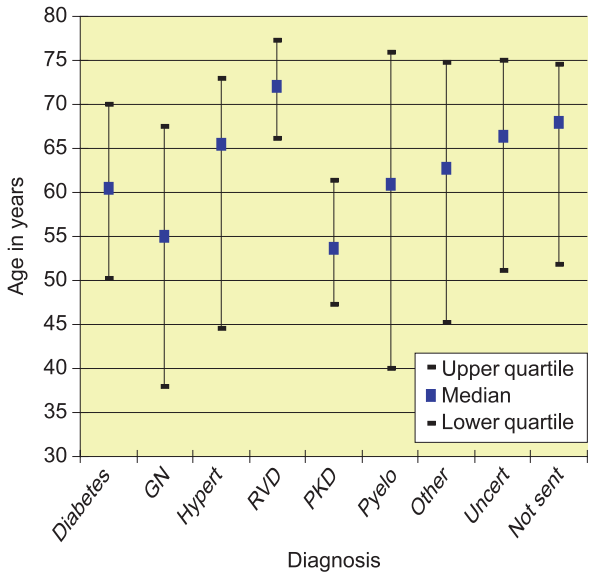


Figure 6.6: Incident patients: age, and primary renal disease

consistent with national data and is detailed in Table 6.6. The median age was 63 years (upper quartile 74, lower quartile 47) (Figure 6.6).

Overall the first modality of therapy was transplantation in 4% (n = 17), peritoneal dialysis in 19% (n = 86) and haemodialysis in 77%, (n = 351) (Table 6.7). Modality was not recorded in three cases. Combining PD, transplantation, AVF and AVG, 45% of patients commenced therapy using definitive access (n = 196). Of patients commencing on HD, only 31% commenced with definitive access (AVF, n = 104; 30%, and AVG, n = 6; 2%) (Table 6.8): Referral for potential transplantation was poorer – 46 (10%) patients were active on the transplant list at first RRT. In renal units with large living donor transplant programmes this may be slightly misleading, as the majority of such patients are never listed for transplantation.

Table 6.6: Ethnicity of incident patients (N = 455)

Ethnicity	Frequency	Percent
Asian	42	9
Black	19	4
Chinese	4	1
Other	6	1
Unknown	3	1
Caucasian	381	84
Missing data = 2		

Table 6.7: Incident patients: 1st treatment modality

Modality	Frequency	Percent
HD	351	77
PD	86	19
Transplant	17	4
Missing data = 3		

Table 6.8: Incident HD patients: Access

Access type	Frequency	Percent
Total HD	351	
AVF	104	30
AVG	6	2
Non tunnel	126	36
Tunnel	115	33

Time of first presentation to nephrology services

Renal units returned data on date of first presentation to nephrology services and date of referral for access. The time from those time points to first RRT was extracted. These data are summarised in Table 6.9.

Overall, data for first contact with nephrology services was unrecorded in only 30 patients. Of the remaining 427, 55% had been referred 12 months or more prior to initiation of RRT, 35% less than 6 months before RRT and 29% (n = 125) reached renal replacement therapy within 3 months of first contact.

Given the small numbers in this study, primary renal disease did not significantly affect the probability of early referral to the renal unit although there was a trend to earlier referral for glomerular pathology, pyelonephritis and hypertension, and diabetes was associated with the lowest proportion (other than missing primary renal disease) (Figure 6.7). The data set

Table 6.9: Time from referral to renal services to 1st RRT

Months	n	%
0–3m	125	29.3
3–6m	23	5.4
6–12m	46	10.8
12m+	233	54.6
Total	**427**	
Missing data	30	

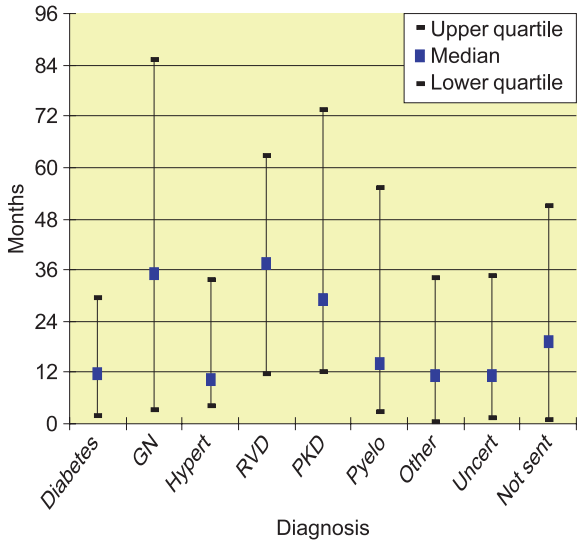


Figure 6.7: Time from first referral to RRT by diagnosis

for those referred for transplantation is too small for adequate analysis of referral dates.

Time of first referral and dialysis modality

As the time from first contact with the renal team, prior to starting renal replacement therapy increases, a higher proportion of patients start on PD. This rises from 11% for those patients with less than 3 months contact to 27% for patients known for 24 months or more (Table 6.10). It appears that relatively little use is being made of PD as an alternative to venous catheters in those patients presenting late. For patients starting on PD the median time between first referral and RRT was 868 days, for HD starters 343 days: 109 patients of 351 total incident patients presented at less than 100 days (31%).

Time of first referral and initial haemodialysis access

The relationship between time of first referral and haemodialysis access first used is shown in Table 6.11.

It is disappointing that of those known for a year or more, only half started HD with definitive access (AVF + AVG), 50% started HD on temp access. For those commencing RRT via an AVF (n = 104) the median time from presentation was 888 days, with 6 patients presenting less than 100 days before RRT. Only 6 incident patients utilised AVG. For those starting with tunnelled venous catheters, the median time was 255 days. The majority of these patients had presented more than 6 months before 1st RRT – 54% (63 of 115) patients. For those commencing via temporary

Table 6.10: Time of first referral and starting dialysis modality

Months from 1st contact	HD %	PD %	HD (N)	PD (N)	Total
<3m	89	11	108	13	121
3 – <6m	78	22	18	5	23
6 – <9m	84	16	21	4	25
9 – <12m	80	20	12	3	15
12 – <24m	78	22	46	13	59
⩾24m	73	27	123	45	168
Total	**80**	**20**	**328**	**83**	**411**

Table 6.11: Time since 1st contact and access type in HD patients

Months from 1st contact	AVF	AVG	Non-tunnel	Tunnel	% catheter	Total
<3m	6	1	65	36	94	108
3 – <6m	4	0	5	9	78	18
6 – <9m	8	0	3	10	62	21
9 – <12m	2	0	3	7	83	12
12 – <24m	22	1	13	10	50	46
⩾24m	58	4	25	36	50	123
Total	**100**	**6**	**114**	**108**	**68**	**328**

venous catheters, the median presentation interval was 42 days. It is notable that 44 of these 126 patients (35%) had been seen more than 6 months prior to first RRT.

Referral for vascular access

Of the total haemodialysis incident group (n = 351) 165 had been referred for access, but the date of referral was available for only 123. The data set does require further analysis to understand the missing data – it may be truly unknown, not recorded because the patient had access or a transplant or may reflect a weakness in the survey layout.

Study of the patients starting on HD who had been seen by the renal service at least 6 months before starting RRT gives insight into performance by renal services in cases where there had been an opportunity to intervene to provide access. The data are summarised in Table 6.12. Of these 198 patients, 157 patients had data available on time of referral for vascular access: only 33% had been referred for access more than 6 months before starting RRT, and only 48% more than 3 months. This demonstrates a significant lag between referral to the renal unit and referral for access, resulting in avoidable late access referral, and with the subsequent delays in surgery and time for access to mature, explains the poor achievement of definitive access at start of RRT. The large proportion of missing data hampers further analysis.

Table 6.12: Referral for vascular access in patients starting on HD referred to renal services more than 6 months before RRT

Total	**198**	**%**
Access referral unknown	11	6
Of those known:		
Not referred	62	33
Referred	125	67
Referral date known	95	76
Referral time before RRT: (157 pts with data)		
Not referred	62	39
<3months	20	13
3–6 months	24	15
6–12 months	28	18
>12 months	23	15

Discussion

Amongst haemodialysis patients infection and in-patient loads are high. The data presented suggest that over 320,000 bed days are utilised by HD patients per annum across the UK.

Overall, nearly one third of prevalent haemodialysis patients utilise some form of venous catheter for vascular access. Such patients are at risk of systemic sepsis, of which Staph. aureus is a major cause, although the data do not demonstrate a clear correlation between venous catheter usage and Staphylococcal bacteraemia; this may reflect problems with data collection and other important local confounding factors.

Renal units continue to be a major source of infection control issues for acute trusts. These 62 renal units reported 1,495 episodes of Staph. aureus septicaemia in haemodialysis patients in 2004, of which 462 were MRSA. The MRSA surveillance data reported 7,212 episodes for trusts in England and Wales (www.doh.gov.uk) for 2003/2004. Extrapolating from these data it appears that patients on haemodialysis may contribute 8–10% of all cases of MRSA septicaemia, rendering renal replacement therapy a strong risk factor for MRSA. The implications are serious for patients and for resource use: each episode requires at least two weeks of intravenous therapy, and is associated with considerable morbidity.

For an individual patient, the pathway towards renal replacement therapy consists of several components. Patients must be first identified in either primary or secondary care, referred to renal services, prepared for RRT (including referral for access and transplantation), initiated on to RRT and then maintained. Evidence from this survey suggests that all aspects of this pathway prior to the initiation of dialysis are subject to delay.

First, only 55% of patients were known to renal services more than 1 year before RRT commences. Even in patients with disease processes known to result in renal failure such as diabetes, referral occurs late. It is unlikely that all renal disease will be picked up in good time, but this suggests groups at high-risk of

established renal failure are still poorly served. The current focus afforded by the adoption of the KDOQI CKD classification may improve this part of the pathway.

Second, once patients are referred to nephrology, further delays occur. Many patients begin dialysis on either temporary (non-tunnelled) or tunnelled vascular access. The median time from first contact to first RRT for patients commencing HD was about 1 year. The optimum time for referral for vascular access can be difficult to judge for a number of factors. For example, the rate of renal decline may be difficult to predict. The preferred timing of placement is also unclear – place too late and it will not be ready, place too early and it may fail whilst the patient is waiting. Nevertheless it is disappointing that of the patients known to the renal units more than 6 months before starting RRT, where data are available only 33% are referred for access within less than 6 months of first RRT: this is rarely sufficient time to provide patients with functioning vascular access, even with ideal surgical pathways.

The third delay has not been analysed – no data on surgical capacity have been presented, but deficits here may represent a further challenge to this later part of the pathway. Such capacity should include the radiology component of service.

Once a patient is established on renal replacement therapy complications, should be minimised and both potential and actual access should be maintained. This survey does not address surveillance of vascular access to reduce access failure, but does show that infection rates are high and that access problem associated hospitalisation rates are high.

The lessons from the Vascular Access pilots are yet to be applied in nephrological practice. There are many issues that cross health care boundaries, particularly around late referral.

At the end of this pathway, only 43% of all patients and 31% of haemodialysis starters commence RRT with definitive access (either an AVF or AVG). Pre-emptive transplantation, despite its recommendation in the NSF, occurs in only 3% of patients, and only 9% are listed for transplantation at the start of dialysis. Fewer than 5% of renal units recorded a pre-emptive transplant in this short one-month period.

The survey demonstrates that such data collection was difficult, with a lack of agreed definitions, and little or no IT capability for it within many renal units. For renal units and commissioners to understand local issues clearly requires data, and to acquire that data requires agreement on a dataset and resource to collect and maintain it.

Summary and recommendations

The data as presented show a mixed bag of good, indifferent and poor service delivery. Whilst there would appear to be pockets of good practice, too many patients are presented to renal services late, too few are worked up for transplantation or access in a timely fashion, and many require hospitalisation for complications related to vascular access. This is a preliminary analysis and the second set of data has now been requested from renal units, looking at outcome of both access and patients at 6 months. This will allow further analysis of the patient pathway, and integration of patient outcome with that.

What are the key drivers to improve these aspects of the care of patients with established renal failure?

Firstly, if renal centres believe this is an important issue, data collection issues must be resolved.

Secondly, renal networks and commissioners must join in ownership of this aspect of renal services.

Thirdly, universal agreement on the currency of the problem must be agreed, to allow comparative performance to be assessed.

At present, nephrologists quote late referral and capacity issues as prime problems, surgeons quote capacity and delayed referral from nephrologists, and little work is carried out in

the field of vascular access preservation. At the end are patients who are poorly served.

It is suggested that the following should be considered.

Firstly, a modified version of this survey is undertaken as an annual exercise by the entire United Kingdom, via the Renal Association UK Renal Registry, pending the development of regular provision of the relevant data through the normal Registry channels. Essentially, an annual return of vascular access details and morbidity for incident and prevalent patients should be made to the Registry. Renal units should obtain microbiological data from Microbiology departments, and not rely solely on local records.

Secondly, local reporting to networks and commissioners, with subsequent audit, must be considered. This could include reporting of demographics, diagnosis and key timeline points (first presentation, access referral, transplantation status and access at first RRT). Then networks should provide breach reports on all patients commencing RRT without agreed definitive access, to inform and provide data for local action and national audit. Ultimately, as reporting of these data to the Registry is developed, the Registry will be able to support this activity.

Finally, there is need for agreed definitions and markers of quality of care for access, to develop recommended measures of care for dialysis access: these ''standards'' should balance achievability with challenge. Such auditable markers might influence and deliver improvement across the entire scope of the Renal NSF. The ability to use them to analyse the patient journey may allow individual networks of commissioners and providers to target resource appropriately.

Acknowledgements

Thank you to everyone involved in the collection of this data, the effort required to supply it is appreciated.

References

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Chapter 7: Adequacy of Haemodialysis and Serum Bicarbonate

Summary

- The urea reduction ratio (URR) has been rising year on year but now appears to have reached a plateau.
- The URR increases the longer an individual has been on dialysis.
- Concentrating on dialysis adequacy during the first few months after starting haemodialysis is likely to improve the median URR for a renal unit.
- Serum bicarbonate is very variable. The reason for the variability is not clear.

Introduction

The Renal Association guidelines offer both KT/V and the URR as markers for the adequacy of haemodialysis but the Registry has chosen the URR for comparative audit.

The Renal Association 3rd Standards Document page 17 states that:

HD should take place at least three times per week in nearly all patients. Reduction of dialysis frequency to twice per week because of insufficient dialysis facilities is unacceptable. (Good practice)

Every patient receiving thrice weekly HD should show:

- ***either urea reduction ratio (URR) consistently >65%***
- ***or equilibrated Kt/V of >1.2 (calculated from pre- and post-dialysis urea values, duration of dialysis and weight loss during dialysis). (B)***

Recommendations

Patients receiving twice weekly dialysis for reasons of geography should receive a higher sessional dose of dialysis, with a total Kt/V urea (combined residual renal and HD) of >1.8. If this cannot be achieved, then it should be recognised that there is a compromise between the practicalities of dialysis and the patient's long-term health. (Good practice)

The Renal Association has endorsed more than one method of sampling for adequacy measurements. The different results produced by the methodologies and whether it accounts for the variations seen between renal units, has been extensively dissected in the 2002 and 2003 Registry reports and will not be discussed further.

As in previous years the number preceding the centre name in all the figures indicates the percentage of missing data for that centre.

Achieved URR

The median URR achieved by each renal unit is shown in Figure 7.1. The variability is wide, ranging from 62% to 76%. This is reflected in the proportion of patients in each renal unit achieving the 65% URR target (Figure 7.2). There is, as expected, a close relationship between a renal unit's median URR and the percentage of patients in the renal unit complying with the 65% target (Figure 7.3). This suggests that in order to achieve 90% compliance with the target, a median URR of at least 72% is required and to achieve 80% compliance a median URR of at least 69% is required.

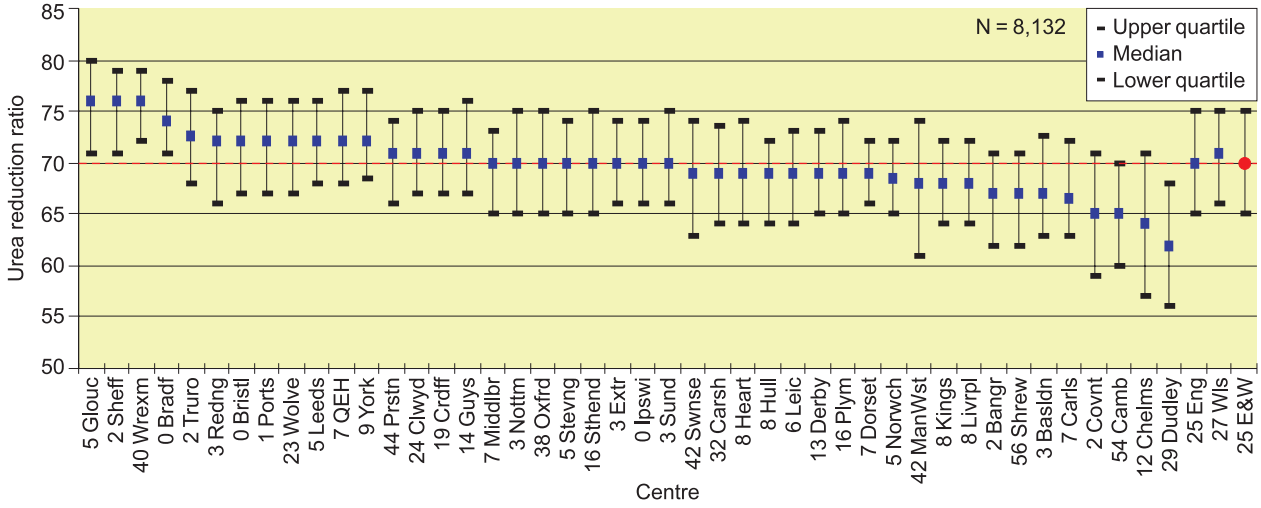

Figure 7.1: Median URR achieved in each centre, 2004

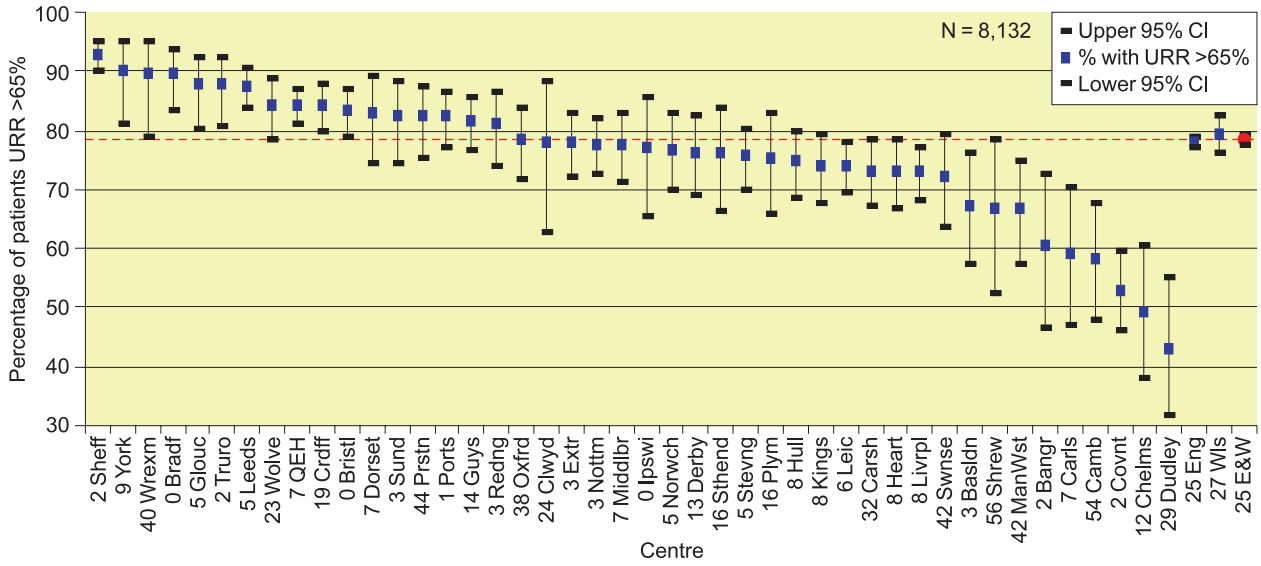

Figure 7.2: Percentage of patients with URR of >65% in each centre, 2004

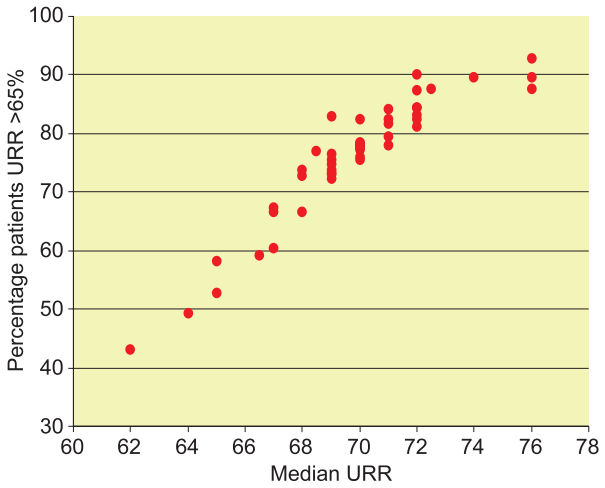

Figure 7.3: Relationship between achievement of URR standard and median URR

Changes in URR over time

Last year, it was reported that in England and Wales the median URR had been rising year on year. The Registry has data on URR for up to seven years (1998–2004), depending on when units joined the Registry, and almost all renal units have demonstrated an improvement in median URR and percentage compliance with the 65% standard over this time. Overall in England and Wales, the rise appears to have reached a plateau (Figures 7.4 and 7.5). Data from individual renal units (Figure 7.6) show that those with the lowest URR several years ago have improved markedly but again suggest that a ceiling has been reached.

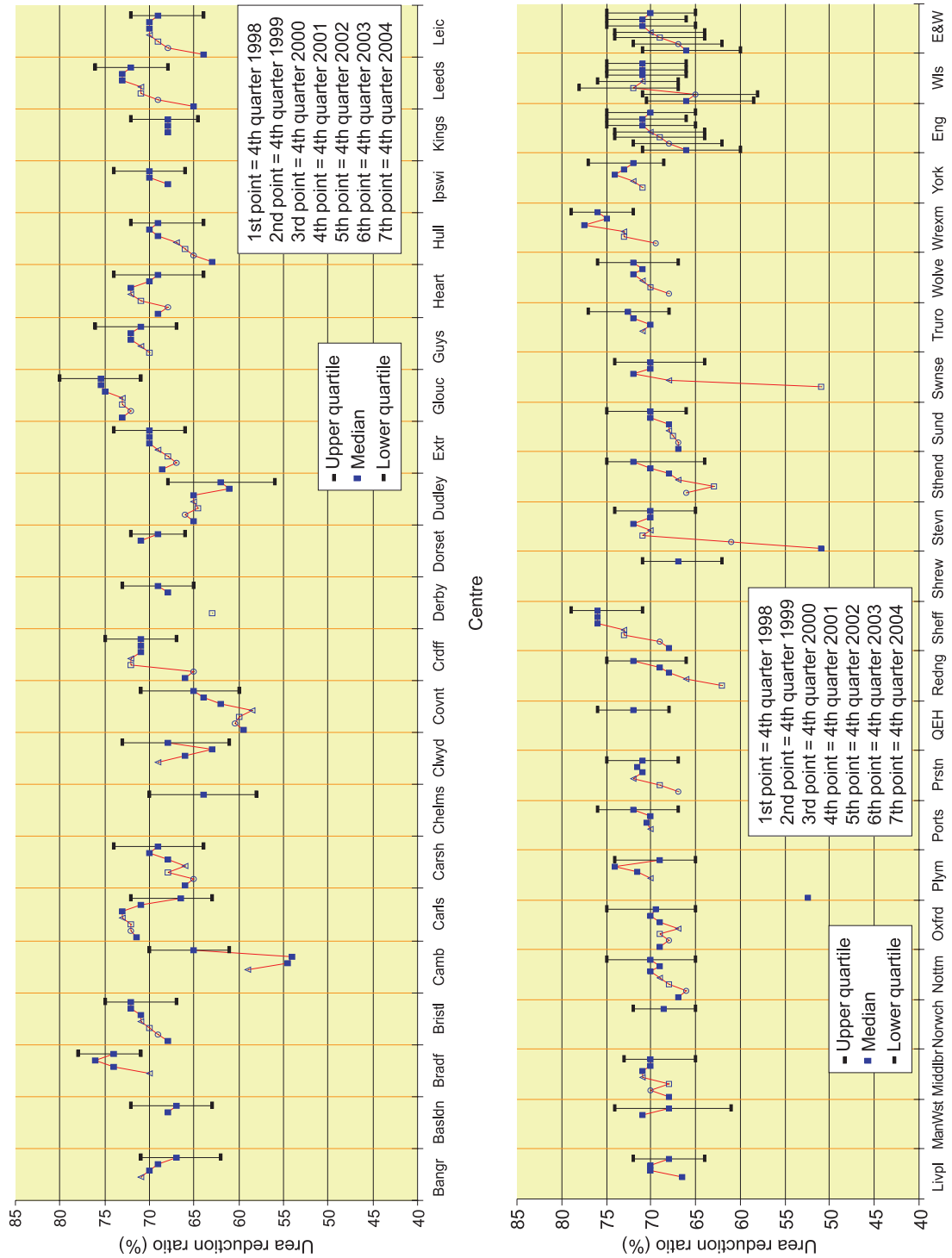

Figure 7.4: Change in median URR from 1998 to 2004

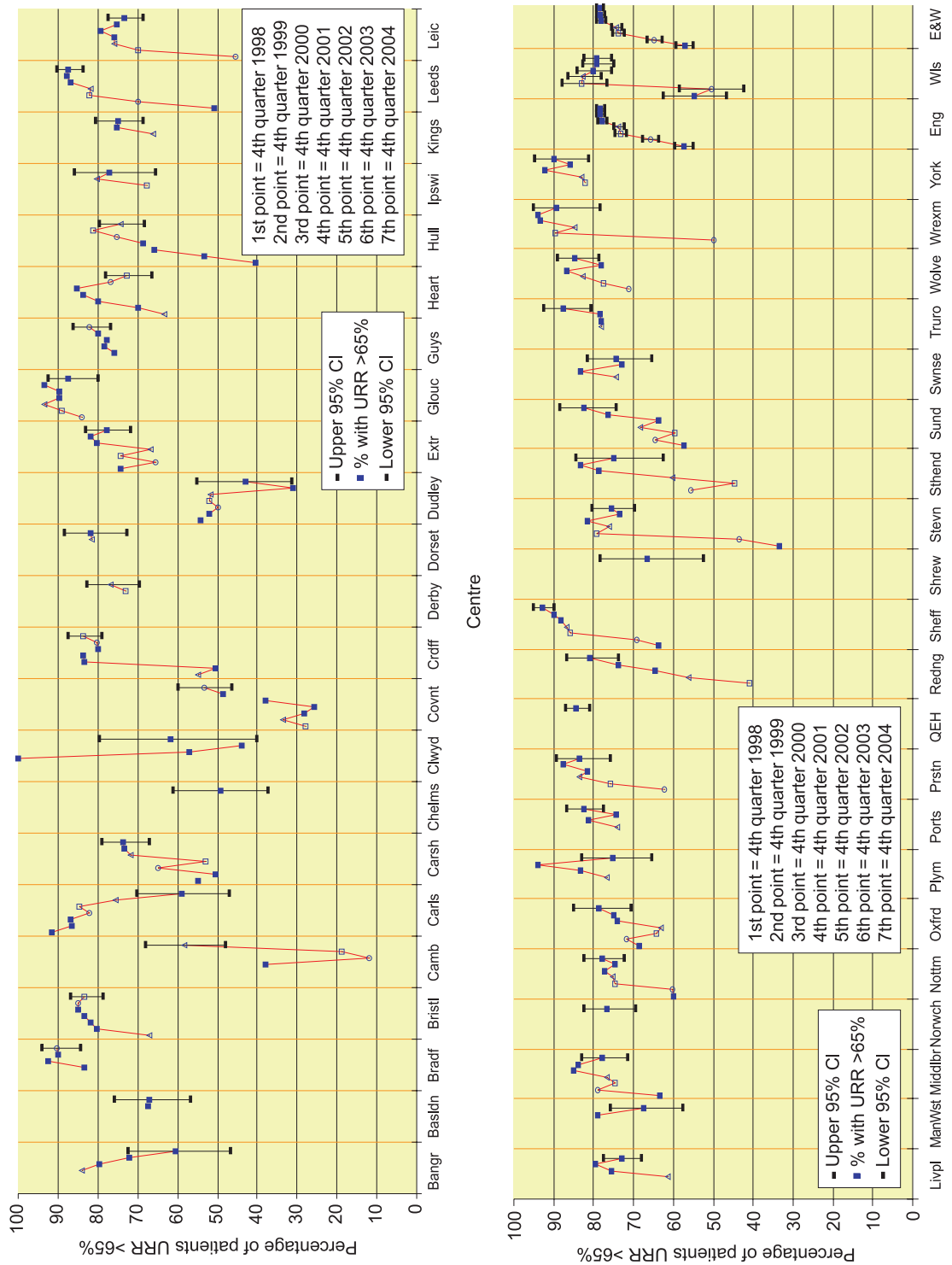

Figure 7.5: Change in achievement of URR standard (>65%) from 1998 to 2004

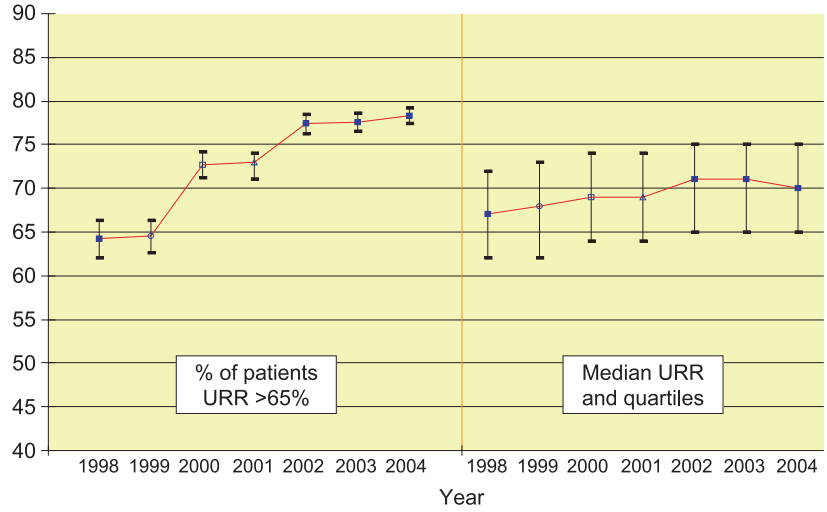

Figure 7.6: Change in the percentage of patients with URR >65% and the median URR between 1998 and 2004 in England & Wales

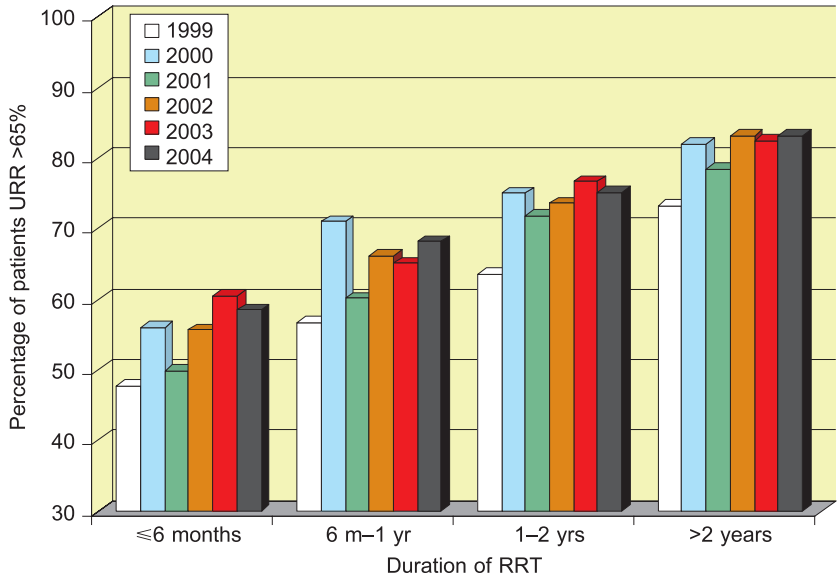

Figure 7.7: Percentage of patients achieving URR standard (>65%) against duration of time on RRT

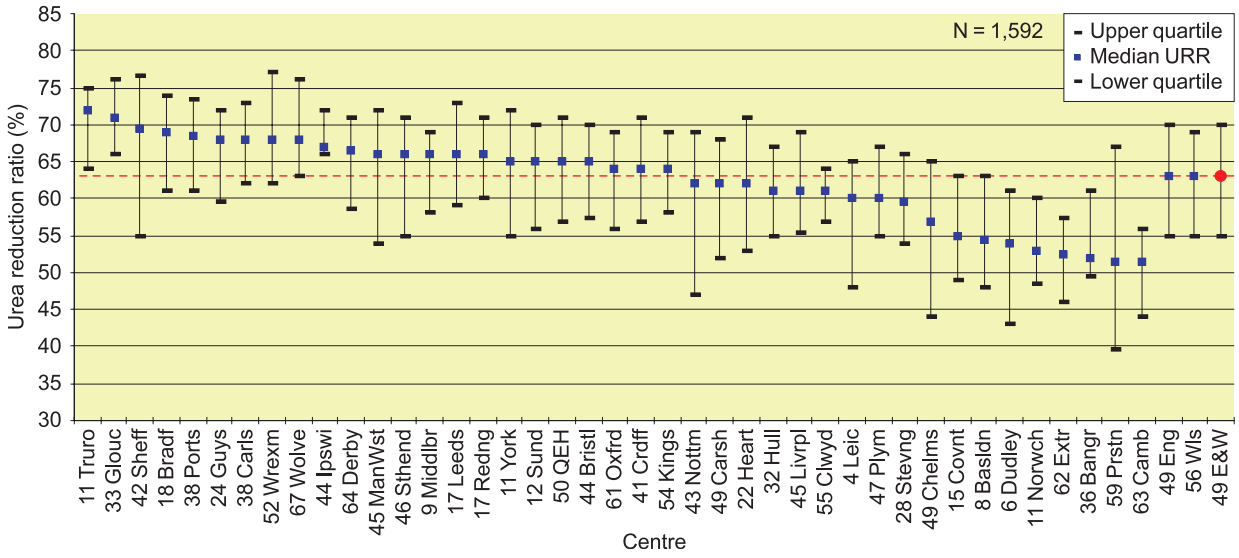

Figure 7.8: Median URR in patients who started dialysis in 2004 at the end of the first quarter after starting

Figure 7.7 shows that patients who have been dialysing the longest have the highest URR. This has been true for the seven years that the Registry has been collecting data. Individual renal unit data for patients starting dialysis in 2004, (Figure 7.8) shows that for patients starting dialysis (Figure 7.8) shows that in this group the median URR can be as low as 51% or as high as 72%. There is no proven explanation for the variability but it is as likely to reflect renal unit practice as it is co-morbidity.

Commentary

What do the 2004 data for dialysis adequacy show us? Probably two things: firstly that for the best performing renal units this may be nearly as good as it is going to get, and secondly that if you want to do well, you have to aim high.

Whilst dialysis is delivered with three, four hour sessions a week then the scope for improving the best dialysis as measured by the URR is limited. Better access, less infection and developments which limit cardiovascular instability will make some improvements possible but our current model for dialysis delivery sets limits and boundaries.

Serum bicarbonate

The Renal Association Standards state that:

Serum bicarbonate, before a haemodialysis (HD) session, measured with minimal delay after venepuncture should be between 20 and 26 mmol/L (evidence level C).

For patients treated with continuous ambulatory peritoneal dialysis (CAPD) serum bicarbonate, measured with minimal delay after venepuncture, should be between 25 and 29 mmol/L (evidence level B).

In Chapter 6 of the 2004 Registry report, it was reported in depth on a renal unit survey investigating the reasons for inter-unit variability in serum bicarbonate.

There was considerable variability in the median bicarbonate and hence compliance with the standard between renal units both for haemodialysis (Figures 7.9 and 7.10) and peritoneal dialysis (Figures 7.11 and 7.12).

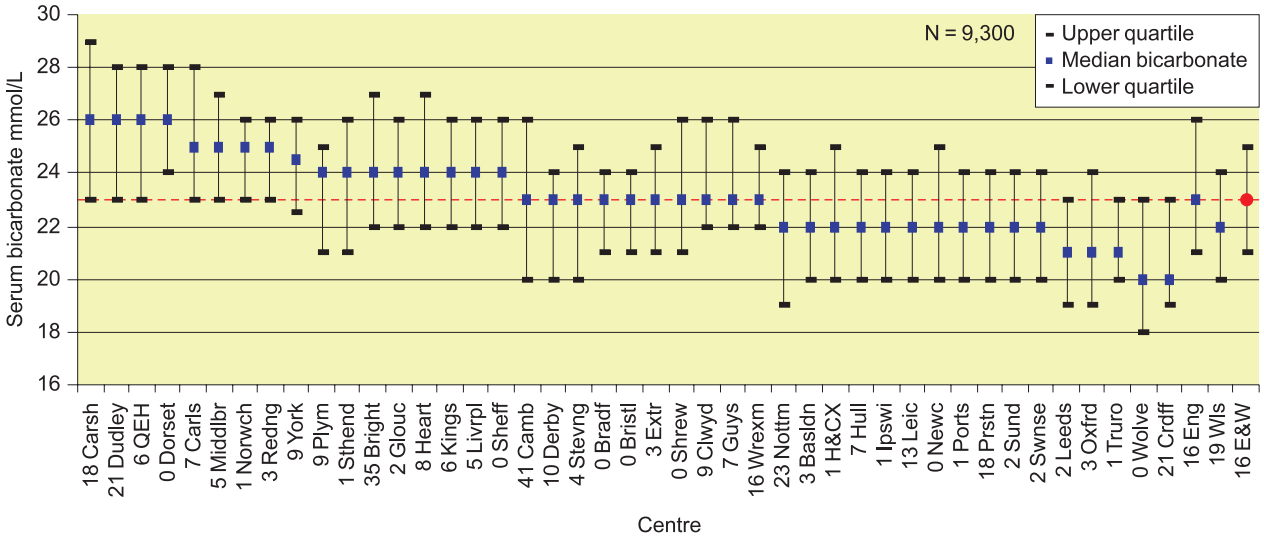

Figure 7.9: Median serum bicarbonate in patients treated with haemodialysis

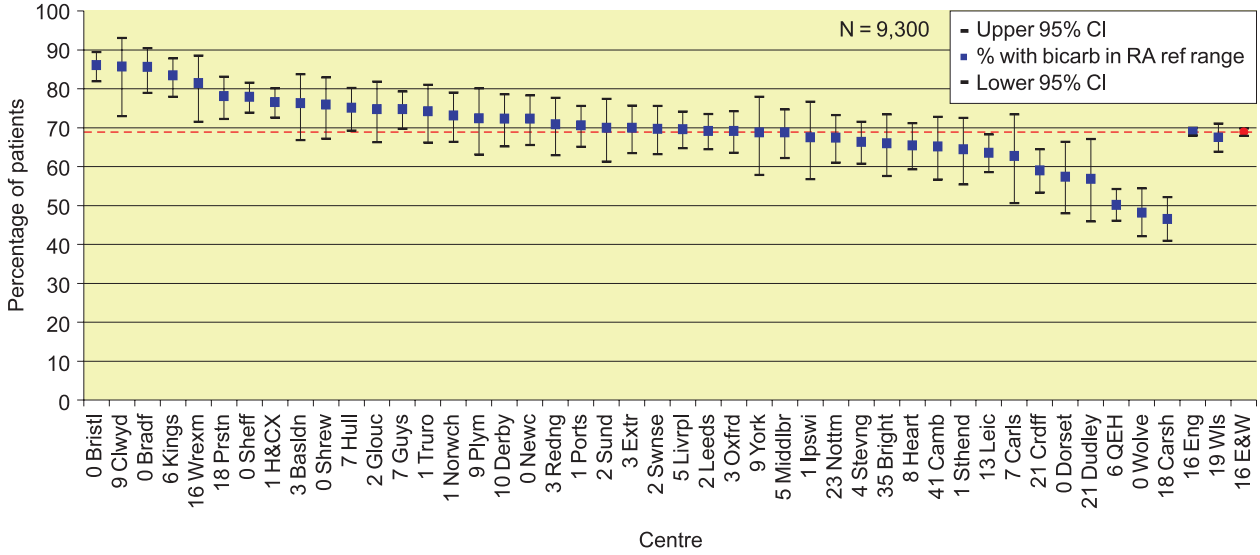

Figure 7.10: Percentage of patients treated with HD with bicarbonate 20–26 mmol/L

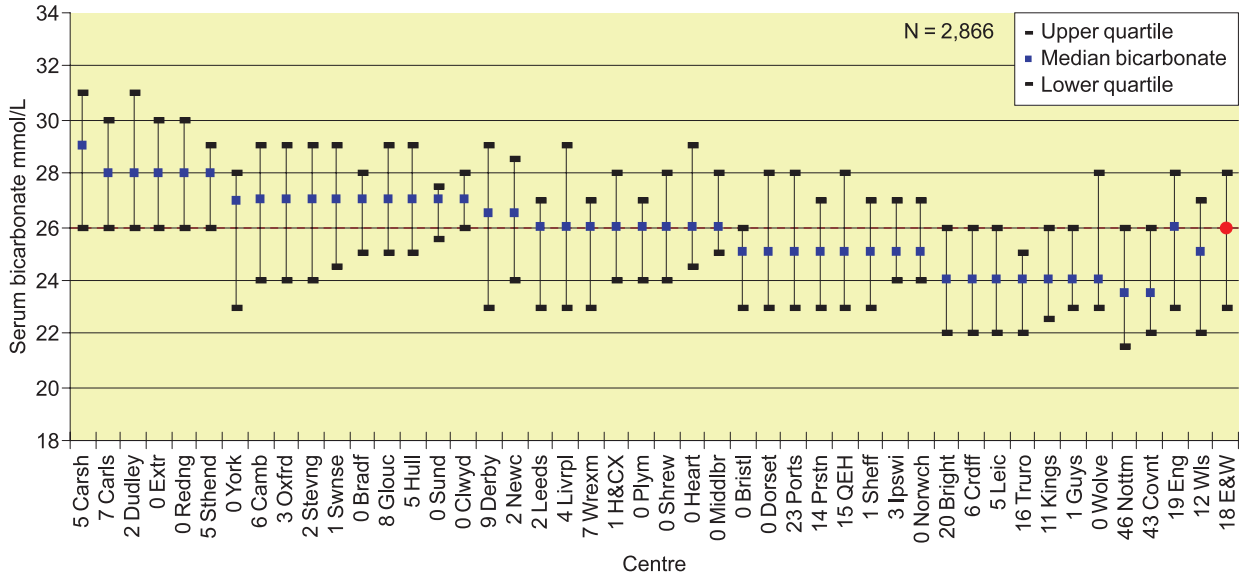

Figure 7.11: Median serum bicarbonate in patients treated with peritoneal dialysis

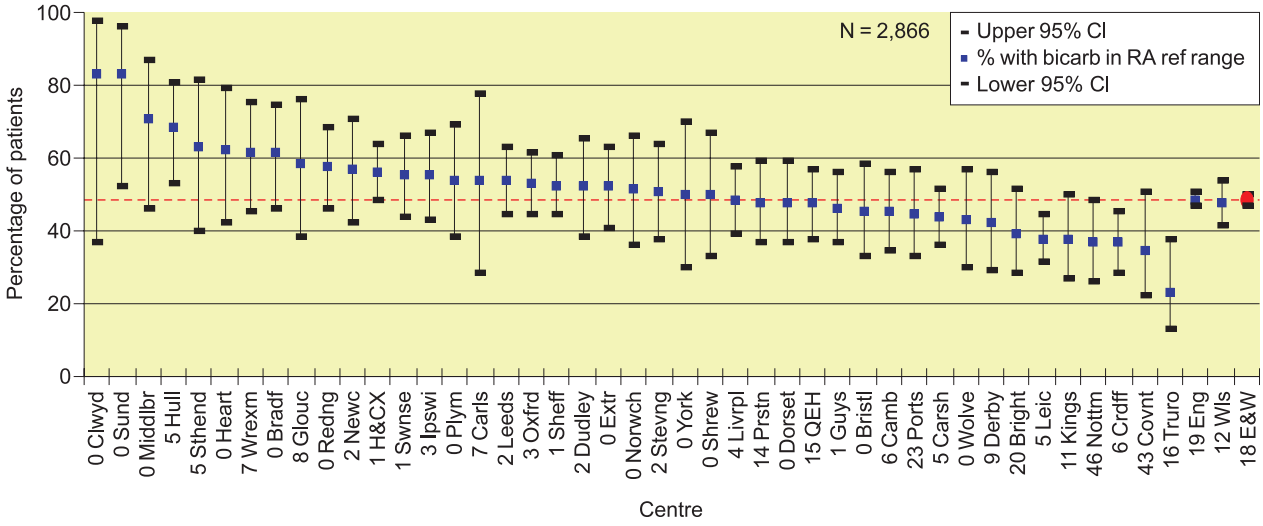

Figure 7.12: Percentage of patients treated with PD with bicarbonate 25–29 mmol/L

Serum bicarbonate is generally higher in patients treated with peritoneal dialysis than in patients treated with haemodialysis. Compliance with the Renal Association Standard is however much lower in the peritoneal dialysis patients compared with the haemodialysis patients, (48.5% vs 68.9% in England and Wales).

Much of the variability may lie in the transportation and processing of the specimens and its significance is uncertain.

Chapter 8: Haemoglobin

Summary

- Improvement in haemoglobin concentrations of patients receiving dialysis treatment continued in 2004.
- At the end of 2004, 85% of haemodialysis patients (HD) and 90% of peritoneal dialysis (PD) patients had a haemoglobin concentration above the Renal Association target of 10 g/dl. This compares with 84% of HD and 88% of PD patients in 2003. In total, 86% of all dialysis achieved an Hb $\geqslant$10 g/dl.
- Only 5% of prevalent HD patients and 4% of PD patients had an Hb <9 g/dl compared with 6% and 4% respectively in 2003.
- Haemoglobin in the first 3 months of starting dialysis treatment has also continued to rise although 40% of individuals new to dialysis still had an Hb <10 g/dl in 2004 (cf 41%, 43% and 45% in 2003, 2002 and 2001 respectively). 19% had an Hb <9 g/dl in 2004 which was unchanged from 2003.
- 68% of haemodialysis patients and 75% of peritoneal dialysis patients achieve a haemoglobin above the European guidelines of 11 g/dl. This compares with 65% and 72% respectively in 2003. 70% of the 11,796 dialysis patients with a haemoglobin returned for the last quarter of 2004 achieved an Hb $\geqslant$11 g/dl.

Introduction

This Chapter describes data reported to the Renal Registry relating to management of renal anaemia at the end of 2004. Correction of anaemia with ESAs (erythropoiesis stimulating agents) is the intervention with the greatest potential for improving quality of life of individuals with chronic renal failure. There are well established guidelines governing management of renal anaemia. In the United Kingdom, the Department of Health (DOH) Renal National Service Framework part 1 states that centres should follow the target level recommended by the Renal Association Standards Document 3rd edition. This standard advises that:

> ***Individuals with CRF should achieve a haemoglobin of 10 g/dl within 6 months of being seen by a nephrologist unless there is a specific reason why it could not be achieved.***

The European (EBPG) guidelines set a minimum target of 11 g/dl for all patients and United States (KDOQI) guidelines set a target haemoglobin range of 11–12 g/dl.

Although the Renal Registry has a record of the date of starting renal replacement therapy and the date of first consultation with a nephrologist, it does not collect a specific six month value for haemoglobin from this date, so it is not possible to assess how frequently the target of 10 g/dl is being reached within 6 months of referral in chronic kidney disease (CKD) patients. Although little data is collected on patients *before* they start renal replacement therapy some indication of the quality of predialysis management can be inferred from data of patients who have recently started dialysis. The Registry is planning to expand its dataset to include extraction of haemoglobin, ferritin and other biochemical data for the 6 months prior to starting renal replacement therapy.

In all the figures where data are shown by the individual centre, the number adjacent to the name of the renal unit indicates the percentage of missing data at that time point.

Inclusion criteria

Patients treated by dialysis during the last quarter of 2004 were included in the analysis if they had been on the same modality of dialysis in the same centre for 3 months. The last available haemoglobin from each patient in the last quarter of 2004 was used.

Haemoglobin of patients with chronic renal failure in England and Wales

Every year since 1997 data reported to the Registry has demonstrated improvement in anaemia management in renal centres and it is remarkable to note further improvement in the 2004 data (Figure 8.1). This year 85% of haemodialysis patients and 90% of peritoneal dialysis patients in England and Wales had a haemoglobin concentration of 10 g/dl or better (Tables 8.1 and 8.2).

Inevitably a higher proportion of incident patients are anaemic compared to prevalent patients, see Table 8.3 and Figure 8.2. This is partly because of late or acute presentation but some centres also experience difficulties with prescription of ESAs before dialysis starts. However haemoglobin concentrations in patients new to dialysis have been improving year on year (Figure 8.3). These improvements have been supported by the long standing Renal Association guidance and more recently by the National Service Framework for renal disease.

Less anaemia amongst new dialysis patients reduces the total number of prevalent patients who are anaemic. In addition there appears to be better understanding in renal centres of the need to target a higher haemoglobin concentration for individuals to ensure that they are maintained at haemoglobin over 10 g/dl. At the end of 2004; 69% of dialysis patients in England and 75% of dialysis patients in Wales had haemoglobins greater than or equal to 11 g/dl. 45% in England and 51% in Wales had haemoglobin concentrations greater than 12 g/dl.

Despite the overall increase in haemoglobin concentration for new and prevalent patients there is no evidence that final haemoglobin is being achieved any more quickly than in previous years. Haemoglobin concentration against time on dialysis is shown in Figures 8.4 and 8.5 indicating a similar rate of increase of haemoglobin in haemodialysis patients since 1999. Haemoglobin falls over the first few years on peritoneal dialysis are likely to be due to loss of residual renal function.

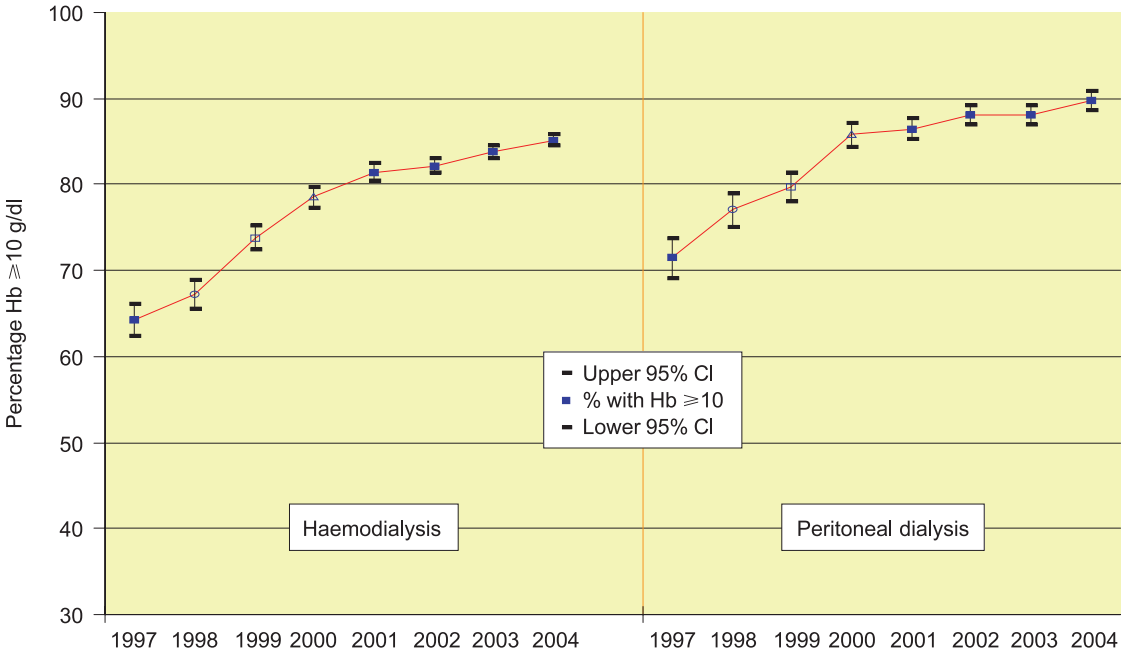

Figure 8.1: Percentage of dialysis patients with Hb ⩾10 g/dl 1997–2004

Table 8.1: Haemoglobin data for patients on haemodialysis

Centre	% data return	Median Hb g/dl	90% range	Quartile range	Mean Hb g/dl	Standard deviation	% with Hb ⩾10	% with Hb ⩾11
Bangor	87	12.1	10.2–14.1	11.4–13.0	12.1	1.3	97	78
Barts	0	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Basildon	97	11.5	8.8–13.9	10.9–12.7	11.5	1.5	87	69
Bradford	100	12.7	9.7–14.9	11.3–13.5	12.4	1.7	94	81
Brighton	71	10.5	8.1–13.5	9.6–11.8	10.6	1.7	63	42
Bristol	100	11.6	9.4–13.8	10.7–12.5	11.6	1.4	88	68
Cambridge	61	11.5	8.9–13.9	10.4–12.5	11.4	1.6	82	63
Carlisle	93	11.4	8.9–13.9	10.1–12.4	11.4	1.5	78	66
Carshalton	86	11.6	8.7–14.7	10.3–12.6	11.5	1.7	80	64
Chelmsford	97	11.7	8.5–14.6	10.6–12.9	11.7	1.9	84	67
Clwyd	89	12.6	9.2–15.5	11.3–14.4	12.7	2.0	90	84
Coventry	99	11.4	8.8–13.9	10.6–12.4	11.4	1.5	86	64
Cardiff	96	12.1	9.3–14.5	11.1–13.0	12.0	1.5	88	78
Derby	91	11.6	8.7–13.8	10.5–12.5	11.5	1.6	87	68
Dorset	100	12.0	8.6–13.9	10.5–12.9	11.7	1.6	85	67
Dudley	84	11.2	8.4–13.3	10.0–12.3	11.1	1.6	76	59
Exeter	98	11.5	8.9–13.7	10.5–12.5	11.5	1.5	85	66
Gloucester	98	11.4	8.8–14.4	10.2–12.4	11.4	1.6	80	59
Guys	92	11.3	9.1–13.9	10.2–12.6	11.4	1.7	81	59
H&CX	99	11.8	9.0–14.1	10.6–12.7	11.6	1.5	85	69
Heartlands	89	11.3	8.6–13.8	10.1–12.5	11.2	1.6	78	62
Hull	96	11.5	8.9–13.7	10.6–12.3	11.4	1.5	86	68
Ipswich	100	11.5	9.8–12.9	10.8–12.1	11.4	1.0	87	70
Kings	95	11.6	9.2–14.2	10.5–12.7	11.6	1.6	86	65
Leeds	99	12.4	9.5–14.8	11.4–13.4	12.4	1.6	94	83
Leicester	98	11.6	8.6–13.9	10.6–12.7	11.5	1.6	83	66
Liverpool	95	12.4	9.2–15.2	11.1–13.4	12.3	1.8	90	78
ManWst	66	11.1	8.5–13.7	9.9–12.4	11.1	1.8	75	55
Middlbrough	95	11.9	8.8–14.5	10.4–13.0	11.7	1.8	86	65
Newcastle	100	11.9	8.0–14.3	10.6–13.1	11.7	1.9	80	70
Norwich	99	11.8	9.9–14.0	11.0–12.7	11.8	1.2	94	75
Nottingham	97	11.5	8.9–13.8	10.7–12.5	11.5	1.5	85	69
Oxford	99	11.5	8.7–14.0	10.4–12.4	11.4	1.6	85	62
Plymouth	55	11.3	8.8–14.0	10.4–12.7	11.5	1.8	86	63
Portsmouth	100	12.0	8.9–14.4	10.6–13.0	11.8	1.7	84	70
Preston	92	11.8	9.0–14.2	10.5–12.9	11.7	1.6	83	64
QEH	96	11.6	8.5–14.0	10.4–12.6	11.5	1.7	82	66
Reading	97	11.8	9.1–14.1	10.6–12.4	11.6	1.5	86	69
Sheffield	100	11.6	8.7–14.0	10.6–12.8	11.6	1.6	86	67
Shrewsbury	100	12.0	9.3–13.7	10.5–12.8	11.7	1.4	90	68
Stevenage	97	12.0	9.4–13.6	11.0–12.6	11.8	1.3	90	75
Southend	99	11.4	9.1–13.1	10.5–11.9	11.2	1.2	86	64
Sunderland	98	12.0	8.9–14.2	10.7–13.1	11.8	1.7	84	71
Swansea	97	11.9	8.6–14.0	10.7–12.8	11.7	1.6	86	71
Truro	100	11.6	9.6–13.4	10.8–12.1	11.5	1.1	90	69
Wirral	6	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Wolverhampton	100	12.6	9.1–14.9	11.3–13.5	12.3	1.8	90	80
Wrexham	84	11.5	8.5–13.8	10.6–12.6	11.5	1.7	84	69
York	94	12.8	8.3–15.1	11.5–13.7	12.4	2.0	89	81
England	89	11.7	8.9–14.2	10.6–12.7	11.6	1.6	85	68
Wales	88	12.0	9.1–14.5	11.0–13.0	11.9	1.6	87	75
E&W	89	11.7	8.9–14.2	10.6–12.8	11.7	1.6	85	68

Table 8.2: Haemoglobin data for patients on peritoneal dialysis

Centre	% data return	Median Hb g/dl	90% range	Quartile range	Mean Hb g/dl	Standard deviation	% with Hb ⩾10 g/dl	% with Hb ⩾11 g/dl
Bangor	96	12.8	10.6–15.1	12.0–13.8	12.9	1.4	96	91
Barts	0	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Basildon	100	12.5	9.9–14.3	11.6–13.6	12.3	1.5	91	82
Bradford	100	12.6	10.3–15.4	11.9–13.3	12.7	1.7	95	86
Brighton	99	11.9	8.5–14.4	11.2–13.0	11.9	1.8	86	78
Bristol	100	12.1	10.0–15.0	11.3–13.0	12.2	1.5	96	85
Cambridge	96	11.9	9.3–15.0	10.9–12.8	11.9	1.7	88	71
Carlisle	93	12.8	9.9–15.7	10.8–14.2	12.7	2.0	92	69
Carsharlton	97	12.1	9.7–14.9	11.2–13.2	12.2	1.6	91	82
Chelmsford	97	12.4	8.3–14.3	10.7–13.1	11.9	1.7	88	72
Clwyd	100	12.1	10.4–16.2	10.9–14.9	12.8	2.3	100	67
Coventry	96	11.8	8.8–14.6	10.7–12.7	11.8	1.7	90	70
Cardiff	97	12.3	9.3–14.2	11.0–13.1	12.0	1.5	92	76
Derby	95	11.9	8.7–14.1	11.3–12.7	11.8	1.5	90	79
Dorset	100	12.2	10.0–15.1	11.2–13.3	12.4	1.6	96	79
Dudley	100	12.0	9.8–15.2	11.3–13.6	12.3	1.6	92	86
Exeter	100	11.7	9.5–13.7	11.0–12.5	11.8	1.3	92	77
Gloucester	96	11.8	9.0–13.1	10.9–12.7	11.6	1.3	88	68
Guys	99	12.0	9.2–14.4	10.8–12.8	11.8	1.7	89	72
H&CX	99	12.0	10.0–14.4	11.1–13.0	12.1	1.4	97	79
Heartlands	100	12.2	10.1–14.5	10.9–12.7	12.0	1.4	96	71
Hull	98	11.9	9.9–14.2	11.0–12.7	12.0	1.5	93	79
Ipswich	100	11.7	9.7–14.1	10.7–12.7	11.7	1.5	90	64
Kings	90	12.4	9.9–14.2	11.5–13.0	12.2	1.5	94	85
Leeds	98	12.4	9.7–16.4	11.3–13.2	12.4	1.9	92	80
Leicester	97	11.8	8.5–15.0	10.5–12.9	11.7	1.9	82	71
Liverpool	93	12.4	9.8–14.7	11.2–13.6	12.4	1.5	91	80
ManWst	98	11.6	7.6–14.2	10.3–12.4	11.3	2.0	77	64
Middlbrough	100	12.7	9.9–14.4	11.4–13.2	12.4	1.2	94	94
Newcastle	100	11.7	8.9–14.3	10.4–13.5	11.8	1.8	80	69
Norwich	100	12.4	10.9–15.8	11.8–13.4	12.7	1.4	100	93
Nottingham	100	11.6	9.2–13.9	10.5–12.7	11.7	1.5	90	68
Oxford	99	12.0	9.0–14.4	10.9–13.0	11.9	1.7	88	74
Plymouth	92	12.1	10.5–14.7	11.8–13.4	12.5	1.3	100	91
Portsmouth	96	12.6	9.6–15.1	11.5–13.9	12.6	1.6	95	81
Preston	100	11.2	9.4–13.3	10.4–12.1	11.3	1.3	87	57
QEH	98	11.5	8.5–15.3	10.5–12.5	11.5	1.8	83	70
Reading	99	12.0	8.9–15.3	11.3–12.6	11.9	1.7	89	77
Sheffield	99	11.6	8.8–14.2	10.8–12.6	11.6	1.6	87	68
Shrewsbury	100	12.7	10.0–15.4	11.4–13.5	12.6	1.6	97	84
Stevenage	98	11.3	9.2–13.5	10.8–12.1	11.3	1.5	87	69
Southend	95	12.1	9.7–16.6	11.1–13.1	12.4	1.8	95	79
Sunderland	100	11.8	10.1–13.2	10.8–12.5	11.7	1.0	100	75
Swansea	99	11.5	8.4–13.6	10.3–12.6	11.3	1.7	79	59
Truro	98	11.8	9.2–14.0	10.7–12.9	11.8	1.6	86	68
Wirral	15	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Wolverhampton	100	12.9	11.0–14.8	12.0–13.8	12.9	1.4	98	98
Wrexham	95	12.4	10.9–14.4	11.8–13.3	12.4	1.3	98	95
York	100	12.7	11.1–15.4	12.1–13.6	12.9	1.4	100	95
England	91	12.0	9.2–14.6	11.0–13.0	12.0	1.7	90	75
Wales	91	12.0	8.8–14.2	10.9–12.9	11.9	1.6	89	74
E&W	91	12.0	9.2–14.6	11.0–13.0	12.0	1.7	90	75

Table 8.3: Haemoglobin levels for new patients starting dialysis

Centre	% data return	Median Hb g/dl	90% range	Quartile range	% Hb ⩾10 g/dl
Bangor	100	10.9	8.7–13.8	9.9–12.6	72
Barts	0	n/a	n/a	n/a	n/a
Basildon	91	10.2	8.0–12.4	9.3–11.2	65
Bradford	98	10.8	8.4–13.2	9.5–12.1	65
Brighton	78	9.8	8.0–12.3	9.1–10.8	44
Bristol	100	10.1	7.8–12.7	9.0–10.9	52
Cambridge	93	10.7	8.0–14.3	9.6–12.1	65
Carlisle	100	10.2	8.2–13.3	9.3–12.7	57
Carshalton	98	10.6	8.3–13.5	9.7–11.7	71
Chelmsford	81	11.1	6.8–13.7	9.7–11.9	72
Clwyd	90	8.9	7.1–11.6	7.8–9.3	22
Coventry	99	10.5	7.6–13.2	9.4–11.2	61
Cardiff	98	10.8	8.1–13.1	9.6–11.8	69
Derby	84	10.0	7.8–12.2	9.1–10.8	53
Dorset	98	10.5	7.8–13.9	9.6–12.0	62
Dudley	100	10.6	8.0–12.9	9.8–11.4	71
Exeter	98	10.3	8.2–12.5	9.5–11.3	60
Gloucester	100	9.9	7.7–12.8	9.0–11.4	50
Guys	94	10.9	8.4–13.7	9.9–12.0	71
H&CX	100	10.0	7.5–13.2	8.9–11.3	51
Heartlands	98	10.1	7.4–12.8	8.7–10.9	51
Hull	100	9.4	6.9–12.5	8.5–10.7	38
Ipswich	90	10.8	8.4–13.2	9.8–11.5	68
Kings	98	10.0	8.2–13.5	9.2–11.0	51
Leeds	97	10.6	7.9–13.8	9.6–11.8	64
Leicester	99	10.1	7.8–13.4	8.9–11.1	56
Liverpool	98	11.1	8.2–14.5	9.9–12.0	74
ManWst	96	10.2	7.6–13.6	9.1–11.9	55
Middlbrough	99	9.9	7.7–13.4	8.9–10.7	48
Newcastle	94	10.1	6.6–13.6	8.7–11.6	51
Norwich	95	10.0	7.8–12.9	8.8–11.1	50
Nottingham	99	10.3	8.4–13.2	9.3–11.4	61
Oxford	99	10.5	8.0–13.4	9.5–11.5	67
Plymouth	71	10.4	8.4–12.8	9.6–11.3	62
Portsmouth	100	10.6	7.8–13.7	9.5–11.6	64
Preston	95	9.8	7.5–13.1	9.3–11.0	48
QEH	87	10.3	7.6–13.1	9.1–11.4	58
Reading	99	10.8	8.2–13.2	9.8–12.0	72
Sheffield	100	10.5	8.1–12.9	9.4–11.6	65
Shrewsbury	100	10.6	8.3–13.7	9.7–11.7	70
Stevenage	97	10.3	7.8–13.1	9.1–11.1	55
Southend	95	10.3	8.3–12.5	9.4–11.2	63
Sunderland	100	10.7	8.3–13.3	9.6–11.1	64
Swansea	96	10.1	8.0–12.5	9.1–11.4	54
Truro	100	10.9	8.8–14.4	9.9–11.6	72
Wirral	2	n/a	n/a	n/a	n/a
Wolverhampton	100	10.8	7.7–14.2	9.2–12.1	65
Wrexham	89	10.6	8.9–12.6	9.5–12.1	60
York	100	10.8	7.9–14.0	9.2–11.8	63
England	91	10.3	7.9–13.2	9.2–11.4	60
Wales	85	10.5	8.0–13.0	9.3–11.6	62
E&W	90	10.3	7.9–13.2	9.2–11.5	60

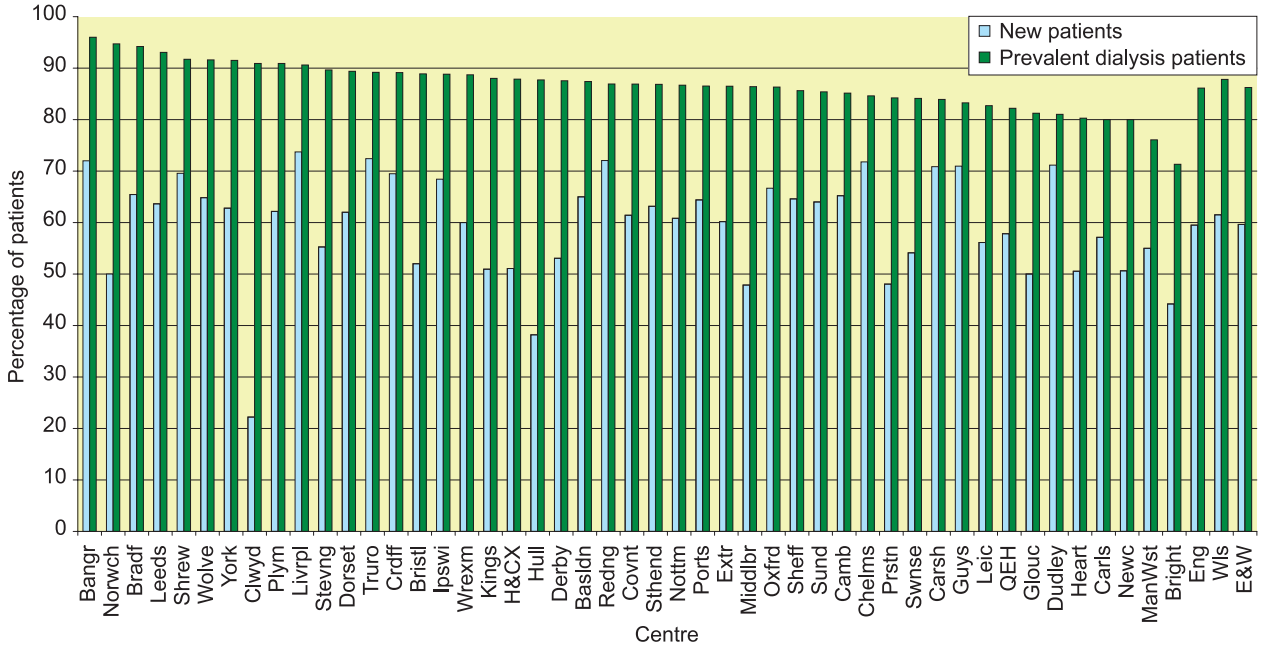

Figure 8.2: Percentage of new and prevalent patients with Hb ⩾10 g/dl

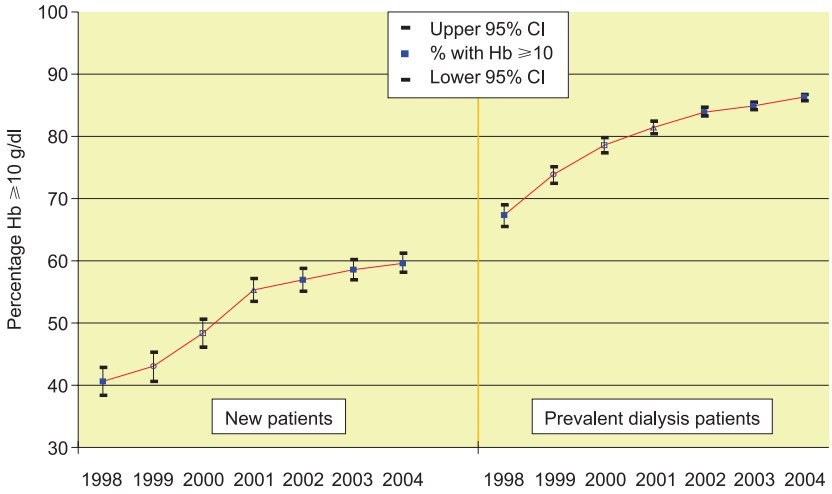

Figure 8.3: Change in % of patients starting RRT with Hb ⩾10 g/dl in E&W 1998–2004

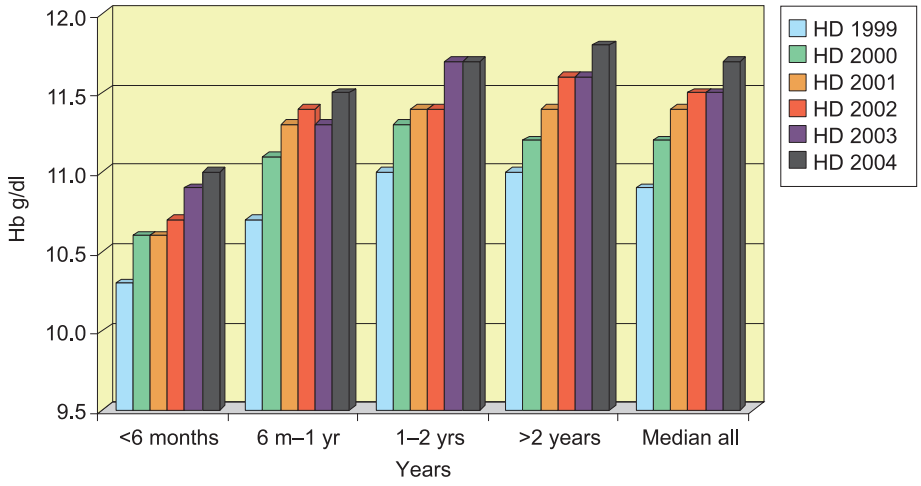

Figure 8.4: Median haemoglobin by length of time on RRT, HD patients

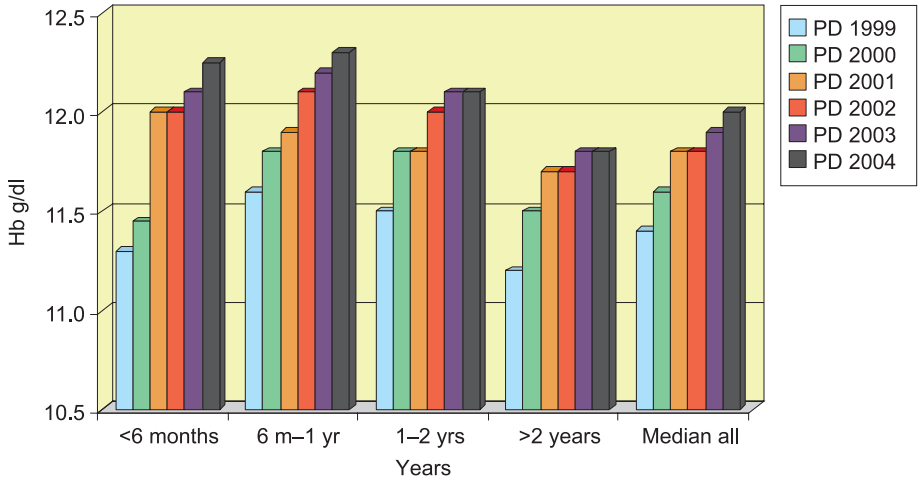

Figure 8.5: Median haemoglobin by length of time on RRT, PD patients

Haemoglobin in individual dialysis centres for prevalent patients

The data describing the haemoglobin distribution in each centre is tabulated in Table 8.1 for haemodialysis and Table 8.2 for peritoneal dialysis. Figures 8.6 and 8.7 show the distributions graphically. Median haemoglobin concentration, percentage with haemoglobin $\geqslant$10 g/dl and $\geqslant$11 g/dl for each centre are shown in Figures 8.8, 8.9 and 8.10 for haemodialysis and Figures 8.11, 8.12, 8.13 for peritoneal dialysis.

In 2004, 30 of 49 centres achieved the target of $\geqslant$85% patients on haemodialysis with haemoglobin $\geqslant$10 g/dl compared to 18 of 40 centres in 2003. For peritoneal dialysis, 8 centres failed to achieve 85% of patients with Hb $\geqslant$10 g/dl in 2003 and this fell to 5 centres in 2004. Median haemoglobin greater than 12g/dl for haemodialysis patients was found in 12 centres in 2004 compared to 4 centres in 2003.

Plotting median haemoglobin against percentage with haemoglobin $\geqslant$10 g/dl for each centre suggests a plateau once the median rises above a level of approximately 12.2 g/dl for both haemodialysis and peritoneal dialysis (Figures 8.14, 8.15, 8.16 and 8.17). A higher median than this does not significantly increase the proportion of patients achieving the Renal Association standard. A proportion of patients receiving dialysis will have non renal causes of anaemia, erythropoietin resistance or an acute fall in haemoglobin associated with illness. The position of the plateau in 2004 suggests that this is approximately 5–10% of haemodialysis patients and 0–10% of peritoneal dialysis patients. Within the range of haemoglobin concentrations reported by UK renal units in 2004 the percentage over 11 g/dl was not sufficient to reach a plateau.

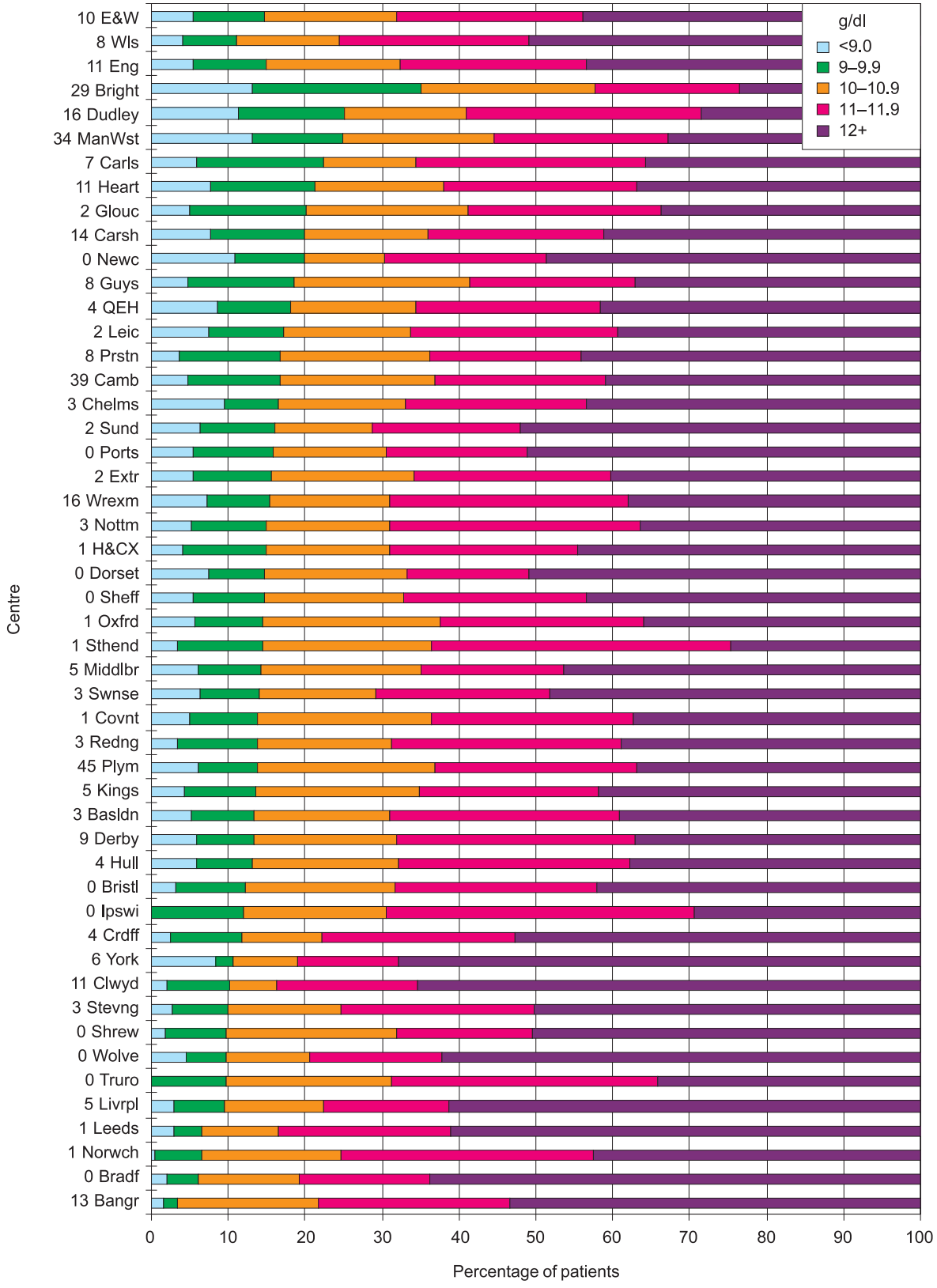

Figure 8.6: Distribution of haemoglobin in patients on HD

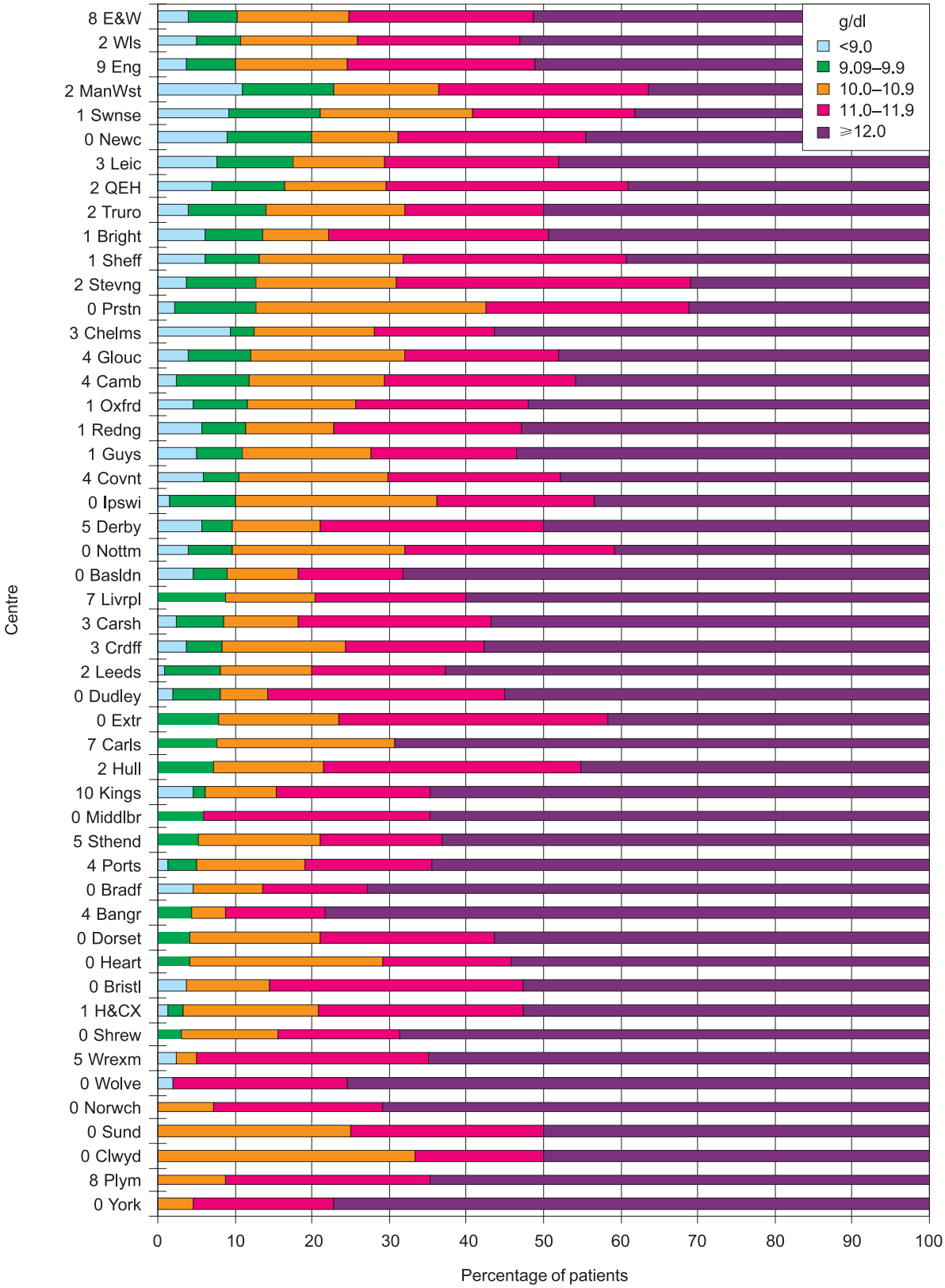

Figure 8.7: Distribution of haemoglobin in patients on PD

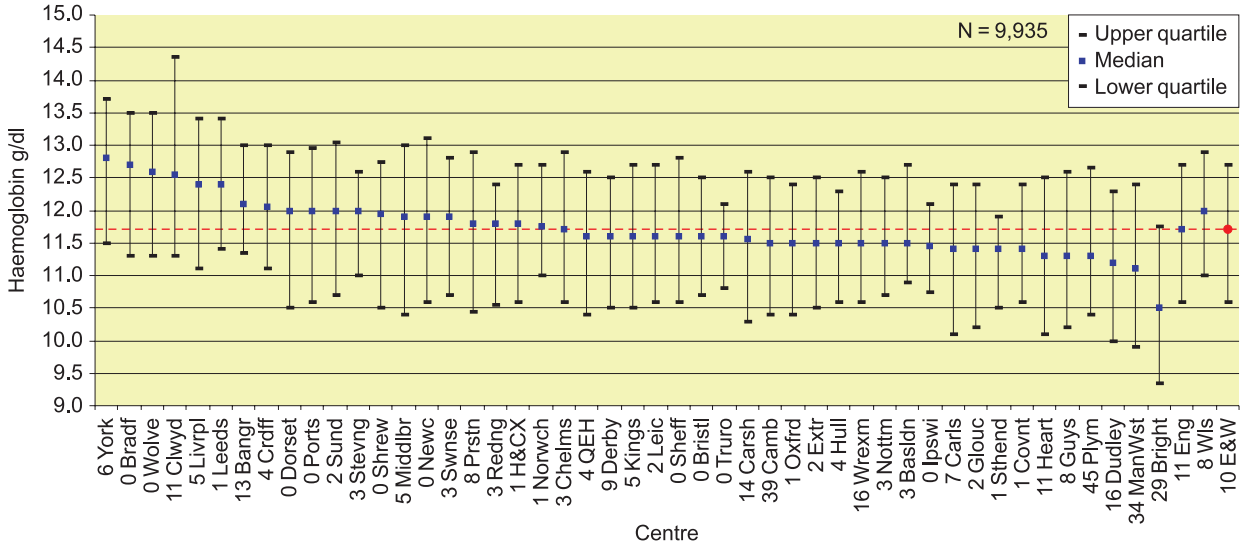

Figure 8.8: Median haemoglobin: HD

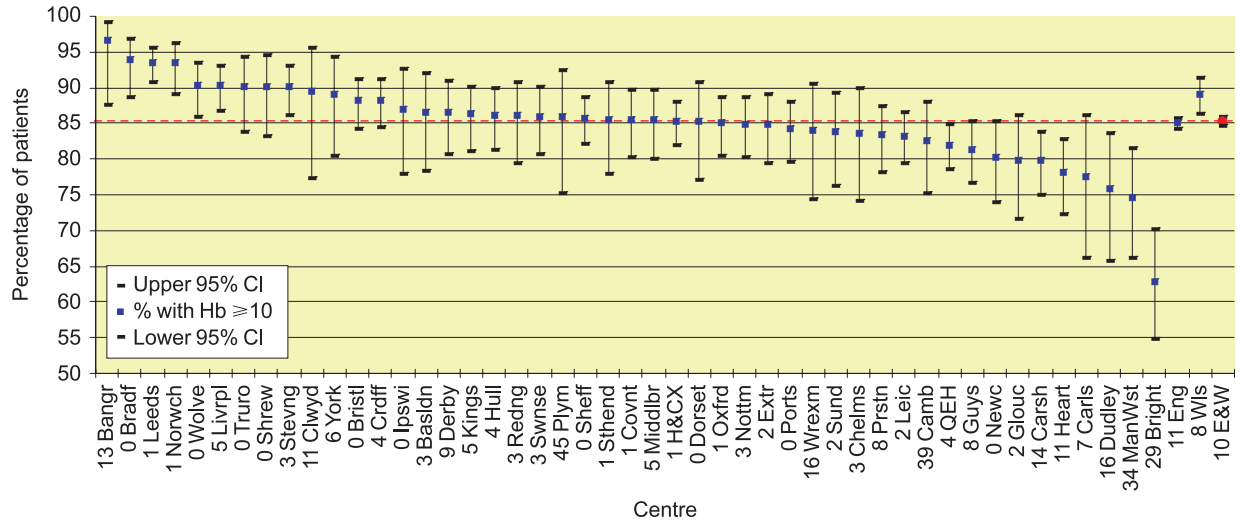

Figure 8.9: Percentage of HD patients with Hb ⩾10 g/dl

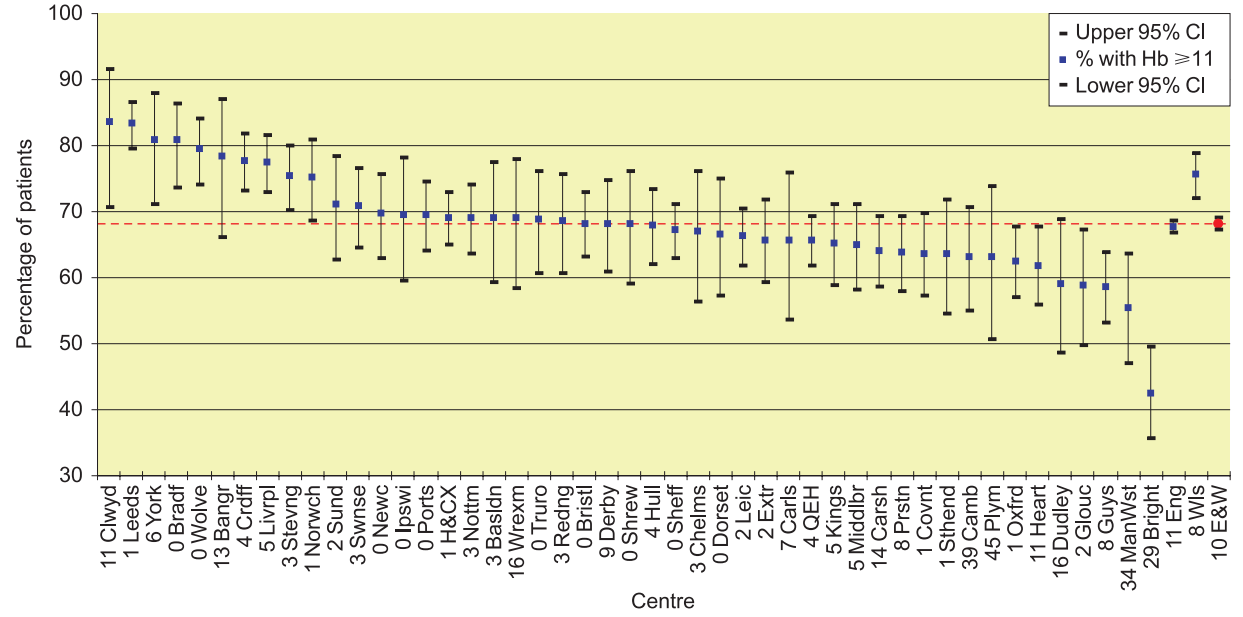

Figure 8.10: Percentage of HD patients with Hb ⩾11 g/dl

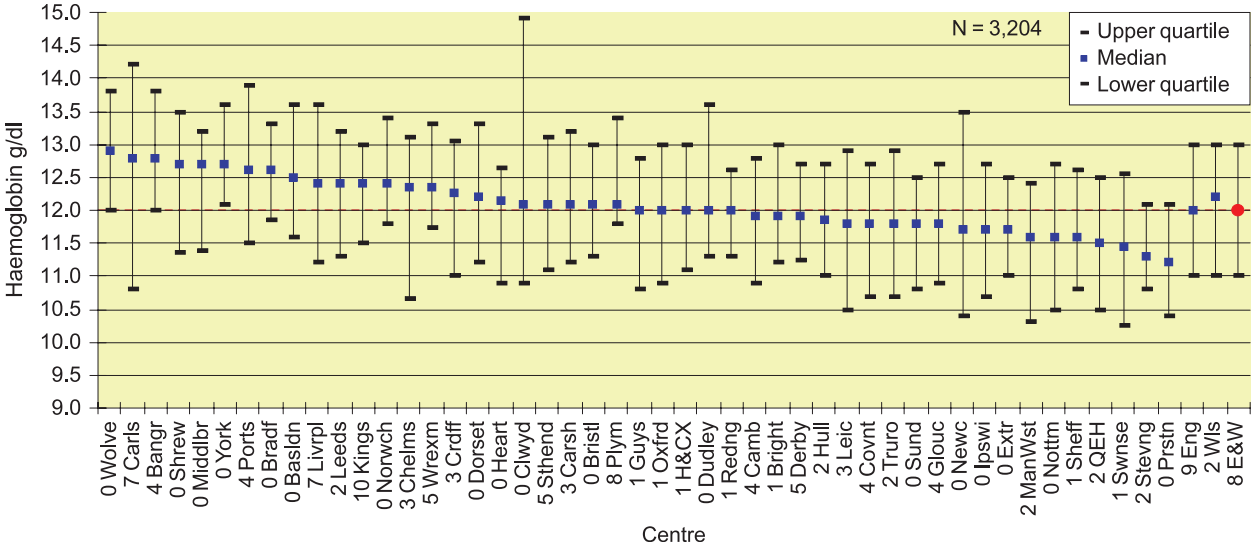

Figure 8.11: Median haemoglobin: PD

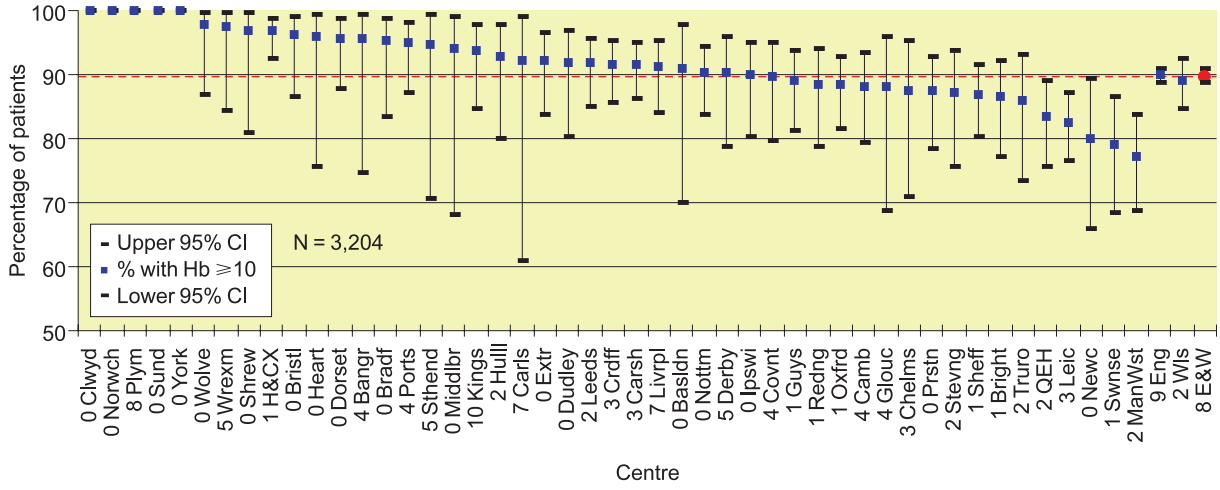

Figure 8.12: Percentage of PD patients with Hb ⩾10 g/dl

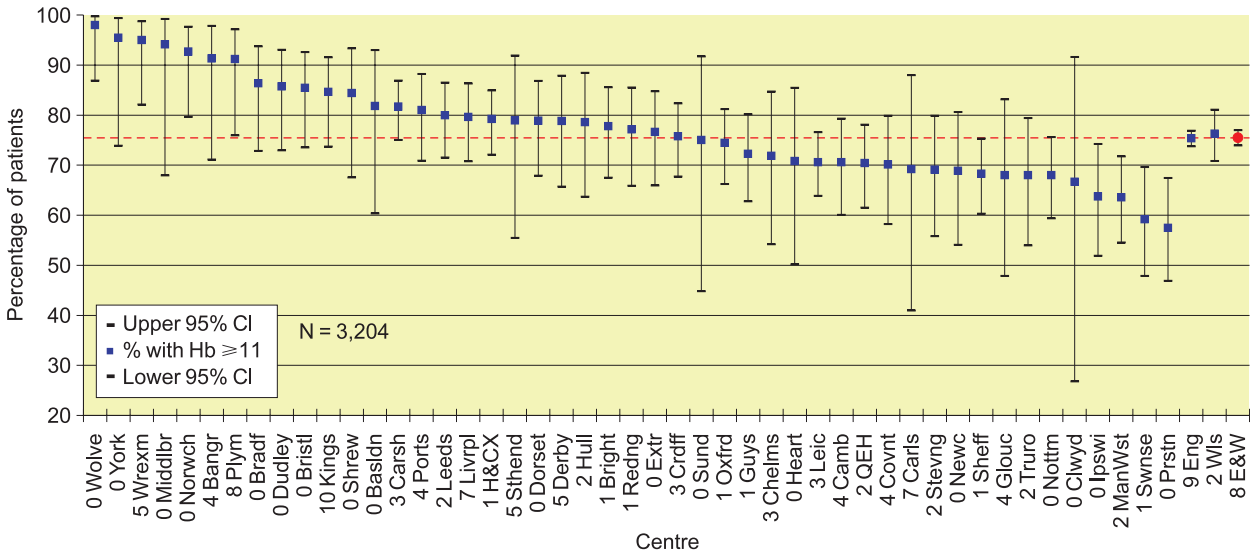

Figure 8.13: Percentage of PD patients with Hb ⩾11 g/dl

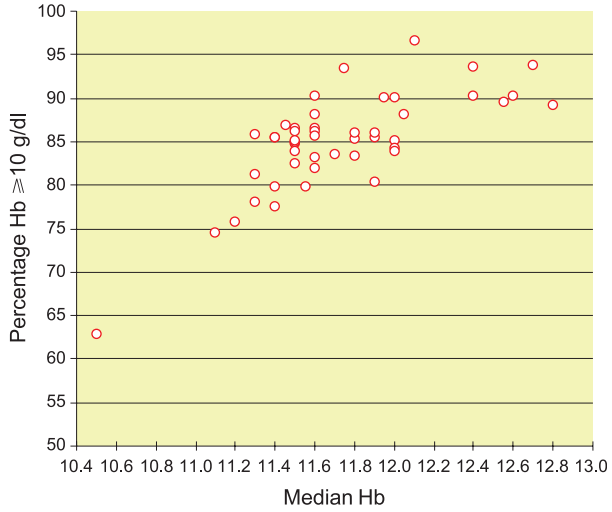

Figure 8.14: Percentage of patients with Hb ⩾10 g/dl plotted against median Hb: HD

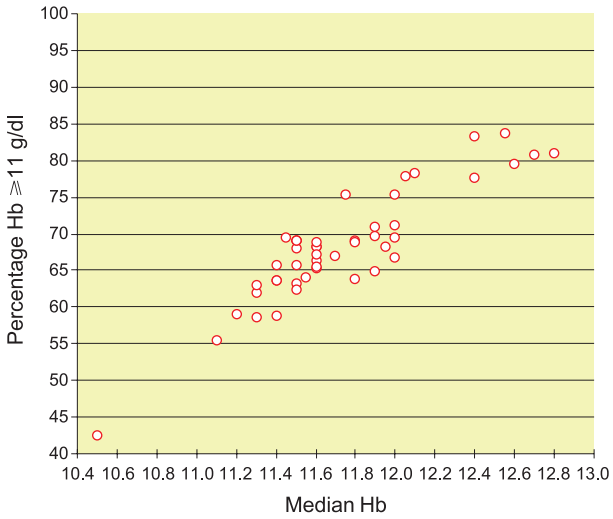

Figure 8.15: Percentage of patients with Hb ⩾11 g/dl plotted against median Hb: HD

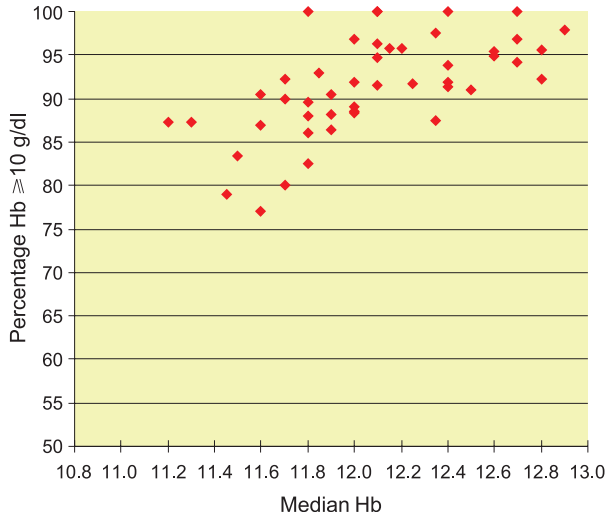

Figure 8.16: Percentage of patients with Hb ⩾10 g/dl plotted against median Hb: PD

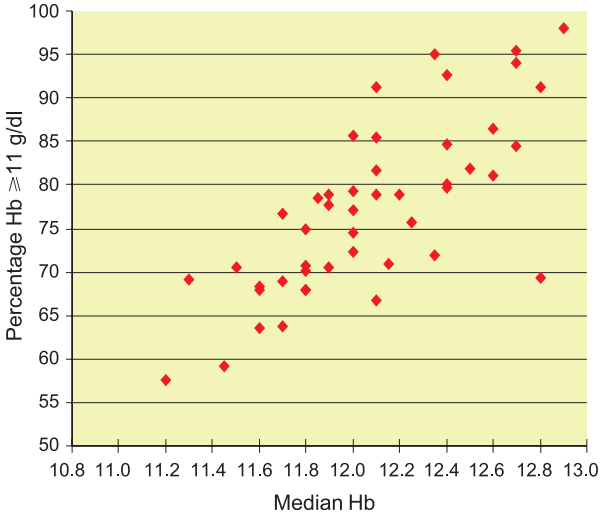

Figure 8.17: Percentage of patients with Hb ⩾11 g/dl plotted against median Hb: PD

Changes in haemoglobin over time in individual centres

Within the general trend to improved anaemia management there is inevitably variation between individual centres. Each centre's data since their entry onto the registry is shown in Figures 8.18, 8.19, 8.20 and 8.21. Unsurprisingly centres with smaller patient numbers have more variable data year to year. The general trend to improvement is shown by the fact that whilst between 1999 and 2003 12 centres recorded less than 75% of patients with Hb ⩾10 g/dl on at least one occasion, in 2004 only one centre was below 75%.

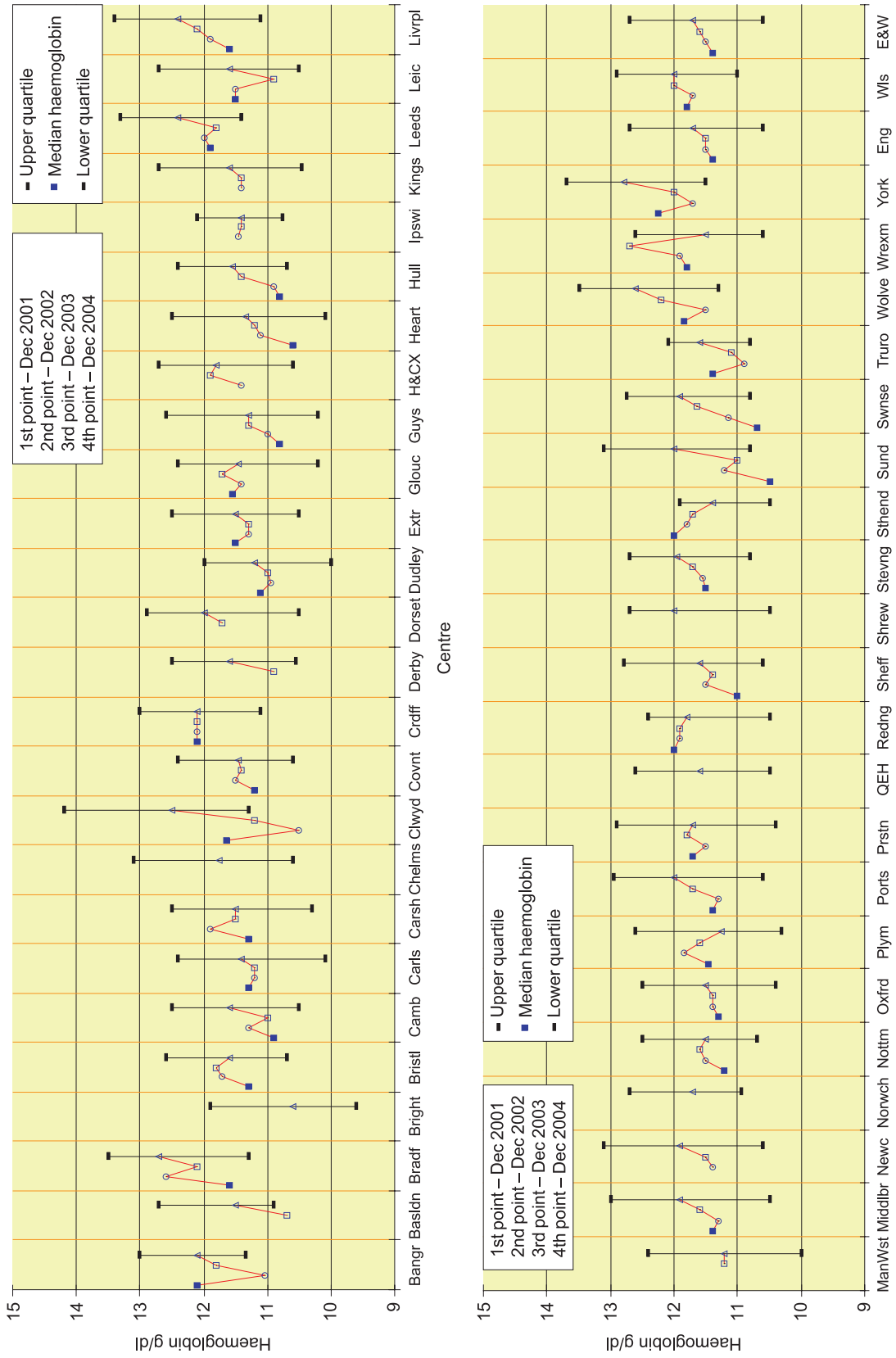

Figure 8.18: Median Hb from end 2001 to end of 2004 by centre: HD

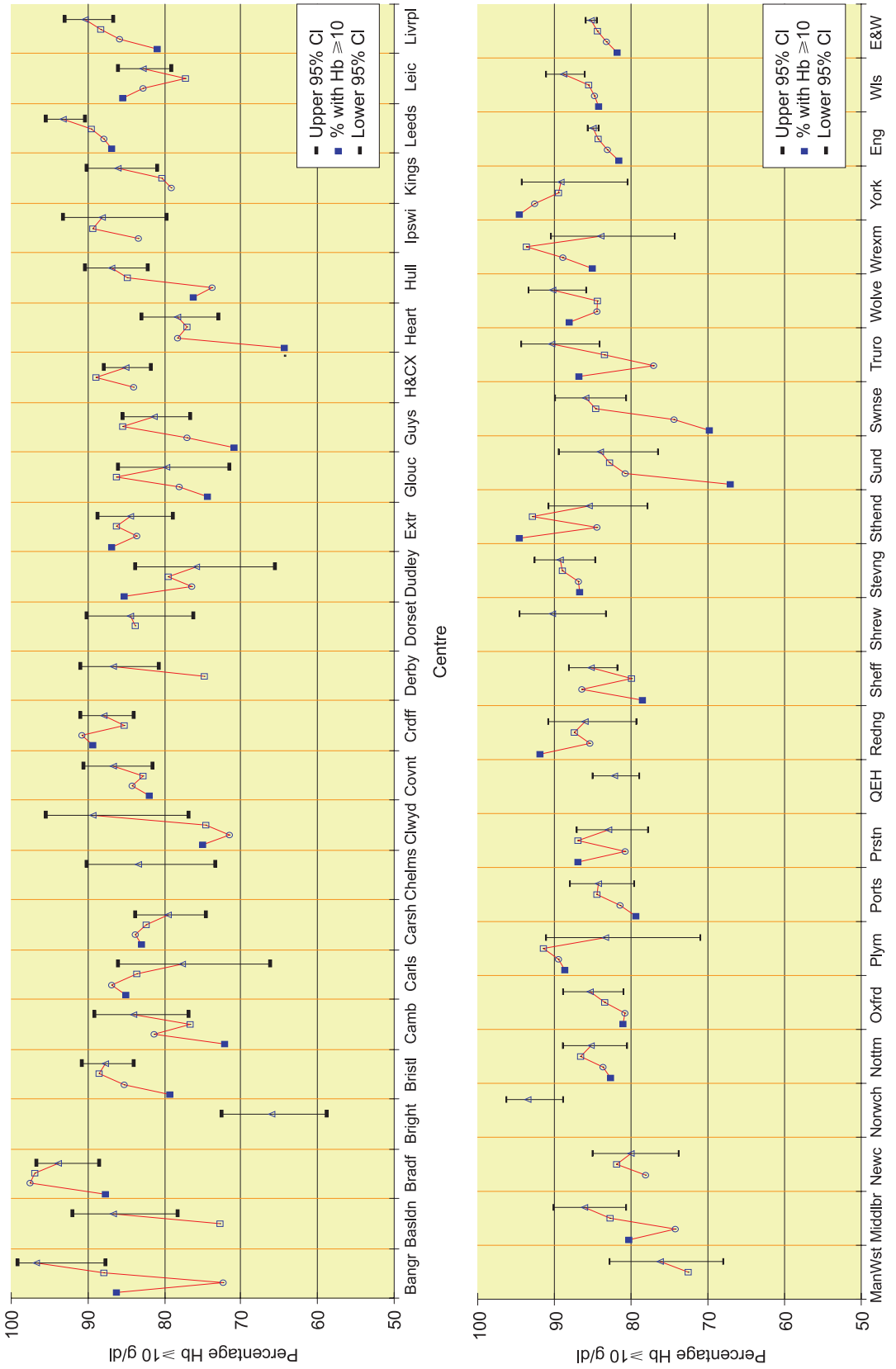

Figure 8.19: Hb ⩾10 g/dl at end of 2001 to end of 2004 by centre: HD

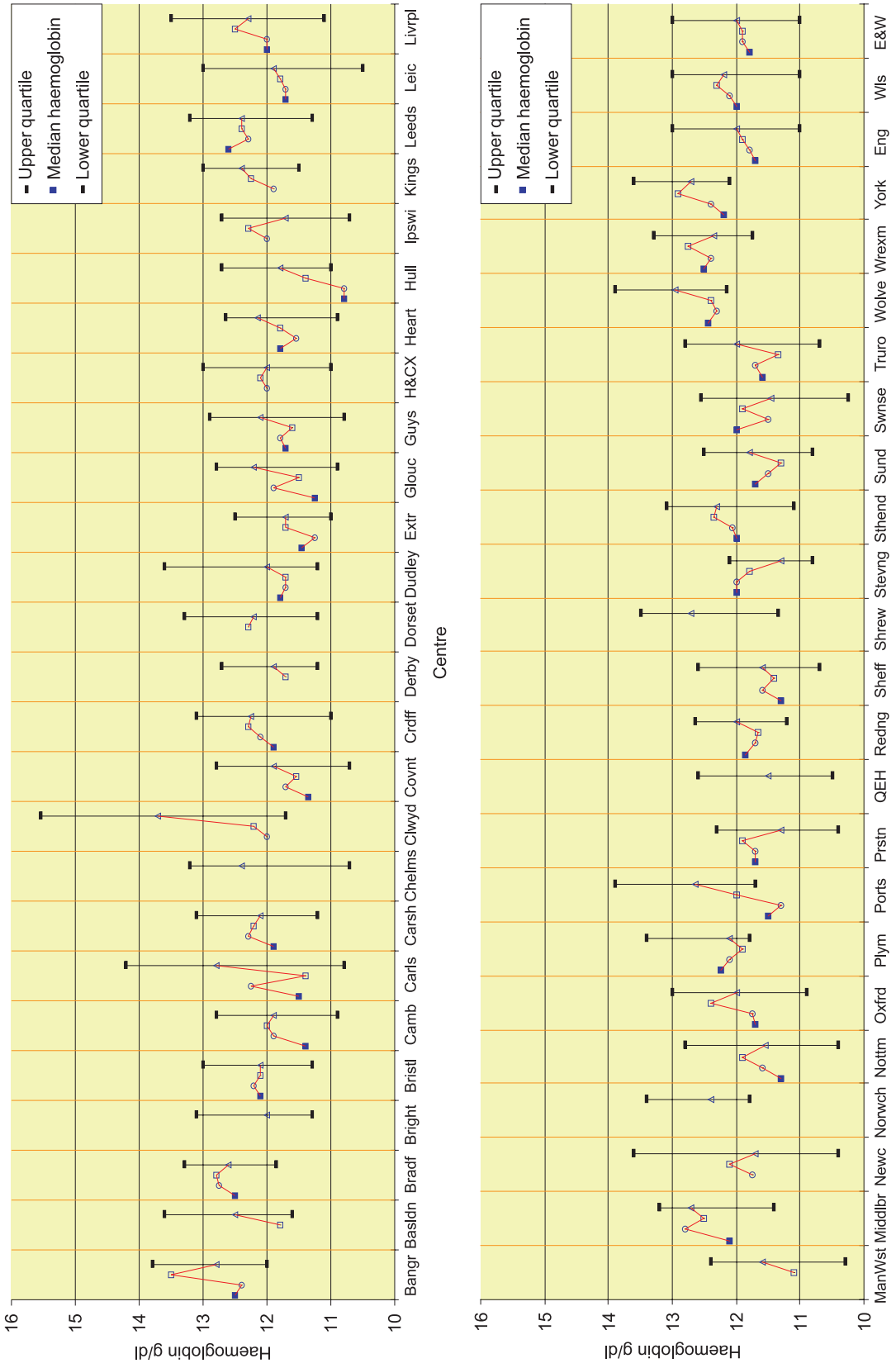

Figure 8.20: Median Hb from end of 2001 to end of 2004 by centre: PD

Figure 8.21: Hb ⩾10 g/dl at end of 2001 to end of 2004 by centre: PD

Haemoglobin data for patients new to RRT

The Registry records a haemoglobin concentration at the end of the quarter that each individual starts dialysis. This is referred to as haemoglobin of 'new' patients and could have been taken between 1 and 90 days from starting treatment. The data for new patients gives an insight into pre-dialysis management and is not separated between those who started on haemodialysis and peritoneal dialysis. There will be some effect of early treatment on dialysis for those patients whose treatment started at the beginning of the quarter.

Data for new patients is shown in Table 8.3 and Figures 8.22 and 8.23. There has been a further small increase in percentage of new patients with haemoglobin $\geqslant 10$ g/dl in 2004 (59.6% in 2004, 58.5% in 2003) continuing the trend of previous years (Figure 8.3). The rate of increase in haemoglobin over the first 12 months of dialysis is shown in Figures 8.24 and 8.25. This rate of increase is not significantly different from that reported for 2003 (Figures 8.26 and

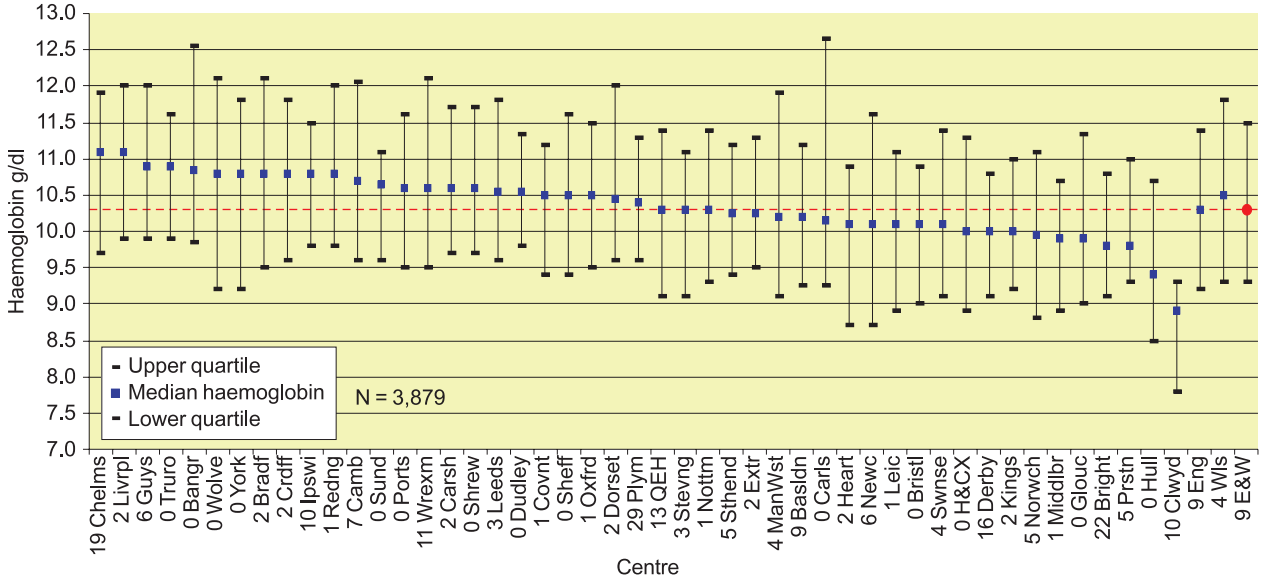

Figure 8.22: Haemoglobin median and quartile range for new patients

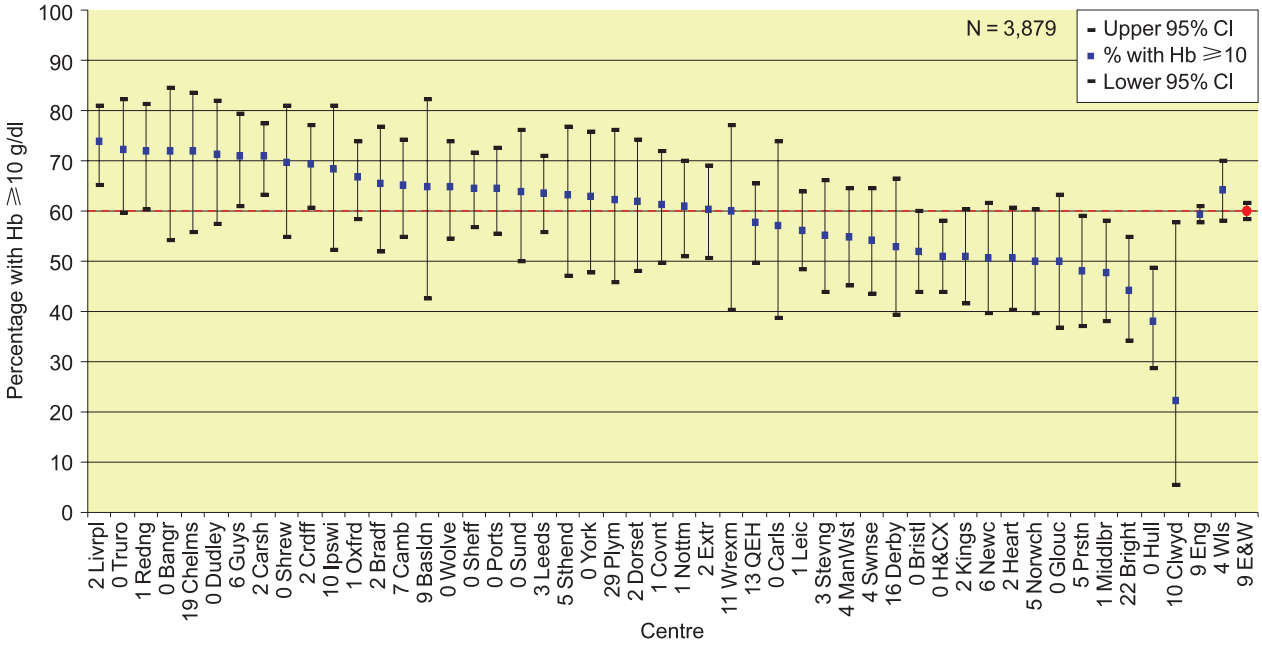

Figure 8.23: Percentage of new patients, by centre, achieving the RA target

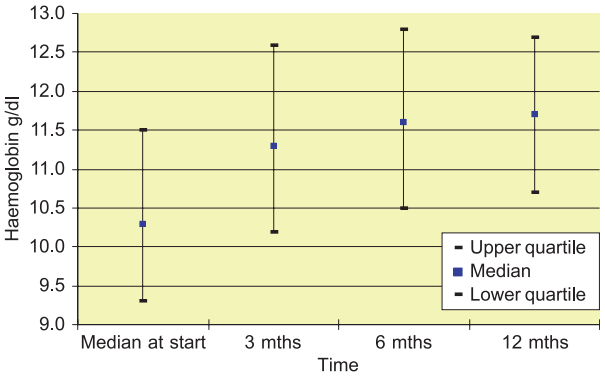

Figure 8.24: Serial median Hb for new patients in 2004

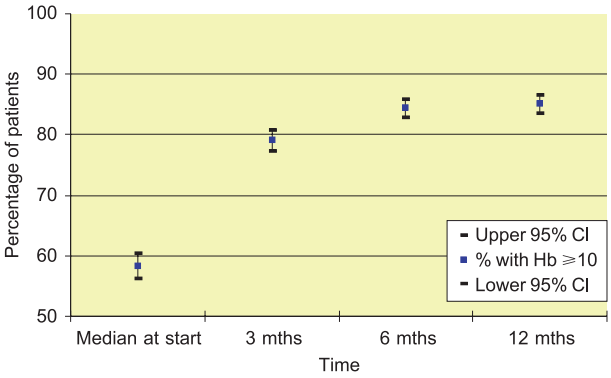

Figure 8.25: Serial percentage of new patients in 2004 with Hb ⩾10 g/dl

8.27). As with prevalent patients there is a broad range of new patient haemoglobins across England and Wales renal centres. Figure 8.2 compares percentage with haemoglobin ⩾10 g/dl between new and prevalent patients. The distribution across the centres is different for new and prevalent patients. The availability of pre-dialysis erythropoietin may have a significant influence. The data needs to be interpreted with some caution however, as some centres have small numbers of new patients. For example there are only 10 new patients included in the Clwyd data.

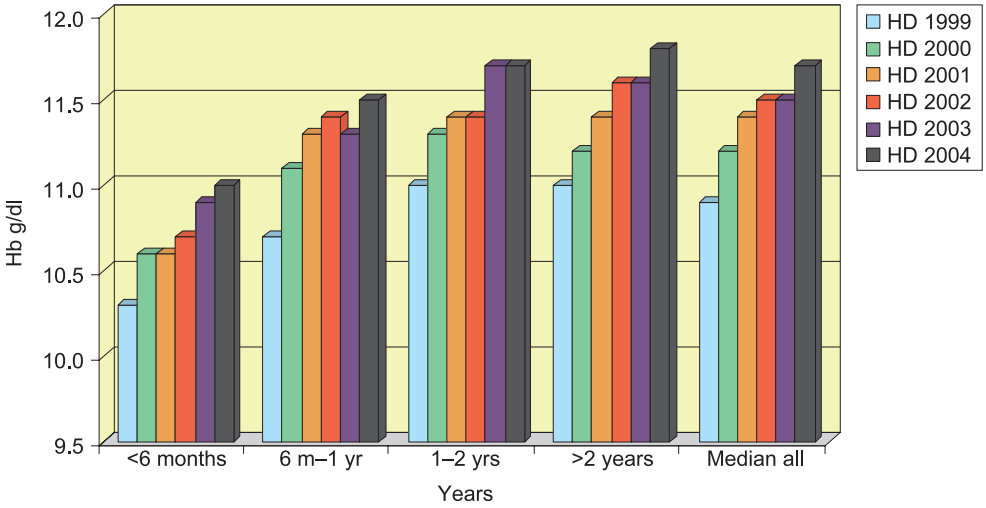

Figure 8.26: Median haemoglobin by length of time on RRT HD

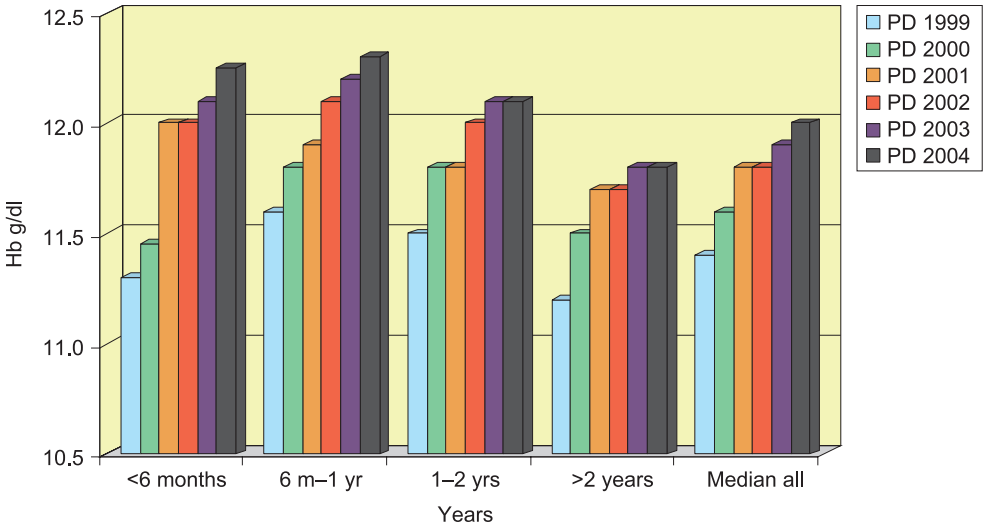

Figure 8.27: Median haemoglobin by length of time on RRT PD

Haemoglobin prior to starting renal replacement therapy

The Registry retrospectively collects haemoglobin prior to starting renal replacement therapy and the date this was collected on. Patients were only included if a haemoglobin value was available within the 2 weeks prior to starting RRT. Patients whose first presentation to a nephrology service was at the time of requiring dialysis (ie an Hb value was not available prior to starting RRT) were excluded.

Table 8.4 Haemoglobin prior to starting RRT and presence of co-morbidity

	Mean Hb g/dl	95% CI
Without co-morbidities	10.1	10.1–10.2
Angina	10.1	10.1–10.2
MI in past 3 months	10.1	9.8–10.3
MI >3 months ago	10.4	10.2–10.5
CABG/angioplasty	10.4	10.2–10.5
Cerebrovascular disease	10.1	10.0–10.2
Diabetes (not cause of ERF)	10.1	10.0–10.3
Diabetes as primary disease	10.0	9.9–10.1
Diabetes of either category	10.1	10.0–10.1
COPD	10.0	9.8–10.1
Liver disease	9.6	9.4–9.9
Malignancy	10.0	9.9–10.1
Claudication	10.1	10.0–10.2
Ischaemic/neuropathic ulcers	9.8	9.6–10.0
Angioplasty/vascular graft	10.3	10.1–10.5
Amputation	9.9	9.6–10.2
Smoking	10.0	9.9–10.1

The mean Hb was 10.1 g/dl and the median time of this result was 3 days prior to the start of RRT.

Table 8.4 shows the mean haemoglobin in patients without any co-morbidity and those with different co-morbidities. Only patients with a previous MI >3 months previously and those with liver disease had a significantly different haemoglobin from patients without comorbidity ($p < 0.001$).

Conclusion

Management of anaemia in England and Wales renal centres continues to improve. There is recognition that to ensure that individuals maintain a minimum haemoglobin level of 10 g/dl much higher levels of haemoglobin concentration must be targeted. Several centres have over 90% of haemodialysis patients with haemoglobin over 10 g/dl but this requires that the median haemoglobin be over 12 g/dl. There is evidence that once the median is significantly over 12 g/dl the percentage with Hb $\geqslant$10 g/dl reaches a plateau. This is explained by the irreducible minimum of patients with anaemia caused by inter-current illness and resistance to ESAs.

Chapter 9: Factors Influencing Haemoglobin

Summary

- The percentage of patients achieving a serum ferritin above 100 µg/L was similar to 2003 for both HD (96% vs 95%) and PD (86% vs 87%).
- Between renal units, for HD patients there is a linear relationship between %Hb $\geqslant$10 g/dl and %ferritin >200 µg/L which is achieved by 85% of HD patients and 62% of PD patients.
- Median ferritin was higher for HD (424 µg/L; quartile range 275–623 µg/L) than for PD (251 µg/L; quartile range 149–413 µg/L).
- There remains a wide difference in achieved ferritin outcome between different centres, medians ranging from 200 to 700 µg/L. In HD there are an increasing number of renal units with median ferritin $\geqslant$500 µg/L (11 of 49 renal units).
- The percentage of patients with serum ferritin >800 µg/L (and potential toxicity) shows a linear relationship with median ferritin for both HD and PD modalities. The contribution of acute phase responses to this relationship is uncertain.
- With improved population Hb, calibration against a minimum standard of %Hb $\geqslant$10 g/dl may not reflect differences in median Hb. Compliance with %Hb $\geqslant$10 g/dl does not improve beyond a median outcome Hb of 12 g/dl (for HD or PD).
- Compliance with Hb $\geqslant$11 g/dl continues to improve in a linear fashion with increasing median Hb (for HD and PD).
- In patients new to HD the median ferritin increases progressively over 20 months from 175 µg/L to 450 µg/L.
- Compared to 2003 the percentage of patients treated with Erythropoiesis Stimulating Agents (ESAs) in 2004 was unchanged for HD (91% vs 91%) and higher for PD (80% vs 77%).
- ESA doses were higher in patients on HD (mean 9,500 units/wk; median 8,000 units/wk) than in PD (mean 6,000 units/wk; median 4,000 units/wk), though ESA data are not yet fully reliable for agent, administration and dose frequency.
- A significantly higher percentage of women than men received ESAs in both HD (92% vs 90% $p = 0.004$) and PD (83% vs 79% $p = 0.03$) modalities.
- Unit performance has been tending to stabilise in this area and further useful information is likely to depend on the collection and presentation of additional variables such as transferrin saturation, reticulocyte Hb concentration, CRP and details of the agents, doses, and administration of ESAs and iron.

Introduction

National and international recommendations for the goals of iron status in chronic kidney disease remain unchanged from previous reports. The 2002 Renal Association Standards Document (SDIII) revised European Best Practice Guidelines (EBPGII) and Dialysis Outcomes Quality Initiatives (KDOQI) guidelines all recommend:

> ***a target serum ferritin greater than 100 µg/L and percentage transferrin saturation (TSAT) more than 20% in patients with chronic kidney disease***

SDIII and EBPGII also recommend:

> ***less than 10% hypochromic red cells (HRC) (evidence level B)***

in addition, EBPGII adds:

> ***a target reticulocyte Hb concentration (CHr) greater than 29 pg/cell (evidence level B)***

To achieve adequate iron status across a patient population, SDIII and EBPGII advocate population medians for ferritin of 200–500 μg/L, for TSAT of 30–40%, for hypochromic red cells of <2.5% and CHr of 35 pg/cell. EBPGII comments that:

> ***a serum ferritin for the treatment population of 200–250 μg/L ensures that 85–90% of patients attain a serum ferritin of >100 μg/L***

All guidelines advise that:

> ***serum ferritin levels should not exceed 800 μg/L*** since the risk of iron toxicity increases without conferring additional benefit.

Serum ferritin has several disadvantages as an index of iron status.

1. It is a marker of storage iron rather than available iron;
2. it behaves as an acute phase reactant, and is therefore increased in inflammatory states and malignancy;
3. it is raised in liver disease;
4. there is limited evidence about the sampling delay after IV administration necessary to allow an accurate reflection of iron stores.

Of the alternative measures of iron status available, HRC and CHr are generally considered superior to TSAT. However, both require specialised analysers to which few UK renal units have easy access and HRC is inaccurate/unreliable if analysis is delayed. Since TSAT is measured infrequently in many centres, and most UK units continue to use serum ferritin for routine iron management, ferritin remains the chosen index of iron status for this report. The collection of TSAT values would enhance explanations of renal unit results, as would knowledge of the agents, routes, frequency and doses of administered iron. However, the drive to higher serum ferritin, towards conventional 'toxic' limits, in order to maximise the effects of ESAs, partly obviates the role of TSAT or other variables in assessing 'functional iron deficiency'.

Information on the use of ESAs has been collected from units where data was available. Doses of darbepoeitin have been converted at protein mass equivalence (200 : 1) and reported as a weekly dose. However, route of administration and frequency of administration data are incomplete and make comparative analysis difficult. Data are presented as total weekly erythropoeitin dose.

Completeness of data returns

The completeness of serum ferritin returns to the Registry over 6 months is shown in Table 9.1. Not all sites use serum ferritin as the sole indicator of iron status.

In all figures where data are shown by the individual centre, the number adjacent to the name of the renal unit indicates the percentage of missing data at that time point.

Table 9.1: Completeness of serum ferritin returns

Centre	Ferritin HD %	Ferritin PD %
Bangor	88	79
Barts	0	0
Basildn	97	100
Bradford	100	100
Brighton	56	88
Bristol	98	98
Cambridge	55	91
Carlisle	93	93
Carshalton	74	80
Chelmsford	88	91
Clwyd	81	100
Coventry	99	83
Cardiff	95	91
Derby	79	64
Dorset	95	97
Dudley	75	88
Exeter	97	100
Gloucester	96	92
Guys	82	91
H&CX	98	97
Heartlands	86	100
Hull	95	93
Ipswich	98	67
Kings	93	90
Leeds	98	98
Leicester	97	93
Liverpool	91	93
ManWst	56	85
Middlesbrough	92	100
Newcastle	100	100
Norwich	97	100
Nottingham	96	97
Oxford	92	82
Plymouth	90	86
Portsmouth	99	79
Preston	97	100
QEH	94	93
Reading	97	96
Sheffield	99	97
Shrewsbury	100	97
Stevenage	92	95
Southend	98	95
Sunderland	91	92
Swansea	98	99
Truro	99	92
Wirral	1	15
Wolverhampton	100	100
Wrexham	84	93
York	91	95
England	87	85
Wales	87	86
England & Wales	87	85

Serum ferritin

Serum ferritin and inter-quartile ranges are presented in Table 9.2 and Figure 9.1 for haemodialysis and Table 9.3 and Figure 9.2 for peritoneal dialysis. The percentages of patients achieving a serum ferritin over 100 μg/L and 200 μg/L for each modality are shown in Figures 9.3 to 9.6.

All centres except one achieved a median ferritin outcome in compliance with the EBPG standard of over 200 μg/L for HD. All units except one achieved at least 85% ferritin >100 μg/L. This year's data in HD suggest a renal unit median ferritin of 300 μg/L to ensure 85–90% achieve the RA Standard ferritin value. 95% compliance is achieved at a median ferritin of 400–450 μg/L.

As in previous reports the overall median was higher for HD (424 μg/L) than for PD (251 μg/L). It is difficult to argue for a ferritin outcome similar to HD for the PD population with the Hb outcome in PD as good as presented at much lower doses of ESA. The median Hb and ferritin outcomes show a linear relationship up to a ferritin of approximately 300 μg/L in PD (Figures 9.7 and 9.8).

As units have increased the use of intravenous iron to increase the median ferritin outcome, the proportion of patients with a ferritin >800 μg/L inevitably increases (Figure 9.9) with about 15% of patients having a ferritin >800 μg/L at a median ferritin of 500 μg/L. The median ferritin outcome appears to approximate to the ceiling for iron administration in clinical systems known to undertake frequent and regular review of iron status.

If ferritin >800 μg/L is associated with increased risk of toxicity, without additional benefit in terms of increase in Hb or reduction in ESA dose, then an upper limit for further iron therapy may need to be considered as approximately 500 μg/L.

EBPGII advocate a population outcome median for ferritin of 200–500 μg/L. Nearly half the renal units in the UK have a median greater than 400 μg/L with 8 out of 47 centres that submitted ferritin data) reaching a median ferritin >500 μg/L.

Table 9.2: Serum ferritin in HD patients

Centre	% data return	Median ferritin	90% range	Quartile range	% ferritin >100 µg/L
Bangor	88	453	158–1,022	329–730	98
Barts	0	n/a	n/a	n/a	n/a
Basildon	97	310	114–508	227–358	97
Bradford	100	493	206–982	374–705	98
Brighton	56	255	39–1,500	140–480	83
Bristol	98	471	155–1,199	309–730	99
Cambridge	55	197	43–579	115–303	82
Carlisle	93	339	130–853	241–449	99
Carshalton	74	344	79–987	238–480	94
Chelmsford	88	472	104–1,056	289–581	96
Clwyd	81	319	122–592	203–432	98
Coventry	99	329	76–1,101	211–519	93
Cardiff	95	519	106–1,175	319–713	95
Derby	79	365	99–952	279–554	95
Dorset	95	467	159–850	330–599	100
Dudley	75	430	140–948	276–564	100
Exeter	97	326	119–620	235–414	98
Gloucester	96	342	70–827	208–555	91
Guys	82	403	92–1,144	270–612	95
H&CX	98	681	209–1,433	392–878	98
Heartlands	86	280	56–699	153–413	90
Hull	95	385	151–796	278–520	98
Ipswich	98	403	116–885	225–579	95
Kings	93	459	187–966	347–624	100
Leeds	98	500	217–904	402–621	100
Leicester	97	384	124–989	247–561	97
Liverpool	91	593	100–1,650	334–891	95
ManWst	56	429	51–1,229	226–774	91
Middlesbrough	92	460	78–1,644	290–806	93
Newcastle	100	478	206–1,143	368–678	100
Norwich	97	430	161–1,101	310–645	98
Nottingham	96	479	222–1,003	374–625	99
Oxford	92	329	72–823	209–449	93
Plymouth	90	392	117–1,449	278–578	96
Portsmouth	99	310	102–719	217–406	96
Preston	97	671	183–1,517	457–876	97
QEH	94	283	85–637	197–397	93
Reading	97	646	258–1,081	459–810	99
Sheffield	99	561	206–1,073	432–747	98
Shrewsbury	100	403	94–1,025	270–573	95
Stevenage	92	412	119–911	251–551	98
Southend	98	358	153–680	293–425	97
Sunderland	91	409	144–1,057	258–580	99
Swansea	98	380	88–786	230–533	93
Truro	99	515	230–1,086	375–681	99
Wirral	1	n/a	n/a	n/a	n/a
Wolverhampton	100	464	212–798	368–552	100
Wrexham	84	497	125–963	328–686	96
York	91	617	307–1,006	501–767	100
England	87	422	115–1,081	275–621	96
Wales	87	447	98–1,096	286–653	95
England & Wales	87	424	114–1,081	275–623	96

Table 9.3: Serum ferritin in PD patients

Centre	% data return	Median ferritin	90% range	Quartile range	% ferritin >100 µg/l
Bangor	79	278	40–678	178–399	95
Barts	0	n/a	n/a	n/a	n/a
Basildon	100	301	120–1,412	185–414	95
Bradford	100	259	33–788	131–402	89
Brighton	88	295	63–1,200	215–480	93
Bristol	98	194	26–638	102–323	76
Cambridge	91	195	62–645	125–361	83
Carlisle	93	410	61–1,580	256–873	92
Carshalton	80	237	47–812	125–368	85
Chelmsford	91	276	64–893	187–500	87
Clwyd	100	203	32–569	141–250	83
Coventry	83	159	24–840	82–367	67
Cardiff	91	226	41–674	119–350	81
Derby	64	309	141–759	235–411	100
Dorset	97	219	66–507	149–345	88
Dudley	88	203	36–830	136–277	84
Exeter	100	163	64–565	120–276	86
Gloucester	92	246	65–554	175–400	92
Guys	91	228	62–722	180–287	87
H&CX	97	279	60–1,118	179–582	90
Heartlands	100	249	42–713	135–363	79
Hull	93	280	84–655	183–372	90
Ipswich	67	309	42–588	166–433	83
Kings	90	251	86–775	189–356	94
Leeds	98	377	86–878	209–465	95
Leicester	93	297	56–861	163–466	89
Liverpool	93	251	70–753	153–413	89
ManWst	85	188	38–779	109–303	79
Middlbrough	100	429	46–1,711	197–521	94
Newcastle	100	313	84–1,098	239–466	93
Norwich	100	478	77–838	364–607	93
Nottingham	97	214	60–578	151–297	89
Oxford	82	214	59–1,065	108–475	79
Plymouth	86	200	42–621	101–426	75
Portsmouth	79	206	34–499	125–278	78
Preston	100	236	64–651	138–398	87
QEH	93	146	32–588	82–245	67
Reading	96	442	102–889	353–499	96
Sheffield	97	300	69–851	188–437	92
Shrewsbury	97	286	97–714	183–455	94
Stevenage	95	184	46–534	115–313	77
Southend	95	315	54–865	170–542	95
Sunderland	92	483	298–1,183	457–743	100
Swansea	99	229	49–766	135–367	83
Truro	92	215	41–900	152–333	83
Wirral	15	n/a	n/a	n/a	n/a
Wolverhampton	100	267	55–779	184–524	88
Wrexham	93	418	204–963	294–576	100
York	95	238	59–530	148–381	86
England	85	251	54–826	150–413	86
Wales	86	247	49–851	139–396	85
England & Wales	85	251	52–830	149–413	86

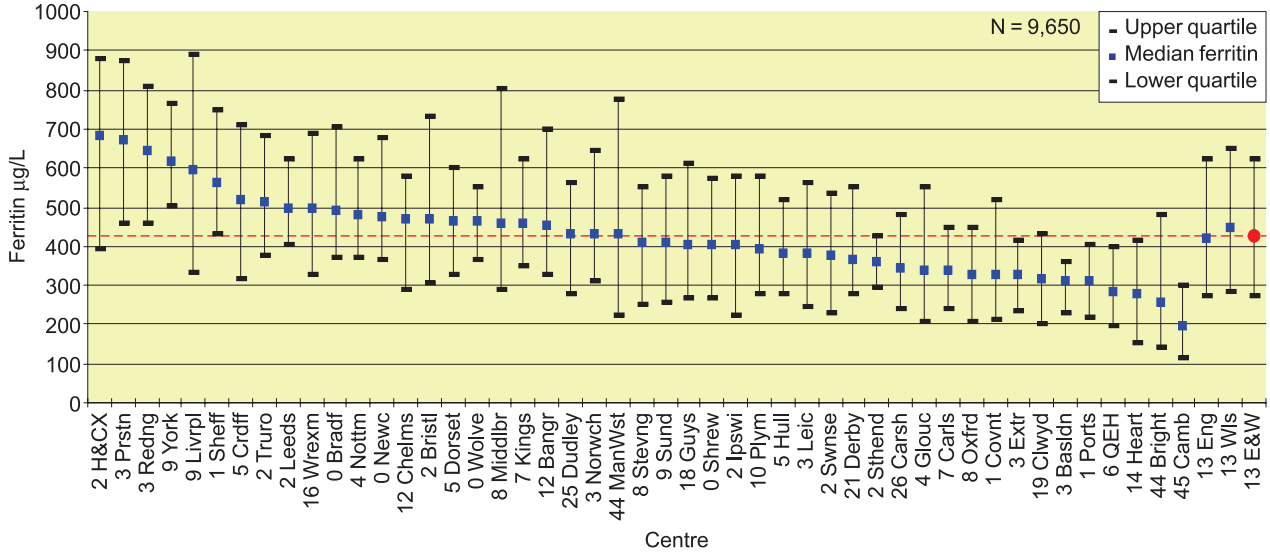

Figure 9.1: Median serum ferritin: haemodialysis

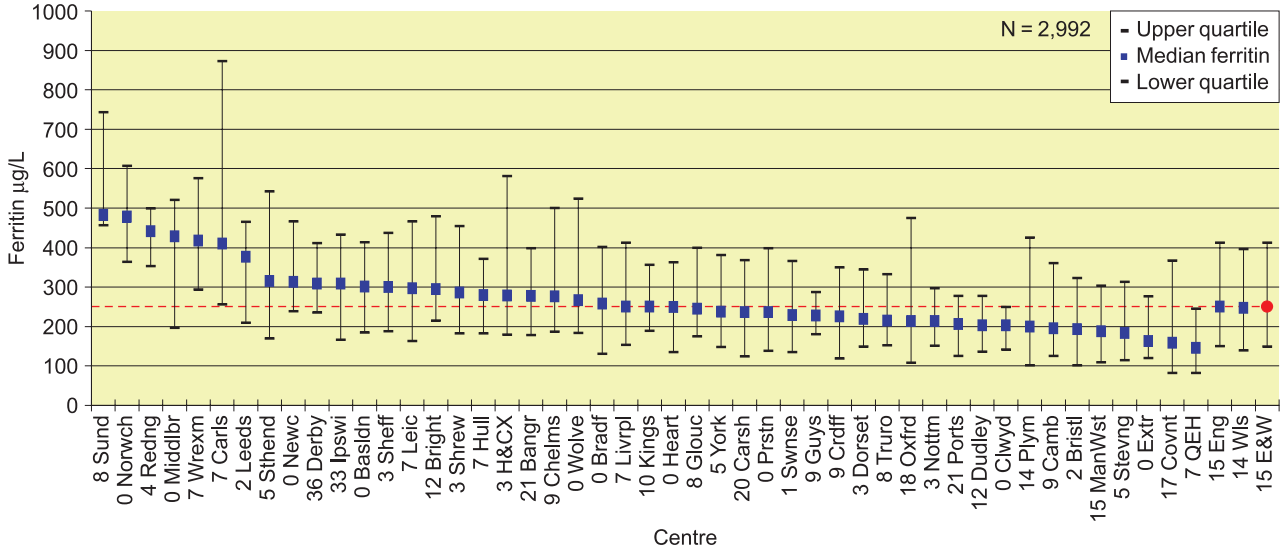

Figure 9.2: Median serum ferritin: peritoneal dialysis

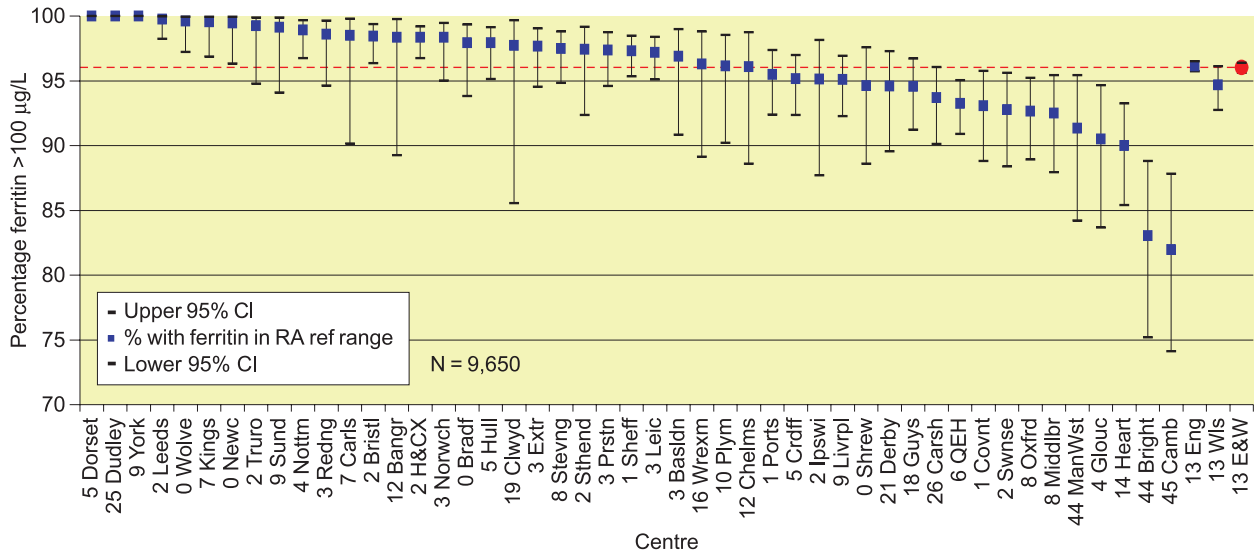

Figure 9.3: Percentage of HD patients with serum ferritin $\geqslant$ 100 µg/L

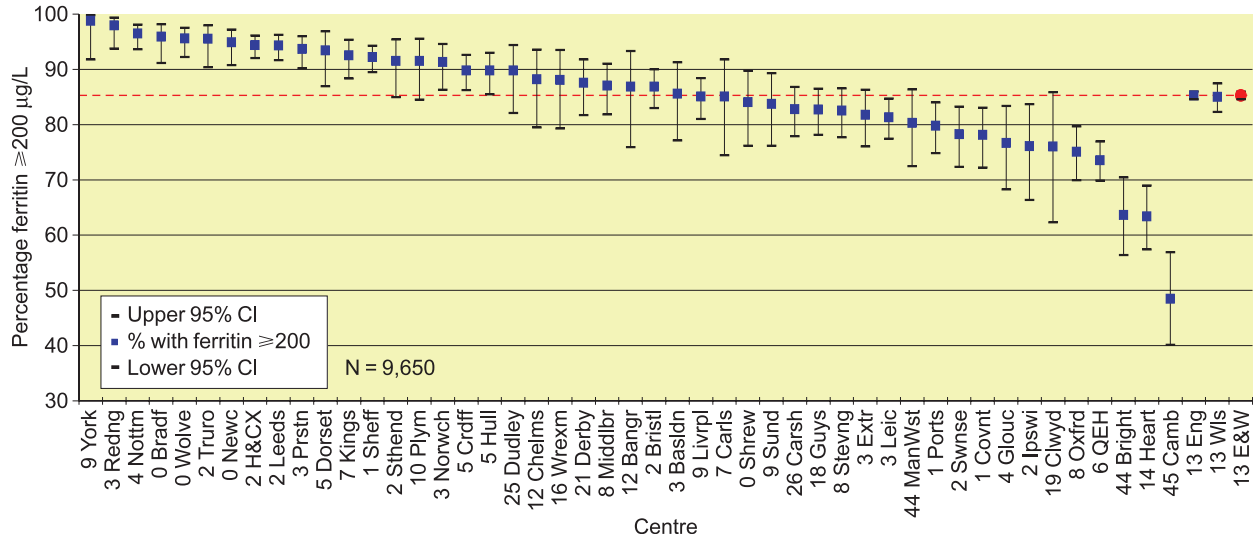

Figure 9.4: Percentage of HD patients with serum ferritin ⩾200 µg/L

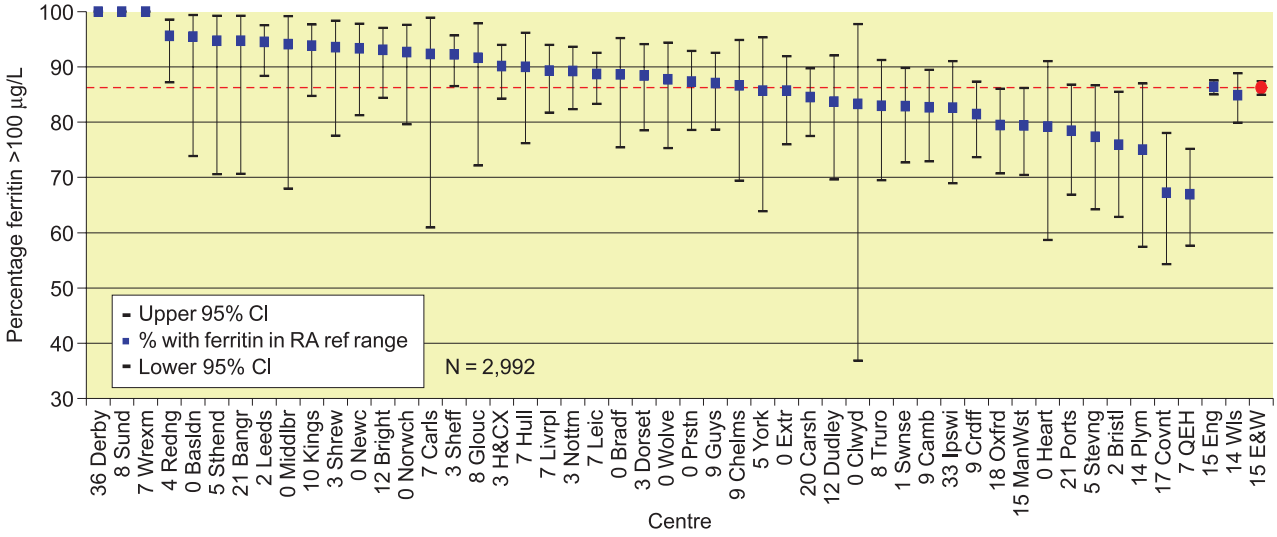

Figure 9.5: Percentage of PD patients with serum ferritin ⩾100 µg/L

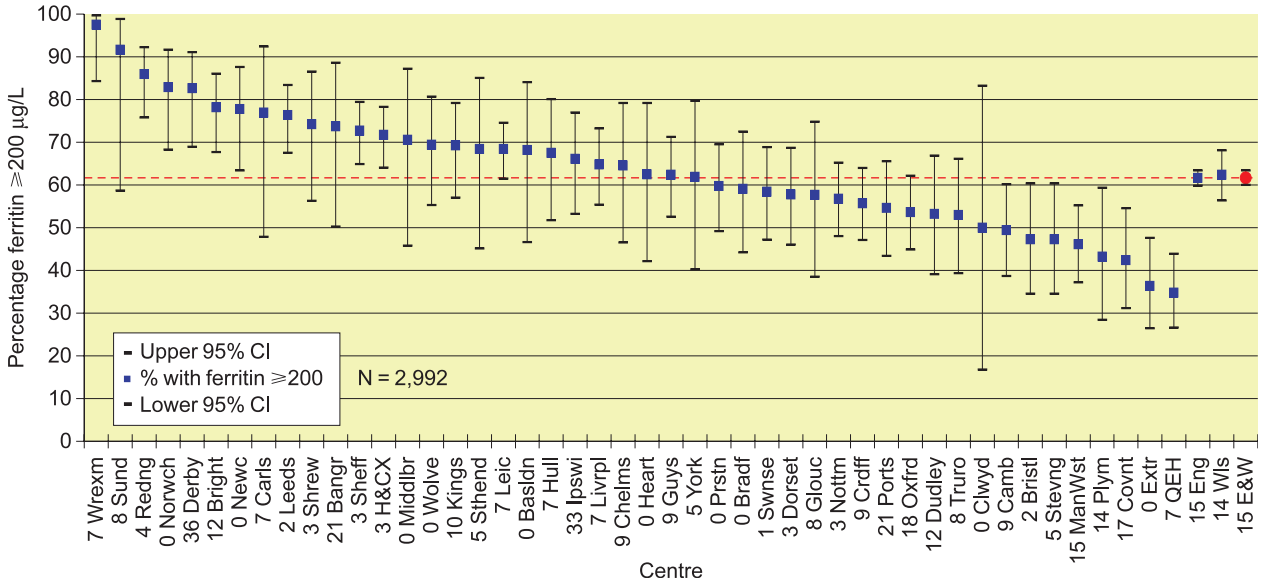

Figure 9.6: Percentage of PD patients with serum ferritin ⩾200 µg/L

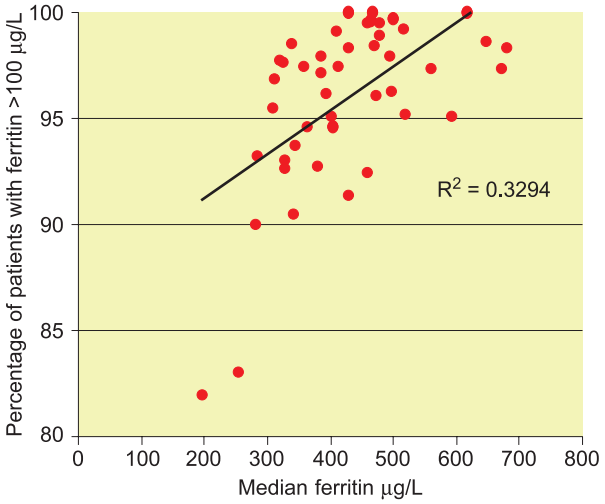

Figure 9.7: Median ferritin vs compliance with RA standard for ferritin by centre in HD

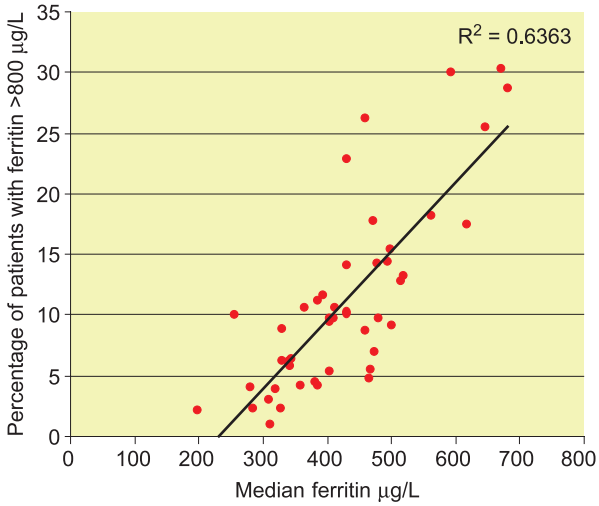

Figure 9.9: Median ferritin vs ferritin >800 µg/L by centre HD

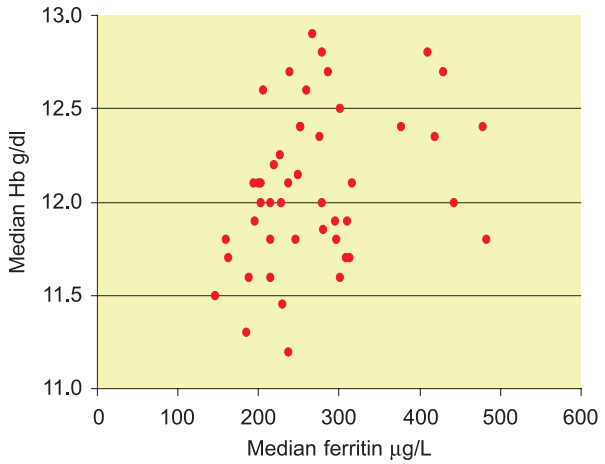

Figure 9.8: Median ferritin by median Hb by centre PD

Changes in serum ferritin 1999–2004 in England and Wales

There is good overall achievement of therapeutic goals for ferritin in HD and PD. The improvement in ferritin in HD in recent years appears to have stabilised. PD outcomes have remained relatively stable for the last 6 years (Figures 9.10 to 9.12).

Many centres showed marked differences in iron status between their HD and PD populations suggesting that iron replacement practices are different for the two modalities, either by design (policy), because of separate team management or possibly because of logistical

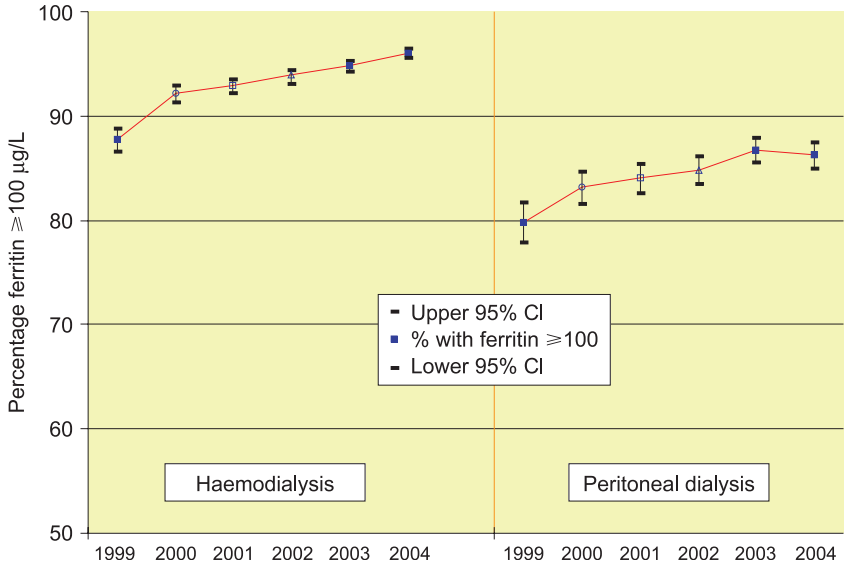

Figure 9.10: Change in achievement of serum ferritin >100 µg/L, 1999–2004

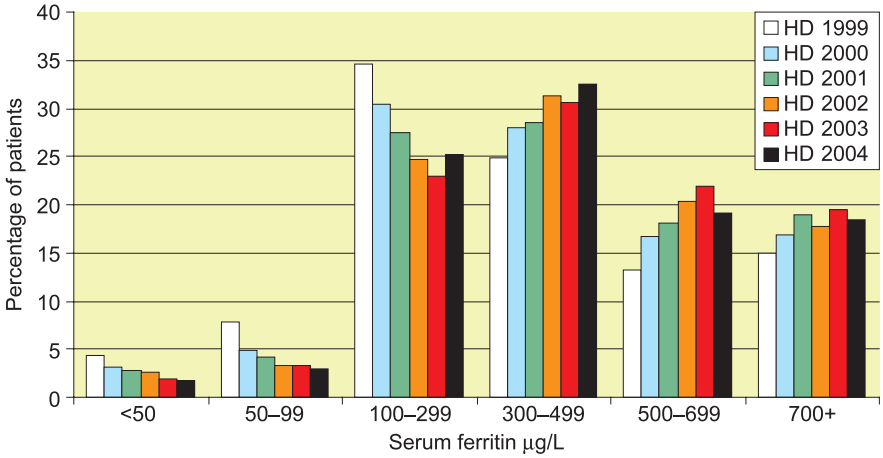

Figure 9.11: Serum ferritin distribution 1999–2004 haemodialysis

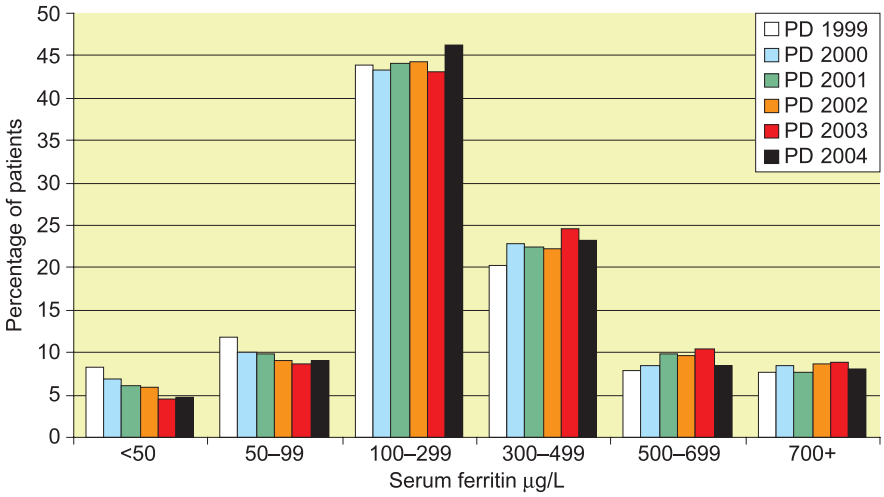

Figure 9.12: Serum ferritin distribution 1999–2004 peritoneal dialysis

problems in providing regular intravenous iron to PD patients.

Given that only one centre for HD had a median serum ferritin less than 200 µg/L, it is unsurprising that no relationship exists for HD between the percentage of patients with serum ferritin above 200 µg/L and a haemoglobin level ⩾10 g/dl (Figures 9.13 and 9.14).

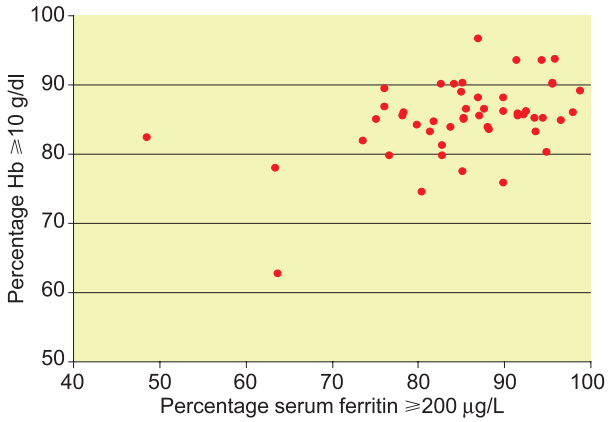

Figure 9.13: Percentage of patients with serum ferritin >200 µg/L and Hb ⩾10 g/dl on HD

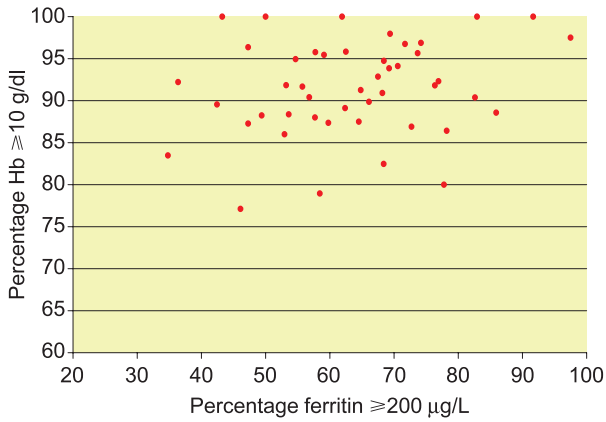

Figure 9.14: Percentage of patients with serum ferritin >200 µg/L and Hb ⩾10 g/dl on PD

Serum ferritin and length of time on renal replacement therapy (RRT)

As in the 2004 Report, the median and lower quartile values for serum ferritin were above 100 µg/L for both HD and PD by the sixth month on dialysis. As before, however, median ferritin continued to increase beyond this time, reaching the respective modality median only two years after the start of dialysis (Figures 9.15 and 9.16).

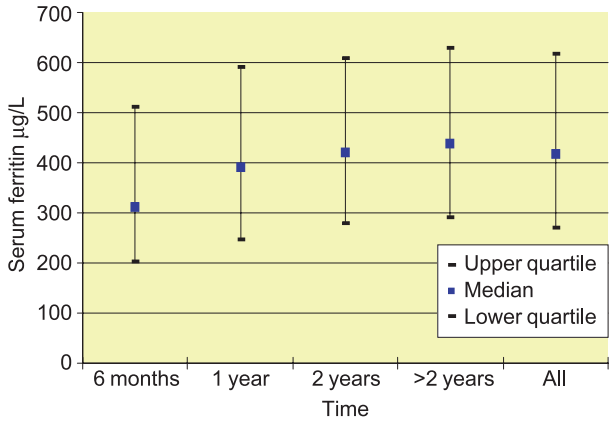

Figure 9.15: Median ferritin by length of time on RRT: HD

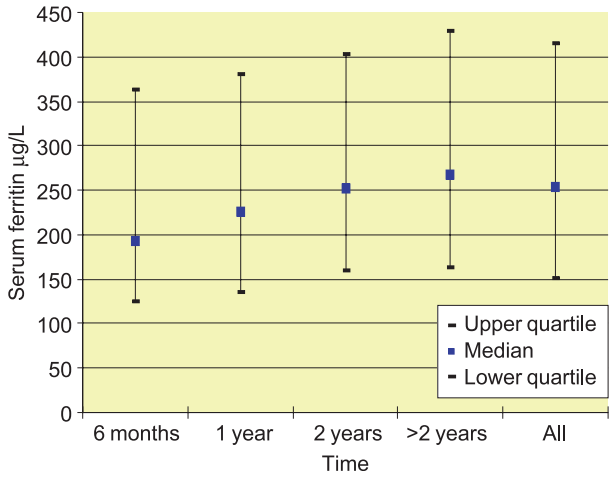

Figure 9.16: Median ferritin by length of time on RRT: PD

Changes in serum ferritin by centre 1999–2004

In HD, serial ferritin values seem to be relatively stable over 2003–2004 (Figure 9.17). Rising medians, and falling levels in units with higher outcomes in earlier years, are followed by stability, suggesting the acceptance of successful achievement of goals. A few units, however, show >15% of patients with a ferritin >800 µg/L.

Year on year changes of median ferritin in PD patients (Figure 9.18) have been less pronounced than in the HD population, although a minority have more than 15% <100 µg/L. Even so, the Hb outcomes reach the RA Standard of 85% Hb ⩾10 g/dl.

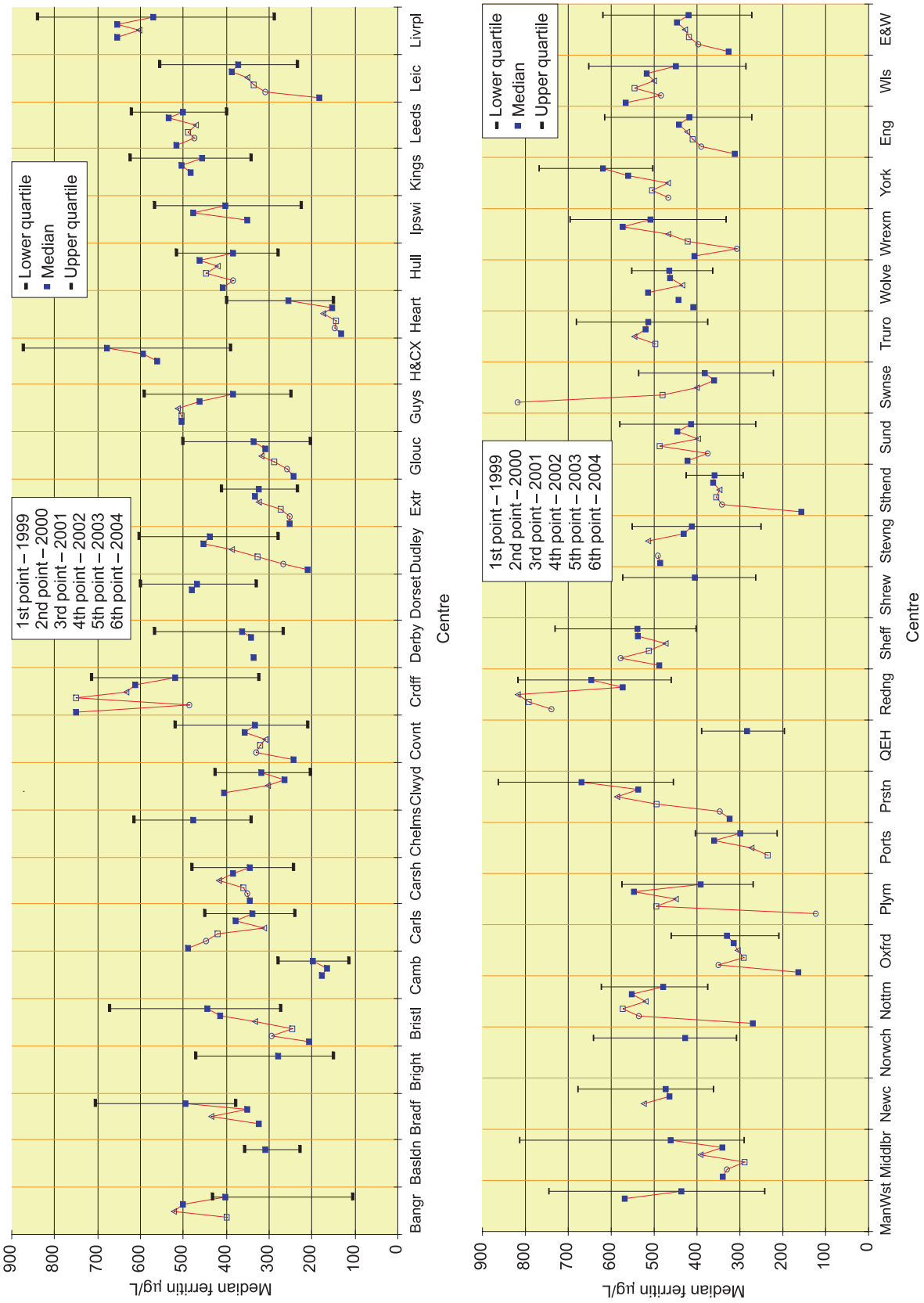

Figure 9.17: Serial ferritin in haemodialysis patients

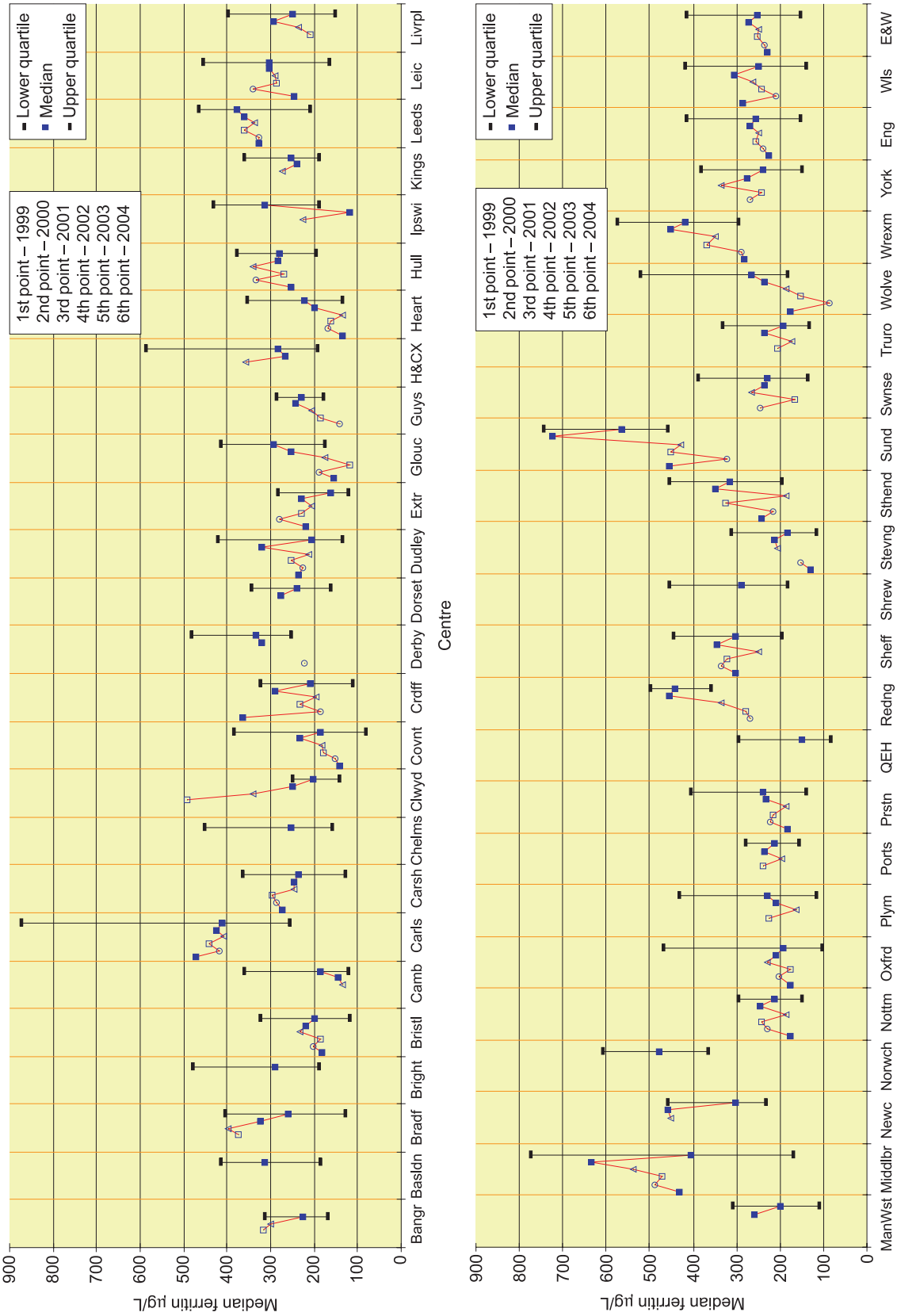

Figure 9.18: Serial ferritin in peritoneal dialysis patients

Erythropoietin stimulating agents

The Hb outcomes across England and Wales are approaching the UK RA Standard although a small number of units still have >15% of point prevalent values in patients on HD with an Hb $\leqslant$10.0 g/dl. Investigation as to the reasons why need to be undertaken at a local level, given that there continues to be an annual increase in the haemoglobin achieved by renal units. For England and Wales, only 11% of HD and 8% of PD patients had an Hb $\leqslant$10 g/dl in these point prevalent data. In HD patients 69% have an Hb $\geqslant$11 g/dl and 80% for PD.

ESA data is collected from renal IT systems in a similar way to the rest of the Registry data, although in contrast to the automated laboratory links, this relies on manual initial data entry. The reliability of these data is likely to depend on who is making the entry (doctor, EPO nurse, or data clerk), whether the renal unit is prescribing the ESA directly (within the renal unit budget), with or without using the computer system, or whether ESAs are prescribed in Primary Care (from the Primary Care Trust budget). In the latter case, the data in the renal IT system may not always be updated in parallel with the GP letter or the GP may decline to prescribe ESAs at the doses advised by the nephrologist.

Weekly ESA dose effectiveness depends on the route of administration, frequency of administration, compliance (patient or clinician administration) and possibly the agent used. Of the 17 units with Hb outcome at less than 85% $\geqslant$10 g/dl, the previous RA Standard, 10 units have provided ESA data. The mean EPO equivalent dose for these 10 units (9,744) is greater than the national mean (9,571) suggesting that availability of ESA is not the only factor involved in achieving desirable outcome ranges.

Patients treated and dose variation

ESA data were returned by 30 centres for HD (Table 9.4), and (the same) 30 centres for PD (Table 9.5). For HD the same proportion of patients were treated with ESAs compared to the 2004 report (90% male, 92% female). In PD a slight increase occurred (79% male, 83% female) though achieved haemoglobins were higher.

The percentage of patients receiving ESAs ranged from 62–99% (mean 91%) for HD and from 50–95% (mean 80%), for PD.

The difference between modalities appears to reflect lower ESA requirements in the PD population, rather than being due to problems in providing ESAs for this group. In some units there may be difficulties in provision of ESAs reflected in low percentage on ESA therapy, yet the Hb outcomes appear reasonable, and do not distinguish them.

As in previous reports, the percentage of patients achieving a haemoglobin over 10 g/dl without ESAs, was markedly higher for PD than HD, despite a higher median ferritin in the HD population of 424 μg/L compared with that of 251 μg/L in the PD population. This reflects the greater susceptibility of HD patients to blood loss, iron deficiency, and inflammation.

HD patients continued to receive larger doses of ESAs than their PD peers (median 8,000 vs 4,000 units/wk; mean 9,500 vs 6,000 units/week respectively). As in previous reports, centres prescribing higher doses of ESAs were not necessarily more successful in meeting haemoglobin targets, reflecting the importance of other influences on renal anaemia including iron status, residual renal function, case mix and dialysis adequacy. Bradford in particular has a median Hb of 12.7 & 12.6 for HD and PD respectively with relatively low reported mean EPO doses of 7,713 and 4,714 IU/wk respectively.

Age and ESA provision

Only minor variations were seen with age in the percentage of HD & PD patients treated with ESAs (Figure 9.19).

ESA prescription and gender

As in previous reports, a greater percentage of women than men were treated with ESAs in both dialysis modalities, despite a lower achieved haemoglobin in women (Tables 9.8 and 9.9). For both modalities, more men than women achieved a haemoglobin over 10 g/dl without ESAs (Tables 9.6 and 9.7 and Figures 9.20 and 9.21).

Table 9.4: ESA prescribing in HD patients

Treatment centre	% data return	Median ferritin	90% range	Quartile range	% ferritin >100 µg/L	Mean Hb	Mean weekly dose for pts on EPO	Median Hb	Median dose for HD pts on EPO
Basildon	97	310	114–508	227–358	97	11.5	10,380	11.5	10,000
Bradford	100	493	206–982	374–705	98	12.4	7,710	12.7	6,000
Bristol	98	471	155–1,199	309–730	99	11.6	8,550	11.6	6,000
Carlisle	93	339	130–853	241–449	99	11.4	9,660	11.4	7,500
Chelmsford	88	472	104–1,056	289–581	96	11.7	10,480	11.7	9,000
Clwyd	81	319	122–592	203–432	98	12.7	8,950	12.6	8,000
Coventry	99	329	76–1,101	211–519	93	11.4	11,560	11.4	10,000
Dorset	95	467	159–850	330–599	100	11.7	11,190	12.0	12,000
Dudley	75	430	140–948	276–564	100	11.1	7,440	11.2	6,000
Exeter	97	326	119–620	235–414	98	11.5	8,470	11.5	7,500
Gloucester	96	342	70–827	208–555	91	11.4	10,890	11.4	9,000
Heartlands	86	280	56–699	153–413	90	11.2	9,370	11.3	8,000
Ipswich	98	403	116–885	225–579	95	11.4	9,190	11.5	8,000
Leeds	98	500	217–904	402–621	100	12.4	8,960	12.4	8,000
Leicester	97	384	124–989	247–561	97	11.5	9,900	11.6	9,000
Liverpool	91	593	100–1,650	334–891	95	12.3	10,280	12.4	9,000
ManWst	56	429	51–1,229	226–774	91	11.1	9,660	11.1	8,000
Middlesbrough	92	460	78–1,644	290–806	93	11.7	7,040	11.9	6,000
Norwich	97	430	161–1,101	310–645	98	11.8	10,020	11.8	8,000
Oxford	92	329	72–823	209–449	93	11.4	8,860	11.5	8,000
Plymouth	90	392	117–1,449	278–578	97	11.5	9,430	11.3	8,000
QEH	94	283	85–637	197–397	93	11.5	10,640	11.6	10,000
Sheffield	99	561	206–1,073	432–747	97	11.6	10,340	11.6	8,000
Shrewsbury	100	403	94–1,025	270–573	95	11.7	11,040	12.0	10,000
Stevenage	92	412	119–910	251–551	98	11.8	10,480	12.0	8,000
Southend	98	358	153–680	293–425	97	11.2	7,540	11.4	6,000
Sunderland	91	409	144–1,057	258–580	99	11.8	8,540	12.0	9,000
Truro	99	515	230–1,086	375–681	99	11.5	5,060	11.6	4,000
Wolverhampton	100	464	212–798	368–552	100	12.3	10,240	12.6	8,000
York	91	617	307–1,006	501–767	100	12.4	9,250	12.8	8,000
England	87	422	115–1,081	275–621	96	11.6	9,590	11.7	8,000
Wales	87	447	98–1,096	286–653	95	11.9	8,710	12.0	8,000
England & Wales	87	424	114–1,081	275–623	96	11.7	9,570	11.7	8,000

Table 9.5: ESA prescribing in PD patients

Treatment centre	% data return	Median ferritin	90% range	Quartile range	% ferritin >100 µg/L	Mean Hb	Mean weekly dose for pts on EPO	Median Hb	Median dose for HD pts on EPO
Basildon	100	301	120–1,412	185–414	95	12.3	5,660	12.5	4,000
Bradford	100	259	33–788	131–402	89	12.7	4,710	12.6	4,000
Bristol	98	194	26–638	102–323	76	12.2	3,970	12.1	4,000
Carlisle	93	410	61–1,580	256–873	92	12.7	8,780	12.8	8,000
Chelmsford	91	276	64–893	187–500	87	11.9	7,000	12.4	5,000
Clwyd	100	203	32–569	141–250	83	12.8	4,400	12.1	4,000
Coventry	83	159	24–840	82–367	67	11.8	8,000	11.8	5,000
Dorset	97	219	66–507	149–345	88	12.4	5,950	12.2	4,000
Dudley	88	203	36–830	136–277	84	12.3	5,670	12.0	6,000
Exeter	100	163	64–565	120–276	86	11.8	6,020	11.7	4,000
Gloucester	92	246	65–554	175–400	92	11.6	5,760	11.8	4,000
Heartlands	100	249	42–713	135–363	79	12.0	6,890	12.2	6,000
Ipswich	67	309	42–588	166–433	83	11.7	6,090	11.7	6,000
Leeds	98	377	86–878	209–465	95	12.4	4,660	12.4	4,000
Leicester	93	297	56–861	163–466	89	11.7	5,620	11.8	4,000
Liverpool	93	251	70–753	153–413	89	12.4	5,880	12.4	6,000
ManWst	85	188	38–779	109–303	79	11.3	6,080	11.6	6,000
Middlesbrough	100	429	46–1,711	197–521	94	12.4	4,600	12.7	4,000
Norwich	100	478	77–838	364–607	93	12.7	6,390	12.4	6,000
Oxford	82	214	59–1,065	108–475	79	11.9	6,660	12.0	6,000
Plymouth	86	200	42–621	101–426	75	12.5	5,400	12.1	6,000
QEH	93	146	32–588	82–245	67	11.5	7,260	11.5	6,000
Sheffield	97	300	69–851	188–437	92	11.6	7,590	11.6	6,000
Shrewsbury	97	286	97–714	183–455	94	12.6	6,080	12.7	6,000
Stevenage	95	184	46–534	115–313	77	11.3	4,400	11.3	3,000
Southend	95	315	54–865	170–542	95	12.4	5,430	12.1	5,000
Sunderland	92	483	298–1,183	457–743	100	11.7	4,800	11.8	4,000
Truro	92	215	41–900	152–333	83	11.8	3,680	11.8	4,000
Wolverhampton	100	267	55–779	184–524	88	12.9	5,900	12.9	4,000
York	95	238	59–530	148–381	86	12.9	4,280	12.7	4,000
England	85	251	54–826	150–413	86	12.0	5,940	12.0	4,000
Wales	86	247	49–851	139–396	85	11.9	4,260	12.0	4,000
England & Wales	85	251	52–830	149–413	86	12.0	5,910	12.0	4,000

Table 9.6: Percentage use of ESAs, by Hb achievement and age, on HD

	% with Hb <10 and on epo	% with Hb ⩾10 who are not on epo
18–34	91	6
35–44	95	10
45–54	95	9
55–64	88	8
65–74	93	7
75+	91	6

Table 9.7: Percentage use of ESAs, by Hb achievement and age, on PD

	% with Hb <10 and on epo	% with Hb ⩾10 who are not on epo
18–34	95	12
35–44	91	15
45–54	95	22
55–64	77	21
65–74	91	18
75+	89	18

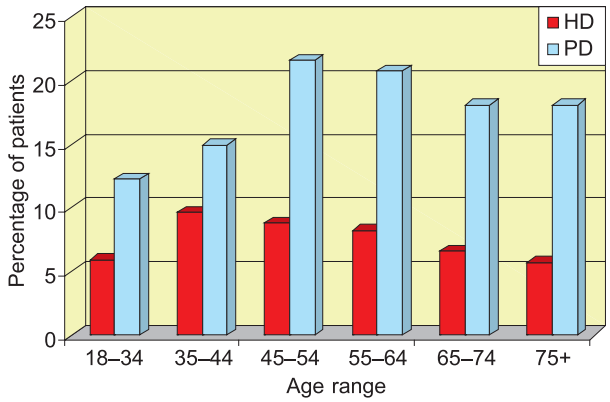

Figure 9.19: Percentage of patients not on EPO with Hb ⩾10 g/dl, by age group and modality

Table 9.8: Percentage ESA use by age and gender, on HD

	Male	Female
18–34	92	91
35–44	87	92
45–54	88	90
55–64	86	93
65–74	91	92
75+	92	91

Table 9.9: Percentage ESA use by age and gender, on PD

	Male	Female
18–34	87	86
35–44	84	86
45–54	74	81
55–64	76	78
65–74	80	85
75+	79	86

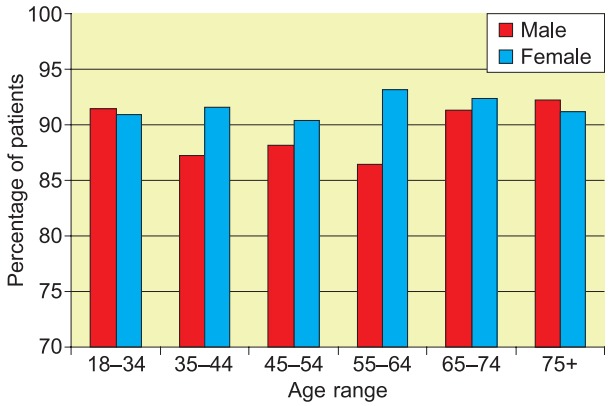

Figure 9.20: Provision of ESAs by age and gender, for patients on HD

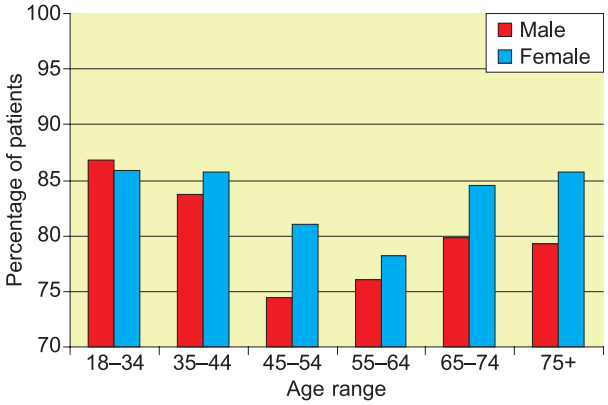

Figure 9.21: Provision of ESAs by age and gender, for patients on PD

Conclusion

The year on year rise in median serum ferritin and the percentage of patients with serum ferritin greater than 100 µmol/L appears to have stabilised in HD and PD. In PD, ferritin outcome has been stable for some time. In HD, the proportion with a ferritin >200 ng/ml has increased further over the last 2 years, suggesting that the provision of intravenous iron for UK dialysis patients is near saturation. Further increases in ferritin in the PD population are

probably unwarranted and results may reflect some clinical hesitation or inability to increase intravenous iron therapy readily in this group.

The proportion of patients with ferritin >800 μg/L is directly linked to median ferritin outcome and centres need to consider how best to avoid toxicity in their patients, when there is little if any benefit demonstrated in increasing the ferritin beyond approximately 500 μg/L. The role of acute phase elements in the values >800 μg/L cannot be assessed without further data on C-reactive protein (CRP), for example. Although the returns on ESA treatment remain incomplete, they show a continuing increase in the number of patients treated compared with 2001 data. The percentage of patients requiring ESAs, and the doses they received, remained markedly higher in HD than PD.

Overall, these data demonstrate that UK renal units continue to improve the outcome for Hb in HD & PD through treatment strategies relating to iron and ESAs. Across England and Wales the UK RA Standard for serum ferritin is close to being met, in point prevalent data, with coincident improvements in Hb outcome.

A more complete and reliable explanation of these results depends on additional data collection, such as TSAT, CRP and the details of ESA and iron treatment. A limit appears to have been reached in the usefulness of descriptive data matching demographic variables with serum ferritin and aggregated ESA data. Improvement in renal unit performance through comparative audit will require a broader base of data collection, possibly through forms of sampling.

Chapter 10: Bone Biochemistry: Serum Phosphate, Calcium, Parathyroid Hormone, Albumin and Aluminium

Summary

- Although serum phosphate control in dialysis patients is unsatisfactory there is a continuing year-on-year trend towards improvement. The Renal Association (RA) target (<1.8 mmol/L) was achieved in 63% of patients overall, (69% of peritoneal dialysis patients and 61% of haemodialysis patients).

- The median corrected calcium for all dialysis patients was 2.40 mmol/L with 74% of both HD and PD patients achieving a concentration within the RA target range.

- The North American Kidney Disease Outcomes Quality Improvement (KDOQI) guidelines[1] recommend the calcium × phosphate product should be less than 4.4 $mmol^2/L^2$ (=55 mg^2/dl^2). Overall 66% of dialysis patients achieved this target. Control was better in PD patients compared to HD patients (71% versus 64% achieving the standard), reflecting the better phosphate control that is achieved with PD. There was wide variation between units in both calcium and phosphate control and in achievement of the KDOQI calcium × phosphate target.

- There remains large between-centre variation in achievement of the RA target for plasma parathyroid hormone. Overall achievement was poor (median 63%, range 45–79% compliance with the standard).

- For haemodialysis patients, the median serum albumin concentration was 39 g/L (BCG) and 33 g/L (BCP). 75% (BCG) and 73% (BCP) of the patients had serum albumin above 35/30 g/L respectively.

- Peritoneal dialysis patients had lower serum albumin compared with haemodialysis patients; the median serum albumin was 35 g/L (BCG) and 29 g/L (BCP). Overall 55% (BCG) and 49% (BCP) of peritoneal dialysis patients had serum albumin concentrations above 35/30 g/L respectively.

- Most transplant patients achieve good phosphate control (99%, range 95–100%) and the percentage of patients achieving serum calcium concentrations within the target range was 84% (range 43–97%), although there was a tendency to hypercalcaemia in some renal units. Nearly all (99%) of transplant patients achieved calcium × phosphate product concentrations within the KDOQI target range. Overall median PTH was above the normal laboratory reference range (median 10, inter-quartile range 6–18 pmol/L) amongst transplant patients, although the majority (89%, range of centre means 70% to 100%) achieve the Renal Association target.

- Amongst patients who had received a renal transplant, median serum albumin was 41 g/L (range 17–56) for centres supported by laboratories using BCG methods and 37 g/L (range 14–48) for centres supported by laboratories using BCP methods. Overall, 95.4% and 95.9% of patients had serum albumin above 35 g/L for the BCG method and 30 g/L for the BCP method respectively.

- An analysis of RA target achievement against age demonstrated a strong effect of age upon phosphate control, with older patients being more likely to achieve target phosphate concentrations. Serum corrected calcium was relatively unaffected by age but better phosphate control was mirrored by better compliance with the KDOQI calcium × phosphate product standard: PTH control was also better amongst older patients.

- Strong evidence of an effect of age on achieved albumin concentration is presented. Given the many caveats to the interpretation of serum albumin data that the Registry reports have explored, it is felt that continued presentation of albumin achievement

data in the Registry annual report is of limited value: ***unless there are strong calls from the renal community with an opposing viewpoint, this data will not be published in next year's report.*** Albumin data will still be collected and used for case-mix adjustment in survival analyses in other sections of the report.

- This report has attempted an analysis of aluminium testing practices in renal units. Although there are concerns about the completeness of the data, there is some evidence to suggest that compliance with RA Standards with respect to aluminium monitoring is poor, with some renal centres possibly having abandoned routine monitoring of aluminium in dialysis patients or doing it on an annual rather than quarterly basis. It is suggested that the role of aluminium monitoring in dialysis patients needs re-evaluation.

Introduction

This Chapter contains information relating calcium, phosphate and PTH control to the RA Standards, and also presents data on the achievement of calcium × phosphate product in relation to the North American KDOQI guidelines. For calcium, phosphate and PTH no separate RA Standards are set for differing dialysis modalities. Nevertheless, differing modalities offer different challenges in achieving metabolic control. Where appropriate, data for HD and PD are shown separately in addition to/instead of the pooled dialysis data.

Data on transplant patients is included here for the first time. Although the RA has not set specific biochemical standards for calcium and phosphate concentrations in transplant patients they have suggested that PTH concentrations should be less than four times the upper limit of normal after transplantation. Calcium and phosphate have been audited here against the same standards that are applied to dialysis patients.

Last year an attempt was undertaken to assess the contribution of inter-laboratory variation to between-centre performance. Although the analysis was fairly crude, little evidence was found to suggest that laboratory variation influences Registry data for serum phosphate or calcium although there was an influence on serum albumin. The current status of analytical methodology did not allow an accurate assessment of the contribution of inter-laboratory variability to between-centre PTH differences. There is no reason to suspect that this situation has changed and so this analysis has not been repeated for this year's report.

Increasingly dialysis and transplantation are offered to older people and patients over 65 years old represent the majority of UK patients receiving renal replacement therapy. This year analyses have been undertaken to assess the effect of age upon RA Standard achievement.

Monitoring of serum aluminium concentration remains routine clinical practice amongst dialysis patients and there are RA Standards addressing this issue. Although the Registry has collected this data it has not previously been reported. This year completeness of aluminium data and its compliance with the RA Standards was surveyed.

As in previous years the number preceding the centre name in all the figures indicates the percentage of missing data for that centre.

Serum phosphate

The RA Standard states:

> ***Serum phosphate (measured before a dialysis session in HD patients) should be below 1.8 mmol/L.***

The RA sets no standard for the lower limit of serum phosphate in contrast to the KDOQI guidelines[2] which set a lower limit of 1.13 mmol/L; the KDOQI upper limit is 1.78 mmol/L, consistent with the RA Standard.

Data completeness

The completeness of data by modality is shown in Table 10.1 for each centre.

Achievement of serum phosphate

Serum phosphate control amongst dialysis patients remains poor with 63% of patients

Table 10.1: Data completeness by centre for serum phosphate

	HD	PD	Tx
Bangor	100	100	n/a
Barts	n/a	n/a	n/a
Basildon	97	100	68
Bradford	100	100	96
Brighton	74	99	75
Bristol	100	100	99
Cambridge	63	94	75
Carlisle	93	93	82
Carshalton	87	98	88
Chelmsford	99	97	60
Clwyd	91	100	100
Coventry	100	91	83
Cardiff	95	97	96
Derby	91	93	36
Dorset	100	100	64
Dudley	84	100	91
Exeter	98	100	92
Gloucester	98	92	96
Guys	92	99	88
H&CX	99	99	95
Heartlands	94	100	75
Hull	97	98	90
Ipswich	100	97	98
Kings	95	90	91
Leeds	98	98	91
Leicester	98	98	91
Liverpool	95	96	93
ManWst	68	98	71
Middlesbrough	96	100	94
Newcastle	100	98	96
Norwich	99	100	93
Nottingham	97	100	89
Oxford	99	99	93
Plymouth	91	100	89
Portsmouth	100	93	88
Preston	99	100	66
QEH	95	98	94
Reading	97	100	97
Sheffield	100	99	99
Shrewsbury	99	100	94
Stevenage	94	98	68
Southend	99	95	90
Sunderland	95	100	98
Swansea	98	99	92
Truro	100	96	95
Wirral	n/a	n/a	n/a
Wolverhampton	100	100	93
Wrexham	83	95	96
York	92	100	93
England	90	91	84
Wales	89	89	95
England & Wales	90	91	85

overall achieving the RA Standard. This should be interpreted in the light of the KDOQI guidelines, where it is reported that <30% of the dialysis population maintain serum phosphate concentrations within the target range. In general, the phosphate control is a little better on peritoneal dialysis, where 69% of patients achieved this standard, compared to haemodialysis where 61% had serum phosphate <1.8 mmol/L (Figures 10.1 and 10.2). Haemodialysis has limited efficacy in phosphate control due to the high distribution volume which leads to rapid rebound of serum phosphate after dialysis[3].

There is reasonable evidence of year-on-year improvements in phosphate control with this year's data representing a very slight improvement over the previous year, continuing the general improvement in phosphate standard achievement reported in last year's Registry report[4] (Figures 10.3 and 10.4).

The variation between units is wide (Figures 10.1 and 10.2). For both HD ($\chi^2 = 313$, $p < 0.001$) and PD ($\chi^2 = 108$, $p < 0.001$), the percentage of patients with a serum phosphate below 1.8 mmol/L differed significantly between centres. Analysis in last year's Registry report suggests that this is unrelated to differing laboratory bias[4].

For both HD ($\chi^2 = 19.1$, $p < 0.0001$, Figure 10.5) and PD ($\chi^2 = 10.9$, $p < 0.0001$, Figure 10.6) patients there was a marked increase in the percentage of patients achieving the RA target with respect to phosphate control with increasing age. This could in part reflect an effect of ageing independent of the presence of kidney disease, since lower serum phosphate concentrations have previously been reported in older healthy males (eg 50th percentile in males aged 68–71 years is 1.00 mmol/L compared to 1.09 mmol/L in males aged 25–34 years), with no change seen in females[5,6]. However, additional mechanisms must be involved, for example improved compliance with dietary or pharmacological control of serum phosphate in older patients, as the changes in median phosphate observed with ageing are far greater amongst particularly haemodialysis patients, than in the background population (Figures 10.7 and 10.8). It is also important to recognise that as there is no UK recommended lower limit for the

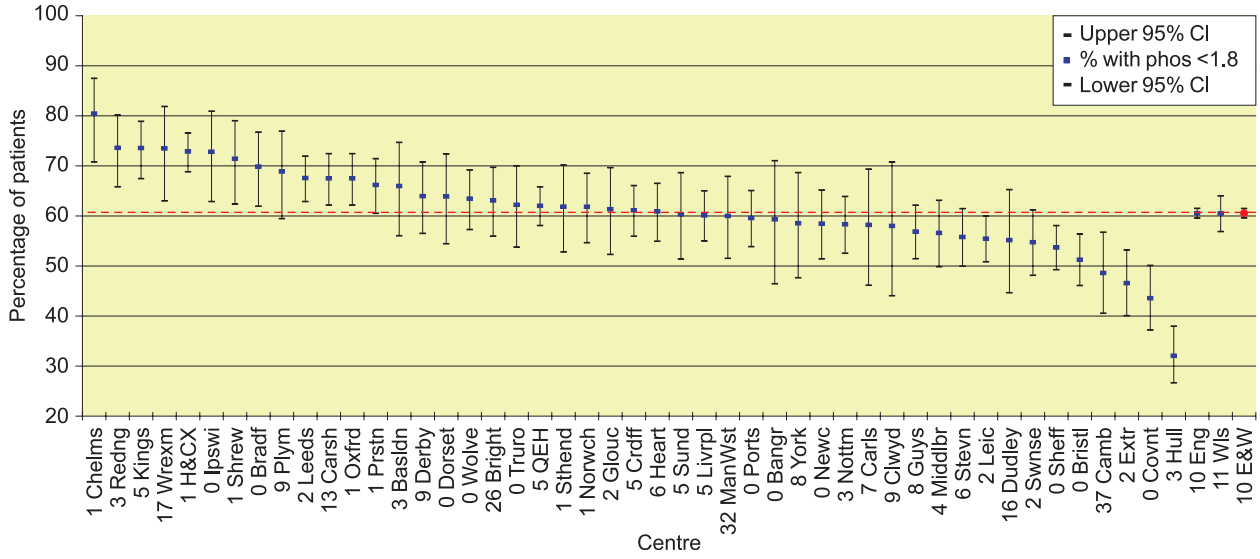

Figure 10.1: Percentage of HD patients in RA range for serum phosphate

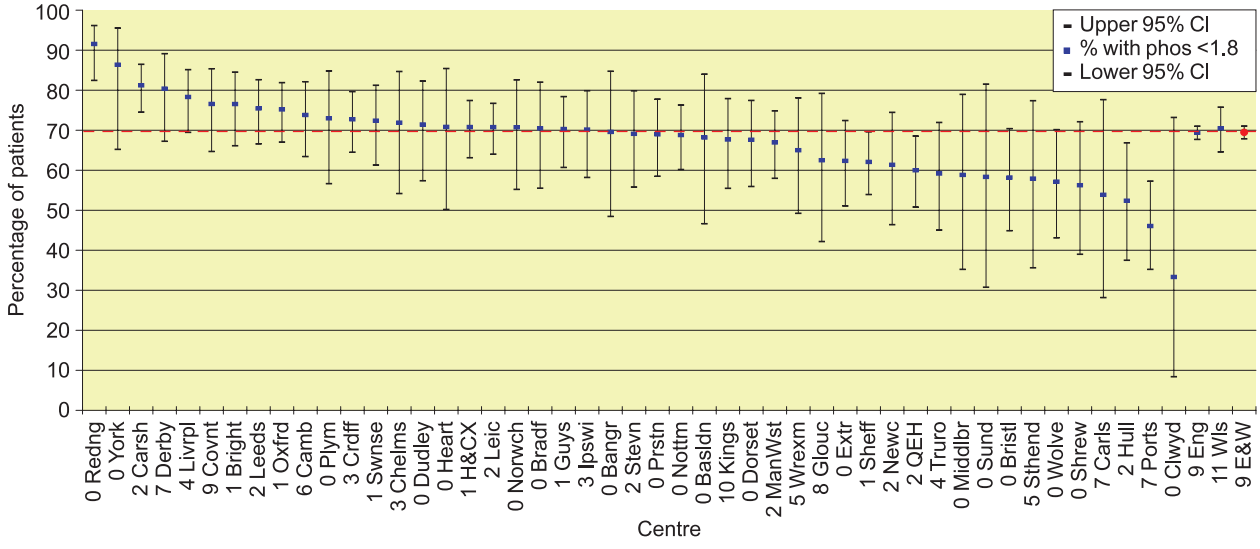

Figure 10.2: Percentage of PD patients in RA range for serum phosphate

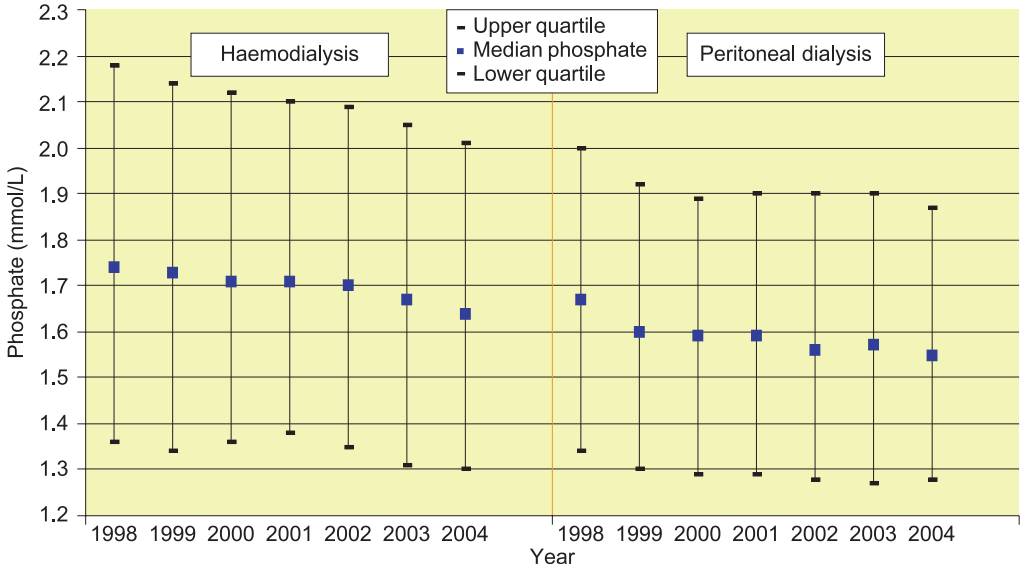

Figure 10.3: Change in median serum phosphate, 1998–2004

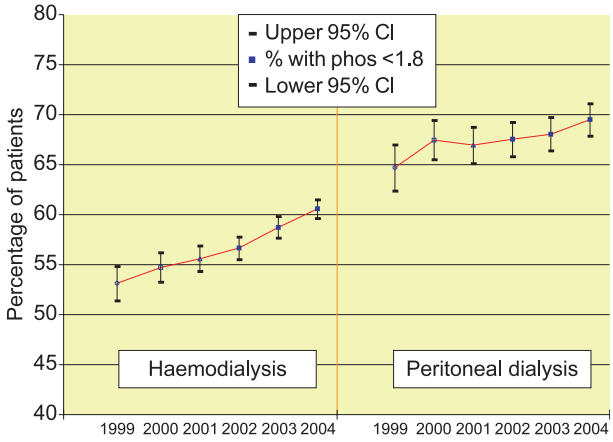

Figure 10.4: Change in percentage of patients achieving serum phosphate <1.8 mmol/L, 1999–2004

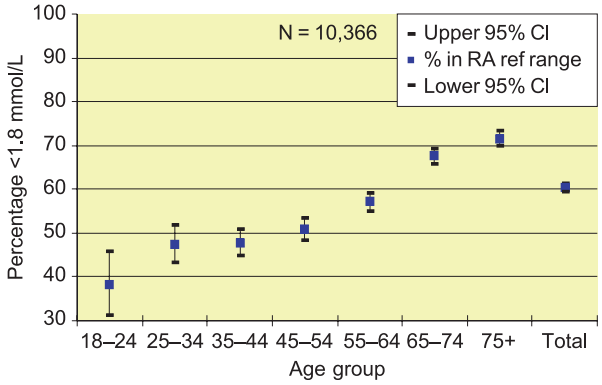

Figure 10.5: Variation in achievement of the RA phosphate standard by age group: HD

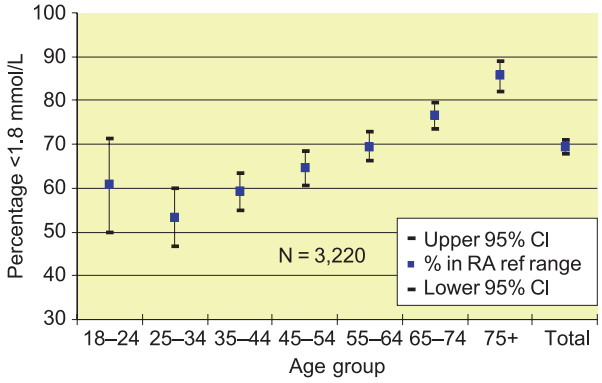

Figure 10.6: Variation in achievement of the RA phosphate standard by age group: PD

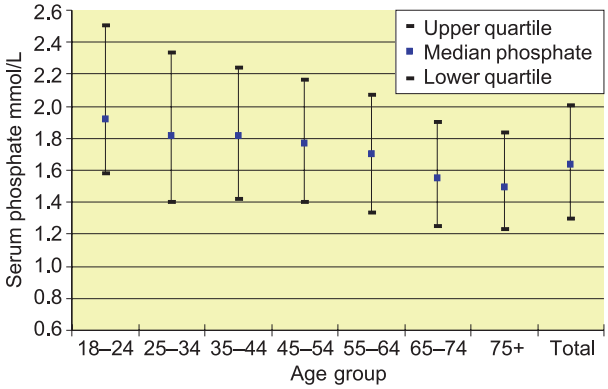

Figure 10.7: Median serum phosphate by age group: haemodialysis

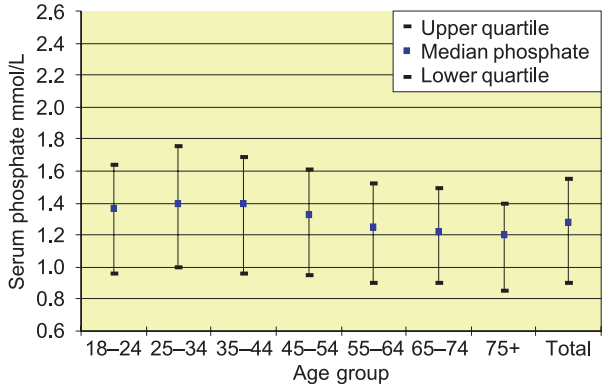

Figure 10.8: Median serum phosphate by age group: peritoneal dialysis

phosphate standard and that 'improved compliance' may reflect inadequate protein intake in the elderly. The authors are unaware of this effect having been reported before or of evidence to support an explanatory mechanism.

Amongst patients who had received a transplant, phosphate control was good (median 1.01 mmol/L, mean 5th–95th centiles 0.66–1.50 mmol/L, Figure 10.9) with 99% of patients (mean range between units 95% to 100%) achieving the target. There was no evidence of significant variation between units ($\chi^2 = 47$, $p = 0.4457$) but there was a statistically significant ($\chi^2 = 3.2$, $p < 0.005$), although minimal, influence of age (data not shown).

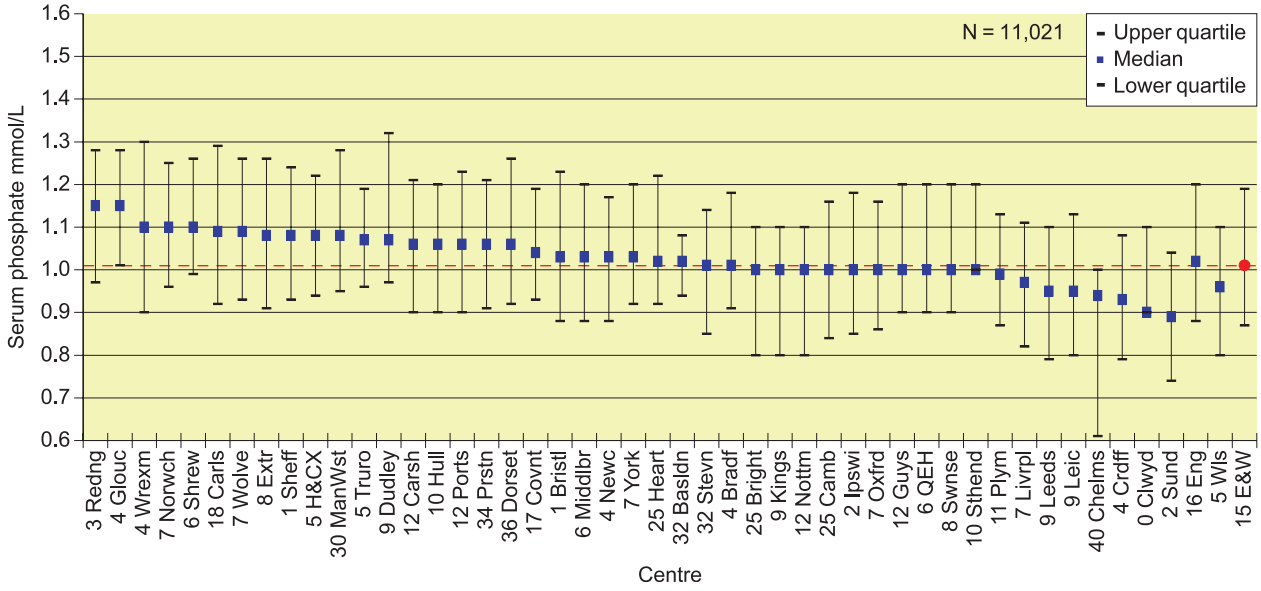

Figure 10.9: Median serum phosphate concentration by centre in transplant patients

Serum calcium

The RA Standard states:

> ***Serum calcium, adjusted for albumin concentration, should be between 2.2 and 2.6 mmol/L, in HD (pre-dialysis sample) and in PD patients.***

Comparative audit in this area remains difficult due to differences in analytical methods between units, (and even between satellite units managed by one clinical team), different mathematical methods being applied to correct serum calcium for serum albumin concentration and different methods in analysing serum albumin (see the Registry reports 1999–2003). However, as discussed in previous Registry reports, since nephrologists in each unit will be making clinical decisions based on their local corrected calcium results, these data are in some sense the most valid and this data has been chosen for illustration. Some units provide data already corrected for albumin concentration and these are analysed directly; uncorrected calcium data provided by some units is corrected using a formula in widespread use[7]:

$$\text{Corrected calcium} = \text{uncorrected calcium} + [(40 - \text{albumin}) \times 0.02]$$

Data completeness

The completeness of data by modality is shown in Table 10.2 for each centre.

Achievement of serum calcium

The median corrected calcium was 2.39 mmol/L for HD patients and 2.42 mmol/L for PD patients with 74% of both HD and PD patients achieving a concentration within the RA target range (Figure 10.10). There has been a general trend towards improved performance over the period 1998–2004 (Figure 10.11). A sub-analysis including only those individual patients that have remained on dialysis throughout that entire period confirmed that this is a true effect and not a consequence of the inclusion of additional renal centres to the Registry database over that period (data not shown). The variation between units is wide and as discussed in last years report, seems unlikely to be related to laboratory variation[4]. For both HD ($\chi^2 = 610$, $p < 0.001$) and PD ($\chi^2 = 337$, $p < 0.001$) modalities, the percentage of patients with a serum corrected calcium within the RA target range differed significantly between centres.

The percentage of patients with serum corrected calcium of 2.2 to 2.6 mmol/L differed significantly between age groups for HD ($\chi^2 = 5.7$, $p < 0.001$, Figure 10.12) but not for PD ($\chi^2 = 0.4$, $p = 0.706$, data not shown) although even amongst HD patients the effect was slight. In the general population, marked changes with age in serum uncorrected total calcium concentrations have not generally been observed[5,8].

Table 10.2: Data completeness by centre for corrected calcium

	HD	PD	Tx		HD	PD	Tx
Bangor	87	96	n/a	Liverpool	99	98	93
Barts	n/a	n/a	n/a	ManWst	69	98	85
Basildon	97	96	92	Middlesbrough	96	100	94
Bradford	100	100	98	Newcastle	100	98	96
Brighton	74	99	76	Norwich	99	100	93
Bristol	100	100	99	Nottingham	100	100	88
Cambridge	63	96	75	Oxford	99	99	93
Carlisle	93	93	87	Plymouth	99	100	92
Carshalton	87	98	88	Ports	100	95	90
Chelmsford	99	97	80	Preston	99	100	89
Clwyd	91	100	100	QEH	96	98	93
Coventry	100	91	83	Reading	99	100	97
Cardiff	96	100	98	Sheffield	100	99	99
Derby	89	93	100	Shrewsbury	99	100	94
Dorset	99	100	92	Stevenage	95	98	68
Dudley	84	100	92	Southend	99	100	85
Exeter	98	100	92	Sunderland	95	100	98
Gloucester	98	92	97	Swansea	97	97	97
Guys	92	99	88	Truro	100	96	95
H&CX	99	99	96	Wirral	n/a	n/a	n/a
Heartlands	94	100	80	Wolverhampton	100	100	99
Hull	97	98	90	Wrexham	80	93	95
Ipswich	100	97	98	York	92	100	56
Kings	95	90	91	England	90	91	86
Leeds	98	97	90	Wales	92	98	97
Leicester	98	98	89	England & Wales	90	92	86

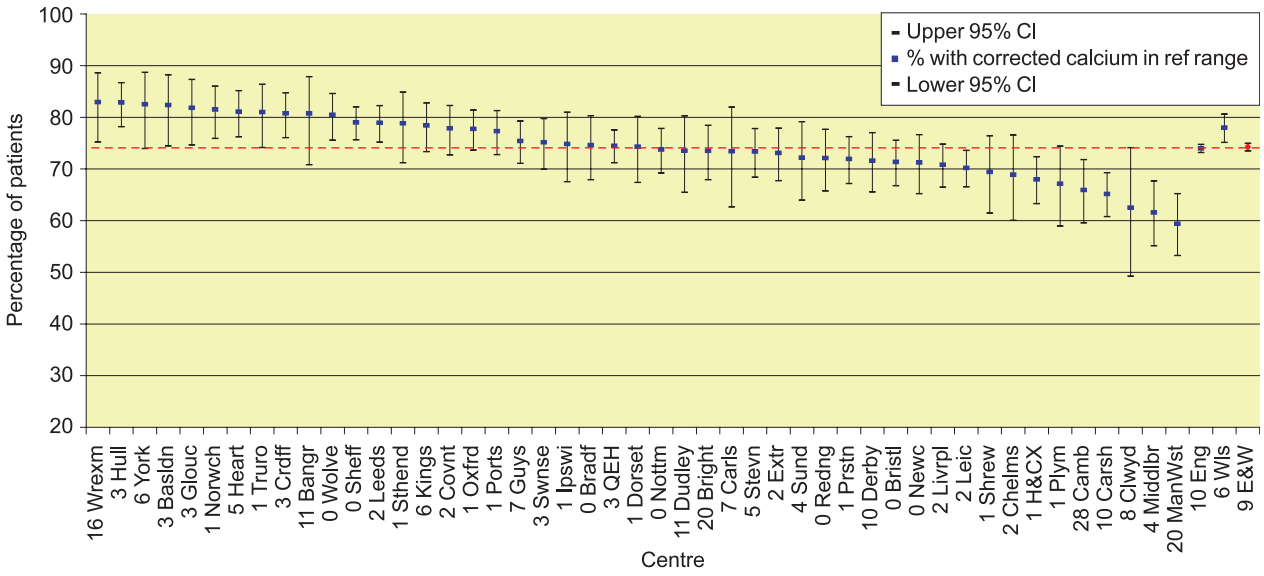

Figure 10.10: Percentage of patients with corrected calcium within 2.2 to 2.6 mmol/L: dialysis

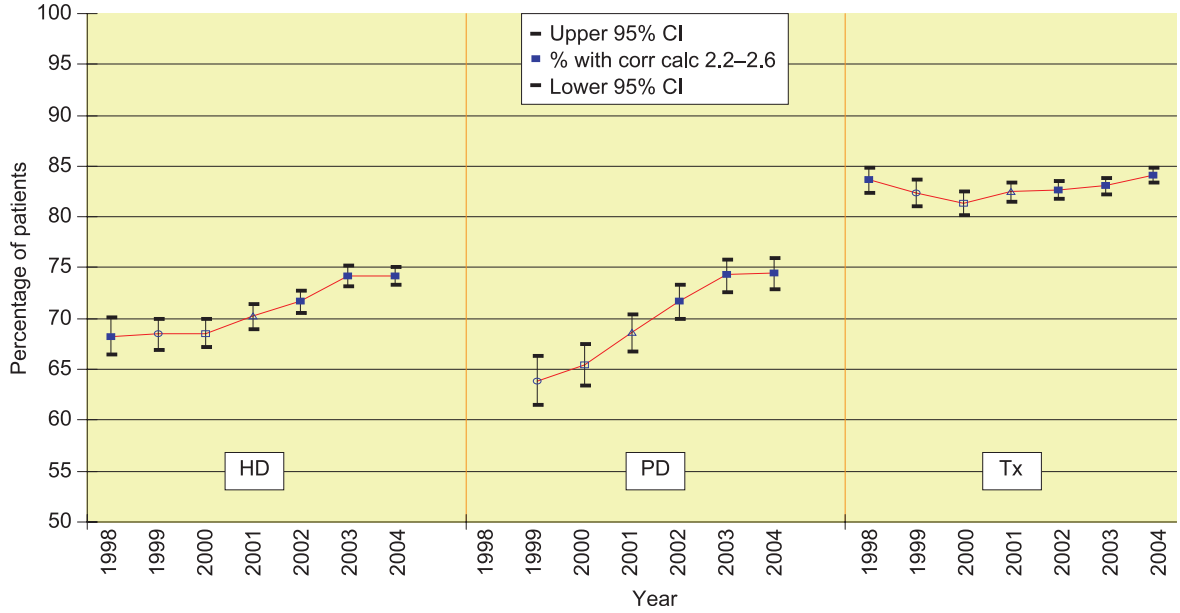

Figure 10.11: Change in percentage of patients achieving serum corrected calcium within the RA target range, 1998–2004

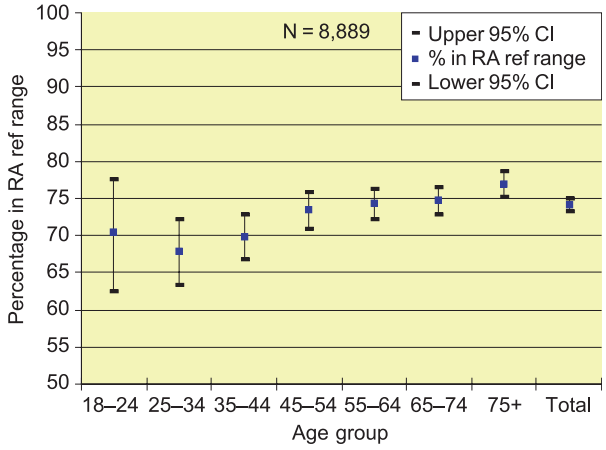

Figure 10.12: Percentage of patients achieving corrected calcium within the RA target range by age band: HD

Achievement of the calcium target amongst patients who had received a transplant was better than that amongst dialysis patients, with 84% of transplant patients achieving corrected calcium concentrations within the target range (Figure 10.13). However, there was a tendency to hypercalcaemia in some centres (Figure 10.14). The percentage of transplant patients with a serum corrected calcium within the RA target range differed significantly between centres ($\chi^2 = 1042$, $p < 0.001$).

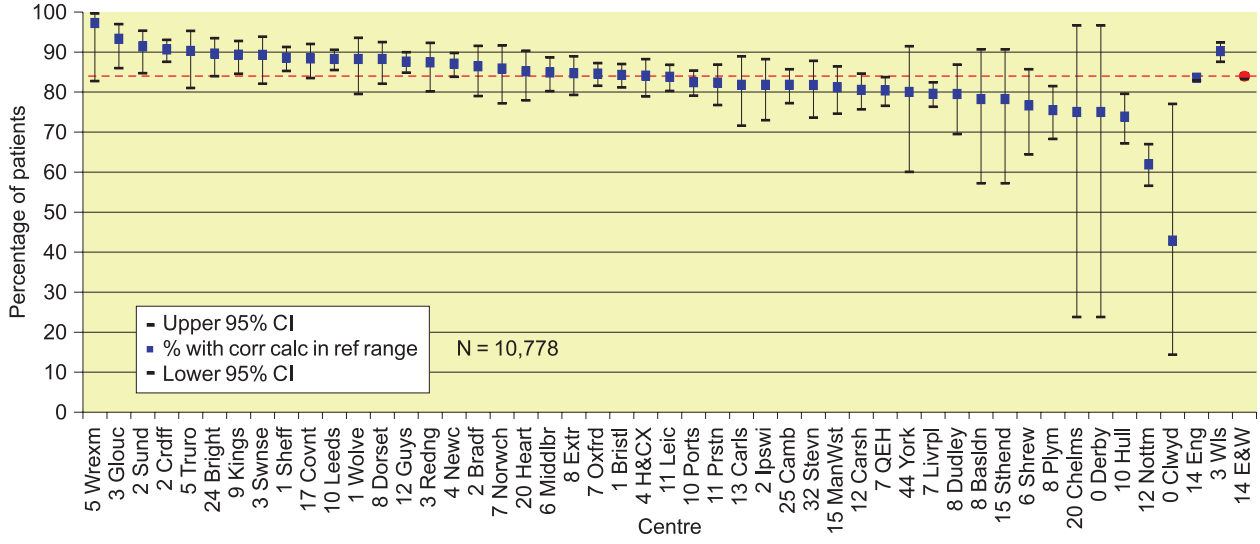

Figure 10.13: Percentage of patients with corrected calcium within 2.2 to 2.6 mmol/L: transplant

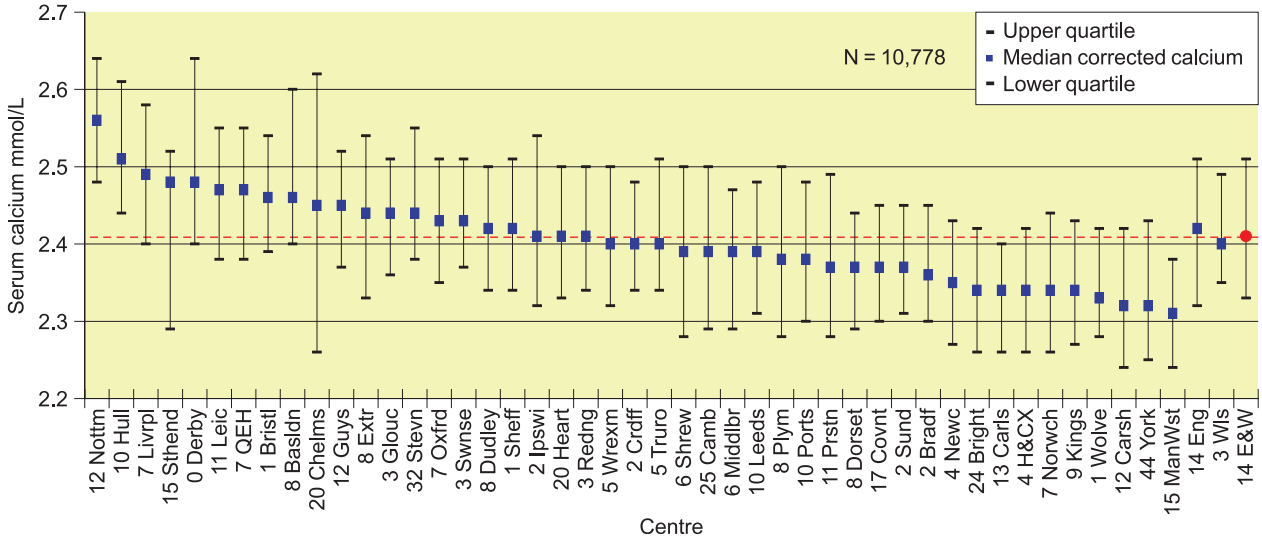

Figure 10.14: Median serum calcium concentration by centre in transplant patients

Serum calcium phosphate product

The RA has no standard for the serum calcium × phosphate product, but the KDOQI guidelines[2] recommend the product should be less than 4.4 $mmol^2/L^2$ (=55 mg^2/dl^2). More than half (66%) of patients achieve this but the range between units is wide (38–83%, Figure 10.15). This is similar to the 67% (range 44–82%) of patients that achieved this standard in the last Registry report[4]. Control was better in PD patients with 71% (range 47–89%) of patients achieving the standard, compared to 64% (range 35–85%) of patients on HD (Figures 10.16 and 10.17). The variation between units was significant for both HD ($\chi^2 = 360$, $p < 0.001$) and PD ($\chi^2 = 104$, $p < 0.001$) modalities.

Amongst patients who had received a transplant, 99% (mean range between units 95–100%) achieved the KDOQI guideline target; there was no evidence of significant variation between units ($\chi^2 = 60$, $p = 0.075$).

In keeping with the age-related changes observed in phosphate achievement, the percentage of patients achieving the KDOQI calcium × phosphate targets increased with

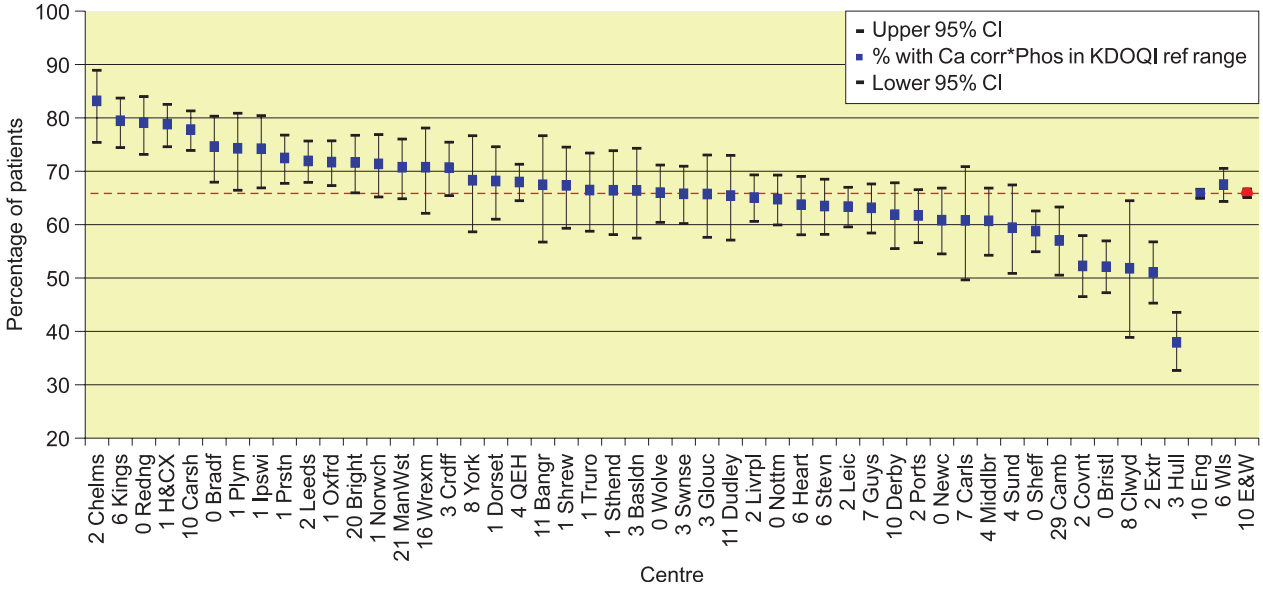

Figure 10.15: Calcium phosphate product in dialysis patients: percentage achieving KDOQI target

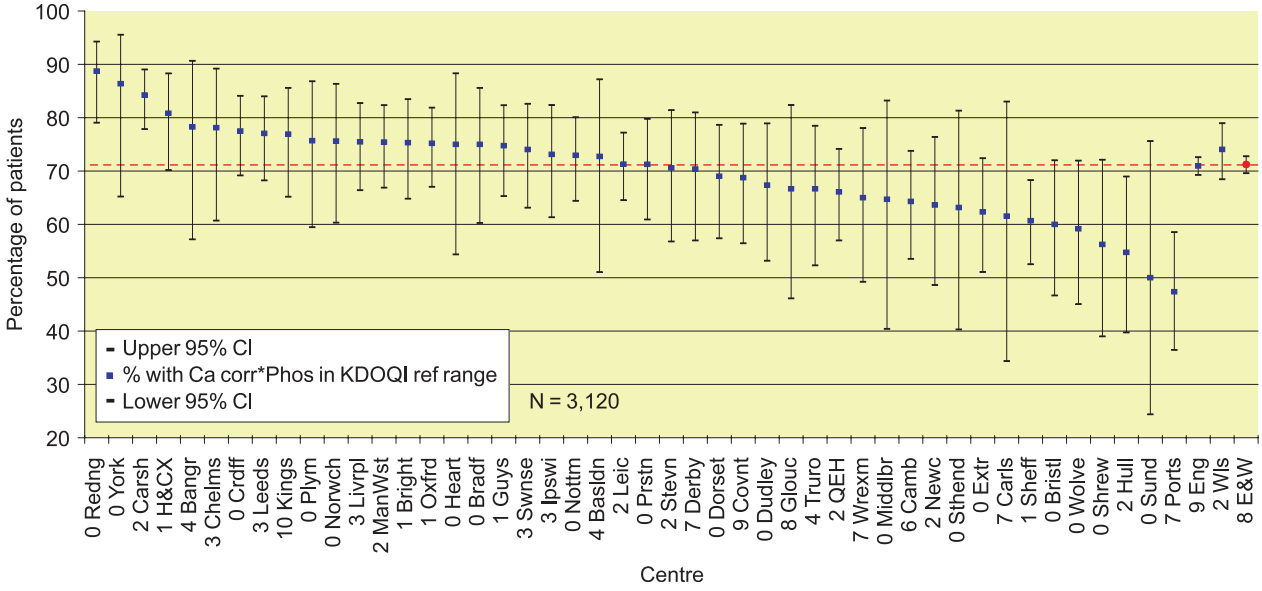

Figure 10.16: Percentage of PD patients with calcium phosphate product in the KDOQI reference range

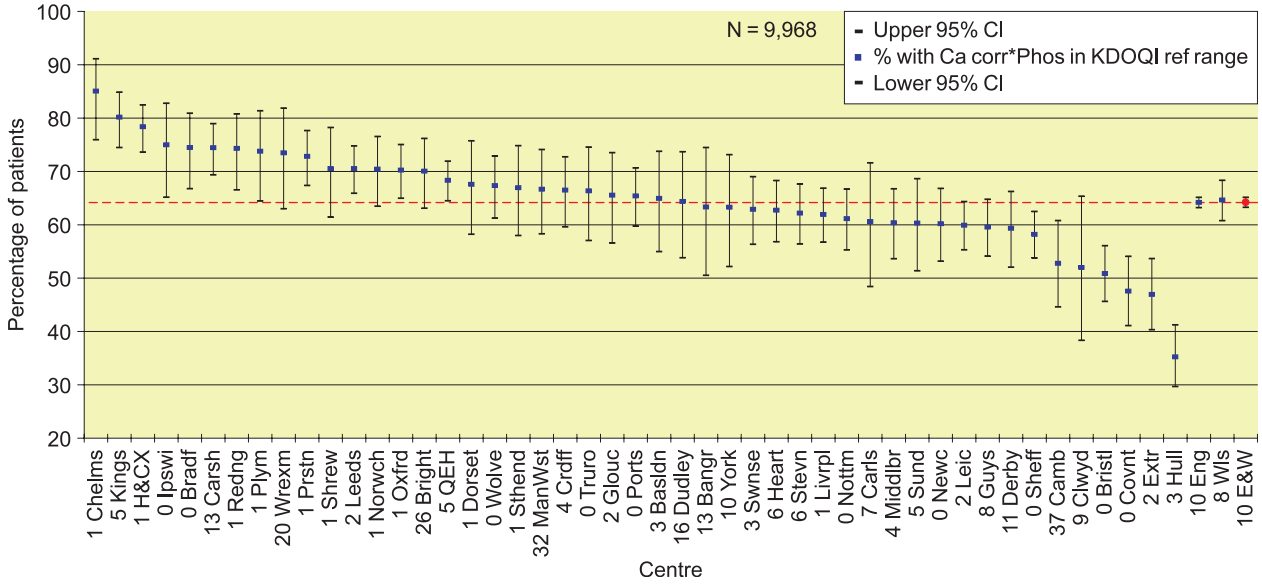

Figure 10.17: Percentage of HD patients with calcium phosphate product in the KDOQI reference range

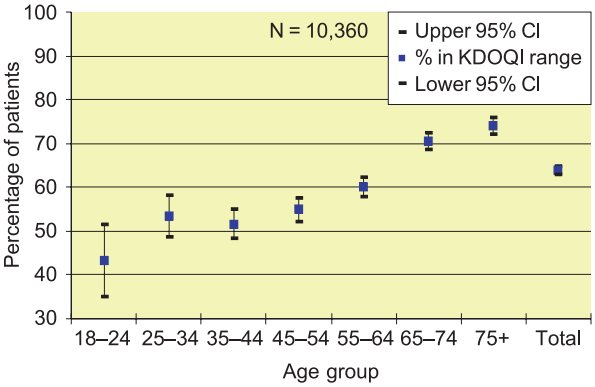

Figure 10.18: Percentage of patients achieving KDOQI calcium × phosphate product by age band: HD

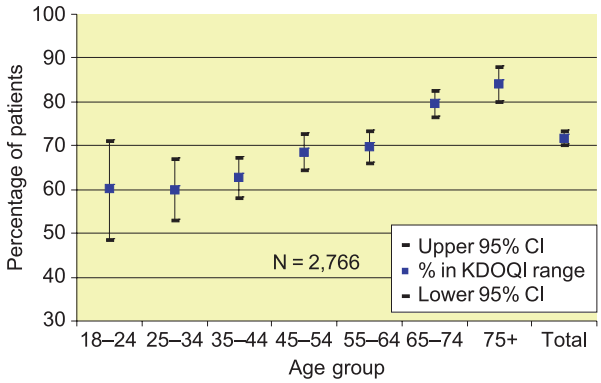

Figure 10.19: Percentage of patients achieving KDOQI calcium × phosphate product by age band: PD

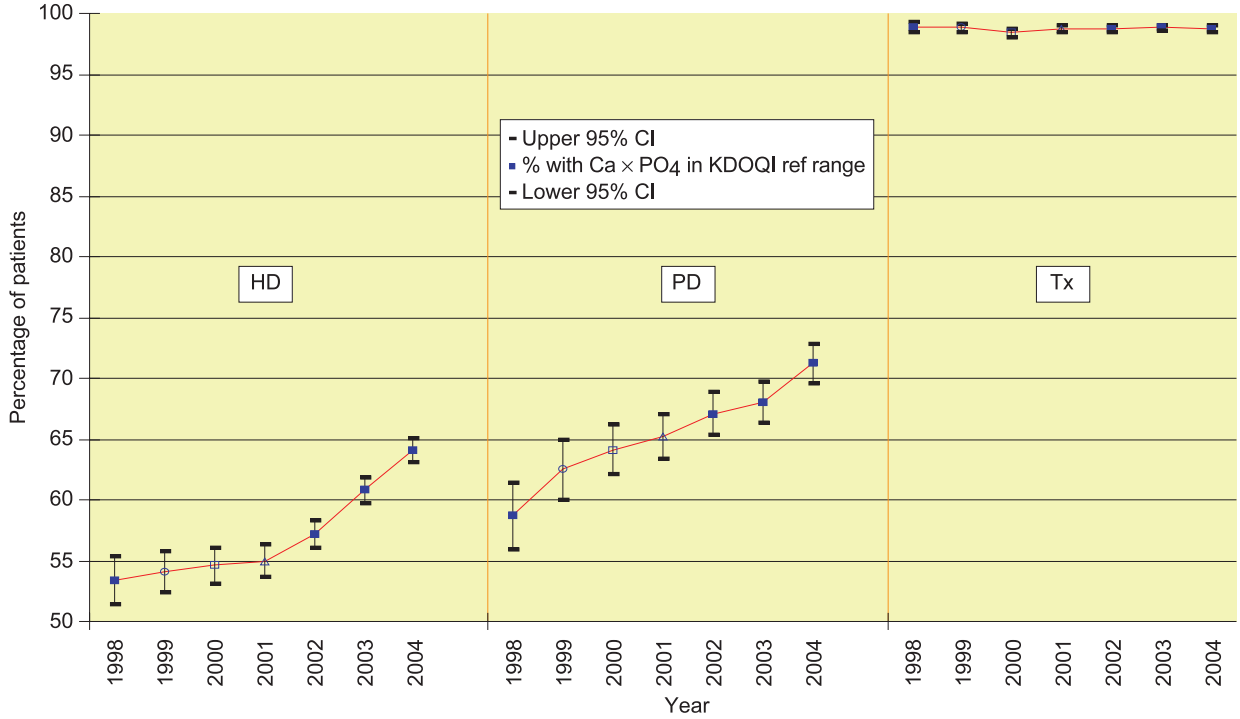

Figure 10.20: Change in percentage of patients achieving the KDOQI calcium × phosphate target, 1998–2004

increasing age in HD ($\chi^2 = 18.6$, $p < 0.0001$), PD ($\chi^2 = 9.3$, $p < 0.0001$) (Figures 10.18 and 10.19) and transplant ($\chi^2 = 3.4$, $p = 0.0006$) patients.

In both modalities, analysis of data from all prevalent dialysis patients within a particular year demonstrates a gradual improvement in achievement of the KDOQI calcium × phosphate target over the period 1998 to 2004 (Figure 10.20). As noted for corrected calcium above, a longitudinal sub-analysis including only those individual patients that have remained on dialysis throughout that entire period confirmed that this is a true effect and not a consequence of the inclusion of additional renal centres to the Registry database over that period (data not shown).

Serum parathyroid hormone

The RA Standard states:

> ***Parathyroid hormone (PTH) concentration should be less than four times the upper limit of normal of the assay used in patients being managed for chronic renal failure or after transplantation and in patients who have been on HD or PD for longer than three months.***

Comparison of serum PTH values from different units is difficult due to the variety of methods and reference ranges in use. Last years report (Chapter 9) discusses these issues in some detail, together with an attempt to assess the influences of laboratory bias and differential reactivities with the PTH 7-84 fragment known to accumulate in uraemia[4]. To enable some form of comparative audit, the Registry has expressed all results in pmol/L, and chosen an upper limit of four times the median upper lab value; this equates to 32 pmol/L.

Data completeness

The completeness of data by modality is shown in Table 10.3 for each centre.

Achievement of serum iPTH

The median PTH for all dialysis patients (22 pmol/L) lies well within the standard although the range of medians was wide (9 to 35 pmol/L, Figure 10.21). Median PTH appeared to be slightly higher overall amongst PD (23 pmol/L, inter-quartile range 11–46 pmol/L, range of medians 12 to 48 pmol/L) patients compared to HD (21 pmol/L, inter-quartile range 9–46 pmol/L, range of medians 4 to 36 pmol/L) patients. Overall, 63% of dialysis patients (62%

Table 10.3: Data completeness by centre for PTH

	HD	PD	Tx		HD	PD	Tx
Bangor	100	83	n/a	Liverpool	82	86	43
Barts	n/a	n/a	n/a	ManWst	64	92	67
Basildon	97	100	56	Middlesbrough	85	59	9
Bradford	98	95	52	Newcastle	97	98	30
Brighton	58	83	13	Norwich	94	68	11
Bristol	94	100	84	Nottingham	95	93	72
Cambridge	57	90	11	Oxford	83	86	29
Carlisle	92	86	10	Plymouth	85	78	33
Carshalton	59	72	8	Ports	93	45	7
Chelmsford	95	88	20	Preston	97	99	37
Clwyd	80	100	43	QEH	69	74	53
Coventry	83	76	21	Reading	97	96	27
Cardiff	84	96	18	Sheffield	96	87	9
Derby	8	7	36	Stevenage	93	93	37
Dorset	90	92	37	Southend	89	95	3
Dudley	n/a	n/a	n/a	Sunderland	96	100	98
Exeter	96	100	25	Swansea	55	88	37
Gloucester	97	88	27	Truro	97	94	32
Guys	76	96	18	Wirral	n/a	n/a	n/a
H&CX	51	90	35	Wolverhampton	97	100	56
Heartlands	79	79	7	Wrexham	66	81	60
Hull	78	81	17	York	91	100	22
Ipswich	92	97	30	England	77	78	32
Kings	91	86	22	Wales	75	90	24
Leeds	97	97	30	England & Wales	77	79	31
Leicester	84	85	58				

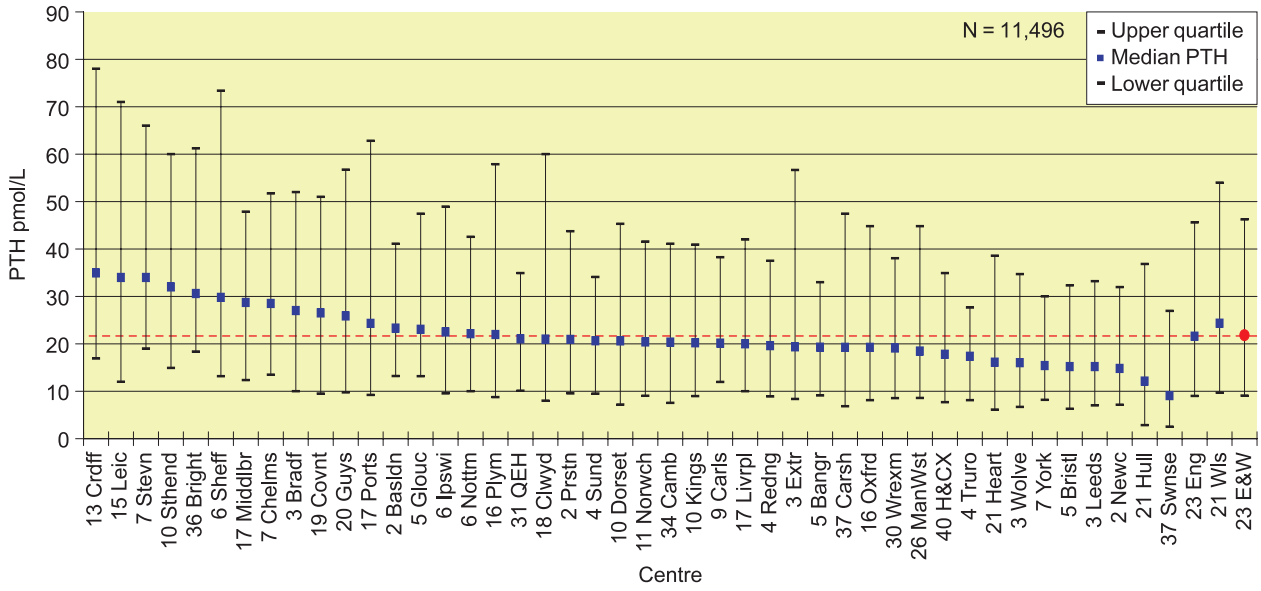

Figure 10.21: Median PTH by centre; dialysis

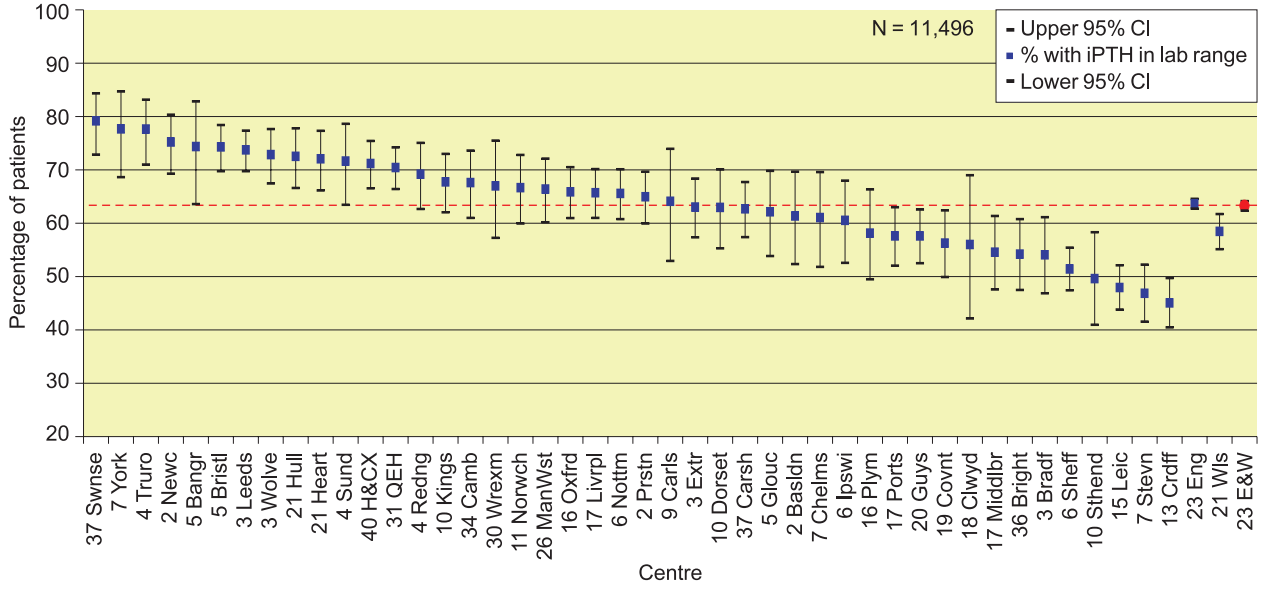

Figure 10.22: Percentage of patients with PTH <32 pmol/L; dialysis

PD; 64% HD) achieved the RA Standard, but the spread of data was remarkable, ranging from 45 to 79% compliance with the standard (Figure 10.22).

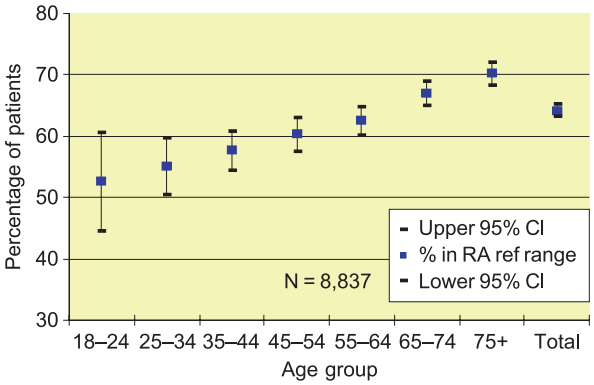

Figure 10.23: Percentage of patients achieving PTH <32 pmol/L by age band: HD

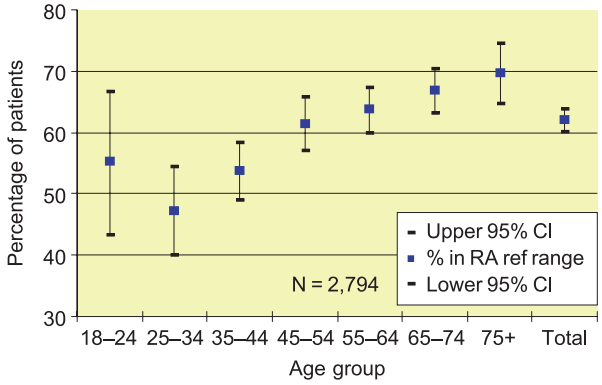

Figure 10.24: Percentage of patients achieving PTH <32 pmol/L by age band: PD

For both HD ($\chi^2 = 9.7$, $p < 0.0001$, Figure 10.23) and PD ($\chi^2 = 6.1$, $p < 0.0001$, Figure 10.24) patients the percentage achieving the RA target with respect to PTH increased with increasing age. This is unlikely to be an effect of ageing per se, since higher serum PTH concentrations have previously been reported in healthy older individuals[5]. This data could reflect improved phosphate control with increasing age as noted above.

Amongst patients who had received a transplant, median PTH is above the normal laboratory reference range (median 10 pmol/L, inter-quartile range 6–18 pmol/L), although the majority of patients (89%, range of centre means 70–100%) achieve the RA target; there was evidence of significant variation between units ($\chi^2 = 428$, $p < 0.0001$) but no evidence ($\chi^2 = 0.7$, $p = 0.47$) of an effect of age upon standard achievement.

Serum albumin

The RA has no standard for the serum albumin.

The RA Standards document[3] recognises the importance of serum albumin as a marker of outcome, but does not recommend setting an audit standard for serum albumin, predominantly due to lack of standardisation of albumin assays between laboratories. Serum albumin concentration is influenced significantly

by the dye used in the assay method; either bromocresol green (BCG) or bromocresol purple (BCP). As in previous years, for this report, centres have been separated both by methodology of albumin measurements and by dialysis modality. The difference between BCG and BCP methods in uraemic patients is widely known and has been discussed at length in previous reports.

Data completeness

The completeness of data by modality is shown in Table 10.4 for each centre.

Achievement of serum albumin

For centres supported by laboratories using BCG methods (n = 35) the median serum albumin was 39 g/L (range 36 to 41 g/L, Figure 10.25). As anticipated, centres using the BCP method (n = 12) generally had lower albumin concentrations (median 33 g/L, range 32 to 34 g/L, Figure 10.26). Overall, 75% of patients had serum albumin above 35 g/L for the BCG method (Figure 10.27) and 73% for BCP (Figure 10.28). For both BCG ($\chi^2 = 217$, $p < 0.001$) and BCP ($\chi^2 = 55$, $p < 0.001$) centres, the percentage of patients achieving serum albumin concentrations above these levels differed significantly between centres.

Serum albumin is generally lower in PD patients than in HD patients, predominantly due to peritoneal protein losses[9]. Furthermore, peritoneal albumin clearance increases with time on treatment due to increasing effective peritoneal surface area[10]. For centres supported by laboratories using BCG methods (n = 35) the median serum albumin was 35 g/L (range 30 to 39 g/L, Figure 10.29). As anticipated, centres using the BCP method (n = 12) generally had lower albumin concentrations (median 29 g/L, range 27 to 33 g/L, Figure 10.30). Overall, 55% of patients had serum albumin above 35 g/L for the BCG method (Figure 10.31) and 49% above 30 g/L for BCP (Figure 10.32), in both cases a slight fall in achievement compared to last years report. For both BCG ($\chi^2 = 240$, $p < 0.001$) and BCP ($\chi^2 = 80$, $p = 0.0015$) centres, the percentage of patients achieving serum albumin concentrations above these levels differed significantly between centres. The data indicate how difficult it is to keep serum

Table 10.4: Data completeness by centre for serum albumin

	HD	PD	Tx
Bangor	100	100	n/a
Barts	n/a	n/a	n/a
Basildon	97	100	92
Bradford	100	100	97
Brighton	75	99	78
Bristol	100	100	99
Cambridge	63	96	75
Carlisle	93	93	87
Carshalton	87	98	90
Chelmsford	99	97	80
Clwyd	89	100	100
Coventry	100	94	84
Cardiff	96	98	96
Derby	91	93	36
Dorset	100	100	93
Dudley	84	100	91
Exeter	98	100	92
Gloucester	98	92	96
Guys	91	99	84
H&CX	99	95	76
Heartlands	94	100	77
Hull	97	98	92
Ipswich	100	97	98
Kings	95	90	91
Leeds	99	98	93
Leicester	98	98	91
Liverpool	95	96	93
ManWst	69	98	71
Middlesbrough	96	100	95
Newcastle	100	98	96
Norwich	99	100	93
Nottingham	97	100	91
Oxford	99	99	93
Plymouth	91	100	93
Portsmouth	100	95	91
Preston	99	100	74
QEH	96	98	94
Reading	97	100	99
Sheffield	100	99	99
Shrewsbury	100	100	95
Stevenage	98	98	69
Southend	99	95	90
Sunderland	95	100	98
Swansea	98	99	94
Truro	100	98	99
Wirral	n/a	n/a	n/a
Wolverhampton	100	100	98
Wrexham	83	95	96
York	96	100	98

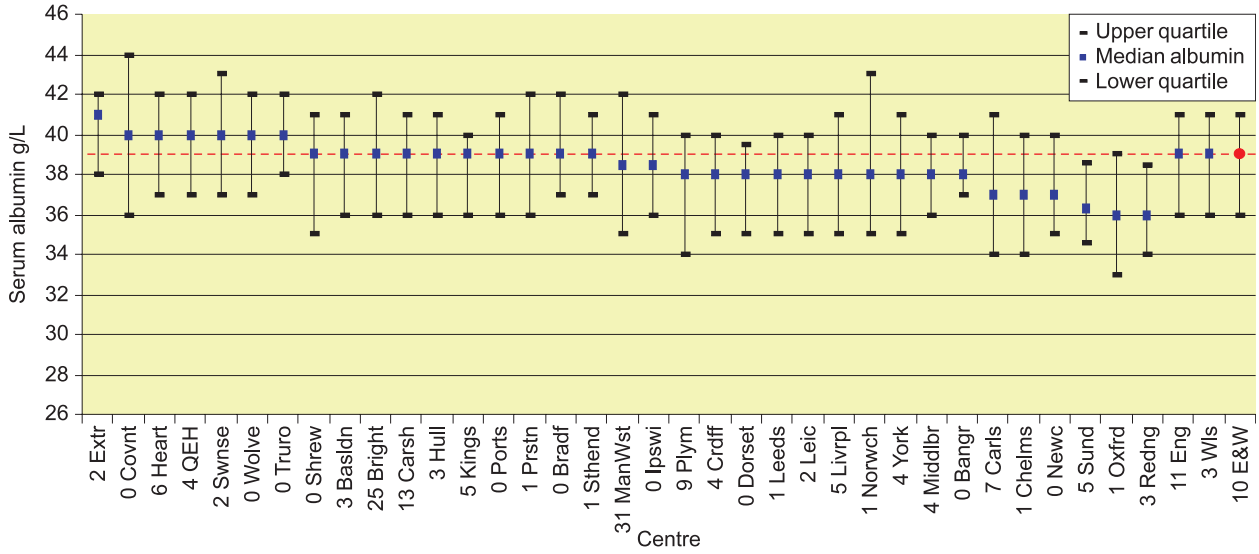

Figure 10.25: Median serum albumin in HD patients by centre: BCG method

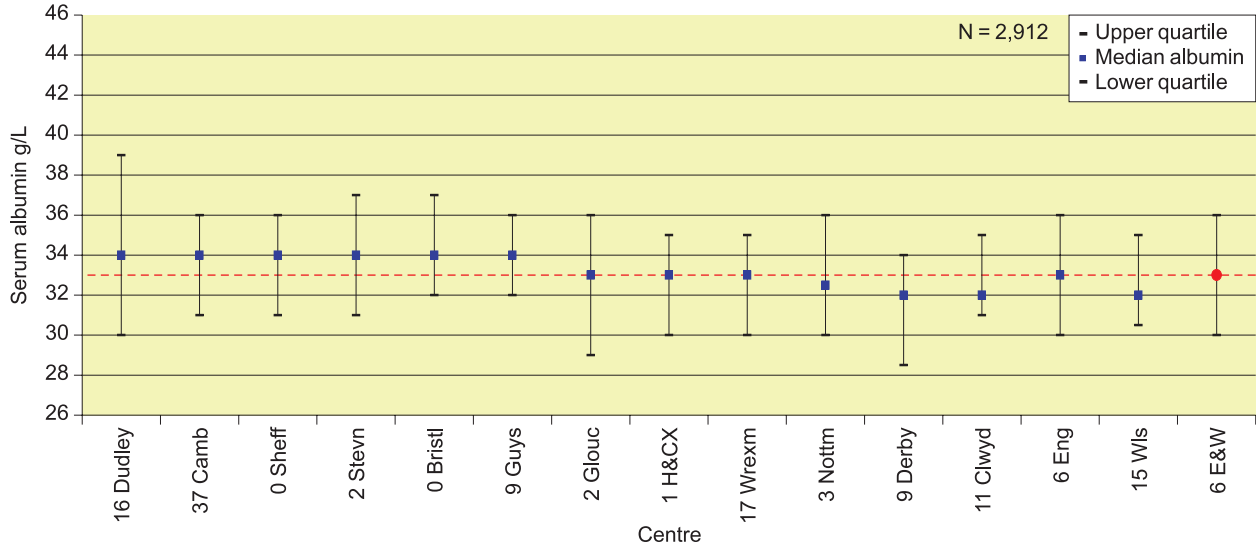

Figure 10.26: Median serum albumin in HD patients by centre: BCP method

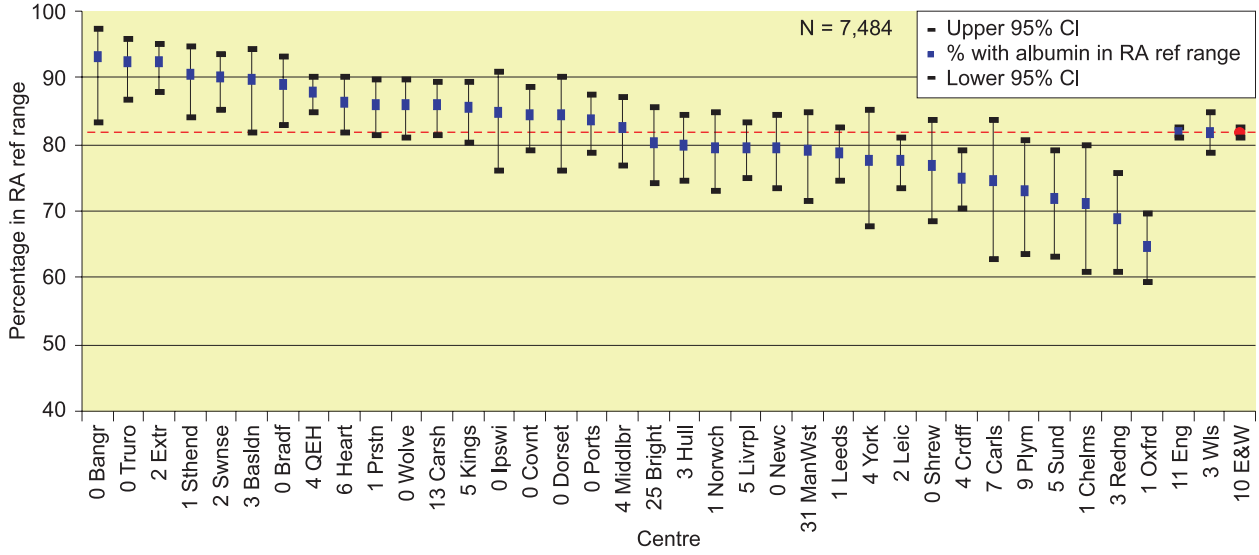

Figure 10.27: Percentage of HD patients by centre with serum albumin >35 g/L (BCG)

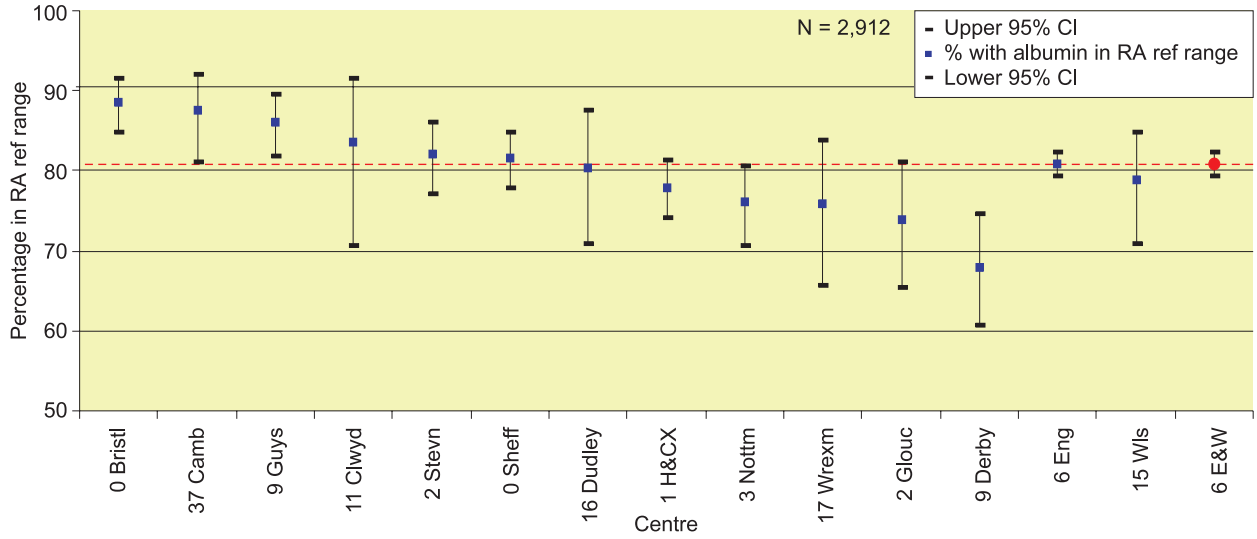

Figure 10.28: Percentage of HD patients by centre with serum albumin >30 g/L (BCP)

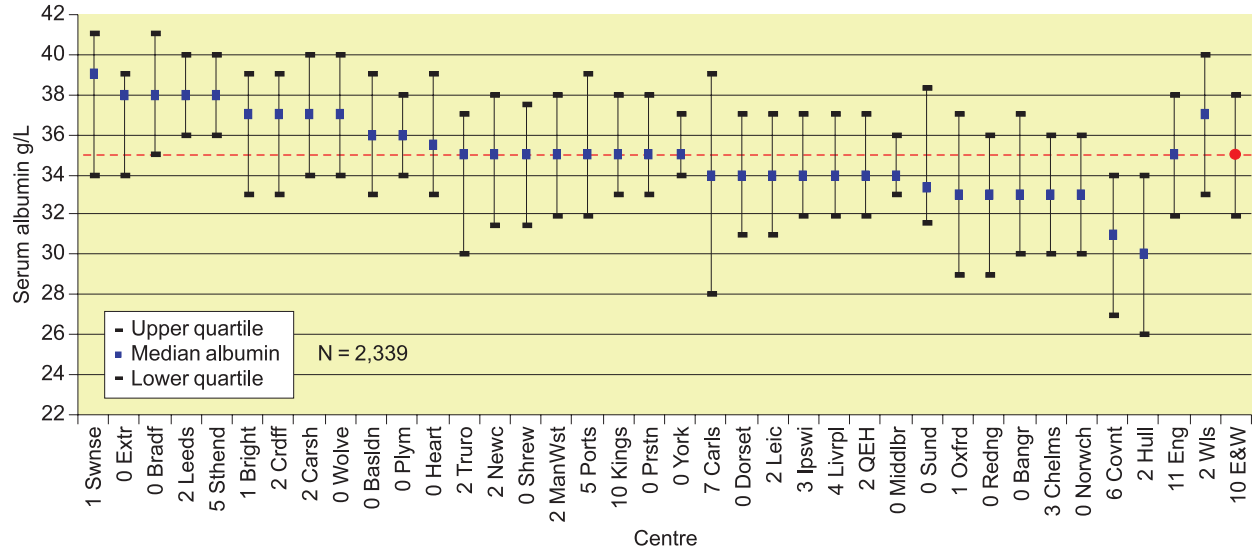

Figure 10.29: Median serum albumin in PD patients by centre: BCG method

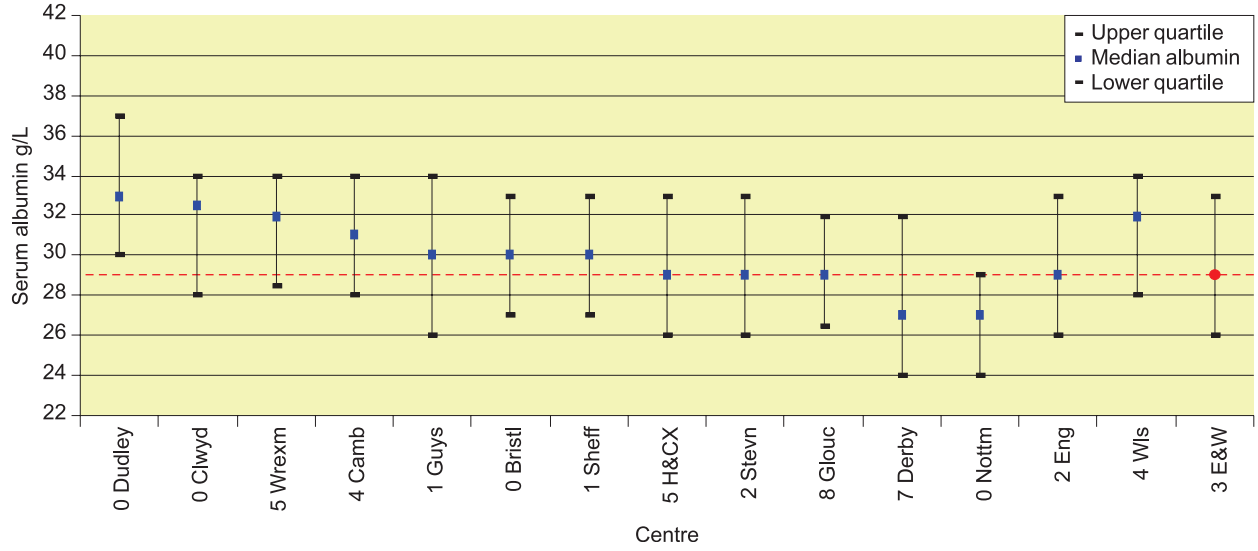

Figure 10.30: Median serum albumin in PD patients by centre: BCP method

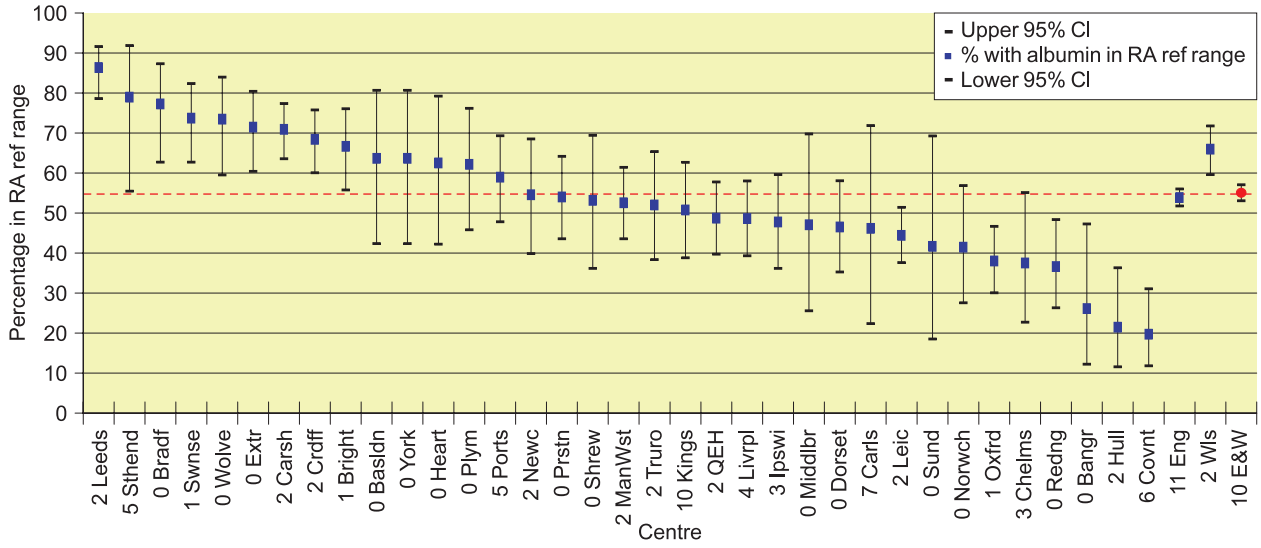

Figure 10.31: Percentage of PD patients by centre with serum albumin >35 g/L (BCG)

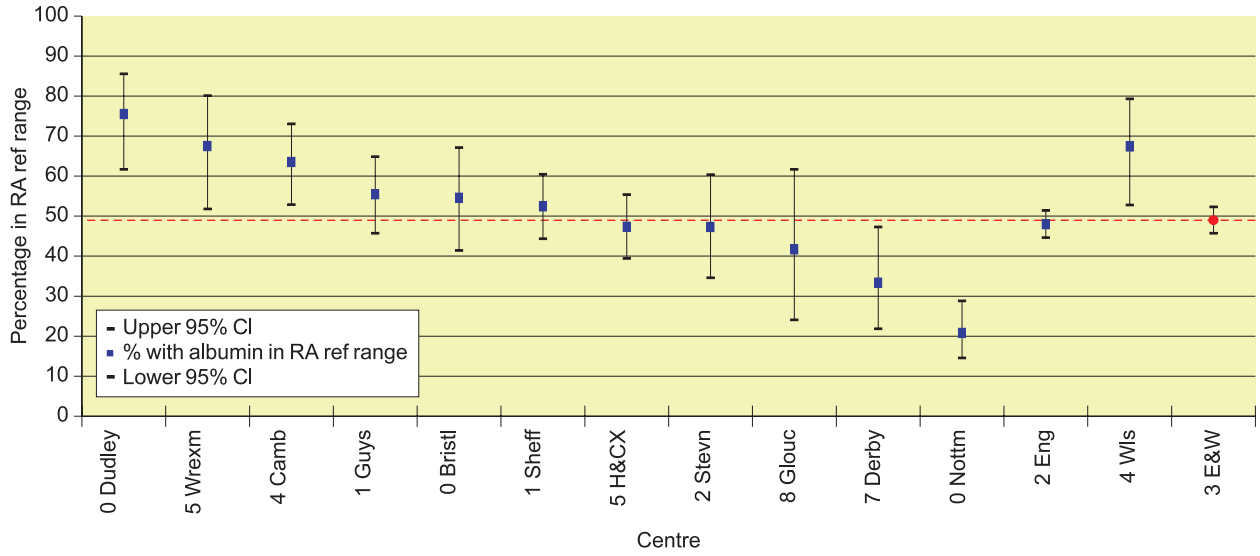

Figure 10.32: Percentage of PD patients by centre with serum albumin >30 g/L (BCP)

albumin above the recommended minimum in patients treated by peritoneal dialysis.

Amongst patients who had received a renal transplant, median serum albumin was 41 g/L (range 17–56) for centres supported by laboratories using BCG methods and 37 g/L (range 14–48) for centres supported by laboratories using BCP methods. Overall, 95.4% and 95.9% of patients had serum albumin above 35 g/L for the BCG method and above 30 g/L for the BCP method respectively.

Albumin concentrations in both PD and HD patients decreased with increasing age. The percentage of HD patients achieving serum albumin $\geqslant 35$ g/L (BCG, $\chi^2 = 9.8$, $p < 0.0001$) or $\geqslant 30$ g/L (BCP, $\chi^2 = 5.8$, $p < 0.0001$) decreased significantly with age. Similarly the percentage of PD patients achieving serum albumin $\geqslant 35$ g/L (BCG, $\chi^2 = 7.3$, $p < 0.0001$) or $\geqslant 30$ g/L (BCP, $\chi^2 = 4.9$, $p < 0.0001$) decreased significantly with age (Figures 10.33 and 10.34, BCG data only shown).

In part, this effect may be attributable to the known age-related decline in serum albumin concentration in the male general population (eg 50th percentile in males aged 68–71 years 45 g/L compared to 48 g/L in males aged 25–34 years)[6]. In a study of community-dwelling individuals aged 75 years and over in Australia, 30% were noted to have serum albumin concentrations below the normal laboratory reference

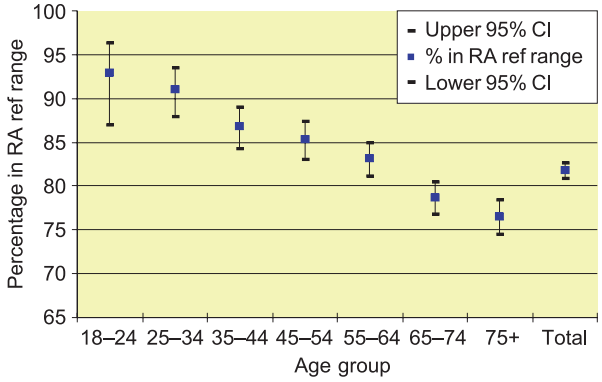

Figure 10.33: Percentage of patients achieving RA albumin standard by age band: HD

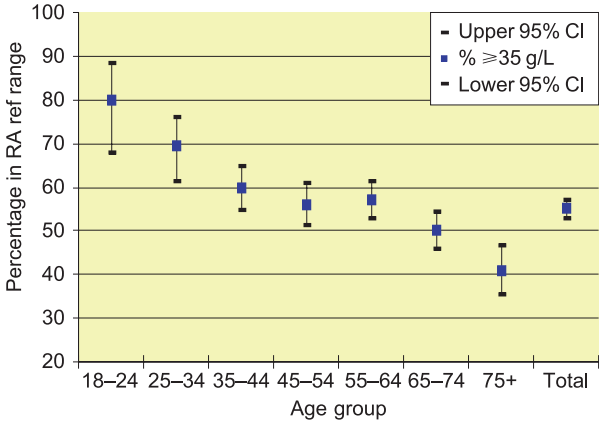

Figure 10.34: Percentage of patients achieving RA albumin standard by age band: PD

range[8]. In support of this it can be seen that the marked decrease in percentage achievement is effected by relatively small decreases in median serum albumin concentration (Figures 10.35 and 10.36; BCG data only shown). Further, achieved serum albumin concentration also

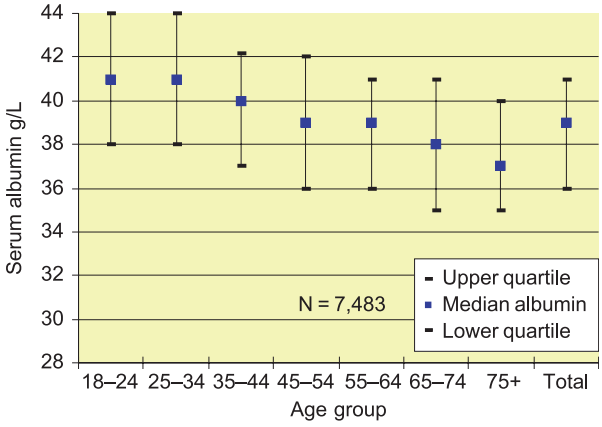

Figure 10.35: Median serum albumin by age group in haemodialysis patients. BCG data only shown

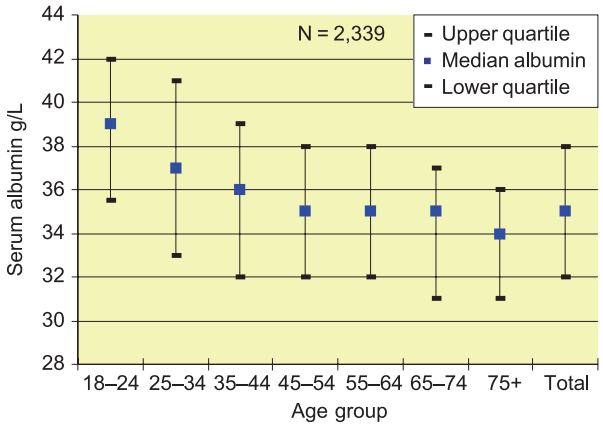

Figure 10.36: Median serum albumin by age group in peritoneal dialysis patients. BCG data only shown

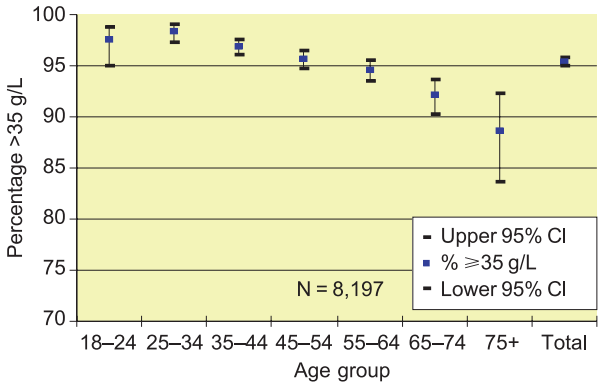

Figure 10.37: Percentage of patients achieving RA albumin standard by age band: transplant

declines with age in renal transplant recipients (BCG; $\chi^2 = 8.5$, $p < 0.0001$, Figure 10.37) although this effect did not achieve significance amongst transplant recipients having albumin measured by BCP methods ($\chi^2 = 0.8$, $p = 0.41$).

Albumin is affected by method of analysis, including a within method group effect[4]. Previous reports have described other influences on serum albumin concentration in dialysis patients including effects of time on treatment and social deprivation. The data presented above, describing the influence of age on serum albumin concentration, further illustrate the difficulties of using serum albumin as an audit standard in this setting. It is felt that continued presentation of albumin achievement data in the Registry annual report is of limited value: unless there are strong calls from the renal community with an opposing viewpoint, this data will not be published in next year's report.

Serum aluminium

The RA Standard states:

> ***Serum aluminium concentration should be measured every three months in all patients on HD and in all PD patients receiving oral aluminium hydroxide. No patient whose ferritin level is <100 μg/L should have a serum aluminium concentration of >60 μg/L (2.2 μmol/L).***

This wording may reflect a typographical error in the Standards document as there is no mention of a Standard for patients who are iron replete and have a serum ferritin above 100 μg/L.

Aluminium measurement is not available in most biochemistry laboratories, tending to be measured in a handful of regional reference centres. It is possible that the reports generated by these laboratories are not transcribed into local pathology or renal unit databases, so the following data interpretation should be regarded with some caution.

During 2004, aluminium was measured on 9,119 HD samples and 780 PD samples. Overall, 39% of HD patients (4,342 of 11,060) and 15% of PD patients (524 of 3,410) had a serum aluminium concentration checked once during the year. However, there was enormous variation in reported compliance with this standard with 14 centres reporting no aluminium data for HD patients and a further 7 reporting data in less than 10% of their patients. Amongst PD patients, 24 centres reported no aluminium data and a further 9 reported data in less than 10% of their patients. The Registry does not collect information on aluminium hydroxide prescription. An analysis of quarterly data suggests that many of those centres that are reporting data may be doing so on an annual basis in most patients rather than the three-monthly interval suggested by the RA.

Median aluminium amongst HD patients in England and Wales was 0.3 μmol/L (95% range 0.1 to 1.3 μmol/L) and amongst PD patients was 0.2 μmol/L (95% range 0.1 to 1.2 μmol/L). Serum aluminium concentration was $\geqslant$2.2 μmol/L in 80 HD patients: concurrent ferritin concentration was <100 μg/L in three of these patients (all of whom had polycystic kidney disease). Serum aluminium concentration was $\geqslant$2.2 μmol/L in 3 PD patients, all of whom had concurrent ferritin concentration <100 μg/L. The Registry has identified audit follow-up of patients with high reported aluminium concentrations as a future area of work.

The RA Standards document states that aluminium may be increased in the presence of relative iron deficiency and that serum aluminium concentration should therefore be re-investigated after iron repletion. However, this is somewhat at odds with the RA Standard recommendation that 'no patient whose ferritin level is <100 μg/L should have a serum aluminium concentration of >60 μg/L (2.2 μmol/L)'. In fact, increased aluminium concentration in the presence of ferritin >100 μg/L may be more likely to imply an underlying aluminium toxicity requiring further investigation including repeat testing.

The Registry data is consistent with a four year study from the north of England[11]. In this report, patients who had aluminium measured had it measured only once a year on average. From 5,918 aluminium determinations, 104 were $\geqslant$2.2 μmol/L. However, the vast majority of these were normal on repeat testing and only one case of true aluminium toxicity was identified. It is likely that this patient would have been identified without an aluminium screening programme: they were receiving alucaps and had erythropoietin-resistant anaemia which was attributed to aluminium toxicity and responded to desferrioxamine treatment.

It is possible that many renal centres have abandoned routine monitoring of aluminium in dialysis patients. Others appear to be deviating from the RA Standard recommendations in terms of frequency of testing whilst the yield of useful clinical information from those centres still undertaking routine monitoring is questionable, although the Registry does not collect information on aluminium hydroxide prescribing so the prevalence of this practice nationally is uncertain. The cost of a single aluminium analysis is approximately £11.25 (Keith Allen, Department of Clinical Biochemistry, Leeds Teaching Hospitals, personal communication) to which must be added sample processing costs from the referring laboratories. The added

value of this practice should probably be examined and we agree with Gault *et al*[11] that the role of aluminium monitoring in dialysis patients needs re-evaluation. The KDOQI guidelines are slightly less stringent than the RA guidelines, with the recommendation that serum aluminium should be measured at least yearly and every three months in patients receiving aluminium-containing medications. Generally it is acknowledged that aluminium-related bone disease is a diminishing problem in units where aluminium-phosphate binders are not widely used.

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Chapter 11: Factors which may Influence Cardiovascular Disease – Blood Pressure and Serum Cholesterol

Summary

- Many units still fail to return blood pressure data to the Renal Registry.
- In England & Wales, 40% of haemodialysis (HD) patients achieve the Renal Association combined pre-dialysis blood pressure standard (inter unit range 12–60%) and 44% of patients achieve the post-dialysis standard (range 31–59%). 29% of peritoneal dialysis (PD) patients (range 0–50%) and 22% of renal transplant (Tx) patients (range 11–51%) achieve the standard.
- During the last 7 years there has been no significant improvement in systolic or diastolic blood pressure control.
- In England & Wales, the cholesterol standard was achieved in 81% of patients on haemodialysis (inter unit range 65–95%), 65% of peritoneal dialysis patients (range 26–83%) and 57% of transplant patients (range 36–77%).
- Cholesterol levels have fallen progressively over the last 7 years and remain consistently lower in patients treated with HD than PD or renal transplant.

Introduction

It is now well recognised that the excessive cardiovascular mortality in patients on renal replacement therapy (RRT) is due to processes distinct from atherosclerosis. Heart failure, arrhythmia and 'sudden death' are more frequent causes of death than myocardial infarction. The condition has been referred to as uraemic cardiomyopathy and arteriopathy but this is a poor descriptor as clinical studies have shown that the process starts at an early stage of chronic kidney disease (CKD)[1]. The heart disease is characterised by left ventricular hypertrophy (LVH), resulting from combined pressure and volume overload, myocardial fibrosis and calcification of coronary arteries and heart valves[2]. In conduit arteries there is hypertrophy of both intimal and medial layers with medial calcification leading to arterial stiffness, an independent risk factor for death[3]. Vascular smooth muscle cells in affected vessels dedifferentiate into osteoblast-like cells capable of producing bone matrix proteins that regulate mineralisation[4]. Arterial calcification increases rapidly with time on dialysis, even in paediatric cases[5] and hyperphosphataemia has been shown to be a major contributory factor.

Recent guidelines recommend a lower blood pressure target for patients with CKD (less than 130/80 mmHg) to reduce progression to renal failure and reduce cardiovascular complications[6,7]. So far clinical trials have been designed to evaluate the effect of lower blood pressure on progression of kidney disease. Cardiovascular outcomes have only been documented as secondary endpoints thus demanding caution when interpreting the data. Trials in non-diabetics include 'Modification of Diet in Renal Disease' (MDRD)[8], 'African–American Study of Kidney Disease and Hypertension' (AASK)[9] and 'Ramipril Efficacy in Nephropathy 2' (REIN-2)[10]. MDRD claims a benefit of 2 years from lower blood pressure on the composite end points of kidney failure and all cause mortality before kidney failure. Achieved blood pressure in the lower and usual blood pressure groups were 126/77 and 134/81 mmHg 4 months after the start of the study. Outcomes were reported to 2000 but no blood pressure data were available after 1993. Both AASK and REIN-2 reported no benefit from lower blood pressure. Achieved blood pressure in the lower and usual blood pressure groups averaged 128/78 versus 141/85 mmHg and 130/80 versus 134/82 mmHg in these respective studies.

Several trials in Type 2 diabetics with established nephropathy assess cardiovascular outcomes as secondary endpoints. The 'Reduction of endpoints in NIDDM with the Angiotensin II Antagonist Losartan Study' (RENAAL)[11] achieved an average blood pressure of 140/74 in the losartan group and 142/74 mmHg in the placebo group by the end of the study. Post hoc analysis indicated losartan significantly reduced

new onset heart failure at all stages of CKD while the incidence of heart failure increased with severity of CKD in the placebo group[12]. Baseline systolic blood pressure proved a strong predictor of outcome with a SBP in the range 140 to 159 mmHg increasing the risk of ESRD or death by 38% when compared with a systolic blood pressure (SBP) below 130 mmHg. In a multivariate model, every 10 mmHg rise in baseline SBP increased the risk for ESRD or death by 6.7%. The 'Irbesartan Diabetic Nephropathy Trial' (IDNT)[13] achieved a mean blood pressure of 140/77 mmHg for the irbesartan group, 141/77 for the amlodipine group and 144/80 mmHg for the placebo group. There was no difference in cardiovascular outcomes between treatment groups. The 'Appropriate Blood Pressure Control in Diabetes Trial' (ABCD) investigated the effect of intensive and moderate blood pressure lowering in Type 2 diabetes with varying degrees of albuminuria. In hypertensive subjects the achieved blood pressure was 132/78 and 138/86 mmHg in the different groups by the end of the study. There was a reduction in all-cause mortality in the intensively treated group[14]. In normotensive subjects the achieved blood pressure was 128/75 and 137/81 mmHg respectively with a significantly lower incidence of cerebrovascular accidents in the intensively treated group[15].

Properly designed randomised controlled trials (RCTs) are needed to assess whether blood pressure control will significantly reduce cardiovascular death in dialysis and renal transplant patients. While uncertainty remains the blood pressure audit for haemodialysis, peritoneal dialysis and renal transplant populations remains important.

In all figures where data are shown by the individual centre, the number adjacent to the name of the renal unit indicates the percentage of missing data at that time point.

Blood Pressure Control

The Renal Association standards for control of hypertension were revised in August 2002. The current standards are:

Pre-haemodialysis blood pressure <140/90 mmHg.

Table 11.1: Percentage of patients with complete returns of blood pressure values by modality

	% completed data			
	Pre HD	**Post HD**	**PD**	**Tx**
Bangor	100	98	96	n/a
Barts	0	0	0	0
Basildon	95	95	100	0
Bradford	11	8	94	92
Brighton	7	28	0	0
Bristol	100	99	100	78
Cambridge	7	0	87	4
Carlisle	93	93	6	0
Carshalton	0	0	0	0
Chelmsford	97	94	100	40
Clwyd	13	0	83	100
Coventry	99	98	78	66
Cardiff	14	0	6	95
Derby	88	88	19	33
Dorset	97	95	64	3
Dudley	81	81	84	80
Exeter	93	79	99	19
Gloucester	97	1	3	0
Guys	66	65	6	1
H&CX	0	0	0	0
Heartlands	91	91	4	1
Hull	78	77	87	1
Ipswich	96	96	1	0
Kings	0	0	0	0
Leeds	97	94	95	69
Leicester	96	93	94	73
Liverpool	16	0	38	66
ManWst	0	0	0	0
Middlesbrough	94	90	100	52
Newcastle	0	0	0	1
Norwich	97	97	13	0
Nottingham	97	96	96	91
Oxford	91	87	71	11
Plymouth	1	1	0	1
Portsmouth	0	0	0	0
Preston	0	0	0	0
QEH	0	0	0	1
Reading	94	0	99	97
Sheffield	100	97	98	98
Shrewsbury	98	98	11	3
Stevenage	95	92	7	4
Southend	98	0	0	0
Sunderland	96	96	0	1
Swansea	69	67	22	8
Truro	99	98	64	81
Wirral	2	0	8	n/a
Wolverhampton	90	90	8	1
Wrexham	0	0	0	4
York	92	92	96	96
England	56	51	42	29
Wales	34	26	18	76
England & Wales	54	49	40	32

Post-haemodialysis, peritoneal dialysis and renal transplant blood pressure <130/80 mmHg.

Separate standards have not been specified for diabetics although diabetic guidelines recommend a lower target if proteinuria is present (BP <125/75 mmHg) to reduce cardiovascular risk.

Data Returns

Units with data for less than 35% of patients in any treatment modality were excluded from the blood pressure analyses. Insufficient returns were obtained from 18 centres for pre-HD blood pressure data, 21 centres for post-HD data, 27 centres for PD blood pressure data and 33 centres for Tx blood pressure data (Table 11.1). This implies units are still having problems transferring data from clinical areas to their renal IT systems. For some units the Renal Registry may not be extracting available data in which case they should contact the Registry.

Distribution of blood pressure by modality

Figure 11.1 shows systolic, diastolic and pulse pressure distributions for each treatment modality (post-HD data are shown). The systolic/diastolic standard deviations for post-HD, PD and Tx were 26/14, 24/13 and 19/11 respectively, with the widest spread for post-HD. The values have not changed substantially over the last few years and should be compared to 18/10 for a hypertensive population without renal disease. As predicted, the mean blood pressure for each modality is approaching the specified blood pressure target of 130/80 mmHg. The significantly lower diastolic blood pressure for HD contributes to the wider pulse pressure in this group.

Achievement of combined systolic and diastolic Standard

Figures 11.2–11.5 show a wide variation between units achieving the combined blood pressure standard for each modality. In England & Wales, 40% of HD patients achieve the standard pre-dialysis (inter unit range 12–60%) and 44% post-dialysis (range 31–59%). 29% of PD patients (range 0–50%) and 22% of Tx patients (range 11–51%) achieve the standard. Chi squared testing indicates the variation between centres for each treatment modality is significant ($p < 0.0001$).

Systolic pressure alone

Figures 11.6–11.13 show wide variation between units in their achievement of the systolic blood pressure standard. In England & Wales, 42% of HD patients achieve the standard pre-dialysis (inter unit range 12–60%) and 48% post-dialysis (range 37–61%). 37% of PD patients (range 19–56%) and 31% of Tx patients (range 14–55%) achieve the standard. Chi squared testing indicates the variation between centres

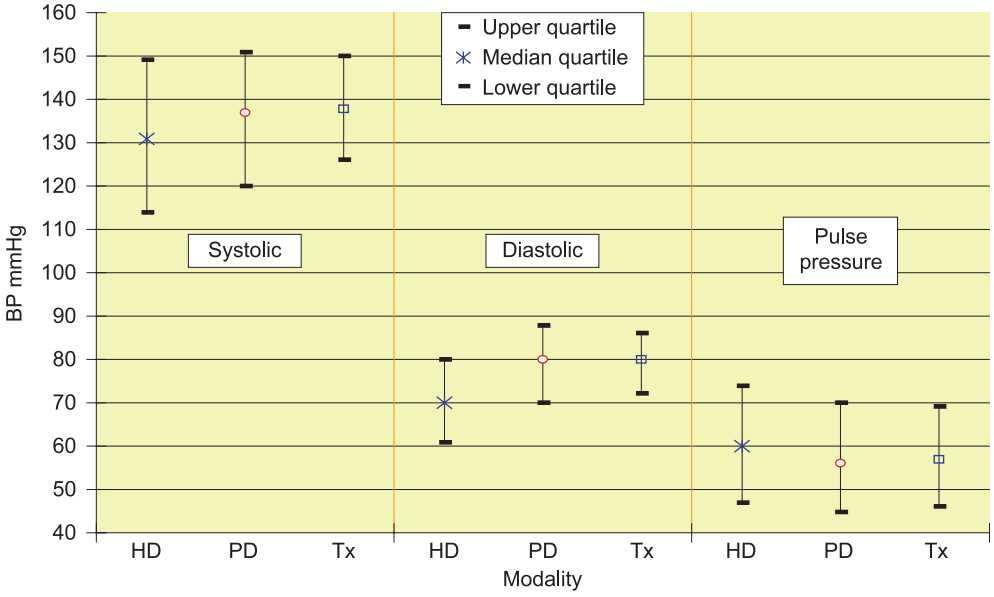

Figure 11.1: Summary of BP achievement

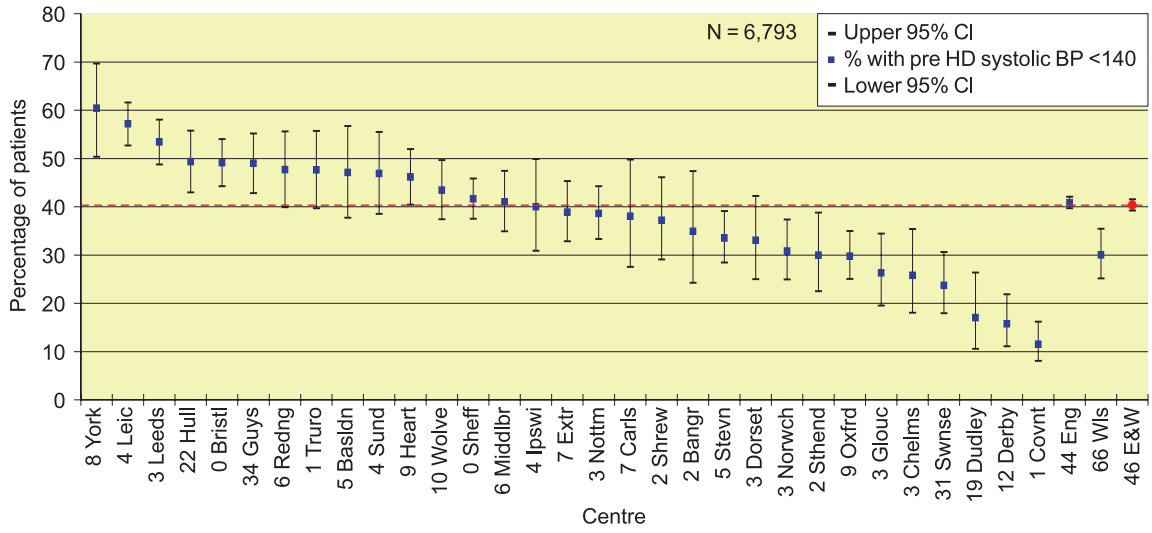

Figure 11.2: Percentage of patients with BP <140/90 mmHg: pre-HD

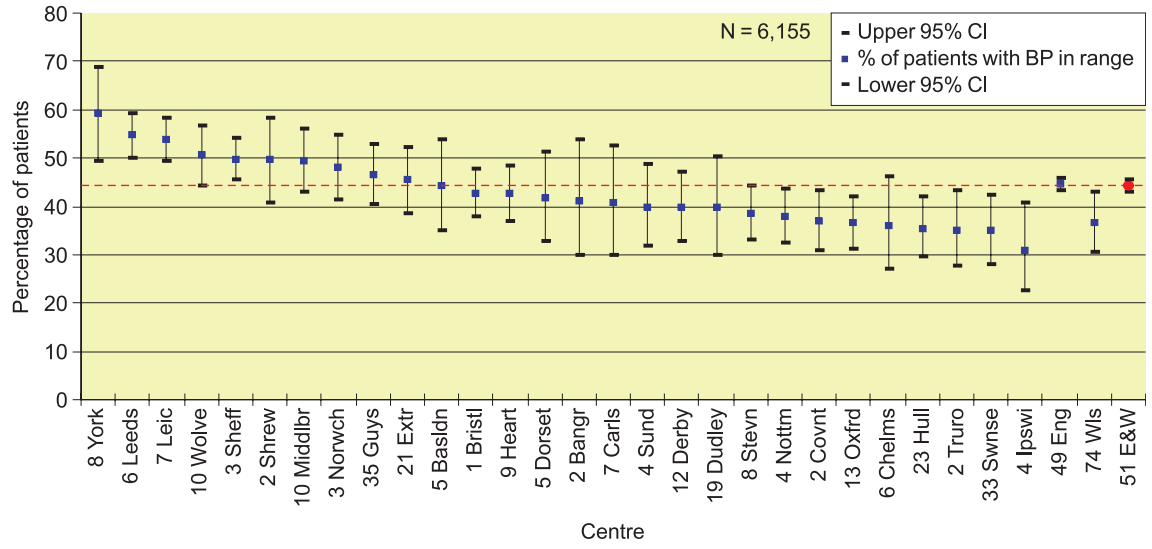

Figure 11.3: Percentage of patients with BP <130/80 mmHg: post-HD

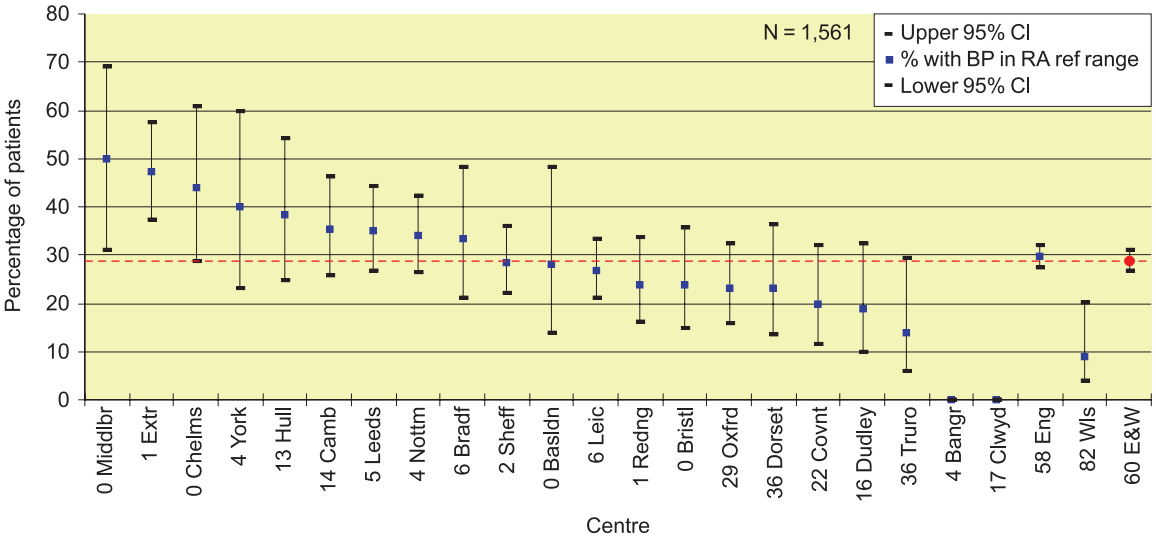

Figure 11.4: Percentage of patients with BP <130/80 mmHg: PD

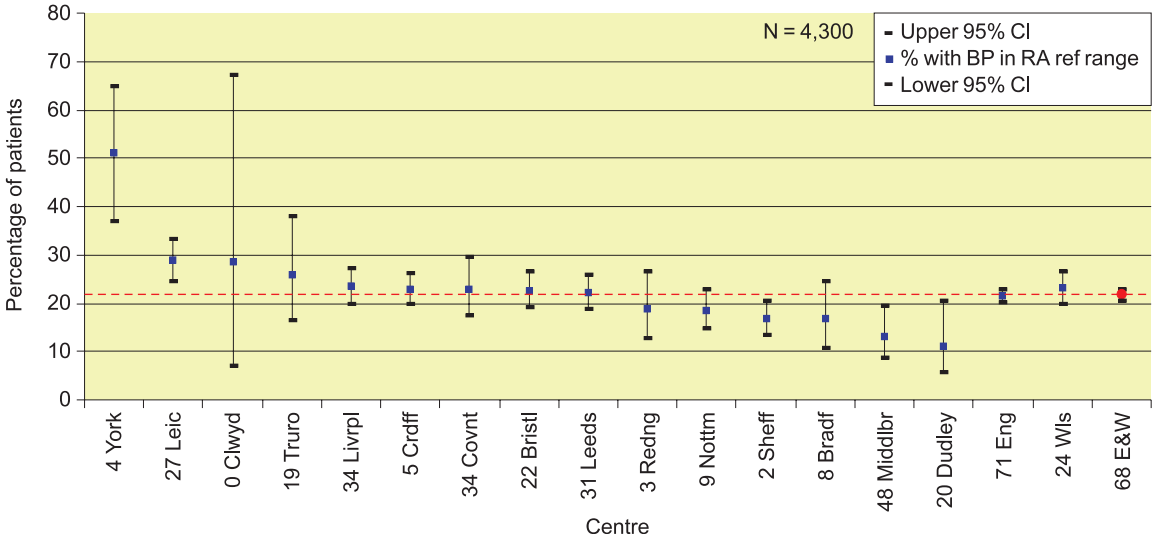

Figure 11.5: Percentage of patients with BP <130/80 mmHg: Tx

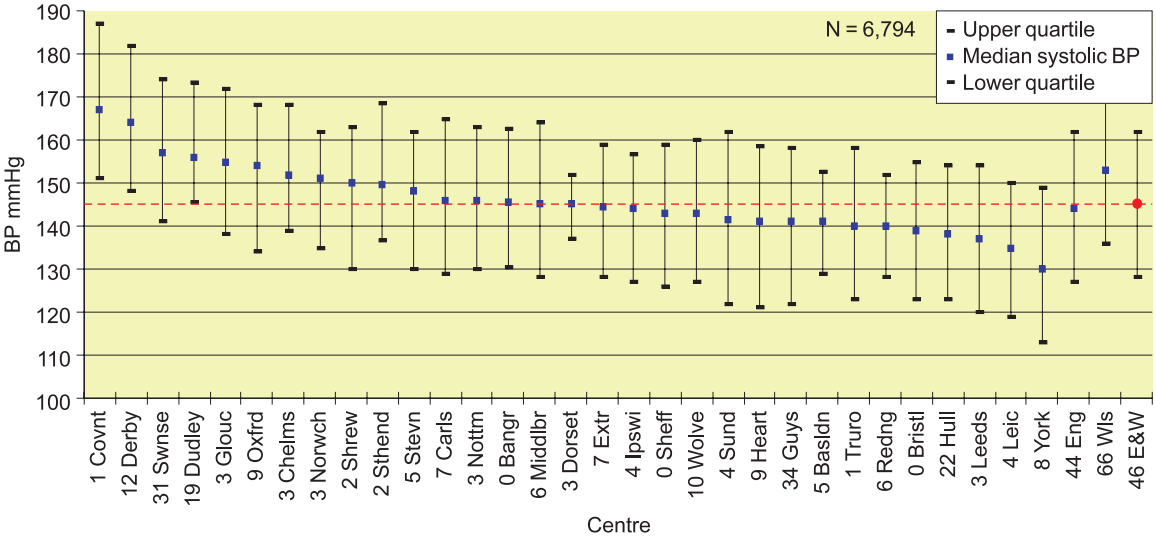

Figure 11.6: Median systolic BP: pre-HD

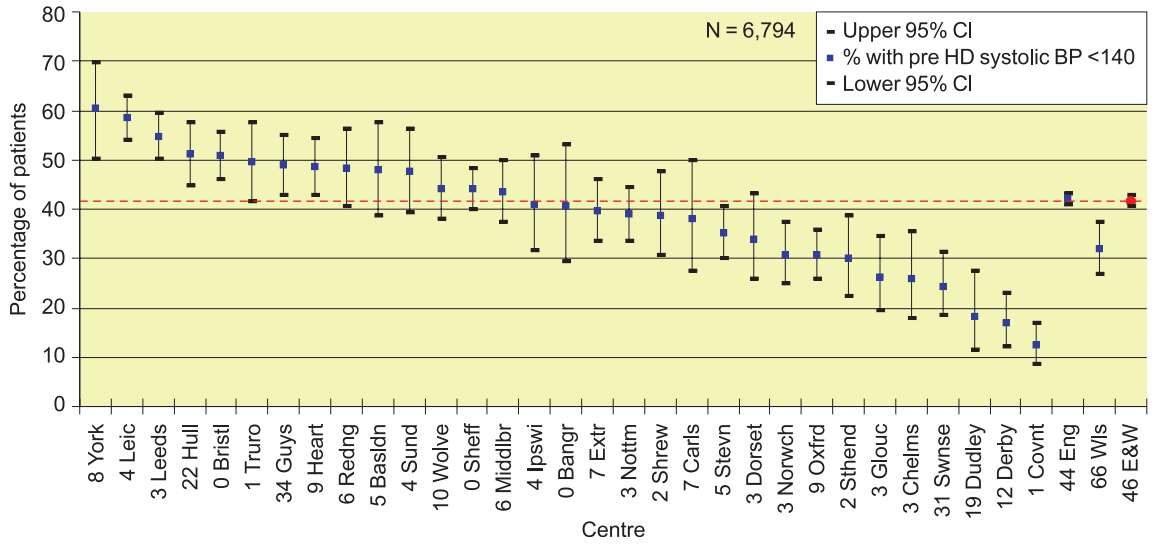

Figure 11.7: Percentage of patients with systolic BP <140 mmHg: pre-HD

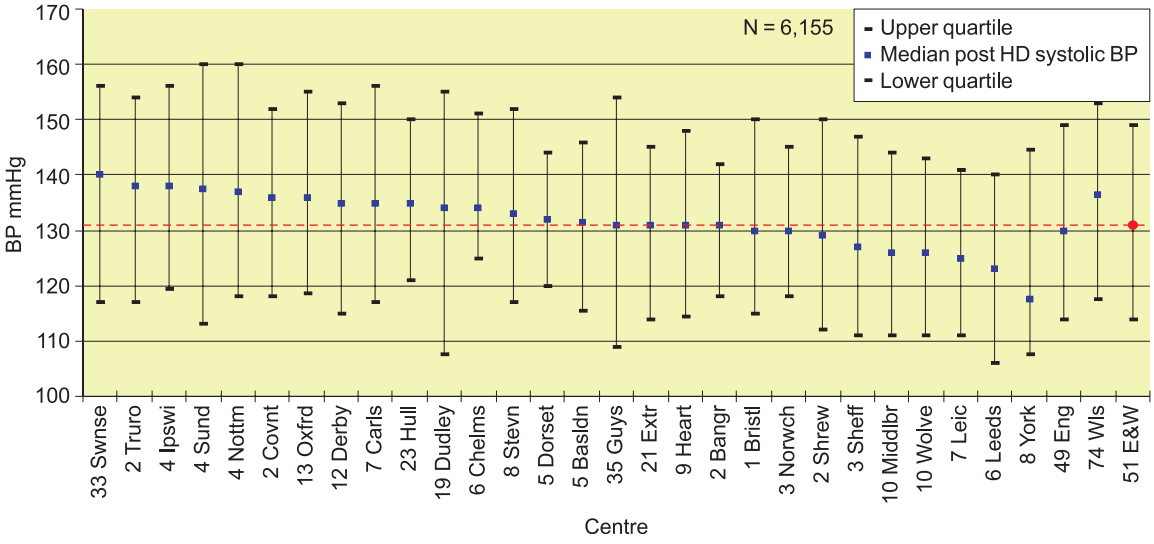

Figure 11.8: Median systolic BP: post-HD

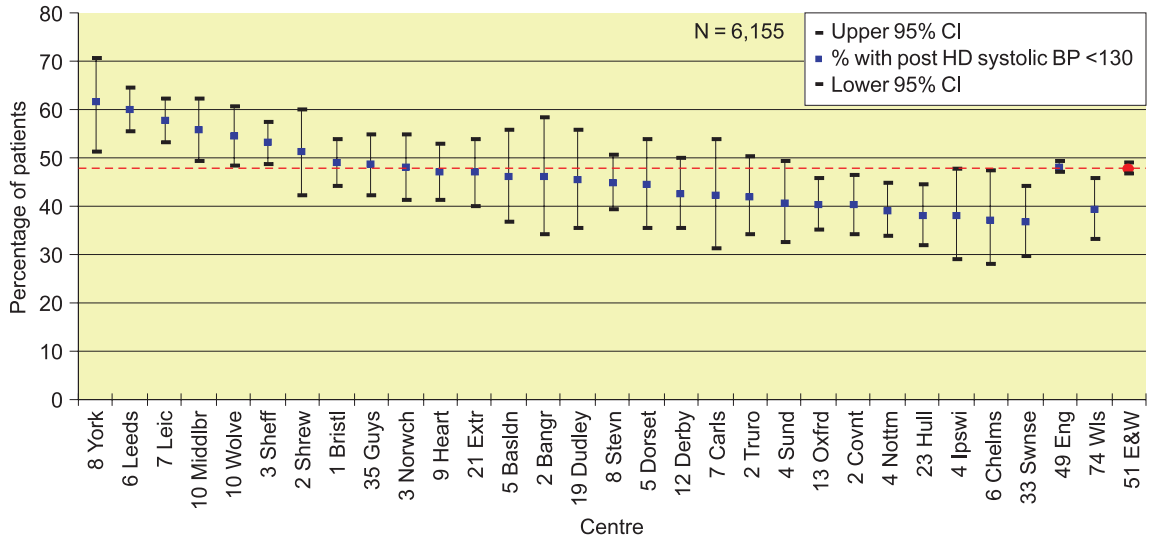

Figure 11.9: Percentage of patients with systolic BP <130 mmHg: post-HD

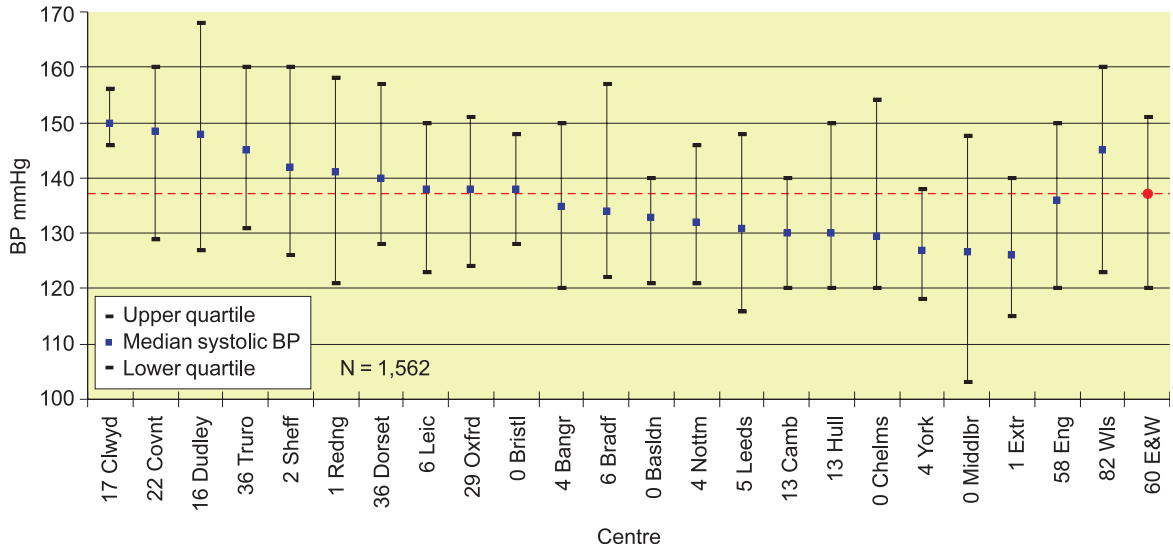

Figure 11.10: Median systolic BP: PD

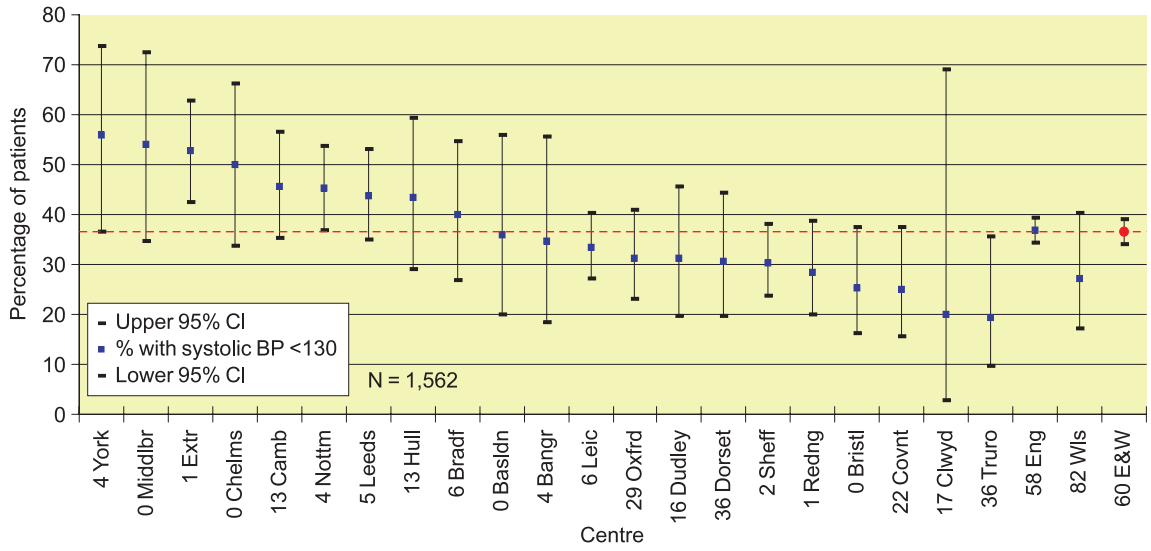

Figure 11.11: Percentage of patients with systolic BP <130 mmHg: PD

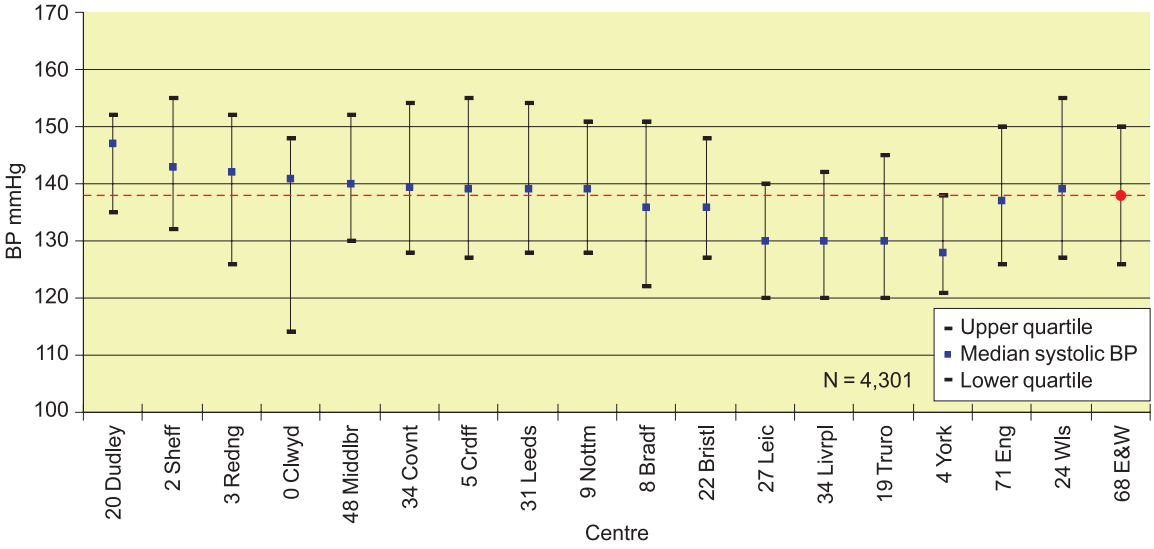

Figure 11.12: Median systolic BP: Tx

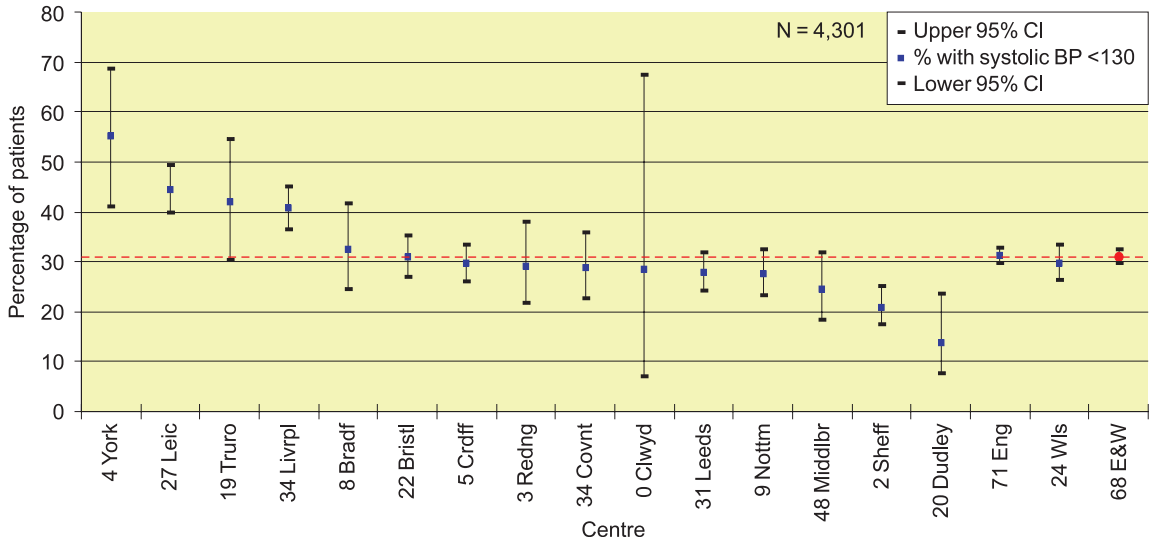

Figure 11.13: Percentage of patients with systolic BP <130 mmHg: Tx

for each treatment modality is significant ($p < 0.001$). The median SBP (England & Wales) for pre-HD, post-HD, PD and Tx is 145, 131, 137 and 138 mmHg respectively.

Diastolic pressure alone

Figures 11.14–11.21 show wide variation between units in their achievement of the diastolic blood pressure (DBP) standard. In England & Wales, 81% of HD patients achieve the standard pre-dialysis (inter unit range 57–95%) and 74% post-dialysis (range 56–86%). 48% of PD patients (range 20–63%) and 46% of Tx patients (range 30–74%) achieve the standard. Chi squared testing indicates the variation between centres for each treatment modality is significant ($p < 0.001$). The median DBP (England & Wales) for pre-HD, post-HD, PD and Tx is 76, 70, 80 and 80 mmHg respectively. It is not clear whether DBP is lower in the HD population because patients are older (DBP starts to fall after 60 years of age in the general population) or because HD patients have increased 'arterial stiffness'.

Mean arterial pressure

Figures 11.22–11.29 show wide variation between units in their achievement of the desired mean arterial pressure (MAP). MAP is calculated as DBP plus one third of the pulse pressure. In England & Wales, 68% of HD patients achieve the standard pre-dialysis (inter

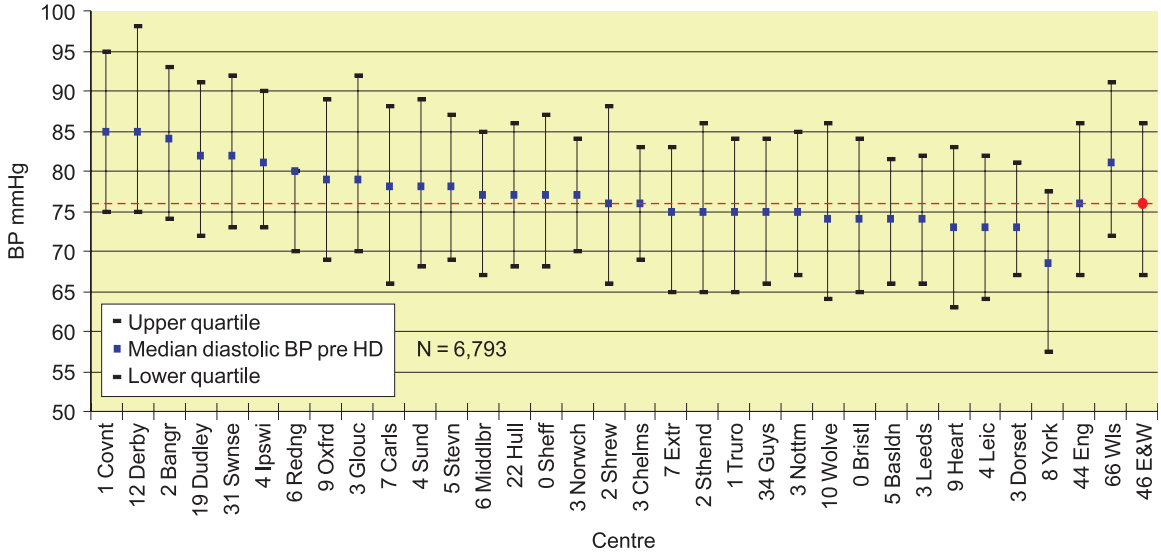

Figure 11.14: Median diastolic BP: pre-HD

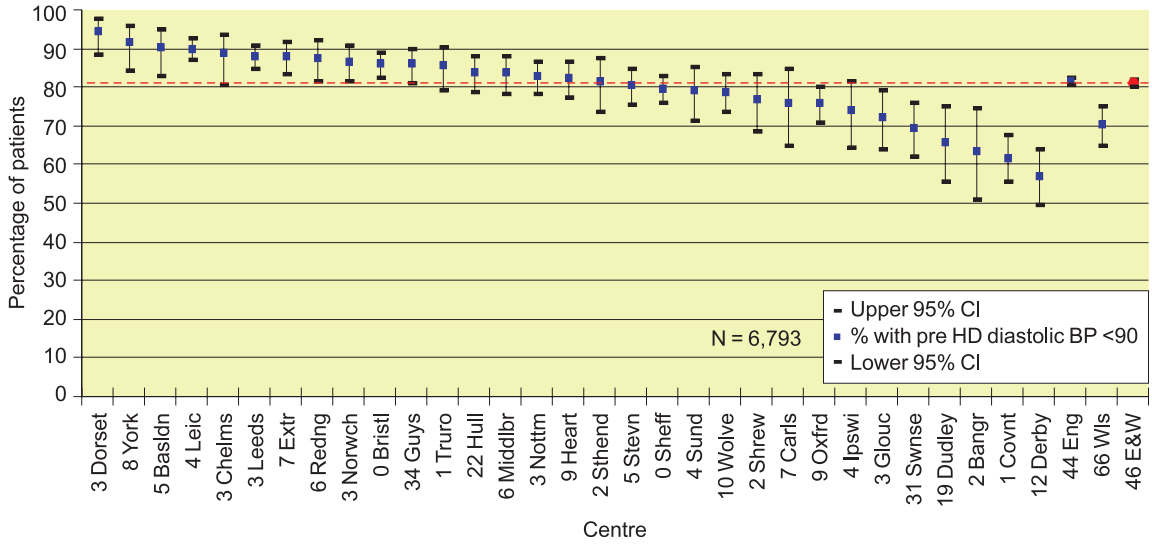

Figure 11.15: Percentage of patients with diastolic BP <90 mmHg: pre-HD

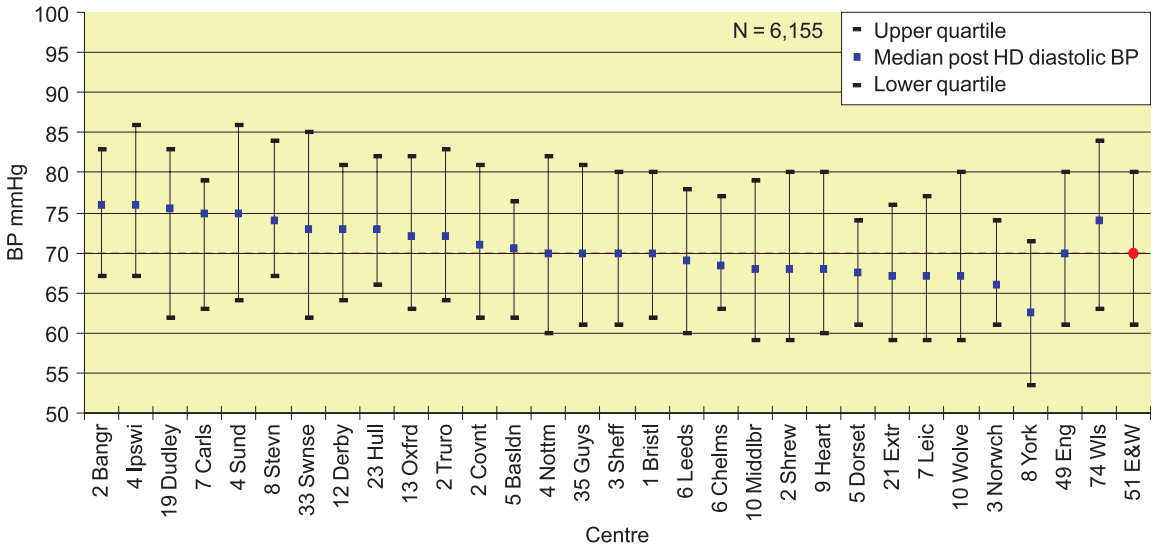

Figure 11.16: Median diastolic BP: post-HD

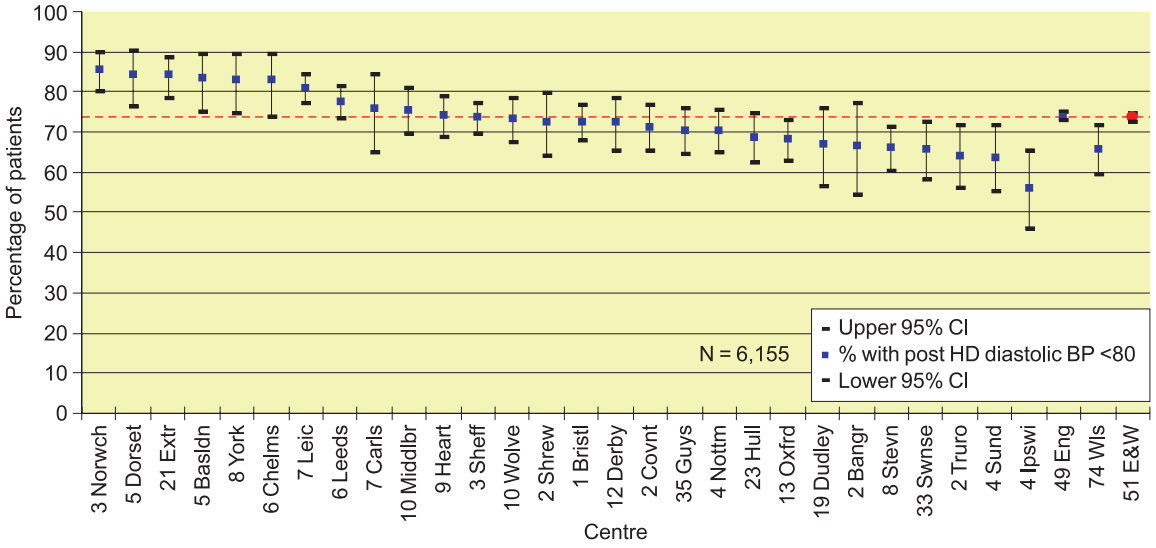

Figure 11.17: Percentage of patients with diastolic BP <80 mmHg: post-HD

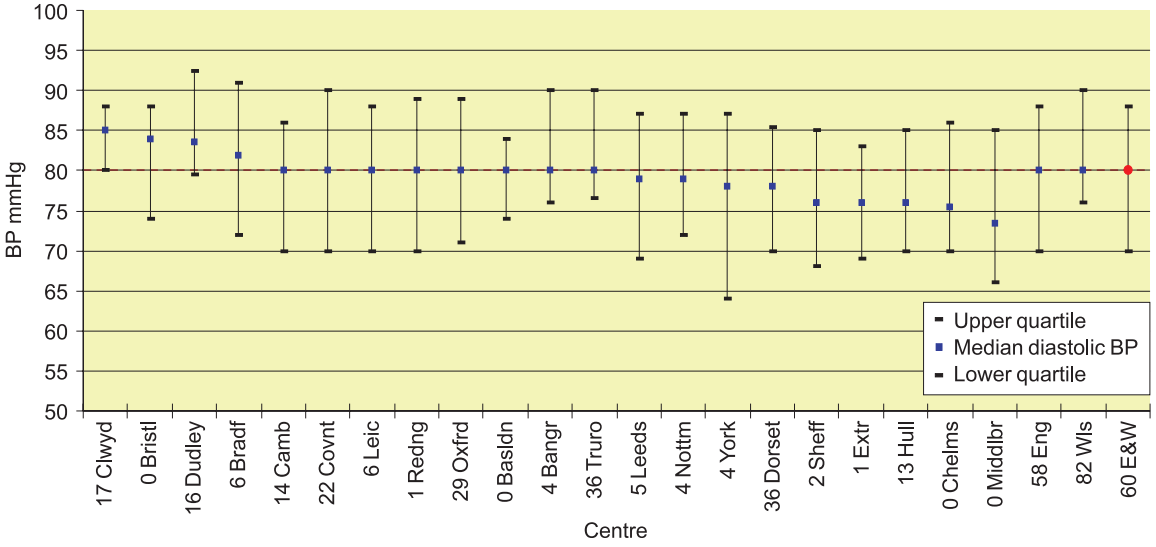

Figure 11.18: Median diastolic BP: PD

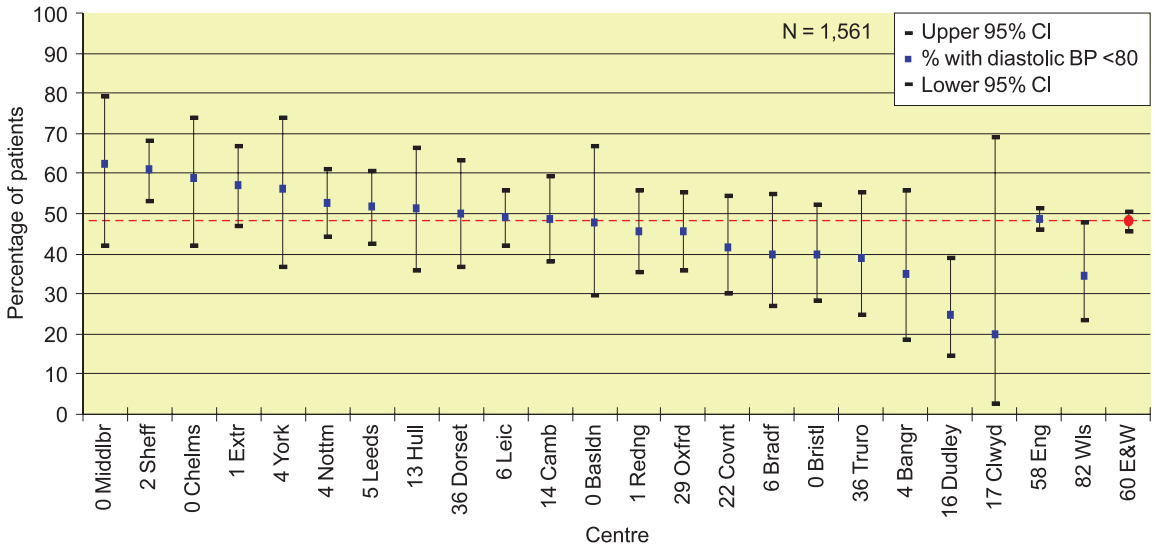

Figure 11.19: Percentage of patients with diastolic BP <80 mmHg: PD

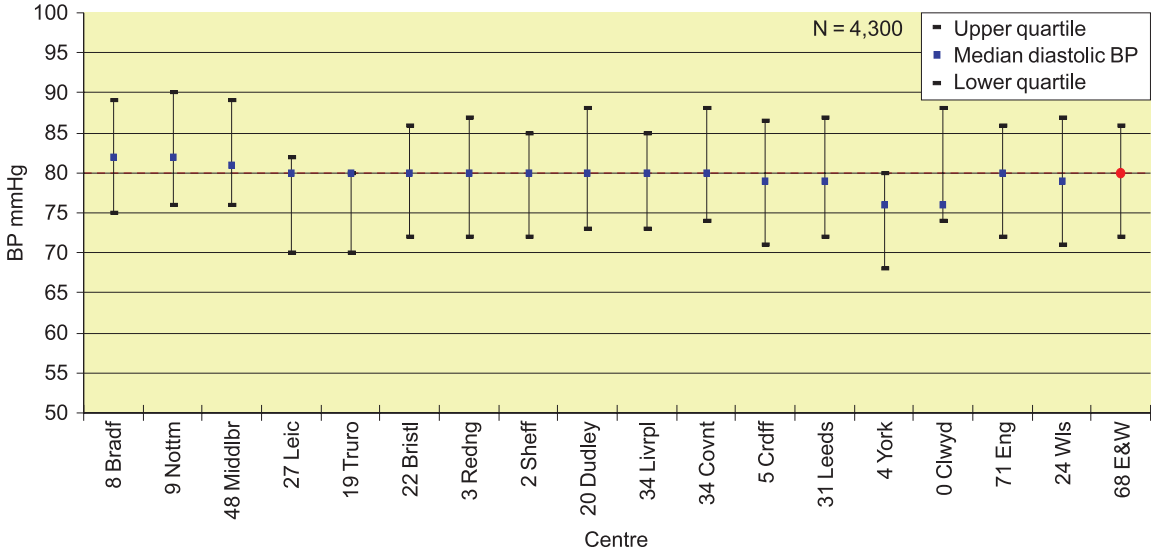

Figure 11.20: Median diastolic BP: Tx

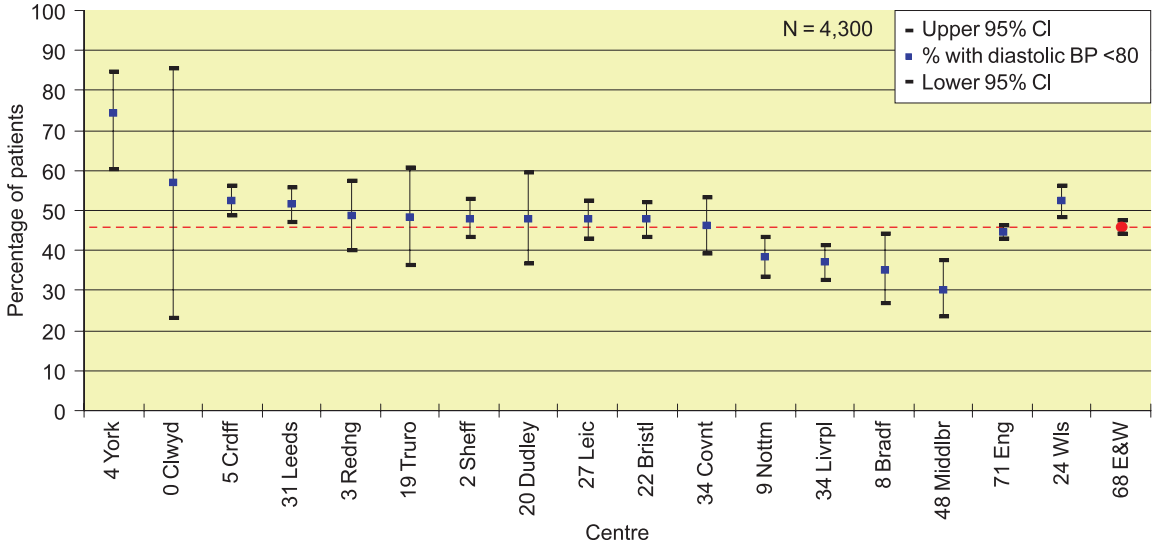

Figure 11.21: Percentage of patients with diastolic BP <80 mmHg: Tx

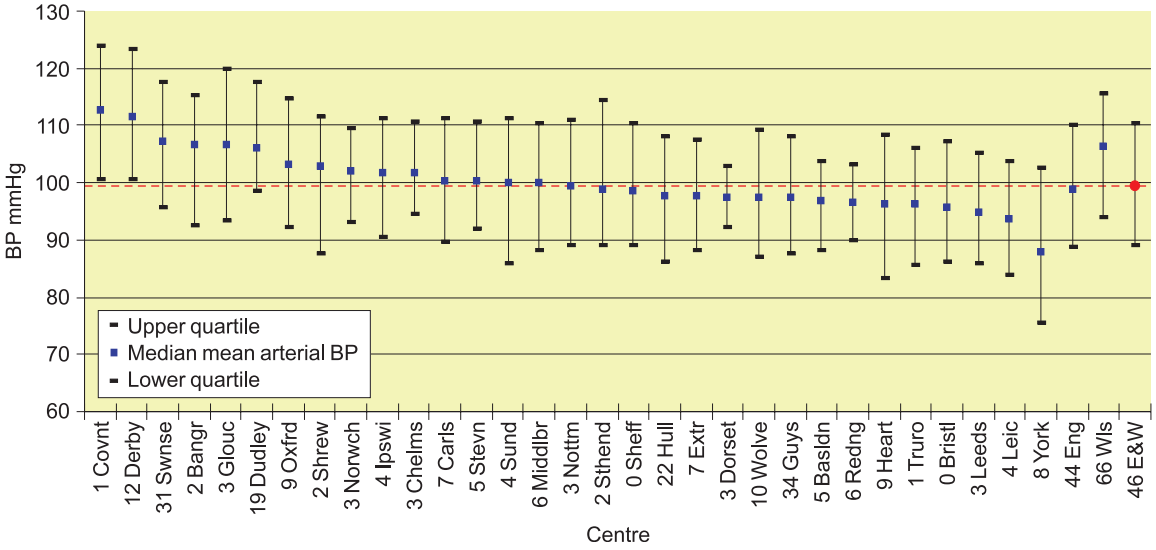

Figure 11.22: Median MAP: pre-HD

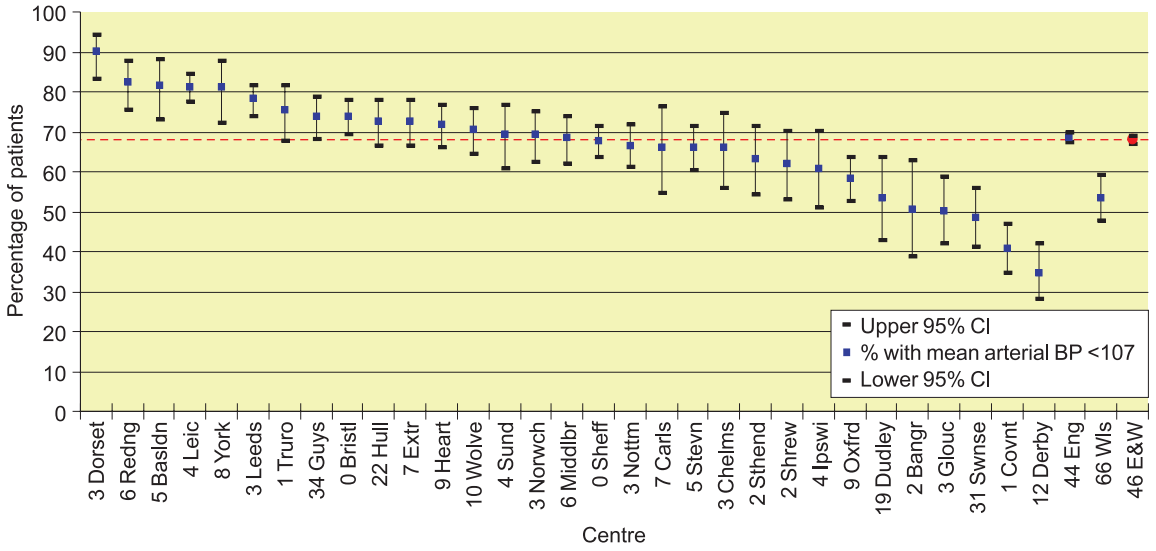

Figure 11.23: Percentage of patients with MAP <107 mmHg: pre-HD

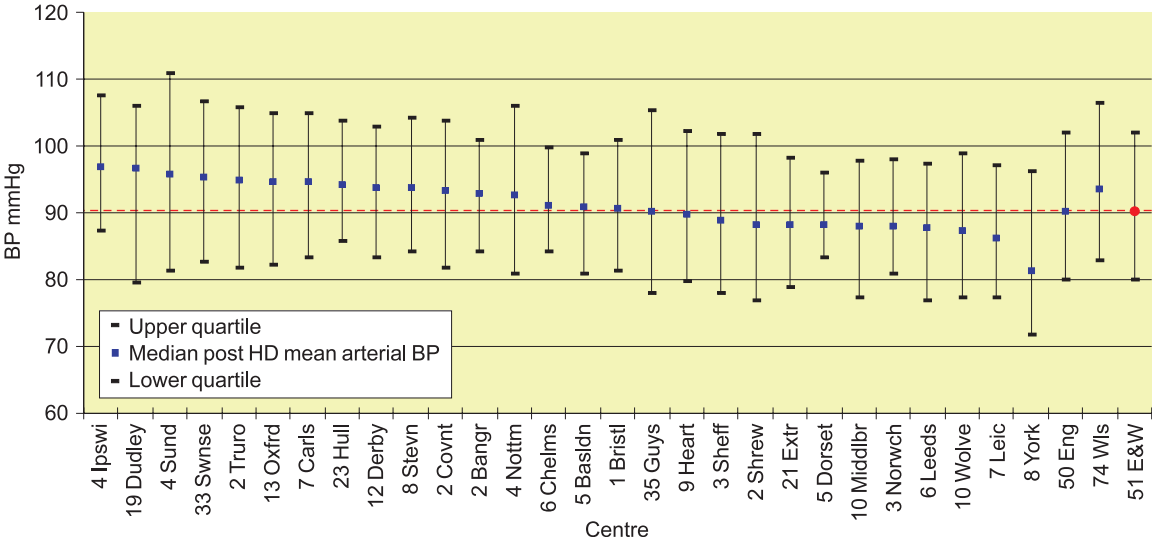

Figure 11.24: Median MAP: post-HD

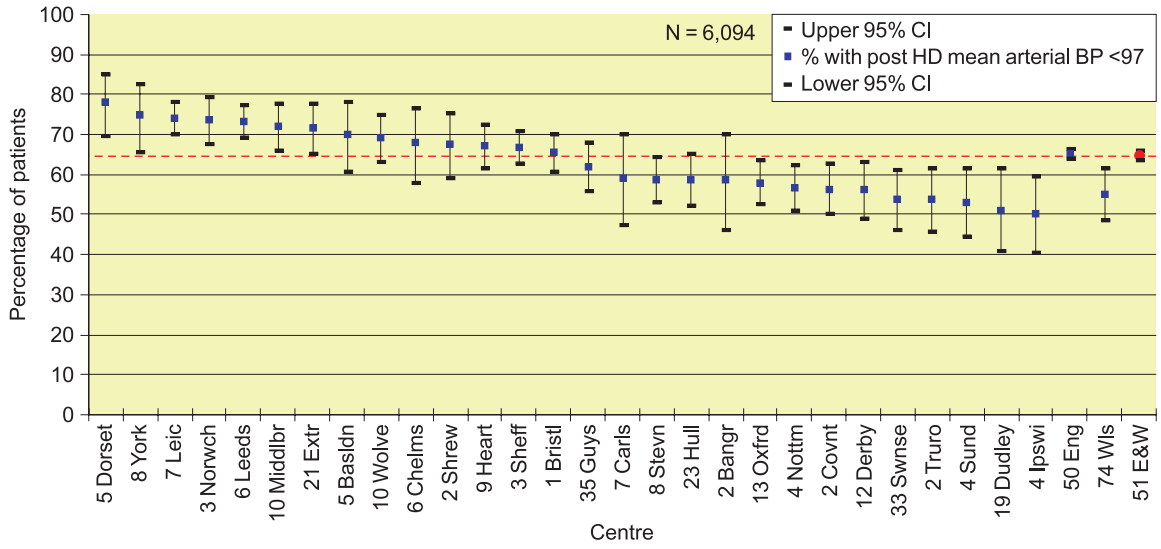

Figure 11.25: Percentage of patients with MAP <97 mmHg: post-HD

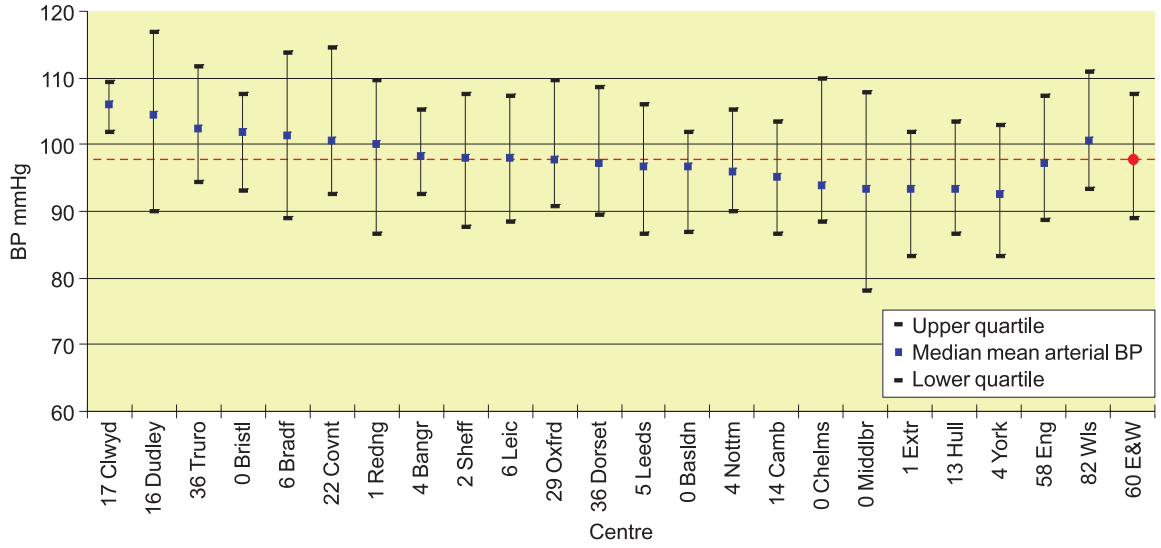

Figure 11.26: Median MAP: PD

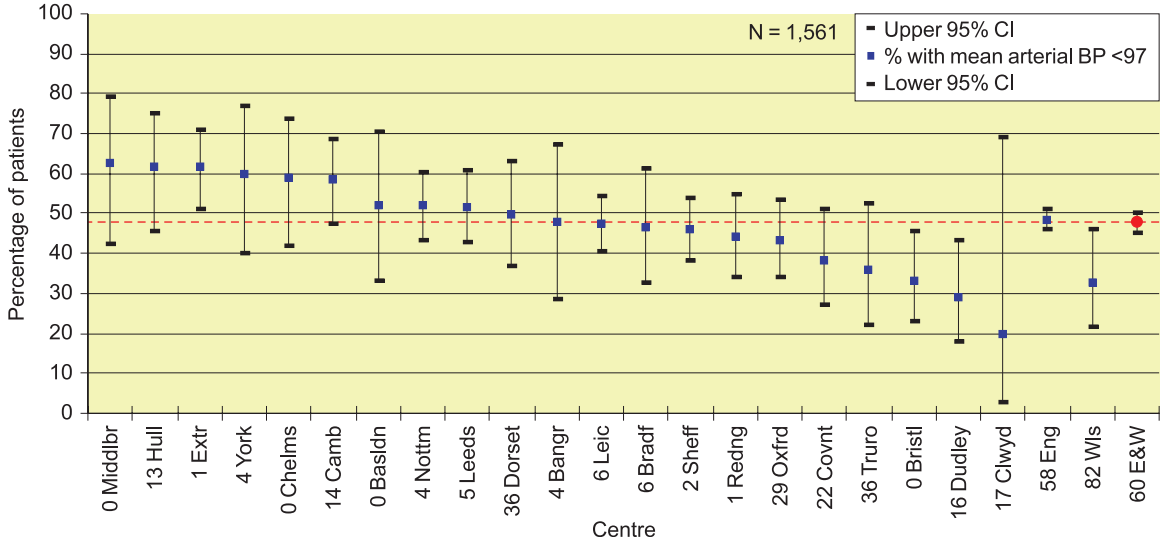

Figure 11.27: Percentage of patients with MAP <97 mmHg: PD

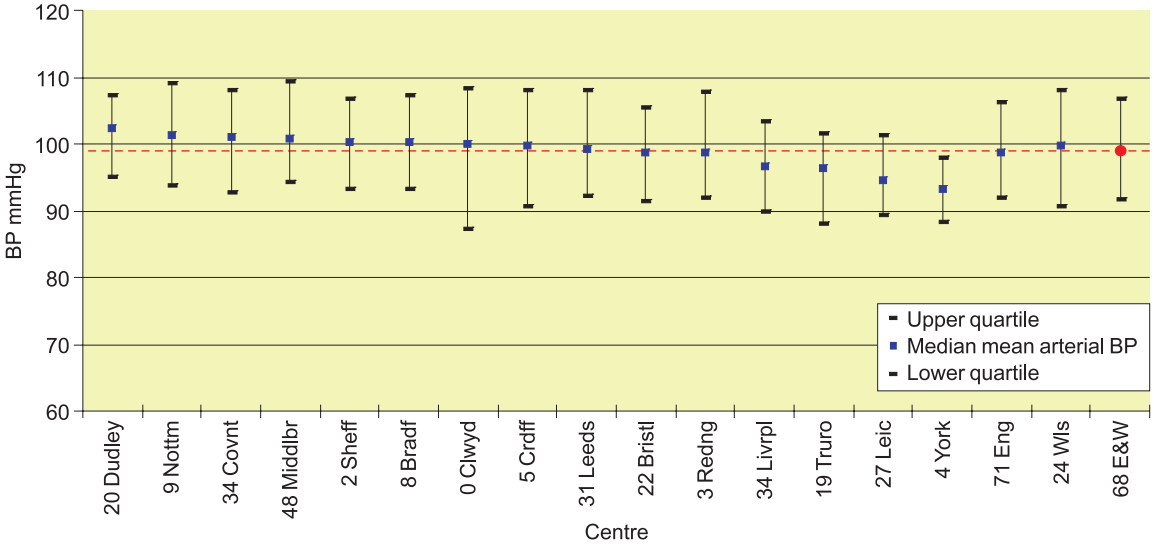

Figure 11.28: Median MAP: Tx

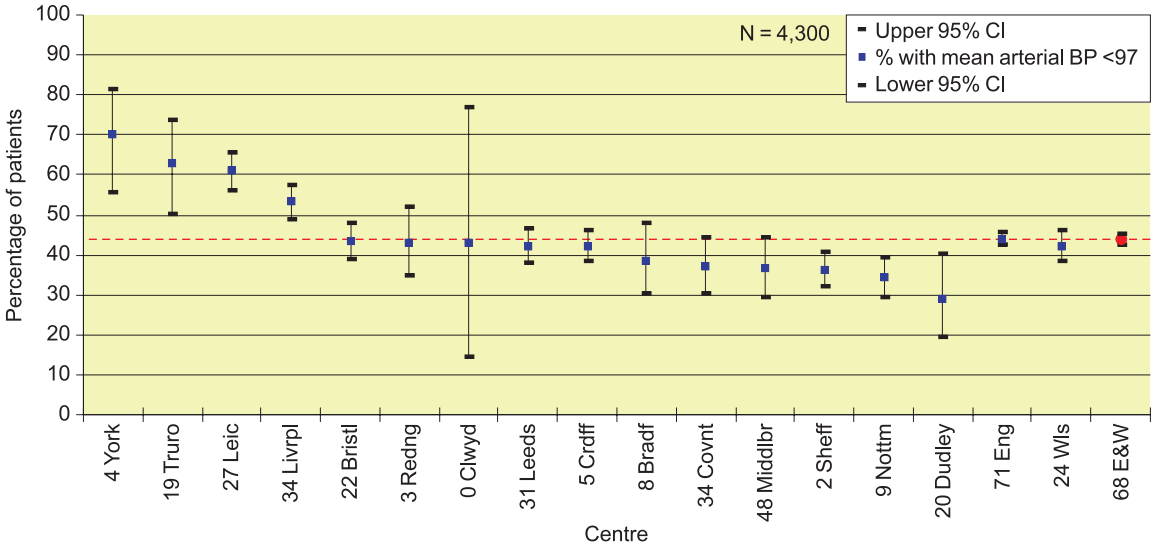

Figure 11.29: Percentage of patients with MAP <97 mmHg: Tx

unit range 35–90%) and 65% post-dialysis (range 50–78%). 48% of PD patients (range 20–63%) and 44% of Tx patients (range 29–70%) achieve the standard. Chi squared testing indicates the variation between centres for each treatment modality is significant ($p < 0.001$). The median MAP for pre-HD, post-HD, PD and Tx is 99, 90, 98 and 99 mmHg respectively.

Pulse pressure

Figures 11.30–11.33 show the variation between units for pulse pressure (PP). PP is calculated as SBP minus DBP. The median PP for pre-HD, post-HD, PD and Tx is 67, 60, 56 and 57 mmHg respectively. A significantly lower DBP contributes to the wider PP in HD patients. Future analyses should be able to determine whether this is an age related phenomenon. If this proves not to be the case, the data would support either better blood pressure control or increased 'arterial stiffness' in the HD population. Interestingly, Renal Registry data show HD patients have consistently poorer phosphate control than PD or Tx patients thus increasing the risk of arterial calcification.

Blood pressure by primary diagnosis

Figures 11.34–11.41 show the variation in blood pressure control for each treatment modality when categorised by primary diagnosis. Diabetes is the most commonly identified cause of renal failure in England & Wales. Both blood pressure and pulse pressure are higher for

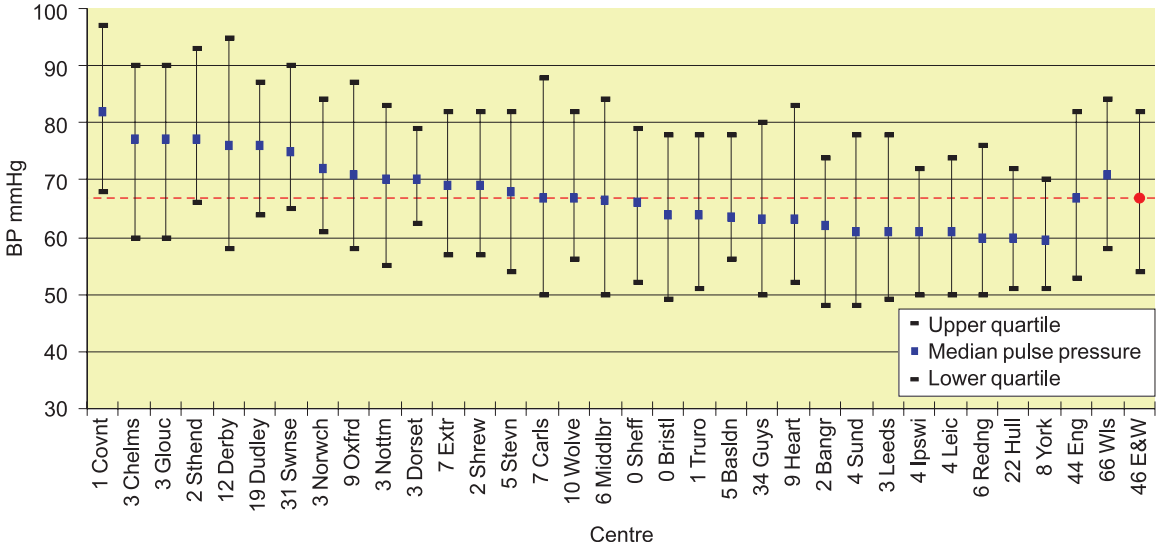

Figure 11.30: Median Pulse Pressure: pre-HD

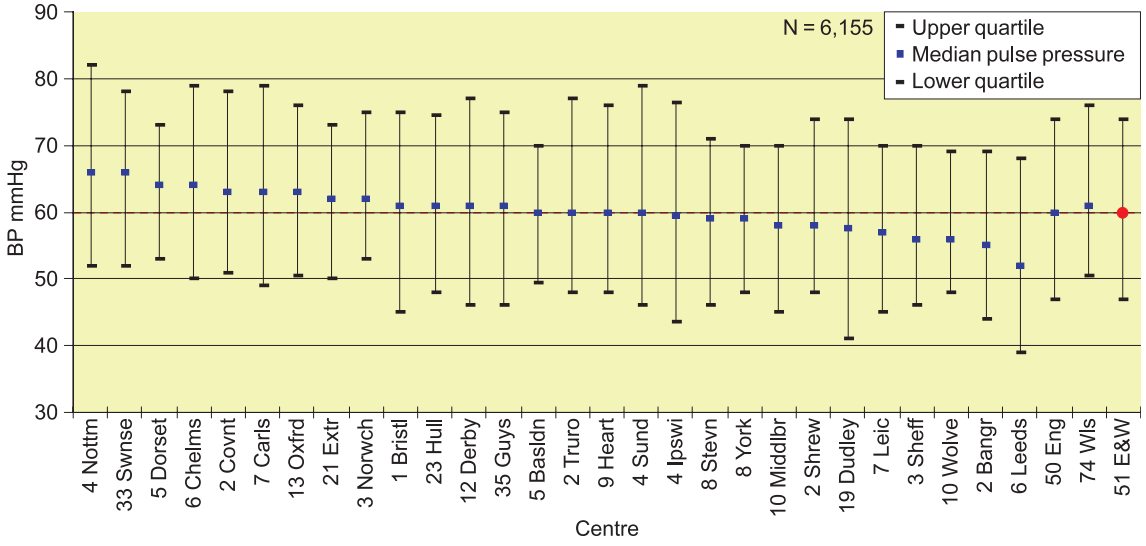

Figure 11.31: Median Pulse Pressure: post-HD

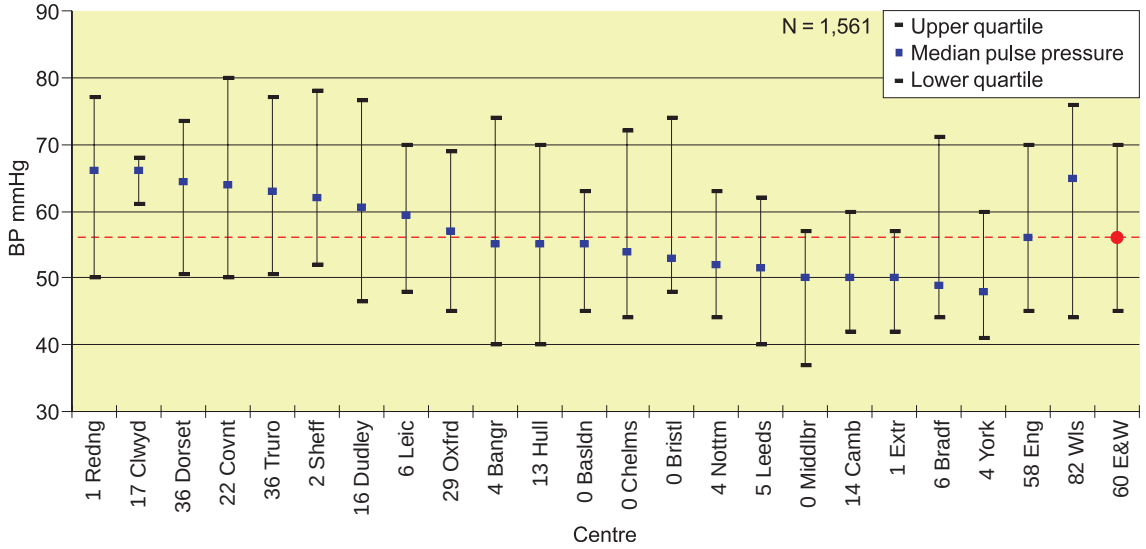

Figure 11.32: Median Pulse Pressure: PD

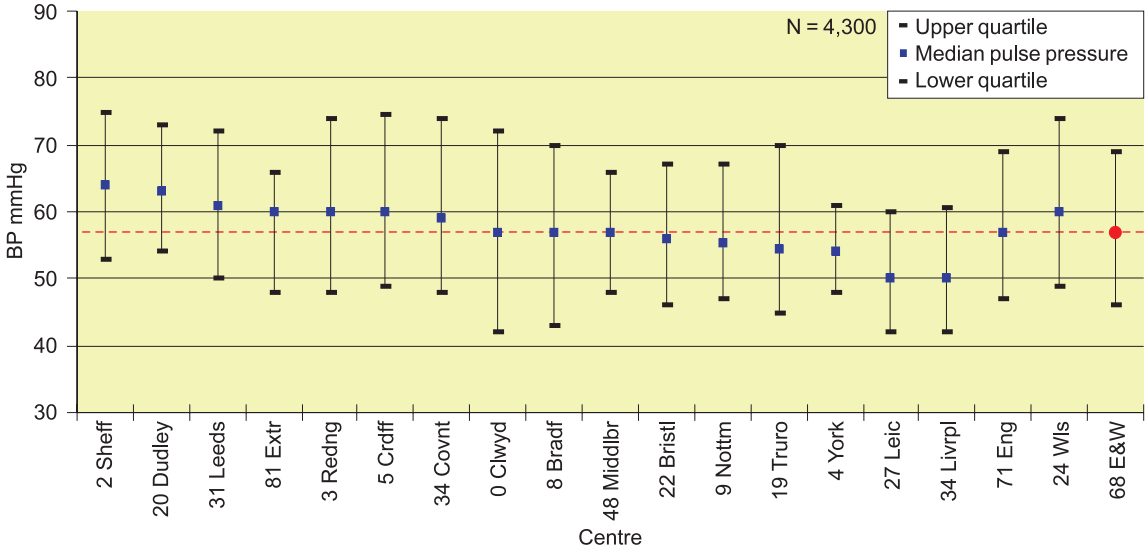

Figure 11.33: Median Pulse Pressure: Tx

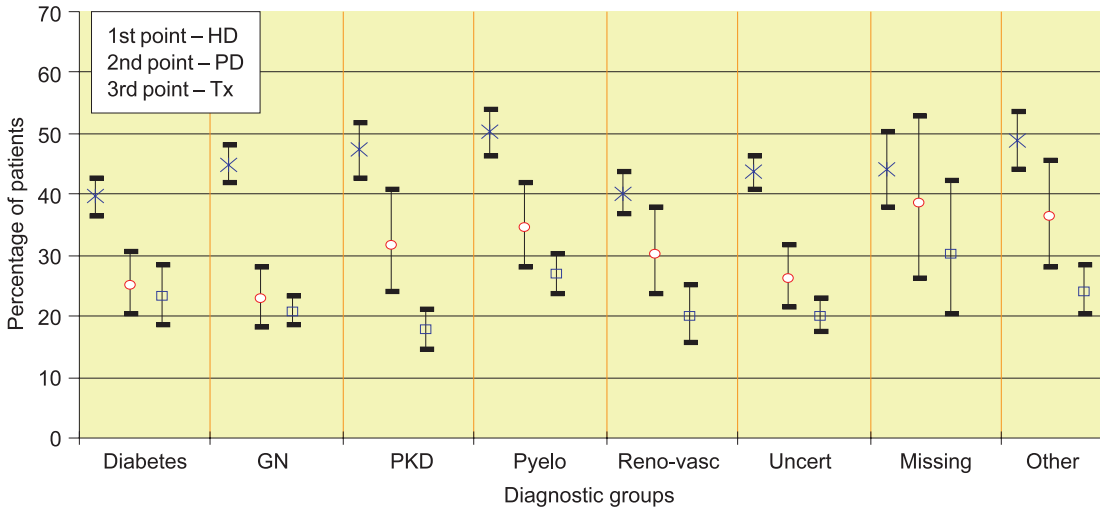

Figure 11.34: Percentage of patients by primary diagnosis achieving BP standard

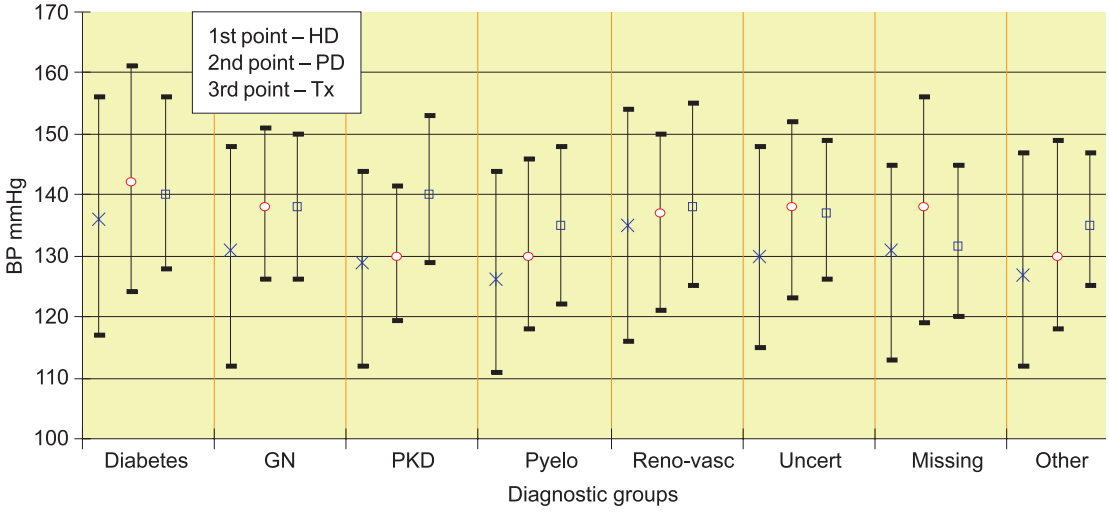

Figure 11.35: Median Systolic BP according to primary diagnosis

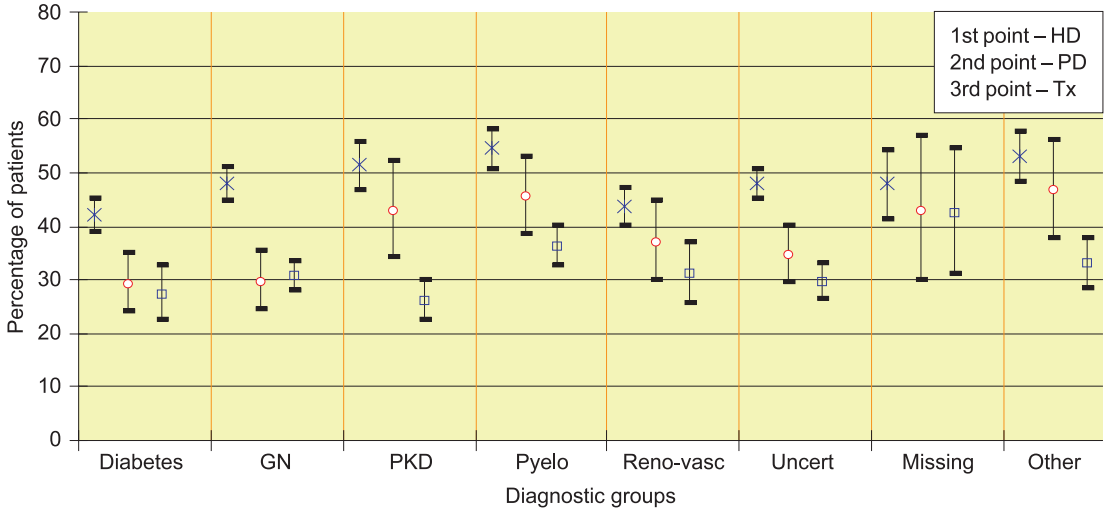

Figure 11.36: Percentage of patients by primary diagnosis achieving SBP standard

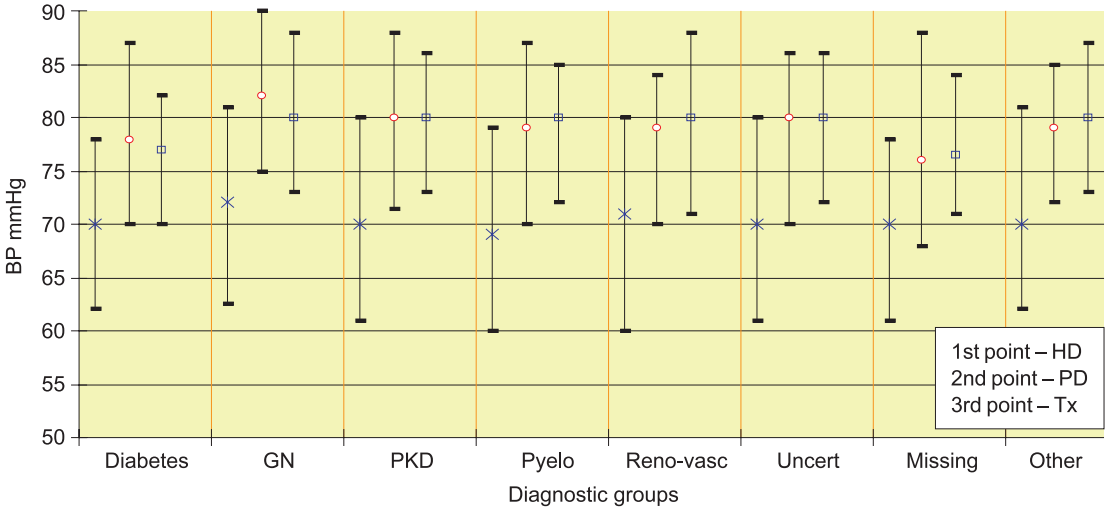

Figure 11.37: Median diastolic BP according to primary diagnosis

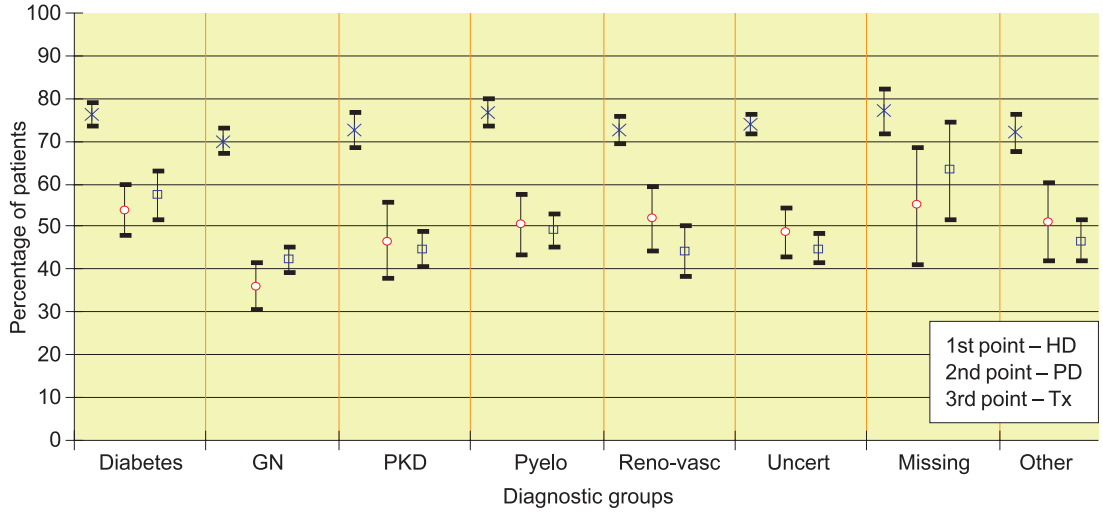

Figure 11.38: Percentage of patients by primary diagnosis achieving DBP standard

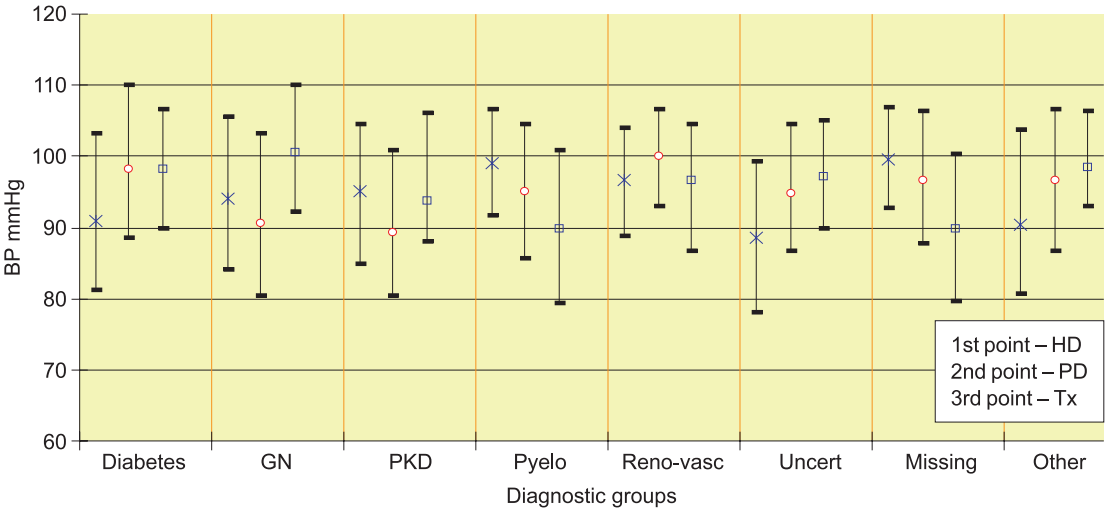

Figure 11.39: Median MAP according to primary diagnosis

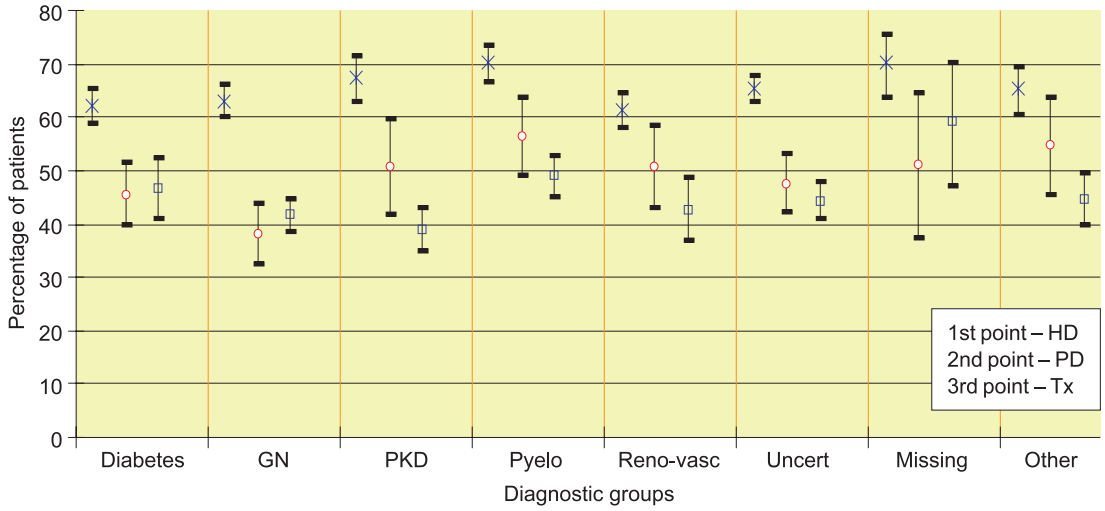

Figure 11.40: Percentage of patients by primary diagnosis achieving MAP standard

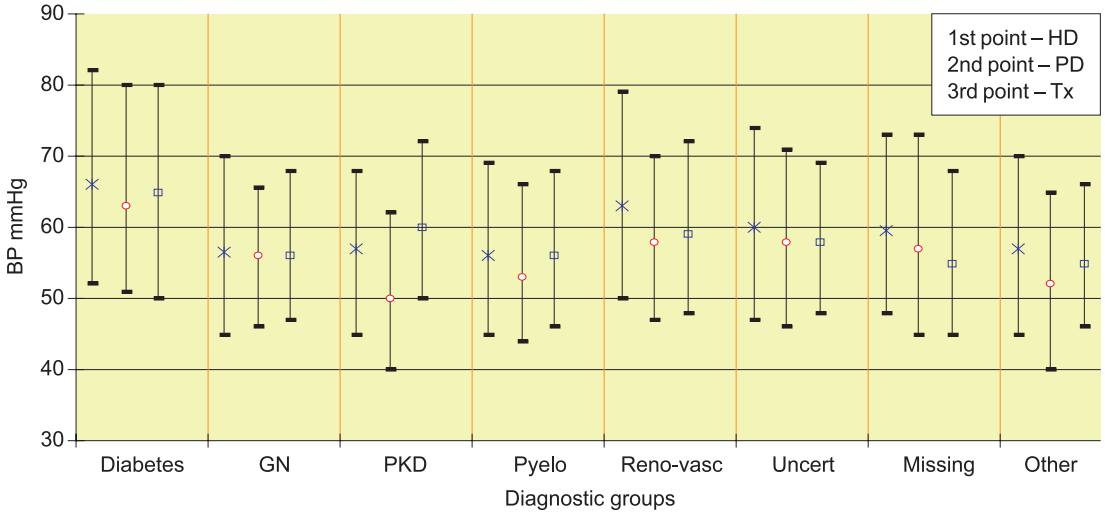

Figure 11.41: Median pulse pressure according to primary diagnosis

diabetics than non-diabetics across all treatment modalities. In non-diabetics on HD, salt intake correlates closely with water intake. Conversely, hyperglycaemia accounts for 50% of the water intake in diabetic patients on HD[16]. As the HbA1c standard was only achieved in 46% HD, 35% PD and 34% Tx patients, poor glucose control may contribute to poor blood pressure control in diabetic patients on RRT. There is a trend towards higher blood pressure readings in patients with glomerular rather than tubular disorders. As has occurred in previous years, blood pressure control is better in patients on HD compared with other treatment modalities for each of the diagnostic groups.

Blood pressure variability

Longitudinal studies in dialysis patients have identified seasonal variation in blood pressure with lower blood pressures in the warmer months, possibly related to temperature and humidity. Climate is also likely to have some effect on blood pressure variability in the UK. Each year the Renal Registry shows significant variation in achievement of the blood pressure standards by different centres suggesting that factors other than climate are responsible. This variability might either reflect differences in co-morbidity or differences in the blood pressure treatment protocols employed by individual units. On the whole, stable patients are treated in satellite units while patients with clinical problems dialyse in main units with more medical supervision. One might therefore predict greater blood pressure variability between patients and within individual patients dialysing in the main units when compared with patients dialysing in the associated satellite units.

Methods

Only main units with satellites were selected for this analysis. Patients were assigned to either a main or satellite unit on the basis of where they were dialysing 90 days after their first dialysis. Pre and post dialysis blood pressure measurements were obtained for each quarter.

- **Blood pressure variability in incident patients**. Patients starting haemodialysis during 2003 and 2004 were selected for this analysis. The first blood pressure recorded after 90 days was obtained for 1,300 patients from 30 main units and 465 patients from 67 satellite units. Blood pressure measurements were analysed for this cohort using the Mixed Model Analysis of Variance (see Appendix B). Initially, two analyses were performed to calculate the 'between centres' and 'residual' variances for main units and satellites separately. Residual variance covers factors that may account for variability that were not included in the model, eg ethnicity, primary renal diagnosis. These values were adjusted for age and the year in which the patient started RRT. The ratio of the variances for main units and satellites were calculated and their significance determined. The ratio is greater than 1.0 if variance is greater in the main units than in their satellite units.

- **Blood pressure variability in prevalent patients**. Patients were selected who started dialysis between 1998 and 2004 and had blood pressure data for at least eight consecutive quarters. Data were available for 1,615 patients in 19 main units and 544 patients in 29 associated satellites. Patients were not censored if dialysis location changed during this period. Initially, two analyses were performed to calculate 'between centres', 'between patients within centres' and 'residual' variances for main units and satellites separately. These values were adjusted for age and the year in which the patient started RRT and the ratios calculated as before.

- **Blood pressure variability by shift and day of the week**. Patients dialysing in Bristol during June and July 2005 were included in this analysis. In total, 317 patients were studied over this two month period. Analysis of variance was used to analyse blood pressure variability between inpatients dialysed on the main unit, main unit day shift patients, main unit twilight patients and satellite patients. Also analysis of variance was used to assess whether there was significant blood pressure variability by day of the week ie Monday–Tuesday vs Wednesday–Thursday vs Friday–Saturday.

Results

Table 11.2 shows blood pressure variability 90 days after starting dialysis using a single observation for patients in main and satellite units. Although there were differences noted

Table 11.2: Variance in BP of incident patients at day 90 in satellite units and their main unit

Parameter	Unit variance	Satellite variance	Ratio	p value
Pre HD				
SBP	19.1	21.4	0.89	0.625
DBP	5.9	3.8	1.54	0.074
MAP	8.3	7.0	1.17	0.288
PP	8.7	11.6	0.75	0.801
Post HD				
SBP	29.2	26.6	1.09	0.367
DBP	7.0	5.5	1.26	0.213
MAP	11.2	8.9	1.25	0.223
PP	14.3	16.2	0.88	0.633

Table 11.3: Variance in BP (over 2 years) between satellite and their main units

Parameter	Unit variance	Satellite variance	Ratio	p value
Pre HD				
SBP	16.2	27.3	0.59	0.873
DBP	3.3	3.9	0.85	0.630
MABP	5.7	9.6	0.59	0.875
PP	8.6	10.9	0.79	0.692
Post HD				
SBP	43.6	20.1	2.17	0.038
DBP	7.3	3.9	1.83	0.081
MAP	14.8	8.2	1.80	0.088
PP	21.0	6.3	3.32	0.003

between the BP variability in the satellite units and their main units none reached significance. As only one reading has been analysed per patient, it is not possible to distinguish whether the variability observed is 'between patients' or 'within patients'.

Table 11.3 shows blood pressure variability over a two year period for main units and their satellites. By comparison with main units, there was greater variability in all pre-dialysis readings in the satellite units although none of these differences reached significance. The trend in observed differences might be a result of differing criteria for patient transfer to satellite units or differences in medical supervision. In contrast, there was greater variability in post-dialysis readings in the main units than in the satellites and this difference was of significance for pulse pressure. Cardiac instability related to pre-existing co-morbidity or inter-current illness may be one possible explanation for this finding.

Table 11.4: Variance in BP (over 2 years) between patients at satellites and patients at main units

Parameter	Unit variance	Satellite variance	Ratio	p value
Pre HD				
SBP	237.0	226.7	1.04	0.272
DBP	55.2	58.8	0.93	0.810
MAP	83.5	83.3	1.01	0.496
PP	145.1	139.6	1.03	0.300
Post HD				
SBP	212.0	220.2	0.96	0.702
DBP	46.8	48.8	0.95	0.723
MAP	73.6	76.3	0.96	0.691
PP	126.5	132.7	0.95	0.746

Table 11.4 shows blood pressure variability over a 2 year period between patients in either main units or satellites. No significant differences were observed.

Tables 11.5 and 11.6, show blood pressure variability and blood pressure of 317 patients dialysing in Bristol over a two month period. Patient age and 'dialysis day within any given week' had significant impact on blood pressure variability. Blood pressure readings were

Table 11.5: BP variability by shift and days of the week

	Pre Haemodialysis				Post Haemodialysis			
Parameter	SBP	DBP	MAP	PP	SBP	DBP	MAP	PP
No of patients	317	317	317	317	317	317	317	317
No of obs used	8071	8068	8068	8068	7967	7967	7967	7967
Age (p-value)	**0.016**	**<0.001**	**0.015**	**<0.001**	**0.005**	**<0.001**	0.088	**<0.001**
Units (p-value)	0.233	0.056	0.084	0.593	0.446	0.095	0.230	0.522
Sessions (p-value)	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**0.029**
MT vs WT (p-value)	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**0.002**	**0.007**	**<0.001**	0.194
MT vs FS (p-value)	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**0.023**
WT vs FS (p-value)	0.336	0.705	0.636	0.924	0.464	0.806	0.560	0.643

Table 11.6: BP (mmHg) by days of the week

	Mon–Tue	Wed–Thu	Fri–Sat
Pre HD			
SBP	141.3	138.2	137.8
DBP	73.2	72.2	72.1
MAP	95.9	94.2	94.0
PP	68.0	65.8	65.7
Post HD			
SBP	132.6	131.3	130.8
DBP	69.5	68.7	68.6
MAP	90.6	89.6	89.4
PP	63.0	62.4	62.1

significantly higher after a 3-day interval (Monday–Tuesday) than they were after a 2-day interval (Wednesday–Thursday or Friday–Saturday) without dialysis. These data support the belief that fluid status has a significant effect on blood pressure in HD patients.

Discussion

In summary, greater blood pressure variability was evident between units rather than within patients within the same unit. The fact that there was not greater variability in the main units than in their satellite units contradicts the hypothesis that blood pressure variability primarily reflects patients' state of health. The Bristol data provide supportive evidence as neither inpatient status, dialysis location, nor dialysis shift had a major effect on blood pressure. There are several possible explanations for the observed trend towards an increased variability in pre-dialysis blood pressure within satellite units than their main unit. The impact of differences in case mix, treatment protocols and degree of medical supervision warrant further investigation. In addition the schedule for logging blood pressure readings into the database may itself generate some of this variability. The majority of main units will have the ability to log blood pressure readings for each dialysis session into their database. Whilst in some satellite units this is possible, in others there is not direct access to the database. In these units, blood pressure readings, which are often only a single observation for each patient per month, have to be transcribed by IT staff from paper into the database. If the date that readings are taken is not accurately recorded into the database the Registry will not be able to assign the reading to the correct day of the week or even the correct quarter for subsequent analyses. The Registry would like to ensure that blood pressure data are collected in a standardised way in units without direct IT links. If only a single observation is recorded for each patient per month the midweek blood pressure may be most informative. Further analysis needs to be performed by the Registry before making specific recommendations.

Serum Cholesterol and Achievement of the Standard

In the general population, higher cholesterol levels are associated with increased risk of cardiovascular death from atherosclerosis. Meta-analysis of 14 trials including 90,000 participants showed a clear benefit from statins for both primary and secondary prevention[17]. The 5-year event rate is typically reduced by 20% per mmol/L reduction in low-density lipoprotein (LDL) cholesterol, irrespective of the initial lipid profile. By contrast, only a weak association is shown between cholesterol reduction and incidence of heart failure, the more common manifestation of uraemic cardiomyopathy. Unfortunately too few patients with CKD were included in these trials to assess whether they also derived benefit from statins.

The typical lipid profile in renal failure includes raised triglycerides, low high-density lipoprotein (HDL) and variable changes in low-density lipoprotein and total cholesterol. It is far from clear whether a high cholesterol level has the same significance in renal patients as it does for the general population. Each year the Renal Registry reports a U-shaped and reverse association between cholesterol level and short term survival for dialysis patients. The Chronic Renal Impairment in Birmingham (CRIB) study shows no association between baseline cholesterol level and four year mortality in a cohort of 370 patients with CKD[18]. Furthermore there is no definitive evidence that statins significantly reduce cardiac death in patients on RRT. The Assessment of Lescol in Renal Transplantation (ALERT) study compared fluvastatin 40 mg vs placebo in 2,102 renal transplant patients[19]. Although LDL fell on average by 1 mmol/L the reduction in cardiac death and myocardial infarction was not significant over six years follow up. The Deutsche Diabetes Dialyse (4-D) study compared atorvastatin 20 mg vs placebo in

1,255 HD patients with Type 2 diabetes[20]. LDL fell on average by 1.2 mmol/L but the reduction in cardiac death and myocardial infarction was not significant over a 4 year period. Only a quarter of cardiac deaths were attributed to acute myocardial infarction in the ALERT and 4-D studies, heart failure, arrhythmia and sudden death being more common. These initial trials therefore support conclusions drawn from general population studies that non-infarction cardiac death is not related to cholesterol level or reduced by statin use. Statins do offer effective secondary prevention in renal patients with established atherosclerosis. The Cholesterol and Recurrent Events (CARE) study showed pravastatin 40 mg reduced further cardiac events in 1,711 patients with previous myocardial infarction and mild CKD[21].

The Renal Association set standards for lipids for the first time in August 2002. The current standards are:

Primary prevention:

Statins should be initiated in dialysis patients with a 10 year risk of coronary disease >30% to achieve:

Total cholesterol <5 mmol/L or a 30% reduction from baseline

Fasting LDL-cholesterol of <3 mmol/L

Secondary prevention:

Patients should be treated with aspirin, an ACE inhibitor, a beta-blocker and a statin unless contraindicated.

As discussed in last year's report, European guidelines suggest the dialysis standards should be applied to transplant patients and recommend lower targets for patients with established cardiovascular disease or diabetes (total cholesterol <4.5 mmol/L and LDL-cholesterol 2.5 mmol/L). Lipid profiles should be checked annually for transplant patients and every 6 months for dialysis patients. Blood samples should be taken immediately before dialysis or at least 12 hours after, preferably with the patient in a fasting state. The current audit is based on random, non-fasting total cholesterol measurements.

Cholesterol data returns

Units with data for less than 35% of patients in a particular treatment modality were excluded

Table 11.7: Percentage of patients with complete returns of cholesterol values by modality

	% completed data		
	HD	**PD**	**Tx**
Bangor	92	96	n/a
Barts	n/a	n/a	n/a
Basildon	97	100	92
Bradford	87	100	94
Brighton	38	77	55
Bristol	94	93	98
Cambridge	58	96	50
Carlisle	82	86	87
Carshalton	3	18	14
Chelmsford	69	76	20
Clwyd	24	17	100
Coventry	0	0	0
Cardiff	87	92	87
Derby	81	76	45
Dorset	83	93	89
Dudley	54	65	63
Exeter	96	90	86
Gloucester	91	96	77
Guys	90	96	71
H&CX	100	99	97
Heartlands	41	96	44
Hull	84	77	54
Ipswich	97	96	93
Kings	82	63	91
Leeds	86	88	94
Leicester	85	96	94
Liverpool	5	2	19
ManWst	64	88	75
Middlesbrough	97	100	84
Newcastle	92	100	97
Norwich	99	100	95
Nottingham	80	94	91
Oxford	94	87	83
Plymouth	89	81	91
Portsmouth	40	61	74
Preston	98	99	72
QEH	94	97	93
Reading	97	96	88
Sheffield	94	61	98
Shrewsbury	97	94	44
Stevenage	47	86	62
Southend	92	95	90
Sunderland	96	100	99
Swansea	85	97	93
Truro	90	94	87
Wirral	n/a	n/a	n/a
Wolverhampton	93	92	87
Wrexham	72	83	81
York	81	86	62
England	72	74	71
Wales	81	91	87
England & Wales	72	75	72

from the cholesterol analyses. Six centres had insufficient data for HD, six centres insufficient data for PD and five centres insufficient data for Tx (Table 11.7). Transfer of laboratory data to renal IT systems is now available in all main renal units but not all satellites. In the centres without data they may either not be measuring cholesterol regularly or the Renal Registry is not extracting available data, in which case they should contact the Registry.

Figures 11.42–11.48 show wide variation between units achieving the cholesterol standard. In England & Wales, the number of patients achieving the standard for HD average 81% (range 65–95%), 65% for PD (range 26–83%) and 57% for Tx (range 36–77%). Chi squared testing indicates the variation between centres for each treatment modality is significant ($p < 0.0001$).

As in previous years, cholesterol levels are significantly lower in HD patients; the median cholesterol concentration for HD, PD and transplant is 4.0, 4.5 and 4.8 mmol/L respectively. The Renal Registry does not have drug data to correlate cholesterol levels with statin use. There are reports that the lower cholesterol level found in HD patients is due to increased plasma water, however the Registry does not collect haematocrit data to test this hypothesis. Furthermore, the Registry does not have

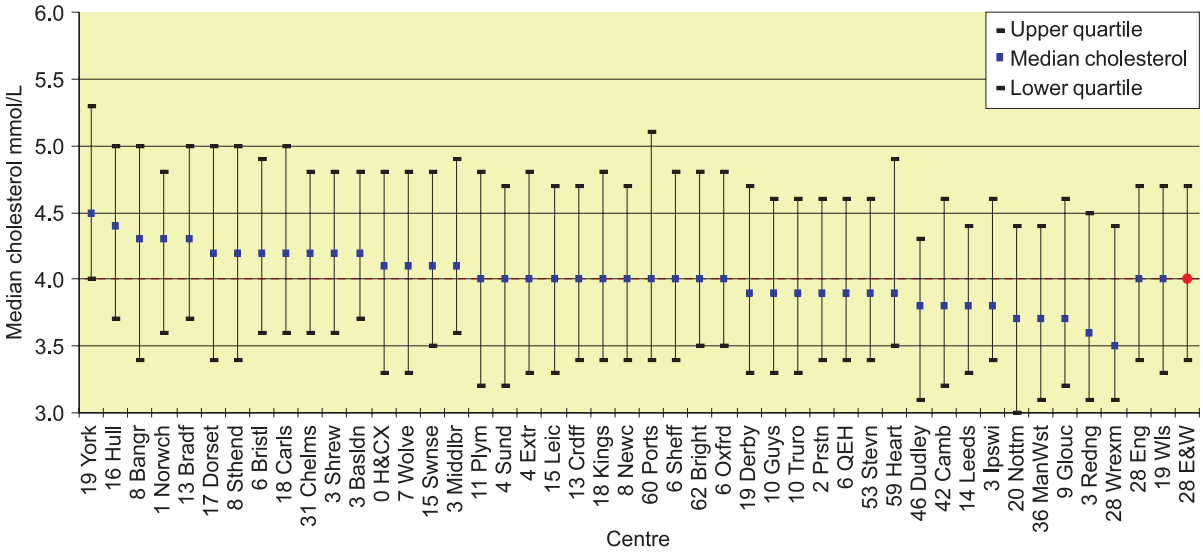

Figure 11.42: Median cholesterol: HD

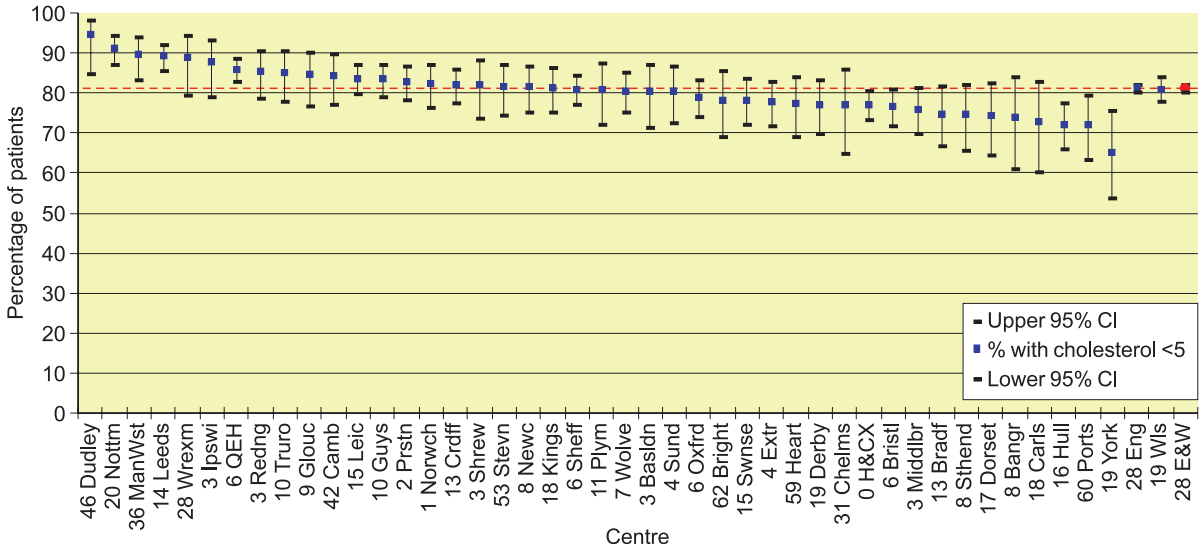

Figure 11.43: Percentage of patients with cholesterol <5 mmol/L: HD

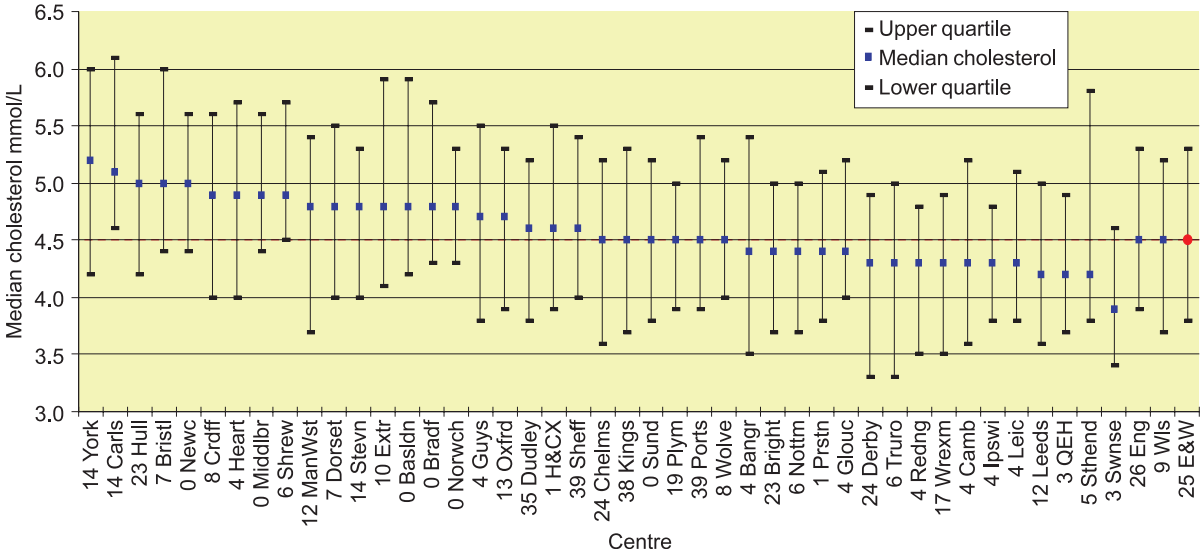

Figure 11.44: Median cholesterol: PD

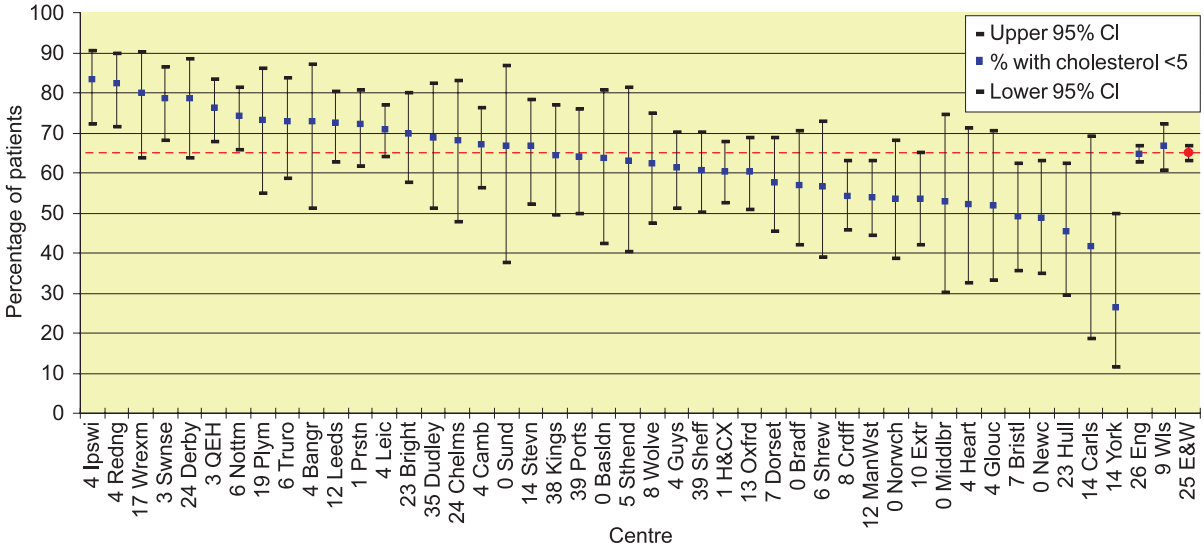

Figure 11.45: Percentage of patients with cholesterol <5 mmol/L: PD

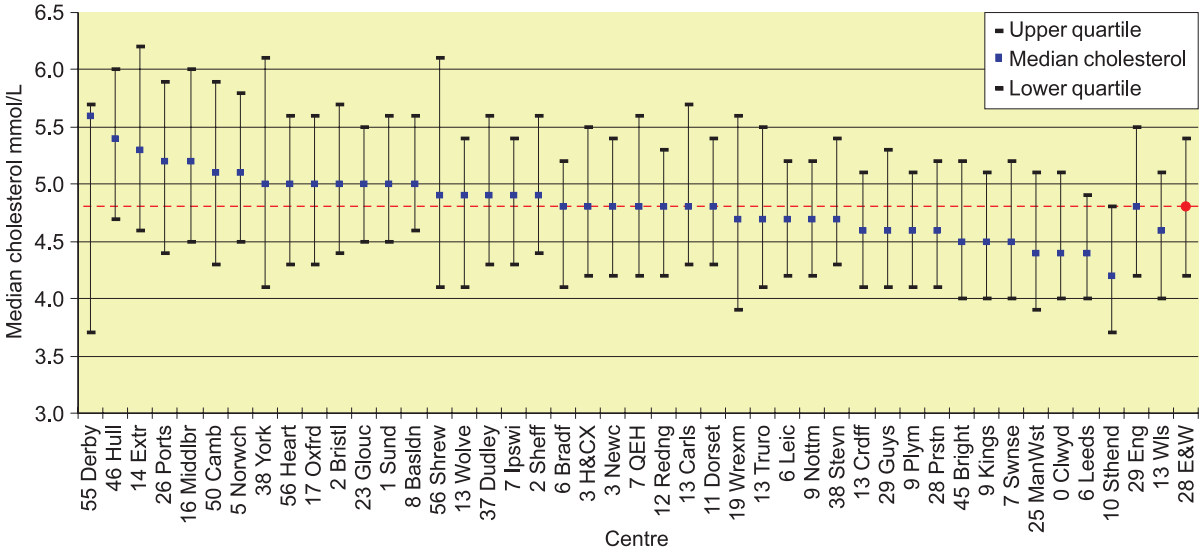

Figure 11.46: Median cholesterol: Tx

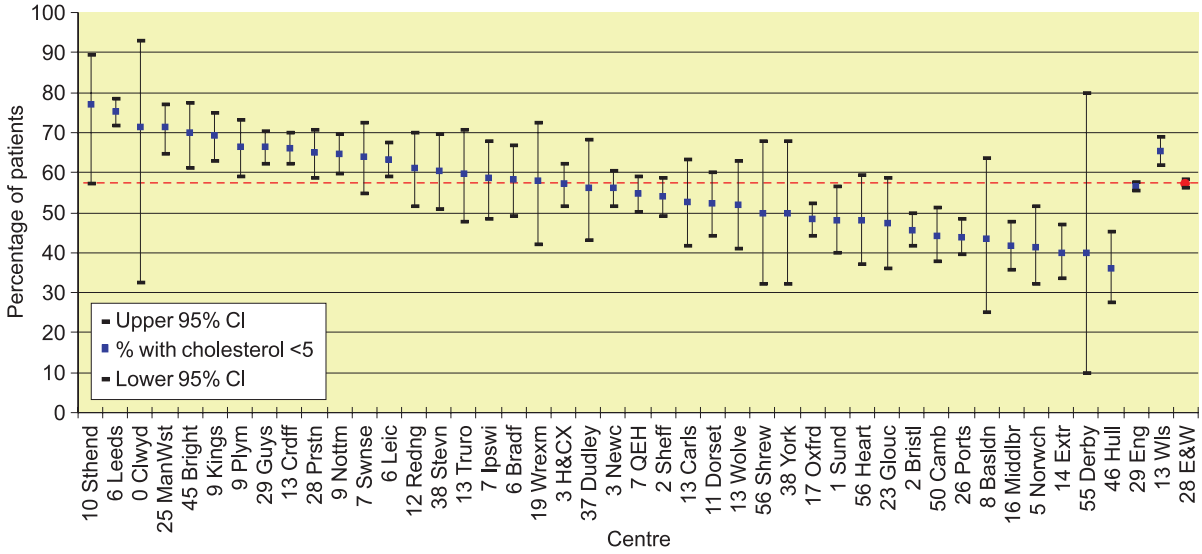

Figure 11.47: Percentage of patients with cholesterol <5 mmol/L: Tx

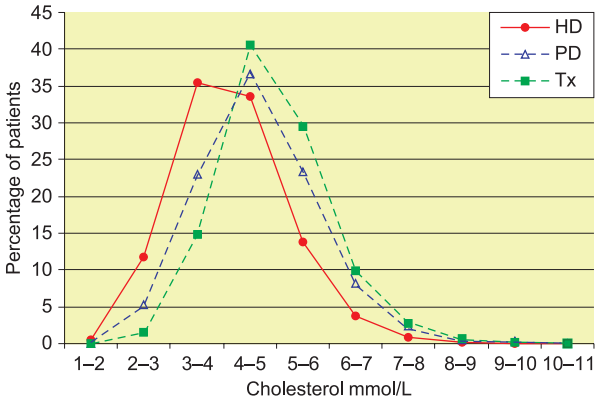

Figure 11.48: Serum cholesterol distribution by modality 31/12/2004

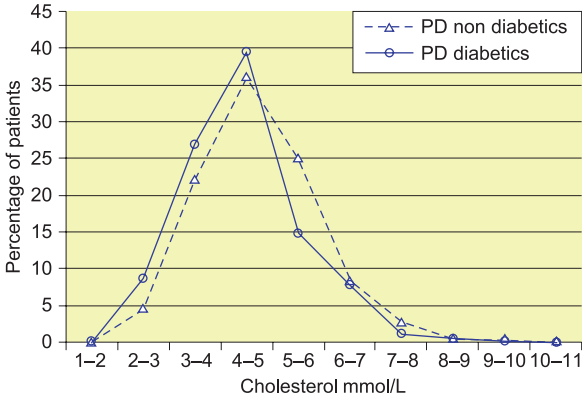

Figure 11.50: Distribution of serum cholesterol diabetics v non-diabetics: PD

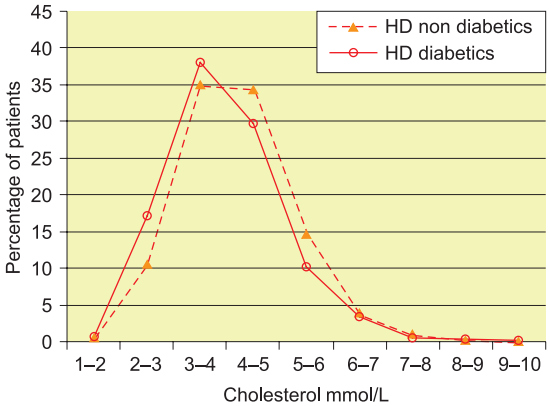

Figure 11.49: Distribution of serum cholesterol diabetics v non-diabetics: HD

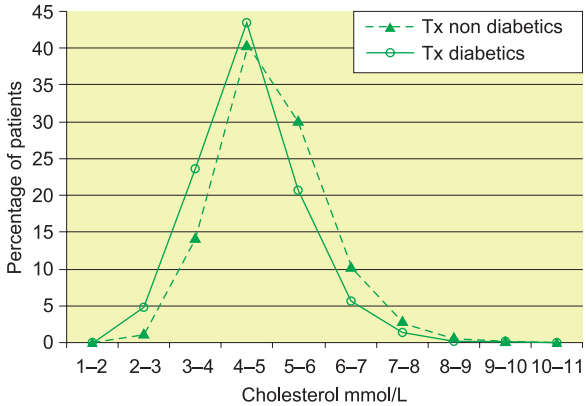

Figure 11.51: Distribution of serum cholesterol diabetics v non-diabetics: Tx

C-reactive protein (CRP) data to correlate with cholesterol levels for the different treatment modalities.

Figures 11.49–11.51 show lower cholesterol levels in diabetics for each treatment modality. However, these differences are not significant.

Change in cholesterol achievement 1997–2004

Figure 11.52 shows the cholesterol data for all treatment modalities between 1997 and 2004. Figures 11.53–11.55 show these data by centre. Over 8 years cholesterol levels have fallen in all treatment groups and it is likely this is due to statin use. The percentage of patients currently achieving the standard for HD, PD and Tx is 81%, 65% and 57% respectively. The majority of units show an improvement in cholesterol control over this period. The units with the worst control initially show a fall in median cholesterol in excess of 1 mmol/L (data not shown). Previously, the Finnish Renal Registry has shown that a fall in total cholesterol is mainly due to a fall in LDL-cholesterol and that triglycerides are highest in PD patients and HDL-cholesterol is highest in Tx patients. Data from the SHARP trial should indicate whether lipid profiles of UK patients show similar trends.

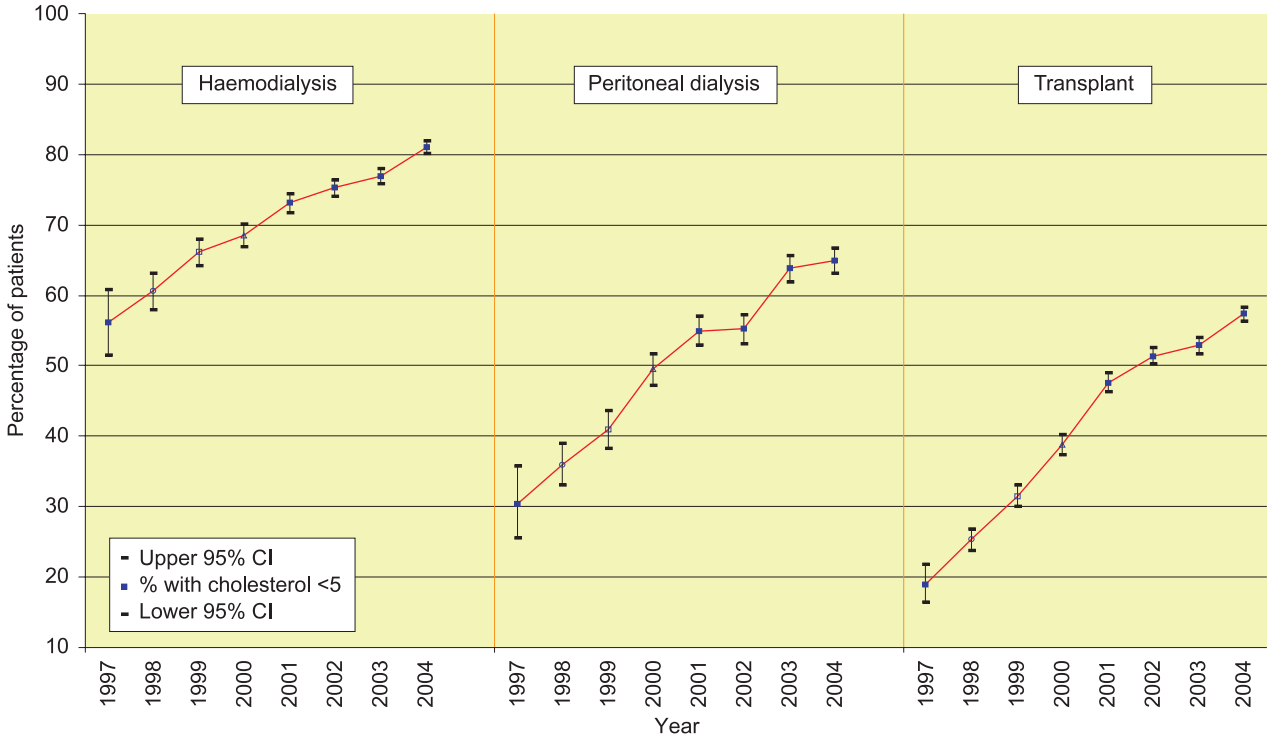

Figure 11.52: Percentage of patients with cholesterol <5 mmol/L HD vs PD vs Tx 1997–2004

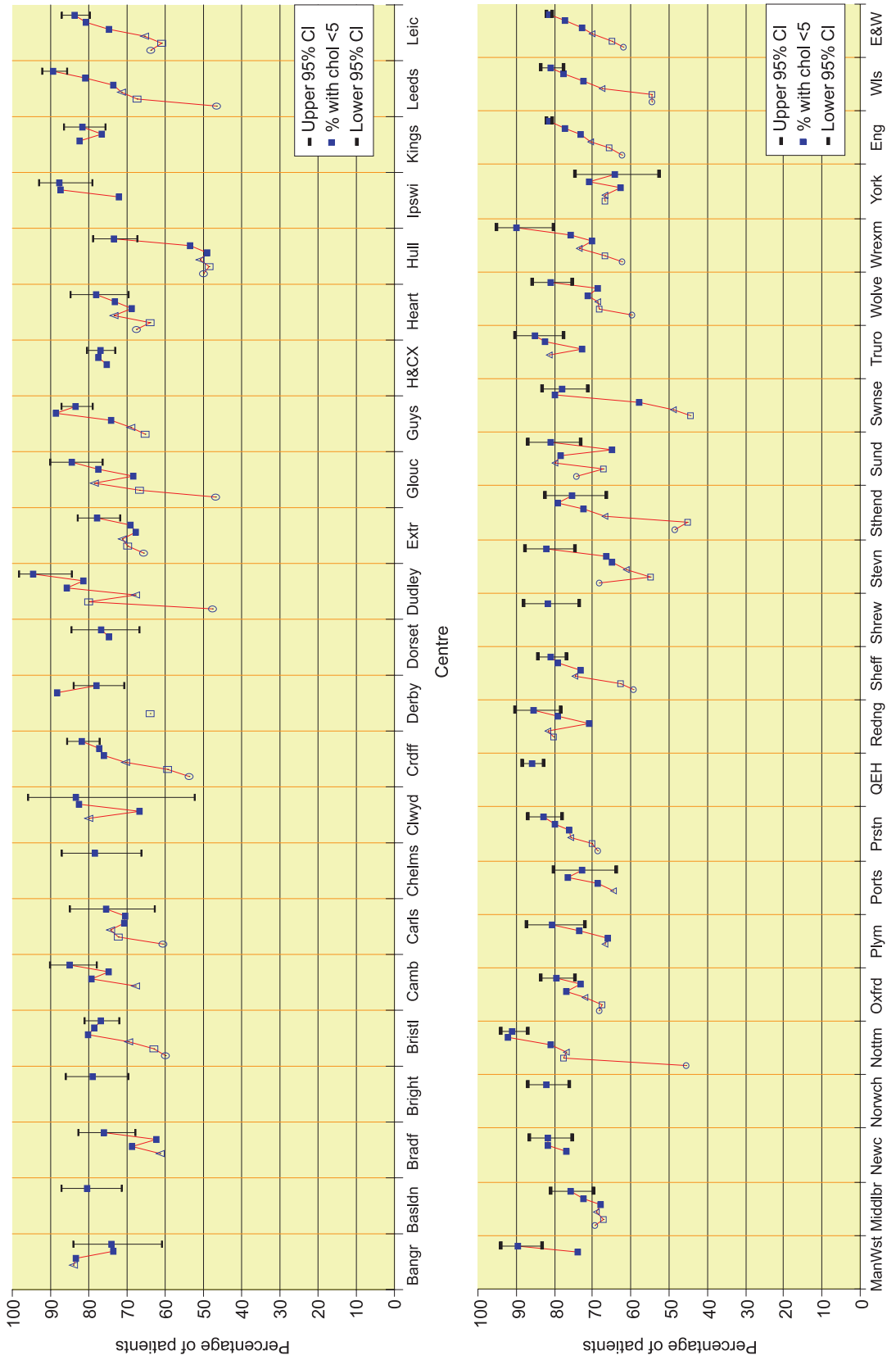

Figure 11.53: Change in % HD patients with cholesterol <5 mmol/L by centre 1998–2004

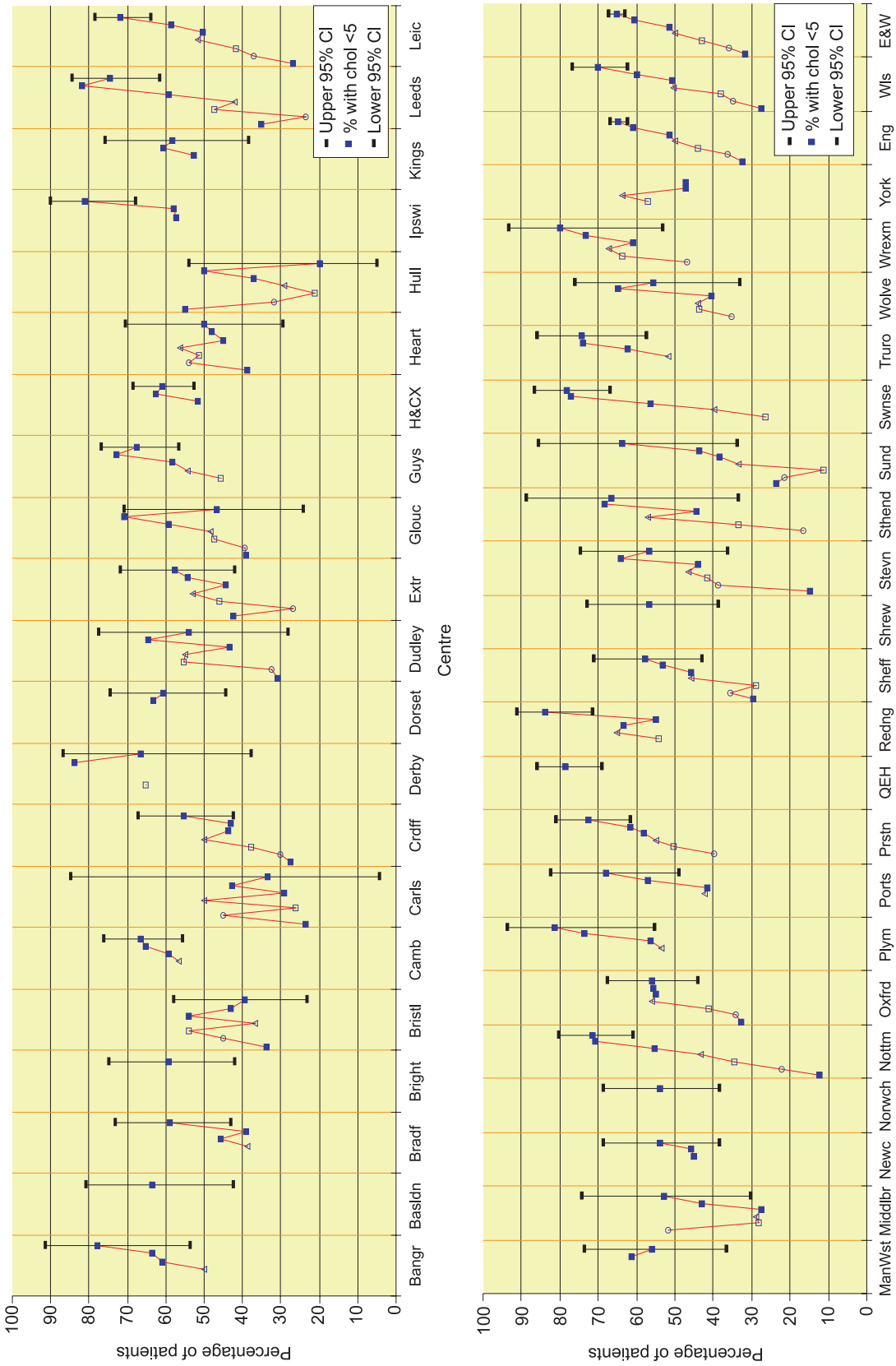

Figure 11.54: Change in % PD patients with cholesterol <5 mmol/L by centre 1998–2004

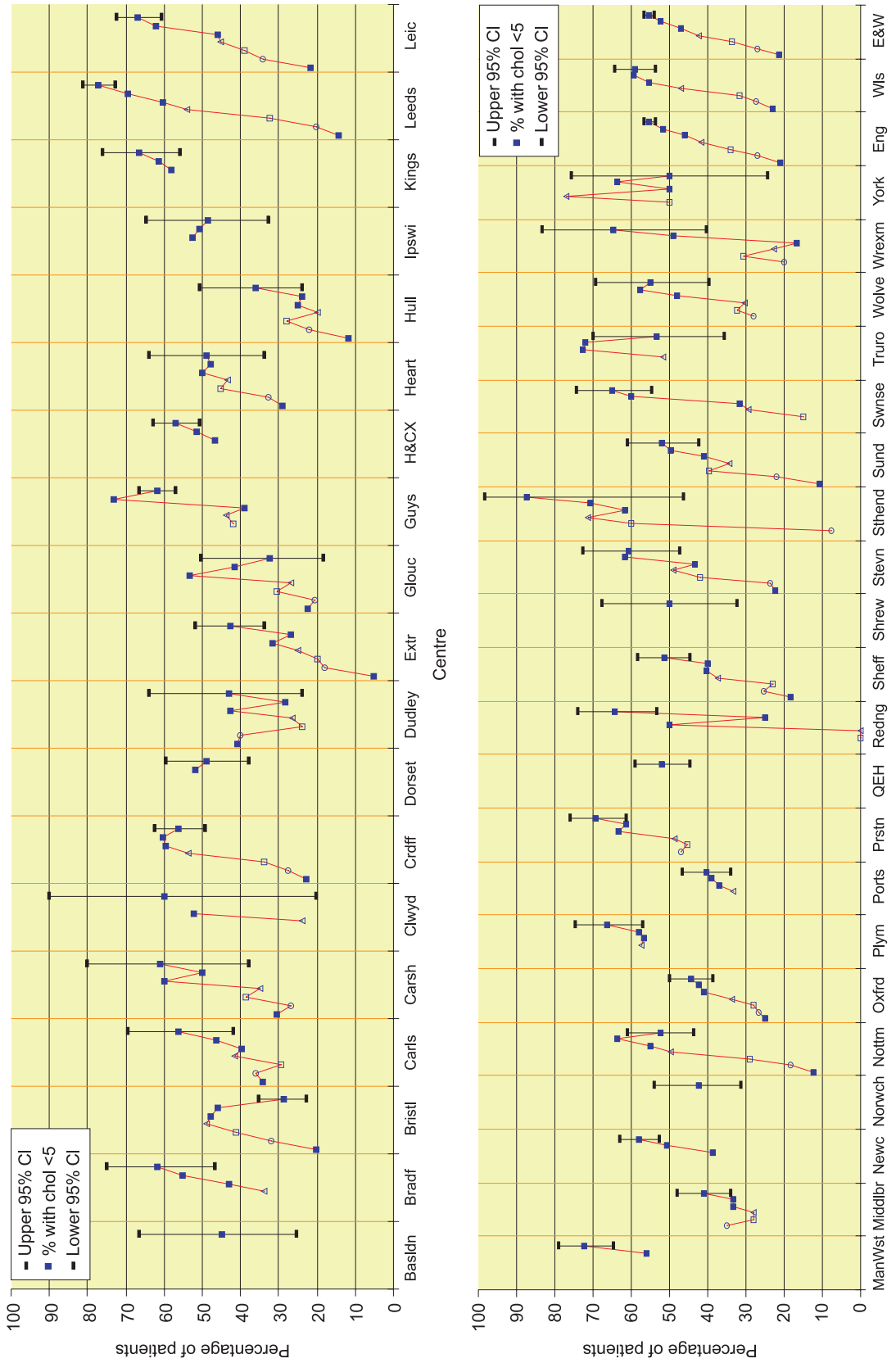

Figure 11.55: Change in % Tx patients with cholesterol <5 mmol/L by centre 1998–2004

Ongoing Trials

The AURORA study is investigating rosuvastatin 10 mg vs placebo in 2,700 HD patients and results are expected in 2008. The SHARP trial is investigating ezetimibe 10 mg/simvastatin 20 mg vs placebo in 9,000 CKD patients (3,000 on dialysis). Results are expected in 2009.

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Chapter 12: Some Measures of Care of Renal Transplant Patients

Summary

- The number of patients waiting on the active transplant list on 31 December 2004 was 5,299 (90 per million population), a 3% rise from 5,156 in 2003. The total number of renal transplants performed in the UK in 2004, was 1,905 which is equivalent to 32 transplants per million population.

- Much of the post renal transplantation follow-up is done in the original referring non-transplant renal unit, starting at varying intervals from the date of original post-transplant discharge up to one or more years later. Interpretation of results by transplant centre is then difficult as this pattern of care transfers much of the responsibility for outcomes on to the referring renal centre.

- Patients from ethnic minorities are listed for transplantation proportionately to their representation on dialysis, but wait significantly longer to receive a transplant.

- There is no significant variation between centres in attained haemoglobin when post transplant eGFR is >30, but when eGFR is <30 some renal units fail to maintain adequate haemoglobin in many patients.

- The collaboration between the UKRR and UKT is complementary, providing a unique database which will enable better understanding of renal transplant related activity, processes and outcomes. Chapter 5 and the work reported in this chapter are a small beginning in exploring the potential of this collaboration.

Introduction

This transplant chapter is produced in collaboration with UK Transplant (UKT) to assess key indicators of quality of care and outcome amongst renal transplant recipients and define trends in such variables in the UK. It includes data from the UK Renal Registry (RR), and from UK Transplant databases. The databases are very different: UKT has detailed data related to the episode of transplantation, tissue matching, etc, the RR has more detailed data on the whole renal patient pathway and sequential variables such as blood pressure, serum creatinine, cholesterol, etc. The collaboration between the RR and UKT is thus complementary, providing a unique database which will enable better understanding of not only renal transplant related activity, but also outcomes post transplantation in the UK. This chapter is a small beginning in exploring the potential of this collaboration.

As in previous years, the number preceding the centre name in the figures indicates the percentage of missing data for that centre.

Overview

There was no change in the number of transplanting centres in the UK in 2004. There remained 14 centres outside of London performing renal transplantation in England – Birmingham, Bristol, Cambridge, Coventry, Leeds, Leicester, Liverpool, Manchester, Newcastle, Nottingham, Oxford, Plymouth, Portsmouth and Sheffield, with one Welsh centre – Cardiff, although patients from North Wales are transplanted in Liverpool. In London, the eight transplant centres have amalgamated to create five centres: St Helier (Carshalton) with St George's, Guy's Hospital in South Thames, the Middlesex with the Royal Free Hospital (combined in April 2005), Hammersmith with St Mary's (combined in October 2005), and the Royal London Hospital in North Thames. There are transplant centres in Belfast for Northern Ireland, and Edinburgh and Glasgow for Scotland.

There has been no change in the number or constituents of transplant centres in any of the alliances: North Thames (Hammersmith/St Mary's, The Royal London, Royal Free/Middlesex), South Thames (St Helier/St

George's & Guy's Hospital), North of England (Leeds, Liverpool, Manchester & Newcastle), Trent (Leicester, Nottingham, Sheffield), South West & Wales (Bristol, Cardiff, Oxford, Plymouth, Portsmouth) and Scotland (Edinburgh & Glasgow). Belfast, Birmingham, Cambridge and Coventry continue to be separate stand-alone centres independent of any alliance.

Information on number of patients on the waiting list, cadaveric and living kidney donor numbers from 1995–2004 is available from the UKT website (http://www.uktransplant.org.uk/ukt/statistics/calendar_year_statistics/kidney/kidney.jsp).

The proportion of all patients requiring renal replacement therapy provided by transplantation stands at 45% in 2004. During 2004, 2.2% of all prevalent renal transplant grafts failed, the same as last year, and the annual death rate in prevalent patients with renal transplant was 2.2%, or 2.4% if patients with failed grafts returning to dialysis are included.

The waiting list and number of transplants performed

The number of patients waiting on the active transplant list on 31 December 2004 was 5,299 (90 per million population), a 3% rise from 5,156 in 2003. The total number of renal transplants performed in the UK in 2004, including those transplanted in combination with other organ transplants, was 1,905 which is equivalent to 32 transplants per million population (Table 12.1).

Table 12.1: Kidney transplants performed in the UK, 1 January 2003–31 December 2004

Organ	2003	2004	% change
Heartbeating kidney[1]	1,134	1,211	7
Non-heartbeating kidney	112	147	31
Living donor kidney	451	463	3
Kidney and heart	1	0	–
Kidney and liver	8	15	–
Kidney and pancreas	42	69	64
Total kidney transplants	**1,748**	**1,905**	**9**

[1]Includes en bloc kidney transplants (4 in 2003, 3 in 2004) and double kidney transplants (6 in 2003, 5 in 2004).
– Percentage not reported when fewer than 10 transplants in either year.

In 2004 there was no significant change in median age (45.8 years) or gender distribution (M : F 1.72) amongst incident transplant patients in comparison to previous years.

Centre specific renal transplant activity and patients on the active waiting list for 2003 and 2004 are shown in Table 12.2.

Table 12.2: Cadaveric and living donor kidney transplants in the UK, 1 January 2003–31 December 2004, by transplant centre/alliance

	2003					2004				
Centre	**HB***	**NHB****	**Living**	**Total**	**Waiting list**	**HB***	**NHB****	**Living**	**Total**	**Waiting list**
Belfast	40	0	5	**45**	204	49	0	9	**58**	206
Birmingham	91	0	19	**110**	452	87	0	32	**119**	457
Bristol	76	12	35	**123**	230	62	15	27	**104**	243
Cambridge	46	15	13	**74**	240	54	21	12	**87**	233
Cardiff	71	0	13	**84**	211	70	2	15	**87**	197
Coventry	5	0	14	**19**	114	17	0	19	**36**	91
Edinburgh	46	0	15	**61**	192	40	0	16	**56**	234
Glasgow	59	0	25	**84**	241	54	0	14	**68**	237
Great Ormond St	11	0	16	**27**	17	14	0	14	**28**	25
Leeds	97	12	28	**137**	340	113	25	31	**169**	331
Leicester	15	3	28	**46**	163	31	0	24	**55**	224
Liverpool	63	0	18	**81**	215	52	0	20	**72**	207
Manchester	103	0	29	**132**	479	125	8	27	**160**	505
Newcastle	71	17	18	**106**	166	61	23	16	**100**	194
North Thames	**120**	**13**	**53**	**186**	**701**	**134**	**18**	**68**	**220**	**709**
St Mary's	32	4	23	**59**		30	5	29	**64**	
Royal Free	21	2	8	**31**		20	2	14	**36**	
Middlesex	11	1	1	**13**		13	3	4	**20**	
Royal London	39	4	15	**58**		42	2	18	**62**	
Hammersmith	17	2	6	**25**		29	6	3	**38**	
Nottingham	20	0	14	**34**	164	31	0	16	**47**	158
Oxford	50	20	14	**84**	169	52	9	17	**78**	186
Plymouth	27	0	13	**30**	93	36	0	3	**39**	109
Portsmouth	30	0	13	**43**	123	44	2	9	**55**	107
Sheffield	37	0	6	**43**	262	36	0	5	**41**	237
South Thames	**107**	**20**	**70**	**197**	**380**	**133**	**24**	**63**	**220**	**409**
Guy's	63	6	42	**111**		79	12	50	**141**	
King's College	2	0	0	**2**		5	0	0	**5**	
St George's	42	14	28	**84**		49	12	13	**74**	
Private hospitals	0	0	2	**2**		0	0	6	**6**	
TOTAL	**1,185**	**112**	**461**	**1,748**	**5,156**	**1,295**	**147**	**463**	**1,905**	**5,299**

*Heart beating.
**Non-heart beating.

Patient and graft survival

Data on patient and graft survival in each transplant centre of cadaveric first kidney transplants performed 1999–2003 were provided by UKT (Table 12.3).

Ethnicity and transplantation

The RR routinely collects ethnicity data for RRT patients from contributing centres, however ethnicity reporting continues to be poor. The proportions of the various ethnic groups amongst prevalent dialysis patients and transplant patients were compared with the proportions on the renal transplant waiting list in Table 12.4. These results suggest that patients from ethnic minorities are listed for transplantation proportionately to their representation on dialysis, but wait significantly longer to receive a transplant. There is further information on this and the role of social deprivation in Chapter 5.

UKT figures show that donors from ethnic minorities comprise 3.4% of all deceased donors in 2004, a lower figure than the

Table 12.3: One-year transplant and patient survival for cadaveric[1] donor first kidney transplants in adult patients, 1 January 1999–31 December 2003

		Risk-adjusted patient survival		Risk-adjusted transplant survival	
Kidney transplant centre	No of transplants	Survival estimate (%)	95% CI	Survival estimate (%)	95% CI
Addenbrooke's Hospital, Cambridge	213	96	81–100	89	75–100
Belfast City Hospital, Belfast	149	97	81–100	87	72–100
Churchill Hospital, Oxford	254	93	81–100	89	78–100
Derriford Hospital, Plymouth	137	92	75–100	82	67–99
Freeman Hospital, Newcastle	349	94	83–100	86	76–97
Guy's Hospital, London	300	96	84–100	91	79–100
Hammersmith Hospital, London	111	93	74–100	89	71–100
Leicester General Hospital, Leicester	142	93	75–100	85	69–100
Manchester Royal Infirmary, Manchester	403	96	86–100	90	80–100
Northern General Hospital, Sheffield	138	97	80–100	89	73–100
Nottingham City Hospital, Nottingham	99	93	73–100	83	65–100
Queen Alexandra Hospital, Portsmouth	141	96	80–100	88	73–100
Queen Elizabeth Hospital, Birmingham	346	95	83–100	86	75–98
Royal Infirmary of Edinburgh, Edinburgh[2]	205	97	83–100	89	76–100
Royal Liverpool University, Liverpool	218	96	81–100	86	73–100
Southmead Hospital, Bristol	212	94	81–100	91	78–100
St George's Hospital, London[3]	262	96	84–100	92	81–100
St James's University Hospital, Leeds	329	95	84–100	85	75–96
St Mary's Hospital, London	126	98	80–100	94	77–100
The Royal Free Hospital, London[4]	69	92	67–100	88	65–100
The Royal London Hospital, London	192	95	80–100	88	74–100
University Hospital of Wales, Cardiff	236	97	83–100	91	78–100
Walsgrave Hospital, Coventry	77	96	73–100	91	69–100
Western Infirmary, Glasgow	224	94	81–100	85	73–99

[1]Heartbeating and non-heartbeating donor transplants included.
[2]Includes transplants carried out by Dundee and Aberdeen at a time before Edinburgh took over all their transplant activity from November 1999 and December 2003, respectively.
[3]Includes transplants carried out by Brighton and Carshalton at a time before St George's took over all their transplant activity from July 1996 and November 2003, respectively.
[4]As of April 2005, all kidney transplant activity ceased at Middlesex following gradual handover to the Royal Free from 2003. Data for the Middlesex are not presented.

Table 12.4: Ethnic distribution of prevalent patients and the transplant waiting list*, and median waiting times to transplant for patients registered on the waiting list**

Ethnicity	Dialysis patients %	Transplant patients %	% waiting for transplant	N waiting for transplant	Median waiting time (days)*	95% CI
White	82	88	84	4,628	719	680–758
Asian	9	6	10	571	1,368	1,131–1,605
Black	5	3	5	255	1,419	1,165–1,673
Other	4	3	1	83	1,043	689–1,397
Total				**5,537**	**798**	**761–835**
Not reported				107		

*31.12.2004.
**Those registered 1998–2000.

proportion of ethnic minorities in the general population of England and Wales (12.5%). However UKT have also surveyed deaths on intensive care units and there appears to be a smaller representation of ethnic minorities dying on intensive care units (6.3%), and therefore fewer are able to become donors. The reason for the low representation on intensive care units needs to be investigated. New organ allocation rules, which come into effect from April 2006, have been devised to some extent with a view to improving access to transplantation for ethnic minorities and decreasing their waiting time on the transplant list.

Post transplant follow up

From the renal registry information it is apparent that where transplant units transplant for other renal units, much of the post renal transplantation follow up is being done in the original referring non-transplant renal unit, starting at varying intervals from the date of original post-transplant discharge up to one or more years later. Interpretation of results by transplant centre is then difficult as this pattern of care transfers much of the responsibility for outcomes on to the referring renal centre.

Post transplant variables

Data on demographic and post-transplant clinical variables are available for analysis from the 49 renal centres in England and Wales contributing to the RR in 2004, 17 of which perform renal transplantation; demographic data are available from Scotland. During 2004, 1,265 (66%) of the 1,905 renal transplants were performed or followed up in renal units contributing data to the Registry. Several large transplant centres did not contribute data for 2004, including Manchester Royal Infirmary, St Mary's Hospital, and St George's Hospital. It is anticipated that the Registry will have full participation of all units within 2 years.

Established transplant function

Transplant function of prevalent patients continues to be assessed by the most recent serum creatinine available within the last six months of 2004 and by estimated GFR using the abbreviated MDRD equation. The median eGFR of prevalent patients is shown in Figure 12.1. This type of analysis may well be influenced by follow-up patterns, and interpretation is difficult. It is noticeable that the centres with the highest median eGFRs are largely the transplant centres. It is probable that patients with failing grafts are sent back to the referring renal units for preparation for dialysis.

The percentages of prevalent transplant patients with eGFR >60 mls/min and >30 mls/min being followed up in each centre are represented in Figures 12.2 and 12.3.

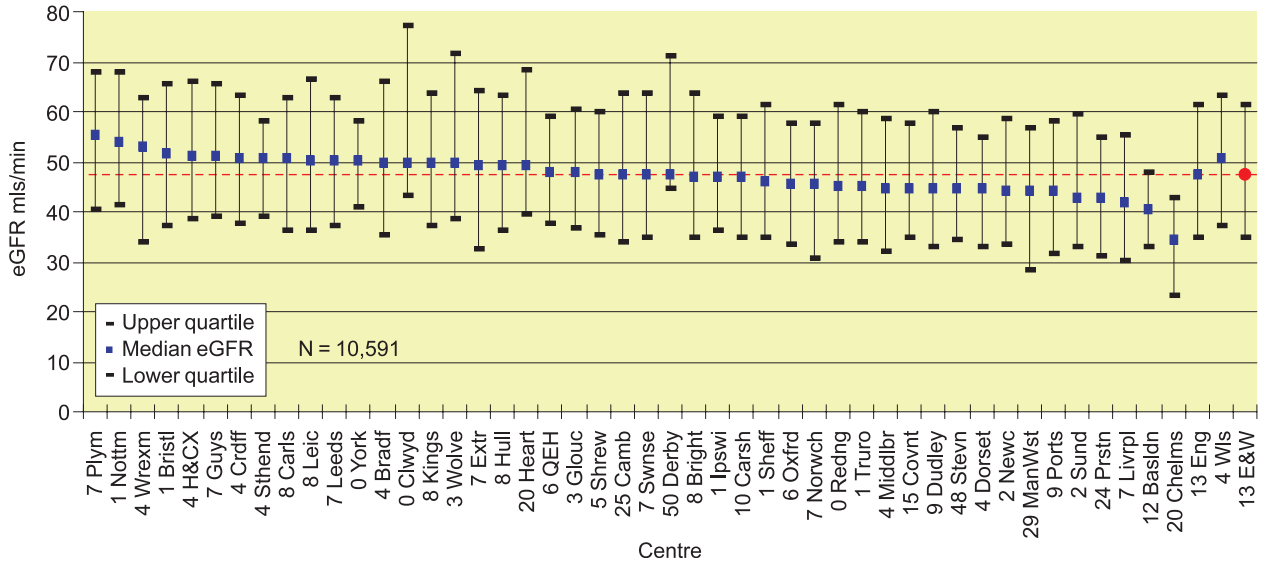

Figure 12.1: Median eGFR of prevalent transplant patients by centre

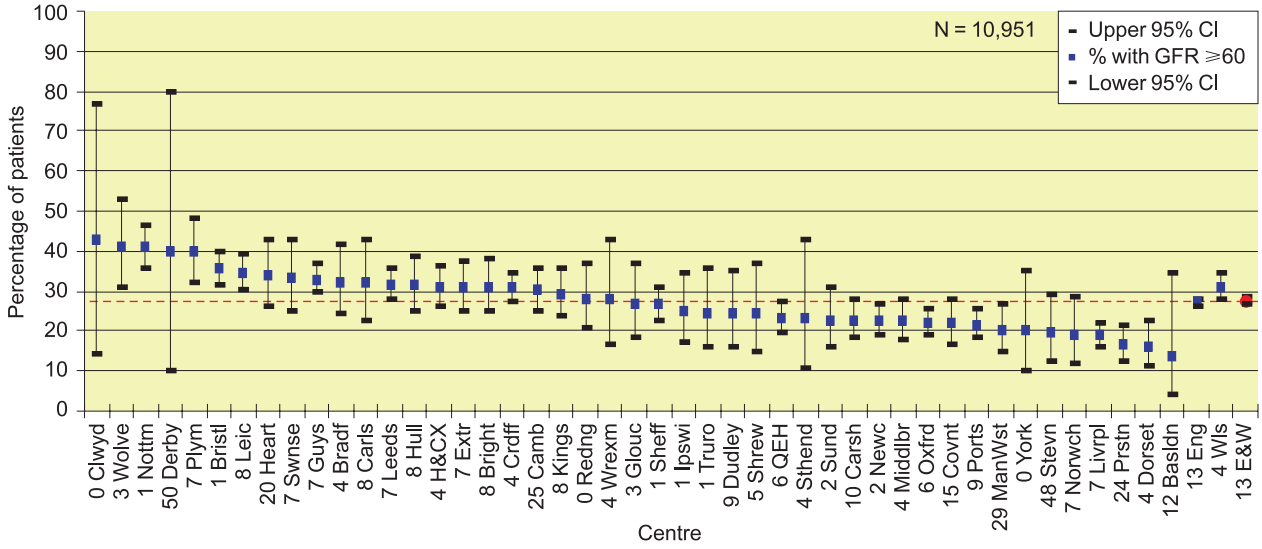

Figure 12.2: Percentage of transplant patients with eGFR ⩾60 mls/min

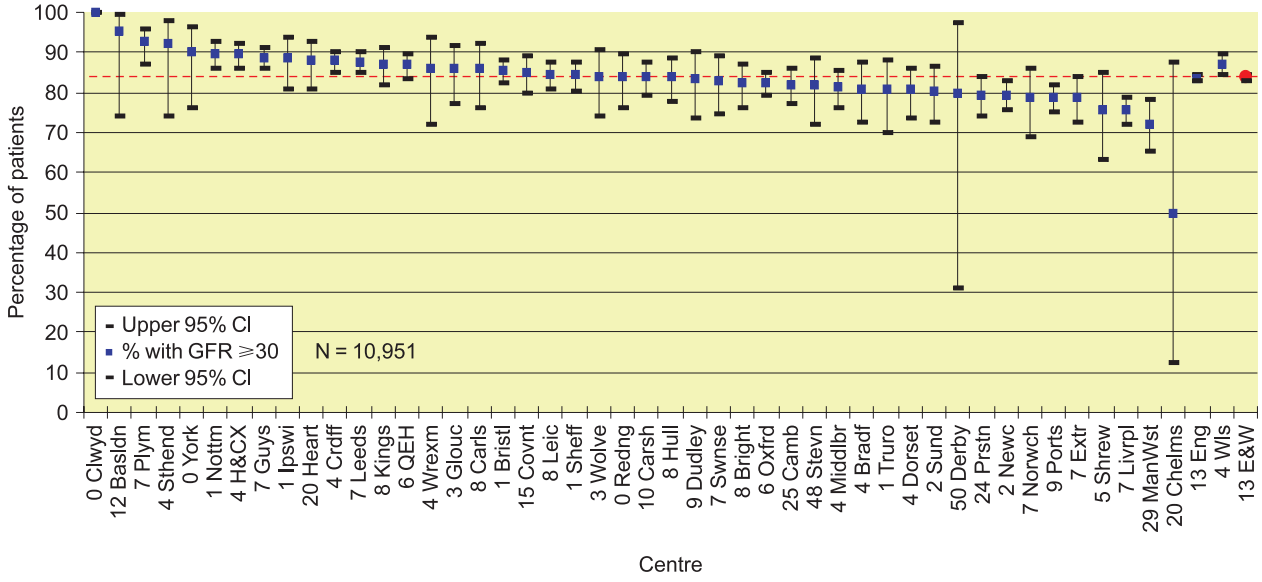

Figure 12.3: Percentage of transplant patients with eGFR ⩾30 mls/min

Haemoglobin in transplanted patients

Haemoglobin values within the last quarter of 2004 for prevalent transplant patients at the end of 2004 who had been transplanted at least 6 months earlier were available for analysis. Percentage completeness of returns from renal units varied from 67–100%. Time post transplantation, duration and intensity of anti-proliferative anti-rejection therapy use and EPO usage are key variables that affect post-transplantation Hb. It is probably because of the interplay of these factors that there is no relationship between median transplant eGFR in a centre and median Hb (Figure 12.4).

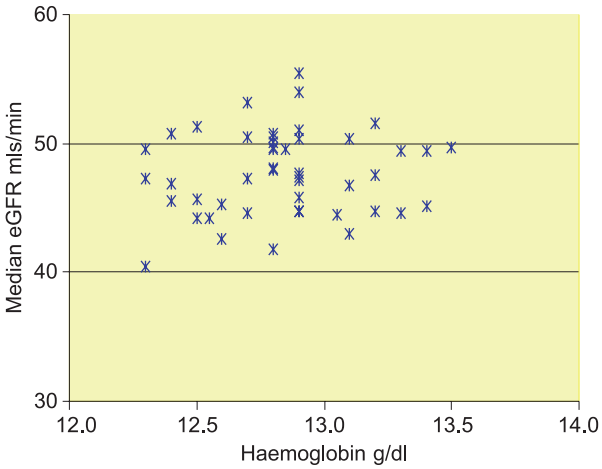

Figure 12.4: Median eGFR and median haemoglobin in transplant patients by centre

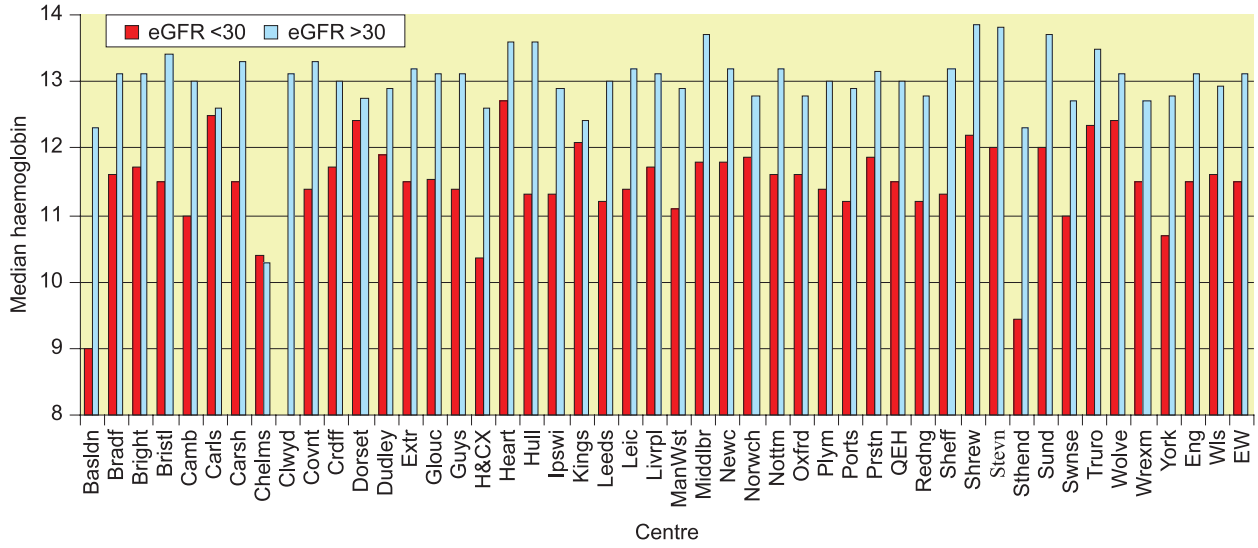

Figure 12.5: Median haemoglobin >6 months after transplant by eGFR

However, although as shown in Figure 12.5 there is no significant variation in Hb between centres when post transplant eGFR is >30, there is some discrepancy in Hb levels when eGFR is <30, with some renal units failing to maintain adequate levels.

Serum cholesterol

This analysis of serum cholesterol includes transplant patients whose kidney allograft has been functioning for at least one year. There are no national or international accepted guidelines for a minimum recommended cholesterol level in prevalent renal transplant patients. However, cardiovascular risk for transplant and dialysis patients is high and therefore an inference is made that elevated serum cholesterol is an additional risk factor for cardiovascular disease in kidney transplant patients. Again there is lack of consensus as to whether total cholesterol or total cholesterol/HDL cholesterol ratio are measured to define cardiovascular risk in these patients.

Returns on serum cholesterol continue to improve with 72% of patients from contributing centres having data compared to 67.6% in 2003. The median cholesterol value amongst prevalent transplant patients >1 yr post transplant is depicted in Figure 12.6.

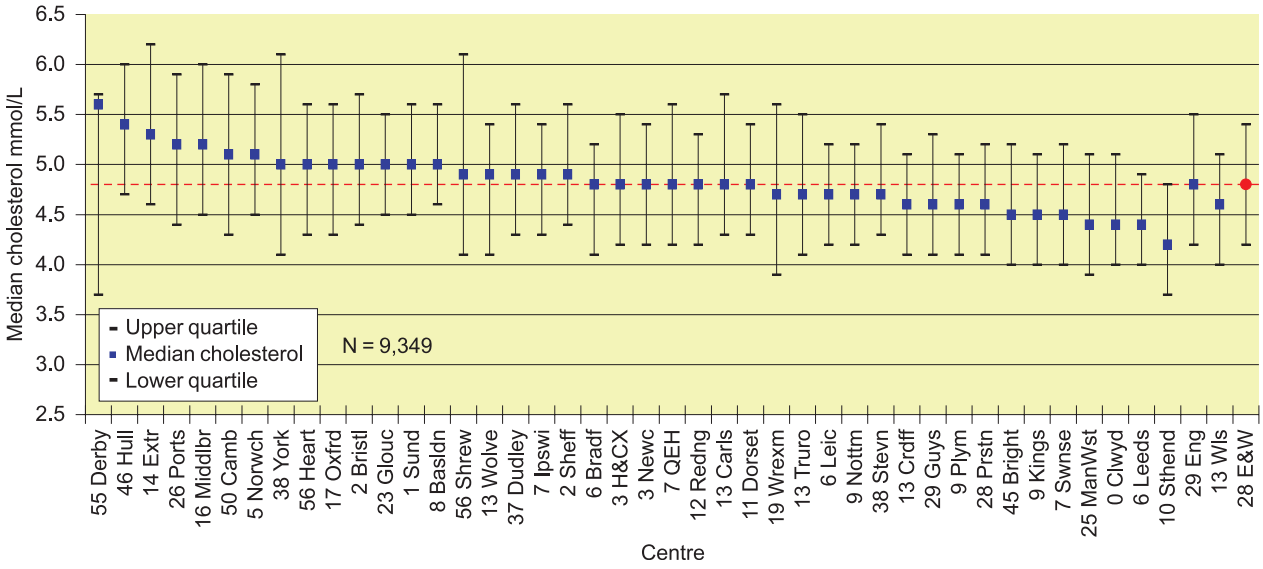

Figure 12.6: Median serum cholesterol: established transplant patients

Conclusion

As indicated in the introduction to this chapter the collaboration between the UKRR and UKT is complementary, providing a unique database which will enable better understanding of renal transplant related activity, processes and outcomes. Chapter 5 and the work reported in this chapter are a small beginning in exploring the potential of this collaboration.

Chapter 13: Performance Against Renal Association Standards by Centre and Patient Age

Summary

- Chi squared testing showed that the percentage of patients achieving the recommended Standard for all the following variables differed significantly between centres for both modalities of dialysis. The variables tested were: haemoglobin, dialysis adequacy, serum ferritin, calcium, phosphate, bicarbonate, intact parathyroid hormone and blood pressure.

- Patient age seems to be an important factor in the degree of achievement of many of the RA standards. The median age of patients on RRT varies between renal units and this may account for part of the variation in achievement of RA Standards.

Introduction

The Standards Committee of the Renal Association has identified a number of laboratory and clinical variables that may relate to quality of care or outcomes, and has recommended minimum Standards or target ranges that should be achieved in established dialysis patients. A revised document was published in autumn 2002 and these are shown in Table 13.1.

Data included on dialysis patients are from the last quarter of 2004 for all items except cholesterol and iPTH which are from the last 6 months. Patients were excluded if they had not been on renal replacement therapy (RRT) for at least 3 months or if they had transferred unit or changed dialysis modality in the 3 month period prior to data sampling. This ensured that the results for a unit reflected stable treatment patterns and were not adversely affected by new patients whom the unit had not had the chance to treat effectively.

The problems of comparing biochemical variables such as albumin, calcium and bicarbonate identified in the previous reports still apply; comparative data must be interpreted with caution. The achievement of Standards defined around the local laboratory reference range is dependent on the source of derivation for the reference range. The urea reduction ratio (URR) may be influenced by post-dialysis sampling techniques (see discussion in previous reports).

Achievement of Standards may also be affected by patient age and so an analysis of achievement by age band and modality has been included.

Table 13.1: Renal Association 3rd Standards

Standard	Haemodialysis	Peritoneal dialysis	Transplant
Albumin	⩾35 g/L BCG	⩾35 g/L BCG	
	⩾30 g/L BCP	⩾30 g/L BCP	
Bicarbonate	20–26 mmol/L	25–29 mmol/L	
Blood pressure	Pre-HD <140/90 mmHg	<130/80 mmHg	<130/80 mmHg
	Post-HD <130/80 mmHg		
Calcium adjusted for albumin	2.2–2.6 mmol/L	2.2–2.6 mmol/L	
Cholesterol – Total	<5 mmol/L	<5 mmol/L	
Dialysis adequacy	Urea reduction ratio >65%		
Ferritin	>100 µg/L	>100 µg/L	
Haemoglobin	⩾10 g/dl	⩾10 g/dl	
HbA1c	<7%	<7%	<7%
Parathyroid hormone	<4× upper local range	<4× upper local range	<4× upper local range
Phosphate	<1.8 mmol/L pre-HD	<1.8 mmol/L	

Overview of presentation

Results have been ranked in order of performance purely for clarity of presentation, otherwise the figures would be difficult to read. The significance of the ranking order is discussed below.

In the following section, many figures use a common modified box-plot format, data being presented separately for haemodialysis (HD) and peritoneal dialysis (PD) and transplantation.

- The figures showing the percentage of patients reaching the Renal Association Standard include the 95% confidence interval calculated for this figure (using the Poisson approximation).
- Where medians are displayed, the 25th and 75th centiles for the unit are included.
- Data completeness is indicated by the 'percentage missing' figure before the renal unit abbreviated name (see Appendix J).

These methods are the best way the Registry has found to convey the underlying data for the larger number of centres.

Performance of Standards by modality and centre

Haemoglobin

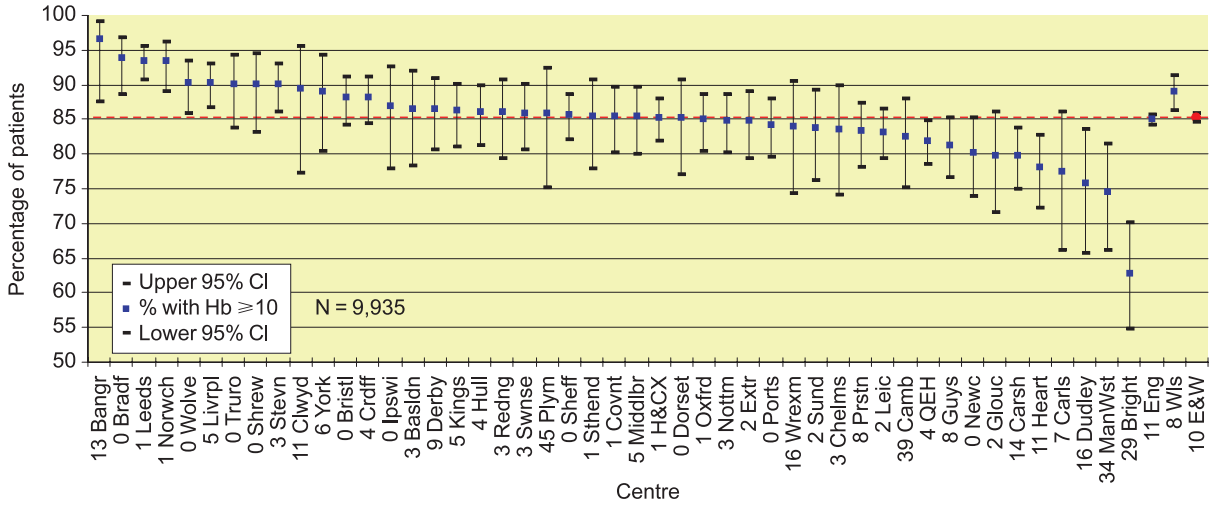

Figure 13.1: Percentage of patients achieving the RA Hb Standard by centre: HD

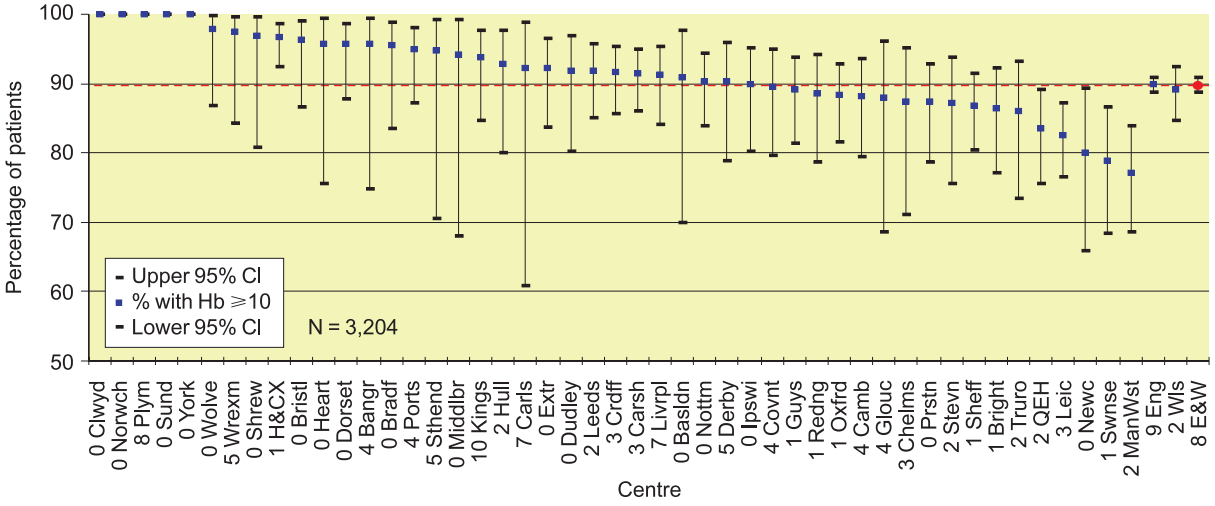

Figure 13.2: Percentage of patients achieving the RA Hb Standard by centre: PD

Serum Ferritin

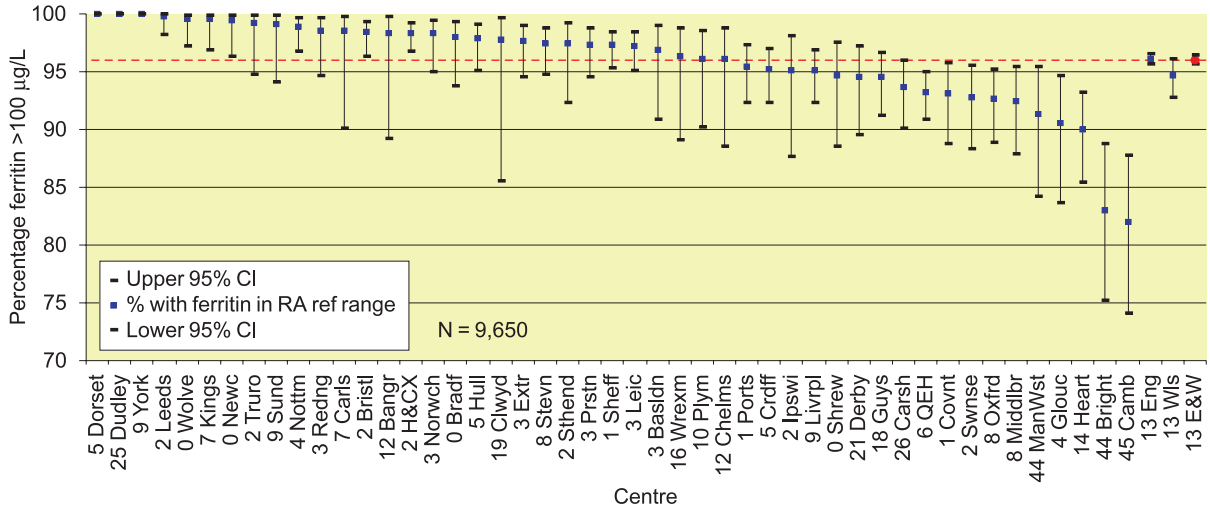

Figure 13.3: Percentage of patients achieving the RA Ferritin Standard by centre: HD

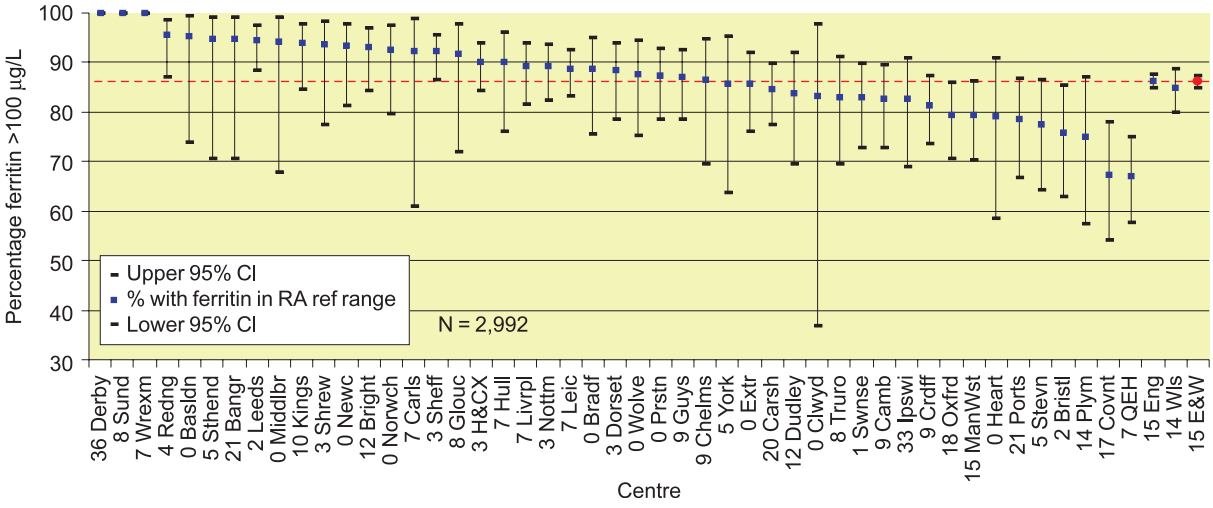

Figure 13.4: Percentage of patients achieving the RA Ferritin Standard by centre: PD

Serum calcium

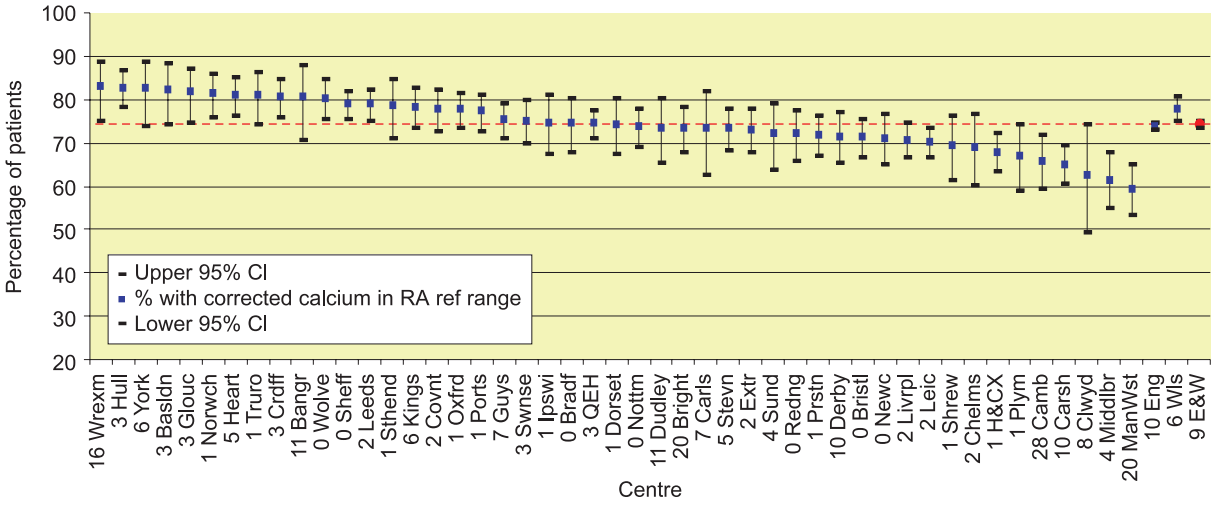

Figure 13.5: Percentage of patients achieving the RA calcium Standard by centre: Dialysis

Serum phosphate

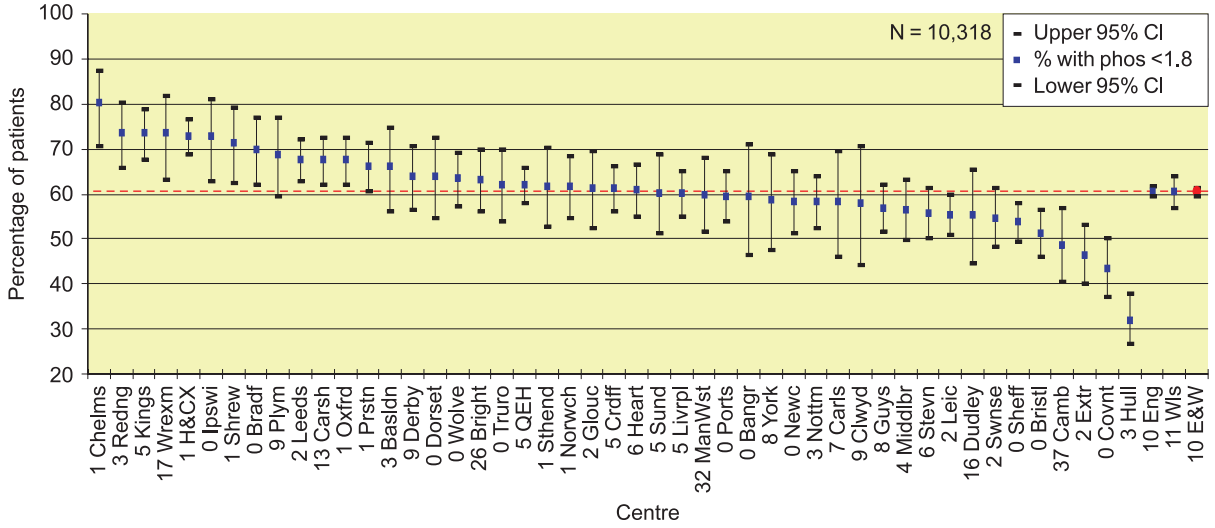

Figure 13.6: Percentage of patients achieving the RA phosphate Standard by centre: HD

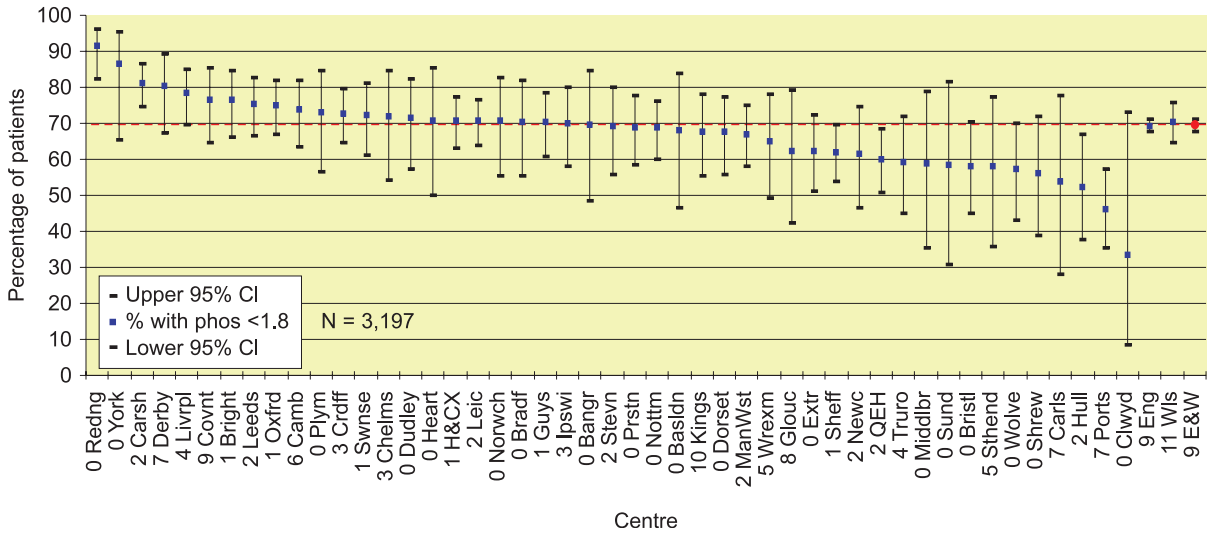

Figure 13.7: Percentage of patients achieving the RA phosphate Standard by centre: PD

Intact parathyroid hormone

As the local laboratory reference range for PTH has not been derived from a local or UK population reference range, the Registry in line with previous years has used the average upper laboratory reference limit (8 pmol/L) and the recommended Standard of $<\times 4$ this limit.

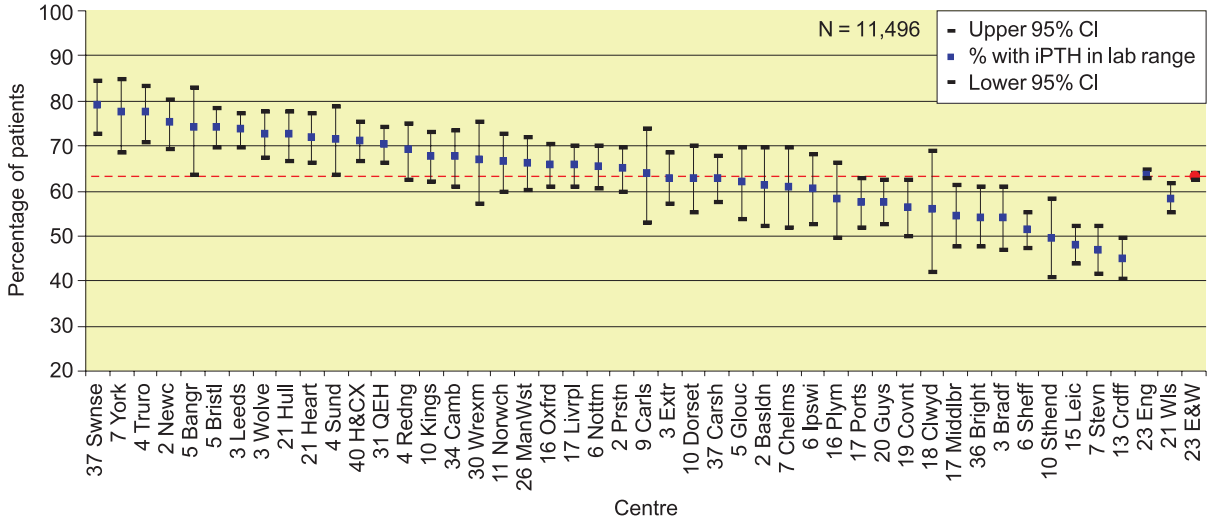

Figure 13.8: Percentage of patients achieving iPTH <32 pmol/L by centre: Dialysis

Dialysis adequacy

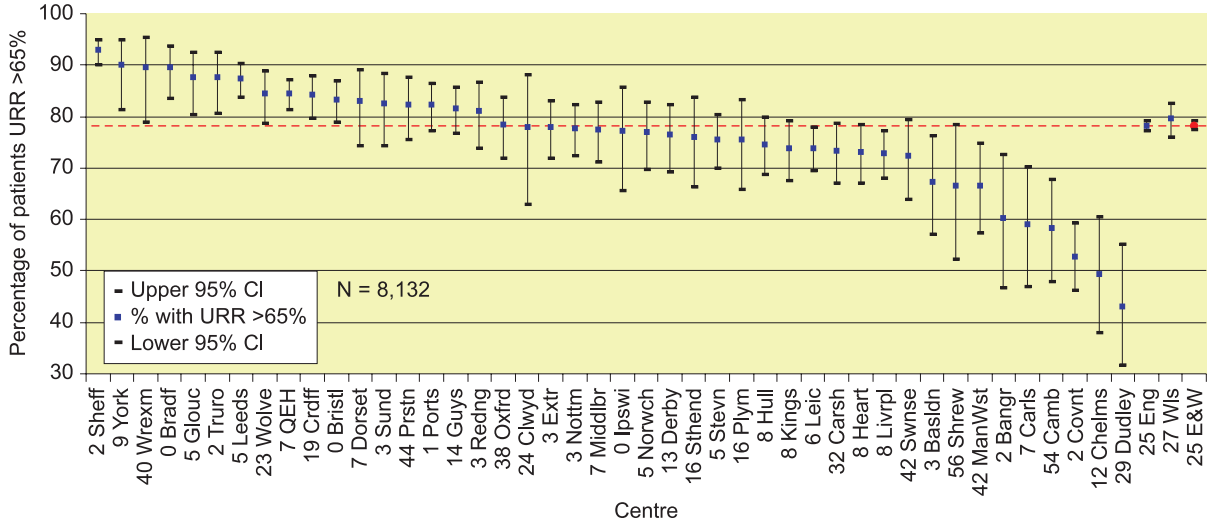

Figure 13.9: Percentage of patients with URR ⩾65% by centre: Haemodialysis

Serum bicarbonate

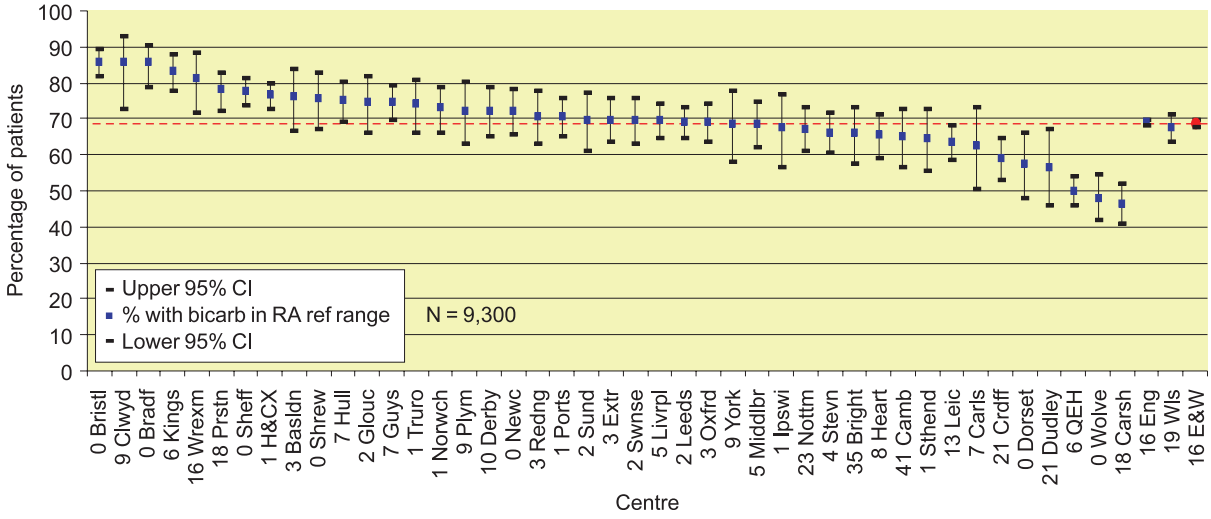

Figure 13.10: Percentage of patients achieving the RA bicarbonate Standard by centre: HD

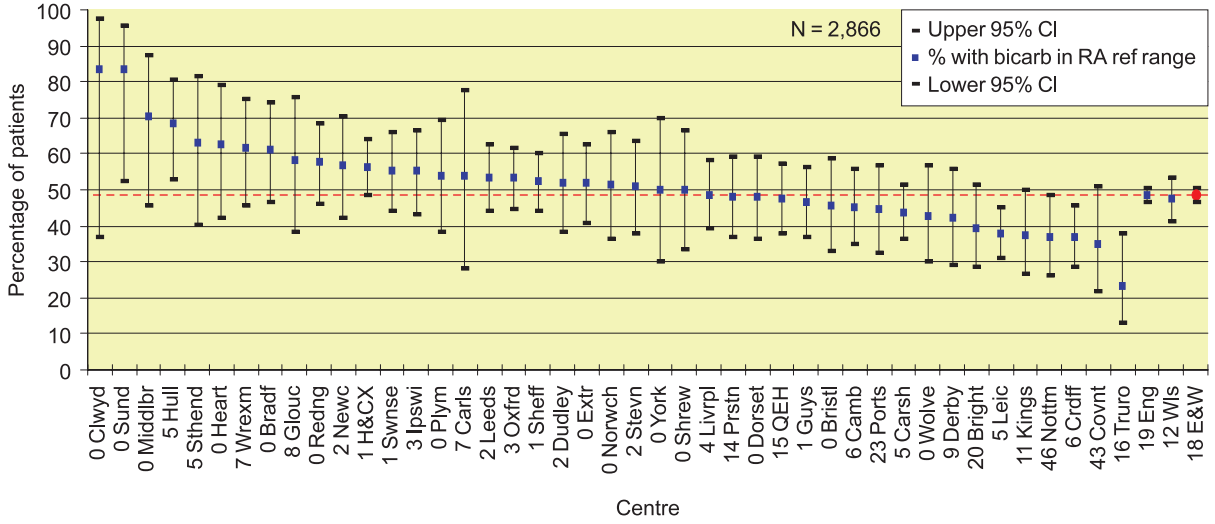

Figure 13.11: Percentage of patients achieving the RA bicarbonate Standard by centre: PD

Serum albumin

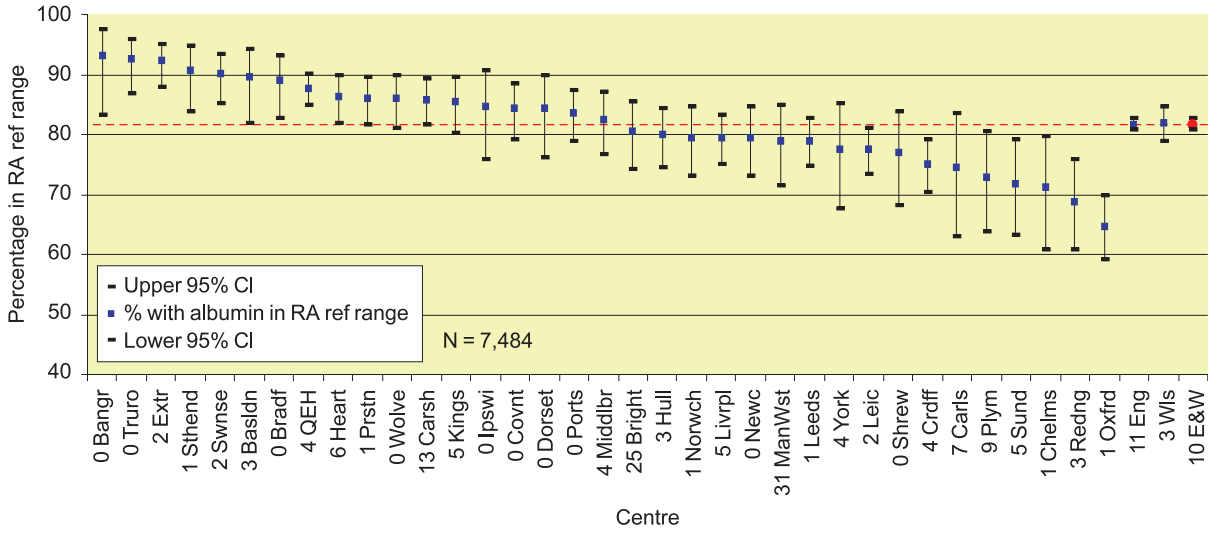

Figure 13.12: Percentage of patients achieving the RA albumin BCG Standard by centre: HD

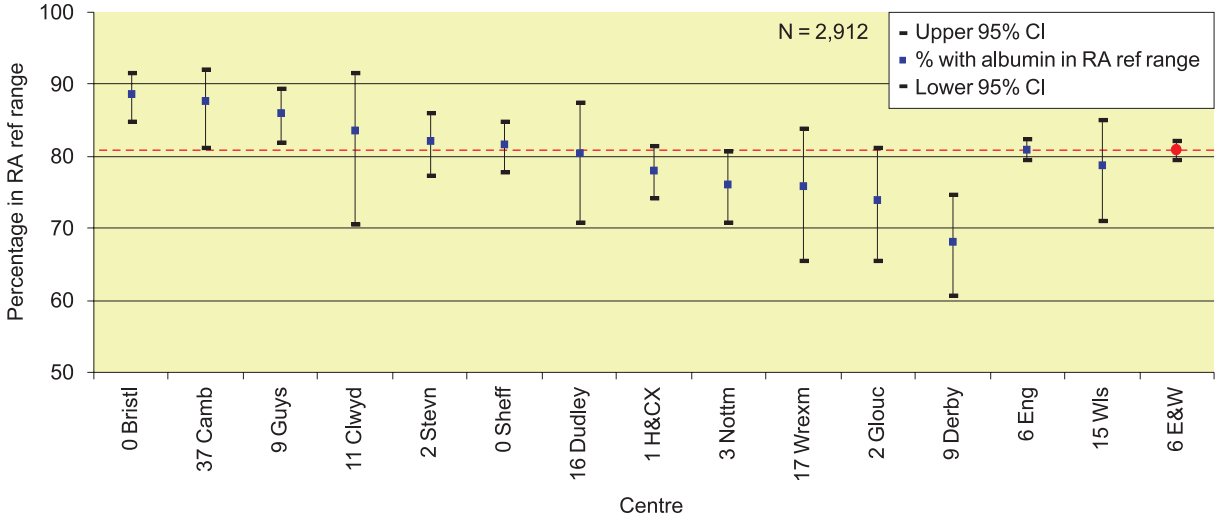

Figure 13.13: Percentage of patients achieving the RA albumin BCP Standard by centre : HD

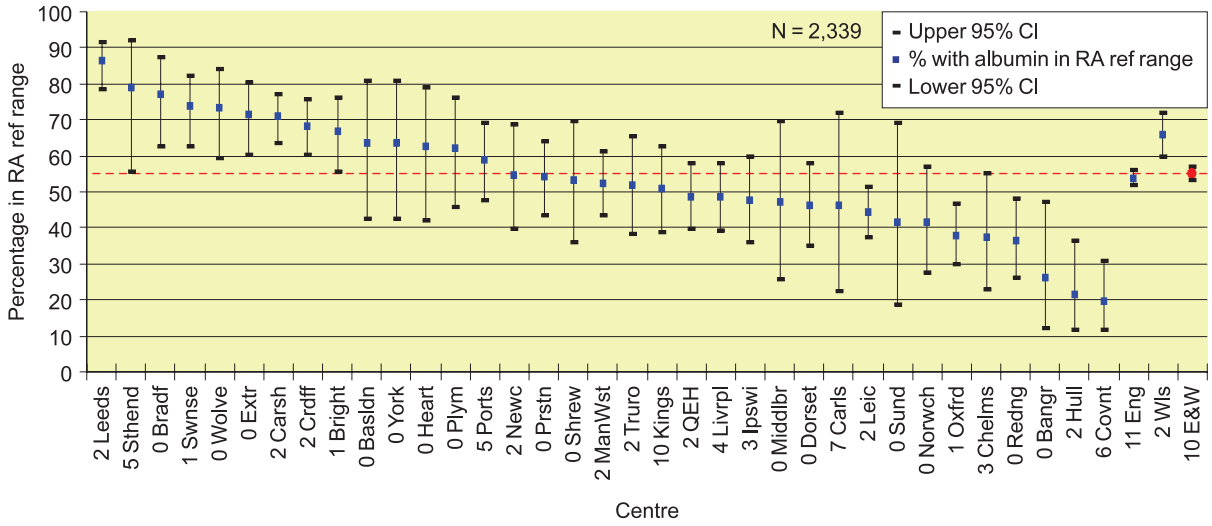

Figure 13.14: Percentage of patients achieving the RA albumin BCG Standard by centre: PD

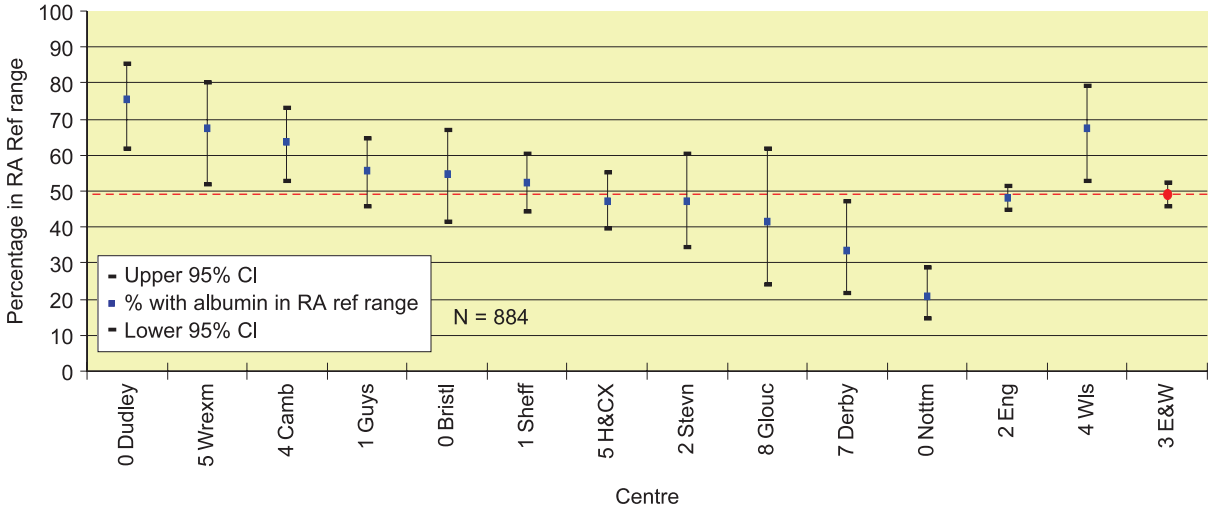

Figure 13.15: Percentage of patients achieving the RA albumin BCP Standard by centre : PD

Blood Pressure

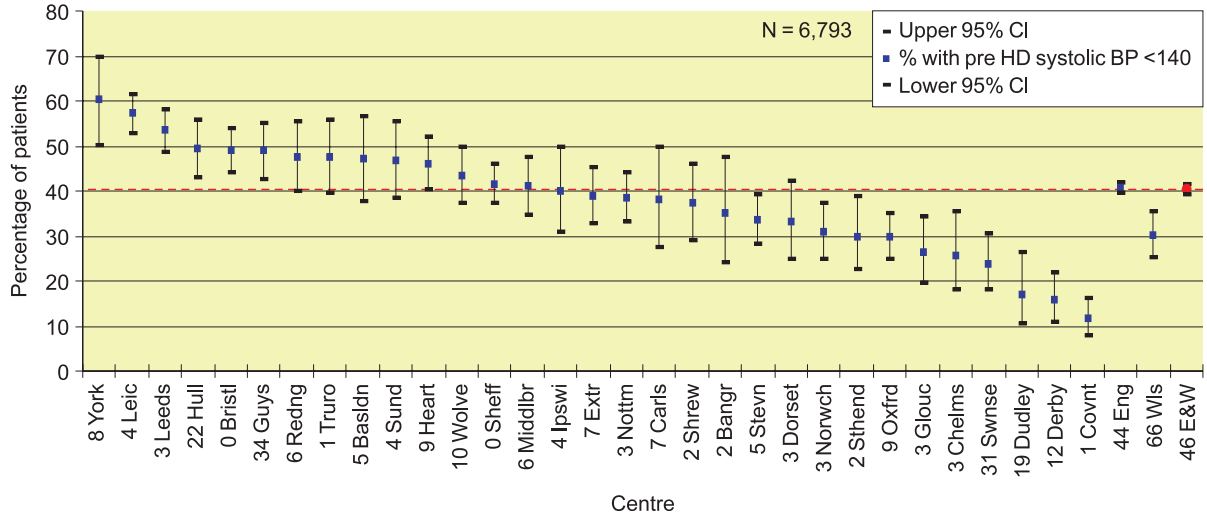

Figure 13.16: Percentage of patients achieving the RA BP Standard by centre: pre-HD

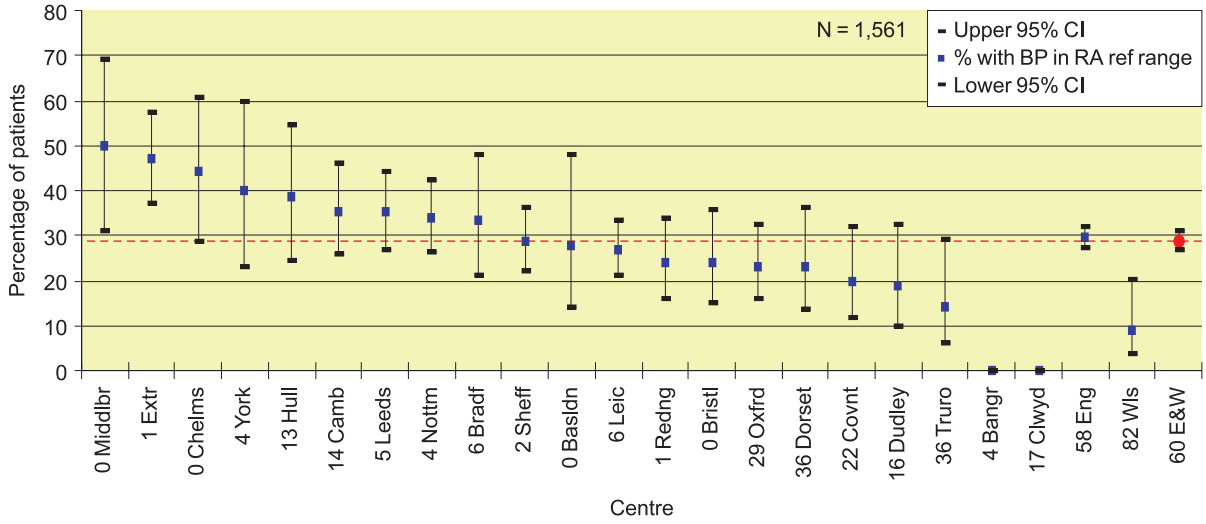

Figure 13.17: Percentage of patients achieving the RA BP Standard by centre: PD

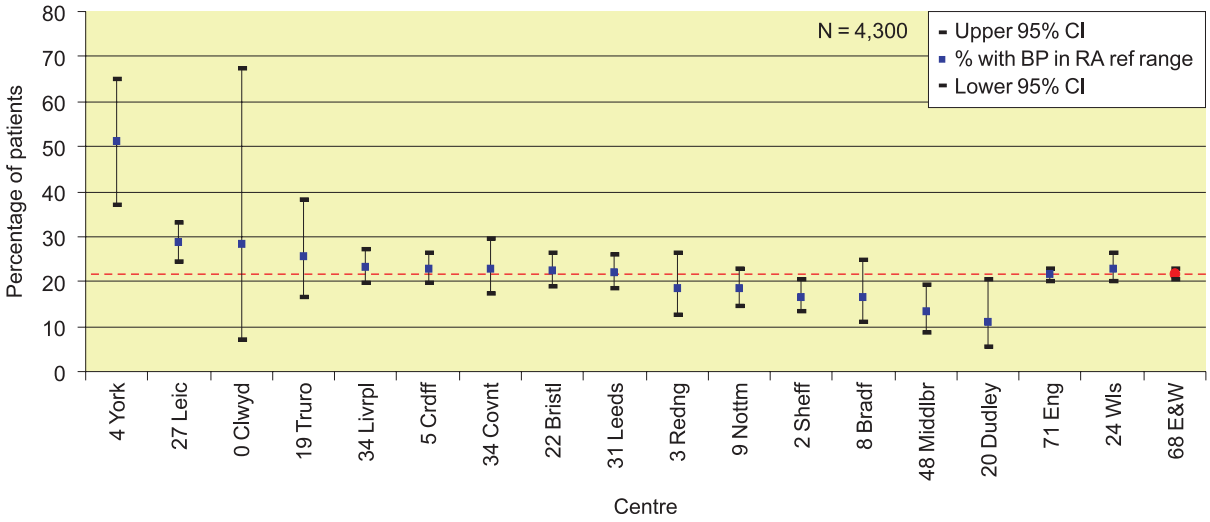

Figure 13.18: Percentage of patients achieving the RA BP Standard by centre: Transplant

Serum Cholesterol

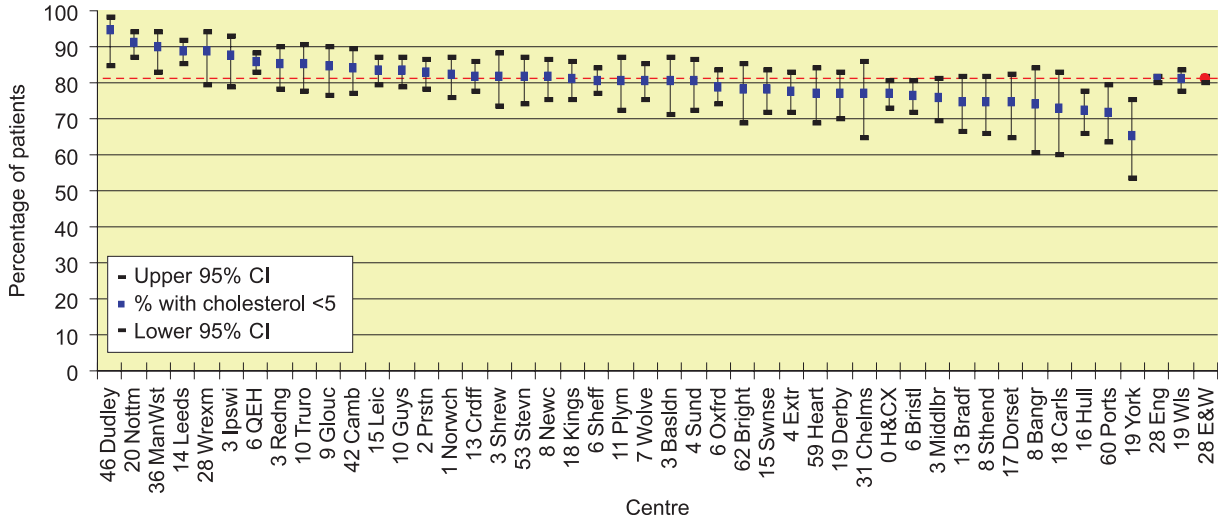

Figure 13.19: Percentage of patients achieving the RA cholesterol Standard by centre: HD

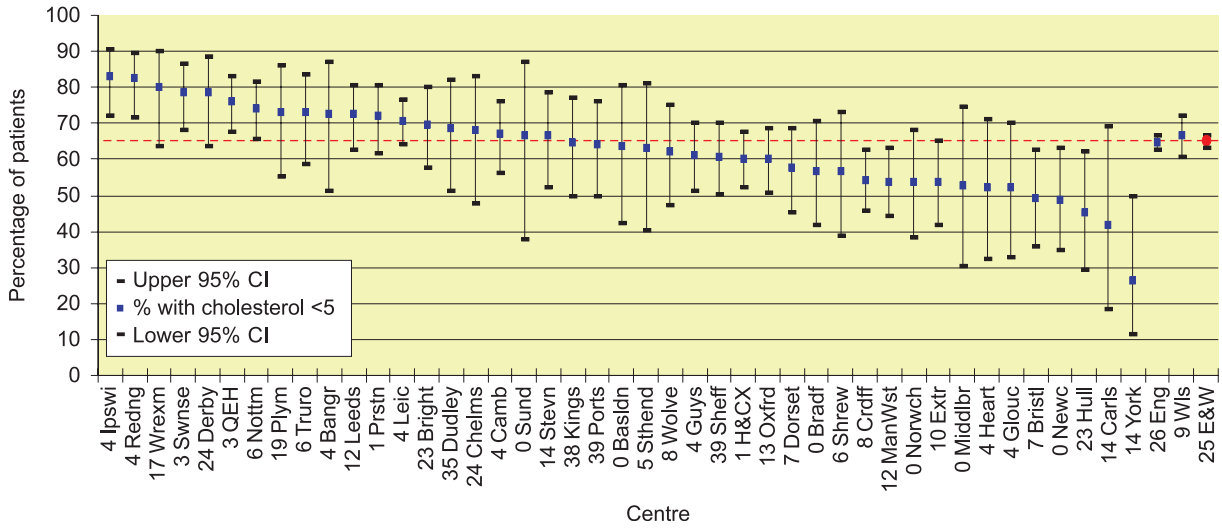

Figure 13.20: Percentage of patients achieving the RA cholesterol Standard by centre: PD

Glycated Haemoglobin

Only patients with a primary diagnosis of diabetes as the cause of ERF were included in this analysis. Patients with post transplant diabetes or who developed diabetes post ERF were excluded from the analysis. Diabetic patients who have received a pancreas transplant have not been excluded from the transplant analysis and may partially explain the lower HbA1c results seen at Guys & Liverpool (also seen in last years Report). The results for Liverpool transplant recipients are not shown due to a high percentage of missing data, which might be causing bias. Guys do not use a steroid sparing regime in transplanted patients so this cannot account for their better HbA1c results. Median HbA1c in transplant recipients at Guys and Hammersmith was 5.6% and 7.5% respectively which compares with a median of 8.6% and 9.4% at Plymouth and Bristol respectively.

Centres with less than 10 patients or <50% completeness of data are not shown in the figures. Although some centres have a high percentage of missing data it cannot be inferred that HbA1c is not being measured. The test may have been taken at a diabetic clinic in the same hospital or elsewhere and the result not transferred to the renal IT system.

Most centres use assays that are DCCT aligned.

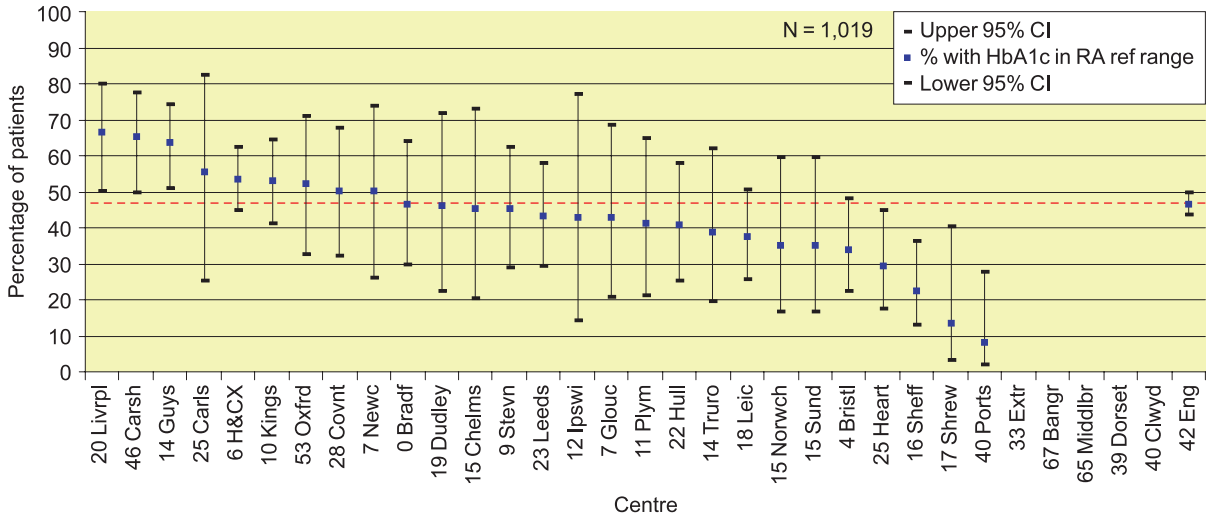

Figure 13.21: Percentage of diabetic patients achieving the RA HbA1c Standard by centre: HD

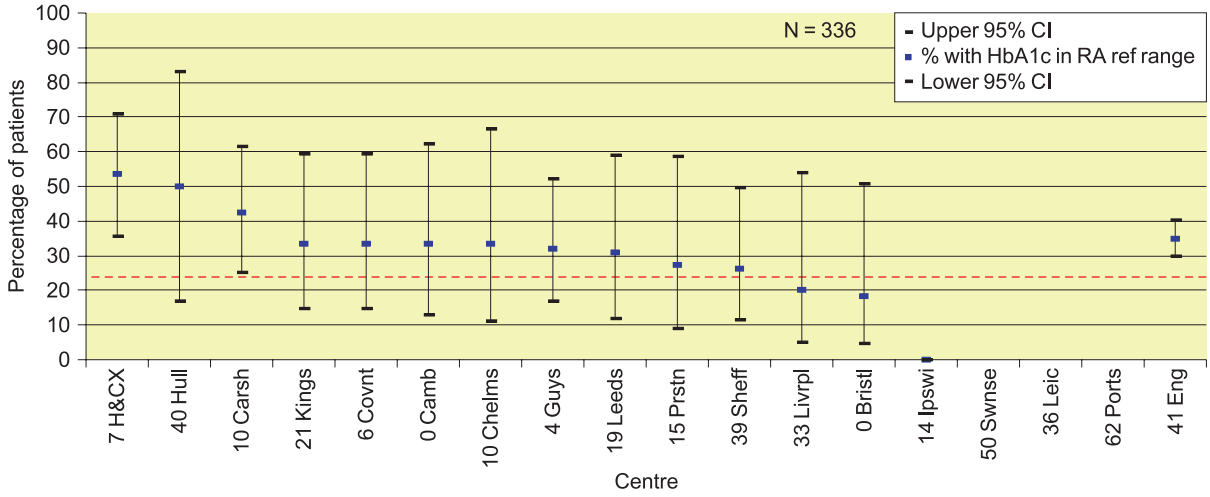

Figure 13.22: Percentage of diabetic patients achieving the RA HbA1c Standard by centre: PD

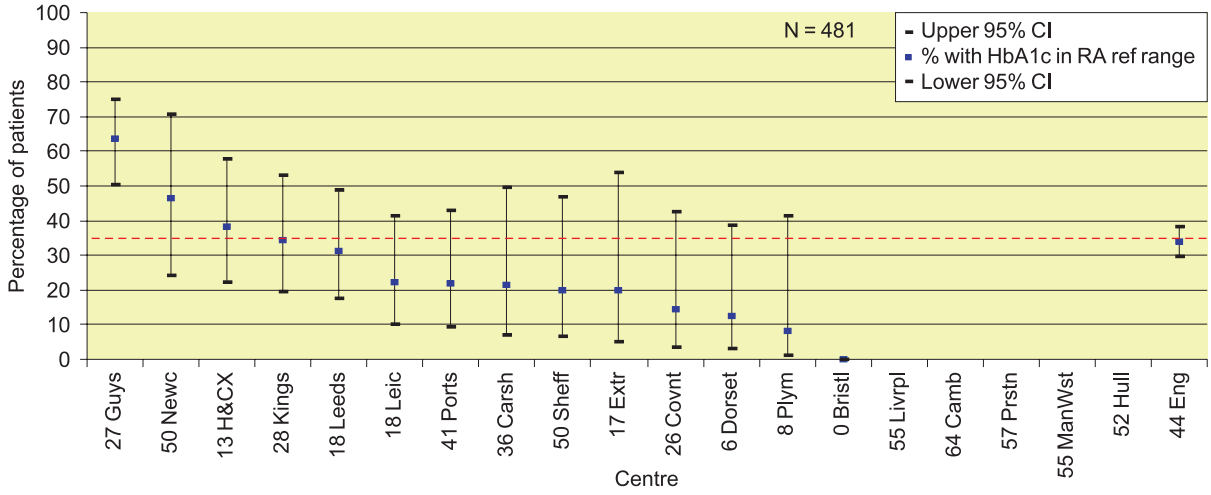

Figure 13.23: Percentage of diabetic patients achieving the RA HbA1c Standard by centre: Transplant

Statistical analysis

Methodology

Chi squared tests were used to see whether the percentage of patients with data in a given range varied significantly between centres. Degrees of freedom are equal to the number of centres with over 50% completeness of data (who were included in the analysis) minus 1.

Due to the large number of statistical tests undertaken, the significance level used was $p < 0.01$ level.

Results

Haemoglobin

A chi squared test was used to determine whether the percentage of patients with a haemoglobin level of 10 g/dl or more differed between centres.

For patients on HD, the percentage of patients with a haemoglobin of 10 g/dl or more was found to differ significantly between centres ($\chi^2 = 198.4$, d.f. = 47, $p < 0.001$).

For patients on PD, the percentage of patients with a haemoglobin of 10 g/dl or more was found to differ significantly between centres ($\chi^2 = 96.9$, d.f. = 47, $p < 0.001$).

Ferritin

A chi squared test was used to determine whether the percentage of patients with a ferritin level of 100 µg/L or more differed between centres.

For patients on HD, the percentage of patients with a ferritin of 100 µg/L or over was found to differ significantly between centres ($\chi^2 = 289.3$, d.f. = 47, $p < 0.001$).

For patients on PD, the percentage of patients with a ferritin of 100 µg/L or over was found to differ significantly between centres ($\chi^2 = 132.4$, d.f. = 47, $p < 0.001$).

Corrected Calcium

A chi squared test was used to determine whether the percentage of patients with a calcium level of 2.2 to 2.6 mmol/L differed between centres.

For patients on HD, the percentage of patients with a serum calcium of 2.2 to 2.6 mmol/L differed significantly between centres ($\chi^2 = 167$, d.f. = 47, $p < 0.001$).

For patients on PD, the percentage of patients with a serum calcium of 2.2 to 2.6 mmol/L differed significantly between centres ($\chi^2 = 93$, d.f. = 47, $p < 0.001$).

Phosphate

A chi squared test was used to determine whether the percentage of patients with a phosphate level of 1.8 mmol/L or less differed between centres.

For patients on HD, the percentage of patients with a serum phosphate of 1.8 mmol/L or less differed significantly between centres ($\chi^2 = 310.6$, d.f. = 47, $p < 0.001$).

For patients on PD, the percentage of patients with a serum phosphate of 1.8 mmol/L or less differed significantly between centres ($\chi^2 = 105.9$, d.f. = 46, $p < 0.001$).

PTH

A chi squared test was used to determine whether the percentage of patients with a PTH of 32 pmol/L or below differed between centres. Note this is slightly different from the RA Standard.

For patients on HD, the percentage of patients with a PTH value of 32 pmol/L or less differed significantly between centres ($\chi^2 = 459.1$, d.f. = 46, $p < 0.001$).

For patients on PD, the percentage of patients with a PTH of 32 pmol/L or less differed significantly between centres ($\chi^2 = 154.1$, d.f. = 46, $p < 0.001$).

URR

A chi squared test was used to determine whether the percentage of patients with a URR of 65% or more differed between centres.

The percentage of patients with a URR of 65% or above was found to vary significantly between centres ($\chi^2 = 390.6$, d.f. = 43, $p < 0.001$).

Bicarbonate

A chi squared test was used to determine whether the percentage of patients with bicarbonate values within 20–26 mmol/L or 25–29 mmol/L respectively for HD and PD varied significantly between centres.

For patients on HD, the percentage of patients with a bicarbonate within 20–26 mmol/L differed significantly between centres ($\chi^2 = 418.3$, d.f. = 46, $p < 0.001$).

For patients on PD, the percentage of patients with a bicarbonate within 25–29 mmol/L differed significantly between centres ($\chi^2 = 90.3$, d.f. = 44, $p < 0.001$).

Albumin

A chi squared test was used to determine whether the percentage of patients with a serum albumin 35 g/L or more measured using a BCG assay or 30 g/L or more measured using a BCP assay varied between centres.

For patients on HD, the percentage of patients with a serum albumin $\geqslant 35$ g/L measured by BCG differed significantly between centres ($\chi^2 = 220$, d.f. = 35, $p < 0.001$) and >30 g/L measured by BCP differed significantly between centres ($\chi^2 = 54.9$, d.f. = 11, $p < 0.001$).

For patients on PD, the percentage of patients with a serum albumin $\geqslant 35$ g/L measured by BCG differed significantly between centres ($\chi^2 = 228$, d.f. = 35, $p < 0.001$) and

>30 g/L measured by BCP differed significantly between centres ($\chi^2 = 75.8$, d.f. = 11, $p < 0.001$).

Blood Pressure

A chi-squared test was used to determine whether the percentage of patients with both systolic and diastolic blood pressure within range differed between centres.

For patients on HD, the percentage of patients with a pre-dialysis blood pressure of ⩽140/90 mmHg differed significantly between centres ($\chi^2 = 397.6$, d.f. = 44, $p < 0.001$).

For patients on PD, the percentage of patients with a blood pressure of ⩽130/80 mmHg differed significantly between centres ($\chi^2 = 96.9$, d.f. = 34, $p < 0.001$).

For patients with a transplant, the percentage of patients with a blood pressure of ⩽130/80 mmHg differed significantly between centres ($\chi^2 = 118.8$, d.f. = 35, $p < 0.001$).

Cholesterol

A chi squared test was used to determine whether the percentage of patients with a serum cholesterol level of 5 mmol/L or less differed between centres.

For patients on HD, the percentage of patients with a serum cholesterol of 5 mmol/L or less differed significantly between centres ($\chi^2 = 136.5$, d.f. = 47, $p < 0.001$).

For patients on PD, the percentage of patients with a serum cholesterol of 5 mmol/L or less differed significantly between centres ($\chi^2 = 121$, d.f. = 45, $p < 0.001$).

HbA1c

A chi squared test was used to determine whether the percentage of patients with a glycated haemoglobin level of less than 7% differed between centres.

For patients on HD, the percentage of patients with an HbA1c of <7% differed significantly between centres ($\chi^2 = 144$, d.f. = 39, $p < 0.001$).

For patients on PD, the percentage of patients with an HbA1c of <7% differed significantly between centres ($\chi^2 = 91$, d.f. = 35, $p < 0.001$).

For patients with a transplant, the percentage of patients with an HbA1c of <7% differed significantly between centres ($\chi^2 = 127$, d.f. = 36, $p < 0.001$).

Performance against Standards by Modality and Age Band

The performance against the RA standards are shown below by age band and modality. Transplantation has been included for most of the variables as the 'control' group. The variation of serum albumin with age in the general non-RRT population (lower in older patients) is well known, and highlights the difficulty in interpreting albumin in the dialysis population.

Serum cholesterol achievement in transplant recipients appears to take a V shaped curve, with a maximum cholesterol level in patients aged 45. It is not known how much this is an influence of immuno-suppressive therapy. The median age of transplantation in the UK is 42 years and the Registry has previously shown in analysis of modality change in the 2004 Report (Chapter 10) that serum cholesterol increases in the first year post transplantation but by the end of 1 year has fallen to pre-transplant levels.

Haemoglobin

Figure 13.24 and Figure 13.25 show that haemoglobin achievement has a non-linear relationship with age (lower in younger patients) which plateaus at age 45. Previous Registry analyses (in the haemoglobin chapter) and other international studies have only tested for linear affects with age and therefore reported this to be negative. An element of this non-linear effect may be due to younger patients having a longer 'vintage' on RRT.

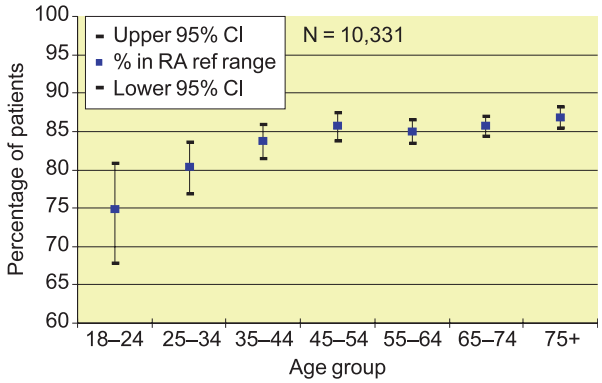

Figure 13.24: Percentage of patients with Hb >10 g/dl by age: HD

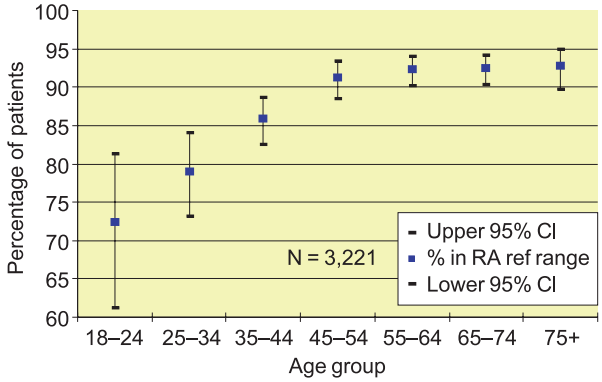

Figure 13.25: Percentage of patients with Hb >10 g/dl by age: PD

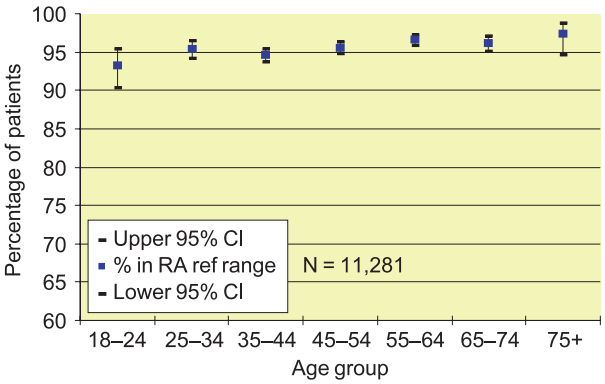

Figure 13.26: Percentage of patients with Hb >10 g/dl by age: Transplant

Serum Ferritin

Patients on PD show an increasing serum ferritin with increasing age. The picture is less clear with HD patients.

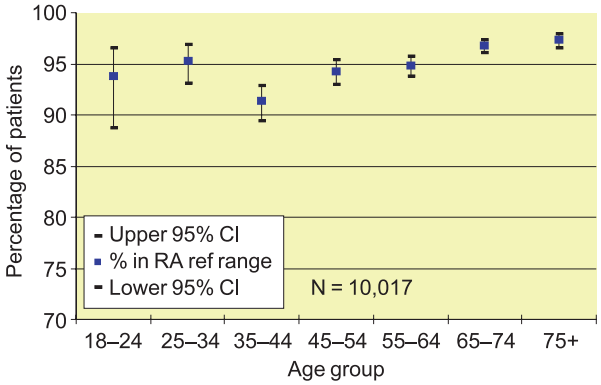

Figure 13.27: Percentage of patients achieving the RA Ferritin Standard by age: HD

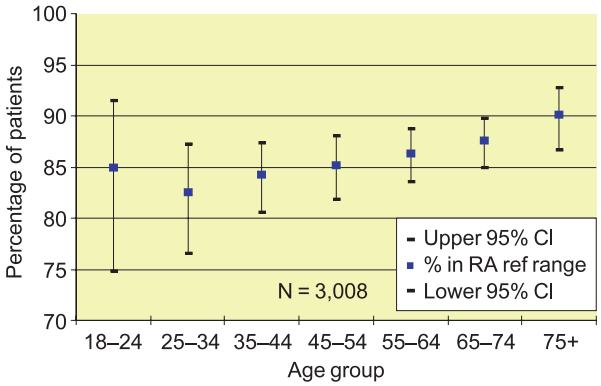

Figure 13.28: Percentage of patients achieving the RA Ferritin Standard by age: PD

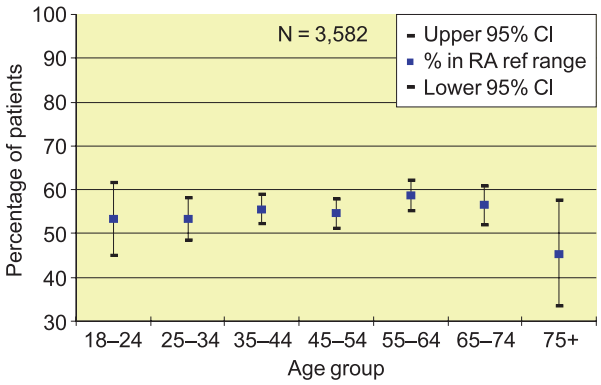

Figure 13.29: Percentage of patients achieving the RA Ferritin Standard by age: Transplant

Serum calcium

Serum calcium in HD patients shows a lower achievement of the Standard (2.2–2.6 mmol/L) with younger age. Analysis of the median, and quartile data show that this is due to lower serum calciums in younger patients. This may be a positive affect from trying to reduce arterial calcification in younger patients. No such affect is seen in PD patients. The non-linear affect seen in transplant patients (lower achievement which plateaus at 45 years) is due to a higher upper range of serum calcium in these patients.

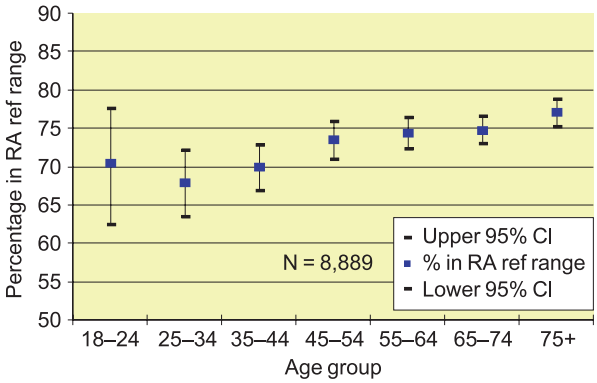

Figure 13.30: Percentage of patients achieving the RA calcium Standard by age: HD

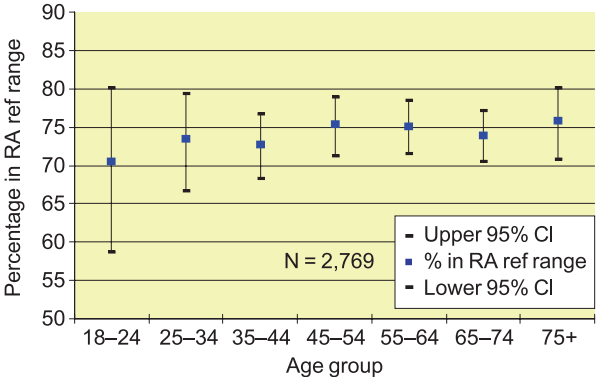

Figure 13.31: Percentage of patients achieving the RA calcium Standard by age: PD

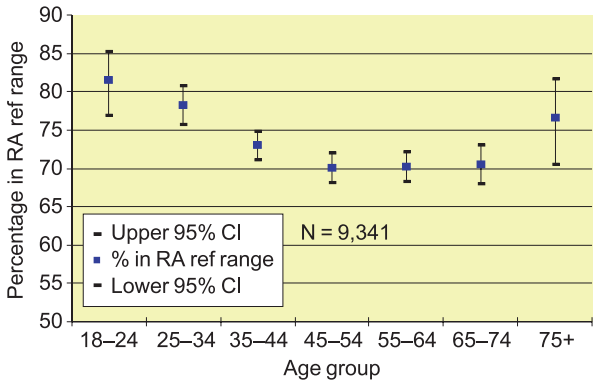

Figure 13.32: Percentage of patients achieving the RA calcium Standard by age: Transplant

Serum phosphate

Only 40% of HD patients compared with 70% of older patients achieve serum phosphate within the target range. A similar affect is seen in patients on PD. This may partly be due to better dietary intake in younger patients (see discussion in Chapter 10). No affect of age is seen in transplant recipients.

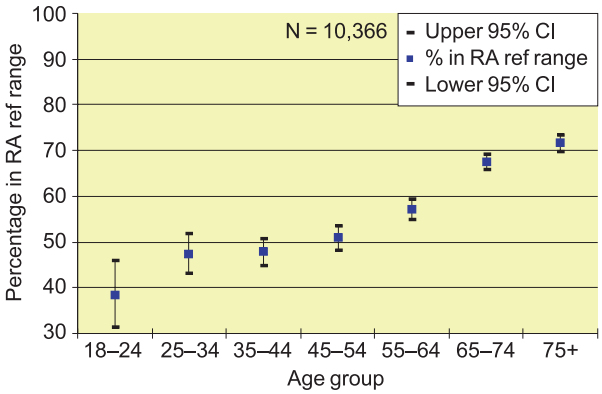

Figure 13.33: Percentage of patients achieving the RA phosphate Standard by age: HD

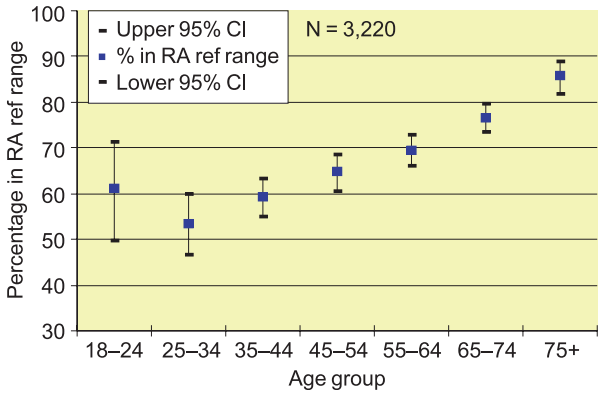

Figure 13.34: Percentage of patients achieving the RA phosphate Standard by age: PD

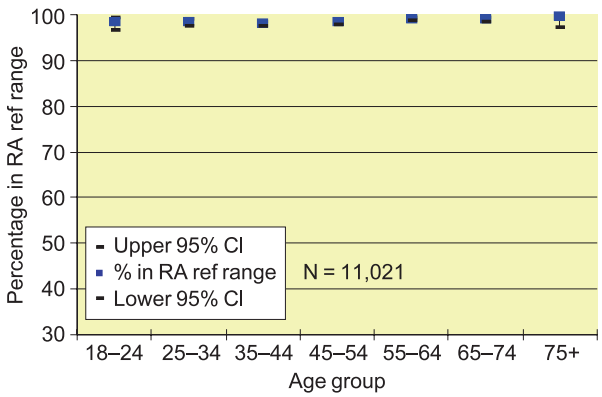

Figure 13.35: Percentage of patients achieving the RA phosphate Standard by age: Transplant

Intact parathyroid hormone

Marked variation in achievement of iPTH with age is seen both in HD and PD patients, although not in transplant recipients. This may reflect serum phosphate control (see discussion in Chapter 10).

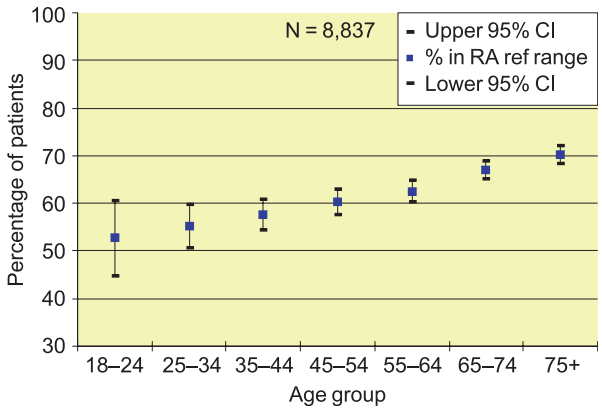

Figure 13.36: Percentage of patients achieving iPTH <32 pmol/L by age: HD

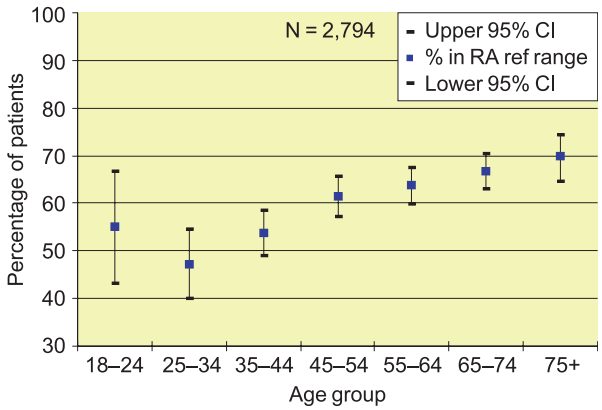

Figure 13.37: Percentage of patients achieving iPTH <32 pmol/L by age: PD

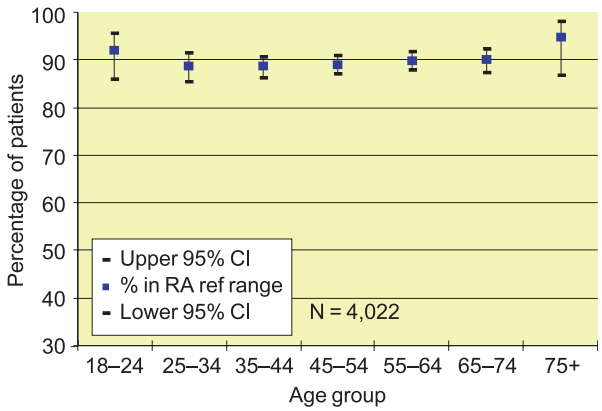

Figure 13.38: Percentage of patients achieving iPTH <32 pmol/L by age: Transplant

Serum albumin

Both BCG and BCP methods show a falling albumin achievement with patient age, for those on HD and PD. A similar affect is noted in BCG albumin levels in transplant recipients.

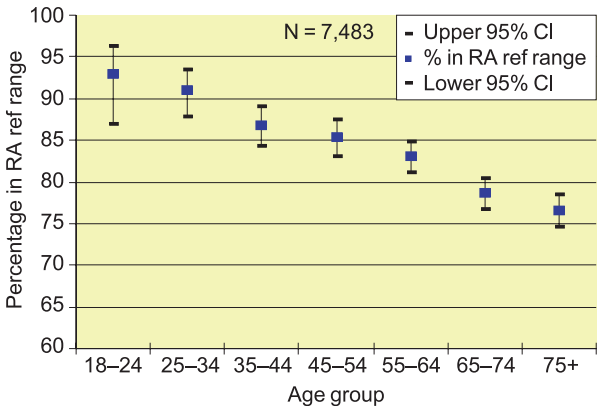

Figure 13.39: Percentage of patients achieving the RA albumin BCG Standard by age: HD

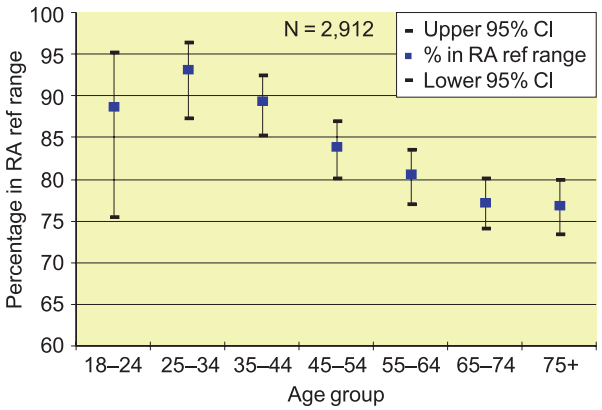

Figure 13.40: Percentage of patients achieving the RA albumin BCP Standard by age: HD

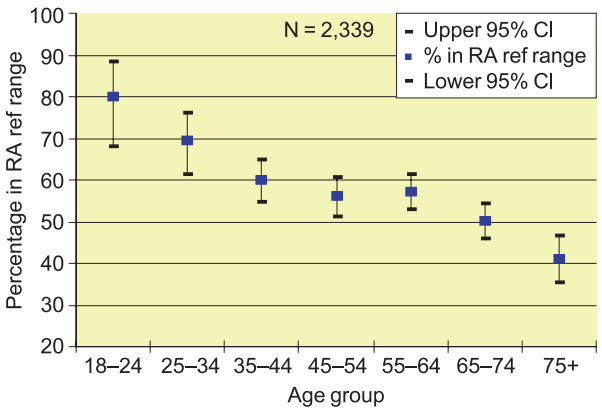

Figure 13.41: Percentage of patients achieving the RA albumin BCG Standard by age: PD

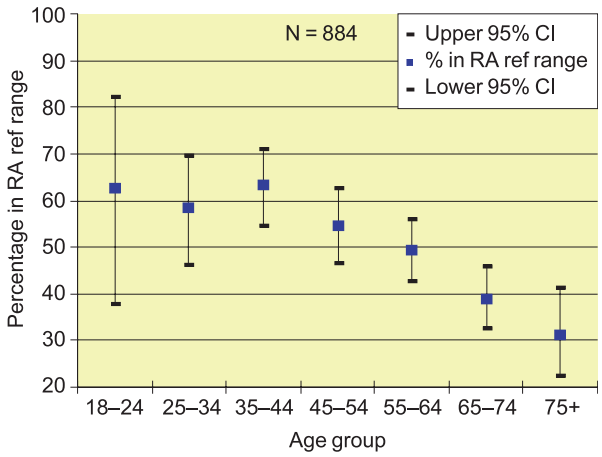

Figure 13.42: Percentage of patients achieving the RA albumin BCP Standard by age: PD

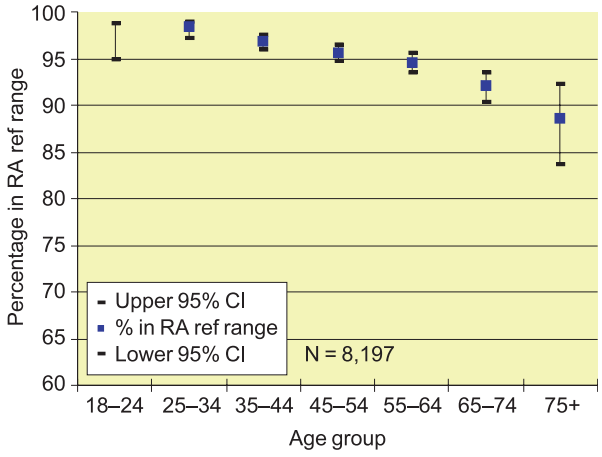

Figure 13.43: Percentage of patients achieving the RA albumin BCG Standard by age: Transplant

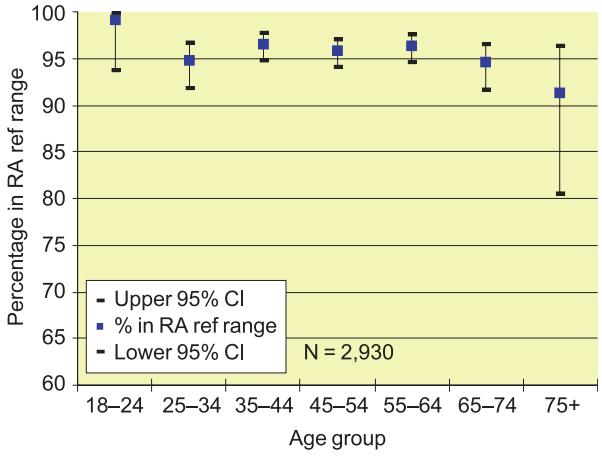

Figure 13.44: Percentage of patients achieving the RA albumin BCP Standard by age: Transplant

Blood Pressure

In HD and PD patients systolic BP achievement remains unchanged with age. Diastolic BP falls with age resulting in increasing pulse pressure, but increasing achievement of the RA Standard. In contrast transplant recipients follow the pattern seen in the general population with increasing systolic BP seen with age and hence poorer achievement of the Standard.

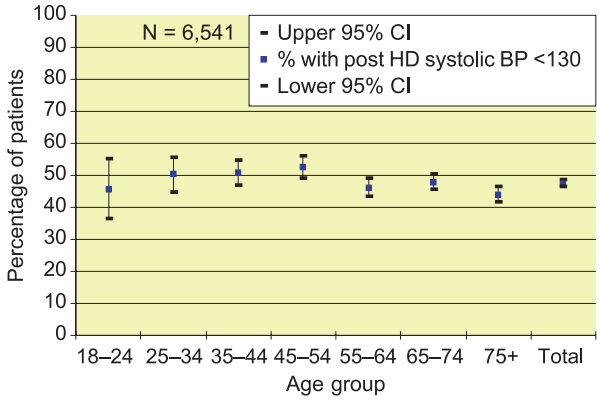

Figure 13.45: Percentage of patients achieving the RA SBP Standard by age: post-HD

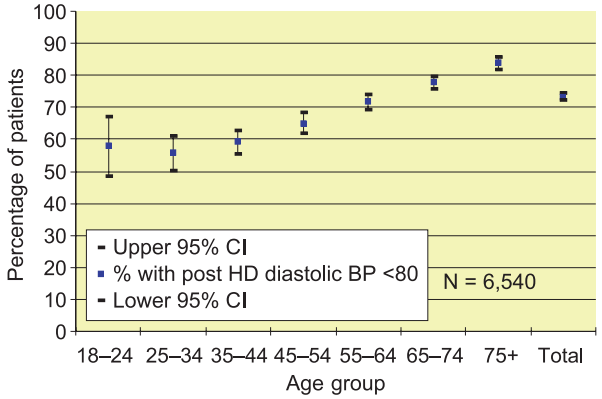

Figure 13.46: Percentage of patients achieving the RA DBP Standard by age: post-HD

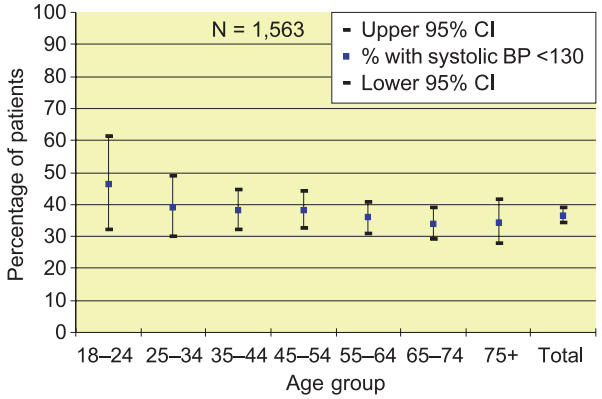

Figure 13.47: Percentage of patients achieving the RA SBP Standard by age: PD

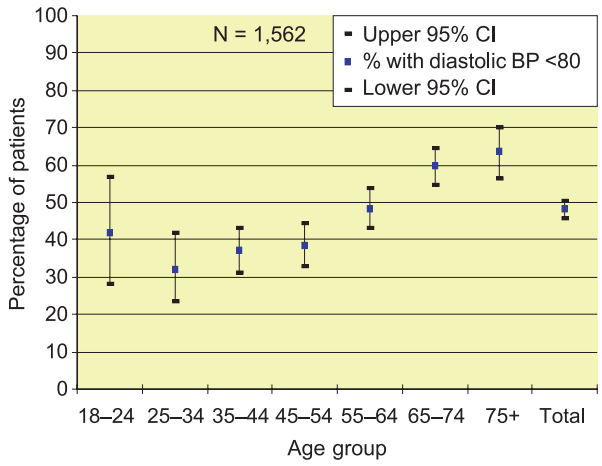

Figure 13.48: Percentage of patients achieving the RA DBP Standard by age: PD

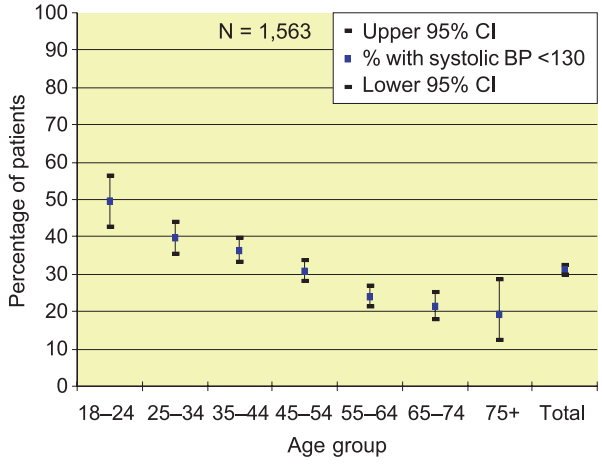

Figure 13.49: Percentage of patients achieving the RA SBP Standard by age: Transplant

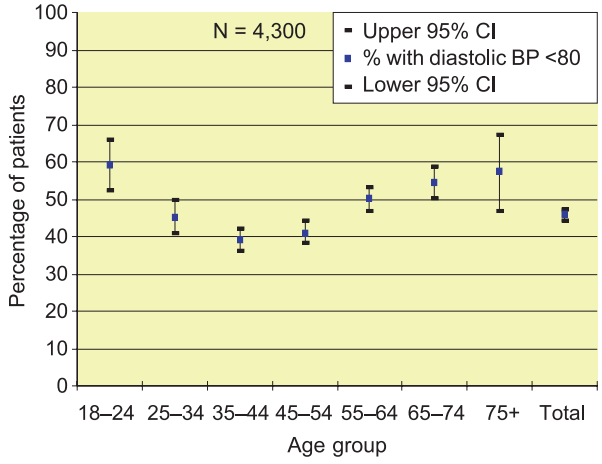

Figure 13.50: Percentage of patients achieving the RA DBP Standard by age: Transplant

Serum Cholesterol

There is no variation of serum cholesterol achievement with age for HD patients. In contrast, achievement of serum cholesterol is slightly better in PD patients aged >55 years. Transplant recipients show a V shaped curve with highest cholesterol in the 45–55 age group. How much this reflects immuno-suppressive regimes or clinical practice in treating perceived 10 year risk of myocardial infarction in these patients is not known.

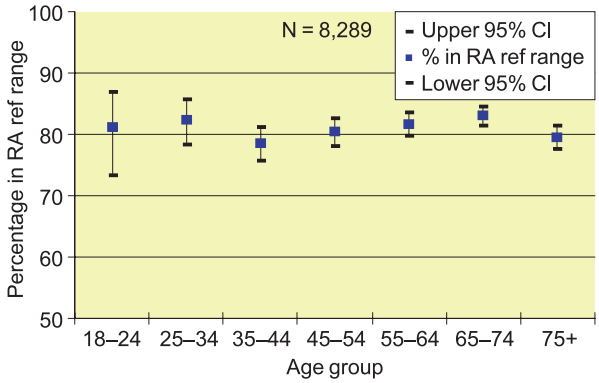

Figure 13.51: Percentage of patients achieving the RA cholesterol Standard by age: HD

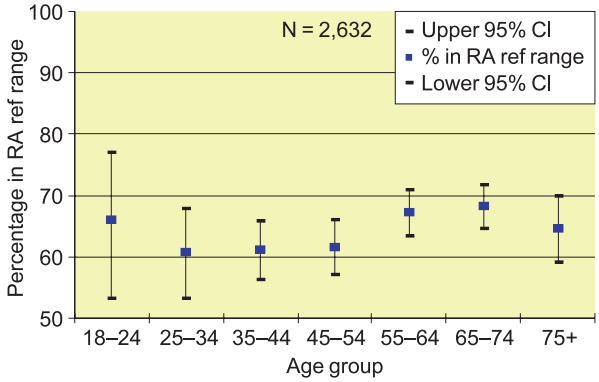

Figure 13.52: Percentage of patients achieving the RA cholesterol Standard by age: PD

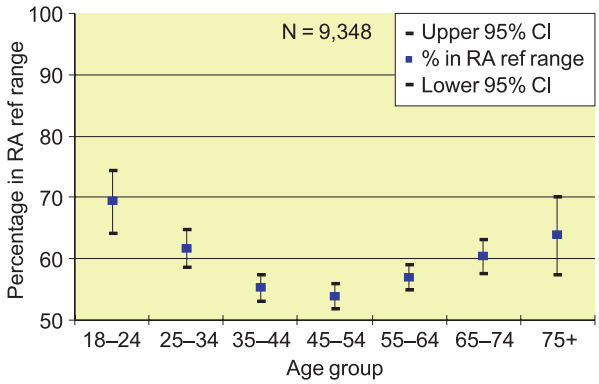

Figure 13.53: Percentage of patients achieving the RA cholesterol Standard by age: Transplant

Glycated Haemoglobin

Only patients with a primary diagnosis of diabetes as the cause of ERF were included in this analysis. Patients with post transplant diabetes or who developed diabetes post ERF were excluded from the analysis.

HD patients with diabetes show a marked trend to lower HbA1c with increasing age although this may partly be accounted for by the different proportions of Type 1 and Type 2 diabetics within the age bands. PD and transplant recipients do not show the same trend with age.

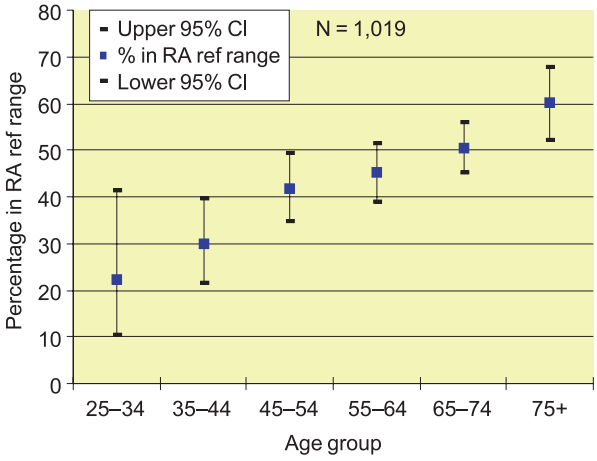

Figure 13.54: Percentage of diabetic patients achieving the RA HbA1c Standard by age: HD

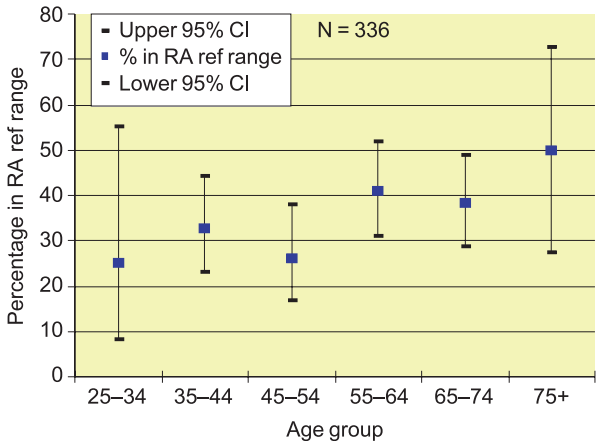

Figure 13.55: Percentage of diabetic patients achieving the RA HbA1c Standard by age: PD

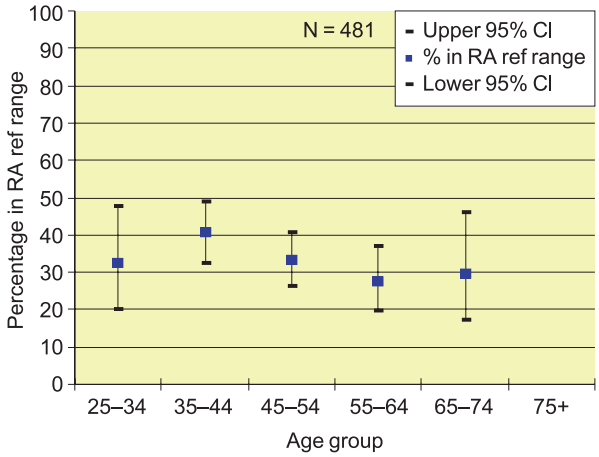

Figure 13.56: Percentage of diabetic patients achieving the RA HbA1c Standard by age: Transplant

Chapter 14: Survival of Incident RRT Patients in the UK

Summary

- 5 year survival of incident patients in the UK on RRT is 42.6%: 64% for those under 65 and 14.5% for older patients.
- The 2003 one-year incident patient survival, adjusted to age 60, on HD and PD was 85.7% and 92.5% respectively, compared with 83.8% and 89.6% for 2002.
- The hazard ratios confirm that the greatest hazard of death occurs in the first 120 days; thereafter the hazard ratio remains stable out to five years.
- For every 10-year increase in patient age, there is an increase in the hazard of death in the year after 90 days of 41% (95% CI 35–47%).
- Although from 1997 to 2001 there appeared to be an overall improvement in one year after 90-day survival from 84.0% to 88.0%, the trend has since levelled.
- The one year after 90 day survival for all renal units falls within 3 standard deviations from the national mean: 2 units have survival more than 2 standard deviations above the mean and 2 units lower than 2 standard deviations from the mean.
- Due to lack of co-morbidity data from many renal units, survival analysis has not been adjusted for co-morbid conditions, so the clinical significance of differences in survival between units is difficult to interpret. This highlights the importance of returning data on co-morbidity.
- In consultation with participating renal units it is hoped next year to remove anonymity from these analyses.

Introduction

The analyses presented in this chapter examine the survival from the start of renal replacement therapy: they encompass the outcomes from the total incident UK dialysis population, including the 31% who start on peritoneal dialysis and the 3% who receive a pre-emptive transplant. The results therefore show a true reflection of the whole UK RRT population. The survivals reported here are better than those reported for the UK by the IDOPPS study, which only includes haemodialysis patients. As shown in Chapter 4, the haemodialysis patients are a selected group with increased co-morbidity and higher death rates than those selected for PD or pre-emptive transplant.

The dataset includes patients from England, Scotland and Wales. Patients returning to dialysis after a failed transplant are not included in this cohort.

Many of the survival figures quoted in this chapter are from the first day of renal replacement therapy: in many instances survival from day 90 is also presented, as this allows comparison with many other Registries, including the US Registry, which record data only from day 90 onwards. The distinction is important, as there is a high death rate in the first 90 days which would distort comparisons.

Survival rates in different centres contributing to the UK Renal Registry are reported here. These are raw data that require interpretation if legitimate centre comparisons are to be attempted. The Registry can adjust for the effects of the different age distributions of the patients in different centres, but lacks sufficient data from many participating centres to enable adjustment for co-morbidity and ethnic origin, which have been demonstrated to have a major impact on outcome. With this lack of

information on case mix, it is difficult to interpret any apparent difference in survival between centres. It is for this reason that in this section the individual renal units are not identified. For the future it is most important that participating centres send more comprehensive data on co-morbidity and ethnic origin.

In consultation with participating renal units it is hoped next year to remove anonymity from these analyses. Patients with no co-morbidity recorded will be assumed to have none: in the adjusted analyses this may have the effect of making the survival in renal units with poor co-morbidity returns look somewhat worse than they might if appropriate adjustments could be made.

Despite the uncertainty about any apparent differences in outcome, for centres which appear to be outliers, the Registry will follow the clinical governance procedures as set out in Chapter 2.

Statistical methods

The 'number of days at risk' was calculated for each patient, the sum of these values for all patients divided by 365 representing the 'number of patient years at risk'. The mortality rate was defined as:

$$\frac{\text{Number of deaths on RRT}}{\text{Number of patient years at risk}}$$

The unadjusted survival probabilities (with 95% confidence intervals) were calculated using the Kaplan-Meier method, in which the probability of surviving more than a given time can be estimated for members of a cohort of patients, without accounting for the characteristics of the members of that cohort. Where centres are small, or the survival probabilities are greater than 90%, the confidence intervals are only approximate.

In order to estimate the difference in survival of different subgroups of patients within the cohort, a stratified proportional hazards model (Cox) was used where appropriate. The results from the Cox model are interpreted using a hazard ratio. When comparing two groups, the hazard ratio is the ratio of the estimated hazards for group A relative to group B, where the hazard is the risk of dying at time t given that the individual has survived until this time. The underlying assumption of a proportional hazards model is that this ratio remains constant throughout the period under consideration. Whenever used, the proportional hazards model was tested for validity.

Validity of the centre adjustment for proportional hazards

For the Cox model to be used to adjust centre survival to a specific age (eg 60 years), the assumption of constant proportionality means that the relationship of survival (hazard of death) to age is similar in all centres within the time period studied. If one centre had a relationship of survival with age different from the other centres, the adjustment would not be valid. Testing showed the relationship to be similar for all centres.

Survival of new patients on RRT

The revised Renal Standards document concluded that:

It is hard to set survival standards at present because these should be age, gender and co-morbidity adjusted and this is not yet possible from Registry data. The last Standards document recommended at least 90% one year survival for patients aged 18-55 years with standard primary renal disease. This may have been too low as the rate in participating centres in the Registry was 97%, though numbers were small.

The Renal Standards document defines Standard Primary Renal Disease using the EDTA diagnosis codes (including only codes 0–49): this excludes patients with renal disease due to diabetes and other systemic diseases. It is more widespread practice to simply exclude diabetics, so these figures are also included in this report to allow comparison with reports from other Registries. The results are shown in Table 14.1.

Table 14.2 contains 90 day adjusted patient survival for the UK countries showing the high initial death rates, and 1 year after 90-day adjusted patient survival.

Table 14.1: One-year patient survival – patients aged 18–55, 2003 cohort

First treatment	Standard primary renal disease	All diseases except diabetes
All %	95.5	95.2
95% CI	*94.0–97.0*	*93.8–96.5*
HD %	94.0	94.1
95% CI	*91.9–96.1*	*92.3–95.9*
PD %	98.1	97.1
95% CI	*96.4–99.7*	*95.4–98.9*

The age-adjusted survival by first established treatment modality is shown in Table 14.3.

The age adjusted one year survival on HD and PD at 85.7% and 92.5% respectively, has improved in 2003 when compared with the previous year of 83.8% and 89.6% respectively. There appears to be better survival on PD compared with HD (Tables 14.1 and 14.3) after age adjustment, similar to data from the USRDS and Australasian (ANZDATA) Registries. However, a straightforward comparison of the modalities in this way is not valid, as there are significant factors in selection for the modalities, and the patients in the two groups are not comparable (Chapter 4).

Tables 14.4 to 14.11 show survival of all patients, and those above and below 65 years of age, for up to seven years after initiation of renal replacement therapy. The UK data show a steep age related decline in survival over all time periods (see also Figures 14.1 and 14.2).

Table 14.3: One-year survival by first established treatment modality 2003 cohort (age adjusted)

	HD	PD
Adjusted 1 year after 90 days %	85.7	92.5
95% CI	*84.3–87.2*	*90.9–94.1*

Table 14.4: Unadjusted 90 day survival of new patients, 2003 cohort by age

Age	KM[1] survival analysis (%)	KM 95% CI	N
18–64	95.4	94.5–96.3	2,221
⩾65	85.6	84.1–87.0	2,307
All ages	90.4	89.5–91.3	4,528

[1]KM = Kaplan-Meier.

Table 14.5: Unadjusted 1 year survival of new patients, 2003 cohort by age

Age	KM survival analysis (%)	KM 95% CI	N
18–64	92.1	91.0–93.3	2,119
⩾65	76.5	74.6–78.5	1,974
All ages	84.6	83.5–85.8	4,093

If the survival data in Tables 14.5 to 14.11 are calculated from day 90 (1 year after day 90 survival, 2 year after 90 day survival, etc) the survival in all cases increases by an additional 3–4% across both age bands. These are the results most comparable to the figures quoted by the USRDS from the USA and most other national registries.

Table 14.2: Patient % survival across the UK, 2002- 2003 cohort*, adjusted to age 60

	England	Wales	Scotland	UK
% 90 day	93.3	91.4	93.8	93.2
95% CI	*92.4–94.2*	*89.0–93.9*	*92.1–95.5*	*92.4–94.1*
% 1 year after 90 days	88.3	86.4	86.0	87.8
95% CI	*87.0–89.5*	*83.0–89.9*	*83.2–88.8*	*86.7–89.0*

*Patients starting RRT from 1.10.2002 to 30.9.2003.

Table 14.6: Unadjusted 2 year survival of new patients, 2002 cohort by age

	KM survival analysis (%)			
Age	1 year	2 year	2 year 95% CI	N
18–64	88.9	83.6	82.0–85.3	1,663
⩾65	67.0	57.0	54.7–59.3	1,806
All ages	77.6	75.6	74.1–77.2	3,469

Table 14.7: Unadjusted 3 year survival of new patients, 2001 cohort, by age

	KM survival analysis (%)				
Age	1 year	2 year	3 year	3 year 95% CI	N
18–64	88.5	81.3	76.4	74.4–78.4	1,524
⩾65	66.8	53.2	44.6	42.1–47.1	1,540
All ages	78.4	67.4	65.8	64.0–67.7	3,064

Table 14.8: Unadjusted 4 year survival of new patients, 2000 cohort by age

	KM survival analysis (%)				I	
Age	1 year	2 year	3 year	4 year	4 year 95% CI	N
18–64	89.6	82.3	75.4	71.2	68.9–73.6	1,211
⩾65	68.1	54.8	41.4	33.7	31.0–36.3	1,156
All ages	79.1	68.7	58.5	58.0	56.0–60.1	2,367

Table 14.9: Unadjusted 5 year survival of new patients, 1999 cohort by age

	KM survival analysis (%)						
Age	1 year	2 year	3 year	4 year	5 year	5 year 95% CI	N
18–64	88.1	82.3	75.6	69.6	65.7	63.1–68.3	1,028
⩾65	67.8	52.6	39.9	29.7	24.8	22.2–27.4	910
All ages	78.5	68.2	58.7	50.7	50.1	47.9–52.4	1,938

Table 14.10: Unadjusted 6 year survival of new patients, 1998 cohort by age

	KM survival analysis (%)							
Age	1 year	2 year	3 year	4 year	5 year	6 year	6 year 95% CI	N
18–64	87.1	80.8	74.5	69.2	62.5	59.3	56.6–62.1	872
⩾65	65.1	50.7	30.7	31.8	24.4	20.1	17.5–22.7	767
All ages	76.9	66.9	58.9	51.2	44.8	43.5	41.3–45.9	1,639

Table 14.11: Unadjusted 7 year survival of new patients, 1997 cohort by age

	KM survival analysis (%)								
Age	1 year	2 year	3 year	4 year	5 year	6 year	7 year	7 year 95% CI	N
18–64	87.4	80.4	74.4	68.3	64.0	59.7	54.8	51.2–58.4	454
⩾65	65.8	45.2	33.6	23.9	14.5	10.8	9.1	6.5–11.8	345
All ages	78.1	65.2	56.8	49.1	42.6	38.6	37.2	34.4–39.9	799

Survival of new patients and age

The incident cohort included in this analysis is all those patients starting RRT in 2003. Patients who recovered function within 90 days (ie patients with acute rather than chronic renal failure) have been excluded.

In Figure 14.1, the unadjusted survival is shown for several age bands for the first 90 days, the first year from day 0 of RRT and the first year after day 90.

The UK Registry has been collecting data on incident patients since its inception in 1997, enabling survival to be estimated for up to seven years after starting renal replacement therapy. The Kaplan-Meier survival curves by age for 7 years are shown in Figure 14.2. Only the older groups reach 50% mortality in a 7-year period. For these, the 50% survival times with 95% CI are: aged 55–64, 66 months ±2.8m; aged 65–74, 33 months ±1.8m; over 75, 21 months ±2.1m. Patients with diabetes have been included in these survival figures. These data include the first 90-day period.

The hazard ratios confirm data previously shown by the Registry that the greatest hazard of death occurs in the first 120 days (Figure 14.3); thereafter the hazard ratio remains stable

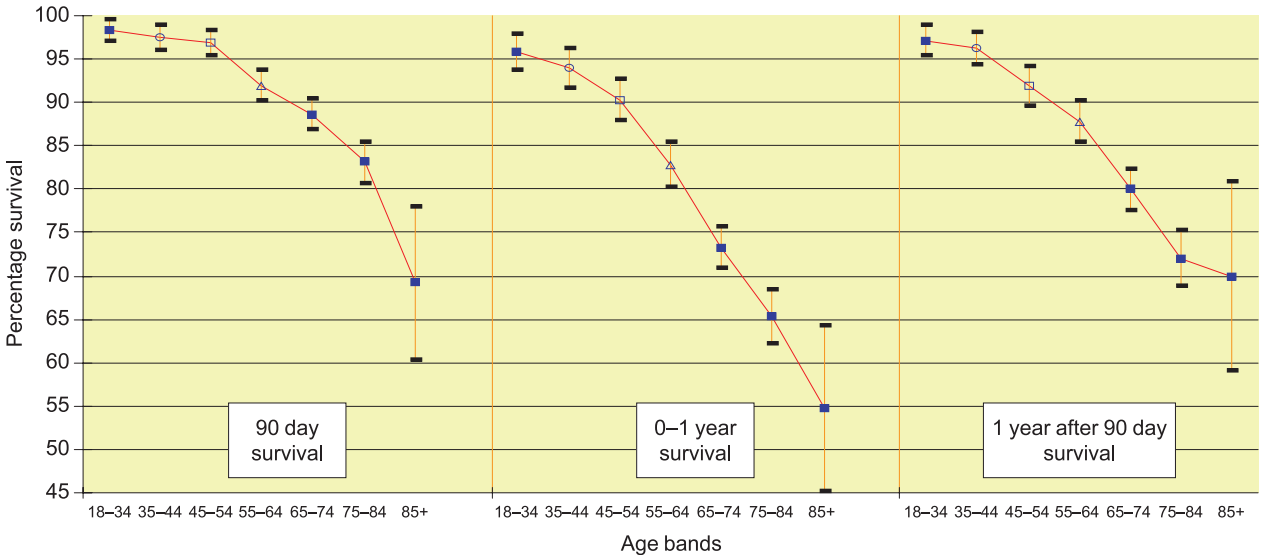

Figure 14.1: Unadjusted survival of all incident patients, by age band

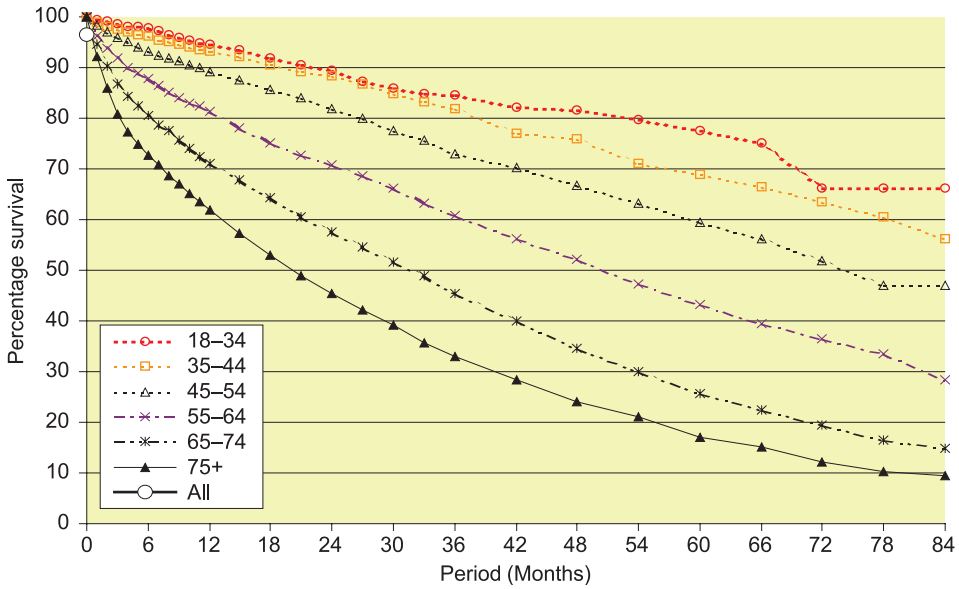

Figure 14.2: Kaplan-Meier 7-year survival of incident patients

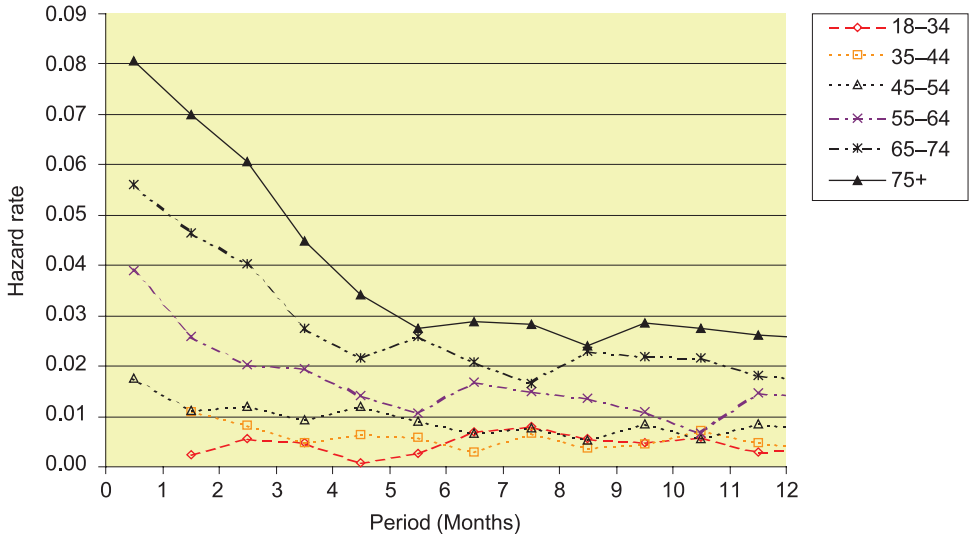

Figure 14.3: 1st-year hazard of death, by age band

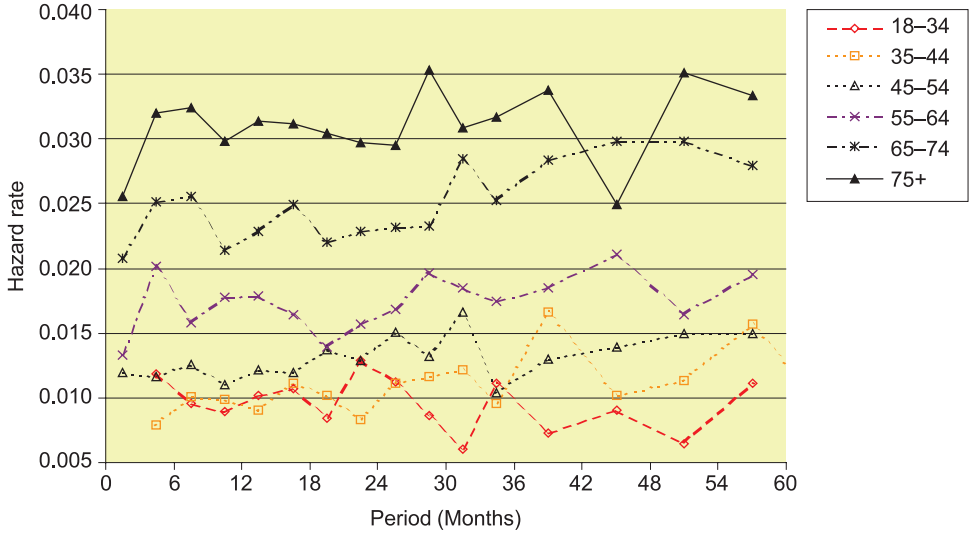

Figure 14.4: 5-year hazard of death, by age band (excluding the first 90 days)

The results beyond 36 months for patients aged 75+ are not reliable as the numbers were very small

out to five years (Figure 14.4): patient numbers are too small for meaningful analysis for later years. These data contrast with the 'vintage effect' seen in data from the USRDS Registry (USA) which demonstrates a rising hazard of death with increasing length of time on renal replacement therapy. Cross sectional analysis of the one year hazard of death in prevalent UK patients also fails to show any effect of 'vintage'.

Age adjustment of survival in the first 90 days and thereafter

Analysing all the patients starting RRT between 1997 and 2000, the proportional hazards for each 1-year increase in age of the patients for the two time intervals of the first 90 days and the subsequent 365 days are shown in Table 14.12.

These data show that in the first 90 days there is a greater risk of death for every 1 year increase in patient age than there is in the subsequent 1-year period. For every 10 year increase in patient age, there is an increase in the hazard of death of 58% (95% CI 50–65%) in the first 90 days, compared with 41% (95% CI 35–47%) in the subsequent 365 days.

These data on their own would not invalidate the proportional hazards model for age

Table 14.12: Increase in proportional hazard of death for each year increase in age, at 90 days and for 1 year thereafter

Interval	Hazard of death	95% CI
First 90 days	1.058	1.050–1.065
1 year after first 90 days	1.041	1.035–1.047

adjustment between centres for the single time period of 0–365 days. However analysis has shown that there are centre variations in the hazards that invalidate the model for this period due to the change over period between these two hazards varying between centres, with some earlier at 80 days and others later at 110 days. The model is valid if the period is divided into 0–90 days and any subsequent period. Analysed over longer periods (eg 3 years) the effect is lost as it becomes very small.

Changes in incident patient survival, 1997–2003

In Figure 14.5, the right-hand graph shows the adjusted one-year after 90-day survival for all incident patients on the Registry in the years 1997–2003. More centres have joined the Registry since 1997 and these centres may have had differing survival rates. The left-hand graph shows the same analysis just for those centres that reported in 1997. It shows that although in the years up to 2001 there appeared to be an overall improvement in survival, from 84.0 to 88.0%, the trend has since levelled. Prevalent patients (see Chapter 4) show a similar trend. These data also demonstrate that the survival profile of the 1997 centres is similar to that of the newer centres.

Survival of incident patients in 2003 by centre

Comparability of figures for survival within the first 90 days is heavily dependent on consistency between renal units in ensuring that all early chronic renal failure deaths are included and that all acute renal failure patient deaths are excluded. The Registry has contacted renal units when apparent anomalies in data occur, and it is clear there is considerable variability between renal units in how these decisions are made, so one must be cautious when making comparative assessment of survival in the first 90 days. For this reason these data are not shown here. As the 1 year survival from day 0 of starting renal replacement therapy includes this time period, the more appropriate figure for comparing renal units is the 1 year after 90 days, which can also be adjusted for age: results are shown in Figure 14.6, adjusted to age 60. To enable this length of follow-up by 31.12.2004 the cohort is those starting RRT from 1.10.2002 to 30.9.2003.

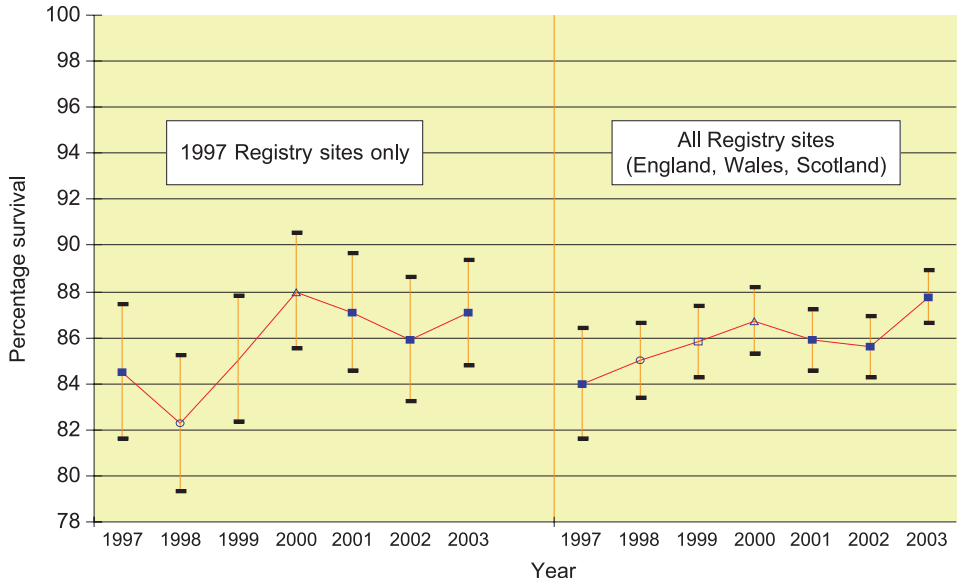

Figure 14.5: Change in one-year after 90 day adjusted (age 60) survival, 1997–2003

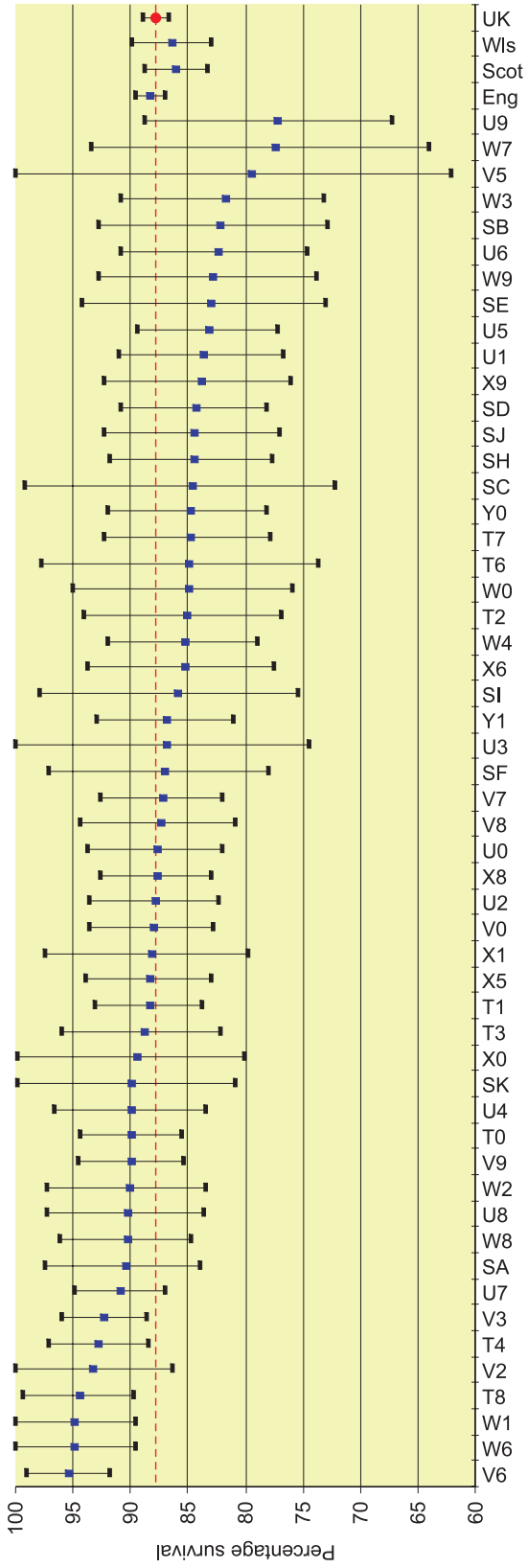

Figure 14.6: Survival 1 year after 90 days, adjusted to age 60; 2003 cohort

Showing 95% confidence intervals. Cohort is those starting RRT from 1.10.2002 to 30.9.2003. These adjusted data and the unadjusted data are shown in Table 14.13 at the end of this chapter

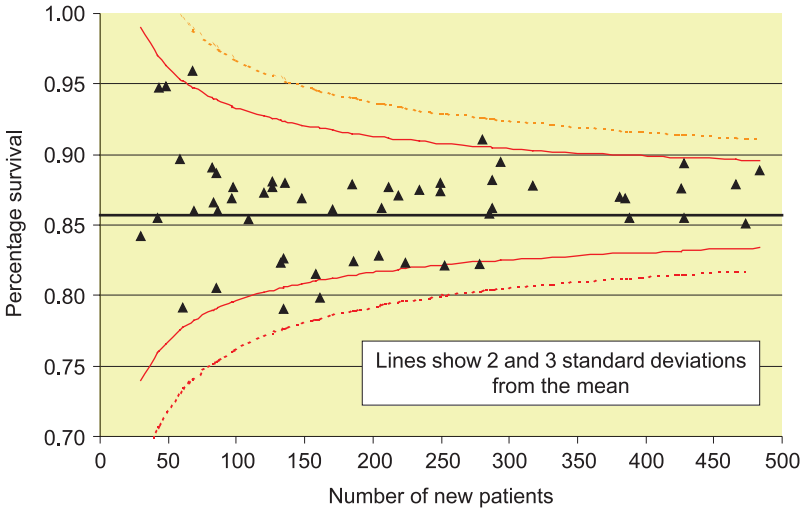

Figure 14.7: Funnel plot for age adjusted 1 year after 90 days survival; 2001–2003 cohorts

Analysis of centre variability in survival in 1 year after 90 days

In the analysis of 2003 data alone, some of the smaller centres have wide confidence intervals. This can be addressed in part by including a larger cohort, including all patients starting RRT 2001–2003: this also assesses recently sustained performance. A few centres have been contributing data to the Renal Registry for only part of this period so will have fewer years included. These data on survival are shown using funnel plots to identify possible outliers (Figure 14.7). From Figure 14.7, for any size of incident cohort (X axis) one can identify whether any given survival rate (Y axis) falls within plus or minus 2 standard deviations (SDs) from the national mean (solid lines, 95% confidence interval) or 3 standard deviations (dotted lines, 99.8% confidence interval).

This analysis has not been adjusted for co-morbid conditions, so the clinical significance of differences in survival is difficult to interpret. This highlights the importance of all renal units needing to return data on co-morbidity. In addition there is a wide scatter of results from the different renal units such that a variation from the mean of 2 standard deviations may not be large enough to indicate statistical significance: 3 standard deviations may be more appropriate.

To adjust survival for case-mix needs better data return from renal units and requires improved methodologies and structure at renal unit level. This is likely to include investment in informatics staff within renal units who would form part of the renal team.

Appendix of survival tables

Table 14.13: 1 year after 90-day survival by centre for 2003

	Unadjusted		Adjusted to age 60	
Centre	1 year after 90 day survival & *95% CI*		1 year after 90 day survival & *95% CI*	
SA	85.5	75.5–95.5	90.4	83.9–97.5
SB	78.7	66.9–90.4	82.2	72.9–92.7
SC	76.9	57.0–96.9	84.6	72.2–99.2
SD	81.1	73.6–88.6	84.2	78.1–90.8
SE	80.5	68.4–92.6	82.9	73.0–94.2
SF	84.3	72.7–95.9	87.1	78.1–97.1
SG	95.0	85.4–100	96.3	89.5–100
SH	80.5	72.0–89.1	84.5	77.7–91.8
SI	80.3	64.8–95.8	85.9	75.4–97.9
SJ	79.8	70.2–89.3	84.4	77.1–92.3
SK	86.4	73.9–98.9	89.8	80.8–99.8
T0	87.6	82.2–93.0	89.9	85.5–94.5
T1	85.5	79.9–91.1	88.3	83.8–93.1
T2	80.7	69.8–91.5	85.0	76.8–94.0
T3	89.8	83.4–96.1	88.8	82.2–95.9
T4	91.8	86.8–96.7	92.7	88.5–97.2
T6	81.1	66.1–96.1	84.9	73.7–97.8
T7	80.5	71.5–89.5	84.8	77.9–92.3
T8	94.0	88.8–99.2	94.4	89.7–99.3
U0	85.0	78.0–92.0	87.6	82.0–93.7
U1	82.9	75.5–90.3	83.6	76.8–91.0
U2	83.9	76.7–91.2	87.8	82.4–93.6
U3	83.3	66.1–100	86.8	74.5–100
U4	86.4	77.7–95.2	89.8	83.4–96.7
U5	76.1	68.1–84.2	83.1	77.3–89.4
U6	78.8	69.2–88.4	82.4	74.6–90.9
U7	88.8	84.0–93.5	90.8	87.0–94.9
U8	85.1	74.8–95.3	90.2	83.6–97.3
U9	68.3	54.3–82.3	77.2	67.2–88.7
V0	85.7	79.3–92.0	88.0	82.7–93.5
V2	90.3	79.9–100	93.3	86.3–100
V3	90.4	85.9–94.9	92.2	88.6–96.0
V5	75.0	50.5–99.5	79.4	62.1–100
V6	94.1	89.6–98.7	95.3	91.8–99.0
V7	85.8	79.9–91.6	87.2	82.0–92.6
V8	83.5	74.9–92.0	87.3	80.8–94.3
V9	87.9	82.5–93.3	89.9	85.4–94.6
W0	84.0	73.8–94.1	84.9	76.0–94.9
W1	93.2	85.7–100	94.9	89.5–100
W2	84.4	73.9–95.0	90.1	83.4–97.3
W3	78.0	67.6–88.3	81.6	73.2–90.9
W4	78.9	70.1–87.6	85.2	78.9–91.9
W6	93.8	86.9–100	94.9	89.5–100
W7	71.1	52.8–89.3	77.4	64.1–93.4
W8	88.8	82.3–95.4	90.3	84.7–96.2
W9	76.3	63.8–88.8	82.7	73.8–92.8
X0	87.0	75.0–99.1	89.4	80.1–99.9

Table 14.13: (continued)

Centre	Unadjusted		Adjusted to age 60	
	1 year after 90 day survival & *95% CI*		1 year after 90 day survival & *95% CI*	
X1	81.8	68.7–95.0	88.2	79.8–97.5
X5	87.0	81.0–93.0	88.2	82.9–93.8
X6	76.2	63.8–88.5	85.3	77.6–93.7
X8	83.3	77.1–89.6	87.7	83.0–92.6
X9	79.5	69.6–89.5	83.8	76.1–92.3
Y0	82.6	74.8–90.3	84.8	78.2–91.9
Y1	79.7	71.0–88.3	86.8	81.1–92.9
England	**85.3**	**84.1–86.6**	**88.3**	**87.0–89.5**
Scotland	**81.9**	**78.6–85.2**	**86.0**	**83.2–88.8**
Wales	**82.3**	**78.0–86.5**	**86.4**	**83.0–89.9**
UK	**84.6**	**83.5–85.8**	**87.8**	**86.7–89.0**

Table 14.14: 90-day survival by centre for 2003

Centre	Unadjusted		Adjusted to age 60	
	90 day survival & *95% CI*		90 day survival & *95% CI*	
SA	85.0	76.0–94.0	91.1	85.7–96.9
SB	90.4	82.4–98.4	92.8	87.0–99.0
SC	90.5	77.9–100.0	94.8	88.3–100.0
SD	87.7	81.9–93.5	91.1	86.8–95.5
SE	80.8	70.1–91.5	85.0	77.0–94.0
SF	97.5	92.7–100.0	98.3	94.9–100.0
SG	95.2	86.1–100.0	96.6	90.6–100.0
SH	94.4	89.7–99.2	96.1	92.9–99.5
SI	100.0	n/a	n/a	n/a
SJ	94.8	89.8–99.8	96.4	93.0–99.9
SK	94.1	86.2–100.0	96.1	91.0–100.0
T0	89.1	84.3–93.8	92.0	88.5–95.7
T1	89.0	84.4–93.7	92.1	88.7–95.7
T2	91.5	84.4–98.6	94.1	89.2–99.2
T3	89.3	83.4–95.3	89.9	84.4–95.7
T4	91.5	86.9–96.1	93.3	89.6–97.0
T6	87.5	76.0–99.0	91.8	84.6–99.7
T7	95.5	91.1–99.8	96.8	93.9–99.9
T8	97.8	94.8–100.0	98.0	95.4–100.0
U0	97.1	94.0–100.0	97.8	95.5–100.0
U1	86.2	79.9–92.5	87.9	82.5–93.6
U2	93.6	89.1–98.2	95.7	92.6–98.9
U3	70.4	53.1–87.6	80.0	68.7–93.2
U4	85.5	77.2–93.8	90.5	85.1–96.3
U5	87.5	81.8–93.2	92.4	88.8–96.1
U6	87.4	80.4–94.3	90.9	86.0–96.2
U7	92.5	88.7–96.3	94.5	91.7–97.4
U8	82.8	73.0–92.5	90.1	84.4–96.2
U9	90.4	82.4–98.4	94.3	89.6–99.2
V0	89.0	83.7–94.2	91.7	87.7–95.9
V2	93.9	85.8–100.0	96.2	91.3–100.0
V3	93.9	90.3–97.4	95.5	92.9–98.1

Table 14.14: (continued)

Centre	Unadjusted		Adjusted to age 60	
	90 day survival & *95% CI*		90 day survival & *95% CI*	
V5	92.3	77.8–100.0	94.4	85.0–100.0
V6	92.0	87.0–97.0	94.0	90.3–97.9
V7	92.5	88.4–96.6	94.0	90.8–97.4
V8	92.5	86.7–98.3	94.8	90.8–98.9
V9	92.3	88.1–96.5	94.1	91.0–97.4
W0	94.3	88.1–100.0	95.4	90.4–100.0
W1	84.6	74.8–94.4	89.3	82.5–96.6
W2	93.8	86.9–100.0	96.6	92.9–100.0
W3	88.2	80.9–95.4	91.7	86.7–97.1
W4	89.9	84.0–95.8	93.9	90.3–97.7
W6	96.0	90.6–100.0	97.0	93.1–100.0
W7	80.6	66.7–94.6	87.4	78.6–97.2
W8	92.8	87.6–97.9	94.3	90.3–98.5
W9	78.1	68.0–88.3	86.9	80.6–93.6
X0	82.9	71.4–94.4	88.4	80.8–96.8
X1	85.0	73.9–96.1	91.4	85.1–98.2
X5	91.3	86.6–96.0	92.9	89.1–96.9
X6	92.3	85.1–99.6	95.7	91.7–99.9
X8	88.7	83.8–93.6	92.6	89.3–96.0
X9	90.1	83.2–97.1	93.1	88.3–98.1
Y0	88.5	82.3–94.6	90.8	86.0–95.9
Y1	89.6	83.5–95.7	93.9	90.3–97.7
England	**90.6**	**89.7–91.6**	**93.3**	**92.4–94.2**
Scotland	**90.9**	**88.6–93.2**	**93.8**	**92.1–95.5**
Wales	**87.1**	**83.7–90.6**	**91.4**	**89.0–93.9**
UK	**90.4**	**89.5–91.3**	**93.2**	**92.4–94.1**

Chapter 15: Co-morbidity in Incident Patients

Summary

- Only a minority of renal units provide adequate data on the co-morbidity of patients starting RRT.
- As a result, data is available on co-morbidity on only 42% of patients starting RRT in 2004.
- For those for whom co-morbidity data is available, over 50% of patients starting RRT in 1999–2004 had at least one co-morbid condition.
- The frequency of co-morbidity increases with age group up to 74, but is lower amongst patients starting RRT aged $\geqslant$75 years.
- Vascular co-morbidity is more common amongst patients whose primary diagnosis is diabetes mellitus.
- The population of patients on peritoneal dialysis at 90 days tends to be younger and to have less co-morbidity than those established on haemodialysis.
- Late referral is less of a problem amongst patients aged <44 years at start of RRT than amongst older patients.
- There was no excess of co-morbidity amongst patients referred for RRT within 3 months compared to those referred earlier.
- Estimated GFR at start of RRT tended to be higher amongst those with co-morbidity compared to those with no co-morbidity.
- Co-morbidity is a powerful predictor of early and late mortality amongst patients starting RRT; adjustment for co-morbidity is therefore critically important for comparisons of survival between renal units.

Co-morbidity data

Collation of data on co-morbidity requires clinicians to provide yes/no answers to the presence or absence of 14 conditions in patients at the time of starting renal replacement therapy. Data on smoking at the time of starting RRT has been collected as a marker for vascular (cardiac, cerebral and peripheral) risk. It is not a co-morbid condition although for the purposes of these analyses, it has been treated as such. Although the operational definitions for each of these conditions have been published annually in the Registry Report, these definitions have not been made available in the form of help screens, at least in the majority of those renal units using the Proton system; data therefore reflect individual clinicians' judgement on the presence or absence of each condition. The conditions are listed in Table 15.1.

Completion of co-morbidity returns requires a clinician's judgement and access to the patient's full medical history. The Registry does not have data on the accuracy of co-morbidity returns when compared with medical records for individual patients.

The analyses reported in this Chapter have been performed using all available data on the 20,110 patients starting RRT between 1999 and 2004, and therefore reflect **cumulative** results on all patients starting RRT for whom co-morbidity has been reported, rather than being confined to patients starting RRT in 2004. In future years it may be possible to compare co-morbidity amongst inception cohorts from each individual year.

Null entries are considered missing data rather than 'no'.

In all the figures where data are shown by the individual centre, the number adjacent to the name of the renal unit indicates the percentage of missing data at that time point.

Table 15.1: Co-morbid conditions listed in the Registry co-morbidity dataset

Angina
Previous MI within 3 months
Previous MI over 3 months ago
Previous CABG or coronary angioplasty
Heart failure
(in some analyses these 5 variables are combined under the term 'cardiovascular disease')
Cerebrovascular disease
Diabetes (when not listed as the cause of ERF)
Chronic obstructive pulmonary disease
Liver disease
Claudication
Ischaemic/neuropathic ulcers
Non-coronary angioplasty, vascular graft, or aneurysm
Amputation for peripheral vascular disease
(in some analyses, these 4 variables are combined under the term 'peripheral vascular disease')
Smoking
Malignancy

Beginning in 2004, the presence or absence of heart failure prior to the start of RRT was also recordable. However, very few units are, to date, reporting the presence or absence of heart failure, and so this variable has not been included in any of the analyses reported in this chapter. Definitions for each co-morbidity are given at the end of this chapter. For some analyses, the major categories of 'cardiovascular disease', cerebrovascular disease, and peripheral vascular disease, as defined in Table 15.1 were used.

Co-morbidity returns by renal units

Returns from the 49 centres reporting data for patients starting RRT in 2004 are given in Table 15.2. Twelve centres (Basildon, Bradford, Chelmsford, Dorset, Hammersmith and Charing Cross, King's, Norwich, Nottingham, Sunderland, Swansea, Wolverhampton, and York) returned data on co-morbidity on at least 90% of their patients. Of these, Chelmsford and Norwich were reporting data for the first time; Sunderland and York had improved from poorer returns on patients starting RRT in 2003, and the remainder performed well in previous years. These units, which vary in size and geographical catchment area, demonstrate that it is possible to provide data reliably. **The Registry will be contacting these centres asking for details of how they organise collection of data on co-morbidity, and will collate that information and with this information, write to Directors of all other centres as soon as possible.**

Twenty-one centres (Brighton, Cambridge, Carshalton, Clwyd, Coventry, Cardiff, Dudley, Guy's, Heartlands Birmingham, Middlesbrough, Newcastle, Oxford, Plymouth, Portsmouth, Preston, Queen Elizabeth Hospital Birmingham, Reading, Shrewsbury, Stevenage, Wirral, and Wrexham) provided data on co-morbidity on less than 10% of incident patients. Of these, most were either newly reporting or had never returned data on more than 10%, the exceptions being Middlesbrough (100% in 2002, 1% in 2004) and Portsmouth (56% in 2001, 8% in 2004). Again, these renal units will be contacted to determine what (if any) procedures they have in place to encourage clinicians to complete database entries on co-morbidity at start of RRT. All four centres that use the Mediqal database achieved returns of $\geqslant 90\%$; Mediqal operates a data validation routine that reminds clinicians on a quarterly basis about missing data items, and Mediqal do not submit data to the Registry until these data items have been completed.

As a result of poor data returns from many renal units, information on co-morbidity at the start of RRT is only available in 1,979 of the 4,704 incident patients in 2004; Table 15.3 gives

Table 15.2: Completeness of co-morbidity returns from individual units on incident patients (1999–2004)

Treatment centre	1999		2000		2001		2002		2003		2004	
	No. incident patients	% returns co-morbidity	No. incident patients	% returns co-morbidity	No. incident patients	% returns co-morbidity	No. incident patients	% returns co-morbidity	No. incident patients	% returns co-morbidity	No. incident patients	% returns co-morbidity
Bangor	–	–	–	–	31	47	29	57	33	42	36	50
Barts	–	–	–	–	–	–	–	–	–	–	187	64
Basildon	–	–	–	–	–	–	–	–	53	100	43	100
Bradford	–	–	–	–	61	93	62	100	75	84	62	92
Brighton	–	–	–	–	–	–	–	–	–	–	113	0
Bristol	118	90	148	94	152	91	123	82	162	83	166	72
Cambridge	–	–	–	–	93	5	74	4	95	1	103	0
Carlisle	27	44	28	39	28	4	26	19	31	0	29	10
Carshalton	111	10	119	12	119	16	171	3	199	3	167	2
Chelmsford	–	–	–	–	–	–	–	–	–	–	52	100
Clwyd	–	–	–	–	16	0	20	0	12	0	13	0
Coventry	92	–	88	0	104	0	95	1	76	0	77	0
Cardiff	137	1	139	1	154	0	181	0	164	2	181	1
Derby	–	–	55	40	–	–	–	–	61	72	65	51
Dorset	–	–	–	–	–	–	–	–	67	99	57	100
Dudley	43	0	40	0	34	0	25	4	41	0	55	0
Exeter	82	32	72	40	98	34	82	50	98	50	116	41
Gloucester	59	3	48	98	50	98	57	68	57	86	55	89
Guys	–	–	126	2	111	1	140	1	93	1	104	0
H&CX	–	–	–	–	–	–	176	99	152	100	196	100
Heartlands	82	0	86	0	85	0	61	2	102	0	98	0
Hull	64	2	81	2	74	0	105	5	80	89	109	85
Ipswich	–	–	–	–	–	–	42	38	35	31	46	15
Kings	–	–	–	–	–	–	117	87	108	100	114	96
Leeds	82	85	160	91	162	86	147	85	169	80	175	70
Leicester	164	80	175	76	185	90	152	88	168	96	165	85
Liverpool	–	–	–	–	183	58	148	49	113	60	126	43
ManWst	–	–	–	–	–	–	–	–	141	29	105	34
Middlesbrough	92	1	86	70	81	90	111	100	103	0	101	1
Newcastle	–	–	–	–	–	–	106	1	100	3	101	0
Norwich	–	–	–	–	–	–	–	–	–	–	99	100
Nottingham	128	24	114	71	121	66	87	99	114	98	107	95
Oxford	142	0	159	3	169	1	165	0	181	1	159	1
Plymouth	68	1	59	0	64	3	79	3	64	0	61	3
Portsmouth	–	–	–	–	143	56	141	46	139	38	119	8
Preston	106	1	116	1	136	1	112	0	98	1	84	0
QEH	–	–	–	–	–	–	–	–	–	–	195	0
Reading	–	–	50	0	63	0	40	0	68	0	67	0
Sheffield	133	24	137	82	153	87	156	61	159	55	169	37
Shrewsbury	–	–	–	–	–	–	–	–	–	–	54	0
Stevenage	103	1	101	1	125	2	88	1	113	0	79	0
Southend	43	2	39	10	35	29	33	48	43	37	41	37
Sunderland	46	0	46	0	38	5	56	46	56	61	51	90
Swansea	–	–	92	77	112	73	113	82	131	96	95	93
Truro	–	–	–	–	37	54	58	66	47	87	60	82
Wirral	–	–	–	–	–	–	40	0	53	0	68	0
Wolverhampton	75	97	78	100	75	99	97	100	89	99	101	96
Wrexham	51	0	54	0	35	0	42	0	33	0	30	0
York	–	–	40	93	37	92	68	76	57	82	48	90
Totals	**2,048**		**2,536**		**3,164**		**3,625**		**4,033**		**4,704**	

Table 15.3: Summary of co-morbidity returns (1999–2004) on incident patients

	Years						
	1999	2000	2001	2002	2003	2004	Totals
Number of renal units	23	28	34	39	43	49	
Total number of new patients	2,048	2,536	3,164	3,625	4,033	4,704	20,110
Number of patients with co-morbid data entries	501	995	1,325	1,589	1,842	1,979	8,231
Percentage of co-morbid returns							
Mean of centres returning co-morbidity	24	39	42	44	46	42	41
Median of centres returning co-morbidity	10	40	55	50	66	71	26

data on the proportion of incident patients starting RRT each year for whom data on co-morbidity was reported to the Registry.

The total number of patients for whom data is available for the years 1999–2003 differs slightly from the numbers given in previous Reports; this is because some centres that joined the Registry in 2004 provided retrospective data on co-morbidity on patients starting RRT in previous years. Chapter 16 in the 2004 Report also gave erroneous data on the numbers of patients starting RRT in Clwyd (28, rather than 9) and Wolverhampton (93, rather than 92).

The analyses in the remainder of this chapter are confined to those in whom data on co-morbidity is available.

Frequency of co-morbidity returned

Table 15.4 outlines the total and age-dependent frequencies of each co-morbid condition separately in the 7,306 patients who survived at least 90 days on RRT and for whom co-morbidity data were available. Cardiovascular diseases, chronic obstructive pulmonary disease (COPD) and malignancy were more common in

Table 15.4: Frequency of co-morbidity amongst 7,306 patients starting RRT in 1999–2004 who survived to 90 days

	Age <65 years		Age ⩾65 years		Total % incidence
Co-morbidity	No patients	%	No patients	%	
Cardiovascular disease	564	14.8	1,129	32.6	23.2
Angina	420	11.0	858	24.9	17.6
MI in past 3 months	70	1.8	107	3.1	2.4
MI >3 months	221	5.8	534	15.5	10.4
CABG/angioplasty	163	4.3	225	6.6	5.4
Cerebrovascular disease	243	6.4	509	14.7	10.3
Diabetes (not a cause of ERF)	182	4.9	319	9.4	7.0
Diabetes as primary disease	874	22.8	561	16.2	19.6
Diabetes of either category	1,056	27.6	880	25.3	26.5
COPD	161	4.3	346	10.1	7.0
Liver disease	97	2.5	59	1.7	2.2
Malignancy	236	6.2	535	15.5	10.6
Peripheral vascular disease	360	9.4	589	17.0	13.0
Claudication	233	6.1	478	13.9	9.8
Ischaemic/neuropathic ulcers	136	3.6	107	3.1	3.4
Angioplasty/vascular graft	79	2.1	162	4.7	3.3
Amputation	88	2.3	57	1.7	2.0
Smoking	752	20.8	471	14.3	17.7
No co-morbidity present	2,104	54.9	1,222	35.2	45.5

patients aged >65 at start of RRT; diabetes and smoking were less commonly reported amongst older patients than in younger patients.

These data allow comparison with US and other international Registries which only report data on patients who survive at least 90 days on RRT.

Co-morbidity totals

Table 15.5 gives data on the number of co-morbidities recorded for each patient starting RRT in 1999–2004 for whom data were available. Nearly half of these patients started RRT without any of the listed co-morbid conditions.

Table 15.5: Cumulative co-morbidity present at the start of RRT

	Number of co-morbidities					
Total	0	1	2	3	4	5+
%	44.6	26.6	14.2	7.6	3.9	3.1

Frequency of co-morbidities by age band

As in previous reports, the frequency of recorded cardiovascular co-morbidity (Figures 15.1 and 15.2) increased with age up until 74 years; the frequency of recorded co-morbidities amongst incident patients aged 75 or more was less than for the 65–74 age group for all co-morbidities (Figures 15.1, 15.2 and 15.3)

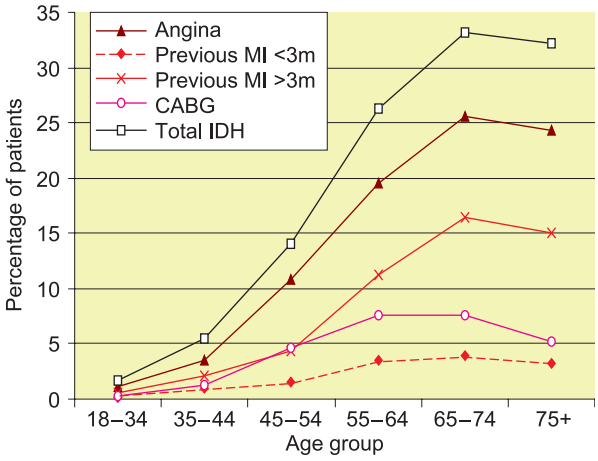

Figure 15.1: Frequency of cardiovascular co-morbidities in incident RRT patients (1999–2004) by age group

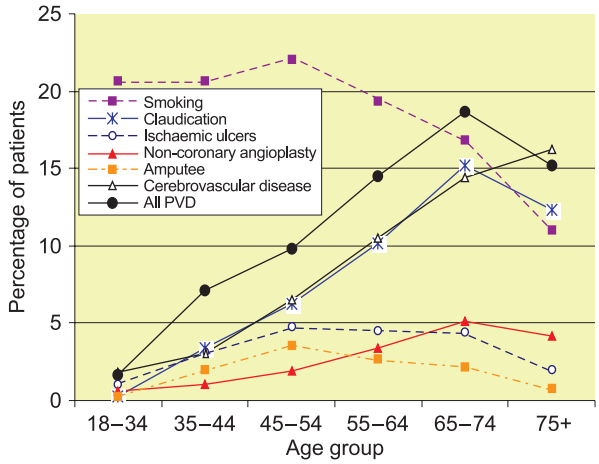

Figure 15.2: Frequency of cerebrovascular and peripheral vascular co-morbidities in incident RRT patients (1999–2004) by age group

other than stroke, malignancy and diabetes when not the primary cause of renal disease. There are several possible explanations for these findings. Firstly, it is possible that negative selection of over 75 year olds with co-morbidity occurs, such that such patients are less likely to be referred to, or accepted by, renal units than patients aged 65–74 with similar degrees of co-morbidity. Secondly, it is possible that patients over 75 with co-morbidity are more likely to choose a palliative care option than those aged

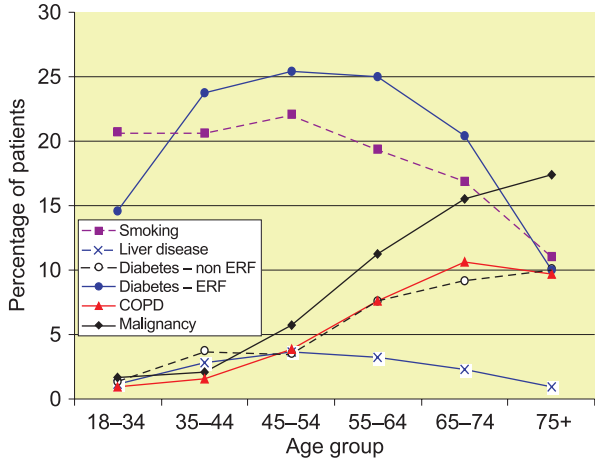

Figure 15.3: Frequency of other co-morbid conditions in incident RRT patients (1999–2004) by age group

Abbreviations: ERF: established renal failure. COPD: chronic obstructive pulmonary disease. 'Diabetes – non ERF' describes patients who were recorded as having diabetes but whose cause of ERF was recorded as non-diabetic kidney disease; 'Diabetes – ERF' describes patients who were recorded as having diabetes and whose cause of ERF was recorded as diabetes

65–74. The Registry does not have reliable data on patients receiving conservative/palliative care for ERF. All renal units have the ability to record on the timeline that a patient has entered a conservative care pathway, so it should be possible to capture these data in future.

Diabetes and co-morbidity

Of the 8,044 patients starting RRT in 1999–2004 for whom co-morbidity returns and a primary diagnosis were available, 1,612 (20%) had a diagnosis of diabetes mellitus as the cause of ERF. Table 15.6 outlines the incidence of co-morbidity for patients with and without diabetes and documents the expected higher prevalence of vascular disease amongst diabetic patients starting RRT compared with non-diabetic patients. The proportion of diabetic and non-diabetic patients who are current smokers when starting RRT is similar. Markedly fewer diabetics than non-diabetics have a history of previous malignancy; this is possibly due to negative selection, ie lower rates of referral or acceptance of patients with stage 5 CKD who have a history of both diabetes mellitus and malignancy.

Table 15.6: Percentage of patients with or without diabetes (either as primary diagnosis or as co-morbidity) who have co-morbid conditions other than diabetes

Co-morbidity	Non-diabetics	Diabetics
Cardiovascular disease	22.0	30.8
Cerebrovascular disease	9.9	14.8
Peripheral vascular disease	10.4	25.7
Smoking	17.3	18.1
COPD	7.7	5.9
Malignancy	13.2	4.7
Liver disease	2.3	2.0

Dialysis modality and co-morbidity

Amongst patients starting RRT who survived to 90 days there was a smaller proportion of the patients treated with peritoneal dialysis aged over 75 years than there was of the patients treated with haemodialysis.

Table 15.7 compares the proportions of patients on HD and PD with each of the co-morbidities for which data were collected and also gives the median age for patients with each type of co-morbidity. Data on co-morbidity were available for 44% of HD and 42% of PD patients. All common co-morbidities are more frequent amongst those treated with HD than with PD which is in keeping with the overall age profile of the populations on HD and PD (Figure 15.4).

Table 15.7: Proportions of co-morbid conditions present in patients starting HD or PD in 1999–2004

	HD		PD		
Co-morbidity	%	Median age	%	Median age	p value
Angina	19	71	16	67	0.0002
MI – more than 3 months ago	11	71	11	68	0.57
MI – within 3 months	3	70	2	67	0.01
CABG	5	68	6	66	0.14
Cerebrovascular disease	12	72	9	66	<0.0001
Diabetes non-ERF	8	71	5	68	<0.0001
COPD	8	71	4	65	<0.0001
Smoking	18	63	17	55	0.22
Liver disease	3	59	1	58	<0.0001
Malignancy	13	72	7	70	<0.0001
Claudication	11	71	8	66	0.001
Ischaemic/neuropathic ulcers	4	65	2	56	<0.0001
Angioplasty of non coronary vessels	4	71	3	65	0.019
Amputation	2	62	1	54	0.001

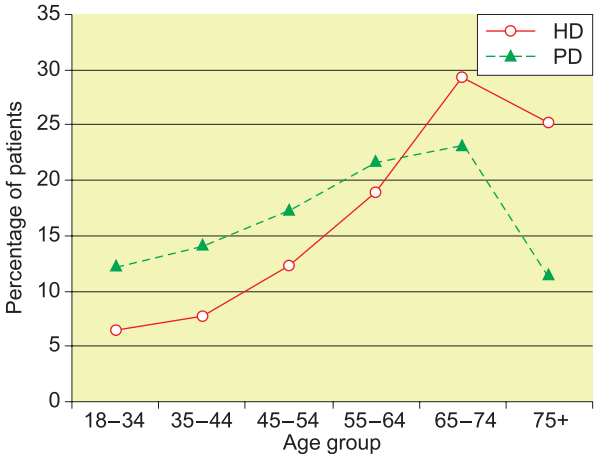

Figure 15.4: Age distribution of patients starting RRT in 1999–2004 who were receiving either HD or PD at 90 days after start of RRT, excluding those who had recovered kidney function

Timing of referral to a nephrologist and co-morbidity

Data on the time between first referral to a nephrologist in a dialysis centre and the start of RRT were available for 6,564 patients starting RRT in 1999–2004 (Figure 15.5). The duration of time between being seen for the first time by a nephrologist and starting renal replacement therapy was shorter with increasing age after age 44, even though most new patients are elderly – suggesting that efforts to improve timely referral of patients for consideration of RRT should focus on older patients. How many of the 'late referrals' were due to predictable, progressive CKD and how many to an unpredictable acute decline in kidney function on the background of previously stable CKD, however, is uncertain.

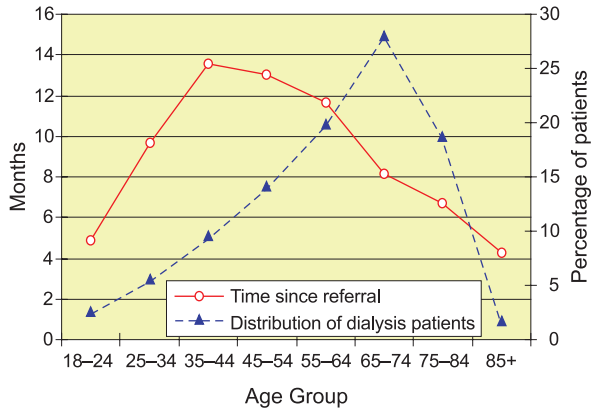

Figure 15.5: Duration of pre-dialysis nephrological care and the proportion of new dialysis patients per age band

Table 15.8: Frequency of specific co-morbidities amongst patients referred late (0–89 days) compared with those referred early (>89 days)

	Referral period (days)		
	0–89	⩾90	p value
Heart disease	19.3	24.6	<0.0001
Peripheral vascular disease	9.9	14.1	<0.0001
Cerebrovascular disease	8.4	11.5	0.002
Diabetes (not cause of ERF)	5.9	7.1	0.1109
COPD	6.7	7.1	0.6276
Liver disease	2.5	1.9	0.2139
Malignancy	13.7	8.5	<0.0001
Smoking	15.9	18.4	0.0458

Table 15.8 gives the frequency with which co-morbidity was present in patients referred to a nephrologist in a dialysis centre according to the timing of referral (less than or greater than 3 months). In contrast to some previously published reports, these data do not support the contention that late-referred patients carry a higher co-morbidity burden than those referred earlier; in fact, significantly more patients in the group referred early had cardiovascular disease, peripheral vascular disease, cerebrovascular disease and malignancy than in the group referred late.

Frequency of co-morbidity by ethnicity

There were 6,731 patients with data returns for both ethnic origin and co-morbidity; 7.8% were of South Asian origin, 3.2% African–Caribbean, 0.4% Chinese, 2.4% 'Other', and 86.2% White. Table 15.9 compares major co-morbidities amongst South Asian, African–Caribbean, and White patients. Smoking and malignancy were more commonly reported amongst White patients; stroke was less common amongst South Asians; and cardiovascular disease less common amongst African–Caribbean patients.

Diabetes (whether listed as the cause of renal failure or not) was more common amongst each ethnic minority population than in the White population (Figure 15.6).

Figure 15.7 shows the age distribution of incident patients according to ethnic origin; by

Table 15.9: Major co-morbidities amongst South Asian, African–Caribbean, and White patients starting RRT 1999–2004

	South Asian	Black	White	p value
Number of patients	526	213	5,804	0.0065
% with co-morbidity				
Smoking	7.8	8.4	19.5	<0.0001
CVA	7.3	10.4	11.2	0.0194
PVD	10.1	4.7	14.3	<0.0001
Cardiovascular disease	24.2	17.5	24.7	0.055
Liver disease	4.0	1.4	2.2	0.0165
COPD	4.3	4.3	8.2	0.001
Malignancy	3.2	5.2	12.2	<0.0001

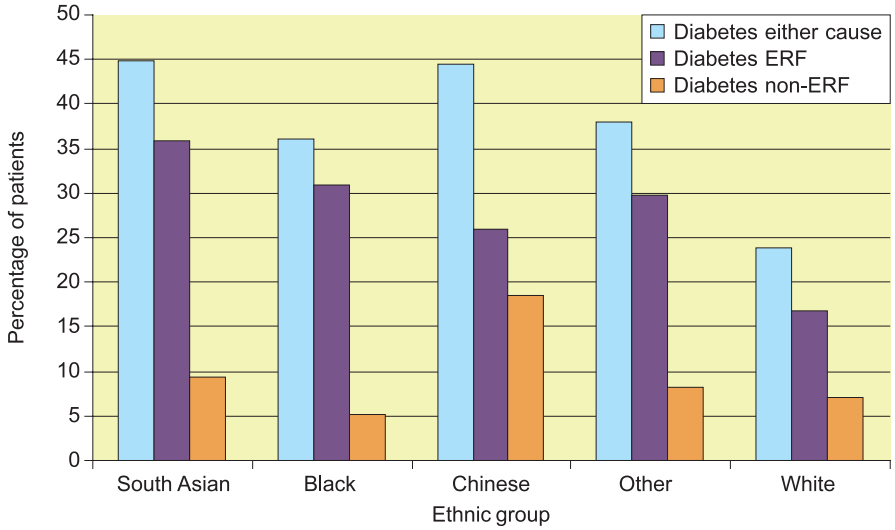

Figure 15.6: Frequency of diabetes by ethnic group

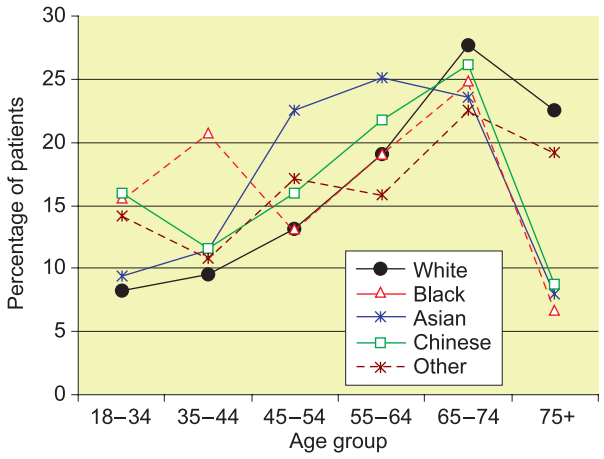

Figure 15.7: Age distribution of incident patients by ethnic group

comparison with White patients there was a smaller proportion of African–Caribbean, South Asian, and Chinese patients starting RRT aged 75 years or over. This is consistent with the younger age structure of these ethnic minority populations in the UK.

Renal function at commencement of dialysis and co-morbidity

Estimated GFR (eGFR), using the 4-variable MDRD equation, was calculated for patients starting RRT using the last available

Table 15.10: Mean eGFR at start of RRT and presence of co-morbidity

	Co-morbidity present		Co-morbidity absent		
	Mean	95% CI	Mean	95% CI	p value
All patients	8.9	8.7–9.1	9.4	9.2–9.5	0.002
Angina	9.9	9.6–10.2	9.0	8.8–9.2	<0.0001
MI in past 3 months	10.6	9.5–11.6	9.1	9.0–9.3	0.001
MI >3 months ago	9.5	9.2–9.9	9.1	9.0–9.3	0.020
CABG/angioplasty	10.3	9.7–10.9	9.1	9.0–9.2	0.000
Cerebrovascular disease	9.3	8.9–9.7	9.1	9.0–9.3	0.113
Diabetes (not cause of ERF)	10.2	9.6–10.8	9.1	8.9–9.2	<0.0001
Diabetes as primary disease	10.3	9.9–10.7	8.9	8.7–9.1	<0.0001
Diabetes of either category	10.3	9.9–10.6	8.8	8.6–8.9	<0.0001
COPD	9.9	9.4–10.5	9.1	9.0–9.3	0.001
Liver disease	9.9	8.8–11.0	9.1	9.0–9.3	0.077
Malignancy	9.3	8.8–9.7	9.1	9.0–9.3	0.154
Claudication	10.0	9.6–10.5	9.1	8.9–9.2	<0.0001
Ischaemic/neuropathic ulcers	9.9	9.1–10.6	9.1	9.0–9.3	0.026
Angioplasty/vascular graft	9.9	9.2–10.7	9.1	9.0–9.3	0.021
Amputation	10.2	9.4–11.1	9.1	9.0–9.3	0.019
Smoking	8.9	8.6–9.2	9.3	9.1–9.5	0.845

measurement of serum creatinine concentration prior to start of RRT (excluding a small number of patients for whom no creatinine result was available within 14 days prior to start of RRT). eGFR was then compared between patients starting RRT with co-morbidity and those without. (Table 15.10) Residual kidney function assessed using this formula was significantly higher at the start of RRT amongst patients with any form of cardiovascular disease, diabetes (whether or not listed as the cause of ERF) and peripheral vascular disease – suggesting that clinicians tend to start RRT earlier in patients with these co-morbidities. This analysis takes no account of the timing of referral.

Haemoglobin at commencement of dialysis and co-morbidity

The mean haemoglobin concentration immediately prior to the start of RRT was also compared between patients starting RRT with and without co-morbidity (Table 15.11). In contrast to the data on eGFR, mean haemoglobin concentration was similar in patients with and without co-morbidity, although haemoglobin was higher in patients with a history of myocardial infarction >3 months ago and coronary revascularisation and lower in those with liver disease and ischaemic/neuropathic ulcers.

Table 15.11: Mean haemoglobin at start of RRT and presence of co-morbidity

	Co-morbidity present		Co-morbidity absent		
	Mean	95% CI	Mean	95% CI	p value
No co-morbidity	10.1	10.1–10.2	10.1	10.0–10.1	0.113
Angina	10.1	10.1–10.2	10.1	10.1–10.1	0.994
MI in past 3 months	10.1	9.8–10.3	10.1	10.1–10.2	0.667
MI >3 months ago	10.4	10.2–10.5	10.1	10.0–10.1	0.005
CABG/angioplasty	10.4	10.2–10.5	10.1	10.1–10.1	0.037
Cerebrovascular disease	10.1	10.0–10.2	10.1	10.1–10.2	0.402
Diabetes (not cause of ERF)	10.1	10.0–10.3	10.1	10.1–10.1	0.701
Diabetes as primary disease	10.0	9.9–10.1	10.1	10.1–10.2	0.892
Diabetes of either category	10.1	10.0–10.1	10.1	10.1–10.2	0.807
COPD	10.0	9.8–10.1	10.1	10.1–10.2	0.061
Liver disease	9.6	9.4–9.9	10.1	10.1–10.2	0.001
Malignancy	10.0	9.9–10.1	10.1	10.1–10.2	0.029
Claudication	10.1	10.0–10.2	10.1	10.1–10.2	0.747
Ischaemic/neuropathic ulcers	9.8	9.6–10.0	10.1	10.1–10.2	0.008
Angioplasty/vascular graft	10.3	10.1–10.5	10.1	10.1–10.1	0.275
Amputation	9.9	9.6–10.2	10.1	10.1–10.2	0.110
Smoking	10.0	9.9–10.1	10.1	10.1–10.2	0.097

Renal transplantation and co-morbidity

This analysis was confined to data on incident patients in each of the years 1999–2004 from centres that had achieved >80% completeness of co-morbidity returns in that year (see Table 15.2). Figure 15.8 gives the age distribution of patients who had received a transplant by the end of 2004 compared with the age distribution of those who remained un-transplanted. Patients who died within this time period without receiving a transplant, were included in the analysis within the non-transplanted group.

Younger patients were more likely to be transplanted and only 3 of 1,289 patients aged >75 years at start of RRT underwent transplantation.

Table 15.12 gives the co-morbidity data for the same dataset and as expected, those undergoing transplantation were considerably less likely to have co-morbid conditions than those remaining on HD or PD.

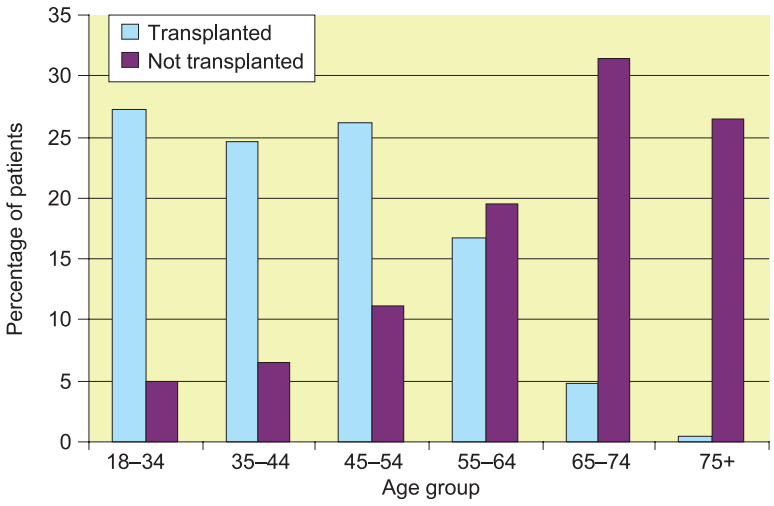

Figure 15.8: Age distribution of incident RRT cohort who had received a transplant and those who had remained on dialysis

Table 15.12: Incidence of co-morbidity in patients who had not been transplanted and in those who had been transplanted

	Not transplanted		Transplanted	
Co-morbidity	**Number**	**%**	**Number**	**%**
Number of patients	4,884	100.0	767	100.0
Without co-morbidities	1,882	38.5	505	65.8
Cardiovascular disease	1,149	25.8	33	5.0
Peripheral vascular disease	657	14.8	19	2.9
Cerebrovascular disease	507	11.4	26	4.0
Diabetes (not cause of ERF)	365	8.3	15	2.3
COPD	361	8.1	14	2.1
Liver disease	110	2.5	3	0.5
Malignancy	551	12.4	10	1.5
Smoking	734	17.2	90	14.8

Survival analysis and co-morbidity

Survival within 90 days of commencing RRT

The Registry collects data on all patients with a 'timeline' entry that indicates that they have started RRT for ERF. Patients who present acutely and continue to require RRT with no evidence of recovery of function can be reclassified by their clinicians as having had ERF from the time of first RRT if there is no recovery of function. This enables the Registry, unlike most other national Registries, to collect data on factors affecting outcome, including survival, in the first 90 days after initiation of RRT for ERF; most other Registries start the collection of data at 90 days after first RRT.

The results of univariate analysis of the association between the presence of reported co-morbidity and the risk of death within the first 90 days of commencing RRT, stratified by age, are given in Table 15.13. In both age-groups, all types of vascular disease are highly predictive of death, as is malignancy; liver disease is only significantly predictive of death in younger patients, but this may be due to small numbers – the Registry contains data on only 59 patients who were over 65 years old with liver disease.

Table 15.13: Univariate analysis, co-morbidity hazards of death by day 90

	Age <65		Age ⩾65	
Co-morbidity	**Hazard ratio**	**p value**	**Hazard ratio**	**p value**
Angina	2.4	0.0002	1.2	0.076
Cardiovascular disease*	2.3	0.0003	1.2	0.065
Vascular disease**	2.9	<0.0001	1.3	0.01
Diabetes (not as cause of ERF)	1.3	0.557	1.2	0.222
Diabetes as primary disease	1.4	0.107	0.7	0.038
Diabetes of either category	1.4	0.077	0.9	0.343
COPD	2.3	0.02	1.2	0.368
Liver disease	6.6	<0.0001	1.1	0.87
Malignancy	4.0	<0.0001	1.6	<0.0001
Claudication	2.1	0.019	1.2	0.286
Ischaemic/neuropathic ulcers	4.4	<0.0001	2.0	0.001
Smoking	0.7	0.251	1.2	0.313

*At least one of angina, myocardial infarction at any time, angioplasty/vascular graft.
**At least one of cerebrovascular disease, claudication, ischaemic/neuropathic ulcer, angioplasty/vascular graft, amputation.

Table 15.14: Cox regression survival analysis of the first 90 days of RRT

Variable	p value	Hazard ratio	95% CI
Age	<0.0001	1.1	1.0–1.1
MI in past 3 months	<0.0001	2.2	1.5–3.2
MI more than 3 months ago	0.016	1.4	1.1–1.7
Malignancy	<0.0001	1.9	1.5–2.3
Liver disease	0.0001	2.5	1.6–4.0
Ischaemic/neuropathic ulcers	<0.0001	2.5	1.7–3.5

On multivariate analysis, six factors independently predicted death within the first 90 days (Table 15.14).

Survival 1yr after 90 days of commencing RRT

To allow comparison with data from other national registries, the Registry has also analysed factors associated with survival amongst patients surviving at least 90 days after start of RRT. On univariate analysis (Table 15.15), stratified for age, all categories of vascular disease were associated with an increased risk of death amongst patients starting RRT under the age of 65 years, as was diabetes, COPD, liver disease, and malignancy. Amongst patients starting RRT over the age of 65 years, all of these categories were still significantly associated with an increased risk of death with the exception of diabetes as a cause of ERF, liver disease, and claudication; however, in this age group, smoking was significantly associated with increased risk of death.

Cox regression multivariate analysis (Table 15.16) was performed. The variables considered in the model were: age, angina, MI in previous 3 months, MI more than 3 months ago, coronary artery bypass grafting (CABG)/ angioplasty, liver disease, malignancy, claudication, ischaemic/neuropathic ulcers, angioplasty/vascular graft, amputation, and smoking. Those variables that were found to be significantly important in the model are included in Table 15.16. Recent MI was no longer significantly associated with increased risk of death (presumably because of an association with other cardiovascular markers). Diabetes is a powerful predictor of an increased risk of death after the first 90 days, as expected.

Table 15.15: Univariate analysis, co-morbidity hazards of death by 1 year after 90 days

	Age <65		Age 65+	
Co-morbidity	Hazard ratio	p value	Hazard ratio	p value
Angina	1.8	0.0003	1.2	0.043
Cardiovascular disease*	2.0	<0.0001	1.3	0.003
Vascular disease**	2.6	<0.0001	1.4	0.001
Diabetes (not as cause of ERF)	2.2	0.0004	1.4	0.008
Diabetes as primary disease	2.5	<0.0001	1.1	0.651
Diabetes of either category	2.8	<0.0001	1.2	0.03
COPD	1.8	0.0227	1.4	0.011
Liver disease	2.8	0.0002	1.5	0.152
Malignancy	4.6	<0.0001	1.3	0.05
Claudication	2.3	<0.0001	1.2	0.089
Ischaemic/neuropathic ulcers	3.6	<0.0001	2.2	<0.0001
Smoking	1.3	0.0621	1.3	0.04

*At least one of angina, myocardial infarction at any time, angioplasty/vascular graft
**At least one of cerebrovascular disease, claudication, ischaemic/neuropathic ulcer, angioplasty/vascular graft, amputation

Table 15.16: Cox regression survival analysis for the 1 year after 90 days

Variable	p value	Hazard ratio	95% CI
Age	<0.0001	1.0	1.0–1.1
MI more than 3 months ago	0.002	1.4	1.1–1.7
Smoking	0.026	1.3	1.0–1.5
COPD	0.027	1.3	1.0–1.7
Cerebrovascular disease	0.007	1.3	1.1–1.6
Malignancy	<0.0001	1.8	1.4–2.1
Liver disease	0.004	1.9	1.2–2.9
Ischaemic/neuropathic ulcers	<0.0001	2.2	1.6–2.9
Diabetes of either category	<0.0001	1.5	1.3–1.8

Discussion

Data returns on co-morbidity remain disappointingly incomplete. The data that are available contain few surprises and are similar to findings in previous reports from the Registry. Although there is no reason to suspect that those centres that provide complete or near-complete co-morbidity returns have a different case-mix to those that provide incomplete returns, this remains a possibility, and limits ability to draw detailed conclusions from the data. However, there is no doubt that co-morbidity is an important determinant of the outcome of dialysis, and may contribute to the marked differences in survival of incident patients between centres (Chapter 14).

There are several options for improving the ability of the Registry to obtain reliable and complete data on co-morbidity.

1. Learn from the best: it is intended to find out how those centres that obtain complete or near-complete returns organise this aspect of data collection, in the hope that there may be simple lessons for poor-performing centres that wish to improve their reporting of co-morbidity.
2. Improve motivation: it is clear that a very low priority is given by some Unit Directors for collection of co-morbidity data.
   a. The most powerful motivation to improve reporting of co-morbidity would be to publish de-anonymised survival statistics for each renal unit. This strategy has been used successfully by other Registries (eg those reporting survival after cardiac surgery); Renal units that have lower than average unadjusted survival, in particular, would be motivated to report co-morbidity accurately in the expectation that their survival statistics would compare more favourably with other units' after adjustment for co-morbidity.
   b. It is possible that the Healthcare Commission will be able to exert pressure on renal units via Chief Executives to ensure complete Registry returns.
3. Use alternative or additional sources of data: for instance, it might be possible to obtain data on co-morbidity from NHS Hospital Episode Statistics and in future from the Secondary Use Services function of Connecting for Health.

Of all the comparisons undertaken by the Registry, those on survival are arguably the most important. If there are real differences in survival rates between renal units that remain after adjustment for co-morbidity, it is critically important that these are discovered, acknowledged, and the reasons explored, so that lessons can be learnt about how to reduce these differences. If revealing the identity of individual renal units in survival analyses is the only way to motivate clinicians to report the simple dataset required for assessment of co-morbidity, then it may be time to take this step.

Appendix to Chapter 15

Important changes to co-morbidity definitions in 2003

The non-coronary angioplasty group has been widened to include other vascular grafts and arterial stents. The new definitions are given below:

Angioplasty, stenting, vascular graft, aneurysm (all non-coronary)

This category now includes vascular grafts (eg aortic bifurcation grafts), arterial stents and aneurysms.

Episode of heart failure (right or left) prior to RRT

This is whether or not it was only the result of fluid overload.

Co-morbidity definitions

Angina

A history of chest pain on exercise with or without ECG changes, exercise tolerance test, radionucleotide imaging or angiography.

Previous MI within the past 3 months

The rise and fall of a biomarker (CK, CK-MB or Troponin) together with one of either ischaemic symptoms, pathologic Q waves, ischaemic ECG changes or a coronary intervention. This definition is from both the European Society of Cardiology and the American College of Cardiology.

Previous MI more than 3 months ago

From the time of the start of RRT.

Previous CABG or coronary angioplasty

Episode of heart failure (right or left)

This is whether or not it was only caused by fluid overload.

Cerebrovascular disease

Any history of strokes (of whatever cause) and including transient ischaemic attacks caused by carotid disease.

Diabetes (not causing established renal failure)

This includes diet-controlled diabetics.

Chronic obstructive pulmonary disease

This is defined as a slowly progressive airways disorder characterised by obstruction of the expiratory airflow, which does not change markedly over several months, it may be accompanied by airway hyper-reactivity and may be partially reversible.

N.B. Chronic bronchitis and emphysema may occur in the absence of airflow obstruction. Asthma patients may rarely develop airflow obstruction that does not improve with steroids.

Liver disease

Persistent enzyme evidence of hepatic dysfunction *or* biopsy evidence *or* hepatitis B e antigen or hepatitis C antigen (polymerase chain reaction) positive serology.

Malignancy

Defined as any history of malignancy (even if curative), for example the removal of a melanoma; excludes basal cell carcinoma.

Claudication

Current claudication based on a history, with or without Doppler or angiographic evidence.

Ischaemic/neuropathic ulcers

The current presence of these ulcers.

Angioplasty, stenting, vascular graft, vascular aneurysm (all non-coronary)

This category now includes vascular grafts (eg aortic bifurcation grafts) and renal artery stents.

Amputation for peripheral vascular disease

Smoking

Being a current smoker or having a history of smoking within the previous year.

Chapter 16: Patients with Diabetic Nephropathy in Established Renal Failure: Demographics, Survival and Biochemical Variables

Summary

- Of the 20,532 patients who started RRT from 1997 to 2004, 19% were reported as having diabetic nephropathy (DN). Of these, the majority (77%) were White. There were many missing data on ethnicity, referral, co-morbidity, cholesterol and HbA1c.

- 20% of patients with DN were referred <3 months before starting RRT and 46% within a year. This is disappointing in patients under regular medical supervision. The National Service Framework for Renal Services advocates referral within a year of established renal failure.

- There was evidence that patients with diabetic nephropathy from socially deprived areas were referred later than those from more affluent areas, both in crude and age and gender adjusted analyses (chi-sq $p < 0.0001$, Mantel–Haenszel: $p = 0.0026$).

- 19% of diabetic nephropathy patients were recorded as smokers at the start of RRT.

- Incident patients with DN were significantly more likely to be from a socially deprived area than others, even within the White population alone ($p < 0.0001$).

- Patients with DN were less likely to receive a transplant.

- After adjusting for age, ethnicity, social deprivation and co-morbidities including cardiovascular disease, long-term survival was significantly worse for DN patients than for other patients on RRT. The difference in crude survival was greatest in younger patients (5-year survival 56% in 18–54 year olds compared to 85% of others of the same age (p-value for interaction <0.001)).

- Blood pressure data were only available for about 40% of the patients. Diabetic nephropathy patients on HD had higher blood pressures than other patients, but there was no difference for other treatment modalities.

- Data on cholesterol were missing in 60% of patients. Overall, patients with DN had lower cholesterol values than other patients on PD and HD.

- HbA1c data were missing in a high proportion of the incident DN cohort although reporting had improved in recent years. Glucose control was worse in PD than HD patients.

Introduction

Diabetic nephropathy is now the most common renal disease leading to renal replacement therapy in developed countries[1,2,3,4]. Within the UK, the number of DN patients accepted for RRT rose steadily in the 1990s[5] especially in the African–Caribbean and South Asian populations[3,4,5,6]. This may be related to the increased prevalence of Type 2 diabetes in the general population, the ageing population and the liberalisation of attitudes to acceptance for RRT[5,7]. The overall rise has slowed in the last 4 years[8]. DN patients starting RRT are likely to have more co-morbidity than other patients, in particular cardiovascular disease, and consequently worse survival on RRT[9,10,11]. In recent years there has been some reduction in the high mortality of such patients, so the prevalence of diabetic nephropathy patients on RRT (currently lower than the percentage of incident patients, see Chapter 3) might increase[12,13].

The National Service Frameworks for Diabetes[14] and for Renal Services[15] have highlighted the importance of the primary prevention of DN in diabetic patients by early detection and aggressive management of hypertension, glucose control and cardiovascular risk factors and of the timely referral (recommendation >1 yr before RRT) of those with progressive renal disease in order to plan for RRT.

There is a key policy drive to reduce health inequalities in England[16]. In the UK there is evidence that diabetic patients in more socially deprived areas have higher all cause mortality even after adjustment for smoking and blood pressure[9], and lower rates of attendance at GP and hospital clinics[17]. The UK Renal Registry 2003 Report highlighted the possible role of social deprivation in the context of DN.

This chapter examines the characteristics of patients developing established renal failure from DN, their access to modalities of treatment and their survival on RRT relative to other incident patients. It also includes data on quality of care (HbA1c, cholesterol and blood pressure).

These analyses were undertaken before individual patient data from the Scottish Registry became available and therefore only includes England and Wales.

Methods

Use of incident patients in analyses

As prevalent patients represent a complex mixture of incident patients and survivors, only incident patients commencing RRT between 1997 and 2004 in centres reporting to the UKRR were included. It was not possible to distinguish accurately between Type 1 and 2 diabetes, most are Type 2.

Measure of social deprivation

All postcodes were validated against the patient's full address using a commercial software package (QAS). The Townsend index of social deprivation was calculated from the 2001 UK Census. This index is based on the percentages of unemployed, households without a car, overcrowding, and non owner occupied homes in each output area[18], a high Townsend score indicating greater social deprivation. The Census output area for each patient's postcode of residence was identified, and the patients were then allocated into five equally sized quintiles according to their estimated level of deprivation. For the 5% of postcodes which cross a Census output area boundary and which therefore have more than one Townsend score, the mean value was taken.

Measures of ethnicity, co-morbidity and referral

Ethnicity was recorded in the renal units largely by self-ascription, and grouped into African–Carribean, South Asian and White descent. To obtain high quality data the analyses in the incident cohort were confined to centres which returned information on ethnicity on at least 85% of patients. Within this restricted group of patients there was a high proportion of missing data on co-morbidity at start of RRT and on referral date; to strike a balance between data quality and quantity for these items, slightly less stringent cut-offs were chosen for inclusion, with centres returning more than 75% referral data and more than 80% co-morbidity data included. For analysis of co-morbidities, 'cardiac disease' included those patients recorded as having angina, previous myocardial infarction, coronary artery by-pass grafts or angioplasty and 'peripheral vascular disease' (including claudication, ischaemic and neuropathic ulcers, non-cardiac angioplasty and amputations due to ischaemia). Late referral was defined as referral to a nephrologist within 90 days of starting RRT; referral within 1 year of RRT was also examined.

Measures of quality of care in patients with DN: blood pressure, HbA1c and cholesterol

For HD patients post-dialysis blood pressure was analysed. In patients on PD and those who were transplanted, blood pressure measured at clinic visits was used. HbA1c measures were only included from laboratories whose assays were validated to ensure comparability between centres; more details on the HbA1c measurements and their validation can be found in the 2003 UKRR Report, Chapter 19[19]. For analyses of changes over time the first available measurement, the measurement at 90 days, and the measurement at 1 year after start of RRT were used. For analyses of prevalent patients the most recent measurement of blood pressure, cholesterol and HbA1c were used.

Survival analyses

Chi-square, Chi-square for trend and Kruskal Wallis tests were performed to identify associations between diabetes and potential predictors

of survival. Mantel–Haenszel tests were used if effects were examined in different strata of age and sex. As there is variability in defining whether patients who die early have acute or chronic renal failure, which would affect early death rates, survival up to 90 days of RRT was assessed separately from survival after 90 days. Follow up was continued until 31st December 2004. Patients were not censored at time of renal transplant. For descriptive analyses of survival in DN incident patients, Kaplan-Meier graphs, life-table methods, and log-rank tests were used where appropriate. Cox's proportional hazards model was then used to explore the independent effect of variables on survival. Age was entered as a linear variable, social deprivation as a categorical variable using the aforementioned quintiles, late referral, diabetes and gender as binary variables. As there was a cohort effect up to 90 days on RRT, all models were adjusted for year of onset of RRT, though this variable had no significant effect on survival after 90 days.

Four different cohorts were used in the analysis.

Cohort 1: patients with available baseline information on Townsend Scores, treatment modality, gender, age, and primary renal disease (n = 20,532 patients, n = 49 units).
Cohort 2: as 1 but restricted to Whites (n = 9,810 patients, n = 24 units), to assess the effect of adjusting for social deprivation independent of ethnicity.
Cohort 3: as 1 but restricted to those with data on co-morbidities at start of RRT (n = 4,530 patients, n = 16 units), to examine whether these were the main mediators of worse outcome of diabetic nephropathy patients while adjusting for social deprivation and all other variables.
Cohort 4: as 3 but restricted to Whites (n = 2,760 patients, n = 10 units).

Prior knowledge and both crude and adjusted analyses suggested the presence of an interaction between DN and age in models after 90 days RRT, both on continuous age-scale as well as using age-categories. For simplicity, the effect in different age categories is reported (18–54 years, 55–64 years and above 65 years of age). However, because of remaining residual confounding due to age, each category was adjusted for age. The assumption of proportionality was investigated by using graphical methods (Nelson–Aalen Plots) and the final model using Schoenfeld tests.

Results

Baseline characteristics of incident RRT patients

Of new patients starting RRT 19% had DN, the most common cause of ERF in the UK (see Chapter 3): just over 60% of both these and other patients were male (Table 16.1). Although DN is common in South Asian and African–Caribbean ethnic minorities within the UK, White diabetic nephropathy patients represent the main burden of ERF. DN patients were younger at the start of RRT when compared with other RRT patients. There may be competing risks as older diabetics are more likely to die of cardiovascular disease (CVD) before RRT than younger ones[19], and it is possible there is a degree of selection.

Incident patients with DN had higher Townsend scores (greater social deprivation) than others. Given the strong association of social deprivation with ethnicity (odds ratio 3.15, 95% CI: 2.81, 3.53; $p < 0.0001$) Whites alone were analysed: a significantly higher proportion of White DN patients were from a more socially deprived background compared to other White patients ($p < 0.0001$) (Figure 16.1). The observed differences in social deprivation in diabetic nephropathy patients and others may be due to the increased incidence of obesity and metabolic syndrome and consequently of Type 2 diabetes in more socially deprived groups[20]. Social deprivation and young age are also associated with poorer diabetic control, poor CVD risk management[9,17,21,22,23] and a high rate of smoking.

Late referral was less common in DN patients than others, but nevertheless 20% of this group of patients under regular medical surveillance who needed RRT were referred less than 90 days from starting RRT and only half within one year. Whilst diabetic nephropathy patients were referred to renal units earlier than others, there remains much scope for improving referral to nephrologists, especially given the difficulties of establishing vascular access in

Table 16.1: Demographics of diabetic nephropathy and other patients

	DN		Others		Total		
	n	%	n	%	n	%	p-value
Number of patients	3,959	19.3	16,573	80.7	20,532	100.0	0.6076
Gender							
Male	2,427	61.3	10,233	61.8	12,660	61.7	
Female	1,532	38.7	6,340	38.3	7,872	38.3	
Total	**3,959**	**100.0**	**16,573**	**100.0**	**20,532**	**100.0**	
Age (years)							<0.0001
Median age start RRT		60.7		65.1		64.1	
Interquartile range	48.8	69.2	50.5	74.3	50.1	73.5	
Age distribution at start of RRT							<0.0001
18–54	1,463	37.0	5,166	31.2	6,629	32.3	
55–64	988	25.0	3,074	18.6	4,062	19.8	
65+	1,508	38.1	8,333	50.3	9,841	47.9	
Total	**3,959**	**100.0**	**16,573**	**100.0**	**20,532**	**100.0**	
Townsend scores							
Distribution of social deprivation quintiles							<0.0001
1	515	13.0	3,064	18.5	3,579	17.4	
2	622	15.7	3,315	20.0	3,937	19.2	
3	728	18.4	3,136	18.9	3,864	18.8	
4	968	24.5	3,635	21.9	4,603	22.4	
5	1,126	28.4	3,423	20.7	4,549	22.2	
Total	**3,959**	**100.0**	**16,573**	**100.0**	**20,532**	**100.0**	
Ethnicity[See note 1]							<0.0001
White	1,707	76.9	8,103	89.3	9,810	86.9	
South Asian	322	14.5	558	6.2	880	7.8	
African-Caribbean	122	5.5	242	2.7	364	3.2	
Other	70	3.2	167	1.8	237	2.1	
Total	**2,221**	**100.0**	**9,070**	**100.0**	**11,291**	**100.0**	
Treatment modality at start of RRT							<0.0001
HD	2,728	68.9	11,616	70.1	14,344	69.9	
PD	1,187	30.0	4,580	27.6	5,767	28.1	
Tx	44	1.1	377	2.3	421	2.1	
Total	**3,959**	**100.0**	**16,573**	**100.0**	**20,532**	**100.0**	
At day 90							<0.0001
HD	2,218	63.3	9,123	63.5	11,341	63.5	
PD	1,237	35.3	4,755	33.1	5,992	33.5	
Tx	49	1.4	493	3.4	542	3.0	
Other[See note 2]	34		106		140		
Died before 90 days	220		1,312		1,532		
Not on RRT for 90 days	201		784		985		
Total	**3,959**	**100.0**	**16,573**	**100.0**	**20,532**	**100.0**	
At one year							<0.0001
HD	1,521	61.3	6,265	59.1	7,786	59.5	
PD	845	34.1	3,335	31.4	4,180	31.9	
Tx	116	4.7	1,007	9.5	1,123	8.6	
Other[See note 3]	37		121		158		
Died before 90 days	596		2,504		3,100		
Not on RRT for 90 days	844		3,341		4,185		
Total	**3,959**	**100.0**	**16,573**	**100.0**	**20,532**	**100.0**	

Table 16.1: (continued)

	DN		Others		Total		
	n	%	n	%	n	%	p-value
Referral[See note 4]							<0.0001
0 to 89 days	179	20.3	1,129	29.2	1,308	27.5	
90 to 365 days	232	26.2	699	18.1	931	19.6	
More than 365 days	473	53.5	2,042	52.8	2,515	52.9	
Total	**884**	**100.0**	**3,870**	**100.0**	**4,754**	**100.0**	
Co-morbidity[See note 5]							
Number of pats with at least one co-morbidity at start	442	59.1	1,623	55.8	2,065	56.5	0.1067
Cardiovascular disease	360	48.1	930	32.0	1,290	35.3	<0.0001
Cardiac disease	230	30.8	671	23.1	901	24.7	<0.0001
Myocardial infarction	121	16.2	335	11.6	456	12.5	0.0006
CABG/angioplasty	44	5.9	142	4.9	186	5.1	0.2763
Angina	190	25.5	523	18.0	713	19.6	<0.0001
PVD	180	24.1	315	10.9	495	13.6	<0.0001
Cerebrovascular disease	105	14.0	290	10.0	395	10.8	0.0015
Malignancy	32	4.3	404	13.9	436	12.0	<0.0001
Smoker	131	18.2	468	16.9	599	17.1	0.3945
COPD	46	6.2	243	8.4	289	7.9	0.0448
Liver disease	14	1.9	68	2.3	82	2.3	0.4378

Note 1: Only centres with ⩾85% ethnicity completeness.

Note 2:

	DN	Others	Total
	n	n	n
Other modalities	34	106	140
Patient transferred out	16	54	70
Treatment stopped	15	49	64
Patient declines RRT	1	1	2
Clinical decision not to offer RRT	0	1	1
Patient lost to follow up	2	1	3

Note 3:

Other modalities	37	121	158
Patient transferred out	29	91	120
Treatment stopped	6	26	32
Patient declines RRT	0	1	1
Patient lost to follow up	2	3	5

Note 4: Only centres with ⩾75% referral completeness.

Note 5: Only centres with ⩾80% comorbidity completeness.

Cardio vascular disease include any one of the following: cardiac disease, PVD, cerebrovascular disease.

Cardiac disease include any one of the following: angina, myocardial infarction at any time, angioplasty/vascular graft.

Peripheral vascular disease (PVD) include any one of the following: claudiation, ischaemic/neuropathic ulcer, angioplasty/vascular graft (non-coronary), amputation.

CABG = coronary artery bypass grafting or coronary angioplasty.

COPD = chronic obstructive pulmonary disease.

Myocardial infarction included previous MI within the past 3 months and MI more than 3 months ago.

diabetics. There was evidence that patients with diabetic nephropathy from socially deprived areas were referred later than those from more affluent areas, both in crude and age and gender adjusted analyses (chi-sq $p < 0.0001$, Mantel–Haenszel: $p = 0.0026$).

Incident DN patients starting RRT are a high-risk group. About half suffer from manifest cardiovascular disease, although malignancy was much less common. Smoking was equally common in DN and other patients (in about a fifth). When adjusted for age and sex, there was a borderline association between social deprivation and CVD (Mantel–Haenzel: $p = 0.050$). Another 270 patients (9.3%) with other causes of ERF also had diabetes but are not included with the DN patients in the survival analyses that follow below; 55% of these patients also had CVD. Renal impairment has been recognised as an independent CVD risk factor[24] and CVD risk reduction and CVD

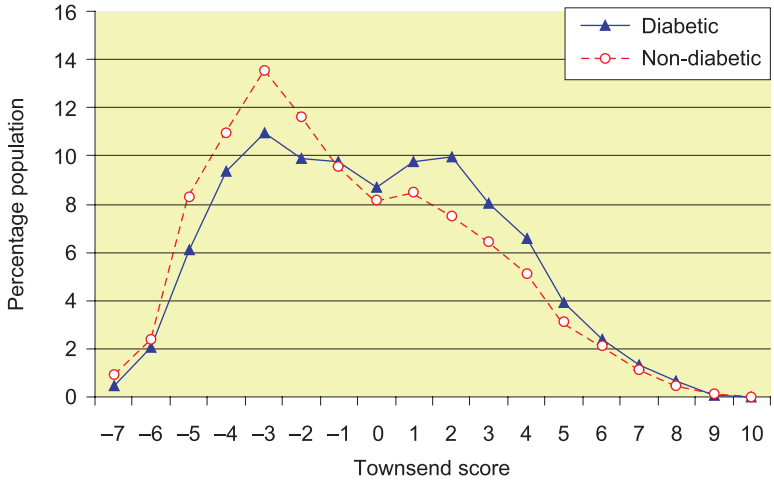

Figure 16.1: Age and sex adjusted distributions of Townsend scores in incident diabetic nephropathy and other White patients in England and Wales

management are important aspects of quality of care[15]. More systematic management of CVD risk factors, including more incentives to reduce the high rate of smoking, is required.

DN patients were slightly more likely to receive peritoneal dialysis and half as likely to be transplanted in the first year of RRT in both the full and White only cohorts, even having adjusted for age and sex (each $p < 0.001$). There is a low rate of transplantation in DN patients, even after adjusting for ethnicity, despite the fact that renal transplantation has been shown to offer the best survival for them[25]. Approaches to pre-emptive and speedy transplant listing vary widely between renal units[26,27], and diabetic patients are not uniformly targeted for transplantation: transplant outcomes are less good than in other patients and many are unfit for major surgery, especially due to CVD.

Survival on dialysis

Survival in first 90 days of RRT

Up to day 90, 1,532 died over 5,010 person-years. 1,125 patients who stopped treatment within 3 months were censored of whom 21% ($n = 235$) had DN. Survival in the first 90 days of RRT improved in recent years.

Even after adjustments for age, gender, modality and deprivation, DN patients had similar or better survival than others at 90 days of RRT. The slight crude survival advantage was due to confounding from earlier referral and less malignancy at start of RRT (Table 16.2). In support of this, malignancies accounted for a significantly higher proportion of deaths in the first 90 days in non-DN patients (9% vs 0%, $p < 0.001$).

Survival after 90 days of RRT

After 90 days, the Kaplan-Meier curves show crude survival of patients with DN was lower than other patients in all age groups (Figure 16.2). The estimated crude mortality rate in DN was 19.3 deaths/100 person-years and in non-diabetics 13.3 deaths/100 person-years. However the difference varied by age (p-value for interaction: $p < 0.0001$). Although older patients had a higher mortality, the difference between DN patients and others was greatest in the young with a tripling of crude hazard in those less than 55 years. At one year after 90 days RRT, the proportion of 18–54 year old DN patients surviving had already dropped to 90%, with only 56% alive at 5 years after commencing RRT, compared with 96% and 85% respectively of others in the same age group (log-rank $p < 0.0001$).

Survival after 90 days RRT was examined with adjustment for social deprivation, late referral and the presence of co-morbidities (cardiovascular, peripheral vascular, smoking, malignancy, chronic obstructive pulmonary disease) (Tables 16.3 and 16.4). DN remained a significant predictor of death with a doubling of hazard for the age groups below 65 compared to others on RRT, even when adjusted for all known co-morbidities and time of referral. In

Table 16.2: Crude and adjusted effects of diabetic nephropathy on survival in the first 3 months after initiation of RRT in the full cohort and the cohort restricted to White patients, with and without available data on co-morbidity and referral (all adjusted for year of onset of RRT)

Effect of diabetic nephropathy on survival at 90 days	HR	95% CI	p-value
Full cohort			
Crude	0.70	0.61–0.81	<0.0001
Adjusted for:			
Age, gender, deprivation, modality	0.86	0.74–0.99	0.0396
Age, gender, deprivation, modality, co-morbidities*	1.05	0.79–1.40	0.7349
Age, gender, deprivation, modality, referral**	0.99	0.75–1.30	0.9225
Age, gender, deprivation, modality, co-morbidities, referral***	1.44	0.93–2.23	0.0996
Restricted to White patients			
Crude	0.69	0.56–0.86	0.0008
Adjusted for:			
Age, gender, deprivation, modality	0.92	0.74–1.14	0.4475
Age, gender, deprivation, modality, co-morbidities	1.14	0.77–1.69	0.5162
Age, gender, deprivation, modality, referral	1.01	0.72–1.42	0.9581
Age, gender, deprivation, modality, co-morbidities, referral	1.48	0.88–2.50	0.1429

HR = Hazard Ratio.
*n = 4,530.
**n = 5,777.
***n = 2,345.

contrast, in Whites above 65 years the effect of DN seemed to be due to co-morbidities. Social deprivation affected survival in White patients with an estimated gender, age and modality adjusted hazard ratio (HR) of 1.16 of the highest versus the lowest quintile (95% CI: 1.03, 1.32; p = 0.0125), which disappeared after further adjustment for co-morbidities (HR 0.93; 95% CI: 0.74, 1.20; p = 0.61). In all analyses, adjustment for referral only increased the effect of DN. This suggests DN has an even stronger association with poor survival despite earlier medical surveillance.

It remains unclear why young and middle-aged patients with DN have such increased mortality after adjusting for co-morbidity and smoking at the start of RRT. It may be that conventional cardiovascular interventions are either less well applied or are less beneficial in diabetics compared to non-diabetics[28]. Asymptomatic undetected coronary artery disease is also more common in DN patients at the start of RRT[29].

The main limitation of these analyses is incomplete data on co-morbidity. Data on vascular access were lacking. However, as data were only analysed from centres with a high data return, and because of the consistency of the findings across different subsets of the data, the results appear robust.

Factors amenable to influence

Reliance is placed on intermediate variables such as cholesterol, blood pressure and HbA1c to indicate cardiovascular risk and the quality of care. However, there is only limited knowledge of their role on outcome in patients on HD and PD. Current guidelines extrapolate from findings from the general population and the population with diabetes that are not yet needing RRT. There has been some recent evidence that cholesterol and blood pressure measurements are inversely associated with mortality in patients on HD and PD[30,31]. Similar observations were made by the UKRR in the 2003 Report[19]. These observations do not show cause and effect, but describe the situation given the limits of current dialysis practice: for example they may reflect that fitter patients feel well and eat more. Thus the following analyses must be interpreted with this in mind, as the optimal standards for HD and PD patients are not clear.

Blood pressure

Blood pressure was reported in 60% of patients at the start of RRT, in 50% at 90 days and in

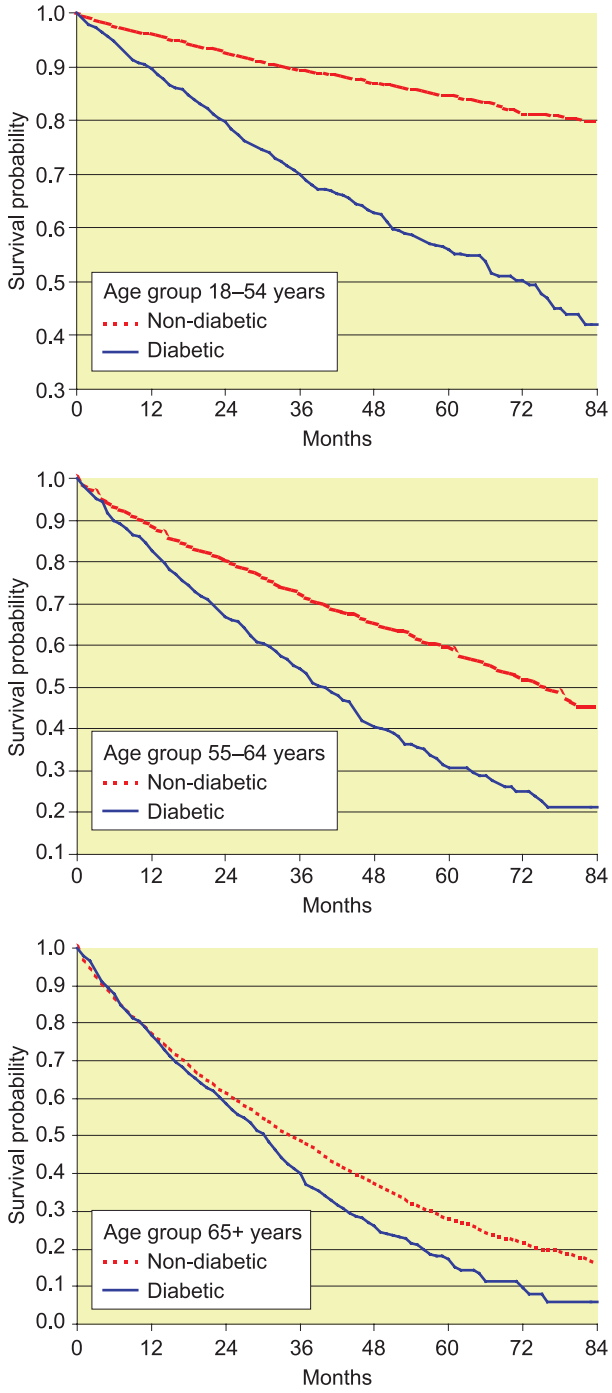

Figure 16.2: Age-dependent survival of diabetic nephropathy patients and others on RRT after 90 days

45% at 12 months. There was no difference between DN patients and others. On average, patients showed small decreases of blood pressure from 90 days to 1 year of RRT, with median values of −1 to −3 mmHg.

There are differences between patients with DN and others established on dialysis in some standard markers of good care, as shown in Table 16.5. These are mostly clinically very small differences, even if sometimes statistically significant. URR is a little lower in DN patients, possibly due to the difficulties in establishing good vascular access. However post-dialysis systolic blood pressure is considerably higher in diabetic nephropathy patients.

In view of the unclear effect of lowering BP on survival in HD and PD, the implications of relatively poor achievement of BP targets are unknown.

Serum cholesterol

At the start of RRT, cholesterol was reported in only 36% of HD patients, in 47% of PD patients and in 44% of those who were transplanted. The reporting of cholesterol for incident dialysis patients has improved over the years; current (2004) 90 day figures are 65% in HD and 71% in PD patients. Data were less complete at 12 months: HD 50%, PD 55%. Cholesterol was reported in 65% of transplanted patients at 12 months.

In most instances, more diabetic nephropathy patients than other patients had a cholesterol level below 5 mmol/L. At the start of RRT the figures for HD were 74% (overall 70%, $p = 0.143$), for PD 63% (overall 56%, $p = 0.002$) and for transplants 67% (overall 52%, $p = 0.25$). All the day 90 results and the 12 month HD results were similar, whereas the 12 month result for PD had fallen to 54% (overall 46%, $p = 0.001$) and the transplant result to 42% (with no difference in DN patients).

HbA1c

HbA1c was not reported in 70% of both HD and PD patients with DN at the start of RRT, but the percentages of missing values decreased from 1997 (95% and 88% missing values for HD and PD respectively) to 2004 (64% missing values for all HD and PD patients). HbA1c values were reported for 11 of the 44 pre-emptively transplanted patients with DN. At 90 days, HbA1c data were reported on 46% of PD and HD patients with similar figures at 12 months. From 1997 to 2004, there was a substantial improvement in reporting of HbA1c values, from 23% of patients in 1997 to 62% of patients in those who had started RRT in 2003.

Table 16.3: Crude and adjusted effects of diabetic nephropathy on survival in the full cohort with and without available data on co-morbidity and referral (all adjusted for year of onset of RRT) stratified by age-category

Effect of diabetic nephropathy	HR	95% CI	p-value
On survival in 18–54 year old patients			
Crude	3.27	2.85–3.75	<0.0001
Adjusted for:			
Age, gender, deprivation, modality	2.91	2.54–3.35	<0.0001
Age, gender, deprivation, modality, co-morbidities	1.87	1.32–2.65	0.0005
Age, gender, deprivation, modality, referral	3.30	2.57–4.23	<0.0001
Age, gender, deprivation, modality, co-morbidities, referral	2.03	1.17–3.50	0.0112
On survival in 55–64 year old patients			
Crude	1.91	1.68–2.17	<0.0001
Adjusted for			
Age, gender, deprivation, modality	1.83	1.61–2.09	<0.0001
Age, gender, deprivation, modality, co-morbidities	1.74	1.30–2.33	0.0002
Age, gender, deprivation, modality, referral	1.98	1.56–2.50	<0.0001
Age, gender, deprivation, modality, co-morbidities, referral	1.70	1.10–2.62	0.0160
On survival in patients aged 65 years and above			
Crude	1.20	1.10–1.31	<0.0001
Adjusted for:			
Age, gender, deprivation, modality	1.30	1.19–1.42	<0.0001
Age, gender, deprivation, modality, co-morbidities	1.15	0.94–1.40	0.1682
Age, gender, deprivation, modality, referral	1.38	1.16–1.64	0.0002
Age, gender, deprivation, modality, co-morbidities, referral	1.21	0.90–1.61	0.1995

HR = Hazard Ratio.

Table 16.4: Crude and adjusted effects of diabetic nephropathy on survival in the White cohort with and without available data on co-morbidity and referral (all adjusted for year of onset of RRT) stratified by age-category

Effect of diabetic nephropathy	HR	95% CI	p-value
On survival in 18–54 year old patients			
Crude	3.54	2.92–4.28	<0.0001
Adjusted for:			
Age, gender, deprivation, modality	3.23	2.66–3.91	<0.0001
Age, gender, deprivation, modality, co-morbidities	2.67	1.75–4.07	<0.0001
Age, gender, deprivation, modality, referral	3.58	2.69–4.75	<0.0001
Age, gender, deprivation, modality, co-morbidities, referral	2.61	1.39–4.93	0.0003
On survival in 55–64 year old patients			
Crude	2.03	1.68–2.44	<0.0001
Adjusted for:			
Age, gender, deprivation, modality	2.00	1.66–2.42	<0.0001
Age, gender, deprivation, modality, co-morbidities	1.94	1.30–2.89	0.0011
Age, gender, deprivation, modality, referral	2.16	1.63–2.86	<0.0001
Age, gender, deprivation, modality, co-morbidities, referral	1.97	1.17–3.31	0.0106
On survival in patients aged 65 years and above			
Crude	1.18	1.03–1.34	0.0135
Adjusted for:			
Age, gender, deprivation, modality	1.26	1.11–1.44	0.0005
Age, gender, deprivation, modality, co-morbidities	1.03	0.78–1.35	0.8466
Age, gender, deprivation, modality, referral	1.36	1.11–1.67	0.0034
Age, gender, deprivation, modality, co-morbidities, referral	1.02	0.71–1.46	0.9018

HR = Hazard Ratio.

Table 16.5: Median values for some markers of quality of care in patients with DN and non DN

Median	DN		Non-DN		Total		p-value
URR*		66.0		68.0		68.0	<0.0001
Interquartile range	59.0	70.0	62.4	73.0			
Number of patients		1,038		4,215		5,253	
Phosphate		1.59		1.61		1.60	0.3928
Interquartile range	1.29	1.95	1.27	2.00	1.27	2.00	
Number of patients		2,331		9,624		11,955	
Haemoglobin		11.4		11.6		11.5	<0.0001
Interquartile range	10.3	12.5	10.4	12.7	10.4	12.6	
Number of patients		2,317		9,578		11,895	
Diastolic BP**		75.0		76.0		76.0	0.0334
Interquartile range	65.0	84.0	66.0	85.0	66.0	85.0	
Number of patients		1,200		5,137		6,337	
Systolic BP**		143.0		135.0		136.0	<0.0001
Interquartile range	125.0	162.0	119.0	153.0	120.0	154.0	
Number of patients		1,200		5,139		6,339	

*Where treatment is HD.
**Post dialysis in HD patients.

At the start of RRT, the HbA1c value was below 7.5% in 58% of HD patients, in 44% of PD patients, and in 5 of the 11 pre-emptively transplanted patients with available HbA1c data. The 90 day figures were very similar but at 1 year, the difference between HD and PD patients was greater, with HbA1c below 7.5% in 54% of HD patients and 31% of PD patients with available data.

Conclusion

At the start of RRT most patients with DN were White; all cohorts had significantly worse long-term survival on RRT compared with other patients. The observed differences in survival were greatest in younger patients, which was not fully explained by known co-morbidity or social deprivation. Currently, the value of these findings is considerably limited by the poor reporting of co-morbidity, time of referral, blood pressure, serum cholesterol and HbA1c. It is hoped that improved data submission to the UKRR will improve audit and knowledge of the role of HbA1c, cholesterol and blood pressure targets in the survival of these patients.

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Chapter 17: Reflections on a Renal Unit Based Data Validation Exercise and Implications for National Renal IT

Summary

- All 5 renal units used at least one additional stand-alone system to record other data external to the renal IT system. One site had 5 additional systems.
- The primary record (against which the data were validated eg case note, renal IT system, PAS) varied for different data items, was different at each centre and varied by renal replacement therapy modality.
- Biochemistry data held by the Registry were accurate.
- Routine review for completeness of Registry data was unusual.
- All sites lacked contingency planning for renal IT system management (leave, sickness, succession).
- No out of hours systems support was available.

Introduction

The UK Renal Registry was commissioned to review and analyse data quality from the five Welsh renal units and to provide recommendations on how it might be improved. This project was initiated by the Project Board leading the development of the National Service Framework in Wales and part funded by the Welsh Assembly Government. The conclusions reached from this project may be applicable to many other renal units in England.

From its inception the Renal Registry had acknowledged that the central component of setting up, maintaining and refining a database along with statistical analysis and data presentation would be the easier part of the project to accomplish. It was recognised that it would be more difficult to monitor and manage data ascertainment and to ensure quality issues at the individual renal unit level, whilst IT infrastructure was so variable across the country.

Initially, this challenge had been addressed using a formal contract with units to supply items according to the Renal Registry dataset. It was anticipated that this would require regular contact with a specific, senior representative of each unit, who would take responsibility for liaising with the Registry. For a variety of reasons such contact has been patchy despite willingness on the part of both the Registry and renal units to participate. The dataset has been expanded and refined, requiring active development that has not always been smooth. Renal units have tended to concentrate on the collection of specific subsets of data, sometimes those of specific interest to their staff or that have been easier to acquire and maintain. The Renal National Service Framework in England has now formalised the role of the Registry in monitoring the performance of the renal units. The Registry dataset is in the process of being formally approved by the NHS Information Standards Board as part of a 'National Renal Dataset'. A project for the Healthcare Commission is currently examining the requirements for national renal audit.

In this context it was of particular interest to examine data validation (completeness and accuracy) in five renal units in detail. A number of other observations arose about the 'structure, process and function' of renal units in respect of their relationship with the Renal Registry. This gave the opportunity for a SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis of the relationship between the Registry and the Renal units. These are indicated here in a condensed form, with some subsequent suggestions that may be helpful to those charged at renal unit and Registry level with sustaining and developing the Renal Registry project.

Historical Note

The support of specialty (eg Nephrology) clinical computing in hospitals has never been a priority for hospital managers and IT departments. Resources have tended to be focused on generic trust-wide, administrative and financial solutions rather than specialty-specific support. This has resulted in inadequate resource for renal unit computing which has limited development and left the workforce vulnerable. Both the national intensive care audit (ICNARC) and the myocardial infarction audit (MINAP) are now utilising specialty level support from administrative staff.

Renal unit computing throughout the 1980s and 90s was based on the widespread use of a single commercially available clinical database (Proton). The informatics infrastructure at unit level was developed more by intuition, opportunity and experience than by reference to a formal model. As a result the majority of renal units have had inadequate support for their clinical databases and input of data to the Renal Registry has lacked supervision. Although a 'best practice' model has not been piloted, experience suggests that the most complete and accurate records will be achieved by data entry at points of clinical activity, such as the outpatient department or dialysis unit, supported by regular informed and multidisciplinary review of the end data record for missing entries and inaccuracies.

The data acquisition task for renal units is complex as patients are treated by a variety of modalities, on a variety of sites (some non-hospital based), by a range of personnel. These circumstances are similar to those being tackled by the national programme for IT ('Connecting for Health') and resulted in the creation of an undeclared renal data spine and associated clinical material. Some of these data are numerical and an automated laboratory linkage is seen as an essential and integral part of renal systems.

These data vary qualitatively and include demographic details (typically not linked to the hospital Patient Administration System and so requiring duplicate entry), clinical data relating to the different modes of renal replacement therapy and workup for transplantation, etc. Some of these data are permanent features of the patient (eg ethnicity) and other items vary day by day (eg blood pressure prior to haemodialysis). Clinical records are complex in this environment, where individual treatment-related data are often not registered in the formal hospital case note folder. Depending on the information, the primary record for a given activity is not necessarily the patient case note, but may be the nursing records, haemodialysis folder or even the local renal computer system itself. This diversity in the 'primary record' source makes any analysis of data quality more complex.

Given the rapid increase in provision of renal replacement therapy during the past two decades, it is not surprising that renal units have lacked the time to focus on informatics. This has resulted in inadequate training for informatics staff which has sometimes contributed to difficulties with staff retention.

The Renal Registry has only an indirect influence on the maintenance and development of renal computing at local sites. The funds received by the Registry through the Registry annual capitation fee have not been directed to the renal unit component of the information network.

All these factors lie behind the enquiries that were made about the ***structure*** and ***processes*** within the renal units, which also relate to the ***outcome*** of data completeness and accuracy.

Structure of the Review

The five renal units in Wales are Bangor, Cardiff, Clwyd, Swansea and Wrexham.

The review was structured around two separate visits to each renal unit. The first visit would enable the Renal Registry to review the operational, administrative and management procedures in the renal units and the second visit would look at data quality.

The first site meeting was scheduled to be with both the informatics and clinical staff. A questionnaire pro-forma was sent to each site in advance and the meeting based on a structured interview encompassing:

1. Organisation structure

2. IT budgetary control
3. Responsibilities of informatics staff
4. IT training
5. Communications within the renal unit
6. Best practice
7. Renal Registry liaison
8. IT infrastructure and systems.

The second visit was to validate the data held by the Renal Registry against that in the patient case notes and the electronic record from the renal IT system. Renal patients typically have a large set of case notes, which makes data validation a lengthy process. Within the available budget, a time frame of one day was available which allowed for validation of data on 20 patients. The data validation visit was undertaken by a qualified renal nurse in conjunction with a request that local informatics staff provide time to support the cross-checking of Registry data with the local IT system.

The Registry randomly selected 20 patients, to cover the different renal replacement therapy modalities and the renal unit was provided with at least 7 days notice to locate the requested patient case notes and supporting documentation. A list of 'reserve' patients was also provided so that alternatives were available should an individual's case notes be unavailable on the day of the visit.

The four patient groups were:

Patient group	Numbers
New haemodialysis patients in 2003, including 2 from a satellite unit and 2 diabetic	5
Peritoneal dialysis patients, including 2 diabetic	5
Transplant patients	5
Deceased patients in 2003	5

Results of Survey

Structure

1. There was a range of software and hardware in use. Sometimes multiple systems were employed to create comprehensive clinical coverage, but that created opportunity for error and missing data.
2. **Access** to the clinical systems for data entry was often remote from the clinical encounter and delayed.
3. The **budgetary control** for IT varied from one unit to another and was not necessarily vested in those responsible for support and development of the IT system.
4. The **primary record** (against which the data were validated eg case note, renal IT system, PAS) varied for different data items, renal replacement therapy modality and centre. An example of this is EPO prescription for which at one site the renal IT system is used for some patients, a separate EPO database for HD patients and the case note/GP letter for PD patients.
5. **Informatics staff** varied in experience, formal status and remuneration. They were not always fully integrated into the functions of the unit, nor aware of UK Registry functions and meetings. There was poor planning for contingencies, such as the absence of staff members.
6. **Documentation** required for the review was available in some centres but not always to hand or familiar to staff.
7. Resources for **training** were not allocated and most learning was in-service.
8. **Job descriptions** were typically incomplete.
9. All units were at risk because of limited succession and contingency planning.

Process

1. **Routine review** of data entries for completeness and accuracy was unusual. Informatics staff were not always present at multidisciplinary clinical review meetings which provide an opportunity to update the database. Likewise, the first encounter or change of modality was not typically used as a **prompt** to complete the dataset.
2. There was scrupulous concern for data quality and validation amongst the informatics staff but a lack of PAS interfaces and up-grades were felt to compromise IT potential. Information from satellite renal units required special care and procedures for collection, particularly in the absence of laboratory links.
3. IT was included in business meetings in some sites but planning was haphazard.
4. All renal units had a **named individual** responsible for running and submitting Registry reports, loading Renal Registry numbers (the unique patient ID supplied by the Registry) into the local system and also for correction of any data errors identified by the Registry.

Outcome

1. The results for the **completeness and accuracy** of the unit databases are given in abbreviated form in the Appendix, as the 'Outcome of Unit IT Activity'.
2. The traditional demographic data were well managed, with minor discrepancies only. The modality changes were best delivered through a timeline mechanism. There was specific selection of data items for collection at some sites, with parts of the Registry Dataset effectively being ignored, whereas other fields were just poorly served by current mechanisms of data collection.

Comment

These results are likely to be broadly representative of renal unit computing nationally.

The bird's eye view of several IT systems revealed much of what might have been expected after many years of rather haphazard development of renal clinical IT. It might be hoped that a new generation of clinicians will take this in hand and attempt more proactive management especially given the changes of context in the NHS. The Renal NSF in England, the Healthcare Commission, the Agenda for Change and Payment by Results all depend to a major extent on the health of IT at unit level. There is confusion and uncertainty arising from the Connecting for Health programme though effort needs to be maintained locally to improve functionality and data returns to the UK Renal Registry (UKRR).

The UKRR acknowledges that much may be facilitated from the 'centre' and in that regard the **Renal Registry** should:

1. Increase awareness and knowledge of Renal Registry purpose and activities.
2. Provide the sites with the dates of quarterly data collection to allow some preparation.
3. Share future plans and timetables as early as possible to allow sites time to implement any necessary changes.
4. Provide relevant feedback to sites to ensure that ongoing data issues are adequately addressed.
5. Help sites resolve data mapping issues and provide necessary software upgrades where appropriate.
6. Help sites share information to facilitate best practice and to ensure that data validation is standardised in all sites.
7. Respond to questions from sites promptly.
8. Provide template information sheets for incorporation into induction documentation, job descriptions, data entry procedures, etc.
9. Assist with the specification of site data validation rules.
10. Assist with the specification of routines to identify incomplete and inaccurate data.
11. Review its remit to see if there is scope to offer additional services.

At renal unit level it seems that more active management of informatics activity must be attempted. The greatest difficulties would seem to be social and cultural rather than clinical or technical, although there is overlap in the procedures designed for data collection and entry. In particular the grading of staff requires clarification as part of, and after, ''Agenda for Change''. Their NHS status as informatics, IT or management staff needs to be established, perhaps in relation to UKCHIP. As part of their professional support a regular review of current and future IT plans would seem essential.

One suggestion would be the production of an **Annual Informatics Plan**, which would deal with the development of, review and collection of the UKRR dataset. This would be invaluable, even if dealing with only one or two items per annum. How this might be achieved at each site will depend on historical and current issues. Greater liaison with hospital-wide informatics staff may be used to support the renal activity and provide career linkages for local staff. Very often the experiences from managing IT within the renal clinical environment will surpass those from other clinical areas within the Trust and the lessons learnt may be offered as a resource, where Trust staff are open to suggestion.

The weaknesses identified in this review are all susceptible to improvement, some more readily than others. The greatest benefit is likely to come from greater staff integration in clinical routine review and processes to make every data entry subject to informed inspection at some juncture, typically when the clinical status of a patient changes.

Resources are needed to enable conversion of the current largely implicit procedural based IT system into a modern explicit form. The national developments give some grounds for optimism for the local request for funds to advance these purposes. The UKRR will do all that it can to facilitate and develop links with the units to allow the maintenance and improvement of 'peripheral' renal unit IT.

Appendix: Outcome of Unit IT Activity

Results on data completeness and accuracy

For the purposes of this analysis, recorded data had to be compared for accuracy against a defined 'primary record'. The patient case note is not necessarily the primary record, since some data may be found only in the renal IT system, which does not enter the patient notes. Moreover, the primary record is not necessarily consistent between sites, for example at one site the IT system may be the primary record for Erythrocyte Stimulating Agent (ESA) prescription (updated by the anaemia specialist nurse), while others may use the patient case notes.

Demographics

1. The **surname** and **first name(s)** of patients were usually correctly recorded in the local renal system. In patients with more than two names the additional ones were not always recorded even when it would have aided identification. Some patients had additional indicators within the name fields, to help with patient identification at the site.
2. **Dates of birth** were usually correctly recorded on the local renal system, although there were some inaccuracies with the day, month or year differing by one digit. This may be due to data input error or due to the necessity to align the date of birth with that held in the laboratory system, to allow automated uploads from the laboratory interfaces.
3. **Postcodes** showed few discrepancies. The Renal Registry validates the address fields received using a commercial post-coding package (QAS systems) that is updated on a monthly basis. Some of the local postcode errors may have been due to recent re-coding of postcodes by the Royal Mail, which would not have been updated in the local renal system.
4. The **NHS number** was often recorded on the patient case notes but had not been entered on to the local system and therefore was not sent to the Renal Registry. One renal unit held no NHS numbers on their local renal IT system.
5. **Ethnicity** is part of the mandatory PAS dataset, although it was rarely recorded in the patient case notes. Only one site recorded ethnicity comprehensively on their renal system.
6. The **primary diagnosis** causing renal failure, had at some sites initially been recorded as unknown for some patients, even though information was available in the patient case notes.
7. **The date of death** often showed a small discrepancy of 1–2 days from the case notes.
8. **Cause of death** (using the European Renal Association codes) was poorly recorded in the patient case notes. Only one unit recorded this information on the local IT system and hence sent this to the Renal Registry.
9. While the **start of renal replacement therapy date** was often recorded in the patient case note, it was not always recorded on the local renal system within the specific field allocated by the Renal Registry. Many sites use the date of first treatment modality in the renal replacement therapy timeline to record this information. Validation has been against the timeline data item. There was often a discrepancy of up to 10 days in the dates recorded for the start renal replacement therapy date in the timeline against the case notes and occasionally much greater than 10 days. It was unknown which of these sources is the most valid, although the earliest might be assumed so.
10. The **first seen date by nephrologists** was not being recorded on the local IT system at some sites. For other sites this was not being received at the Renal Registry again suggesting a data mapping issue. Low accuracy rates were due to minor discrepancies of a few days in the dates recorded which would not be clinically significant.
11. **Height** was often not recorded in the patient case notes but was available

generally on the local IT system. The Renal Registry did not always receive this information.

12. The **timeline** (RRT modality history) usually included all the information required by the Renal Registry. Where patients were seen by more than one hospital (transplanted patients) there were occasionally slight discrepancies in date of transplant supplied by the different renal units.
13. The **last RRT modality** was usually accurate and discrepancies were likely to be due to a recent change in modality.

Biochemistry

The biochemistry readings for most patients at the hospitals were complete and accurate when compared to the primary record in the local renal IT system, although there were exceptions.

1. The **parathyroid hormone** (iPTH) measurement gave cause for concern. There are two different laboratory units of measurement, which vary by a factor of 10. Combining this item from two different laboratory data sources (satellite/main hospital) into a single field in an IT system without adjusting the units is a source of clinical error.
2. **HbA1c** (only measured for diabetic patients) was only available from one patient throughout the five hospitals. This does not imply that HbA1c was not being monitored in patients, as it may have been measured in the diabetic clinic and not repeated when the patient was seen at a renal clinic. Laboratory linkage should make results available.

Blood Pressure

1. **Systolic** and **diastolic blood pressures** were complete and accurate for dialysis patients at one centre, although no data were recorded for transplant patients. At the other renal units, blood pressure data were not being recorded on the local renal IT systems.
2. While **post haemodialysis systolic** and **diastolic blood pressure** were nearly complete when available, it was not always being picked up by the Renal Registry, suggesting a data mapping issue with Proton sites.

Erythrocyte Stimulating Agents

ESA prescriptions were the data showing the most variation in completeness and accuracy across the sites and there are many different factors governing this.

1. In HD patients monitoring may be done by the HD nurses who are involved in anaemia management. Recording may vary at satellite units.
2. Some sites employ an 'EPO nurse' whose salary is funded by a pharmaceutical company. These nurses may keep ESA prescription updated in the company-supplied standalone database, rather than the main renal IT system.
3. Part of the ESA budget at several sites resides with the GPs. Data on prescription of ESA may therefore be absent from the main renal IT system. Monitoring of haemoglobin achievement at renal unit level is difficult as GPs may also refuse to prescribe the ESA dose recommended by the consultant nephrologist.
4. Within an individual renal unit, monitoring of ESA prescription may be by GPs, nephrologists or 'EPO nurses' depending on whether a patient is on haemodialysis, peritoneal dialysis or has a transplant.
5. Several sites use a free text (un-coded) field for storage of ESA data within the renal IT system. Registry data extraction routines are prone to error in the interpretation of free text fields.

Serology

The number of patients where it was possible to determine the **hepatitis B** and **CMV status** was low at all sites, particularly for CMV, which is clinically only required for patients on the transplant waiting list.

Co-morbidity

Co-morbidity prior to the start of renal replacement therapy was only recorded regularly at two of the renal units.

Chapter 18: Report of the Paediatric Renal Registry

Summary

The demographics of the paediatric ERF population have changed little from previous reports, though it is now clear that the population is continuing to grow rather than plateauing as was inferred in last year's report. The total number of patients in paediatric renal units in April 2004 was 836, with a male to female ratio of 1.56 : 1. There remains a high prevalence of ERF in the South Asian population with an even higher incidence, suggesting that the prevalence is likely to rise in years to come.

The aetiology of ERF in childhood varies with both gender and ethnicity. Overall, renal dysplasia is the most common cause followed closely by glomerular disease. Obstructive dysplasia is now the third most common cause. Obstructive uropathy and renal dysplasia are both significantly more common in males. Amongst the ethnic minority groups the distribution of diseases causing ERF is different with a high incidence of autosomal recessively inherited diseases. As a consequence, the gender distribution in the ethnic minority population is less weighted towards males.

There has been a fall of 1.3% over the past 12 months in the proportion of patients with a functioning allograft. Looking at the proportion of patients in individual renal units transplanted, there is a linear relationship between the proportion of transplants obtained from living donors and the proportion of prevalent patients with allografts, confirming the relative shortage of cadaveric organs. Both the proportion of and the absolute number of patients on haemodialysis has risen, though the majority are still treated with automated peritoneal dialysis. CAPD is only regularly employed by two renal units.

At presentation, 21.6% of patients have paediatric specific co-morbidities; the single most common problem being developmental delay which is present in 8.8%. Co-morbidity at presentation is significantly more common in those presenting under the age of 8 years and in those taken on for dialysis in paediatric units over the age of 16 years. Intellectual disability affects 17% of the paediatric ERF population on cross-sectional analysis with this disability being moderate or severe in 7%. Physical disability is the next most common problem with visual and auditory disability being relatively rare. Overall, the presence of disability does not appear to prevent patients receiving a transplant.

Almost 28% of patients who were on dialysis on 1st April 2004 had been on dialysis for two or more consecutive years, with 7% having been on dialysis for five or more years. Over one third of those who had been on dialysis for more than two years were from ethnic minority groups. The majority of patients on dialysis for prolonged periods were on haemodialysis.

With the large numbers of paediatric patients with obstructive uropathy as a cause of ERF, the outcome of transplantation into the abnormal bladder is important. On cross-sectional analysis the outcome of transplantation into the bladders of patients with obstructive uropathy is no different to that of patients with renal dysplasia as a cause of ERF. However, looking specifically at those with abnormal bladder function requiring intermittent catheterisation, bladder augmentation or a urinary diversion, the outcome is worse with a 10 mls/min/1.73 m^2 reduction in median GFR.

Introduction

Progress towards the development of a system of continual data acquisition for analysis is ongoing with regard to paediatric data for the Renal Registry. To date, information is only being transmitted to the Registry directly from a limited number of renal units. For this reason, the body of this report contains data from our annual data trawl as reported in previous years.

In this report, the demographics of ERF in childhood in the UK, are described together with a focus on co-morbidity and disability in the paediatric population. Also discussed are the demographics of patients on long-term dialysis and the outcomes of transplantation into abnormal bladders.

Paediatric ERF population

The paediatric arm of the Renal Registry currently contains data on 1,697 patients treated for ERF within paediatric units. Of these, 1,023 are male and 674 are female, giving an overall male to female ratio of 1.52 : 1. Of these, 138 patients are known to have died and many have been transferred to adult services. Some of those transferred will also have died at some point after transfer. The patients reported to the registry who appeared to remain under the care of paediatric units on 1st April 2004 numbered 836. Of these patients, there was no current data submission for 52. Thirty two of these 52 patients were over the age of 16 at the time and had probably been transferred to adult units. For the purpose of analysis, data available on the remaining 804 patients was used.

The figure of 804 current patients signifies a rise in the total number under active treatment in paediatric units, countering the small fall in prevalence in our report for 2003. Table 18.1 shows the total number of patients broken down according to gender and ethnicity, together with the numbers of these who were under 18 years of age in April 2004 and those who were under 15 years of age at this time. Figure 18.1 shows the growth in patient numbers for those under the age of 15 years

Table 18.1: Current prevalent patients by gender and ethnicity

	Patients	Male	Female	Ratio	Total %
Total	804	490	314	1.56 : 1	100.0
White	668	414	254	1.63 : 1	83.0
Asian	110	57	53	1.08 : 1	13.6
Black	15	10	5	2.00 : 1	1.8
Other	11	9	2	4.50 : 1	1.6
<18 years	781	476	305	1.56 : 1	97.1
<15 years	558	349	209	1.67 : 1	69.4

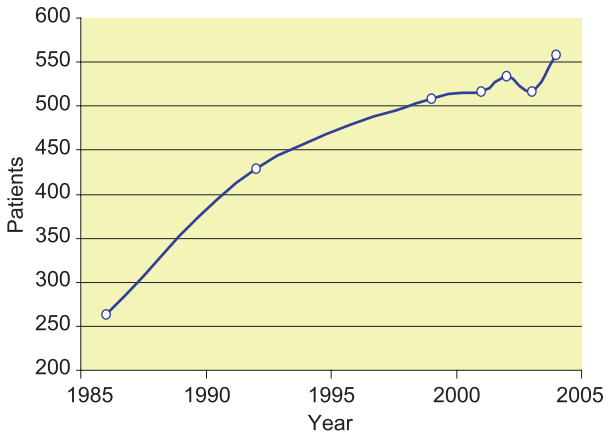

Figure 18.1: ERF patients below the age of 15 years, by year of data collection

and Table 18.2 shows the population changes for all age-groups. Although in our last report it was felt that growth in the population had reached a plateau, this appears not to be the case. Figure 18.2 shows the age distribution of the population compared with that in 2002 and 2003. It is clear from this that there is no specific trend in the ages of patients being treated.

The overall gender distribution also remains unchanged with a male to female ratio in the order of 1.5 : 1. The gender distribution across the paediatric age spectrum is shown in Figure 18.3 and Table 18.3. Male predominance is greatest in the early years of childhood but persists throughout the paediatric age range. This is secondary to specific diagnoses only seen in male patients which are discussed in the section on ERF diagnoses.

Returning to Table 18.1 and the ethnic distribution of the population, two things are

Table 18.2: ERF population by age and year of data collection

	Patient prevalent data						
Age (yrs)	**1986**	**1992**	**1999**	**2001**	**2002**	**2003**	**2004**
0–1.9		16	18	13	14	10	12
2–4.9		55	46	56	58	56	51
5–9.9		150	151	146	147	141	166
10–14.9		208	293	301	315	310	329
15–19.9			253	274	259	256	244
Total <15	**263**	**429**	**508**	**516**	**534**	**517**	**558**
Total <20			**761**	**790**	**793**	**773**	**802**

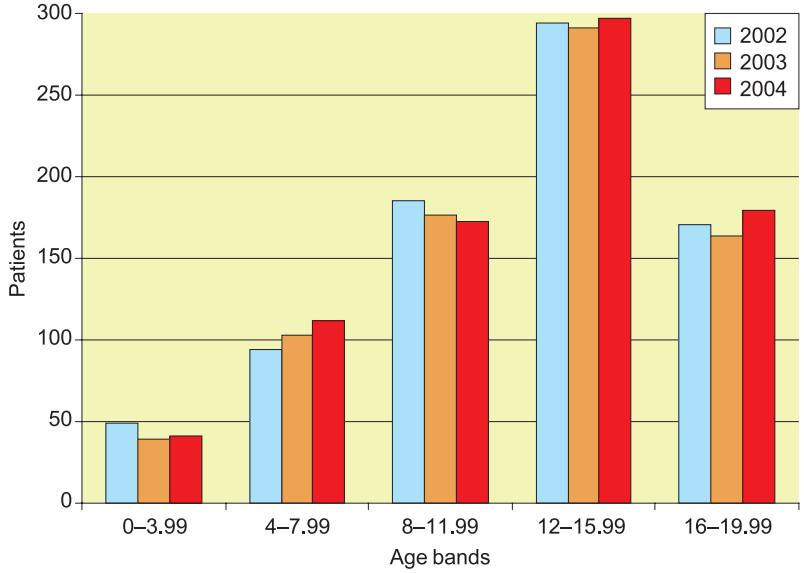

Figure 18.2: Prevalent paediatric ERF population 2002–2004 by age

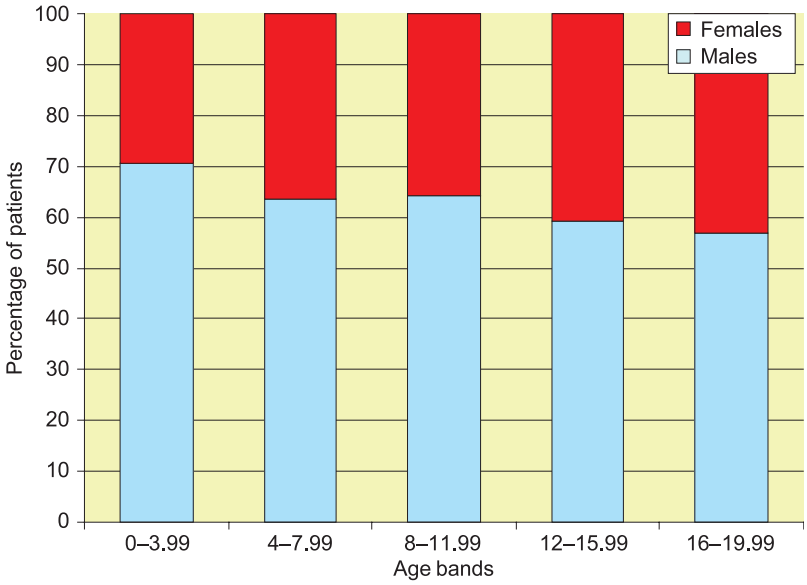

Figure 18.3: Gender distribution of the paediatric ERF population

clear. Firstly, as expected, the majority (83.0%) of the ERF population are White. However the observation that 17.0% come from ethnic minority groups, demonstrates that ethnic minorities are over-represented within the ERF population as these groups comprise just 7.9% of the total UK population. Within this, the greatest over-representation is from the South Asian community who form 13.6% of the paediatric ERF population, whilst just 4% of the general UK population is of South Asian origin. This is dealt with further in the section on prevalence. The other feature of note in Table 18.1 is that the male to female ratio is much lower in the South Asian population than in the White population. This difference is statistically significant ($p = 0.046$, Fisher's exact test). This relates to the different causes of ERF in the South Asian population and is dealt with further below.

Table 18.3: Age and gender distribution of the ERF population

Age (yrs)	Patients	Total %	Males	Females	Ratio
0–3.9	41	5.1	29	12	2.42 : 1
4–7.9	112	14.0	71	41	1.73 : 1
8–11.9	173	21.6	111	62	1.79 : 1
12–15.9	297	37.0	176	121	1.36 : 1
16–19.9	179	22.3	102	77	1.32 : 1
All <20	802	100.0	489	313	1.56 : 1

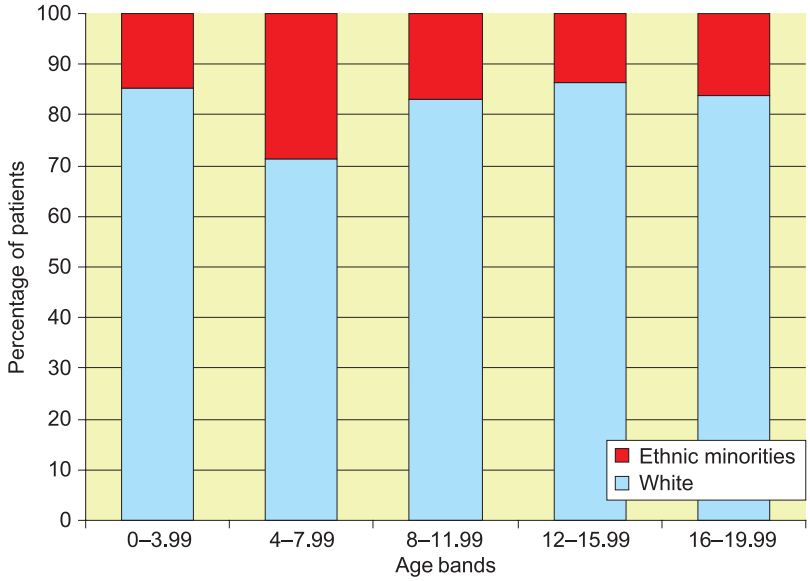

Figure 18.4: Ethnic distribution of the paediatric ERF population

Table 18.4: Age and ethnic distribution of the ERF population

Age (yrs)	Patients	White	South Asian	Black	Other
0–3.9	41	35	6	0	0
4–7.9	112	80	22	5	5
8–11.9	173	144	25	3	1
12–15.9	297	257	35	2	3
16–19.9	179	150	22	5	2
All <20	802	666	110	15	11

Table 18.4 shows a breakdown of the population according to ethnicity and age. This is shown graphically in Figure 18.4. There appears to be an excessive proportion of South Asian patients between the ages of 4 and 8 years. Grouping the populations into two groups of "White" and "ethnic minority" to allow meaningful analysis, the difference between the age distributions of the White and ethnic minority populations are statistically significant (Chi-square = 13.53, p = 0.009).

Whilst the UK has a large ethnic minority population, it is well recognised that this population is not evenly distributed across the UK. Indeed, 50% of the ethnic minority population reside in the Greater London area with significant pockets of ethnic minorities in other specific regions whilst some regions have very few citizens from ethnic minorities. Table 18.5 shows the distribution of the patients according to ethnicity within the 13 paediatric ERF units in the UK. The determinants of the number of patients being actively treated in each unit are both the size of the population covered and the proportion of this population that belongs to the ethnic minorities. Whilst 6 of the 13 renal units have very low proportions of patients from the ethnic minorities (under the 8% figure that constitutes the overall proportion of the ethnic minority citizens in the population), 4 units have an ethnic minority population over 20% (Figure 18.5). As discussed in previous reports, this will have implications for the provision of resources.

Table 18.5: Ethnicity distribution by unit

Centre	White	South Asian	Black	Other	Patients	% ethnic minority
Belfast	31	0	0	0	31	0.0
Birmingham	47	14	2	1	64	26.5
Bristol	50	2	0	0	52	3.8
Cardiff	29	1	0	0	30	3.3
Glasgow	54	3	0	0	57	5.2
GOSH	106	29	9	6	150	29.3
Guys	64	9	4	1	78	12.9
Leeds	48	15	0	0	63	23.8
Liverpool	34	1	0	0	35	2.9
Manchester	66	25	0	1	92	28.2
Newcastle	50	0	0	1	51	2.0
Nottingham	78	10	0	1	89	12.3
Southampton	11	1	0	0	12	8.3

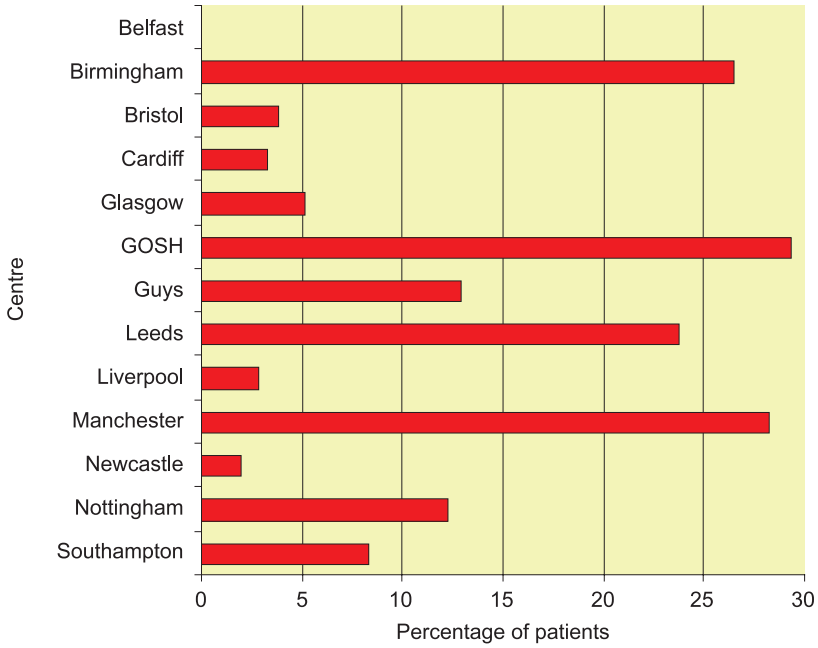

Figure 18.5: Percentage of each unit's patients from ethnic minority groups

Prevalence and take-on rate

Data on the UK population divided according to age and ethnic background was taken from the Office for National Statistics' Website (www.statistics.gov.uk). Data for this report is based upon population estimates for mid-2004 which themselves are based upon the United Kingdom Census of 2001. Table 18.6 shows the UK population in thousands according to age. For ethnicity, the statistics only allowed for the calculation of a total population under the age of 16 in each ethnic group. This is an important calculation as the proportion of children within ethnic minority families varies tremendously. 19% of the White population are under the age of 16, compared to 23% of the Indian population, 29% of the Black population and 38% of the Bangladeshi population. Failure to take account of the increased proportion of children in some of the ethnic minority populations can lead to an over-inflated prevalence and take-on rate.

Table 18.7 shows the prevalence of ERF according to age and gender. These figures are comparable to those in previous registry reports and to those published by the USRDS. The prevalence appears to drop over the age of 16 years but this is secondary to the transfer of

Table 18.6: Projected UK population in mid 2004 (thousands)

Age (yrs)	Total	Male	Female
0–3.9	2,708	1,387	1,321
4–7.9	2,829	1,449	1,380
8–11.9	2,967	1,521	1,446
12–15.9	3,142	1,613	1,529
16–19.9	3,142	1,617	1,524
<15	10,867	5,570	5,297
<18	13,222	6,780	6,442
<20	14,788	7,587	7,201
Total pop	59,835	29,271	30,564

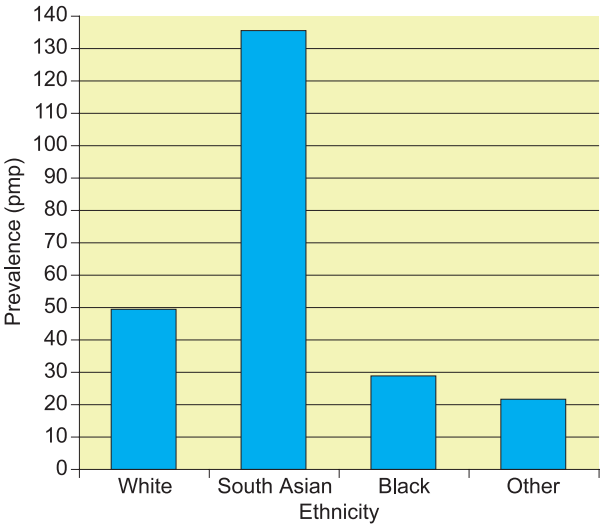

Figure 18.6: Prevalence of ERF in children by ethnicity

patients to adult renal units. In reality, the prevalence of ERF continues to rise with age. This will be clarified once all renal units can submit data electronically to the UK Renal Registry, allowing for continuity of analysis between paediatric and adult centres. As prevalence data obtained by the paediatric Registry is currently unreliable above the age of 16 years, only patients below this age were included for the calculation of prevalence by ethnicity. Figure 18.6 shows the prevalence of ERF in children according to ethnicity. These figures are calculated taking account of the increased proportion of children comprising the ethnic minority population as detailed above. Whilst the prevalence of ERF in the White population is similar to that reported from other developed nations, the prevalence in those from the South Asian community is almost three times as high. This difference in prevalence between the two communities is highly significant (Chi-square = 82.52, $p < 0.0001$). The reason for this seems to reside in the different patterns of renal pathology seen in this population as discussed below. The prevalence of ERF in the Black population appears to be lower than might be expected. Again, this is likely to be related to the patterns of disease seen in this population. The prevalence of ERF in the Black population is much higher than that reported from Nigeria (although reporting systems there are poor) but lower than that reported in the US. The difference in prevalence between the Black and the White population fails to meet statistical significance (Chi-square = 2.477, $p = 0.1155$).

To reduce the year to year variability seen when the number of new patients are relatively small, the acceptance rate has been calculated using an average of the patients accepted onto the ERF programme over the 5 years up to 1st April 2004. Table 18.8 shows the patients accepted onto the paediatric ERF programme over the past 5 years. This incidence data is shown graphically according to ethnicity rather than age in Figure 18.7. The picture for take-on rate shows an identical pattern to that for prevalence. The take-on rate for South Asians

Table 18.7: Prevalence of ERF per million childhood population

	All patients		Males		Females	
Age (yrs)	Patients	Prevalence	Patients	Prevalence	Patients	Prevalence
0–3.9	41	15.1	29	20.9	12	9.1
4–7.9	112	39.6	71	49.0	41	29.7
8–11.9	173	58.3	111	73.0	62	42.9
12–15.9	297	94.5	176	109.1	121	79.2
16–19.9	179	57.0	102	63.1	77	50.5
<15	558	51.4	349	62.7	209	39.5

Table 18.8: Take on rate for patients with ERF per million childhood population

	All patients		Males		Females	
Age (yrs)	Patients	Take on rate	Patients	Take on rate	Patients	Take on rate
0–3.9	23	8	14	10	9	7
4–7.9	16	5	9	6	7	5
8–11.9	26	9	14	9	12	9
12–15.9	37	12	19	12	18	12
<15	93	9	51	9	42	8

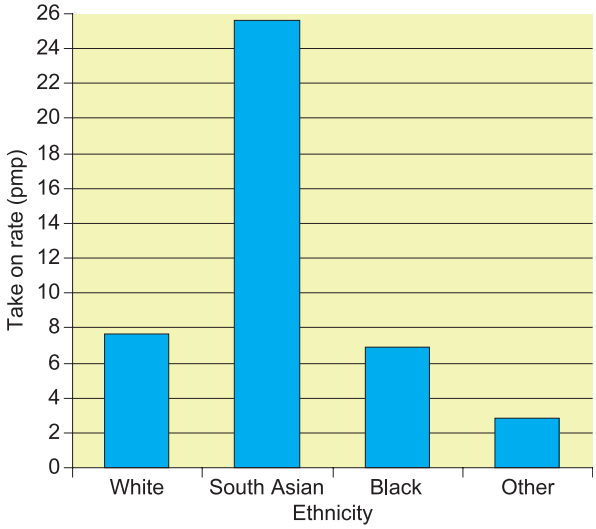

Figure 18.7: Take on rate for children starting RRT by ethnicity

is 3.35 times that of the White population. Currently the prevalence of ERF in the South Asian population is 2.75 times that of the White population. This would suggest that the proportion of South Asians on the paediatric ERF programme is likely to continue rising.

Causes of ERF in Children

The return rate for ERF diagnosis was higher than for any other data item with 96.3% of current patients having an ERF diagnosis allocated. To give a true picture of the distribution of diagnoses, all patients presenting after 1st April 1996 (when data collection began) were analysed even if they had been transferred or died. Using the current population for this analysis gives a false picture as those with specific diseases associated with early onset ERF in childhood are over-represented because of their lengthy stay in paediatric care, whilst those with later onset ERF are under-represented because they are transferred after just a brief period of paediatric care.

Primary ERF diagnoses were available for 845 patients presenting after 1st April 1996. These diagnoses have been grouped into 12 broad categories. Table 18.9 shows the distribution of patients between these categories. When analysed this way renal dysplasias remain the most common group of disorders causing ERF in childhood, closely followed by glomerular

Table 18.9: ERF diagnostic grouping for 845 patients presenting after 1st April 1996

Diagnostic group	Patients	Males	Females	Ratio
Dysplasia	198	124	74	1.68 : 1
Glomerulopathy	195	88	107	0.82 : 1
Obstructive uropathy	131	116	15	7.73 : 1
Reflux nephropathy	67	32	35	0.91 : 1
Tubulo-interstitial diseases	63	34	29	1.17 : 1
Congenital nephrotic syndrome	45	18	27	0.67 : 1
Metabolic diseases	41	23	18	1.28 : 1
Reno-vascular problems	31	16	15	1.06 : 1
Polycystic kidney disease	24	8	16	0.50 : 1
CRF of uncertain aetiology	23	11	12	0.92 : 1
CRF from drug nephrotoxicity	17	12	5	2.40 : 1
Malignancy & associated disease	10	5	5	1.00 : 1

diseases. Obstructive uropathy is the third most common group. For those groups of disorders comprising more than one diagnosis, a further breakdown of cause is given in Tables 18.10–18.19.

Within the renal dysplasia group, the most common diagnosis is renal dysplasia itself. Of these 164 patients with renal dysplasia, 40 (24.4%) had an associated syndromic diagnosis, chromosomal anomaly or other congenital anomalies. Ten of this subgroup had associated developmental delay at presentation whilst just 7 of the remaining 124 patients with renal dysplasia as a cause of ERF had developmental delay. This significant increase in developmental delay at presentation ($p = 0.0014$, Fisher's exact test) in children with other congenital problems

Table 18.10: Diagnoses for patients with renal dysplasia

Diagnoses in renal dysplasia group	Patients	Males	Females	Ratio
Renal dysplasia	164	102	62	1.65 : 1
Multicystic dysplastic kidneys	11	5	6	0.83 : 1
Prune belly syndrome	8	8	0	
Renal hypoplasia	7	3	4	0.75 : 1
Branchio-oto-renal syndrome	3	3	0	
Lawrence Moon Bardet Biedl syndrome	3	1	2	0.50 : 1
Megacystis megaureter	2	2	0	

Table 18.11: Diagnoses for patients with glomerulopathy

Diagnoses in glomerulopathy group	Patients	Males	Females	Ratio
Primary focal segmental glomerulosclerosis	83	40	43	0.93 : 1
Diarrhoea positive HUS	17	8	9	0.89 : 1
Henoch Schoenlein nephritis	13	4	9	0.44 : 1
Diarrhoea negative HUS	11	3	8	0.38 : 1
GN (unspecified)	10	6	4	1.50 : 1
Alport's syndrome	9	8	1	8.00 : 1
IgA nephropathy	9	5	4	1.25 : 1
Mesangio-capillary GN type 1	9	4	5	0.80 : 1
Crescentic GN	8	4	4	1.00 : 1
Proliferative GN	6	2	4	0.50 : 1
Systemic lupus erythematosis	6	1	5	0.20 : 1
Anti GBM disease	3	0	3	
Mesangio-capillary GN type 2	3	0	3	
Microscopic polyarteritis nodosa	3	1	2	0.50 : 1
Wegner's granulomatosis	3	2	1	2.00 : 1
Macroscopic polyarteritis nodosa	1	0	1	
Vasculitis (unspecified)	1	0	1	

Table 18.12: Diagnoses for patients with obstructive uropathy

Diagnoses in Obstructive uropathy group	Patients	Males	Females	Ratio
Posterior urethral valves	98	98	0	
Neuropathic bladder	13	3	10	0.30 : 1
Bladder outlet obstruction*	11	9	2	4.50 : 1
Congenital obstructive uropathy**	7	4	3	1.25 : 1
Acquired obstructive uropathy	2	2	0	

*Excluding posterior urethral valves.
**Excluding bladder outlet obstruction.

Table 18.13: Diagnoses for patients with tubulo-interstitial disease

Diagnoses	Patients	Males	Females	Ratio
Nephronophthisis	51	26	25	1.04 : 1
Primary interstitial nephritis	7	5	2	2.50 : 1
Bartter's syndrome	2	1	1	1.00 : 1
Nephrocalcinosis	1	0	1	
Renal tubular acidosis	1	1	0	
Tubular disorders (other)	1	1	0	

Table 18.14: Diagnoses for patients with congenital nephrotic syndrome

Diagnoses	Patients	Males	Females	Ratio
CNS unspecified	20	5	15	0.33 : 1
Finnish type	17	8	9	0.89 : 1
Diffuse mesangial sclerosis	5	4	1	4.00 : 1
Focal segmental glomerulosclerosis	3	1	2	0.50 : 1

Table 18.15: Diagnoses for patients with metabolic diseases

Diagnoses	Patients	Males	Females	Ratio
Cystinosis	34	19	15	1.27 : 1
Primary hyperoxaluria type 1	3	2	1	2.00 : 1
Mitochondrial cytopathy	3	1	2	0.50 : 1
Metabolic disease (other)	1	1	0	

Table 18.16: Diagnoses for patients with reno-vascular disease

Diagnoses	Patients	Males	Females	Ratio
Cortical necrosis	20	9	11	0.82 : 1
Renal vein thrombosis	7	5	2	2.50 : 1
Renal artery stenosis	2	1	1	1.00 : 1
Renal trauma	2	1	1	1.00 : 1

Table 18.17: Diagnoses for patients with polycystic kidney disease

Diagnoses	Patients	Males	Females	Ratio
Recessive PKD	18	5	13	0.38 : 1
PKD (other)	4	2	2	1.00 : 1
Dominant PKD	1	1	0	
Tuberous sclerosis with PKD	1	0	1	

Table 18.18: Diagnoses for patients with CRF from drug nephrotoxicity

CRF from drug nephrotoxicity	Patients	Males	Females	Ratio
Calcineurin inhibitor nephrotoxicity	13	10	3	3.30 : 1
Cytotoxic drug nephrotoxicity	4	2	2	1.00 : 1

Table 18.19: Diagnoses for patients with malignant disease

Diagnoses	Patients	Males	Females	Ratio
Wilms' tumour	7	3	4	0.75 : 1
Wilms' nephropathy	3	2	1	2.00 : 1

is not surprising but has not previously been quantified. Even excluding diagnoses such as prune belly syndrome, where the patients are by definition male, renal dysplasia is a more common cause of renal failure in males than females (Table 18.10). This is not offset by the slightly increased frequency of reflux nephropathy as a cause of ERF in females (Table 18.9) and contributes significantly to the overall preponderance of males with ERF.

Within the group of patients with glomerular disease as a cause of ERF, it can be seen from Table 18.11 that primary focal segmental glomerulosclerosis is the single most common disorder accounting for 43% of all cases. Diarrhoea associated haemolytic uraemic syndrome and Henoch Schoenlein nephritis are the next two most common problems and together these three disorders, which are rare causes of ERF in adults, account for 58% of paediatric patients with ERF from glomerulopathy.

Within the group of patients with obstructive uropathy as a cause of ERF, the vast majority (74.8%) have posterior urethral valves. This by definition is limited to males and is the other major contributor to the preponderance of males in the paediatric ERF population. Within the small group with ERF secondary to a neuropathic bladder, females significantly outnumber males.

For those patients with tubulo-interstitial disease, nephronophthisis was the predominant diagnosis accounting for 80.9% of cases. Twenty seven percent of these (14 of 51) were in-patients who also had a syndromic diagnosis, chromosomal abnormality or congenital abnormality recognised at presentation. Six of this group had developmental delay evident at presentation, 3 of these were in the group who had a syndromic diagnosis.

For those with congenital nephrotic syndrome, 44% are in the ''unspecified group'', the majority of these will be presumed to have Finnish type disease. In many centres, after a typical presentation with congenital nephrotic syndrome, obtaining a firm histological diagnosis is not felt to be a procedure where the benefits outweigh the risks or influence management.

Cystinosis is the main cause of ERF in those with metabolic disease whilst cortical necrosis predominates in those with ERF from renovascular problems. Recessive polycystic kidney disease, not surprisingly, accounts for 75% of those with polycystic disease leading to ERF. What is surprising in this group is the preponderance of females in a disease with autosomal recessive inheritance.

Renal failure from drug nephrotoxicity is presented as a separate group for the first time. Although it only accounts for 1.5% of patients it is an important group as the numbers appear to be increasing and, theoretically, it is a preventable cause of renal failure. Whilst historically this group comprised patients who had renal failure secondary to the toxicity of cytotoxic drugs used to treat malignancy, now the majority of patients have renal failure secondary to calcineurin inhibitor toxicity. Of these 13 patients, 4 were documented to have a liver allograft, four a heart allograft and one heart and lungs grafted.

Wilms' tumour is the only malignancy causing ERF in this paediatric group. Some children with the WT1 mutation are documented to be in established renal failure from the associated nephropathy without ever developing a tumour. In some instances this will be because elective bilateral native nephrectomy has been undertaken after making a diagnosis to prevent the progression to malignancy.

ERF aetiology and ethnicity

The pattern of disease causing ERF in children varies between ethnic groups and this accounts for much of the difference noted above in the incidence and prevalence of ERF in the different ethnic groups. Table 18.20 shows the diagnostic groups detailed above but broken down according to ethnicity rather than gender. Dysplasia, glomerulopathy and obstructive uropathy predominate in the White population, these 3 groups accounting for 64.1% of patients. In South Asian patients there is a more even spread across the groups with only 48.4% of patients having dysplasia, glomerulopathy or obstructive uropathy. In the Black population glomerulopathy alone accounts for 64.7% of patients, with dysplasia being relatively rare and no cases of obstructive uropathy

Table 18.20: Ethnic distribution of ERF diagnostic groups

Diagnostic group	White	South Asian	Black	Other
Dysplasia	176	19	3	0
Glomerulopathy	155	25	11	4
Obstructive uropathy	112	17	0	2
Reflux nephropathy	58	6	1	2
Tubulo-interstitial diseases	46	15	0	2
Congenital nephrotic syndrome	29	16	0	0
Metabolic diseases	29	12	0	0
Reno-vascular problems	29	2	0	0
Polycystic kidney disease	17	5	1	1
CRF of uncertain aetiology	16	6	1	0
CRF from drug nephrotoxicity	15	2	0	0
Malignant disease	9	1	0	0

Table 18.21: Ethnic distribution of ERF combined diagnostic groups

Combined diagnostic groups	White	South Asian	Black	Other
Group 1	346	42	4	4
Group 2	155	25	11	4
Group 3	121	48	1	3
Group 4	69	11	1	0

Group 1 = Dysplasia + Obstructive + Reflux
Group 2 = Glomerulopathy
Group 3 = Tubulo-interstitial disease + Metabolic disease + PKD + CNS
Group 4 = Reno-vascular disease + Malignant disease + Drug nephrotoxicity + CRF of uncertain aetiology

being included in this cohort. This different pattern of disease in the Black population is the likely cause of the low incidence and prevalence in this group.

To allow meaningful statistical analysis of the pattern of disease, these have been further grouped into four categories. The first of these contains patients who have structural problems and includes patients from the dysplasia, obstructive uropathy and reflux nephropathy groups. The second is just for patients with glomerulopathy. The third contains the patients with mostly inherited diseases – tubulo-interstitial disease, metabolic disease, congenital nephrotic syndrome and polycystic disease. The fourth group contains the other remaining patients. The results of this regrouping are shown in Table 18.21. Whilst 50% of White patients belong to group 1, the largest single group in the South Asian population is group 3. This comprises 38% of the patients and demonstrates the importance of inherited disease in the aetiology of renal failure in this population. The difference in the distribution of disease groups between the White and South Asian populations is significant (Chi square = 23.78, $p < 0.0001$). This difference remains significant when the White population is compared to the total ethnic minority population (Figure 18.8).

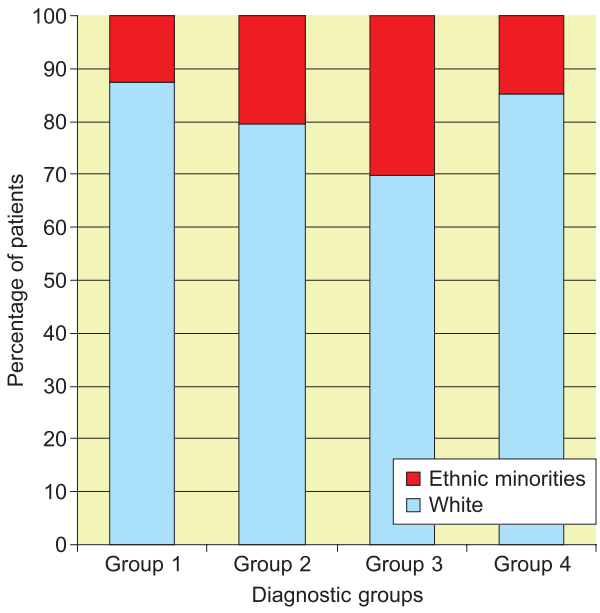

Figure 18.8: Ethnic distribution of the grouped ERF diagnoses

Table 18.22: Ethnic distribution disease by inheritance

Disease inheritance	White	South Asian	Black	Other
Autosomal recessive	108	45	1	2
Autosomal dominant	5	0	0	0
Sex linked	6	2	1	0
Mitochondrial disease	3	0	0	0
Not directly inherited	569	79	15	9

To confirm that these findings are due to inherited diseases, compounded in the South Asian community by a high frequency of consanguineous marriage, these data have been analysed according to the known usual inheritance of each pathology. This is shown in Table 18.22.

Almost 80% of patients have diseases leading to renal failure which are not directly inherited. Of the rest, 90% are diseases which are inherited in an autosomal recessive manner. The higher proportion of patients with autosomal recessive disease in the South Asian population compared with the White population is very significant ($p < 0.0001$, Fisher's exact test, Figure 18.9). This suggests that consanguinity and consequent autosomal recessive disease is a large factor in the high incidence and prevalence of ERF in the South Asian community. Reducing the frequency of autosomal recessive disease in the South Asian community to that of the White population would lead to a 26% reduction in incidence and prevalence. Such a reduction would make the incidence of ERF in the South Asian community 18.9 per million population. Thus, although significantly reduced, the incidence would still be 2.48 times that of the White population (compared with a current incidence ratio of 3.35). Clearly, there are other factors that also contribute to the high incidence of ERF in children in the South Asian population.

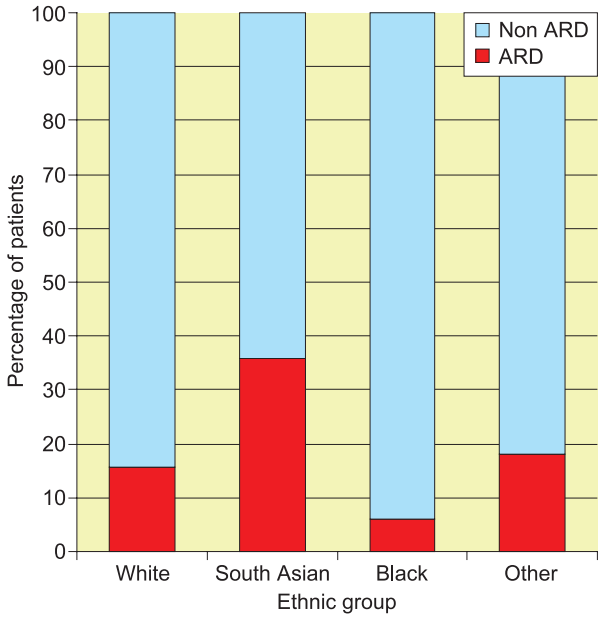

Figure 18.9: Autosomal recessive disease (ARD) as a cause of ERF by ethnicity

Current treatment of paediatric ERF patients

Details of treatment modality on 1st April 2004 were available for 786 of the 804 patients (97.5%). The distribution of treatments is shown in Figure 18.10. A total of 195 patients were on dialysis whilst 591 (75.2%) had a functioning allograft. Of those with a functioning graft, 151 (25.5%) had grafts from living donors (LD) whilst the majority (74.5%) had cadaveric (CAD) grafts. Peritoneal dialysis was the preferred mode of dialysis management with 58% of dialysis patients being treated this way. Of these 111 patients, 99 were on automated

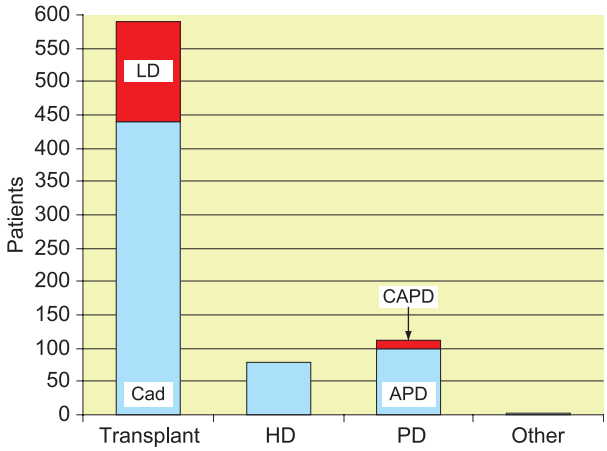

Figure 18.10: Distribution of patients by modality on 1st April 2004

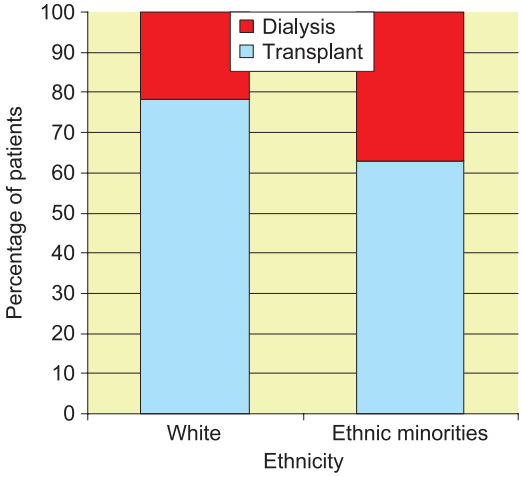

Figure 18.11: Distribution of dialysis and transplant patients by ethnicity

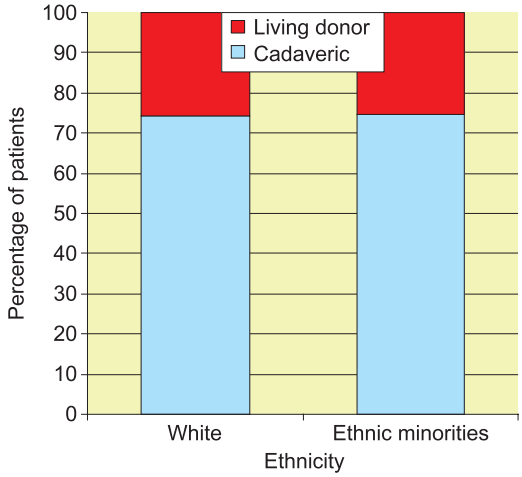

Figure 18.12: Distribution of transplant patients by ethnicity

peritoneal dialysis whilst just 12 were on CAPD. Two patients were not receiving any active treatment at the time. In one patient active management had been ceased whilst in the other the patient was between dialysis modalities and was surviving on residual renal function.

As in previous years, a significantly greater proportion of the White population had a functioning allograft compared with the ethnic minority groups ($p = 0.0003$, Fisher's exact test, Figure 18.11). For those who did have a functioning allograft, there was no difference in the proportion that had a graft from a living donor rather than a cadaveric graft between the ethnic minority groups and the White population (Figure 18.12.) Thus, despite the difficulty in getting cadaveric grafts for ethnic minority patients, there has been no move towards the more aggressive promotion of living donor transplantation. This explains the excessive proportion of ethnic minority patients being treated with dialysis (Table 18.23).

For those patients on dialysis, almost two thirds of the White population were being

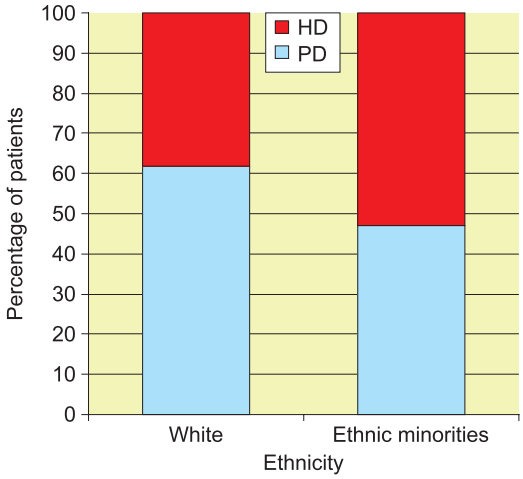

Figure 18.13: Distribution of dialysis patients by ethnicity

treated with peritoneal dialysis whilst over 50% of the ethnic minority population were on haemodialysis (Figure 18.13). Whilst in previous years the difference between dialysis modality in the White and ethnic minority populations was statistically significant, this year it was not ($p = 0.0925$, Fisher's exact test). The reason for this is shown in Figure 18.14, which compares the dialysis population for 2003 and 2004.

Table 18.23: Modality on 1st April 2004 by ethnicity

Modality	White	South Asian	Black	Other
Transplant (All)	508	68	8	7
Transplant (Cadaveric)	378	53	5	4
Transplant (Living donor)	130	15	3	3
Haemodialysis	54	21	3	2
Peritoneal dialysis	88	18	3	2
Other	2	0	0	0

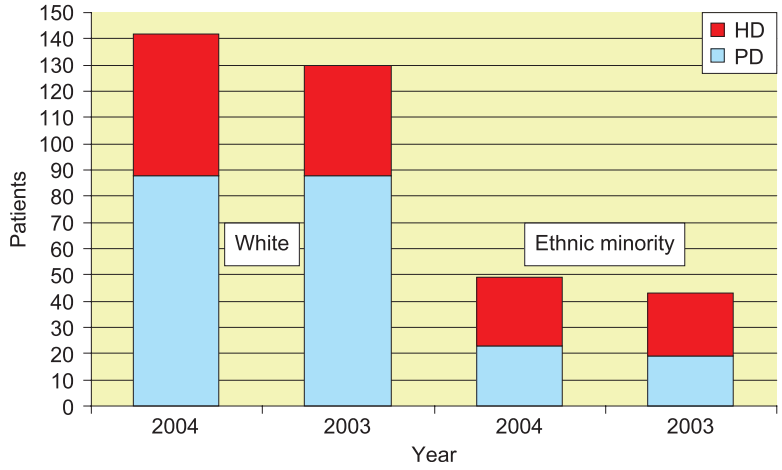

Figure 18.14: Change in the numbers of dialysis patients between 2004 and 2003 by ethnicity

Whilst for the ethnic minority groups there has been an equal increase in both the haemodialysis and peritoneal dialysis population, in White patients the number of peritoneal dialysis patients has been static whilst the haemodialysis population has grown. This change is related to the management of long-term dialysis patients and those returning to dialysis after allograft failure as peritoneal dialysis remains the primary initial treatment modality in this population.

Differences exist between renal units in the proportion of patients transplanted and, for those remaining on dialysis, the proportions using each dialysis modality available. Table 18.24 shows a breakdown of the number of patients with a functioning allograft or on dialysis according to treatment centre. The proportion of patients with a functioning allograft varies widely from 49–91%. In part, this difference will undoubtedly relate to the ethnic distribution of the population covered by the treatment centre. Another factor is the individual centre's approach to living donation. Table 18.25 shows the proportion of engrafted patients in each treatment centre who have living donor allografts. Again, there is a wide variation from 3% to almost 86%. Currently, 10 of the 13 regional paediatric nephrology units within the UK are performing transplantation. By allocating all patients to their transplanting centre, it is possible to compare the proportion of transplanted patients with living donor allografts to the overall proportion

Table 18.24: Proportion of patients transplanted by centre

	Patients			
Renal unit	**Transplant**	**Dialysis**	**Total**	**% grafted**
Belfast	19	12	31	61.9
Birmingham	31	32	63	49.2
Bristol	41	12	53	77.4
Cardiff	23	7	30	76.7
Glasgow	45	9	54	83.3
GOSH	116	31	147	78.9
Guys	72	5	77	93.5
Leeds	41	22	63	65.1
Liverpool	22	7	29	75.8
Manchester	70	22	92	76.1
Newcastle	32	15	47	68.1
Nottingham	72	16	88	81.8
Southampton	7	5	12	58.3
Total	**591**	**195**	**786**	**75.2**

Table 18.25: Living donor vs cadaveric allografts by centre

	Patients with allografts			
Renal unit	**Living donor**	**Cadaveric**	**Total**	**% living donor**
Belfast	1	18	19	5.3
Birmingham	1	30	31	3.2
Bristol	9	32	41	22.0
Cardiff	2	21	23	8.7
Glasgow	17	28	45	37.8
GOSH	41	75	116	35.3
Guys	32	40	72	44.4
Leeds	3	38	41	7.3
Liverpool	4	18	22	18.1
Manchester	14	56	70	20.0
Newcastle	8	24	32	25.0
Nottingham	13	59	72	18.1
Southampton	6	1	7	85.7
Total	**151**	**440**	**591**	**25.5**

of transplanted patients. These data are shown in Figure 18.15. There is a clear correlation between the proportion with living donor allografts and the overall proportion engrafted ($p = 0.0053$). These differences between renal units may relate to both the populations served and also the approach to living donation taken. These data emphasise the shortage of deceased donor grafts; if there were an unlimited supply of grafts, the transplantation rates between centres would not vary in this way. More research in this area is required to see if an alteration in approach could improve the living donor transplant rates in some centres.

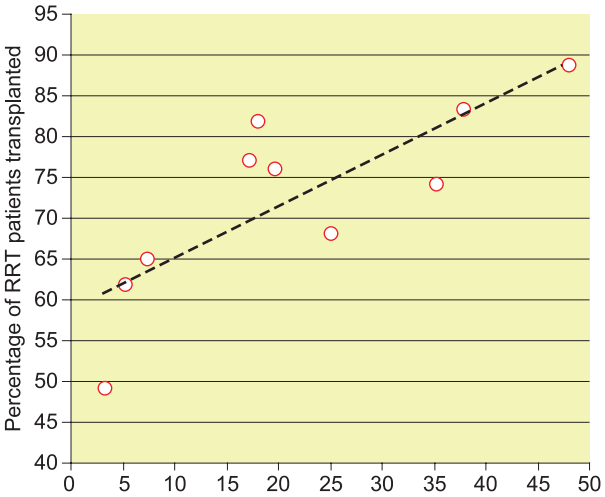

Figure 18.15: Percentage of grafted patients with living donor graft by centre

With regard to dialysis modality, there is wide variation between renal units in the proportion of patients receiving peritoneal rather than haemodialysis. Interpretation of these snapshot data, however, is difficult as the numbers are small and the situation is very fluid with patients moving from one modality to another. One thing that does stand out is the popularity of APD with CAPD only being a regular treatment option in one renal unit (Table 18.26).

Table 18.26: Dialysis modality by centre

	Patients with allografts			
Renal unit	**CAPD**	**APD**	**HD**	**% PD**
Belfast	0	6	6	50.0
Birmingham	0	20	12	62.5
Bristol	0	8	4	66.7
Cardiff	0	2	5	28.5
Glasgow	0	4	5	44.4
GOSH	1	22	8	74.2
Guys	0	2	3	40.0
Leeds	0	14	4	77.7
Liverpool	0	6	1	85.7
Manchester	8	5	9	59.1
Newcastle	0	5	10	33.3
Nottingham	0	6	10	37.5
Southampton	2	0	3	40.0
Total	**11**	**100**	**80**	**58.1**

Co-morbidity in paediatric ERF patients

In addition to the well recognised co-morbid conditions that influence outcome in both adults and children with ERF, there are a number of problems that are specific to those commencing ERF as children, though with successful management of ERF, these will also have an impact upon management in adult units in time. The paediatric registry documents the presence or absence of a number of specific co-morbid features at presentation with ERF. These include cerebral palsy, developmental delay, chromosomal anomalies, non-renal tract congenital abnormalities, syndromal diagnoses, neural tube defects and congenital heart disease. Figure 18.16 shows the incidence of these problems amongst 868 patients presenting with ERF between the 1st April 1996 and 1st April 2004. Overall, 21.7% of patients had one or more of these co-morbid problems at presentation. The most common of these is developmental delay affecting 8.9% of patients. This figure will actually be an under-estimate of the true incidence of developmental delay as, in those patients presenting at birth or within infancy, developmental delay may not be apparent at the time of presentation.

Table 18.27 shows the numbers of patients with and without these co-morbid problems at the time of presentation with ERF, broken down according to age at presentation. It is clear that these co-morbidities are more common in the younger age-groups. Comparing patients starting ERF management below the age of 8 years with those starting between 8 and 16 years of age, there is a significant difference in the incidence of co-morbidity ($p = 0.0013$, Fisher's exact test). Over the age of 16 years there seems to again be a high incidence of patients with co-morbidity starting ERF treatment. This is likely to be because patients with these co-morbidities will be kept on and treated in paediatric units initially whilst patients without co-morbidity in this age-group will often start ERF treatment in an adult unit.

Table 18.27: Presentation co-morbidity by age at ERF start

Age band	Normal	Co-morbidity	Total	% with co-morbidity
0–3.9	129	52	181	28.7
4–7.9	88	31	119	29.4
8–11.9	166	35	201	17.4
12–15.9	245	54	299	18.1
16–19.9	52	16	68	23.5

Co-morbidity is not associated with ethnic origin. Of 706 White patients in this cohort, 156 had co-morbidities at presentation, whilst 32 of 159 patients from ethnic minorities were affected by these. There was, however, an association between co-morbidity at presentation and gender with females being more frequently

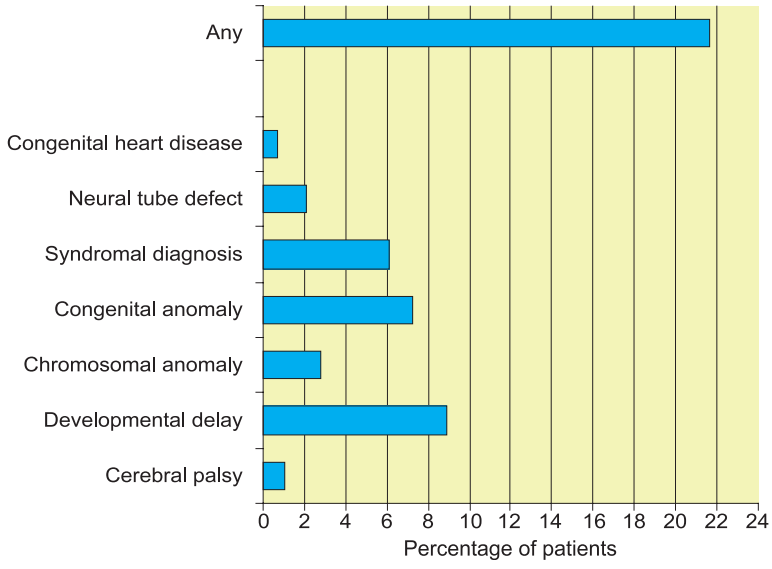

Figure 18.16: Percentage of patients with co-morbidity noted at presentation

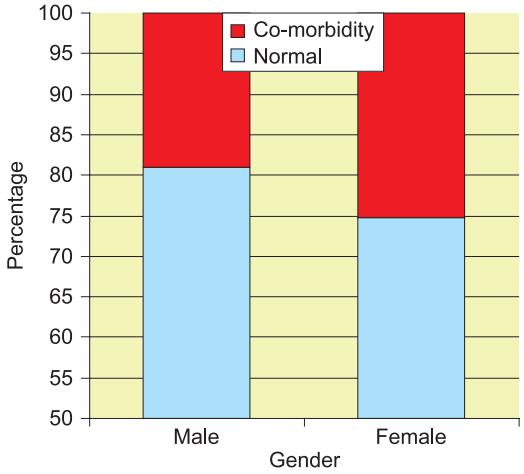

Figure 18.17: Presentation co-morbidity by gender

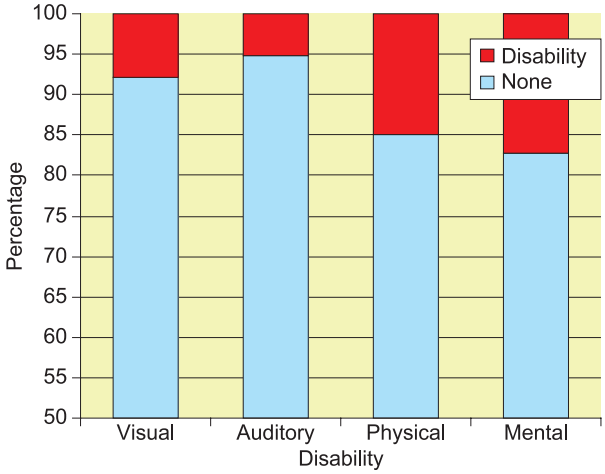

Figure 18.18: Prevalence of disability in the ERF population

affected than males ($p = 0.0301$, Fisher's exact test, Figure 18.17). This seems to be related to the aetiology of renal failure with the large number of young boys with either posterior urethral valves or renal dysplasia as a cause of ERF reducing the proportion of patients with other pathologies associated with co-morbid problems.

The collection of data about ongoing and new co-morbidity is difficult when dealing with a cohort of children with widely ranging problems and backgrounds. To allow comparisons to be made, the annual data collection tool includes four broad questions about the presence or absence of disability in four areas. These are visual disability, auditory disability, physical disability and mental disability. Each of these disabilities is graded as "none", "mild", "moderate" or "severe". Current status records were available for 748 patients in 2004. Of these, the fields detailing disabilities were completed for 723 patients (96.7%). Table 18.28 shows the results of the analysis of these records. Mental disability was the most common problem with 17.2% of patients having some degree of disability in this area and 7.3% having moderate or severe disability. The proportions of patients showing any disability in these areas or just moderate or severe disability in these areas are shown graphically in Figures 18.18 and 18.19. There was no significant difference in the prevalence of moderate or severe physical or mental disability between the genders nor was there any association between these disabilities and ethnicity. The disappearance of the association between female gender and mental impairment on current analysis when compared with presentation is secondary to the appreciation of disability in those boys presenting with ERF in infancy. Whether these patients have acquired disability as a complication of ERF management or were destined to have these disabilities anyway is impossible to determine from the available information.

Table 18.28: Levels of disability in the current ERF population

Disability	None	Mild	Moderate	Severe
Visual	666	41	10	6
Auditory	685	15	12	11
Physical	615	66	33	9
Mental	599	71	42	11

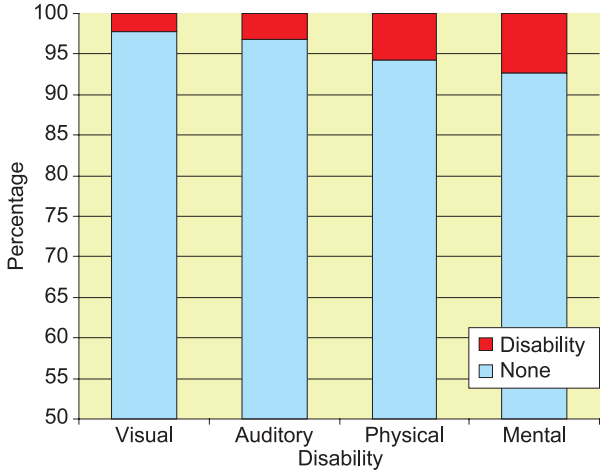

Figure 18.19: Prevalence of significant disability in the ERF population

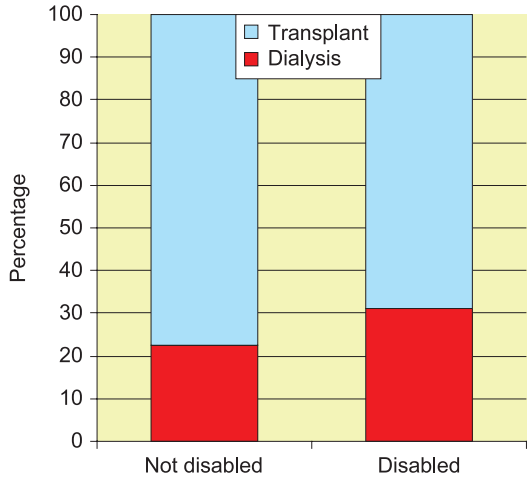

Figure 18.20: Treatment modality in those with moderate or severe mental and/or physical disability compared with patients with no disability

There are undoubtedly some patients in whom their degree of disability and the nature of this disability influences ERF management. Looking at the population as a whole, however, this was not the case. Figure 18.20 shows those patients with moderate or severe mental or physical disability compared to those with no disability. Although the proportion of patients on dialysis, rather than having a functioning allograft, is greater in the group of patients with disabilities, this did not reach statistical significance ($p = 0.1087$, Fishers exact test).

Patients on long-term dialysis

The overall mortality rate for children on renal replacement therapy is 25–30 times higher than expected for age[1,2,3]. Cardiovascular events cause up to 50% of these deaths[1,2,3].

Overall, children on dialysis have a 4-fold risk of death compared to children with a functioning renal transplant. There was no difference in mortality between children receiving a pre-emptive transplant and those who had received up to 24 months of dialysis pre-transplant[1]. However, those who have "relatively long-term dialysis", defined as having more days of RRT on dialysis than with a functioning transplant, have a mortality hazard ratio of 7.2 compared to children receiving RRT as a functioning transplant but not dialysis[2]. Those children with relatively long-term haemodialysis have a higher mortality rate than those on relatively long-term peritoneal dialysis. This may reflect the more complex medical problems or longer total duration of dialysis of children who need to be on haemodialysis, as most paediatric units favour peritoneal dialysis as the initial mode of dialysis where possible. Prolonged peritoneal dialysis was associated with a significant increase in aortic valve calcification when compared to haemodialysis[4].

Table 18.29: Duration of continuous dialysis treatment for current patients

Dialysis duration (yrs)	Patients	Previous allograft	No previous allograft
<1	65	8	57
1–1.9	54	7	47
2–2.9	25	4	21
3–3.9	18	2	16
4–4.9	8	2	6
⩾5	13	1	12

Apart from the increased mortality risk, cumulative dialysis duration of more than 4 years was associated with a 3.4-fold increased risk of the full-scale IQ being ⩾1 SD below the mean[5].

Of the 191 patients being treated with dialysis in paediatric units on the 1st April 2004, a previous treatment history was available for 183 (95.8%). One hundred and eleven of these patients had been on dialysis for less than two years whilst 80 had been on dialysis for over two years. Table 18.29 shows the duration of continuous dialysis therapy for this cohort. Although in clinical practice, prolonged dialysis used to be associated with the wait for a second allograft in sensitised patients, only 9 of the patients who had been on dialysis for over two years had previously had a transplant. Thirteen patients, 7% of the dialysis population, had been on dialysis for 5 or more years. As would be expected from the information given in the current treatment section, there was an excess of ethnic minority patients on dialysis for a prolonged period. Of 51 patients who had been on dialysis continually for 2 or more years and had not previously received an allograft, 19 (37.2%) were from ethnic minority groups.

For those patients being treated with long-term dialysis, there were more on haemodialysis

than peritoneal dialysis. Thirty of the 64 patients on continuous dialysis for 2 or more years were on peritoneal dialysis whilst 34 were on haemodialysis. In part, this will be related to ethnicity as we know haemodialysis is used more in patients from ethnic minority groups who form over a third of this cohort. However, in many cases this will be secondary to loss of peritoneal access or peritoneal function. Twelve of the patients in this cohort had switched from peritoneal dialysis to haemodialysis whilst just one patient moved from haemodialysis to peritoneal dialysis. Clearly this is a concern, both with regard to long-term co-morbidity and also with regard to the potential for ongoing dialysis. The majority of paediatric haemodialysis patients are dialysed through central venous catheters rather than arterio-venous fistulae. If patients are losing peritoneal function and then get central venous occlusion secondary to dialysis catheters, the potential for dialysis in these patients when they reach adulthood is greatly reduced.

Figure 18.21 shows the age distribution of the 64 patients who have been on dialysis continuously for two or more years. It is not surprising that there are fewer patients in the 0–3.9 year age-group considering that many of these patients would not have been in ERF for over two years. What is surprising is the dip in numbers in the 8–11.9 year age-group. There is no clear reason for this and only future analyses will reveal whether this is a persistent trend.

Transplantation and the abnormal bladder

Obstructive uropathy from posterior urethral valves is one of the more common causes of chronic kidney disease in children. In one long-term series, 6% died from chronic renal failure, 16% developed ERF and 6% had ongoing chronic renal failure (creatinine greater than 150 μmol/l)[6]. Children with posterior urethral valves and other children with primary neuropathic bladder or secondary nephropathy from bladder outlet obstruction are at risk of urinary infections and incontinence as a result of their abnormal bladders and upper urinary tracts. Of particular concern is the persistence of bladder dysfunction in the form of detrusor hyperreflexia or poor bladder compliance with small capacity, that may result in a high pressure bladder, or detrusor failure with a hypotonic bladder where the bladder fails to empty resulting in recurrent infections. Modern management for these children now includes bladder augmentation cystoplasty to create a low pressure, high capacity bladder and clean intermittent catheterisation to achieve bladder emptying.

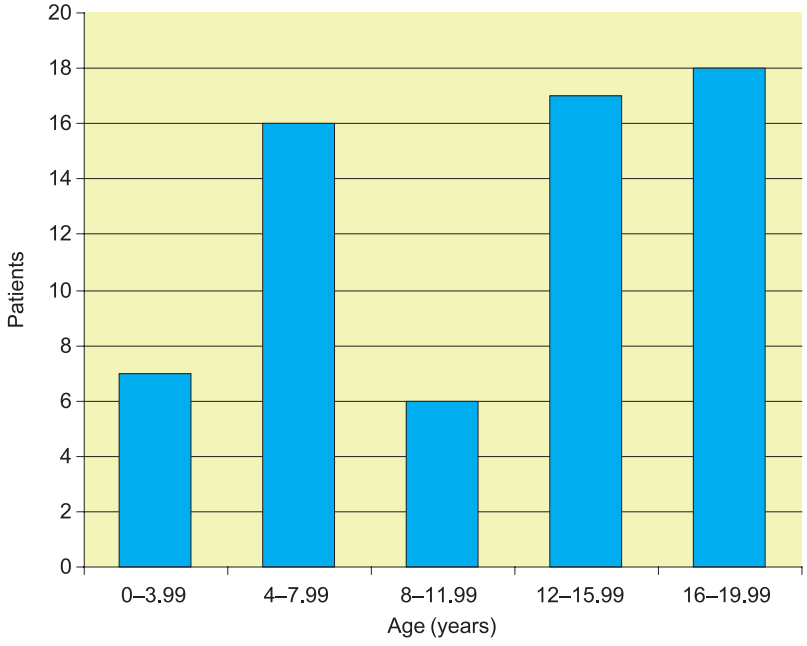

Figure 18.21: Patients on dialysis for two or more years, by current age

There is some debate as to the outcome of renal transplantation in these children. In the early days of transplantation, patients with "bad bladders" were considered unsuitable for transplantation. Historically, it has been asserted that children with posterior urethral valves have a worse outcome following renal transplantation[7,8]. More recently, however, a number of authors have reported good outcomes both for transplantation into abnormal bladders including those with augmented bladders and urinary diversions; graft and patient survival being in the range of 70–80% and 85–100% at 5 years respectively[9].

Theoretically, the paediatric Registry ought to be an ideal source of data for the comparison of outcomes of transplantation into normal and abnormal bladders. Unfortunately this becomes difficult once one takes into account that data collection is only annual, complications such as urinary sepsis are often not recorded and at present the lack of continuous data tracking patients through both their childhood and adult careers. In addition, to assess outcome solely related to bladder function, one needs to take account of other factors that lead to allograft dysfunction and loss such as matching, rejection, immunosuppression, non-urinary tract infection and recurrent renal disease. In an attempt to overcome these analytical difficulties we have compared two cohorts of current patients. In the April 2004 review of paediatric patients there were 109 patients with a functioning allograft whose original cause of renal failure was bladder related obstructive uropathy. As expected posterior urethral valves was the cause in 92 of these patients with 8 patients having a neuropathic bladder and 9 patients having obstructive uropathy from bladder outlet obstruction that was not posterior urethral valves. The second cohort consisted of 146 patients for whom the primary cause of renal failure was renal dysplasia and who were documented to have a functionally normal bladder. Using this cohort for comparison removed the potential confounding factors of recurrent disease and systemic disease and previous immunosuppression. Also, the observed male to female ratio in paediatric patients with ERF from renal dysplasia went some way to counter the gender differences between the groups, where, by definition, the vast majority of those with obstructive uropathy would be male.

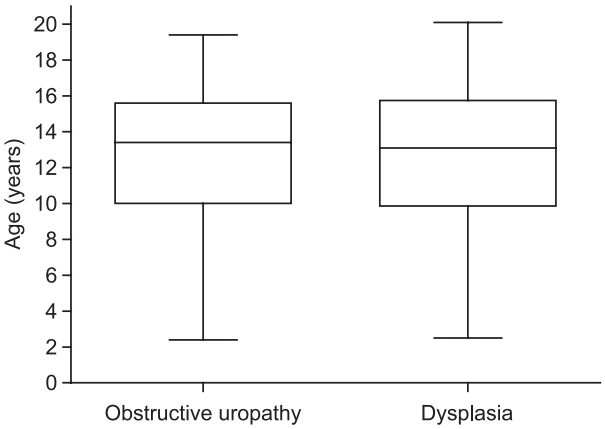

Figure 18.22: Age distribution of patients with obstructive uropathy compared to those with renal dysplasia

As predicted by selection, all those in the renal dysplasia cohort had normal bladder function and passed urine normally. There was no reliable record of how many of these patients suffered from urinary tract infections or had native or transplant vesico-ureteric reflux. For the cohort with renal failure from obstructive uropathy, 67 were thought to have normal bladder function or at least a "safe" bladder requiring no intervention. Sixteen patients were on clean intermittent catheterisation alone, 10 patients had a bladder augmentation and were on clean intermittent catheterisation, 5 patients had an ileal loop urinary diversion and in 11 patients the nature of the bladder and mode of drainage was not clearly defined.

There was no difference in the age distribution of the two cohorts (Figure 18.22). As expected, there was a preponderance of males in the obstructive uropathy group with 102 of the 109 patients in this group being male compared to 100 of 146 patients in the dysplasia group ($p < 0.0001$, Fisher's exact test). Similarly, there was no difference between the two groups with regard to the age of the allograft (Figure 18.23).

To assess renal function in these groups, predicted GFR from the patient height and serum creatinine using a single constant of 40 was used:

$$\text{ie pGFR} = \frac{40 \times \text{Height}}{\text{plasma creatinine}}$$

The results of this analysis are shown in Figure 18.24. There was no significant difference

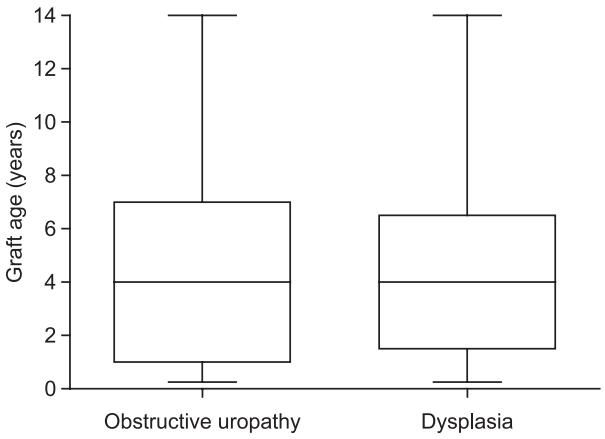

Figure 18.23: Graft age distribution of patients with obstructive uropathy compared to those with renal dysplasia

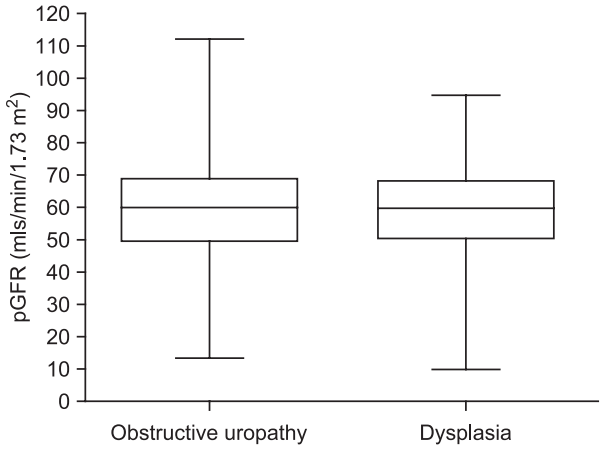

Figure 18.24: Predicted GFR in transplanted patients with obstructive uropathy compared to those with renal dysplasia

between the distribution of predicted GFR between the two groups.

The failure to show any difference in function between the two groups could be because of successful interventive management in those with obstructive uropathy but it could also be secondary to the presence of a majority of patients in the obstructive uropathy group who were deemed to have normal bladder function. To assess the impact of having both obstructive uropathy as a cause of renal failure and subsequent bladder dysfunction, the predicted GFR of those patients requiring clean intermittent catheterisation, bladder augmentation or urinary diversion (intervention group) were compared with patients who had obstructive uropathy as a cause of renal failure but in whom bladder function was normal (normal bladder function group). The patients were matched for both chronological and graft age. The results of this analysis are shown in Figure 18.25. Although the range of GFR's between the two groups remains similar, the distributions are different, with the median GFR in the patients with abnormal bladder function (53.0 mls/min/1.73 m^2) being significantly lower than that of those with normal bladder function (63.9 mls/min/1.73 m^2) ($p = 0.0048$ Wilcoxon signed rank test).

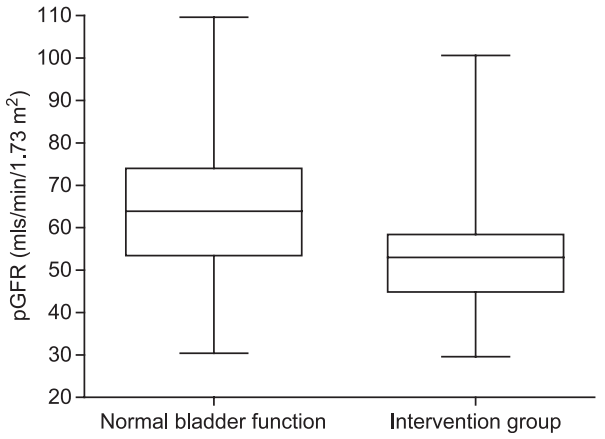

Figure 18.25: Predicted GFR in transplanted patients with obstructive uropathy according to bladder type

These data confirm that bladder function is an important determinant of graft function and hence graft longevity. More longitudinal studies are required to determine which aspects of bladder dysfunction and intervention are related to poor outcome.

Conclusions

Demography

- The demographics of the paediatric ERF population are unchanged.
- The growth of the paediatric ERF population has not plateaued but continues to increase.
- There remains a high incidence and prevalence of ERF in South Asian children.
- This is in part accounted for by an increased incidence of genetic diseases in this group.

- These patients are more likely to be on haemodialysis and less likely to have a functioning allograft than White patients.
- A greater proportion of the paediatric population are on dialysis than in previous years.
- There is a linear relationship between the proportion of living related transplants being performed and the proportion of the population who are transplanted – confirming the shortage of cadaveric allografts.

Co-morbidity

- 21.6% of children have one or more paediatric specific co-morbidity at presentation with ERF.
- The most common of these is developmental delay affecting 8.7%.
- Co-morbidity is significantly more common in those presenting below the age of 8 years and in those commencing dialysis in paediatric units over the age of 16 years.
- On cross-sectional analysis, intellectual disability affects 17% of the paediatric ERF population with 7% having moderate or severe impairment.
- Overall, the presence of disability does not seem to influence patient management (with regard to progression to transplantation).

Patients on prolonged dialysis

- 27.9% of paediatric dialysis patients have been on dialysis for 2 or more consecutive years.
- 7% have had 5 or more consecutive years of dialysis.
- 37.2% of those patients on dialysis for two or more consecutive years are from ethnic minority groups.
- Haemodialysis is the most common modality of treatment in this population.

Transplantation into the abnormal bladder

- Overall, allograft function is no different between patients who have had obstructive uropathy as a cause of renal failure compared to those who had renal dysplasia.
- Compared to those with a functionally normal bladder, allograft function is significantly worse in those who have a significant functional bladder abnormality requiring intermittent catheterisation, bladder augmentation or urinary diversion.

Acknowledgements

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This report was reviewed, revised and approved by the Paediatric Renal Registry subcommittee comprising:

Dr Kate Verrier-Jones
Dr Chris Reid
Dr Jonathon Evans
Dr Nicholas Webb
Dr Rodney Gilbert
Dr Malcolm Lewis

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Appendix A: The Renal Registry Rationale

1. Executive summary
2. Introduction
3. Statement of intent
4. Relationships of the Renal Registry
5. The role of the Renal Registry for patients
6. The role of the Renal Registry for nephrologists
7. The role of the Renal Registry for Trust managers
8. The role of the Renal Registry for commissioning agencies
9. The role of the Renal Registry national quality assurance schemes
10. References and websites

A:1 Executive summary

1.1 The Renal Registry was established by the Renal Association to act as a resource in the development of patient care in renal disease.

1.2 The Registry acts as a source of comparative data for audit/benchmarking, planning, policy and research. The collection and analysis of sequential biochemical and haematological data is a unique feature of the Registry.

1.3 Agreements have been made with participating renal centres, which ensure a formal relationship with the Registry and safeguard confidentiality.

1.4 The essence of the agreement is the acceptance of the Renal Registry Data Set Specification (RRDSS) as the basis of data transfer and retention.

1.5 Data is collected quarterly to maintain unit-level quality assurance, with the results being published in an annual report.

1.6 Activity is funded from commissioning agencies by a capitation fee on renal patients.

1.7 The Registry is responsible, with the express agreement of participants, for providing data to Trusts, Primary Care Trusts (PCTs), commissioning authorities and the European Renal Association – European Dialysis and Transplant Association (ERA–EDTA) Registry.

1.8 The development of the Registry is open to influence from all interested parties, including clinicians, Trusts, commissioning authorities and patient groups.

1.9 The Registry is non-profit making and has a registered charitable status through the Renal Association.

A:2 Introduction

2.1 Registry-based national specialty comparative audit is one of the cornerstones of NHS development. The Renal *National Service Framework* (NSF), published in two sections in 2004 and 2005, recommended the participation of all renal units in comparative audit through the Renal Registry, with co-temporaneous documents defining the necessary information strategies[1,2,3,4].

2.2 The shape of future national audit will be set not only by conventional medical criteria, but also by NSF recommendations, prompted through the Healthcare Commission. The necessary detail is currently the subject of a formal scoping project, in which the Registry is represented. The final relationship of the Registry to the Healthcare Commission has yet to be defined.

2.3 The Chief Executives of Trusts are responsible for clinical governance, and audit will be an essential part of that agenda[5].

2.4 Demographic information on patients receiving renal replacement therapy (RRT) throughout Europe was collected from 1965 in the Registry of the ERA–EDTA. This voluntary exercise was conducted on paper and by post, demanded considerable effort and time from participating units and eventually proved impossible to sustain. Latterly, the incompleteness of UK data returns to the ERA–EDTA made it impossible to build a picture of the activity of RRT in the UK for planning and policy purposes. Subsequently, five ad hoc national data collections from England & Wales were solicited from renal centres in 1992, 1996, 1999, 2002 and 2004 to fill this gap. The Registry is well placed to put such surveys on a permanent and regular footing, and extend their remit, to chronic kidney disease (CKD), for example.

2.5 Together with the need to know the demographic and structural elements, the NHS has developed a need to underpin clinical activity more rigorously through the scientific evidence base (for example, the Cochrane Initiative) and by quality assurance activity through audit. These initiatives require comprehensive information about the structures, processes and outcomes of RRT, which go well beyond the detail previously compiled by the ERA–EDTA.

2.6 The Registry is recognised as one of the very few high-quality clinical databases available for general use[6]. The collection of data by download of electronic records from routine clinical databases is uncommon, has been highly successful, and is being imitated worldwide.

2.7 The Renal Association has made a start in the area of audit by publishing guidelines in 'Renal Standards' documents. It was apparent during the development of the Standards that many of the desirable criteria of clinical performance were uncertain or unknown, and that only the accumulated data of practising renal units could provide the evidence for advice on best practice and what might be achievable. A common data registration provides the simplest device for such an exercise.

2.8 The continuing emphasis on evidence-based practice is being supported by changes in research funding (Culyer Report and recent national statements), which lean towards collaborative projects and include both basic science and 'health services research' components. It is apparent that an RRT database is invaluable to a wide range of research studies.

2.9 It can be seen that the need for a Registry of RRT has developed for a variety of reasons: international comparisons, national planning, local Trust, PCT and health authority management, standard setting, audit and research. The opportunity for data gathering arises partly from improvements in information technology. Although it was possible to see the need for a national renal database 20 years ago, the circumstances have become ideal for the maintenance of a data repository, supported by the clinical users and resourced for national benchmarking as a routine part of RRT management.

2.10 The provisional expectations of earlier Annual Reports can now be replaced by confident assertions, built on the experience of seven years of publication, about the role and potential of the Registry. The integration of the various elements of Renal Association strategy is being pursued through the recently established Clinical Affairs Board (CAB).

A:3 Statement of intent

The Renal Registry provides a focus for the collection and analysis of standardised data relating to the incidence, clinical management and outcome of renal disease. Data will be accepted quarterly according to the RRDSS by automatic downloading from renal centre databases. There will be a core dataset, with optional elements of special interest that may be entered by agreement for defined periods. A report will be published annually to allow a comparative audit of facilities, patient demographics, quality of care and outcome measures. Participation is mandated through the recommendation in the Renal National Service Framework. There will be an early concentration on RRT, including transplantation, with an extension to other nephrological activity at a later date. The Registry will provide an independent source of data and analysis on national activity in renal disease.

A:4 Relationships of the Renal Registry

4.1 The Registry is a registered charity through the Renal Association (No. 2229663). It was established by a committee of the Renal Association, with additional representation from the British Transplantation Society, the British Association for Paediatric Nephrology, the Scottish Renal Registry, Wales and Northern Ireland. There is cross-representation with both the Renal Association Standards and Clinical Trials Committees and the Clinical Affairs Board. The Registry has a Chairman and Honorary Secretary nominated by the Renal Association. The Registry has an observer from the Department of Health and a participant from the National Kidney Federation (NKF) (patients' association). It has not been possible in the past to co-opt a member to represent the Health Care Commissioners.

4.2 A number of sub-committees have been instituted as the database and renal unit participation developed, particularly for data analysis and interpretation for the Annual Report. Further specialised panels may be developed for publications and the dissemination of Registry analyses.

4.3 The Scottish Renal Registry sends data to the Renal Registry for joint reporting and comparison.

4.4 The return of English, Welsh and Northern Ireland data to the ERA Registry will be through the Renal Registry. The Scottish Renal Registry already sends data directly to the ERA Registry.

4.5 A paediatric database has been developed in collaboration with the Renal Registry, and the two databases are compatible. These two databases are in the process of being integrated, which will allow long-term studies of renal cohorts over a wide range of age.

4.6 Close collaboration has been achieved with UK Transplant, to the benefit of both organisations. Data aggregation and integration has led to joint presentations and publication. The description of the entire patient journey in RRT by this means is a source of continuing insight and usefulness.

4.7 The basis of participation for renal units nationally is an agreement to accept the RRDSS for the transmission and retention of data. This consists of a core dataset of some 200 items and further optional elements, which will be returned on a special understanding with the unit for a defined period of reporting. The dataset is a considerable part of a National Renal Dataset (England) being developed currently by a project team, which includes Registry representation.

4.8 The Registry is part of the team undertaking an investigation into the necessary scope of national audit for the Healthcare Commission, in the light of the NSF.

4.9 The retention of patient identifiable information, necessary in particular for the adequate tracing of patients, has been approved by the Patient Information Advisory Group (PIAG), under Section 60 of the Health and Social Care Act. This is pending the introduction of mechanisms that will preserve patient anonymity through encryption of a unique patient identifier.

4.10 The Registry has collaborated with the NKF to produce a leaflet for patients explaining how they may, if they wish, have their records anonymised in the data collection exercise.

4.11 It is anticipated that the Registry will receive data from the secondary users service (SUS) of the national IT programme, Connecting for Health, when it is fully instituted. The detail of data routing from renal unit clinical systems to the national database has yet to be established.

A:5 The role of the Renal Registry for patients

5.1 The goal of the Registry is to improve care for patients with renal disease. The appropriate use of Registry information should improve equity of access to care, adequacy of facilities, availability of important but high-cost therapies such as erythrocyte stimulating agents, and the efficient use of resources. The continuing comparative audit of the quality of care should facilitate the improvement of care and outcomes of care. It is intended to identify

and publish examples of good practice. In such ways, patients will be the ultimate beneficiaries of the exercise.

5.2 A leaflet has been provided, in collaboration with the NKF, by which patients may opt out of the collection of identifiable data by the Registry, if they wish.

5.3 Information from the Registry will complement the individual records available on 'RenalPatientView' where it is accessible.

A:6 The role of the Renal Registry for nephrologists

6.1 The clinical community have become increasingly aware of the need to define and understand their activities, particularly in relation to national standards and in comparison with other renal units.

6.2 The Registry is run by a committee of the Renal Association and therefore by colleagues with similar concerns and experience.

6.3 The Renal standards documents are designed to give a basis for unit structure and performance, as well as patient-based elements such as case mix and outcomes. It is anticipated that Standards will become increasingly based on research evidence and the Cochrane Collaboration has recently resourced reviews of renal topics, which will support this conversion.

6.4 The Registry data are available to allow the comparative review of many elements of renal unit practice. Centre data are presented to allow a contrast of individual unit activity and results against national aggregated data. Sophisticated analyses of patient survival, for example, are a unique resource to exclude any anomalies of performance and standardise for unit caseload etc.

6.5 Reports of demographic and treatment variables are available to the participating centres for distribution to Trusts, PCTs, Strategic Health Authorities and Commissioners, as well as renal networks, as required and agreed with the unit. Reports should facilitate discussion between clinicians, Trust officers and commissioners.

6.6 Customised data reports can be made available by agreement with the Registry Committee. A donation to cover any costs incurred may be requested.

6.7 The Registry is developing the publication of focused and extended synopses of chapters from the Annual Report. These 'dips' will facilitate the appreciation and application of comparative data and will allow wider distribution.

6.8 The Registry Committee welcome suggestions for topics of national audit or research that colleagues feel are of sufficiently widespread interest for the Registry to undertake.

6.9 The database has been designed to provide research facilities for future participation in national and international trials. Members of the Renal Association and other interested parties are welcome to apply to the Registry committee to conduct local or national audit and research using the database. All such projects will need the agreement of the Registry Committee, and any costs involved will need to be met by the applicants.

6.10 These facilities will be sustainable only through co-operation between nephrologists and the Registry. There is a need for high-quality and comprehensive data entry at source.

6.11 The sustaining of data collection, organisation and transmission from peripheral sites is not centrally resourced. The lack of clear status for many informatics staff at renal unit level, the imminent inroads of the national IT programme Connecting for Health, and the potential disruptions of Agenda for Change will be balanced by the development of formal informatics organisations (The UK Council for Health Informatics Professions (UK CHIP[7]), NHS Faculty of Health Informatics[8]and the Association of ICT Professionals in Health and Social Care (ASSIST[9]).

6.12 Units will need to develop an 'annual informatics plan', to review the maintenance and improvement of data collection organisation

and return to the Registry. This will help maintain the accuracy, timeliness and completeness of clinical data and also in parallel, support the career development of informatics staff.

A:7 The role of the Renal Registry for Trust managers

7.1 As the basis of the clinical governance initiative, the gathering and presentation of clinical data are regarded as essential parts of routine patient management in the health service.

7.2 One of the principles of health service informatics is that the best data are acquired from clinical information recorded at the point of health care delivery.

7.3 Renal services data entered on local systems by staff directly engaged with patients are likely to be of the highest quality and it is these that the Registry intends to capture.

7.4 The Registry provides a cost-effective source of detailed information on renal services.

7.5 The regular reports of the Registry supply details of patient demographics, treatment numbers, treatment quality and outcomes. Data are compared with both national standards and national performance, for benchmarking and quality assurance. The assessment of contract activity and service delivery is possible through these data returns, without the need for further costly Trust or commissioner administrative activity. These data should be particularly valuable to contracts managers and those responsible for clinical governance.

7.6 Data are available on unit case mix, infrastructure and facilities.

7.7 It is anticipated that data on patients with renal disease other than those requiring RRT will become available in time (CKD).

7.8 It is anticipated that Trust interests may be served through the participation of a national Trust representative on the Registry Committee.

A:8 The role of the Renal Registry for commissioners of health care

8.1 The commissioners of health care include Regional Specialty Commissioning Groups, the networks or joint renal strategy groups supporting them, and the Primary Care Trusts.

8.2 The use of information sources such as the Registry is advised in the National Renal Review[6] in order to promote benchmarking and quality assurance of renal programmes. The comprehensive tracking of relatively small but costly renal cohorts should be regarded as a routine part of speciality case management.

8.3 The Registry provides validated, comparative reports of renal unit activity on a regular basis to participating centres. These allow assessment of unit performance in a wide range of variables relating to structure, process and outcome measures.

8.4 There are economies of scale in the performance of audit through the Registry, since multiple local audits are not required.

8.5 The incidence of RRT treated locally, their mortality and also renal transplant rates should also be of interest. The assessment of referral and treatment patterns of patients with established renal failure by postcode analysis indicates the geographical origin. This information also allows the expression of differences relating to geography, ethnicity and social deprivation. These data may also identify potential unmet need in the population and permit assessment on the equity of service provision. In the future, the Registry database should also provide information on nephrology and pre-dialysis patients (CKD). This will allow a prediction of the need for RRT facilities, as well as indicating the opportunities for beneficial intervention.

8.6 Registry data are used to track patient acceptance and prevalence rates over time, which allows the modelling of future demand and the validation of these predictions.

8.7 Information on the clinical diagnosis of new and existing RRT patients may help identify areas where possible preventive measures may have maximal effect.

8.8 The higher acceptance rates in the elderly, and the increasing demand from ethnic groups due to a high prevalence of renal, circulatory and diabetic disease, are measurable.

8.9 Comparative data are available in all categories for national and regional benchmarking.

8.10 The Registry offers independent expertise in the analysis of renal services data and their interpretation, a resource that is widely required but difficult to otherwise obtain.

8.11 The current cost of supporting the Registry is £15 per registered patient per annum, which is less than 0.05% of the typical cost of a dialysis patient per annum. It is expected that this cost will need to be made explicit within the renal services contract.

8.12 The Registry Committee would like to accept a representative from health care commissioners. This would allow an influence on the development of the Registry and the topics of interest in data collection and analysis.

A:9 The role of the Renal Registry for national quality assurance agencies

9.1 The role of the Registry in the national quality assurance programme of the Healthcare Commission, will depend on the decisions on the role and responsibilities of that agency and their means to discharging them.

9.2 The demographic, diagnostic and outcomes data could support the investigation of clinical effectiveness.

9.3 There is pressure to publish reports in which survival data from renal units are clearly identified. The case mix information and co-morbidity data that would allow better assessment of survival statistics remains incomplete. There is also some clinical scepticism whether 'correction' of outcome data would reflect the realities of clinical practice. Current analyses of survival data show all renal units as within a normal distribution of outcomes, with no relation to take-on rates. All other 'non-survival' data are identified and reported by renal unit name.

9.4 Consideration of this issue in particular would be welcome in nephrological circles, with correspondence to the Registry Committee.

A:10 References

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Appendix B: Definitions, Statistical Methodology, Analysis Criteria

B:1 Definitions of analysis quarters

Quarter	Dates
Quarter 1	1 January–31 March
Quarter 2	1 April–30 June
Quarter 3	1 July–30 September
Quarter 4	1 October–31 December

The quarterly biochemistry data are extracted from renal unit systems as the last data item stored for that quarter. If the patient treatment modality is haemodialysis, the software will try to select a pre-dialysis value.

B:2 Renal Registry modality definitions

Home haemodialysis

Home haemodialysis patients cease to be classed as such if they need longer than 2 weeks of hospital dialysis when not an inpatient.

Satellite dialysis unit

A renal satellite unit is defined as a haemodialysis facility that is linked to a main renal unit and not autonomous for medical decisions, and that provides chronic outpatient maintenance haemodialysis but with no acute or inpatient nephrology beds on site.

Treatment modality at 90 days

This is used by the United States Renal Data System (USRDS) and is the modality that the patient is on at day 90 regardless of any changes from the start. It is a general indicator of initial dialysis but could miss failed CAPD. This would also miss patients intended for home haemodialysis who were not home yet. This modality is calculated by the Registry, which allows the definition to be changed.

Start of established renal failure

Established renal failure (also known as end-stage renal failure/end-stage renal disease) is defined as the date of the first dialysis (or of pre-emptive transplant).

If a patient is started as 'acute' renal failure and does not recover, the date of start of renal replacement should be backdated to the start of acute dialysis.

If a patient is started on dialysis and dialysis is temporarily stopped for less than 90 days for any reason (including access failure and awaiting the formation of further access) except the recovery of renal function, the date of start of renal replacement therapy (RRT) remains the date of first dialysis. If the patient has stopped for longer than 90 days, he or she is classed as 'recovered'.

Change of modality from PD to HD

Sites are requested to log in their timeline changes from PD to HD if the modality switch is for longer than 30 days.

Analyses that include PD technique survival, patients on peritoneal dialysis who changed to haemodialysis for less than 31 days before changing back to PD were classified as remaining on PD. Those remaining on haemodialysis for more than 30 days and then changing back to PD were classified as having changed to haemodialysis.

B:3 Analysis criteria

Definition of the take-on population (Incidence)

The take-on population in a year included patients who later recovered from ERF after 90 days from the start of treatment. Patients newly transferred into a centre who were already on RRT were **excluded** from the take-on population for that centre. Patients restarting dialysis after a failed

transplant were also excluded (unless they started RRT in that current year).

Since patients who restarted RRT after recovering from ERF are included in the take-on population, the following scenario can occur: a patient may start RRT in 2004, recover and then restart RRT in 2004. Such patients are counted twice in the analysis providing they have been receiving RRT for more than 90 days on each occasion.

Patients who started treatment at a centre and then transferred out soon after receiving treatment are counted at the original centre for all analyses of treatment on the 90th day.

Definition of the prevalent population

This is calculated as all patients who are alive on 31 December and includes the incident cohort for that year alive on that date.

Confidence Interval

The 95% confidence intervals have been calculated using the normal approximation of the Poisson.

Death rate calculation

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 3 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.

Odds ratio

The odds of dying is the:

$$\frac{\text{(Probability of dying for someone with a phosphate of 1.71}-\text{2.10 mmol/L)}}{\text{(Probability of surviving for someone with a phosphate of 1.71}-\text{2.10 mmol/L)}}$$

The odds ratio is the:

$$\frac{\text{(Odds of dying with a phosphate of 1.71}-\text{2.10 mmol/L)}}{\text{(Odds of dying in the reference group)}}$$

Hazard function

The hazard function is the probability of dying in a short time interval considering survival to that interval.

Hazard ratio

$$\frac{\text{(Probability of dying in the next interval for a phosphate of 1.71}-\text{2.10 mmol/L)}}{\text{(Probability of dying in the next interval for a phosphate in the reference range)}}$$

Relative Hazard

Following the notation of Collett, D (2003): Modelling survival data in medical research, Chapman & Hall, p 57:

$$h_i(t) = \exp(\beta x_i) \,.\, h_0(t)$$

The relative hazard is the $\exp(\beta x_i)$ component in the general proportional hazards model with age, the variable of interest and it's square as covariates. The plots were done for $\exp(\beta x_i)$ for different values of the variable of interest only, in other words, age was taken as a constant value of zero.

Z-Scores

The enquiry into the excess of paediatric cardiac deaths at the Bristol Royal Infirmary defined an outlier as lying beyond 3 standard deviations from the mean, using the statistical methodology of Shewhart's control theory. This analysis relies on the centre sizes, and hence their standard deviation, being very similar. Renal units in the UK vary greatly in size, catchment populations varying from 300,000 to over 2 million. There is a consequent variation in the total patient number on RRT so the figure for the standard deviation will vary greatly between centres. The standard deviation for the total RRT population is not an appropriate number as this will be very small. Therefore, the Shewhart methodology cannot be applied. The Registry has used the accepted statistical technique of Z-scores to identify any outliers.

Definition

Z-scores are sometimes called "standard scores". It is a measure of the distance in standard deviations of a sample from the mean.

The Z-score transformation is especially useful when seeking to compare the relative standings of items from distributions with different means and/or different standard deviations. The Z-score for an item indicates how far and in what direction, that item deviates from its distribution's mean, expressed in units of its distribution's standard deviation.

Mathematically:

the survival Z-score

$$= \frac{\text{Survival for centre X} - \text{survival for all centres}}{\text{Standard error for centre X}}$$

The Z-score is therefore an adjustment for the size of the centre and when comparing the different Z-scores for all the centres, they should be normally distributed. The observed Z value compared with the expected Z value (see explanation below) should be on a straight line.

Calculation of the expected Z value

Suppose there is a normally distributed population from which we repeatedly draw random samples of some specific size, say 10. These 10 values from each such random sample are sorted into increasing order, smallest value to largest value. When the sample data is sorted in this way, the individual numbers are called **order statistics**. The smallest value will vary somewhat from one such sample to another, but over the long run, the smallest values should tend to cluster around some average smallest value and produce a **mean** or **expected values of the order statistics**. These data have been compiled into tables so that for every specific total number of ordered samples (eg 38 centres with Registry survival data) there is an expected Z value for each ordered centre in that list.

Survival analyses of prevalent cohort

These analyses exclude the current year's incident cohort. Note some Renal Registries include these patients in the prevalent survival.

Criteria for analysis by treatment modality in a quarter

The following quarterly entries were included and excluded:

- Patients on haemodialysis with a treatment centre of 'elsewhere' were **removed**. It should be noted that there were some patients on transplant with a treatment centre of 'elsewhere'; these patients were **included.**

- Entries for which the hospital centre was not the primary treatment centre were removed from the analysis of data for that centre.

- Patients who had been on RRT for less than 90 days were removed (by definition of ERF).

There were, however, a few exceptions to these rules:

1. If a patient's initial entry on the treatment timeline contained a **'transferred in'** code, the patient was assumed to have been on RRT for longer than 90 days since the patient must have started RRT earlier than this elsewhere. Therefore, patients with an initial entry on the treatment timeline with a **'transferred in'** code were included for all quarters. A patient with an initial treatment modality of **'transferred in'** on 1 March 2004 would, for example, be included for the quarter 1 2004 even though the number of days on RRT would be calculated as 30 days.

2. For patients who **recovered** renal function for a period of time and then went into ERF, the length of time on RRT was calculated from the day on which the patient restarted RRT. For a patient with an initial treatment start date of 1 March 2004 who recovered on the 1 June 2004 and then resumed RRT again on 1 November 2004, for example, the number of days on RRT would be calculated from 1 November 2004. The patient would be excluded from the analysis for quarter 4/04 since on 31 December 2004, he or she would have been on RRT for less than 90 days. The patient would be included in the analysis from quarter 1/05 onwards.

If recovery was for less than 90 days, the start of renal replacement therapy will be calculated from the date of the first episode and the recovery period will be ignored.

Patients who had **transferred out** or **stopped treatment without recovery of function** before the end of the quarter were excluded.

Criteria for analysis of biochemistry in a quarter

The analysis used information from the quarterly treatment table. In addition to the treatment modality criteria listed above, patients with the following quarterly entries were also excluded:

1. Patients who had **'transferred in'** to the centre in that particular quarter were excluded. If, for example, a patient transferred in on 1 March 2004, the patient was excluded from that biochemistry analysis of the centre transferred to in that quarter.

2. Patients who had changed treatment modality in that particular quarter were excluded.

Treatment modality on day 90 of starting RRT

This is obtained from the treatment modality of the take-on population after 90 days of being on RRT. For this reason, patients who started treatment between 1 October 2003 and 31 September 2004 were used in this analysis.

The sample used was that defined by the take-on population.

Patients were counted at their take-on hospital centre rather than at their hospital centre on day 90. This is important as some patients had transferred out of their initial hospital centre by day 90.

Patients who died before they reached 90 days were excluded.

One-year survival of the take-on population

The sample used was the same as that defined for the take-on population except for recovered renal function patients, who were excluded.

Patients who transferred out of their initial treatment centre were censored on the day they transferred out if there was no further information in the timeline.

Analysis of 1 year survival of prevalent patients

The death rate within the year was calculated separately for the patients established on dialysis and with a functioning transplant on 1 January 2004. As there is an increased death rate in the first 3 months following transplantation, patients were included in the analysis only if they had not received a transplant between 1 October 2003 and 31 December 2003. The sample criteria thus became:

1. Patients who had been receiving RRT for more than 90 days on 1 January 2004.

2. Patients who had a transplant between 1 October 2003 and 31 December 2003 were excluded.

3. Patients who transferred into a Registry centre were excluded if information was not available to confirm that they had not received a transplant between 1 October 2003 and 31 December 2003.

4. The few patients who recovered renal function in 2004 were excluded.

5. Patients who transferred out of a Registry centre to a non-Registry centre were censored at that date.

6. A transplant patient whose transplant failed was censored at the time of restarting dialysis, and dialysis patients who received a transplant were censored at the time of transplantation.

7. Patients who died, received a transplant, or transferred out on 1 January 2004 were included and were counted as being at risk for 1 day.

8. Patients who died on the day of the transplant were censored on this day rather than counted as a dialysis death.

Appendix C: Renal Services Described for Non-physicians

(Reproduced from the third edition of the Renal Association Standards document, August 2002.)

This appendix provides information on the issues discussed in this Report, background information on renal failure and discusses the services available for its treatment.

Renal Diseases

1.1 Diseases of the kidney are not as common as cardiovascular conditions or cancers but are much more common than some well known disorders such as multiple sclerosis or muscular dystrophy. Renal conditions account for about 7,000 deaths per annum according to the Registrar General's figures, but these are probably an underestimate since about one third of deaths of patients with renal failure are not recorded as such in mortality statistics. These figures exclude deaths from cancers of the kidney and associated organs of the urinary tract such as bladder and prostate.

1.2 Over 100 different diseases affect the kidneys. These diseases may present early with features such as pain, the presence of blood or protein in the urine, or peripheral oedema (swelling of the legs), but much renal disease is self-limiting; it occurs and heals with few or no symptoms or sequelae. On the other hand, some kidney diseases start insidiously and progress but are undetected until renal failure develops.

Acute Renal Failure

1.3 Renal failure may be acute and reversible. It occurs in previously normal kidneys when their blood supply is compromised by a fall in blood pressure caused by crush injuries, major surgery, failure of the heart's pumping action, loss of blood, salt or water, or when they are damaged by poisons or overwhelming infection. Renal support is then needed for a few days or weeks before renal function returns. However, about half such patients die during these illnesses because of another condition, often the one which caused the renal failure.

Chronic Renal Failure (CRF) and Established Renal Failure (ERF)

1.4 More common is irreversible chronic renal failure, in which the kidneys are slowly destroyed over months or years. To begin with there is little to see or find, and this means that many patients present for medical help very late in their disease, or even in the terminal stages. Tiredness, anaemia, a feeling of being 'run down' are often the only symptoms. However, if high blood pressure develops, as often happens when the kidneys fail, or is the prime cause of the kidney disease, it may cause headache, breathlessness and perhaps angina. Ankle swelling may occur if there is a considerable loss of protein in the urine.

1.5 Progressive loss of kidney function is also called chronic renal failure. Early chronic renal failure is sometimes referred to as chronic renal impairment or insufficiency, and established renal failure when it reaches its terminal stage. At this point, if nothing is done the patient will die. Two complementary forms of treatment – dialysis and renal transplantation – are available and both are needed if established renal failure is to be treated.

1.6 The incidence of chronic renal disease and established renal failure rises steeply with advancing age. Consequently, an increasing proportion of patients treated for established renal failure in this country are elderly and the proportion is even higher in some other developed countries. Evidence from the United States suggests that the relative risk of established renal failure in the African–Caribbean population is 2 to 4 times higher than for Whites. Data collected during the review of renal specialist services in London suggest that there is in the Thames regions a similar greater risk of renal failure in certain ethnic populations (Asian and African–Caribbean)

than in Whites, this is supported by national mortality statistics. People from the Indian subcontinent have a higher prevalence of non-insulin dependent diabetes, and those with diabetes are more likely than Whites to develop renal failure. This partly explains the higher acceptance rate of Asians onto renal replacement programmes.

Causes of Renal Failure

1.7 Most renal diseases that cause renal failure fall into six categories.

1. Systematic disease. Although many generalised diseases such as systematic lupus, vasculitis, amyloidosis and myelomatosis can cause kidney failure, by far the most important cause is diabetes mellitus (about 20% of all renal disease in many countries). Progressive kidney damage may begin after some years of diabetes, particularly if the blood sugar and high blood pressure have been poorly controlled. Careful lifelong supervision of diabetes has a major impact in preventing kidney damage.

2. Autoimmune disease. 'Glomerulonephritis' or 'nephritis' describes a group of diseases in which the glomeruli (the filters that start the process of urine formation) are damaged by the body's immunological response to tissue changes or infections elsewhere. Together, all forms of nephritis account for about 30% of renal failure in Britain. The most severe forms are therefore treated with medications that suppress response, but treatment makes only a small impact on the progress of this group of patients to established renal failure.

3. High blood pressure. Severe ('accelerated') hypertension damages the kidneys, but the damage can be halted – and to some extent reversed – by early detection and early treatment of high blood pressure. This is a common cause of renal failure in patients of African origin.

4. Obstruction. Anything that obstructs the free flow of urine can cause backpressure on the kidneys. Much the commonest cause is enlargement of the prostate in elderly men.

5. Infection of the urine. Cystitis is a very common condition, affecting about half of all women at some time in their lives, but it rarely has serious consequences. However, infections of the urine in young children or patients with obstruction, kidney stones or other abnormalities of the urinary tract may result in scarring of the kidney and eventual kidney failure.

6. Genetic disease. One common disease, polycystic kidneys, and many rare inherited diseases, which affect the kidneys, account for about 8% of all kidney failure in Britain. Although present at birth, polycystic kidney disease often causes no symptoms until middle age or later. Understanding of its genetic basis is rapidly advancing and may lead to the development of effective treatment.

Prevention

1.8 Although many diseases causing chronic renal failure cannot be prevented or arrested at present, better control of diabetes and high blood pressure and relief of obstruction have much to offer, provided they are employed early in the course of the disease before much renal damage has occurred. It has also been shown that a group of antihypertensives called angiotensin converting enzyme inhibitors (ACEI) delay the progression of renal failure. Screening for renal disease has not been widely practised because the relatively low incidence of cases renders population screening inefficient and costly. Urine tests for protein or blood, or blood tests for the level of some substances normally excreted by the kidney such as creatinine and urea, are potentially useful methods for screening if populations at risk of renal failure can be identified, eg diabetics and the elderly.

Complications and Co-morbidity

1.9 Renal failure is often accompanied by other disease processes. Some are due to the primary disease, eg diabetes may cause blindness and diseases of the nerves and blood vessels. Others, such as anaemia, bone disease and heart failure, are consequences of the renal failure. Coincidental disease such as chronic bronchitis and arthritis are particularly common in older patients with renal failure. In addition, many patients with established renal failure have diseases affecting the heart and blood vessels (vascular) particularly ischaemic heart disease and peripheral vascular disease. All these conditions, collectively called co-morbidity, can influence the choice of treatment for renal failure and may reduce its benefits. Expert assessment of the patient before established renal failure can reduce co-morbidity and increase the benefit and cost effectiveness of treatment. Thus early detection and referral of patients at risk of renal failure is important.

Renal Replacement Therapy

1.10 The term renal replacement therapy (RRT) is used to describe treatments for established renal failure in which, in the absence of kidney function, the removal of waste products from the body is achieved by dialysis and other kidney functions are supplemented by drugs. The term also covers the complete replacement of all kidney functions by transplantation.

Therapeutic Dialysis ('renal dialysis')

1.11 Dialysis involves the removal of waste products from the blood by allowing these products to diffuse across a thin membrane into dialysis fluid which is then discarded along with the toxic waste products. The fluid is chemically composed to draw or 'attract' excess salts and water from the blood to cross the membrane, without the blood itself being in contact with the fluid.

Haemodialysis

1.12 The method first used to achieve dialysis was the artificial kidney, or haemodialysis. This involves the attachment of the patient's circulation to a machine through which fluid is passed and exchange can take place. A disadvantage of this method is that some form of permanent access to the circulation must be produced to be used at every treatment. Each session lasts 4 to 5 hours and is needed three times a week.

Peritoneal Dialysis

1.13 The alternative is peritoneal dialysis, often carried out in the form of continuous ambulatory peritoneal dialysis (CAPD). In this technique, fluid is introduced into the peritoneal cavity (which lies around the bowel) for approximately 6 hours before withdrawal. The washing fluid must be sterile in order to avoid peritonitis (infection and inflammation of the peritoneum), which is the main complication of the treatment. A silastic tube must be implanted into the peritoneum and this may give problems such as kinking and malposition. Each fluid exchange lasts 30 to 40 minutes and is repeated three or four times daily. Neither form of dialysis corrects the loss of the hormones secreted by the normal kidney so replacement with synthetic erythropoietin and vitamin D is often necessary.

Renal Transplantation

1.14 Renal transplantation replaces all the kidneys functions, so erythropoietin and vitamin D supplementation are unnecessary. A single kidney is placed, usually in the pelvis close to the bladder to which the ureter is connected. The kidney is attached to a nearby artery and vein. The immediate problem is the body's acute rejection of the foreign graft, which is largely overcome during the first months using drugs such as steroids and cyclosporin. These drugs, and others that can be used for that purpose, have many undesirable side effects, including the acceleration of vascular disease. This often means that myocardial

infarcts and strokes are commoner in transplant patients than in age-matched controls. During subsequent years there is a steady loss of transplanted kidneys owing to a process of chronic rejection; treatment of this is quite unsatisfactory at the moment, so many patients require a second or even a third graft over several decades, with further periods of dialysis in between.

1.15 The main problem with expanding the transplantation service is the shortage of suitable kidneys to transplant. Although the situation can be improved, it is now clear that whatever social and medical structures are present and whatever legislation is adopted, there will inevitably be a shortage of kidneys from humans. This remains the case even if kidneys from the newly dead (cadaver kidneys) are retrieved with the maximum efficiency, and living donors (usually, but not always from close blood relatives of the recipient) are used wherever appropriate. Hope for the future rests with solving the problems of xenotransplantation (which involves using animal kidneys), probably from pigs, although baboons have also been suggested and are closer to humans. Many problems remain unsolved and it is thought highly unlikely that xenotransplantation will become a reliable treatment for established renal failure within the next 10 years.

Nature of Renal Services

1.16 The work of a nephrologist includes the early detection and diagnosis of renal disease and the long-term management of its complications such as high blood pressure, anaemia and bone disease. The nephrologist may share the management with the general practitioner or local hospital physician, and relies on them to refer patients early for initial diagnosis and specific treatment. At any one time perhaps only 5% of patients under care are inpatients in wards, the remainder being treated in their homes with 20% of these attending the renal unit regularly for haemodialysis. However, inpatient nephrology and the care of patients receiving centre-based dialysis are specialised, complex and require experienced medical advice to be available on a 24 hour basis. This implies sufficient staff to provide expert cover; cross-covering by inexperienced staff is inappropriate and to be condemned. The other 95% of renal work is sustained on an outpatient basis; this includes renal replacement therapy by dialysis and the care of transplant patients.

1.17 There are five major components to renal medicine.

1. Renal replacement therapy. The most significant element of work relates to the preparation of patients in established renal failure for RRT and their medical supervision for the remainder of their lives. The patient population will present increasing challenges for renal staffing as more elderly and diabetic patients are accepted for treatment.

2. Emergency work. The emergency work associated with the speciality consists of:

   i. Treatment of acute renal failure, often involving multiple organ failure and acute-on-chronic renal failure. Close cooperation with other medical specialties, including intensive care, is therefore a vital component of this aspect of the service.

   ii. Management of medical emergencies arising from an established renal failure programme. This workload is bound to expand rapidly as the number, age and co-morbidity of patients starting renal replacement therapy increases, and this may interrupt the regular care of patients already on renal replacement therapy, so increased resources may be required.

3. Routine nephrology. A substantial workload is associated with the immunological and metabolic nature of renal disease which requires investigative procedures in an inpatient setting. It is estimated that 10 inpatient beds per million of the population are required for this work.

4. Investigation and management of fluid and electrolyte disorders. This makes up a variable proportion of the nephrologists

work, depending on the other expertise available in the hospital.

5. Outpatient work. The outpatient work in renal medicine consists of the majority of general nephrology together with clinics attended by dialysis and renal transplant patients.

Further Reading

Further details of renal services for renal failure, written for non-physicians, can be found in:

Cameron JS. *Kidney Failure – the Facts*. London: Oxford University Press, 1996.

Appendix D: Methodology of Standardised Acceptance Rates Calculation and Administrative Area Geography and Registry Population Groups in England & Wales

Chapter 3, on the incidence of new patients, includes an analysis of standardised acceptance rates in England & Wales for areas covered by the Registry. The methodology is described below. This methodology is also used in Chapter 4 for analysis of prevalent patients.

Only some of the boundaries of the PCTs and Local Authorities in England are similar. The Office for National Statistics (ONS) is in the process of re-aligning the PCT boundaries with those of Local Authorities and hopes to complete this process by 2007. The data in this Report uses the PCT & LA boundaries from the 2001 census as the ONS have not issued new population tables for any of the changed boundaries.

Patients

All new cases accepted onto RRT in each year recorded by the Registry were included. Each patient's postcode was matched to a 2001 Census output area.

Geography: Unitary Authorities, counties and other areas

In contrast to 2002 contiguous 'county' areas were not derived by merging Unitary Authorities (UAs) with a bordering county. For example, Southampton UA and Portsmouth UA were kept separate from Hampshire county. The final areas used were Metropolitan counties, Greater London districts, Welsh areas, Shire counties and Unitary Authorities – these different types of area were called 'Local Authority (LA) areas'.

Lists of areas (English counties as at 31/12/2000; English UAs as at 31/12/2000; Welsh UAs as at 31/12/2000 and English districts as at 31/12/2000) were taken from *http://www. statistics.gov.uk/geography/geographic_area_ listings/administrative.asp*

Administrative area geography in England and Wales

There are currently 46 unitary authorities in England, 34 shire counties and six metropolitan counties. Greater London forms a unique area type. Shire counties and metropolitan counties are subdivided into districts; Unitary Authorities are not subdivided. Greater London is subdivided into the London Boroughs and the City of London.

Unitary Authorities

Table D.1: Unitary Authorities

Code	UA name
00EB	Hartlepool
00EC	Middlesbrough
00EE	Redcar and Cleveland
00EF	Stockton-on-Tees
00EH	Darlington
00ET	Halton
00EU	Warrington
00EX	Blackburn with Darwen
00EY	Blackpool
00FA	Kingston upon Hull, City of
00FB	East Riding of Yorkshire
00FC	North East Lincolnshire
00FD	North Lincolnshire
00FF	York
00FK	Derby
00FN	Leicester
00FP	Rutland
00FY	Nottingham
00GA	Herefordshire, County of
00GF	Telford and Wrekin
00GL	Stoke-on-Trent
00KF	Southend-on-Sea
00HA	Bath and North East Somerset
00HB	Bristol, City of
00HC	North Somerset
00HD	South Gloucestershire
00HG	Plymouth
00HH	Torbay
00HN	Bournemouth
00HP	Poole

Table D.1: (continued)

Code	UA name
00HX	Swindon
00JA	Peterborough
00KA	Luton
00KG	Thurrock
00LC	Medway
00MA	Bracknell Forest
00MB	West Berkshire
00MC	Reading
00MD	Slough
00ME	Windsor and Maidenhead
00MF	Wokingham
00MG	Milton Keynes
00ML	Brighton and Hove
00MR	Portsmouth
00MS	Southampton
00MW	Isle of Wight

Shire counties

There are 34 shire counties, subdivided into non-metropolitan districts.

Table D.2: Shire counties

Code	County name
09	Bedfordshire
11	Buckinghamshire
12	Cambridgeshire
13	Cheshire
15	Cornwall and Isles of Scilly
16	Cumbria
17	Derbyshire
18	Devon
19	Dorset
20	Durham
21	East Sussex
22	Essex
23	Gloucestershire
24	Hampshire
26	Hertfordshire
29	Kent
30	Lancashire
31	Leicestershire
32	Lincolnshire
33	Norfolk
34	Northamptonshire
35	Northumberland
36	North Yorkshire
37	Nottinghamshire
38	Oxfordshire
39	Shropshire

Table D.2: (continued)

Code	County name
40	Somerset
41	Staffordshire
42	Suffolk
43	Surrey
44	Warwickshire
45	West Sussex
46	Wiltshire
47	Worcestershire

Metropolitan counties

There are six metropolitan counties, all in England and representing heavily built-up areas (other than Greater London). These are subdivided into metropolitan districts.

Table D.3: Metropolitan counties

Code	Area name	Metropolitan district
00BL	Greater Manchester	Bolton
00BM		Bury
00BN		Manchester
00BP		Oldham
00BQ		Rochdale
00BR		Salford
00BS		Stockport
00BT		Tameside
00BU		Trafford
00BW		Wigan
00BX	Merseyside	Knowsley
00BY		Liverpool
00BZ		St. Helens
00CA		Sefton
00CB		Wirral
00CC	South Yorkshire	Barnsley
00CE		Doncaster
00CF		Rotherham
00CG		Sheffield
00CH	Tyne and Wear	Gateshead
00CJ		Newcastle upon Tyne
00CK		North Tyneside
00CL		South Tyneside
00CM		Sunderland
00CN	West Midlands	Birmingham
00CQ		Coventry
00CR		Dudley
00CS		Sandwell
00CT		Solihull
00CU		Walsall
00CW		Wolverhampton

Table D.3: (continued)

Code	Area name	Metropolitan district
00CX	West Yorkshire	Bradford
00CY		Calderdale
00CZ		Kirklees
00DA		Leeds
00DB		Wakefield

Greater London

This is an administrative unit covering the London metropolis. There are 32 boroughs and also the City of London (a City Corporation).

Table D.4: London boroughs

Code	Area name	Borough name
00AA	Greater London	City of London
00AB		Barking and Dagenham
00AC		Barnet
00AD		Bexley
00AE		Brent
00AF		Bromley
00AG		Camden
00AH		Croydon
00AJ		Ealing
00AK		Enfield
00AL		Greenwich
00AM		Hackney
00AN		Hammersmith and Fulham
00AP		Haringey
00AQ		Harrow
00AR		Havering
00AS		Hillingdon
00AT		Hounslow
00AU		Islington
00AW		Kensington and Chelsea
00AX		Kingston upon Thames
00AY		Lambeth
00AZ		Lewisham
00BA		Merton
00BB		Newham
00BC		Redbridge
00BD		Richmond upon Thames
00BE		Southwark
00BF		Sutton
00BG		Tower Hamlets
00BH		Waltham Forest
00BJ		Wandsworth
00BK		Westminster

Welsh Local Authorities

Table D.5: Welsh Local Authorities

Code	Area name	LA name
00PP	Gwent	Monmouthshire
00PK		Caerphilly
00PR		Newport
00PL		Blaenau Gwent
00PM		Torfaen
00PT	Bro Taf	Cardiff
00PF		Rhondda; Cynon; Taff
00PD		The Vale of Glamorgan
00PH		Merthyr Tydfil
00NS	Dyfed Powys	Pembrokeshire
00NQ		Ceredigion
00NU		Carmarthenshire
00NN		Powys
00NC	North Wales	Gwynedd
00NE		Conwy
00NA		Isle of Anglesey
00NL		Wrexham
00NJ		Flintshire
00NG		Denbighshire
00NZ	Morgannwg	Neath Port Talbot
00NX		Swansea
00PB		Bridgend

Areas included in Registry 'covered' population

The Renal Registry identified all areas in England and Wales for which they estimated to have complete coverage. Analysis was restricted to these areas.

The right hand column indicates whether the area has been included in the incident population calculation. This is dependant on whether the renal unit in the area is sending data to the Registry and that there are no overlapping areas with renal units not yet connected to the Registry.

This has been grouped by area in the UK, then Strategic Health Authority (SHA) for England and Area for Wales.

Table D.6: Renal Registry coverage of England and Wales

UK area	SHA (Eng)/Area (Wales)	Name	Area type	Code	Covered in 2004?
North East	County Durham and Tees Valley	Darlington	Unitary Authority	00EH	✓
		Durham	Shire County	20	✓
		Hartlepool	Unitary Authority	00EB	✓
		Middlesbrough	Unitary Authority	00EC	✓
		Redcar and Cleveland	Unitary Authority	00EE	✓
		Stockton-on-Tees	Unitary Authority	00EF	✓
	Northumberland, Tyne & Wear	Gateshead	Metropolitan District	00CH	✓
		Newcastle upon Tyne	Metropolitan District	00CJ	✓
		North Tyneside	Metropolitan District	00CK	✓
		Northumberland	Shire County	35	✓
		South Tyneside	Metropolitan District	00CL	✓
		Sunderland	Metropolitan District	00CM	✓
North West	Cheshire & Merseyside	Cheshire	Shire County	13	×
		Halton	Unitary Authority	00ET	✓
		Knowsley	Metropolitan District	00BX	✓
		Liverpool	Metropolitan District	00BY	✓
		Sefton	Metropolitan District	00CA	✓
		St. Helens	Metropolitan District	00BZ	✓
		Warrington	Unitary Authority	00EU	✓
		Wirral	Metropolitan District	00CB	✓
	Cumbria and Lancashire	Blackburn with Darwen	Unitary Authority	00EX	✓
		Blackpool	Unitary Authority	00EY	✓
		Cumbria	Shire County	16	✓
		Lancashire	Shire County	30	✓
	Greater Manchester	Bolton	Metropolitan District	00BL	✓
		Bury	Metropolitan District	00BM	✓
		Manchester	Metropolitan District	00BN	×
		Oldham	Metropolitan District	00BP	✓
		Rochdale	Metropolitan District	00BQ	✓
		Salford	Metropolitan District	00BR	✓
		Stockport	Metropolitan District	00BS	×
		Tameside	Metropolitan District	00BT	×
		Trafford	Metropolitan District	00BU	×
		Wigan	Metropolitan District	00BW	✓
Yorkshire and the Humber	North and East Yorkshire and Northern Lincolnshire	East Riding of Yorkshire	Unitary Authority	00FB	✓
		Kingston upon Hull, City of	Unitary Authority	00FA	✓
		North East Lincolnshire	Unitary Authority	00FC	✓
		North Lincolnshire	Unitary Authority	00FD	✓
		North Yorkshire	Shire County	36	✓
		York	Unitary Authority	00FF	✓
	South Yorkshire	Barnsley	Metropolitan District	00CC	✓
		Doncaster	Metropolitan District	00CE	✓
		Rotherham	Metropolitan District	00CF	✓
		Sheffield	Metropolitan District	00CG	✓
	West Yorkshire	Bradford	Metropolitan District	00CX	✓
		Calderdale	Metropolitan District	00CY	✓
		Kirklees	Metropolitan District	00CZ	✓
		Leeds	Metropolitan District	00DA	✓
		Wakefield	Metropolitan District	00DB	✓

Table D.6: (continued)

UK area	SHA (Eng)/Area (Wales)	Name	Area type	Code	Covered in 2004?
East Midlands	Leicestershire, Northamptonshire and Rutland	Leicester	Unitary Authority	00FN	✓
		Leicestershire	Shire County	31	✓
		Northamptonshire	Shire County	34	✓
		Rutland	Unitary Authority	00FP	✓
	Trent	Derby	Unitary Authority	00FK	✓
		Derbyshire	Shire County	17	✓
		Lincolnshire	Shire County	32	✓
		Nottingham	Unitary Authority	00FY	✓
		Nottinghamshire	Shire County	37	✓
West Midlands	Birmingham and the Black Country	Birmingham	Metropolitan District	00CN	✓
		Dudley	Metropolitan District	00CR	✓
		Sandwell	Metropolitan District	00CS	✓
		Solihull	Metropolitan District	00CT	✓
		Walsall	Metropolitan District	00CU	✓
		Wolverhampton	Metropolitan District	00CW	✓
	Coventry, Warwickshire, Herefordshire and Worcestershire	Coventry	Metropolitan District	00CQ	✓
		Herefordshire, County of	Unitary Authority	00GA	✓
		Warwickshire	Shire County	44	✓
		Worcestershire	Shire County	47	✓
	Shropshire and Staffordshire	Shropshire	Shire County	39	✓
		Staffordshire	Shire County	41	×
		Stoke-on-Trent	Unitary Authority	00GL	×
		Telford and Wrekin	Unitary Authority	00GF	✓
East of England	Bedfordshire and Hertfordshire	Bedfordshire	Shire County	9	✓
		Hertfordshire	Shire County	26	✓
		Luton	Unitary Authority	00KA	✓
	Essex	Essex	Shire County	22	✓
		Southend-on-Sea	Unitary Authority	00KF	✓
		Thurrock	Unitary Authority	00KG	✓
	Norfolk, Suffolk and Cambridgeshire	Cambridgeshire	Shire County	12	✓
		Norfolk	Shire County	33	✓
		Peterborough	Unitary Authority	00JA	✓
		Suffolk	Shire County	42	✓
London	North Central London	Barnet	London Borough	00AC	×
		Camden	London Borough	00AG	×
		Enfield	London Borough	00AK	×
		Haringey	London Borough	00AP	×
		Islington	London Borough	00AU	×
	North East London	Barking and Dagenham	London Borough	00AB	✓
		City of London	London Borough	00AA	×
		Hackney	London Borough	00AM	✓
		Havering	London Borough	00AR	×
		Newham	London Borough	00BB	✓
		Redbridge	London Borough	00BC	✓
		Tower Hamlets	London Borough	00BG	✓
		Waltham Forest	London Borough	00BH	×

Table D.6: (continued)

UK area	SHA (Eng)/Area (Wales)	Name	Area type	Code	Covered in 2004?
London (continued)	North West London	Brent	London Borough	00AE	×
		Ealing	London Borough	00AJ	✓
		Hammersmith and Fulham	London Borough	00AN	✓
		Harrow	London Borough	00AQ	×
		Hillingdon	London Borough	00AS	✓
		Hounslow	London Borough	00AT	✓
		Kensington and Chelsea	London Borough	00AW	×
		Westminster	London Borough	00BK	×
	South East London	Bexley	London Borough	00AD	✓
		Bromley	London Borough	00AF	✓
		Greenwich	London Borough	00AL	✓
		Lambeth	London Borough	00AY	✓
		Lewisham	London Borough	00AZ	✓
		Southwark	London Borough	00BE	✓
	South West London	Croydon	London Borough	00AH	✓
		Kingston upon Thames	London Borough	00AX	×
		Merton	London Borough	00BA	×
		Richmond upon Thames	London Borough	00BD	×
		Sutton	London Borough	00BF	×
		Wandsworth	London Borough	00BJ	×
South East	Hampshire and Isle of Wight	Hampshire	Shire County	24	✓
		Isle of Wight	Unitary Authority	00MW	✓
		Portsmouth	Unitary Authority	00MR	✓
		Southampton	Unitary Authority	00MS	✓
	Kent and Medway	Kent	Shire County	29	×
		Medway	Unitary Authority	00LC	×
	Surrey and Sussex	Brighton and Hove	Unitary Authority	00ML	✓
		East Sussex	Shire County	21	✓
		Surrey	Shire County	43	✓
		West Sussex	Shire County	45	✓
	Thames Valley	Bracknell Forest	Unitary Authority	00MA	✓
		Buckinghamshire	Shire County	11	✓
		Milton Keynes	Unitary Authority	00MG	✓
		Oxfordshire	Shire County	38	✓
		Reading	Unitary Authority	00MC	✓
		Slough	Unitary Authority	00MD	✓
		West Berkshire	Unitary Authority	00MB	✓
		Windsor and Maidenhead	Unitary Authority	00ME	×
		Wokingham	Unitary Authority	00MF	✓
South West	Avon, Gloucestershire and Wiltshire	Bath and North East Somerset	Unitary Authority	00HA	✓
		Bristol, City of	Unitary Authority	00HB	✓
		Gloucestershire	Shire County	23	✓
		North Somerset	Unitary Authority	00HC	✓
		South Gloucestershire	Unitary Authority	00HD	✓
		Swindon	Unitary Authority	00HX	✓
		Wiltshire	Shire County	46	✓
	Dorset and Somerset	Bournemouth	Unitary Authority	00HN	✓
		Dorset	Shire County	19	✓
		Poole	Unitary Authority	00HP	✓
		Somerset	Shire County	40	✓

Table D.6: (continued)

UK area	SHA (Eng)/Area (Wales)	Name	Area type	Code	Covered in 2004?
South West (continued)	South West Peninsula	Cornwall and Isles of Scilly	Shire County	15	✓
		Devon	Shire County	18	✓
		Plymouth	Unitary Authority	00HG	✓
		Torbay	Unitary Authority	00HH	✓
Wales	Bro Taf	Cardiff	Welsh LA	00PT	✓
		Merthyr Tydfil	Welsh LA	00PH	✓
		Rhondda, Cynon, Taff	Welsh LA	00PF	✓
		The Vale of Glamorgan	Welsh LA	00PD	✓
	Dyfed Powys	Carmarthenshire	Welsh LA	00NU	✓
		Ceredigion	Welsh LA	00NQ	✓
		Pembrokeshire	Welsh LA	00NS	✓
		Powys	Welsh LA	00NN	✓
	Gwent	Blaenau Gwent	Welsh LA	00PL	✓
		Caerphilly	Welsh LA	00PK	✓
		Monmouthshire	Welsh LA	00PP	✓
		Newport	Welsh LA	00PR	✓
		Torfaen	Welsh LA	00PM	✓
	Morgannwg	Bridgend	Welsh LA	00PB	✓
		Neath Port Talbot	Welsh LA	00NZ	✓
		Swansea	Welsh LA	00NX	✓
	North Wales	Conwy	Welsh LA	00NE	✓
		Denbighshire	Welsh LA	00NG	✓
		Flintshire	Welsh LA	00NJ	✓
		Gwynedd	Welsh LA	00NC	✓
		Isle of Anglesey	Welsh LA	00NA	✓
		Wrexham	Welsh LA	00NL	✓

Population

The populations and age/gender breakdown for the LA areas were taken from Casweb. Casweb is a web interface to statistics and related information from the United Kingdom Census of Population, developed at Manchester University for academic use.

Calculation of acceptance rates

Crude rate

The crude rate of acceptance onto RRT was calculated for each LA area for each year

$$\frac{observed\_cases}{population} \times 1{,}000{,}000$$

per million population (pmp).

Standardised acceptance rate ratio (SARR)

The age/gender standardised rate ratio of acceptance onto RRT was calculated for each LA area for the year 2004:

$$\frac{observed\_cases}{expected\_cases}$$

Observed cases (O_i) were calculated by summing all cases in all age and gender bands for each LA area. Expected cases (E_i) for each LA area were calculated by: for each age/gender band the observed rate over all LA areas (the standard population) was applied to the population of that age/gender band to determine the expected number of referrals. The expected cases in each age/gender band were summed to give an expected number of cases in each LA area. 95% confidence limits were calculated for each area. The

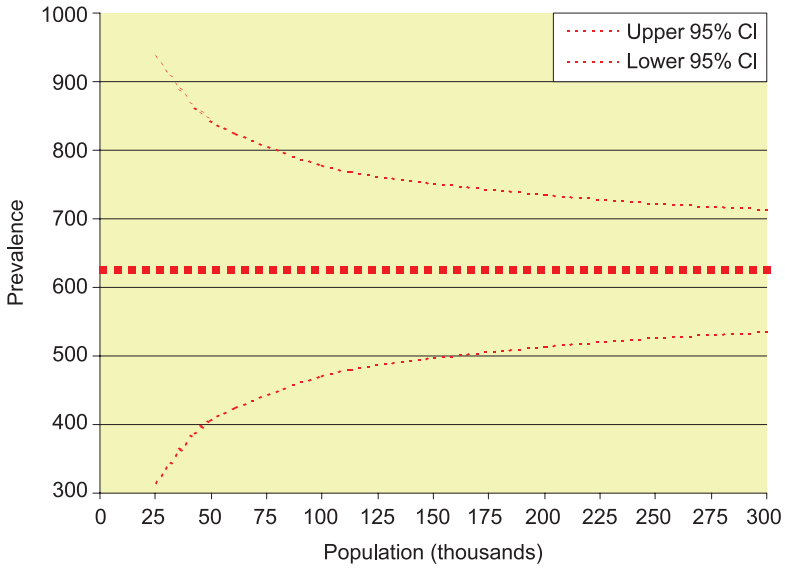

Figure D.1: 95% confidence limits for prevalence of 625 pmp for population size 50,000–300,000

expected cases were calculated for each of the individual years to calculate the age/gender standardised rate ratios.

A ratio of 1 indicates that the LA area's acceptance rate was as expected if the age/gender rates found in the total covered population applied to the LA area's population structure; a level above 1 indicates that the observed rate is greater than expected given the LA area's population structure, if the lower confidence limit was above 1 this is statistically significant at the 5% level. The converse applies to standardised rate ratios under one.

Analysis of prevalent patients by PCT

Groups such as primary care trusts, which represent relatively small populations of 30,000 to 250,000, often wish to assess their performance. When assessing a relatively infrequent occurrence such as prevalence of RRT in such small populations there are wide confidence intervals for any observed frequency.

To enable assessment of whether an observed prevalence is likely to be significantly different from the national average Figure D.1 has been included in the report. From these, for any size of population (X axis) the upper and lower 1 in 20 confidence intervals around the national average prevalence (dotted lines) can be read from the Y axis. Any observed prevalence for renal failure must be outside these limits for the given population to be statistically significantly different from the national average. Thus for a population of 50,000 the observed prevalence would have to be outside the limits of 400 per million population to 850 per million population. However for a population of 300,000 these limits are from 535 per million population to 715 per million population.

These rates **have not** been adjusted for ethnicity. Much higher rates are expected in populations with a high percentage of patients from South Asian and African–Caribbean backgrounds.

The PCT analysis uses the patient postcode and not the GP postcode.

Table D.7: Prevalent renal replacement therapy patients by PCT

UK area	SHA	Name	Code	Tot exp	Tot pop	Tot obs	O/E	L 95% CL	U 95% CL	Crude rate pmp
North East	County Durham & Tees Valley	Darlington PCT	5J9	64	97,849	59	**0.92**	0.72	1.19	**602.97**
		Derwentside PCT	5KA	57	85,171	55	**0.97**	0.74	1.26	**645.76**
		Durham & Chester-le-Street PCT	5KC	91	140,644	72	**0.79**	0.63	1.00	**511.93**
		Durham Dales PCT	5J8	59	85,531	60	**1.02**	0.80	1.32	**701.50**
		Easington PCT	5KD	62	93,971	62	**1.01**	0.79	1.29	**659.78**
		Hartlepool PCT	5D9	57	88,711	59	**1.04**	0.81	1.34	**665.08**
		Langbaurgh PCT	5KN	65	97,028	72	**1.11**	0.88	1.39	**742.06**
		Middlesbrough PCT	5KM	108	176,806	108	**1.00**	0.82	1.20	**610.84**
		North Tees PCT	5E1	112	177,992	104	**0.92**	0.76	1.12	**584.29**
		Sedgefield PCT	5KE	58	87,204	65	**1.13**	0.88	1.44	**745.38**
	Northumberland, Tyne & Wear	Gateshead PCT	5KF	127	191,133	129	**1.02**	0.86	1.21	**674.92**
		Newcastle PCT	5D7	158	259,470	145	**0.92**	0.78	1.08	**558.83**
		North Tyneside PCT	5D8	128	191,999	121	**0.94**	0.79	1.13	**630.21**
		Northumberland Care Trust	TAC	211	305,536	193	**0.92**	0.79	1.05	**631.68**
		South Tyneside PCT	5KG	101	152,785	91	**0.90**	0.74	1.11	**595.61**
		Sunderland Teaching PCT	5KL	179	280,805	181	**1.01**	0.88	1.17	**644.58**
North West	Cheshire & Merseyside	Bebington & West Wirral PCT	5F8	83	118,951	81	**0.97**	0.78	1.21	**680.95**
		Birkenhead & Wallasey PCT	5H2	122	193,264	135	**1.11**	0.94	1.31	**698.53**
		Central Cheshire PCT	5H4				**n/a**			**n/a**
		Central Liverpool PCT	5HA	141	237,680	160	**1.14**	0.97	1.33	**673.17**
		Cheshire West PCT	5H3	103	151,111	92	**0.90**	0.73	1.10	**608.82**
		Eastern Cheshire PCT	5H5				**n/a**			**n/a**
		Ellesmere Port & Neston PCT	5H6	53	81,580	60	**1.12**	0.87	1.45	**735.48**
		Halton PCT	5J1	73	118,185	73	**1.01**	0.80	1.27	**617.68**
		Knowsley PCT	5J4	91	150,494	109	**1.19**	0.99	1.44	**724.28**
		North Liverpool PCT	5G9	61	102,529	70	**1.14**	0.90	1.44	**682.73**
		South Liverpool PCT	5HC	63	98,107	79	**1.25**	1.00	1.56	**805.24**
		South Sefton PCT	5M5	108	168,764	97	**0.90**	0.73	1.09	**574.77**
		Southport & Formby PCT	5F9	81	114,120	59	**0.73**	0.57	0.94	**517.00**
		St Helens PCT	5J3	114	176,810	87	**0.76**	0.62	0.94	**492.05**
		Warrington PCT	5J2	121	190,391	108	**0.89**	0.74	1.08	**567.25**
	Cumbria & Lancashire	Blackburn With Darwen PCT	5CC	78	137,556	86	**1.10**	0.89	1.35	**625.20**
		Blackpool PCT	5HP	98	142,184	71	**0.73**	0.58	0.92	**499.35**
		Burnley, Pendle & Rossendale PCT	5G8	151	244,449	147	**0.97**	0.83	1.14	**601.35**
		Carlisle & District PCT	5D4	77	113,582	58	**0.76**	0.59	0.98	**510.65**
		Chorley & South Ribble PCT	5F2	133	203,189	71	**0.54**	0.42	0.68	**349.43**
		Eden Valley PCT	5D5	49	69,020	42	**0.85**	0.63	1.15	**608.52**
		Fylde PCT	5HE	53	72,657	32	**0.61**	0.43	0.86	**440.43**
		Hyndburn & Ribble Valley PCT	5G7	80	124,672	80	**1.00**	0.81	1.25	**641.68**
		Morecambe Bay PCT	5DD	206	308,189	153	**0.74**	0.63	0.87	**496.45**
		Preston PCT	5HD	85	140,065	88	**1.04**	0.84	1.28	**628.28**
		West Cumbria PCT	5D6	88	130,409	87	**0.99**	0.80	1.22	**667.13**
		West Lancashire PCT	5F3	71	108,541	64	**0.90**	0.70	1.15	**589.64**
		Wyre PCT	5HF	75	105,713	69	**0.91**	0.72	1.16	**652.71**

Table D.7: (continued)

UK area	SHA	Name	Code	Tot exp	Tot pop	Tot obs	O/E	L 95% CL	U 95% CL	Crude rate pmp
North West (continued)	Greater Manchester	Ashton, Leigh & Wigan PCT	5HG	192	301,207	129	**0.67**	0.56	0.80	**428.28**
		Bolton PCT	5HQ	162	261,329	128	**0.79**	0.66	0.94	**489.80**
		Bury PCT	5JX	113	180,637	49	**0.43**	0.33	0.57	**271.26**
		Central Manchester PCT	5CL				**n/a**			**n/a**
		Heywood & Middleton PCT	5F4				**n/a**			**n/a**
		North Manchester PCT	5CR				**n/a**			**n/a**
		Oldham PCT	5J5	132	217,456	70	**0.53**	0.42	0.67	**321.90**
		Rochdale PCT	5JY	79	131,546	60	**0.76**	0.59	0.98	**456.12**
		Salford PCT	5F5	135	215,817	90	**0.67**	0.54	0.82	**417.02**
		South Manchester PCT	5AA				**n/a**			**n/a**
		Stockport PCT	5F7				**n/a**			**n/a**
		Tameside & Glossop PCT	5LH				**n/a**			**n/a**
		Trafford North PCT	5F6				**n/a**			**n/a**
		Trafford South PCT	5CX				**n/a**			**n/a**
Yorkshire and the Humber	North & East Yorkshire & Northern Lincolnshire	Craven, Harrogate & Rural District PCT	5KJ	137	202,790	113	**0.82**	0.68	0.99	**557.23**
		East Yorkshire PCT	5E3	115	169,845	98	**0.85**	0.70	1.03	**577.00**
		Eastern Hull PCT	5E5	68	113,309	73	**1.07**	0.85	1.34	**644.25**
		Hambleton & Richmondshire PCT	5KH	75	108,030	61	**0.82**	0.63	1.05	**564.66**
		North East Lincolnshire PCT	5AN	101	159,214	104	**1.03**	0.85	1.24	**653.21**
		North Lincolnshire PCT	5EF	99	148,965	94	**0.95**	0.77	1.16	**631.02**
		Scarborough, Whitby & Ryedale PCT	5KK	112	157,007	87	**0.77**	0.63	0.96	**554.12**
		Selby & York PCT	5E2	176	271,280	173	**0.98**	0.85	1.14	**637.72**
		West Hull PCT	5E6	79	129,614	79	**1.01**	0.81	1.25	**609.50**
		Yorkshire Wolds & Coast PCT	5E4	102	143,581	88	**0.86**	0.70	1.06	**612.89**
	South Yorkshire	Barnsley PCT	5JE	142	218,125	171	**1.20**	1.04	1.40	**783.95**
		Doncaster Central PCT	5CK	45	70,401	64	**1.42**	1.11	1.81	**909.07**
		Doncaster East PCT	5EK	73	110,122	68	**0.93**	0.73	1.18	**617.50**
		Doncaster West PCT	5EL	67	104,970	68	**1.01**	0.80	1.28	**647.81**
		North Sheffield PCT	5EE	72	117,114	91	**1.27**	1.03	1.56	**777.02**
		Rotherham PCT	5H8	160	248,352	194	**1.22**	1.06	1.40	**781.15**
		Sheffield South West PCT	5EP	80	124,598	59	**0.73**	0.57	0.95	**473.52**
		Sheffield West PCT	5EN	65	107,094	73	**1.12**	0.89	1.41	**681.64**
		South East Sheffield PCT	5EQ	105	164,239	124	**1.18**	0.99	1.41	**755.00**
	West Yorkshire	Airedale PCT	5AW	75	116,192	73	**0.97**	0.77	1.22	**628.27**
		Bradford City PCT	5CF	66	135,189	132	**2.01**	1.69	2.38	**976.41**
		Bradford South & West PCT	5CG	80	132,310	99	**1.24**	1.02	1.51	**748.24**
		Calderdale PCT	5J6	122	192,381	139	**1.14**	0.97	1.35	**722.52**
		East Leeds PCT	5HK	100	162,757	108	**1.08**	0.89	1.30	**663.57**
		Eastern Wakefield PCT	5E7	110	171,976	91	**0.83**	0.68	1.02	**529.14**
		Huddersfield Central PCT	5LJ	85	137,821	104	**1.22**	1.01	1.48	**754.60**
		Leeds North East PCT	5HJ	73	111,524	91	**1.25**	1.02	1.54	**815.97**
		Leeds North West PCT	5HM	107	185,393	94	**0.88**	0.72	1.07	**507.03**
		Leeds West PCT	5HH	67	108,892	73	**1.09**	0.86	1.37	**670.39**
		North Bradford PCT	5CH	54	84,257	60	**1.12**	0.87	1.44	**712.10**
		North Kirklees PCT	5J7	101	170,627	141	**1.39**	1.18	1.64	**826.37**
		South Huddersfield PCT	5LK	52	80,460	45	**0.86**	0.64	1.15	**559.28**
		South Leeds PCT	5HL	88	145,835	76	**0.86**	0.69	1.08	**521.14**
		Wakefield West PCT	5E8	92	142,712	84	**0.91**	0.74	1.13	**588.60**

Table D.7: (continued)

UK area	SHA	Name	Code	Tot exp	Tot pop	Tot obs	O/E	L 95% CL	U 95% CL	Crude rate pmp
East Midlands	Leicestershire, Northamptonshire & Rutland	Charnwood & North West Leicestershire PCT	5JC	148	230,214	156	**1.06**	0.90	1.24	**677.63**
		Daventry & South Northamptonshire PCT	5AC	65	101,006	34	**0.52**	0.37	0.73	**336.61**
		Eastern Leicester PCT	5EY	98	173,316	202	**2.06**	1.79	2.36	**1165.50**
		Hinckley & Bosworth PCT	5JA	76	115,004	73	**0.96**	0.76	1.21	**634.76**
		Leicester City West PCT	5EJ	59	106,430	78	**1.32**	1.06	1.65	**732.87**
		Melton, Rutland & Harborough PCT	5EH	93	137,726	89	**0.95**	0.78	1.18	**646.21**
		Northampton PCT	5LW	126	208,645	81	**0.64**	0.52	0.80	**388.22**
		Northamptonshire Heartlands PCT	5LV	180	283,758	144	**0.80**	0.68	0.94	**507.47**
		South Leicestershire PCT	5JD	104	158,350	91	**0.87**	0.71	1.07	**574.67**
	Trent	Amber Valley PCT	5ED	78	116,564	69	**0.88**	0.70	1.12	**591.95**
		Ashfield PCT	5FA	53	81,777	53	**0.99**	0.76	1.30	**648.11**
		Bassetlaw PCT	5ET	72	107,327	61	**0.85**	0.66	1.10	**568.36**
		Broxtowe & Hucknall PCT	5EV	90	136,951	88	**0.97**	0.79	1.20	**642.57**
		Central Derby PCT	5AL	36	64,320	54	**1.50**	1.15	1.96	**839.55**
		Chesterfield PCT	5EA	66	98,882	77	**1.17**	0.93	1.46	**778.71**
		Derbyshire Dales & South Derbyshire PCT	5H7	71	107,461	59	**0.83**	0.65	1.08	**549.04**
		East Lincolnshire PCT	5H9	195	265,403	152	**0.78**	0.67	0.91	**572.71**
		Erewash PCT	5ER	71	110,123	61	**0.86**	0.67	1.10	**553.93**
		Gedling PCT	5EC	75	111,795	76	**1.01**	0.81	1.27	**679.81**
		Greater Derby PCT	5EX	101	157,342	122	**1.20**	1.01	1.44	**775.38**
		High Peak & Dales PCT	5HN	69	100,153	23	**0.33**	0.22	0.50	**229.65**
		Lincolnshire South West PCT	5D3	107	160,683	81	**0.76**	0.61	0.94	**504.10**
		Mansfield District PCT	5AM	64	97,993	64	**1.00**	0.79	1.28	**653.11**
		Newark & Sherwood PCT	5AP	71	105,709	83	**1.16**	0.94	1.44	**785.17**
		North Eastern Derbyshire PCT	5EG	116	168,767	104	**0.90**	0.74	1.09	**616.23**
		Nottingham City PCT	5EM	152	266,780	197	**1.29**	1.12	1.49	**738.44**
		Rushcliffe PCT	5FC	69	105,507	64	**0.92**	0.72	1.18	**606.59**
		West Lincolnshire PCT	5D2	144	217,042	124	**0.86**	0.72	1.03	**571.32**
West Midlands	Birmingham & The Black Country	Dudley Beacon & Castle PCT	5HV	73	112,378	75	**1.03**	0.82	1.29	**667.39**
		Dudley South PCT	5HT	129	192,702	111	**0.86**	0.71	1.03	**576.02**
		Eastern Birmingham PCT	5MY	120	203,367	190	**1.59**	1.38	1.83	**934.27**
		Heart of Birmingham PCT	5MX	139	274,656	311	**2.24**	2.01	2.51	**1132.33**
		North Birmingham PCT	5MW	97	150,593	114	**1.18**	0.98	1.41	**757.01**
		Oldbury & Smethwick PCT	5MG	55	91,896	99	**1.79**	1.47	2.17	**1077.30**
		Rowley, Regis & Tipton PCT	5MH	53	86,429	62	**1.16**	0.91	1.49	**717.35**
		Solihull PCT	5D1	132	199,486	133	**1.01**	0.85	1.19	**666.71**
		South Birmingham PCT	5M1	206	347,594	279	**1.35**	1.20	1.52	**802.66**
		Walsall PCT	5M3	162	253,316	202	**1.25**	1.09	1.44	**797.42**
		Wednesbury & West Bromwich PCT	5MJ	68	104,403	86	**1.27**	1.03	1.57	**823.73**
		Wolverhampton City PCT	5MV	150	236,453	200	**1.34**	1.16	1.54	**845.83**
	Coventry, Warwickshire, Herefordshire & Worcestershire	Coventry PCT	5MD	181	300,667	223	**1.23**	1.08	1.41	**741.69**
		Herefordshire PCT	5CN	121	174,133	105	**0.86**	0.71	1.05	**602.99**
		North Warwickshire PCT	5MP	117	180,975	141	**1.20**	1.02	1.42	**779.11**
		Redditch & Bromsgrove PCT	5MR	105	162,126	91	**0.87**	0.71	1.07	**561.29**
		Rugby PCT	5M9	57	87,253	75	**1.31**	1.04	1.64	**859.57**
		South Warwickshire PCT	5MQ	161	237,509	152	**0.95**	0.81	1.11	**639.98**
		South Worcestershire PCT	5MT	187	277,881	146	**0.78**	0.66	0.92	**525.40**
		Wyre Forest PCT	5DR	69	101,100	62	**0.90**	0.70	1.16	**613.26**

Table D.7: (continued)

UK area	SHA	Name	Code	Tot exp	Tot pop	Tot obs	O/E	L 95% CL	U 95% CL	Crude rate pmp
West Midlands (continued)	Shropshire & Staffordshire	Burntwood, Lichfield & Tamworth PCT	5DQ	97	151,448	100	**1.03**	0.85	1.26	**660.29**
		Cannock Chase PCT	5MM	81	127,829	67	**0.82**	0.65	1.05	**524.14**
		East Staffordshire PCT	5ML	73	112,718	68	**0.93**	0.74	1.18	**603.28**
		Newcastle-Under-Lyme PCT	5HW				**n/a**			**n/a**
		North Stoke PCT	5ME				**n/a**			**n/a**
		Shropshire County PCT	5M2	192	279,717	161	**0.84**	0.72	0.98	**575.58**
		South Stoke PCT	5MF				**n/a**			**n/a**
		South Western Staffordshire PCT	5MN				**n/a**			**n/a**
		Staffordshire Moorlands PCT	5HR				**n/a**			**n/a**
		Telford & Wrekin PCT	5MK	95	158,142	85	**0.89**	0.72	1.11	**537.49**
East of England	Bedfordshire & Hertfordshire	Bedford PCT	5GD	92	147,829	91	**0.99**	0.81	1.21	**615.58**
		Bedfordshire Heartlands PCT	5GE	147	232,867	136	**0.92**	0.78	1.09	**584.03**
		Dacorum PCT	5GW	87	137,177	69	**0.79**	0.62	1.00	**503.00**
		Hertsmere PCT	5CP				**n/a**			**n/a**
		Luton PCT	5GC	105	184,294	124	**1.18**	0.99	1.41	**672.84**
		North Hertfordshire & Stevenage PCT	5GH	112	179,745	116	**1.03**	0.86	1.24	**645.36**
		Royston, Buntingford & Bishops Stortford PCT	5GK	38	61,985	28	**0.74**	0.51	1.07	**451.72**
		South East Hertfordshire PCT	5GJ	109	171,365	72	**0.66**	0.52	0.83	**420.16**
		St Albans & Harpenden PCT	5GX				**n/a**			**n/a**
		Watford & Three Rivers PCT	5GV				**n/a**			**n/a**
		Welwyn Hatfield PCT	5GG				**n/a**			**n/a**
	Essex	Basildon PCT	5GR	61	102,623	60	**0.98**	0.76	1.26	**584.66**
		Billericay, Brentwood & Wickford PCT	5GP	88	131,718	70	**0.79**	0.63	1.00	**531.44**
		Castle Point & Rochford PCT	5JP	113	165,218	89	**0.79**	0.64	0.97	**538.68**
		Chelmsford PCT	5JN	86	133,719	67	**0.78**	0.61	0.99	**501.05**
		Colchester PCT	5GM	97	155,376	78	**0.80**	0.64	1.00	**502.01**
		Epping Forest PCT	5AJ	80	120,964	60	**0.75**	0.58	0.96	**496.02**
		Harlow PCT	5DC	48	78,935	40	**0.84**	0.61	1.14	**506.75**
		Maldon & South Chelmsford PCT	5GL	57	87,435	50	**0.88**	0.66	1.16	**571.85**
		Southend On Sea PCT	5AK	104	160,344	108	**1.04**	0.86	1.25	**673.55**
		Tendring PCT	5AH	102	136,487	78	**0.76**	0.61	0.95	**571.48**
		Thurrock PCT	5GQ	86	143,212	79	**0.92**	0.74	1.15	**551.63**
		Uttlesford PCT	5GN	47	70,928	37	**0.79**	0.57	1.08	**521.65**
		Witham, Braintree & Halstead	TAG	80	125,628	60	**0.75**	0.58	0.97	**477.60**
	Norfolk, Suffolk & Cambridgeshire	Broadland PCT	5JL	84	118,302	77	**0.92**	0.74	1.15	**650.88**
		Cambridge City PCT	5JH	61	108,466	56	**0.92**	0.71	1.19	**516.29**
		Central Suffolk PCT	5JT	68	97,953	46	**0.68**	0.51	0.90	**469.61**
		East Cambridgeshire & Fenland PCT	5JK	92	136,129	72	**0.78**	0.62	0.98	**528.91**
		Great Yarmouth PCT	5GT	63	90,889	25	**0.40**	0.27	0.59	**275.06**
		Huntingdonshire PCT	5GF	89	140,111	87	**0.98**	0.80	1.21	**620.94**
		Ipswich PCT	5JQ	90	141,672	85	**0.95**	0.77	1.17	**599.98**
		North Norfolk PCT	5JM	75	97,168	82	**1.09**	0.88	1.35	**843.90**
		North Peterborough PCT	5AF	59	99,239	66	**1.12**	0.88	1.42	**665.06**
		Norwich PCT	5A2	74	121,145	82	**1.10**	0.89	1.37	**676.87**
		South Cambridgeshire PCT	5JJ	85	129,562	76	**0.89**	0.71	1.12	**586.59**
		South Peterborough PCT	5AG	55	86,912	60	**1.09**	0.85	1.40	**690.35**
		Southern Norfolk PCT	5G1	140	200,492	123	**0.88**	0.74	1.05	**613.49**
		Suffolk Coastal PCT	5JR	69	98,237	59	**0.85**	0.66	1.10	**600.59**
		Suffolk West PCT	5JW	135	195,747	113	**0.84**	0.70	1.01	**577.28**
		Waveney PCT	5JV	86	121,238	39	**0.46**	0.33	0.62	**321.68**
		West Norfolk PCT	5CY	113	154,724	86	**0.76**	0.61	0.94	**555.83**

Table D.7: (continued)

UK area	SHA	Name	Code	Tot exp	Tot pop	Tot obs	O/E	L 95% CL	U 95% CL	Crude rate pmp
London	North Central London	Barnet PCT	5A9				**n/a**			**n/a**
		Camden PCT	5K7				**n/a**			**n/a**
		Enfield PCT	5C1				**n/a**			**n/a**
		Haringey PCT	5C9				**n/a**			**n/a**
		Islington PCT	5K8				**n/a**			**n/a**
	North East London	Barking & Dagenham PCT	5C2	94	164,344	93	**0.99**	0.81	1.21	**565.89**
		Chingford, Wanstead & Woodford PCT	5C7				**n/a**			**n/a**
		City & Hackney PCT	5C3	110	210,480	127	**1.16**	0.97	1.38	**603.38**
		Havering PCT	5A4				**n/a**			**n/a**
		Newham PCT	5C5	120	244,280	176	**1.46**	1.26	1.70	**720.48**
		Redbridge PCT	5C8	104	176,883	312	**3.01**	2.69	3.36	**1763.88**
		Tower Hamlets PCT	5C4	97	196,567	121	**1.24**	1.04	1.49	**615.57**
		Walthamstow, Leyton & Leytonstone PCT	5C6				**n/a**			**n/a**
	North West London	Brent PCT	5K5				**n/a**			**n/a**
		Ealing PCT	5HX	173	301,433	265	**1.53**	1.36	1.73	**879.13**
		Hammersmith & Fulham PCT	5H1	92	165,058	144	**1.57**	1.33	1.85	**872.42**
		Harrow PCT	5K6				**n/a**			**n/a**
		Hillingdon PCT	5AT				**n/a**			**n/a**
		Hounslow PCT	5HY	121	212,397	210	**1.73**	1.51	1.99	**988.71**
		Kensington & Chelsea PCT	5LA				**n/a**			**n/a**
		Westminster PCT	5LC				**n/a**			**n/a**
	South East London	Bexley PCT	TAK	138	218,675	155	**1.12**	0.96	1.31	**708.81**
		Bromley PCT	5A7	191	295,865	181	**0.95**	0.82	1.10	**611.77**
		Greenwich PCT	5A8	122	214,597	116	**0.95**	0.80	1.14	**540.55**
		Lambeth PCT	5LD	141	266,487	196	**1.39**	1.21	1.60	**735.49**
		Lewisham PCT	5LF	137	249,428	236	**1.72**	1.52	1.96	**946.16**
		Southwark PCT	5LE	133	245,357	225	**1.70**	1.49	1.93	**917.03**
	South West London	Croydon PCT	5K9	196	331,406	225	**1.15**	1.01	1.31	**678.93**
		Kingston PCT	5A5				**n/a**			**n/a**
		Richmond & Twickenham PCT	5M6				**n/a**			**n/a**
		Sutton & Merton PCT	5M7				**n/a**			**n/a**
		Wandsworth PCT	5LG				**n/a**			**n/a**
South East	Hampshire & Isle of Wight	East Hampshire PCT	5FD	115	168,691	95	**0.83**	0.68	1.01	**563.16**
		Eastleigh & Test Valley South PCT	5LY	104	161,617	86	**0.83**	0.67	1.02	**532.12**
		Fareham & Gosport PCT	5LX	118	180,116	106	**0.89**	0.74	1.08	**588.51**
		Isle of Wight PCT	5DG	95	131,502	68	**0.72**	0.57	0.91	**517.10**
		Mid-Hampshire PCT	5E9	111	169,042	88	**0.79**	0.64	0.98	**520.58**
		New Forest PCT	5A1	122	168,914	79	**0.65**	0.52	0.80	**467.69**
		North Hampshire PCT	5DF	129	206,226	103	**0.80**	0.66	0.97	**499.45**
		Portsmouth City PCT	5FE	108	177,571	132	**1.23**	1.03	1.46	**743.36**
		Blackwater Valley & Hart PCT	5G6	102	168,106	72	**0.70**	0.56	0.89	**428.30**
		Southampton City PCT	5L1	127	217,329	118	**0.93**	0.78	1.11	**542.96**
	Kent & Medway	Ashford PCT	5LL				**n/a**			**n/a**
		Canterbury & Coastal PCT	5LM				**n/a**			**n/a**
		Dartford, Gravesham & Swanley PCT	5CM				**n/a**			**n/a**
		East Kent Coastal PCT	5LN				**n/a**			**n/a**
		Maidstone Weald PCT	5L2				**n/a**			**n/a**
		Medway PCT	5L3				**n/a**			**n/a**
		Shepway PCT	5LP				**n/a**			**n/a**
		South West Kent PCT	5FF				**n/a**			**n/a**
		Swale PCT	5L4				**n/a**			**n/a**

Table D.7: (continued)

UK area	SHA	Name	Code	Tot exp	Tot pop	Tot obs	O/E	L 95% CL	U 95% CL	Crude rate pmp
South East (continued)	Surrey & Sussex	Adur, Arun & Worthing PCT	5L8	151	216,387	117	**0.78**	0.65	0.93	**540.70**
		Bexhill & Rother PCT	5FH	67	87,368	52	**0.78**	0.59	1.02	**595.18**
		Brighton & Hove City PCT	5LQ	154	248,061	126	**0.82**	0.69	0.98	**507.94**
		Crawley PCT	5MA	60	99,679	64	**1.06**	0.83	1.35	**642.06**
		East Elmbridge & Mid Surrey PCT	5KP	175	260,806	136	**0.78**	0.66	0.92	**521.46**
		East Surrey PCT	5KQ	104	159,808	72	**0.69**	0.55	0.87	**450.54**
		Eastbourne Downs PCT	5LR	120	166,311	100	**0.84**	0.69	1.02	**601.28**
		Guildford & Waverley PCT	5L5	145	222,319	80	**0.55**	0.44	0.69	**359.84**
		Hastings & St Leonards PCT	5FJ	55	85,325	54	**0.99**	0.76	1.29	**632.87**
		Horsham & Chanctonbury PCT	5MC	66	100,790	45	**0.68**	0.51	0.92	**446.47**
		Mid-Sussex PCT	5FK	86	130,195	62	**0.72**	0.56	0.93	**476.21**
		North Surrey PCT	5L6	132	199,554	128	**0.97**	0.81	1.15	**641.43**
		Sussex Downs & Weald PCT	5LT	105	153,865	93	**0.88**	0.72	1.08	**604.42**
		Western Sussex PCT	5L9	149	206,581	102	**0.68**	0.56	0.83	**493.75**
		Woking PCT	5L7	127	199,939	103	**0.81**	0.67	0.98	**515.16**
	Thames Valley	Bracknell Forest PCT	5G2	63	108,151	58	**0.93**	0.72	1.20	**536.29**
		Cherwell Vale PCT	5DV	78	122,009	75	**0.97**	0.77	1.21	**614.71**
		Chiltern & South Buckinghamshire PCT	5G4	108	159,751	79	**0.73**	0.58	0.91	**494.52**
		Milton Keynes PCT	5CQ	122	211,671	125	**1.03**	0.86	1.22	**590.54**
		Newbury & Community PCT	5DK	58	93,090	59	**1.01**	0.78	1.30	**633.80**
		North East Oxfordshire PCT	5DT	43	69,101	55	**1.29**	0.99	1.68	**795.94**
		Oxford City PCT	5DW	89	154,597	105	**1.18**	0.98	1.43	**679.18**
		Reading PCT	5DL	114	194,294	128	**1.12**	0.94	1.34	**658.80**
		Slough PCT	5DM	67	119,059	114	**1.70**	1.42	2.05	**957.51**
		South East Oxfordshire PCT	5DX	62	92,996	46	**0.74**	0.55	0.99	**494.65**
		South West Oxfordshire PCT	5DY	122	190,520	135	**1.11**	0.94	1.31	**708.59**
		Vale of Aylesbury PCT	5DP	110	176,322	143	**1.30**	1.10	1.53	**811.01**
		Windsor, Ascot & Maidenhead PCT	5G3	91	143,891	73	**0.80**	0.64	1.00	**507.33**
		Wokingham PCT	5DN	92	148,789	86	**0.93**	0.75	1.15	**578.00**
		Wycombe PCT	5G5	82	134,621	88	**1.07**	0.87	1.32	**653.69**
South West	Avon, Gloucestershire & Wiltshire	Bath & North East Somerset PCT	5FL	111	168,857	95	**0.86**	0.70	1.05	**562.60**
		Bristol North PCT	5JF	126	210,325	193	**1.53**	1.33	1.76	**917.63**
		Bristol South & West PCT	5JG	101	170,088	121	**1.20**	1.00	1.43	**711.40**
		Cheltenham & Tewkesbury PCT	5KW	102	156,444	80	**0.78**	0.63	0.97	**511.37**
		Cotswold & Vale PCT	5KY	129	187,831	107	**0.83**	0.68	1.00	**569.66**
		North Somerset PCT	5M8	131	188,787	144	**1.10**	0.94	1.30	**762.76**
		Kennet & North Wiltshire PCT	5K4	124	191,978	82	**0.66**	0.53	0.82	**427.13**
		South Gloucestershire PCT	5A3	156	244,909	174	**1.11**	0.96	1.29	**710.47**
		South Wiltshire PCT	5DJ	75	111,984	47	**0.62**	0.47	0.83	**419.70**
		Swindon PCT	5K3	113	183,706	112	**0.99**	0.83	1.20	**609.67**
		West Gloucestershire PCT	5KX	141	218,086	150	**1.06**	0.91	1.25	**687.80**
		West Wiltshire PCT	5DH	77	116,612	64	**0.83**	0.65	1.06	**548.83**
	Dorset & Somerset	Bournemouth PCT	5CE	96	147,140	81	**0.84**	0.68	1.05	**550.50**
		Mendip PCT	5FX	70	106,714	63	**0.90**	0.70	1.15	**590.36**
		North Dorset PCT	5CD	60	84,882	53	**0.89**	0.68	1.16	**624.40**
		Poole PCT	5KV	123	177,766	91	**0.74**	0.60	0.91	**511.91**
		Somerset Coast PCT	5FW	100	141,121	91	**0.91**	0.74	1.12	**644.84**
		South & East Dorset PCT	5FN	114	146,810	80	**0.70**	0.57	0.88	**544.92**
		South Somerset PCT	5K1	101	145,686	81	**0.80**	0.65	1.00	**555.99**
		South West Dorset PCT	5FP	95	131,532	97	**1.02**	0.84	1.25	**737.47**
		Taunton Deane PCT	5K2	68	101,955	66	**0.96**	0.76	1.23	**647.34**

Table D.7: (continued)

UK area	SHA	Name	Code	Tot exp	Tot pop	Tot obs	O/E	L 95% CL	U 95% CL	Crude rate pmp
South West (continued)	South West Peninsula	Central Cornwall PCT	5KT	130	184,265	157	**1.21**	1.04	1.42	**852.03**
		East Devon PCT	5FT	89	117,674	64	**0.72**	0.56	0.92	**543.88**
		Exeter PCT	5FR	82	130,206	84	**1.02**	0.83	1.27	**645.13**
		Mid Devon PCT	5FV	64	92,204	75	**1.17**	0.93	1.46	**813.42**
		North & East Cornwall PCT	5KR	112	156,064	132	**1.18**	1.00	1.40	**845.81**
		North Devon PCT	5FQ	104	146,216	88	**0.84**	0.69	1.04	**601.85**
		Plymouth PCT	5F1	148	234,266	153	**1.03**	0.88	1.21	**653.10**
		South Hams & West Devon PCT	5CV	79	109,761	56	**0.70**	0.54	0.92	**510.20**
		Teignbridge PCT	5FY	75	105,290	66	**0.88**	0.69	1.12	**626.84**
		Torbay PCT	5CW	92	129,848	96	**1.04**	0.85	1.27	**739.33**
		West of Cornwall PCT	5FM	111	156,156	114	**1.03**	0.86	1.23	**730.04**
Wales	Bro Taf	Cardiff	6A8	186	314,969	224	**1.21**	1.06	1.38	**711.18**
		Merthyr Tydfil	6B8	35	55,566	62	**1.76**	1.38	2.26	**1115.78**
		Rhondda, Cynon, Taff	6A9	142	223,693	194	**1.37**	1.19	1.57	**867.26**
		Vale of Glamorgan	6C3	76	116,751	72	**0.94**	0.75	1.19	**616.70**
	Dyfed Powys	Carmarthenshire	6B7	120	172,960	136	**1.14**	0.96	1.34	**786.31**
		Ceredigion	6A4	49	73,544	49	**1.00**	0.75	1.32	**666.27**
		Pembrokeshire	6A3	80	115,618	69	**0.86**	0.68	1.09	**596.79**
		Powys	6C4	89	125,503	76	**0.86**	0.68	1.07	**605.56**
	Gwent	Blaenau Gwent	6C2	44	68,272	52	**1.17**	0.89	1.54	**761.66**
		Caerphilly	6B2	108	170,390	121	**1.12**	0.94	1.34	**710.13**
		Monmouthshire	6A1	59	85,343	71	**1.21**	0.96	1.53	**831.94**
		Newport	6B9	88	138,497	106	**1.21**	1.00	1.46	**765.36**
		Torfaen	6B6	57	89,636	87	**1.51**	1.23	1.87	**970.59**
	Morgannwg	Bridgend	6B3	84	128,145	103	**1.22**	1.01	1.48	**803.78**
		Neath Port Talbot	6A5	89	131,456	108	**1.22**	1.01	1.47	**821.57**
		Swansea	6A6	149	226,286	198	**1.33**	1.16	1.53	**875.00**
	North Wales	Conwy	6A7	79	112,599	75	**0.94**	0.75	1.18	**666.08**
		Denbighshire	6C1	63	92,531	59	**0.93**	0.72	1.21	**637.62**
		Flintshire	6B5	96	148,393	110	**1.14**	0.95	1.38	**741.27**
		Gwynedd	6A2	77	116,068	88	**1.14**	0.92	1.40	**758.18**
		Isle of Anglesey	6B1	47	67,660	46	**0.98**	0.73	1.31	**679.87**
		Wrexham	6B4	81	125,346	108	**1.34**	1.11	1.61	**861.61**

Appendix E: Data Tables

E:1 Patients starting renal replacement in 2004

Table E.1.1: Take-on of new dialysis patients

Treatment centre	Take-on figures for new patients in dialysis			
	Aged <65		Aged >65	
	% on HD	% on PD	% on HD	% on PD
Abrdn	58	42	84	16
Airdr	68	32	95	5
Bangr	86	14	71	29
Barts	64	36	55	45
Basldn	94	6	57	43
Bradf	59	41	97	3
Bright	64	36	77	23
Bristl	79	21	92	8
Camb	53	47	89	11
Carls	78	22	89	11
Carsh	71	29	80	20
Chelms	50	50	78	22
Clwyd	100	0	100	0
Covnt	42	58	60	40
Crdff	75	25	87	13
D&Gall	67	33	80	20
Derby	68	32	87	13
Dorset	44	56	39	61
Dudley	52	48	78	22
Dunde	52	48	89	11
Dunfn	80	20	93	7
Edinb	75	25	93	7
Extr	64	36	82	18
GlasRI	70	30	93	7
GlasWI	60	40	83	17
Glouc	63	38	93	7
Guys	53	47	87	13
H&CX	66	34	87	13
Heart	84	16	86	14
Hull	60	40	90	10
Inver	36	64	59	41
Ipswi	45	55	69	31
Klmarnk	44	56	93	7
Kings	61	39	85	15
Leeds	71	29	78	22
Leic	57	43	68	32
Livrpl	72	28	88	12
ManWst	54	46	57	43
Middlbr	77	23	95	5
Newc	76	24	79	21
Norwch	75	25	88	12
Nottm	49	51	78	22
Oxfrd	67	33	70	30
Plym	67	33	76	24
Ports	55	45	77	23
Prstn	47	53	72	28
QEH	77	23	93	7
Redng	48	52	58	42
Sheff	56	44	68	32
Shrew	37	63	82	18
Stevn	64	36	85	15
Sthend	82	18	96	4
Stob	100	0	100	0
Sund	94	6	88	13
Swnse	75	25	81	19
Truro	43	57	75	25
Wirrl	75	25	88	12
Wolve	65	35	89	11
Wrexm	50	50	100	0
York	56	44	70	30
Eng	64	36	79	21
Sct	63	37	88	12
Wls	74	26	85	15
UK	64	36	81	19

Table E.1.2: Take-on totals of new dialysis patients

	Take on figures for new patients on dialysis			
	Aged <65		Aged >65	
	HD	PD	HD	PD
Eng	1,201	685	1,391	361
Sct	162	94	222	31
Wls	92	33	156	27
UK	1,455	812	1,769	419

Table E.1.3: Treatment modalities at 90 days

Centre	% on HD	% on PD	% transplant	% transferred out	% stopped treatment	% died
Abrdn	67	23	–	–	–	10
Airdr	73	18	–	–	2	6
Bangr	54	18	–	3	3	23
Barts	51	33	7	1	–	8
Basldn	60	18	–	–	8	15
Bradf	74	22	–	–	–	5
Bright	67	27	–	–	–	6
Bristl	72	11	4	–	–	13
Camb	61	27	4	–	–	8
Carls	83	14	3	–	–	–
Carsh	66	22	2	2	–	9
Chelms	59	30	–	–	–	11
Clwyd	89	–	–	–	–	11
Covnt	42	40	9	–	–	10
Crdff	70	16	6	–	–	9
D&Gall	60	20	–	–	–	20
Derby	68	18	–	3	–	11
Dorset	33	46	–	–	13	8
Dudley	54	30	–	–	–	15
Dunde	67	22	1	–	–	9
Dunfn	81	12	–	–	–	8
Edinb	73	15	1	–	1	9
Extr	71	21	–	–	1	7
GlasRI	75	18	–	–	–	7
GlasWI	59	27	3	–	–	11
Glouc	70	16	6	–	–	8
Guys	53	30	13	1	–	3
H&CX	69	24	–	–	1	7
Heart	79	14	1	–	1	5
Hull	62	19	–	–	1	18
Inver	43	46	–	–	–	11
Ipswi	49	41	–	–	–	10
Klmarnk	68	32	–	–	–	–
Kings	62	26	4	3	1	5
Leeds	60	21	5	–	–	13
Leic	53	32	10	–	–	6
Livrpl	68	19	3	–	1	9
ManWst	53	43	–	–	–	4
Middlbr	75	13	–	1	–	11
Newc	57	17	14	–	–	12
Norwch	63	13	–	15	3	6
Nottm	57	30	3	1	–	9
Oxfrd	57	27	7	2	1	7
Plym	54	21	–	–	1	24
Ports	58	33	4	–	–	4
Prstn	56	35	4	–	–	4
QEH	72	14	4	–	–	10
Redng	50	44	1	–	–	4
Sheff	55	35	3	–	–	7
Shrew	50	36	–	2	–	12
Stevn	66	25	2	–	–	7
Sthend	78	10	–	2	–	10
Stob	86	–	–	–	–	14
Sund	86	9	–	–	–	5

Table E.1.3: (continued)

Centre	% on HD	% on PD	% transplant	% transferred out	% stopped treatment	% died
Swnse	71	19	–	–	–	10
Truro	61	38	–	–	2	–
Wirrl	71	16	–	–	–	13
Wolve	65	22	1	–	–	12
Wrexm	70	19	4	4	–	4
York	55	32	–	–	–	13
Eng	62	25	3	1	1	9
Sct	68	22	1	–	0	9
Wls	69	17	3	1	0	10
UK	63	24	3	1	0	9

Table E.1.4: Number of patients per treatment modality at 90 days

	Treatment modalities at 90 days					
	HD	PD	Transplant	Transferred out	Stopped treatment	Died
Eng	2,592	1,046	139	29	22	360
Sct	384	125	5	–	2	51
Wls	248	60	12	2	1	37
UK	3,224	1,231	156	31	25	448

Table E.1.5: First treatment modality

Centre	First treatment modality			Centre	First treatment modality		
	% HD	% PD	% transplant		% HD	% PD	% transplant
Abrdn	74	26	–	Klmarnk	68	32	–
Airdr	86	14	–	Kings	72	27	2
Bangr	82	18	–	Leeds	72	24	4
Barts	59	36	5	Leic	57	35	7
Basldn	83	18	–	Livrpl	77	21	2
Bradf	77	23	–	ManWst	52	48	–
Bright	69	31	–	Middlbr	84	16	–
Bristl	82	14	4	Newc	69	19	11
Camb	69	27	4	Norwch	87	13	–
Carls	76	24	–	Nottm	66	32	2
Carsh	78	22	–	Oxfrd	64	31	5
Chelms	67	33	–	Plym	76	24	–
Clwyd	100	–	–	Ports	59	37	3
Covnt	51	43	6	Prstn	55	40	4
Crdff	78	18	4	QEH	81	17	2
D&Gall	80	20	–	Redng	51	47	1
Derby	79	21	–	Sheff	60	37	3
Dorset	48	52	–	Shrew	64	36	–
Dudley	65	35	–	Stevn	72	25	3
Dunde	78	22	–	Sthend	88	12	–
Dunfn	88	12	–	Stob	100	–	–
Edinb	85	15	–	Sund	90	10	–
Extr	77	23	–	Swnse	77	23	–
GlasRI	81	19	–	Truro	59	41	–
GlasWI	70	27	3	Wirrl	85	15	–
Glouc	76	18	6	Wolve	75	25	–
Guys	57	33	10	Wrexm	78	22	–
H&CX	73	26	1	York	62	38	–
Heart	83	17	–	Eng	70	28	3
Hull	81	19	–	Sct	77	22	1
Inver	54	46	–	Wls	79	19	2
Ipswi	56	44	–	UK	71	27	2

Table E.1.6: First treatment modality – patient numbers

	First treatment modality		
	HD	PD	Transplant
Eng	2,921	1,161	107
Sct	438	126	3
Wls	284	69	7
UK	3,643	1,356	117

Table E.1.7: Treatment modalities by gender

	Treatment by gender					
	Haemodialysis			Peritoneal dialysis		
Centre	% Male	% Female	M:F Ratio	% Male	% Female	M:F Ratio
Abrdn	63	37	1.7	44	56	0.8
Airdr	53	47	1.1	44	56	0.8
Bangr	67	33	2.0	86	14	6.0
Barts	57	43	1.3	59	41	1.4
Basldn	75	25	3.0	71	29	2.5
Bradf	65	35	1.8	50	50	1.0
Bright	67	33	2.1	57	43	1.3
Bristl	64	36	1.8	58	42	1.4
Camb	69	31	2.3	77	23	3.3
Carls	75	25	3.0	75	25	3.0
Carsh	62	38	1.6	54	46	1.2
Chelms	52	48	1.1	43	57	0.7
Clwyd	100	0	–	–	–	–
Covnt	59	41	1.4	66	34	1.9
Crdff	62	38	1.6	55	45	1.2
D&Gall	50	50	1.0	100	–	–
Derby	57	43	1.3	55	45	1.2
Dorset	81	19	4.2	59	41	1.4
Dudley	64	36	1.8	86	14	6.0
Dunde	58	42	1.4	53	47	1.1
Dunfn	48	52	0.9	33	67	0.5
Edinb	48	52	0.9	50	50	1.0
Extr	70	30	2.3	59	41	1.4
GlasRI	67	33	2.0	54	46	1.2
GlasWI	60	40	1.5	38	62	0.6
Glouc	74	26	2.9	38	63	0.6
Guys	66	34	1.9	53	47	1.1
H&CX	59	41	1.4	65	35	1.9
Heart	60	40	1.5	79	21	3.7
Hull	74	26	2.9	44	56	0.8
Inver	47	53	0.9	38	63	0.6
Ipswi	63	37	1.7	75	25	3.0
Klmarnk	67	33	2.0	40	60	0.7
Kings	63	37	1.7	61	39	1.5
Leeds	63	37	1.7	55	45	1.2
Leic	68	32	2.2	55	45	1.2
Livrpl	62	38	1.6	52	48	1.1
ManWst	58	42	1.4	65	35	1.8
Middlbr	64	36	1.8	92	8	11.0
Newc	60	40	1.5	68	32	2.2
Norwch	76	24	3.1	33	67	0.5
Nottm	53	47	1.1	59	41	1.5
Oxfrd	61	39	1.6	64	36	1.7
Plym	75	25	3.0	71	29	2.5
Ports	58	42	1.4	74	26	2.9
Prstn	58	42	1.4	45	55	0.8
QEH	58	42	1.4	35	65	0.5
Redng	59	41	1.4	67	33	2.0
Sheff	62	38	1.7	63	37	1.7
Shrew	67	33	2.0	87	13	6.5
Stevn	71	29	2.4	68	32	2.1
Sthend	55	45	1.2	40	60	0.7

Table E.1.7: (continued)

	Treatment by gender					
	Haemodialysis			Peritoneal dialysis		
Centre	% Male	% Female	M:F Ratio	% Male	% Female	M:F Ratio
Stob	42	58	0.7	–	–	–
Sund	64	36	1.8	80	20	4.0
Swnse	59	41	1.4	84	16	5.3
Truro	44	56	0.8	71	29	2.5
Wirrl	61	39	1.6	50	50	1.0
Wolve	76	24	3.2	71	29	2.5
Wrexm	63	37	1.7	80	20	4.0
York	54	46	1.2	27	73	0.4
Eng	63	37	1.7	61	39	1.6
Sct	57	43	1.3	45	55	0.8
Wls	63	37	1.7	70	30	2.3
UK	62	38	1.7	60	40	1.5

Table E.1.8: Treatment modality numbers by gender

	Haemodialysis		Peritoneal dialysis	
	Male	Female	Male	Female
Eng	1,638	954	636	410
Sct	218	166	56	69
Wls	156	92	42	18
UK	2,012	1,212	734	497

E:2 Current patients 2004

Table E.2.1: Treatment modalities for patients aged under 65 and over 65

	Treatment modalities by centre							
	Patients aged <65				Patients aged >65			
Centre	% HD	% PD	% transplant	HD:PD	% HD	% PD	% transplant	HD:PD
Abrdn	30	12	58	2.4	73	8	19	9.2
Airdr	72	28	0	2.6	92	8	0	11.8
Bangr	73	27	0	2.7	76	24	0	3.2
Barts	28	15	56	1.9	47	22	31	2.1
Basldn	64	16	21	4.1	75	17	8	4.4
Bradf	33	17	50	2.0	77	11	13	7.1
Bright	35	14	52	2.5	66	18	17	3.7
Bristl	21	6	73	3.6	67	6	27	11.9
Camb	20	12	68	1.7	63	12	25	5.1
Carls	25	8	67	3.0	75	10	15	7.5
Carsh	37	18	45	2.1	59	22	19	2.6
Chelms	67	26	7	2.5	78	22	0	3.5
Clwyd	73	10	17	7.5	94	6	0	15.5
Covnt	30	11	58	2.7	64	17	19	3.9
Crdff	23	10	67	2.2	60	13	27	4.5
D&Gall	62	15	23	4.0	76	24	0	3.2
Derby	71	26	3	2.7	80	20	1	4.0

Table E.2.1: (continued)

	Treatment modalities by centre							
	Patients aged <65				Patients aged >65			
Centre	% HD	% PD	% transplant	HD : PD	% HD	% PD	% transplant	HD : PD
Dorset	25	16	59	1.6	43	33	23	1.3
Dudley	34	23	43	1.5	58	21	21	2.8
Dunde	27	13	60	2.0	63	13	23	4.8
Dunfn	53	19	27	2.8	81	11	8	7.4
Edinb	28	8	64	3.3	60	11	29	5.7
Extr	24	18	59	1.3	75	13	12	5.9
GlasRI	71	27	2	2.7	94	6	0	16.6
GlasWI	15	6	78	2.4	42	8	50	5.0
Glouc	32	13	55	2.5	78	9	13	8.2
Guys	22	7	70	3.0	58	12	31	4.9
H&CX	39	17	44	2.4	67	12	21	5.6
Heart	49	6	45	8.4	84	5	11	18.0
Hull	40	10	50	4.2	80	5	15	15.3
Inver	29	14	57	2.1	60	31	9	1.9
Ipswi	27	24	49	1.1	55	33	11	1.7
Klmarnk	44	35	20	1.2	74	19	7	3.8
Kings	33	14	53	2.4	65	14	21	4.5
Leeds	23	9	68	2.7	66	11	23	6.3
Leic	30	15	55	2.0	58	20	21	2.9
Livrpl	26	9	65	3.1	48	11	41	4.4
ManWst	28	19	53	1.5	52	29	19	1.8
Middlbr	30	5	65	5.9	71	2	27	32.7
Newc	21	6	73	3.8	45	7	48	6.2
Norwch	47	14	38	3.4	79	10	11	8.1
Nottm	24	16	60	1.5	62	18	20	3.5
Oxfrd	21	11	69	2.0	50	14	36	3.6
Plym	26	11	64	2.4	53	16	31	3.4
Ports	22	8	70	2.8	52	13	35	4.0
Prstn	32	11	56	2.8	64	16	19	3.9
QEH	39	11	50	3.6	74	9	17	8.6
Redng	35	19	45	1.8	54	31	15	1.8
Sheff	38	13	49	3.0	64	18	18	3.7
Shrew	42	20	38	2.1	76	11	13	6.8
Stevn	45	13	42	3.6	78	9	14	9.1
Sthend	56	18	27	3.2	91	7	3	13.8
Stob	100	0	0		100	0	0	
Sund	43	4	53	10.1	67	6	27	10.8
Swnse	46	17	38	2.8	68	21	12	3.3
Truro	33	24	43	1.4	71	16	13	4.4
Wirrl	84	16	0	5.4	90	10	0	9.0
Wolve	57	13	30	4.5	80	13	7	6.3
Wrexm	45	29	26	1.6	73	19	9	3.9
York	44	12	44	3.8	76	18	5	4.1
Eng	31	12	56	2.5	64	14	21	4.5
Sct	31	12	58	2.6	67	11	22	6.1
Wls	32	14	54	2.3	66	16	18	4.1
UK	31	12	56	2.5	65	14	21	4.6

Table E.2.2: Numbers of patients under and over 65 per treatment modality

	Treatment modality numbers					
	Patients aged <65			Patients aged >65		
	HD	PD	Transplant	HD	PD	Transplant
Eng	5,968	2,343	10,724	5,633	1,246	1,866
Sct	743	281	1,411	785	129	253
Wls	429	183	714	483	119	128
UK	7,140	2,807	12,849	6,901	1,494	2,247

Table E.2.3: Treatment modality median ages by centre

	Median ages and treatment modalities by centre			
Centre	Median age on HD	Median age on PD	Median age on transplant	Median age for all
Abrdn	65.1	57.9	50.3	56.1
Airdr	64.8	47.0	–	62.7
Bangr	68.2	66.7	–	68.0
Barts	57.7	56.5	48.9	52.6
Basldn	61.3	60.2	47.2	59.8
Bradf	66.6	54.8	46.3	55.6
Bright	67.1	63.5	50.5	61.3
Bristl	70.3	58.0	50.4	57.6
Camb	66.5	58.8	48.8	54.6
Carls	68.3	56.9	50.4	59.4
Carsh	62.0	57.5	51.9	57.8
Chelms	66.2	62.9	38.4	64.3
Clwyd	65.3	56.3	49.4	59.3
Covnt	63.8	60.4	47.6	55.7
Crdff	67.0	59.4	49.8	55.7
D&Gall	66.4	66.4	43.7	65.7
Derby	65.0	58.9	47.6	63.4
Dorset	64.3	67.7	54.3	58.7
Dudley	61.9	58.4	54.6	58.3
Dunde	69.9	59.6	52.5	59.4
Dunfn	67.5	60.6	47.0	61.7
Edinb	63.8	56.4	51.1	55.4
Extr	70.6	58.2	50.6	60.0
GlasRI	66.3	52.5	51.4	62.2
GlasWI	60.8	55.4	47.6	50.5
Glouc	70.2	60.6	51.3	62.1
Guys	62.0	54.5	48.1	51.4
H&CX	62.8	55.0	53.2	57.8
Heart	65.5	59.2	50.4	60.4
Hull	65.3	51.8	50.2	57.5
Inver	67.8	67.8	45.4	56.8
Ipswi	65.4	59.6	50.6	56.9
Klmarnk	67.1	54.0	50.2	60.5
Kings	64.9	56.1	49.8	55.2
Leeds	65.4	54.2	48.5	53.7
Leic	63.2	60.7	50.1	56.1
Livrpl	58.5	50.6	49.7	52.0
ManWst	58.1	56.9	46.0	52.2
Middlbr	65.8	53.2	49.8	56.1
Newc	59.5	55.4	52.5	53.9

Table E.2.3: (continued)

Centre	Median ages and treatment modalities by centre			
	Median age on HD	Median age on PD	Median age on transplant	Median age for all
Norwch	66.1	56.5	50.1	60.5
Nottm	66.4	57.7	46.7	54.5
Oxfrd	65.4	60.3	51.6	55.6
Plym	63.5	62.9	51.5	57.3
Ports	64.3	59.1	49.9	55.1
Prstn	61.3	55.6	49.0	54.0
QEH	63.0	55.3	48.5	55.7
Redng	64.2	64.7	52.6	59.5
Sheff	61.6	61.2	48.8	56.6
Shrew	64.6	56.0	50.4	58.9
Stevn	65.8	59.6	51.3	59.9
Sthend	69.1	60.2	54.0	63.3
Stob	66.6	–	–	66.6
Sund	60.6	54.3	50.5	55.6
Swnse	66.5	63.7	53.2	61.8
Truro	73.2	60.6	55.4	65.5
Wirrl	65.1	61.7	–	64.5
Wolve	64.1	60.8	44.7	61.0
Wrexm	66.4	57.7	50.8	59.7
York	67.8	65.8	42.8	59.9
Eng	64.3	58.3	49.8	56.3
Sct	65.4	57.0	49.0	55.8
Wls	66.8	60.1	50.2	57.8
UK	64.7	58.3	49.7	56.4

Table E.2.4: Dialysis modalities for patients aged less than 65

Centre	Dialysis modalities for patients aged under 65							
	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD $\geqslant$6 nights	% on cycling PD <6 nights	% on unknown type of PD
Abrdn	5	66	0	0	28	1	0	0
Airdr	0	72	0	0	13	16	0	0
Bangr	0	73	0	0	7	20	0	0
Barts	2	45	18	0	17	17	0	0
Basldn	0	80	0	0	8	11	1	0
Bradf	0	50	17	0	14	19	0	0
Bright	19	31	22	0	12	16	0	0
Bristl	13	15	50	0	18	3	0	0
Camb	2	47	13	0	32	4	2	0
Carls	0	60	15	0	18	8	0	0
Carsh	1	46	21	0	16	17	0	0
Chelms	0	72	0	16	1	9	1	0
Clwyd	3	85	0	3	6	3	0	0
Covnt	5	69	0	0	27	0	0	0
Crdff	0	36	32	0	32	0	0	0
D&Gall	5	75	0	0	15	5	0	0
Derby	1	72	0	3	23	0	1	0

Table E.2.4: (continued)

Centre	Dialysis modalities for patients aged under 65							
	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ⩾6 nights	% on cycling PD <6 nights	% on unknown type of PD
Dorset	0	62	0	2	21	13	1	1
Dudley	1	59	0	0	40	0	0	0
Dunde	3	64	0	0	8	26	0	0
Dunfn	2	72	0	0	6	21	0	0
Edinb	3	74	0	0	13	10	0	0
Extr	1	29	27	0	28	14	1	0
GlasRI	0	73	0	0	9	18	0	0
GlasWI	0	71	0	0	13	15	1	0
Glouc	0	71	0	0	23	6	0	0
Guys	6	29	39	0	13	0	12	0
H&CX	2	39	29	0	17	12	0	0
Heart	12	72	5	0	8	2	0	0
Hull	6	44	31	0	10	9	0	0
Inver	0	68	0	0	17	15	0	0
Ipswi	7	46	0	0	24	22	1	0
Klmarnk	3	53	0	0	23	20	1	0
Kings	0	38	32	0	24	4	0	2
Leeds	2	41	30	0	20	8	0	0
Leic	4	24	39	0	15	18	0	0
Livrpl	1	35	40	1	9	13	2	0
ManWst	7	28	25	0	37	3	0	0
Middlbr	2	59	24	0	14	0	0	0
Newc	4	75	0	0	6	15	0	0
Norwch	0	77	0	0	19	4	0	0
Nottm	1	36	24	0	14	25	0	0
Oxfrd	6	61	0	0	14	19	0	0
Plym	1	70	0	0	22	7	0	0
Ports	0	45	29	0	26	0	0	0
Prstn	7	34	34	0	17	7	2	0
QEH	4	23	51	22	0	0	0	0
Redng	0	35	30	0	35	0	0	0
Sheff	9	29	37	0	25	0	0	0
Shrew	1	67	0	0	32	0	0	0
Stevn	0	36	42	0	22	0	0	0
Sthend	0	76	0	0	24	0	0	0
Stob	30	70	0	0	0	0	0	0
Sund	1	66	24	0	3	6	0	0
Swnse	7	41	25	0	27	0	0	0
Truro	3	44	12	0	35	8	0	0
Wirrl	0	50	34	0	8	7	0	0
Wolve	0	28	54	0	18	1	0	0
Wrexm	3	57	0	0	1	38	0	0
York	2	53	25	0	21	0	0	0
Eng	4	43	25	1	18	8	1	0
Sct	3	69	0	0	14	13	0	0
Wls	2	46	22	0	23	7	0	0
UK	3	46	22	1	18	9	1	0

Table E.2.5: Dialysis modalities for patients aged over 65

	Dialysis modalities for patients aged over 65							
Centre	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ⩾6 nights	% on cycling PD <6 nights	% on unknown type of PD
Abrdn	3	87	0	0	10	0	0	0
Airdr	0	92	0	0	6	1	0	0
Bangr	0	76	0	0	9	15	0	0
Barts	0	48	20	0	25	7	0	0
Basldn	0	81	0	2	8	8	0	0
Bradf	0	60	28	0	8	4	0	0
Bright	5	42	31	0	13	8	0	0
Bristl	1	18	73	0	6	1	0	0
Camb	2	60	22	0	16	1	0	0
Carls	0	78	10	2	8	2	0	0
Carsh	0	53	19	0	12	16	0	0
Chelms	0	78	0	16	0	4	1	0
Clwyd	0	94	0	6	0	0	0	0
Covnt	0	79	0	0	21	0	0	0
Crdff	0	36	45	0	18	0	0	0
D&Gall	0	76	0	0	6	18	0	0
Derby	0	80	0	1	17	1	1	0
Dorset	0	56	0	0	36	7	0	1
Dudley	0	74	0	0	26	0	0	0
Dunde	0	83	0	0	7	10	0	0
Dunfn	0	88	0	0	2	10	0	0
Edinb	1	84	0	0	10	5	0	0
Extr	0	41	44	0	13	1	1	0
GlasRI	0	94	0	0	6	0	0	0
GlasWI	0	83	0	0	9	6	2	0
Glouc	0	89	0	0	8	3	0	0
Guys	1	26	57	0	11	0	6	0
H&CX	0	51	34	0	7	8	0	0
Heart	1	85	9	0	5	0	0	0
Hull	1	46	47	0	2	4	0	0
Inver	0	66	0	0	22	13	0	0
Ipswi	1	61	0	0	18	12	8	0
Klmarnk	0	79	0	0	17	3	0	0
Kings	1	38	43	0	16	2	0	0
Leeds	0	46	40	0	11	3	0	0
Leic	1	26	47	0	18	8	0	0
Livrpl	1	51	30	0	13	4	1	1
ManWst	0	40	24	0	35	1	0	0
Middlbr	0	66	31	0	3	0	0	0
Newc	0	86	0	0	2	12	0	0
Norwch	0	89	0	0	11	0	0	0
Nottm	0	45	32	0	14	9	0	0
Oxfrd	3	75	0	0	15	7	0	0
Plym	0	77	0	0	19	4	0	0
Ports	0	42	38	0	20	0	0	0
Prstn	1	30	49	0	17	2	1	0
QEH	1	29	60	10	0	0	0	0
Redng	0	37	26	0	36	0	0	0
Sheff	1	38	39	0	21	0	0	0
Shrew	0	87	0	0	13	0	0	0
Stevn	0	44	46	0	10	0	0	0
Sthend	0	93	0	0	7	0	0	0

Table E.2.5: (continued)

Centre	Dialysis modalities for patients aged over 65							
	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ⩾6 nights	% on cycling PD <6 nights	% on unknown type of PD
Stob	5	95	0	0	0	0	0	0
Sund	0	66	25	0	5	3	0	0
Swnse	1	50	26	0	23	0	0	0
Truro	1	53	28	0	16	2	0	0
Wirrl	0	56	34	0	7	3	0	0
Wolve	0	25	61	0	12	1	0	0
Wrexm	0	79	0	0	0	19	1	0
York	0	56	25	0	18	1	0	0
Eng	1	51	31	1	13	4	0	0
Sct	1	85	0	0	9	5	0	0
Wls	0	52	28	0	16	4	0	0
UK	1	55	27	1	13	4	0	0

Table E.2.6: Age ranges by centre

Centre	Patient age range by centre (%)							
	18–24	25–34	35–44	45–54	55–64	65–74	75–84	85+
Abrdn	3	8	15	22	23	17	12	1
Airdr	2	8	12	19	16	24	18	1
Bangr	2	4	7	13	19	26	24	4
Barts	3	10	19	24	20	19	5	0
Basldn	2	10	9	19	20	24	15	1
Bradf	4	8	19	18	17	21	12	1
Bright	3	6	13	15	23	21	16	2
Bristl	4	7	16	18	21	19	13	2
Camb	2	9	19	21	22	17	9	1
Carls	1	7	16	15	28	18	14	1
Carsh	2	9	19	15	24	20	11	1
Chelms	2	5	10	14	21	22	25	1
Clwyd	5	4	14	16	16	20	22	3
Covnt	2	9	20	19	21	17	13	0
Crdff	3	9	17	19	22	17	11	2
D&Gall	0	7	12	8	17	40	13	3
Derby	1	4	12	17	18	27	19	1
Dorset	2	6	13	19	24	21	14	1
Dudley	2	5	13	22	24	21	12	1
Dunde	2	8	16	15	19	19	17	3
Dunfn	3	7	12	18	13	27	17	3
Edinb	2	9	19	20	22	21	8	1
Extr	2	6	14	18	22	18	17	2
GlasRI	1	5	12	19	18	26	18	2
GlasWI	2	12	22	23	19	16	6	0
Glouc	2	6	10	16	22	22	19	3
Guys	3	10	23	21	20	16	7	1
H&CX	2	7	13	21	24	22	10	1
Heart	2	8	13	15	23	19	17	2
Hull	3	8	15	18	21	19	13	2
Inver	2	9	16	18	16	26	12	1
Ipswi	3	5	17	20	21	20	12	2
Klmarnk	1	9	16	16	16	22	19	1
Kings	1	8	21	20	17	22	11	1

Table E.2.6: (continued)

Centre	Patient age range by centre (%)							
	18–24	25–34	35–44	45–54	55–64	65–74	75–84	85+
Leeds	6	10	17	20	20	17	9	1
Leic	3	9	17	19	22	19	11	1
Livrpl	3	10	21	22	21	16	8	0
ManWst	2	12	21	20	20	18	7	0
Middlbr	3	8	20	17	21	19	12	1
Newc	4	8	18	23	23	17	7	1
Norwch	1	6	14	16	23	20	17	3
Nottm	5	10	16	20	19	18	11	1
Oxfrd	2	9	19	19	21	19	10	2
Plym	2	10	16	17	24	18	12	1
Ports	4	8	19	19	23	17	10	1
Prstn	2	9	19	22	21	18	8	1
QEH	3	8	17	20	20	20	10	1
Redng	3	7	12	21	19	23	13	2
Sheff	2	8	16	20	23	21	9	1
Shrew	2	7	15	18	23	21	13	1
Stevn	2	7	15	17	22	25	13	1
Sthend	1	6	9	12	28	21	17	5
Stob	1	2	9	16	18	32	22	2
Sund	2	12	14	21	20	19	10	0
Swnse	2	5	11	17	22	27	15	2
Truro	1	4	10	13	20	27	19	5
Wirrl	3	5	10	12	22	26	19	4
Wolve	3	8	14	16	20	23	15	1
Wrexm	3	7	12	17	22	26	12	3
York	5	6	17	15	13	20	17	6
Eng	3	8	17	19	21	19	11	1
Sct	2	9	17	20	19	20	11	1
Wls	3	8	14	18	22	21	13	2
UK	3	8	17	19	21	19	11	1

Table E.2.7: Dialysis modalities for non-diabetic patients (all ages)

Centre	Dialysis modalities for non-diabetic patients (all ages)							
	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ⩾6 nights	% on cycling PD <6 nights	% on unknown type of PD
Abrdn	5	75	0	0	19	1	0	0
Airdr	0	81	0	0	9	9	0	0
Bangr	0	75	0	0	8	17	0	0
Barts	2	44	20	0	19	15	0	0
Basldn	0	81	0	1	7	10	1	0
Bradf	0	53	24	0	12	11	0	0
Bright	63	10	8	0	6	13	0	0
Bristl	7	15	65	0	10	2	0	0
Camb	2	54	16	0	24	3	1	0
Carls	0	68	13	1	14	4	0	0
Carsh	1	47	20	0	14	18	0	0
Chelms	0	78	0	14	0	7	1	0
Clwyd	2	91	0	4	4	0	0	0
Covnt	3	75	0	0	22	0	0	0
Crdff	0	34	40	0	26	0	0	0
D&Gall	2	76	0	0	8	14	0	0

Table E.2.7: (continued)

Centre	Dialysis modalities for non-diabetic patients (all ages)							
	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ⩾6 nights	% on cycling PD <6 nights	% on unknown type of PD
Derby	1	73	0	2	23	0	0	0
Dorset	0	58	0	1	29	11	1	1
Dudley	1	65	0	0	34	0	0	0
Dunde	1	78	0	0	5	16	0	0
Dunfn	1	83	0	0	2	14	0	0
Edinb	2	80	0	0	10	8	0	0
Extr	1	32	37	0	22	8	1	0
GlasRI	0	83	0	0	6	11	0	0
GlasWI	0	77	0	0	12	10	1	0
Glouc	0	82	0	0	14	4	0	0
Guys	5	28	46	0	12	0	9	0
H&CX	2	40	33	0	14	11	1	0
Heart	8	78	6	0	6	1	0	0
Hull	4	46	38	0	6	6	0	0
Inver	0	64	0	0	22	14	0	0
Ipswi	4	55	0	0	20	16	5	0
Klmarnk	2	63	0	0	22	14	0	0
Kings	0	35	40	0	22	3	0	1
Leeds	1	39	39	0	15	6	0	0
Leic	3	24	41	0	17	15	0	0
Livrpl	1	38	38	0	10	11	1	0
ManWst	5	33	23	0	37	3	0	0
Middlbr	1	62	29	0	9	0	0	0
Newc	3	81	0	0	4	12	0	0
Norwch	0	82	0	0	16	2	0	0
Nottm	1	40	29	0	14	16	0	0
Oxfrd	5	70	0	0	12	12	0	0
Plym	1	73	0	0	19	6	0	0
Ports	0	44	34	0	22	0	0	0
Prstn	5	30	41	0	17	5	1	0
QEH	3	25	55	17	0	0	0	0
Redng	0	39	27	0	33	0	0	0
Sheff	6	33	40	0	22	0	0	0
Shrew	0	74	0	0	26	0	0	0
Stevn	0	40	45	0	15	0	0	0
Sthend	0	85	0	0	15	0	0	0
Stob	17	83	0	0	0	0	0	0
Sund	1	66	25	0	3	5	0	0
Swnse	4	47	26	0	23	0	0	0
Truro	1	52	22	0	20	5	0	0
Wirrl	0	54	33	0	8	6	0	0
Wolve	0	26	59	0	14	1	0	0
Wrexm	3	72	0	0	1	22	1	0
York	1	50	28	0	20	1	0	0
Eng	3	46	28	1	16	6	1	0
Sct	2	77	0	0	11	10	0	0
Wls	1	48	26	0	20	4	0	0
UK	3	50	25	1	15	6	0	0

Table E.2.8: Numbers of non-diabetic patients by treatment modalities

	Treatment modalities for non-diabetic patients (all ages)		
	HD	PD	Transplants
Eng	9,212	2,809	11,279
Sct	1,258	319	1,532
Wls	685	217	732
UK	11,155	3,345	13,543

Table E.2.9: Dialysis modalities for non-diabetic patients aged less than 65

	Dialysis modalities for non-diabetic patients aged under 65							
Centre	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ⩾6 nights	% on cycling PD <6 nights	% on unknown type of PD
Abrdn	7	64	0	0	27	1	0	0
Airdr	0	71	0	0	12	17	0	0
Bangr	0	73	0	0	8	20	0	0
Barts	3	44	18	0	17	19	0	0
Basldn	0	82	0	0	5	11	2	0
Bradf	0	51	16	0	15	18	0	0
Bright	66	11	11	0	3	9	0	0
Bristl	16	14	50	0	16	4	0	0
Camb	3	48	14	0	29	4	2	0
Carls	0	59	15	0	21	6	0	0
Carsh	1	44	22	0	14	19	0	0
Chelms	0	76	0	14	0	10	0	0
Clwyd	4	88	0	0	8	0	0	0
Covnt	6	72	0	0	23	0	0	0
Crdff	0	36	30	0	33	0	0	0
D&Gall	6	72	0	0	17	6	0	0
Derby	2	70	0	3	25	0	0	0
Dorset	0	58	0	1	24	14	1	1
Dudley	1	60	0	0	39	0	0	0
Dunde	2	68	0	0	7	24	0	0
Dunfn	2	76	0	0	4	18	0	0
Edinb	3	76	0	0	11	9	0	0
Extr	2	28	24	0	29	16	1	0
GlasRI	0	73	0	0	7	20	0	0
GlasWI	0	74	0	0	13	13	1	0
Glouc	0	69	0	0	24	7	0	0
Guys	8	30	38	0	12	0	12	0
H&CX	3	37	30	0	18	12	1	0
Heart	16	70	5	0	7	3	0	0
Hull	7	45	29	0	10	10	0	0
Inver	0	64	0	0	18	18	0	0
Ipswi	8	49	0	0	24	20	0	0
Klmarnk	3	51	0	0	24	22	0	0
Kings	0	36	34	0	24	4	0	1
Leeds	2	37	33	0	19	9	0	0
Leic	5	22	37	0	16	20	0	0
Livrpl	1	32	43	0	8	14	1	0
ManWst	7	27	24	0	38	3	0	0
Middlbr	2	58	26	0	14	0	0	0
Newc	5	77	0	0	5	13	0	0
Norwch	0	76	0	0	20	4	0	0
Nottm	2	36	25	0	15	22	0	0

Table E.2.9: (continued)

Centre	Dialysis modalities for non-diabetic patients aged under 65							
	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ⩾6 nights	% on cycling PD <6 nights	% on unknown type of PD
Oxfrd	7	62	0	0	12	18	0	0
Plym	2	71	0	0	18	9	0	0
Ports	0	45	30	0	26	0	0	0
Prstn	8	33	34	0	17	6	2	0
QEH	5	22	52	22	0	0	0	0
Redng	0	40	26	0	34	0	0	0
Sheff	11	29	37	0	23	0	0	0
Shrew	0	67	0	0	33	0	0	0
Stevn	0	37	43	0	20	0	0	0
Sthend	0	74	0	0	26	0	0	0
Stob	30	70	0	0	0	0	0	0
Sund	1	65	25	0	1	7	0	0
Swnse	7	44	24	0	25	0	0	0
Truro	2	45	13	0	32	9	0	0
Wirrl	0	52	32	0	9	8	0	0
Wolve	0	26	55	0	18	1	0	0
Wrexm	6	61	0	0	2	31	0	0
York	2	49	26	0	23	0	0	0
Eng	4	43	25	1	17	8	1	0
Sct	4	70	0	0	13	13	0	0
Wls	3	47	21	0	24	5	0	0
UK	4	46	23	1	17	9	1	0

Table E.2.10: Numbers of non-diabetic patients aged less than 65 by treatment modalities

	Treatment modalities for non-diabetic patients aged under 65		
	HD	PD	Transplant
Eng	4,763	1,822	9,575
Sct	612	216	1,288
Wls	314	130	620
UK	5,689	2,168	11,483

Table E.2.11: Dialysis modalities for non-diabetic patients aged over 65

	Dialysis modalities for non-diabetic patients aged over 65							
Centre	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ⩾6 nights	% on cycling PD <6 nights	% on unknown type of PD
Abrdn	3	89	0	0	8	0	0	0
Airdr	0	94	0	0	6	0	0	0
Bangr	0	77	0	0	9	14	0	0
Barts	1	45	25	0	24	6	0	0
Basldn	0	80	0	2	9	9	0	0
Bradf	0	55	32	0	8	4	0	0
Bright	54	8	0	0	15	23	0	0
Bristl	1	16	76	0	6	1	0	0
Camb	1	62	18	0	18	1	0	0
Carls	0	75	11	2	9	2	0	0
Carsh	0	52	16	0	14	18	0	0
Chelms	0	80	0	15	0	4	2	0
Clwyd	0	93	0	7	0	0	0	0
Covnt	0	78	0	0	22	0	0	0
Crdff	0	31	50	0	19	0	0	0
D&Gall	0	77	0	0	3	19	0	0
Derby	0	76	0	2	20	1	1	0
Dorset	0	58	0	0	34	8	0	1
Dudley	0	73	0	0	27	0	0	0
Dunde	0	86	0	0	4	11	0	0
Dunfn	0	90	0	0	0	10	0	0
Edinb	1	84	0	0	9	6	0	0
Extr	0	34	48	0	16	1	1	0
GlasRI	0	96	0	0	4	0	0	0
GlasWI	0	83	0	0	10	7	1	0
Guys	1	24	59	0	11	0	5	0
H&CX	0	46	36	0	8	9	0	0
Heart	1	85	8	0	6	0	0	0
Hull	1	47	47	0	2	2	0	0
Inver	0	64	0	0	25	11	0	0
Ipswi	0	63	0	0	16	12	9	0
Klmarnk	0	77	0	0	20	4	0	0
Kings	1	32	47	0	18	1	0	0
Leeds	0	42	45	0	10	2	0	0
Leic	1	25	47	0	19	8	0	0
Livrpl	1	50	29	0	14	4	1	1
ManWst	0	41	23	0	35	1	0	0
Middlbr	0	65	31	0	3	0	0	0
Newc	0	87	0	0	2	11	0	0
Norwch	0	89	0	0	11	0	0	0
Nottm	0	45	34	0	13	9	0	0
Oxfrd	4	77	0	0	13	7	0	0
Plym	0	76	0	0	21	3	0	0
Ports	0	42	39	0	19	0	0	0
Prstn	1	27	51	0	18	3	1	0
QEH	1	29	59	12	0	0	0	0
Redng	0	39	29	0	33	0	0	0
Sheff	0	37	43	0	21	0	0	0
Shrew	0	86	0	0	14	0	0	0
Stevn	0	43	47	0	10	0	0	0
Sthend	0	95	0	0	5	0	0	0
Stob	6	94	0	0	0	0	0	0

Table E.2.11: (continued)

Centre	Dialysis modalities for non-diabetic patients aged over 65							
	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ⩾6 nights	% on cycling PD <6 nights	% on unknown type of PD
Sund	0	68	24	0	6	2	0	0
Swnse	1	50	28	0	22	0	0	0
Truro	1	56	28	0	13	2	0	0
Wirrl	0	56	34	0	7	3	0	0
Wolve	0	25	63	0	11	2	0	0
Wrexm	0	85	0	0	0	13	3	0
York	0	51	30	0	18	2	0	0
Eng	1	50	31	1	14	3	0	0
Sct	1	85	0	0	8	5	0	0
Wls	0	50	31	0	16	2	0	0
UK	1	54	28	1	13	4	0	0

Table E.2.12: Numbers of non-diabetic patients aged over 65 by treatment modalities

	Treatment modalities for non-diabetic patients aged over 65		
	HD	PD	Transplant
Eng	4,449	987	1,704
Sct	646	103	244
Wls	371	87	112
UK	5,466	1,177	2,060

Table E.2.13: Dialysis modalities for diabetic patients

Centre	Dialysis modalities for diabetic patients							
	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ⩾6 nights	% on cycling PD <6 nights	% on unknown type of PD
Abrdn	3	81	0	0	17	0	0	0
Airdr	0	77	0	0	13	10	0	0
Bangr	0	73	0	0	7	20	0	0
Barts	0	50	15	0	23	11	0	0
Basldn	0	80	0	0	10	10	0	0
Bradf	0	63	15	0	7	15	0	0
Bright	100	0	0	0	0	0	0	0
Bristl	1	18	64	0	16	1	0	0
Camb	2	44	27	0	27	0	0	0
Carls	0	85	8	0	0	8	0	0
Carsh	0	55	19	0	15	10	0	0
Chelms	0	54	0	29	4	8	4	0
Clwyd	0	86	0	7	0	7	0	0
Covnt	0	71	0	0	29	0	0	0
Crdff	0	31	42	0	27	0	0	0
D&Gall	0	75	0	0	25	0	0	0
Derby	0	84	0	0	16	0	0	0
Dorset	0	67	0	4	22	7	0	0
Dudley	0	62	0	0	38	0	0	0
Dunde	3	62	0	0	15	21	0	0
Dunfn	0	64	0	0	18	18	0	0
Edinb	0	65	0	0	26	10	0	0
Extr	0	37	48	0	7	7	0	0
GlasRI	0	82	0	0	9	9	0	0
GlasWI	0	68	0	0	13	18	0	0

Table E.2.13: (continued)

Centre	Dialysis modalities for diabetic patients							
	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ⩾6 nights	% on cycling PD <6 nights	% on unknown type of PD
Glouc	0	83	0	0	13	4	0	0
Guys	0	29	46	0	14	0	11	0
H&CX	0	53	27	0	12	8	0	0
Heart	1	80	10	0	9	0	0	0
Hull	0	41	40	0	9	10	0	0
Inver	0	86	0	0	0	14	0	0
Ipswi	8	38	0	0	27	23	4	0
Klmarnk	0	85	0	0	8	0	8	0
Kings	0	46	32	0	17	4	0	1
Leeds	0	49	29	0	17	5	0	0
Leic	0	29	46	0	15	10	0	0
Livrpl	0	53	23	2	13	5	5	0
ManWst	0	30	39	0	30	0	0	0
Middlbr	2	68	22	0	7	0	0	0
Newc	0	62	0	0	8	31	0	0
Norwch	0	87	0	0	13	0	0	0
Nottm	0	41	21	0	14	24	0	0
Oxfrd	0	56	0	0	26	17	1	0
Plym	0	77	0	0	18	5	0	0
Ports	0	45	28	0	27	0	0	0
Prstn	0	41	34	0	16	8	2	0
QEH	0	28	57	15	0	0	0	0
Redng	0	22	31	0	47	0	0	0
Sheff	3	34	29	0	35	0	0	0
Shrew	0	87	0	0	13	0	0	0
Stevn	0	40	40	0	21	0	0	0
Sthend	0	84	0	0	16	0	0	0
Stob	8	92	0	0	0	0	0	0
Sund	0	64	24	0	8	4	0	0
Swnse	2	51	19	0	28	0	0	0
Truro	0	55	19	0	26	0	0	0
Wirrl	0	25	75	0	0	0	0	0
Wolve	0	29	52	0	19	0	0	0
Wrexm	0	64	0	0	0	36	0	0
York	0	57	29	0	14	0	0	0
Eng	1	48	26	1	17	6	1	0
Sct	1	74	0	0	14	11	0	0
Wls	0	47	25	0	20	7	0	0
UK	1	51	24	1	17	6	1	0

Table E.2.14: Number of diabetic patients by treatment modalities

	Treatment modalities of diabetic patients			
	Type of diabetes	HD	PD	Transplant
Eng	Type 1	990	360	749
	Type 2	897	264	156
Sct	Type 1	113	47	120
	Type 2	86	18	6
Wls	Type 1	98	42	47
	Type 2	50	14	1
UK	Type 1	1,201	449	916
	Type 2	1,033	296	163

Table E.2.15: Diabetics

Centre	M:F ratio	Median age on 31/12/2004	Median age at start of treatment	Median time on ESRF treatment	
				in days	in years
Abrdn	1	59	55	913	2.5
Airdr	2	57	55	578	1.6
Bangr	4	69	67	697	1.9
Barts	2	62	58	945	2.6
Basldn	2	58	57	440	1.2
Bradf	1	58	55	912	2.5
Bright	5	57	48	1,035	2.8
Bristl	1	60	54	1,086	3.0
Camb	2	53	44	1,178	3.2
Carls	1	60	57	1,452	4.0
Carsh	1	60	56	678	1.9
Chelms	2	56	52	512	1.4
Clwyd	1	58	45	756	2.1
Covnt	2	58	52	1,144	3.1
Crdff	2	59	54	1,006	2.8
D&Gall	2	66	64	1,040	2.8
Derby	2	62	58	1,079	3.0
Dorset	2	55	49	778	2.1
Dudley	2	63	58	578	1.6
Dunde	1	61	58	725	2.0
Dunfn	1	65	63	518	1.4
Edinb	2	53	46	1,445	4.0
Extr	1	58	54	1,159	3.2
GlasRI	1	63	62	705	1.9
GlasWI	1	52	42	1,697	4.6
Glouc	1	59	53	998	2.7
Guys	1	54	51	1,365	3.7
H&CX	2	62	58	911	2.5
Heart	2	63	61	565	1.5
Hull	1	58	54	1,005	2.8
Inver	1	56	55	1,052	2.9
Ipswi	2	51	48	1,047	2.9
Klmarnk	1	53	50	1,063	2.9
Kings	2	64	61	1,022	2.8
Leeds	2	57	53	1,200	3.3
Leic	2	57	54	784	2.1
Livrpl	2	52	45	1,744	4.8
ManWst	2	60	58	1,054	2.9
Middlbr	2	51	47	799	2.2
Newc	2	53	47	1,552	4.2
Norwch	2	60	56	567	1.6
Nottm	1	58	52	1,383	3.8
Oxfrd	1	57	51	1,218	3.3
Plym	2	53	48	1,040	2.8
Ports	2	53	48	1,259	3.4
Prstn	1	57	54	975	2.7
QEH	2	61	56	1,012	2.8
Redng	2	58	55	795	2.2
Sheff	2	56	49	1,052	2.9
Shrew	6	66	63	893	2.4
Stevn	2	58	53	979	2.7
Sthend	2	63	58	661	1.8
Stob	1	70	69	758	2.1

Table E.2.15: (continued)

Centre	M:F ratio	Median age on 31/12/2004	Median age at start of treatment	Median time on ESRF treatment	
				in days	in years
Sund	2	51	46	885	2.4
Swnse	2	61	57	611	1.7
Truro	2	65	65	608	1.7
Wirrl	3	62	59	1,118	3.1
Wolve	2	58	55	777	2.1
Wrexm	3	56	55	865	2.4
York	1	51	48	408	1.1
Eng	2	58	54	1,005	2.8
Sct	1	57	51	1,010	2.8
Wls	2	60	55	858	2.3
UK	2	58	54	998	2.7

Table E.2.16: Transplant gender ratios

	% of males	% of females	No of males	No of females	M:F ratio
Eng	60.9	39.1	7,671	4,919	1.6
Sct	58.8	41.2	978	686	1.4
Wls	64.1	35.9	540	302	1.8
UK	60.9	39.1	9,189	5,907	1.6

E:3 EDTA Primary Diagnosis Groups

Table E.3.1: Collation of EDTA Primary Renal Diagnoses

Code	Title	Group
0	Chronic renal failure; aetiology uncertain unknown/unavailable [0]	Uncertain
10	Glomerulonephritis; histologically NOT examined [10]	Uncertain
11	Focal segmental glomeruloscerosis with nephrotic syndrome in children [11]	Glomerulonephritis
12	IgA nephropathy (proven by immunofluorescence, not code 76 and not 85) [12]	Glomerulonephritis
13	Dense deposit disease; membrano-proliferative GN; type II (proven by immunofluorescence and/or electron microscopy) [13]	Glomerulonephritis
14	Membranous nephropathy [14]	Glomerulonephritis
15	Membrano-proliferative GN; type I (proven by immunofluorescence and/or electron microscopy – not code 84 or 89) [15]	Glomerulonephritis
16	Crescentic (extracapillary) glomerulonephritis (type I, II, III) [16]	Glomerulonephritis
17	Focal segmental glomeruloscerosis with nephrotic syndrome in adults [17]	Glomerulonephritis
19	Glomerulonephritis; histologically examined, not given above [19]	Glomerulonephritis
20	Pyelonephritis – cause not specified [20]	Pyelonephritis
21	Pyelonephritis associated with neurogenic bladder [21]	Pyelonephritis
22	Pyelonephritis due to congenital obstructive uropathy with/without vesico-ureteric reflux [22]	Pyelonephritis
23	Pyelonephritis due to acquired obstructive uropathy [23]	Pyelonephritis
24	Pyelonephritis due to vesico-ureteric reflux without obstruction [24]	Pyelonephritis
25	Pyelonephritis due to urolithiasis [25]	Pyelonephritis
29	Pyelonephritis due to other cause [29]	Pyelonephritis
30	Interstitial nephritis (not pyelonephritis) due to other cause, or unspecified (not mentioned above) [30]	Interstitial
31	Nephropathy (interstitial) due to analgesic drugs [31]	Interstitial
32	Nephropathy (interstitial) due to cis-platinum [32]	Interstitial
33	Nephropathy (interstitial) due to cyclosporin A [33]	Interstitial
34	Lead induced nephropathy (interstitial) [34]	Interstitial
39	Drug induced nephropathy (interstitial) not mentioned above [39]	Interstitial

Table E.3.1: (continued)

Code	Title	Group
40	Cystic kidney disease – type unspecified [40]	Cystic/poly
41	Polycystic kidneys; adult type (dominant) [41]	Cystic/poly
42	Polycystic kidneys; infantile (recessive) [42]	Cystic/poly
43	Medullary cystic disease; including nephronophtisis [43]	Other
49	Cystic kidney disease – other specified type [49]	Other
50	Hereditary/Familial nephropathy – type unspecified [50]	Other
51	Hereditary nephritis with nerve deafness (Alport's Syndrome) [51]	Other
52	Cystinosis [52]	Other
53	Primary oxalosis [53]	Other
54	Fabry's disease [54]	Other
59	Hereditary nephropathy – other specified type [59]	Other
60	Renal hypoplasia (congenital) – type unspecified [60]	Other
61	Oligomeganephronic hypoplasia [61]	Other
63	Congenital renal dysplasia with or without urinary tract malformation [63]	Other
66	Syndrome of agenesis of abdominal muscles (Prune Belly) [66]	Other
70	Renal vascular disease – type unspecified [70]	Renal Vascular Disease
71	Renal vascular disease due to malignant hypertension [71]	Renal Vascular Disease
72	Renal vascular disease due to hypertension [72]	Renal Vascular Disease
73	Renal vascular disease due to polyarteritis [73]	Renal Vascular Disease
74	Wegener's granulomatosis [74]	Other
75	Ischaemic renal disease/cholesterol embolism [75]	Other
76	Glomerulonephritis related to liver cirrhosis [76]	Other
78	Cryoglobulinemic glomerulonephritis [78]	Other
79	Renal vascular disease – due to other cause (not given above and not code 84–88) [79]	Renal Vascular Disease
80	Type 1 diabetes with diabetic nephropathy [80]	Diabetes
81	Type 2 diabetes with diabetic nephropathy [81]	Diabetes
82	Myelomatosis/light chain deposit disease [82]	Malignancy
83	Amyloid [83]	Amyloid
84	Lupus erythematosus [84]	Other
85	Henoch–Schoenlein purpura [85]	Other
86	Goodpasture's Syndrome [86]	Other
87	Systemic sclerosis (scleroderma) [87]	Other
88	Haemolytic Ureaemic Syndrome (including Moschcowitz Syndrome) [88]	Other
89	Multi-system disease – other (not mentioned above) [89]	Other
90	Tubular necrosis (irreversible) or cortical necrosis (different from 88) [90]	Other
91	Tuberculosis [91]	Other
92	Gout nephropathy (urate) [92]	Other
93	Nephrocalcinosis and hypercalcaemic nephropathy [93]	Other
94	Balkan nephropathy [94]	Other
95	Kidney tumour [95]	Other
96	Traumatic or surgical loss of kidney [96]	Other
99	Other identified renal disorders [99]	Other
199	Code not sent [199]	Other

Appendix F: National Programme for IT Output Based Specification 167 – Renal Services

Introduction

The text of the Output Based Specification (OBS) contract for renal services is provided below. This is section 167 within the contract signed by the regionally based Local Service Providers (LSPs) as a component of the National Programme for IT (now renamed Connecting for Health).

This has been included in the Registry Report so that renal unit managers may reference this document in their negotiations within the Trust and with the LSPs.

OBS 167 – Renal Services

NSFs are not just about collecting data, and this part of the specification will not substitute for each LSP making particular reference to the specific documents available to help in satisfying the policy and service requirements for the prevention of renal disease and management of people with renal failure.

It is recognised that every area of specialist activity will have variations in the data it uses and the way it operates the basic primary clinical (and other) activity. This part of the specification identifies that which, in terms of overall activity and monitoring, is specific to people with renal disease, particularly those with renal failure.

In February 2001, the Secretary of State announced his intention to establish a new set of national standards to improve services for 30,000 kidney patients.

The incidence and prevalence of kidney failure is increasing steadily, and as such there is a real need to address issues of prevention and capacity to reduce incidence and increase choice and treatment options. This will be addressed through a number of processes:

- The development of improved preventative strategies based around well established risk factors and interventions.
- Reduction in the variation in treatment rates and quality of service, including referral to nephrologists and the development of care plans.
- Provision of sufficient capacity to ensure that patients consistently receive optimal care (ie choice of treatment and frequency of dialysis).
- Optimisation of access to and outcome of renal transplantation.

The new Renal Services NSF will be developed with the help of health and social care professionals and managers, patients, carers, partners, agencies and other advocates. It will be the blueprint for national standards and services that will improve treatment and care for the 30,000 patients in the UK on dialysis or living with a kidney transplant.

As with other published NSF's, the Renal Services NSF Standards will be supported by an information strategy, which will build on work already underway for existing national service frameworks to ensure that the specific renal issues can be addressed in an appropriate manner.

This will include (through close collaboration with the Renal Registry and UKT) the development of a nationally approved dataset. The dataset is expected to incorporate the two existing data sets and be developed to include those elements required that are not within the scope of the two current collections.

The Renal Services NSF is expected to be published later this year. Further information can be found at the URL http://www.doh.gov.uk/nsf/renal.htm.

Scope

The Renal NSF has been developed in 4 modules to consider the whole patient journey. This starts with those at risk because of congenital, acquired or inherited renal disease or risk factors, through the process of diagnosis, progression to renal failure, dialysis and transplantation and supported care and decisions at the end of life.

Module 1 This is concerned with haemodialysis and peritoneal dialysis and includes the year prior to the start of renal replacement therapy and issues surrounding appropriate and timely access surgery.

Module 2 This is concerned with maximising the benefits of transplantation, and includes key issues relating to live and cadaveric donors. Some donor issues are dealt with in the Transplant Framework, published by the DoH.

Module 3 This module is concerned with:

- Identification of people at risk of renal failure because of previously identified renal disease or congenital, inherited or acquired conditions predisposing to renal disease, and renal disease.
- Detection of early progressive renal disease and early signs of renal failure by detection of proteinuria, hypertension or reduced or falling GFR.
- Prevention of renal failure by evidence based management of those identified.
- Lifestyle choices that reduce risk and increase longevity.

This module also addresses acute renal failure which is an important source of morbidity and mortality and also provides a source of patients who do not recover and therefore have unplanned acute onset chronic renal failure.

Module 4 End of life care is an important choice for people with ERF, a difficult condition from which there can be no recovery. Planned and supported care at the end of life is an important component of the services provided.

It should be noted that, at the time of publication of the OBS, modules 1 and 2 are further advanced than modules 3 and 4. As a consequence, the renal services requirements of ICRS address the needs within primary and secondary care settings. Further requirements relating to primary and palliative care settings are yet to be articulated.

Governance and audit

The ICRS spine and LSP must provide a facility for the direct care of the patient with renal disease in primary, secondary and tertiary care and provide the functionality to deliver data for secondary purposes.

For the direct care of patients with renal failure the ICRS will ensure that the system will:

- Provide a continuous lifelong record of the patient's history, care, discussions and wellbeing;
- Provide the ability to support serial online biochemical and other tests, X-rays and biopsies;
- Provide facilities for data transformation for assessing progress and adequacy of care (eg estimated GFR using the Cockroft and Galt formula or KT/V for dialysis adequacy);
- Enable the patient and health professionals to participate in the development and use of a personal care plan which enables the patient to have access to their own records and participate in their own management and joint decisions;
- Share information appropriately between health sectors, members of the multidisciplinary team and other specialists in an accurate and timely way with due regard to confidentiality and with the patient's consent;
- Provide the facility for prescribing information for patients with various levels of impaired renal function and with renal transplants;
- Enable patients waiting for a transplant to access their status on the transplant list;
- Provide decision support based on evidence;
- Provide access to the knowledge base for patients and health professionals;
- Provide functionality for decision support to clinicians at the point of care informed by evidence based information such as that developed by the NeLH;
- Provide information to monitor the standards of the Renal Association, the British Transplantation Society, other relevant professional bodies and the ICRS Output Based Specification;
- Provide information to monitor the standards outlined in the Renal National Service Framework for renal disease and other NSFs such as Diabetes, CHD and Children's & Maternity Services when published.

For the management of donors there should be facilities to support:

(For live donors)

- The needs of live donors as patients and organ donors;
- The ability of live donors to see the results of their tests and participate in shared decision making;
- The ability to provide statutory information about live donation to UK Transplant;
- The ability to provide follow up of the donor.

(For cadaveric donors)

- The needs of cadaveric donors, both heart beating and non-heart beating, including records that continue to function and are accessible after the death of the donor;
- Functionality to support links for health professionals to the organ donor register in order to establish the status and wishes of a potential donor;
- Functionality to enable health professionals to view the medical records of potential donors, both non-heart beating and heart beating donors to inform decisions about proceeding with organ donation;
- Functionality to support UK Transplant in the process of organ allocation and statutory duties related to organ donation;
- Functionality to enable health professionals to view the records of cadaveric kidney donors or if the recipient has a subsequent problem or to research newly identified problems and to identify the recipients if the donor is later found to have an unexpected problem (eg cancer found at post mortem or CJD);
- Information to be transferred from donor to recipients and from one recipient to others from a common donor when required, with appropriate levels of confidentiality;
- Information required for organ allocation through UK Transplant.

(For healthy people)

- Those who wish to register on the organ donor register;
- Data for secondary purposes.

In addition the data required for secondary purposes (epidemiology, incidence, prevalence, activity, outcome, treatment modalities, audit, benchmarking, management, clinical governance, planning, commissioning and research) must be derived from the patient record.

Information about patients with renal failure:

- Information about patients with renal failure in primary, secondary and tertiary care;
- Data required for the Renal Registry and other key stakeholders. *(The details of the information required will be informed by a review of information to be undertaken by the NHSIA and commissioned by the DoH)*;
- Information on the waiting times and outcome of transplantation.

Information about donated organs:

- Information required by UK Transplant for statutory duties;
- Information required to monitor the outcome of renal transplantation in relation to the type of organ, its condition and transfer;
- Information about the organ allocation and transplantation process.

Information about donors:

- Information on live donors, including follow up;
- Information about cadaveric donors.

Appendix G: Vascular Access Survey Form

The Renal Association

Renal Association Vascular Access Survey 2005

Renal Unit: . . . . . .

Contact Name of person filling in form . . . . . .

Please return to UK Renal Registry, Southmead Hospital, Southmead Rd, Bristol BS10 5NB

Part 1 Prevalent data

Census date Thursday 31st March 2005 (Please count based on most recent modality of treatment)

Name of unit (Main or satellite)	Type of unit M / S	Total PD patients	Total HD patients	HD (native AVF)	HD (Gortex graft or similar)	HD (Tunnelled line)	HD (Temporary access)	HD (other access)

Completion notes for Part 1 Fill out Name of unit and Type (Main or Satellite). Put actual numbers of patients in each column based on the last modality and access type before or on the census date.

Section 1A – Morbidity data

1. How many Staph Aureus septicaemias have occurred in HD patients from your prevalent population last year (2004) (include MSSA and MRSA):

   If available, how many of these were related to MRSA septicaemias in 2004

   (This data should be available from hospital infection control).

2. On the 31st March 2005, at 9 am, how many patients from the chronic haemodialysis program were deemed to be in patients under either a renal consultant or access surgeon?

   Do not count in patients in other hospitals or under other firms.

   How many of these were due to vascular access complications or issues? (include line sepsis, fistula problems such as bleeding or occlusion)

Part 2 Incident data

Detail **all** patients commencing RRT for presumed CRF during April 2005.
Include pre-emptive transplanted patients. transplant failures with restart of dialysis, **exclude** acute renal failure.

Renal Unit: . . . . . .

ID	Gender	DoB	Ethnicity	Date of 1st contact with Renal Team	Referred for access prior to 1st RRT (Y/N/Unknown)	Date of referral (if known)	Active on transplant list at 1st RRT (Y/N)	Access and modality at time of 1st RRT	Date of 1st RRT	Diagnosis (EDTA code)

Notes for completion:

ID: Hospital number
Gender: Male/female
DoB: Date of Birth

Ethnicity:

W	White
B	Afro Caribbean
A	South Asian
C	Chinese / East Asian
O	Other
UK	Unknown

Date of First RRT: Date of first renal replacement therapy for *this* episode of ERF (ie if transplant failure it is access at the time of reinstitution of HD or PD).

Date of 1st contact: Date when first seen by dialysing nephrologist (either OP or IP).

Access and modality at first treatment:

Treatment and access	Code
Peritoneal dialysis (CAPD or CCPD)	PD
HD with AVF	AVF
HD with graft	Graft
HD with tunnelled line	Tunnel
HD with non tunnelled (temporary) line	TempL
Transplant	Tx

Referred for access: Yes/No as to whether referred prior to 1st RRT for vascular access.

Date of referral: Date of above referral if known.

EDTA codes: Primary renal diagnosis (if known).

Part 3 Follow up data 6 months (patients commencing RRT in April 2005)

Renal Unit: . . . . . .

Please return to UK Renal Registry, Southmead Hospital, Southmead Rd, Bristol BS10 5NB

ID	Gender M/F	DoB	Date at 6 months from 1st RRT	Access and modality at 6 months	Date of death	Date of transplant	Date of referral for outstanding vascular access (if known)	Diagnosis revised (EDTA code)	On transplant list? (code)

Access and modality	Code
Peritoneal dialysis (CAPD or CCPD)	PD
HD with AVF	AVF
HD with graft	Graft
HD with tunnelled line	Tunnel
HD with temporary line	TempL
Transplant	Tx
Recovered independent renal function	Recovered
Died	Dead
Unknown	UK

Notes for completion:

First four columns will be pre-filled based on the previous incident data. Data will be filled in using the 6 month date as the census date.

On transplant list (includes suspended): Yes / WKUP (working up) / No (suitable) / Unfit (permanently unfit) / Unknown.

The EDTA code will be re-entered by the unit (the diagnosis may have been 'refined').

Part 4 Organisational outline (NKRF data set)

(Please return with part 2)
Please indicate whether your answers throughout this section represent opinion **(O)** or data **(D)** by appending a letter after the reply.

The National Kidney Research Fund
Caring about people with kidney disease
www.nkrf.org.uk

1. How many surgical vascular access procedures were performed in April 2005? ☐

   i. How many medical staff provide Vascular Access for your patients?

	Consultants	Non consultant grade
Total Number	☐	☐
Vascular trained	☐	☐
Transplant trained	☐	☐

   Note people may be counted twice ie vascular and transplant trained.

   ii. Please select Local vascular access service provided ☐

   Patients travel to another centre for access placement ☐

iii. Who puts in tunnelled central venous catheters?

	Nephrologist	Surgeon	Radiologist	Anaesthetists	Nurses	Others
Relative %	☐	☐	☐	☐	☐	☐

iv. Total number of temporary (untunnelled) catheters placed in April 2005. ☐

v. Is your radiology department able to provide an adequate service for vascular access? (tick one).

Always ☐ Usually ☐ Infrequently ☐ Rarely or never ☐

2. How many theatre sessions are available per week for vascular access surgery? (in April 2005). ☐

How many of these are dedicated to vascular access? ☐

What do you see as the main problems with VA services in your unit?
Please rate the following options 1–5 with 1 being the most important problem:

☐ Lack of surgeons

☐ Lack of surgical interest

☐ Lack of operating theatre time or resource (including support staff)

☐ Lack of beds

☐ Other (please state) ☐

3. How many surgical vascular access procedures were cancelled in April 2005? ☐

4. Recent guidelines recommend the use of duplex mapping. Does your unit routinely map veins pre and/or post operatively?

Yes, pre and post operatively ☐

Yes, pre operatively only ☐

Yes, post operatively only ☐

No ☐

Other options (specify as free text) ☐

5. Vascular access co-ordination.

   Does your unit have a non-medical staff member(s) involved in the organization or management of vascular access (eg coordinator, nurse specialist, administrator)?

   Yes ☐ No ☐

   If YES What proportion of time is spent in this role? ☐ % FTE

   What band or grade are they? _____

   How are they funded? _____

   What professional group are they from (eg nurse, admin etc) _____

   Tick which tasks they perform and provide free text of additional tasks

   Make referrals ☐ Organise and prioritise lists ☐ Provide education ☐

   Insert Lines ☐ Monitor existing access ☐ Other (specify) ☐

   ☐

Vascular access issues

6. Is vascular access a separately identified part of your commissioning process?

   Yes ☐ No ☐

7. Please feel free to comment on the organization of vascular access in your unit, highlighting any issues of concern, or areas of good practice:

   ☐

Appendix H: Acronyms and Abbreviations used in the Report

ACE (inhibitor)	Angiotensin converting enzyme (inhibitor)
APD	Automated peritoneal dialysis
ARF	Acute renal failure
ASSIST	The Association of ICT Professionals in Health and Social Care
AVF	Arteriovenous fistula
BAPN	British Association of Paediatric Nephrology
BCG	Bromocresol green
BCP	Bromocresol purple
BMI	Body mass index
BOO	Bladder output obstruction
BP	Blood pressure
BTS	British Transplant Society
CAB	Clinical Affairs Board (Renal Association)
CABG	Coronary artery bypass grafting
CAPD	Continuous ambulatory peritoneal dialysis
CCL	Clinical Computing Limited
CCPD	Cycling peritoneal dialysis
CI	Confidence interval
CIC	Clean intermittent catheterisation
CKD	Chronic kidney disease
CMMS (CMS)	US Centre for Medicare and Medicaid Services
COPD	Chronic obstructive pulmonary disease
CRF	Chronic Renal Failure
CRP	C-reactive protein
CXR	Chest X Ray
DBP	Diastolic blood pressure
DCCT	Diabetes Control and Complications Trial
DFS	Date first seen
DM	Diabetes mellitus
DOH	Department of Health
DOPPS	Dialysis Outcomes and Practice Patterns Study
DOQI	Disease Outcomes Quality Initiative
E&W	England and Wales
EBPG	European Best Practice Guidelines
ERA-EDTA	European Renal Association – European Dialysis and Transplant Association
eGFR	Estimated GFR
EPO	Erythropoietin
EPR	Electronic Patient Record
ERA	European Renal Association
ER	Early referral
ERF	Established Renal Failure
ESA	Erythropoietin stimulating agent
FSGS	Focal segmental glomerulosclerosis
GFR	Glomerular Filtration Rate
GN	Glomerulonephritis
HA	Health Authority
HbA1c	Glycated Haemoglobin

HCFA	USA Health Care Finance Administration – now replaced by CMMS
HD	Haemodialysis
HDL	High-density lipoprotein
Hb	Haemoglobin
HLA	Human Leucocyte Antigen
HR	Hazard ratio
ICNARC	National intensive care audit
ICRS	Integrated Care Records System
IHD	Ischaemic heart disease
IDOPPS	International Dialysis Outcomes and Practice Patterns Study
IFCC	International Federation of Clinical Chemistry & Laboratory Medicine
IM&T	Information Management & Technology
IPD	Intermittent Peritoneal Dialysis
iPTH	Intact Parathyroid hormone
ITU	Intensive Therapy Unit
ISB	Information Standards Board
KDOQI	Kidney Disease Outcomes Quality Initiative
KM	Kaplan Meier
LA	Local Authorities
LDL	Low-density lipoprotein
LR	Late referral
LSPs	Local Service Providers
LV	Left ventricular
LVH	Left ventricular hypertrophy
MAP	Mean arterial blood pressure
MDRD study	Modified Diet in Renal Disease study
MI	Myocardial infarction
MINAP	Myocardial infarction audit
MRSA	Methicillin resistant Staphylococcal aureus
NAS	National Analytical Society
NASP	National Application Service Providers
NCRS	National Care Records Service
NeLH	National electronic Library for health
NEQAS	UK National External Quality Assessment Scheme
NFKPA	National Federation of Kidney Patients' Associations
NHS	National Health Service
NHID	National Health Informatics Development
NHSIA	NHS Information Agency
NICE	National Institute of Clinical Excellence
NpfIT	National Programme for Information Technology
NSF	National service framework
OA	Output area (Census)
OBSC	Output Based Specification Contract
ONS	Office of National Statistics
PCT	Primary Care Trust
PD	Peritoneal dialysis
PIAG	Patient Information Advisory Group
PKD	Polycystic kidney disease
PMCP	Per million child population
PMPO	Per million population
PP	Pulse pressure
PTH	Parathyroid hormone
PUV	Posterior urethral valves

PVD	Peripheral vascular disease
RA	Renal Association
RNSF	Renal National Service Framework (or NSF)
ROCR	Review of Central Information Requirements
RR	Relative risk
RRDSS	Renal Registry Data Set Specification
RRT	Renal replacement therapy
SARR	Standardised acceptance rate ratio
SAS	Statistical Analysis System (statistical software used by the Registry)
SBP	Systolic blood pressure
SD	Standard deviation
SDS	Standard deviation score
SDII	Renal Standards document – second edition
SDIII	Renal Standards document – third edition
SES	Socio-economic status
SHARP	Study of Heart and Renal Protection
SI	System International (units)
SIRS	Study of Implementation of Renal Standards
SMR	Standardised mortality ratios
StHAs	Strategic health authorities
SUS	Secondary use service
TOR	Take-on rate
TSAT	Transferrin saturation
UA	Unitary Authorities
UKRR	UK Renal Registry
UKT	UK Transplant
USRDS	United States Renal Data System
URR	Urea reduction ratio
WEQAS	Welsh External Quality Assurance Study
WTE	Whole time equivalent

Appendix I: Laboratory Conversion Factors

	Conversion factors from SI units
Albumin	$g/dl = g/L \times 0.1$
Aluminium	$\mu g/L = \mu mol/L \times 0.037$
Bicarbonate	$mg/dl = mmol/L \times 6.1$
Calcium	$mg/dl = mmol/L \times 4$
Calcium × phosphate	$mg^2/dl^2 = mmol^2/L^2 \times 12.4$
Cholesterol	$mg/dl = mmol/L \times 38.6$
Creatinine	$mg/dl = \mu mol/L \times 0.011$
Glucose	$mg/dl = mmol/L \times 18$
Haemoglobin	$Hct = g/dl \times 3.11$ (*NB this factor is variable*)
Phosphate	$mg/dl = mmol/L \times 3.1$
PTH	$ng/L = pmol/L \times 9.5$
Urea	$mg/dl = mmol/L \times 2.8$

Appendix J: Abbreviations used for the renal units names in the figures and data tables

City	Hospital	Abbreviation	Country
Basildon	Basildon Hospital	Basldn	England
Birmingham	Heartlands Hospital	Heart	England
Birmingham	Queen Elizabeth Hospital	QEH	England
Bradford	St Luke's Hospital	Bradf	England
Brighton	Royal Sussex County Hospital	Bright	England
Bristol	Southmead Hospital	Bristl	England
Cambridge	Addenbrookes Hospital	Camb	England
Carlisle	Cumberland Infirmary	Carls	England
Carshalton	St Helier Hospital	Carsh	England
Chelmsford	Broomfield Hospital	Chelms	England
Coventry	Walsgrave Hospital	Covnt	England
Derby	Derby City General Hospital	Derby	England
Dorset	Dorchester Hospital	Dorset	England
Dudley	Russells Hall Hospital (previously reported as Wordsley, Stourbridge)	Dudley	England
Exeter	Royal Devon and Exeter Hospital	Extr	England
Gloucester	Gloucester Royal Hospital	Glouc	England
Hull	Hull Royal Infirmary	Hull	England
Ipswich	Ipswich Hospital	Ipswi	England
Leeds	St James's Hospital and Leeds General Infirmary	Leeds	England
Leicester	Leicester General Hospital	Leic	England
Liverpool	Royal Liverpool University Hospital	Livrpl	England
London	Barts and The London Hospital	Barts	England
London	Guy's & St Thomas' Hospital	Guys	England
London	Hammersmith & Charing Cross Hospitals	H&CX	England
London	King's College Hospital	Kings	England
Manchester	Hope Hospital	ManWst	England
Middlesbrough	James Cook University Hospital	Middlbr	England
Newcastle	Freeman Hospital	Newc	England
Norwich	Norfolk and Norwich University Hospital	Norwch	England
Nottingham	Nottingham City Hospital	Nottm	England
Oxford	Oxford Radcliffe Hospital (previously reported as Churchill Hospital)	Oxfrd	England
Plymouth	Derriford Hospital	Plym	England
Portsmouth	Queen Alexandra Hospital	Ports	England
Preston	Royal Preston Hospital	Prstn	England
Reading	Royal Berkshire Hospital	Redng	England
Sheffield	Northern General Hospital	Sheff	England
Shrewsbury	Royal Shrewsbury Hospital	Shrew	England
Southend	Southend Hospital	Sthend	England
Stevenage	Lister Hospital	Stevn	England
Sunderland	Sunderland Royal Hospital	Sund	England
Truro	Royal Cornwall Hospital	Truro	England
Wirral	Arrowe Park Hospital	Wirrl	England
Wolverhampton	New Cross Hospital	Wolve	England
York	York District Hospital	York	England

City	Hospital	Abbreviation	Country
Bangor	Ysbyty Gwynedd	Bangr	Wales
Cardiff	University Hospital of Wales	Crdff	Wales
Clwyd	Ysbyty Glan Clwyd	Clwyd	Wales
Swansea	Morriston Hospital	Swnse	Wales
Wrexham	Wrexham Maelor Hospital	Wrexm	Wales
Aberdeen	Aberdeen Royal Infirmary	Abrdn	Scotland
Airdrie	Monklands District General Hospital	Airdr	Scotland
Dumfries	Dumfries & Galloway Royal Infirmary	D&Gall	Scotland
Dundee	Ninewells Hospital	Dunde	Scotland
Dunfermline	Queen Margaret Hospital	Dunfn	Scotland
Edinburgh	Edinburgh Royal Infirmary	Edinb	Scotland
Glasgow	Western Infirmary	GlasWI	Scotland
Glasgow	Glasgow Royal Infirmary	GlasRI	Scotland
Glasgow	Stobhill Hospital	Stob	Scotland
Inverness	Raigmore Hospital	Inver	Scotland
Kilmarnock	Crosshouse Hospital	Klmarnk	Scotland