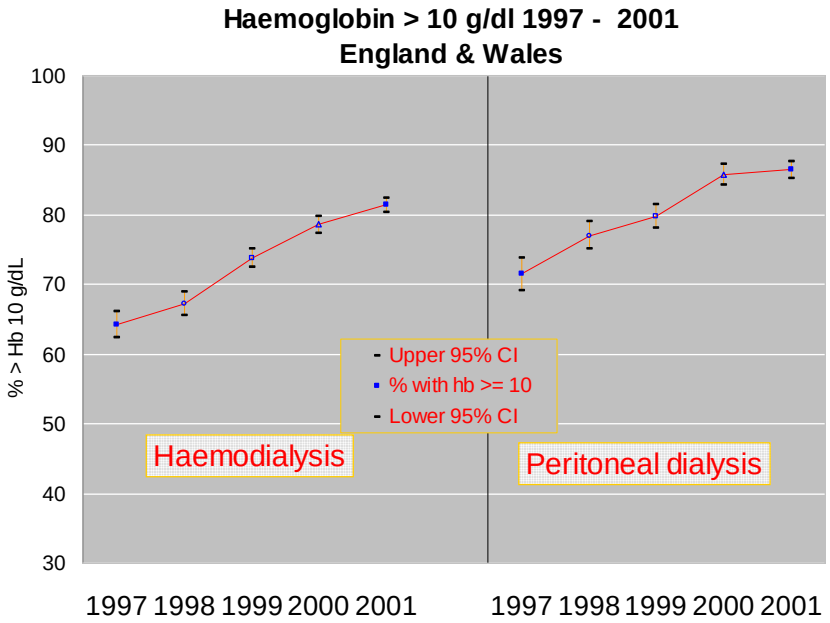
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Chapter 1: Summary

The 2002 UK Renal Registry report refers to activity in 2001 and covers 72% of the UK adult population. The report on the 2002 data will cover up to 80% of the UK.

Anonymity has been removed from all the adult data except for survival figures in individual renal units. A meaningful comparison of mortality between renal units requires the ability to correct for case mix: robust data are not yet available for this.

The annual acceptance of new patients in the UK has not risen in the past 4 years. At 93.2 per million population (pmp) for adults and 1.7 pmp for children, it is lower than in most other Western European countries. The annual acceptance rates in the (superseded) health authorities vary from 51 pmp to 154 pmp. Differences in age structure and ethnic minority distributions do not fully explain the variation.

Diabetic nephropathy as a cause of renal failure, seen in 18% of new patients, is not increasing and remains lower than in the USA and much of Europe.

The annual growth in the number of those receiving renal replacement therapy (RRT) is 7%, largely occurring for haemodialysis (HD). On 31 December 2001, a minimum of 33,363 patients (566 pmp) received RRT in the UK; 52.8% were treated by dialysis.

Of prevalent White patients, 10% are diabetic compared with 20% from ethnic minorities.

Of prevalent patients, 46.6% are transplanted, 37.1% are on HD and 16.3% receive peritoneal dialysis (PD). PD is more common in the young, especially in diabetics. Connect PD has virtually disappeared, and cycling PD has increased very little.

The number on RRT is predicted to rise for 20 years until a steady state position is reached, with a future prevalence approaching 60,000 patients.

In 2001, there was only a small improvement in the adequacy of delivered dialysis. A survey showed there are diverse post-dialysis urea sampling methods in current use.

The management of anaemia improved further, with 81% of HD and 86% of PD patients achieving the haemoglobin standard of >10 g/dL.

Haemoglobin level prior to the start of RRT has increased over the past 3 years. PD patients had higher prior haemoglobin levels than those starting HD.

Ninety-three per cent of HD and 84% of PD patients achieved a serum ferritin level above 100 mcg/L. This has shown a continuing, albeit small, annual increment.

Of all dialysis patients, 71% had a corrected serum calcium concentration within the standard range, and there was no significant difference between HD and PD patients. Only 50% of patients had a serum phosphate within the standard range, phosphate levels being significantly lower in PD patients. Serum parathyroid hormone fell within the standard range in 58% of dialysis patients. There has been no improvement in the control of these variables in 5 years.

The method of measurement of serum albumin has a major effect on the interpretation of differences between centres and changes with time, The centres using BCP have lower serum albumin readings.

For HD patients, the median serum bicarbonate varied from 18 to 26 mmol/L between centres. More detailed information concerning sample handling by laboratories and units is required to explore this difference in results. Sixty-two per cent of HD patients achieved the recommended standard, as did most PD patients .

In England & Wales, the recommended blood pressure standard was achieved in 42% (inter-unit range 15–68%) of young HD patients and 64% (range 23–84%) of older patients. Of young PD patients, 52% (range 40–75%) achieved the standard, of older patients, 69% (range 45–88%). Variations between units were significant.

For HD, 73% (inter-unit range 47–86%) of patients achieved a cholesterol level of 5 mmol/L or less. Of PD patients, the figure was 56% (range 30–72%). The data show significantly higher cholesterol levels in PD patients.

There is a U-shaped association between cholesterol level and 1 year mortality.

There has been a progressive decline in the proportion of the prevalent RRT stock made up by renal transplant patients, from 51% in 1997 to 46.6% in 2001. Of transplant patients on the Registry database, 21.4% are managed by non-transplanting centres.

The percentage of patients achieving the recommended standard for all the following variables differed significantly between centres: haemoglobin, dialysis adequacy, serum ferritin, calcium, phosphate, bicarbonate and intact parathyroid hormone, and blood pressure.

Patients on RRT show a high relative risk of death compared with the general population. This is most pronounced in the young and diminishes with increasing age. Cardiovascular disease is the most common cause of death, especially in diabetics.

Established renal failure presents at all ages in childhood, with a slow increase with age. Boys significantly outnumber girls in early childhood, but by the teenage years, more females are presenting than males. Renal dysplasia and obstructive uropathy remain the most common causes of RRT in childhood. Most paediatric patients are transplanted. The cadaveric transplantation rate is falling.

The 1 year survival of incident RRT patients ranges from 95% in young adults to 75% in those aged 65–74, and 50% in those over 85. Data from the past 4 years show a small steady improvement in all age groups. Four-year survival is 48% (67% <65 years, 24% >65 years). There is no significant difference in survival between centres, except that one centre has an unexplained good survival in the first year after 90 days.

Multivariate analysis showed that the four comorbidity factors most closely related to poor 1 year survival are age, ischaemic ulcers, malignancy and smoking. A better return of comorbidity data is needed to improve the quality of survival analysis.

Chapter 2: Introduction to the 2002 Report

Area covered by the Renal Registry

The 2002 UK Renal Registry report refers to activity in 2001 and covers 72% of the UK adult population (Figure 2.1). In total, 38 of the 63 adult units (60%) in England & Wales (Table 2.1) participated in the Registry in 2001, although data from four of these units could not be included in the report. The English and Welsh units cover 69% of the population of 52.2 million. Northern Ireland units have submitted numbers for incidence and prevalence, and it is hoped that a full dataset will be submitted electronically via their new data system in 2003. Summary data from the Scottish Renal Registry on incidence and prevalence throughout Scotland are also included, but more detailed data were not available in time to be included.

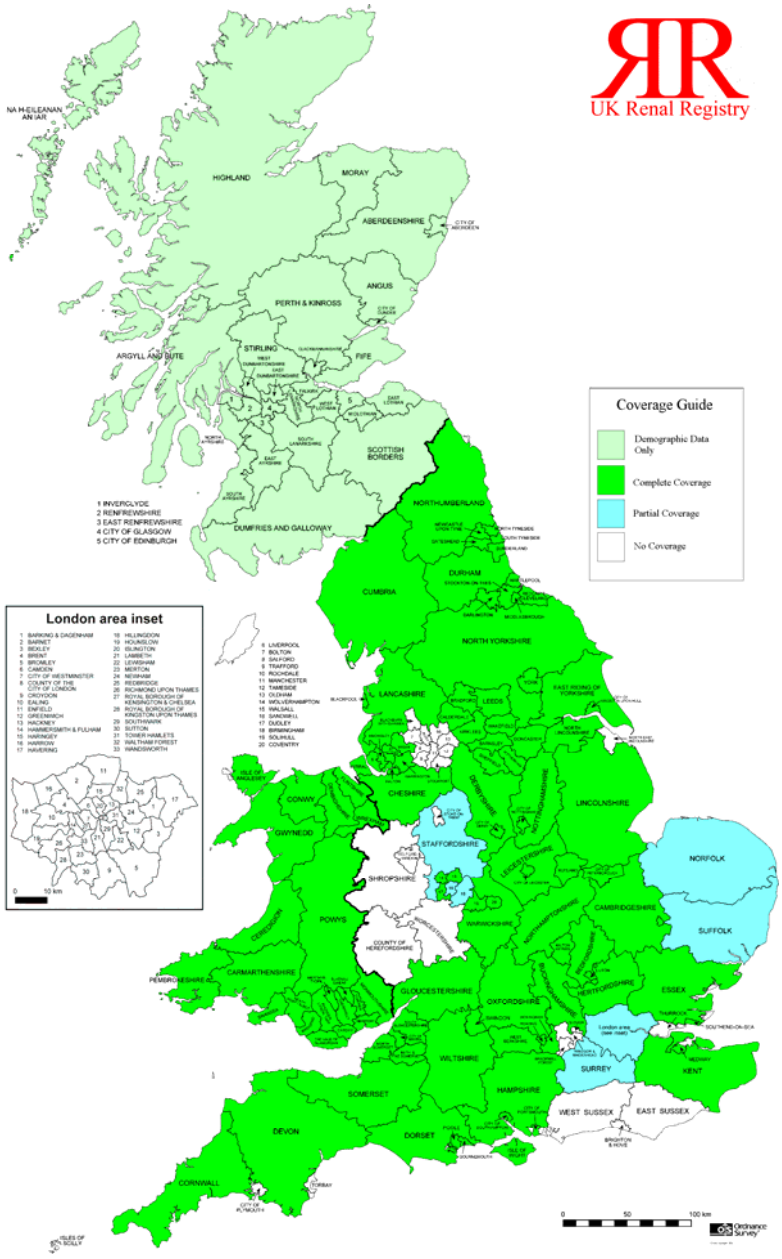


Figure 2.1: Area covered by the Renal Registry

Centres in the 2002 Registry report

		Estimated population (millions)
England & Wales		**33.01**
Birmingham	Heartlands Hospital	0.60
*Bradford	St Luke's Hospital	0.60
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
Coventry	Walsgrave Hospital	0.85
Exeter	Royal Devon and Exeter Hospital	0.75
Gloucester	Gloucester Royal Hospital	0.55
Hull	Hull Royal Infirmary	1.02
Leeds	Leeds General Infirmary	0.90
Leeds	St James's Hospital	1.30
Leicester	Leicester General Hospital	1.80
*Liverpool	Royal Infirmary	1.35
London	Guys and St Thomas' Hospital	1.70
Middlesborough	James Cook University Hospital	1.00
Nottingham	Nottingham City Hospital	1.16
Oxford	Churchill Hospital	1.80
Plymouth	Derriford Hospital	0.55
*Portsmouth	St Mary's Hospital	2.00
Preston	Royal Preston Hospital	1.48
Reading	Royal Berkshire Hospital	0.60
*Rhyl	Ysbyty Clwyd	0.15
Sheffield	Northern General Hospital	1.75
Stevenage	Lister	1.25
Southend	Southend Hospital	0.35
Sunderland	Sunderland Royal Hospital	0.34
Swansea	Morriston Hospital	0.70
*Truro	Royal Cornwall Hospital	0.36
Wolverhampton	Newcross Hospital	0.49
Wordsley	Stourbridge Hospital	0.42
Wrexham	Maelor General Hospital	0.42
York	York District Hospital	0.39

Table 2.1: Centres in the 2002 Registry
*These units are being reported by the Registry for the first time.

All the above renal units in England & Wales run the CCL Proton software, except Newcastle (CCL clinical vision) and Stevenage (Lister's own system).

For technical reasons, the data in this year's report from the Rhyl renal unit have been reported partly with the Liverpool data, except in the health authority analysis, where postcode analysis was used.

Exclusion of data from the report

Although data were collected from the Newcastle, Wirral, Derby and St Mary's London renal units, these sites have not been included in this report (Table 2.2). Validation routines run for creating the report revealed inaccuracies in the patient treatment history timelines so it was not possible accurately to calculate the number of incident and prevalent patients for these units. These sites were unaware of these problems, and it was not possible to correct the

errors in time for inclusion. Although the demographic data are incomplete for the Derby renal unit, the centre has been included for some of the laboratory analyses on prevalent patients as it is a representative sample for this centre.

		Estimated population (millions)
Derby	Derby City Hospital	0.48
London	St Mary's Paddington	0.81
Newcastle	Freeman Hospital	1.31
Wirral	Arrowe Park Hospital	0.53

Table 2.2: Excluded centres

The Scottish Registry was unable to submit the data in time to be included in this analysis, although numbers for incidence and prevalence in Scotland have been provided directly by the Scottish Registry.

The participating centres are shown in Table 2.1 and the areas represented in Figure 2.1.

Centres who have recently joined the Registry

The renal units shown in Table 2.3 have joined the Registry since the database was closed for this report. At least one file has been successfully loaded onto the Registry database from each site.

	(Indicates IT system used by hospital)	Estimated population (millions)
Bangor	Ysbyty Gwynedd (Baxter system)	0.18
London	Kings College Hospital (Filemaker Pro own system)	1.01
London	Hammersmith + Charing Cross (own system)	1.30
Ipswich	Ipswich Hospital (Baxter system)	0.33
Norwich	James Paget Hospital (Mediqal sytem)	0.84

Table 2.3: IT systems used by hospitals

Centres in the process of joining the Registry

Work is in progress to connect the centres listed in Table 2.4 to the Registry.

	(Indicates IT system used by hospital)	Estimated population (millions)
Basildon	(Mediqal)	
Birmingham	Queen Elizabeth Hospital (own system)	1.82
Dorset	Dorchester Hospital (Mediqal)	0.60
Canterbury	Kent & Canterbur (Velos system)	1.20
London	Royal Free (King's system)	0.67
London	Royal London (King's system)	
Manchester	Hope Hospital (EPR hospital system)	
Northern Ireland	Belfast + three renal units (Mediqal system)	
Stoke	North Staffs (Cybernius Canadian system)	0.70

Table 2.4: IT systems being implemented

Centres in discussion with the Registry

All the remaining renal units in England have made contact with the Registry and are considering how to facilitate joining. These are listed below in Table 2.5.

	(Indicates IT system used by hospital)	Estimated population (millions)
Brighton	(Buying system – undecided)	0.98
Chelmsford	Broomfield Hospital (buying Mediqal)	
London	St George's (own system – not suitable)	
London	Middlesex /UCLH (buying Kings system)	1.40
Manchester	Royal Infirmary (buying system – undecided)	
Shrewsbury	(Buying Lister system)	

Table 2.5: Centres without Registry-compatible IT

The factor preventing these remaining units joining the Registry is that they do not yet have satisfactory computerised patient information systems. For some of these units, there has been a lack of available finance to purchase suitable systems.

Future coverage by the Registry

From the data presented here, it can be seen that the report on the 2002 data will cover up to 80% of the UK, and that by the end of 2003, some 90% or more of the UK will be covered by the Registry. This process may be accelerated because, if the anticipated support from the Renal National Service Framework (RNSF) is forthcoming, commissioners will be encouraged to enable the provision of adequate data systems for all units to join the Registry.

Software and links to the Registry

From the above information, it is evident that there are now 13 systems available for purchase and use in renal units. The Registry is working with the relevant companies to help them to provide appropriate software links to the Registry.

In addition, the Lister renal unit in Stevenage has developed an in-house system that has a working Registry interface. The software has been offered free by the Trust to the NHS Information Agency (NHSIA), and there has been an agreement with the NHSIA to support the system. There is an annual support charge levied by the NHSIA for this system.

Paediatric Registry links

There are in the UK an estimated 750 patients under 18 years old 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. As in previous years, this report includes a chapter of analyses from these data.

In order to integrate these data with the adult Registry, and also provide funded resources for data management, the BAPN has asked the adult Registry to assess ways of collecting these paediatric data. The plans for these sites are listed in Table 2.6.

Sites	Comments
Belfast	Plan to join the adult system
Birmingham	Linking directly to Registry
Bristol	Sent with adult data
Cardiff	Sent with adult data
Dublin	Plan to join adult system
Leeds	Sent with adult data
Liverpool	Join Bristol's system
London Gt Ormond St	Joining Bristol's system till local EPR developed
London Guys	Joining Guys adult system
Manchester	Joining Bristol's system
Newcastle	Sent with adult data
Nottingham	Sent with adult data
Southampton	No agreement
Glasgow	Sent via Scottish Registry

Table 2.6: Paediatric renal unit plans

It is hoped that the paediatric data will be integrated with those from the UK Renal Registry within a year.

Links with other organisations

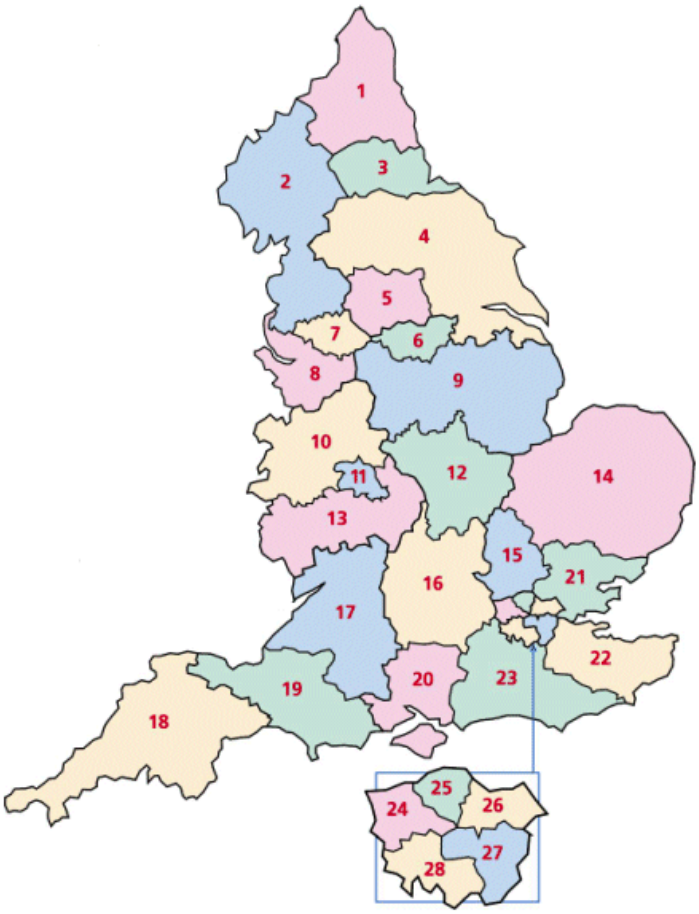
The UK Renal Registry has been active in supporting the the Renal Association Standards Sub-committee in the production of the new standards document. Support has been given to the Department of Health in gaining the basic data necessary for the future planning of renal services; the Registry has also participated in formulating the advice for ministers for the RNSF and is working with the NHSIA on the information strategy to support the RNSF. The Registry is part of the Kidney Alliance, and discussions are taking place on forging closer links with the Royal College of Physicians Audit Unit.

The Registry has been working with the UK Transplant Authority to produce analyses utilising the strengths of both databases. The UK Registry sends data to the European Renal Association registry and is currently represented on its committee. There has been contact with the International Federation of Renal Registries, but patient data are not sent to this organisation.

New methods of commissioning renal services

In April 2002, the 95 existing health authorities in England were reformed as 28 strategic health authorities (StHAs) shown in Figure 2.2.

Within the current financial year – 2002/03 – the previous funding arrangements for renal units have largely been continued, but primary care Trusts (PCTs) are becoming increasingly involved in funding negotiations. The Registry has received requests for data from some individual PCTs that are becoming involved in commissioning. They have been informed about the inaccuracies of trying to budget for the incidence of established renal failure in an individual PCT. The Registry has therefore declined to analyse or supply data at this level.



1. Tyne, Wear and Northumberland
2. Cumbria & Lancashire
3. County Durham & Tees Valley
4. North Yorkshire and York, East Riding & Hull, North & North East Lincolnshire
5. West Yorkshire
6. South Yorkshire
7. Greater Manchester
8. Cheshire & Merseyside
9. Trent
10. West Midlands North
11. West Midlands Central
12. Leicestershire & Northamptonshire & Rutland
13. West Midlands South
14. Norfolk, Suffolk and Cambridgeshire
15. Bedfordshire & Hertfordshire
16. Thames Valley
17. Avon, Gloucestershire & Wiltshire
18. South West Peninsula
19. Somerset & Dorset
20. Hampshire & Isle of Wight
21. Essex
22. Kent
23. Surrey & Sussex
24. London North West
25. London Central
26. London North East
27. London South East
28. London South West

Figure 2.2: Map of new StHAs

Established renal failure has been designated by the government as a service for specialist commissioning, and it is envisaged that the StHAs will have a role in monitoring the performance of the specialised commissioning consortia. The Registry will try to assist specialised commissioning consortia with appropriate data and analyses.

The Registry and clinical governance

There has been considerable debate within the Renal Association Trustee and Executive Committees, and the Registry Sub-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. Where outcome data appear to be seriously flawed, the Registry will discuss them further with the renal unit and accepts a responsibility to establish the validity of the data. The Registry Report is also sent to the Chief Executive of the Trust in which a renal unit is situated since the responsibility for clinical governance within the Trust lies with the Chief Executive. The Chief Executive is informed of the code of the relevant unit within the report. If, after such investigation, the problems persist, the Registry will recommend that the renal unit seek an external peer review, and may need to consider informing the local commissioners.

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 would not only aid the development of comparative audit and assist learning from best practice, but also assure public accountability. This has been discussed in the Renal Registry Committee and at the Renal Association Executive Committee, and both have recommended the introduction of a timescale for the removal of anonymity. After consultation with the participating renal units, a phased programme towards the removal of anonymity was agreed.

In 2001, the incidence and prevalence data were identified by named renal unit, which has generated increased feedback from sites and improved the accuracy of the data transmitted to the Registry. In 2002, anonymity has been removed from all the adult data except for the survival figures in individual renal units. A meaningful comparison of mortality between renal units requires the ability to correct for case mix, and robust data are not yet available for this from many units. This Report includes, however, the first analysis of the comorbidity data collected by the Registry, which shows the importance of being able to adjust for these factors. It is hoped that this will encourage more renal units to collect these data so that accurate comparative results may be achieved.

There has been only slow progress in standardising post-dialysis sampling techniques in England & Wales. The removal of anonymity in the chapter on dialysis adequacy will hopefully speed up this process. Agreement from the units to publish these data with units identified was conditional upon publication of the post-dialysis sampling techniques used in each centre. A survey of techniques used showed great variability, as is discussed in Chapter 7.

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 analysis; only the Renal Registry director, data manager and statistician are able to identify the centres. This identification is necessary so that any issues raised, and discrepancies in the analysis, can be discussed with the relevant centre.

As it may be possible to identify a centre by the number of patients treated there, throughout this report the anonymous analyses that compare centres do not show the actual number of patients in each centre.

Interpretation of the data within the report

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

As in last year's report, 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 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 40 centres and then centre Y with the other 39 centres. Thus, 79 comparisons have been made, and in any comparison at least four are likely to be 'statistically significant' by chance at the commonly accepted 1 in 20 level. If 41 centres were compared with each other, 860 individual comparisons would be made, and one would expect to find 42 'statistically significant' differences. Thus, if the units with the highest and lowest achievement of a standard are selected and compared, it is probable that a 'statistically significant result' will be obtained. Such comparisons of units selected after reviewing the data are invalid in statistical terms. 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 identifiable 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. The Registry is investigating the most appropriate methods of performing such comparisons.

Integration with the audit cycle

The UK Renal Registry has a unique database: no other national renal registry is collecting such detailed sequential data on each individual patient encompassing information related to the quality of care delivered. This is essential if the Registry is to achieve its aim of improving the quality of care provided. In the UK, the Registry lies at the forefront of speciality-based national developments in quality assurance/improvement and is part of an implicit national renal audit cycle, as shown in Figure 2.3.

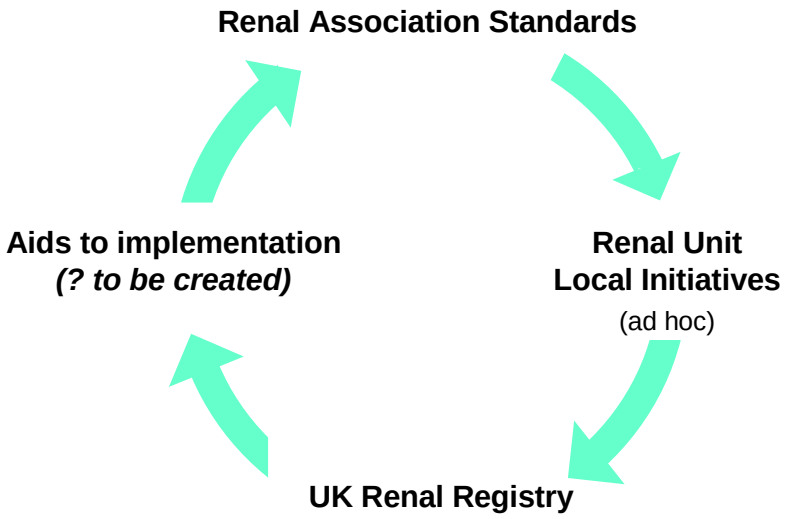


Figure 2.3: Renal Registry audit cycle

With the presentation of these Registry data to the renal community, the challenge to nephrologists is to find effective and creative ways of using the data in the implementation part of the cycle in order 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 presented by the Registry data. The Renal Association is currently considering structures to use the Registry data to facilitate closing the audit loop.

Future potential

National Service Framework

The Registry has been an active participant in developing the advice to ministers for the RNSF. With almost complete coverage of the UK, the Registry is ideally situated to aid the implementation and monitoring of this National Service Framework.

Scientific studies

The Renal Registry data collection system has huge potential for the future. The Registry software resources in place at renal units offer an opportunity for automated data collection for multi-centre studies and trials. From the outset, the database was designed to facilitate this, with provision for patients to be specifically flagged, allowing the easy addition of new data items without requiring any alteration to the existing basic software. The extension to research applications will require attention to compliance with Data Protection Act, an issue that is further discussed in Appendix C.

Pre-'end-stage renal failure' cohorts

There is also considerable interest in collecting data on cohorts of pre-end-stage renal failure patients: many renal units already hold these data in their systems. Once the work of connecting the rest of the UK sites has been completed, the members of the Renal Association will be consulted on these future projects.

A move towards explanation

The resource that has been necessary to enlist the majority of UK renal units to the Registry should increasingly become available to improve the usefulness of the data held by the Registry. It is apparent that mere analysis and presentation of the data will need to be developed into the assessment of significance and explanation. This will require further interaction with units to improve the quality and breadth of data capture, for example accurate related to erythropoietin dosage and comorbidity data. In this way, the Registry will be in an excellent position to support the improvement in clinical care and outcomes that it was intended to serve.

A more detailed analysis of the current data is being performed and will be presented to the 2003 spring meeting of the Renal Association.

Distribution of the Registry Report

The Renal Association has made a grant towards meeting part of the cost of the report so that it can be distributed to all members of the Association. The report will also be distributed to StHAs 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 towards the £12 cost of printing and postage would be appreciated

The full report will also appear on the Registry website – *www.renalreg.com*

Chapter 3: Data Validation Procedures

Introduction

It is the appropriate time to publish a description of the data validation procedures of the Renal Registry. Not only has the experience of data analysis from previous years reached a significant level, but it is also opportune in the year in which centres are identified in the report to demonstrate the care that the Registry has taken to ensure the quality of the data held. This chapter explains some of the extensive validation processes run by the Registry to make sure that the data are as accurate as possible.

The data validation process at the Renal Registry is divided into four separate parts:

1. Consistency checks when each of the quarterly files is loaded
2. Validation against previous data on the database after the quarterly file has been loaded
3. Validation on the database for consistency of data for the whole of the year
4. Statistical routines written in the SAS statistical language that run other consistency checks.

Processes 1 and 4 were in place at the end of the original 2 year pilot project but were often performed at a late stage. Delays in the Registry report resulted particularly from finding errors in the data at the fourth step. As a consequence, it was necessary to discuss problems with the affected renal units, eliminate any local database issues, re-run extractions, reload the Registry database, revalidate and then re-extract the data into SAS, a process that could add months to the reporting timescale. Over the past year, the Registry has increased the number of processes at stages 2 and 3 to be performed quarterly as data are received in order to reduce the number of potential errors picked up at a late stage.

Common data errors

The most common errors resulting in calls to renal units from the data management team are listed below:

1. Missing EDTA disease primary disease codes
2. Missing haemodialysis supervision code (i.e. home, hospital or satellite) against a treatment modality
3. Incorrect figures, e.g. blood pressure 130/4 mmHg
4. Dates that do not match, e.g. the date of starting dialysis being earlier than the date of birth
5. Checks on discrepancies relating to patient names and dates of birth between transplant and dialysis centres. These problems were particularly common when patients transferred for transplantation
6. Text in a numeric data field.

The Renal Registry modality timeline

The modality timeline contains information on the changes of modality. It is the most important item in the data sent to the Registry as the local extraction software uses this information to decide whether or not to send data to the Registry.

1. Local software detects renal replacement therapy (RRT) modality entries in this field to flag the patient as being on RRT and sends data to the Registry.
2. If a patient recovers function, the software sends no more data to the Registry for that patient until a new modality is detected (so 'recovered function' must not be used for transplanted patients).
3. If a patient 'transfers out', the software sends no more data to the Registry for that patient until the patient is transferred back in.

Accuracy is essential as analysis of these data by the Registry is critical in the following areas:

1. Take-on rates are calculated from the first modality in the timeline.
2. If the first modality is 'transferred in', the patient is excluded from the incident calculations.
3. Recovery of function excludes these patients from subsequent prevalence figures.
4. Prevalence rates are calculated by excluding any patients transferred out.
5. If patients are not recorded as having transferred out, no further results thus being obtained, they will be included in the analysis as having data missing.

The validation process

From the experience of the first 5 years, the Registry staff have recognised many common sources of error and have developed automated processes to check for these errors as early as possible in the data-loading process in order to avoid delays in data analysis after the data for the last quarter of the year have been loaded.

Consistency checks at load

Range tests for numeric items (e.g. biochemistry) and all the numeric data have simple range checks on them. These ranges have to be very wide to accommodate both physiological ranges (creatinine = 130 micromoles/L) and the pathological range (creatinine = 3500 micromoles/L). They also have to accept paediatric values.

The most frequent errors are found in the manual entry fields as a result of mis-keying the data. Many sites have not set up local range validation within their own database; instituting this feature would reduce the number of calls received from the data management team at the Registry. The most frequent errors are found in the blood pressure data, where for example an entry of 14 instead of 140 might be recorded. The second most common error is length of time on dialysis, hours being entered instead of minutes or, in other systems, minutes instead of hours. Similar mis-keying has been found in many other data fields, particularly where satellites units manually enter laboratory data.

We encourage sites, wherever possible, to add these range checks locally.

1. *Validity of coded entry fields.* Whenever possible, the Renal Registry uses Read codes or EDTA codes (for primary diagnosis and cause of death), these being validated against their acceptable ranges. Some renal units have modified the European EDTA codes, which this can cause validation errors.

   Again, a lack of fixed coding in the local renal unit database is the source of these errors. Some renal units allow manual entry of the EDTA code number rather than a specific diagnosis that is internally converted by the database into an EDTA code number. Sites that offered the ICD10 list of diagnoses for the primary diagnosis field have been successfully discouraged from this practice as this can result in errors – on one occasion, cerebrovascular accident was given as the primary cause of chronic renal failure.

2. *Avoidance of duplicate patients.* As patient data are received from both dialysis and transplant centres, it can be very easy, if the right systems are not in place, for patients to be duplicated on the database. This is not just a simple process of flagging up patients with the same surname, forename and date of birth. Many patients have their names spelt in a slightly different way on different databases, and it is impossible to impose consistency between two sites. In addition, dates of birth can vary (by days or months), and renal units have been unwilling to change these data, partly perhaps because the local automated laboratory links may refuse to load patient data if the date of birth or name is spelt differently from that held in the laboratory systems.

   Detecting these duplicated patients relies on a complex series of procedures:

1. *The NHS number.* This is a unique identifier for patients in patients in England & Wales, but many sites do not store this number in their renal system so it has not yet been found to be useful. The Registry submits files to the NHS number tracing service.

2. *UK Transplant number.* Patients on the transplant waiting list, or who have been transplanted, are allocated a unique number that should be stored on the local renal unit database (although it may be held only at the transplanting centre). This is recorded by the Registry as a non-duplicated indexed field. The Registry validates these numbers annually with UK Transplant, this process detecting mis-keyed data entry errors (e.g. 97074 instead of 90774). Renal units are informed of any mis-keying errors found.

3. *Soundex database index on names.*

4. *Check on the address field.*

   Once a new patient has been identified, the Registry allocates its own unique ID number for the patient, which is transmitted back to the renal unit and loaded electronically to avoid any mis-keying.

5. *Validation of the postcode.* The Renal Registry uses a commercial postcoding package (QAS systems), which checks the validity of the postcode against the address fields, the software automatically correcting any postcode errors. This is important as postcodes are used for NHS number tracing and also by the Registry for health authority mapping and deprivation scoring.

6. *Date fields.* All date fields must be in the format dd/mm/yyyy and are checked for validity.

7. There are other consistency checks, some of which are listed below:

    1) Date of first RRT < date of birth (as mis-keying has been found)

    2) Date of death < date of birth and < date of first RRT (as mis-keying of the date of death has occurred)

    3) Data are loaded for a patient already registered as dead. A transplant unit may have accidentally logged a patient as dead when he or she has returned to dialysis

    4) Mandatory fields (e.g. cause of primary renal disease) missing

    5) Inappropriate data for specific treatment modalities. A urea reduction ratio value or length of time on haemodialysis cannot be sent while the patient is on peritoneal dialysis

    6) There must be new patients starting RRT in every quarterly file received from the renal unit

    7) There must be some deaths in every quarterly file.

Consistency checks after loading

There are many errors that cannot be checked at the time the file is loaded. This is because these errors relate to the overall data integrity for the renal unit compared with the data from previous quarter.

1. Many long-standing transplant patients are not seen quarterly. Missing creatinine data over three consecutive quarters result in a telephone call to the unit in case the patient has died or transferred elsewhere without this being logged in the renal unit database.
2. Incorrect modality in a timeline. Some patients have had a modality of 'recovered renal function', rather than 'graft functioning', sent to the Registry after transplantation. This is invalid but can only be checked once the data have been loaded. Renal units are contacted to change this item.
3. The date of death must be later than last modality entry in the timeline. This item produced an error for 28 patients on one annual check, all caused by mis-keying the date of death.

Annual data checks

1. The number of patients starting RRT should be spread across all quarters, and the total number must be consistent with previous years.
2. Prevalent patient totals should rise on an annual basis.
3. Health authority take-on rates should show consistency.

4. In every centre, there should be timeline entries with a treatment start date for every quarter over which the Registry collected data (Table 3.1). There will always be some patients in a quarter who have changed modality; lack of modality changes indicates either a software problem or missing data.

Quarter no.	No. of new timeline entries
12	45
13	52
14	42
15	50
16	66
17	71
18	52
19	87
20	42
21	36
22	52
23	45
24	1

Table 3.1: Frequency of timeline entries per quarter – an example

5. Deaths should occur in every quarter, and the total number of deaths should be evenly spread. A lack of deaths registered often represents a software extraction fault rather than an error of logging by the renal unit. An excess of deaths in a given quarter can also be identified and of course investigated.

When errors such as those listed are found, the Registry contacts the renal unit for clarification and correction where appropriate.

SAS analysis

Many of these potential errors are rechecked through SAS, outliers being identified. Examples include the following:

1. *Have centres transferred patients in and out?* (The number of transfers in and out is usually roughly equal.) The results shown in Table 3.2 indicate that some dialysis centres do not transfer patients out prior to transplantation at another centre, and some centres do not transfer them back in. In such cases, the Registry adds the appropriate code to the timeline in the Registry database. This is important as, during the analysis, each patient is allocated to a centre for a specific time point. This is not only for calculating the total number of patients at a centre, but also for allocating missing biochemistry data to a centre.

Centre	Transfer in	Transfer out
RAJ01	50	61
RAQ01	181	195
RAZ	122	79
RCJAT	441	441
RCSLB	203	98
REE01	316	251
RF201	403	349
RFBAK	82	58
RFPFG	8	15

Centre	Transfer in	Transfer out
RGD03	2	
RH641	140	157
RH8	171	116
RHW01	29	48
RJ121	91	94
RK7CC	89	65
RK950	152	56
RKB01	190	207
RKHA4	134	210
RL403	169	149
RL7	411	396
RLGAY	146	147
RLNGH	274	234
RMF01	242	306
RNA03	200	232
RNX02	401	188
RQHC7	113	260
RQR13	1149	1118
RQS01		1
RRBBV	353	230

Table 3.2: Frequency of timeline transfer

2. *How many patients at each centre recover renal function during the first 360 days of starting RRT?* All hospitals should have a few patients who recover renal function during the course of their first year. If the number for a particular centre is too low, some patients are probably being misclassified as 'acute'. Conversely, centres with an excessive number of patients recovering within the first 90 days are probably including a large number with acute renal failure. Patients may be correctly classified as having chronic renal failure and recover function within 90 days.

3. *What are the first treatment modalities, and do any patients have two different treatment modalities on the same day of their first modality?*

4. *Have any patients been transplanted at a 'dialysis' centre?* Some dialysis centres do not transfer patients out for a transplant and furthermore may log the transplant as having taken place at their centre.

5. *Is there a variation in biochemistry results?* Software errors have been picked up by identifying centres if patients' results have not changed on a quarterly basis (e.g. haemoglobin level 10.6 g/dL) for two sequential quarters.

6. *Is there a difference between the pre-dialysis and post-dialysis blood pressure?* Such a difference is usually seen, so if the systolic and diastolic pressures are identical, one value is likely to be invalid.

7. *Has there been a large increase in missing data within a quarter for any data item*? This will be queried with the site. One site showed a large increase in missing urea reduction ratio data that had arisen from an undetected clerical error in storage of the post-dialysis sample data in the local database. Similarly, a reduction in returns for ethnicity was shown to be due to a change in the method of coding this item.

8. *Is there a complete absence of an expected biochemistry item (e.g. ferritin)?* This will be confirmed with the site. At two sites, the internal software links to these tables in the database were shown to be faulty.

9. The haemoglobin data for one site this year had begun arriving as an integer (e.g. 9 or 10 g/dL). This error will pass all the other validation checks and was shown up only on analysis of the distribution of these results (quartiles). This resulted in a software fix at the site and the necessity of re-exporting all the patient quarterly haemoglobin data for 2001. This was reloaded into the database and into SAS, and all the haemoglobin analyses were re-run (as the overall means will change) and graphs replaced in the text.

Comment

This is not an exhaustive description of the data validation routines, but the complexity of the task is evident. Much of the data quality depends on the monitoring of data entry at the originating centre. The local verification of data on a regular basis, through review meetings or weekly or monthly printed reports, is a necessary component of quality to assure the entries. The careful induction of new renal staff is another important issue. These checks may also be supplemented by automated routines for missing data and anomalous entries, a process with which the Registry is willing to help. A renal unit's progressive attention to the detail of data registration should allow a reduction in the validation effort required of Registry staff and a shorter interval between download and the production of the Report.

The key to further improvement in data quality is an open exchange of information and an increasing scrupulousness at renal unit level, which the UK Registry always attempts to match.

Chapter 4: New Adult Patients Starting Renal Replacement Therapy

Summary

- The annual acceptance rate of new patients in the UK has not risen over the past 4 years. At 93.2 per million population (pmp) for adults and 1.7 pmp for children, it is lower than that of most other Western European countries.

- The annual acceptance rates in Wales, Scotland and England are converging, the higher rates seen in Wales and Scotland in the late 1990s appearing not to have been maintained.

- The annual acceptance rates in the old health authorities varied from 51 pmp to 154 pmp. This variation cannot be fully explained by the age distribution and ethnic mix of the communities served.

- An analysis of acceptance rates by age shows that crude rates can be misleading and demonstrates the importance of the age distribution of the population served.

- Diabetic nephropathy, seen in 18% of new patients, is not increasing and remains less prevalent than in the USA and much of Europe.

- Haemodialysis is the mode of dialysis on day 90 in 53% of new patients in England, 56% in Wales, 64% in Scotland and 82% in Northern Ireland. Higher rates are seen in those over age 65 than in those younger than this.

- Survival rates show consistency in the cohorts of patients starting renal replacement therapy from 1997 to 2000. One-year survival is 79% (89% for those below age 65, 68% for those above). Four-year survival is 48% (67% below age 65, 24% above this age).

Introduction

Earlier Registry reports demonstrated wide variations between renal units in both the incidence and prevalence of renal replacement therapy (RRT). The precision of these data was limited by difficulties encountered in determining the catchment populations of individual renal units. By mapping patient postcodes to health authorities in those areas with complete or near-complete coverage by the Registry, a start was made in the last report to relate these data to local populations rather than to the perceived catchment area of each unit. This showed that some of the apparent variation between units was the result of an inaccurate estimate of catchment areas. This work has been extended in 2002 to take account of population age differences. The preliminary data were circulated to the provider units in an attempt to improve accuracy, several corrections being made as a result.

In this year's report, there is complete coverage of 51 health authorities in England and all five in Wales, comprising a total population of 28.6 million. The data for Wales were made complete by the addition of some information from the 2002 Annual Report of the Welsh Association of Renal Physicians and Surgeons, provided by Dr Peter Drew.

Methodology

To facilitate the comparison of acceptance rate between units, an acceptance ratio has been calculated thus: (Unit acceptance rate / Registry mean acceptance rate)*100

A result higher than 100 indicates the percentage increase over the mean, one of less than 100 a decrease. The Registry mean is the total for the 28.6 million population thought to have complete coverage.

Because the incidence and prevalence of established renal failure increase markedly with increasing age, and there is a significant variation in age structure across the UK (the proportion aged over 65 rising from 12% to 21% across the 56 health authorities), it is intended in future to calculate indirect age-standardised ratios for both the incidence and prevalence of RRT to facilitate comparisons of care provision. Although this has not been possible in 2002, acceptance rates have been calculated for the age groups 18–65 and over 65 found in the whole population represented by the 56 health authorities (see Table 4.2 below). Other factors known to determine the extent of renal disease in a community, but not taken into account, are ethnicity and socio-economic status. The number treated may also depend on the distance from a main renal unit as this may affect the referral pattern. There may also be a variation in the local criteria for referral and acceptance. The effect of satellite units on treatment rate needs to be explored further.

It will in future be possible to use the 2001 national census data to explore the effects of ethnicity and socio-economic status on take-on rate and to undertake more complete age and gender standardisation. To improve precision, several years' data per health authority will be combined.

Acceptance rates

	England	**Wales**	**N Ireland**	**Scotland**	**Total UK**
No. of units	31	5	4	10	70
No. of new patients	2847 (4500**)	308	194	513	5515*
Population (millions)	49.5	2.93	1.7	5.1	59.2
New patients pmp	90.8	105	115	101	93.2*
95% CI	90.5–91.0	102.7–108.3	110–120	99.4–102.6	
New patients per unit	83***	72	49	51	79

Table 4.1: Summary of new adult patients accepted during 2001

*Includes estimated number for England.

**Estimated number for England derived from Registry catchment population.

***Calculated for all England. For Registry participants only, the figure is 92.

The acceptance rate this year for England has been calculated from those parts of the country known to have complete health authority coverage by the Registry, the result being a minimum annual incidence for adults of 90.8 pmp total population. This could underestimate the incidence if any patients from those areas were treated in non-Registry units. If calculated from the total incident patients recorded using the estimated catchment populations from renal units, the annual incidence is 93.5 pmp. The paediatric annual incidence rate adds an additional 1.7 pmp total population.

The 'Registry' population of England appears to be representative of England as a whole, as the percentage of Registry health authority population aged 65 and over is 15.8%, compared with 15.9% in the 2001 UK Census.

Changes in acceptance patterns in the UK over 20 years are shown in Figure 4.1. This clearly demonstrates the overall rise in acceptance rates in the UK during the 1980s and early 90s. This rise was most striking in the older age groups and in diabetics. It is, however, important to note that although the prevalence of people receiving RRT continues to rise, as more people are started on RRT each year than die (see Chapter 5), the acceptance rate in the UK has not risen for 4 years. There does not appear to have been an increase in the incidence figure for England since 1998. Although the populations of both Wales and Scotland are relatively small, giving wide confidence limits, the rise in incidence rates seen during the 1990s has stopped, both countries showing a recent fall in incidence, and the acceptance rates of the three countries are converging (Figure 4.2). These acceptance rates are well below those seen in many other European countries (see Table 4.29 below).

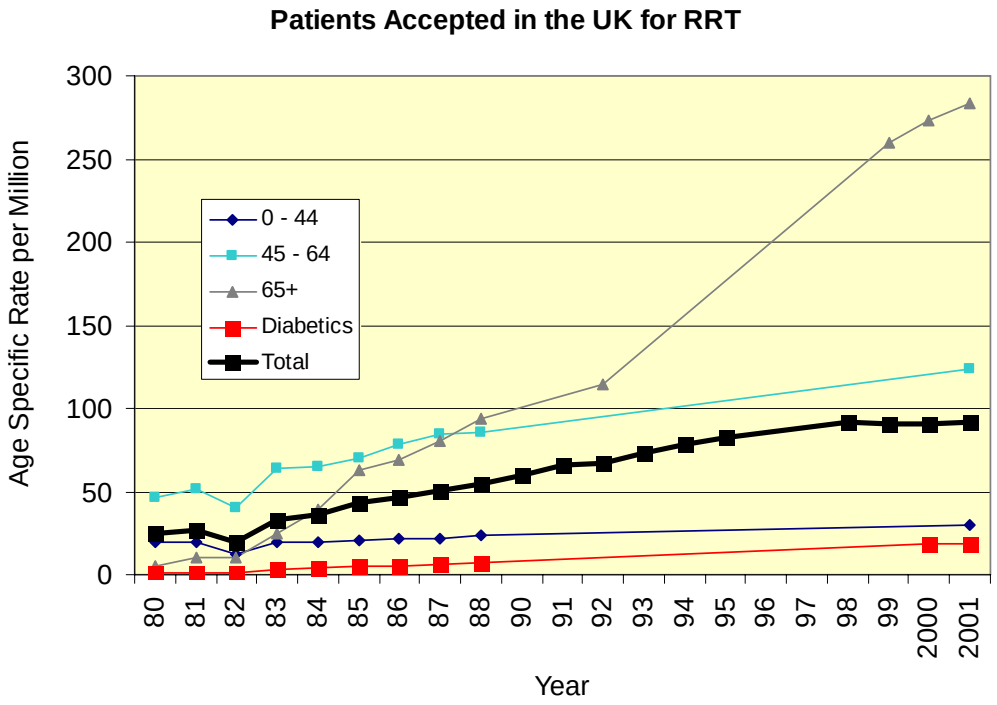


Figure 4.1: Trends in acceptance rates for RRT in the UK, 1980–2001
Sources: EDTA Registry, National Renal Reviews, UK Renal Registry.
For the age groups, the incidence rates are annual pmp alive in that age group.

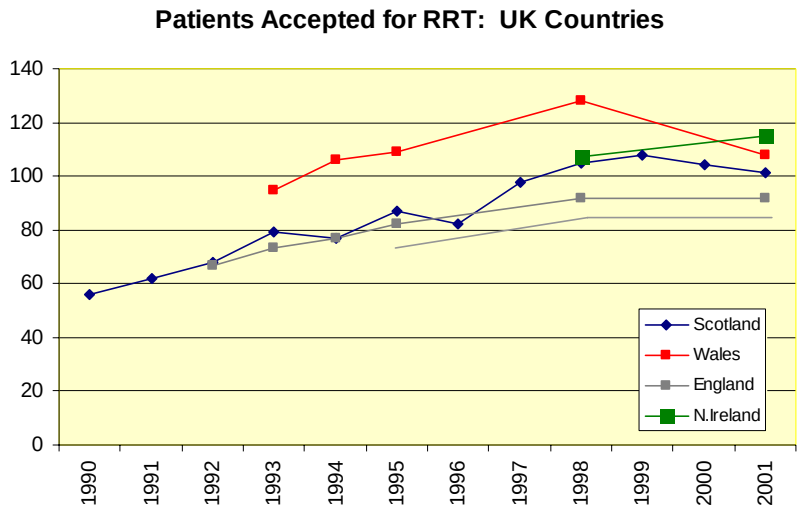


Figure 4.2: Trends in acceptance rate for RRT in the countries of the UK, 1990–2001
Sources: National Renal Reviews, UK Renal Registry, Scottish Renal Registry

Acceptance rates of health authorities

These data have been calculated by mapping patient postcodes (after using a postcode correction package) to health authorities, using the NHS organisational postcode mapping supplied by the Department of Health. Figures for England and Wales population denominators by age for each health authority were obtained from the Office for National Statistics.

Tables 4.2 and 4.3 include only those health authorities with, as far as can be ascertained, complete coverage by the Registry. For these, the annual incident rate in adults was 90.8 pmp.

Region	Health authority	All patients							
		Population	Pat. count	All pmp	AR	95% CI	pmp 18–64	pmp >65	% new pats from ethnic minority
Y01	Bradford	483,300	58	120	133	114–152	94	448	
Y01	Calderdale and Kirklees	583,800	55	94	104	89–120	78	310	
Y01	County Durham and Darlington	607,800	35	58	64	50–78	48	174	
Y01	East Riding and Hull	574,500	49	85	94	79–110	81	222	
Y01	Leeds	727,400	67	92	102	89–114	67	335	
Y01	North Cumbria	319,300	25	78	87	59–114	46	288	
Y01	North Yorkshire	742,400	63	85	94	82–106	53	293	
Y01	Sunderland	292,300	15	51	57	28– 85	28	226	0
Y01	Tees	556,300	47	84	93	77–110	77	255	
Y01	Wakefield	318,800	23	72	80	52–107	60	237	
Y02	Barnsley	228,100	15	66	73	35–111	28	304	0
Y02	Doncaster	290,500	27	93	103	72–134	68	329	
Y02	Leicestershire	928,700	100	108	119	109–129	81	390	29
Y02	Lincolnshire	623,100	48	77	85	71–99	61	211	
Y02	North Derbyshire	370,200	32	86	96	71–120	48	329	3
Y02	North Nottinghamshire	388,900	35	90	100	76–123	62	316	
Y02	Nottingham	642,700	72	112	124	110–138	81	401	15
Y02	Rotherham	254,400	38	149	165	128–202	152	362	9
Y02	Sheffield	531,100	48	90	100	83–117	92	209	15
Y02	South Humber	308,600	17	55	61	34–88	48	157	
Y07	Coventry	304,300	47	154	171	140–202	116	552	
Y07	Solihull	205,600	23	112	124	79–168	86	366	
Y07	South Staffordshire	592,100	44	74	82	67–97	45	314	

Region	Health authority	Population	All patients Pat. count	All pmp	AR	95% CI	pmp 18–64	pmp >65	% new pats from ethnic minority
Y07	Walsall	261,200	29	111	123	88–158	50	509	31
Y07	Warwickshire	506,700	51	101	111	93–129	66	375	
Y07	Wolverhampton	241,600	28	116	128	90 –166	92	376	43
Y08	East Lancashire	511,200	44	86	95	78–113	97	184	13
Y08	Liverpool	461,500	69	150	165	145–186	121	519	
Y08	Morecambe Bay	310,300	22	71	78	50–107	70	158	0
Y08	North Cheshire	311,900	29	93	103	74–132	76	332	
Y08	NW Lancashire	466,300	45	97	107	87–126	101	192	14
Y08	Sefton	287,700	27	94	104	72–135	99	184	
Y08	South Lancashire	312,700	21	67	74	47–102	51	238	0
Y08	St Helens and Knowsley	333,000	27	81	90	63–116	78	229	
Y09	Bedfordshire	556,600	49	88	97	81–114	74	320	
Y09	Cambridgeshire	468,000	47	100	111	92–131	104	251	
Y09	Hertfordshire	1,033,600	83	80	89	80–97	73	233	
Y11	Berkshire	800,200	75	94	104	92–115	82	330	29%
Y11	Buckinghamshire	681,900	59	87	96	83–109	67	348	
Y11	IOWight, Portsmouth & SE Hampshire	671,700	48	71	79	66–92	56	228	
Y11	North & Mid Hampshire	556,900	34	61	68	52–83	48	229	
Y11	Northamptonshire	615,800	52	84	93	79–108	71	286	
Y11	Oxfordshire	616,700	51	83	91	77–106	62	317	
Y11	Southampton & SW Hampshire	542,300	36	66	73	57–89	51	207	
Y12	Avon	999,300	109	109	121	111–130	84	353	9
Y12	Cornwall and Isles of Scilly	490,400	51	104	115	96–134	83	274	
Y12	Gloucestershire	557,300	46	83	91	75–107	74	218	
Y12	North and East Devon	479,300	44	92	102	83–120	46	312	
Y12	Somerset	489,300	43	88	97	79–116	62	264	
Y12	South and West Devon	589,100	75	127	141	125–157	89	387	
Y12	Wiltshire	605,500	40	66	73	59–87	53	215	
	England	**25,632,200**	**2317**	**90**	**100**	**90.5–91.1**	**72**	**292**	

Table 4.2: Incident rates, by age, for health authorities in England, with acceptance ratio

W00	Bro Taf	739600	63	85	94	82–106	67	288	
W00	North Wales	657500	68	103	114	101–128			
W00	Dyfed Powys	479400	51	106	118	99–137	77	312	
W00	Gwent	557200	63	113	125	109–142	104	312	
W00	Morgannwg	499700	63	126	139	121–158	100	372	
	Wales	**2,933,400**	**240**	**105**	**117**	**103-108**	**86**	**318**	
	Total E&W	**28,565,600**	**2317**	**90**		**100**	**72**	**292**	

Table 4.3: Incident rate, by age, for health authorities in Wales, with acceptance ratio

There is considerable variation in the acceptance ratios. Several health authorities (e.g. Bradford, Leicester and Nottingham) have ratios significantly higher than 100 with a lower CI of over 100; in others (e.g. County Durham, Sunderland, North & Mid Hampshire and Wiltshire), the converse applies. Local knowledge will be required to understand the reasons for such variation.

The age-specific acceptance rates show a huge variation. In younger patients, the rate varies from 28 pmp in Sunderland to 152 pmp in Rotherham; for the elderly, the range extends from 157 pmp in South Humber to 552 pmp in Coventry. Whereas some units have relatively similar rates for both age groups, others have a high rate in one age group and a low one in the other (Table 4.2 and Figure 4.3).

These data illustrate how crude acceptance rates can be misleading with regard to practice. Thus, Cornwall and Warwickshire have a similar acceptance rate pmp per year (104 and 101 respectively). With the higher proportion of elderly people in Cornwall, one would expect a higher overall take-on rate than Warwickshire. Cornwall is, however, accepting fewer patients from its high-elderly population (274 pmp) than Warwickshire is from its smaller elderly population (375 pmp).

Trends in acceptance for those health authorities with reliable data over 3 or 4 years are shown in Table 4.4.

Region	Health authority	Population	1998 pmp	1999 pmp	2000 pmp	2001 pmp	Patient count
Y01	Calderdale and Kirklees	583,800			80.5	94.2	55
Y01	County Durham and Darlington	607,800	100.4	74.0	72.4	57.6	35
Y01	East Riding and Hull	574,500	71.4	71.4	88.8	85.3	49
Y01	North Cumbria	319,300	125.3	72.0	68.9	78.3	25
Y01	Sunderland	292,300	51.3	85.5	82.1	51.3	15
Y01	Tees	556,300	107.9	91.7	82.7	84.5	47
Y02	Barnsley	228,100	70.1	83.3	61.4	65.8	15
Y02	Doncaster	290,500	75.7	82.6	79.2	92.9	27
Y02	Leicestershire	928,700	107.7	89.4	91.5	107.7	100
Y02	Lincolnshire	623,100	81.8	91.5	88.3	77.0	48
Y02	North Derbyshire	370,200	51.3	62.1	59.4	86.4	32
Y02	North Nottinghamshire	388,900	115.7	95.1	108.0	90.0	35
Y02	Nottingham	642,700	119.8	110.5	96.5	112.0	72
Y02	Rotherham	254,400	51.1	62.9	102.2	149.4	38
Y02	Sheffield	531,100	88.5	90.4	81.0	90.4	48
Y02	South Humber	308,600	103.7	64.8	74.5	55.0	17
Y07	Coventry	304,300	111.7	115.0	118.3	154.5	47
Y07	Solihull	205,600	82.7	73.0	87.5	111.9	23
Y07	South Staffordshire	592,100		45.6	55.7	74.3	44
Y07	Walsall	261,200	11.5	114.9	76.6	111.0	29
Y07	Warwickshire	506,700	96.7	116.4	100.7	100.7	51
Y07	Wolverhampton	241,600		99.3	157.3	115.9	28
Y08	East Lancashire	511,200		68.5	74.3	86.1	44
Y08	Morecambe Bay	310,300		70.9	99.9	70.9	22
Y08	North-West Lancashire	466,300	75.1	68.63	79.3	96.5	45
Y11	Northamptonshire	615,800	71.5	73.1	89.3	84.4	52
Y11	Oxfordshire	616,700	76.2	64.9	61.6	82.7	51
Y12	Avon	999,300	82.1	84.1	109.1	109.1	109
Y12	Gloucestershire	557,300	89.7	95.1	87.9	82.5	46
Y12	North and East Devon	479,300	81.4	87.6	91.8	91.8	44
Y12	Somerset	489,300	67.4	83.8	69.5	87.9	43
Y12	South and West Devon	589,100	118.8	106.9	96.8	127.3	75
W00	Gwent	557,200	102.3	75.4	93.3	113.1	63
W00	Bro Taf	739,600	87.9	110.9	97.3	85.2	63

Table 4.4: Changes in incident rate of health authorities

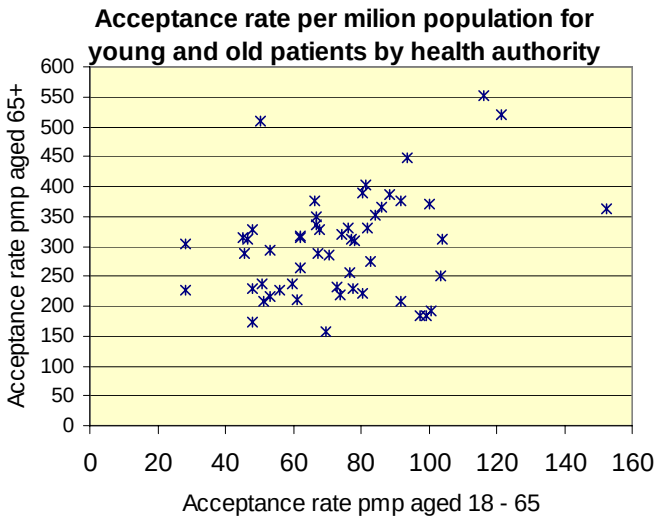


Figure 4.3: Scatter plot of acceptance rate by health authority in young and elderly patients

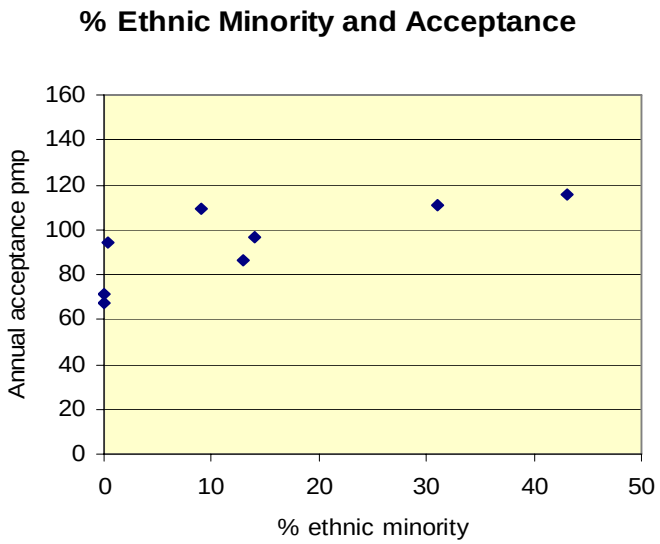


Figure 4.4: Percentage from ethnic minorities and acceptance rates in health authorities

Complete or near-complete ethnicity data are available for very few health authorities (Table 4.2). The variation of acceptance with ethnicity is illustrated in Figure 4.4.

Acceptance of new patients by individual renal units

The number of patients accepted by each renal unit is shown in Table 4.5.

		No. of new patients			
Centre	**Estimated catchment population**	**1998**	**1999**	**2000**	**2001**
Bradford	0.60				61
Bristol	1.50	122	119	151	151
Cambridge	1.42				84
Cardiff	1.30	137	138	137	142
Carlisle	0.36	40	26	27	25
Carshalton	1.67	141	108	117	120
Coventry	0.85	87	92	89	103
Exeter	0.75	74	82	71	99
Gloucester	0.55	49	59	46	49
Guys	1.73			122	109
Heartlands	0.60	71	71	77	85
Hull	0.84	73	65	81	75
Leeds GI	0.90			68	74
Leicester	1.73	181	161	177	182
Liverpool	1.35				182
Nottingham	1.16	129	128	113	121
Oxford	1.80	146	139	144	168
Plymouth	0.55	71	67	63	63
Portsmouth	2.00				144
Preston	1.56	79	105	118	135
Reading	0.60			54	71
S Cleveland	1.00	109	92	90	82

Centre	Estimated catchment population	No. of new patients 1998	1999	2000	2001
Sheffield	1.75	129	134	136	152
Stevenage	1.25	116	105		125
Southend	0.35		43	39	35
St James, Leeds	1.30	71	79	89	87
Sunderland	0.34	41	45	46	35
Swansea	0.70		23	61	110
Truro	0.36				35
Wolverhampton	0.49		75	77	76
Wordsley	0.42	46	43	40	34
Wrexham	0.42		51	58	36
York	0.34			40	36
Total E&W	**33.01**	–	–	–	3086

Table 4.5: Number of new patients accepted by individual renal units

The total number of patients shown in Table 4.5 is higher than that in Table 4.2 as the latter excludes health authorities where the coverage is incomplete.

Ethnicity

There is still considerable variation in the provision of ethnicity data (Table 4.6). There are no data from Scotland or Wales, and in England, only 10 units returned ethnicity data for over 90% of patients, and 11 units provided little or no data at all. The Registry needs to work over the next year to assist other units in improving on this as ethnicity is an important variable for determining equity of provision, outcomes and emerging trends as ethnic minority populations age. Overall, about 12% of new acceptances to participating units with over 85% completeness came from Indo-Asian or African-Caribbeans population. Some units serving large ethnic minority populations have over 15% Indo-Asian and Black populations, and this proportion is likely to grow as these populations age.

Treatment centre	%	White	Black	Asian	Chinese	Other
Words	100.0	97.1	0.0	2.9		0
Sheff	100.0	92.1	1.3	5.3		1
Notts	100.0	90.9	5.0	3.3		1
Heart	100.0	74.1	8.2	15.3		1
Leic	98.9	81.7	1.1	15.0		2
Redng	98.6	81.4	5.7	11.4		0
Plym	98.4	91.9	6.5	1.6		0
Prstn	97.0	91.6	0.8	7.6		0
Wolve	95.9	78.9	5.6	15.5		0
Bristl	91.4	92.8	5.8	1.4		0
Covnt	85.4	86.4	2.3	11.4		0
Guys	84.8	79.8	14.6	4.5		0
Carsh	77.5	*73.1*	*5.4*	*8.6*		*13*
Hull	70.7	*100.0*	*0.0*	*0.0*		*0*
Sthend	65.7	*100.0*	*0.0*	*0.0*		*0*
Sund	65.7	*100.0*	*0.0*	*0.0*		*0*
Derby	61.2	*93.3*	*6.7*	*0.0*		*0*
Extr	57.6	*100.0*	*0.0*	*0.0*		*0*
StJms	52.9	*84.8*	*8.7*	*4.3*		*2*
Scleve	42.7	*82.9*	*0.0*	*14.3*		
Carls	12.0					

Treatment centre	%	White	Black	Asian	Chinese	Other
Livrpl	9.3					
Camb	6.0					
Stevn	1.6					
Oxfrd	0.6					
Bradf	0.0					
Glouc	0.0					
LGI	0.0					
Ports	0.0					
Truro	0.0					
York	0.0					
Total England		82.9	4.2	7.7	0.4	0.5

Table 4.6: Ethnicity, by centre

The italicised results for units with low (<85%) returns for ethnicity have less validity, so the results for England were calculated only from those units with an 85% or more return on ethnicity data.

The results from units recording 100% White patients have been checked and are correct.

With regard to data relating to health authorities, in Birmingham, where there is part coverage (this therefore not being listed in the health authority data above), 50% of patients recorded as starting RRT were from the ethnic minority groups, and in Lambeth, Southwark and Lewisham 37% came from ethnic minority groups.

	Median age of incident patients	
Centre	**Ethnic minority**	**All**
Bristl	57.5	65
Covnt	64	66
Guys	60	57
Heart	60	65
Leic	59	64
Notts	61	65
Plym	51	67
Prstn	55	57
Redng	54	62
Sheff	47	64
Wolve	69	68
Words	67	63
Total England	**57**	**64**

Table 4.7: Median age of ethnic groups accepted for RRT
Data included only from units with 85% or more returns.

Patients from ethnic minority populations are usually younger, reflecting the age distribution of such populations, although this finding is not universal in each area. The number of patients from ethnic minorities is very small in many units, so there are large error margins on these figures for individual units.

Age

There is a slow shift with time to an older median age (Figure 4.5). The median age in England & Wales is 64, being marginally higher in Wales than England. The proportion of patients over 75 was 23.5% in Wales and 20.9% in England, the overall figure being 21%.

The median age for each unit is shown in Figure 4.6. These data may be misleading with regard to unit policies as the median age will in part reflect the population served. The acceptance rates in the younger and older age groups (Table 4.2) provide a much better indication of referral and acceptance policies. Comparing Table 4.2 with Figure 4.6, it becomes apparent that some of the units with the highest median age do not have as liberal an acceptance practice for accepting the elderly as do some other units; they simply have a high proportion of elderly people in their population. Thus, York, with the highest median age, has an exactly average acceptance rate for older people, and many units with a lower median age accept relatively more patients from the elderly population they serve.

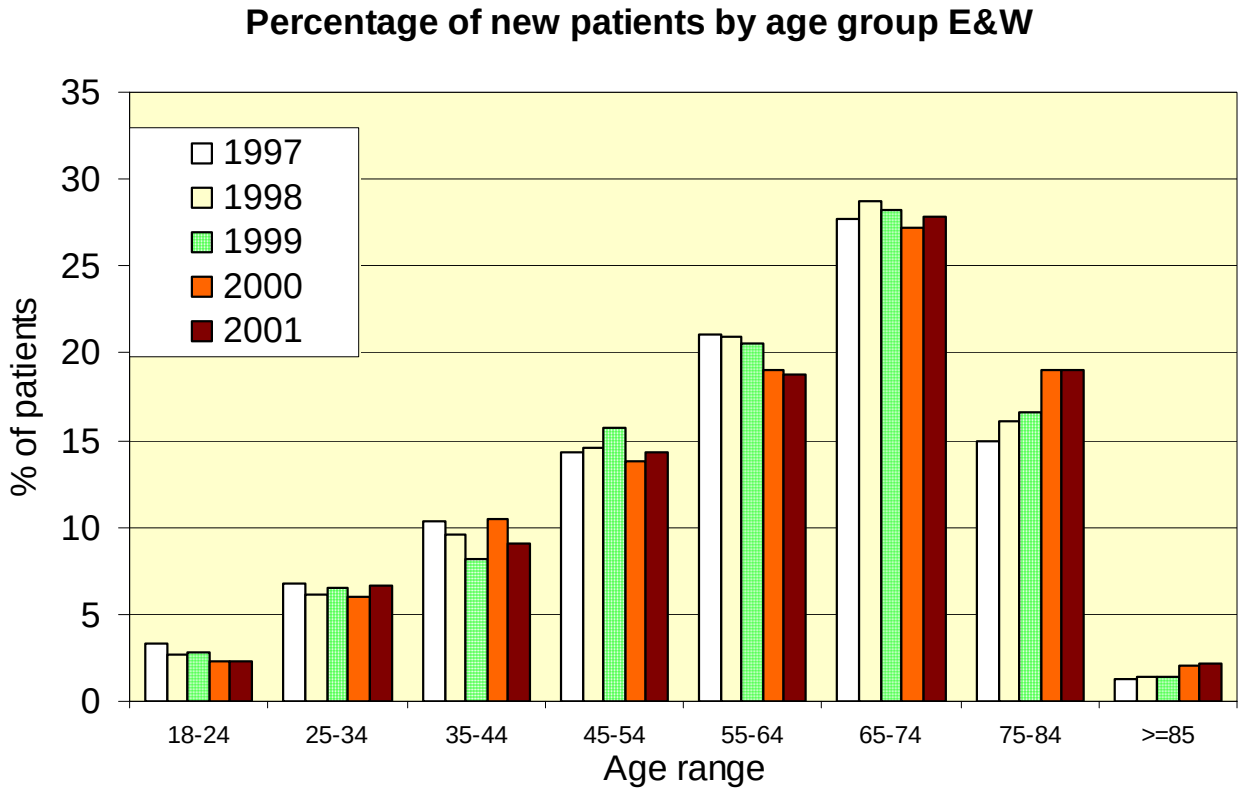


Figure 4.5: New patients, by age group, 1997–2001

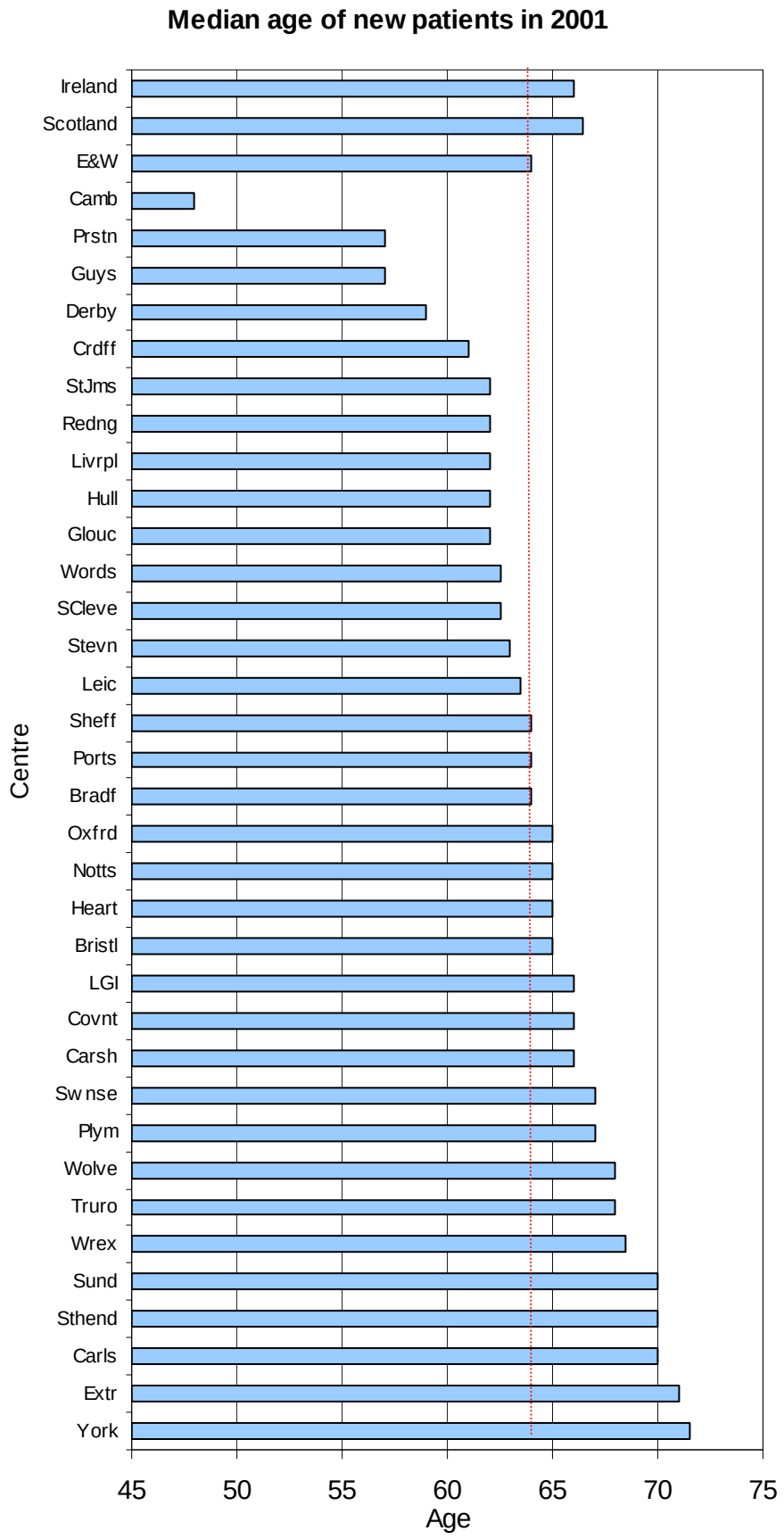


Figure 4.6: Median age of new patients in 2001

Gender

	1998	1999	2000	2001
England & Wales	62.8	62.2	59.3	63.2

Table 4.8: Percentage of males, by age, 1998–2001

As anticipated, there is a male excess of about 1.5:1 (Table 4.8). Gender ratios within specific age groups are ideally needed; these will be available as national coverage is achieved and when the 2001 Census data can be used. In 2001, there appeared to be a trend towards a reduction in the percentage of males, but this has not been confirmed by the latest figures.

Primary renal diagnosis

The distribution of new patients by age, gender and centre is shown in Tables 4.9 and 4.10.

Diagnosis	E&W <65	E&W > 65	M:F
Aetiology uncertain/GN NP	15.8	22.8	1.6
Glomerulonephritis	13.6	6.1	2.5
Pyelonephritis	9.2	8.7	1.5
Diabetes	20.2	11.8	1.6
Renal vascular disease	2.4	11.9	2.4
Hypertension	6.1	7.3	2.2
Polycystic kidney	8.9	3.3	1.4
Not sent	10.5	15.2	1.8
Other	13.3	13.0	1.4

Table 4.9: Percentage primary renal diagnosis, by age, and gender ratio
GN NP, glomerulonephritis not proven

Unit	Not sent	Aetiology uncertain/ GN NP	Diabetes	GN	Polycystic kidney	Hypertens.	Renal vascular	Pyelo-nephritis	Other
Heart	0.0	35.3	25.9	5.9	3.5	4.7	7.1	5.9	11.8
Livrpl	0.0	30.8	17.6	4.9	4.4	15.9	1.1	9.9	15.4
Notts	0.0	26.4	19.8	7.4	5.0	5.0	6.6	7.4	22.3
Redng	0.0	25.4	16.9	14.1	5.6	5.6	5.6	12.7	14.1
SCleve	0.0	13.4	23.2	9.8	7.3	11.0	3.7	8.5	23.2
Sheff	0.0	15.8	17.8	16.4	5.9	16.4	7.9	7.9	11.8
Wolve	0.0	14.5	22.4	7.9	5.3	21.1	6.6	10.5	11.8
Words	0.0	11.8	23.5	11.8	11.8	20.6	2.9	5.9	11.8
Covnt	1.9	18.4	15.5	2.0	5.8	8.7	16.5	16.5	14.6
Bradf	3.3	14.8	27.8	8.2	8.2	4.9	6.6	9.9	16.3
Guys	3.7	19.3	23.9	11.9	8.3	2.8	7.3	10.1	12.8
Bristl	4.0	17.9	14.6	11.2	8.0	6.0	8.0	15.3	15.3
Prstn	5.2	12.6	19.2	15.5	7.4	6.6	6.6	11.1	15.5
Sund	5.7	5.8	8.6	8.6	8.6	22.8	8.6	22.8	8.6
Swnse	6.4	8.1	14.5	15.4	4.6	18.2	13.7	6.4	12.7
Stevn	8.0	36.0	10.4	9.6	5.6	2.4	5.6	2.4	20.0
Plym	9.5	9.5	15.8	12.7	9.5	4.8	15.8	9.5	12.7
Ports	9.7	16.0	13.2	11.1	11.1	4.2	9.0	11.8	13.9
Leic	9.9	26.9	14.9	11.5	5.5	1.6	13.2	7.1	9.4

Unit	Not sent	Aetiology uncertain/ GN NP	Diabetes	GN	Polycystic kidney	Hypertens.	Renal vascular	Pyelo-nephritis	Other
Derby	10.2	12.2	30.6	14.3	10.2	2.1	0.0	14.3	6.1
Oxfrd	10.7	22.1	16.7	9.6	4.7	2.4	6.5	11.9	15.4
Glouc	12.2	22.5	10.2	10.2	6.1	2.0	2.0	6.1	28.6
Sthend	17.1	17.2	14.3	11.4	2.8	5.7	11.4	8.5	11.4
StJms	17.2	11.5	17.2	9.2	8.0	9.2	12.7	5.7	9.2
Carls	20.0	16.0	16.0	0.0	8.0	0.0	4.0	8.0	28.0
Hull	20.0	20.0	17.4	8.0	6.6	4.0	2.6	12.0	9.4
York	22.2	*27.8*	*8.3*	*2.8*	*0.0*	*11.1*	*13.9*	*2.8*	*11.1*
Camb	23.8	*17.8*	*15.5*	*14.3*	*7.2*	*1.2*	*1.2*	*8.3*	*10.7*
Truro	25.7	*14.3*	*8.5*	*17.2*	*5.7*	*0.0*	*0.0*	*20.0*	*8.5*
Crdff	28.2	*37.3*	*10.6*	*9.8*	*7.0*	*0.7*	*0.0*	*3.5*	*2.8*
LGI	31.1	*10.8*	*12.1*	*10.8*	*2.7*	*5.4*	*8.1*	*9.4*	*9.4*
Carsh	50.0	*5.9*	*10.9*	*4.2*	*3.4*	*3.4*	*8.4*	*4.2*	*10.0*
Extr	66.7	*2.0*	*5.1*	*6.1*	*5.1*	*0.0*	*6.1*	*1.0*	*8.1*
Wrex	75.0	*2.8*	*8.3*	*5.6*	*2.8*	*0.0*	*0.0*	*5.6*	*0.0*
E&W	**5.3**	**18.6**	**17.6**	**11.8**	**6.5**	**6.6**	**7.1**	**9.7**	**18.1**

Table 4.10: Percentage distribution of diagnoses for new RRT patients, by centre
The E&W total is calculated from those units with 80% or more returns.

The italicised results in Table 4.10 for units with a low (<80%) return for diagnosis have less validity and should be ignored. They have not been included in the calculation for the total for England & Wales.

Patients with no diagnostic information have been included in the total percentages. If these were assumed to be randomly distributed, the percentage contribution of each diagnosis to the total would be slightly increased, with results as shown in Table 4.11.

Unit	Aetiology uncertain/ GN NP	Diabetes	GN	Polycystic kidney	Hypertens.	Renal vascular	Pyelo-nephritis	Other
E&W	19.4	18.6	12.5	6.7	6.8	6.9	10.2	19.1

Table 4.11: Percentage diagnoses, excluding 'not sent'

In older patients, the proportion with an unknown diagnosis is much higher, primary renal diseases such as polycystic kidney disease and glomerulonephritis being much more common in younger patients. Diabetic nephropathy is still more common in younger individuals. The UK is not treating the increasing proportion of patients with diabetic nephropathy seen in the USA and much of Europe, where diabetic nephropathy may be the cause of ERF in over 40% of patients.

Treatment modality

The proportion of patients in each unit established on haemodialysis by day 90, and the variations with age, are shown in Figures 4.7 and 4.8. The proportions are higher in Northern Ireland and Scotland than in England and Wales. Elderly patients are much more likely to start on haemodialysis (HD) than are younger patients. Only two units showed a higher proportion of elderly patients starting on peritoneal dialysis (PD) rather than HD.

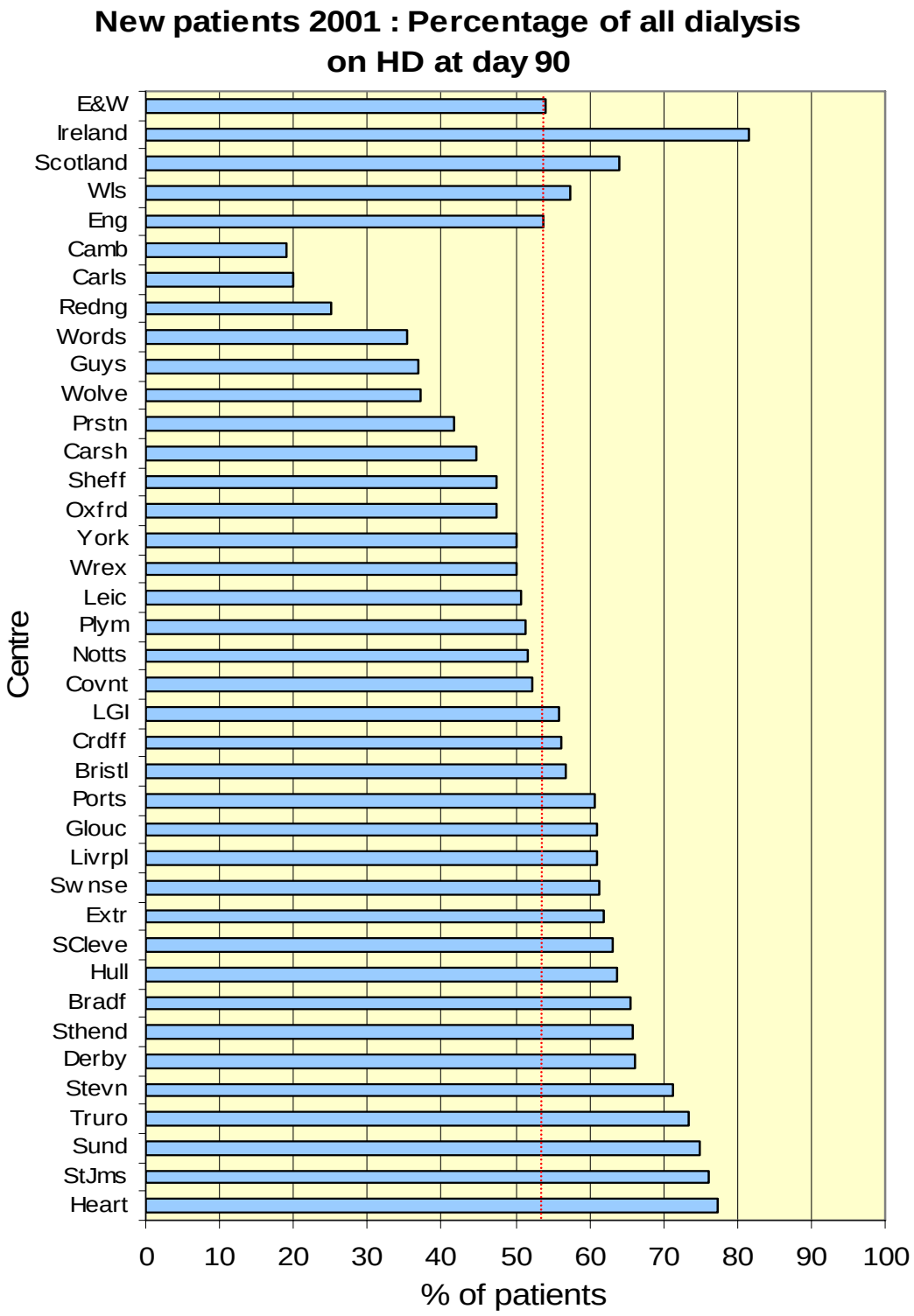


Figure 4.7: New patients, 2001 – percentage of all dialysis patients on HD at day 90

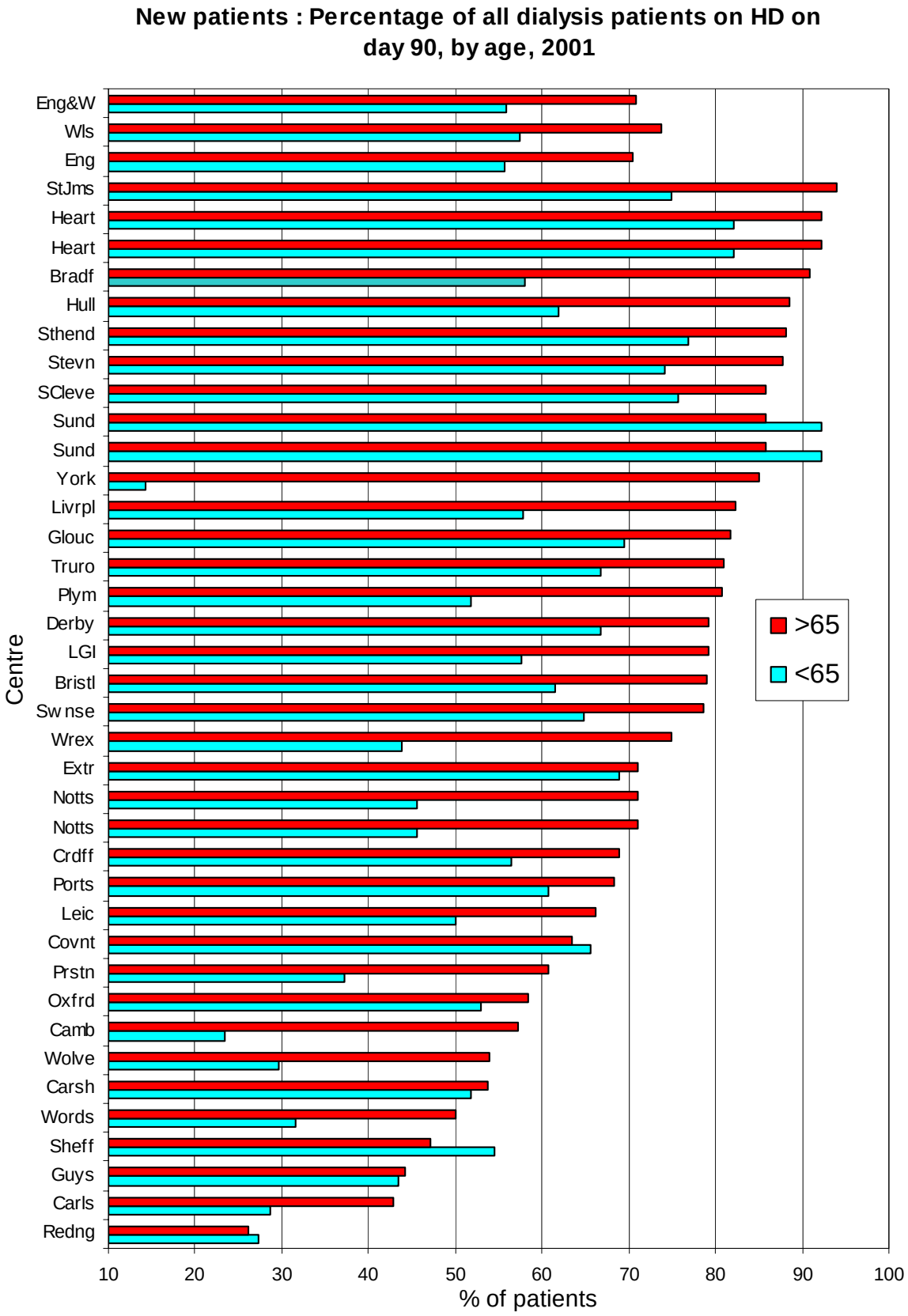


Figure 4.8: New patients – percentage of all dialysis patients on HD at day 90, by age

The first change of treatment modality

Change of treatment modality within the first year

Established on HD (n=1256)		
Modality	**No. of patients**	**Percentage**
Remains on HD	883	71.2
Changed to PD	65	5.2
Transplanted	37	3
Transferred out elsewhere	6	0.5
Recovered	14	1.3
Stopped treatment (died)	19	1.5
Died (no change in modality)	232	18.7

Table 4.12: HD patients at 90 days – changes in modality in the subsequent year

The results in Table 4.12 are almost identical to those contained in the 2000 and 2001 reports. The reported change to PD was 5% for 2002 and 4% respectively for the previous 2 years. The data from those previous years included Scotland, which has a lower use of PD.

Established on PD (n=850)		
Modality	**No. of patients**	**Percentage**
Remains on PD	559	65.8
Change to HD	131	15.4
Transplanted	71	8.4
Transferred out elsewhere	11	1.3
Recovered	7	.8
Stopped treatment (died)	0	
Died (no change in modality)	71	8.4

Table 4.13: PD patients at 90 days – changes in modality in 1 year

The PD modality change results in Table 4.13 are also identical to those in the 2000 and 2001 reports, with a 15% change to HD.

The consistency of these data covering more varied regions of the country strongly suggests that this practice reflects that of the UK as a whole.

First modality change over 2 years

Only centres on the Registry in 1999 that had a full annual cohort of patients available for a 2 year follow-up period were included. This analysis includes 1962 patients.

Patients who were on HD after the first 90 days

The 2 year modality change is consistent with the data seen in last year's report. By the end of 2 years, only 10% of patients on HD had received a transplant, compared with 18% of those on PD (Tables 4.14 and 4.15).

Established on HD First change in modality	At end of 1 year % of patients	At end of 2 years % within 2nd year	 % of all patients
Remains on HD	68.6	74.9	51.4
Changed to PD	4.4	1.1	5.2
Transplanted	5.0	7.0	9.8
Transferred out elsewhere	0.5	0.8	1.0
Recovered	1.3	0.4	1.5
Died (with no change in modality)	20.2	15.9	31.1
Total patients	**1104**	**757**	

Table 4.14: Changes in modality over the first 2 years for patients on HD

Patients who were on PD after the first 90 days

Established on HD First change in modality	At end of 1 year % of patients	At end of 2 years % within 2nd year	 % of all patients
Remains on PD	67.2	62.2	41.8
Changed to HD	11.4	12.0	19.5
Transplanted	9.9	12.5	18.3
Transferred out elsewhere	1.2	0.0	1.2
Recovered	0.7	0.3	0.9
Died (with no change in modality)	9.6	13.0	18.3
Total patients	**858**	**577**	

Table 4.15: Changes in modality over the first 2 years for patients on PD

As seen in earlier years, there is little transition from HD to PD in the first year and virtually none thereafter. A transition from PD to HD is much more frequent and continues after the first year. PD patients are of a younger group than HD patients, explaining the higher transition to transplantation from PD and the higher death rate from HD. There is a high use of PD in the UK compared with other European countries, so haemodialysis patients in the UK comprise a different group from those in the rest of Europe. This may explain the apparent differences between the UK and other European countries shown by the International Dialysis Outcomes and Practice Patterns (IDOPPS) HD study in the modality transition rate from HD to transplant and in the death rate as IDOPPS studies only HD patients.

Comparison between renal units of PD modality technique survival for incident patients

Aims

To investigate whether there is a difference in PD modality technique survival between those renal units which start a high proportion of patients on PD and those which start a low proportion.

Inclusion criteria

All new patients starting RRT between 1 October 1999 and 30 September 2000 who were on PD on their 90th day of RRT. They were followed for 1 year from the start of RRT.

Analysis

Centres were allocated to low, medium and high use of PD by dividing the centres into three equal groups (Table 4.16).

Groups	% of patients on PD technique	Median % started on PD	Mean age at start
Low	<26%	24%	54.7
Medium	26–34.9%	36%	54.9
High	≥35%	46%	55.7

Table 4.16: Use of PD across groups

These data were analysed first including all patients starting, and then excluding those patients who died during the study period. The second analysis was to take into account those patients who were more sick and might have been more likely to transfer to HD prior to death.

Results

The results are shown in Tables 4.17–4.20.

	High PD	Medium PD	Low PD
Remains on PD	68.9% (n=264)	63.4% (n=184)	62.7% (n=111)
Changed to HD	13.8% (n=53)	14.8% (n=43)	19.7% (n=35)
Transplanted	7.3% (n=28)	10.6% (n=31)	6.78% (n=12)
Transferred out	1.8% (n=7)	1% (n=3)	0.5% (n=1)
Recovered	0.5% (n=2)	1.7% (n=5)	0% (n=0)
Died	7.5% (n=29)	8.2% (n=24)	10.1% (n=18)

Table 4.17: Modality changes from PD – all patients

	High PD	Medium PD	Low PD
Remains on PD	57.3	57.5	55.6
Changed to HD	57.9	52.4	56.8
Transplanted	37.7	40.1	42.9
Transferred out			
Recovered			
Died	66.6	59.4	63.2

Table 4.18: Mean age of patients for each modality change

	High PD	Medium PD	Low PD
Remains on PD	76.5% (n=293)	71.4% (n=207)	72.9% (n=129)
Changed to HD	13.8% (n=53)	14.8% (n=43)	19.8% (n=35)
Transplanted	7.3% (n=28)	10.7% (n=31)	6.9% (n=12)
Transferred out	1.8%(n=7)	1% (n=3)	0.6% (n=1)
Recovered	0.5% (n=2)	1.7% (n=5)	0% (n=0)

Table 4.19: Modality changes from PD, excluding those who died in the first year

	High PD	Medium PD	Low PD
Remains on HD	87.3% (n=303)	86.8% (n=364)	91.1% (n=432)
Changed to PD	6.9% (n=24)	6.4% (n=27)	2.9% (n=14)
Transplanted	2.5% (n=9)	2.8% (n=12)	3.3% (n=16)
Stopped treatment	1.4% (n=5)	1.4% (n=6)	1.6% (n=8)
Recovered	0.5% (n=2)	1.9% (n=8)	0.8% (n=4)

Table 4.20: Modality changes from HD

Discussion

There is some indication from Tables 4.17–4.20 that centres with a low use of PD are more willing to transfer patients to HD and transfer fewer patients from HD to PD, perhaps because the option of HD is more easily available. PD may also be used as a temporary measure until a fistula matures, rather than using a line. Overall, the high users of PD transfer 10.8% of patients between the two modalities in the first year, the medium users 9.99% of patients and the low users of PD 7.5%, although these differences are not statistically significant (chi squared 4.40, p=0.11). This is not support for the concept that units short of HD facilities are starting a lot of unsuitable people on PD who then have a high early failure rate on the technique. Longer-term follow-up analysis is indicated.

In the centres making greatest use of PD, the mean age of patients starting PD was 1 year older than in the two other groups, but this is not of statistical significance.

It is important to understand the reasons for any change of dialysis modality, but most units record these poorly and there are insufficient data for analysis. It is hoped that the recording of this information will improve.

Survival of new patients starting RRT

Comparison with the 2nd edition standards recommendation

The second edition standards document recommended that patient groups aged 18–55 years, excluding patients with diabetic nephropathy, should have a greater than 90% 1 year survival rate. The figures for England & Wales in 2000 are shown in Table 4.21.

First treatment	Standard primary renal disease 2000	All diseases except diabetes 2000
Recommended standard	**>90%**	**>90%**
All	93.0	95.1
	91.3–94.7	93.5–96.7
HD	90.3	92.3
	87.8–93.0	98.7–94.9
PD	96.3	98.6
	94.4–98.2	97.2–99.9

Table 4.21: One-year patient survival – patients aged 18–55, 2000 cohort

Survival of new patients by age

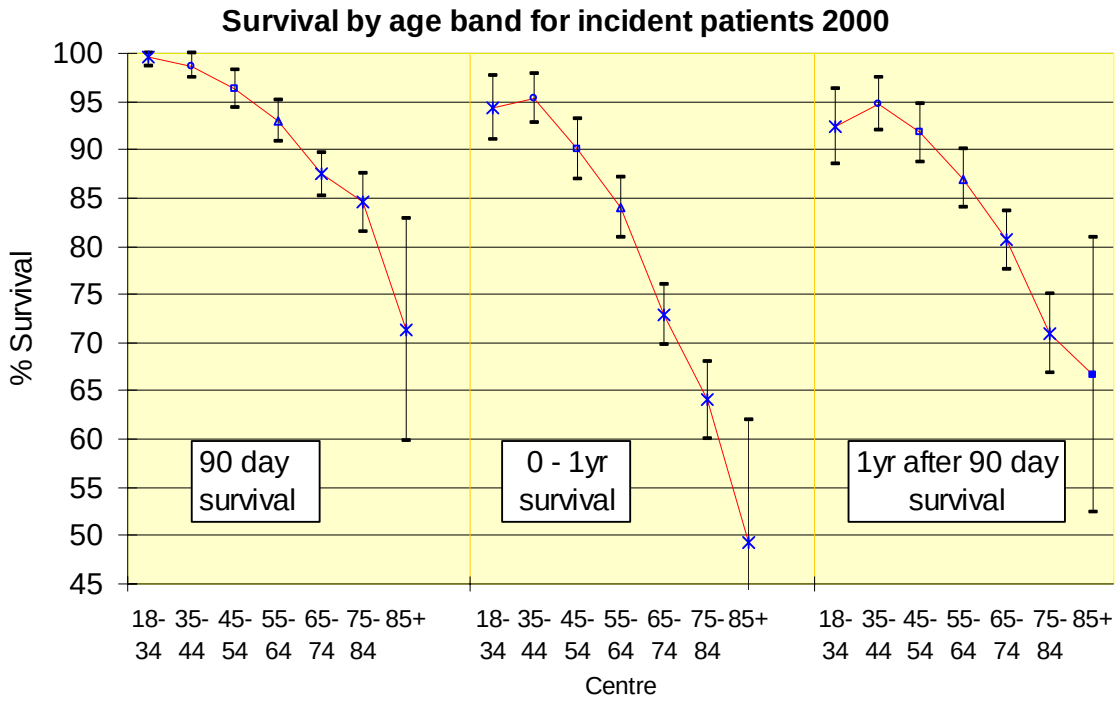


Figure 4.9: Unadjusted survival of incident patients, by age band
95% CI are shown.

In Figure 4.9, unadjusted survival has been shown for the first 90 days, the first year survival from day 0 of RRT and also the 1 year survival after day 90. The last figure allows comparison with other registries that record only data from day 90 onwards and excludes the errors introduced by the uncertain definition of acute patients who die.

Survival of all new patients by country

Patient survival for England and Wales are shown in Table 4.22.

	England	Wales	England & Wales
Adjusted 90 day	93.4 92.3–94.5	94.0 91.6–96.4	93.4 92.4–94.5
Adjusted 1 year after 90 days	86.2 84.6–87.7	87.5 83.6–91.6	86.3 84.8–87.8

Table 4.22: Patient survival across England and Wales

The 1 year unadjusted survival rate for England & Wales is 83.4%.

Survival by modality

The survival by first treatment modality is shown in Table 4.23.

	HD	PD
Adjusted 1 year after 90 days	80.8 78.9–82.8	89.5 87.4–91.5

Table 4.23: One-year survival by first treatment modality

As also shown by the US and Canadian Registries, there is an apparent difference in survival between patients started on HD and those started on PD even after adjusting for age. This is partly related to patient selection bias (diabetics and patients with high comorbidity scores being more likely to go on to HD). The data from the US Registry do, however, indicate a 1 year survival advantage for PD patients even after attempting to adjust for these factors.

As shown before, a high proportion (43%) of deaths within the first year occur within the first 90 days (Tables 4.24 and 4.25), a period excluded from the USA Registry report.

Age	KM survival analysis (%)	KM 95% CI	No.
18–64	96.0	94.9–97.1	1182
≥65	85.1	83.0–87.1	1155
All	90.6	89.4–91.8	2337

Table 4.24: Unadjusted 90 day survival of new patients, 2000 cohort
KM = Kaplan–Meier.

Age	KM survival analysis (%)	KM 95% CI	No.
18–64	89.4	87.7–91.2	1182
≥65	68.4	65.7–71.1	1155
All	78.9	77.2–80.6	2337

Table 4.25: Unadjusted 1 year survival of new patients, 2000 cohort

Age	KM survival analysis (%)		KM 95% CI	No.
	1 year	2 year	2 year survival	
<65	88	**82**	80–84	1058
≥65	68	**53**	50–56	952
All	79	**70**	66–70	2010

Table 4.26: Unadjusted 2 year survival of new patients, 1999 cohort

Age	KM survival analysis (%)			KM 95% CI	No.
	1 year	2 year	3 year	3 year survival	
<65	87	79	**72**	69–75	825
≥65	65	50	**39**	36–43	767
All	76	64	**56**	54–59	1592

Table 4.27: Unadjusted 3 year survival of new patients, 1998 cohort

Age	KM survival analysis (%)				KM 85% CI	
	1 year	2 year	3 year	4 year	4 year survival	No.
<65	87	78	74	**67**	62–71	444
≥ 65	66	45	34	**24**	19–28	344
All	78	64	56	**48**	44–51	788

Table 4.28: Unadjusted 4 year survival of new patients, 1997 cohort

These results show the expected marked difference in survival with age, which increases with time. The 1, 2 and 3 year survivals are consistent for the four different cohorts.

International comparisons

The incidence rates for RRT in the USA, Canada, Australasia and several European countries are listed in Table 4.29. Despite the increases seen in the UK over the past 20 years, patients' acceptance for RRT is still lower than it is in most comparable countries (Figure 4.10).

Annual Incidence of ERF, pmp				
Country	**1998**	**1999**	**2000**	**2001**
Australia	86	92	90	
Austria	129	135	133	132
Canada	138	146	143	
Catalonia	135	150	143	
Czech Republic	133	128	151	
Finland	90	90	94	
Germany	148	148	175	
Greece	114	124	157	
Hungary	127	123	129	
Italy	104	130		
Japan	234	249	252	

Annual Incidence of ERF, pmp				
Country	**1998**	**1999**	**2000**	**2001**
Netherlands	94	98	93	
New Zealand	98	98	107	
Norway	90	89	89	94
Sweden	127	125	126	
Taiwan	288	315	311	
UK	**94.6***	**90***	**89***	**94.9**
USA	313	325	337	
Uruguay	137	145	126	

Table 4.29: Incidence rates for RRT in developed countries
*Adults only. The figure for 2001 includes 1.7 pmp paediatric patients.

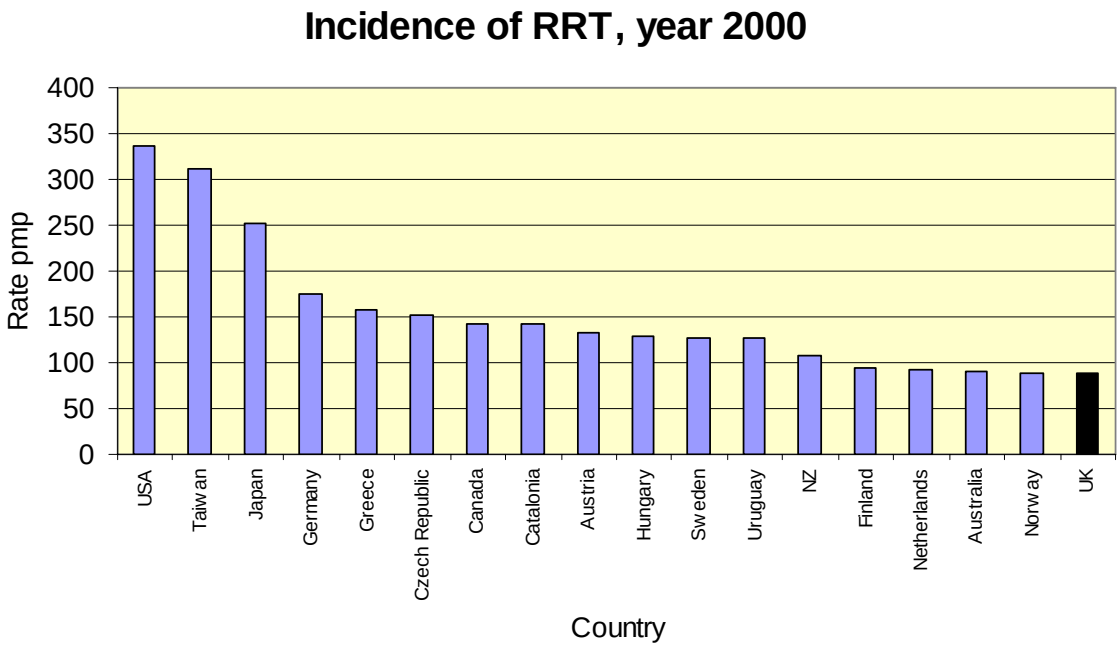


Figure 4.10: Incidence rates for RRT in developed countries, 2000

Chapter 5: All Patients Receiving Renal Replacement Therapy In 2001

Summary

- On 31 December 2001, a minimum of 33,363 patients in the UK were receiving renal replacement therapy, 17,637 (52.8%) of whom were treated by dialysis. This is a point prevalence of 566 per million population (pmp).

- The overall prevalence in the old health authorities ranged from 281 pmp in South Lancashire to 723 pmp in Coventry. A study of age-specific prevalence shows variations of acceptance at different ages that are hidden by the overall figure, but age and ethnic minority distributions do not fully explain the variation in prevalence.

- The median age of patients established on renal replacement therapy is 55, 1 year more than in 2000. Thirty per cent of patients are over 65 years old and 11% over 75.

- The gender ratio is unchanged, 61% of patients being male.

- Returns of data on ethnicity remain poor, although a few units have excellent returns. Overall, data were returned on 65% of patients. Of patients with ethnicity data, 83% were White, the variation between units ranging from 57% to 99%. Patients from ethnic minorities have the same distribution of dialysis modality as the overall group.

- Of prevalent White patients, 10% are diabetic, compared with 20% from ethnic minorities.

- The year-on-year growth of the number receiving renal replacement therapy appears to be around 7%. The growth is largely in haemodialysis, with a small growth in the number of transplant patients and the peritoneal dialysis number being relatively static.

- Of all patients, 37.1% are on haemodialysis, 46.6% are transplanted, and 16.3% receive peritoneal dialysis. Peritonal dialysis is more common in the young, especially young diabetics. Connect peritoneal dialysis has virtually disappeared. Cycling peritoneal dialysis has increased very little in the past year: cycling is used by 14% of patients in England & Wales, 38% in Scotland and 67% in Northern Ireland, with a large variation between units.

- The 1 year survival of established prevalent patients in England & Wales is 84% for dialysis and 97% for transplantees. For dialysis patients, 1 year survival is 90% for those under 65 and 77% for older patients. For diabetics on dialysis, the figures are 82% and 72% respectively.

Prevalence rates

Figures for the estimated number of patients receiving renal replacement therapy (RRT) in the four countries of the UK are shown in Tables 5.1 and 5.2. The results from Scotland are precise, being provided by the Scottish Renal Registry, which has complete coverage of Scotland. The results from Wales and Northern Ireland are complete as Registry data have been supplemented by data from questionnaires sent to clinicians.

It has proved difficult to estimate the prevalence for England. The figures for England include estimates of the total number of patients receiving treatment in England, and the modalities they receive, which are calculated by extrapolation from the Renal Registry units. There is a particular problem in calculating prevalence, as opposed to incidence, rates as many patients are transferred away from the parent renal unit for transplantation. Several transplant units do not refer the patients back to the parent unit, or do so at a very late stage. Manchester, Birmingham and Newcastle in particular have this practice, and these three major transplant centres were not part of the Registry in 2001. Thus, when calculating prevalence rates by health authority, or by renal unit, there is likely to be a shortfall of transplant patients. This appears to be a particular problem when calculating prevalence using health authority data, as many of the health authorities for which the Registry has complete coverage are geographically close to the three major transplant units listed.

In addition, although current referral patterns are well established and show little variability, some of the long-standing prevalent patients started treatment before the current patterns were established and stayed with their original renal units, adding further possible errors to the health authority data. For these reasons therefore, any estimate of prevalence in England has to be a minimum estimate, in the understanding that there will be a slightly greater number of patients, and the error will occur largely in the transplant population. Overall, it appeared more appropriate to derive estimates for the prevalence in England from renal unit data, accepting the estimated catchment populations of each renal unit.

The population covered by the Renal Registry is similar to that of the whole of England with regard to age.

	England	**Wales**	**Scotland**	**N Ireland**	**UK**
No. of units	31	5	11	4	**71**
No. of patients	16,850 *27,087*	1,883	3,286	1,107	**33,556****
Population (million)	49.5	2.93	5.1	1.69	**59.23**
Patients (pmp)	547	642	644	656	**566****
Mean patients/unit	531**	326	299	277	

*Estimated figures. **Includes estimated figures for England.

Table 5.1: Summary of adult patients registered and total population covered, 31/12/01

	Total	Dialysis (%)	Population
Scotland	3,286	1,684 (51)	5.1
N Ireland	1,107	587 (53)	1.7
Wales	1,883	966 (51)	2.93
England	27,087	14,400 (53)	49.5
UK	**33,363**	**17,637 (53)**	**59.23**

Table 5.2: Patients on dialysis and total RRT in the four countries of the UK, 31/12/01

The prevalence in England is lower than the rest of the UK, reflecting the lower acceptance rates over the past decade. It is also noticeable that the English units are significantly larger, treating more patients per unit, than those in the rest of the UK. Table 5.3 lists the current patients by modality treated in each renal unit participating in the Renal Registry from England & Wales. Figure 5.1 shows that some units have a very low number of transplants as their transplant patients are cared for by adjacent large transplant centres.

The estimated total for the UK is lower than that recently published by the National Kidney Research Fund but refers to a time period at least 6 months earlier. During that period, 2500 patients would be expected to start RRT. Allowing for deaths, transplants and returns from transplantation, the figures are compatible.

Treatment Centre	Dialysis No.	Transplant No.	RRT No.	% Transplant
Oxfrd	493	818	1311	62.4
Guys	463	710	1173	60.5
Livrpl	549	620	1169	53.0
Leic	605	429	1034	41.5
Crdff	422	609	1031	59.1
Ports	418	605	1023	59.1
Bristl	433	520	953	54.6
Sheff	561	385	946	40.7
StJms	375	473	848	55.8
Notts	467	355	822	43.2
Carsh	363	333	696	47.8
Camb	250	414	664	62.3
Covnt	302	248	550	45.1
Prstn	371	113	484	23.3
Extr	285	194	479	40.5
Stevn	356	109	465	23.4
Heart	313	142	455	31.2
Hull	286	152	438	34.7
SCleve	209	218	427	51.1
Plym	178	229	407	56.3
Swnse	269	103	372	27.7
LGI	187	161	348	46.3
Wolve	274	66	340	19.4
Words	156	83	239	34.7
Wrex	156	70	226	31.0
Sund	110	107	217	49.3
Bradf	117	91	208	43.8
Redng	198	6	204	2.9
Glouc	144	51	195	26.2
Truro	137	50	187	26.7
Carls	75	80	155	51.6
Sthend	123	17	140	12.1
York	101	23	124	18.5

Treatment Centre	Dialysis No.	Transplant No.	RRT No.	% Transplant
Eng	8899	7802	16701	46.7
Wls	847	782	1629	48.0
E&W	9746	8584	18330	46.8

Table 5.3: Prevalent RRT patients in each unit, 31 December 2001

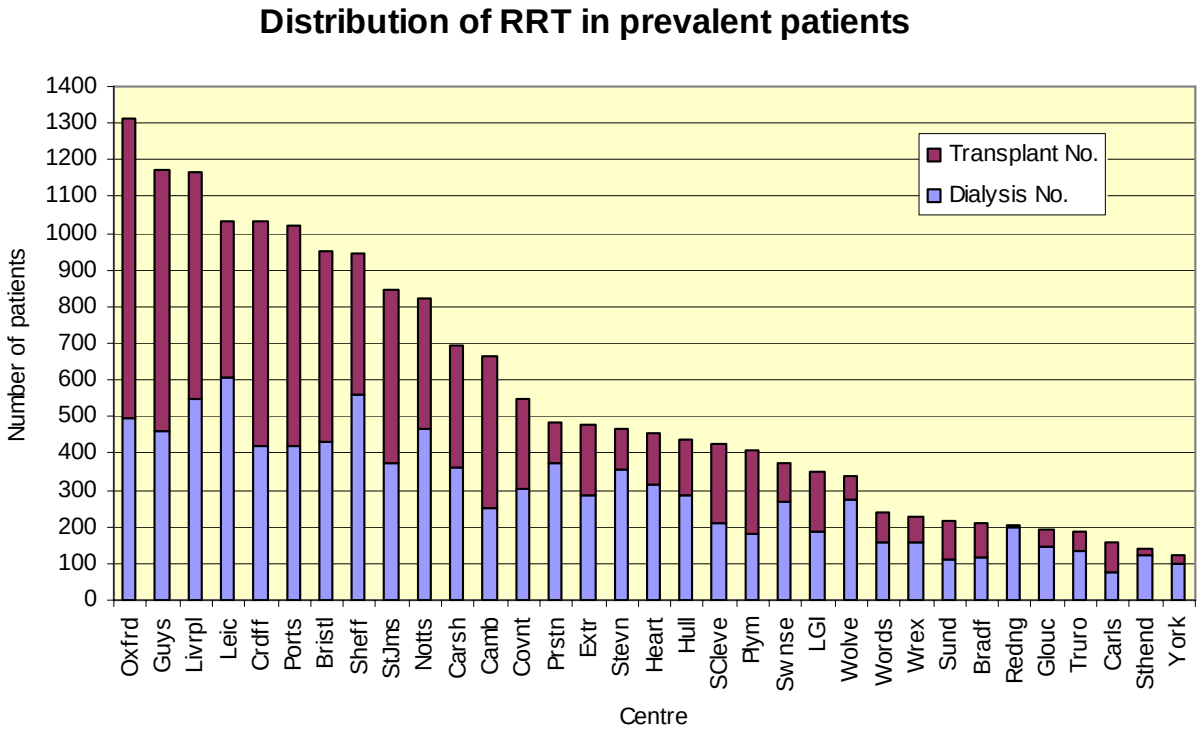


Figure 5.1: Modality changes with time in the UK

Prevalence by health authority

Details of the prevalence of RRT patients in the old health authorities fully covered by the Registry, with a split into older and younger age ranges, are shown in Table 5.4. Patients are allocated to a health authority by postcode of residence. The prevalence ratio is calculated as for the acceptance ratio (see Chapter 4). The variation in prevalence between authorities is illustrated.

			All patients				18–65	65+
Reg–ion	Health authority	Population	Pat count	pmp	Prevalence ratio	95%CI	pmp	pmp
Y01	Bradford	483,300	280	579	112	108–115	725	1,026
Y01	Calderdale and Kirklees	583,800	338	579	112	109–114	726	897
Y01	County Durham and Darlington	607,800	283	466	90	87–92	530	858
Y01	East Riding and Hull	574,500	275	479	92	90–95	567	823
Y01	Leeds	727,400	408	561	108	106–110	636	1,114
Y01	North Cumbria	319,300	173	542	104	99–109	636	864
Y01	North Yorkshire	742,400	341	459	88	86–91	521	790
Y01	Sunderland	292,300	143	489	94	89–100	572	925
Y01	Tees	556,300	304	546	105	102–108	661	948
Y01	Wakefield	318,800	166	521	100	95–105	575	1,080
Y02	Barnsley	228,100	135	592	114	107–121	723	993

Reg–ion	Health authority	Population	All patients				18–65	65+
			Pat count	pmp	Prevalence ratio	95%CI	pmp	pmp
Y02	Doncaster	290,500	154	530	102	97–108	637	899
Y02	Leicestershire	928,700	593	639	123	121–125	737	1,241
Y02	Lincolnshire	623,100	332	533	103	100–105	619	1,076
Y02	North Derbyshire	370,200	177	478	92	88–96	505	956
Y02	North Nottinghamshire	388,900	229	589	113	109–118	689	994
Y02	Nottingham	642,700	430	669	129	126–131	731	1,425
Y02	Rotherham	254,400	164	645	124	118–130	774	1,087
Y02	Sheffield	531,100	278	523	101	98–104	650	767
Y02	South Humber	308,600	150	486	94	89–99	514	1,060
Y07	Coventry	304,300	220	723	139	134–145	854	1,402
Y07	Solihull	205,600	90	438	84	77–92	439	1,038
Y07	South Staffordshire	592,100	189	319	61	59–64	352	662
Y07	Walsall	261,200	110	421	81	75–87	371	1,235
Y07	Warwickshire	506,700	311	614	118	115–121	704	1,100
Y07	Wolverhampton	241,600	160	662	128	121–134	743	1,379
Y08	East Lancashire	511,200	166	325	63	60–65	357	736
Y08	Liverpool	461,500	267	579	111	108–115	717	979
Y08	Morecambe Bay	310,300	97	313	60	55–65	311	685
Y08	North Cheshire	311,900	137	439	85	80–90	530	782
Y08	North-West Lancashire	466,300	173	371	71	68–75	406	678
Y08	Sefton	287,700	137	476	92	86–97	566	735
Y08	South Lancashire	312,700	88	281	54	50–59	306	605
Y08	St Helens and Knowsley	333,000	167	502	97	92–101	628	791
Y09	Bedfordshire	556,600	304	546	105	102–108	613	1,240
Y09	Cambridgeshire	468,000	313	669	129	125–132	791	1,192
Y09	Hertfordshire	1,033,600	418	404	78	76–79	424	938
Y11	Berkshire	800,200	402	502	97	95–99	576	1,070
Y11	Buckinghamshire	681,900	366	537	103	101–106	565	1,393
Y11	IOW, Portsmth & SE Hamps	671,700	369	549	106	103–108	625	1,029
Y11	North and Mid Hampshire	556,900	215	386	74	72–77	482	592
Y11	Northamptonshire	615,800	338	549	106	103–108	633	1,098
Y11	Oxfordshire	616,700	334	542	104	102–107	615	1,126
Y11	Southampton & SW Hampshire	542,300	246	454	87	85–90	540	730
Y12	Avon	999,300	617	617	119	117–121	672	1,257
Y12	Cornwall and Isles of Scilly	490,400	315	642	124	120–127	644	1,298
Y12	Gloucestershire	557,300	261	468	90	87–93	525	862
Y12	North and East Devon	479,300	256	534	103	100–106	596	897
Y12	Somerset	489,300	255	521	100	97–104	606	845
Y12	South and West Devon	589,100	357	606	117	114–119	683	1,037
Y12	Wiltshire	605,500	274	453	87	85–90	515	872
	Units from England	**25,632,200**	**13305**	**519**				
W00	Gwent	557,200	351	630	121	118–124	748	1,103
W00	Bro Taf	739,600	479	648	125	123–127	738	1,309
W00	Dyfed Powys	479,400	239	499	96	93–99	520	978
W00	North Wales	657,500	345	525	101	99–103	621	832
W00	Morgannwg	499,700	308	616	119	116–122	701	1,104
	Units from Wales	**2933400**	**1722**	**587**				
	England & Wales	**28,565,600**	**15027**	**526**			**600**	**997**

Table 5.4: Variation in overall prevalence between old health authorities

The overall variation in prevalence ranges from 281 pmp in South Lancashire to 723 pmp in Coventry. A study of the age-specific prevalence shows variations hidden by the overall figure. Thus, for the under-65s, the prevalence in South Lancashire is 306 pmp and that in Coventry 854 pmp. For older patients, North and Mid Hampshire is lowest at 592 pmp and Nottingham highest at 1425 pmp. Walsall has a relatively low prevalence at 421 pmp but a high prevalence among the elderly of 1235 pmp. The overall low Walsall rate probably reflects a low proportion of elderly people in the population.

Although, in general, areas with a high prevalence in the elderly have a high prevalence among the young, there are variations (Figure 5.2). Where there is a large ethnic minority population, which is likely to be relatively young, a high prevalence in younger patients would be expected. This does not, however, explain all the variation seen.

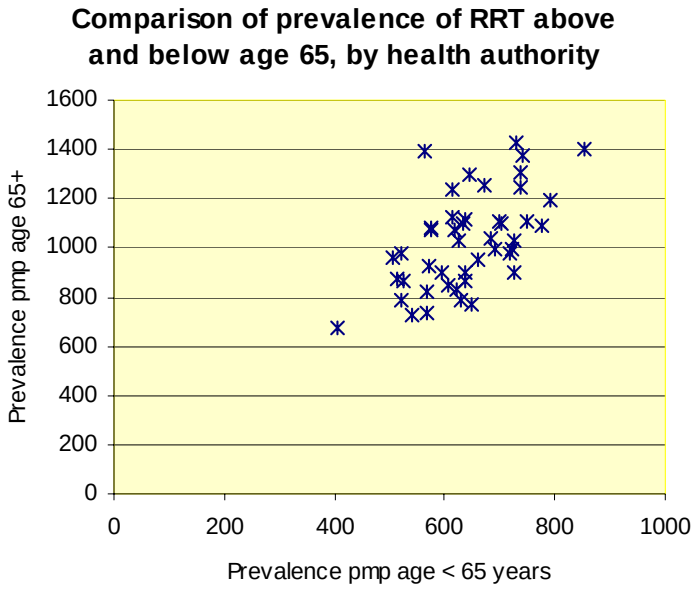


Figure 5.2: Comparison of prevalence of RRT in health authorities by age

Change in prevalence 1998–2001

Table 5.5 illustrates the serial changes in prevalence rate in the old health authorities from which the Registry has reliable data for 3 or 4 years.

HA Code	Region	Health authority	Population	1998 pmp	1999 pmp	2000 pmp	2001 pmp	2001 Pat count
QDT	Y01	Calderdale and Kirklees	583,800	346.0	335.7	519.0	579.0	338
QDE	Y01	Durham &Darlington	607,800	335.6	343.9	393.2	465.6	283
QDF	Y01	East Riding and Hull	574,500	447.3	463.0	511.7	478.7	275
QDK	Y01	North Cumbria	319,300	485.4	501.1	504.2	541.8	173
QDN	Y01	Sunderland	292,300	431.1	437.9	451.6	489.2	143
QDP	Y01	Tees	556,300	465.6	481.8	517.7	546.5	304
QCG	Y02	Barnsley	228,100	460.3	508.5	574.3	591.8	135
QCK	Y02	Doncaster	290,500	423.4	464.7	512.9	530.1	154
QCL	Y02	Leicestershire	928,700	599.8	601.9	649.3	638.5	593
QCM	Y02	Lincolnshire	623,100	425.3	455.8	513.6	532.8	332
QCH	Y02	North Derbyshire	370,200	397.1	405.2	445.7	478.1	177
QCN	Y02	North Nottinghamshire	388,900	465.4	496.3	550.3	588.8	229
QCP	Y02	Nottingham	642,700	577.3	623.9	653.5	669.1	430
QCQ	Y02	Rotherham	254,400	448.1	459.9	562.1	644.7	164
QCR	Y02	Sheffield	531,100	408.6	442.5	512.1	523.4	278
QDL	Y02	South Humber	308,600	531.4	544.4	589.8	486.1	150
QEA	Y07	Coventry	304,300	670.4	663.8	677.0	723.0	220
QEG	Y07	Solihull	205,600	364.8	355.1	413.4	437.7	90
QEJ	Y07	South Staffordshire	592,100		256.7	324.3	319.2	189
QEK	Y07	Walsall	261,200		333.1	379.0	421.1	110
QEL	Y07	Warwickshire	506,700	519.0	554.6	609.8	613.8	311

QEM	Y07	Wolverhampton	241,600		591.9	678.8	662.3	160
QCX	Y08	East Lancashire	511,200	270.0	275.8	361.9	324.7	166
QC4	Y08	Morecambe Bay	310,300	225.6	235.3	328.7	312.6	97
QCY	Y08	North-West Lancashire	466,300	300.2	315.2	411.8	371.0	173
QCC	Y11	Northamptonshire	615,800	444.9	462.8	513.2	548.9	338
QCE	Y11	Oxfordshire	616,700	431.3	454.0	491.3	541.6	334
QD8	Y12	Avon	999,300	534.4	550.4	592.4	617.4	617
QDY	Y12	Gloucestershire	557,300	457.6	511.4	642.4	468.3	261
QDX	Y12	North and East Devon	479,300	463.2	502.8	546.6	534.1	256
QD5	Y12	Somerset	489,300			500.7	521.2	255
QD6	Y12	South and West Devon	589,100	502.5	534.7	587.3	606.0	357
QD7	Y12	Wiltshire	605,500	341.9	336.9	353.4	452.5	274
QW1	W00	Gwent	557,200	549.2	559.9	622.8	629.9	351
QW2	W00	Bro Taf	739,600	532.7	581.4	632.8	647.6	479

Table 5.5: Changes in prevalence in health authorities, 1998–2001

Age

The median age for all patients on treatment on 31 December 2001 was 55 years (Table 5.6). This is 1 year older than in the last report, with the median age of transplanted patients and haemodialysis (HD) patients rising by 1 year. The median age of patients on peritoneal dialysis (PD) remains lower than that of those on HD. Northern Ireland patients appear to be older. The age profile of prevalent patients is shown in Figure 5.3. In the UK, 30% are over 65 and 11% over 75.

	Transplants	PD	HD	All
England & Wales	49	58	64	**55**
Range between units	44–54	51–63	57–71	51–64
Northern Ireland	–	–	–	**62**
Scotland	–	–	–	**54**

Table 5.6: Median age, country and treatment modality

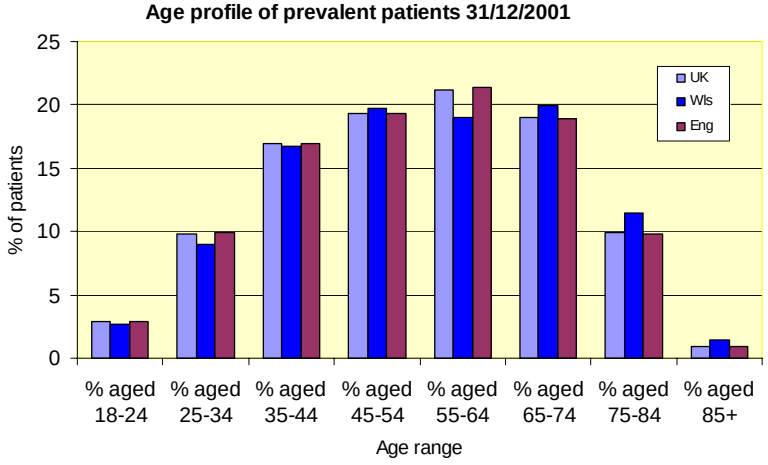


Figure 5.3: Age profile of prevalent patients

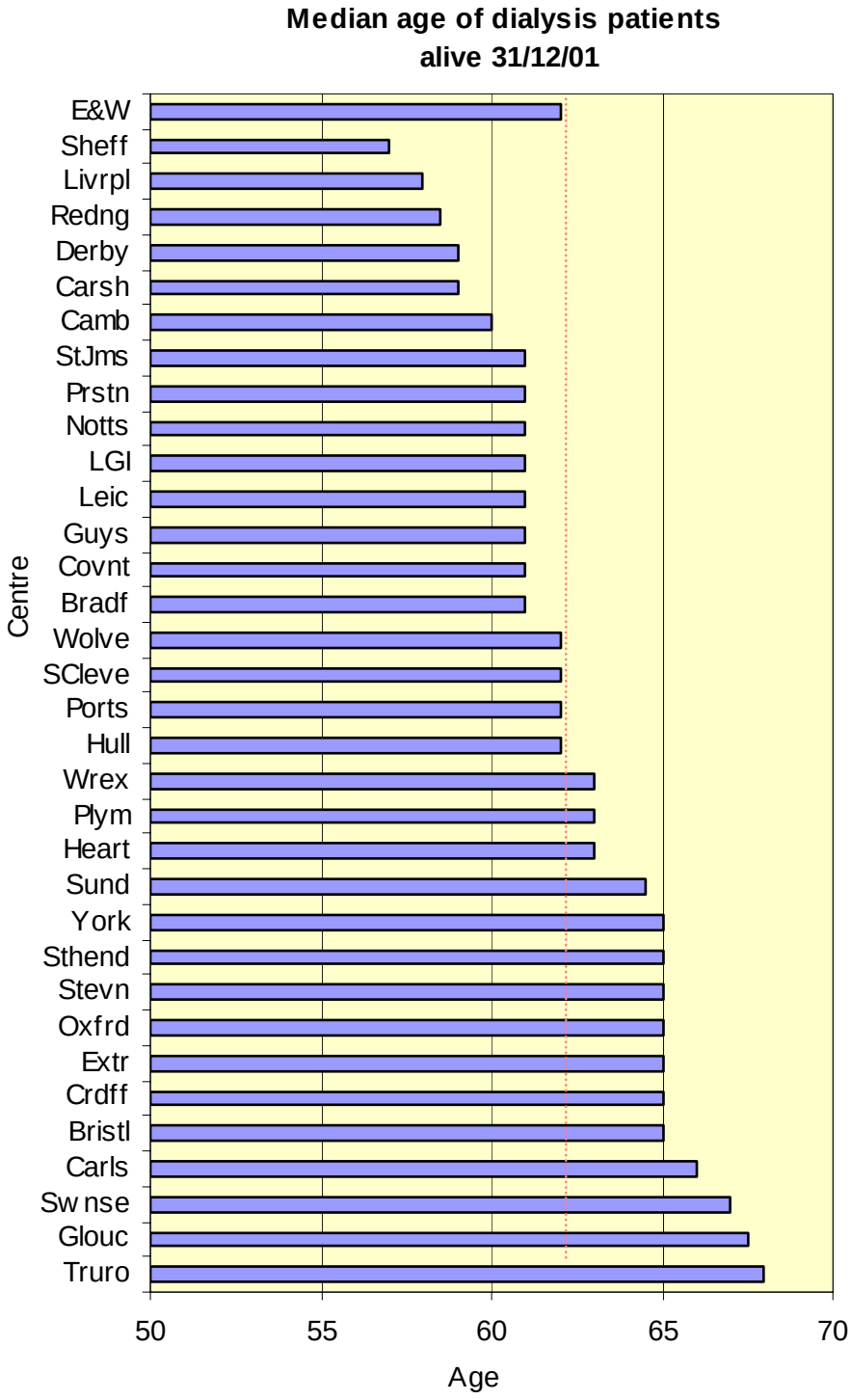


Figure 5.4: Median age of dialysis patients alive at 31 December 2001

Figure 5.4 demonstrates the wide variation in the median age of dialysis patients between individual units. This difference is significant (chi squared $p<0.0001$). Possible reasons for this include differences in local population, referral and acceptance policies, survival rates and available resources.

Gender

Overall, 61% of all patients on treatment were male, the male preponderance occurring at all ages (Figure 5.5). In particular, of the 102 patients who were aged over 85 on 31 December 1999, 72% were male compared with 62% in the previous year. Although the numbers are small, this is a high proportion of males in the older age groups considering the greater proportion of women in the general population at that age. Age/gender-specific rates will be calculated next year using Census data

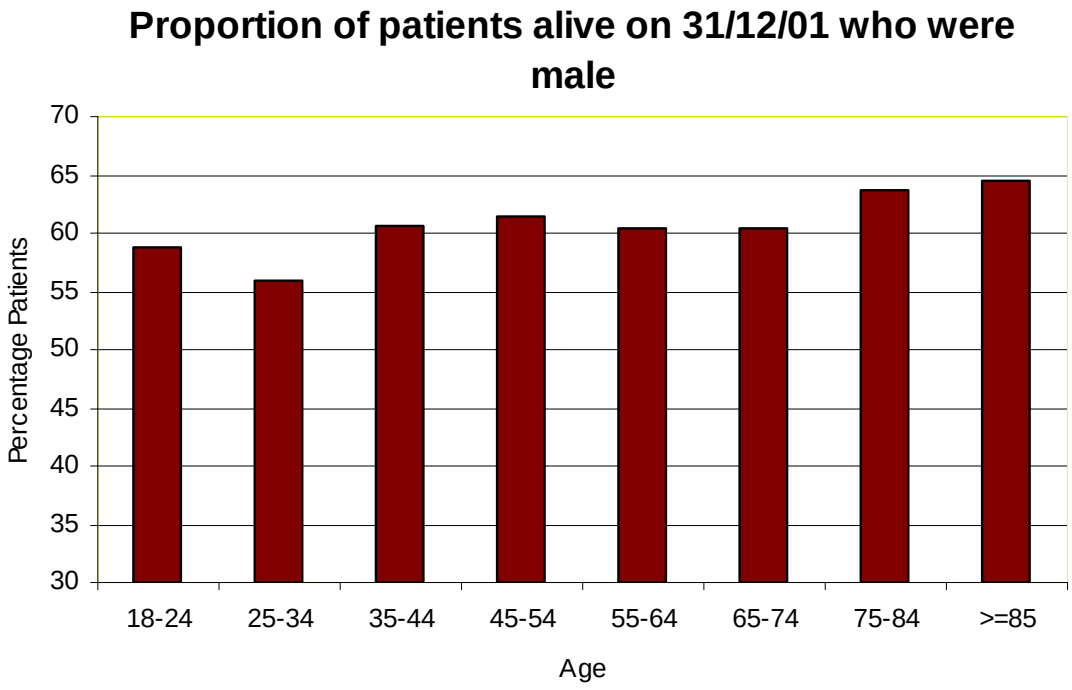


Figure 5.5: Percentage of male patients according to age

Ethnicity

With some exceptions (notably Exeter), few units managed to improve the data on ethnicity for existing patients (Table 5.7).

Treatment centre	% Return	% White	% Black	% Asian	% Chinese	% Other
Sheff	100	94.1	1.6	3.2	0.7	0.4
Words	100	90.4	0.8	8.4	0.4	
Prstn	99	89.0	0.8	10.0		0.2
Wolve	99	77.3	6.3	15.8	0.6	
Heart	98	75.1	5.8	17.5	0.9	0.7
Plym	98	96.0	2.5	0.5	0.5	0.5
Redng	98	72.5	7.5	17.0	1.5	1.5

Treatment centre	% Return	% White	% Black	% Asian	% Chinese	% Other
Bristl	96	92.8	3.3	2.5	0.8	0.7
Hull	96	98.8	0.5	0.2	0.2	0.2
Leic	96	81.2	2.3	15.2	0.2	1.0
Carsh	94	70.6	5.2	5.7	0.8	17.7
Notts	94	88.5	4.5	6.1		0.9
Covnt	93	82.4	2.5	14.5	0.4	0.2
Guys	92	80.0	14.5	3.9	1.5	0.1
Sthend	92	94.6	3.1	2.3		
Sund	92	98.5	1.0		0.5	
Extr	91	99.5	0.5			
St Jms	88	87.4	3.1	9.0		0.5
Swnse	87	98.8	0.3	0.6		0.3
S Cleve	78	94.9		4.2	0.9	
Derby	77	87.7	3.5	6.1	0.9	1.8
Bradf	*58*	*66.9*	*0.8*	*30.6*		*1.7*
Wrex	*57*	*59.4*	*39.8*		*0.8*	
Livrpl	44					
Crdff	31					
Truro	24					
York	19					
Camb	16					
Carls	16					
Glouc	6					
Oxfrd	4					
Stevn	3					
LGI	2					
Ports	1					
Eng	*67*	*82.8*	*8.3*	*6.9*	*0.5*	*1.5*

Table 5.7: Ethnicity

The median age of ethnic minority patients was 55.6 years, compared with a slightly younger median age of 54 for all patients. Considering the younger median age of ethnic patients starting RRT, this higher median age of prevalent ethnic patients may indicate a higher survival rate, similar to that shown in the USA Black RRT population when compared with the White population. This is shown in this report to be true for UK incident patients (see Chapter 17). The gender ratio in the ethnic minority group was the same as for the White population, 62% of patients being male.

Within the ethnic minorities group, 67% of dialysis patients were on HD, which was similar to the percentage for non-ethnic population in England & Wales. The rate of PD is surprising, as several units have reported difficulties in establishing patients on PD, particularly with many units having PD education programmes available only in English.

Diabetes was reported as the primary renal disease causing renal failure in 20% of prevalent patients from the ethnic minority groups, compared with 10% in patients whose ethnicity was reported as White.

Primary renal disease

Details of primary renal disease, based on the original EDTA coding classification, are shown in Table 5.8. Unlike with incident patients, the single most common diagnosis in those under 65 years old was glomerulonephritis, followed by pyelonephritis (which includes outflow obstruction). In as many as 30% of those aged over 65, it was not possible to give a diagnosis. Missing data were much more common in patients over 65 – 10% missing, compared with 3% in patients aged under 65. Diabetes accounted for just over 10% of patients in both age groups, a much lower proportion than the 18% in current incident patients.

Diagnosis	% All patients	Interunit range(%)	% Age <65	% Age ≥65	M:F ratio
Aetiology uncertain*	22.4	11–35	21.1	27.1	1.7
Glomerulonephritis**	15.3	5–21	17.4	7.9	2.3
Pyelonephritis	14.1	7–18	14.9	10.7	1.0
Diabetes	10.6	5–19	10.7	11.1	1.5
Polycystic kidney	3.3	4–13	1.6	9.9	2.1
Hypertension	6.1	0–17	5.9	7.4	2.4
Renal vascular disease	9.1	0–16	10.3	4.6	1.1
Not sent	5.5	0–42	4.0	10.8	1.8
Other	13.5	7–21	14.2	10.5	1.3
All patients total	18,479		13,910	3,826	1.5

Table 5.8: Primary renal disease in all prevalent patients, with age and gender

*Includes patients listed as 'glomerulonephritis not biopsy proven'.

**Biopsy proven.

Diabetes

The median age and modalities of diabetics compared with other patients are shown in Tables 5.9a and b.

	Type I	Type II	All diabetes	Non-diabetics
Number	1,356	605	1,961	15,489
M:F ratio	1.4	1.6	1.2	1.56
Median age on 31/12/01	51	65	56	55
Median age started end-stage	46	62	53	45
renal failure	2.9	2.04	2.64	5.8
Median years on treatment				
% HD	39.1	61.5	46.0	34.4
% PD	25.2	25.6	25.4	15.1
% Transplant	36.6	12.9	28.6	50.5

Table 5.9a: Type of diabetes – median age, gender ratio and modality

	Type I <65	Type II <65	Non-diabetics <65	Type I ≥65	Type II ≥65	Non-diabetics ≥65
Number	1,107	289	11,003	248	316	4,486
% HD	33	55	34	68	67	57
% PD	26	24	15	23	27	19
% Transplant	42	21	50	9	6	24

Table 5.9b: Type of diabetes – age, sex ratio and treatment

Of those type I diabetics on dialysis and aged under 65, 44% are on PD, compared with 31% of under-65 non-diabetics and 30% of type II diabetics. In the over-65s, the use of PD was less common in the type I diabetics but broadly similar in the three groups (25% in type I diabetics, 25% in non-diabetics and 29% in type II diabetics).

Modalities of treatment

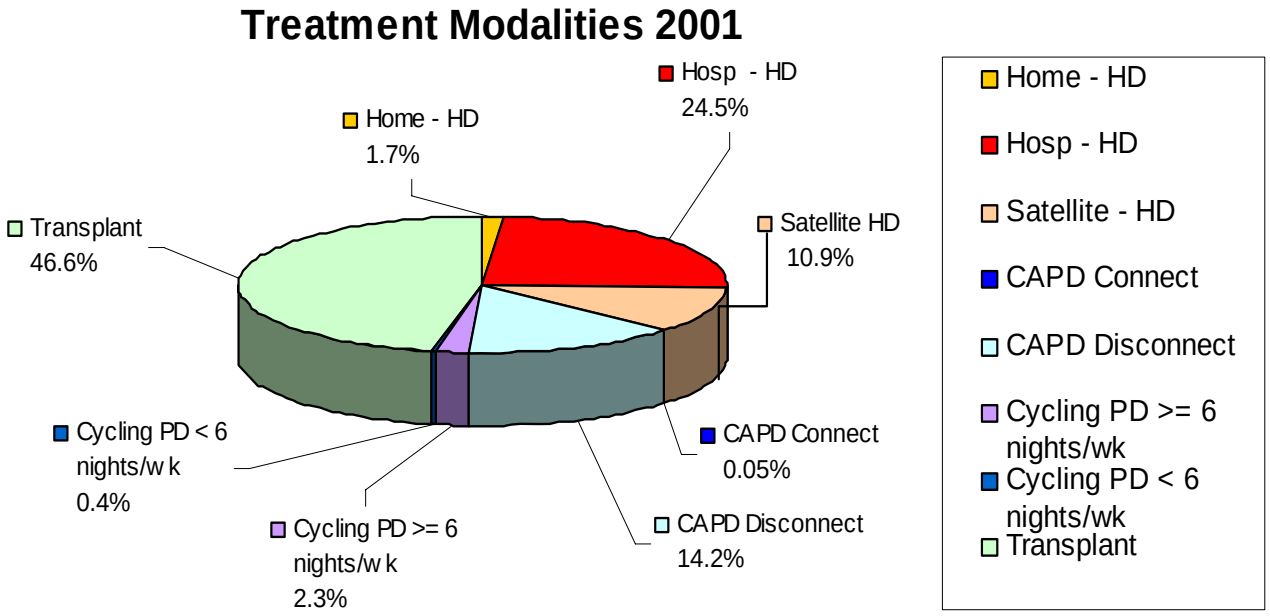


Figure 5.6: Percentage of patients on each dialysis modality, 31 December 2001
CAPD, continuous ambulatory PD

At the end of 2001, 16.8% of RRT patients were on PD: this was a fall from 17.4% in 2001 and accounts for 31.4% of all dialysis patients. Figure 5.6 shows that very few patients in the UK remain on connect PD. The use of cycling PD has not increased since last year. Home HD fell from 4.7% in 2000 to 3.5% of HD patients in 2001. So few patients are now on 'standard' CAPD that it should no longer be called 'standard', 'connect PD' being a better term. In England & Wales, 66% of dialysis patients were on HD, compared with 73% in Scotland.

The variations in patterns of treatment with age are shown in Figure 5.7. Up to the age of 54, more patients are treated by transplantation than by dialysis. HH is the predominant form of dialysis at all ages but especially in the older age groups.

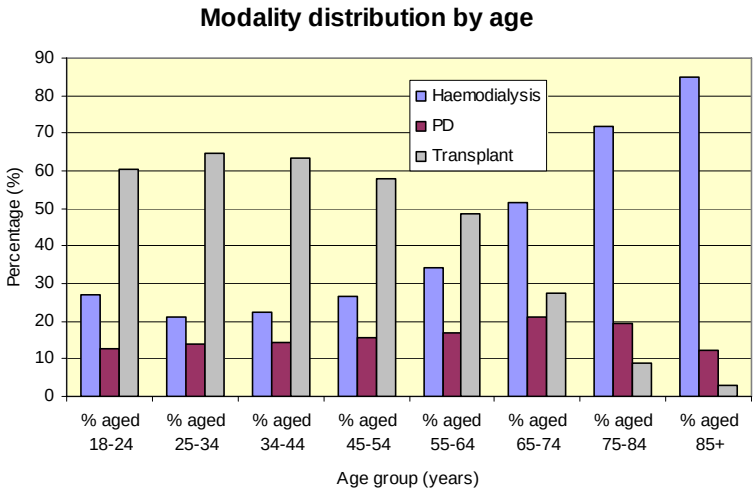


Figure 5.7: Patients on each modality according to age

Haemodialysis

The proportion of dialysis patients treated by HD as opposed to PD varied widely from unit to unit and cannot be explained by age alone (Figure 5.8). The percentage of patients on HD treated in satellite units in England & Wales was 30% (Figure 5.9).

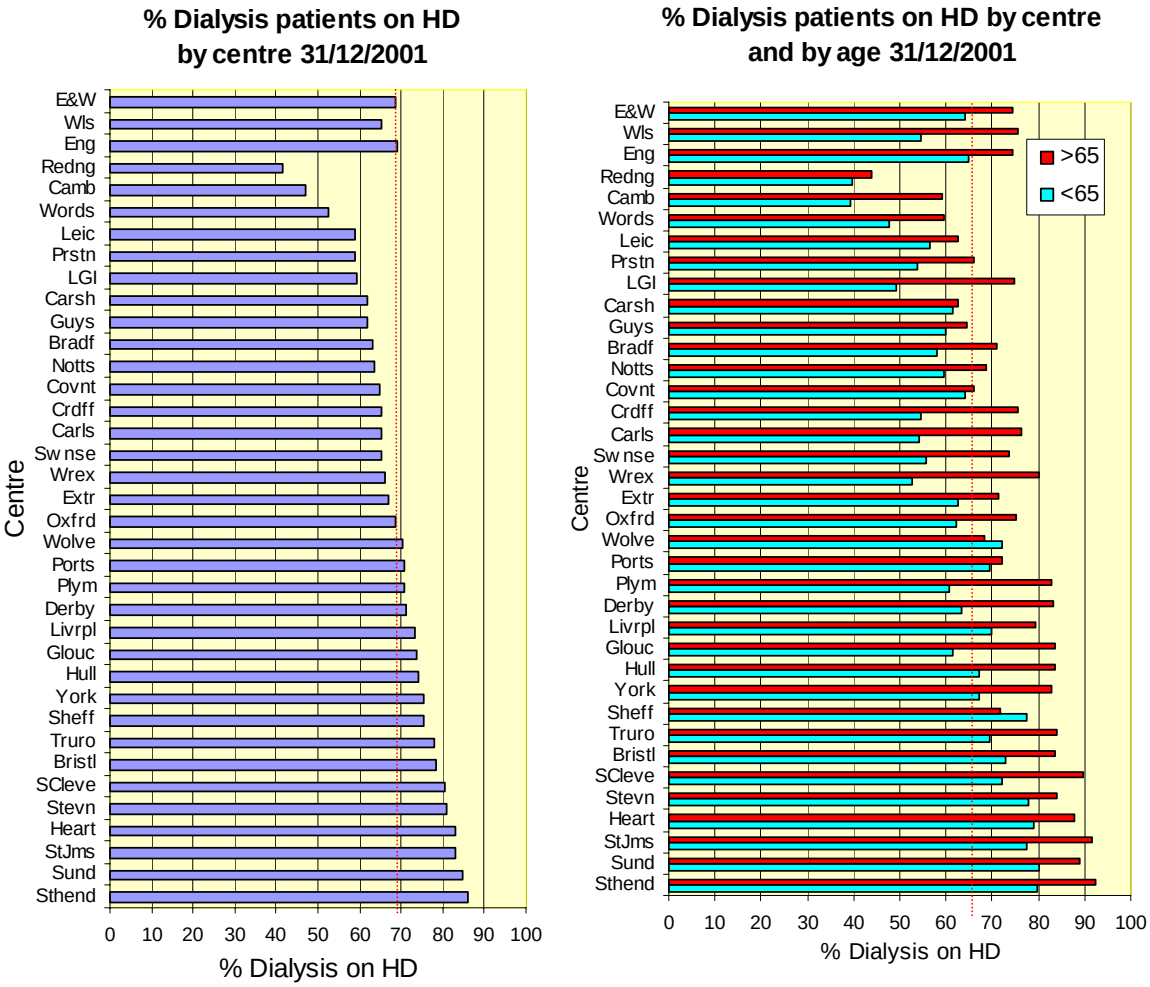


Figure 5.8: Proportion of patients treated by HD according to centre and age

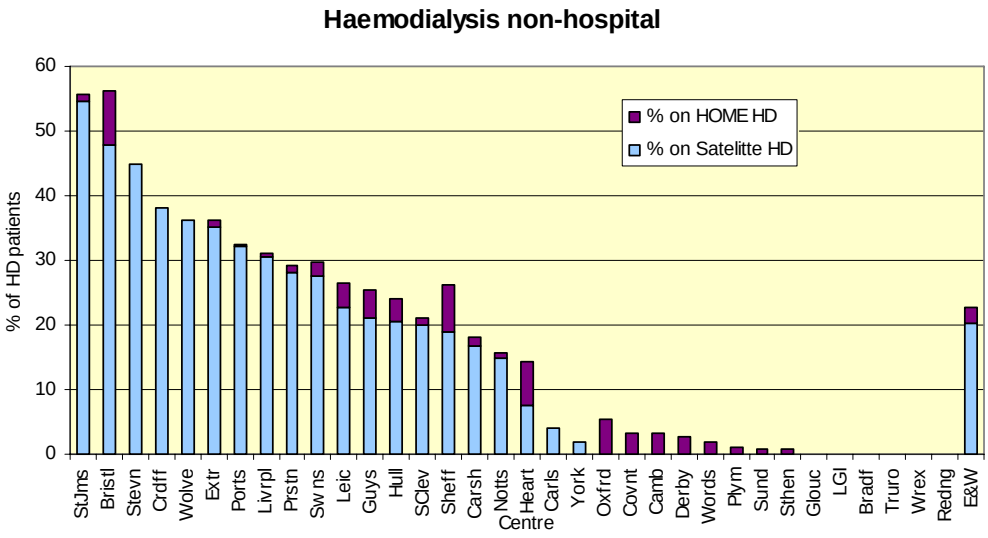


Figure 5.9: Percentage of HD patients treated at home and in satellite units

Peritoneal dialysis

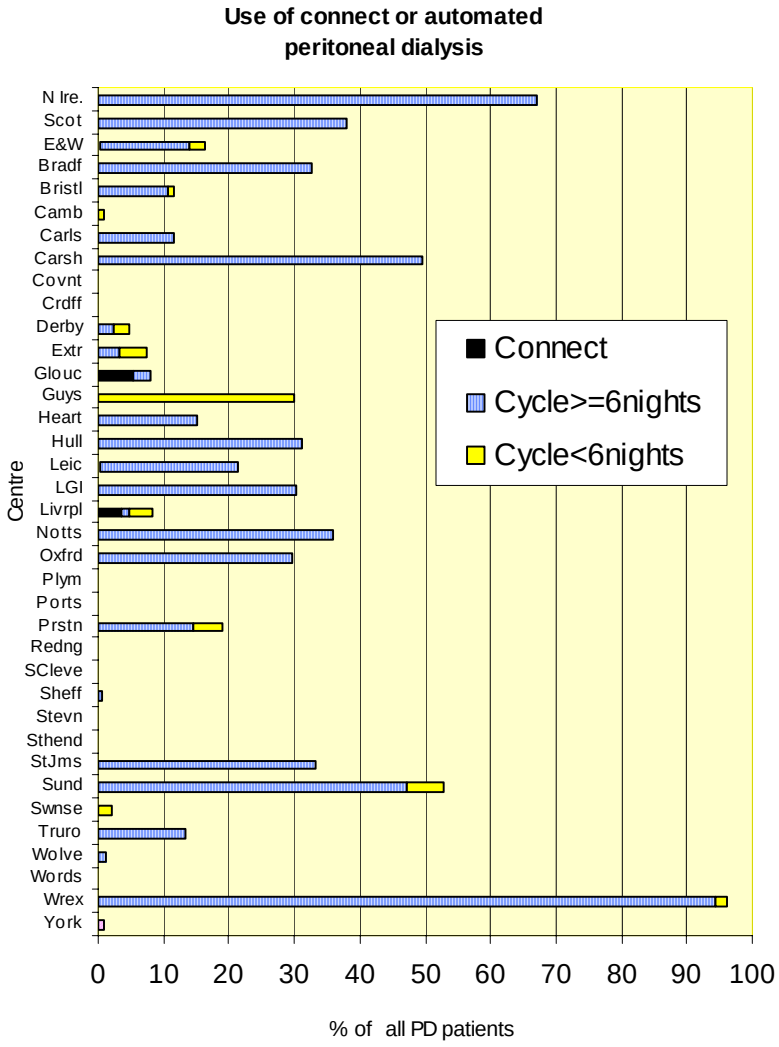


Figure 5.10: Use of connect and automated PD as a percentage of total PD

The percentages of patients on each of the main types of PD in individual units are shown in Figure 5.10. Connect PD has virtually disappeared. Cycling PD was more widely used in Scotland (38%) than in England and Wales, and most frequently used in Northern Ireland (67%). There was a wide variation in the percentage of patients treated with one or other form of cycling PD between centres.

A relatively high proportion (38%) of patients with a primary diagnosis of diabetes were treated by PD, as shown in Table 5.10. This may partly relate to the younger age of diabetic patients as PD is more common in younger than older patients.

Diagnosis	% on PD
Diabetes	36
Aetiology uncertain*	29
Glomerulonephritis	35
Polycystic kidney	31
Pyelonephritis	31
Hypertension	30
Renal vascular disease	28
Other	29
Not sent	27

Table 5.10: Proportion of patients on PD, by diagnostic category
*Includes patients listed as 'glomerulonephritis not biopsy proven'.

Modality and gender

There were no differences in the type of treatment according to gender except that 4.5% of males, compared with 2.5% of females, were on home HD.

Change in treatment modality 2000–01

	% HD home	% HD hospital	% HD satellite	% HD total	% PD standard	% PD disconnect	% PD cycling	% PD total	% With Transplant
1st qtr 2000	1.8	24.1	8.9	34.8	0.2	16.4	2.8	19.4	45.9
1st qtr 2001	1.4	24.1	9.9	35.4	0.1	14.7	2.6	17.4	47.2
4th qtr 2001	1.3	24.5	10.9	36.7	0.04	14.1	2.7	16.8	46.5

Table 5.11: Proportion of patients with different modalities of RRT, 2000 and 2001

	1999	2000	2001
4th qtr 2000	11447	12447	13222

Table 5.12: Number of patients in the same 23 centres on RRT, 1999–2001

Comparing only the 23 England & Wales centres for which there were data from1999, there was a 15.25% overall percentage increase in the number of patients over 2 years (Table 5.11). The year-on-year growth is running at 7–8%; the rise is largely in the number of HD patients, with a small rise in transplantees and the PD number remaining almost static.

Long-term trends

In England & Wales, 68% of dialysis patients were on HD, compared with 73% in Scotland.

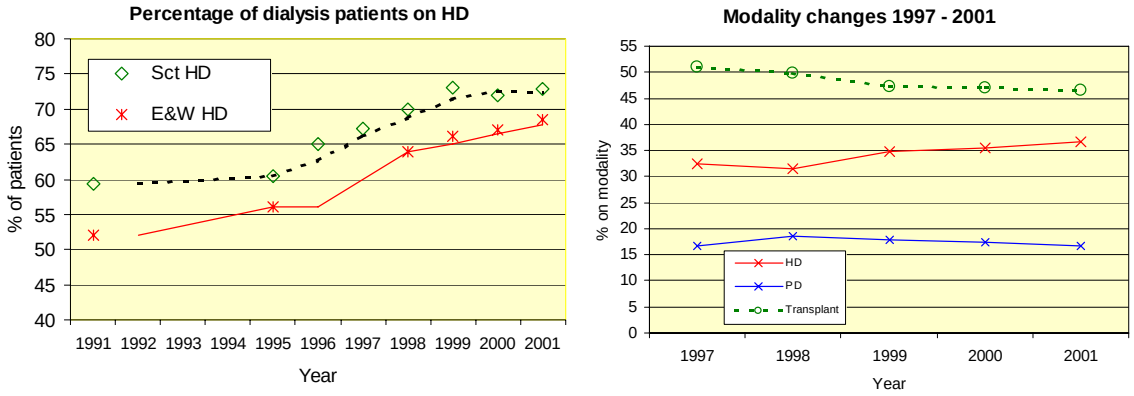


Figure 5.11: Percentage of dialysis patients on HD, by year

England & Wales show an increasing percentage of patients being treated with HD, the steepest rise being since 1995. These percentages are occurring on the background of an increasing prevalent pool so the number on HD has risen even more steeply. This rise is continuing in England & Wales, although there is still a lower percentage of patients on HD than in Scotland. The English data for 1992 and 1995 came from the national review. The data show a continuing slow decline in the overall percentage of patients with a functioning transplant.

Survival of patients established on RRT

This section analyses the 1 year survival of all patients established on RRT for at least 90 days on 1 January 2001, and the 2 year survival of similar patients alive on 1 January 2000.

	E&W 2000	Eng 2001	Wales 2001	E&W 2001
No. of patients	6846	8342	779	9121
No. of deaths	1073	1233	106	1339
Kaplan–Meier 1 year survival	83.4	84.3	84.2	84.3
(95% CI)	82.3–84.5	83.3–85.3	80.4–88.0	83.3–85.3

Table 5.13: One-year survival of dialysis patients alive on 1/01/00 and 1/01/01

	Transplant censored at dialysis			Transplant including dialysis returns		
	England	Wales	E&W	England	Wales	E&W
No. of patients	5896	745	6641	5896	745	6641
No. of deaths	154	15	169	169	16	185
KM 1 yr survival	97.3	98.0	97.4	97.1	97.8	97.2
(95% CI)	96.9–97.8	96.9–99.0	97.0–97.8	96.7–97.5	96.8–98.9	96.8–97.6

Table 5.14: Survival during 2001 of transplant patients alive on 1 January 2001

	Dialysis aged less than 65			Dialysis aged 65 and over		
	England	**Wales**	**E&W**	**England**	**Wales**	**E&W**
No. of patients	4710	410	5120	3449	369	3818
N. of deaths	438	36	474	785	70	855
KM 1 yr survival	90.1	90.3	90.1	77.0	80.9	77.4
(95% CI)	89.2–90.9	87.3–93.3	89.2–90.9	75.6–78.4	76.9–84.9	76.1–78.7

Table 5.15: Survival during 2001 of dialysis patients alive on 1 January 2001, by age

	Diabetic <65			Non-diabetic <65		
	England	**Wales**	**E&W**	**England**	**Wales**	**E&W**
No. of patients	721	65	786	3986	344	4330
No. of deaths	127	12	139	311	24	335
KM 1 yr survival	81.7	79.8	81.6	91.6	92.4	91.7
(95% CI) 2001	78.8–84.6	69.5–90.0	78.9–84.3	90.7–92.5	89.4–95.3	90.8–92.5
KM 1 yr survival			78.7			92.1
(95% CI) 2000			75.1–82.4			91.1–93.2

Table 5.16: Survival during 2001 of dialysis patients, diabetic and non-diabetic, aged <65

	Diabetic ≥ 65			Non-diabetic ≥.65c		
	England	**Wales**	**E&W**	**England**	**Wales**	**E&W**
No. of patients	408	46	454	3041	323	3364
No of deaths	120	9	129	665	61	726
KM 1 yr survival	70.4	80.4	71.5	77.9	80.9	78.2
(95% CI) 2001	66.0–74.9	69.0–91.9	67.3–75.6	76.4–79.4	76.6–85.2	76.8–79.6
KM 1 yr survival			71.7			76.0
(95% CI) 2000			66.4–77.1			74.1–77.9

Table 5.17: Survival during 2001 of dialysis patients, diabetic and non–diabetic, aged ≥65

The overall survival of prevalent patients shows little change, with a trend towards improvement (Table 5.13). Transplanted patients have a lower mortality than even the younger dialysis patients (Tables 5.14 and 5.15), but these patients are a selected younger, fit population with a median age of 48 years, compared with one of 55 years in the dialysis population, and less comorbidity. Comparing transplant patients with non-diabetic dialysis patients aged less than 55 (Tables 5.16 and 5.17), there is still a lower mortality, with a 97.4% versus 92.1% survival during 2001.

There was a significant difference in survival between non-diabetic and diabetic patients, the difference in mortality remaining consistent when analysed by 10 year age band (Table 5.18).

	<55 Non-diabetic			55–64 Non-diabetic		
	England	**Wales**	**E&W**	**England**	**Wales**	**E&W**
No. of patients	2609	224	2833	1379	121	1500
No. of deaths	142	10	152	169	14	183
KM 1 yr survival (95% CI)	94.0 93.1–95.0	95.0 91.9–98.0	94.1 93.2–95.0	87.1 85.3–88.9	88.0 82.1–93.9	87.2 85.5–88.9
	65–74 Non-diabetic			**≥75 Non-diabetic**		
	England	**Wales**	**E&W**	**England**	**Wales**	**E&W**
No. of patients	1700	161	1861	1341	162	1503
No. of deaths	302	27	329	363	34	397
KM 1 yr survival (95% CI)	82.0 80.1–83.8	83.2 77.4–89.0	82.1 80.3–83.8	72.8 70.4–75.2	78.7 72.4–85.1	73.4 71.2–75.7

Table 5.18: Survival during 2001 of non–diabetic dialysis patients, by age

Survival by Centre

Figure 5.12 shows the adjusted 1 year survival by centre for all dialysis patients alive on 1/1/2001.

Changes in 1 year survival 1997 – 2001

Figure 5.13 shows the one year survival by centre for the period 1997 – 2001. Overall there is a significant trend in both England and Wales for improved 1 year survival. Several centres like E9, F0, F2, F4 show an improving trend while E1,E3, H1, H4 show no significant change. Reasons for these differences need to be discussed between centres.

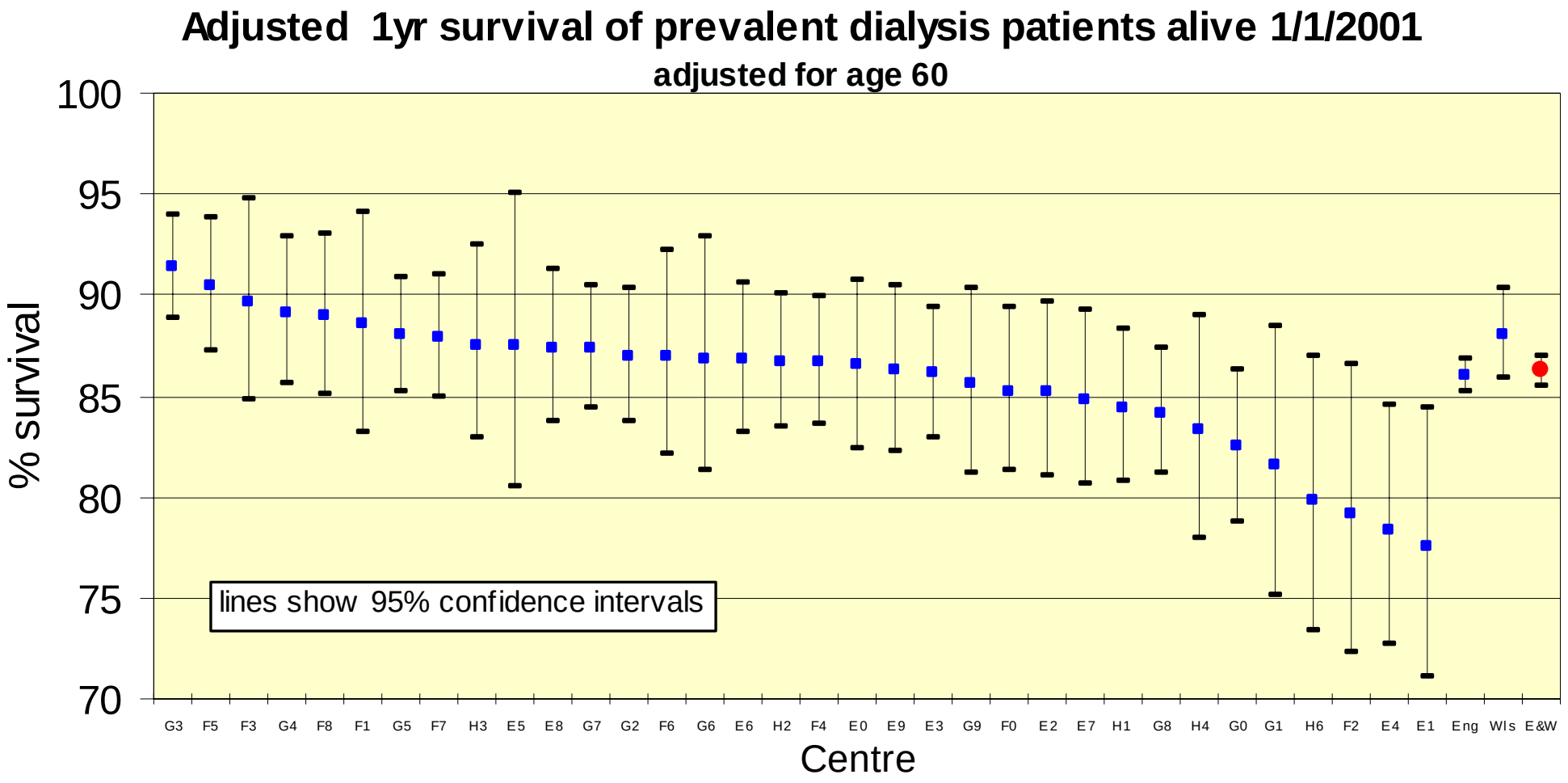


Figure 5.12 one year prevalent dialysis survival by centre 2001

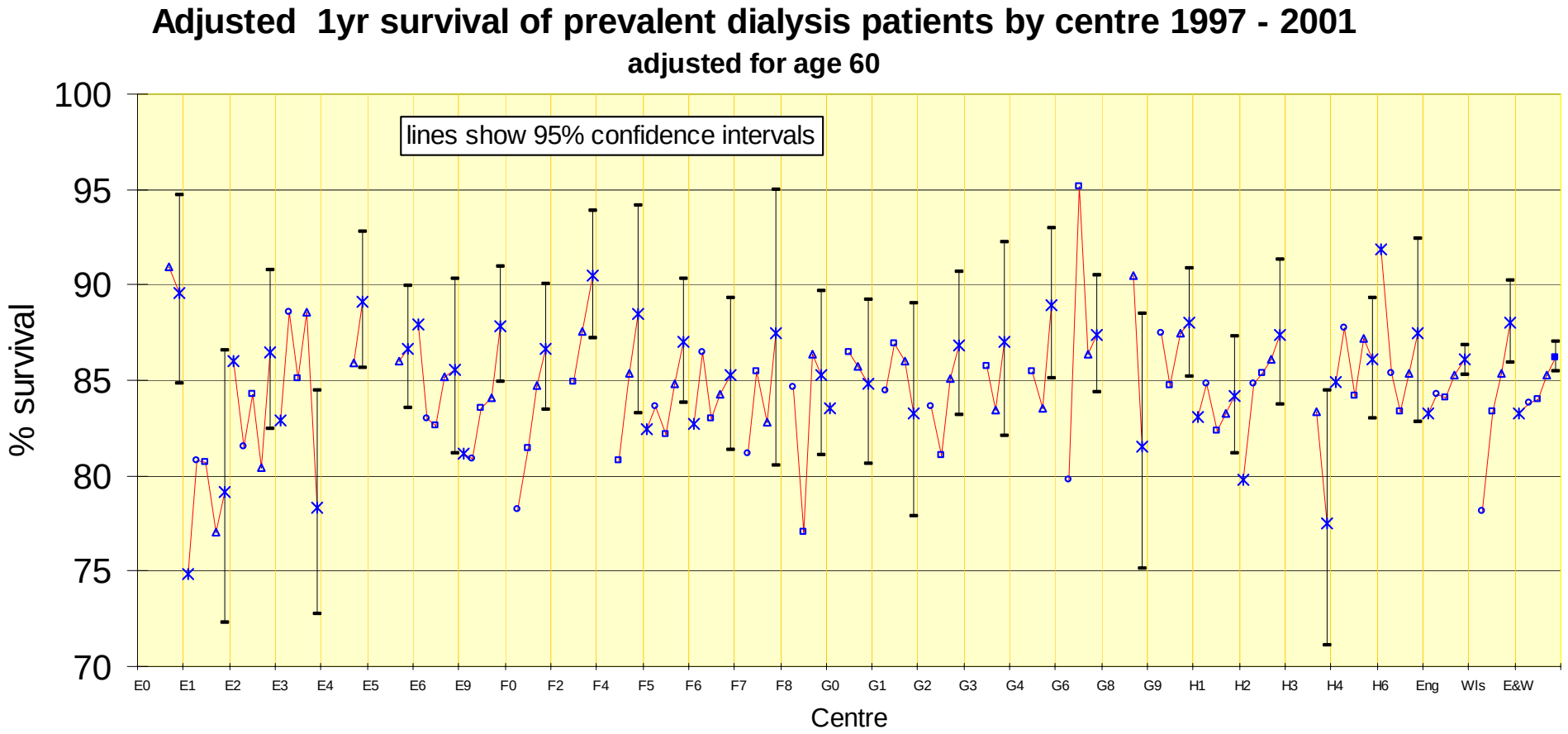


Figure 5.13 Change in 1 year survival 1997 - 2001

Chapter 6: Predicting Future Demand in England, a Simulation Model of Renal Replacement Therapy

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This chapter is based on a study funded by the Department of Health. A full report has been submitted and, once agreed, will be available. This will contain all the working papers and appendices, as well as a more detailed explanation of the model.

Summary

- A discrete event simulation model has been developed to model the future demand for renal replacement therapy in England. The data used to populate the model are largely derived from the UK Renal Registry and UK Transplant. The model describes the transitions between modalities and takes account of unmet need for renal replacement therapy, the impact of changing demography and diabetes incidence, transplant supply, and patterns of use and outcomes of renal replacement therapy.

- The predicted number on renal replacement therapy will continue to rise for 20 years until a steady state position has been reached, with a future prevalence approaching 60,000 patients. By 2010, the current prevalence will have increased from about 30,000 to between 42,000 and 51,000, depending on assumptions about acceptance rate and patient survival. Much of the rise in demand will occur even if there is no increase in the current acceptance rate. This growth will occur disproportionately in the elderly treated by haemodialysis. The most realistic figures are over 45,000 patients (900 pmp), or a 4.5% average annual increase over the decade.

- More work is required to investigate the cost of renal replacment therapy, and the model's estimates will need to be revised as new data emerge on patterns of acceptance, transplant supply and patient and mode survival. The potential demand for renal replacement therapy highlights the importance of addressing the prevention of chronic kidney disease.

Background

The main driver to growth of the renal replacement therapy (RRT) programme has been a rising acceptance rate. This was only 20 per million population (pmp) in 1982 but has reached over 93 pmp in 2001.[1,2] An increasing proportion of these patients are elderly, the median age being over 65 in 2000, and many patients have associated comorbidity such as cardiovascular disease.

The current acceptance rate is, however, lower than that of many Western countries; it should be higher to cover the assumed unmet population need, which is largely found in the elderly and in patients with comorbidity. Future need will also be influenced by demographic change, particularly in terms of the ageing of ethnic minority populations,[3,4] which have a higher rate of established renal failure (ERF). There is, in Europe and the USA, an epidemic of type II diabetes, which may lead to a higher incidence of diabetic ERF[5] in the future despite therapeutic advances in preventing diabetic nephropathy.

Davies and Roderick[6] have reported results from a simulation model, using a variant of discrete event simulation called POST.[7] This used data collected from the first National Renal Review in 1991–93. It showed that, from 1991/92, based on an acceptance rate of 80 pmp, the steady state would not be reached for 20 years or more, and the final steady prevalence rate might be twofold higher, at 800 pmp.[6] Key determinants of the predicted growth were patient survival and acceptance rate. Transplant supply determined the dialysis to transplant ratio and hence the overall projected cost of the programme. The use of the model was, however, limited by the availability of data at the time; it was, for example, not possible to separate the types of dialysis despite the significant organizational and resource differences between them.

There have been significant changes in the pattern of modes of treatment in recent years.[1,8] Although there are almost as many patients with functioning grafts as with dialysis, the availability of cadaver kidney donors has been falling, leading to an increase in the transplant waiting list.[9] UK Transplant (UKT) is, however, addressing the problems of this shortage.[10] Measures have been instigated to improve the situation for both cadaver and live organs. The effects of achieving such targets need to be evaluated.

Peritoneal dialysis (PD) was the mainstay of the expansion in dialysis in the 1980s, but haemodialysis (HD) is the now the most common option.[8] The fastest growth in recent years, in both absolute and relative terms, has been in hospital HD, particularly as delivered in renal satellite units.[11] There is a need to take patient choice of mode into account.[12]

The Renal Association Standards document, continuing an audit by the UK Renal Registry, the forthcoming National Service Framework and initiatives by UKT, should bring about changes in patterns of treatment and improvements in patient survival to a level comparable with that of other European countries.[13,14] This will increase the prevalence of patients on RRT but may be partly offset by accepting more patients who are older, with associated comorbidity, and who are therefore likely to have a poorer survival.

The earlier simulation model has been rewritten to provide a Windows interface, now takes account of transitions between PD and HD and includes live transplantation. The use of this model provides more robust estimates of the likely growth of the RRT programme and the effect of different scenarios.

This chapter presents a development of the original model and an assessment of the impact on patient numbers of:

- a rising acceptance rate, including the effect of demographic change using national population projections in England 2000–10 and specifically change in the ethnic minorities and potential increases in diabetic ERF;
- the effect of an increasing cadaveric and live donor organ supply;
- the balance of the use of HD and PD, given patient choice;
- increasing patient survival on RRT.

A report containing full details of the work, including appendices and supporting working papers, is available from the authors (pjr@soton.ac.uk).

Methods

The methods are explained in the full report.

Simulation model

Risk groups

The discrete event simulation describes the flow of patients between states, a flow that is dependent on the patient's risk factors. We chose to use 14 risk groups: seven age groups together with the presence or absence of diabetic ERF. Patients over the age of 16 were divided into 10 year age groups up to 75+. Comorbidity is an important factor in the survival of patients on RRT, but these data are currently incomplete from UK Renal Registry, so the presence of diabetes as a cause of renal disease has been used as a proxy. One further possibility was to subdivide the population by ethnic group. Diabetic ERF and hypertension are more common in certain ethnic minorities, and one might therefore assume that these groups have a poorer outcome on RRT. There is some evidence for this in US Blacks but limited UK data as yet. To keep the model simple, we have not stratified by ethnicity, although the change in the population and differential pattern of diabetic ERF by ethnic group are taken into account.

Patient flow through the model

Figure 6.1 shows the flow of patients through the model. Incident patients enter the model at the point in time at which they need RRT. Prevalent patients are allocated to their current treatment mode. The time spent in each state is determined by samples from patient and mode survival distributions. When a patient receives a transplant, he or she is removed from dialysis and the survival distributions are re-sampled. When a graft fails, the patient returns to dialysis, the mode being based on probabilities derived from Renal Registry data in 2000.

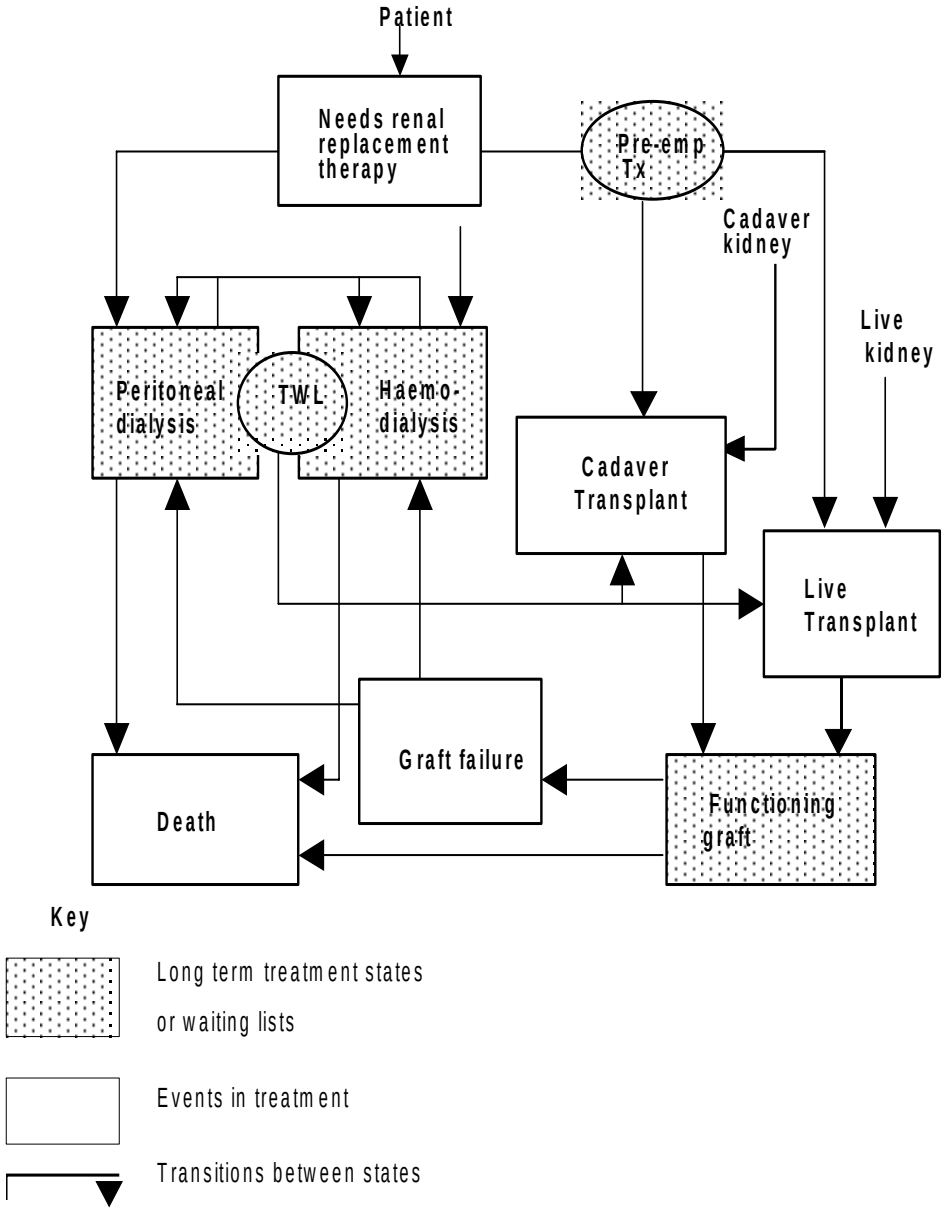


Figure 6.1: Schematic diagram of the flow of patients through the mode
Note: The model does not currently allow for pre-emptive live transplantation.

Simulation output

The user can specify the number of simulated years, the time intervals at which information is made available and the number of iterations. The programme collects information on patient activities as the simulation progresses and averages the results over all iterations. The output data, by time interval, are as follows:

- average patient numbers on HD, PD, functioning cadaver graft, functioning live graft and transplant waiting list;
- number of cadaver transplants, live transplants, new dialysis patients, failed transplant patients, dialysis mode change and deaths;
- average patient numbers by risk group for HD, PD, functioning cadaver graft and functioning live graft.

Simulation input

The parameters used in the simulation are discussed below, the following sections covering the derivation of:

Future acceptance rates	Initial acceptances
Starting prevalence (prevalence)	Patient and mode survival on dialysis
Transplant survival	Transplant waiting list
Transplant supply	Chances of receiving a transplant

Future acceptance rates onto RRT

Background

The acceptance rate in England for RRT estimated from the 1998 Renal Survey (92 pmp) is lower than that of other developed countries; in 2000, for example, rates in Spain and Germany were 132 pmp and 175 pmp respectively. Both Wales (128 pmp) and Scotland (107 pmp) had a higher acceptance rate than England despite having smaller ethnic minority populations.[2] It is therefore necessary to take account of the probable increase in demand for treatment in England arising from treating current unmet need, and to take account of the ageing of the population, particularly of ethnic minorities of Indo-Asian and African-Caribbean origin because of their higher rate of renal disease.

To achieve this population, projections to 2010 for the ethnic and non-ethnic minority groups were derived separately. The recent Scottish- and Welsh-based non-ethnic minority acceptance rates were used to give some idea of the non-ethnic minority need in England. The ethnic minority rates were proportionately higher. These acceptance rates were then applied to the 2010 population estimates.

Starting population in England by ethnic minority

Although the age and ethnic breakdown will be available from the 2001 Census, it was necessary to use the Labour Force Survey to derive this.[15] It shows that 85% of the White UK population, 97% of the African-Caribbean, 99% of the Indo-Asian and 97% of 'Other ethnic minorities' is resident in England. Using these figures, the numbers of the White, African-Caribbean, Indo-Asian and 'Other ethnic minority' population for England by 5 year age bands were estimated for 2000. This assumes that the age distributions for the different ethnic groups are similar in England, Wales and Scotland.

Projected population in England in 2010

We had to calculate population projections by ethnic group as the available population projections for England published by the Office for National Statistics (ONS) are not broken down by ethnicity. The population of the UK in 2010 was predicted using 'all cause mortality' data from the ONS for 1999. The population was split into the four ethnic groups above: White, Indo-Asian, African-Caribbean and all others. Each 5 year age band from each group of the 2000 population was split equally into single years for both males and females, who then experienced the mortality for that age, and then the next year for the next age and so on for 10 years. The data were then reaggregated into 5 year age bands. Excluding migrants, the population of England in 2010 was projected to be 50.1 million, 0.3 million less than the current estimate for 2000. Including data on net migration available from ONS, the projection rises to 50.6 million; this compares well with the ONS estimated population in 2011 of 51 million.

Current RRT rate in England

All scenarios need the RRT rate in England in 2000 (Table 6.1). The coverage of UK Registry of renal units in England is only partial and excludes many large units in London. It was necessary to adjust Registry data to estimate the national picture. Two methods were used.

Data source	Renal units included	English Acc rate (pmp)	Scots Acc rate (pmp)	Welsh Acc rate (pmp)	E &W Acc rate (pmp)
1998 National Renal Survey	52 (all UK)	92	105	128	94.6
1999 Renal Registry	23	–	107	–	88.7
2000 Renal Registry	28	87	–	–	89

Table 6.1: Recent data on acceptance rates for England, Wales and Scotland

Method 1 (RR)

The simplest estimate assumes that the unit catchment populations are accurate and that the population not covered by units participating in the Renal Registry has the same age and ethnic structure as those in the Registry. We assumed, however, that the estimated unit catchment populations might be slightly inflated, and we allowed for some growth since 1998 and estimated a starting acceptance rate of 94 pmp in 2000 and a total number accepted for England of 4750. These 4750 cases were partitioned by age and diabetes by taking the actual data from the Registry for 2000 on 2101 patients, broken down by age and diabetic ERF, and scaling them up in proportion to generate the total of 4750 patients. This estimate is called 'RR' – an acceptance rate of 94 pmp, with 49% of patients aged over 65 and 17% having diabetic ERF (Table 6.2).

Method 2 (RS)

Method 1 may underestimate the ethnic minority pattern and total number as there were several big renal units in London with large local ethnic minority populations not contributing to the Renal Registry in 2000. An alternative approach is to use the 1998 National Renal Survey, which had an 100% response rate from all renal units,[2] as a basis for comparing the contributing and non-contributing units. The comparison showed that Renal Registry units contributed 40% of all acceptances in 1998. The proportion of patients over 65 was higher for Registry than non-Registry units, at 46% and 36% respectively. The proportions with

diabetic ERF were both approximately 17%. An adjusted acceptance rate was calculated using these data (Table 6.3); this gives a higher starting acceptance rate of 104 pmp (5253 cases), with 42% aged over 65 and 17% having diabetic ERF.

	18-24	25-34	35-44	45-54	55-64	65-74	75-84	>=85	Total
UKRR diabetics	1	22	50	47	92	115	32	1	360
UKRR non-diabetics	90	122	148	166	337	527	295	56	1741
UKRR total	91	144	197	212	431	643	326	57	2101
Model-derived diabetics for England	1	50	112	105	208	261	71	1	692
Model derived non-diabetics for England	205	275	335	374	765	1192	666	128	3367
Model-derived total for England	205	326	445	480	974	1454	737	128	4750

Table 6.2: RR current acceptance scenario (UK Renal Registry-derived acceptances for 2000)
UKRR, UK Renal Registry.

	18-34	35-44	45-54	55-64	65-74	75+	Total
UKRR diabetics	23	50	47	92	115	33	360
UKRR non-diabetics	212	148	166	337	527	351	1741
Model adjustment factor	2.82	2.82	2.82	2.82	2.17	2.17	
Model-derived diabetics for England	64	138	130	259	251	70	911
Model-derived non-diabetics for England	599	416	467	955	1143	760	4342
Model-derived total for England	663	555	598	1214	1394	830	5253

Table 6.3: RS acceptance rate scenario (UK Renal Registry derived using 1998 National Renal Survey)
UKRR, UK Renal Registry.

Ethnicity

Age-specific increased relative rates (Table 6.4) were used to derive the numbers accepted onto RRT from each age group in the two ethnic minority groups. It was assumed that 'other' ethnic minorities have the same risk of ERF as Whites.

Ethnic group	Age group		
	16–54	55–64	65+
Indo-Asian	3.7	6.8	7.0
African-Caribbean	3.3	5.1	7.5

Table 6.4: Age-specific relative risk of renal disease by ethnic group

These data were converted into age and diabetic ERF using the age ethnic and diabetic ERF pattern available from the nine units participating in the Registry in 2000 who had high completeness for these data items.

Scenario 1: Current RR and current RS applied to the 2010 population – 103 pmp RR, 115 pmp RS

This was used to show what growth in prevalence would occur if there were no further increase in acceptance rate over and above that arising from population change. Applying the current RR rate (scenario 1a) to the projected non-ethnic minority and ethnic minority populations for England in 2010 gives 5169 acceptances for RRT (103 pmp) in 2010, an increase of 8% on the 4750 acceptances for 2000, with 49% aged over 65 and 17% diabetic. Using the RS rate (scenario 1b), this figure rises to 5772 (115 pmp) in 2010, with 42% over 65 and 17% with diabetic ERF.

Scenario 2: Current Scottish acceptance rates – 125 pmp

Methods similar to those described above were used to calculate the likely RRT rate in England in 2010 if the recent acceptance rates seen in Scotland were to apply in England. The number of new patients accepted onto RRT in 2010 would be 6286, an overall rate of 125 pmp, with 51% over 65 and 18% having diabetic ERF.

Scenario 3: Current Welsh acceptance rates – 162 pmp

The predictions were repeated using the recent Welsh acceptance rates. This scenario estimates 8112 new cases accepted onto RRT in 2010, an overall rate of 162 pmp, 51% being aged over 65 and 17% having diabetic ERF.

Scenario 4: Current Welsh over 45 years and current English less than 45 years – 147 pmp

In this scenario, it is assumed that the current rate of acceptance for RRT in the younger English age groups is meeting need and will remain constant, whereas the take-on rate in older groups will increase. Scenario 4 therefore uses the higher Welsh rates in the 54+ age groups and each of the current English acceptance scenarios (RR and RS) for those less than 54 years old. This produces an acceptance rate in 2010 of 144 pmp (7234 new patients) if RR based and 147 pmp (7345 patients) if RS based.

Scenario 5: Current Welsh acceptance rate with an estimated migrant population – 162 pmp

This assumes that the English 2010 take-on rate will increase to that of the current Welsh rate and that the ethnic minority population will increase further to include new immigrants. With this scenario, there would be 8213 new patients accepted for RRT in 2010 (162 pmp), 50% being over 65 years old and 17% having diabetic ERF.

Scenario 6

This used a 2001 survey of all UK renal units undertaken by the Renal Association (John Scoble, personal communication) for the starting stock. There is an emerging epidemic of type II diabetes. The World Health Organization is predicting an increase in the prevalence of diabetes in the UK from 1.28 million in 1995 to 3.09 million in 2010.[16] To take account of this, data were used from a study of trends in diabetes prevalence based on the General Practice Research Database data, which found an increase of just under 20% in prevalence from 1994 to 1998.[17] A conservative 10% increase in the number of new patients with diabetic ERF predicted in 2010 was applied to the Welsh acceptance rate scenario; this gave a total acceptance rate of 158 pmp, 19% of whom would have diabetic ERF.

All the scenarios excluded paediatric cases (<16 years), but their rates are very low compared with those of adults (1.9 pmp in the under-16s).

Starting acceptance arrays and the initial mode of therapy, by age group and diabetes status

The starting acceptance arrays were based on the current acceptance data adjusted by the RR or RS method, as discussed, and shown in Tables 6.2 and 6.3 above broken down by age and diabetic ERF. Data on all new patients accepted onto the Renal Registry from 1997 to 2000 were used; these included age, sex, primary renal disease and timelines of all the modes of treatment and death. The proportions allocated to PD, HD or a pre-emptive transplant were derived from Registry data**.**

In a further scenario, to allow for a different balance of HD and PD that took account of patient choice with the wider availability of HD, the proportion of incident patients over 55 starting HD was increased by 10% in absolute terms, that for PD being similarly reduced.

Prevalence of patients on RRT in 2000 at start, by age, mode and diabetes

These were based on an extrapolation of Registry data on stock (RR method), extrapolation taking into account the 1998 National Survey (RS method) and also the use of the 2001 survey of all UK renal units (adjusted to England in 2000 with Renal Registry data being used to group patients by age and diabetes). The three starting stocks were 29,312, 33,307 and 29,400 patients respectively.

Dialysis survival

Data from international and national registries were collected to assess whether there was any evidence of an improvement in patient survival over time and also whether the UK survival figures differed from those of other countries. Survival trends in recent years appear largely to have stabilised; however, the International Dialysis Outcomes and Practice Patterns Study (IDOPPS) suggests that the survival rate on HD may be lower in the UK than in comparable European countries.[14] An analysis of the age- and diabetes-specific HD survival rates for the UK and European IDOPPS centres, based on confidential unpublished data, showed a significant difference in survival at 1 year. A scenario is therefore included whereby HD survival for the Welsh-based RS acceptances has been increased by the difference between the UK and European centres.

Transplant graft and patient survival

Transplant survival data by live grafts, cadaveric first grafts and cadaveric regrafts, as well as by age group, were provided by UKT. For the model, two piecewise exponential curves were fitted to each survival curve, one for early survival (up to 3 months) and one for later survival (after 3 months). Data from international and national registries were again used to assess the likely improvement in transplant survival. This showed that, following a period of initial improvement, transplant survival has been largely static over the past 10 years.

The mode of dialysis before and after transplantation for those patients returning to dialysis was examined to assess the effect of failures not returning to their pre-transplant mode. This showed that approximately 80% of HD patients returned to HD post-graft failure, whereas only 60% of PD patients returned to their initial mode. These percentages were incorporated into the model.

Transplant waiting list and allocation

Incident patients

Data were provided by the UK Renal Registry and UKT on the proportion of those patients, by age group and diabetic ERF, starting dialysis between 1 January 1998 and 31 December 1999 who became registered on the transplant waiting list within the first year of RRT. This showed that those with diabetes were only 70% as likely to be listed as those without. This was used to calculate an age- and diabetes-specific chance of listing for transplant.

Prevalence patients

Renal Registry data were available on the percentage of all those on RRT, by age group, who were on the active transplant waiting list at 1 January 1999. Data were available on the proportion of diabetics listed, although not by age. These data, together with Renal Registry data on the total numbers in each age and diabetic group, were used to derive a proportion listed by age and diabetes.

Previously transplanted patients

An analysis was undertaken completed by UKT on the chances of listing for transplant following previous transplantation, by age and time since the failure of the previous graft. The proportions being relisted stabilised at around 24 months; these proportions were used in the model. There were also data on the proportion of diabetics relisted, although not by age. Despite their being less chance of relisting following a failed graft, the number involved was, however, very small, and the model assumed diabetics had the same chance of relisting as non-diabetics. Therefore all those previously transplanted were given a lower probability of going back onto the transplant waiting list compared with patients not previously transplanted.

Transplant supply

Data were provided by UKT on the number of transplants performed in the UK in 2000 by age group. A rate for England by type of transplant (cadaver or live) was estimated using data from the UKT 1990–98 Renal Transplant Audit on the proportion of total transplants by type performed by each centre. These data were used to estimate the number of live and cadaver transplants for England. Three scenarios were used (Base, UKT and Pragmatic) to estimate how transplant supply might change over time. 'Base' assumed no change in the number of transplants (22 pmp cadaver, 5 pmp live). The 'UKT' scenario used estimates from the UKT Business Case, which detailed the steps being taken to increase the number of organs available.[10] This was for an increase of the number of cadaver kidneys to 1540 (26 pmp), that of non-heartbeating donors to 210 (4 pmp) and that of live donors to 765 (13 pmp) in the UK. The final scenario was a less optimistic one, with only 90% of the predicted live and 65% of the predicted cadaver increase to 2005. The second and third scenarios assumed that the rate of organ availability would remain constant after 2005.

The model combined non-heartbeating and heartbeating donors and assumed the same survival.

Chances of transplant

Data were provided by UKT on an analysis of the time to transplant for 3957 new patients listed for transplant in 1998–99. A risk score was developed using the factors age at listing, gender, diabetic status, ethnicity and number of previous transplants. People were then grouped into one of five categories according to their chance of a transplant. A simplified risk score, from 1 to 3, based on age group, diabetic status and whether there had been a previous transplant, was used in the simulation model.

Early start on dialysis

The implications of an early start to dialysis were not modelled as no change in the current pattern is envisaged, although the model could be used to do this.

Results

The simulation was run with data for the whole of England for 15 years with 10 replications. Table 6.5 summarises all the scenarios shown.

	2010 Acc rate	2010 Prevalence	2010 Prevalence (pmp)	2010 on HD	% on Dx	Average annual % HD growth	Average annual % RRT growth	% >65yrs
1a: Current RR	103	37,297	744	12,818	46	2.1	2.7	32.1
1b: Current Base RS	115	41,811	834	16,132	52	3.9	2.6	31.3
1b: Current RS	115	42,570	849	14,542	45	2.6	2.8	31.1
1b: Current UKT RS	115	42,777	853	14,489	45	2.5	2.8	31.1
2: Scots Base RS	125	42,935	856	16,953	53	4.7	2.9	31.9
2: Scots Prag RR	125	39,869	795	14,309	48	3.5	3.6	33.7
2: Scots Prag RS	125	43,704	872	15,374	47	3.3	3.1	31.7
2: Scots UKT RS	125	43,926	876	15,247	46	3.2	3.2	31.7
3: Welsh Base RS	162	47,472	947	20,076	58	7.4	4.3	32.6
3: Welsh Prag RR	162	44,499	888	16,818	51	5.9	5.2	34.2
3: Welsh Prag RS	162	48,170	961	18,343	52	5.9	4.5	32.3
8: Scoble RS	156	45,829	914	17,687	52	6.7	5.6	33.2
3: Welsh UKT RS	162	48,407	966	17,943	50	5.5	4.5	32.3
4: Eng & Wales Prag RS	147	45,781	913	16,897	49	4.6	3.7	34.2
5: Welsh & Migs Prag RS	162	48,553	958	18,621	52	6.1	4.6	32.1
6: Diabetes increase 10% (Scoble RS)	158	46,155	921	17,925	53	6.9	5.7	33.2
7: Dialysis choice (Welsh Prag RS)	162	48,045	958	19,047	51	6.5	4.4	32.3

	2010 Acc rate	2010 Prevalence	2010 Prevalence (pmp)	2010 on HD	% on Dx	Average annual % HD growth	Average annual % RRT growth	% >65yrs
9: IDDOPS survival (Welsh Prag RS)	162	50,951	1016	20,976	54	8.1	6.2	34.0

Table 6.5: Summary of all scenarios

Current, Scots & Welsh, current English, current Scots and current Welsh take-on rates applied to the 2010 population.
Scoble, John Scoble's 2000 starting stock with current Welsh acceptance rates applied to the 2010 population
E&W, current English young (<54 years old) take-on rates and Welsh elderly (55+ years) take-on rates.
Welsh &Migs, Welsh take-on rates with migrants added to the 2010 population.
Diabetes increase 10%, John Scoble's 2000 starting stock with current Welsh acceptance rates applied to the 2010 population, with a 10% increase in all diabetic ERF.
Dialysis choice, current Welsh acceptance rates applied to the 2010 population, with a 10% increase in those aged over 55 starting RRT on HD and a 10% reduction in those over 55 starting RRT on PD.
IDOPPS, Welsh acceptance rates applied to the 2010 population with HD survival increased to that of the European centres in the IDOPPS study.
Base, current transplant supply; prag, pragmatic increase in transplant supply; UKT, UKT Business Case increase in transplant supply; Dx, dialysis.
Annual percentage increases were calculated by simply dividing the absolute percentage increase for each scenario by 10, the starting position being RR or RS as appropriate.

The confidence limits of the estimated means of treatment for England in 10 years time, given the expected variability in the acceptance and transplant rates, lie within 2.5% of the total for each mode and within 1% for the total. None of the totals is significantly different for different transplant supply rates. All the totals are significantly different from each other except where the migrant population is taken into account.

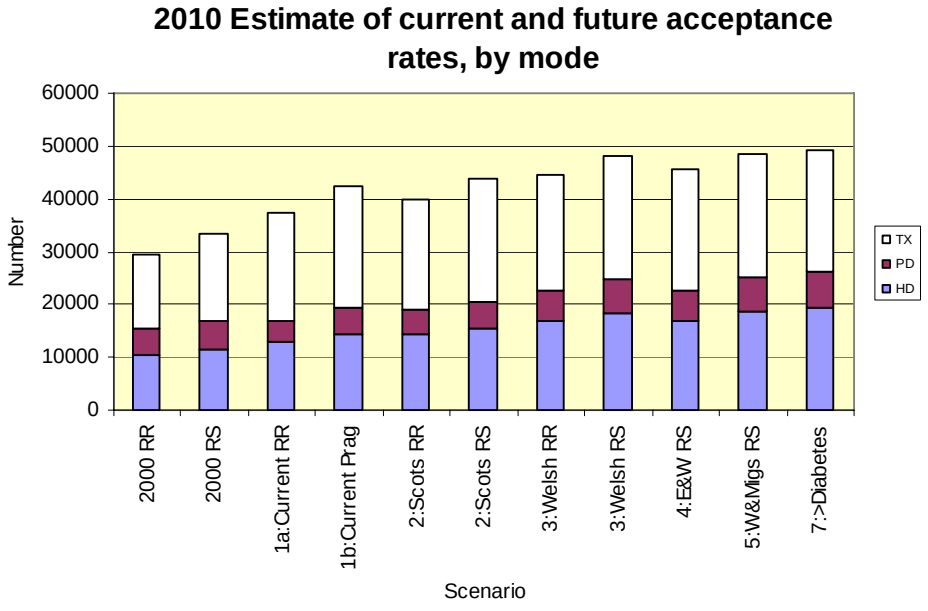


Figure 6.2: Predicted number on RRT in 2010, by mode, for pragmatic transplant numbers

Figure 6.2 shows the effect on future prevalence in 2010 of differences in estimating the current acceptance/prevalence rate in 2000, and of the various acceptance rate scenarios. The estimates of the starting acceptance and prevalence rates are higher using RS, and this increases the estimated future prevalence. Even if current age-specific acceptance rates apply (scenarios 1a and 1b), there will be significant growth in the demand for RRT because of population change and because a steady state has not been reached. Increasing the acceptance rate to that of Scotland or Wales (scenarios 2– 6) produces, as expected, higher growth in the future prevalence of RRT. Including ethnic minority migrants has little additional effect as they are mainly in the younger age groups. The future prevalence of RRT by 2010 is likely to lie in the region of 42,000–51,000 cases, a prevalence rate of about 850–1016 pmp. This is an average annual arithmetic growth rate of about 4.5%. Even assuming here an increase in transplant supply, the largest absolute and relative increase is in HD; the proportion on dialysis rises with the increase in the estimated acceptance rate. If patient survival on dialysis were to improve (based on the difference between the UK and European rates, using the IDOPPS data), the estimated mean number on RRT would be 50,951, with 20,976 (40%) on HD (using Welsh RS acceptance rates and the pragmatic transplant supply). Using Renal Association (Scoble) survey data for starting prevalence gives a future estimated number of 45,829. Increasing the incidence of diabetic ERF by 10% by 2010 with Scoble's starting prevalence indicates 46,155 patients.

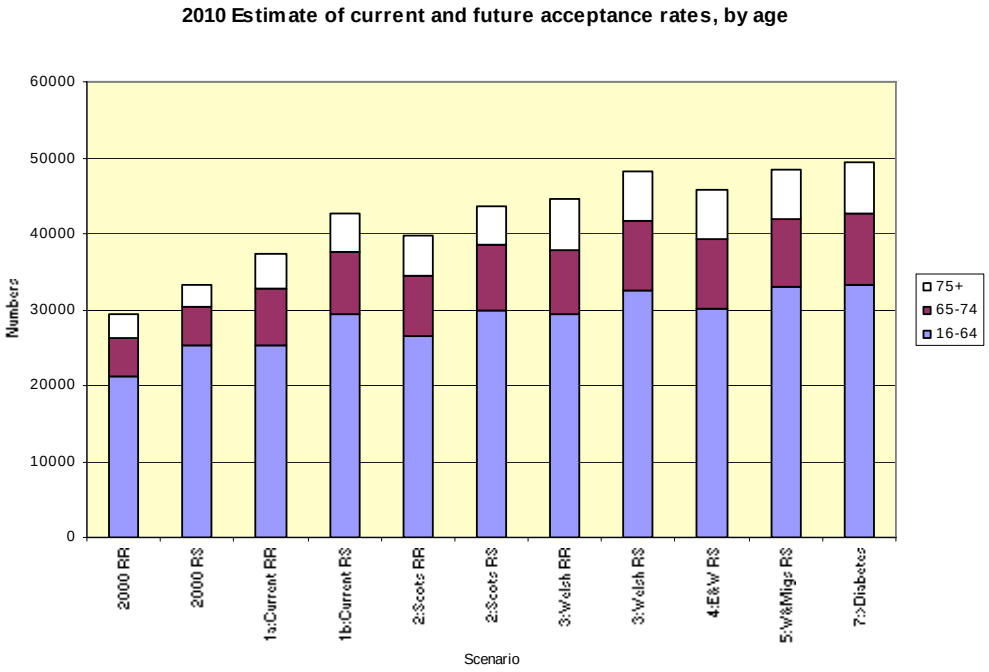


Figure 6.3: Predicted number on RRT in 2010, by age, for pragmatic transplant numbers

Figure 6.3 shows the age breakdown for these scenarios. The proportion over 65 increases in all scenarios similarly from 24% (RS) or 28% (RR) to about a third, the absolute numbers increasing even more steeply. It is, for example, estimated that the starting number of patients on RRT over 65 is 7920 (RS) or 8148 (RR). Using the scenario Welsh acceptance rate/RS current acceptance rate/pragmatic transplant rate, the number of patients on RRT aged over 65 is estimated to be 15,648 in 2010.

Figure 6.4 estimates the future number on RRT in 2010 for changes in transplant supply for three acceptance rate scenarios (1b, 2 and 3). Achieving the UKT-targeted increase in donor organs by 2005 does not significantly affect the total number but reduces the proportion on dialysis. In scenario 3, for example, the proportion falls from 58% if there is no increase in transplant supply to 50% if the plan is achieved, a difference of over 3000 patients on dialysis. Transplant supply has little effect on age distribution.

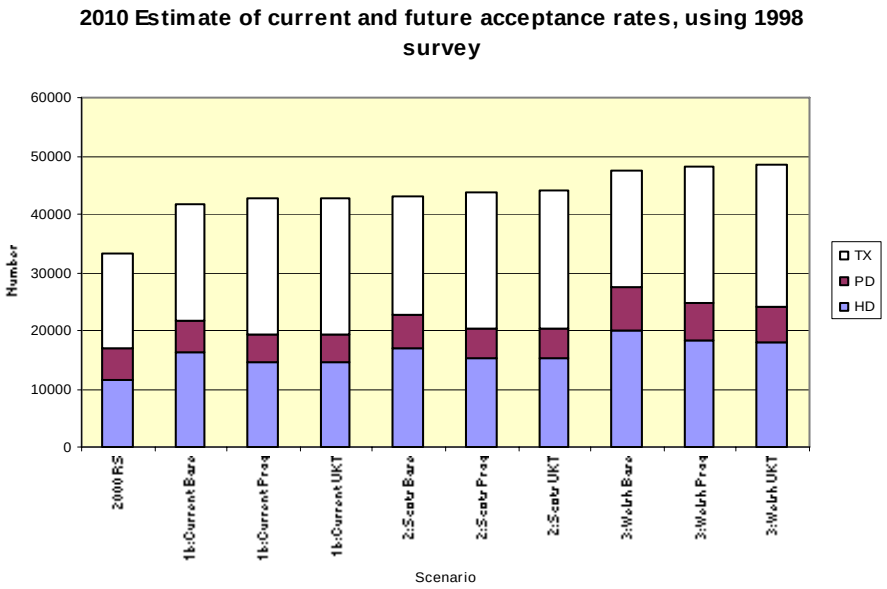


Figure 6.4: Predicted number on RRT in 2010, by mode, using the RS starting prevalence

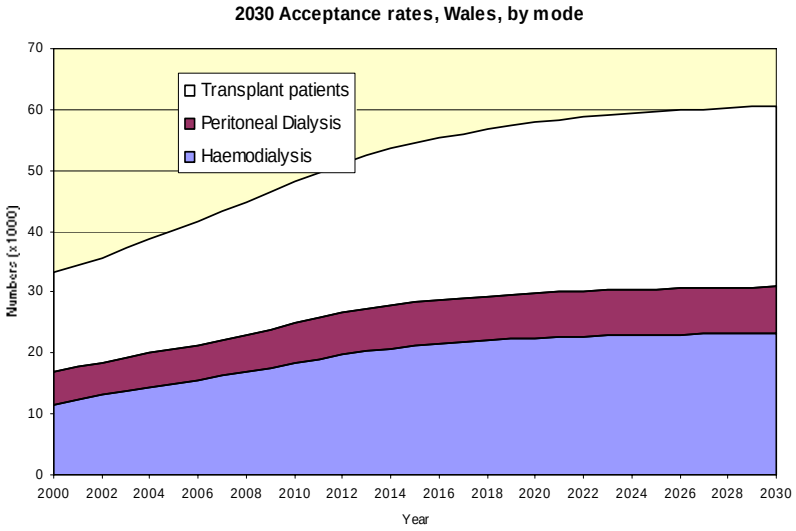
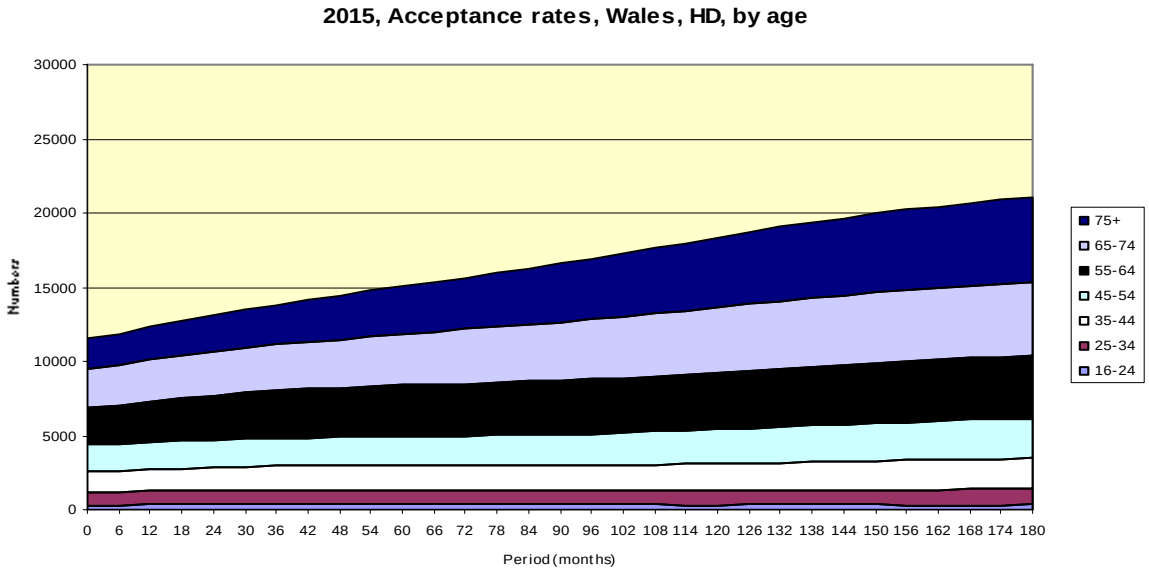


Figure 6.5: Predicted number on RRT in 2030 for Welsh acceptance rates, by mode, RS starting rate and pragmatic transplant supply

Figure 6.5 shows, using scenario 3 (Welsh acceptance rate, RS current acceptance rate and pragmatic transplant rate), the impact of running the model for longer than 10 years, on the assumption that all parameters stay the same after 2010. RRT growth continues, albeit at a declining rate, so that by 30 years the total number of RRTs is nearly 60,000 patients, and beyond that time a steady state appears to be reached. Even projecting the current acceptance scenarios, the steady state number would approach 50,000 patients.

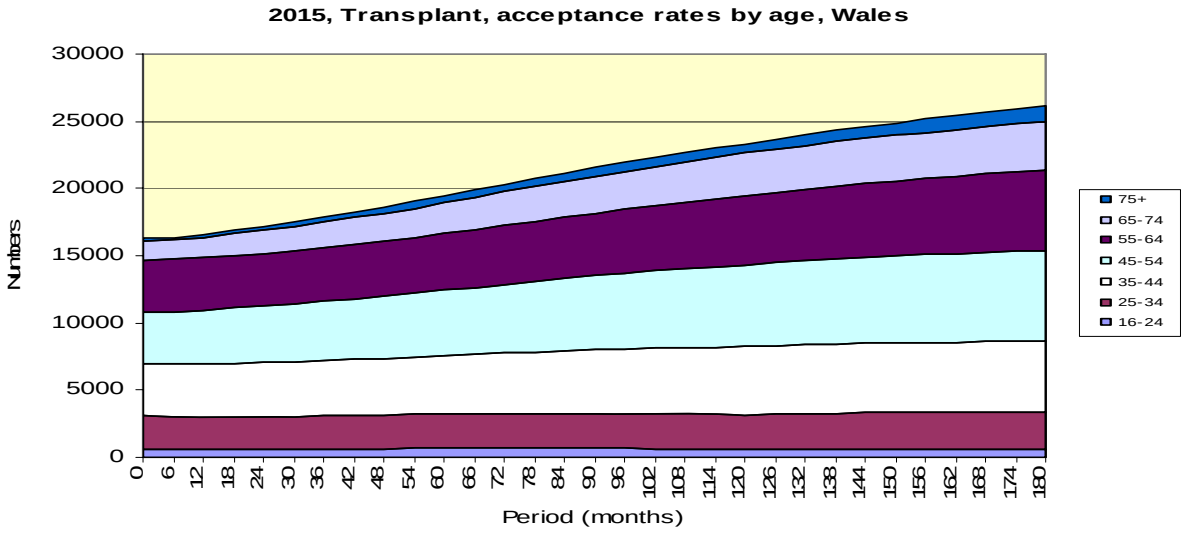
Figures 6.6 and 6.7 show how the age structure changes differently for HD and transplants over a 15 year follow-up, again highlighting the increase in the number of elderly individuals



on HD.

Figure 6.6: Predicted number on HD, by age, up to 2015 for Welsh RS scenarios with pragmatic transplant increase

Figure 6.7: Predicted numbers with transplant, by age, for Welsh RS scenarios with pragmatic transplant increase



The effect of increasing the proportion starting HD where patients have a choice of modality (scenario 8) is to increase the growth rate in HD from 5.9% to 6.5% and the number on HD in 2010 from 18,342 to 19,047, other factors being equal.

Discussion

A previous discrete event simulation model, which was used in the mid-1990s to predict demand for RRT, has been rewritten. It now allows for transfers between HD and PD, includes live transplants and models realistic acceptance rate scenarios that allow for meeting current and future population need to 2010.

The model has a user-friendly Windows interface. Input data may be entered and saved for use in different scenarios. The simulation, now easy to use for national and regional scenarios, may describe the treatment and transfer of thousands of patients, and the output data may be saved on a spreadsheet and analysed using Excel. The parameters have been derived mainly from the UK Renal Registry and UKT.

The scenarios presented so far are the first stage of using the model to evaluate future demand. Others scenarios are being worked on, and more will be possible as new data emerge, not least from the UK Renal Registry as national coverage is achieved.

Impact of changing acceptance rates

Even without any increase in the current acceptance rate, the demand for RRT will continue to rise as a steady state has not yet been reached. Moreover, future population changes alone may increase the incidence of ERF; it is estimated the acceptance rate would change for RR from 94 pmp to 103 pmp, and for RS from 104 pmp to 115 pmp by 2010 as a result of such changes.

A more realistic scenario is, however, that there will be an additional increase in acceptance rate to treat unmet need, which will lead to a large increase in RRT, predominantly caused by an increase in HD, with a commensurate increase in cost. For example, the Welsh acceptance rate scenario with a pragmatic increase in transplant supply predicts, by 2010, a prevalent number of 48,000 patients. The types of patient (in terms of age and diabetic ERF) also change, not, however, in proportion but in absolute number. For the same scenario, the increase in those aged over 65 between 2000 and 2010 would be a doubling from 8,000 to nearly 16,000; the number on HD would increase from about 11,600 to 18,300.

We do not know what future acceptance rates will be. Our estimates are based on the current Welsh rate, and the future need for treatment may prove to be different from that, but the age rates used in the Welsh scenario are similar to those of European countries with high rates (Figure 6.8). We do not currently even know exactly what the current rates are. A clearer picture should emerge from the Registry over the next few years as coverage increases.

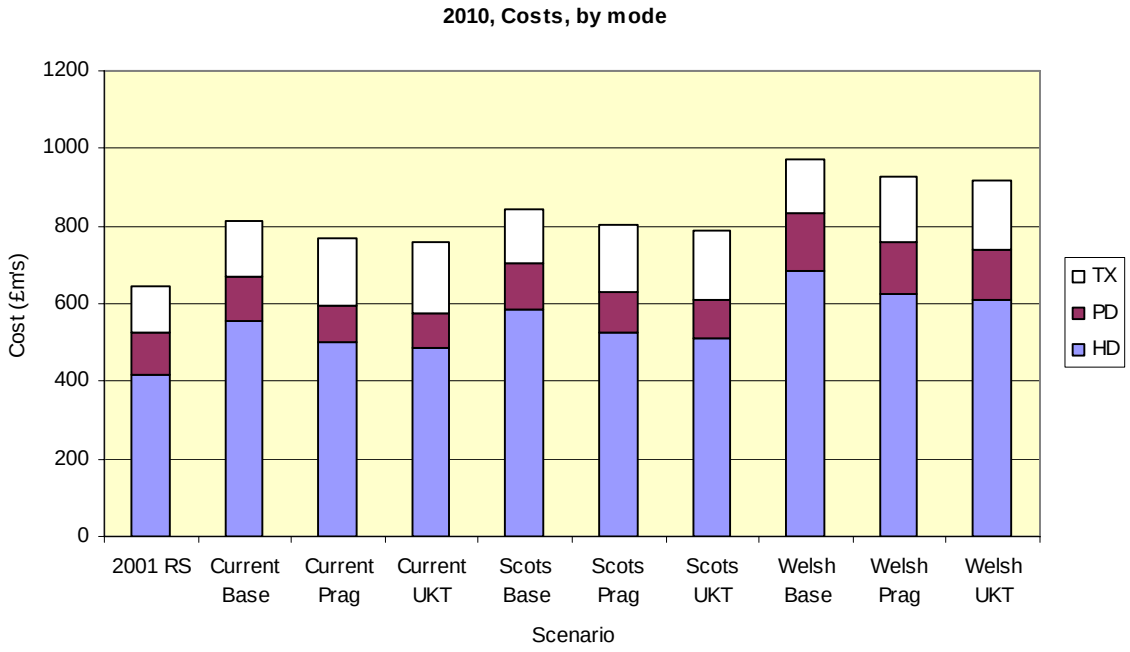


Figure 6.8: Take-on rate pmp by age and country in 2000

Diabetic ERF

There is a substantial variation in the estimated acceptance rate for diabetic ERF in developed countries, from under 10 pmp to over 100 pmp. This is the result of several factors: the variation in the underlying epidemiology of diabetes (largely type II), the effectiveness of the health care system in preventing diabetic nephropathy, referral/acceptance patterns and the classification and coding of diabetic ERF. The Scottish and Welsh acceptance rates increase the diabetic ERF rate from the current 17 pmp seen in England. Furthermore, the estimates take account of the ageing of the population, particularly in the ethnic minority groups, which will cause the amount of diabetic ERF to rise in absolute terms.

It is predicted that there will be a substantial rise in the incidence and prevalence of type II diabetes over the coming decades. The key question is whether the transition to ERF can be prevented or reduced by more effective management and, by implication, whether the rate of diabetic ERF can be reduced, even given this larger pool of diabetic patients. There is good evidence that progression can be reduced by tight glucose control, control of hypertension and specifically the use of angiotensin-converting enzyme inhibitors. Most countries are, however, seeing a rise in the diabetic ERF rate with the increased incidence of diabetes. This, together with the probable unmet need in diabetics, may on balance prevail and drive the ERF rate up. Furthermore, improvements in survival in patients at high risk of death (e.g. by reducing cardiovascular risk) would potentially have a big impact on demand. We have used conservative estimates of the increase in diabetic nephropathy (a 10% increase in all ages); the impact on the total number receiving RRT was minimal at this level, in part because of poorer patient survival in those with diabetic ERF.

Transplant supply

Increasing the transplant supply as targeted by UKT did, as expected, change the number and proportion of patients with a transplant by 2010. The difference between no change and achieving the plan was, for example, a reduction in the proportion on dialysis from 58% to 50% (using Welsh RS scenario 3). Because of the demand from the existing waiting list and the increased input from the rising acceptance rate, organ supply would, however, still be insufficient. Taking the Welsh RS scenario as an example, the transplant waiting list would increase from 4228 to 5224.

The proportions on different modes of therapy are clearly affected by transplant supply. The predominant mode of treatment, even with the transplant increase, would be HD. Reductions in graft failure through the use of more effective immunosuppression would also reduce the proportion on dialysis. The National Institute of Clinical Excellence is reviewing immunosuppression to take account of newer agents such as mycophenolate; again, this issue can be considered using the model.

The model does not currently factor in ethnic minority group directly and therefore has not been able to explore the mismatch between supply and demand for cadaver transplants in this group.

Conclusion

In summary, this national model has demonstrated that there will continue to be substantial growth in the RRT population in England, estimated to be over 45,000 patients by 2010. This is due to several factors:

- an increasing prevalence arising from past changes, even in projecting a constant acceptance rate until a steady state has been reached;
- projections of an increased take-on rate to meet estimated population need in England (using extrapolation from other countries);
- the impact of demographic change;
- the increasing numbers of type II diabetes patients;
- improving patient survival.

The total pool is significantly influenced by the expected acceptance rate. This highlights the importance of implementing strategies to prevent the incidence and progression of chronic kidney disease; the National Service Framework for Renal Disease will begin to address this. There is preliminary evidence from the Scottish Renal Registry that the acceptance rate has flattened after the continuous rises seen in the 1980s and first half of the 1990s. Even so, there is still likely to be a substantial increase in demand even if current acceptance rates do stabilise. Transplant supply does have an impact on the dialysis to transplant ratio, but, even with an optimistic projection of the future supply, there is still likely to be a substantial increase in the demand for HD, especially in the elderly.

Further issues need to be explored: the cost of RRT, changes in patient and mode survival, including the impact of comorbidity, the effect of newer immunosuppressive regimes on graft survival, and the use of acceptance rates from other countries with higher rates.

Given the uncertainty related to several of the parameter estimates, the model needs to take account of new evidence on trends in demographic and outcome data. These should be forthcoming from the UK Renal Registry with the recruitment of all renal units and as more follow-up time is available. The model can be used at regional and sub-regional level, although any difference in local parameters will have to be taken into account.

Acknowledgements

We are very grateful to Professor Dirk Jacobus van Schalkwyk and Dr David Ansell from the UK Renal Registry, and Mr Chris Rudge, Rachel Johnson and Phil Pocock from UK Transplant, for their help with and advice over relevant data. We thank Ron Pisoni from the IDOPPS group for unpublished data on HD survival, and Dr Jon Scoble for national survey data.

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Chapter 7: Adequacy of Haemodialysis (Urea Reduction Ratio)

Summary

- Haemodialysis facilities are still in short supply. Twice-weekly dialysis was used in more than 5% of patients in 38% of renal units, and in more than 20% in 5% of units.

- In 2001, there was only a small improvement from 2000 in the adequacy of dialysis achieved in England & Wales, although there were large changes in some individual units.

- A telephone survey of dialysis units showed that there are diverse post-dialysis sampling methods in current use.

- Thirteen out of 45 dialysis centres surveyed were using one of the three post-dialysis sampling methods for urea measurement that are recommended in the third edition of the Renal Association Standards document.

Haemodialysis frequency

The Standards document states:
'*The frequency of dialysis should be three times per week in the majority of patients. Reduction of dialysis frequency to twice per week because of insufficient dialysis facilities is unacceptable.'*

In a Renal Association survey of all 71 renal units in the UK conducted by Dr John Scoble early in 2002, 10 units (14%) had no patients, and a total of 43 units (62%) had fewer than 5% of patients, dialysing fewer than three times a week (Figure 7.1). Six units had, however, more than 20% of patients dialysing twice weekly, the highest figure being 39%.

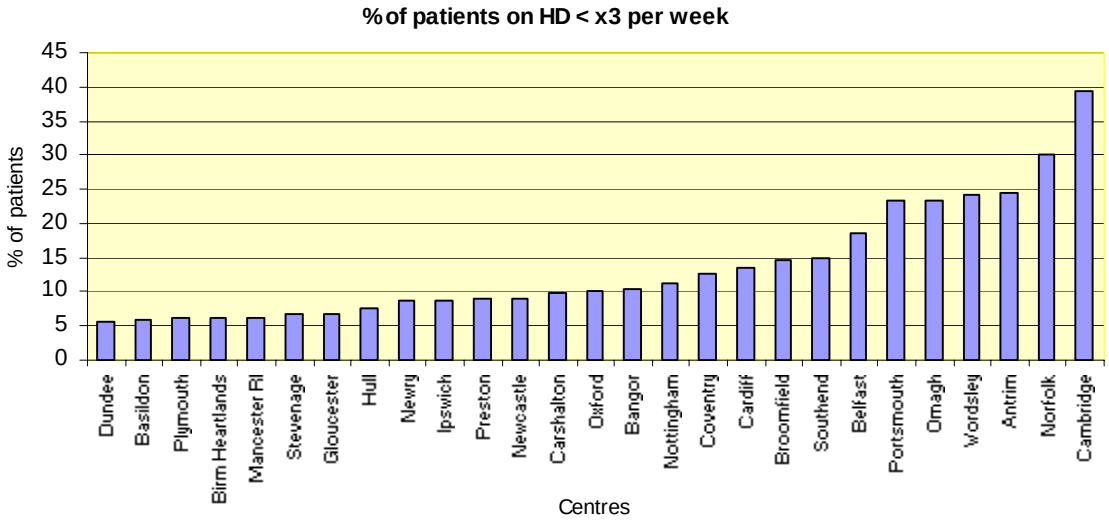


Figure 7.1: Renal units with more than 5% of patients dialysing less than three times / week

In renal units with a severely limited capacity for haemodialysis (HD), one might expect a greater proportion of patients to be on peritoneal dialysis (PD), with a high proportion also on twice-weekly HD. Figure 7.2 shows that there was no obvious relationship between the percentage of patients in a unit on PD and the percentage dialysing twice weekly. Looking at only those centres with more than 15% of patients on twice-weekly dialysis, there is an apparent relationship with the increased use of PD.

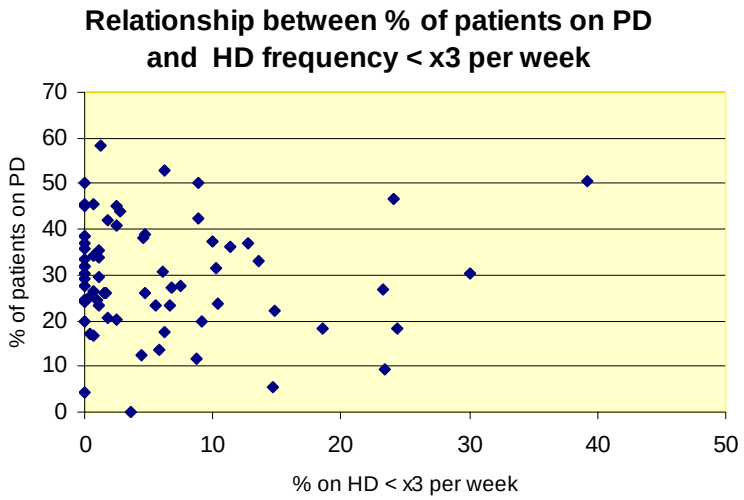


Figure 7.2: Relationship between PD use and percentage on HD less than three times /week

Solute clearance standards

The second edition of the Renal Standards document (SDII) considers both Kt/V and urea reduction ratio (URR) to be indicators of adequacy of HD and recommends that all patients stable on three times a week HD should have:

URR > 65%
or ***Kt/V > 1.2 (dialysis and residual renal function)***

Formulae for calculation of dialysis clearance

Several different methods are in use for calculating Kt/V, these giving results that vary significantly. Some calculations include the contribution from residual renal function and need the collection of post-dialysis blood urea samples from the previous dialysis. Other formulae ignore residual renal function and require, as a minimum, a knowledge of pre- and post-dialysis weights and duration of treatment. To obtain meaningful comparisons, the Renal Registry would need to calculate Kt/V by a single method from the raw data, data that are not currently available from many units. The simpler calculation of URR, the percentage fall in blood urea during a dialysis session, requires only a knowledge of pre- and post-dialysis blood urea level and thus remains the method used by the Registry. This ratio ignores any contribution to clearance by residual renal function or ultrafiltration. Despite the theoretical limitations, URR has been shown to correlate with patient survival (Owen, Held).

Post-dialysis urea samples

Unfortunately, even the apparently simple URR is flawed as a comparator because of the non-uniformity of post-dialysis sampling methods. This was discussed more fully in the 1999 Registry Report, but there appears to have been little progress by renal units in moving towards standardisation or even in using one of the methods recommended in the third edition of the Standards document (SDIII) or by the US organisation Disease Outcomes Quality Initiative (DOQI).

The goal of a reproducible comparison of URR while at the same time calculating valid Kt/V values continues to create debate. It may therefore not be surprising that progress towards standardisation has been slow. The Registry is not mandated for the task of increasing uniformity in sampling methods, but the following short analysis may be useful for highlighting the issues.

Recommended methods for post-dialysis blood sampling

The following three methods are recommended in SDIII. These all differ from the only technique recommended in SDII, which was the one current in 2001.

A. Simplified stop blood flow sampling technique:

- When you are ready to take the sample, turn the blood pump slowly down to 50 mL/min.
- **Start counting to 5**; if the venous pressure alarm has not already stopped the blood pump when you get to 5, stop the pump manually.
- Disconnect the arterial line and take a sample from the needle tubing (or the arterial connector of the catheter) **within 20 seconds** of slowing the blood pump to 50 mL/min.
- If more than one sample is required, the urea sample should be the first one taken, wash back blood, take patient off as normal.

Guidelines developed by EJ Lindley, V Osborne, S Sanasy, D Swales and M Wright, The Leeds Teaching Hospitals NHS Trust.

Timing is **important** in this technique.

B. Slow blood flow sampling technique:

- At the end of dialysis, turn the blood pump down to 100 mL/min.
- Override the alarms to keep the blood flowing.
- **Wait 15–30 seconds** and take samples from the 'A' line sampling post.
- If more than one sample required, the urea should be the first one taken, wash back blood, take patient off as normal.

Guidelines developed by F Gotch and M Keen, Davis Medical Centre, San Francisco, and used since 1990 by the Lister Renal Unit, East & North Herts NHS Trust.

Timing is **important** in this technique.

C. Stop dialysate – continue blood flow method:

- Turn off the dialysate flow, leaving the blood flow unchanged.
- Sample 5 minutes after this from any point in the extracorporeal circuit.

Developed by Drs Mactier, Geddes and Traynor at Stobhill Hospital Glasgow.

Timing is less critical in this technique. It is acceptable to stop the blood flow at 5 minutes and then sample immediately from the 'A' line.

The direct calculation of a 'single-pool' Kt/V with an 'equilibrated' post-dialysis urea level is possible only when blood sampling is deferred to at least 30 minutes after stopping dialysate/blood flow and 'washback'. A peripheral venous blood sample is then adequate. Most centres find this impractical in a busy dialysis unit, and many patients also find the extra wait unacceptable. Derby is the only renal unit included in the Registry that takes such a post-rebound sample. Sampling earlier than 30 minutes will lead to an underestimation of the degree of rebound in blood urea value.

To avoid the 30 minute wait after dialysis has ceased, a series of **early** blood sampling techniques have been developed; samples are taken within 10–30 seconds of stopping or slowing the blood pump in order to abolish access re-circulation. These vary in the sequence of recommended events. The rebound fraction can then be calculated and the results used in urea kinetic modelling (UKM). The variations depend on whether the blood flow is actually stopped (method A) or simply slowed (method B), and on how quickly the sample is taken. In other guidelines, it is recommended that the dialysate flow also be stopped, with a choice of the stop or slow (blood) flow methods (DOQI). The difference between stopping and slowing the blood flow is in the extent to which the desired sample is trapped in the arterial needle tubing or sampled from the circuit arterial port.

There is evidence from work in Scotland that a fixed delay before sampling of less than 30 minutes can give consistent results for the comparison of the URR; this is method C above. Such values may not be suitable for use in rigorous UKM and Kt/V calculations. Such techniques form a family of **late** sampling methods, with a continuation of the blood flow only over a relatively short (5 minute) interval or for the full rebound interval.

Consequences for URR comparison

The effect of 'late' sampling methods will be systematically to raise the measured post-dialysis urea values compared with early sampling methods, and reduce the calculated ratio (URR). Centres using these techniques will appear to have lower dialysis clearance and a lower achievement of the Standard compared with centres using 'early' sampling methods.

Sampling methods in use by renal units

When the Registry surveyed renal units with regard to removing anonymity, several units agreed with this on condition that the post-dialysis sampling technique in use at each centre was detailed. Registry staff subsequently telephoned nurses at all main dialysis units, and many satellites, to identify sampling methodologies. It was anticipated that a maximum of

four or five techniques would be in use, which could then be indicated by different symbols when displaying the URR results for each dialysis unit. A very different situation was, however, discovered, with a multiplicity of sampling techniques in use.

Conduct of the survey

The renal unit data managers, both experienced renal nurses, telephoned each main dialysis unit and each of its satellites and spoke to the most senior nurse available on the day. The following questions were asked:

1. What method do you use for post-dialysis blood sampling?
2. Does your dialysis unit have a policy?
3. Is this method the unit policy?

In some instances, the nurse went to look up the precise unit policy and called back. A total of 32 main dialysis units and 13 satellites were contacted.

It is recognised that a survey such as this may not accurately report the policy of the dialysis unit with respect to post-dialysis sampling as the respondent was not expecting the call, might have been busy at the time and might not have given a carefully considered answer. The answer given by the respondent may also not reflect the practice of many other staff. The survey does, however, highlight an organisational problem and reflects the actual practice of many of the senior staff in dialysis units. A postal survey of renal unit directors might have elicited different policies, but these policies may not necessarily be put into practice much of the time.

The results of this survey will be sent to the clinical director of each unit.

Results of the survey

Table 7.1 indicates the answers given.

	Yes	No	Don't know
Does your unit have a policy?	30	10	5
Do all staff use the same method?	40		5

Table 7.1: Responses to survey questions

With regard to the technique reported by the nurse questioned, no units appeared to be following the recommendation of the Standards document current in 2001. Of the methods defined above, 6 centres used method A, 3 used method B, 3 used method C, and 1 used a 30 minute sample. Centres reporting that they sampled at an unspecified time interval were not included in this total. The list provided in Table 7.2 may be as a source of advice for dialysis units looking to implement one of the three methods in the new Standards document.

Centre	Method
Bradford	Method A
Bristol main unit	Method C
Bristol Weston	Method C
Cambridge	Method B
Carlisle	Method C
Coventry	Method B

Centre	Method
Derby	Sample at 30 minutes
Leicester main unit	Method A
Leicester Lincoln	Method A
Leeds St James	Method A
Plymouth	Method A
Swansea	Method B
York	Method A

Table 7.2: Correct technique

In all the other units, either another technique or a variation of one of the recommended techniques was reported. In many instances, different techniques were reported in main units and their various satellites. A sample of the replies is given in Table 7.3. Venous sampling immediately after dialysis was stopped was reported in many cases: this will give relatively low post-dialysis blood urea values and thus an apparently high dialysis clearance.

Method A sample 1 min
Method B sample immediately
Method B sample after 1 minute
Method B sample after 2 minutes
Method B sample after 5 minutes
Method B Sample after unspecified time
Method B Sample after a 'few' minutes
Method C wait 10 minutes
Stop dialysate stop blood sample immediately (method in use at 15 centres)
Stop dialysate stop blood sample within 2 minutes
Stop dialysate wait 2 minutes. (Full speed blood pump.) Stop pump sample at 10 seconds
Continue dialysate continue blood flow sample

Table 7.3: Non-standard techniques currently in use

Most commonly used was an 'early' technique, misapplied as *stop dialysate, stop blood pump, sample immediately from A needle during wash back.* This was also the recommended technique for all the HD units managed by one commercial company. Measuring post-dialysis urea level in this way will give low urea values, which will tend to exaggerate the calculated adequacy of dialysis.

It is hoped that the publication of these data will help the move towards standardisation.

Interpretation of results

The figures show the achievement compared with the Renal Association Standard for each centre. Each centre on the graph has an abbreviated name (see Appendix D), and the number preceding this is the percentage data missing for the centre.

In the graph of the percentage of patients achieving a URR of over 65%, the centres indicated by a 'closed circle' ● on the data point are using the 'late' sampling methodology, which tends to give lower URR results.

URRs achieved

The median URRs achieved in each renal unit are shown in Figure 7.3; the results from satellite units are included with those from the parent renal unit. Patients who had not been established on HD for at least 3 months were excluded.

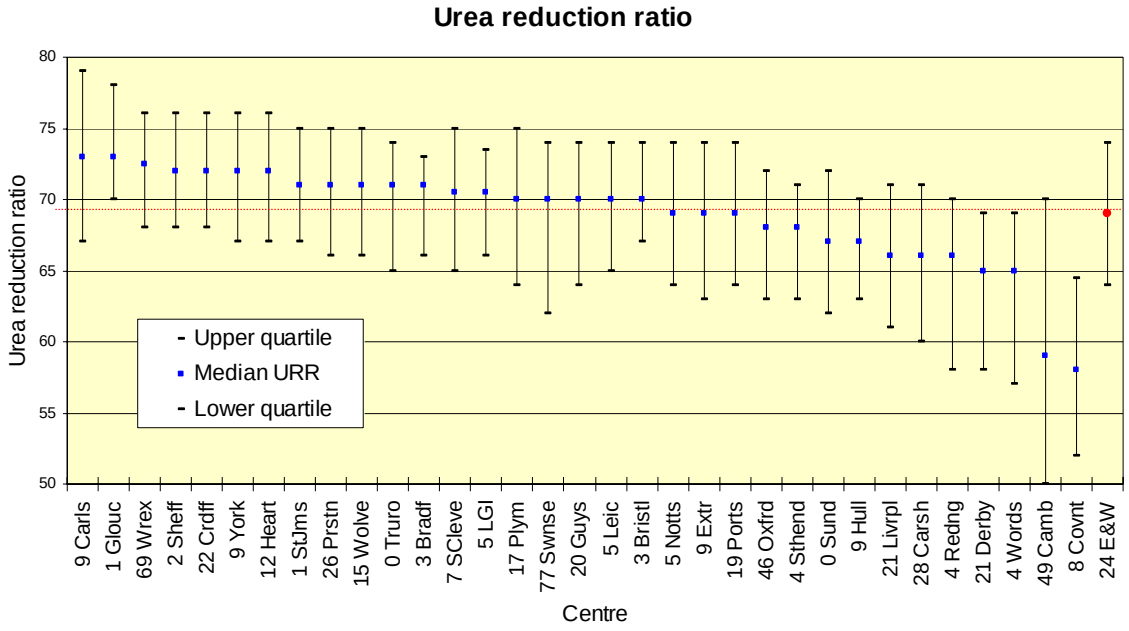


Figure 7.3: Median URR achieved in each renal unit

The high percentage of missing data from Swansea was found to be due to a clerical error in the renal unit's local data entry rather than to a lack of measurement of URR. The post-dialysis urea results had been entered into the pre-dialysis field so it was not possible for the Registry to calculate a valid URR result; the Registry has therefore counted the result as missing. URRs are measured every 3 months at the Swansea unit.

A proportion of the missing data for Wrexham resulted from pre-dialysis samples occurring in sequence after the post-dialysis sample, the local software being unable to correct for this. The software has now been updated to take account of this situation.

Derby is the only renal unit using the 30 minutes post-dialysis blood sample. This leads to a lower URR result than is seen in most other renal units.

The Coventry renal unit has shown an 'apparent' low achievement of dialysis adequacy from 1998 to 2001. Clearances may be low as many patients in Coventry are only receiving 3 hours of dialysis three times a week because of a shortage of facilities. It has, however, been practice in Coventry to collect the post-dialysis urea sample 15 minutes after the end of dialysis (a 'late' method). This will give a higher urea value than most sampling techniques and thus a lower calculated URR. In 2002, the Coventry unit changed to the Renal Association Standard methodology (method B), and the next Registry report will more accurately reflect the dialysis adequacy achieved in this renal unit.

Some units demonstrate a narrow quartile range, whereas in others it is wide, which suggests that some units have more effective procedures for monitoring URR and/or implementing therapeutic change. This is further illustrated in Figure 7.4.

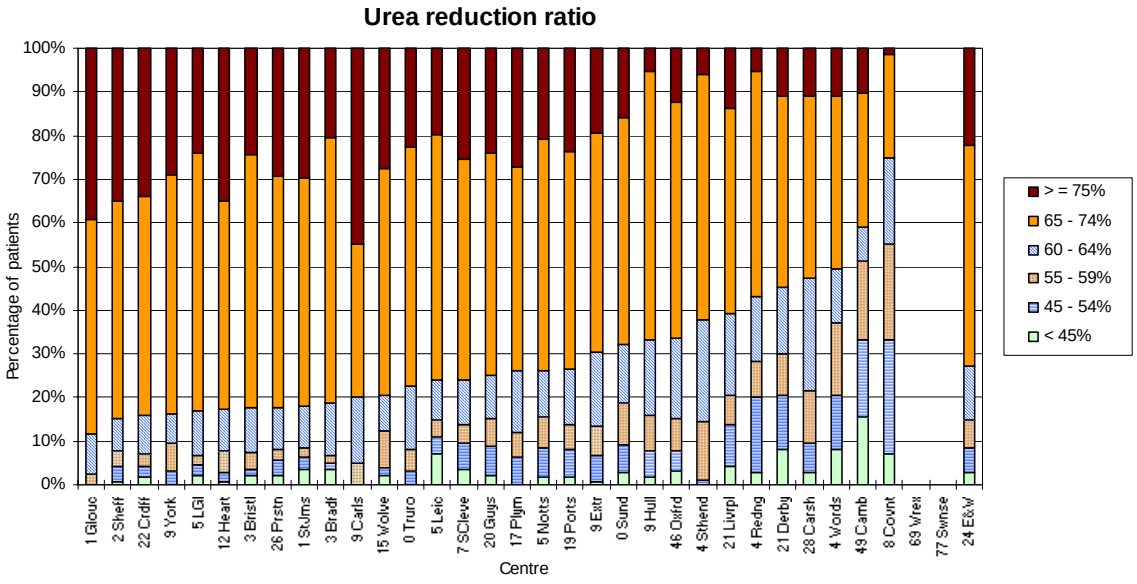


Figure 7.4: URR distribution, by centre

One effect of differing ranges of URR results between units is illustrated in Figure 7.5, which shows the percentage of patients in each unit achieving the recommended Standard for URR. When Figure 7.5 is compared with Figure 7.3, some of the units with an 'average' median URR have a relatively high attainment of the Standard as the quartile range is narrow, and relatively few patients fall below the Standard. Although two centres using the 'late' sampling methodology achieved a result below the average for England & Wales, there were also three centres with above-average results.

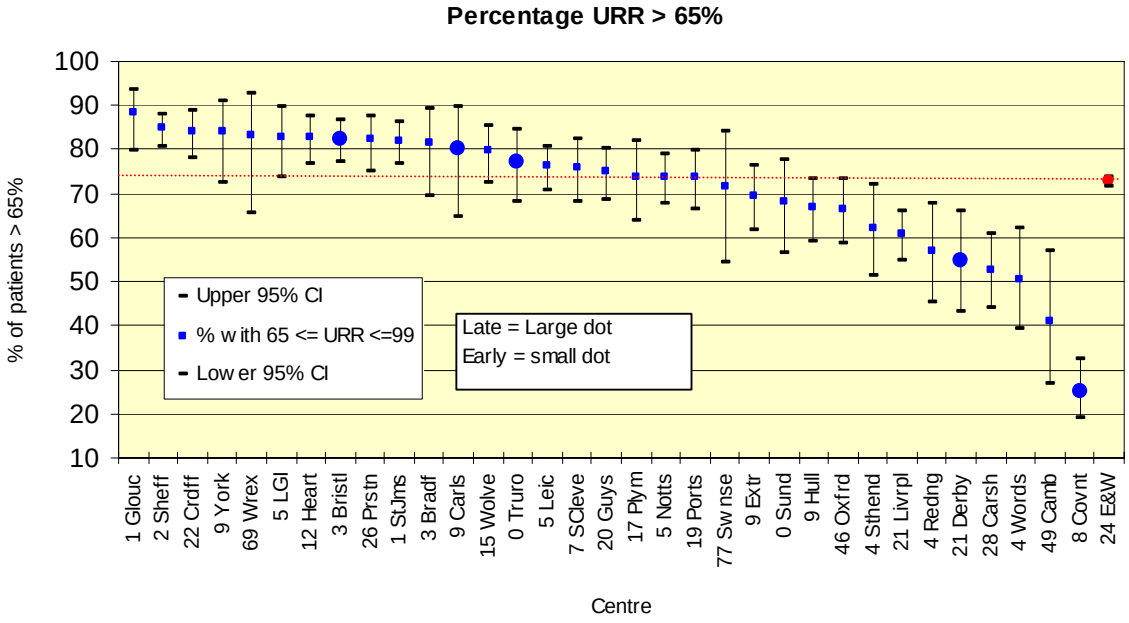


Figure 7.5: % patients, by centre, with a URR of 65% or more in the last quarter of 2001

Changes in meeting the URR Standard during 2001

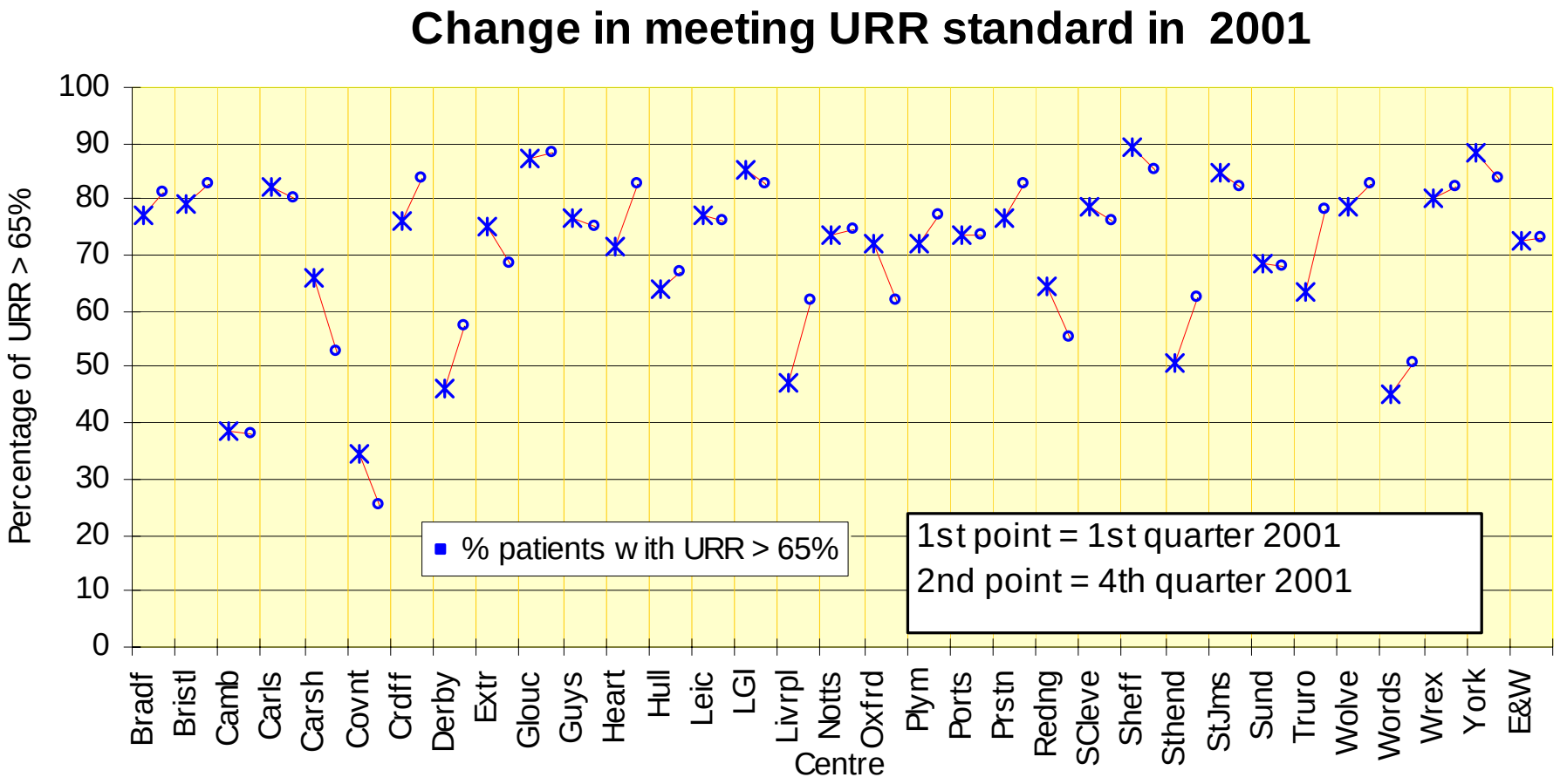


Figure 7.6: Change in meeting the URR Standard in 2001

The change in the percentage of patients achieving the recommended Standard for URR in each participating renal unit from the first to the last quarter of 2001 is shown in Figure 7.6.

Change in achievement of URR Standard during 1997–2001

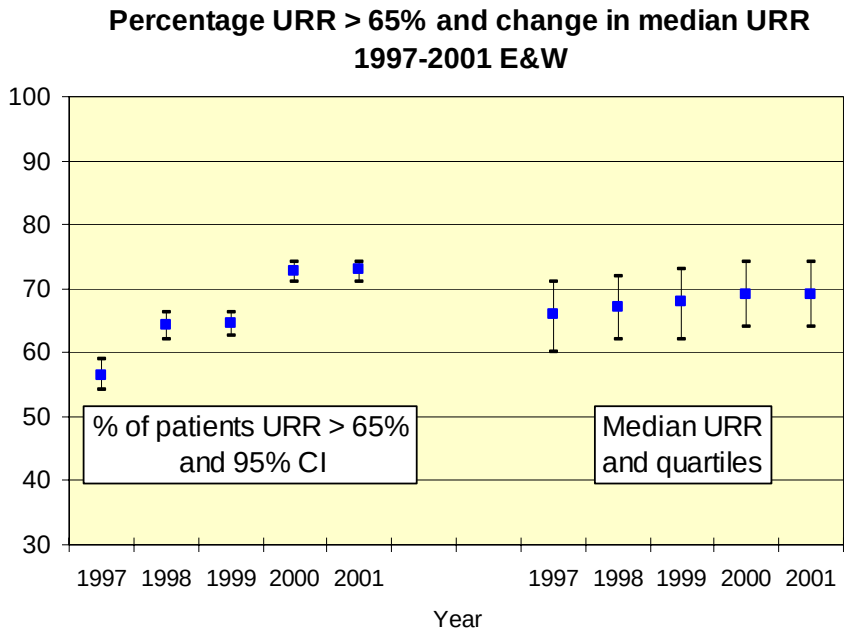


Figure 7.7: % URR over 65% and change in median URR 1997–2001, England & Wales

In the past 4 years in England & Wales, there has been a substantial rise in the percentage of patients achieving a URR of over 65%, to the current level of 72% (n=4426 in 2001, n=3280 in 2000, n=2560 in 1999 and n=2405 in 1998), but there was only a small improvement in the achievement of dialysis adequacy during 2001 (Figures 7.6 and 7.7). The median URR in England & Wales was 69% at the end of 2001. The England & Wales results appear to be less satisfactory than those from the USA, where 82% of patients achieve the recommended URR, with a median URR of 71.4% (sample size 8416).[1] The US department of the Veterans Health Administration reported separately and showed results more similar to those from England & Wales: only 75% of their patients achieved a URR of over 65%, with a median URR of 69.5% (sample size 1759). The standardisation of post-dialysis sampling may have been more successful in the USA.[1]

The improvement in attainment of the URR Standard in England & Wales from 1997 to 2000 looks impressive (Figure 7.7), but some caution must be used in interpretation as there is an increasing number of renal units each year, and thus different renal units included. That the improvement is real is suggested by the significant improvement in performance of participating units when sequential data are analysed for each individual renal unit (Figure 7.8).

Large changes are likely to depend on the systematic use of larger dialysers or a rationalisation of dialysis duration. The consistency shown by some units may be due to application of protocols while centres showing variation on a year-to-year basis may be working less systematically.

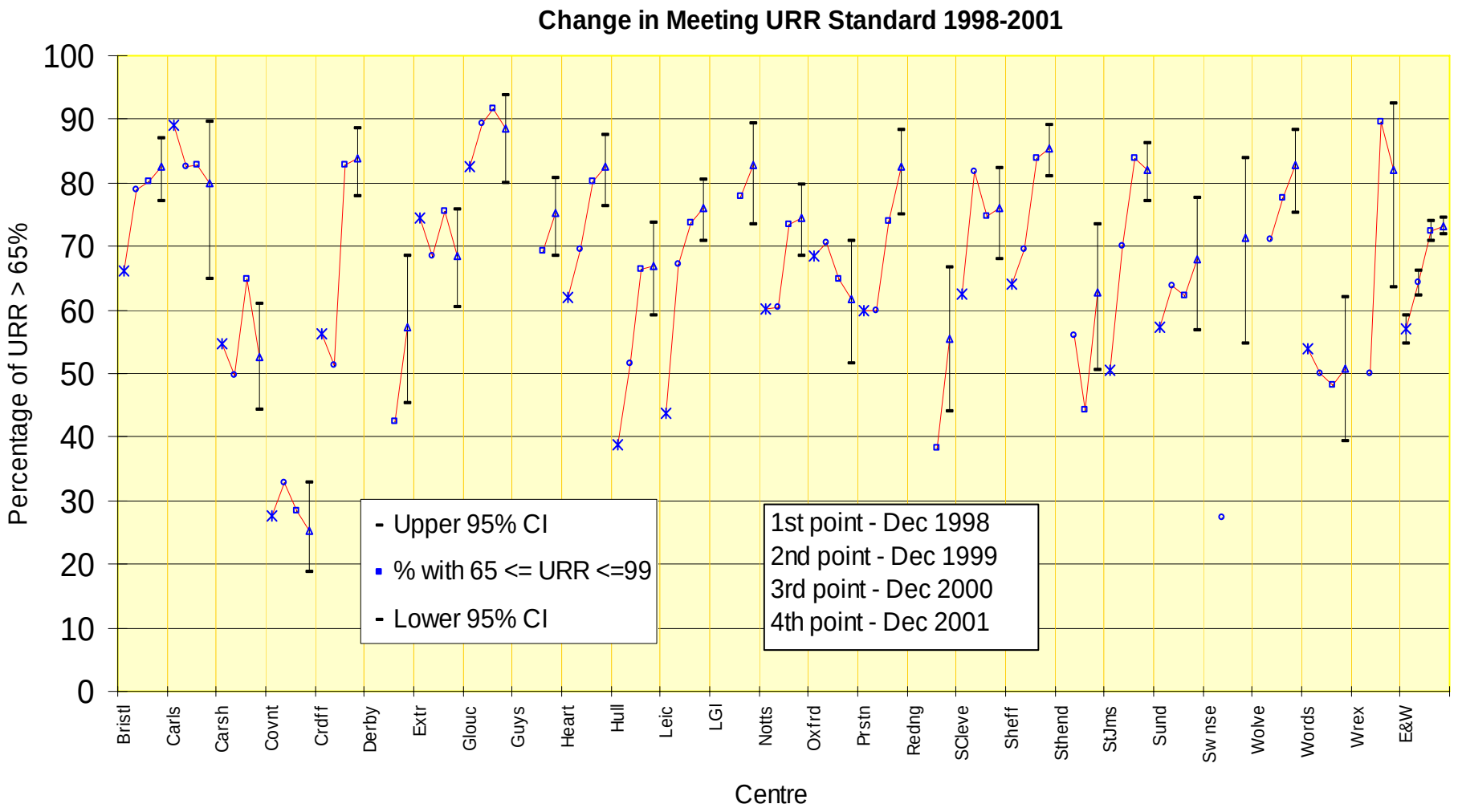


Figure 7.8: Change in meeting URR Standard in 2001

The median URR in England & Wales is 69%. Because of the steepness of the distribution curve around this point, there need only be a small change in median URR to achieve a large change in achievement of the Standard, as is illustrated in Figure 7.9.

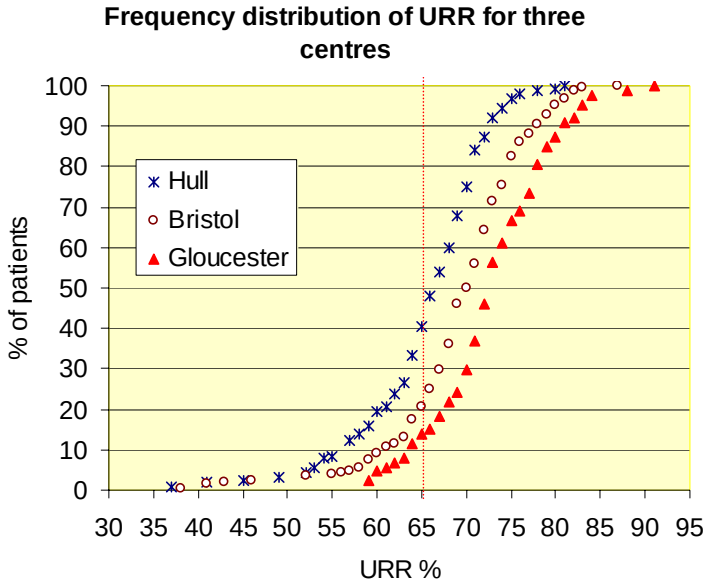


Figure 7.9: Frequency distribution of URRs for three centres

In Figure 7.10, the predictive line of identity between the achievement of URR and the median is identical to that calculated in the last report using data from 2000. The US data sit on the England & Wales predictive line of identity, which this indicates that distributions of data and working practice in the two countries may have close similarities. The previous comments on the necessary outcome median values (overachieved) to reach Standard recommendations remain valid.

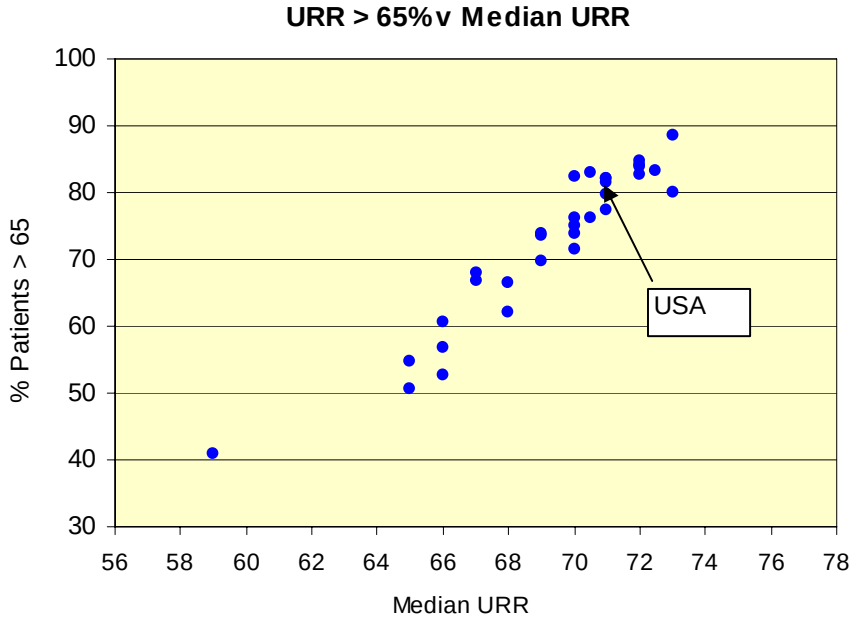


Figure 7.10: URR achievement and median URR at each renal unit

URR in new renal replacement therapy patients starting HD

The URR results for patients in the first 3 months of HD are shown in Figure 7.11.

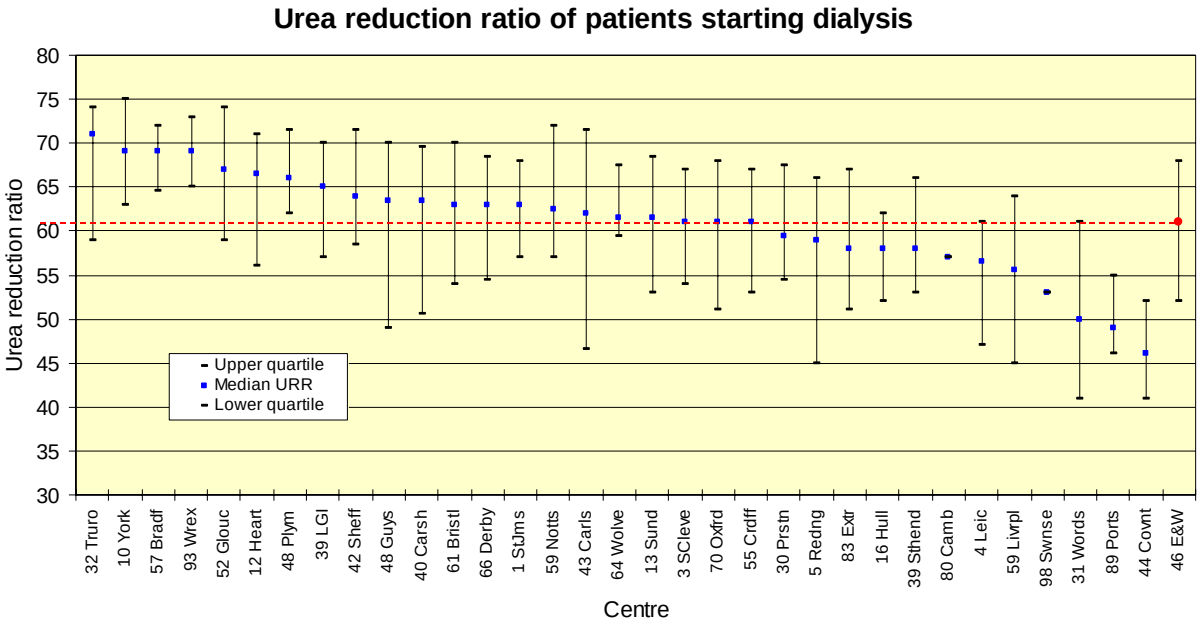


Figure 7.11: Median URR in each dialysis centre within the first 3 months of HD

As reported before, URRs were lower in patients starting HD than in other HD patients at the same unit who had been established on HD for at least 3 months. This may in part be due to initial uncertainties related to the appropriate dialysis prescription for each individual and to its subsequent modification. The International Dialysis Outcomes and Practice Patterns Study vascular access research shows that the UK has a high percentage of patients starting dialysis using central lines: these provide lower clearances than fistulae because of a combination of lower flow rate and increased recirculation. It is also likely that patients who are starting renal replacement therapy (RRT) for the first time have a degree of residual renal function and do not need such a high dialysis clearance. The number of units measuring residual renal function and combined Kt/V is unknown.

Figure 7.12 shows that, at later treatment periods, an increasing proportion of patients remaining on HD have a URR above 65%. The median URR is 64% at 3 months and 69% at 2 years. These data do not indicate that the URRs of individuals remaining on HD necessarily increase. At each time point, these are different cohorts of patients. As discussed in last year's report, those who survived and remained on HD might initially have had higher URRs than those who died or transferred to another modality. To investigate this, the Registry has analysed the URRs of HD technique survivors compared with non-survivors.

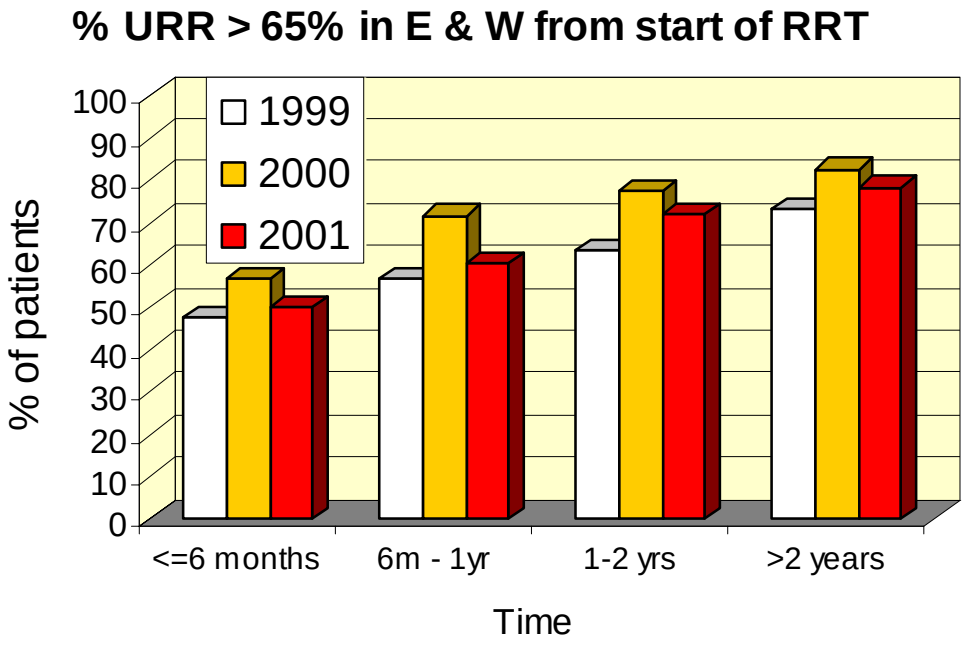


Figure 7.12: Change in URR by length of time on RRT in 1999–2001

This figure shows 'cross-sectional' results for all patients at the year-end on dialysis for the specified time since the start of RRT.

Analysis of URR in the 1999 incident cohort: 2 year survivors versus non-survivors

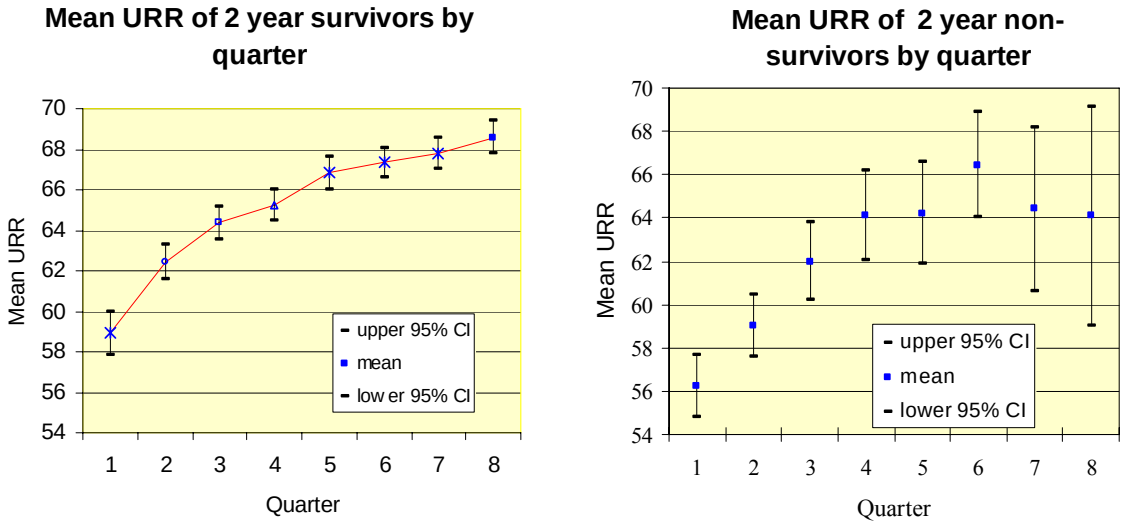


Figure 7.13: Mean URR, survivors versus non-survivors

All patients starting RRT on HD in 1999 (n=1281) were included in this analysis, of whom 473 died within 2 years. The URR was monitored from the time of starting RRT. Data were not available for every patient each quarter. As all patients died in the non-survivor group, there are fewer readings in this group in each sequential quarter: with only 33 alive in the last (eighth) quarter, there are wide confidence intervals.

In the left-hand panel of Figure 7.13, the mean sequential URR over 2 years is shown for 'survivors'. This clearly demonstrates that the mean URR has risen on a quarterly basis for the same patient cohort. Part of this rise is due to the overall rise in dialysis adequacy for all prevalent patients in this period. The patients who died within the first 2 years (right-hand panel, Figure 7.13) had a significantly lower URR than the survivors in the first 6 months (two quarters) only.

These data indicate that those patients who die within the first 6 months are probably a separate clinical cohort from the survivors and are have lower URRs. These data are also consistent with the high death rates shown by the Registry in the first 4–5 months of starting RRT. It is not suggested that the lower URRs in this group are a causal factor in their death. More probably they reflect patients with more comorbidity, especially cardiovascular, who also may more frequently have temporary lines.

Conclusion

The URRs achieved in the UK in the past 4 years have increased, although this increase is slowing and these results are still lower than those obtained from the USA. These data show a marked variation between renal centres, but how much of this is due to a variation between methods of post-dialysis urea sampling is unknown. Through highlighting in this report the diverse sampling methods in current use, it is hoped to encourage centres to introduce an approved method. The consistency shown by some units may result from the application of protocols, whereas centres showing variation on a year-to-year basis may be working less systematically. The easy treatment gain of moving all patients to larger dialysers can only be made once, and further improvement is likely to be more difficult to achieve. Some centres with a low achievement of the recommended URR Standard have indicated that this is because of a severe limitation of resources, especially HD facilities.

References

1. Centre for Medicare and Medicaid Services. *Report Title Here Please*. Place of publication: CMMS, 2001.

Chapter 8: Haemoglobin

Summary

- There is continued improvement in anaemia management in centres submitting data to the Registry, 81% of haemodialysis and 86% of peritoneal dialysis patients achieving the haemoglobin Standard of over 10 g/dL (mean haemoglobin 11.3 and 11.8 g/dL respectively).

- An analysis of haemoglobin and survival indicated a significantly increased risk of death for patients with a haemoglobin level of less than 10g/dL when compared with one of 10–10.9 g/dL. Survival was also improved in patients achieving a haemoglobin greater than 11 g/dL when compared with one of 10–10.9 g/dL.

- Haemoglobin level prior to start of renal replacement therapy has been increasing over the past 3 years, possibly because of an increase in the use of erythropoietin prior to starting therapy.

- Patients who started renal replacement therapy with peritoneal dialysis had higher haemoglobin levels on starting treatment than those treated with haemodialysis, indicating a selection bias.

Introduction

This chapter describes the position at the end of 2001 for all renal centres in England & Wales that report data to the Registry. There are Renal Association, European and US Kidney Disease Outcomes Quality Initiative (K/DOQI) guidelines established for the management of renal anaemia.

The second edition of the Renal Association Standards document, published in 1997, recommends that:
'a target haemoglobin concentration of 10g/dl should be achieved in 85% of patients after 3 months on dialysis'.

European best practice guidelines recommend:
'the target is that ≥85% of the patient population should have a haemoglobin concentration of >11 g/dl'.

The US K/DOQI guideline states:
'The target range for haemoglobin (haematocrit) should be 11 g/dl (33%) to 12 g/dl (36%).'

The third edition of the Renal Association Standards document (SDIII), published in 2002, again recommends the target of 10 g/dL but suggests that the 85% target should apply after 6 months on dialysis.

Inclusion criteria

Patients treated with dialysis at some time during the last quarter of 2001 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 reading from each patient in the last quarter of 2001 was used in the analysis.

Haemoglobin achievement by dialysis units

The data describing haemoglobin distribution in each centre are presented in Table 8.1 for haemodialysis (HD) and Table 8.2 for peritoneal dialysis (PD), and Figures 8.1–8.6. This year, the 70% quantile around the median (excluding the upper 15% and lower 15%) has been included as it is broad enough to demonstrate differences between centres but excludes outliers. It provides an additional indication of the proximity to achievement of the Renal Association Standard (85% of patients). Additional information on quartile range, 90% range, mean and standard deviation is presented in Appendix F.

Centre	% Data return	Median Hb (g/dL)	90% Range	70% Quantile	Mean Hb (g/dL)	Standard deviation	% with Hb ≥10	% with Hb ≥11
Bradf	100	11.8	8.9–13.9	10.3–12.6	11.5	1.7	86	65
Bristl	100	11.3	8.6–13.7	10.3–12.4	11.2	1.6	79	59
Camb	85	10.9	8.0–13.5	9.7–12.1	10.9	1.6	73	49
Carls	96	11.3	8.4–12.6	10.4–12.2	11.1	1.3	81	65
Carsh	88	11.3	9.0–14.2	10.3–12.3	11.4	1.6	83	60
Covnt	99	11.2	8.5–13.4	10.2–12.2	11.1	1.5	81	58
Crdff	96	12.1	9.5–14.4	11.0–13.1	12.0	1.6	91	77
Derby	85	10.4	7.8–13.0	9.7–11.8	10.4	1.6	67	37
Extr	100	11.5	9.2–14.0	10.6–12.3	11.5	1.4	85	64
Glouc	100	11.4	7.7–13.5	9.8–12.2	11.0	1.7	73	56
Guys	89	10.7	8.4–13.2	9.7–11.9	10.8	1.6	69	45
Heart	87	10.6	8.0–12.8	9.5–11.5	10.5	1.5	64	40
Hull	96	10.8	8.4–13.0	9.9–11.7	10.8	1.5	75	47
Leic	98	11.4	9.0–14.1	10.3–12.5	11.4	1.6	83	62
LGI	97	11.8	8.5–14.3	10.3–12.9	11.6	1.8	83	65
Livrpl	89	11.6	8.4–14.9	10.3–12.9	12.0	6.9	81	63
Notts	96	11.2	9.0–14.2	10.2–12.1	11.2	1.6	81	58
Oxfrd	99	11.3	8.7–13.6	10.2–12.3	11.3	1.5	80	59
Plym	91	11.5	9.1–14.6	10.6–13.0	11.7	1.6	87	67
Ports	91	11.4	8.3–14.2	10.2–12.7	11.3	1.8	80	57
Prstn	92	11.6	8.6–14.2	10.4–12.7	11.5	1.7	84	63
Redng	99	12.0	9.5–14.8	10.6–13.0	11.9	1.5	92	71
S Cleve	97	11.5	7.7–14.1	10.3–12.4	11.3	1.9	79	63
Sheff	94	10.9	8.5–13.0	10.1–11.8	10.9	1.4	76	49
Stevn	98	11.4	8.6–13.4	10.4–12.3	11.3	1.4	86	63
Sthend	100	12.0	9.7–14.0	11.15–12.8	12.0	1.3	94	81
St Jms	100	11.9	9.2–14.3	10.8–13.0	11.8	1.5	88	72
Sund	100	10.5	8.3–13.5	9.6–12.0	10.7	1.7	67	46
Swnse	86	11.1	8.7–13.6	10.1–11.9	11.1	1.5	77	54
Truro	80	11.3	9.0–12.4	10.5–11.9	11.2	1.1	91	62

Centre	% Data return	Median Hb (g/dL)	90% Range	70% Quantile	Mean Hb (g/dL)	Standard deviation	% with Hb ≥10	% with Hb ≥11
Wolve	99	11.9	9.1–14.7	10.8–12.8	11.9	1.7	88	71
Words	100	11.0	8.7–13.5	10.1–12.1	11.0	1.4	82	51
Wrex	84	11.8	8.6–13.6	10.5–12.7	11.5	1.6	84	67
York	96	12.0	10.1–14.1	11.2–13.1	12.1	1.4	95	82
Eng	94	11.3	8.6–13.9	10.2–12.3	11.3	2.3	80	59
Wls	91	11.7	8.9–14.3	10.6–12.8	11.7	1.6	85	68
E&W	94	11.3	8.6–13.9	10.3–12.4	11.3	2.3	81	60

Table 8.1: Haemoglobin data for patients on haemodialysis

Centre	% Data return	Median Hb (g/dL)	90% Range	Quantile range	Mean Hb (g/dL)	Standard deviation	% with Hb ≥10	% with Hb ≥11
Bradf	100	12.5	9.6–15.0	11.4–13.8	12.4	1.6	95	84
Bristl	100	12.0	9.4–14.5	11.0–13.2	12.0	1.5	93	76
Camb	98	11.4	8.7–14.2	10.4–12.6	11.4	1.6	83	64
Carls	100	11.5	9.1–13.4	10.5–13.0	11.6	1.7	79	63
Carsh	99	11.9	9.4–15.1	11.2–12.9	12.0	1.6	93	79
Covnt	94	11.3	9.2–14.0	10.3–12.4	11.4	1.6	84	60
Crdff	97	11.9	9.0–14.5	10.9–12.8	11.9	1.7	89	75
Derby	95	11.6	8.9–13.5	10.8–12.7	11.5	1.6	87	72
Extr	100	11.5	9.1–13.9	10.5–12.5	11.6	1.6	91	64
Glouc	94	11.3	8.9–13.4	10.0–12.2	11.2	1.6	77	65
Guys	99	11.8	8.9–14.2	10.8–12.8	11.7	1.7	86	70
Heart	94	11.5	8.4–13.4	10.1–12.8	11.4	1.6	75	63
Hull	97	11.0	8.3–13.9	10.0–11.8	11.0	1.7	76	51
Leic	99	11.7	9.1–14.0	10.65–12.7	11.7	1.6	86	68
LGI	96	12.9	9.4–15.4	12.0–13.6	12.7	1.7	93	87
Livrpl	93	12.2	8.4–14.6	11.0–13.0	11.9	1.8	85	76
Notts	96	11.3	9.3–13.6	10.3–12.4	11.4	1.5	82	58
Oxfrd	100	11.7	8.9–14.4	10.5–12.8	11.6	1.7	86	67
Plym	100	12.3	10.0–14.6	11.4–13.3	12.3	1.4	96	83
Ports	87	11.6	8.6–14.6	10.1–13.0	11.6	1.9	79	63
Prstn	99	11.7	8.9–15.1	10.35–13.1	11.8	1.9	85	65
Redng	100	11.9	8.6–14.4	10.3–13.0	11.7	1.7	83	68
SCleve	100	12.5	9.4–15.7	10.8–13.7	12.4	1.8	95	72
Sheff	98	11.3	8.8–13.9	10.1–12.3	11.3	1.8	80	56
Stevn	97	12.0	8.0–14.9	10.9–13.0	11.8	1.7	88	71
Sthend	100	11.8	9.5–15.9	11.0–12.6	12.1	1.6	93	79
StJms	100	12.3	9.7–14.5	11.9–13.1	12.4	1.3	93	88
Sund	100	11.7	9.8–15.4	10.9–12.5	11.9	1.6	93	73
Swnse	95	11.9	9.1–14.3	11.0–13.3	11.9	1.7	90	77
Truro	62	11.3	8.1–13.0	10.6–12.3	11.3	1.3	83	72
Wolve	100	12.4	9.1–14.3	11.25–13.4	12.2	1.7	88	82
Words	100	11.8	9.2–13.9	10.9–12.6	11.7	1.4	87	72
Wrex	94	12.5	11.0–14.7	11.8–13.3	12.6	1.2	98	96
York	100	12.3	9.8–14.0	11.3–13.3	12.3	1.4	91	86
Eng	97	11.8	9.0–14.4	10.6–12.9	11.7	1.7	86	69
Wls	96	12.0	9.2–14.6	11.1–13.1	12.0	1.6	91	79
E&W	97	11.8	9.0–14.4	10.7–12.9	11.8	1.7	86	70

Table 8.2: Haemoglobin data for patients on PD

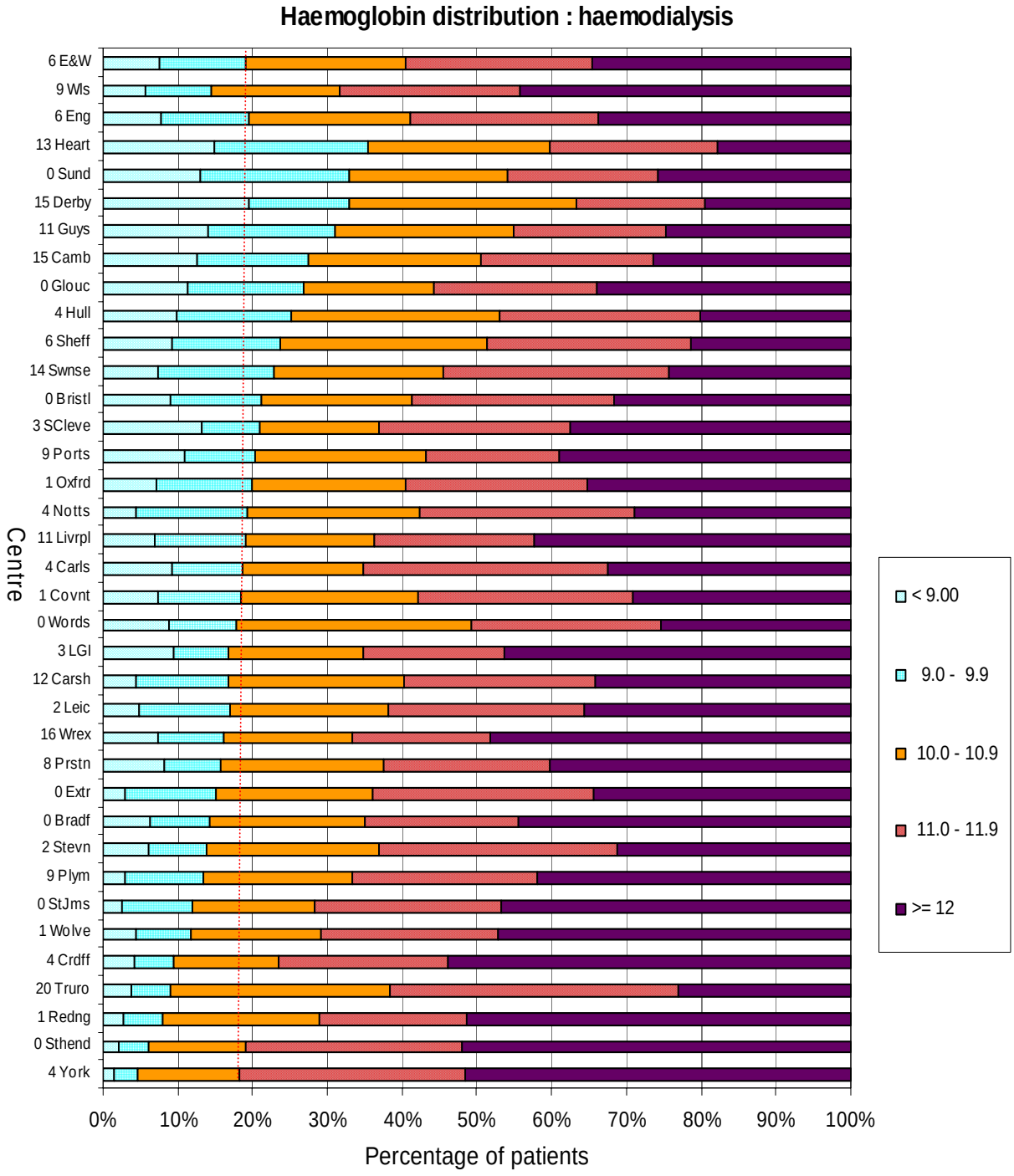


Figure 8.1: Distribution of haemoglobin in patients treated with HD

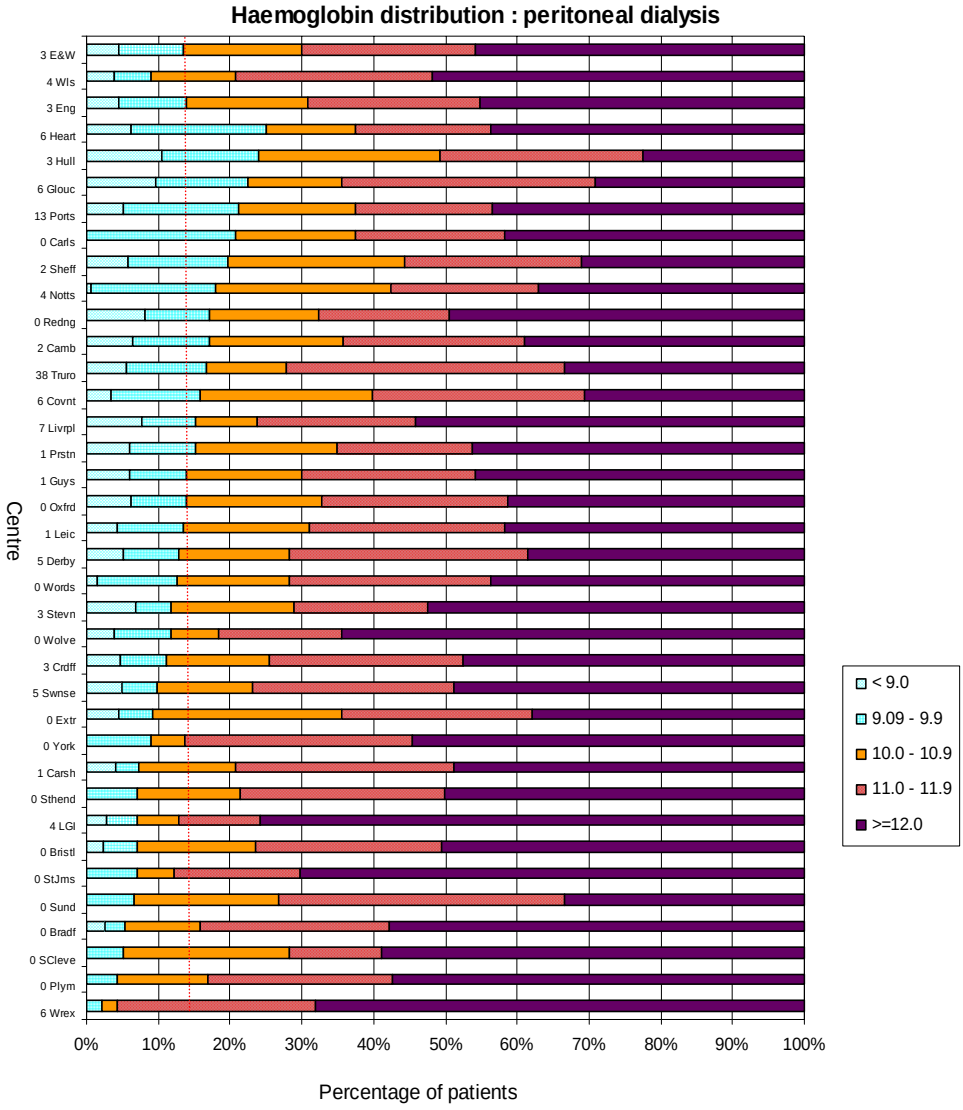


Figure 8.2: Distribution of haemoglobin for patients on PD, by 1 g/dL bands

The proportion of centres achieving the Renal Association Standard for haemoglobin in patients treated with HD (five centres of 27 in 2000, 13 centres of 34 in 2001) has continued to rise. In a further eight centres, the Standard falls within the 95% confidence interval. The proportion of centres achieving the Standard for PD shows little change (19 centres of 27 in 2000, 23 centres of 34 in 2001), but the 95% confidence interval included 85% of patients with a haemoglobin level of 10 g/dL or more in all centres. For HD, 81% of all patients treated in centres reporting to the Renal Registry had a haemoglobin of 10 g/dL or more, the equivalent figure for PD being 86%.

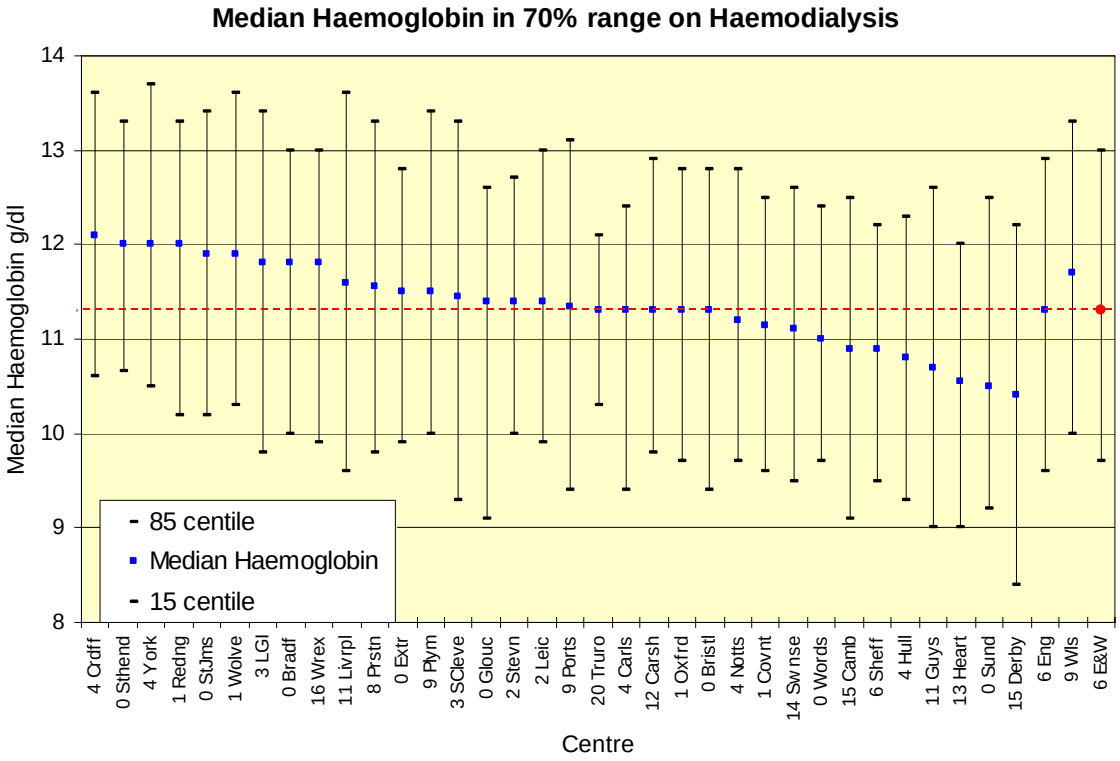


Figure 8.3: Haemoglobin median and 70% range for HD patients

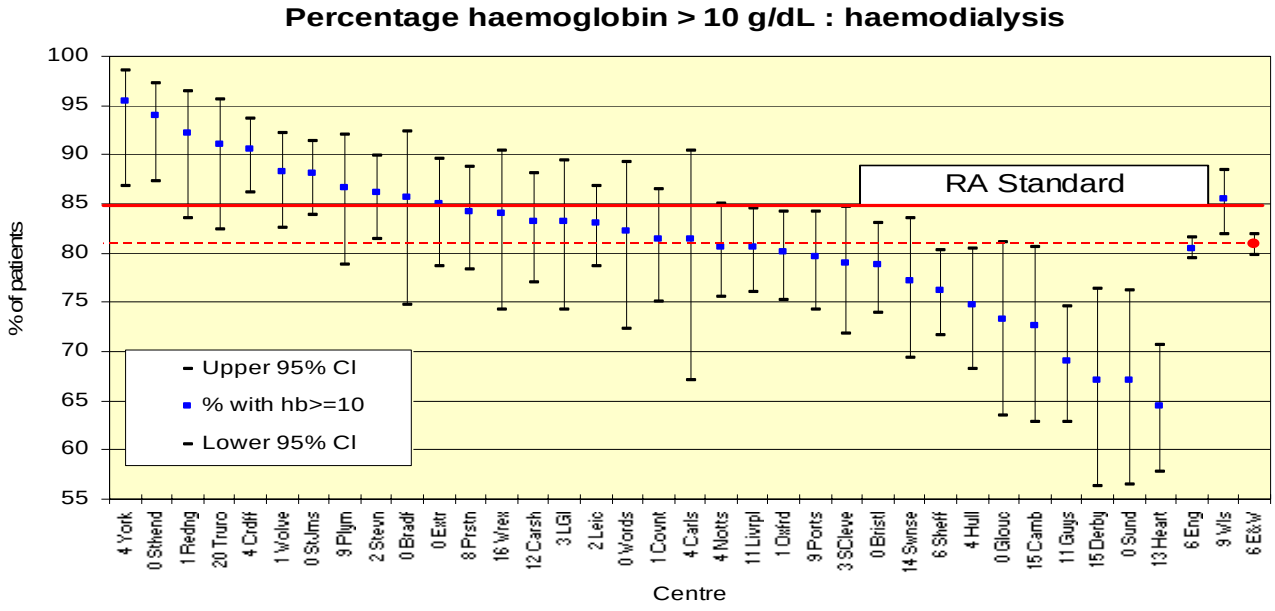


Figure 8.4: Percentage of HD patients, by centre, achieving the Renal Association Standard

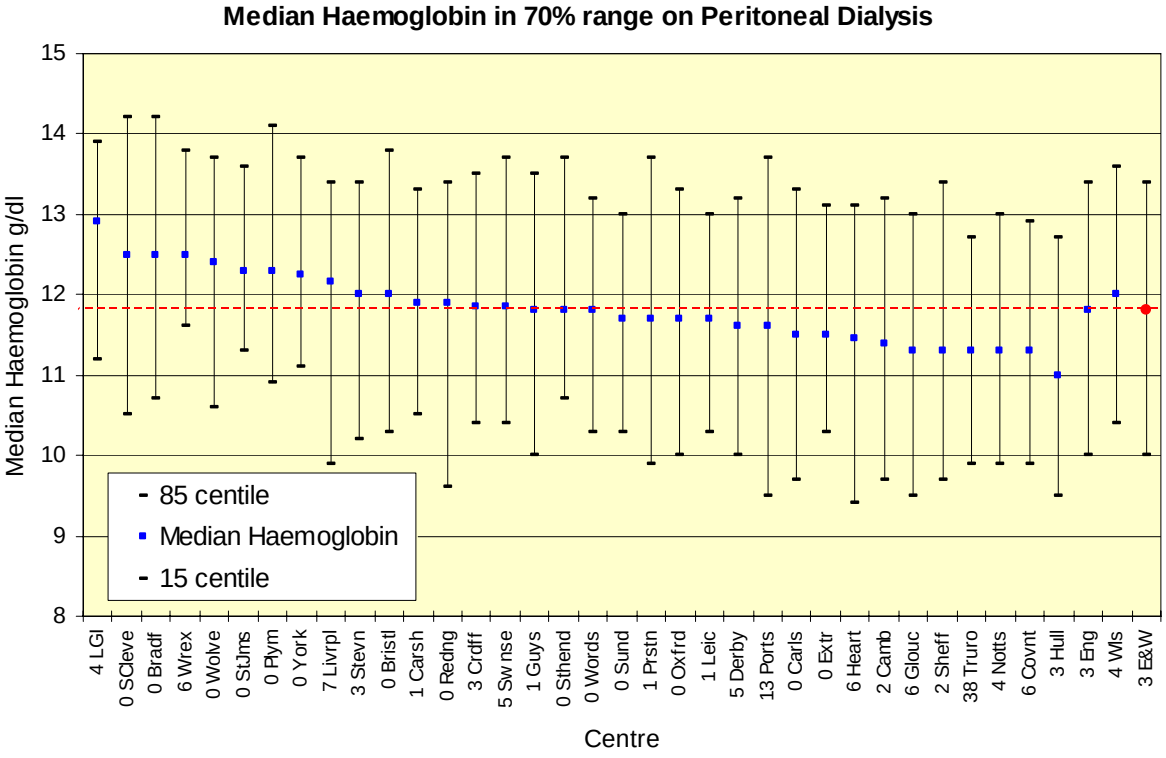


Figure 8.5: Haemoglobin median and 70% range for PD patients

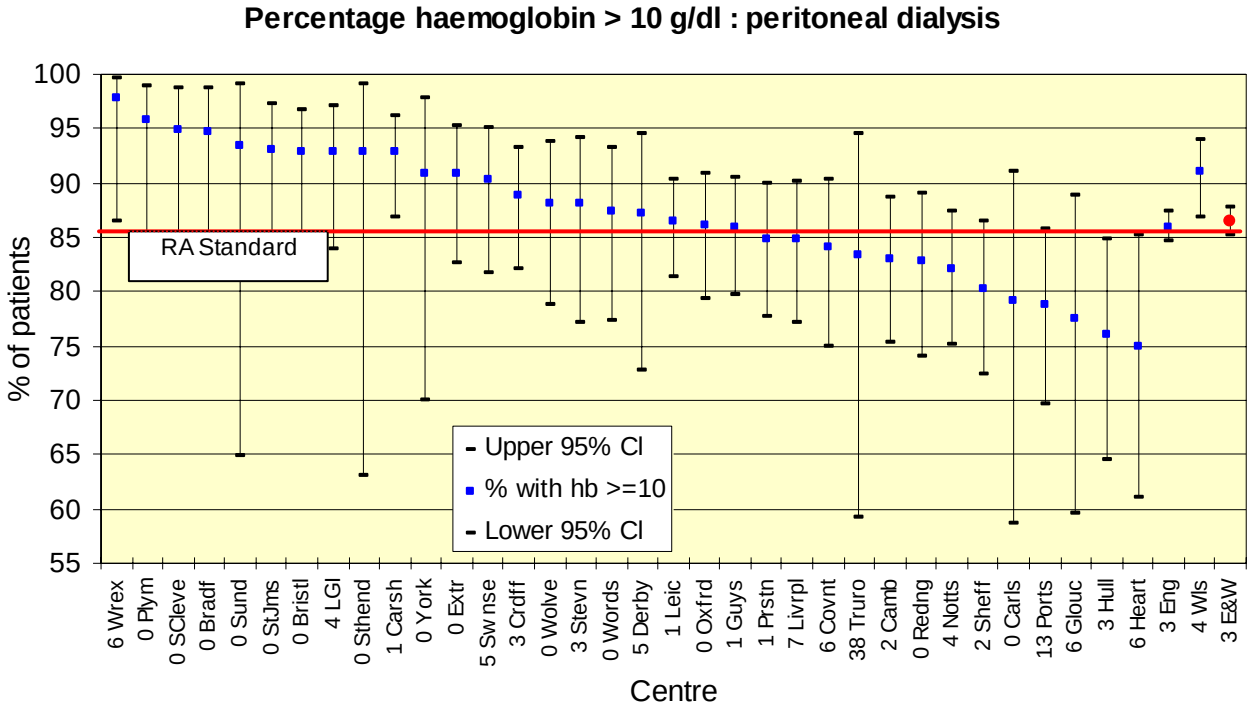


Figure 8.6: Percentage of PD patients, by centre, achieving the Renal Association Standard

The correction of anaemia in dialysed patients has improved considerably over the past 4 years, but the extent to which this has occurred varies from one centre to another. More than

30% of HD patients in four centres have a haemoglobin level of less than 10 g/dL, and in one of these centres, PD patients also have low haemoglobin readings. In the other three centres, the distribution of haemoglobin for PD patients is closer to the overall median for England & Wales. This may reflect differences in the management of anaemia in HD and PD in these centres or patient for each mode of dialysis. In Sunderland, for example, where the majority (85%) of patients are treated with HD, 67% of HD patients and 93% of PD patients have a haemoglobin level of more than 10 g/dL. This may reflect a selection bias that ensures a good haemoglobin value in PD patients.

The optimum management of renal anaemia could be described as the achievement of target haemoglobin in the maximum number of patients with the minimum use of expensive drugs such as intravenous iron or erythropoietin. Efficient management may be inferred by a high achievement of the Renal Association target haemoglobin with a low median haemoglobin. A narrow spread of haemoglobin would be expected in those centres which have a successful targeting policy.

For example, among the six centres with a median haemoglobin concentration of 11.4 g/dL for HD, achievement of the Renal Association target ranges from 73% to 88%. Those centres with the lowest degree of spread have the greater proportion with a haemoglobin over 10 g/dL, suggesting better targeting. The ability to manage anaemia efficiently does not appear to be dependent upon the size of the unit. Both Stevenage (260 HD patients) and Truro (78 HD patients), for example, achieve the Renal Association target with a narrow spread of data.

Overall, there is still a close relationship between the median haemoglobin concentration in a centre and the percentage of patients with a haemoglobin reading of 10 g/dL or more (Figures 8.7 and 8.8).

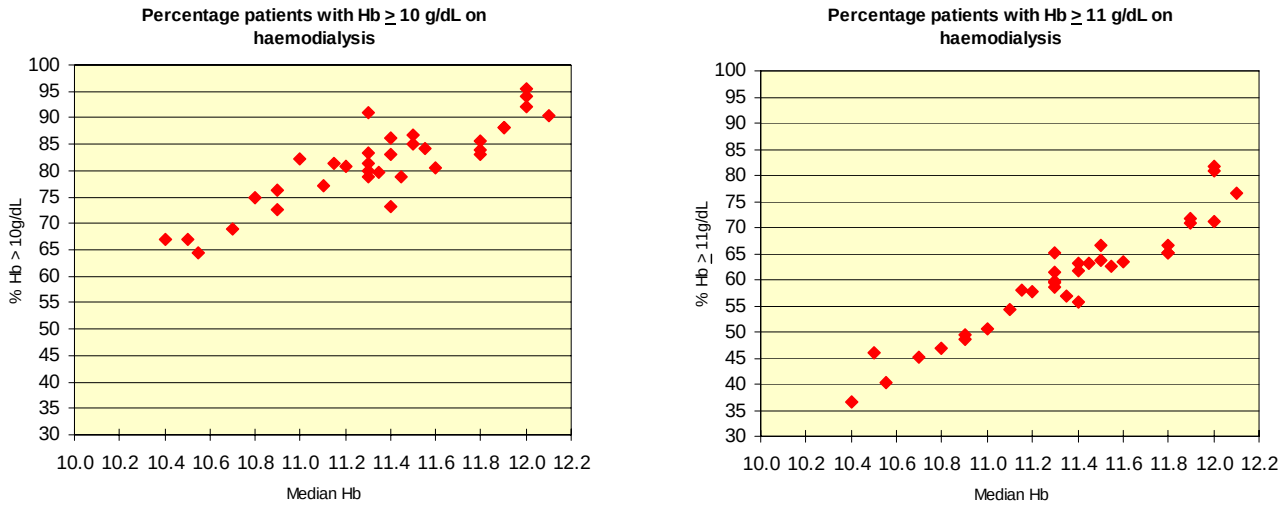


Figure 8.7: Percentage patients with (left) Hb ≥10 g/dL and (right) Hb>11 g/dL plotted against median Hb for HD patients

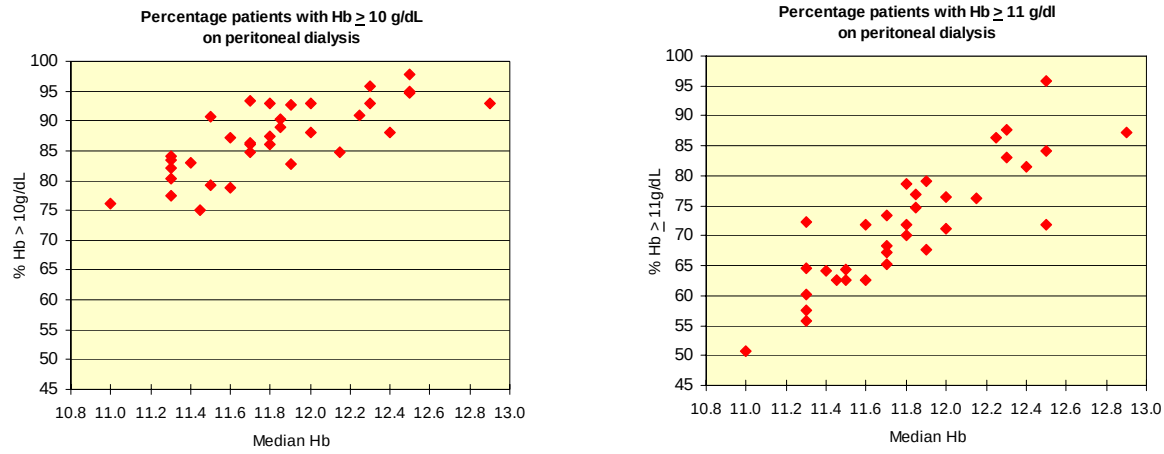


Figure 8.8: Percentage patients with (left) Hb ≥10 g/dL and (right) Hb>11 g/dL plotted against median Hb for PD patients

Some centres may have taken the view that a target of 11 g/dL, as recommended in Europe and the USA, is more appropriate than the UK figure of 10 g/dL; these data are shown in Figures 8.9 and 8.10.

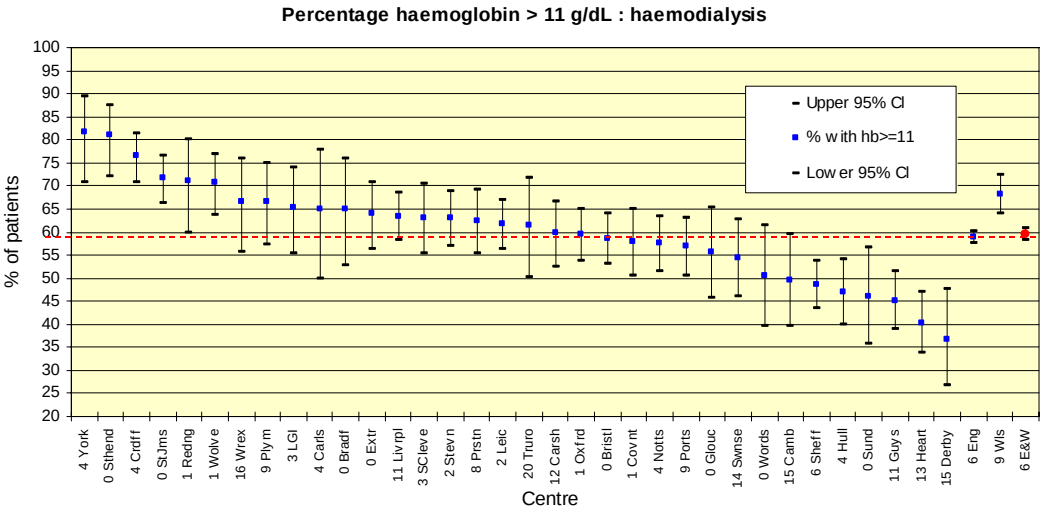


Figure 8.9: Percentage of HD patients with haemoglobin ≥11 g/dL

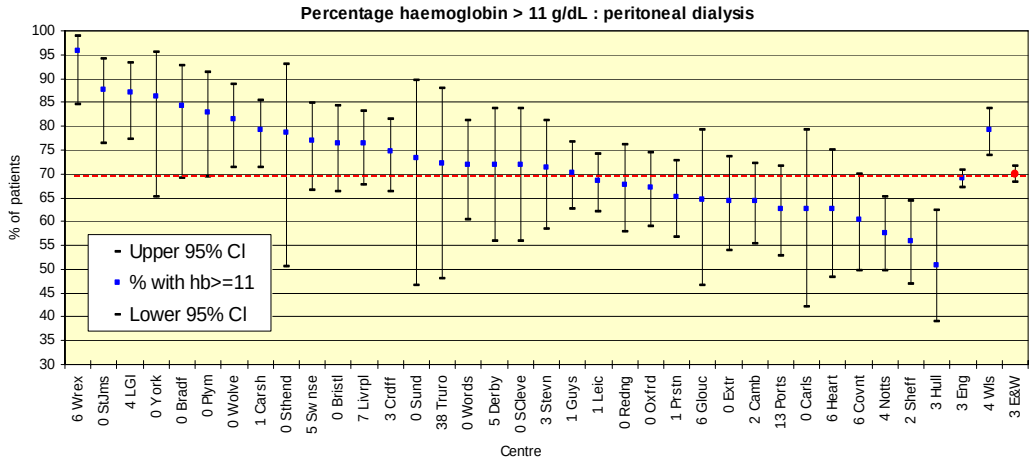


Figure 8.10: Percentage of PD patients with haemoglobin ≥11 g/dL

Four centres achieved 85% of patients with a haemoglobin concentration of 11 g/dL or more with PD. No centres achieved the European target for HD patients, although both York and Southend achieved a haemoglobin value of 11 g/dL or more in over 80% of patients, and 85% fell within the 95% confidence interval. Sixty per cent of HD patients and 70% of PD patients in the registry had a haemoglobin of 11 g/dL or more. Most centres, however, fall well short of the European target of 11 g/dL, suggesting that they are concentrating on the Renal Association Standard. Nevertheless, within the European arm of the International Dialysis Outcomes and Practice Patterns Study of HD patients, the mean haemoglobin level from the UK (11.1 g/dL, compared with a Registry mean of 11.3 g/dL) was higher than that from the other countries.

Haemoglobin concentrations of recently started patients

Haemoglobin concentrations within the first 3 months of starting dialysis have been analysed, data being shown in Table 8.3 and Figures 8.11–8.13. The haemoglobin data were extracted locally as the latest value in the quarter. The haemoglobin levels of these 'new' patients may be influenced by the management of anaemia prior to starting dialysis, the basis on which the decision to start dialysis is made and the proportion of patients who start dialysis following late referral or on presentation as uraemic emergencies.

Haemoglobin at start of dialysis

Centre	% Data return	Median Hb (g/dL)	90% Range	Quartile range	% Hb > 10 g/dL
Bradf	87	10.4	8.8–12.6	9.35–11.25	60.4
Bristl	99	10.1	7.6–13.0	9.0–11.3	50.0
Camb	95	10.7	8.1–12.85	9.5–11.85	66.3
Carls	96	10.4	8.1–12.3	9.4–11.3	60.0
Carsh	96	10.5	8.0–13.5	9.3–11.7	62.3
Covnt	82	10.1	8.0–13.3	9.2–11.0	52.7
Crdff	95	11.0	8.2–13.8	9.9–12.0	74.1
Derby	86	9.5	7.65–11.8	8.5–10.5	35.0
Extr	99	10.1	8.0–12.8	9.3–10.8	56.2
Glouc	98	9.6	7.3–11.5	8.7–10.6	41.3
Guys	90	10.6	8.6–13.3	9.5–11.5	64.2
Heart	68	9.4	6.8–11.7	8.4–10.4	30.9
Hull	95	9.5	6.9–11.6	8.6–10.5	40.0
Leic	93	10.7	8.1–13.2	9.7–11.7	71.3
LGI	81	10.4	7.8–13.1	9.2–11.1	59.2
Livrpl	93	10.2	7.9–12.9	9.1–11.1	48.4
Notts	96	10.0	7.6–13.0	9.0–10.9	47.8
Oxfrd	96	10.4	7.9–13.4	9.3–11.5	58.2
Plym	81	10.7	8.5–12.8	10.0–11.65	77.1
Ports	89	9.8	7.6–11.9	8.9–11.0	44.8
Prstn	94	10.2	7.15–13.45	8.95–11.5	49.2
Redng	99	10.9	8.4–13.4	9.7–11.9	69.6
S Cleve	100	9.0	7.2–12.4	7.8–9.9	24.7
Sheff	87	10.1	7.6–12.5	9.0–11.2	49.6
Stevn	100	9.9	7.2–12.4	9.1–10.7	52.2
Sthend	91	9.4	7.6–11.5	8.1–10.6	40.0
St Jms	98	10.3	7.7–13.8	9.1–11.3	52.2
Sund	76	10.5	7.7–12.8	9.8–11.4	69.0
Swnse	55	10.2	7.0–13.4	8.8–12.0	58.2
Truro	34	11.0	9.5–14.4	9.9–11.6	70.0

Centre	% Data return	Median Hb (g/dL)	90% Range	Quartile range	% Hb > 10 g/dL
Wolve	95	10.8	7.7–13.5	9.9–11.9	73.9
Words	100	10.4	8.1–13.6	9.1–11.8	51.6
Wrex	72	10.8	8.5–14.1	9.45–11.6	70.8
York	83	10.3	8.1–12.6	9.2–11.9	50.0
E&W	90	10.2	7.7–13.1	9.1–11.3	55.3

Table 8.3: Haemoglobin levels for new patients starting renal replacement therapy

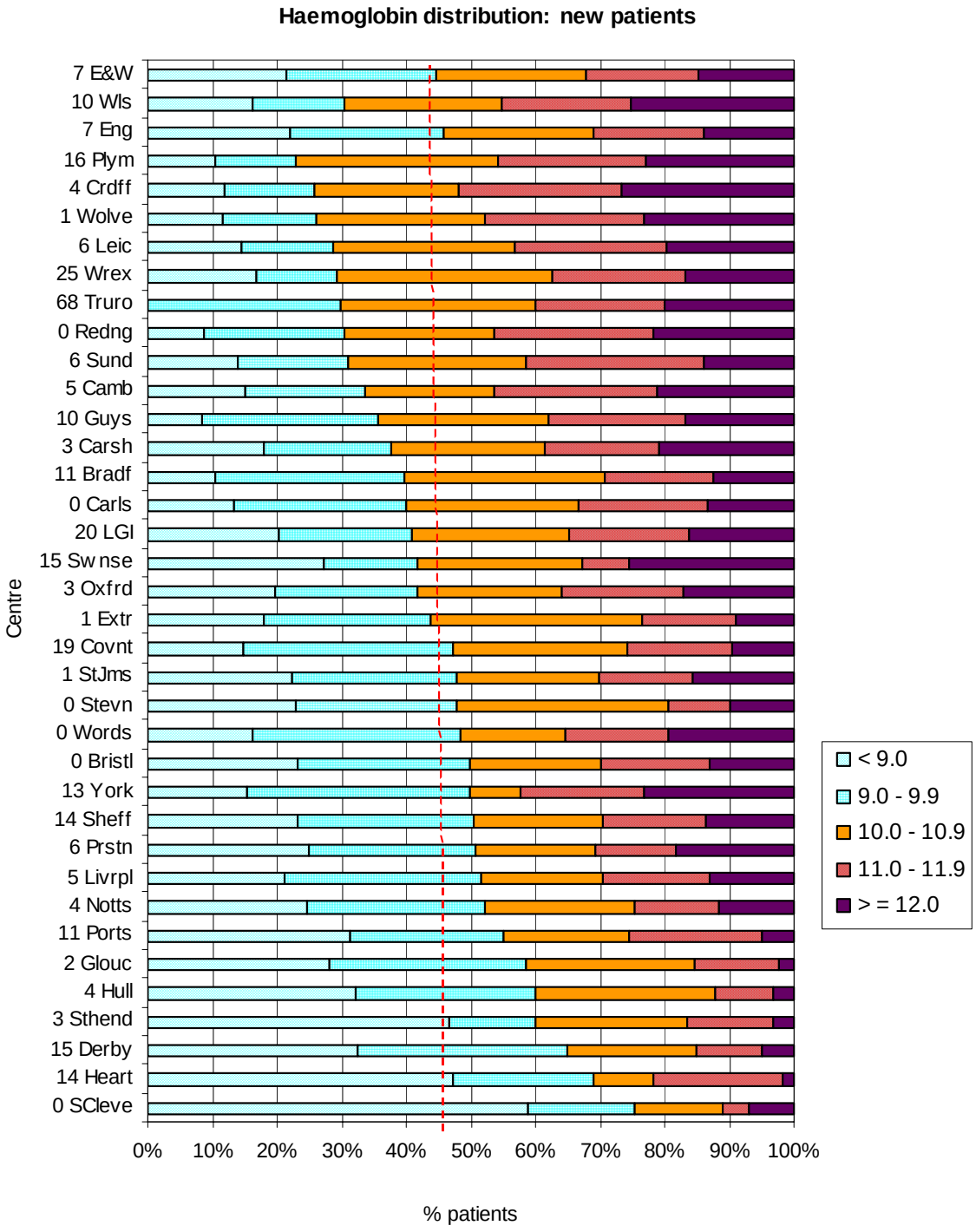


Figure 8.11: Distribution of haemoglobin for new patients, by 1 g/dL bands

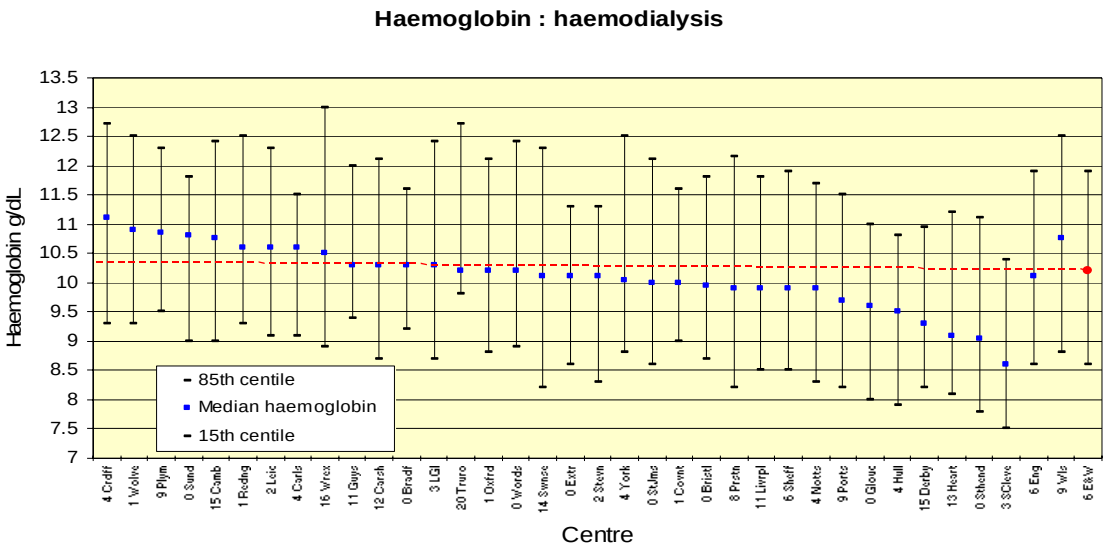


Figure 8.12: Haemoglobin median and 70% range for new patients

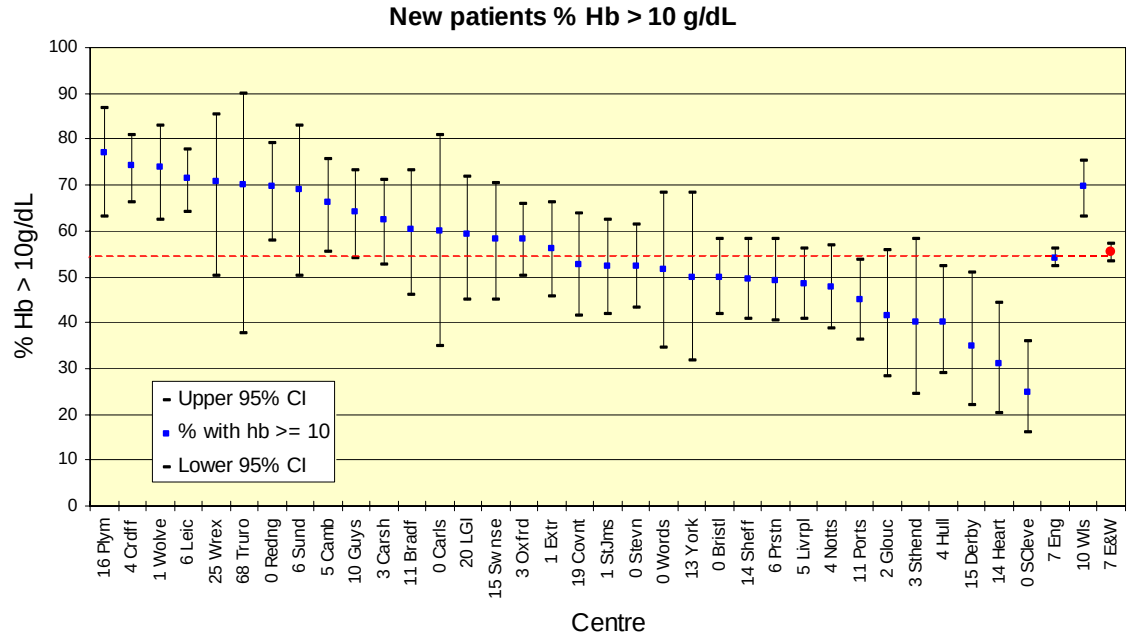


Figure 8.13: Percentage of new patients, by centre, achieving the RA Standard

There is wide variation in new patient haemoglobin concentration between centres. In Plymouth, 77% have readings greater than 10 g/dL, and 10% have a haemoglobin of less than 9.0 g/dL. In South Cleveland, 15% have haemoglobin level greater than 10 g/dL, and 59% have values less than 9 g/dL. One of the factors that may contribute to this discrepancy is the extent to which erythropoietin is used to treat patients before they start dialysis. The difference in haemoglobin level between new and prevalent patients is shown in Figure 8.14.

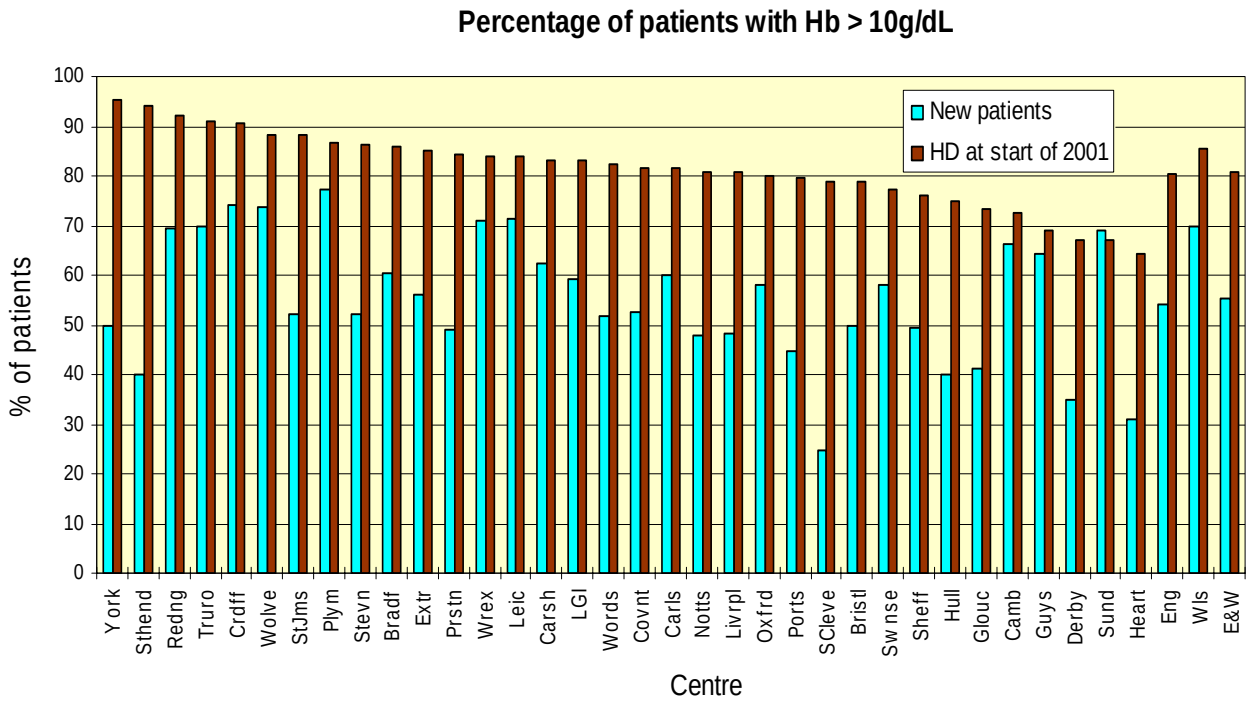


Figure 8.14: Percentage of patients with haemoglobin >10 g/dL: new and prevalent patients

Changes in anaemia management over time

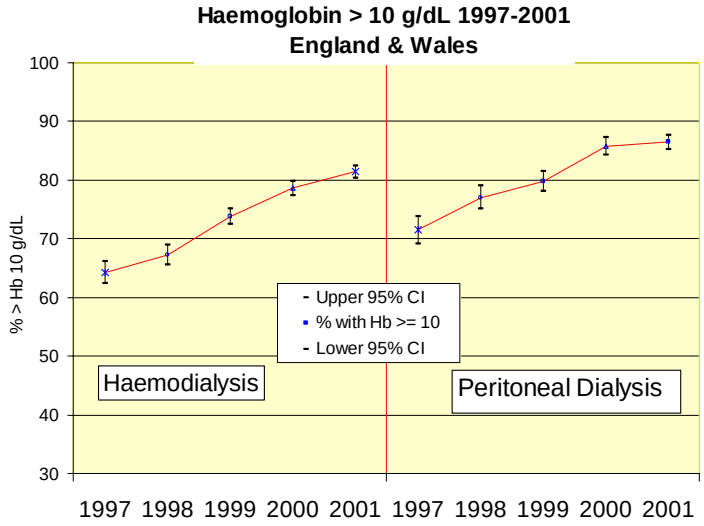


Figure 8.15: Change in the % of patients with Hb ≥10 g/dL in England &Wales, 1997–2001

The cumulative data for all units in England & Wales that contribute to the Renal Registry (Figure 8.15) demonstrate a continued improvement in the management of anaemia in HD. The percentage of PD patients with a haemoglobin of 10 g/dL or more has not changed over the past year, although the mean haemoglobin has risen slightly. Many centres still do not reach the Renal Association Standard.

Figure 8.16 is a cross-sectional analysis of median haemoglobin by length of time on renal replacement therapy (RRT). The median haemoglobin of HD patients who have been on dialysis less than 6 months showed little change between 2000 and 2001. Whereas in 2000, the haemoglobin continued to rise up to the 1–2 year cohort, there was in 2001 little difference between the 6 months – 1 year cohort and patients who had been dialysing for longer. The haemoglobin of PD patients declined with a longer time on dialysis. In 1999 and 2000, the 6 month – 1 year cohort of PD patients had the highest median haemoglobin level. In 2001, the less than 6 month cohort had the highest median haemoglobin. The earlier peaks in 2001 for both HD and PD could reflect a more aggressive early treatment of anaemia or an increased use of pre-dialysis erythropoietin.

	Mean	SD	Median	90% Range	Quartile range	% Hb ≥10 g/dL
Haemodialysis						
1999	10.7	1.7	10.7	7.9–13.6	9.6–11.8	67
2000	11.2	1.6	11.2	8.3–13.8	10.1–12.2	79
2001	11.3	1.6	11.4	8.6–14.0	10.3–12.4	81
Peritoneal dialysis						
1999	11.1	1.7	11.0	8.3–13.9	10.0–12.1	76
2000	11.6	1.6	11.6	9.0–14.3	10.6–12.7	86
2001	11.8	2.6	11.8	9.0–14.4	10.7–12.9	86

Table 8.4: Change in haemoglobin for all centres in 1999, 2000 and 2001

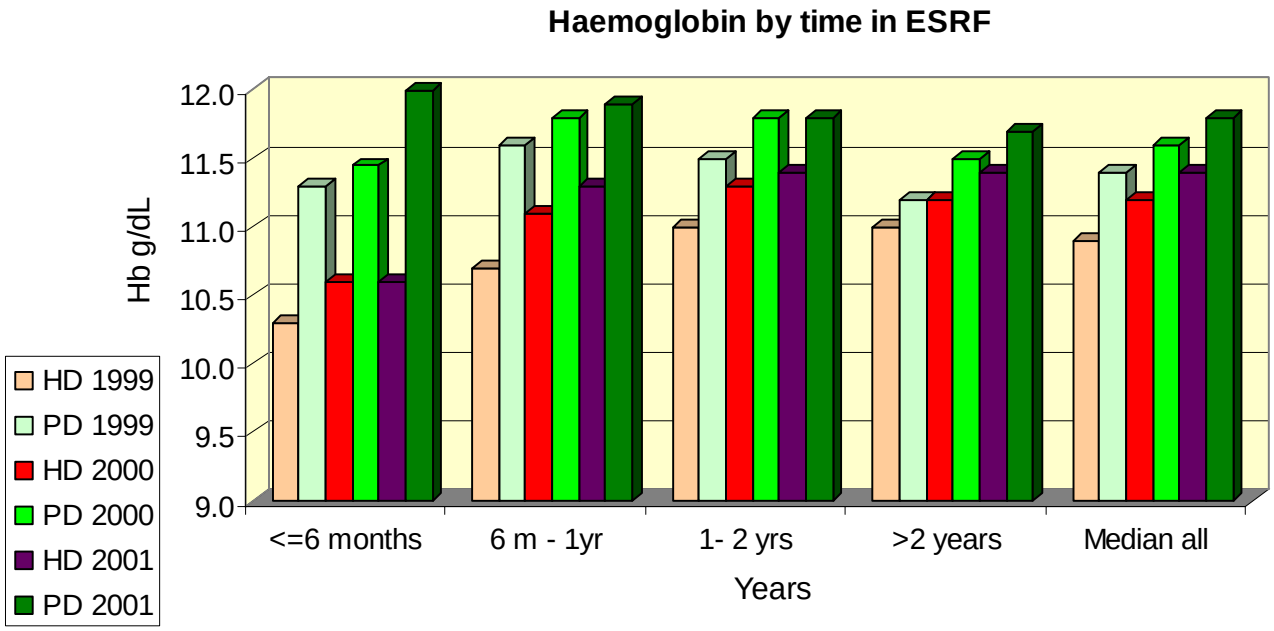


Figure 8.16: Median haemoglobin vs against time patients have been treated with RRT

An analysis of pre-dialysis haemoglobin level and modality of treatment is provided at the end of this chapter.

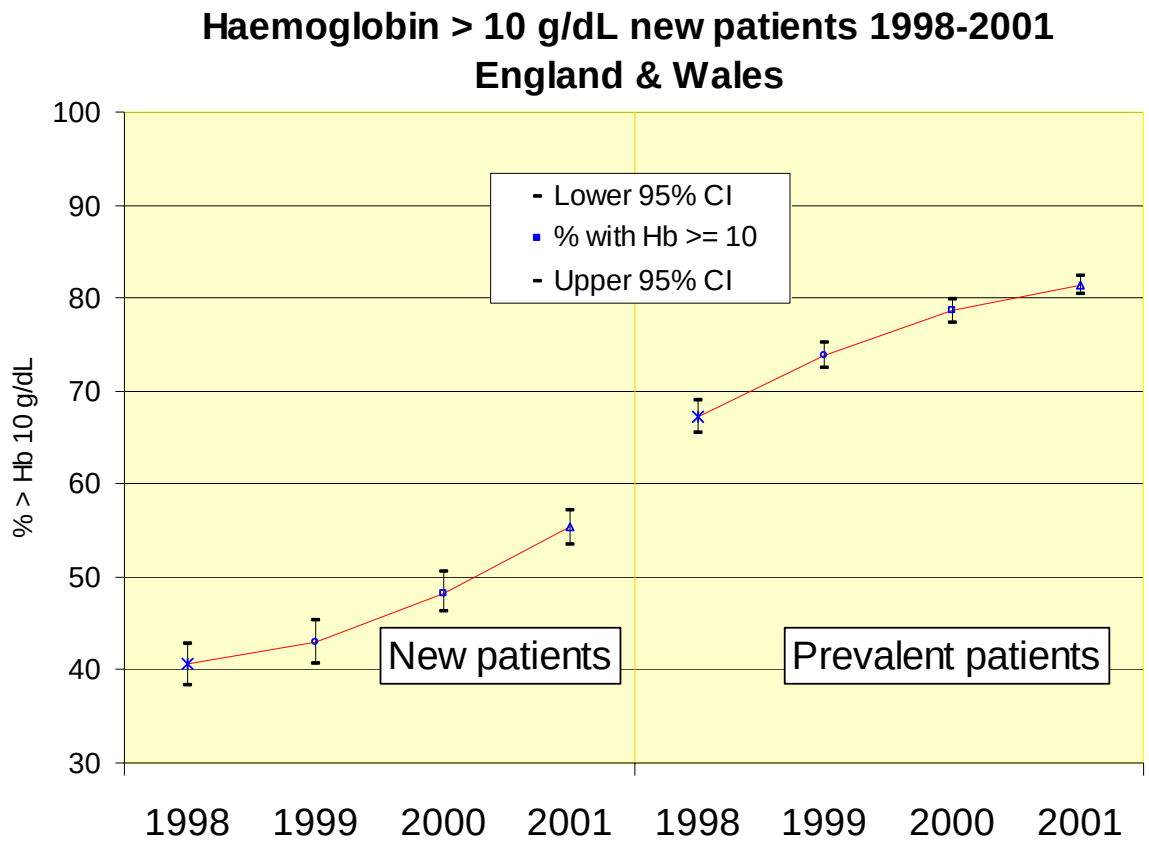


Figure 8.17: Change in haemoglobin ≥10 g/dL, new and prevalent patients 1998– 2001

In the years 2000 and 2001, the attainment of haemoglobin targets in patients commencing RRT has continued to improve (Figure 8.18), although haemoglobin levels are lower than in those patients already treated with dialysis.

Temporal changes in haemoglobin in the different renal units

Serial data are shown for all centres. Figures 8.18 and 8.19 show the percentage of HD and PD patients with a haemoglobin of 10 g/dL or more in the first and fourth quarters of 2001 from those centres reporting for the first time this year.

For the centres that have more than have contributed to the Registry for more than 1 year, the percentage of patients with a haemoglobin concentration of 10 g/dL or above in the final quarter of each year that the centre has reported data is shown in Figures 8.20 and 8.21.

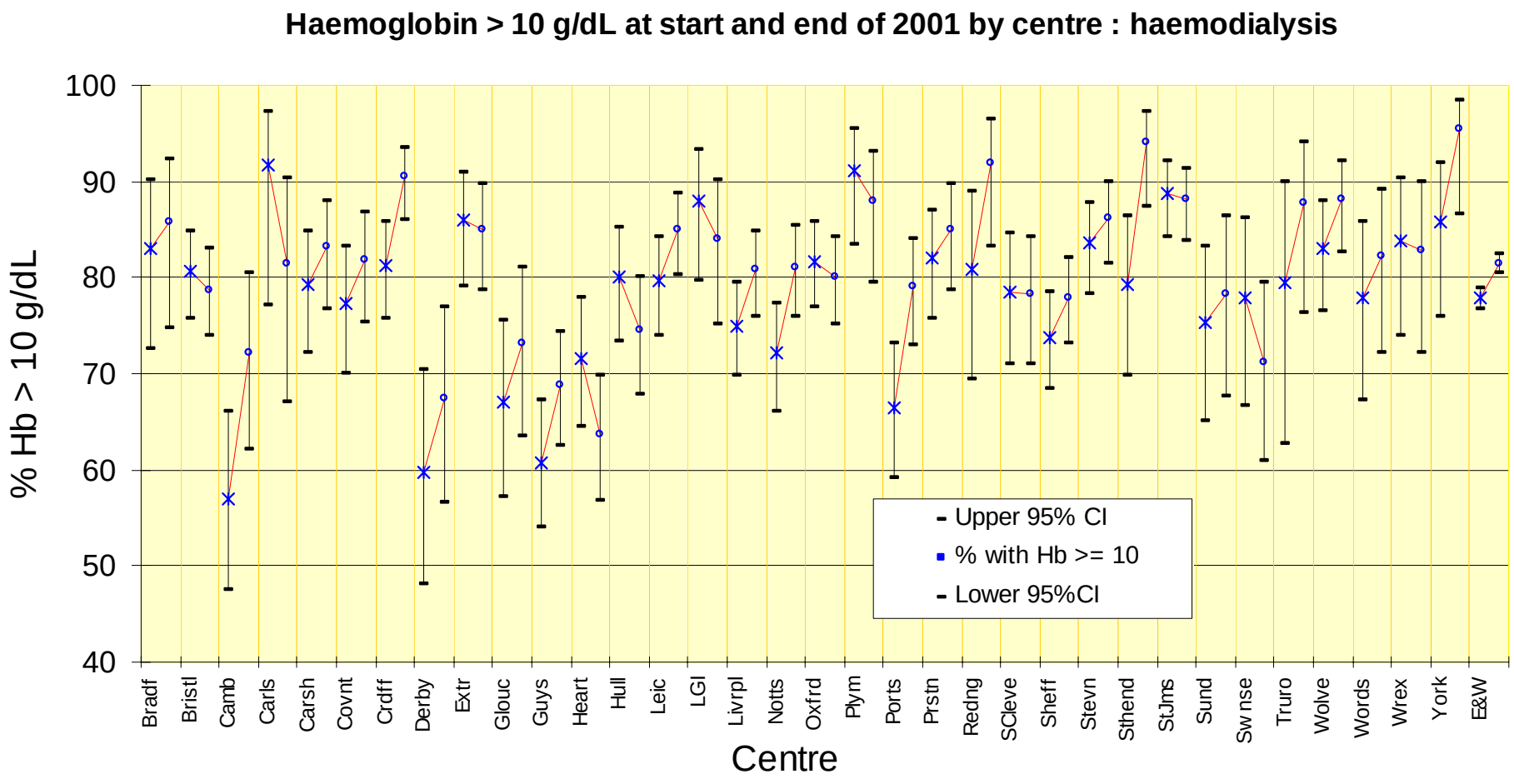


Figure 8.18: Percentage of HD patients with Hb ≥10 g/dL in the 1st and 4th quarters of 2001 by centre

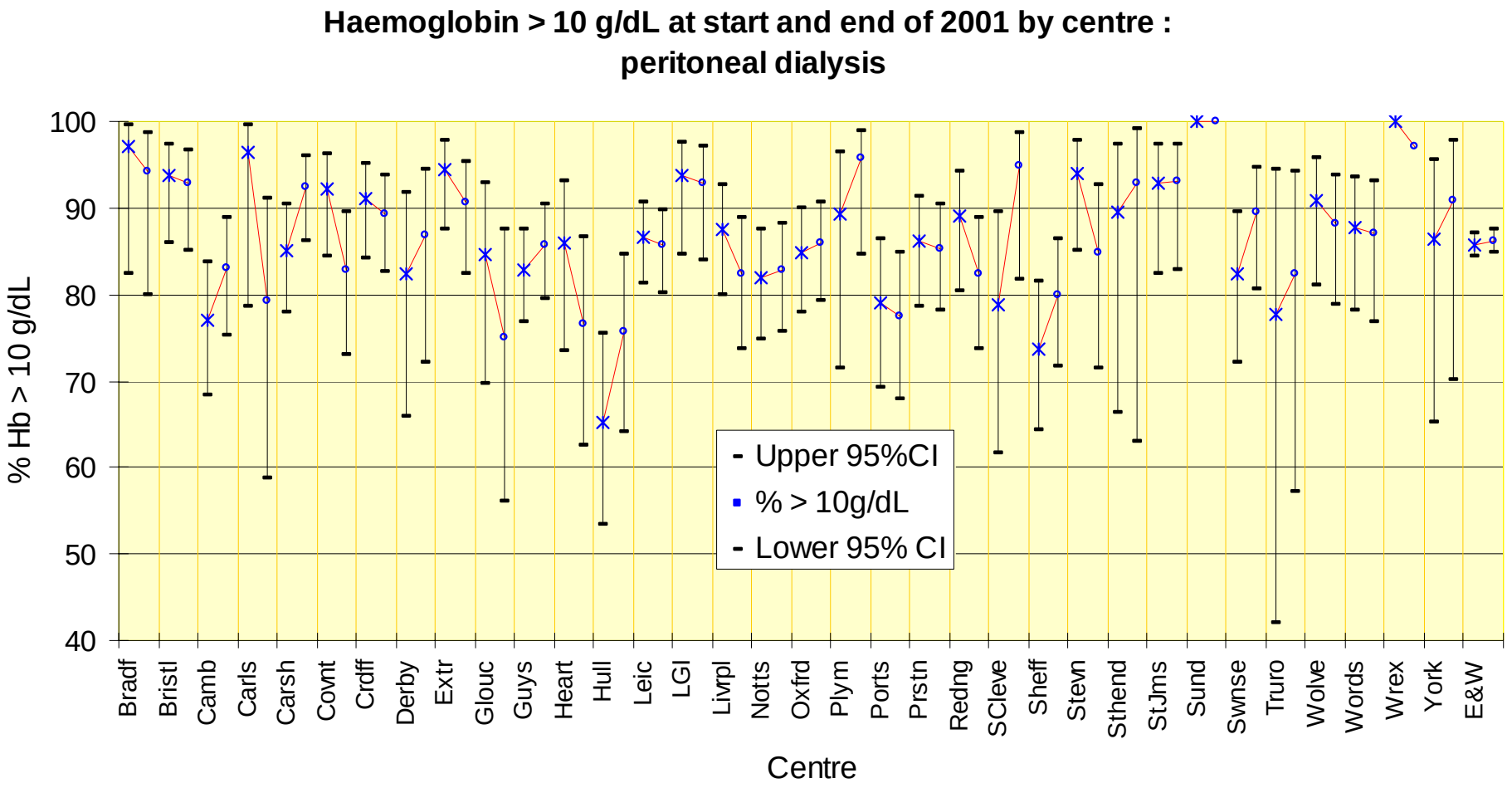


Figure 8.19: Percentage of PD patients with Hb ≥10 g/dL in the 1st and 4th quarters of 2001 by centre

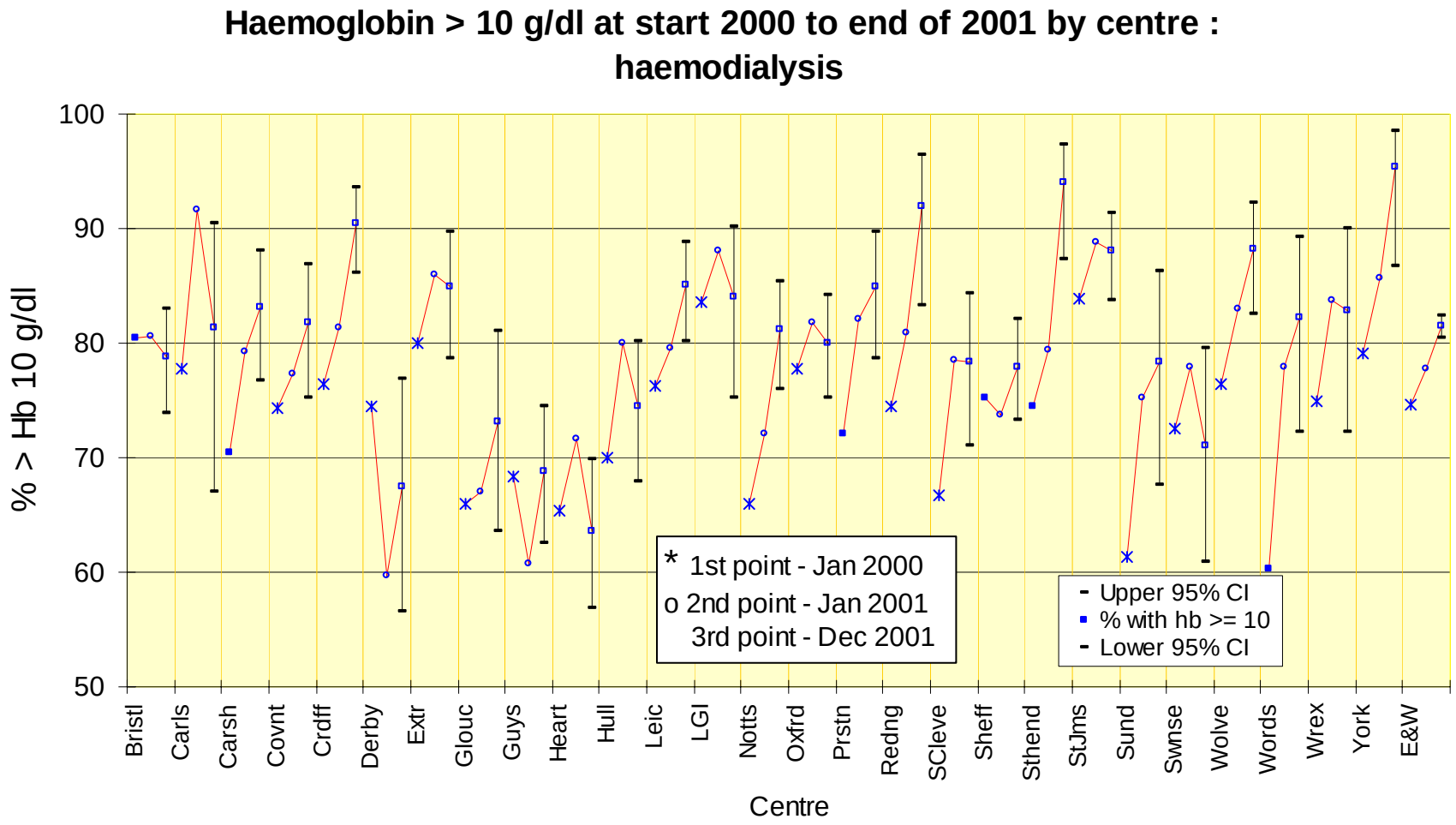


Figure 8.21: Haemoglobin >10 g/dL at start of 2000 and end of 2001, on HD

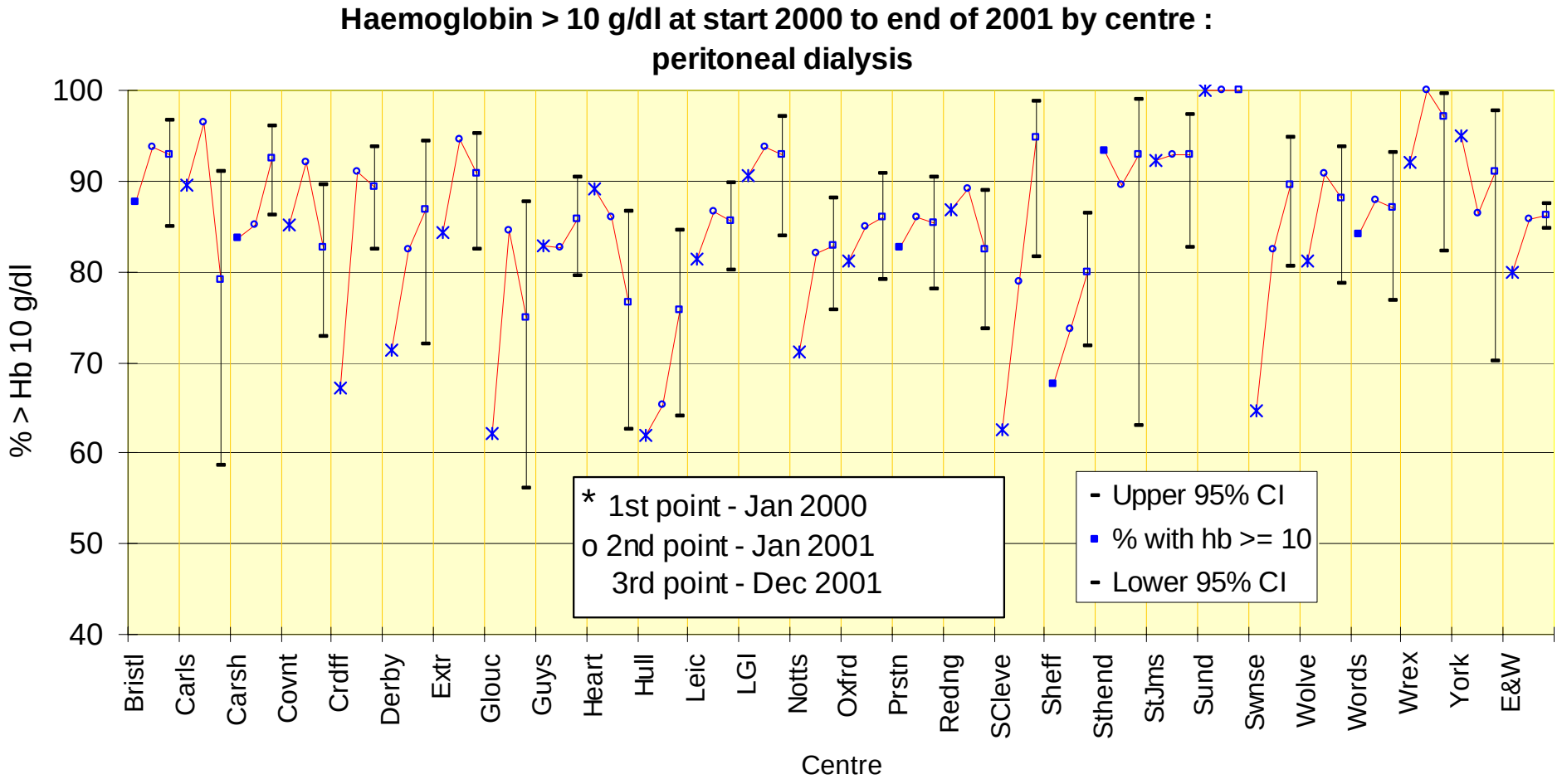


Figure 8.20: Haemoglobin >10 g/dL at start of 2000 and end of 2001, on PD

	Mean	SD	Median	90% Range	Quartile range	% Hb ≥10 g/dLl
Haemodialysis						
Qtr 1 2001	11.1	1.6	11.2	8.4–13.8	10.1–12.2	81
Qtr 4 2001	11.3	1.6	11.4	8.6–14.0	10.3–12.4	81
Peritoneal dialysis						
Qtr 1 2001	11.7	1.7	11.6	8.9–14.5	10.6–12.7	86
Qtr 4 2001	11.8	2.6	11.8	9.0–14.4	10.7–12.9	86

Table 8.5: Change in haemoglobin - all centres returning data, 1st and 4th quarters of 2001

Haemoglobin and survival

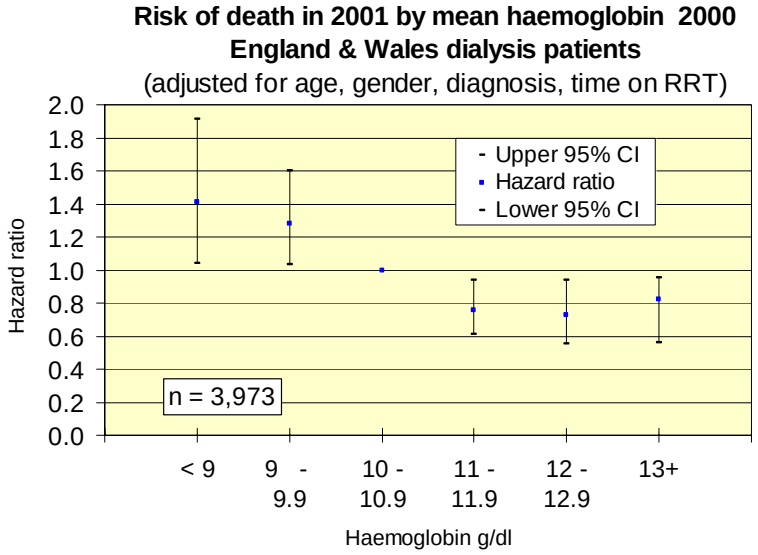


Figure 8.22: Haemoglobin and hazard ratio for death

Figure 8.22 shows the mean haemoglobin achieved through 2000 for patients alive on 31 December 2000 and their hazard ratio for death in 2001. All patients included in the analysis had haemoglobin data from three or more quarters of 2000.

When compared with those with a haemoglobin level of 10–10.9 g/dL, patients with lower haemoglobins had a significantly increased hazard of death. Patients with a haemoglobin of 11–11.9 g/dL had a significantly better survival than those with a haemoglobin of 10–10.9 g/dL (Renal Association Standard), indicating support for the European best practice guideline of a haemoglobin concentration of over 11 g/dL. There was no improvement in survival to be gained from increasing the haemoglobin concentration beyond this level.

Haemoglobin level before start of RRT and first treatment modality

The Registry collects electronically the last haemoglobin reading before start of RRT and the date on which this was measured. Data were only included in this analysis if the haemoglobin had been measured within 3 months prior to the start of RRT.

This analysis included incident patients starting in 1999 through to end of 2001.

Centres were excluded if they had less than 50% completeness of the pre-RRT haemoglobin for incident patients. All the centres remaining in the analysis were using automated laboratory links.

The data were analysed by the year of start of RRT and by first treatment modality of HD or HD. Patients with a pre-emptive transplant were excluded.

Results

Year	HD	PD	All
Hb (g/dL) 1999	9.4	9.9	9.6
95% CI	[9.3–9.5]	[9.8–10.0]	[9.5–9.7]
Median days before RRT	3	6	4
Hb (g/dL) 2000	9.7	10.2	9.9
95% CI	[9.6–9.8]	[10.1–10.3]	[9.8–9.9]
Median days before RRT	2	5	4
Hb (g/dL) 2001	9.8	10.6	10.1
95% CI	[9.7–9.9]	[10.5–10.7]	[10.0–10.1]
Median days before RRT	2	6	3
Hb (g/dL) all	9.7	10.3	9.9

Table 8.6: Haemoglobin prior to the start of RRT 1999–2001

Table 8.6 showsn that the haemoglobin level prior to start of RRT has been rising successively from 9.6 g/dL to 10.1 g/dL over the past 3 years.

Patients starting on HD had significantly lower haemoglobins than those starting on PD (Table 8.7), this gap being largest in 2001.

Age	HD	PD
Hb age <65	9.6	10.2
95% CI	[9.55–9.71]	[10.16–10.32]
n	(n=1729)	(n=1349)
Hb age 65+	9.7	10.3
95% CI	[9.64–9.78]	[10.18–10.40]
n	(n=2079)	(n=740)
	9.7	10.3
n	(n=3808)	(n=2089)

Table 8.7: Haemoglobin prior to the start of RRT, by first modality of RRT

In Table 8.7, the haemoglobin prior to the start of RRT was not significantly different between the two age groups (under-65 and 65+).

When analysed by age, patients starting RRT on PD had significantly higher haemoglobin concentrations than those starting on HD (p=<0.0001 ANOVA) in both patients aged under 65 and over 65 years.

Discussion

Haemoglobin levels prior to the start of RRT have risen progressively over the past 3 years. This in part probably reflects the increasing prescription of erythropoietin for patients before they reach established renal failure, although over 50% of patients remain anaemic at the start of RRT. In some renal units, the use of pre-dialysis erythropoietin is prevented or very restricted by inadequate funding. SDIII mandates the use of erythropoietin in anaemic patients prior to the start of RRT.

The Registry has shown in previous reports that haemoglobin levels within the first 3 months of starting RRT have been significantly lower in patients starting on HD than on PD. These results show that pre-dialysis haemoglobin values are also lower in those patients starting HD than those starting PD. The haemoglobin result was taken a median of 2 days prior to starting HD. Most of the patients presenting acutely or late, who are more likely to require HD and are unlikely to receive pre-dialysis erythropoietin, will have had results that have been included in the above analysis. These results indicate that patients starting on PD and HD are two differently selected groups. This highlights the problems of studies trying to assess differences between the techniques of PD and HD. The Registry plans to analyse this in more detail by obtaining haemoglobin data 1 week and 1 month prior to the tart of RRT, which would exclude these patients presenting acutely.

Conclusion

There has been a continued improvement in anaemia management in centres submitting data to the Registry, the improvement being most marked for HD patients.

Several centres are now achieving the Renal Association Standard for haemoglobin in both PD and H, although some centres are still falling significantly short of the Standard.

It is interesting to note that centres with the same median haemoglobin may have a quite varying achievement of the Renal Association target, although there is overall still a close relationship between median haemoglobin and percentage achievement of the Renal Association Standard.

There is little evidence to suggest that centres have adopted the European Standard for haemoglobin. There is a significant gap between current practice and the achievement of a haemoglobin level of over 11 g/dL in 85% of patients.

Chapter 9: Factors Influencing Haemoglobin

Summary

- Ninety–three per cent of haemodialysis and 84% of peritoneal dialysis patients achieved a serum ferritin level above 100 mcg/L. This has shown a continuing, albeit small, annual improvement.
- Three-year changes in serum ferritin by centre show that few centres have protocols that are consistently applied across both modalities of peritoneal dialysis and haemodialysis.
- There was a wide variation in erythropoietin dosages between centres, which was not always reflected in the achievement of haemoglobin targets.
- There was a trend towards a greater prescription of erythropoietin at the extremes of age, and advancing age was not a barrier to erythropoietin provision.

Haemoglobin and serum ferritin

Introduction

The second edition of the Renal Standards document did not recommend a specific Standard, whereas, in contrast, the third edition (SDIII) recommends (evidence level B):
'A serum ferritin > 100 mcg/l and <10% hypochromic red cells (transferrin saturation > 20%) and* that *levels should not consistently exceed 800 mcg/l'.

Both the European best practice and Disease Outcomes Quality Initiative guidelines also advocate a target serum ferritin of over 100 mcg/L. Although centres use different measures of iron status, including serum ferritin, transferrin saturation and percentage red cell hypochromicity, serum ferritin is the most widely used and comprehensively recorded index and is presented in this report.

The distribution of ferritin concentration is expressed as median and 90% ranges, and is presented in Table 9.1 for haemodialysis (HD) and Table 9.2 for peritoneal dialysis (PD). The percentage of patients achieving a serum ferritin of over 100 mcg/L is presented graphically in Figures 9.1 and 9.2. The numbers by each centre name in the figures indicate the percentage of missing data.

Treatment centre	% Data return	Median ferritin mcg/L	90% Range	Quartile range	% Ferritin >100 mcg/L
Bradf	98.4	273	118–837	118–414	96.8
Bristl	99.7	229	27–837	27–411	75.9
Carls	93.3	404	222–837	222–507	97.6
Carsh	77.8	358	106–837	106–468	94.9
Covnt	99.4	327	83–837	83–579	93.8
Crdff	96.4	731	146–837	146–1037	97.5
Derby	83.5	242	27–837	27–527	76.5

Treatment centre	% Data return	Median ferritin mcg/L	90% Range	Quartile range	% Ferritin >100 mcg/L
Extr	100.0	273	88–837	88–390	93.4
Glouc	100.0	289	44–837	44–424	87.6
Guys	87.9	488	70.5–837	70.5–726	92.5
Heart	85.8	164	27–837	27–238	73.1
Hull	93.6	445	159–837	159–570	98.9
Leic	96.7	332	87.5–837	87.5–544	93.8
LGI	95.9	430	119–837	119–638	96.8
Livrpl	89.5	618	112–837	112–982	96.1
Notts	95.7	568	214–837	214–712	99.3
Oxfrd	98.1	283	65–837	65–441	90.4
Plym	94.8	484	190–837	190–643	99.1
Ports	92.6	219	51–837	51–319	87.3
Prstn	96.5	460	78–837	78–781	92.8
Redng	98.7	784	237–837	237–958.5	97.4
S Cleve	92.3	292	68–837	68–574.5	88.9
Sheff	98.5	503	101–837	101–700	94.9
Sthend	100.0	351	190.5–837	190.5–422	100.0
St Jms	100.0	485	177–837	177–621	97.9
Sund	96.5	447	162–837	162–695	98.8
Swnse	79.9	515	123–837	123–683	97.6
Truro	100.0	494	192–837	192–752	100.0
Wolve	99.4	514	216–837	216–736	98.3
Words	100.0	312	59–837	59–484	92.4
Wrex	86.6	414	201–837	201–597	98.8
York	91.3	496	268–837	268–567	98.4
Eng	88.6	395	73–837	73–599	92.4
Wls	89.4	564	146–837	146–860	97.8
E&W	88.6	405	77–837	77–619	92.9

Table 9.1: Serum ferritin concentration in HD patients

Centre	% Data return	Median ferritin mcg/L	90% Range	Quartile range	% Ferritin >100 mcg/L
Bradf	100	373	86–801	215–513	87
Bristl	98	196	39–697	85–417	72
Carls	100	441	166–1260	341.5–567.5	100
Carsh	90	293	80–973	173–442	91
Covnt	89	163	32–988	84.5–341.5	67
Crdff	95	280	55–1023	144–412	86
Derby	93	183	27–654	85–389	74
Extr	100	238	31–942	141–416	84
Glouc	97	175	5–800	78–318	72
Guys	93	180	43–683	99–364	73
Heart	92	162	32–477	101–256	77
Hull	97	269	111–784	192–423	97
Leic	98	283	112–1140	208–489	95
LGI	95	397	22–681	271–506	88
Livrpl	94	199	24–721	91–382	71
Notts	96	246	60–826	146–418	90
Oxfrd	99	178	41–716	106–365	75
Plym	100	224	58–694	142–350	85
Ports	68	273	20–1082	141–448	81
Prstn	100	222	54–789	137–338	83
Redng	100	278	89–710	211–396	95
S Cleve	100	480	91–1626	244–729	95
Sheff	96	293	78–917.5	189–457.5	90
Sthend	100	329	43–702	233–396	93

Centre	% Data return	Median ferritin mcg/L	90% Range	Quartile range	% Ferritin >100 mcg/L
St Jms	100	319	107–732	229–433	96
Sund	100	476	150–855	274–743	100
Swnse	95	172	65–644	120–318	85
Truro	100	215	40–415	122–302	76
Wolve	100	166	37–551	94.5–296.5	72
Words	80	220	40–681	120–410	82
Wrex	98	368	45–867	240–501	90
York	100	221	68–447	127–323	86
Eng	88	249	43–826	140–416	84
Wls	95	245	53–959	137–432	87
E&W	89	248	44–840	140–417	84

Table 9.2: Serum ferritin concentration in PD patients

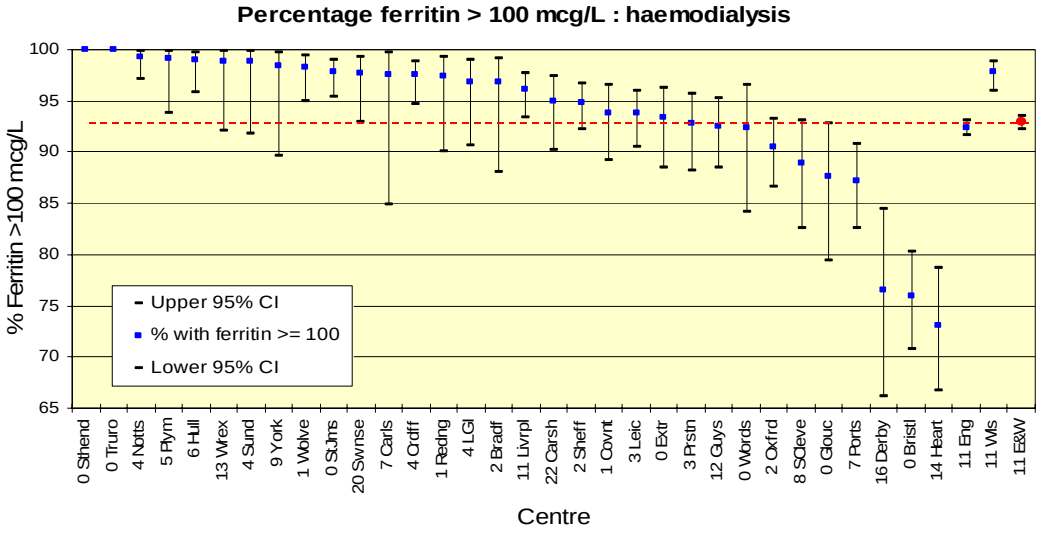


Figure 9.1: Percentage of HD patients with serum ferritin >100 mcg/L

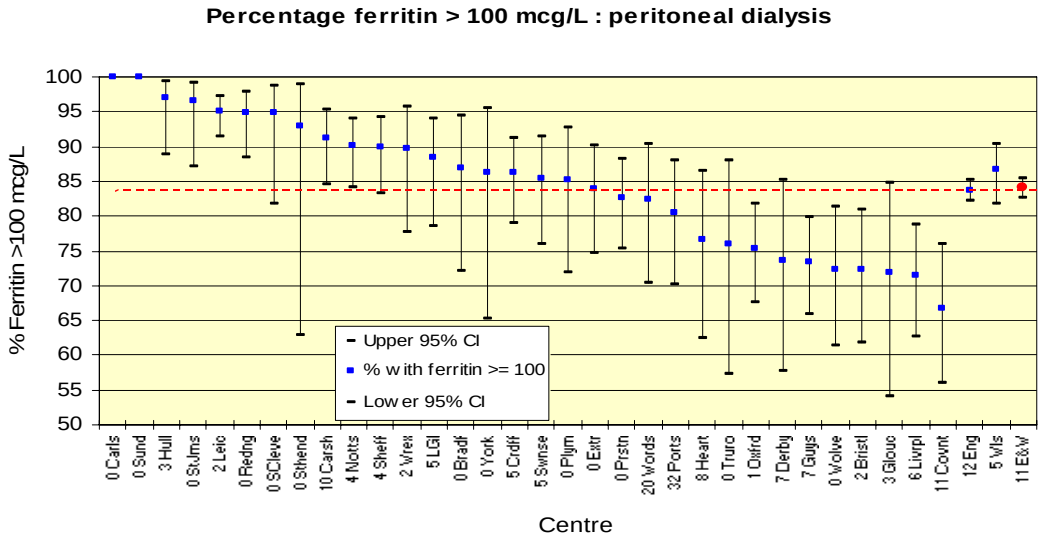


Figure 9.2: Percentage of PD patients with serum ferritin >100 mcg/L

As in previous reports, HD patients had a consistently higher serum ferritin level than PD patients. The median ferritin exceeded 100 mcg/L in all centres for both HD and PD, although a greater percentage of HD than PD patients had a serum ferritin above 100 mcg/L (93 versus 84% respectively), and the lower limit of the 90% range was under 100 mcg/L in only 13 centres for PD compared with 27 centres for HD. As can be expected, there is, with such a high achievement of the ferritin Standard by all centres, no relationship between the achievement of a haemoglobin level of over 10 g/dL and a serum ferritin of more than 100 mcg/L. Figure 9.3 shows an apparent relationship between the percentage of patients with a serum ferritin above 200 mcg./L and the achievement of the haemoglobin Standard for patients on HD. This relationship was not apparent for PD patients.

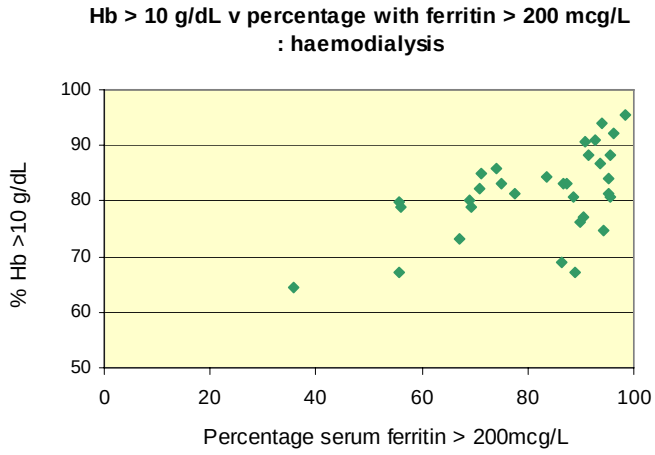


Figure 9.3: Percentage of patients with serum ferritin >200 mcg/L and Hb >10 g/dL on HD

The Southend and Hull renal units achieved a high attainment of the Standard for serum ferritin in patients on HD and PD; this contrasts with the Truro renal unit, which had an equally high achievement of the Standard for HD patients but was in the lower end of achievement for PD patients.

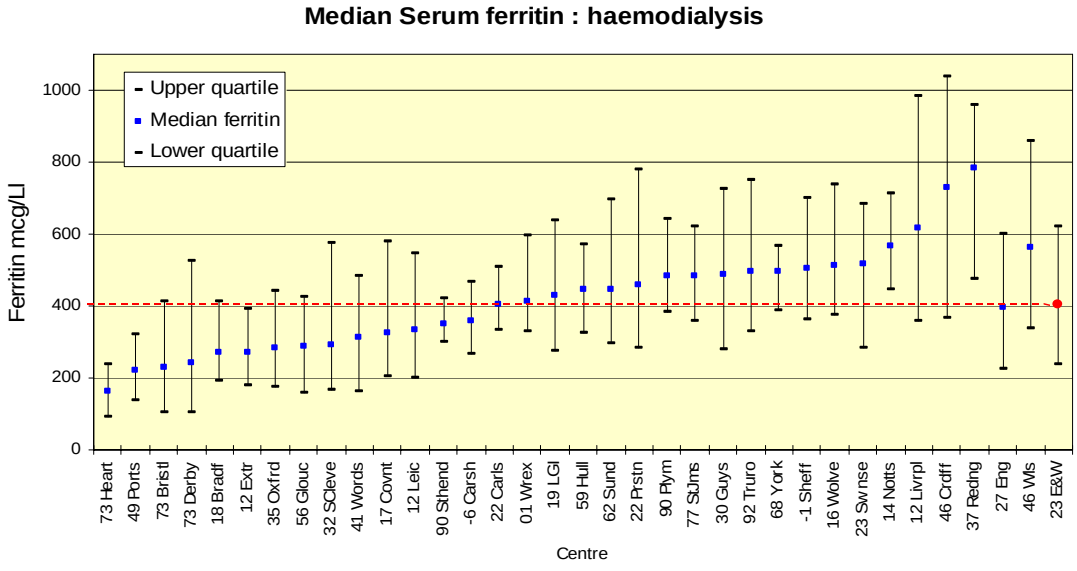


Figure 9.4: Median serum ferritin on HD

The median serum ferritin by centre is shown in Figures 9.4 and 9.5 for HD and PD respectively. Southend and Truro achieved the ferritin Standard for all patients on HD, but Southend had a median serum ferritin below average for England & Wales, and Truro was just above average, indicating that achievement of the Standard does not have to be attained at the expense of a high serum ferritin level for all patients.

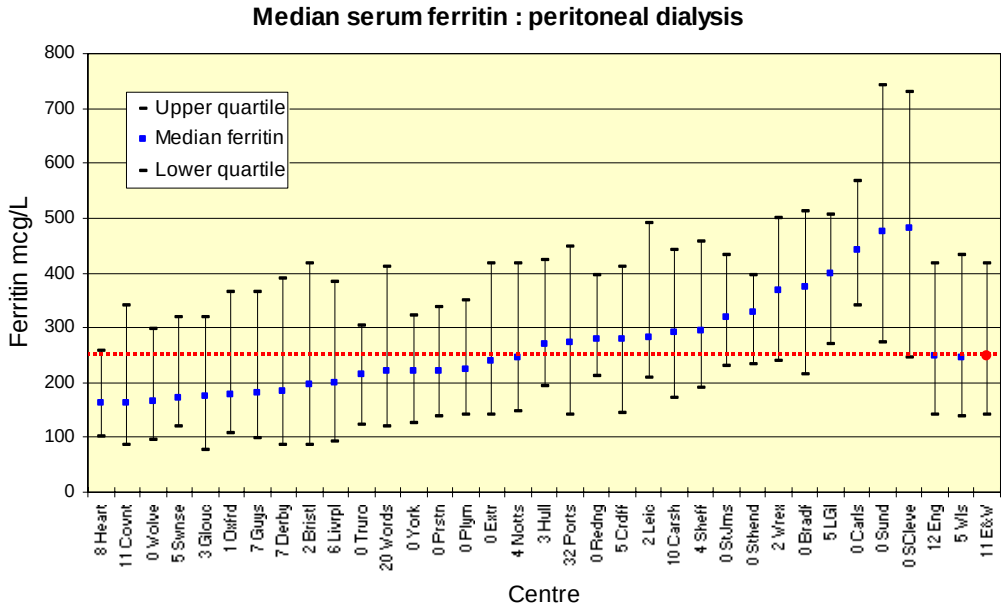


Figure 9.5: Median serum ferritin on PD

Changes in serum ferritin 1999–2001 in England & Wales

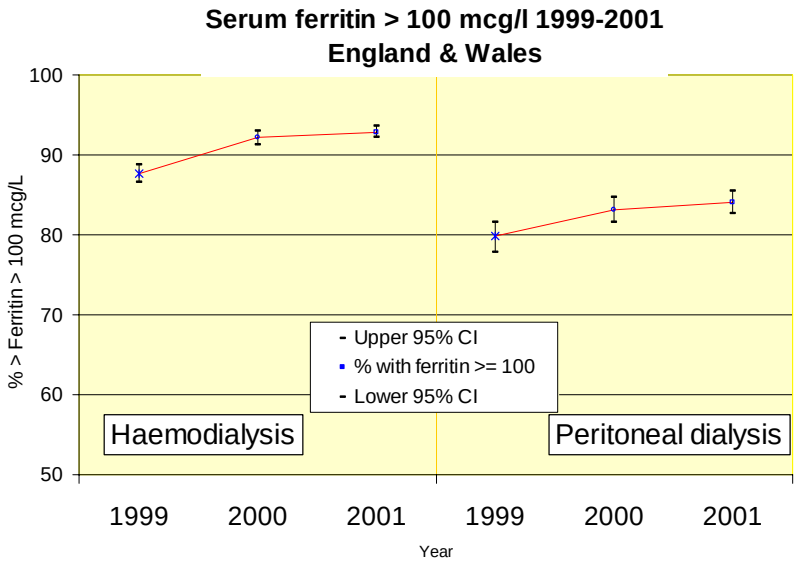


Figure 9.6: Change in achievement of a serum ferritin >100 mcg/L, 1999–2001

Figure 9.6 shows the continuing increase in median serum ferritin in England & Wales from 1999 through to 2001. In Figure 9.7, both HD and PD patients showed a trend of increasing serum ferritin during the period 1999–2001, with a reduction in the number of patients with a ferritin concentration of less than 100 mcg/L and a corresponding rise in those with a ferritin level above 300 mcg/L.

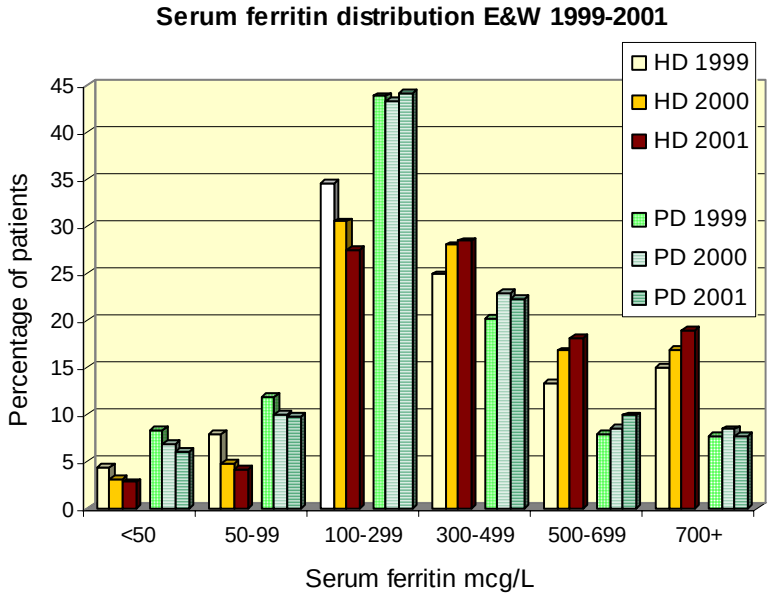


Figure 9.7: Serum ferritin distribution, 1999–2001

This trend suggests either that centres are increasingly effective in the provision of intravenous iron or that ferritin targets greater than the recommended minimum of 100 mcg/L are being adopted. HD patients show a small rise in the percentage of patients with a serum ferritin above 700 mcg/L; this will be analysed according to SDIII in the next report.

Serum ferritin and length of time on renal replacement therapy

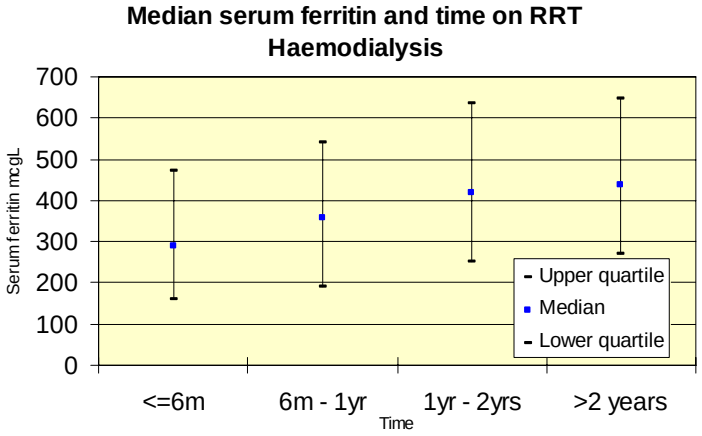


Figure 9.8: Median ferritin, by length of time on renal replacement therapy: HD

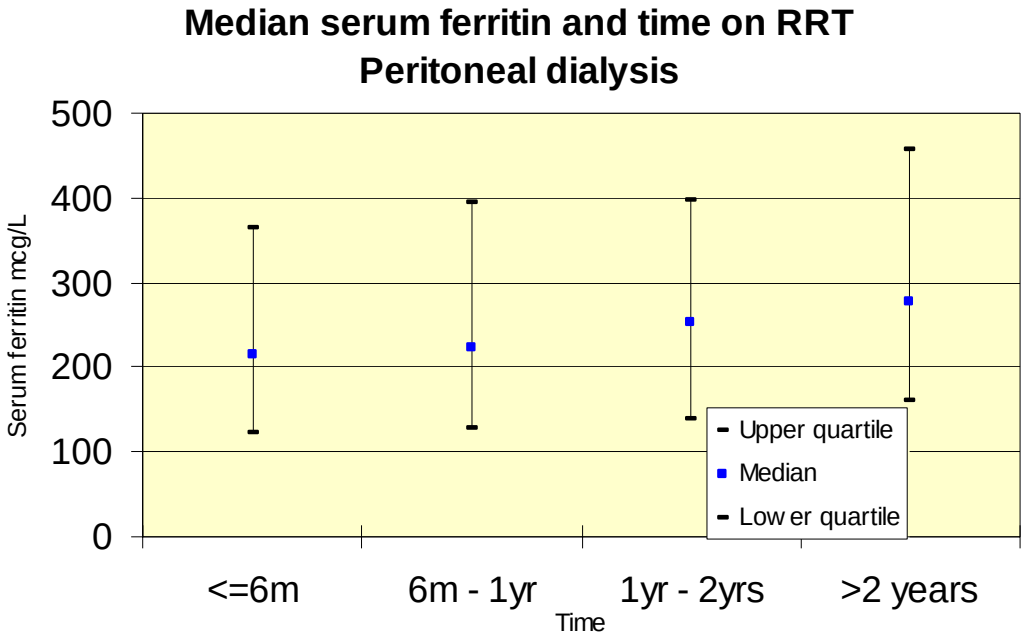


Figure 9.9: Median ferritin, by length of time on renal replacement therapy: PD

Figures 9.8 and 9.9 are a cross-sectional analysis of patients at the end of 2001 by their length of time on renal replacement therapy (RRT). These data show an increase with time for both HD and PD patients, the median serum ferritin rising from 290 to 440 mcg/L in patients on HD by the end of 2 years and from 220 to 280 mcg/L for patients on PD.

Changes in serum ferritin by centre 1999–2001

Although both HD and PD patients showed a progressive increase in serum ferritin level with increasing time on dialysis, the incremental rise was more marked in HD than PD. Assuming that ferritin levels achieved after 2 years on HD more closely approximate to individual centres' target levels, it is likely that the slower rate of rise of ferritin in the PD population results from practical difficulties in administering intravenous iron to this patient group.

Figure 9.10 and 9.11 demonstrate that Cardiff and Swansea show a marked variation in the year-on-year variability of serum ferritin in HD patients, Cardiff also showing the same variability in PD patients. Some centres, for example, Nottingham, Plymouth and Southend have made consistent improvements in median serum ferritin level for patients on HD, in contrast with centres who have not changed their practice. Carlisle has shown a big improvement in serum ferritin for patients on PD, and now patients on PD have serum ferritin levels similar to those of patients on HD.

These 3 year changes in serum ferritin show clearly which centres have changed practice in the use of intravenous iron. Several centres have similar ferritin levels for both their PD and HD patients, suggesting that there are consistent protocols that are applied across all patients on dialysis.

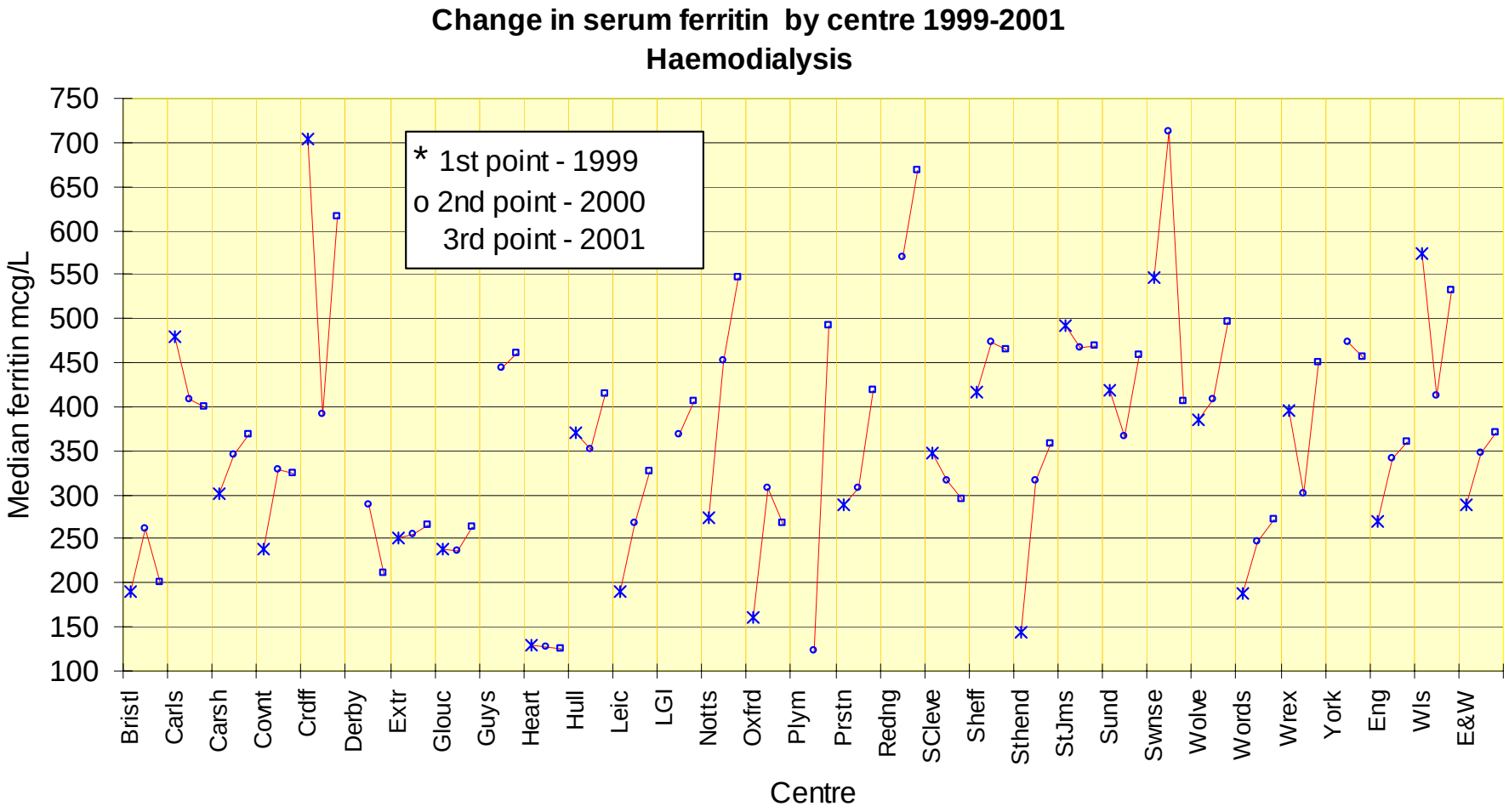


Figure 9.10: Serial ferritin concentrations in HD patients

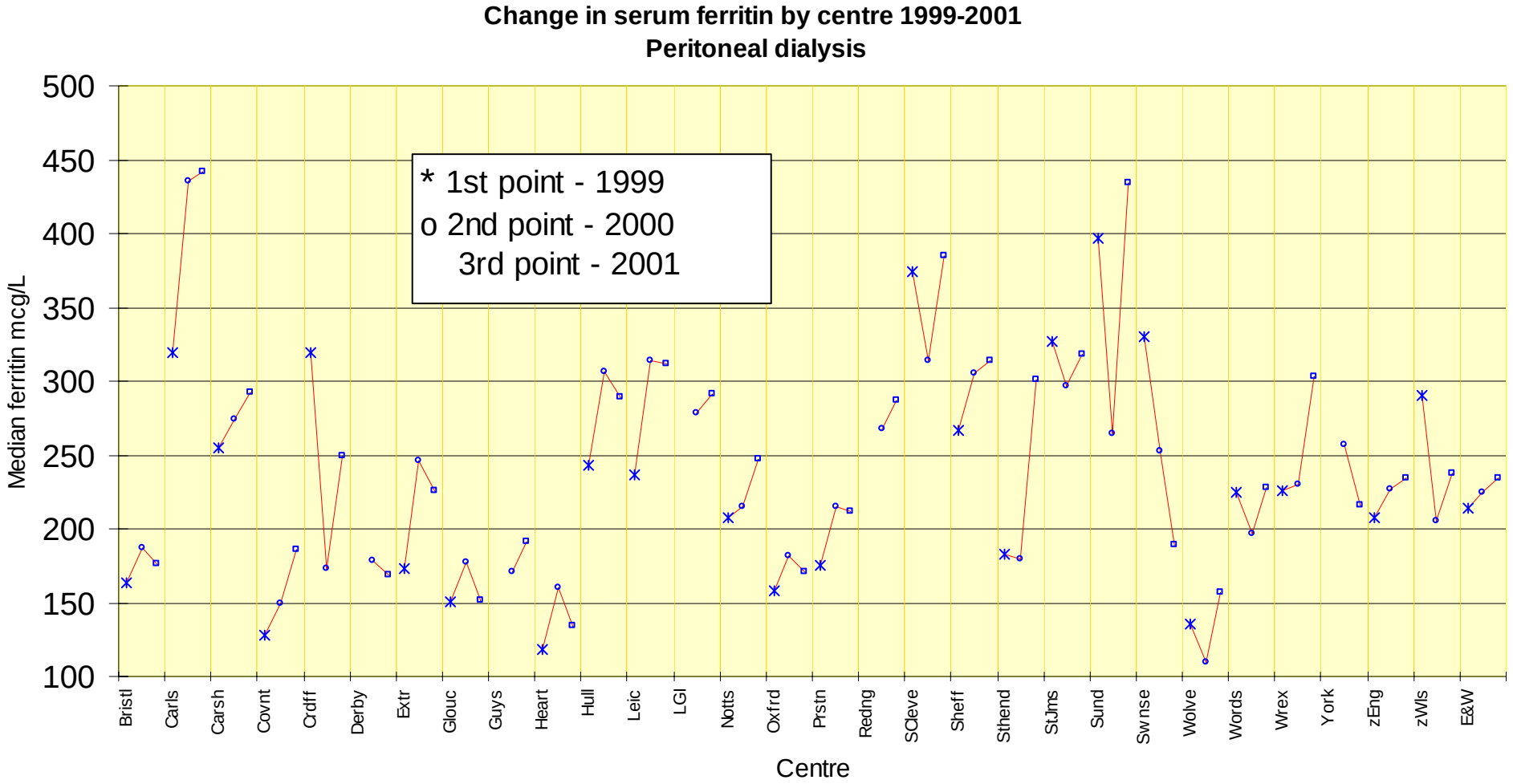


Figure 9.11: Serial ferritin concentrations in PD patients

Haemoglobin and erythropoietin

Dosage of erythropoietin

The number of centres returning data on erythropoietin provision has risen from 9 to 19 during the period 2000–02 (Tables 9.3 and 9.4). The percentage of HD patients prescribed erythropoietin ranged from 54 to 97% (mean 83%), and for PD from 28 to 93% (mean 68%). Consistent with these figures, all but three centres treated a greater percentage of HD than PD patients with erythropoietin.

For patients with a haemoglobin level of under 10g/dL, however, the median percentage treated was virtually identical for PD and HD, suggesting that centres are targeting treatment to more anaemic patients in both modalities. Behind this general picture, individual units showed a striking variation between HD and PD in the provision of erythropoietin to patients whose haemoglobin was below 10 g/dL. St James's and Bristol treated many more HD than PD patients in this category, whereas Bradford, Carlisle and Oxford treated more of the PD population. Although a better provision of erythropoietin to unit-based HD patients is an expected consequence of their easier accessibility to medical and nursing staff, it is less clear why some centres apparently treated PD patients with a haemoglobin of under 10 g/dL more effectively than did their HD peers.

Treatment centre	% on EPO	Mean weekly dose for those on EPO	Median dose for patients on EPO	Hb <10g/dL % on EPO	Hb ≥10 g/dL % not on EPO
Bradf	59	6,790	6,000	44	33
Bristl	90	10,151	8,000	91	8
Camb	54	8,283	6,000	73	29
Carls	62	8,589	8,000	60	33
Covnt	57	10,151	8,000	94	9
Exeter	92	8,198	8,000	96	8
Glouc	97	6,622	6,000	100	3
Guys	80	5,845	4,000	72	10
Lpool	83	12,667	12,000	89	12
Oxford	85	7,062	6,000	60	11
Sheff	72	7,252	6,000	83	24
St James	87	8,350	6,000	100	12
Steven	88	4,929	4,000	89	8
Sund	95	6,790	6,000	100	4
Swan	84	7,083	6,000	100	4
Wolve	94	8,283	6,000	89	6
Words	85	6,388	6,000	100	13
Wrex	67	8,700	9,000	77	17
York	91	9,723	9,000	100	5
E&W	83	7,992	6,000	85	13

Table 9.3: Erythropoietin (EPO) prescribing in HD patients

Treatment centre	% on EPO	Mean weekly dose for those on EPO	Median dose for patients on EPO	Hb <10 g/dL % on EPO	Hb ≥10g/dL % not on EPO
Bradf	66	4929	4000	100	34
Bristl	74	6593	6000	67	24
Camb	56	6058	5000	67	25
Carls	63	4200	4000	96	29
Covnt	57	6593	6000	50	33
Exeter	75	4918	4000	100	36

Treatment centre	% on EPO	Mean weekly dose for those on EPO	Median dose for patients on EPO	Hb <10 g/dL % on EPO	Hb ≥10g/dL % not on EPO
Glouc	70	4372	4000	100	26
Guys	60	4014	4000	74	70
Lpool	69	N/A	N/A	84	27
Oxford	68	5062	4000	94	27
Sheff	44	5073	6000	63	48
St.James	77	5250	4000	59	23
Steven	74	4696	4000	86	25
Sund	93	4929	4000	86	7
Swansea	64	4800	4000	91	38
Wolve	79	6058	5000	88	20
Words	77	5336	4000	87	23
Wrex	28	7125	6000	100	70
York	91	4778	4000	100	9
E&W	65	5266	4500	84	31

Table 9.4: Erythropoietin (EPO) prescribing in PD patients

There was a striking predominance of PD patients among those achieving a haemoglobin level of over 10g/dL without erythropoietin, implying that the greater susceptibility of HD patients to anaemia outweighs the advantages of their better access to intravenous iron than PD patients. Interestingly, Wrexham, which prescribed erythropoietin for the smallest proportion of its PD population of any centre and achieved a haemoglobin of over 10 g/dL without erythropoietin in 70% of PD patients, reported ferritin levels that, although just exceeding the median for England & Wales, were lower than those of many centres, with far fewer haemoglobins reaching the target without erythropoietin. This illustrates the fact that iron provision is only one of several factors that influence anaemia in patients not receiving erythropoietin.

As in previous reports, there was wide variation between centres in erythropoietin dosage, HD patients receiving higher average doses than their PD peers. Even within modalities, however, centres giving higher doses were not necessarily more successful in meeting the Renal Association haemoglobin target. As an example, Liverpool HD patients received the highest average dose of erythropoietin of any centre and achieved a target haemoglobin in 81% of cases. In Stevenage, however, which gave the lowest average dose of erythropoietin to its HD population, 86% of patients had a haemoglobin of over 10 g/dL. Some centres with GP prescribing of erythropoietin may not be logging all the prescriptions and accurate dosage of erythropoietin, which may account for their apparently lower usage.

Erythropoietin and time on RRT

In contrast with the 2000 data, the cross-sectional analysis of the 2001 returns (Table 9.5) shows was no increase in the proportion of patients treated with erythropoietin with increasing time on dialysis.

Time on treatment	<1 year	1–2 years	2–3 years	3–5 years	5–10 years	>10 years
HD %	81 (490)	87 (546)	84 (429)	83 (551)	84 (526)	80 (351)
PD %	66 (237)	61 (213)	67 (161)	66 (160)	63 (108)	69 (65)

Table 9.5: Erythropoietin use and length of time on dialysis

The percentage of HD and PD patients treated during the first year (81% and 66% respectively) was similar to the combined means for the first 10 years of treatment (80% and 68%). This suggests an increasing provision of pre-dialysis erythropoietin and an earlier commencement of erythropoietin in patients on dialysis, consistent with the earlier peaks in haemoglobin shown in Chapter 8.

Age and erythropoietin provision

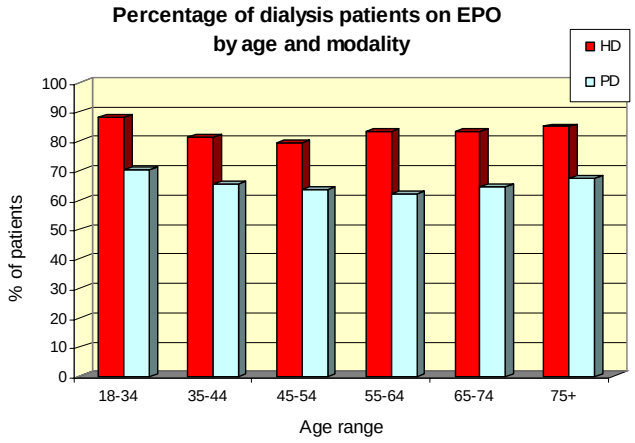


Figure 9.12: Age and the provision of erythropoietin (EPO), by modality

Although the difference between age groups in the percentage of patients prescribed erythropoietin was small, Figure 9.12 shows a trend towards a greater provision at the extremes of age. For HD, but not PD, this trend also applied to the provision of erythropoietin to patients with a haemoglobin level less than 10 g/dL. Data on erythropoietin prescription in the over-75 age group demonstrate that advancing age is not considered a barrier to erythropoietin provision (Figure 9.13).

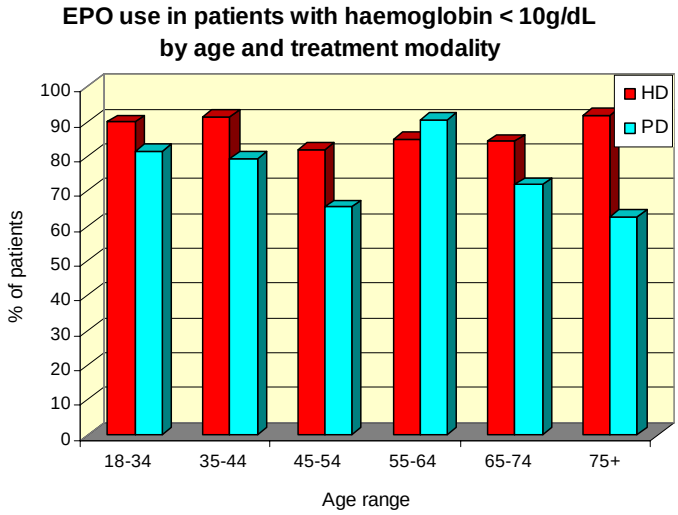


Figure 9.13: Erythropoeitin (EPO) use in patients with haemoglobin <10 g/dL, by age group

Consistent with the high erythropoietin requirements of the 18–34-year-old group shown in Figure 9.12, the proportion of patients in this category achieving a haemoglobin of 10 g/dL or more without erythropoietin was the lowest of all groups for both HD and PD patients (Tables 9.6 and 9.7). In addition, and consistent with the 2000 data, there was a trend towards a higher achievement of a haemoglobin level of 10 g/dL without erythropoietin in middle age than in the young or elderly.

Age group (years)	18–34	35–44	45–54	55–64	65–74	75+
% on EPO	88	81	79	83	83	85
%Hb >10 g/dL no EPO	8	16	15	12	12	10
%Hb <10 g/dL on EPO	90	91	82	85	84	92

Table 9.6: Percentage use of erythropoietin , by Hb achievement, for patients on HD

Age group (years)	18–34	35–44	45–54	55–64	65–74	75+
% on EPO	70	65	64	62	65	67
%Hb >10 g/dL no EPO	23	31	33	37	33	25
% Hb <10 g/dL on EPO	82	79	65	91	72	63

Table 9.7: Percentage use of erythropoietin, by Hb achievement, for patients on PD

Erythropoietin prescription and gender

Consistent with the overall year-on-year improvement in the treatment of anaemia, Tables 9.8 and 9.9 demonstrate that haemoglobin values in both males and females were higher than in the 2000 report for both dialysis modalities.

Gender	Mean Hb (g/dL)	Standard deviation	% on EPO	Hb <10 g/dL % on EPO	Hb >10 g/dL % without EPO
Male	11.4	1.66	82	86	14
Female	11.2	2.97	86	88	9

Table 9.8: Erythropoietin, by gender, on HD

Gender	Mean Hb(g/dL)	Standard deviation	% on EPO	Hb <10 g/dL % on EPO	Hb >10g/dL % without EPO
Male	11.9	1.69	62	79 (78)	36 (315)
Female	11.6	3.58	70	72 (65)	25 (143)

Table 9.9: Erythropoietin, by gender, on PD

As in all previous Registry reports, the mean haemoglobin was higher in males than females for both HD and PD, although a greater proportion of females than males received erythropoietin, demonstrating an appropriate targeting of treatment.

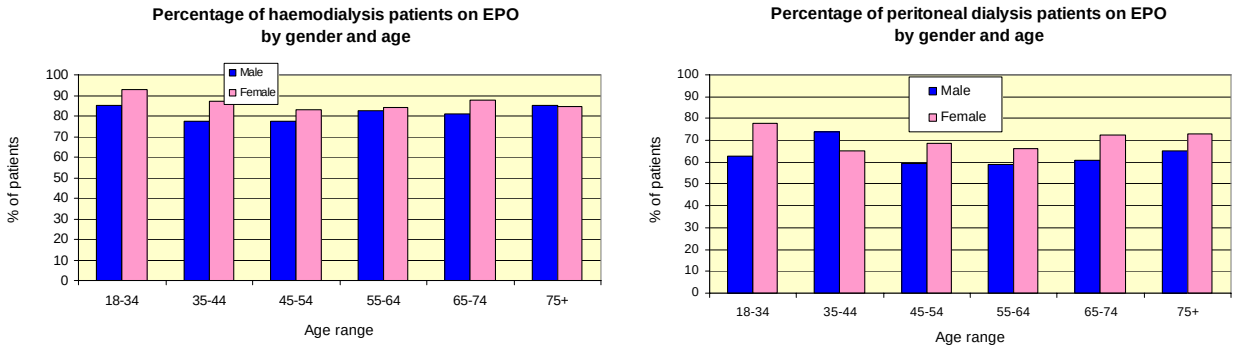


Figure 9.14: Erythropoietin (EPO) use by age, gender and dialysis modality

Figure 9.14 demonstrates that the prescription of erythropoietin for more females than males applied to all age groups and both modalities, with the exception of PD patients aged 35–44. In addition, a greater proportion of males than females achieved a haemoglobin concentration of 10 g/dL without erythropoietin.

Conclusion

An increasing proportion of HD and PD patients are achieving the target serum ferritin of 100 mcg/L.

The median serum ferritin was higher with HD than PD.

All patients showed a progressive rise in ferritin level with increasing time on dialysis, although this effect was more marked for HD than PD.

A greater proportion of HD than PD patients were treated with erythropoietin, although for patients with a haemoglobin concentration of less than 10g/dL, the percentage treated was similar for both modalities.

There was a wide variation in erythropoietin dosage between centres, which was not always reflected in the achievement of haemoglobin targets.

There was a trend towards a greater prescription of erythropoietin at the extremes of age, and advancing age was not a barrier to erythropoietin provision.

The mean haemoglobin reading was higher in males than females for both dialysis modalities, although a greater proportion of females than males were prescribed erythropoietin across all age groups for HD and in all but the 35–44-year-old group for PD.

Chapter 10: Serum Calcium, Phosphate and Parathyroid Hormone

Summary

- Results for corrected calcium are highly dependent on serum albumin measurement. Units using the BCP method of albumin measurement have higher levels of corrected calcium and fewer patients within the standard range.

- Of all dialysis patients, 71% had a corrected serum calcium within the standard range. There was no significant difference between haemodialysis and peritoneal dialysis patients.

- Only 50% of dialysis patients had a serum phosphate within the standard range. The phosphate level was significantly lower in peritoneal dialysis patients.

- Serum intact parathyroid hormone fell within the standard range in 58% of dialysis patients.

- For corrected calcium, serum phosphate and intact parathyroid hormone, the range of difference between units was significant.

- There has been no improvement in control of these variables in the 5 years for which the Registry has data.

- With current dialysis techniques and drugs available, renal units find compliance with the recommended standards extremely difficult.

Introduction

The control of calcium, phosphate and parathyroid hormone (PTH) activity in patients receiving renal replacement therapy (RRT) is important in preventing progressive renal osteodystrophy and ectopic calcification. There is increasing evidence that a poor control of calcium/phosphate metabolism accelerates cardiac and vascular disease. Recommended target concentrations for all of these analytes are published in the Renal Association Standards document.

Considering that the measurement of 'routine' biochemical parameters is bread and butter medicine for nephrologists, and that it is easy to establish consensus that a low albumin and poorly controlled calcium metabolism are to be avoided, comparative audit in this area is very hard.

The problem stems first from the well–rehearsed differences in measurement of serum albumin from centre to centre, both in terms of the assay and in terms of defining normality. This is compounded by differing mathematical approaches to 'correcting' the calcium. This means that a corrected calcium that is apparently the same from two centres may not actually *be* the same.

These problems lead to more than semantic arguments. Small differences can make a centre compliant or non-compliant with Renal Association Standards. Renal units with several satellites may use different laboratories and make even internal comparison difficult. It has been suggested that using uncorrected calcium might facilitate comparative audit, but this probably brings an equally difficult set of unquantifiable confounding variables. Measuring ionised calcium would be the ideal approach.

The latest Renal Association Standards document sets the same standards for calcium, phosphate and PTH whatever the modality of treatment. The concept of a 'renal failure career' is gaining currency, so although we continue to report haemodialysis (HD) and peritoneal dialysis (PD) data separately, the different treatment modality data are also combined for each unit, unlike in previous reports.

When comparing the percentage achievement of standards by different renal units, chi squared analysis confirms that these differences are significant (see Chapter 14).

The Standards

The recommended Standards for these variables in 2001 were:

Serum calcium: 'Total calcium within the normal range quoted by the local pathology laboratory, corrected for serum albumin concentration, or normal serum ionised calcium.' For HD patients, samples should be taken pre-dialysis.

Serum phosphate: HD, pre-dialysis sample, 1.2–1.7 mmol/L.
PD, 1.1–1.6 mmol/L.

Serum intact PTH: Should be maintained at between two and three times the local normal range.

Serum calcium

Measurement

Since different units use different assay methods for calcium and albumin, different correction factors for albumin and different reference ranges for both variables, these are tabulated (Table 10.1). The Renal Registry has used the formula:

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

The registry has either calculated the corrected calcium from the total calcium and the serum albumin or 'back–calculated' the total calcium using the local value for corrected calcium, the serum albumin level and the local correction factor.

The BCG method of albumin measurement overestimates low levels of serum albumin (see Chapter 11). Consequently, when the albumin is low, the calculated corrected calcium will be lower than the 'true' corrected calcium, possibly concealing hypercalcaemia.

City	Hospital	Method (calcium)	Method (albumin)	Ref range (total calcium)	Correcting formula
Birmingham	Heartlands Hospital	CPC	BCG	2.05– 2.60	+0.025(40–Alb)
Bradford	St Luke's Hospital	CPC	BCG	Not reported	+(40–Alb/40)
Bristol	Southmead Hospital	CPC	BCG	2.10–2.65	+0.02(40–Alb)
Cardiff	University of Wales Hospital	Arsenazo	BCG	2.20–2.60	+0.02(40–Alb)
Carlisle	Cumberland Infirmary	Arsenazo	BCG	2.10–2.60	+0.02(40–Alb)
Carshalton	St Helier Hospital	CPC	BCG	2.20–2.60	+0.02(40–Alb)
Coventry	Walsgrave Hospital	Arsenazo	**BCP**	2.22–2.58	–((0.0116×Alb)+0.4652)
Derby	Derby District Hospital	Aresenazo	**BCP**	2.25–2.60	+0.012× (40–Alb)
Exeter	Royal Devon and Exeter Hospital	Arsenazo	BCG	2.20–2.70	+0.02(40–Alb)
Gloucester	Gloucester Road Infirmary	Electrode	**BCP**	2.13–2.63	+0.02(40–Alb)
Hull	Hull Royal Infirmary	Electrode	**BCP**	2.20–2.60	+(–0.016×Alb)+0.59
Leeds	St James's Hospital	CPC	BCG	2.20–2.60	+0.016(46–Alb)
Leeds	LGI	CPC	BCG	2.25–2.60	+(Alb–40) ×0.0225
Leicester	Leicester General Hospital	Arsenazo	BCG	2.10–2.60	+0.02(40–Alb)
Liverpool	Liverpool Royal Hospital	CPC	BCG	2.20–2.60	+0.003(40.4–Alb)
London	Guys St Thomas'	Electrode	**BCP**	2.20–2.60	+0.02(40–Alb)
Middlesborough	South Cleveland	Arsenazo	BCG	2.10–2.60	+0.02(40–Alb)
Newcastle	Royal	Arsenazo	BCG	2.12–2.60	+0.02× (40–ALB)
Nottingham	Nottingham City Hospital	Arsenazo	**BCP**	2.40–2.80	+0.017(43–Alb)
Oxford	Churchill Hospital	Arsenazo	BCG	2.12–2.62	Not reported
Plymouth	Derriford Hospital	CPC	BCG	2.12–2.55	+0.025(40–Alb)
Portsmouth	Queen Alex	CPC	BCG	2.15–2.60	–(Alb×0.017) +0.70
Preston	Royal Preston Hospital	CPC	BCG	2.18–2.63	+0.02(40–Alb)
Reading	Royal Berkshire	Arsenazo	BCG	2.10–2.55	+1–(albumin/41)
Sheffield	Northern General Hospital	Arsenazo	BCG	2.20–2.60	–((0.0175×Alb)+0.7)
Stevenage	Lister Hospital	Electrode	**BCP**	2.20–2.63	+0.025(40–Alb)
Stourbridge	Wordsley Hospital	Arsenazo	BCG	2.20–2.60	+0.02(40–Alb)
Southend	Southend Hospital	CPC	BCG	2.05–2.65	+ (40–Alb) 0.02
Sunderland	Sunderland Royal Hospital	CPC	BCG	2.12–2.65	Not reported
Swansea	Morriston	CPC	BCG	2.15–2.60	+0.02× (40–Alb)
Truro	Royal Cornwell Hospital Trust	CPC	BCG	2.15–2.60	+0.02× (41–Alb)
Wolverhampton	Newcross Hospital	Arsenazo	BCG	2.17–2.66	+1–(alb/40)
Wrexham	Maelor General Hospital	Electrode	**BCP**	2.10–2.65	–((0.071×Alb)+0.692)
York	York District Hospital	CPC	BCG	2.10–2.60	–(Alb× 0.25) +1

Table 10.1: Methods used to measure and 'correct' serum calcium

Results

The new Renal Association Standard for calcium states that the serum calcium, adjusted for albumin concentration, should be between 2.2 and 2.6 mmol/L, measured pre-dialysis in HD patients and PD patients. For current data, given the variability in albumin measurement techniques and local normal ranges, the Registry has calculated compliance using a Standard of 2.25–2.65 mmol/L, which was current in 2001, but will use with the new Renal Association Standard next year.

Figure 10.1 shows the corrected calcium for PD and HD patients combined, and Figure 10.2 what proportion of patients in any unit have values within the range 2.25–2.65 mmol/L. It is apparent that hypocalcaemia is not a significant issue but that several units have median corrected calcium concentrations that lie above the standard range. This probably represents a different approach to calcium metabolism in these units.

Figures 10.3–10.6 show similar data for the same units but with the data split by treatment modality.

There seems to be little difference between HD and HD with regard to corrected calcium, but there is more variability between units in the PD data. Overall, very close to 70% of UK patients are compliant with the Standard, regardless of treatment modality.

In all the figures, units that use the BCP method of measuring serum albumin have been indicated with large blocks. It is interesting that seven out of the eight units using this method have a median corrected calcium *above* the national median. This is the expected result of obtaining a lower serum calcium reading, assuming the use of formulae for correction similar to those used in BCG laboratories. It thus appears that the subsequent clinical response to these readings does not fully modify the corrected calcium obtained back towards the median.

The distribution of differences between units in compliance with the standard is statistically significant for corrected calcium and also for serum phosphate and intact PTH (iPTH).

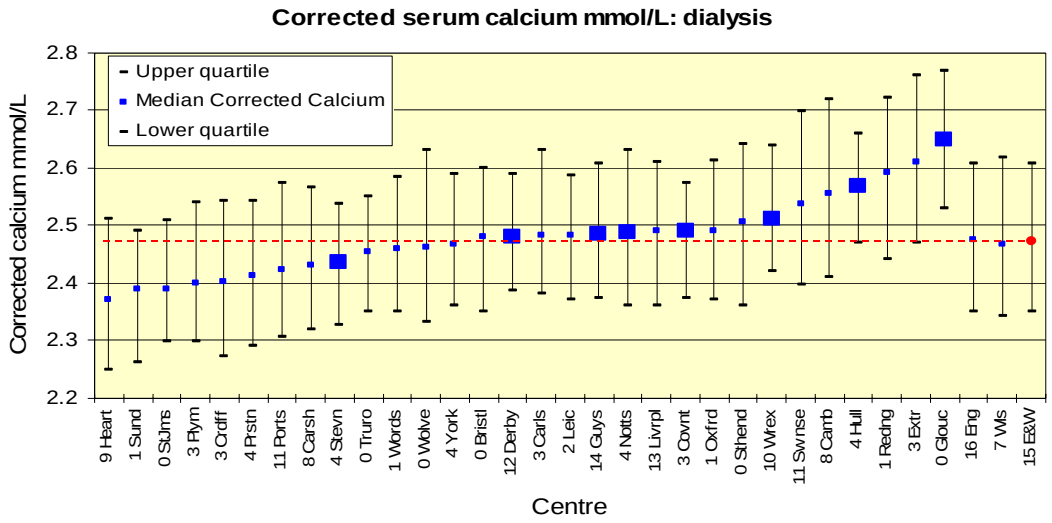


Figure 10.1: Median corrected calcium, all HD and PD patients (large block = BCP centre)

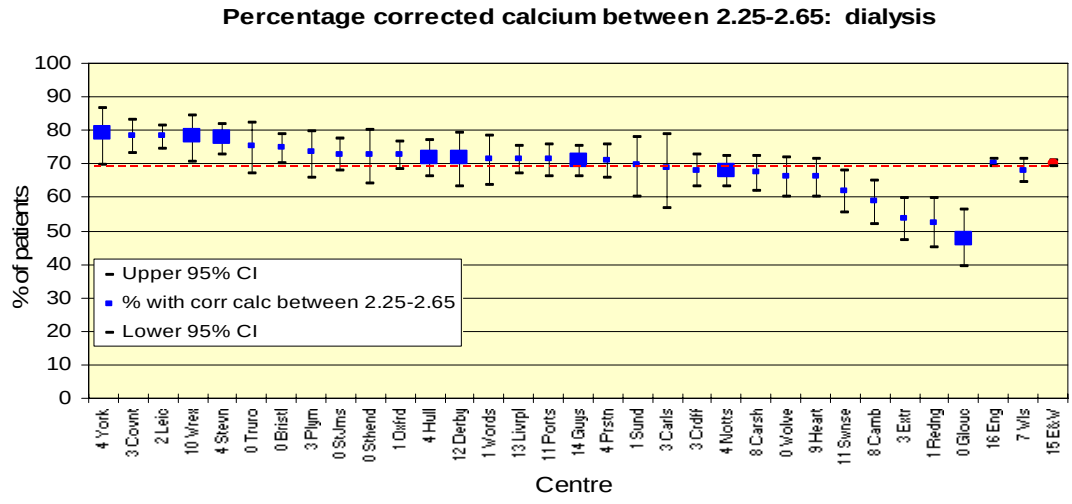


Figure 10.2: Percentage corrected calcium in the range 2.25–2.65 mmol/L: dialysis

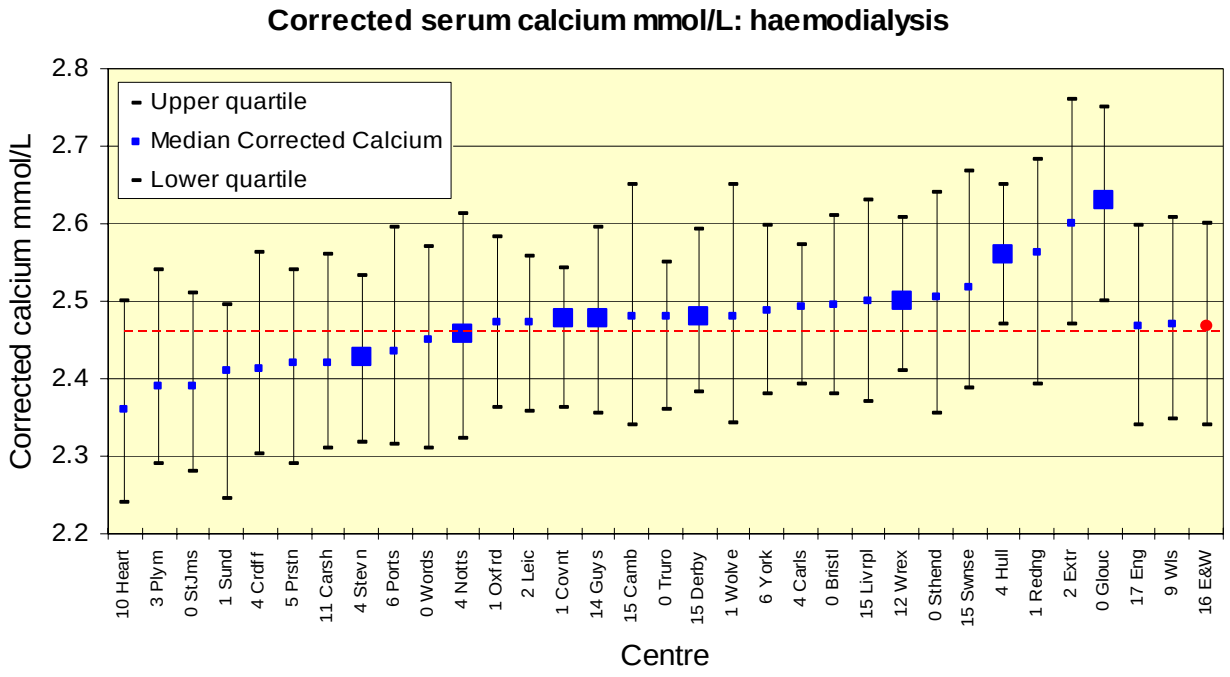


Figure 10.3: Median corrected calcium: HD (large block = BCP centre)

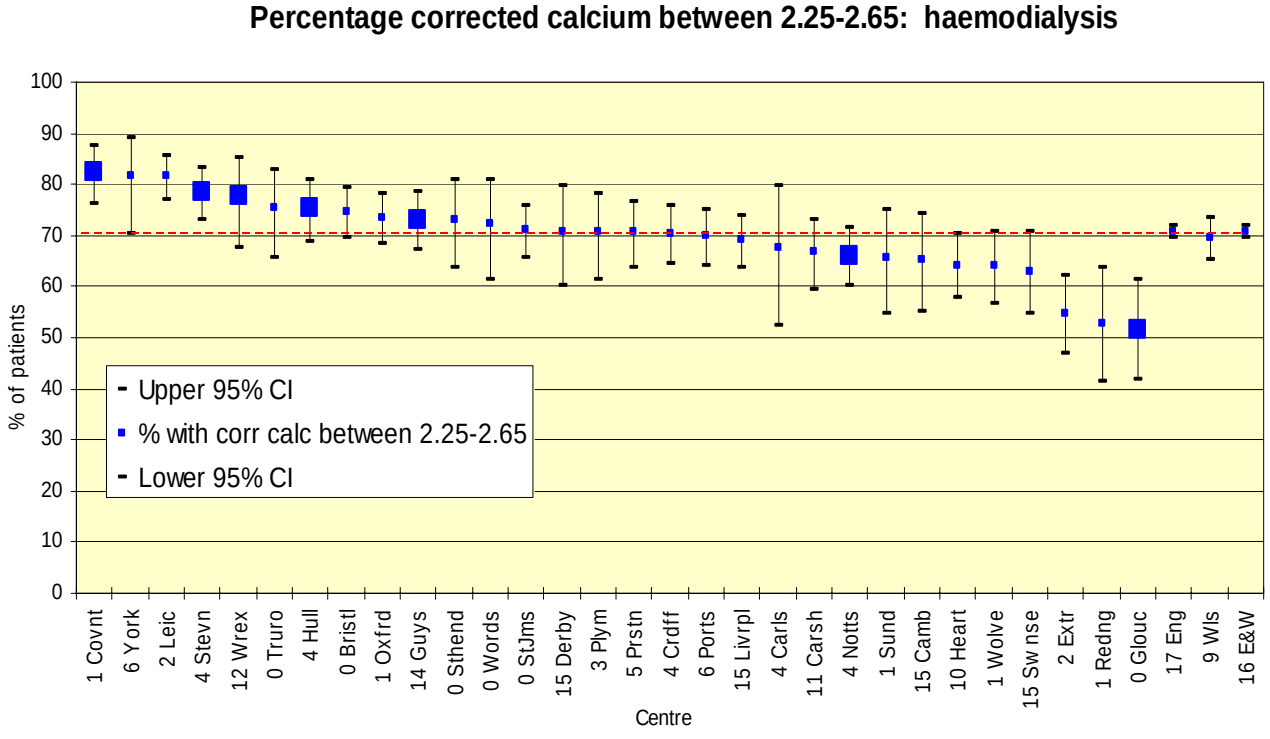


Figure 10.4: Percentage corrected calcium within 2.25–2.65 mmol/L: HD

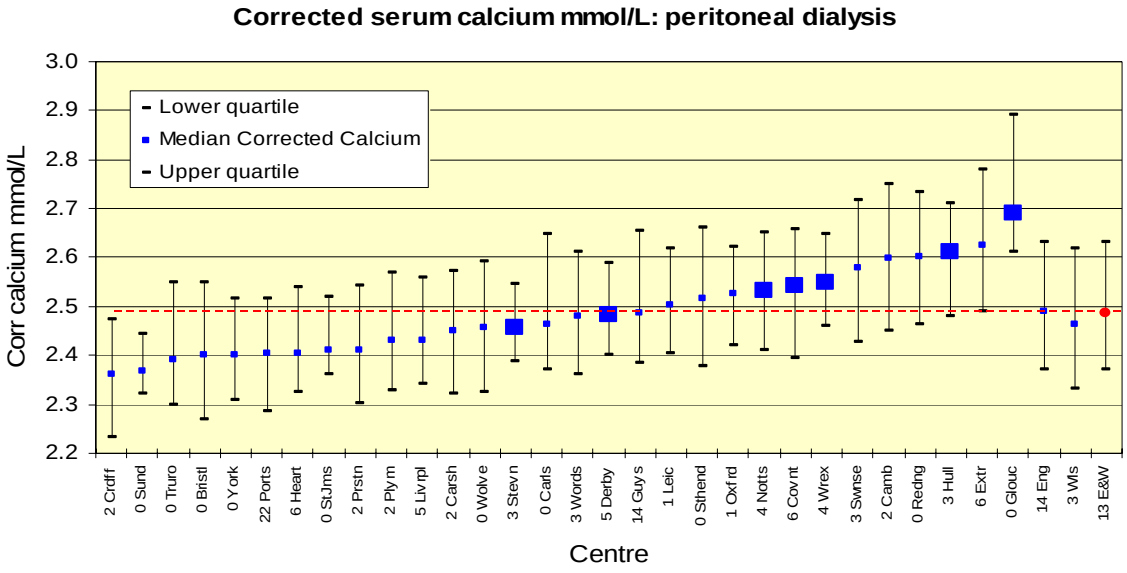


Figure 10.5: Median corrected calcium: PD (large block = BCP centre)

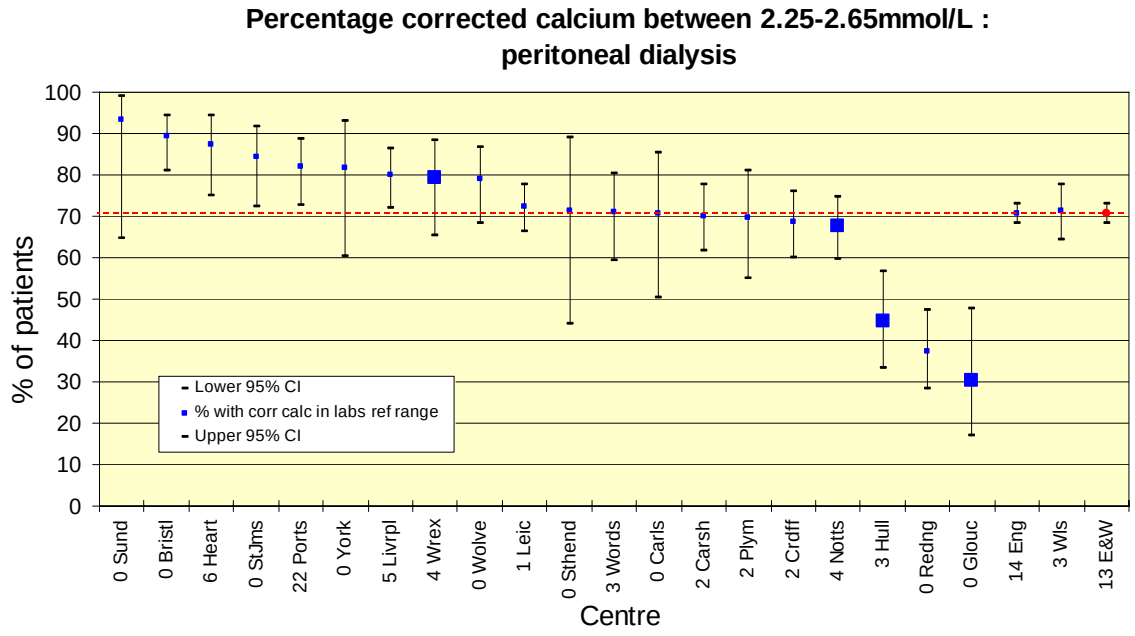


Figure 10.6: Percentage corrected calcium within 2.25–2.65 mmol/L: PD

Changes in calcium over time

The registry has serial data for corrected calcium over 3 years, and there is no visible trend in calcium either for HD or PD patients (Figures 10.7 and 10.8). Renal Units changing albumin methodology (e.g. Exeter) from BCG to BCP show an apparent rise in serum calcium.

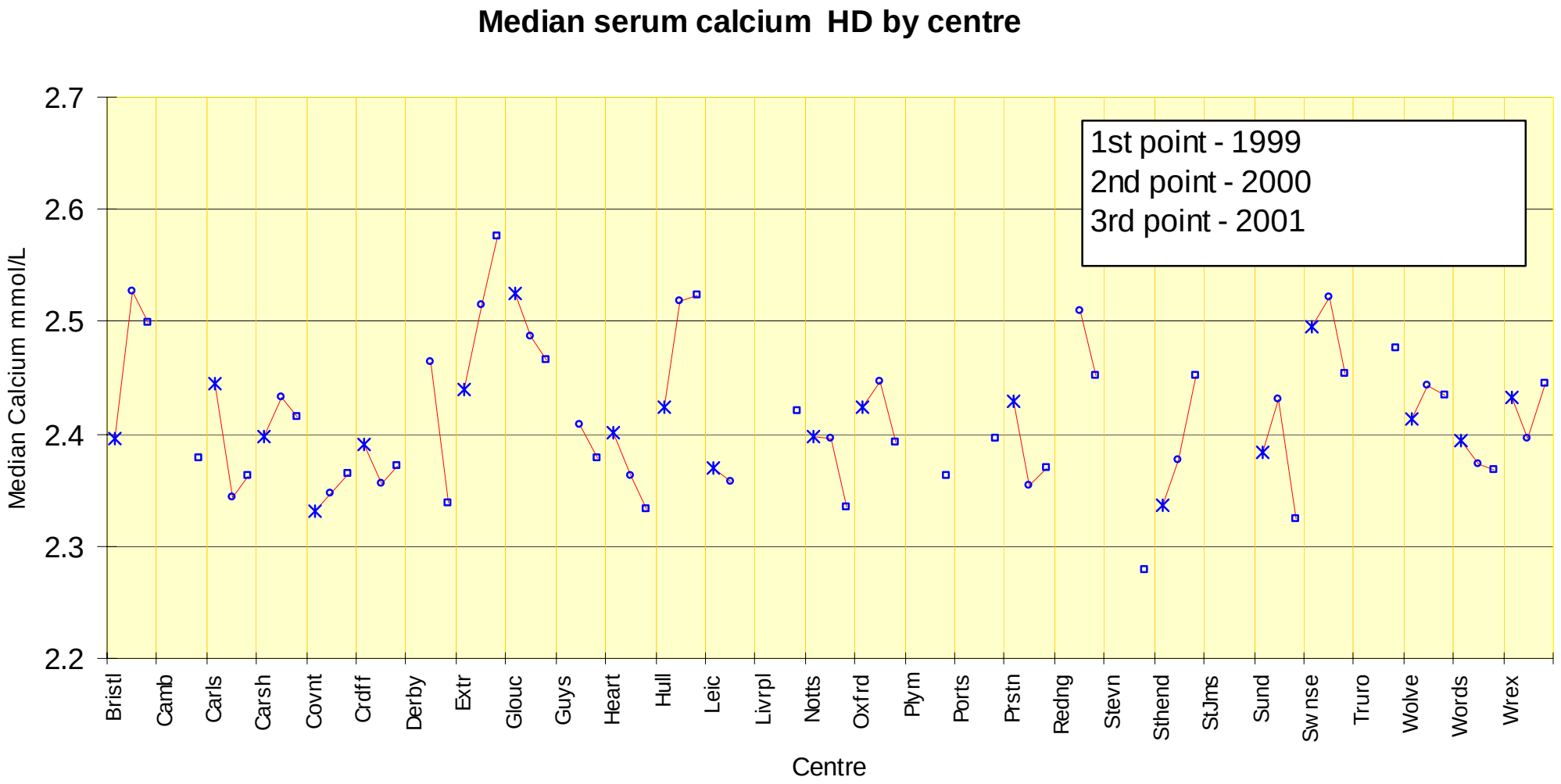


Figure 10.7: Median serum calcium by centre over 3 years: HD

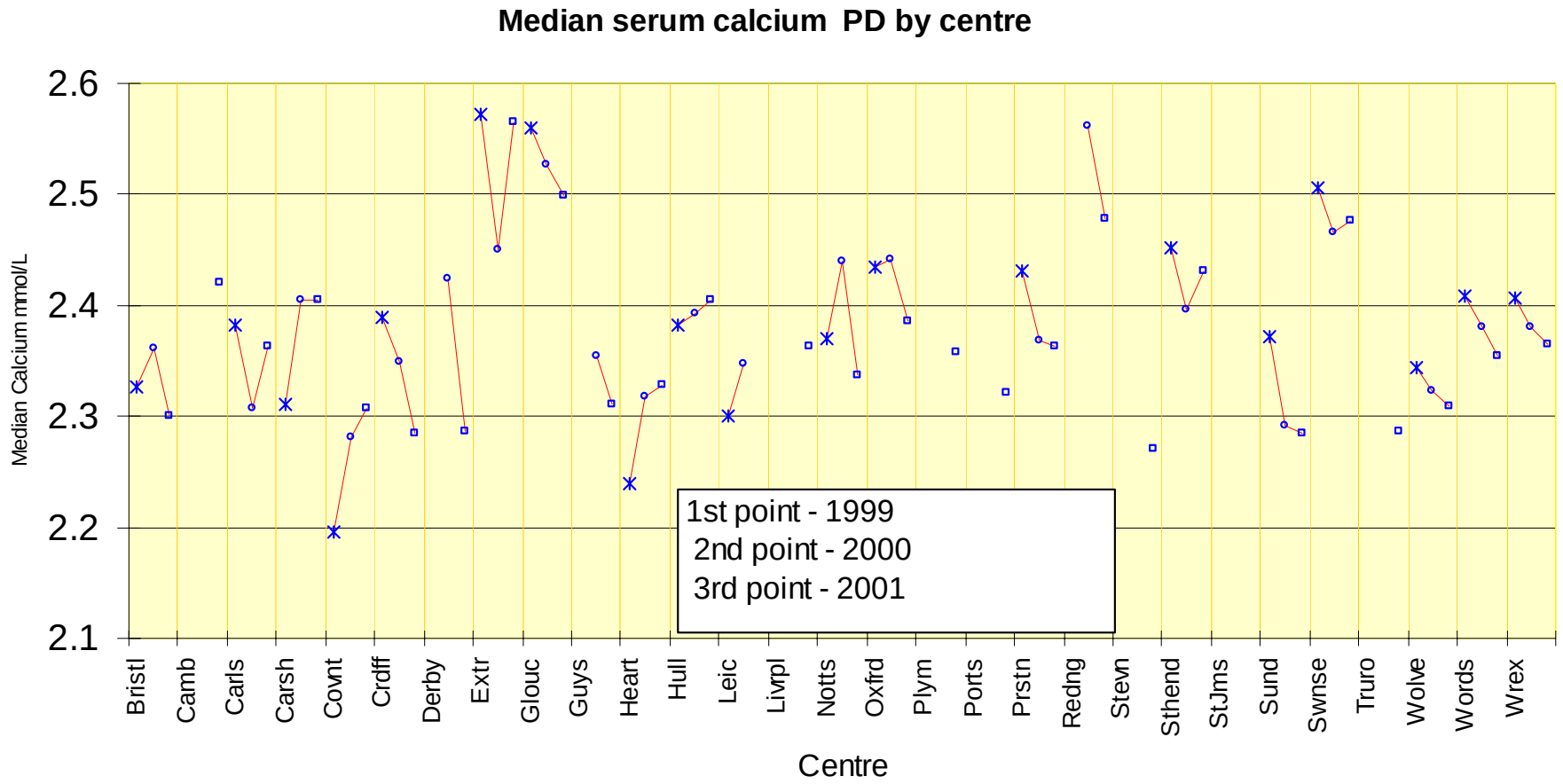


Figure 10.8: Median serum calcium by centre over 3 years: PD

Serum phosphate

Measuring serum phosphate has far fewer problems so audit is easier; the methodologies for measuring serum phosphate are listed in Table 10.2. All centres bar one use the same method, but there is still a variation in the quoted normal range for laboratories using the same method of measurement.

Measurement of phosphate

City	Hospital	Method	Ref range
Birmingham	Heartlands Hospital	PMb	0.80–1.45
Bradford	St Luke's Hospital	PMb	0.80–1.31
Bristol	Southmead Hospital	PMb	0.75–1.35
Cardiff	University of Wales Hospital	PMb	0.80–1.45
Carlisle	Cumberland Infirmary	PMb	0.90–1.50
Carshalton	St Helier Hospital	PMb	0.80–1.40
Coventry	Walsgrave Hospital	PMb	0.75–1.40
Derby	Derby District General	PMb	0.80–1.45
Exeter	Royal Devon and Exeter Hospital	PMb	0.50–2.30
Gloucester	Gloucester Road Infirmary	PMb	0.82–1.55
Hull	Hull Royal Infirmary	PMb	0.70–1.50
Leeds	St James's Hospital	PMb	0.80–1.30
Leeds	LGI	PMb	0.80–1.31
Leicester	Leicester General Hospital	PMb	0.80–1.40
Liverpool	Liverpool Royal Hospital	PMb	0.70–1.40
London	Guys St Thomas'	PMb	0.80–1.50
Middlesborough	South Cleveland Hospital	PMb	0.74–1.40
Newcastle	Royal	PMb	0.80–1.44
Nottingham	Nottingham City Hospital	PMb	0.80–1.40
Oxford	Churchill Hospital	PMb	0.80–1.45
Plymouth	Derriford Hospital	PMb	0.80–1.40
Portsmouth	Queen Alex	PMb	0.80–1.50
Preston	Royal Preston Hospital	PMb	0.80–1.45
Reading	Royal Berkshire	PMb	0.81–1.45
Sheffield	Northern General Hospital	Fish/Sub	0.80–1.40
Stevenage	Lister Hospital	PMb	0.75–1.36
Stourbridge	Wordsley Hospital	PMb	0.80–1.40
Southend	Southend Hospital	PMb	0.80–1.45
Sunderland	Sunderland Royal Hospital	PMb	0.80–1.40
Swansea	Morriston	PMb	0.80–1.40
Truro	Royal Cornwall Hospital Trust	PMb	0.87–1.46
Wolverhampton	Newcross Hospital	PMb	0.80–1.40
Wrexham	Maelor General Hospital	PMb	0.80–1.40
York	York District Hospital	PMb	0.80–1.40

Table 10.2: Methodologies for measurement of serum phosphate
Conversion factor: mg/dL = mmol/L × 3.1

Results

The new Standard for phosphate concentration is that serum phosphate should be below 1.8 mmol/L; the Standard was previously 1.2–1.7 mmol/L pre-dialysis in HD and 1.1–1.6 mmol/L in PD. Centres will have been working towards this Standard during the period of data collection. Figures 10.9–10.14 show these data, first for all dialysis patients and then for

separate dialysis modalities. There is immense variability between patients in serum phosphate level, shown by the wide error bars, and the national median is only just below the standard of 1.8 mmol/L. The distribution of median phosphate concentration suggests that all units find this an almost impossible standard to comply with.

There is a small but significant difference ($p<0.01$) between HD and PD, and the national median is lower in PD patients. Eight units managed to get the upper quartile of the serum phosphate below 1.8 for PD patients, whereas only one centre managed this for their HD patients. Whether this effect is due to better control or globally poorer dietary intake in PD patients is not certain.

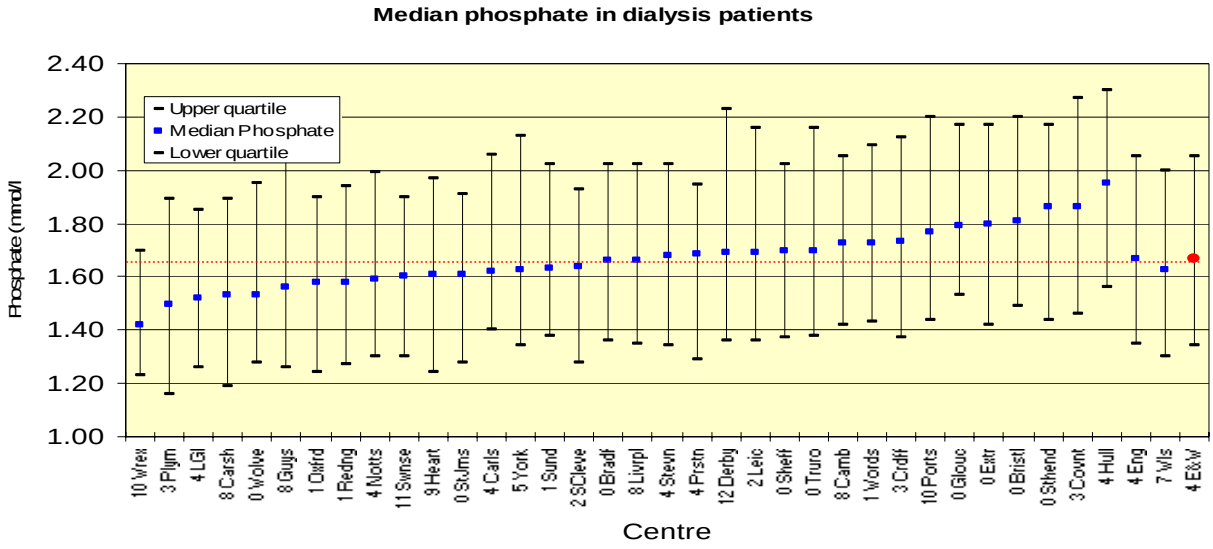


Figure 10.9: Median serum phosphate in all dialysis patients

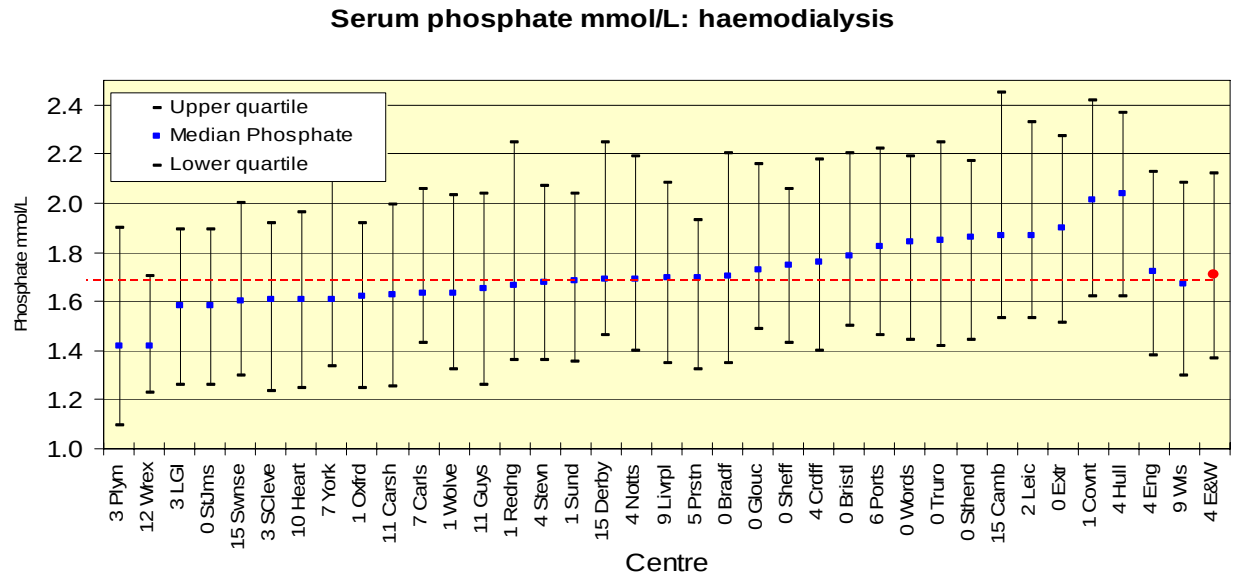


Figure 10.10: Median serum phosphate in HD patients

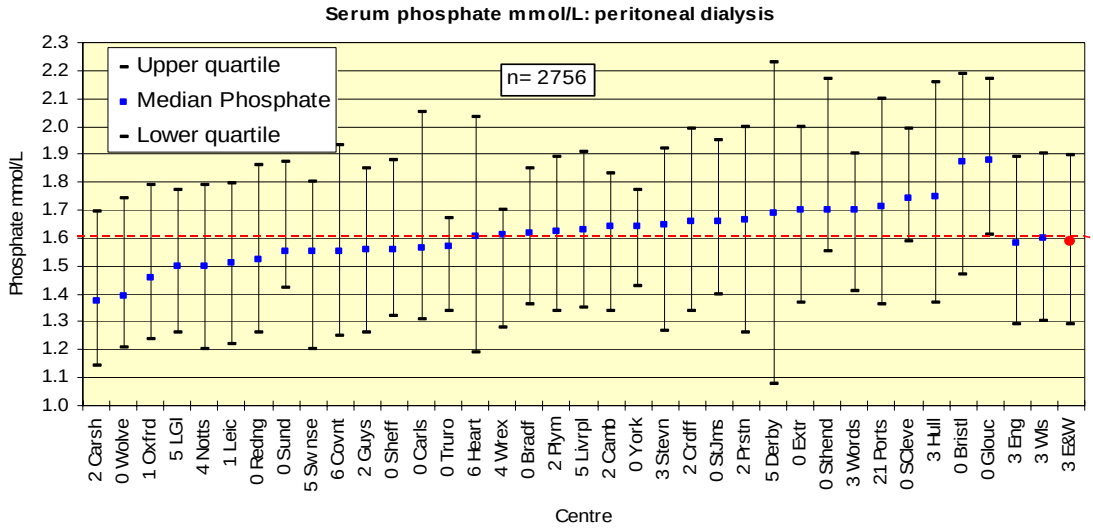


Figure 10.11: Median serum phosphate in PD patients

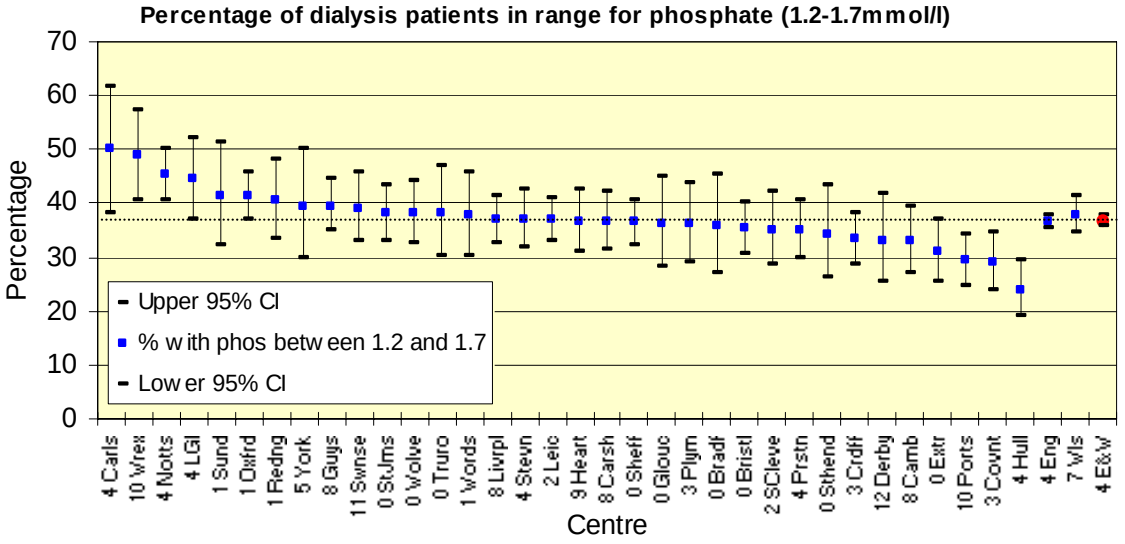


Figure 10.12: Phosphate: percentage compliance with the Standard in all dialysis patients

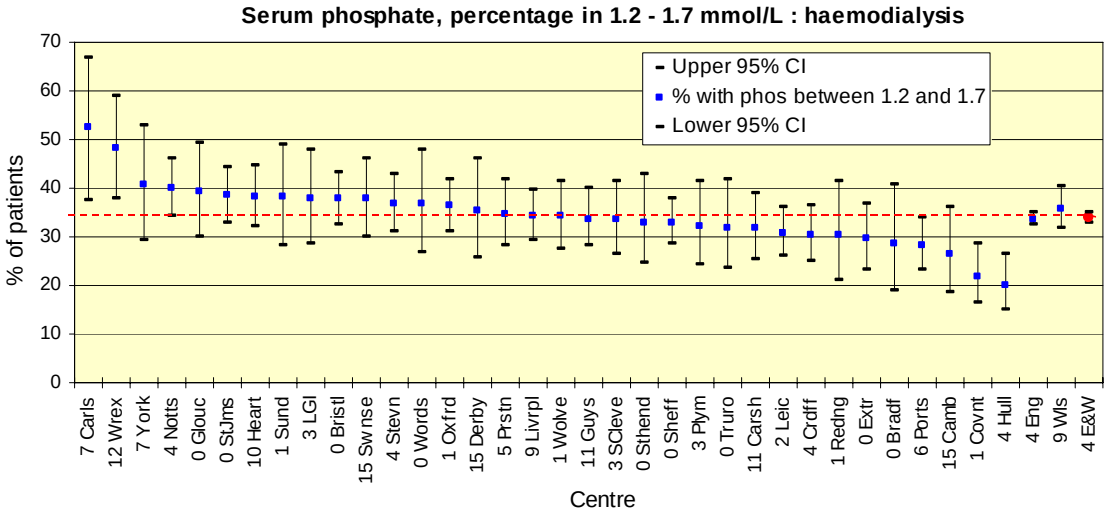


Figure 10.13: Phosphate: percentage compliance with the Standard in HD patients

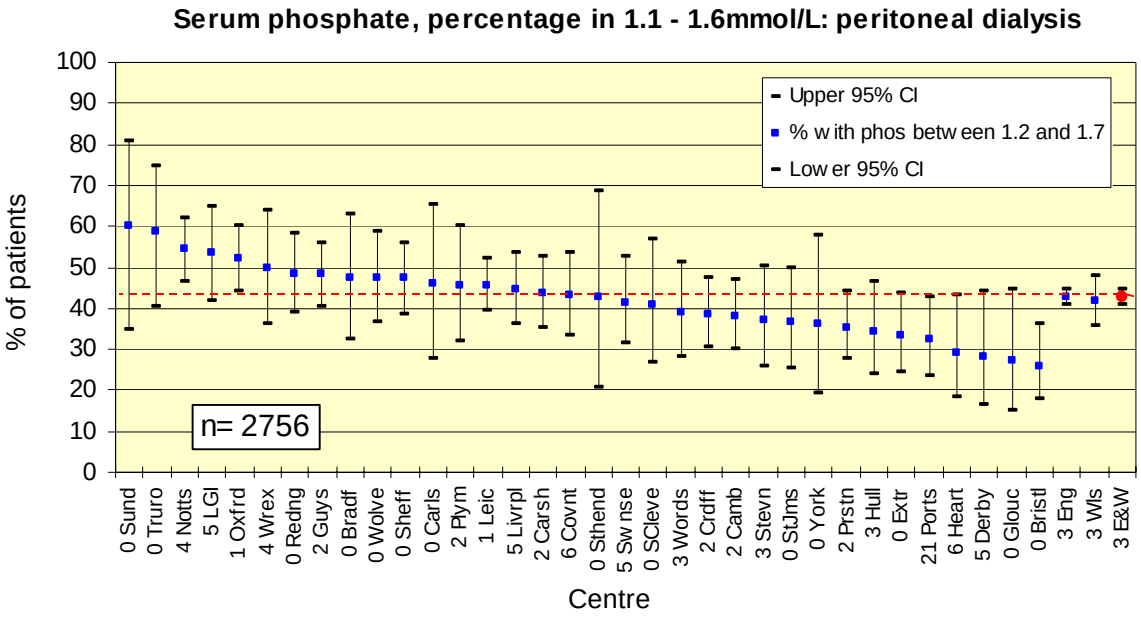


Figure 10.14: Phosphate: percentage compliance with the Standard in PD patients

Changes with time

Figures 10.15 and 10.16 represent the frequency distribution of serum phosphate concentration in 1997, 1999 and 2001. United States Renal Data System data are included for comparison. There is a growing desire to control phosphate better and an increase in the number of phosphate binders available, but these factors have not yet resulted in any measurable change. If change cannot be demonstrated in the next year or two, the cost-effectiveness of the newer phosphate binders will be called into question.

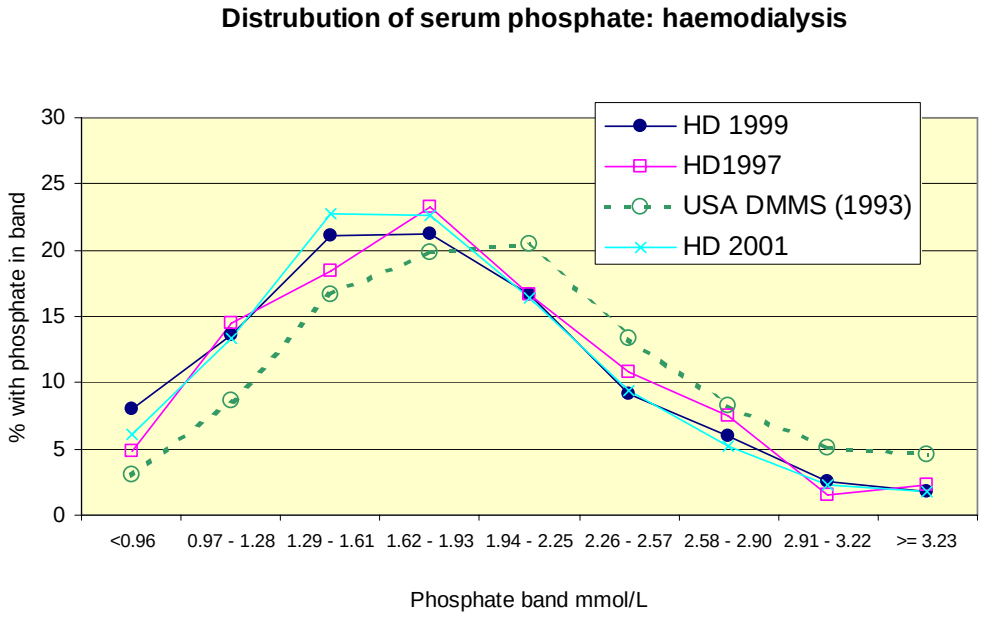


Figure 10.15: Distribution of serum phosphate in HD patients, 1999–2001

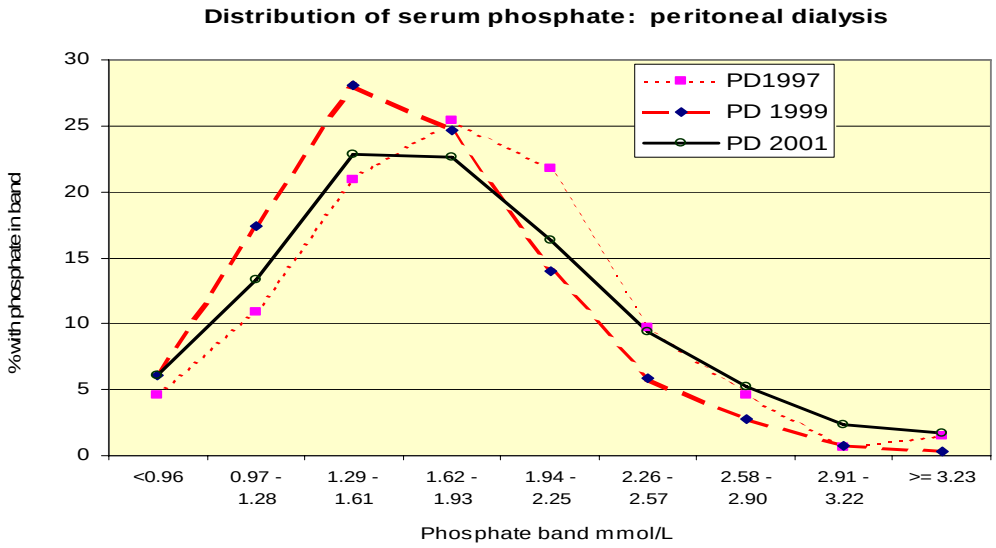


Figure 10.16: Distribution of serum phosphate in PD patients, 1999–2001

Parathyroid hormone

Assays

Different laboratories use different assays and have different reference ranges for PTH. These are tabulated for the various renal centres in Table 10.3.

City	Hospital	Method	Ref range
Birmingham	Heartlands Hospital	Elecsys (P Clark)	30–400 ng/mL
Bradford	St Luke's Hospital	Nichols (LGI)	<65 ng/mL
Bristol	Southmead Hospital	DPC	1.3–7.6 pmol/L
Cardiff	University of Wales Hospital	Nichols	0.9–5.4 pmol/L
Carlisle	Cumberland Infirmary	Elecsys	15–65 ng/L
Carshalton	St Helier Hospital	DPC	3–48 ng/L
Coventry	Walsgrave Hospital	IDS	1.1–4.2 pmol/L
Derby	Derby District General	DPC	12–72 ng/L
Exeter	Royal Devon and Exeter Hospital	DPC	0.6–4.6 pmol/L
Gloucester	Gloucester Road Infirmary	Nichols	0.9–5.4 pmol/L
Hull	Hull Royal Infirmary	DPC	7–53 ng/mL
Leeds	St James's Hospital	Nichols	11–55 ng/mL
Leeds	LGI	Nichols	11–55 ng/L
Leicester	Leicester General Hospital	DPC	1.3–7.6 pmol/L
Liverpool	Liverpool Royal Hospital	Nichols	1.1–6.9 pmol/L
London	Guys St Thomas'	Nichols	10–65 ng/L
Middlesborough	South Cleveland Hospital	DPC	12–72 ng/L
Newcastle	Royal	Nichols	10–65 ng/L
Nottingham	Nottingham City Hospital	DPC	8–78 ng/mL
Oxford	Churchill Hospital	Nichols	1.0–6.1 pmol/L
Plymouth	Derriford Hospital	DPC	12–72 ng/L
Portsmouth	Queen Alex	DPC Immulite	<4.7 pmol/L
Preston	Royal Preston Hospital	Roche Elecys	15–65 ng/L
Reading	Royal Berkshire	DPC	0.7–5.6 pmol/L
Sheffield	Northern General Hospital	Chiron	10–65 ng/L
Stevenage	Lister Hospital	DPC	11–65 ng/L
Stourbridge	Wordsley Hospital	DPC	0.45–5.0 pmol/L

City	Hospital	Method	Ref range
Southend	Southend Hospital	Roche Elecys	1.05–6.9 pmol/L
Sunderland	Sunderland Royal Hospital	DPC	1.3–7.6 pmol/L
Swansea	Morriston	Diasorin	10–50 ng/L
Truro	Royal Cornwall Hospital Trust	DPC	12–7 2ng/L
Wolverhampton	Newcross Hospital	DPC	0.76–7.42 ng/L
Wrexham	Maelor General Hospital	Nichols	0.9–5.4 pmol/L
York	York District Hospital	Nichols	10–60 ng/L

Table 10.3: Laboratory methodology for serum iPTH
Conversion factor: ng/L = pmol/L × 9.5

Results

The Renal Association Standards are based on multipliers of the individual laboratory's normal range. At the time when the data were collected, the recommendation was that iPTH (intact hormone assay) should be maintained at between two and three times the normal range. The data have been standardised between units, by the Registry, to an upper acceptable limit of 23 pmol/L to facilitate comparison.

The new recommendation is that iPTH should be less than four times the upper limit of normal, presumably reflecting the view that adynamic bone disease represents a theoretical rather than a real risk.

Figures 10.17 and 10.18 show the very wide variation in PTH within and between units, with the percentage compliance varying from 80% in Wrexham to less than 40% in Cambridge.

Figures 10.19–10.23 show these data split according to dialysis modality.

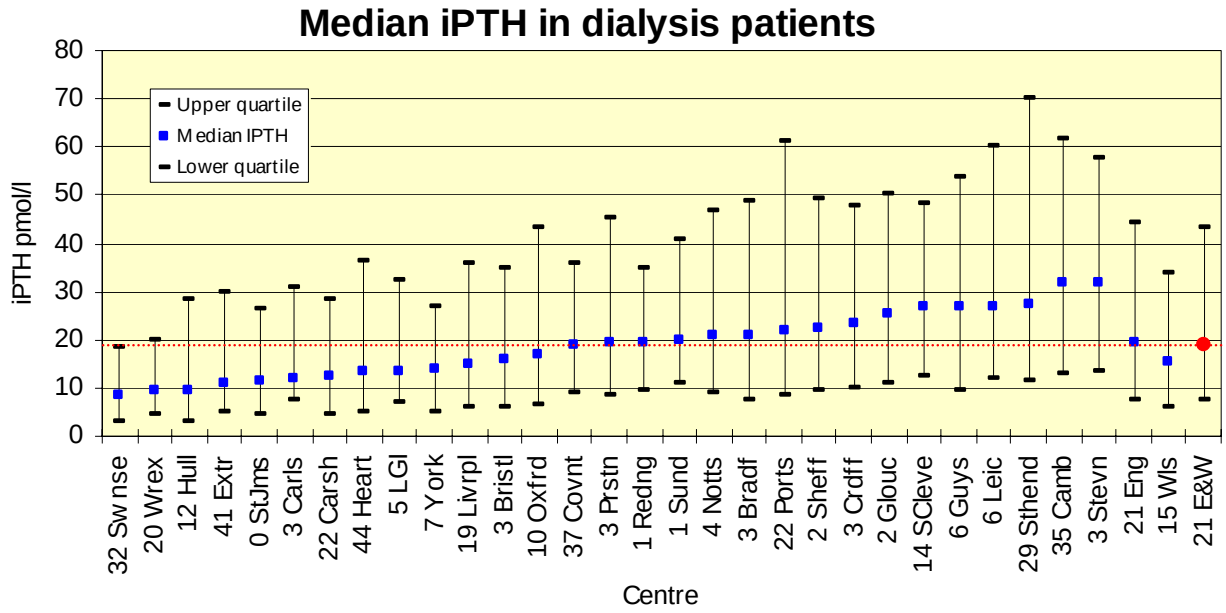


Figure 10.17: Median iPTH in all dialysis patients

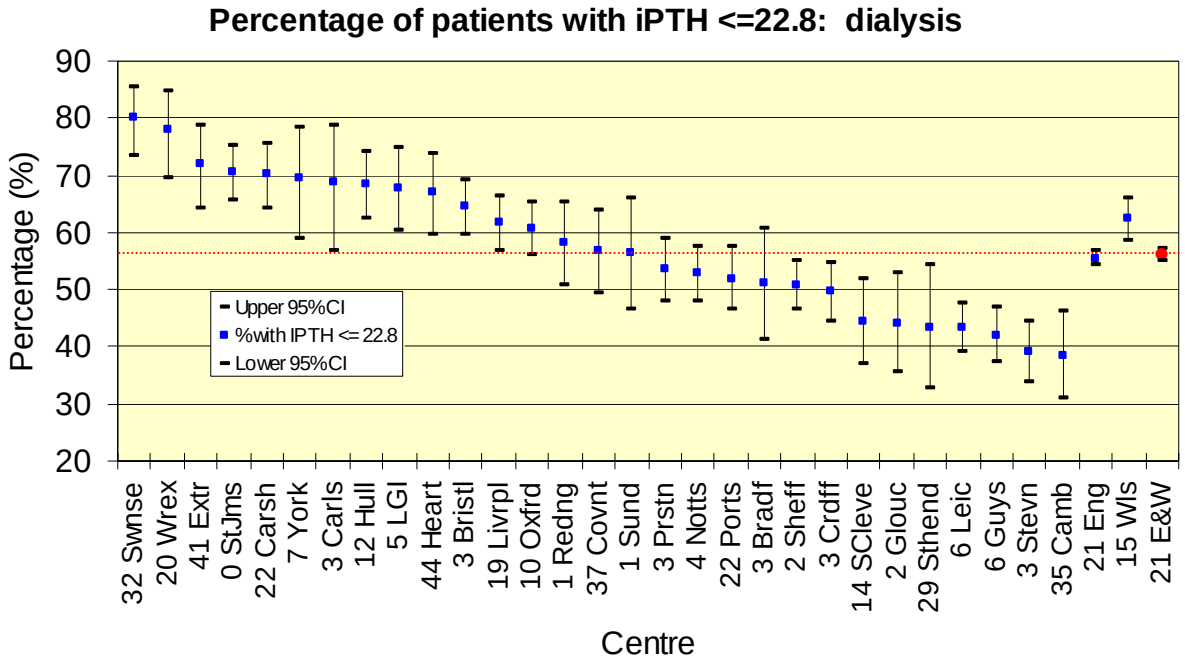


Figure 10.18: Percentage of patients with iPTH < 22.8 pmol/L in all dialysis patients

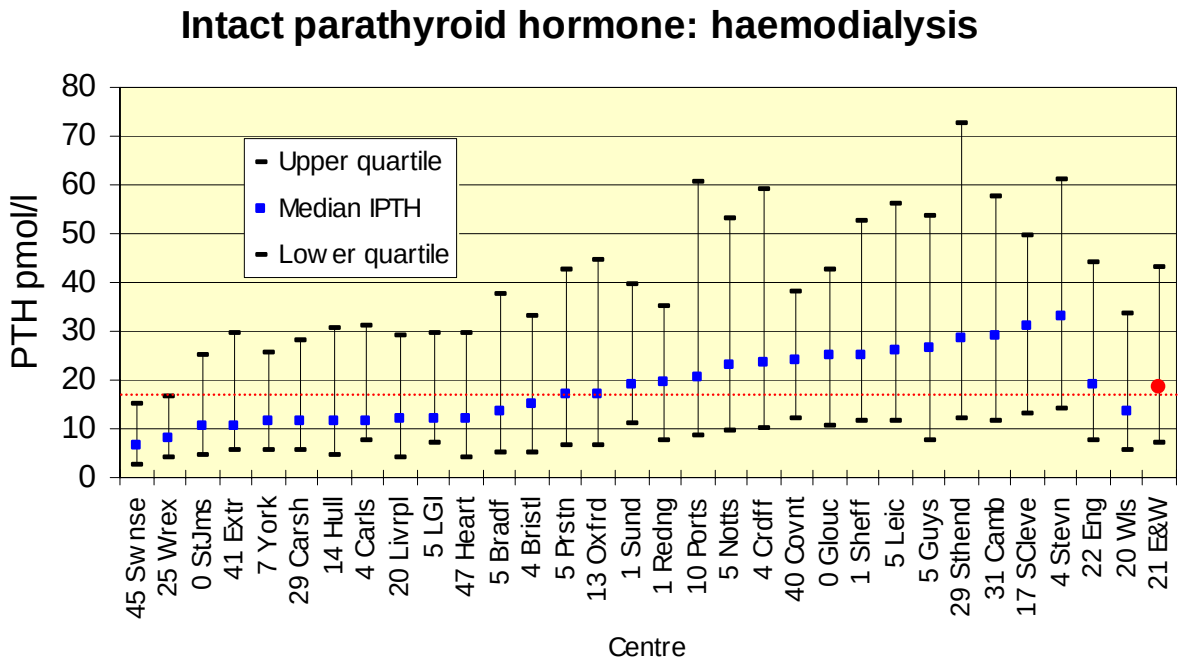


Figure 10.19: Median iPTH in HD patients

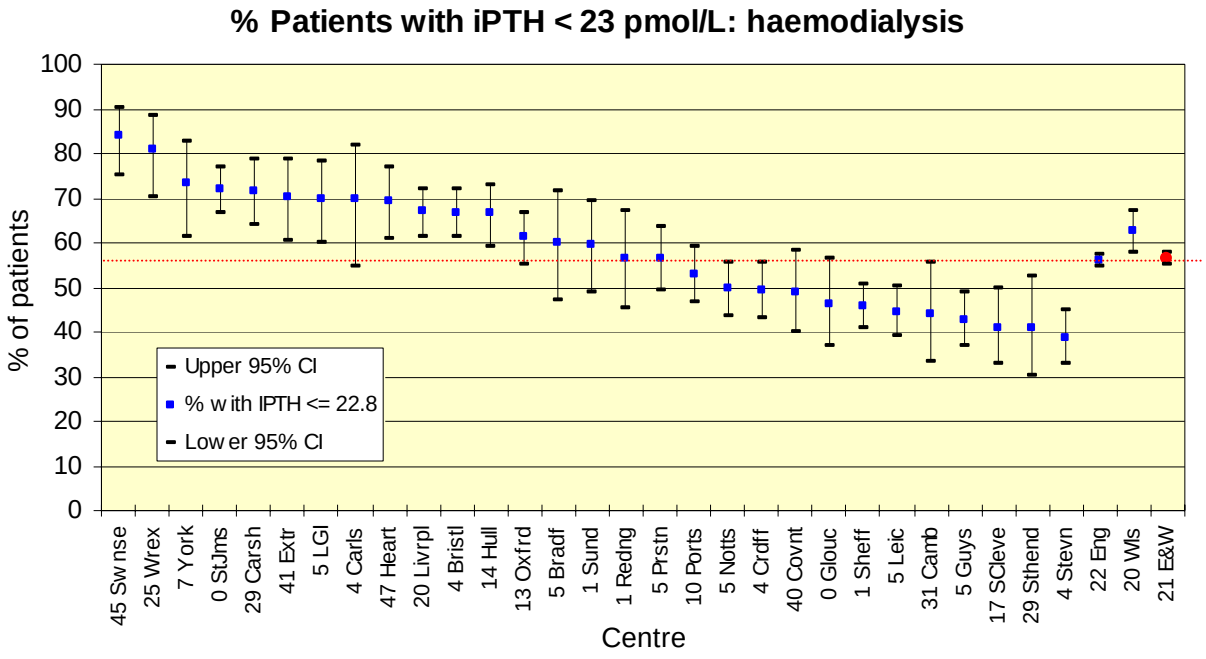


Figure 10.20: Percentage of patients with iPTH <23 pmol/L in HD patients

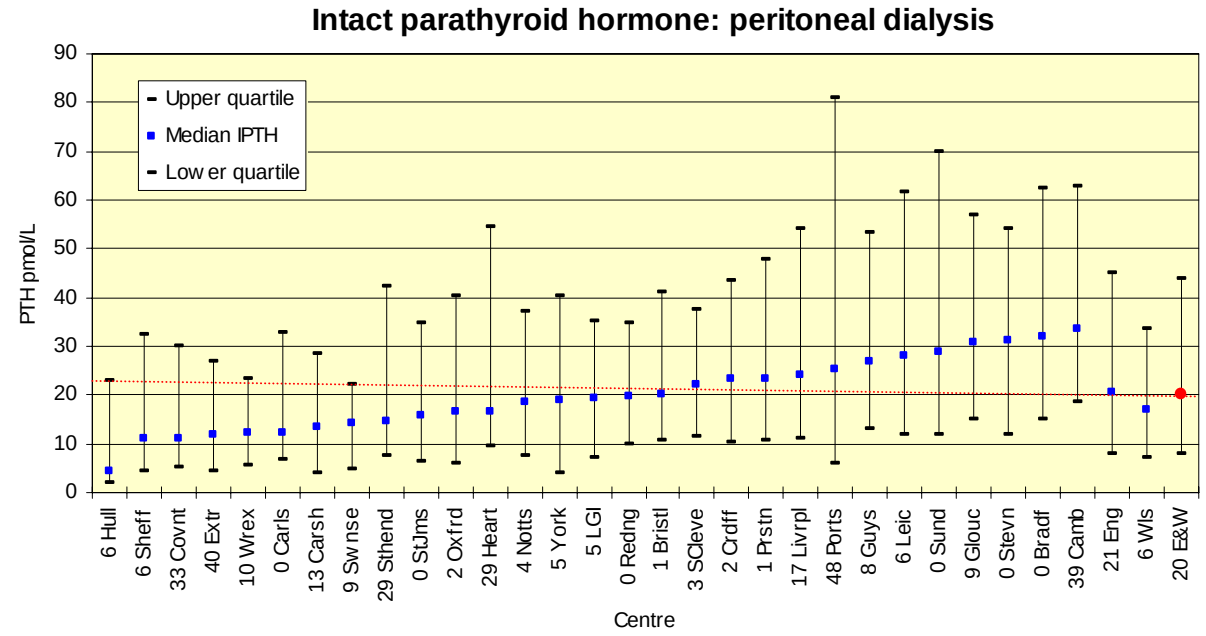


Figure 10.21: Median iPTH in PD patients

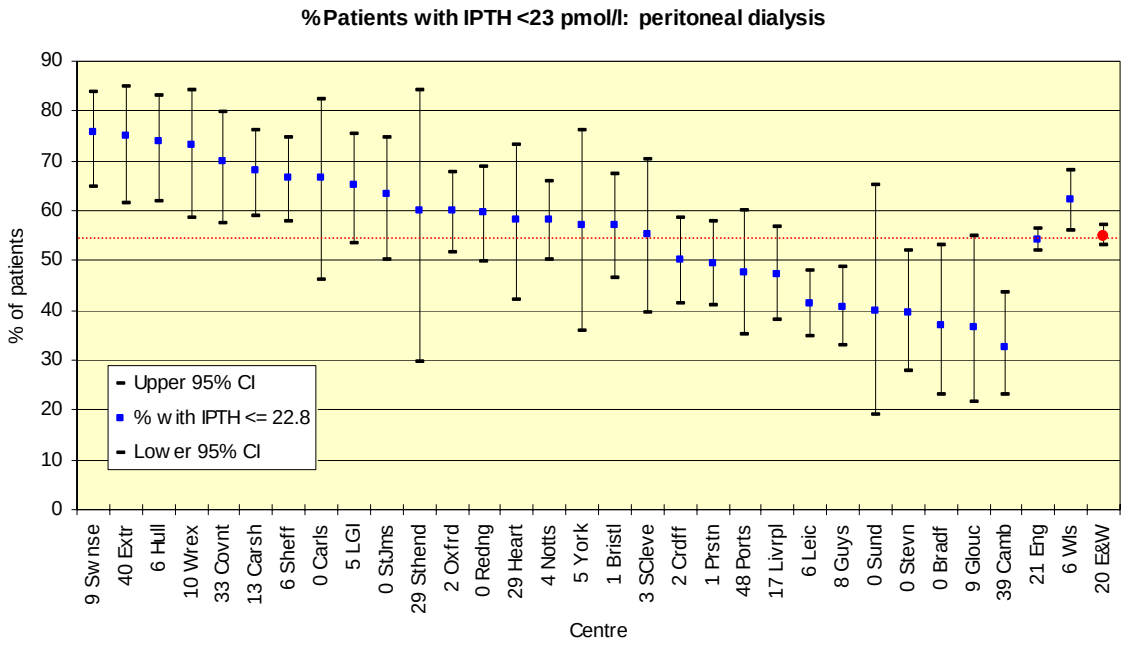


Figure 10.22: Percentage of patients with iPTH <23 pmol/L in PD patients

Conclusion

Achieving a good control of calcium metabolism is a desirable aim with expected benefits to patients in terms of controlling both bone and vascular disease. Comparative audit, particularly of serum calcium, is difficult because different assays, ranges and corrections are made in different units. Despite the difficulties, the data demonstrate that this is an area in which there is considerable variability between units and in which the renal community struggles to achieve agreed standards, many units failing to do so. This is particularly true of serum phosphate – even the best units can manage only 50% compliance with the Standard. Although this may lead to a slackening of the Standard, it is to be hoped that comparative audit will reduce the variability and bring centres with poorer results closer to their competitors.

Chapter 11: Serum Albumin and Serum Bicarbonate

Summary

- The method of measurement of serum albumin has a major effect on the interpretation of differences between centres and changes with time. The centres using BCP have lower serum albumins. This is most apparent within the peritoneal dialysis population, in whom the albumin concentrations overall are significantly lower. The BCG method will overestimate serum albumin concentration by several grams per litre below 30g/L (as assessed by BCG).

- For haemodialysis patients, there was a variation in the median serum albumin within both the BCP group (overall median = 34 g/L, units ranging from 33 to 37 g/L) and the BCG group (overall median = 38 g/L, units ranging from 34 to 41 g/L).

- For peritoneal dialysis patients, the median serum albumin was 30 g/L by BCP (units varying between 27 and 32 g/L) and 35 g/L by BCG (units varying between 33 and 37 g/L).

- For haemodialysis patients, median serum bicarbonate varied from 18 to 26 mmol/L between centres. More detailed information concerning sample handling by laboratories and units is required to explore the difference in results before any suggestion that this is the result of differences in clinical practice can be considered. There appears to be no relationship between analytical method and median bicarbonate level. Sixty-two per cent of patients achieved the recommended Standard, the large majority of PD patients achieving the standard.

Serum albumin

Albumin measurement

In general, serum albumin is measured by one of two methods, both of which utilise a colour change induced by a dye binding to albumin:

1. **BCG** (bromocresol green) is the most commonly used agent, but this has been criticised for the fact BCG binds to a range of proteins other than albumin such that, at low albumin concentrations, there may be a significant overestimation of the albumin concentration
2. **BCP** (bromocresol purple) is slightly more expensive than BCG and is available on fewer clinical laboratory analysers. The advantage of BCP is that it predominantly binds to albumin and thus gives a more accurate measure of albumin concentration, especially below 30g/L.

Immunoassay can also be employed. The reference procedure for serum albumin measurement is to use a specific antibody along with either immunonephelometric or immunoturbidimetric detection.

Most of the above statements with regard to the relative performance of BCG and BCP hold true even in uraemic serum where uraemic toxins (unknown) bind to albumin and alter the ability of other substances, for example drugs and dyes such as BCP and BCG, to bind.

The remaining issue related to albumin in previous Registry reports was the variation in reference range reported by laboratories and the different sources that had been used to obtain them. In principle, and supported by most manufacturers and published sources, there should be no great difference in the reference ranges that would be appropriate for use with the BCG and BCP methodologies. As can be seen from Table 11.1, most laboratories are using broadly similar reference ranges, only two out 34 showing a significant difference at the low end. One laboratory previously having a lower limit of 30 g/L has now increased this to 34 g/L following the introduction of a new analyser. Consensus within the laboratory community is moving towards the adoption of common laboratory reference ranges for many analytes.

City	Hospital	Method	Ref range
Birmingham	Heartlands Hospital	BCG	35–48
Bradford	St Luke's Hospital	BCG	37–49
Bristol	Southmead Hospital	BCG	35–50
Cardiff	University of Wales Hospital	BCG	35–50
Carlisle	Cumberland Infirmary	BCG	36–47
Carshalton	St Helier Hospital	BCG	35–50
Coventry	Walsgrave Hospital	**BCP**	34–48
Derby	Derby District General	**BCP**	30–45
Exeter	Royal Devon and Exeter Hospital	BCG	34–48
Gloucester	Gloucester Road Infirmary	**BCP**	35–53
Hull	Hull Royal Infirmary	**BCP**	36–48
Leeds	St James's Hospital	BCG	37–49
Leeds	LGI	BCG	37–49
Leicester	Leicester General Hospital	BCG	35–55
Liverpool	Liverpool Royal Hospital	BCG	34–45
London	Guys St Thomas'	**BCP**	35–45
Middlesborough	South Cleveland Hospital	BCG	35–50
Newcastle	Royal	BCG	34–50
Nottingham	Nottingham City Hospital	**BCP**	30–52
Oxford	Churchill Hospital	BCG	35–50
Plymouth	Derriford Hospital	BCG	35–50
Portsmouth	Queen Alex	BCG	37–50
Preston	Royal Preston Hospital	BCG	35–55
Reading	Royal Berkshire	BCG	35–49
Sheffield	Northern General Hospital	BCG	36–50
Stevenage	Lister Hospital	**BCP**	35–50
Stourbridge	Wordsley Hospital	BCG	35–47
Southend	Southend Hospital	BCG	35–50
Sunderland	Sunderland Royal Hospital	BCG	34–50
Swansea	Morriston	BCG	36–53
Truro	Royal Cornwall Hospital Trust	BCG	35–50
Wolverhampton	Newcross Hospital	BCG	36–52
Wrexham	Maelor General Hospital	**BCP**	35–50
York	York District Hospital	BCG	35–50

Table 11.1: Methods and ranges of albumin measurement
Conversion factor: g/dL = g/L × 0.1.

To study the influence of albumin assay methodology on the distribution of results for different centres, a large box symbol has been used in Figure 11.1 to highlight those supported by laboratories using BCP methodology.

The Renal Association Standard for albumin is that ***all patients should lie within the local normal range***.

Haemodialysis (HD)

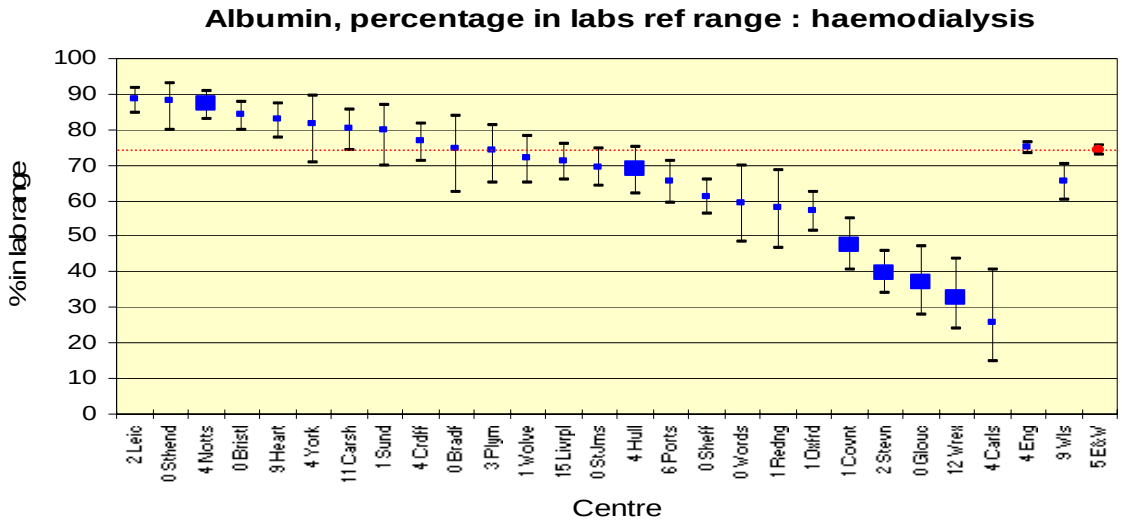


Figure 11.1: Percentage albumin in the laboratory reference range, HD

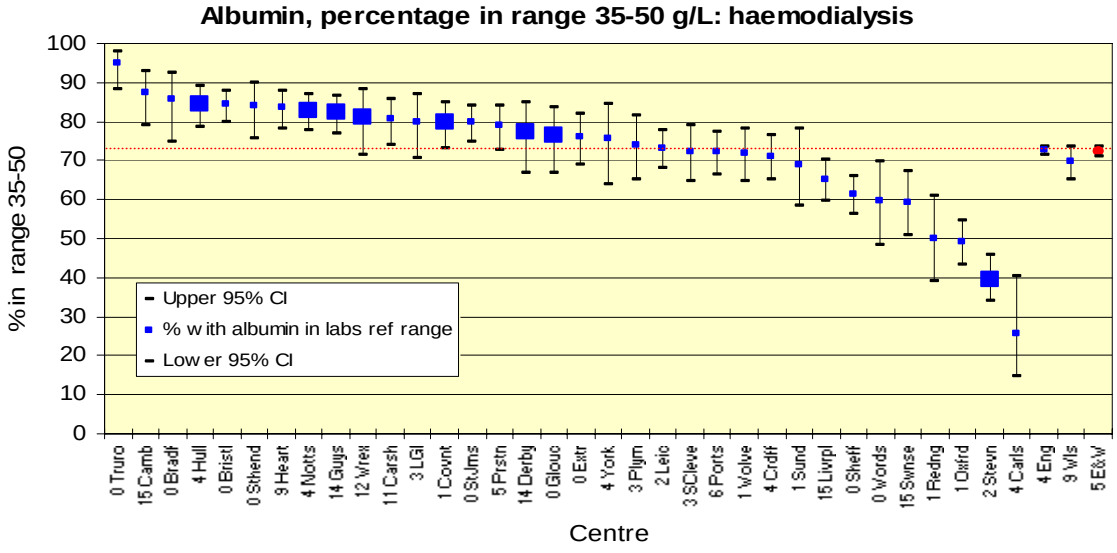


Figure 11.2: Percentage albumin in the range 35–50 g/L, HD

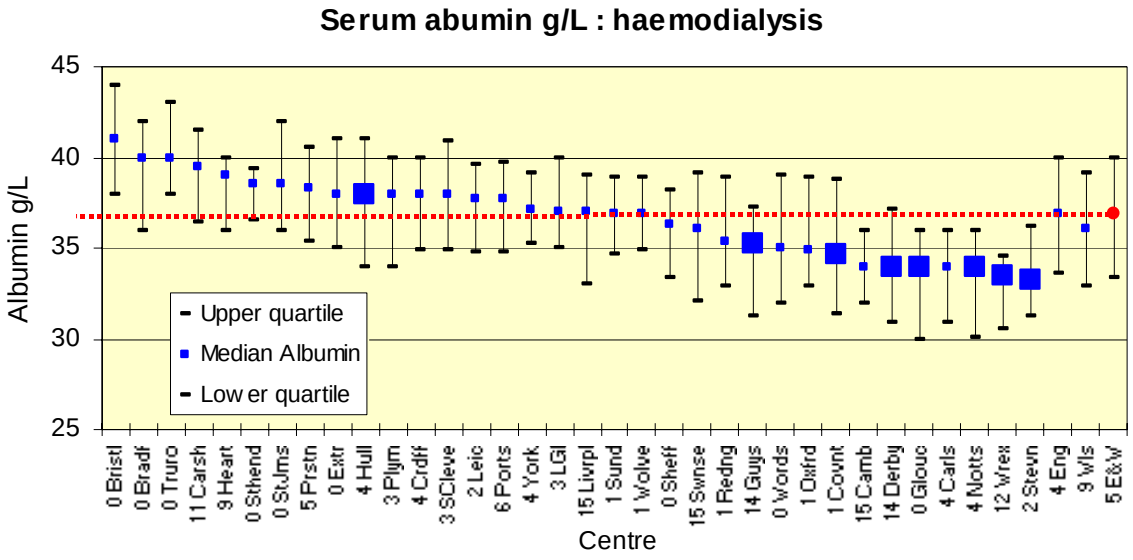


Figure 11.3: Serum albumin, HD

Figure 11.3 shows that there was a variation in the median serum albumin level within both the BCP group (overall median = 34 g/L, units ranging from 33 to 37g/L) and the BCG group (overall median = 38 g/L, units ranging from 34–41 g/L). Figure 11.1 above shows that no unit achieved the Renal Association Standard.

Data were incomplete for Figure 11.2 looking at the proportion of patients within the laboratories' reference range because, at the time of data analysis, reference ranges had not yet been provided. A comparison of Figures 11.2 and 11.3 would support the use of a common reference range as the BCP users were a less distinctive group in the latter Figure, in which 35–50 g/L was used.

Peritoneal dialysis (PD)

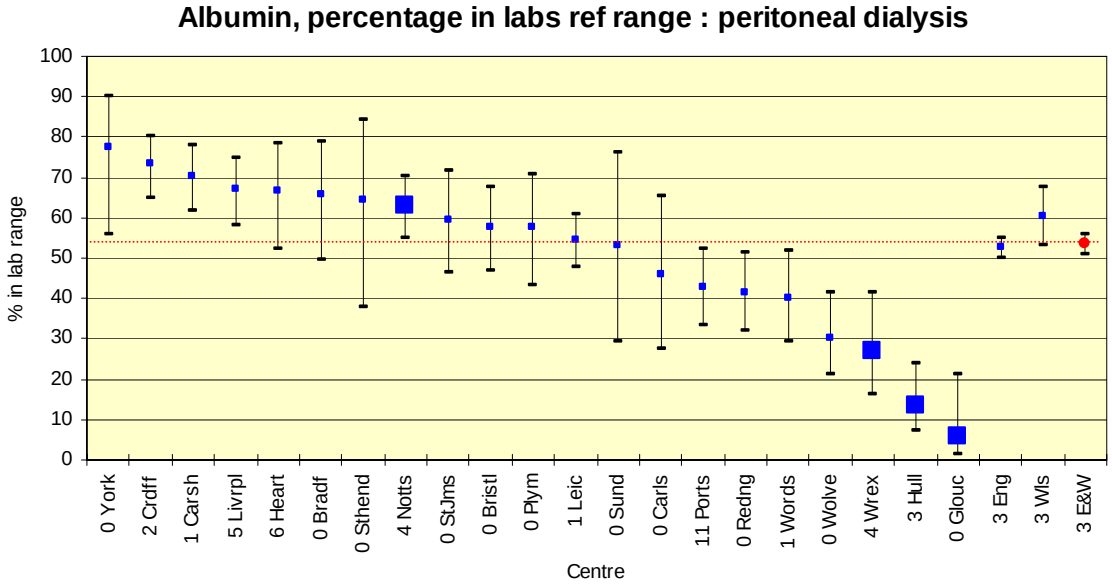


Figure 11.4: Percentage albumin in the laboratory reference range, PD

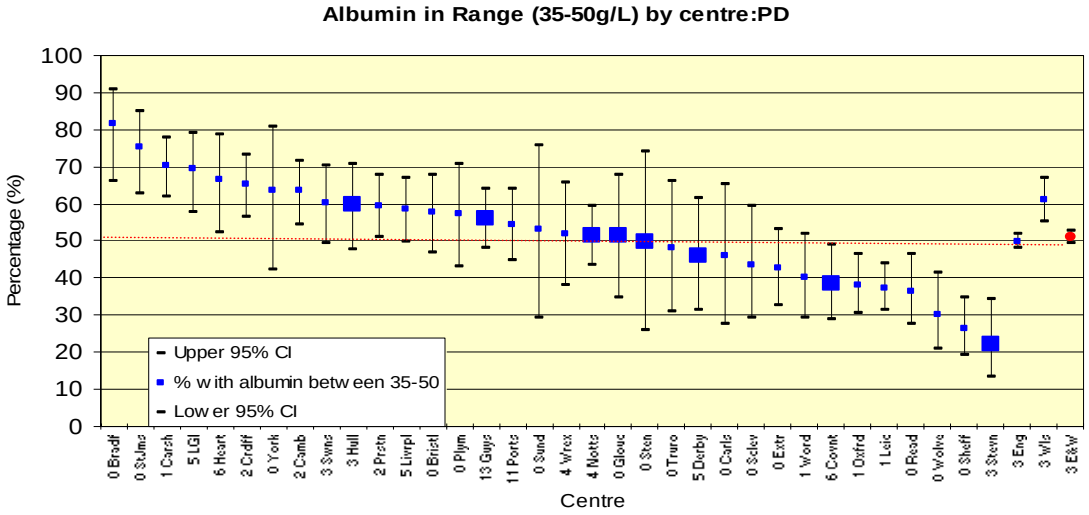


Figure 11.5: Percentage albumin in the range 35–50 g/L, PD

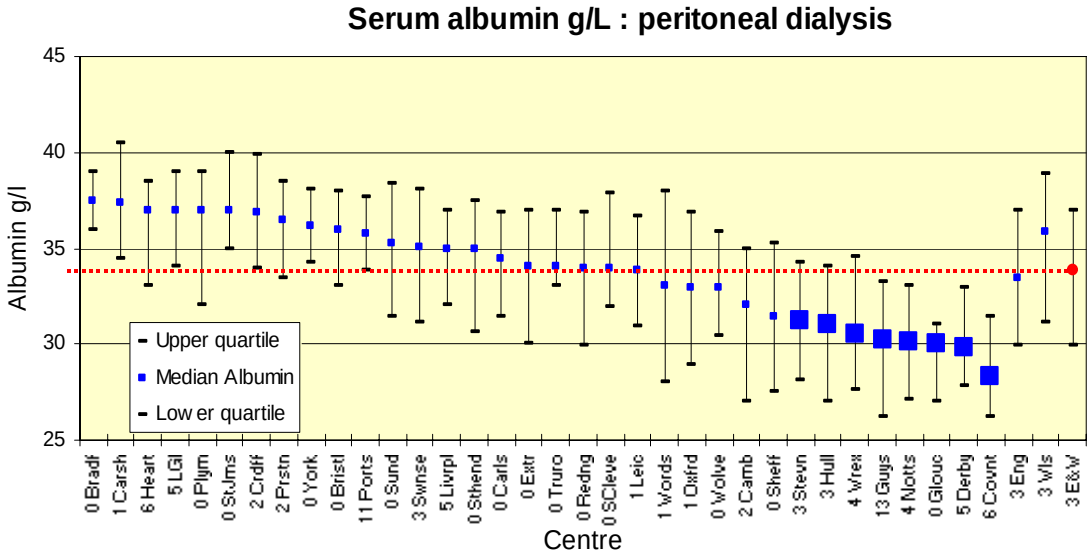


Figure 11.6: Serum albumin, PD

As shown in Figure 11.6, the median serum albumin was 30 g/L by BCP (units varying between 27 and 32 g/L) and 35 g/L by BCG (units varying between 33 and 37 g/L). Figure 11.4 shows that no unit achieved the Renal Association Standard. Data were incomplete for Figure 11.5 looking at proportion of patients within the laboratories' reference range because, at the time of data analysis, reference ranges had not yet been provided.

Discussion

The centres using BCP are clearly grouped towards one side of the figures, being most apparent within the PD population, in whom the albumin concentration overall is significantly lower. The BCG method will overestimate serum albumin concentration by several grams per litre below 30g/L (as assessed by BCG). Applying different reference ranges did not significantly modulate the relative positions. It is clear, within the PD population, that a significant proportion of the variation in albumin concentration arises from methodological factors.

Changes in albumin 1998–2001

Haemodialysis

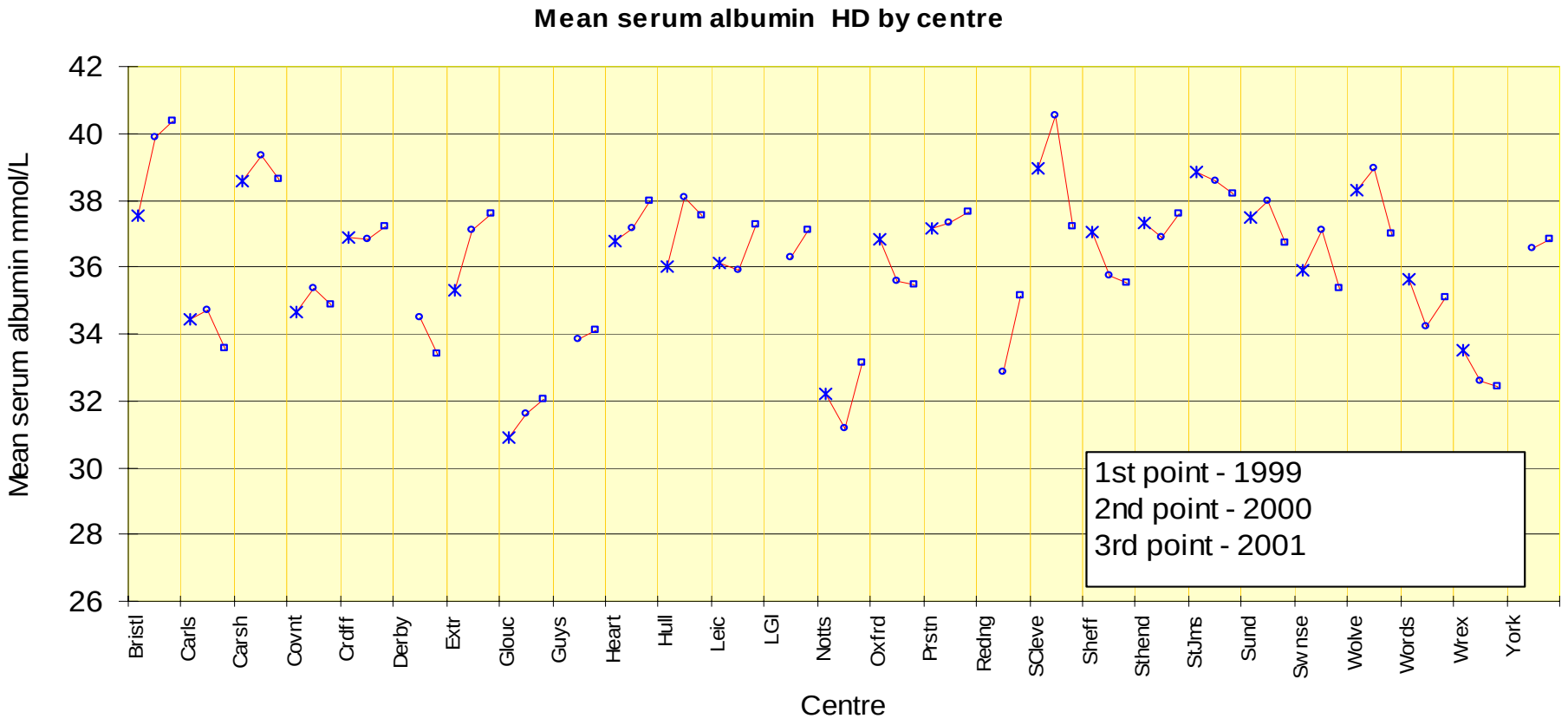


Figure 11.7: Mean serum albumin over 3 years, by centre, HD

Peritoneal dialysis

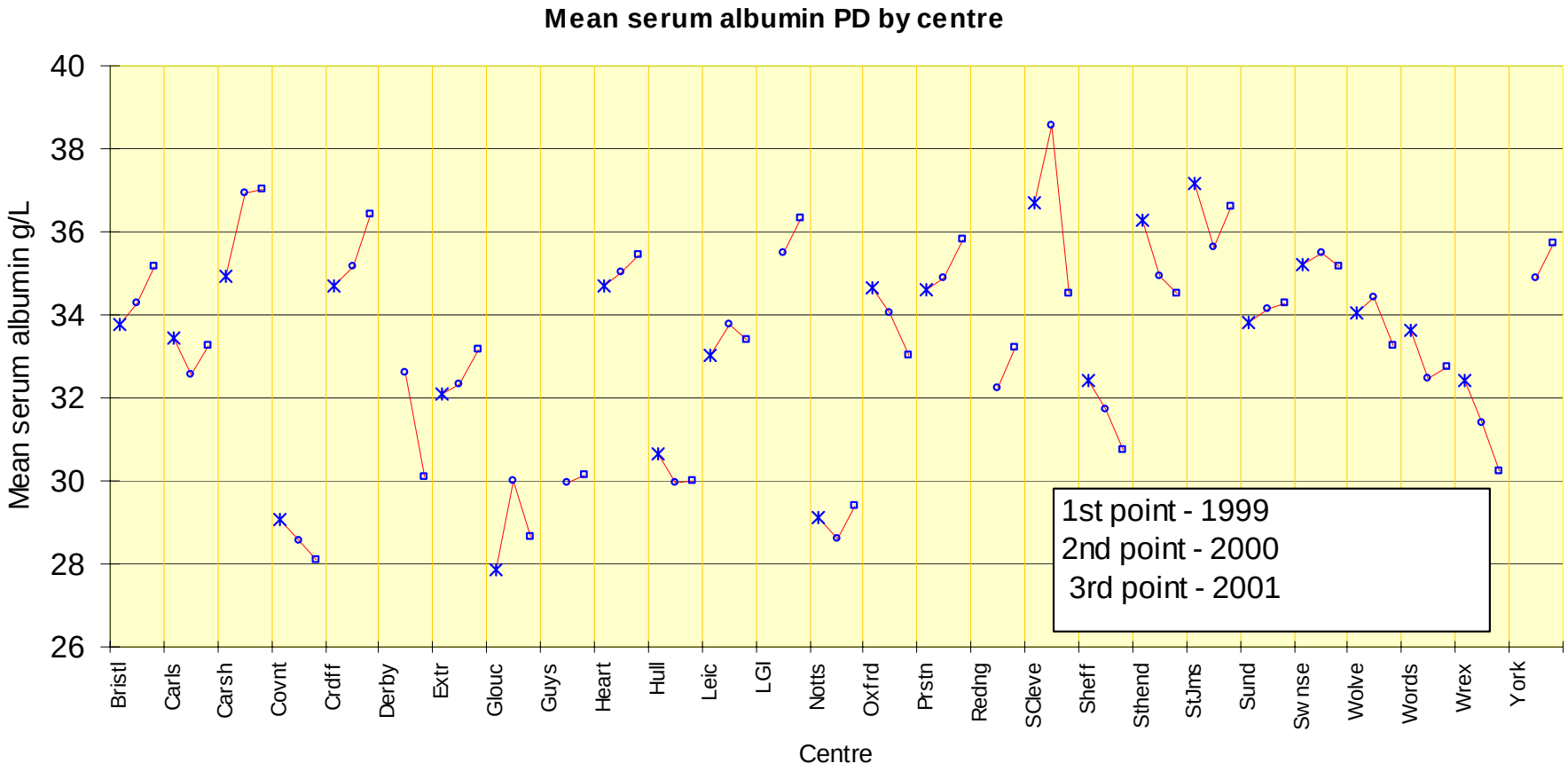


Figure 11.8: Mean albumin over 3 years, by centre, PD

Discussion

Figures 11.7 and 11.8 indicates the serial albumin level by centre over 3 years. From the laboratory survey carried out each year, the Registry is alerted to changes in laboratory methodology and instrumentation. Across the 3 year period shown here, Birmingham, Cardiff, Exeter, Preston and Wolverhampton all changed main-line analyser with only a minor change in median albumin concentration. Some centres appear to demonstrate an improvement in serial albumin measurement. In patients on PD, this may be due to a more careful selection of patients, and the Registry is undertaking further work to establish whether the changes in albumin concentration over time that are shown above are caused by changes in clinical practice or result from method performance.

Conclusion

The measurement of serum albumin and its value to nephrologists as a surrogate outcome measure is dependent upon the method used. This is particularly evident in PD patients, in whom the methodological differences are most pronounced. The relationship of BCP to BCG albumin concentration with mortality in this population is deserving of study.

Serum bicarbonate

Bicarbonate measurement

As can be seen from Table 11.2, there are two main methodologies in use for the measurement of bicarbonate. There is a variation in reference range, but this is not the only factor that will determine the distribution of results between centres. Bicarbonate is relatively unstable, and concentration changes will result from delayed analysis, as can happen with samples sent from GPs, home HD and possibly satellite dialysis units. Bicarbonate concentration can fall by as much as 6 mmol/L in an hour as the dissolved carbon dioxide in plasma is at a much greater concentration than it is in atmospheric air. Home HD patients have been excluded from the HD analysis. Another factor that will alter bicarbonate distribution will be the proportion of patients receiving acetate dialysis solutions.

Laboratory values for bicarbonate have not been harmonised for methodological differences.

City	Hospital	Method	Ref range
Birmingham	Heartlands Hospital	PEPC	22–30
Bradford	St Luke's Hospital	PEPC	23–32
Bristol	Southmead Hospital	PEPC	20–29
Cardiff	University of Wales Hospital	Enzymatic	22–30
Carlisle	Cumberland Infirmary	PEPC	23–30
Carshalton	St Helier Hospital	PEPC	24–30
Coventry	Walsgrave Hospital	PEPC	24–30
Derby	Derby District General	PEPC	23–30
Exeter	Royal Devon and Exeter Hospital	Electrode	23–30
Gloucester	Gloucester Road Infirmary	Electrode	24–32
Hull	Hull Royal Infirmary	Electrode	24–32
Leeds	St James's Hospital	PEPC	20–28
Leeds	LGI	PEPC	23–32
Leicester	Leicester General Hospital	PEPC	22–30

City	Hospital	Method	Ref range
Liverpool	Liverpool Royal Hospital	PEPC	22–33
London	Guys St Thomas'	Electrode	22–32
Middlesborough	South Cleveland Hospital	PEPC	22–29
Newcastle	Royal	PEPC	22–30
Nottingham	Nottingham City Hospital	PEPC	19–28
Oxford	Churchill Hospital	PEPC	24–30
Plymouth	Derriford Hospital	PEPC	23–31
Portsmouth	Queen Alex	PEPC	24–32
Preston	Royal Preston Hospital	Electrode	19–32
Reading	Royal Berkshire	PEPC	22–31
Sheffield	Northern General Hospital	PEPC	22–31
Stevenage	Lister Hospital	Electrode	20–30
Stourbridge	Wordsley Hospital	PEPC	22–29
Southend	Southend Hospital	PEPC	22–30
Sunderland	Sunderland Royal Hospital	PEPC	23–30
Swansea	Morriston	Enzymatic	20–35
Truro	Royal Cornwall Hospital Trust	Enzymatic	22–26
Wolverhampton	Newcross Hospital	PEPC	24–32
Wrexham	Maelor General Hospital	Electrode	24–32
York	York District Hospital	PEPC	22–26

Table 11.2: Bicarbonate methodology and reference ranges

Haemodialysis

The Renal Association Standard is that all patients ***should fall within the local normal range***.

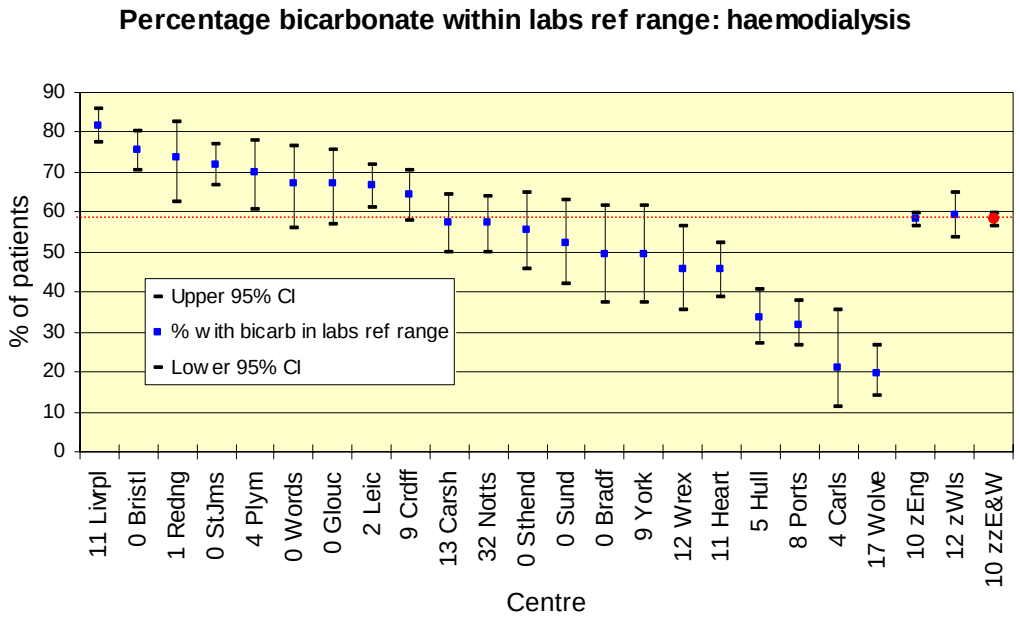


Figure 11.9: Percentage bicarbonate in the laboratory reference range, HD

There is a wide distribution in bicarbonate concentrations found to fall within the laboratory local reference range. This is not, however, entirely explained by different lower limits of normal as Nottingham has the lowest reference range of the units shown in Figure 11.9. In Figure 11.10, Bristol, Leeds, Nottingham, Stevenage, Wolverhampton and Preston (the lowest reference limits) are scattered across the dataset, again suggesting that reference limits cannot totally explain the distribution in results. No unit achieved the Renal Association Standard.

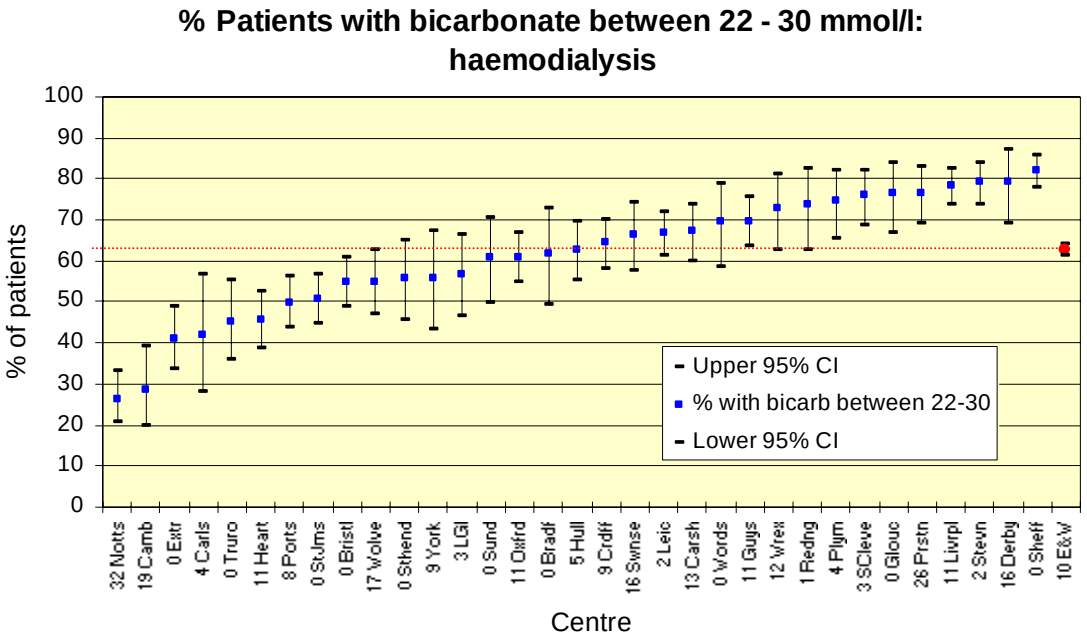


Figure 11.10: Percentage of patients with bicarbonate in the range 22–30 mmol/L, HD

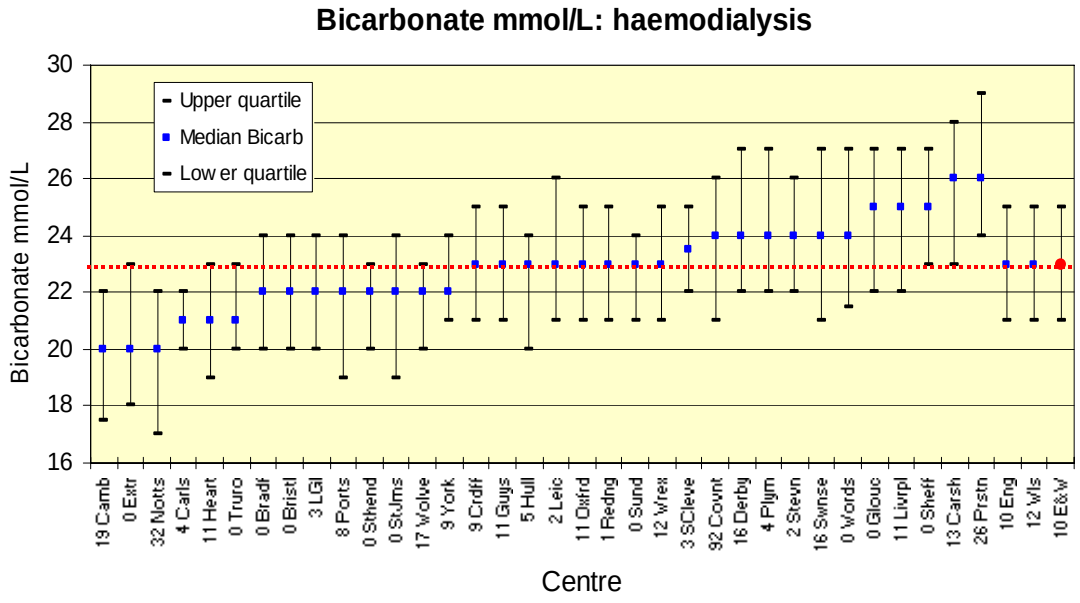


Figure 11.11: Median bicarbonate (mmol/L), HD

Median serum bicarbonate varied from 18 to 26 mmol/L between centres. More detailed information concerning sample handling by laboratories and units is required to explore the difference in results before any suggestion that this is due to differences in clinical practice can be considered. There appears to be no relationship between analytical method and median bicarbonate level. The Welsh External Quality Assurance Scheme (WEQAS) bicarbonate scheme data suggest that a variation in bicarbonate concentration of at least ±2 mmol/L could be expected to arise from method performance.

Peritoneal dialysis

The Renal Association Standard is that patients should have a serum bicarbonate between ***the lower local normal and upper local normal +3mmol/L.***

In England & Wales 78% of patients on peritoneal dialysis achieved the Standard (figure 11.12). There was significant variation between centres (Chi squared p = <.001)

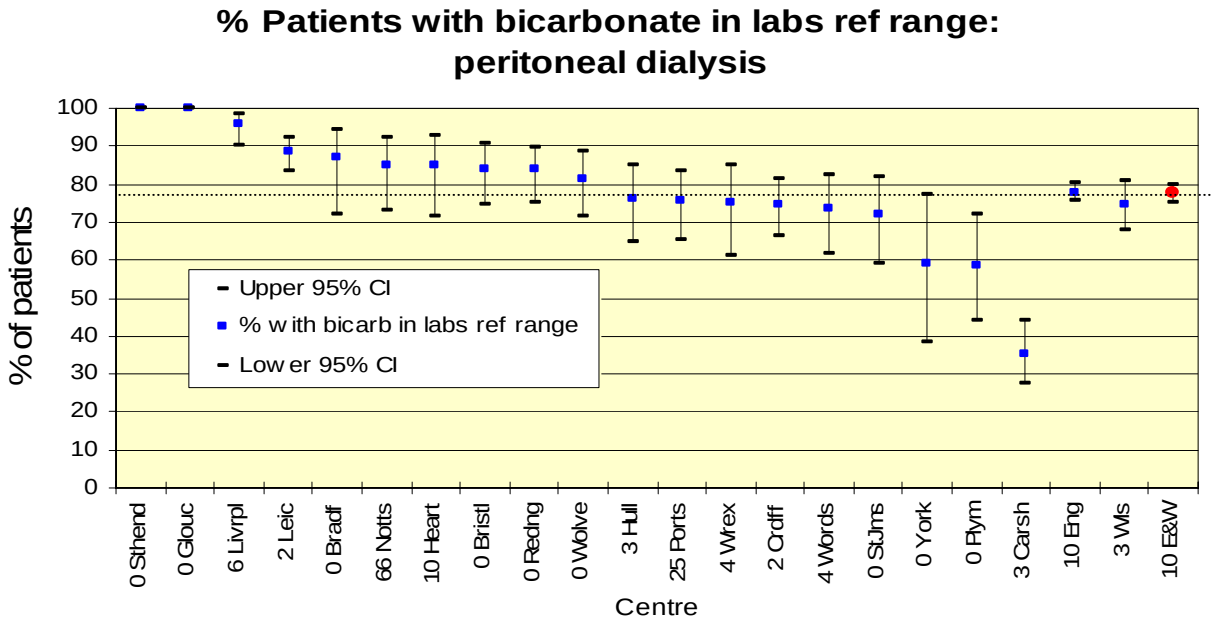


Figure 11.12: Percentage of patients with bicarbonate in the laboratory reference range, PD

In figure 11.14, the median serum bicarbonate varied between 24 and 31 mmol/L. Unlike the HD results, most units achieved the Renal Association PD Standard for bicarbonate

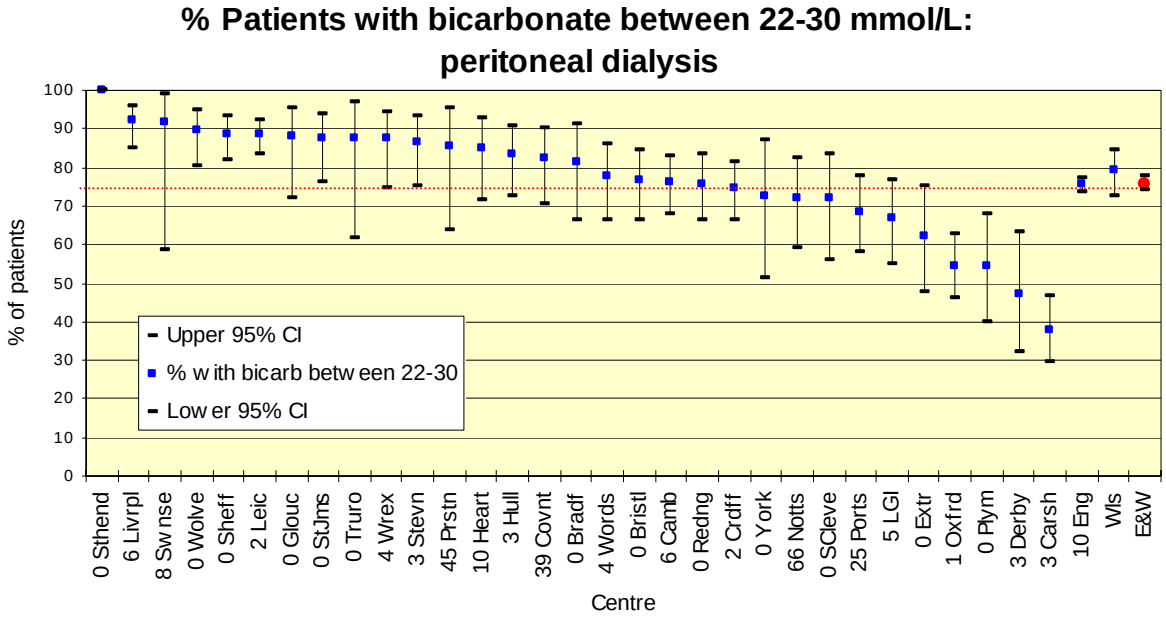


Figure 11.13: Percentage of patients with bicarbonate in the range 22–30 mmol/L, PD

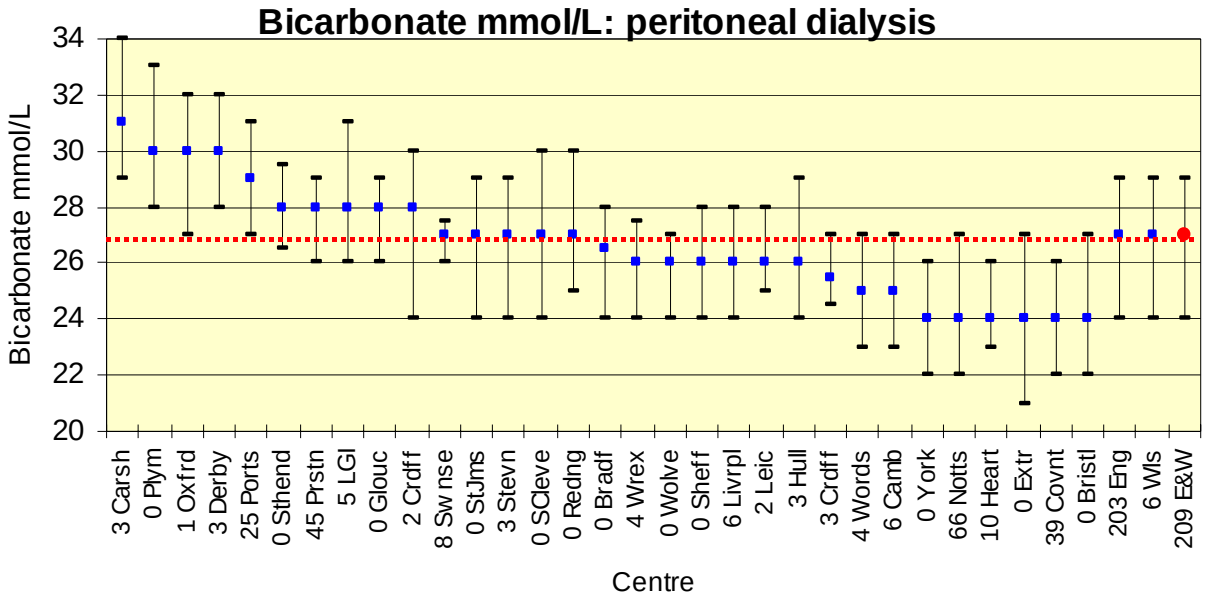


Figure 11.14: Median serum bicarbonate, PD

Changes in serum bicarbonate 1999 – 2001

In figures 11.15 and 11.16, there are large variations shown in serum bicarbonate results across these time periods. Some, but not all, of these variations may be caused by changes in the main-line analyser, which occurred at Birmingham, Cardiff, Exeter, Preston and Wolverhampton. The Welsh QA scheme, WEQAS, organises a bicarbonate service, and these data will now be used to explore the significance of changes in bicarbonate concentration between laboratories

It is hard to interpret these changes without further information. The large changes seen at Carshalton are mirrored both in the haemodialysis and peritoneal dialysis population indicating a methodology change In contrast, the Bristol renal unit showed a change in bicarbonate levels in 2000 for haemodialysis patients only indicating a dialysis technique change.

As the renal units have been identified this year, it will be useful if each centre could discuss these changes observed with their supporting laboratories to identify any possible explanations. These could include transport of samples to the laboratory from satellite units and changes in laboratory practice. There may also be changes in patient mix, the use of dialysis fluids and the use of dialysis technology (e.g. ambulatory PD). This could then be fed back to the Registry and discussed at the annual users' meeting.

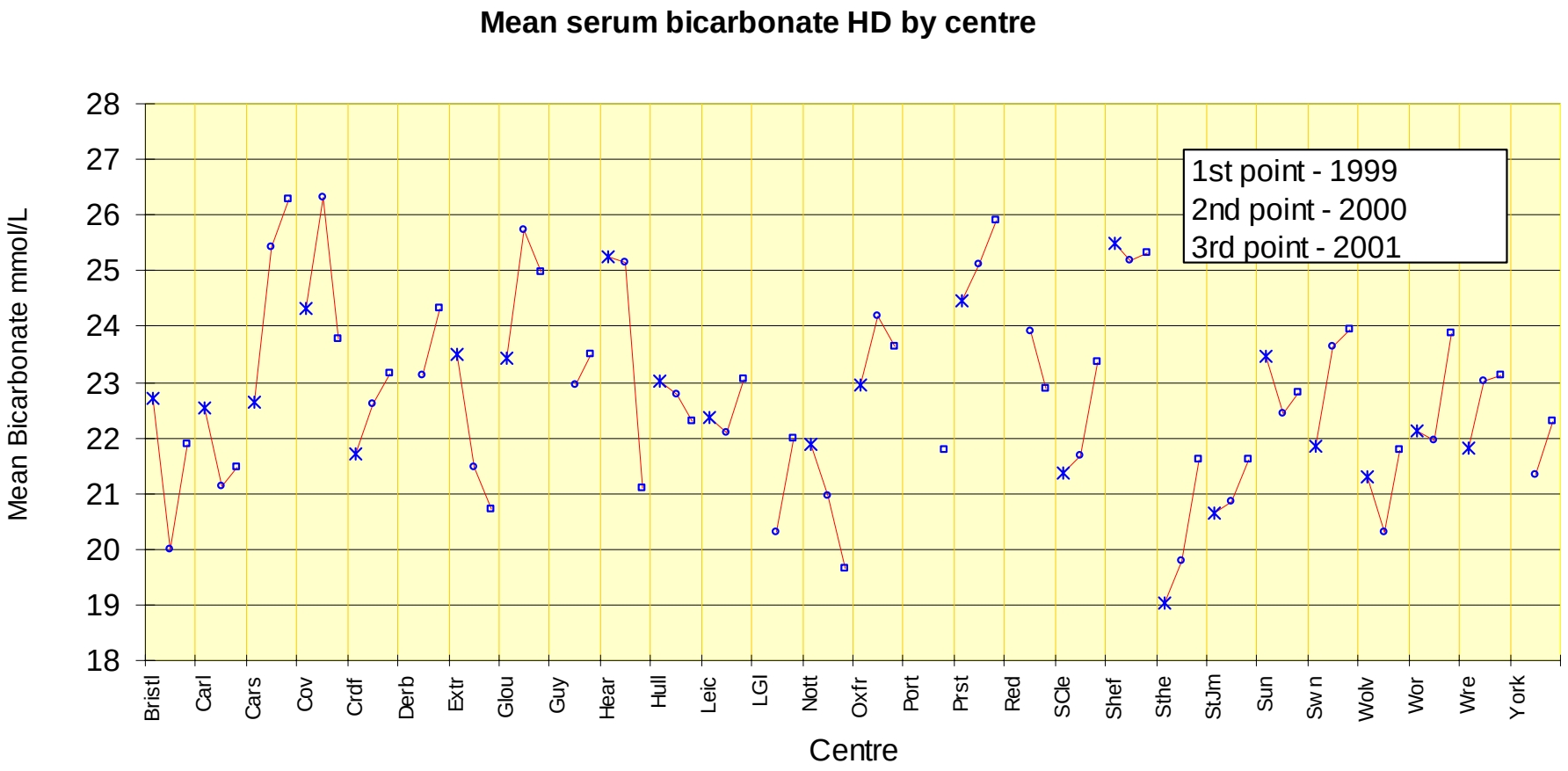


Figure 11.15: Mean serum bicarbonate, by centre, HD

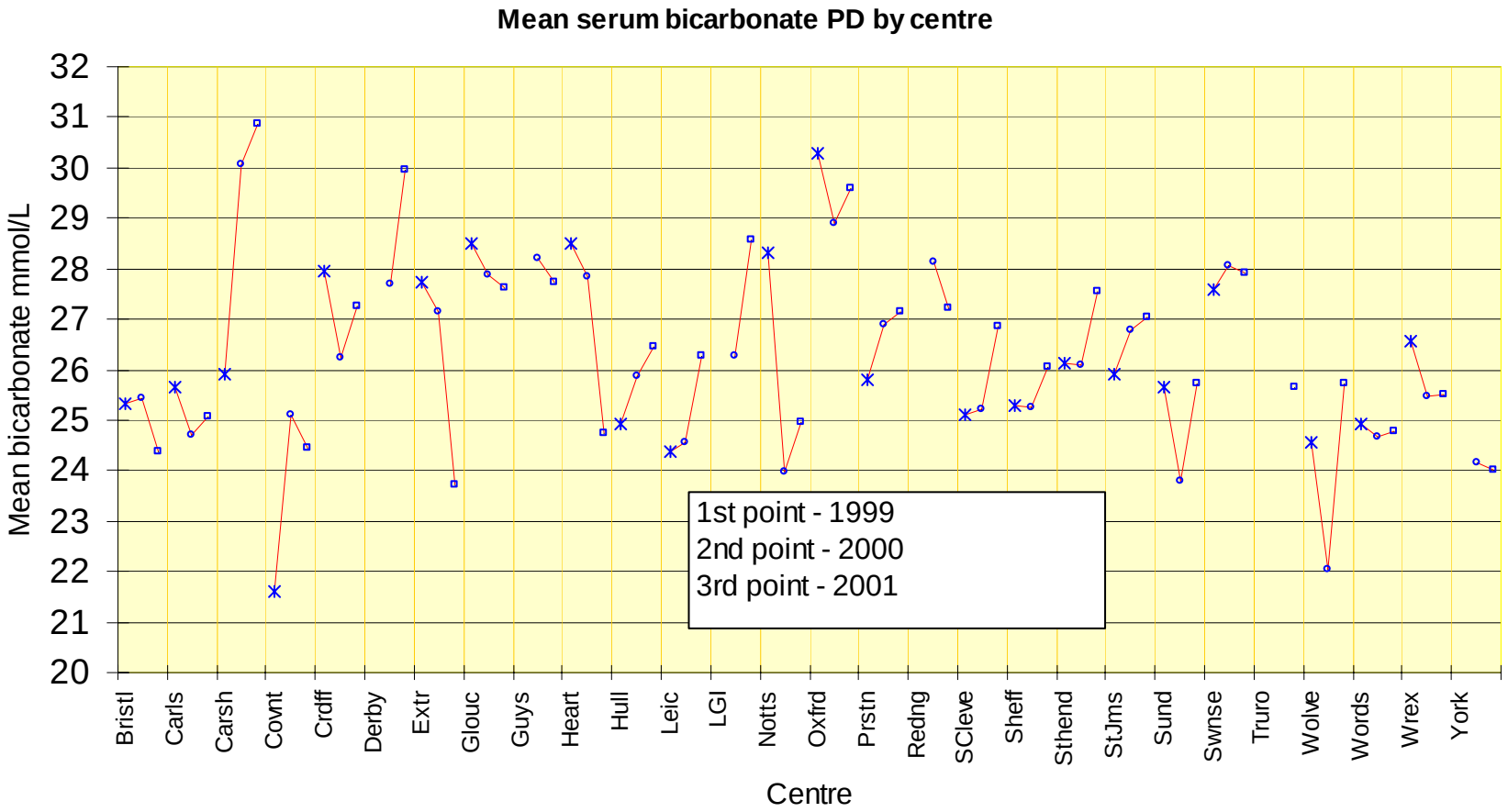


Figure 11.16: Mean serum bicarbonate, by centre, on PD

Chapter 12: Factors that May Influence Cardiovascular Disease – Blood Pressure and Serum Cholesterol

Summary

- In England & Wales, the recommended blood pressure Standard was achieved in 42% (inter-unit range 15–68%) of young haemodialysis patients and 64% (range 23–84%) of older patients. Of young peritoneal dialysis patients, 52% (range 40–75%) achieved the Standard, the percentage being 69% (range 45–88%) for older patients. Variations between renal units in attainment of the Standard were significant.

- In the past 3 years, very few centres have shown any significant improvement in blood pressure control. A reduction in mean systolic blood pressure of 5 mmHg or more for haemodialysis patients has been achieved in only four centres.

- In HD patients, the median falls from pre- to post-dialysis systolic and diastolic blood pressure were 13 mmHg and 5 mmHg respectively.

- For haemodialysis, 73% (inter-unit range 47–86%) of patients achieved a cholesterol level of 5 mmol/L or less. For peritoneal dialysis patients, the figures were 56% (range 30–72%). These variations are significant between centres. The data show significantly higher cholesterol levels in peritoneal dialysis patients.

- There is a U-shaped association between cholesterol level and 1 year mortality. Short-term survival is optimal for patients with a serum cholesterol of 5–8 mmol/L, presumably because this reflects good nutrition.

Introduction

The cardiovascular burden of the prevalent dialysis population is vast, 45% of patients dying from cardiovascular complications.[1,2] The excess risk of death from cardiovascular disease compared with the general population has previously been shown to range from 500-fold in patients aged 25–35 years to fivefold in patients over 85.[3] Recent data show that the corresponding risk for dialysis patients in England & Wales is 157-fold for 25–29-year-olds and fivefold for 80–84-year-olds (see Chapter19). For individuals aged more than 64 years starting dialysis, the 5 year prognosis is worse than that for carcinoma of colon, prostate or breast. In the general population, hypertension and hyperlipidaemia are major risk factors for atherosclerosis; as such, they are major targets for treatment intervention. Other uraemia-related factors also contribute to the extensive vascular calcification and myocardial fibrosis characteristic of the changes seen in dialysis patients. These include anaemia, salt and water overload, excessive fistula flow rates, abnormalities of calcium and phosphate metabolism, hyperparathyroidism, hyperhomocysteinaemia, inflammation, increased oxidant stress and prothrombotic tendency. Longitudinal studies are needed to establish the extent of the risk associated with each of these factors.

Blood pressure and dialysis mortality

The relationship between blood pressure and mortality is bimodal in the dialysis population, a very high or low blood pressure having an adverse effect.[4] Patients with a low blood pressure (pre-dialysis systolic blood pressure [systolic BP] <110 mmHg) will include high-risk patients with established heart disease, poor myocardial function and poor outcome. The majority of patients have poorly controlled blood pressure despite an extensive use of anti-hypertensive drugs. Long-standing hypertension in chronic renal failure induces a cardiomyopathy characterised by small vessel disease. The sequence of events can be monitored by echocardiography.[5] Left ventricular (LV) hypertrophy initially develops, followed by LV dilatation and ultimately systolic dysfunction. Low blood pressure subsequently causes cardiac ischaemia and myocardial fibrosis, which ultimately leads to diastolic dysfunction and LV conduction abnormalities. Death is usually the result of cardiac failure or arrhythmia induced by sudden ischaemia or electrolyte changes. The development of LV hypertrophy per se predicts a premature cardiac death with a median survival of 5 years, the presence of systolic dysfunction or congestive cardiac failure reducing the median survival to 3 years. Atherosclerosis affecting the main coronary arteries is a distinct process and affects roughly 14% of dialysis patients. Myocardial infarction is a catastrophic event; 1 year survival is 40% and 5 year survival just 10%.

Although there have been no controlled trials to date, there is mounting evidence that hypertension reduces survival on dialysis:

- High systolic BP is associated with the development of LV hypertrophy.[6]
- High diastolic blood pressure (DBP) is associated with the development of *de novo* heart failure.[7]
- A high pulse pressure is associated with arterial stiffness and increased mortality.[8]
- Treating isolated systolic hypertension in the elderly improves survival.[9]
- Lowering blood pressure in diabetics improves survival.[10,11]
- The dry weight control of blood pressure improves survival.[12] This approach is not effective in diabetics or high-risk patients (those with a failure of two other organs or with malignancy).

The Standards for control of hypertension current in 2001, published in 1997, were:

Age <60: BP < 140/90 mmHg (pre-dialysis for haemodialysis patients)
Age ≥60: BP < 160/90 mmHg (pre-dialysis for haemodialysis patients)
(Korotkoff V sound if auscultation is used)

Distribution of blood pressure on dialysis

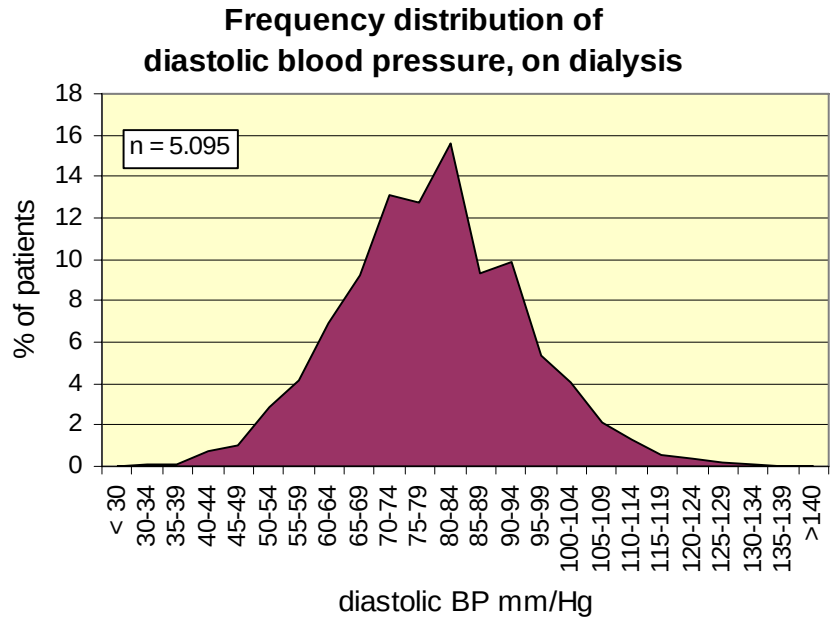


Figure 12.1: Frequency distribution of diastolic BP, on dialysis

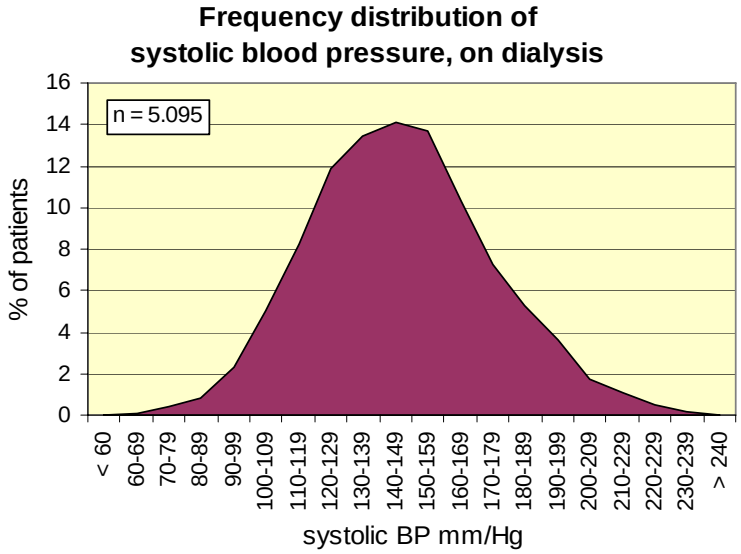


Figure 12.2: Frequency distribution of systolic BP, on dialysis

systolic BP clearly shows a normal distribution for the dialysis population (Figures 12.1 and 12.2). diastolic BP does not follow this pattern, although it might also be expected to be normally distributed. Instead, the observed distribution suggests a 'rounding down' so that diastolic pressures in the range 85–89 mmHg are rounded down to 80–84 mmHg. Centres should ensure that manual blood pressure readings taken by nursing staff are accurately recorded. The introduction of electronic devices should curtail this practice and provide more accurate data.

Achievement of combined systolic and diastolic Standard

Haemodialysis

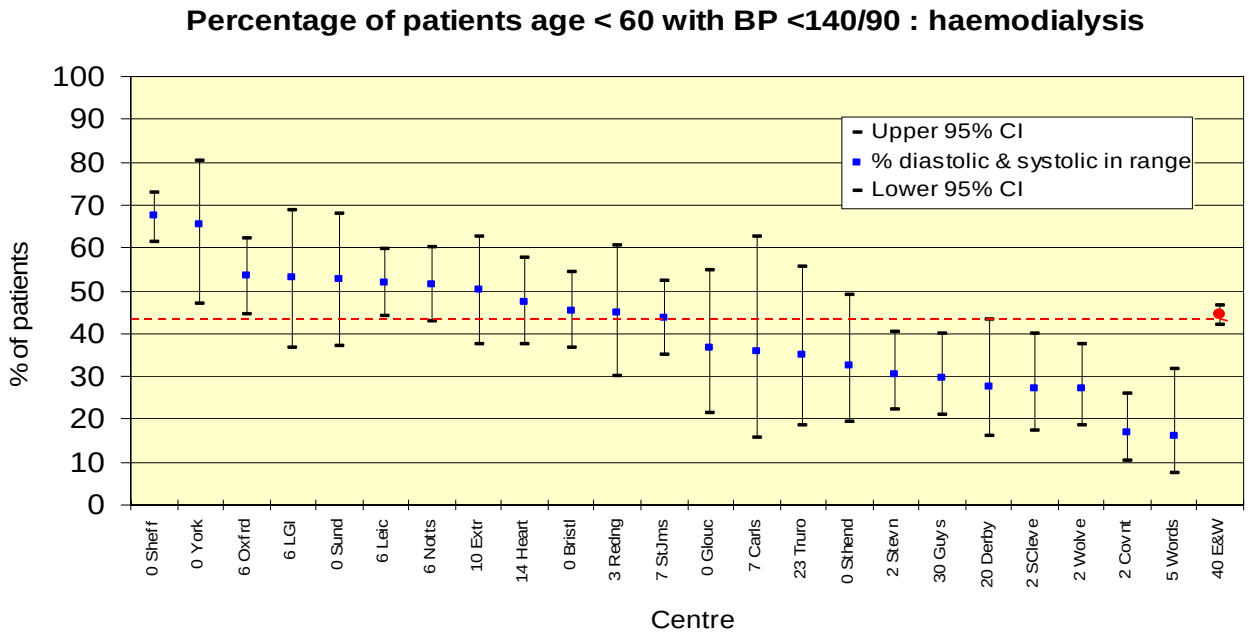


Figure 12.3: Percentage of patients aged <60 with a blood pressure <140/90 mmHg, HD

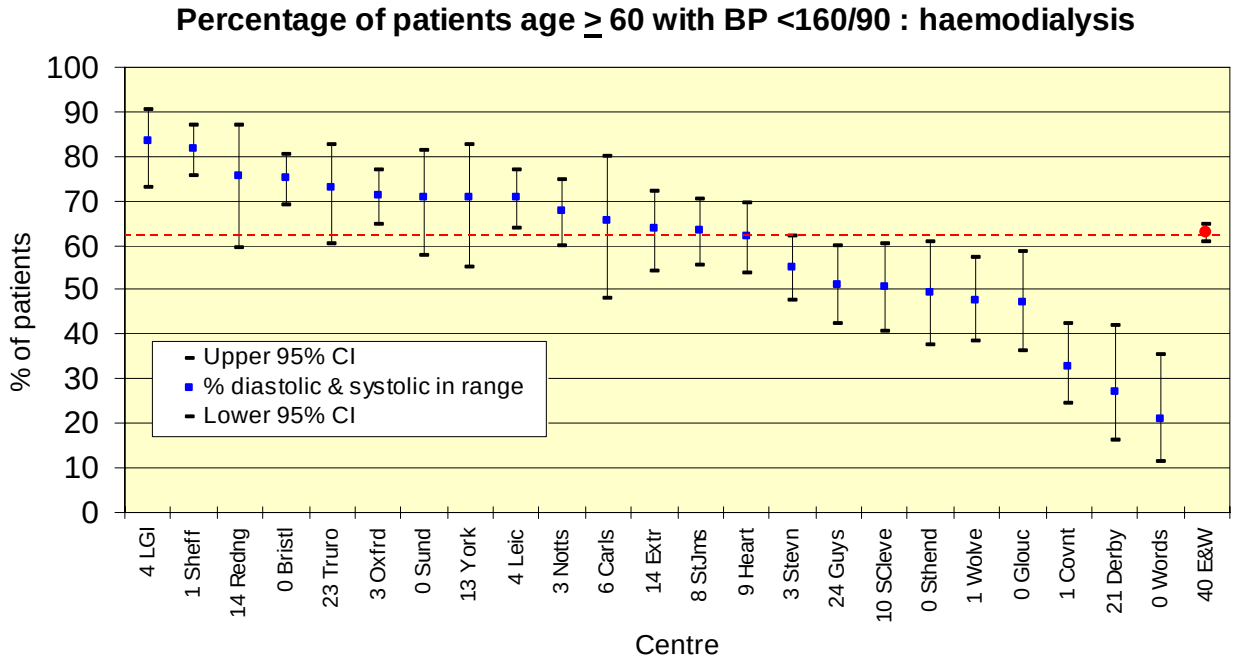


Figure 12.4: Percentage of patients aged >60 with a blood pressure <160/90 mmHg, HD

Peritoneal dialysis

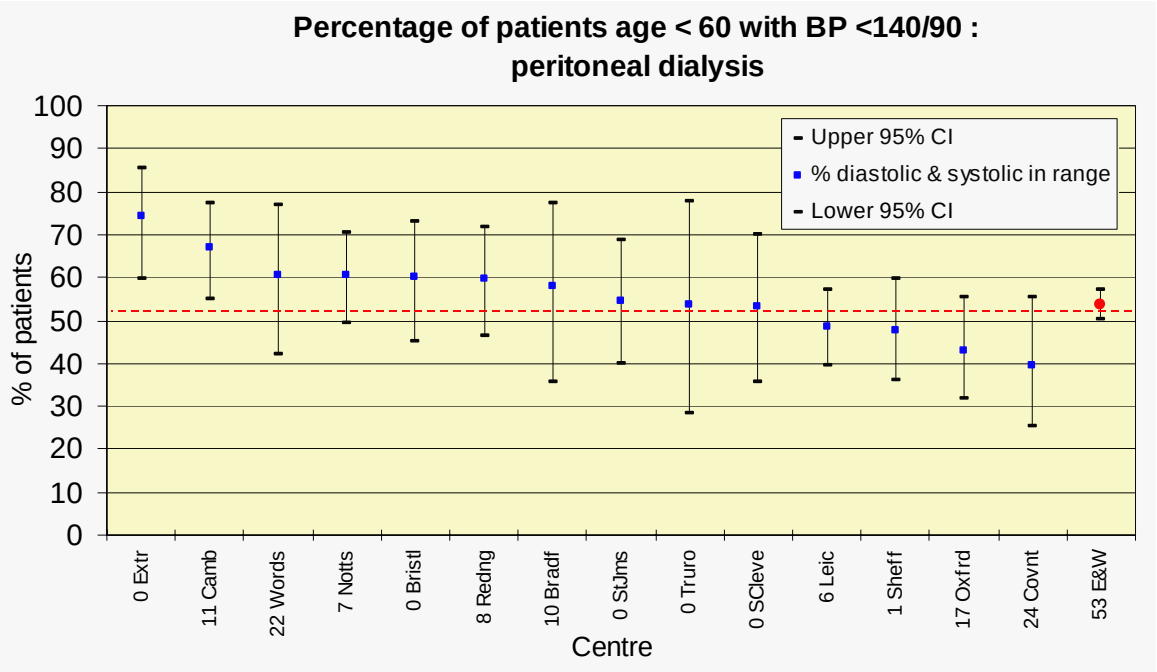


Figure 12.5: Percentage of patients aged <60 with a blood pressure <140/90 mmHg, PD

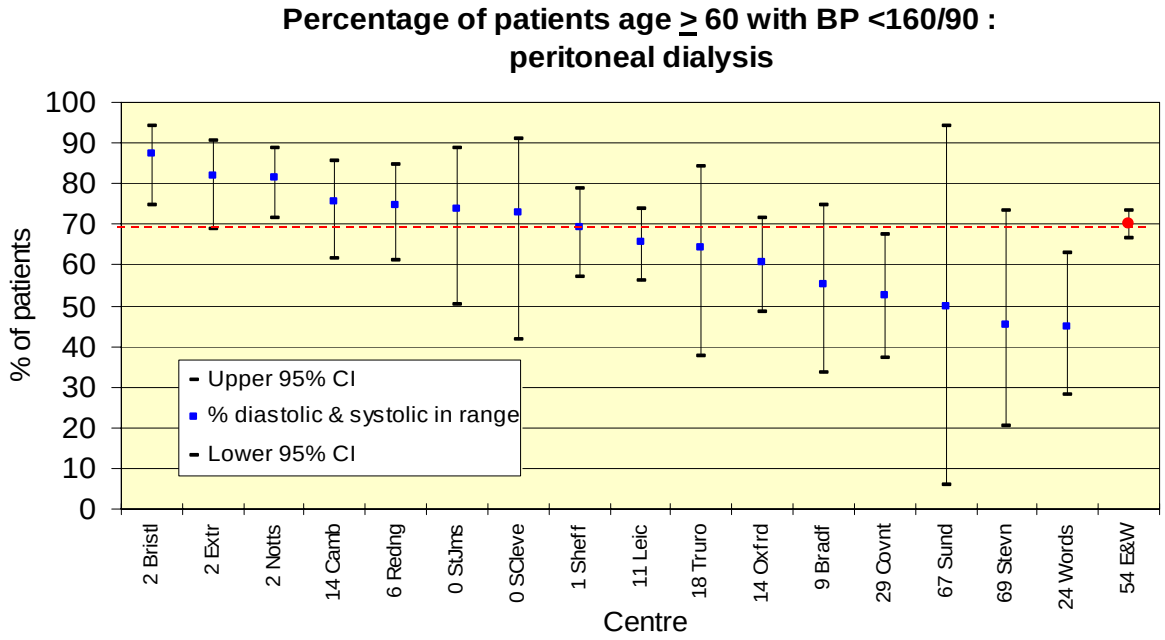


Figure 12.6: Percentage of patients aged >60 with a blood pressure <160/90 mmHg, PD

Figures 12.3–12.6 show a wide variation between units achieving the combined blood pressure Standard. For England & Wales, the percentage of young HD patients achieving the Standard averaged 42% (range 15–68%) and older patients averaged 64% (range 23–84%). Young PD patients averaged 52% (range 40–75%) and older patients 69% (range 45–88%). Chi squared testing indicates that these variations are significant within the different age groups for both dialysis modalities. The results are similar to those of previous years, with more elderly patients achieving the Standard because the target was more liberal. PD patients achieve the Standard more frequently, but this is only because their blood pressure readings are equivalent to those seen post-dialysis (see below).

Systolic pressure alone

Haemodialysis

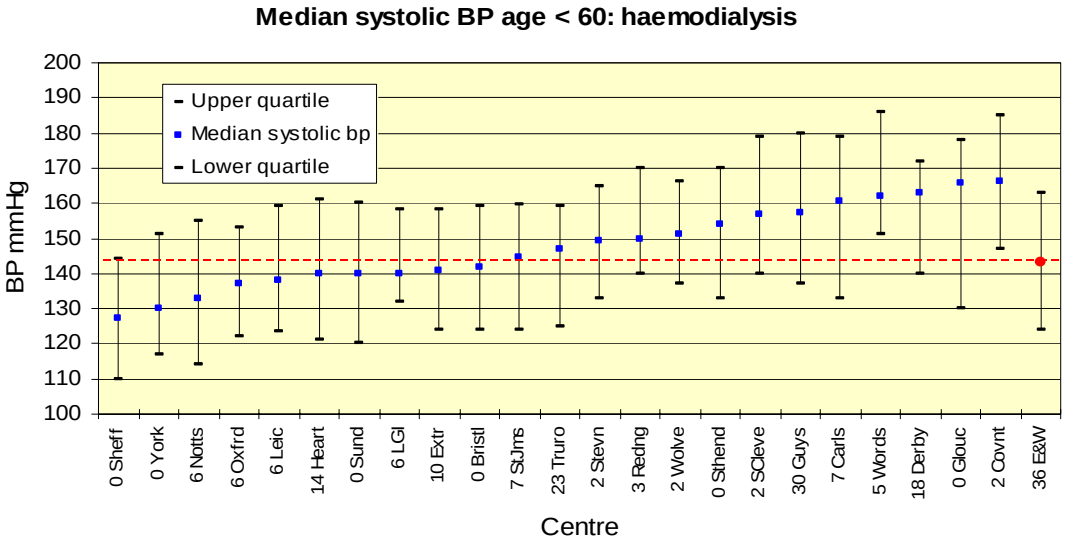


Figure 12.7: Median systolic BP, age <60, HD

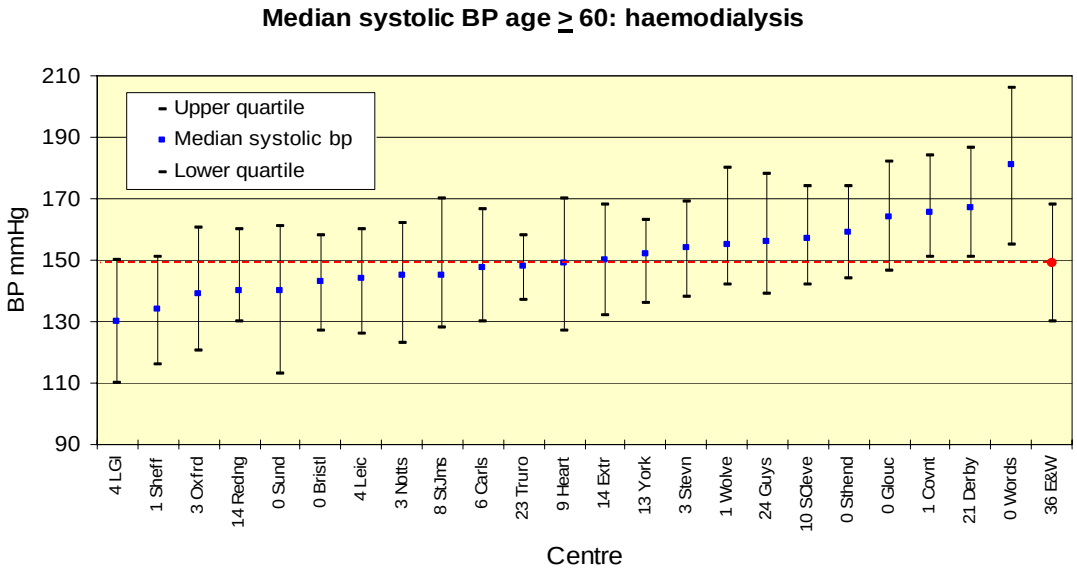


Figure 12.8: Median systolic BP, age >60, HD

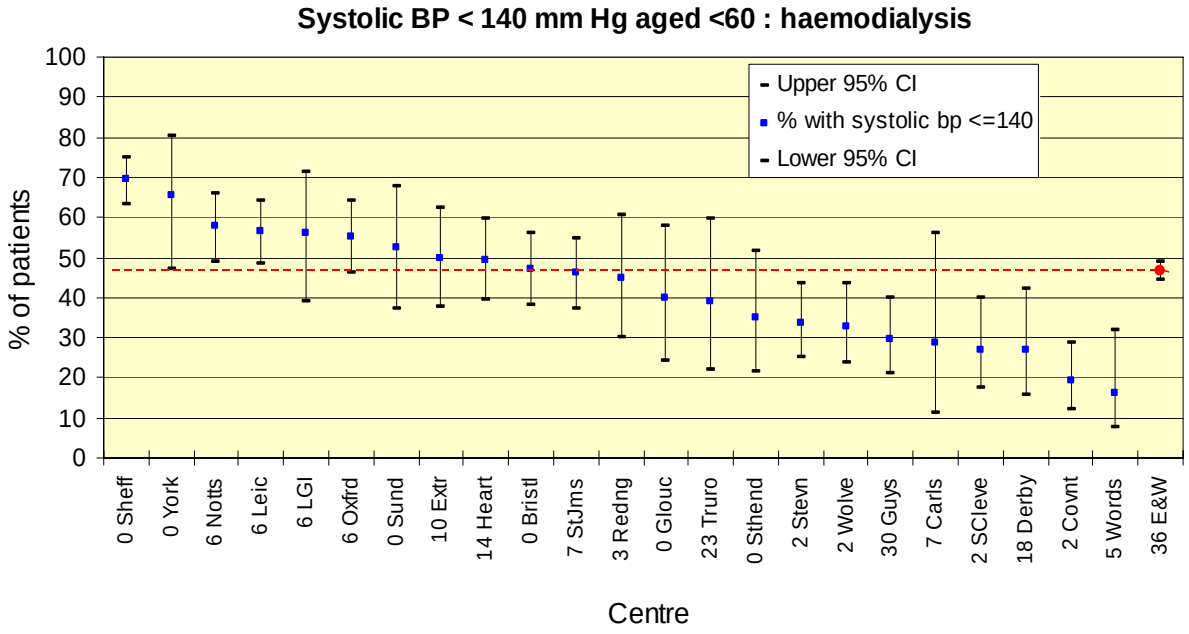


Figure 12.9: Percentage of patients aged <60 years with systolic BP <140 mmHg, HD

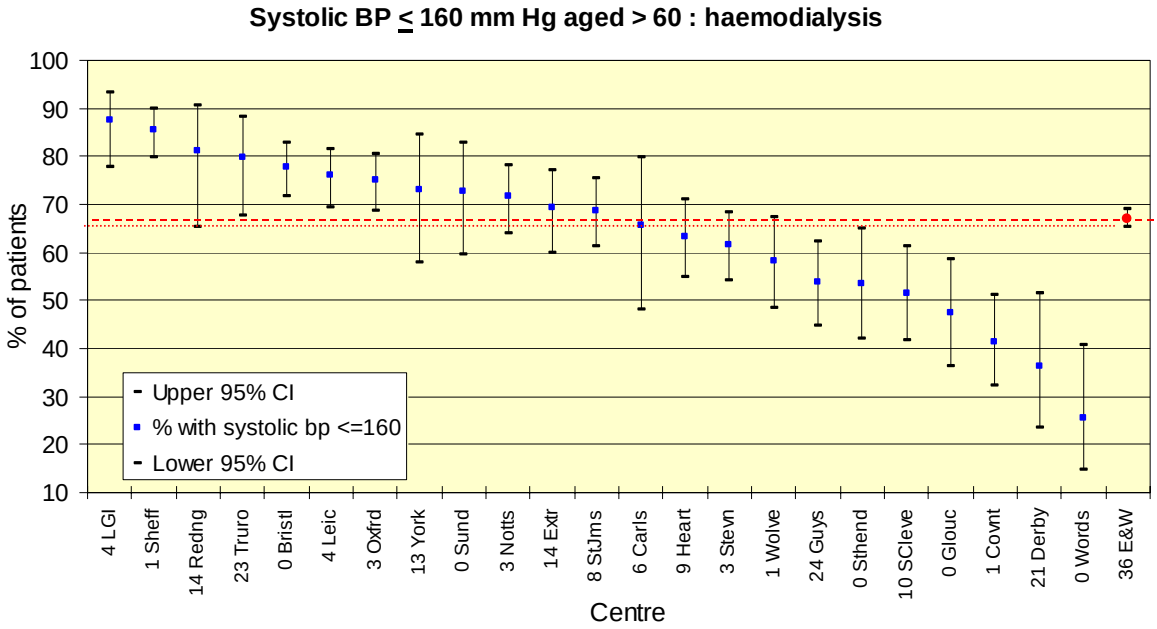


Figure 12.10: Percentage of patients aged ≥60 with systolic BP <160 mmHg, HD

Figures 12.7–12.10 show that, for HD, the percentage of elderly patients achieving the systolic Standard is higher than is encountered with younger patients. The median systolic BP was 144 mmHg for younger patients and 152 mmHg for older ones. The variations in patients achieving the Standard differed significantly between centres.

Peritoneal dialysis

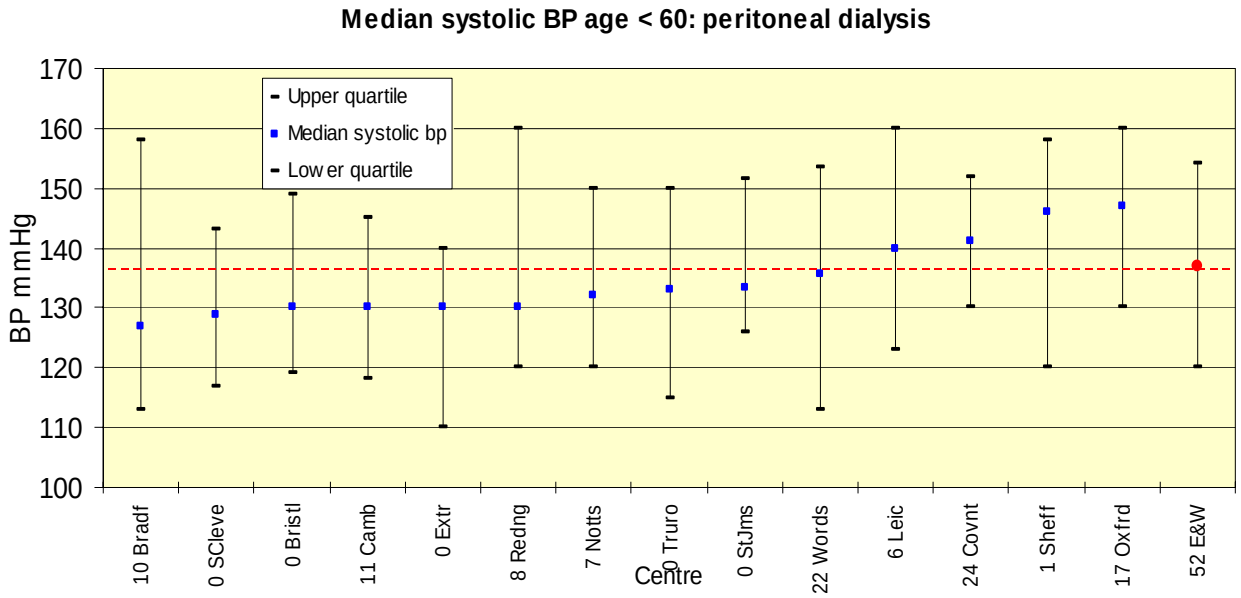


Figure 12.11: Median systolic BP, age <60, PD

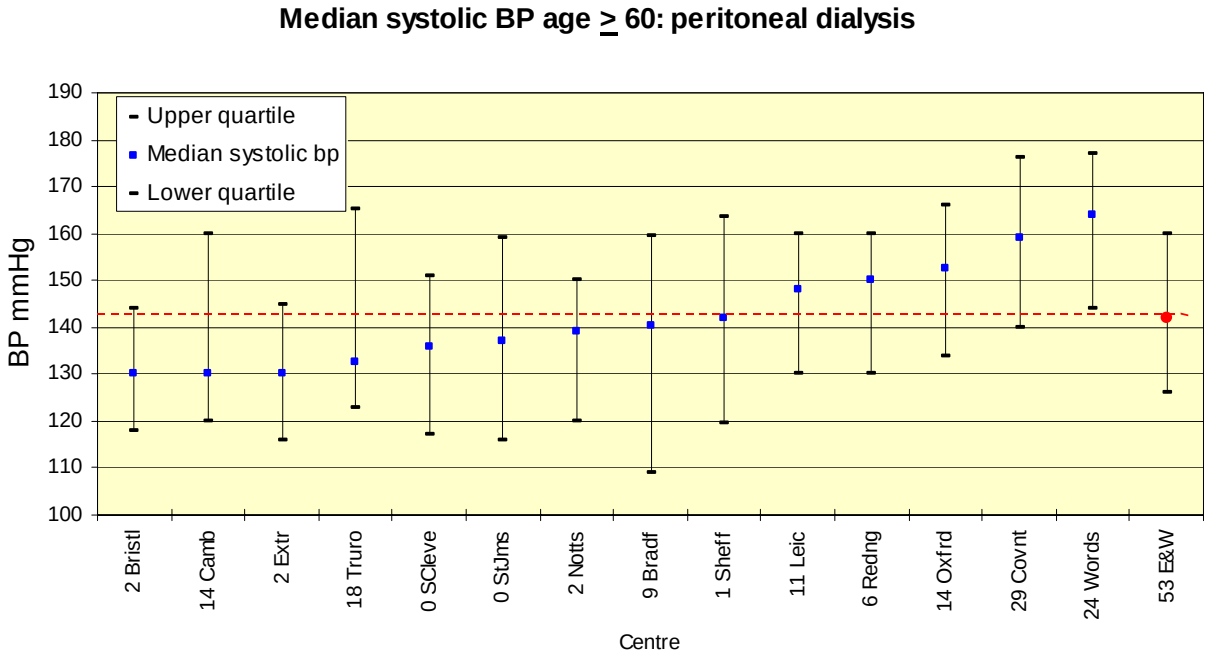


Figure 12.12: Median systolic BP, age >60, PD

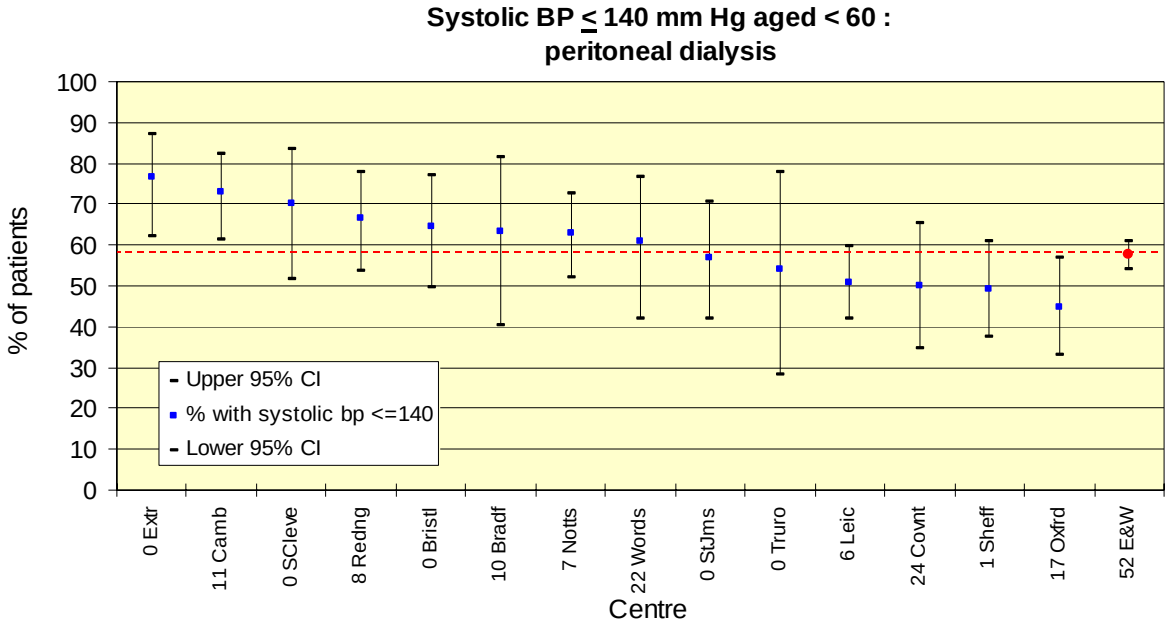


Figure 12.13: Percentage of patients aged <60 with systolic BP <140 mmHg, PD

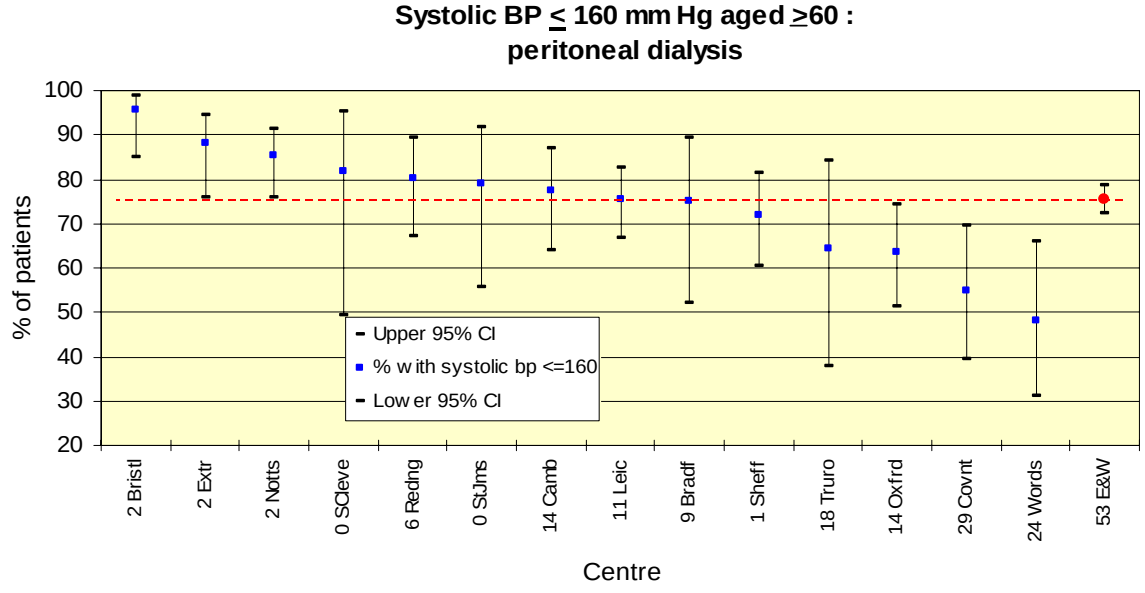


Figure 12.14: Percentage of patients aged ≥ 60 with systolic BP <160 mmHg, PD

Figures 12.11–12.14 show that, for PD, the percentage of elderly patients achieving the systolic Standard is higher than is seen younger patients, and again the variation between centres is significantly different. Lower systolic pressures were achieved in PD patients than HD patients, the difference being 7 mmHg for younger patients and 10 mmHg for older ones. These differences confirm that blood pressure readings in PD are equivalent to post-dialysis blood pressure.

Diastolic pressure alone

Haemodialysis

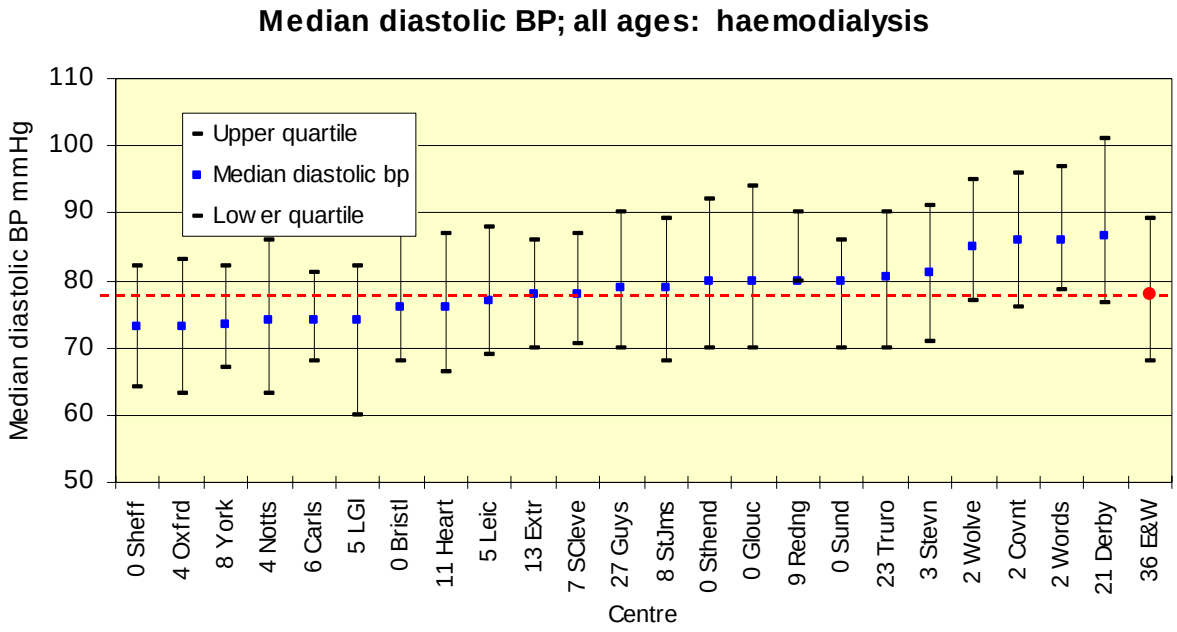


Figure 12.15: Median diastolic BP, all ages, HD

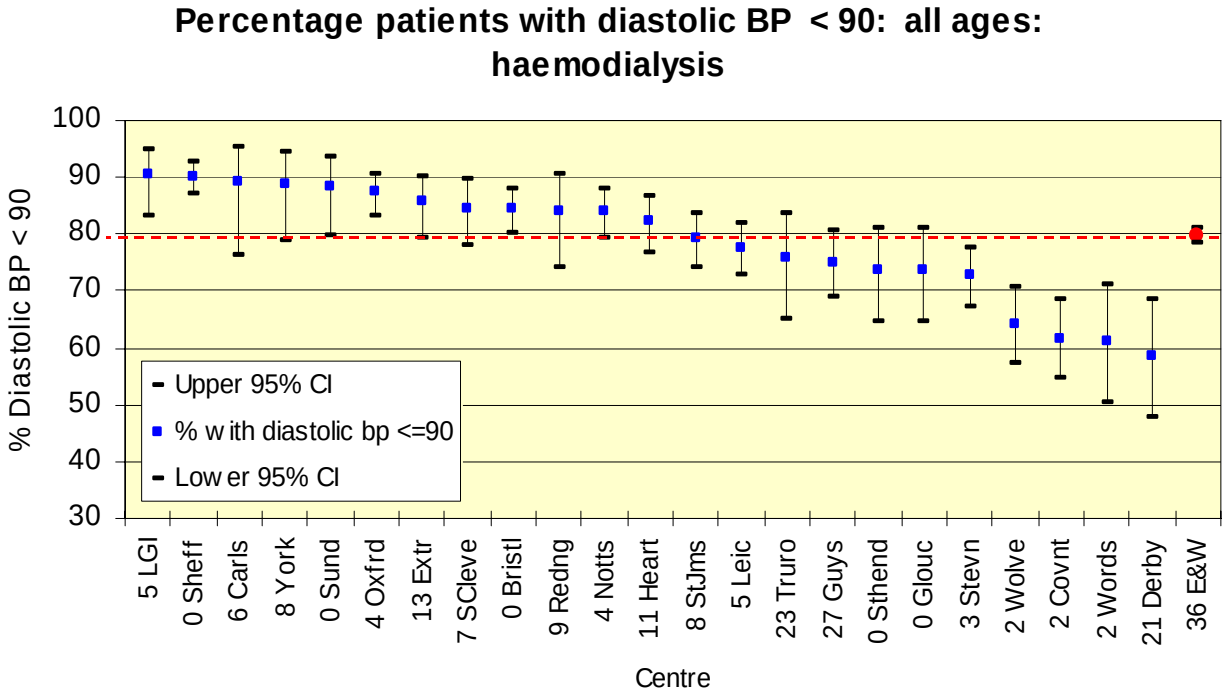


Figure 12.16: Percentage of patients with diastolic BP <90 mmHg, all ages, HD

Peritoneal dialysis

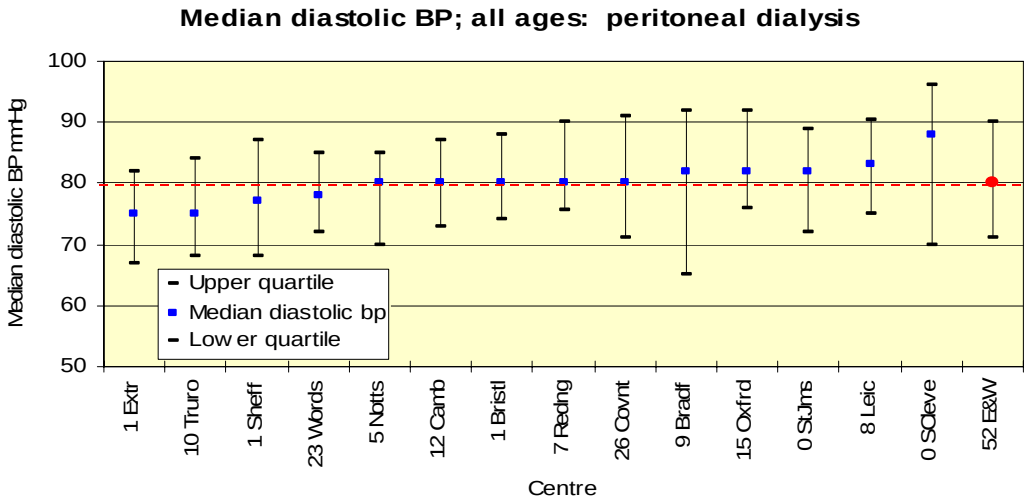


Figure 12.17: Median diastolic BP, all ages, PD

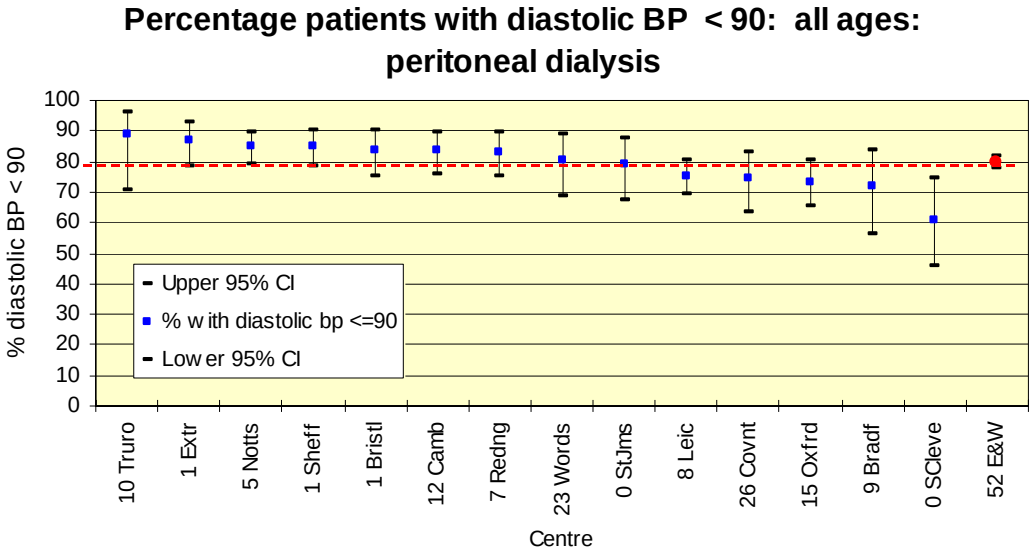


Figure 12.18: Percentage of patients with diastolic BP <90 mmHg, all ages, PD

From Figures 12.15–12.18, it can be seen that the median diastolic BP was 78 mmHg for HD patients and 79 mmHg for PD patients. The percentage of patients achieving the Standard varies significantly between centres but not across dialysis modality.

The median diastolic BP of younger patients on HD was 81 mmHg, compared with 75 mmHg in patients aged over 65 years. Thus, fewer younger patients achieve the Renal Association Standard. The median diastolic BP of patients on PD was also 81 mmHg in the younger patients, whereas those aged over 65 years on PD had a diastolic BP of 80 mmHg. This indicates that the older patients HD had more co-morbidity than those on PD. The greater use of PD in the UK (selecting patients with less comorbidity) compared with all other countries may account for the apparently lower UK survival rates on HD.

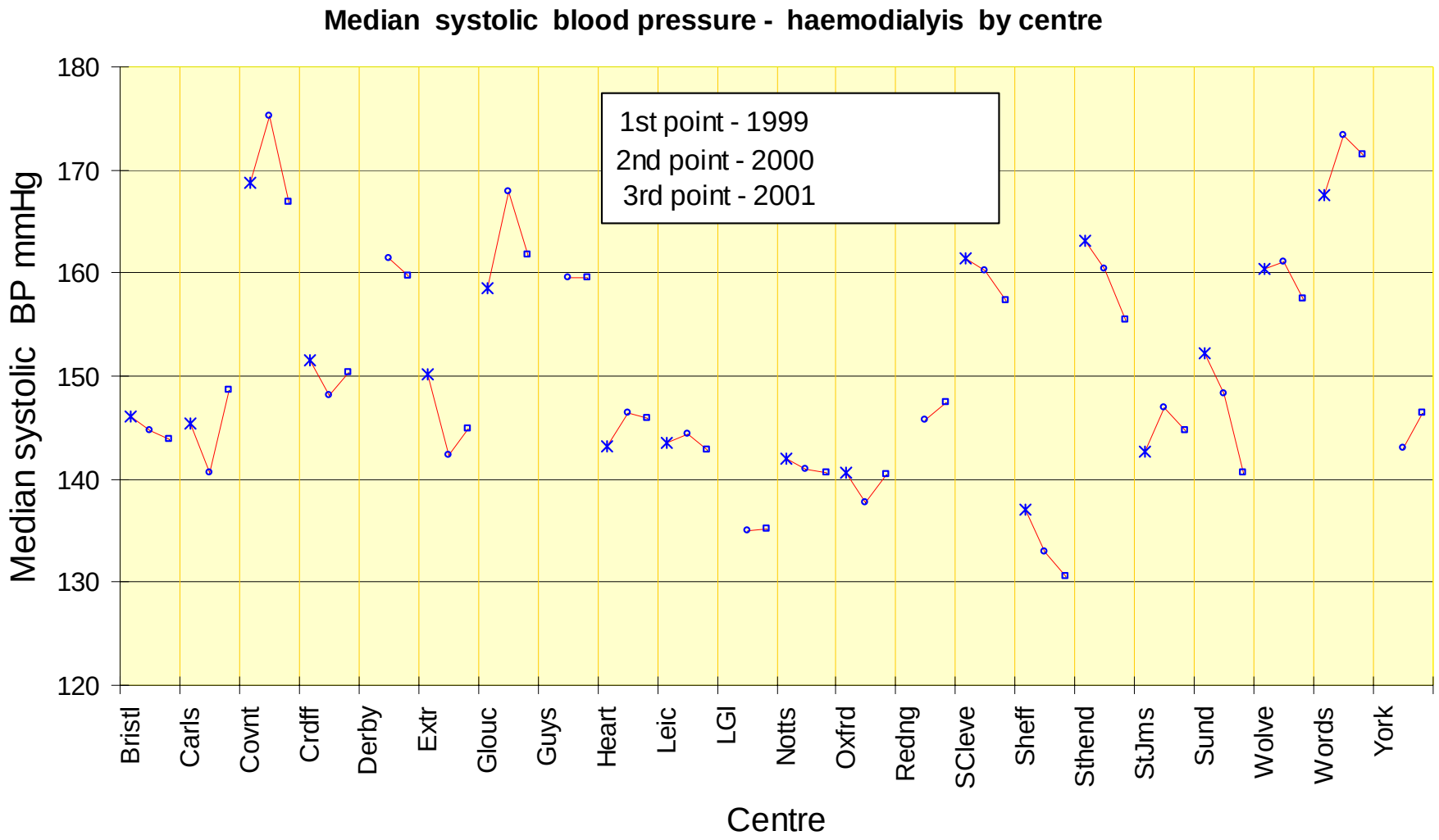


Figure 12.19: Median systolic BP, by centre, HD

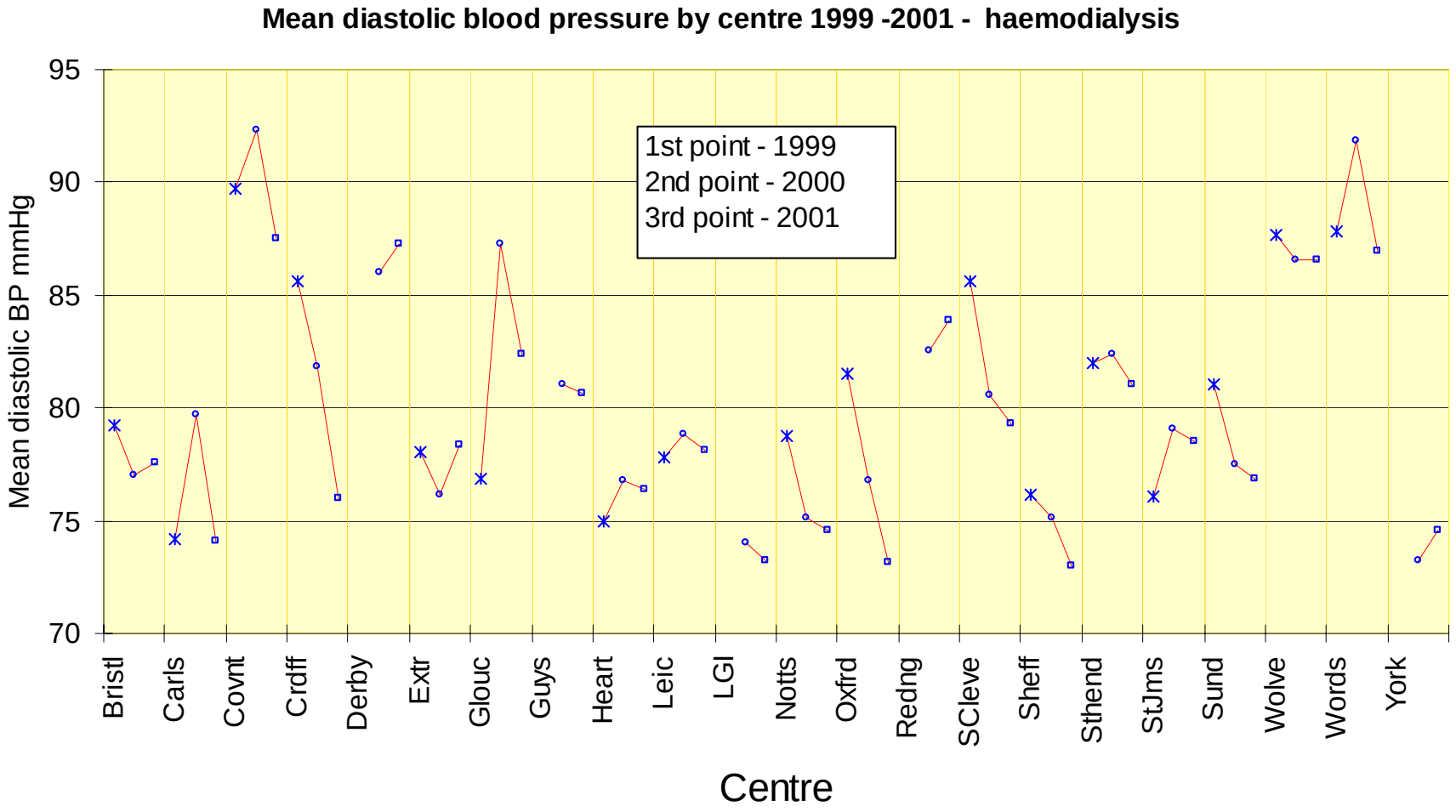


Figure 12.20: Median diastolic BP, by centre, HD

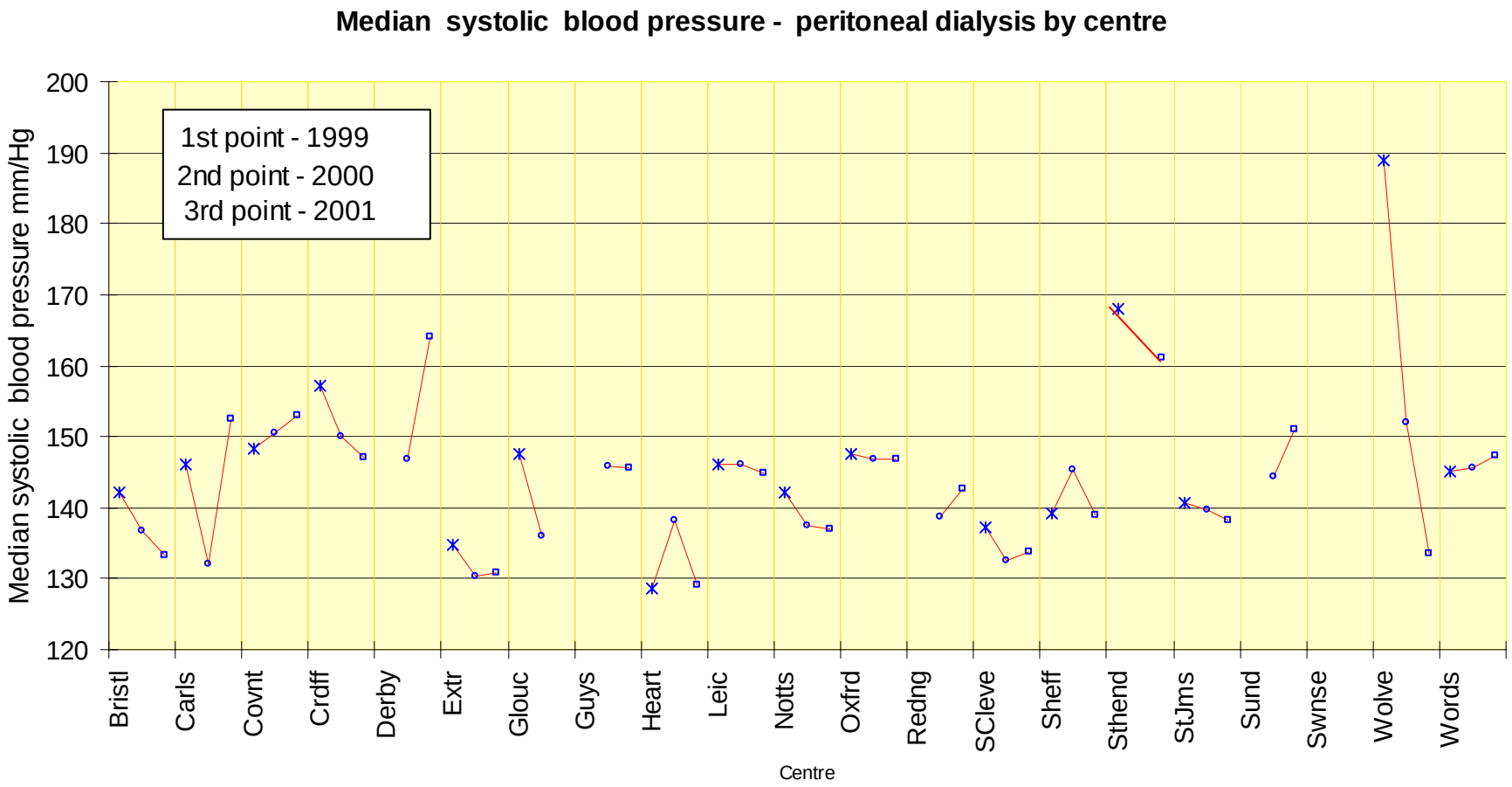


Figure 12.21: Median systolic BP, by centre, PD

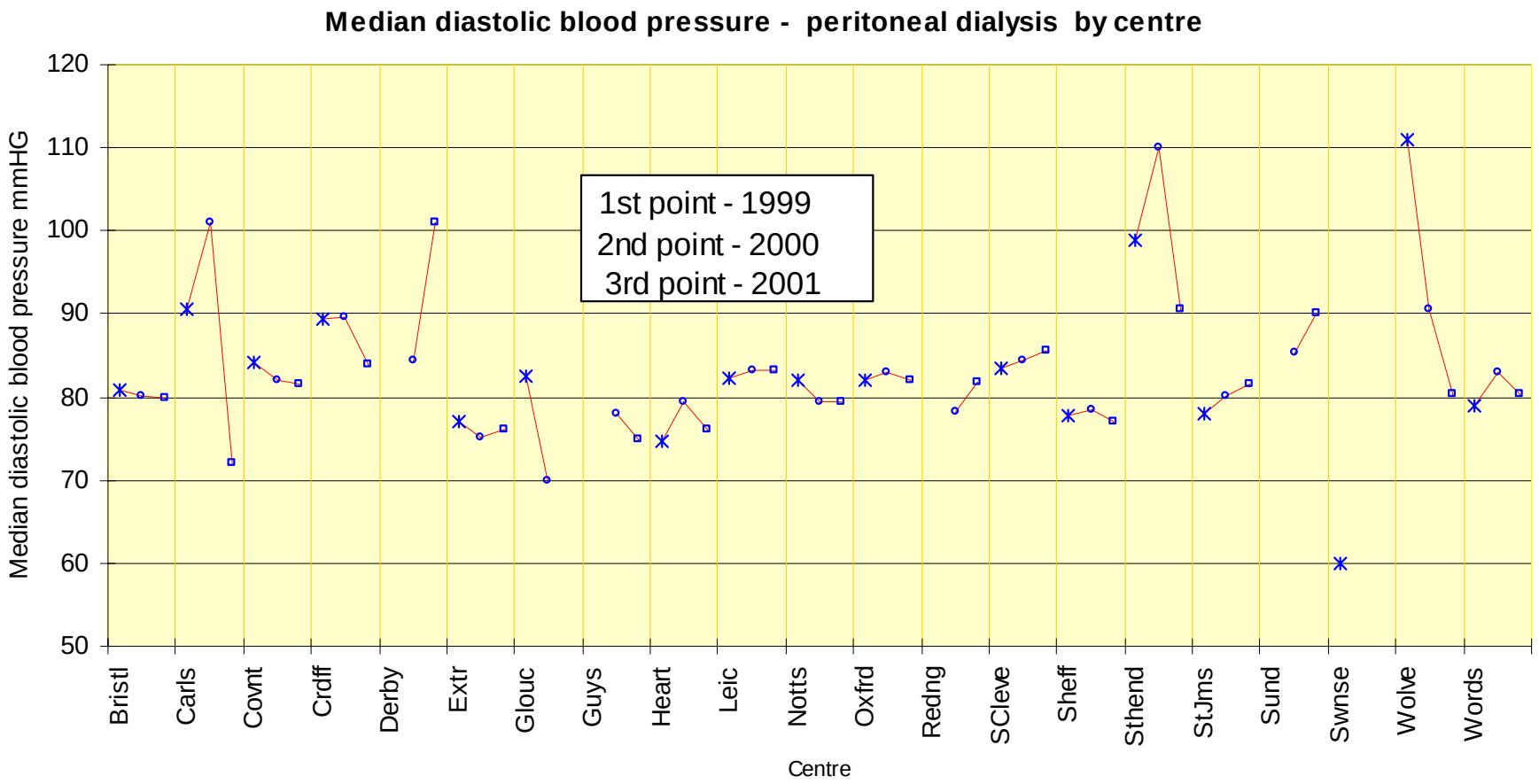


Figure 12.22: Median diastolic BP, by centre, PD

Figures 12.19–12.21 show that, in the past 3 years, only a few centres in England & Wales have shown a significant improvement in blood pressure control. A reduction in mean systolic BP by 5 mmHg or more for HD patients has been achieved in only four centres. Mean systolic BP and diastolic BP have remained constant for PD patients over this period. A few centres show a huge variation for mean systolic BP and diastolic BP. Although part of this variance is artefactual, relating to a small number of patients, some may result from changes in practice and requires further investigation.

Individual patient variability of blood pressure in 2001

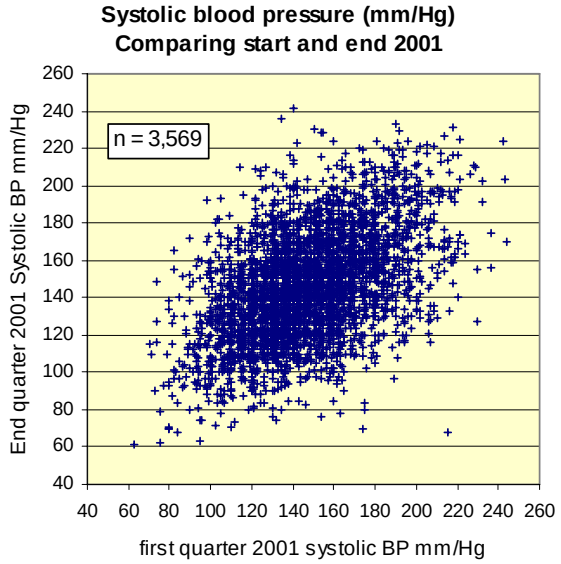


Figure 12.23: systolic BP, comparing the start and end of 2001

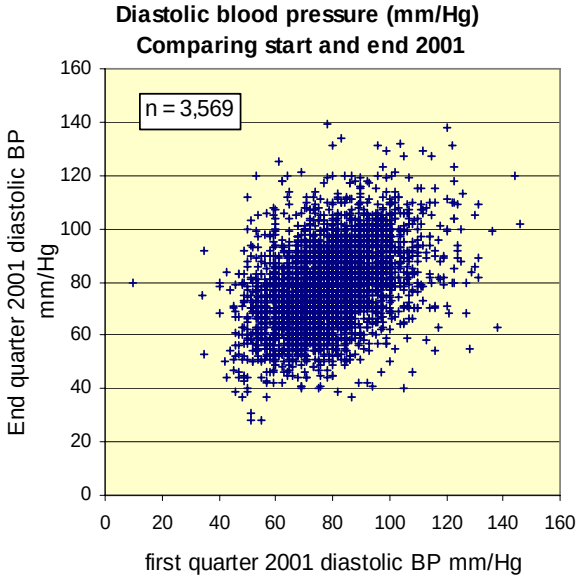


Figure 12.24: diastolic BP, comparison by quarter

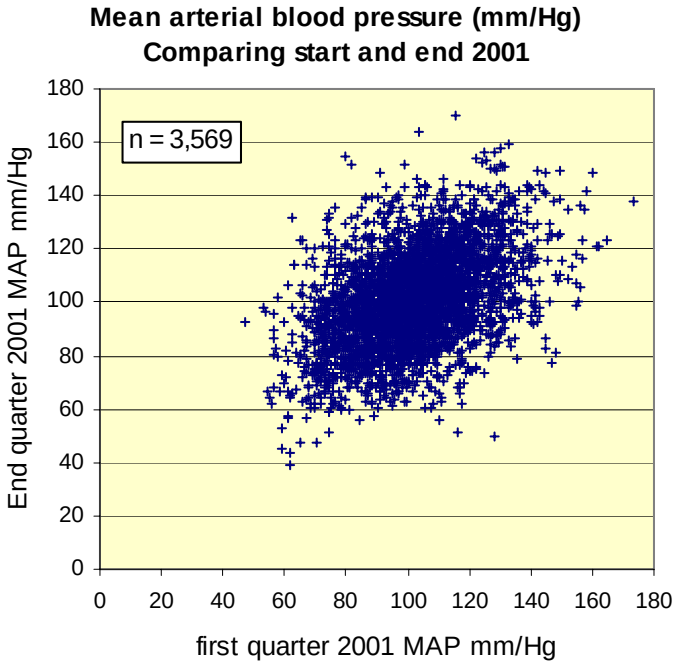


Figure 12.25: Mean arterial blood pressure (MAP)

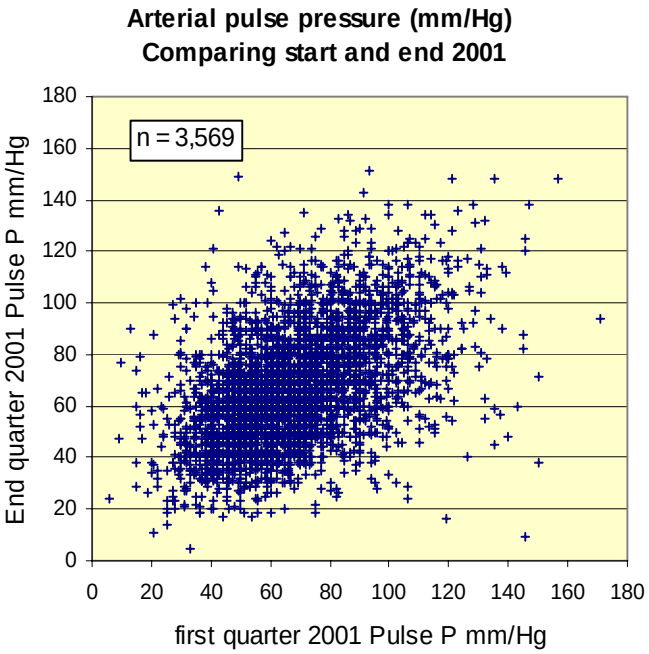


Figure 12.26: Arterial pulse pressure, start and end of 2001

Figures 12.22–12.26 show a large degree of individual patient variability in blood pressure. Readings taken from the start of 2001 were compared with readings from the end of 2001 for each individual patient. The mean difference in blood pressure was zero for both systolic BP and diastolic BP, demonstrating no change in blood pressure control over the year.

Analysis of difference between pre- and post-dialysis blood pressure

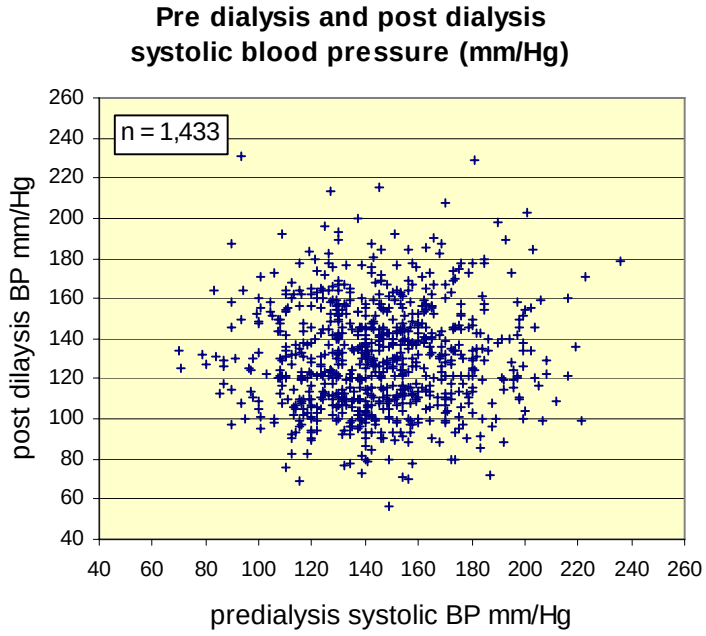


Figure 12.27: systolic BP pre- and post-dialysis

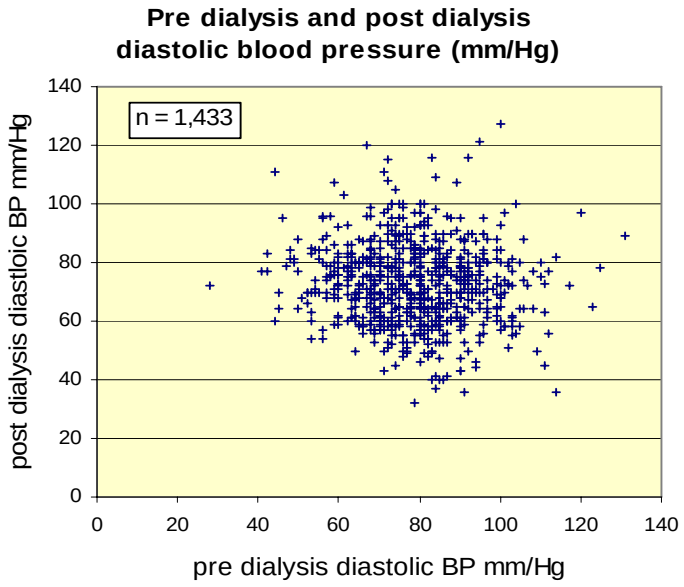


Figure 12.28: diastolic BP pre- and post-dialysis

Figures 12.27 and 12.28 demonstrate the difference between pre- and post-dialysis blood pressure for each HD patient. Only eight centres returned sufficient data to be included in this analysis. The median drop in post-dialysis systolic BP and diastolic BP was 13 mmHg and 5 mmHg respectively.

Blood pressure on dialysis and patient age

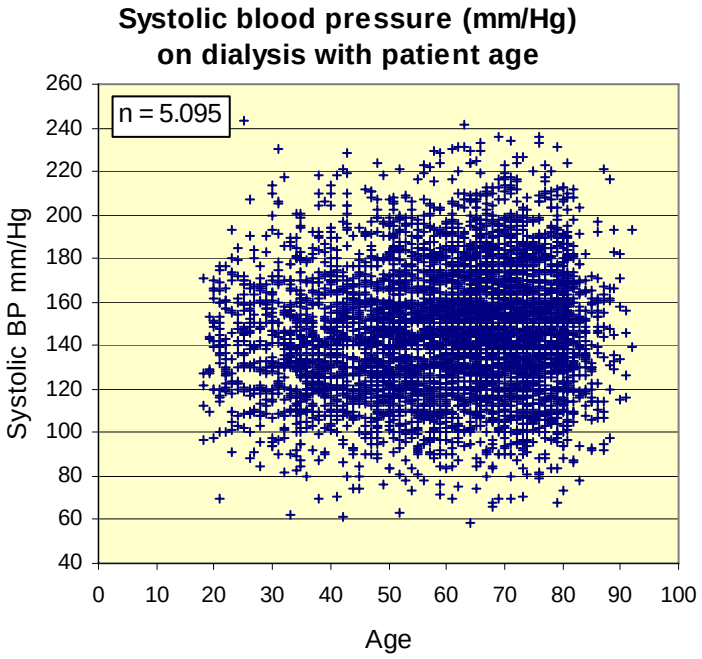


Figure 12.29: systolic BP on dialysis, by age

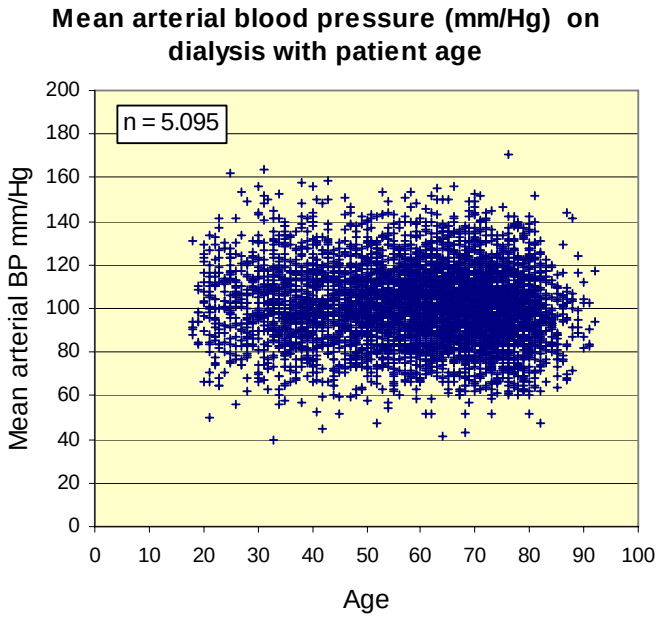


Figure 12.30: Mean arterial blood pressure on dialysis, by patient age

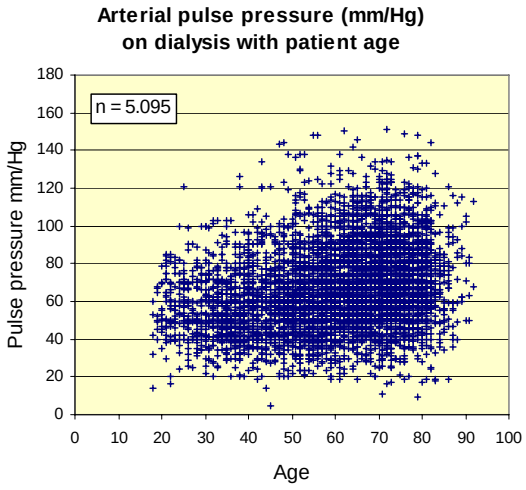


Figure 12.31: Arterial pressure on dialysis, by age

Figures 12.29–12.31 demonstrate how blood pressure varies with age on dialysis. Median systolic BP remains at 140 mmHg throughout the 18–54-year age group but rises in those patients aged over 55 to a mean of 147 mmHg. diastolic BP shows a linear decline with age from 83 mmHg in the under-35s to 74 mmHg in patients aged over 75 years, but mean arterial pressure does not change significantly.

There is a progressive, significant rise in arterial pulse pressure and its variability within the population with age. Current Standards set the arterial pulse pressure at 50 mmHg for young patients and 70 mmHg for patients 60 years or more old. The proportion of patients exceeding the Standard, and therefore the non-compliance of blood vessels, increases with age.

New Renal Association blood pressure guidelines

The third edition of The Renal Association Standards document has included new recommendations for blood pressure targets, which are the same in all adult age groups:

Pre-dialysis: blood pressure <140/90 mmHg
Post-dialysis: blood pressure <130/80 mmHg

Post-dialysis BP should be taken after completion of dialysis, including wash back.

Peritoneal dialysis: BP <130/80 mmHg

The British Hypertension Society advises how blood pressure readings should be taken. Patients should sit for 5 minutes, with the non-fistula arm supported at heart level, 30 minutes after abstention from caffeine or nicotine. Two measurements are recommended and a third if these vary significantly from each other. These conditions are probably unrealistic for most renal units. Mercury sphygmomanometers have raised environmental concerns that have led to the imposition of bans in some European countries. Although no ban has yet been imposed on the use of medical devices containing mercury in the UK, it is possible that this may change in the future. The introduction of the Control of Substances Hazardous to Health Regulations has resulted in a decline in the use of these medical devices. It is therefore recommended that consideration be given to the selection of mercury-free products when the opportunity arises.

For the first time, post-dialysis blood pressure has been included in the Standards. Several ambulatory blood pressure studies have shown that this correlates more closely with mean inter-dialytic ambulatory blood pressure as the blood pressure rises rapidly a few hours before dialysis.[13–14] The best reading is one taken 20 minutes post-dialysis, when adaptations to the reduction in extracellular volume are complete.[14] It has, however, to be acceptable to record blood pressure immediately following dialysis as it is recognised that few patients will wait 20 minutes to have their blood pressure checked. The Standards document does not qualify why blood pressure for PD patients should be equivalent to post-dialysis BP. The data from this year's report show that these readings are comparable. For HD patients, the median drop in systolic BP and diastolic BP following dialysis was 13 mmHg and 5 mmHg respectively. This suggests that the new Standards for diastolic pressure may be difficult to achieve.

The uniformity of blood pressure targets across age groups is an acknowledgement that blood pressure control benefits patients up to 80 years of age. Interestingly, a lower blood pressure target has not been set for diabetics, and international guidelines differ in their recommended targets for blood pressure in diabetics with nephropathy.[15,16] Existing evidence shows a reduced incidence of cardiovascular complications when systolic BP lies in the range 120–140 mmHg and diastolic BP in the range 75–85 mmHg. Diabetics with proteinuria exceeding 1 g/day are at greatest risk, and guidelines recommend a target blood pressure of less than 125/75 mmHg for this group. Should survival rates for the diabetic dialysis patients not improve significantly with the new blood pressure Standards, a lower target blood pressure should be considered.

Future directions

The new blood pressure Standards will not be achieved unless there is as major change in practice among renal units in England & Wales. Antihypertensive medications alone do not adequately control blood pressure in dialysis patients. Indeed, there is a strong argument that antihypertensive medication must be discontinued so that dry weight may be achieved using ultrafiltration.[17] Poor salt and water balance is undoubtedly a major contributor to poor blood pressure control in the dialysis population, yet most nephrologists are reluctant to acknowledge this. Techniques that normalise blood pressure include long slow dialysis, short daily dialysis, nocturnal HD and dietary salt and fluid restriction in combination with a low dialysate sodium concentration. Dry weight control of blood pressure not only yields short-term benefits such as increased LV ejection fraction,[18] but also significantly improves long-term survival.[12] In the past, data from Tassin showing improved survival associated with long, slow HD was dismissed on grounds of patient selection. More recent analysis has, however, clearly shown a survival advantage over comparable patients in the UK. Significantly, the dry weight control of blood pressure does not improve survival for diabetics or patients with severe cardiovascular disease. Adequate fluid and sodium removal to normalise blood pressure have also been shown to improve the survival of PD patients.[19]

There is no conclusive evidence that blood pressure control cannot be achieved with 'conventional' HD. Indeed, some of the centres that have improved results for blood pressure control in this year's analysis have done so by adopting a more aggressive fluid balance policy to achieve dry weight. This has inevitably involved closer medical supervision, and it is likely this is the main reason why nephrologists have been reluctant or unable to tackle the fluid overload issue in their patients, and thus centres continue to fail to achieve blood pressure Standards. Appropriate dietary advice regarding modest sodium restriction will also be needed if patients are to comply with fluid intake restrictions.[20]

Serum cholesterol

Hyperlipidaemia is common in the dialysis population, the typical pattern being raised triglycerides, low high-density lipoprotein (HDL) cholesterol and variable changes in low-density lipoprotein (LDL) and total cholesterol dependent on nutritional state and dialysis modality. An inverse or U-shaped association has been reported between cholesterol and mortality for the dialysis population in the USA[21,22] and is confirmed in this report (see below). Whereas low cholesterol is a marker of chronic disease, chronic inflammation and malnutrition, hypercholesterolaemia has a similar role in the genesis of atherosclerosis as in the general population. It is therefore a major target for treatment intervention. The current Renal Standards document does not contain any recommendations on the control of serum cholesterol.

Haemodialysis

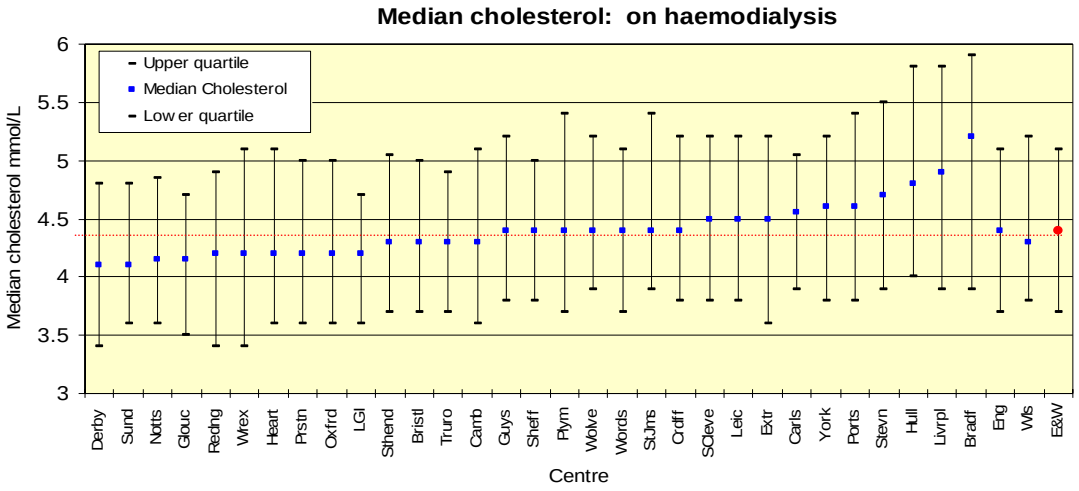


Figure 12.32: Median cholesterol against quartile ranges, HD

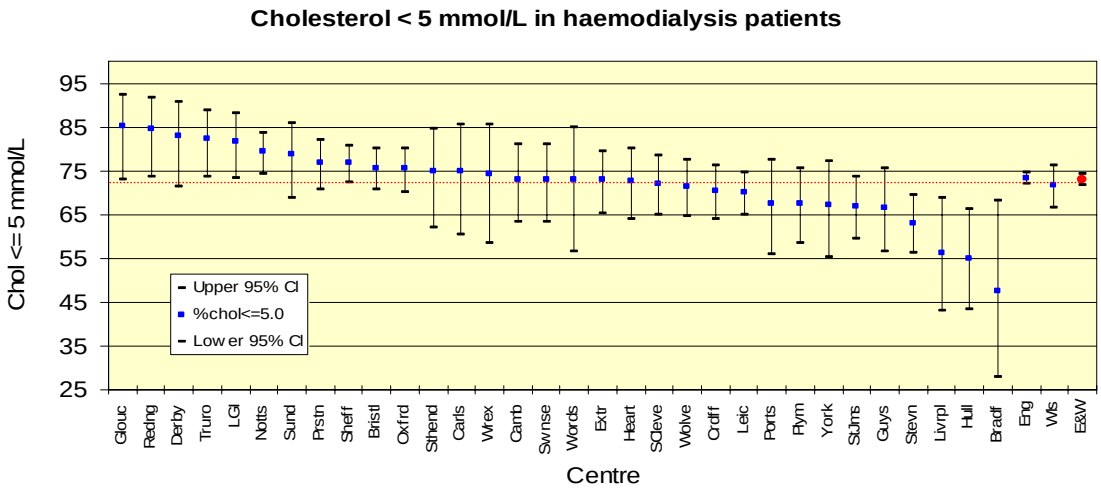


Figure 12.33: Cholesterol ≤ 5 mmol/L in HD patients

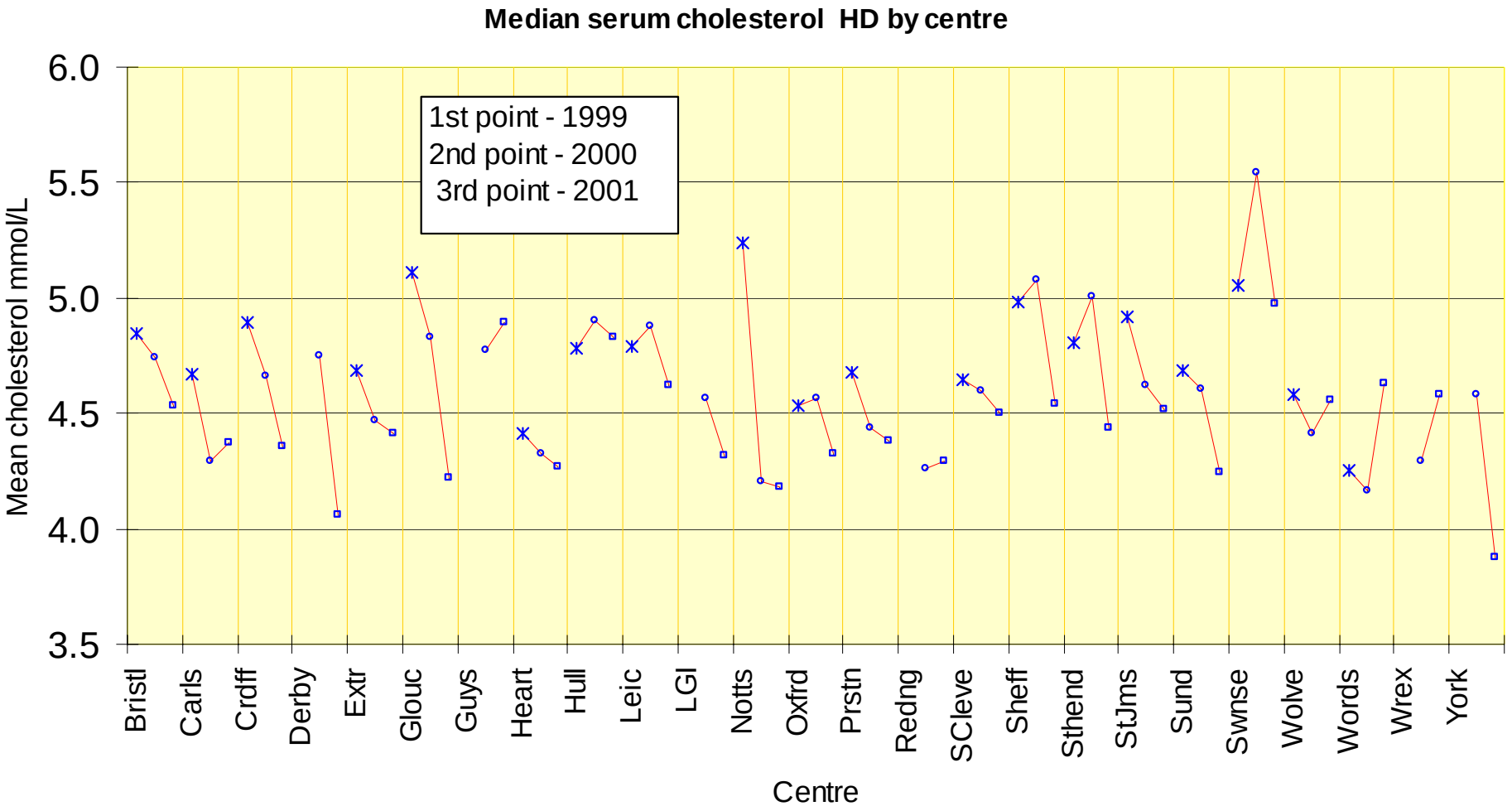


Figure 12.34: Median serum cholesterol on HD, by centre

Peritoneal dialysis

Figures 12.31–12.33 show cholesterol data for HD patients. The median cholesterol level is 4.4 mmol/L, and the percentage of patients achieving a cholesterol level of 5 mmol/L or less averages 73% (range 47–86%). Chi squared testing indicates that these variations are significant between centres (p<.001). Figure 12.37, showing the 3 year serial mean cholesterol level by centre, indicates that centres with the highest cholesterol levels have achieved the most marked improvements initially.

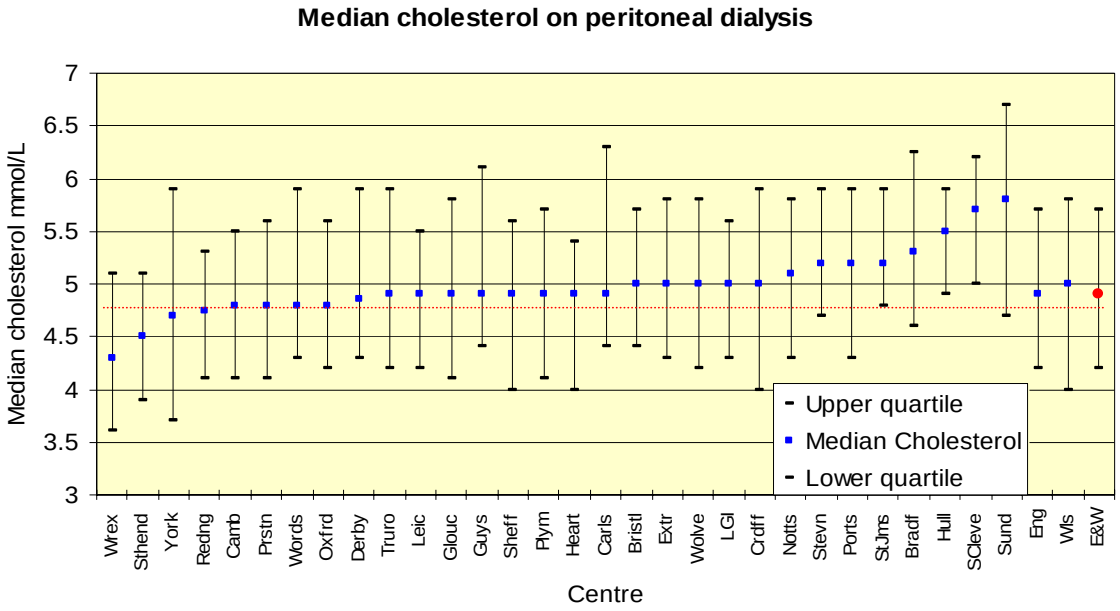


Figure 12.35: Median cholesterol in PD

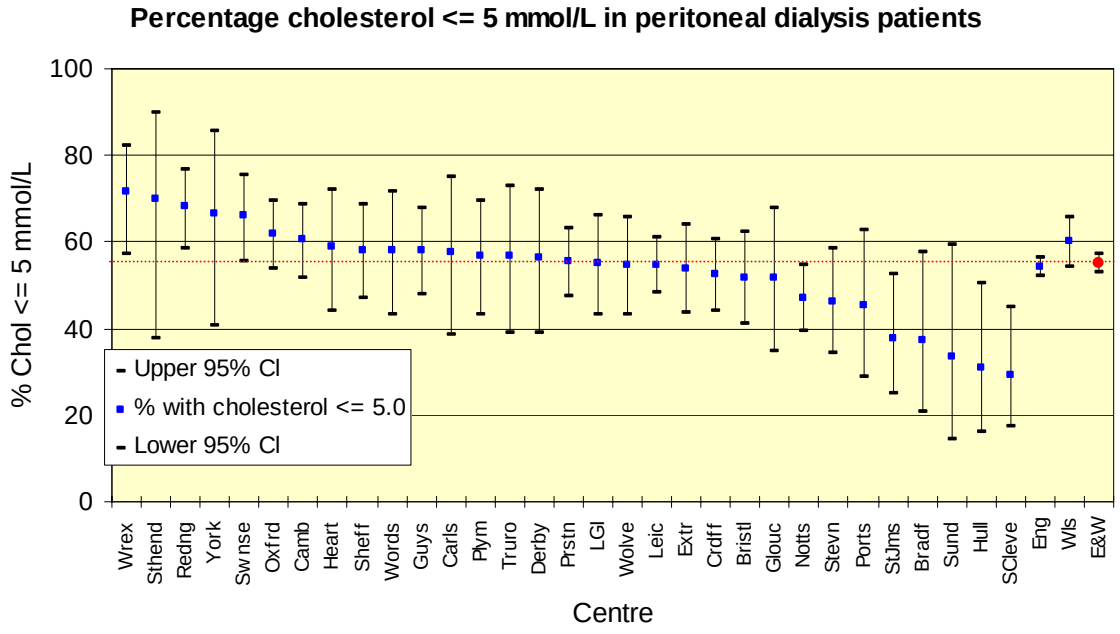


Figure 12.36: Percentage cholesterol ≤ 5 mmol/L in PD patients

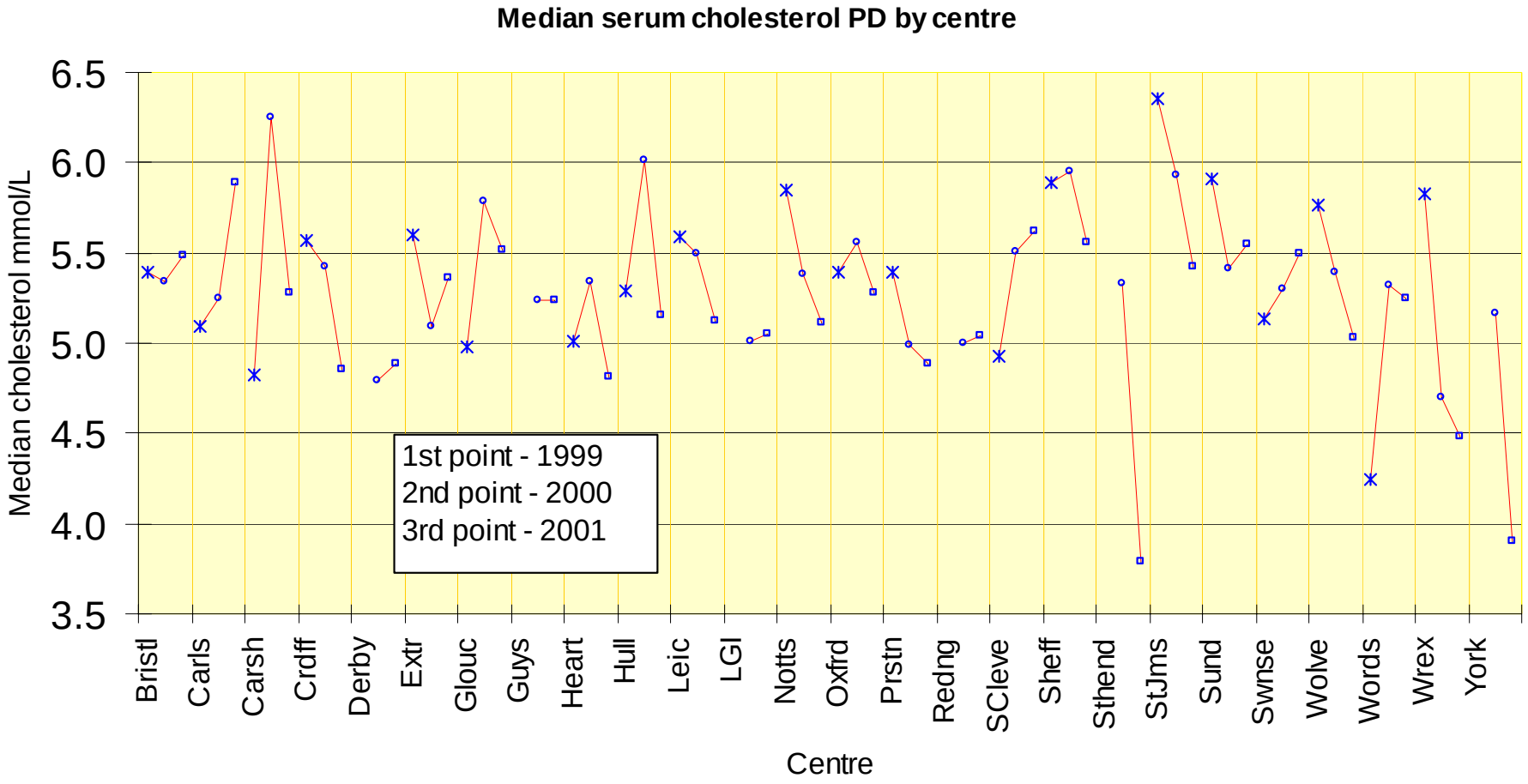


Figure 12.37: Median serum cholesterol, 1999–2001, PD

Figures 12.34–12.36 show cholesterol data for PD patients, the median cholesterol level being 4.9 mmol/L. The percentage of patients achieving a cholesterol level of 5 mmol/L or less averages 56% (range 30–72%). Chi squared testing indicates that these variations are significant between centres. The data show significantly higher cholesterol levels in PD patients and significantly fewer achieving a cholesterol level below 5 mmol/L, compared with HD patients. Serial mean cholesterol levels by PD centre again indicate that centres with the highest cholesterol levels have achieved the most marked improvements initially.

Serum cholesterol and survival on dialysis

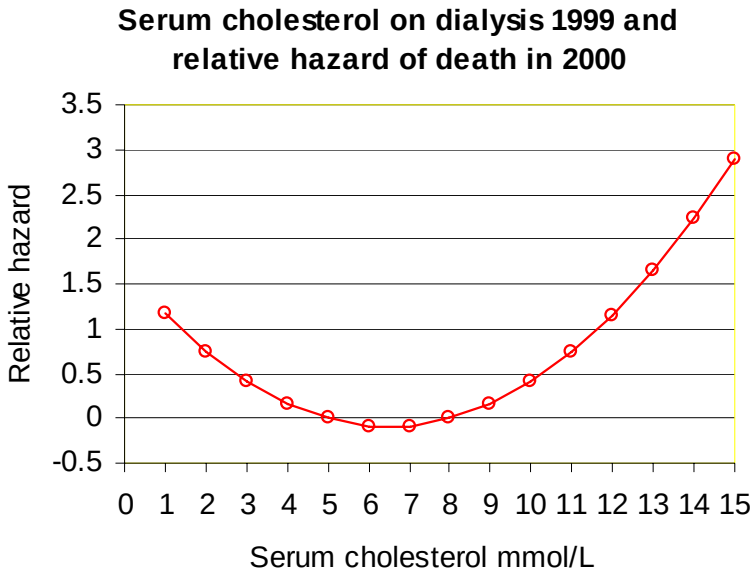


Figure 12.38: Serum cholesterol on dialysis

Figure 12.38 shows a U-shaped association between cholesterol level and mortality for the dialysis population in England & Wales over the 1 year period 1999–2000. Short-term survival is optimal for patients with a serum cholesterol level of 5–8 mmol/L, presumably because this reflects good nutrition. Long-term survival data are not currently available. The new Standards will require centres to collect information in such a way that it will be possible in future to audit serum cholesterol against risk for cardiovascular death.

New Renal Association cholesterol guidelines

The third edition of The Renal Association Standards document has included new recommendations for cholesterol targets.

Primary prevention

Start an HMG-CoA reductase inhibitor if the 10 year risk of coronary disease is over 30% (this is calculated according to the Joint British Societies Chart of the Coronary Risk Calculator).

Aim to achieve a total cholesterol of less than 5 mmol/L or a fasting LDL cholesterol of below 3 mmol/L.

To calculate cardiovascular risk, renal units will need to record on their databases smoking, family history of premature vascular disease (males <55 years and women <65 years), blood pressure, total and HDL cholesterol levels, diabetes, age and sex.

Secondary prevention

Start an HMG-CoA reductase inhibitor if there is a history of myocardial infarction, stroke, peripheral vascular disease, acute coronary syndrome or a revascularisation procedure (surgical or angiographic).

Aim to achieve a total cholesterol concentration of less than 5 mmol/L, or reduction in its value by 30%, or a fasting LDL cholesterol of below 3 mmol/L.

To audit this effectively, renal units will need to record on their databases symptoms of vascular disease and vascular events so that such patients can be identified.

European guidelines suggest that lipids should be measured at the initiation of dialysis, 3 months later and 6 monthly thereafter.[23] Blood should be drawn immediately before a regularly scheduled HD treatment or at least 12 hours after, preferably with the patient in a fasting state.

It is acknowledged that the coronary risk calculator underestimates the risk for patients with renal dysfunction and diabetics. Few renal units will currently be performing the appropriate level of screening for hyperlipidaemia and treatment monitoring, as laid down by European guidelines. Taking a progressive, staged approach to coronary prevention with the new Standards ensures that those at highest risk are targeted first. Continuing audit is needed to determine whether the current level of medical care is able to identify, treat and monitor patients appropriately and establish whether all dialysis patients indeed carry a high risk.

Clinical trial of cholesterol-lowering in chronic renal failure

The UK Heart and Renal Protection pilot study was designed to assess the safety and efficacy of simvastatin in patients with chronic renal failure. Total cholesterol was reduced by 20%, LDL cholesterol by 26% and triglycerides by 13%, but there was no significant effect on HDL cholesterol.[24] A large-scale international randomised trial (Study of Heart and Renal Protection) is planned; this will assess the impact of lowering cholesterol on major vascular outcomes and on the progression of renal disease among patients with chronic kidney disease. A combination of simvastatin and ezetimibe, a novel cholesterol absorption inhibitor, will be used. Interested centres should contact the Clinical Trials Support Unit in Oxford on (01865) 404846.

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Chapter 13: Renal Transplantation

Summary

- This chapter reports on data returned from 33 units, of which 14 are renal transplant centres.

- Of all the transplant patients on the Registry database, 21.4% are managed by non-transplant centres.

- There has been a progressive decline in the proportion of the prevalent renal replacement therapy patients made up by renal transplants from 51% in 1997 to 46.6% in 2001.

- Variation exists between centres with respect to access to transplantation. There are a number of possible explanations for these differences, which need to be examined further.

- Six per cent of all patients starting dialysis in 2001 were patients with failed transplants; 2.3% of all prevalent transplant failed during 2001.

- The annual death rate of patients with established renal transplants for England & Wales is 2.8% (including patients with failed grafts returning to dialysis).

- The quality of transplant function differs significantly between centres, as does the haemoglobin level.

- Differences in modifiable risk factors for cardiovascular disease also exist, and the control of these factors is often poor. In most centres, there has been a progressive reduction in median serum cholesterol level since 1998.

- Blood pressure measurements returns to the Renal Registry from some centres continue to be poor.

Introduction

In 2001, there were 25 centres in England and Wales performing renal transplantation. A much greater number of renal units, however, contribute to the management and follow-up of patients after transplantation. This chapter reports on data returned from 33 units, of which 14 perform renal transplantation.

As with other sections of this report, individual units can now be identified. This may enable a more meaningful interpretation to be made of the data in future reports when epidemiological, demographic and other differences between units can be considered. Emphasis is placed on access to transplantation, quality of transplant function, haemoglobin level and potentially modifiable cardiovascular risk factors such as blood pressure and

cholesterol. Data comparison with centres with a small number of transplant patients should be interpreted with caution. Centres with fewer than 50 prevalent transplant patients (see Table 13.3 below) have been excluded from further analysis.

Transplants performed in 2001

In 2001, 871 renal transplants were performed by centres contributing to the Renal Registry. This represents 50% of all renal transplants performed in the UK in that year. The median age of the new transplant recipients was 49 years; 62.6% were male and 37.4% female (Table 13.1).

	Number	Median age	% >65	Median age dialysis	% Dialysis >65
E&W (23 renal units)	871	49.0	13.2%	62	44.1%

Table 13.1: New transplants from the Renal Registry, 2001

For the whole of the UK, there were 1385 cadaver transplants and 358 live transplants reported during 2001 (www.uktransplant.org.uk). Of these, 1231 cadaver transplants and 319 live transplants were performed in England and Wales.

Table 13.2 shows the primary renal diagnoses in newly transplanted patients and in the established transplant population.

	New transplants in 2001		Established transplants 1/1/01	
	%	No	%	No.
Aetiology uncertain/GN NP	17.7	156	22.4	2051
Glomerulonephritis	20.0	176	18.6	1703
Pyelonephritis	14.6	128	16.8	1536
Diabetes	9.0	79	6.5	596
Renal vascular disease	1.4	12	1.3	122
Hypertension	5.8	51	5.4	497
Polycystic kidney	10.4	91	10.9	996
Not sent	6.9	61	4.1	379
Other	14.2	125	14.0	1288

Table 13.2: Primary diagnosis of transplant patients in the UK
GN NP, glomerulonephritis – not histologically proven.

For comparison, in 1999, 7.8% of new transplants occurred in patients whose primary renal diagnosis was diabetic nephropathy.

Patients with established renal transplants

In 2001, there were 8584 prevalent transplant patients in participating centres; Table 13.3 shows the number of prevalent transplant patients at each centre. Overall, 78.6% of all transplant patients reported to the Registry are managed by centres performing renal transplantation.

Centre	No. of prevalent transplant patients
Bradf	91
Bristl	520
Camb	414
Carls	80
Carsh	333
Covnt	248
Crdff	609
Extr	194
Glouc	51
Guys	710
Heart	142
Hull	152
Leic	429
LGI	161
Livrpl	620
Notts	355
Oxfrd	818
Plym	229
Ports	605
Prstn	113
Redng	6
S Cleve	218
Sheff	385
Stevn	109
Sthend	17
St Jms	473
Sund	107
Swnse	103
Truro	50
Wolve	66
Words	83
Wrex	70
York	23
Eng	7802
Wls	782
E&W total	**8584**

Table 13.3: Number of prevalent transplant patients in each Renal Registry centre
Centres that perform renal transplantation are shown in bold type.

The transfer of patients from the transplant centre back to the referring unit occurs at a variable time after transplantation, ranging from 7 days to 1 year or longer. A more meaningful way of presenting this data is therefore as the transplant prevalence rate (per million population, or pmp) according to health authority of the recipient (Table 13.4).

Region	Health authority	Transplant prevalence pmp
Y01	Gwent	357
Y01	Bro Taf	337
Y01	Avon	320
Y01	Cambridgeshire	318
Y01	Warwickshire	318
Y01	Morgannwg	316
Y01	Oxfordshire	313
Y01	Tees	313
Y01	IOWight, Portsmouth and SE Hampshire	305
Y01	North Cumbria	294
Y01	Sunderland	294
Y01	Calderdale and Kirklees	291
Y01	Leicestershire	286
Y02	Barnsley	281
Y02	Southampton and SW Hampshire	280
Y02	Bradford	277
Y02	Buckinghamshire	277
Y02	South and West Devon	275
Y02	Northamptonshire	265
Y02	County Durham and Darlington	263
Y02	Cornwall and Isles of Scilly	263
Y02	Leeds	261
Y02	Wiltshire	256
Y02	Liverpool	256
Y07	North Wales	252
Y07	Berkshire	251
Y07	Wakefield	248
Y07	Rotherham	248
Y07	Coventry	246
Y07	North and East Devon	244
Y07	Wirral	238
Y07	East Surrey	238
Y07	Nottingham	237
Y07	Brent and Harrow	235
Y07	North and Mid Hampshire	233
Y07	North Nottinghamshire	231
Y07	St Helens and Knowsley	231
Y08	Lincolnshire	226
Y08	Somerset	225
Y08	Bedfordshire	225
Y08	Dyfed Powys	221
Y08	Lambeth, Southwark and Lewisham	217
Y08	North Derbyshire	213
Y08	North Yorkshire	209
Y08	Bexley, Bromley and Greenwich	208
Y08	Gloucestershire	203
Y08	North Cheshire	199
Y08	Sefton	198
Y08	Doncaster	196
Y08	Sheffield	194
Y08	Croydon	192
Y09	East Riding and Hull	174
Y09	South Humber	172
Y09	West Surrey	172
Y09	Dudley	170
Y10	Hertfordshire	155
Y10	Wolverhampton	132

Region	Health authority	Transplant prevalence pmp
Y10	Solihull	126
Y10	South Staffordshire	123
Y10	South Lancashire	118
Y10	South Cheshire	98
Y10	North-West Lancashire	97
Y11	East Lancashire	80
Y11	Morecambe Bay	74
Y11	Walsall	61

Table 13.4: Transplant prevalence rate pmp by resident Health Authority of transplant patient

The proportion of renal replacement therapy (RRT) patients with a functioning transplant has progressively fallen, from 51% in 1997 to 46.6% in 2001 (Table 13.5). Reference to other sections of this report shows that the falling proportion of transplant patients is caused by the increasing number of patients starting dialysis who are over 65 years old and therefore less likely to be suitable for transplantation, together with static transplant activity.

Year	% with functioning transplant
1997	51.0
1998	49.9
1999	47.3
2000	46.9
2001	46.6

Table 13.5: Annual proportion of RRT patients with a functioning transplant since 1997 (E&W)

Figure 13.1 shows the age distribution of prevalent transplant patients compared with that of the dialysis population from which they were drawn. The median age of the transplant patients was 49 years, compared with 62 years for the dialysis population; 13.2% of the total prevalent transplant population and 44.1% of the prevalent dialysis population were over 65 years old.

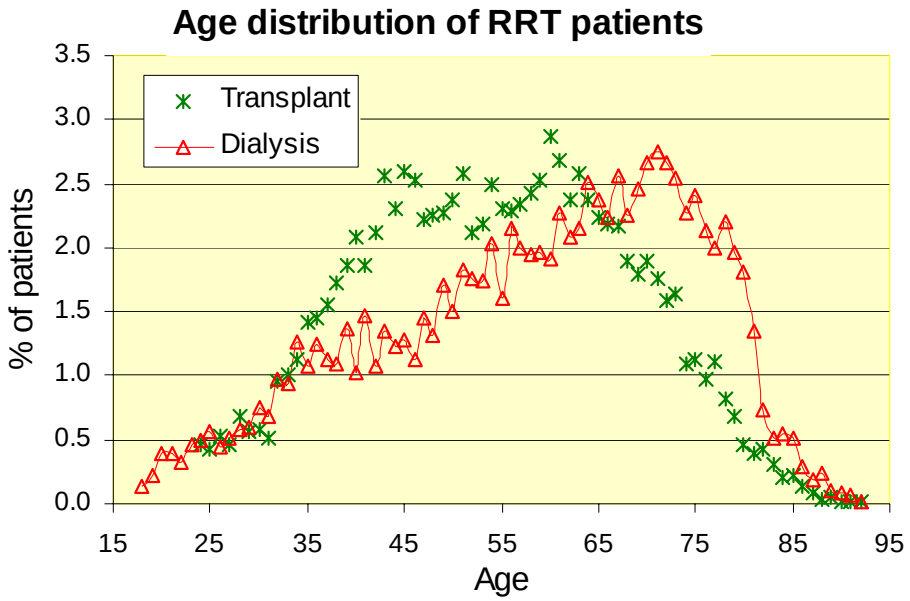


Figure 13.1: Age histogram of dialysis and transplant patients

Figure 13.2 shows the proportion of prevalent patients at each participating centre aged less than 65 years receiving renal replacement therapy according to treatment modality at the end of 2001. This age cut off has been chosen as most patients receiving a renal transplant for the first time are less than 65 years old. Overall for England and Wales, 57% of all RRT patients under 65 years is made up by transplant patients. If all patients receiving RRT are included (i.e. those over 65 years old as well), this proportion falls to 46.6%.

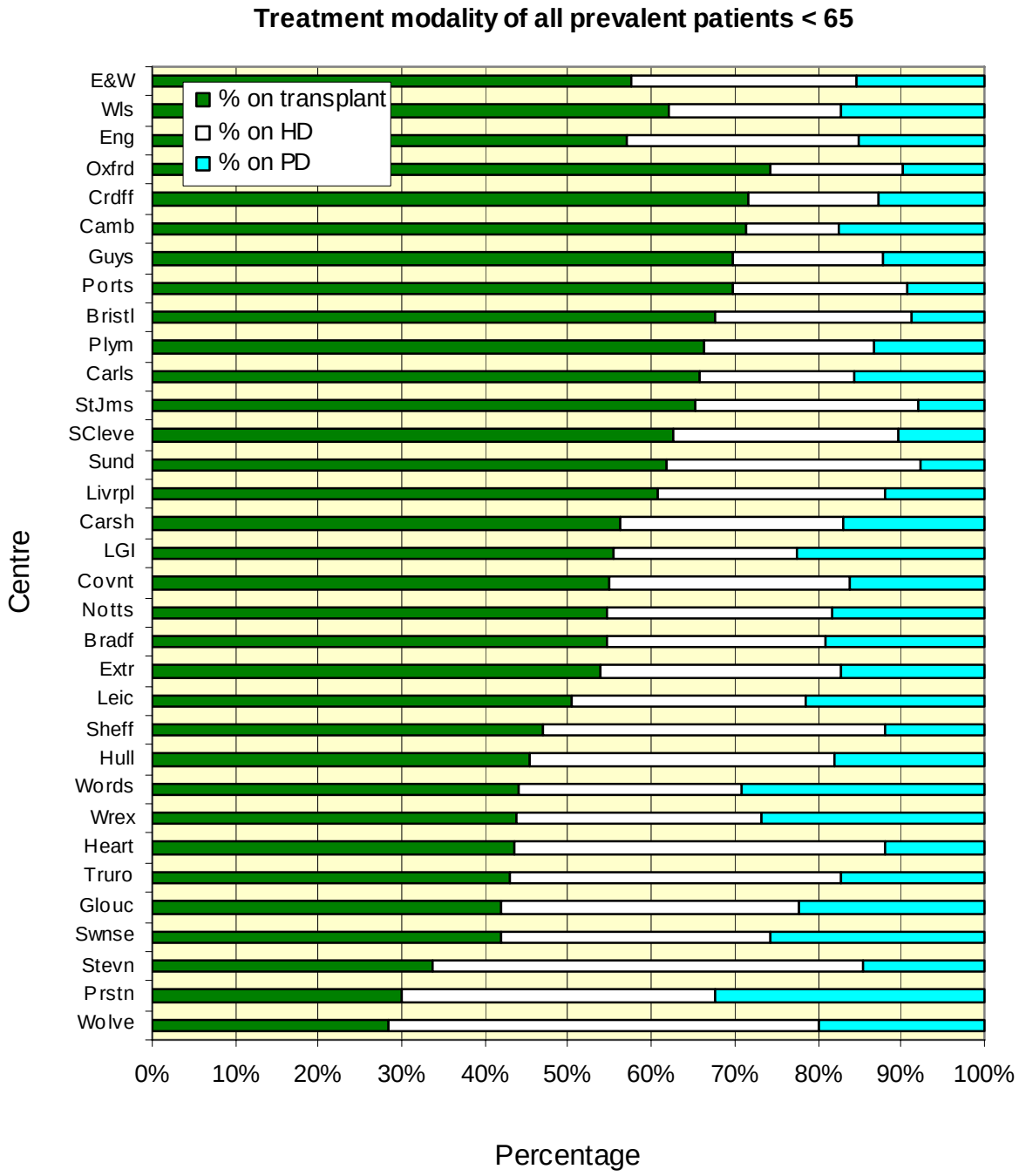


Figure 13.2: Treatment modality of all prevalent patients under 65 years old

Figure 13.3 shows the proportion of prevalent dialysis patients under 65 years at each participating centre old who have *ever* had a renal transplant. These figures are an underestimate, as some patients had no information regarding previous transplantation when transferring in on dialysis from a non-Registry unit and are treated as 'unknown'. In spite of this, there is an apparent wide variation (7.2–34.7%) between centres in access to transplantation. As stated earlier, a proportion of patients originating from non-transplant units may be followed up at the main transplant centre after transplantation (particularly those in clinical trials) and may account for some of the observed difference. A difference may also exist between transplant centres in the selection criteria used for accepting patients onto the waiting list. In addition, patients in older units are likely to have had a longer opportunity for transplantation than those in newer units, and older units are consequently more likely to have a larger number of transplant patients. Another possible explanation for this variation is the difference in the proportion of prevalent dialysis patients made up of individuals from ethnic minority groups (who are harder to blood group and HLA match and thus transplant). Data returns from Registry centres on ethnicity unfortunately remain incomplete, making this hypothesis impossible to test at present.

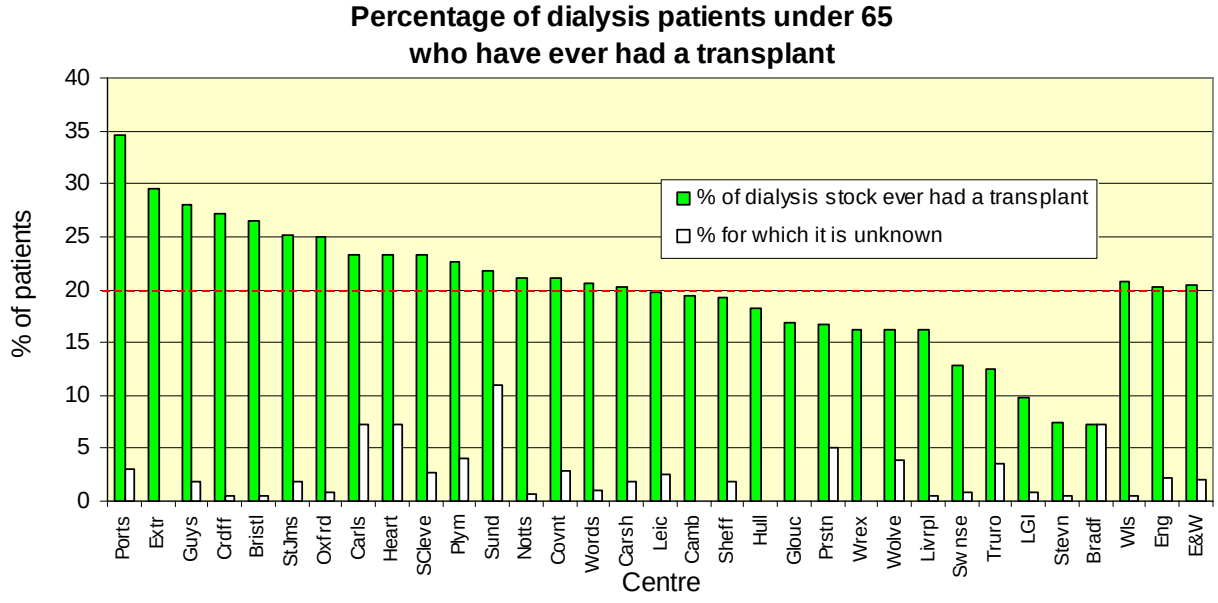


Figure 13.3: % of prevalent dialysis patients aged <65 years who have ever received a transplant

Transplantation in patients with diabetes mellitus

Figure 13.4 shows the proportion of all patients in each Registry centre with a functioning renal transplant on 31 December 01 whose primary renal failure diagnosis was diabetes mellitus. Overall, in England and Wales, 6.7% of all transplant patients have diabetes mellitus as the cause of end-stage renal failure (ESRF).

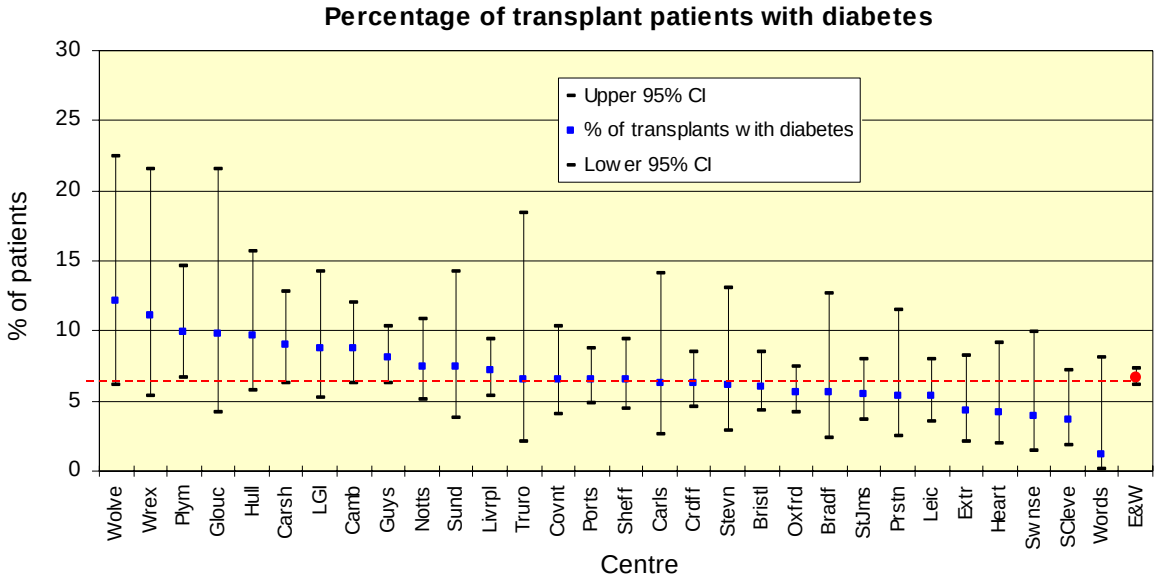


Figure 13.4: Percentage of current transplant patients with diabetes mellitus, by centre

The percentage of diabetic ESRF patients with a transplant was examined by Registry unit to explore whether there was a difference between centres in their approach to transplanting patients with this diagnosis (Figure 13.5).

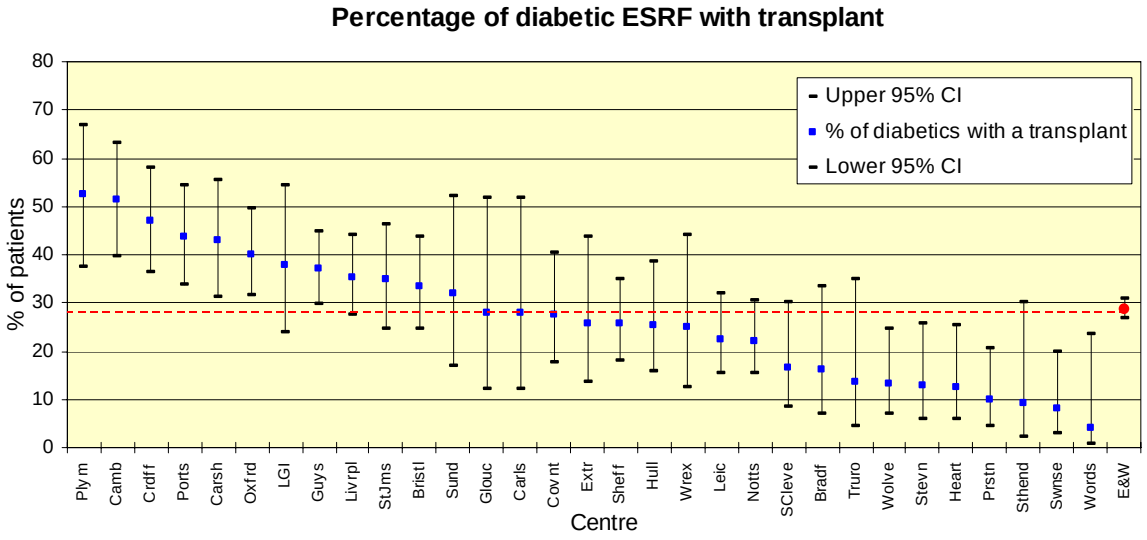


Figure 13.5: Percentage of diabetic ESRF patients with a transplant, by centre

There is a very wide variation (4–52.4%) between centres in the proportion of diabetic patients with ESRF who have a transplant. To explore further a possible difference in access to transplantation for diabetic patients between centres, the proportion of transplanted diabetic patients and transplanted non-diabetic patients under 65 was expressed as a ratio for each centre (Figure 13.6). This age limit was used in an effort to make the populations more comparable, as most patients receiving a transplant are under 65, and diabetic patients on RRT have a lower median age than other patients.

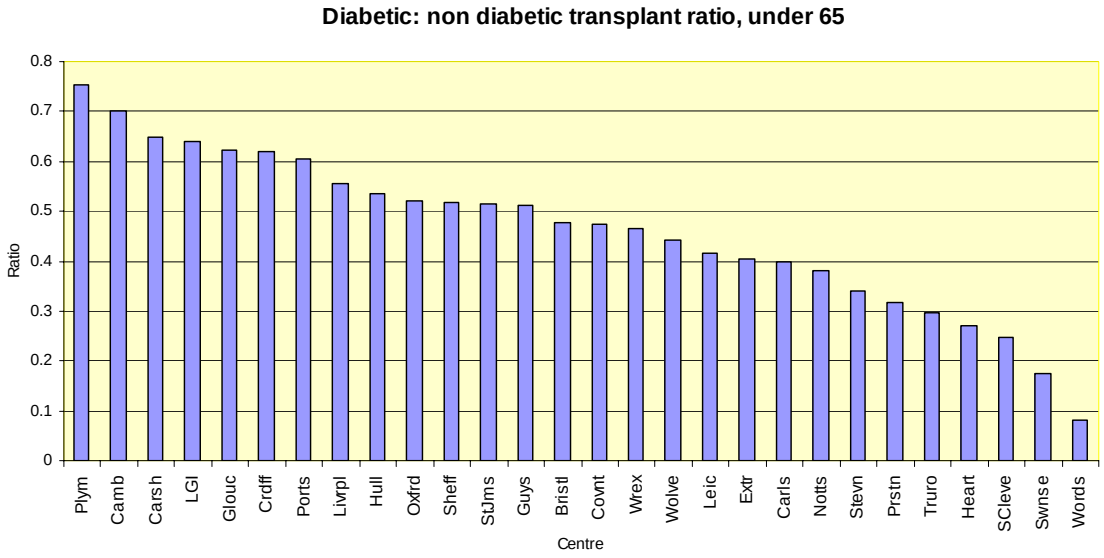


Figure 13.6: Ratio of patients aged l<65 years with a transplant, diabetics: non-diabetics

The ratio was wide, ranging from 0.75 to less than 0.1. To identify reasons for the observed differences between centres, a number of variables would need to be examined. These include the overall percentage of live ESRF patients with diabetes, the median age of this diabetic cohort and the percentage of the cohort originating from ethnic minorities (and thus likely to experience difficulty in blood group and HLA matching).

Nevertheless, ESRF patients with diabetes mellitus seem less likely to receive a transplant than other ESRF patients because of a number of possible factors, including ethnicity. It is also likely that significant comorbidity may make them less suitable for transplantation. This hypothesis will be tested in future Registry reports as more complete comorbidity data become available.

Failed transplants

In 2001, patients whose transplants failed in that year made up 6% of the total number of patients starting RRT. Among prevalent transplant patients, 2.3% of transplants failed during 2001, similar to figures reported from the Australian and Canadian Registries.

Survival of patients with established renal transplants

Table 13.6 shows the Kaplan–Meier 1 year patient survival for established transplant patients (transplanted for at least 6 months) alive on 1 January 2001.

	Transplant censored at dialysis			Transplant including dialysis returns		
	England	Wales	E&W	England	Wales	E&W
No. of patients	5896	745	6641	5896	745	6641
Kaplan-Meier						
1 year survival	97.3%	98.0%	97.4%	97.1%	97.8%	97.2%
95% CI	96.9–97.8	96.9–99.0	97.0–97.8	96.7–97.5	96.8–98.9	96.8–97.6

Table 13.6: Survival during 2001 of established transplant patients alive on 1 January 2001

Quality of transplant function

This analysis considered transplant patients on 31 December 2001 whose transplant had been functioning for at least 1 year. The most recent serum creatinine reading within 6 months was used in the analysis. The relationship between primary diagnosis and graft function is shown in Table 13.7. A greater percentage of patients with diabetes mellitus have a creatinine level above 200 mmol/L than do patients in other diagnostic groups.

Diagnosis	% with creatinine < 200 mcmol/L (no. of pts)
Aetiology uncertain*	80.5
Glomerulonephritis	76.6
Pyelonephritis	78.0
Diabetes	72.0
Renal vascular disease	88.0
Hypertension	77.2
Polycystic kidney	82.7
Not sent	83.1
Other	78.4

* Includes 'glomerulonephritis – not histologically proven'.

Table 13.7: Relationship between transplant function and primary renal diagnosis

Figure 13.7 shows the median serum creatinine of prevalent transplant recipients for each centre. There is no statistically significant difference in median creatinine values between centres.

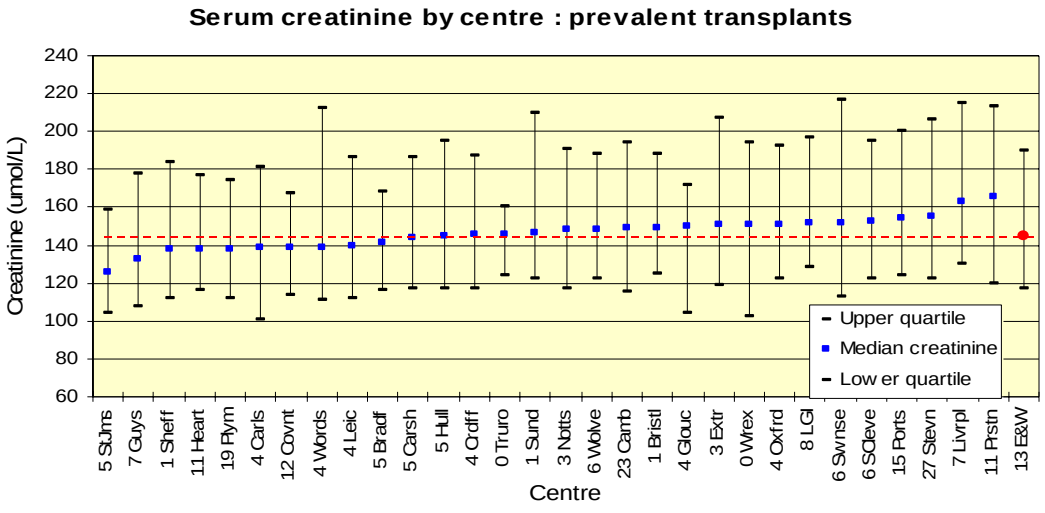


Figure 13.7: Median serum creatinine level of prevalent transplant patients, by centre

Figure 13.8, however, shows the percentage of established transplant patients with a serum creatinine greater than 250 mcmol/L for each unit. The differences between units are significant but unexplained, although they may include differences in the degree of HLA matching, immunosuppressive regimens and attitude to the use of marginal donors.

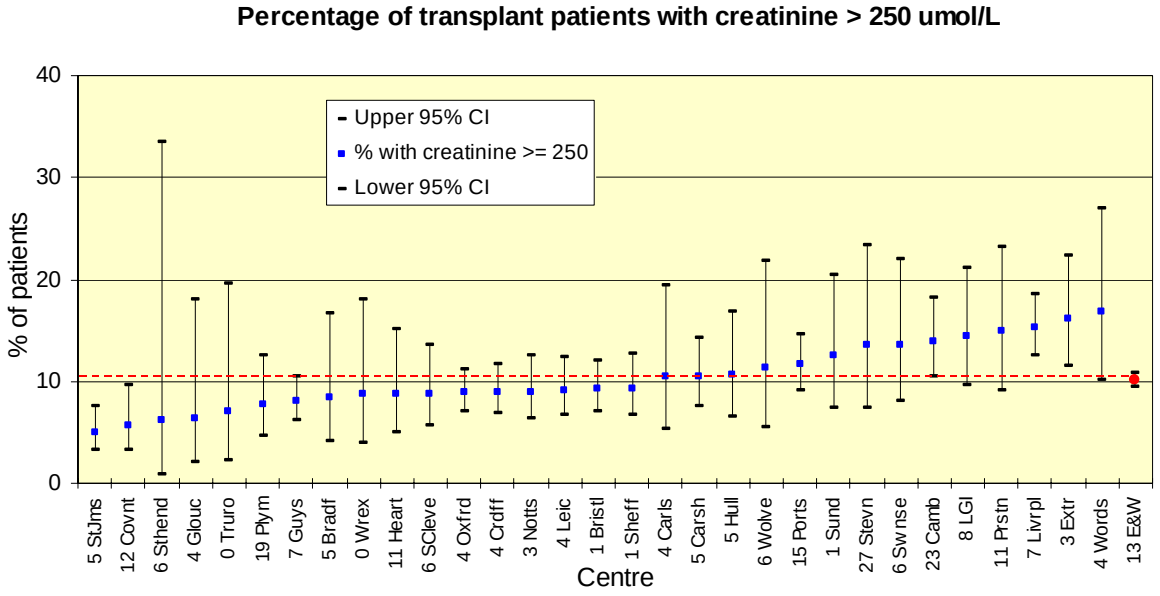


Figure 13.8: % of established transplant patients with a serum creatinine > 250 mcmol/L

Haemoglobin in transplanted patients

Considering the whole transplant population on the Registry, haemoglobin level was, as expected, lower in women and in patients with a higher serum creatinine concentration (Table 13.8).

					Haemoglobin				
Gender	Creatinine mcmol/L	Mean Hb	Std dev	5th Centile	Lower quartile	Median Hb	Upper quartile	95th Centile	No. with data
Male	<250	13.4	1.7	10.6	12.3	13.4	14.6	16.1	3344.0
Male	250+	11.4	1.7	8.8	10.4	11.4	12.5	14.7	456.0
Female	<250	12.4	1.6	9.7	11.3	12.4	13.5	15.0	2216.0
Female	250+	10.8	1.6	8.1	9.9	10.9	11.9	13.2	206.0

Table 13.8: Relationship between Hb, creatinine and gender in transplant patients

There are no recommended haemoglobin Standards for renal transplant patients. Figure 13.9 shows the median haemoglobin level for prevalent transplant patients at least 6 months after transplantation according to Registry centre.

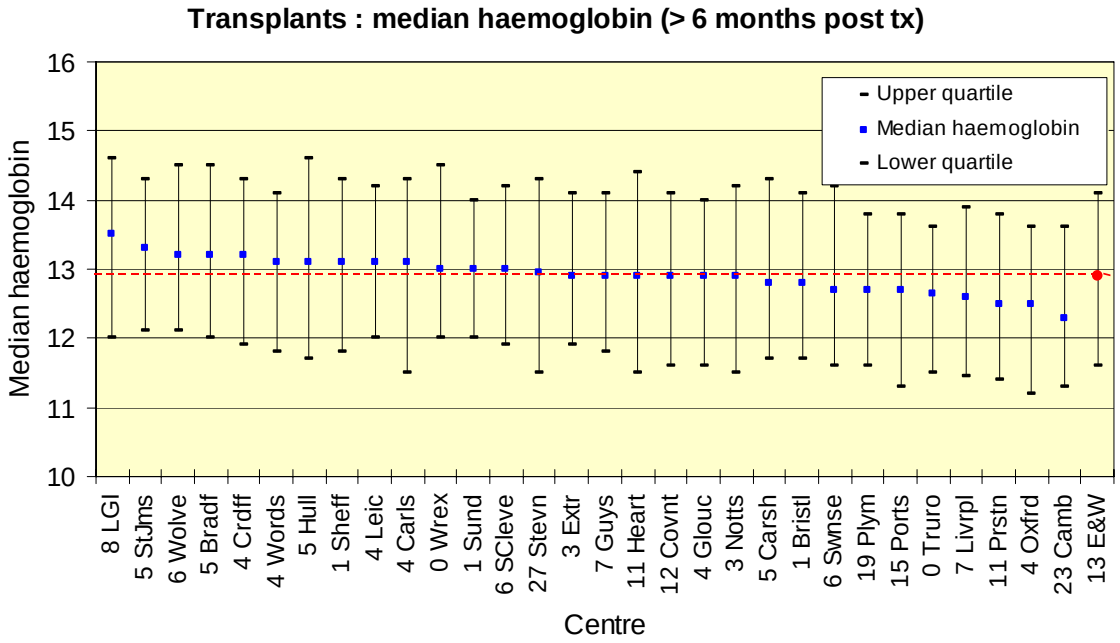


Figure 13.9: Median haemoglobin of transplant patients, by centre

Figure 13.10 shows the percentage of transplant patients in each unit with a haemoglobin concentration of less than 10 g/dL. The variation of 0.8–9.5% between centres with a level less than 10 g/dL is unexplained. Possible reasons include quality of graft function, type of immunosuppression (i.e. the use of azathioprine and mycophenolate mofetil) and use of erythropoietin when there are failing grafts.

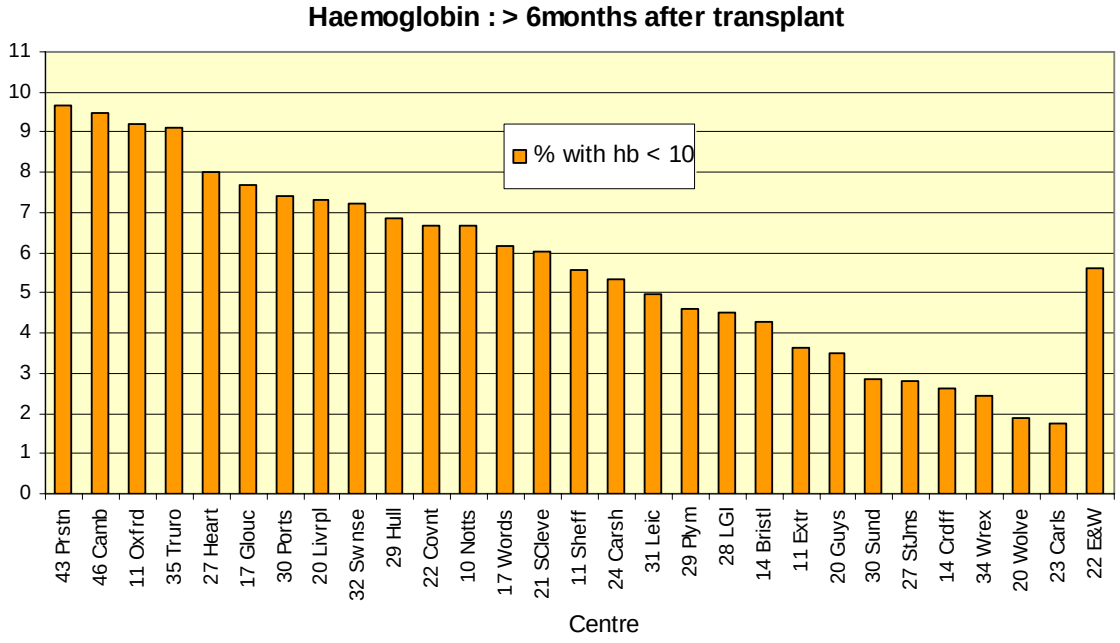


Figure 13.10: Haemoglobin level achieved in established transplant patients, by centre

Figure 13.11 shows the relationship between median haemoglobin and median serum creatinine of the transplantees at each centre. This relationship between haemoglobin and serum creatinine levels in centres did not reach significance, suggesting that factors related to centres other than graft function (e.g. type of immunosuppression and use of erythropoietin) are important.

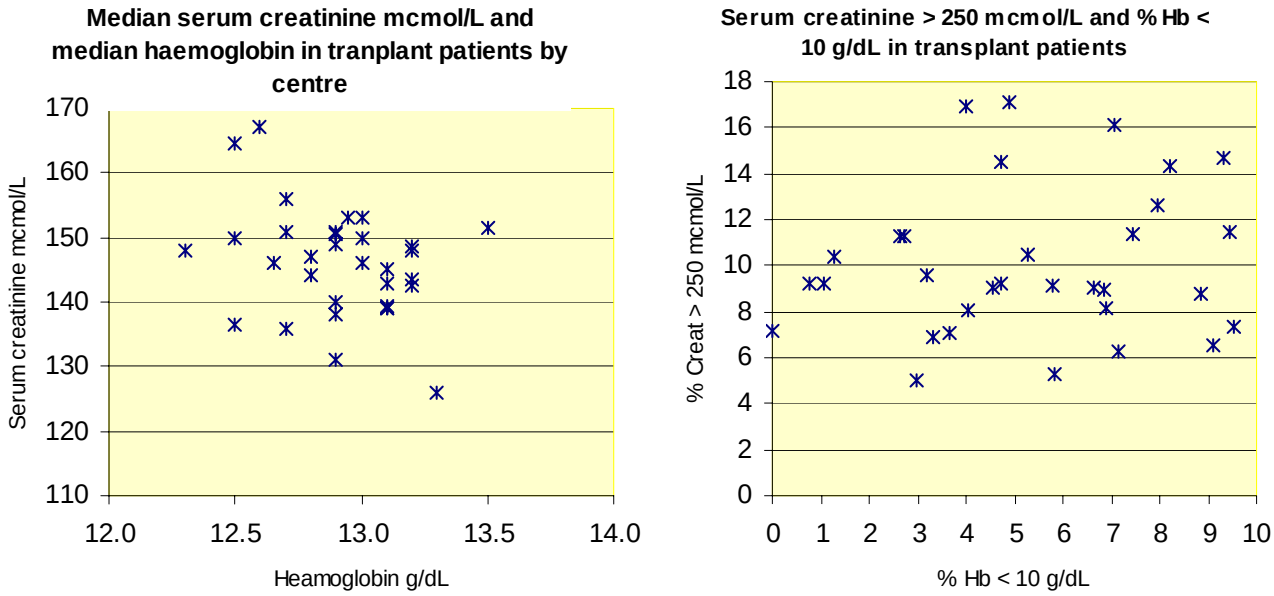


Figure 13.11: Scattergrams showing the relationship of Hb and serum creatinine by centre

Serum cholesterol

No recommendations have been made in either the Renal Association or British Transplant Society Standards documents regarding a target cholesterol level in renal transplant recipients.

This analysis considered all transplant patients on 31 December 2001 whose grafts had been functioning for at least 1 year. The most recent serum cholesterol over a 12 month period was used, and the cholesterol level was harmonised for inter-laboratory variation. Results were available from 4714 patients. No serum cholesterol value had been recorded in 32.6% of the prevalent transplant patients over that year, but this figure has improved from one of 47% in 1999.

The distribution of serum cholesterol in prevalent transplant recipients according to centre is shown in Figure 13.12.

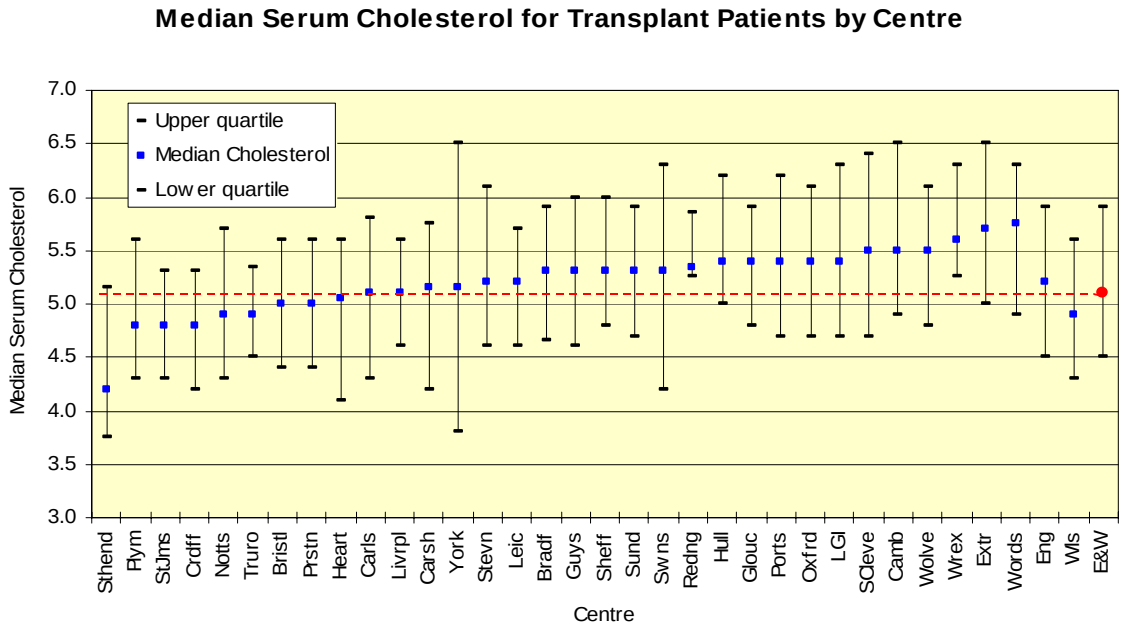


Figure 13.12: Median serum cholesterol for transplant patients, by centre

In most units, the median serum cholesterol level is above the recommended level for primary prevention in the high-risk, non-transplant population (5.0 mmol/L). [1]

Figure 13.13 shows the percentage of prevalent transplant patients for each Registry centre with a serum cholesterol level below 5.0 mmol/L. A chi-squared test showed significant differences between units ((χ^2=288, d.f.=31, p<0.001) and may be accounted for by differences in the use of HMG CoA reductase inhibitors (statins) as well as immunosuppressive drug regimes.

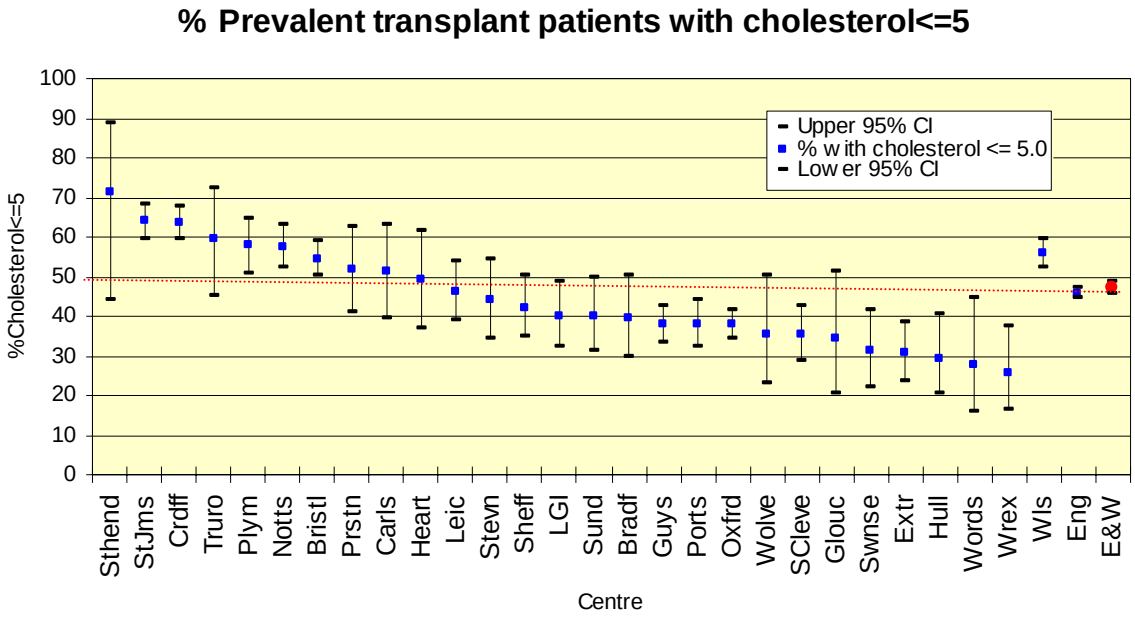


Figure 13.13: Percentage of transplant patients with a cholesterol level of 5 mmol/L or less

Changes in serum cholesterol 1998–2001

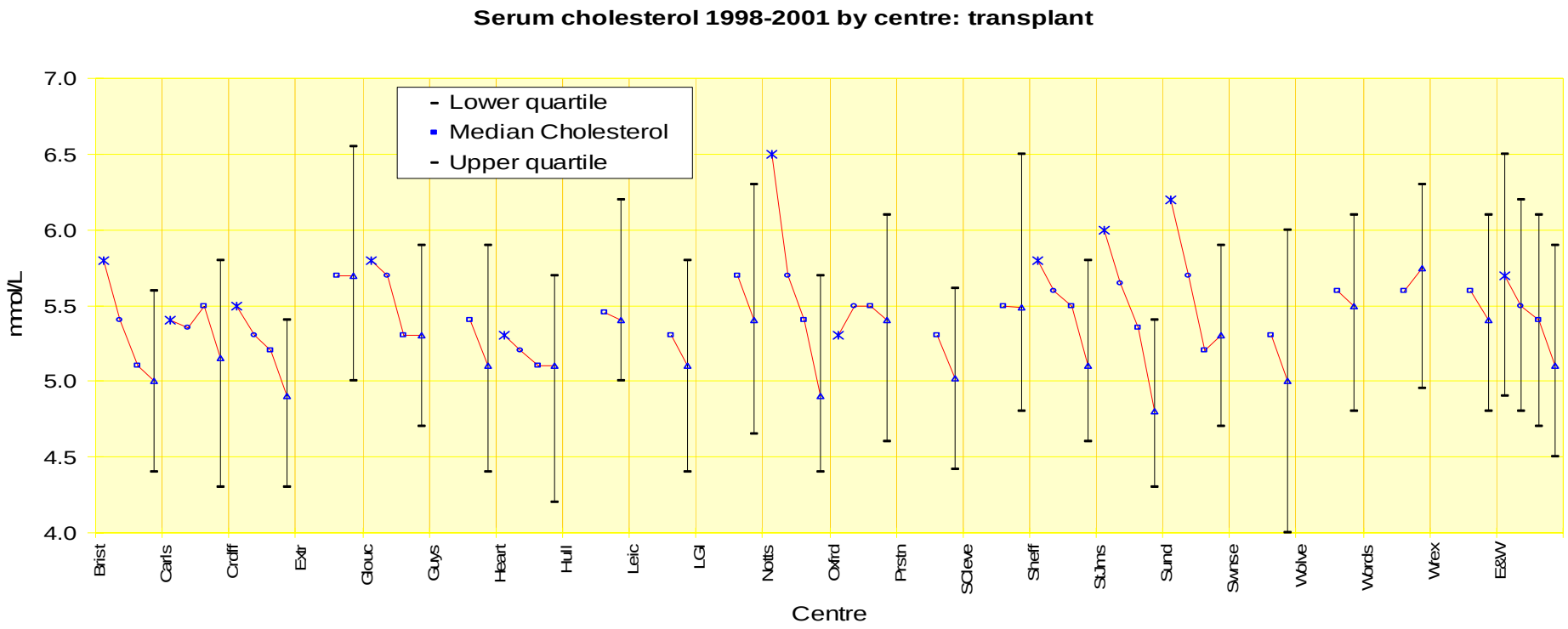


Figure 13.14: Median serum cholesterol in transplant patients, by centre, 1998–2001

Figure 13.14 shows the consecutive annual median serum cholesterol by centre since 1998. In most cases, a progressive fall in cholesterol level is observed. Similarly, Figure 13.15 shows the annual percentage of patients with a serum cholesterol below 5.0 mmol/L for each centre since 1998. Although there is a significant difference between centres, there is in most cases within centres overall a progressive improvement in cholesterol level. The marked improvement observed in some centres suggests a change in policy over this time, with a more active approach to cholesterol lowering.

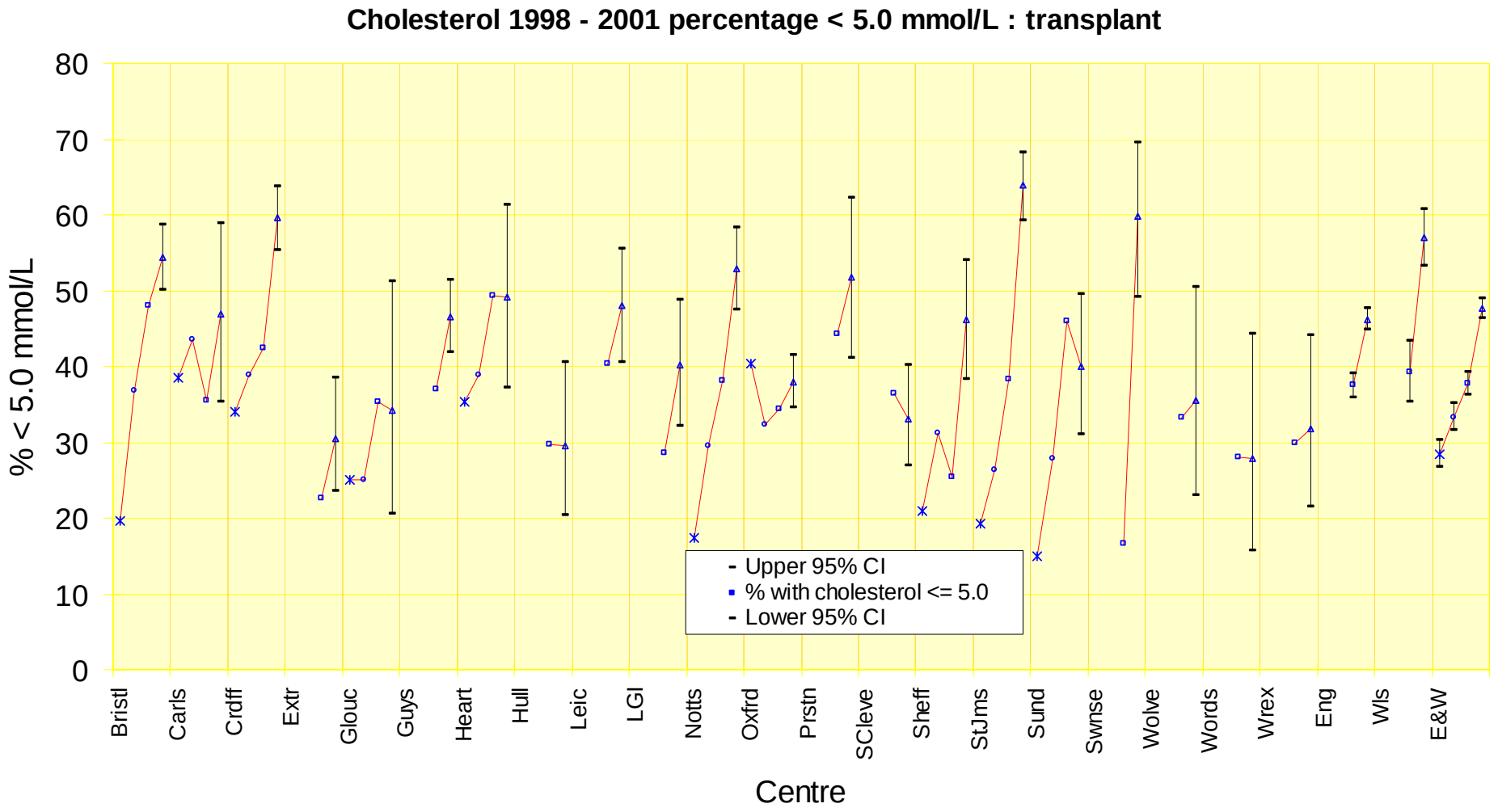


Figure 13.15: % of transplant patients with a serum cholesterol of <5.0 mmol/L, 1998–2001

Blood pressure

The third edition of the Renal Association's *Standards and Audit Measures*, published in August 2002, recommends blood pressure targets for renal transplant recipients of less than 130 mmHg systolic blood pressure (SBP) and less than 80 mmHg diastolic blood pressure (DBP) (strength of recommendation B).[2] However, during the period of data collection for this report (2001 and before), no recommendations existed. Therefore, as in earlier reports, the Standards recommended for dialysis patients in the second edition (<140/90 mmHg for age <60 years, and <160/90 mmHg for age 60 or over)have been adopted for the following analysis.[3]

There may be errors caused by incomplete data returns. Table 13.9 shows the percentage of renal transplant recipients with blood pressure data. Disappointingly, the completeness of blood pressure returns continues to be poor, and efforts will need to be taken to encourage better returns in the future.

% with a blood pressure return from last 6 months		
Centre	Age <60	Age >60
Notts	88.9	95.3
Sheffield	86.2	96.5
Cardiff	81.6	94.2
St James	71.7	97.6
Bradford	67.2	100
Words	61.8	81.0
Leicester	56.2	92.1
Liverpool	55.1	81.5
Coventry	53.8	70.7
Cambridge	50.9	66.2
Truro	44.4	60.0
Stevenage	35.8	33.3
S Cleveland	29.3	45.3
Bristol	25.9	37.9
Oxford	23.2	34.3
Exeter	11.2	13.6
LGI	1.9	0.0
Guys	0.4	0.0
Sunderland	0.0	0.0
Hull	0.0	0.0
Gloucester	0.0	10.0
Swansea	0.0	4.3
Southend	0.0	0.0
Carlisle	0.0	0.0
Preston	0.0	0.0
Wrexham	0.0	0.0
Wolves	0.0	0.0
Carlshalton	0.0	0.0
Portsmouth	0.0	0.0
York	0.0	0.0
Heartlands	0.0	0.0

% with a blood pressure return from last 6 months		
Centre	Age <60	Age >60
Reading	0.0	0.0
Plymouth	0.0	0.0
E&W	35.1	44.0

Table 13.9: Completeness of blood pressure returns for transplant patients

Blood pressure recordings may also be subject to a variety of biases. Healthy patients with infrequent clinic attendance will have infrequent blood pressure assessment. High blood pressure readings may be selectively included or excluded from computer records depending on operator bias. The method and number of blood pressure measurements has not been standardised between units. Figures 13.15 and 13.16 reflect the bias of digit preference when blood pressure is measured by manual devices, with frequent rounding of readings to the nearest zero.

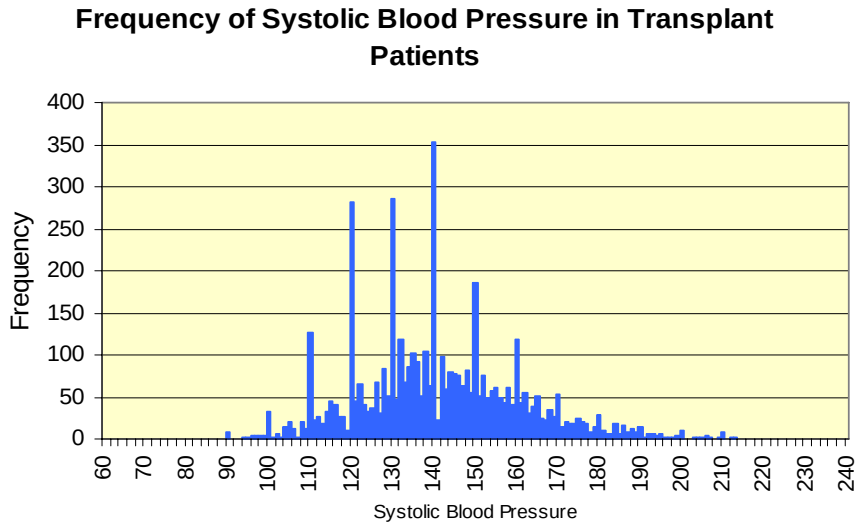


Figure 13.16: Frequency of SBP in transplant patients

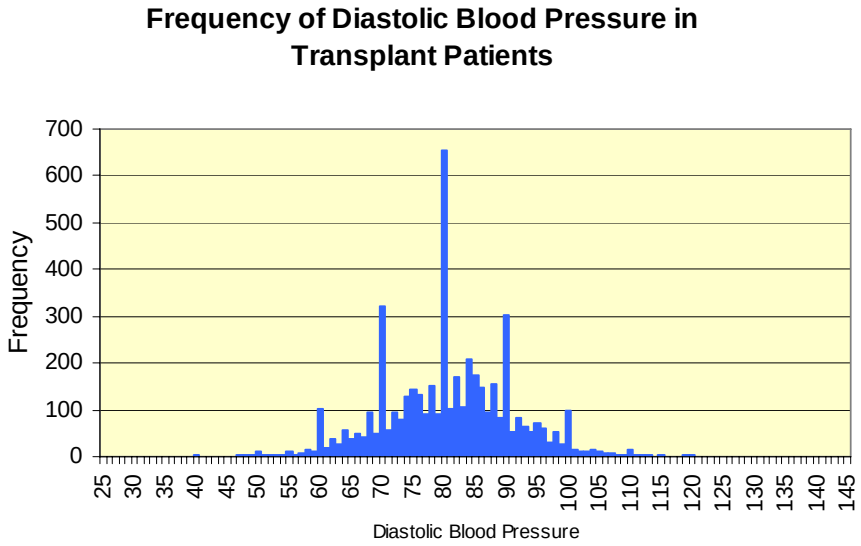


Figure 13.17: Frequency of DBP in transplant patients

Figures 13.17 and 13.18 show the proportion of transplant patients achieving the Renal Association Standards for chronic renal failure (second edition) in each centre for those aged less than 60 years and those aged 60 years or older respectively.

Because the blood pressure target for older patients is less stringent, a greater proportion of older patients achieved the blood pressure standards overall: 68.4% versus 54.9% in the younger age group. These overall results for E&W have not changed since 1999.

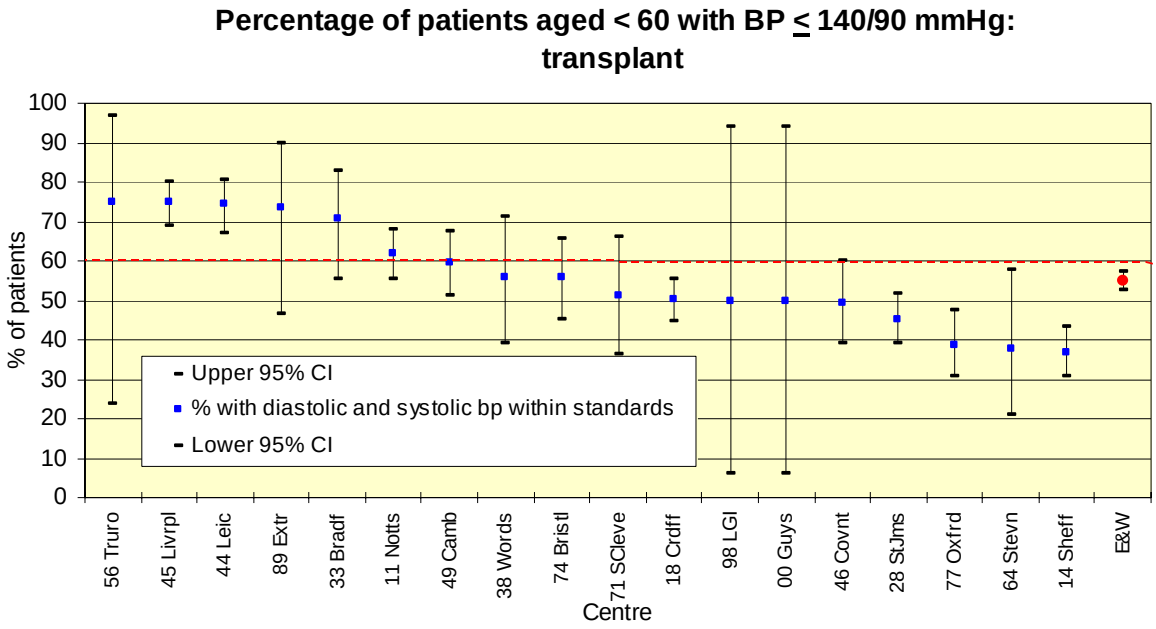


Figure 13.18 Percentage of patients aged <60 with a BP below 140/90 mmHg

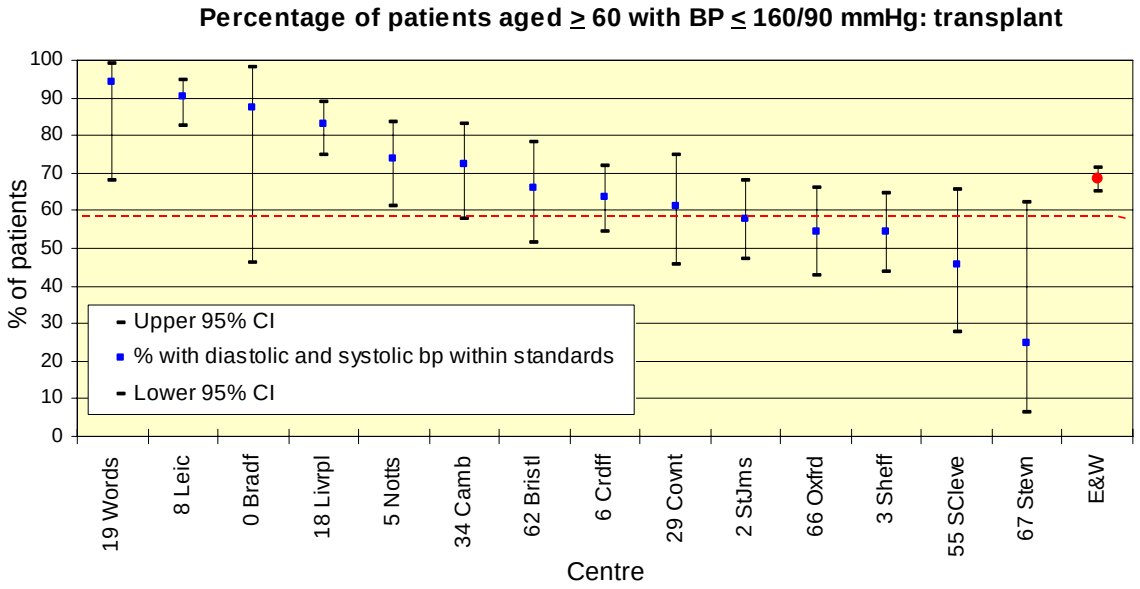


Figure 13.19: Percentage of patients aged over 60 with a BP below 160/90 mmHg

For transplant patients, aged under 60, the percentage of patients reaching the Standard for both systolic and diastolic blood pressure differed significantly between centres (X^2 = 150.6, d.f. = 18, p<0.001).
For transplant patients, aged 60 or more, the percentage of patients reaching the Standard for both systolic and diastolic blood pressure differed significantly between centres (X^2 = 80.4 d.f. = 17, p<0.001).

Figures 13.20–13.25 show the SBP and DBP for each age range by centre together with the proportion of patients achieving the Renal Association chronic renal failure Standards (second edition) for each measure. The overall median SBP is higher in those aged over 60 years, at 147 mmHg compared with 138 mmHg in the younger age group. The overall median DBP in those below and above 60 years is 80 mmHg.

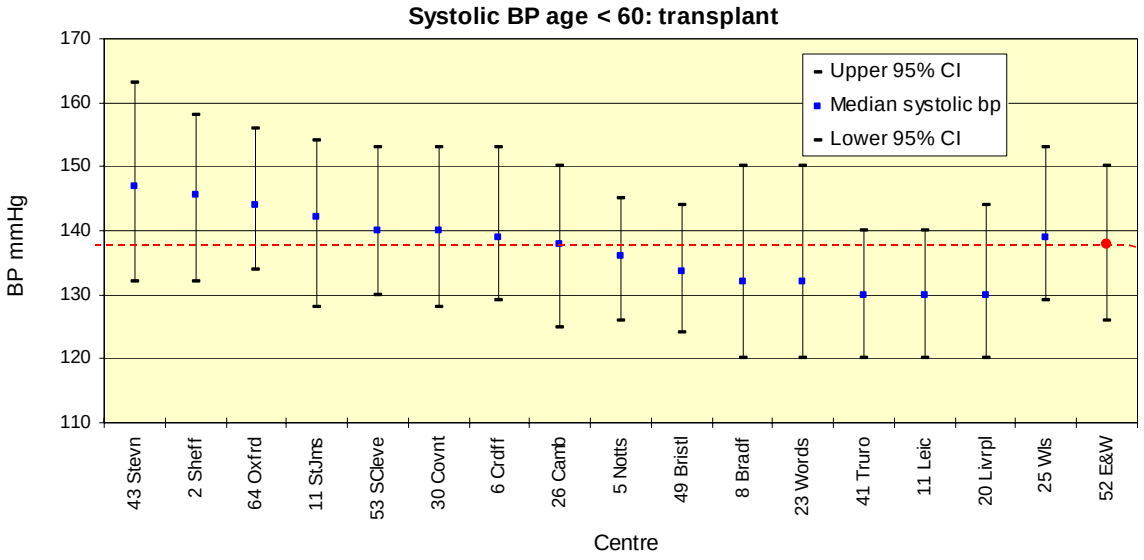


Figure 13.20: Transplant patients aged less than 60: median SBP

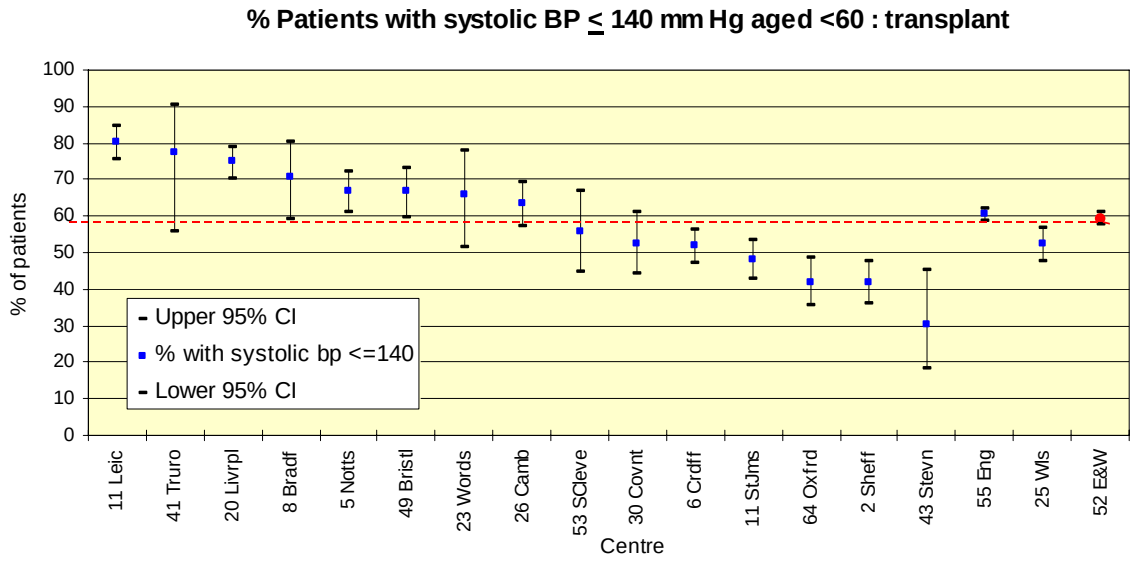


Figure 13.21: Percentage of transplant patients aged less than 60 with SBP under 140 mmHg

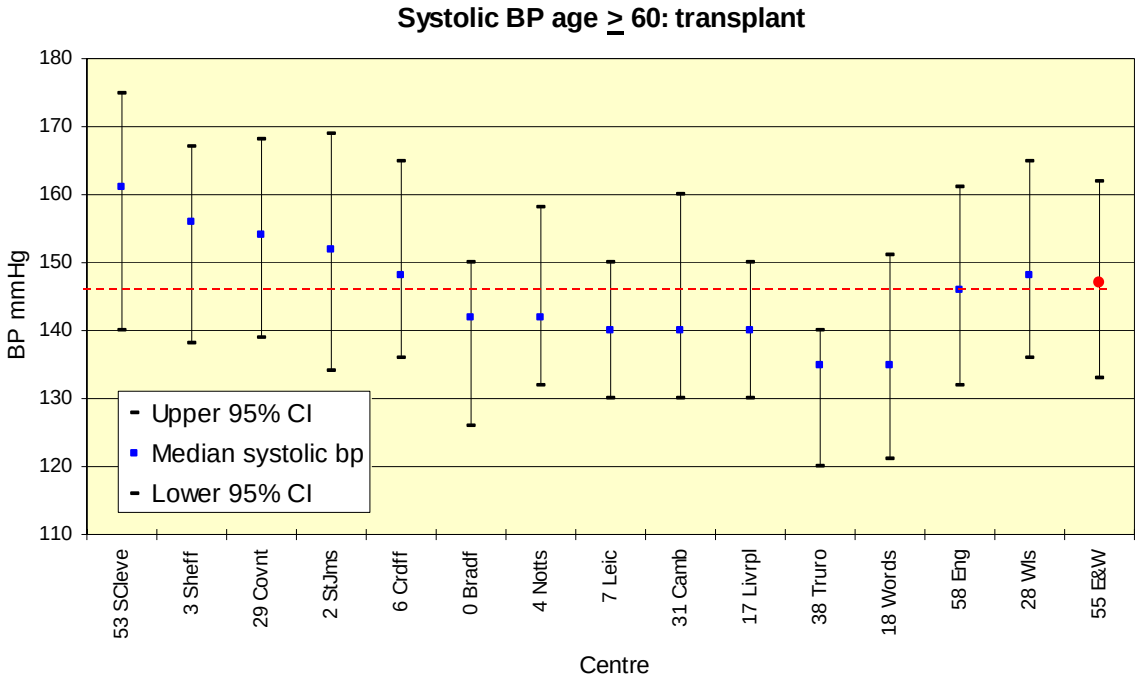


Figure 13.22: Transplant patients aged over 60: median SBP

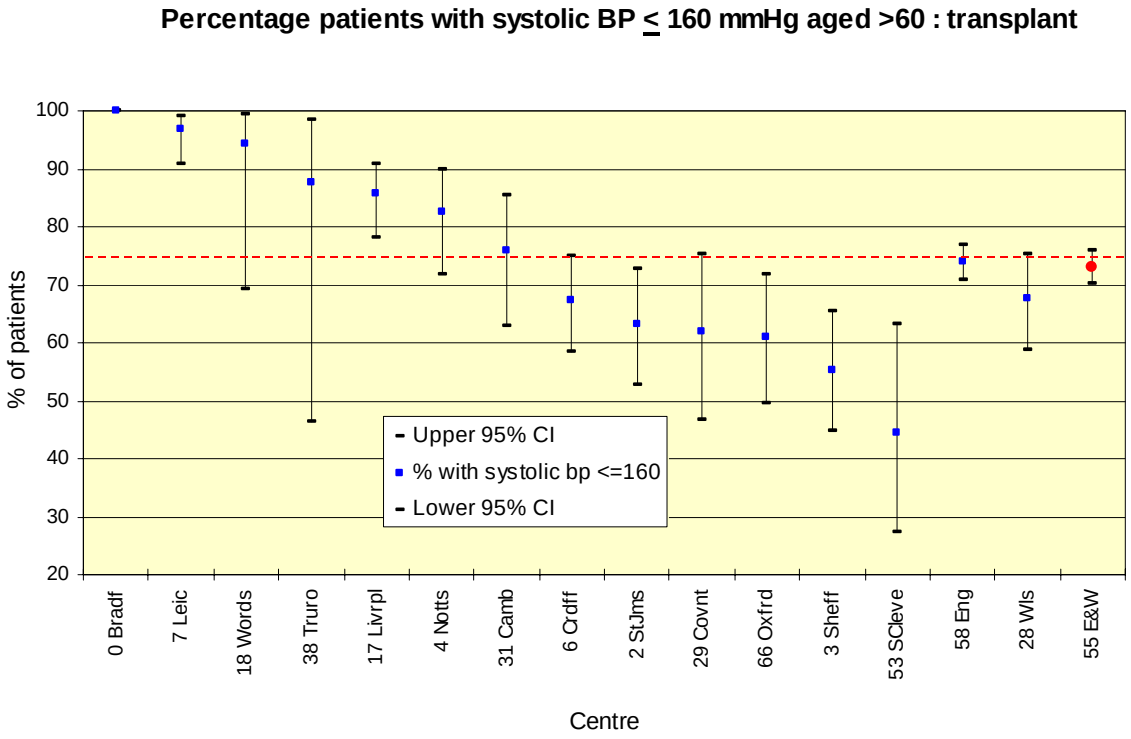


Figure 13.23: Percentage of patients aged over 60 with SBP less than 160 mmHg

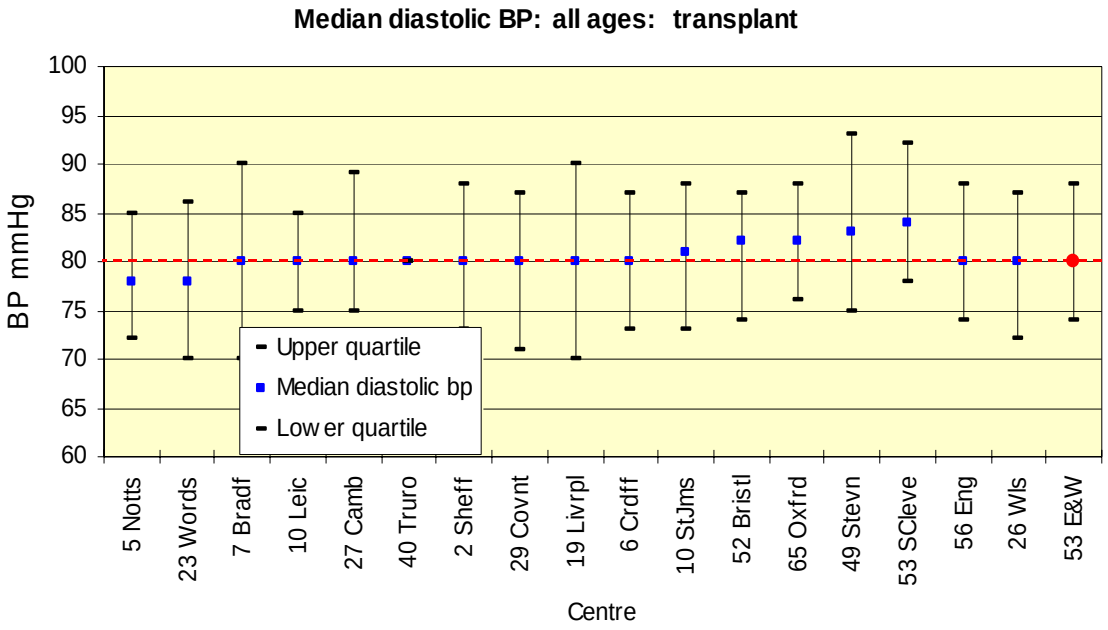


Figure 13.24: Transplant patients, all ages: median DBP

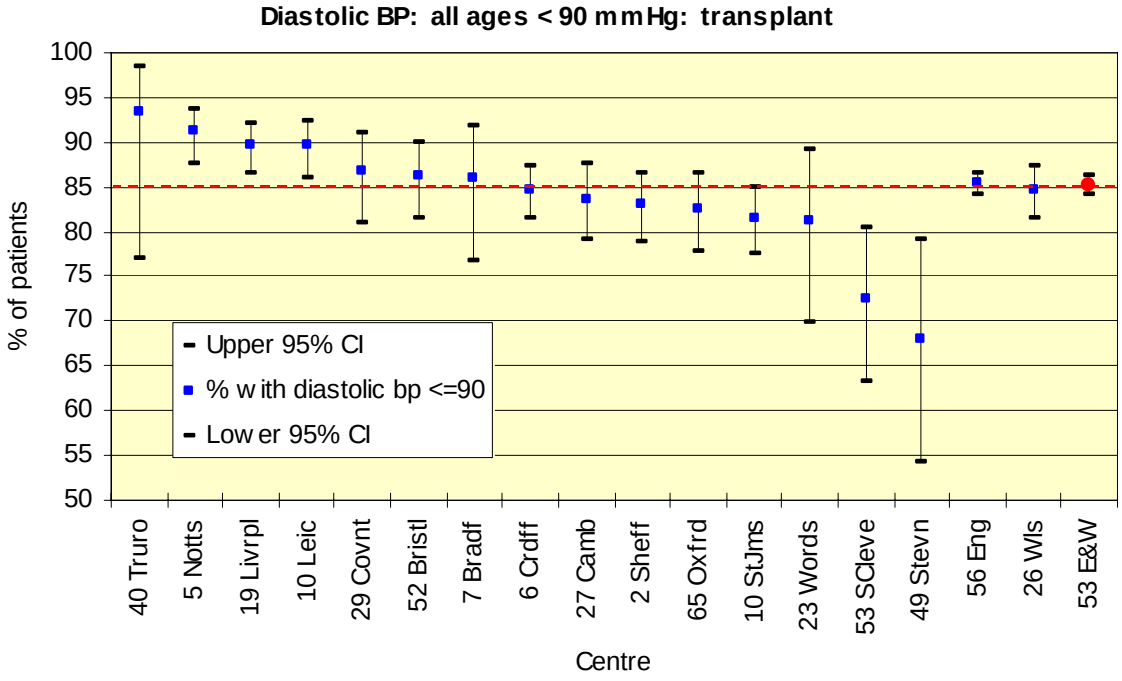


Figure 13.25: Percentage of patients of all ages with DBP less than 90 mmHg

The relationship between SBP, DBP and mean arterial blood pressure and transplant function, as reflected by serum creatinine level, is shown in Table 13.10. It is not possible to determine whether higher blood pressure causes or results in poorer graft function. As the Registry collects further sequential data on these patients, the relationship of blood pressure both before and after transplantation to graft and patient survival will be investigated.

Serum creatinine	Median mean arterial blood pressure	Median SBP	Median DBP
< 150 mmol/L	99.0	138.0	80.0
150–250 mmol/L	101.0	140.0	80.0
> 250 mmol/L	103.0	143.0	82.0

Table 13.10: Relationship between BP and graft function in transplant patients in E&W

Figures 13.26 and 13.27 show the relationship between blood pressure and age in transplant patients, the pattern observed being similar to that seen in the general population. SBP rises with age; DBP rises up to the age of 50–60 years, then stabilises and subsequently falls slightly.[4]

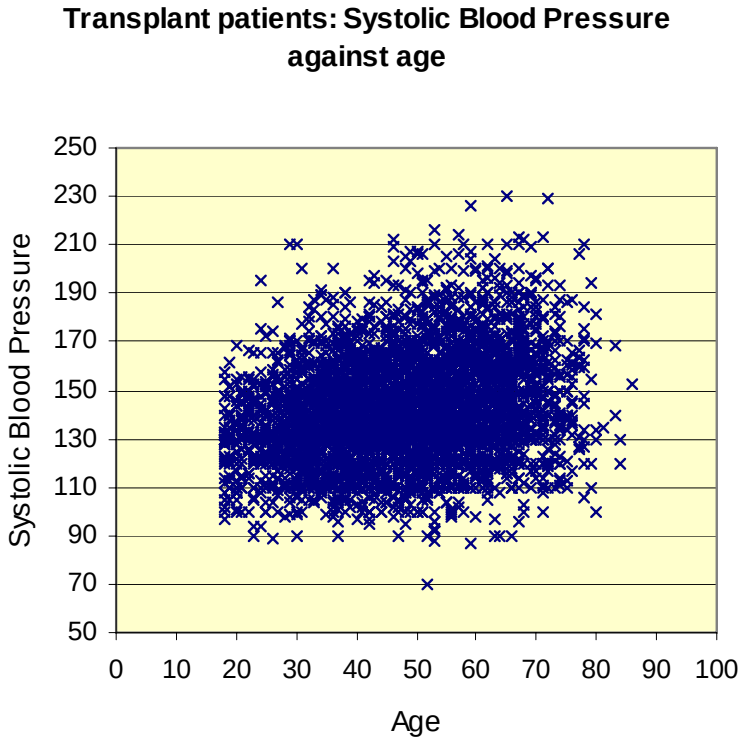


Figure 13.26: Transplant patients: SBP versus age

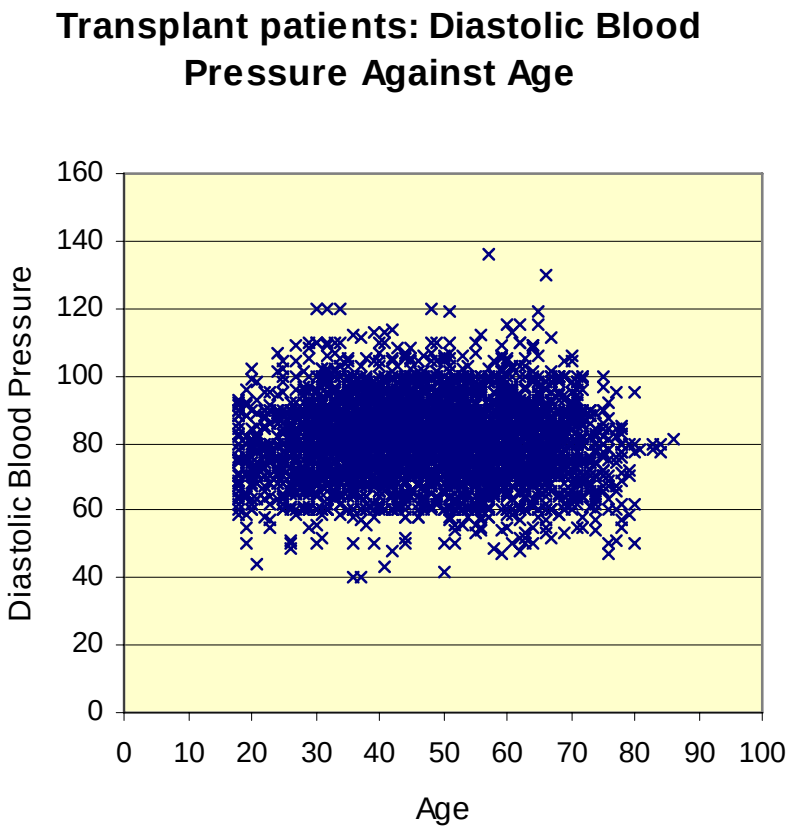


Figure 13.27: Transplant patients: DBP versus age

Conclusion

This chapter reports on data returned from 30 units with 50 or more prevalent transplant patients. Fourteen units perform renal transplantation and account for 78.6% of the Registry prevalent transplant patients. Data on 50% of all renal transplants performed in 2001 in the UK are presented, together with data on the prevalent renal transplant population.

There has been a progressive decline in the proportion of the prevalent renal replacement therapy patients made up by renal transplants, from 51% in 1997 to 46.6% in 2001.

Variation exists between centres with respect to access to transplantation for both all patients receiving RRT and those whose primary diagnosis is diabetes mellitus. More complete returns on ethnicity are required to be able to examine further the reasons for this difference.

Six per cent of all patients starting dialysis in 2001 were patients with failed transplants; 2.3% of all prevalent transplant failed during 2001.

The annual death rate of patients with established renal transplants for England & Wales is 2.8% (including patients with failed grafts returning to dialysis).

The quality of transplant function differs significantly between centres, as does the haemoglobin level. Differences in modifiable risk factors for cardiovascular disease such as serum cholesterol and blood pressure also exist. Overall, there has been a progressive

reduction in the median serum cholesterol level from 1998 to 2001. The return of blood pressure data from some centres remains poor.

The identification of individual centres may enable a more meaningful interpretation to be made of the data in future reports when epidemiological, demographic and other differences can be considered.

References

1. Wood D, Durrington P, Poulter N, McInnes G, Rees A, Wray R. Joint British recommendations on prevention of coronary heart disease in clinical practice. *Heart* 1998;80(2):S1–S29.

2. Renal Association Standards Subcommittee. *Treatment of Adult Patients with Renal Failure: Recommended Standards and Audit Measures*, 3rd edn. London: Royal College of Physicians, 2002.

3. Renal Association Standards Subcommittee. *Treatment of Adult Patients with Renal Failure: Recommended Standards and Audit Measures*, 2nd edn. London: Royal College of Physicians, 1997.

4. Whelton PK. Epidemiology of hypertension. *Lancet* 1994;344:101–106.

Chapter 14: Performance Against Renal Association Standards

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 and intact parathyroid hormone, and blood pressure.

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, but the Standards current in 2001 were from the 1997 document, the second edition; these are shown in Table 14.1.

Standard	**Haemodialysis**	**Peritoneal dialysis**
Haemoglobin	≥10g/dL in >85% of patients	≥10g/dL in >85% of patients
Calcium	Local normal range	Local normal range
Phosphate	1.2–1.7 mmol/L	1.1–1.6 mmol/L
Albumin	Local normal range	70% of patients in the local normal range
Bicarbonate	Local normal range	Lower local normal to upper local normal +3mmol/L
Parathyroid hormone	2–3× local normal range	2–3× local normal range
Systolic blood pressure	≤160 mmHg aged over 60 ≤140 mmHg aged under 60	≤160 mmHg aged over 60 ≤140 mmHg aged under 60
Diastolic blood pressure	≤90 mmHg	≤90 mmHg
Dialysis adequacy	Urea reduction ratio ≥65% or Kt/V ≥1.2	CrCl Kt/V CAPD: >50l/week 1.7 APD >65l/week 2.0

Table 14.1: Renal Association Standards

This year, because of previously mentioned problems with albumin measurement and correction of calcium, these results have not been included here, although they will be released in the Internet publication. The parathyroid hormone (PTH) results from laboratories using different assays have been adjusted to a common range, the upper limit complying with the Standard being less than 23 pmol/L.

Data are included from the last quarter of 2001. 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 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. Biochemical data have been harmonised as described previously; the harmonisation constants for an individual laboratory change year on year and are monitored. The urea reduction ratio (URR) may be influenced by post-dialysis sampling techniques. This is discussed in detail in Chapter 7, further information being provided in Appendix D.

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). The figures showing the percentage of patients reaching the Renal Association Standard include the 95% confidence interval calculated for this figure. Where medians are displayed, the 25th and 75th centiles for the unit are included. Data completeness is indicated by the 'percentage missing' figure below the unit code letter. These methods are the best way the Registry has found to convey the underlying data for the larger number of centres.

Haemoglobin

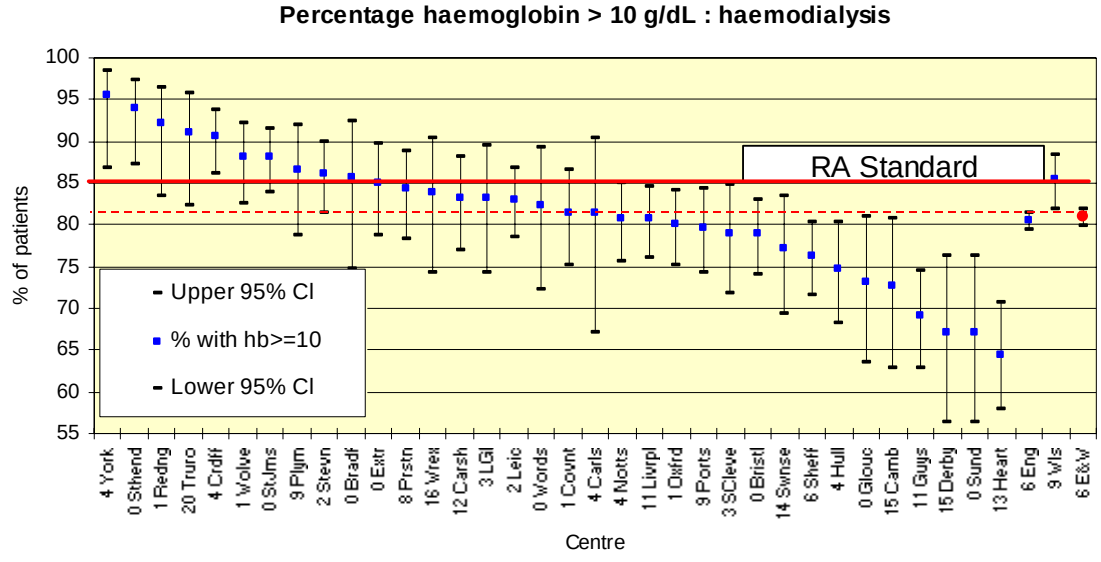


Figure 14.1: % of HD patients achieving the Renal Association Hb Standard by centre

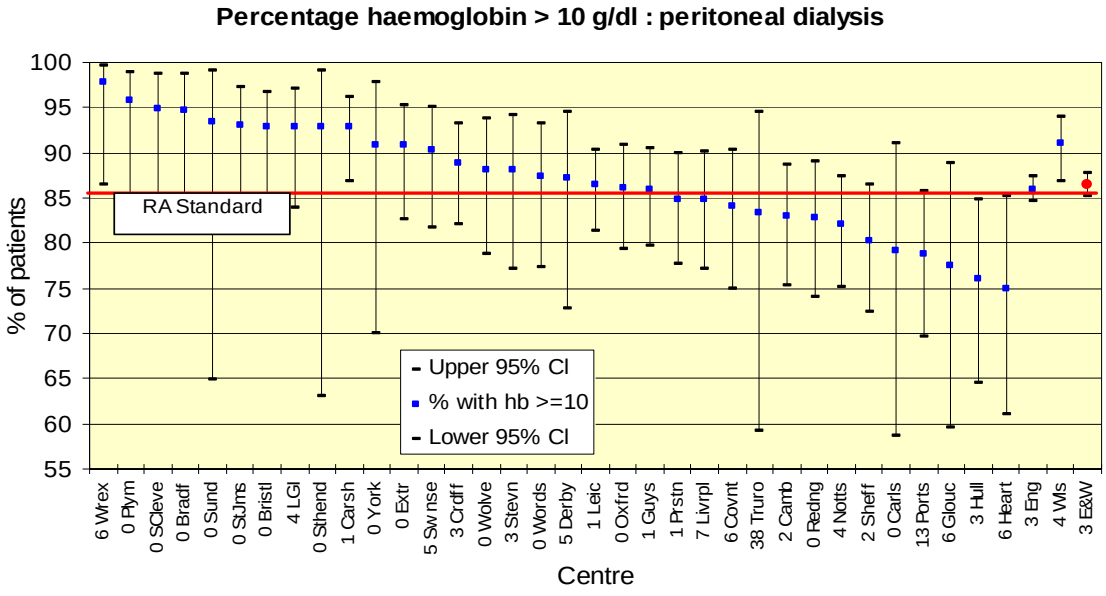


Figure 14.2: % of PD patients achieving the Renal Association Hb Standard by centre

Serum bicarbonate

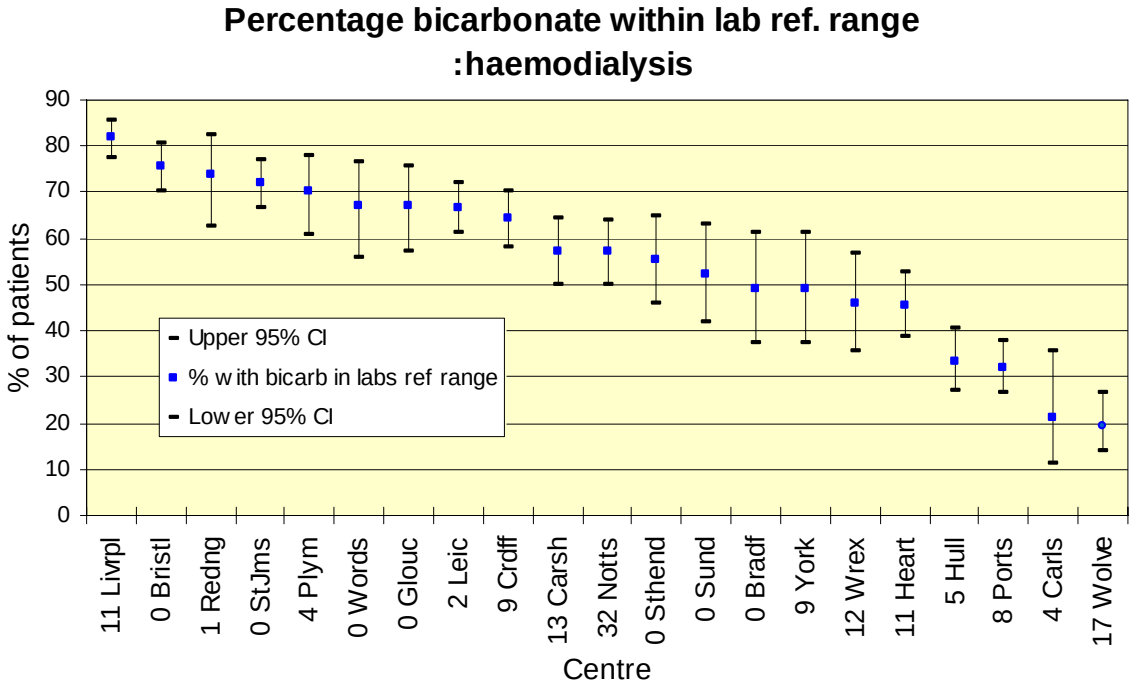


Figure 14.3: % bicarbonate in the laboratory reference range for HD by centre

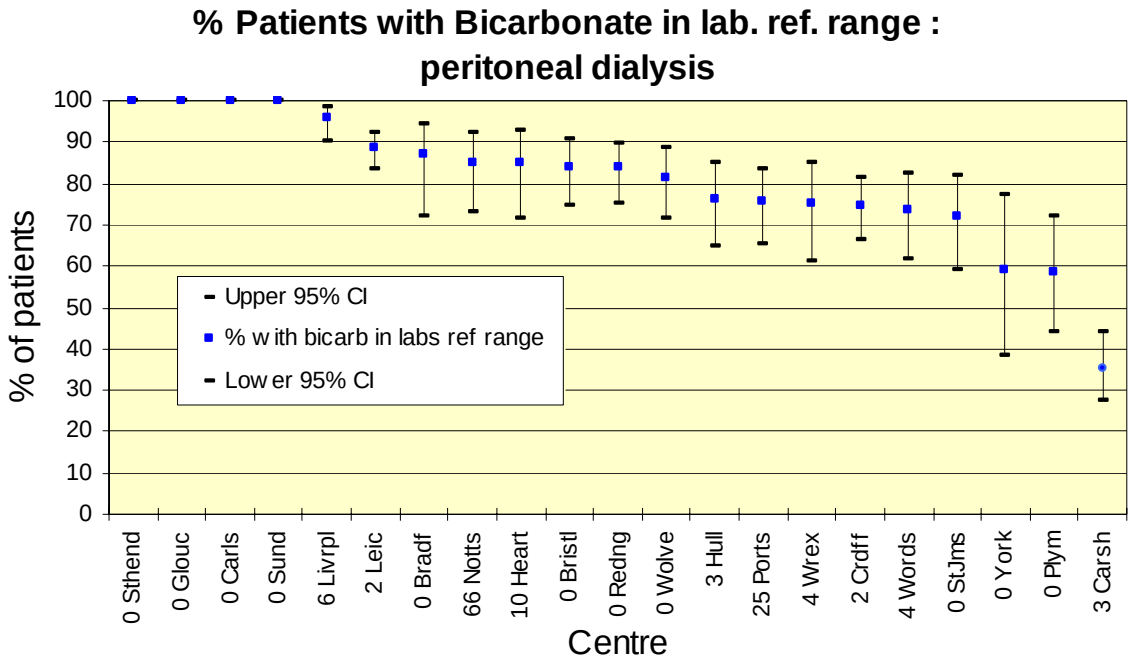


Figure 14.4: % bicarbonate in the laboratory reference range for PD by centre

Serum phosphate

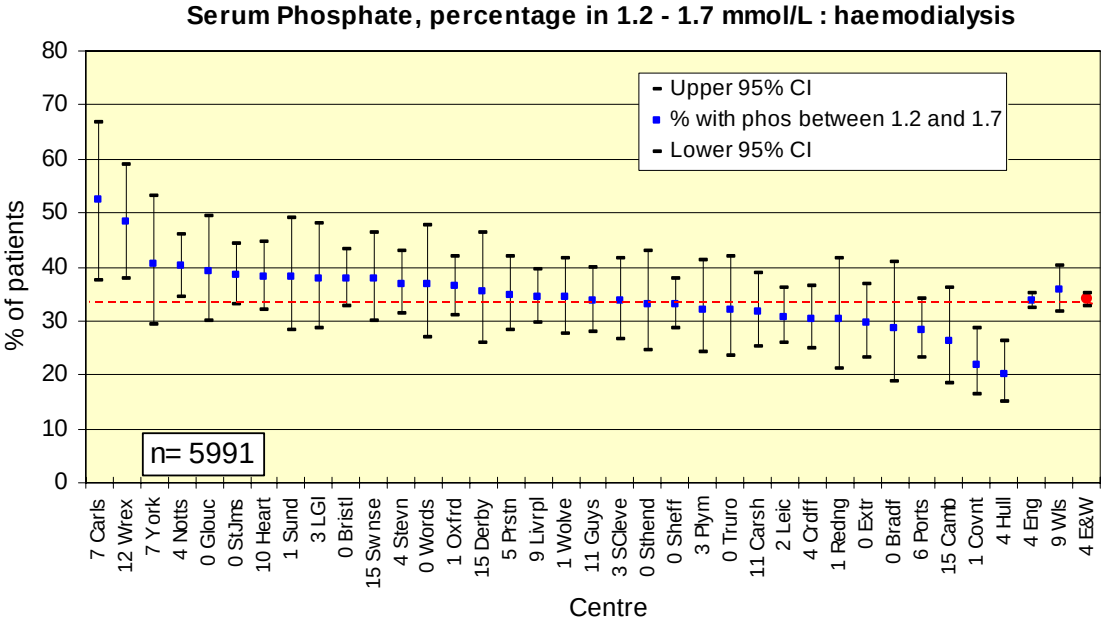


Figure 14.5: % serum phosphate in the range 1.2-1.7 mmol/L for HD by centre

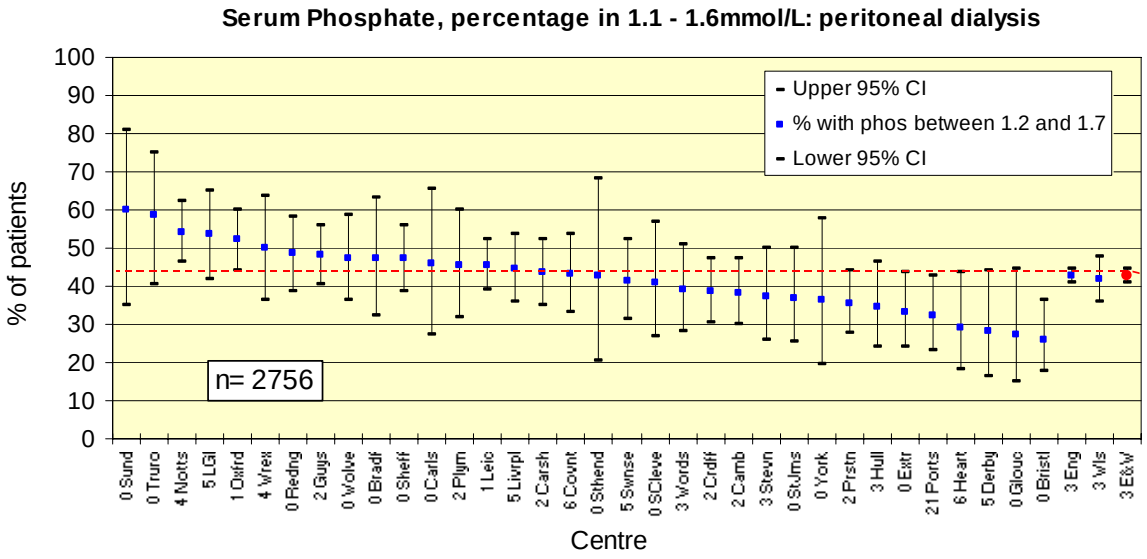


Figure 14.6: % with serum phosphate 1.1–1.6 mmol/L for PD in each centre

Intact parathyroid hormone

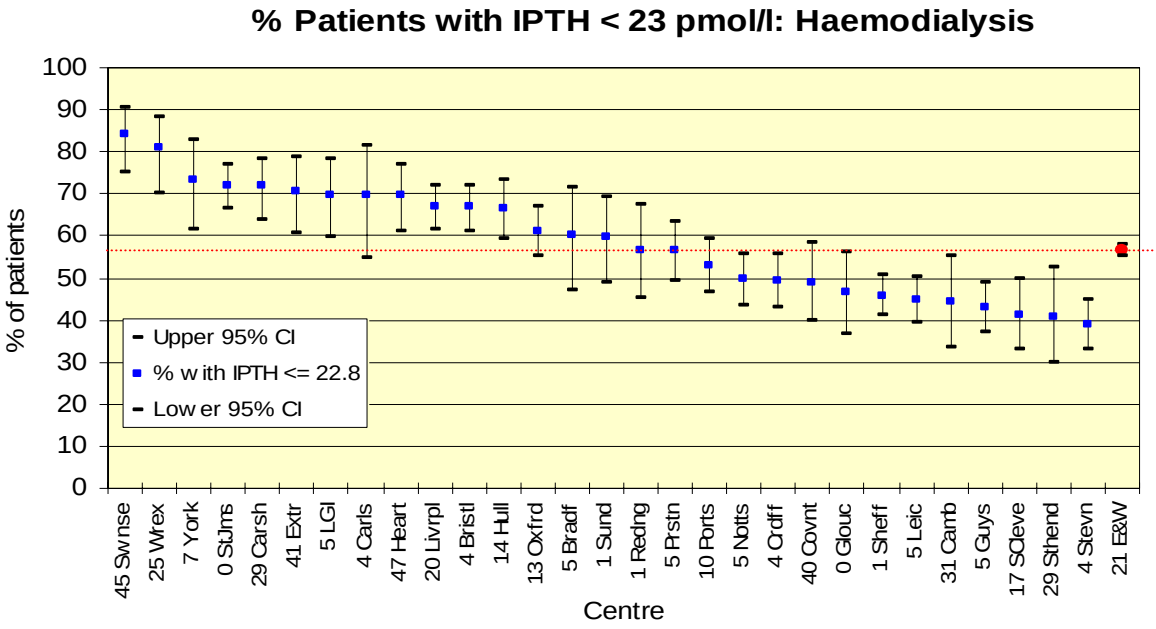


Figure 14.7: % of patients with iPTH in three times the laboratory range on HD by centre

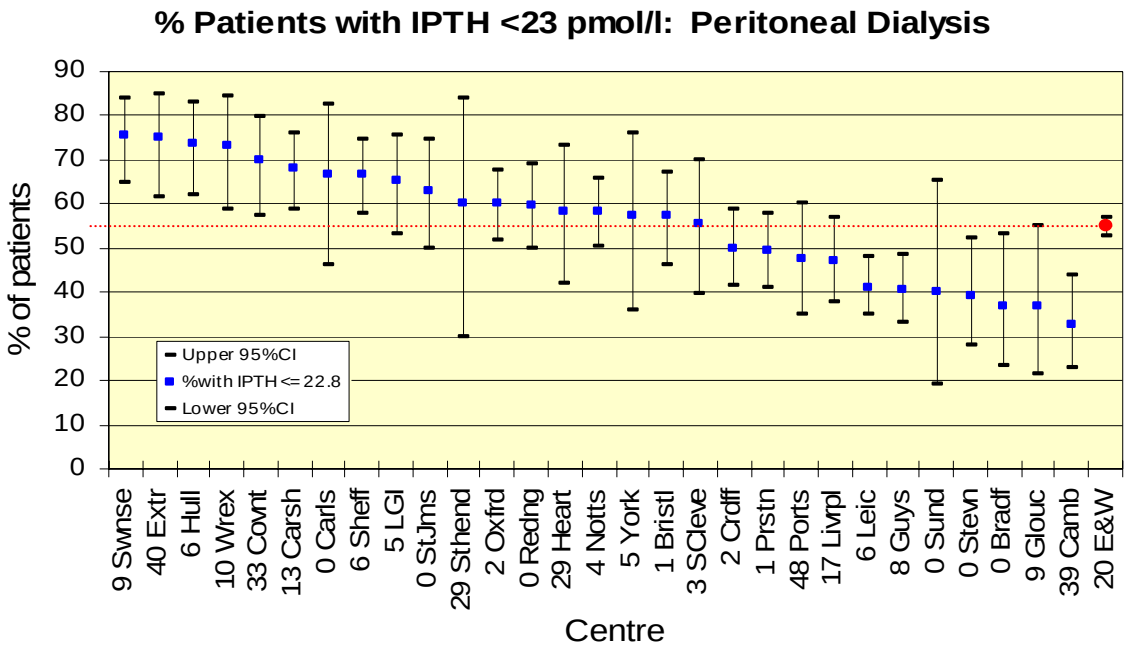


Figure 14.8: % of patients with iPTH in three times the laboratory range on PD by centre

Dialysis adequacy

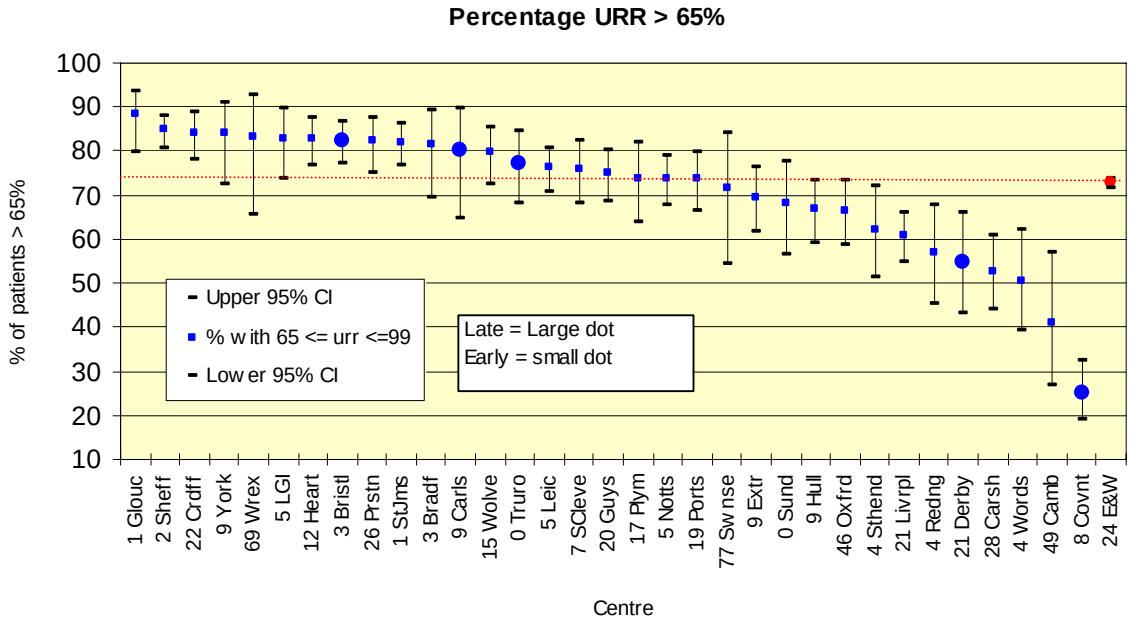


Figure 14.9: % of patients with URR over 65% in each centre

Blood Pressure

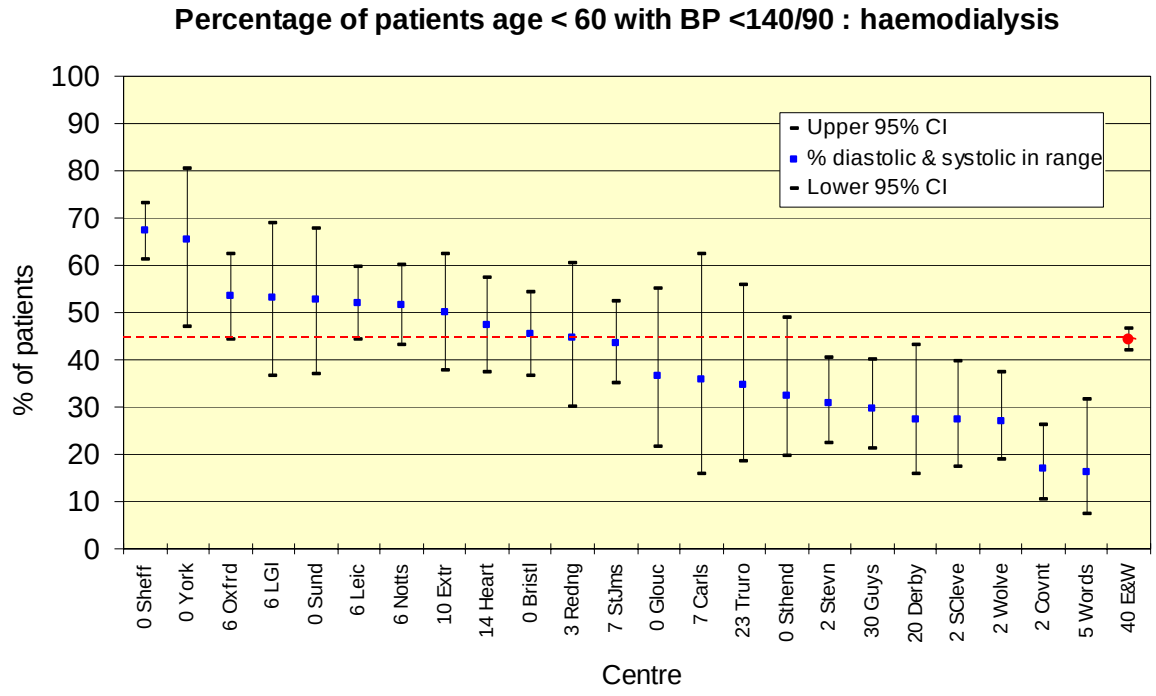


Figure 14.10: % of patients aged less than 60 on HD with BP in the RA Standard range

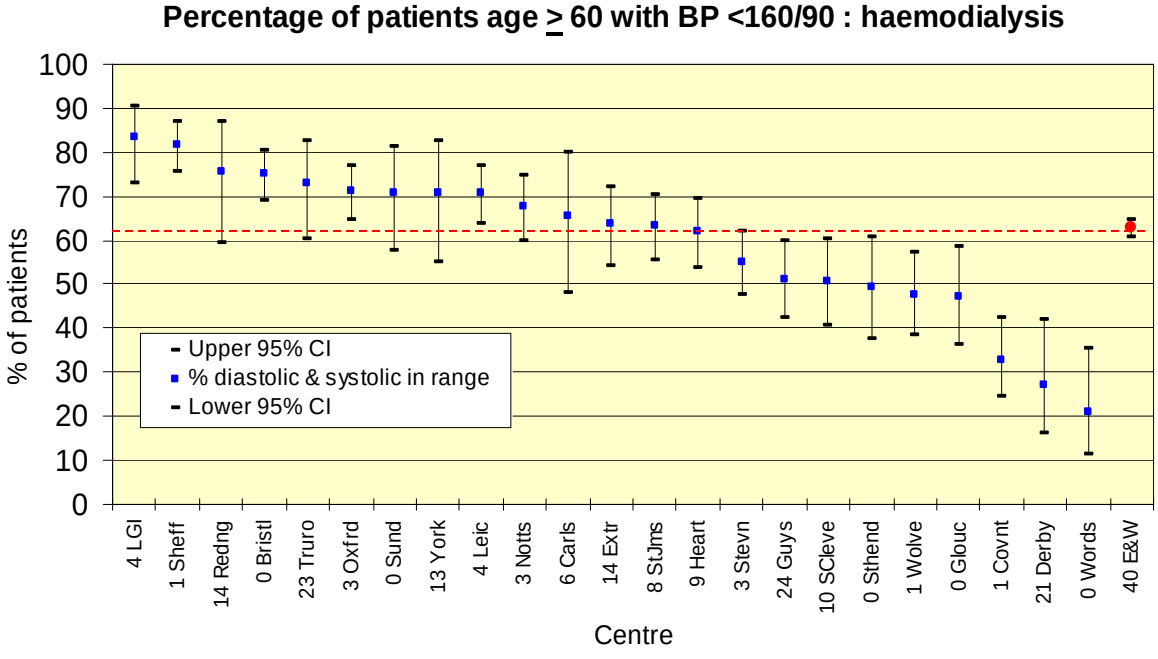


Figure 14.11: Percentage patients aged over 60 on HD with BP in the RA Standard range

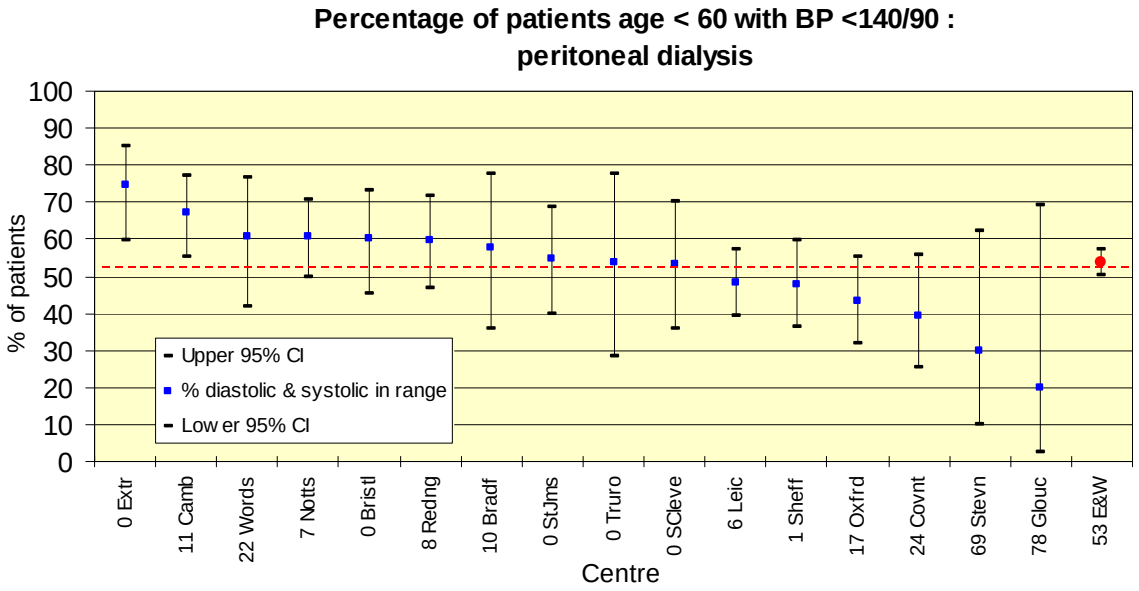


Figure 14.12: Percentage patients aged <60 on PD with BP in the RA Standard range

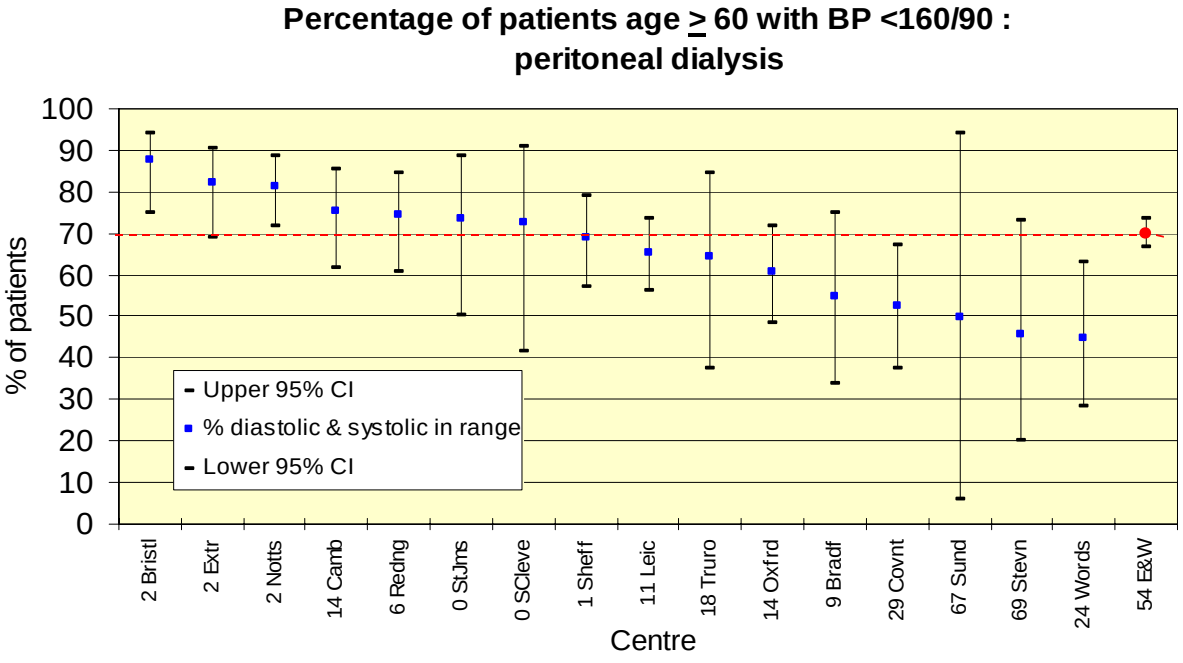


Figure 14.13: Percentage of patients aged over 60 on PD with BP in the RA Standard range

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 minus 1.

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 (χ^2=178, d.f.=33, 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 (χ^2=63.45 d.f.=33, p<0.001).

Ferritin

A chi squared test was used to determine whether the percentage of patients with a ferritin level of 100 mcg/L or more differed between centres.

For patients on PD, the percentage of patients with a ferritin of 100 mcg/L or over was found to differ significantly between centres (χ^2=169, d.f.=32, p<0.001).

Bicarbonate

A chi squared test was used to determine whether the percentage of patients with bicarbonate values within the Standard varied between centres. For this analysis, patients were categorised as having a bicarbonate within the Standard or not having a bicarbonate within the Standard (regardless of whether the patient's bicarbonate level was below or above the Standard). It should be noted that the Standards are different for HD and PD.

For patients on HD, the percentage of patients with a bicarbonate within the Standard differed significantly between centres (χ^2=466.8, d.f.=20, p<0.001).

For patients on PD, the percentage of patients with a bicarbonate reading within the Standard differed significantly between centres (χ^2=310.5, d.f.=20, p<0.001).

Phosphate

For patients on HD, a chi squared test was used to determine whether the percentage of patients with a phosphate concentration of 1.70 mmol/L or less differed between centres. For patients on PD, a chi squared test was used to determine whether the percentage of patients with a phosphate of 1.60 mmol/L or less differed between centres. Note that the analysis considered laboratory-harmonised phosphate.

For patients on HD, the percentage of patients with a phosphate reading of 1.70 mmol/L or less differed significantly between centres (χ^2=196.7, d.f.=33, p<0.001).
For patients on PD, the percentage of patients with a phosphate level of 1.60 mmol/L or less differed significantly between centres (χ^2=108.7, d.f.=33, p<0.001).

PTH

A chi squared test was used to determine whether the percentage of patients with a PTH of 22.8 pmol/L or below differed between centres. The analysis considered laboratory-harmonised PTH.

For patients on HD, the percentage of patients with a PTH value of 22.8 pmol/L or less differed significantly between centres (χ^2=142.8, d.f.=17, p<0.001).

For patients on PD, the percentage of patients with a PTH of 22.8 pmol/L or less differed significantly between centres (χ^2=60.0, d.f.=17, 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. This analysis only included the English and Welsh units.

The percentage of patients with a URR of 65% or above was found to vary significantly between centres (χ^2=408.7, d.f.=33, 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. Note that the analysis for transplant patients excluded patients who had a transplant in 1999.

For patients on HD, aged 60 or more, the percentage of patients reaching the Standard for both systolic and diastolic blood pressure differed significantly between centres (X^2 = 218.9, d.f. = 26, p<0.001).

For patients on HD, aged under 60, the percentage of patients reaching the Standard for both systolic and diastolic blood pressure differed significantly between centres (X^2 = 156.5, d.f. = 28, p<0.001).

For patients on PD, aged 60 or more, the percentage of patients reaching the Standard for both systolic and diastolic blood pressure differed significantly between centres (X^2 = 49.9, d.f. = 25, p=0.002).

For patients on PD, aged under 60, the percentage of patients reaching the Standard for both systolic and diastolic blood pressure differed significantly between centres (X^2 = 75.6, d.f. = 25, p<0.001).

Chapter 15: Causes of Death on Renal Replacement Therapy

Summary

- Cardiovascular disease is the most common cause of death in the renal population and is most evident in diabetics.

- Patients on renal replacement therapy have a much higher relative risk of death compared with the general population. This is most pronounced in the young and diminishes with longevity.

- Underlying primary renal diagnosis affects the death rate. Cystic/polycystic patients have the lowest rate of death, patients with malignancy the highest.

- The UK compares favourably with other international Renal Registries when assessing causes and rates of death, although USA patients under 65 years of age have a significantly lower death rate than those in the UK. The comparisons have not been adjusted for the higher ethnic minority component in the USA, who are known to have better survival.

Introduction

This is the first analysis of cause of death for patients on the UK Renal Registry. This work has been partly funded through a grant from the National Kidney Research Fund.

There have been 11,607 deaths reported since the Registry was started in 1997, 6237 (54%) having a cause recorded coded from the European Dialysis and Transplant Association (EDTA) diagnostic list for causes of death (Table 15.1).

Many centres do not return a cause of death to the Registry, and it is not a mandatory field. The percentage completeness by centre of the returns for causes of death has remained constant over the years, indicating that there has been no change at the centre level in the practice of completion of this item.

An initial analysis limited to centres with a high rate of return for cause of death, compared with an analysis of all the cause of death data on the database, showed that the percentages in corresponding EDTA categories remained unchanged if the latter data were included.

The EDTA codes of death were grouped into the categories (see Table 15.28):

1. cardiovascular disease
2. cerebrovascular disease
3. infection
4. malignancy
5. treatment withdrawal
6. others
7. uncertain or not determined

The data for all prevalent patients on renal replacement therapy (RRT) since the inception of the UK Renal Registry to 2001 and with a recorded cause of death were analysed initially by treatment modality (dialysis or transplant; see Appendix F). Subgroup analysis for both incident and prevalent patients, in conjunction with the relationship of age, primary diagnosis and gender to the cause of death, were then examined. For the incident cohort, an analysis of the interaction between comorbidity at the start of RRT and cause of death was also undertaken. The ethnicity data were too incomplete to be included. The primary diagnoses for cause of renal failure categorised by EDTA coding were grouped into 10 categories (see Appendix F).

The incident cohort included all patients starting RRT since individual renal units joined the Registry. Transplanted patients were excluded from the analysis in the incident cohort because of the small number transplanted in this group (fewer than 100 per year) and very low death rate. The subgroup prevalent cohort of patients were defined as those on dialysis on or before 30 September 01 and alive on 31 December 01.

Comparisons of the data were made with the general population of England & Wales and also with data from other international Renal Registries. The two-tailed Student 't' test was used for testing significance.

Prevalent patients from 1998 to 2001

By EDTA code for cause of death, the most common cause of death in the dialysis population was myocardial ischaemia or infarction (n=872, 17.7%; see Appendix F), closely followed by 'uncertain' or 'not identified' (n= 758, 15.4%). In the transplant population, these were again the two most common causes, accounting for 22.2% and 10.5% of deaths respectively (see Appendix F). The EDTA codes were regrouped as outlined above, and cardiovascular disease remained the most common cause of death in both the transplant and dialysis populations (37% and 31% respectively; Table 15.1). Using the two-tailed Student 't' test, the effect of cardiovascular disease appeared greater in the transplant population; this may have been due to the lower proportion of transplant patients who withdrew from treatment or who had an uncertain/undetermined cause of death. Statistically, there were significant differences between the dialysis and transplant groups for each category except cerebrovascular disease and infection.

	Dialysis No.	**Dialysis %**	**Transplt No.**	**Transplt %**	**Total No.**	**Total %**	***p* value**
Cardiovascular	1511	30.7	480	36.6	1991	31.9	<0.001
Cerebrovascular accident	398	8.1	87	6.6	485	7.8	0.089
ERF treatment stopped	616	12.5	43	3.3	659	10.6	<0.001
Infection	865	17.6	243	18.5	1108	17.8	0.424
Malignancy	324	6.6	149	11.4	473	7.6	<0.001
Others	456	9.3	178	13.6	634	10.2	<0.001
Uncertain or not determined	757	15.4	130	9.9	887	14.2	<0.001
Total	4927	100	1310	100	6237	100	

Table 15.1: Cause of death by treatment modality
ERF, established renal failure.

	Dial <55		Dial 55+		Total trans		Dialysis <65		Dialysis ≥65		Total Dialysis	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Cardiovascular	220	37.2	260	36.2	480	36.6	588	33.3	923	29.2	1511	30.7
Cerebrovascular accident	41	6.9	46	6.4	87	6.6	159	9.0	239	7.6	398	8.1
ERF treatment stopped	19	3.2	24	3.3	43	3.3	116	6.6	500	15.8	616	12.5
Infection	116	19.6	127	17.7	243	18.5	318	18.0	547	17.3	865	17.6
Malignancy	50	8.4	99	13.8	149	11.4	123	7.0	201	6.4	324	6.6
Others	90	15.2	88	12.3	178	13.6	190	10.8	266	8.4	456	9.3
Uncertain or not determined	56	9.5	74	10.3	130	9.9	273	15.4	484	15.3	757	15.4
Total	592	100	718	100	1310	100	1767	100	3160	100	4927	100

Table 15.2: Cause of death by modality and age

Incident patients

The data for incident patients were analysed for cause of death within the first 90 days and for the period 1 year after 90 days. These subsets (early deaths) were defined to allow a meaningful comparison with the USA and other international registries, where data on RRT are not collected for the first 90 days. International data were retrieved from the respective national registries and the European Renal Association (ERA).[1–6] Causes of death were also analysed for those who had survived at least 3 years, and at least 5 years, on RRT (late deaths).

Analysis of deaths in the first 90 days

For the incident cohort, there were a total of 1030 deaths within the first 90 days (Table 15.3), of which 564 (55%) had a recorded cause. The single largest cause of death was cardiovascular disease (31.9%). Proportionately, the causes of death were similar to those in the prevalent population, except fewer died of 'other' causes (6.6% versus 12.1% respectively).

	All Deaths	All % of those with data	<65 Deaths	<65 % of those with data	65+ Deaths	65+ % of those with data
Cardiovascular	180	31.9	58	39.5	122	29.3
Cerebrovascular accident	39	6.9	9	6.1	30	7.2
ERF treatment stopped	67	11.9	7	4.8	60	14.4
Infection	106	18.8	18	12.2	88	21.1
Malignancy	45	8.0	15	10.2	30	7.2
Others	37	6.6	13	8.8	24	5.8
Uncertain or not determined	90	16.0	27	18.4	63	15.1
Total with cause of death	564		147		417	
No cause of death sent	466		104		362	

Table 15.3: Cause of death by age in incident patients in the first 90 days

Primary diagnosis	Exposure years	Deaths	Rate per 1000 pt years exposed	Lower 95% CI	Upper 95%CI	Ref with GN
Amyloid	41.3	27	654.2	407.4	900.9	6.20
Cystic/polycystic	259.3	9	34.7	12.0	57.4	0.33
Diabetes	507.8	122	240.2	197.6	282.9	2.28
Glomerulonephritis	398.3	42	105.5	73.6	137.4	1.00
Interstitial	50.7	8	157.9	48.5	267.2	1.50
Malignancy	55.1	63	1142.8	860.6	1425.0	10.84
Pyelonephritis	372.5	49	131.5	94.7	168.4	1.25
Renal vascular disease	374.6	151	403.1	338.8	467.3	3.82
Other	572.4	317	553.8	492.8	614.8	5.25
Uncertain	734.2	242	329.6	288.1	371.2	3.13
Unknown	0.2	0	0	0	0	0
Total	3366.5	1030	306.0	287.2726	324.6	2.90

Table 15.4: Death rate, by primary diagnosis, in incident patients in the first 90 days
Ref with GN, referenced against glomerulonephritis.

When analysed by age group, there was no difference in the rate of recording a cause of death for those patients aged less than 65 years and those aged 65 and over. Cardiac death remained the most common cause in both age groups, although proportionally more of the younger patients died of cardiovascular causes (39.5% versus 29.3%) and more of the older patients died of infection-related illnesses (21.1% versus 12.2%) and treatment withdrawal (14.4% versus 4.8%).

The average death rate for all incident patients within the first 90 days was 306 per 1000 patient years exposed (pt yrs exp) (Table 15.5).

Age group	Exp years	Deaths	Rate per 1000 exposed years
15–19	40.4	0	0.0
20–24	126.4	2	15.8
25–29	140.9	3	21.3
30–34	170.9	4	23.4
35–39	202.8	8	39.5
40–44	206.7	12	58.1
45–49	246.8	23	93.2
50–54	280.4	37	131.9
55–59	315.9	60	189.9
60–64	341.4	102	298.7
65–69	395.8	187	472.5
70–74	411.9	226	548.7
75–79	318.4	208	653.3
80–84	128.3	113	881.0
85–89	35.0	42	1198.3
90+	4.4	3	683.1
Total	3366.5	1030	306.0

Age group	Exp years	Deaths	Rate per 1000 exposed years
20–44	847.7	29	34.2
45–64	1184.6	222	187.4
65+	1293.8	779	602.1

Table 15.5: Death rate, by age, in incident patients in the first 90 days

When the effect of primary diagnosis was analysed, patients with cystic/polycystic disease had the best outcome, with a rate of death of 34.7/1000 pt yrs exp (Table 15.4) and malignancy the poorest (1142.8/1000 pt yrs exp). When using glomerulonephritis (GN) as a reference point, cystic/polycystic patients had a significantly lower death rate and pyelonephritis a similar rate, whereas all other primary diseases had a significantly higher rate of death. These findings were similar to those in the subsequent analysis of the prevalent cohort (see Table 15.15 below). The effect of malignancy was substantially greater in this cohort than in the prevalent group (10.8 versus 3.3), as too was amyloidosis (6.2 versus 1.8). Women had a non-significant lower rate of death overall (279 versus 323; Table 15.6).

	Exp years	Deaths	Rate/1000
Male	2074	669	323
Female	1293	361	279
Total	3367	1030	306

Table 15.6: Death rate, by gender, in incident patients in the first 90 days

It is important to note the relevance of accuracy in the enrolment of patients for potentially long-term renal replacement therapy in this 90 day incident cohort. Evidence suggests variation in the criteria applied in different units, and some cases are bound to be subject to interpretation. Uncertainties of classification will inevitably bias the outcome data and are unlikely to be fully resolved in current Registry practice.

Analysis of deaths in the first year after 90 days

There were 1857 deaths in the 1 year after the 90 days analysis (Table 15.7), with a recorded cause in 1023 (55%) patients. The overall rate of death was 188/1000 pt yrs exp (Table 15.9), contrasting with 306/1000 pt yrs exp within the first 90 days (see Table 15.5 above); these figures increased with increasing patient age.

Table 15.7 shows that cardiac disease, accounting for 29% of deaths, remained the most common cause of death, although it accounted for a smaller percentage of deaths in those aged less than 65 years than occurred for the 90 day cohort (32% versus 40%). Similar to the 90 day analysis, treatment withdrawal was more common in those aged over 65 years (18.2% versus 9.7%, $p<0.01$), although, as a group, withdrawal was slightly more common in the 1 year after 90 days group (15.5% versus 11.9% respectively). Infection-related deaths were similar in both age groups (16.6% versus 18.3%), and this contrasts with the first 90 day period, in which infections accounted for a lower proportion of deaths in patients aged less than 65 years (12% versus 21%).

Cause of death	All Deaths	All % of those with data	<65 Deaths	<65 % of those with data	65+ Deaths	65+ % of those with data
Cardiovascular	298	29.1	102	32.0	196	27.8
Cerebrovascular accident	79	7.7	25	7.8	54	7.7
ESRF treatment stopped	159	15.5	31	9.7	128	18.2
Infection	182	17.8	53	16.6	129	18.3
Malignancy	94	9.2	29	9.1	65	9.2
Others	76	7.4	30	9.4	46	6.5
Uncertain or not determined	135	13.2	49	15.4	86	12.2
Total with cause of death	1023		319		704	
No cause of death sent	834		224		610	

Table 15.7: Cause of death, by age, in incident patients at 1 year + 90 days

	Exp years	Deaths	Rate/1000	Lower 95% CI	Upper 95% CI	Compare to GN
Amyloid	113.6	43	378.5	265.4	491.7	5.69
Cystic/polycystic	834.3	31	37.2	24.1	50.2	0.56
Diabetes	1447.4	310	214.2	190.3	238.0	3.22
Glomerulonephritis	1262.0	84	66.6	52.3	80.8	1
Interstitial	140.2	24	171.2	102.7	239.7	2.57
Malignancy	111.6	116	1039.8	850.6	1229.0	15.62
Pyelonephritis	1190.3	112	94.1	76.7	111.5	1.41
Renal vascular disease	1040.2	239	229.8	200.6	258.9	3.45
Other	1534.9	474	308.8	281.0	336.6	4.64
Uncertain	2187.5	424	193.8	175.4	212.3	2.91
Total	9861.8	1857	188.3	179.7	196.9	2.83

Table 15.8: Death rate, by primary diagnosis, in incident patients at 1 year + 90 days

Age group	Exposure years	Deaths	Rate per 1000 exp years
15–19	144.9	1	6.9
20–24	448.6	7	15.6
25–29	492.4	9	18.3
30–34	565.7	25	44.2
35–39	664.3	28	42.1
40–44	671.8	29	43.2
45–49	797.1	53	66.5
50–54	867.0	72	83.0
55–59	975.9	122	125.0
60–64	979.7	197	201.1
65–69	1096.9	318	289.9
70–74	1061.8	412	388.0
75–79	756.1	345	456.3
80–84	270.0	176	651.7
85–89	62.7	54	861.3
90+	7.0	9	1293.8
Total	9861.8	1857	188.3

Age group	Exp years	Deaths	Rate per 1000 exp years
20–44	2842.8	98.0	34.5
45–64	3619.7	444.0	122.7
65+	3254.5	1314.0	403.8

Table 15.9: Death rate, by age, in incident patients at 1 year + 90 days

In the analysis of the effect of primary diagnosis, the results were similar to those for incident patient deaths at 90 days (Table 15.8). Ratios using GN as a reference were similar in both incident cohorts, but it should be noted, although not significant, that men had a lower rate of death than women (185 versus 192/1000 pt yrs exp; Table 15.10).

	Exp years	Deaths	Rate/1000
Male	6058	1125	185
Female	3803	732	192
Total	9861	1857	188

Table 15.10: Death rate, by gender, in incident patients at 1 year + 90 days

Comparing the first 90, and 1 year after 90, days, rates of death were identical in the 20–44-year age band (34/1000 pat yrs exp), but rates were higher in the first 90 days than 1 year after 90 days in the age bands 45–64 years (187 versus 123/1000 pat yrs exp) and 65+ years (602 versus 404/1000 pat yrs exp). Overall, the rate of death was lower in the 1 year after 90 days (188/1000 pat yrs exp), compared with the first 90 days (306/1000 pat yrs exp).

Table 15.11 analysed cause of death by time on RRT (less than 3 years and longer than 3 years) with age under 65 or over 65, and similarly Table 15.12 in relation to 5 years. Cardiac death was again the most common cause across age groups and independent of time on RRT. Withdrawal of treatment as a proportion of deaths fell with increasing time on RRT; this was most pronounced in those patients aged 65 years and over (12%, 16%, 13%, 8% at 90 days, 1 year after 90 day, 3 years and 5 years respectively).

	All ages	<65		65+	
Cause of death	**3+ yrs on RRT**	**3+ yrs on RRT**	**<3 yrs on RRT**	**3+ yrs on RRT**	**<3 yrs on RRT**
Cardiovascular	390 (29.8%)	886 (32.9%)	469 (34.1%)	496 (35.8%)	636 (29.4%)
Cerebrovascular accident	93 (7.1%)	208 (7.7%)	111 (8.1%)	115 (8.3%)	166 (7.7%)
ERF treatment stopped	175 (13.4%)	236 (8.8%)	83 (6.0%)	61 (4.4%)	340 (15.7%)
Infection	233 (17.8%)	477 (17.7%)	255 (18.5%0	244 (17.6%)	376 (17.4%)
Malignancy	90 (6.9%)	203 (7.5%)	107 (7.8%)	113 (8.2%)	163 (7.5%)
Others	123 (9.4%)	303 (11.2%)	154 (11.2%)	180 (13.0%)	177 (8.2%)
Uncertain or not determined	205 (15.7%)	381 (14.1%)	198 (14.4%)	176 (12.7%)	308 (14.2%)
Total	1309	2694	1377	1385	2166

Table 15.11: Cause of death, by time, on RRT at 3 years

When comparing rates of death between incident and prevalent patients, causes of death were similar (Tables 15.4 and 15.15, and see Table 15.8 above), although age had an effect. Proportionately, there were higher rates of stroke, treatment withdrawal and infection in prevalent patients aged less than 65 when compared with incident patients who died in the first 90 days, but not those dying 1 year after 90 days.

	All ages	<65		65+	
Cause of death	**5+ yrs on RRT**	**<5 yrs on RRT**	**5+ yrs on RRT**	**<5 yrs on RRT**	**5+ yrs on RRT**
Cardiovascular	572 (32.7%)	607 (34.0%)	358 (36.6%)	812 (30.0%	214 (27.8%0
Cerebrovascular accident	136 (7.8%)	146 (8.2%)	80 (8.2%)	203 (7.5%)	56 (7.3%)
ESF treatment stopped	133 (7.6%)	105 (5.9%)	39 (4.0%)	421 (15.6%)	94 (12.2%)
Infection	297 (17.0%)	338 (19.0%)	161 (16.4%)	473 (17.5%)	136 (17.7%)
Malignancy	143 (8.2%)	136 (7.6%)	84 (8.6%)	194 (7.2%)	59 (7.7%)
Others	182 (10.4%)	221 (12.4%)	113 (11.5%)	231 (8.5%)	69 (9.0%)
Uncertain or not determined	285 (16.3%)	230 (12.9%)	144 (14.7%)	372 (13.7%)	141 (18.3%)
Total	1748	1783	979	2706	769

Table 15.12: Cause of death, by time, on RRT at 5 years

Prevalent patients and comparison with the general population

Cause of death	**All No. of Deaths**	**All % of those with data**	**<65 Deaths**	**<65 % of those with data**	**65+ Deaths**	**65+ % of those with data**
Cardiovascular	157	31.2	57	33.7	100	29.9
Cerebrovascular accident	40	8.0	17	10.1	23	6.9
ERF treatment stopped	71	14.1	15	8.9	56	16.8
Infection	86	17.1	28	16.6	58	17.4
Malignancy	31	6.2	13	7.7	18	5.4
Others	61	12.1	24	14.2	37	11.1
Uncertain or not determined	57	11.3	15	8.9	42	12.6
Total with cause of death	503		169		334	
No cause of death sent	547		151		396	

Table 15.13: Cause of death in prevalent patients, by age

There were a total of 1050 deaths in this cohort, 503 (48%) of which had a recorded cause. In total, 66% of deaths occurred in those patients aged over 65 years. Cardiac death was the most common cause (31.2%) irrespective of age group under or over 65 years (Table 15.13). Treatment withdrawal was significantly (p<0.05) more common in those aged over 65 than those under 65 (16.8% versus 8.9% respectively).

The rates of death by primary diagnosis (Table 15.14) and age (Tables 15.16) were calculated; not unexpectedly, death rate increased with increasing age, the highest rate of death being seen in those with underlying malignancy (497/1000 pat yrs exp). The three lowest rates were seen in those with either cystic/polycystic disease (117/1000 pat yrs exp), GN (151/1000 pat yrs exp) or pyelonephritis (159/1000 pat yrs exp). A comparison of primary diagnoses with GN as the reference (Table 15.15) showed that all other primary diseases had a significantly different rate of death except pyelonephritis. Cystic/polycystic disease had a better, and pyelonephritis a similar, outcome related to GN, whereas other conditions had a significantly poorer one. Gender differences were not significant, with rates of death 214/1000 pat yrs exp in males compared with 198 in females (Table 15.14).

EDTA group	Exposure years	Deaths	Rate/1000 yrs exp
Amyloid	48.0	13	271.0
Cystic/polycystic	375.0	44	117.3
Diabetes	812.5	223	274.5
Glomerulonephritis	548.9	83	151.2
Interstitial	89.1	26	291.9
Malignancy	50.3	25	496.7
Pyelonephritis	546.0	87	159.3
Renal vascular disease	587.0	128	218.1
Other	820.3	166	202.4
Uncertain	1185.6	255	215.1
Total	5062.7	1050	207.4
Male	3027.9	648	214.0
Female	2034.8	402	197.6

Table 15.14: Rate of death, by gender and primary diagnosis, in prevalent patients

EDTA group	Exp years	Deaths	Rate/1000	Lower 95% CI	Upper 95% CI	Compare with GN
Amyloid	48.0	13	271.0	123.68	418.32	1.79
Cystic/polycystic	375.0	44	117.3	82.65	151.98	0.78
Diabetes	812.5	223	274.5	238.44	310.48	1.82
Glomerulonephritis	548.9	83	151.2	118.67	183.73	1
Interstitial	89.1	26	291.9	179.69	404.09	1.93
Malignancy	50.3	25	496.7	302.00	691.42	3.29
Pyelonephritis	546.0	87	159.3	125.86	192.83	1.05
Renal vascular disease	587.0	128	218.1	180.29	255.85	1.44
Other	820.3	166	202.4	171.58	233.15	1.34
Uncertain	1185.6	255	215.1	188.68	241.48	1.42
Total	5062.7	1050	207.4	194.85	219.94	1.37

Table 15.15: Rate of death in prevalent patients, by primary diagnoses

Table 15.16 uses data from the Office for National Statistics (ONS) and shows the population by age band for England & Wales, and the number of deaths per thousand in the general population. The death rates of patients on RRT were calculated and a figure derived for the observed number of deaths on RRT. This was divided by the expected number of deaths calculated for the general population to provide the relative risk (RR) of dying given

underlying established renal failure (ERF), compared with another individual of the same age group without ERF in England & Wales. Results showed that although the death rate increases with increasing age, the risk of death compared with the general population without ERF is greatest in the younger age bands (Table 15.16 and Figure 15.1). The RR of dying for 20–24-year-olds on RRT was 121.4 compared with 5.1 in the 80–84-year-olds.

Age	E&W Pop mid-98 (000)	E&W deaths	E&W /1000 pop	Ren Reg exposed years	Expected	RenReg deaths	RenReg deaths per 1000	Obs/exp
20–24	3084.2	1832	0.6	83.2	0.0	6	72.1	121.4
25–29	3883.4	2364	0.6	140.2	0.1	6	42.8	70.3
30–34	4294	3187	0.7	163.4	0.1	19	116.3	156.7
35–39	4035.4	4345	1.1	247.7	0.3	19	76.7	71.3
40–44	3479.8	5643	1.6	276.7	0.4	37	133.7	82.5
45–49	3403.8	8331	2.4	355.7	0.9	41	115.3	47.1
50–54	3500.1	14132	4.0	472.2	1.9	64	135.5	33.6
55–59	2709.4	18481	6.8	553.8	3.8	96	173.3	25.4
60–64	2489.8	27244	10.9	610.2	6.7	130	213.0	19.5
65–69	2314.6	40735	17.6	747.4	13.2	174	232.8	13.2
70–74	2085.8	62384	29.9	694.4	20.8	210	302.4	10.1
75–79	1781.3	88977	50.0	488.6	24.4	168	343.8	6.9
80–84	1089.6	88123	80.9	156.0	12.6	64	410.2	5.1
85–89	669	89474	133.7	34.6	4.6	13	375.3	2.8
90+	347.7	76482	220.0	3.6	0.8	3	834.6	3.8
Total	42386.5	533035	12.6	5027.7	90.6	1050	208.8	11.6

Table 15.16: Death rate, by age, for prevalent patients: comparisons with the general population

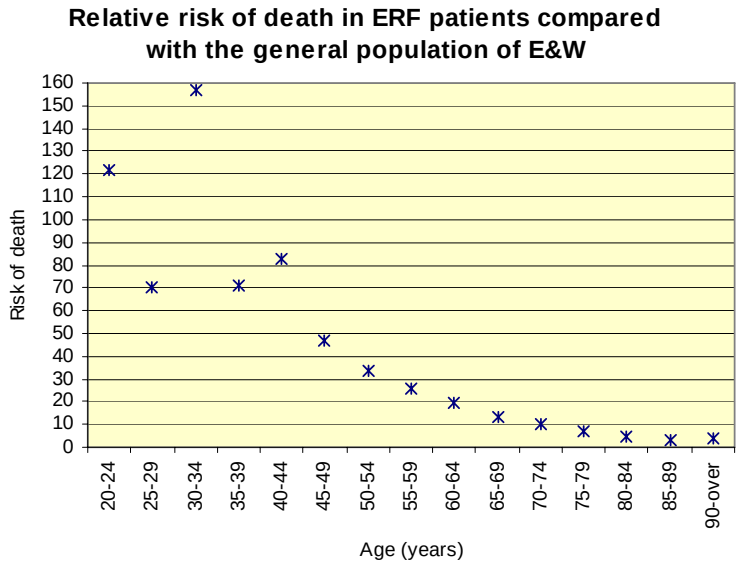


Figure 15.1: Relative risk of death in ERF patients

We also compared causes of death in the ERF population with that in the general population of England & Wales as supplied by the ONS (Table 15.17). In the general population, the three most common causes of death were classified as 'other' (27.8%), malignancy (25.2%) and cardiovascular disease (24%). Very few people had a recorded cause of death of diabetes, or one of its associated complications, although this probably reflects the stringency applied to death certification. When compared with the ERF population, proportionately more renal patients died of a cardiac cause (31.2% versus 24%), reflecting a 23% or 1.3-fold increased

risk of death in these patients. Similarly, infection was more common as a cause of death in renal patients (17.1% versus 11.5%) reflecting a 33% or 1.5-fold increase in risk. Maybe as a consequence, or as a reflection of the selection of patients taken on for RRT, the risk of malignancy in the ERF group was much lower than that of the general population (6.2% versus 25.2%, a 75% or fourfold decreased risk).

	Sex	No. 15–64	No. 65+	No. Total	% 15–64	% 65+	% Total
Cardiovascular	All	16,475	111,559	128,034	19.0	25.0	24.0
Cerebrovascular accident	All	3,968	48,491	52,459	4.6	10.9	9.8
Diabetes	All	860	4,902	5,762	1.0	1.1	1.1
Infection	All	4,187	57,215	61,402	4.8	12.8	11.5
Malignancy	All	32,745	101,495	134,240	37.7	22.7	25.2
Other	All	26,445	121,837	148,282	30.4	27.3	27.8
Uncertain or not determined	All	2,180	676	2,856	2.5	0.2	0.5
Total	All	86,860	446,175	533,035	100.0	100.0	100.0

Table 15.17: Population deaths, by sex and age

Age	E&W Pop mid-98 (000)	E&W Deaths	E&W/1000 pop	Ren Reg exp years	Ren Reg deaths	UK RR deaths per 1000	USA deaths per 1000	RR/USA
20–44	18,515.6	13,029.0	0.7	911.1	87	95.5	56.1	1.70
45–64	13,093.1	46,587.0	3.6	1,991.9	331	166.2	136.3	1.22
65+	10,430.1	396,937.0	38.1	2,124.7	632	297.5	340.4	0.87
Total	42,038.8	456,553.0	10.9	5,027.7	1050	208.8	179.3	1.16

Table 15.18: Death rate, by age, for prevalent patients and comparison with the USA

In Table 15.18, UK prevalent patients in the younger age group had a higher rate of death than those in the USA. The UK deaths, unlike the USA data, include those patients who died within the first 90 days, and this may account for the higher rate of death. UK patients aged over 65 years have a lower rate of death than in the USA, which is probably related to the high take-on rate in the USA, with a higher rate of comorbidity in these patients.

Effect of comorbidity

The influence of comorbidity on death was assessed in the incident population of RRT patients. The number of patients with both comorbidity at the start of RRT and cause of death recorded were currently too small to analyse the effect of these factors on death at 90 days and 1 year after 90 days. The analysis includes all incident patients with complete records who died within 3 years of starting RRT. There were 640 deaths in the patient group with completed comorbidity. Of these, 365 patients (57%) had a cause of death recorded, a similar level of completion to both the incident and prevalent groups.

Comparison of cardiovascular and peripheral vascular comorbidity

Because of the limited data, comorbidity was grouped into:

1. cardiovascular disease;
2. generalised (mainly peripheral) vascular disease;
3. either of these groups;
4. patients recorded as having no comorbidity present.

In Table 15.19, of those patients recorded as having cardiovascular disease at the time of starting RRT (n=129), 52.7% (n=68) died from a cardiac cause. In comparison, of patients recorded as having no cardiovascular disease (n=236), only 17.8% (n=42) died from cardiac causes, and their causes of death were more widely distributed. The presence of generalised vascular disease at the start of RRT (Table 15.20) did not affect the rate of cardiac death when compared with the previous analysis of the complete incident population.

	No cardiovasc	No %	Yes cardiovasc	Yes %	Total No.	Total %
Cardiovascular	42	17.8	68	52.7	110	30.1
Cerebrovascular accident	19	8.1	8	6.2	27	7.4
ERF treatment stopped	54	22.9	16	22.4	70	19.2
Infection	43	18.2	15	11.6	58	15.9
Malignancy	28	11.9	6	4.7	34	9.3
Others	28	11.9	6	4.7	34	9.3
Uncertain or not determined	15	6.4	9	7.0	24	6.6
Total	236		129		365	

Table 15.19: Cardiovascular comorbidity and cause of death

	No Vasc dis	No %	Yes Vasc dis	Yes %	Total No.	Total %
Cardiovascular	64	27.9	46	33.8	110	30.1
Cerebrovascular accident	16	7.0	11	8.1	27	7.4
ERF treatment stopped	41	17.9	29	21.3	70	19.2
Infection	40	17.5	18	13.2	58	15.9
Malignancy	27	11.8	7	5.1	34	9.3
Others	29	12.7	13	9.6	42	11.5
Uncertain or not determined	12	5.2	12	8.8	24	6.6
Total	229		136		365	

Table 15.20: Generalised vascular comorbidity and cause of death

	None	No %	Any	Yes %	Total No.	Total %
Cardiovascular	27	16.4	83	41.5	110	30.1
Cerebrovascular accident	13	7.9	14	7.0	27	7.4
ERF treatment stopped	34	20.6	36	18.0	70	19.2
Infection	33	20.0	25	12.5	58	15.9
Malignancy	24	14.5	10	5.0	34	9.3
Others	24	14.5	18	9.0	42	11.5
Uncertain or not determined	10	6.1	14	7.0	24	6.6
Total	165		200		365	

Table 15.21: Cardiovascular or peripheral vascular comorbidity and cause of death

In those patients without cardiac or circulatory disease on starting RRT (Table 15.21), treatment withdrawal was the most common cause of death (20.6%), although causes were more evenly distributed across all the categories.

Diabetes and cause of death

Patients with type I and II diabetes were analysed as a single group. Patients were included in this analysis if they had diabetes as the primary diagnosis for the cause of their renal disease or if it was recorded as a comorbidity response. Prevalent and incident patients were assessed separately.

Incident patients with diabetes

In the incident patients, diabetics had a lower rate of death in the first 90 days than non-diabetics (Table 15.22), probably because of their younger age (58 versus 60 years). Of the 1030 deaths in the first 90 days, 12% occurred in patients with diabetes. Table 15.23 shows that these diabetic patients had a significantly greater rate of cardiac death than the non-diabetics (53% versus 29%, $p<0.01$).

	Exp years	Deaths	Rate/1000	Lower 95% CI	Upper 95% CI
Non-diabetics	2858.63	908	317.6	296.97	338.30
Diabetics	507.847	122	240.2	197.60	282.86

Table 15.22: Death rate, by diabetes, in incident patients at 90 days

	Non-diabetic No.	Non-diabetic %	Diabetic No.	Diabetic %	Total	%	*p*	Adjust *p*
Cardiovascular	139	28.5	41	53.2	180	31.9	0.00	<0.01
Cerebrovascular accident	35	7.2	4	5.2	39	6.9	0.52	NS
ERF treatment stopped	62	12.7	5	6.5	67	11.9	0.12	NS
Infection	98	20.1	8	10.4	106	18.8	0.04	NS
Malignancy	45	9.2	0	0	45	8.0	0.06	NS
Others	32	6.6	5	6.5	37	6.6	0.98	NS
Uncertain or not determined	76	15.6	14	18.2	90	16.0	0.57	NS
Total	487	100	122	100	609	100		
No data	421		45		466			

Table 15.23: Cause of death, by diabetes, in incident patients at 90 days

In the 1 year after 90 days period (Table 15.24), the death rate was higher in diabetics than non-diabetics (214 versus 184/1000 pat yrs exp respectively). Again, cardiac death was significantly more common in the diabetic patients (42% versus 26%, $p<0.01$; Table 15.25).

	Exp years	Deaths	Rate/1000	Lower 95% CI	Upper 95% CI
Non-diabetics	8414.45	1547	183.9	174.69	193.01
Diabetics	1447.36	310	214.1	190.34	238.03

Table 15.24: Death rate, by diabetes, in incident patients at 1 year after 90 days

Cause of death	Non-diabetic No.	Non-diabetic %	Diabetic No.	Diabetic %	Total	%	*p*	Adjust *p*
Cardiovascular	221	26.4	77	41.6	298	29.1	<0.01	<0.01
Cerebrovascular accident	65	7.8	14	7.6	79	7.7	0.93	NS
ERF treatment stopped	130	15.5	29	15.7	159	15.5	0.96	NS
Infection	152	18.1	30	16.2	182	17.8	0.54	NS
Malignancy	91	10.9	3	1.6	94	9.2	<0.01	<0.01
Others	69	8.2	7	3.8	76	7.4	0.04	NS
Uncertain or not determined	110	13.1	25	13.5	135	13.2	0.89	NS
Total	1547	100	310	100	1857	100		
No cause of death sent	709		125		834			

Table 15.25: Cause of death, by diabetes, in incident patients at 1 year after 90 days

Prevalent patients with diabetes

Of the 1050 prevalent patients in Table 15.26, 223 (21%) were diabetic, and their rate of death was significantly higher than that of non-diabetics (275 versus 195/1000 pt yrs exp, $p<0.01$). Of these diabetics, 112 (50%) had a cause of death recorded.

In analysing those with data (Table 15.27), diabetics had a proportionately higher incidence of cardiac deaths compared with non-diabetics (41% versus 28%); this did not reach statistical significance. They did, however, have significantly more deaths from cerebrovascular accident ($p<0.05$).

	Exp Years	Deaths	Rate/1000	Lower 95% CI	Upper 95% CI
Non-diabetics	4250.2	827	194.6	181.32	207.84
Diabetics	812.5	223	274.5	238.44	310.48

Table 15.26: Death rate for prevalent diabetic patients

Cause of death	Non-diabetic	Non-diabetic %	Diabetic n	Diabetic %	Total	%	*p*	Adjust *p*
Cardiovascular	111	28.3	46	41.4	157	31.2	0.01	NS
Cerebrovascular accident	24	6.1	16	14.4	40	8.0	<0.01	<0.05
ERF treatment stopped	60	15.3	11	9.9	71	14.1	0.15	NS
Infection	63	16.1	23	20.7	86	17.1	0.25	NS
Malignancy	27	6.9	4	3.6	31	6.2	0.20	NS
Others	57	14.5	4	3.6	61	12.1	<0.01	<0.05
Uncertain or not determined	50	12.8	7	6.3	57	11.3	0.06	NS
Total	827	100	223	100	1050	100		
No cause of death sent	435		112		547			

Table 15.27: Effect of diabetes on cause of death in prevalent patients

International comparisons

Comparisons were possible with data from European, North American and Australasian Registries.

USA

Using data from the US Renal Data System (USRDS) 2001 annual report,[4] rates of death for UK patients were compared by age band (see Table 15.18 above). Rates of death in the UK were significantly higher than in USA in the younger and middle-aged bands but significantly lower in the 65+ age group ($p<0.01$). This difference in the elderly may be due to the fact that, in the USA, patients with very high rates of comorbidity (but who survive more than 90 days) all start RRT, whereas in England & Wales, take-on rates are much lower and there is selection bias. The USA data omit deaths in the first 90 days, which may be part of the reason for the apparently higher mortality in the UK in the younger age groups.

In the USRDS report, causes of death categories were divided into many subgroups within the cardiovascular causes. With the larger patient number, deaths were split by myocardial infarction, cardiac arrest, cause unknown and cardiac other. The data showed that cardiovascular disease was the most common cause of death across all RRT modalities, although most transplant patients died of unknown cause (31.7 per 1000 patient years exposed).

Canada

The 2001 Canadian report, based on data from RRT patients in 1999,[5] provided details on 2652 deaths in 26,209 prevalent patients (10.1%). Cardiovascular disease remained the most common cause of death (38.2%), although the proportion was higher than in UK patients (31.7%). The next most common cause was 'social' (15.4%), and although this category included suicide as well as treatment withdrawal, the rate was comparable to that recorded for the UK (14.1%). Infection was believed responsible for only 9.7% of deaths, much less common than the 18.3% for the UK cohort.

Norway

The registries of Norway and Finland both quoted cause of death by proportions, and their categories differed slightly from those used in the UK. Of 278 deaths in prevalent patients on RRT in 2001 in Norway,[3] 11% died from treatment withdrawal, 33% from cardiac causes, 23% from infection, 20% from vascular disease and 12% from malignancy. Results are comparable with those from the UK for cardiac disease and treatment withdrawal, but proportionately more Norwegian than UK patients died from infection and malignancy.

Finland

In Finland, cardiac and cerebrovascular diseases were combined as a cause of death, this category accounting for 48% of all deaths on RRT.[2] The proportion of deaths from infective causes was similar to the UK Registry figures (18% versus 17.1%), but other diagnostic categories were not suitable for direct comparison.

Australia and New Zealand

In the combined Australia and New Zealand Registry report,[6] death rate was analysed by proportion and per 100 patient years at risk. This included all patients treated during the year 2000. Within Australia, 12% of dialysis patients died (15.7 deaths/100 pt yrs exp), compared with 2.9% of those with a functioning transplant (3.2 deaths/100 pt yrs exp). The rates in New Zealand differed, with 19.2 deaths per 100 patient years for dialysis and 2.5 for transplant recipients. In both dialysis patients and transplant recipients, cardiac events were the most common cause of death (46% versus 29% in Australia, 43% versus 24% in New Zealand). Within the dialysis cohort, treatment withdrawal accounted for 21% and 22% of deaths respectively in Australia and New Zealand, the majority of these cases having underlying diabetes. The cardiac death rate in Australia was higher than that in England & Wales (46% versus 32%). The treatment withdrawal rate was also substantially higher in Australia (48% of dialysis patients) and New Zealand (18%), compared with England & Wales (14%), whereas the infection rate was lower in Australia (12% in dialysis patients).

European ERA/EDTA Registry

The ERA report for 2000 included data from Austria, Belgium, Finland, France, the Netherlands, Norway and Scotland. The ERA has analysed data on causes of death from the years 1991–99.[1,7] During this period, there were 19,851 deaths, and the distribution of causes of death did not change. The most common cause of death was cardiac, accounting for the deaths of 36% of dialysis patients and 35% of transplant patients (Figure 15.2), followed by infection and malignancy in decreasing order of frequency. All these data were comparable with the results from the UK.

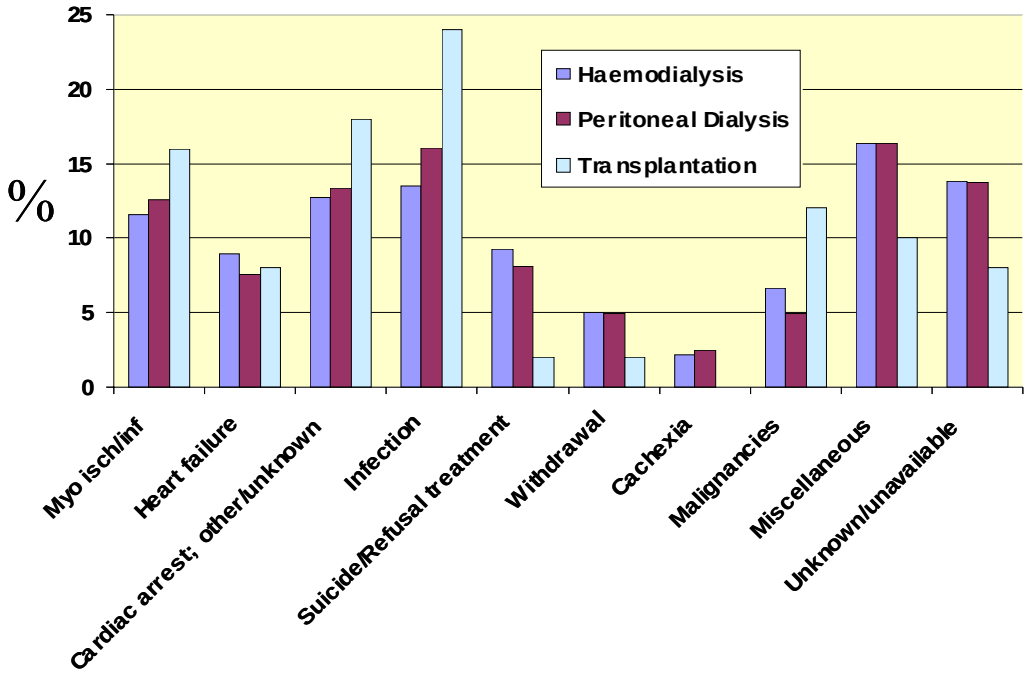


Figure 15.2: ERA-EDTA causes of death

Conclusion

These data confirmed what has been shown by other national Renal Registries, that cardiovascular disease is the most common cause of death in patients on RRT and that this is most evident in the diabetic population. In patients aged 65 years and over, there was also a high frequency of deaths caused by treatment withdrawal.

When compared with the general population of England & Wales, cardiac deaths were proportionately more common in patients on RRT – a 23% increase. This may be a reflection of the comorbidity present at the start of renal replacement, the ageing RRT population and the effect of ERF itself. In those patients with comorbidity data and a recorded cause of death, 50% of patients with cardiac disease on starting RRT died of a cardiac cause. Diabetics were more likely to die from cardiac disease but also had an increased risk of death from cerebrovascular disease. Causes of death were similar among prevalent and incident patients irrespective of time on RRT.

Infection-related deaths were more common in the ERF cohort than in the general population (17.1% versus 11.5%), representing a 33% increase. These deaths will be related to a combination of factors, including vascular access, peritonitis, atypical infections, and also the effect of immunosuppressive regimes.

As expected, death rate increased with increasing age, and although women tended to have a better outcome, this did not reach statistical significance. When looking at all-cause death by age, 25–29-year-olds with ERF had a 156-fold higher risk of death compared with the general population. This contrasts with a 5.1-fold increase in the 80–84-year-old patients on RRT.

The underlying primary renal diagnosis had a significant effect on death rate, irrespective of age. Those patients with malignancy, not surprisingly, had the poorest outcomes, whereas cystic/polycystic patients had the best. Patients with pyelonephritis and GN also showed an improved outcome compared with those with other diseases.

In general, the UK data compared favourably with those of other Registries. When compared with USRDS data, younger patients in the UK had a significantly higher rate of death. This may be in part explained by differences in timing of the data collection (the 90 day rule) and ethnic mix. UK data include all patients on RRT from day 0, whereas US figures exclude patients for the first 90 days of RRT because of collection issues and therefore miss a proportion of early deaths. Our data were unadjusted for ethnicity, yet the USRDS has shown that African-Caribbean males on dialysis have an improved survival. They had a death rate of 169.2/1000 pt yrs exp, compared with 288.4 in Whites.[4] Differences between ethnic groups were also seen in women, albeit to a lesser extent (204.0 versus 295.2/1000 pt yrs exp for African-Caribbean individuals and Whites respectively). In the over-65 age group, the UK had a better rate of survival, although this may be because of differences in case mix. A lack of uniformity in categorisation impedes the comparison of data from international sources.

With improved data returns, the Registry will be able to analyse further the effects of comorbidity and ethnicity on cause and rate of death. It will also be possible to analyse in greater detail particular diagnoses and their associated risk of death, and examine the effect of treatment modality.

EDTA causes of death and groupings

EDTA	Title	SubgroupB
0	Cause of death uncertain/not determined [0]	Uncertain or not determined
11	Myocardial ischaemia and infarction [11]	Heart
12	Hyperkalaemia [12]	Others
13	Haemorrhagic pericarditis [13]	Others
14	Other causes of cardiac failure [14]	Heart
15	Cardiac arrest/sudden death; other cause or unknown [15]	Heart
16	Hypertensive cardiac failure [16]	Heart
17	Hypokalaemia [17]	Others
18	Fluid overload/pulmonary oedema [18]	Heart
21	Pulmonary embolus [21]	Others
22	Cerebrovascular accident, other cause or unspecified [22]	Cerebrovascular accident
23	Gastrointestinal haemorrhage (digestive) [23]	Others
24	Haemorrhage from graft site [24]	Others
25	Haemorrhage from vascular access or dialysis circuit [25]	Others
26	Cerebral haemorrhage from ruptured vascular aneurysm (not code 22 or 23) [26]	Others
27	Haemorrhage from surgery (except digestive haemorrhage) [27]	Others
28	Other haemorrhage, other site and/or other cause [28]	Others

EDTA	Title	SubgroupB
0	Cause of death uncertain/not determined [0]	Uncertain or not determined
29	Mesenteric infarction [29]	Others
31	Pulmonary infection (bacterial) [31]	Infection
32	Pulmonary infection (viral) [32]	Infection
33	Pulmonary infection (fungal or protozoal; parasitic) [33]	Infection
34	Infections elsewhere except viral hepatitis	Infection
35	Septicaemia [35]	Infection
36	Tuberculosis (lung) [36]	Infection
37	Tuberculosis (elsewhere) [37]	Infection
38	Generalised viral infection [38]	Infection
39	Peritonitis (all causes except for peritoneal dialysis) [39]	Infection
41	Liver disease due to hepatitis B virus [41]	Others
42	Liver disease due to other viral hepatitis [42]	Others
43	Liver disease due to drug toxicity [43]	Others
44	Cirrhosis – not viral (alcoholic or other cause) [44]	Others
45	Cystic liver disease [45]	Others
46	Liver failure – cause unknown [46]	Others
51	Patient refused further treatment for ESRF [51]	ESRF treatment stopped
52	Suicide [52]	Others
53	ESRF treatment ceased for any other reason [53]	ESRF treatment stopped
54	ESRF treatment withdrawn for medical reasons [54]	ESRF treatment stopped
61	Uraemia caused by graft failure	ESRF treatment stopped
62	Pancreatitis [62]	Others
63	Bone marrow depression (aplasia) [63]	Others
64	Cachexia [64]	Others
66	Malignant disease in patient treated by immunosuppressive therapy [66]	Malignancy
67	Malignant disease: solid tumours except those of 66 [67]	Malignancy
68	Malignant disease: lymphoproliferative disorders (except 66) [68]	Malignancy
69	Dementia [69]	Others
70	Peritonitis (sclerosing, with peritoneal dialysis) [70]	Others
71	Perforation of peptic ulcer [71]	Others
72	Perforation of colon [72]	Others
73	Chronic obstructive pulmonary disease [73]	Others
81	Accident related to ESRF treatment (not 25) [81]	Others
82	Accident unrelated to ESRF treatment [82]	Others
99	Other identified cause of death [99]	Others
100	Peritonitis (bacterial, with peritoneal dialysis) [100]	Others
101	Peritonitis (fungal, with peritoneal dialysis) [101]	Others
102	Peritonitis (due to other cause, with peritoneal dialysis) [102]	Others

Table 15.28: Collation of EDTA codes for cause of death

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1. ERA–EDTA Report

2. Finnish Registry for Kidney Diseases. Report 2000.

3. Annual Report 2001, Norwegian Renal Registry.

4. US Renal Data System. *USRDS 2001 Annual Data Report, Atlas of End Stage Renal Disease in the US National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases*. Bethseda, MD: NIH, 2001.

5. Canadian Institute for Health Information. *Register 2001 Report*. Vol 1: *Dialysis and Renal Transplantation. Canadian Organ Replacement Register*. Ottowa: Canadian Institute for Health Information, 2001.

6. Disney APS, Russ Graeme R. *Australia and New Zealand Dialysis and Transplant Registry Report 2001*. Adelaide: ANZDATA, 2001.

7. van Dijk Paul CW, et al. Renal replacement therapy in Europe: the results of a collaborative effort by the ERA–EDTA registry and six national or regional registries. *Nephrol Dial Transplant* 2001;16:1120–9.

Chapter 16: Report from the Paediatric Renal Registry

Summary

- Paediatric data collection has continued across the UK from the 13 regional tertiary paediatric nephrology units. This has provided information on an almost complete cohort of children under the age of 15 years on renal replacement therapy. Although the incidence of established renal failure in children is fairly constant, there has been a significant increase in the prevalence over the past 10 years. Established renal failure in children therefore continues to be a cumulative service: this has significant implications for the need for resources.

- There is a significant overrepresentation of patients from the Asian subcontinent on renal replacement therapy, and these patients are geographically concentrated in a few units. This has implications for workforce and resource planning in these areas.

- Established renal failure presents at all ages in childhood, with a slowly increasing incidence with age. Males significantly outnumber females in early childhood, but by the teenage years, more females are presenting than males.

- Renal dysplasia and obstructive uropathy remain the most common causes of renal replacement therapy in childhood. Patients with these problems present with established renal failure at all ages throughout childhood. Reflux nephropathy becomes more frequent in the older groups as renal dysplasia reduces, and the overall incidence of renal dysplasia plus reflux nephropathy is constant, suggesting that they are different ends of the spectrum of one condition.

- The majority of paediatric renal replacement therapy patients have a functioning transplant, but the rate of cadaveric transplantation is falling. This is, however, balanced by an associated trend of an increase in live related transplants, allowing a constant transplant rate overall.

- The data in this report relate to the under-15-year-old age group, which represents only 64% of the total workload of the paediatric nephrology units. Many children with chronic conditions do not transfer to the adult services until the age of 18.

Introduction

In the first report from the paediatric arm of the Renal Registry in 1999, the incidence and prevalence of established renal failure (ERF) in children across the UK was reported. At the time the report was compiled, the Registry data collection mechanism was in its infancy, and the data represented a cross-sectional analysis of the population as it appeared at that time. Since this first report, data collection has continued, and the Registry is now in a position to

look at sequential data sets for a 5 year period. This report looks at the paediatric population as it stood on the 1 April 2001 and centres around an analysis of the incidence and prevalence of renal replacement therapy (RRT) in children in the UK, taking particular account of the breakdown according to diagnosis, age of presentation, ethnic origin and current management.

The 1999 report included the paediatric RRT population for both the UK and Eire. Data for Eire were not available for this report, and appropriate adjustments to the 1999 report figures have therefore been made to allow for meaningful comparisons.

The paediatric RRT population

As discussed in previous paediatric reports, any assessment of the size of the paediatric RRT population is hampered by the variable referral and treatment of teenage patients between paediatric and adult units. The Renal Registry is rapidly expanding towards 100% capture of data from adult units across the UK, and with this a complete analysis of the split of treatment in teenage patients will become possible. Until then, complete assessment is possible only for the population under the age of 15 years, who virtually are all looked after in paediatric units. Patients on RRT who are under the age of 15 but are not being seen within a designated paediatric renal unit will be the small number with multiorgan problems receiving combined transplants in specialised units and 11 patients in Scotland who did not, at that time, attend the one designated unit there.

The total number of patients being cared for in the 13 paediatric nephrology centres providing RRT treatment on 1 April 2001 was 800, with a gender ratio of 1.54:1 males to females. Of these 800 patients, 753 were under the age of 18 years. This represents a growth in the prevalent patient population of 3.8% from the 725 patients under the age of 18 years in 1999. Table 16.1 gives a breakdown of this patient group by age and gender. As might be expected, through the survival of young patients on RRT and the continuing uptake of new patients on RRT throughout the age spectrum, there is an increasing number of patients in each age group until a fall-off occurs from the transfer to adult units. This is shown graphically in Figure 16.1, where the population has been split into equal 4 year age bands to allow ease of comparison between these groups.

Age group (years)	Males	Females	Total (%)
0–1.9	9	4	13 (1.6)
2–4.9	38	18	56 (7.0)
5–9.9	94	52	146 (18.3)
10–14.9	183	118	301 (37.6)
15–17.9	135	102	237 (29.6)
≥18	28	19	47 (5.9)
Total	488	316	800

Table 16.1: Age and gender distribution of the paediatric RRT population

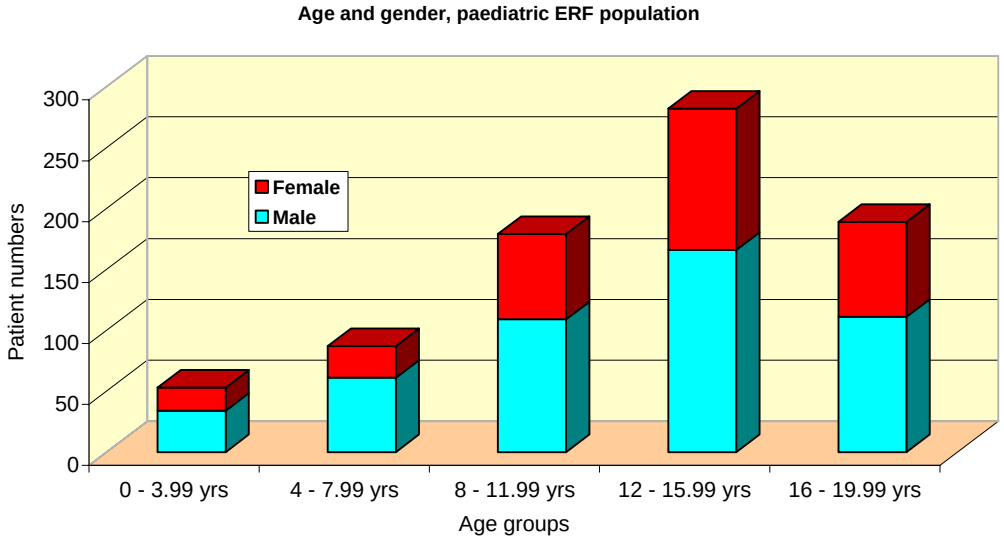


Figure 16.1: Age and gender distribution of the paediatric RRT population

Table 16.2 shows the change in prevalent patient population for those under the age of 15 years. Data from the Paediatric Registry for 1999 and 2001 have been compared with those published in the 1995 British Association of Paediatric Nephrology (BAPN) document *Report on the Provision of Services in the United Kingdom for Children and Adolescents with Renal Disease*. Between 1992 and 2001, there has been a 20% increase in the number of patients under the age of 15 years receiving ERF management. Some of this increase may be the result of incomplete data collection for the 1995 report. Although patient prevalence has continued to increase, the rate of increase appears recently to have slowed.

Age group (years)	1986	1992	1999	2001
0–1.99		16	18	13
2–4.99		55	46	56
5–9.99		150	151	146
10–14.99		208	293	301
Total	263	429	508	516
Per annum increase in prevalence		27.67	11.29	4.00

Table 16.2: Changes in the under-15-year-old prevalent RRT population, by year

Figures collected for 1992 and published in the 1995 working party report were based upon a total childhood population under the age of 15 years of 11.05 million in the UK at that time. Based on this, the prevalence of ERF in children under the age of 15 years in the UK in 1992 was 38.8 per million and the incident rate of new ERF patients 9.7 per million. For this report, population statistics were taken from the UK Government website (www.statistics.gov.uk), which quoted figures from the Office for National Statistics and General Register Office for Scotland. Figures given were for the projected population at mid-2000. Table 16.3 shows a breakdown of the population according to age and gender, and also shows the prevalence of RRT in children in each of these groups. As expected, prevalence rises with age. Within all age groups, there is an excess of males, which is similar to what is found in the adult population. Assuming the projected figures for childhood population are correct, there has been a significant increase in prevalence, to 47.5 per million, since 1992, matching the increase in current patient population.

Age group (years)	UK population (millions)			ERF population			Prevalence (pmp)		
	Males	Females	Total	Males	Females	Total	Males	Females	Total
0–4.99	1.7711	1.6854	3.4565	46	23	69	25.97	13.65	20.25
5–9.99	1.9140	1.8208	3.7348	94	52	146	49.11	28.56	39.36
10–14.99	1.9246	1.8250	3.7496	183	118	301	95.08	64.66	80.81
All <15	5.6097	5.3312	10.9409	323	193	516	57.76	36.76	47.53
UK population	28.6270	29.4309	58.0579				11.32	6.66	8.96

Table 16.3: Prevalence of ERF in children under 15 years of age in the UK
pmp, per million population.

Table 16.4 shows the uptake of new RRT patients over the past 5 years. This is further broken down according to age at start of RRT and gender. It can be seen that the average uptake of new patients is 81 patients per year. There is some year-to-year variation but no trend in this regard. The relative take-on rate for males to females is 1.8:1 for those starting RRT in the first 5 years of life. This falls to 1.2:1 for those starting RRT between 5 and 10 years and reverses to 1:1.03 for the 10–15-year-olds. This relates to the differing patterns of disease causing ERF at differing ages and is discussed in more detail later. The uptake of new patients under the age of 15 years in 1992 was 106 patients. These data suggest that the annual incidence rate of children presenting with ERF is currently stable and certainly not rising at a rate of 5–6% per annum, as was suggested in 1992 based upon the 1992 figures and data from 1984 and 1986. This may well be secondary to an upsurge in the number of patients being treated in the late 1980s and early 1990s as units began to accept patients with ERF starting at birth and in early infancy. Since the initial inclusion of these patients, the numbers have remained stable.

Age group (years)	New patients starting ERF treatment, by year (April to April)															Average		
	1996–97			1997–98			1998–99			1999–2000			2000–2001					
	M	F	T	M	F	T	M	F	T	M	F	T	M	F	T	M	F	T
0–4.99	8	6	14	26	5	31	17	11	28	10	6	16	11	12	23	14.4	8.0	22.4
5–9.99	12	6	18	11	11	22	14	12	26	14	4	18	6	13	19	11.4	9.2	20.6
10–14.99	22	22	44	21	13	34	23	20	43	14	28	32	13	13	26	18.6	19.2	37.8
All <15	42	34	76	58	29	87	54	43	97	38	38	76	30	38	68	44.4	36.4	80.8

Table 16.4: Patients under the age of 15 years entering the RRT programme

Due to the year-to-year variability seen when dealing with a relatively small population of new RRT patients, the incidence rate has been calculated using the average figures over the past 5 years. This is shown with the overall population statistics in Table 16.5. Overall, the new patient rate is 7.4 per million children under the age of 15 years, compared with 9.7 in 1992. For the 1999 report, the age distribution of the RRT population at the start of dialysis was compared with that of the population at the time of the report. These two graphs are shown side by side in Figure 16.2.

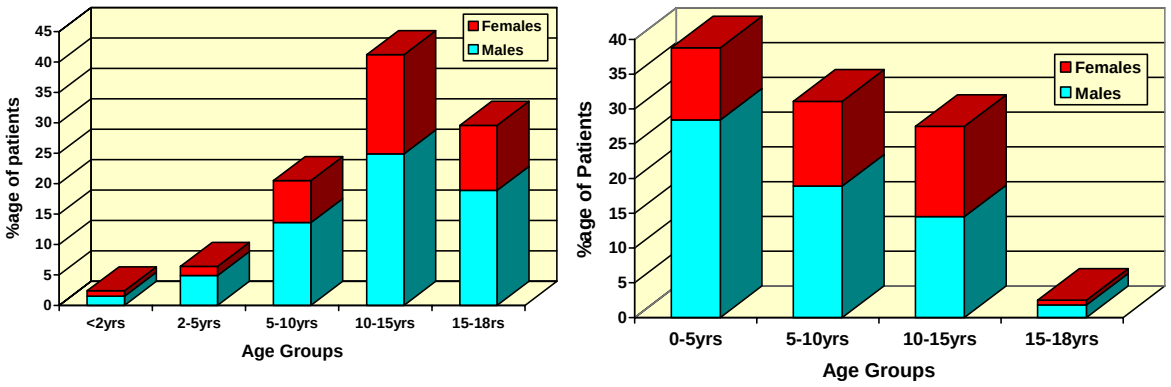


Figure 16.2: Age distribution of the population in 1999 compared with the start of RRT

With the majority of patients commencing dialysis early in life, it was concluded that the most common age of presentation was in early childhood and that the current age distribution was a result of improved life expectancy among this cohort. With the current data, the new patient rate has been analysed by age and gender (Figure 16.3). From these data, it is clear that presentation with ERF occurs throughout childhood, and, if anything, more patients present with ERF over the age of 10 years than below the age of 5.

The current age distribution of the population, as shown in Figure 16.1 above, is not significantly different from that shown in Figure 16.2 for 1999, and similarly there is no real change in the age of commencement of ERF of the current population. The explanation for the apparent discrepancy between the age of starting ERF management for the current patient cohort and the age of presentation with ERF over the past 5 years lies in the regular transfer of older patients to adult units, leaving a disproportionately large cohort of patients commencing ERF management early within the paediatric clinic.

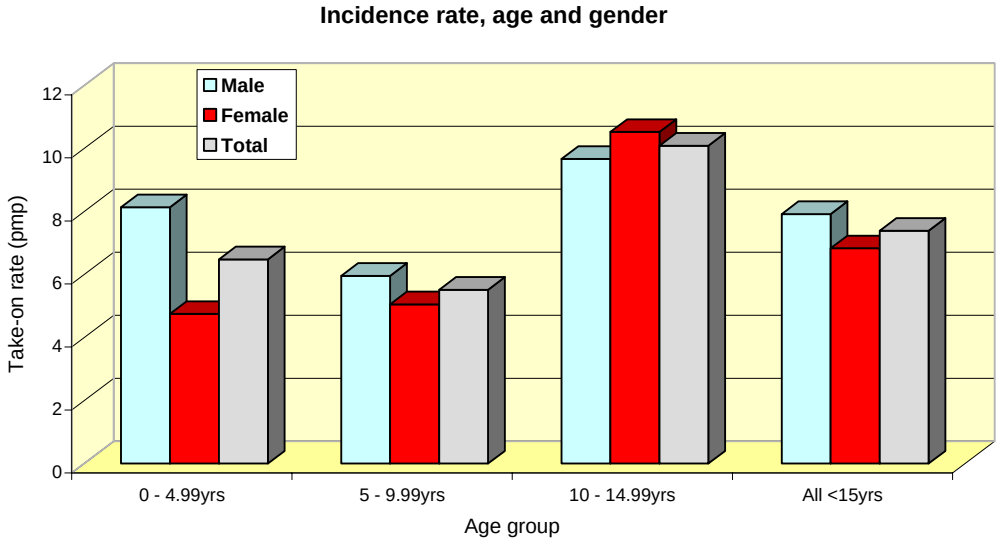


Figure 16.3: Average take-on rate of new ERF patients per year, by age and gender

	UK population (millions)			New patients (average)			Take-on rate (pmp)		
Age group (years)	**Males**	**Females**	**Total**	**Males**	**Females**	**Total**	**Males**	**Females**	**Total**
0–4.99	1.7711	1.6854	3.4565	14.4	8.0	22.4	8.1	4.7	6.5
5–9.99	1.9140	1.8208	3.7348	11.4	9.2	20.6	6.0	5.1	5.5
10–14.99	1.9246	1.8250	3.7496	18.6	19.2	37.8	9.7	10.5	10.1
All <15	5.6097	5.3312	10.9409	44.4	36.4	80.8	7.9	6.8	7.4
UK population	28.6270	29.4309	58.0579				1.6	1.2	1.4

Table 16.5: Incident rate of children under 15 years of age on RRT in the UK

The 1999 report highlighted the relative excess of patients from the Asian subcontinent among the childhood RRT population when compared with the general population. To study this further, the prevalence and new patient rate were analysed by ethnic origin, breaking this down into four groups: White, Black, Asian (defined as patients from the Asian subcontinent of India, Pakistan and Bangladesh) and Other. When looking at data on ethnic distribution, account has to be taken of different age distributions of the population between ethnic groups. Thus, for the White population, 20% of the population is under 16 years of age. For the Indian population, this figure is 23%, and for the Pakistani and Bangladeshi communities it is 37%.

Using these data on age and ethnic distribution, Table 16.6 below shows the number of children in the UK according to ethnic origin, and the prevalence of RRT and incidence rate of new cases of ERF for these populations. It can be seen that both the prevalence and incidence rate for the Asian population was well in excess of that of the other ethnic groups. These data are shown graphically in Figure 16.4. The distribution of ethnic minority groups around the UK is not even, and it might be expected that a concentration of these groups in certain areas would lead to an increased workload and an increased prevalence of ERF for units serving these locations. This would have implications for the distribution of resources and manpower.

Ethnicity	**Population**	**Prevalence (pmp)**	**Take-on rate (pmp)**
Asian	539,386	102.0	23.4
Black	401,531	27.4	4.5
Other	235,229	59.5	9.4
White	9,764,753	44.7	6.6
All <15	10,940,900	47.2	7.4

Table 16.6: Prevalence of ERF in children and take-on rate of new patients by ethnicity

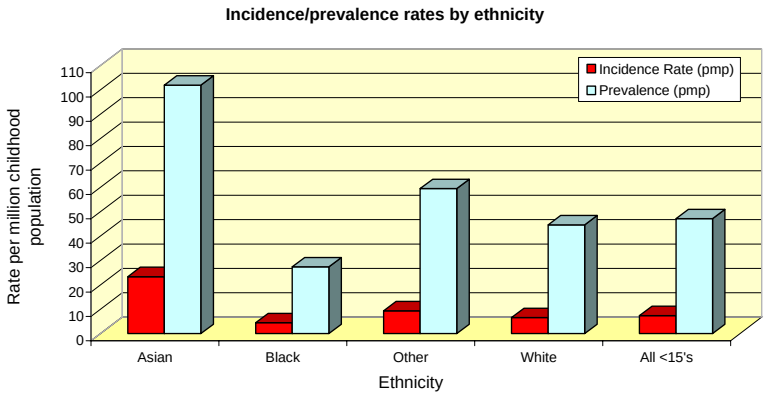


Figure 16.4: Prevalence of RRT in children and take-on rate of new patients by ethnicity

Table 16.7 shows the ethnic distribution of patients below the age of 15 years presenting to the 13 UK paediatric nephrology units over the past 5 years, together with the ethnic distribution of the current patient prevalence under the age of 15 years. Also shown is the approximate childhood population served by each unit, and from this the prevalence and new patient rate for each unit have been calculated.

It can be seen that there are vast differences between the units with regard to the proportion of ethnic minority patients being treated. Although there is a general trend, with regard to both new and existing patients (Figures 16.5a and 16.5b), there is currently no significant correlation between the proportion of the patients on the RRT programme in individual units and the prevalence of RRT in the area covered or the new patient rate. This is likely to be due to the presence of other factors influencing the new patient rate (such as the high prevalence of certain inherited diseases in specific areas) and the imprecision of our current ethnic breakdown. Other evidence suggests that, among patients from the Asian subcontinent, there are wide ranges of disease patterns. Thus, areas with a large Indian population may have a very different incidence and prevalence of childhood ERF from those in areas with a large Pakistani population. This may be studied by a more precise analysis of ethnic origin within the database.

	New patients <15 years of age, 96 – Apr 01					Patient prevalence 15 years age in Apr 01					Population <15 years	Prevalence	TOR
Centre	**White**	**Asian**	**Black**	**Other**	**Total**	**White**	**Asian**	**Black**	**Other**	**Total**	**served**	**(pmp)**	**(pmp)**
Belfast	13	0	0	0	13	18	0	0	0	18	381,468	47.19	6.82
Birmingham	25	10	1	0	36	42	9	1	1	53	1,238,900	42.78	5.81
Bristol	32	1	0	0	33	31	0	0	0	31	881,800	35.16	7.48
Cardiff	7	0	0	0	7	15	0	0	0	15	342,084	43.85	4.09
Glasgow	19	0	0	0	19	40	0	0	0	40	936,147	42.73	4.06
GOS	38	15	5	4	62	64	17	6	8	95	1,780,400	53.36	6.96
Guys	35	6	2	5	48	41	6	4	4	55	1,432,200	38.40	6.70
Leeds	23	13	0	0	36	31	7	0	0	38	756,800	50.21	9.51
Liverpool	15	1	0	0	16	23	1	0	0	24	494,342	48.55	6.47
Manchester	34	14	0	0	48	46	13	0	0	59	919,900	64.14	10.44
Newcastle	23	0	0	0	23	29	1	0	0	30	535,800	55.99	8.59
Nottingham	44	4	0	1	49	47	1	0	1	49	1,122,700	43.64	8.73
Southampton	13	0	0	1	14	9	0	0	0	9	359,000	25.07	7.80

Table 16.7: Prevalence and take-on rate (TOR), by centre and ethnicity

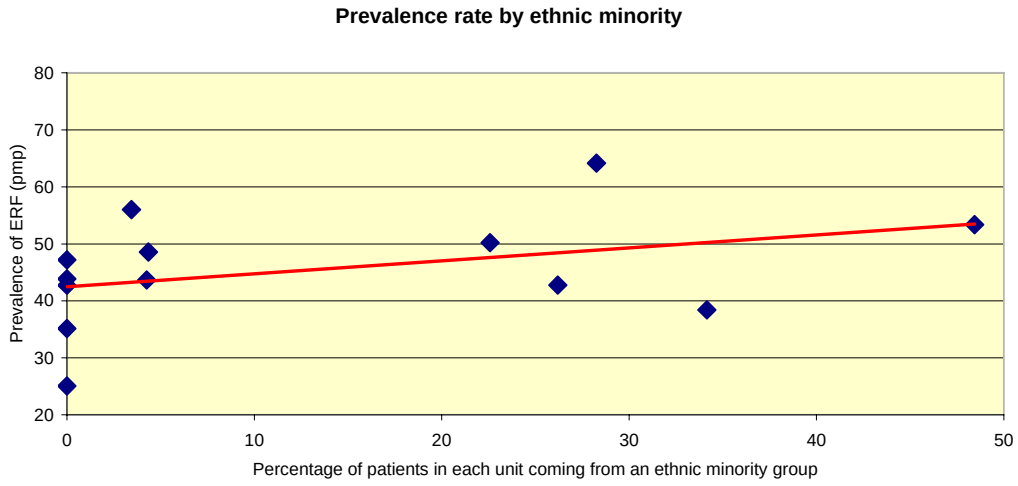


Figure 16.5a: Relationship between take-on rate and % from ethnic minority groups, by centre

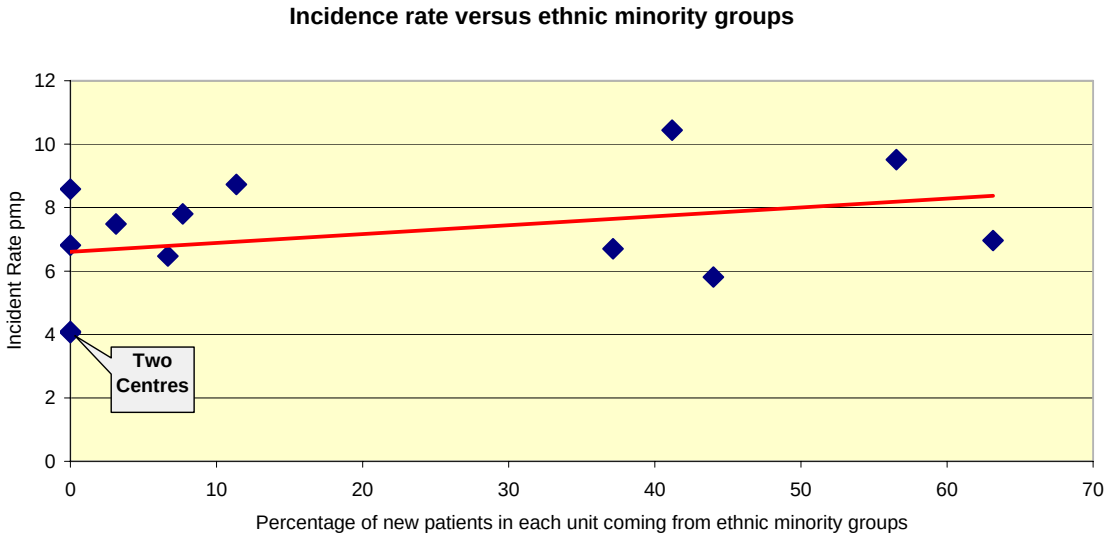


Figure 16.5b: Relationship between prevalence of RRT and ethnic minority group, by centre

Causes of ERF in childhood

The primary cause of ERF was available for 759 of the 800 patients (95%) being cared for in paediatric units on 1 April 2001. The diagnoses are listed alphabetically in Table 16.8 and grouped into disease bands in Table 16.9. Renal dysplasia, either isolated or associated with a syndromal diagnosis, remains the predominant cause of ERF in this population, accounting for 27.7% of the total. Obstructive uropathy is the next largest group, at 19.2%; 73% of this group were boys with posterior urethral valves. Glomerulonephritides account for 18.5% of childhood ERF, with primary focal segmental sclerosis accounting for 38.5% of these cases. The number of patients with reflux nephropathy has fallen slightly from 7.2% to 5.3% of the total. There has been little change in the proportions of patients on RRT secondary to conditions in the other diagnostic headings.

Superficial analysis of the causes of ERF in the childhood population through cohort analysis, as given above, is prone to giving an incorrect picture or disease incidence and prevalence. Diseases that cause ERF in early childhood will create a group of patients who have a prolonged stay on the paediatric unit, whereas patients with diseases presenting late in childhood might be common but underrepresented as their stay with a paediatric unit is limited. To overcome this problem, the primary ERF diagnosis in all the children registered with the BAPN registry in whom both an ERF diagnosis and an age of ERF onset was available has been analysed. Many of these patients are from the current cohort, but some will have been transferred to adult units and some will have died. Only patients with an age of onset of ERF before the age of 15 years were considered so that an accurate picture of pathology in the paediatric age range could be obtained without the data being skewed by patients being referred primarily to adult units.

Diagnosis	Males	Females	Total	%
Acquired obstructive uropathy	2	0	2	0.26
Alport's syndrome	4	2	6	0.79
Anti-GBM disease	0	2	2	0.26
Autosomal recessive polycystic kidney disease	9	5	14	1.84
Barrter's syndrome	0	0	0	0.00
Branchio-oto-renal syndrome	3	1	4	0.53
Chronic renal failure – uncertain aetiology	6	7	13	1.71
Cis-platinum nephrotoxicity	0	0	0	0.00
Congenital nephrotic syndrome (DMS)	5	1	6	0.79
Congenital nephrotic syndrome (Finnish)	10	11	21	2.77
Congenital nephrotic syndrome (FSGS)	3	5	8	1.05
Congenital nephrotic syndrome (unspecified)	7	15	22	2.90
Congenital obstructive uropathy – bladder outlet obstruction (not PUV)	10	2	12	1.58
Congenital obstructive uropathy (not BOO)	5	4	9	1.19
Congenital obstructive uropathy – posterior urethral valves	107	0	107	14.10
Cortical necrosis	8	8	16	2.11
Crescentic glomerulonephritis	1	3	4	0.53
Cyclosporin nephrotoxicity	4	2	6	0.79
Cystinosis	11	11	22	2.90
D-pos haemolytic uraemic syndrome	9	16	25	3.29
D-neg haemolytic uraemic syndrome	2	1	3	0.40
Drug nephrotoxicity (unspecified)	0	0	0	0.00
Glomerulonephritis (unspecified)	2	3	5	0.66
Henoch Schoenlein nephritis	7	9	16	2.11
IgA nephropathy	1	3	4	0.53
Lawrence–Moon–Biedl syndrome	2	2	4	0.53
Megacystis megaureter	2	0	2	0.26
Mesangio-capillary glomerulonephritis type 1	3	2	5	0.66
Mesangio-capillary glomerulonephritis type 2	1	4	5	0.66
Mesoblastic nephroma	1	0	1	0.13
Microscopic polyarteritis nodosa	0	1	1	0.13
Mitochondrial cytopathy	1	1	2	0.26
Multicystic dysplastic kidneys	5	4	9	1.19
Nephrocalcinosis	0	1	1	0.13
Nephronophthisis	23	18	41	5.40
Neuropathic bladder	7	9	16	2.11
Other cytotoxic drug nephrotoxicity	0	2	2	0.26
Polycystic kidney disease (other)	4	1	5	0.66
Primary focal segmental glomerulosclerosis	24	30	54	7.11
Primary hyperoxaluria type 1	2	1	3	0.40
Primary interstitial nephritis	6	4	10	1.32
Proliferative glomerulonephritis	1	1	2	0.26
Prune belly syndrome	14	0	14	1.84
Reflux nephropathy	15	25	40	5.27
Renal artery stenosis	2	1	3	0.40
Renal artery thrombosis	1	1	2	0.26
Renal dysplasia	110	56	166	21.87
Renal hypoplasia	5	6	11	1.45
Renal trauma	0	1	1	0.13
Renal tubular acidosis	2	0	2	0.26
Renal vein thrombosis	6	3	9	1.19

Diagnosis	Males	Females	Total	%
Systemic lupus erythematosus	0	3	3	0.40
Tuberous sclerosis polycystic kidney disease	0	1	1	0.13
Tubular disorders (other)	1	0	1	0.13
Vasculitis (unspecified)	1	3	4	0.53
Wegner's granulomatosis	0	1	1	0.13
Wilms' nephropathy	1	0	1	0.13
Wilms' tumour	5	5	10	1.32

Table 16.8: Primary ERF diagnosis for the paediatric RRT population on 1 April 2001

Diagnostic group	Males	Females	Total	% of total
Renal dysplasia and related conditions				
Renal dysplasia	110	56	166	21.87
Prune belly syndrome	14	0	14	1.84
Renal hypoplasia	5	6	11	1.45
Multicystic dysplastic kidneys	5	4	9	1.19
Branchio-oto-renal syndrome	3	1	4	0.53
Lawrence–Moon–Biedl syndrome	2	2	4	0.53
Megacystis megaureter	2	0	2	0.26
Total with primary renal dysplasia	141	69	210	27.67
Obstructive uropathy				
Posterior urethral valves	107	0	107	14.10
Neuropathic bladder	7	9	16	2.11
Congenital bladder outlet obstruction (not PUV)	10	2	12	1.58
Congenital obstructive uropathy (not BOO)	5	4	9	1.19
Acquired obstructive uropathy	2	0	2	0.26
Total with obstructive uropathy	131	15	146	19.24
Glomerulonephritis, vasculitis and glomerulopathy				
Primary focal segmental glomerulosclerosis	24	30	54	7.11
D-pos haemolytic uraemic syndrome	9	16	25	3.29
Henoch Schoenlein nephritis	7	9	16	2.11
Alport's syndrome	4	2	6	0.79
Glomerulonephritis (unspecified)	2	3	5	0.66
Mesangio-capillary glomerulonephritis type 1	3	2	5	0.66
Mesangio-capillary glomerulonephritis type 2	1	4	5	0.66
Crescentic glomerulonephritis	1	3	4	0.53
IgA nephropathy	1	3	4	0.53
Vasculitis (unspecified)	1	3	4	0.53
D-neg haemolytic uraemic syndrome	2	1	3	0.40
Systemic lupus erythematosus	0	3	3	0.40
Anti-GBM disease	0	2	2	0.26
Proliferative glomerulonephritis	1	1	2	0.26
Microscopic polyarteritis nodosa	0	1	1	0.13
Wegner's granulomatosis	0	1	1	0.13
Total with glomerular disease	56	84	140	18.45
Reflux nephropathy and CRF of uncertain aetiology				
Reflux nephropathy	15	25	40	5.27
Chronic renal failure – uncertain aetiology	6	7	13	1.71
Total with reflux nephropathy and CRF of uncertain aetiology	21	32	53	6.98
Primary tubular and interstitial disorders				
Nephronophthisis	23	18	41	5.40
Primary interstitial nephritis	6	4	10	1.32
Renal tubular acidosis	2	0	2	0.26
Tubular disorders (other)	1	0	1	0.13
Barrter's syndrome	0	0	0	0.00
Total with primary tubular and interstitial disorders	32	22	54	7.11
Congenital nephrotic syndrome				
Congenital nephrotic syndrome (unspecified)	7	15	22	2.90

Diagnostic group	Males	Females	Total	% of total
Congenital nephrotic syndrome (Finnish)	10	11	21	2.77
Congenital nephrotic syndrome (FSGS)	3	5	8	1.05
Congenital nephrotic syndrome (DMS)	5	1	6	0.79
Total with congenital nephrotic syndrome	25	32	57	7.51
Renal vascular disorders				
Cortical necrosis	8	8	16	2.11
Renal vein thrombosis	6	3	9	1.19
Renal artery stenosis	2	1	3	0.40
Renal artery thrombosis	1	1	2	0.26
Renal trauma	0	1	1	0.13
Total with renal vascular disorders	17	14	31	4.08
Metabolic diseases and drug nephrotoxicity				
Cystinosis	11	11	22	2.90
Cyclosporin nephrotoxicity	4	2	6	0.79
Primary hyperoxaluria type 1	2	1	3	0.40
Mitochondrial cytopathy	1	1	2	0.26
Other cytotoxic drug nephrotoxicity	0	2	2	0.26
Nephrocalcinosis	0	1	1	0.13
Cis-platinum nephrotoxicity	0	0	0	0.00
Drug nephrotoxicity (unspecified)	0	0	0	0.00
Total with metabolic diseases and drug nephrotoxicity	18	18	36	4.74
Polycystic kidney disease				
Autosomal recessive PKD	9	5	14	1.84
Tuberous sclerosis PKD	0	1	1	0.13
Polycystic kidney disease (other)	4	1	5	0.66
Total with polycystic kidney disease	13	7	20	2.64
Malignant and related diseases				
Wilms' tumour	5	5	10	1.32
Mesoblastic nephroma	1	0	1	0.13
Wilms' nephropathy	1	0	1	0.13
Total with malignant and related diseases	7	5	12	1.58

Table 16.9: Primary ERF diagnoses, grouped by disease category

For this analysis, there were 882 patients with data available. These patients were divided into three groups, consisting of 324 patients on RRT commencing before the age of 5 years, 257 patients on RRT commencing between the ages of 5 and 10 years, and 301 patients on RRT commencing between the ages of 10 and 15 years. Figure 16.6 shows the gender distribution of these three groups. As expected, there is a massive preponderance of boys in the under-5 age group, which reduces in the 5–10-year-old group. Interestingly, there are still more boys than girls in the 10–15-year-old group, contrary to the trend over the past 5 years shown in Figure 16.3 above, where girls presenting with ERF outnumber boys at this age. This difference was not statistically significant.

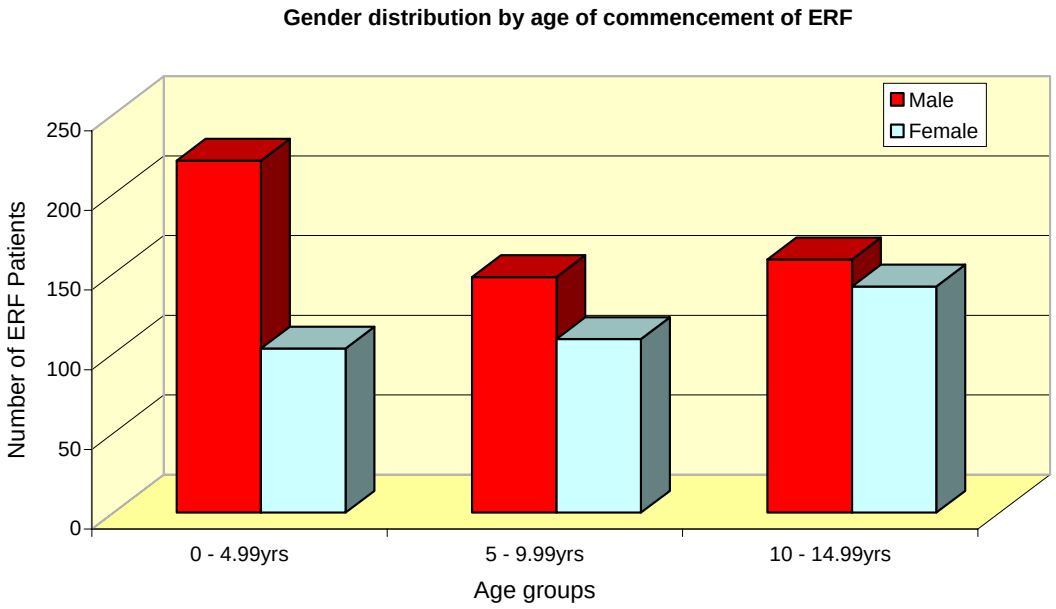


Figure 16.6: Gender distribution of patients, by age at start of RRT

Table 16.10 shows the diagnostic groupings used for the ERF population and the percentage of patients belonging to each group for the current cohort of patients and the cohorts of patients presenting at different ages. The data from the three age cohorts are shown graphically in Figure 16.7. It is clear that there are some diagnostic groups, such as the congenital nephrotic syndromes, in which the vast majority of patients enter ERF early in life, some entering in the middle years of childhood, and in which the commencement of ERF after the age of 10 years is rare. Polycystic kidney diseases and malignant and related disorders follow a similar pattern. Other diseases, for example glomerular diseases, tubular and interstitial disorders and metabolic diseases, become increasingly common with age.

Diagnostic group	Percentage of children on RRT			
	Current patient cohort	ERF start <5 years	ERF start 5–10 years	ERF start 10–15 years
Primary renal dysplasia	27.52	31.79	28.40	17.61
Obstructive uropathy	19.13	22.22	17.12	16.28
Glomerular disease	18.35	8.64	21.40	26.91
Reflux nephropathy and CRF of uncertain aetiology	6.95	3.09	6.23	17.61
Primary tubular and interstitial disorders	7.08	3.70	7.78	10.30
Congenital nephrotic syndrome	7.47	15.74	3.89	0.33
Renal vascular disorders	4.06	5.56	4.28	1.99
Metabolic diseases and drug nephrotoxicity	4.72	0.93	9.34	6.98
Polycystic kidney disease	2.62	5.25	1.17	1.00
Malignant and related diseases	1.57	3.09	0.39	1.00

Table 16.10: Percentage of patients, by diagnostic group and age at start of RRT
CRF, chronic renal failure.

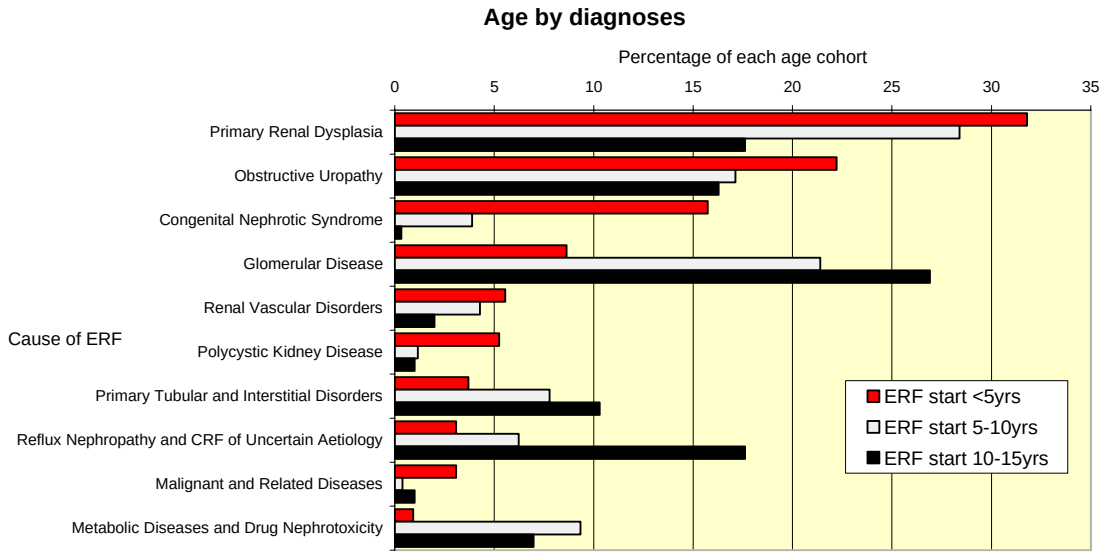


Figure 16.7: Percentage of patients in each diagnostic group, by age at start of RRT

The importance of primary focal segmental glomerulosclerosis (FSGS) as a cause of ERF in childhood is shown in Figure 16.8. Here, the number of children in each age group on RRT secondary to a glomerulopathy is shown, together with the number of these that are secondary to primary FSGS. Primary FSGS accounts for almost 50% of ERF from glomerular disease in the first decade of life. Other major contributions to this disease category are Henoch Schoenlein nephritis and ERF secondary to haemolytic uraemic syndrome. All other forms of glomerulonephritis and systemic vasculitis causing ERF are rare in childhood.

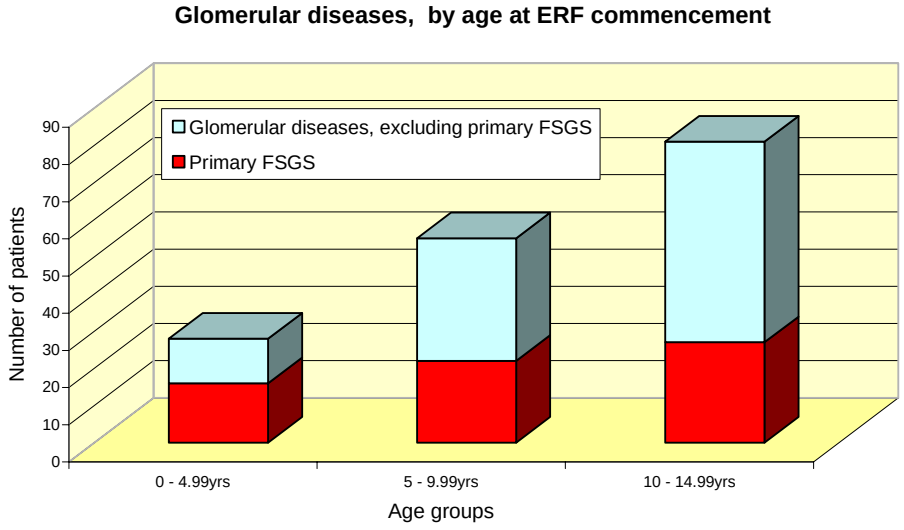


Figure 16.8: Glomerular diseases causing ERF in childhood, by age at start of RRT

Obstructive uropathy is one of those conditions that is very common in those presenting with ERF at a young age and reduces in frequency as a cause of ERF with increasing age. The reduction is, however, not as dramatic as with other conditions, even though the vast majority of patients have congenital lesions. Figure 16.9 shows this graphically. Posterior urethral

valves account for almost all ERF resulting from obstructive uropathy in the first 5 years of life and for 59% of ERF arising from obstructive uropathy in patients presenting between the ages of 10 and 15 years. Other congenital abnormalities causing obstruction account for 12.7% of patients on RRT from obstructive uropathy. The only significant acquired form of obstructive uropathy in childhood is neuropathic bladder, which accounts for 9.7% of these patients. These data emphasise the need for a close follow-up of all patients with congenital obstructive uropathies and also the requirement for the early diagnosis and active management of neuropathic bladder in childhood.

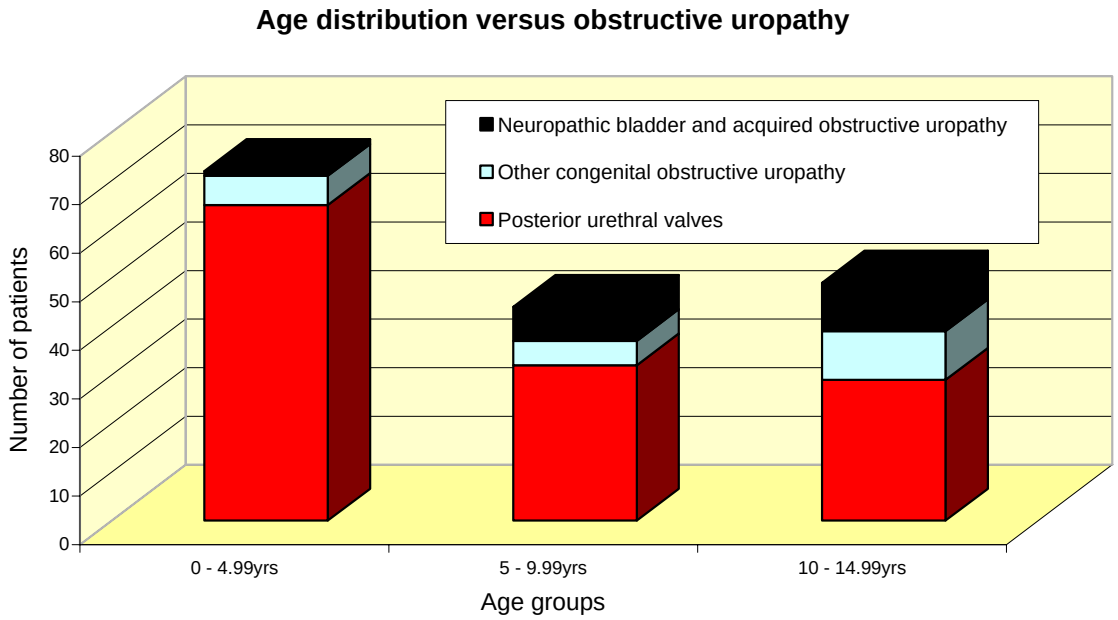


Figure 16.9: Age distribution and type of obstructive uropathy in children on RRT

Renal dysplasia, the predominant cause of ERF in the childhood population, shows a similar and more dramatic fall in incidence with age. There are several syndromal conditions associated with renal dysplasia (such as prune belly syndrome and branchio-oto-renal syndrome), but, as can be seen from Figure 16.10, the majority of cases have primary dysplasia or hypoplasia. From Figure 16.7 above, it can be seen that reflux nephropathy and chronic renal failure of uncertain aetiology follow the opposite distribution, steadily rising in frequency with age. Figure 16.11 shows that this is accounted for by an increasing incidence of reflux nephropathy, with only a small cohort throughout having chronic renal failure of uncertain aetiology. This is important as one of the achievements of paediatric nephrology has been the apparent reduction of ERF caused by reflux nephropathy. In those presenting with ERF between 10 and 15 years of age, however, reflux nephropathy still accounts for 14.6% of all renal failure. What is intriguing is the relationship between renal dysplasia (in which vesico-ureteric reflux is often an associated feature) and reflux nephropathy. Paediatric nephrologists are well accustomed to patients with vesico-ureteric reflux who develop numerous urinary infections but do not progress to a decline in renal functional. Similarly, patients presenting in ERF with what is felt to be reflux nephropathy often have no preceding history of urinary sepsis.

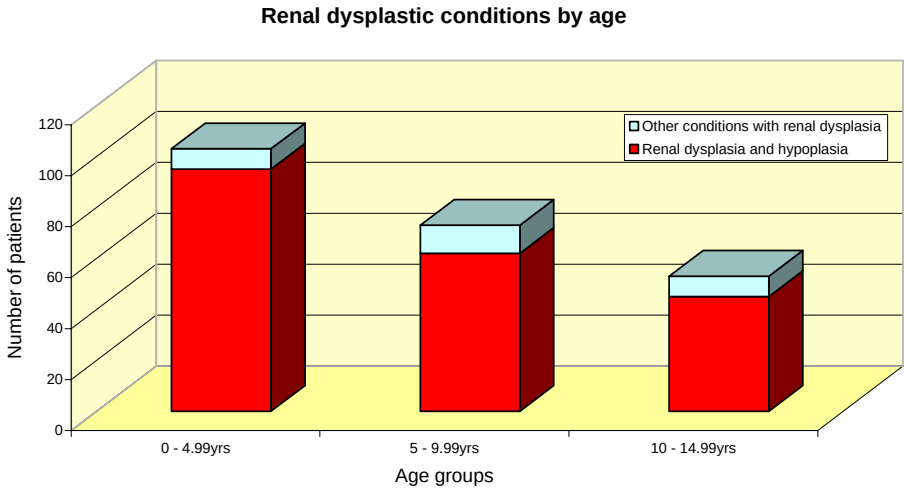


Figure 16.10: Patients with renal dysplastic conditions causing ERF, by age at start of RRT

Figure 16.12 shows the percentage of patients with ERF from renal dysplasia and that of patients with reflux nephropathy summated. It is clear that the overall incidence of either reflux nephropathy or renal dysplasia as a cause of ERF is virtually constant throughout childhood. There is, however, a shift from the use of renal dysplasia as a diagnostic category to reflux nephropathy with age. This raises the possibility that this is a single condition (renal dysplasia with or without vesico-ureteric reflux) with a varied time progression to renal failure. History has dictated that patients presenting in late childhood with ERF, small shrunken kidneys and vesico-ureteric reflux are labelled as having reflux nephropathy. Treating all these patients as children with renal dysplasia and the eventual exhaustion of a reduced and abnormal nephron mass would explain the ongoing presentation of reflux nephropathy at a time at which the awareness of urinary infection is increased. It also explains the absence of a history of urinary infection in patients presenting in ERF.

One unexplained feature of the 1999 report analysis was the excess of boys with renal dysplasia, which had not been seen before or reported in Registry reports from other countries. The ratio of boys to girls with renal dysplasia as a cause of ERF remains high, at 1.9:1 (2:1 in the 1999 report). When these are combined with patients with reflux nephropathy, the ratio falls to 1.4:1. For both renal dysplasia and reflux nephropathy, girls present at a later age than boys (Figure 16.13).

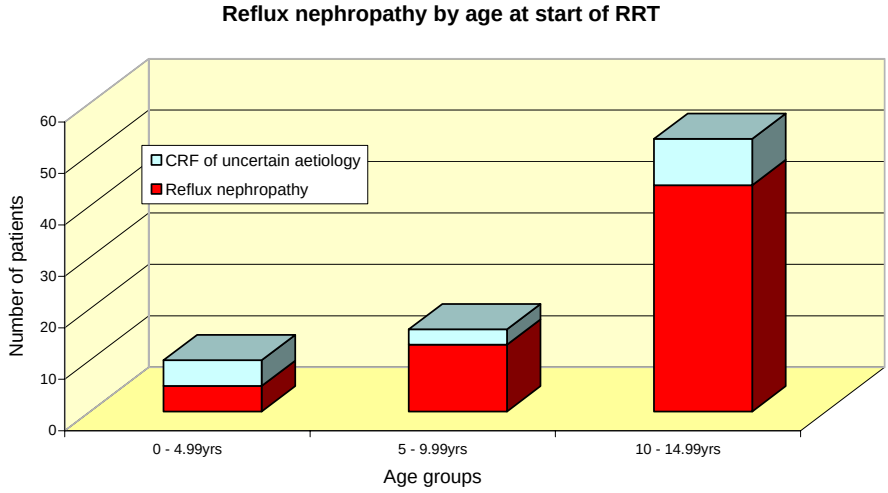


Figure 16.11: Patients with reflux nephropathy causing ERF, by age at start of RRT

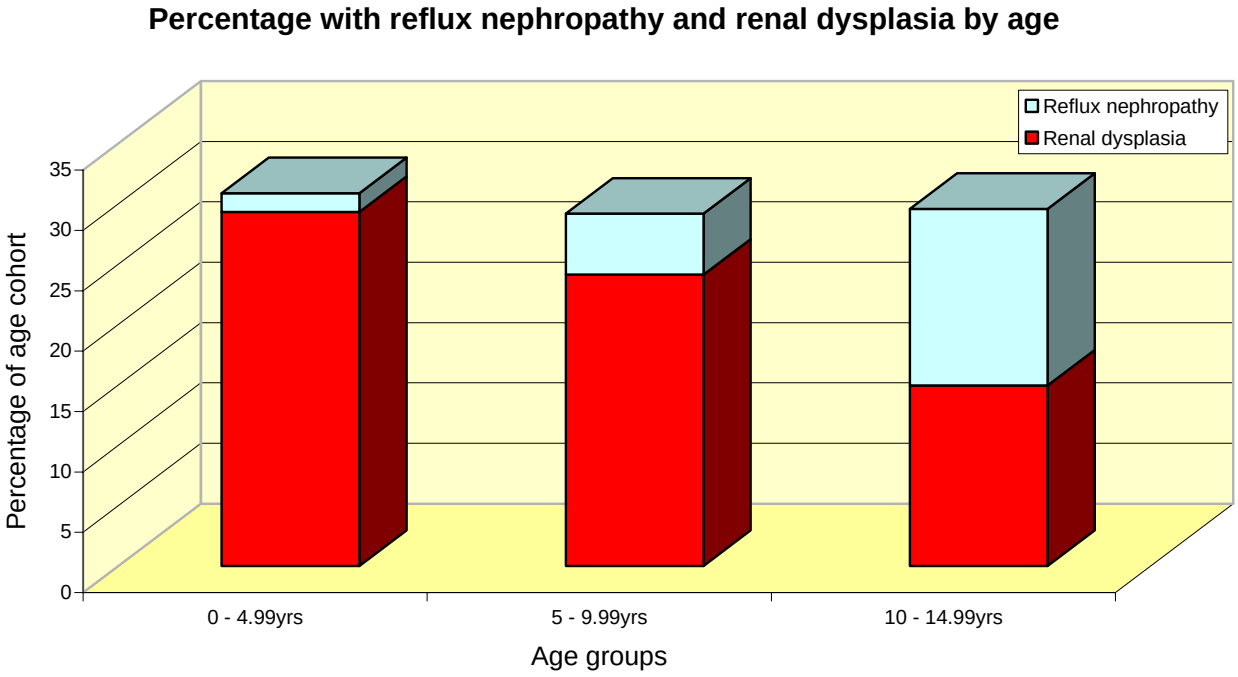


Figure 16.12: % of patients with renal dysplasia and reflux nephropathy causing ERF, by age group

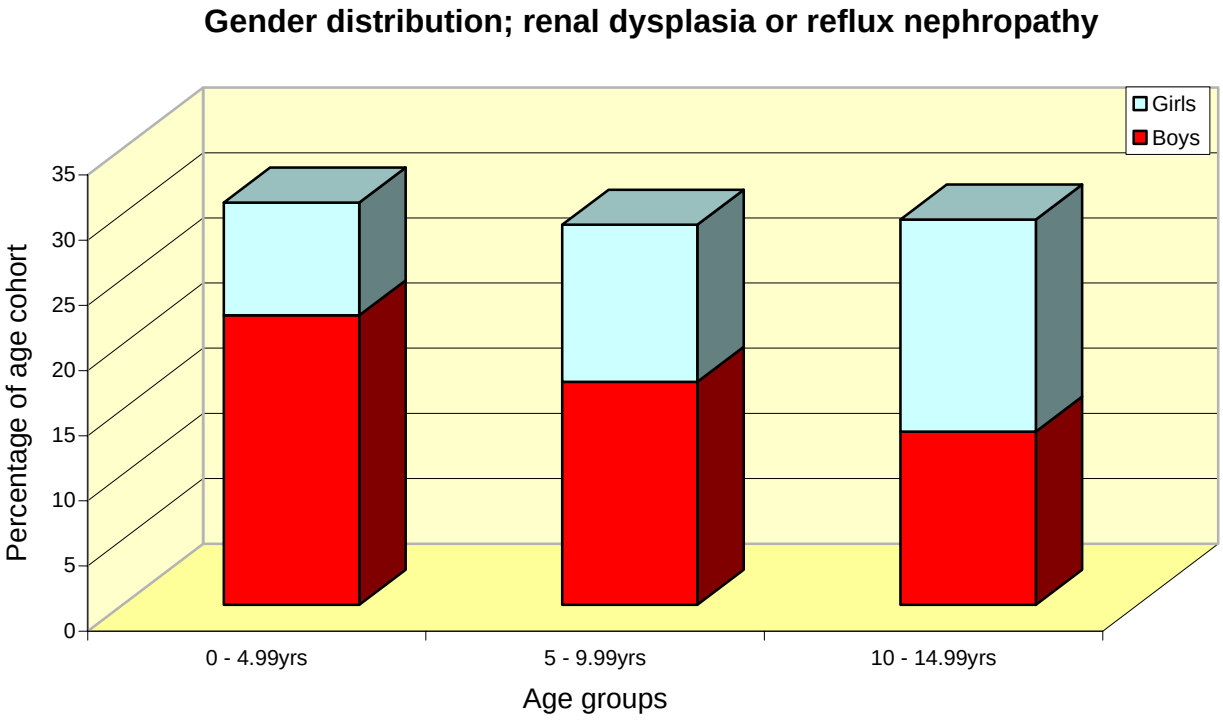


Figure 16.13: Gender distribution of children with renal dysplasia or reflux nephropathy, by age at start of RRT

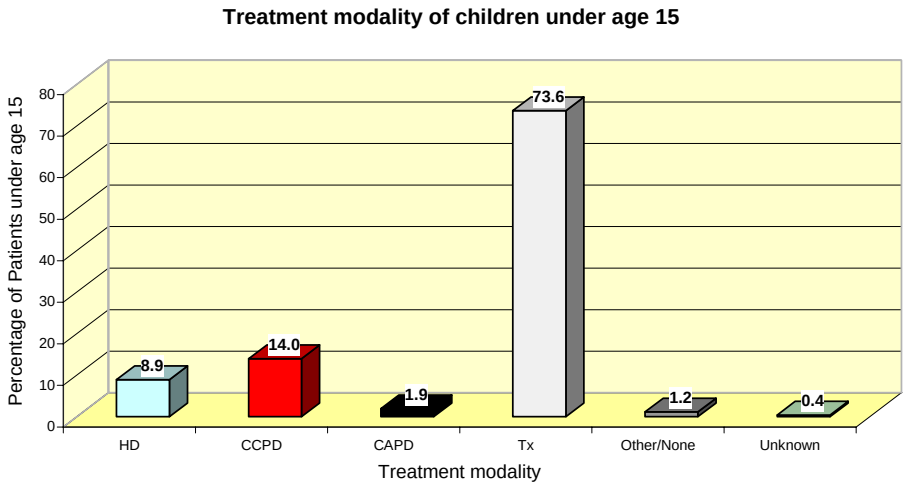


Figure 16.14: ERF management of children under 15 years of age in the UK

Current management of ERF in childhood

As shown in the 2000 annual report of the UK Renal Registry, the majority of children on RRT in the UK have functioning renal allografts. Data from April 2001 are shown in Figure 16.14; it is clear that this is still the case, 73.6% of patients cared for in the 13 regional paediatric units having a functioning renal allograft in April 2001. For those on dialysis, cycling peritoneal dialysis was the most popular form. Peritoneal dialysis was being used in 64% of patients and haemodialysis in 36%. Of those who were on peritoneal dialysis, 88% were having overnight cycling dialysis, with or without a daytime dwell, and just 12% were being treated with continuous ambulatory peritoneal dialysis (CAPD).

Although there has been a small fall in the proportion of patients with a functioning allograft, from 76% in 2000 to 73.6% currently, there has also been a reduction in the rate of transplantation. These percentages are protected by the buffer effect of having many young children, transplanted early, who remain with functioning allografts throughout their stay with the paediatric unit. Figure 16.15 shows the number of transplants performed in children under the age of 15 years in the 11 UK centres for paediatric renal transplantation over the past 6 years. It can be seen that there has been a trend towards a reduced number of cadaveric allografts over the past 5 years. The effect on the total number of transplants has been reduced by the increasing number of living related donations.

With the high flux of paediatric patients, because of their presentation at varying times in childhood and then their movement a few years later into an adult unit, this reduction in the rate of transplantation has an effect on the workload of the paediatric renal units. Looking at the population of children with renal transplants in 2000, 22% received a pre-emptive allograft, avoiding a preceding period of dialysis. Figure 16.16 shows the proportion of new patients presenting in each of the 5 years from 1996 to 2001 who received a pre-emptive transplant. It can be seen that the recent trend is towards a decreasing number of pre-emptive cadaveric allografts, and, as there is no trend towards increasing pre-emptive living related donations, there is an overall reduction in the total number of pre-emptive transplants.

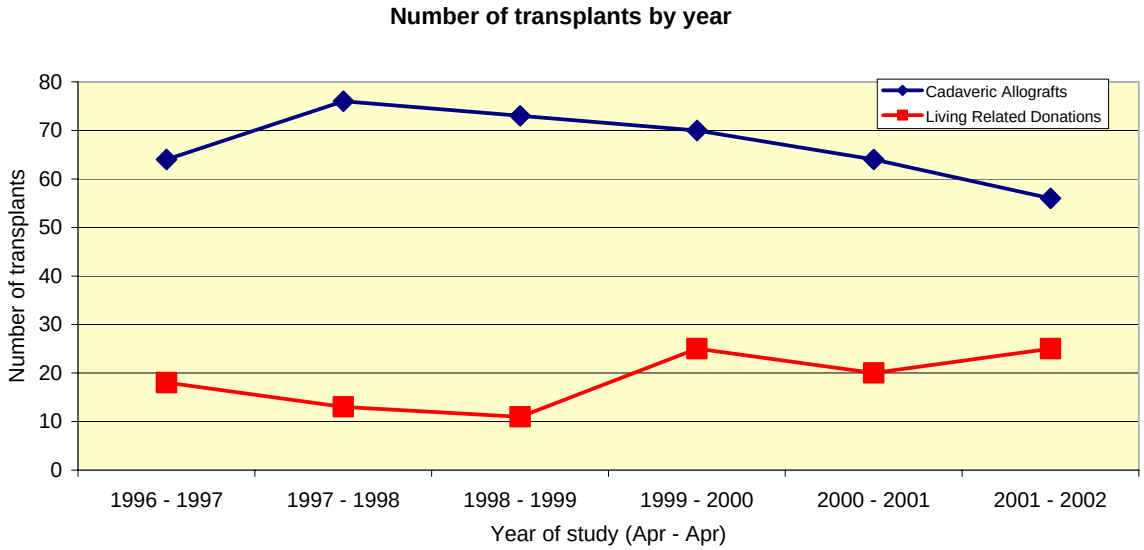


Figure 16.15: Transplant activity in patients aged <15 years over the past 6 years

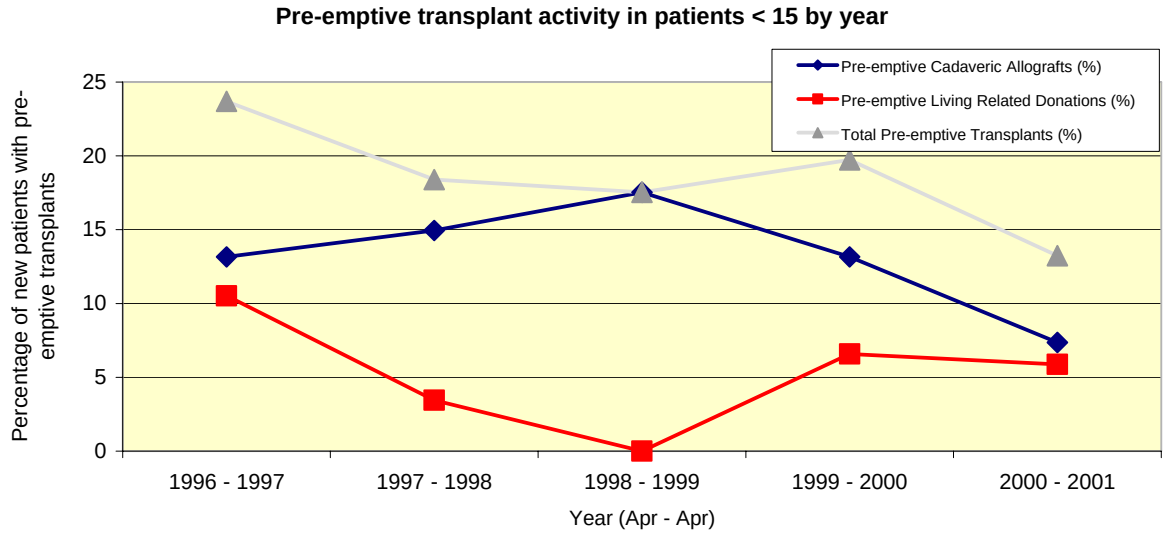


Figure 16.16: Pre-emptive transplants in children under the age of 15 years

As there has been no significant change in the number of patients presenting to paediatric renal units with ERF over the past 5 years, the result of the above is an increase in the dialysis workload for the individual units. Figure 16.17a shows the number of under-15-year-old patients on RRT in the 13 paediatric units in the UK, divided according to whether they have a functioning allograft or are on dialysis. Figure 16.17b shows these same data but divides the patients according to the proportion on each treatment modality rather than the absolute number. It can be seen that there is a large variability between units in their dialysis workload, ranging from just 7% of patients being on dialysis to 43% being on dialysis. Table 16.11 shows these data by individual renal units in greater detail. In addition to the variable proportion of patients with a transplant, it is clear that there is great variability in the

proportion receiving haemodialysis. All this has major implications for the provision of resources. Staffing levles in units with a high proportion of dialysis patients, particularly those with many haemodialysis patients, will need to increase. Paediatric haemodialysis patients often require one-to-one nursing during dialysis sessions, and a further analysis of the current trends over the next few years will be important for both manpower planning and the provision of appropriate training.

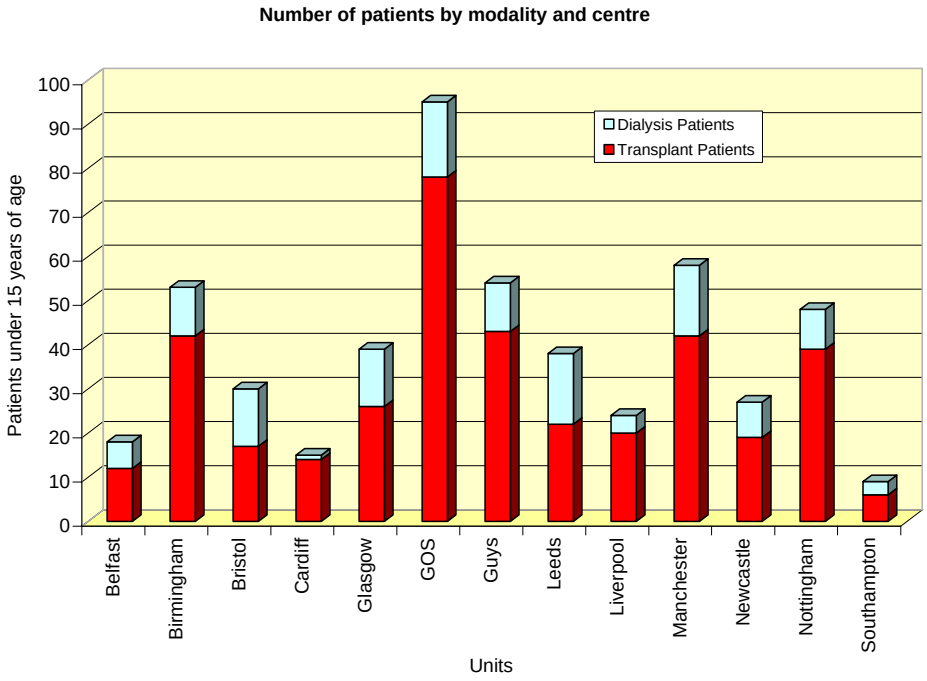


Figure 16.17a: Patients aged <15 years on dialysis or with a functioning allograft, by centre

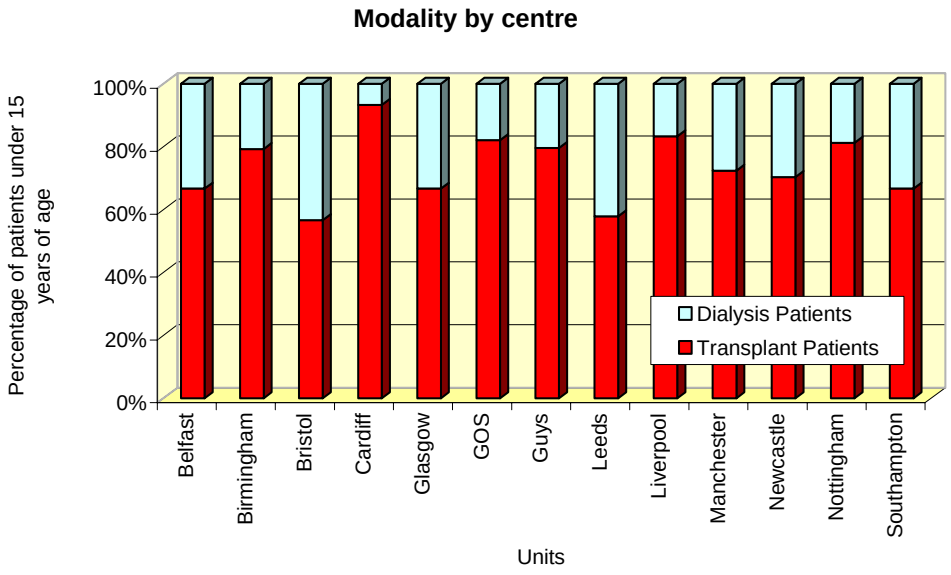


Figure 16.17b: Proportion of patients under 15 years of age, by modality and centre

	Treatment modality						
Centre	**HD**	**CCPD**	**CAPD**	**Tx**	**Other/none**	**Unknown**	**Total**
Belfast	2	4	0	12	0	0	18
Birmingham	5	5	1	42	0	0	53
Bristol	5	8	0	17	1	0	31
Cardiff	0	1	0	14	0	0	15
Glasgow	2	11	0	26	0	1	40
GOS	9	6	2	78	0	0	95
Guys	5	6	0	43	0	1	55
Leeds	6	9	1	22	0	0	38
Liverpool	2	2	0	20	0	0	24
Manchester	3	7	6	42	1	0	59
Newcastle	5	3	0	19	3	0	30
Nottingham	2	7	0	39	1	0	49
Southampton	0	3	0	6	0	0	9
Total	46	72	10	380	6	2	516

Table 16.11: Modality of patients under the age of 15 years, by centre, on 1 April 2001
HD, haemodialysis; CCPD, continuous cycling peritoneal dialysis.

Conclusion

Although there has been a gradual increase in the total number of patients being cared for in paediatric renal units in the UK, the overall incidence of ERF in children appears to be fairly stable. The local incidence and prevalence of ERF are affected by the ethnic mix of the population served, and the high rate of ERF in children with ethnic origins in the Asian subcontinent may have implications for the provision of services locally and the resources that need to be made available. ERF presents at all ages in childhood, with a slowly increasing incidence with age. Males significantly outnumber females in early childhood, but by the teenage years more females are presenting than males.

The causes of childhood ERF vary with age. Renal dysplasia and obstructive uropathy are the predominant causes in the first 5 years of life. For those presenting between 5 and 10 years of age, renal dysplasia is still the most common cause, but glomerular diseases are the second leading cause. For those presenting after the age of 10 years, glomerular diseases become the most common cause, relegating renal dysplasia to second place. Within this latter age group, reflux nephropathy remains a significant cause of renal failure, accounting for 15% of all cases. The combination of renal dysplasia and reflux nephropathy accounts for just under 30% of all cases of childhood ERF across the age ranges, raising the possibility that these are different ends of the same spectrum of disease. Indeed, it may well be better to relabel the two diagnostic entities together as ‘congenital renal malformation with or without vesico-ureteric reflux but without obstruction’.

Transplantation remains the overwhelming treatment of choice for children on RRT, and 73% of children have functioning allografts. The rate of cadaveric transplantation appears to be decreasing, however, offset slightly by an increasing rate of living related donations. Fewer pre-emptive transplants are now being performed, which is leading to an increasing workload for paediatric dialysis units. If this trend continues, there will be significant resource implications. For those on dialysis, 64% are on peritoneal dialysis and 36% haemodialysis. Cycling peritoneal dialysis is the modality of choice, with only a small number of patients on CAPD.

Acknowledgements

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The report was reviewed by the Paediatric Renal Registry Subcommittee, comprising: Dr Jane Tizard, Dr Chris Reid, Dr William van't Hoff, Prof Adrian Woolf, Dr Rodney Gilbert and Dr Malcolm Lewis.

Acknowledgements is due to Mrs R Johnson at UK Transplant for the transplantation statistics, and Roche pharmaceuticals for a financial grant.

Chapter 17: Survival of Incident Patients

Summary

- The 1 year survival of incident renal replacement therapy patients ranges from 95% in young adults to 75% in those aged 65–74, and 50% in those over 85.

- Data from the past 5 years show a small but steady improvement in 1 year survival in all age groups.

- There is evidence that, as in the USA, patients from ethnic minorities may have a better survival than White patients.

- An analysis of variability in survival using Z-scores shows that there is no significant difference in survival between centres, with the exception that one centre has exceptionally good survival in the first year after 90 days.

Introduction

The Renal Registry database enables an analysis of the influence of different factors on patient survival. These factors are related to patient case mix (e.g. age, gender, ethnicity, underlying diagnosis and other comorbidity) or are dependent on treatment quality (e.g. haemoglobin achieved, mode of dialysis and serum phosphate level). For individual renal units, such analysis allows a comparison with performance in previous years and with other centres.

Survival rates can either be looked at in relation to:

- an *incident cohort*, in which patients who started renal replacement therapy (RRT) in a particular year are included;

or

- a *prevalent cohort*, in which all (or a defined group of) patients undergoing RRT at a particular time are included.

The analyses presented in this chapter examine the survival while on RRT, including transplantation, of incident patients. Patients are censored when moving to a centre that does not report to the Registry.

Death rates in different centres contributing to the UK Renal Registry are reported here. These are very crude data. An adjustment can be made between centres on the basis of age, but there is need for more detailed information relating to comorbidity and ethnic origin. With this lack of information on case mix, no significance can currently be attributed to any apparent difference in survival between centres.

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:

$$\frac{\text{Number of deaths on dialysis}}{\text{Number of patient years at risk}}$$

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. For diabetics compared with non-diabetics, for example, the hazard ratio is the ratio of the estimated hazards for diabetics relative to non-diabetics, 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. The proportional hazards model was tested for validity in all cases.

Validity of the centre adjustment for proportional hazards

When the Cox model is used to adjust centre survival to a specific age (e.g. 60 years), it relies on, in addition to the assumption of proportionality within the period studied, the proportionality between centres of the slope of this relationship. If one centre had a relationship of survival with age with a slope of the graph that was different from those of the other centres, the adjustment would not be valid. Testing showed the slopes to be similar for all centres.

Survival of new patients by age

The incident cohort included in this analysis is all those patients starting RRT in 2000. Patients who recovered function within 90 days (i.e. patients with acute rather than chronic renal failure) have been excluded.

In Figure 17.1, the unadjusted survival has been shown for the first 90 days, the first year from day 0 of RRT, and the first year after day 90. The last figure allows comparison with many other Registries, including the US Registry, which record data only from day 90 onwards.

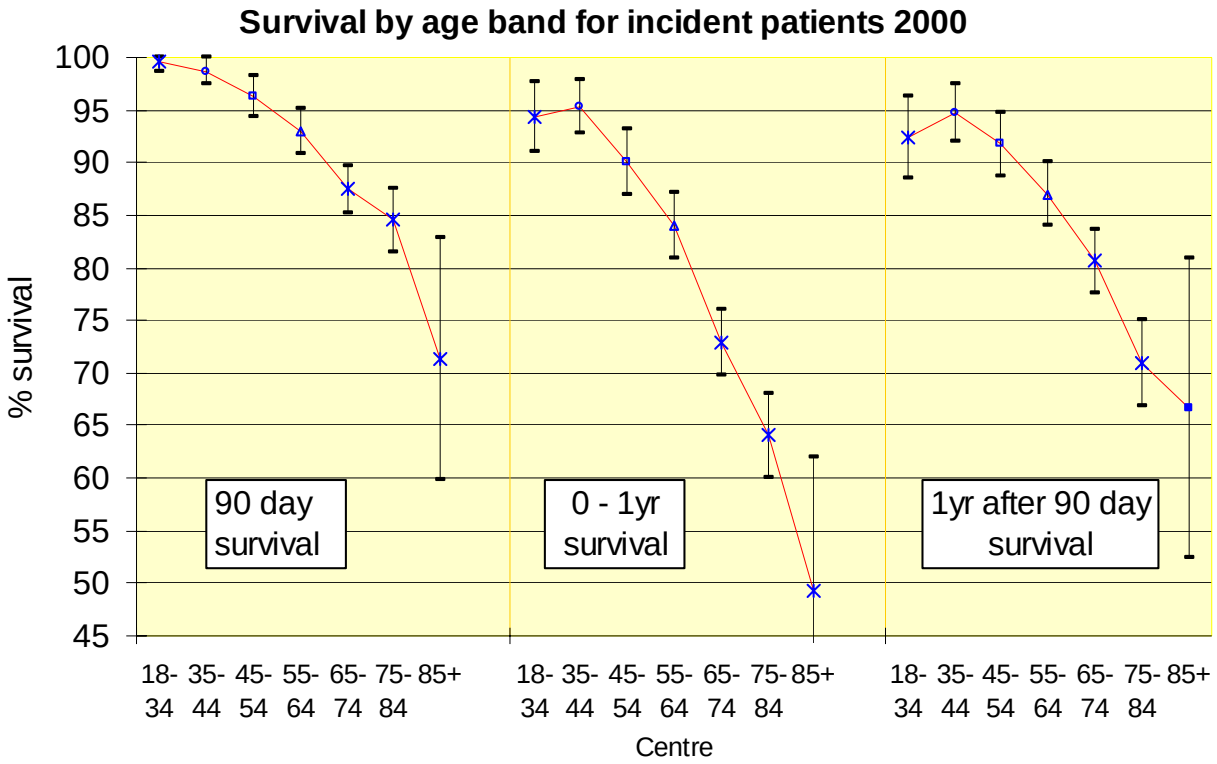


Figure 17.1: Unadjusted survival of incident patients, by age band

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 17.1.

Interval	Proportional hazards	95% CI
First 90 days	1.058	1.050–1.065
1 year after first 90 days	1.041	1.035–1.047

Table 17.1: Survival at 90 days and 1 year

These data show that there is, in the first 90 days, a greater risk of death for every 1 year increase in patient age than there is in the subsequent period. This confirms, as stated in the Registry's previous reports, that it is incorrect to apply a single proportional hazards model for the first 365 days of starting RRT.

For every 10 year increase in patient age, there was 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.

Changes in incident patient survival, 1997–2000

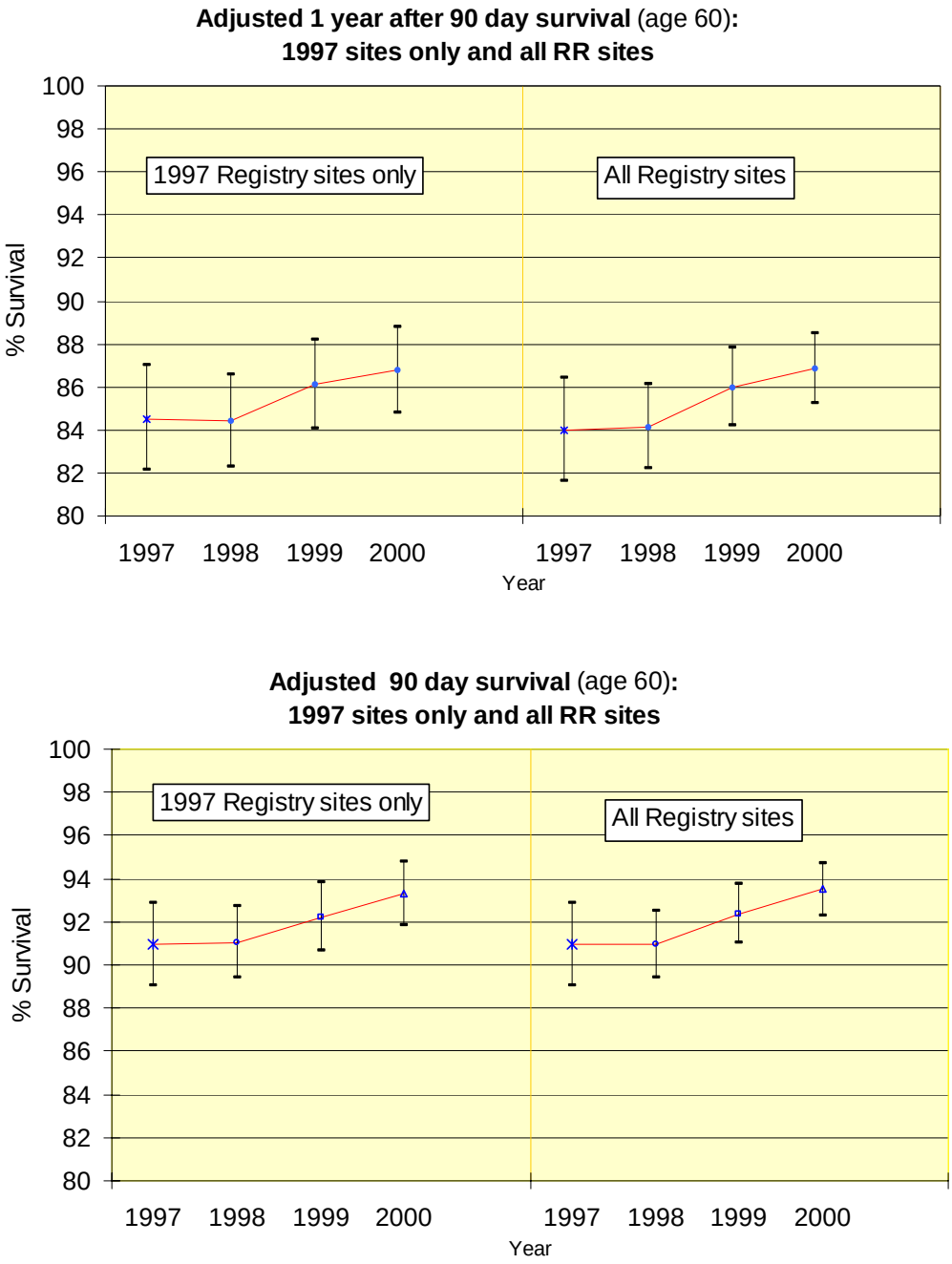


Figure 17.2: Change in survival, 1997–2000

In Figure 17.2, the right-hand graphs show the 90 day survival for all incident patients on the Registry in the years 1997–2000. There is an apparent improvement in 90 day survival, but this could be an artefact as many more centres have joined the Registry since 1997, and these centres may have had a better survival. The left-hand graphs show the same analysis just for those centres which joined in 1997. This shows the same overall improvement in survival, from 90.95 to 93.31%, which is a 26% reduction in 90 day mortality. This linear trend was significant (p<0.01). These data also demonstrate that the survival profile of the 1997 centres is similar to that of the newer centres.

The adjustment for age using the Cox proportional hazards method has been calculated for each of the above years in the two groups. There has been no change over these 4 years in the increase in hazard of death for each 1 year increase in age. This indicates that the improvement in survival occurs across all age bands.

Survival by ethnicity

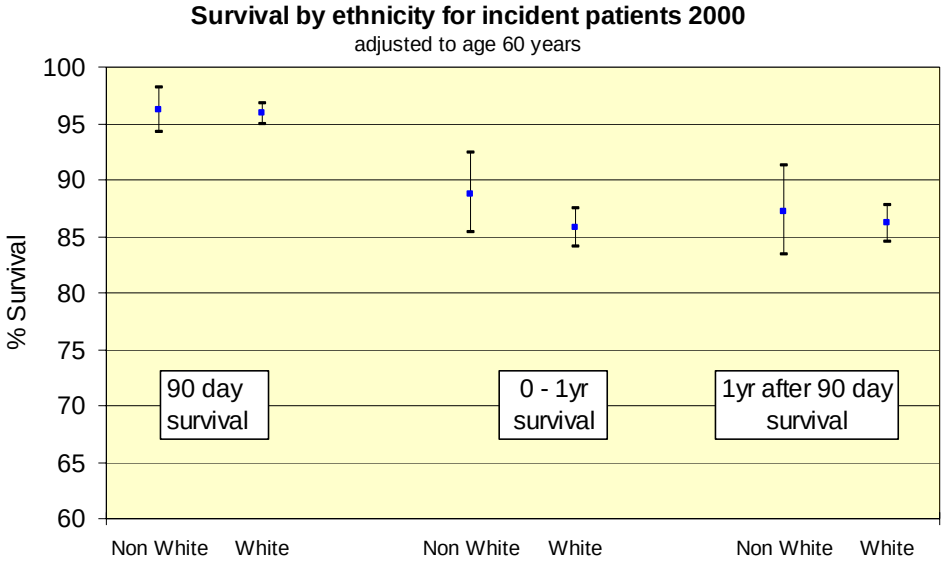


Figure 17.3: Survival by ethnicity

The overall completeness of ethnicity data is still poor, and data are available only from England. In 2002, ethnicity was recorded in 56% of incident patients. It appears that many of the centres with a high percentage of ethnic minority patients are more conscientious at collecting these data.

The number of ethnic minority patients is small, and the confidence intervals on survival estimates are therefore wide. As the median age of this cohort is less than that of White patients, the data have been age-adjusted to age 60. There is an apparent trend towards improved survival in the ethnic minority patients starting RRT when compared with those who are White (Figure 17.3). As a larger proportion of the ethnic minority patients are diabetic, who would be expected to have a worse survival, this difference in survival is probably even greater.

Survival of incident patients in 2000 by centre

Figures for survival within the first 90 days are heavily dependent on making sure that renal units include all their early chronic renal failure deaths and exclude all acute renal failure patients who have died. The 1 year survival will also be influenced by the deaths within the first 90 days, so the more important in Figures 17.4 and 17.5 with the 95% confidence intervals.

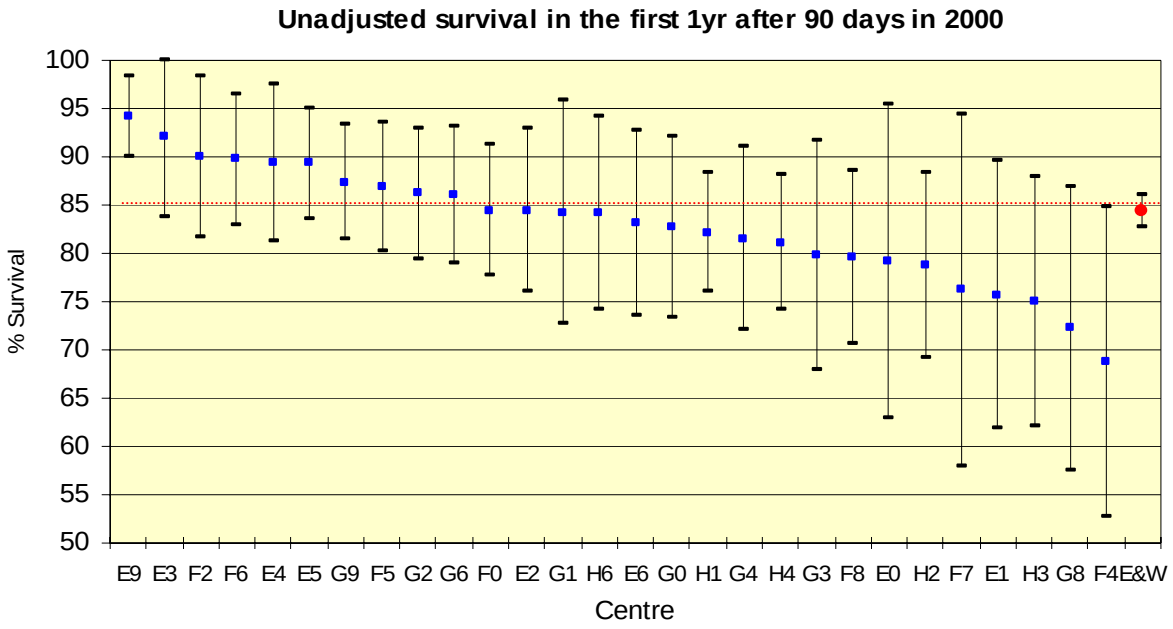


Figure 17.4: Unadjusted survival 1 year after 90 days in 2000

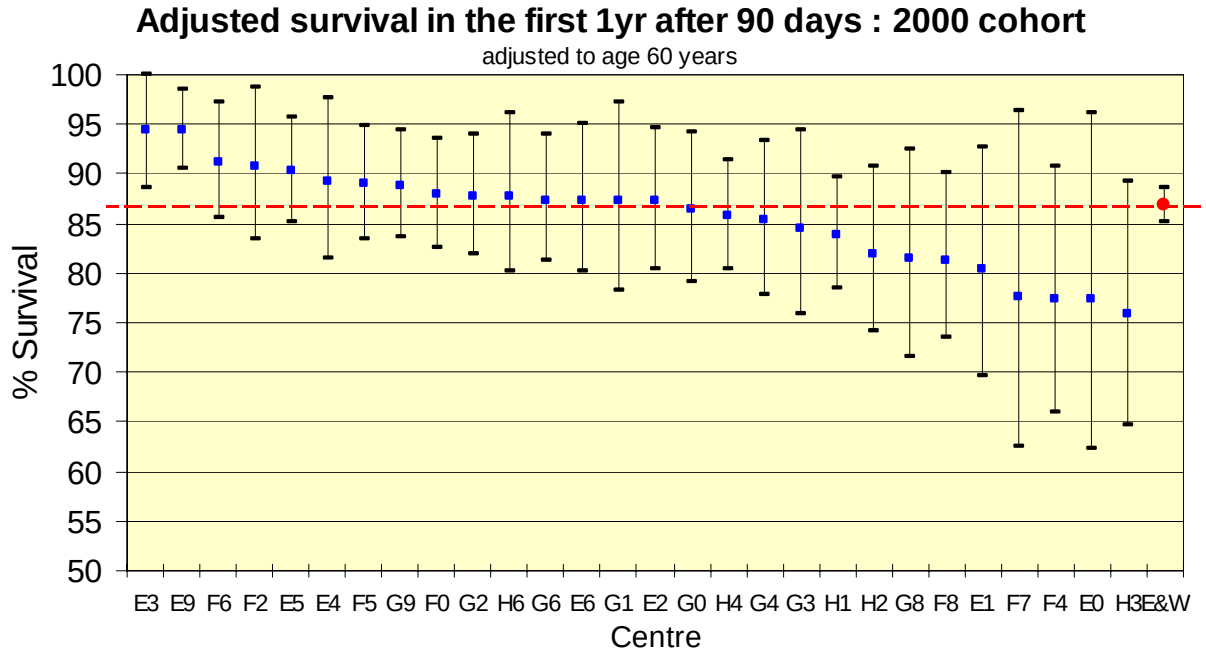


Figure 17.5: Adjusted survival 1 year after 90 days in 2000

Some of the smaller centres have wide confidence intervals. An analysis for any significant differences between centres is described below.

Analysis of variability in survival in 1 year after 90 days

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 thus investigated other accepted statistical techniques to identify any outliers.

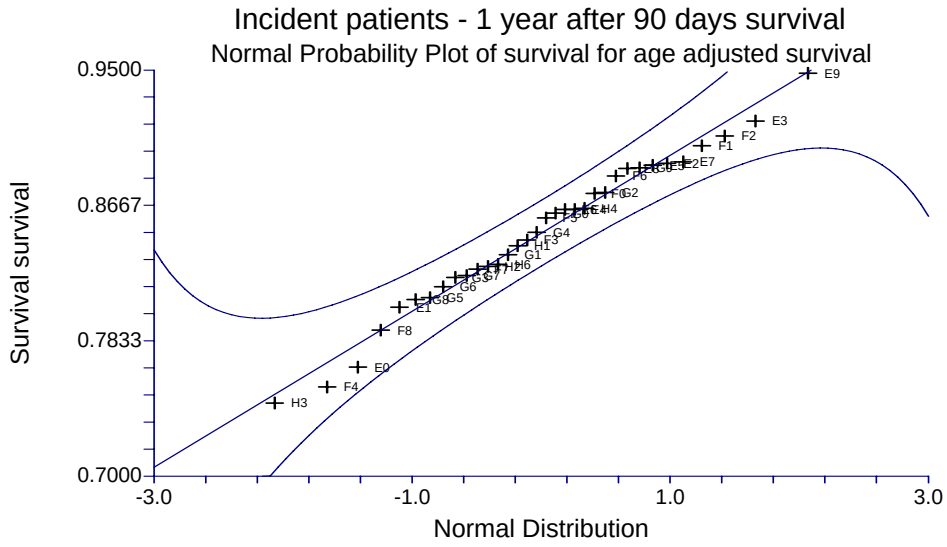


Figure 17.6: One-year after 90 day survival by expected Z-score

A normal probability plot can be drawn to look at the distributions of the adjusted survival scores. This graph would have on the y-axis the observed values and on the x-axis the expected values given that this sample had come from a normal distribution. If it is true that these observations are normally distributed, they should lie on a straight line. Figure 17.6 has been plotted using the adjusted survival data for each centre and shows that the results are relatively close to a normal distribution. The 95% confidence intervals have been plotted for these data. This analysis does not take into account the size of the centre and hence the standard error attached to each centre's survival score. In order to do this, a Z-score must be calculated, which is an adjustment for the size of the centre, and these data should be normally distributed.

Z-scores are derived from:

$$\frac{\text{Survival for centre X} - \text{survival for all centres}}{\text{Standard error for centre X}}$$

Plotting the observed values on the y-axis against the expected value on the x-axis should produce a straight line. In Figure 17.7, centres above the line have a better than expected

survival, whereas those below it have a worse than expected survival. Centres are identified as outliers if they are outside the 95% confidence interval.

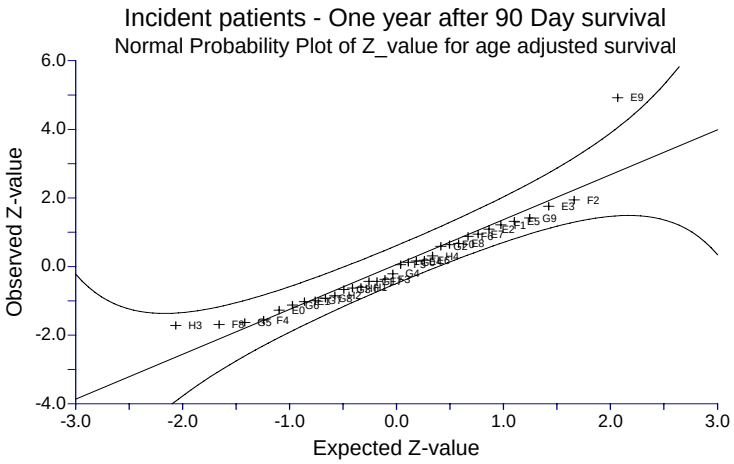


Figure 17.7: Z-score for 1 year after 90 day survival

Centre E9 appears as an outlier with a better than expected adjusted survival at 1 year after 90 days. This analysis indicates that this variation is unlikely to be the result of chance.

The two largest factors influencing patient survival are age and diabetes. Both the median age of new patients and the percentage of diabetic patients for this centre are close to the Registry mean. This centre reprocesses high-flux dialysers for nearly all patients, has a dedicated dialysis adequacy nurse and has a high achievement of dialysis adequacy according to Registry data. Case mix may also be important. In the year 2000, this centre had a lower than expected take-on rate owing to limitations in the facilities available. Thus, some patients with high comorbidity scores may not have started on RRT in 2000.

Analysis of centre survival within the first 90 days

The unadjusted and age-adjusted 90 day survivals of patients incident in 2000 are shown in Figures 17.8 and 17.9.

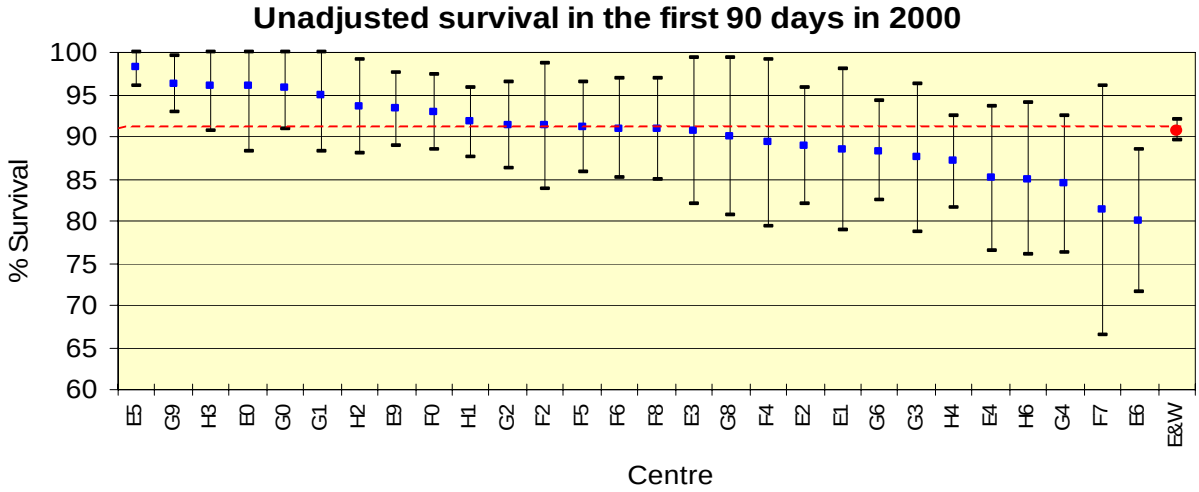


Figure 17.8: Unadjusted survival in the first 90 days, 2000 cohort

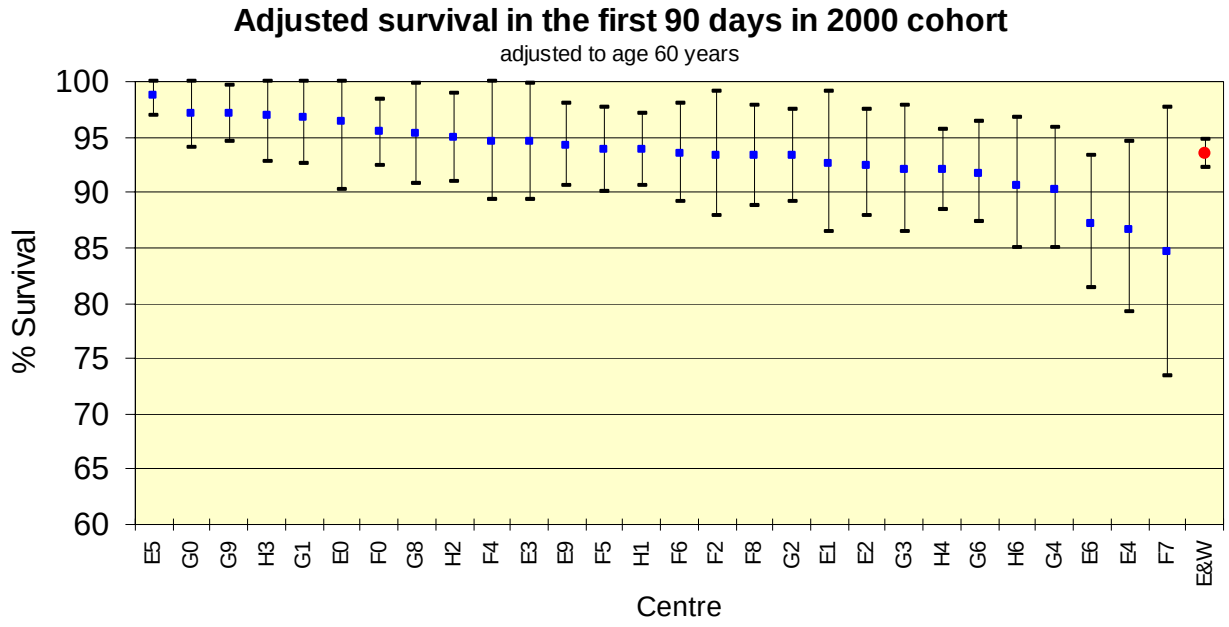


Figure 17.9: Adjusted survival in the first 90 days, 2000 cohort

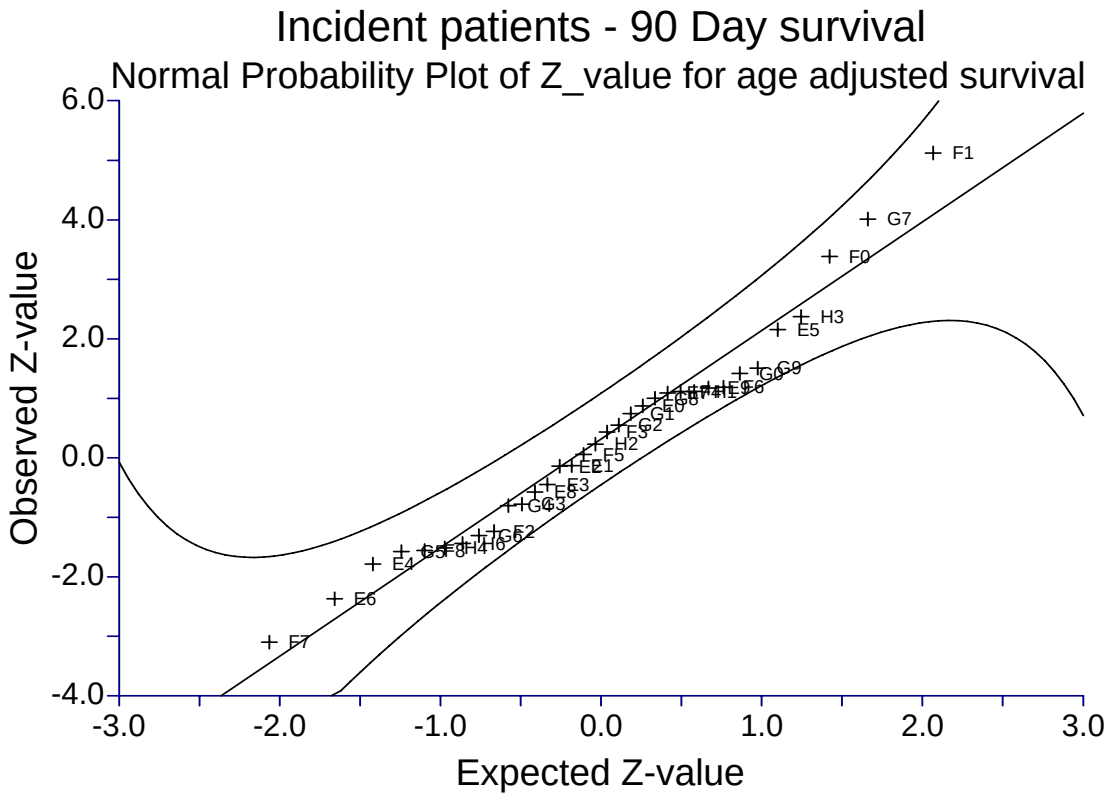


Figure 17.10: Z-score for survival within the first 90 days

The Z-scores indicate that all centres fall within the 95% confidence intervals.

Comparison of the 90 day and 1 year after 90 day survival

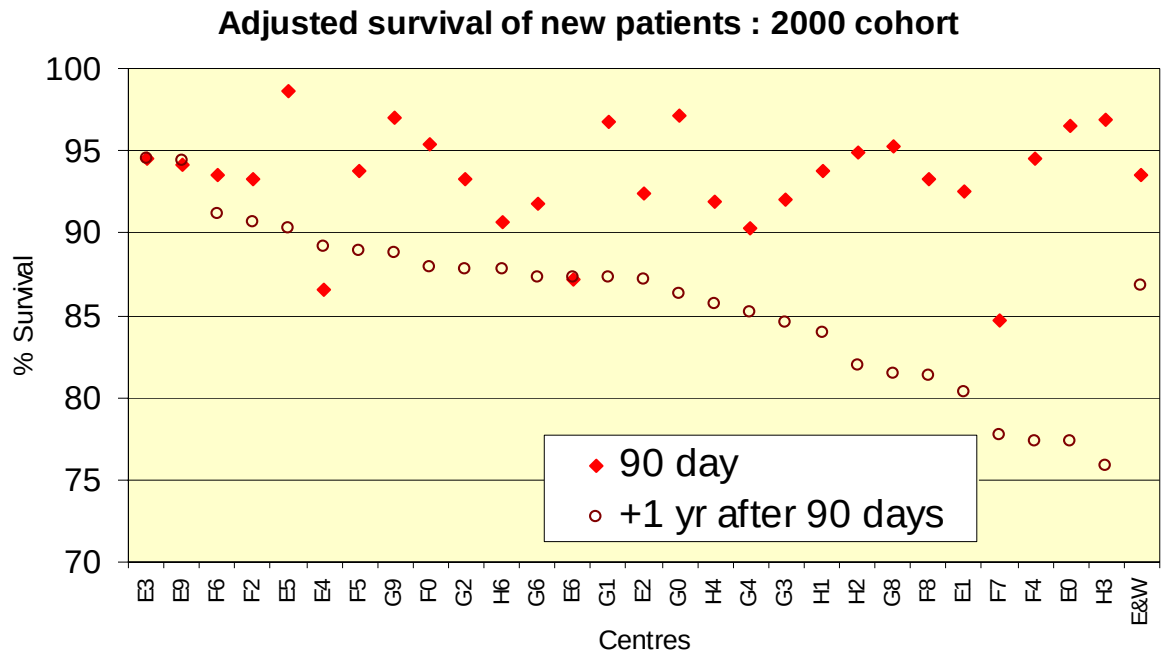


Figure 17.11: Adjusted survival of new patients, 2000 cohort

In Figure 17.11, there is no relationship apparent between the 1 year after 90 day survival and the survival of patients within the first 90 days. This supports the view that problems related to the definition of acute renal failure patients make interpretation of the first 90 days difficult.

Changes in survival

Changes in survival in individual units are shown in Figures 17.12 and 17.13. In the 2001 Registry report, Figure 9.14 of serial 90 day survival data was incorrect, as the data were of the 1 year survival of prevalent patients. The correct data are shown in Figure 17.12, with the current data from 2000 added.

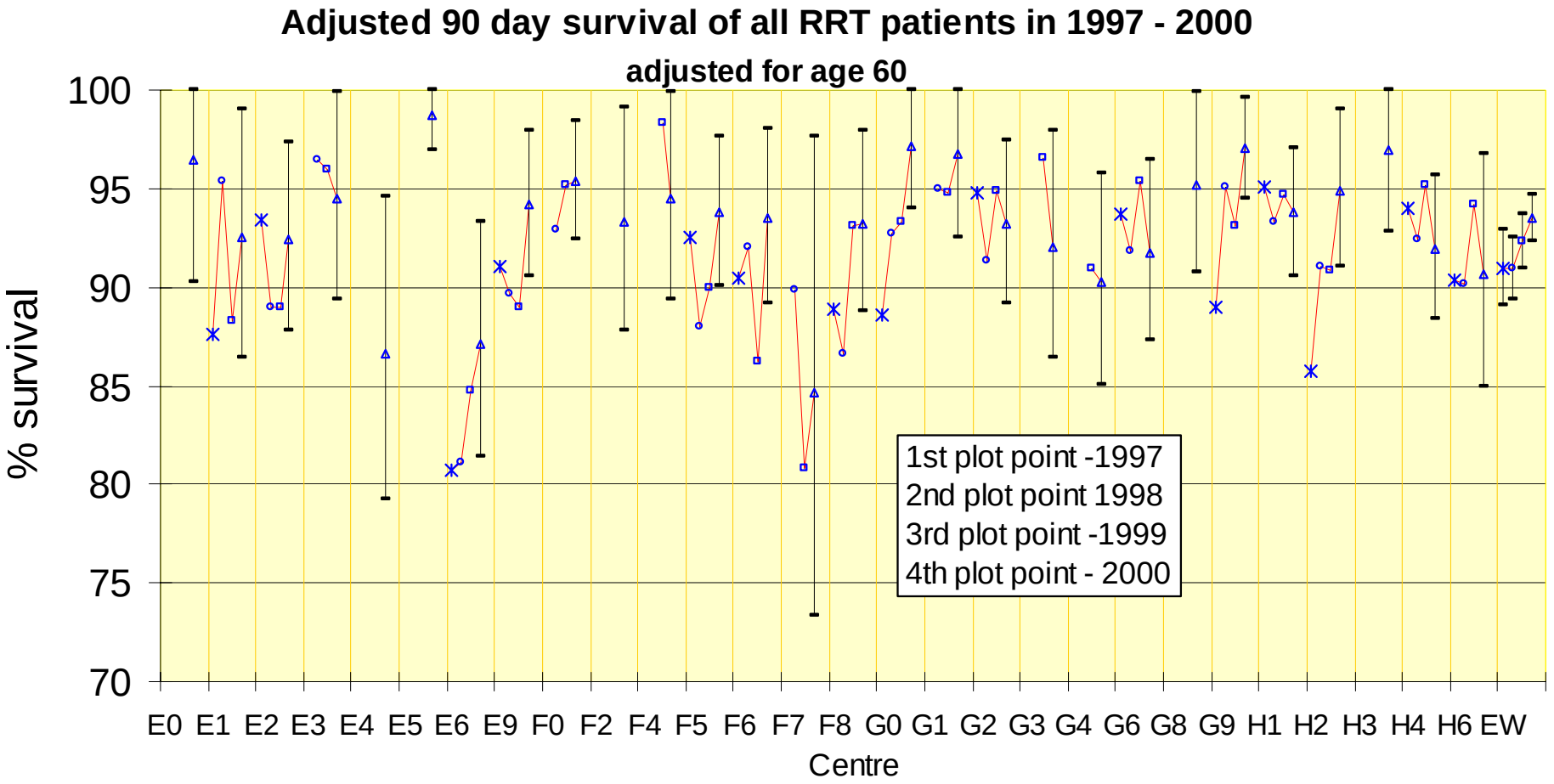


Figure 17.12: Survival in the first 90 days, 1997–2000

Changes in survival from individual units are shown in Figures 17.12 and 17.13.

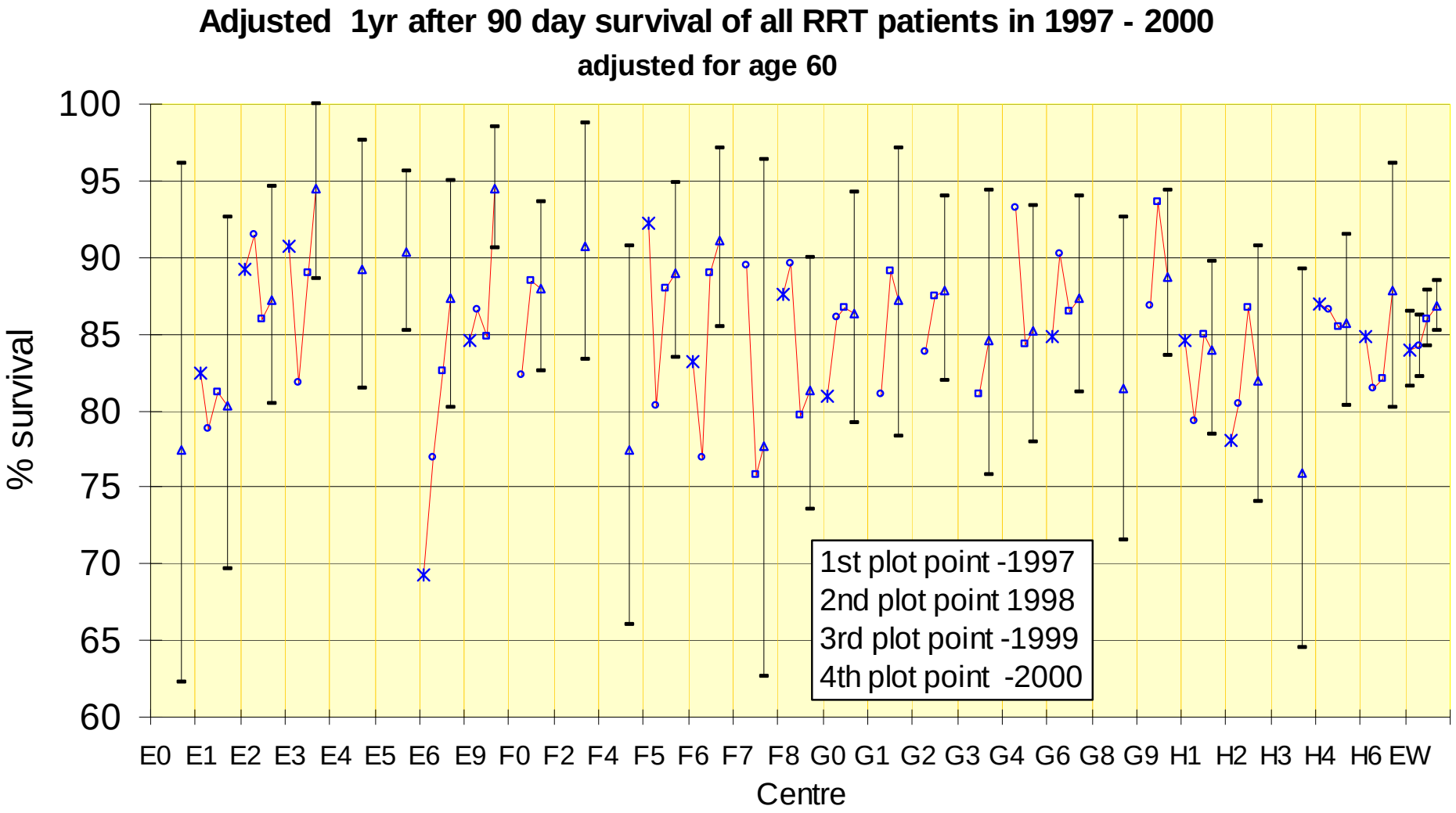


Figure 17.13: Adjusted survival, 1 year after 90 days, 1997–2000

Chapter 18: Co-morbidity in Incident Patients

Summary

- There is a pressing need for the Registry is to improve the returns of comorbidity data for patients starting renal replacement therapy. Previous Registry reports have demonstrated a marked difference in survival between units, after both 90 days and 1 year of treatment. These differences are, however, not consistent and show no obvious correlation with background population mortality. At least part of the variation in survival will be explained by differing comorbidity among incident patients. Only by correcting for such comorbidity can the impact of differences in the process of care be clarified.

- This first analysis has shown the impact of comorbidity upon the survival of UK patients and therefore the importance of adjusting survival analyses for comorbidity. Without good comorbidity data, the value of survival analysis and a comparative audit of groups of apparently similar patients will be greatly reduced.

- Including the 7.3% of patients with diabetes registered as a comorbidity rather than the primary cause of renal failure, diabetic patients account for 24% of the incident patients starting renal replacement therapy.

- An analysis of bias in patient survival and comorbidity reporting indicates that the Registry comorbidity returns currently underestimate the true level of comorbidity in the renal replacement therapy population

- Multivariate analysis shows that the four comorbidity factors with the greatest adverse effect on survival in the first year after 90 days are age, ischaemic ulcers, malignancy and smoking.

Co-morbidity data

The Registry has defined 15 'yes' (present) or 'no' questions relating to comorbidity and asks clinicians to complete this record at the time of starting renal replacement therapy (RRT). As an example, the screen made available to renal units using the CCL Proton system is shown in Figure 18.1. A patient may therefore have a fully completed screen recording no co-morbid conditions to be present. Null entries are considered missing data rather than 'no'.

Beginning in 2003, the presence or absence of heart failure will also be recorded. Definitions for each comorbidity are given at the end of this chapter.

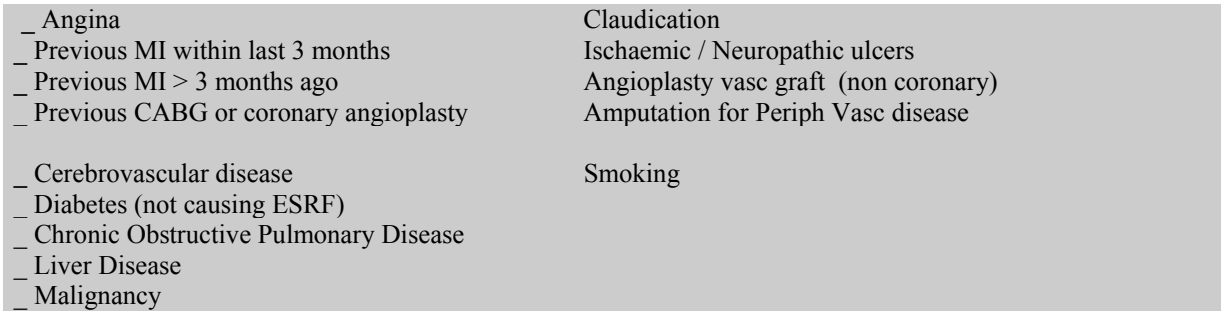


Figure 18.1: Comorbidity entry screen for the CCL Proton system

Co-morbidity returns by renal unit

The return of comorbidity data for incident patients in 2001 remains very incomplete, although it has increased from previous years. Prior to 1999, comorbidity data were rarely returned to the Registry. In 1999, at least one item of comorbidity was reported for 20.8% of those patients registered as starting RRT that year. In 2000, 31.9% of incident patients, and in 2001 33.4% of incident patients, had at least one item of comorbidity data returned. When all incident patients ever notified to the Registry are considered, 18.9% have comorbidity data registered, representing 2854 incident patients. The returns by unit and year of starting RRT are shown in Table 18.1.

Treatment centre	1999		2000		2001	
	No. incident	% Return comorbidity	No. incident	% Return comorbidity	No. incident	% Return comorbidity
Bradford	–	–	39	48.7	61	91.8
Bristol	117	88.9	147	93.2	149	83.2
Cambridge	–	–	64	0	48	0
Cardiff	135	0	134	0	136	0
Carlisle	26	46.2	28	35.7	25	4.0
Carshalton	108	10.2	116	10.3	118	12.7
Coventry	91	0	88	0	101	0
Derby	25	0	40	0	49	0
Exeter	82	28.0	72	34.7	99	18.2
Gloucester	59	1.7	46	97.8	49	87.8
Guys	119	0	120	0	103	0
Heartlands	82	0	86	0	64	0
Hull	64	1.6	81	2.5	75	0
Leeds LGI	62	25.8	68	85.3	74	70.3
Leicester	158	80.4	171	76.6	174	86.8
Livrpool	–	–	154	31.2	182	35.2
Notts	128	24.2	113	71.7	121	64.5
Oxford	134	0	132	1.5	163	0
Plymouth	67	0	60	0	63	0
Portsmouth	–	–	104	0	141	39.7
Preston	104	0	116	0	134	0
Reading	45	0	54	0	72	0
S Cleveland	90	0	87	70.1	81	90.1
Sheffield	133	17.3	134	78.4	150	84.7

Treatment centre	1999		2000		2001	
	No. incident	% Return comorbidity	No. incident	% Return comorbidity	No. incident	% Return comorbidity
Stevenage	–	–	103	0	126	0
Southend	43	2.3	39	2.6	35	20.0
St James	79	86.1	91	93.4	86	76.7
Sunderland	45	0	45	0	35	0
Swansea	83	26.5	90	58.9	110	40.0
Truro	–	–	38	7.9	35	37.1
Wolverhmtn	75	0	77	0	77	0
Wordsley	43	0	40	0	34	0
Wrexham	51	0	55	0	36	0
York	51	74.5	40	92.5	36	77.8
Totals	2299	20.8	2872	31.9	3042	33.4

Table 18.1: Comorbidity data returns, by centre, at the start of RRT
Total number of patients registered each year and percentage of total incident patients with comorbidity returned.

Frequency of co-morbidities returned

Comorbidity	Age <65 years		Age >65 years		Total incidence
	No. pts	%	No. pts	%	
Angina	1543	13.3	1288	29.7	20.8 %
MI in past 3 months	1542	2.1	1285	3.4	2.7 %
MI >3 months ago	1545	6.2	1283	16.3	10.8 %
CABG/angioplasty	1543	4.1	1284	6.2	5.0 %
Cerebrovascular disease	1548	8.2	1289	17.8	12.5 %
Diabetes (not as cause of ERF)	1530	5.1	1281	9.8	7.3 %
Diabetes as primary disease	1557	20.0	1297	12.8	16.7 %
Diabetes of either category	1557	25.0	1297	22.5	23.9 %
COPD	1548	4.3	1288	9.6	6.7 %
Liver disease	1546	3.0	1286	1.6	2.4 %
Malignancy	1538	6.8	1284	15.3	10.7 %
Claudication	1541	7.1	1288	16.9	11.6 %
Ischaemic/neuropathic ulcers	1538	4.8	1285	4.6	4.7 %
Angioplasty/vascular graft	1546	2.5	1281	5.1	3.7 %
Amputation	1549	2.9	1286	2.6	2.8%
Smoking	1504	24.7	1258	17.1	21.3 %

Table 18.2: Frequency of comorbidity at the time of starting RRT

Total number of patients with data entered for each comorbidity and percentage of total incident patients with each comorbidity present.
MI, myocardial infarction; CABG, coronary artery bypass grafting; ERF, established renal failure; COPD, chronic obstructive pulmonary disease.

The frequency of each of the co-morbid conditions at the time of starting RRT in all 2854 incident patients who have comorbidity recorded on the Registry are shown in Table 18.2. In a small number of these patients, some of the items were left blank, and it is not known whether this indicated that this co-morbid condition was not present or that the data were unknown. Smoking was the category that centres found most difficult to complete and was

returned for 2762 of the 2854 patients. Altogether, comorbidity categories had between 17 and 92 patients with missing data.

Diabetes occurred as a co-morbid condition in 7.3% of patients. When included with the category of diabetes as the primary cause of established renal failure, this increased the frequency of diabetes to 24% of all incident patients.

Co-morbidity reporting selection bias

It is possible that those patients with comorbidity reported to the Registry were not representative of the distribution of comorbidity within the total incident RRT population. Patients with completed comorbidity data may be those who had little comorbidity (so details were easier to complete), had survived longer than 90 days on RRT or had greater comorbidity (more important to fill in) than other patients on RRT.

To analyse the possibility of selection bias, the patients registered by the four units (Bristol, Leicester, St James's and York) who had the most complete comorbidity returns in both 1999 and 2000 were studied. The 1 year survival of patients from these four centres was compared with the that from centres with a low rate of comorbidity data. The 2001 comorbidity data returns could therefore not be included in this analysis as 1 year survival data were incomplete. This analysis for bias does not adjust for any difference in practice in reporting between renal units. The results are displayed in Tables 18.3 and 18.4.

	High return units *with* comorbidity registered		**High return units *no* comorbidity registered**	
	<65 years	**>65 years**	**<65 years**	**>65 years**
90 day survival	97.1%	88.7%	89.0%	65.6%
95% CI	(95.7–98.6)	(85.9–91.5)	(81.9–96.2)	(56.1–75.1)
Patients	n=530	n=488	n=76	n=96
1 year + 90 day survival	90.4%	79.7%	81.3%	54.8%
95% CI	(87.1–93.8)	(74.8–84.6)	(69.6–93.0)	(39.7–69.8)
Patients	n=318	n=261	n=44	n=42

Table18.3: Survival at 90 days and 1 year + 90 days with high comorbidity returns

	Low return units *with* comorbidity registered		**Low return units *no* comorbidity registered**	
	<65 years	**>65 years**	**<65 years**	**>65 years**
90 day survival	97.3%	88.3%	95.0%	84.9%
95% CI	(96.1–98.6)	(85.5–91.0)	(94.1–95.8)	(83.5–86.3)
Patients	n=640	n=532	n=2563	n=2506
1 year + 90 day survival	95.3%	86.4%	89.9%	73.9%
95% CI	(92.8–97.8)	(81.8–91.0)	(88.3–91.4)	(71.5–76.2)
Patients	n=283	n=216	n=1533	n=1329

Table18.4: Survival at 90 days and 1 year + 90 days with low comorbidity returns

Those patients in whom comorbidity had been returned (as either present or absent) appear to have better survival, at both 90 days and 1 year later, than those in whom comorbidity was not recorded. This is true for renal units with either a high or a low rate of comorbidity reporting. The implication is that comorbidity is more likely to be reported to the Registry for relatively

healthy uncomplicated patients or those patients who survive long enough for the centres to complete the process of comorbidity registration.

Therefore the reported incidence of comorbidity is likely to be an underestimation of the total burden of comorbidity in patients starting RRT in the UK.

Survival and co-morbidity

Inclusion criteria

In the years up to the end of 2001, there were 2854 incident patients with comorbidity data recorded on the Registry. Those patients starting RRT between 1 January 1999 and 30 September 2001 were included in the 90 day survival analysis. Patients incident in 1998 with comorbidity recorded were excluded from the analysis as the overall return was low. By necessity, 1 year survival analysis excludes patients incident in 2001, as 1 year of follow-up was incomplete. Patients with no comorbidity recorded were excluded from the analyses.

The impact of co-morbidity on patient survival at 90 days

The effect of each individual comorbidity upon patient survival was assessed by univariate analysis. The effect of each comorbidity category was assessed for all patients recorded as having that condition irrespective of whether or not they also had another comorbidity recorded.

For each co-morbid condition, a **co-morbidity hazard** is quoted. This is the risk of death for those with the comorbidity in question (irrespective of whether or not they have other comorbidity recorded), compared with those in the same age group with no comorbidity. A patient aged over 65 years with claudication has, for example, an increased hazard of death by 90 days that is 1.3 times greater then that of someone aged over 65 without claudication. This compares with an increased hazard of death of 4.9 for a patient aged under 65 with claudication, compared with a patient in the same age group without claudication. The results are shown in Table 18.5.

Co-morbidity	**Co-morbidity hazard**	
	<65 years	**>65 years**
Angina	2.6	1.6
Heart disease*	2.4	1.7
Vascular disease**	4	1.6
Diabetes (not as cause of ERF)	3.0	1.7
Diabetes as primary disease	1.6	1.7
Diabetes of either category	1.7	1.7
COPD	2.1	2.0
Liver disease	10.9	3.2
Malignancy	1.6	2.1
Claudication	4.9	1.3
Ischaemic/neuropathic ulcers	7.3	2.4
Smoking	1.2	1.7

Table 18.5: Univariate analysis, co-morbidity hazards of death by 90 days
*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.
ERF, established renal failure; COPD, chronic obstructive pulmonary disease.

The combined effect of age and each of the individual co-morbidities upon 90 day patient survival after starting RRT was examined by Cox regression analysis. Variables considered in the model were: age, angina, myocardial infarction (MI) in previous 3 months, MI more than 3 months ago, coronary artery bypass grafting (CABG)/angioplasty, cerebrovascular disease, diabetes of either category, chronic obstructive pulmonary disease (COPD), liver disease, malignancy, claudication, ischaemic/neuropathic ulcers, angioplasty/vascular graft, amputation and smoking. Those variables found to be significantly important in the model are shown in Table 18.6.

Variable	Chi squared	*p*-value	Hazard ratio	95% Confidence interval	
Age	69.9	<0.0001	1.07	1.06	1.09
Liver disease	21.4	<0.0001	4.67	2.43	8.98
Ischaemic/neuropathic ulcers	15.0	0.0001	2.90	1.69	4.96
Smoking	5.6	0.02	1.59	1.09	2.34
MI in past 3 months	4.8	0.03	2.23	1.09	4.56
Malignancy	5.7	0.02	1.64	1.09	2.47

Table 18.6: Cox regression survival analysis of the first 90 days of RRT

This multivariate analysis shows that those factors with the greatest influence on survival at 90 days are age, liver disease, the presence of malignancy or limb ulcers, be they neuropathic or ischaemic in origin, smoking habit and the occurrence of an MI within 3 months of starting RRT. The 95% confidence interval for liver disease is wide, mainly because of the low number of patients with this disease; therefore the importance of liver disease may be overestimated (or underestimated!).

The impact of co-morbidity upon survival at 1 year after 90 days

As for survival at 90 days, the effect of each individual comorbidity upon patient survival was assessed by univariate analysis, and a hazard risk was calculated. The results are displayed in Table 18.7.

The impact of each individual comorbidity is greater in the under-65 age group because those without comorbidity in this age group might be expected to have a good prognosis. Once again, liver disease and ischaemic or neuropathic ulcers are seen to have a high hazard of death. As one might expect, malignancy likewise carries a high hazard of death by 1 year after 90 days, in contrast to the hazard of death at 90 days.

Co-morbidity	Co-morbidity hazard	
	<65 years	>65 years
Angina	7.0	2.2
Heart disease*	7.3	2.5
Vascular disease**	9.3	2.0
Diabetes (not as cause of ERF)	8.0	3.4
Diabetes as primary disease	6.6	2.8
Diabetes of either category	6.8	3.0
COPD	14.7	2.1

Co-morbidity	Co-morbidity hazard	
	<65 years	>65 years
Liver disease	12.3	2.4
Malignancy	10.5	3.5
Claudication	11.1	2.4
Ischaemic/neuropathic ulcers	13.0	5.2
Smoking	6.5	2.4

Table 18.7: Univariate analysis, co-morbidity hazards of death by 1 year after 90 days

*At least one of angina, MI at any time, angioplasty/vascular graft.

**At least one of cerebrovascular disease, claudication, ischaemic/neuropathic ulcer, angioplasty/vascular graft, amputation.

ERF, established renal failure.

Multivariate analysis was also performed to examine the effect of the same variables upon survival at 1 year after 90 days. Those variables found to be significantly important in the model are shown in Table 18.8.

Variable	Chi squared	*p*-value	Hazard ratio	95% Confidence interval	
Age	43.2	<0.0001	1.04	1.03	1.05
Ischaemic/neuropathic ulcers	30.4	<0.0001	3.71	2.33	5.91
Malignancy	12.3	0.0004	1.94	1.34	2.80
Smoking	8.0	0.005	1.63	1.16	2.28

Table 18.8: Cox regression survival analysis of the 1 year after 90 days of RRT

This multivariate analysis of survival in the year after 90 days following the start of RRT shows that those factors with the greatest influence on survival are age, the presence of malignancy or limb ulcers and smoking habit.

Appendix to Chapter 18

Important changes to co-morbidity definitions 2002

The non-coronary angioplasty group has been widened to include other vascular grafts and arterial stents. The new definition is given below:

Angioplasty, stenting, vascular graft (all non-coronary)

This category now includes vascular grafts (e.g. aortic bifurcation grafts) and arterial stents.

Episode of heart failure (right or left)

This is whether or not it was only the result of fluid overload.

(This item has now been included as there is new evidence that heart failure caused by fluid overload is a bad prognostic sign. It was previously excluded as it was difficult to define whether or not it was the result of fluid overload).

Comorbidity 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

MI diagnosed by ST segment elevation, Q waves in relevant leads, a rise in enzyme levels of more than twice the upper limit of normal (or a rise in creatine kinase-MB above the local reference range).

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, 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 (all no- coronary)

This category now includes vascular grafts (e.g. 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 19: The Registry and use of 2002 Report

The 2002 Report dealing with data from 2001 explores the demographic and treatment variables of the renal replacement programmes in England and Wales in a timely and increasingly comprehensive way. Summary demographic data are presented for Scotland and Northern Ireland.

This is the first year that units have been identified within the report. Renal unit anonymity has been maintained only for mortality analyses as the data cannot be standardised enough for case mix to make interpretation reliable and therefore useful. It is essential that comorbidity data are as complete and accurate as possible for this purpose, as for others. The responsibility of the Registry to the nephrology community and patients is shown by the extensive chapter on data validation. This year, there has been far more feedback to units, and subsequent dialogue, in order to improve the quality and accuracy of data.

These data are longitudinal rather than cross-sectional, and therefore represent a different perspective from reports from the Center for Medicare and Medicaid Services, which is the successor to the US Health Care Finance Administration annual sampling review, and from the International Dialysis Outcomes and Practice Patterns Study (IDOPPS) exercises. Comparison with other studies should be carried out with caution as patient cohorts are not always comparable. The UK data start, for example, from the first day of dialysis. Many countries do not record this information: in the USA, data are captured from day 90. The pattern within Europe is highly variable and not always consistent within a country. This makes the interpretation of outcome data subject to error.

Furthermore, patient cohorts may be selected for analysis in different ways. IDOPPS, for example, is a comprehensive study not of dialysis practice, but of haemodialysis (HD) practice. In most participating countries, peritoneal dialysis (PD) is little used, but in the UK there is a large contribution of PD to dialysis and involves typically younger, fitter patients. For this reason, the UK cohort on HD, in particular, is a 'selected' group of patients who are older and less fit. The cohort cannot be compared without reservation to a cohort of HD patients from a country where PD is rarely used. Sampling strategies developed for purposes such as IDOPPS offer useful experience and frameworks for future Registry studies, in which more detail is required than might be expected from a routine clinical database.

The UK Renal Registry holds data that would allow the identification of individual patients. These data allow complete follow-up despite unit transfers, which are especially common across transplantation. A failure to be able to follow patients as they moved centres was the Achilles heel of previous large-scale Registry data collection (e.g. the European Dialysis and Transplant Association). Identification is essential for the validation of sequential data with renal units and for many of the functions of the Registry, such as epidemiological studies, the assessment of equity of access to treatment, outcomes adjusted for age and all long-term analyses. Patients are never identified in any output. These data are securely held and accessible only by the handful of Registry staff members responsible for the characterisation of unit patient cohorts. The Registry is in discussion with Patient Information Advisory Group and other organisations concerning its ability to continue in this way within the data protection laws. Meanwhile, permission has been given to continue as at present, pending further discussion. These problems are not unique to the Renal Registry, other clinical Registries also joining in discussion.

The Report includes an analysis funded by the National Kidney Research Fund of causes of death and comorbidity. The data on paediatric established renal failure were provided by the Paediatric Registry, which is in the process of merging with the UK Renal Registry. A subset of the data on renal transplantation were provided and analysed in collaboration with UK Transplant.

The hypothesis – that regular, timely electronic data capture from clinical databases is feasible and productive – is under rigorous examination. The Registry has demonstrated that it is possible technically. Exactly how reliable and useful it can be remains to be seen, and the Registry is keenly aware of the need to sustain a pattern of IT and clinical improvement that will allow a further exploration of the approach. The signs are that the exercise will be able to underpin the Renal National Service Framework, generate hypotheses and support the systematic improvement of patient management.

This year also sees the beginning of attempts to move beyond the analysis and presentation of outcome data, towards explaining the results being achieved, for example the role of sampling methods in dialysis adequacy and the context of renal anaemia management with regard to serum ferritin level and erythropoietin dosage. More work is required to extend these analyses and to make them more comprehensive and reliable. This will need to be followed by effort at unit level to standardise management policies where appropriate.

The Renal Registry dataset is incomplete. In particular, there is a need extend into vascular access registration and data. For this to happen, however, individual units will need to have a systematic record of vascular access, something that has proved difficult in many centres. It is also hoped to collect more data on pre-dialysis management. The Registry has the capacity to collect a much greater dataset but can only work with data that are accurately and reliably recorded on an electronic database by the units themselves. The scale of any exercise that will be required to establish a higher standard of peripheral data registration is currently uncertain.

The UK Renal Registry is one of the very few sources world-wide of clinical as well as demographic data in renal replacement therapy, but this has yet to be put to full use by the nephrology community in a national renal audit cycle. With declared Standards, and the outcome data from UK Renal Registry, a plan–do–check–act sequence is almost complete. The scope for improvement is apparent, and it should be possible to bring a repertoire of resources to bear, both financial and clinical, where outcomes are less than desirable. The variation in consistency from centre to centre hints at a variety of renal unit policies and processes that might be improved. How far this should be further formulated is being explored by the Renal Association, which has set up a group to explore the relationship between the declared Standards and monitoring and audit by the Registry. This is likely to involve both the implementation of changes in practice and the dissemination of good practice.

Finally, the effort of the renal ‘constituency’ has been substantial. There could be no Registry without the efforts of individual renal centres and the personnel who have contributed to it, and they thoroughly deserve any reward that the 2002 Report may generate for them in their efforts to improve patient management.

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 nephrologists
6. The role of the Renal Registry for Trust managers
7. The role of the Renal Registry for commissioning agencies
8. The role of the Renal Registry national quality assurance schemes
9. The role of the Renal Registry for patients
10. Abbreviations
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A:1 Executive summary

1.1 The Renal Registry has been established by the Renal Association to act as a resource in the development of patient care in renal disease.

1.2 The Registry will act as a source of comparative data for audit/benchmarking, planning, policy and research. The collection and analysis of sequential biochemical and haematological data will be a unique feature of the Registry.

1.3 Agreements will be made with participating renal centres which ensure a formal relationship with the Registry and safeguard confidentiality.

1.4 The essence of the Agreement will be the acceptance of the Renal Registry Data Set Specification (RRDSS) as the basis of data transfer and retention.

1.5 Data will be collected quarterly to maintain unit-level quality assurance, with an annual report and 6-monthly unit reports.

1.6 Activity will ultimately have to be self-funded by the capitation of renal patients from commissioning agencies.

1.7 The Registry is likely, with the express agreement of participants, to become responsible for providing data to Trusts, commissioning authorities and Regional Offices, and the new European Renal Association–European Dialysis and Transplant Association (ERA–EDTA) Registry.

1.8 The development of the Registry will be open to influence from all interested parties, including clinicians, Trusts, commissioning authorities and patient groups.

1.9 The Registry has charitable status through the Renal Association.

A:2 Introduction

2.1 Registry-based National Specialty Comparative Audit is likely to be one of the cornerstones of NHS development. The *National Renal Review*, published in 1995, recommended the participation of renal units in comparative audit.[1] Chief Executives are now responsible for clinical governance, and comparative audit at national level will be an essential part of this agenda.[2] The UK Renal Registry will facilitate such audit. This audit demands the regular transmission of large volumes of data, which has become possible with developments in electronic data handling. The Scottish Renal Registry, established with financial support from the Scottish Office, demonstrated the practicalities of electronic data collection in a UK renal environment.

2.2 The need for careful comparative audit is likely to be confirmed through the development of government agencies such as the National Institute for Clinical Excellence (NICE) and the Centre for Health Improvement (CHIMP). The final relationship of the Registry to these organisations as they develop has yet to be defined.

2.3 Demographic information on patients receiving renal replacement therapy (RRT) throughout Europe was collected from 1965 in the Registry of the EDTA. This voluntary exercise was conducted on paper and by post, demanded considerable effort and time from participating units and eventually proved impossible for many UK renal units. In recent years, the incompleteness of UK data returns to EDTA has meant that it has not been possible to build a picture of activity of RRT in the UK for planning and policy purposes, although three ad hoc national data collections from England & Wales were solicited from renal centres in 1992, 1996 and 1999. The Registry will meet this need for demographic and economic data necessary for effective planning.

2.4 Together with the need to know the demographic and economic elements of 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 EDTA.

2.5 The Registry is recognised as one of the few high-quality clinical databases available for general use.[3]

2.6 The aspiration for renal services to be provided within a National Service Framework (NSF) is underpinned by the development of the Renal Registry.[4] Although the Department of Health has no immediate plans for an NSF for renal services, the Renal Alliance, a group comprising patients, nephrologists and representatives of other groups involved with renal care, is in the process of developing a shadow NSF. Input from the Renal Registry will be an important feature of the Framework.

2.7 Similar cultural pressures have more recently affected all clinical disciplines, so that Registries are implemented or planned in cardiac surgery, intensive care, diabetes, etc.

2.8 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 guidelines that many 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 realistically be achieved. A common data registration provides the simplest device for such comparative audit.

2.9 The recent emphasis on evidence-based practice is being supported by the changes in research funding (Culyer Report), which lean towards collaborative projects and include both basic science and 'health services research' components. It is apparent that an RRT database could be invaluable to a wide range of research studies.

2.10 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 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 a decade and a half ago, the circumstances are now ideal for the maintenance of a data repository for all the purposes described above, supported by the clinical users and resourced for national benchmarking as a routine part of RRT management.

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 voluntary, but the expectation is that all UK renal and transplant units will take advantage of the database by their ultimate involvement. 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. 800733). It was established by a sub-committee of the Renal Association, with additional representation from the British Transplantation Society, the British Association for Paediatric Nephrology, and the Scottish Renal Registry. There is cross-representation with the Renal Association Standards and Clinical Trials Committees. The Registry has a Chairman and Secretary nominated by the Renal Association. The Registry has an observer from the Department of Health and participants from the National Federation of Kidney Patients' Associations and Health Care Commissioners.

4.2 It is anticipated that there will be a need for the development of a number of sub-committees as the database and participation enlarge, particularly for data analysis and interpretation.

4.3 The Scottish Renal Registry sends data to the Renal Registry for joint reporting and comparison.

4.4 It is anticipated that the return of English, Welsh and Northern Irish data to the EDTA registry will be through the Renal Registry. The Scottish Renal Registry already sends data to EDTA.

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4.5 A paediatric database has been developed in collaboration with the Renal Registry, and the two databases are compatible. Data from paediatric renal units will be entered on the database, which will allow long-term studies of renal cohorts over a wide range of age.

4.6 The basis of participation for renal units nationally will be an Agreement to accept the RRDSS for the transmission and retention of data. This will consist 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 Agreement will specify the conditions of participation and guarantee unit anonymity until there is general agreement to disclosure of unit identity. The responsibilities of the unit and Registry are clarified in the clauses of the Agreement, as well as the conditions of publication of data. The recent Data Protection Act may have implications for the Registry,[5] but the Department of Health has indicated that Registry activity may continue in its present form pending further discussion and clarification of the Act.

A:5 The role of the Renal Registry for nephrologists

5.1 The clinical community have become increasingly aware of the need to define and understand their activities, particularly in relation to national standards and other renal units.

5.2 The Registry is run by a sub-committee of the Renal Association and therefore by colleagues with similar concerns and experience.

5.3 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 the conversion from clinical anecdote.

5.4 The Registry data will be available to allow the comparative review of many elements of renal unit practice. Data will be anonymised and presented to allow a contrast of individual unit activity and results against national aggregated data.

5.5 Reports of demographic and treatment variables will be available to the participating centres for distribution to Trusts, health authorities and Regional Offices as required and agreed with the unit. Reports should facilitate discussion between clinicians, Trust officers and commissioners.

5.6 Customised data reports can be made available by agreement with the Registry sub-committee. A donation to cover any costs incurred will be requested.

5.7 The Registry Committee will welcome suggestions for topics of national audit or research that colleagues feel are of sufficient widespread interest for the Registry to undertake.

5.8 The database has been designed to provide research database 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 Sub-committee to conduct local or national audit and research using the database. All such projects will need the agreement of the Registry Sub-committee, and any costs involved must be met by the applicants.

5.9 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. Attention will be necessary to the conditions listed in formal Agreements with the Registry.

A:6 The role of the Renal Registry for Trust managers

6.1 As the basis of the clinical governance initiative, the gathering and registration of data relating to patient management is regarded as an essential part of routine patient management in the health service.

6.2 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.

6.3 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.

6.4 The Registry will provide a cost-effective source of detailed information on renal services.

6.5 The regular reports of the Registry will supply details of patient demographics, treatment numbers and changes, treatment quality and outcomes. Data will be compared with national standards and national performance for benchmarking and quality assurance. The assessment of contract activity and service delivery will be possible through the 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.

6.6 Data will be available on unit case mix, infrastructure and facilities.

6.7 It is anticipated that data on patients with renal disease other than those requiring RRT will become available in time.

6.8 It is anticipated Trust interests will ultimately be served by the participation of a national Trust representative in the management body of the Registry as Registry activity expands.

A:7 The role of the Renal Registry for commissioners of health care

7.1 The commissioners of health care are taken to include Regional Specialty Commissioning Groups and those supporting them, and the primary care Trusts.

7.2 The use of information sources such as the Registry is advised in the National Renal Review in order to promote benchmarking and quality assurance on renal programmes. The comprehensive tracking of relatively small but costly renal cohorts should be regarded as a routine part of case management.

7.3 The Registry will be able to provide validated, comparative reports of renal unit activity on a regular basis to participating centres. These will allow assessment of unit performance in a wide range of variables relating to structure, process and outcome measures.

7.4 There are economies of scale in the performance of audit through the Registry since multiple local audits will no longer be required.

7.5 The incidence of RRT treated locally will be apparent from new patient registrations. Mortality and renal transplant rates should also be of interest. The geographical origin of established renal failure cases will be indicated by postcode data, which allows the assessment of referral and treatment patterns. This information will allow the expression of geographical and ethnic variations. These data will indicate unmet need in the population and permit judgements of the equity of service provision. The future Registry database should give information on nephrology and pre-dialysis patients, which will allow a prediction of the need for RRT facilities.

7.6 Registry data will be used to track patient acceptance and prevalence rates over time, which will allow the modelling of future demand and the validation of predictions.

7.7 Information on the clinical diagnosis of new and existing RRT patients will point to areas where possible preventive measures will have maximal impact.

7.8 The results of higher acceptance rates in the elderly and the consequences of increasing demand from ethnic groups bearing a high prevalence of renal, circulatory and diabetic disease will be measurable.

7.9 Comparative data will be available in all categories for national and regional benchmarking.

7.10 The Registry offers independent expertise in the analysis of renal services data and their interpretation, a resource that is widely required but difficult to obtain.

7.11 The cost of supporting the Registry is estimated to be between £10 and £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 the costs will need to be made explicit in renal services contracts in order to ensure the continuation of the Registry on a sound basis.

7.12 The Registry Sub-committee now includes a representative of health care commissioners, which allows an influence on the development of the Registry and the topics of interest in data collection and analysis.

A:8 The role of the Renal Registry for national quality assurance agencies

8.1 The role of the Registry in national quality assurance as developed through NICE and Commission for Health Audit and Improvement will depend on decisions as to the roles of those agencies.[6]

8.2 The demographic, diagnostic and outcomes data could support the investigation of clinical effectiveness in a variety of ways, depending on the focus of interest.

8.3 There may be pressure from some quarters to publish reports in which renal units are clearly identified. The maintenance of unit anonymity is likely to be important to some, and it may significantly compromise co-operation if abrogated without agreement. It is ultimately possible that a decision could be forced on the Registry from outside, although it is hoped that this situation will not arise. Consideration of this issue in particular would be welcome in nephrological circles, with correspondence to the Registry Sub-committee.

A:9 The role of the Renal Registry for patients

The ultimate aim 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 erythropoietin, and the appropriate and 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.

A:10 Abbreviations

ARF	Acute Renal Failure
BAPN	British Association of Paediatric Nephrology
BTS	British Transplantation Society
CCL	Clinical Computing Limited
CHAI	Commission for Health Audit and Improvement
EDTA	European Dialysis and Transplant Association
ERA	European Renal Association
ESRF	End Stage Renal Failure
HCFA	USA Health Care Finance Administration
NFKPA	National Federation of Kidney Patients' Associations
NHS	National Health Service
NICE	National Institute of Clinical Excellence
PCG	Primary Care Group
RRDSS	Renal Registry Data Set Specification
RRT	Renal Replacement Therapy
UKTSSA	United Kingdom Transplant Support Service Authority
USRDS	United States Renal Data System

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Appendix B: Definition, 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 is modality is calculated by the Registry, which allows the definition to be changed.

Start of end-stage renal failure

End-stage renal failure (ESRF) 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 are classed as 'recovered'.

B:3: Analysis criteria

Definition of the take-on population (Incidence)

The take-on population in a year included patients who later recovered from ESRF 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 ESRF are included in the take-on population, the following scenario can occur: a patient may start RRT in 2001, recover and then restart RRT in 2001. 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.

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 :

$$\frac{\text{Probability of dying for someone with a phosphate of 1.71–2.10 mmol/L}}{\text{Probability of surviving for someone with a phosphate of 1.71–2.10 mmol/L}}$$

The odds ratio is the:

$$\frac{\text{Odds of dying with a phosphate of 1.71–2.10 mmol/L}}{\text{Odds of dying in the reference group}}$$

Hazard function

The hazard function is the probability of dying in a short time interval considering survival to that interval.

Hazard ratio

$$\frac{\text{Probability of dying in the next interval for a phosphate of 1.71–2.10 mmol/L}}{\text{Probability of dying in the next interval for a phosphate in the ref range}}$$

Survival analyses of prevalent cohort

These analyses exclude the current year's incident cohort.

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 ESRF).

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 2001 would, for example, be included for the quarter 1/01 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 ESRF, 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 2001 who recovered on the 1 June 2001 and then resumed RRT again on 1 November 2001, for example, the number of days on RRT would be calculated from 1 November 2001. The patient would be excluded from the analysis for quarter 4/01 since on 31 December 2001, he or she would have been on RRT for only 90 days. The patient would be included in the analysis from quarter 1/2002 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 01, 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 2000 and 31 September 2001 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 2001. As there is an increased death rate in the first 6 months following transplantation, patients were included in the analysis only if they had not received a transplant between 1 July 2000 and 31 December 2000. For the same reason, patients who received a transplant within the year were censored at the time of transplantation.

The sample criteria thus became:

1. Patients who had been receiving RRT for more than 90 days on 1 January 2001.
2. Patients who had a transplant between 1 July 2000 and 31 December 2000 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 July 2000 and 31 December 2000.

4. The few patients who recovered renal function in 2001 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 2001 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: Data Protection and the UK Renal Registry in 2002

C:1: Introduction

The political and social context of data management has changed since the UK Renal Registry was established. In particular, there has been growing concern that the NHS should become more 'patient centred'. In addition, the benefits of data collection for science and research are no longer assumed to be self-evident but need to be demonstrated outside the medical arena. Whenever patient identification is a necessary component of research or data collection, it has become important to obtain informed consent.

This has ethical and legal considerations. Although the formal position has evolved with the Data Protection and Human Rights Acts of 1998, certain circumstances have suggested the need for further legislation. Very large research exercises, for example, make consent impractical to obtain, the condition of some patients makes consent impossible, and the bias introduced by selective refusal/omissions might make data un-interpretable.

C:2: European law – Directive 95/46/EC

This law relates to the protection of individuals with regard to the processing of personal data and the free movement of such data.

Member States shall prohibit the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, and the processing of data concerning health or sex life.

Paragraph 1 shall not apply where processing of the data is required for the purposes of preventive medicine, medical diagnosis, the provision of care or treatment or the management of health care services, and where those data are processed by a health professional subject under national law or rules established by national competent bodies to the obligation of professional secrecy or by another person also subject to an equivalent obligation of secrecy.

European Union law therefore excludes the collection of medical information from the data protection laws.

C:3: The Health and Social Care Act 2001 (England & Wales)

In England & Wales, Section 60 of the Health and Social Care Act 2001 provides discretionary powers to the Secretary of State ensuring that patient-identifiable information needed to support essential NHS activity can be used without the individual consent of patients. These powers can be used only to support medical purposes that are in the interests of patients or the wider public, when consent is not a practicable alternative and when anonymised information will not suffice. The decisions are to be reviewed annually. An effort towards obtaining consent or the development of patient anonymity is expected of any group seeking to use Section 60.

The Patient Information Advisory Group (PIAG) has been established as the advisory mechanism to the Secretary of State. Because of the numerous activities that might require consideration, it has been anticipated that broad classes of exceptions will be formulated, with only a limited number of applications requiring detailed PIAG consultation. The Registry hopes that one such class might encompass generic, Registry-type, data collection. The UK Renal Registry has submitted its application to PIAG for the consideration of exemption from the need to seek individual patient consent.

C:4: The Registry case

The Registry is the cornerstone of the monitoring of RRT in Britain. The involvement of all UK renal units is confidently expected within the next few years. This has been mandated by advice from the Department of Health to health authorities. The Registry is funded by a capitation fee from health authorities, endorsed by the Department of Health. The annual reports are the basis of assessment for health provision, management and outcomes in renal disease nationally. The accurate demographic and quality performance data will be one foundation of the Renal National Service Framework (NSF), which is currently under development. The evidence of treatment distribution is critical to ensure the developing NHS agenda on equity of patient access. These clinical data are the basis of national comparative audit and quality improvement initiatives that are equal to, or in advance of, any developments in other medical specialities. It is hoped that these benefits of the Registry will be recognised as being sufficiently important to invoke the term 'essential NHS activity', thus enabling the Secretary of State to use his discretionary powers (Section 60, Health & Social Care Act).

There are over 39,000 patients on the Registry database. Some will have been identified retrospectively after an acute presentation; others may have been unable to give consent through incapacity of one kind or another. The need for patient identification hinges on the need to track the course of treatment between renal dialysis and transplant units. If any compelling example of this need were required, the demise of the previous European Renal Registry occurred in part because of the intractable difficulties of following patients during transitions of treatment, with a huge 'lost to follow-up' cohort.

The Renal Registry will lie at the heart of the Renal NSF and supplies crucial information to government about an expanding and resource-intensive service. Patient identification is required for data validation.

C:5: The way forward

The principles of data protection are scrupulously observed at the Registry, and only those directly involved in data validation and analysis have access to patent-identifiable material.

It is nevertheless necessary to explore how individual patient consent can best be obtained. This might involve a single Registry-solicited enrolment at the start of renal treatment. It is also important to establish, perhaps from data already available, what bias would be introduced were selective refusal to consent a factor. The suggestion that receiving NHS treatment for renal disease should carry an obligation to individuals to provide consent is not

widely supported. A formula for satisfying all the ethical and legal issues may yet develop from other experience of the practicalities of NHS data collection. It should be noted that other applications of the Registry database would have to be examined on their merits, and the availability of the data for all purposes, such as the identification of patients for research, cannot be assumed.

The current Renal Registry data collection has continued in the confidence that existing data protection procedures, apart from consent, are well established and that the case for exception under Clause 60 provisions will have a *prima facie* validity. The Registry submitted to PIAG, and while further clarification on some issues was awaited by PIAG, the Registry was given permission to continue data collection. It is hoped that the Registry's new role in monitoring the NSF will strengthen its submission, in conjunction with the support of patient groups, the Department of Health, the NHS Information Agency and the Royal College of Physicians, while the possibility of obtaining consent is examined further within the discipline.

Appendix D: Measurement of Dialysis Adequacy

D:1: Urea rebound and timing of blood samples

The urea reduction ratio (URR), like all methods of calculating haemodialysis adequacy, requires a precise and reproducible method of pre-dialysis and, more importantly, post-dialysis blood sampling. The standardisation of post-dialysis blood sampling is critical to limit the overestimation of urea removal that is inevitable if no account is taken of post-dialysis urea rebound. The dilutional effects of access recirculation (in patients dialysing using arterio-venous fistulae) and cardiopulmonary recirculation cease within a few minutes of stopping haemodialysis (Figure D.1). The remaining rebound is caused by intercompartmental urea disequilibrium, equilibration taking 30–45 minutes. The percentage increase in urea after 30 minutes may be as much as 17–45%.[1]

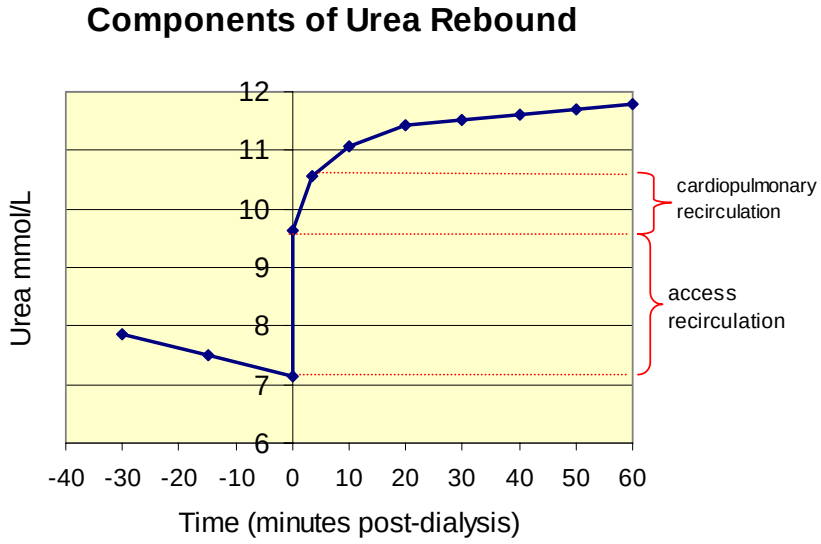


Figure D.1: Components of urea rebound (from the Disease Outcomes Quality Initiative report)

D:2: Practical problems of timing of blood samples

It is not practical to ask patients to wait for such a delayed blood sample to be taken, so estimations of this late rebound are often used. Methods of sampling are considered in some detail in the second edition (page 98) and third edition (pages 27 and 35) of the Standards document. The National Kidney Foundation Dialysis Outcomes Quality Initiative guidelines[2] currently advise 'slow flow methods' of post-dialysis blood sampling since they negate the effects of access recirculation and partially allow for cardiopulmonary recirculation. The third edition of the Renal Association document includes three acceptable methods for post dialysis sampling. However the 'early' sampling methods involve four steps and require accurate timing of the blood samples during the early period of most rapid urea rebound: this may be difficult to achieve in a busy renal unit. In North America, dialysis centres have revealed that at least 20 methods of post-dialysis blood sampling were recently in use, and more than 40% of the haemodialysis centres used a method of post-dialysis sampling that did not attempt to allow for the effects of access and cardiopulmonary recirculation.[3]

The observation that patient survival in the USA improves as URR increases up to 60% was made using undefined post-dialysis sampling methods thatare likely to have been similar to the post-dialysis methods described more recently in North American haemodialysis facilities.

D:3: Current UK practice in blood sampling

A survey in 2002 by the Registry of the methods of post-dialysis sampling used by participating UK renal units has shown a wide range of sampling techniques in use. Many units obtain the post-dialysis blood sample immediately at the end of the dialysis session with no 'slow flow' period. A similar observation was made in a survey of all adult renal units in Scotland in early 1998.[4] This widespread use of immediate post-dialysis sampling will overestimate urea removal during dialysis, and hence URR, as the sample is diluted by the access recirculation of 'just dialysed blood', and there is no account of cardiopulmonary recirculation and the disequilibrium component of the urea rebound.

For good comparative audit, it is essential that a standardised post-dialysis sampling technique is used that is simple and reproducible.

In the absence of a formal programme of standardisation of dialysis methods in the UK, only one method of sampling has been under evaluation. Most renal units in Scotland, and some in England, have utilised a standardised method of post-dialysis blood sampling from any point in the extracorporeal circuit, 5 minutes after stopping the dialysate flow while the dialyser blood flow rate remains unchanged.[5] This 'stop dialysate continue blood flow' method does not require an exact timing of blood sampling, permits blood sampling from the arterial or venous limb of the extracorporeal circuit and is practical to perform in a busy unit. This has proved reproducible, allowing for both access and cardiopulmonary recirculation, if not for the disequilibrium component of urea rebound. This technique has been verified in 117 patients. During the same haemodialysis session, the URR was 69.1 (s.d. 9.3%) when using the 'stop dialysate flow' method, compared with 71.7 (s.d. 8.3%) when blood sampling was performed immediately at the end of haemodialysis ($p<0.0001$). The method is being further evaluated.

It should be noted that the extent of urea rebound depends on the intensity of dialysis in terms of K/V and t, so that a wide range of treatment conditions is required to validate any sampling method. The 'stop dialysate flow' method is not suitable for conversion to estimate Kt/V, unlike versions of 'slow flow', so that international and historical data comparisons may be compromised by concentrating on this method.

D:4: Implications for URR results calculated by the Renal Registry

Without a standardised post-dialysis sampling technique being used by all units, it must be accepted that many units will be overestimating URR by taking immediate 'no slow flow' samples. This is part of a wider problem with URR, however, because it takes no account of urea removal by ultrafiltration. This distorts the equivalence of URR 65% and Kt/V 1.2, which is further flawed because of the effects of a variable dialysis time, *t*. For these reasons, URR is not, despite its relationship to outcomes, a reliable indicator of haemodialysis dosage.

This is particularly important when the distribution of unit results clusters around the Standard 65% value because even a small bias in the data will profoundly shift the percentage compliance with the Standard. Values well above (or below) the Standard will be scarcely affected. The chapter on dialysis adequacy shows clearly that a very small change in the median URR achieved can make a profound difference to compliance with the Standard.

Any attempt to increase URR values will, however, tend to increase the dialysis doses delivered. In very large-scale mortality studies, these details appear to be less relevant. It should again be stressed that the observation that patient survival in the USA improves as URR increases up to 60% was made using undefined post-dialysis sampling methods.

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Appendix E: Renal Services Described for Non-physicians

(Reproduced from the third edition of the Renal Association Standards document)

This annex gives information on the issues discussed above in this document, provides background information on renal failure, and discusses the services available for its treatment.

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Renal Diseases

E.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.

E.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

E.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 the illnesses because of other conditions, often the one which caused the renal failure.

Chronic Renal Failure (CRF) and Established Renal Failure (ERF)

E.1.4 More common is chronic irreversible 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.

E.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 end stage renal disease 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 end stage renal disease is to be treated.

E.1.6 The incidence of chronic renal disease and end stage renal failure rises steeply with advancing age. Increasing numbers of patients treated for end stage renal disease 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 end stage renal failure in the black population (predominantly of African origin) is two to four 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 Afro-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 on to renal replacement programmes.

Causes of Renal Failure

E.1.7 Most renal diseases that cause renal failure fall into a few 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 end stage 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, although only a small proportion of them develop kidney failure over the age of 70.

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 much rarer inherited disease, affecting 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

E.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 angiotension1 converting enzyme inhibitors (ACE1) 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 for renal failure can be identified, e.g. diabetics and the elderly.

Complications and Co-morbidity

E.1.9 Renal failure is often accompanied by other disease processes. Some are due to the primary disease, e.g. 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 end stage renal disease have diseases affecting the heart and blood vessels (vasculitis) 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 end stage 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

E.1.10 The term renal replacement therapy is used to describe treatments for end stage 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')

E.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

E.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 4–5 hours and is needed three times a week.

Peritoneal Dialysis

E.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 30–40 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

E.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 has largely been 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, so myocardial infarcts and strokes are commoner in transplant patient 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

E.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 inevitable 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 not always from close blood relatives of the recipient) are used wherever appropriate. Hope for the future rests with solving the problems of xenotransplantation (that is 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 end stage renal failure within the next 10 years.

Nature of Renal Services

E.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, another 20% attending the renal unit regularly for haemodialysis. However, inpatient nephrology and the care of patients receiving centre-based dialysis are specialised and 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.

E1.17 There are five major components to renal medicine.

1. Renal replacement therapy. The most significant element of work is in relation to the preparation of patients in end stage renal failure for renal replacement therapy 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 end stage renal failure programme. This workload is bound to expand rapidly as the number, age and co-morbidity of patients starting renal replacement therapy increase, and this may interrupt the regular care of patients already on renal replacement therapy, so increased resources may be required.

   iii. 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.

   iv. Investigation and management of fluid and electrolyte disorders. This is a variable proportion of the nephrologist's work, depending on the other expertise available in the hospital.

   v. 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 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 F: Data Tables

F:1. Patients starting renal replacement in 2001

Take-on figures for new patients on dialysis				
	Aged >65		Aged <65	
Centre	% on HD	% on PD	% HD	% on PD
Bristl	78	22	49	51
Carls	50	50	60	40
Carsh	60	40	46	54
Covnt	70	30	58	42
Crdff	80	20	40	60
Derby	83	17	50	50
Extr	70	30	40	60
Glouc	67	33	47	53
Guys	55	45	24	76
Heart	89	11	74	26
Hull	97	3	74	26
Leic	54	46	55	45
LGI	89	11	58	42
Notts	73	27	39	61
Oxfrd	73	27	35	65
Plym	70	30	50	50
Prstn	53	47	36	64
Redng	29	71	4	96
S Cleve	93	7	53	47
Sheff	67	33	56	44
Stevn	64	36	81	19
Sthend	88	13	53	47
St Jms	91	9	71	29
Sund	96	4	88	13
Swnse	82	18	50	50
Wolve	61	39	47	53
Words	39	61	22	78
Wrex	81	19	68	32
York	67	33	50	50
E&W	72	28	49	51

Table F.1.1: Take-on of new dialysis patients
HD, haemodialysis; PD, peritoneal dialysis.

Take-on figures for new patients on dialysis				
	aged <65		aged >65	
	No. on HD	No. on PD	No. on HD	No. on PD
England	705	559	769	321
Wales	62	46	98	35
E&W	767	605	867	356

Table F.1.2: Take-on totals of new dialysis patients

Treatment modalities at 90 days						
Treatment centre	% on HD	% on PD	% on Transplant	% Transferred out	% Stopped treatment	% Died
Bradf	66	25.				7
Bristl	57	28.				11
Camb	19	39.				11
Carls	20	34	3			13
Carsh	45	15	1			7
Covnt	52	27.			4	17
Crdff	56	39.				9
Derby	66	29	2			17
Extr	62	48	7			8
Glouc	61	37	6			7
Guys	37	24.				3
Heart	77	26				9
Hull	64	26	1			10
Leic	51	68.		5		2
LGI	56	38	3	1		10
Livrpl	61	25	1			9
Notts	52	33.		.		6
Oxfrd	48	18.		3		8
Plym	51	45	3	1	1	9
Ports	61	28.				16
Prstn	42	10.				15
Redng	25	56.				9
S Cleve	63	22.				17
Sheff	48	13.		11		11
Stevn	71	40	3			11
Sthend	66	33	7			4
St Jms	76	25	3			15
Sund	75	37	41			4
Swnse	61	11.				11
Truro	74	36.				44
Wolve	37	23	1			15
Words	35	47.		1	4	10
Wrex	50	16	1	1		18
York	50	45.		1		7
Eng	54	32	3	1	0	10
Wales	57	29	4			10
E&W	54	32	3	1	0	10

Table F.1.3: Treatment modalities at 90 days

Treatment modalities at 90 days						
	No. on HD	No. on PD	No. on transp	No. transf out	No. stopped treatment	No. died
Eng	1474	880	72	21	8	281
Wales	160	81	11			27
E&W	1634	961	83	21	8	308

Table F.1.4: Number of patients per treatment modality at 90 days

Treatment centre	First treatment modality % on HD	% on PD	% on transplant
Bradf	69	31	
Bristl	73	26	1
Camb	22	38	41
Carls	60	40	
Carsh	51	47	2
Covnt	67	31	2
Crdff	62	34	5
Derby	68	32	
Extr	70	30	
Glouc	73	27	
Guys	37	57	6
Heart	85	15	
Hull	71	27	1
Leic	56	40	5
LGI	72	28	
Livrpl	68	32	
Notts	57	43	
Oxfrd	57	39	4
Plym	71	29	
Ports	62	36	3
Prstn	46	54	
Redng	30	70	
S Cleve	81	17	2
Sheff	55	43	1
Stevn	82	18	
Sthend	76	24	
St Jms	81	18	1
Sund	90	10	
Swnse	74	26	
Truro	74	26	
Wolve	49	51	
Words	41	59	
Wrex	63	37	
York	61	39	
Eng	62	35	3
Wls	67	31	2
E&W	63	35	2

Table F.1.5: First treatment modality

	First treatment modality No. on HD	No. on PD	No. on transplant
Eng	1711	972	69
Wls	186	87	6
E&W	1897	1059	75

Table F.1.6: First treatment modality – patient numbers

Treatment by Gender						
	Haemodialysis			Peritoneal Dialysis		
Treatment Centre	% Male	% Female	M:F Ratio	% Male	% Female	M:F Ratio
Bradf	61	39	1.5	73	27	2.8
Bristl	59	41	1.4	70	30	2.4
Camb	73	27	2.8	76	24	3.1
Carls	.	100.		22	78	0.3
Carsh	65	35	1.8	72	28	2.5
Covnt	54	46	1.2	69	31	2.3
Crdff	59	41	1.4	72	28	2.6
Derby	62	38	1.6	80	20	4.0
Extr	62	38	1.6	55	45	1.2
Glouc	56	44	1.3	33	67	0.5
Guys	50	50	1.0	52	48	1.1
Heart	62	38	1.6	40	60	0.7
Hull	61	39	1.6	53	47	1.1
Leic	66	34	1.9	58	42	1.4
LGI	66	34	1.9	58	42	1.4
Livrpl	57	43	1.3	74	26	2.9
Notts	55	45	1.2	59	41	1.4
Oxfrd	70	30	2.4	57	43	1.3
Plym	67	33	2.0	63	37	1.7
Ports	62	38	1.6	59	41	1.4
Prstn	57	43	1.3	63	37	1.7
Redng	53	47	1.1	54	46	1.2
SCleve	58	42	1.4	71	29	2.5
Sheff	72	28	2.5	75	25	2.9
Stevn	62	38	1.6	77	23	3.4
Sthend	88	12	7.3	100.	.	
StJms	56	44	1.3	62	38	1.6
Sund	53	47	1.1	25	75	0.3
Swnse	56	44	1.3	56	44	1.3
Truro	64	36	1.8	75	25	3.0
Wolve	72	28	2.6	76	24	3.1
Words	92	8	11.0	89	11	8.5
Wrex	68	32	2.2	54	46	1.2
York	37	63	0.6	80	20	4.0
Eng	61	39	1.6	65	35	1.8
Wls	59	41	1.4	64	36	1.8
E&W	61	39	1.6	65	35	1.8

Table F.1.7: Treatment modalities, by gender

Treatment by gender						
	Haemodialysis			**Peritoneal dialysis**		
	No. male	**No. female**	**No. unknown**	**No. male**	**No. female**	**No unknown**
Eng	904	568	0	568	311	0
Wls	94	66	0	52	29	0
E&W	998	634	0	568	311	0

Table F.1.8: Treatment modality numbers, by gender

F:2 Current patients 2001

Treatment modalities by centre								
	For patients aged over 65				For patients under 65			
Treatment centre	**% on HD**	**% on PD**	**% on transplant**	**HD:PD**	**% on HD**	**% on PD**	**% on transplant**	**HD:PD**
Bradf	61	25	14	2.4	26	19	55	1.4
Bristl	63	13	24	5.1	24	9	68	2.7
Camb	42	29	29	1.4	11	17	71	0.6
Carls	62	19	19	3.2	19	16	66	1.2
Carsh	47	28	25	1.7	27	17	56	1.6
Covnt	52	27	21	1.9	29	16	55	1.8
Crdff	55	18	27	3.1	16	13	72	1.2
Derby	83	17		4.9	63	37		1.7
Extr	60	24	16	2.5	29	17	54	1.7
Glouc	80	16	5	5.1	36	22	42	1.6
Guys	44	24	31	1.8	18	12	70	1.5
Heart	80	11	9	7.1	45	12	43	3.8
Hull	74	14	12	5.1	37	18	45	2.0
Leic	50	30	20	1.7	28	22	50	1.3
LGI	58	20	22	2.9	22	23	56	1.0
Livrpl	56	15	30	3.8	28	12	61	2.3
Notts	58	26	15	2.2	27	18	55	1.5
Oxfrd	51	17	32	3.0	16	10	74	1.6
Plym	56	12	32	4.8	20	13	66	1.6
Ports	49	19	32	2.6	21	9	70	2.3
Prstn	58	30	12	1.9	38	32	30	1.2
Redng	43	56	1	0.8	38	58	4	0.7
S Cleve	68	8	24	8.7	27	10	63	2.6
Sheff	55	22	23	2.5	41	12	47	3.5
Stevn	78	15	7	5.2	52	15	34	3.5
Sthend	91	8	2	11.8	63	16	21	3.9
St Jms	67	6	27	10.8	27	8	65	3.4
Sund	67	8	25	8.2	31	8	62	4.0
Swnse	67	24	9	2.8	32	26	42	1.3
Truro	76	15	9	5.2	40	17	43	2.3
Wolve	66	30	4	2.2	52	20	28	2.6
Words	51	35	15	1.5	27	29	44	0.9
Wrex	73	18	10	4.1	30	27	44	1.1
York	77	16	7	4.8	49	24	28	2.1
Eng	59	20	21	2.9	21	17	62	1.2
Wales	61	20	19	3.1	27	15	57	1.8
E&W	59	20	21	2.9	28	15	57	1.8

Table F.2.1: Treatment modalities for patients aged under and over 65

	Treatment modality numbers					
	For patients aged over 65			For patients aged under 65		
	No. on HD	No. on PD	No. on transplant	No. on HD	No. on PD	No. on transplant
Eng	2939	1013	1031	3298	1798	6762
Wls	328	105	102	226	188	680
E&W	3267	1118	1133	3524	1986	7442

Table F.2.2: Number of patients under and over 65, by treatment modality

Median ages and dialysis modalities by centre					
Centre	Median age on dialysis	Median age on HD	Median age on PD	Median age transplant	Median age for all
Bradf	61.0	62.0	60.0	44.0	52.5
Bristl	65.0	66.0	61.0	49.0	56.0
Camb	60.0	64.5	57.0	48.0	52.0
Carls	66.0	68.0	59.5	49.5	57.0
Carsh	59.0	59.0	59.0	50.0	55.0
Covnt	61.0	61.5	61.0	46.5	55.0
Crdff	65.0	67.0	57.0	48.0	53.0
Derby	59.0	61.5	55.0	.	59.0
Extr	65.0	66.0	61.5	49.0	58.0
Glouc	67.5	69.5	55.0	49.0	61.0
Guys	61.0	62.0	59.0	47.0	52.0
Heart	63.0	64.0	60.0	45.5	57.0
Hull	62.0	63.5	54.0	48.0	55.0
Leic	61.0	61.5	59.0	48.0	55.0
LGI	61.0	65.0	55.0	51.0	56.0
Livrpl	58.0	60.0	53.0	48.0	53.0
Notts	61.0	62.0	59.0	47.0	54.0
Oxfrd	65.0	67.0	59.0	51.0	54.0
Plym	63.0	68.0	58.5	51.0	56.0
Ports	62.0	62.0	63.0	49.0	54.0
Prstn	61.0	63.0	57.0	51.0	58.0
Redng	61.0	60.5	58.0	48.5	58.0
S Cleve	58.5	66.0	50.0	51.0	56.0
Sheff	62.0	57.0	60.0	48.0	54.0
Stevn	57.0	66.0	62.0	50.0	62.0
Sthend	65.0	66.0	53.0	54.0	62.0
St Jms	65.0	63.0	51.0	45.5	51.0
Sund	61.0	67.0	56.0	51.0	56.0
Swnse	64.5	68.0	62.0	50.0	62.0
Truro	67.0	71.0	61.0	52.5	64.0
Wolve	68.0	62.0	63.0	48.5	60.0
Words	62.0	61.5	60.5	51.0	57.0
Wrex	63.0	69.0	55.0	48.0	58.0
York	65.0	67.0	54.0	49.0	59.5
E&W	62.0	64.0	58.0	49.0	55.0

Table F.2.3: Treatment modality median age, by centre

Dialysis modalities for patients aged under 65								
Treatment centre	**% on home HD**	**% on hosp HD**	**% on satellite HD**	**% on standard PD**	**% on disconnect PD**	**% on cycling PD ≥6 nights/wk**	**% on cycling PD <6 nights/wk**	**% on unknown type of PD**
Bristl	21	24	30	1	19	5	0	0
Carls	0	53	3	0	42	3	0	0
Carsh	2	37	15	0	33	13	0	0
Covnt	7	52	0	0	41	0	0	0
Crdff	0	27	29	0	45	0	0	0
Derby	6	51	0	0	40	2	2	0
Extr	2	26	27	0	39	3	2	0
Glouc	0	60	0	0	37	3	0	0
Guys	6	40	6	0	31	0	16	0
Heart	14	59	5	0	19	3	0	0
Hull	6	46	13	0	24	10	0	0
Leic	7	33	15	0	37	8	0	0
LGI	0	50	0	0	31	18	0	0
Notts	1	45	14	0	26	14	0	0
Oxfrd	8	49	0	0	35	7	0	0
Plym	2	51	0	0	47	0	0	0
Prstn	2	33	22	0	35	7	2	0
Redng	0	36	0	0	61	3	0	0
S Cleve	1	55	11	0	33	0	0	0
Sheff	11	43	22	0	23	1	0	0
Sthend	0	74	0	0	26	0	0	0
St Jms	2	35	39	0	19	5	0	0
Sund	2	79	0	0	3	16	0	0
Swnse	3	28	17	0	48	0	3	0
Wolve	0	35	37	0	28	0	0	0
Words	3	50	0	0	47	0	0	0
Wrex	0	58	0	0	1	39	2	0
York	0	53	20	0	27	0	0	0
E&W	5	42	14	0	32	6	1	0

Table F.2.4: Dialysis modalities for patients aged under 65

Dialysis modalities for patients aged over 65								
Treatment centre	**% on home HD**	**% on hosp HD**	**% on satellite HD**	**% on standard PD**	**% on disconnect PD**	**% on cycling PD ≥6 nights/wk**	**% on cycling PD <6 nights/wk**	**% on unknown type of PD**
Bradf	0	71	0	0	21	8	0	0
Bristl	1	20	63	0	15	1	0	0
Camb	1	58	0	0	41	0	0	0
Carls	0	68	8	0	24	0	0	0
Carsh	1	44	17	0	23	14	0	0
Covnt	0	66	0	0	34	0	0	0
Crdff	0	28	47	0	25	0	0	0
Derby	0	83	0	0	17	0	0	0
Extr	0	32	39	0	27	1	0	1
Glouc	0	83	0	3	14	0	0	0
Guys	1	36	28	0	24	0	11	0
Heart	2	75	10	0	10	2	0	0

Dialysis modalities for patients aged over 65								
Treatment centre	**% on home HD**	**% on hosp HD**	**% on satellite HD**	**% on standard PD**	**% on disconnect PD**	**% on cycling PD ≥6 nights/wk**	**% on cycling PD <6 nights/wk**	**% on unknown type of PD**
Hull	1	49	34	0	12	4	0	0
Leic	1	33	28	0	33	5	0	0
LGI	0	75	0	0	20	5	0	0
Livrpl	0	55	24	1	18	0	0	0
Notts	0	52	16	0	24	7	0	0
Oxfrd	2	73	0	0	20	5	0	0
Plym	0	83	0	0	17	0	0	0
Ports	0	40	32	0	28	0	0	0
Prstn	0	31	35	0	29	1	4	0
Redng	0	44	0	0	56	0	0	0
S Cleve	0	61	29	0	10	0	0	0
Sheff	2	51	19	0	28	1	0	0
Stevn	0	36	48	0	16	0	0	0
Sthend	2	90	0	0	8	0	0	0
St Jms	0	27	65	0	5	4	0	0
Sund	0	89	0	0	9	2	0	0
Swnse	1	41	32	0	26	0	0	0
Truro	0	84	0	0	15	1	0	0
Wolve	0	32	37	0	32	0	0	0
Words	0	59	0	0	41	0	0	0
Wrex	0	80	0	0	0	20	0	0
York	0	83	0	0	17	0	0	0
E&W	1	50	24	0	22	2	1	0

Table F.2.5: Dialysis modalities for patients aged over 65

Patient age range by centre								
Treatment centre	**% 18–24**	**% 25–34**	**% aged 35–44**	**% aged 45–54**	**% aged 55–64**	**% aged 65–74**	**% aged 75–84**	**% aged 85+**
Bradf	5	11	20	20	18	21	6	
Bristl	5	8	16	19	23	18	11	1
Camb	3	12	20	23	21	17	4	1
Carls	1	11	12	19	26	22	8	
Carsh	2	11	20	17	23	17	8	1
Covnt	2	12	18	17	21	18	11	0
Crdff	3	10	19	22	19	18	10	1
Derby	3	8	16	13	19	20	18	1
Extr	3	7	16	17	22	20	14	1
Glouc	4	7	10	16	21	21	18	4
Guys	2	12	21	21	20	17	6	1
Heart	5	10	14	15	22	22	13	1
Hull	3	8	16	19	21	18	12	2
Leic	2	10	15	21	22	20	9	1
LGI	1	9	17	18	27	21	7	
Livrpl	2	11	20	22	21	17	8	1
Notts	4	11	18	19	19	20	8	0
Oxfrd	2	9	18	21	22	18	9	1
Plym	3	8	17	19	24	16	12	1
Ports	4	10	19	20	21	17	10	1

Patient age range by centre								
Treatment centre	**% 18–24**	**% 25–34**	**% aged 35–44**	**% aged 45–54**	**% aged 55–64**	**% aged 65–74**	**% aged 75–84**	**% aged 85+**
Prstn	1	10	13	19	19	21	14	1
Redng	1	9	13	20	17	26	13	1
S Cleve	5	8	17	16	23	18	11	0
Sheff	3	10	17	22	22	19	7	0
Stevn	2	8	12	14	22	26	15	1
Sthend	1	5	12	11	24	25	17	4
St Jms	6	14	17	20	19	15	8	1
Sund	1	11	17	19	19	24	9	0
Swnse	3	6	13	15	21	26	14	3
Truro	3	6	7	13	22	24	21	3
Wolve	4	9	12	16	23	23	13	1
Words	1	8	13	23	25	21	11	
Wrex	2	8	14	20	18	20	15	2
York	4	9	12	17	13	23	20	2
E&W	3	10	17	20	21	19	10	1

Table F.2.6: Age range, by centre

Non-diabetic dialysis modalities (all patients)								
Treatment centre	**% on home HD**	**% on hospital HD**	**% on satellite HD**	**% on CAPD connect**	**% on CAPD disconnect**	**% on cycling PD ≥6 nights/wk**	**% on cycling PD <6 nights/wk**	**% on PD type unknown**
Bradf	0	64	0	0	27	9	0	0
Bristl	10	20	48	0	20	2	0	0
Camb	4	42	0	0	53	0	1	0
Carls	0	61	3	0	34	2	0	0
Carsh	3	45	16	0	19	17	0	0
Covnt	4	62	0	0	34	0	0	0
Crdff	0	30	34	0	36	0	0	0
Derby	3	69	0	0	27	0	0	0
Extr	2	29	37	0	30	0	1	0
Glouc	0	75	0	2	23	1	0	0
Guys	6	36	22	0	24	0	13	0
Heart	8	69	7	0	13	3	0	0
Hull	5	50	20	0	18	8	0	0
Leic	4	31	23	0	31	10	0	0
LGI	0	59	0	0	28	13	0	0
Livrpl	1	41	32	1	24	0	1	0
Notts	1	47	15	0	22	15	0	0
Oxfrd	6	65	0	0	21	8	0	0
Plym	2	72	0	0	27	0	0	0
Ports	1	38	33	0	28	0	0	0
Prstn	1	28	28	0	35	6	2	0
Redng	0	44	0	0	56	0	0	0
S Cleve	1	58	21	0	20	0	0	0
Sheff	8	49	20	0	23	0	0	0
Stevn	0	38	43	0	19	0	0	0
Sthend	1	86	0	0	13	0	0	0
St Jms	1	25	57	0	10	6	0	0
Sund	1	83	0	0	7	8	1	0
Swnse	2	36	28	0	32	0	1	0

Non-diabetic dialysis modalities (all patients)								
Treatment centre	**% on home HD**	**% on hospital HD**	**% on satellite HD**	**% on CAPD connect**	**% on CAPD disconnect**	**% on cycling PD ≥6 nights/wk**	**% on cycling PD <6 nights/wk**	**% on PD type unknown**
Truro	0	76	0	0	21	3	0	0
Wolve	0	34	36	0	30	0	0	0
Words	2	52	0	0	45	0	0	0
Wrex	0	65	0	0	3	31	1	0
York	0	76	2	0	21	0	0	0
E&W	**3**	**46**	**21**	**0**	**26**	**4**	**1**	**0**

Table F.2.7: Treatment modalities for non-diabetic patients

Non-diabetic dialysis modalities (all patients)			
	No. on HD	**No. on PD**	**No on Transplant**
E&W	5327	2343	7819

Table F.2.8: Number of non-diabetic patients, by treatment modality

Non-diabetic treatment modalities for patients aged under 65								
Treatment centre	**% on home HD**	**% on hospital HD**	**% on satellite HD**	**% on CAPD connect**	**% on CAPD disconnect**	**% on cycling PD ≥6 nights/wk**	**% on cycling PD <6 nights/wk**	**% on PD Type Unknown**
Bradf	0	60	0	0	31	10	0	0
Bristl	19	21	33	0	24	3	1	0
Camb	6	35	0	0	58	0	1	0
Carls	0	55	0	0	41	3	0	0
Carsh	3	47	17	0	17	16	0	0
Covnt	7	59	0	0	34	0	0	0
Crdff	0	27	28	0	45	0	0	0
Derby	5	62	0	0	32	0	0	0
Extr	3	28	27	0	39	0	2	0
Glouc	0	65	0	0	33	2	0	0
Guys	9	36	17	0	26	0	12	0
Heart	13	63	6	0	15	4	0	0
Hull	7	50	9	0	22	11	0	0
Leic	7	31	19	0	31	12	0	0
LGI	0	48	0	0	34	18	0	0
Livrpl	1	33	36	0	28	1	1	0
Notts	1	43	14	0	21	20	0	0
Oxfrd	10	56	0	0	23	11	0	0
Plym	3	61	0	0	36	0	0	0
Ports	1	37	34	0	29	0	0	0
Prstn	2	27	23	0	38	10	0	0
Redng	0	40	0	0	60	0	0	0
S Cleve	1	55	14	0	30	0	0	0
Sheff	11	47	20	0	21	0	0	0
Stevn	0	39	38	0	23	0	0	0
Sthend	0	84	0	0	16	0	0	0
St Jms	2	28	49	0	15	6	0	0
Sund	2	79	0	0	2	14	2	0
Swnse	4	30	23	0	41	0	2	0
Truro	0	68	0	0	27	5	0	0

Non-diabetic treatment modalities for patients aged under 65								
Treatment centre	% on home HD	% on hospital HD	% on satellite HD	% on CAPD connect	% on CAPD disconnect	% on cycling PD ≥6 nights/wk	% on cycling PD <6 nights/wk	% on PD Type Unknown
Wolve	0	39	34	0	26	1	0	0
Words	4	45	0	0	51	0	0	0
Wrex	0	55	0	0	5	38	2	0
York	0	68	5	0	28	0	0	0
E&W	5	42	18	0	29	5	1	0

Table F 2.9: Treatment modalities for non-diabetic patients aged under 65

Non-diabetic dialysis modalities for patients aged <65			
	No. on HD	No. on PD	No. on transplant
E&W	2776	1480	6747

Table F.2.10: Number of non-diabetic patients aged under 65, by treatment modality

Non-diabetic treatment modalities for patients aged over 65								
Treatment centre	% on home HD	% on hospital HD	% on satellite HD	% on CAPD standard	% on CAPD disconnect	% on cycling PD ≥6 nights/wk	% on cycling PD <6 nights/wk	% on PD type unknown
Bradf	0	71	0	0	21	9	0	0
Bristl	1	19	63	0	15	2	0	0
Camb	1	53	0	0	45	0	0	0
Carls	0	66	6	0	28	0	0	0
Carsh	3	40	14	0	24	19	0	0
Covnt	0	65	0	0	35	0	0	0
Crdff	0	33	41	0	26	0	0	0
Derby	0	80	0	0	20	0	0	0
Extr	0	31	52	0	18	0	0	0
Glouc	0	82	0	3	15	0	0	0
Guys	1	35	29	0	22	0	14	0
Heart	2	76	9	0	10	2	0	0
Hull	1	48	35	0	11	4	0	0
Leic	1	32	29	0	32	6	0	0
LGI	0	76	0	0	18	5	0	0
Livrpl	0	54	24	2	19	0	1	1
Notts	1	52	17	0	23	8	0	0
Oxfrd	3	73	0	0	19	6	0	0
Plym	0	86	0	0	14	0	0	0
Ports	0	39	33	0	27	0	0	0
Prstn	0	29	37	0	29	1	4	0
Redng	0	49	0	0	51	0	0	0
S Cleve	0	62	29	0	9	0	0	0
Sheff	2	53	19	0	26	0	0	0
Stevn	0	36	47	0	16	0	0	0
Sthend	2	88	0	0	10	0	0	0
St Jms	0	22	70	0	4	5	0	0
Sund	0	87	0	0	11	2	0	0
Swnse	1	42	33	0	25	0	0	0
Truro	0	82	0	0	17	2	0	0

Non-diabetic treatment modalities for patients aged over 65								
Treatment centre	% on home HD	% on hospital HD	% on satellite HD	% on CAPD standard	% on CAPD disconnect	% on cycling PD ≥6 nights/wk	% on cycling PD <6 nights/wk	% on PD type unknown
Wolve	0	28	37	0	34	0	0	0
Words	0	63	0	0	38	0	0	0
Wrex	0	76	0	0	0	24	0	0
York	0	84	0	0	16	0	0	0
E&W	1	50	24	0	22	2	1	0

Table F.2.11: Treatment modalities for non-diabetic patients aged over 65

Non-diabetic dialysis modalities for patients aged 65 and over			
	No. on HD	No. on PD	No. on transplant
E&W	2551	863	1072

Table F.2.12: Number of non-diabetic patients aged over 65, by treatment modality

Diabetic patient dialysis modalities								
Treatment centre	% on home HD	% on hospital HD	% on satellite HD	% on CAPD standard	% on CAPD disconnect	% on cycling PD ≥6 nights/wk	% on cycling PD <6 nights/wk	% on PD type unknown
Bradf	0	58	0	0	19	23	0	0
Bristl	3	27	48	0	18	3	0	0
Camb	0	44	0	0	56	0	0	0
Carls	0	62	8	0	15	15	0	0
Carsh	0	25	22	0	25	28	0	0
Covnt	0	62	0	0	38	0	0	0
Crdff	0	26	50	0	24	0	0	0
Derby	0	60	0	0	40	0	0	0
Extr	0	30	30	0	39	0	0	0
Glouc	0	69	0	0	31	0	0	0
Guys	0	40	18	0	34	0	8	0
Heart	0	67	10	0	24	0	0	0
Hull	0	49	24	0	15	12	0	0
Leic	1	42	16	0	33	8	0	0
LGI	0	61	0	0	26	13	0	0
Livrpl	0	51	22	1	23	0	2	0
Notts	0	51	15	0	26	8	0	0
Oxfrd	1	48	0	0	31	19	0	0
Plym	0	55	0	0	45	0	0	0
Ports	0	32	28	0	40	0	0	0
Prstn	0	31	31	0	33	4	0	0
Redng	0	33	0	0	67	0	0	0
S Cleve	3	63	18	0	18	0	0	0
Sheff	4	51	12	0	32	1	0	0
Stevn	0	35	38	0	28	0	0	0
Sthend	0	75	0	0	25	0	0	0
St Jms	0	36	45	0	17	2	0	0
Sund	0	88	0	0	6	6	0	0

Diabetic patient dialysis modalities								
Treatment centre	% on home HD	% on hospital HD	% on satellite HD	% on CAPD standard	% on CAPD disconnect	% on cycling PD ≥6 nights/wk	% on cycling PD <6 nights/wk	% on PD type unknown
Swnse	2	29	22	0	47	0	0	0
Truro	0	79	0	0	16	5	0	0
Wolve	0	35	38	0	27	0	0	0
Words	0	42	0	0	58	0	0	0
Wrex	0	71	0	0	0	29	0	0
York	0	60	0	0	40	0	0	0
E&W	1	46	18	0	30	5	1	0

Table F.2.13: Treatment modalities for diabetic patients

Diabetic patient dialysis modalities			
	No. on HD	No. on PD	No. on transplant
E&W	5327	2343	7819

Table F.2.14: Number of diabetic patients, by treatment modality

Centre	Median age on 31 Dec 01	Median age at start of treatment	% with age known at start of treat	M:F ratio	Median time on ESRF treatment	
					In days	In years
Bradf	54	51		1	545	1
Bristl	55	53		1	1088	3
Camb	49	42		1	1258	3
Carls	59	57		1	1413	4
Carsh	53	47		1	1503	4
Covnt	51	47		1	906	2
Crdff	55	53		2	1158	3
Derby	57	56		3	263	1
Extr	59	56		2	931	3
Glouc	57	53		1	963	3
Guys	55	53		1	1044	3
Heart	60	56		1	667	2
Hull	57	55		1	752	2
Leic	54	51		2	1153	3
LGI	51	49		1	747	2
Livrpl	55	50		2	827	2
Notts	58	54		1	1092	3
Oxfrd	52	48		1	1112	3
Plym	54	52		1	962	3
Ports	53	48		1	1265	3
Prstn	64	58		2	515	1
Redng	54	53		2	630	2
S Cleve	58	57		2	514	1
Sheff	54	50		3	816	2
Stevn	58	55		1	894	2
Sthend	59	56		2	812	2
St Jms	52	49		1	1098	3
Sund	49	49		3	1005	3
Swnse	61	57		1	699	2
Truro	65	65		1	776	2
Wolve	60	57		2	969	3

Centre	Median age on 31 Dec 01	Median age at start of treatment	% with age known at start of treat	M:F ratio	Median time on ESRF treatment	
					In days	In years
Words	61	58		2	1094	3
Wrex	52	48		2	1311	4
York	47	47		1	291	1
E&W	42	41		1	427	1

Table F.2.15: Diabetics

Treatment Centre	% of males	% of females	% unknown	No. of males	No. of females	No. unknown	Male to Female Ratio
E&W	62.6	37.4	0.0	545.0	325.0	0.0	1.7

Table F.2.16: Transplant gender ratio

F:3 Haemoglobin

Age (years) Group	18–34	35–44	45–54	55–64	65–74	75+
% on EPO	88	81	79	83	83	85
% Hb>10 g/dl no EPO	8 (21)	16 (60)	15 (74)	12 (82)	12 (105)	10 (66)
% Hb < 10 g/dl on EPO	90 (53)	91 (73)	82 (87)	85 (118)	84 (139)	92 (102)

Table F.3.1: Erythropoietin (EPO) prescription, by age, in haemodialysis patients

F:4 Cause of Death

	Count			Percentage		
	<65	65+	Total	<65	65+	Total
Myocardial ischaemia and infarction [11]	320	552	872	18.1%	17.5%	17.7%
Hyperkalaemia [12]	17	1	18	1.0%	0.0%	0.4%
Haemorrhagic pericarditis [13]	3	1	4	0.2%	0.0%	0.1%
Other causes of cardiac failure [14]	74	115	189	4.2%	3.6%	3.8%
Cardiac arrest/sudden death; other cause or unknown [15]	158	210	368	8.9%	6.6%	7.5%
Hypertensive cardiac failure [16]	10	13	23	0.6%	0.4%	0.5%
Hypokalaemia [17]		1	1	0.0%	0.0%	0.0%
Fluid overload/pulmonary oedema [18]	26	33	59	1.5%	1.0%	1.2%
Pulmonary embolus [21]	9	15	24	0.5%	0.5%	0.5%
Cerebrovascular accident, other cause or unspecified [22]	159	239	398	9.0%	7.6%	8.1%
Gastrointestinal haemorrhage (digestive) [23]	21	47	68	1.2%	1.5%	1.4%
Haemorrhage from graft site [24]	5	1	6	0.3%	0.0%	0.1%
Haemorrhage from vascular access or dialysis circuit [25]	1	6	7	0.1%	0.2%	0.1%
Haemorrhage from ruptured vascular aneurysm (not code 22 or 23) [26]	18	32	50	1.0%	1.0%	1.0%
Haemorrhage from surgery (not codes 23, 24, 26) [27]	2	1	3	0.1%	0.0%	0.1%
Other haemorrhage (not codes 23-27) [28]	16	22	38	0.9%	0.7%	0.8%
Mesenteric infarction [29]	8	20	28	0.5%	0.6%	0.6%
Pulmonary infection bacterial (not code 73) [31]	102	244	346	5.8%	7.7%	7.0%
Pulmonary infection (viral) [32]	2	3	5	0.1%	0.1%	0.1%
Pulmonary infection (fungal or protozoal; parasitic) [33]	1	1	2	0.1%	0.0%	0.0%
Infections elsewhere except viral hepatitis	17	27	44	1.0%	0.9%	0.9%
Septicaemia [35]	158	197	355	8.9%	6.2%	7.2%
Tuberculosis (lung) [36]	1	2	3	0.1%	0.1%	0.1%

	Count			Percentage		
	<65	65+	Total	<65	65+	Total
Tuberculosis (elsewhere) [37]	3	1	4	0.2%	0.0%	0.1%
Generalised viral infection [38]	1	2	3	0.1%	0.1%	0.1%
Peritonitis (all causes except for peritoneal dialysis) [39]	33	70	103	1.9%	2.2%	2.1%
Liver disease due to hepatitis B virus [41]	1	1	2	0.1%	0.0%	0.0%
Liver disease due to other viral hepatitis [42]	1		1	0.1%	0.0%	0.0%
Cirrhosis – not viral (alcoholic or other cause) [44]	4	1	5	0.2%	0.0%	0.1%
Cystic liver disease [45]	1		1	0.1%	0.0%	0.0%
Liver failure – cause unknown [46]	2	1	3	0.1%	0.0%	0.1%
Patient refused further treatment for ESRF [51]	28	113	141	1.6%	3.6%	2.9%
Suicide [52]	10		10	0.6%	0.0%	0.2%
ESRF treatment ceased for any other reason [53]	54	231	285	3.1%	7.3%	5.8%
ESRF treatment withdrawn for medical reasons [54]	34	156	190	1.9%	4.9%	3.9%
Uraemia caused by graft failure [61]		2	2	0.0%	0.1%	0.0%
Pancreatitis [62]	4	1	5	0.2%	0.0%	0.1%
Bone marrow depression (aplasia) [63]		2	2	0.0%	0.1%	0.0%
Cachexia [64]	17	23	40	1.0%	0.7%	0.8%
Malignant disease in patient treated by immunosuppressive therapy [66]	9	10	19	0.5%	0.3%	0.4%
Malignant disease: solid tumors except those of 66 [67]	105	173	278	5.9%	5.5%	5.6%
Malignant disease: lymphoproliferative disorders (except 66) [68]	9	18	27	0.5%	0.6%	0.5%
Dementia [69]	7	14	21	0.4%	0.4%	0.4%
Peritonitis (sclerosing, with peritoneal dialysis) [70]	9	3	12	0.5%	0.1%	0.2%
Perforation of peptic ulcer [71]	5	4	9	0.3%	0.1%	0.2%
Perforation of colon [72]	5	15	20	0.3%	0.5%	0.4%
Chronic obstructive pulmonary disease [73]	10	27	37	0.6%	0.9%	0.8%
Accident related to ESRF treatment (not 25) [81]		5	5	0.0%	0.2%	0.1%
Accident unrelated to ESRF treatment [82]	3	5	8	0.2%	0.2%	0.2%
Other identified cause of death [99] uncertain/not determined [0]	274	484	758	15.5%	15.3%	15.4%
Peritonitis (bacterial, with peritoneal dialysis) [100]	10	13	23	0.6%	0.4%	0.5%
Peritonitis (fungal, with peritoneal dialysis) [101]		1	1	0.0%	0.0%	0.0%
Peritonitis (due to other cause, with peritoneal dialysis) [102]		1	1	0.0%	0.0%	0.0%
	1767	3160	4927	100.0%	100.0 %	100.0%

Table F.4.1: Cause of death, by European Dialysis and Transplant Association code, in dialysis patients

DIALYSIS	Cerebro-vascular accident	ESRF trt stopped	Heart	Infection	Malignancy	Others	Uncertain or not determined	Total	Cerebro-vascular accident	ESRF trt stopped	Heart	Infection	Malignancy	Others	Uncertain or not determined	Total	Med age at start	Med age at death	Med age at start
Chronic renal failure; aetiology uncertain [0]	89	154	366	231	78	119	187	1224	7.3%	12.6%	29.9%	18.9%	6.4%	9.7%	15.3%	100.0%	68.0	71.0	65
Glomerulonephritis; histologically **not** examined [10]	30	22	110	45	23	32	40	302	9.9%	7.3%	36.4%	14.9%	7.6%	10.6%	13.2%	100.0%	54.0	62.0	49
Focal segmental glomeruloscerosis with nephrotic syndrome in children [11]			2	1	1	1		5	0.0%	0.0%	40.0%	20.0%	20.0%	20.0%	0.0%	100.0%	18.0	21.0	45.5
IgA nephropathy (proven by immunofluorescence, not code 76 and not 85) [12]	4	5	26	8	10	8	11	72	5.6%	6.9%	36.1%	11.1%	13.9%	11.1%	15.3%	100.0%	59.0	62.5	44
Dense deposit disease; membrano-proliferative GN; type II (proven by immunofluorescence and/or electron microscopy) [13]	1	1	3	1	2	2		10	10.0%	10.0%	30.0%	10.0%	20.0%	20.0%	0.0%	100.0%	58.5	64.5	32
Membranous nephropathy [14]	13	3	19	11	5	5	3	59	22.0%	5.1%	32.2%	18.6%	8.5%	8.5%	5.1%	100.0%	64.0	66.0	60
Membrano-proliferative GN; type I (proven by immunofluorescence and/or electron microscopy – not code 84 or 89) [15]	5	5	16	8	7	6	7	54	9.3%	9.3%	29.6%	14.8%	13.0%	11.1%	13.0%	100.0%	58.5	63.0	45.5
Crescentic (extracapillary) glomerulonephritis (type I, II, III) [16]	6	2	9	8	3	4	11	43	14.0%	4.7%	20.9%	18.6%	7.0%	9.3%	25.6%	100.0%	68.0	70.0	61
Focal segmental glomeruloscerosis with nephrotic syndrome in adults [17]		2	5	2		1	1	11	0.0%	18.2%	45.5%	18.2%	0.0%	9.1%	9.1%	100.0%	59.5	65.0	44

DIALYSIS	Cerebro-vascular accident	ESRF trt stopped	Heart	Infection	Malignancy	Others	Uncertain or not determined	Total	Cerebro-vascular accident	ESRF trt stopped	Heart	Infection	Malignancy	Others	Uncertain or not determined	Total	Med age at start	Med age at death	Med age at start
Glomerulonephritis; histologically examined, not given above [19]	24	15	104	49	19	35	34	280	8.6%	5.4%	37.1%	17.5%	6.8%	12.5%	12.1%	100.0%	54.0	61.0	48
Pyelonephritis – cause not specified [20]	20	23	67	41	15	35	32	233	8.6%	9.9%	28.8%	17.6%	6.4%	15.0%	13.7%	100.0%	50.0	60.0	44.5
Pyelonephritis associated with neurogenic bladder [21]	3	2	5	6	3	2	6	27	11.1%	7.4%	18.5%	22.2%	11.1%	7.4%	22.2%	100.0%	32.0	43.0	36
Pyelonephritis due to congenital obstructive uropathy with/without vesico-ureteric reflux [22]	4	4	8	4	4	6	5	35	11.4%	11.4%	22.9%	11.4%	11.4%	17.1%	14.3%	100.0%	42.0	48.0	34
Pyelonephritis due to acquired obstructive uropathy [23]	18	43	77	30	32	27	30	257	7.0%	16.7%	30.0%	11.7%	12.5%	10.5%	11.7%	100.0%	71.0	74.0	70
Pyelonephritis due to vesico-ureteric reflux without obstruction [24]	4	2	19	12	4	8	5	54	7.4%	3.7%	35.2%	22.2%	7.4%	14.8%	9.3%	100.0%	41.0	52.5	34
Pyelonephritis due to urolithiasis [25]	5	8	23	16	4	7	8	71	7.0%	11.3%	32.4%	22.5%	5.6%	9.9%	11.3%	100.0%	63.0	68.0	63
Pyelonephritis due to other cause [29]	4	1	8	11	2		2	28	14.3%	3.6%	28.6%	39.3%	7.1%	0.0%	7.1%	100.0%	65.0	71.0	59.5
Interstitial nephritis (not pyelonephritis) due to other cause, or unspecified (not mentioned above) [30]	2	7	4	6	3	5	2	29	6.9%	24.1%	13.8%	20.7%	10.3%	17.2%	6.9%	100.0%	66.0	68.0	61
Nephropathy (interstitial) due to analgesic drugs [31]	4	2	10	6	1	6	5	34	11.8%	5.9%	29.4%	17.6%	2.9%	17.6%	14.7%	100.0%	56.0	63.5	61
Nephropathy (interstitial) due to cyclosporin A [33]	2		10	3	2	2	3	22	9.1%	0.0%	45.5%	13.6%	9.1%	9.1%	13.6%	100.0%	50.5	53.0	55
Drug induced nephropathy (interstitial) not mentioned above [39]		1	7	4	2	2	2	18	0.0%	5.6%	38.9%	22.2%	11.1%	11.1%	11.1%	100.0%	56.5	59.5	57

DIALYSIS	Cerebro-vascular accident	ESRF trt stopped	Heart	Infection	Malignancy	Others	Uncertain or not determined	Total	Cerebro-vascular accident	ESRF trt stopped	Heart	Infection	Malignancy	Others	Uncertain or not determined	Total	Med age at start	Med age at death	Med age at start
Cystic kidney disease – type unspecified [40]	2		11	7	1	2	1	24	8.3%	0.0%	45.8%	29.2%	4.2%	8.3%	4.2%	100.0%	56.5	59.5	63.5
Polycystic kidneys; adult type (dominant) [41]	29	24	102	58	25	49	53	340	8.5%	7.1%	30.0%	17.1%	7.4%	14.4%	15.6%	100.0%	56.0	63.0	53
Polycystic kidneys; infantile (recessive) [42]	1					1		2	50.0%	0.0%	0.0%	0.0%	0.0%	50.0%	0.0%	100.0%	22.5	32.0	40.5
Medullary cystic disease; including nephronophtisis [43]			4	1	1	3		9	0.0%	0.0%	44.4%	11.1%	11.1%	33.3%	0.0%	100.0%	34.0	46.0	41
Cystic kidney disease – other specified type [49]	1		2	1	1		1	6	16.7%	0.0%	33.3%	16.7%	16.7%	0.0%	16.7%	100.0%	46.0	50.5	64
Hereditary/familial nephropathy – type unspecified [50]			4	4	2	2	1	13	0.0%	0.0%	30.8%	30.8%	15.4%	15.4%	7.7%	100.0%	37.0	42.0	37
Hereditary nephritis with nerve deafness (Alport's ayndrome) [51]			4	3	2			9	0.0%	0.0%	44.4%	33.3%	22.2%	0.0%	0.0%	100.0%	30.0	45.0	27.5
Cystinosis [52]	1			1				2	50.0%	0.0%	0.0%	50.0%	0.0%	0.0%	0.0%	100.0%	62.0	68.0	21
Primary oxalosis [53]				1				1	0.0%	0.0%	0.0%	100.0%	0.0%	0.0%	0.0%	100.0%	43.0	45.0	22
Fabry's disease [54]			1		1			2	0.0%	0.0%	50.0%	0.0%	50.0%	0.0%	0.0%	100.0%	43.0	51.5	40
Hereditary nephropathy – other specified type [59]					1		1	2	0.0%	0.0%	0.0%	0.0%	50.0%	0.0%	50.0%	100.0%	58.5	61.5	32
Renal hypoplasia (congenital) – type unspecified [60]		1	3	3	1	2		10	0.0%	10.0%	30.0%	30.0%	10.0%	20.0%	0.0%	100.0%	24.0	33.0	38
Congenital renal dysplasia with or without urinary tract malformation [63]			8	3		1	2	14	0.0%	0.0%	57.1%	21.4%	0.0%	7.1%	14.3%	100.0%	26.5	34.5	28
Renal vascular disease – type unspecified [70]	15	25	85	41	6	30	25	227	6.6%	11.0%	37.4%	18.1%	2.6%	13.2%	11.0%	100.0%	70.0	72.0	70

DIALYSIS	Cerebro-vascular accident	ESRF trt stopped	Heart	Infection	Malignancy	Others	Uncertain or not determined	Total	Cerebro-vascular accident	ESRF trt stopped	Heart	Infection	Malignancy	Others	Uncertain or not determined	Total	Med age at start	Med age at death	Med age at start
Renal vascular disease due to malignant hypertension [71]	11	7	36	12	8	12	19	105	10.5%	6.7%	34.3%	11.4%	7.6%	11.4%	18.1%	100.0%	56.0	62.0	51
Renal vascular disease due to hypertension [72]	30	35	133	50	18	40	73	379	7.9%	9.2%	35.1%	13.2%	4.7%	10.6%	19.3%	100.0%	65.0	69.0	63
Renal vascular disease due to polyarteritis [73]	5	10	21	17	4	10	10	77	6.5%	13.0%	27.3%	22.1%	5.2%	13.0%	13.0%	100.0%	65.0	69.0	65
Wegener's granulomatosis [74]	5	16	14	20	2	10	8	75	6.7%	21.3%	18.7%	26.7%	2.7%	13.3%	10.7%	100.0%	70.0	72.0	65
Ischaemic renal disease/cholesterol embolism [75]	2	2	14	5	1	4	2	30	6.7%	6.7%	46.7%	16.7%	3.3%	13.3%	6.7%	100.0%	68.0	69.0	72
Renal vascular disease – due to other cause (not given above and not code 84-88) [79]	5	19	37	13	7	9	2	92	5.4%	20.7%	40.2%	14.1%	7.6%	9.8%	2.2%	100.0%	72.0	73.0	72
Type 1 diabetes with diabetic nephropathy [80]	55	67	273	115	18	48	115	691	8.0%	9.7%	39.5%	16.6%	2.6%	6.9%	16.6%	100.0%	54.0	57.0	52
Type 2 diabetes with diabetic nephropathy [81]	29	36	130	63	5	22	47	332	8.7%	10.8%	39.2%	19.0%	1.5%	6.6%	14.2%	100.0%	65.0	67.0	65
Myelomatosis/light chain deposit disease [82]	12	28	18	30	72	11	19	190	6.3%	14.7%	9.5%	15.8%	37.9%	5.8%	10.0%	100.0%	68.0	69.0	68
Amyloid [83]	11	16	38	30	9	18	20	142	7.7%	11.3%	26.8%	21.1%	6.3%	12.7%	14.1%	100.0%	64.0	65.5	63
Lupus erythematosus [84]	2	2	18	11	1	4	6	44	4.5%	4.5%	40.9%	25.0%	2.3%	9.1%	13.6%	100.0%	42.5	50.0	35
Henoch Schoenlein purpura [85]	2	2	6	3	2	1	3	19	10.5%	10.5%	31.6%	15.8%	10.5%	5.3%	15.8%	100.0%	47.0	59.0	36
Goodpasture's Syndrome [86]		3	6	10	3		3	25	0.0%	12.0%	24.0%	40.0%	12.0%	0.0%	12.0%	100.0%	65.0	68.0	59
Systemic sclerosis (scleroderma) [87]	2	1	6	3	1	1	3	17	11.8%	5.9%	35.3%	17.6%	5.9%	5.9%	17.6%	100.0%	56.0	58.0	63
Haemolytic uraemic syndrome (including Moschcowitz Syndrome) [88]	2	1	1	2	3		3	12	16.7%	8.3%	8.3%	16.7%	25.0%	0.0%	25.0%	100.0%	60.5	65.5	33

DIALYSIS	Cerebro-vascular accident	ESRF trt stopped	Heart	Infection	Malignancy	Others	Uncertain or not determined	Total	Cerebro-vascular accident	ESRF trt stopped	Heart	Infection	Malignancy	Others	Uncertain or not determined	Total	Med age at start	Med age at death	Med age at start
Multisystem disease – other (not mentioned above) [89]		3	2	4	3	1	3	16	0.0%	18.8%	12.5%	25.0%	18.8%	6.3%	18.8%	100.0%	65.0	67.5	64
Tubular necrosis (irreversible) or cortical necrosis (different from 88) [90]	1	3	16	10	3	1	7	41	2.4%	7.3%	39.0%	24.4%	7.3%	2.4%	17.1%	100.0%	69.0	70.0	66.5
Tuberculosis [91]		1	4	2	1	3	3	14	0.0%	7.1%	28.6%	14.3%	7.1%	21.4%	21.4%	100.0%	63.0	66.5	49.5
Gout nephropathy (urate) [92]			1	2		1	1	5	0.0%	0.0%	20.0%	40.0%	0.0%	20.0%	20.0%	100.0%	59.0	59.0	45.5
Nephrocalcinosis and hypercalcaemic nephropathy [93]		1	4	4	4	1		14	0.0%	7.1%	28.6%	28.6%	28.6%	7.1%	0.0%	100.0%	60.5	65.0	50.5
Kidney tumour [95]	3	2	7	6	21		8	47	6.4%	4.3%	14.9%	12.8%	44.7%	0.0%	17.0%	100.0%	67.0	70.0	65
Traumatic or surgical loss of kidney [96]		4	5	3	6	4	2	24	0.0%	16.7%	20.8%	12.5%	25.0%	16.7%	8.3%	100.0%	63.0	67.0	59
Other identified renal disorders [99]	5	14	20	22	8	6	9	84	6.0%	16.7%	23.8%	26.2%	9.5%	7.1%	10.7%	100.0%	62.0	64.0	59
Code not sent [199]	16	34	59	45	12	24	43	233	6.9%	14.6%	25.3%	19.3%	5.2%	10.3%	18.5%	100.0%	69.0	71.0	68
TOTAL	485	659	1991	1108	473	634	887	6237	7.8%	10.6%	31.9%	17.8%	7.6%	10.2%	14.2%	100.0%	63.0	66.0	59

Table F.4.2: Cause of death by primary renal diagnosis

TRANSPLANT	Count			Percent		
	<55	55+	Total	<55	55+	Total
Myocardial ischaemia and infarction [11]	123	168	291	20.8%	23.4%	22.2%
Hyperkalaemia [12]	11	3	14	1.9%	0.4%	1.1%
Haemorrhagic pericarditis [13]	2		2	0.3%	0.0%	0.2%
Other causes of cardiac failure [14]	31	43	74	5.2%	6.0%	5.6%
Cardiac arrest/sudden death; other cause or unknown [15]	48	44	92	8.1%	6.1%	7.0%
Hypertensive cardiac failure [16]	8	2	10	1.4%	0.3%	0.8%
Fluid overload/pulmonary oedema [18]	10	3	13	1.7%	0.4%	1.0%
Pulmonary embolus [21]	11	9	20	1.9%	1.3%	1.5%
Cerebrovascular accident, other cause or unspecified [22]	41	46	87	6.9%	6.4%	6.6%
Gastrointestinal haemorrhage (digestive) [23]	11	6	17	1.9%	0.8%	1.3%
Haemorrhage from graft site [24]	6	1	7	1.0%	0.1%	0.5%
Haemorrhage from ruptured vascular aneurysm (not code 22 or 23) [26]	7	9	16	1.2%	1.3%	1.2%
Haemorrhage from surgery (not codes 23, 24, 26) [27]	1	4	5	0.2%	0.6%	0.4%
Other haemorrhage (not codes 23-27) [28]	4	4	8	0.7%	0.6%	0.6%
Mesenteric infarction [29]	4	10	14	0.7%	1.4%	1.1%
Pulmonary infection bacterial (not code 73) [31]	29	48	77	4.9%	6.7%	5.9%
Pulmonary infection (viral) [32]	7	1	8	1.2%	0.1%	0.6%
Pulmonary infection (fungal or protozoal; parasitic) [33]	5	4	9	0.8%	0.6%	0.7%
Infections elsewhere except viral hepatitis [34]	11	4	15	1.9%	0.6%	1.1%
Septicaemia [35]	47	54	101	7.9%	7.5%	7.7%
Generalised viral infection [38]	7	5	12	1.2%	0.7%	0.9%
Peritonitis (all causes except for peritoneal dialysis) [39]	10	10	20	1.7%	1.4%	1.5%
Liver disease due to hepatitis B virus [41]		1	1	0.0%	0.1%	0.1%
Liver disease due to other viral hepatitis [42]		2	2	0.0%	0.3%	0.2%
Liver disease due to drug toxicity [43]	1	1	2	0.2%	0.1%	0.2%
Cirrhosis – not viral (alcoholic or other cause) [44]		1	1	0.0%	0.1%	0.1%
Patient refused further treatment for ESRF [51]	10	7	17	1.7%	1.0%	1.3%
Suicide [52]	6	3	9	1.0%	0.4%	0.7%
ESRF treatment ceased for any other reason [53]	5	9	14	0.8%	1.3%	1.1%
ESRF treatment withdrawn for medical reasons [54]	4	8	12	0.7%	1.1%	0.9%
Uraemia caused by graft failure [61]	3	1	4	0.5%	0.1%	0.3%
Pancreatitis [62]	8	1	9	1.4%	0.1%	0.7%
Bone marrow depression (aplasia) [63]	1		1	0.2%	0.0%	0.1%
Cachexia [64]	1	2	3	0.2%	0.3%	0.2%
Malignant disease in patient treated by immunosuppressive therapy [66]	27	52	79	4.6%	7.2%	6.0%
Malignant disease: solid tumors except those of 66 [67]	21	47	68	3.5%	6.5%	5.2%
Malignant disease: lymphoproliferative disorders (except 66) [68]	2		2	0.3%	0.0%	0.2%
Dementia [69]		4	4	0.0%	0.6%	0.3%
Peritonitis (sclerosing, with peritoneal dialysis) [70]	2	1	3	0.3%	0.1%	0.2%
Perforation of peptic ulcer [71]	2		2	0.3%	0.0%	0.2%
Perforation of colon [72]	1	5	6	0.2%	0.7%	0.5%
Chronic obstructive pulmonary disease [73]	4	6	10	0.7%	0.8%	0.8%
Accident related to ESRF treatment (not 25) [81]		2	2	0.0%	0.3%	0.2%
Accident unrelated to ESRF treatment [82]	1	3	4	0.2%	0.4%	0.3%
Other identified cause of death [99] uncertain/not determined [0]	57	80	137	9.6%	11.1%	10.5%
Peritonitis (bacterial, with peritoneal dialysis) [100]	1	4	5	0.2%	0.6%	0.4%
Peritonitis (fungal, with peritoneal dialysis) [101]	1		1	0.2%	0.0%	0.1%
	592	718	1310	100.0%	100.0%	100.0%

Table F.4.3: Cause of death, by European Dialysis and Transplant Association code, in transplant patients

EDTA 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
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

EDTA CODE	TITLE	Group
76	Glomerulonephritis related to liver cirrhosis [76]	Other
78	Cryoglobulinaemic 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 I diabetes with diabetic nephropathy [80]	Diabetes
81	Type II 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 uraemic syndrome (including Moschcowitz syndrome) [88]	Other
89	Multisystem 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

Table F.4..4: Collation of European Dialysis and Transplant Association primary renal diagnoses

Appendix G: Laboratory Conversion Factors and Centre Names

Laboratory conversion factors from SI

	Conversion factors from SI units
Albumin	g/dL = g/L × 0.1
Bicarbonate	mg/dL = mmol/L × 6.1
Bilirubin	mg/dL = mmol/L × 0.058
Calcium	mg/dL = mmol/L × 4
Creatinine	mg/dL = umol/L × 0.011
Glucose	mg/dL = mmol/L × 18
Phosphate	mg/dL = mmol/L × 3.1
Cholesterol	mg/dL = mmol/L × 38.6
Parathyroid hormone	ng/L = pmol/L × 9.5
Urea	mg/dL = mmol/L × 2.8
Haemoglobin	Hct = g/dL × 3.11 (this is factor is variable)

Centre abbreviations used in Chapters 4 and 5

City	**Abbrev**	**Renal unit**
Birmingham Heartlands	Heart	Heartlands Hospital
Bristol	Bristl	Southmead Hospital
Cardiff	Crdff	University of Wales Hospital
Carlisle	Carls	Cumberland Infirmary
Carshalton	Carsh	St Helier Hospital
Coventry	Covnt	Walsgrave Hospital
Derby	Derby	Derby City Hospital
Exeter	Extr	Royal Devon and Exeter Hospital
Gloucester	Glouc	Gloucester Royal Hospital
Hull	Hull	Hull Royal Infirmary
Leeds LGI	LGI	Leeds General Infirmary
Leeds, St James's	St Jms	St James's Hospital
Leicester	Leic	Leicester General Hospital
London – Guys	Guys	Guys and St Thomas Hospital
Middlesbrough	S Cleve	James Cook University Hospital
Nottingham	Notts	Nottingham City Hospital
Oxford	Oxfrd	Churchill Hospital
Plymouth	Plym	Derriford Hospital
Preston	Prstn	Royal Preston Hospital
Reading	Redng	Royal Berkshire Hospital
Sheffield	Sheff	Northern General Hospital
Southend	Sthend	Southend Hospital
Stourbridge	Words	Stourbridge Hospital
Sunderland	Sund	Sunderland Royal Hospital
Swansea	Swnse	Morriston Hospital
Wolverhampton	Wolve	Newcross Hospital
Wrexham	Wrex	Maelor General Hospital
York	York	York District Hospital

Addendum to 2002 Report

There has been a very important addendum to the 2002 report after an error was found in the SAS coding of analyses of a statistician who was employed to help us with the report.

Chapter 15 Causes of death on renal replacement therapy

The previously released chapter in the hardcopy and CD version has been replaced on the internet version. In brief these are the changes :-

1) The wrong cohort of patients were included in the incident calculations. This has not changed the percentages of the different causes of death, but HAS changed the death rates. The corrected tables are shown below.

2) Comparison of prevalent death rates with the US appeared to show that the UK survival was worse in the patients under 65 and better in the over 65s. The UK data was taken from the dialysis population and wrongly compared with the US total renal replacement therapy population which accounts for this discrepancy. **The UK survival is better across ALL age bands**. The corrected tables are also listed below.

All (dialysis and transplant) modalities

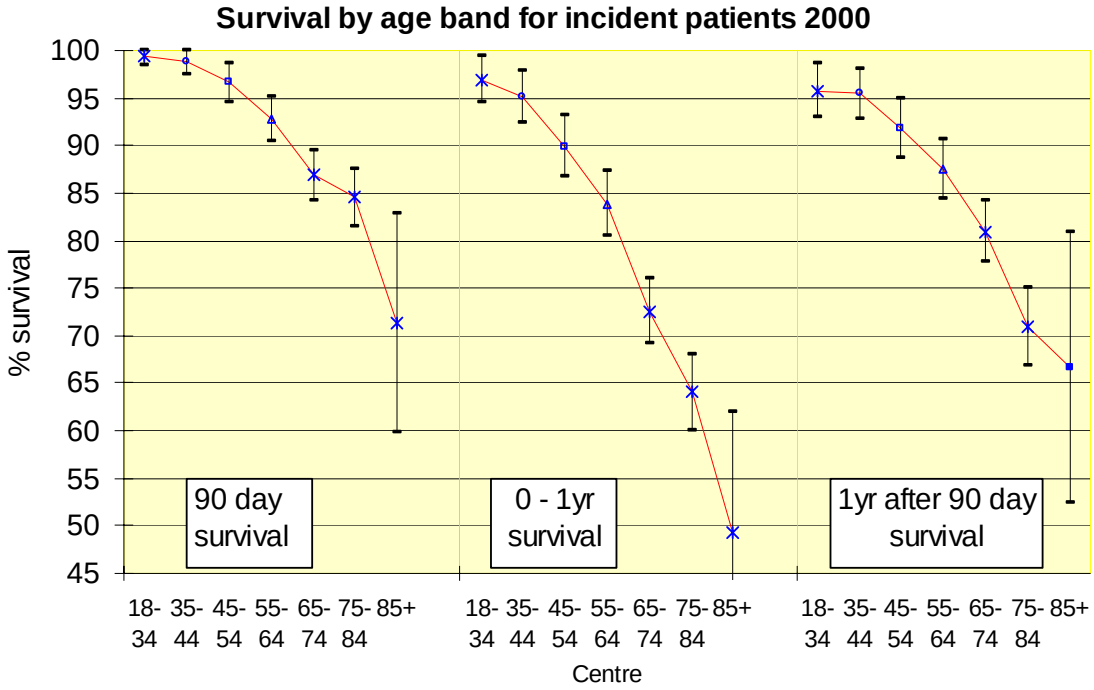
Age	UK exposure years	UK Deaths	UK deaths per 1000	USA deaths per 1000	UK Registry /USA
20-44	3218.44	95	29.52	56.1	0.526
45-64	5285.83	375	70.94	136.3	0.521
65+	3679.10	801	217.72	340.4	0.640
Total	12183.38	1271	104.32	179.3	0.582

Dialysis patients only

Age	UK exposure years	UK Deaths	UK deaths per 1000	USA deaths per 1000	UK Registry /USA
20-44	696.16	60	86.19	93.7	0.920
45-64	1732.59	242	139.68	179.3	0.779
65+	2630.53	689	261.92	360.3	0.727
Total	5059.28	991	195.88	239	0.820

Survival of incident patients starting renal replacement therapy

The SAS code of survival analysis was found to be censoring transplant patients. This has a small impact in the first year UK survival data with a false reduction in survival (although there is a much bigger impact on the younger patients), but the impact of this censoring is increases by 2 and 3 years as more patients are transplanted. The methodology of the analyses as described on page 310 is how these data should have been calculated. The tables below show the data for these according to analysis by this methodology.



Other minor amendments

Page / figure	text	Correction
P 3 / Fig 2.1		North East Lincolnshire has full coverage
P4 / Table 2.1	Hull catchment population 1.02 million	Hull catchment population 1.04 million
P27/ Table 4.5	Hull catchment population 0.85 million	Hull catchment population 1.04 million
P47 / Table 5.3	Scleve (Middlesborough) Transp no 218	Transplant no 284
P157 / Fig 11.2 *	albumin % in 35 – 50 g/l range HD	albumin % in 35 – 50 g/l range BCG and 30 – 45 g/l BCP on HD
P 159 Fig 11.5 *	albumin % in 35 – 50 g/l range PD	albumin % in 35 – 50 g/l range BCG and 30 – 45 g/l BCP on PD
P201 Table 13.3		The following are also transplant centres :- Liverpool, Nottingham, Oxford, Portsmouth
P326 / Table F.1.3	Truro deaths 44	Truro deaths
Appendix		95% confidence intervals have been calculated using the normal approximation of the poisson

* Text should read :- The figures showing the percentage in 35 –50 g/L are laboratory harmonised and in addition use a range 30-45 g/L for the centres on BCP.

Page 123 – 124 Table 9.1
The upper 90% range for ferritin (haemodialysis) was incorrect

Treatment Centre	% data return	Median ferritin	90% range	Quartile range	% ferritin > 100ug/l
Sthend	100.0	351	190.5-637.5	190.5-422	100.0
Truro	100.0	494	192-1390	192-752	100.0
Notts	95.7	568	214-1122	214-712	99.3
Plym	94.8	484	190-1139	190-643	99.1
Hull	93.6	445	159-794	159-570	98.9
Wrex	86.6	413.5	201-1076	201-597	98.8
Sund	96.5	446.5	162-1177	162-695	98.8
York	91.3	496	268-674	268-567	98.4
Wolve	99.4	514	216-1275	216-736	98.3
StJms	100.0	484.5	177-1122	177-621	97.9
Swnse	79.9	515	123-1000	123-683	97.6
Carls	93.3	404	222-934	222-507	97.6
Crdff	96.4	731	146-1524	146-1037	97.5
Redng	98.7	784	237-1516	237-958.5	97.4
LGI	95.9	430	119-1006	119-638	96.8
Bradf	98.4	272.5	118-837	118-414	96.8
Livrpl	89.5	618	112-1703	112-982	96.1
Carsh	77.8	357.5	106-1095	106-468	94.9
Sheff	98.5	503	101-1151	101-700	94.9
Covnt	99.4	326.5	83-1199	83-579	93.8
Leic	96.7	332	87.5-988.5	87.5-544	93.8
Extr	100.0	272.5	88-758	88-390	93.4
Prstn	96.5	459.5	78-1276	78-781	92.8
Guys	87.9	488	70.5-1519.5	70.5-726	92.5
Words	100.0	312	59-785	59-484	92.4
Oxfrd	98.1	283	65-751	65-441	90.4
SCleve	92.3	291.5	68-1154	68-574.5	88.9
Glouc	100.0	289	44-1171	44-424	87.6
Ports	92.6	219	51-576	51-319	87.3
Derby	83.5	242	27-1215	27-527	76.5
Bristl	99.7	229	27-868	27-411	75.9
Heart	85.8	164	27-421	27-238	73.1
Eng	88.6	395	73-1128	73-599	92.4
Wls	89.4	564	146-1451	146-860	97.8
E&W	88.6	405	77-1171	77-619	92.9