ISSN 1471-3349

The Renal Association

UK Renal Registry

The Sixth Annual Report

December 2003

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Suggested Citation

UK Renal Registry Report 2003
UK Renal Registry, Bristol, UK

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Hannah Jordan from Southampton University undertook the calculation of Townsend Social deprivation index from the 2001 census data (used in several chapters) and also the calculation of age standardised acceptance rates by local authorities.

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Dr David Newman

Dr David Newman died tragically in April 2003 whilst ice climbing on Ben Nevis.

David had been instrumental in establishing the methodology by which the Registry is able to compare results from different laboratories. His scientific contribution to the Registry is greatly missed.
The committee members and all those who worked with him have also lost a valued friend.

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Chapter 1: Summary of findings

- In 2002 the annual acceptance rate and prevalence of RRT for adults in the UK continued to increase at 101 patients per million population (p.m.p.). and 626 patients p.m.p. respectively. The annual acceptance for children is 2.0 p.m.p. Of adults, 50% of new patients were aged over 65 years.

- The number of satellite units has increased by 41% (83 to 117) since 1998, accommodating 43% of unit-based HD patients.

- The majority of units reported a wide variety of resource constraints preventing the appropriate development of services.

- Annual acceptance varied from 52 p.m.p. in Calderdale to 165 p.m.p. in Wolverhampton. Standardised acceptance ratios correlate with social deprivation and ethnicity.

- 46% of the prevalent patients had a functioning transplant. Of dialysis patients, 73% were on HD. APD increased to 26% of PD patients. All CAPD is disconnect.

- 78% of HD patients achieve a URR > 65%, a continuing improvement. High flux dialysis was used in 25% of HD patients in N Ireland compared with 12% for other UK countries.

- Improvement in Hb of dialysis patients continued. 82% of HD patients and 88% of PD patients had an Hb above the Renal Association target of 10g/dl. The European guideline of 11 g/dl was achieved in 63% of HD and 73% of PD patients.

- Serum phosphate control in dialysis patients is poor, and the variation between units is wide and significant. Only 60% of dialysis patients have serum phosphate under 1.8mmol/L. Registry data show that both poor serum phosphate control for HD or PD, and poor calcium phosphate product control, correlate with poor survival.

- In England & Wales, the combined blood pressure standard was achieved in 39% of patients pre-HD (inter unit range 14-64%), 48% of patients post-HD (range 32-67%), 32% of PD patients (range 15-55%) and 27% of transplant patients (range 12-47%). There has been no improvement in 4 years.

- Serum cholesterol levels continue to fall for RRT patients on HD or PD or with a transplant. Cholesterol levels are consistently lower in HD patients than in PD or transplant patients.

- 30% of patients are referred less than 3 months before starting RRT, and 20% less than a month prior to start of RRT. The late referral group tend to be older.

- Acceptance rates for renal replacement therapy appeared to be higher in more deprived areas. This is partly due to patients on RRT from ethnic minorities being from more socially deprived areas. Patients from the most deprived areas are younger and have more co-morbidity. Social deprivation was a significant factor associated with 1-year survival on RRT after adjusting for age and primary renal diagnosis, but it was not significant after adjusting for cardiovascular co-morbidity.

- Patients on RRT have a higher relative risk of death compared with the general population. This is more pronounced in

the young (42 fold increase) than in 80-84 year olds (4 fold).

- The UK distribution of causes of death was similar when compared with other international Renal Registries. When assessing rates of death however, UK RRT patients had significantly lower death rates in all age groups than those in the USA.

- The Renal Association has recommended HbA1c levels of <7% in ERF patients. This is only achieved in 47% of HD, 25% of PD and 33% of transplanted patients with diabetes.

- Cardio-vascular, cerebrovascular and peripheral vascular disease were more common in diabetics than in non-diabetics, $p< 0.001$. After adjusting survival for age, ethnicity, social deprivation and co-morbidity, diabetes remained a significant additional factor.

- Within the cohort of 6599 incident patients starting RRT in 27 units with good data returns, 87% were White, 7% Indo-Asian and 2% African-Caribbean. There was considerable variation in ethnicity breakdown between units from 44% White to 100%. Indo-Asian and African-Caribbean patients were significantly younger than Whites.

- The annual acceptance rate for new paediatric patients in the UK in 2002 was 9 patients per million child population. 15% of these new patients required dialysis as an emergency.

- In the paediatric population, there is a disproportionately large proportion of patients from the Asian subcontinent with 18% of Indo-Asian origin, and white (78%).

- There are significant differences in the distribution of diseases causing ERF in childhood across the ethnic groups with three autosomal recessive conditions accounting for 19.2% of all Asian patients starting RRT.

- 50% of patients with developing ERF in early life were diagnosed antenatally.

- Of paediatric patients presenting with chronic kidney disease progressing to ERF, 50% do so within two years of presentation, leaving little time for intervention with regard to growth and nutrition. For the remaining 50% there is a fall in height SDS from presentation to ERF, though this is limited to those presenting in the first 4 years of life.

- Five year survival of the paediatric ERF population is 92%, but is only 66% in those starting RRT in the first year of life.

- Of the prevalent cohort of paediatric patients, 76% have a functioning allograft, with 15% on PD and 9% on HD. Of those with functioning allografts, 81% are cadaveric.

- Each Whole Time Equivalent (WTE) consultant paediatric nephrologist was, on average, responsible for 21 paediatric RRT patients, compared to 160 adult RRT patients for each WTE consultant adult nephrologist.

- Patient survival in the UK is improving year by year: the 5 year survival is 43% overall, 64% in those under 65 and 14% in those over 65. Survival is average for Europe and better than reported figures for the USA.

- The Registry has been given permission to continue collecting the Registry data set through exemption from the Data Protection Act granted on behalf of the Secretary of State under section 60 of the Health and Social Care Act 2001.

Chapter 2: Introduction to the 2003 Report

Summary

In 2002, 42 renal units from England and Wales sent data to the Renal Registry, including seven new units that had not previously submitted data and all the renal units in Wales. In 2003 two further units joined the Registry, and 10 more units are actively in the process of joining during 2004. Some data from Scotland are submitted by the Scottish Renal Registry, and a summary of data from Northern Ireland has been received. It is hoped that during 2004 full data from Northern Ireland will be transmitted. By the end of 2004 the Registry should be receiving data covering at least 90% of patients in the UK receiving renal replacement therapy.

This has been a remarkably significant twelve months for renal patients and Renal Medicine in several ways.

The publication of the Renal National Service Framework (NSF) for England also promises to be a watershed for the Registry. This document firmly recommends that all renal units should participate in national comparative audit through the Renal Registry. The Registry is likely to be an active agent in monitoring implementation of the NSF, and is working closely with the Centre for Health Audit and Inspection (CHAI), and the National Health Service Information Agency (NHSIA), in developing this role.

One potential barrier to the development of the Registry was the need to reconcile the identification of patients as they moved between units with recent legislation designed to protect personal information held on computer databases. A most important step for the Registry has been the success of its application to the Patient Information Advisory Group for temporary exemption under section 60 of the Health and Social Care Act 2001 from some provisions of the Data Protection Act, which will allow the Registry to continue to collect some patient identifiable data whilst procedures are put in place to facilitate the accurate collection of anonymised data. Full details of this are included in this chapter.

The Registry has worked closely with the Department of Health in carrying out a further National Review of Renal Services throughout the UK. There was 100% response and, in addition to some of the information routinely collected by the Registry, details of staff and facilities available for the treatment of renal disease were collected. A summary of the findings will be found in Chapter 3; the full report will be published by the Department of Health.

As the Registry develops the role of monitoring the implementation of the NSF, it is essential that it works efficiently and accurately. This, and the growth of the work of the Registry, has necessitated an increase in staff. A part-time general manager has been recruited; there are now three statisticians, and two Registry Specialist Registrars participating in the work of the Registry, audit and research. To allow this enhanced capability there has been an increase in the annual capitation fee charged to renal units, which puts the Registry on a firm financial footing.

This is the largest and most ambitious report published by the Registry, and contains several new analyses. Of particular interest is the work on equity of access to Renal Replacement Therapy in Chapter 4. The calculation of acceptance ratios for patients in different local authorities, using the national census data to allow correction for population structure, is the first work of its kind. There is also new information concerning ethnic minority groups.

New work is presented on the survival of patients with established Renal Failure and on the influence of both initial co-morbidity and subsequent quality of care on eventual

clinical outcome (Chapter 15). Contrary to reports from the International Dialysis Outcomes and Practice Patterns Study (iDOPPS), survival of patients in the UK compares favourably with Europe and the USA. The reasons for this are discussed further in Chapter 21, where several international comparisons are reported. In essence, the iDOPPS study is a study of haemodialysis practice. The UK has a high proportion of patients with renal transplants or receiving peritoneal dialysis, and the haemodialysis patients are a selected group of above average risk patients. They should not be compared with cohorts of haemodialysis patients from countries where other modalities are much less utilised.

There is new work on serum calcium/phosphate product (Chapter 9), hypertension (Chapter 11), date of first referral and timing of initiation of RRT (Chapter 16), and on social deprivation and ERF (Chapter 17). This report also contains new data and analyses concerning diabetics with ERF, and the control of their diabetes (Chapter 19). The influence of ethnicity is considered in Chapter 20 and the incidence of co-morbidity in patients starting renal replacement therapy is considered in Chapter 21.

It may be worth repeating that the UK Renal Registry is firmly part of the Renal Association, and remains independent of the Department of Health, and of Government. It provides an independent source for auditing the care provided for renal patients throughout the UK, and for monitoring the implementation of the Renal NSF in England.

Areas covered by the UK Renal Registry

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

Centres in the 2003 Registry report

All the renal units in England & Wales (listed in Table 2.1) run the CCL Proton software, except :-
Ipswich and Bangor (Baxter system), Hammersmith (own system), Newcastle (CCL clinical vision), Kings (Own system - Renalware) and Stevenage (Lister's own system Renalplus).

Exclusion of data from the report

Derby and St Mary's London renal units have not been included in this report (Table 2.2). Due to inaccuracies in the units' patient treatment history timelines it was not possible accurately to calculate the number of incident and prevalent patients for these units.

The Scottish Registry was unable to submit the detailed data in time to be included in this analysis, although summary numbers for incidence and prevalence in Scotland were provided. Summary data from Northern Ireland on incidence and prevalence were also obtained.

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. Data from these units will be included in the next Report.

Centres in the process of joining the Registry

Work is in progress to connect the centres listed in Table 2.4 to the Registry. Some, if not all, will be included in the next Report.

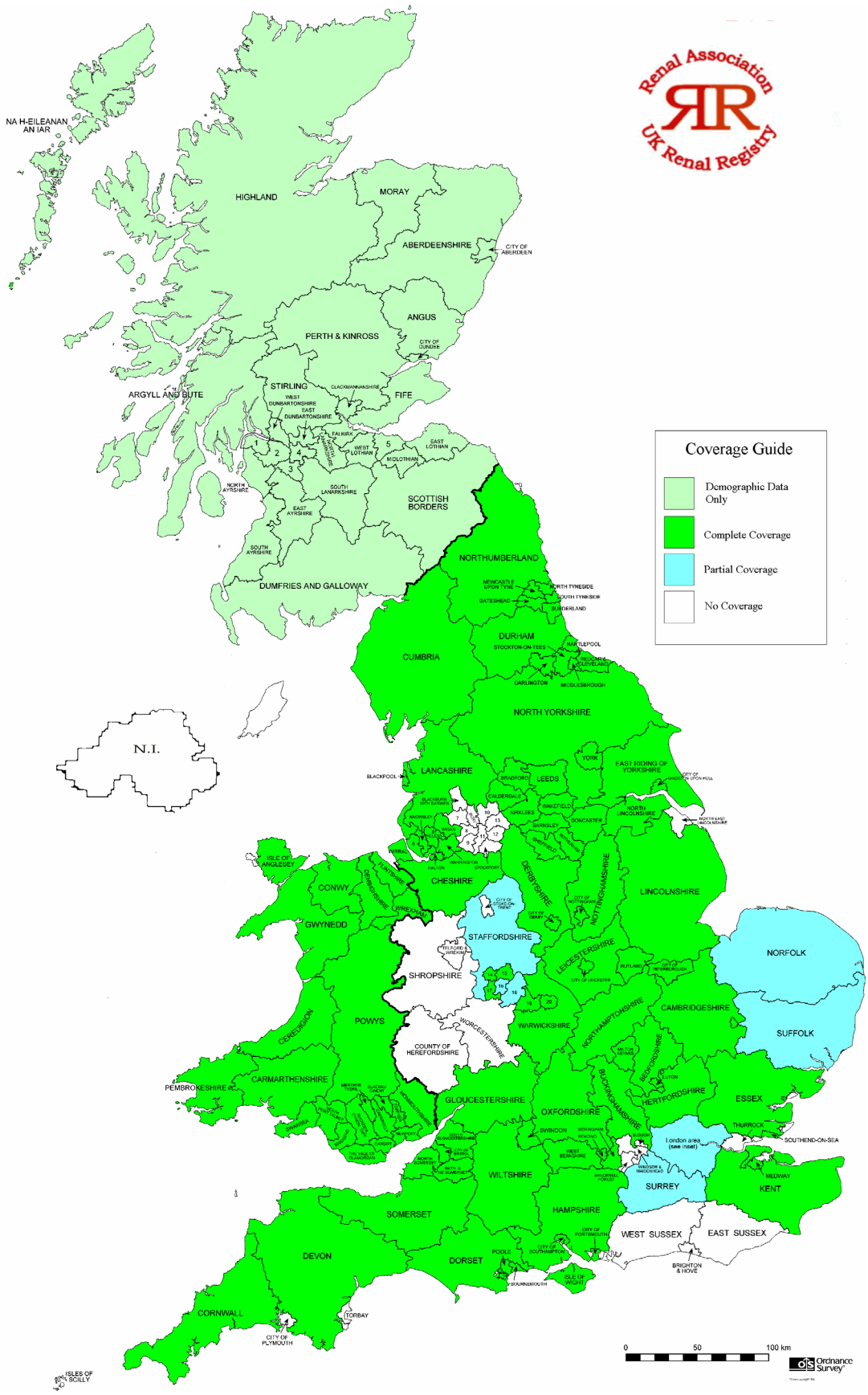

Figure 2.1. Areas covered by the Renal Registry

Table 2.1. Centres in the 2003 Registry Report

England & Wales		**Estimated population (millions)**
*Bangor	Ysbyty Gwynedd	0.18
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	1.04
*Ipswich	Ipswich Hospital	0.33
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
*London	Hammersmith + Charing Cross	1.30
*London	Kings College Hospital	1.01
Middlesborough	James Cook University Hospital	1.00
*Newcastle	Freeman Hospital	1.31
Nottingham	Nottingham City Hospital	1.16
Oxford	Churchill Hospital	1.80
Plymouth	Derriford Hospital	0.55
Portsmouth	Queen Alexandra Hospital	2.00
Preston	Royal Preston Hospital	1.48
Reading	Royal Berkshire Hospital	0.60
*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
*Wirral	Arrowe Park Hospital	0.53
Wolverhampton	Newcross Hospital	0.49
Wordsley	Stourbridge Hospital	0.42
Wrexham	Maelor General Hospital	0.42
York	York District Hospital	0.39
Total		37.69

*These units are included in the report for the first time.

Table 2.2. Excluded centres

		Est pop (mil)
Derby	Derby City Hospital	0.48
London	St Mary's Paddington	0.81

Table 2.3. Centres who have recently joined the Registry

	(Indicates IT system used by hospital)	Estimated population (millions)
Norwich	James Paget Hospital (Mediqal system)	0.84
Birmingham	Queen Elizabeth Hospital (own system)	1.82

Table 2.4. IT systems being implemented

	(Indicates IT system used by hospital)	Estimated population (millions)
Basildon	(Mediqal)	
Brighton	Royal Sussex County Hospital– CCL windows	0.98
Canterbury	Kent & Canterbury (Velos system)	1.20
Dorset	Dorchester Hospital (Mediqal)	0.60
London	Royal Free (King's system)	0.67
Manchester	Hope Hospital (EPR hospital system)	0.94
Northern Ireland	Belfast + four renal units (Mediqal system)	
Stoke	North Staffs (Cybernius Canadian system)	0.70

Centres in discussion with the Registry

All the remaining renal units in England have made contact with the Registry and are considering the steps needed to join. These are listed below in Table 2.5. 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 covers up to 80% of the UK for some items, and that by the end of 2003 some 90% or more of the UK will be covered by the Registry. With the recommendation in the Renal National Service Framework (NSF) that all units should par-

Table 2.5. Centres without Registry-compatible IT

	(Indicates IT system used by hospital)	Estimated population (millions)
Chelmsford	Broomfield Hospital (buying Mediqal)	-
Manchester	Royal Infirmary (buying system – undecided)	2.51
Shrewsbury	(Buying Lister system)	0.40
London	Middlesex / UCLH (buying system - undecided)	0.75

ticipate in audit through the Registry, complete coverage of the UK should be accelerated. The Commission for Healthcare Audit and Inspection (CHAI) wishes to use the Registry as one vehicle for monitoring implementation of the NSF. Commissioners of renal services will thus be encouraged to enable the provision of adequate data systems for all 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 Renal Registry links

In the UK there are 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 develop ways of collecting these paediatric data. The plans for these sites are listed in Table 2.6. All of the adult renal IT systems require some modifications to collect the extra data specifically required in the paediatric dataset. This process of integration of paediatric data is now well under way.

Links with other organisations

The UK Renal Registry has been active in supporting 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 providing data to help formulate the advice for ministers for the renal NSF, and is working with the National Health Service Information Authority (NHSIA) on the information strategy to support the renal NSF. The Registry is part of the Kidney Alliance. Discussions are taking place on forging closer links with the Commission for Healthcare Inspection and Audit.

The Registry has been working with the UK Transplant Authority to produce analy-

Table 2.6. Paediatric renal unit plans

Sites	Comments
Belfast	Plan to join the adult system
Birmingham	Linked 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	Joining Bristol's system
London Gt Ormond St	Joining Bristol's system until local EPR developed
London Guy's	Joined Guy's adult system
Manchester	Joined Bristol's system
Newcastle	Sent with adult data
Nottingham	Sent with adult data
Southampton	Joining Bristol's system
Glasgow	Sent via Scottish Registry

ses utilising the strengths of both databases. The UK Registry sends fully anonymised data to the European Renal Association Registry. There has been contact with the International Federation of Renal Registries, but patient data are not sent to this organisation.

New arrangements for commissioning renal services

In April 2002, the 95 existing health authorities in England were reformed as 28 strategic health authorities (StHAs). Established renal failure has been designated by the government as a service for specialist commissioning. In the Renal NSF the Strategic Health Authorities have been given a clear role in monitoring the performance of the specialised commissioning consortia. The Registry will try to assist specialised commissioning consortia with appropriate data and analyses. The Registry has also received requests for data from some individual PCTs that are involved in commissioning.

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 show cause for concern, the Registry will first discuss them further with the renal unit to establish the validity of the data. 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.

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

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 was removed from all the adult data except for the survival figures in individual renal units.

A meaningful comparison between renal units of survival requires the ability to correct for case mix, which needs robust initial co-morbidity data: these are not yet available from many units. In some of the analyses in this report, it has been possible to study the influence of initial co-morbidity. However, as is evident in Chapter 20, reporting of initial co-morbidity is still very poor in many units, and is not sufficient for meaningful adjustments to outcome data. For this reason, survival data are still reported anonymously. The renal NSF encourages reporting of such data, and it is hoped this will encourage more renal units to collect these data so that accurate comparative results may be achieved.

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 statisticians are able to identify the centres. This identification is necessary so that the Registry can discuss with the relevant centre any issues raised or discrepancies in the analysis.

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

Summary

The Registry has been granted section 60 exemption from compliance with the 1998 Data Protection Act with regard to collecting patient identifiable data.

Section 60 exemption is only granted on a temporary basis until full compliance with the Data Protection Act can be achieved. For full compliance data must be anonymous, or collected with permission of the individual patient. Progress towards this is reviewed annually by the Patient Information Advisory Group (PIAG).

The steps required by the Registry and renal units to gain compliance with the Data Protection Act are detailed below.

Introduction

Under the 1998 Data Protection Act it is only legal to transmit patient identifiable data to a third party with the permission of the patient, and for agreed purposes. This has created problems for several medical registries, including the Renal Registry.

The key patient identifiers collected by the Renal Registry are name, date of birth, and postcode. Even without a name, date of birth and full postcode enable patient identification. The Registry currently requires these patient identifiable data for both data validation, and analysis, as follows:

(a) Validation:

1. To avoid duplication of patients in the database, particularly when they transfer between centres, often for transplantation. Matching of these items, together with a unique identifier allocated by the Registry, when available, is currently important in avoiding this.
2. To validate postcodes with the address fields, using a postcoding package.
3. To use the above items to trace missing NHS numbers using the national tracing service.

(b) Analysis (this is an indicative list):

1. To analyse areas where age is a factor
2. To assess geographical equality of access to treatment, e.g. by local authority wards
3. To assess the influence of social deprivation by calculating deprivation scores from the validated postcode.

One option for full compliance would be to attempt to obtain permission for data transmission from each patient. This would have to be done by the renal units and would be a large workload. More importantly, it would lead to incomplete data collection as some patients would refuse permission, and it is likely that this would not be a representative group of patients. Centres would also default in obtaining permission, or delay 3–6 months from obtaining permission in some patients. This would render many of the analyses invalid.

The alternative is for the Registry to develop processes to anonymise the data whilst retaining enough information for purposes of validation and analysis. The committee has decided to take this course. Whilst this is being developed, in order to continue to obtain identifiable patient data, the Registry needs temporary exemption from compliance with the 1998 Data Protection Act under the Health and Social Care Act 2001, section 60 (England & Wales).

For England & Wales, this can be granted by the Patient Information Advisory Group (PIAG). Section 60 exemption is only granted on a temporary basis until full compliance with the Data Protection Act can be achieved. Progress towards this is reviewed annually by the PIAG.

In common with the experience of UK Transplant and most other medical registries, an initial application to PIAG in 2001 from the Renal Registry was turned down. The Registry was invited to re-submit its application. After consultation with, and support from, the National Kidney Patients Federation, the Department of Health, CHAI, the NHS Information Authority, and PIAG, this has been done. This was considered at the March 2004 meeting of PIAG, and the Registry has been granted temporary exemption under section 60.

Path towards compliance

In the application to PIAG the Registry set out a four-stage path towards full compliance with the Data Protection Act:

> It is government policy in England & Wales, that patient's NHS numbers will be used for all hospital episodes. The ultimate aim of the Registry is to use an encrypted NHS number as a patient marker. This will not allow identification of the patient. In parallel with this approach, a system will be developed to allocate the necessary characteristics to patients with regards to age, social deprivation, geographical area of residence such as local authority or health authority. It will then not be necessary to store the full post code in the database.

Stage 1

1.1. *Posters & Patient Information leaflets*
In the interim period before anonymisation is achieved, formal consent for data transfer will not be necessary. However, patients must be fully informed about what is happening. With the support of the National Kidney Federation (of patients associations), the Registry will produce posters and information leaflets for use in renal units. These communications will describe the extent of the information that is stored regarding patients with established renal failure, and the fact that patient identifiers are only accessible to a small number of skilled and trusted staff. It will also explain how that information is used, and that all outputs are anonymous. Through these communications, patients will be offered the opportunity to contact their local renal unit to withhold consent from sharing their patient identifiable record with the Registry if they wish to do so. Software will be installed on all renal unit clinical databases to enable this opting out to be recorded.

1.2. *Move towards NHS numbers and deletion of patient names in the Registry database*

1.2.1. The Registry will develop a software application that holds patient identifiable data received from renal units in a temporary database.

1.2.2. Where necessary data is incomplete, the Registry will use an existing 'postcode lookup application' to obtain a valid full postcode and then use the NHS Strategic Tracing Service to obtain the NHS Number. It will then advise the renal unit to update the patient demographic data to include the missing data and ask them to use the unique UK Renal Registry Number allocated by the Registry for further communications with the Registry.

1.2.3. The Registry will characterise the patient and check for duplicate records with the records

held in the analysis database containing anonymised patient data.

1.2.4. The Registry will then delete the patient identifiable data from the temporary database at the time of the next submission of data (next calendar quarter) with the proviso that the renal unit is submitting data with a complete set of patient demographic data including the NHS Number and the UK Renal Registry Number.

1.2.5. The Registry will also apply this methodology to the records of deceased patients held in the database.

Stage 2

2.1. The National Programme for Information Technology (NPfIT) National Care Records Service (NCRS) is allocating an NHS Number to every patient. When this becomes available from all renal systems, the Registry will modify the software application that handles pre-analysis characterisation of the patient and checking for duplicate records so that all other patient identifiable data is deleted once this pre-analysis activity has been completed

Stage 3

3.1 The National Programme for IT (NPfIT) National Care Records Service (NCRS) is working on software for a secure encryption system for the NHS Number. This encryption is consistent for the NHS nationally so that record linkage can still be made even if the patient moves between Trusts/Strategic Health Authority areas. The Registry will modify its software to handle the encrypted NHS Number format. The renal software providers will have to modify software to link with the encryption software.

Stage 4

4.1. With the implementation of the electronic Integrated Care Records System (ICRS) the Local Service Providers (LSPs) will take responsibility for making the UK Renal Registry data available in the national set (spine) as a secondary use service (SUS). The UK Renal Registry will then become a user and not a custodian of anonymised patient data.

4.2 In partnership with the NHSIA Datasets Development Programme, the Registry is currently seeking Information Standards Board approval for the National Renal Dataset, which will include data needed by the Registry, for completion by March 2005.

4.3 Through the NHSIA NSF Information Strategy Programme, the Registry will work with Local Service Providers to implement the Renal NSF Core Service that includes the requirement for Local Service Providers to provide the functionality for renal units to send data for the National Renal Dataset to the SPINE, and for the National Application Service Provider to make this available in the National Care Records Service Secondary Users Service. The data held will then be compliant with existing legislation and standards.

After publication of this report, the Registry will be contacting renal units to discuss the implementation of these plans. It is acknowledged by PIAG that some of the timescales may not be achieved due to unresolved technical issues / lack of progress with the NHS IT infrastructure. All these issues will be reviewed annually by PIAG.

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 previous reports, the 95% confidence interval is shown for compliance with a Standard. The calculation of this confidence interval (based on the Poisson distribution), and the width of the confidence interval, depends on the number of patients within the Standard and the number of patients with 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 41 centres and then centre Y with the other 40 centres. Thus, 81 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.

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 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

Support for Renal Specialist Registrars undertaking a non-clinical secondment

Dr Catherine Byrne has just completed a fruitful two-year post, seconded to the Renal Registry. This was time taken out from an SpR training programme for research and audit experience and training. Dr Alison Armitage, working within the Registry in similar circumstances, was awarded her MD in 2003. Dr Az Ahmad has taken research and audit time from his SpR training and is currently working for an MD in the Registry. Through links with the Universities of Southampton and Bristol some training is available in epidemiology and in statistics. It is hoped that this will encourage other Registrars, who are also interested in undertaking epidemiological work, to consider working with the Registry.

New data collection and analysis

There is considerable interest in collecting data on cohorts of pre-end-stage renal failure patients: many renal units already hold

these data in their systems. It is also clearly important to collect and analyse data on access for dialysis. The members of the Renal Association will be consulted on these and other possible future projects.

A move towards explanation

The analysis and presentation of these data is still being developed, and more work is planned in the assessment of significance and explanation of differences and investigation of good practice. This requires more involvement with renal units to improve the quality and breadth of data capture. In this way, the Registry will be in an excellent position to support the improvement in clinical care and outcomes that is its intended purpose.

Distribution of the Registry Report

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

Further copies of the report will be sent to individuals or organisations on request: a donation 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: National Renal Review 2002: summary report on adult and paediatric renal services

Summary

- The total annual acceptance rate of new patients for Renal Replacement Therapy (RRT) in the UK was 103.0 patients per million population (p.m.p.).

Adults

- The annual acceptance rate and prevalence rate of RRT for adults in the UK continued to increase; the rates for 2002 were 101 patients p.m.p. and 626 patients p.m.p. respectively.

- 50% of new patients were over 65 years old and 18% had a primary diagnosis of diabetic nephropathy.

- 34% of patients started RRT with an emergency or unplanned dialysis.

- 46% of the prevalent patients had a functioning transplant; of the dialysis patients, 73% were on haemodialysis.

- The number of satellite units increased by 41% (83 to 117) since 1998, accommodating 43% of unit-based haemodialysis patients.

- There were more haemodialysis stations p.m.p. in Scotland and Northern Ireland when compared to England and Wales.

- For haemodialysis, fewer patients were being dialysed twice weekly and there was an increased usage of synthetic membranes compared to 1998.

- For peritoneal dialysis, 99% of patients on CAPD were using the disconnect system, and there was also an increased use of APD for PD patients (26% of PD patients).

- There were more consultant nephrologists per million population in Scotland and Northern Ireland when compared to England and Wales.

- The majority of units reported a wide variety of resource constraints which were preventing the appropriate development of services. 18 units reported that due to lack of resources they had turned away a total of 230 patients considered suitable for treatment; none of these were in Scotland.

Children

- The annual acceptance rate for new paediatric patients in the UK in 2002 was 9 patients per million child population (2.0 per million total population). 15% of these new patients required dialysis as an emergency.

- Whilst the majority of new paediatric patients were white (78%), 18% were of Indo-Asian origin. However, in adult services, 85% of new patients were white and only 7% were Indo-Asian.

- The number of children receiving RRT remained stable. At the end of 2002, there were 827 paediatric patients receiving RRT; 74% had a transplant, and 64% of dialysis patients were on PD.

- Each Whole Time Equivalent consultant paediatric nephrologist (WTE) was, on average, responsible for 21 paediatric RRT patients, compared to 160 adult RRT patients for each WTE consultant adult nephrologist.

- At the end of 2002, 90% of funded trained paediatric renal nursing staff posts were filled, providing a ratio of 16.4 WTE trained nurses per million child population in the UK.

- The major factor reported as limiting development of the service was availability of trained specialist nurses. A shortage of consultant staff was also highlighted.

Introduction

This is the fourth renal survey since 1993. The purpose is to provide up to date information on incidence and prevalence rates of RRT, renal service provision, staffing levels, and satellite unit usage. Also to provide a base in England from which a regular review of National Service Framework implementation can be made. For the first time, paediatric services have been included in the UK review. This chapter will first consider the services for adults, and then children. This work was funded by a grant from the Department of Health.

Adults

Over the last two decades, there has been a substantial continual increase in the number of patients receiving RRT in the UK. The number of prevalent patients receiving therapy is dependent on acceptance rates and the survival of those receiving treatment. The UK rates have however seen a 4-fold increase since 1980. The 1993 National Renal Review returned a figure, for all patients receiving RRT in England, of 396 patients p.m.p.[1]. The reports of 1995 and 1998 returned figures of 476 patients p.m.p.[2] and 523 patients p.m.p.[3] respectively. Similar trends were observed in Scotland and Wales and quoted in the last report at 546 patients p.m.p. and 585 patients p.m.p. respectively. This may be compared with a current figure in many European countries of 700-900 patients p.m.p. Modelling work undertaken at Southampton University has indicated that a steady state position is not expected for at least 15 years[4].

The annual acceptance rate of new patients requiring RRT continues to rise worldwide, with provision in the UK trailing many developed countries. Annual acceptance rates for RRT relate to the incidence of established renal failure, and referral and selection for treatment. Since 1980 they have risen in the UK from around 25 patients p.m.p. annually to 101 patients p.m.p. for adults, but are much higher in most developed countries (see Chapter 21).

Methods

This work was funded through an unrestricted grant by the Department of Health and conducted by the UK Renal Registry. The survey was developed to document the provision of renal care in the UK up to the end of 2002 (31/12/02). A questionnaire was sent to all adult and paediatric renal units within the UK. Information was sought on the structure of care (beds, dialysis stations, staffing levels, satellite units), processes of dialysis use (treatment modality, membrane types) and patient numbers (new patients accepted during 2002, prevalent patients at the end of 2002, patients who were declined RRT during 2002). Information was also sought on the numbers of patients with Hepatitis B, C or HIV.

The questionnaires were sent to the adult and paediatric units in summer 2003. For the majority of returned questionnaires, there was at least one missing piece of data which required the Registry to contact the renal unit. Those units registered with the UK Renal Registry had much of the data supplied from the Registry database; this facilitated the return of more detailed and validated data than was possible by questionnaire. The Scottish Renal Registry supplied the data for two of the Scottish

units. The final validated data were not complete until March 2004, providing complete data for the 71 adult and 13 paediatric renal units in the UK.

These data were analysed using SAS software. The Office for National Statistics' (ONS) population estimates for the UK were used to calculate the population denominators for the annual acceptance, prevalence, staffing and provision rates per million population. The 95% confidence intervals for rates were calculated using normal approximations to the Poisson distribution, and elsewhere confidence intervals were calculated using normal approximations to the binomial distribution. Poisson regression analysis was used to determine whether the variation in acceptance and prevalence rates were statistically significant.

Data were compared with those collected from the 1998 Renal Survey and the UK Renal Registry. Discrepancies were checked with the original paper return, and if necessary by a telephone call to the renal unit director.

New patients starting renal replacement therapy

The annual acceptance rate for new adult patients in the UK in 2002 was 101 patients p.m.p.; these data are shown in Table 3.1. There was significant variation between the annual acceptance rates p.m.p. in England, Wales, Scotland and N. Ireland ($p < 0.0001$, Poisson regression) with the rate lowest in England at 98 p.m.p. Given the larger ethnic minority population in England, a higher rate would have been expected, suggesting there may be unmet need there.

The renal units were also asked whether they were able to accommodate all patients onto their RRT programme. In Table 3.2, 18 units reported that they had to turn away some patients, with the maximum being turned away ranging from 2-50 patients. It is unknown how many of these patients were then accepted by another renal unit onto their RRT programme. The renal unit with the highest refusal was based in London, where large cross boundary flows are known to occur. Due to these cross boundary flows, rates were calculated by region rather than for each renal unit. Units in Scotland were able to accept all patients referred for RRT.

Table 3.1. Annual acceptance data for adult new patients accepted onto RRT in 2002

	England	Wales	Scotland	N.Ireland	UK
No of renal units	52	5	10	4	71
Patient numbers	4,863	343	602	185	5,993
Population (millions)	49.6	2.9	5.0	1.7	59.2
Unit Median	94	42	65	33	82
(range)	(12-176)	(19-142)	(18-116)	(25-94)	(12-176)
Acceptance rate pmp	98	118	120	109	101
(95% CI)	(95-101)	(106-131)	(111-130)	(93-125)	(99-104)

Table 3.2. Refusal rate

	England	Wales	Scotland	N.Ireland	UK
No of Units	15	2	0	1	18
No of Patients Refused	222	4	0	4	230
Range No of Patients	0-50	0-2	0	0-4	0-50

There were 62 renal units able to provide data regarding the patients' primary diagnoses. From these units, 18% of patients started RRT due to diabetic nephropathy. There was no substantial variation between the 4 countries, however between centres, the percentage ranged from 3% to 40%. Data regarding age groups were more complete with 70 units able to provide the age grouping. Of those patients starting RRT in 2002, 50% were aged 65 or over, with no substantial variation between the 4 countries, however between centres, the percentage ranged from 26 to 70% (Table 3.3).

The renal units in England had a higher mix of ethnic minorities starting RRT than other UK countries. However these data were poorly recorded and available from only 53 renal units. For these units, 7%, 4% and 1% of new patients were Indo-Asian,

Table 3.3. Profile of adult new patients accepted onto RRT in the UK in 2002

	England	Wales	Scotland	N.Ireland	UK
No of centres	44	5	9	4	62
No of patients	4,057	343	572	185	5,157
Number diabetic (%)	758 (19%)	43 (13%)	94 (16%)	42 (23%)	937 (18%)
Median % (range)	17 (3-40)	14 (5-37)	16 (8-28)	24 (12-25)	17 (3-40)
No of centres	51	5	10	4	70
No of patients	4,744	343	602	185	5,874
No of patients 65+ (%)	2,343 (49%)	187 (54%)	324 (54%)	99 (53%)	2,953 (50%)
Median % (range)	51 (26-70)	55 (48-68)	53 (38-69)	56 (38-58)	52 (26-70)
No of centres	39	2	8	4	53
No of patients	3,666	130	454	185	4,435
Indo-Asian (%)	304 (8%)	1 (0.9%)	3 (0.8%)	1 (0.5%)	309 (7%)
African/Caribbean (%)	194 (5%)	0 (0%)	1 (0.2%)	1 (0.5%)	196 (4%)
Chinese (%)	22 (1%)	0 (0%)	2 (0.4%)	1 (0.5%)	25 (1%)
Others (%)	150 (4%)	0 (0%)	0 (0%)	0 (0%)	150 (3%)
No of centres	36	5	6	4	51
No of patients	3,447	343	401	185	4,376
No of emergency dialysis (%)	1,108 (32%)	144 (42%)	129 (32%)	111 (60%)	1,492 (34%)
Median % (range)	30 (5-80)	40 (11-70)	26 (16-50)	45 (5-85)	30 (5-85)

Table 3.4. Annual acceptance rate for new adult patients on RRT 1991-2002 in the UK

Year	England		Wales		Scotland*		N. Ireland		UK	
	Pts No	Rate pmp	Pts No	Rate pmp	Pts No	Rate pmp	Pts No	Rate pmp	Pts No	Rate pmp
1991/2	3,247	67	-	-	317	62	-	-	-	-
1993	3,197	73	275	95	404	79	-	-	-	-
1994	3,371	77	308	106	388	76	-	-	-	-
1995	3,726	82	318	109	445	87	-	-	-	-
1998	4,566	92	374	128	536	105	181	107	5,657	96
2002	**4,863**	**98**	**343**	**118**	**602**	**120**	**185**	**109**	**5,993**	**101**

*Pre 1998 data from Scottish Renal Registry

African/Caribbean and Chinese respectively (Table 3.3).

Data regarding new patients presenting as an emergency (defined as requiring an unplanned start of dialysis e.g. acute pulmonary oedema or presenting with end stage renal disease) were also collected. Within this category 34% of patients in the UK were started as an emergency. There were marked variations between centres (5-85%), which could be due to the varying interpretation of the definition of emergency (Table 3.3).

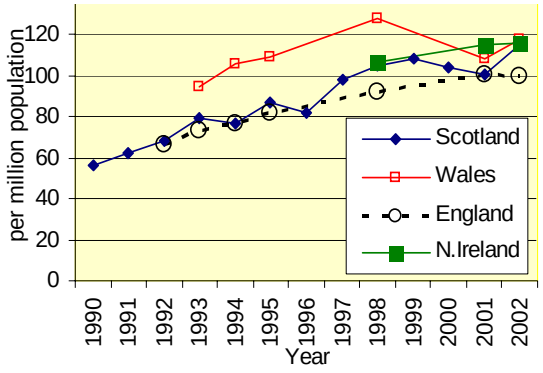

Figure 3.1. Annual acceptance rate for new adult patients on RRT 1990-2002 in the UK

Changes in acceptance rates in England and Wales 1993-2002

The annual acceptance rate for England has been progressively rising (Table 3.4 and Figure 3.1) and the annual acceptance rates for Wales and Northern Ireland in 2002 appear to have reached a plateau compared to 1998. Data from the Scottish Registry from 1999 – 2001 also indicate that their annual acceptance rate has now reached a plateau.

For 2002, the proportion of new patients aged 65 years or over continued to increase and equated to 50% of total new patients. However, the proportion of patients with diabetes as the primary cause for renal failure seemed to have reached a plateau (18%, Table 3.5).

Table 3.5. Changing profile of new patients accepted onto RRT in the UK

	% over 65	% diabetic
1976-78 (UK)	1	2
1982-84 (UK)	11	8
1986-88 (UK)	23	12
1991-92 (Eng)	37	14
1995 (E & W)	39	15
1998 (UK)	47	19
2002 (UK)	50	18

Sources: EDTA 1976-1988, National Renal Surveys 1991-2002

Prevalent adult patients receiving renal replacement therapy 31/12/2002

The UK is now treating over 37,000 patients with established renal failure, with a prevalence rate of 626 patients p.m.p. (Table 3.6).

There was significant variation between the prevalence rates for the four countries, with England having the lowest prevalence rate ($p<0.0001$, Poisson regression). England had the lowest number of renal units per million population, and as a consequence these units were larger than in the other UK countries.

Haemodialysis is the predominant dialysis modality, with the percentage of dialysis patients on haemodialysis ranging from 66 to 87 between countries.

Data for Wales were originally calculated by using the sum of the data supplied by the Welsh renal units on the Registry. However, this analysis appeared to show an unexpected low percentage of transplant patients for Wales. When these data were re-analysed by individual patients' postcode, 104 transplant patients receiving treatment at the Liverpool renal unit were then reallocated to North Wales.

More detailed analyses of prevalence rates are demonstrated in Chapter 5 of this report. Large variations in the prevalence

rates by postcode were found within England.

Changes in adult prevalence 1993-2002

The changes in the numbers and distribution of prevalent patients from between 1993 to 2002 are shown in Table 3.7 and the trend is illustrated in Figures 3.2 and 3.3 for England, and Figure 3.4 for the UK. The general pattern is for the greatest increase to be in unit based haemodialysis (including satellite unit dialysis). In England, the number of patients on home haemodialysis in 2002 fell by nearly 50% compared to 1993 figure. Although some of this decrease was due to the increased availability of satellite dialysis nearer to home, many renal units were no longer able to provide a home dialysis service. The 2002 NICE guidance appraisal to provide increased provision of home haemodialysis may reverse this trend.

For all countries except Wales, the number of patients on peritoneal dialysis fell when compared with the 1998 survey. Whilst the numbers with a functioning transplant continued to rise, the percentage growth was less than that of the haemodialysis patients, thus producing a proportional fall as a percentage of total renal replacement therapy.

Table 3.6. UK Patients receiving Renal Replacement Therapy - December 31, 2002

	England	Wales	Scotland	N.Ireland	UK
No of renal units	52	5	10	4	71
Total RRT patients	30,498	2006	3,418	1,117	37,039
Rate pmp (95% CI)	615 (608-622)	692 (652-722)	684 (661-707)	657 (619-696)	626 (620-633)
Rate per unit	587	401	342	279	522
Units pmp	1.0	1.7	2.0	2.4	1.2
Haemodialysis	11369 (37%)	720 (36%)	1380 (40%)	512 (46%)	13981 (38%)
Home haemodialysis	420 (1%)	9 (0%)	52 (2%)	1 (0%)	482 (1%)
Peritoneal dialysis	4605 (15%)	380 (19%)	376 (11%)	80 (7%)	5441 (15%)
Transplants	14,104* (46%)	897 (45%)	1,610 (47%)	524 (47%)	17,135* (46%)
% dialysis pts on HD	72%	66%	79%	87%	73%

* the number of transplant patients in one centre was estimated from previous 1998 survey data and using the average national growth rate

Table 3.7. Adult patients receiving RRT in UK (1993-2002)

Country	Year	Patient No	Rate pmp	HD	Home HD	PD	Transplants
England	1993	19,212	396	3,899 (20%)	806 (4%)	4,340 (23%)	10,167 (53%)
	1995	22,322*	458	5,383(24%)	725 (3%)	4,880(22%)	11,334 (51%)**
	1998	25,892	523	7,788 (30%)	516 (2%)	5,101 (20%)	12,487 (48%)
	2002	**30,498**	**615**	**11,369 (37%)**	**420(1%)**	**4,605(15%)**	**14,104 (46%)‡**
Wales	1995	1,560	535	388 (27%)	33 (2%)	314 (22%)	685 (48%)
	1998	1,716	585	451 (26%)	17 (1%)	301 (18%)	947 (55%)
	2002	**2,006**	**692**	**720 (36%)**	**9 (0%)**	**380 (19%)**	**897 (45%)**
Scotland	1998	2,798	546	976 (35%)	69 (2%)	441 (16%)	1,312 (47%)
	2002	**3,418**	**684**	**1,380 (40%)**	**52 (2%)**	**376 (11%)**	**1,610 (47%)**
N Ireland	1998	741	439	356 (48%)	0	84 (11%)	301 (41%)
	2002	**1,117**	**657**	**512 (46%)**	**1 (0%)**	**80 (7%)**	**524 (47%)**
UK	1998	31,347	529	9,571 (30%)	602 (2%)	5,927 (19%)	15,247 (49%)
	2002	**37,039**	**626**	**13981 (38%)**	**482 (1%)**	**5441 (15%)**	**17,135 (46%)**

* Includes estimated data from the two missing units in England.

** Error in transplant data 1995 corrected from 1995 national review.

‡ the number of transplant patients in one centre was estimated from previous 1998 survey data and using the average national growth rate

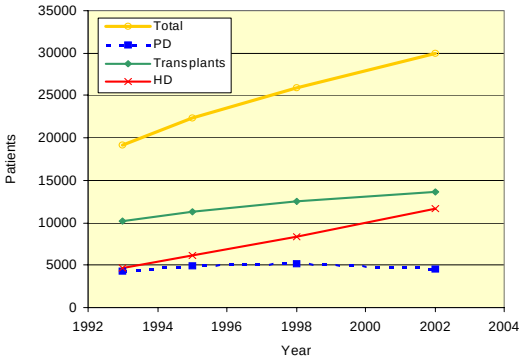

Figure 3.2. Number of adult patients on each modality and total RRT in England 1993-2002

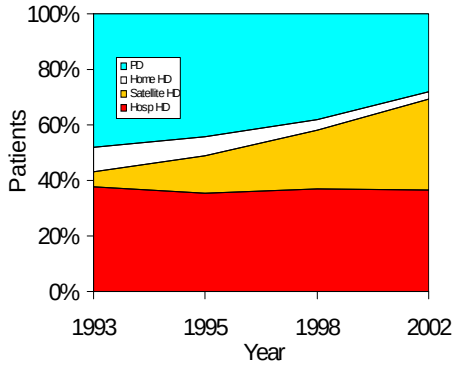

Figure 3.3. Percentage of adult patients on each dialysis modality in England 1993-2002

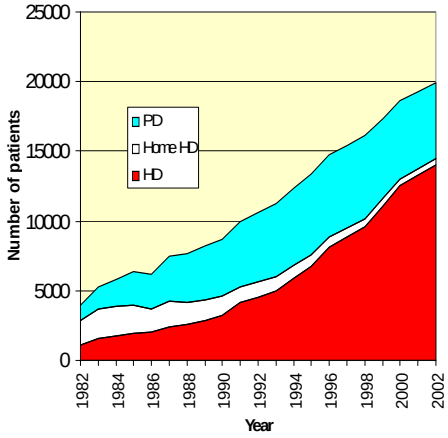

Figure 3.4. Dialysis modality trends in adults in the UK 1982-2002

Renal unit facilities for adults

Renal unit facilities at the end of 2002 are summarised in Table 3.8. 'Temporary' haemodialysis stations were defined as stations which were not part of an agreed establishment with the commissioners, but had been temporarily created to deal with excessive patient loads. These stations were usually in in-patient areas. Temporary stations were utilised by 34 renal units and the 141 temporary stations made up 4% of the total haemodialysis stations in use.

Of permanent haemodialysis stations, 47% were in satellite units. There was a wide variation of 4-59 haemodialysis stations for main unit hospital based haemodialysis and a similar variation of 2-51 haemodialysis stations for satellite unit haemodialysis (Tables 3.8 and 3.9).

There were more haemodialysis stations p.m.p. in Scotland and Northern Ireland when compared to England and Wales. Due to the low ratio of renal units p.m.p. in England, the renal units in England had a much higher mean number of haemodialysis stations per unit.

In England, a higher percentage of haemodialysis stations (52%) and haemodialysis patients (45%) were in satellite units compared to Wales and Scotland. This reflects the larger size of renal units in England and the necessity for more localised provision of haemodialysis facilities, combined with the space limitation in expanding haemodialysis capacity within the main renal units (Tables 3.8 and 3.9).

There has only been a small increase in the renal inpatient bed provision in England (from 24 beds p.m.p. in 1998 to 28 beds p.m.p. in 2002) to support the rise in numbers of dialysis patients, many of whom have co-morbid diseases and require episodes of in-patient care. The number of beds in both Scotland and Wales fell (38 beds p.m.p. to 35 beds p.m.p. and 32 beds p.m.p. to 28 beds p.m.p. respectively), with

Wales then having the same bed provision as England.

Some units (4 in England, one each in the other countries) reported no dedicated renal beds, as the nephrologists were also general physicians, and renal patients were admitted to general medical beds.

Changes in adult renal facilities in England and Wales 1993-2002

Despite the large growth in patient numbers there was no increase in the total number of UK renal units between 1993 and 2002 (Table 3.10). Although there had been several new renal units in England there had also been mergers among the London renal units, resulting in no overall increase in number. The number of renal units p.m.p. was lower in England (1.0) than in Scotland

Table 3.8. Renal unit facilities in the UK – 31/12/2002

	England	Wales	Scotland	N.Ireland	UK
Main renal units	52	5	10	4	71
Units per million population	1.0	1.7	2.0	2.4	1.2
Total beds	1,401	82	176	37	1,696
Unit no of beds median (range)	24 (0-75)	15 (0-37)	21 (0-33)	7 (0-23)	23 (0-75)
Beds per million population	28	28	35	22	29
Haemodialysis					
No of permanent stations in main unit	1,198	81	236	106	1,621
Median no of permanent stations (range)	22 (4-59)	16 (11-20)	23 (11-42)	23 (20-40)	22 (4-59)
No of Satellite stations (% of satellite to total number of permanent stations)	1,276 (52%)	65 (45%)	90 (28%)	0 (0%)	1,431 (47%)
Total permanent stations	2,474	146	326	106	3,052
No of units with temporary stations	28	2	3	1	34
No of temporary stations (range)	108 (0-12)	14 (0-11)	14 (0-6)	5 (0-5)	141 (0-12)
Total no of HD stations	2,582	160	340	111	3,193
HD stations per million population	52	55	68	65	54
Mean HD stations per unit	50	32	34	28	45
No of HD patients per station	4.6	4.9	4.2	4.8	4.6
HD shifts / week	938	84	164	63	1,249
Unit median (range)	18 (12-24)	18 (15-18)	18 (12-20)	17 (12-18)	18 (12-24)

Table 3.9. Satellite dialysis units in the UK – 31/12/2002

	England	Wales	Scotland	N. Ireland	Total UK
No. of units with current satellites	41	2	6	0	49
No. of current satellites (%NHS managed)	101 (77%)	5 (0%)	11 (91%)	0 (N/A)	117 (75%)
Current satellite units per million population	2.0	1.7	2.2	0.0	2.0
Range per renal unit	0-6	0-3	0-4	N/A	0-6
Total HD stations in satellite unit	1,276	65	90	N/A	1,431
Median no of stations per satellite (range)	12 (3-51)	13 (6-18)	6 (2-28)	N/A	12(2-51)
Total patients in satellites units	5,112	244	347	0	5,703
(% of patients on unit HD in satellite units)	(45%)	(45%)	(25%)	(0%)	(43%)
Median no of patients per satellite (range)	45 (3-222)	53 (15-64)	18 (3-112)	N/A	44 (3-222)
No. of units with planned satellites	37	2	7	2	48
No. of units without satellites planning to start a satellite centre	6	1	3	2	12
No of planned new satellites	34*	3	8	2	47
No of planned new stations	379	64	57	28	528
Median no of stations per satellite (range)	12 (8-31)	N/A(?-64)	6(4-16)	N/A (8-20)	12 (4-64)

* some planned satellites are to be shared by more than one renal unit.

(2.0), Wales (1.7) or Northern Ireland (2.4) (Table 3.8).

The expansion in patient numbers was accommodated by increasing the number of haemodialysis stations available to renal units (from 2,341 stations in 1998 to 3,193 stations in 2002) without an increase in the number of units. There was an increase in the size of the main units, but this was achieved to a major extent by increasing the number of satellite units and stations. Since 1998, the number of haemodialysis stations in satellite units in the UK increased by 70% (842 to 1,431 stations) and the number of patients dialysing in satellite units increased by 79% (3,182 to 5,703 patients). Satellite stations made up 47% of total HD stations in 2002, compared to 36% in 1998 (Tables 3.10 and 3.11).

During the periods 1993-1995, 1995-1998, 1998-2002 the absolute annual rate of increase in England of total haemodialysis stations varied from 164 to 117 to 138 respectively (Table 3.10).

Table 3.10. Changes in adult renal unit facilities in UK 1993-2002

Country		Main renal units	Total HD stations	Total HD stations per renal unit	Main units permanent stations	Main HD stations per renal unit	Satellite stations	Temp stations
England	1993	52	932	18	743	14	189	N/A
	1995	51	1,423	28	832	16	472	119
	1998	52	1,890	36	1021	20	761	108
	2002	52	2,582	50	1198	23	1276	108
Wales	1995	5	97	19	65	13	28	4
	1998	5	130	26	83	17	47	0
	2002	5	160	32	81	16	65	14
Scotland	1998	11	247	22	210	19	24	13
	2002	10	340	34	236	24	90	14
N.Ireland	1998	3	74	25	62	21	10	2
	2002	4	111	28	106	27	0	5
UK	1998	71	2341	109	1376	77	842	123
	2002	71	3193	144	1621	90	1431	141

Table 3.11. Changes in satellite unit facilities in UK 1993-2002

Country	Year	Units with satellites	Current satellite units	Total HD Stations	Median per satellite (range)	Total no of patients	Median per satellite (range)	Planned Satellites
England	1993	17	36	189	6 (2-10)	476	15 (1-41)	14
	1995	30	60	472	7 (2-31)	1,476	24 (1-68)	37
	1998	36	73	761	8 (3-41)	2,847	35 (6-160)	28
	2002	41	101	1276	12 (3-51)	5,112	44 (3-222)	34
Wales	1995	2	3	28	8 (6-14)	64	32 (25-39)	5
	1998	2	4	47	13 (9-13)	194	49 (36-60)	2
	2002	2	5	65	13 (6-18)	244	53 (15-64)	3
Scotland	1998	3	5	24	4 (2-9)	102	16 (3-52)	5
	2002	6	11	90	6 (2-28)	347	18 (3-112)	8
N. Ireland	1998	1	1	10	10	39	39	0
	2002	0	0	N/A	N/A	0	N/A	2
UK	1998	42	83	842	9 (2-41)	3,182	36 (3-160)	35
	2002	49	117	1,431	12 (2-51)	5,703	44 (3-222)	47

Staffing in adult renal units

Details of staffing in renal units are shown in Tables 3.12, 3.13 and 3.14. Relating the changes in WTE staffing in UK to the changes in patient numbers, there had been an improvement in the ratio of RRT patients, and dialysis patients, per WTE consultant nephrologist in England and Scotland. The ratio for Scotland had improved from 1 WTE consultant per 82 dialysis patients in 1998 to 1 per 68 dialysis patients in 2002, and for England from 1 per 96 dialysis patients to 1 per 87 dialysis patients. In Northern Ireland the ratio was 1 WTE consultant nephrologist per 64 dialysis patients in 2002 (56 in 1998), but in Wales it was 1 per 150 dialysis patients, with little change in the last 7 years.

There had been no substantial increase in the number of transplant surgeons in the UK since 1998. The numbers of WTE consultant transplant surgeons p.m.p. throughout the UK were similar. Wales had a higher proportion of non-consultant grade physicians.

Table 3.12. Medical staffing in adult renal units in the UK 2002

	England	Wales	Scotland	N. Ireland	UK
Consultant nephrologists:					
Numbers	250	14	39	11	314
Number p.m.p.	5.0	4.8	7.8	6.5	5.3
Number per unit	4.8	2.8	3.9	2.8	4.4
WTE nephrology	188.4	7.4	26.5	9.2	231.5
WTE p.m.p.	3.8	2.6	5.3	5.4	3.9
No of pts per consultant*	122	136	88	102	118
No of pts per WTE consultant*	162	257	129	121	160
Age group:					
30-34	3 (1%)	0	0	0	3 (1%)
35-39	53 (21%)	0	6 (15%)	4 (36%)	63 (20%)
40-44	61 (24%)	8 (57%)	10 (26%)	2 (18%)	81 (26%)
45-49	53 (21%)	0	10 (26%)	1 (9%)	64 (20%)
50-54	33 (13%)	6 (43%)	6 (15%)	3 (27%)	48 (15%)
55-59	21 (8%)	0	3 (8%)	1 (9%)	25 (8%)
60-64	13 (5%)	0	0	0	13 (4%)
Unknown	13 (5%)	0	4 (10%)	0	17 (5%)
Transplant surgeons:					
Numbers	68	5	10	1	84
Number p.m.p.	1.4	1.7	2.0	0.6	1.4
No. of units	24	2	3	1	30
WTE transplant surgeons	35.3	2.6	4.7	1	43.6
WTE p.m.p.	0.7	0.9	0.9	0.6	0.7
Associate specialists	17	5	5	0	27
Clinical assistants/Staff grades	34	6	7	2	49
Clinical/Research fellows	67	1	5	3	76
Specialist Registrars NTN/ LAT/LAS	145	7	15	3	170
SHOs/Trust grade doctors	199	11	24	6	240
HOs	41	3	6	3	53

* For the RRT patients/consultant ratio, the numbers were calculated from the total number of patients via the renal units attribution and not via the postcode attribution

In 2002, Northern Ireland had the highest rate of WTE trained nurses p.m.p. at 58.0, compared to 50.6 in Scotland, 32.6 in Wales and 29.5 in England. The ratio of numbers of WTE nursing staff to main unit haemodialysis patients was 0.2 in all 4 countries. Scotland had a higher ratio of trained to untrained nursing staff (5.4) than Northern Ireland (3.1), England (2.6) and Wales (2.3).

All units had a dietitian working for the renal department. Only 9 units reported having a dedicated renal physiotherapist, and 7 units had a dedicated renal occupational therapist. Only 3 units had a complete multi-professional renal team. Details are listed in Table 3.15.

Table 3.13. Changes in number of consultant nephrologists and ratio of patients per consultant in the UK, 1993-2002, for adults

		Numbers	Number pmp	Number per unit	WTE	WTE pmp.	No of RRT pts p.c*	No of RRT pts p.w.c**	No of dialysis pts p.c	No of dialysis pts p.w.c
England	1993	129	-	-	n/a	-	149	-	70	-
	1995	151	-	3.0	98.4	-	148	227	73	112
	1998	192	3.9	3.7	139.7	2.8	135	185	70	96
	2002	**250**	**5.0**	**4.8**	**188.4**	**3.8**	**122**	**162**	**66**	**87**
Wales	1995	11		2.2	5.5		142	284	80	159
	1998	12	4.1	2.4	6.8	2.3	143	252	64	113
	2002	**14**	**4.8**	**2.8**	**7.4**	**2.6**	**136*** **	**257*** **	**79**	**150**
Scotland	1998	33	6.4	3.0	18.1	3.5	85	155	45	82
	2002	**39**	**7.8**	**3.9**	**26.5**	**5.3**	**88**	**129**	**46**	**68**
N. Ireland	1998	9	5.3	3.0	7.9	4.7	105	119	49	56
	2002	**11**	**6.5**	**2.8**	**9.2**	**5.4**	**102**	**121**	**54**	**64**
UK	1998	246	4.2	3.5	172.5	2.9	127	182	65	93
	2002	**314**	**5.3**	**4.4**	**231.5**	**3.9**	**120**	**162**	**63**	**86**

* p.c = per consultant ** p.w.c = per WTE consultant *** some Welsh transplant patients are cared for in England.

Table 3.14. Changes in number of other medical staffing in UK 1993-2002, for adults

		Transplant surgeons		Assoc Spec	Staff Grade/ Clin Assist	Research Fellows	SpR*	SHO	HO
		WTE (No.)	WTE pmp	No.	No.	No.	No.	No.	No.
England	1993	- (60)	-	8	21	25	99	122	29
	1995	24.4 (55)	-	9	28	35	106	131	27
	1998	35.8 (69)	0.7	13	25	49	126	144	35
	2002	**35.3 (68)**	**0.7**	**17**	**34**	**67**	**145**	**199**	**41**
Wales	1995	1.4 (2)	-	3	7	0	6	10	2
	1998	2.1 (3)	0.7	5	3	0	8	11	3
	2002	**2.6 (5)**	**0.9**	**5**	**6**	**1**	**7**	**11**	**3**
Scotland	1998	3.5 (12)	0.7	1	8	8	16	25	4
	2002	**4.7 (10)**	**0.9**	**5**	**7**	**5**	**15**	**24**	**6**
N.Ireland	1998	1.1 (1)	0.7	0	0	2	3	6	3
	2002	**1 (1)**	**0.6**	**0**	**2**	**3**	**3**	**6**	**3**
UK	1998	42.5 (85)	0.7	19	36	59	153	186	45
	2002	**43.6 (84)**	**0.7**	**27**	**49**	**76**	**170**	**240**	**53**

* Senior Registrar and Registrar prior to 2002

Table 3.15. Professions allied to medicine staffing adult renal units in the UK 31/12/2002

	England	Wales	Scotland	N. Ireland	UK
Nursing Staff:					
WTE available funding	1586.7	98.8	279.0	105.0	2069.5
Actual WTE in post (and %)	1465.4 (92)	94.6 (96)	252.8 (91)	98.7 (94)	1911.5 (92)
WTE per million population	29.5	32.6	50.6	58.0	32.3
No. of units replying	51	5	10	4	70
Median (range)	23 (7-78)	17 (11-25)	28 (12-36)	27 (13-31)	24 (7-78)
% of nurses with ENB qualification	38%	25%	11%	27%	34%
Ratio of trained nurses to main unit HD patients	0.2	0.2	0.2	0.2	0.2
Ratio of trained nurses to non trained nursing staff	2.6	2.3	5.4	3.1	2.8
Non trained nursing staff:					
WTE available funding	628.7	42.8	47.1	32.0	750.6
Actual WTE in post (and %)	567.6 (90)	41.2 (96)	47.1 (100)	32 (100)	687.9 (92)
WTE per million population	11.4	14.2	9.4	18.8	11.6
No. of units	51	5	10	4	70
Median (range)	7.2 (0-40)	4.8 (1-16)	2.4 (0-15)	3.0 (0-26)	6.2 (0-40)
Dietitians numbers WTE	110.8	6.2	15.8	5.8	138.6
% NHS	99%	100%	98%	100%	99%
No. of units with dedicated dietitians	52	5	10	4	71
Average per unit	2.1	1.2	1.6	1.5	2.0
Social workers numbers WTE	40.7	3.4	7.1	5.5	56.7
% NHS	66%	74%	70%	100%	70%
No. of units with dedicated social worker	35	4	6	4	49
Average per unit	0.8	0.7	0.7	1.4	0.8
Technicians numbers WTE	160.9	5	25.5	12	203.4
% NHS	98%	90%	100%	83%	97%
No. of units with own technicians	46	4	8	4	62
Average per unit	3.1	1.0	2.6	3.0	2.9
Counsellors numbers WTE	14.5	0.5	0.0	2.7	17.7
% NHS funded	87.2%	100%	N/A	100%	89.5%
No. of units with renal counsellors	22	1	0	1	24
Average per unit	0.3	0.1	N/A	0.7	0.2
IT support numbers WTE	38.9	5.5	5.5	0	49.9
% NHS	96.4%	87%	100%	N/A	95.8%
No. of units with dedicated IT staff	31	4	4	0	40
Average per unit	0.8	1.1	0.6	N/A	0.7
Pharmacists WTE	38.6	0.8	5.5	3.0	47.9
% NHS	97.4%	100%	100%	100%	97.9%
No of units with dedicated pharmacist	40	1	7	3	51
Average per unit	0.7	0.2	0.6	0.8	0.7

Table 3.16. Changes in professions allied to medicine in the UK 1995-2002, for adults

		Dietitians WTE	Average per unit	Social workers WTE	Average per unit	Technicians WTE	Average per unit
England	1995	70.5	1.4	32.9	0.7	156.5	3.2
	1998	88.4	1.7	42.6	0.8	150	2.9
	2002	**110.8**	**2.1**	**40.7**	**0.8**	**160.9**	**3.1**
Wales	1995	5	1	2.7	0.5	11	2.2
	1998	5.5	1.1	3.8	0.8	8	1.6
	2002	**6.2**	**1.2**	**3.4**	**0.7**	**5.0**	**1.0**
Scotland	1998	14.3	1.3	5.4	0.5	21.5	2
	2002	**15.8**	**1.6**	**7.1**	**0.7**	**25.5**	**2.6**
N.Ireland	1998	4.2	1.4	3.1	1	8.3	2.8
	2002	**5.8**	**1.5**	**5.5**	**1.4**	**12**	**3**
UK	1998	112.4	1.6	54.9	0.8	187.8	2.6
	2002	**138.6**	**2.0**	**56.7**	**0.8**	**203.4**	**2.9**

Processes of care for adults

Information on processes of care is listed in Tables 3.17a, 3.17b, 3.18a and 3.18b. Northern Ireland had the highest percentage of haemodialysis patients dialysing twice weekly (11%), but this was a marked improvement from 35% in 1998. In Scotland geographical problems accounted for 25% of those patients who were dialysed twice weekly. The main reasons for UK patients currently dialysing twice weekly appeared to be because of preserved renal function or patient choice. In the UK, 95% of haemodialysis patients were dialysed in 3-5 hours sessions. Almost all patients on CAPD were using the disconnect system. Northern Ireland made the highest use of modified cellulose dialysers and the least use of synthetic membranes compared with the other UK countries.

Factors restricting development of adult renal services

The questionnaire contained a section requesting information on factors which had constrained what was considered as necessary development to meet the needs of the local population. The replies are summarised below in Table 3.19; they were similar to the replies received in the 1995 and 1998 surveys.

Regional comparisons for adults

The prevalence and annual acceptance rates for patients on renal therapy in different regions in England and countries are shown in Tables 3.20 and 3.21 and illustrated in Figure 3.5. These data do not take account of cross-regional boundary flows, nor differences in the key population characteristics such as age and ethnic minority distribution. These are considered in more detail in Chapters 4 and 5.

Table 3.17a. Process measures of haemodialysis care for renal units in the UK 2002, for adults

Process measures	England	Wales	Scotland	N. Ireland	UK
Units	52	5	10	4	71
% of dialysis patients on hospital/satellite HD	69%	65%	76%	86%	70%
Unit median (range)	71% (44-100%)	64% (63-79%)	77% (62-82%)	86% (82-89%)	71% (44-100%)
% of HD patients on twice weekly	4%	8%	0.6%	11%	4%
Unit median (range)	2% (0-38%)	2% (0-15%)	0.4% (0-2%)	12% (1-17%)	2% (0-38%)
Units with >5% twice weekly HD of HD patients	16	2	0	3	21
Reasons for twice weekly:					
Geographical reasons	3%	7%	25%	-	3%
Preserved renal function	58%	89%	50%	70%	62%
Financial restrictions	9%	-	-	15%	9%
Lack of facilities	10%	-	-	15%	10%
Others	20%	4%	25%	-	17%
Prescribed time on HD					
3-5 hours	96%	95%	93%	100%	96%
Unit median (range)	100% (45-100%)	100% (82-100%)	98% (75-100%)	100% (100-100%)	100% (45-100%)
% of HD patients using: (95% CI)					
Standard membrane	0%	0%	0%	0%	0%
Modified cellulose	29% (28-30%)	7% (5-9%)	30% (28-33%)	64% (60-68%)	29% (28-30%)
Synthetic membrane	59% (58-60%)	83% (80-85%)	57% (54-59%)	11% (9-14%)	58% (57-59%)
High Flux membrane	12% (11-13%)	11% (8-13%)	13% (11-15%)	25% (21-29%)	13% (11-13%)
% of HD patients on Haemodiafiltration (95% CI)	2.9% (2.6-3.2%)	2.9% (1.7-4.1%)	1.6% (0.9-2.3%)	0% (0-0%)	2.6% (2.4-2.9%)
Unit median (range)	0% (0-56%)	0% (0-20%)	0% (0-13%)	0% (0-0%)	0% (0-56%)
% of HD patients on Erythropoietin (95% CI)	89% (88-90%)	97% (95-99%)	92% (90-94%)	96% (95-98%)	90% (89-91%)
Unit median (range)	91% (52-99)	96% (92-100%)	91% (88-98)	98% (85-100%)	92% (52-100%)
Units	45	4	9	4	62
% of non-home HD patients reusing their dialysers (95% CI)	5.2% (4.8-5.6%)	0%	0%	0%	4.2% (3.9-4.6%)
Unit median (range)	0% (0-95%)	0%	0%	0%	0% (0-95%)
Units	51	5	10	4	70

Table 3.17b. Process measures of peritoneal dialysis care for renal units in the UK 2002, for adults

Process measures	England	Wales	Scotland	N. Ireland	UK
% of CAPD patients with disconnect (95% CI)	100% (100-100%)	98% (96-100%)	91% (87-95%)	96% (81-100%)	99% (99-99%)
Unit median (range)	100% (84-100%)	100% (40-100%)	100% (0-100%)	100% (94-100%)	100% (0-100%)
Units	49	5	10	4	68
% of PD patients on APD/CCPD (95% CI)	24% (23-25%)	19% (15-23%)	47% (42-52%)	65% (54-75%)	26% (25-27%)
Unit median (range)	19% (0-78%)	8% (0-97%)	48% (25-95%)	74% (51-86%)	26% (0-97%)
Units	49	5	10	4	68
% of PD patients on Erythropoietin (95% CI)	76% (75-78%)	83% (78-88%)	71% (67-76%)	74% (63-83%)	76% (75-77%)
Unit median (range)	77% (42-97%)	79% (67-94%)	74% (51-84%)	78% (67-86%)	76% (42-97%)
Units	44	4	10	4	62

Table 3.18a. Changes in process measures in England and Scotland 1995-2002, for adults

Process measures	England 1995	England 1998	England 2002	Scotland 1998	Scotland 2002
% of dialysis patients on hospital/ satellite HD	-	58%	69%	66%	76%
Unit median (range)	-	58%(30-100%)	71% (44-100%)	67% (40-77%)	77% (62-82%)
Units	-	52	52	11	10
% of HD patients on Erythropoietin (95% CI)	-	80% (79-81%)	89% (88-90%)	79% (76-81%)	92% (90-94%)
Unit median (range)	-	80% (10-99%)	91% (52-99)	80% (50-99%)	91% (88-98)
Units	-	51	45	11	9
% of HD patients on thrice weekly	82%	92%	96%	99.8%	99.4%
Unit median (range)	90% (10-100%)	96% (14-100%)	98% (64-100)	100% (99-100%)	99.6% (98-100%)
% of HD patients using					
standard membrane	29.50%	10%	0%	9%	0%
modified cellulose	45.50%	53%	29%	47%	30%
synthetic membrane	25%	37%	59%	45%	57%
high flux membrane	-	-	12%	-	13%
Units	47	50	51	10	10
% of CAPD patients with disconnect catheters	79%	93%	100%	100%	91%
Unit median (range)	92% (0-100%)	100% (0-100%)	100% (84-100%)	100% (100-100%)	100% (0-100%)
Units	46	52	49	11	10
% of PD patients on Erythropoietin (95% CI)	-	64% (63-66%)	76% (75-78%)	64% (59-68%)	71% (67-76%)
Unit median (range)	-	62% (10-100%)	77% (42-97%)	60% (25-90%)	74% (51-84%)
Units	-	51	44	10	10

Table 3.18b. Changes in process measures in Wales and Northern Ireland 1995-2002, for adults

Process measures	Wales 1995	Wales 1998	Wales 2002	N. Ireland 1998	N. Ireland 2002
% of dialysis patients on hospital/satellite HD	52%	59%	65%	83%	86%
Unit median (range)	56% (48-74%)	62% (56-69%)	64% (63-79%)	N/A	86% (82-89%)
Units	4	5	5	3	4
% of HD patients on Erythropoietin (95% CI)	-	87% (84-90%)	97% (95-99%)	87% (83-90%)	96% (95-98%)
Unit median (range)	-	88% (83-90%)	96% (92-100%)	N/A	98% (85-100%)
Units	-	5	4	3	4
% of HD patients on thrice weekly	77%	96%	92%	65%	89%
Unit median (range)	88% (53-98%)	99%(92-100%)	98% (85-100%)	N/A	88% (83-99%)
Units	5	5	5	3	4
% of HD patients using					
standard membrane	44%	0%	0%	0%	0%
modified cellulose	29%	17%	7%	86%	64%
synthetic membrane	27%	83%	83%	14%	11%
high flux membrane	-	-	11%	-	25%
Units	4	5	5	3	4
% of CAPD patients with disconnect catheters	64%	90%	98%	100%	96%
Unit median (range)	100% (46-100%)	100%(72-100%)	100% (40-100%)	N/A	100% (94-100%)
Units	5	5	5	3	4
% of PD patients on Erythropoietin (95% CI)	-	56% (50-61%)	83% (78-88%)	55% (44-66%)	74% (63-83%)
Unit median (range)	-	62% (29-100%)	79% (67-94%)	N/A	78% (67-86%)
Units	-	5	4	3	4

Table 3.19. Constraining factors of the responding adult units

Constraining factors	% of units				
	England	Wales	Scotland	N.Ireland	UK
Physical space	83	80	70	75	80
Capital funding	77	80	90	50	77
Nursing staff	69	60	80	75	70
Revenue funding	71	60	80	50	70
Provision of access	60	80	60	100	63
Junior posts	54	60	60	25	54
Surgical staff	44	20	50	75	45
Nephrology staff	46	40	50	25	45
Others	27	40	40	25	30

Table 3.20. Regional treatment rates 2002 p.m.p., for adults

Region/Country	Annual Acceptance (pmp)	Prevalence (pmp)
Anglia Oxford	75	539
North West	83	541
South West	93	554
Trent	93	618
S Thames	106	586
Northern Yorkshire	107	622
W Midlands	113	696
N Thames	113	782
England	98	615
Scotland	120	684
Wales	118	692
N. Ireland	109	657
UK	101	626

Table 3.21. Changes in regional treatment rates p.m.p. 1995-2002, for adults

Region/Country	Acceptances (pmp)			Prevalent patients (pmp)		
	1995	1998	2002	1995	1998	2002
N Thames	105	107	113	608	693	782
W Midlands	92	105	113	470	556	696
Trent	84	101	93	470	494	618
N Yorkshire	80	97	107	421	527	622
S Thames	76	92	106	420	495	586
South West	72	83	93	381	454	554
North West	84	79	83	441	489	541
Anglia Oxford	64	76	75	425	456	539
England	82	92	98	458	523	615
Wales	109	128	118	487	585	692
Scotland	-	105	120	-	546	684
N.Ireland	-	107	109	-	557	657
UK	-	96	101	-	529	626

Table 3.22. Regional units, facilities, and consultant numbers 1998-2002, for adults

	South West		Anglia Oxford		N Thames		S Thames		N Yorkshire		North West		Trent		W Midlands		England		Wales		Scotland		N. Ireland	
	1998	**2002**	1998	**2002**	1998	**2002**	1998	**2002**	1998	**2002**	1998	**2002**	1998	**2002**	1998	**2002**	1998	**2002**	1998	**2002**	1998	**2002**	1998	**2002**
No of units	7	**7**	5	**6**	8	**8**	6	**6**	10	**9**	5	**5**	4	**4**	7	**7**	52	**52**	5	**5**	11	**10**	3	**4**
No of satellites	13	**15**	4	**5**	11	**14**	7	**15**	11	**14**	13	**15**	7	**8**	7	**15**	73	**101**	4	**5**	5	**11**	1	**0**
HD stations pmp (main unit)	18	**21**	16	**24**	33	**33**	22	**22**	27	**35**	15	**17**	23	**26**	28	**35**	23	**26**	28	**33**	44	**50**	38	**65**
HD stations pmp (satellite unit)	16	**30**	7	**12**	26	**38**	8	**30**	12	**23**	16	**24**	13	**18**	24	**58**	15	**29**	16	**22**	5	**18**	6	**0**
WTE consultant Nephrologist pmp	2.8	**3.5**	1.8	**2.3**	3.4	**4.4**	3.5	**4.6**	2.9	**4.0**	2.6	**2.9**	2.2	**3.3**	3.4	**4.8**	2.8	**3.7**	2.3	**2.6**	3.5	**5.3**	4.7	**5.4**
No of RRT patients per WTE consultant		**157**		**236**		**176**		**128**		**154**		**185**		**189**		**146**		**165**		**257**		**129**		**121**
No of HD patients per station		**3.9**		**4.8**		**4.6**		**3.7**		**4.1**		**4.3**		**5.5**		**3.2**		**4.6**		**4.6**		**4.2**		**4.6**

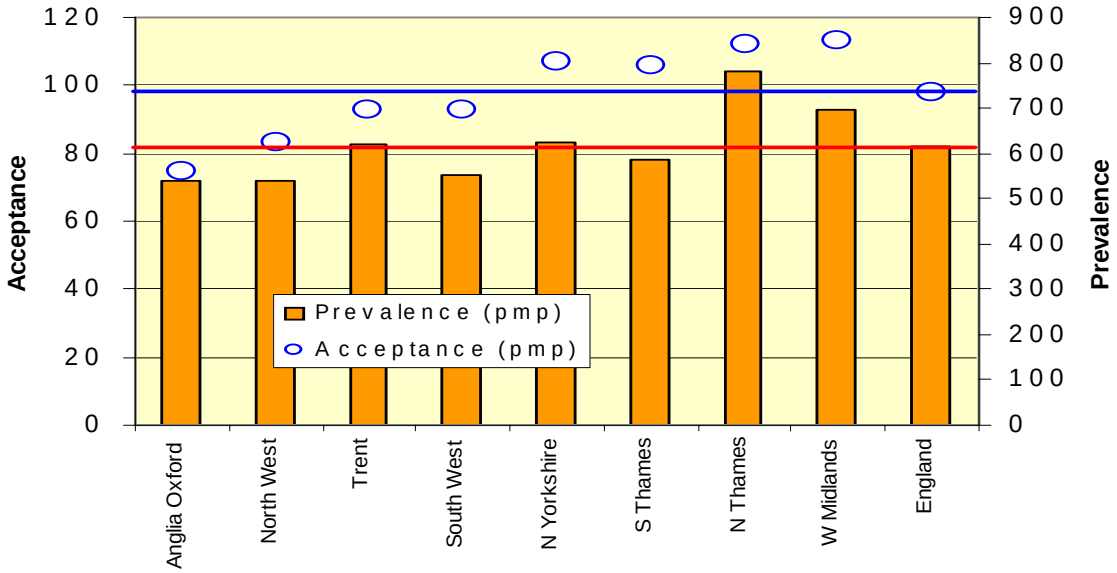

Figure 3.5. Annual acceptance and prevalence rates of RRT patients by region in England 2002

Prevalence of Hepatitis B and C, and HIV, in patients on renal replacement therapy.

Prevalence of Hepatitis B and C, and HIV (Table 3.23), was low amongst the patients receiving RRT in the UK in 2002. There were less than 2% of RRT patients who were Hepatitis C positive and less than 1% who were Hepatitis B or HIV positive.

Palliative care

Only 13 out of the 71 UK renal units had a dedicated palliative care team for renal patients. For units with such services, the number of patients using the service in 2002 ranged from 0 to 60 (Table 3.24).

Discussion

The RRT programme in the UK continues to expand. Although the annual acceptance rate grew slowly between 1998 (96 patients p.m.p.) and 2002 (101 patients p.m.p.), the prevalence rate increased from 526 patients p.m.p. in 1998 to 626 patients p.m.p. in 2002, a growth rate of around 4% per annum. In England, both the absolute and relative growth rates were greatest for haemodialysis patients, especially in satellite units. Of the 3,485 extra prevalent haemodialysis patients in 2002 compared with 1998, 72% were in satellite units. The number of satellite units had correspondingly increased by 38%, with the number of satellite-based haemodialysis stations increasing by 68% since 1998. The number of patients utilising home-based RRT (home haemodialysis or peritoneal dialysis) had for the first time decreased. The numbers on home haemodialysis decreased by 19%, and those on peritoneal dialysis by 10%, since the 1998 survey.

The regional variation in annual acceptance and prevalence rates seen in Tables 3.20 and 3.21 should be interpreted with caution as some regions, such as London have a high proportion of the population from ethnic minority groups, while others have a disproportionately elderly population, both resulting in the need for higher treatment rates than other regions. This is analysed in detail in Chapters 4 and 5.

Table 3.23. Prevalence of Hepatitis B and C, and HIV, in RRT patients in the UK 2002, for adults

	England	Wales	Scotland	N. Ireland	UK
No of Hep B patients (%)	274 (0.9%)	0	17 (0.5%)	7 (0.6%)	298 (0.8%)
% range	0-3	0	0-1	0-1	0-3
No of Hep C patients (%)	524 (1.8%)	4 (0.2%)	82 (2.4%)	7 (0.6%)	617 (1.7%)
% range	0-6	0-1	0-5	0-1	0-6
No of HIV patients (%)	136 (0.4%)	0	14 (0.4%)	7 (0.6%)	158 (0.4%)
% range	0-2	0	0-1	0-1	0-2

Table 3.24. Palliative Care services for renal units in the UK

	England	Wales	Scotland	N. Ireland	UK
No of units with a dedicated palliative team	10	1	1	1	13
No of patients who used a palliative care facility	206	2	30	6	244
Median no. of patients (range)	18 (0-60)	-	-	-	10 (0-60)

The profile of patients starting the RRT programme is also changing. The proportion of patients who were over 65 at the start of treatment increased to 50% in 2002. The percentage of patients with diabetic nephropathy as a primary diagnosis remained stable at 18%.

Cadaveric organ donor rates in the UK have fallen slightly in recent years from 1330 in 1998 to 1286 in 2002 (3% decrease). In contrast the number of live donor renal transplants had increased from 252 in 1998 to 372 in 2002 (48% increase), resulting in a 5% overall increase in the number of renal transplants in 2002.[5]

The number of patients with a functioning transplant in the UK continued to increase, but the proportion of prevalent RRT patients with a functioning transplant had reduced to 46% compared to 49% in 1998, 51% in 1995 and 53% in 1993. The proportion of patients with a functioning renal transplant is the result of the balance between the rate of annual acceptance of new patients, the proportion of those patients suitable for transplantation, the rate of renal transplantation, the rate of graft loss, and the death rate from the dialysis programme. UK Transplant, in conjunction with the Department of Health, is looking at ways to increase the transplant rate through establishing non-heart beating donor programmes, increasing organ donation rates from ITUs, and further increasing rates of live donation.

The UK Renal Registry has reported an annual rate of prevalent graft loss (due to graft failure and deaths) of 4.9%. The number of functioning transplants in Wales appeared to have fallen compared to the 1998 data. This is possibly due to problems with the 1998 survey data; transplants were overestimated due to duplicate notification from within the two renal units in the South Wales region. As both renal units now participate in the UK Renal Registry, it has been possible to validate these data and remove duplicate patients.

The size of both renal and satellite units varied considerably (Tables 3.8 and 3.9). In Scotland there were more main renal units and satellite units p.m.p. than England, partly as a result of the more widely scattered population. In the UK, 75% of the satellite units were directly funded and managed through the NHS. However, in

Wales, all the satellite units were commercially managed. The pattern of care in satellite units varied considerably, from units which had near permanent medical attendance to those which had infrequent regular visits from a doctor. Over half the main renal units in the UK in 2002 had satellite haemodialysis facilities (49/71), with yet more planned. Within the next three to four years 61 of the 71 units should have satellites. Some of the satellite units in England had a larger haemodialysis capacity than many of the main renal units, with up to 51 dialysis stations. With the predicted continual increase in patient numbers to 2020, consideration needs to be given in establishing these larger satellites as independent renal units with onsite medical support.

Although the number of the WTE consultant nephrologists p.m.p. in England increased, the number of dialysis patients had also increased, resulting in a similar ratio of dialysis patients per WTE consultant to that of 1998. Of the 4 countries, Northern Ireland had the highest number of WTE consultants p.m.p. and the lowest ratio of patients per WTE consultant. There had been a greater increase of non-consultant grade nephrology staff than the increase of trainee nephrologists.

The acceptance and prevalence rates are low in the UK, when compared to most other European countries (Chapter 22) and as patient numbers increase an even greater investment in human resources will be required.

Data regarding the trained and non-trained haemodialysis nursing staff are comparable with the data published by the British Renal Society in the report *The Renal Team: A Multi Professional Renal Workforce Plan for Adults and Children with Renal Disease*.[6]

Due to the more precise phrasing used in the 2002 survey questionnaire the data were not directly comparable with the 1998 survey. The role of non-trained nursing staff varied, with some units offering considerable responsibility such as involvement in needling fistulae and grafts, and also using a central venous catheter. Increased haemodialysis provision had been achieved through an increased number of HD stations, and by increasing the number of dialysis shifts.

Data regarding the members of multidisciplinary teams were also collected. The NSF for Renal services advised that patients approaching RRT should have a multi-skilled renal team available to them, to ensure adequate preparation both clinically and psychologically. The report *The Renal Team: A Multi Professional Renal Workforce Plan for Adults and Children with Renal Disease*,[6] outlined the personnel that constitute a multi-skilled renal team. The availability of the recommended renal team members varied between the units, with very few units having the full recommended complement.

The provision of facilities p.m.p. also showed considerable variation; this partly reflected the historical patterns of development in renal services.

Information on the processes of care showed an increased use of synthetic membranes and high flux membranes when compared with modified cellulose membranes, and virtually no standard cuprophane membranes were used. Some units were also adopting the use of haemodiafiltration (as recommended in the 3rd Renal Standards document) to reduce the risk of dialysis-related amyloidosis in patients on long-term dialysis who are unlikely to receive a transplant. Only 2 units in England were still reusing dialysers, one of which was planning to stop in 2003. All units were monitoring the dialysis adequacy for patients on haemodialysis on a regular basis, with the majority of units monitoring the adequacy every 3 months.

It is hoped that the publication of this renal survey's findings will help the NHS to gauge, plan and manage the continued expansion in provision of renal services that are projected till 2020[4].

Table 3.25. Changes in patient renal medical staff in England 1998-2002, for adults

	1998	2002	% increase
Consultant nephrologists WTE	139.7	188.4	35
Non-Consultant nephrologists	38	51	34
Trainee nephrologists	126	145	15
Dialysis Patients	13,405	16,394	22

Children

Introduction

The management of Established Renal Failure (ERF) in children is currently delivered by 13 specialist paediatric renal units in the UK. This survey commissioned by the Department of Health is the first survey conducted by the UK Renal Registry to collect data regarding the provision of paediatric renal services by these centres. However, the British Association for Paediatric Nephrology (BAPN) has been reporting its annual activities via the UK Renal Registry, and in 2002 they conducted a review of paediatric nephrology services in the UK. This survey will concentrate more on the service provision aspect, as the demographic details are covered in Chapter 14.

New paediatric patients starting Renal Replacement Therapy

The acceptance rate for new paediatric patients in the UK is 9 patients per million child population (p.m.c.p.; refers to those within the age groups quoted) and 15% of the new patients required dialysis as an emergency (Table 3.26). In contrast, the UK adult take on rate is 101 p.m.p and 34% required emergency dialysis. When analysed by age group, the highest acceptance rate is in the 10-14.99 years age group (12 p.m.c.p.) and only 1 patient is aged over 18 years (Table 3.27a). Whilst the majority of new paediatric patients were white (78%), 18% were of Indo-Asian origin (Table 3.27b). However, in adult services, 85% of new patients were white and only 7% were Indo-Asian.

Table 3.26. New patients accepted onto Renal Replacement Therapy (RRT) in 2002

	Total U.K
No of renal units	13
Patient numbers	120
Unit median (range)	8 (2-27)
Acceptance rate p.m.c.p. (95% C.I)	9 (7-10)
% Emergency	15%*

*Data from 12 units only

Table 3.27a. Profile of new patients – age groups

Age groups	Population (millions)	Number	Median (range)	Acceptance rate p.m.c.p.
0 - 4.99 years	3.4	28	2 (0-7)	8
5 - 9.99 years	3.7	26	2 (0-6)	7
10 - 14.99 years	3.9	45	3 (0-8)	12
15 - 17.99 years	2.3	20	1 (0-6)	9
18 - 18.99 years	0.7	1	N/A	1

Prevalent paediatric patients receiving Renal Replacement Therapy 31/12/2002

At the end of 2002, there were 827 paediatric patients receiving RRT. The size of the units varied from 20 to 159 patients. 74% of the patients had a functioning transplant, and of the dialysis patients 64% were on peritoneal dialysis. More detailed analyses are presented in Chapter 14.

Paediatric renal unit facilities

There were 13 paediatric renal units in the UK, 10 in England and one each in Wales, Scotland and Northern Ireland, equating to 0.9 units p.m.c.p. (Table 3.29). There were 8 paediatric transplant centres in England, 1 each in Scotland and Northern Ireland, and none in Wales. The median number of beds in each unit was 8, but one unit had no specific paediatric renal beds. The number of fixed haemodialysis (HD) stations varied from 0 to 7, with one unit having temporary

Table 3.27b. Profile of new patients - ethnicity

Ethnicity	Number	%	Range
White	94	78	7-17
Indo-Asians	22	18	1-9
African/Caribbean	1	1	0-1
Chinese	0	0	N/A
Others	3	3	0-2

Table 3.28. UK paediatric patients receiving Renal Replacement Therapy – December 31, 2002

	Total U.K
No of renal units	**13**
Patient numbers	**827**
Unit median (range)	**63 (20-159)**
Prevalence rate p.m.c.p. (95% C.I)	**59 (55-63)**
Haemodialysis	**76 (9%)**
Peritoneal dialysis	**138 (17%)**
Transplants	**613 (74%)**

Table 3.29. Paediatric renal unit facilities in the UK – 31/12/2002

	UK
Main Units	**13**
Units per million child population	**0.9**
Total beds	**107**
Unit no of beds median (range)	**8 (0-18)**
Beds per million child population	**7.6**
Haemodialysis	
Unit no of fixed stations median (range)	**5 (0-7)**
Fixed stations	**58**
Temporary stations	**6**
Total HD stations	**64**
Stations per million child population	**4.6**
Stations per unit	**4.9**
No of haemodialysis patients per station	**1.2**
HD shifts / week	**70**
Unit median (range)	**6 (3-8)**

haemodialysis station facilities only. The average unit had 4.9 stations with 1.2 HD patients using each station.

Staffing in paediatric renal units

In 2002, there were 47 consultant paediatric nephrologists, when nephrology sessions were taken into account this resulted in 39.3 WTE consultants. This equated to 3.4 consultant paediatric nephrologists p.m.c.p., and 2.8 WTE consultant paediatric nephrologists p.m.c.p. Each WTE consultant paediatric nephrologist provided care for 21 paediatric renal patients on RRT. In most of the transplant centres, the transplant services were shared with the adult renal services, hence making it difficult to separate the amount of work dedicated to paediatric renal services alone. The majority of the middle grades were specialist registrars,with very few clinical assistants, staff grades or research fellows (Table 3.30).

Compared with adult renal services, there were fewer consultant paediatric nephrologists per unit (3.6 per unit versus 4.4 per unit). Each WTE consultant paediatric nephrologist was on average responsible for 21 paediatric RRT patients and also undertakes many distant peripheral clinics.

At the end of 2002, 90% of funded trained nursing staff posts were filled, providing a ratio of 16.4 WTE trained nurses p.m.c.p. in the UK (Table 3.31). Most paediatric renal units had one dietitian and social worker (Table 3.32) but minimal IT support (0.1 WTE per unit). Of note, only 60% of social workers and 38% of teachers were NHS funded.

Table 3.30. Medical staffing in paediatric renal units in the UK 2002

Consultant nephrologists:			
Numbers	47		Nos
Number p.m.c.p.	3.4	Associate specialists	1
Average number per unit	3.6	Clinical assistants/Staff grades	2
WTE nephrology	39.3	Clinical/Research Fellows	2
WTE p.m.c.p.	2.8	Specialist Registrars (LAT/NTN)	26
Average WTE per unit	3.0	SHO/Trust grade doctors	19
No of RRT pts per consultant	18		
No of RRT pts per WTE consultant	21		

Table 3.31. Nursing staff in paediatric renal units in the UK 31/12/2002

	UK
Nursing Staff:	
WTE available funding	254.5
Actual WTE in post (and %)	229.7 (90)
WTE per million population	16.4
No. of units	13
Median (range)	18 (4-39)
% of nurses with ENB qualification	26%
Ratio of nurses to main unit HD patients	3.0
Ratio of nurses to non nursing trained staff	23.0
Non nursing trained staff:	
WTE available funding	11.3
Actual WTE in post (and %)	10 (88)
WTE per million population	0.7
No. of units	13
Median (range)	0.6 (0-3)

Processes of care in paediatric nephrology

In 2002, 36% of the paediatric dialysis patients were on hospital haemodialysis. 82% were dialysed in 3-5 hour sessions, with only 9% having twice weekly sessions of haemodialysis. The majority of these patients were on twice weekly HD because of preserved renal function, but geographical problems were the other major reason for not having three times a week HD. 80% of the patients were haemodialysing using synthetic membranes and all were on erythropoietin (EPO) (Table 3.33a).

The majority of patients on peritoneal dialysis were on either APD or CCPD (86%). Of the patients on CAPD, 94% were using the disconnect system. Once more, a high percentage of patients were on EPO (96%) (Table 3.33b).

Table 3.32. Professions allied to medicine staffing in the UK 2002

	Dietitians	Social Workers	Technicians	Counsellors	Physios	IT support members	Pharmacists	Play specialists	Teachers
Numbers WTE	12.0	10.9	20.1	5.3	0	1.9	5.7	10.2	7.6
% NHS	96%	60%	100%	100.0%	-	100%	100%	100%	38%
Average per unit	0.9	0.8	1.5	0.4	-	0.1	0.4	0.8	0.6

Table 3.33a. Process measures of haemodialysis care for paediatric renal units in the UK

	UK
Process measures	
% of dialysis patients on hospital HD	36%
Unit median (range)	40% (6-64%)
Units	13
% of HD patients on Erythropoietin (95% CI)	100% (95-100%)
Unit median (range)	100% (100-100%)
Units	12
% of HD patients on twice weekly	9%
Unit median (range)	0% (0-50%)
Units	13
Reasons for twice weekly:	
Geographical reasons	21.4%
Preserved renal function	78.6%
Financial restrictions	0.0%
Lack of facilities	0.0%
Others	0.0%
Prescribed time on HD	
3-5 hours	82%
Unit median (range)	100% (33-100%)
Units	13
% of HD patients using: (95% CI)	
Standard membrane	0% (0-5%)
Modified cellulose	20% (11-30%)
Synthetic membrane	80% (70-89%)
High flux membrane	0% (0-5%)
Units	13

Table 3.33b. Process measures of haemodialysis care for paediatric renal units in the UK

	UK
Process measures	
% of CAPD patients with disconnect (95% CI)	94% (71-100%)
Unit median (range)	0% (0-100%)
Units	12
% of PD patients on APD/CCPD (95% CI)	86% (77-95%)
Unit median (range)	96% (50-100%)
Units	12
% of PD patients on Erythropoietin (95% CI)	96% (93-99%)
Unit median (range)	100 (80-100)
Units	12

Factors restricting development of paediatric renal services

All units responded to this question. The main factors restricting development of the paediatric renal services in the UK were similar to those mentioned by the adult renal units, although funding (capital and revenue) was more of an issue for the adult services. Other specific problems mentioned were difficulties transferring the childrens' care to the adult services, and the impact of the reduction in junior doctors' hours on service provision in what is a very specialised field (Table 3.34).

Table 3.34. Constraining factors of the responding units

Constraining factors	% of units
Nursing staff	77%
Space	54%
Revenue funding	46%
Capital funding	31%
Nephrology staff	23%
Junior posts	23%
Surgical staff	15%
Provision of access	15%
Other	23%

Discussion

The number of new paediatric patients starting RRT each year in the UK has remained largely unchanged since 1996. The prevalent number of paediatric RRT patients in the UK has also remained stable, with a total number of 827 patients at the end of 2002. Of the paediatric RRT patients, 74% had a functioning transplant, and of the dialysis patients 64% were on peritoneal dialysis. This was in contrast to the adult patients where 46% had a functioning transplant, and only 27% of dialysis patients were on peritoneal dialysis. The proportion of paediatric patients requiring dialysis as an emergency was just less than half that of the adult population (15% versus 34%). A higher proportion of the new patients were Indo-Asian compared with in the adult renal units (18% versus 7%). This has implications for those reaching the adult nephrology service, and in particular dialysis, because of issues regarding transplant availability.

The data regarding numbers of doctors, nurses and other professions allied to medicine in the paediatric renal units in the UK wFere consistent with those published by the British Renal Society in their report: *The Renal Team: A Multi Professional Renal Workforce Plan for Adults and Children with Renal Disease*[6], although there had been an increase since its release. An international comparison showed that the UK had a lower ratio of consultant paediatric nephrologists p.m.c.p. compared to America[8] and some of the other European

countries[9], and the BAPN recommendations from 2001 of 68 WTE consultants remained unmet. There had however been an increase in the number of trainees from 15 to 27, which may help alleviate this shortfall. The Workforce Planning document recommended that the minimum number of consultants required to deliver the clinical service, comply with the European working time directive and ensure that non-clinical activities are fulfilled, is at least 5 WTE per unit. The survey has shown that in 2002 the UK falls short of this target with 3.0 WTE per unit.

The BAPN also made recommendations regarding the minimum number of other allied professions needed for each paediatric renal unit[7] and most of the centres still needed to reach these levels. Of note, paediatric nephrology wards should be managed by a registered children's nurse with the ENB147/136 qualification on a daily basis, but in 2002 only 26% of nursing staff had this qualification.

The main constraining factor to future development and expansion of paediatric renal services in the UK, as reported by the renal units, was the staffing of nursing posts. This was in contrast to the adult renal services where funding issues were thought to be a more prominent problem. Plans are afoot within the paediatric nephrology service to try to both attract and retain nursing staff.

Collation of this dataset will hopefully provide units with increased power when in negotiation with their commissioners, and enable the continued regular follow up of both service provision and manpower within nephrology in the UK.

The data in the paediatric section has not been fully reviewed by the BAPN and a full report will be published with the finalised DOH survey.

Acknowledgement

This work was funded by a grant from the Department of Health.

The Renal Registry would like to thank all the staff at UK renal units for collaborating in this study and for the huge effort that has gone into this data collection.

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Chapter 4: New Adult Patients Starting Renal Replacement Therapy in England and Wales

Summary

- The Registry data are compatible with the annual acceptance rate of 101 adult new patients p.m.p. for RRT in England and Wales, as reported by the National Renal Review.

- The Registry identified 3583 new patients starting RRT in 2002, from 72% of the population of England and Wales.

- For the first time, using data from the National Census, standardised acceptance ratios, standardised for age and gender of the population served, for acceptance for RRT in different local authority areas were calculated.

- Crude annual acceptance rates varied from 52 p.m.p. in Calderdale to 165 p.m.p.in Wolverhampton. Standardised acceptance ratios varied from 0.58 in Calderdale to 1.88 in Lewisham.

- Standardised acceptance ratios correlate significantly with both social deprivation and with ethnicity.

- Areas submitting data since 1998 show a 6.4% rise in the acceptance rate over this period, with wide variations between different areas.

- Diabetic nephropathy was the cause of ERF in 19.8% of new patients in 2002, a proportion which is slowly rising each year.

- Of the 2002 patient cohort, the established modality at 90 days was haemodialysis in 68.8%: only 2.7 % had received a transplant.

- At 3 years, of patients first established on HD, 42% remain on HD, 3.4% had changed to PD, 13% had been transplanted, and 38% had died. For established PD patients, 28% remain on PD, 23% converted to HD, 21% were transplanted and 25% had died.

Introduction

Whilst the UK Renal Registry does not have complete coverage of the UK, any assessment of the incidence and characteristics of new patients starting renal replacement therapy in the whole UK must be an extrapolation from data from the units participating in the Registry, which has inherent potential errors. For this reason, for data relating to the whole UK, the results reported from the National Renal Review in Chapter 3 should be used. However, for comparison between renal units, and between local areas fully covered by the Renal Registry, the data from the Registry are fully valid . Such analyses are reported in detail in this chapter.

The National Renal Review contains summary data from Scotland and Northern Ireland. No further data from these countries for 2002 were made available to the UK Renal Registry, so this chapter refers entirely to England and Wales.

Paediatric data are not included in this chapter.

Adult patients accepted for Renal Replacement Therapy in England and Wales, 2002

35 of the 52 renal units in England, and all 5 units in Wales, returned data on new patients accepted for Renal Replacement Therapy in 2002. The estimated catchment population for the units was 37.5 million (Table 4.1), representing 72% of the population of England and Wales. These units recorded 3583 new patients.

The proportion of the population aged over 65 years was similar in the covered population compared with the general population of England and Wales (16.1 and 16.0% respectively).

The proportion from an ethnic minority group was lower in the covered population (4.9%) compared with 6.5% in the total population. This is because the areas not reporting to the Registry include parts of London and Manchester where there are high ethnic minority populations. If an attempt is made to calculate the acceptance rate of new patients for the whole UK from the Registry data, the difference in ethnic mix between the populations served by the Registry and the whole population of the UK will inevitably lead to an underestimate, as the incidence of renal failure is high in the ethnic minority populations.

Estimates of renal unit catchment populations are unreliable; in general there is usually a slight overestimate of catchment populations.

One estimate of acceptance rate might be obtained by studying the areas of England and Wales from which all patients needing renal replacement therapy are treated by renal units reporting to the Registry. It is estimated that a total population of 30,319,815 of the population of England and Wales (51,923,966) lived in areas completely covered by the Registry. This is 58% of the population of England and Wales. There were 2792 cases accepted from this population. However, 4.9% of patients did not have a valid postcode and were thus not included in such calculations. It would thus be necessary to inflate any estimate of acceptance rate by this method by 4.9%. There is also the possibility that some local authority areas for which Registry coverage was not quite complete were included. The last argument particularly applies to London and surrounding areas as not all renal units are covered by the Registry (e.g. note Hammersmith has a lower than expected rate).

Calculating the acceptance rate in England and Wales using Renal Units' data together with estimates of their catchment populations gives a crude acceptance rate of 95.9 patients per million population per annum. Calculating the figure from the local authority areas fully covered by the Registry gives a figure of 96.6 patients per million per annum. Taking into account the above potential errors, together with a small inflation for under representation of ethnic minorities in the Registry units one would calculate the take on rate to be around 100 patients per million per annum, as was found in the National Renal Review (see Chapter 3).

Table 4.1. Number of new patients accepted by individual renal units

		No. of new patients				
Centre	**Estimated catchment population**	**1998**	**1999**	**2000**	**2001**	**2002**
Bangor	0.18					29
Bradford	0.60				61	60
Bristol	1.50	122	119	151	151	125
Cambridge	1.42				84	75
Cardiff	1.30	137	138	137	142	142
Carlisle	0.36	40	26	27	25	29
Carshalton	1.67	141	108	117	120	173
Clwyd	0.15					19
Coventry	0.85	87	92	89	103	97
Exeter	0.75	74	82	71	99	82
Gloucester	0.55	49	59	46	49	57
Guys	1.73			122	109	140
Hammers /ChX	1.3					174
Heartlands	0.60	71	71	77	85	59
Hull	0.84	73	65	81	75	105
Ipswich	0.33					21
Kings	1.01					117
Leeds GI	0.90			68	74	63
Leicester	1.73	181	161	177	182	151
Liverpool	1.35				182	150
Middlesbrough	1.00	109	92	90	82	112
Newcastle	1.31					105
Nottingham	1.16	129	128	113	121	87
Oxford	1.80	146	139	144	168	160
Plymouth	0.55	71	67	63	63	86
Portsmouth	2.00				144	143
Preston	1.56	79	105	118	135	113
Reading	0.60			54	71	43
Sheffield	1.75	129	134	136	152	156
Stevenage	1.25	116	105		125	97
Southend	0.35		43	39	35	35
St James, Leeds	1.30	71	79	89	87	80
Sunderland	0.34	41	45	46	35	56
Swansea	0.70		23	61	110	111
Truro	0.36				35	58
Wirral	0.53					40
Wolverhampton	0.49		75	77	76	99
Wordsley	0.42	46	43	40	34	25
Wrexham	0.42		51	58	36	42
York	0.34			40	36	67

Geographical variation in acceptance rates in England and Wales

Introduction

Geographical equity of acceptance onto renal replacement therapy (RRT) is an important goal of renal service provision. However different areas will have different needs for RRT depending on demographic composition, particularly their age and ethnic minority composition. Comparison of crude acceptance rates onto RRT by geographical area alone can be misleading without taking account of such factors. This section outlines a new analysis of 2002 acceptance data, which uses age and gender standardisation to compare RRT rates, and relates these to the ethnic minority and social deprivation profiles. The total population used for the standardisation is the combination of all areas for which the Registry had complete coverage in 2002. This analysis is restricted to England and Wales.

Methods

Patients

All new cases accepted onto RRT in 2002 recorded by the Registry were included. Each patient's postcode was matched to a 2001 Census output area. In 2002 172/3501 (4.9%) of postcodes had no match; there was no obvious clustering by renal unit.

Geography: Unitary Authorities, Counties and other areas

Postcodes were assigned to 2001 Census Output Areas (OAs) using a look-up table (available from census.gov) and SPSS software.

OAs are the smallest geographical unit to which postcode data can be aggregated. They were aggregated to a higher level geography of Unitary Authorities and Local Authority Districts (both Metropolitan and non-Metropolitan) in order to create a manageable number of areas (see Appendix D for a description of UK administrative geography).

For the final analysis, contiguous 'county' areas were derived by merging Unitary Authorities (UAs) with a bordering county. For example, Southampton UA was merged with Hampshire County, Rutland UA with Leicestershire County, and Bristol UA with Somerset County (for a complete list of data merges see Appendix D). The final areas used were Metropolitan counties, Greater London districts, Welsh areas and county areas – these different types of area were called 'LA areas'.

Lists of areas (English Counties as at 31/12/2000; English UAs as at 31/12/2000; Welsh UAs as at 31/12/2000 and English districts as at 31/12/2000) were taken from http://www.statistics.gov.uk/geography/geographic_area_listings/administrative.asp .

Population

The populations for Unitary Authorities and Districts were taken from http://www.statistics.gov.uk/census2001/population_data.asp .

Coverage: the covered population

The Renal Registry identified all areas in England and Wales for which they estimated to have complete coverage. Analysis was restricted to these areas. See Appendix D for a complete list of covered areas.

Calculation of acceptance rates

Crude rate

The crude rate of acceptance onto RRT was calculated for each LA area for the year 2002

$$\frac{observed\_cases}{population} \times 1000000$$

per million population (p.m.p.)

Standardised acceptance rate ratio (SARR)

The age/gender standardised rate ratio of acceptance onto RRT was calculated for each LA area for the year 2002

$$\frac{observed\_cases}{\exp ected\_cases} \times 100$$

Observed cases (O_i) were calculated by summing all cases in all age and gender bands for each LA area. Expected cases (E_i) for each LA area were calculated by: for each age/gender band the observed rate over all LA areas (the standard population) was applied to the population of that age/gender band to determine the expected number of referrals. The expected cases in each age/gender band were summed to give an expected number of cases in each LA area. 95% confidence limits were calculated for each area.

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

LA area level social deprivation

For each LA area the Townsend social deprivation score was calculated. This is a measure of material deprivation available for all output areas in England and Wales using 2001 Census data.

Variables in the Townsend score are: the proportion of households without a car or van; the proportion of households living in overcrowded accommodation; the proportion of households which are owner occupied; and the proportion of the population who are unemployed. The unemployment and overcrowding variables are log transformed, and all four variables are then standardised to give Z-scores. The Townsend score for each OA is calculated by summing the four Z-scores.

To calculate Townsend scores for LA areas the raw census data for each OA in the LA area are summed to the new area boundaries. The four variables are then recalculated for the new area populations.

The range of scores runs from negative to positive with a high score indicating higher social deprivation. LA area social deprivation scores were correlated with LA acceptance rates and with the proportion of the population from ethnic minorities for each LA area.

The acceptance rate by quintile of social deprivation was calculated for the combination of populations covered by the Registry and with < 3% from ethnic minorities to reduce the confounding effect of ethnicity on the association between social deprivation and acceptance rate.

Results

Age and Gender

The rates of acceptance increased with age and were higher in men (Table 4.2 and Figure 4.1). The rates in the over 75s reflect the balance between the higher rates of ERF and the effect of referral/acceptance for RRT in the elderly. The different pattern in men and women over 75 is of interest and requires further analysis.

Standardised acceptance ratios

The standardised acceptance ratios for local authorities with complete coverage by the registry are shown in Table 4.3

Table 4.2. Age/gender specific acceptance rates in the covered population

		N (covered population)	N (cases in covered population)	Crude rate per million covered population
15-29	Women	2,811,437	50	18
	Men	2,823,347	60	21
30-44	Women	3,437,675	155	45
	Men	3,339,093	225	67
45-59	Women	2,917,298	233	80
	Men	2,875,081	348	121
60-74	Women	2,140,803	398	186
	Men	1,948,888	652	335
75+	Women	1,458,578	249	171
	Men	847,500	422	498
All		**30319815**	**2792**	**92**

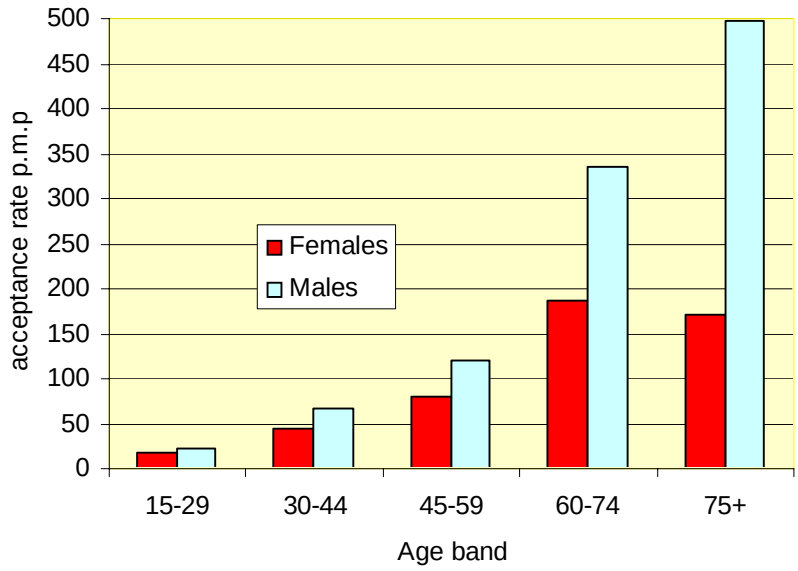

Figure 4.1. Acceptance rate p.m.p by age band and gender

Table 4.3. Adult acceptance rates, social deprivation and ethnicity for LA areas with full coverage

County name	2002 crude rate per 1,000,000 population	2002 age/ gender standardised rate-ratio	95% CI lower	95% CI upper	Townsend deprivation score	% of the population from an ethnic minority[1]
Barnsley	110.1	**1.18**	0.79	1.76	-.43	.39
Bedfordshire	72.4	**0.86**	0.63	1.17	-2.26	11.28
Bexley	119.1	**1.31**	0.89	1.93	-2.68	6.24
Bradford	115.5	**1.39**	1.06	1.81	.46	19.83
Bromley	91.4	**0.98**	0.67	1.43	-2.72	5.47
Buckinghamshire	68.5	**0.81**	0.61	1.08	-3.80	5.95
Calderdale	52.0	**0.58**	0.31	1.07	-.43	5.92
Cambridgeshire	67.7	**0.77**	0.58	1.02	-3.16	3.29
Cornwall & I of Scilly	163.6	**1.54**	1.24	1.91	-2.37	.34
Coventry	139.6	**1.60**	1.19	2.17	.37	13.07
Croydon	121.0	**1.49**	1.09	2.03	.60	24.64
Cumbria	86.1	**0.85**	0.63	1.16	-2.30	.24
Devon	99.5	**0.96**	0.79	1.16	-2.48	.38
Doncaster	87.2	**0.93**	0.63	1.38	-.82	1.44
Durham (county)	104.2	**1.12**	0.94	1.34	.06	1.28
Ealing	126.3	**1.64**	1.19	2.26	2.20	33.33
Gateshead	115.1	**1.19**	0.78	1.81	1.81	.83
Gloucestershire	93.8	**0.99**	0.79	1.25	-4.31	1.43
Greenwich	125.9	**1.61**	1.10	2.34	4.71	17.86
Hammersmith	60.5	**0.83**	0.45	1.54	6.52	15.57
Hampshire	72.0	**0.78**	0.65	0.92	-3.44	1.65
Hertfordshire	54.2	**0.61**	0.47	0.79	-3.70	4.14
Kirklees	97.8	**1.13**	0.82	1.55	-.71	12.70
Knowsley	86.4	**1.01**	0.58	1.73	2.99	.44
Lambeth	109.0	**1.60**	1.11	2.30	7.77	30.33
Lancashire	74.2	**0.80**	0.66	0.97	-2.12	5.55
Leeds	74.1	**0.85**	0.65	1.11	.42	5.96
Leicestershire	86.6	**0.97**	0.78	1.21	-2.30	12.67
Lewisham	136.6	**1.88**	1.34	2.62	5.36	27.20
Lincolnshire	74.2	**0.74**	0.59	0.93	-2.66	.75
Liverpool	88.7	**1.02**	0.75	1.40	4.44	2.32
Newcastle upon	88.6	**1.01**	0.67	1.51	3.26	4.75
Northamptonshire	99.7	**1.12**	0.85	1.47	-3.09	3.19
Northumberland	78.1	**0.78**	0.52	1.17	-1.36	.42
Nottinghamshire	74.8	**0.82**	0.65	1.02	-.76	3.93
Oxfordshire	76.0	**0.87**	0.65	1.16	-3.94	2.56
Rotherham	64.5	**0.70**	0.43	1.15	-.75	2.39
Sefton	106.0	**1.07**	0.75	1.53	-1.03	.58
Sheffield	91.6	**1.01**	0.76	1.34	1.14	6.34
Solihull	70.2	**0.73**	0.43	1.23	-3.56	3.49
Somerset & Avon	84.9	**0.88**	0.73	1.06	-2.86	1.97
Southwark	130.7	**1.84**	1.30	2.60	8.65	29.96
St. Helens	96.1	**1.05**	0.65	1.69	-.50	.48
Sunderland	99.7	**1.10**	0.76	1.60	1.81	1.13
Sutton	116.9	**1.38**	0.90	2.11	-2.24	7.29
Tyneside - North	99.1	**1.02**	0.65	1.59	.19	.94
Tyneside - South	91.6	**0.94**	0.56	1.59	3.53	1.75
Wakefield	76.2	**0.84**	0.56	1.25	-.85	1.54
Walsall	114.4	**1.24**	0.86	1.78	.33	11.83
Warwickshire	100.8	**1.06**	0.81	1.40	-3.88	3.15
Wiltshire	62.0	**0.68**	0.49	0.93	-4.18	1.24
Wirral	83.3	**0.86**	0.59	1.26	-1.12	.59
Wolverhampton	164.9	**1.77**	1.29	2.42	1.98	18.91
Yorkshire - East	108.3	**1.14**	0.92	1.42	-.79	.86
Yorkshire - North	129.9	**1.30**	1.03	1.63	-4.07	.29
North Wales	117.6	**1.19**	0.95	1.48	-2.04	.33
Dyfed Powys	100.4	**0.96**	0.73	1.28	-2.64	.33
Morgannwg	121.3	**1.24**	0.96	1.61	-1.64	.68
Gwent	110.9	**0.99**	0.75	1.30	-1.46	.96
Bro Taf	92.3	**1.25**	1.00	1.55	-1.44	2.26

[1] Data on numbers self reported as Black or Indo-Asian in the 2001 census as a proportion of the entire population (using the five categories of Black, South Asian, white, other and mixed ethnic origin).

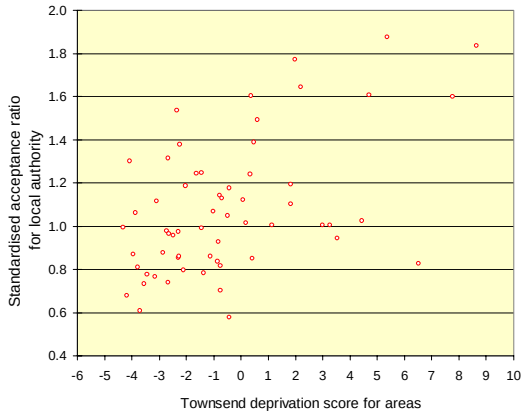

Figure 4.2a. Standardised Acceptance Ratio for local authority and Townsend deprivation score

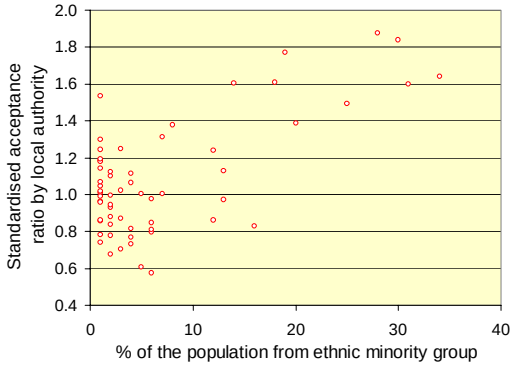

Figure 4.2b. Standardised acceptance ratio by local authority and % of population from ethnic minorities (standardised for age and sex)

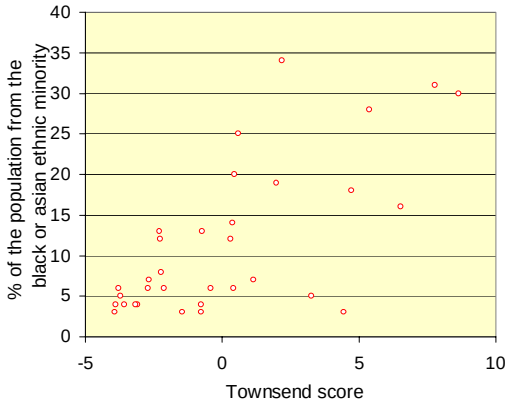

Figure 4.2c. Percentage from ethnic minorities in each Local Authority and Townsend score

Social deprivation

Standardised acceptance ratios are correlated with social deprivation (r^2 = 0.27, $p<0.001$) and with ethnicity (r^2 = 0.45, $p<0.001$) (Figures 4.2a and 4.2b). However, there is a strong relationship between ethnicity and social deprivation (Figure 4.2c, $r^2=0.47$, $p<0.001$). To determine the separate effects on acceptance ratio of social deprivation, ethnic mix, and the reaction between the two, stepwise multiple regression analysis was performed. The results of the correlation matrix are shown in Table 4.4. As the data are not normally distributed, log transformations were used.

This stepwise multiple regression analysis shows that the most dominant factor affecting the acceptance ratio is the interaction between ethnic mix and social deprivation ($p<0.0001$). However ethnic mix also has an effect on acceptance ratio which is independent of social deprivation ($p=0.0003$), but after eliminating the effects of these two factors there is little independent effect of social deprivation.

Discussion

There is substantial variation in the crude LA area acceptance rates from 57 p.m.p (Calderdale) to 187 p.m.p (Lewisham). Relatively small numbers of cases mean that the confidence limits are often quite wide for most areas so that the standardised rate ratios usually include one. However, some areas have significantly high ratios. In some, this is commensurate with their high ethnic minority population and/or deprived population, good examples being Ealing and Wolverhampton. In other areas, the high rate is unexplained e.g. Cornwall. Possibilities here include the artefact of misclassification of ARF as ERF (the Registry has checked that this is not the case in Cornwall) and a true increase in acceptance. High acceptance rates could be due to unexplained high rates of ERF, or to high rates of recognition/referral and acceptance of cases

Table 4.4. Correlation matrix of variables in the stepwise multiple regression analysis of Ethnicity, Social Deprivation and Standardised Acceptance Ratio

Correlation				
	Pearson Correlation Coefficients, N = 60			
	Standardised acceptance ratio	log_townsend_plus	log_ethnic minority	interaction
rate-ratio	1	0.4984	0.40911	0.52928
		<.0001	0.0012	<.0001
log_townsend_plus	0.4984	1	0.39591	0.55134
	<.0001		0.0017	<.0001
log_ethnic minority	0.40911	0.39591	1	0.96495
	0.0012	0.0017		<.0001
interaction	0.52928	0.55134	0.96495	1
	<.0001	<.0001	<.0001	

Dependent variable: standardised acceptance ratio

of ERF along with sufficient dialysis facilities.

Some LA areas have significantly low rate ratios. In some, this is consistent with low ethnic minority numbers and lower social deprivation e.g. Wiltshire. The standardised rates are all relative to an overall acceptance rate that probably does not meet population need for RRT.

The correlation between both an area's ethnic minority population and its social deprivation score and the acceptance rate highlights the impact such factors have on RRT rates. However, ethnic minority status and social deprivation are associated: the individual effect of social deprivation is also demonstrated in an analysis restricted to areas with a low ethnic minority proportion. This analysis is confounded by access to renal services (area of high social deprivation are in urban areas and hence have better access), the effect being to increase the association between social deprivation and acceptance rates.

This overall analysis has shown that it is possible to compare age/gender standardised acceptance rates at a meaningful area level using the latest population denominators. In future years the covered population will increase and hence the number of LAs. One can combine more than one year's acceptance data to increase the precision of the acceptance rate estimate.

Ethnic specific acceptance rates and standardisation of areas by ethnic status will be more difficult because of incomplete ethnic coding of patients, and age/gender breakdown of the Census output areas is not available by ethnic group.

Local changes in acceptance rate

Changes in acceptance by 'old' Health Authorities

The Registry has not yet analysed acceptance rates before 2002 by Local Authorities. The data are therefore presented by old Health Authorities as in previous years to show comparison over time (Table 4.5).

Previous calculations of the UK acceptance rate have been based on 'complete' Health Authorities. For some areas around London it has been difficult to know the extent of cross boundary flows. With the Hammersmith and Kings Renal units submitting data this year, the acceptance rates for some of the London HAs have apparently risen indicating that coverage was incomplete in the previous years.

Analysing these data by complete HAs submitting data since 1998, these HAs show a 6.4% rise in the acceptance rate over this period.

Changes in acceptance by renal unit

The number of patients accepted by each renal unit in England and Wales is shown in Table 4.1. There is variation in the pattern of time trends by unit which may reflect chance fluctuation, completeness of reporting, rising incidence of ERF, changes in referral patterns or catchments and the introduction of conservative care teams.

Ethnicity

There is substantial variation in the completeness of ethnicity data (Table 4.6). No ethnicity data were available for Scotland. In England and Wales 18 units now provide over 90% complete data. In contrast 10 provide less than 30%. Such levels of incompleteness make it difficult to assess reliably the ethnic breakdown in such units.

There is a lower proportion of patients from ethnic minority populations in the Registry data than found in the National Renal Review, showing that the Registry units are not totally representative of the whole UK.

Within the units with over 90% returns there is significant variation in the percentages of new patients from the ethnic minorities with high rates of ERF i.e. South Asian and Black, ranging from 0% to 38%.

Table 4.7 demonstrates the younger age of ethnic minorities in most though not all renal units. There is variation in the age differences even in units with a significant ethnic minority population (e.g. compare Heartlands with Preston). It is unclear to what extent this reflects differences in the units' catchment populations, or patterns of ERF or referral pathways. Overall new patients from ethnic minorities are 6 years younger than Whites. Compared with similar data for new patients in 2001 the median age of ethnic minorities has increased by 3 years. This rise in median age over one year cannot be due simply to the ageing of these populations, and indicates increasing acceptance rates in older ages.

Table 4.5. Acceptance rate by 'old' Health Authorities

Region	HA Text	Population	1998 pmp	1999 pmp	2000 pmp	2001 pmp	2002 pmp
Y01	Bradford	483,300			95.8	120.0	113.8
Y01	Calderdale and Kirklees	583,800			80.5	94.2	89.1
Y01	County Durham and Darlington	607,800	100.4	74.0	72.4	75.7	98.7
Y01	East Riding and Hull	574,500	71.4	71.4	88.8	85.3	92.3
Y01	Gateshead and South Tyneside	353,500					101.8
Y01	Leeds	727,400			77.0	92.1	77.0
Y01	Newcastle & North Tyneside	470,100					89.3
Y01	North Cumbria	319,300	125.3	72.0	68.9	78.3	94.0
Y01	North Yorkshire	742,400			92.9	84.9	137.4
Y01	Northumberland	309,600					77.5
Y01	Sunderland	556,300	51.3	85.5	82.1	88.9	95.8
Y01	Tees	318,800	107.9	91.7	82.7	93.5	116.8
Y01	Wakefield	228,100			100.4	84.7	78.4
Y02	Barnsley	290,500	70.1	83.3	61.4	65.8	105.2
Y02	Doncaster	928,700	75.7	82.6	79.2	92.9	89.5
Y02	Leicestershire	623,100	107.7	89.4	91.5	107.7	92.6
Y02	Lincolnshire	370,200	81.8	91.5	88.3	77.0	73.8
Y02	North Derbyshire	388,900	51.3	62.1	59.4	86.4	75.6
Y02	North Nottinghamshire	642,700	115.7	95.1	108.0	90.0	87.4
Y02	Nottingham	254,400	119.8	110.5	96.5	112.0	70.0
Y02	Rotherham	531,100	51.1	62.9	102.2	149.4	78.6
Y02	Sheffield	308,600	88.5	90.4	81.0	90.4	94.1
Y02	South Humber	292,300	103.7	64.8	74.5	55.1	100.5
Y07	Coventry	304,300	111.7	115.0	118.3	154.5	134.7
Y07	Dudley	311,500	80.3	64.2	70.6	54.6	64.2
Y07	Solihull	205,600	82.7	73.0	87.5	111.9	68.1
Y07	Walsall	261,200	11.5	114.9	76.6	111.0	122.5
Y07	Warwickshire	506,700	96.7	116.4	100.7	100.7	100.7
Y07	Wolverhampton	241,600		99.3	157.3	115.9	169.7
Y08	East Lancashire	511,200		68.5	74.3	86.1	99.8
Y08	Liverpool	461,500			121.3	149.5	91.0
Y08	Morecambe Bay	310,300		70.9	99.9	70.9	58.0
Y08	North Cheshire	311,900			60.9	93.0	93.0
Y08	North-West Lancashire	466,300	75.1	68.63	79.3	96.5	75.1
Y08	Sefton	287,700			104.3	93.8	104.3
Y08	St Helens and Knowsley	333,000			96.1	81.1	90.1
Y08	Wirral	327,100				100.9	79.5
Y09	Bedfordshire	556,600	80.8	73.7	72.5	88.0	82.6
Y09	Cambridgeshire	468,000			126.1	100.4	109.0
Y10	Bexley, Bromley and Greenwich	730,000				91.8	111.0
Y10	Croydon	338,200			88.7	79.8	130.1
Y10	Ealing, Hammersmith & Hounslow	617,200				168.5	170.1
Y10	Hillingdon	251,200				96.5	99.5
Y10	Lambeth, Southwark and Lewisham	745,200			77.8	107.4	134.2
Y11	Buckinghamshire	681,900	57.0	68.9	64.5	86.5	68.9
Y11	East Surrey	419,900	71.4	78.6	45.2	59.5	83.4
Y11	I of Wight, Portsmouth & S-E Hampshire	671,700				71.5	72.9
Y11	North and Mid Hampshire	556,900				61.1	73.6
Y11	Northamptonshire	615,800	71.5	73.1	89.3	84.4	86.1
Y11	Oxfordshire	616,700	76.2	64.9	61.6	82.7	74.6
Y11	Southampton & SWest Hampshire	542,300				66.4	70.1
Y11	West Surrey	640,600					73.4
Y12	Avon	999,300	82.1	84.1	109.1	109.1	93.1
Y12	Cornwall and Isles of Scilly	490,400			120.3	104.0	175.4
Y12	Gloucestershire	557,300	89.7	95.1	87.9	82.5	93.3
Y12	North and East Devon	479,300	81.4	87.6	91.8	91.8	87.6
Y12	Somerset	489,300	67.4	83.8	69.5	87.9	98.1
Y12	South and West Devon	589,100	118.8	106.9	96.8	127.3	115.4
Y12	Wiltshire	605,500				66.1	61.1
W00	Gwent	557,200	102.3	75.4	93.3	113.1	98.7
W00	Bro Taf	739,600	87.9	110.9	97.3	85.2	110.9
W00	Dyfed Powys	479,400			83.4	106.4	102.2
W00	North Wales	657,500			111.0	120.2	123.2
W00	Morgannwg	499,700			116.1	126.1	128.1

Table 4.6. % patients in different ethnic groups, by centre

Treatment centre	% returns	% White	% Black	% Asian	% Chinese	% Other
Glouc	100.0	100.0	0.0	0.0	0.0	0.0
H&C	100.0	42.7	12.4	25.8	0.0	19.1
Heart	100.0	66.1	5.1	25.4	0.0	3.4
Notts	100.0	94.3	2.3	3.4	0.0	0.0
Redng	100.0	83.7	14.0	2.3	0.0	0.0
Sheff	100.0	92.9	0.6	4.5	0.6	1.3
Stevn	100.0	87.2	3.2	7.4	1.1	1.1
Wolve	100.0	80.8	5.1	13.1	1.0	0.0
Words	100.0	100.0	0.0	0.0	0.0	0.0
Prstn	99.1	84.4	2.8	11.9	0.0	0.9
Newc	99.0	94.2	1.0	3.9	1.0	0.0
Leic	98.7	85.2	0.7	12.8	0.0	1.3
Bristl	98.4	94.3	2.5	0.8	0.8	1.6
Carls	96.6	100.0	0.0	0.0	0.0	0.0
Plym	92.9	98.7	1.3	0.0	0.0	0.0
York	92.5	100.0	0.0	0.0	0.0	0.0
Ports	91.6	95.4	0.8	3.1	0.8	0.0
Sund	91.1	98.0	0.0	2.0	0.0	0.0
Livrpl	88.0	94.7	0.8	0.0	3.0	1.5
Middlbr	83.9	95.7	0.0	2.1	2.1	0.0
Swnse	78.4	98.9	0.0	1.1	0.0	0.0
Covnt	77.3	81.3	5.3	13.3	0.0	0.0
Guys	76.8	76.0	17.7	5.2	1.0	0.0
Hull	61.9	98.5	0.0	0.0	1.5	0.0
Camb	37.3	100.0	0.0	0.0	0.0	0.0
Truro	31.0	100.0	0.0	0.0	0.0	0.0
Bradf	30.0	27.8	0.0	72.2	0.0	0.0
StJms	28.8	91.3	0.0	0.0	0.0	0.0
Sthend	28.6	100.0	0.0	0.0	0.0	0.0
Extr	26.8	90.9	4.5	0.0	4.5	0.0
Carsh	23.1	85.0	2.5	7.5	0.0	5.0
Clwyd	21.1	100.0	0.0	0.0	0.0	0.0
Wrex	19.0	100.0	0.0	0.0	0.0	0.0
Bangr	13.8	100.0	0.0	0.0	0.0	0.0
LGI	11.1	100.0	0.0	0.0	0.0	0.0
Wirrl	7.5	66.7	0.0	0.0	0.0	33.3
Crdff	4.2	100.0	0.0	0.0	0.0	0.0
Eng	69.6	88.1	3.0	6.7	0.7	1.5
Wls	31.8	99.1	0.0	0.9	0.0	0.0
E&W	65.9	88.6	2.8	6.5	0.7	1.4
E& W for units >90% returns	**> 90%**	**87.2**	**3.5**	**6.4**	**0.6**	**2.2**

Table 4.7. Median age of ethnic groups accepted for RRT

Median Age of Incident Patients related to ethnicity		
Centre	**Ethnic Minority**	**All**
Bradf	60.3	65
Bristl	42.1	67
Carsh	66.6	65
Covnt	64.0	63
Extr	57.8	71
Guys	48.1	60
Heart	68.8	69
Hull	74.9	66
Leic	66.0	65
Livrpl	55.6	66
Notts	69.2	68
Oxfrd	70.2	66
Plym	38.0	66
Ports	48.3	63
Prstn	52.0	61
Redng	63.4	63
Sheff	60.4	61
Stevn	53.6	59
StJms	56.0	65
Sund	51.2	64
Swnse	67.0	69
Wolve	58.0	62
E&W	**60.1**	**66**

Age

The median age of patients starting renal replacement therapy is rising and was 65.5 years in 2002. This has risen from 64.8 years in 2001 and 64.4 years in 2000. The percentage of patients by age band and change from 1997 – 2002 is shown in Figure 4.3.

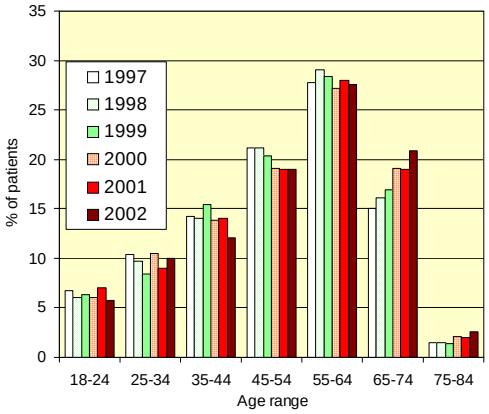

Figure 4.3. Percentage of new patients by age group 1997 -2002

The median age by centre is shown in Figure 4.4.

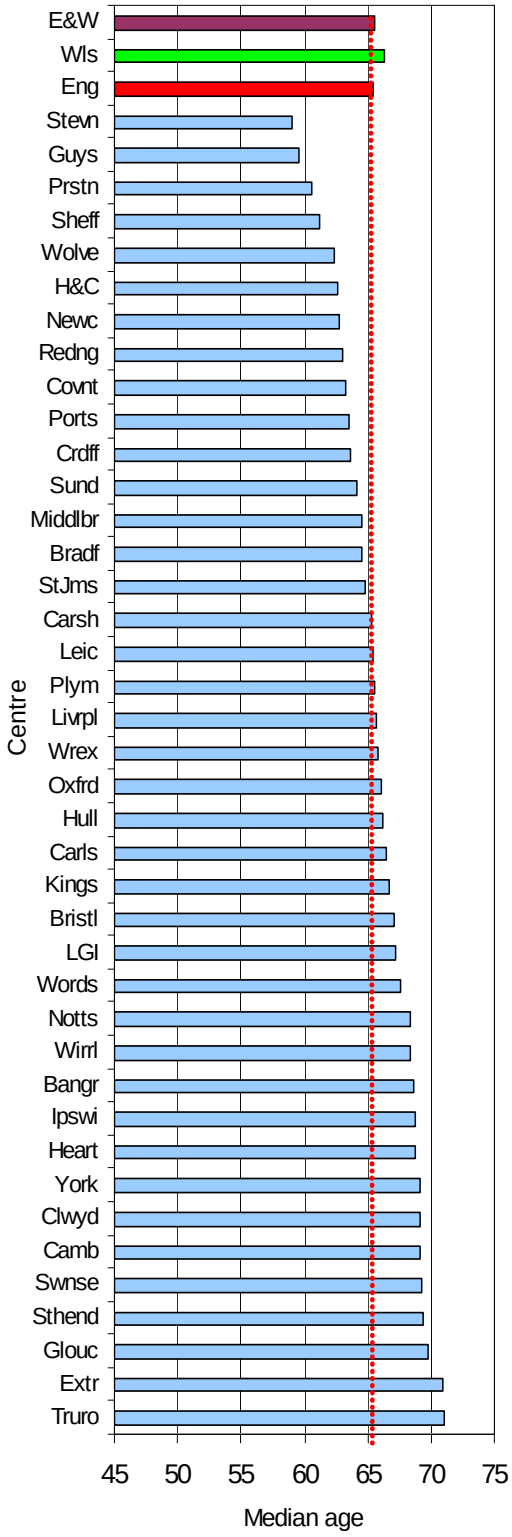

Figure 4.4. Median Age new patients by centre

Gender

Gender specific acceptance rates for the contiguous population covered by the UKRR are shown in Table 4.1. There has been little change in the overall proportion of new cases who are male, which remains at just over 60% (Table 4.8).

Combining the 2001 and 2002 cohort (Figure 4.5), there was a trend over the age of 45 for an increasing proportion of males starting renal replacement therapy.

Table 4.8. Percentage of males, by age, 1998–2002

	1998	1999	2000	2001	2002
England & Wales	62.8	62.2	59.3	63.2	61.8

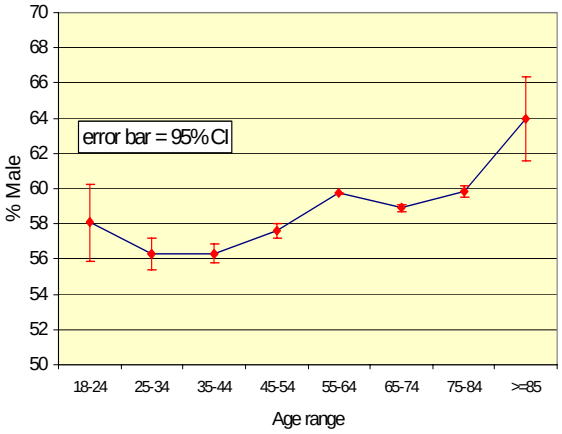

Figure 4.5. Percentage males starting RRT by age band

Primary renal diagnosis

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

Diabetes is the commonest specific cause overall, and increasing. This is due to the very high incidence in those under 65, although it is not the most common cause in elderly patients. The aetiology uncertain/ glomerulonephritis not proven (GN NP) group is an important category, especially in the elderly, and there is still a high percentage of cases given 'no cause'.

The male:female ratio is over one as expected for most types of kidney disease. The PKD gene is distributed equally amongst the general population so the excess of males on renal replacement therapy may be related to hypertension and reno-vascular disease being more common in males. There is also a gender imbalance in patients with diabetic nephropathy and this may be for a similar reason.

There is a significant variation between units in the percentage starting RRT with diabetic kidney disease, which generally follows the pattern of population distribution of ethnic minorities (Tables 4.10, 4.11). In the absence of firm definitions for diagnostic categories e.g. hypertensive disease, reno-vascular disease, some centre variation in cause is likely to reflect differences in classification rather than geographical differences in underlying disease.

Diabetic nephropathy was the cause of ERF in 18.6% of patients starting RRT in 2001 (after excluding patients with a missing diagnosis) and 18.7% in 1999. The apparent rise this year to 19.8% may be related to the two renal units from inner London joining, with their high ethnic minority population.

Table 4.9. Percentage primary renal diagnosis, by age, and gender ratio

Diagnosis	E&W <65 N=1714	E&W > 65 N=1790	E&W all N=3504	M:F
Aetiology uncertain/GN NP*	17.5	26.5	21.9	1.5
Glomerulonephritis	13.5	6.5	9.8	2.0
Pyelonephritis	6.7	6.3	6.5	1.5
Diabetes	20.4	14.5	17.6	1.6
Renal vascular disease	2.8	11.2	7.0	2.1
Hypertension	5.1	5.9	6.1	2.3
Polycystic kidney	9.9	3.0	6.3	1.3
Other	14.4	12.6	13.6	1.3
Not sent	9.6	13.6	11.4	1.6

* GN NP, glomerulonephritis not proven

Table 4.10. Percentage distribution of diagnoses for new RRT patients by centre

Unit	Not sent	Aetiology unc. / Glomer. NP	Diabetes	GN	Polycystic Kidney	Hypertension	Reno-vascular	Pyelo-nephritis	Other
Bangr	0	42.9	21.4	3.6		7.1	3.6	10.7	10.7
Bradf	0	20.0	36.7	8.3	3.3	5.0	6.7	11.7	8.3
Bristl	0	33.1	14.5	10.5	12.1	0.8	8.1	10.5	10.5
Camb	14.7	37.3	13.3	1.3	4.0	1.3	8.0	4.0	16.0
Carls	6.9	24.1	3.4	13.8	6.9	13.8	17.2		13.8
Carsh	17.9	5.2	16.2	9.2	11.0	9.8	9.2	4.6	16.8
Clwyd	5.3	36.8	36.8		10.5			5.3	5.3
Covnt	8.2	23.7	16.5	9.3	5.2	1.0	7.2	13.4	15.5
Crdff	9.9	51.4	9.2	10.6	7.0	2.1	2.1	4.9	2.8
Extr	31.7	19.5	3.7	7.3	7.3	1.2	9.8	6.1	13.4
Glouc	1.8	28.1	10.5	21.1	12.3		5.3	5.3	15.8
Guys	22.9	7.1	27.1	10.0	5.7	6.4	7.1	2.9	10.7
H&C	7.3	14.0	28.1	4.5	4.5	19.1	2.2	2.2	18.0
Heart	0	18.6	16.9	6.8		10.2	15.3	10.2	22.0
Hull	12.4	22.9	26.7	8.6	5.7	2.9	2.9	5.7	12.4
Ipswi	0	28.6	28.6	4.8			4.8	4.8	28.6
Kings	0	17.9	23.9	7.7	6.8	17.9	8.5	5.1	12.0
Leic	4.6	23.8	18.5	13.2	9.3	0.7	11.9	6.0	11.9
LGI	41.3	7.9	11.1	7.9	3.2	7.9	4.8	3.2	12.7
Livrpl	2.0	36.7	16.7	6.0	5.3	12.0	2.7	6.7	12.0
Middlbr	0.9	25.0	18.8	17.0	5.4	6.3	7.1	4.5	15.2
Newc	29.5	3.8	7.6	9.5	14.3	5.7	5.7	7.6	16.2
Notts	0	32.2	19.5	11.5	6.9	3.4	5.7	5.7	14.9
Oxfrd	16.9	20.0	17.5	5.6	8.8	1.9	8.8	9.4	11.3
Plym	24.4	11.6	15.1	8.1	2.3		10.5	9.3	18.6
Ports	10.5	21.7	16.1	14.7	9.8	4.2	4.9	6.3	11.9

Table 4.10. (continued)

Unit	Not sent	Aetiology unc. / Glomer. NP	Diabetes	GN	Polycystic Kidney	Hypertension	Reno-vascular	Pyelo-nephritis	Other
Prstn	8.8	14.2	22.1	17.7	3.5	8.0	2.7	6.2	16.8
Redng	0	23.3	25.6	9.3	2.3	4.7	14.0	7.0	14.0
Sheff	0.6	12.2	15.4	19.9	7.1	14.1	4.5	12.2	14.1
Stevn	2.1	36.1	18.6	2.1	6.2	3.1	3.1	2.1	26.8
Sthend	48.6	20.0	5.7	11.4			5.7	5.7	2.9
StJms	15.0	16.3	15.0	11.3	7.5	2.5	10.0	6.3	16.3
Sund	10.7	8.9	23.2	14.3	3.6	8.9	8.9	8.9	12.5
Swnse	5.4	16.2	13.5	6.3	3.6	4.5	21.6	10.8	18.0
Truro	20.7	20.7	19.0	12.1	3.4	1.7	5.2	5.2	12.1
Wirrl	0	90.0	7.5						2.5
Wolve	0	19.2	28.3	10.1	4.0	5.1	7.1	8.1	18.2
Words	0	40.0	12.0	16.0	4.0	16.0			12.0
Wrex*	90.5	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
York	32.8	19.4	4.5	10.4	4.5	6.0	13.4	6.0	3.0
Eng	10.8	20.8	18.1	10.1	6.5	6.4	6.9	6.4	14.1
Wales	17.3	32.2	12.6	7.0	4.7	2.9	8.2	7.0	8.2
E&W**	11.4	21.8	17.6	9.8	6.3	6.1	7.0	6.5	13.6

*With so few returns from Wrexham, no calculations could be made
**The E&W total is calculated from those units with 80% or more returns.

Table 4.11. Percentage diagnoses, excluding 'not sent'

Unit	Aetiology uncertain/ GN NP	Diabetes	GN	Polycystic kidney	Hypertension	Reno-vascular	Pyelo-nephritis	Other
E&W	24.7	19.8	11.1	7.1	6.8	7.9	7.3	15.3

First established treatment modality

In 2002, haemodialysis was the very first modality of RRT in 68.2% of patients in England and Wales. Many patients, especially those referred late to a renal unit, undergo a brief period of haemodialysis before being established on peritoneal dialysis. As an indication of the elective treatment modality, the established modality at 90 days is a more clearly defined and representative figure (Figure 4.6). Of the 2002 patient cohort on day 90 of treatment, 68.8% of all dialysis patients were on haemodialysis; only 2.7 % had received a transplant.

There is a wide variation between units in the proportion of patients on HD at day 90 (Figure 4.7).

The comparison of HD usage in the under and over 65 age group is shown in Figure 4.8. The data for Salford and Manchester have been supplied from the Manchester SIRS database.

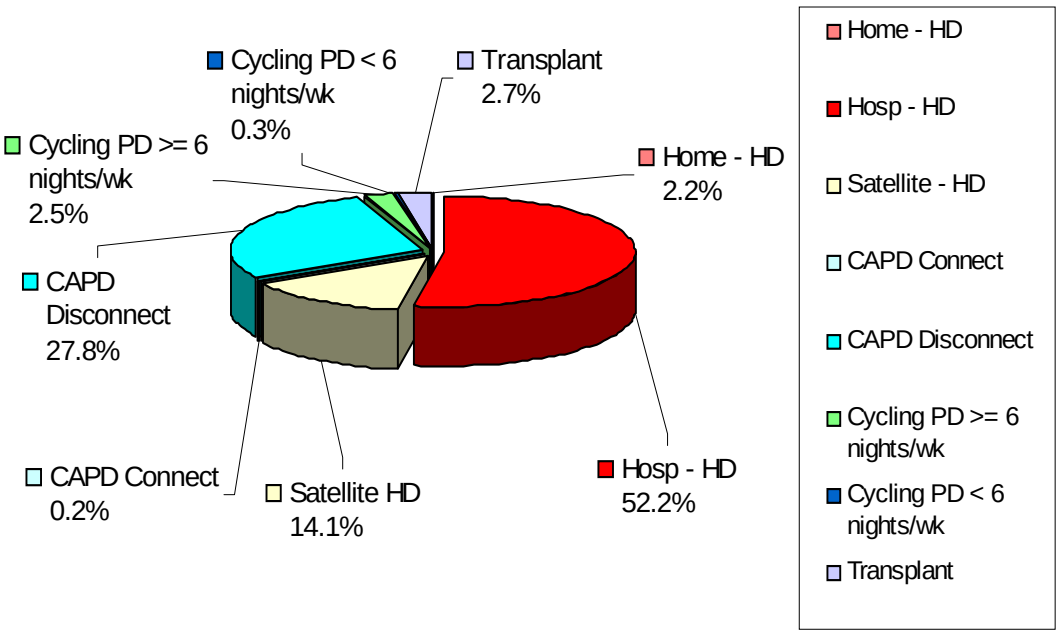

Figure 4.6. RRT modality at day 90 - 2002 cohort

When analysing modality by age <65 and 65+, 58% and 79% of patients respectively were on HD at day 90 in England & Wales (Figure 4.8).

There were significant differences between individual units within England and Wales in the percentage of new patients established on haemodialysis (p< 0.0001). Peritoneal dialysis patients have a lower median age than HD patients (57.8 years and 67.8 years respectively, p<0.0001).

Changes in established treatment modality in the first 3 years of RRT

Changes in modality from the start of RRT are shown for up to 3 years from the start in Tables 4.12-4.15. The patterns are similar to those seen in previous reports.

The first year

The switch from PD to HD is much larger than the converse switch, and continues for at least 3 years (p<0.0001). For the combined 1999-2001 cohort it was 11.7% in the first year after 90 days (Tables 4.12, 4.13). Patients starting PD have a greater chance of receiving a transplant (p<0.0001), reflecting their younger age. PD mortality is also lower than that of HD (p<0.0001): this probably largely reflects the differences in age and clinical factors associated with selection of patients for modality.

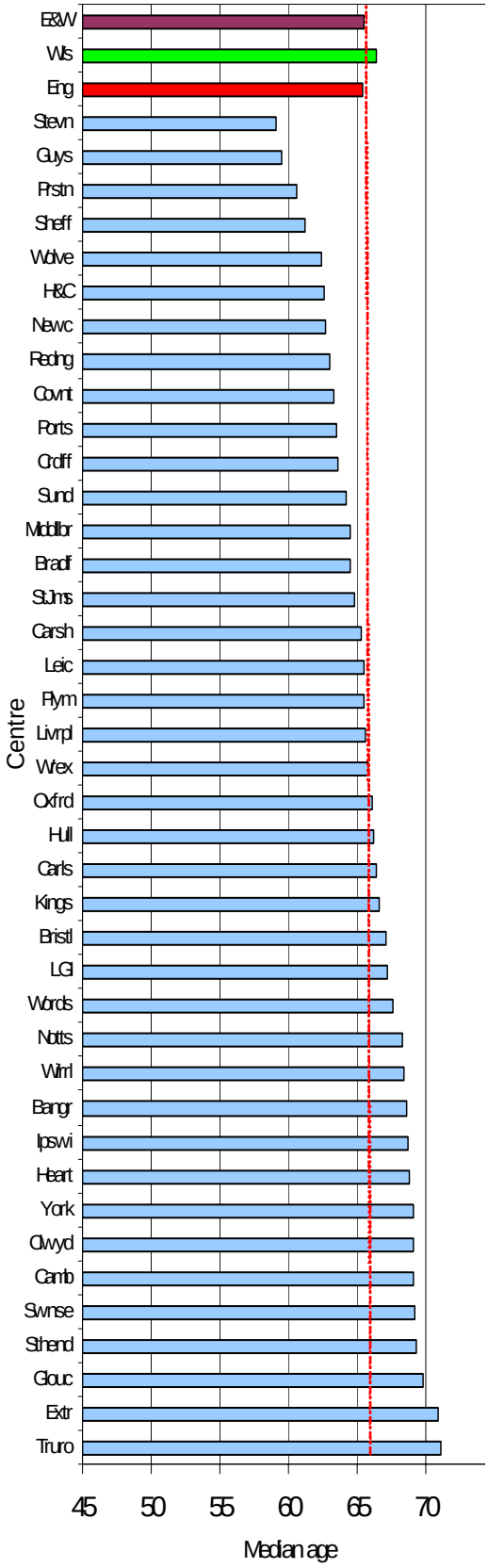

Figure 4.7. Percentage of incident dialysis patients on HD on day 90

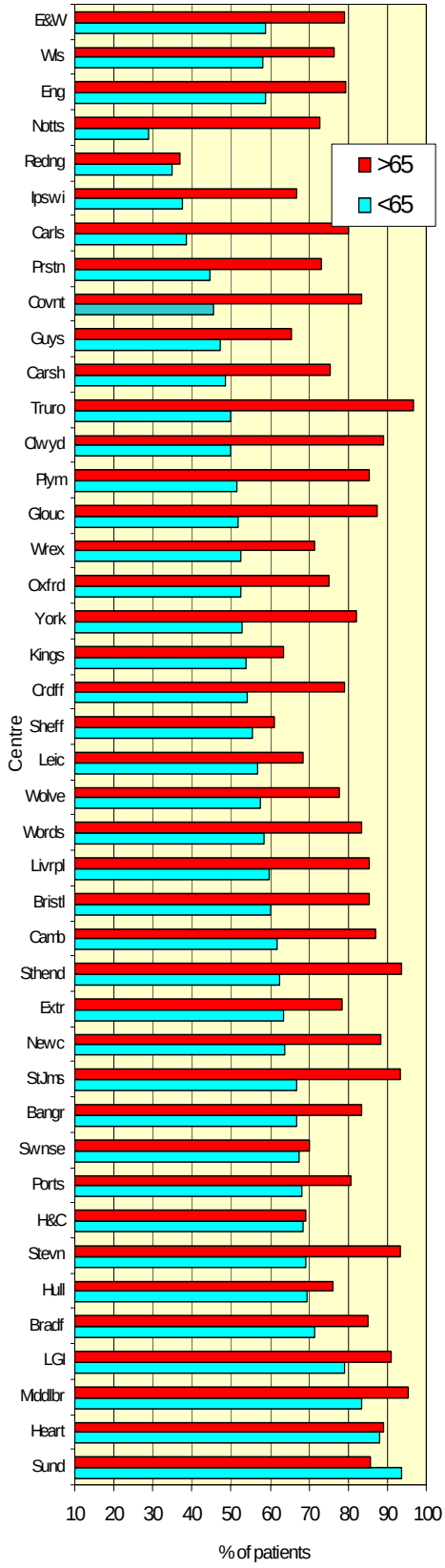

Figure 4.8. Percentage of incident dialysis patients on HD on day 90, by age, 2002

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

Established on HD (n=3157)		
Modality	**No. of patients**	**Percentage**
Remain on HD	2791	71.4
Changed to PD	125	3.2
Transplanted	161	4.1
Transferred out elsewhere	24	0.6
Recovered	51	1.3
Stopped treatment (died)	6	0.2
Died (no change in modality)	749	19.2

1999-2001 cohort

Table 4.13. PD patients at 90 days – changes in modality in the subsequent year

Established on PD (n=2482)		
Modality	**No. of patients**	**Percentage**
Remain on PD	1670	67.3
Change to HD	290	11.7
Transplanted	239	9.6
Transferred out elsewhere	27	1.1
Recovered	16	0.6
Stopped treatment (died)	1	0.04
Died (no change in modality)	239	9.6

1999-2001 cohort

The first 3 years

The results from combining the 3-year follow up data from the 1997 – 1999 incident patient cohort are shown in Tables 4.14 and 4.15.

These tables show that the attrition rate for patients starting on PD is much higher than that for those starting on HD, and is constant in each successive year. The rate of conversion from PD to HD is very much higher than the reverse. Conversion from HD to PD is virtually confined to the first year of treatment. By the end of year 3, 25% of patients that started on PD had died compared with 38% of HD patients, and 21% of PD patients were transplanted at the end of the 3rd year compared with only 13% of patients on HD.

These data are presented in a slightly different format in Tables 4.16 and 4.17, in which the proportions of patients on the treatment at the start of each year who subsequently change treatment in year are shown.

Table 4.14. 3 year HD technique survival

n = 1,803	End of year 1	End of year 2	End of year 3
Remain on PD	71.3	54.2	42.4
Changed to HD	2.7	3.2	3.4
Had a transplant	4.9	10.5	13.3
Stopped treatment	0.1	0.2	0.4
Don't know	0.2	0.3	0.3
Recovered	1.3	1.7	1.7
Died	19.5	29.8	38.3

Table 4.15. 3 year PD technique survival

n= 818	End of year 1	End of year 2	End of year 3
Remain on PD	67.2	43.9	28.4
Changed to HD	10.8	17.9	22.9
Had a transplant	10.2	17.1	21.1
Stopped treatment	0.0	0.1	0.2
Don't know	0.6	0.8	0.9
Recovered	0.6	1.1	1.2
Died	10.5	19.1	25.3

Table 4.16. Changes in modality over the first 3 years for patients on HD

Established on HD First change in modality	End of 1 year % of new patients starting RRT	End of 2 years % of patients alive at end of year 1	End of 3 years % of patients alive at end of year 2
Remains on HD	71.4	76.8	75.5
Changed to PD	3.2	0.8	0.4
Transplanted	4.1	6.3	5.2
Transferred out elsewhere	0.6	0.8	0.5
Recovered	1.3	0.2	0
Died (no change in modality)	19.4	15.2	18.4
Total patients	**3157**	**1674**	**575**

Table 4.17. Changes in modality over the first 3 years for patients on PD

Established on PD First change in modality	End of 1 year % of patients	End of 2 years % of patients alive at end of year 1	End of 3 years % of patients alive at end of year 2
Remains on PD	67.3	62.5	65.3
Changed to HD	11.7	12.5	10.2
Transplanted	9.6	11.5	8.6
Transferred out elsewhere	1.1	0.3	0.3
Recovered	0.6	0.2	0.3
Died (no change in modality)	9.6	12.9	15.0
Total patients	**2482**	**1045**	**314**

Survival of incident patients

This is considered in Chapter 15. International comparisons will be found in Chapter 22.

Chapter 5: All Patients Receiving Renal Replacement Therapy in 2002

Summary

- The UK prevalence of RRT was 626 p.m.p with 34% aged over 65.
- The annual increase in prevalent RRT patients is 4%.
- The median age of all patients on RRT was 55.9 years. This was 64.5, 58.3, 49.6 years for HD, PD and transplant patients respectively.
- While the median age of prevalent patients on HD has increased from 1998 – 2002, the median age of those on PD is decreasing.
- 46% of RRT patients had a functioning transplant and although the overall numbers are increasing, this as a % of total RRT patients has fallen year on year.
- The 1 year prevalent transplant and dialysis survival was 97.6% and 86.1% respectively.
- After adjusting for age, there was no significant difference in dialysis survival between centres.
- Analysis of seasonal variations in death rates indicate that the winter peak of deaths in HD patients precedes the peak seen in the general population. This occurred across all age bands for HD patients. Deaths in transplant patients followed a similar pattern to that of the general population.

Prevalence rates

In Chapter 3, data from the Renal Survey 2003 showed that the prevalence rate for patients receiving renal replacement therapy in the UK at the end of 2002 was 626 patients per million population (p.m.p.). As all units in the UK participated in the survey, this is the most accurate estimation of the RRT prevalence rate currently available. There is a significant variation between the four countries with England having the lowest prevalence rate amongst the 4 countries (Table 5.1). There were more units per million population in Wales, Scotland and Northern Ireland than in England, resulting in the units in England being on average larger in size.

The number of units participating in the UK Renal Registry activity has increased to 40, providing data for 22,412 RRT patients, which were 60% of the total UK RRT patients (69% of total England and Wales patients). The number of prevalent patients in each of the units in England and Wales providing data to the Registry is given in Table 5.2 and Figure 5.1. The wide variation in the proportion of transplanted patients in each unit is partly the result of different policies for follow-up of patients at transplant centres. Some transplant centres continue to follow up the patients they transplant for other renal units; others transfer them back to their parent unit but at variable times post transplant. Some renal units do not follow any transplanted patients. Thus, units with a transplant centre tend to have higher proportion of transplant patients under follow up in the unit compared with units without a transplant centre. The table now includes Newcastle, but two of the other large transplant centres, Birmingham and Manchester, which do not return patients to the parent unit until a relatively late stage, are still not contributing to the Registry.

For the 23 units which have been participating with Registry activity since 1999, the prevalent number continues to increase year by year (Table 5.3). However, the actual and proportional increase year by year seems to be decreasing in the last 3 years. Data from the Renal Survey 2002 in Chapter 3 showed an annual increase of around 4%.

Table 5.1. UK Patients receiving Renal Replacement Therapy – December 31, 2002

	England	Wales	Scotland	N.Ireland	UK
No of renal units	52	5	10	4	71
Total RRT patients	30,498	2006	3,418	1,117	37,039
Rate p.m.p (95% CI)	615 (608-622)	692 (652-722)	684 (661-707)	657 (619-696)	626 (620-633)
Rate per unit	587	401	342	279	522
Units p.m.p	1.0	1.7	2.0	2.4	1.2
Haemodialysis	11369 (37%)	720 (36%)	1380 (40%)	512 (46%)	13981 (38%)
Home haemodialysis	420 (1%)	9 (0%)	52 (2%)	1 (0%)	482 (1%)
Peritoneal dialysis	4605 (15%)	380 (19%)	376 (11%)	80 (7%)	5441 (15%)
Transplants	14,104* (46%)	897 (45%)	1,610 (47%)	524 (47%)	17,135* (46%)
% dialysis pts on HD	72%	66%	79%	87%	73%

Table 5.2. Prevalent RRT patients in each unit, 31 December 2002

Treatment Centre	Dialysis No.	Transplant No.	RRT No.	% Transplant
Oxford*	515	859	1374	63
Guys*	487	706	1193	59
Livrpl*	540	632	1172	54
Cardiff*	504	615	1119	55
Ham &Cx*	679	406	1085	37
Leics*	610	460	1070	43
Ports*	429	613	1042	59
Sheff*	618	410	1028	40
Bristl*	433	561	994	56
StJms*	334	484	818	59
Notts*	435	380	815	47
Carsh*	455	339	794	43
Camb*	324	392	716	55
Newc*	189	465	654	71
Prstn	410	191	601	32
Covnt*	312	262	574	46
Kings	337	237	574	41
Stevn	383	147	530	28
SCleve*	242	280	522	54
Hull	328	192	520	37
Extr	297	222	519	43
Heart	302	185	487	38
Plym*	177	221	398	56
Swnse	289	105	394	27
LGI	226	164	390	42
Wolve	282	84	366	23
Bradf	181	100	281	36
Sund	127	129	256	50
Words	141	94	235	40
Ipswi	128	87	215	41
Truro	152	63	215	29
Glouc	161	51	212	24
Wrex	165	47	212	22
Redng	197	7	204	3
Sthend	148	29	177	16
York	138	34	172	20
Carls	85	85	170	50
Wirrl	137	0	137	0
Bangr	90	0	90	0
Clwyd	61	26	87	30

* transplant centres

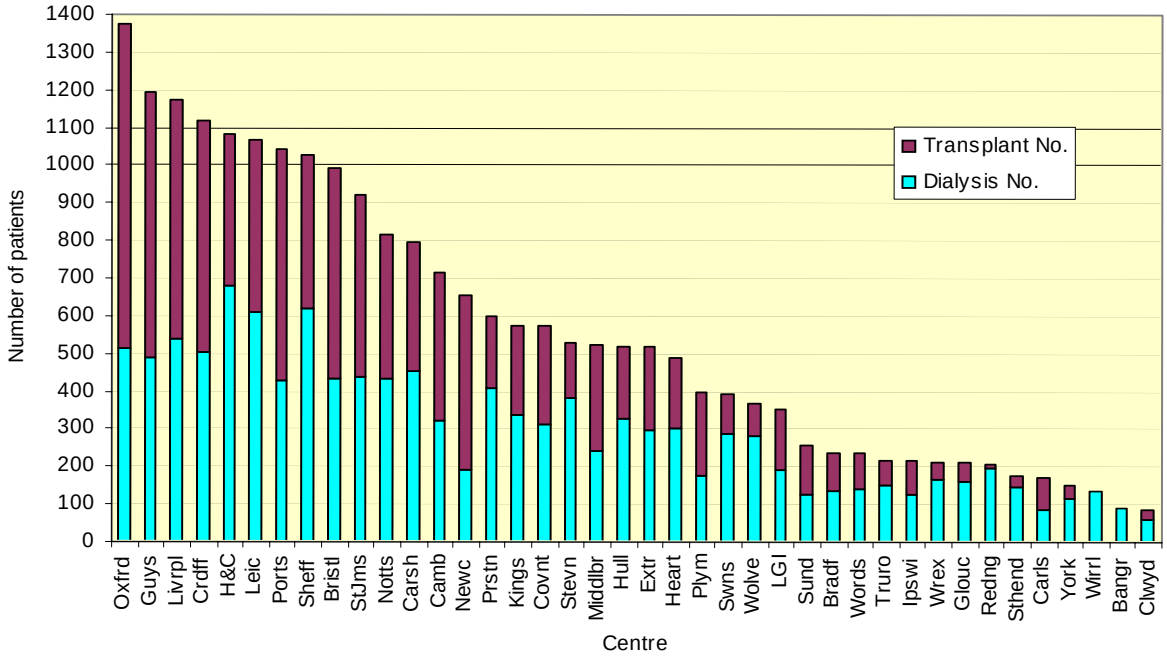

Figure 5.1. Distribution of RRT in prevalent patients

Table 5.3. Number of patients in the same 23 centres on RRT, 1999–2002

	1999	2000	2001	2002
No of RRT patients in the 4th qtr	11447	12447	13222	13791
Actual increase in number	-	1000	775	569
% increase	-	9%	6%	4%

Prevalence by Health Authority

Table 5.4 shows prevalent patients according to the old Health Authorities by postcode of residence in England and Wales. Only those Health Authorities where there is more or less complete coverage by the Registry are included. This allows an estimate of the prevalence (p.m.p.) to be made. Comparisons across England and Wales are more valid from these data than when the information is presented according to renal unit (see Chapter 4). There are wide variations between Health Authorities for reasons which include differences in local age structure, ethnicity and social deprivation, as well as differing policies for referral and acceptance of patients and service provisions.

For parts of England and Wales where there has been complete coverage by the Registry for 5 years there are some interesting differences. For instance, in Calderdale & Kirklees and County Durham & Darlington, the prevalence has increased by almost 50% whereas there has been much less of an increase in Leicestershire, Nottingham, Coventry and Dudley Health Authorities. Although this may be partly due to incomplete data in earlier years it may represent growth in areas where the prevalence was relatively low 5 years ago. The highest overall prevalence was in Ealing, Hammersmith and Hounslow which also had the highest dialysis prevalence, presumably reflecting the ethnicity of the local population.

Table 5.4. Changes in prevalence rate in health authorities, 1998–2002

		Prevalence rates					Modalities 2002			No of pts
		1998	1999	2000	2001	2002			%	2002
Health Authority	**Population**	**All**	**All**	**All**	**All**	**All**	**Transp**	**Dial**	**transp**	**All**
England										
Bradford	483,300				579	662	283	379	43	320
Calderdale & Kirklees	583,800	346	336	519	579	624	324	300	52	364
County Durham & Darlington	607,800	336	344	393	466	579	326	253	56	352
East Riding and Hull	574,500	447	463	512	479	541	216	326	40	311
Gateshead & S Tyneside	353,500				280	600	362	238	60	212
Leeds	727,400			571	561	587	268	319	46	427
Newcastle & N Tyneside	470,100				232	574	357	217	62	270
North Cumbria	319,300	485	501	504	542	526	279	247	53	168
North Yorkshire	742,400	321	280	469	459	537	229	308	43	399
Northumberland	309,600				207	604	365	239	60	187
Sunderland	292,300	431	438	452	489	558	349	209	63	163
Tees	556,300	466	482	518	546	561	325	235	58	312
Wakefield	318,800			555	521	521	248	273	48	166
Barnsley	228,100	460	509	574	592	666	307	359	46	152
Doncaster	290,500	423	465	513	530	596	220	375	37	173
Leicestershire	928,700	600	602	649	639	672	305	367	45	624
Lincolnshire	623,100	425	456	514	533	534	238	297	44	333
North Derbyshire	370,200	397	405	446	478	494	213	281	43	183
North Nottinghamshire	388,900	465	496	550	589	594	255	339	43	231
Nottingham	642,700	577	624	653	669	633	249	384	39	407
Rotherham	254,400	448	460	562	645	668	240	428	36	170
Sheffield	531,100	409	442	512	523	587	217	371	37	312
South Humber	308,600	531	544	590	486	583	230	353	39	180
Coventry	304,300	670	664	677	723	723	276	447	38	220
Dudley	311,500	472	494	526	465	462	186	276	40	144
Solihull	205,600	365	355	413	438	462	151	311	33	95
Walsall	261,200					497	84	413	17	130
Warwickshire	506,700	519	555	610	614	653	326	328	50	331
Wolverhampton	241,600		592	679	662	712	145	567	20	172
East Lancashire	511,200	270	276	362	325	426	127	299	30	218
Liverpool	461,500				579	615	247	368	40	284
Morecambe Bay	310,300	226	235	329	313	371	126	245	34	115
North Cheshire	311,900				439	455	202	253	44	142
North-West Lancashire	466,300	300	315	412	371	444	150	294	34	207
Sefton	287,700				476	521	205	316	39	150
St Helens and Knowsley	333,000				502	571	255	315	45	190
Wirral	327,100				345	611	263	349	43	200
Bedfordshire	556,600	214	225		546	562	228	334	41	313
Cambridgeshire	468,000	111	122		669	756	321	436	42	354
Hertfordshire	1,033,600	483	472			342	92	250	27	353
Suffolk	671,100				176	378	182	197	48	254
Bexley, Bromley, Greenwich	730,000			355	356	582	275	307	47	425
Croydon	338,200	322	355	441	446	535	210	325	39	181
Ealing, Hammrsm, Hounslow	617,200				125	930	262	668	28	574
Hillingdon	251,200				68	506	195	311	39	127
Lambeth, Sthwark Lewisham	745,200			515	514	789	309	480	39	588
Merton, Sutton, Wandsworth	627,000	214	220	305	285	364	155	209	43	228
Berkshire	800,200	331	347	693	502	569	295	274	52	455
Buckinghamshire	681,900	422	431	524	537	553	301	252	54	377
East Surrey	419,900	324	348	402	405	460	262	198	57	193
IoW, Portsmouth, SE Hamps	671,700				549	572	331	241	58	384
North and Mid Hampshire	556,900				386	406	223	183	55	226
Northamptonshire	615,800	445	463	513	549	562	268	294	48	346
Oxfordshire	616,700	431	454	491	542	582	318	264	55	359
Southampton, SW Hamps	542,300				454	476	278	197	59	258
West Surrey	640,600	190	211	268	304	436	204	231	47	279
Avon	999,300	534	550	592	617	648	346	302	53	648
Cornwall and Isles of Scilly	490,400				642	693	281	412	41	340
Gloucestershire	557,300	458	511	642	468	535	248	287	46	298
North and East Devon	479,300	463	503	547	534	547	246	300	45	262
Somerset	489,300			501	521	576	260	317	45	282
South and West Devon	589,100	502	535	587	606	606	290	316	48	357
Wiltshire	605,500	342	337	353	453	467	256	211	55	283
Wales										
Gwent	557,200	549	560	623	630	727	377	350	52	405
Bro Taf	739,600	533	581	633	648	699	339	346	50	517
Dyfed Powys	479,400			638	499	565	215	330	39	271
North Wales	657,500				525	695	259	437	37	457
Morgannwg	499,700			558	616	706	326	380	46	353

Age

Table 5.5 shows the age breakdown of the prevalent patients in the UK in 2002 from the National Renal Review. 34% of the patients on RRT were over 65 years old. The proportion of over 65s in Northern Ireland seems to be high, but for this analysis Belfast City Hospital could not be included as it was not able to provide the age breakdown for stock patients. As Belfast City Hospital is the transplant centre for Northern Ireland, inclusion of their data would most likely change the age distribution to be more in line with the rest of the UK.

Table 5.5. Age groups of prevalent patients in the UK in 2002: data from the National Review

Age groups	Eng	W	Scot	N I	UK
18-44	27%	25%	31%	18%	27%
45-64	39%	41%	33%	36%	38%
65+	34%	34%	35%	46%	34%

From the Registry data, we were able to analyse the age profile further and calculate the median age for each of the treatment modalities (Figure 5.2). As expected, the median age is lowest for the transplant patients, followed by the peritoneal dialysis patients, with the haemodialysis patients having the highest median age. Compared with previous years, the median age for all prevalent RRT patients has increased from 54.3 years in 1998 to 55.9 years in 2002. The median age for patients on peritoneal dialysis has shown a trend to decrease where as the median age for haemodialysis patients has increased from 62.6 years to 64.5 years (Table 5.6). The wide variation in the median age of dialysis patients between each unit is shown in Figure 5.3. This may be due to differences in the demography of the local population, referral and acceptance policies, survival rates, and facilities for service provision.

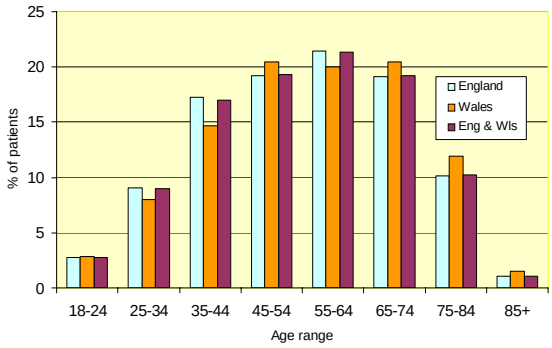

Figure 5.2. Age profile of prevalent patients

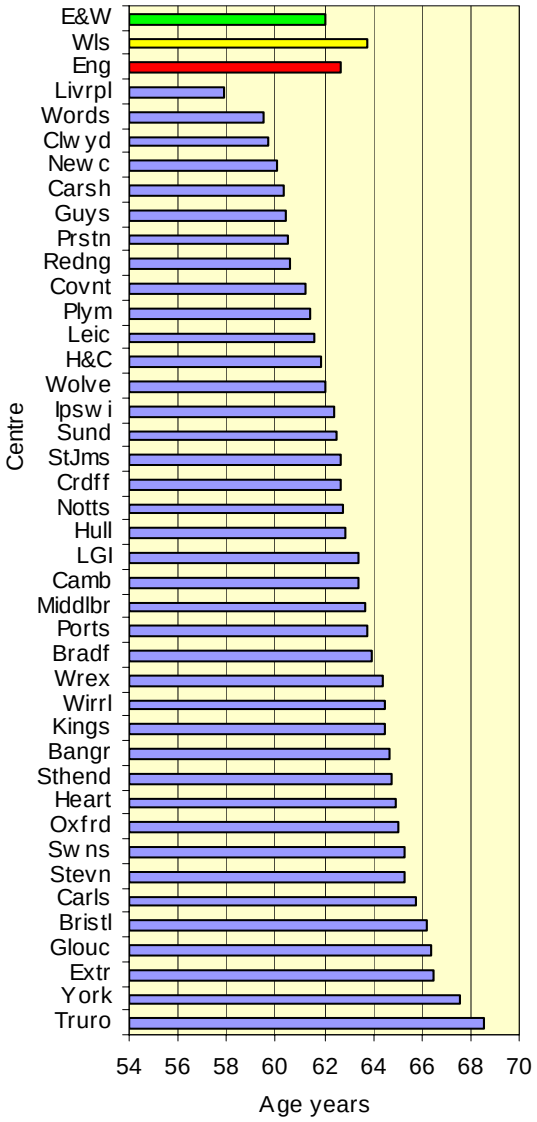

Figure 5.3. Median age of dialysis patients at 31 December 2002 by centre

Table 5.6. Median age and treatment modality for England and Wales 2002

	Transplants	PD	HD	All
Median age 2002	49.6	58.3	64.5	55.9
Interquartile range	39-60	45-69	51-74	43-68
Range between units	40-55	49-64	58-71	52-65
Median age 2001	48.9	58.7	64.0	55.1
Median age 2000	48.9	58.6	63.5	54.9
Median age 1999	48.9	58.8	62.7	54.6
Median age 1998	49.0	58.9	62.6	54.3

Gender

Of the prevalent patients 61% were male, and this male preponderance was evident across all age groups (Figure 5.4).

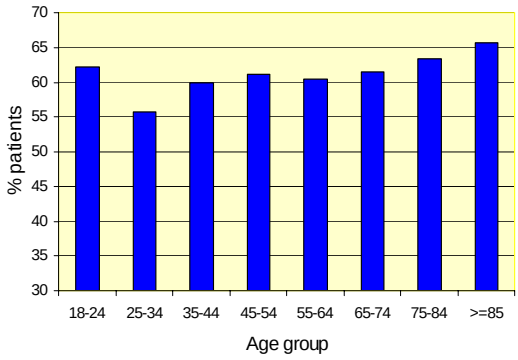

Figure 5.4. Percentage of male patients according to age

Ethnicity

The number of units providing data on ethnicity for prevalent patients has increased. 22 units had completed data returns on at least 90% of patients compared with 17 last year. There were 9 newcomers to this category (Gloucester, Hammersmith and Charing Cross, Newcastle, Carlisle, Liverpool, Portsmouth, Swansea, Middlesbrough and Stevenage), however in 4 of the units (Hull, Exeter, Carshalton and Southend) the percentage of completed data had fallen. It is to be hoped that providing feedback on returns will encourage units to develop means of providing this important information.

From these 22 units, the percentage of Indo-Asian was 7%, African-Caribbean 3.6% and Chinese 0.5%. There was a marked variation of ethnic mix amongst the different units reflecting the ethnic diversity of the different catchment areas. The units with the higher proportion of Indo-Asians and African-Caribbean patients were in the London/South East area, West Midlands and Yorkshire regions (Table 5.7).

In Chapter 4, a high proportion of ethnic minorities has been shown to be associated with a higher standardised acceptance ratio. It would therefore be envisaged that units in such areas may expand more rapidly than units serving mainly white catchment areas.

A more detailed analysis of the different ethnic groups is presented in Chapter 20.

Primary Renal Disease

Table 5.8 shows detail of the primary renal disease based on the original EDTA coding. Although the number of prevalent patients on the Registry has increased by 16% there has been no difference in the pattern of diagnoses compared with last year. The most common identifiable diagnosis for the under 65s was glomerulonephritis (17.8%), and for those over 65 was diabetes (12.9%). Overall 11.5% of the prevalent patients had a primary diagnosis of diabetic nephropathy in contrast to the 18% of the incident patients, although a significant proportion of patients also have diabetes mellitus as a co-morbid disease. Another

interesting observation is the low percentage of over 65s with diagnosis of reno-vascular disease (4.6%) in comparison to the 11.2% in the over 65s in the incident group. These differences between incidence and prevalence of these two groups may be due to lower survival of such patients.

Diabetes

Tables 5.9a and 5.9b show the median age and modalities of treatment for diabetic patients compared with other patients. The only notable difference from previous years is in the modality of treatment of non-diabetics under the age of 65, in whom the proportion on HD has fallen from 34% to 27%. The proportion transplanted has increased from 50% to 60%, whilst there has been a smaller change in those on PD from 15% to 13%. This may reflect the influence of the new large transplanting units which have joined the Registry. There is further discussion and analysis of the diabetic renal patients in Chapter 19.

Table 5.7. Ethnicity groups of prevalent patients 2002

Treatment centre	% Return	% White	% Black	% Asian	% Chinese	% Other
Glouc	100	99.1	0.5	-	0.5	-
Ham & Cx	100	43.1	12.1	22.6	0.7	21.5
Heart	100	73.9	5.3	19.1	0.6	1.0
Sheff	100	93.9	1.6	3.3	0.7	0.6
Words	100	90.6	0.9	8.1	0.4	-
Newc	99	97.5	0.3	1.7	0.5	-
Prstn	99	86.6	1.2	11.7	-	0.5
Wolve	99	74.8	6.6	17.5	1.1	-
Bristl	98	93.1	3.2	2.3	0.7	0.7
Redng	98	70.0	11.0	16.0	1.5	1.5
Carls	97	99.4	-	0.6	-	-
Leic	97	81.1	2.2	15.4	0.2	1.1
Plym	97	95.6	3.1	0.5	0.3	0.5
Livrpl	95	96.5	1.3	0.5	1.1	0.6
Sund	95	97.5	0.4	0.8	0.4	0.8
Notts	94	88.9	4.4	5.7	-	0.9
Ports	94	96.9	0.4	2.1	0.2	0.3
Swnse	93	98.9	0.3	0.5	-	0.3
Middlbr	92	95.4	-	3.7	0.8	-
Covnt	91	82.1	3.2	14.5	0.2	-
Guys	91	80.0	15.0	3.7	1.3	0.1
Stevn	90	82.0	4.7	12.7	0.6	-
Hull	89	98.7	0.2	0.2	0.4	0.4
York	87	98.5	-	1.5	-	-
Extr	84	98.9	0.7		0.2	0.2
StJms	82	86.0	3.2	10.2	-	0.7
Carsh	80	74.2	6.3	7.4	0.9	11.1
Sthend	77	92.7	4.4	2.9	-	-
Total	**77**	**86.8**	**3.6**	**7.0**	**0.5**	**2.1**
Bradf	62	63.7	1.4	34.2	-	0.7
Clwyd	59	96.1	2.0	-	2.0	-
Wrex	59	99.2	-	-	0.8	-
Bangr	56	98.0	2.0	-	-	-

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

Diagnosis	% All patients	Inter unit range(%)	% Age <65	% Age ≥65	M:F ratio
Aetiology uncertain*	22.5	3-61	21.0	27.9	1.6
Glomerulonephritis**	15.6	5-25	17.8	7.8	2.2
Pyelonephritis	13.3	5-24	14.2	9.9	1.1
Diabetes	11.5	7-26	11.2	12.9	1.5
Polycystic kidney	3.6	0-6	1.7	10.0	2.2
Hypertension	6.6	1-14	6.0	8.4	2.2
Renal vascular disease	9.1	5-15	10.4	4.6	1.1
Not sent	4.5	0-29	3.4	8.4	1.7
Other	13.3	7-23	14.2	10.1	1.3

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

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

	Type I	Type II	All diabetes	Non-diabetics
Number	1670	896	2566	18815
M:F ratio	1.49	1.57	1.52	1.54
Median age on 31/12/02	51	66	57	55
Median age started RRT	47	63	54	47
Median years on treatment	3.2	2.1	2.8	5.7
% HD	41	65	49	37
% PD	22	23	23	14
% Transplant	36	12	28	50

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

	Type I <65	Type II <65	Non-diabetics <65	Type I ≥65	Type II ≥65	Non-diabetics ≥65
Number	1335	409	13201	335	487	5575
% HD	34	58	27	71	71	59
% PD	23	23	13	19	23	16
% Transplant	43	19	60	10	7	24

Table 5.10. Treatment modalities of prevalent patients in the UK 2002

	England	Wales	Scotland	N Ireland	UK
Haemodialysis	11369 (37%)	720 (36%)	1380 (40%)	512 (46%)	13981 (38%)
Home haemodialysis	420 (1%)	9 (0%)	52 (2%)	1 (0%)	482 (1%)
Peritoneal dialysis	4605 (15%)	380 (19%)	376 (11%)	80 (7%)	5441 (15%)
Transplants	14,104* (46%)	897 (45%)	1,610 (47%)	524 (47%)	17,135* (46%)
% dialysis pts on HD	72%	66%	79%	87%	73%

Modalities of Treatment

From the National Renal Review, at the end of 2002, 46% of the prevalent patients in the UK had a functioning transplant. Of the remaining patients on dialysis, 73% were on haemodialysis. Apart from Northern Ireland where there was less use of peritoneal dialysis, the distributions were similar in the other 3 countries. (Table 5.10)

Figure 5.5 shows the breakdown according to treatment modalities from the Registry data. The breakdown of 46.0% transplants, 37.5% haemodialysis, 1.2% home haemodialysis and 14.8% peritoneal dialysis is comparable to the data from the National Renal Review.

The variation in patterns of treatment with age are shown in Figure 5.6. Transplantation is the predominant treatment modality in patients less than 65 years old. In contrast it is haemodialysis which is more used in the over 65s. In terms of dialysis modality, haemodialysis is the main modality across all age groups, ranging from 63% in the 18-24 age group to 87% in the 85+ age group (Table 5.11).

Table 5.11. Dialysis modality percentages according to age groups

Age group	HD%	PD%
18-24	63	37
25-34	65	35
35-44	65	35
45-54	66	34
55-64	69	31
65-74	75	25
75-84	82	18
85+	87	13
All	72	28

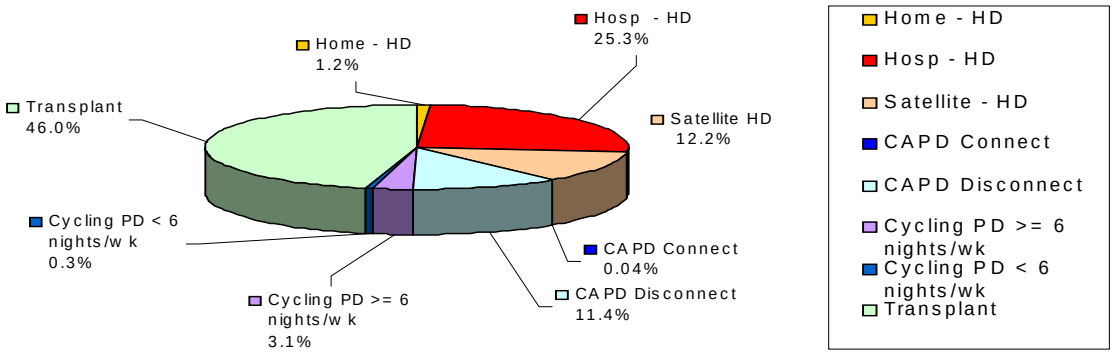

Figure 5.5. Percentage of patients on each dialysis modality, 31 December 2002

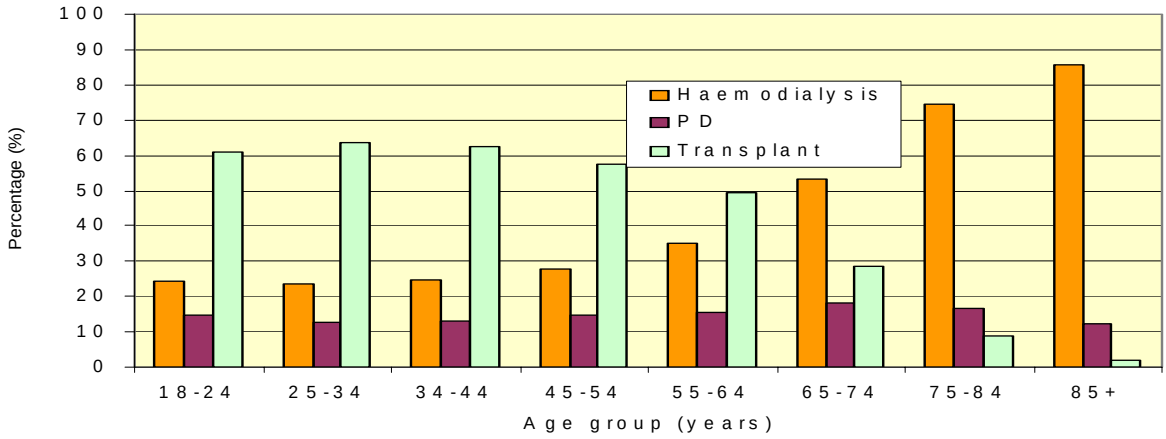

Figure 5.6. Patients on each modality according to age groups

Change in Treatment Modality 1997 – 2002

Table 5.12 and Figure 5.7 show the proportion of treatment modalities for prevalent patients in the Registry units only in 2002. There is a trend of increasing proportion of patients in haemodialysis facilities especially in satellite units and decreasing proportion of peritoneal dialysis and transplant patients. The proportion and the trend were the same as the data obtained from the National Renal Review presented in Chapter 3.

Haemodialysis

The proportion of dialysis patients treated by haemodialysis varied widely between the units and cannot be explained by age alone (Figure 5.8). The overall percentage of patients on HD dialysing in satellite units was 32% (Figure 5.9).

Table 5.12. Proportion of patients with different modalities of RRT, 1997 - 2002

	% HD home	% HD hospital	% HD satellite	% HD total	% PD standard	% PD disconnect	% PD cycling	% PD total	% With Transplant
1997	3.7	19.7	9.0	32.4	2.7	12.9	1.0	16.7	51.0
1998	2.4	23.6	5.6	31.6	0.9	16.6	1.0	18.5	49.9
1999	2.0	21.9	10.9	34.8	0.7	15.0	2.1	17.9	47.3
2000	1.7	26.1	7.8	35.6	0.1	14.2	3.1	17.4	46.9
2001	1.3	24.5	10.9	36.6	0.0	14.0	2.7	16.8	46.6
2002	1.2	25.3	12.2	38.7	0.0	11.4	3.4	14.8	46.0

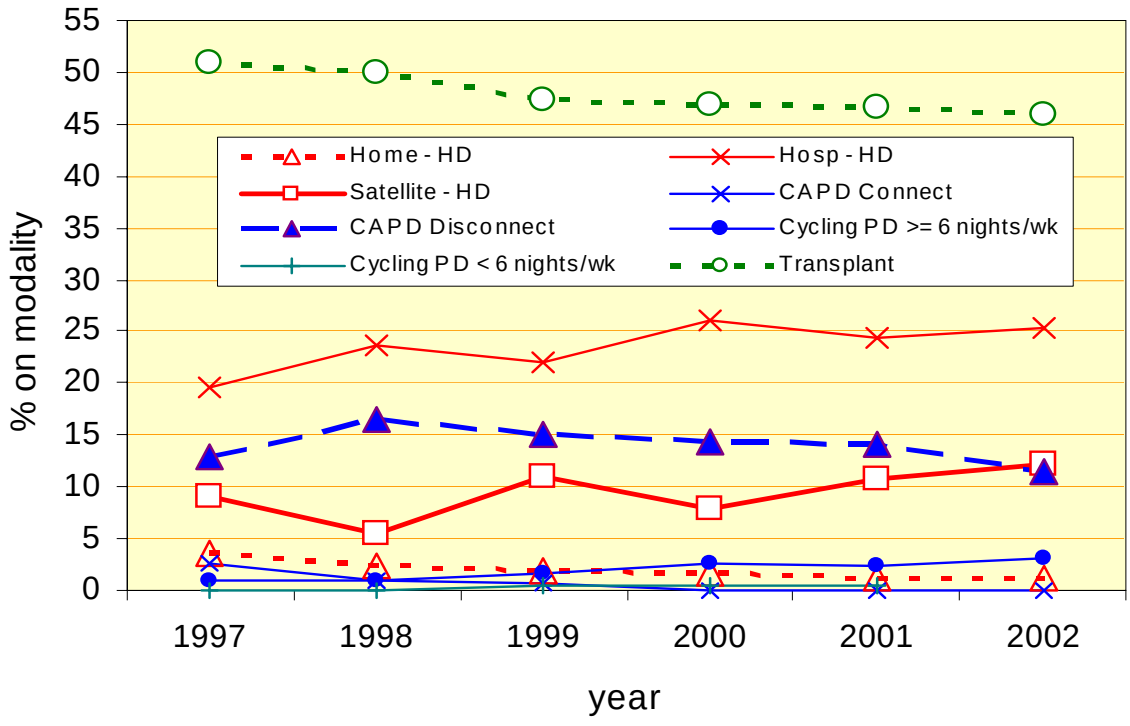

Figure 5.7. Trends of modality changes 1997-2002

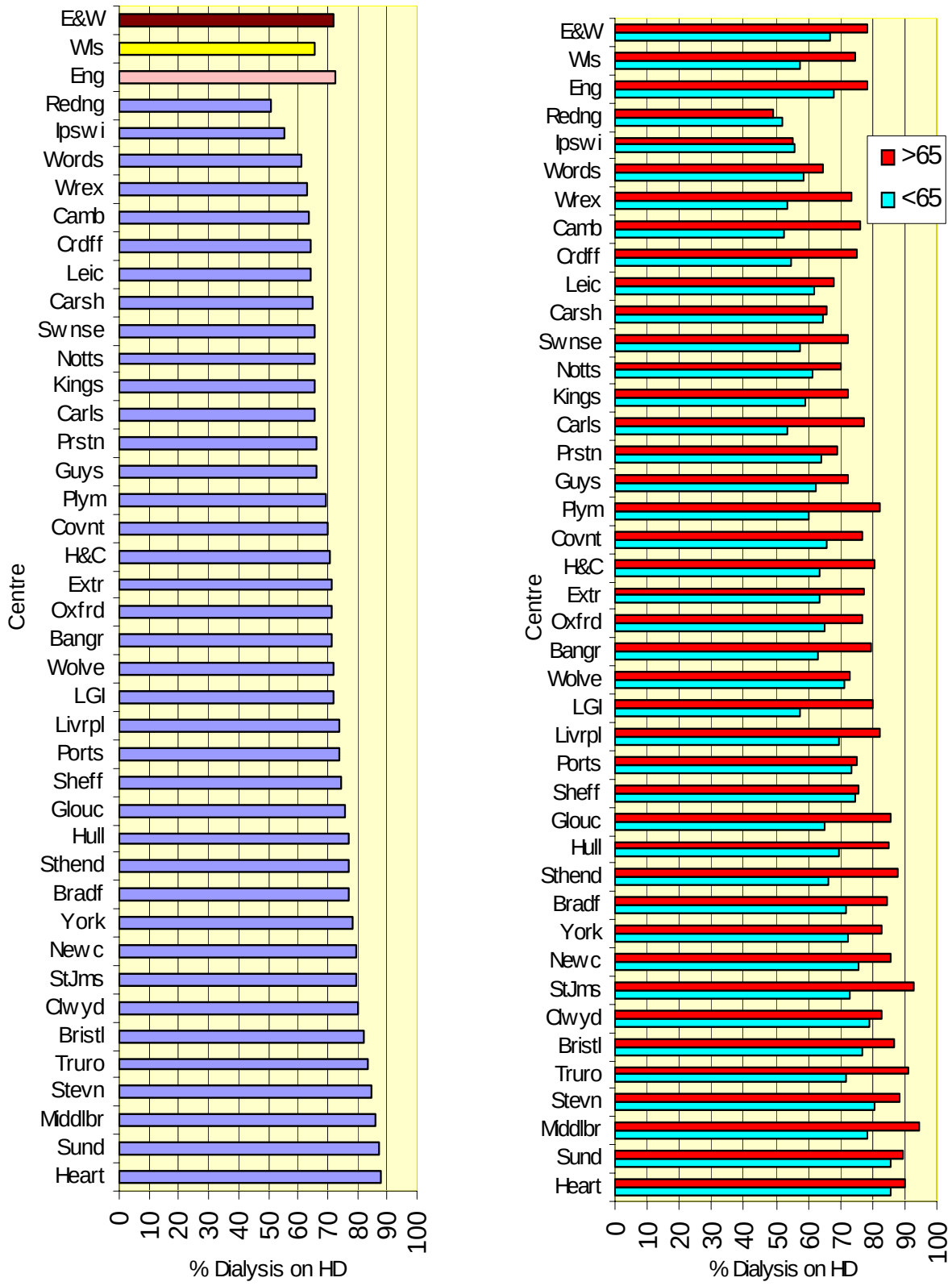

Figure 5.8. Proportion of patients on haemodialysis according to centre and age

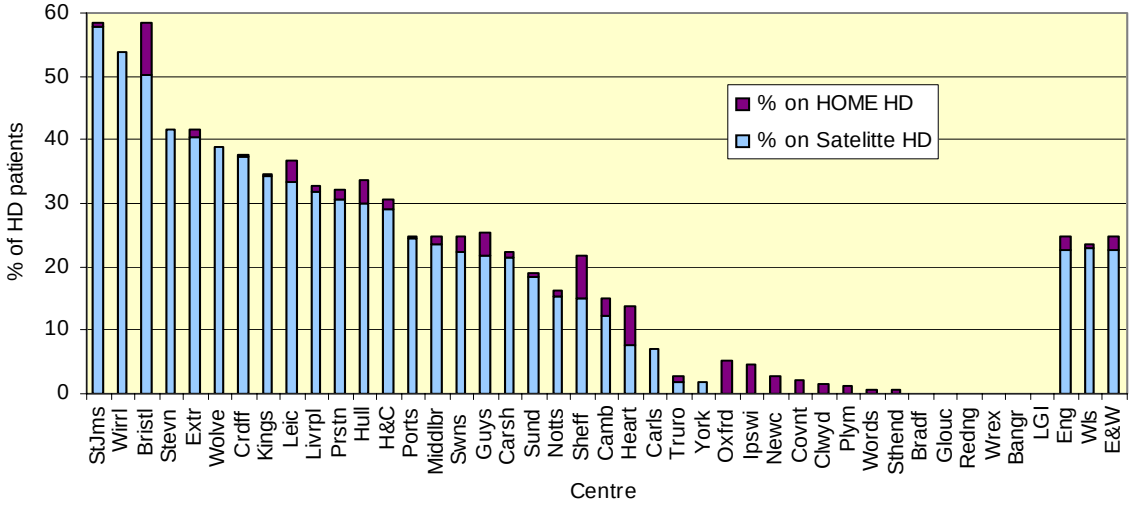

Figure 5.9. Percentage of HD patients treated at home and in satellite units

Peritoneal dialysis

Table 5.13 shows the distribution of types of peritoneal dialysis being used in the UK at the end of 2002. The two main types were CAPD disconnect and APD/CCPD, with a high percentage of patients in Scotland and Northern Ireland using the APD/CCPD methods.

For units in the Registry, the percentages of patients on each of the main types of PD are shown in Figure 5.10.

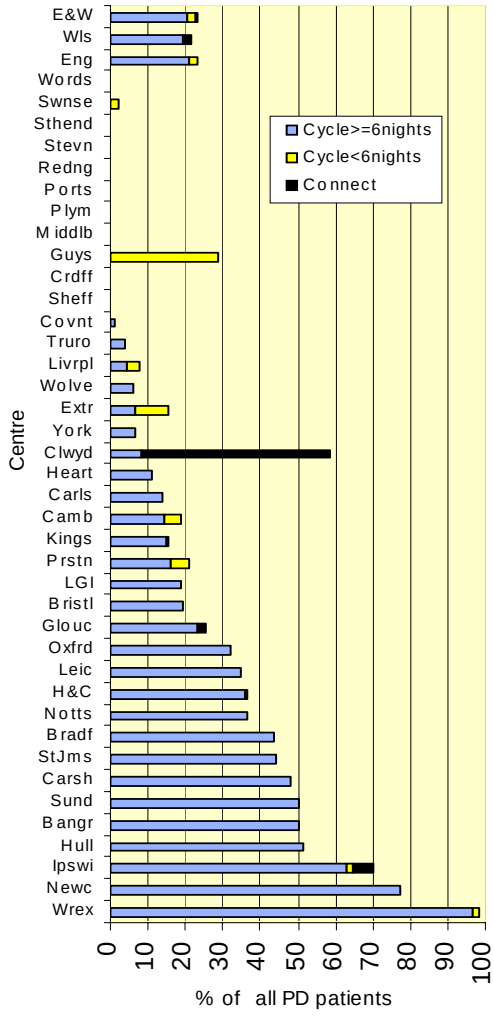

Figure 5.10. Use of connect and automated PD as a percentage of total PD

Survival of Patients Established on RRT

This section analyses the one year survival of all patients who had been established on RRT for at least 90 days on 1 January 2002. Where survival of dialysis patients is shown, patients have been censored at transplantation.

In Figure 5.11 the survival of prevalent dialysis patients for each age band is shown.

There were no significant differences between England and Wales, so the combined data are presented. The one year survival of HD patients in England & Wales has increased significantly from 83.4 in 2000 to 84.3 in 2001 and 86.1 in 2002.

Transplanted patients had better survival

than even the younger non-diabetic patients on dialysis and the data are shown in Table 5.14. The one year death rate for prevalent dialysis patients is 15.0 per 100 patient years (95% CI 14.3 – 17.8).

Table 5.13. Types of peritoneal dialysis in UK (National Review)

	Eng	W	Scot	N I	UK
CAPD disconnect %	74.2	78.2	47.9	32.5	72.0
APD/CCPD %	23.9	19.2	47.3	65.0	25.8
CAPD connect %	0.2	1.6	4.8	1.3	0.6
IPD %	1.6	0.8	0.0	1.3	1.5

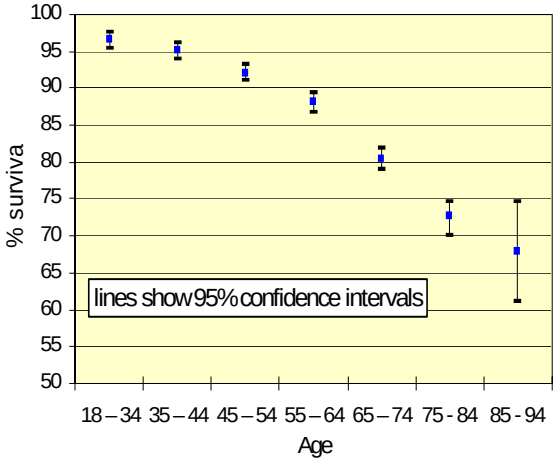

Figure 5.11. One year survival of prevalent dialysis patients by age group

Table 5.14. One year survival of established prevalent RRT patients in England and Wales

Patient group	No. of patients	No. of deaths	KM survival	KM 95% CI.
Transplant patients 2002				
Censored at dialysis	9285	215	**97.6**	97.3-98.0
Not censored at dialysis	9285	235	**97.5**	97.1-97.8
Dialysis patients 2002				
All 1/1/2001 (2 year)	9121	1339	**84.3**	83.3-85.3
All 2002	12484	1683	**86.1**	85.5-86.7
All age <65	5809	544	**92.1**	91.5-92.7
All age =>65	4619	1091	**77.1**	75.9-78.3
Non-diabetic <55	3036	165	**94.2**	93.3-95.0
Non-diabetic 55-64	1635	189	**87.9**	86.3-89.6
Non-diabetic 65-74	2051	401	**80.1**	78.4-81.9
Non-diabetic =>75	1624	439	**72.9**	70.7-75.1
Non-Diabetic <65	4678	354	**92.0**	91.2-92.8
Diabetic <65	906	159	**81.7**	79.1-84.2
Non-Diabetic =>65	3678	840	**76.9**	75.5-78.3
Diabetic =>65	602	171	**71.5**	67.9-75.1

Cohorts of patients alive 1/1/2002 unless indicated otherwise

Survival of Patients Established on RRT by Centre

The unadjusted survival of prevalent dialysis patients alive on 1/1/2002 is shown for each centre on the Registry in Figure 5.12. Survival has again been censored at the time of transplantation. The age adjusted analysis is shown in Figure 5.13. Although there is a significant difference in the unadjusted survival between centres ($p<0.0001$) this is not significant after adjusting for age. In Figure 5.14, the plot of unadjusted Z-scores (see Appendix B for statistical explanation) clearly shows that some centres fall outside the 95% confidence limits, with some below the line (worse survival) and some above the line (better survival). After adjustment for age (Figure 5.15) all the centres fall within the 95% confidence limits. These data have not been adjusted for the presence of co-morbidity and so the centre anonymity has been retained. Figures 5.15 and 5.16 show the data separated by those aged less than 65 years and those aged over 65 years.

The median age of death for patients on dialysis ranged from 67.0 to 76.3 years by centre and this may reflect the local age spread and co-morbidity of the general population.

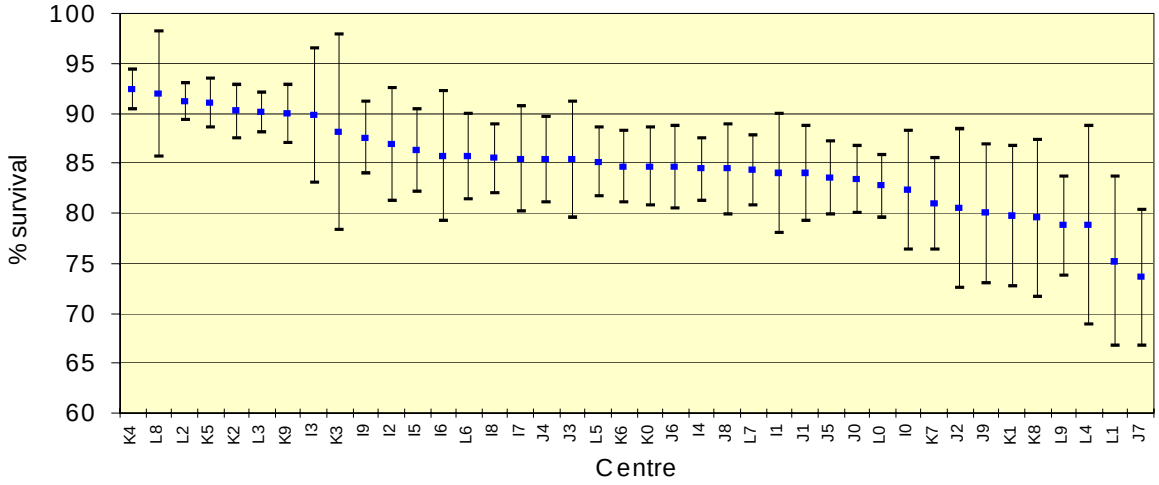

Figure 5.12. One year unadjusted survival of prevalent dialysis patients by centre

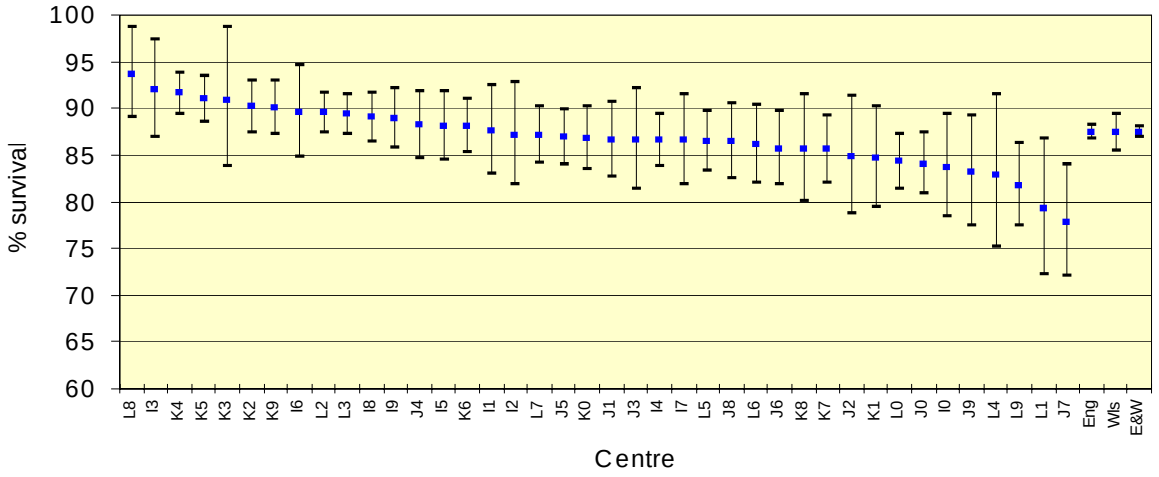

Figure 5.13. One year adjusted (age 60) survival of prevalent dialysis patients by centre

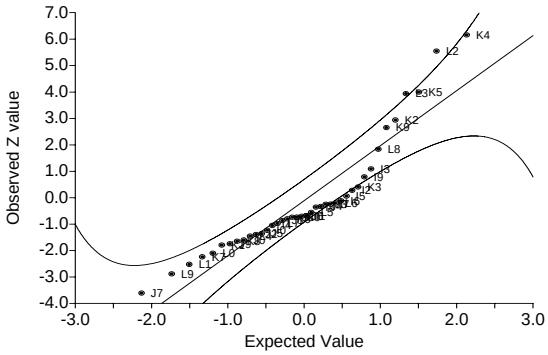

Figure 5.14. Un-adjusted Z scores of 1 year prevalent dialysis survival

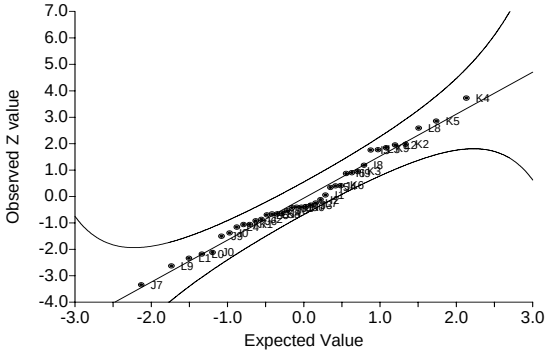

Figure 5.15. Adjusted Z scores of 1 year prevalent dialysis survival

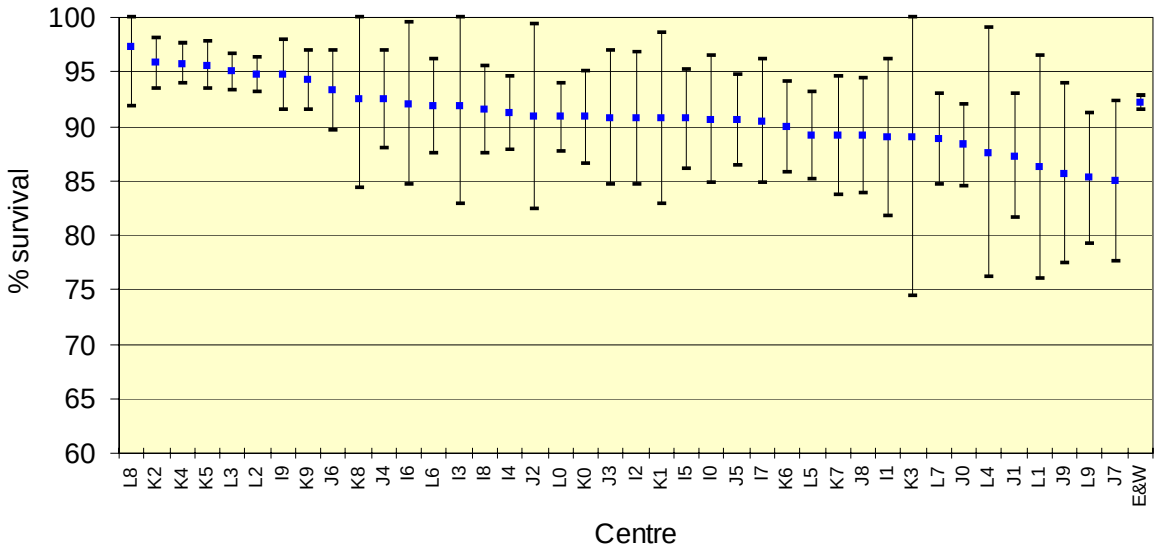

Figure 5.16. One year survival of prevalent dialysis patients aged <65 years by centre

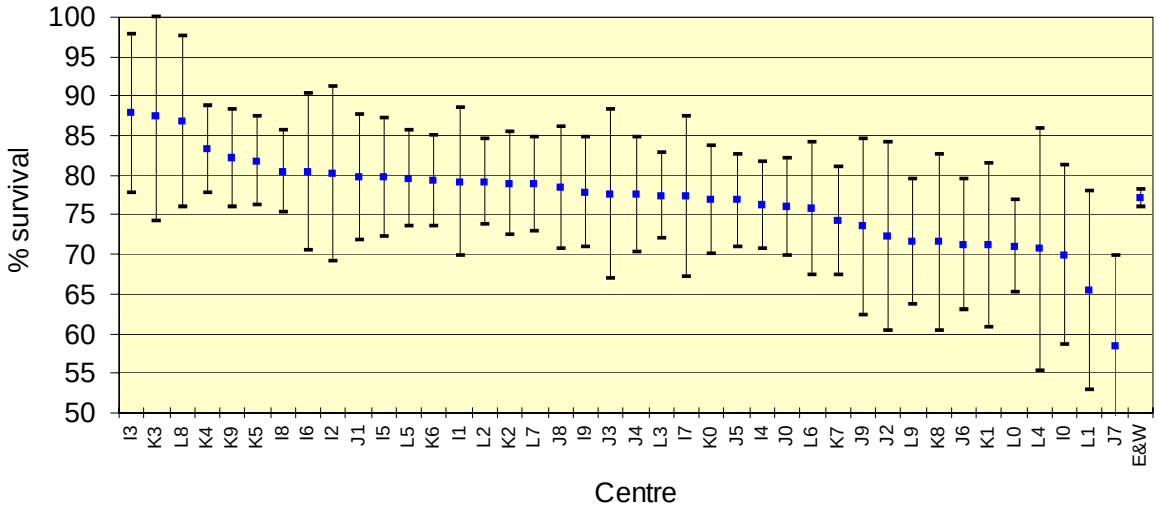

Figure 5.17. One year survival of prevalent dialysis patients aged 65+ years by centre

Seasonal variation in deaths of prevalent patients on renal replacement therapy

There has been no previous literature on seasonal variations in deaths on renal replacement therapy. Understanding of the reasons for the fluctuation in these seasonal deaths would assist in looking for avoidable causes of death.

Deaths in the general population

Data from the Office for National Statistics show a seasonal fluctuation in deaths in the general population, with a peak of deaths occurring in January. In Figure 5.18, there is a slightly higher percentage of the annual deaths occurring in females in this month than males (12.3% v 11.6%). The pattern is similar for the years 2000 and 2001.

The deaths in the general population over 3 years have been averaged by month and adjusted to a standardised mortality ratio. This shows a similar pattern, with a peak in January which appeared to be more marked in females although this was not significant ($p = 0.75$).

The average monthly temperatures in England & Wales (Figure 5.19) have been plotted against the standardised mortality ratios for each month during the period 1998 – 2000. There is an exponential inverse relationship (Figure 5.20) between average monthly temperature and the monthly standardised mortality ratios (log SMR = 2.23 – 0.24x log temp, $p < 0.0001$).

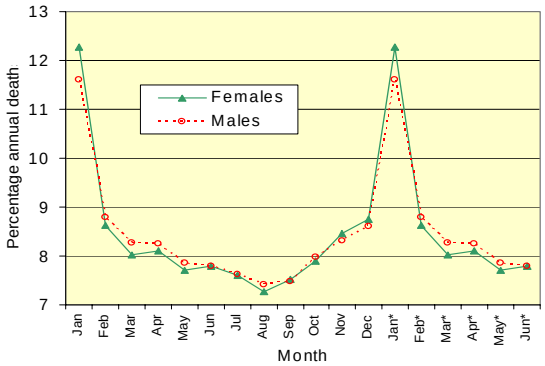

Figure 5.18. England & Wales population, percentage of deaths by gender, 2000

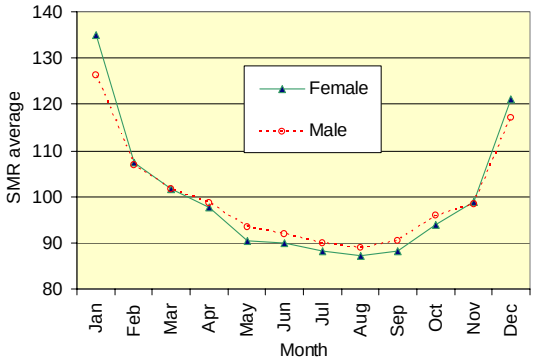

Figure 5.19. England & Wales population, SMR and month and gender, 1998 -2000

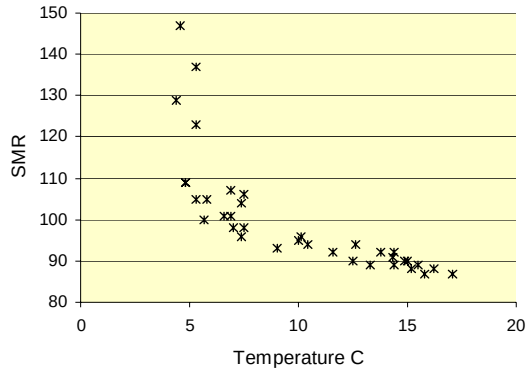

Figure 5.20. England & Wales population, monthly temperature and SMR, 1998 -2000

Deaths on renal replacement therapy

Deaths by month

In contrast with the general population, deaths on renal replacement therapy peak in December rather than January (Figure 5.21). The data were analysed by causes of death. The percentage of the monthly deaths that were due to a cardiac cause did vary, with the lowest at 27% throughout the spring and summer months April to August, compared with 33% in the winter months. The overall chi squared test for seasonal differences between causes of death was significant ($p = 0.015$). The data showed no monthly variation in treatment withdrawal.

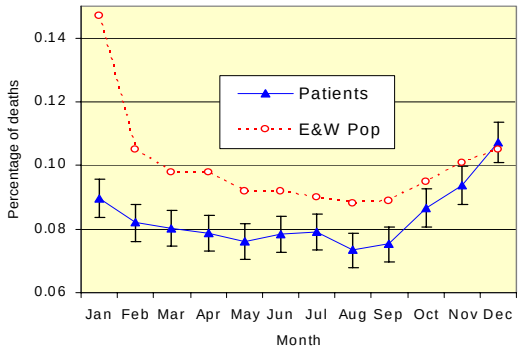

Figure 5.21. Deaths on RRT by month

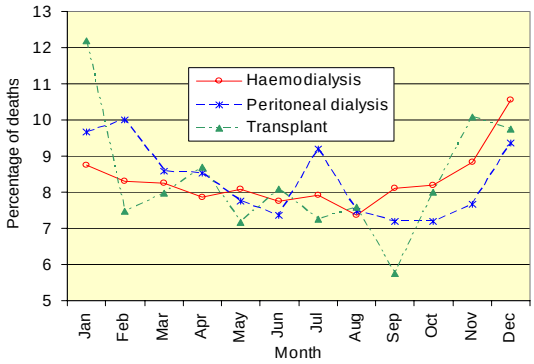

Figure 5.23. Deaths on RRT by month and treatment modality

Deaths by age group

The December peak of deaths (Figure 5.22) was similar for all the three age bands of 18 – 64, 65 –74 and 75+ (p = 0.53).

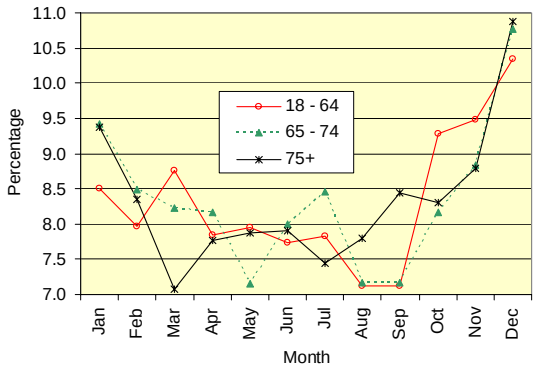

Figure 5.22. Deaths on RRT by month and age band

Deaths by modality

When analysed by modality, unlike dialysis patients, transplant patients have a similar monthly pattern of death to that of the general population (Figure 5.23). The increase in deaths in the haemodialysis population starts in November and peaks in December. In contrast deaths in the peritoneal dialysis population remain high for the 3 months throughout December to February, and also possibly peak again in July. The difference in deaths between modalities was significant (p = 0.05).

Discussion

In the general population the winter increase in deaths from cardiac causes is known to peak 2 weeks earlier than those from pneumonia. It is tempting to speculate that the earlier peak in deaths on dialysis compared with that of the general population may be due to a carwdiac peak, as the main cause of death in the dialysis population is cardiac disease (31% of deaths see Chapter 18). However, transplant deaths do not peak early, and cardiac deaths are also the largest cause of death in the transplant population (37%) with infection accounting for 19% of deaths (18% in the dialysis population). The peritoneal dialysis population has a more general spread of deaths throughout the winter. Further analyses are being undertaken and comparitive data with other countries are required.

Chapter 6: Adequacy of Haemodialysis (Urea Reduction Ratio)

Summary

- 4% of UK patients were on twice weekly dialysis, although in N Ireland it reached 11%.
- Synthetic dialyser membranes were used in most patients in England, Wales and Scotland, with N Ireland using modified cellulose.
- High Flux dialysis was used in 25% of HD patients in N Ireland compared with 12% for other UK countries.
- The dialysate calcium concentrations in use in England and Wales are equally split between 1.5 mmol/L and 1.25 mmol/L.
- 78% of HD patients on thrice weekly dialysis achieve a URR ≥65%, which continues the annual improvement seen in achievement of dialysis adequacy.
- Standardisation of post dialysis urea sampling methodology remains a problem.

Introduction

The lowering of Blood Urea concentration, as a marker for waste nitrogen products derived from the diet and protein breakdown, is one measure of the delivered 'dose' of haemodialysis (HD). The 'adequacy' of dialysis treatment has been related to this dose through studies of patient survival and is given by the ratio between pre- and post-dialysis concentrations of Urea. The overall delivered dose is a multiple of the efficiency of individual treatments and their frequency.

The Renal Association 3rd Standards Document p.25 suggests that:

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

Every patient receiving thrice weekly HD should show:

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

Recommendations

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

Measurement of the 'dose' or 'adequacy' of HD should be performed monthly in all patients. All dialysis units should collect, and report to the Registry, data on pre- and post-dialysis, urea values, duration of dialysis, and weight loss during dialysis. (Good practice)

Haemodialysis frequency

In Chapter 3 of this report is a summary of the national renal survey undertaken on behalf of the Department of Health. All UK renal units were surveyed and questions included information on the frequency of dialysis, reasons for use of twice weekly dialysis, length of time on dialysis and types

Table 6.1. Summary table of HD process measures

Process measures	England	Wales	Scotland	N. Ireland	UK
Number of renal units	52	5	10	4	70
% of patients on twice weekly	4%	8%	0.6%	11%	4%
Unit median (range)	2% (0–36%)	2% (0–15%)	0.4% (0–2%)	12% (1–17%)	2% (0–36%)
Reasons for twice weekly:					
Geographical reasons	3%	7%	25%	–	3%
Preserved renal function	60%	89%	50%	70%	64%
Financial restrictions	9%	–	–	15%	9%
Lack of facilities	10%	–	–	15%	10%
Others	18%	4%	25%	–	15%
Prescribed 3–5 hours on HD	95%	95%	93%	100%	95%

of dialysis membranes used. The summary in Table 6.1 shows that very few patients were on twice weekly dialysis with the main reason for use of twice weekly dialysis a 'preserved renal function'.

All UK renal units returned data of the frequency of use of twice weekly dialysis. Only those with >3% of HD patients on twice weekly have been included in Table 6.2. An intermediate group have around 8% (Freeman, Preston, Southend) and seven English units are in double figures – Addenbrooke's 18, Broomfield 14, Ipswich 18.5, Queen Alexandra 17, Walsgrave 14, Wordsley 15 and Norfolk & Norwich 38% (66 of 175). Broomfield, Ipswich and Wordsley were reporting from a patient base of less than 100 patients under treatment. Two Welsh units are in double figures – UH Wales 15% and Ysbyty Gwynedd 11% (7 of 64). The figures were high from three of the four reporting Northern Ireland units – Antrim 17, Belfast City 10 and Tyrone 15%, although the latter two treat only 81 and 101 patients respectively. None of the Scottish units reported appreciable twice weekly haemodialysis.

These findings are consistent with those presented in the 2002 Registry report, although there have been major reductions in twice weekly treatment in Addenbrooke's (39 to 18%), and lesser changes in Nottingham, Oxford, Southend and two of the Northern Ireland units. Ipswich, Norwich and Wordsley show an increase. No change in pattern is observed for Broomfield, Freeman, Preston and Walsgrave.

It is difficult to know how much these results represent a partial response to the collaborative audit process, although large changes would seem most likely to be due to re-consideration of policy and lack of change or increase, may well be due to resource constraints rather than clinical decision. The figures for the East Anglian hospitals, suggest that a constraint on facilities is being managed through an undesirable reduction in dialysis frequency.

A trend in clinical management, to gradually increase dialysis dose as native kidney clearance diminishes and for some units to start dialysis earlier in the course of declining renal function may account for some of these differences[1–3].

Table 6.2. UK Hospitals with > 3% of patients on 2x/ week HD

Hospital name	% on 2x HD
Norfolk & Norwich University Hospital	37.7
Ipswich Hospital	18.5
Addenbrookes Hospital	18.3
Queen Alexandra Hospital	17.0
Antrim Hospital	16.8
Wordsley Hospital	15.3
University Hospital of Wales	14.9
Tyrone County Hospital	14.8
Broomfield Hospital	13.9
Walsgrave Hospital	13.7
Ysbyty Gwynedd	10.9
Belfast City Hospital	10.0
Southend Hospital	8.8
Royal Preston Hospital	8.0
Freeman Hospital	7.0
Royal Infirmary Manchester	5.6
Guy's and St Thomas's Hospital	5.2
Basildon Hospital	5.2
Hull Royal Infirmary	5.0
Royal London Hospital	5.0
Nottingham City Hospital	5.0
Lister Hospital	4.9
Derriford Hospital	4.1
St James's University Hospital	3.8
Arrowe Park Hospital	3.7
Churchill Hospital	3.5
Gloucester Royal Hospital	3.3
Leeds General Infirmary	3.1

Dialyser membranes

The Registry has not previously reported on membranes in use in the UK. These data were collected in the 2003 national survey questionnaire. Table 6.3 shows that in England Wales and Scotland most patients were on synthetic membranes (57%, 82%, and 64% respectively). This contrasts with N Ireland, where most patients were on modified cellulose membranes (64%), but there was also the highest use of high flux membranes at 25%.

In Table 6.4, only Hope Hospital in Manchester used standard cuprophane membranes.

Dialysate Calcium

For this year's report an additional telephone survey (speaking to the nurse in charge of the haemodialysis unit on that day) was carried out of 34 main renal and 20 satellite units asking whether they had a standard dialysate calcium concentration that was used for most patients. Results in Table 6.5, were categorised from high to low dialysate calcium. Several renal units indicated that they had no standard dialysate calcium to be used and that it depended on doctor's instructions. Surprisingly this response was more common from satellite units where there is often no medical presence.

Achieved URR (Prevalent patient cohort)

The Renal Association Standards are highlighted at the start of this chapter. In view of a lack of progress in Unit recording of dialysis duration and the weight loss associated with each treatment, only the URR, the fractional reduction of urea concentration, are available for Registry calculation and display.

Table 6.3. Summary of dialyser membranes by country

	England	Wales	Scotland	N. Ireland	UK
Standard membrane	1% (1-1%)	0% (0–0%)	0% (0–0%)	0% (0–0%)	1% (1–1%)
Modified cellulose	29% (29–29%)	7% (6–8%)	29% (28–31%)	64% (59–68%)	29% (29–29%)
Synthetic membrane	57% (57–58%)	82% (80–84%)	58% (56–60%)	11% (9–13%)	57% (57–57%)
High Flux membrane	12% (12–12%)	11% (9–12%)	13% (12–13%)	25% (21–28%)	13% (13–13%)
Units	50	5	10	4	69

Table 6.4. Dialyser membranes by centre

	Hospital name	Modified cellulose %	Synthetic %	High flux %
Eng	Addenbrookes Hospital	2	98	0
Eng	Arrowe Park Hospital	0	92	8
Eng	Basildon Hospital	70	0	30
Eng	Broomfield Hospital	100	0	0
Eng	Churchill Hospital	0	99	1
Eng	Cumberland Infirmary	No data	No data	No data
Eng	Derby City General Hospital	94	0	6
Eng	Derriford Hospital	0	85	15
Eng	Dorset County Hospital	0	67	33
Eng	Freeman Hospital	0	100	0
Eng	Gloucester Royal Hospital	0	100	0
Eng	Guy's and St Thomas's Hospital	0	100	0
Eng	Hammersmith & Charing Cross Hospital	0	87	12
Eng	Heartlands Hospital	100	0	0
Eng	Hope Hospital	0	0	0
Eng	Hull Royal Infirmary	95	4	1
Eng	Ipswich Hospital	0	86	14
Eng	James Cook University Hospital	100	0	0
Eng	Kent & Canterbury Hospital	2	98	0
Eng	Kings College Hospital	88	0	12
Eng	Leeds General Infirmary	5	95	0
Eng	Leicester General Hospital	0	100	0
Eng	Lister Hospital	0	0	100
Eng	New Cross Hospital	97	0	3
Eng	Norfolk & Norwich University Hospital	0	100	0
Eng	North Staffordshire Royal Infirmary	0	98	2
Eng	Northern General Hospital	15	0	85
Eng	Nottingham City Hospital	0	100	0
Eng	Queen Elizabeth Hospital	32	68	0
Eng	Royal Berkshire Hospital	94	0	6
Eng	Royal Cornwall Hospital (Treliske)	100	0	0
Eng	Royal Devon and Exeter Hospital	0	100	0
Eng	Royal Free Hospital	4	80	16
Eng	Royal Infirmary Manchester	0	90	10
Eng	Royal Liverpool University Hospital	0	90	10
Eng	Royal London Hospital	98	2	0
Eng	Royal Preston Hospital	0	58	42
Eng	Royal Shrewsbury Hospital	30	60	10
Eng	Royal Sussex County Hospital	0	100	0
Eng	Southend Hospital	75	0	25
Eng	Southmead Hospital	38	42	20
Eng	St George's Hospital	100	0	0
Eng	St Helier Hospital	0	100	0
Eng	St James's University Hospital	0	87	14

Table 6.4. (continued)

	Hospital name	Modified cellulose %	Synthetic %	High flux %
Eng	St Lukes Hospital	0	100	0
Eng	Queen Alexandra Hospital	0	88	12
Eng	St Mary's Paddington	100	0	0
Eng	Sunderland Royal Hospital	0	100	0
Eng	Walsgrave Hospital	70	15	15
Eng	Wordsley Hospital	20	54	26
Eng	York District General Hospital	0	90	10
NI	Antrim Hospital	82	0	18
NI	Belfast City Hospital	80	0	20
NI	Daisy Hill Hospital	50	35	15
NI	Tyrone County Hospital	0	42	58
Sct	Aberdeen Royal Infirmary	99	1	0
Sct	Crosshouse Hospital	0	66	33
Sct	Dumfries & Galloway Royal Infirmary	0	0	100
Sct	Glasgow Royal Infirmary	25	75	0
Sct	Monklands District General Hospital	0	96	4
Sct	Ninewells Hospital & Medical School	0	32	68
Sct	Queen Margaret Hospital	0	90	10
Sct	Raigmore Hospital	100	0	0
Sct	Royal Infirmary of Edinburgh	7	86	7
Sct	Western Infirmary	50	50	0
Wls	Maelor General Hospital	0	80	20
Wls	Morriston Hospital	0	90	10
Wls	University Hospital of Wales	90	10	0
Wls	Ysbyty Glan Clwyd	100	0	0
Wls	Ysbyty Gwynedd	0	92	8

The figures show the URR data for the patient population of each named centre. Each centre has an abbreviated name (see Appendix H) and the number preceding this is the percentage of data missing in the data return for the 3 month period. The Standard states that adequacy measurements should be performed monthly.

The 2002 Report included a discussion on post dialysis blood sampling methodologies in use in England & Wales. The Renal Association 3rd Standards recommends 3 methods which are described in full at the end of this chapter:

- simplified stop blood flow sampling technique (early method)
- slow blood flow sampling technique (early method)
- stop dialysate – continue blood flow method (late method).

Table 6.5. Dialysate calcium

	Main unit	Satellite
High 1.75 mmol/L	3 (9%)	1
Medium 1.5 mmol/L	14 (41%)	5
Low ≤1.25 mmol/L	14 (41%)	7
Variable	3 (9%)	7
Total	34	20

Registry staff this year again telephoned nurses at all main dialysis units, and many satellites, to identify sampling methodologies. Centres were grouped by early sampling methods (<5 minutes after stopping

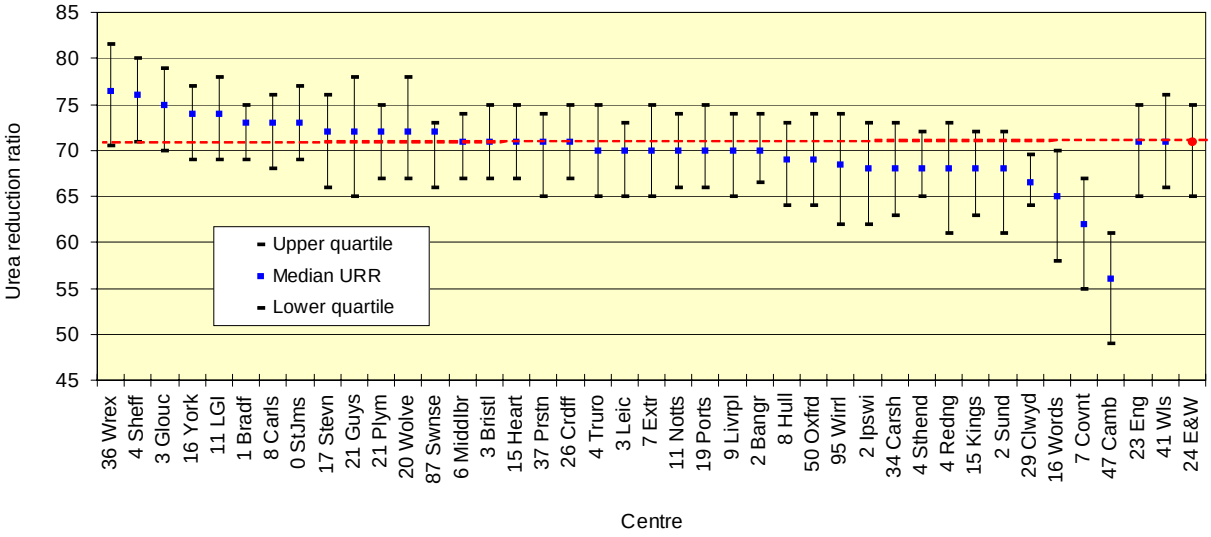

Figure 6.1. Median URR achieved in each renal unit

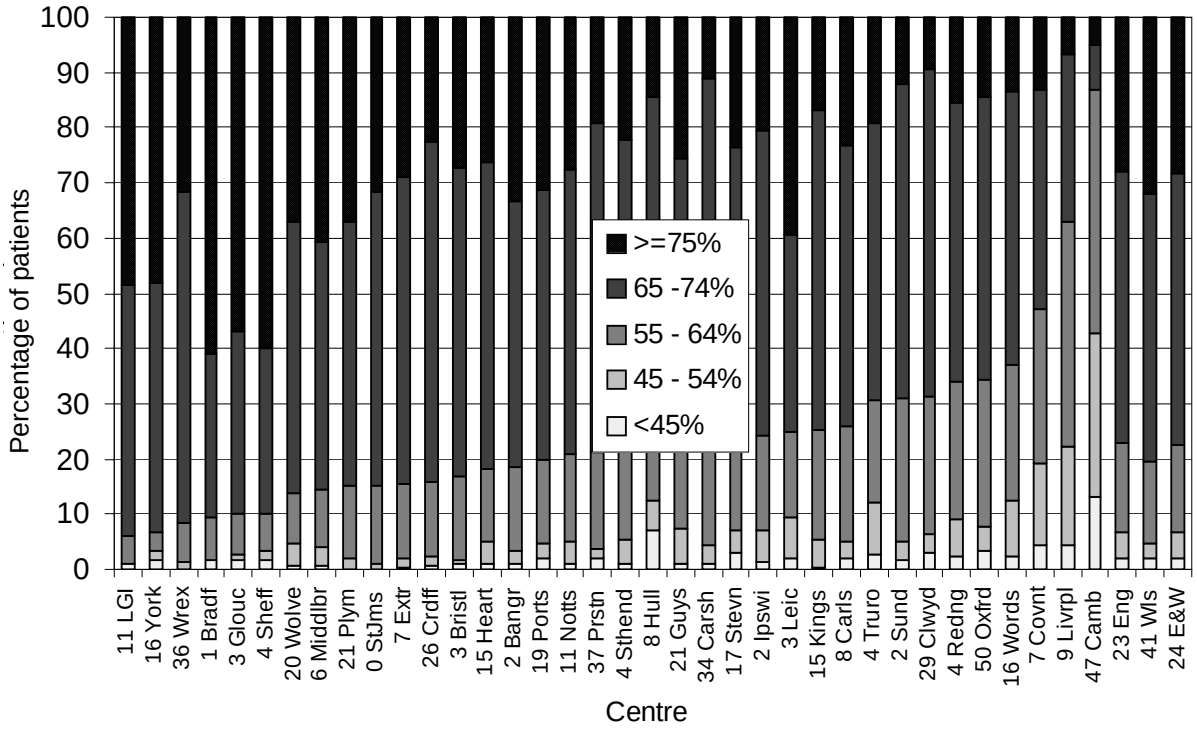

Figure 6.2. URR distribution, by centre

dialysate flow or slowing the blood flow) and late sampling (≥5 minutes). In Figure 6.3, showing the percentage of patients achieving a URR of over 65%, the centres indicated by a 'large closed circle' on the data point are believed to be using a 'late' post-dialysis sampling methodology for blood urea, which would be expected to give lower results for URR.

The median URR values, with interquartile ranges, for each Unit are shown in Figure 6.1. They include satellite treated patients with the main centre, but patients treated for less than three months at the time of sampling were excluded. There has been little redistribution of achievement between

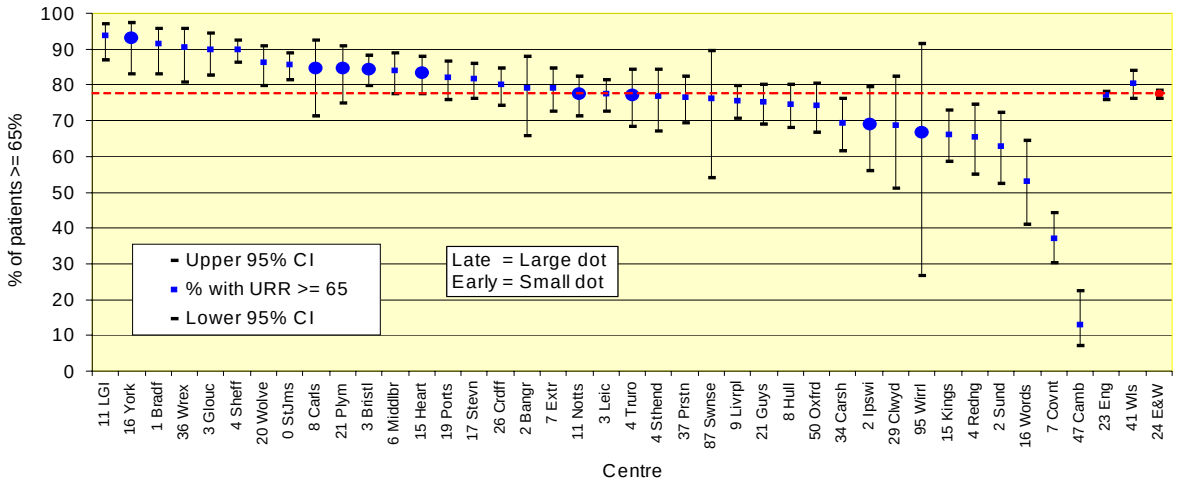

Figure 6.3. % patients, by centre, with a URR of ≥ 65% in the last quarter of 2002

units in 2001 compared to 2002. Several of the lower values are associated with incomplete returns, as shown by a high percentage of missing data (Cambridge, Newcastle, Oxford, Plymouth, Swansea, Wirral, Wordsley, and Wrexham). The URR calculation by the Registry relies on extraction of paired urea values (two measured on the same day) from renal IT systems which is not dependent on pre/ post identifiers being held in the system. At Swansea a local software error was identified in the storage of URR within the IT system and Wirral lacks an automated laboratory system link to Liverpool renal system. Whether through lack of measurement or lack of data logging, little progress has been made in improving the returns in some units.

Change in meeting the URR Standard during 2002

Within the first quarter of 2002 to the end quarter the achievement of the URR standard in England & Wales increased from 75% (95%CI 74%–76%) to 78% (95% CI 76%–79%).

It was not possible in 2002 to acquire reliable demographic data from Derby, so that URRs are not available to allow comparison of their late sampling method with previous and other data. The results from Coventry are improved but remain at the lower margin, despite implementation of changes in methodology highlighted in the 2002 Report. Cambridge is the only renal unit showing a significant drop in URR during 2002.

Change in achievement of dialysis adequacy

Since 1997 the percentage of patients achieving a URR >65% has risen from 56% to 78% in England and Wales (Figure 6.5). The median URR of 71% in 2002 is associated with 22% nationally falling below 65%. The trend to increasing URR values has been sustained, having risen at 1-2% per annum over the past six years.

The change by centre is shown in Figures 6.6 and 6.7. These data suggest that there has been greater compliance from Bradford, Coventry, King's and Sunderland, and something of a deterioration in performance at Cambridge, Carlisle, Plymouth and Preston. It seems unlikely that policies have changed in the latter group, so case-mix or other unexplained factors may be involved, as well as the incompleteness of data noted above. In the absence of data on dialysis duration, blood flow and dialyser size, it is

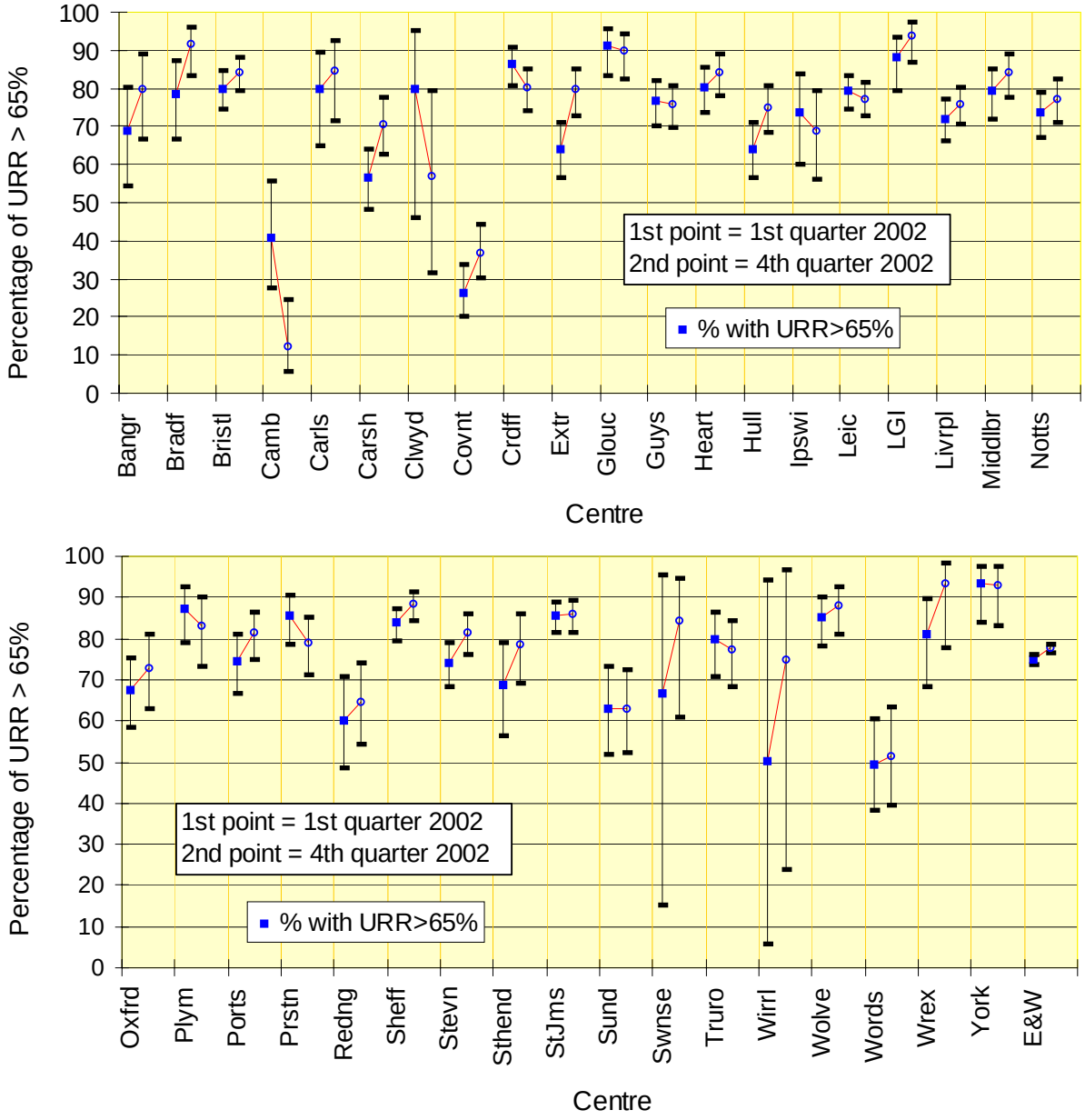

Figure 6.4. Change in meeting the URR Standard in 2002

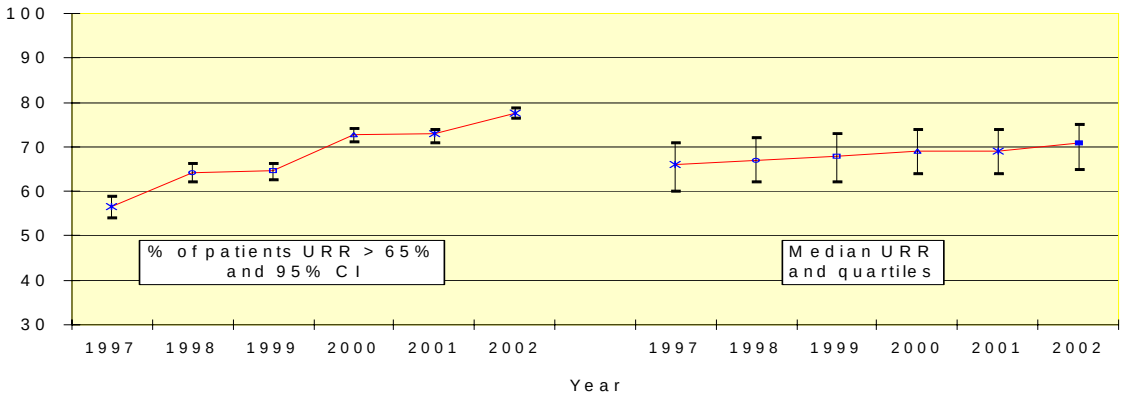

Figure 6.5. % URR over 65% and change in median URR 1997–2002, England & Wales

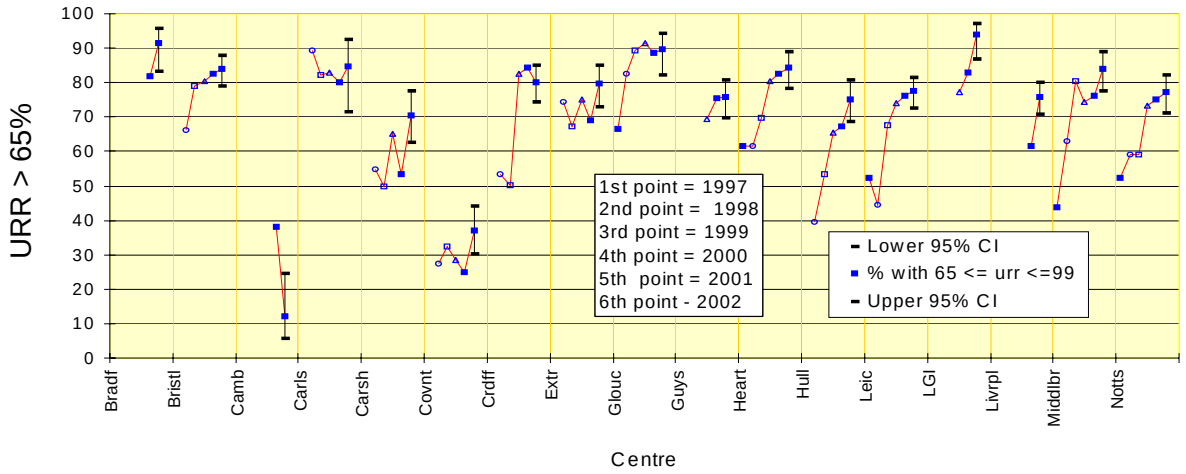

Figure 6.6. Change in meeting the URR Standard in 1997–2002

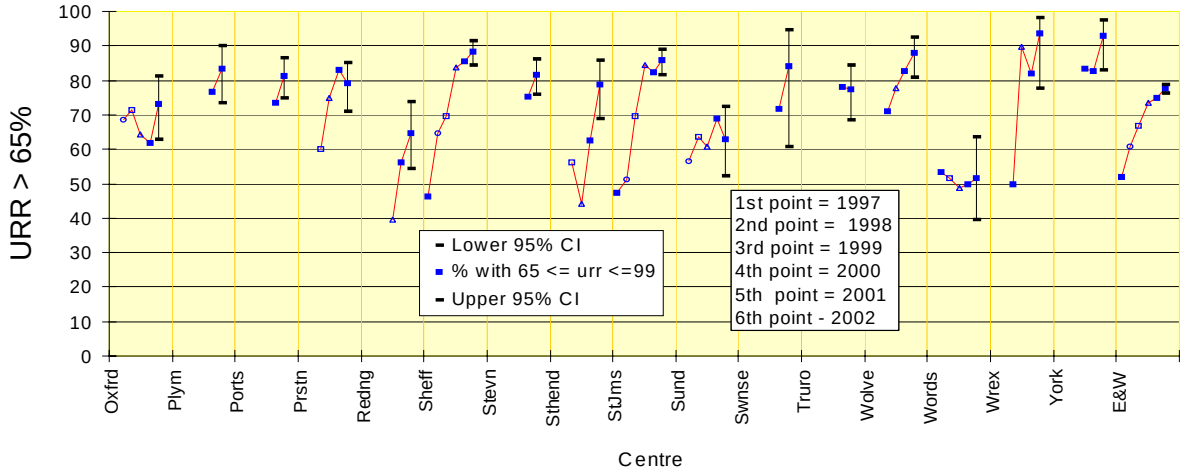

Figure 6.7. Change in meeting the URR Standard in 1997–2002

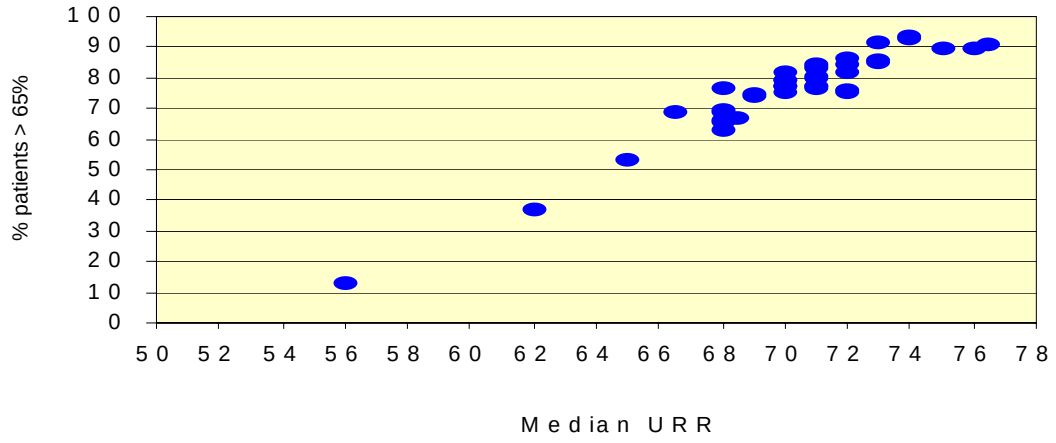

Figure 6.8. URR achievement and median URR at each renal unit

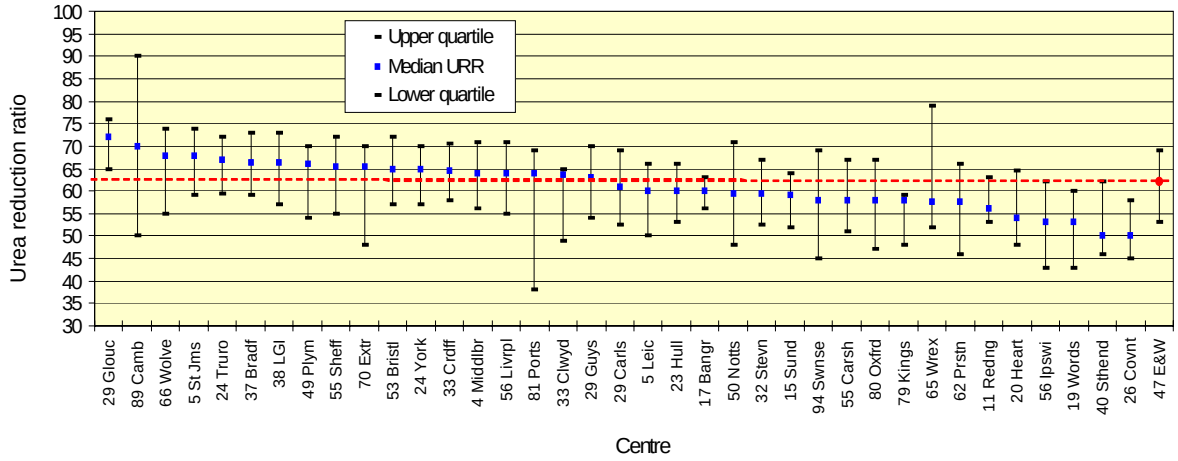

Figure 6.9. URR achievement in new patients within first 3 months

not possible to explain the results in terms of the determinants of dialysis dose.

These data show a modest improvement in Unit URR performance, with a 2% increase in median URR from 69% to 71%. Analysed by renal unit, this changes ranges from +4 to –3%. It would be of interest to be able to assess the effect of body weight on these changes.

Distribution of URR

Figure 6.8 shows the relationship of Unit median URR and the percent of values falling above the 65% standard (Rose–Day plot). The progressive improvement of compliance at the 65% level is demonstrated again, with some 'flattening' of the curve at the upper end of the graph. The need for centre median URR to be at or near 73% for even 85% compliance is clear, given the dispersion of URR values that may be expected from a centre cohort measured on one occasion (i.e. the dispersion would be reduced if the 4 quarter's results were averaged).

URR in the 2002 incident patient cohort

As in previous years the patients starting haemodialysis (within the first 3 months) show lower URR values than the established prevalent group (Figure 6.9). This is partly due to residual renal function being excluded from this calculation. The iDopps data has shown that in the UK it takes much longer than other European countries to establish permanent vascular access. This also accounts for the low dialysis adequacy achieved within the first 3 months. The data from the US Centre for Medicare and Medicaid Services indicate that mean blood pump flow rates were 345 ml/min for patients with catheters compared with 410 ml/min in those with a fistula. With the Renal NSF published, it is hoped that resources will now be targeted to reduce the waiting time required for access surgery and improvements in achievement of dialysis adequacy within the first 6 months will follow.

The cross-sectional analysis in Figure 6.10 implies that there has been some small improvement in early URR achievement with time.

International comparison

It is of interest to compare data with the US Centre for Medicare and Medicaid Services (CMMS) Report for 2002 published in July 2003.[4] Their reported population was a random sample of approximately 500 haemodialysis patients from each of the 18 US 'Networks' (n = 8,863 3.5% US HD popula-

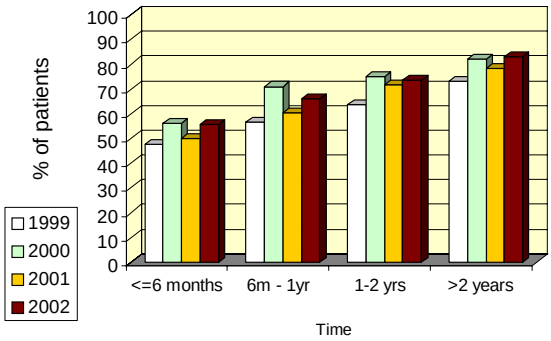

Figure 6.10. Change in URR by length of time on RRT 1999–2002

tion) with data from the last quarter of 2001.

Eighty two per cent of patients had monthly adequacy measurements, 11% measured twice and 5% only once. These individual results were averaged and this methodology (using the means of mean values) would be expected to give a narrower dispersion of results (s.d. 6.7%) than the current UKRR single quarterly sample system (s.d. 9.0%).

1. Mean URR was 70.9% to compare with 71% in this year's Registry Report.
2. For the 65% level of URR, 84% were compliant in the US data compared with 78% in the UK (post dialysis sampling in the US is largely by early methods, since Kt/V calculations based on best-fit formulae have required it).
3. Median dialysis session length was 212 minutes.
4. Median Kt/V was 1.49. The distribution of Kt/V (and hence mean KT/V) did not change for US data samples 1999-2001.
5. 29% of incident patients were dialysed using an AV fistula (AVF).
6. 31% of prevalent patients were dialysed using an AVF.
7. 19% of prevalent patients were dialysed with a chronic catheter continuously for 90 days or longer.
8. 51% of prevalent patients with an AV graft were routinely monitored for the presence of stenosis.

Independent analyses of the CMS data published in abstract form, of 2,500 US units, showed an average improvement in meeting URR guideline values of 1.6% per annum over the years 1998–2002, to compare with the data reported here for England and Wales (Figure 6.5). There was such variation that it 'suggests that some organisations were more effective than others in quality improvement'.[5] In addition, and perhaps more important, the changes in URR when related to Standardised Mortality Ratios suggested that improvements in URR (and anaemia) tended to be associated with greater improvements in mortality 1999–2002 at Unit level[6].

Discussion

URR and survival

The patient requiring renal replacement is at risk from many factors, particularly vascular and infective co-morbidity. The desire to minimise the effects of the renal failure has been the motive to find an adequate dose of dialysis, above which there would be no further benefits in both mortality and morbidity.

URR, despite a relative lack of sophistication, has been associated with mortality in large studies of haemodialysis patients.[7,8] Current experience suggests that thrice-weekly dialysis of a practical duration is not at the beneficial limit and 2003 saw the publication of the HEMO Study, which could show no benefit for achievable changes in urea reduction using modern techniques, thrice weekly.[9] The reduction of urea at current best-practice levels is a relevant associated factor in overall mortality of dialysis patients, but one analysis suggests

that all the possible biochemical optimisations by dialysis will only account for 13 to 37% of the factors involved. URR is a much less potent associated factor than Serum Albumin.[10] Others have shown that when URR is standardised at best practice levels nutritional elements seem to dominate the potential moderators of mortality.[11] To that extent adequacy through URR may be achieved.

Quality improvement

The effort to increase URR in haemodialysis populations has had limited success internationally. The incentive value of collaborative audit must be assessed against a background of improving through intuitive clinical management. Within comparative audit there are important 'centre effects' (for example, the understandable reluctance to change established blood sampling protocols). Patterns of provision (for example, twice-weekly dialysis) take some time to resolve, when facilities are constantly stretched. Improvements in access provision of AV fistulae, will also take time to show benefit at centre level. Such improvements generally require a substantial change of policy in clinical management and previous Registry reports have shown that these changes are realistic.

There needs to be an improvement in local clinical informatics supporting the clinical IM&T and data retrieval infrastructure required to monitor this process. The renal NSF Information Strategy document (see Appendix E) highlights the importance of a renal unit's infrastructure for collection of data.

Methodology

The Registry use of single data points has some disadvantages, not least errors in estimating true URR.[15,16] The dispersion of these data would be smaller if the mean of the year's quarterly values were taken, since profiles change slowly within any given year (Figures 6.6 and 6.7). It is unlikely that this would significantly change the interpretation of data.

Sampling techniques for the post dialysis urea concentration remain controversial, although calibration of late sampling, in a limited range of treatment conditions, may yet allow derivation of Kt/V.[17]

Future role of URR

The results of the HEMO study were not encouraging for those who thought there was a linear relationship between increasing URR or Kt/V and reducing dialysis morbidity and mortality.[9] The negative findings of the HEMO study were rationalised to have reflected too narrow a range of dialysis dose, on a 'flat' section of the dialysis dose-response curve. Other data linking mortality with URR, however, are not compromised, simply unexplained. It is clear that dialysis at any dose level has a parallel effect on many metabolites, volume control/blood pressure etc., which are very relevant to 'adequate' dosing and effective reversal of the uraemic state. Others have claimed that the inevitable relationship of URR to Kt/V means that it is flawed as a guide to dose, since the implicit standardisation to body water content is confounding.[18] The relative risk of mortality appears independently associated with dialysis dose *and* body weight so that measures that combine them are complicated composites.[19]

One study suggested that from 1994 to 1997, the threshold for mortality benefit with URR had increased from 61% to 71%. The explanation given for this was that improved URR may only have been achieved through a change in dialysis procedure or blood sampling favouring a higher measurement of URR![20] The attempts in some patients to increase URR to very high levels may have negative benefits.[21] This is assumed to be related to the relative ease of achieving a high URR dose in lighter, possibly less healthy, individuals, when greater body mass is associated with better dialysis

outcomes. By contrast, body size over 81kg in one study militated against 'adequate' URR.[22] Without renal units electronically storing data on body weight, the Registry is unable to contribute to this debate.

In so far that URR >65% may be used to reflect adequate dialysis dosing, with all its related benefits, it continues to be an appropriate surrogate outcome indicator. The annual UK improvement in achievement of URR appears that in time, it will plateau and come to be accepted as a readily achievable norm. The focus of attention to dialysis 'adequacy' may then shift to other indicators of outcome, carried in nutritional, inflammatory and cardiovascular variables.

Recommended post dialysis sampling techniques

The following three methods are recommended in 3rd Standards document.

A. Simplified stop blood flow sampling technique

- When you are ready to take the sample, turn the blood pump slowly down to 50 mls/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.

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Chapter 7: Haemoglobin

Summary

- Improvement in haemoglobin concentrations of patients receiving dialysis treatment continued in 2002. 82% of haemodialysis patients and 88% of peritoneal dialysis patients had a haemoglobin concentration above the Renal Association target of 10g/dl.

- Haemoglobin in the first quarter of dialysis treatment has also risen but 43% of individuals new to dialysis still had a haemoglobin <10g/dl in 2002 (45% in 2001).

- 63% of haemodialysis patients and 73% of peritoneal dialysis patients achieve a haemoglobin above the European guidelines of 11 g/dl.

- There is still wide variation between dialysis centres in proportion of new and prevalent patients who are anaemic. The variation in haemoglobin from year to year in small dialysis centres reflects the fluctuations in haemoglobin concentration of individuals receiving dialysis treatment. It is not possible to make judgements about quality of treatment in a centre on the basis of a single set of data.

Introduction

This chapter describes data reported to the Renal Registry relating to management of renal anaemia at the end of 2002. Correction of anaemia in individuals with chronic renal failure has been shown to improve quality of life and is likely to increase length of life. The importance of this aspect of patient care is reflected in the fact that both national and international standards have been set for management of renal anaemia.

US and European guidelines set a target for an individual's haemoglobin of 11g/dl. The Renal Association have set a target haemoglobin of 10g/dl and this was confirmed in the latest addition of the Standards document published in August 2002. However, the third edition of the Renal Association Standards document has made changes to the standards relating to anaemia treatment. Whilst the target haemoglobin has not been altered the standard of 85% of patients on dialysis having a haemoglobin ≥10g/dl has been removed.

The standard now states that :

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

There is no longer a fixed benchmark against which renal centres can be compared. Instead, comparison with other centres through data submitted to the Renal Registry provides the guide to performance.

The Renal Registry records data on patients receiving renal replacement therapy (RRT) and the date of start of RRT is recorded. At present the Registry cannot provide information on haemoglobin levels 6 months after seeing a nephrologist. Therefore, whilst the Registry data give information on the performance of renal centres with regard to prevalent dialysis patients and patients close to the start of dialysis, there is no information on whether centres are reaching the target within 6 months of first seeing a patient.

Inclusion criteria

Patients treated with dialysis during the last quarter of 2002 were included in the analy-

sis if they had been on the same modality of dialysis in the same centre for 3 months. The latest available haemoglobin reading from each patient in the last quarter of 2002 was used in the analysis.

Haemoglobin achievement by dialysis units

The data describing the haemoglobin distribution in each centre are presented in Table 7.1 for haemodialysis (HD) and Table 7.2 for peritoneal dialysis (PD) and in Figures 7.1 and 7.2. The percentage with haemoglobin ≥11g/dl is included as this is the European standard and may be used by some centres.

The percentage achieving the Renal Association target for haemodialysis patients was 82% in England and 84% in Wales, whilst for patients on PD this was 88% and 89% for England and Wales respectively. As described in previous reports there was considerable variation in performance. Two centres in 2002 had 27% of prevalent HD patients with a haemoglobin <10g/dl whilst Bradford achieved a haemoglobin of ≥10g/dl in 97% of haemodialysis patients and ≥11g/dl in 86%. Two centres (Sunderland and Clwyd) reported haemoglobin ≥10g/dl in 100% of PD patients whilst 2 centres appeared to be outliers with a low percentage of PD patients reaching the target (72% and 77% ≥10g/dl)

Caution needs to be applied when interpreting data from smaller centres. High levels of achievement of the target were reported by a number of centres in last year's report that this year have considerably reduced. Southend reduced from 94% ≥10g/dl for HD in 2001 to 84% in 2002, Truro reduced from 91% in 2001 to 78% in 2002 whilst Sunderland increased from 67% in 2001 to 80% in 2002. It is unlikely that all of these variations reflect real changes in practice and they are more likely to be due to the inherent variability of haemoglobin in individuals with chronic renal failure. Such variation is hidden in the data from large centres but not when the number of data points is small. Individual centres will wish to investigate apparently significant changes in data year on year but it was not possible to make qualitative judgments about the standard of management on the basis of a single set of data.

Overall the spread of data does not appear to be different this year compared to previous years. The 90% ranges for England and Wales have not changed. There is no evidence that centres are in general becoming more successful at targeting haemoglobin, which is perhaps not surprising given the observed variability in individual haemoglobin concentration.

As in previous years a close relationship between median haemoglobin and percentage with haemoglobin greater than 10g/dl or 11g/dl is demonstrated for haemodialysis patients. Whilst less tight, the relationship has also held true for peritoneal dialysis patients in previous years, but in this years data the relationship is less clear. There is a suggestion that the percentage over target may reach a plateau around 90–95% ≥10g/dl. This could be an indication of the proportion of individuals on dialysis whose anaemia cannot be corrected, even with best management, together with those who become anaemic because of illness regardless of their pre-illness haemoglobin level.

Haemoglobin concentrations of patients recently started RRT

Haemoglobin concentrations in the first 3 months of starting dialysis have been analysed and the data are shown in Table 7.3 and Figures 7.11 to 7.15. The haemoglobin data were extracted locally as the latest value in that quarter. The large range of percentage ≥10g/dl between centres shown in previous years has been maintained. In one centre as few as 33% of patients had haemoglobin ≥10g/dl in the first quarter whilst in other centres this was as high as 80%.

Table 7.1. Haemoglobin data for patients on haemodialysis

Centre	% data return	Median Hb g/dl	90% range	Quartile range	Mean Hb g/dl	Standard deviation	% with Hb ≥10	% with Hb ≥11
Bangr	100	11.1	9–13.5	9.9–12.2	11.1	1.4	73	54
Bradf	100	12.4	10.5–14.9	11.4–13.6	12.5	1.5	97	86
Bristl	100	11.7	9–14.1	10.6–12.6	11.6	1.5	84	67
Camb	75	11.3	8.5–13.2	10.1–12.3	11.2	1.4	82	57
Carls	92	11.2	8.9–12.7	10.3–11.9	11.1	1.1	87	63
Carsh	86	11.8	8.9–14.2	10.7–12.9	11.7	1.7	83	68
Clwyd	85	10.5	8.8–13.5	9.8–11.9	10.9	1.4	69	44
Covnt	97	11.4	8.5–13.9	10.4–12.2	11.3	1.5	83	64
Crdff	93	12.1	9.5–14.7	11.1–13.1	12.1	1.6	91	77
Extr	98	11.2	8.8–13.2	10.3–12.1	11.1	1.4	81	58
Glouc	99	11.3	8.5–14.2	10.1–12.5	11.2	1.8	76	56
Guys	88	11.0	8.5–13.7	10–12.2	11.1	1.7	76	50
H&C	100	11.4	8.9–13.7	10.3–12.4	11.3	1.5	83	60
Heart	91	11.1	8.8–13.2	10.1–12	11.1	1.4	78	53
Hull	95	10.9	8.9–12.9	9.9–11.6	10.8	1.3	73	49
Ipswi	100	11.4	9.5–13.1	10.2–12.3	11.3	1.2	83	63
Kings	99	11.3	8–14.3	10–12.4	11.2	1.9	77	57
Leic	98	11.4	8.6–14.4	10.3–12.6	11.5	1.8	81	58
LGI	97	12.0	9.1–14.4	10.8–12.9	11.8	1.7	88	72
Livrpl	97	11.9	9.1–14.6	10.5–13	11.8	1.8	86	68
Middlbr	96	11.3	7.9–13.6	9.8–12.4	11.1	1.8	74	57
Newc	97	11.4	8.3–14.1	10.1–12.4	11.3	1.8	79	58
Notts	94	11.5	8.7–14.2	10.5–12.5	11.5	1.7	82	66
Oxfrd	99	11.4	8.6–14	10.3–12.3	11.3	1.7	80	59
Plym	85	11.8	9.4–14.2	11.1–12.7	11.9	1.4	90	75
Ports	86	11.3	8.1–14.1	10.2–12.5	11.3	1.8	80	59
Prstn	94	11.3	8.1–14.3	10.1–12.4	11.3	1.8	78	59
Redng	97	11.7	8.6–13.7	10.1–12.8	11.5	1.7	80	66
Sheff	94	11.4	9.1–13.7	10.5–12.2	11.4	1.4	85	61
Stevn	94	11.6	9.1–14	10.6–12.4	11.5	1.5	86	66
Sthend	98	11.8	8.5–13.7	10.8–12.8	11.6	1.6	84	70
StJms	100	12.1	9.1–14.8	10.9–13.1	12.0	1.7	89	73
Sund	94	11.2	8.7–13.8	10.3–12.5	11.2	1.6	80	55
Swnse	68	11.2	8.3–13.2	10.1–12.2	11.1	1.6	77	57
Truro	98	10.9	9.1–12.6	10.1–11.5	10.9	1.1	78	48
Wirrl	79	12.4	8.7–14.9	10.85–13.5	12.1	2.0	90	74
Wolve	98	11.5	9.1–14.6	10.3–12.7	11.6	1.7	82	65
Words	90	10.9	8.8–13.8	9.8–12.1	10.9	1.5	74	47
Wrex	86	11.9	9.2–14.2	10.5–12.7	11.7	1.6	88	64
York	90	11.7	9.2–14.1	10.7–12.5	11.6	1.5	90	68
Eng	94	11.5	8.7–14.1	10.3–12.5	11.4	1.6	82	62
Wls	86	11.7	8.8–14.2	10.5–12.8	11.6	1.6	84	66
E&W	94	11.5	8.8–14.1	10.4–12.5	11.4	1.6	82	62

Table 7.2. Haemoglobin data for patients on peritoneal dialysis

Centre	% data return	Median Hb g/dl	90% range	Quartile Range	Mean Hb g/dl	Standard deviation	% with Hb ≥10	% with Hb ≥11
Bangr	100	12.2	9.6–14	11–13.2	12.0	1.4	91	78
Bradf	100	12.8	9.4–15.8	11.6–14.3	12.9	2.0	95	85
Bristl	100	12.3	9.6–14.3	11–13.25	12.1	1.6	93	76
Camb	97	11.8	9.4–14.8	10.7–13.05	11.9	1.6	90	72
Carls	96	12.3	8.6–14.6	10.5–13.5	12.0	1.8	88	67
Carsh	98	12.3	8.7–14.8	11.1–13	12.1	1.7	90	78
Clwyd	91	11.9	10.5–14	10.9–12.8	12.0	1.3	100	60
Covnt	97	11.7	9–14	10.6–12.8	11.7	1.6	87	67
Crdff	98	12.0	9.5–15	11–13.3	12.1	1.7	92	75
Extr	100	11.3	9.4–14.1	10.2–12.2	11.4	1.5	84	55
Glouc	97	11.9	9–13.8	10.9–12.7	11.8	1.5	86	74
Guys	99	11.8	9.5–14	10.9–12.7	11.9	1.4	92	72
H&C	100	11.9	8.8–15	10.7–12.8	11.8	1.9	84	71
Heart	100	11.6	8.5–14.5	10.5–12.3	11.6	1.5	92	68
Hull	94	10.8	7.9–13.3	9.85–11.85	10.8	1.6	72	46
Ipswi	100	12.0	10.3–15	11.4–12.9	12.2	1.4	98	84
Kings	99	12.0	8.1–14.5	10.7–13.1	11.8	1.8	85	71
Leic	100	11.7	9.15–14.5	10.5–12.75	11.7	1.7	85	68
LGI	97	12.6	9.7–15	11.4–13.7	12.6	1.6	93	85
Livrpl	92	12.0	8.6–14.8	11.1–13.1	12.0	1.8	88	78
Middlbr	100	12.8	8.7–14.6	12.1–13.2	12.5	1.6	90	87
Newc	100	11.7	7.6–15.2	10.8–13.3	11.8	2.2	86	71
Notts	97	11.6	9.3–14.3	10.6–12.4	11.6	1.5	88	64
Oxfrd	100	11.8	8.9–15.2	10.8–12.7	11.8	1.9	87	70
Plym	92	12.0	10.2–14	11.1–12.8	12.0	1.3	98	76
Ports	86	11.4	8.2–14.9	10.2–12.8	11.5	1.9	80	58
Prstn	100	11.7	9.5–14.9	10.7–13.1	11.9	1.6	90	69
Redng	100	11.7	9.2–13.8	11.15–12.5	11.8	1.3	90	82
Sheff	98	11.6	9–14.3	10.5–12.8	11.7	1.7	86	63
Stevn	100	12.1	8.5–14.7	10.8–13.3	11.9	1.8	87	73
Sthend	57	12.1	8.8–15.7	10.8–13.65	12.2	1.9	88	69
StJms	100	12.2	9.2–14.6	11.2–13	12.1	1.6	89	81
Sund	88	11.7	10.1–12.9	11.1–12.1	11.7	0.8	100	86
Swnse	80	11.3	8.9–13.5	10–12.3	11.2	1.6	77	59
Truro	100	11.7	10.6–13.1	11–12.4	11.7	1.3	96	76
Wirrl								
Wolve	100	12.3	8.7–14.4	11.05–13.15	12.0	1.6	90	79
Words	100	11.7	9.1–14.2	10.7–12.9	11.7	1.6	85	69
Wrex	94	12.4	10.4–14.7	11.6–12.8	12.3	1.4	96	88
York	100	12.4	9.5–14.6	11–13.1	12.2	1.7	92	76
Eng	97	11.8	9.1–14.6	10.8–12.9	11.8	1.7	88	71
Wls	93	12.0	9.2–14.7	10.9–12.8	11.9	1.7	89	73
E&W	97	11.8	9.1–14.6	10.8–12.9	11.8	1.7	88	71

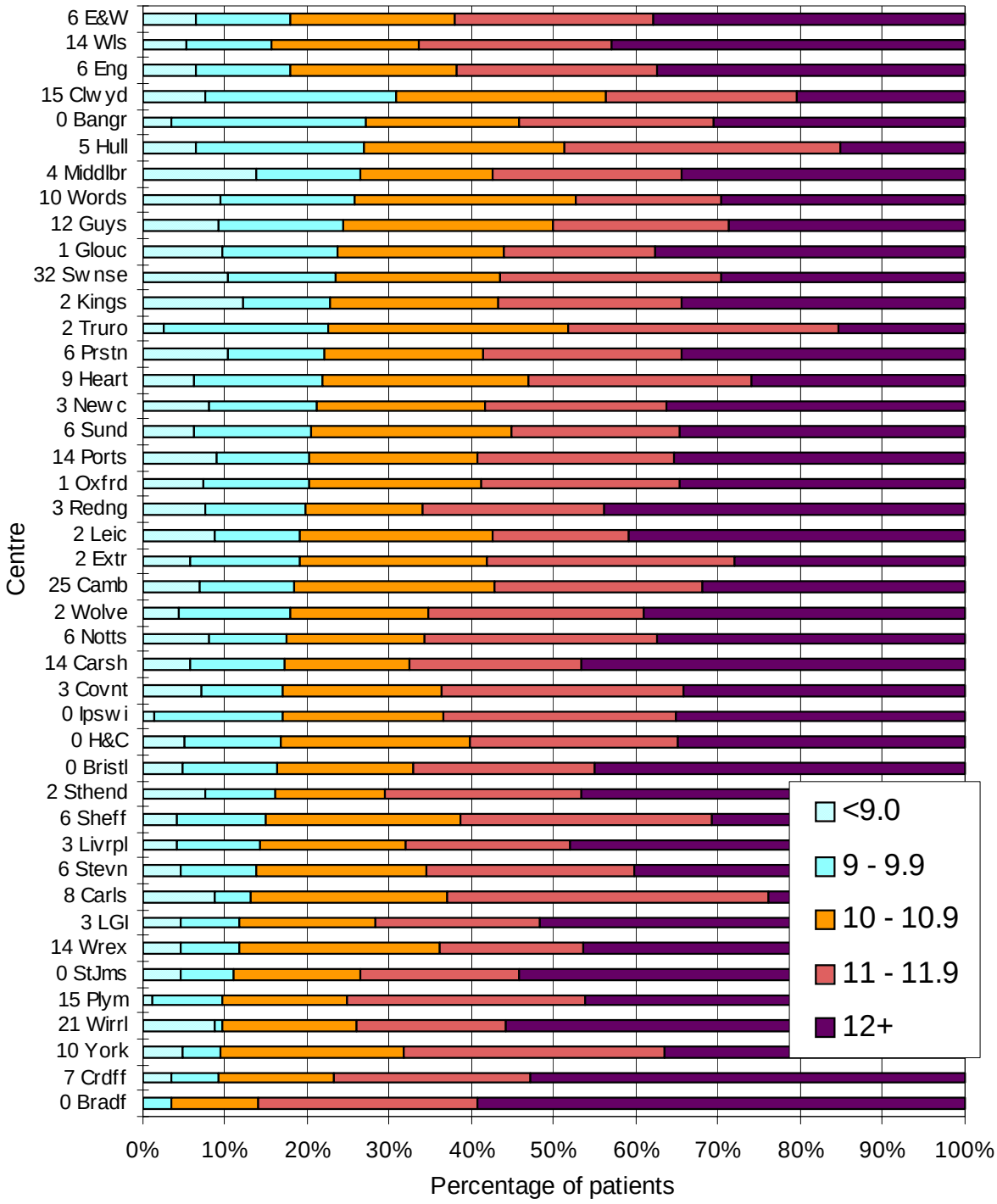


Figure 7.1. Distribution of haemoglobin in patients on HD

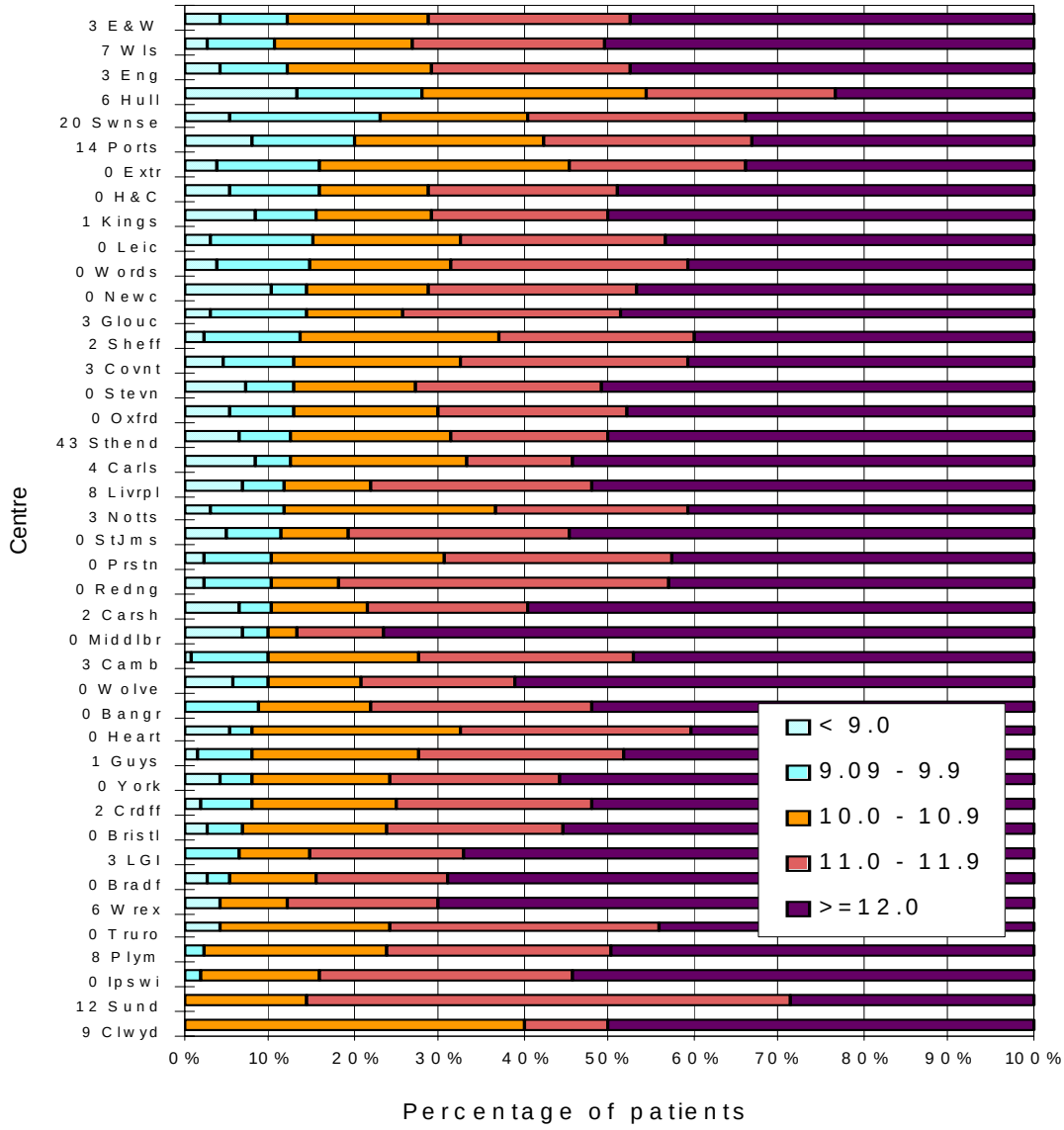


Figure 7.2. Distribution of haemoglobin in patients on PD

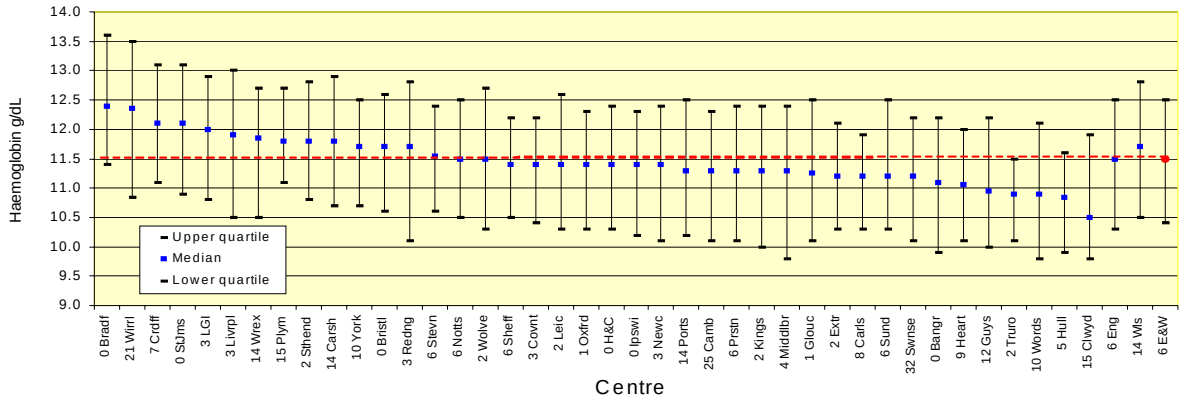


Figure 7.3. Haemoglobin and quartile ranges for HD patients

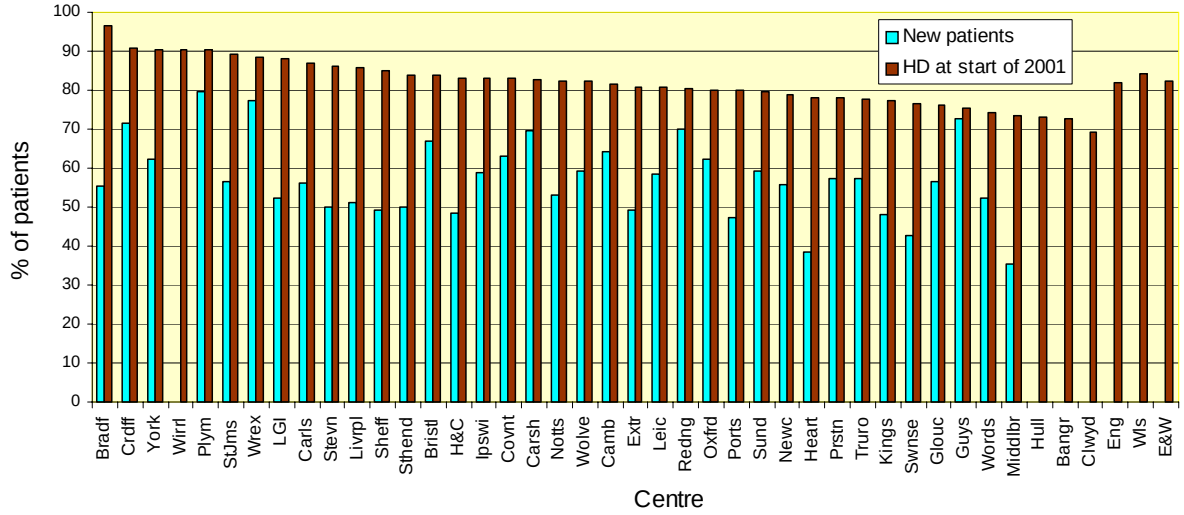


Figure 7.4. Percentage of HD patients, by centre, achieving the Renal Association target Hb

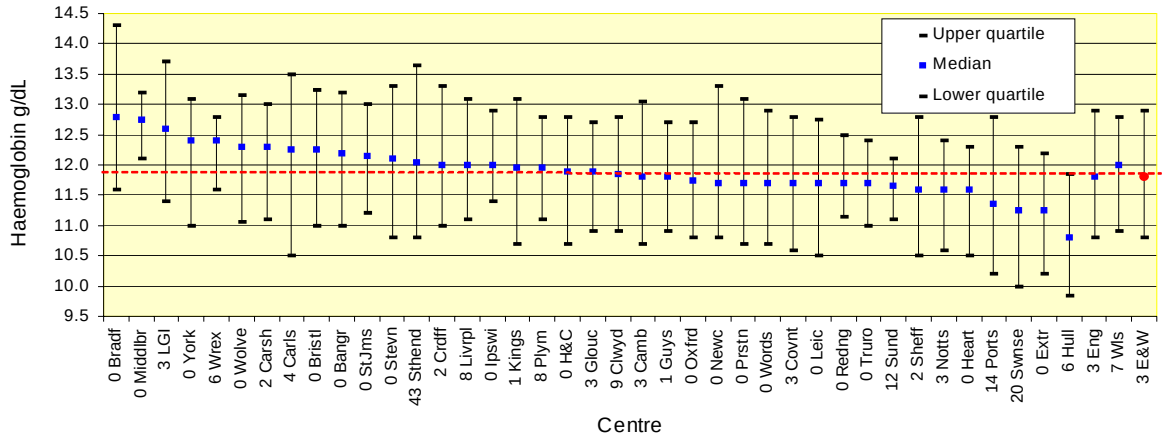


Figure 7.5. Haemoglobin and quartile ranges for PD patients

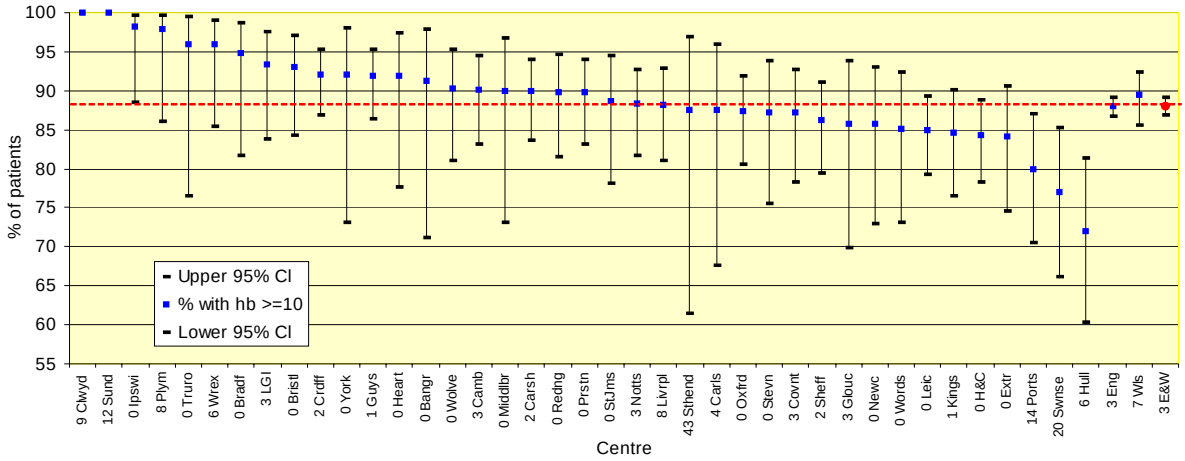


Figure 7.6. Percentage of HD patients, by centre, achieving the Renal Association target Hb

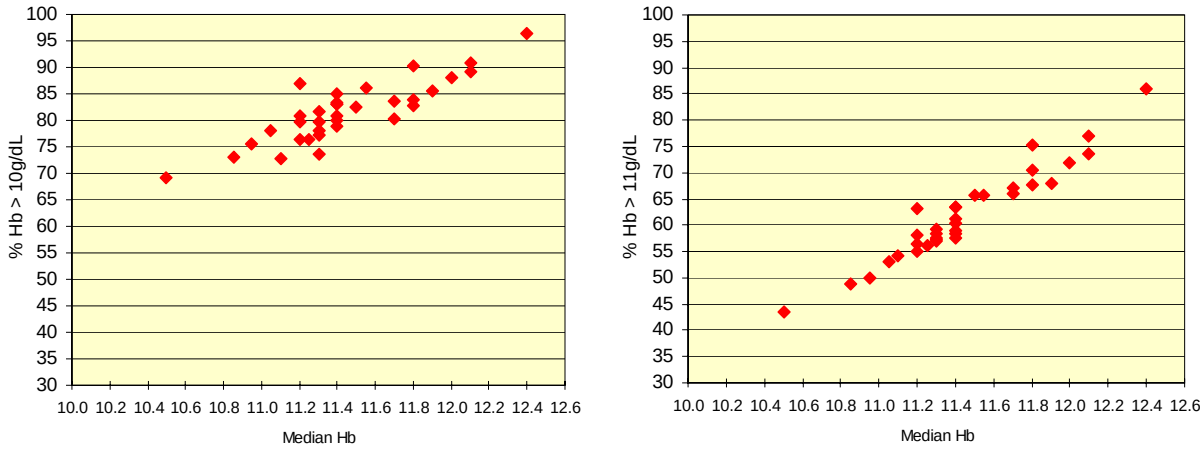


Figure 7.7. Percentage patients with Hb >10g/dl and HB >11g/dl plotted against median Hb for HD patients

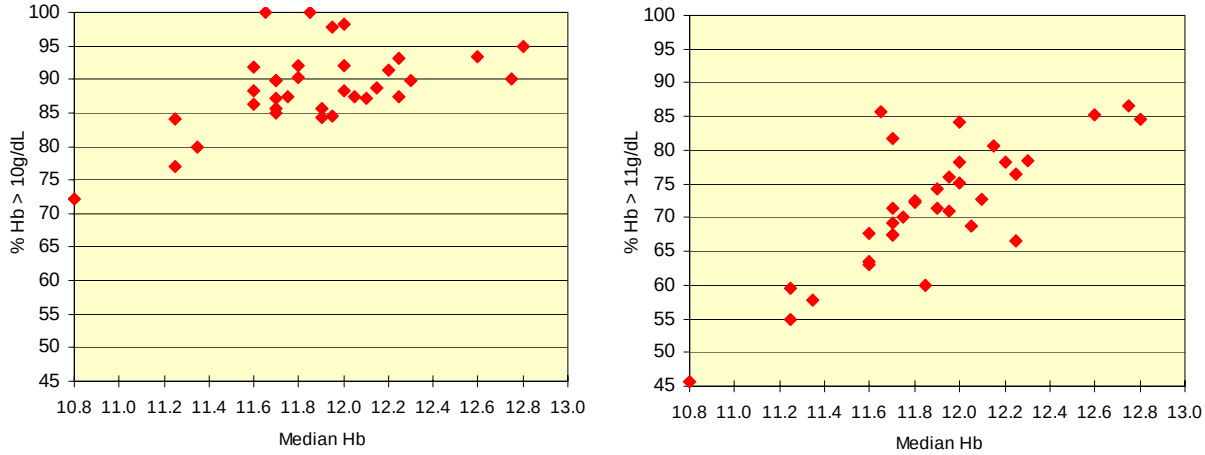


Figure 7.8. Percentage patients with Hb >10g/dl and HB >11g/dl plotted against median Hb for PD patients

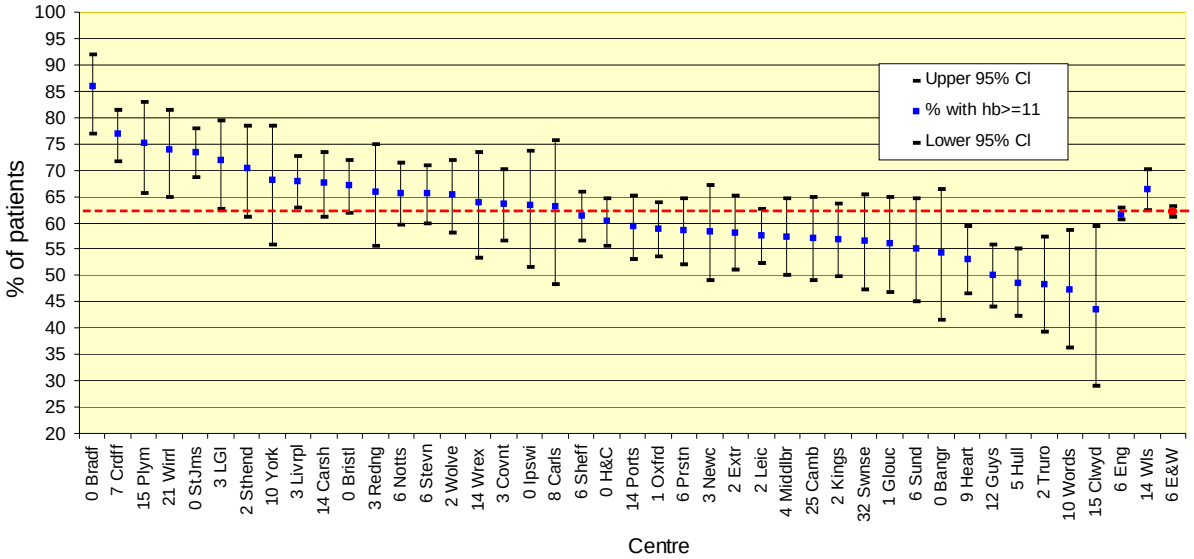


Figure 7.9. Percentage of HD patients with haemoglobin >11g/dl

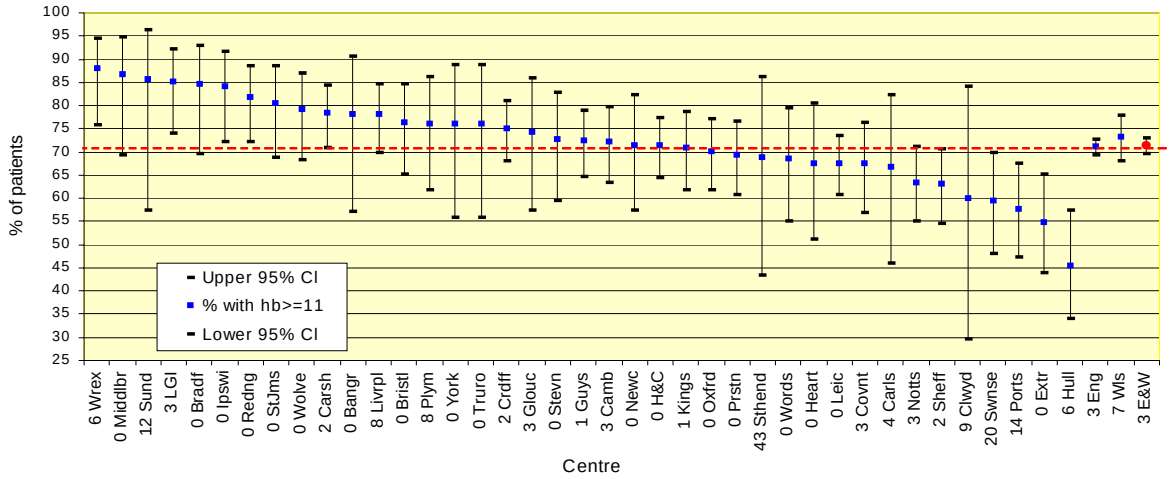


Figure 7.10. Percentage of PD patients with haemoglobin >11g/dl

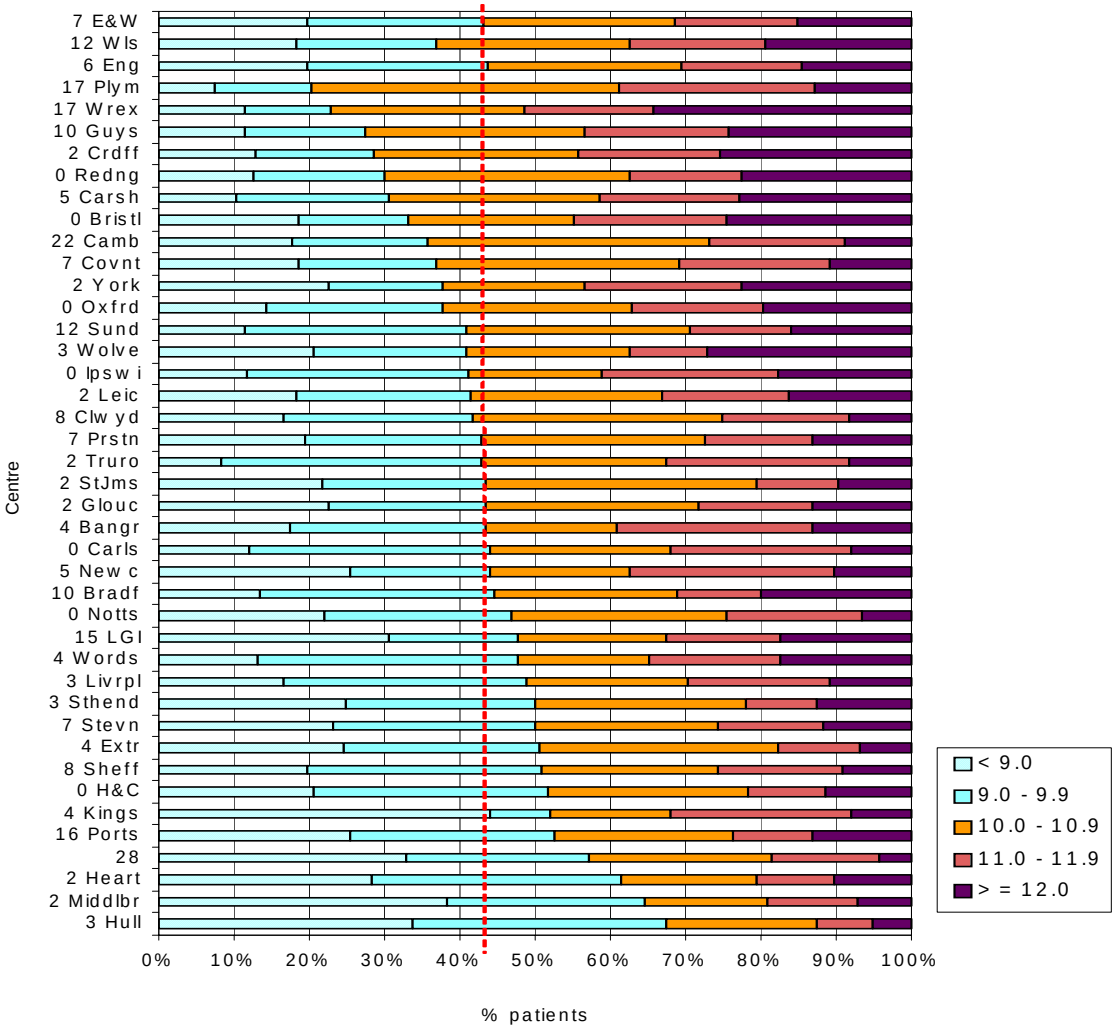


Figure 7.11. Distribution of haemoglobin for new patients

Table 7.3. Haemoglobin levels for new patients starting dialysis

Centre	% data return	Median HB g/dl	90% range	Quartile range	% HB >10g/dl
Bangr	95.8	10.3	8.6–12.7	9.2–11.6	56.5
Bradf	90.0	10.5	8.7–13.3	9.3–11.6	55.6
Bristl	100.0	10.7	8.1–13.8	9.7–11.9	66.9
Camb	77.8	10.3	7.8–12.5	9.45–11.15	64.3
Carls	100.0	10.3	8.6–12.4	9.3–11.3	56.0
Carsh	94.6	10.8	8.3–13.3	9.8–11.8	69.4
Clwyd	92.3	10.3	7.9–13	9.5–10.85	58.3
Covnt	92.9	10.3	8.2–12.4	9.4–11.2	63.1
Crdff	97.8	10.9	8.5–13.6	9.7–12	71.4
Extr	96.1	9.9	7.9–12.2	9–10.6	49.3
Glouc	98.1	10.2	8–13.2	9.2–11.1	56.6
Guys	89.9	10.8	8.6–13.5	9.6–11.9	72.6
H&C	100.0	10.0	7.7–12.9	9.1–10.9	48.3
Heart	97.5	9.8	7.4–12.8	8.9–10.4	38.5
Hull	96.9	9.5	7.2–12.1	8.5–10.3	32.6
Ipswi	100.0	10.4	6.6–13.6	9.4–11.2	58.8
Kings	96.2	9.7	7.5–12.2	8.5–11.1	48.0
Leic	97.9	10.4	8–13.2	9.3–11.3	58.5
LGI	85.2	10.1	7.5–13.4	8.5–11.3	52.2
Livrpl	96.8	10.2	8.1–12.5	9.3–11.1	51.2
Middlbr	98.0	9.4	6.6–12.2	8.2–10.6	35.4
Newc	95.2	10.1	6.9–12.5	8.9–11.3	55.9
Notts	100.0	10.0	7.9–12.2	9.1–10.9	53.2
Oxfrd	100.0	10.6	8–14.4	9.5–11.8	62.2
Plym	83.1	10.8	8.4–13.2	10–11.6	79.6
Ports	83.8	9.9	7.2–12.7	8.9–10.9	47.4
Prstn	93.3	10.1	7.1–12.7	9.2–11.1	57.1
Redng	100.0	10.7	8.6–13.5	9.7–11.8	70.0
Sheff	91.7	10.1	7.9–12.4	9.2–11	49.2
Stevn	93.5	10.1	7.4–13.3	9–11	50.0
Sthend	97.0	10.0	6.6–13.9	8.85–10.7	50.0
StJms	97.6	10.0	7.9–12.5	9–10.7	56.6
Sund	88.0	10.3	8.5–13	9.3–11.4	59.1
Swnse	72.2	9.7	7.7–11.9	8.7–10.7	42.9
Truro	98.0	10.3	8.6–12.4	9.7–11.1	57.1
Wolve	96.7	10.7	8–14.6	9.3–12	59.1
Words	95.8	10.4	8.2–12.7	9.3–11.6	52.2
Wrex	83.3	11.3	7.9–14.9	10–12.4	77.1
York	98.1	10.6	7.7–13.7	9.1–11.7	62.3
Eng	93.6	10.3	7.8–13.1	9.2–11.3	56.3
Wls	87.5	10.6	7.9–13.6	9.3–11.6	63.0
E&W	93.0	10.3	7.8–13.1	9.2–11.3	56.9

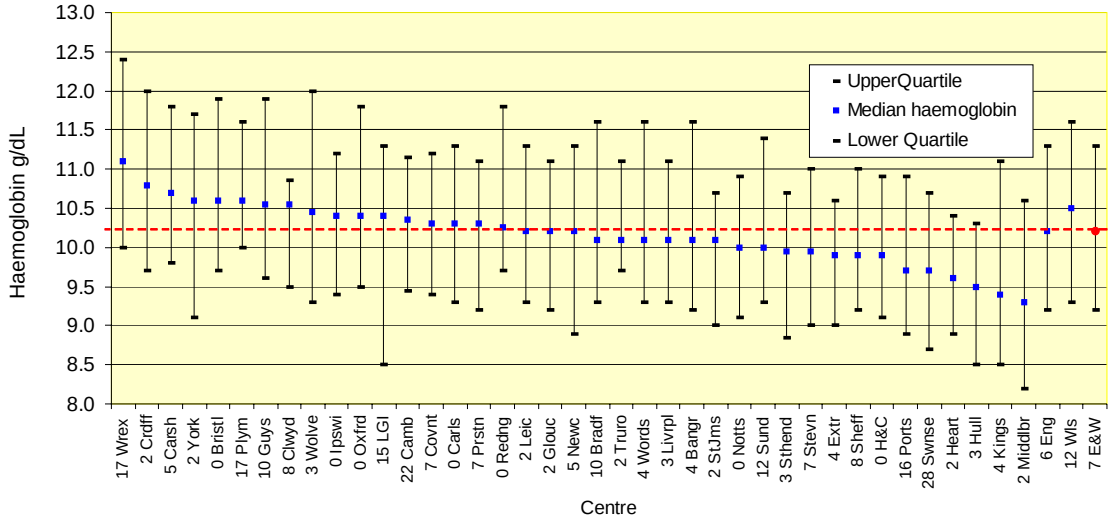


Figure 7.12. Haemoglobin median and quartile range for new patients

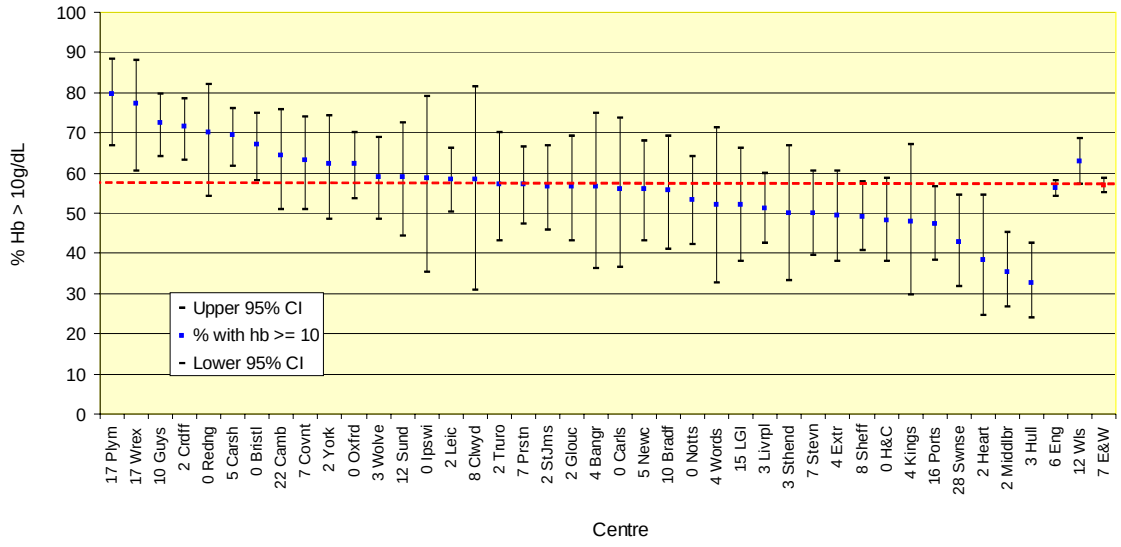


Figure 7.13. Percentage of new patients, by centre, achieving the Renal Association target

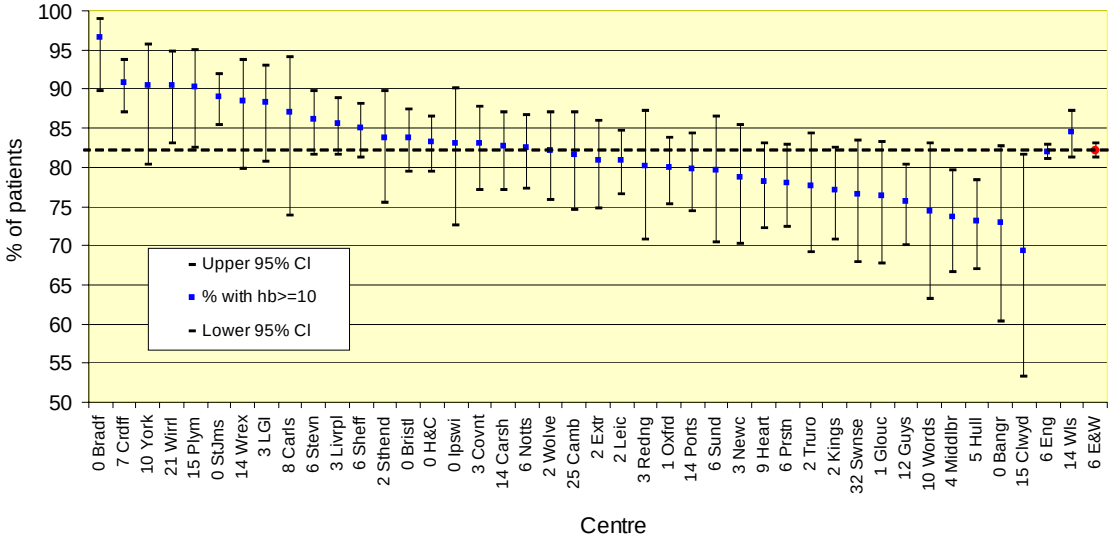


Figure 7.14. Percentage of patients with haemoglobin >10g/dl: new and prevalent patients

Figure 7.14 compares the first quarter haemoglobin value of new patients with the haemoglobin of prevalent patients. In some centres the percentage with target haemoglobin in the first quarter of dialysis is very close to that percentage in prevalent patients. In other centres there is a large gap. This variation is likely to reflect differences in pre-dialysis anaemia management but will also be influenced by proportions of patients referred late for treatment. The change in the Renal Association standard to require a haemoglobin ≥10g/dl in all patients whether on dialysis or pre-dialysis, within 6 months of being seen by a nephrologist may impact upon these variations in the future.

Changes in anaemia management over time

Every year that the Registry has reported, there has been an increase in median haemoglobin and an increase in percentage reaching the target haemoglobin, although the percentage increase has slowed (Figure 7.15). In haemodialysis patients 82.2% have a haemoglobin >10 g/dl compared with 81.4% at the end of 2001. For peritoneal dialysis patients this has increased from 86.5% >10 g/dl at the end of 2001, to 88.1% >10 g/dl at the end of 2002.

In 1998 only 40% of patients starting RRT had a haemoglobin >10 g/dl (Figure 7.16)

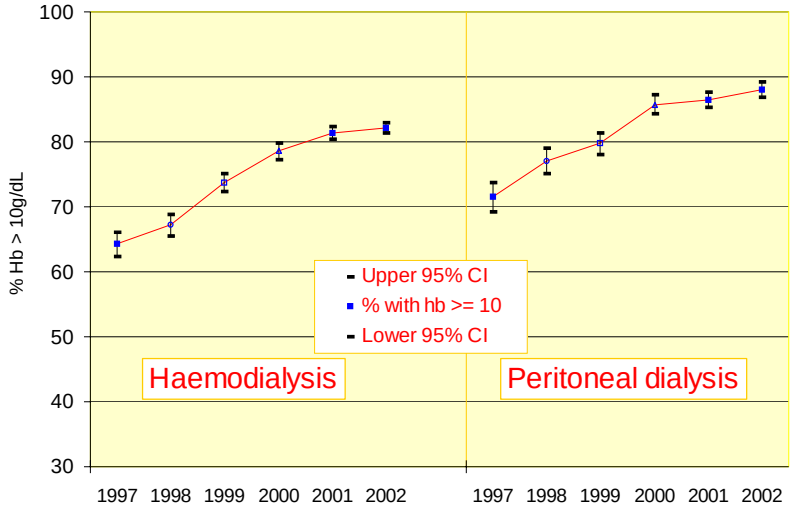


Figure 7.15. Change in percentage of prevalent patients with Hb >10g/dl in E&W 1997–2002

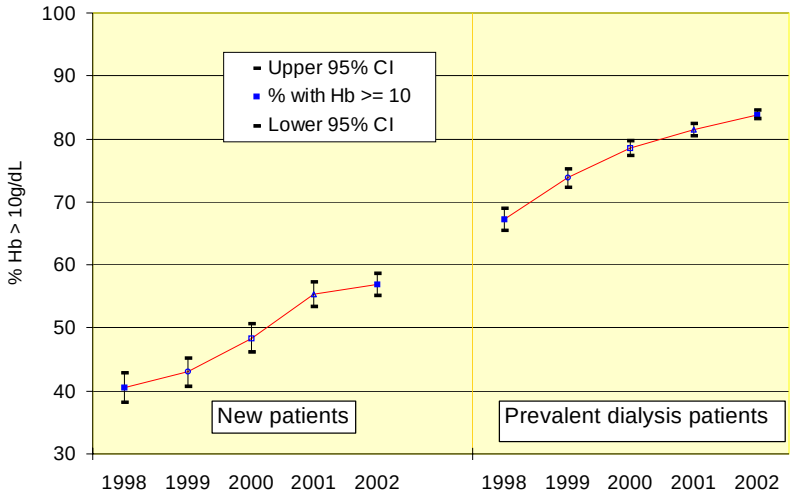


Figure 7.16. Change in percentage of patients starting RRT with Hb >10g/dl in E&W 1998–2002

compared with 57% in 2002. The years 1999–2001 showed a dramatic increase, although the rate of this increase is now slowing. In this year's report, Chapter 16 analyses data on the late referral (seen by a nephrologist <3 months before starting renal replacement therapy) of patients. Late referral occurs in 30% of patients starting renal replacement therapy and analysis indicates this rate has remained unchanged over 1998–2002. Further large improvements in haemoglobin of patients starting renal replacement therapy may rely on targeting late referral.

Analysing these data by a cross-sectional basis on the 31st December each year (Figure 7.17), the time taken to increase haemoglobin can be seen. It is still taking 6–12 months for patients on haemodialysis to achieve maximum haemoglobin level. The Renal Standards document recommends these targets should be achieved within 6 months of seeing a nephrologist.

Temporal changes in haemoglobin in different renal units

Serial data are shown for those centres that have submitted data to the Registry since the first quarter 2001. As has previously been noted there is great variation in haemoglobin levels and proportion of patients achieving the target in small centres from one quarter to the next. This variation is much less obvious in larger centres.

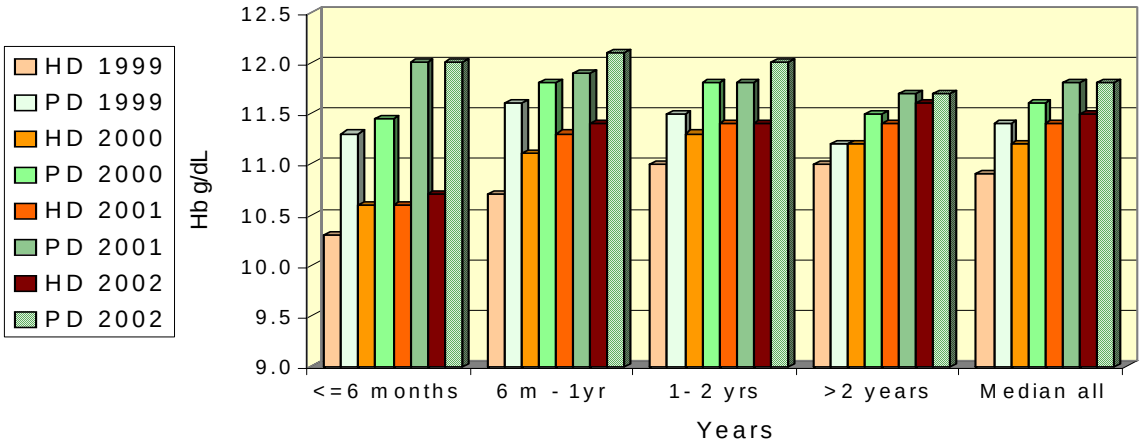


Figure 7.17. Change in median Hb by length of time on RRT

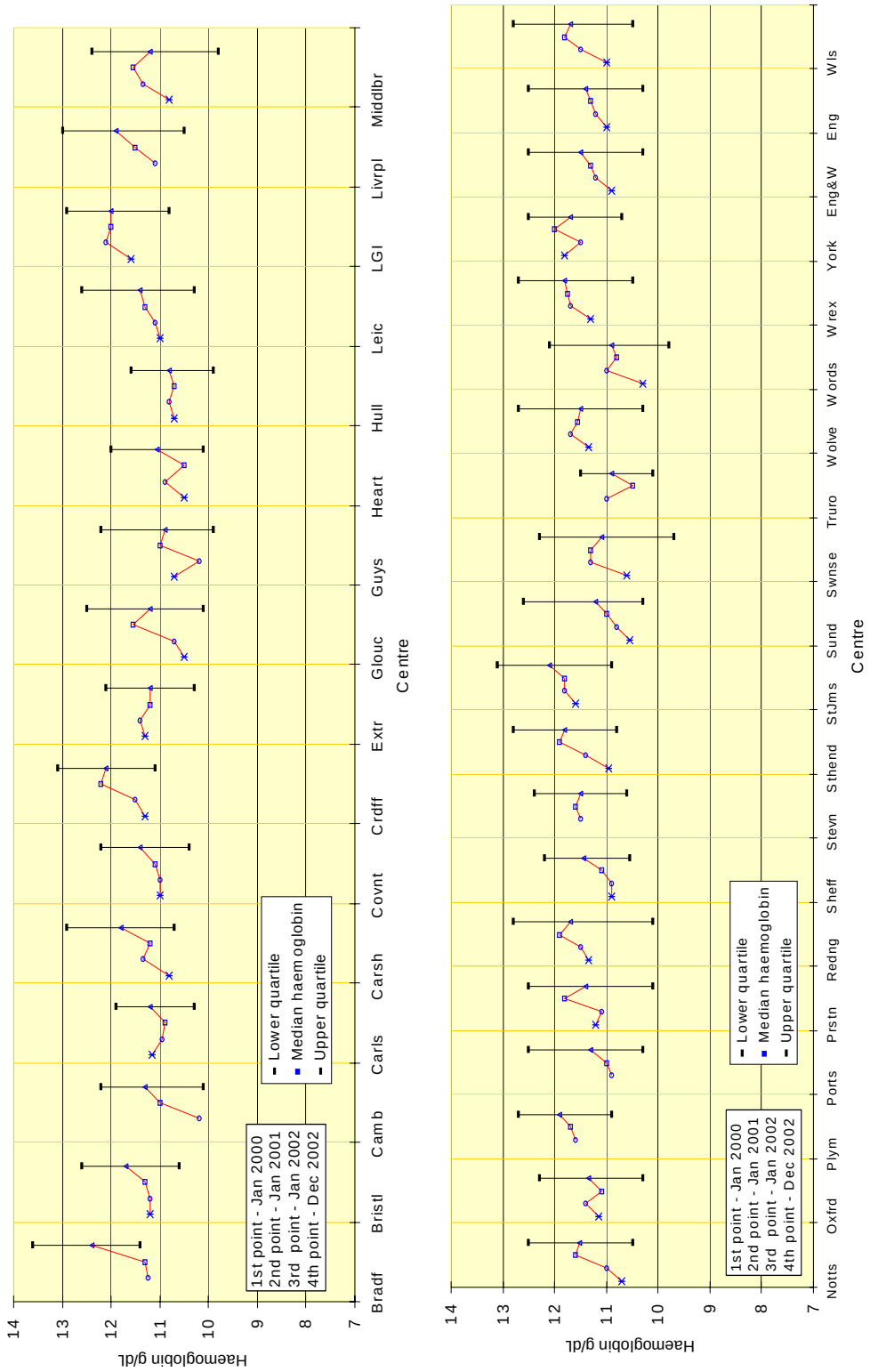


Figure 7.18. Median haemoglobin and quartile range January 2000–December 2002 for patients receiving haemodialysis

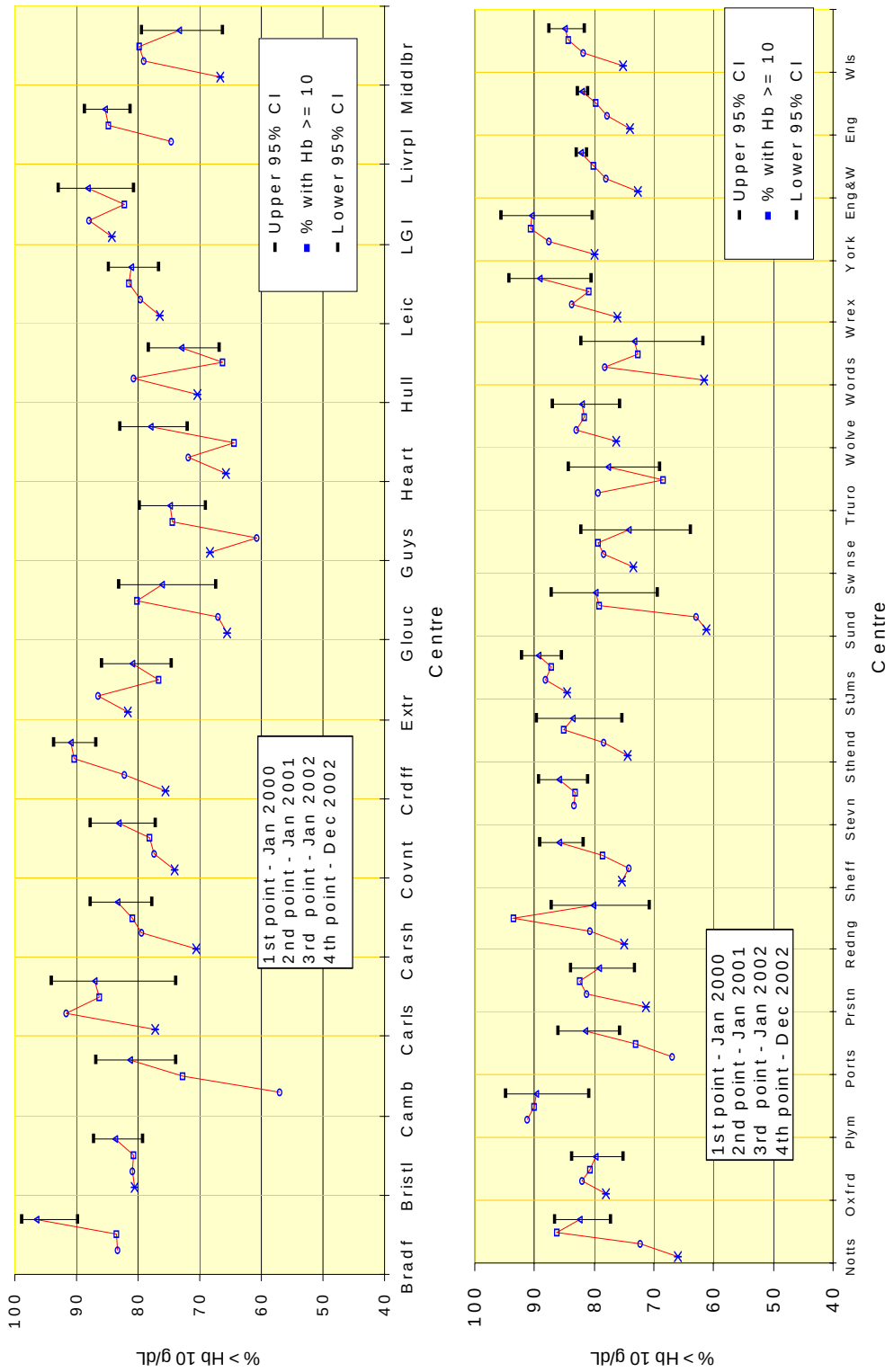


Figure 7.19. Percentage haemoglobin >10g/dl January 2000–December 2002 for patients receiving haemodialysis

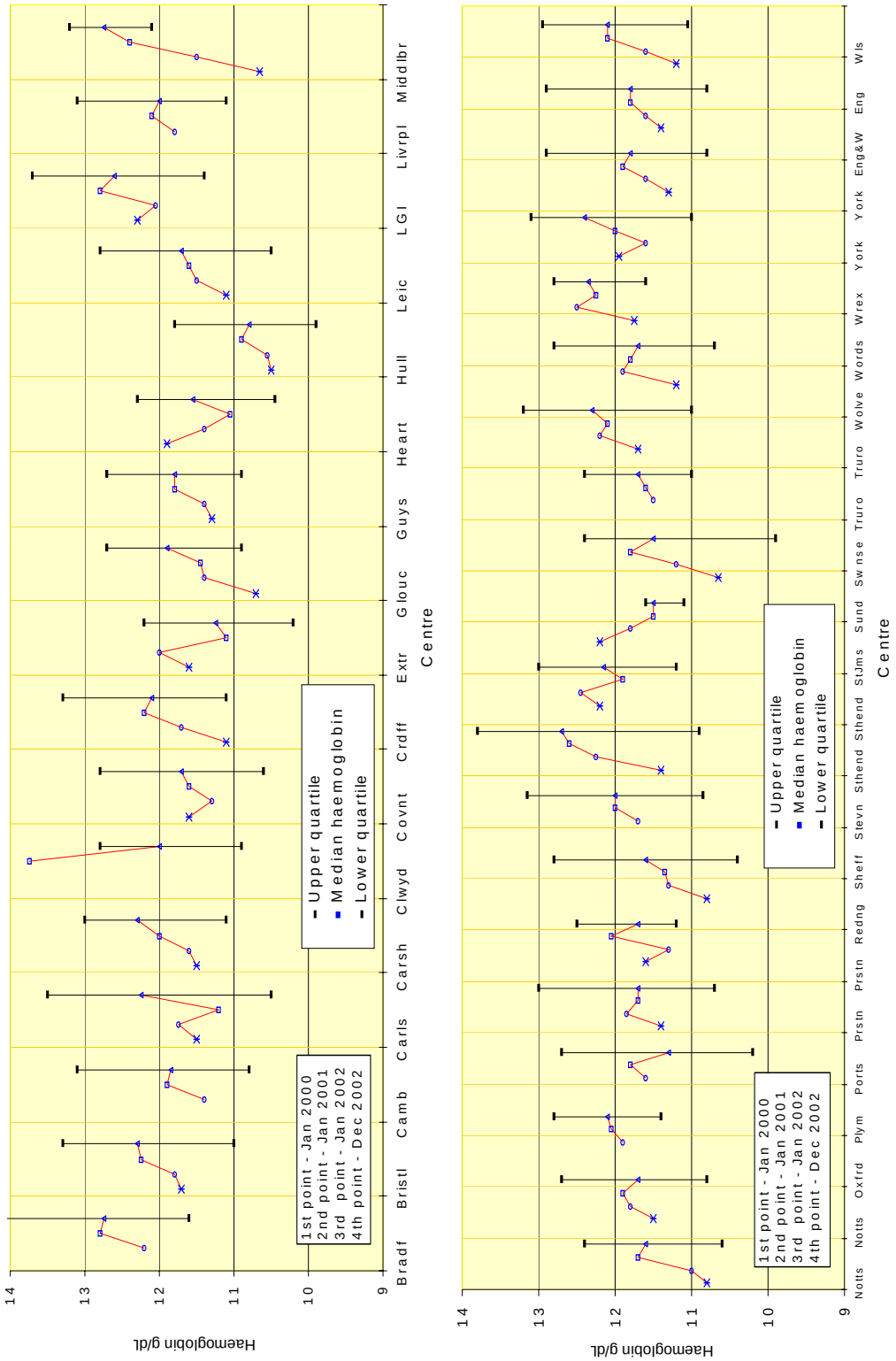


Figure 7.20. Median haemoglobin and quartile range January 2000–December 2002 for patients receiving peritoneal dialysis

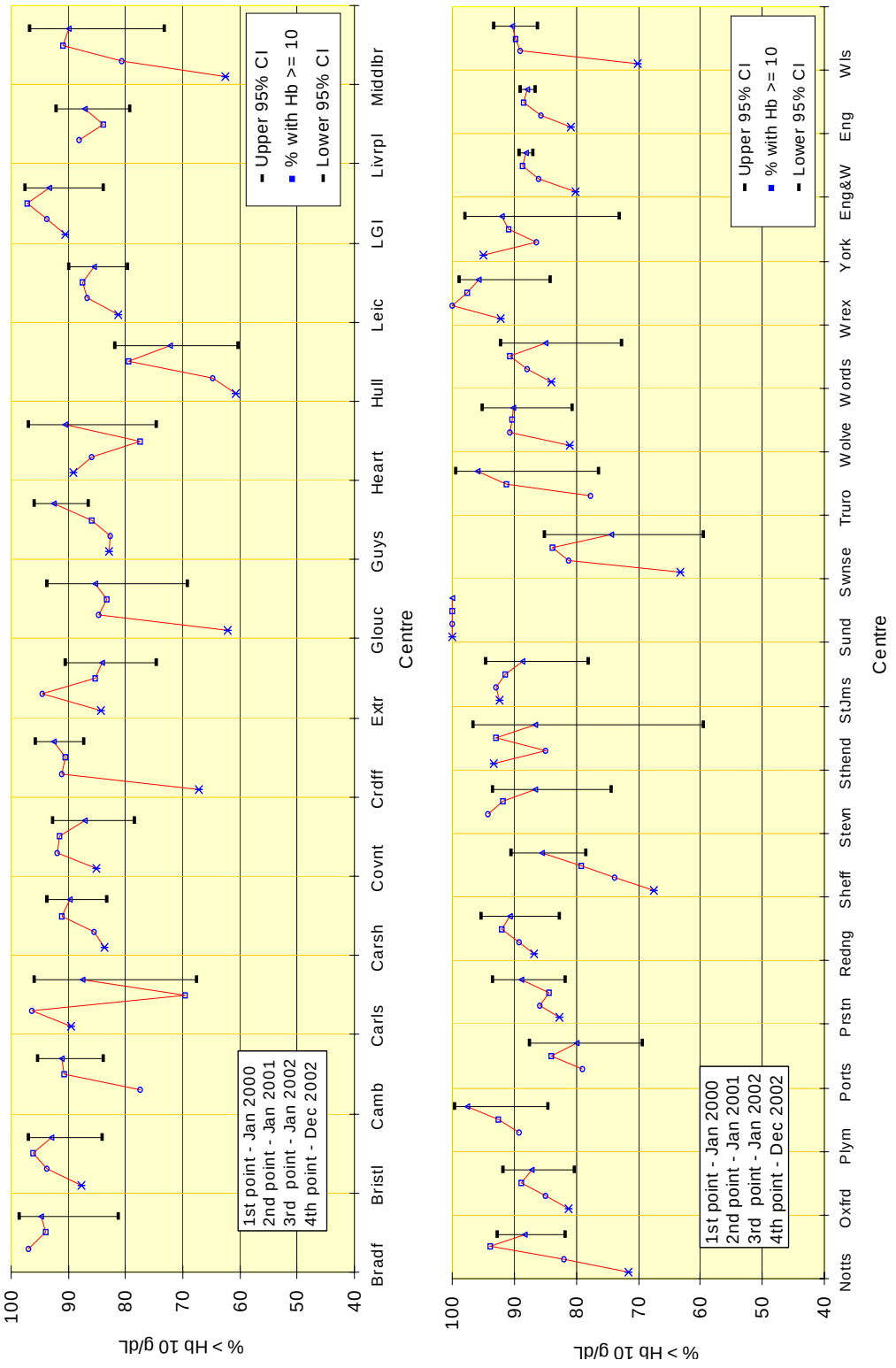


Figure 7.21. Percentage haemoglobin >10g/dl January 2000–December 2002 for patients receiving peritoneal dialysis

Conclusion

There has been a continued rise in the haemoglobin concentrations of dialysis patients and the proportion reaching the Renal Association target. There is some evidence that this rise may be reaching a plateau in peritoneal dialysis patients.

There continues to be marked difference in haemoglobin concentrations between recently started patients and prevalent dialysis patients. Anaemia is unavoidable when patients present as uraemic emergencies but is also the result of both late referral to nephrologists and variations in predialysis anaemia management that could be improved.

There is evidence of variation of haemoglobin levels in centres over time. This reflects the effect of fluctuating haemoglobin concentrations in individuals receiving dialysis treatment, which has also been identified in previous Registry reports. It is therefore not possible to make judgements about quality of treatment within a centre on the basis of a single set of data especially if it has relatively few dialysis patients.

Chapter 8: Factors Influencing Haemoglobin

Summary

- The median serum ferritin on HD continued to show a small annual rise from 405 mcg/L in 2001 to 420 mcg/L in 2002, with the percentage of patients exceeding a median serum ferritin of 100mcg/L rising from 93% to 94%. In contrast the median serum ferritin for PD patients remained unchanged at 249 mcg/L.

- The rise in median serum ferritin on HD was due to a higher percentage of ferritin values between 300 and 699 mcg/L and a corresponding fall in the percentage of values less than 300 mcg/L in haemodialysis patients. The percentage of patients with a ferritin above 700 mcg/L did not increase this year. In contrast, the ferritin distribution in peritoneal dialysis patients was similar to 2002.

- Although the median serum ferritin exceeded 100 mcg/L by 6 months after starting treatment by haemodialysis or peritoneal dialysis, levels continued to increase during the first two years on dialysis, reaching the overall modality median by 2 years.

Introduction

The 2002 Renal Association 3rd Standards document (SDIII), European Best Practice Guidelines (EBPG) and Dialysis Outcomes Quality Initiatives (DOQI) guidelines all advocate:

> ***a target serum ferritin of greater than 100*** *μmol in patients with CKD*

and advise that:

> ***levels consistently exceeding 800*** *μmol/L, which carry the risk of iron toxicity without conferring additional benefit and should be avoided.*

The three guidelines also agree target values for red cell hypochromicity of less than 10% and for transferrin saturation (TSATs) of greater than 20%. To achieve these minimum criteria across the CKD population, SDIII and EBPG advocate population target medians of 200–500 μmol/L for ferritin, <2.5% for red cell hypochromicity and 30–40% for transferrin saturation. As serum ferritin is the most accessible, widely used and comprehensively recorded parameter in UK renal units, it remains the chosen index of iron status for this report.

Data on haematinics other than iron are not currently collected by the Registry and do not therefore appear in this report. Serum B_{12} and folate levels are however routinely measured by renal units and since deficiencies of either are easily and cheaply corrected, it is unlikely that B_{12} or folate deficiency contribute significantly to renal anaemia or poor erythropoietin response in UK renal units.

Because of variations in the recording of erythropoietin data on renal computer systems and the provision of erythropoietin from primary care in some parts of the UK, comprehensive and accurate data on erythropoietin usage are difficult to gather, though where available these were included in the last three Registry reports. The increasing usage of darbepoietin/Aranesp, which was licensed for use in the UK in 2001, has complicated the electronic data collection, with dosage errors produced for patients on fortnightly and monthly doses. As a result it has not been possible to include information about erythropoietin in this report. These

problems will be addressed in preparation of the 2004 report, which will include all available data on the prescription of both erythropoietin and darbepoietin.

For renal units that are measuring red hypochromicity and have this data available via their laboratory link, the Registry will add this to its database as a new data item for 2004, along with B12 and red cell folate.

Serum ferritin

The distribution of ferritin concentration is presented in Table 8.1 for haemodialysis and Table 8.2 for peritoneal dialysis. The percentage of patients achieving a serum ferritin of over 100 mcg/L is presented graphically in Figures 8.1 and 8.2 and the median serum ferritin with interquartile range appears in Figures 8.3 and 8.4.

All centres achieved a median ferritin over 100 mcg/L for both HD and PD, though as in previous reports, median ferritin and the percentage of patients exceeding a ferritin of 100 mcg/L were consistently higher in HD than PD patients. Behind this general picture however, several units had fewer than 75% of PD patients with serum ferritin over 100mcg/L, though this applied to only one centre for patients on haemodialysis.

Centres with the highest median ferritin for HD (Reading, Cardiff, Liverpool and Preston) all had upper quartile values exceeding 800 mcg/L and in the case of the Reading unit, the median value was 796, with an upper quartile of over 1000mcg/L. However, PD patients from this unit, whilst also iron replete, had median values less than half those of their HD peers (328 vs 796), suggesting that even in units with an aggressive iron replacement policy, practical difficulties continue to constrain the administration of intravenous iron to home dialysis patients. Despite the generally higher ferritin in HD than PD patients, several units (e.g. Newcastle, Sunderland and Carlisle) achieved a median ferritin for PD which was very similar to (and in the case of the Carlisle unit higher than) that for HD. This demonstrates that consistent provision of iron across all modalities is possible, though at present is achieved in only a small number of units. It would be of interest to compare iron programmes in these centres with those in units reporting larger disparities in achieved ferritin between HD and PD.

As in last year's report, no relationship exists either for HD or PD patients between the percentage achieving a haemoglobin level of greater than 10 g/dl and the percentage with serum ferritin above the target level of 100 mcg/L. The apparent relationship identified in last year's report between the percentage of haemodialysis patients with a serum ferritin above 200 mcg/L and a haemoglobin level greater than 10 g/dl is less pronounced this year (Figure 8.5) and as before there is no clear relationship between the percentage of PD patients with ferritin greater than 200 mcg/L and the percentage achieving the haemoglobin standard (Figure 8.6).

Table 8.1. Serum ferritin concentrations in HD patients

Centre	% data return	Median ferritin	90% range	Quartile range	% ferritin > 100ug/L
Bangr	100.0	524	199–1126	199–660	100
Bradf	100.0	455	182–888	182–597	99
Bristl	99.4	329	39–835	39–502	87
Camb	72.6	166	11–639	11–300	63
Carls	92.0	314	140–692	140–464	100
Carsh	75.6	409	111–793	111–541	95
Clwyd	97.8	295	140–570	140–383	96
Covnt	98.0	306	74–923	74–441	92
Crdff	92.8	622	148–1264	148–836	96
Extr	97.9	325	117–902	117–411	97
Glouc	98.3	288	93–982	93–509	94
Guys	88.5	484	58–1395	58–690	92
H&C	99.6	563	234–1299	234–740	97
Heart	90.4	178	32–513	32–280	78
Hull	95.0	420	152–847	152–548	99
Ipswi	100.0	349	45–720	45–485	82
Kings	98.0	466	162–1083	162–667	97
Leic	97.2	352	84–968	84–524	93
LGI	97.3	488	167–1052	167–604	97
Livrpl	96.5	599	73–1293	73–846	94
Middlbr	92.9	392	53–1221	53–639	90
Newc	40.2	532	133–1322	133–902	96
Notts	92.9	516	225–1105	225–655	99
Oxfrd	98.2	315	71–944	71–460	90
Plym	84.5	437	159–1304	159–555	99
Ports	91.3	274	77–711	77–398	93
Prstn	97.7	572	138–1322	138–821	98
Redng	96.8	796	326–1496	326–1060	99
Sheff	99.8	480	100–801	100–611	95
Stevn	69.5	507	100–1086	100–738	95
Sthend	97.2	347	155–613	155–397	97
StJms	100.0	459	165–805	165–565	98
Sund	97.1	392	71–1356	71–628	93
Swnse	67.3	403	84–1385	84–614	95
Truro	96.6	545	212–989	212–666	98
Wirrl	37.9	475	71–1064	71–669	94
Wolve	98.9	428	203–829	203–562	98
Words	90.2	374	61–938	61–568	90
Wrex	83.0	469	269–1040	269–702	98
York	88.6	455	234–904	234–588	100
Eng	91.8	416	82–1062	82–605	94
Wls	86.0	498	138–1190	138–734	96
E&W	91.3	420	85–1074	85–617	94

Table 8.2. Serum ferritin concentrations in PD patients

Centre	% data return	Median ferritin	90% range	Quartile range	% ferritin > 100ug/L
Bangr	87	301	46–898	134–596	85
Bradf	100	351	46–1162	203–549	92
Bristl	100	231	46–892	115–402	82
Camb	97	138	19–536	64–216	65
Carls	96	373	73–1446	263–792	92
Carsh	88	246	96–823	183–399	94
Clwyd	100	299	103–601	109–448	100
Covnt	96	176	38–784	114–318	78
Crdff	95	204	30–884	128–386	81
Extr	100	205	70–665	137–327	90
Glouc	92	181	47–631	137–401	82
Guys	97	207	39–838	120–362	77
H&C	98	330	49–944	165–536	86
Heart	95	241	32–834	131–355	86
Hull	92	345	103–821	247–436	95
Ipswi	91	227	38–832	117–356	83
Kings	99	275	65–610	172–377	90
Leic	100	312	69–847	191–540	90
LGI	97	365	36–888	280–565	92
Livrpl	97	242	41–849	114–419	79
Middlbr	97	516	220–1520	356–957	97
Newc	55	494	259–940	414–701	100
Notts	97	193	66–798	122–368	84
Oxfrd	97	239	33–698	127–341	79
Plym	98	172	49–584	85–298	69
Ports	78	211	38–1026	135–348	83
Prstn	100	201	39–758	117–356	77
Redng	100	328	59–647	260–430	93
Sheff	100	256	60–772	157–403	87
Stevn	62	204	70–636	137–327	91
Sthend	54	188	32–822	87–404	73
StJms	100	268	118–708	200–485	95
Sund	100	414	105–1102	323–523	100
Swnse	93	256	87–836	193–450	94
Truro	96	172	24–552	114–297	75
Wolve	100	180	49–543	104–293	78
Words	94	205	26–946	108–496	78
Wrex	96	346	118–760	237–471	96
York	100	337	114–802	182–402	96
Eng	95	249	45–838	141–415	84
Wls	94	258	39–851	149–447	88
E&W	95	249	45–838	142–418	85

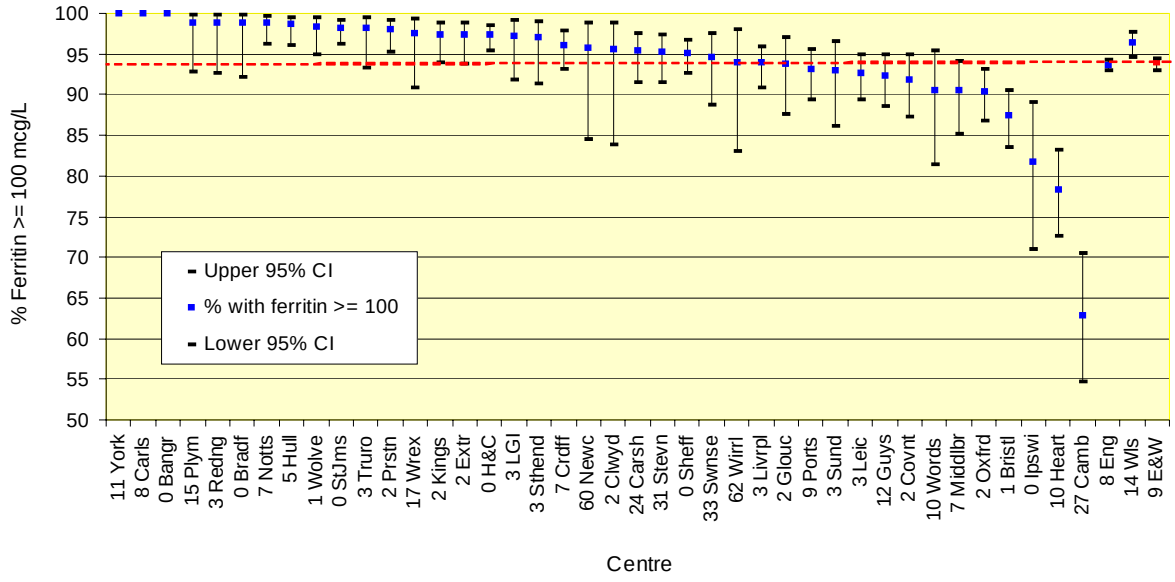


Figure 8.1. Percentage of HD patients with serum ferritin ≥ 100 mcg/L

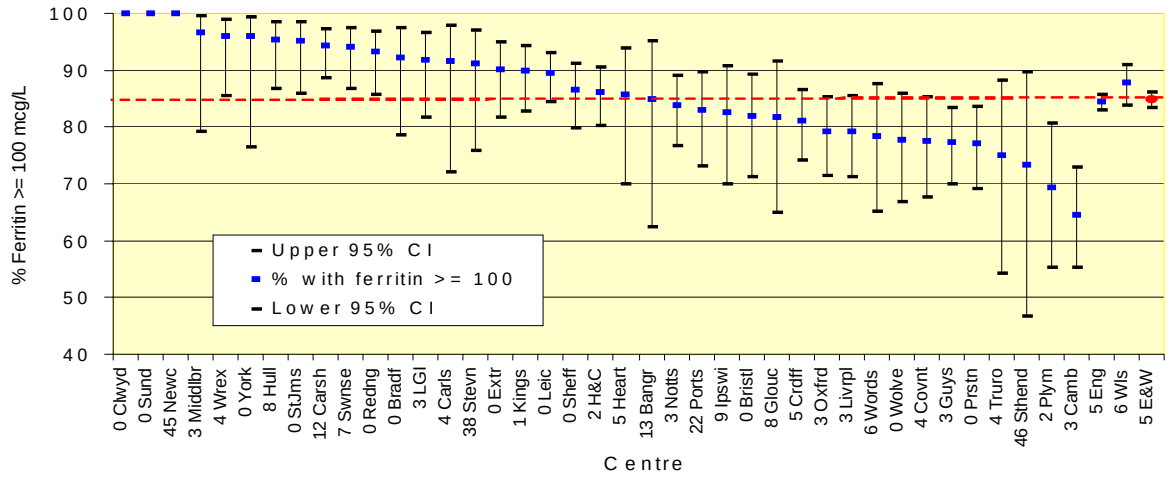


Figure 8.2. Percentage of PD patients with serum ferritin ≥ 100 mcg/L

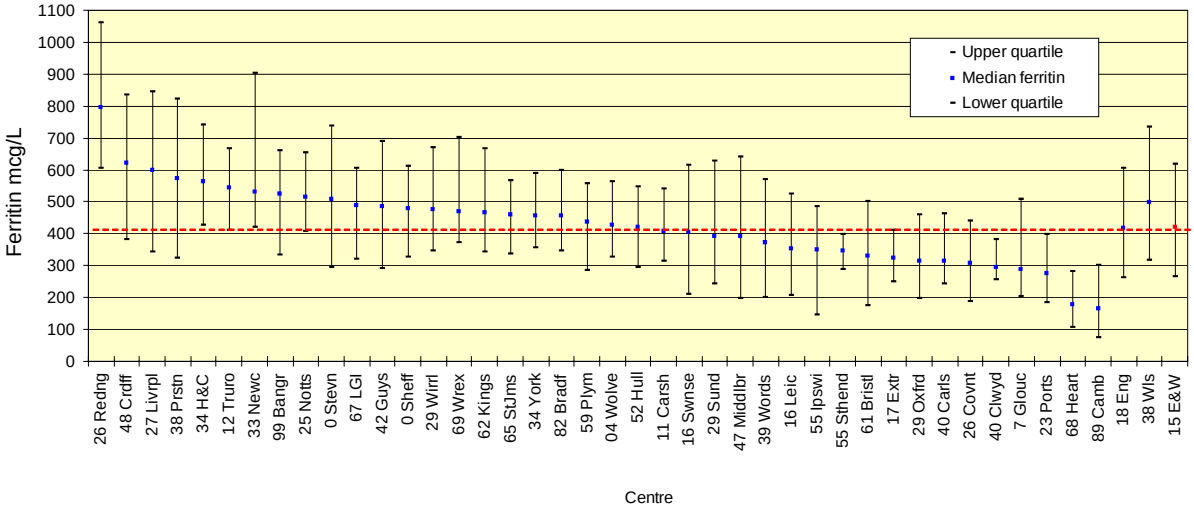


Figure 8.3. Median serum ferritin: haemodialysis

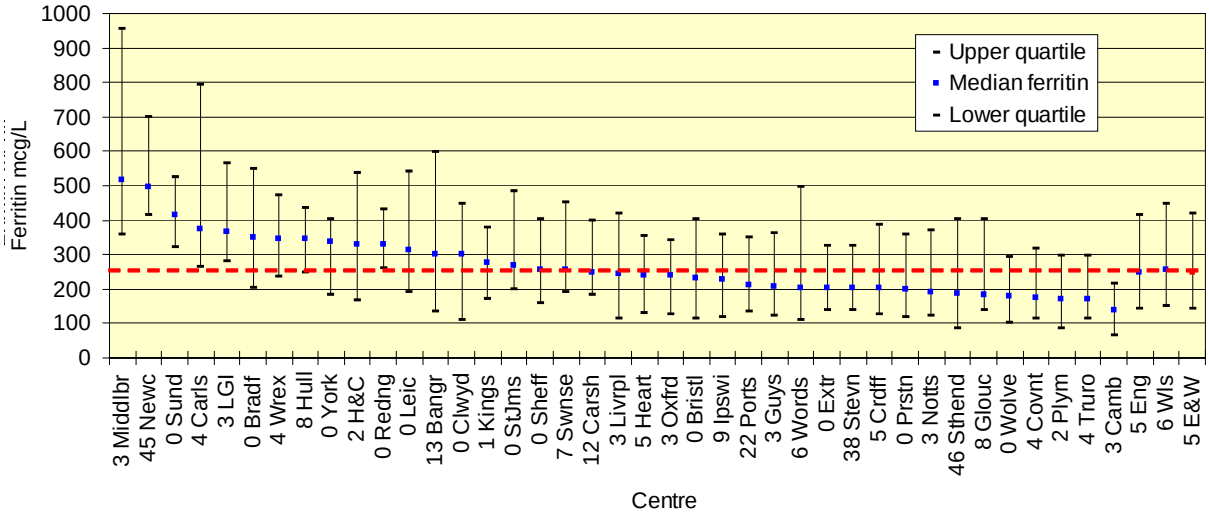


Figure 8.4. Median serum ferritin: peritoneal dialysis

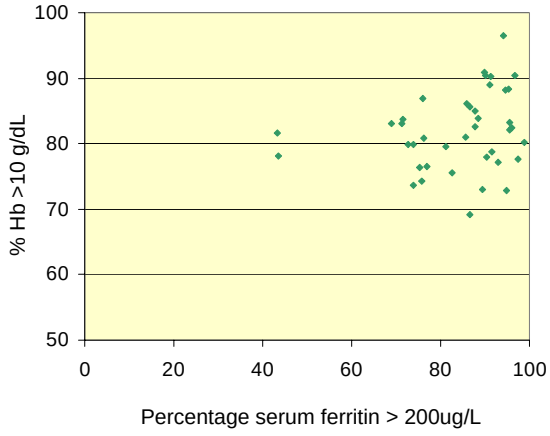


Figure 8.5. Percentage of patients with serum ferritin >200 mcg/L and Hb >10g/dl on HD

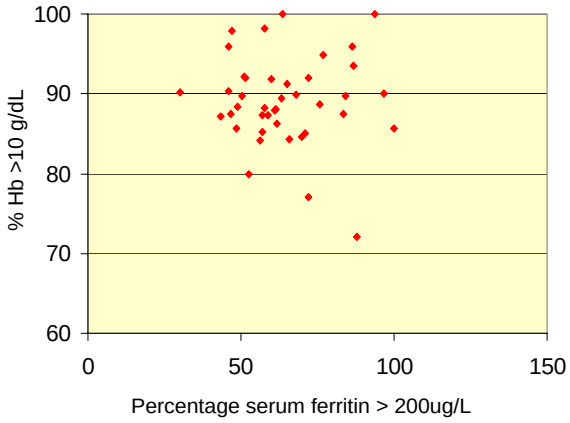


Figure 8.6. Percentage of patients with serum ferritin >200 mcg/L and Hb >10 g/dl on PD

Changes in serum ferritin 1999–2002 in England and Wales

Figures 8.7 and 8.8 show that the rise in serum ferritin values between 300 and 699 mcg/L and the corresponding fall in values below 300 mcg/L identified in last year's report continued for haemodialysis patients during 2002. However, for patients on peritoneal dialysis there was little change in ferritin distribution between 2001 and 2002. This again suggests that units were aspiring to target values for ferritin of greater than 100 mcg/L and that whilst this was achievable for unit-based HD patients who receive intravenous iron on dialysis, it remained difficult to attain in home dialysis patients, who need separate arrangements for the provision of intravenous iron. Whilst data relating to home haemodialysis patients are not reported separately, it is likely that ferritin values in this group were similar to or lower than those in peritoneal dialysis patients, reflecting regulatory constraints on self-administration of parenteral iron and the consequent dependence of this patient group on hospital based provision.

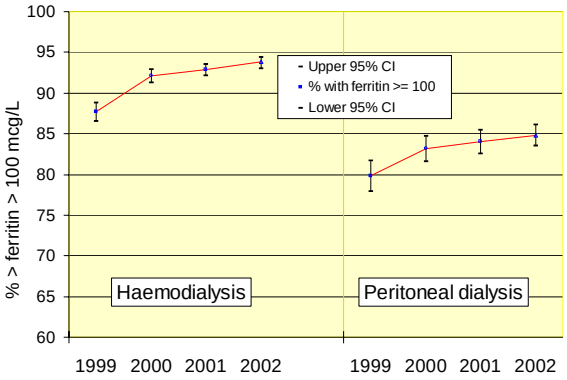
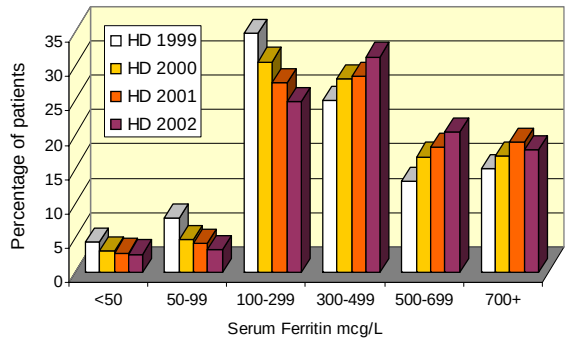
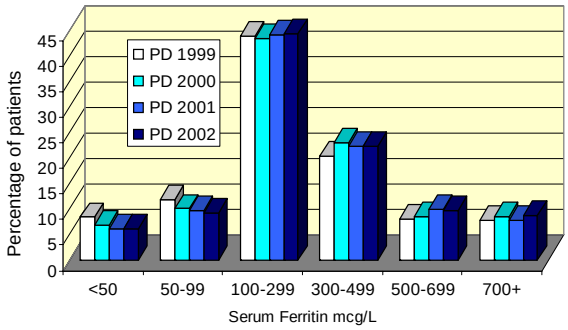


Figure 8.7. Change in achievement of serum ferritin > 100 mcg/L, 1999–2002



(a)



(b)

Figure 8.8. (a) Serum ferritin distribution 1999–2002 haemodialysis. (b) Serum ferritin distribution 1999–2002 peritoneal dialysis

Serum ferritin and length of time on renal replacement therapy

Median and lower quartile values for serum ferritin were above target for both HD (Figure 8.9) and PD (Figure 8.10) patients by the sixth month on dialysis and continued to increase throughout the first two years of renal replacement therapy, reaching the overall median for the modality only by the second year. For peritoneal dialysis patients,

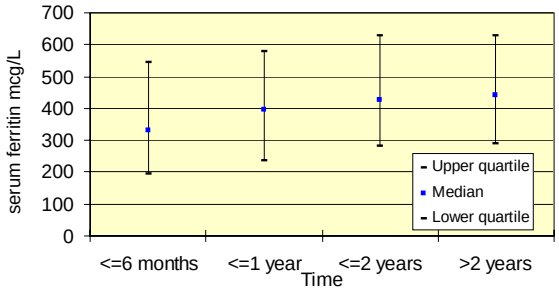


Figure 8.9. Median ferritin by length of time on renal replacement therapy: haemodialysis

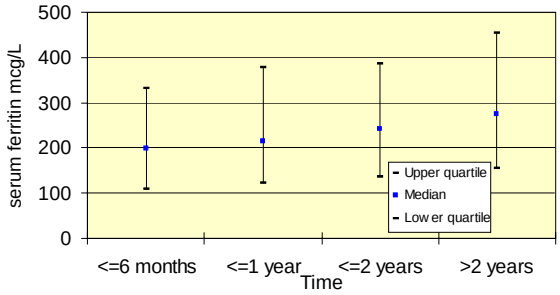


Figure 8.10. Median ferritin by length of time on renal replacement therapy: peritoneal dialysis

levels rose further (to exceed the overall median) after two years on dialysis. Despite achievement of the recommended target for ferritin soon after the commencement of dialysis, units continued to drive up ferritin levels, presumably in pursuit of a higher local target, for a further 18 months or more. It would be of interest to compare ferritin immediately before the commencement of dialysis with values at six months, to establish whether units achieving a higher ferritin in the dialysis population gained advantage by the commencement of intravenous iron in the pre-dialysis phase. Since pre-dialysis ferritin values are not submitted to the Registry at present, this cannot be tested using available data.

Changes in serum ferritin by centre 1999–2002

Figures 8.11 and 8.12 show the changes of median serum ferritin in each centre from 1999–2002 according to modalities.

The majority of centres are showing an increase of the median serum ferritin in their

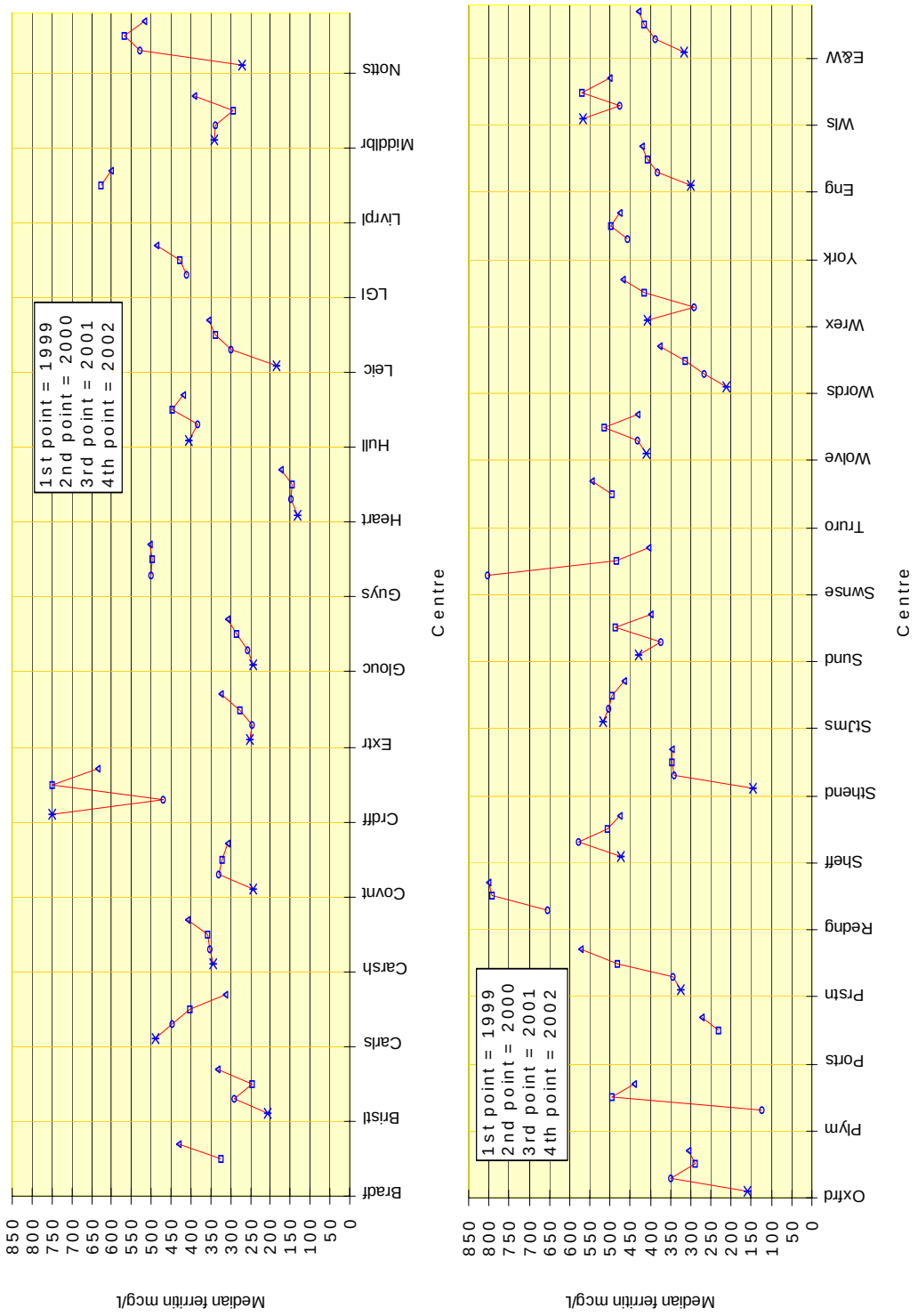


Figure 8.11. Serial ferritin concentration in haemodialysis patients

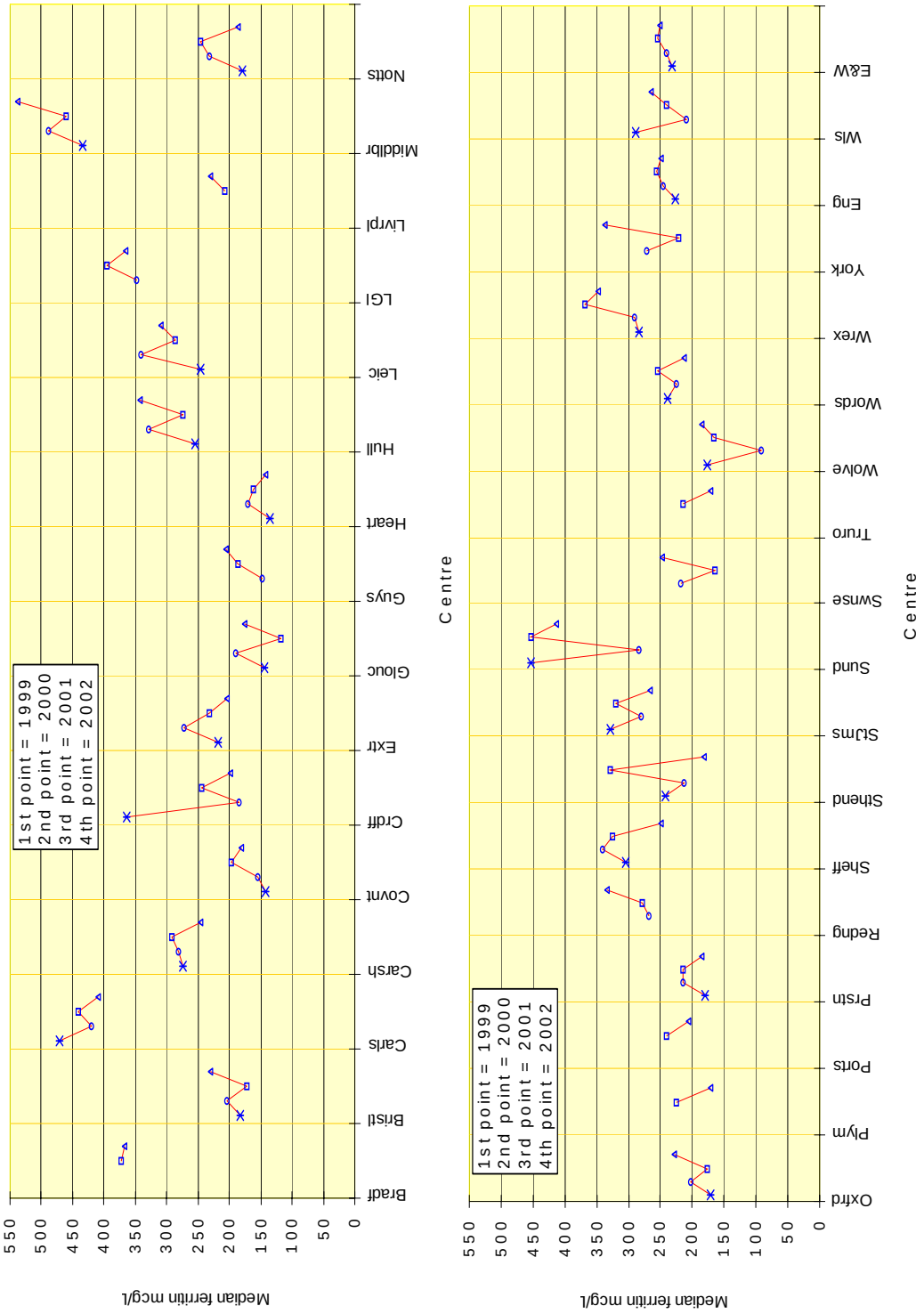


Figure 8.12. Serial ferritin concentration in peritoneal dialysis patients

haemodialysis patients from 1999 to 2002, whereas the patterns for peritoneal dialysis across the centres are more variable.

In 2002, apart from Carlisle, Middlesbrough and Sunderland, all the centres have a higher median serum ferritin for the haemodialysis patients in comparison to the peritoneal dialysis patients.

Conclusion

- Although the great majority of patients met ferritin targets, there remained large variations in achieved serum ferritin between different renal units.

- Achieved ferritin levels remained higher in haemodialysis patients than in the peritoneal dialysis population, though a small number of units achieved similar levels in both groups.

- Despite the attainment of target values by 6 months after commencement of dialysis, median ferritin continued to increase until the second year of dialysis, suggesting that local targets for serum ferritin exceed national recommendations.

Chapter 9: Serum Phosphate, Calcium and Parathyroid Hormone

Summary

- Serum phosphate control in dialysis patients is poor, and the variation between units is wide and significant. Four units have median serum phosphates above the standard of 1.8 mmol/L. Overall, only 60% of dialysis patients have serum phosphate under 1.8mmol/L.

- Comparative audit of serum calcium is rendered difficult by the problems of serum albumin measurement and the differences between the BCG and BCP methods for this. The median corrected calcium is just under 2.5 mmol/L for all units and modalities.

- The median PTH for all patients lies well within the standard with little difference between modalities. The spread of PTH levels is remarkable: some units – York and Wrexham – achieve over 90% compliance with the standard, some only 50%.

- The Renal Association has no standard for the serum calcium phosphate product, but the DOQI guidelines recommend the product should be less than 4.4 $mmol^2/L^2$ (= 55 mg^2/dl^2). Control is better on PD; 71% of PD patients achieve the standard, and 62% on HD ($p < 0.01$), with a wide variation between units.

- Registry data show that both poor serum phosphate control and poor calcium phosphate product control correlate with poor survival.

Introduction

Traditionally, control of phosphate, calcium, and parathyroid hormone metabolism has been regarded as control of renal bone disease: while nephrologists have recognised its importance, previous audit data from the Renal Registry reports show that this has never been done well. The clinical focus on this area of metabolism has shifted in the last few years with the appreciation that serum calcium and phosphate control are important to prevent accelerated vascular disease. There is thus a shift of emphasis from what is important in controlling bone disease (when a relatively high serum calcium may be considered acceptable), to what is important in preventing vascular disease, for which control of the serum calcium/phosphate product may be critically important. For this reason, data on control of the serum calcium/phosphate product are included in this chapter.

Recommended target concentrations for all of these analytes are published in the Renal Association Standards document. No separate standards are set for differing dialysis modalities. Nevertheless, differing modalities offer different challenges in achieving metabolic control, so as well as the pooled dialysis data, data for haemodialysis and CAPD are also shown separately.

Serum phosphate

The Renal Association Standard states

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

As ever, serum phosphate control is poor, but the variation between units is wide (Figures 9.1–9.6). Four units have median serum phosphate which lies outside the standard of 1.8 mmol/L. Overall, 60% of dialysis patients have serum phosphate under 1.8mmol/L. In general, the phosphate control is a little better on peritoneal dialysis. For patients on HD, the percentage of patients with a serum phosphate of <1.8 mmol/L differed significantly between centres (χ^2 = 221, d.f. = 39, p < 0.001). For patients on PD, the percentage of patients with a serum phosphate of <1.8 mmol/L differed significantly between centres (χ^2 = 102, d.f. = 38, p < 0.001).

Even the best units have poor phosphate control, but the variability does suggest that a clinical focus on phosphate control can bring biochemical benefits, which might be translated into future survival benefits.

Previous data from the Registry[1] have shown that patients with moderate elevation of serum phosphate have the best prognosis, as was suggested by earlier American studies.[2,3] These patients are thought to be fitter, relatively well dialysed, more active and eating well. The serum phosphate elevation reflects the limits of current dialysis techniques. It should not be assumed that a high phosphate is a good thing; if it could be lowered in these patients it would probably be beneficial to them.

Good phosphate control has not historically been a high clinical priority in many units. Control is largely achieved by a combination of dietary restriction and the use of phosphate binders, but the Registry

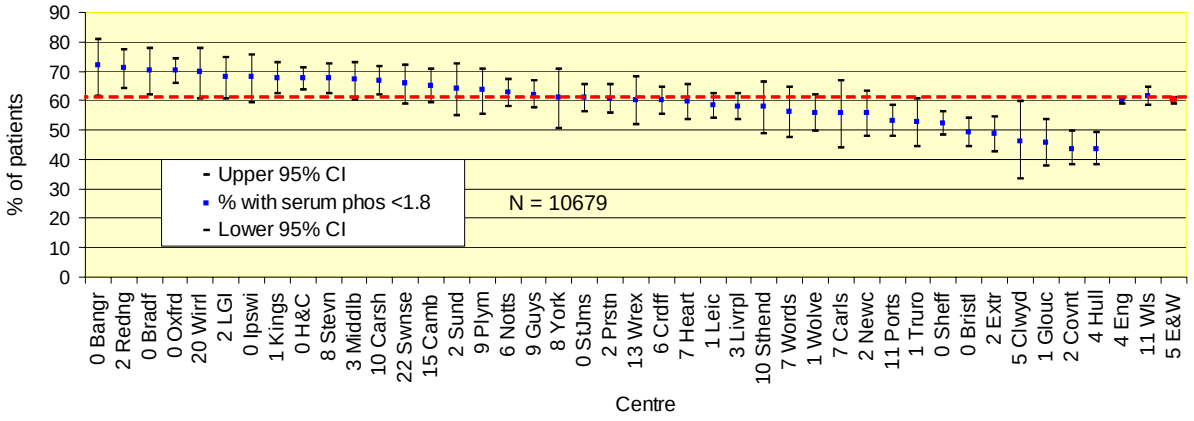


Figure 9.1. Percentage of dialysis patients in RA range for serum phosphate

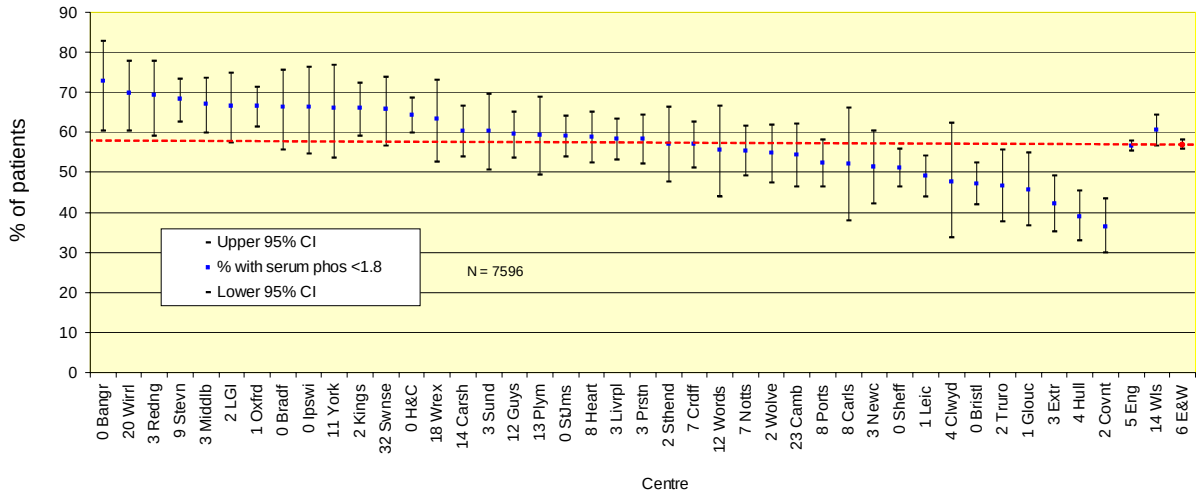


Figure 9.2. Percentage of HD patients in RA range for serum phosphate

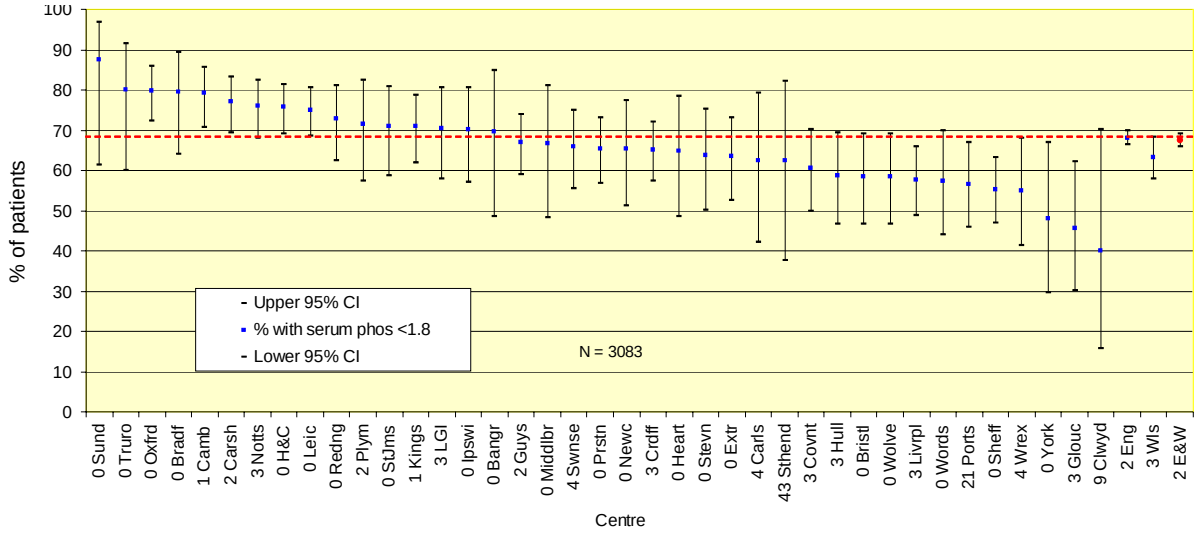


Figure 9.3. Percentage of PD patients in RA range for serum phosphate

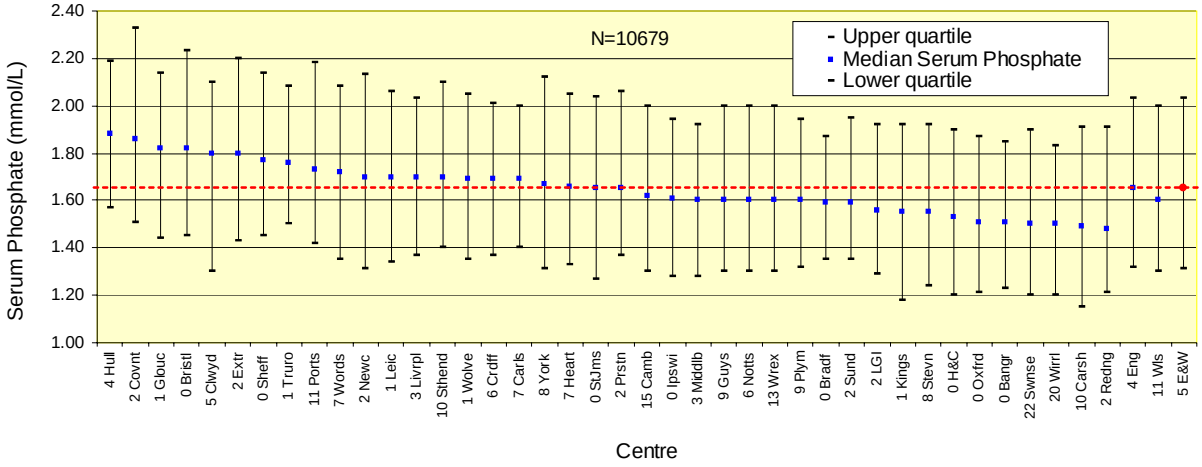


Figure 9.4. Median serum phosphate mmol/L: dialysis patients

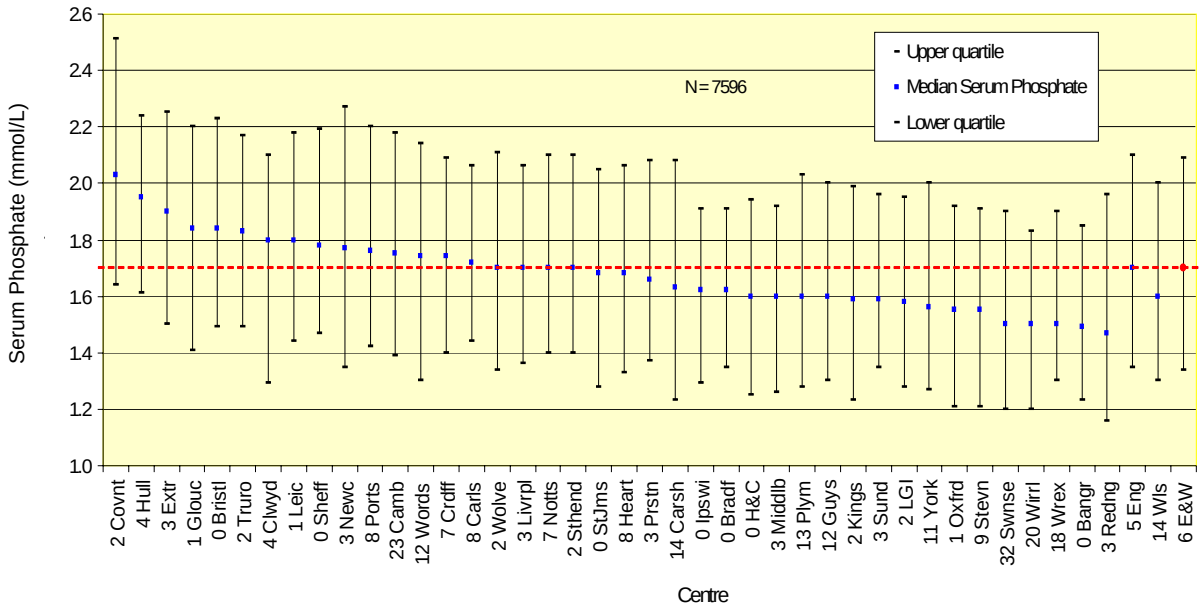


Figure 9.5. Median serum phosphate mmol/L: HD patients

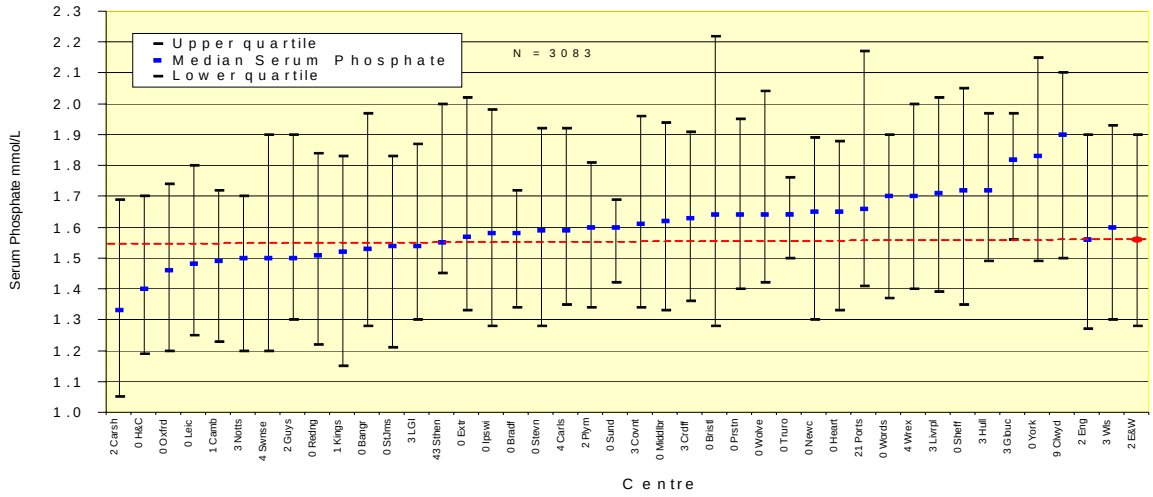


Figure 9.6. Median serum phosphate mmol/L: PD patients

does not have detailed data on the means used to attempt serum phosphate control in individual patients or renal units. A significant number of patients use Alucaps as a phosphate binder, especially if there is a tendency towards hypercalcaemia. This drug will shortly cease to be available in the UK, which will reduce the therapeutic armamentarium, and will have enormous cost implications in patients who cannot take calcium containing phosphate binders. This will put further pressure on the ability of renal units to effect good serum phosphate control.

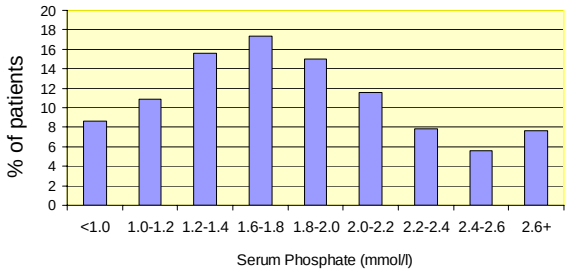


Figure 9.7. Distribution of serum phosphate: all dialysis

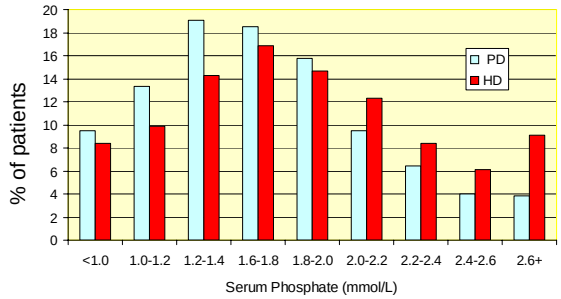


Figure 9.8. Distribution of serum phosphate by PD and HD

The distribution of serum phosphate values for all dialysis patients is shown in Figure 9.7. The differences between HD and PD patients are illustrated in Figure 9. 8.

Figure 9.9 shows the change over 5 years in the mean serum phosphate in all patients from the 19 units who have contributed to the Registry throughout that time. Change has been very small with a fall from 1.74 mmol/L to 1.70 mmol/L for patients on HD and 1.67 mmol/L to 1.56 mmol/L for patients on PD.

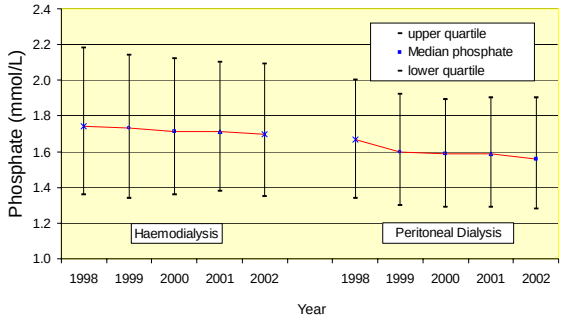


Figure 9.9. Change in median phosphate 1998–2002

Serum calcium

The Renal Association Standard states:

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

As ever, comparative audit in this area is difficult if not impossible. This is largely because of differences in analytical methods between units, and even between satellite units managed by one clinical team. The main problems are:

1. Different methods in analysing serum albumin, particularly the changing use of the BCG and BCP methods, which are not directly comparable in patients with renal failure (see the Registry reports 1999–2002).
2. Different mathematical methods being applied to correct serum calcium for serum albumin concentration.

Consequently, there have been suggestions that the uncorrected calcium should be used for comparative audit. Although all units measure this and hence the data are complete, the Renal Association Standard is for the corrected serum calcium (2.2–2.6 mmol/L).

In previous years, the Registry has uncorrected each unit's corrected calcium using the renal unit's correction formula, and then recorrected the calcium with a single correction formula. This use of a single correction formula allowed a degree of standardisation, but was still susceptible to the problems of serum albumin measurement. Unfortunately, not all units have reported their formula, so

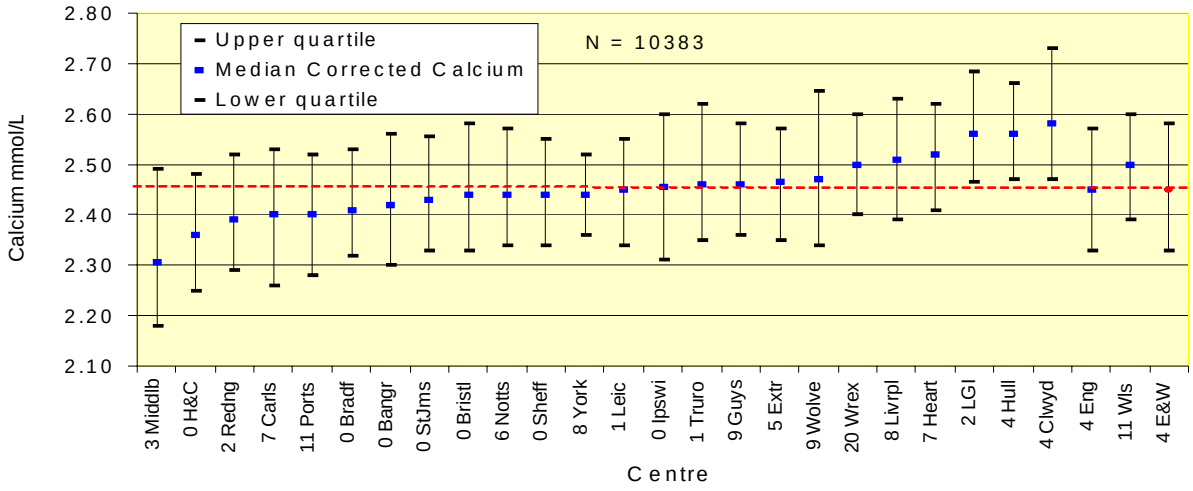


Figure 9.10. Median corrected calcium by centre: dialysis

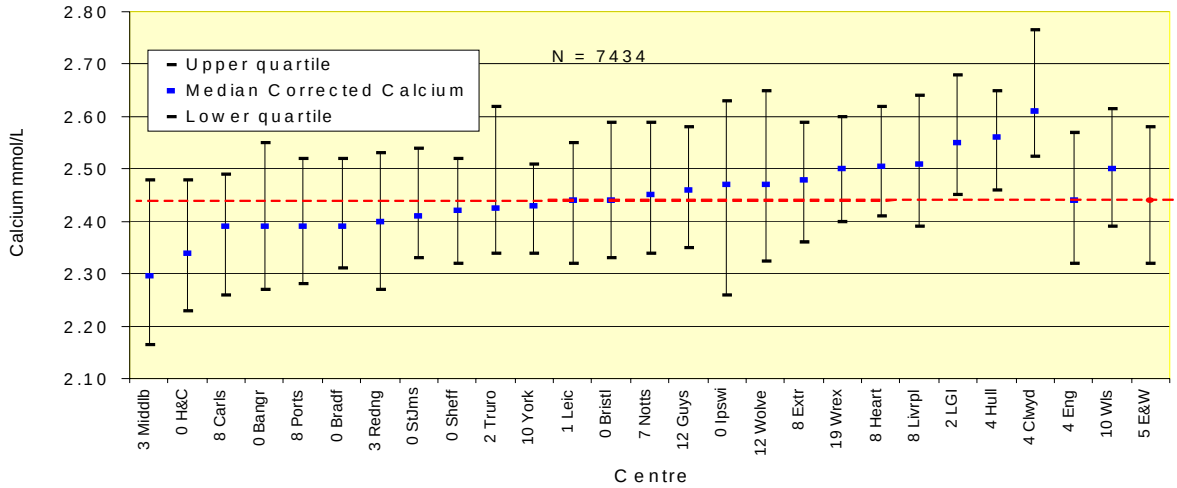


Figure 9.11. Median corrected calcium by centre: HD

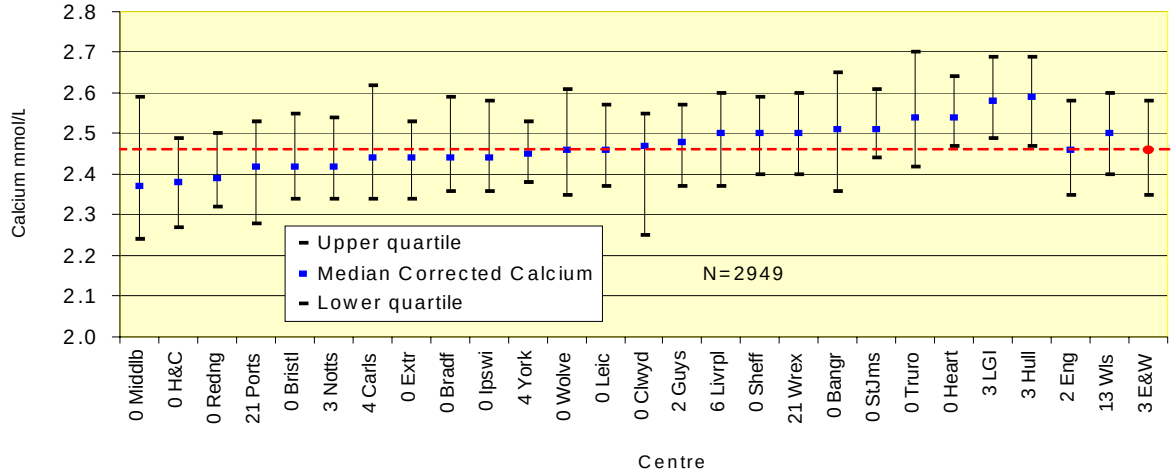


Figure 9.12. Median corrected calcium by centre: PD

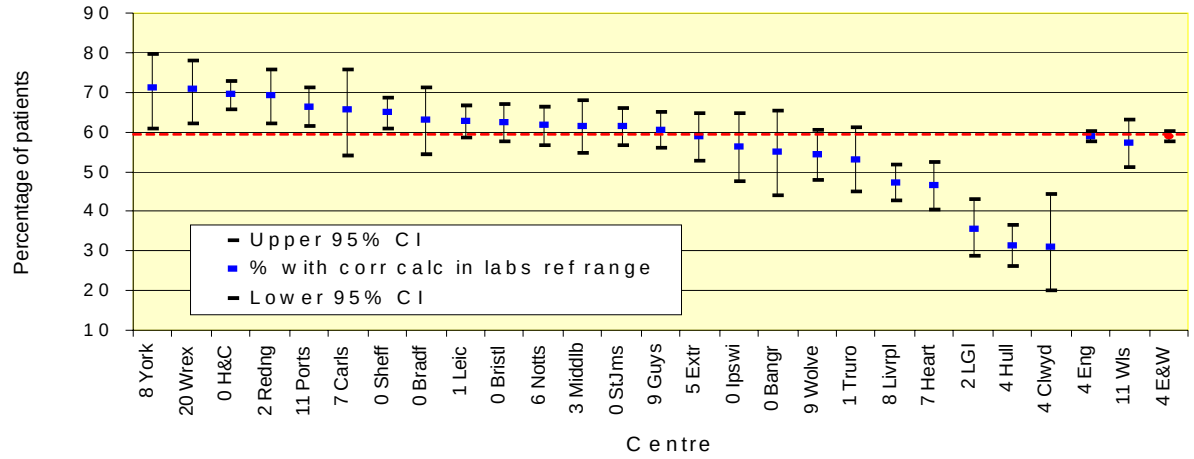


Figure 9.13. Percentage of patients with corrected calcium within 2.2 to 2.6 mmol/L: dialysis

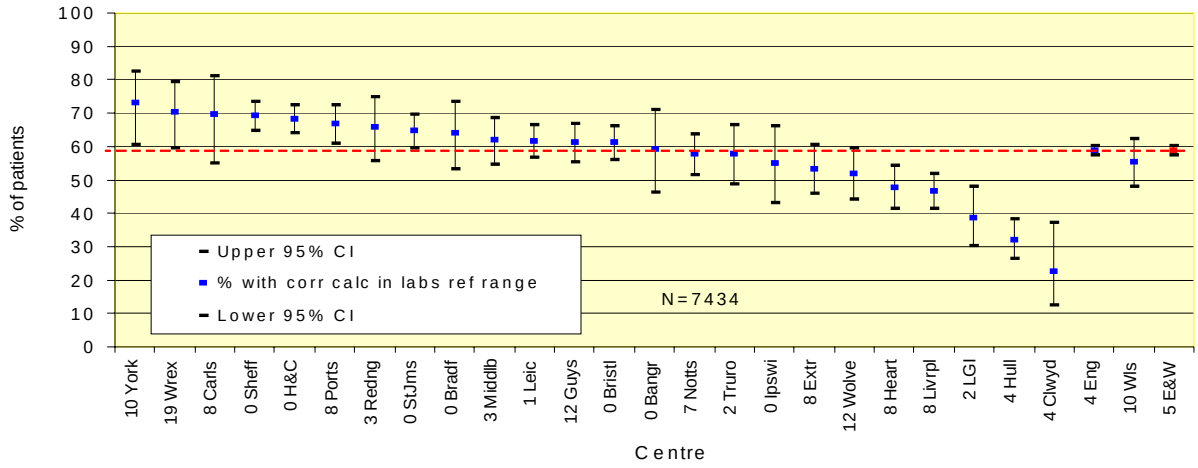


Figure 9.14. Percentage of patients with corrected calcium within 2.2 to 2.6 mmol/L: HD

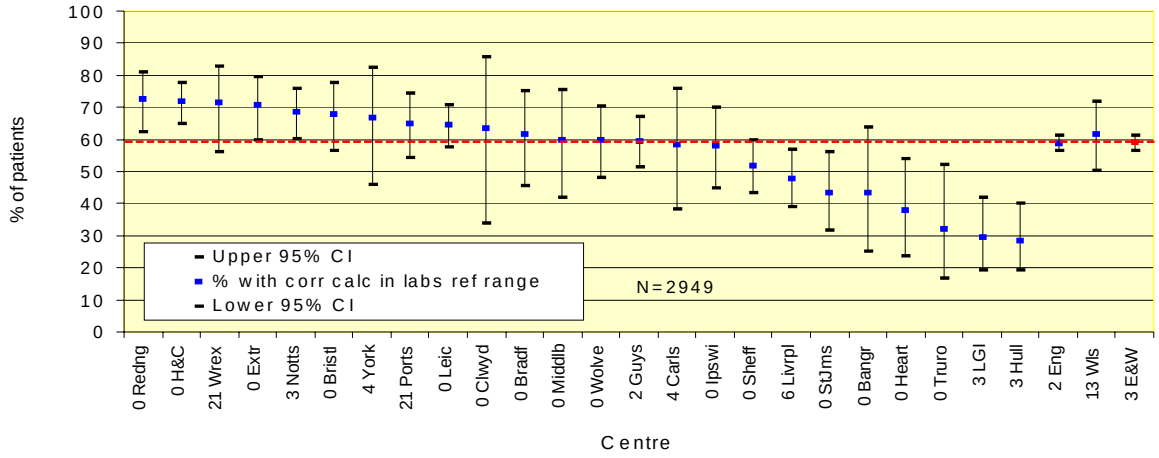


Figure 9.15. Percentage of patients with corrected calcium within 2.2 to 2.6 mmol/L: PD

even standardisation in this way has not been possible this year.

Since nephrologists in each unit will be making clinical decisions based on their local corrected calcium results, these data are in some sense the most valid. Such data allow audit of how well a unit is achieving what it sets out to achieve. Whether a corrected serum calcium of, say, 2.4 mmol/L in Cardiff is the same as a corrected serum calcium of 2.4 mmol/L in Bristol is unknown.

Only 24 units have reported adequate percentages of their own corrected calciums so the data are incomplete. These data are illustrated in Figures 9.10 to 9.15.

The median corrected calcium lies just under 2.5 mmol/L for all units and all modalities: it appears a little higher in PD patients than in those on haemodialysis, but this is not statistically significant. Hypocalcaemia is much less of a clinical problem than hypercalcaemia, perhaps related to the prevalence of calcium based phosphate binders in current use.

Serum parathyroid hormone

The Renal Association Standard states:

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

Comparison of serum PTH values from different units is difficult. Analysis from previous years has shown that most laboratories have either taken their upper limit of normal from textbooks, or the assay manufacturer's leaflet (usually derived from USA population). This leads to variations in the quoted normal range. In addition several different assays are in use. The assays used and variations in quoted normal range are listed at the end of this chapter in Table 9.2. To enable some form of comparative audit, the Registry has converted all results to the pmols/L range, and chosen an upper limit of 4 times the median upper lab value.

The Renal Association Standard for serum PTH in dialysis patients gives an upper limit only – four times the upper limit of normal for a laboratory, and does not suggest that there is a clinical risk associated with over suppression of PTH. The median PTH for all patients lies well within the standard although the distribution is wide (Figures 9.16 to 9.21). There seems little difference in absolute PTH between PD and haemodialysis patients. The spread of PTH levels is remarkable however, with some

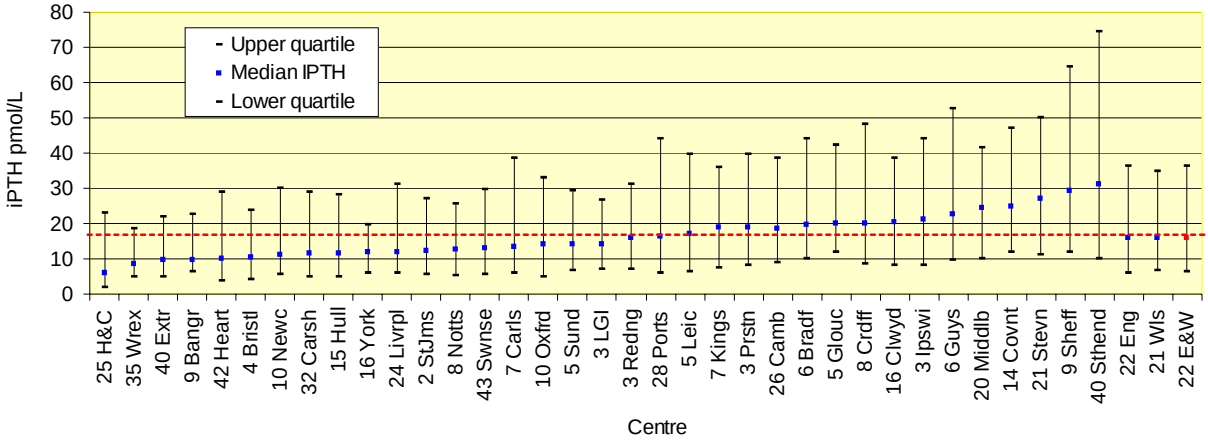


Figure 9.16. Median iPTH by centre: dialysis

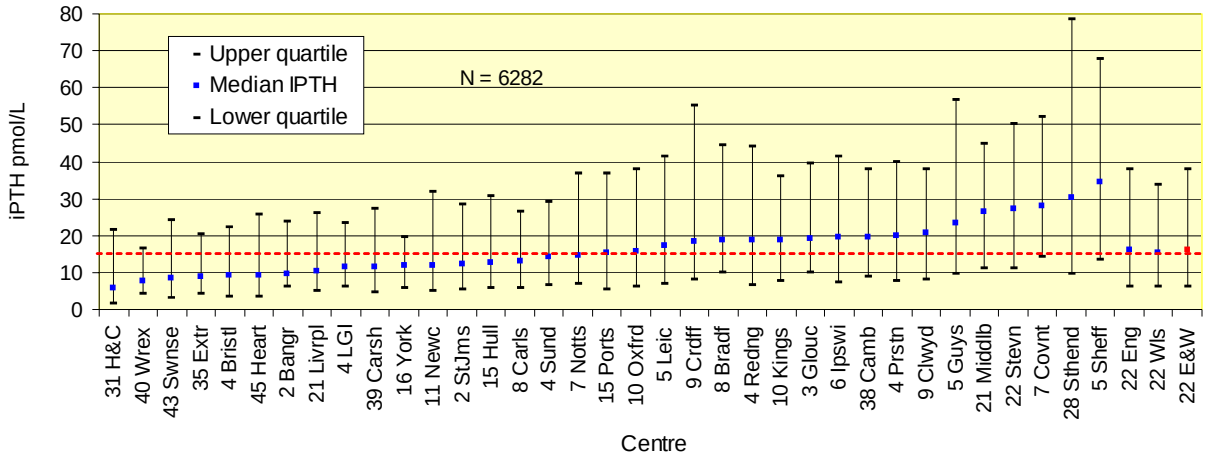


Figure 9.17. Median iPTH by centre: HD

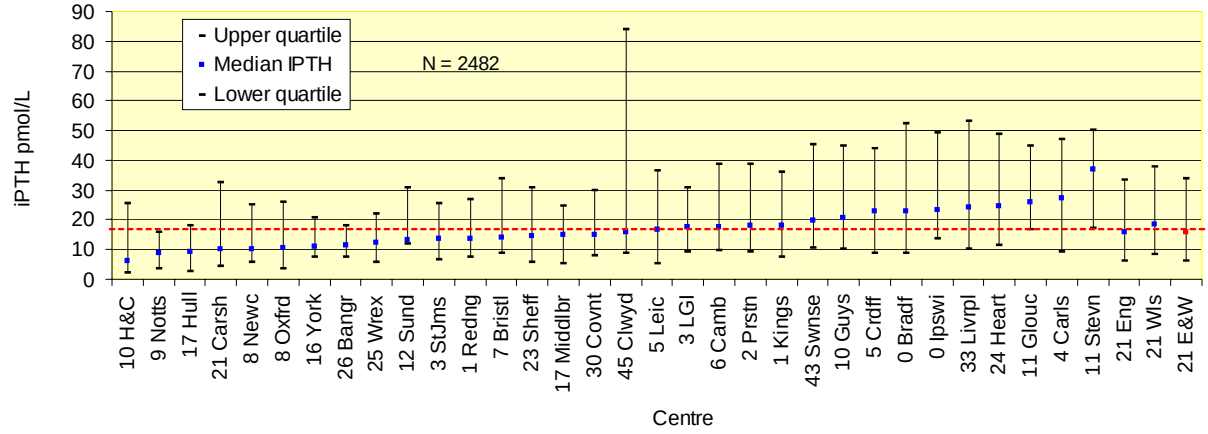


Figure 9.18. Median iPTH by centre: PD

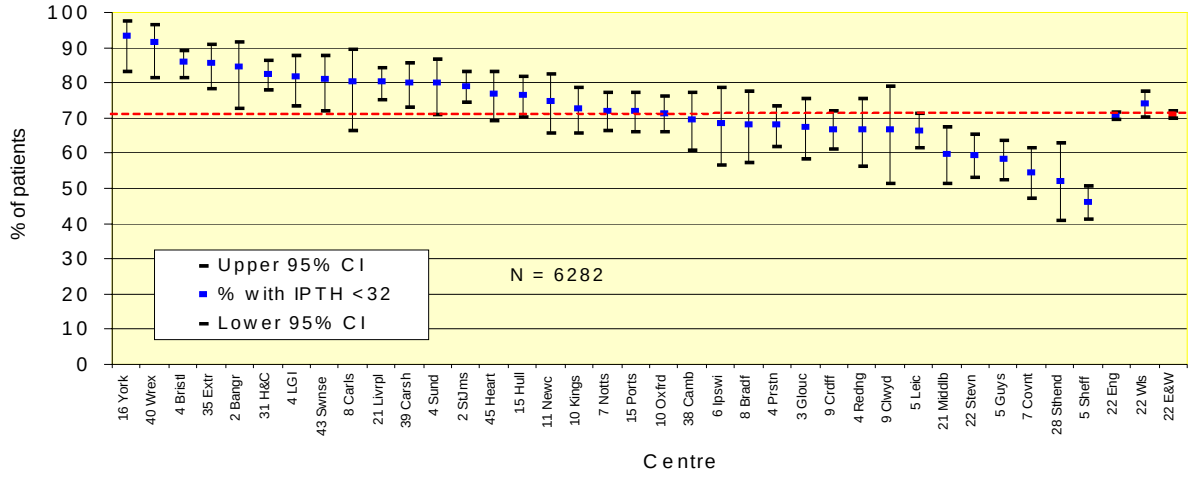


Figure 9.19. Percentage of patients with iPTH < 32 pmol/L: dialysis

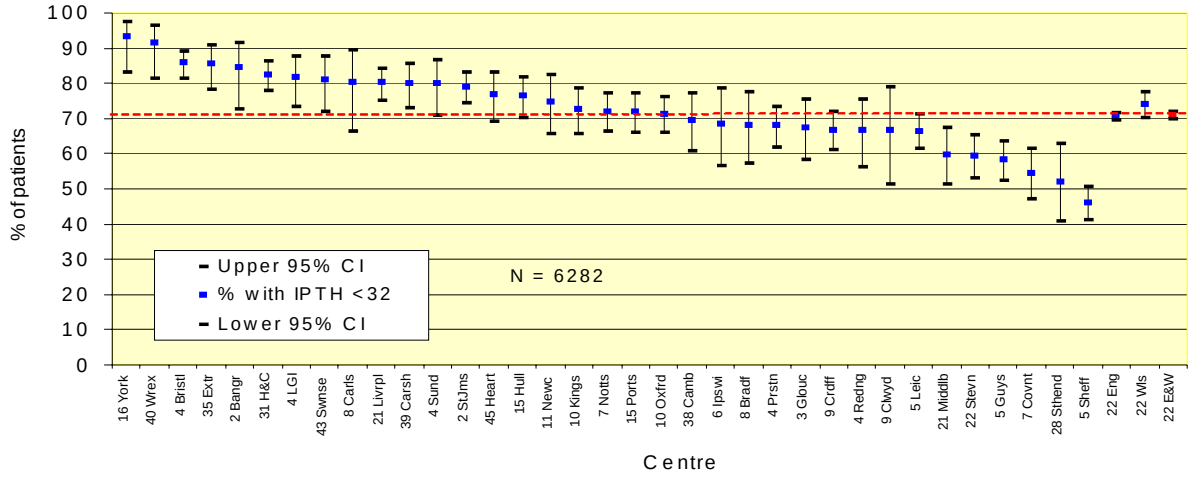


Figure 9.20. Percentage of patients with iPTH < 32 pmol/L: HD

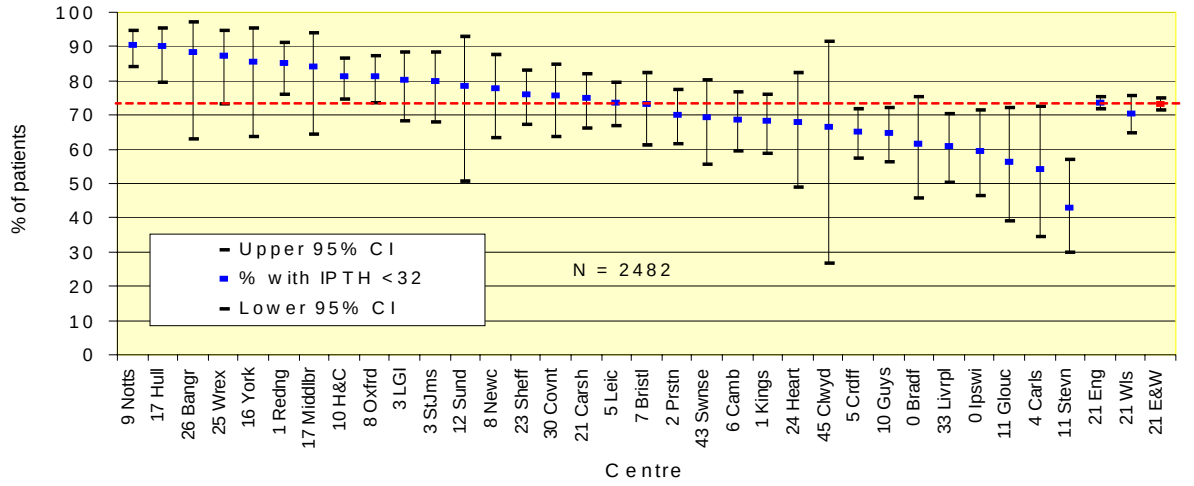


Figure 9.21. Percentage of patients with iPTH < 32 pmol/L: PD

units – York and Wrexham – achieving over 90% compliance with the standard, while at the other end of the scale, only 50% compliance is achieved.

Calcium/phosphate product

The Renal Association has no standard for the serum calcium phosphate product.

The Renal Association has no standard for the serum calcium phosphate product, but the DOQI guidelines recommend the product should be less than 4.4 $mmol^2/L^2$ (= 55 mg^2/dl^2). A little over half of our reporting units achieve this as a median but the range is wide. Control is better on PD, with 71% of patients achieving the standard, than HD (62%) ($p < 0.01$) (Figures 9.22 and 9.23).

Serum phosphate and survival

Registry data show that poor phosphate control and poor calcium phosphate product control correlate with poor survival, although they are clearly not entirely independent variables. However, differing calcium methodology confuses this somewhat. This emphasises the importance of this area of metabolism with the links to cardiovascular disease being potentially more important than damage to the skeleton.

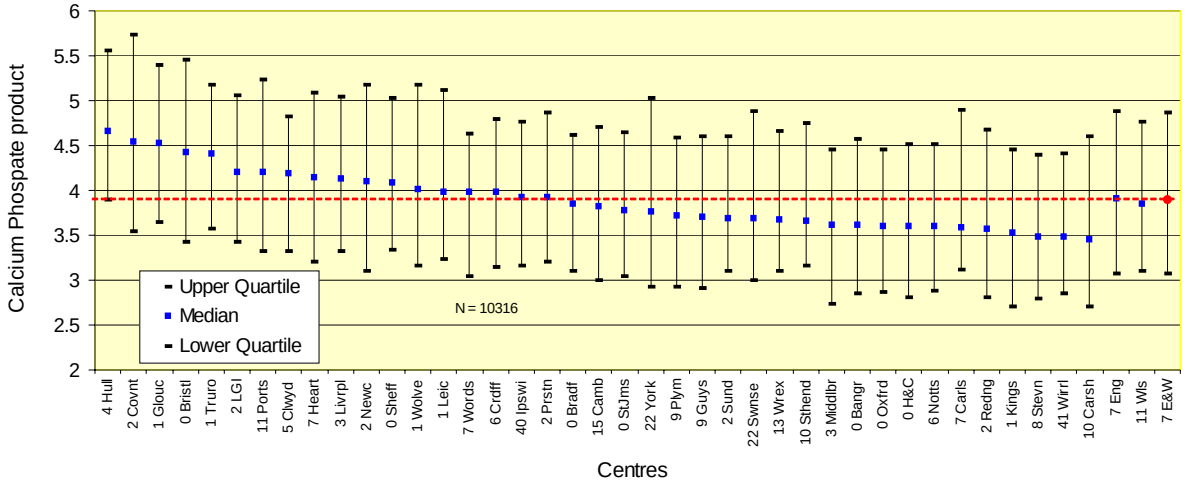


Figure 9.22. Calcium phosphate product in dialysis patients

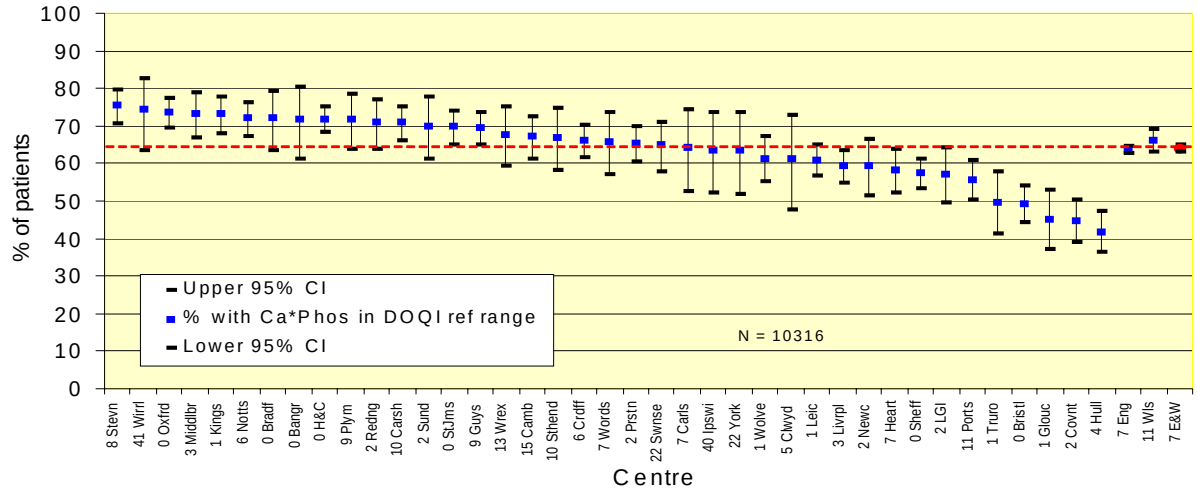


Figure 9.23. Compliance with the calcium phosphate DOQI guidelines in dialysis patients

Figure 9.24 shows the increased hazard of death with increasing serum phosphate. This has not been previously analysed by modality, but the risk of death with increasing phosphate is the same for both HD and PD. The non-linear association with survival was significant for both HD and PD ($p = 0.003$ and $p = 0.016$ respectively).

As serum albumin is an inverse inflammatory marker it has been shown in many studies to be closely linked with patient survival. Analysis of uncorrected calcium and survival shows a strong inverse correlation with survival as low uncorrected calcium is linked to low serum albumin levels ($p \leq 0.009$ HD, $p \leq 0.004$ PD). Using an albumin correction factor for calcium (BCG methodology only) this correlation with survival disappears ($p = 0.95$ HD and PD). Although the suggested correction formulae for BCP and BCG albumin methodologies are identical, the albumin values are very different so results have been analysed separately.

The uncorrected calcium phosphate product and hazard of death show a similar relationship for both HD and PD. Treated non-linearly, there is a significant effect of calcium/phosphate product on survival in HD patients and to a lesser extent PD (HD $p=0.007$, PD $p=0.009$). After adjusting for albumin, the risk increases for PD patients (Figures 9.25 and 9.26).

Laboratory methodologies

The methodologies used in each laboratory are listed in Tables 9.1 and 9.2.

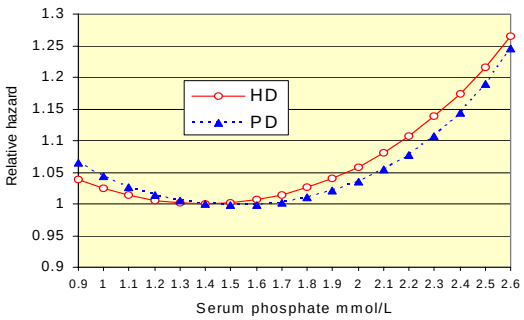


Figure 9.24. Serum phosphate and relative hazard of death by modality

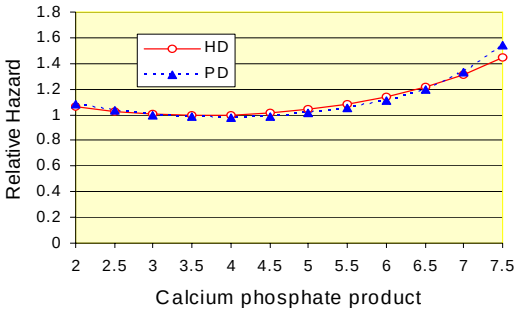


Figure 9.25. Uncorrected calcium phosphate product and relative hazard of death

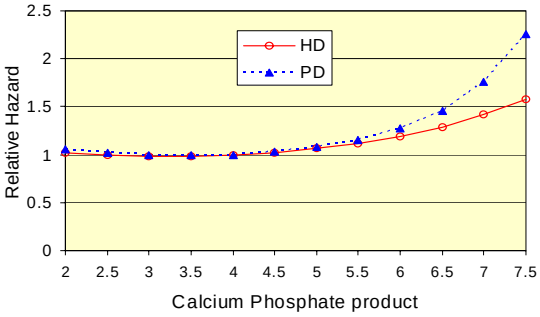


Figure 9.26. Corrected calcium (BCG albumin) phosphate product and relative hazard of death

Table 9.1. Serum calcium methodology

Laboratory	Method	Uncorrected Ref Range	Corrected Ref Range	Formula
Birmingham Heartlands	CPC	2.05–2.60	N/A	+0.025(40 –Alb)
Bradford	CPC	Not Reported	2.15–2.55	+(40 – Alb/40)
Cardiff (UHW) New analyser	Arsenazo	2.20–2.60	2.20–2.60	+0.02(40 – Alb)
Carlisle/Cumberland	Arsenazo	2.10–2.60	2.10–2.60	+0.02(40 – Alb)
Carshalton, St Helier	CPC	2.20–2.60	2.20–2.60	+0.02(40 – Alb)
Gloucester	Electrode	2.13–2.63	2.13–2.63	+0.02(40 – Alb)
Hull	Electrode	2.20–2.60	2.20–2.60	+(–0.016 × Alb) + 0.59
Leicester (LRI)	Arsenazo	2.10–2.60	2.10–2.60	+0.02(40 – Alb)
Leeds St James	CPC	2.20–2.60	2.20–2.60	+0.016(46 – Alb)
Liverpool (Royal)	CPC	2.20–2.60	2.20–2.60	+0.003(40.4 – Alb)
Nottingham	Arsenazo	2.40–2.80	N/A	+0.017(43 – Alb)
Plymouth Derriford	CPC	2.12–2.55	2.12–2.55	+0.025(40 – Alb)
Portsmouth (Queen Alex)	CPC	2.15–2.60	2.15–2.60	–(Alb × 0.017) + 0.70
Reading (Royal Berkshire)	Arsenazo	2.10–2.55	2.10–2.55	+1 – (albumin/41)
Southend*2 instruments in use Beckman& Dax	CPC	2.05–2.65	2.10–2.60	+(40 – Alb)0.02
Stourbridge/Wordsley (analysed at Dudley)	Arsenazo	2.20–2.60	2.20–2.60	+0.02(40 – Alb)
Sunderland	CPC	2.12–2.65	N/A	N/A
York	CPC	2.10–2.60	2.10–2.60	–(Alb × 0.25) +1
Wolverhampton	Arsenazo	2.17–2.66	2.17–2.66	+1 – (alb/40)
Wrexham	Electrode	2.10–2.65	2.10–2.65	–((0.071 × A3b) + 0.692)

* Conversion factor for calcium: mg/dl = mmol/L × 4s

Table 9.2. Serum phosphate and PTH methodologies

	Phosphate (mmol/L)		PTH	
Laboratory	**Method**	**Ref Range**	**Method**	**Ref Range**
Birmingham Heartlands	PMb	0.80–1.45	Elecsys (P Clark)	30–400ng/ml
Bradford	PMb	0.80–1.31	Nichols (LGI)	<65 ng/ml
Cardiff (UHW) New analyser	PMb	0.80–1.45	Nichols	0.9–5.4 pmol/L
Carlisle/Cumberland	PMb	0.90–1.50	Elecsys	15 – 65 ng/L
Carshalton, St Helier	PMb	0.80–1.40	DPC	3–48 ng/L
Gloucester	PMb	0.82–1.55	Nichols	0.9–5.4 pmol/L
Hull	PMb	0.70–1.50	DPC	7–53 ng/ml
Leicester (LRI)	PMb	0.80–1.40	DPC	1.3–7.6 pmol/L
Leeds St James	PMb	0.80–1.30	Nichols	11–55 ng/ml
Liverpool (Royal)	PMb	0.70–1.40	Nichols	1.1–6.9 pmol/L
Nottingham	PMb	0.80–1.40	DPC	8–78 ng/ml
Plymouth Derriford	PMb	0.80–1.40	DPC	12–72 ng/L
Portsmouth (Queen Alex)	PMb	0.80–1.50	DPC Immulite	<4.7 pmol/L
Reading (Royal Berkshire)	PMb	0.81–1.45	DPC	0.7–5.6 pmol/L
Southend*2 instruments in use Beckman& Dax	PMb	0.80–1.45	Roche elecys	1.05–6.9 pmol/L
Stourbridge/Wordsley (analysed at Dudley)	PMb	0.80–1.40	DPC	0.45–5.0 pmol/L
Sunderland	PMb	0.80–1.40	DPC	1.3–7.6 pmol/L
York	PMb	0.80–1.40	Nichols	10–60 ng/L
Wolverhampton	PMb	0.80–1.40	DPC	0.76–7.42 ng/L
Wrexham	PMb	0.80–1.40	Nichols	0.9–5.4 pmol/L

* Conversion factor for phosphate: mg/dl = mmol/L × 3.1
PMb = Phospho-molybdate method

References

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2. Lowrie E. G., Lew N. L. Death risk in hemodialysis patients: the predictive value of commonly measured variables and an evaluation of death rate differences between facilities. *Am J Kidney Dis*. 1990;15(5):458–82.
3. Block G. A., Hulbert-Shearon T. E., Levin N. W., Port F. K. Association of serum phosphorus and calcium x phosphate product with mortality risk in chronic hemodialysis patients: a national study. *American Journal of Kidney Diseases*. 1998;31(4):607–17.

Chapter 10: Serum Albumin and Serum Bicarbonate

Summary

- The method of measurement of serum albumin has to be taken into account in interpreting the differences between centres and changes with time. Centres using bromocresol green (BCG) method have higher serum albumins compared to centres using bromocresol purple (BCP) method.
- For haemodialysis patients, the median serum albumin was 38 g/L (BCG) and 34 g/L (BCP). 79% (BCG) and 83% (BCP) of the patients had serum albumin above the lower limit recommended in the Standards document.
- Peritoneal dialysis patients had lower serum albumin compared with haemodialysis patients; the median serum albumin was 36 g/L (BCG) and 31 g/L (BCP). Approximately 60% of peritoneal dialysis patients had serum albumin above the lower limit recommended in the Standards document.
- Comparison of bicarbonate data is difficult due to different laboratory methodologies and non-clinical factors such as the time delay in transport to laboratories.
- For haemodialysis patients, the mean value for percentage of patients in a renal unit with pre-dialysis serum bicarbonate below 22 mmol/L was 15% (range 3–62%).
- For peritoneal dialysis, the mean value for percentage of patients in a renal unit with serum bicarbonate below 25 mmol/L was 24% (range 8–64%).

Albumin

Previous reports from the UK Renal Registry and other publications[1,2,3] have recognised the difficulties in using serum albumin as an audit measure in patients with renal failure. Serum albumin concentration is influenced significantly by the dye used in the assay method. Bromocresol green (BCG) is the more commonly used method but tends to overestimate serum albumin when compared with antibody-based methods, especially at lower levels of serum albumin as are often seen in RRT patients. Bromocresol purple (BCP) may underestimate serum albumin in uraemia.[3] In addition, laboratories using the same methods often quote different normal ranges. For this report, centres have been separated by methodology of albumin measurements.

The Renal Association Standards document 3rd edition[4] recognises the importance of serum albumin as a marker of outcome, but does not recommend setting an audit standard for serum albumin. The Standards document continues to recommend collecting data for serum albumin, as serial measurements may be useful for monitoring individual patients. A careful search for causative factors (e.g. inflammation/infection, tissue ischaemia/necrosis, protein losses, volume overload) is recommended if serum albumin is <35g/L (BCG method) or <30g/L (BCP method).

Haemodialysis

The median serum albumin ranged from 41 to 32g/L (Figure 10.1). As anticipated, centres using the BCP method generally had lower albumin concentrations (BCG median 38g/L v. BCP median 34g/L). Overall, 83% of patients had serum albumin above the lower limit recommended in the Standards

document for BCP method and 79% for BCG. However, this varied from 46 to 93% among units (Figure 10.2).

Peritoneal dialysis

Serum albumin is generally lower in CAPD patients probably due to peritoneal protein losses. The median serum albumin ranged from 39 to 29g/L (Figure 10.3). The effect of using the BCP method was even more striking in PD patients. Ten out of 12 units using this method had median values below the lowest median for BCG. The E&W overall median concentration for the BCG method was 36g/L compared to 31g/L for BCP. The data indicate how difficult it is to keep serum albumin above the recommended minimum in patients treated by peritoneal dialysis. Approximately 40% of patients had serum albumin below the target concentration for either method: this varied from 21% to 65% among centres (Figure 10.4).

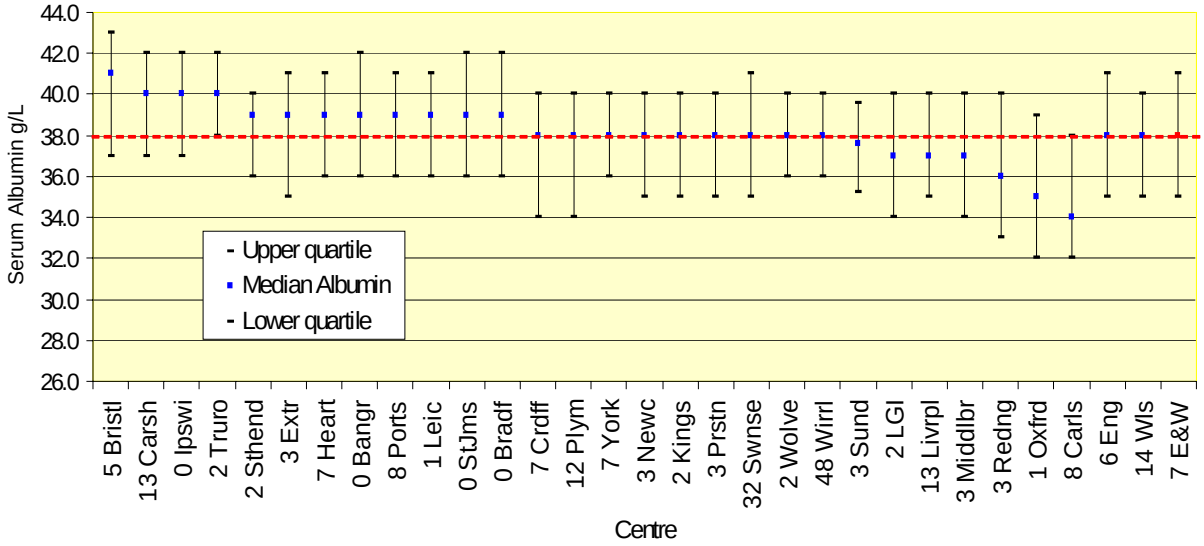

Figure 10.1a. Median serum albumin in HD patients (BCG)

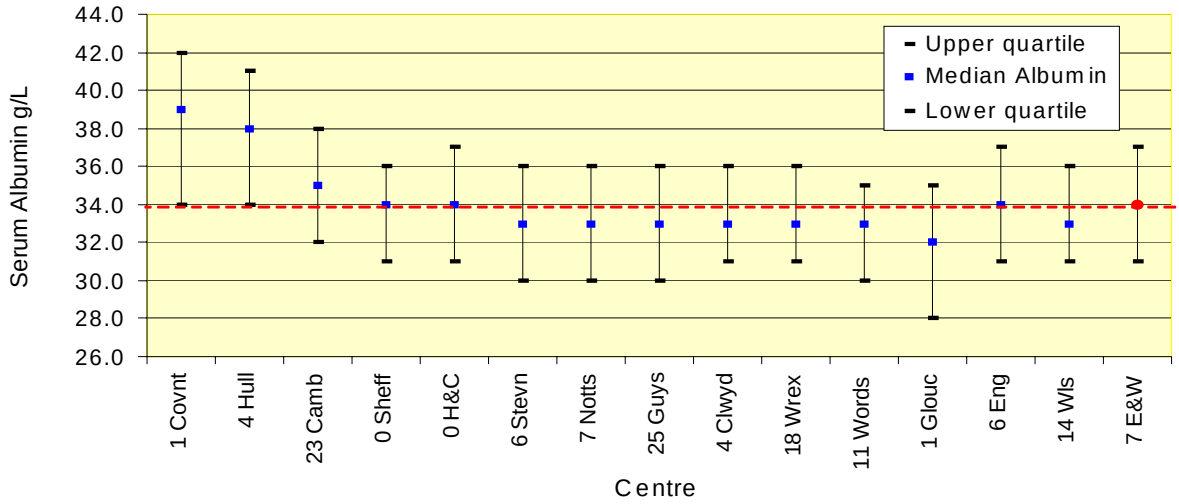

Figure 10.1b. Median serum albumin in HD patients (BCP)

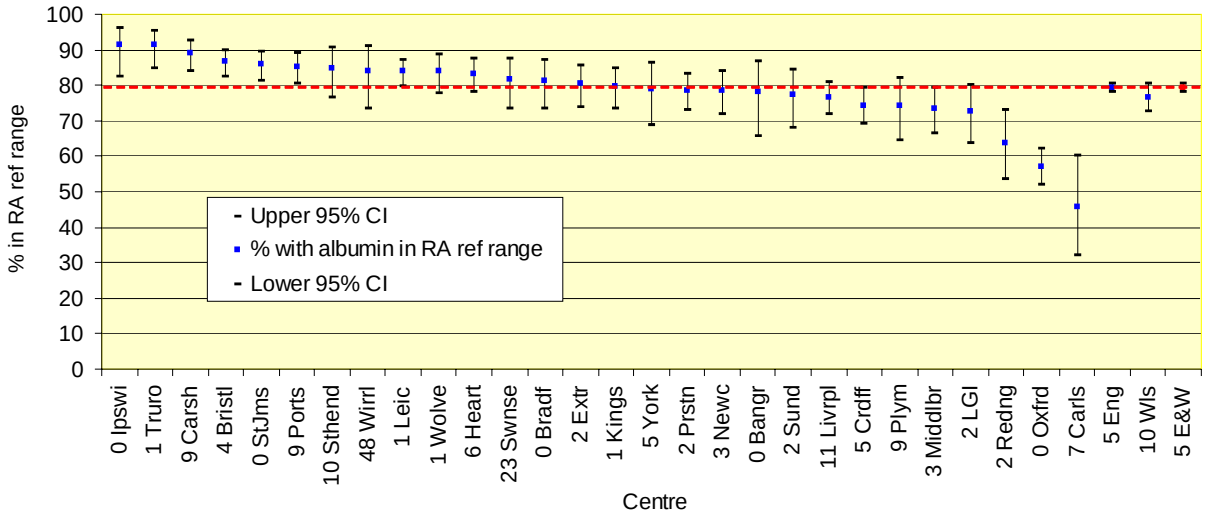

Figure 10.2a. Percentage of HD patients by unit with serum albumin >35g/L (BCG)

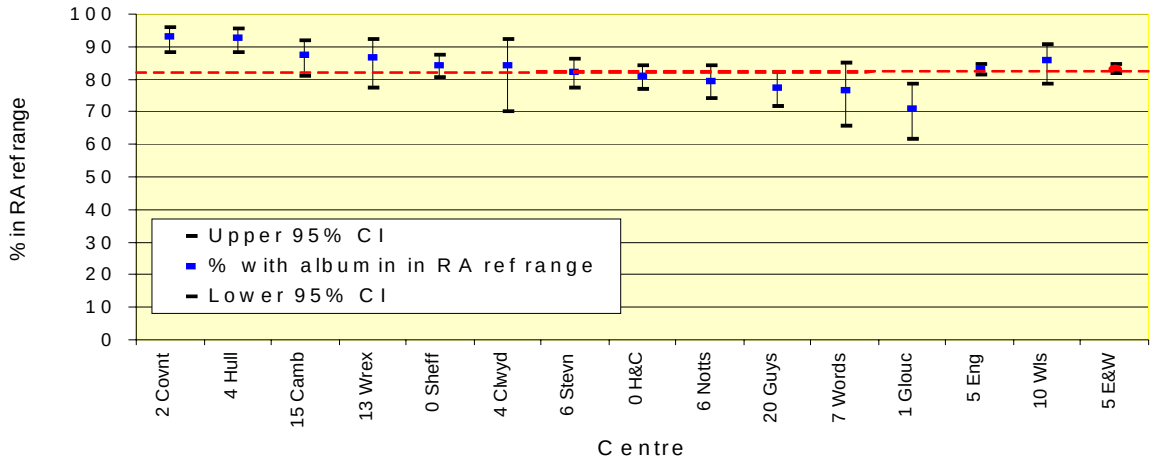

Figure 10.2b. Percentage of HD patients by unit with serum albumin >30g/L (BCP)

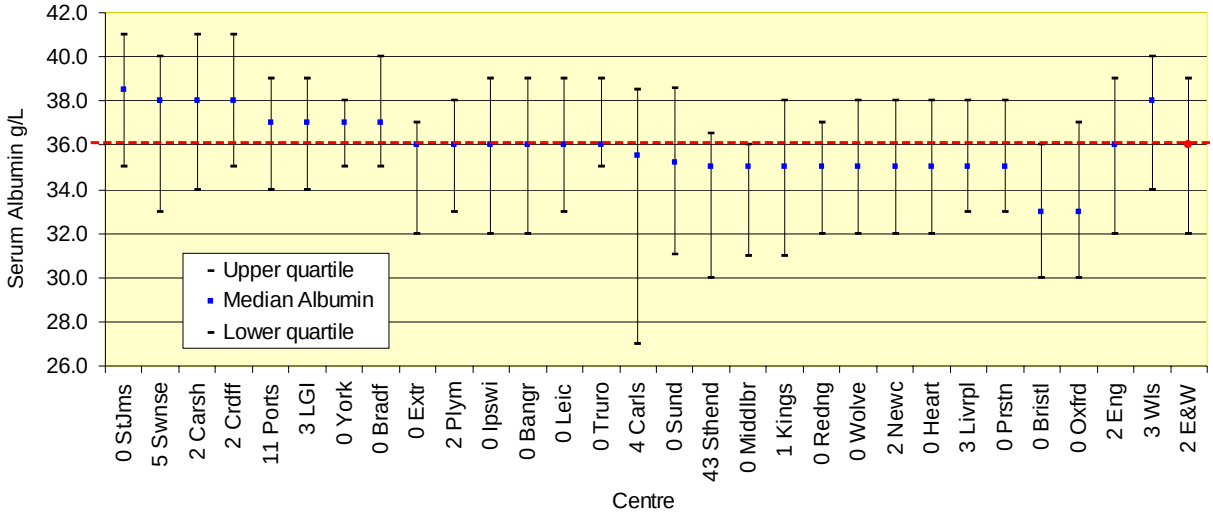

Figure 10.3a. Median serum albumin in peritoneal dialysis patients (BCG)

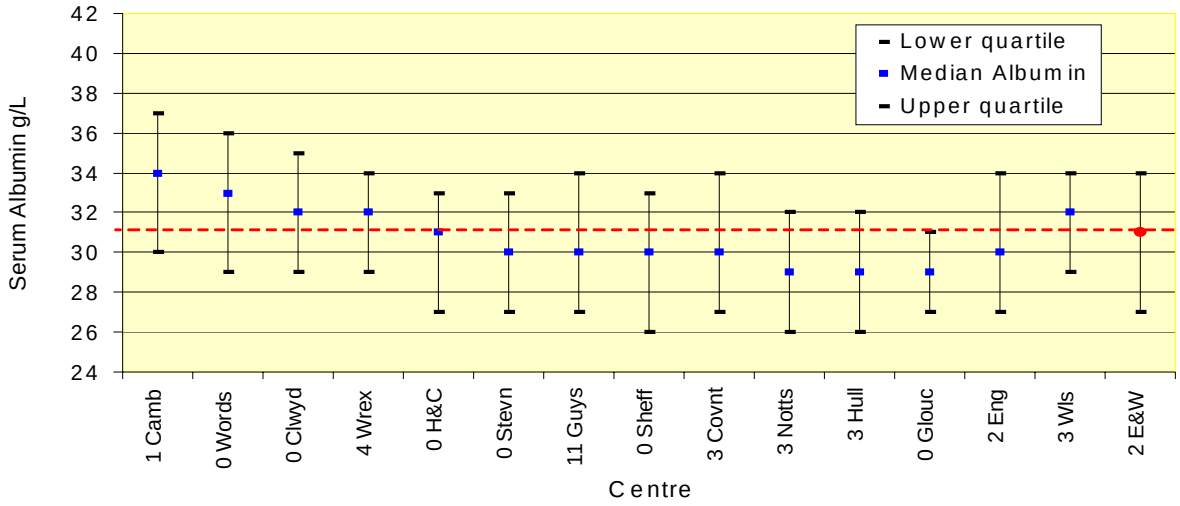

Figure 10.3b. Median serum albumin in peritoneal dialysis patients (BCP)

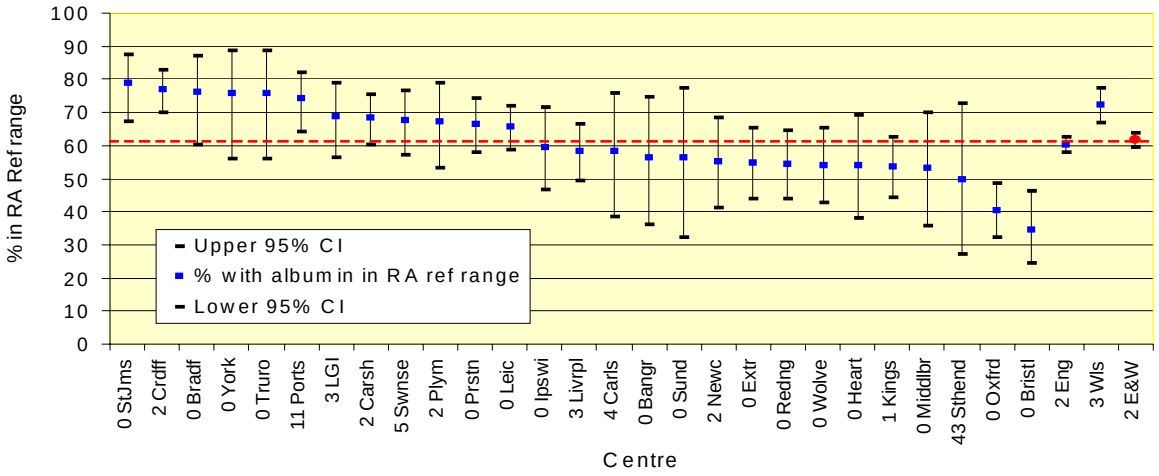

Figure 10.4a. Percentage of peritoneal dialysis patients by unit with serum albumin >35g/L (BCG)

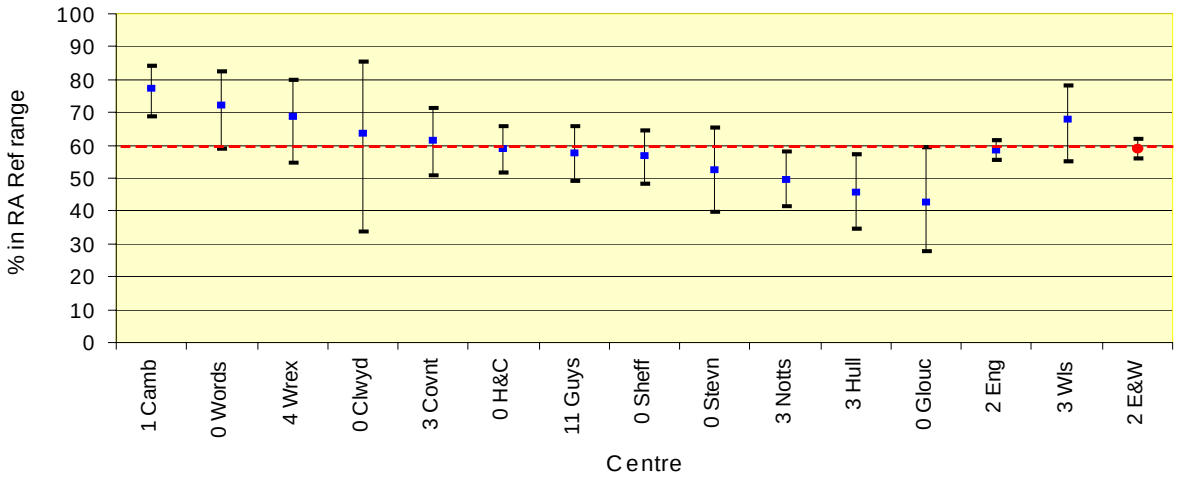

Figure 10.4b. Percentage of peritoneal dialysis patients by unit with serum albumin >30g/L (BCP)

Effect of time on treatment

Figure 10.5 demonstrates the effect of time on treatment on the percentage of patients with serum albumin in the target range for both haemodialysis and PD. Over time, on haemodialysis, the number of patients with higher serum albumin rises, probably due to reduced survival of patients with lower serum albumin. In contrast, over time on peritoneal dialysis, serum albumin tends to fall. Possible explanations are the cumulative effect of serum albumin losses via the peritoneum, repeated peritonitis and underdialysis on prolonged PD.

Bicarbonate

Comparative audit of serum bicarbonate among renal units is also hampered by non-clinical factors. Different methodologies are used in different laboratories, and even when methods are the same, different normal ranges may be used.[1] Delay in transport to the laboratories can lead to significant reductions in serum bicarbonate[5] and this is difficult to standardise. A small number of units had few data for serum bicarbonate, particularly for haemodialysis patients, suggesting that this was not collected on a routine basis.

The RA Standards document 3rd edition[4] recommended changes in the standards used for audit of serum bicarbonate for both haemodialysis and peritoneal dialysis patients.

The current recommendations are:

Serum bicarbonate before a HD session measured with minimal delay after venepuncture should be between 20 and 26mmol/L
For continuous peritoneal dialysis (CAPD) patients, serum bicarbonate measured with minimal delay after venepuncture should be between 25 and 29mmol/L

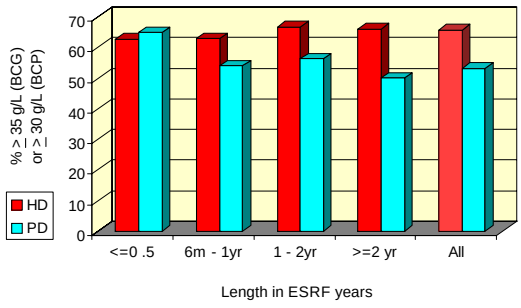

Figure 10.5. Changes over time on haemodialysis and peritoneal dialysis shown as percentage of patients with serum albumin ≥ 35g/L (BCG method) or ≥ 30g/L (BCP)

Haemodialysis

The median serum bicarbonate varied from 27mmol/L to 19mmol/L. The median value for all E&W patients was 23mmol/L (5–95% centile range 17–30) (Figure 10.6). The percentage of patients with serum bicarbonate below 22mmol/L predialysis ranged from 3 to 62% with a mean value of 15% (Figure 10.7).

A comparison of the units at each end of the scale suggests there must be a systematic difference accounting for the differences in acid base balance. This might be due to prescribed dialysis treatment (e.g. standard dialysis bicarbonate concentration) or measurement methods. Carshalton had the highest median value (27 mmol/L) with 53% of patients above the range 22–26mmol/L pre-dialysis indicating a significant number of alkalotic patients even at the start of dialysis. Informal enquiries indicated that 40% of patients at Carshalton are treated by on-line haemodiafiltration and that use of a higher bicarbonate dialysate concentration (40 mmol/L) is common (J Kwan, personal communication). In contrast, the Nottingham data indicate poor control of acidosis with the majority of patients (74%) with pre-dialysis bicarbonate less than the lower limit of normal range (19 mmol/L). The Nottingham laboratory had the lowest reference range in the 2002 report, but it is unlikely that this alone explains these variations. Delays in transportation and handling in the laboratory

may be additional factors (S Roe, R Burden, personal communication) but further detailed comparisons between units are required to understand these differences.

Peritoneal dialysis

Again there are large differences in control of acidaemia across the UK with median values varying from 31 to 23 mmol/L, with a median for E&W of 27 mmol/L (5–95% centile range 21–33) (Figure 10.8). The percentage of patients with serum bicarbonate below 25mmol/L ranged from 8 to 64% with a mean value of 24% (Figure 10.9). The precise influence of attempts to control acidaemia more aggressively by prescription of oral bicarbonate supplements or other strategies is unknown.

Conclusions

Continued difficulties with albumin and bicarbonate measurement methodologies, and with the normal ranges, make it difficult to draw any definitive conclusions from comparative audit of these parameters.

However, serial albumin measurements performed in a single laboratory are still useful markers in individual patients, mainly as a negative acute phase reactant. Further progress will only be made by standardisation of albumin measurement methods, and by advances in diagnosis and treatment which lead to correction of hypoalbuminaemia and parallel improvement in clinical outcomes.

There is a huge variation in the control of acidaemia across UK nephrology centres.

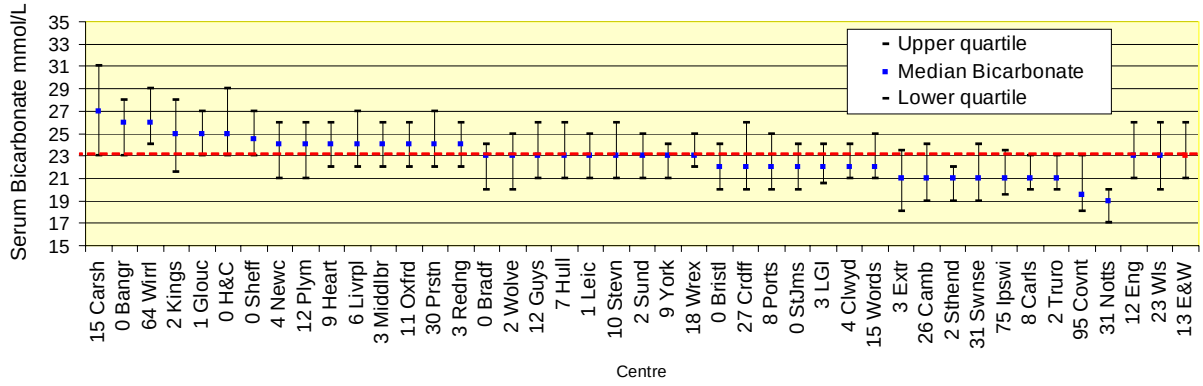

Figure 10.6. Serum bicarbonate in haemodialysis patients (median and quartile values)

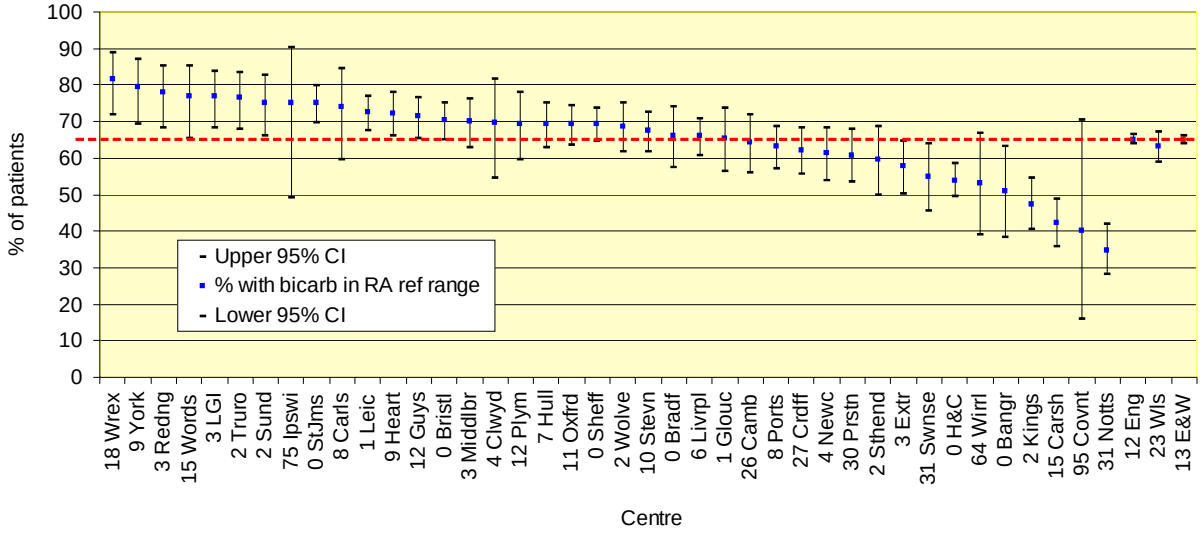

Figure 10.7. Percentage of haemodialysis patients with pre-dialysis serum bicarbonate in range 20–26mmol/L

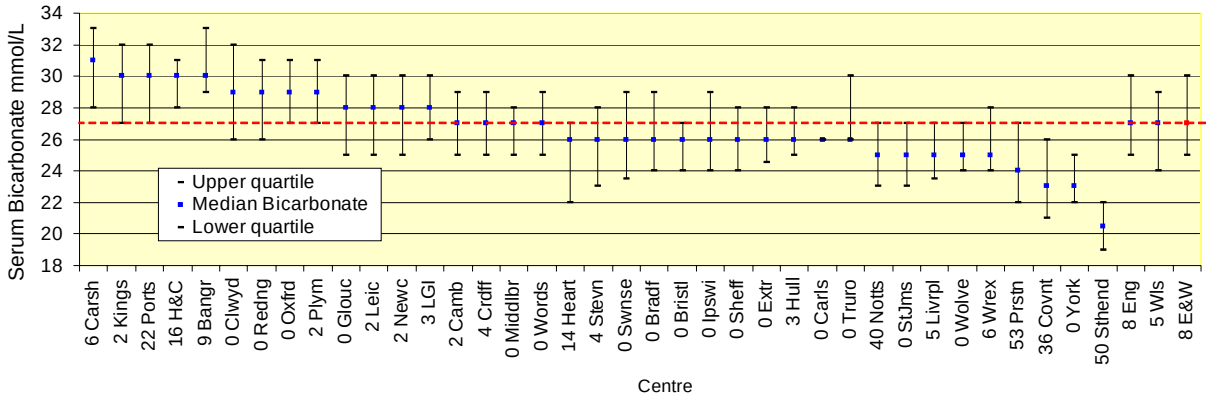

Figure 10.8. Serum bicarbonate in peritoneal dialysis patients (median and quartile values)

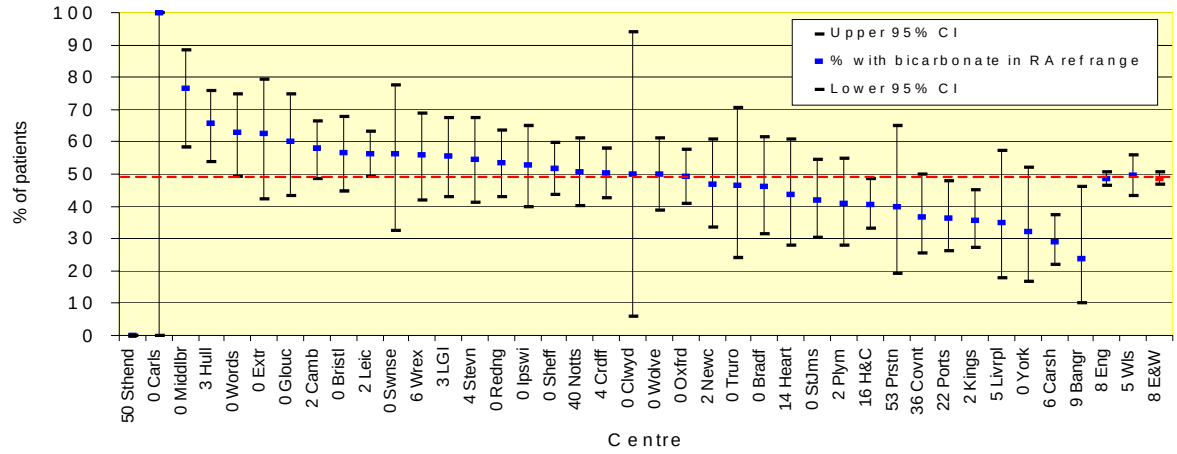

Figure 10.9. Percentage of peritoneal dialysis patients with serum bicarbonate in range 25–29mmol/L

Both acidosis and alkalosis are prevalent in some units. The Standards document has previously highlighted the theoretical dangers of alkalosis. Methodological factors are contributory but it is also likely that this reflects significant differences in practice. These differences require further investigation and explanation.

References

1. UK Renal Registry: Third Annual Report. UK Renal Registry, Bristol, UK 2000
2. Wick MJ, Wilkems K, Moritz MA. Albumin testing methods differ: implications for the dialysis patient. *Dial Transplant* 1994;23:282–286
3. Carfray A, Patel K, Whitaker P, *et al.* Albumin as an outcome measure in haemodialysis patients: the effect of variation in assay method. *Nephrol Dial Transplant* 2000;15:1819–1822
4. Renal Association Standards Committee. *Treatment of adults and children with renal failure: standards and audit measures* (3rd edition). Royal College of Physicians, London 2002
5. Kirschbaum B. Spurious metabolic acidosis in hemodialysis patients. *Am J Kid Dis* 2000;35:1068–1071

Chapter 11: Factors that may Influence Cardiovascular Disease – Blood Pressure and Serum Cholesterol

Summary

- In England and Wales, the combined blood pressure standard was achieved in 39% of patients pre-haemodialysis (inter unit range 14–64%), 48% of patients post-haemodialysis (range 32–67%), 32% of peritoneal dialysis patients (range 15–55%) and 27% of transplant patients (range 12–47%).

- The wide scatter of recorded blood pressure, especially in haemodialysis patients, implies that the ease of achievement of standards is dependent on the modality of renal replacement. Achievement of blood pressure standards in transplant cohorts appears to be easier than in haemodialysis. The framing of standards in terms of percentage compliance deserves examination.

- Widening pulse pressure increases risk of death within the first year of haemodialysis for patients with systolic blood pressure <119 mmHg, i.e. patients with cardiac failure.

- Over 4 years there has been no significant change in systolic or diastolic blood pressure achievement in England and Wales for patients on HD or PD.

- Blood pressure returns to the Renal Registry continue to be poor from some centres.

- Analysis of digit bias in the BP data returns suggests non-automated, 'rounded' values in some haemodialysis settings, and even more marked distortion in peritoneal and transplant clinics.

- Serum cholesterol levels continue to fall for renal replacement therapy patients on HD or PD or transplanted.

- Cholesterol levels are consistently lower in haemodialysis patients than in PD or transplant patients. Cholesterol levels fell significantly by 0.58 mmol/L when patients transfer from peritoneal dialysis to haemodialysis and rise by 0.59 mmol/L when dialysis patients are transplanted.

- Serum cholesterol shows a J shaped curve with (short term 1 year) survival. The curves are different for HD and PD.

- Ways by which renal units record post-haemodialysis blood pressure and episodes of symptomatic hypotension during haemodialysis, beta blocker and statin usage need to be explored so that the Registry can collect these data.

Introduction

Hypertension and hypercholesterolaemia are major risk factors for cardiac disease in the general population. Evidence from numerous randomised controlled trials indicates the lower the blood pressure or cholesterol level achieved, the lower the risk of future cardiovascular events, particularly for diabetics. The situation has not been clarified for patients with renal disease, even though cardiovascular disease is the main cause of premature death among dialysis patients. The purpose of this audit is to establish whether aggressive lowering of blood pressure and cholesterol will benefit all patients on renal replacement therapy or only certain subsets of patients. To date the Renal Registry has had insufficient data to address this important issue.

Hypertension plays a direct role in the development of LVH, LV dilatation, *de novo* ischaemic heart disease and cardiac failure in the dialysis population (discussed in detail in the last report). There is a U-shape rela-

tionship between hypertension and mortality in the dialysis population.[1] Widening pulse pressure (systolic minus diastolic blood pressure) is the strongest risk factor for increased cardiac mortality. In a retrospective analysis of 37,069 haemodialysis patients, widening pulse pressure was associated with age, diabetes, white race, female sex and number of years receiving dialysis.[2] For any given systolic or diastolic blood pressure, the wider the pulse pressure the higher the risk of death. An isolated high systolic blood pressure or low diastolic blood pressure is also associated with cardiovascular death.[3,4] More recently, post-dialysis blood pressure has been shown to correlate more closely with outcome than pre-dialysis blood pressure for the haemodialysis population.[1,2]

Co-morbidity adjustments markedly affect associations and are essential for survival analyses. Only 19% of patients logged with the Renal Registry have completed co-morbidity data returns and this must clearly improve. One omission from the co-morbidity list was cardiac failure because of difficulties in deciding whether it was primarily related to fluid overload or ischaemic heart disease. This has now been added as a co-morbidity item at the start of renal replacement therapy, due to either course. For units with poor access to echocardiography, pulmonary oedema on CXR will be sufficient to make the diagnosis. Over recent years there has been compelling evidence that beta blockers improve patient survival in cardiac failure, renal impairment and end-stage renal failure.[5,6] The Registry needs to explore with users an easy way to log these data on local IT systems so that it can be collected and analysed by the Registry.

Blood pressure control

The Renal Association standards for control of hypertension were revised in August 2002.[7] The current standards are:

Pre-haemodialysis systolic blood pressure < 140 mmHg.
Pre-haemodialysis diastolic blood pressure < 90 mmHg.
Post-haemodialysis, peritoneal dialysis and renal transplant recipient systolic blood pressure < 130 mmHg.
Post-haemodialysis, peritoneal dialysis and renal transplant recipient diastolic blood pressure < 80 mmHg.

The Renal Association does not specify separate standards for diabetics. Diabetic guidelines suggest a lower target (BP < 125/75 mmHg) to reduce cardiovascular risk.

For audit purposes the Renal Registry needs to liaise with renal units to discuss ways of collecting additional data sets which may be useful in identifying factors which impact on survival:

BP every 3 months for dialysis and 6 months for transplant patients.
Post-haemodialysis blood pressure.
Episodes of symptomatic hypotension during haemodialysis (see 3rd standards document)**.**
Beta blocker use.

Data returns

A large number of units returned incomplete blood pressure data. Lack of returns implies that blood pressure results have not been transferred to renal IT systems, rather than not recorded. This is particularly a problem for off-site clinics and satellite haemodialysis units where there may not be links in place to the renal unit main IT system. The renal NSF Information Strategy document (see Appendix E) highlights the importance of a renal unit's IT infrastructure and linkage with external sites.

Units with more than 50% missing data were excluded from the analyses. These include Bradford, Cambridge, Clwyd, Hull, Kings, Liverpool and Reading for haemodialysis (HD), Kings for peritoneal dialysis

Table 11.1. Percentage of patients with complete returns of blood pressure values by modality

Centre	Pre HD	Post HD	PD	Transp
Bangr	98	98	92	N/A
Bradf	8	8	100	97
Bristl	100	99	100	54
Camb	12	0	97	79
Carls	93	0	17	6
Carsh	0	0	0	0
Clwyd	18	0	67	96
Covnt	98	94	94	82
Crdff	30	0	8	93
Extr	94	91	100	20
Glouc	99	99	8	2
Guys	68	66	9	3
H&C	0	0	0	0
Heart	91	91	8	2
Hull	1	1	0	0
Ipswich	97	96	0	0
Kings	10	1	43	73
Leic	97	92	94	80
LGI	91	90	5	4
Livrpl	11	0	6	78
Middlbr	93	92	100	52
Newc	0	0	0	0
Notts	93	93	97	95
Oxfrd	98	86	85	24
Plym	0	0	0	0
Ports	0	0	1	0
Prstn	0	0	0	0
Redng	89	1	95	14
Sheff	100	76	99	97
Stevn	86	76	10	8
Sthend	97	0	6	3
StJms	89	99	99	90
Sund	98	97	19	2
Swnse	0	0	0	0
Truro	77	76	92	45
Wirrl	54	0	N/A	N/A
Wolve	98	91	14	5
Words	91	91	98	84
Wrex	0	0	0	0
York	92	92	90	94

(PD) and Truro for transplant. The new Renal Association blood pressure standards were used in this year's report.

Distribution of blood pressure by modality

Figures 11.1–11.6 indicate systolic and diastolic blood pressure distributions for each treatment modality. The distributions have standard deviations approaching twice the values found in hypertensive populations without ERF, with the widest spread for haemodialysis. The data have not changed materially over the past two years where systolic/diastolic standard deviations for pre HD, PD, transplant were 27/15, 25/12.5, 20/11 respectively for 2001 data and 26.9/15, (27/13.9 post-HD), 24.5/13.4 and 19.3/10.9 for 2002 data. These values should be compared to 18/10 for non-renal replacement therapy hypertensive population. (Note: this analysis used only data from units offering more than 50 values for analysis, with minor digit bias.) Where an upper limit of desired blood pressure is specified (e.g. 140 systolic for HD patients), typically this only becomes the achieved mean blood pressure of the group.

Figure 11.7 shows a plot of a centre's median systolic blood pressure for pre HD and transplant respectively, revealing the different regression of achieved outcome on the median values. The flatter the slope the greater the dispersion of data (standard deviation). The greater blood pressure dispersion of the haemodialysis population implies a lower median blood pressure is required to achieve any given standard compared with more typical hypertensive groups. A median systolic blood pressure of 115 mmHg is required for 85% of HD patients to achieve a systolic blood pressure <140 mmHg, for example.[8] If a centre achieves a median systolic pressure of 125 mmHg then 90% of transplant patients, but only 70% of HD patients (pre-HD values), will be under 140 systolic. These data relate to single readings, rather than the mean of several separate measurements, which would narrow these distributions.

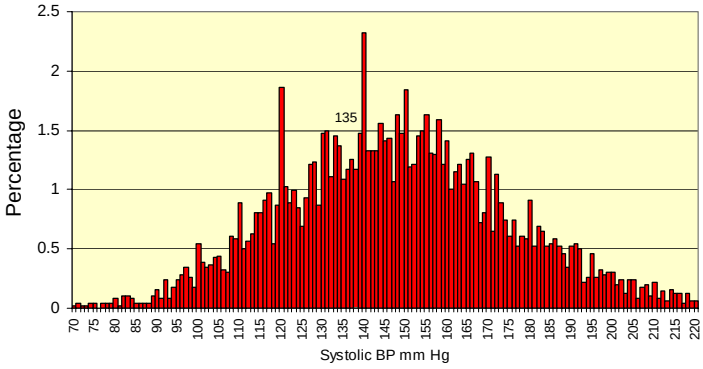

Figure 11.1. Systolic BP: pre-haemodialysis

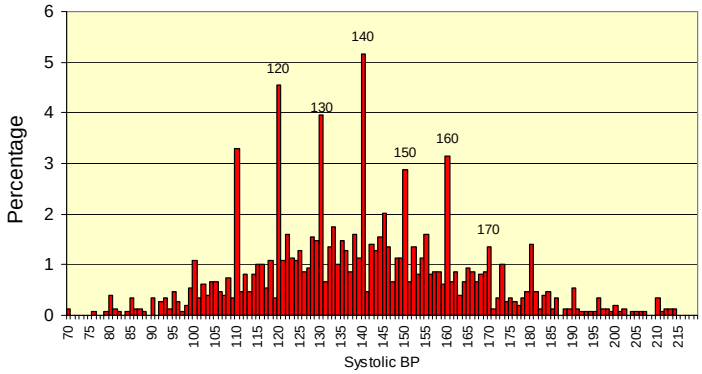

Figure 11.2. Systolic BP: peritoneal dialysis

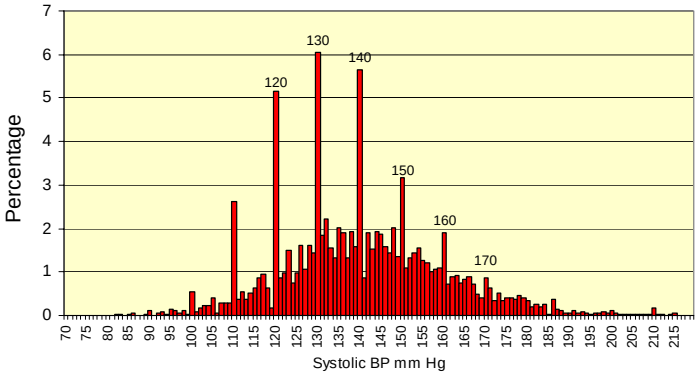

Figure 11.3. Systolic BP: transplant

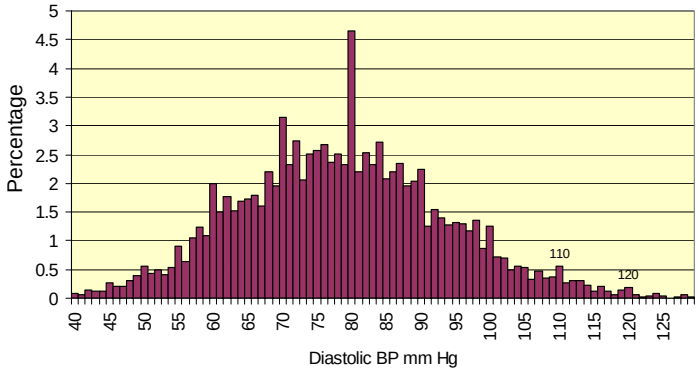

Figure 11.4. Diastolic BP: pre-haemodialysis

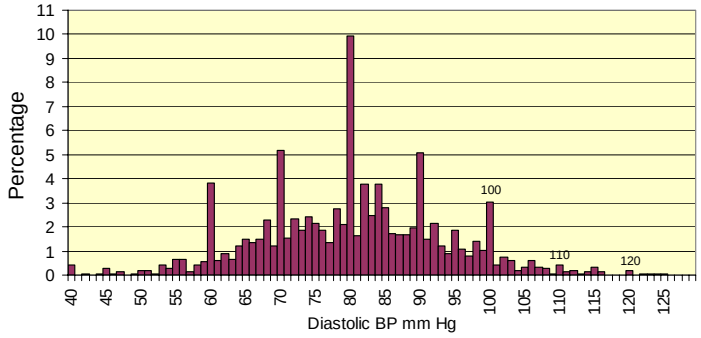

Figure 11.5. Diastolic BP: peritoneal dialysis

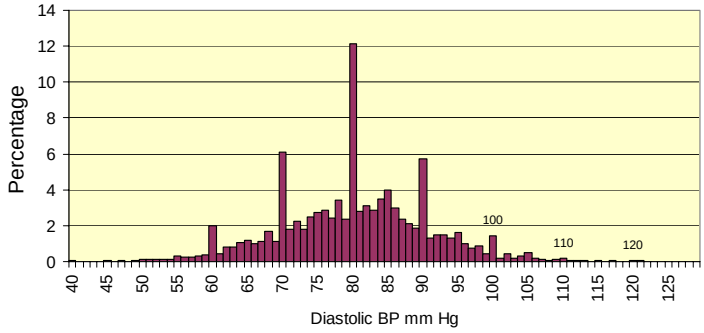

Figure 11.6. Diastolic BP: transplant

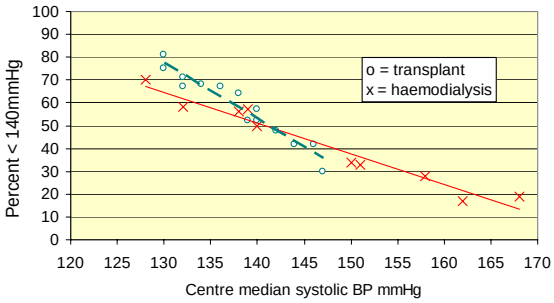

Figure 11.7. Centre median systolic BP and percentage achieving <140 mmHg

These analyses provide material for discussion on the recommended Standards and the means by which outcomes should be presented. Since ideal blood pressure standards are only partially achievable (e.g. all patients should have a systolic BP < 140), consideration should be given to reframing Standards in terms of percent compliance with the desirable maximum BP (e.g. 50% should have a systolic < 140). An auditable item defined in this fashion as a performance measure, would be a practical intermediate step between Standard declarations and clinical practice in the guidance of patient management.

Blood pressure measurement and digit bias

The information given in Figures 11.8–11.11, which indicate the accuracy with which blood pressure readings are measured and recorded, is a cause for concern. In many dialysis units and renal clinics, blood pressure is not measured according to the British Hypertension Society recommendations. Furthermore, digit bias (the tendency to round the numbers up or down) occurs when blood pressure measurements are recorded on to clinical databases.

The tendency for units to round systolic and diastolic blood pressure measurements to zero (zero should occur on average only 10% of the time) was analysed. The data shows zero digit bias is more prevalent in PD and transplant patients, presumably with measurements made in a clinic setting. It may even occur in HD patients when the blood pressure has been measured electronically and must be transcribed! There is little evidence of rounding to ‘fives’. Methods of measurement and recording must be standardised and accurate for audit purposes.

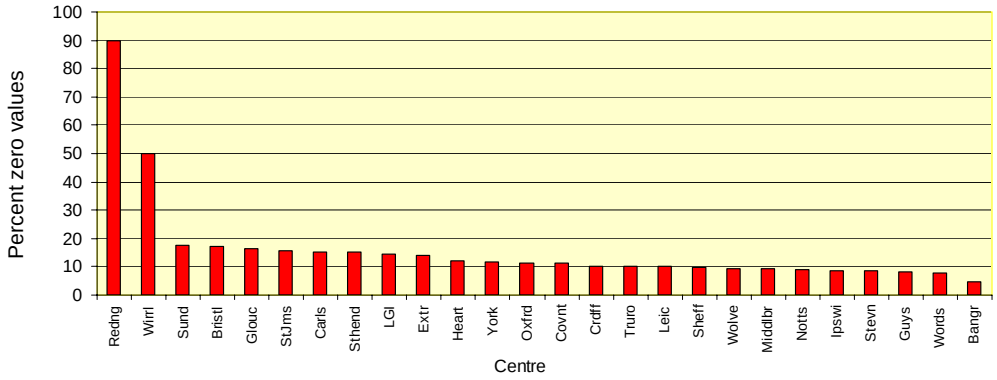

Figure 11.8. Zero digit bias pre-HD SBP 2002

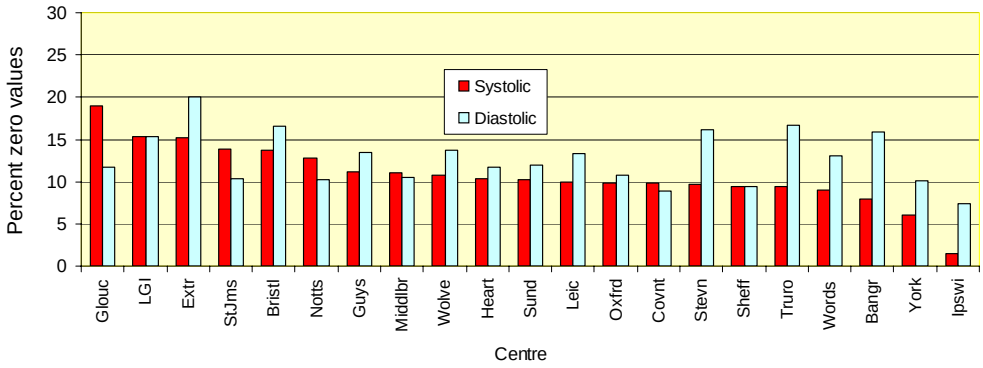

Figure 11.9. Zero digit bias of post-HD BP 2002

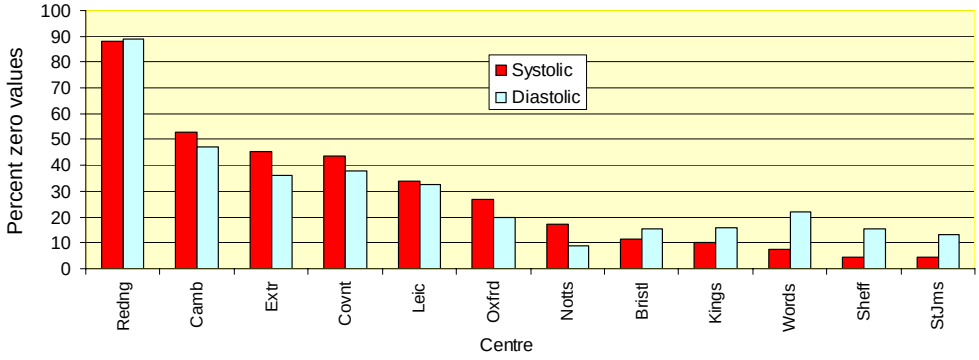

Figure 11.10. Zero digit bias of peritoneal dialysis blood pressure 2002

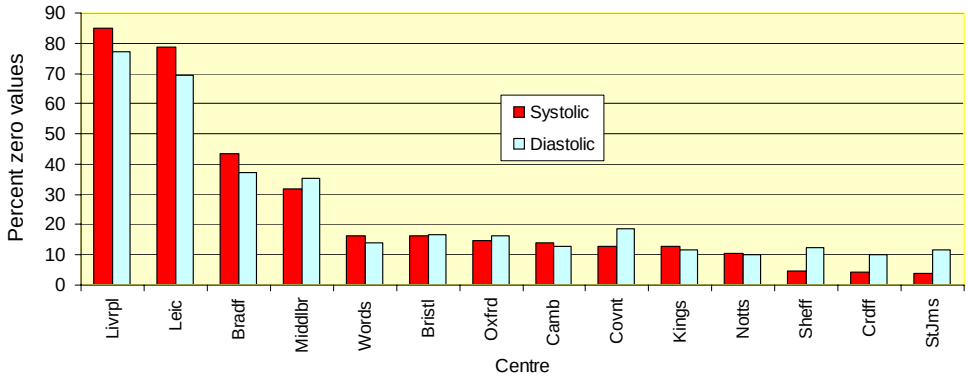

Figure 11.11. Zero digit bias of transplant blood pressure 2002

Achievement of combined systolic and diastolic Standard

Figures 11.12–11.15 show a wide variation between units achieving the combined blood pressure standard for each modality. In England and Wales, the percentage of HD patients achieving the standard pre-dialysis average 39% (range 14–64%) and post-dialysis average 48% (range 32–67%). An average of 32% of PD patients achieve the standard (range 15–55%) and 27% of transplant patients (range 12–47%). Chi squared testing indicates the variation between centres for each treatment modality is significant ($p < 0.0001$).

The median blood pressure for pre-HD, post-HD, PD and transplant is 147/78, 131/72, 139/80 and 140/80 mmHg. This equates to a pulse pressure of 69, 59, 59 and 60 mmHg respectively. The results are similar to those reported by the Finnish Registry for Kidney Diseases.[9]

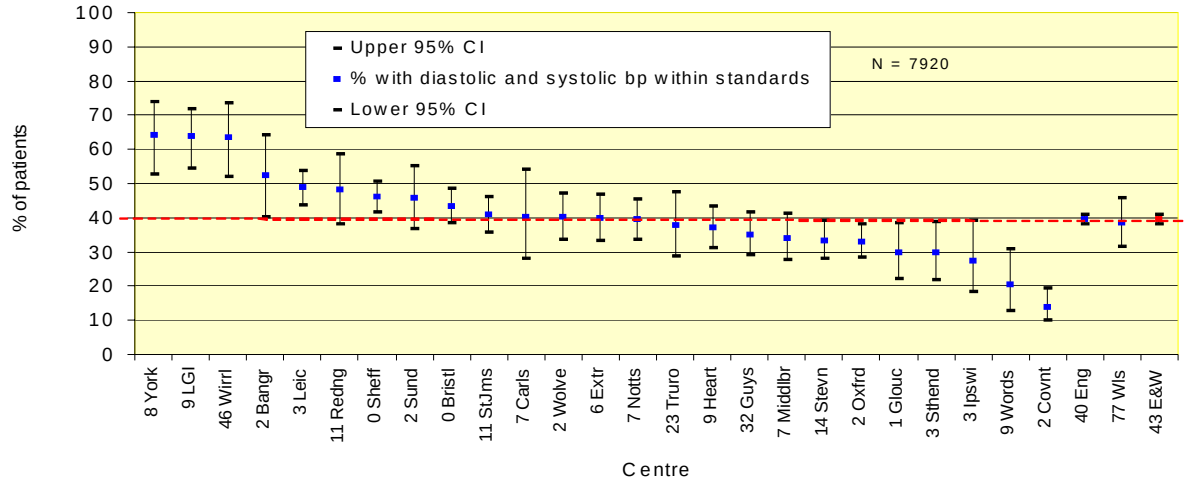

Figure 11.12. Percentage of patients with BP < 140/90 mmHg: pre-HD

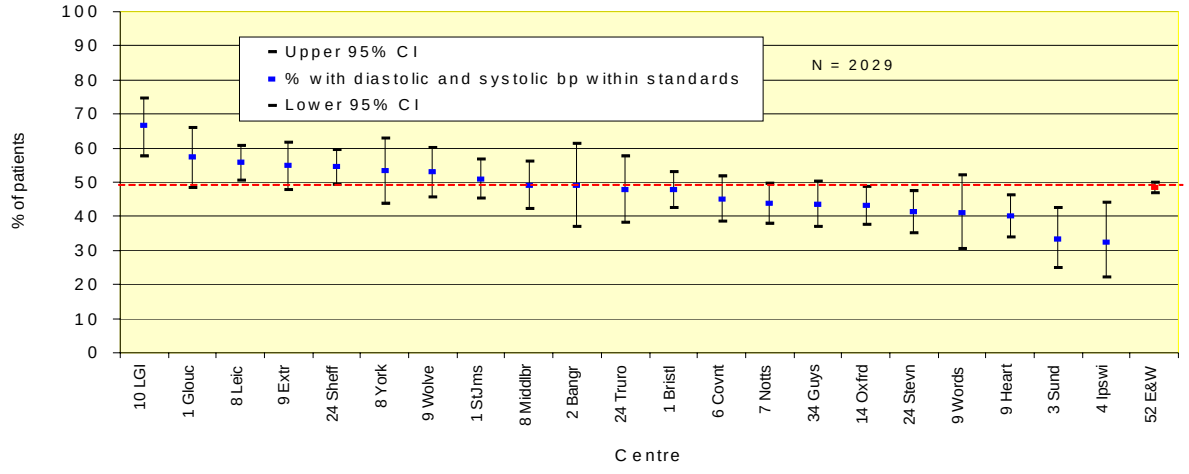

Figure 11.13. Percentage of patients with BP < 130/80 mmHg: post-HD

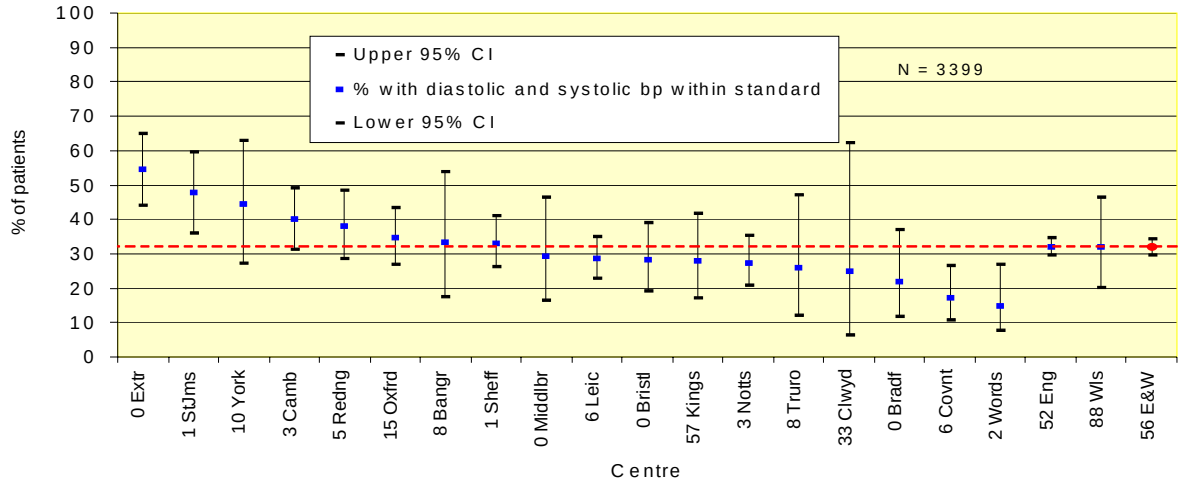

Figure 11.14. Percentage of patients with BP < 130/80 mmHg: PD

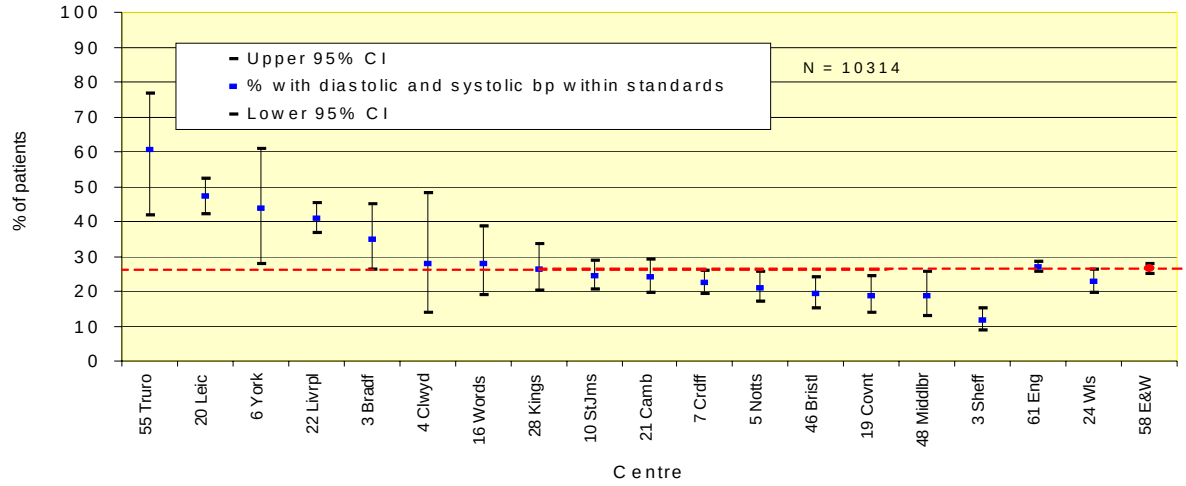

Figure 11.15. Percentage of patients with BP < 130/80 mmHg: transplant

Systolic pressure alone

Figures 11.16–11.23 show a wide variation between units achieving the systolic blood pressure standard. In England & Wales, the percentage of HD patients achieving the standard pre-dialysis average 41% (range 15–66%) and post-dialysis average 49% (range 34–66%). An average of 39% of PD patients achieve the standard (range 20–65%) and 33% of transplant patients (range 16–53%). Chi squared testing indicates the variation between centres for each treatment modality is significant ($p < 001$).

The median systolic blood pressure for pre-HD, post-HD, PD and transplant is 147, 131, 139 and 140 mmHg respectively. Diabetics and patients with reno-vascular disease have the highest systolic blood pressures post-haemodialysis (see Chapter 19 on diabetes). This is a major cause for concern given the more stringent blood pressure targets recommended by diabetic guidelines to reduce cardiovascular risk.

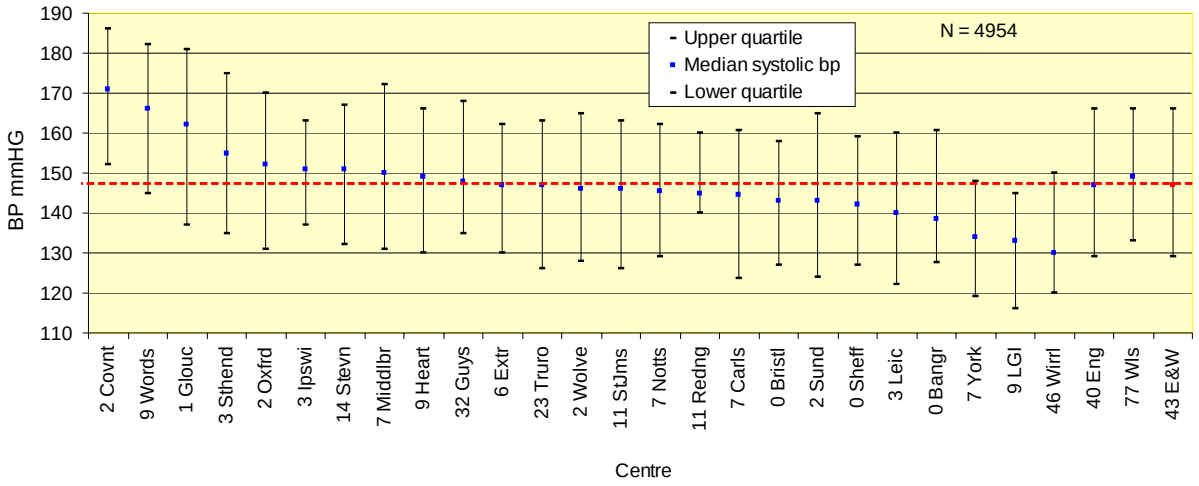

Figure 11.16. Median systolic BP; pre-HD

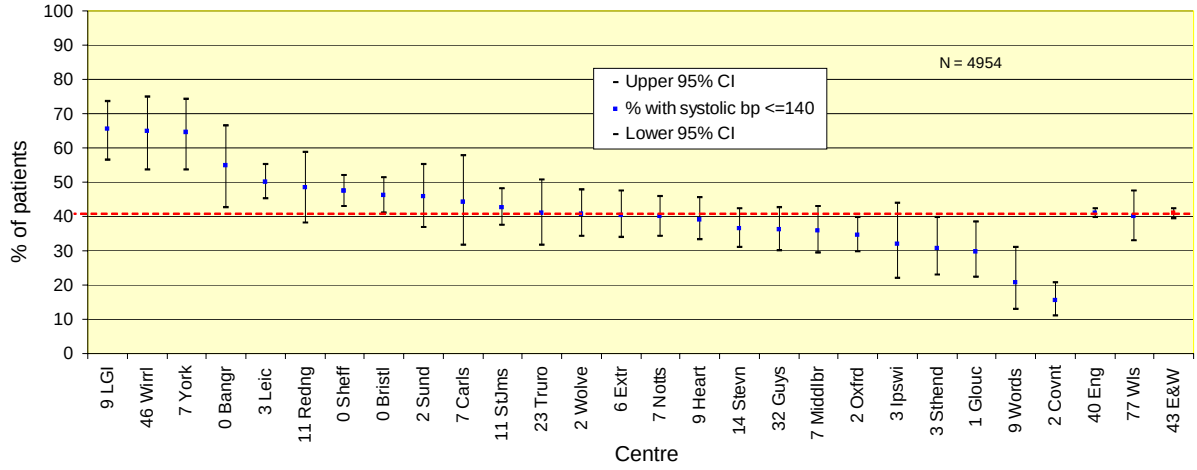

Figure 11.17. Percentage of patients with systolic BP < 140 mmHg; pre-HD

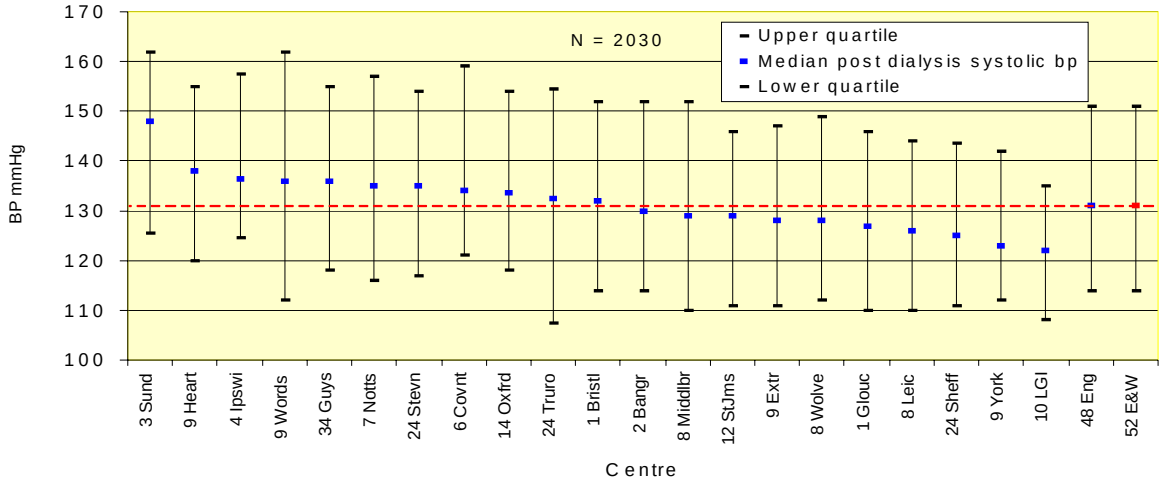

Figure 11.18. Median systolic BP; post-HD

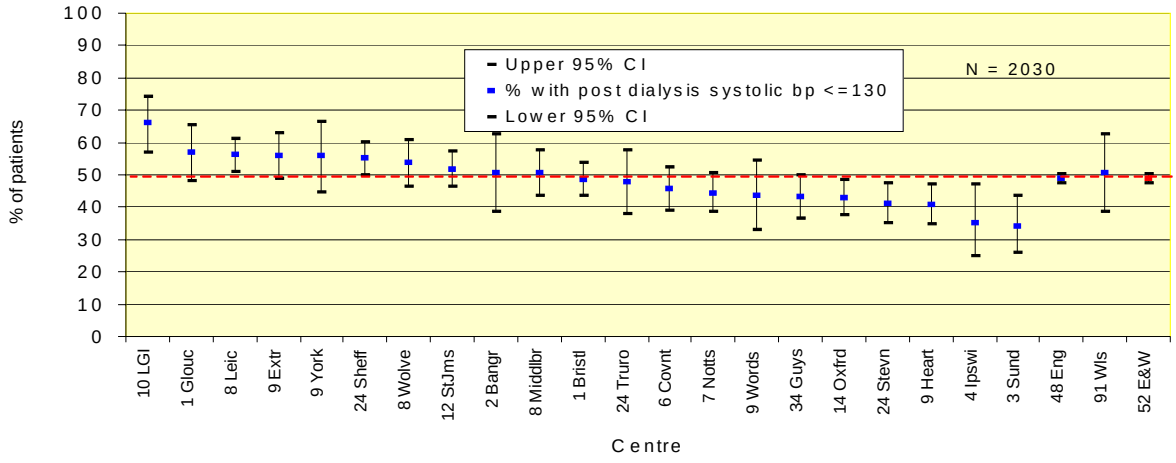

Figure 11.19. Percentage of patients with systolic BP < 130 mmHg; post-HD

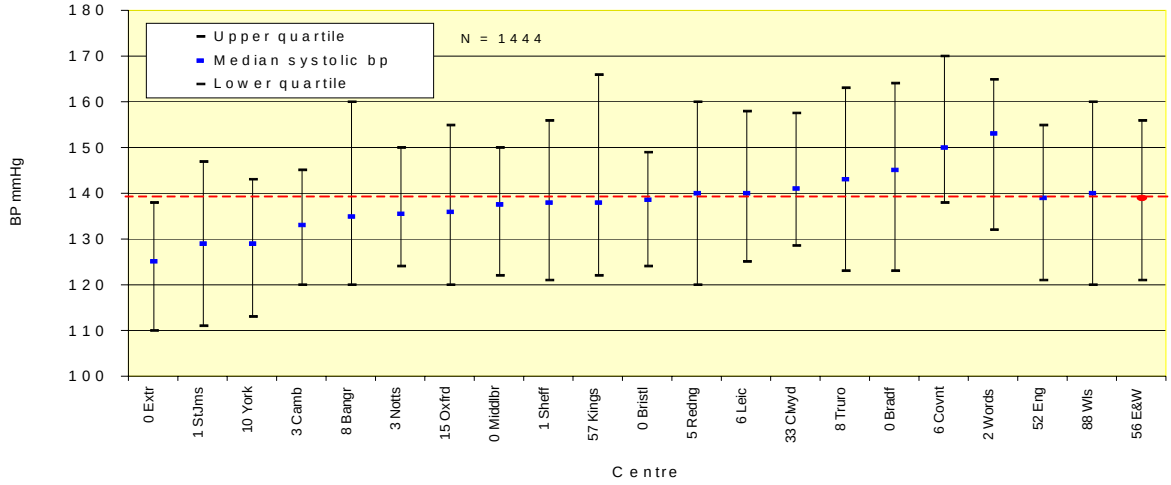

Figure 11.20. Median systolic BP; PD

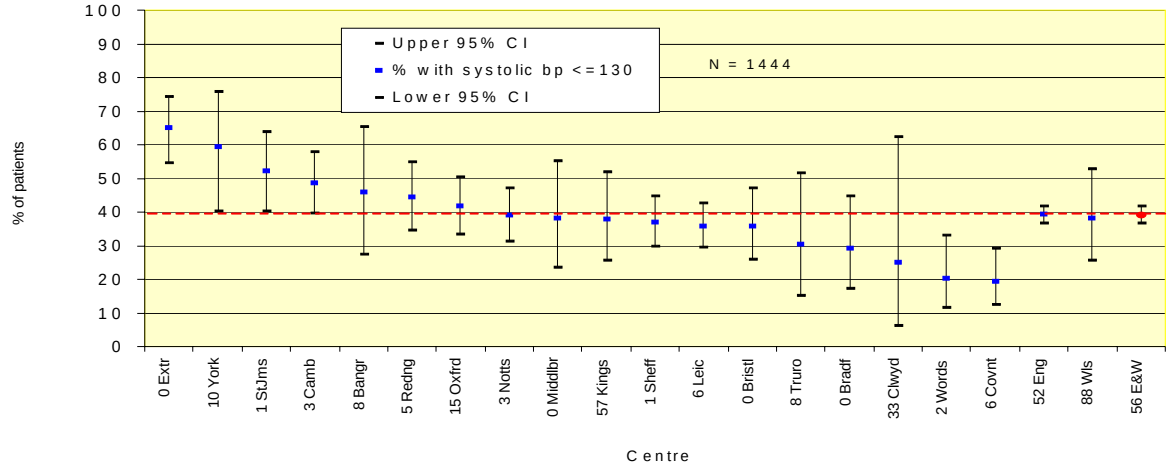

Figure 11.21. Percentage of patients with systolic BP < 130 mmHg; PD

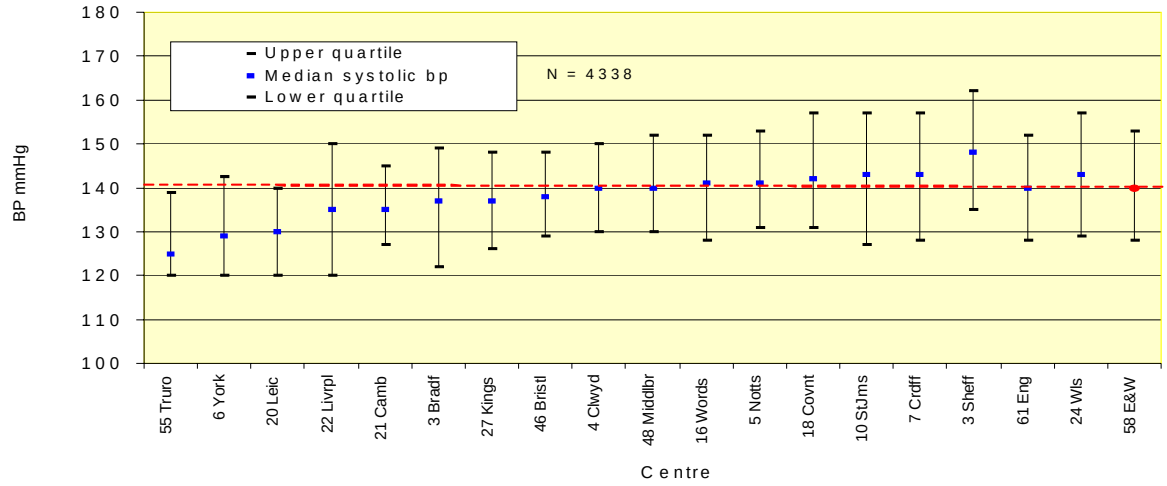

Figure 11.22. Median systolic BP; transplant

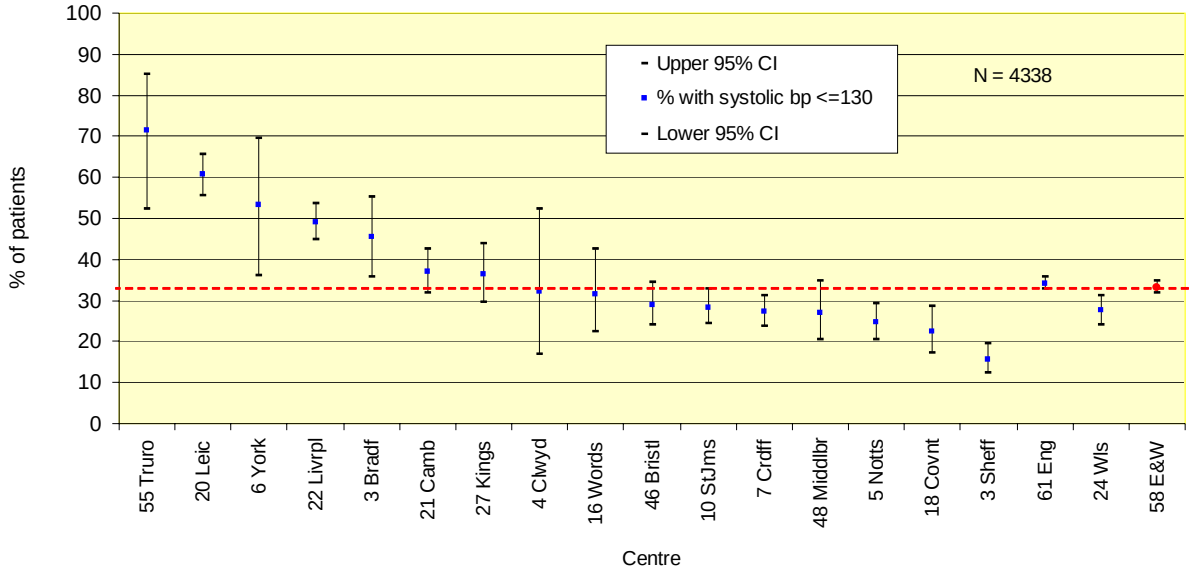

Figure 11.23. Percentage of patients with systolic BP < 130 mmHg; transplant

Diastolic pressure alone

Figures 11.24–11.31 show wide variation between units achieving the diastolic blood pressure standard. In England and Wales, the percentage of HD patients achieving the standard pre-dialysis average 80% (range 59–95%) and post-dialysis average 74% (range 49–87%). An average of 53% of PD patients achieve the standard (range 25-72%) and 54% of transplant patients (range 40–75%). Chi squared testing indicates the variation between centres for each treatment modality is significant ($p < 0.001$). The median diastolic blood pressure for pre-HD, post-HD, PD and transplant is 78, 72, 80 and 80 mmHg respectively.

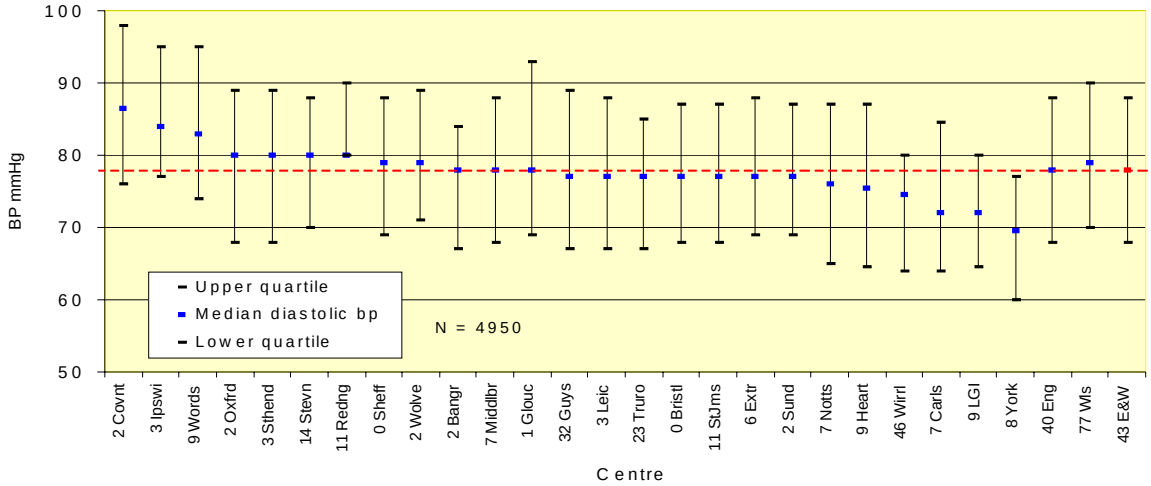

Figure 11.24. Median diastolic BP; pre-HD

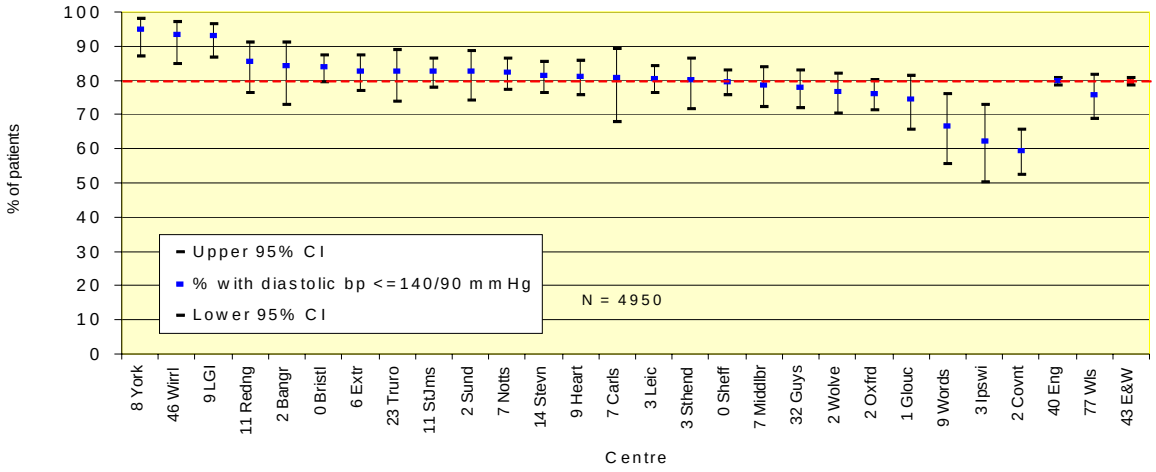

Figure 11.25. Percentage of patients with diastolic BP < 90 mmHg; HD

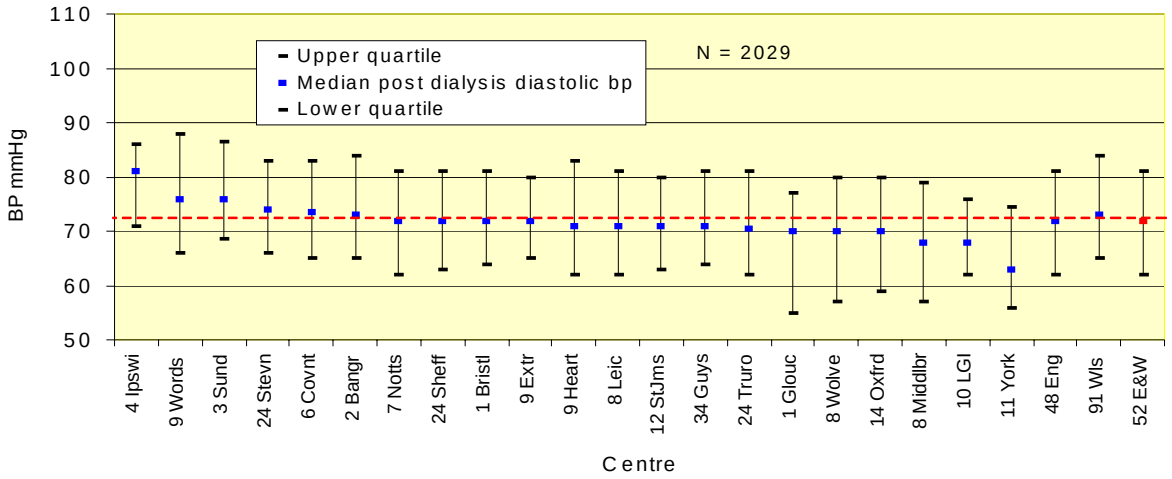

Figure 11.26. Median diastolic BP; post-HD

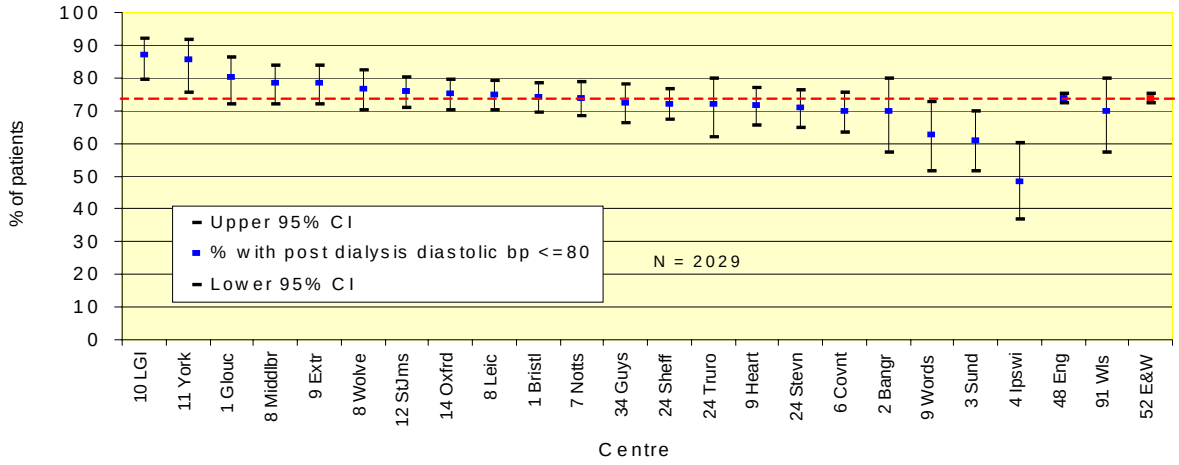

Figure 11.27. Percentage of patients with Diastolic Blood Pressure <80 mm Hg : post haemodialysis

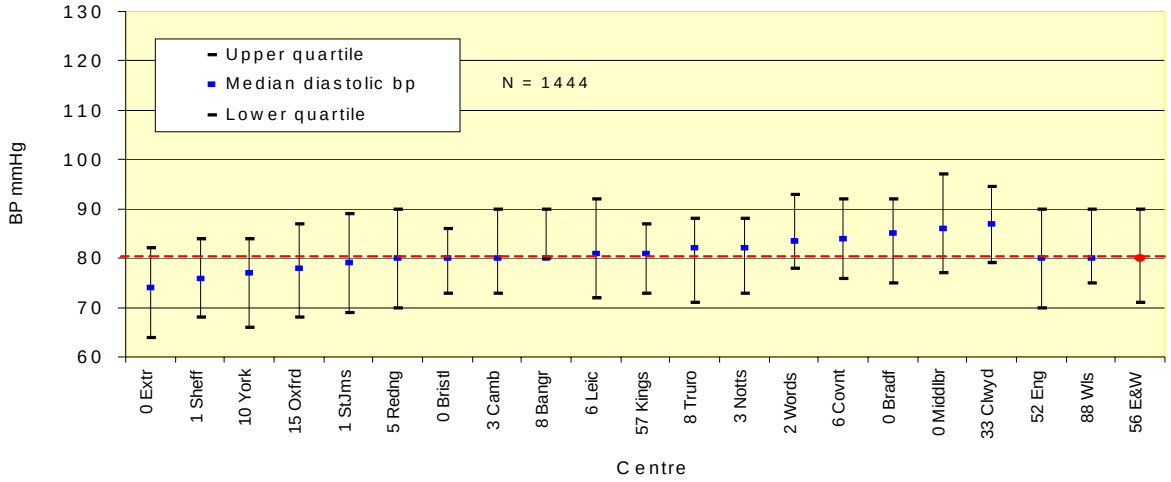

Figure 11.28. Median Diastolic Blood Pressure mm Hg : peritoneal dialysis

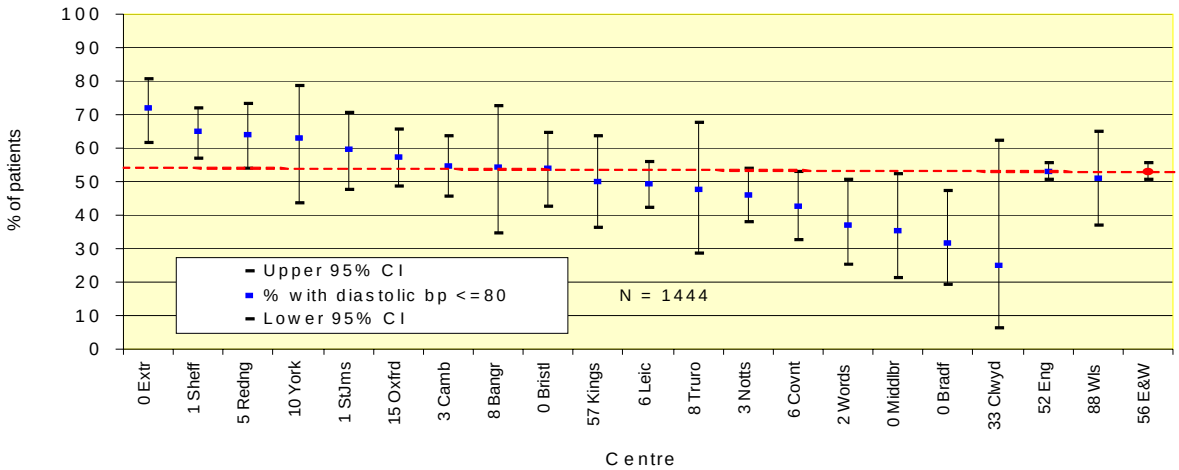

Figure 11.29. Percentage of patients with Diastolic Blood Pressure <=80 mm Hg : peritoneal dialysis

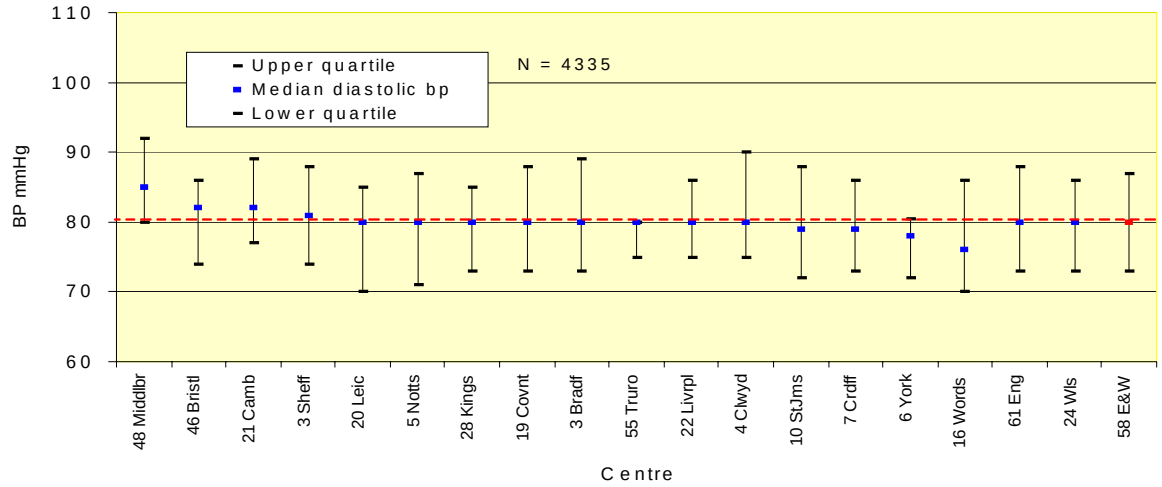

Figure 11.30. Median diastolic BP; transplant

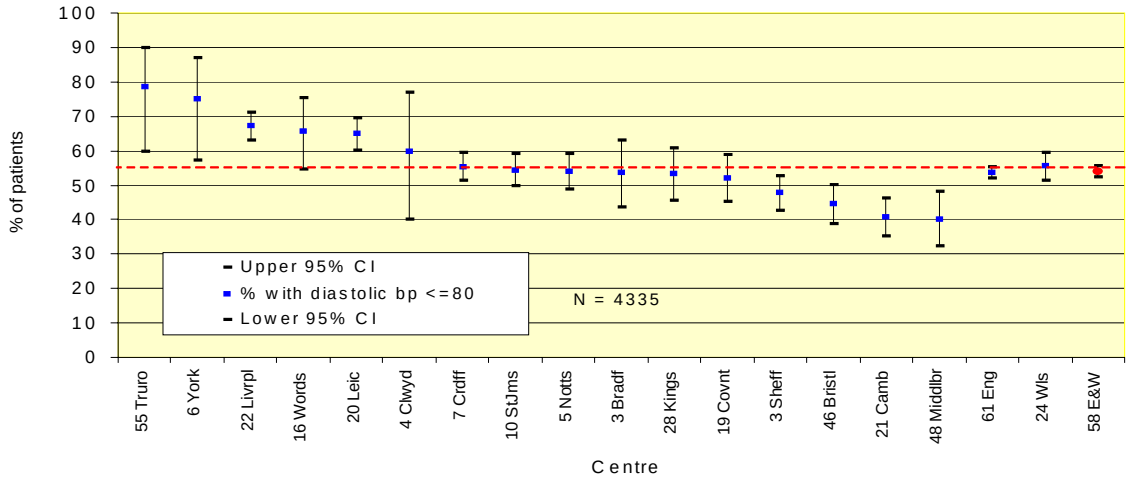

Figure 11.31. Percentage of patients with diastolic BP < 80 mmHg; transplant

Change in blood pressure achievement 1999–2002

Figure 11.32 indicates that for England and Wales as a whole there has been no change in improving systolic BP in patients. Only the Sheffield renal unit appears to have made a significant improvement in systolic BP achievement during this 4 year time period. During the same period, the Oxford renal unit is the only centre to have shown a change in improvement of diastolic blood pressure achievement (64% compliance in 1999 to 76% compliance in 2002), although this is now only in line with England and Wales average of 78% with diastolic BP ≤ 90 mmHg. It is too early to tell whether the 2002 change in Renal Association 3rd Standards will have any impact on achievement.

There were no significant changes in achievement of PD BP standards apart from the Oxford renal unit where achievement of the diastolic BP standard again improved from 41% in 1999 to 58% in 2002 (compared with E&W 54% 1999–2002).

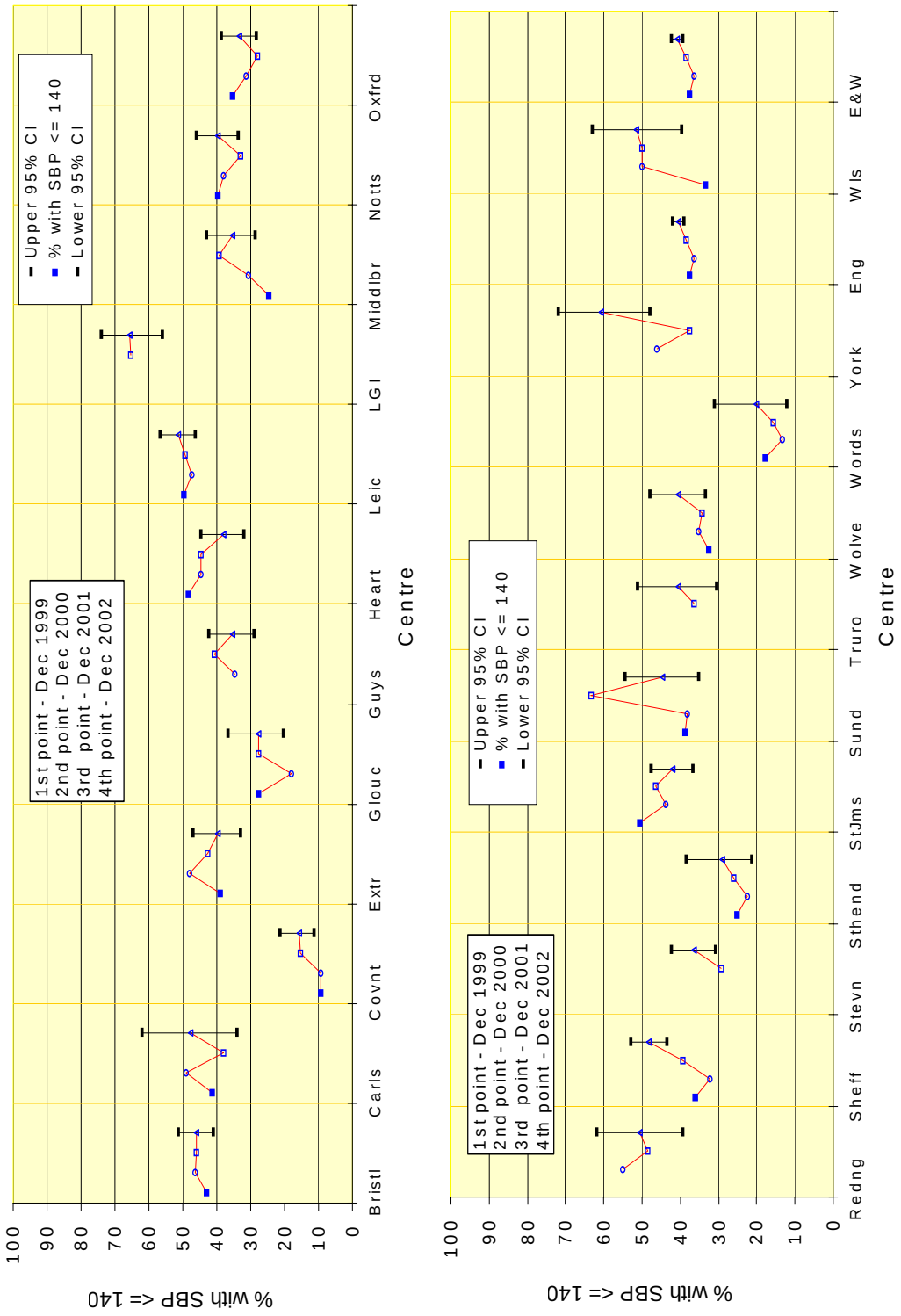

Figure 11.32. Change in achievement of systolic BP pre HD 1999–2002

Blood pressure changes during haemodialysis

This is the first time the Registry has analysed blood pressure changes that occur during haemodialysis. For patients with cardiac function normal (defined as systolic BP > 110 mmHg pre-dialysis), systolic blood pressure falls in 72% of patients and rises in 26%. The median drop in systolic blood pressure post HD is 16 mmHg, but in 10% of patients it rises and exceeds 30% of the pre-dialysis value. Diastolic blood pressure falls in 65% of patients and rises in 31% post HD. The median drop in diastolic blood pressure is 6 mmHg but in 8% of patients it rises and exceeds 30% of the pre-dialysis value. Pulse pressure changes during haemodialysis have not been analysed.

Data were available for only 267 patients with poor cardiac function (defined as systolic blood pressure <110 mmHg pre-haemodialysis). Systolic blood pressure falls in 41% of patients and rises in 55% post HD. Diastolic blood pressure falls in 47% of patients and rises in 48% post HD.

It is not clear what these blood pressure changes mean. For example, a rise in blood pressure following dialysis may reflect improved cardiac output in patients with cardiac failure or increased peripheral resistance in patients with normal cardiac function. The prognostic implications of these blood pressure changes should become clearer as these patients are observed over a longer period.

Pulse pressure and mortality in incident haemodialysis patients

As discussed at the start of this chapter, patients with end-stage renal disease (ESRD) exhibit vascular abnormalities that contribute to elevated pulse pressure, including increased arterial stiffness and pulse wave velocity. Pulse pressure has been shown as a risk factor for mortality or cardiovascular events in several dialysis cohorts. The Registry has previously analysed the effect of systolic and diastolic blood pressure on a prevalent cohort survival (Report 2000, Chapter 18).

This analysis looks at the importance of pulse pressure for predicting mortality in incident chronic haemodialysis patients in England & Wales.

Methods

Patients starting haemodialysis between January 1997 and September 2001 were included in the study and followed for 1 year (excluding the first 90 days). Pre and post dialysis blood pressure measurements were averaged over the four quarters:

- For patients who died, blood pressure readings from the quarter of their death were excluded from the analysis.
- Patients with a diagnosis of diabetes (as primary cause of renal replacement therapy or as a co-morbidity) were excluded as systolic BPs were higher than in non-diabetics, and their risk factors are different).
- Patients were censored if they changed modality or were lost to follow up.
- Patients who died within the first 90 days of starting renal replacement therapy were excluded from the analysis.

The final sample included 2181 pre-dialysis incident non-diabetic HD patients and 1642 post-dialysis incident non-diabetic HD patients.

The principal outcome in this analysis was all-cause mortality during the first year after 90 days. The effects of both systolic (SBP), diastolic (DBP) and pulse pressure (PP), pre- and post-dialysis, on total mortality were analysed using Cox proportional hazards regression with age as a linear variable. These BP measurements were categorised and the proportional hazard measured relative to a reference category.

Results

Table 11.2. Study cohort

Number included	2181
Mean Age	63 years
Percentage Male	63%
Died (%)	218 (10%)
Mean Systolic BP pre HD (s.d.)	148 (21) mm Hg
Mean Systolic BP post HD (s.d.)	138 (21) mm Hg
Mean Diastolic BP pre HD (s.d.)	79 (11) mm Hg
Mean Diastolic BP post HD (s.d.)	75 (12) mm Hg
Pulse pressure pre HD (s.d.)	68 (16) mm Hg
Pulse pressure post HD (s.d.)	63 (17) mm Hg

Figures 11.33–11.34 show the results of age adjusted Cox proportional hazard model relating systolic blood pressure to one year mortality. There is a non linear inverse relationship between pre-HD systolic blood pressure and mortality although only patients with a systolic blood pressure above 160 mm Hg had a significantly different survival (better) from patients with a BP of 140–149. There was no significant relationship between survival and post HD systolic BP.

Figures 11.35–11.36 show the results of age adjusted Cox proportional hazard model relating pulse pressure to all cause mortality at one year. There is a non-linear relationship between pre-HD pulse pressure and mortality but no significant relationship post-HD. A low pulse pressure pre HD (<40 mmHg) is associated with a significantly greater risk of death than the reference group of 40–49 mm Hg.

The relationship between systolic blood pressure, pulse pressure and death is shown in Figure 11.37. A widening pulse pressure may be associated with greater mortality risk only when the systolic blood pressure is <119 mmHg (i.e. very low diastolic pressures and diastolic dysfunction). With high systolic pressure the combination with higher diastolic pressure was associated with the highest risk of death.

This analysis shows the risk of death within the first year of dialysis is greatest for

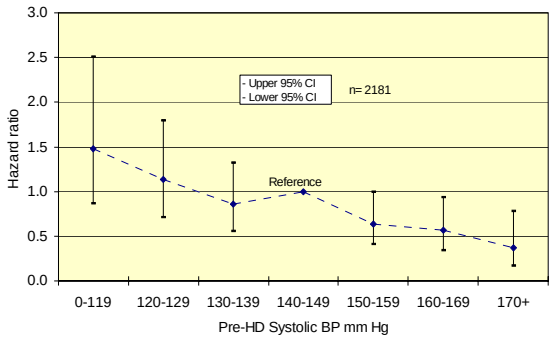

Figure 11.33. Hazard ratio for first year mortality associated with pre-HD systolic BP

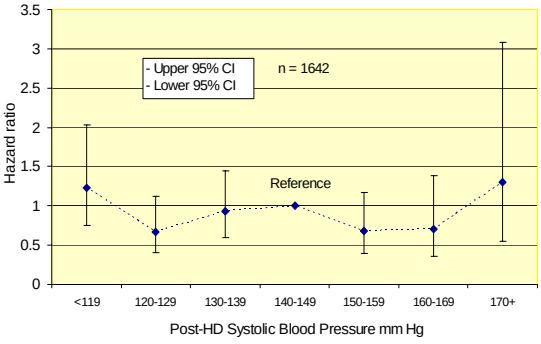

Figure 11.34. Hazard ratio for first year mortality associated with post-HD systolic BP

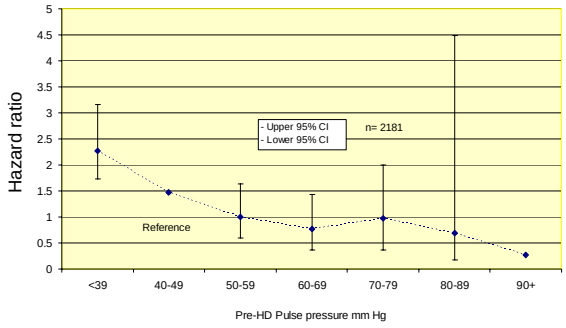

Figure 11.35. Hazard ratio for first year mortality associated with pre-HD pulse pressure

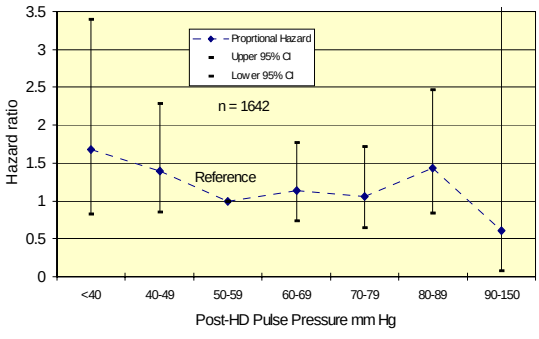

Figure 11.36. Hazard ratio for first year mortality associated with post-HD pulse pressure

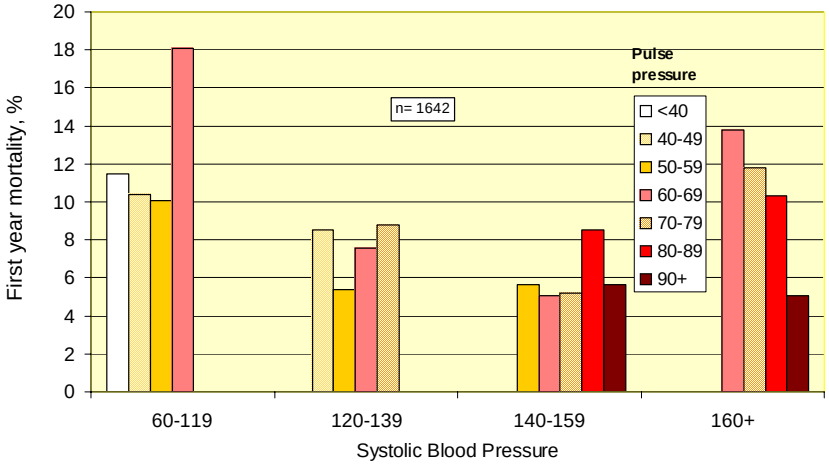

Figure 11.37. % of patients who died in 1st year by post-HD systolic BP and pulse pressure

patients with low systolic blood pressure and high pulse pressure, i.e. patients with cardiac failure. Although patients with blood pressure readings above the Renal Association standards are at low risk of dying during the first year on haemodialysis, hypertension precedes cardiac failure by many years. It will take a longer period of observation to demonstrate the true association between hypertension and mortality in this haemodialysis population.

Cholesterol and achievement of the Standard

Hyperlipidaemia is common in the dialysis population. The typical changes are raised triglycerides, low high-density lipoprotein (HDL) and variable changes in low-density lipoprotein (LDL) and total cholesterol. Less than a quarter of cardiac mortality is attributed to acute myocardial infarction, a condition potentially avoided by lowering cholesterol. More common causes of cardiac death such as cardiac arrest and arrhythmia may not be related to serum cholesterol concentration. There is a J-shaped relationship between cholesterol level and short term mortality in the dialysis population.[10,11] Last year's report indicated optimal survival for a cholesterol range between 5 and 8 mmol/L, presumably reflecting better nutrition. Malnutrition, chronic disease and chronic inflammation are all associated with low cholesterol levels and are major independent risk factors for death. Co-morbidity adjustments and statin use will help unravel these confounding associations. As discussed at the start of this chapter, the Registry needs to investigate methods to facilitate collection of this data item by renal units.

Atherosclerosis is an inflammatory process and in the general healthy population, C-reactive protein (CRP) is a stronger predictor of future cardiovascular events than LDL-cholesterol.[12] The Framingham risk score and European SCORE system do not take CRP into account. A single CRP level using a high-sensitivity assay has been shown to have prognostic value for both haemodialysis and peritoneal dialysis populations.[13,14] Generally the process of haemodialysis is considered to be pro-inflammatory. However, the Finnish Registry in 2002 showed no difference in CRP concentrations between haemodialysis and peritoneal dialysis populations.[9] The Renal Registry will now start to collect CRP as part of the data returns from centres that download this item in their laboratory link.

The Renal Association set standards for lipids for the first time in August 2002.[7] The current standards are:

Primary prevention:

Statins should be initiated in dialysis patients with a 10 year risk of coronary disease >30% to achieve:

Total cholesterol <5 mmol/L or a 30% reduction from baseline

Fasting LDL-cholesterol of <3mmol/L

Secondary prevention:

Patients should be treated with aspirin, an ACE inhibitor, a beta-blocker and a statin unless contra-indicated.

The Renal Association does not specify separate standards for patients with established cardiovascular disease, diabetics or renal transplant patients. Neither does it recommend how frequently lipids should be measured.

European guidelines suggest the dialysis standards should also be applied to transplant patients.[15] Patients with established cardiovascular disease and diabetics have lower targets (total cholesterol <4.5 mmol/L and LDL-cholesterol 2.5 mmol/L).[16] Lipid profiles are advised annually for transplant patients and every 6 months for dialysis patients.[15] Blood samples should be taken immediately before dialysis or at least 12 hours after, preferably with the patient in a fasting state.

Currently few UK renal units collect data on fasting samples or full lipid profiles but a number of units will collate detail of the latter as part of the SHARP trial and the Renal Registry will present this data if sufficient numbers of units participate. The current audit is based on random, non-fasting total cholesterol measurements only.

For audit purposes, the Renal Registry is seeking ways to collect the following new data sets:

- CRP every 6 months
- Statin use.

Achievement of cholesterol standard

Figures 11.38–11.44 show wide variation between units achieving the cholesterol standard. In England and Wales, the number of patients achieving the standard for HD average 75.3% (range 52–86%), 55.2% for PD (range 27–77%) and 51% for transplant (range 27–76%). Chi squared testing indicates the variation between centres for each treatment modality is significant ($p < 0.0001$).

Cholesterol levels are lower in haemodialysis patients; the median cholesterol concentration for HD, PD and transplant is 4.3, 4.9

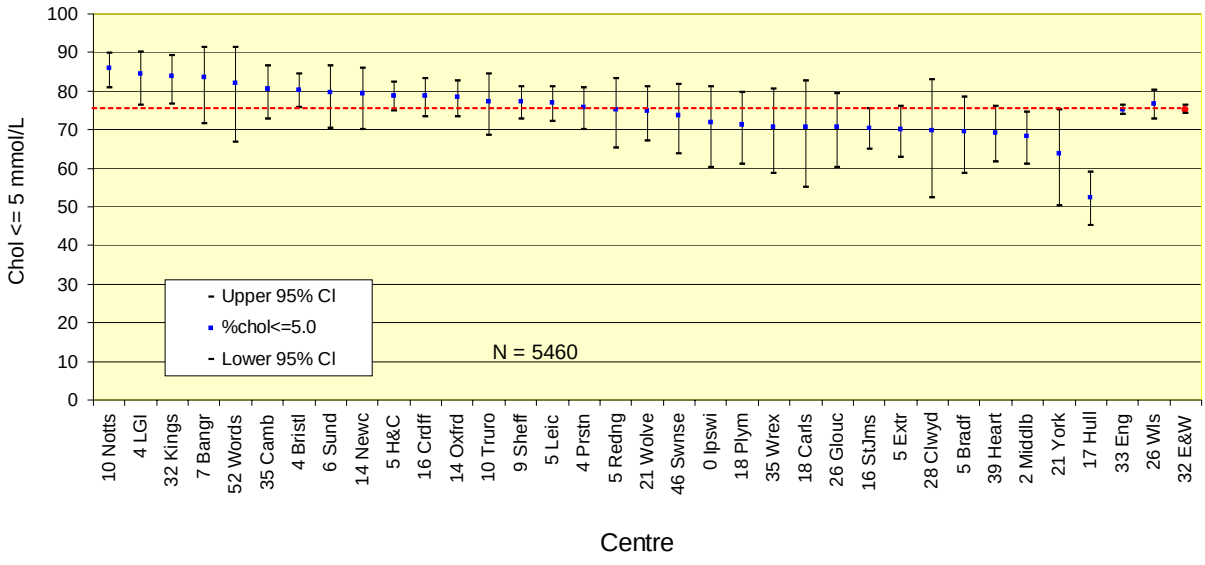

Figure 11.38. Percentage of patients with cholesterol <5 mmol/L; HD

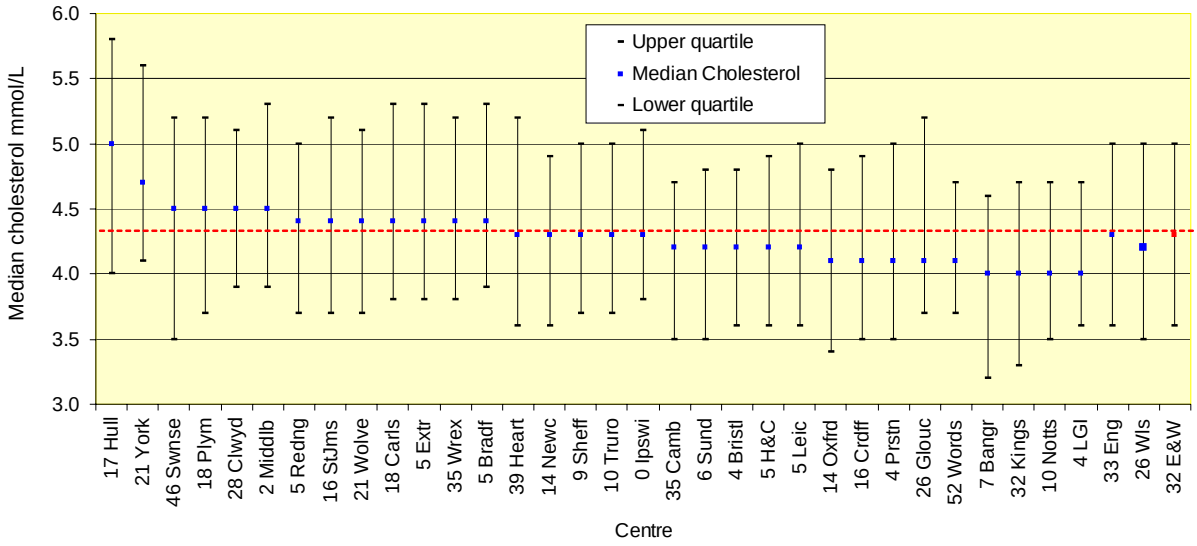

Figure 11.39. Median cholesterol; HD

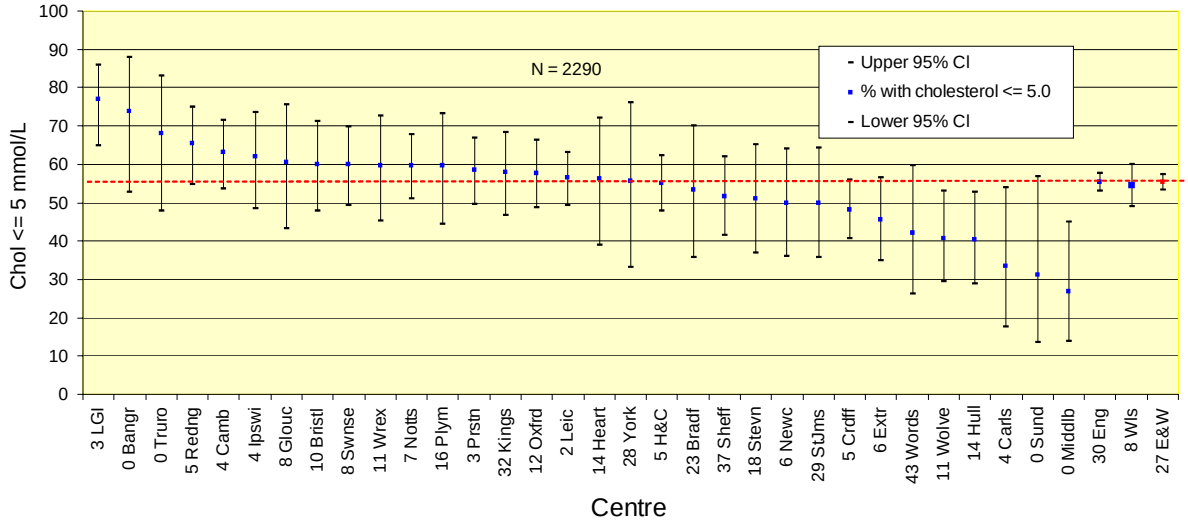

Figure 11.40. Percentage of patients with cholesterol <5 mmol/L; PD

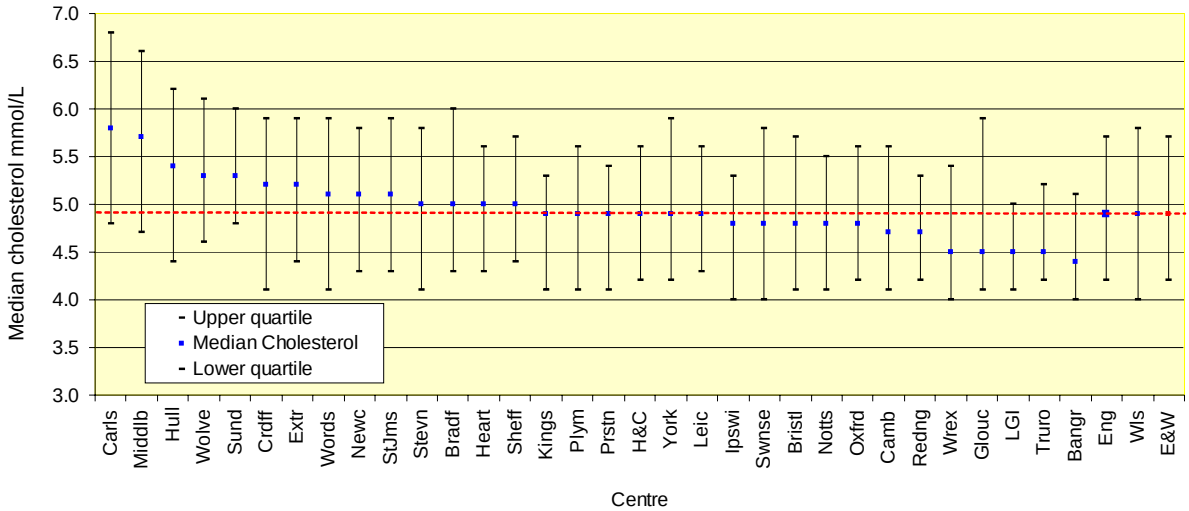

Figure 11.41. Median cholesterol; PD

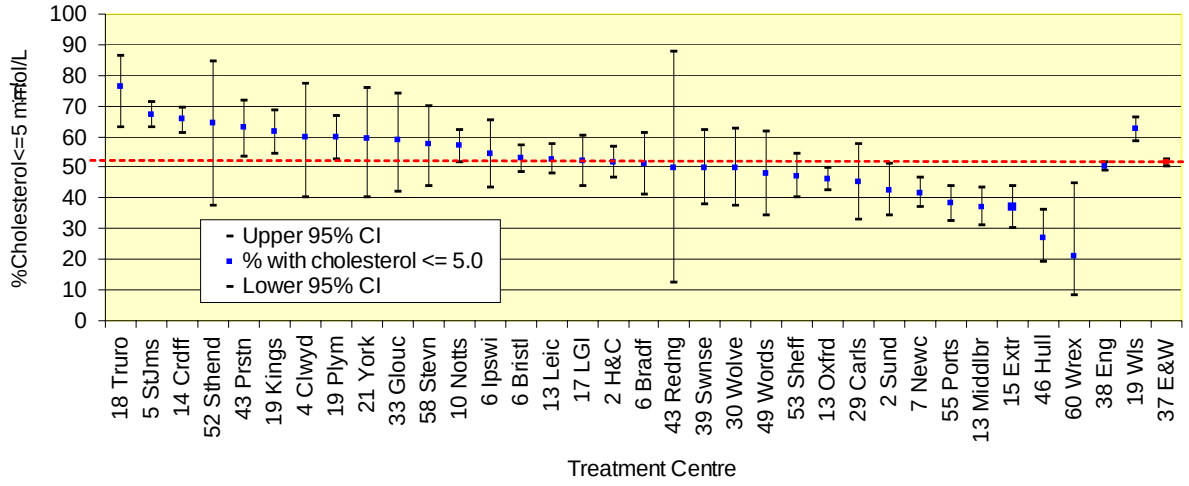

Figure 11.42. Percentage of patients with cholesterol <5 mmol/L; transplant

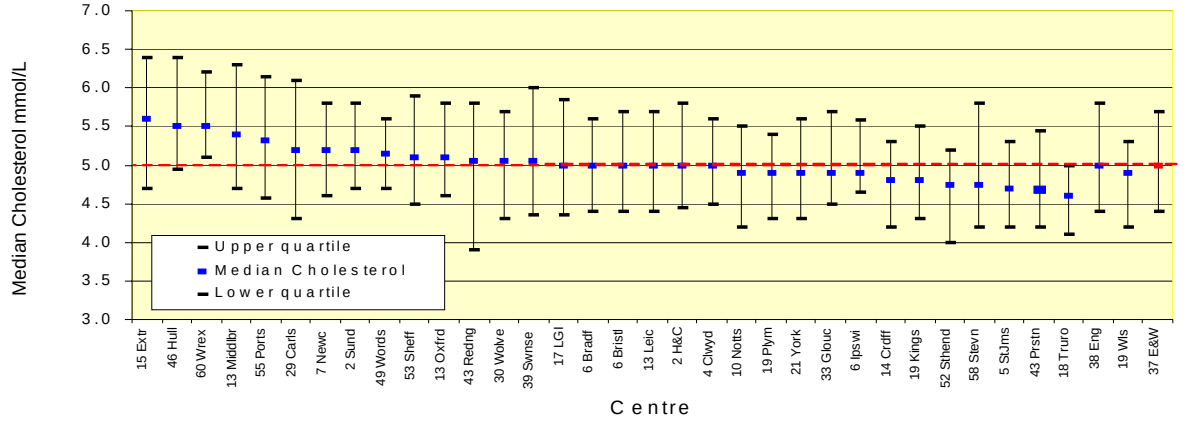

Figure 11.43. Median cholesterol; transplant

and 5.0 mmol/L respectively. Possible explanations include better targeting with statin therapy, exposure to inflammatory processes during haemodialysis and concentration of the sickest patients (malnourished with the greatest co-morbidity) on the haemodialysis programme. In addition, PD patients are in a 'nephrotic' protein loss state and may have increased cholesterol production (see cholesterol and modality change below).

Figures 11.45–11.47 show that diabetic patients have lower cholesterol concentrations compared to non-diabetics for each treatment modality. The difference is most marked for transplant patients.

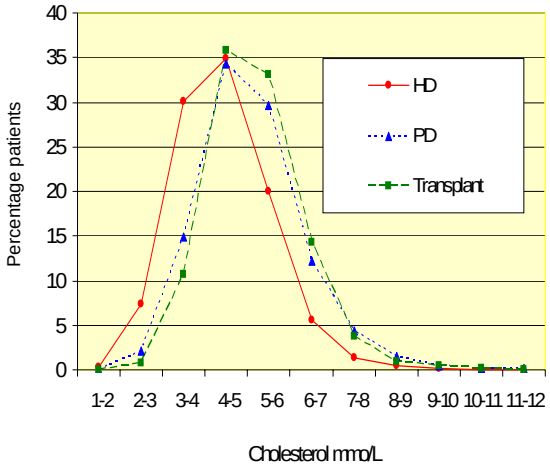

Figure 11.44. Serum cholesterol distribution by modality 31/12/2002

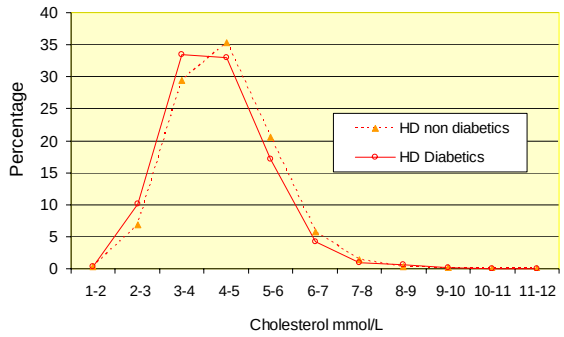

Figure 11.45. Distribution of serum cholesterol diabetics v non-diabetics; HD

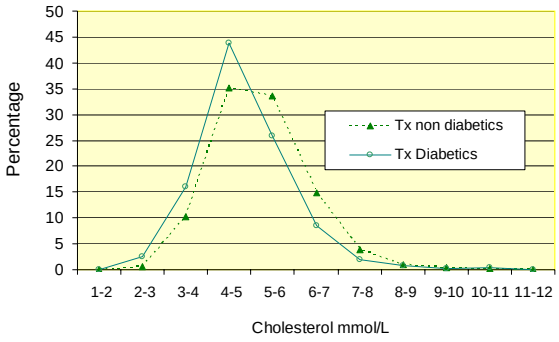

Figure 11.47. Distribution of serum cholesterol diabetics v non-diabetics; transplant

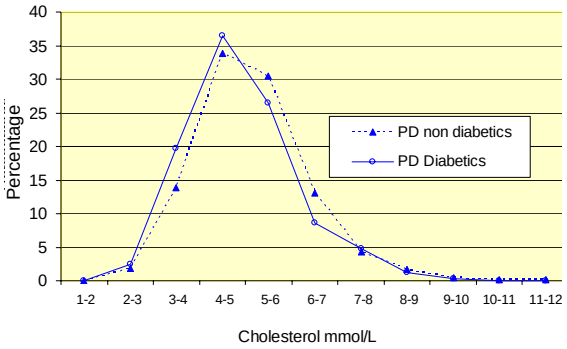

Figure 11.46. Distribution of serum cholesterol diabetics v non-diabetics; PD

Change in cholesterol achievement 1997–2002

Figure 11.48 shows the cholesterol data for all treatment modalities between 1997 and 2002 and Figures 11.49 and 11.50 show these data by each centre. Over these 5 years the concentration of total cholesterol has decreased in all treatment groups. The percentage of patients achieving the stan-

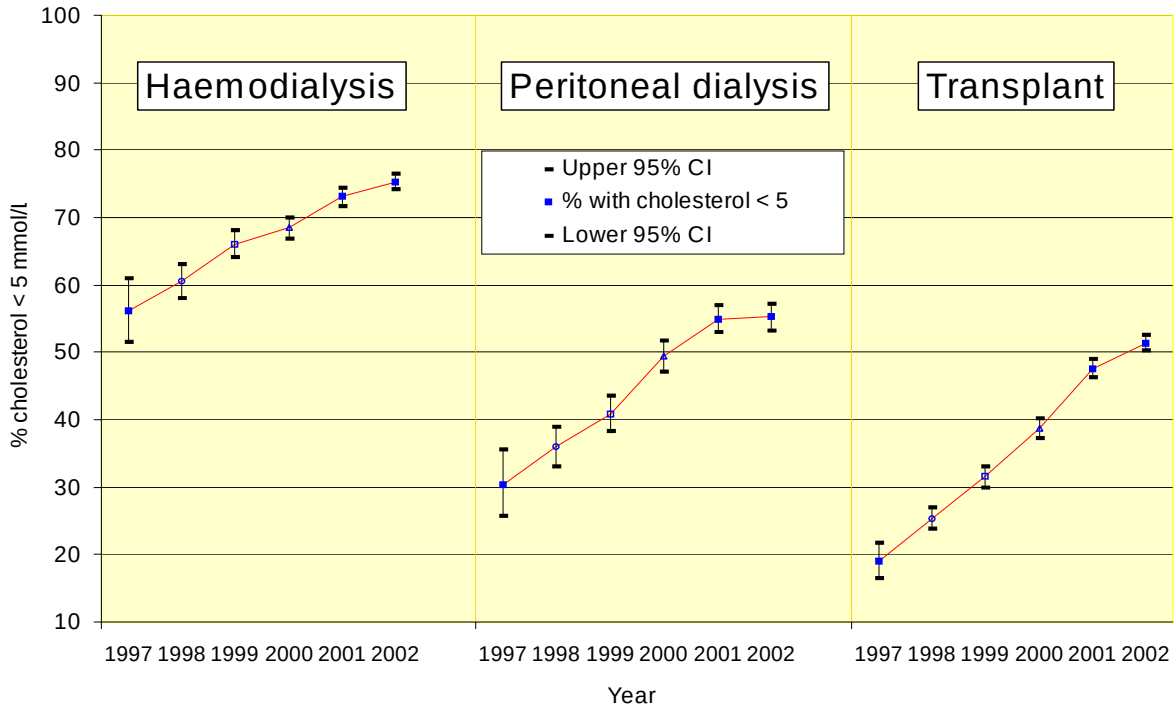

Figure 11.48. % of patients with cholesterol <5 mmol/L HD vs PD vs Tx 1997–2002

dard over this period has risen by 36%, 80% and 150% for HD, PD and transplant respectively. However, the number of PD patients achieving the cholesterol standard plateaued between 2001 and 2002. By comparison, Finnish Registry data shows cholesterol has decreased in all treatment groups between 1999 and 2002 because of a reduction in LDL-cholesterol. In Finland, triglyceride levels have remained static with higher levels in PD patients and HDL-cholesterol levels have also remained constant with higher levels in transplant patients.

Cholesterol levels following modality change

Figure 11.51 shows the change in serum cholesterol when patients switch from one treatment modality to another. The means have been adjusted for the fall in cholesterol for each modality each year. When patients transfer from PD to HD the mean serum cholesterol falls by 0.58 mmol/L. The drop in cholesterol occurs within the first quarter and is maintained over the following year. It is not clear whether systemic inflammation induced by HD or withdrawal of PD solutions are responsible for the fall in cholesterol level. By contrast when dialysis patients are transplanted their cholesterol levels rise within the first quarter by 0.59 mmol/L. These levels are sustained until the end of the first year when the mean cholesterol falls by 0.2 mmol/L. This may reflect hyperlipidaemia induced by immunosuppression as higher doses are used initially to prevent acute rejection.

Serum cholesterol and mortality

Figure 11.52 shows a J-shaped association between cholesterol level and mortality for HD and PD poppulations in England & Wales over the 1 year period in 2001. Only 1% of patients have cholesterol levels outside the range 2.5–9 mmol/L and within this range the curve is the same as last year. The Registry has not previously produced a separate analysis by dialysis modality. Short-term survival is optimal for a serum cholesterol level of 5–7.5 mmol/L for HD patients and 5–9 mmol/L for PD patients. A raised serum cholesterol in PD patients appears to have less impact on short term survival than in HD patients.

A recent prospective study of 823 HD patients shows the inverse association between cholesterol level and mortality is due to the cholesterol-lowering effect of systemic inflammation and malnutrition, not to a protective effect of high cholesterol concentration.[17] This supports treatment of raised cholesterol in the dialysis population. Following the publication of this study, the UK data has been reanalysed adjusting for the effect of albumin (Figure 11.53). As albumin methodology is split between BCG and BCP, the analysis included only sites using the BCG methodology as there were insufficient numbers for a separate BCP analysis. After adjustment for albumin, the relative risk of a raised cholesterol increases in the HD population. These data need to be analysed over a longer term.

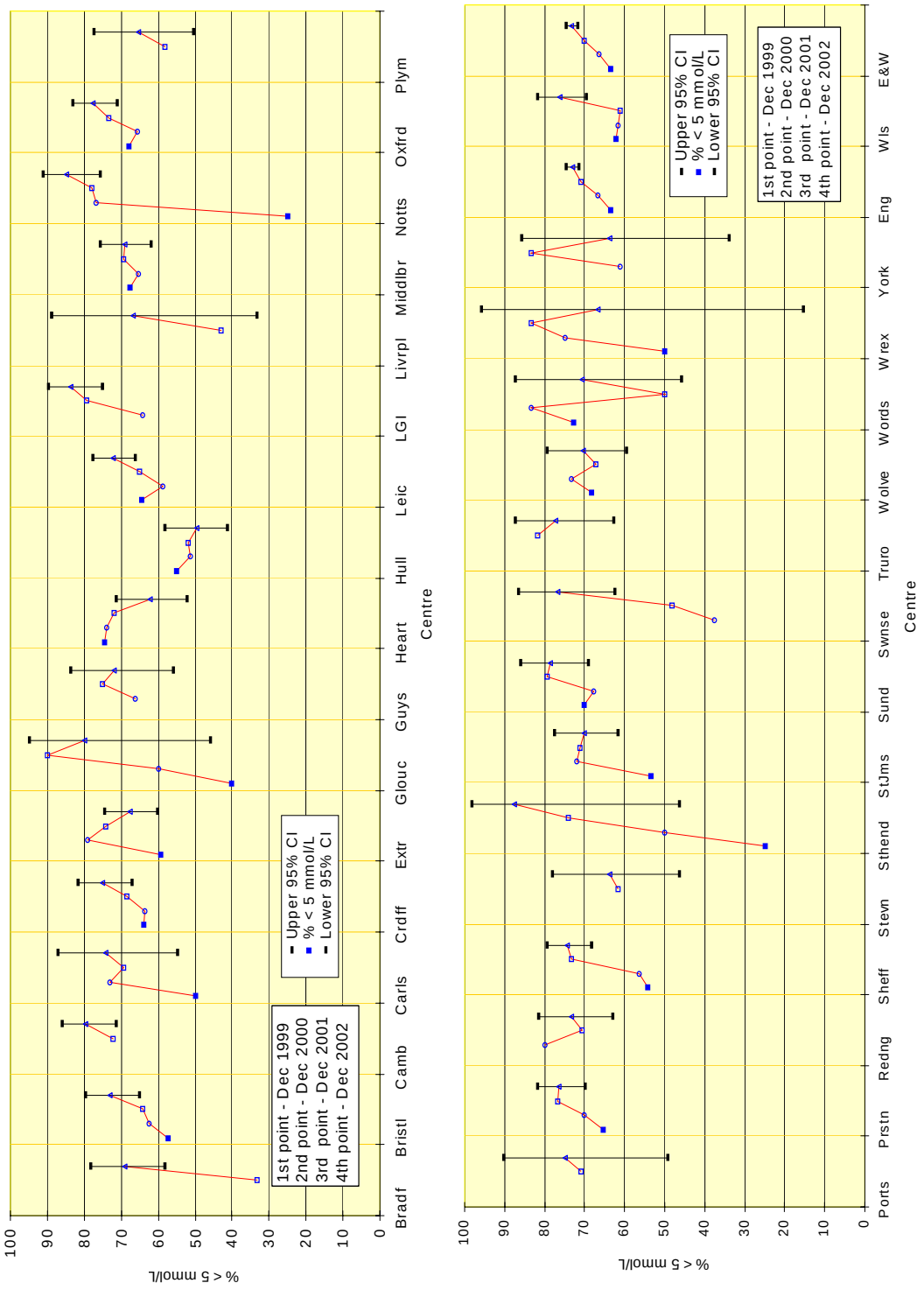

Figure 11.49. Change in % of HD patients with cholesterol <5 mmol/L by centre 1999–2002

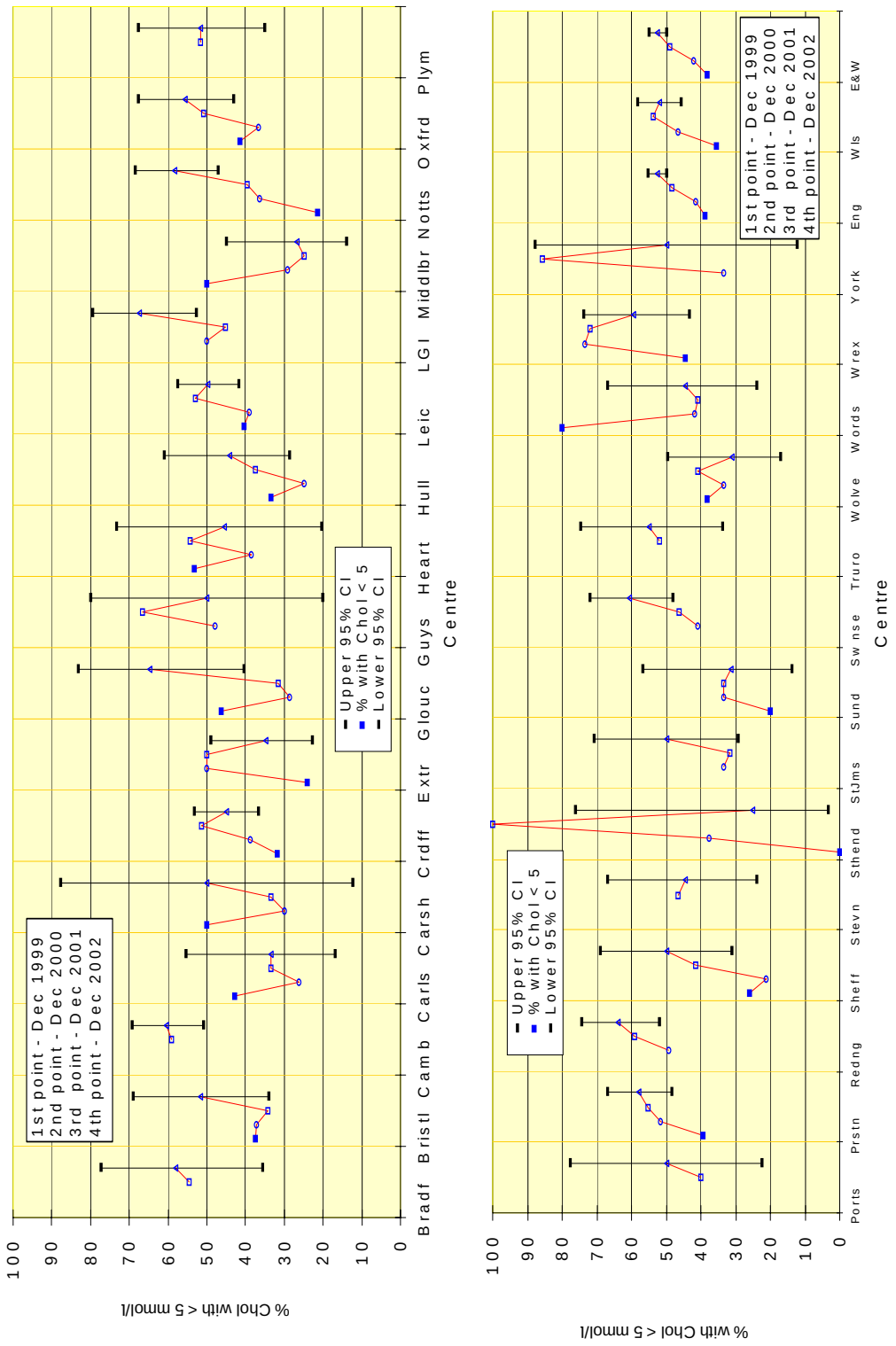

Figure 11.50 Change in % of PD patients with cholesterol <5 mmol/L by centre 1999–2002

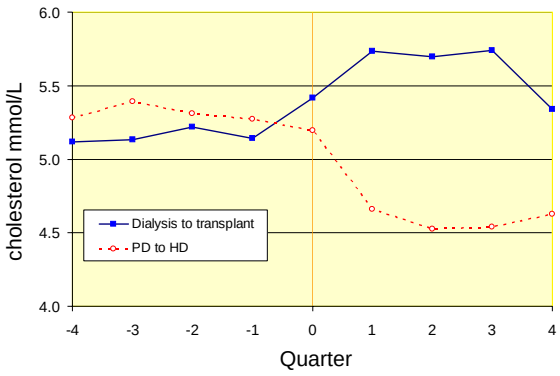

Figure 11.51. Serum cholesterol by quarter before and after modality change

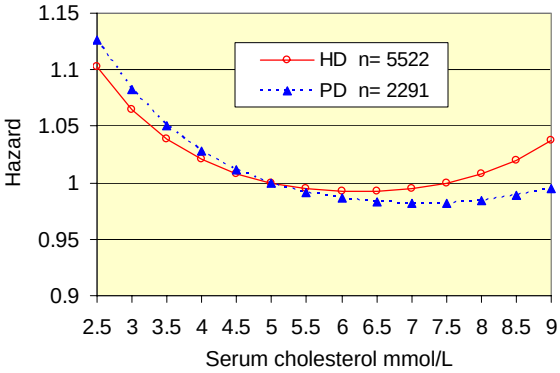

Figure 11.52. Serum cholesterol and relative hazard, by dialysis modality

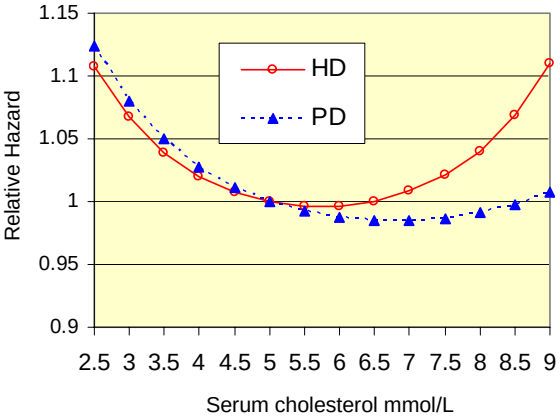

Figure 11.53. Serum cholesterol and relative hazard adjusted for albumin

In Lowrie's original report from 1990, the relative risk of death for HD patients with cholesterol <2.5 mmol/L or >9.3 mmol/L was 4.0 and 1.3 respectively.[11] The relative risk of death for these cholesterol levels in our population are very much lower, 1.1 and 1.05 for HD and 1.125 and 1.0 for PD. Age and diabetes increases risk of death at any given cholesterol level. The hazard ratios for each 1 year increase in age for HD, PD, and transplant are 1.03, 1.043, and 1.039 respectively. The hazard ratios for diabetes are 1.75, 1.84, and 1.87 respectively. This is comparable with iDOPPS data that shows risk of death on haemodialysis increases by 1.036 for each year and doubles for diabetes.

Clinical trials of cholesterol lowering in chronic renal failure

The UK Heart and Renal Protection study showed simvastatin 10mg/d reduced total cholesterol in dialysis patients by 20%, LDL by 26%, triglycerides by 13% but HDL levels remained stable.[18] SHARP, an international randomised trial (Study of Heart and Renal Protection), is designed to assess the impact of lowering cholesterol on major vascular outcomes and progression of chronic kidney failure. A combination of simvastatin and ezetimibe will be used to achieve the lowest cholesterol level possible. Recruitment is currently in progress and it is important that all UK nephrologists support enrolment into this study. The Clinical Trials Support Unit in Oxford can be contacted on 01865 404846.

The 4D study is expected to provide insight into the link between triglycerides and cardiovascular outcomes. Type 2 diabetics on haemodialysis are assigned either atorvastatin 20mg daily or placebo and the results are expected in 2004.

Acknowledgements

Dr Sarju Shrestha, Clinical Research Fellow, Southmead Hospital for the analysis on blood pressure, pulse pressure and mortality in incident haemodialysis patients.

Dr Es Will, Consultant Nephrologist, St James's University Hospital, Leeds for data on blood pressure distributions and digit bias.

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Chapter 12: Renal transplantation in adults

Summary

- This chapter reports on data returned from 40 units of which 17 are renal transplant centres.
- Data on 60% of all transplant patients in the UK and 69% from England and Wales are reported to the UK Renal Registry.
- 26% of all transplant patients on the Registry database are managed by non-transplant centres.
- The proportion of new transplant patients with a primary renal diagnosis of diabetic nephropathy has progressively increased from 7.5% in 1999 to 9.6% in 2002.
- 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.
- 2.3% of all prevalent transplants failed during 2001 (excluding death with a functioning transplant).
- The annual death rate of patients with established renal transplants for England and Wales is 2.4% (excluding 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 control of these factors is often poor. In most centres there has been a progressive reduction in median serum cholesterol levels since 1998. In 2002, 51.4% of all transplant patients had a cholesterol level of less than 5.0 mmol/L. Cholesterol levels rise during the first year after transplantation and overall are similar to the distribution of cholesterol in patients treated by peritoneal dialysis. Cholesterol levels are lower in diabetic compared with non-diabetic transplant patients.
- Blood pressure control falls far short of Renal Association standards. Reporting of blood pressure is poor from some centres, who will need to explore ways of storing blood pressure records electronically to facilitate audit.
- There is a need to provide more complete transplant information by merging data from UK Transplant and the UK Renal Registry.

Introduction

In 2002, there were 25 centres in England and Wales performing renal transplantation in adults. However, a greater number of renal units contribute to the management and follow up of patients after transplantation. This chapter reports on data returned from 40 units, of which 17 perform renal transplantation. Two units do not follow up their patients who are transplanted and one follows only 7 patients. The others all follow more than 25 transplantees.

Other data on renal transplantation are available from www.uktransplant.org.uk. In the year April 2001-2002, UK Transplant reported a total of 1245 cadaver donor transplants and 438 live donor transplants; this was a fall of 2.0% over the previous year. There were 4963 patients on the transplant waiting list on 31st March 2002, a figure which had increased by 2.4% over the previous year. Subsequently the number of transplants performed has increased by 1.5% and the waiting list has increased by a further 2.2%. UK Transplant figures include paediatric patients. The paediatric renal replacement therapy population accounted for 119 of these transplants, 65% of which were living donors.

In this chapter, emphasis is placed on access to transplantation, quality of

transplant function (expressed as estimated GFR using abbreviated MDRD formula), patient survival, haemoglobin and potentially modifiable cardiovascular risk factors such as blood pressure and cholesterol. For the first time, information on social deprivation and the ethnic distribution of transplant recipients is provided.

Data comparison between centres managing a small number of transplant patients should be made with caution.

Transplants performed 2002

In 2002, 935 renal transplants were performed in patients from centres contributing to the Renal Registry. This represents 62% of all renal transplants performed in England and Wales and 56% of all renal transplants performed in the UK in that year. The median age of the new transplant recipients was 46.8 years, 61.3% were male and 38.7% female. Table 12.1 shows the change in median age of new adult transplant recipients in England and Wales since 1998.

Since 1999, data on an increasing proportion of new and prevalent transplant patients have been included in the UK Renal Registry (Table 12.2).

Table 12.3 shows the primary renal diagnosis in newly transplanted patients and in the established transplant population. The proportion of new transplants whose primary renal diagnosis was diabetic nephropathy has progressively increased through 1999, 2000, 2001 from 7.8%, to 9.0% to 9.6% in 2002.

Patients with established renal transplants

In 2002 there were 10372 prevalent transplant patients in participating centres. Table 12.4 shows the number of prevalent transplant patients at each centre. Overall, 74% of all transplant patients reported to the Registry are managed by centres performing renal transplantation.

The transfer of patients from the transplant centre back to the referring unit occurs at variable times after transplantation ranging from 7 days to 1 year or longer. Therefore, a more meaningful way of presenting this data is as the transplant prevalence rate (p.m.p.) according to the resident area populations organised by postcode. The data in Table 12.5 has been presented using postcode links to the 'old' Health Authorities (HAs) as there has been insufficient time to remap these data to Local Authorities and PCTs in current use. HAs that are known to have incomplete coverage have been removed. The two transplant units in Birmingham and Manchester, which are not currently submitting data to the Registry, account for much of the incomplete data for the HAs in these regions.

The transplant prevalence rate of 271 p.m.p in England is in keeping with the 2002 national survey in Chapter 3 of this years report. The falling proportion of renal replacement therapy patients with a functioning transplant shown in Table 12.6 is due to the increasing number of patients starting dialysis who are aged over 65 years and therefore less likely to be suitable for transplantation, together with falling cadaveric donation rates.

Table 12.1. Median age of new transplant recipients in Registry units in England and Wales since 1999

	Median age	Number
1998	42.9	496
1999	41.6	517
2000	45.4	646
2001	43.7	830
2002	46.8	935

Table 12.2. Number of new and prevalent transplant patients in UK units reporting to the Renal Registry

	New transplants UK (inc children)	Prevalent transplants UK	New transplants Renal Registry E&W	Prevalent transplants Renal Registry E&W
1999	1581	Not available	517	5433
2000	1671	Not available	646	6689
2001	1691	Not available	830	8688
2002	1658	17135	935	10372

Table 12.3. Primary diagnosis of transplant patients in the UK

	New transplants in 2002		**Established transplants 1/1/02**	
	%	**No**	**%**	**No**
Aetiology unc. /Glomer. NP	16.4	153	22	2282
Glomerulonephritis	23.4	219	19	1971
Pyelonephritis	12.7	119	16	1660
Diabetes	9.6	90	7	726
Renal Vascular disease/Hypert.	6.3	59	7	726
Polycystic Kidney	13.1	122	11	1141
Not sent	4.4	41	3	311
Other	14.1	132	15	1556

Table 12.4. Number of prevalent transplant patients according to registry centre.

Treatment Centre	**Prevalent Transplant Patients**
Bangr	0
Bradf	100
Bristl	561
Camb	392
Carls	85
Carsh	339
Clwyd	26
Covnt	262
Crdff	615
Extr	222
Glouc	51
Guys	706
H&Cx	406
Heart	185
Hull	192
Ipswi	87
Kings	237
Leic	460
LGI	164
Livrpl	632
Newc	465
Notts	380

Treatment Centre	**Prevalent Transplant Patients**
Oxfrd	859
Plym	221
Ports	613
Prstn	191
Redng	7
SCleve	280
Sheff	410
Stevn	147
Sthend	29
StJms	484
Sund	129
Swnse	105
Truro	63
Wirrl	0
Wolve	84
Words	94
Wrex	47
York	34
Eng	9571
Wales	793
E&W	10372

Centres that perform renal transplantation are shown in bold type

Table 12.5. Transplant prevalence rate per million population (p.m.p) according to resident Health Authority of transplant patient

Region	HA Text	Population	Transp prev p.m.p	% transp	No patients with transp
Y01	Bradford	483,300	283	43	137
Y01	Calderdale and Kirklees	583,800	324	52	189
Y01	County Durham and Darlington	607,800	326	56	198
Y01	East Riding and Hull	574,500	216	40	124
Y01	Gateshead and South Tyneside	353,500	362	60	128
Y01	Leeds	727,400	268	46	195
Y01	Newcastle & North Tyneside	470,100	357	62	168
Y01	North Cumbria	319,300	279	53	89
Y01	North Yorkshire	742,400	229	43	170
Y01	Northumberland	309,600	365	60	113
Y01	Sunderland	292,300	349	63	102
Y01	Tees	556,300	325	58	181
Y01	Wakefield	318,800	248	48	79
Y02	Barnsley	228,100	307	46	70
Y02	Doncaster	290,500	220	37	64
Y02	Leicestershire	928,700	305	45	283
Y02	Lincolnshire	623,100	238	44	148
Y02	North Derbyshire	370,200	213	43	79
Y02	North Nottinghamshire	388,900	255	43	99
Y02	Nottingham	642,700	249	39	160
Y02	Rotherham	254,400	240	36	61
Y02	Sheffield	531,100	217	37	115
Y02	South Humber	308,600	230	39	71
Y07	Coventry	304,300	276	38	84
Y07	Warwickshire	506,700	326	50	165
Y08	Liverpool	461,500	247	40	114
Y08	Morecambe Bay	310,300	126	34	39
Y08	Sefton	287,700	205	39	59
Y08	St Helens and Knowsley	333,000	255	45	85
Y08	Wirral	327,100	263	43	86
Y09	Bedfordshire	556,600	228	41	127
Y09	Cambridgeshire	468,000	321	42	150
Y09	Suffolk	671,100	182	48	122
Y10	Bexley, Bromley and Greenwich	730,000	275	47	201
Y10	Ealing, Hammersmith & Hounslow	617,200	262	28	162
Y10	Lambeth, Southwark and Lewisham	745,200	309	39	230
Y11	Berkshire	800,200	295	52	236
Y11	Buckinghamshire	681,900	301	54	205
Y11	East Surrey	419,900	262	57	110
Y11	I o Wight, Portsmouth, SE Hampshire	671,700	331	58	222
Y11	North and Mid Hampshire	556,900	223	55	124
Y11	Northamptonshire	615,800	268	48	165
Y11	Oxfordshire	616,700	318	55	196
Y11	Southampton & SWest Hampshire	542,300	278	59	151
Y11	West Surrey	640,600	204	47	131
Y12	Avon	999,300	346	53	346
Y12	Cornwall and Isles of Scilly	490,400	281	41	138
Y12	Gloucestershire	557,300	248	46	138
Y12	North and East Devon	479,300	246	45	118
Y12	Somerset	489,300	260	45	127
Y12	South and West Devon	589,100	290	48	171
Y12	Wiltshire	605,500	256	55	155
W00	Gwent	557,200	377	52	210
W00	Bro Taf	739,600	339	50	251
W00	Dyfed Powys	479,400	215	39	103
W00	North Wales	657,500	259	37	170
W00	Morgannwg	499,700	326	46	163
	England	29,528,000	267		7,823
	Wales	2,933,400	306		897
	England & Wales	32,461,400	271		8,720

Figure 12.1 shows the age distribution of the prevalent transplant patients compared with that for the dialysis population from which they were drawn. The median age of the transplant patients was 49.6 years compared with 62.7 years for the dialysis population. 14% of the total prevalent transplant population and 45% of the prevalent dialysis population were over 65 years old.

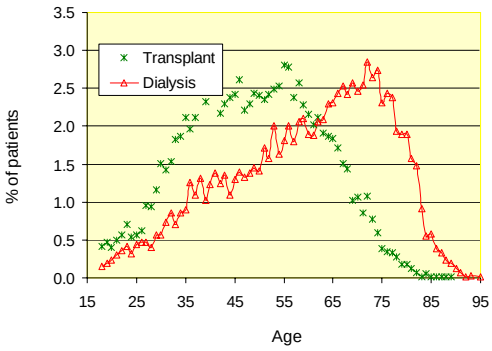

Figure 12.1. Age histogram of dialysis and transplant patients

Figure 12.2 shows the proportion of prevalent patients at each participating centre aged less than 65 years receiving renal replacement therapy by RRT modality at the end of 2002. This age cut off has been chosen as most patients receiving a renal transplant for the first time are aged 65 years or under. Overall for England and Wales, 57% of the prevalent RRT patients under 65 years are transplanted patients. If all patients receiving RRT are included (i.e. those aged over 65 years as well), this proportion falls to 46%.

Figure 12.3 shows the proportion of prevalent dialysis patients at each participating centre under 65 years old that has *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 are apparent wide variations (7.6-47.4%) between patients' access to transplantation in different centres.

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 differences. Differences may also exist between transplant centres in the selection criteria used for accepting patients onto the waiting list. The demographics of the local population are also important. Renal units in areas with an elderly population will have a larger proportion of elderly dialysis patients with co-morbidity, who are unfit for transplant. In addition, patients in older units are likely to have had a longer opportunity for transplantation than in newer units and older units are consequently more likely to have a larger proportion of transplanted patients. Another possible explanation for these variations is the difference in the proportion of prevalent dialysis patients made up by ethnic minorities (harder to match both blood group and HLA type and thus transplant) in each centre. It is hoped in the future to produce figures for access to transplantation which are standardised for age and gender.

Amongst all transplanted patients in 2002, the ethnic origin was recorded as Caucasian in 85.6%, as African-Caribbean in 4.9%, as Indo-Asian in 7.7%, as Chinese in 0.2% and as other in 1.6%. Figure 12.4 shows the proportion of patients in each ethnic group under 65 years old that have ever received a renal transplant.

Table 12.6. Annual proportion of RRT patients with functioning transplant, recipient median age and % aged>65

Year	% all RRT with functioning transplant	Median age of transplant recipients	% transplant recipients >65 yrs old
1997	51.0	-	-
1998	49.9	42	-
1999	47.3	43	5%
2000	46.9	-	-
2001	46.6	49.0	13.2%
2002	46.0	49.6	14.0%

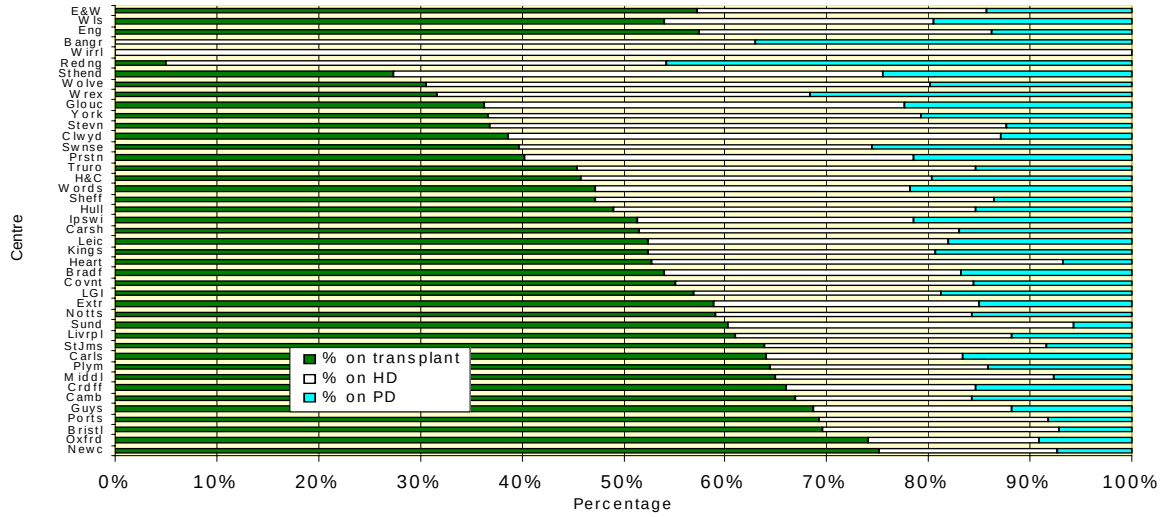

Figure 12.2. Treatment modality of all prevalent patients < 65 years old

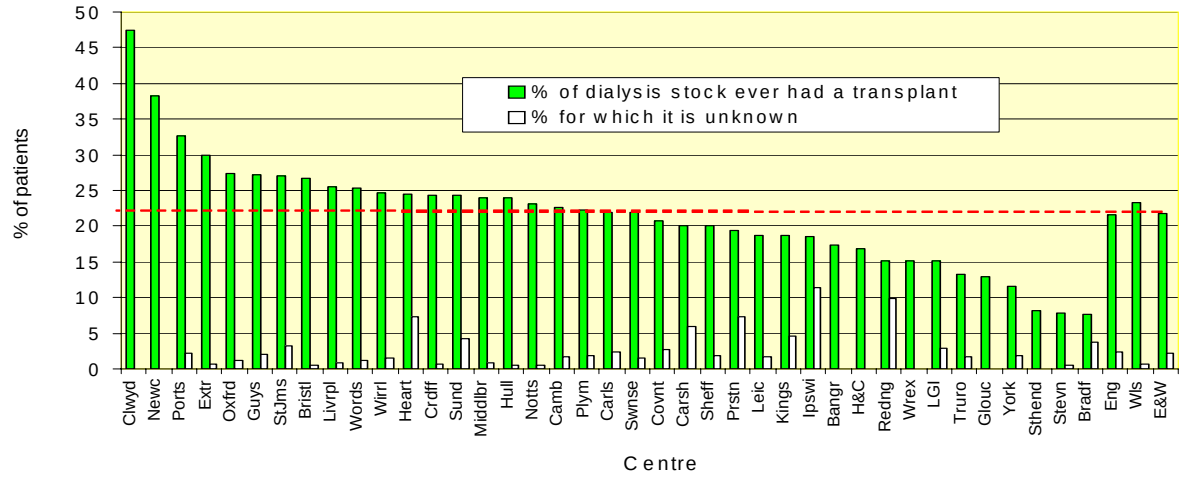

Figure 12.3. % of prevalent dialysis patients aged <65 years who have ever received a transplant

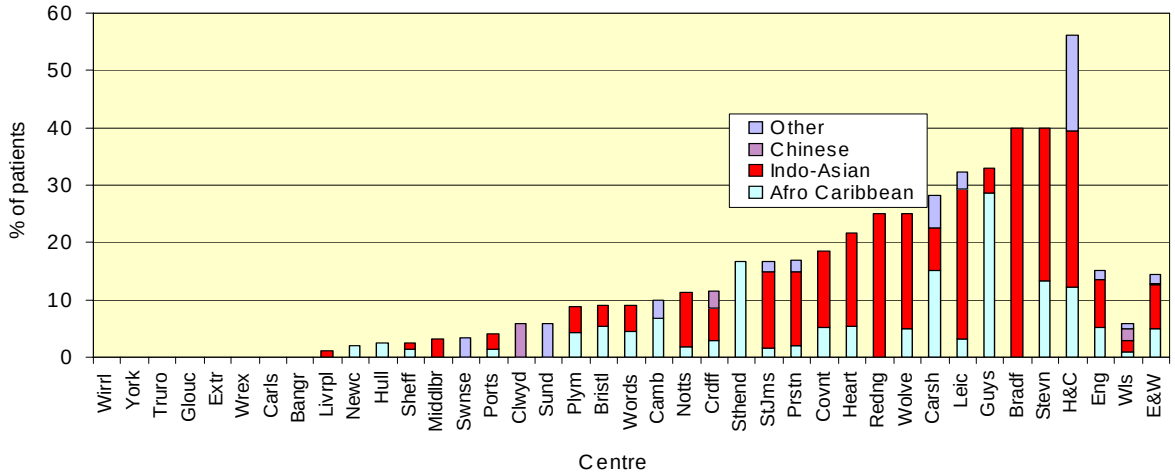

Figure 12.4. Proportion of patients <65 years ever received a transplant, by ethnicity

Transplantation in patients with diabetes mellitus

Figure 12.5 shows the proportion of all patients in each registry centre with a functioning renal transplant on 31/12/02 whose primary renal failure diagnosis was diabetes mellitus. Overall in England and Wales, 7.2% of all prevalent transplant patients have diabetes mellitus as the cause of end-stage renal failure. This proportion has increased annually from 5.8% in 1997. The median age of prevalent transplant patients in England and Wales with a primary diagnosis of diabetes mellitus was 49 years compared with 46.8 years for the whole group of prevalent transplant patients.

The percentage of diabetic ERF patients under 65 years old with a transplant was examined by centre to explore whether there was a difference between centres in their approach to transplanting patients with this diagnosis (Figure 12.6).

There is a very wide variation (6.5-64.9%) between centres in the proportion of diabetic patients under 65 years old with end-stage renal failure that have a transplant (37.6% overall mean for England & Wales). 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 12.7). 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.

The ratio was wide ranging from 0.86 down to 0.14. Because differences in the overall proportion of ERF patients with diabetes under 65 years may partially account for this variability, these percentages are also shown for each centre. Inspection of Figure 12.7 shows that a significant difference still exists between centres with either a high or low prevalence of diabetic ERF patients. Differences in the percentage of the cohort originating from ethnic minorities (and thus likely to experience difficulty in blood group and HLA matching) are unlikely to account for all the observed differences.

ERF patients with diabetes mellitus are less likely to receive a transplant than other ERF patients due to a number of possible factors, including co-morbidity and ethnicity. However, other differences between centres must also exist to account for the observed variation in the proportion of patients with diabetes mellitus transplanted.

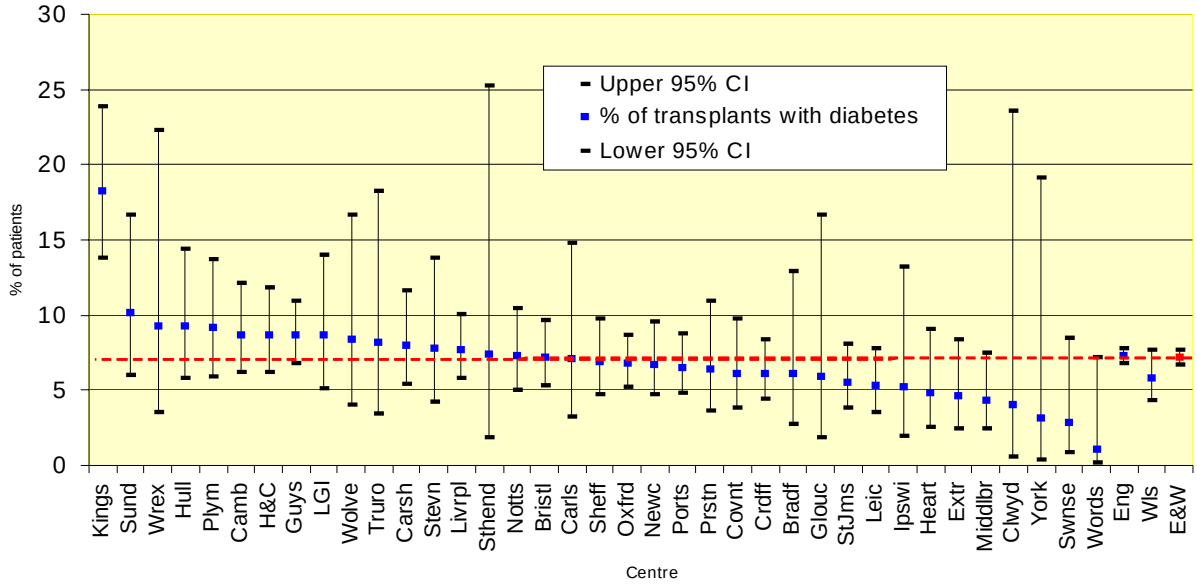

Figure 12.5. Percentage of current transplant patients with diabetes mellitus, by centre

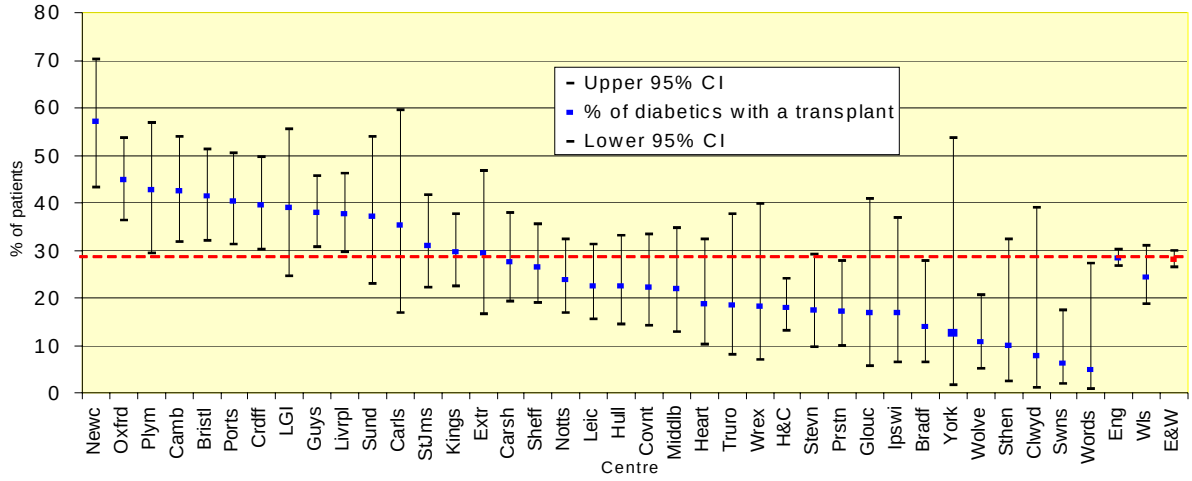

Figure 12.6. Percentage of diabetic ERF patients with a transplant, by centre

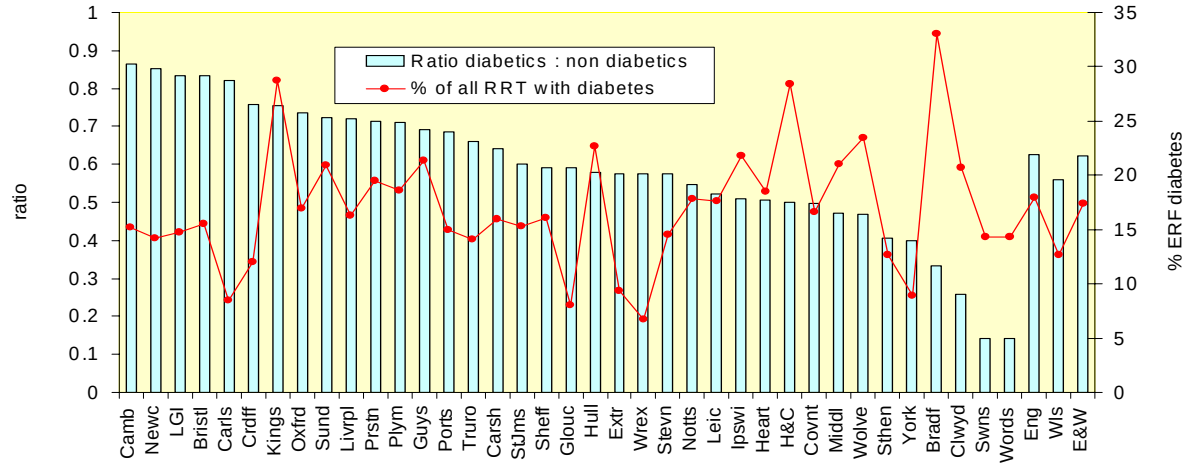

Figure 12.7. Ratio of patients with a transplant under 65, diabetics: non-diabetics and proportion of all ERF patients under 65 with a primary diagnosis of diabetic nephropathy

Social Deprivation

Social deprivation was examined and scored using the Townsend score which was derived from the patient's postcode. The Townsend score is a composite measure of deprivation based on total unemployment rate, no car households, overcrowded households and not owner occupier households based on the electoral ward as at the 2001 Census. The higher the Townsend index, the greater is the deprivation (see Chapter 17).

Analysing the incident cohort, patients who received a transplant within the first 90 days of starting renal replacement therapy (including those with a pre-emptive transplant) were the least socially deprived (Townsend score -1) compared with those on PD (Townsend score -0.33) and HD (Townsend score 0.3) at day 90.

Analysing the prevalent cohort by median Townsend index, renal replacement therapy modality and age (Figure 12.8), in nearly every age band the Townsend index for transplanted patients is lower than for patients treated by peritoneal dialysis or haemodialysis. In addition, for each modality, the index falls with increasing age. The observed differences may be accounted

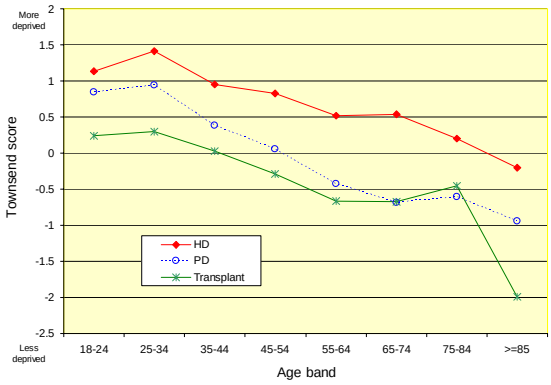

Figure 12.8. Townsend score by different RRT modalities and age

for by a number of factors including differences in co-morbidity and ethnicity, which are different in different social groups (see Chapter 17 for further discussion).

Failed transplants

Among prevalent transplant patients, 2.3% of transplants failed during 2002, excluding patients who died with a functioning graft. The overall failure rate is dropping and was about 3% in 1998.

Survival of patients with established renal transplants

Table 12.7 shows the Kaplan-Meier one-year patient survival for established transplant patients (transplanted for at least 6 months) alive on 1/1/2002. Data censored for return to dialysis and including death after return to dialysis within 2002 are shown.

Quality of transplant function

This analysis considered transplant patients on 31/12/2002 whose transplant had been functioning for at least one year. The most recent serum creatinine within 6 months was used in the analysis. There was no relationship between primary diagnosis and graft function as judged by estimated GFR using the abbreviated MDRD equation.

Figure 12.9 shows the median estimated GFR of prevalent transplant recipients for each centre. There are no statistically significant differences in median GFR values between centres.

Figures 12.10 and 12.11 show the percentage of established transplant patients at each unit with a calculated GFR of greater than 30 mls/min and 60 mls/min (MDRD) respectively. The differences between units are significant but unexplained; they may include differences in degree of HLA matching, immunosuppressive drug regimens and attitude to use of marginal donors.

Table 12.7. Survival during 2002 of established transplant patients alive 1.1.2002

	Transplant censored at dialysis			Transplant including dialysis returns		
	England	**Wales**	**E&W**	**England**	**Wales**	**E&W**
No. of patients	8503	782	9285	8503	782	9285
No of deaths	193	22	215	211	24	235
Death rate (95% CI)	2.3 (2.0-2.7)	2.9 (1.8-4.4)	2.4 (2.1-2.7)	2.5 (2.2-2.9)	3.1 (2.0-4.7)	2.6 (2.3-2.9)
K-M 1 yr survival (95% CI)	97.7 (97.4-98)	97.1 (96.0-98.3)	97.6 (97.3-98.0)	97.5 (97.2-97.8)	96.9 (95.7-98.1)	97.5 (97.1-97.8)

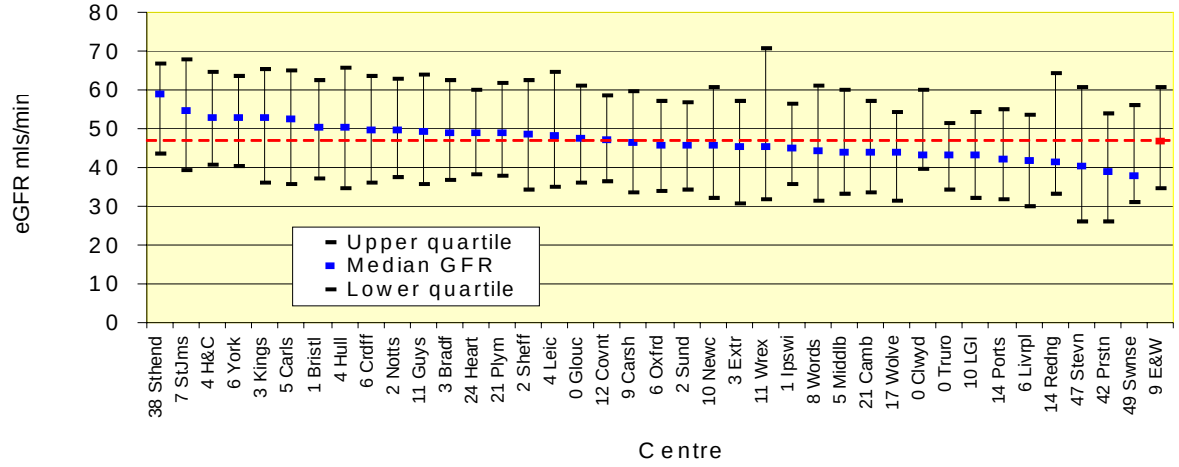

Figure 12.9. Median GFR of prevalent transplant patients, by centre

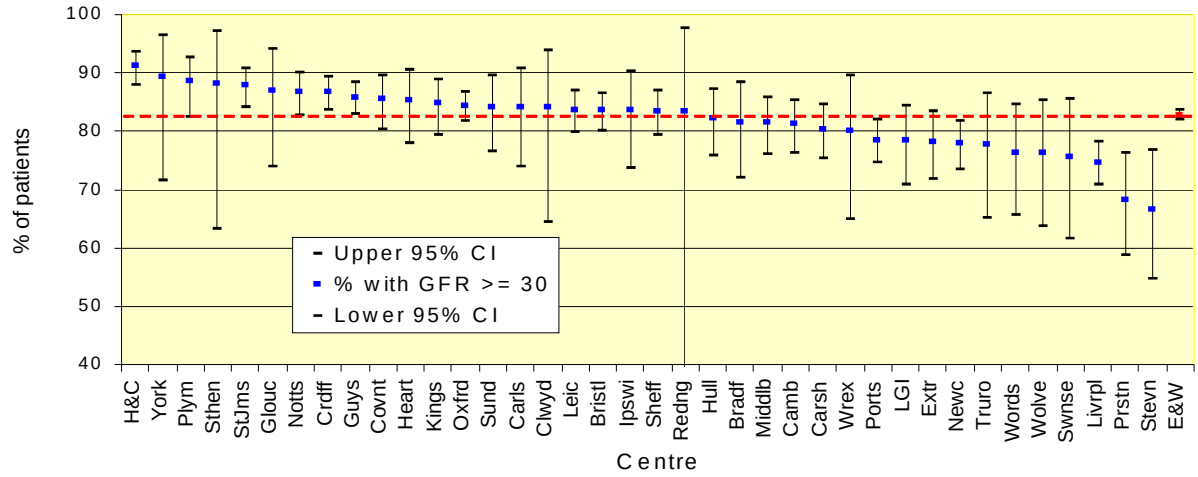

Figure 12.10. Percentage of established transplant patients with eGFR >30 mls/min (MDRD)

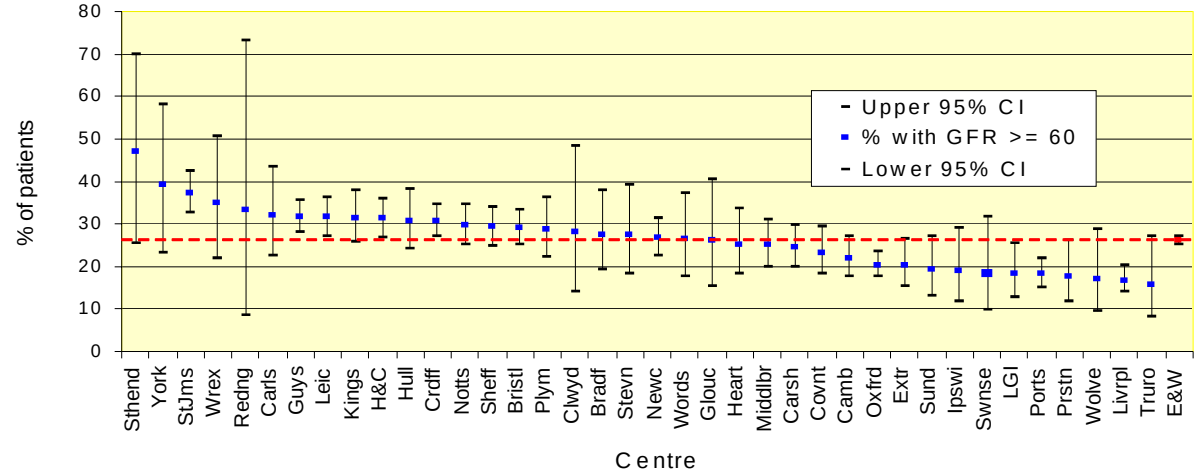

Figure 12.11. Percentage of established transplant patients with eGFR >60 mls/min (MDRD)

Haemoglobin in transplanted patients

There are no recommended haemoglobin standards for renal transplant patients although patients with failing transplants (eGFR < 30 mls/ min) should fall into the same category as patients with chronic kidney disease and the Renal Association Standard (Hb > 10g/dl) should be applied for these patients. Figure 12.12 shows the median haemoglobin for all prevalent transplant patients at least 6 months after transplantation according to Registry centre.

Figure 12.13 shows the percentage of transplant patients in each unit with a haemoglobin concentration less than 10g/dL. Overall, 5.4% of all transplant patients (at least 6 months after transplantation) have a haemoglobin level below 10g/dL. The variation of 1.8-15% between centres with Hb <10g/dL is unexplained. Possible reasons include quality of graft function (see below), type of immunosuppression (i.e. use of azathioprine and mycophenolate mofetil) and use of erythropoietin when there are failing grafts.

Figure 12.14 shows the median haemoglobin at each centre according to level of renal transplant function (calculated GFR greater or less than 30mls/ min). Centres with 10 or fewer patients in each group have been excluded. Not surprisingly, the median haemoglobin was lower in patients with a GFR below 30 mls/min compared with those whose GFR was above this value (11.5 vs 13.1 g/dL; $p < 0.001$).

As expected haemoglobin was lower in women and in patients with a lower GFR (Table 12.8).

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. However, for primary prevention in dialysis patients, the Renal Association Standards 3rd edition recommends that ;

> ***patients with a 10-year risk of coronary disease calculated as 30% should receive treatment with a HMG-CoA reductase inhibitor ("statin") to achieve a total cholesterol of <5 mmol/L, or a 30% reduction from baseline or a fasting LDL-cholesterol of <3mmol/L (whichever is the greatest reduction).***

This analysis included all transplant patients on 31/12/2002 whose grafts had been functioning for at least one year. The most recent serum cholesterol over a 12-month period was used. Results were available from 6501 patients. At least one serum cholesterol value had

Table 12.8. Relationship between haemoglobin, GFR and gender in transplant patients

		Haemoglobin							
Gender	GFR mls/ min	Mean Hb	Std dev	5th centile	Lower quartile	Median Hb	Upper quartile	95th centile	No. with data
Male	<30	11.7	1.7	9.0	10.4	11.6	12.8	14.6	664
Male	>30	13.5	1.7	10.7	12.4	13.5	14.7	16.2	3475
Female	<30	11.4	1.6	8.9	10.4	11.3	12.4	14.0	582
Female	>30	12.5	1.5	10.1	11.5	12.5	13.5	14.9	2026

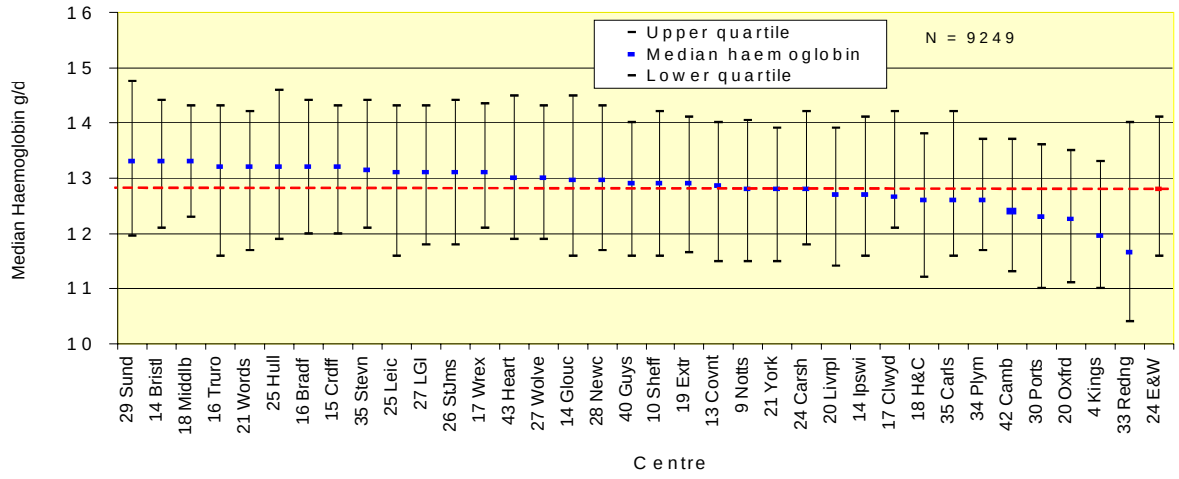

Figure 12.12. Median Hb of transplant patients >6 months post-transplant by centre

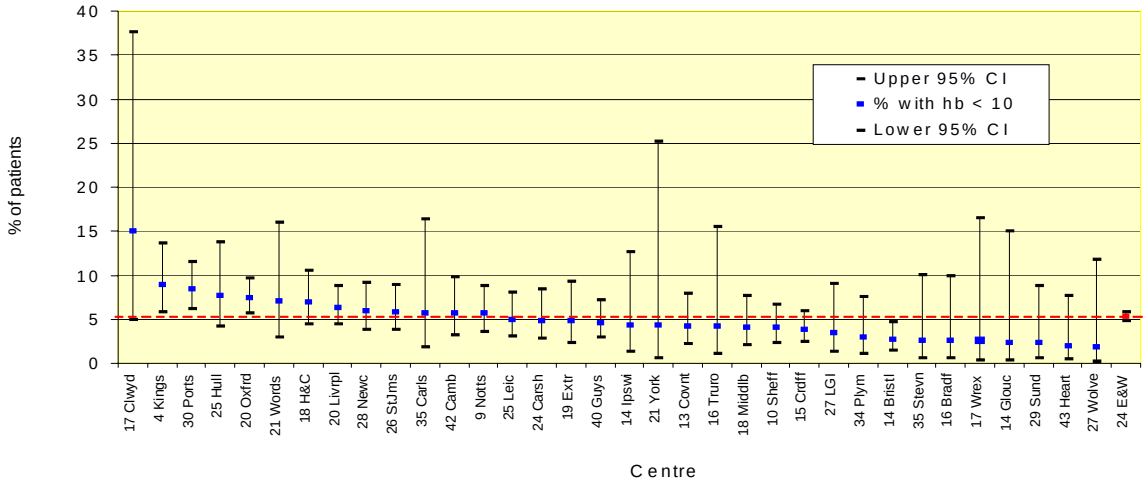

Figure 12.13. Percentage of transplant patients with haemoglobin <10g/dL by centre

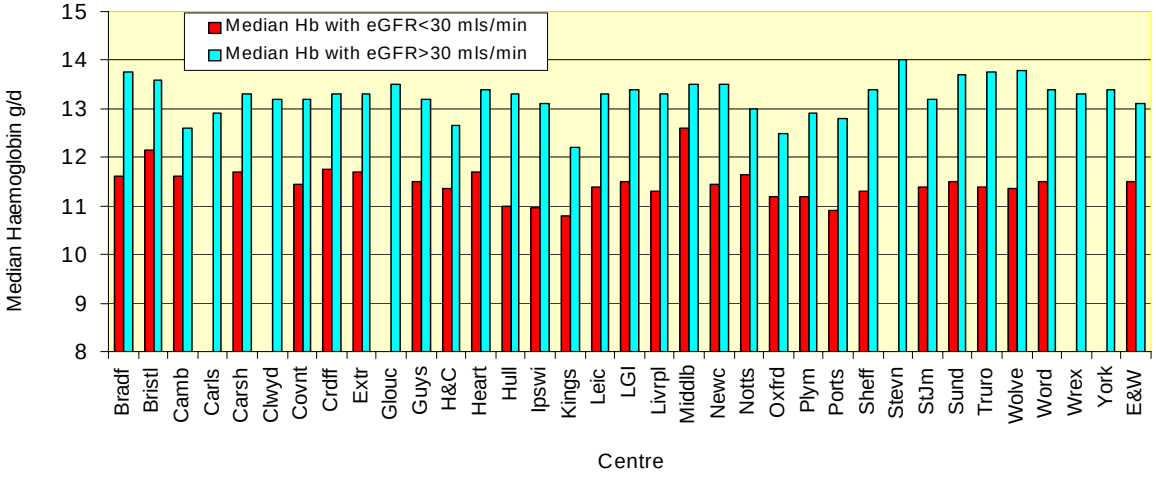

Figure 12.14. Median Hb of transplant patients by centre according to GFR (< or > 30mls/min)

been recorded in only 63% of the prevalent transplant cohort over that year.

The median serum cholesterol of prevalent transplant by centre is shown in figure 12.15. The percentage of missing data (cholesterol measured within the year) is shown before each centres name. Overall for England and Wales, the median cholesterol level was 5.0 mmol/L (range 4.5-5.5 mmol/L) equating to 50% of patients with a cholesterol < 5 mmol/L (range 80 – 18%).

The distribution of cholesterol levels amongst transplanted patients is similar to that of patients treated with peritoneal dialysis. When compared to patients on haemodialysis however, the cholesterol distribution curve for transplanted patients is shifted to the right i.e. serum cholesterol is lower in haemodialysis patients (Figure 12.16).

Interestingly, the distribution curve of serum cholesterol values among diabetic renal transplant patients is shifted to the left compared with non-diabetic transplant patients (Figure 12.17). More aggressive use of HMG-CoA reductase inhibitors amongst this patient group at high risk of cardiovascular disease may account for this observation.

Figure 12.18 shows the serial cholesterol for patients one year before and one year after a change in RRT modality from dialy-

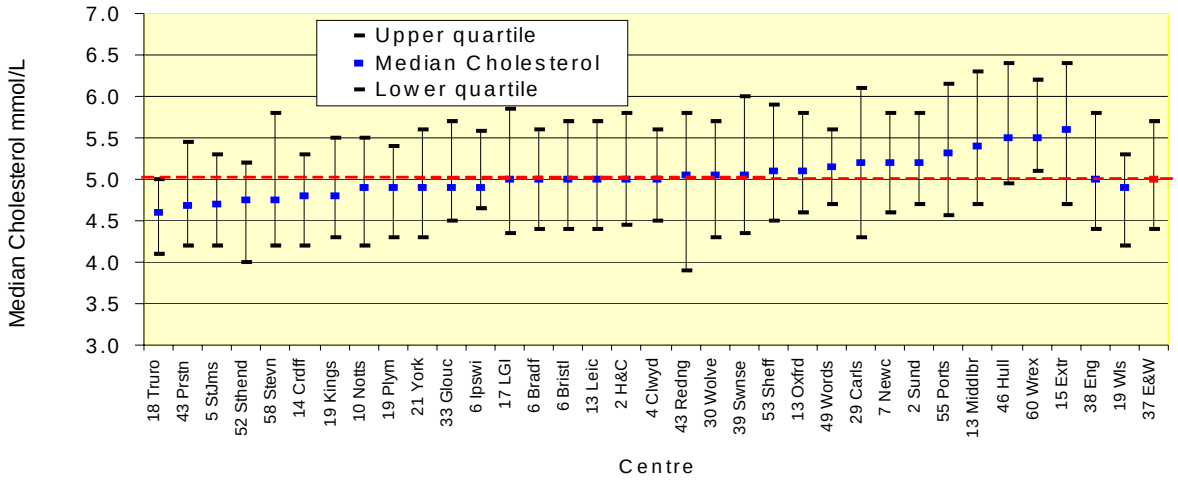

Figure 12.15. Median serum cholesterol transplant patients – by centre

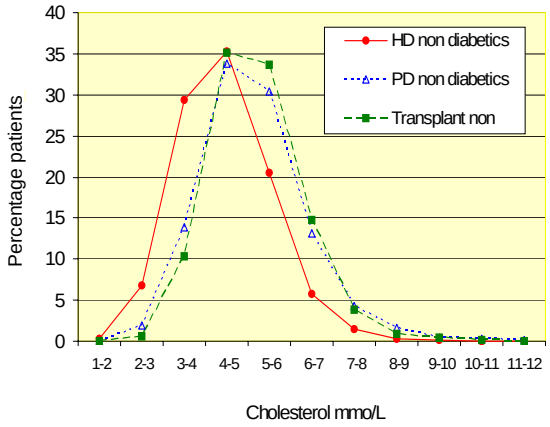

Figure 12.16. Cholesterol distribution curves according to RRT modality

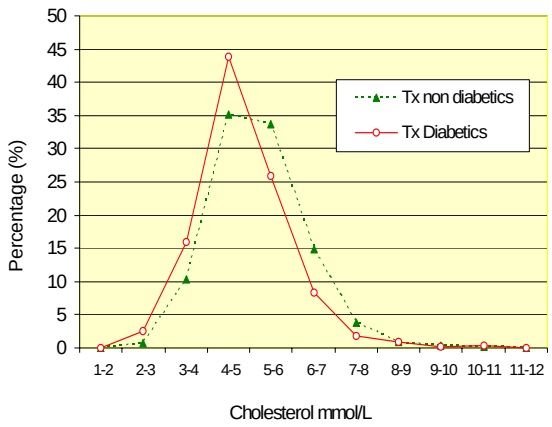

Figure 12.17. Cholesterol distribution curves according to diabetic status in transplant patients

sis to transplantation. The rise in cholesterol following transplantation is unexplained but may be related to use of immunosuppressive drugs (corticosteroids and calcineurin inhibitors), the lifting of dietary restrictions, the appetite stimulated by the initial relatively high steroid doses, or the discontinuation of HMG-CoA reductase inhibitors at the time of transplantation. Explanations for the observed fall in cholesterol in the last quartile after transplantation are again speculative but may relate to a reduction in immunosuppressive drug dose, especially steroids, and/or recommencement of HMG-CoA reductase inhibitors.

The consecutive annual median serum cholesterol by centre since 1998 is shown in Figure 12.19. For most centres a progressive fall in cholesterol is observed. Overall for England and Wales, the median cholesterol level has fallen annually from 5.7 mmol/L in 1998 to 5.0 mmol/L in 2002.

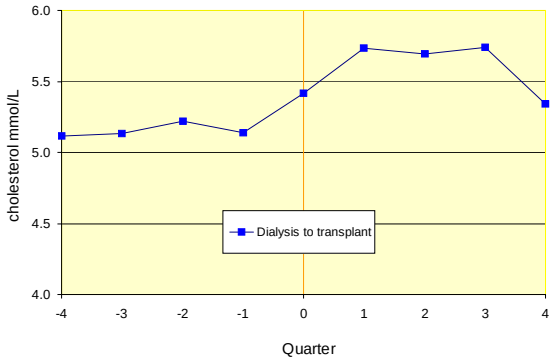

Figure 12.18. Cholesterol levels one year before and after a change in modality from dialysis to transplantation

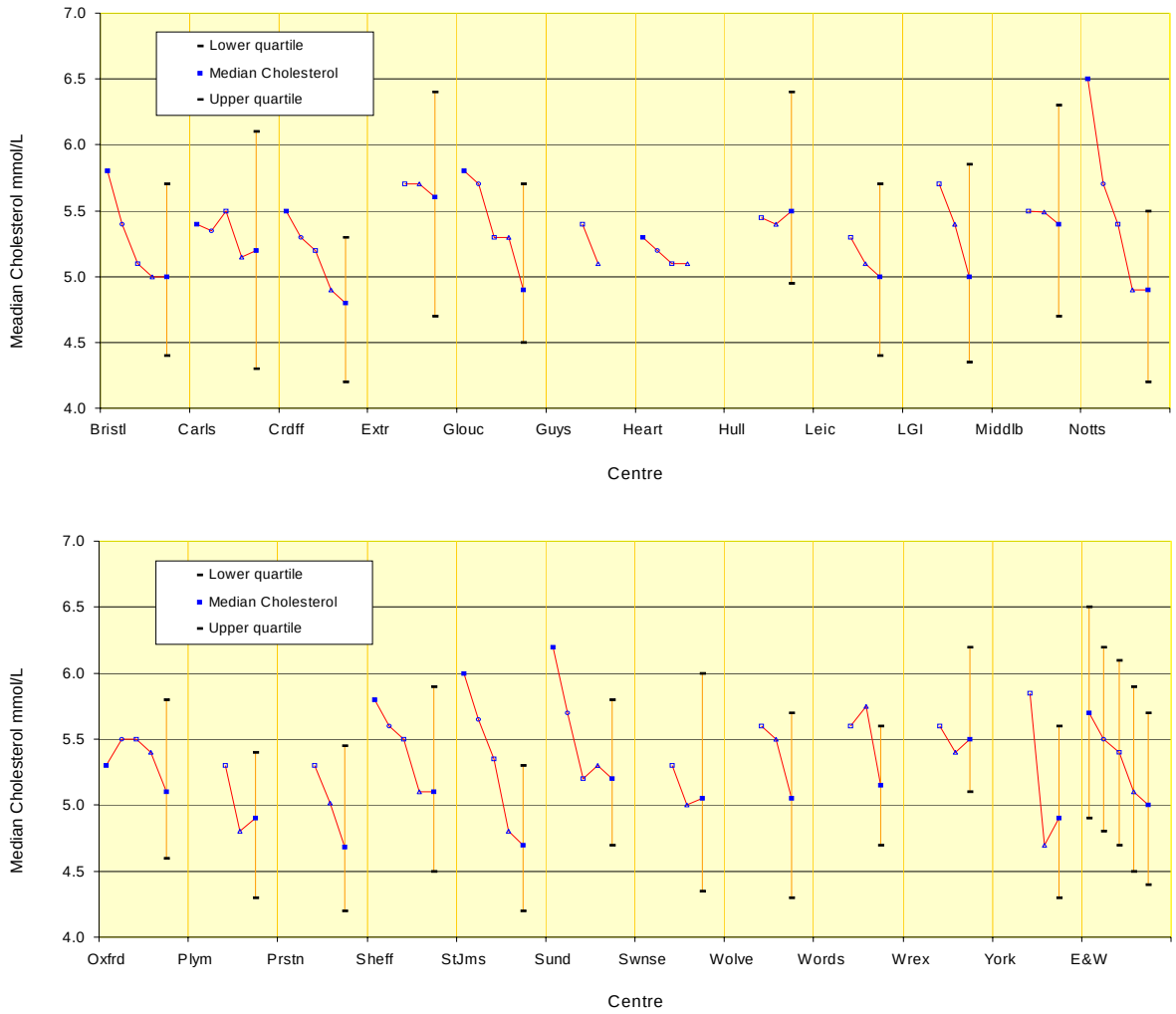

Figure 12.19. Median serum cholesterol, mmol/L, in transplant patients by centre 1998-2002

Figure 12.20 shows the percentage of prevalent transplant patients for each registry centre with a serum cholesterol level below 5.0 mmol/L. Significant differences between units are observed and may be accounted for by differences in HMG-CoA reductase inhibitor use and immunosuppressive drug regimes.

Figure 12.21 shows the annual percentage of patients with a serum cholesterol below 5.0 mmol/L for each centre since 1998. Although there are differences between centres, in most cases within centres there is overall a progressive improvement in cholesterol levels. The marked improvement observed in some centres suggests a change in policy over this time with a more active approach to cholesterol lowering.

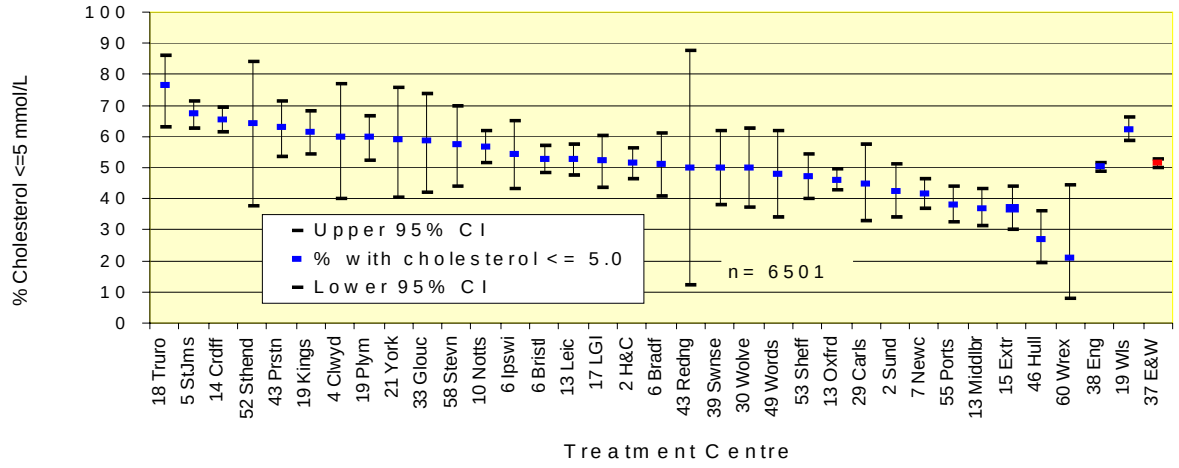

Figure 12.20. Percentage of transplant patients with cholesterol <5.0 mmol/L

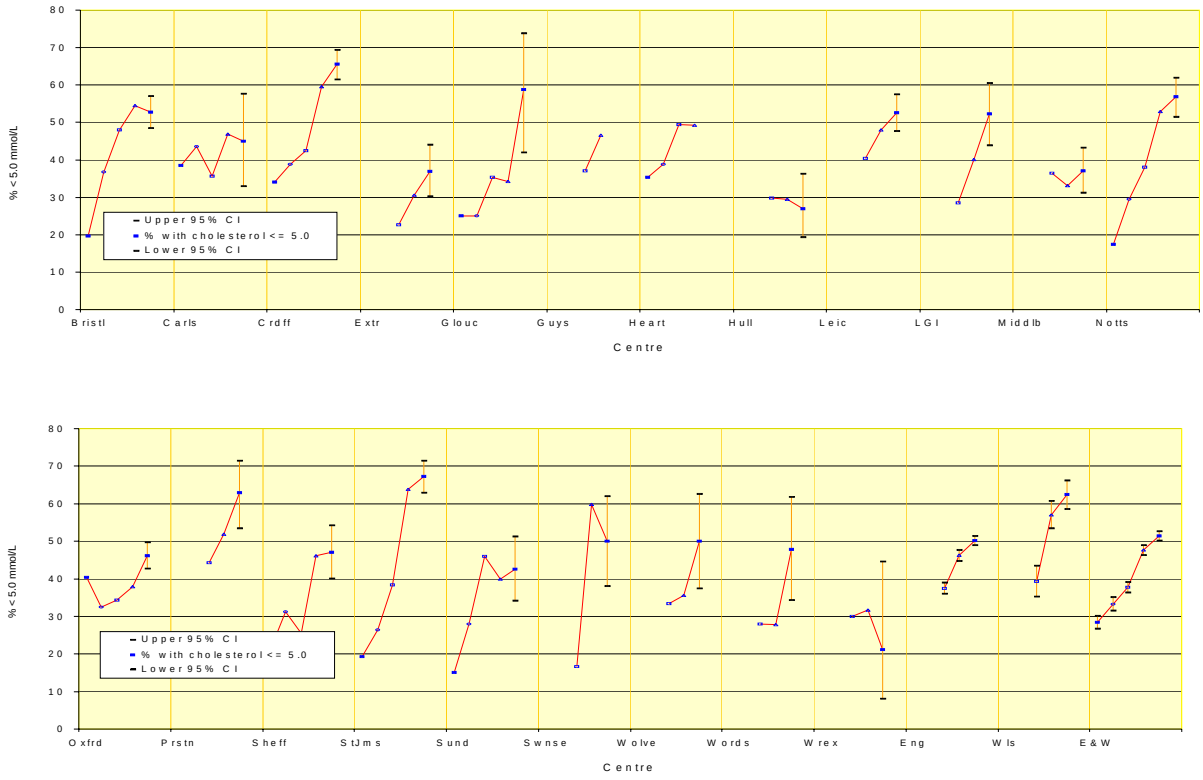

Figure 12.21. Percentage transplant patients with a serum cholesterol $\leq$ 5.0 mmol/L between 1998-2002 by centre

Blood pressure

The Renal Association Standards 3rd edition and Audit Measures published in August 2002 recommends ;

> ***blood pressure targets for renal transplant recipients of <130 mmHg systolic and <80 mmHg diastolic (strength of recommendation B).***

There are problems due to incomplete data returns. Table 12.9 shows the percentage of renal transplant recipients with blood pressure data returned to the Registry. Although the completeness of blood pressure returns has improved, only a small number of centres have an electronically stored record of blood pressure and centres need to explore ways of capturing this information for audit purposes.

Blood pressure recordings may also be subject to a variety of biases. Healthy patients with infrequent clinic attendance will have infrequent BP assessment. High BP readings may be selectively included or excluded from computer records depending on operator bias. The method and number of BP measurements has not been standardised between units. Figures 12.22 and 12.23 reflect the bias of digit preference when blood pressure is measured by manual devices, with frequent rounding of readings to the nearest ten.

Table 12.9. Completeness of BP returns for transplant patients

Centre	% BP return from last 6 months
Sheff	97
Bradf	97
Clwyd	96
Notts	95
York	94
Crdff	93
StJms	90
Words	84
Covnt	81
Leic	80
Camb	79
Livrpl	78
Wls	76
Kings	72
Bristl	54
Middlbr	52
Truro	45
Oxfrd	24
Extr	20
Redng	14
Stevn	8
Carls	6
Wolve	5
LGI	4
Sthend	3
Guys	3
Sund	2
Heart	2
Glouc	2
Plym	0
Carsh	0
E&W	42

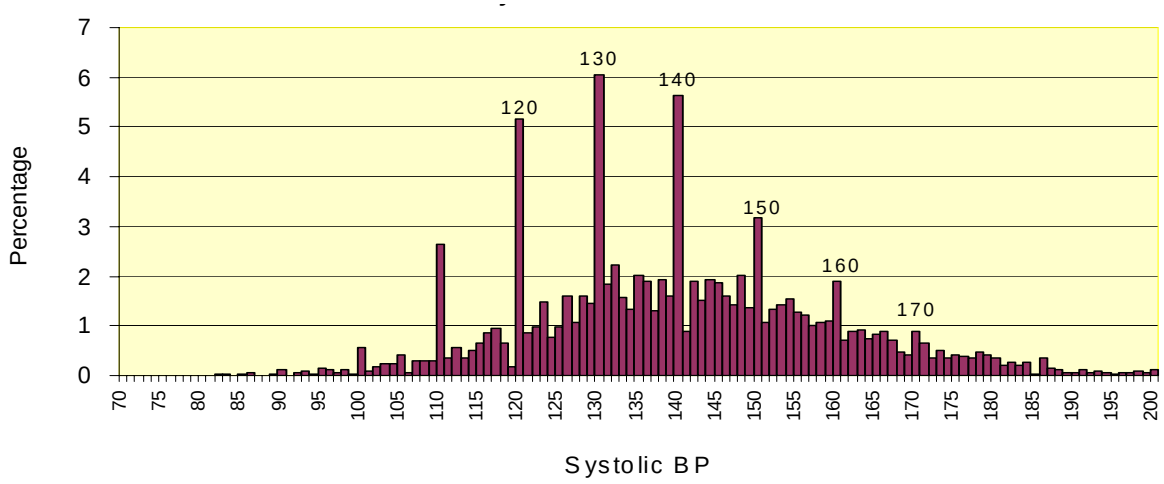

Figure 12.22. Frequency distribution of systolic blood pressure in transplant patients

Figure 12.24 shows that in almost all centres significantly fewer than 50% of patients achieved the Renal Association target blood pressure of less than 130/80. Overall for England and Wales, only 27% of patients reached this target.

Figures 12.25 and 12.26 show the median systolic and diastolic blood pressure for transplant recipients at each centre.

Figure 12.27 shows the percentage of patients at each centre with a systolic blood pressure below 130 mmHg and Figure 12.28 shows the percentage with a diastolic blood pressure below 80 mmHg.

The relationship between systolic, diastolic and mean arterial blood pressure and transplant function as reflected by calculated GFR is shown in Table 12.10. It is not possible to determine whether higher blood pressure causes, or results from, 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.

Table 12.10. Relationship between BP and graft function in transplant patients in E&W

eGFR (MDRD)	Median arterial BP	Median Systolic BP	Median Diastolic BP
< 30 mls/min	102.0	143.0	80.0
30-60 mls/min	100.0	140.0	80.0
> 60 mls/min	98.0	137.0	80.0

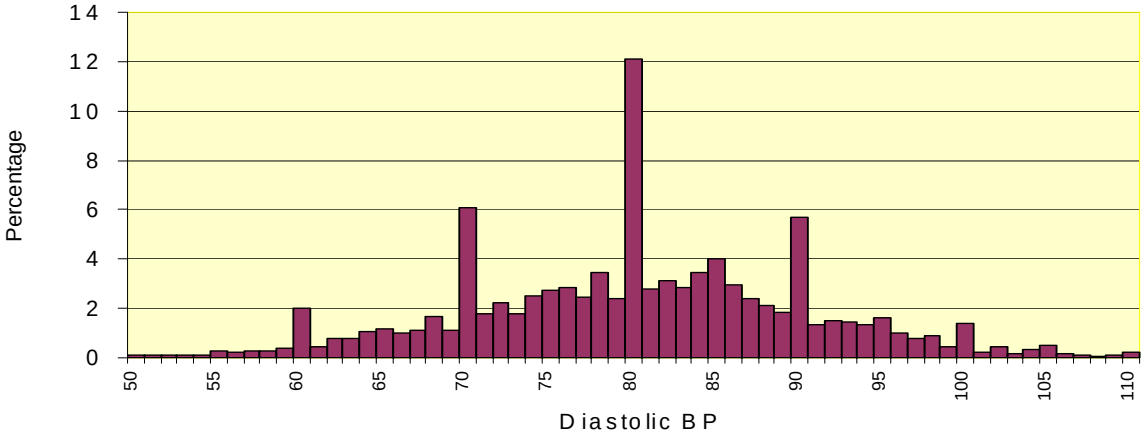

Figure 12.23. Frequency distribution of diastolic blood pressure in transplant patients

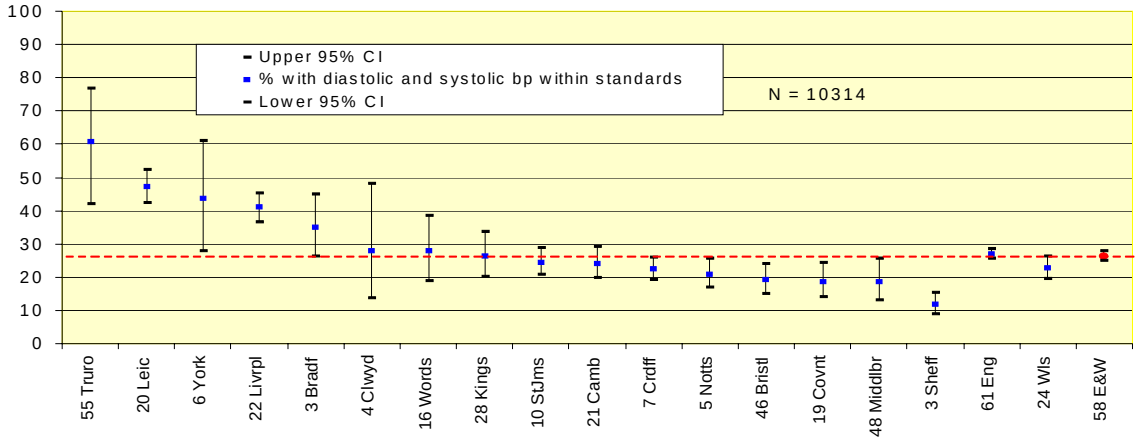

Figure 12.24. Percentage patients with systolic and diastolic BP below 130/80 mmHg

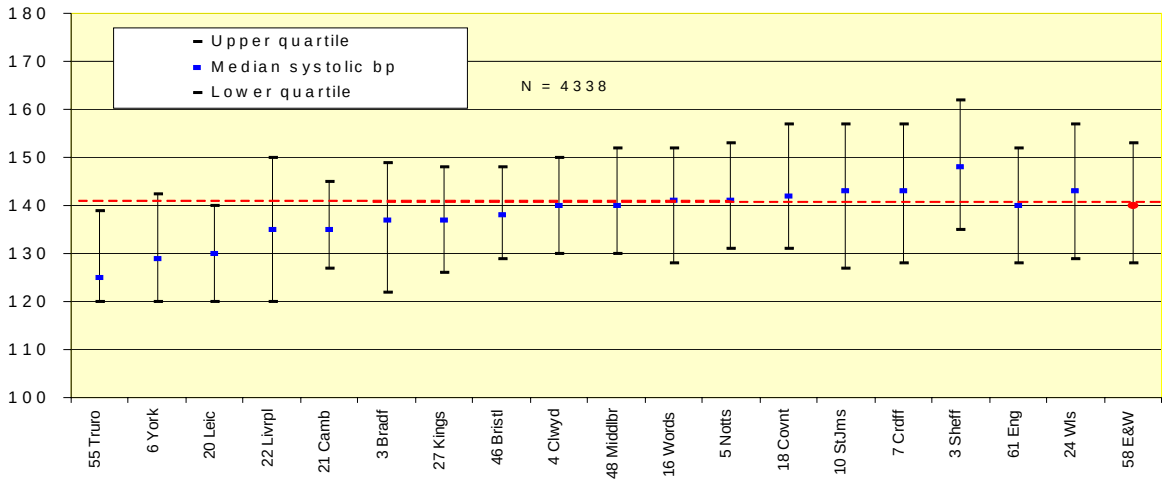

Figure 12.25. Median systolic blood pressure for transplant patients at each centre

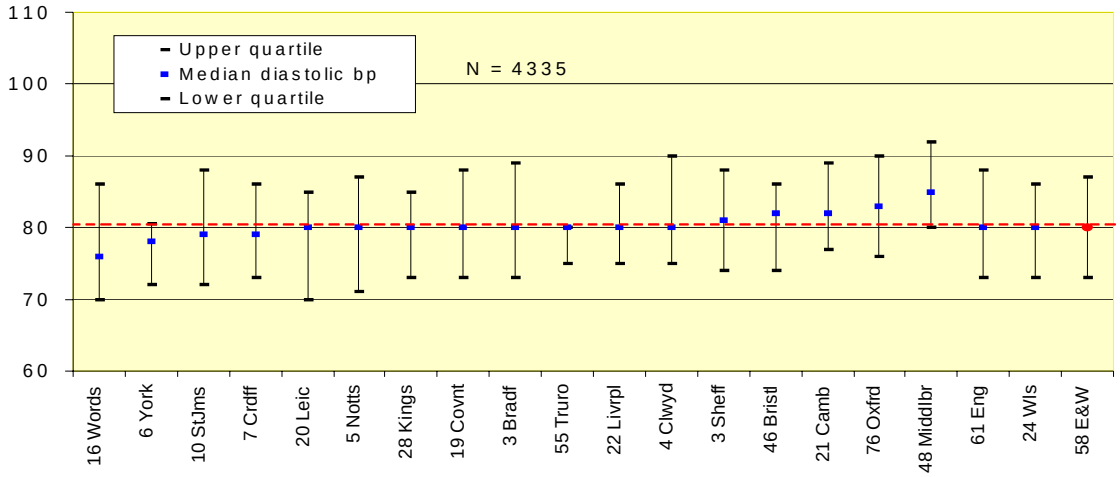

Figure 12.26. Median diastolic blood pressure for transplant patients at each centre

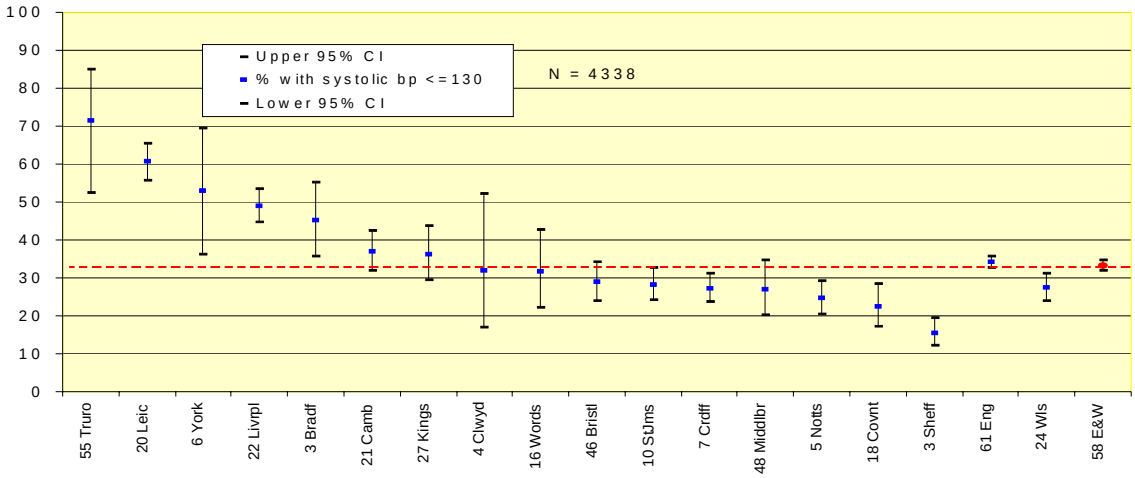

Figure 12.27. Percentage of patients with systolic BP <130 mmHg at each centre

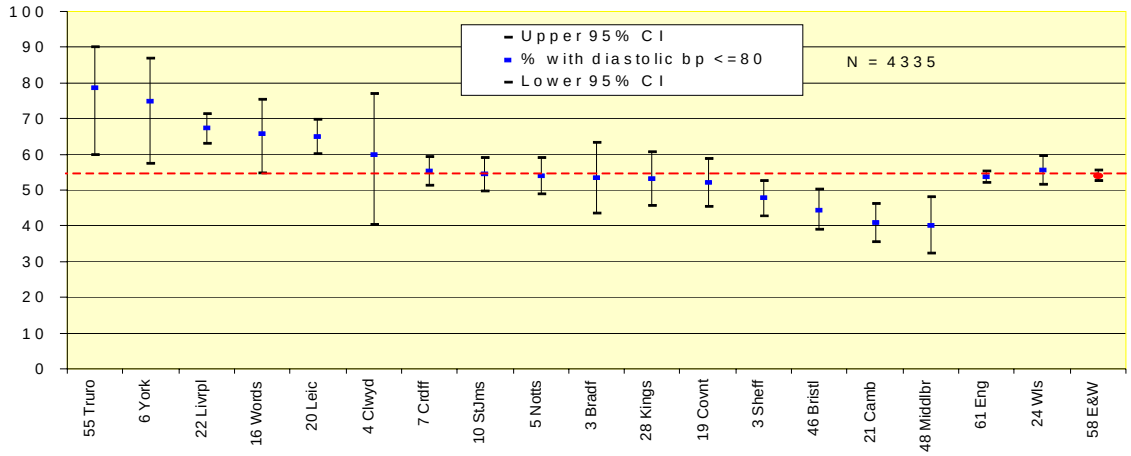

Figure 12.28. Percentage of patients with diastolic BP <80 mmHg at each centre

Conclusion

This chapter reports on data returned from 40units: 37 follow significant numbers of prevalent transplant patients. 17 units perform renal transplantation and follow up 78% of the Registry prevalent transplant cohort. Data on 56% of all renal transplants performed in 2002 in the UK are presented together with data on 62% of the total prevalent renal transplant population for England and Wales.

There has been a progressive decline from 51% in 1997 to 46% in 2002, in the proportion of the prevalent RRT patients with a functioning renal transplant.

Variation exists between centres with respect to access to transplantation for all prevalent patients receiving renal replacement therapy and for patients whose primary diagnosis is diabetes mellitus. However, 9.6% of new transplants performed in 2002 were in patients whose primary renal diagnosis was diabetic nephropathy compared with 7.5% in 2000.

The proportion of patients aged under 65 years from each ethnic group who have ever received a renal transplant is 69% for Caucasian, 57% for Chinese, 52% for Indo-Asians, and 46% for African-Caribbeans.

2.3% of all prevalent transplants failed during 2002.

The annual death rate of patients with established renal transplants for England and Wales is 2.4% (excluding patients dying after returning to dialysis during 2002).

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 2002 with 51.4% of all patients having a cholesterol level <5 mmol/L. Blood pressure control however, falls far short of Renal Association targets for most centres returning blood pressure data.

Chapter 13: 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 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 and these are shown in Table 13.1.

Data included on dialysis patients are from the last quarter of 2002 for all items except cholesterol and iPTH which are from the last 6 months. Patients were excluded if they had not been on renal replacement therapy (RRT) for at least 3 months or if they had transferred unit or changed dialysis modality in the 3 month period prior to data sampling. This ensured that the results for a unit reflected stable treatment patterns and were not adversely affected by new patients whom the unit had not had the chance to treat effectively.

The problems of comparing biochemical variables such as albumin, calcium and bicarbonate identified in the previous reports still apply; comparative data must be interpreted with caution. The achievement of Standards defined around the local laboratory reference range is dependent on the source of derivation for the reference range. The urea reduction ratio (URR) may be influenced by post-dialysis sampling techniques.

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.

Table 13.1. Renal Association 3rd Standards

Standard	Haemodialysis	Peritoneal dialysis	Transplant
Albumin	≥35 g /L BCG ≥30 g/L BCP	≥35 g /L BCG ≥30 g/L BCP	
Bicarbonate	20–26 mmol/L	25–29 mmol/L	
Blood pressure	Pre HD ≤140/90 mmHg Post HD ≤130/80 mmHg	≤130/80 mmHg	≤130/80 mmHg
Calcium adjusted for albumin	2.2.–2.6 mmol/L	2.2.–2.6 mmol/L	
Cholesterol - Total	<5mmol/L	<5mmol/L	
Dialysis adequacy	Urea reduction ratio ≥65%		
Ferritin	≥100 mcg/L	≥100 mcg/L	
Haemoglobin	≥10g/dL	≥10g/dL	
HbA1c	<7%	<7%	< 7%
Parathyroid hormone	<4 × upper local range	<4 × upper local range	<4 × upper local range
Phosphate	<1.8 mmol/L pre HD	<1.8 mmol/L	

In the following section, many figures use a common modified box-plot format, data being presented separately for haemodialysis (HD), and peritoneal dialysis (PD) and transplantation.

- The figures showing the percentage of patients reaching the Renal Association Standard include the 95% confidence interval calculated for this figure (using the Poisson approximation).
- Where medians are displayed, the 25th and 75th centiles for the unit are included.
- Data completeness is indicated by the 'percentage missing' figure before the renal unit abbreviated name (see Appendix H).

These methods are the best way the Registry has found to convey the underlying data for the larger number of centres.

Haemoglobin

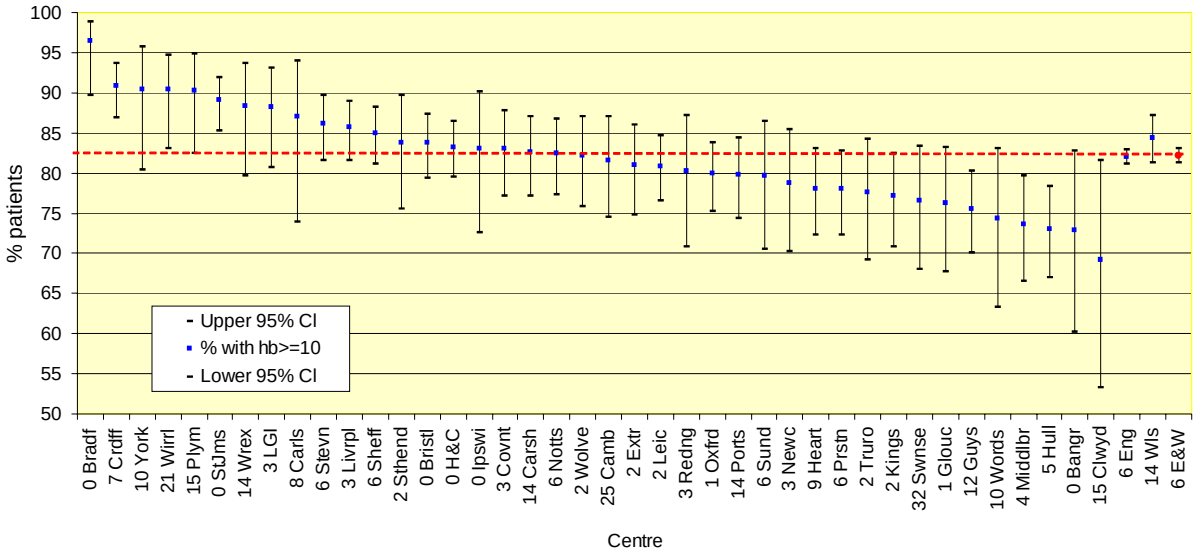

Figure 13.1. % of HD patients achieving the RA Hb Standard by centre

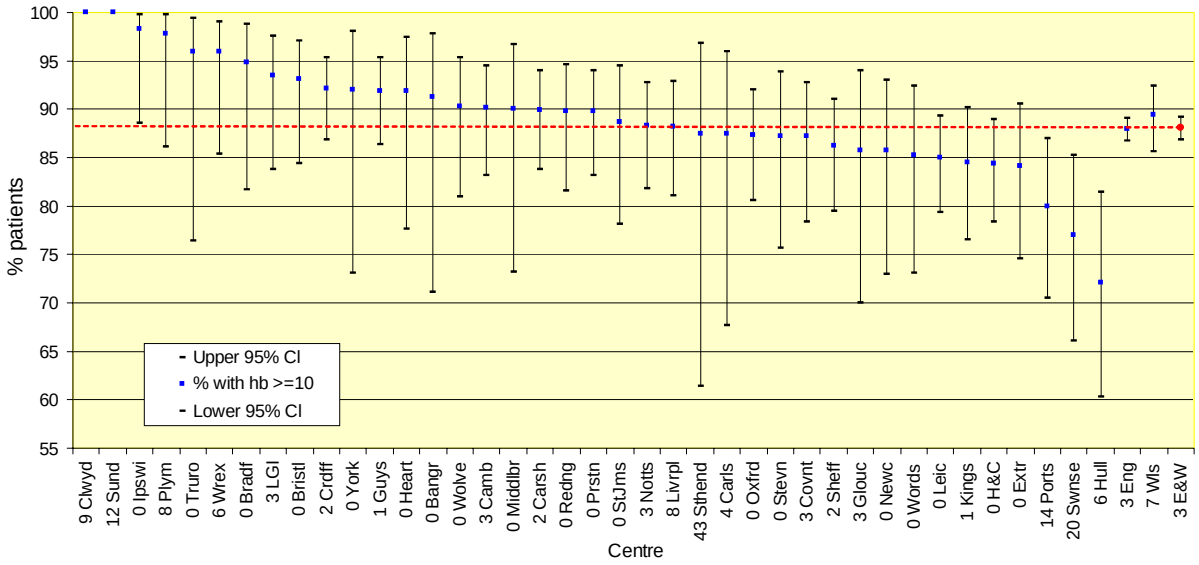

Figure 13.2. % of PD patients achieving the RA Hb Standard by centre

Serum Ferritin

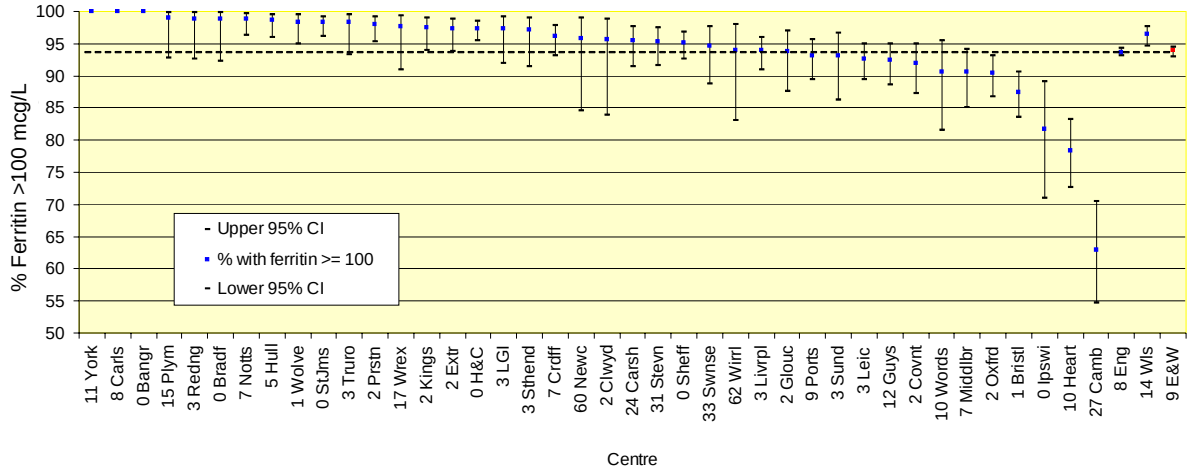

Figure 13.3. % of HD patients achieving the RA Ferritin Standard by centre

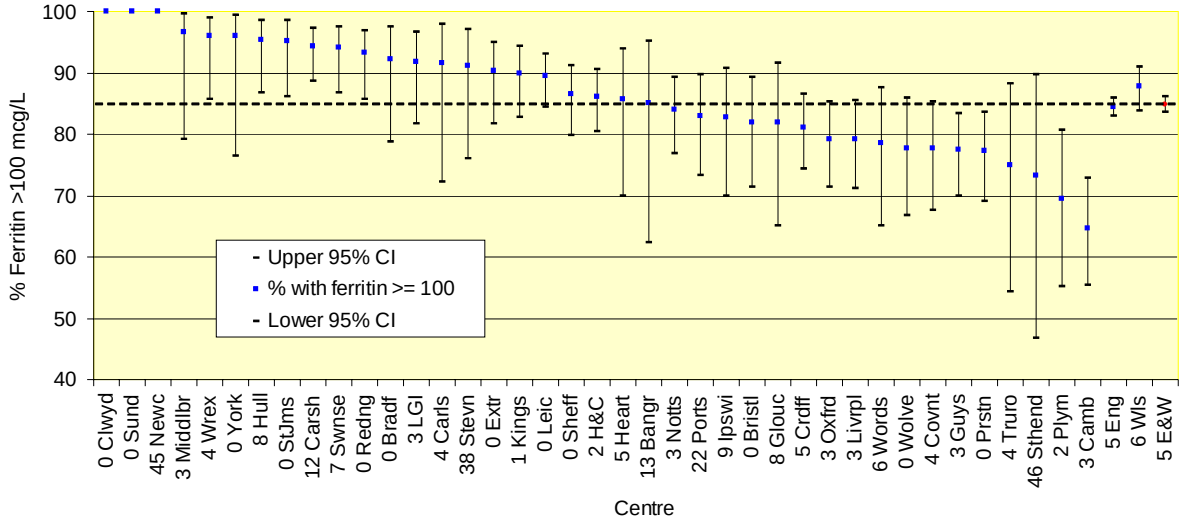

Figure 13.4. % of PD patients achieving the RA Ferritin Standard by centre

Serum calcium

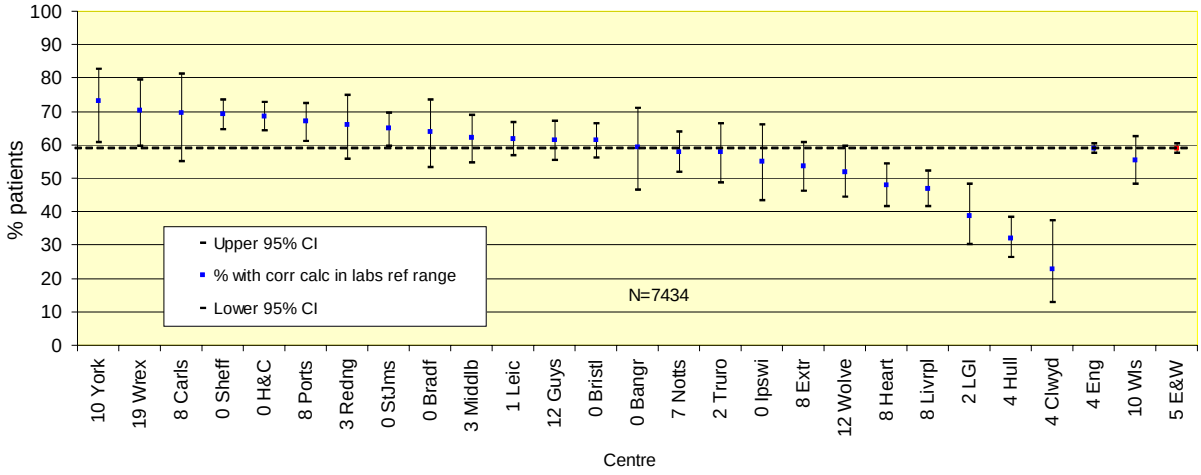

Figure 13.5. % of HD patients achieving the RA calcium Standard by centre

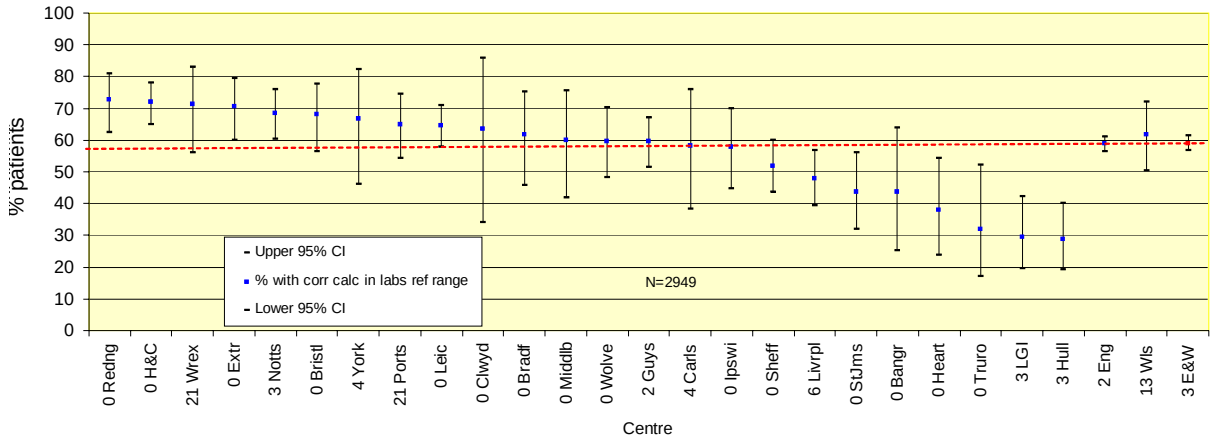

Figure 13.6. % of PD patients achieving the RA calcium Standard by centre

Serum phosphate

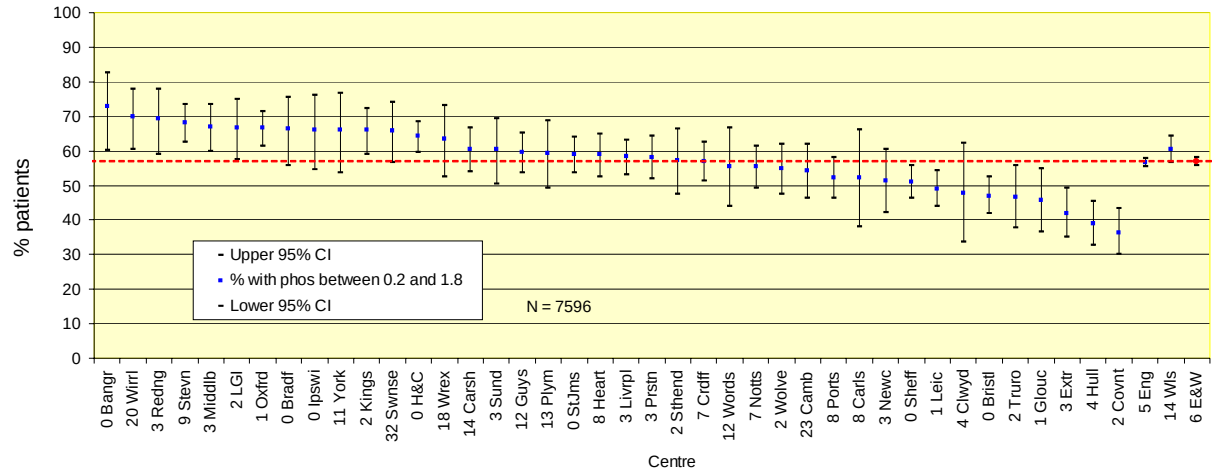

Figure 13.7. % of HD patients achieving the RA phosphate Standard by centre

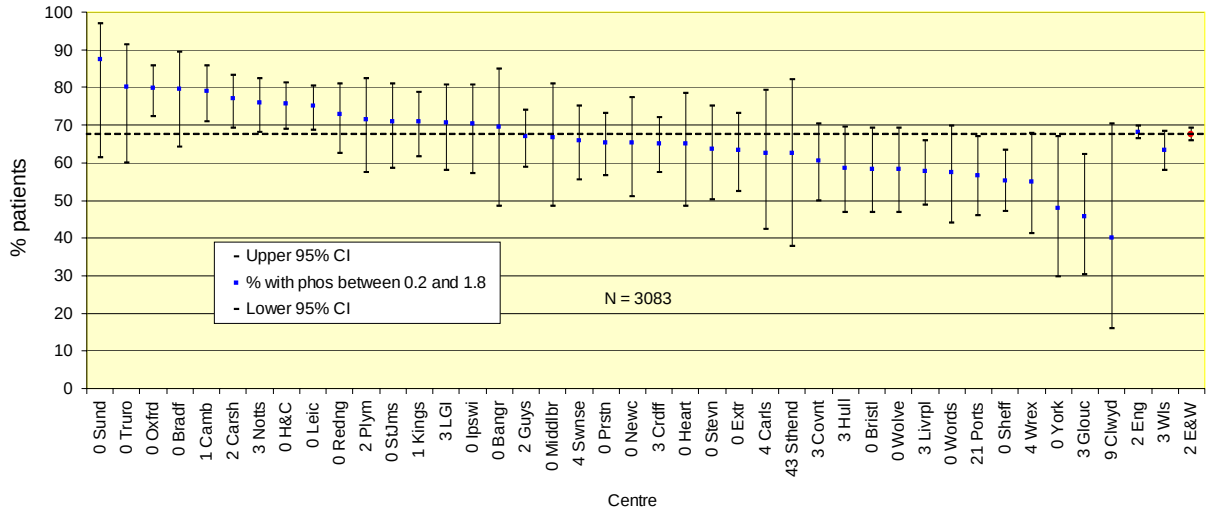

Figure 13.8. % of PD patients achieving the RA phosphate Standard by centre

Intact parathyroid hormone

As the local laboratory reference range for PTH has not been derived from a local or UK population reference range, the Registry in line with previous years has used the average upper laboratory reference limit. In the new Standards this is <×4 rather than <×3.

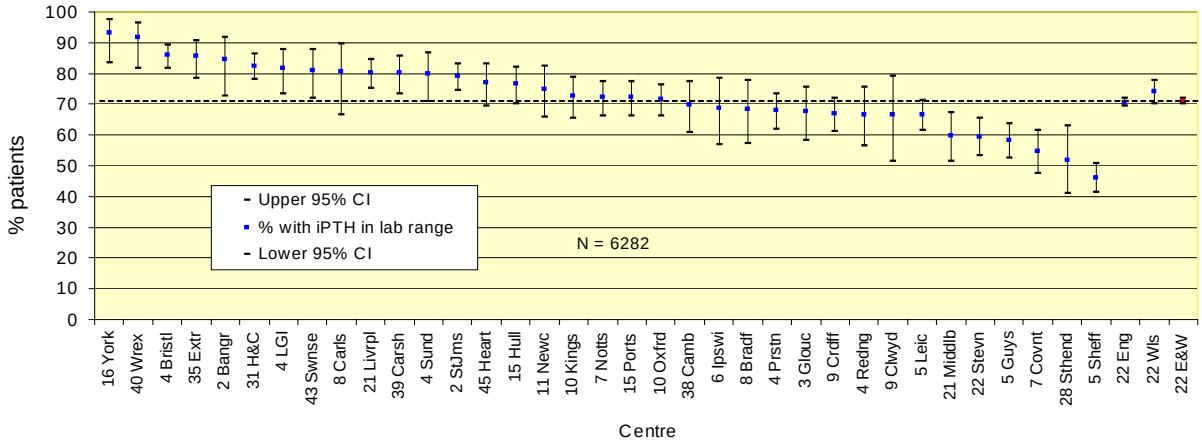

Figure 13.9. % of HD patients achieving iPTH < 32 pmol/L by centre

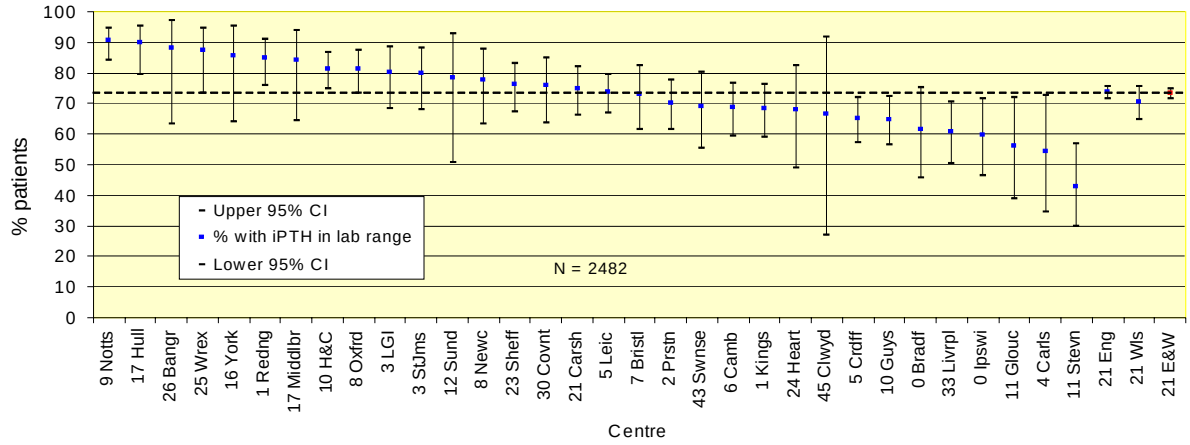

Figure 13.10. % of PD patients achieving iPTH < 32 pmol/L by centre

Dialysis adequacy

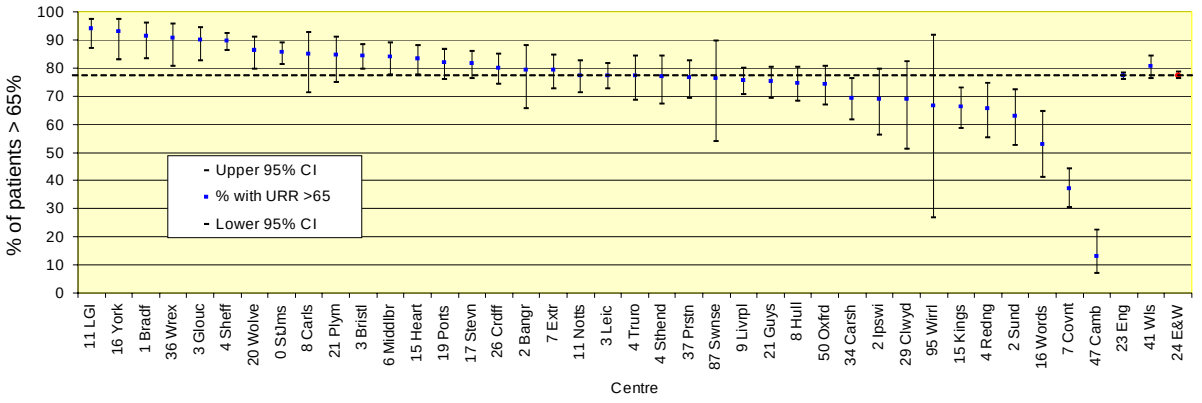

Figure 13.11. % of HD patients with URR ≥ 65% by centre

Serum bicarbonate

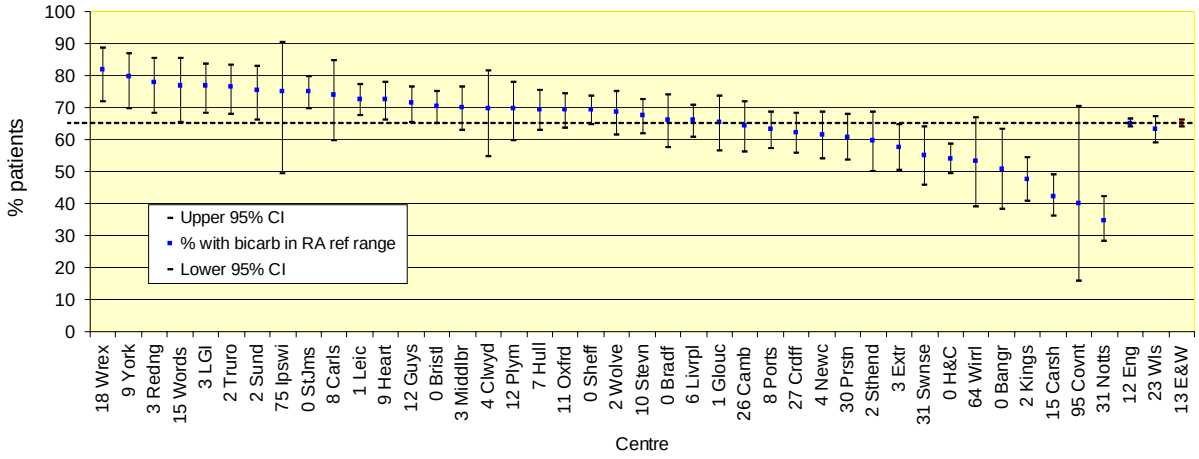

Figure 13.12. % of HD patients achieving the RA bicarbonate Standard by centre

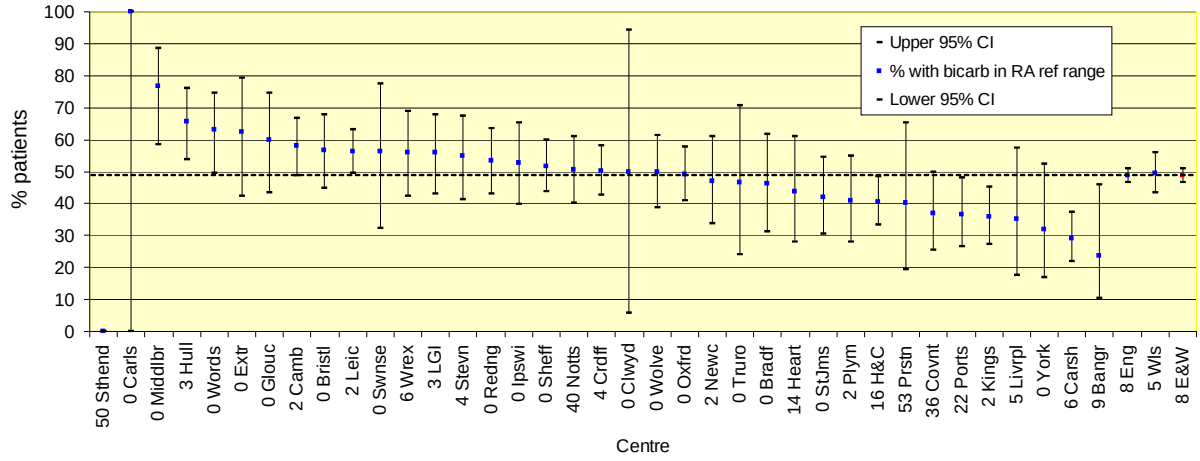

Figure 13.13. % of PD patients achieving the RA bicarbonate Standard by centre

Serum albumin

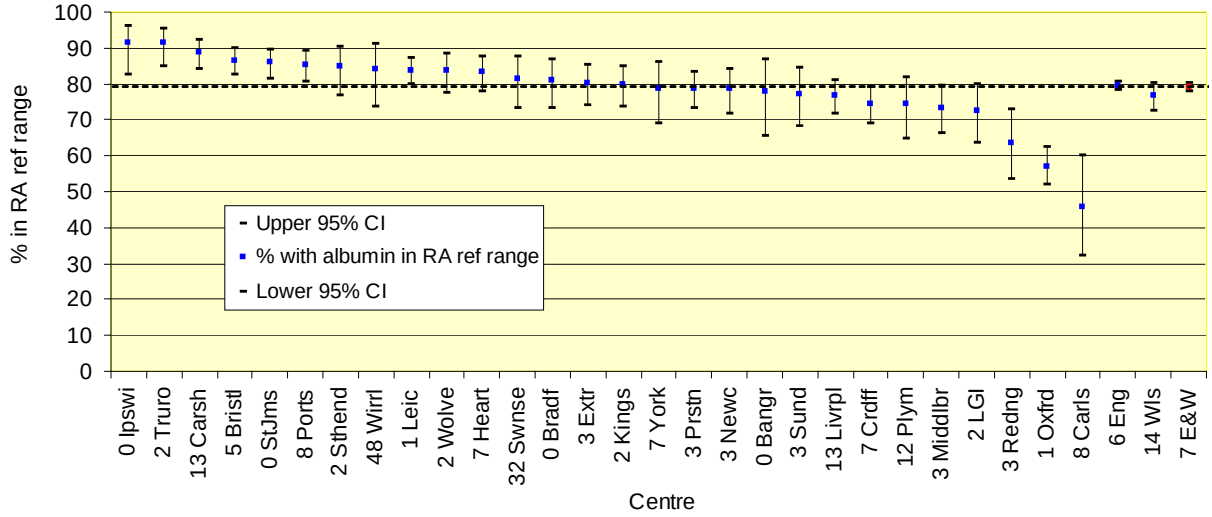

Figure 13.14. % of HD patients achieving the RA albumin BCG Standard by centre

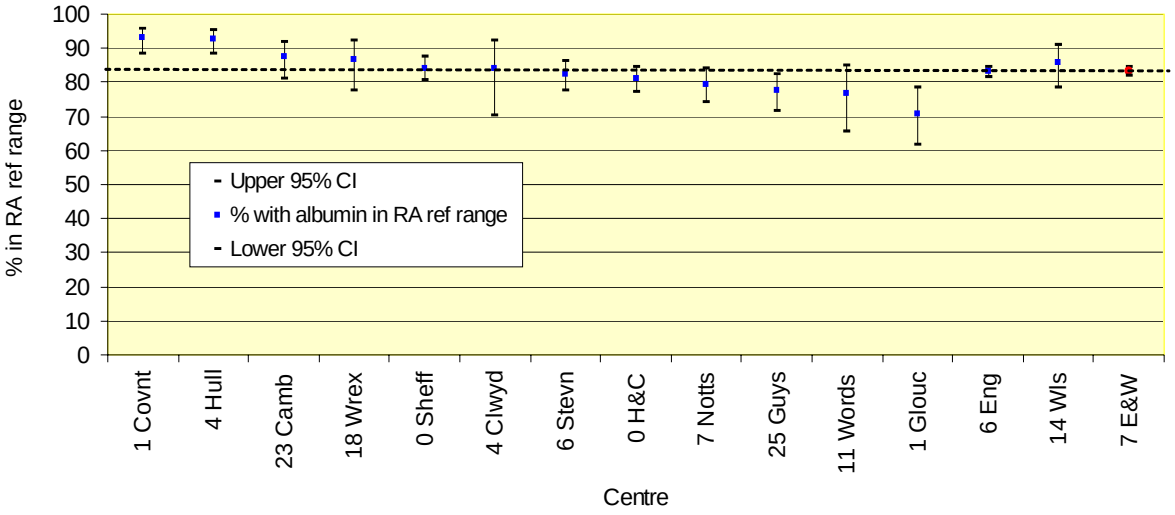

Figure 13.15. % of HD patients achieving the RA albumin BCP Standard by centre

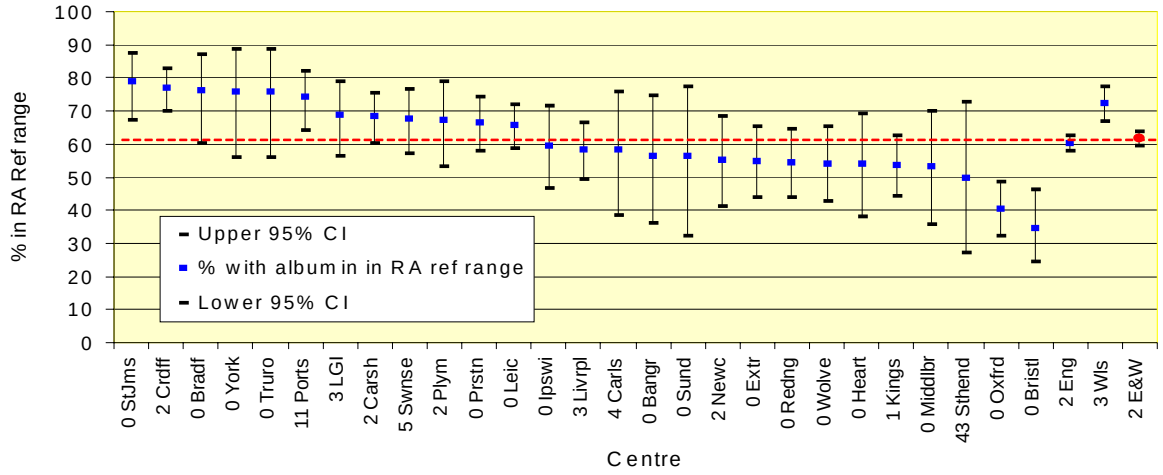

Figure 13.16. % of PD patients achieving the RA albumin BCG Standard by centre

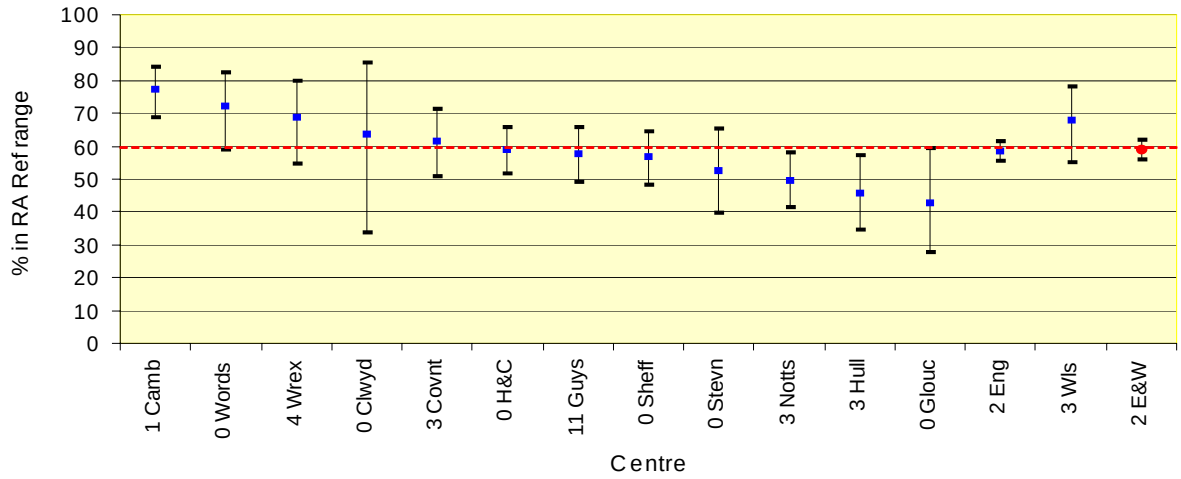

Figure 13.17. % of PD patients achieving the RA albumin BCP Standard by centre

Blood pressure

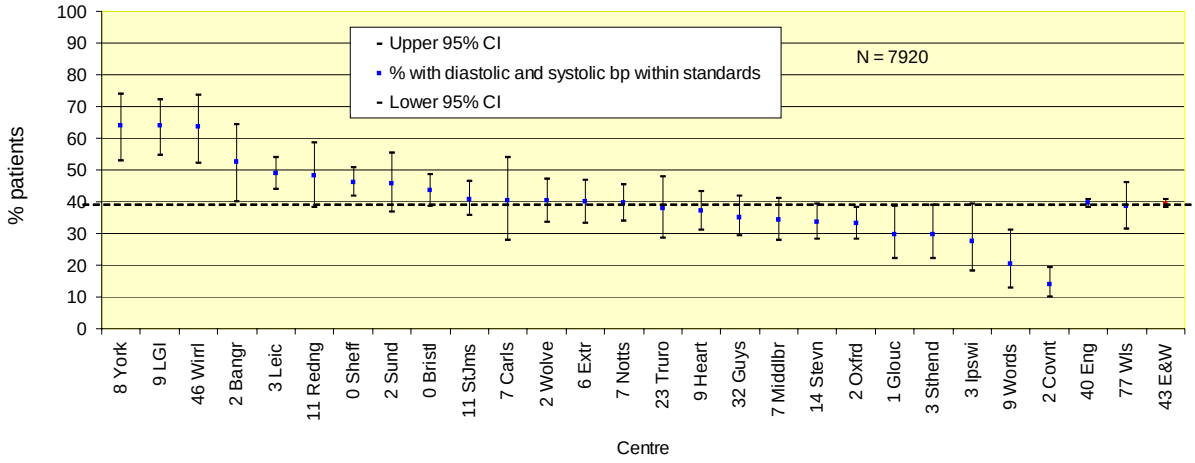

Figure 13.18. % of HD patients achieving the RA BP Standard by centre

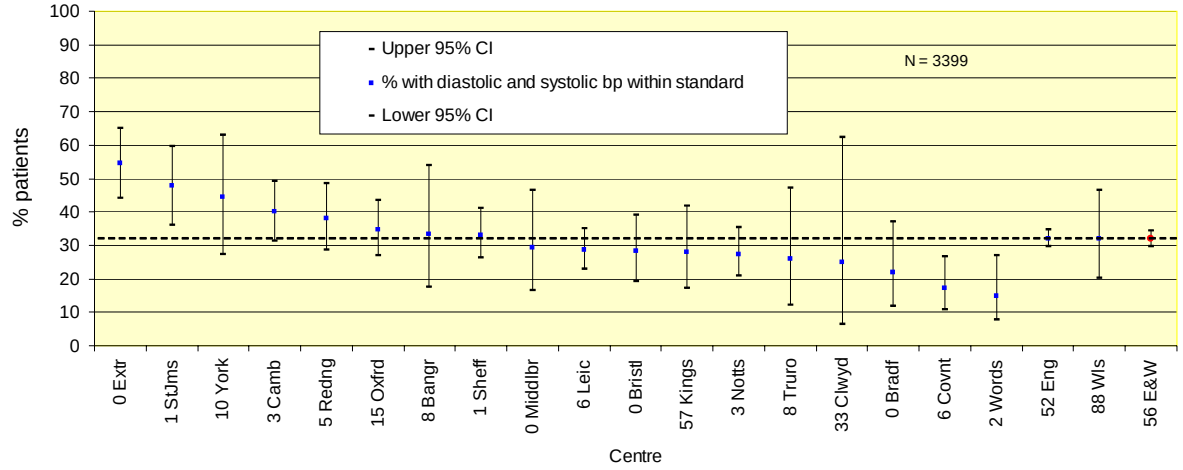

Figure 13.19. % of PD patients achieving the RA BP Standard by centre

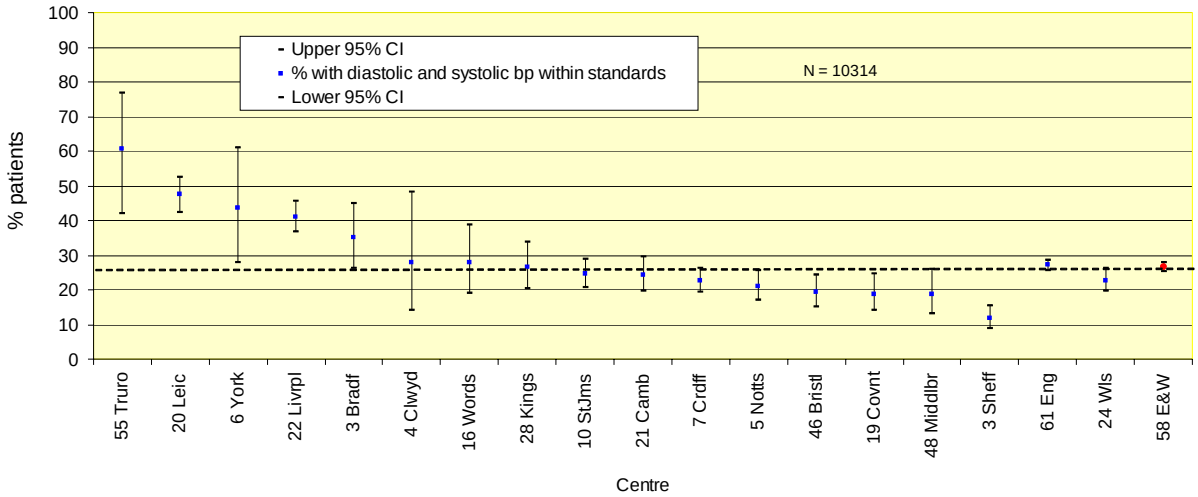

Figure 13.20. % of transplant patients achieving the RA BP Standard by centre

Serum Cholesterol

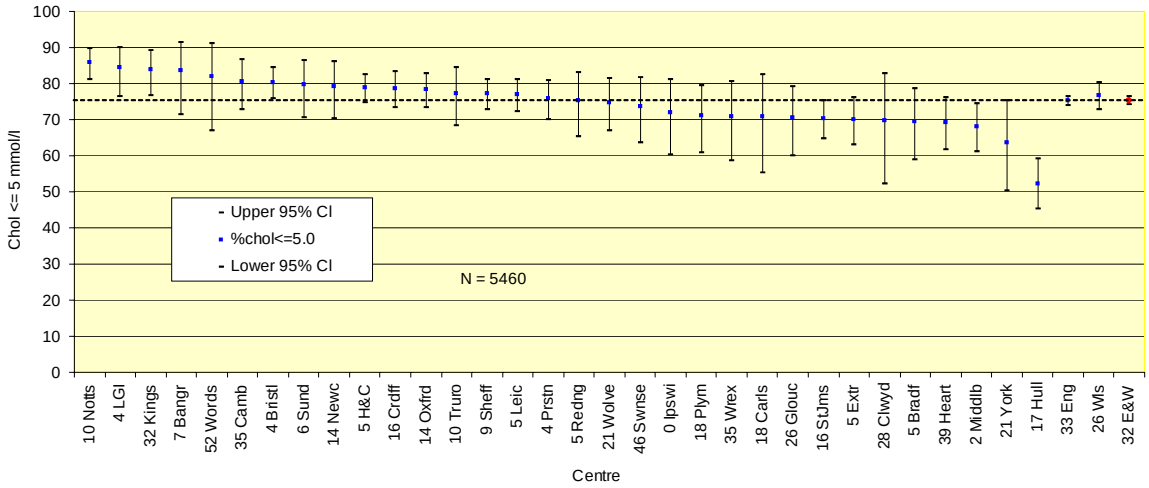

Figure 13.21. % of HD patients achieving the RA cholesterol Standard by centre

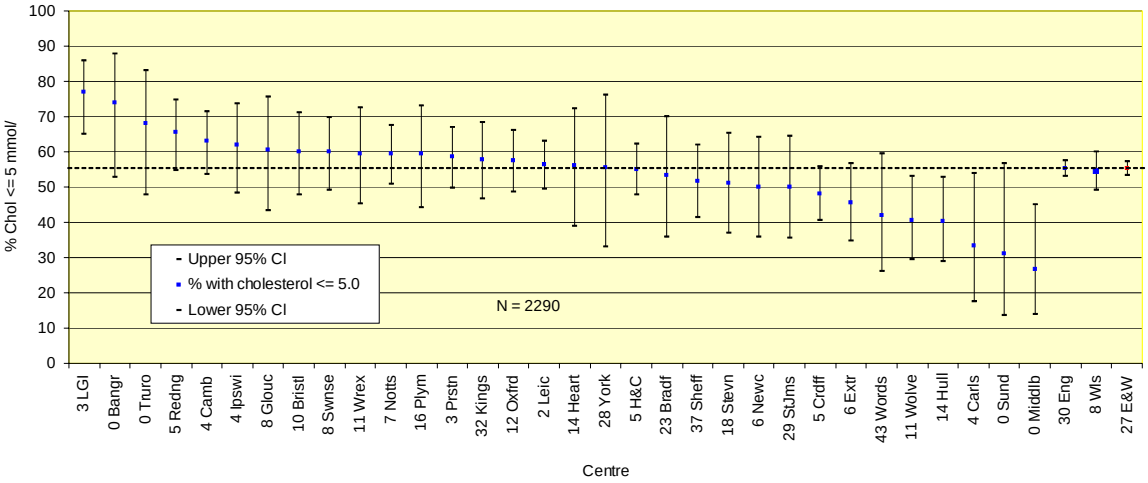

Figure 13.22. % of PD patients achieving the RA cholesterol Standard by centre

Glycated Haemoglobin

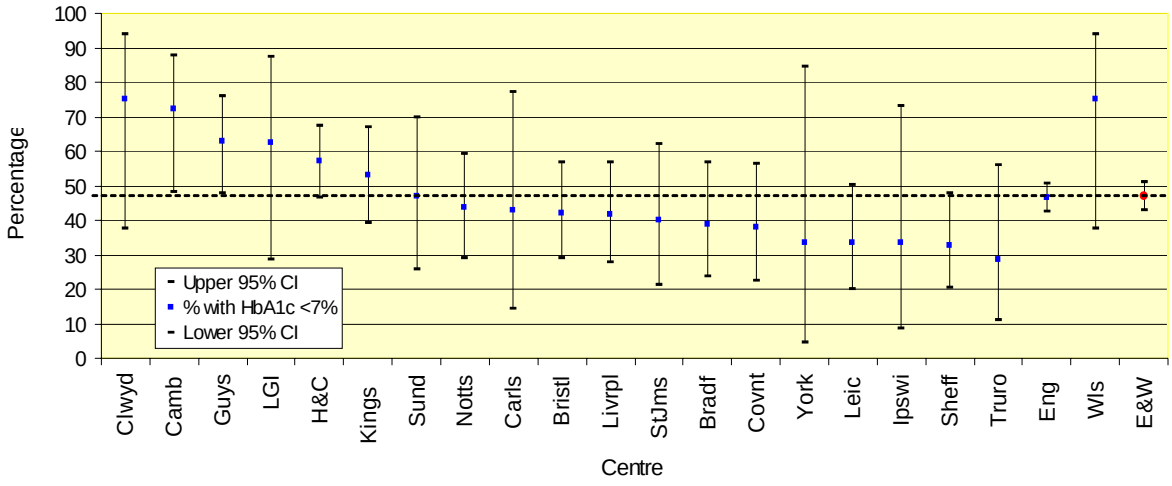

Figure 13.23. % of diabetic HD patients achieving the RA HbA1c Standard by centre

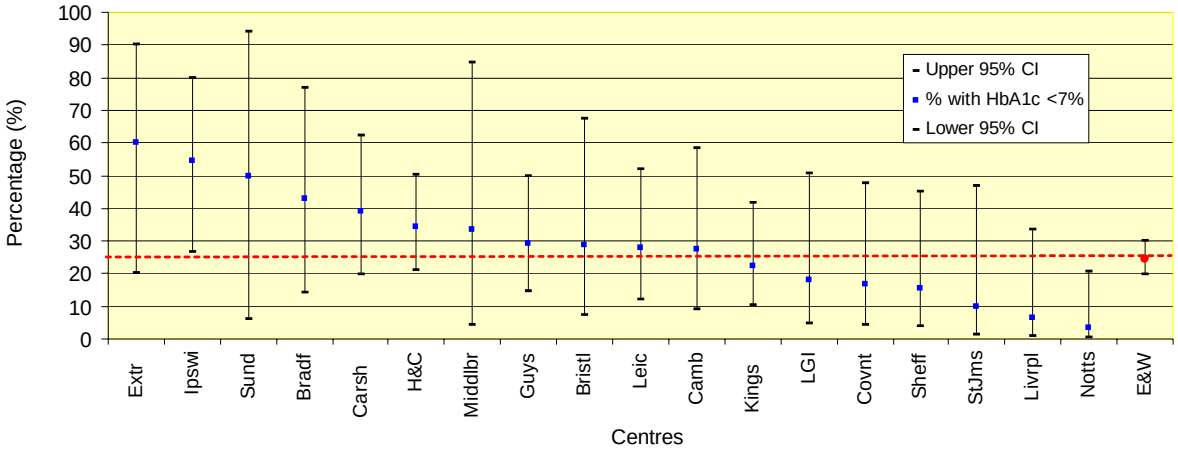

Figure 13.24. % of diabetic PD patients achieving the RA HbA1c Standard by centre

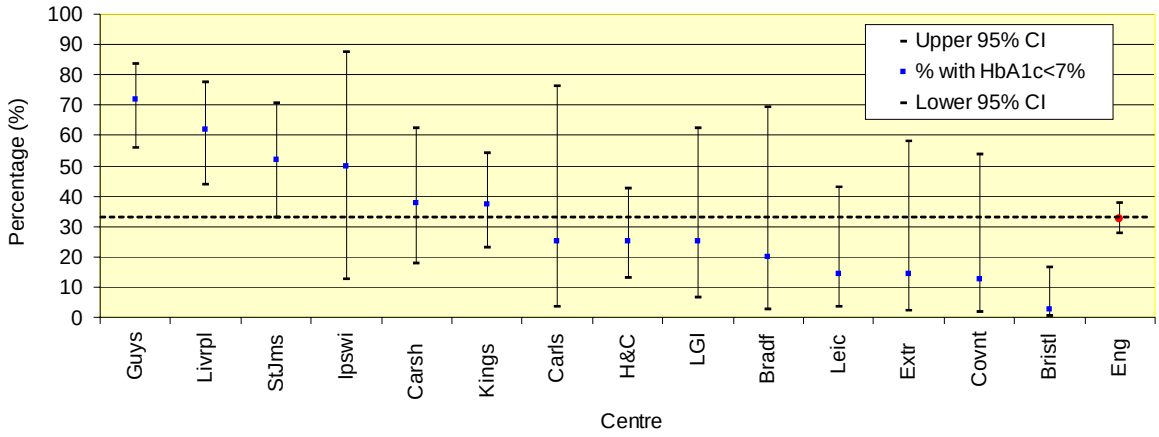

Figure 13.25. % of diabetic transplant patients achieving the RA HbA1c Standard by centre

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 = 126.3, d.f. = 39, 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 = 69.6, d.f. = 38, p < 0.0013).

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 HD, the percentage of patients with a ferritin of 100 mcg/L or over was found to differ significantly between centres ($\chi^2 = 512.5$, d.f. = 39, $p < 0.001$).

For patients on PD, the percentage of patients with a ferritin of 100 mcg/L or over was found to differ significantly between centres ($\chi^2 = 142$, d.f .= 38, $p < 0.001$).

Calcium

A chi squared test was used to determine whether the percentage of patients with a calcium level of 2.2 to 2.6mmol/L differed between centres.

For patients on HD, the percentage of patients with a serum calcium of 2.2. to 2.6 mmol/L differed significantly between centres ($\chi^2 = 420$, d.f. = 26, $p < 0.001$).

For patients on PD, the percentage of patients with a serum calcium of 2.2. to 2.6 mmol/L differed significantly between centres ($\chi^2 = 248$, d.f. = 26, $p < 0.001$).

Phosphate

A chi squared test was used to determine whether the percentage of patients with a phosphate level of 1.8mmol/L or less differed between centres.

For patients on HD, the percentage of patients with a serum phosphate of 1.8 mmol/L or less differed significantly between centres ($\chi^2 = 221$, d.f. = 39, $p < 0.001$).

For patients on PD, the percentage of patients with a serum phosphate of 1.8 mmol/L or less differed significantly between centres ($\chi^2 = 102$, d.f. = 38, $p < 0.001$).

PTH

A chi squared test was used to determine whether the percentage of patients with a PTH of 32 pmol/L or below differed between centres. Note this is slightly different from the RA standard.

For patients on HD, the percentage of patients with a PTH value of 32 pmol/L or less differed significantly between centres ($\chi^2 = 377$, d.f. = 38, $p < 0.001$).

For patients on PD, the percentage of patients with a PTH of 32 pmol/L or less differed significantly between centres ($\chi^2 = 138$, d.f. = 35, $p < 0.001$).

URR

A chi squared test was used to determine whether the percentage of patients with a URR of 65% or more differed between centres.

The percentage of patients with a URR of 65% or above was found to vary significantly between centres ($\chi^2 = 542.9$, d.f. = 37, $p < 0.001$).

Bicarbonate

A chi squared test was used to determine whether the percentage of patients with bicarbonate values within 20–26 mmol/L or 25–29 mmol/L respectively for HD and PD varied between centres.

For patients on HD, the percentage of patients with a bicarbonate within 20–26 mmol/L differed significantly between centres ($\chi^2 = 899.9$, d.f. = 39, $p < 0.001$).

For patients on PD, the percentage of patients with a bicarbonate within 20–26 mmol/L differed significantly between centres ($\chi^2 = 168.8$, d.f. = 36, $p < 0.001$).

Albumin

A chi squared test was used to determine whether the percentage of patients with a serum albumin 35 g/L or more measured using a BCG assay or 30 g/L or more measured using a BCP assay varied between centres.

For patients on HD, the percentage of patients with a serum albumin ≥35 g/L measured by BCG differed significantly between centres ($\chi^2 = 331.5$, d.f. = 28, $p < 0.001$) and > 30 g/L measured by BCP differed significantly between centres ($\chi^2 = 142.8$, d.f. = 10, $p < 0.001$).

For patients on PD, the percentage of patients with a serum albumin ≥35 g/L measured by BCG differed significantly between centres (χ^2 = 114.8, d.f. = 27, p < 0.001) and >30 g/L measured by BCP differed significantly between centres (χ^2 = 39.9, d.f. = 10, p < 0.001).

Blood pressure

A chi-squared test was used to determine whether the percentage of patients with both systolic and diastolic blood pressure within range differed between centres.

For patients on HD, the percentage of patients with a pre-dialysis blood pressure of ≤140/90 mmHg differed significantly between centres (χ^2 = 208.3, d.f. = 31, p < 0.001).

For patients on PD, the percentage of patients with a blood pressure of ≤130/80 mmHg differed significantly between centres (χ^2 = 68.5, d.f. = 29, p < 0.001).

For patients with a transplant, the percentage of patients with a blood pressure of ≤130/80 mmHg differed significantly between centres (χ^2 = 200.1, d.f. = 20, p < 0.001).

Cholesterol

A chi squared test was used to determine whether the percentage of patients with a serum cholesterol level of 5 mmol/L or less differed between centres.

For patients on HD, the percentage of patients with a serum cholesterol of 5 mmol/L or less differed significantly between centres (χ^2 = 124.4, d.f. = 36, p < 0.001).

For patients on PD, the percentage of patients with a serum cholesterol of 5 mmol/L or less differed significantly between centres (χ^2 = 132.1, d.f. = 38, p < 0.001).

HbA1c

A chi squared test was used to determine whether the percentage of patients with a glycated haemoglobin level of less than 7% differed between centres.

For patients on HD, the percentage of patients with an HbA1c of < 7% differed significantly between centres (χ^2 = 52.9, d.f. = 23, p < 0.001).

For patients on PD, the percentage of patients with an HbA1c of <7% *did not* differ significantly between centres (χ^2 = 29.9, d.f. = 22, p = 0.122).

For patients with a transplant, the percentage of patients with an HbA1c of <7% differed significantly between centres (χ^2 = 89.7, d.f. = 20, p < 0.001).

Chapter 14: Report of the Paediatric Renal Registry

Summary

The demographics of the paediatric established renal failure (ERF) population have changed little over the past few years though there is a slow but steady growth in the total number of paediatric patients being cared for. There remains a disproportionately large prevalence and take-on rate of patients from the Asian subcontinent. The distribution of diseases causing ERF in childhood is similar to that given in previous reports. There are, however, significant differences in the distribution of these diseases across the ethnic groups with three autosomal recessive conditions accounting for 19.2% of all Asian patients presenting with ERF.

Primary focal segmental glomerulosclerosis is the single most common glomerular disease causing ERF in the paediatric population. This is a difficult condition to manage and carries an increased mortality compared to the ERF population as a whole. Cross-sectional analysis also shows that fewer patients with this condition have a functioning renal allograft.

An antenatal diagnosis of renal problems is often made. However, even with serious disorders that lead to ERF early in life, a routine 18–20 week anomaly scan is not guaranteed to detect the disorder. Overall, just 50% of patients with severe renal disorders leading to ERF in early life, who were born live and did not have major problems from pulmonary hypoplasia, were diagnosed antenatally.

Of patients presenting with chronic kidney disease progressing to ERF, 50% do so within two years of presentation, leaving little time for intervention with regard to growth and nutrition. For the remaining 50% there is a fall in height standard deviation score (SDS) from presentation to ERF, though this is limited to those presenting in the first 4 years of life. Nutrition was not apparently a problem with no significant change in weight SDS from presentation to ERF. Some of the height loss can be explained by patients with metabolic or syndromic diagnoses in the group of patients presenting in the first 4 years of life.

Five year survival of the paediatric ERF population is 92%. Death is more common in patients requiring dialysis within the first year of life, where the 5 year survival is just 66%.

Of the prevalent cohort of patients, 76% have a functioning allograft, with 15% on peritoneal dialysis and 9% on haemodialysis. Of those with functioning allografts, 81% are cadaveric. For patients on peritoneal dialysis just 13% are on CAPD. Significantly fewer patients from ethnic minority groups have a functioning renal allograft compared to White patients ($p < 0.0001$). For those on dialysis, significantly more patients from ethnic minority groups are on haemodialysis rather than peritoneal dialysis ($p = 0.0279$).

For patients with renal allografts, overall renal function as assessed by the calculation of predicted GFR from the serum creatinine is excellent. The mean predicted GFR for the cohort was 60 ml/min/1.73 sq.m. There was a slow fall in mean GFR with the longevity of the graft. The most accurate prediction of GFR from the serum creatinine was with the use of the Schwartz formula and a constant of 40 for all ages and genders. Cross-sectional analysis of the population, did not show any reduction in GFR for those patients who had abnormal bladders and were either on clean intermittent catheterisation (with or without bladder augmentation) or had a urinary diversion.

Allograft rejection episodes remain common within the first year of transplantation with between 25 and 50% of patients suffering rejection episodes. Thereafter, rejection remains a problem affecting between 10 and 15% of patients for each year of graft life.

The majority of late rejection episodes are biopsy proven, whereas a third of patients in the first year post-transplant, are still managed on the basis of a clinical diagnosis. Immunosuppressive regimes vary tremendously within the prevalent patient cohort. The majority of patients are managed with triple immunosuppression, consisting of a calcineurin inhibitor, steroids and either Azathioprine or Mycophenolate (76.7%). There has been a trend towards increasing usage of Tacrolimus with fewer patients now being started on Cyclosporin. Rejection episodes are increasingly being treated with Tacrolimus and Mycophenolate. Only a small number of patients received anti-lymphocyte or anti-thymocyte globulins.

Introduction

Whilst continuing to make progress in the installation of systems to allow continuous data acquisition from paediatric nephrology centres, the Paediatric Registry has maintained a system of annual data return to allow analysis of the population. Within this report, the demographics of the paediatric ERF population are explored, paying particular note to age and ethnic distribution. For the first time, the Registry has also been able to look at differences in the ethnic distribution of the diseases causing ERF.

Having achieved six years of continuous data collection, it is now possible to analyse mortality within the paediatric ERF population. Presentation of patients is re-explored for the first time since the 1999 report and the role of antenatal diagnosis is also examined.

Included in this report is a breakdown of the current treatment of patients with particular attention paid to the differences in management of ethnic minority groups. There is a special focus on primary focal segmental glomerulosclerosis being the single most common glomerular disease in childhood and there is a close examination of renal function, allograft rejection and immunosuppression in the current cohort of transplanted patients.

Paediatric ERF population

The demographics of the paediatric ERF population has changed little since the last report. Figure 14.1 shows the paediatric ERF population as it stood on the 1st April 2002. Within England, Wales and Northern Ireland virtually all patients under the age of 16 years are looked after within one of the 12 paediatric nephrology tertiary referral centres. Within Scotland, patient capture by the tertiary unit is less complete. However, for the purposes of this report, prevalence and take-on rate statistics were calculated using all the patients up to the age of 16 years. This allows for the inclusion of more patients than with the previous cut off point of 15 years and also allows the population to be broken down into four age bands each covering 4 years for comparison.

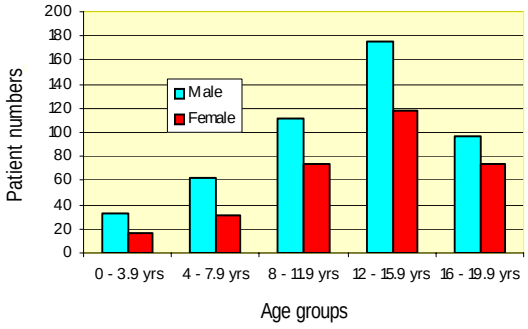

Figure 14.1. Age and sex distribution of the UK paediatric ERF population

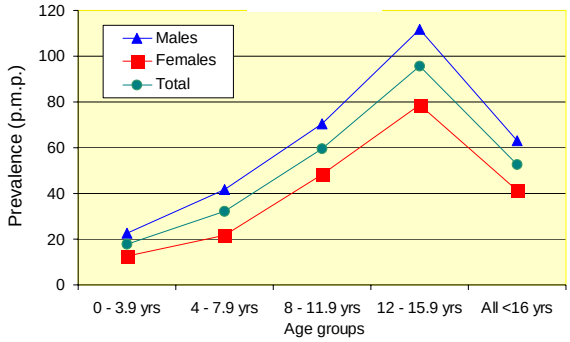

Figure 14.2. Prevalence of ERF in the UK under 16 year old population

The total number of patients being cared for in the 13 UK paediatric units in April 2002 was 804. Of these, 11 patients were actually above the age of 20 years and have therefore not been included in any further calculations of demographic statistics. 793 patients were below the age of 20 years, of whom 760 were below 18 years of age and 622 were below 16 years of age. This data is set out in Table 14.1. It is clear from this that although the majority of the workload of paediatric units is with patients under the age of 16 years, patients in late teenage and early adulthood constitute 21% of prevalent patient total and thus contribute significantly to unit activity. The age of transfer of patients from paediatric to adult units varies significantly. Decisions about patient transfer to adult units are generally made on an individual basis and will depend upon many factors, particularly, the presence or absence of co-morbid features, the patients' developmental and academic status and the duration of time the patient has been cared for within the paediatric setting. One final feature which influences transfer is the availability of dialysis spaces within adult units.

The prevalence of ERF in paediatric patients in the UK is shown in Table 14.2. Population statistics for this table have been taken from data available from the UK National Census conducted in 2001 and published at the www.statistics.gov.uk site. It can be seen that the total childhood population is estimated at 11.9 million and the prevalence of ERF overall stands at 52.4 per million of the childhood population. Looking at each age band individually, it can be seen that males outweigh females. The overall male to female ratio is 1.53:1. There is a steady increase in the prevalence of ERF all the way up to 16 years of age. This data is shown graphically in Figure 14.2.

The calculation of take-on rate is made difficult by the small numbers of new patients presenting, particularly when this is broken down further into different age-groups. For the purposes of this analysis, only the new patients taken on from April 1996 until April 2002 have been included. The take-on rates have then been calculated using average yearly figures over this 6 year period to eliminate problems of year to year variability.

Table 14.1. Age and sex distribution of the paediatric ERF population

Age Group	Males	Females	Total (%)
0–1.9 yrs	10	4	14 (1.7)
2–3.9 yrs	22	13	35 (4.4)
4–7.9 yrs	63	31	94 (11.7)
8–11.9 yrs	112	73	185 (23.0)
12–15.9 yrs	176	118	294 (36.6)
16–19.9 yrs	97	74	171 (21.3)
Total	480	313	793

Table 14.2. Prevalence of ERF in the UK under 16 year old population

	UK Population (millions)			ESRF Population			Prevalence (p.m.p)		
Age Group	**Males**	**Females**	**Total**	**Males**	**Females**	**Total**	**Males**	**Females**	**Total**
0–3.9 yrs	1.4100	1.3431	2.7531	32	17	49	22.70	12.66	17.80
4–7.9 yrs	1.5016	1.4277	2.9293	63	31	94	41.96	21.71	32.09
8–11.9 yrs	1.5915	1.5163	3.1078	112	73	185	70.37	48.14	59.53
12–15.9 yrs	1.5775	1.5013	3.0788	176	118	294	111.57	78.60	95.49
All <16 yrs	6.0806	5.7884	11.8690	383	239	622	62.99	41.29	52.41
UK Population	28.5812	30.2080	58.7892				13.40	7.91	10.58

Table 14.3 shows the take-on rate per million childhood population, divided according to age-group. The overall take-on rate is similar to that in other countries at about 7.7 per million of the childhood population. Take-on rate for patients presenting with ERF between the ages of 0–4 years and between the ages of 8–12 years is similar to this overall average. The take-on rate for patients between the ages of 12–16 years is higher at 11.3 per million childhood population, whilst there is a lower take-on rate of just 4.2 per million childhood population for patients between the ages of 4–8 years. This data is shown graphically in Figure 14.3 where the dip in the 4–8 year old group is quite apparent. This also shows the variability between the sexes with males being grossly over-represented in the 0–4 year old group.

The raw statistics for the patients being taken onto the ERF programme over the 6 year period from 1996–2002 are shown in Table 14.4. It can be seen that there is significant year to year variability in the total numbers presenting. It is also clear that there is an increasing number of patients between the ages of 16 and 20 years of age starting ERF management within paediatric units. Figure 14.4 shows the number of patients taken on over the past 6 years graphically. The variability from year to year seems to relate to a variable number of males accepted onto the programme, rather than any great variability in the number of females taken on. Although there is a lot of year to year oscillation, the slope of the trend line is clearly slowly rising.

Although older patients are being accepted onto the paediatric ERF programme, the relatively high take-on rate for patients between the ages of 12-15 years, together with the survival of patients taken on at a young age, is steadily increasing the total number of prevalent paediatric patients. Figure 14.5 shows the number of patients

Table 14.3. Take-on rate of patients under the age of 16 years with ERF in the UK.

	UK Population (millions)			New patients (average)			Take on Rate (p.m.p)		
Age Group	**Males**	**Females**	**Total**	**Males**	**Females**	**Total**	**Males**	**Females**	**Total**
0–3.9 yrs	1.4100	1.3431	2.7531	13.5	7.7	21.2	9.6	5.7	7.7
4–7.9 yrs	1.5016	1.4277	2.9293	7.3	5.0	12.3	4.9	3.5	4.2
8–11.9 yrs	1.5915	1.5163	3.1078	12.3	10.7	23.0	7.7	7.1	7.4
12–15.9 yrs	1.5775	1.5013	3.0788	18.8	16.0	34.8	11.9	10.7	11.3
All <16 yrs	6.0806	5.7884	11.8690	52.0	39.3	91.3	8.6	6.8	7.7
UK Population	28.5812	30.2080	58.7892				1.8	1.3	1.6

Table 14.4. New patients starting ERF treatment in paediatric units in the UK from 1996 to 2002

	New Patients Starting ESRF Treatment by Year (April to April)																				
	1996–1997			**1997–1998**			**1998–1999**			**1999–2000**			**2000–2001**			**2001–2002**			**Average**		
Age Group	**M**	**F**	**T**	**M**	**F**	**T**	**M**	**F**	**T**	**M**	**F**	**T**	**M**	**F**	**T**	**M**	**F**	**T**	**M**	**F**	**T**
0–3.9 yrs	7	4	11	25	5	30	15	9	24	9	7	16	12	13	25	13	8	21	13.5	7.7	21.2
4–7.9 yrs	4	3	7	8	7	15	10	8	18	9	0	9	7	6	13	6	6	12	7.3	5.0	12.3
8–11.9 yrs	15	10	25	6	8	14	14	9	23	11	10	21	8	16	24	20	11	31	12.3	10.7	23.0
12–15.9 yrs	17	18	35	23	13	36	23	18	41	14	24	38	13	10	23	23	13	36	18.8	16.0	34.8
16–19.9 yrs	3	0	3	2	3	5	5	1	5	4	6	10	9	8	17	10	3	13	5.5	3.5	9.0
All <16 yrs	43	35	78	62	33	95	62	44	106	43	41	84	40	45	85	62	38	100	52.0	39.3	91.3

under the age of 15 years being treated in paediatric units from 1986 until 2002. An upper age limit of 15 years has been used for this data to allow it to become comparable to statistics from previous reports. The upward trend is clearly apparent on this graph. Table 14.5 shows this data with a breakdown according to age-group. Here the data for patients between the ages of 15 and 20 years being looked after in paediatric units is included to give a true perspective of the workload. Again, it is clear that the numbers for patients up to the age of 5 years are remaining fairly constant, whereas the numbers of patients in later childhood being cared for in paediatric units, are increasing.

In the 2002 report, the increased prevalence and take-on rate of patients from the Asian sub-continent as compared with White patients and other ethnic minority groups were highlighted. Figure 14.6 shows the overall prevalence of ERF in children and the breakdown according to ethnicity. It can be seen that the prevalence of ERF in Asian patients is over twice that of White patients. The actual prevalence ratio of Asians to Whites is 2.3:1, whereas the prevalence ratio for Black patients compared to Whites is 0.74:1. Table 14.6 shows the absolute numbers of patients in each age-group, broken down according to ethnicity. This is shown graphically in Figure 14.7 where the percentage of patients belonging to each ethnic group is divided according to age-band.

It can be seen that there is no statistical difference in the age distribution of patients with ERF according to ethnicity.

The data for take-on rate, broken down according to age at starting ERF treatment, and ethnicity, is shown in Table 14.7. It can be seen that the take-on rate for patients from the Asian sub-continent is over 3 times that of White patients. Figure 14.8 shows the percentage of patients being taken on, broken down by age-group and ethnicity. Again, the age distribution of patients being taken on is no different between the ethnic minority groups and the White group. However, there is an increased take-on rate throughout childhood in the Asian population.

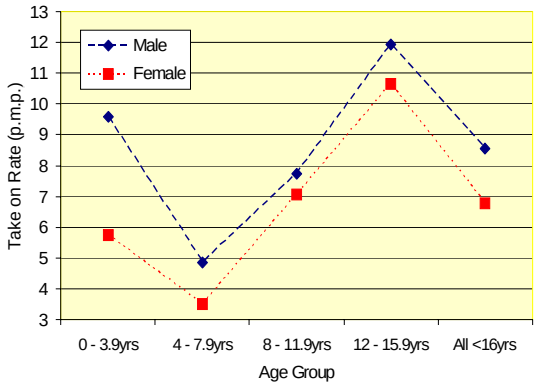

Figure 14.3. Take on rate of patients under the age of 16 years with ERF in the UK

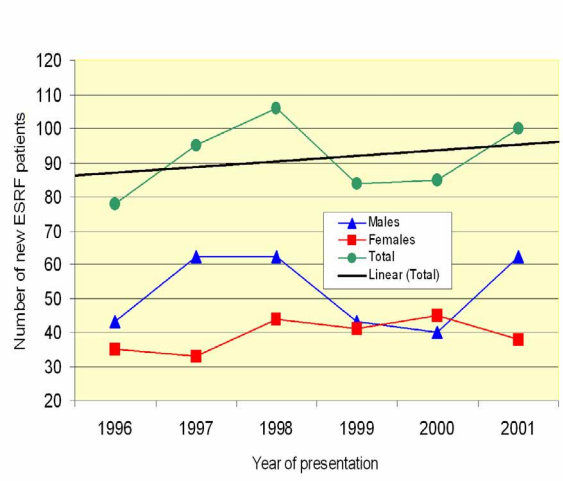

Figure 14.4. New patients starting ERF treatment each year

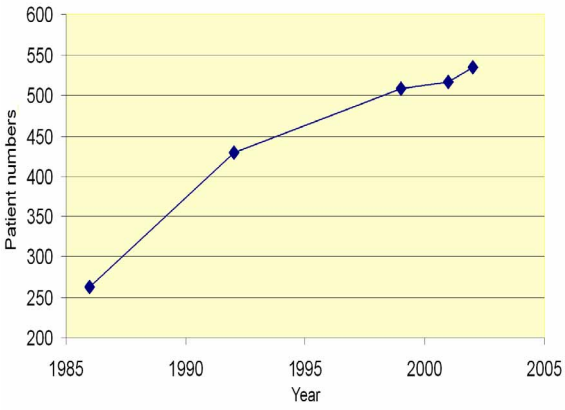

Figure 14.5. Trend in the number of patients with ERF below the age of 15 years

Table 14.5. All patients in paediatric renal units from '86 to '02

Age Group	Patient stock data for the years of; 1986	1992	1999	2001	2002
0 - 1.99 yrs		16	18	13	14
2 - 4.99 yrs		55	46	56	58
5 - 9.99 yrs		150	151	146	147
10 - 14.99 yrs		208	293	301	315
15 - 19.99 yrs			253	274	259
Total under 15 yrs	263	429	508	516	534
Total under 20 yrs			761	790	793

Table 14.6. Ethnic distribution of the paediatric ERF population.

Age Group	White	Asian	Black/Other	Total (%)
0 - 3.99 yrs	36	11	2	49 (6.2)
4 - 7.99 yrs	76	12	6	94 (11.7)
8 - 11.99 yrs	159	24	2	185 (23.0)
12 - 15.99 yrs	249	34	11	294 (36.6)
16 - 19.99 yrs	138	27	6	171 (21.3)
Total	658	108	27	793

Table 14.7. Take on rate of children with ERF in the UK, by ethnicity.

Ethnicity	UK Population (millions)	Patients starting ESRF treatment '96 - '02 0 - 3.99yrs	4 - 7.99yrs	8 - 11.99yrs	12 - 15.99yrs	Take on Rate (p.m.p)
White	10.62431	99	62	115	162	6.87
Asian	0.71849	24	11	20	37	21.34
Black	0.38558	3	0	3	6	5.19
Other	0.34094	1	1	0	4	2.93
Total	12.06032	127	74	138	209	7.57

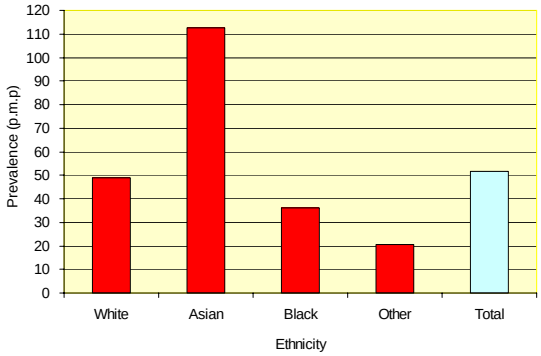

Figure 14.6. Prevalence of ERF in children in the UK, by ethnicity

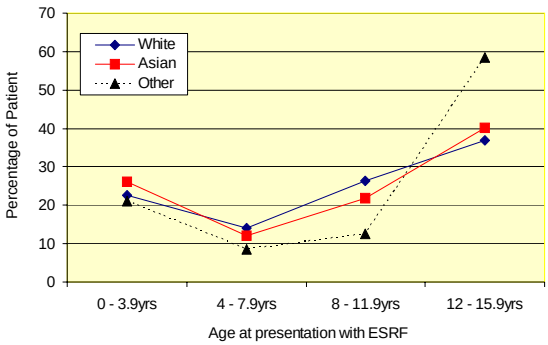

Figure 14.8. Percentage of patients starting ERF management divided by age and ethnicity

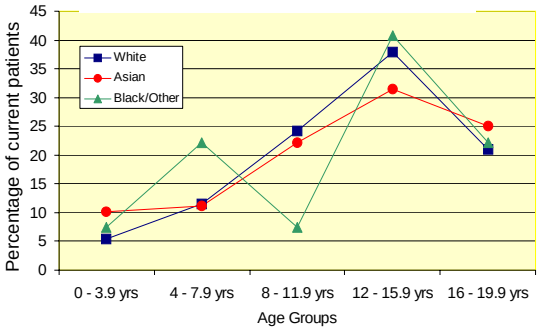

Figure 14.7. Proportion of patients presenting in each age band, by ethnicity

Causes of ERF in childhood

The underlying ERF diagnoses have been analysed with the cohort of 1186 patients registered on the Paediatric ERF Database for whom a primary cause of renal failure was given. Table 14.8 gives a breakdown of the diagnoses of these patients, divided into the 10 broad bands used for previous

reports. It is clear that the leading cause of ERF in childhood is renal dysplasia in one form or another; renal dysplasia itself and conditions associated with renal dysplasia, accounting for 25.8% of patients in ERF. Glomerulonephritides are the next most common cause, accounting for 20.7% of patients. This is a wide diagnostic group, covering a number of conditions, and the single most common glomerulopathy which is primary focal segmental glomerulosclerosis, accounts for just 8.2% of patients. Obstructive uropathy, accounts for 18.1% of patients and 75.7% of these patients had posterior urethral valves leading to obstructive uropathy.

Table 14.9 shows the broad diagnostic groups broken down according to age at commencement of ERF treatment. It can be seen that for some diagnoses such as renal dysplasia, the number of patients presenting steadily decrease with time through childhood. As one might expect, the opposite is the case for glomerular disease. This is shown graphically in Figure 14.9 for the four groups of renal dysplasia, obstructive uropathy, glomerular disease and reflux nephropathy. Whilst glomerular disease as a cause of renal failure increases with age and the number of patients presenting with obstructive uropathy slowly decreases with age, the graphs for renal dysplasia and reflux nephropathy can again be shown to be a mirror image of each other, renal dysplasia falling at the same rate as reflux nephropathy rises. As discussed in the 2002 report, it seems likely that this is a spectrum of the same condition (renal tract dysplasia with vesico-ureteric reflux) as the overall incidence of reflux nephropathy and renal dysplasia together is constant throughout childhood, accounting for a little over 30% of all paediatric ERF.

Figure 14.10 shows the same data for tubulo-interstitial disease, congenital nephrotic syndrome, metabolic disease and polycystic kidney disease. As expected, whilst there is a sharp fall-off in the number of patients with congenital nephrotic syndrome and polycystic kidney disease, presenting with ERF with age, there is a steady rise throughout the first 12 years of life in the numbers of patients starting ERF treatment with tubulo-interstitial and metabolic disease.

Table 14.10 again shows the breakdown of patients according to diagnostic categories but this time the table has been subdivided according to the ethnic origin of the patient. Overall, 45.1% of White patients have either renal dysplasia or obstructive uropathy as a cause of renal failure. This figure is just 34.7% for the Asian population and this difference in the proportions of patients with dysplasia and obstructive uropathy compared to other diagnoses is significant ($p = 0.007$ – Fisher's exact test). The numbers of Black patients are small making statistical analysis difficult, but it is noticeable that whilst the proportion of patients with renal dysplasia is similar to the White population, obstructive uropathy is rare in Black patients.

The frequency of tubulo-interstitial and metabolic diseases is significantly increased in the Asian population compared to the White population ($p < 0.0001$ – Fisher's exact test). Within the tubulo-interstitial disorders group, this is secondary to a relatively large number of Asian patients with nephronophthisis as the cause of renal failure (17 of 167 Asian patients vs. 38 of 972 White patients, $p = 0.0014$ – Fisher's exact test). Within the metabolic disorders group, there is a relative excess of patients with cystinosis and primary hyperoxaluria type 1 (PH1) in the Asian population. In the White population there were 35 patients with cystinosis and 3 patients with PH1 out of a total of 972 patients. In the Asian population there were 11 patients with cystinosis and 4 patients with PH1 out of a total of 167 patients. Combining these two recessively inherited conditions, the difference between the White and Asian communities is significant ($p = 0.0083$ – Fisher's exact test).

Thus, from studying the whole cohort of patients registered on the Paediatric Registry, it is clear that one explanation for the increased prevalence and incidence of ERF

in the Asian community may be, at least in part, secondary to these three autosomal recessive conditions. Together they account for 19.2% of Asian patients with ERF. Consanguinity and a small genetic pool will play a major role in dictating the incidence of these conditions.

Within the Black population renal failure from glomerulonephritides, auto-immune disease and vasculitis was significantly more common than in the White population. Twelve of 29 Black patients with ERF had glomerular disease compared with just 195 of 972 White patients ($p = 0.0093$ – Fisher's exact test). It has been noted earlier that Blacks are relatively under represented in the ERF population. One explanation for this might will be the different patterns of disease seen in the Black population. With the paucity of obstructive uropathy causing renal failure and a tendency towards glomerular disease which present later in childhood, one could expect the total cohort of Black patients to be reduced. This data is shown graphically in Figure 14.11.

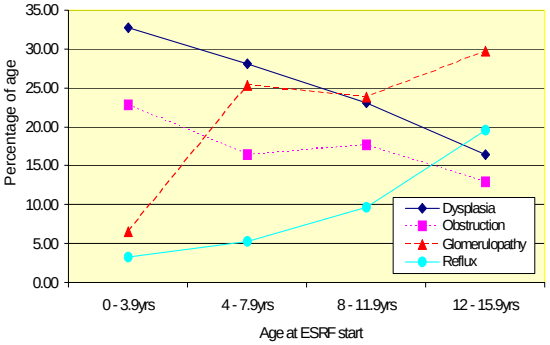

Figure 14.9. Percentage of incident patients with renal dysplasia, obstructive uropathy, glomerular disease and reflux nephropathy presenting by age

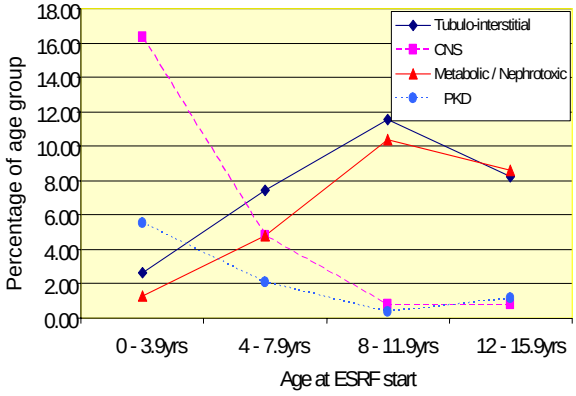

Figure 14.10. Percentage of incident patients with tubulo-interstitial disease, congenital nephrotic syndrome, metabolic/nephrotoxic disease and polycystic kidney by age

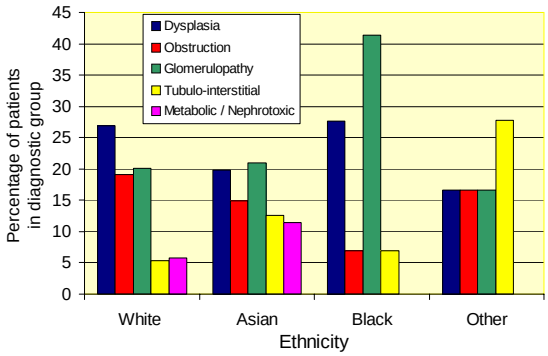

Figure 14.11. Frequency of diagnostic categories in different ethnic groups

Focus on primary focal segmental glomerulosclerosis

Primary focal segmental glomerulosclerosis accounts for 39.6% of paediatric patients in ERF from a glomerulopathy. Focal segmental glomerulosclerosis (FSGS) is a histological diagnosis and this term covers a spectrum of clinical disorders ranging from congenital nephrotic syndrome to childhood steroid resistant nephrosis. Typically congenitalnephrotic syndrome is either present from birth or becomes apparent over the first fewmonths of life. It would be considered unusual for true congenital nephrotic syndrome. Within the paediatric ERF regis-

Table 14.8. Grouped ERF diagnoses for 1186 patients registered on the Paediatric Registry.

Diagnostic Group	Males	Females	Total	% of Total
Renal Dysplasia and related conditions				
Renal dysplasia	161	73	234	19.73
Prune belly syndrome	22	0	22	1.85
Renal hypoplasia	8	13	21	1.77
Multicystic dysplastic kidneys	9	6	15	1.26
Branchio-oto-renal syndrome	5	2	7	0.59
Lawrence Moon Biedl syndrome	2	2	4	0.53
Megacystis megaureter	3	0	3	0.25
Total with Primary Renal Dysplasia	210	96	306	25.80
Obstructive Uropathy				
Posterior urethral valves	163	0	163	13.74
Neuropathic bladder	9	10	19	1.60
Congenital bladder outlet obstruction (not PUV)	10	5	15	1.26
Congenital obstructive uropathy (not BOO)	11	4	15	1.26
Acquired obstructive uropathy	3	0	3	0.25
Total with Obstructive Uropathy	196	19	215	18.13
Glomerulonephritis, Vasculitis and Glomerulopathy				
Primary focal segmental glomerulo-sclerosis	45	52	97	8.18
D+ Haemolytic uraemic syndrome	14	20	34	2.87
Henoch Schoenlein nephritis	10	11	21	1.77
Alport's syndrome	13	4	17	1.43
Glomerulonephritis (unspecified)	4	6	10	0.84
Mesangio-capillary glomerulonephritis Type 1	6	2	8	0.67
Mesangio-capillary glomerulonephritis Type 2	2	6	8	0.67
D neg Haemolytic uraemic syndrome	3	5	8	0.67
Crescentic glomerulonephritis	5	6	11	0.93
IgA nephropathy	3	4	7	0.59
Proliferative glomerulonephritis	3	4	7	0.59
Systemic Lupus Erythematosis	1	4	5	0.42
Anti-GBM disease	0	4	4	0.34
Vasculitis (unspecified)	0	3	3	0.25
Microscopic polyarteritis nodosa	1	1	2	0.17
Wegner's granulomatosis	1	1	2	0.17
Membanous nephropathy	0	1	1	0.08
Total with Glomerular Disease	111	134	245	20.66
Reflux Nephropathy and CRF of Uncertain Aetiology				
Reflux nephropathy	42	47	89	7.50
Chronic renal failure - uncertain aetiology	9	11	20	1.69
Total with Reflux Nephropathy and CRF of Uncertain Aetiology	51	58	109	9.19
Primary Tubular and Interstitial Disorders				
Nephronophthisis	31	29	60	5.06
Primary interstitial nephritis	8	5	13	1.10
Renal tubular acidosis	3	0	3	0.25
Tubular disorders (other)	1	1	2	0.17
Barrter's syndrome	2	0	2	0.17
Total with Primary Tubular and Interstitial Disorders	45	35	80	6.75

Table 14.8 (continued)

Diagnostic Group	Males	Females	Total	% of Total
Metabolic Diseases and Drug Nephrotoxicity				
Cystinosis	24	22	46	3.88
Cyclosporin Nephrotoxicity	8	3	11	0.93
Primary hyperoxaluria type 1	4	3	7	0.59
Other cytotoxic drug nephrotoxicity	1	3	4	0.34
Mitochondrial Cytopathy	1	1	2	0.17
Metabolic Diseases (other)	2	0	2	0.17
Nephrocalcinosis	0	1	1	0.08
Cis-Platinum nephrotoxicity	1	0	1	0.08
Drug nephrotoxicity (unspecified)	0	1	1	0.08
Total with Metabolic Diseases and Drug Nephrotoxicity	41	34	75	6.32
Congenital Nephrotic Syndrome				
Congenital nephrotic syndrome (unspecified)	7	23	30	2.53
Congenital nephrotic syndrome (Finnish)	13	14	27	2.28
Congenital nephrotic syndrome (DMS)	6	1	7	0.59
Congenital nephrotic syndrome (FSGS)	2	2	4	0.34
Total with Congenital Nephrotic Syndrome	28	40	68	5.73
Renal Vascular Disorders				
Cortical necrosis	10	10	20	1.69
Renal vein thrombosis	9	4	13	1.10
Renal artery stenosis	2	1	3	0.25
Renal artery thrombosis	1	1	2	0.17
Renal trauma	1	1	2	0.17
Total with Renal Vascular Disorders	23	17	40	3.37
Polycystic Kidney Disease				
Autosomal recessive PKD	11	12	23	1.94
Polycystic kidney disease (other)	4	3	7	0.59
Tuberous Sclerosis PKD	0	1	1	0.08
Total with Polycystic Kidney Disease	15	16	31	2.61
Malignant and Related Diseases				
Wilms' tumour	8	6	14	1.18
Wilms' nephropathy	1	1	2	0.17
Mesoblastic nephroma	1	0	1	0.08
Total with Malignant and Related Diseases	10	7	17	1.43

Table 14.9. ERF diagnostic groups for 1011 patients registered on the paediatric registry by age at start of ERF

	ESRF diagnoses for patient with ESRF start aged:							
	0–3.9yrs		4–7.9yrs		8–11.9yrs		12–15.9yrs	
Diagnostic Group	**No**	**% of total**	**No**	**% of total**	**No**	**% of total**	**No**	**% of totals**
Dysplasia	100	32.68	53	28.04	60	23.08	42	16.41
Obstruction	70	22.88	31	16.40	46	17.69	33	12.89
Glomerulopathy	20	6.54	48	25.40	62	23.85	76	29.69
Reflux	10	3.27	10	5.29	25	9.62	50	19.53
Tubulo-interstitial	8	2.61	14	7.41	30	11.54	21	8.20
CNS	50	16.34	9	4.76	2	0.77	2	0.78
Reno-vascular	19	6.21	8	4.23	6	2.31	5	1.95
Metabolic / Nephrotoxic	4	1.31	9	4.76	27	10.38	22	8.59
PKD	17	5.56	4	2.12	1	0.38	3	1.17
Malignant	8	2.61	3	1.59	1	0.38	2	0.78

Table 14.10. ERF diagnostic groups, divided according to ethnicity

ESRF diagnoses split by ethnic group:	White patients		Asian patients		Black patients		Other patients	
Diagnostic Group	No	% of Total	No	% of Total	No	% of Total	No	% of Total
Renal Dysplasia	262	26.95	33	19.76	8	27.59	3	16.67
Obstructive Uropathy	185	19.03	25	14.97	2	6.90	3	16.67
Glomerular Disease	195	20.06	35	20.96	12	41.38	3	16.67
Reflux Nephropathy and CRF of Uncertain Aetiology	94	9.67	11	6.59	2	6.90	2	11.11
Primary Tubular and Interstitial Disorders	52	5.35	21	12.57	2	6.90	5	27.78
Congenital Nephrotic Syndrome	53	5.45	14	8.38	1	3.45	0	0.00
Renal Vascular Disorders	36	3.70	3	1.80	1	3.45	0	0.00
Metabolic Diseases and Drug Nephrotoxicity	56	5.76	19	11.38	0	0.00	0	0.00
Polycystic Kidney Disease	24	2.47	5	2.99	1	3.45	1	5.56
Malignant and Related Diseases	15	1.54	1	0.60	0	0.00	1	5.56

try 102 patients have been registered with FSGS as a cause of ERF. There were only 5 patients documented as having "congenital nephrotic syndrome with FSGS" and interestingly some of these presented beyond the age of 1 year. Similarly, some patients registered as just having primary FSGS as a cause of ERF, presented before the age of one year. For the purposes of this analysis, therefore, both of these groups have been amalgamated.

Table 14.11 shows the ethnic distribution of the patients with FSGS. It is clear that this is a condition affecting all ethnic groups. There is a slight but not statistically significant increase in the incidence in the Black population. Similarly, this condition is evenly distributed between males and females. Of the total of 102 patients with this diagnosis, data on presentation and some details of their clinical course were available in 85 patients. Figure 14.12 shows the age at presentation to a paediatric nephrologist for these patients. The figure is divided into 4 year age bands but for clarity the 0–3.99 year band is further subdivided into two. It is clear that this condition presents with decreasing frequency with time. Almost half (39) of the 85 patients presented in the first 4 years of life though only 5 of these presented within the first year. Roughly a quarter of patients presented between the ages of 4 to 8 years and the final quarter presented between the ages of 8 and 16 years.

FSGS is a condition (or rather group of conditions) for which there is no proven treatment. Despite the use of cytotoxic agents, steroids, immunosuppressants and, in some cases, plasma exchange, approximately 50% progress to renal failure. Figure 14.13 shows the time from presentation to ERF for this cohort. There is a decline in the number of patients maintaining renal function with time. 50% of those who are going to progress to ERF will have done so within 2 years of presentation and 80% by 5 years

Table 14.11. Ethnic distribution of patients with FSGS

Ethnicity	Patients	Cohort	% of cohort
White	83	972	8.5
Asian	14	167	8.4
Black	4	29	13.8
Other	1	18	5.6
Total	102	1186	8.6

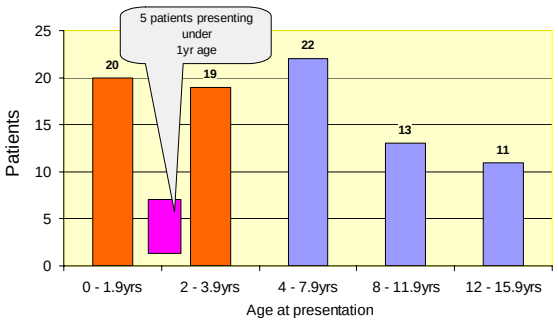

Figure 14.12. Age at presentation to nephrology services of patients with FSGS

after presentation. Age of onset of disease has no bearing on the time taken to progress to ERF. Figure 14.14 shows the median time to ERF from presentation broken down according to age of presentation. It must be stressed that this data relates only to those who progressed to ERF. As the Registry only currently collects data on ERF patients we have no data on the total patient number with FSGS and those not progressing to ERF. It is clear that the trend is for a decreased time from presentation to ERF with increasing age of disease onset. However, the variability in each group is exceedingly wide (Table 14.12) and this trend is not statistically significant.

Management of primary FSGS once ERF ensues is the same as for any other patient with ERF. However, there are frequently problems before the onset of renal failure secondary to complications of the nephrotic state. In addition, the risk of disease recurrence in a renal allograft is recognised to be in the order of 20–40%. As it has only been possible to study the current cohort cross-sectionally, outcome data is limited. At the time of the analysis, 31 of the cohort of 102 patients had been transferred to adult nephrology units and follow up data were not available. Nine patients (8.8%) had died. As will be shown later, this is greater than one would expect for paediatric patients with ERF as a whole – demonstrating the difficulties in caring for patients with this condition. Forty patients had functioning renal allografts. Six of these had received living related donations and 34 had cadaveric grafts. Twenty two patients were on dialysis, 15 on peritoneal dialysis and 7 on haemodialysis. Thus just 64.5% of patients being treated in the paediatric centres had a functioning allograft. This compares with an overall figure for paediatric patients of 76.3% of patients having a functioning allograft on cross-sectional analysis. The difference between the proportion of patients with FSGS with an allograft and those with other conditions who have an allograft is significant (p = 0.0297 – Fisher's exact test).

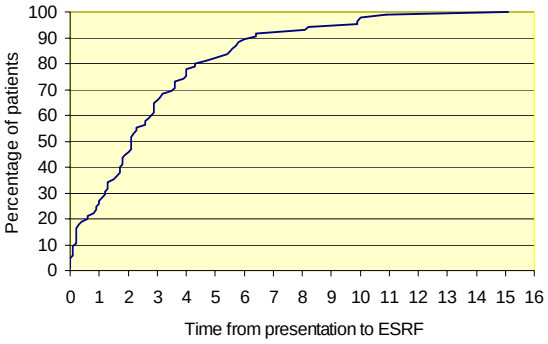

Figure 14.13. Time from presentation to ERF for patients with FSGS

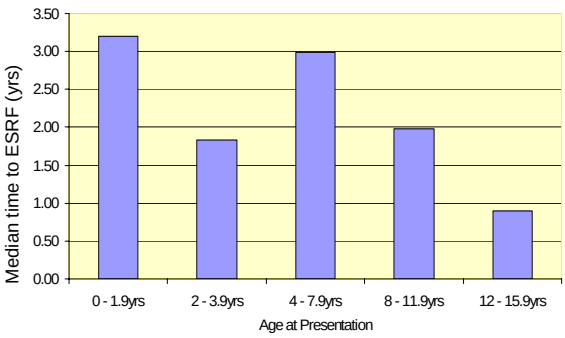

Figure 14.14. Median time from presentation to ERF in patients with FSGS by age

Table 14.12. Time from presentation to ERF for patients with FSGS.

Presentation		Time to ESRF			
Age group	**Patients**	**Mean (yrs)**	**Median (yrs)**	**Min (yrs)**	**Max (yrs)**
0–1.9yrs	20	4.57	3.20	0.00	15.10
2–3.9yrs	19	2.41	1.83	0.00	9.97
4–7.9yrs	22	3.36	2.99	0.02	9.86
8–11.9yrs	13	1.84	1.98	0.19	4.98
12–15.9yrs	11	1.27	0.90	0.05	1.27

Antenatal diagnosis

One major difference between ERF in children and adults is the possibility of detecting the conditions that lead to ERF antenatally. This can then lead to two forms of intervention. In cases where a severe abnormality is detected, a termination of the pregnancy can be offered. Alternatively, in cases of obstructive uropathy, antenatal intervention can be attempted, though evidence that this has a significant effect on outcome is sparse. The ability to make an antenatal diagnosis has increased with time as has the number of potential mothers having an anomaly scan at 18–20 weeks of gestation. Study of the whole paediatric ERF population tends to be biased towards those who present with ERF early in life as they have a greater duration of care within the paediatric unit. For the purposes of this analysis, the cohort includes the 602 new patients presenting with ERF from April 1996 until April 2002.

Amongst the 602 patients presenting over this six year period with ERF, 59 (9.8%) had an antenatal diagnosis of renal disease made. Clearly the possibility of making an antenatal diagnosis depends upon the disease in question being a developmental rather than an acquired problem. In addition, it would have to be detectable on antenatal ultrasonography. This would entail there being either significant dilatation of the renal tract or an abnormal appearance to the kidneys – usually either increased size and echogenicity or the presence of large visible cysts.

Table 14.13 shows the conditions in which an antenatal diagnosis was made together with the total number of patients in the cohort with these conditions. One patient was noted to have had an antenatal diagnosis but an ERF diagnosis was not given, leading to their exclusion from this data set.

As expected, the limitations of antenatal ultrasound mean that only five conditions were diagnosable on antenatal scans. Of these, only 26.3% of patients were diagnosed antenatally. As antenatal ultra-sonography is dealing with the detection of varying degrees of either dilatation of the renal tract and/or renal echogenicity, one might expect that there would be a higher diagnosis rate in patients who were more severely affected and were destined to progress to ERF earlier. Equally, one might expect that a greater proportion of those entering ERF within the first few years of life would be detected antenatally than those who enter ERF in later childhood.

Figure 14.15 shows the proportion of patients with each of the antenatally diag-

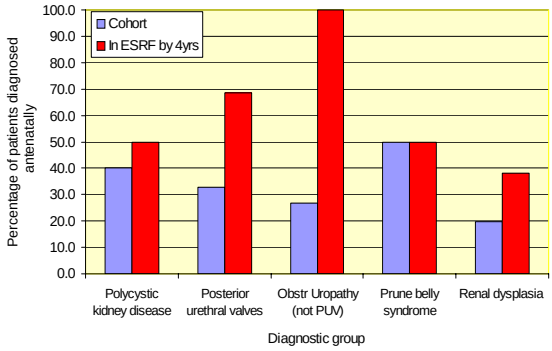

Figure 14.15. The proportion of patients in whom an antenatal diagnosis was made, by diagnostic group and age at entry into ERF

Table 14.13. Conditions for which antenatal diagnoses were made

Antenatal Dx	Patients in Cohort	Diagnosed	Cohort	In ESRF by 4 yrs	Diagnosed	In ESRF by 4 yrs
Polycystic kidney disease	15	6	40.0	10	5	50.0
Posterior urethral valves	58	19	32.8	19	13	68.4
Obstr Uropathy (not PUV)	15	4	26.7	2	2	100.0
Prune belly syndrome	8	4	50.0	2	1	50.0
Renal dysplasia	126	25	19.84	42	16	38.1
Total	222	58	26.13	75	37	49.33

nosable conditions who were diagnosed antenatally. The figure is divided into two sections. For each condition the first bar shows the overall proportion with that condition who were detected antenatally, whereas, the second bar shows the proportion of those who entered ERF within the first four years of life who were detected antenatally.

Renal dysplasia was the most common condition in this group that could be detected antenatally. However, only 20% of cases were diagnosed antenatally. Even when considering the patients who were in ERF within the first four years of life, only 38% had been antenatally detected. These results clearly highlight the limitations of antenatal ultrasound scanning. Renal dysplasia is a condition where there might be clear cut signs of abnormality at ultrasonography, with renal tract dilatation and cyst formation or echogenicity of the kidneys. Equally, the kidneys may appear small or relatively normal on ultrasound. Oligohydramnios is often the first sign that leads to concern in patients with a major renal anomaly. However, patients with renal dysplasia often have salt losing polyuric renal failure. This leads to normal amniotic fluid volumes.

Posterior urethral valves is the next most common condition diagnosable antenatally. Although one might expect the renal tract dilatation accompanying this condition to make it easily diagnosable, it is noteworthy that only 32.8% of cases presenting were diagnosed antenatally and even for those with early onset renal failure, only 68.4% were antenatally detected. This clearly highlights the limitations of 18 to 20 week anomaly scans. Although many patients with severe obstructive uropathy from posterior urethral valves will be detected at this stage through a combination of renal tract dilatation and oligohydramnios, it is perfectly possible to have normal appearances at this stage or just mild renal tract dilatation, only to develop the evidence of severe obstructive uropathy later in pregnancy. These cases would only be detectable if a further routine antenatal scan at about 28 weeks gestation were added to the current routine anomaly scan which is performed at 18–20 weeks gestation.

The picture for polycystic kidney disease is similar. One might expect polycystic kidney disease to be easily detectable antenatally through the combination of enlarged echogenic kidneys and oligohydramnios. In fact only 50% of cases entering ERF in the first 4 years of life were diagnosed antenatally. As with obstructive uropathy, it needs to be stressed that this is due to the nature of the disease and the timing of routine anomaly scans rather than the ability of those performing these scans to detect problems. Though a proportion are detected early, an 18 week scan can appear completely normal whilst a 24–28 week scan can then show enlarged echogenic kidneys and oligohydramnios. This pregnancy may then continue with the development of massive renal enlargement, anhydramnios and the birth of an infant who dies of pulmonary hypoplasia.

It thus appears from the data analysed that antenatal scanning is an inaccurate tool, diagnosing an average of just 50% of severe renal disorders that lead to early ERF. However, the data here only include patients who have been born and have survived long enough to become included in a regional ERF programme. There are no data on the number of patients detected where a termination of pregnancy has taken place, nor are there any data on the patients who have either been born and suffered early neonatal death, usually through pulmonary hypoplasia, or have not developed renal failure. If these patients were to be included, the proportion of infants with significant renal anomalies being diagnosed by antenatal screening would improve significantly. Collaboration with regional foetal management registries and neonatal units will be necessary in order to compile these statistics.

Presentation of patients to nephrology services

The timing of presentation to nephrology services is of particular importance in paediatric renal disease if clinicians are going to have enough time to prepare patients for ERF management and, more importantly, optimise care, to delay the onset of ERF where feasible and ensure that growth and nutrition are appropriate.

When last reviewed for the 1999 report, it was only possible to analyse a cross-sectional view of the population. These data would inevitably give a somewhat biased result as it did not represent the true spectrum of the ages of patients presenting with ERF. Whilst those who presented within the first few years of childhood would have been included in this data, even if their entry into ERF had been 12 years earlier, those who entered renal failure late in childhood would have been transferred to adult services and omitted from the analysis. To look at the presentation details of an accurate representation of the paediatric ERF population, the complete cohort of 602 patients presenting in ERF over the past 6 years from 1996 was analysed.

Presentation data were available for 570 members of this cohort (94.7%). Figure 14.16 shows the percentage of patients entering the ERF programme each year after presentation. With just over 40% of patients entering ERF within the first year of their presentation to nephrology services, and a further 9% entering ERF within the second year after presentation, only 50% of patients spend a significant time under nephrology care before starting the ERF programme. The timing of entry into ERF for this 50% is spread out over a decade. As might be expected, age of commencement of ERF influences this picture. Those starting ERF at a younger age have declined into ERF faster and 64% of those presenting in ERF within the first 4 years of life have entered ERF within the first year of their presentation to nephrology services. For the other age groups the pattern is similar. There is an initial peak with between 25 and 40% going into ERF within the first year of presentation. Six to 16% will then enter ERF over the second year and the rest are then spread out with time.

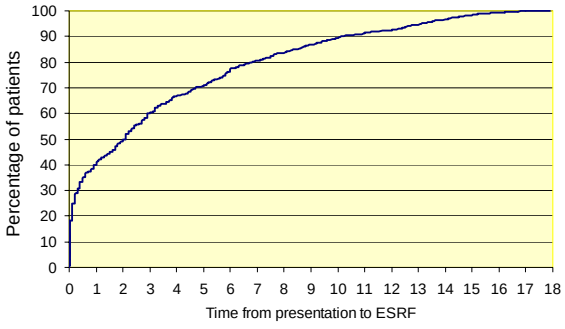

Figure 14.16. Percentage of patients who have entered ERF for each year after presentation

Clearly, patients who start ERF treatment within two years of presentation have diseases that are rapidly progressive at the time of presentation, or have progressed markedly by the time they have presented. Whichever, there is little leeway in these patients to optimise growth and nutritional status before entering the ERF programme. The remaining 50%, however, do spend a significant time with nephrology services and it would be hoped that, with the help of supplementary or gastrostomy feeds, growth hormone, control of renal osteodystrophy and erythropoietin, patient care would be improved.

Of the 288 patients who took in excess of two years from presentation to enter ERF, data on height were available for 277 (96%) and data on weight were available for 223 (77%). Figure 14.17 shows a box and whisker plot of height SDS at presentation and at the commencement of ERF treatment. The central line in the box represents the media and the outer lines the 25th and 75th percentiles, whilst the whiskers denote the range.

Overall, there is clearly a fall in height SDS from presentation to the start of ERF treatment. The data is normally distributed and the difference between the two groups is significant ($p < 0.0001$ – paired t test). Breaking the group down according to age of presentation, it is clear that most of the

patients with poor growth presented in the first year of life. Figure 14.18 shows a similar box and whisker plot for patients heights of patients presenting in the first four years of life (both at presentation and at ERF) and the heights of patients presenting above the age of four years (both at presentation and at ERF). While there is a fall in height SDS between presentation and ERF, for those presenting in the first 4 years of life ($p < 0.0001$ – paired t test), there was no significant difference between the height SDS at presentation and ERF for those presenting over the age of 4 years ($p = 0.847$ – paired t test).

One factor that could well explain the poor growth in those presenting in the first four years of life is nutrition. Much effort has been made to optimise the nutrition of children in ERF, whose appetites are exceedingly poor, using supplementary and gastrostomy feeds. Figure 14.19 shows a box and whisker plot of weight SDS for the whole group at presentation and ERF. It is clear that although the median weight at both points is slightly below average, there is no significant fall in weight SDS between presentation and ERF.

Breaking this group down into those who present in the first four years of life and those who present later (Figure 14.20) it can be seen that there is in fact a mean weight gain, with a narrowing of the spectrum of weight SDS, for those presenting early whilst those who present later show a small fall in weight SDS. These data would suggest that, overall, the nutritional policy being implemented is successful and that other factors are instrumental in the poor height gain for those presenting in the first four years of life. In some, this could be related to syndromic or metabolic diagnoses that are associated with inherent poor growth. Another factor that needs to be investigated is the timing and extent of the use of growth hormone in this specific population.

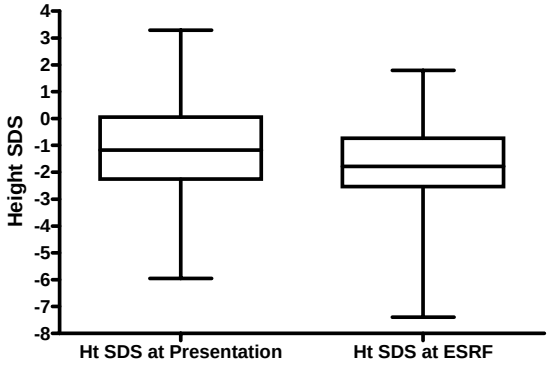

Figure 14.17. Height SDS at presentation and at entry into ERF

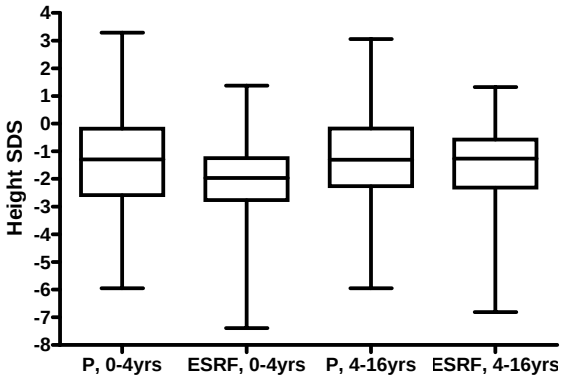

Figure 14.18. Height SDS at presentation and entry into ERF, by age of presentation

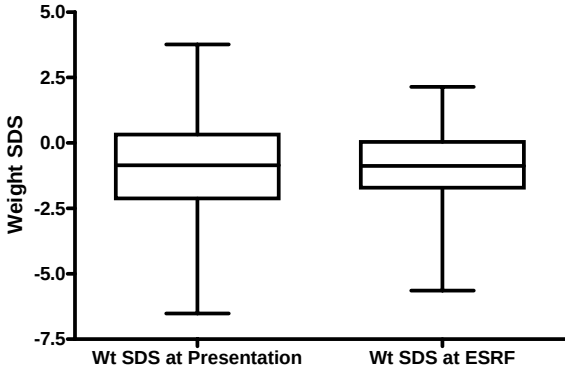

Figure 14.19. Weight SDS at presentation and entry into ERF

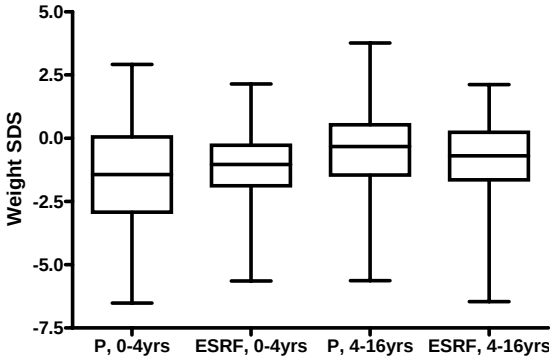

Figure 14.20. Weight SDS at presentation and entry into ERF, by age of presentation

Death in the paediatric ERF population

The study of mortality is clearly important when considering the paediatric ERF population. Unfortunately, although a large number of patients have been entered into the Registry, this cohort will not include all the patients dying as the entry of patients at the inception of the Registry only included then "current" patients. To analyse subsequent mortality as a proportion of the number of patients entered, would thus give a falsely low figure. To analyse mortality, the incident cohort of patients commencing ERF treatment from April 1996 was used.

As patients commencing treatment in 2001–2002 will often have only entered ERF shortly before the data collection time of April 2002 (and therefore will have a very short follow-up period), they have been excluded. A cohort of 489 patients who started ERF treatment between the 1st April 1996 and the 31st March 2001 remained. These patients all have a minimum follow up of 1 year with a range of 1 to 6 years.

Of the 489 patients, 29 had died giving an overall mortality of 5.9%. Death in the paediatric ERF patients fell into three broad categories.

1. Patients who died through either the inability to obtain or to maintain dialysis access.
2. Patients who died from severe secondary complications – usually infection.
3. Patients who died from problems associated with co-morbid conditions – usually syndromic diagnoses, other congenital abnormalities or major handicaps.

Figure 14.21 shows a life table analysis for these patients. It can be seen that the 5 year survival for patients presenting with ERF in childhood is 92%. There is a marked discrepancy between the mortalities for patients presenting at different ages. The mortality for those presenting within the first 4 years of life, was almost 19%. The mortality for those presenting later in childhood was fairly constant at between 2 and 4%.

Table 14.14 gives the number of patients who died within each age-group. Of the 20 patients who died having started ERF treatment within the first 4 years of life, 13 (65%) were actually in ERF within the first year of life. Within the cohort, there were 47 patients starting ERF treatment within the first year of life, giving an overall mortality for this selected population of 27.7%.

Figure 14.22 shows a life table analysis for those entering ERF within the first year of life. It demonstrates that the one year survival for this group of patients is 78% whilst the 5 year survival is just 66%. Table 14.15 details the diagnoses of the patients starting ERF treatment within the first year of life and also gives the number with each

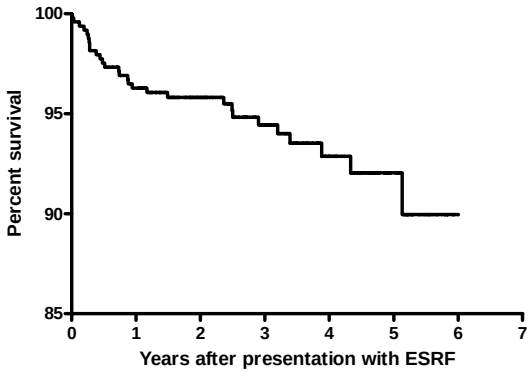

Figure 14.21. Survival analysis for patients starting ERF treatment from 1st April 1996 to 31st March 2001

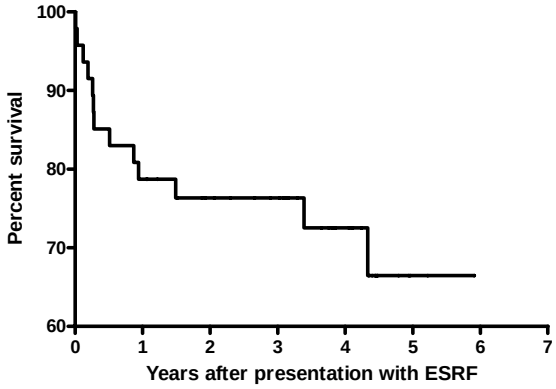

Figure 14.22. Survival analysis for patients below the age of 1 year starting ERF treatment from 1st April 1996 to 31st March 2001

Table 14.14. Number of patients with ERF who have died, by age at the start of ERF

ESRF start age	Patients	Deceased	% deceased
0–3.9yrs	106	20	18.9
4–7.9yrs	62	2	3.2
8–11.9yrs	107	2	3.7
12–15.9yrs	173	4	2.9
16–19.9yrs	41	1	2.4
Total	489	29	5.9

diagnosis who died. It is clear that there is a marked discrepancy in the mortality rates between diagnoses.

Of the 9 patients with obstructive uropathy, 8 had posterior urethral valves and one had a different form of bladder outlet obstruction. The mortality within this group was the highest at 55.6%. The 6 patients with renovascular disease, consisted of 3 with renal venous thromboses and 3 who developed bilateral cortical necrosis. Patients with renovascular disease and those with polycystic kidney disease both also had a high mortality rate at 50% and 40% respectively. The outcome for patients with renal dysplasia was better with only a 15% mortality, whilst there were no deaths amongst the small cohort with congenital nephrotic syndrome (Figure 14.23). Of the three patients with "other" diagnoses, one patient suffered from atypical haemolytic uraemic syndrome, whilst two did not have a cause for their ERF given. Clearly, if both of these patients were to have any of the three main diagnoses associated with a high mortality, the overall mortality figures for these diagnoses would be significantly changed because of the small cohort being examined.

Table 14.16 shows a break-down of the total patient cohort according to ethnicity. It is clear that the overall mortality within the ethnic minority groups appears to be higher

Table 14.15. Number of patients starting RRT in the 1st year of life and the number dying, by cause of ERF

ESRF diagnosis	Patients	Deceased	% deceased
Obstructive uropathy	9	5	55.6
Renovascular disease	6	3	50.0
Polycystic kidney disease	5	2	40.0
Renal dysplasia	20	3	15.0
Congenital nephrotic syndrome	4	0	0.0
Other	3	0	0.0
Total	47	13	27.7

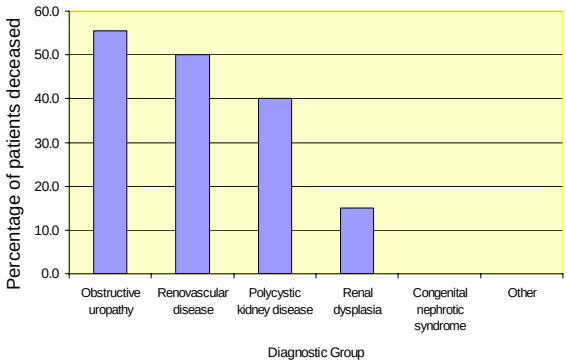

Figure 14.23. Percentage of patients starting dialysis in the first year of life who died, by cause of ERF

Table 14.16. Deaths in patients with ERF, divided according to ethnicity

Ethnicity	Patients	Deceased	% deceased
White	400	22	5.5
Asian	72	8	11.1
Black	12	1	8.3
Other	5	1	20

than for White patients and in particular the mortality for patients from the Asian subcontinent was twice that of White patients. This was not secondary to an excess of ethnic minority group patients starting ERF treatment within the first 4 years of life. Due to the overall small number of patients who died, these differences failed to reach statistical significance but will need to be reconsidered in the future.

Current ERF modalities

Of the 804 patients with ERF being treated within the 13 tertiary paediatric nephrology centres on 1st April 2002, data on current treatment modality was available for 756 (94%). Table 14.17 shows the break-down of patients according to treatment modality compensated by an increase in the number of living related donations (Figure 14.25).

As before, just over 75% of patients have a functioning transplant. Of the remaining quarter of the population, two thirds are managed on peritoneal dialysis and one third on haemodialysis. Figure 14.24 shows this distribution graphically and also details the proportion of peritoneal dialysis patients who are on CAPD as opposed to cycling peritoneal dialysis and the proportion of transplant patients who have received a living related rather than cadaveric allograft.

It can be seen that CAPD is becoming increasingly unpopular within paediatric practice with only 13% of patients on peritoneal dialysis using this form of treatment. The proportion of patients overall with allografts from living donors is still low at 18.6%, though the trend has been for there to be fewer cadaveric transplants performed year by year and this has been compensated by an increase in the number of living related donations (Figure 14.25).

There were notable differences in the treatment modalities used between different ethnic groups. This data is shown in Table 14.18. Whilst almost 80% of White patients had a functioning renal allograft, only 62% of Asian patients had a functioning allograft and this figure reduced further to just under 50% for the small number within other ethnic groups.

Comparing the proportion of patients with a functioning allograft in the White population with that from all other ethnic groups combined, the difference was highly significant ($p < 0.0001$ – Fisher's exact test). For those who do have a functioning allograft, the proportion with grafts from living related donations is greater within the White patients than in other ethnic groups, though this difference fails to reach statistical significance (Table 14.19).

Whilst more patients from ethnic minority groups are on dialysis compared to the

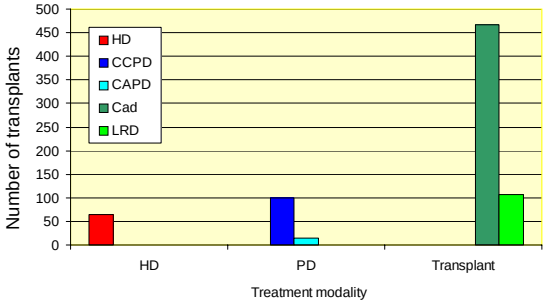

Figure 14.24. Current modality of ERF treatment for the paediatric population in April '02

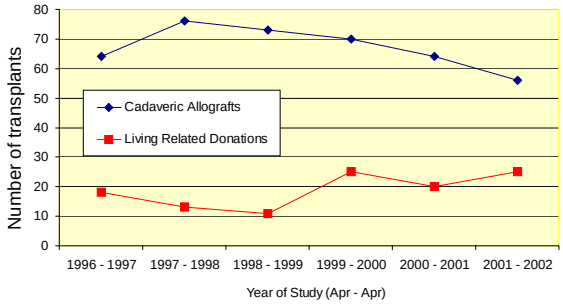

Figure 14.25. Paediatric transplant activity 1996–2002

Table 14.17. Current modality of ERF treatment for the paediatric population in April '02

Treatment modality	Total	(%)	CCPD	(%)	CAPD	(%)	Cadaveric	(%)	Living Related	(%)
Haemodialysis	64	8.5								
Peritoneal dialysis	114	15.2	99	86.8	15	13.2				
Transplant	574	76.3					467	81.4	107	18.6

White population, it is also interesting to note the differences in the modality of dialysis treatment employed between ethnic groups. Just 30.6% of White patients undergoing dialysis are being treated with haemodialysis, whereas, 48% of patients from ethnic minority groups are being treated with haemodialysis. The difference between the proportions of dialysis patients on haemodialysis is significant (p = 0.0279 – Fisher's exact test).

This data is of tremendous importance when planning paediatric ERF services across the UK. Factors determining the lower proportion of patients with a functioning allograft amongst ethnic minority groups probably relate to the differences between their HLA pool and that of the pool of cadaveric donors. The large number of patients from ethnic minority groups who are blood group B also makes cadaveric transplantation more difficult. Data on waiting times is not available at present to make this analysis complete. Increased use of living related transplantation in the ERF population from ethnic minority groups would clearly be an advantage.

It is not clear from the data available exactly why patients from ethnic minority groups are more likely to be on haemodialysis than peritoneal dialysis. Factors determining this would include practical medical considerations such as the length of time a patient has been on dialysis and previous graft loss or problems with peritoneal dialysis. Other factors that could influence the decision include problems with communication and accommodation. As was shown in the 2001 report, the distribution of ethnic minority group patients is uneven across the 13 paediatric tertiary referral centres with some having none and others having a very large proportion. Until the exact reasons for the increased use of haemodialysis in those from ethnic minority groups have been established and addressed, it is clear that some paediatric units are going to require increased resources with regard to the provision of haemodialysis places, nursing staff and vascular access.

Table 14.19. Type of allograft in transplanted patients, divided according to ethnicity.

	Type of Allograft			
Ethnicity	**Cadaveric**	**(%)**	**LRD**	**(%)**
White	403	80.9	95	19.1
Asian	53	84.1	10	15.9
Black	8	88.9	1	11.1
Other	3	75.0	1	25.0

Patients with functioning renal allografts

As patients with functioning renal allografts formed 76% of the current paediatric ERF population, analysis of this group is clearly important with regard to assessing the effectiveness of paediatric ERF management. Previously, only crude cross-sectional analyses have been performed. Even now with a limited number of years' follow-up (functional data collection only began in 1999) and the ever-changing population due to new transplants being performed and older patients being transferred or losing their grafts, meaningful, longitudinal analysis is difficult.

Clearly, one of the main faults with cross-sectional analysis is that it fails to take

Table 14.18. Current treatment modality for paediatric patients, divided according to ethnicity.

	Treatment Modality							
Ethnicity	**HD**	**(%)**	**PD**	**(%)**	**Transplant**	**(%)**	**Other**	**(%)**
White	38	6.1	86	13.8	498	79.7	3	0.5
Asian	20	19.6	19	18.6	63	61.8	0	0.0
Black	5	25.0	6	30.0	9	45.0	0	0.0
Other	1	12.5	3	37.5	4	50.0	0	0.0
Total	64	8.1	114	15.1	574	76.0	3	0.4

account of the longevity of a graft and the differences that occur between grafts which have recently been performed compared with those that have been in place for many years. To try and overcome this problem, data have been collected based upon the age of each graft. As the Paediatric Registry is currently only collecting data at a single point each year, the data collection has now been structured to ensure that for patients with functioning allografts the point of data collection coincides with the transplant anniversary. For those patients whose grafts have been recently implanted, data are collected at 3 months (0.25 years) post-transplant. Thereafter, data are collected on or around the anniversary of the transplant yearly. This way, even using cross-sectional analysis, it is now possible to group allografts according to time since engraftment, in order to allow meaningful comparisons to be made.

Transplant function

Of 574 patients with functioning renal allografts and data logged for April 2002, 14 had no details of graft age and were therefore omitted from the analysis. Figure 14.26 shows the number of allografts with data collected for each transplant anniversary. As would be expected, the majority of transplants are relatively recent with 121 being at or under their first anniversary at the point of data collection and 101 being at their second anniversary. There is, thereafter, the expected steady decline in the number of grafts at later anniversaries. There were, however, 46 grafts which had reached their 10th anniversary or above. It must be stressed that the falling numbers of patients with grafts that have been in place for some years is not a reflection on graft survival. Transfer of patients to adult units is the main reason for this.

Assessment of renal function has been mainly through analysis of the serum creatinine recorded at the time of the graft anniversary. To correct for size, a predicted GFR

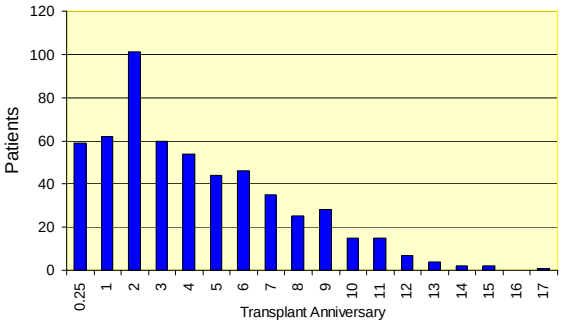

Figure 14.26. Current longevity of transplants on cross-sectional analysis of the paediatric population

(pGFR), can be calculated using the variable constant according to age and sex as described by Haycock and Schwartz. The formula used is:

$$\text{pGFR} = \frac{\text{Height (cm)} \times K}{\text{Creatinine } (\mu\text{mol/L})}$$

where K is a constant which varies with age and sex. Excluding the neonate, a constant of 40 is used in the first 2 years of life, 49 between 2 years and 13 years of age, 60 for males over the age of 13 years, and 49 for females over 13 years. These formulae have only been validated in normal populations. For ease of use and also to avoid abrupt transitions in pGFR, many nephrologists use a single factor of 40 for all patients irrespective of age and sex.

It is well-recognised that the accuracy of prediction of the GFR from the serum creatinine on the patients' height is variable. Particularly in transplant patients where tubular toxicity from calcineurin inhibitors can be significant, tubular secretion of creatinine can contribute to renal creatinine clearance leading to a falsely high pGFR. The aim of the Registry has been to collect data on formal GFR assessment annually. Not all units routinely perform formal GFR assessments and so for 2002, only 100 formal GFR results were available. These results have been used to examine the accuracy of prediction of GFR from the creatinine using the formulae available.

Figure 14.27 shows the age and sex distribution of the 100 patients with a formal GFR,

a height and creatinine measurement to allow calculation of a pGFR. Figure 14.28 shows the age and sex distribution of all 525 patients for whom a pGFR could be calculated.

It can be seen that there is no major difference between the distributions, though there are no children under the age of 4 years in the cohort with a formal GFR. In neither group were there any patients below the age of two years. Within the 100 with a formal GFR measurement, there were 13 who were male and over the age of 13 years. Thus using the standard formula, there would be 87 patients for whom the pGFR calculation constant would be 49 and 13 for whom it would be 60. No patients would have a calculation constant of 40, which in the standard formula is reserved for those under 2 years of age, but which many UK nephrologists use for all patients irrespective of age.

Figure 14.29 shows the mean and standard deviation of the formal GFR in this patient group compared with the pGFR using a constant of 40 for all patients, a constant of 49 for all those above 2 years of age (all patients in this group) and the true formula with a constant of 60 for males over 13 years of age and a constant of 49 for others. It can be seen that in all scenarios the pGFR is significantly greater than the formal GFR ($p < 0.0001$, paired t tests).

The agreement between the formal GFR and the pGFR was closest when a constant of 40 was used for all patients. Figures 14.30 and 14.31 show the formal GFR on the 'x' axis plotted against the pGFR on the 'y' axis using different constants as described above. For each graph a regression line is drawn with the line forced through the origin. These confirm that the best agreement between GFR and pGFR is when a constant of 40 is used at all ages.

There are several reasons why this may be the case. The formulae have been derived to account for varying muscle mass at different ages. The relationship between height and muscle mass is not likely to be the same in patients who have had ERF compared to the normal population. Puberty is often delayed in ERF patients leading to a delay in the accompanying increase in muscle mass – particularly in boys. Patients with transplants are likely to have increased tubular creatinine losses leading to a lower plasma creatinine level for any particular GFR. On the basis of this, all subsequent calculations of pGFR have been made using a constant of 40 at all ages.

As discussed earlier, height and creati-

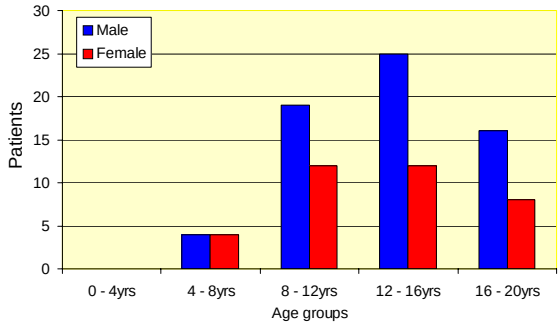

Figure 14.27. Age and sex distribution of 100 transplanted patients with a formal GFR estimation

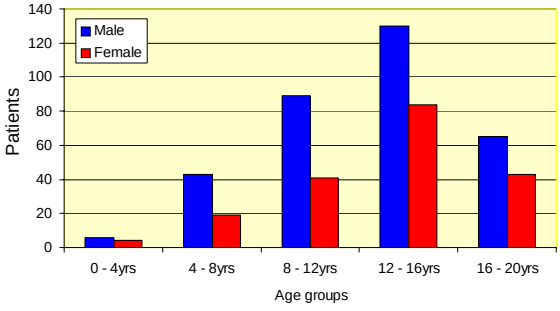

Figure 14.28. Age and sex distribution of 524 transplanted patients with a pGFR estimation

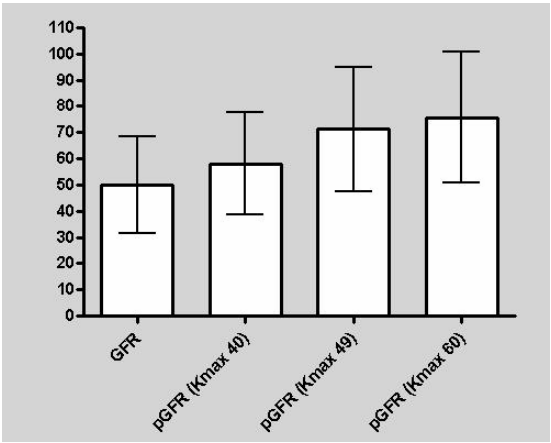

Figure 14.29. Formal GFR compared with pGFR using different constants.

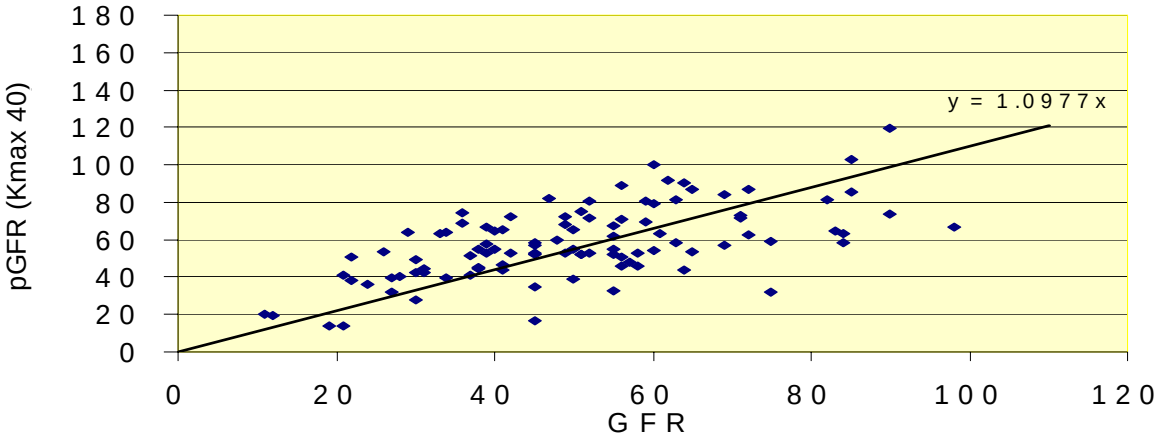

Figure 14.30. Formal GFR compared with pGFR using a constant of 40 for all patients

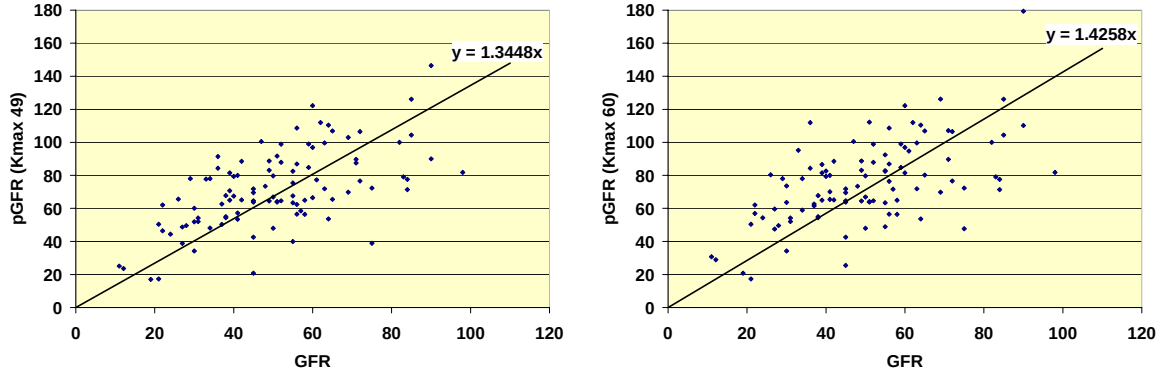

Figure 14.31. Formal GFR compared with pGFR using a constant of 49 for all patients (left) and 60 for males over 13 years age, 49 for other patients (right)

nine were recorded in 525 patients (91.4%), allowing the calculation of pGFR. Figure 14.32 shows the mean pGFR for the population divided according to transplant anniversary. The error bars denote the standard deviation of the mean. Overall, the mean GFR at each age was excellent and ranges from 67 to 90 ml/min/1.73 sq.m.

There is a slow trend towards declining GFR with age of allograft as demonstrated in Figure 14.33. The correlation between allograft age and pGFR is significant ($p = 0.0175$). These data are skewed by the absence of patients who have lost grafts and also those who have transferred to adult units. Inclusion of the patients who have lost grafts with time would significantly increase the slope of the line. In time, when more longitudinal data is collected, a more accurate picture of the changes in allograft function and the generation of life table analyses will become possible.

One feature which is specific to paediatric transplantation is the large proportion of patients with urological problems and abnormal bladders as a cause of their renal failure. This leads to a relatively large proportion of patients who are either on clean intermittent catheterisation (CIC), an augmented bladder which requires CIC, or who have a urinary diversion. In all these circumstances the risk of infection is increased and the chances of then having worse renal function increased.

In the cohort of 574 patients, 477 had details of urinary drainage (83.1%). Of these, 410 had normal bladders and 390 of these had heights and creatinines available for the calculation of a pGFR. There were 25 patients on CIC alone, of whom, 23 had a pGFR available and 23 patients with bladder augmentations on CIC of whom 20 had a pGFR available. Nineteen patients were documented as having a urinary diversion of

whom 18 had a pGFR available.

Figure 14.34 shows the mean and standard deviation for the pGFR in each of these groups. There was no significant difference in pGFR with mode of urinary drainage. It must, however, be noted that due to the small numbers available, these data are not corrected for graft age. Longitudinal data on renal function will be required to see if the rate of decline in pGFR with time is different in those with abnormal urinary drainage.

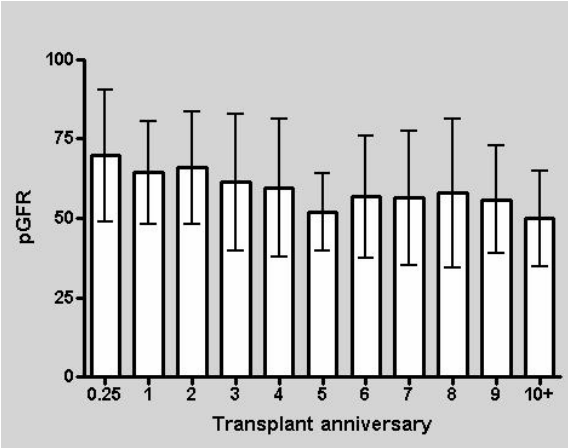

Figure 14.32. Predicted GFR (mean + SD) in renal allografts of varying age

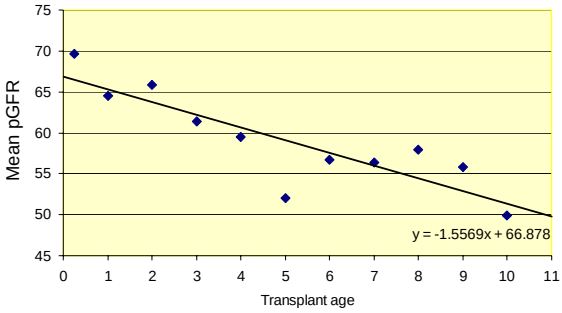

Figure 14.33. Change in mean predicted GFR with age of transplant.

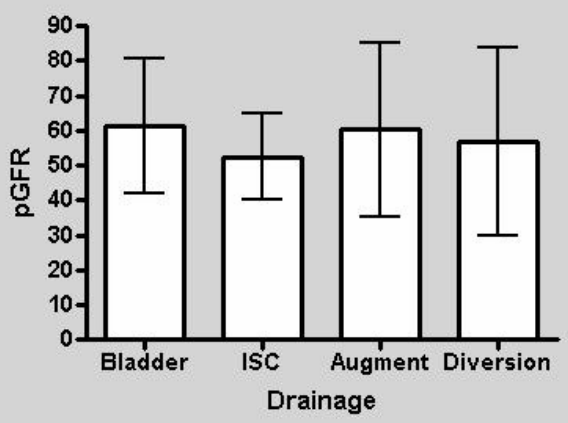

Figure 14.34. Analysis of pGFR in prevalent patients with functioning allografts by mode of drainage

Transplant rejection and immunosuppression

Rejection, acute or chronic, remains a major cause of allograft dysfunction and loss. Over the past 5 years there have been a number of trials of differing forms of immunosuppression with the aim of limiting rejection. The Paediatric Registry records for each transplant anniversary both the number of rejection episodes that have occurred since the last anniversary record and the number of these rejection episodes that were biopsy proven. Interpretation of these figures is somewhat hampered by differing interpretations of what constitutes a single rejection episode. For this reason, this analysis simply looked at the number of patients who had rejection episodes and the proportion of these patients whose rejection episodes were at one time or another biopsy proven.

Figure 14.35 shows the percentage of patients at each anniversary review having rejection episodes since the previous anniversary. It is clear that within the first year many patients are suffering rejection episodes, though under two thirds of these patients have had biopsy proven rejection and the remainder have been treated on a clinical basis.

In patients who have had their grafts longer, the number having rejection episodes is much reduced and the proportion of these rejection episodes which are biopsy proven are greater. By two years after transplantation, roughly 10% of patients have biopsy proven episodes of rejection each year; whereas within the first two years, between 25 and 30% are having these episodes.

The immunosuppressive regimes used in this cohort of patients were very variable. Data on immunosuppression were available for 544 patients (97%). The vast majority

were receiving immunosuppression with a calcineurin inhibitor. Only 19 patients (3.5%) were not on either Cyclosporin or Tacrolimus; with these patients being treated with a combination of either Mycophenolate and Prednisolone or Azathioprine and Prednisolone.

For those receiving a calcineurin inhibitor, 317 (58.3%) were taking Cyclosporin whilst 208 (38.2%) were taking Tacrolimus. In both groups, the vast majority were on triple therapy with either additional Azathioprine and Prednisolone or additional Mycophenolate and Prednisolone. 12.5% of the patients on Tacrolimus were on dual therapy with Tacrolimus and either Prednisolone, Azathioprine or Mycophenolate, whilst 24.5% of those on Cyclosporin were on dual therapy with these agents. Three patients were on Cyclosporin monotherapy. This data is shown graphically in Figure 14.36.

Figure 14.37 shows the percentage of patients receiving either Tacrolimus or Cyclosporin at varying times from transplantation. The mirror image trend lines clearly show the steady trend towards the usage of Tacrolimus rather than Cyclosporin, with 70% of the most recently transplanted patients receiving Tacrolimus. When analysed by intention to treat, these data show that many units still start immunosuppression with Cyclosporin-based treatment. Of the 114 patients with a transplant at or under one year of age, 55 (48.2%) started on Cyclosporin-based therapy but 10 patients were converted to Tacrolimus following episodes of rejection leading to the

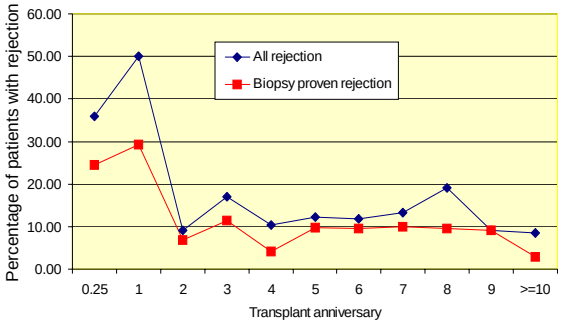

Figure 14.35. Percentage of patients with rejection episodes according to graft age

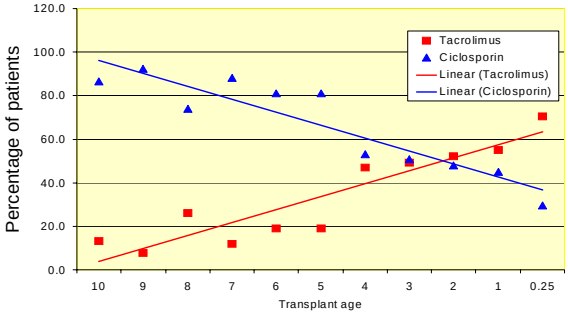

Figure 14.37. Percentage of patients receiving either Tacrolimus or Cyclosporin, according to age of graft

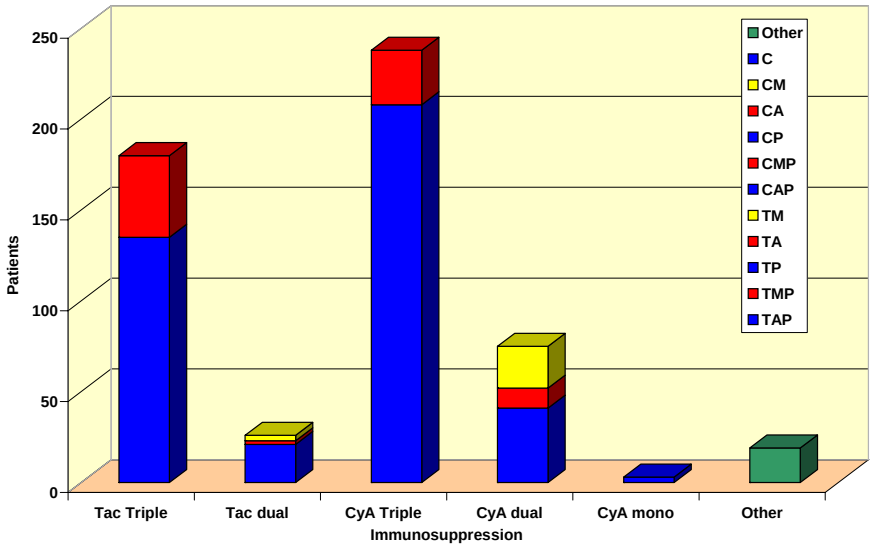

Figure 14.36. Immunosuppressive regimes in patients with renal allografts (C = cyclosporin, T = tacrolimus, A = azathioprine, M = mycophenolate and P = prednisolone)

marked increase in the proportion receiving Tacrolimus.

Most rejection episodes were treated with pulsed Methylprednisolone followed in a proportion by either a change from Cyclosporin to Tacrolimus or from Azathioprine to Mycophenolate. Just 5 of the 114 patients receiving an allograft in the past year, received anti-thymocyte globulin (4.4%).

Conclusion

The demographics of the paediatric ERF population are not changing greatly, though the steadily rising numbers of prevalent patients will have resource implications. There are marked differences in the current management of patients from the ethnic minority groups with fewer patients having functioning renal allografts and more patients being treated with haemodialysis. Not only does this have resource implications overall, but the high proportion of ethnic minority group patients in certain localities will require special attention to the provision of paediatric ERF services in these areas.

The timing of patient presentation to nephrology services is variable and although 50% are in ERF within two years of presentation, this is not unreasonable, bearing in mind the nature of the diseases causing their renal failure. For the remaining population, it is noteworthy that poor growth is principally a problem of those presenting within the first 4 years of life and that nutrition appears to be being well-managed with no fall in weight SDS. The cause for poor growth in those presenting early in life needs to be explored further to ascertain whether intervention might be effective. The earliest presentation is with antenatal diagnosis but it is unclear from the data presented that only a proportion of those with severe renal anomalies causing ERF are diagnosed early. It needs to be recognised that this is an inevitable result of reliance on an 18–20 week anomaly scan. If increased antenatal detection of serious renal anomalies is desired, additional third trimester scanning will be required.

In paediatric ERF patients, death was relatively rare with an overall 92% 5 year survival rate. Death was more frequent, in those commencing dialysis in the first year of life where the 5 year survival rate is just 66%. In addition, the specific high mortality rate of patients with congenital obstructive uropathy and polycystic kidney disease who enter ERF in the first year of life needs to be taken into account when counselling parents for whom an antenatal diagnosis has been made.

Over 75% of the prevalent paediatric ERF population have a functioning transplant. For those on dialysis, twice as many patients are on peritoneal dialysis than haemodialysis. The use of CAPD is rare with 87% of peritoneal dialysis patients receiving home machine cycling dialysis. Significantly, fewer patients from ethnic minority groups had a transplant compared to the White population and hence more were on dialysis. For those on dialysis, patients from ethnic minority groups were more likely to receive haemodialysis than peritoneal dialysis.

Renal function in transplanted patients is good, though GFR declines with graft longevity. It needs to be recognised that predicted GFR from the serum creatinine overestimates true GFR, though the latter remains very acceptable in those patients where it has been measured. For the calculation of a predicted GFR from the serum creatinine the Schwartz formula can be used with a constant of 40 for all age-groups and both sexes.

The diagnosis and treatment of acute allograft rejection seems to be variable between centres with only two thirds of patients having rejection episodes confirmed by biopsy in the first year after transplantation. Immunosuppressive regimes are equally varied, though the general trend is clearly towards the usage of Tacrolimus-based triple immunosuppression. With just ten centres undertaking paediatric renal transplantation in the UK, the use of a single

protocol for immunosuppression and the diagnosis of allograft rejection would be a sensible step forward. Uniformity of approach would also make the incorporation of clinical trials of immunosuppressive regimes easier.

This report was compiled by Dr MA Lewis and Mrs J Shaw.

It was reviewed, revised and approved by the Paediatric Renal Registry subcommittee comprising:

Dr Jane Tizard
Dr Chris Reid
Dr William van't Hoff
Dr Nicholas Webb
Dr Rodney Gilbert
Dr Malcolm Lewis

This report is presented on behalf of the BAPN.

We would like to thank:

- Rachel Johnston at UKT for all her help confirming transplant statistics.

- Roche for financial support.

Chapter 15: Survival of Incident Patients

Summary

- From the first RRT, the one year survival of all patients is 78%. From the 90th day of RRT, the one year survival is 87%.
- The 5 year survival is 43% overall, 64% in those under 65 and 14% in those over 65 at start of RRT.
- Poor reporting by renal units of patient co-morbidity and ethnicity renders interpretation of differences in patient survival between centres difficult.
- Using Z-score analysis, no significant difference in patient survival between centres was found.
- UK renal units achieve the standards set for incident patient survival in the Renal Association Standards document.
- Patient survival in the UK, adjusted for age, is improving year by year.

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 co-morbidity) 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. In contrast with DOPPS, the UK Registry includes the outcomes from the 33% of dialysis population that are on peritoneal dialysis and the 3% of the ERF population who receive a pre-emptive transplant.

Survival rates can either be analysed 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 from start of 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 co-morbidity 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.

Z-scores

The enquiry into the excess of paediatric cardiac deaths at the Bristol Royal Infirmary defined an outlier as lying beyond 3 standard deviations from the mean, using the statistical methodology of Shewhart's control theory. This analysis relies on the centre sizes, and hence their standard deviation, being very similar. Renal units in the UK vary greatly in size, catchment populations varying from 300,000 to over 2 million. There is a consequent variation in the total patient number on RRT so the figure for the standard deviation will vary greatly between centres. The standard deviation for the total RRT population is not an appropriate number as this will be very small. Therefore, the Shewhart methodology cannot be applied. The Registry has used the accepted statistical technique of Z-scores to identify any outliers.

Definition

Z-scores are sometimes called "standard scores". It is a measure of the distance in standard deviations of a sample from the mean.

The Z-score transformation is especially useful when seeking to compare the relative standings of items from distributions with different means and/or different standard deviations. The Z-score for an item indicates how far and in what direction, that item deviates from its distribution's mean, expressed in units of its distribution's standard deviation.

Mathematically: the survival Z-score =

$$\frac{\text{Survival for centre X} - \text{survival for all centres}}{\text{Standard error for centre X}}$$

The Z-score is therefore an adjustment for the size of the centre and when comparing the different Z-scores for all the centres, they should be normally distributed. The observed Z value compared with the expected Z value (see explanation below) should be on a straight line.

Calculation of the expected Z value

Suppose there is a normally distributed population from which we repeatedly draw random samples of some specific size, say 10. These 10 values from each such random sample are sorted into increasing order, smallest value to largest value. When the sample data is sorted in this way, the individual numbers are called **order statistics**. The smallest value will vary somewhat from one such sample to another, but over the long run, the smallest values should tend to cluster around some average smallest value and produce a **mean** or **expected values of the order statistics**. These data have been compiled into tables so that for every specific total number of ordered samples (e.g.

38 centres with Registry survival data) there is an expected Z value for each ordered centre in that list.

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 on RRT

The revised Renal Standards document concluded that:

> ***It is hard to set survival standards at present because these should be age, gender and co-morbidity adjusted and this is not yet possible from Registry data. The last Standards document recommended at least 90% one year survival for patients aged 18-55 years with standard primary renal disease. This may have been too low as the rate in participating centres in the Registry was 97%, though numbers were small.***

Standard Primary Renal Disease is a definition using the EDTA diagnosis codes (including only codes 0 – 49) which excludes patients with renal disease due to diabetes and other systemic diseases. It is more widespread practice to simply exclude diabetics, so these figures have also been quoted to allow comparison with reports from other registries. There are apparent differences from last year, as previously an incorrect definition of Standard Primary Renal Disease was applied to the cohort at a programming level. The results are in Table 15.1.

All the one and two year survival figures quoted in this chapter are from the first day of dialysis unless stated otherwise, not from day 90 as quoted from the USA. The data for Scotland were taken from the Scottish Renal Registry Report 2000/2001.

The key findings to note are: the high death rate in the first 90 days, the steep age related decline in survival, the greater survival on PD compared with HD after age adjustment (probably reflecting selection differences), and the similarity of survival in England and Wales. The 5 year survival is only 14% in those over 65, 64% in those under 65 and 43% overall.

Table 15.2 contains 90 day and 1 year after 90-day adjusted patient survival for England and for Wales, showing the high initial death rate.

Table 15.1. One-year patient survival – patients aged 18–55, 2001 cohort

First treatment	Standard primary renal disease	All diseases except diabetes
Recommended standard	**>90%**	
All	96.3	93.3
95% CI	95.0-97.5	91.9-94.7
HD	93.6	89.7
95% CI	91.1-96.0	86.8-92.5
PD	98.9	98.3
95% CI	97.7-100	96.8-99.8

Table 15.2. Patient survival across England and Wales, 2001 cohort

	Eng	W	E & W
Adjusted (age 60) 90 days	92.8	93.5	92.9
95%CI	91.7-93.9	91.2-96.0	91.8-93.9
Adjusted (age 60) 1 year after 90 days	86.6	85.7	86.5
95%CI	85.1-88.0	81.8-89.7	85.1-87.9

The survival by first established treatment modality is shown in Table 15.3.

Tables 15.4 – 15.9 show survival patterns, split around age 65, for up to five years after the first renal replacement therapy.

Survival of new patients by age

The incident cohort included in this analysis is all those patients starting RRT in 2001. Patients who recovered function within 90 days (i.e. patients with acute rather than chronic renal failure) have been excluded.

In Figure 15.1, 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.

The UK Registry has been collecting data on incident patients since its inception in 1997. The Kaplan Meier survival curves are only able to show data for the first 6 years from starting renal replacement therapy (Figure 15.2). Because of this factor it has only been possible to calculate the 50% patient survival for those patients starting renal replacement therapy aged over 75 (21 months ±2.1m 95%CI), aged 65 – 74 (33 months ± 1.8m 95%CI) and 55 – 64 (66 months ±2.8m 95%CI). Patients with diabetes have been included in these survival figures. These data include the first 90-day period and so patients may appear to show a lower survival than data from other international Registries which exclude this period.

The hazard ratios confirm data previously shown by the Registry that the greatest hazard of death occurs in the first 120 days; thereafter the hazard ratio remains stable (Figure 15.3).

Table 15.3. One-year survival by first established treatment modality

	HD	PD
Adjusted 1 year after 90 days 95% CI	84.4 83.0-85.8	90.3 88.9-91.8

Table 15.4. Unadjusted 90 day survival of new patients, 2001 cohort by age

Age	KM[1] survival analysis (%)	KM 95% CI	No.
18–64	95.5	94.5-96.6	1524
≥65	84.7	82.9-86.5	1540
All E&W	90.1	89.0-91.2	3064

[1]KM = Kaplan–Meier.

Table 15.5. Unadjusted 1 year survival of new patients, 2001 cohort by age

Age	KM survival analysis (%)	KM 95% CI	No.
18–64	**88.0**	86.4-89.7	1524
≥65	**68.9**	66.5-71.2	1540
All E&W	**78.4**	76.9-79.9	3064

Table 15.6. Unadjusted 2 year survival of new patients, 2000 cohort by age

Age	KM survival analysis (%)		KM 95% CI	No.
	1 year	2 year	2 year survival	
<65	89.7	**82.4**	80.3-84.6	1211
≥65	68.4	**55.0**	52.1-57.9	1156
All E&W	79.3	**68.9**	67.1-70.8	2367

Table 15.7. Unadjusted 3 year survival of new patients, 1999 cohort, by age

Age	KM survival analysis (%)			KM 95% CI	No.
	1 year	2 year	3 year	3 year survival	
<65	88.1	82.3	**75.6**	72.9-78.3	1028
≥65	67.8	52.6	**39.9**	36.7-43.1	910
All	78.5	68.2	**58.7**	56.5-60.9	1938

Table 15.8. Unadjusted 4 year survival of new patients, 1998 cohort by age

Age	KM survival analysis (%)				KM 95% CI	
	1 year	2 year	3 year	4 year	4 year survival	No.
<65	86.9	80.4	73.9	**68.4**	65.3-71.5	872
≥ 65	64.8	49.7	39.7	**30.3**	27.0-33.6	767
All E&W	76.6	66.1	57.9	**50.6**	48.2-53.1	1639

Table 15.9. Unadjusted 5 year survival of new patients, 1997 cohort by age

Age	KM survival analysis (%)					KM 95% CI	
	1 year	2 year	3 year	4 year	5 year	5 year survival	No.
<65	87.4	80.4	74.4	68.3	**64.0**	59.6-68.5	454
≥ 65	65.8	45.2	33.6	23.9	**14.5**	10.7-18.2	345
All E&W	78.1	65.2	56.8	49.1	**42.6**	39.2-46.1	799

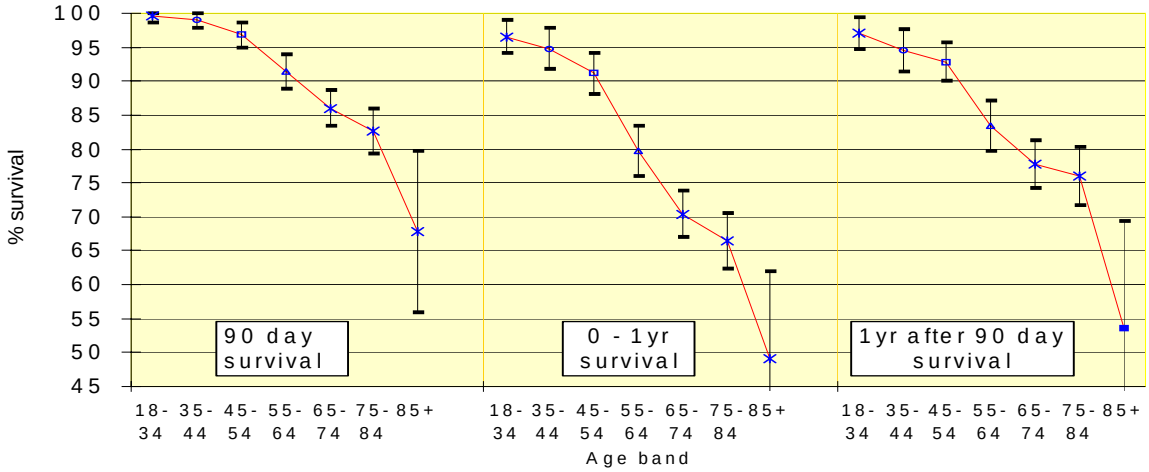

Figure 15.1. Unadjusted survival of all incident patients, by age band

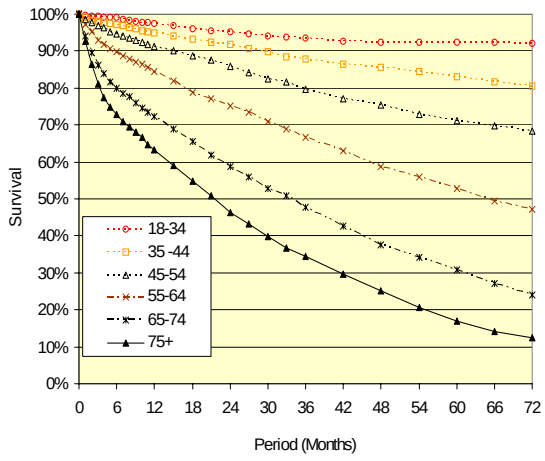

Figure 15.2. Kaplan-Meier 6-year survival

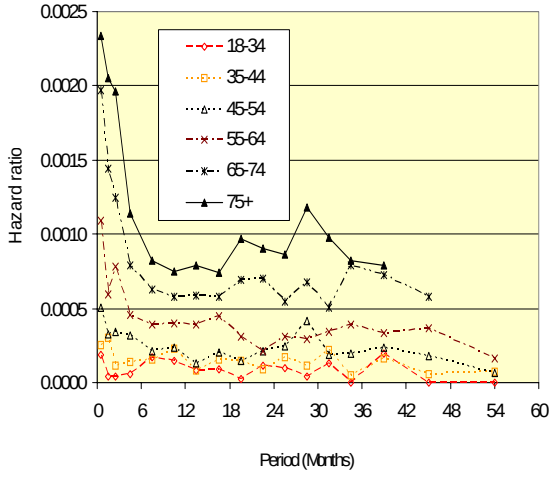

Figure 15.3. Five-year hazard of death ratios, by age band

The results beyond 36 months for the older age group are not reliable as the numbers were very small.

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 15.10.

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 1-year 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, 1997–2001

In Figure 15.4, the right-hand figures show the one-year after 90-day survival for all incident patients on the Registry in the years 1997–2001. There is an apparent improvement in one-year after 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 figures show the same analysis just for those centres which joined in 1997. This shows the same overall improvement in survival, from 84.0 to 86.9%, which is an 18% reduction in one-year after 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 5 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

This analysis has been included in Chapter 20.

Survival of incident patients in 2001 by centre

Comparability of figures for survival within the first 90 days are heavily dependent on consistency between renal units in ensuring that all early chronic renal failure deaths are included and that all acute renal failure patient deaths are excluded. This is not the case. As the 1 year survival from day 0 of starting renal replacement therapy includes this time period, the more appropriate figure for comparing renal units is the 1 year after 90 days, shown in figures 15.5 (unadjusted) and 15.6 (adjusted to age 60), with their 95% confidence intervals.

Some of the smaller centres have wide confidence intervals. An analysis using the Z-score technique (see description at the start of this chapter) for any significant differences between centres is described below.

Table 15.10. Increase in proportional hazard of death for each year increase in age, at 90 days and for 1 year thereafter

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

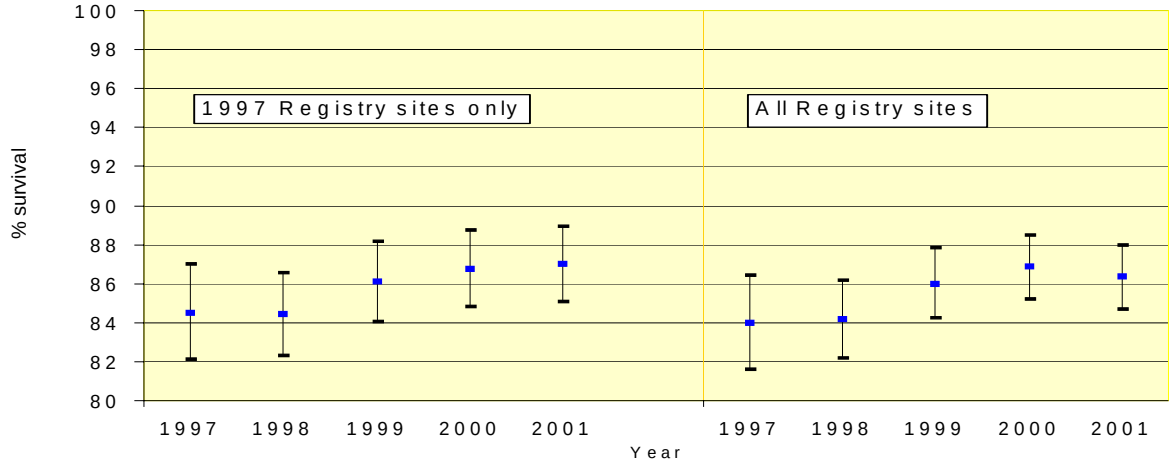

Figure 15.4. Change in one-year after 90 day adjusted (age 60) survival, 1997-2001

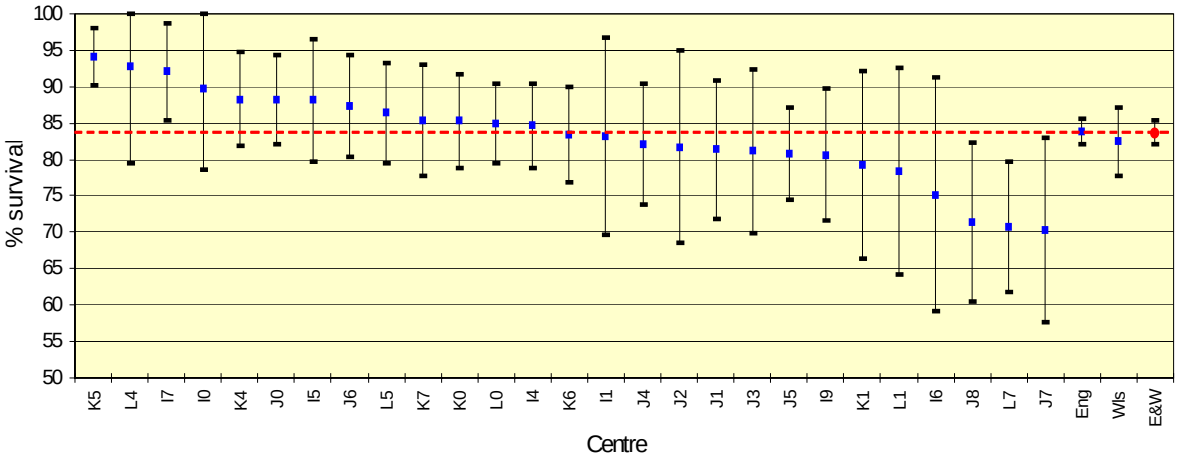

Figure 15.5. Unadjusted survival 1 year after 90 days; 2001 cohort

Showing 95% confidence intervals

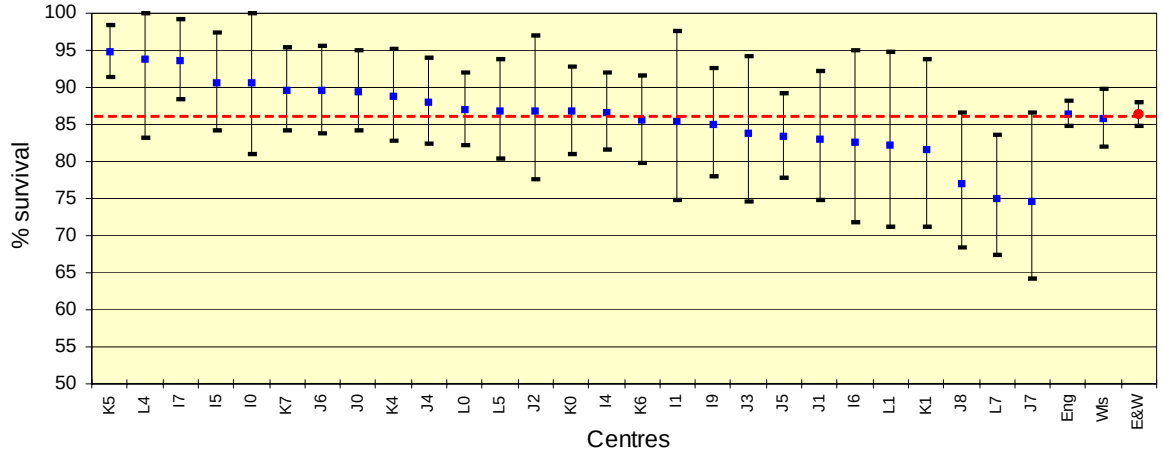

Figure 15.6. Adjusted survival 1 year after 90 days; 2001 cohort

Showing 95% confidence intervals

Analysis of centre variability in survival in 1 year after 90 days

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. To overcome the variability in centres with small numbers, the 1999, 2000, and 2001 cohorts of patients have been combined (Figure 15.7).

If it is true that these observations are normally distributed, they should lie on a straight line. Centres above the line have a better than expected survival, whereas those below it have a worse than expected survival. Figure 15.7 has been plotted using the adjusted survival data for each centre and shows that the results are relatively close to a normal distribution. Centres above the line have a better than expected survival, whereas those below it have a worse than expected survival. The 95% confidence intervals have been plotted for these data. If centres have a significantly different survival from the mean they fall outside the confidence intervals.

In this analysis, none of the centres fall outside the 95% confidence intervals.

Analysis of centre survival within the first 90 days

The unadjusted and age-adjusted 90-day survivals of patients incident in 2001 are shown in Figures 15.8 and 15.9.

Figure 15.10 shows the age adjusted Z-scores for the 2001 cohort, and figure 15.11 for a 3-year cohort 1999-2001.

Comparison of the 90 day and 1 year after 90 day survival

Similar to previous years, Figure 15.12 demonstrates that there is no relationship between the 1 year after 90 days survival and the survival of patients within the first 90 days. This supports the view that part of this variability is related to the definition of acute renal failure patients, which makes interpretation of the first 90-day survival difficult.

Changes in survival by centre 1997 - 2001

Annual changes in survival by individual renal units are shown in Figures 15.13 and 15.14.

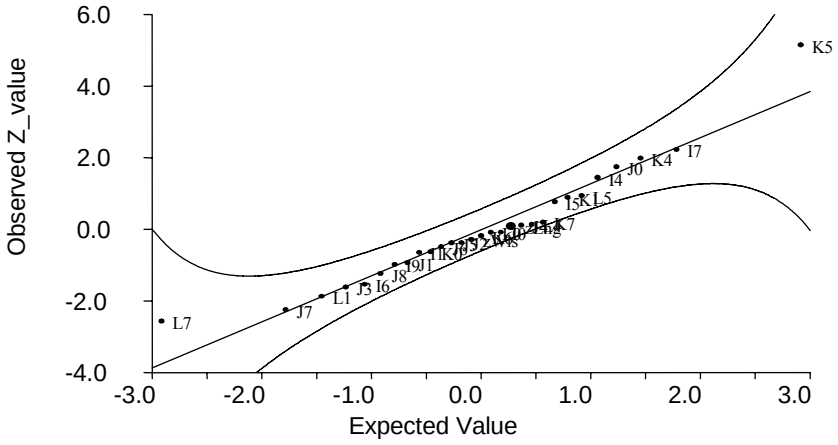

Figure 15.7. Z-score for age adjusted 1 year after 90 days survival 1999 - 2001 cohort

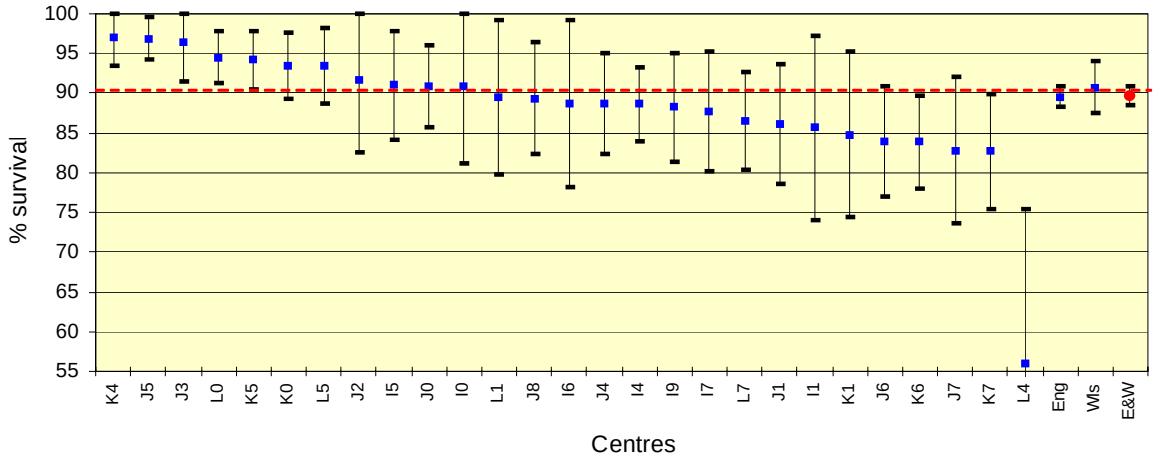

Figure 15.8. Unadjusted survival in the first 90 days; 2001 cohort

Showing 95% confidence intervals

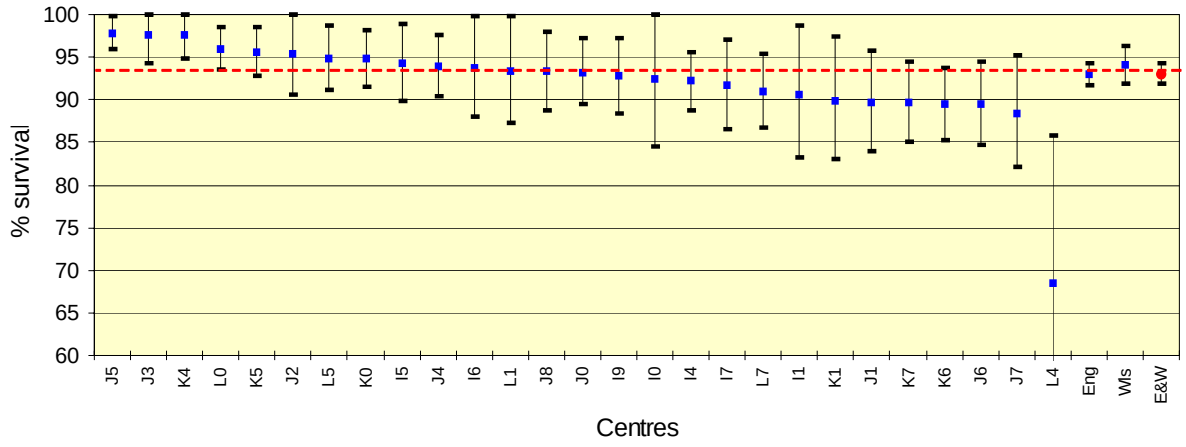

Figure 15.9. Age adjusted survival in the first 90 days; 2001 cohort

Showing 95% confidence intervals

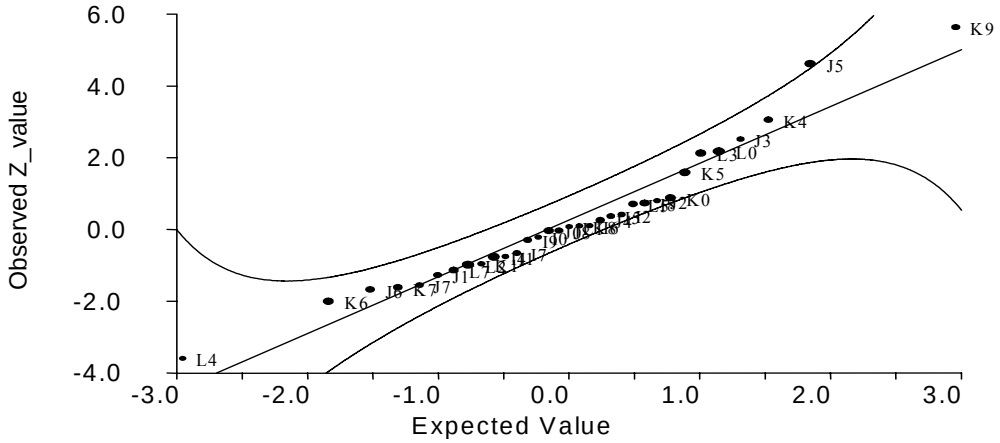

Figure 15.10. Z-score for age-adjusted survival within the first 90 days; 2001 cohort

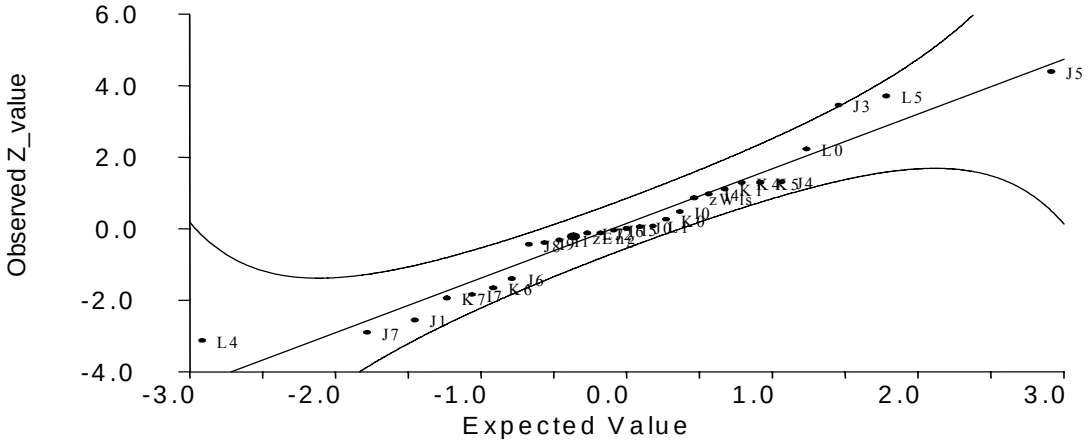

Figure 15.11. Z-score for age-adjusted survival within the first 90 days; 1999-2001 cohort

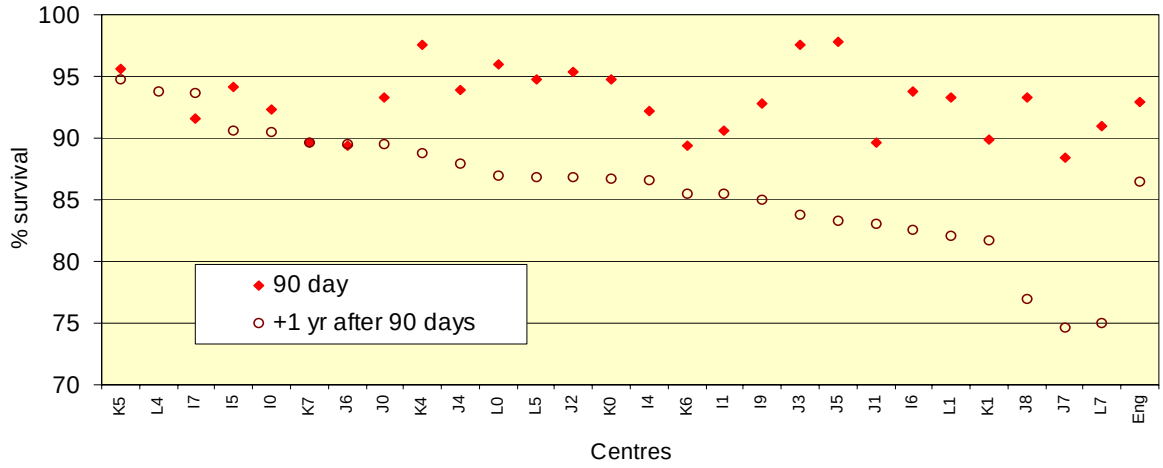

Figure 15.12. Adjusted survival of new patients, 90 day compared with 1 year after 90 days

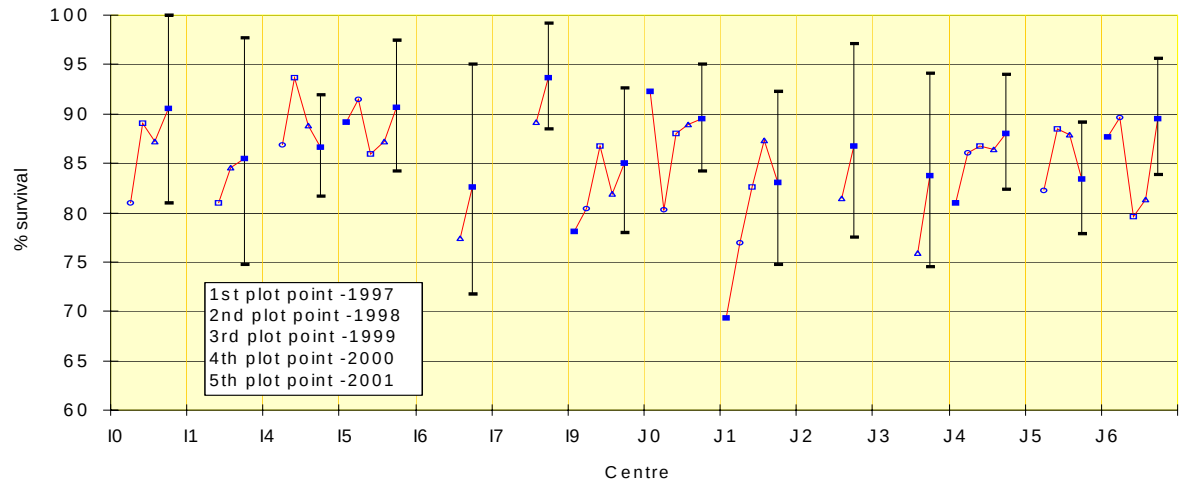

Figure 15.13a. Age adjusted survival, 1 year after 90 days; 1997–2001 cohort

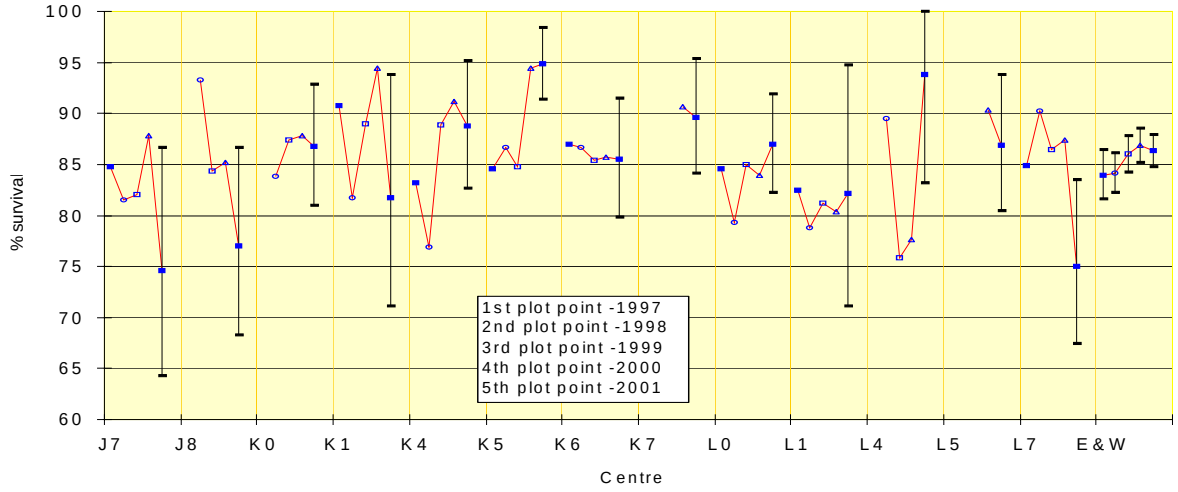

Figure 15.13b. Age adjusted survival, 1 year after 90 days; 1997–2001 cohort

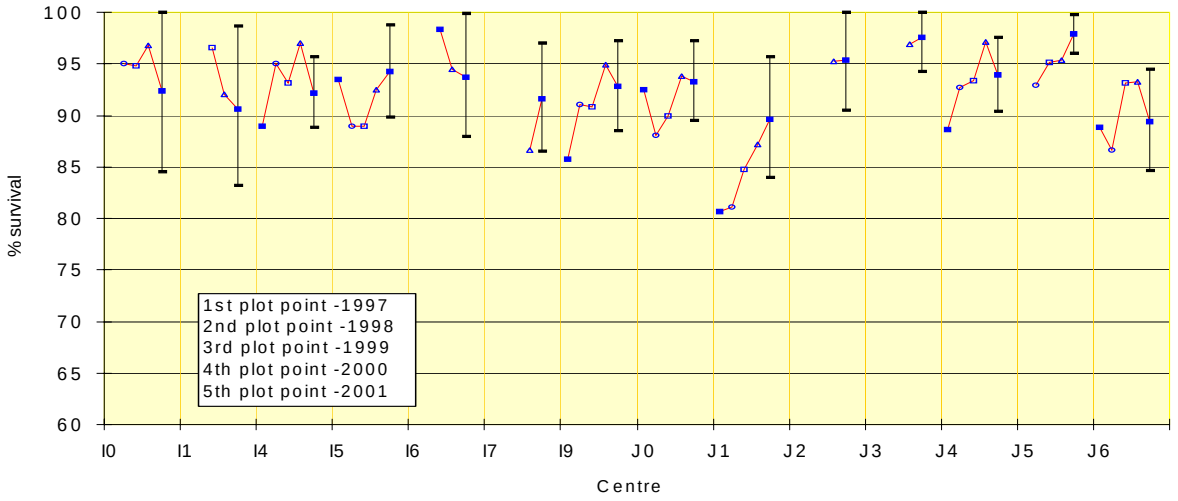

Figure 15.14a. Age adjusted survival in the first 90 days; 1997–2001 cohort

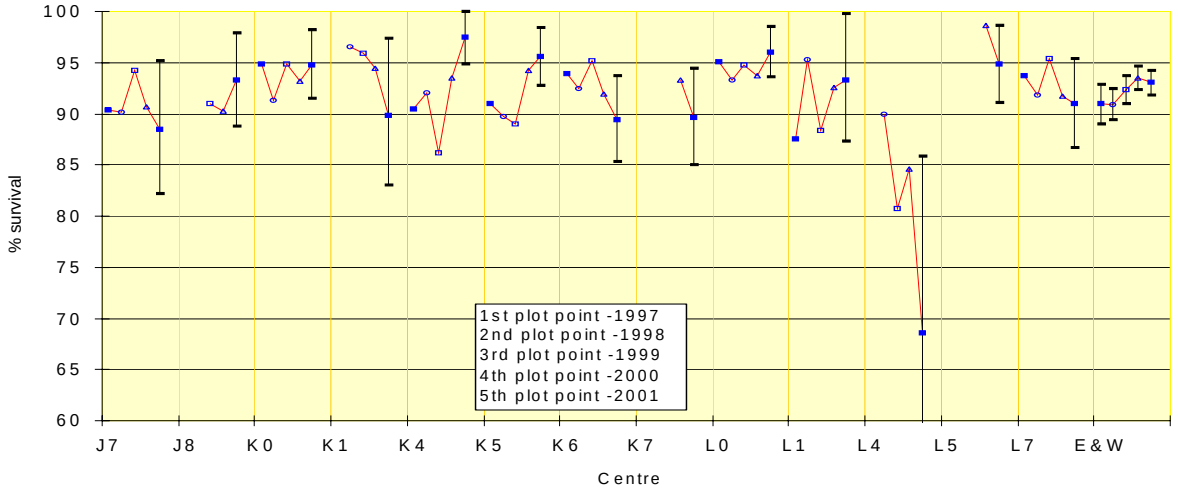

Figure 15.14b. Age adjusted survival in the first 90 days; 1997–2001 cohort

Chapter 16: Referral to Nephrology Services of Patients Starting Renal Replacement Therapy in England & Wales

Summary

- Date of referral to a nephrologist is still poorly recorded by many renal units.
- 30% of patients are referred less than 3 months before starting RRT, and 20% less than a month prior to start of RRT. This is consistent with other published data from the UK and elsewhere.
- The late referral group tend to be older than others, but gender, ethnicity and social deprivation were not significant factors influencing the referral timing.
- 13% of the late referral group had a primary diagnosis of diabetic nephropathy, and 23% of all patients with diabetic nephropathy were referred late.
- 83% of the late referral group started on haemodialysis compared with 62% of those referred earlier as their first mode of RRT. ($p = 0.0044$)
- There was no difference in estimated GFR (MDRD) between the early and late referral group. The estimated GFR at the start of RRT in the UK is the same as that quoted in a 21 centre European study (6.7 mls/min v 6.6 mls/min respectively).
- The late referral group has poorer 1 year after 90 days survival than others (81.5% v 88.5% respectively, $p<0.0001$), even after adjusting for age and the lower haemoglobin levels in this group.

Introduction

Within the UK there has been no previous analysis comparing the differences in timing of referral between renal units. The previous published studies from the UK have all used varying definitions of the late referral period, from less than 1 month to less than 4 months.[1–6] Consequently it is difficult to directly compare these studies and 'late referral' of patients appears to vary from 25% to 47% of patients starting RRT.

Roderick *et al*.[3] analysed the reasons for late referrals and found that nearly 50% of the late referrals were potentially avoidable, with 80% of this group having previously had evidence of progressive renal damage. Similarly in the study by Ellis *et al.*[6] nearly 50% of the late referrals were known to have had renal disease for more than 8 weeks prior to referral.

These studies also showed that late referred patients were in a poorer clinical state at the start of RRT, more likely to require emergency dialysis, have a longer median hospitalisation period and have a higher rate of mortality compared to those referred early. A recent study also showed that late referral of elderly patients may influence the nephrologist's decision in considering the appropriateness of RRT, therapy being offered less frequently.[7]

This analysis of data from England and Wales compares the differences between early and late referral groups by demographics (age, gender and ethnicity), primary diagnosis, modality of first RRT, social deprivation (Townsend score) and survival. Differences between renal units were also analysed.

Patient Cohort

The UK Renal Registry collects the 'date first seen by dialysing nephrologist' for incident patients. To improve the data, for 2001 and 2002, centres which had returned more than 50% of the item 'date first seen' (DFS) for their incident patients were identified. These units were then contacted to obtain the missing data wherever possible. Only the centres with more than 75% completed data were included in the analysis.

Additional data were also obtained from the Manchester based study of Implementation of Renal Standards (SIRS). This study involves Manchester Royal Infirmary, Hope Hospital, and Royal Preston Hospital who also collect this data item and have kindly provided the Registry with their data to be included in the analysis. The SIRS group have prospectively collected their data from April 2000 onwards, although this analysis includes only the SIRS data for the complete years 2001 and 2002. The Royal Preston Hospital is already part of the UK Renal Registry.

Table 16.1 lists the centres that send this data item to the Registry.

Number of patients

Of the 13221 new patients who started RRT in centres registered with UKRR or the SIRS study between 1997 and 2002, 36% (4790 patients) commenced at the centres included in this analysis. 93% of these (4478 patients) had their 'date first seen by nephrologists' recorded in the database. The number of patients included from each centre is as shown in Table 16.1.

Results

Analysis for bias from missing data

The demographic details of the two patient groups (with and without a date first seen) were compared (age, gender and primary diagnosis). The results are shown in Table 16.2. There were no significant differences between the two groups for age and gender. There was a higher percentage of missing primary diagnoses in the group of patients with no recorded date of referral, which probably reflects the incomplete data entry for these patients.

Referral pattern

In published studies, definitions of late referral vary from 1 to 6 months. This analysis has defined late referral as being seen by a dialysing nephrologist less than 3 months before starting RRT. In Table 16.3, the time from referral to RRT was further divided into 3–6 months, 6–12 months and more than a year prior to start of RRT.

Late referral occurred in 30% of patients commencing RRT and 66% of these patients

Table 16.1. Renal units included in the analysis with the number of patients included in the analysis and % completed data

	1997		1998		1999		2000		2001		2002	
	Pts No	%*	Pts No	%*	Pts No	%*	Pts No	%*	Pts No	%*	Pts No	%*
Notts	107	97	120	96	117	97	106	98	118	100	82	98
Sheff	108	98	124	100	126	99	132	99	141	97	147	99
StJms	64	77	57	83	64	79	78	88	87	100	79	100
Mid	76	83							82	100	112	100
Leic			143	81	130	81	134	76	176	99	149	99
Bristl					114	98	142	97	148	99	112	92
Extr									97	100	78	98
York									31	84	64	98
Ports									138	100	137	99
Hope									76	91	72	88
Prstn									106	94	78	77
MRI									102	86		
NewC											103	100
Bangr											21	78
Total	355	90	444	90	551	91	592	91	1302	97	1234	95

*Percentage completed data

presented within 1 month of starting RRT. To enable comparison with other published data, the data were re-analysed by four separate monthly intervals. Using 4 months as the definition of late referral, 33% were late referrals. (Table 16.4)

For 2002, the percentage of late referrals varied significantly between units (p = <0.001) and ranged from 24% to 56% (Figure 16.1). These differences in late referral could not be explained by the variation between units in demographic profile, primary diagnosis, ethnicity or social deprivation scores.

Trend over last 5 years

As there were fewer centres included in the analysis of the earlier years (Table 16.1), it was not valid to directly compare data between the different years. To identify any change in late referral patterns with time, the 4 centres with high percentages of completed data from 1998–2002 (Nottingham, Sheffield, Leicester and St James, Leeds) were included in a separate analysis (Table 16.5). There has been no significant change in the percentages of late referrals at these centres over these 5 years (p = 0.78).

Table 16.2. Comparison between patients with and without date first seen

	Patients with Date first seen	Patients without a Date first seen
Age (median)	64	62
Male (%)	61	61
Diagnosis		
Diabetes	17.6	17.6
Reno-vascular disease	13.2	11.5
Glomerulonephritis	13.5	9.3
Pyelonephritis	8.8	9.3
Polyc	7.3	4.8
Uncert	20.4	18.9
OtherH	7.2	5.1
OtherL	7.6	9.0
Missing	4.3	14.4

Age, Gender and Primary Diagnosis

Table 16.6 shows the demographic data for the Early Referrals (ER) and Late Referrals (LR) groups.

The late referrals have an older median age of 67 years at the start of RRT compared to that of 62 in the early referrals (p < 0.0001). There was no difference in the gender distribution (61% male) between the two groups (p = 0.76). Diabetic nephropathy was the main primary diagnosis in the early referral group (19.5%), but disappointingly also accounted for 13.3% of the late referral group (p < 0.0001). When analysed separately, 24% of the Type I and 22% of the Type II diabetics who started RRT during these period were referred late.

Ethnicity

For the analysis of the effect of ethnicity on late referral (Table 16.7), only centres with >70% completeness of ethnicity data were included (11 out of 14 centres). Therefore for the study period, there were 3681 of 4098 patients with both referral date and ethnicity data who were included in this analysis.

Table 16.3. Time to referral by year 1997-2002

	< 3 months		3–6 months		6–12months		> 12 months	
Year	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**
1997	124	35	26	7	50	7	155	44
1998	114	26	49	11	49	11	230	52
1999	157	29	45	8	45	8	284	52
2000	176	30	44	7	44	7	307	52
2001	385	30	101	8	101	8	656	50
2002	399	32	100	8	100	8	582	47
Total	1355	30	365	8	544	12	2214	49

Table 16.4. Referral distribution between 0–4 months for 1997–2002

Days	< 1 month		1–2 months		2–3 months		3–4 months	
	No	%	No	%	No	%	No	%
	913	20	270	6	172	4	137	3

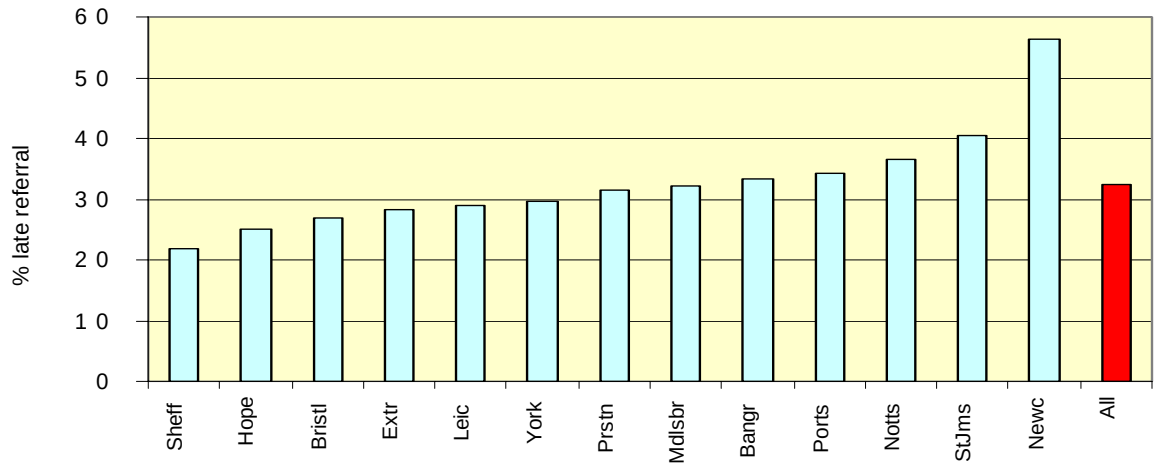

Figure 16.1. Late referral by centre for 2002

Table 16.5. Late referral trend in 4 centres

	< 3 months		3–6 months		6–12months		> 12 months	
	Freq	**%**	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**
1998	113	26	49	11	51	12	230	52
1999	126	29	37	9	57	13	217	50
2000	132	29	36	8	51	11	230	51
2001	134	26	38	7	66	13	275	54
2002	127	30	34	8	38	9	222	53
Total	632	28	194	9	263	12	1174	52

Table 16.6. Comparison between late and referrals groups

	ER	LR
Median Age at RRT (years)	62	67
Male (%)	61	61
Diagnosis (%)		
Diabetes Mellitus	19.5	13.3
Reno-vascular disease	12.9	14.0
Glomerulonephritis	15.3	9.4
Pyelonephritis	9.8	6.6
Polycystic Kidney Disease	9.4	2.3
OtherH	4.9	12.6
OtherL	6.3	10.6
Uncertain	18.9	24.0
Missing	3.0	7.4

For these centres, 90% of incident patients were white, 7% were Indo-Asian and 2% were African-Caribbean. There was no significant difference in late referral in the ethnic minorities when compared with those of white ethnicity.

Although only 21% of the Indo-Asians were referred late compared with 29% of the white population, this difference is probably due to the higher percentage of Indo-Asians with diabetes (31% v 16% respectively), who would be expected to be referred earlier. In the African-Caribbean population 34% were referred late and diabetic nephropathy accounted for 33% of those starting RRT.

Table 16.7 Ethnicity and referral

	ER	LR	Total
White	70.8 (2359	29.2 (973)	3332
Indo-Asian	78.8 (186)	21.2 (50)	236
African Caribbean	65.8 (50)	34.2 (26)	76
Chinese	70.6 (12)	29.4 (5)	17
Other	65.0 (13)	35.0 (7)	20
Total	71.2 (2620)	28.8 (1061)	3681

Social Deprivation

The Townsend index was used as the scoring system for social deprivation, which was derived from the patient's postcode. The Townsend index is a composite measure of deprivation based on total unemployment rate, no car households, overcrowded households and not owner-occupier households based on the electoral ward as at the 2001 Census. The higher the Townsend index, the greater the deprivation. For this analysis, the UK general population was divided into quintiles of deprivation (1 lowest, 5 highest).

There was no significant trend relating late referral to social deprivation (Chi squared p = 0.23); see Table 16.8.

Table 16.8 Social deprivation and referral by Townsend quintiles

Deprivation Score	ER % (N)	LR % (N)	Total
1	70.9 (579)	29.1 (238)	817
2	70.9 (545)	29.1 (224)	769
3	71.9 (577)	28.1 (226)	803
4	68.5 (703)	31.5 (323)	1026
5	67.6 (719)	32.4 (344)	1063
Total	69.7 (3123)	30.3 (1355)	4478

Table 16.9. Modality choice at day 0 and day 90

	ER day 0 (day 90)	LR day 0 (day 90)
HD	62.2% (58.4%)	83.2% (74.9%)
PD	35.9% (38.8%)	16.4% (24.3%)
Transplant	2.0% (2.7%)	

Modality of Renal Replacement Therapy

Table 16.9 demonstrates that patients who were referred late were less likely to start on peritoneal dialysis than those who were referred early (16.4% v 35.9% p = <0.0001). These late referred patients were also more likely to have changed modality from HD to PD by day 90 than those referred early (Table 16.10).

From Figure 16.2 it can be seen that patients from more deprived backgrounds in the early referral group are more likely to go on haemodialysis. There is a linear trend (r^2 = 0.96) with deprivation (Cochran-Armitage trend test, p < 0.0001). There is no relationship between modality and deprivation in the late referral group.

For both referral groups, patients who started RRT on PD are younger than those starting with HD. In the late referral group, the median age is 68 v 59 years for HD and PD respectively (p < 0.0001). In the early referral group, the median age is 65 v 59 years respectively (p < 0.0001).

Haemoglobin and estimated GFR by referral

For these analyses, only measurements within 14 days prior to starting RRT were used. There was no significant difference of the median of the estimated GFR (abbreviated MDRD formula) between late referral and early referral groups at the start of RRT (6.63 ml/min v 6.72 ml/min; p = 0.2786). Both HD and PD groups started RRT at a similar estimated GFR (eGFR).

As would be expected (Table 16.11), the

Table 16.10 Modality by deprivation and referral

Deprivation Score	ER % on HD	LR % on HD
1	57.5	78.2
2	59.1	85.3
3	60.8	78.8
4	64.0	84.5
5	67.7	86.6

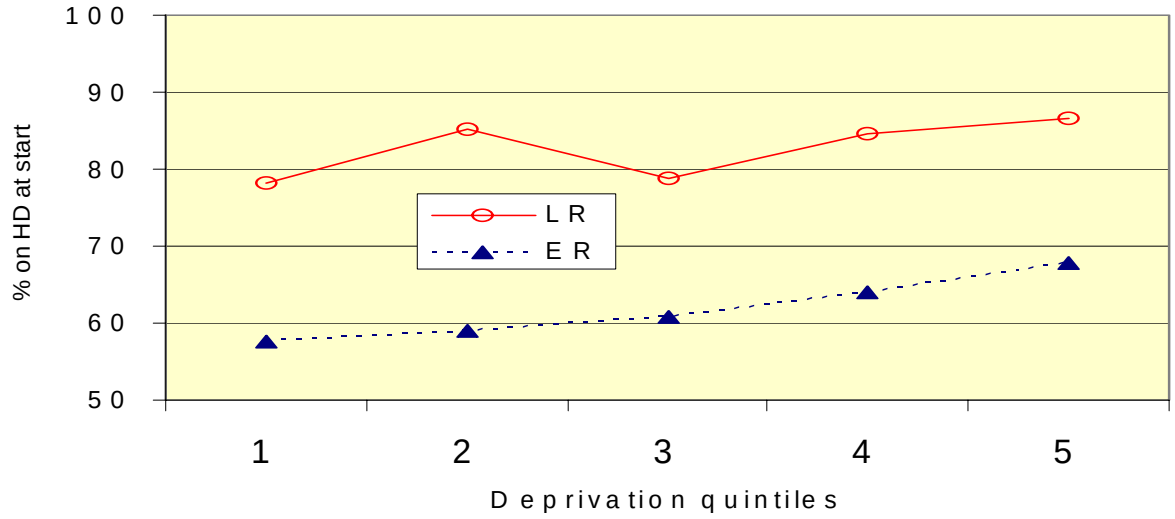

Figure 16.2. Modality by deprivation and referral

median haemoglobin is significantly lower in the late referral group (9.3 g/dl v 9.9 g/dl; $p < 0.0001$). PD patients had higher haemoglobin level than HD patients at start of RRT in both the late referral and early referral groups.

Survival

The analysis of survival (Tables 16.12–16.13) showed that the late referral group has a significantly lower survival probability than the early referral group at both day 90 and 1 year after day 90, even after adjusting for age and haemoglobin. When analysed by age group above and below 65, the increased risk of death in the late referral group remained at day 90 and 1 year after day 90 in both age groups. In patients aged over 65, there was a 50% increased risk of death in the late referral group at both time periods.

Patients on PD had a better survival than those on HD. This is probably due to a patient selection bias.

Discussion

There is no agreed definition of late referral within the UK or internationally. The studies listed in Tables 16.14 and 16.15 reflect the confusion in this lack of definition.

The aim of early referral is to optimise patient care prior to starting RRT: this would include:

- dialysis education
- correction of anaemia, acidosis, hyperparathyroidism
- good blood pressure control
- appropriate dialysis access ready for use at start of RRT
- immunisation against hepatitis B
- full assessment for fitness for transplantation and pre-emptive transplant listing
- work up potential live donor

In order to satisfy most of these requirements, the National Service Framework[8] states that referral to a renal multi-professional team should be at least 12 months prior to the anticipated start of RRT

Ratcliffe *et al.*[14] published a study regarding late referral in the early 1980s showing 42% of new RRT patients were referred within a month of starting RRT. Subsequently, UK-based studies show that this has improved to around 35% of new patients starting RRT being referred within 3

Table 16.11. Median Hb and eGFR (MDRD) at start of RRT

	Early referral			Late referral		
	All modality	**HD**	**PD**	**All modality**	**HD**	**PD**
N	2437	1474	920	959	775	183
Median eGFR (ml/min)	6.7	6.6	6.8	6.6	6.6	6.5
	Early referral			**Late referral**		
	All modality	**HD**	**PD**	**All modality**	**HD**	**PD**
N	2324	1394	887	876	697	178
Median Hb (g/dl))	9.9	9.7	10.2	9.3	9.2	9.7

Table 16.12 Survival at day 90 by modality and age

	ER Survival (95%CI)	**LR Survival (95%CI)**	**p value**
ALL adjusted age 60	94.8 (94.0–95.6)	89.2 (87.6–91.0)	p < 0.0001
HD adjusted age 60	93.3 (92.2–94.5)	87.9 (86.0- 90.0)	p < 0.0001
PD adjusted age 60	97.4 (96.4–98.3)	94.7 (91.9–98.3)	p = 0.0541
Age group 18–64	97.2 (96.4 – 98.0)	92.8 (90.7-94.9)	p < 0.0001
Age group 65+	88.8 (87.1-90.5)	78.3 (75.2–81.3)	p < 0.0001

months.

The problem of late referral is not confined to the UK. In 2001, 23% of new patients in Australia and 25% in New Zealand were late referrals (<3 months prior to start of RRT). Of those referred late, 43% (Australia) and 50% (New Zealand) had a primary disease diagnosis of either diabetes or hypertension.[15] In the US, 40% and 27% of patients starting on HD and PD were referred < 3 months prior to the start of RRT. This study was from the Dialysis Morbidity and Mortality Study (DMMS) wave 2, in which patients self-reported via a questionnaire the date of their first nephrological contact.[16] In Canada, Curtis *et al.*[17] reported a late referral percentage of 35%. In Europe, data from the Lombardy Registry showed that 46% of 1137 were referred late (<2 months).[18] The Flemish-speaking Belgian Society of Nephrology reported 34% of their new patients were referred within 1 month of starting RRT and another 15% were within 1–6 months.[19]

Roderick *et al.*[3] showed that 55% of the late referrals in their studies were unavoidable (Table 16.16). This refers to patients who were asymptomatic till the start of RRT and those with rapidly progressing renal diseases. However, the other 45% were missed opportunities for nephrological intervention. These were patients with signs/symptoms of early renal disease not acted upon (81%), or patients with risk factors such as diabetes or hypertension who should have been screened for signs of renal involvement (19%).

These late referral patients were disadvantaged by starting RRT in a poorer clinical state with possible lower residual renal function, lower haemoglobin, worse renal bone profile and lack of vascular access.[20–22] The Manchester SIRS group collected data regarding access at the start of RRT (Table 16.17). While only 1% of the late referrals starting on HD ($n = 100$) had an AV fistula or graft, disappointingly only 34% of the early referrals ($n = 155$) had permanent access in place.

Another study showed that 57% needed to start RRT as an emergency and 24% presented with pulmonary oedema.[23] The UK

Registry/SIRS cohort of late referral patients did have a lower Hb at the start of RRT. However there was no significant difference in the estimated creatinine clearance. Poorer survival in the Registry/SIRS cohort extended to the 1 year after ninety day period (after adjustment for age and haemoglobin). Similar results have been shown before in other studies,[2,22,24,25] although these mainly concentrated on the early mortality rate (1 year). In Australia, Cass *et al*.[26] analysed the 5-year survival for dialysis patients who survived the first year, and showed that the survival disadvantage of late referral remained.

The Registry is not yet in the position to analyse the co-morbidity of this patient cohort due to poor returns of these data items. Other studies have shown that late referral was associated with higher hospitalisation rates, longer duration of hospital stay[2,6,27] and a poorer quality of life.[28]

It is hoped that implementation of the NICE guideline regarding diabetic nephropathy in Type II diabetics will reduce late referral in this cohort.

The UK data on creatinine clearance at the start of RRT is identical to that shown in the multi-centre European survey on predialysis anaemia management[11] after the European creatinine data has been converted using MDRD estimation (6.7 mls/min UK and 6.6 mls/min Europe) rather than the Cockroft–Gault formula used in the paper (9.1 mls/min) which overestimates clearance at low levels. The UK also has a higher median haemoglobin at the start of RRT when compared with the multi-centre European study where the median haemoglobin was 9.4 g/dl (combined for early and late referral patients).

In conclusion, late referral remains a significant problem both in the UK and worldwide. Australia has reported the lowest incidence of late referral (20% at 3 months) and the UK should be aiming to reduce late referral down to these levels. This goal is compatible with the study of avoidable reasons for late referral.

Table 16.13 Survival at 1 year after day 90 by modality and age

	ER Survival (95%CI)	LR Survival (95%CI)	p value
ALL adjusted age 60	88.5 (87.2–89.9)	81.5 (79.0–84.2)	p < 0.0001
HD adjusted age 60	87.3 (85.5–89.0)	80.2 (77.4–83.3)	p < 0.0001
PD adjusted age 60	90.2 (88.3–92.3)	86. 9 (81.8–92.3)	p = 0.2104
Age group 18-64	92.2 (90.9–93.7)	87.6 (84.5–90.7)	p = 0.0022
Age group 65+	80.6 (78.0–83.2)	69.3 (65.0–73.6)	p < 0.0001

Table 16.14. Late referral studies based in the UK

Author	Publication	Study Year	Study No	Def	% Late Referral
Ratcliffe	BMJ 1984	1981	55	<1m	42
Eadington	NDT 1996	1987–92	325	<4m	47
Ellis	QJM 1998	1996–97	198	<3m	32
Stoves	PMJ 2001	1980–1999	1260	<3m	37
Roderick	NDT 2002	1996–97	361	<4m	35
Roderick	QJM 2002	1997–98	250	<4m	38
Metcalfe	KI 2003	10/97–9/98	523	<1m	25
Steel	EDTNA 2002	1/96–12/00	494	<3m	33

Table 16.15. Late referral studies in other countries (ordered by definition and study year)

Author	Publication	Country	Study Year	Study No	Def	% Late Referral
Lameire N[9]	NDT 1999	Europe	1993–95	2236	<1m	26
Schmidt R[10]	AJKD 1998	USA	90–97	238	<1m	24
Astor BC	AJKD 2001	USA	10/95–6/98	356	<1m	25
Kessler M	AJKD 2003	France	6/97–6/99	502	<1m	23
Paris V	EDTNA ERCA 2002	Italy	1/98–12/99	1137	<1m	46
Horl WH[11]	AJKD 2003	Europe	8/99–4/00	3918	<1m	14
Curtis BM	CN 2002	Canada	10/98–12/99	238	<3m	35
Avorn J	AIM 2002	USA	1991–96	3014	<3m	35
Winkelmayer WC[12]	KI 2001	USA	1991–96	3014	<3m	35
USRDS	USRDS 1997	USA	1996	3468	<3m	39*
Australia	ANZDATA 2002	Australia	2001	1882	<3m	23
New Zealand	ANZDATA 2002	New Zealand	2001	458	<3m	25
Roubicek C	AJKD 2000	France	1989–96	270	<4m	31
Arora P	JASN 1999	USA	10/92–12/97	135	<4m	22
Cass A	MJA 2002	Australia	4/95–12/98	4243	<3m	27
Kinchen KS	AIM 2002	USA	10/95–6/98	828	<4m	48
Stack A	AJKD 2003	USA	5/96–7/97	2522	<4m	32
Joly D	JASN 2003	France	1989–00	144	<4m	35
Jungers P[13]	NDT 2001	France	1989–98	1057	<6m	24

* calculated from data given separately for HD and PD patients

Table 16.16. Avoidable late referrals and source of referrals (adapted from Roderick et al.[3])

				Avoidable LR		Unavoidable LR	
				No	%	No	%
Total (*n* = 250)	No	%	Gen Physicians	29	67	21	43
Late referrals	96	38	GPs	4	9	7	14
Avoidable late referrals	43	45	Urologists	2	5	3	6
Renal damage ignored	35	81	Diabetologists	2	5	1	2
Missed opportunities for detection	8	19	Others	6	14	17	35

Table16. 17 Haemodialysis access at first dialysis (SIRS group)

	AVF/graft	Permcath	Temp line
LR (%)	1	29	70
ER (%)	34	17	49

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Chapter 17: Social Deprivation on Renal Replacement Therapy

Summary

- Acceptance rates for renal replacement therapy (RRT) appeared to be higher in more deprived areas. Whilst this is partly due to patients on RRT from ethnic minorities being from more socially deprived areas, White patients with ERF were also from more socially deprived areas.

- Patients from the most deprived areas are younger and have more co-morbidity.

- There appears to be no difference in timing of referral to a nephrologist between the deprivation quintiles.

- Patients commencing RRT on PD have significantly lower Townsend scores (i.e. are less socially deprived) than those commencing on HD. Similarly patients receiving a pre-emptive renal transplant have significantly lower Townsend scores ($p \geq 0.0001$).

- Social deprivation was a significant factor associated with 1 year survival on RRT after adjusting for age and primary renal diagnosis, but it was not significant after adjusting for cardiovascular co-morbidity.

Introduction

A strong relationship exists between social deprivation and all-cause mortality in the UK general population, with higher mortality rates observed in areas of higher social deprivation than in more affluent areas.[1] The increasing mortality with increasing deprivation remains clear even within individual diseases such as ischaemic heart disease (IHD) and cancer. For example, in men with IHD living in more deprived areas, there is a 2.7-fold increase in death rate relative to those with IHD and from more affluent areas.[1]

Lower socio-economic status (SES) has been shown to be associated with reduced survival for several types of cancer, over and above any effect on incidence.[2,3] Explanations for such an effect include:

- Disease severity at presentation (e.g. delay in presentation or referral);
- Quality of care (surgery, adjuvant therapies);
- Host factors altering the responses to the treatment and cancer, e.g. co-morbidity at start, compliance with therapy, lifestyle factors affecting risk (e.g. smoking, diet), psychosocial factors.[4]

Considering the relationship with renal disease, annual household income and education-based socio-economic status have been shown to correlate with the development of established renal failure (ERF) in the North American general population[5] and ethnic minorities.[6] Although not all studies concur,[7] there is some evidence that in the USA socio-economic status influences survival on RRT.[8,9] In the more recent of these two US studies, rising levels of neighbourhood income were associated with reduced mortality on RRT, suggesting that personal or environmental factors that differ by social group effect survival.[9] It is likely that rates of co-morbidity, including smoking differ by socio-economic status though this has not been adequately investigated.[10] Patients in lower socio-economic groups may also have reduced compliance with medication.[11]

The National Health Service in the UK provides health care for all which is free-at-the-point-of-use. This includes primary care, secondary care and prescription medicines,

contrasting with the US where many people in lower socio-economic groups lack access to both primary health care and medications. Care must therefore be exercised in extrapolating from US data to the UK. When social deprivation of prevalent patients was examined in the 2000 UK Renal Registry report, it was not found to have a significant influence on survival (n = 2874, p = 0.4). One flaw in analysing a prevalent cohort is that it assumes that a large number of patients in one subgroup have not died early on in the RRT programme leaving a biased subset of survivors in different deprivation groups. The 1998 cohort of 1500 incident patients was considered too small to analyse trends in social deprivation and survival and the Registry had been waiting for the new 2001 Census data before repeating these analyses on the much larger incident cohort now available.

In the intervening years data from Trent, Scotland and North-West England have been examined. Junor analysed the combined 20 year incident cohort from 1980–1999 in Scotland and demonstrated a trend to lower survival in the most socially deprived patients under 55 years of age but no difference in those over 55 years.[12] Further, a prospective study in North-West England (n = 620) found that the most socially deprived dialysis patients were significantly less likely to achieve the Renal Association targets for haemoglobin and phosphate and had higher hospitalisation rates, although these data were not adjusted for diabetes.[13]

The effect of socio-economic status on access to the different modes of renal replacement therapy also requires consideration. Data, again from the US, have shown that socially deprived individuals are less likely to receive peritoneal dialysis as their initial mode of treatment.[14] Although these patients had an equal opportunity of receiving a renal transplant once wait-listed, their chance of getting onto the renal transplant waiting list was significantly less than those of more affluent patients.[15] Maheswaran analysed social deprivation using the Townsend score in prevalent patients on renal replacement therapy in the Trent Region, and found an increased prevalence in patients from more deprived backgrounds. This effect was most marked for haemodialysis and least marked for transplantation.[16]

The aim of this chapter is to describe the area-level social deprivation characteristics of a cohort of incident and prevalent RRT patients in the UK, examine how clinical characteristics vary by deprivation group and evaluate the impact of deprivation on initial and 90-day mode of RRT and patient survival.

Methods

Study sample

All patients commencing RRT between 1997 and 2002 in centres reporting to the Registry were included. Patients in Scotland and Northern Ireland could not be included because of time pressures and anticipated difficulties linking postcodes to 2001 Census data in these countries.

Additional data were also obtained from the Manchester based study of Implementation of Renal Standards (SIRS). This study involves Manchester Royal Infirmary, Hope Hospital and Royal Preston Hospital who have kindly provided the Registry with their data to be included in the analysis (A Trehan). The SIRS group have prospectively collected their data from April 2000 onwards, although this analysis includes only the SIRS data for the complete years 2001 and 2002. The Royal Preston Hospital is already part of the UK Renal Registry.

Each individual patient postcode was validated against the address fields using a commercial postcoding software package (QAS systems).

In the Cox model, deaths occurring in the first 90 days were excluded from the analysis as some renal units may have included a number of patients with acute renal failure which would influence early death rates.

Patients were censored at the end of follow up and not at the time of renal transplantation.

Data used in the comparative prevalent cohort were from patients alive on the 31st December 2002.

Calculating the Townsend deprivation score

The Townsend index was used as the scoring system for social deprivation, which was derived from the patient's postcode. The Townsend index (calculated for the Registry from the 2001 Census data, by Hannah Jordan of Southampton University) is a composite measure of deprivation based on total unemployment rate, no-car households, overcrowded households and not owner-occupier households based on the electoral ward as at the 2001 Census. The higher the Townsend index, the greater is the deprivation. A comparison with other UK methods of scoring deprivation is shown at the end of this chapter (Annex A, Table 17.11).

Using 2001 Census data, a profile was created for all 1.25 million postcodes in England and Wales. The postcodes were ordered by Townsend score from lowest to highest and then divided into quintiles of Townsend scores (Table 17.1). For those postcodes with more than one Townsend score (5% of postcode areas cross a census boundary), the mean Townsend score was calculated.

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

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

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

Statistical analysis

ANOVA (Wilcoxon for non-parametric data) and chi-squared tests were performed to look for differences in continuous and categorical variables between the Townsend quintiles.

Differences in survival between the Townsend deprivation quintiles were studied using Kaplan–Meier survival curves.

To analyse the relationship between Townsend score and risk of death, two Cox Proportional Hazard models were created. All variables were entered into the model regardless of whether they had an independent effect on survival or not.

1. The first model included all patients with postcode data. Variables included in this model were limited to age, Townsend score (both as linear variables) and primary renal diagnosis (PRD), as these variables have high levels of completeness in all centres.
2. The second model included only patients in centres with >85% completeness of data for co-morbidity and ethnicity in the year they began RRT. As well as age, Townsend score (both as linear variables) and PRD, this model included the ethnicity and co-morbidity variables.

Table 17.1. Townsend scores by postcode quintile

Townsend quintile	1	2	3	4	5
	Least deprived			Most deprived	
Townsend score range	≤–3.35	–3.36 to –1.95	–1.96 to –0.14	–0.15 to 2.59	>2.60

Results

Townsend scores were available for 13,454 (97%) of the 13,859 patients commencing RRT in England and Wales between 1st January 1997 and the 31st December 2002 in centres reporting to the Registry. The SIRS database also contributed 412 patients (382 with Townsend data).

Socio-economic status of the renal replacement therapy population

In Figure 17.1, the distribution of Townsend score for the Registry incident and prevalent cohort was compared with that of the England & Wales general population. It has not been possible to derive the Townsend distribution for general population in areas just covered by the Registry. The figure shows that prevalent cohort patients have an identical Townsend distribution to that of the incident cohort. There appears to be an increased incidence of RRT in patients within the more deprived areas. This may be due to:

1. The Registry not being fully representative of the UK general population. However this is unlikely to explain these differences. The 20% of the E&W population missing from this analysis are from mixed deprivation areas. The South East of England, which is less deprived overall, is more than balanced in numbers by those cohorts missing from the more deprived areas of Birmingham, Stoke and inner London.
2. Confounding by ethnicity, if ethnic minorities with a higher incidence of renal replacement therapy live in more deprived areas than the general population.
3. A true increase in ERF in deprived areas for both diabetic ERF (accounting for 18% of incident patients) and non diabetic causes.
4. A confounding effect of different incident cohorts over the period of 1997–2002, with early renal units deriving from a more deprived area and submitting 5 annual cohorts compared with a less deprived renal unit joining in 2002 and submitting only one cohort.

Item four was addressed by separately analysing the incident cohorts for the individual years. All the annual cohorts showed a similar distribution of patients, with an excess of ERF patients from the more deprived population.

The figure was re-calculated separately for the Whites only and the ethnic minorities (Figure 17.2). The ethnic minorities were from a more socially deprived group than the Whites. But even after this adjustment there still appeared to be an excess of patients from those with a Townsend score of 1–5.

To investigate whether this effect was due to an effect of diabetics coming from a more

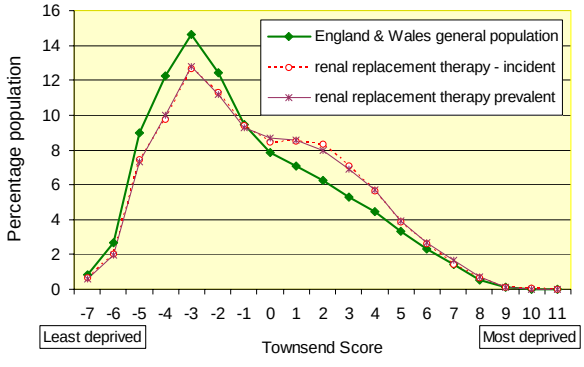

Figure 17.1 Population distribution of Townsend scores

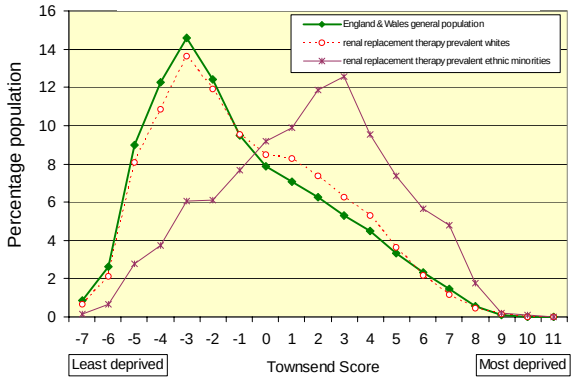

Figure 17.2. Population distribution of Townsend scores, effect of ethnicity

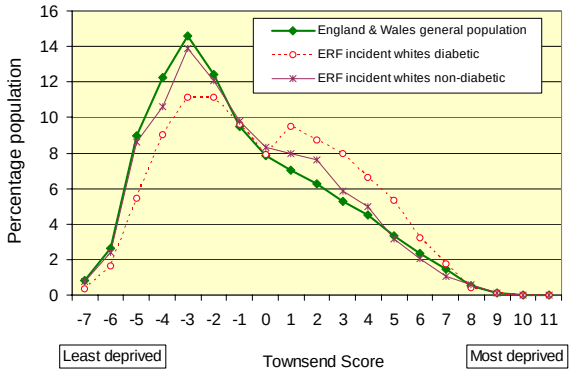

Figure 17.3. Population distribution of Townsend scores, effect of diabetes

deprived background, the figure was recalculated for Whites excluding diabetic patients and the White diabetics separately (Figure 17.3). This confirmed that there was an increased incidence of diabetics with renal failure from socially deprived backgrounds when compared with the general population. Type 1 and Type 2 diabetics were included together in this analysis. It was not possible to say to what extent this reflected a difference in incident rates of diabetes or progression rates or a combination of these two between areas. There still remained a small increased rate for non-diabetic White patients in deprived areas.

Centre

The mean Townsend deprivation score for incident renal replacement therapy patients in England & Wales is 0.08 (95% CI 0.03 to 0.14). This is more deprived than the UK general population mean Townsend score of –0.448. Patients starting RRT in Wales have a lower mean Townsend score (i.e. are less socially deprived) than those in England (–0.15, 95% CI –0.31 to 0.01 v 0.11, 95% CI 0.05 to 0.17 respectively). These values mask considerable variation in mean Townsend score between centres (Figure 17.4).

Although the sample size for some of the individual centres was small, the overall trend was for centres in the South tending to be less deprived (i.e. towards the left hand side of the graph), and those in the North and in London tending to be more deprived (i.e. towards the right hand side of the graph).

Modality and deprivation

Patients commencing RRT on PD have significantly lower Townsend scores (i.e. are less socially deprived) than those commencing on HD (Figure 17.5). Similarly, patients receiving a pre-emptive renal transplant have significantly lower Townsend scores (p 0.0001).

This finding persists when modality is considered at 90 days, indeed the difference is slightly increased – the mean Townsend score for HD patients increases slightly and the mean score for PD patients and trans-

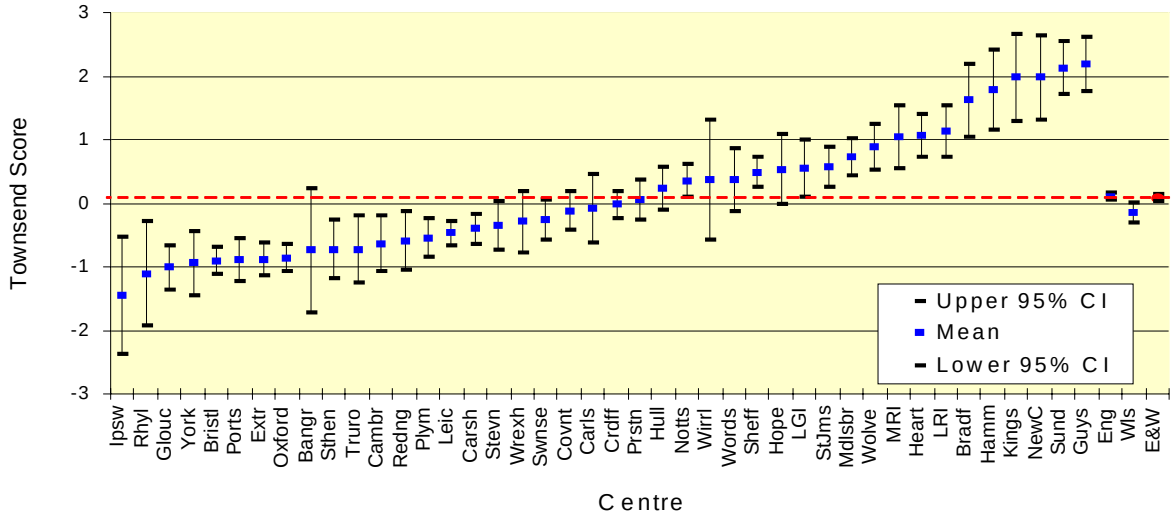

Figure 17.4 Mean Townsend score by renal unit

Table 17.2. Mean Townsend score by renal unit and numbers of invalid postcodes

Centre	Valid postcodes	Invalid postcodes	Mean Townsend	Townsend 95% CI
Ipsw	19	2	–1.44	–2.36 to –0.52
Rhyl	19	0	–1.11	–1.93 to –0.28
Glouc	283	16	–1.01	–1.36 to –0.66
York	144	1	–0.94	–1.45 to –0.43
Bristl	736	29	–0.9	–1.11 to –0.69
Ports	273	14	–0.89	–1.22 to –0.56
Extr	403	4	–0.88	–1.14 to –0.61
Oxford	742	29	–0.86	–1.06 to –0.65
Bangr	28	1	–0.74	–1.72 to 0.24
Sthend	152	2	–0.72	–1.19 to –0.26
Truro	93	3	–0.72	–1.24 to –0.2
Cambrid	178	1	–0.63	–1.07 to –0.19
Redng	156	2	–0.59	–1.05 to –0.13
Plym	375	11	–0.55	–0.85 to –0.24
Leic	972	16	–0.47	–0.67 to –0.27
Carsh	649	13	–0.4	–0.65 to –0.16
Stevn	219	3	–0.35	–0.73 to 0.03
Wrexh	171	13	–0.29	–0.78 to 0.19
Swnse	300	11	–0.26	–0.58 to 0.05
Covnt	459	7	–0.12	–0.42 to 0.18
Carls	139	7	–0.07	–0.62 to 0.47
Crdff	694	17	–0.02	–0.24 to 0.2
Prstn	464	7	0.06	–0.26 to 0.37
Hull	392	5	0.24	–0.11 to 0.58
Notts	673	17	0.35	0.09 to 0.61
Wirrl	39	1	0.37	–0.58 to 1.32
Words	185	1	0.37	–0.13 to 0.86
Sheff	788	27	0.49	0.25 to 0.72
Hope	147	19	0.53	–0.02 to 1.08
LGI	205	2	0.56	0.11 to 1.01
StJms	472	24	0.57	0.25 to 0.89
Mdlsbr	561	14	0.73	0.44 to 1.02
Wolve	313	14	0.89	0.53 to 1.25
MRI	235	11	1.04	0.54 to 1.54
Heart	440	24	1.07	0.73 to 1.41
LRI	318	13	1.14	0.74 to 1.55
Bradf	120	1	1.62	1.05 to 2.2
Hammers	95	2	1.79	1.15 to 2.42
Kings	110	7	1.98	1.29 to 2.66
NewC	103	2	1.98	1.32 to 2.65
Sund	224	4	2.12	1.71 to 2.54
Guys	366	8	2.19	1.77 to 2.61
Eng	12242	363	0.11	0.05 to 0.17
Wls	1212	42	–0.15	–0.31 to 0.01
E&W	13454	405	0.08	0.03 to 0.14

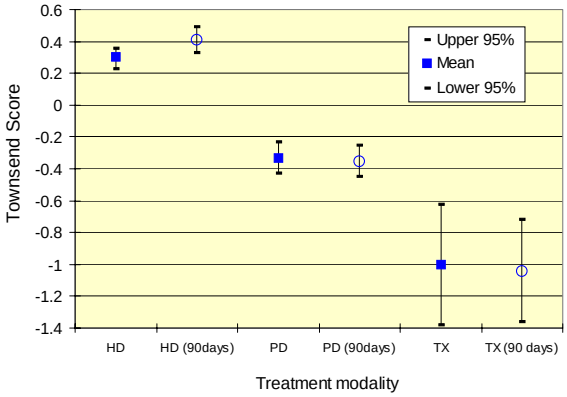

Figure 17.5. Townsend score by treatment modality at day 0 and day 90

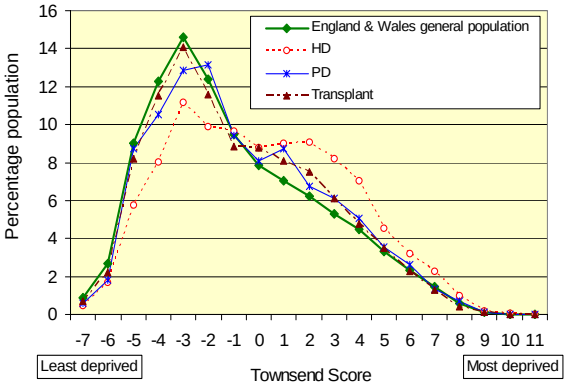

Figure 17.6. Population distribution of Townsend scores in prevalent patients, by modality

Table 17.3. First mode of treatment

Treatment	N Obs	N	Mean	95% CI
HD	9465	9163	0.3	0.23 to 0.36
PD	4125	4031	–0.33	–0.43 to –0.23
Transplant	265	256	–1	–1.38 to –0.62
Missing	4	4		

Table 17.4. Day 90 mode of treatment

Treatment	N Obs	N	Mean	CL for Mean
HD	6962	6786	0.41	0.33 to 0.49
PD	4320	4234	–0.35	–0.45 to –0.25
Transplant	340	329	–1.04	–1.36 to –0.72
Transfer out	63	60	0.55	–0.3 to 1.4
Treat stop	35	34	0.87	–0.4 to 2.15
Died	1226	1126	0.01	–0.18 to 0.21
Missing	913	885		

plant patients decreases slightly ($p \leq 0.0001$).

The prevalent group was used to compare the effect of modality and age, as few patients were transplanted in the incident group.

Similar to the incident cohort, prevalent transplant patients came from the least socially deprived group, then PD patients and then HD in increasing order of deprivation. The differences in the Townsend distributions are shown in Figure 17.6.

Figure 17.7 demonstrates that across all

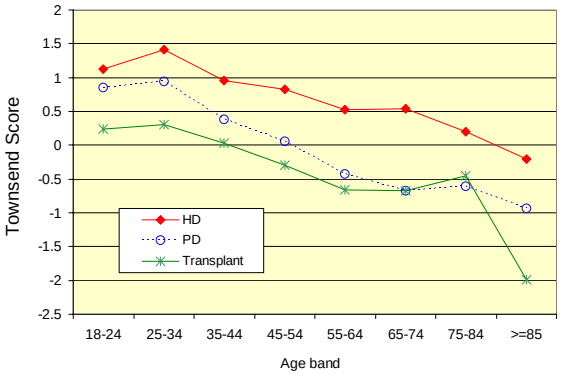

Figure 17.7. Townsend score by treatment modality and age band

the three modalities, Townsend scores decreased with age. Further analyses will look at the effect of deprivation on mode of renal replacement therapy after adjusting for other factors such as age, ethnicity and primary renal disease.

Patient characteristics

Univariate analysis reveals that patients from the most deprived quintile are significantly younger than those in the least deprived quintile (62.2 years v 65.4 years, $p < 0.0001$).

There were also significant differences in ethnicity across the deprivation quintiles, with a greater proportion of those in the most deprived quintile being of South Asian or African-Caribbean origin. Primary renal disease differs significantly ($p < 0.0001$), with

Table 17.5. Patient characteristics of the incident cohort

	1	2	3	4	5	Total included	No. missing	p-value
Age								
Median age	65.4	65.2	64.6	64.7	62.2	13453	405	<0.0001
Primary Renal Disease								
Diabetes	11	14	18	24	33	2316	55	<0.0001
Glomerulonephritis	17	18	19	24	22	1630	55	
Polycystic kidney disease	22	18	19	22	19	861	15	
Pyelonephritis	16	17	20	24	24	1091	25	
Reno-vascular disease	15	17	19	23	26	1661	53	
Other	19	19	18	24	21	1797	58	
Uncertain	16	15	19	24	26	2743	99	
Missing diagnosis	16	19	19	25	21	1355	45	
Ethnicity								
Asian	6.9	5.7	10.3	30.4	46.7	668	17	<0.0001
Black	3.0	5.7	7.8	22.8	60.7	333	11	
Chinese	14.9	17.0	14.9	17.0	36.2	47	1	
White	17.0	17.9	19.5	23.2	22.4	8906	226	
Other	8.0	16.0	14.4	18.4	43.2	125	1	
Missing	15.9	16.7	19.7	25.3	22.3	3375	149	

more diabetes, pyelonephritis, reno-vascular disease and uncertain diagnosis in the more deprived groups than the more affluent groups.

Despite their younger age, the more socially deprived groups also have higher rates of co- morbid illnesses than the more affluent groups, with more diabetes, circulatory problems and COPD. They were also significantly more likely to be current smokers (21.5% v 14.8%, $p < 0.0001$). The incidence of malignancy was reduced in the more socially deprived groups.

There appears to be no difference in timing of referral to a nephrologist between the deprivation quintiles, but patients in the most deprived quintile have significantly lower haemoglobin prior to starting renal replacement therapy than those in the most affluent quintile (9.7g/dl v 10.1g/dl, $p < 0.0001$).

Survival

Patients were followed for a median of 482 days beyond day 90. Unadjusted survival according to the Kaplan–Meier survival graph (Figure 17.8) does not seem to differ between the five deprivation groups ($p = 0.3$), although, four and five years into renal replacement therapy the groups seem to be separating, with slightly better survival in the more affluent groups. The various effects of age, ethnicity (e.g. African-Caribbeans have better survival) and co-morbidity are all operating.

In the first Cox Proportional Hazard Model, (Table 17.8) age and PRD appear to be significant independent predictors of patient mortality. In this model, knowing a patient's Townsend score significantly improves the ability of the model to predict mortality ($p = 0.027$). The effect of being socially deprived appears small, with a one unit increase in

Table 17.6. Co-morbidity

	1	2	3	4	5	Total included	No. missing	p-value
Cardio-vascular disease								
No	17	17	20	23	24	3129	91	0.2417
Yes	14	17	19	25	24	1029	20	
Missing	16	17	18	24	25	9296	294	
Peripheral vascular disease								
No	17	16	20	23	24	3232	88	0.0429
Yes	14	18	18	25	25	926	23	
Missing	16	17	18	24	25	9296	294	
Diabetes (co-morbidity, not PRD)								
No	17	16	20	23	24	3780	99	0.0141
Yes	11	21	17	27	25	322	9	
Missing	16	17	18	24	25	9352	297	
Diabetes (co-morbidity or PRD)								
No	18	17	20	23	21	3094	84	<0.0001
Yes	11	16	17	25	31	1064	27	
Missing	16	17	18	24	25	9296	294	
Smoker								
No	18	18	20	23	21	3099	79	<0.0001
Yes	12	13	19	25	32	809	22	
Missing	16	17	18	24	25	9546	304	
Liver disease								
No	16	17	19	23	24	4032	107	0.9115
Yes	16	15	17	26	27	94	1	
Missing	16	17	18	24	25	9328	297	
Malignancy								
No	16	16	19	24	24	3673	93	0.0023
Yes	19	22	20	19	21	448	15	
Missing	16	17	18	24	25	9333	297	
Chronic obstructive pulmonary disease								
No	17	17	19	23	23	3813	100	<0.0001
Yes	9	13	19	27	32	317	10	
Missing	16	17	18	24	25	9324	295	

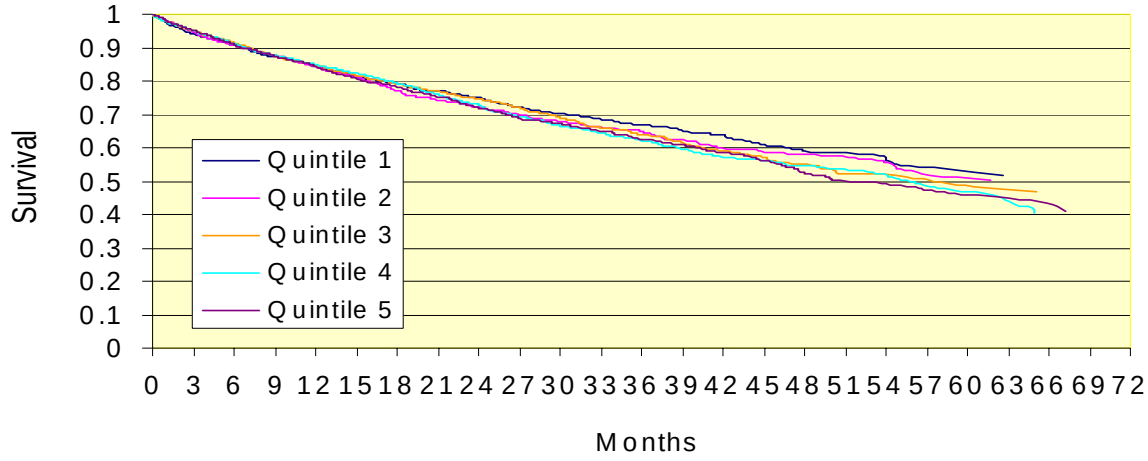

Figure 17.8 KM survival by deprivation

Table 17.7 Late referral and haemoglobin

	1	2	3	4	5	Total included	No. missing	p-value
0–89	14	16	18	25	27	1772	66	0.3409
90–179	16	19	18	22	25	399	8	
180–364	15	16	18	25	27	556	19	
365+	16	17	19	24	24	2018	47	
Missing	16	17	19	24	24	8709	265	
Haemoglobin								
Mean Hb before start	10.1	10.0	10.0	10.0	9.7	10630	230	<0.0001
Missing						2824	175	

Table 17.8. Cox model 1

Variable	Parameter Estimate	Standard Error	Chi-Square	Pr > ChiSq	Hazard Ratio	95% Confidence Limits
Age	0.046	0.0015	966	<.0001	1.05	1.05–1.05
Diabetes	0.860	0.0774	123	<.0001	2.36	2.03–2.75
PKD	–0.660	0.1417	22	<.0001	0.52	0.39–0.68
Pyelonephritis	0.084	0.0985	0.7	0.3904	1.09	0.90–1.32
RVD	0.338	0.0841	16	<.0001	1.40	1.19–1.65
Other	0.839	0.0810	107	<.0001	2.31	1.97 -2.71
Uncertain	0.346	0.0778	20	<.0001	1.41	1.21–1.65
Missing	0.682	0.0866	62	<.0001	1.98	1.68 -2.34
GN	0					
Townsend	0.012	0.00561	4.9	0.0267	1.013	1.00–1.02

Townsend score (more deprived) being associated with only a 1% increase in mortality and this could be partly due to the reesidual effect of co-morbidity.

The second Cox Proportional Hazard Model in Table 17.9, is based only on patients commencing RRT in centres whose data completeness for ethnicity and co-morbidity was >85% in that year (n = 1,086). These data cover only twelve centre years. In this model, age and several of the primary renal diseases continue to be independent predictors of mortality. From the co-morbidity and ethnicity variables, only cardiovascular disease and malignancy independently predict mortality. A relationship between social deprivation and mortality is not observed in this model (p = 0.97).

Table 17.10. Centres with both >85% ethnicity and >85% co-morbidity

Year					
1999	Bristl				
2000	Bristl	StJms			
2001	Bristl	Hope	Leic	MRI	Sheff
2002	Hope	Hammers	MRI	Notts	

Discussion

This report demonstrates regional differences in levels of social deprivation of patients commencing RRT in the UK. The North–South pattern of this variation reflects that found in the UK general population.[17] Even with the caveat that the Registry population coverage is not yet

Table 17.9. Cox model 2

Variable	Parameter Estimate	Standard Error	Chi-Square	Pr > ChiSq	Hazard Ratio	95% Confidence Limits
Age	0.0434	0.0065	45	<.0001	1.04	1.03–1.06
Diabetes	0.6195	0.2891	4	0.0321	1.86	1.05–3.27
PKD	-2.3035	1.0265	5.	0.0248	0.10	0.01–0.75
Pyelonephritis	0.0525	0.3616	0.02	0.8846	1.05	0.52–2.14
RVD	0.2389	0.3156	0.57	0.4490	1.27	0.68–2.36
Other	1.0689	0.2724	15	<.0001	2.91	1.71–4.67
Uncertain	-0.0216	0.2871	0.005	0.9401	0.98	0.56–1.72
Missing	0.9718	0.6442	2	0.1315	2.64	0.75–9.3
GN	0					
Cardio-vascular	0.4627	0.1679	7.	0.0056	1.59	1.15–2.20
PVD	0.2637	0.1749	2	0.1319	1.30	0.92–1.83
Liver disease	0.3733	0.3923	0.9	0.3413	1.45	0.67–3.13
Malignancy	0.5346	0.1826	8	0.0034	1.71	1.19–2.44
COPD	0.2573	0.2336	1	0.2707	1.29	0.82–2.04
Diabetes not ERF	0.1888	0.2502	0.56	0.4506	1.21	0.74–1.97
Black	-0.5310	0.7198	0.56	0.4531	0.58	0.14–2.39
Asian	-0.3683	0.3775	0.95	0.3292	0.69	0.33–1.45
Chinese	-12.4026	401.9464	0.001	0.9754	0.00	
Other ethnic	-12.6465	449.0557	0.001	0.9775	0.00	
White	0					
Townsend	-0.0344	0.0236	2	0.1442	0.97	0.9–1.01

complete, these data suggest that the acceptance rate of RRT is higher in more deprived areas. Full population coverage will allow more detailed analysis of age, gender, ethnic and deprivation acceptance rates.

A relationship between socio-economic status and health still exists in the UK general population.[1] Although a previous prevalent cohort analysis from the Registry in 2000 did not show a relationship between deprivation and renal replacement therapy survival, other data have suggested that socio-economic status may be related to outcomes in patients on renal replacement therapy in the UK.[12] Interpreting such comparisons at the national level requires an appreciation of some of the weaknesses of the measures being used. Although generic area-measures of deprivation, such as the Townsend index, relate strongly with long term illness and mortality in urban areas, the relation in fringe and rural populations is much weaker.[18] Further, they have been shown to relate less strongly to mortality in the elderly[19,20] and in ethnic minority groups.[21] In the South-West of England it has also been demonstrated that the apparent deprivation of a region can be quite markedly altered by varying the measure of deprivation that is applied.[22] Finally, individuals are being labelled by the characteristics of their area of residence rather than on an individual based measure of socio-economic status. Such limitations must be borne in mind when comparing deprivation in quite disparate regions and populations in the UK, and their impact is likely to reduce the chances of finding significant associations.

The observation that patients in the most deprived quintile are younger than those in the more affluent quintile may be due to one or more of a number of factors:

1. The natural history of CKD in patients from more deprived areas may be that RRT is reached at a younger age because of faster progression;
2. It may reflect the higher rates of ERF in ethnic minority groups with their younger age distribution;
3. A higher incidence of Type 2 diabetes in more deprived areas and these patients may also be younger than type 2 diabetics from more affluent areas.
4. Patients living in more deprived areas tend to have more co-morbidity and therefore may possibly be considered medically unsuitable for dialysis, with this effect increasing with age. Similarly the differences in competing risks of cardiovascular and other mortality, higher in deprived areas, increases with age.

Re-analysis of the Whites-only data indicates that patients in the most deprived quintile are still younger than the most affluent quintile (62.5 and 64.5 years respectively). After exclusion of diabetes in this Whites-only cohort, the median ages were similar (64.5 and 65.2 years respectively). It was not possible to test the effect of the other two hypotheses with the current dataset.

There was no evidence found of a difference in referral pattern (early v late referral) between patients living in the most socially deprived and the most affluent areas. Despite this, a strongly significant difference in the deprivation mix of patients on the three modes of RRT was observed, similar to the prevalent group to those of Maheshwaran *et al.*,[16] with patients on HD generally being from more deprived areas. This may partly reflect the greater access to HD in urban areas, with most main renal units being based in cities or large towns. The observation that patients having a pre-emptive transplant and in the prevalent patients of having a transplant were likely to live in more affluent areas may reflect differences in co-morbidity affecting suitability for transplantation, and ethnic minority origin influencing allocation of kidneys. It is also possible, that as has been described in North

America,[15,23] patients from more affluent areas are progressing through the various stages of the renal transplant workup more rapidly than those from more deprived areas, and/or that they have a greater probability overall of being placed on the transplant waiting list. This is the subject of an ongoing combined analysis with UK Transplant.

For this year's report the evaluation of social deprivation and outcomes on RRT was restricted to survival, although relationships with other intermediate outcome measures are being examined. From the larger dataset of all incident patients, the deprivation score of a patient's home address did predict mortality, but the effect was small. To allow adjustment for confounding by ethnicity and co-morbidity, a second smaller dataset was defined which included only patients going onto RRT in centres whose co-morbidity and ethnicity data were more than 85% complete in that year. Although this provided a more robust dataset, the sample size was greatly reduced (1,086 v 11,314 patients) and the finding of no relationship between social deprivation and mortality in this second model is open to type 2 error. In support of the possibility of a type 2 error is the lack of effect of ethnicity on survival in this model. This variable is examined in Chapter 20 of this report, in a larger cohort (patients in centres with >85% ethnicity data, n = 6,000), where African-Caribbean had an improved survival at 1 year after 90 days (HR 0.575, 95%CI 0.349–0.947, p = 0.03).

These initial analyses suggest that there is no strong relationship between the deprivation score of a patient's home address and their outcome on RRT, once factors such as differences in co-morbidity are taken into account. This agrees with the conclusions on survival of prevalent patients in the UK Renal Registry Report 2000, social deprivation chapter.[24] Any effect of social deprivation on health outcomes is complex and consideration needs to be given to not only factors such as age, co-morbidity and ethnicity, but also compliance with therapy, lifestyle factors (smoking and diet), psychosocial factors and access to and quality of health care. In this chapter the results of a first analysis of the relationship between social deprivation and incident RRT patient's characteristics and outcomes have been presented, with many more analyses and contemplation planned for the months ahead.

In summary, these early data demonstrate differences in social deprivation of patients entering renal replacement therapy programmes in England and Wales which suggest an increased incidence of RRT in more deprived populations. Patients in the most socially deprived group were significantly younger than those in the most affluent group, but had more diabetes, co-morbidity and were more likely to be smokers. There are differences between renal units in the social deprivation of their patients, which together with the associated increased co-morbidity may add to the burden on resources within these renal units. Patients of lower socio-economic status were considerably less likely to be receiving peritoneal dialysis or have a renal transplant at 90 days. Any effect of social deprivation on survival on RRT appears to be small, but these interim results are the subject of ongoing subgroup analyses of survival that will explore for example interactions between social deprivation, age and ethnicity.

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Annex A Comparison of UK Deprivation Scores

Table 17.11. Comparative UK deprivation scoring systems

Indicator	DoE (1983)	Townsend	Jarman	Carstairs	LWT	DoE, ILC (1994)
Total unemployment rate	*	*	*		*	All levels
Male unemployment rate				*		
Overcrowded households	*	*	*	*		All levels
Households lacking amenities	*					All levels
Not owner-occupier households		*			*	
No-car households		*		*	*	All levels
Low social class (4&5 or SEG 11)			*	*	*	
Lone-parent household	*		*		*	
Lone-pensioner households	*		*			
Under 5s			*			
Children in unsuitable accom.						All levels
Children in low-earning h/h						All levels
Moving with previous year			*			
Limiting long-term illness					*	
Born New Commonwealth	*		*			
17 yr olds not in full time ed.						ward/district
Non-census data						
Standard mortality ratio						district
Long-term unemployment						district
Income support recipients						district
House contents insurance						district
Low GCSE attainment						district
Derelict land						district

* included in the calculation of the scoring system.

Chapter 18: Causes of Death on Renal Replacement Therapy

Summary

- This chapter corrects the errors found after publication of the 2002 Report in the chapter analysing causes of death. When comparing UK survival with the USA, UK dialysis patients had inadvertently been compared with the US cohort of the combined dialysis and transplant population (thus wrongly showing better outcomes in the USA).

- Death rates, as expected, increased with increasing age. There were significant differences between rates of death in the incident and prevalent cohorts for the age bands 45–64 and 65+ ($p < 0.05$). Gender had no effect on outcome.

- Cardiac disease was the most common cause of death in the renal population. This was independent of age (<65 or ≥65 years) although it appeared proportionately more common in the ≥65-year age group in the prevalent cohort ($p > 0.05$). In the prevalent cohort 1997-2001, cardiac disease accounted for significantly more deaths in transplant patients than those on dialysis (36.6% versus 30.7%, $p < 0.001$). Proportionately more patients with established renal failure (ERF) died from heart disease compared with the general population (32.5% versus 24%); renal patients were 1.4 times more likely to die from a cardiac cause.

- Infection related deaths were much more common in patients with ERF than the general population (16.8% versus 11.5%) representing a 1.5-fold (46%) increase. It was the second commonest cause of death in incident patients in the first 90 days (20%) and appeared more common in the ≥65 year olds although this did not reach statistical significance. In the one year after 90 days, 16% of deaths were infection related and there was no difference between the age groups. In the prevalent cohort, infection related deaths were similar in dialysis and transplant patients (17.6% versus 18.5%) and age appeared to have little effect.

- Incident and prevalent patients had similar causes of death in similar proportions. The length of time a patient has spent on renal replacement therapy (RRT) had no effect on the overall cause of death; 41% of patients on RRT for 3–5 years died from cardiac disease compared with 32% who had been on treatment for <3 years. With increasing time on RRT, however, proportionately fewer people withdrew from treatment as a cause of death (18%, 15%, 12% at 1 year after 90 days, <3 years and 3–5 years).

- Treatment withdrawal was an important cause of death. In the prevalent cohort, significantly more of the older patients withdrew from treatment ($p < 0.05$). In the smaller number of incident patients, a similar trend was observed, which did not attain statistical significance.

- At all ages, patients on RRT have a much higher relative risk of death compared with the general population. This is most pronounced in the young; 25–29 year olds with ERF were 42 times more likely to die from any cause in a given year compared with someone of the same age in the general population. The disparity diminished with longevity; there is only a 4-fold increase in risk of death in 80–84 year olds on RRT. The general population had lower proportions of death from

cardiac disease, but higher from malignancy.

- Underlying primary renal diagnosis affected death rates irrespective of age. Cystic/polycystic patients have the lowest rate of death, patients with malignancy the highest in both incident and prevalent cohorts. Using glomerulonephritis as a reference, all other primary diagnostic groups had significantly worse outcomes.

- If patients had cardiac disease on initiating RRT, 56% of the cohort died from a cardiac cause.

- Diabetics had significantly more cardiac deaths in the first 90 days compared with non-diabetics. Proportions were higher in the 1-year after 90-day incident and prevalent cohorts but this did not reach statistical significance. Rates of death were interestingly lower in the diabetics in the first 90 days compared with non-diabetics (319.4 versus 464.6/1000 patient years exposed). This may in part be due to the younger age at start of RRT of diabetics (68 versus 72 years) and their possible earlier start of treatment. However, the reverse was true in the 1 year after 90-day period when diabetics again had a younger age at start of treatment (64 and 71 years respectively), and in the prevalent cohort.

- The UK distribution of causes of death was similar when compared with other international Renal Registries. When assessing rates of death however, UK RRT patients had significantly lower death rates in all age groups than those in the USA. The comparisons were not adjusted for ethnicity. In the USA, the ethnic minorities on RRT are known to have better survival.

Introduction

Using UK Renal Registry data, 11,607 deaths were reported since the Registry was started in 1997, 6237 (54%) having a recorded cause coded from the European Dialysis and Transplant Association (EDTA) diagnostic list for causes of death (Appendix F). Whilst many other international renal registries have examined cause of death in prevalent patients, analysis of this in incident patients has only previously been reported in the USA.

Some centres have high data returns to the Registry regarding cause of death, whilst others return no information. Provision of this information is not mandatory. 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.

Methods

Adult patients aged 18 years and over, from England or Wales, were included in the analyses on cause of death. The data for all prevalent patients on RRT since the inception of the UK Renal Registry to 2001 with a recorded cause of death were analysed initially by treatment modality (dialysis or transplant) (Appendix F). An initial analysis was limited to centres with a high rate of return for cause of death. When compared with an analysis of all the cause of death data on the database, the percentages in corresponding EDTA categories remained unchanged so the latter data were included subsequently.

Incident and prevalent patients were analysed as separate cohorts in order to establish causes of death in different time periods. The incident cohort included all patients starting RRT since individual renal units joined the Registry, and causes of death at day 90 and 1 year after 90 days were analysed. Many international renal registries do not include the

first 90 days of RRT in their analysis whereas in the UK day 0 is recorded as the start of treatment. Analysing separately the time periods of 90 days, and 1 year after 90 days enables accurate comparisons with other countries. 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 their very low death rate. The prevalent cohort of patients was defined as those alive on 31 December 2000. The '2001' cohort was defined as those on RRT on or before 30 September 2000 and alive on 31 December 2001. Analysis of these patients provided larger numbers for analysis and comparisons of causes of death with the general population of England and Wales to be made.

To compare rates of death between incident (90 days and 1 year after 90 days) and prevalent patients a rate per 1000 patient years exposed was calculated. This is not entirely accurate in the 90-day incident cohort as we are looking at only approximately a three-month snapshot within a one-year period. However, examining death rates by patient days exposed is not something other registries quote as they exclude the first 90 day period from their analyses. Confidence intervals were calculated around the 90-day period and then converted to that of 1000 patient year equivalents.

Subgroup analysis for both incident and prevalent patients was performed examining the relationship of age, primary diagnosis and gender to the cause of death. For the incident cohort, an analysis of the interaction between co-morbidity at the start of RRT and cause of death was also undertaken together with effect of time on RRT. 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 (Appendix F, Table F.3.4).

The EDTA codes of death were grouped into the following categories (Table 18.30):

1. Cardiac disease
2. Cerebrovascular disease
3. Infection
4. Malignancy
5. Treatment withdrawal (ERF treatment stopped)
6. Others
7. Uncertain or not determined

Comparisons of the prevalent 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 the significance of proportional differences, and proportional hazard ratios, for comparisons between primary renal diagnoses.

Incident patients

The incident cohort of 6732 patients was analysed for cause of death within the first 90 days and for the period 1 year after 90 days. Two patients were excluded because of inconsistencies in the data. 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. Causes of death were also analysed for those who had survived at least 3 years on RRT (late deaths).

Analysis of deaths in the first 90 days

For this incident cohort there were a total of 679 deaths within the first 90 days (Table 18.1), of which 401 (59%) had a recorded cause. The single largest cause of death was cardiac disease (34.9% of those recorded). Proportionately, the causes of death were similar to those in the prevalent population (Tables 18.15 and 18.17).

Table 18.1. Cause of death by age in incident patients in the first 90 days

Cause of death	All Deaths	All % of those with data	<65 Deaths	<65 % of those with data	65+ Deaths	65+ % of those with data
Cardiac disease	140	34.9	41	41.8	99	32.7
Cerebrovascular disease	29	7.2	7	7.1	22	7.3
ERF treatment stopped	50	12.5	5	5.1	45	14.9
Infection	80	20.0	11	11.2	69	22.8
Malignancy	34	8.5	12	12.2	22	7.3
Others	27	6.7	10	10.2	17	5.6
Uncertain or not determined	41	10.2	12	12.2	29	9.6
Total with cause of death	401		98		303	
No cause of death sent	278		62		216	

When analysed by age group, there was little 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 cardiac causes (41.8% versus 32.7%; p = 0.52) and more of the older patients died of infection-related illnesses (22.8% versus 11.2%; p = 0.09) and treatment withdrawal (14.9% versus 5.1%; p = 0.08). Although the differences in proportions were large, significant differences on statistical testing were not found. This may be a consequence of small numbers.

The average death rate for all incident patients within the first 90 days was 437 per 1000 patient years exposed (pt yrs exp) (Table 18.2, Figure 18.1).

When the effect of primary diagnosis was analysed, patients with cystic/polycystic disease had the best outcome, with a rate of death of 78.7/1000 pt yrs exp (Table 18.3) and malignancy the poorest (1309.1/1000 pt yrs exp, p < 0.001). When using glomerulonephritis (GN) as a reference point and adjustment made for the effect of age (Table 18.4), cystic/polycystic patients had a non-significantly lower risk of death, and interstitial disease and pyelonephritic patients similar rates. All other primary diseases had a significantly higher risk of death. These findings were similar to those in the subsequent analysis of the prevalent cohort (Table 18.19) except the lower risk of death in cystic/ polycystic prevalent patients reached statistical significance and interstitial disease had a significantly higher risk (Hazard Ratio 1.97, p = 0.001). Women had a non-significant lower rate of death overall (422 versus 447; Table 18.5).

It is important to note the relevance of accuracy in the enrolment of patients for potentially long-term RRT 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.

Table 18.2. Death rate, by age, in incident patients in the first 90 days

Age group	Exposure Days	Exposure years	Deaths	Rate per 90 day period	Rate per 1000 exposed years
15–19	3865	10.6	0	0	0
20–24	10627	29.1	1	0.01	34.4
25–29	13808	37.8	0	0	0
30–34	21247	58.2	4	0.02	68.8
35–39	26583	72.8	7	0.02	96.2
40–44	27337	74.8	7	0.02	93.5
45–49	37168	101.8	16	0.04	157.2
50–54	46534	127.4	24	0.05	188.4
55–59	53353	146.1	46	0.08	314.9
60–64	63773	174.6	55	0.08	315.0
65–69	75095	205.6	122	0.15	593.4
70–74	83650	229.0	157	0.17	685.5
75–79	68490	187.5	134	0.18	714.6
80–84	26953	73.8	76	0.25	1029.9
85–89	8084	22.1	27	0.30	1219.9
90+	883	2.4	3	0.31	1240.9
Total	567450	1553.6	679	0.12	437.1

Age group	Exposure days	Exposure years	Deaths	Rate per 90 day period	Rate per 1000 exposed years
20–44	99602	272.7	19	0.02	69.7
45–64	200828	549.8	141	0.06	256.4
65+	263155	720.5	519	0.18	720.4

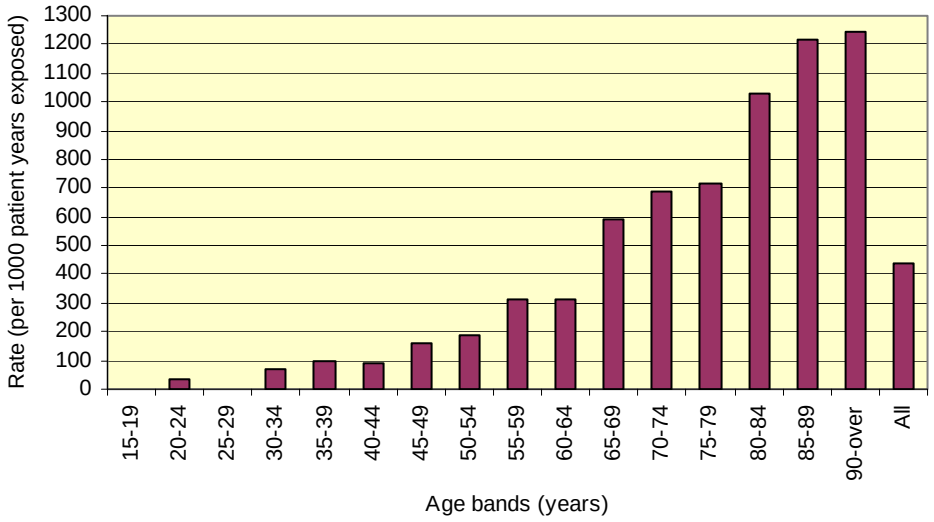

Figure 18.1. Death rate in incident patients in the first 90 days

Table 18.3. Death rate, by primary diagnosis, in incident patients in the first 90 days

Primary diagnosis	Exposure days	Exposure years	Deaths	Rate per 90 day period	Rate per 1000 exposed years
Amyloid	8362	22.9	21	0.226	917.3
Cystic/polycystic	37132	101.7	8	0.019	78.7
Diabetes	98261	269.0	82	0.075	304.8
Glomerulonephritis	58577	160.4	27	0.041	168.4
Interstitial	8836	24.2	4	0.041	165.3
Malignancy	11439	31.3	41	0.323	1309.1
Pyelonephritis	47478	130.0	34	0.064	261.6
Renal vascular disease	61178	167.5	100	0.147	597.0
Other	110176	301.6	198	0.162	656.4
Uncertain	126011	345.0	164	0.117	475.4
Total	567450	1553.6	679	0.108	437.1

Table 18.4. Risk of death by primary diagnosis compared with GN, age adjusted, in the first 90 days

Primary diagnosis	Ref with GN	Lower 95% CI	Upper 95%CI	p value
Amyloid	4.16	2.35	7.37	<0.001
Cystic/polycystic	0.48	0.22	1.05	0.067
Diabetes	1.67	1.08	2.58	0.021
Interstitial	0.81	0.28	2.32	0.699
Malignancy	4.85	2.98	7.90	<0.001
Pyelonephritis	1.24	0.75	2.05	0.413
Renal vascular disease	2.18	1.42	3.34	<0.001
Other	2.73	1.83	4.10	<0.001
Uncertain	1.81	1.20	2.73	0.005

Ref with GN, Hazard Ratio referenced against glomerulonephritis adjusted for age.

Table 18.5. Death rate, by gender, in incident patients in the first 90 days

	Exposure years	Deaths	Rate per 1000 exposed yrs
Male	951.7	425	446.6
Female	601.9	254	422.0
Total	1553.6	679	437.1

Analysis of deaths in the first year after 90 days

There were 899 deaths in the 1-year after 90 days analysis (Table 18.6), with a recorded cause in 483 (54%) patients. The overall rate of death was 185/1000 pt yrs exp (Table 18.7), contrasting with 437/1000 pt yrs exp within the first 90 days (Table 18.2); these figures increased with increasing patient age (Figure 18.2).

Table 18.6 shows that cardiac disease, 29% of cohort deaths, remained the most common cause of death, but proportionately fewer deaths in those aged less than 65 years were cardiac than in the 90 day cohort (29% versus 42%). Similar to the 90-day analysis, treatment withdrawal was more common in those aged over 65 years (21.1% versus 13.3%, p = 0.24), although, as a group, withdrawal was more common in the 1 year after 90 days group (18.4% versus 12.5% respectively). Infection-related deaths were similar in both age groups (17.6% versus 15.1%): 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 (11% versus 23%).

In the analysis of the effect of primary diagnosis, malignancy again appeared to carry the highest rate of death, and cystic/polycystic the lowest (Table 18.8). Results were similar to those for incident patient deaths at 90 days (Table 18.3) but the rates were lower at 1 year after 90 days in all groups except interstitial disease. This may in part be due to having to calculate rates per 1000 patient years from a 90 day censored period in the earlier incident cohort. In the case of interstitial disease, the fact that there were only four deaths in the 90-day cohort may have given an artificially low death rate. Ratios using glomerulonephritis as a reference were similar in both time periods except interstitial disease and malignancy ratios were lower in the first 90 days (0.81 v 2.33; and 4.85 v 6.27 respectively). The reverse was true of amyloidosis with a lower ratio at 1 year after 90 days (4.16 v 2.86). Although not significant, men had a lower rate of death than women (178 versus 195/1000 pt yrs exp; Table 18.10).

Comparing the first 90, and 1 year after 90 days, rates of death were higher in the first 90 days than 1 year after 90 days, especially from age band 40–44 years upwards. Using USA age banding, rates of death at 90 days were two and a half times that at 1 year after 90 days in those aged 65 and above (720 versus 292/1000 pt yrs exp). Overall, the rate of death was lower in the 1 year after 90 days (185/1000 pt yrs exp), compared with the first 90 days (437/1000 pt yrs exp) (Figure 18.3).

Table 18.6. Cause of death, by age, in incident patients at 1 year + 90 days

Cause of death	All deaths	All % of those with data	<65 deaths	<65 % of those with data	65+ deaths	65+ % of those with data
Cardiac disease	139	28.8	47	28.5	92	28.9
Cerebrovascular disease	42	8.7	15	9.1	27	8.5
ERF treatment stopped	89	18.4	22	13.3	67	21.1
Infection	77	15.9	29	17.6	48	15.1
Malignancy	49	10.1	14	8.5	35	11.0
Others	34	7.0	12	7.3	22	6.9
Uncertain or not determined	53	11.0	26	15.8	27	8.5
Total with cause of death	483		165		318	
No cause of death sent	416		123		293	

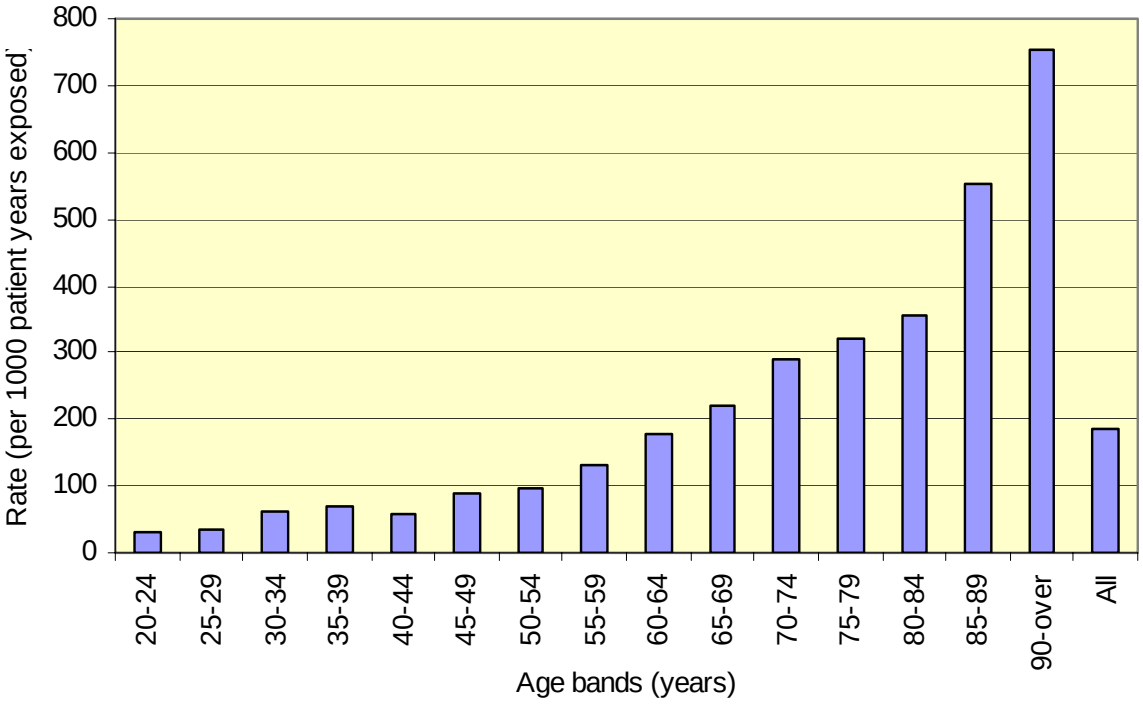

Figure 18.2. Death rate in incident patients in the 1 year after 90 days

Table 18.7. Death rate, by age, in incident patients at 1 year + 90 days

Age group	Exposure years	Deaths	Rate per 1000 exposed years
15–19	36.0	0	0
20–24	99.1	3	30.3
25–29	138.3	5	36.1
30–34	191.9	12	62.5
35–39	244.5	17	69.5
40–44	257.2	15	58.3
45–49	336.3	30	89.2
50–54	431.6	42	97.3
55–59	480.3	64	133.2
60–64	560.5	100	178.4
65–69	630.6	140	222.0
70–74	678.9	198	291.6
75–79	535.1	172	321.5
80–84	196.3	70	356.6
85–89	49.0	27	551.6
90+	5.3	4	753.5
Total	4870.7	899	184.6

Age group	Exposure years	Deaths	Rate per 1000 exposed years
20–44	931.0	52	55.9
45–64	1808.7	236	130.5
65+	2095.1	611	291.6

Table 18.8. Death rate, by primary diagnosis, in incident patients at 1 year + 90 days

Primary Diagnosis	Exposure years	Deaths	Rate per 1000 exposed years
Amyloid	65.4	19	290.4
Cystic/polycystic	341.8	18	52.7
Diabetes	875.4	179	204.5
Glomerulonephritis	537.3	43	80.0
Interstitial	73.7	17	230.7
Malignancy	70.7	55	777.6
Pyelonephritis	431.5	56	129.8
Renal vascular disease	515.4	109	211.5
Other	864.3	200	231.4
Uncertain	1095.1	203	185.4
Total	4870.7	899	184.6

Table 18.9. Risk of death by primary diagnosis compared with GN, age adjusted, 1 year + 90 days

Primary diagnosis	Ref with GN	Lower 95% CI	Upper 95% CI	P value
Amyloid	2.86	1.67	4.92	<0.001
Cystic/polycystic	0.63	0.36	1.11	0.109
Diabetes	2.33	1.67	3.25	<0.001
Interstitial	2.33	1.33	4.09	0.003
Malignancy	6.27	4.20	9.35	<0.001
Pyelonephritis	1.33	0.90	1.99	0.158
Renal vascular disease	1.68	1.18	2.40	0.004
Other	2.13	1.53	2.97	<0.001
Uncertain	1.57	1.13	2.19	0.008

Table 18.10. Death rate, by gender, in incident patients at 1 year + 90 days

	Exposure years	Deaths	Rate per 1000 exposed years
Male	2996.0	534	178.2
Female	1874.7	365	194.7
Total	4870.7	899	184.6

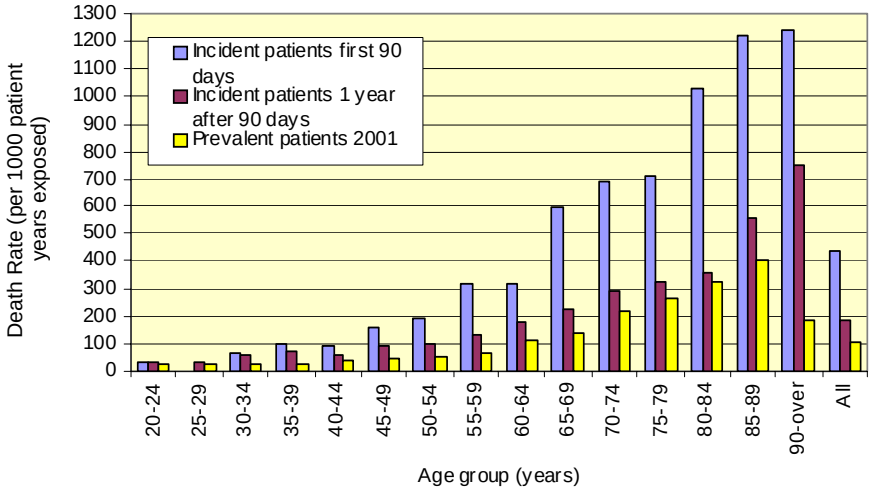

Figure 18.3. Death rates in incident and prevalent patients with ERF

Table 18.11 analysed cause of death by time on RRT (less than 3 years and 3–5 years) with age under 65 or 65 and over. 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 (18%, 15%, 12% at 1 year after 90 days, less than 3 years and 3–5 years respectively; Figure 18.4). Infection was an important cause of death in both age groups though less so in the over 65s who had been on dialysis for three or more years. This may in part be due to the small numbers within the group as a whole.

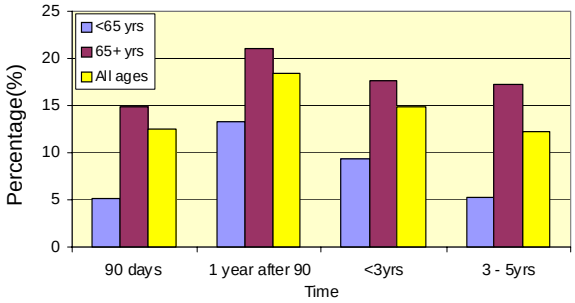

Figure 18.4. Treatment withdrawal over time in incident patients

When comparing incident and prevalent patients, causes of death were similar (Tables 18.1, 18.6, 18.15 and 18.17),

Table 18.11. Cause of death, by time, on RRT at 3 years

	All ages	<65		65+	
Cause of death	**3–5 yrs on RRT**	**3–5 yrs on RRT**	**<3 yrs on RRT**	**3–5 yrs on RRT**	**<3 yrs on RRT**
Cardiac disease	37 (41.1%)	16 (42.1%)	148 (34.4%)	21 (40.4%)	271 (30.2%)
Cerebrovascular disease	7 (7.8%)	5 (13.2%)	38 (8.8%)	2 (3.8%)	70 (7.8%)
ERF treatment stopped	11 (12.2%)	2 (5.3%)	40 (9.3%)	9 (17.3%)	158 (17.6%)
Infection	15 (16.7%)	10 (26.3%)	74 (17.2%)	5 (9.6%)	162 (18.0%)
Malignancy	6 (6.7%)	3 (7.9%)	37 (8.6%)	3 (5.8%)	82 (9.1%)
Others	7 (7.8%)	1 (2.6%)	41 (9.5%)	6 (11.5%)	66 (7.3%)
Uncertain/not determined	7 (7.8%)	1 (2.6%)	52 (12.1%)	6 (11.5%)	89 (9.9%)
Total	90	38	430	52	898
No cause of death sent	64	21	305	43	775

although age had an effect especially in relation to treatment withdrawal. Proportionately, there were higher rates of treatment withdrawal and infection in prevalent patients aged less than 65 when compared with incident patients who died in the first 90 days.

Effect of co-morbidity

The influence of co-morbidity on death was assessed in the incident population of RRT patients. The number of patients with both co-morbidity at the start of RRT and cause of death recorded were 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 468 deaths in the patient group with completed co-morbidity. Of these, 277 patients (59%) had a cause of death recorded, a similar level of completion to both the incident and prevalent groups.

Comparison of cardiac and peripheral vascular co-morbidity

Because of the limited data, co-morbidity was grouped into:

1. Cardiac disease
2. Generalised (mainly peripheral) vascular disease
3. Either of these groups
4. Patients recorded as having no co-morbidity present.

In Table 18.12, of those patients recorded as having cardiac disease at the time of starting RRT (n = 167), only 100 (59.8%) also had a recorded a cause of death and of these, 56% (n = 56) died from a cardiac cause. In comparison, of patients recorded as having no cardiac disease (n = 301; 177 also with a recorded cause of death), only 18.1% (n = 32) died from cardiac causes. In this group, the causes of death were more widely distributed with treatment withdrawal being the commonest cause. The presence of generalised vascular disease at the start of RRT (Table 18.13) had less impact on the rate of cardiac death, only slightly increasing the risks (35.7% v 29.6%).

In those patients without cardiac or circulatory disease on starting RRT (Table 18.14), treatment withdrawal was the most common cause of death (23.2%), although causes were generally evenly distributed across all the categories. It is interesting to note that the presence of underlying cardiac or generalised vascular disease did not appear to affect the proportion of cerebrovascular deaths.

Table 18.12. Cardiac co-morbidity and cause of death

	No cardiac disease	No %	Yes cardiac disease	Yes %	Total Number	Total %
Cardiac disease	32	18.1	56	56.0	88	31.8
Cerebrovascular disease	11	6.2	7	7.0	18	6.5
ERF treatment stopped	47	26.6	9	9.0	56	20.2
Infection	33	18.6	10	10.0	43	15.5
Malignancy	17	9.6	5	5.0	22	7.9
Others	26	14.7	6	6.0	32	11.6
Uncertain or not determined	11	6.2	7	7.0	18	6.5
Total	177		100		277	
Cause of death not sent	124		67		191	

Table 18.13. Generalised vascular co-morbidity and cause of death

	No vascular disease	No %	Yes vascular disease	Yes %	Total number	Total %
Cardiac disease	53	29.6	35	35.7	88	31.8
Cerebrovascular disease	11	6.1	7	7.1	18	6.5
ERF treatment stopped	33	18.4	23	23.5	56	20.2
Infection	33	18.4	10	10.2	43	15.5
Malignancy	18	10.1	4	4.1	22	7.9
Others	21	11.7	11	11.2	32	11.6
Uncertain or not determined	10	5.6	8	8.2	18	6.5
Total	179		98		277	
Cause of death not sent	121		70		191	

Table 18.14. Cardiac or peripheral vascular co-morbidity and cause of death

	None	None %	Either	Either %	Total number	Total %
Cardiac disease	21	16.8	67	44.1	88	31.8
Cerebrovascular disease	8	6.4	10	6.6	18	6.5
ERF treatment stopped	29	23.2	27	17.8	56	20.2
Infection	27	21.6	16	10.5	43	15.5
Malignancy	15	12.0	7	4.6	22	7.9
Others	17	13.6	15	9.9	32	11.6
Uncertain or not determined	8	6.4	10	6.6	18	6.5
Total	125		152		277	
Cause of death not sent	89		102		191	

Prevalent Patients

Prevalent Patients 1997–2001

The 6237 deaths with a recorded cause on the database since the inception of the UK Renal Registry were analysed. 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%; 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 (Table F.4.3 Appendix). The EDTA codes were regrouped as outlined in the methods, and cardiac disease remained the most common cause of death in both the transplant and dialysis populations (37% and 31% respectively; Table 18.15), irrespective of age (Table 18.16). Using the two-tailed Student 't' test, the proportion of cardiac deaths appeared significantly 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.

Table 18.15. Cause of death by treatment modality

	Dialysis No.	Dialysis %	Transplant No.	Transplant %	Total No.	Total %	p value
Cardiac disease	1511	30.7	480	36.6	1991	31.9	<0.001
Cerebrovascular disease	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		1310		6237		

Table 18.16. Cause of death by modality and age

	Trans <55		Trans 55+		Total trans		Dialysis <65		Dialysis =65		Total dialysis	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Cardiac disease	220	37.2	260	36.2	480	36.6	588	33.3	923	29.2	1511	30.7
Cerebrovascular disease	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		718		1310		1767		3160		4927	

Prevalent patients in 2001 and comparison with the general population

There were a total of 1271 deaths in this cohort of 12855 patients, 572 (45%) of which had a recorded cause. In total, 63% of deaths occurred in those patients aged over 65 years. Cardiac death was the most common cause (32.5%) irrespective of age group under or over 65 years (Table 18.17). Treatment withdrawal was significantly ($p < 0.05$) more common in those aged over 65 than those under 65 (17.1% versus 7.7% respectively).

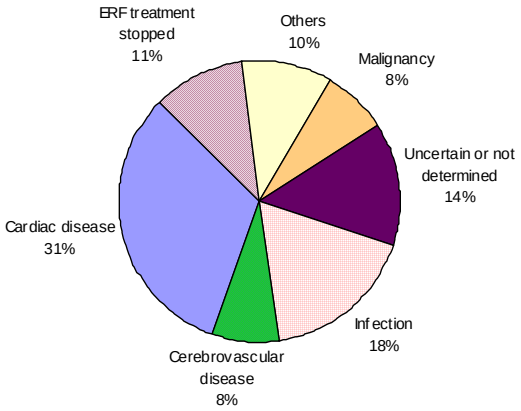

Figure 18.5. Cause of death in prevalent patients 1997-2001

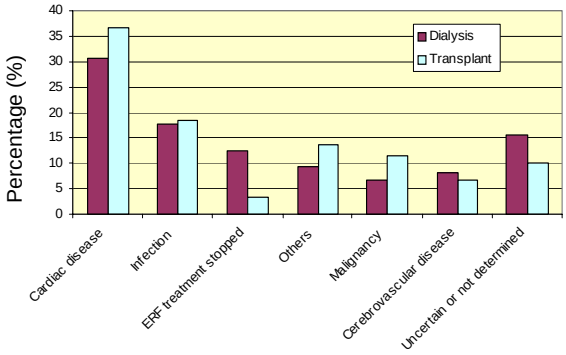

Figure 18.6. Cause of death in prevalent patients by modality

Table 18.17. Cause of death in prevalent patients, by age

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
Cardiac disease	186	32.5	80	36.2	106	30.2
Cerebrovascular disease	40	7.0	19	8.6	21	6.0
ERF treatment stopped	77	13.5	17	7.7	60	17.1
Infection	96	16.8	36	16.3	60	17.1
Malignancy	46	8.0	23	10.4	23	6.6
Others	66	11.5	28	12.7	38	10.8
Uncertain or not determined	61	10.7	18	8.1	43	12.3
Total with cause of death	572		221		351	
No cause of death sent	699		249		450	

Table 18.18. Rate of death, by gender and primary diagnosis, in prevalent patients

EDTA group	Exposure years	Deaths	Rate per 1000 pt years exposed
Amyloid	81.9	13	158.7
Cystic/polycystic	1217.9	73	59.9
Diabetes	1277.0	236	184.8
Glomerulonephritis	1956.2	124	63.4
Interstitial	158.7	28	176.5
Malignancy	51.9	26	500.6
Pyelonephritis	1742.6	123	70.6
Renal vascular disease	1103.8	154	139.5
Other	1783.6	182	102.0
Uncertain	2809.8	312	111.0
Total	12183.4	1271	104.3
Male	7605.9	784	103.1
Female	4885.3	487	99.7

The rates of death by primary diagnosis (Table 18.18) and age (Table 18.20) were calculated; not unexpectedly, death rate increased with increasing age, the highest rate of death being seen in those with underlying malignancy (501/1000 pt yrs exp). The three lowest rates were seen in those with cystic/polycystic disease (60/1000 pt yrs exp), glomerulonephritis (63/1000 pt yrs exp) and pyelonephritis (71/1000 pt yrs exp). A comparison of primary diagnoses with glomerulonephritis (GN) as the reference (Table 18.19) showed that all other primary diseases had a significantly different rate of death except pyelonephritis and 'uncertain'. Cystic/polycystic disease had a better, and pyelonephritis and 'uncertain' a similar, outcome related to GN, whereas other conditions had a significantly poorer one. Gender differences were not significant, with rates of death 103/1000 pt yrs exp in males compared with 100 in females (Table 18.18).

Table 18.19. Risk of death by primary diagnosis compared with GN, age adjusted, in prevalent patients

EDTA group	Ref with GN	Lower 95% CI	Upper 95% CI	p value
Amyloid	1.97	1.11	3.48	0.021
Cystic/polycystic	0.72	0.54	0.96	0.024
Diabetes	2.36	1.90	2.94	<0.001
Interstitial	1.97	1.31	2.97	0.001
Malignancy	3.75	2.45	5.74	<0.001
Pyelonephritis	0.99	0.77	1.27	0.941
Renal vascular disease	1.29	1.01	1.64	0.038
Other	1.28	1.01	1.60	0.038
Uncertain	1.19	0.97	1.47	0.104

Ref with GN, Hazard Ratio referenced against glomerulonephritis adjusted for age

Table 18.20. Death rate, by age, for prevalent patients: comparison with the general population

Age	E&W Pop mid-98 (000)	E&W deaths	E&W /1000 pop	Ren Reg exposed years	Expected no. of deaths	RenReg deaths	RenReg deaths per 1000	Observed Expected Ratio
20–24	3084.2	1832	0.6	122.9	0.1	3	24.4	41.1
25–29	3883.4	2364	0.6	354.2	0.2	9	25.4	41.8
30–34	4294	3187	0.7	648.8	0.5	15	23.1	31.2
35–39	4035.4	4345	1.1	1002.3	1.1	28	27.9	26.0
40–44	3479.8	5643	1.6	1090.4	1.8	40	36.7	22.6
45–49	3403.8	8331	2.4	1142.1	2.8	53	46.4	19.0
50–54	3500.1	14132	4.0	1355.1	5.5	70	51.7	12.8
55–59	2709.4	18481	6.8	1457.9	9.9	100	68.6	10.1
60–64	2489.8	27244	10.9	1330.8	14.6	152	114.2	10.4
65–69	2314.6	40735	17.6	1233.4	21.7	172	139.5	7.9
70–74	2085.8	62384	29.9	1122.8	33.6	241	214.6	7.2
75–79	1781.3	88977	50.0	777.8	38.9	207	266.1	5.3
80–84	1089.6	88123	80.9	424.1	34.3	136	320.7	4.0
85–89	669	89474	133.7	104.8	14.0	42	400.7	3.0
90+	347.7	76482	220.0	16.1	3.5	3	185.9	0.9
Total	39167.9	531734	13.6	12183.4	165.4	1271	104.3	7.7

Table 18.20 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. The observed number of deaths on RRT 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 18.20 and Figure 18.7). The RR of dying for 20–24 year olds on RRT was 41.1 compared with 4.0 in the 80–84 year-olds.

The same procedure was repeated looking at dialysis patients alone (Figure 18.8). This showed that the risk of death in a dialysis patient from all cause mortality was very much greater compared with the general population and more so than when transplant patients were included in the analysis. The

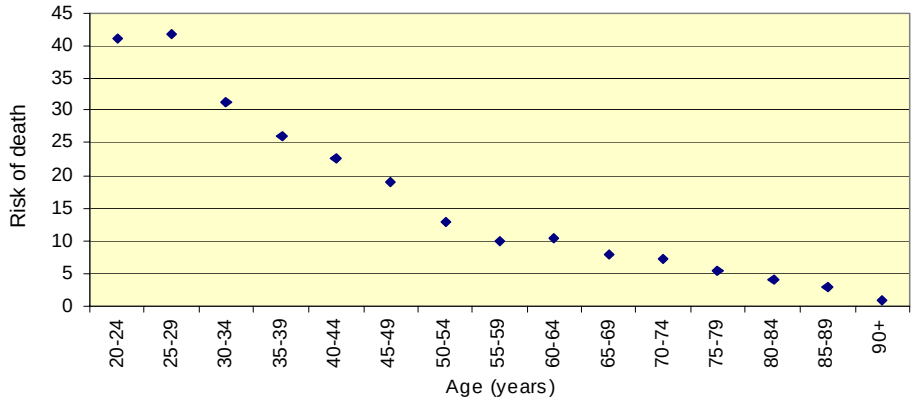

Figure 18.7. Relative risk of death in ERF patients

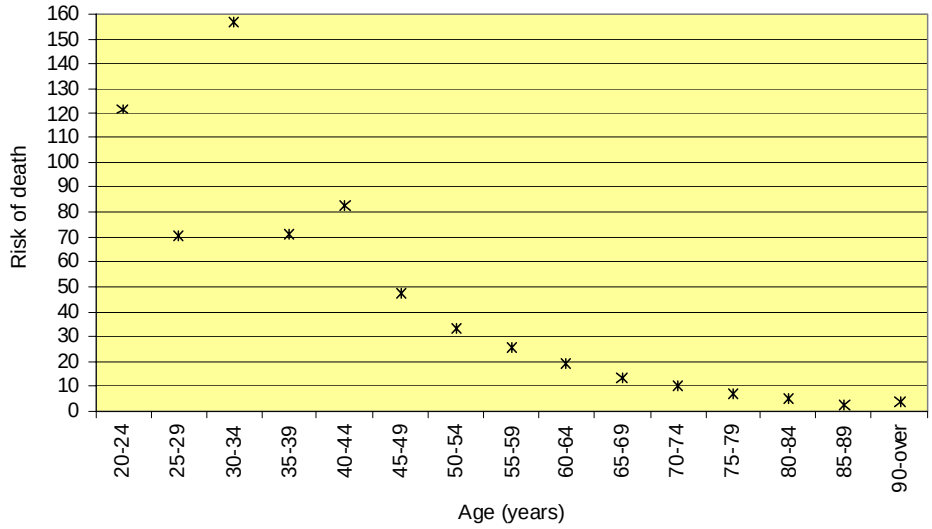

Figure 18.8. Relative risk of death in dialysis patients

risks were again highest in the young such that a 20–24 year old on dialysis had a RR of death of 121.

Causes of death in the ERF population were also compared with those in the general population of England & Wales as supplied by the ONS (Table 18.21). In the general population, the three most common causes of death were classified as 'other' (27.8%), malignancy (25.2%) and cardiac 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. This category doesn't appear in the EDTA coding for cause of death. When compared with the ERF population, proportionately more renal patients died of a cardiac cause (32.5% versus 24%), reflecting a 35% or 1.4-fold increased risk of cardiac death in these patients (Figure 18.9). Similarly, infection was more common as a cause of death in renal patients (16.8% versus 11.5%) reflecting a 46% 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 (8.0% versus 25.2%, a 68% or threefold decreased risk). Of note, some differences may be related to the fact that the ONS data includes deaths in people from age 15 whereas our renal data starts from age 18.

Table 18.21. Population deaths, by sex and age

	Sex	No. 15–64	% 15–64	No. 65+	% 65+	No. Total	% Total
Cardiac disease	All	16,475	19.0	111,559	25.0	128,034	24.0
Cerebrovascular disease	All	3,968	4.6	48,491	10.9	52,459	9.8
Diabetes	All	860	1.0	4,902	1.1	5,762	1.1
Infection	All	4,187	4.8	57,215	12.8	61,402	11.5
Malignancy	All	32,745	37.7	101,495	22.7	134,240	25.2
Other	All	26,445	30.4	121,837	27.3	148,282	27.8
Uncertain or not determined	All	2,180	2.5	676	0.2	2,856	0.5
Total	All	86,860	100.0	446,175	100.0	533,035	100.0

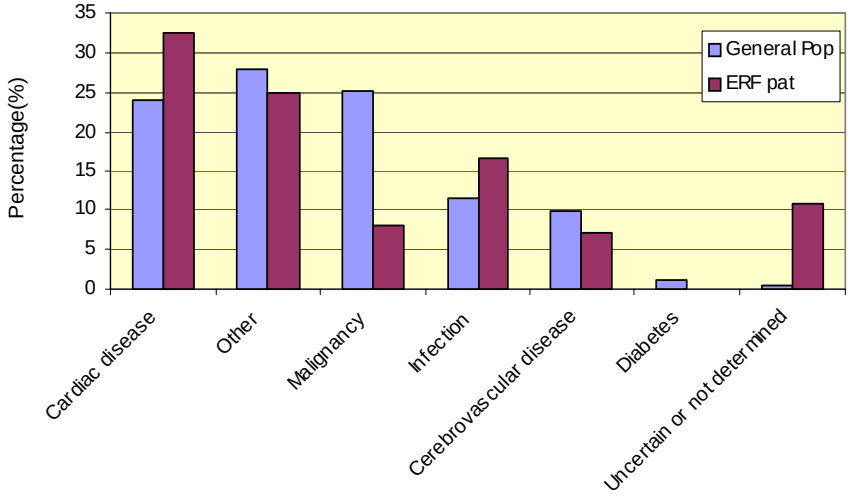

Figure 18.9. Causes of death in the general and ERF population

International comparisons of prevalent patients

Comparisons were possible with data from European, North American and Australasian Registries.[1–6]

USA

Using data from the USA Renal Data System (USRDS) 2001 annual report,[1] rates of death for UK patients were compared by age band (Tables 18.22 and 18.23). Rates of death in the UK were significantly lower than in the USA in all age bands in both the combined dialysis and transplant cohort and dialysis patients alone ($p < 0.05$) with the exception of 20-44 year old dialysis patients where rates were similar. The differences, especially in the elderly, may be due to the fact that in the USA, patients with very high rates of co-morbidity (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.

In the USRDS report, causes of death categories were divided into many subgroups within the cardiac causes. With the larger patient number, cardiac deaths were split by myocardial infarction, cardiac arrest, cause unknown and cardiac other. The data showed that cardiac disease was the most common cause of death across all RRT modalities, although most transplant patients died of unknown cause (31.7 per 1000 pt yrs exp).

Table 18.22. Death rate, by age, for all prevalent patients and comparison with the USA

Age	E&W Pop mid-98 (000)	E&W Deaths	E&W/ 1000 pop	Ren Reg exposure years	Ren Reg deaths	UK RR deaths per 1000	USA ERF deaths per 1000	UK/USA
20–44	18,776.8	17,371	0.9	3218.4	95	29.5	56.1	0.53
45–64	12,103.1	68,188	5.6	5285.8	375	70.9	136.3	0.52
65+	8,288.0	446,175	53.8	3679.1	801	217.7	340.4	0.64
Total	39,167.9	531,734	13.6	12183.4	1271	104.3	179.3	0.58

Table 18.23. Death rate, by age, for dialysis prevalent patients and comparison with the USA

Age	E&W Pop mid-98 (000)	E&W Deaths	E&W/ 1000 pop	Ren Reg exposure years	Ren Reg deaths	UK RR deaths per 1000	USA ERF deaths per 1000	UK/USA
20–44	18,776.8	17,371	0.9	911.1	60	86.2	93.7	0.92
45–64	12,103.1	68,188	5.6	1,991.9	242	139.7	179.3	0.78
65+	8,288.0	446,175	53.8	2,124.7	689	261.9	360.3	0.73
Total	39,167.9	531,734	13.6	5,027.7	991	195.9	239.0	0.82

Canada

The 2001 Canadian report, based on data from RRT patients in 1999,[2] provided details on 2652 deaths in 26,209 prevalent patients (10.1%). Cardiac disease remained the most common cause of death (38.2%), although the proportion was higher than in UK patients (32.5%). 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 (13.5%). Infection was believed responsible for only 9.7% of deaths, much less common than the 16.8% 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.[4] The proportion of deaths from infective causes was similar to the UK Registry figures (18% versus 16.8%), but other diagnostic categories were not suitable for direct comparison.

Australia and New Zealand

In the combined Australia and New Zealand Registry report,[5] deaths were 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 proportion of cardiac deaths in Australia was higher than in England & Wales (46% versus 33%). 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.[6,7] 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 18.10), followed by infection and malignancy in decreasing order of frequency. All these data were comparable with the results from the UK (31% and 37% respectively).

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 co-morbidity response. Prevalent and incident patients were assessed separately. There were 548 incident diabetic patients who died, of whom 52 had diabetes as co-morbidity.

Incident patients with diabetes

In the incident patients, diabetics had a lower rate of death in the first 90 days than non-diabetics (Table 18.24), possibly because of their younger age at start of RRT (68 versus 72 years). Of the 679 deaths in the first 90 days, only 94 (14%) occurred in patients with diabetes. Of these, only 58 had a recorded cause of death. Diabetic patients had a significantly higher proportion of deaths from cardiac disease than non-diabetics (60% versus 31%, $p < 0.01$; Table 18.25).

In the 1 year after 90 days period (Table 18.26), the death rate was higher in diabetics than non-diabetics (213 versus 178/1000 pt yrs exp respectively) despite their younger average age at start of RRT (64 versus 71

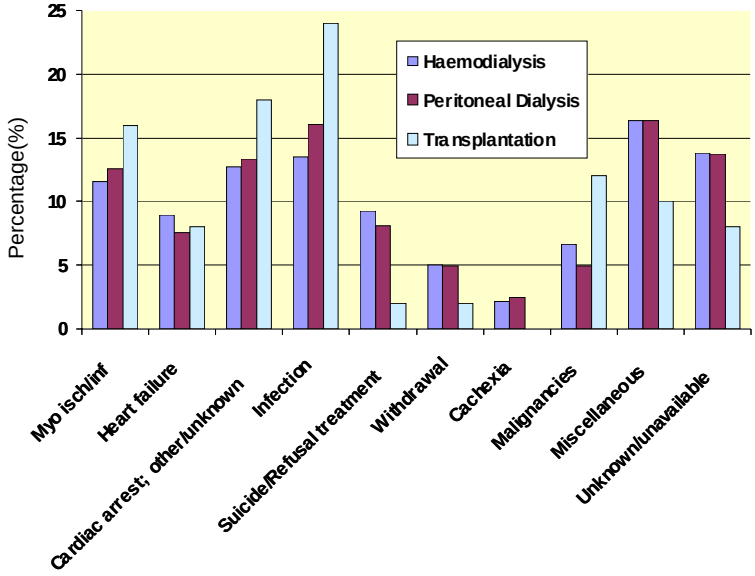

Figure 18.10. ERA-EDTA causes of death
Myo isch/inf = myocardial ischaemia/infarction

Table 18.24. Death rate, by diabetes, in incident patients at 90 days

	Exposure days	Exposure years	Deaths	Rate/ 90 day period	Rate/1000 yrs exposed	Lower 95% CI	Upper 95% CI
Non-diabetics	459952	1259.3	585	0.11	464.6	429.1	500.0
Diabetics	107498	294.3	94	0.08	319.4	257.4	381.4

Table 18.25. Cause of death, by diabetes, in incident patients at 90 days

	Non-diabetic Number	Non-diabetic %	Diabetic Number	Diabetic %	Total Number	%	p	Adjust p
Cardiac disease	105	30.6	35	60.3	140	34.9	<0.001	<0.001
Cerebrovascular disease	27	7.9	2	3.4	29	7.2	0.23	NS
ERF treatment stopped	47	13.7	3	5.2	50	12.5	0.07	NS
Infection	75	21.9	5	8.6	80	20.0	0.02	NS
Malignancy	34	9.9	0	0	34	8.5	0.01	NS
Others	22	6.4	5	8.6	27	6.7	0.54	NS
Uncertain or not determined	33	9.6	8	13.8	41	10.2	0.33	NS
Total	343		58		401			
No data	242		36		278			

NS, not significant

Table 18.26. Death rate, by diabetes, in incident patients at 1 year after 90 days

	Exposure years	Deaths	Rate/1000 yrs exposed	Lower 95% CI	Upper 95% CI
Non-diabetics	3920.2	697	177.8	165.8	189.8
Diabetics	950.5	202	212.5	186.5	238.5

years). Again, cardiac death was more common in the diabetic patients but this did not reach statistical significance (35% versus 27%, p = 0.44; Table 18.27). The only statistically significant difference was the lower proportion of diabetics dying from cancer (p = 0.02).

Prevalent patients with diabetes

Of the 1271 prevalent patients in Table 18.28, 255 (20%) were diabetic, and their rate of death was significantly higher than that of non-diabetics (189 versus 94/1000 pt yrs exp, p < 0.01). Of these diabetics, 123 (48%) had a cause of death recorded. In analysing those with data (Table 18.29), diabetics had a higher proportion of cardiac deaths compared with non-diabetics (41% versus 30%); this did not reach statistical significance.

Conclusion

The UK analysis of causes of death in patients on RRT confirm the analyses by other national Renal Registries, that cardiac disease is the most common cause of death in patients on RRT. This was independent of age although it appeared proportionately more common in the ≥65-year age group (p > 0.05). There were significant differences in the proportions of deaths from cardiac

Table 18.27. Cause of death, by diabetes, in incident patients at 1 year after 90 days

Cause of death	Non-diabetic Number	Non-diabetic %	Diabetic Number	Diabetic %	Total Number	%	p	Adjust p
Cardiac disease	96	26.7	43	35.0	139	28.8	0.08	NS
Cerebrovascular disease	27	7.5	15	12.2	42	8.7	0.11	NS
ERF treatment stopped	66	18.3	23	18.7	89	18.4	0.93	NS
Infection	58	16.1	19	15.4	77	15.9	0.86	NS
Malignancy	45	12.5	4	3.3	49	10.1	0.004	0.024
Others	29	8.1	5	4.1	34	7.0	0.14	NS
Uncertain or not determined	39	10.8	14	11.4	53	11.0	0.87	NS
Total	360		123		483			
No cause of death sent	337		79		416			

NS, not significant

Table 18.28. Death rate for prevalent diabetic patients

	Exposure years	Deaths	Rate/1000 yrs exposed	Lower 95% CI	Upper 95% CI
Non-diabetics	10835.0	1016	93.8	88.3	99.3
Diabetics	1348.41	255	189.1	168.2	210.0

Table 18.29. Effect of diabetes on cause of death in prevalent patients

Cause of death	Non-diabetic Number	Non-diabetic %	Diabetic number	Diabetic %	Total Number	Total %	p	Adjust p
Cardiac disease	136	30.3	50	40.7	186	32.5	0.03	NS
Cerebrovascular disease	25	5.6	15	12.2	40	7.0	0.01	NS
ERF treatment stopped	64	14.3	13	10.6	77	13.5	0.29	NS
Infection	71	15.8	25	20.3	96	16.8	0.24	NS
Malignancy	41	9.1	5	4.1	46	8.0	0.07	NS
Others	61	13.6	5	4.1	66	11.5	<0.01	<0.05
Uncertain or not determined	51	11.4	10	8.1	61	10.7	0.30	NS
Total	449		123		572			
No cause of death sent	567		132		699			

NS, not significant

disease in the dialysis and transplant prevalent cohorts, 30.7% in the dialysis group compared with 36.6% in the transplant group ($p < 0.001$). Although cardiac disease appeared more common in the diabetic population, this didn't reach statistical difference except in the first 90 days. This may in part be due to the small numbers involved making significant differences harder to prove, and the younger age at start of treatment in diabetics.

Death rates, as expected, increased with increasing age and there were significant differences between incident and prevalent

cohorts with the highest rates occurring in the first 90 days. Death rates were also similar in the age group 20–44 years amongst patient cohorts, but there were significant differences for the age bands 45–64 and 65+ in the incident and prevalent cohorts. The very much higher rate in the first 90 days may be due to the fact there is misdiagnosis/misclassification of some acute renal failure patients as chronic. Likewise, there may be a significant number of chronic patients who, referred late to a nephrologist, require RRT imminently, and it is known these patients have a poorer prognosis. Most other international renal registries do not include the first 45–90 days in their analyses thus excluding this period of high death rates. As a consequence, for comparative purposes, it is important to look at our 1 year after 90-day death rates. In the younger age group, 20–44 years, these effects seem to have less impact and it may be related to their relatively better underlying general health and better co-morbidity. More work would need to be done to look at these cases individually, to look for differences between the survivors and non-survivors.

Gender did not appear to have any statistically significant impact on death rates though there may have been a tendency for females to have a better outcome, particularly in incident patients.

Incident and prevalent patients had similar causes of death in similar proportions. Except for treatment withdrawal, the length of time a patient has spent on RRT had no effect on the overall main cause of death; 41% of patients on RRT for 3–5 years died from cardiac disease compared with 32% who had been on treatment for <3 years. With increasing time on RRT, however, proportionately fewer people withdrew from treatment as a cause of death (18%, 15%, 12% at 1 year after 90 days, <3 years and 3–5 years).

Treatment withdrawal was an important cause of death in both incident and prevalent cohorts, especially in the older age group. As patients get older, they tend to have more associated co-morbidity and this may well lead to stopping treatment, especially in the first 90 days when dialysis may prove to be problematic. There was also a significant difference in the proportion of transplant patients withdrawing from treatment compared with those on dialysis (3.3% and 12.5% respectively, $p < 0.001$). Transplant patients often die with a functioning graft so it would only be the small number of patients with a failing transplant who did not want to go back onto dialysis that would potentially fall into this category. Age had no impact in the transplant cohort.

When compared with the general population of England & Wales, cardiac deaths were proportionately more common in patients on RRT – a 35% increase. This may be a reflection of the co-morbidity present at the start of renal replacement, the ageing RRT population and the effect of ERF itself.

Infection-related deaths were much more common in patients with established renal failure than the general population (16.8% versus 11.5%) representing a 1.5-fold increase. It was the second commonest cause of death in incident patients and appeared more common in the cohort aged ≥65 years. In the prevalent cohort, similar proportions of death were attributable to infection in both the dialysis and transplant patients with little effect of age. These deaths will be related to a combination of factors, including importantly, immunosuppression induced by renal failure itself and immunosuppressive drugs used in transplant and some dialysis patients. Infections related to neck lines, and to a lesser extent PD catheters, will also play an important role.

In those patients with co-morbidity data and a recorded cause of death, 56% of patients with cardiac disease on starting RRT died of a cardiac cause. Generalised vascular disease did not appear to affect the risk of dying from cardiac or cerebrovascular disease. Unfortunately, inadequate co-morbidity data meant we were unable to assess the impact of individual categories on cause of death, and in particular, smoking

status was very poorly recorded.

The underlying primary renal diagnosis had a significant effect on death rate, irrespective of age. Those patients with malignancy had the poorest outcomes, whereas cystic/polycystic patients had the best. Pyelonephritic patients had comparable rates of death with those with glomerulonephritis, cystic/polycystic patients had better outcomes and most others had significantly worse outcomes.

Diabetics had higher death rates and were more likely to die from cardiac disease.

All patients on RRT have a much higher relative risk of death compared with the general population. This is most pronounced in the young; 20–24 year olds with ERF had a 41-fold higher risk of all cause death compared with someone of the same age in the general population. The disparity diminished with longevity; a 4-fold increase in the rate of death in 80–84 year old patients on RRT. In the general population, younger people have a much lower rate of death than the older generations with their concomitant co-morbidity, hence the impact of renal failure is much greater in the young. When looking at just dialysis patients i.e. excluding those prevalent patients with a transplant, the relative risk of death was higher again compared with the general population such that 20–24 year olds on dialysis had a 121-fold higher risk of death and 80–84 year olds a 5-fold increased risk. This suggests that transplant patients have significantly lower rates of death than dialysis patients.

Most international renal registries have only analysed cause of death in their prevalent patients and in general, the UK data were similar. When compared with USRDS data, UK prevalent renal patients had significantly lower rates of death across all age bands. UK data were not adjusted 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.[1] 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). The UK better rate of survival 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 and increasing numbers of units joining, the Registry will be able to analyse further the effects of co-morbidity 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.

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Table 18.30. Collation of EDTA codes for cause of death

EDTA	Title	Subgroup B
0	Cause of death uncertain/not determined [0]	Uncertain or not determined
11	Myocardial ischaemia and infarction [11]	Cardiac disease
12	Hyperkalaemia [12]	Others
13	Haemorrhagic pericarditis [13]	Others
14	Other causes of cardiac failure [14]	Cardiac disease
15	Cardiac arrest/sudden death; other cause or unknown [15]	Cardiac disease
16	Hypertensive cardiac failure [16]	Cardiac disease
17	Hypokalaemia [17]	Others
18	Fluid overload/pulmonary oedema [18]	Cardiac disease
21	Pulmonary embolus [21]	Others
22	Cerebrovascular accident, other cause or unspecified [22]	Cerebrovascular disease
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
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]	ERF treatment stopped
52	Suicide [52]	Others
53	ESRF treatment ceased for any other reason [53]	ERF treatment stopped
54	ESRF treatment withdrawn for medical reasons [54]	ERF treatment stopped
61	Uraemia caused by graft failure	ERF 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

Table 18.30 (continued)

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]	Infection
101	Peritonitis (fungal, with peritoneal dialysis) [101]	Infection
102	Peritonitis (due to other cause, with peritoneal dialysis) [102]	Infection

Chapter 19: Diabetes in Patients with Established Renal Failure: Demographics, Survival and Biochemical parameters

Summary

- The Renal Association has recommended HbA1c levels of <7% in ERF patients. This is only achieved in 47% of HD, 25% of PD and 33% of transplanted patients with diabetes.

- Of prevalent transplant patients, only 7% have diabetes at the start of renal replacement therapy. 28% of diabetic patients on RRT have a functioning graft.

- Diabetic patients have significantly lower survival rates over 6 years compared with non-diabetics irrespective of age. The discrepancy is greatest in younger patients (76% of non-diabetics aged 18–34 alive at 6 years compared with 42% of diabetics).

- Diabetic patients are more likely to have associated co-morbidity at the start of renal replacement therapy than non-diabetics (45% v 36%, $p < 0.001$).

- Cardio-vascular, cerebrovascular and peripheral vascular disease were all more common in diabetics as an associated co-morbidity than in non-diabetics, $p < 0.001$.

- Diabetic patients have significantly lower median serum cholesterol levels compared with non-diabetics (4.4 mmol/L v 4.8mmol/L $p = < 0.0001$). They were also significantly lower within each modality (HD $p = 0.004$, PD $p = 0.003$, transplant $p = <0.0001$). HD patients have lower median levels than PD or transplant patients, irrespective of diabetic status.

- Diabetic patients with ERF are more likely to have higher Townsend scores, suggesting increased social deprivation, when compared with either the general population of England and Wales, or non-diabetic patients on renal replacement therapy ($p < 0.0001$).

- Systolic blood pressure was 10 mmHg higher in diabetic patients on HD and PD than in non-diabetics ($p < 0.0005$). There was no difference in diastolic blood pressure.

- After adjusting patient survival for age, ethnicity, social deprivation and co-morbidity (cardiovascular, peripheral vascular, smoking, malignancy, COPD), diabetes remained a significant factor in the Cox model.

- Many renal units do not provide information relating to HbA1c levels in diabetics to the UK Renal Registry.

- The majority of laboratories linked to renal units align their measurement of HbA1c with the USA assay used in the Diabetes Control and Complications Trial (DCCT study). Practice may change in future years following the introduction of international standardisation.

Introduction

Diabetes is the commonest identifiable cause of established renal failure (ERF) in the UK, accounting for 18% of new patients starting renal replacement therapy (RRT) (see Chapter 4) and 11% of prevalent renal patients: there was considerable variation between units (Table 19.1).

In England & Wales the proportion of patients with diabetes as the primary cause of renal failure is lower than that of many other developed countries (Table 19.2).

Table 19.1. Diabetes at start of RRT by modality in prevalent patients

Renal Unit	% Dialysis pats with DM (no.)	% Transplant pats with DM (no.)	% All RRT with DM (no.)
Kings	29 (97)	17 (41)	24 (138)
Reading	21 (42)	N/A	21 (42)
Wolves	21 (59)	8 (7)	18 (66)
Bradford	27 (37)	6 (6)	18 (43)
H&C	23 (157)	8 (34)	18 (191)
Hull	18 (59)	9 (17)	15 (76)
Clwyd	20 (12)	4 (1)	15 (13)
Sunderland	17 (22)	10 (13)	14 (35)
Nottingham	20 (87)	7 (27)	14 (114)
Coventry	18 (56)	6 (16)	13 (72)
Truro	14 (22)	8 (5)	13 (27)
Guys	20 (99)	8 (60)	13 (159)
Preston	14 (58)	6 (12)	12 (70)
Swansea	16 (46)	3 (3)	12 (49)
Plymouth	15 (27)	9 (20)	12 (47)
Carshalton	14 (63)	7 (24)	11 (87)
Stevenage	12 (46)	7 (10)	11 (56)
Middlesbrough	18 (43)	4 (12)	11 (55)
Ipswich	16 (20)	5 (4)	11 (24)
Southend	12 (18)	7 (2)	11 (20)
Liverpool	15 (80)	8 (48)	11 (128)
Portsmouth	14 (59)	7 (40)	10 (99)
Bristol	13 (57)	7 (40)	10 (97)
Cambridge	13 (42)	8 (31)	10 (73)
Heartlands	13 (39)	5 (9)	10 (48)
LGI	12 (22)	9 (14)	10 (36)
Wrexham	11 (18)	9 (4)	10 (22)
Carlisle	13 (11)	7 (6)	10 (17)
Leicester	14 (83)	5 (24)	10 (107)
Sheffield	13 (78)	7 (28)	10 (106)
St James	13 (58)	5 (26)	9 (84)
Bangor	9 (8)	N/A	9 (8)
Wordsley	14 (20)	1 (1)	9 (21)
Oxford	13 (69)	7 (56)	9 (125)
Cardiff	11 (57)	6 (37)	8 (94)
Gloucester	15 (9)	6 (3)	8 (18)
Newcastle	11 (21)	6 (28)	7 (49)
Exeter	8 (24)	5 (10)	7 (34)
Wirral	6 (8)	N/A	6 (8)
York	6 (7)	3 (1)	5 (8)
England	16 (1705)	7 (675)	12 (2380)
Wales	13 (141)	6 (45)	10 (186)
Eng & Wales	15 (1846)	7 (720)	11 (2566)

Table 19.2. New patients starting RRT by country: total and diabetic

Country	Year	Population (millions)	Acceptance ERF pmp	Accepted ERF with diabetes pmp	% Accepted with diabetes
Australia	2002	19.6	94	25	26
Austria	2001	8.1	137	44	32.1
Canada	2001	31.4	152	51	33.3
Germany	2001	82.5	184	67	36.2
Italy	2001	57.9	136	24	17.4
Japan	2001	127.1	252	96	38.1
New Zealand	2002	3.9	115	52	45
Norway	2001	4.5	95	14	14.5
Sweden	2001	8.9	124	31	25.2
United Kingdom	**2002**	**59.2**	**101**	**18**	**18**
USA	2001	285.3	334	148	44.3

The Renal Association Standards 3rd edition does not specify the frequency of measurements but recommends that:

> ***Diabetic patients on dialysis should aim for HbA1c levels <7%, measured using an assay method that has been harmonised to the DCCT standard.***

Other organisations have also issued recommended standards;

1. The UK National Service Framework (NSF) for diabetes recommends that 'health professionals should work in partnership with people with diabetes to achieve the best possible level of metabolic control, with HbA1c stabilised in the normal range'. Ideally an HbA1c of less than 7.0% (DCCT-aligned) should be achieved by the end of the first year after diagnosis. The frequency of blood glucose monitoring should be 'reviewed regularly at intervals negotiated between the person with diabetes and those providing their diabetes care', but usually at least once every six months and more frequently in young adults and in those whose control is sub-optimal.
2. The US Diabetes Association recommends measurement of HbA1c four times a year.
3. The European Best Practice Guidelines for Transplantation recommend that HbA1c should be measured 3 monthly.

For this report the Registry has analysed HbA1c data from those centres that have provided at least 50% data returns for respective modalities of treatment, and several new validation processes have arisen as a consequence. Survival rates in diabetic incident patients over the last 6 years have been calculated and compared with non-diabetics, together with co-morbidity data, serum cholesterol levels, transplantation rates and social deprivation levels.

Glycated haemoglobin assay

Glycated haemoglobin is measured as HbA1c and is the result of an irreversible non-enzymatic glycation of the beta chain of haemoglobin A. In people who do not have diabetes, 3–6 % of their haemoglobin is in the form of HbA1c. There are more than 20 assays currently in use using a range of techniques, including cation-exchange chromatography, electrophoresis, affinity chromatography and immunoassays. Each of these techniques measures a different fraction of the glycated haemoglobin.

In 2000 a consensus statement paper was published which recommended that HbA1c assays should be adjusted to produce HbA1c results that are aligned to the assay systems (cation-exchange HPLC method) used in the US for the Diabetes Control and Complications Trial (DCCT). Many laboratories in the UK have followed this guidance.[1]

In January 2002 the International Federation of Clinical Chemistry & Laboratory Medicine (IFCC) HbA1c working Group published a full reference measurement system for the measurement of HbA1c in human blood. An international network of reference laboratories comprising laboratories from Europe, Japan and the USA has evaluated the analytical performance of the reference method and possible interferences have been carefully investigated. Due to the higher specificity of the reference method, the results are lower than those generated with most of the currently available commercial methods. The new reference method has been approved by the member societies of the IFCC and will be the basis for standardization of HbA1c assays worldwide in the future.[2]

UK centres use a range of different assays, not all of which are DCCT aligned (Table 19.4 at the end of this chapter). A questionnaire compiled by Elizabeth Burgess (Clinical Biochemist, Gloucestershire Hospitals NHS Trust) was sent out to each of the laboratories based in hospitals with renal units that subscribe to the Renal Registry. Information was obtained about the precise method used for measurement of HbA1c and whether it was DCCT aligned or calibrated by some other method. The reference range and comments that related to it on the printed results were also requested. The responses, outlined in Table 19.5 at the end of this chapter, show that 7 different assay systems (using either ion exchange chromatography or boronate affinity chromatography as assay principle) were in use during 2002. Of 38 replies from the 42 laboratories questioned 34 used an assay that was DCCT aligned whilst the other 4 used an alternative method for calibration. It is not possible to directly compare HbA1c levels between centres that are not DCCT aligned with DCCT aligned assays, but the results from these centres have been included to help inform local service provision. Only one centre (Carshalton) using a non-DCCT aligned assay provided sufficient HbA1c data on their patients with diabetes to be included in the analyses.

Data validation of glycated haemoglobin

Before the data could be analysed, the Registry had to ensure that only measurements of HbA1c from diabetic patients were included. Initially many centres were found to have a median HbA1c that was within the normal range of individuals who are not diabetic. Many of these measurements had been recorded on patients who were not registered as having diabetes (either as a primary renal diagnosis or as a co-morbidity). A list of patients with an HbA1c > 7% on more than one occasion was compiled from the database as well as a list of patients with a recorded HbA1c = 7% who had not been registered as having diabetes. These patients were grouped by centre and each renal unit contacted by letter and a telephone call to answer four questions about them:

1. Does the patient have diabetes?
2. If so, is this the primary renal diagnosis?
3. If the answer to (2) is no, was diabetes present as a co-morbidity at the start of renal replacement therapy (RRT)?
4. If the answer to (2) and (3) is no, did diabetes arise following transplantation?

In total, 107 of those patients with an HbA1c ≥ 7% who had not originally been registered as diabetic were in fact diabetic; 14 had diabetes as a primary diagnosis (13%), 39 (36%) had diabetes as co-morbidity at start of RRT and 30 (28%) had developed diabetes

following transplantation. 187 were either not diabetic or their diabetic status was unknown (some of these patients had died).

Glycated haemoglobin by RRT modality

Many renal units (Birmingham Heartlands, Cardiff, Gloucester, Hull, Newcastle, Oxford, Preston, Plymouth, Reading, Southend, Swansea, Wordsley and Wrexham) have not provided information about HbA1c levels in their diabetic patients (see Table 19.5 at the end of the chapter). Many centres do not have HbA1c in their automated laboratory link to the renal system. Of those that did, there was wide variation between centres in both median HbA1c levels and the proportion of their diabetic patients achieving Renal Association standards. Of those 1058 diabetic patients who had an HbA1c measured in 2002, 21% had it measured once only, 27% twice only, 27% three times only and a further 25% four times.

Some renal units do not look after transplant and/or peritoneal dialysis patients. The Wirral renal unit only has patients on HD with PD and transplant patients being followed up at Liverpool Royal Infirmary. At Clwyd there were no diabetic patients on PD and both these centres were excluded from the analyses.

Several centres had less than ten diabetic patients on PD, and Carlisle, Bangor and Truro were excluded because they had fewer than 3 patients with diabetes on PD. Overall in England and Wales, diabetic patients on PD had a median HbA1c of 8.0% (Figure 19.1), with variation between centres of 6.4 to 9.0%. The percentage of patients achieving Renal Association targets of HbA1c <7 % on PD ranged from 3 to 60%, with only 25% overall in England and Wales (Figure 19.2). This difference between centres did not reach statistical significance.

Those centres that were able to provide HbA1c results for only a small proportion of their diabetic PD patients also tended to do the same with their HD patients. The median HbA1c of diabetic HD patients in England and Wales was 7.1% (Figure 19.3), but only 6 centres achieved a median reading <7%. The proportion of diabetic HD patients achieving RA standards in the different units varied from 75% to 29% (Figure 19.4, $p < 0.001$). Diabetic patients on haemodialysis had a lower median HbA1c (7.1%) than patients treated with PD and transplant (8%), (Figure 19.1, $p = 0.0009$). This is probably related to the high glucose load associated with PD bags and the weight gain consequent on it. As a result of this poor control, only 25% of diabetic PD patients achieve RA standards (Figure 19.2) compared with 47% of HD patients.

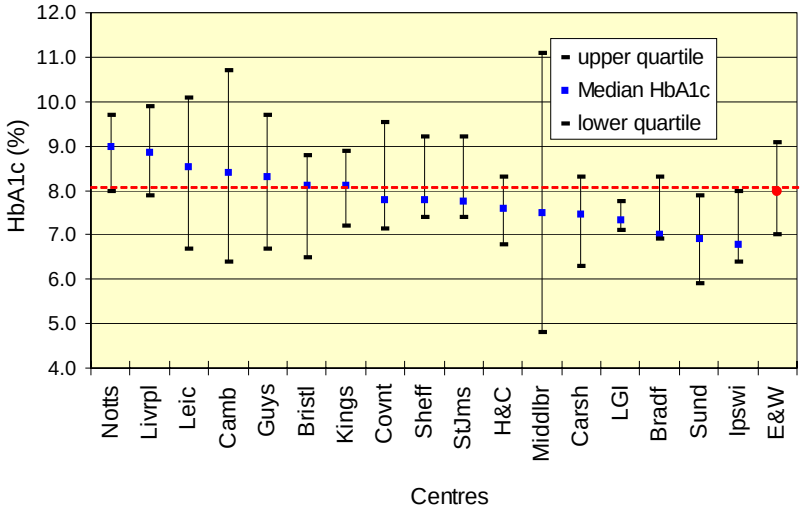

Figure 19.1. Median HbA1c in diabetic patients on PD by centre

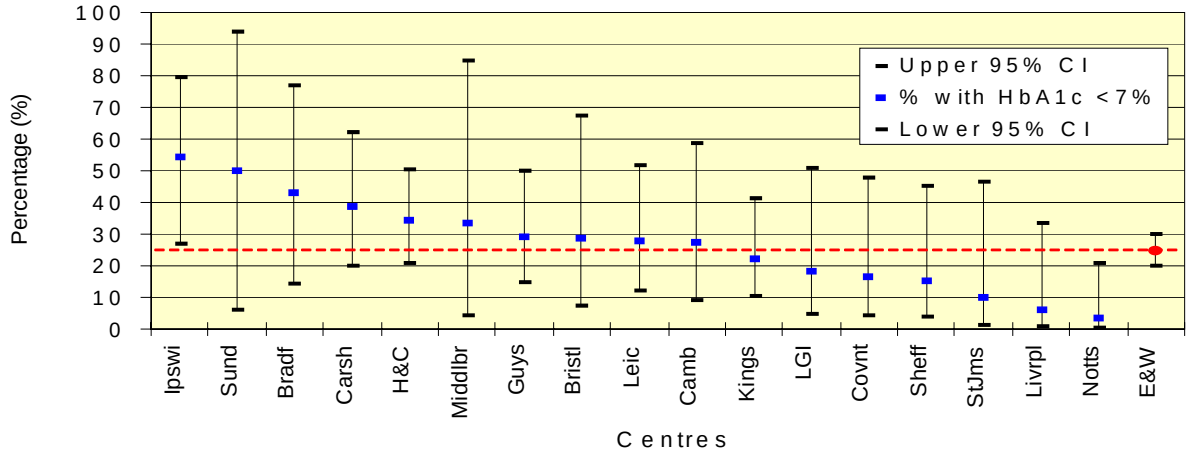

Figure 19.2. Centres achieving RA HbA1c standards in diabetic patients on PD

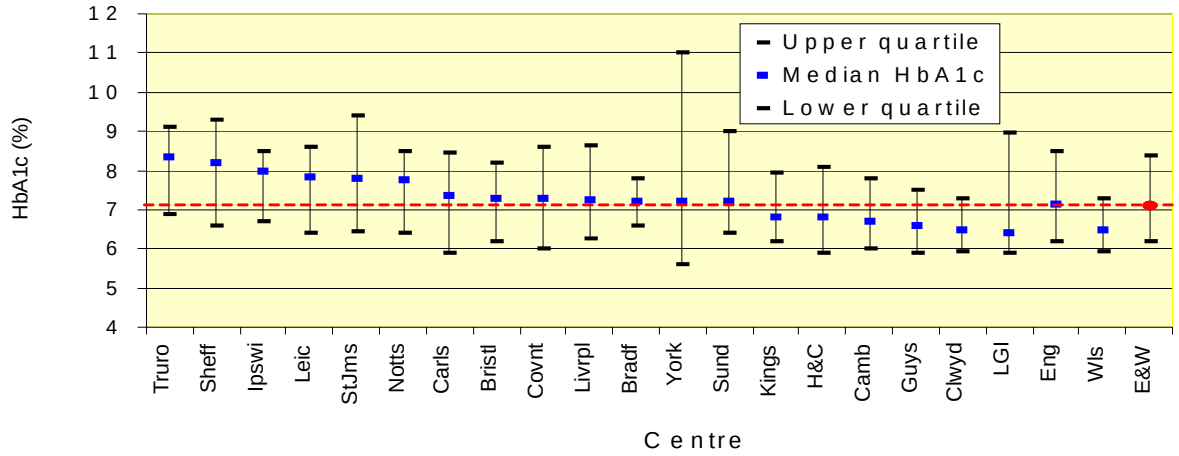

Figure 19.3. Median HbA1c in diabetic patients on HD by centre

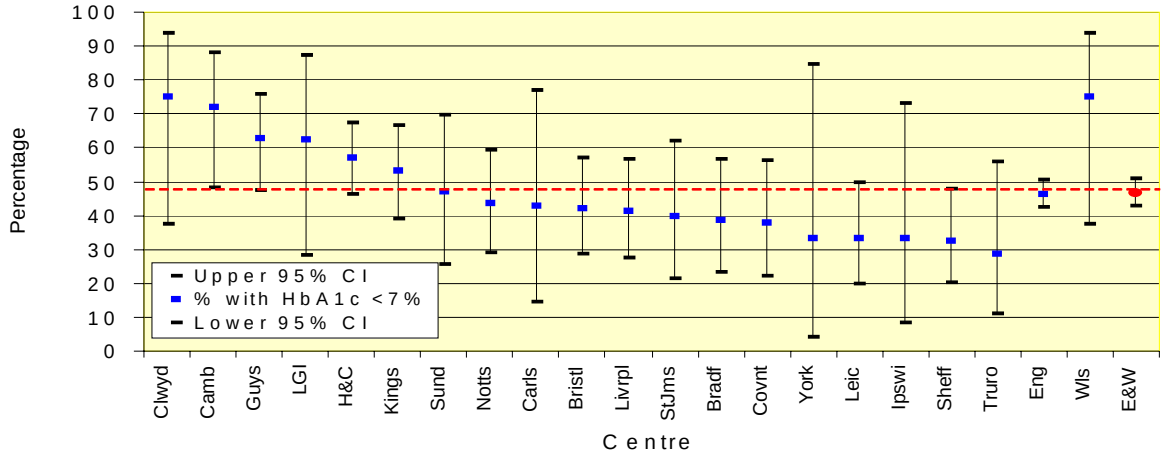

Figure 19.4. Centres achieving RA HbA1c standards in diabetic patients on HD

Only 16 centres sent HbA1c results on ≥50% of their diabetic patients with transplants. This may partly be a result of patients being seen at peripheral transplant clinics whose hospitals do not have automated laboratory links to the main renal unit. This provided a cohort of 382 patients in which the median HbA1c was 7.7% (Figure 19.5). This was not significantly lower than in the PD patients ($p = 0.29$) but significantly higher

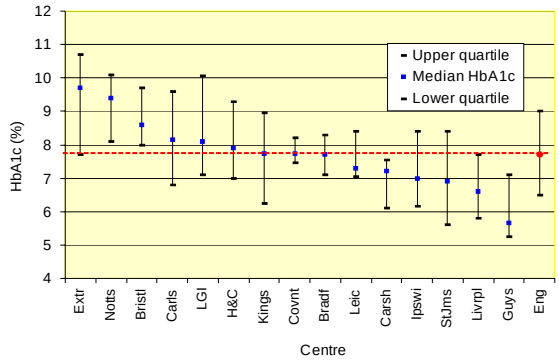

Figure 19.5. Median HbA1c in diabetic patients with a transplant by centre

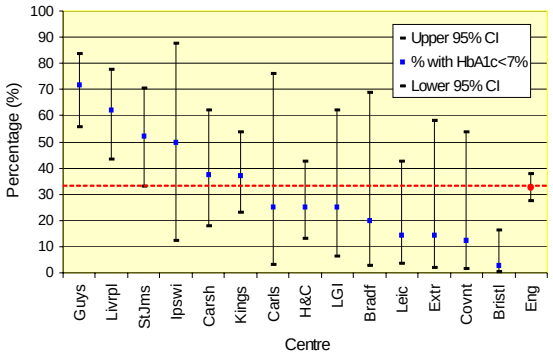

Figure 19.6. Centres achieving RA HbA1c standards in diabetic patients with a transplant

than HD patients ($p < 0.0001$). The median HbA1c between centres (range 9.7–5.7%) varied significantly ($p < 0.001$). Guy's Hospital renal unit with the lowest median HbA1c also had the greatest proportion of diabetic transplant patients meeting Renal Association standards (72%). Overall only 33% of transplant diabetics achieved the target (Figure 19.6).

Survival of diabetic ERF patients

Diabetic patients are known to have an increased risk of death when compared with non-diabetics, although in the study of cause of death in patients with ERF, diabetics had lower death rates in the first 90 days (Chapter 18). Kaplan–Meier graphs were created to show survival rates of diabetic patients on RRT in the first 90 days (Figure 19.7) and over 6 years of RRT (Figure 19.9). By day 90 (Figure 19.7), there were 93% of 18–44 year olds alive compared with 89% of 45–64 year olds and 85% of those aged ≥65.

Figure 19.8 shows the difference in 6 year survival between the diabetics and non diabetics. The diabetics have a younger median age at start of renal replacement therapy (62 years for diabetics and 65 years for non-diabetics) which accounts for the apparent smaller than expected difference in survival between diabetics and non-diabetics. The 6 year survival of diabetics by age band in Figure 19.9 can be compared with the non diabetics by age band in Figure 19.10. In the first 9 months, the youngest diabetic patients had significantly better survival than all other age groups, but by 12 months only 75% of 18–34 year old diabetics were alive on RRT.

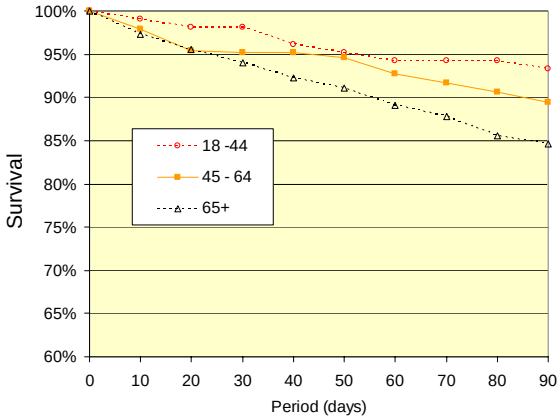

Figure 19.7. Survival of diabetic patients during first 90 days on renal replacement therapy

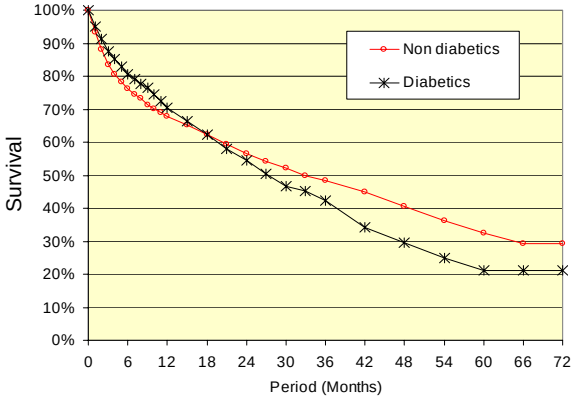

Figure 19.8. 6 year survival of diabetic and non-diabetic patients on RRT

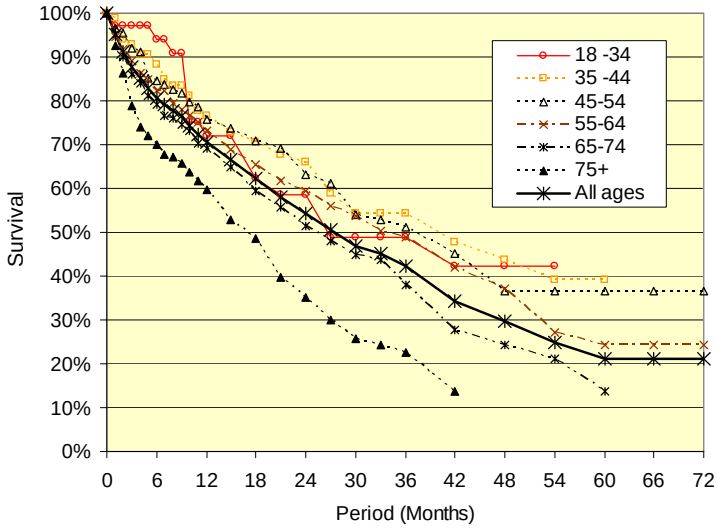

Figure 19.9. 6 year survival of diabetic patients on RRT by age band

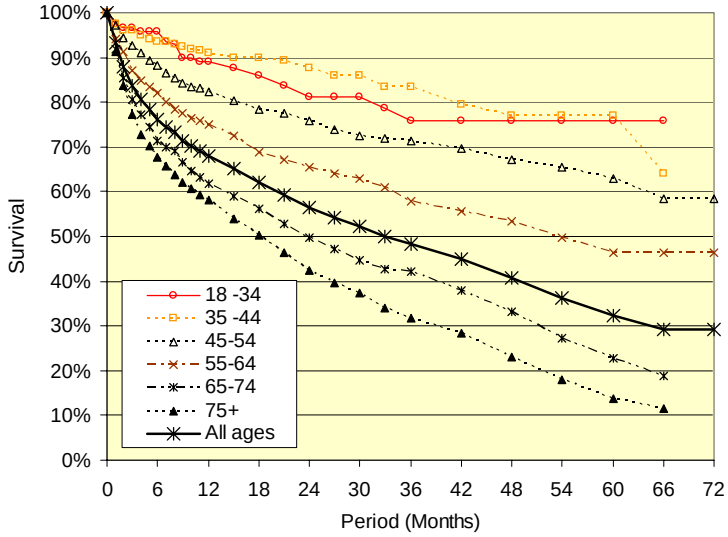

Figure 19.10. 6 year survival of non-diabetic patients on RRT by age band

Compared with non-diabetic patients (Figures 19.9 and 19.10), survival of diabetic ERF patients (Figures 19.7, 19.9) was much lower both overall and by age band. By 6 years, 21% of diabetics on RRT were alive compared with 29% of non-diabetics. The younger the patient, the greater the survival differences (76% of non-diabetics aged 18–34 years alive at 6 years compared with 42% of diabetics), $p < 0.0001$.

Transplantation in diabetic patients

The proportion of patients with diabetes at initiation of RRT with a functioning renal transplant varies considerably across centres (1.1–18.3%, Figure 19.11). Some of this variation is related to the variation between renal units in the incidence of diabetes and diabetic nephropathy in the general popula-

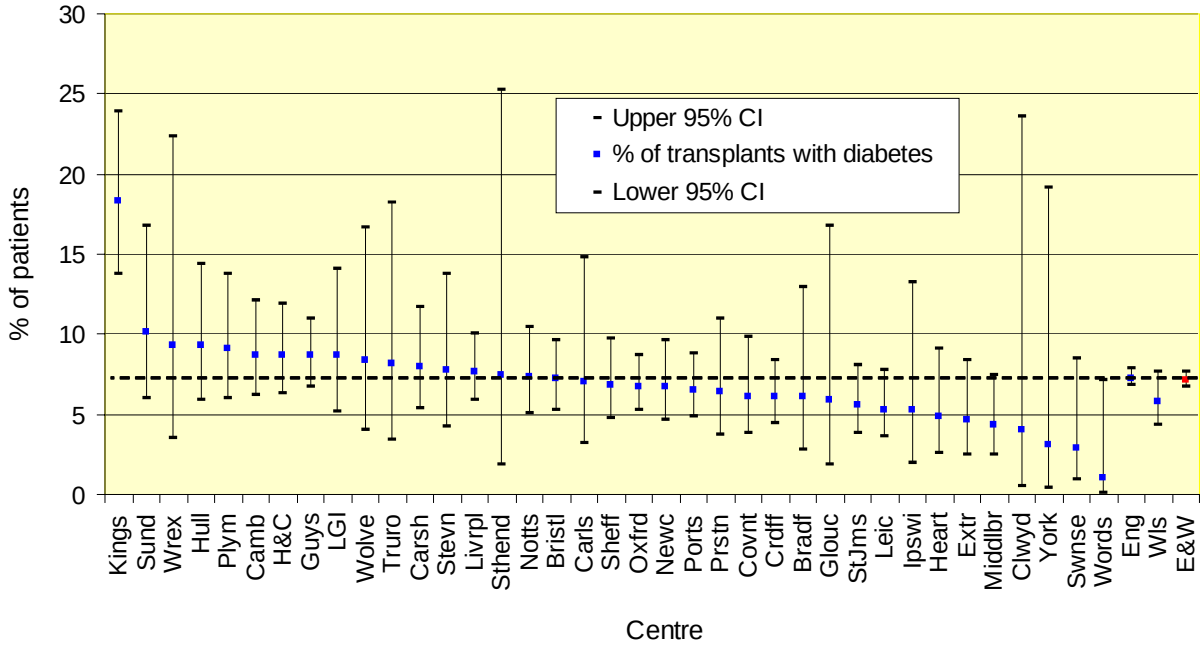

Figure 19.11. Prevalent transplant patients with diabetes as cause of renal failure

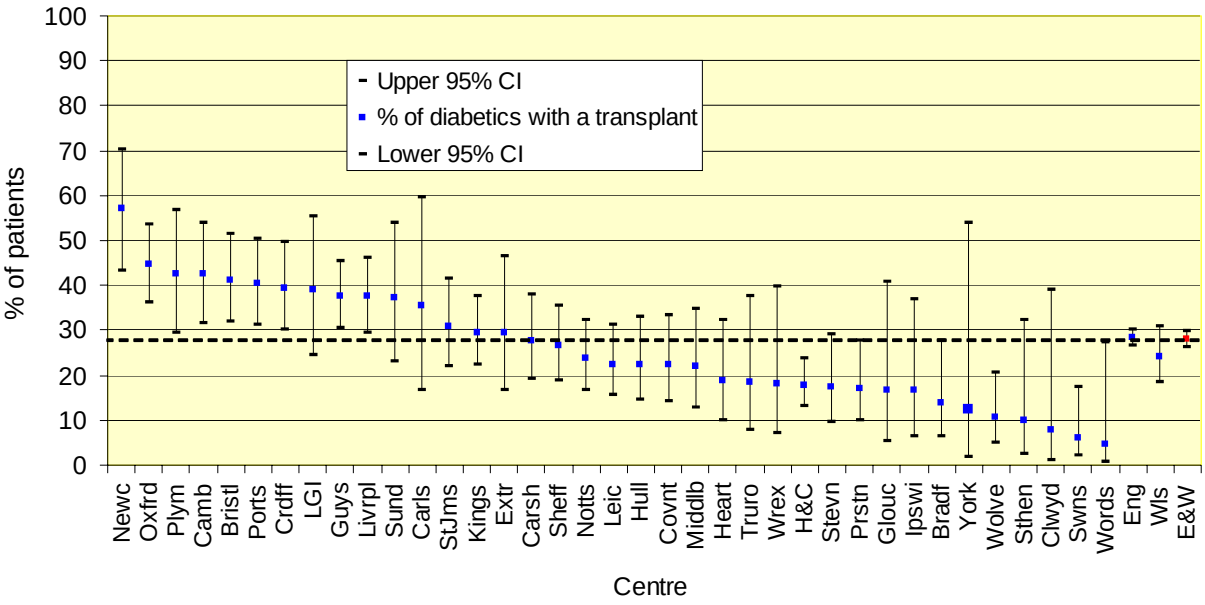

Figure 19.12. Percentage of diabetics on RRT with a functioning transplant

tion. The Kings renal unit had the largest proportion of transplant patients with diabetes (18%) but they also have a large proportion of RRT patients from the ethnic minorities, in whom prevalence of diabetes is high. Guy's unit, with 28% of incident patients from an ethnic minority group however, has only 9% of transplant recipients with diabetes. Overall only 7% of transplant patients have diabetes as the cause of their renal failure.

Figure 19.12 shows the proportion of diabetics with a functioning transplant. In Newcastle, 57% of diabetics have a transplant compared with 28% overall in England and Wales. Further analyses of diabetic transplant patients have been included in Chapter 12.

Co-morbidity in diabetic patients

The data from the 12 centres that had provided co-morbidity information on ≥80% of their incident patients in the years 2001 and 2002 were analysed to assess differences between diabetic and non-diabetic patients. The incident cohort included patients from these centres over the period 1998–2002. The size of the cohort with co-morbidity was 3392. The proportion of diabetic patients at these centres for whom information was available about co-morbidity was similar (63%) to the proportion of non-diabetics (61%).

In the cohort of 3392 patients for whom co-morbidity data was available, the underlying diagnosis appeared to influence the number and type of co-morbidity present on starting renal replacement therapy. As expected, diabetic patients were less likely than others to have no co-morbidity at the start of RRT (45% v 36% respectively, $p < 0.001$) and more likely to have multiple associated co-morbidity (Figure 19.13).

Patients with either polycystic disease or glomerulonephritis were more likely than those with other primary renal diagnoses to have no associated co-morbidity (Table 19.3, $p < 0.001$). By contrast, patients with renovascular disease were more likely to have at least one associated co-morbidity on starting renal replacement therapy ($p < 0.01$).

Figure 19.14 shows the frequency of the different categories of co-morbidity in patients with and without diabetes. Smoking was the most frequent co-morbidity in both diabetic and non-diabetic patients (22% and 20% respectively). Malignancy was more common at the start of renal replacement treatment in non-diabetic (12%) than in dia-

Table 19.3. Range of co-morbidity in ERF patients by primary renal diagnosis

	No. of co-morbidity types present					
	0	**1**	**2**	**3**	**4**	**>4**
Diabetes	36% (213)	23% (134)	19% (114)	10% (59)	7% (42)	5% (33)
GN	55% (243)	30% (133)	9% (38)	4% (20)	2% (7)	0% (4)
PKD	73% (167)	16% (37)	7% (17)	3% (6)	1% (2)	0% (0)
Pyeloneph	51% (151)	32% (93)	12% (34)	4% (12)	1% (3)	0% (2)
Reno-vasc	24% (121)	25% (127)	19% (96)	14% (74)	10% (49)	8% (45)
Other	42% (211)	35% (175)	13% (66)	6% (30)	2% (11)	2% (8)
Uncertain	43% (320)	26% (194)	17% (124)	8% (56)	4% (29)	2% (19)
Missing	45% (33)	22% (16)	18% (13)	11% (8)	4% (3)	0% (0)
Total	43% (1459)	27% (909)	15% (502)	8% (265)	4% (146)	3% (111)

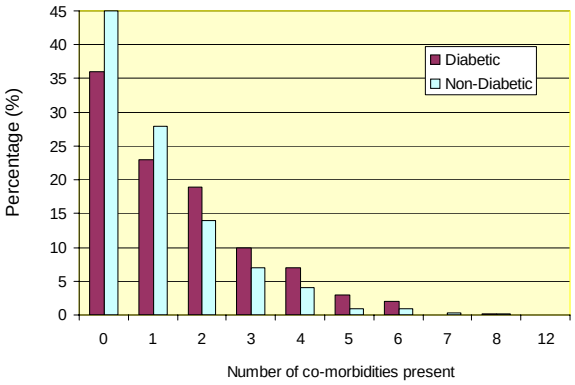

Figure 19.13. Co-morbidity totals for diabetic and non-diabetic RRT patients

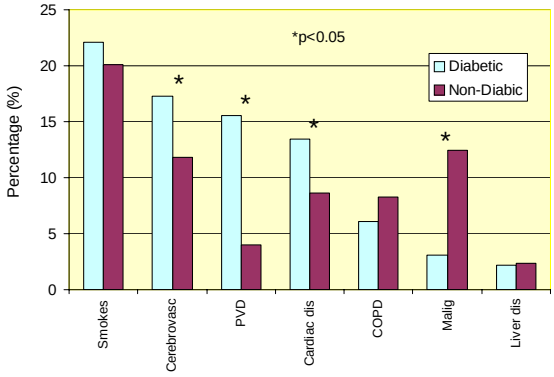

Figure 19.14. Co-morbidity in diabetic and non-diabetic patients starting RRT

betic patients (3%, p < 0.0001). In diabetic ERF patients, cerebrovascular disease, peripheral vascular disease and cardiac disease were all significantly more common at the start of treatment than in non-diabetic patients. For this analysis, cardiac disease included 'angina', 'previous myocardial infarction' (MI) and previous cardiac by-pass grafts. When analysed separately, angina was present in 30% of diabetics at start of RRT compared with 20% of non-diabetics (p < 0.0001) and an MI more than 3 months prior to start of treatment was significantly more common in diabetics (14% v 11%, p = 0.02). There was no difference in the proportion of diabetics and non-diabetics who had suffered an MI less than 3 months before the start of RRT (4% v 3%, p = 0.17); similarly, previous coronary angioplasty was uncommon in both diabetics and non-diabetics (6% v 5% respectively, p = 0.22). Peripheral vascular disease (PVD), which included 'claudication', 'ischaemic and neuropathic ulcers', 'non-cardiac angioplasty' and 'amputations due to ischaemia', was significantly more common in diabetic patients (p < 0.001). The differences in co-morbidity are likely to be one of the explanations for the observed difference in survival between diabetic and non-diabetic patients with ERF.

A Cox proportional hazards model including age (linear variable), ethnicity, primary diagnosis (including diabetes) and co-morbid diagnoses was constructed to analyse incident patient survival, excluding the first 90 day period. In the first model, centres were excluded if they had less than 80% co-morbidity returns (n = 1,139). In the second model, all patients from centres returning co-morbidity were included (n = 3,206). In both these models, diabetes remained a significant variable in the model after adjusting for co-morbidity (p = 0.02 and p < 0.0001 respectively). Diabetes also remained significant in the second model as a co-morbidity (i.e. not as the primary diagnosis for renal failure), (p = 0.0054).

Serum cholesterol in diabetic patients

The distribution of serum cholesterol between renal replacement modalities has been analysed and discussed in Chapter 11. The analysis below, concentrates on differences between diabetic and non-diabetic ERF patients.

Figure 19.15 shows the distribution of serum cholesterol amongst diabetic and non-diabetic patients on haemodialysis and peritoneal dialysis. There was a significant difference in serum cholesterol between the diabetic and non-diabetic patients across all the modalities (HD p = 0.004, PD p = 0.003, transplant p < 0.0001). Patients on HD, irrespective of their diabetic status have lower serum cholesterol levels than those on PD. Transplant patients have similar serum cholesterol levels to PD patients and significantly lower serum cholesterol than non-diabetics (Figure 19.16).

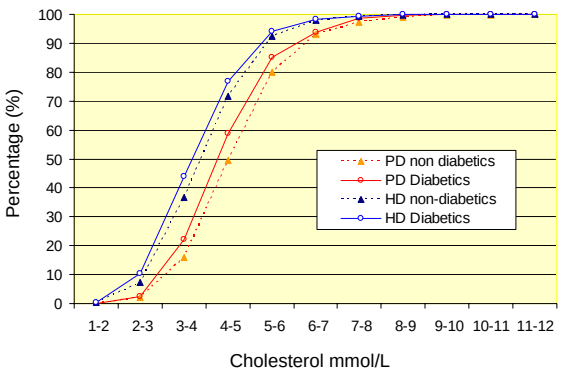

Figure 19.15. Distribution of serum cholesterol by dialysis modality and diabetic status

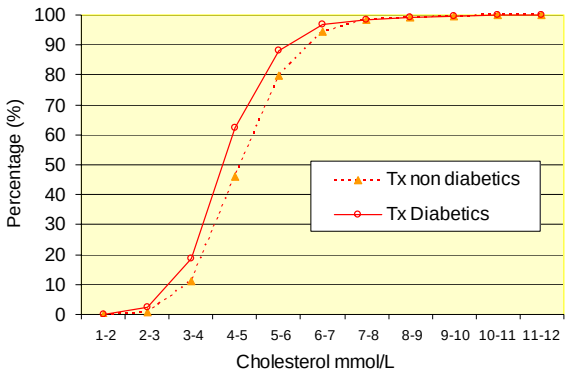

Figure 19.16. Distribution of serum cholesterol in transplant patients by diabetic status

The difference between treatment modalities in diabetics (Figure 19.17) reflects the pattern seen in the non-diabetic population; HD patients tend to have lower serum cholesterol levels than either PD or transplant patients, where levels are similar.

Diabetics on renal replacement therapy had lower median serum cholesterol levels (4.4 mmol/L versus 4.8 mmol/L), compared with non-diabetic patients (Figure 19.18). The pattern followed that of the general distribution with HD patients having the lowest median levels, PD and transplant patients with similar levels (HD 4.2, PD 4.7 and transplant 4.7mmol/L in diabetic patients; HD 4.3, PD 5.0 and transplant 5.0mmol/L in non-diabetic patients) irrespective of diabetic status. The Registry at present does not collect 'statin' usage from affiliated renal units but this may account for the difference in serum cholesterol levels between diabetic and non-diabetic renal patients.

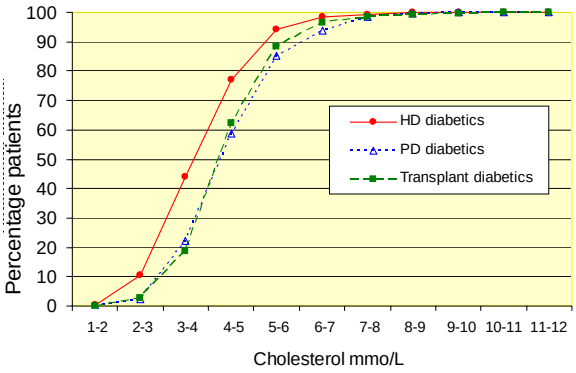

Figure 19.17. Distribution of serum cholesterol in diabetics by treatment modality

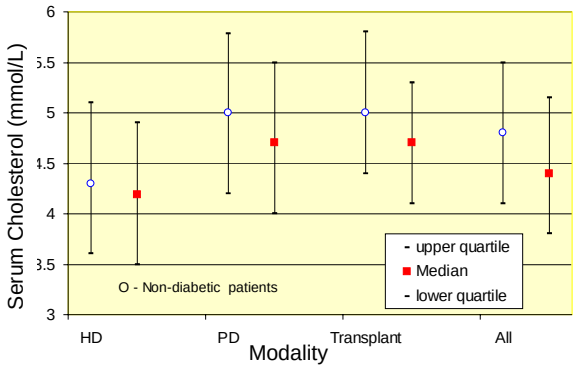

Figure 19.18. Median serum cholesterol by modality in diabetics and non-diabetics

Median blood pressure in diabetic patients

The median systolic blood pressures were 10 mm Hg higher in diabetic patients on HD and PD compared with non diabetics ($p \leq 0.0001$, 0.0003 respectively). Diastolic pressures were not significantly different to non-diabetics. Blood pressure goals in diabetics are lower but this is clearly not being achieved in clinical practice.

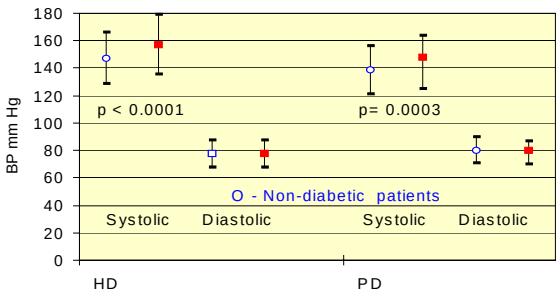

Figure 19.19. Median blood pressure in diabetics and non-diabetics

Social Deprivation in diabetic patients

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

The relationship between social deprivation and diabetic nephropathy was analysed and compared to that of the general population of England and Wales. In this analysis, patients from ethnic minorities on renal replacement therapy were excluded (they have a high incidence of diabetes and are from a more socially deprived group see Chapter 17) so that the cohorts were more comparable.

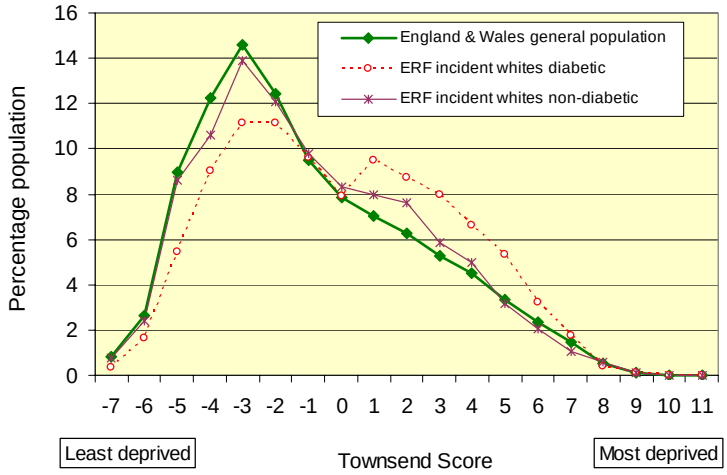

Figure 19.20. Townsend deprivation scores and diabetic status

In the incident cohort, non-diabetic white patients starting RRT closely followed the distribution of the general population (Figure 19.20). This contrasted with the white diabetics, where a significantly higher proportion were from a more socially deprived background ($p \leq 0.0001$). The diabetic cohort were not analysed separately by Type 1 or 2 diabetes. These differences between the diabetics and non-diabetics may be due to the increased incidence of obesity, higher body mass index (BMI) and consequently higher incidence of Type 2 diabetes in more socially deprived groups.

Conclusion

Measurement of HbA1c using DCCT aligned assays remains the mainstay of monitoring and assessing diabetic control. The Renal Association has set target HbA1c levels of <7% in all renal replacement therapy patients in order to minimise further diabetic complications, in particular cardiovascular disease. There have been no recommendations by the Renal Association as to the frequency of this monitoring, although the diabetes NSF recommends at least 6 monthly monitoring. This analysis has highlighted the diversity of glycated haemoglobin assay methodologies used across England and Wales. These differences should resolve once definitive national recommendations for HbA1c assay in the UK have been promulgated.

The percentage of missing HbA1c data was extremely variable between centres and it is hoped that these analyses will help renal units to address this issue. Few diabetic patients are achieving the recommended standard for HbA1c of <7% although this difficulty is not solely confined to patients on renal replacement therapy. The standard was achieved in 47% of HD patients, 25% of PD patients and 33% of transplanted patients. The results in PD patients are possibly due to the high glucose load received in the PD bags, while results in transplant patients may be related to steroids and other immunosuppressant therapies.

Median serum cholesterol levels were significantly lower in diabetic ERF patients irrespective of modality. Diabetic HD patients tend to have lower serum cholesterol levels than those on PD or with a functioning transplant.

The distribution between centres of diabetic ERF patients with a functioning renal transplant varies widely. Some of this variation may relate to the ethnic breakdown of prevalent patients within centres.

The Kaplan–Meier curves confirm published results of lower survival rates in diabetics across all age groups. Although older patients had higher rates of death, the difference between comparable age adjusted diabetic and non-diabetic patients was greatest

in the young. The lower survival rates in diabetics may well be related to the significant difference in both number and type of co-morbidity present on initiation of renal replacement therapy. Diabetics were more likely to have co-morbidity at the start of RRT especially cardio-vascular and peripheral vascular disease. Improved diabetic control prior to and after starting renal replacement therapy may help to improve survival. Further analyses are being undertaken on the importance of diabetic control, blood pressure and cholesterol in diabetic outcomes.

Laboratory glycated haemoglobin reference ranges

Table 19.4. HbA1c assay methodology 2002 by renal unit

Laboratory	DCCT aligned	Range	Reference comment	Assay method
Bangor – Ysbyty Gwynedd	YES	4.6–6.5 %	Reference range applies to non-diabetics only.	Menarini HA – 8160
Birmingham Heartlands Hospital	No	<4.9%		HPLC ion exchange in-house methodology. DCCT aligned values post November 2002
Bradford – St Lukes Hospital	YES	4.4–6.2%		Primus affinity chromatography(hospital) DCA 2000(primary care)
Bristol – Southmead Hospital	YES		Interpretation in adult DM less than 7% is desirable. Greater than 9%, suggest consider review of control.	Menarini HA – 8140 HPLC system
Cambridge – Addenbrookes Hospital	YES	4.9–6.3%	Up to 8.0% acceptable control, 8–10% desirable to improve control, 10–12% poor control >12% very poor control.	Tosoh HPLC analyser
Cardiff – University of Wales Hospital	YES		Non-diabetic age related range determined locally.	Menarini HA – 8140
Carlisle – Cumberland Infirmary	YES	< 6.1% Non-diabetic range	Target for good control 7.0% or less.	HPLC Tosoh G7
Carshalton -St Helier Hospital	No	3.8–6.0%	Indicates satisfactory control.	In house HPLC
Clwyd – Ysbyty Clwyd	YES			Biorad Variant ll
Coventry – Walsgrave Hospital	YES	3.6–6.8%		Biorad Variant II
Derby City Hospital	YES		< 7% is very good control. However the target value should be tailored for each patient to maximize blood glucose control without increasing the risk of hypoglycaemia.	Biorad Variant II
Exeter – Wonford Hospital	YES			Jan–Oct in house HPLC Oct–Dec TOSOH G7
Gloucester Royal Hospital	YES		Adult diabetic control guidelines <7% ideal <8% desirable >9% review.	Primus boronate affinity chromatography

Table 19.4 (continued)

Laboratory	DCCT aligned	Range	Reference comment	Assay method
Hull Royal Infirmary	YES		<7% good glycaemic control, 7–8% borderline glycaemic control, >8% poor glycaemic control.	Menarini HA – 8140
Ipswich Hospital	YES		NICE recommend target HbA1c of 6.5–7.5%. However targets should be individualised, based on risk of micro-vascular complications, risk of hypoglycaemia, personal circumstances..	Biorad Variant II
Leceister General Hospital	YES	4.0–6.1%		Biorad Variant II
Leeds – St James' University Hospital	YES	4.5–6.4%		Primus boronate affinity chromatography
Leeds General Infirmary	YES	4.5–6.4%		Primus boronate affinity chromatography
Liverpool Royal Infirmary	YES	<6.5%	HbA1c <7% target control, >9% poor control, <6.5% good control (non-diabetics).	Menarini HA – 8140 ion exchange
London – Guy's Hospital	YES	4.2–6.2%		Primus boronate affinity chromatography
London – Hammersmith Hospital	YES	4.3–5.5%	Non-diabetic reference range.	Primus boronate affinity chromatography
London – Kings	YES	<6% non-diabetic range		primus boronate affinity chromatography
Middlesborough – James Cook University Hospital	YES	<6.1% for non-diabetic population	Good: 6.5–7.5 Fair 7.5–9 Poor 9–10 Too high >10.	Biorad Variant II
Newcastle – Freeman Hospital				
Nottingham – City Hospital	YES		Very good control: HbA1c less than 7. Good blood sugar control is known to reduce the risk of diabetic complications, but increases the risk of hypoglycamia. Control should be tailored to suit individual patients needs.	Menarini HA – 8140 ion exchange
Oxford – Churchill Hospital	YES	4.3–6.1%		HPLC
Plymouth – Derriford Hospital	YES	.	As a guideline on therapy HbA1c results <7% are considered good, 7–8.5% acceptable, 8.5–9.5% moderate and >9.5% poor	Menarini HA – 8160 ion exchange

Table 19.4 (continued)

Laboratory	DCCT aligned	Range	Reference comment	Assay method
Portsmouth – Queen Alexandra Hospital	YES		The DRIVE guidelines target level for HbA1c is <7.5%,	Menarini HA 8410
Preston – Royal Preston Hospital	YES		well controlled <7%	Tosoh G7 automated HPLC
Reading – Royal Berkshire Hospital	YES		Good control up to 7% and interpretative comment	Biorad Variant II
Sheffield – Northern General Hospital				
Southend – Southend Hospital	YES	<5.5%	>9% poor control 8–9% sub optimal control 7–8% satisfactory control 5.5–7% excellent control	Biorad Variant ll
St Georges Hospital	YES	4.6–6.2%		Biorad Variant II
Stevenage- Lister Hospital				
Stourbridge- Wordsley Hospital	YES	4.6-5.6%		Tosoh G7 automated HPLC
Sunderland Royal Infirmary	YES		Guidance for standards of control: good <6.2% acceptable 6.2–7.5% poor 7.6–9.0% very poor >9.1%.	Menarini HA – 8160 (up to 18/11/02) Arkray 8160 after
Swansea – Morriston Hospital	No	3.5–5.4% for non-diabetic subjects	Use of this test to diagnose diabetes is not advised.	Menarini HA – 8140
Truro – Royal Cornwall Hospital	YES		Good control <7.0% acceptable control 7.0–8.5% moderate control 8.5–9.5% poor >9.5%.	Menarini HA – 8140 ion exchange chromatography
Wirral – Arrowe Park Hospital				
Wolverhampton - Newcross Hospital	No		<6 excellent control 6–<7 good control 7–<8 poor control 8–<10 bad control >10 very bad.	Menarini HA – 8140
Wrexham – Maelor General Hospital	YES	3.2–6.5%		Biorad Variant II
York District Hospital	YES	4.4–6.1%		HPLC tosoh G7

Table 19.5. Percentage completeness of HbA1c data over 9 months by modality

Centre	% HD complete	No of diabetics on HD	% PD complete	No of diabetics on PD	% Transplant complete	No of diabetics transplant
Bangr	0	5	50	2	N/A	N/A
Bradf	100	31	82	11	83	6
Bristl	98	46	100	7	95	40
Camb	60	30	92	12	23	31
Carls	100	8	100	2	67	6
Carsh	35	31	78	23	67	24
Clwyd	89	9	0	1	0	1
Covnt	94	32	60	20	50	16
Crdff	0	42	0	11	0	38
Extr	11	19	100	5	70	10
Glouc	0	8	0	5	0	3
Guys	74	58	74	34	67	60
H&C	88	99	86	44	97	34
Heart	0	31	0	7	0	9
Hull	0	41	0	16	0	17
Ipswi	67	9	100	11	100	4
Kings	84	57	84	32	88	41
Leic	78	46	64	28	67	24
LGI	89	9	100	12	57	14
Livrpl	79	56	80	20	62	47
Middlbr	45	33	50	6	15	13
Newc	0	17	0	6	0	32
Notts	79	53	88	33	58	26
Oxfrd	0	37	0	27	0	56
Plym	0	14	0	11	0	20
Ports	35	43	20	15	33	40
Prstn	0	36	0	15	0	12
Redng	0	15	0	23	N/A	N/A
Sheff	86	51	62	21	46	28
Stevn	0	36	0	6	0	10
Sthend	0	14	0	4	0	2
StJms	61	33	83	12	100	25
Sund	94	18	100	2	23	13
Swnse	0	22	0	22	0	3
Truro	82	17	100	3	60	5
Wirrl	38	8	N/A	N/A	N/A	N/A
Wolve	0	32	5	20	0	7
Words	0	11	0	9	0	1
Wrex	0	12	0	4	0	4
York	60	5	0	1	0	1
All	51	1174	51	543	45	723

References

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Acknowledgements

Elizabeth Burgess, Clinical Biochemist, Gloucestershire Hospitals NHS Trust, for her help in co-ordinating the laboratory HbA1c questionnaire.

David Bullock and Jonathon Middle, UKNEQAS quality assurance scheme, Birmingham.

Chapter 20: Analysis of Characteristics and Survival of Incident Patients from Different Ethnic Groups starting Renal Replacement Therapy

Summary

- Within the cohort of 6599 incident patients starting RRT with a completed ethnic code in 27 units with good data returns, 87% were White, 7% Indo-Asian, 2% African-Caribbean, 0.5% Chinese and 0.9% Other.

- There was considerable variation in ethnicity breakdown between units; at the Hammersmith/Charing Cross only 44% of incident were White compared with 100% at others.

- Whilst Indo-Asian and White patients had predominantly males on RRT (58% and 62% respectively), far more women were represented in the African-Caribbean cohort (52% female, $p < 0.05$).

- Indo-Asian and African-Caribbean patients were significantly younger than Whites (median ages 59, 60 and 64.8 respectively, $p < 0.001$).

- Fewer Whites have diabetes as their underlying primary renal disease (16%) compared to Indo-Asians (33%) and African-Caribbeans (31%).

- Whites tended to have a lower eGFR at start of RRT compared with the ethnic minority groups. In all groups, irrespective of treatment modality, older patients tended to have a higher eGFR at start.

- Patients on PD had higher haemoglobin levels at start compared to HD patients in all ethnic groups. African-Caribbeans had the lowest Hb levels of all the ethnic groups.

- Indo-Asians were significantly more likely to be referred to nephrology services a year or more prior to starting RRT (53%, $p < 0.05$) compared with African-Caribbeans (38%) and Whites (45%). African-Caribbeans were the most likely to be referred late (44%).

- Ethnicity had no impact on the choice of modality at day 90 of treatment.

- Co-morbidity differences between the ethnic groups revealed that significantly more Whites were smokers at the start of RRT ($p < 0.001$), and probably as a consequence were more likely to have COPD ($p = 0.004$). Malignancy was also significantly more common in Whites ($p < 0.001$).

- Diabetes present as co-morbidity or the underlying cause of a patient's renal disease was significantly more common in Indo-Asians and African-Caribbeans than Whites ($p < 0.001$).

- Significantly more ethnic minority ERF patients had higher social deprivation scores compared to Whites ($p < 0.05$).

- African-Caribbeans had a significantly lower risk of death at 90 and 1-year after 90 days compared with Whites ($p = 0.03$). This was not true of the Indo-Asian group, where death rates were similar.

Introduction

Established, or End stage, renal failure (ERF) is 4–6 times more common in the Indo-Asian and African-Caribbean ethnic minority groups than in the White population. USRDS data show better survival amongst African-Caribbeans, native Ameri-

cans and South East Asians, but few data are available for Indo-Asians, who make up an increasing proportion of patients starting renal replacement therapy (RRT) in the UK. UK Renal Registry data were analysed to compare the characteristics, and survival on RRT, of incident patients in different ethnic groups.

Table 20.1. Centres included in the analyses

Centre	Number of patients by year					Total
	1998	1999	2000	2001	2002	
Bristol	109	115	144	139	123	630
Carlisle	0	0	0	0	28	28
Carsh	0	101	0	0	0	101
Covnt	0	80	82	93	75	330
Exeter	0	72	69	0	0	141
Glouc	0	0	0	0	57	57
Guys	111	108	119	96	111	545
Hammers	0	0	0	0	97	97
Heart	71	80	85	85	58	379
L'pool	0	0	0	0	130	130
Leic	163	161	173	179	149	825
Mbro	0	0	0	0	94	94
NewC	0	0	0	0	104	104
Notts	122	125	114	120	85	566
Oxford	0	0	0	0	145	145
Plym	69	66	57	60	79	331
Ports	0	0	0	0	130	130
Preston	0	0	115	130	112	357
Redng	0	45	47	64	43	199
Sheff	0	129	134	151	153	567
StJms	0	0	79	0	0	79
Stevn	0	0	0	0	96	96
Sthend	0	0	36	0	0	36
Sund	40	44	44	0	51	179
Wolve	0	0	77	73	99	249
Words	0	43	40	34	25	142
York	0	0	0	0	62	62
Total	685	1169	1415	1224	2106	6599

Methods

Data from annual cohorts of patients from 27 renal units with ≥85% complete ethnicity data during any year since 1998 were included in the analysis (Table 20.1). In most centres, data completeness was consistent year on year, but as can be seen, some centres were excluded for certain years if their data returns fell below 85%.

To ensure there was no selection bias associated with selecting those patients with an ethnic code compared to those without, age, gender and primary diagnosis of 315 patients with a missing ethnic code in any of the centres included were analysed. There was no significant difference except that more patients in the cohort without an ethnic code also had a missing primary diagnosis code.

Using these criteria a cohort of 6599 incident patients over a 5-year period was obtained. Ethnic groups were categorised as White, African-Caribbean, Indo-Asian, Chinese or Other. Due to the small number of Chinese (35 patients) or Other (62 patients) ethnic minorities over the 5 years, these were excluded from the statistical analyses.

The breakdown by ethnic group (White, African-Caribbean, Indo-Asian) within centres as shown in Table 20.2, shows considerable variation between units. At the Hammersmith unit only 44% of incident patients on RRT are white compared with 100% at Carlisle, Gloucester and York units. Overall, 87% of the cohort were White, 7% Indo-Asian, 5% African-Caribbean, 0.5% Chinese and 0.9% Other. Within the UK population as a whole, 92% are White and 7.9% belong to an ethnic minority (4% Indo-Asian, 2% African-Caribbean and 1.6% other).[1] Within the UK as a whole, there is wide geographical variation in the distribution of ethnic minorities (Figure 20.1), with 48% living in London, 1% in Wales and 2% in Scotland. Table 20.3 shows the ethnic breakdown by region and correlations are clearly seen between the distribution of the population as a whole, and renal patients.

The following characteristics were studied in the three main ethnic groups: age, gender, primary diagnosis, pre-dialysis estimated GFR, pre-dialysis haemoglobin, time of referral, treatment modality at day 90, co-morbidity and survival. The SAS statistical package was used with proportional Hazard Ratios for comparing survival risk, Fishers exact and chi-square test for analysing small number groupings, and Wilcoxon Rank sums for median age distributions.

Table 20.2. Ethnicity by centre

Centre	Ethnic group No. %			Total
	Asian	Black	White	
Bristol	3% (18)	4% (23)	93% 583	630
Carls	0	0	28 (100)	28
Carsh	5% (5)	4% (4)	84% (85)	101
Covnt	14% (45)	3% (11)	83% (274)	330
Exeter	0	1% (1)	99% (140)	141
Glouc	0	0	100% (57)	57
Guys	4% (21)	24% (132)	70% (383)	545
Hammer	24%(23)	11% (11)	45% (44)	97
Heart	16% (59)	5% (20)	77% (291)	379
L'pool	0	1% (1)	95% (123)	130
Leic	14% (112)	2% (13)	84% (691)	825
Mbro	2% (2)	0	96% (90)	94
NewC	4% (4)	1% (1)	94% (98)	104
Notts	5% (29)	5% (26)	89% (506)	566
Oxford	3% (5)	2% (3)	94% (136)	145
Plym	1% (3)	2% (8)	96% (319)	331
Ports	3% (4)	1% (1)	95% (124)	130
Preston	11% (39)	2% (6)	87% (311)	357
Redng	9% (18)	7% (13)	82% (164)	199
Sheff	4% (22)	1% (6)	93% (530)	567
StJms	8% (6)	1% (1)	90% (71)	79
Stevn	7% (7)	3% (3)	88% (84)	96
Sthend	0	3% (1)	97% (35)	36
Sund	1% (1)	1% (2)	98% (175)	179
Wolve	14% (34)	6% (14)	80% (198)	249
Words	6% (9)	0	94% (133)	142
York	0	0	100% (62)	62
Total	7.1% (466)	4.6% (301)	86.9% (5735)	6599

Results

Age & Gender

Overall 61% of the patients were male, comparable with total Renal Registry data. White and Indo-Asian ethnic groups had similar proportions of male patients, but African-Caribbean patients were more evenly distributed between the genders (52% males, 48% females Table 20.4) with significantly more females with ERF ($p < 0.05$).

In the UK as a whole, 16% of the general population are aged ≥65 years compared with 51% of incident ERF patients on the UK Renal Registry database. This varied considerably between ethnic groups in the general population with only 2% of African-Caribbeans and 3% of Indo-Asians aged ≥65 years, compared with 16% of Whites. In the ERF cohort, 47% of patients were aged ≥65 years and this varied significantly by ethnic group (Figure 20.2). In the White cohort, there were roughly equal proportions of patients in the two age groups (51% <65 years, 49% ≥65 years), but in both ethnic minority groups, significantly more patients were aged <65 years (69% Indo-Asians, 65% African-Caribbeans, $p < 0.001$). When split further into 3 age bands (Figure 20.2) there were widely varying patterns between the three ethnic groups. African-Caribbeans had similar proportions of patients within the three age bands, slightly increasing with increasing age; Indo-Asians on RRT were mainly in the 45–64 year age group; whilst Whites have significantly increasing proportions of patients on RRT with increasing age. The median age of Whites was significantly older than that of African-Caribbeans and Indo-Asians (64.8 v 60 v 59 years respectively, $p < 0.001$). Gender had no effect on the trend of age distribution by ethnic group.

Primary Diagnosis

Type 2 diabetes is known to occur more frequently in Indo-Asians and African-Caribbeans, and this was reflected in the Registry cohort (16% v 33% & 31% respectively p = < 0.001). Analysis initially included all ages (Table 20.5) and then analysed by aged above and below 65 years (Tables 20.6 and 20.7).

Diabetes appeared proportionately more common in the ≥65 year old African-Caribbeans and to a lesser extent in Whites, but age had little impact on the distribution of diabetes in the Indo-Asian population. This may reflect a difference in the underlying type of diabetes leading to ERF between ethnic groups.

Adult polycystic kidney disease accounted for a lower proportion of renal disease in the ethnic minority groups compared with Whites (0% Indo-Asians, 4% African-Caribbeans v 7% Whites) irrespective of age. Reno-vascular disease accounted for a higher proportion in Indo-Asians and Whites aged 65+, but in the African-Caribbean population was roughly equally distributed across the two age bands. Amongst all groups many patients had an uncertain diagnostic code (19–29%).

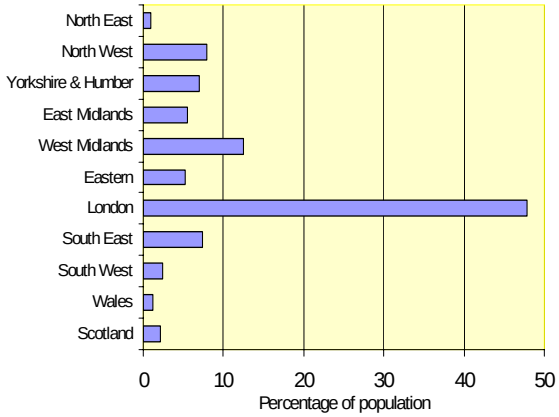

Figure 20.1. Regional distribution of ethnic minorities in the general population of GB

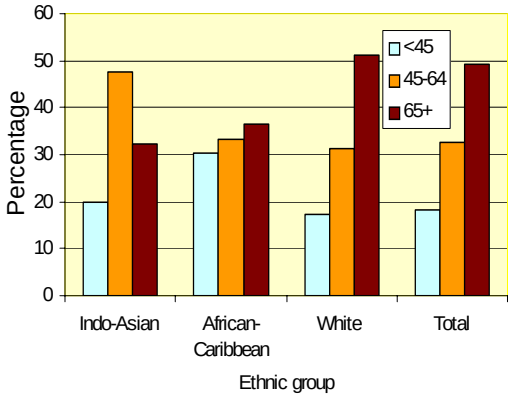

Figure 20.2 Age bands by ethnic groups

Table 20.3. Regional distribution of UK population by ethnic group

	White	Afr-Carib	Indo-Asian	Chinese	Non-White	Other
N.East	98.3	0.1	1.1	0.1	1.7	0.3
N. West	94.8	0.8	3.3	0.3	5.2	0.9
Yorks & Humb	93.7	0.7	4.4	0.2	6.3	1.0
E.Mids	94.1	1.1	3.8	0.2	5.9	0.7
W.Mids	89.3	2.0	7.0	0.3	10.7	1.4
Eastern	95.7	0.8	2.0	0.2	4.3	1.1
London	70.7	11.3	12.1	0.9	29.3	5.0
S.East	95.8	0.6	2.0	0.3	4.2	1.2
S.West	97.8	0.5	0.7	0.2	2.2	0.8
Wales	98.1	0.2	0.8	0.2	1.9	0.7
Sct	98.1	0.5	1.0	0.2	1.9	0.4
Eng	91.2	2.4	4.3	0.3	8.8	1.6
E&W	91.6	2.3	4.2	0.3	8.4	1.5

Table 20.4. Gender by ethnic group

Gender	Ethnic group % (number)			Total
	Indo-Asian	African-Carib	White	
Male	58% (268)	52% (157)	62% (3555)	61% (3980)
Female	42% (198)	48% (144)	38% (2180)	59% (2522)
Total	466	301	5735	6502

Table 20.5. Primary diagnosis by ethnic group all ages

Primary diagnosis	Ethnic group % (number)			
	Asian	Black	White	Total
Diabetes	33% (155)	31% (94)	16% (935)	1184
GN	12% (55)	10% (31)	13% (728)	814
PKD	0% (1)	4% (11)	7% (409)	421
Pyelonephritis	7% (31)	3% (8)	9% (544)	583
Reno-vascular	7% (33)	15% (45)	14% (797)	875
Other	8% (38)	12% (36)	15% (861)	935
Uncertain	29% (133)	21% (63)	19% (1087)	1283
Missing	4% (20)	4% (13)	7% (374)	407
Total	466	301	5735	6502

Table 20.6. Primary diagnosis by ethnic group aged <65 yrs

Primary diagnosis	Ethnic group % (number)			
	Asian	Black	White	Total
Diabetes	34% (109)	24% (47)	21% (594)	750
GN	15% (50)	14% (27)	16% (472)	549
PKD	0% (0)	5% (9)	11% (314)	323
Pyelonephritis	7% (23)	3% (5)	10% (286)	314
Reno-vascular	4% (14)	16% (32)	8% (235)	281
Other	9% (29)	14% (28)	16% (454)	511
Uncertain	27% (88)	21% (42)	14% (402)	532
Missing	3% (10)	4% (7)	5% (141)	158
Total	323	197	2898	3418

Table 20.7. Primary diagnosis by ethnic group aged ≥65 yrs

Primary diagnosis	Ethnic group % (number)			
	Asian	Black	White	Total
Diabetes	32% (46)	45% (47)	12% (341)	434
GN	4% (5)	4% (4)	9% (256)	265
PKD	1% (1)	2% (2)	3% (95)	98
Pyelonephritis	6% (8)	3% (3)	9% (258)	269
Reno-vascular	13% (19)	13% (13)	20% (562)	594
Other	6% (9)	8% (8)	14% (407)	424
Uncertain	31% (45)	20% (21)	24% (685)	751
Missing	7% (10)	6% (6)	8% (233)	249
Total	143	104	2837	3084

Table 20.8. eGFR (by MDRD) prior to start of RRT

		eGFR (no. of obs)			
Age	Modality	Indo-Asian	African-Caribbean	White	All
<65	HD	8.06 (174)	8 (65)	7.6 (1228)	7.67 (1468)
	PD	7.13 (95)	7.72 (71)	7.43 (1032)	7.42 (1198)
	Tx	6.77 (1)	10.71 (4)	7.82 (80)	7.94 (85)
65+	HD	8.34 (83)	9.44 (54)	8.24 (1561)	8.28 (1698)
	PD	8.97 (21)	8.71 (24)	7.64 (613)	7.72 (658)
	Tx	.	.	6.27 (2)	6.27 (2)

Estimated GFR (eGFR) prior to start of RRT

To assess whether there were any differences between ethnic groups in the pre-dialysis period, GFR, haemoglobin (Hb), and patterns of referral time were studied. The effect of age, first established treatment modality and gender were also analysed.

The eGFR was calculated using the abbreviated MDRD formula, with validated adjustments made for the African-Caribbean.[2] No adjustments were required for the Indo-Asian cohort.[3] To calculate the MDRD, the last creatinine reading taken no longer than 14 days prior to treatment start was used. The cohort size as a consequence of these restrictions was reduced to 5108.

There were few pre-emptive transplants within the cohort, reflecting the small numbers occurring generally within the renal population and so no statistical analysis was undertaken for this group.

In the majority of HD patients the eGFR at start was higher than in PD patients, irrespective of age and ethnic group, with the exception of Indo-Asians aged =65 (Table 20.8). In this latter group, Indo-Asians aged =65 on HD had an eGFR of 8.34 compared with 8.97 in PD patients. Between ethnic groups, the trend showed that Whites had a lower eGFR compared with the other ethnic minority groups. This reached statistical significance for the African-Caribbeans and Whites (p=0.002) although there was difference for the Indo-Asian and Whites (p=0.19), refuting sugges-

tions that ethnic minorities start late.[4] The older patients had a higher eGFR at start of RRT, irrespective of modality (p<0.0001).

Haemoglobin prior to start of RRT

As with the GFR calculation, haemoglobin measurements prior to initiation of RRT (taken no longer than 14 days prior to start) were used, reducing the cohort size to 5140. The mean haemoglobin levels were calculated (Table 20.9).

Within the White cohort, there was no difference in haemoglobin at start between the two age groups above and below 65 (11.1 g/dl). Within the African-Caribbean cohort, haemoglobin levels appeared lower at start in both PD (Hb 9.9 aged <65, Hb 9.6 aged =65) and HD (Hb 9.3 aged <65, Hb 9.8 aged =65) modality groups, irrespective of age, compared with the other two ethnic groups (p=0.0004 compared with Whites, p=0.018 compared with Indo-Asians). PD patients had significantly higher haemoglobin levels at start of RRT compared with HD patients(p<0.0001).

Referral patterns

It is well recognised that patients referred late to renal services have increased mortality rates that persist for at least 3 years. It has been suggested that ethnic minority groups have a higher proportion of late referrals than Whites: this was evaluated. The definition of late referral has varied between authors in the literature from 1 month to 6 months before initiation of RRT. The renal National Service Framework suggests that patients should be referred to a nephrologist 12 months prior to requiring RRT. For the purposes of this analysis, 3 months was used as the cut off for late referral (LR). The cohort size was reduced to 2736 as not all patients had both completed ethnicity and a completed date of referral.

Overall, patients were mainly referred a year or more prior to start of RRT (46% Table 20.10) but there were significant differences between the ethnic groups. More Indo-Asians were referred a year or more prior to start (53%, $p < 0.05$) compared with 38% of African-Caribbeans and 45% of Whites. Using 3 months as the definition of late referral, 34% of patients were referred late, Whites and Indo-Asians having similar proportions (34%) whilst 44% of African-Caribbeans were late referrals ($p = 0.1$). The number of African-Caribbeans in the cohort were small, thus reducing the power.

Those aged <65 were proportionately more likely to be referred more than a year prior to start of RRT than those aged ≥65 (51% v 40% respectively, $p < 0.001$, Table 20.11). They were also less likely to be referred late (31% v 39% respectively, $p < 0.001$, Table 20.11). Within the ethnic groups aged ≥65, numbers were small in all

Table 20.9. Mean Hb prior to start of RRT

		Mean Hb prior to start (number)			
Age	**Modality**	**Indo-Asian**	**African-Carib**	**White**	**All**
<65	HD	9.73 (178)	9.26 (69)	9.8 (1214)	9.87 (1651)
	PD	10.1 (101)	9.9 (71)	10.35 (1057)	10.3 (669)
	Tx	9.2 (1)	11.8 (4)	11.12 (82)	11.15 (2)
65+	HD	9.75 (87)	9.78 (55)	9.9 (1538)	9.87 (1651)
	PD	11.33 (22)	9.64 (25)	10.3 (634)	10.3 (669)
	Tx	.	.	11.15 (2)	11.15 (2)

Table 20.10. Referral patterns by ethnic group

Time (days)	Ethnic group - % (number)			
	Asian	Black	White	All
0–89	34% (63)	44% (31)	34% (849)	34% (943)
90–179	7% (13)	4% (3)	9% (219)	9% (235)
180–364	6% (11)	14% (10)	12% (291)	11% (312)
365+	53% (100)	38% (27)	45% (1119)	46% (1246)
Total	187	71	2478	2736

except Whites, and meaningful analysis was not possible.

Gender had no effect on referral patterns except within the African-Caribbean cohort, where women were less likely to be referred late than males (33% v 56% respectively, p = 0.06).

Diabetes was postulated as a possible reason as to why some ethnic minority groups may have been referred earlier than Whites. A model was constructed with ethnic group, diabetes, age group (above/below 65), gender, and interactions between ethnic group and diabetes, ethnic group and age, ethnic group and gender for Analysis of Variance. The only significant interaction was ethnic group and diabetes (p = 0.0086). The least squared means from the ANOVA were tested (diabetic v non diabetic by ethnicity).

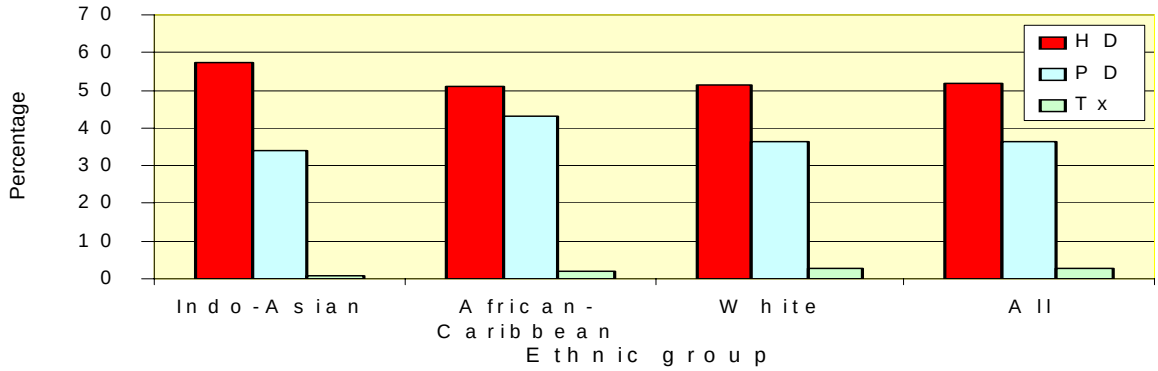

Figure 20.3. Treatment modality on Day 90 by ethnic group

Table 20.11 Referral patterns by ethnic group and age

Time (days)	Ethnic group % (number)							
	Indo-Asian		African-Caribbean		White		All	
	<65	65+	<65	65+	<65	65+	<65	65+
0 –89	34% (45)	34% (18)	46% (19)	40% (12)	30% (386)	39% (463)	31% (450)	39% (493)
90–179	5% (7)	11% (6)	5% (2)	3% (1)	8% (101)	10% (118)	8% (110)	10% (125)
180–364	6% (8)	6% (3)	10% (4)	20% (6)	12% (149)	12% (142)	11% (161)	12% (151)
365+	55% (74)	49% (26)	39% (16)	37% (11)	51% (652)	39% (467)	51% (742)	40% (504)
Total	134	53	41	30	1288	1190	1463	1273

Table 20.12. Referral patterns by diabetic status and ethnic origin

Time (days)	Ethnic Groups. % (Number)					
	Indo-Asian		African-Caribbean		White	
	Diabetes	Non-diabetes	Diabetes	Non-diabetes	Diabetes	Non-diabetes
0–89	29% (37)	44% (26)	52% (28)	18% (3)	36% (744)	25% (105)
90–179	5% (7)	10% (6)	6% (3)	0	8% (166)	12% (53)
180–364	7% (9)	3% (2)	4% (2)	47% (8)	11% (222)	16% (69)
365+	59% (75)	42% (25)	39% (21)	35% (6)	45% (921)	47% (198)
Total No.	128	59	54	17	2053	425

There were fewer diabetic African-Caribbean patients referred late compared with non-diabetics (18% v 52% respectively, p = 0.03, Table 20.12). Although there appeared to be a similar trend seen in Whites (25% of diabetics referred late compared with 36% of non-diabetics), the ANOVA analysis indicated this was not significant (p=0.9) . In the Indo-Asian group the trend was reversed with 44% of diabetics referred late v 29% of non-diabetics p = 0.002).

Treatment modality

Ethnicity had no effect on the choice of modality at day 90 of treatment (Figure 20.3). Haemodialysis (HD) was the commonest modality in all groups (52%) but appeared slightly more common in Indo-Asians (58%).

Co-morbidity

For this analysis, only those centres with annual cohorts of at least 85% ethnicity returns and 80% co-morbidity returns were included. As a consequence, only 6 centres were included (Bristol 1999–2001, Leicester 1998–1999 & 2001, Sheffield 2001, St. James 2000, Nottingham 2002 and Hammersmith/Charing Cross 2002), providing a cohort of 1153 patients (111 Indo-Asian, 34 African-Caribbean and 1008 White). The Fisher's exact test was used to calculate statistical significance as there were small numbers in the ethnic minority groups.

Although there was a trend towards more Whites having cardio-vascular or peripheral vascular disease, this did not reach statistical significance (Figure 20.4). Whites however were more likely than Indo-Asians or African-Caribbeans to be smokers at initiation of RRT (p < 0.001) and probably as a consequence more patients had chronic obstructive airways disease (COPD) (p = 0.004). Malignancy was also significantly more common in Whites (13%) than Indo-Asians (3%) and African-Caribbeans (6%) (p < 0.001).

The presence of diabetes as an associated co-morbidity, but not as the primary cause of renal failure, appeared more common in Indo-Asians (12%) and African-Caribbeans (9%) than Whites (7%), but this did not reach statistical significance. When considered present as either co-morbidity or underlying primary renal disease, this difference then reached statistical significance (p < 0.001).

Social deprivation

The Townsend index was used as the scoring system for social deprivation, which was derived from the patient's postcode. The Townsend index (calculated for the Registry from the 2001 census data, by Hannah Jordan of Southampton University) is a com-

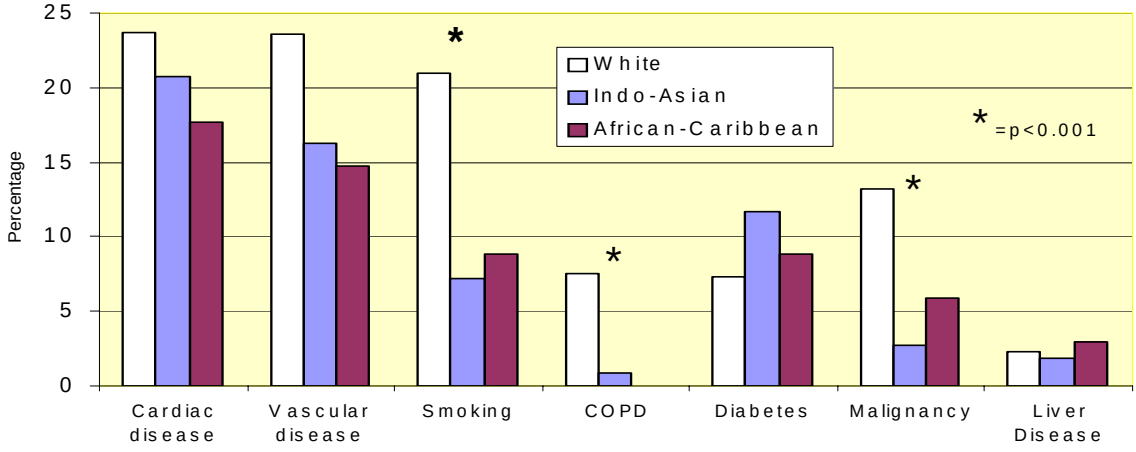

Figure 20.4. Co-morbidity by ethnicity

Table 20.13 Deprivation group by ethnicity

	Deprivation Group % (number)				
Ethnic group	**1**	**2**	**3**	**4**	**5**
Indo-Asian	8.3% (38)	5.5% (25)	12.5% (57)	30.4% (139)	43.3% (198)
African-Caribbean	3.1% (9)	4.4% (13)	6.8% (20)	24.2% (71)	61.6% (181)
White	17.5% (987)	17.7% (1000)	19.4% (1095)	22.8% (1286)	22.6% (1272)
All	16.2% (1034)	16.2% (1038)	18.3% (1172)	23.4% (1496)	25.8% (1651)

posite measure of deprivation based on total unemployment rate, no-car households, overcrowded households and not owner-occupier households based on the electoral ward as at the 2001 Census. The higher the Townsend index, the greater is the deprivation. For this analysis, the UK general population was divided into quintiles of deprivation (1 lowest, 5 highest).

Significant differences in the distribution quintiles of social deprivation scores were seen in the different ethnic groups on RRT (Table 20.13).

In all three ethnic groups there was a tendency for increasing deprivation to be associated with an increased incidence of ERF. There was a marked difference between the patterns seen in Whites and non-Whites. Approximately 74% of Indo-Asians and 86% of African-Caribbeans on RRT were in deprivation group 4 or 5, compared with 45% of Whites. In the African-Caribbean population, there were significantly higher proportions of people in group 5 (62%, $p < 0.05$). African-Caribbean patients were likewise represented the least in group 1 (3%) closely followed by Indo-Asians with 8% and 18% of Whites in comparison ($p < 0.05$).

The Office for National Statistics has not yet released the 2001 Census information on deprivation by ethnicity. It is therefore not possible to know to what extent the above differences may reflect greater deprivation in the ethnic minority UK population or be related to an increased burden of renal disease.

Survival Analyses

Survival was analysed at 90 days and 1 year after 90 days. In the first 90 days there were 484 (8%) deaths in the incident cohort, 27 Indo-Asian (6%), 9 African-Caribbean (3%), and 448 White (8%). In the 1-year after 90 days, there were 172 (12%) deaths, (11% Indo-Asian, 8% African-Caribbean, 16% White). Adjustments were made for age and hazard ratios (HR) were calculated for the ethnic minorities as compared with Whites (Table 20.14). African-Caribbeans had a significantly lower risk of death in the first 90 days (HR 0.48, 95%CI 0.25–0.94, $p = 0.03$) compared to Whites, whilst Indo-Asian rates were similar (HR 0.68, 95%CI 0.68–1.49, $p = 0.97$). At 1 year after 90 days, this survival advantage persisted (HR 0.575, 95%CI 0.349–0.947, $p = 0.03$).

To assess the impact of primary renal diagnosis, time of nephrological referral, haemoglobin immediately before RRT, and eGFR prior to start of RRT, a multivariate analysis was undertaken on the survival data (Tables 20.15 and 20.16).

Table 20.14. Survival hazard ratios by age and ethnicity; Whites as reference

	90 days	**1 year after 90 days**
Variable	**Hazard Ratio (95% HR CI)**	**Hazard Ratio (95% HR CI)**
Age	1.056 (1.048–1.065)	1.050 (1.043–1.058)
African-Caribbean	0.484 (0.25–0.937)	0.575 (0.349–0.947)
Indo-Asian	1.007 (0.681–1.489)	0.919 (0.642–1.317)

Those patients coded with a ‘missing’ primary renal diagnosis had a significantly higher risk of death (HR 4.23, 95%CI 1.33–

Table 20.15. 90 day survival; White and GN as reference

Variable	Hazard ratio	95% Hazard ratio	Confidence
Age	1.059**	1.040	1.079
Male gender	1.141	0.761	1.713
African-Caribbean	0.347	0.048	2.511
Indo-Asian	0.617	0.224	1.700
Diabetes	1.573	0.643	3.849
PKD	0.640	0.132	3.105
Pyelonephritis	1.806	0.671	4.862
Reno-vascular	1.824	0.776	4.287
Missing	4.226*	1.328	13.446
Other	1.697	0.693	4.158
Uncertain	1.414	0.610	3.279
Hb pre RRT	1.066	0.936	1.214
eGFR pre RRT	1.068 *	1.015	1.124
Late Referral	1.589	1.056	2.393

Table 20.16. 1 year after 90 days survival; White and GN as reference

Variable	Hazard ratio	95% Hazard ratio	Confidence
Age	1.045**	1.032	1.059
Male gender	0.858	0.622	1.185
African-Caribbean	0.314	0.077	1.279
Indo-Asian	0.669	0.324	1.379
Diabetes	4.135**	1.938	8.820
PKD	0.935	0.247	3.538
Pyelonephritis	1.377	0.516	3.675
Reno-vascular	2.394*	1.092	5.245
Other	4.854**	2.265	10.400
Missing	6.661**	1.982	22.386
Uncertain	1.920	0.888	4.152
Hb pre RRT	0.934	0.847	1.031
eGFR pre RRT	1.085**	1.042	1.129
Late Referral	1.345	0.967	1.870

* $p < 0.05$; ** $p < 0.001$

13.45, p = 0.01 at 90 days, and HR 6.66, 95%CI 1.98–22.39 at 1-year after 90 days), although confidence limits were large due to small numbers.

Haemoglobin prior to start of RRT, did not affect survival rates but the higher the eGFR at initiation of RRT, the higher the likelihood of death within 90 days (HR 1.07, 95%CI 1.02–1.12, p = 0.01) and 1-year after 90 days (HR 1.09, 95%CI 1.04–1.13, p < 0.001).

At 1 year after 90 days, primary renal diagnosis had a significant impact on survival. Patients with diabetes as a primary diagnosis had a significantly higher chance of death in the year after 90 days (HR 4.14, 95%CI 1.94–8.82, p < 0.001), as did those with reno-vascular disease (HR 2.39, p = 0.03) or a missing diagnostic code (HR 6.66, p = 0.002). Despite these factors, African-Caribbean patients still had a significantly lower risk of death but only at 1 year after 90 days.

In this subgroup analysis of ethnicity (unlike the total late referral cohort analysis in Chapter 16), being referred late to nephrology services did not statistically affect survival at 1 year after 90 days (p = 0.07), its

inclusion in the multivariate analysis did render any survival advantage in African-Caribbeans non-significant (HR 0.31, 95%CI 0.08–1.28, p = 0.1). This is possibly due to the large drop in cohort size to 1411 of which only 202 were African-Caribbean. The multivariate analysis excluding adjustments for referral time (*n* = 2863) suggested African-Caribbeans had a survival HR of 0.44 (95%CI 0.22–0.86, p = 0.016).

Co-morbidity was not factored into our survival analyses, as cohort numbers became very small.

Discussion

These data show differences between the three major ethnic groups in the UK in demographic characteristics, initial treatment, haemoglobin, and survival rates, particularly at 1 year after 90 days. Current analyses are under way to look at the Kaplan–Meier survival curves over the longer term to see if this survival advantage persists, as has been reported from the USA.

Median age in Whites was much higher than in the ethnic minorities. This may reflect the younger age of ethnic minorities within the UK population as a whole although primary diagnosis may also influence this. Diabetes is the commonest identifiable cause of ERF in all ethnic groups, but is far more frequent in Indo-Asians and African-Caribbeans. It has been postulated that Type 2 diabetes tends to have an earlier onset in Indo-Asian minorities than in Whites, possibly contributing to the lower median age at start in non-Whites. In African-Caribbeans, ERF secondary to Type 2 diabetes typically presents in the 5th and 6th decade. In this cohort however, Indo-Asian and African-Caribbean diabetic renal patients were significantly older than their non-diabetic counterparts (p < 0.001); the reverse was true in Whites (Table 20.17).

Table 20.17. Median age of patients by ethnic group and diabetes status

Diabetes status	Indo-Asian	African-Caribbean	White
Diabetic	61.1	63.3	62.0
Non-diabetic	49.4	58.3	65.2

Diabetes may also contribute to the gender differences between the African-Caribbean population and the Whites and Indo-Asians. African-Caribbean males had twice the incidence of diabetes as White males, but in females the difference was four-fold.

Although many African-Caribbeans starting RRT were diabetic and as a consequence had regular surveillance, it was surprising that a larger proportion of these patients were referred late. This may be a consequence of a combination of the above factors with social deprivation. The African-Caribbean cohort had the largest proportion of patients in social group 5, although analyses in Chapter 16 have shown no significant relationship between high deprivation and late referral.

Haemoglobin levels were higher prior to starting RRT in PD patients than HD patients. In African-Caribbeans, haemoglobin levels are lower than in other groups, but as they are more likely to be referred late, this may simply be a reflection of inadequate pre-dialysis anaemia management.

Estimated GFR was higher in patients starting HD than those starting PD. The older patients tended to have a higher eGFR at start of RRT.

Numerous factors affect survival on RRT including age at onset of RRT,[5,6] co-morbid disease prior to start of RRT,[5] and primary renal diagnosis.[6,7,8] None of these factors have been shown to account for the survival differences apparent in some ethnic minority groups. Suggested reasons in the litera-

ture have included the low voluntary withdrawal rates in ethnic minorities,[5,9] but the percentage of deaths explained by this means are relatively small, accounting for only up to 23% of the difference in 1 year survival rates between whites and African-Caribbean.[10]

Lower co-morbidity rates in ethnic groups have led to suggestions that sicker patients in these groups may not be offered RRT. Whites were significantly more likely to have malignancy, COPD and to smoke than the ethnic minorities. In the literature, white smokers with symptomatic cardiovascular disease at the start of RRT were at very high risk of death.[11] Despite these possibilities, non-smoking Whites still have a tendency to an increased risk of death compared with Indo-Asians and African-Caribbean, suggesting that smoking is not the only factor influencing survival.

In our study, although there was a trend for White patients compared with the ethnic minorities to have cardiac disease at initiation of RRT, this did not reach statistical significance. Pei *et al.* found that although the prevalence of cardiovascular disease as co-morbidity at the start of RRT was higher in Whites,[11] this did not explain the survival difference between the ethnic groups. There may be a differential susceptibility to cardiovascular complications that is environmentally or genetically controlled.

Within the US general population, there is also a longer life span in African-Caribbeans when compared with the White population. No such general data are available for the UK ethnic minorities, but there may be genetic factors unrelated to any associated renal condition that provides African-Caribbeans with a survival advantage.

Conclusion

These data demonstrate that patients starting RRT from different racial groups show differences in many demographic and other characteristics, and survival rates, particularly at 1 year after 90 days. Current analyses are under way to look at the Kaplan–Meier survival curves over the longer term to see if this survival advantage persists, as has been reported from the USA.

Ethnicity is an important variable that must be taken into account when determining equity of provision and outcomes between renal centres. The Registry needs to work with renal units to achieve improved reporting levels of ethnicity. These data will both aid further analyses and also facilitate planning adequate provision of RRT services in differing communities.

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Chapter 21: Co-morbidity in Incident Patients

Summary

- Adjustment for co-morbidity has been increasingly used in analyses throughout this years report (Chapters 16, 17, 18, 19 and 20).

- Co-morbidity adjustment was important for calculating survival. After adjusting for co-morbidity, social deprivation was no longer significant in the Cox model.

- The incidence of co-morbidity increased with age up to age 75. In patients aged over 75, the percentage starting RRT with cardiovascular and cerebrovascular disease appeared to reduce.

- Diabetic patients starting RRT had higher co-morbidity than non-diabetics despite their younger age (45% v 36%, $p<0.001$). Even after adjusting for co-morbidity in the Cox survival model, being diabetic was still a significant additional risk factor.

- Patients with co-morbidity tended to start RRT earlier with higher eGFRs.

- Co-morbidity returns are still poor and this is restricting survival analyses. Compared with the previous year, 4 centres had improved returns by more than 50% and 4 centres had worse returns.

- In 2003 co-morbidity, at start of RRT, was altered to include heart failure and non-coronary grafts and stents.

Co-morbidity data

The Registry has defined 15 'yes' (present) or 'no' questions relating to co-morbidity and asks clinicians to complete this record at the time of starting RRT. As an example, the screen made available to renal units using the CCL Proton system is shown in Figure 21.1. A patient may therefore have a fully completed screen, which has recorded that there are no co-morbid conditions present. Null entries are considered as missing data rather than a 'no'.

Beginning in 2003, the presence or absence of heart failure prior to the start of renal replacement therapy was also recordable. Definitions for each co-morbidity are given at the end of this chapter.

These data are used, together with age, ethnicity, primary diagnosis, etc., in survival and other analyses.

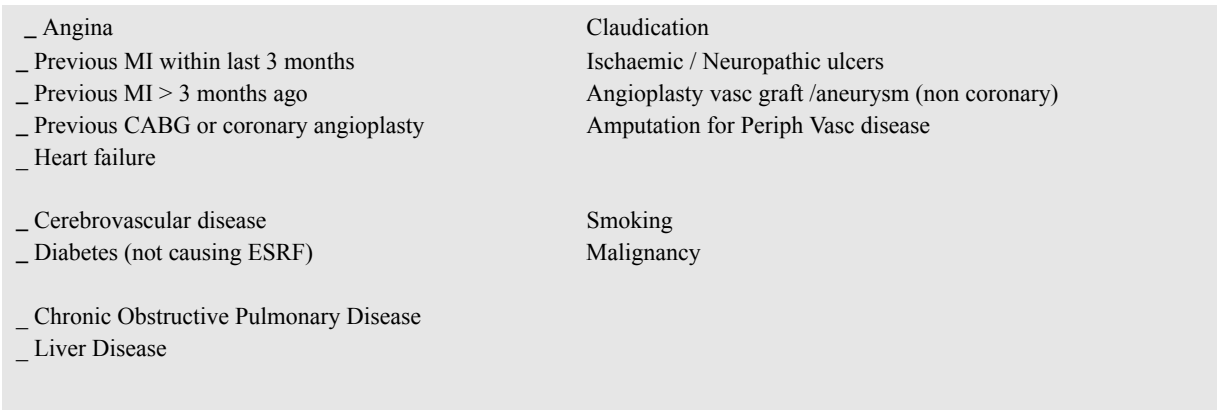

Figure 21.1. Co-morbidity entry screen for the CCL Proton system

Co-morbidity returns by renal units

The return of co-morbidity data for incident patients in 2002 remained very incomplete, although it had increased from previous years. Prior to 1999, co-morbidity data were rarely returned to the Registry. In 1999, at least one item of co-morbidity was reported for 20.8% of those patients registered as starting RRT that year. The returns by unit and year of starting RRT are shown in Table 21.1.

Table 21.1. Co-morbidity data returns, by centre, at the start of RRT

Treatment centre	1999		2000		2001		2002	
	No. incident	% Return co-morbidity	No. incident	% Return co-morbidity	No. incident	% Return co-morbidity	No. incident	% Return co-morbidity
Bradford	–	–	39	48.7	61	91.8	61	100
Bristol	117	88.9	147	93.2	149	83.2	151	75
Cambridge	–	–	64	0	48	0	104	4
Cardiff	135	0	134	0	136	0	155	0
Carlisle	26	46.2	28	35.7	25	4.0	26	20.7
Carshalton	108	10.2	116	10.3	118	12.7	119	0.6
Coventry	91	0	88	0	101	0	104	0
Derby	25	0	40	0	49	0	-	-
Exeter	82	28.0	72	34.7	99	18.2	98	39
Gloucester	59	1.7	46	97.8	49	87.8	50	64.9
Guys	119	0	120	0	103	0	109	0
Heartlands	82	0	86	0	64	0	85	0
Hull	64	1.6	81	2.5	75	0	75	3.8
Leeds LGI	62	25.8	68	85.3	74	70.3	76	50.8
Leicester	158	80.4	171	76.6	174	86.8	183	76.2
Liverpool	–	–	154	31.2	182	35.2	183	8.7
Notts	128	24.2	113	71.7	121	64.5	121	98.9
Oxford	134	0	132	1.5	163	0	170	0
Plymouth	67	0	60	0	63	0	64	0
Portsmouth	–	–	104	0	141	39.7	144	36.4
Preston	104	0	116	0	134	0	137	0
Reading	45	0	54	0	72	0	65	0
S Cleveland	90	0	87	70.1	81	90.1	82	0
Sheffield	133	17.3	134	78.4	150	84.7	152	57.1
Stevenage	–	–	103	0	126	0	125	1.0
Southend	43	2.3	39	2.6	35	20.0	37	31.4
St James	79	86.1	91	93.4	86	76.7	87	76.3
Sunderland	45	0	45	0	35	0	40	46.4
Swansea	83	26.5	90	58.9	110	40.0	111	74.8
Truro	–	–	38	7.9	35	37.1	38	63.8
Wolverhmtn	75	0	77	0	77	0	76	0
Wordsley	43	0	40	0	34	0	34	0
Wrexham	51	0	55	0	36	0	36	0
York	51	74.5	40	92.5	36	77.8	38	68.7
Totals	2299		2872		3042		3136	

Frequency of co-morbidity returned

Table 21.2. Frequency of co-morbidity at the time of starting RRT

Co-morbidity	Age <65 years		Age >65 years		Total %
	No. pts	%	No. pts	%	incidence
Angina	57	10.1	169	26.7	18.8
MI in past 3 months	13	2.3	28	4.4	3.4
MI >3 months ago	29	5.1	103	16.3	11.0
CABG/angioplasty	23	4.1	33	5.2	4.7
Cerebrovascular disease	40	7.0	105	16.6	12.1
Diabetes (not as cause of ERF)	25	4.5	68	10.8	7.8
Diabetes as primary disease	350	20.4	259	14.5	17.6
Diabetes of either category	55	23.6	84	19.2	21.4
COPD	32	5.6	71	11.3	8.6
Liver disease	13	2.3	11	1.8	2.0
Malignancy	31	5.5	105	16.7	11.3
Claudication	25	4.4	85	13.5	19.2
Ischaemic/neuropathic ulcers	20	3.5	28	4.5	4.0
Angioplasty/vascular graft	4	0.7	27	4.3	2.6
Amputation	13	2.3	9	1.4	1.8
Smoking	105	19.1	85	13.9	16.4

Abbreviation: MI - myocardial infarction; CABG - coronary artery bypass grafting; ERF - established renal failure; COPD - chronic obstructive pulmonary disease

Total number of patients with data entered for each co-morbidity, and percentage of total incident patients with each co-morbidity present, are shown in Table 21.2.

Frequency of co-morbidity by age band

In Figure 21.2 there is an increase in the presence of cardiac and cerebrovascular co-morbidity with age although in patients over 75 this appears to reduce. Within the general population co-morbidity would be expected to increase with age. Whether this reduction is due to these patients either dying prior to starting renal replacement therapy, or not being referred or accepted for renal replacement therapy is unknown.

Figure 21.3 demonstrates the increased incidence of diabetes and malignancy with age of patients starting renal replacement therapy. The incidence of smoking in patients starting renal replacement therapy reduces from the age of 45, while peripheral vascular disease follows a similar pattern to cardiac co-morbidity, decreasing in patients aged 75 or more years.

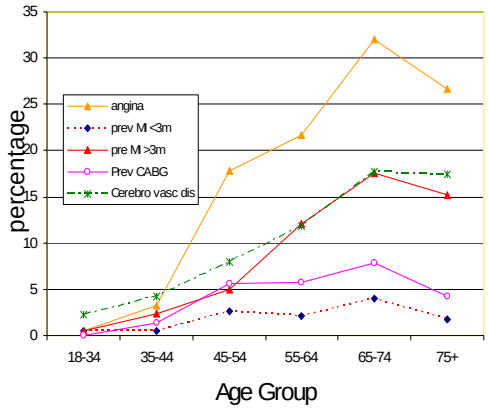

Figure 21.2. Frequency of cardiac and cerebrovascular co-morbidity in incident patients

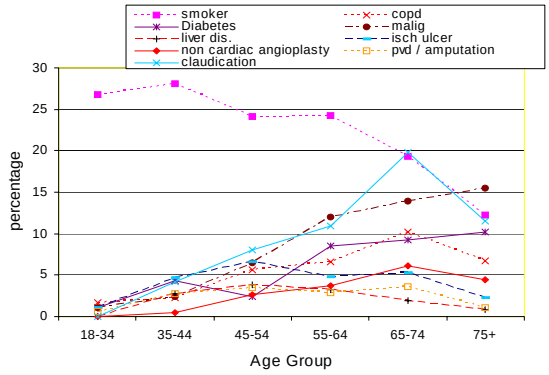

Figure 21.3. Frequency of co-morbidity in incident patients

Frequency of co-morbidity by modality at day 90

The frequency of co-morbidity within the different dialysis modalities varies (Figure 21.4). Interpretation of these differences is difficult, as not only is the median age of PD patients less than that of HD patients, those starting RRT aged over 75 (who are more likely to be on HD) have less co-morbidity than those aged 65 – 75 years (see Figures 21.2 and 21.3).

Frequency of co-morbidity in diabetics and non-diabetics

Figure 21.5 shows that diabetic patients have significantly more co-morbidity than non-diabetics, despite having a younger median age.

Smoking was the most frequent co-morbidity in both diabetic and non-diabetic patients (22% and 20% respectively). Malignancy was more common at the start of renal replacement treatment in non-diabetic than in diabetic patients (12% v 3%, p<0.0001). In diabetic ERF patients, cerebrovascular disease, peripheral vascular disease and cardiac disease were all significantly more common at the start of treatment than in non-diabetic patients. For this analysis cardiac disease included 'angina', 'previous myocardial infarction' (MI) and previous cardiac by-pass grafts. When analysed separately, angina was present in 30% of diabetics at start of RRT compared with 20% of non-diabetics (p<0.0001) and 'MI more than 3 months prior to start of treatment' was significantly more common in diabetics (14% v 11%, p=0.02). There was no difference in the proportion of diabetics and non-diabetics who had an 'MI less than 3 months before the start of renal replacement therapy' (4% v 3%, p=0.17); similarly, previous coronary angioplasty was uncommon in both

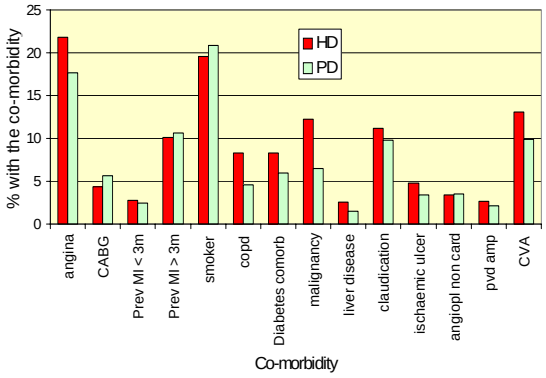

Figure 21.4. Frequency of co-morbidity by modality at day 90

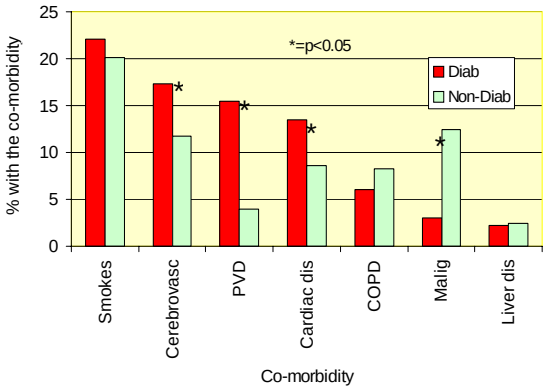

Figure 21.5. Frequency of co-morbidity in diabetics and non-diabetics

diabetics and non-diabetics (6% v 5% respectively, p=0.22). Peripheral vascular disease (PVD), which included 'claudication', 'ischaemic and neuropathic ulcers', 'non-cardiac angioplasty' and 'amputations due to ischaemia', was significantly more common in diabetic patients (p<0.001).

A Cox proportional hazards model, which included age (as a linear variable), ethnicity, primary diagnosis (including diabetes) and co-morbid diagnoses, was constructed to analyse incident patient survival, excluding the first 90 day period. In the first model, centres were excluded if they had less than 80% co-morbidity returns (n= 1,139). In the second model all patients from centres returning co-morbidity were included (n = 3,206). In both these models diabetes remained a significant variable in the model after adjusting for other co-morbidity (p= 0.02 and p = <0.0001 respectively). Diabetes also remained significant in the second model as a co-morbidity (i.e. not as the primary diagnosis for renal failure) (p= 0.0054).

Social deprivation and Co-morbidity

The Townsend index was used as a measure of social deprivation (calculated for the Registry from the patients' postcode from the 2001 census data, by Hannah Jordan of Southampton University). It is a composite measure of social deprivation based on total unemployment rate, no car households, overcrowded households and not owner-occupier households, based on the electoral ward as at the 2001 Census. The higher the Townsend index, the greater is the social deprivation. A full analysis is included in Chapter 17 of this years report.

The analysis used an incident cohort which was analysed by dividing the UK general population according to quintiles of social deprivation. The results showed that the more socially deprived groups were younger and had higher rates of co-morbid illnesses (more diabetes, cardiovascular disease, peripheral vascular disease, and COPD) than the more affluent groups. They were also significantly more likely to be current smokers (21.5% v 14.8% p<0.0001). The incidence of malignancy was reduced in the more socially deprived groups.

In the univariate analyses, increasing social deprivation was correlated with reduced patient survival (after adjusting for age). After including the co-morbidity data (which remained an independent predictor of survival) in the Cox proportional hazards model, social deprivation was no longer an independent predictor of survival (p= 0.97). These analyses showed the importance of being able to adjust each centre's survival for the presence of co-morbidity.

Estimated GFR prior to RRT and co-morbidity

Using the abbreviated MDRD calculation, the eGFR prior to starting renal replacement therapy is shown in Table 21.3.

Patients with co-morbidity generally started renal replacement therapy earlier than those without co-morbidity and appeared to have a higher median eGFR, although these differences may be smaller than might have been expected clinically.

Table 21.3. Median eGFR and presence or absence of co-morbidity

	Present (95%CI)	Absent (95%CI)
Angina	7.7 (8.0 – 8.6)	6.8 (7.2 – 7.5)
MI in past 3 months	7.6 (7.3 – 9.5)	6.9 (7.4 – 7.7)
MI >3 months ago	7.3 (7.6 – 8.4)	6.9 (7.4 – 7.7)
CABG/angioplasty	7.8 (7.7 – 9.1)	6.9 (7.4 – 7.7)
Cerebrovascular disease	7.6 (7.9 – 8.8)	6.9 (7.3 – 7.6)
Diabetes (not as cause of ERF)	7.5 (7.4 – 8.7)	6.9 (7.4 – 7.7)
Diabetes as primary disease	8.0 (8.3 – 8.6)	6.9 (7.5 – 7.6)
Diabetes of either category	-	-
COPD	7.5 (7.7 – 8.8)	6.9 (7.4 – 7.7)
Liver disease	7.3 (7.2 – 8.9)	7.0 (7.4 – 7.7)
Malignancy	6.9 (7.1 – 8.1)	7.0 (7.4 – 7.7)
Claudication	7.8 (7.9 – 8.8)	6.9 (7.3 – 7.6)
Ischaemic/neuropathic ulcers	7.7 (7.7 – 9.2)	6.9 (7.4 – 7.7)
Angioplasty/vascular graft	7.8 (7.5 – 9.4)	7.0 (7.4 – 7.7)
Amputation	8.7 (8.5 – 10.8)	6.9 (7.4 – 7.7)
Smoking	7.1 (7.3 – 8.0)	6.9 (7.4 – 7.7)

Appendix to Chapter 21

Important changes to co-morbidity definitions in 2003

The non-coronary angioplasty group has been widened to include other vascular grafts and arterial stents. The new definitions are given below:

Angioplasty, stenting, vascular graft and aneurysm (all non-coronary)

This category now includes vascular grafts (e.g. aortic bifurcation grafts), vascular aneurysms and arterial stents.

Episode of heart failure (right or left) prior to RRT

This is whether or not it was only the result of fluid overload.

Co-morbidity definitions

Angina

A history of chest pain on exercise with or without ECG changes, exercise tolerance test, radionucleotide imaging or angiography.

Previous MI within the past 3 months

The rise and fall of a biomarker (CK, CK-MB or Troponin) together with one of either: ischaemic symptoms, pathologic Q waves, ischaemic ECG changes or a coronary intervention. This definition is from both the European Society of Cardiology and the American College of Cardiology.

Previous MI more than 3 months ago

From the time of the start of RRT.

Previous CABG or coronary angioplasty

Episode of heart failure (right or left)

This is whether or not it was only caused by fluid overload.

Cerebrovascular disease

Any history of strokes (of whatever cause) and including transient ischaemic attacks caused by carotid disease.

Diabetes (not causing established renal failure)

This includes diet-controlled diabetics.

Chronic obstructive pulmonary disease

This is defined as a slowly progressive airways disorder characterised by obstruction of the expiratory airflow, which does not change markedly over several months, may be accompanied by airway hyper-reactivity and may be partially reversible.

N.B. Chronic bronchitis and emphysema may occur in the absence of airflow obstruction. Asthma patients may rarely develop airflow obstruction that does not improve with steroids.

Liver disease

Persistent enzyme evidence of hepatic dysfunction *or* biopsy evidence *or* hepatitis B e antigen or hepatitis C antigen (polymerase chain reaction) positive serology.

Malignancy

Defined as any history of malignancy (even if curative), for example the removal of a melanoma; excludes basal cell carcinoma.

Claudication

Current claudication based on a history, with or without Doppler or angiographic evidence.

Ischaemic/neuropathic ulcers

The current presence of these ulcers.

Angioplasty, stenting, vascular graft, vascular aneurysm (all non-coronary)

This category now includes vascular grafts (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 22: International Comparisons: incidence, prevalence markers of quality of care, and survival

Summary

- Amongst developed countries, the UK has a relatively low acceptance rate for RRT, with a low proportion due to diabetic nephropathy.
- The percentage of prevalent patients in the UK on peritoneal dialysis is in the upper quartile.
- The prevalence of renal transplant patients in the UK is near the median for Europe.
- Biochemical markers of quality of care in the UK are comparable with the USA and Australia and better than New Zealand.
- Two year survival of incident patients in the UK is around the European average.
- Death rates of point prevalent RRT patients in the UK are better than those in the USA.

Problems of international comparison

When making international comparisons of renal replacement therapy it is essential to ensure that the data sets are truly comparable. There are two main types of data used; data sets from national registries and data sets from sample studies, such as the Dialysis Outcomes and Practice Pattern Study (DOPPS). There are problems associated with both types of data set. Registries may have complete or near complete coverage of their country or region, but often lack detail (e.g. co-morbidity) and depend on the rigour of individual renal units to ensure the accuracy of the data. Not all renal units are mobilised or motivated for accurate data collection. The UK Renal Registry is now accumulating a useful volume of detailed data, including some co-morbidity data. Sample studies such as DOPPS are often well-funded and enthusiastically pursued, and record detailed data, but are open to sampling errors, which may be important when it comes to interpretation.

The DOPPS Study was originally set up to study the influence of practice patterns on renal replacement therapy outcomes, and not to make international comparisons. A series of valuable papers have recently been published, especially on the relationship of practice to outcomes. However, despite the original intentions, the Study has published some international comparisons.[1] There are major differences in the data on outcomes published by DOPPS and results found from the UK Renal Registry, which deserve evaluation. The differences are due to an inevitable modality sampling bias in the DOPPS Study.

The DOPPS Study is not a general study of dialysis practice, but of haemodialysis practice in particular. The haemodialysis population in any country is a selected population, dependent on the prevailing and historical use of alternative therapies (peritoneal dialysis) and transplant rates. Thus, in the five European DOPPS countries (France, Germany, Italy, Spain, UK) the proportion of prevalent patients on haemodialysis varies from 33% in the UK to 71% in Germany. The respective figures for peritoneal dialysis are 18% and 4%, and for renal transplantation the range is from 47% in the UK to 21% in Italy (Table 22.1a).

In Chapter 4 of this report it is demonstrated that patients starting peritoneal dialysis are very different from those starting haemodialysis. Peritoneal dialysis patients are much younger, are fitter with less co-morbidity and are twice as likely to receive a renal transplant within 2 years of starting dialysis.

Table 22.1a. Percentage of patients on each modality in European DOPPS countries dialysis

Country	HD	Home HD	PD	Transplant
France	Not available			
Germany	71	-	4	24
Italy	70	-	9	21
Spain	52	-	5	43
UK	33	2	18	47

Table 22.1b. Percentage of dialysis patients on each modality in European DOPPS countries

Country	HD	Home HD	PD
France	87	3	10
Germany	93	1	5
Italy	89	-	11
Spain	91	-	9
UK	63	3	34

The haemodialysis population is thus a relatively selected group of patients not fit for transplantation or not yet transplanted. It is not surprising that the survival of a point-prevalent sample of haemodialysis patients from the UK, as reported by DOPPS, is less than that of a sample of patients from Germany or Italy, where over 70% of patients are treated by haemodialysis, with a low use of peritoneal dialysis and renal transplantation. When DOPPS attempted to allow for these factors the differences in outcome ceased to be significant.

In contrast with the DOPPS results, the results in this chapter show that survival for renal replacement therapy patients in the UK is at least as good as for other European countries, and significantly better than in the USA.

The data used for international comparisons in this chapter are all derived from large national or renal registries.

International comparative incidence data

The estimated UK annual acceptance rate has slowly risen to 103.0 p.m.p., inclusive of 2.0 p.m.p. paediatric patients, over the last 5 years (Table 22.2) (see Chapter 3, National Renal Review).

Table 22.2. Annual incidence rates of RRT by country, per million population

	Incidence			
Country	**2000**	**2001**	**2002**	**% diabetic**
USA	337	334	334	44
Taiwan	311	331	-	35
Japan	252	252	262	38
Germany	175	184	174	36
Belgium (French)	-	-	170	17
Czech Republic	151	163	157	35
Canada	143	152	-	34
Greece	157	164	151	27
Italy	131	136	-	17
Austria	133	136	132	34
Denmark	-	-	130	26
Hungary	129	130	-	21
Spain	132	127	126	22
Uruguay	126	-	-	18
Sweden	126	124	125	25
New Zealand	110	119	115	45
Netherlands	93	100	-	16
UK	**89***	**95**	**103**	**20**
Poland	-	-	99	24
Australia	92	97	94	26
Finland	95	90	92	33
Norway	89	95	92	12
Turkey	52	-	-	23

*Adults only.

Criteria in establishing data sets

International comparisons are subject to the problems of different definitions and levels of ascertainment. It is not clear whether the small number of paediatric patients is included in the figures for all countries. In many countries there is uncertainty about the earliest date recorded – in the UK it is the first RRT, in the USA it is the 90th day of RRT. In the other European countries there is considerable variation between these extremes: it is often the date at which a patient is transferred to the renal service, although dialysis or haemofiltration may have been occurring for some weeks before. The later the date, the lower the incidence and early mortality, as the initial 90-day high mortality will be lost.

Some countries show a very similar pattern to the UK with a rate around 90-100 p.m.p., with/without a small upward trend – this group includes several Northern European countries (Finland, Netherlands, Norway) and Australia. Sweden and New Zealand, which might be expected to have this pattern, have higher rates. Southern European countries, which have lower rates of cardiovascular disease and longer life expectancy than the UK, have higher rates of RRT (Italy, Greece, Spain). One might speculate that the competing risk of cardiovascular disease, with earlier death in the UK, is a significant factor contributing to these differences.

Germany and Austria both have high rates, Germany higher than Austria. The more developed South-East Asian countries, and the USA, have the highest rates, with small upward trends.

There are complex factors that may affect RRT acceptance rates including demography, the incidence and progression rates of chronic kidney disease, competing health risks (largely cardiovascular), health care access and referral/acceptance patterns.

Diabetic nephropathy is the major contributor to the incidence of RRT in the developed world. The proportion of patients with diabetic nephropathy in the UK is relatively low for developed countries (Table 22.2). This accounts for some of the differences in incidence observed. The reasons for this are not fully understood. The USA has a higher incidence of diabetics starting on renal replacement therapy each year than total incidence rate of all patients starting RRT in the UK.

The variation in take-on rate in different age groups is shown in Table 22.3.

Table 22.3. Age specific annual incidence of renal replacement therapy, p.m.p., by country

	Age range				
Country	**0-19**	**20-44**	**45-64**	**65-74**	**75+**
Australia	8.7	47.2	142.8	344.8	255.4
Austria	6.0	53.8	208.3	441.0	355.8
Canada	11.7	51.3	199.3	567.2	611.2
Finland	8.7	49.2	140.3	339.2	145.9
Greece	8.1	39.1	185.5	491.8	621.7
Netherlands	10.8	43.8	132.0	359.9	241.2
N. Zealand	7.0	62.7	251.3	289.5	172.9
Norway	9.4	33.0	128.1	365.3	237.4
Sweden	5.7	51.5	145.2	406.2	398.5
Taiwan	8.8	104.3	648.9	1,487.5	1,771.5
UK	**9.7**	**42.3**	**123.7**	**299.3**	**274.0**
USA	16.0	132.0	534.0	1,271.0	1,349.0
Uruguay	9.5	61.9	184.9	435.0	636.3

Prevalent patients

The changing prevalence of RRT over three years in selected countries is shown in Table 22.4 and the distribution of modality for dialysis patients is in Table 22.5.

The prevalence of a functioning transplant is shown in Table 22.6.

Comparison of biochemical and haematological results

Some comparative data on biochemical and haematological variables are shown in Table 22.7. These USA data are from the Centre for Medicare & Medicaid Services, 2002 Annual Report of Clinical Performance Measures Project. The Australia and New Zealand data are from the Australia and New Zealand Dialysis and Transplant Registry Report, 2003.

Table 22.4. Prevalence rates of RRT, p.m.p., by country

	Prevalence		
Country	**2000**	**2001**	**2002**
Japan	1,576	1,642	-
Taiwan	1,439	1,423	-
USA	1,360	1,403	-
Spain	871	880	950
Germany	870	919	918
Belgium (Flemish)	-	-	877
Canada	768	841	-
Italy	804	835	-
Greece	797	815	-
Austria	712	748	781
Sweden	714	735	756
Denmark	638	679	699
Czech Republic	625	663	695
New Zealand	611	652	685
Australia	608	634	658
Norway	581	613	641
Netherlands	621	640	-
UK	**540**	**580**	**640**
Finland	583	609	-
Hungary	517	580	-
Chile	423	473	506
Belgium (French)	-	-	492
Poland	316	353	390
Turkey	275	359	-
Uruguay	782	-	-

Table 22.5. Percentage dialysis modalities in prevalent patients

Country	**Year**	**HD**	**PD**	**% of HD pts on Home HD**
Australia	2002	75	25	14
Austria	2002	92	8	0.3
Belgium (Flemish)	2002	94	6	-
Belgium (French)	2001	91	9	1.3
Denmark	2002	75	25	0.8
Finland	2001	79	21	2
Germany	2002	95	5	0.8
Greece	2000	89	11	0
Hungary	2001	94	6	0
Italy	2001	90	10	1
Japan	2001	96	4	0
Netherlnd	2001	68	32	2
NZ	2002	52	48	27
Norway	2002	84	16	0.3
Poland	2002	89	11	0
Spain	2002	90	10	-
Sweden	2001	76	24	3
UK	**2002**	**73**	**27**	**3**
Uruguay	2000	94	6	-
USA	2001	91	9	0.4

Table 22.6. Prevalence of a functioning transplant

Country	**Prevalence p.m.p.**
Norway	436.9
Spain	408.5
Austria	407.4
Sweden	377.6
USA	375.4
Finland	353.2
Netherlands	317.2
UK	**290.0**
Canada	289.8
Australia	273.3
New Zealand	264.7
Czech Republic	240.0
Germany	230.2
Hungary	153.8
Greece	139.4
Chile	126.9
Uruguay	104.9
Poland	97.9
Bulgaria	43.4
Russia	17.1

Table 22.7. Comparative data on indicators of quality of care – England & Wales, USA, Australia, and New Zealand

	E & W	USA	Australia	N. Zealand
Median URR	71%	71.4 (n=8416)	73%	68%
% patients with URR > 65%	78%	82 (n=8416)	86%	63%
% Hb ≥ 10	82% HD, 88% PD	91 (n=1341)	-	-
%Hb ≥ 11	63% HD, 73% PD	73 (n=1341)	66%	37%
Median ferritin	420 HD, 249 PD	600 (n=1280)	-	-
% ferritin > 100	94% HD, 85% PD	92% (n=1280)	90%	86%
Albumin median HD BCG	38	35.7 (n=1340)	-	-
Albumin median HD BCP	34	32.1 (n=1340)	-	-

One and two-year survival of incident patients

All European Registry Countries

These data are taken from the European Renal Registry report.

The survival of incident patients in the first 2 years in the UK is very close to the European average (Tables 22.8 and 22.9). The use of the 90-day starting point avoids some of the potential errors associated with the variability of the first date recorded. By excluding the initial 3-month high mortality period for all countries, the comparisons are more valid.

Death rates of point prevalent renal replacement therapy patients – UK and USA

Death rates of point prevalent RRT patients in different age groups, established on RRT in the UK and USA, are shown in Table 22.10. The figures for dialysis patients alone are shown in Table 22.11. In both cases the death rates in the UK are significantly better than in the USA. The USA data are from the USRDS Annual Report 2002.

Table 22.8. All European Registry Countries – Adjusted Survival of Incident RRT Patients

	1 year survival from 90 days (95% CI)	2 year survival from 90 days (95% CI)
0-19	96.4 (95.1 - 97.8)	95.1 (93.5 - 96.6)
20-44	95.5 (95.1 - 96.0)	92.0 (91.4 - 92.7)
45-64	88.6 (88.1 - 89.1)	79.8 (79.2 - 80.4)
65-74	79.2 (78.5 - 79.9)	63.1 (62.3 - 64.0)
75+	70.6 (69.6 - 71.6)	50.4 (49.3 - 51.6)
Male	87.3 (86.9 - 87.6)	76.7 (76.2 - 77.2)
Female	87.6 (87.2 - 88.1)	77.6 (77.0 - 78.2)
Diabetes	82.4 (81.7 - 83.1)	66.7 (65.8 - 67.7)
Non DM	88.3 (88.0 - 88.6)	79.0 (78.6 - 79.5)
All	87.4 (87.1 - 87.7)	77.0 (76.6 - 77.4)

Adjusted for age, gender and primary diagnosis

Table 22.9. UK, England/Wales Adjusted Survival of Incident RRT Patients

	1 year survival from 90 days (95% CI)	2 year survival from 90 days (95% CI)
0-19	Not available	Not available
20-44	95.4 (94.0 - 96.8)	91.7 (89.9 - 93.6)
45-64	88.3 (86.8 - 89.9)	80.3 (78.4 - 82.3)
65-74	77.0 (74.6 - 79.5)	61.1 (58.3 - 64.0)
75+	72.4 (69.0 - 76.0)	51.3 (47.6 - 55.4)
Male	88.0 (86.9 - 89.1)	77.8 (76.3 - 79.3)
Female	85.4 (83.8 - 87.1)	75.3 (73.3 - 77.4)
Diabetes	82.7 (80.0 - 85.5)	65.6 (62.1 - 69.2)
Non DM	88.0 (87.1 - 89.0)	79.3 (78.0 - 80.5)
All	87.1 (86.2 - 88.0)	77.0 (75.8 - 78.2)

Adjusted for age, gender and primary diagnosis

Table 22.10. Death rates per 1000 years exposed, point prevalent RRT patients, USA and UK

Age	UK deaths Per 1000 pat.yrs.	USA deaths Per 1000 pat.yrs.	UK Registry/USA
20-44	30	56	0.53
45-64	71	136	0.52
65+	218	340	0.64
Total	104	179	0.58

Table 22.11. Death rates per 1000 years exposed, point prevalent dialysis patients, USA and UK

Age	UK deaths Per 1000 pat. yrs	USA deaths Per 1000 pat.yrs.	UK Registry/USA
20-44	87	94	0.92
45-64	140	179	0.78
65+	262	360	0.73
Total	196	239	0.82

Reference

1. 1. Rayner HC, Pisoni RL, Bommer J, et al. Mortality and hospitalization in haemodialysis patients in five European countries: results from the Dialysis Outcomes and Practice Patterns Study (DOPPS). Nephrol Dial Transplant, 2004. 19:108-120

Chapter 23: Afterword

Content

The 2003 Report contains information and analysis from data on patients from 2002. In addition to presenting the demographic information and studies of quality of care seen in previous reports, the Report contains many new analyses, particularly the standardised acceptance ratios, work on seasonal variation in mortality, analysis of the calcium phosphate product, new work on hypertension, study of the date of first referral and initiation of RRT, study of the influence of social deprivation, and some consideration of the problems of international comparisons in relation to Registry data as compared to sample studies. There is included a summary of the National Renal Review commissioned by the Department of Health, which also includes data on facilities and staffing of renal units. The Report is otherwise based on data from England and Wales, with some summary demographic data from Scotland and Northern Ireland. It is hoped that in the 2004 Report there will be detailed data from Northern Ireland.

The need for better quality data

Renal unit anonymity has been discarded apart from the survival analyses. The quality and completeness of data regarding co-morbidity and ethnicity are not yet good enough from many units to allow for appropriate adjustment of survival figures. Without such adjustment, comparison between units would be misleading. It is recognised that it is time-consuming, and often inconvenient, to record some of these data, but for future audit they will be essential. The Registry is keen to encourage the nephrology community to find ways to capture this material more completely and reliably.

The need for dedicated and trained IT staff has been identified by many renal units. They will be important in improving the collection and quality of data. The sections in this report pertaining to calcium and phosphate, hypertension, ethnicity and co-morbidity all demonstrate the need for better data validation at renal unit level. In addition, it is acknowledged that the Renal Registry dataset is incomplete. There is a particular need to collect vascular access data. The Registry has the capacity to include such data and could propose a much bigger dataset. The limitation is largely in the data which can be reliably recorded on electronic databases within the Renal Units themselves. Vascular access data, which involve collation of activity in several parts of any hospital, can be difficult to capture without staff employed for the purpose and carefully designed procedures.

The NSF and its information strategy

Collection of co-morbidity, vascular access, and other data may be facilitated as a result of the recently published Renal National Service Framework. This strongly recommended that all renal units should participate in comparative audit through the Renal Association UK Renal Registry. This should help renal units to negotiate appropriate resources and staff for data capture, in particular dedicated trained IT staff. This is underlined by the carefully considered Renal NSF Information Strategy, which is in Appendix E.

The Data Protection Act

The decision by the Patient Information Advisory Group to grant the UK Renal Registry exemption from the Data Protection Act under section 60 of the Health and Social Care Act 2001, was a critical step for the future of the Registry. Currently the

Registry is unable to avoid duplicate registration of patients or to follow sequential data on individual patients without holding some patient identifiable data. The Registry outlined its plans to develop systems which will avoid the need for specific patient identification and yet avoid duplication and allow serial follow up. This will be possible within planned developments of the National Programme for Information Technology (NpfIT). The exemption from Section 60 is temporary, until these plans are implemented successfully.

The potential of the Registry

The Renal Association UK Renal Registry is one of the very few sources worldwide of clinical as well as demographic data on renal replacement therapy. Whilst the reports published so far are interesting and may have contributed to the improvements in renal care that they document, the data are nowhere near being put to full use. The wide variations between renal units in many aspects of care are highlighted by the Report. The Report does not explain these variations, nor identify where there is a serious lack of resources. It does not automatically identify and help to spread good practice. The Renal Association in the last year set up a Working Party to recommend changes to improve coordination of its activities in clinical areas. As a result, a Clinical Affairs Board has been instituted under the chairmanship of a Clinical Vice President. Amongst others, the Registry, the Standards subcommittee, and the Clinical Directors subcommittee will be represented on this board. This focused effort should enable increasing use of the Registry data in bringing about improvements in clinical care.

Monitoring the NSF

The Renal Association UK Renal Registry is working closely with CHAI, the NHS Information Agency, and the Department of Health. All these agencies believe that the Renal Registry will be an essential part of monitoring the implementation of the NSF. This places the Registry in a unique and exciting position as an independent organisation working with official agencies in this way. The relationship will give the clinical renal community an important and influential role in the development of renal services.

Conclusion

The renal community should be proud that it has taken the lead in developing a Registry, unique in its detail, which has become a component of clinical practice in many renal units, and a nationally and internationally respected tool for national collaborative renal audit. It is only through the efforts of individual renal centres together with the personnel who work within them, and the enthusiastic support of the Renal Association, that this has been achieved, and we are pleased to present the 2003 Report as a testament to that joint effort.

Appendix A: The Renal Registry Rationale

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 and 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.

.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 £12 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 is pressure from some quarters to publish reports in which survival data from 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 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 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 2002, recover and then restart RRT in 2002. Such patients are counted twice in the analysis providing they have been receiving RRT for more than 90 days on each occasion.

Patients who started treatment at a centre and then transferred out soon after receiving treatment are counted at the original centre for all analyses of treatment on the 90th day.

Definition of the prevalent population

This is calculated as all patients who are alive on 31 December and includes the incident cohort for that year alive on that date.

Confidence Interval

The 95% confidence intervals have been calculated using the normal approximation of the Poisson.

Death rate calculation

The death rate per 100 patient years was calculated by counting the number of deaths and dividing by the person years exposed. This includes all patients, including those who died within the first 3 months of therapy. The person years at risk were calculated by adding up, for each patient, the number of days at risk (until they died or transferred out) and dividing by 365.25.

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

$$\frac{\text{(Probability of dying in the next interval for a phosphate of 1.71–2.10 mmol/L)}}{\text{(Probability of dying in the next interval for a phosphate in the ref range)}}$$

Z-Scores

Z-scores are sometimes called 'standard scores'. They are a measure of the distance in standard deviations of a sample from the mean.

The Z-score transformation is especially useful when seeking to compare the relative standings of items from distributions with different means and/or different standard deviations. The Z-score for an item indicates how far, and in what direction, that item deviates from its distribution's mean, expressed in units of its distribution's standard deviation.

Mathematically:

$$\text{the survival Z-score} = \frac{\text{(Survival for centre X – survival for all centres)}}{\text{(Standard error for centre X)}}$$

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 2002 would, for example, be included for the quarter 1/02 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 2002 who recovered on the 1 June 2002 and then resumed RRT again on 1 November 2002, for example, the number of days on RRT would be calculated from 1 November 2002. The patient would be excluded from the analysis for quarter 4/02 since on 31 December 2002, he or she would have been on RRT for only 90 days. The patient would be included in the analysis

from quarter 1/2003 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 02, 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 2001 and 31 September 2002 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 2002. 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 2001 and 31 December 2001. 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 2002.

2. Patients who had a transplant between 1 July 2001 and 31 December 2001 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 2001 and 31 December 2001.

4. The few patients who recovered renal function in 2002 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 2002 were included and were counted as being at risk for 1 day.

8. Patients who died on the day of the transplant were censored on this day rather than counted as a dialysis death.

Appendix C: Renal Services Described for Non-physicians

(Reproduced from the third edition of the Renal Association Standards document)

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

Renal Diseases

1.1 Diseases of the kidney are not as common as cardiovascular conditions or cancers but are much more common than some well known disorders such as multiple sclerosis or muscular dystrophy. Renal conditions account for about 7,000 deaths per annum according to the Registrar General's figures, but these are probably an underestimate since about one third of deaths of patients with renal failure are not recorded as such in mortality statistics. These figures exclude deaths from cancers of the kidney and associated organs of the urinary tract such as bladder and prostate.

1.2 Over 100 different diseases affect the kidneys. These diseases may present early with features such as pain, the presence of blood or protein in the urine, or peripheral oedema (swelling of the legs), but much renal disease is self-limiting; it occurs and heals with few or no symptoms or sequelae. On the other hand, some kidney diseases start insidiously and progress but are undetected until renal failure develops.

Acute Renal Failure

1.3 Renal failure may be acute and reversible. It occurs in previously normal kidneys when their blood supply is compromised by a fall in blood pressure caused by crush injuries, major surgery, failure of the heart's pumping action, loss of blood, salt or water, or when they are damaged by poisons or overwhelming infection. Renal support is then needed for a few days or weeks before renal function returns. However, about half such patients die during the illnesses because of other conditions, often the one which caused the renal failure.

Chronic Renal Failure (CRF) and Established Renal Failure (EsRF)

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.

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.

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 African-Caribbean) than in whites this is supported by national mortality statistics. People from the Indian subcontinent have a higher prevalence of non-insulin dependent diabetes, and those with diabetes are more likely than whites to

develop renal failure. This partly explains the higher acceptance rate of Asians on to renal replacement programmes.

Causes of Renal Failure

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

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

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

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')

1.11 Dialysis involves the removal of waste products from the blood by allowing these products to diffuse across a thin membrane into dialysis fluid which is then discarded along with the toxic waste products. The fluid is chemically composed to draw or 'attract' excess salts and water from the blood to cross the membrane, without the blood itself being in contact with the fluid.

Haemodialysis

1.12 The method first used to achieve dialysis was the artificial kidney, or haemodialysis. This involves the attachment of the patient's circulation to a machine through which fluid is passed, and exchange can take place. A disadvantage of this method is that some form of permanent access to the circulation must be produced to be used at every treatment. Each session lasts 4–5 hours and is needed three times a week.

Peritoneal Dialysis

1.13 The alternative is peritoneal dialysis, often carried out in the form of continuous ambulatory peritoneal dialysis (CAPD). In this technique, fluid is introduced into the peritoneal cavity (which lies around the bowel) for approximately 6 hours before withdrawal. The washing fluid must be sterile in order to avoid peritonitis (infection and inflammation of the peritoneum), which is the main complication of the treatment. A silastic tube must be implanted into the peritoneum and this may give problems such as kinking and malposition. Each fluid exchange lasts 30–40 minutes and is repeated three or four times daily. Neither form of dialysis corrects the loss of the hormones secreted by the normal kidney so replacement with synthetic erythropoietin and vitamin D is often necessary.

Renal Transplantation

1.14 Renal transplantation replaces all the kidneys functions, so erythropoietin and vitamin D supplementation are unnecessary. A single kidney is placed, usually in the pelvis close to the bladder to which the ureter is connected. The kidney is attached to a nearby artery and vein. The immediate problem is the body''s acute rejection of the foreign graft, which 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.

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

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.

1.17 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, J.S. *Kidney Failure – the Facts*. London: Oxford University Press, 1996.)

Appendix D: Methodology of administrative area geography and Registry population groups in England & Wales

Chapter 4 on the incidence of new patients, includes an analysis of standardised acceptance rates in England & Wales for areas covered by the Registry. The methodology is described below.

Administrative area geography in England and Wales

There are currently 46 unitary authorities in England, 34 shire counties and six metropolitan counties. Greater London forms a unique area type. Shire counties and metropolitan counties are subdivided into districts; unitary authorities are not subdivided. Greater London is subdivided into the London Boroughs and the City of London.

Unitary authorities

Code	UA name
00EB	Hartlepool
00EC	Middlesbrough
00EE	Redcar and Cleveland
00EF	Stockton-on-Tees
00EH	Darlington
00ET	Halton
00EU	Warrington
00EX	Blackburn with Darwen
00EY	Blackpool
00FA	Kingston upon Hull, City of
00FB	East Riding of Yorkshire
00FC	North East Lincolnshire
00FD	North Lincolnshire
00FF	York
00FK	Derby
00FN	Leicester
00FP	Rutland
00FY	Nottingham
00GA	Herefordshire, County of
00GF	Telford and Wrekin
00GL	Stoke-on-Trent
00KF	Southend-on-Sea
00HA	Bath and North East Somerset
00HB	Bristol, City of
00HC	North Somerset
00HD	South Gloucestershire
00HG	Plymouth
00HH	Torbay
00HN	Bournemouth
00HP	Poole
00HX	Swindon
00JA	Peterborough
00KA	Luton
00KG	Thurrock
00LC	Medway
00MA	Bracknell Forest
00MB	West Berkshire
00MC	Reading
00MD	Slough
00ME	Windsor and Maidenhead
00MF	Wokingham
00MG	Milton Keynes
00ML	Brighton and Hove
00MR	Portsmouth
00MS	Southampton
00MW	Isle of Wight

Shire counties

There are 34 shire counties, subdivided into non-metropolitan districts

Code	County name
09	Bedfordshire
11	Buckinghamshire
12	Cambridgeshire
13	Cheshire
15	Cornwall and Isles of Scilly
16	Cumbria
17	Derbyshire
18	Devon
19	Dorset
20	Durham
21	East Sussex
22	Essex
23	Gloucestershire
24	Hampshire
26	Hertfordshire
29	Kent
30	Lancashire

31	Leicestershire
32	Lincolnshire
33	Norfolk
34	Northamptonshire
35	Northumberland
36	North Yorkshire
37	Nottinghamshire
38	Oxfordshire
39	Shropshire
40	Somerset
41	Staffordshire
42	Suffolk
43	Surrey
44	Warwickshire
45	West Sussex
46	Wiltshire
47	Worcestershire

Metropolitan counties

There are six metropolitan counties, all in England and representing heavily built-up areas (other than Greater London).

These are subdivided into metropolitan districts.

Code	Area Name	Metropolitan District
00BL	Greater Manchester	Bolton
00BM		Bury
00BN		Manchester
00BP		Oldham
00BQ		Rochdale
00BR		Salford
00BS		Stockport
00BT		Tameside
00BU		Trafford
00BW	Merseyside	Wigan
00BX		Knowsley
00BY		Liverpool
00BZ		St. Helens
00CA		Sefton
00CB		Wirral
00CC	South Yorkshire	Barnsley
00CE		Doncaster
00CF		Rotherham
00CG		Sheffield
00CH	Tyne and Wear	Gateshead
00CJ		Newcastle upon Tyne
00CK		North Tyneside
00CL		South Tyneside
00CM		Sunderland
00CN	West Midlands	Birmingham
00CQ		Coventry
00CR		Dudley
00CS		Sandwell
00CT		Solihull
00CU		Walsall
00CW		Wolverhampton
00CX	West Yorkshire	Bradford
00CY		Calderdale
00CZ		Kirklees
00DA		Leeds
00DB		Wakefield

Greater London

This is an administrative unit covering the London metropolis. There are 32 boroughs and also the City of London (a City Corporation).

Code	Area Name	Borough name
00AA	Greater London	City of London
00AB		Barking and Dagenham
00AC		Barnet
00AD		Bexley
00AE		Brent
00AF		Bromley
00AG		Camden
00AH		Croydon
00AJ		Ealing
00AK		Enfield
00AL		Greenwich
00AM		Hackney
00AN		Hammersmith and Fulham
00AP		Haringey
00AQ		Harrow
00AR		Havering
00AS		Hillingdon
00AT		Hounslow
00AU		Islington
00AW		Kensington and Chelsea

00AX	Kingston upon Thames
00AY	Lambeth
00AZ	Lewisham
00BA	Merton
00BB	Newham
00BC	Redbridge
00BD	Richmond upon Thames
00BE	Southwark
00BF	Sutton
00BG	Tower Hamlets
00BH	Waltham Forest
00BJ	Wandsworth
00BK	Westminster

Welsh Unitary Authorities

Code	Area Name	UA Name
00PT	Gwent (955)	Cardiff
00PR		Newport
00PP		Monmouthshire
00PM		Torfaen
00PL		Blaenau Gwent
00PK		Caerphilly
00PH	Bro Taf (954)	Merthyr Tydfil
00PF		Rhondda; Cynon; Taff
00PD		The Vale of Glamorgan
00PB	Morgannwg (953)	Bridgend
00NZ		Neath Port Talbot
00NX		Swansea
00NU	Dyfed Powys (952)	Carmarthenshire
00NS		Pembrokeshire
00NQ		Ceredigion
00NN		Powys
00NL	North Wales (951)	Wrexham
00NJ		Flintshire
00NG		Denbighshire
00NE		Conwy
00NC		Gwynedd
00NA		Isle of Anglesey

Construction of contiguous areas by merging Shire Counties with Unitary Authorities.

The unitary authorities in the right-hand column have been combined into a contiguous ‘county’ area. These groupings into counties may differ from those used locally by renal commissioners. (The Registry will investigate standardising this with those used by local commissioners.

Contiguous county (ID code)	Code	Constituent Unitary Authorities
Bedfordshire (09)	00KA	Luton
Bucks (11)	00MG	Milton Keynes
Cambridgeshire (12)	00JA	Peterborough
Cheshire (13)	00ET	Halton
	00EU	Warrington
Derbyshire (17)	00FK	Derby
Devon (18)	00HG	Plymouth
	00HH	Torbay
Dorset (19)	00HN	Bournemouth
	00HP	Poole
County Durham (20)	00EB	Hartlepool
	00EC	Middlesbrough
	00EE	Redcar and Cleveland
	00EF	Stockton-on-Tees
	00EH	Darlington
East Sussex (21)	00ML	Brighton and Hove
Essex (22)	00KF	Southend-on-Sea
	00KG	Thurrock
Gloucestershire (23)	00HD	South Gloucestershire
Hampshire (24)	00MR	Portsmouth
	00MS	Southampton
	00MW	Isle of Wight
Kent (29)	00LC	Medway
Lancashire (30)	00EX	Blackburn with Darwen
	00EY	Blackpool
Leicestershire (31)	00FN	Leicester
	00FP	Rutland
Lincolnshire (32)	00FC	North East Lincolnshire
	00FD	North Lincolnshire
Nottinghamshire (37)	00FY	Nottingham
Shropshire (39)	00GF	Telford and Wrekin

Contiguous county (ID code)	Code	Constituent Unitary Authorities
Somerset (40)	00HA	Bath &North East Somerset
	00HB	Bristol, City of
	00HC	North Somerset
Staffordshire (41)	00GL	Stoke-on-Trent
Wiltshire (46)	00HX	Swindon
East Yorkshire (100)	00FA	Kingston upon Hull, City of
	00FB	East Riding of Yorkshire
	00FF	York
Herefordshire (102)	00GA	Herefordshire, County of
Berkshire (103)	00MA	Bracknell Forest
	00MB	West Berkshire
	00MC	Reading
	00MD	Slough
	00ME	Windsor and Maidenhead
	00MF	Wokingham
North Wales (951)	00NA	Isle of Anglesey
	00NC	Gwynedd
	00NE	Conwy
	00NG	Denbighshire
	00NJ	Flintshire
	00NL	Wrexham
Dyfed Powys (952)	00NN	Powys
	00NQ	Ceredigion
	00NS	Pembrokeshire
	00NU	Carmarthenshire
Morgannwg (953)	00NX	Swansea
	00NZ	Neath Port Talbot
	00PB	Bridgend
	00PT	Cardiff
Bro Taf (954)	00PD	The Vale of Glamorgan
	00PF	Rhondda Cynon Taff
	00PH	Merthyr Tydfil
Gwent (955)	00PK	Caerphilly
	00PL	Blaenau Gwent
	00PM	Torfaen
	00PP	Monmouthshire
	00PR	Newport

Areas included in Registry ‘covered’ population

The right-hand column indicates whether the ‘county’ has been included in the incident population calculation. This is dependant on whether the renal unit in the area is sending data to the Registry and that there are no overlapping areas with renal units not yet connected to the Registry.

Area name	County / UA ID code	Covered?
Bedfordshire	9	✓
Buckinghamshire	11	✓
Cambridgeshire	12	✓
Cheshire	13	×
Cornwall and Isles of Scilly	15	✓
Cumbria	16	✓
Derbyshire	17	×
Devon	18	✓
Dorset	19	×
Durham (county)	20	✓
East Sussex	21	×
Essex	22	×
Gloucestershire	23	✓
Hampshire	24	✓
Hertfordshire	26	✓
Kent	29	×
Lancashire	30	✓
Leicestershire	31	✓
Lincolnshire	32	✓
Norfolk	33	×
Northamptonshire	34	✓
Northumberland	35	✓
North Yorkshire	36	✓
Nottinghamshire	37	✓
Oxfordshire	38	✓
Shropshire	39	×
Somerset	40	✓
Staffordshire	41	×
Suffolk	42	×
Surrey	43	×
Warwickshire	44	✓
West Sussex	45	×
Wiltshire	46	✓
Worcestershire	47	×
East Yorkshire	100	✓
Herefordshire	102	×

Berkshire	103	×
City of London	201	×
Barking and Dagenham	202	×
Barnet	203	×
Bexley	204	✓
Brent	205	×
Bromley	206	✓
Camden	207	×
Croydon	208	✓
Ealing	209	✓
Enfield	210	×
Greenwich	211	✓
Hackney	212	×
Hammersmith	213	✓
Haringey	214	×
Harrow	215	×
Havering	216	×
Hillingdon	217	×
Hounslow	218	×
Islington	219	×
Kensington	220	×
Kingston upon Thames	221	×
Lambeth	222	✓
Lewisham	223	✓
Merton	224	×
Newham	225	×
Redbridge	226	×
Richmond upon Thames	227	×
Southwark	228	✓
Sutton	229	✓
Tower Hamlets	230	×
Waltham Forest	231	×
Wandsworth	232	×
Westminster	233	×
Bolton	301	×
Bury	302	×
Manchester	303	×
Oldham	304	×
Rochdale	305	×
Salford	306	×
Stockport	307	×
Tameside	308	×
Trafford	309	×
Wigan	310	×
Knowsley	401	✓
Liverpool	402	✓
St. Helens	403	✓
Sefton	404	✓
Wirral	405	✓
Barnsley	501	✓
Doncaster	502	✓
Rotherham	503	✓
Sheffield	504	✓
Gateshead	601	✓
Newcastle upon Tyne	602	✓
North Tyneside	603	✓
South Tyneside	604	✓
Sunderland	605	✓
Birmingham	701	×
Coventry	702	✓
Dudley	703	×
Sandwell	704	×
Solihull	705	✓
Walsall	706	✓
Wolverhampton	707	✓
Bradford	801	✓
Calderdale	802	✓
Kirklees	803	✓
Leeds	804	✓
Wakefield	805	✓
Isle of Anglesey	901	✓
Gwynedd	902	✓
Conwy	903	✓
Denbighshire	904	✓
Flintshire	905	✓
Wrexham	906	✓
Powys	907	✓
Ceredigion	908	✓
Pembrokeshire	909	✓
Carmarthenshire	910	✓
Swansea	911	✓
Neath Port Talbot	912	✓
Bridgend	913	✓
The Vale of Glamorgan	914	✓
Rhondda Cynon	915	✓
Merthyr Tydfil	916	✓
Caerphilly	917	✓
Blaenau Gwent	918	✓
Torfaen	919	✓
Monmouthshire	920	✓
Newport	921	✓
Cardiff	922	✓

Appendix E: Renal National Service Framework IS Support Strategy

This document was commissioned from the NHSIA by the Department of Health, as the IS support document for the renal NSF in England.

The project board members were :

David Ansell	Renal Registry Director
Tony Borowiec	NHSIA Project Support
Anne-Marie Campbell	DOH Renal NSF project manager
Peter Doyle	DOH Renal NSF team
Sherrin Moss	NHSIA Programme Manager
Simon Pearson	NHSIA Information Policy Unit
Sue Sutherland	UKTransplant Chief Executive
Kate Verrier Jones	NHSIA Project Lead

Executive Summary

1. Implementation of the Renal Services Information Strategy will help deliver the National Service Framework (NSF) for Renal Services through the provision of tools and resources. In particular, the Information Strategy supports the NSF around national comparative audit and provision of nationally available data to support planning and identify local priorities.

2. The Information Strategy consists of a series of tables containing National and related Local Actions developed to support Part 1 of the NSF which addresses kidney transplantation and dialysis for people with established renal failure. Each action, where appropriate, is linked to further information that explains the background to and the reasoning behind the action.

3. The tables are divided into themed sections as follows:

Section 1: Information for Direct Care of the Patient

1. The National and Local Actions in Section 1 have been developed to take into account the plans of the National Programme for Information Technology (NPfIT), in particular the plans for a national spine record (National Actions 1.1 to 1.3). Trusts with Renal Services are encouraged to work with the Local Service Providers (LSP) under the National Care Records Service programme (Local Actions 1.1 and 1.2).

2. The National and Local Actions in Section 1 also pick up the theme of the development of care plans (National Action 1.4 and Local Actions 1.3 and 1.4).

3. Patients will be able to see their registration to receive a transplant on the transplant list and to check their status (National Action 1.5).

4. Trusts with Renal Services are encouraged to examine the issues surrounding the sharing of information and to use the results to ensure that the interests of patients, donors and care professionals are recognised and properly safeguarded (Local Action 1.5).

5. Trusts with Renal Services are encouraged to provide care professionals with decision support at the point of care (Local Action 1.6).

Section 2: Information for Secondary Purposes

9. The data that will reach the national spine record will be derived from datasets approved by the NHS Information 3.Standards Board (National Actions 2.1 and 2.2). Trusts with Renal Services are encouraged to ensure that data required for secondary purposes can be collected and submitted electronically and in accordance with the approved datasets (Local Action 2.1 and 2.2).

10. National comparative audit and national data to support planning and to identify local priorities are addressed in National Actions 2.3 to 2.6 and Local Actions 2.3 to 2.5.

Section 3: Access to Knowledge

11. The National Actions in this section discuss the provision by the Department of Health of a national website of information links (National Action 3.1) and a series of actions for the National electronic Library for Health, NHS Direct Online and NHS Direct (National Actions 3.2 to 3.8).

12. The Local Actions in this section encourage the development and provision of information for patients, carers and the public (Local Action 3.1) together with the necessary IT infrastructure to make this possible (Local Action 3.5).

Section 4: Training and Development

13. The National Health Informatics Development (NHID) programme of the NHS Information Authority will lead on the development of a renal informatics special interest group (National Action 4.1) and a series of educational packages in the use of systems and for career development in support of staff within the renal community (National Actions 4.2 and 4.3).

14. Locally Trusts with Renal Services are encouraged to offer their staff appropriate training and support in developing their skills and knowledge (Local Action 4.1) and to ensure that patients understand how to access and use the information that they receive (Local Action 4.2). Similarly PCTs are encouraged to ensure that GP surgeries provide online access to information for their patients (Local Action 4.3).

1 Information for Direct Care of the Patient

National Actions

Implementation of the Renal NSF Core Service

1.1 Under the National Care Records Service (NCRS) programme Cluster Management Boards will instruct Local Service Providers (LSP) as they are appointed to implement the Renal NSF Core Service.

Support for Renal Data on the NCRS Spine Record

1.2 The Spine Project of the National Programme for Information Technology (NPfIT) will ensure that the NCRS Spine Record will support a National Renal Dataset in Phase 2 of its programme.

NHSIA NSF Implementation Information Strategy Implementation Programme

1.3 The NHS Information Authority (NHSIA) NSF Implementation Strategy Programme has the remit to advise the NPfIT Clinical Advisory Board of the specific needs of Renal Services (clinicians, renal patients and donors) during the period of implementation of National Actions 1.1 and 1.2 and to monitor progress on behalf of the Department of Health.

Care Plans

1.4 By 2004 the Department of Health will initiate the development of a care plan to support all people with chronic renal failure in managing their condition as an interim solution in advance of its inclusion within the NCRS.

Status on the Transplant List

1.5 Pending the likely provision of this function by My HealthSpace, the Department of Health will work with UK Transplant and other possible partners, such as NHS Direct Online, to make arrangements for a nationally agreed mechanism to enable patients to see their registration, to receive a transplant on the transplant list and to check their status as to whether they are active or suspended. There will be clear guidelines on how their status can be changed where this is necessary.

1 Information for Direct Care of the Patient

Local Actions

Use of Electronic Clinical Information Systems

1.1 Local Service Providers (LSP) will work with Trusts with Renal Services through the National Care Records Service (NCRS) programme Cluster Management Boards to ensure that the electronic clinical information systems (ECIS) are embedded in the management and care of patients with established renal failure

Access to Information for Primary Care Teams

1.2 PCTs should work with their Cluster Management Boards and LSP to ensure that primary care teams can access the records of patients with ERF, including a facility to view the patient's registration and status on the national transplant list.

Introduction of Care Plans in Trusts with Renal Services

1.3 Trusts with Renal Services will be able to draw upon the national care plan model developed by the Department of Health to meet the needs of their patients and to encourage its use by both patients and health professionals.

Support for Care Plans by PCTs

1.4 PCTs are encouraged to work with local renal units to access their care plan model, in order that primary care teams can promote its use by both health professionals and patients in the community.

Information Sharing

1.5 Trusts with Renal Services are encouraged to lead a formal examination of the issues relating to information sharing for all relevant stakeholders including those in primary care and to use the results to ensure that the interests of patients, donors and care professionals are recognised and properly safeguarded.

Decision Support

1.6 Trusts with Renal Services are encouraged to provide care professionals treating patients with ERF with access to decision support at the point of care in advance of this functionality being provided in the Renal NSF Core Service.

2 Information for Secondary Purposes

National Actions

UK Renal Registry and UK Transplant

2.1 In recognition of the work that has been and is currently being undertaken and planned by the UK Renal Registry and UK Transplant, the Department of Health and the Commission for Healthcare Audit & Inspection (CHAI) will include both these organisations together with all other key renal stakeholders in future developments for the definition, collection and reporting of data on patients with ERF.

National Dataset for Dialysis and Transplantation Services

2.2 The Department of Health and CHAI will commission the UK Renal Registry and UK Transplant to develop a National Dataset to cover both dialysis and transplantation services. The UK Renal Registry and UK Transplant will commission the NHSIA Datasets Development Programme to achieve Information Standards Board (ISB) approval. The work will start in April 2004 and be completed by April 2005 to fit with National Action 1.2. In preparation for the development of a national dataset, a steering group with representation from Department of Health, CHAI, UK Renal Registry, UK Transplant and NHS Information Authority will establish the requirement and then cost and schedule the development of a national dataset prior to April 2004.

National Analytical Services (NAS)

2.3 The NHS Information Authority is developing a National Analytical Service (NAS) to support national secondary information requirements, e.g. activity and outcome for epidemiology, clinical governance, public health and service planning based on the Secondary Uses System under development by the NPfIT Spine Project. The renal services community will call upon the services of the NAS as they become available.

Renal National Survey

2.4 The Department of Health has commissioned a national survey of renal treatment facilities in England for the year 2002. This survey will continue subject to approval by the Committee for Review of Central Information Requirements (ROCR) until the data can be provided automatically through the implementation of the actions in this Information Strategy.

Performance Indicators

2.5 CHAI will work with the Department of Health and other key stakeholders to develop suitable performance indicators for national and local use.

Information for Audit

2.6 CHAI will work with the Department of Health, the Renal Association, the UK Renal Registry, UK Transplant and the renal services community to develop national comparative clinical audit plans within a framework of standards for national audit as a matter of priority.

2 Information for Secondary Purposes

Local Actions

Clinical Information Systems

2.1 In order to submit the required data for secondary purposes, Trusts with Renal Services may use the agreed procedure to extract the data used by UK Transplant and the UK Renal Registry electronically.

Datasets

2.2 Trusts with Renal Services should collaborate with the LSP to implement the National Dataset upgrade to their electronic clinical information systems when available.

Analytical Capacity

2.3 Access to the analytical and epidemiological skills required to handle and interpret the data required for audit and other purposes is essential if data are to be handled and interpreted correctly. It is good practice to use such services for data interpretation locally and nationally.

Information about Services

2.4 Renal collaborative commissioning groups are advised to use information including local population demographic data and information about staffing, facilities and current capacity in renal services provided by Trusts with Renal Services to identify gaps and inequalities and plan future services to meet demand. National Survey data (see National Action 3.4) will be available as a baseline for comparison and improvement.

Information for Audit

2.5 It is good practice for Trusts with Renal Services to participate in national comparative audit of the structure, process and outcome of their work. This could include, for example, patients' opinions, suggestions, transport arrangements, as well as audit of activity, outcomes, waiting lists and admissions to non-renal wards with feedback used to inform change.

3 Access to Knowledge

National Actions

National Website of Information Links

3.1 The Department of Health Renal NSF website will act as a central link to supporting programmes of work including links to the NeLH, NHS Direct Online, the UK Renal Registry, UK Transplant, professional organisations such as the Renal Association and the British Transplantation Society as well as charitable organisations such as the National Kidney Federation and the National Kidney Research Fund.

National electronic Library for Health (NeLH) – Central Repository

3.2 Whilst designed primarily for the use of health professionals, the NeLH will act as the central repository for information from accredited organisations and sources about end-stage renal failure and its treatment and management, whether for patients and their carers, the public or health professionals. Their information resource will be used by NHS Direct and NHS Direct Online to develop information suitable for the needs of patients, their carers and the public.

National electronic Library for Health (NeLH) – Renal Specialist Library

3.3 The NeLH, along with key stakeholders, will develop a Renal Specialist Library designed for the use of health professionals. It will provide access to the evidence base where this exists, and identify areas where research is required to strengthen the evidence where it is lacking.

National electronic Library for Health (NeLH) – Information from National Agencies

3.4 The NeLH will incorporate knowledge about end-stage renal failure and its treatment from all the national agencies such as NICE, UK Transplant and the Modernisation Agency and present this as a single interoperable source for healthcare professionals and interested members of the public.

NHS Direct Online – General Information for Patients, Carers and the Public

3.5 Drawing on information from the National electronic Library for Health (NeLH), NHS Direct

Online will provide a web-based service giving access to recognised sources of high quality information about established renal failure and its treatment and management, designed primarily for use by patients and their carers and members of the public, as well as access to information about organ donation for the public and potential live donors.

NHS Direct Online – Information for Third Parties

3.6 Drawing on information from the National electronic Library for Health (NeLH), NHS Direct Online will make available information about renal failure and its treatment written for use by third parties such as educational establishments, employers and insurance companies.

NHS Direct Online – Information for Children and Young People

3.7 Drawing on information from the National electronic Library for Health (NeLH), NHS Direct Online will make available information and advice for children and young people with renal failure about the problems of adjusting to their disease and how they might have a greater say in managing their disease as they grow up.

NHS Direct – Provision of Information and Advice for the Public

3.8 Working with all the appropriate stakeholders and sources of medical knowledge NHS Direct will undertake the necessary actions to enable it to become a safe source of information and advice for people with renal failure and members of the public enquiring over the telephone about issues relating to established renal failure and about the possibility of becoming kidney donors.

3 Access to Knowledge

Local Actions

Information for Patients, Carers and the Public

3.1 Trusts with Renal Services could, by using the services described in National Actions 3.1 to 3.7, make available a full range of information for patients, carers and the public about renal failure, its treatment and management and services available locally.

Information for Third Parties

3.2 Trusts with Renal Services should ensure that patients are aware of how to obtain information, such as through the services described in National Action 3.6, about renal failure and its treatment that has been written for use by third parties, for example educational establishments, employers and insurance companies.

Information for Children and Young People

3.3 Trusts with Renal Services should ensure that children and young people, as well as their parents and carers, are aware of how to find the information and advice, such as through the services described in National Action 3.7, about the problems of adjusting to their disease and how they might have a greater say in managing their disease as they grow up.

Information for Transferring to Other Units

3.4 Trusts with Renal Services should give patients transferring to other units either within or outside their local renal network information about the receiving unit before they are transferred in order to ensure smooth transition.

Access to the IT Infrastructure

3.5 Trusts with Renal Services need to consider how to ensure that professional staff and patients have ready access to the knowledge base through implementation of the necessary IT infrastructure.

4 Training and Development

National Actions

Renal Informatics Special Interest Group

4.1 The NHSIA in partnership with the renal community, UK Renal Registry and UK Transplant will develop a renal informatics special interest group through the Informatics Learning Network available from the National Health Informatics Development (NHID) programme of the NHSIA. The first step will be to establish a web site and moderator.

Educational Packages for Use of Systems

4.2 NHID, in partnership with the renal community,

the UK Renal Registry and UK Transplant, will develop an educational package for units embarking on electronic data collection and for units who have systems not yet fully utilised, to provide a practical guide on how to embed an electronic clinical information system in the delivery of direct care.

Educational Packages for Career Development

4.3 NHID, in partnership with the renal community, the UK Renal Registry and UK Transplant, will develop an educational package to support Trusts with Renal Services in providing career development and succession planning.

4 Training and Development

Local Actions

Training and Support for Staff

4.1 Trusts with Renal Services are encouraged to give staff with responsibilities for data and the preparation of information the appropriate training and support in developing their skills and knowledge.

Support for Patients at Trust Premises

4.2 Trusts with Renal Services are encouraged to ensure that, wherever access to information is given to patients via, for example, a workstation located on their premises, help and support as well as sufficient material are readily available so that patients can use the IT system appropriately and understand the information they receive.

Support for Patients at GP Surgeries

4.3 PCTs are encouraged to ensure that GP surgeries provide online access for patients to information about renal disease, renal failure, its management, local services and organ donation possibly by accessing the services described in National Actions 3.1 to 3.7, with appropriate support from staff.

Supporting Information For The National Actions

Information for the Direct Care of the Patient

Implementation of the Renal NSF Core Service

1.1 Under the National Care Records Service (NCRS) programme Cluster Management Boards will instruct Local Service Providers (LSP) as they are appointed to implement the Renal NSF Core Service.

The National Care Records Service (NCRS) programme, initiated by the National Programme for Information Technology (NPfIT) will support the availability of electronic patient records enabling timely and accurate delivery of results and communication between health professionals and care sectors and between the patient and the renal multi-skilled team through the development and use of care plans. Through the NHS Direct Online My Health Space portal it will also provide the means for patients to view their own health records and thereby encourage them to participate in the management of their own care.

The NCRS will implement its programme across the country in regions known as ‘clusters’. Each cluster will be overseen by a ‘Cluster Management Board’ whose role, amongst other things, will be to ensure that the implementation runs to time and to budget and to ensure that all required resources are made available.

The Cluster Management Boards will instruct the local suppliers of the service, known as Local Service Providers (LSP), to proceed with the implementation of the services that have been specified in the Output Based Specification Contract (OBSC) Section 167. These contractual requirements have been prepared based on the Output Based Specification (OBS) for the NCRS that was developed to enable LSP and National Application Service Providers (NASP) to understand the requirements and to quote for and carry out the work of developing the necessary systems. The OBS includes the requirements for the published Information Strategies as well as information for those under development.

In essence the Core Service requirement for Renal Services consists of the following steps for implementation by each LSP:

- To maintain and upgrade as required electronic clinical information systems (ECIS) hardware and software, e.g. Proton etc. in use in Trusts with

Renal Services for children, young people and adults
- To deploy ECIS in any Trusts with Renal Services that do not have them
- To send donor and recipient data to UK Transplant for organ allocation and transplantation
- To deploy the Renal National Dataset (scheduled for April 2005), working as required with the renal software package vendors to modify their packages to support the new dataset and deploy any such upgrades
- To deploy an extract programme to send data to UK Transplant and the UK Renal Registry for the National Dataset
- To deploy a set of renal messages based on the National Dataset to populate the national Spine Record

The limitations of conventional records are well known. Problems are related to completeness, accuracy, and volume of notes, indexing and accessibility. Patients with established renal failure (ERF) have a lifetime dependent on medical and nursing care. They attend primary, secondary and tertiary care centres for diagnosis and treatment by dialysis and transplantation and for accompanying problems and complications. They require the services of several members of the renal multi-skilled team and frequently access other health services such as those for diabetes or coronary heart disease both in hospital and in primary care. Important information is often unavailable when required because treatment has taken place at another location or because the notes are unavailable due to loss, miniaturisation, storage or recent consultation. Notes become very large, disintegrate, are split into several folders and may ultimately become separated. It becomes increasingly difficult to locate the information required.

Through the NCRS paper records and conventional X-rays will eventually be replaced by electronic information. Electronic records are capable of being organised in such a way that information can be readily filed and extracted as required and the record can be easily shared with appropriate parties, including the patient, using information sharing protocols agreed with the local Caldicott Guardian and local clinicians. These should ensure that patients are adequately prepared and supported when accessing their notes, that there are no surprises and that confidential information on third parties is appropriately protected. Data required for management and audit should be derived from the electronic record with minimal need for keying in data a second time. This will improve efficiency and accuracy.

Local clinical information systems have been evolving over the past two decades to meet the local needs for patient care and to aid management and audit. In the management of patients with ERF local systems have been particularly important because of the need to monitor a large number of biochemical and physiological parameters in every patient on a recurring basis for life. These systems have generally been developed and run from within renal units to meet the specific requirements of patients with renal failure and other renal diseases. Use of systems that receive results directly from the laboratory has been combined with the ability to transform data to assess renal function, dialysis adequacy or to correlate functions. These numeric functions can be combined with records of dialysis treatment sessions, the facility for free text and the ability to transfer data to (and from) national organisations for clinical care (UK Transplant) or audit (UK Renal Registry and UK Transplant) has further enhanced the value of such systems in some units. This functionality must not be lost in the development of the NCRS and the national actions seek to ensure that the needs of Renal Services in these respects will not be neglected. However, ultimately the success of the NCRS will be determined at local level through participation by Trusts in the development and implementation process with the LSP.

Generic requirements of clinical information systems that are particularly relevant to renal Services include:

- Generation of the data required for secondary purposes described in National Action 3 including data on kidney donors
- The ability for professionals to share information in an accurate and timely way when patients are seen in primary and secondary care or when they transfer from one unit to another, for example when young people transfer to an adult unit.
- The need to ensure that patient-related data, wherever clinically appropriate, is recorded once only in order to minimise the frustration often experienced by patients of repeating details of, for example, family history to different care professionals at different times
- Functionality to enable patients to access their own records through the NHS Direct Online web site
- The ability to share information within the constraints of safety and confidentiality for the patient and third parties and with adequate preparation and support for the patient. For further information visit the data protection website at http://www.dataprotection.gov.uk/

Specific requirements to support the direct care and management of children, young people and adults

with ERF in primary and secondary care should include, but not be limited to, the following:

- Ability to support serial online biochemical and other tests, X-rays and biopsies with electronic links to laboratories. This should include alerts for abnormal results.
- Ability to transform and collate data for estimation of functions such as glomerular filtration rate and dialysis adequacy
- Ability to provide decision support systems based on national guidelines or protocols, e.g. NICE.
- Remote monitoring of home haemodialysis treatment
- Information to monitor the standards of the Renal Association, the British Transplantation Society and other relevant professional bodies.
- Information to monitor the standards outlined in the Renal National Service Framework and other NSFs such as Diabetes, CHD and Children's & Maternity Services when published.
- Functionality to support prescribing for patients with impaired renal function, on dialysis and with renal transplants
- Provision of a facility for patients to view their own records and participate in the development and management of their own care plan including the ability for patients to review their status on the transplant list through NHS Direct Online's 'Health Space' facility or other agreed mechanisms
- Functionality to transmit the recipient dataset to UK Transplant for patients wishing to receive a transplant
- Information to meet the requirements of live and cadaveric kidney donation including:
  - Functionality to support secure and confidential links for authorised health professionals to the Organ Donor Register in order to establish the status and wishes of a potential donor.
  - Functionality to enable authorised health professionals secure access to view the medical records of potential non-heart beating and heart beating donors to inform decisions about proceeding with organ donation
  - Functionality to support UK Transplant in the process of organ allocation and statutory duties related to organ donation
  - Functionality to enable health professionals to view the records of deceased kidney donors if the recipient has a subsequent problem or to research newly identified problems and to identify the recipients if the donor is later found to have an unexpected problem (e.g. cancer found at post mortem or CJD)
  - The ability of live donors to see the results of their tests and participate in shared decision-making.
  - The need to ensure that the information required by the national potential donor audit, primarily but not exclusively patient information from intensive care units, is routinely recorded and transmitted to UK Transplant so that ongoing potential for organ donation in the UK is understood and maximised.
  - Information to enable monitoring of the Human Organ Transplant (HOT) Act and the requirements of ULTRA (Unrelated Live Transplant Regulatory Authority).

Support for Renal Data on the NCRS Spine Record

1.2 The Spine Project of the National Programme for Information Technology (NPfIT) will ensure that the NCRS Spine Record will support a National Renal Dataset in Phase 2 of its programme.

The specific functions to support the direct care and management of children, young people and adults with ERF in primary and secondary care which will need to be present in electronic clinical information systems as implemented by the LSP under the Core Service (see the supporting information for National Action 1.1 above) must also be capable of providing all the data needed for secondary analysis purposes both for local and national use.

At the centre of the NCRS is the 'Spine Record', the collection of data and information for each patient for whom data are collected through the medium of national datasets approved by the NHS Information Standards Board (ISB). The Spine Record is to be designed and implemented at national level by the selected National Application Service Provider (NASP) and the work is to be overseen by the Spine Project of the National Programme for Information Technology (NPfIT).

In order for the Spine Record to be maintained for patients within Renal Services a National Dataset for dialysis and transplantation services (including the donor dataset) will be developed (See National Action 2.2) during Phase 2 of the NPfIT and the project within the National Programme for Information Technology (NPfIT) known as the Spine Project has agreed that the Spine Record will be capable of being updated by the data collected by this dataset once it has been approved by the ISB and implemented in local electronic clinical information systems.

NHSIA NSF Implementation Strategy Programme

1.3 The NHS Information Authority (NHSIA) NSF Implementation Strategy Programme has the remit to advise the NPfIT Clinical Advisory Board of the specific needs of Renal Services (clinicians, renal patients and donors) during the period of implementation of National Actions 1.1 and 1.2 and to monitor progress on behalf of the Department of Health.

The work of the Cluster Management Boards and the Spine Project in fulfilling their roles as set out in National Actions 1.1 and 1.2 will be informed by the knowledge and expertise of the NHS Information Authority (NHSIA) NSF Implementation Programme via the NPfIT Clinical Advisory Board. The Programme is resourced by clinical and information specialists across the whole spectrum of NSF Information Strategies and is able to take the broader view of information needs within the NHS as well as being able to reflect the needs of particular conditions and client groups.

Care Plans

1.4 By 2004 the Department of Health will initiate the development of a care plan to support all people with chronic renal failure in managing their condition as an interim solution in advance of its inclusion within the NCRS.

Care plans have long been a feature of nurse-led patient care on wards but have not necessarily been shared or seen as a tool for promoting a multi-skilled team environment and self-management of long-term disease by patients.

The NSF has set out a role for the care plan and the NCRS will need to accommodate this facility in the future in order to help both to achieve the standards laid down in the NSF and to go some way towards addressing the standardisation of information for exchange within the multi-skilled team.

In the meantime professionals caring for people with ERF, and indeed with other conditions, would benefit from having available a model of such a plan as a basis for local development in advance of the feature becoming available as part of the NCRS. The Department of Health will initiate the development of a care plan for local development for use in the short to medium term.

Local Action 1.3 encourages Trusts with Renal Services to tailor the model, once it becomes available, to meet the needs of their patients and to encourage its use by both patients and health professionals. Local Action 1.4 encourages Primary Care Trusts to promote the use of care plans in primary care. Part of the development of care plans should include the facility for patients to hold their own records electronically. Patients should be able to have access to sources of knowledge to help them manage their own condition.

The action to develop a care plan is referred to as part of the modernisation programme in the Renal Services National Service Framework.

Status on the Transplant List

1.5 Pending the likely provision of this function by My HealthSpace, the Department of Health will work with UK Transplant and other possible partners, such as NHS Direct Online, to make arrangements for a nationally agreed mechanism to enable patients to see their registration to receive a transplant on the transplant list and to check their status as to whether they are active or suspended. There will be clear guidelines on how their status can be changed where this is necessary.

UK Transplant is a Special Health Authority with responsibility to support solid organ and corneal transplantation across the United Kingdom. As part of that responsibility UK Transplant:

- Maintains a national list of all patients registered to receive a transplant
- Matches and allocates organs as they become available according to a set of rules that ensure the best use of scarce organs whilst trying to achieve equity of access for all patients
- Transfers data to recipient units
- Maintains the National Transplant Database as a central, up-to-date, and accurate computer record of transplantation from donation to the death of the recipient
- Manages the NHS organ donor register.
- Has measures in place to increase the number of organs available for transplant

In a national system such as organ allocation it can be difficult for patients to know whether they are active or suspended from the list of those registered for transplant at any moment in time and of course some patients may be included on the list for many years before a suitable organ becomes available, making the opportunity for multiple suspensions (e.g. for holidays or inter-current illness) greater.

It is envisaged that the health professionals will be able to register patients for transplantation electronically via their local renal IT system and subsequently amend the patient's status from 'active' to 'suspended' or vice versa through links to UK Transplant.

In the interim, UK Transplant should make arrangements with local units to ensure that there are satisfactory arrangements for patients to ensure that

they know whether or not they are registered and that they can check their status and are not suspended for longer than necessary. There should be clear guidance for patients and health professionals on the correct route to take to ensure that their patient status is changed quickly when this is appropriate.

The Department of Health and UK Transplant will work together to find a national solution that will allow patients, subject to security and confidentiality safeguards, to gain access to information about their status on the transplant list with the minimum of difficulty until such time as the National Care Records Service can provide the functionality.

2 Information for Secondary Purposes

UK Renal Registry and UK Transplant

2.1 In recognition of the work that has been and is currently being undertaken and planned by the UK Renal Registry and UK Transplant, the Department of Health and the Commission for Healthcare Audit & Inspection (CHAI) will include both these organisations together with all other key renal stakeholders in future developments for the definition, collection and reporting of data on patients with ERF.

For a short description of the UK Renal Registry and UK Transplant please see the Glossary of Terms. More information on these organisations can be found at:

- http://www.renalreg.com and
- http://www.uktransplant.org.uk/default.htm.

Other key stakeholders for renal data include, but will not necessarily be limited to, the following organisations:

- Association of Clinical Biochemists
- British Association for Paediatric Nephrology
- British Transplant Society
- Charities, e.g. National Kidney Federation, National Kidney Research Federation
- Commission for Health Improvement (CHI)
- Commission for Healthcare Audit & Inspection (CHAI) (from 2004)
- Department of Health
- Intensive Care National Audit & Research Centre (ICNARC)
- National Institute for Clinical Effectiveness (NICE)
- National Patient Record Analysis Service (NPRAS)
- Patient Information Advisory Group (PIAG)
- Proton Users' Group
- NHS Information Authority
- Renal Association
- Renal Collaborative Commissioning Groups
- Royal College of Anaesthetists
- Royal College of Nursing (Nephrology Nursing Network)
- Royal College of Paediatrics and Child Health
- Royal Colleges of Physicians
- Royal College of Surgeons
- Strategic Health Authorities
- Trust Chief Executives and Medical Directors of Trusts with Renal Services and of Trusts which commission renal services

In addition, national coverage of renal units will enable English data to be included in the Registry of the European Dialysis and Transplantation Society

National Dataset for Dialysis and Transplantation Services

2.2 The Department of Health and CHAI will commission the UK Renal Registry and UK Transplant to develop a National Dataset to cover both dialysis and transplantation services. The UK Renal Registry and UK Transplant will commission the NHSIA Datasets Development Programme to achieve Information Standards Board (ISB) approval. The work will start in April 2004 and be completed by April 2005 to fit with National Action 1.2. In preparation for the development of a national dataset, a steering group with representation from Department of Health, CHAI, UK Renal Registry, UK Transplant and NHS Information Authority will establish the requirement and then cost and schedule the development of a national dataset prior to April 2004.

The UK Renal Registry is central to the collection of data about patients on Renal Replacement Therapy and contribution to this Registry is essential in order to support national audit and to provide information on renal patients and their treatment nationally for management and planning.

UK Transplant has the leading role in overseeing and monitoring the activity and outcome of organ transplantation.

The Department of Health and CHAI will commission the UK Renal Registry and UK Transplant to develop a National Dataset which will cover both dialysis and transplantation services. Much work to develop datasets has already been undertaken by both these organisations and it will be important, in developing a national dataset, to be aware that datasets such as those for CHD and Diabetes will already contain some of the data items needed.

The approval of datasets by the Information Standards Board is a pre-requisite for the NPfIT to allow patient data to pass onto the national Spine Record within the NCRS. The NHS Information Authority through its Datasets Development Programme has the

expertise and the experience of ensuring that data items in the many datasets that it has developed meet the required NHS standards and also that the processes required by the NHS Information Standards Board to gain their formal approval for use in the NHS are fully complied with.

The NHS Information Authority is, therefore, well placed to work alongside renal stakeholders both to help them define their needs in terms of data for secondary purposes and to ensure that the resulting datasets and collection, verification and transfer methods are implemented with the full approval of the NHS Information Standards Board.

Information about the NHS Information Standards Board approval processes, including ISB Draft Standards Submission Guidance, may be found on the ISB website at http://www.isb.nhs.uk/pages/default.asp

National Analytical Services (NAS)

2.3 The NHS Information Authority is developing a National Analytical Service (NAS) to support national secondary information requirements, e.g. activity and outcome for epidemiology, clinical governance, public health and service planning based on the Secondary Uses System under development by the NPfIT Spine Project. The renal services community will call upon the services of the NAS as they become available.

For further information about this developing programme of work please refer to the NHS Information Authority website at http://nww.nhsia.nhs.uk/def/home.asp

Renal National Survey

2.4 The Department of Health has commissioned a national survey of renal treatment facilities in England for the year 2002. This survey will continue subject to approval by the Committee for Review of Central Information Requirements (ROCR) until the data can be provided automatically through the implementation of the actions in this Information Strategy.

The last renal national survey covered data from 1998. The analysis of this new renal national survey data will be completed in early 2004 and will be fed back to Renal Collaborative Commissioning Groups. This is step one of the early actions to be taken by 2006 mentioned in the Renal Services National Service Framework.

It is essential that basic information about the number of people entering the chronic renal failure programme and the prevalence of dialysed and transplanted people is known in total as well as within high risk groups. This is to ensure that the renal replacement programme can be planned and commissioned appropriately.

Data must be timely, accurate, accessible and intelligible if it is to help with planning and commissioning in a meaningful way. Commissioners and units can then use these data to support planning and to identify in local development the local priorities for improvement. See Local Action 3.4.

Performance Indicators

2.5 CHAI will work with the Department of Health and other key stakeholders to develop suitable performance indicators for national and local use.

As part of the NHS performance rating assessment one or more high-level performance indicators are being developed with the Commission for Healthcare Audit & Inspection (CHAI) along with key stakeholders. Such indicators should be capable of collection as a by-product of the direct care given to patients and should be available from the clinical information systems to be developed under the National Care Records Service.

CHAI will also include comparative information about renal services in its development programme of indicators for the NHS to use as appropriate locally. These will be based on the NSF standards and markers of good practice, professional standards, on NICE guidelines and appraisals, and will also cover other aspects of service quality such as equality of access, patient choice and resource utilisation.

Information for Audit

2.6 CHAI will work with the Department of Health, the Renal Association, the UK Renal Registry, UK Transplant and the renal services community to develop national comparative clinical audit plans within a framework of standards for national audit as a matter of priority.

This action is designed to enable data items identified to be collected and analysed to review clinical outcomes for audit and benchmarking purposes both nationally and locally.

Because of the importance of local and national audit it is essential that all Trusts with Renal Services are adequately served by electronic renal data management systems capable of transferring data to the UK Renal Registry and UK Transplant at the earliest opportunity. This need has been foreseen in National Action 1.1 regarding implementation of the Renal NSF Core Service by Local Service Providers under the National Care Records Service.

There is a need to monitor management of the quality of care through estimates of dialysis adequacy and technique failure, and the complications of renal failure such as anaemia, metabolic bone disease,

ischaemic heart disease and hypertension must be assessed so that quality of life is as good as possible within the limitations of the condition.

For transplant recipients the outcome of the transplant must be monitored, including not only graft and patient survival but also as a minimum graft function, the number and type of rejection episodes and the development of major complications such as chronic allograft nephropathy, recurrent renal disease, post-transplant lymphoproliferative disease and cancer. Donor audit includes retrieval rate, condition of donated organs and cold ischaemic time.

3 Access to Knowledge

National Website of Information Links

3.1 The Department of Health Renal NSF website will act as a central link to supporting programmes of work including links to the NeLH, NHS Direct Online, the UK Renal Registry, UK Transplant, professional organisations such as the Renal Association and the British Transplantation Society as well as charitable organisations such as the National Kidney Federation and the National Kidney Research Fund.

National electronic Library for Health (NeLH) – Central Repository

3.2 Whilst designed primarily for the use of health professionals, the NeLH will act as the central repository for information from accredited organisations and sources about end-stage renal failure and its treatment and management, whether for patients and their carers, the public or health professionals. Their information resource will be used by NHS Direct and NHS Direct Online to develop information suitable for the needs of patients, their carers and the public.

The National electronic Library for Health at http://www.nelh.nhs.uk/ was established to provide a single source of health information primarily for health professionals but also accessible by patients and the general public. It provides links to national agencies, access to a wide range of expert knowledge and a wealth of information in its specialist libraries. NHS Direct and NHS Direct Online draw from the NeLH when they develop their services that, however, are designed specifically for the use of patients and the general public. Maintaining this information centrally aids in document management and ensures that all material used is in as current a format as possible.

National electronic Library for Health (NeLH) – Renal Specialist Library

3.3 The NeLH, along with key stakeholders, will develop a Renal Specialist Library designed for the use of health professionals. It will provide access to the evidence base where this exists, and identify areas where research is required to strengthen the evidence where it is lacking.

The Renal Specialist Library to be developed by the NeLH will be one of many such repositories of specialist information designed for health professionals. The NeLH will bring together knowledge from a variety of different sources. It will form a National Knowledge Service for renal disease because it will be able to incorporate the knowledge into the electronic patient record itself. In the short term the NeLH will develop an electronic library, namely an integrated collection of best current knowledge. It will also be providing links to NHS Direct Online so that the patient who wants to know more than is in NHS Direct Online will be able to automatically go through to the appropriate section of NeLH.

National electronic Library for Health (NeLH) – Information from National Agencies

3.4 The NeLH will incorporate knowledge about end-stage renal failure and its treatment from all the national agencies such as NICE, UK Transplant and the Modernisation Agency and present this as a single interoperable source for healthcare professionals and interested members of the public.

Information from national agencies will be linked so that, for example, guidance from NICE will be automatically linked to the appropriate part of the British National Formulary.

NHS Direct Online – General Information for Patients, Carers and the Public

3.5 Drawing on information from the National electronic Library for Health (NeLH), NHS Direct Online will provide a web-based service giving access to recognised sources of high quality information about established renal failure and its treatment and management, designed primarily for use by patients and their carers and members of the public, as well as access to information about organ donation for the public and potential live donors.

The main source of knowledge for the general public will be NHS Direct Online which is expected to offer a full range of information about ERF and its treatment and kidney donation in formats suitable for all ages, educational backgrounds, physical disabilities, cultural backgrounds and mother tongues. This will be achieved through a partnership with UK Transplant and other recognised sources including professional organisations such as the Renal Association,

British Association for Paediatric Nephrology and the British Transplantation Society and charities such as the National Kidney Federation (NKF), the umbrella organisation of patients' associations.

Individual sources of information can be quality checked using instruments such as DISCERN and Plain English guidance. The Information Partners Programme, run by NHS Direct Online provides an accreditation mechanism whereby the organisation's processes for creating information can be accredited and their information then released onto a range of resources including the NHS Direct Online website as a direct link from the Encyclopaedia and Self Help Guide. This accreditation process will also ensure links into the new NHS Digital TV channel as well as NHS Direct Kiosk information resources and can, if the organisation wishes, allow use of an NHS endorsement mark as an Information Partner.

The NHS Direct HealthSpace portal, due to be launched later in 2003, aims ultimately to link with the National Care Records Service to allow patients enhanced facilities, potentially, for example, for those waiting for a transplant to be able to check their registration status.

NHS Direct Online will be able to provide members of the public with access to the Organ Donor Register as well as enrolment facilities for new potential donors. This will be available via the Health Space portal section of its website that will access the Organ Donor Register details through the Spine Record of the National Care Records Service.

Potential live donors need independent advice from a well-informed source, not linked to family or to their unit, where they can receive unbiased advice without any pressure. Families of cadaveric donors also need information and reassurance that they are doing the right thing if they are called upon to make a decision about organ donation. NHS Direct Online will aim to be able to link to UK Transplant forall issues related to transplantation and organ donation in order to avoid duplication or giving conflicting information and to increase consistency and reliability of information.

Information for Third Parties

3.6 Drawing on information from the National electronic Library for Health (NeLH), NHS Direct Online will make available information about renal failure and its treatment written for use by third parties such as educational establishments, employers and insurance companies.

Renal failure and its treatment disrupt the lives of patients and their families and lack of knowledge about the needs of patients on dialysis or with a functioning transplant can cause problems in various ways. In order to further a better understanding of the needs of these patients, educational establishments, employers and insurance companies will be able to find information on NHS Direct Online that will enable them to better assess the needs of such individuals with whom they come in contact.

Local Action 3.2 encourages Trusts with Renal Services to ensure that patients know where to get this information from so that, when necessary, they can pass it on to third parties or tell them where to look for it.

Information for Children and Young People

3.7 Drawing on information from the National electronic Library for Health (NeLH), NHS Direct Online will make available information and advice for children and young people with renal failure about the problems of adjusting to their disease and how they might have a greater say in managing their disease as they grow up.

The needs of children and young people with renal failure, particularly as they start to get older, more independent and free-spirited, pose particular problems related to their increasing awareness and understanding of this life-limiting condition. They may or may not be reliant for the maintenance of their well-being on parents or carers and may or may not be easily disposed to the strict regimen required of them when receiving dialysis.

Information and advice that is seen by children and young people to be independent of parents, carers and the Renal Unit might be less threatening and intrusive, but it needs to be presented sympathetically and in a way which recognises the special needs of children and young people at different stages of their lives when looking at and trying to absorb and act upon information. It must also be sensitive to the needs and concerns of parents and carers.

Local Action 3.3 encourages Trusts with Renal Services to ensure that children and young people, as well as their parents and carers, are aware of how to find this information and advice on NHS Direct Online.

NHS Direct – Provision of Information and Advice for the Public

3.8 Working with all the appropriate stakeholders and sources of medical knowledge NHS Direct will undertake the necessary actions to enable it to become a safe source of information and advice for people with renal failure and members of the public enquiring over the telephone about issues relating to established renal failure and about the possibility of becoming kidney donors.

NHS Direct will have access to a full range of information about ERF in order to be able to handle call-

ers appropriately and in confidence. In emergency situations callers will be advised to contact their local Renal Unit for advice and treatment. NHS Direct will carry out a review of existing algorithms to ensure that they are safe for people known to have renal failure.

Callers who show an interest in becoming kidney donors and wish to go on the Organ Donor Register will be given details in confidence of how to contact the Organ Donor Line which provides information about organ donation and a link to the UK Transplant website. Those who need further advice on live donation will be referred in confidence to their local live donor co-ordinator through UK Transplant, who could also arrange for independent advice from another renal unit if required.

Information about renal failure services and organ donation will be included in the information sources used in NHS Direct call centres including the NHS Clinical Assessment System and DORIS (Directory of Resources and Information Services) and will be compatible with that given by NHS Direct Online.

NHS Direct will link to UK Transplant for all organ donor issues in order to avoid duplication or giving conflicting information and to increase consistency and reliability of information.

4 Training and Development

Renal Informatics Special Interest Group

4.1 The NHSIA in partnership with the renal community, UK Renal Registry and UK Transplant will develop a renal informatics special interest group through the Informatics Learning Network available from the National Health Informatics Development (NHID) programme of the NHSIA. The first step will be to establish a web site and moderator.

For further information about this developing programme of work please refer to the NHS Information Authority website at http://nww.nhsia.nhs.uk/nhid/pages/default.asp

Educational Packages for Use of Systems

4.2 NHID, in partnership with the renal community, the UK Renal Registry and UK Transplant, will develop an educational package for units embarking on electronic data collection and for units who have systems not yet fully utilised, to provide a practical guide on how to embed an electronic clinical information system in the delivery of direct care.

For further information about this developing programme of work please refer to the NHS Information Authority website at http://nww.nhsia.nhs.uk/nhid/pages/default.asp

Educational Packages for Career Development

4.3 NHID, in partnership with the renal community, the UK Renal Registry and UK Transplant, will develop an educational package to support Trusts with Renal Services in providing career development and succession planning.

For further information about this developing programme of work please refer to the NHS Information Authority website at http://nww.nhsia.nhs.uk/nhid/pages/default.asp

Supporting Information For The Local Actions

1 Information for the Direct Care of the Patient

Use of Electronic Clinical Information Systems

1.1 Local Service Providers (LSP) will work with Trusts with Renal Services through the National Care Records Service (NCRS) programme Cluster Management Boards to ensure that the electronic clinical information systems (ECIS) are embedded in the management and care of patients with established renal failure.

The National Programme for Information Technology (NPfIT) has responsibility for delivering the National Care Records Service through partnerships with national and local suppliers, known respectively as 'National Application Service Providers' (NASP) and Local Service Providers' (LSP).

The LSP will work within specified geographical areas known as 'clusters'. Cluster Management Boards will ensure that the implementation within the cluster runs to time and to budget and that all required resources are made available. They will instruct the LSP to proceed with the implementation of the services that have been specified in the documents known as Core Services.

The LSP will need to work with Trusts with Renal Services to ensure that information systems are specified, designed, developed and implemented to meet the needs of patients and staff as specified within the Renal NSF Core Service requirement under National Actions 1.1.

At its most fundamental the NCRS will deliver the mechanisms to enable professionals to have access to the views they need to support integrated care at the time and place required and to inform accurate diagnosis and optimum treatment. It will also support the goal of enabling people with renal failure to have access to and to be able to update their

own records so as to assist them in becoming fully involved with their care through joint decision-making in a multi-skilled team environment.

As the National Programme moves forward with the National Care Records Service, Trusts with Renal Services will need to come together to work in partnership with the designated LSP to ensure that the systems developed for use within their cluster meet both their generic requirements for running the service and also those specific requirements that are essential to support patients with renal failure and the health professionals caring for them.

Great care should be taken by those Trusts providing renal services in working with the LSP to ensure that the functions of existing successful renal systems are not lost in this process, that new systems should be flexible and capable of evolving over time and that provision is made for them to be supported by well trained staff familiar with the special requirements of a renal unit. This applies to those who input data as well as those who will operate the system. It is essential that every Renal Unit should have its own system which integrates with other Trust systems. Historically this has not usually been the case since many renal information systems preceded wider hospital systems and have largely remained separate.

Approximately 20% of satellite dialysis centres in England are run by commercial organisations. Trusts with Renal Services contracting with these external organisations will need to include controls and specifications within contracts which will support an IT infrastructure for data returns to the parent renal unit. This will be essential for the continued provision of data for the direct care of the patient as well as to the UK Renal Registry from these patients in support of monitoring clinical governance and will help to ensure that this data does not lose visibility within the renal community. The ownership of any patient information held by these commercial organisations must remain with the renal unit commissioning these services.

Finally, the National Actions in section 4 Training and Development and the corresponding Local Actions are designed to ensure that staff with the responsibility for data receive adequate and ongoing training and support. See in particular National Actions 4.2 and 4.3 and Local Action 4.1

Access to Information for Primary Care Teams

1.2 PCTs should work with their Cluster Management Boards and LSP to ensure that primary care teams can access the records of patients with ERF, including a facility to view the patient's registration and status on the national transplant list.

The NCRS development must include the facility to share information about patients with ERF with primary care health professionals. PCTs will have a responsibility to ensure this is possible.

Introduction of Care Plans in Trusts with Renal Services

1.3 Trusts with Renal Services will be able to draw upon the national care plan model developed by the Department of Health to meet the needs of their patients and to encourage its use by both patients and health professionals.

Care plans have long been used for the management of patients on wards, being largely the domain of the nursing staff. However, with conditions such as diabetes and renal failure, where self-management plays a crucial role in maintaining the patient's health and where professionals from not only within health but also frequently from other agencies such as social care and education services may have regular input to a patient's management and treatment, the use of care plans beyond wards in the form of a personalised plan drawn up and agreed in partnership with the patient is now seen as a vital element of the management and care of patients. The concept of the care plan may encompass the provision of a facility whereby the patient can enter details of events and results along the lines of a daily log book and review their results.

While there are undoubtedly examples of good practice in the use of care plans in this way there is no single recognised model available that can help to kick-start the process locally. The Department of Health has begun work on developing one such model in response to the Diabetes NSF and intends to use this work to inform care plans for people with renal failure.

The Department of Health is initiating this work through a national workshops with patients to discover their preferences – what care plans mean to patients and how they would like them to be recorded and reviewed. The outcome of this will help determine the care plan and how it links to primary care, other specialist services and social care.

The care plan will be the interim solution to NCRS and will probably be electronic, but some patients may prefer paper. The Modernisation Agency may pilot care plans and the pilots will look at the cost of implementation.

Support for Care Plans by PCTs

1.4 PCTs are encouraged to work with local renal units to access their care plan model, in order that primary care teams can promote its use by both health professionals and patients in the community.

Information Sharing

1.5 Trusts with Renal Services are encouraged to lead a formal examination of the issues relating to information sharing for all relevant stakeholders including those in primary care and to use the results to ensure that the interests of patients, donors and care professionals are recognised and properly safeguarded.

'Information sharing' is about communicating promptly, accurately and effectively with the patient and others involved in the patient's care within the legal framework of the Data Protection Act for the patient's benefit. Patients need to know what personal information about them is or may be shared by the professional caring for them with another care professional or indeed with another third party, knowing why that information is shared and giving or withholding consent for it to happen. For patients who may wish to view their own records there should be no surprises. For care professionals it is about ensuring that patients are prepared for and supported in viewing their own records and knowing what personal information about a patient or patients they can or cannot share with others and with whom they can or cannot share it. Special consideration must be given to the proper protection of third parties such as organ donors.

It is the intention to ensure that, by understanding these issues in a practical way and in ways that reflect local practice and by developing procedures that are clear to follow the interests of patients, third parties and care professionals are recognised and properly safeguarded.

In the case of renal patients special consideration should be given to the confidentiality of donors while maintaining the ability to access information relevant to the care of the recipient.

The local Caldicott Guardian should be involved to ensure that information is shared within the permitted limits of security and confidentiality. Reference can also be made to ongoing work within the National Programme for Information Technology (NPfIT) on the subject of Security and Confidentiality.

Because of the complex nature of renal disease, patients often come under the care of a number of different care professionals who will not always be on one site. They may belong to other agencies such as education and social care. Procedures, therefore, will need to address the geographical and the multi-agency issues and, whilst such issues may be best solved by sharing information electronically, the fundamental decisions about giving patients and care professionals the understanding about what may or may not be shared must be addressed whatever the method of sharing, be it on paper or electronically. Strategic Health Authorities might wish to take the lead in this respect with Primary Care Trusts working with the other agencies to bring together those Trusts with Renal Services where clear procedures for sharing information would be of benefit to all concerned.

Sharing information with patients will need to be recognised as a challenging process and great care will need to be taken over the delivery mechanisms taking into account language differences and differences of cultural background. Personal communication with face-to-face delivery is advised to be the primary method for sharing information with patients, backed up by written information.

Providing people with access to their own results and records, including sending them copy letters, helps to empower them and support them in becoming expert in managing their own care. However it is essential that the patient has been adequately prepared for any bad or unexpected information that may be included. The primary stakeholder is the patient and it is only logical that patients should be able to view their own records. This enables them to ensure completeness and accuracy of the content. Patient care is a partnership and sharing records is part of that process.

Special consideration should be given to information sharing when patients move from one unit to another, from dialysis to transplant units or for young people transferring from children's to adult units.

Access to information about donors also requires special consideration because of the need for information at short notice and the need for confidentiality. For example, at the time of death leading to organ donation the donor records must be accessed to consider the suitability of a potential donor or following the development of post transplant problems in the recipient there may be a need to review the donor details.

This action, therefore, seeks to encourage Trusts, PCTs and SHAs to help patients and care professionals to understand what information may or may not be shared and thereby to lead on to further benefits for patients of making results and records available to them and of enabling them to participate actively in their own care.

The NHS Information Authority, as part of its work to support the implementation of the Mental Health Information Strategy, has collated examples of information sharing protocols that have been developed around the country and links to those examples as well as to available guidance on the development of information sharing protocols can be found at *NHSIA : Mental Health Information Strategy.*

Decision Support

1.6 Trusts with Renal Services are encouraged to provide care professionals treating patients with ERF with access to decision support at the point of care in advance of this functionality being pro-

vided in the Renal NSF Core Service.

Decision support can take a number of different forms and, by its nature, is intended to support clinicians in their routine clinical work but not to replace the knowledge and experience that clinicians have of individual decision making as a result of the face-to-face interaction with patients.

At the simplest level decision support may take the form of prompts that highlight unusual or dangerous results or situations that require decisions to be made. More sophisticated systems may be based on a series of algorithms within a computer's clinical information system that gives simple prompts or complex responses when different measurable criteria are present. Clinicians see the prompts and responses and decide on their validity in the particular circumstances, choosing either to act or not to act, knowing that they have given due consideration in all cases.

On the other hand decision support could take the form of evidence-based guidelines accessible from a repository of knowledge such as the National electronic Library for Health (NeLH). Typically these would be based on existing publications such as NICE guidelines or other evidence-based material. Access to the guidelines might or might not be built into the clinical information system for use by the clinician at the point of care.

Decision support may take the form of locally produced practical guidelines or checklists indicating the local arrangements for procedures such as transplantation. In situations where no evidence-based guidelines exist best practice guidelines have been developed based on expert opinion. Such opinion-based documents do not have the rigorous basis of evidence-based guidelines. Relevant guidelines could be selected or adapted locally and made available either in paper format or via a local intranet.

The information contained within the developing Renal Specialist Library of the NeLH will provide valuable assistance for developing local protocols and guidelines for decision support at the point of care. Through its ready availability on the Internet it will reduce the difficulty for health professionals of accessing and processing quality information, and thus contribute to improvement in the care of patients.

Much of the training of doctors has focussed on gathering information about the individual patient and his or her condition and making individual decisions at every point in the patient journey. Now that so many patients have been treated for ERF by dialysis and transplantation it is logical to ensure that similar problems are managed in similar ways firstly to ensure that the best evidence-based practice informs each decision and secondly to ensure equity of access to treatment (e.g. organ allocation, management of haemoglobin). Although some information will be available nationally through the NeLH, the implementation of best practice when considering local circumstances such as geography and historical development require local interpretation of national guidelines.

The NCRS is expected to support functionality to enable decision support at the point of care. However, until such time as this becomes available every unit should be considering the introduction of a range of local protocols to enable consistent implementation of common procedures and treatments. Clinical staff could work with Chief Information Officers in identifying how local developments can enable decision support.

2 Information for Secondary Purposes

Clinical Information Systems

2.1 In order to submit the required data for secondary purposes, Trusts with Renal Services may use the agreed procedure to extract the data used by UK Transplant and the UK Renal Registry electronically.

The Renal NSF Core Service requirement referred to in National Action 1.1 will specify that the LSP will write an extract programme to enable Trusts with Renal Services to send data to UK Transplant and the UK Renal Registry based on the National Dataset for transplantation and dialysis services to be commissioned by the Department of Health and CHAI under National Action 2.2.

It will be the responsibility of Trusts with Renal Services to ensure that data are submitted to UK Transplant and the UK Renal Registry as required for audit and other secondary purposes. It would be good practice to use the electronic processes developed by the LSP.

Datasets

2.2 Trusts with Renal Services should collaborate with the LSPto implement the National Dataset upgrade to their electronic clinical information systems when available.

Once the National Dataset is complete and has received NHS Information Standards Board approval the Local Service Providers will be responsible for ensuring that system suppliers provide Trusts and Renal Units with the necessary upgrade to their systems. Trusts with Renal Services should collaborate in this process when the upgrade is offered to them.

Analytical Capacity

2.3 Access to the analytical and epidemiological skills required to handle and interpret the data

required for audit and other purposes is essential if data are to be handled and interpreted correctly. It is good practice to use such services for data interpretation locally and nationally.

Outcome data once collected should be collated and adjusted for a variety of confounding factors, for example age, diabetes and ethnic mix, if data are to be meaningful and interpreted correctly. Inappropriate data management can lead to serious problems for planners and providers. Similarly, when interpreting audit data, the appropriate methods mustshould be used to ensure a meaningful outcome.

Trusts with Renal Services will have a relatively small number of patients, and so the effect of demographic and physiological variables on outcome generally needs to be analysed on a national basis. This means that Trusts will need access to the statistical and epidemiological skills required to handle and interpret the data required for audit and other purposes so that local data are interpreted appropriately in the national context and are available to inform management, planning and quality improvement.

It is acknowledged, however, that not only may such skills be in short supply but also there may not be enough patients in any one area to justify an individual Trust appointing such resources. It may, therefore, be prudent and more practical to use the resources of organisations such as the UK Renal Registry, UK Transplant or the National Analytical Service (NAS) who may be able to provide them with the feedback that they need. Alternatively, Strategic Health Authorities may consider a central pool of such resources to act on behalf of Trusts within their area.

In order to address this issue in a comprehensive way Strategic Health Authorities might wish to establish a review of the required and available analytical capacity in their area and work with Renal Collaborative Commissioning Groups to decide how such resources may be put to best use for the benefit of individual Renal Units.

Information about Services

2.4 Renal collaborative commissioning groups are advised to use information including local population demographic data and information about staffing, facilities and current capacity in renal services provided by Trusts with Renal Services to identify gaps and inequalities and plan future services to meet demand. National Survey data (see National Action 3.4) will be available as a baseline for comparison and improvement.

The incidence of ERF is rising and services have not kept pace with demand, leading to a shortage of facilities for patients and heavy workloads for staff. The prevalence is projected to continue to rise at least until 2020. It would be good practice to plan for an annual expansion of services to meet this need.

Unless providers, planners and commissioners are aware of the local resources in terms of beds, outpatient sessions, haemodialysis stations and staff, they will not be able to plan a safe and effective service to meet the projected changes in demand. Overcapacity is inefficient and wasteful while undercapacity will lead to difficulty in providing a service.

Local providers, planners and commissioners will receive information about their local services from UK Transplant, UK Renal Registry and the National Survey. It will be up to them to adapt this information according to local circumstances.

Information for Audit

2.5 It is good practice for Trusts with Renal Services to participate in national comparative audit of the structure, process and outcome of their work. This could include, for example, patients' opinions, suggestions, transport arrangements, as well as audit of activity, outcomes, waiting lists and admissions to non-renal wards with feedback used to inform change.

This approach will provide a more patient focussed service more able to meet the needs of individuals. The information would also be valuable for commissioners in performance management. Further, CHAI expects participation in national audit using electronic transmission of renal unit data to the UK Renal Registry and UK Transplant to demonstrate their level of success to both CHAI and commissioners.

An efficient unit should have processes and systems in place to ensure that patient care is continuously improved. For example, the availability of patient information and organisation of patient education could form part of a structured process. A named person could be responsible for acquiring relevant information, organising and updating it and ensuring systematic delivery to each patient in an appropriate format. There should be a clear mechanism for patients and others to make constructive suggestions or voice complaints, backed up by a system for responding.

In the absence of such systems, problems that occur may not be addressed or not even recognised. Use of processes available for audit improves the efficiency of a unit and enables it to respond to problems and improve the service to patients systematically.

3 Access to Knowledge

Information for Patients, Carers and the Public

3.1 Trusts with Renal Services could, by using the services described in National Actions 3.1 to 3.7, make available a full range of information for

patients, carers and the public about renal failure, its treatment and management and services available locally.

Personal, face-to-face communication is advised to be regarded as the principal method of communication with patients and their carers. Written and other media should be available to back up and reinforce points made during discussion.

Some patients, their carers and members of the public may wish to go into more detail than others. The information available must cover the needs of these individuals without compromising the needs of those who want only limited information.

By accessing the website of information links under National Action 3.1, and particularly by reference to the information to be provided by NHS Direct Online under National Action 3.5 to 3.7, Trusts with Renal Services should be in a position to develop a full range of information for patients, carers and the public about renal failure.

Trusts with Renal Services should ensure that there is a named individual responsible for the development and availability of information for patients. Renal units linked through networks should move towards consistency of information across the network. Renal collaborative commissioning groups may take a view on this.

The information provided locally would include information about ERF, its treatment and management, about what to do in an emergency, holiday dialysis and information about the transplant list and how it works. Trusts with Renal Services should add information about their own local services.

The information should be suitable for all patients, carers and members of the public, including different age groups, ethnic minorities, those with literacy problems or learning difficulties and those with sensory deficits. Depending on local circumstances Trusts with Renal Services may wish to concentrate their efforts, and their budgets, on one or more target groups and prepare the material in a way that meets the needs of the particular group or groups. For example, the delivery of information in a particular language may be more urgent in one area or material prepared for young people in a way that captures their attention might be more important in another.

Many patients who do not speak English are not able to read leaflets in their own language. For those patients it may be more useful and cost effective to have an interpreter present at a consultation using a good quality English leaflet as the basis for the discussion. This approach may be preferable to having large quantities of translated material that may only rarely be used and may quickly become obsolete. Questions can be asked and answered through the interpreter who can make notes that he/she can understand.

Not all patients have or wish to have access to the Internet. Those who do not may or may not wish to find out information for themselves. If they do they should be supported in doing so by having access to a computer terminal at the renal unit and offered help in using the equipment to find the information they require. Alternatively, patients who prefer written information could be offered material that meets their needs either prepared locally or downloaded from a reliable web-based source such as NHS Direct Online.

Initially patients' needs often centre on information about illnesses and their treatments and about the services that are available to them both locally and nationally. However, patients also need information about the things that will have a positive impact on their lives and not just about the things that they should not be doing. With the proposed approach local Trusts with Renal Services should be in a position to provide access to information that gives positive information about lifestyle decisions including diet, exercise, travel, holidays and work.

As a quality check, Trusts with Renal Services may wish to use the Centre for Health Information Quality (CHIQ – see www.hfht.org/chiq/) and DISCERN (see www.discern.org.uk/ for a brief online questionnaire which provides users with a valid and reliable way of assessing the quality of written information on treatment choices for a health problem) to assess the information products that they make available in this way to their local patients, carers and public.

Information for Third Parties

3.2 Trusts with Renal Services should ensure that patients are aware of how to obtain information, such as through the services described in National Action 3.6, about renal failure and its treatment that has been written for use by third parties, for example educational establishments, employers and insurance companies.

Under National Action 3.6 NHS Direct Online will make available on its website information about renal failure and its treatment that will be written for use by third parties such as educational establishments, employers and insurance companies.

In order to ensure that third parties get to see this information when it is needed patients must themselves know how to obtain it so as to be able to pass it on to third parties or to know where to direct third parties so that they can look at it on the NHS Direct Online website.

Information for Children and Young People

3.3 Trusts with Renal Services should ensure that

children and young people, as well as their parents and carers, are aware of how to find the information and advice, such as through the services described in National Action 3.7, about the problems of adjusting to their disease and how they might have a greater say in managing their disease as they grow up.

Under National Action 3.7 NHS Direct Online will make available information and advice for children and young people with renal failure about the problems of adjusting to their disease and how they might have a greater say in how they manage their disease as they grow up.

In order to ensure that not only children and young people, but also parents and carers, get to see this information and advice they must know how and where to find it on the NHS Direct Online website.

Trusts with Renal Services can add their own local information for children and young people to that provided by the NHS Direct Online website. This might, for example, include information about transferring to an adult unit, including detailed information about their new unit, its staff and organisation prior to transfer in order to reduce the risk of non-adherence, anxiety, misunderstandings and treatment failure associated with transfer at this vulnerable time. Consideration will need to be given to the format of the local information bearing in mind the special needs of children at different ages.

Information for Transferring to Other Units

3.4 Trusts with Renal Services should give patients transferring to other units either within or outside their local renal network information about the receiving unit before they are transferred in order to ensure smooth transition.

Transferring to another renal unit in England for a transplant, for dialysis or for any reason can be inconvenient to patients at the least and traumatic at the worst. It will always be helpful for patients to receive information about their new unit before they transfer.

Access to the IT Infrastructure

3.5 Trusts with Renal Services need to consider how to ensure that professional staff and patients have ready access to the knowledge base through implementation of the necessary IT infrastructure.

Information for patients, carers and care professionals must be easily accessible otherwise there is a real danger that it will not be used and will fall into disrepute. Most information today, if it is to be up-to-date, consistent and readily available needs to be held in electronic format. For patients, carers and care professionals to be able to see that information they must have access to it via a reliable IT infrastructure with hardware and software that is easy to use.

It would be good practice for the Chief Information Officer of Trusts with Renal Services to examine the extent of the coverage of their IT networks for patients and staff and to consider extending it, where necessary and appropriate, in the light of the information needs proposed in these Local Actions.

4 Training and Development

Training and Support for Staff

4.1 Trusts with Renal Services are encouraged to give staff with responsibilities for data and the preparation of information the appropriate training and support in developing their skills and knowledge.

The information needs of health professionals in Trusts with Renal Services will be satisfied only if they have staff trained in the use of information systems, in data entry and data interpretation and whose skills and knowledge are kept up-to-date.

In addition, staff dealing with large amounts of data on patients who are receiving treatment for renal failure need special expertise about the conditions and treatments that can only be gained from within the renal unit.

Chief Information Officers of Trusts with Renal Services, therefore, may wish to review this element of their activities with a view to deciding how best to train as well as to support their staff and develop their careers and thereby to make the most of their investment in clinical information systems hardware and software. Support is also available through the services of UK Transplant and the UK Renal Registry. See also the support available from the National Health Informatics Development (NHID) programme of the NHSIA under National Actions 4.1, 4.2 and 4.3.

Support for Patients at Trust Premises

4.2 Trusts with Renal Services are encouraged to ensure that, wherever access to information is given to patients via, for example, a workstation located on their premises, help and support as well as sufficient material are readily available so that patients can use the IT system appropriately and understand the information they receive.

In the same way that the information needs of health professionals in Trusts and renal networks across the local community in both primary and secondary care will be satisfied only if they have properly trained staff, so too the information needs of patients and their carers will not be met if they do not have the knowledge of how to use the facilities that may be offered to them, such as a workstation located within

their Renal Unit. Help should be available either in written form or ideally from an informed member of staff who can be on hand to support patients when they are looking for information.

Support for Patients at GP Surgeries

4.3 PCTs are encouraged to ensure that GP surgeries provide online access for patients to information about renal disease, renal failure, its management, local services and organ donation possibly by accessing the services described in National Actions 3.1 to 3.7, with appropriate support from staff.

Glossary of Terms

Term	Description
Care Professional	Any professional, whether for example, from health, social care or education, providing care to a patient.
Commission for Healthcare Audit & Inspection (CHAI)	CHAI is due to come into operation in April 2004 when it be responsible for monitoring standards of healthcare in the NHS and private healthcare organisations across England and Wales. It will take over from the CHI, the National Care Standards Commission for inspecting private healthcare providers, the Mental Health Act Commission, and the Audit Commission's value for money studies in health.
Clinical Information System (CIS)	A comprehensive computerised system operating within a healthcare environment recording data from healthcare professionals about patients' interaction with the service from appointment to discharge.
Local Service Provider (LSP)	Suppliers of local systems and/or services appointed by the National Programme to support the National Care Records Service.
National Application Service Provider (NASP)	Suppliers of national systems and/or services appointed by the National Programme to support the National Care Records Service.
National Care Records Service (NCRS)	One of the four key programmes for delivery by the National Programme, the NCRS concentrates on delivery of electronic patient records and integrated systems for the NHS.
National electronic Library for Health (NeLH)	The National electronic Library for Health provides a single source of health information primarily for health professionals but also accessible by patients and the general public. It provides links to national agencies, access to a wide range of expert knowledge and a wealth of information in its specialist libraries.
National Institute for Clinical Excellence (NICE)	NICE was set up as a Special Health Authority for England and Wales on 1 April 1999. It is part of the NHS, and its role is to provide patients, health professionals and the public with authoritative, robust and reliable guidance on current "best practice". The guidance covers both individual health technologies (including medicines, medical devices, diagnostic techniques, and procedures) and the clinical management of specific conditions. NICE offers the NHS and its patients a new service, which it is intended, shall earn, and retain, the confidence and respect of the community as a whole.
National Programme for Information Technology (NPfIT)	The National Programme for IT in the NHS focuses on the key developments that will make a significant difference to improving the patient experience and the delivery of care and services. There are four key deliverables: electronic appointment booking, an electronic care records service, electronic prescribing and an underpinning IT infrastructure with sufficient connectivity and broadband capacity to support the critical national applications and local systems. To ensure delivery of the National IT Programme there are also several supporting workstreams around streamlining procurement, managing implementation in the NHS and improving the partnership and capacity with IT suppliers.

NHS Direct	NHS Direct operates a 24-hour nurse advice and health information service, providing confidential information on what to do if people are feeling ill, particular health conditions, local healthcare services, such as doctors, dentists or late night opening pharmacies and self help and support organisations.
NHS Direct Online	NHS Direct Online is a website providing high quality health information and advice for the people of England. It is unique in being supported by a 24 hour nurse advice and information helpline. If users of NHS Direct Online are in any doubt about information they read or about what action to take, they can call NHS Direct on 0845 4647
NHS Information Authority	Special Health Authority established in April 1999 to replace the previous NHS Information Management Group (IMG) and the FHS Computer Unit.
NHS Information Standards Board (ISB)	The ISB is the governing board responsible for approving data standards and other changes for adoption by the NHS.
NHS Modernisation Agency	The NHS Modernisation Agency exists to help NHS staff and their partner organisations to improve services for patients. The Agency works in close partnership with Strategic Health Authorities to align its work to local priorities and commits funding, resources and expertise to local modernisation objectives. Operating across all sectors of the NHS - acute trusts, primary care, ambulance and Mental Health Trusts- the system redesign work of the Agency is underpinned by the major principles of quality of patient safety, leadership and workforce development.
Renal Collaborative Commissioning Groups	Groups established by PCTs to commission services identified in the Specialised Services National Definition Set. They are overseen by Strategic Health Authorities. Their decisions are binding on all PCT members.
Renal Unit	A unit, either run by the NHS or privately, that is dedicated to dialysis of patients with established renal failure.
Transplant List	A list, maintained by UK Transplant, of people waiting to receive an organ transplant.
Trusts with Renal Services	In the context of the Renal Services Information Strategy National and Local Actions any organisation within the NHS that delivers care to patients with impaired renal function. This could be, for example, a hospital or group of hospitals forming a trust which provides dialysis or transplantation either directly or through outreach clinics.
UK Renal Registry (UKRR)	The UK Renal Registry is a non-profit making organisation and, as part of the Renal Association, is registered as a charitable activity by the Charity Commission. The Registry was established by the Renal Association in 1997 with support from the Department of Health, the British Association of Paediatric Nephrologists, and the British Transplant Society as a resource for the development of patient care in renal disease. It provides a focus for the collection and analysis of standardised data relating to the incidence, clinical management and outcome of renal disease. It thus acts as a source of comparative data, for audit/benchmarking, planning, clinical governance and research. The UK Renal Registry monitors indicators of the quality as well as quantity of care, with the aim of improving the standard of care. There is currently a concentration on data concerning renal replacement therapy, including transplantation. At a later date there will be an extension to other forms of treatment of renal disease. For further information: http://www.renalreg.com/

UK Transplant (UKT)	UK Transplant is a special health authority. It has a statutory responsibility to acquire, record, update, keep and make available information about donors and recipients and organs that are or may be available for transplantation. It fulfils this responsibility by maintaining the national transplant database as a central, complete, accurate and up-to-date record of transplantation from donation to the death of the recipient. Thereafter UKT undertakes an ongoing programme of clinical audit and statistical analyses to both demonstrate and improve the quality of service delivered to patients. For further information: http://www.uktransplant.org.uk/default.htm)

Appendix F: Data Tables

F:1 Patients starting renal replacement in 2002

Table F.1.1. Take-on of new dialysis patients

Take-on figures for new patients on dialysis				
	Aged <65		Aged >65	
Centre	% on HD	% on PD	% on HD	% on PD
Bangr	67	33	83	17
Bradf	71	29	85	15
Bristl	60	40	85	15
Camb	62	38	87	13
Carls	38	62	80	20
Carsh	49	51	75	25
Clwyd	50	50	89	11
Covnt	46	54	83	17
Crdff	54	46	79	21
Extr	63	37	78	22
Glouc	52	48	88	13
Guys	47	53	65	35
H&C	68	32	69	31
Heart	88	12	89	11
Hull	70	30	76	24
Ipswi	38	63	67	33
Kings	54	46	63	37
Leic	57	43	68	32
LGI	79	21	91	9
Livrpl	60	40	85	15
Middlbr	83	17	95	5
Newc	64	36	88	12
Notts	29	71	73	27
Oxfrd	53	47	75	25
Plym	52	48	85	15
Ports	68	32	81	19
Prstn	45	55	73	27
Redng	35	65	37	63
Sheff	55	45	61	39
Stevn	69	31	93	7
Sthend	63	38	94	6
StJms	67	33	93	7
Sund	94	6	86	14
Swnse	67	33	70	30
Truro	50	50	97	3
Wirrl	100	.	100	.
Wolve	57	43	78	22
Words	58	42	83	17
Wrex	52	48	71	29
York	53	47	82	18
Eng	59	41	79	21
Wls	58	42	76	24
E&W	59	41	79	21

Table F.1.2. Take-on totals of new dialysis patients

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	815	570	1048	273
Wales	86	62	123	38
E&W	901	632	1171	311

Table F.1.3. Treatment modalities at 90 days

	Treatment modalities at 90 days					
Centre	% on HD	% on PD	% on transplant	% transferred out	% stopped treatment	% died
Bangr	77.8	22.2	.	.	.	.
Bradf	71.7	20.0	.	2	.	7
Bristl	60.6	21.2	3.6	.	.	15
Camb	63.5	19.8	10.4	1	.	5
Carls	48.1	37.0	.	.	.	15
Carsh	57.8	35.1	.	1	.	6
Clwyd	66.7	20.0	.	.	.	13
Covnt	47.7	29.0	8.4	1	1	13
Crdff	61.4	31.0	5.1	.	.	3
Extr	64.8	24.2	1.1	.	.	10
Glouc	67.2	26.2	1.6	2	.	3
Guys	49.7	40.6	4.2	1	.	4
H&C	61.3	28.0	1.3	4	.	5
Heart	76.7	10.0	.	.	.	13
Hull	65.7	24.5	.	.	.	10
Ipswi	42.9	38.1	.	5	.	14
Kings	52.2	36.7	2.2	.	1	8
Leic	59.5	35.1	2.0	.	.	3
LGI	79.4	12.7	.	.	.	8
Livrpl	61.6	23.8	.	1	2	12
Middlbr	77.3	9.3	1.0	1	.	11
Newc	52.9	20.6	10.3	.	3	13
Notts	46.7	42.4	.	.	.	11
Oxfrd	53.7	28.7	6.1	1	.	11
Plym	54.2	24.1	.	.	1	20
Ports	67.4	24.0	.	.	2	7
Prstn	48.0	40.8	2.4	1	.	8
Redng	33.3	60.0	.	2	.	4
Sheff	52.3	38.4	.	1	1	7
Stevn	65.4	19.2	6.7	.	.	9
Sthend	62.5	12.5	3.1	.	.	22
StJms	70.6	21.2	.	.	.	8
Sund	85.5	9.1	1.8	.	.	4
Swnse	56.4	25.5	.	.	.	18
Truro	66.7	15.8	.	.	.	18
Wolve	59.1	30.1	.	.	2	9
Words	60.7	25.0	.	4	.	11
Wrex	56.5	34.8	.	.	.	9
York	62.7	25.5	.	2	.	10
Eng	60.3	27.3	2.2	1	0	9
Wls	60.2	28.8	2.3	.	.	9
E&W	60.3	27.4	2.2	1	0	9

Table F.1.4. Number of patients per treatment modality at 90 days

	Treatment modalities at 90 days					
	No on HD	No on PD	No on Transplant	No transferred out	No stopped treatment	No died
Eng	1863	843	68	21	14	283
Wales	209	100	8	.	.	30
E&W	2072	943	76	21	14	313

Table F.1.5. First treatment modality

	First treatment modality		
Centre	% on HD	% on PD	% on transplant
Bangr	78	22	
Bradf	77	23	

Table F.1.5. First treatment modality (cont.)

	First treatment modality		
Centre	% on HD	% on PD	% on transplant
Bristl	74	23	2
Camb	63	25	13
Carls	63	37	
Carsh	64	36	
Clwyd	80	20	
Covnt	64	32	5
Crdff	62	34	4
Extr	77	23	
Glouc	74	26	
Guys	50	48	2
H&C	68	31	1
Heart	85	15	
Hull	75	25	
Ipswi	62	38	
Kings	56	43	1
Leic	60	39	1
LGI	86	14	
Livrpl	75	25	
Middlbr	91	9	
Newc	71	19	10
Notts	57	43	
Oxfrd	63	31	7
Plym	75	25	
Ports	71	22	6
Prstn	52	48	
Redng	31	69	
Sheff	59	40	1
Stevn	73	20	7
Sthend	81	19	
StJms	79	20	1
Sund	89	11	
Swnse	74	26	
Truro	77	23	
Wolve	66	34	
Words	68	32	
Wrex	61	39	
York	76	24	
Eng	68	30	2
Wls	67	31	2
E&W	68	30	2

Table F.1.6. First treatment modality - patient numbers

	First treatment modality		
	No on HD	No on PD	No on transplant
England	2128	921	64
Wales	233	108	6
E&W	2361	1029	70

Table F.1.7. Treatment modalities by gender

	Treatment by gender					
	Haemodialysis			Peritoneal Dialysis		
Centre	% Male	% Female	M:F Ratio	% Male	% Female	M:F Ratio
Bangr	57	43	1.3	25	75	0.3
Bradf	60	40	1.5	50	50	1.0

Table F.1.7. Treatment modalities by gender (Cont.)

	Treatment by gender					
	Haemodialysis			Peritoneal Dialysis		
Centre	% Male	% Female	M:F Ratio	% Male	% Female	M:F Ratio
Bristl	63	37	1.7	48	52	0.9
Camb	61	39	1.5	63	37	1.7
Carls	38	62	0.6	60	40	1.5
Carsh	64	36	1.8	56	44	1.3
Clwyd	80	20	4.0	67	33	2.0
Covnt	63	37	1.7	52	48	1.1
Crdff	64	36	1.8	47	53	0.9
Extr	56	44	1.3	55	45	1.2
Glouc	61	39	1.6	81	19	4.3
Guys	62	38	1.6	67	33	2.1
H&C	61	39	1.6	62	38	1.6
Heart	54	46	1.2	67	33	2.0
Hull	61	39	1.6	76	24	3.2
Ipswi	44	56	0.8	63	38	1.7
Kings	62	38	1.6	67	33	2.0
Leic	57	43	1.3	60	40	1.5
LGI	72	28	2.6	50	50	1.0
Livrpl	58	42	1.4	67	33	2.0
Middlbr	64	36	1.8	44	56	0.8
Newc	67	33	2.0	71	29	2.5
Notts	65	35	1.9	51	49	1.1
Oxfrd	61	39	1.6	51	49	1.0
Plym	78	22	3.5	65	35	1.9
Ports	60	40	1.5	52	48	1.1
Prstn	53	47	1.1	51	49	1.0
Redng	67	33	2.0	56	44	1.3
Sheff	67	33	2.0	48	52	0.9
Stevn	68	32	2.1	50	50	1.0
Sthend	65	35	1.9	75	25	3.0
StJms	53	47	1.1	72	28	2.6
Sund	57	43	1.4	60	40	1.5
Swnse	60	40	1.5	75	25	3.0
Truro	53	47	1.1	44	56	0.8
Wirrl	76	24	3.1			
Wolve	56	44	1.3	61	39	1.5
Words	41	59	0.7	71	29	2.5
Wrex	54	46	1.2	75	25	3.0
York	50	50	1.0	54	46	1.2
Eng	61	39	1.6	58	42	1.4
Wls	62	38	1.6	59	41	1.4
E&W	61	39	1.6	58	42	1.4

Table F.1.8 Treatment modality numbers by gender

	Treatment by gender			
	Haemodialysis		Peritoneal dialysis	
	No of male	No of female	No of male	No of female
England	1136	727	490	353
Wales	129	80	59	41
E&W	1265	807	549	394

F:2 Current patients 2002

Table F.2.1. Treatment modalities for patients aged under 65 and over 65

	Treatment modalities by centre							
	Patients aged <65				Patients aged >65			
Centre	% on HD	% on PD	% on transplant	HD:PD	% on HD	% on PD	% on transplant	HD:PD
Bangr	63	37		1.7	80	20		3.9
Bradf	38	15	47	2.6	78	14	8	5.5
Bristl	23	7	70	3.3	62	9	28	6.6
Camb	17	16	67	1.1	60	19	21	3.2
Carls	19	17	64	1.2	61	18	21	3.4
Carsh	31	17	52	1.8	51	27	22	1.9
Clwyd	48	13	39	3.8	76	16	8	4.8
Covnt	29	15	55	1.9	59	18	23	3.3
Crdff	19	15	66	1.2	54	18	28	3.0
Extr	26	15	59	1.7	67	19	14	3.4
Glouc	41	22	36	1.9	79	13	8	6.0
Guys	19	12	69	1.6	51	19	29	2.6
H&C	34	20	46	1.7	66	16	18	4.1
Heart	40	7	53	5.9	81	9	10	9.1
Hull	36	15	49	2.3	75	13	12	5.8
Ipswi	27	22	51	1.3	48	39	12	1.2
Kings	28	19	52	1.5	59	22	18	2.6
Leic	30	18	52	1.6	54	25	21	2.1
LGI	25	19	56	1.3	62	16	22	4.0
Livrpl	27	12	61	2.3	56	12	32	4.6
Middlbr	28	8	65	3.6	69	4	27	17.8
Newc	20	7	73	3.1	47	8	45	6.0
Notts	25	16	59	1.6	58	25	17	2.3
Oxfrd	17	9	74	1.9	51	15	33	3.3
Plym	21	14	64	1.5	57	12	31	4.7
Ports	23	8	69	2.8	51	17	32	3.0
Prstn	38	21	40	1.8	60	27	13	2.3
Redng	49	46	5	1.1	49	50	1	1.0
Sheff	39	14	47	2.9	60	19	21	3.1
Stevn	51	12	37	4.1	81	10	9	7.8
Sthend	48	25	27	2.0	87	12	1	7.2
StJms	24	9	67	2.7	69	5	25	13.4
Sund	34	6	60	6.0	64	8	29	8.5
Swnse	35	26	40	1.4	66	25	9	2.6
Truro	39	15	45	2.5	81	8	12	10.5
Wolve	50	20	31	2.5	67	25	9	2.7
Words	31	22	47	1.4	50	27	23	1.8
Wrex	37	32	32	1.2	67	24	8	2.8
York	48	19	33	2.6	79	16	5	4.9
Eng	29	14	57	2.1	62	17	21	3.7
Wls	26	20	54	1.3	62	21	18	3.0
E&W	29	14	57	2.0	62	17	21	3.6

Table F.2.2 Numbers of patients under and over 65 per treatment modality

	Treatment modality numbers					
	Patients aged <65			Patients aged >65		
	No on HD	No on PD	No on transplants	No on HD	No on PD	No on transplants
England	4131	1966	8247	3863	1054	1333
Wales	332	246	679	397	134	114
E&W	4463	2212	8926	4260	1188	1447

Table F.2.3. Treatment modality median ages by centre

Median ages and treatment modalities by centre

Centre	Median age on HD	Median age on PD	Median age on transplant	Median age for all
Bangr	67.2	62.1		64.6
Bradf	64.6	60.1	44.5	55.7
Bristl	67.5	58.9	50.6	56.5
Camb	67.2	56.6	48.5	54.3
Carls	69.4	56.3	50.4	57.7
Carsh	60.4	60.3	51.0	56.0
Clwyd	60.2	53.3	52.3	56.4
Covnt	62.9	57.6	46.8	54.5
Crdff	67.0	56.5	49.0	54.3
Extr	68.8	60.4	49.9	59.0
Glouc	69.8	58.3	50.5	62.2
Guys	63.3	56.5	47.6	52.3
H&C	63.8	57.7	53.3	57.5
Heart	65.4	62.4	46.9	57.6
Hull	65.1	56.2	48.8	56.3
Ipswi	63.3	62.3	47.8	54.8
Kings	66.1	61.5	48.2	56.5
Leic	62.9	59.9	49.5	56.3
LGI	65.8	57.8	50.8	56.9
Livrpl	60.8	48.6	48.6	52.4
Middlbr	66.2	49.1	49.3	56.1
Newc	61.0	54.7	51.7	53.7
Notts	64.4	60.9	46.7	54.1
Oxfrd	67.1	59.7	51.8	55.6
Plym	64.6	57.3	51.0	55.9
Ports	63.8	63.7	50.7	55.4
Prstn	61.3	57.2	48.9	55.9
Redng	61.1	59.9	40.5	60.0
Sheff	58.4	60.4	48.7	55.0
Stevn	65.7	56.8	49.7	60.4
Sthend	67.7	57.0	54.8	61.5
StJms	64.5	50.4	46.7	52.0
Sund	63.5	55.3	51.0	55.5
Swnse	68.4	61.6	51.3	60.8
Truro	70.8	60.4	52.3	64.2
Wirrl	64.5			64.5
Wolve	62.4	60.3	46.3	59.1
Words	59.8	59.6	52.2	56.5
Wrex	66.9	58.0	47.3	59.5
York	69.7	57.9	41.5	61.5
Eng	64.2	58.3	49.6	55.8
Wls	66.9	58.7	49.4	56.4
E&W	64.5	58.3	49.6	55.9

Table F.2.4. Dialysis modalities for patients aged under 65

Dialysis modalities for patients aged under 65

Centre	% on home HD	% on hosp HD	% on Satellite HD	% on connect PD	% on disconnect PD	% on cycling PD >=6 nights	% on cycling PD < 6 nights	% on unknown type of PD
Bangr	0	63	0	0	20	17	0	0
Bradf	0	63	0	0	19	18	0	0
Bristl	17	26	34	0	18	5	0	0
Camb	5	39	9	0	38	7	2	1
Carls	0	46	7	0	37	10	0	0
Carsh	1	43	21	0	18	18	0	0
Clwyd	3	76	0	5	11	3	0	3
Covnt	3	62	0	0	34	0	0	0
Crdff	0	29	25	0	45	0	0	0
Extr	2	27	34	0	26	2	4	0

Table F.2.4. Dialysis modalities for patients aged under 65 (Cont.)

Glouc	0	64	0	1	25	9	0	0
Guys	6	39	18	0	27	0	11	0
H&C	3	33	28	0	22	15	0	0
Heart	11	69	6	0	13	1	0	0
Hull	6	42	22	0	12	18	0	0
Ipswi	9	47	0	0	11	30	0	0
Kings	0	30	28	0	34	8	1	0
Leic	5	28	28	0	24	14	0	0
LGI	0	57	0	0	34	9	0	0
Livrpl	1	34	34	0	17	1	0	0
Middlbr	2	54	22	0	22	0	0	0
Newc	4	66	0	0	5	24	0	0
Notts	1	48	12	0	22	16	0	0
Oxfrd	8	57	0	0	21	14	0	0
Plym	2	58	0	0	31	0	0	0
Ports	0	49	24	0	27	0	0	0
Prstn	3	34	25	0	27	8	2	0
Redng	0	52	0	0	48	0	0	0
Sheff	11	49	14	0	25	0	0	0
Stevn	0	42	39	0	19	0	0	0
Sthend	0	66	0	0	34	0	0	0
StJms	1	26	50	0	13	11	0	0
Sund	1	64	20	0	7	7	0	0
Swnse	4	36	18	0	41	0	1	0
Truro	0	70	2	0	28	0	0	0
Wirrl	0	55	45	0	0	0	0	0
Wolve	0	34	37	0	26	2	0	0
Words	1	57	0	0	41	0	0	0
Wrex	0	53	0	0	1	44	1	0
York	0	63	4	0	33	0	0	0
Eng	4	44	20	0	23	7	1	0
Wls	1	40	16	0	33	8	1	0
E&W	4	44	19	0	24	7	1	0

Table F.2.5 Dialysis modalities for patients aged over 65

	Dialysis modalities for patients aged over 65							
Centre	% on home HD	% on hosp HD	% on Satellite HD	% on connect PD	% on disconnect PD	% on cycling PD >=6 nights	% on cycling PD < 6 nights	% on unknown type of PD
Bangr	0	80	0	0	9	11	0	0
Bradf	0	79	0	0	14	7	0	0
Bristl	1	21	65	0	11	2	0	0
Camb	1	59	16	0	20	3	1	0
Carls	0	70	7	0	23	0	0	0
Carsh	1	42	23	0	19	16	0	0
Clwyd	0	83	0	17	0	0	0	0
Covnt	1	76	0	0	22	1	0	0
Crdff	0	24	52	0	25	0	0	0
Extr	1	31	46	0	19	1	1	0
Glouc	0	86	0	0	12	2	0	0
Guys	0	45	27	0	20	0	7	0
H&C	0	49	31	0	14	5	0	0
Heart	2	79	9	0	9	1	0	0
Hull	1	45	39	0	10	5	0	0
Ipswi	0	55	0	5	14	22	2	0
Kings	1	30	41	0	25	3	0	0
Leic	1	27	40	0	22	10	0	0
LGI	0	80	0	0	18	2	0	0
Livrpl	0	54	28	0	12	0	1	1
Middlbr	0	69	26	0	5	0	0	0
Newc	0	75	0	0	8	16	0	0
Notts	0	51	18	0	21	8	0	0
Oxfrd	2	75	0	0	19	5	0	0

Table F.2.5 Dialysis modalities for patients aged over 65 (Cont.)

Plym	0	82	0	0	16	0	0	0
Ports	0	50	25	0	25	0	0	0
Prstn	0	31	38	0	28	2	1	0
Redng	0	49	0	0	51	0	0	0
Sheff	0	59	16	0	25	0	0	0
Stevn	0	44	45	0	11	0	0	0
Sthend	1	86	0	0	12	0	0	0
StJms	0	26	68	0	4	2	0	0
Sund	0	74	16	0	5	5	0	0
Swnse	1	44	27	0	28	0	0	0
Truro	1	88	2	0	8	1	0	0
Wirrl	0	37	63	0	0	0	0	0
Wolve	0	31	42	0	26	1	0	0
Words	0	65	0	0	35	0	0	0
Wrex	0	73	0	0	0	27	0	0
York	0	79	0	0	17	3	0	0
Eng	1	52	26	0	17	3	0	0
Wls	0	44	30	1	20	5	0	0
E&W	1	51	26	0	18	4	0	0

Table F.2.6 Age ranges by centre

	Patient age range by centre (%)							
Centre	**18-24**	**25-34**	**35-44**	**45-54**	**55-64**	**65-74**	**74-84**	**85+**
Bangr	1	2	8	19	21	28	21	0
Bradf	4	10	20	17	22	20	7	0
Bristl	5	7	17	18	21	19	12	1
Camb	2	11	19	20	21	19	8	1
Carls	1	9	14	20	24	21	12	1
Carsh	3	10	20	15	23	20	9	1
Clwyd	3	3	13	28	24	23	5	1
Covnt	2	12	19	18	20	18	10	1
Crdff	3	10	17	22	19	17	10	1
Extr	2	8	16	17	21	18	16	2
Glouc	4	6	8	17	21	20	18	4
Guys	2	11	22	21	20	17	7	1
H&C	1	7	15	21	24	21	10	1
Heart	3	9	14	16	22	20	13	1
Hull	3	8	16	19	21	18	12	3
Ipswi	3	7	17	23	19	17	12	1
Kings	1	8	18	20	18	23	11	1
Leic	2	10	15	20	23	20	9	1
LGI	1	8	15	19	25	22	9	0
Livrpl	2	11	21	20	21	16	8	1
Middlbr	4	8	21	16	22	19	11	0
Newc	4	8	20	23	24	16	5	1
Notts	5	10	18	19	19	21	9	1
Oxfrd	2	9	18	20	23	18	9	1
Plym	3	8	18	18	25	15	12	1
Ports	3	9	19	18	23	18	9	1
Prstn	2	11	15	20	21	19	10	1
Redng	2	7	12	19	17	27	14	1
Sheff	3	8	17	21	22	20	8	0
Stevn	2	7	13	17	20	25	14	1
Sthend	2	6	12	13	24	23	15	5
StJms	7	12	16	21	18	16	10	1
Sund	1	12	16	20	20	21	9	0
Swnse	2	6	12	18	20	25	15	2
Truro	2	7	10	13	19	27	18	4
Wirrl	3	7	12	12	17	27	20	2
Wolve	4	8	16	16	21	21	14	1
Words	3	6	15	23	23	21	9	0
Wrex	3	5	12	18	21	25	15	1
York	5	8	13	15	15	19	21	5
Eng	3	9	17	19	21	19	10	1
Wls	3	8	15	21	20	21	12	1
E&W	3	9	17	19	21	19	10	1

Table F.2.7. Dialysis modalities for non-diabetic patients (all ages)

	Dialysis modalities for non-diabetic patients (all ages)							
Centre	% on home HD	% on hosp HD	% on Satellite HD	% on connect PD	% on disconnect PD	% on cycling PD >=6 nights	% on cycling PD < 6 nights	% on unknown type of PD
Bangr	0	71	0	0	16	13	0	0
Bradf	0	69	0	0	20	11	0	0
Bristl	9	23	49	0	15	4	0	0
Camb	3	46	11	0	32	6	2	0
Carls	0	60	3	0	32	4	0	0
Carsh	2	47	19	0	18	14	0	0
Clwyd	2	77	0	13	8	0	0	0
Covnt	3	69	0	0	28	0	0	0
Crdff	0	28	33	0	39	0	0	0
Extr	2	29	38	0	24	2	3	0
Glouc	0	76	0	1	19	4	0	0
Guys	5	39	24	0	22	0	10	0
H&C	2	39	30	0	17	12	0	0
Heart	7	75	7	0	10	2	0	0
Hull	5	45	27	0	10	13	0	0
Ipswi	5	52	0	1	10	29	1	0
Kings	0	29	35	0	29	6	0	0
Leic	4	27	34	0	23	12	0	0
LGI	0	68	0	0	25	7	0	0
Livrpl	1	39	34	0	16	1	1	0
Middlbr	1	60	26	0	13	0	0	0
Newc	3	67	0	0	7	23	0	0
Notts	1	48	17	0	22	13	0	0
Oxfrd	7	66	0	0	18	9	0	0
Plym	2	71	0	0	21	0	0	0
Ports	0	48	25	0	26	0	0	0
Prstn	2	30	32	0	28	6	1	0
Redng	0	53	0	0	47	0	0	0
Sheff	7	52	16	0	25	0	0	0
Stevn	0	41	43	0	16	0	0	0
Sthend	1	88	0	0	11	0	0	0
StJms	1	25	61	0	7	7	0	0
Sund	1	65	20	0	7	7	0	0
Swnse	3	41	24	0	31	0	1	0
Truro	1	82	0	0	16	1	0	0
Wirrl	0	46	54	0	0	0	0	0
Wolve	0	37	38	0	23	2	0	0
Words	1	61	0	0	38	0	0	0
Wrex	0	65	0	0	1	32	1	0
York	0	77	2	0	19	1	0	0
Eng	3	47	23	0	20	6	1	0
Wls	1	42	23	1	29	4	0	0
E&W	3	47	23	0	21	5	1	0

Table F.2.8. Numbers of non-diabetic patients by treatment modalities

	Treatment modalities for non-diabetic patients (all ages)		
	No on HD	No on PD	No on transplants
England	6316	2312	8586
Wales	546	286	730
E&W	6862	2598	9316

Table F.2.9. Dialysis modalities for non-diabetic patients aged under 65

	Dialysis modalities for non-diabetic patients aged under 65							
Centre	% on home HD	% on hosp HD	% on Satellite HD	% on connect PD	% on disconnect PD	% on cycling PD >=6 nights	% on cycling PD < 6 nights	% on unknown type of PD
Bangr	0	63	0	0	21	16	0	0
Bradf	0	65	0	0	23	12	0	0
Bristl	18	24	34	0	20	5	0	0
Camb	5	40	8	0	37	8	2	1
Carls	0	47	3	0	41	9	0	0
Carsh	2	50	18	0	16	13	0	0
Clwyd	3	76	0	7	14	0	0	0
Covnt	4	65	0	0	30	0	0	0
Crdff	0	31	21	0	47	0	0	0
Extr	3	26	30	0	28	3	5	0
Glouc	0	64	0	2	27	8	0	0
Guys	8	37	19	0	24	0	12	0
H&C	3	33	28	0	20	16	0	0
Heart	13	68	6	0	12	2	0	0
Hull	8	46	17	0	11	19	0	0
Ipswi	9	48	0	0	10	31	0	0
Kings	0	30	32	0	30	7	1	0
Leic	6	29	29	0	24	13	0	0
LGI	0	58	0	0	31	11	0	0
Livrpl	2	32	36	0	17	1	0	0
Middlbr	2	53	24	0	21	0	0	0
Newc	4	65	0	0	6	25	0	0
Notts	2	45	14	0	24	16	0	0
Oxfrd	10	56	0	0	20	13	0	0
Plym	3	62	0	0	25	0	0	0
Ports	1	48	25	0	27	0	0	0
Prstn	4	30	27	0	28	9	2	0
Redng	0	54	0	0	46	0	0	0
Sheff	11	47	16	0	25	0	0	0
Stevn	0	40	41	0	19	0	0	0
Sthend	0	84	0	0	16	0	0	0
StJms	2	27	50	0	11	11	0	0
Sund	2	60	23	0	8	8	0	0
Swnse	4	36	18	0	40	0	2	0
Truro	0	72	0	0	28	0	0	0
Wirrl	0	56	44	0	0	0	0	0
Wolve	0	39	39	0	20	2	0	0
Words	1	58	0	0	41	0	0	0
Wrex	0	57	0	0	3	38	3	0
York	0	67	5	0	28	0	0	0
Eng	4	44	20	0	22	7	1	0
Wls	1	41	15	0	37	5	1	0
E&W	4	44	20	0	23	7	1	0

TableF.2.10. Numbers of non-diabetic patients aged under 65 by treatment modalities

	Treatment modalities for non-diabetic patients aged under 65		
	No on HD	No on PD	No on transplants
England	3301	1491	7348
Wales	251	188	622
E&W	3552	1679	7970

Table F.2.11. Dialysis modalities for non-diabetic patients aged over 65

	Dialysis modalities for non-diabetic patients aged over 65							
Centre	% on home HD	% on hosp HD	% on Satellite HD	% on connect PD	% on disconnect PD	% on cycling PD >=6 nights	% on cycling PD < 6 nights	% on unknown type of PD
Bangr	0	79	0	0	10	10	0	0
Bradf	0	74	0	0	15	10	0	0
Bristl	1	22	63	0	11	3	0	0
Camb	1	54	15	0	25	4	1	0
Carls	0	74	3	0	24	0	0	0
Carsh	1	43	20	0	20	16	0	0
Clwyd	0	79	0	21	0	0	0	0
Covnt	1	73	0	0	26	0	0	0
Crdff	0	24	48	0	28	0	0	0
Extr	1	31	45	0	19	2	2	0
Glouc	0	86	0	0	13	1	0	0
Guys	1	42	31	0	19	0	7	0
H&C	0	48	34	0	13	6	0	0
Heart	2	81	7	0	8	1	0	0
Hull	2	43	41	0	9	6	0	0
Ipswi	0	57	0	2	10	27	2	0
Kings	1	28	39	0	28	4	0	0
Leic	1	25	41	0	23	10	0	0
LGI	0	82	0	0	16	2	0	0
Livrpl	0	49	30	0	14	0	1	1
Middlbr	0	67	28	0	5	0	0	0
Newc	0	73	0	0	10	17	0	0
Notts	1	52	20	0	19	8	0	0
Oxfrd	3	77	0	0	16	5	0	0
Plym	0	84	0	0	14	0	0	0
Ports	0	49	25	0	26	0	0	0
Prstn	0	30	40	0	27	2	1	0
Redng	0	51	0	0	49	0	0	0
Sheff	0	59	17	0	24	0	0	0
Stevn	0	41	46	0	13	0	0	0
Sthend	2	90	0	0	8	0	0	0
StJms	0	22	75	0	1	2	0	0
Sund	0	71	16	0	7	7	0	0
Swnse	2	46	29	0	23	0	0	0
Truro	1	88	0	0	10	1	0	0
Wirrl	0	36	64	0	0	0	0	0
Wolve	0	35	38	0	26	1	0	0
Words	0	66	0	0	34	0	0	0
Wrex	0	75	0	0	0	25	0	0
York	0	87	0	0	11	2	0	0
Eng	1	51	27	0	17	3	0	0
Wls	1	44	31	1	21	3	0	0
E&W	1	50	27	0	17	3	0	0

Table F.2.12. Numbers of non-diabetic patients aged over 65 by treatment modalities

	Treatment modalities for non-diabetic patients aged > 65		
	No on HD	No on PD	No on transplants
England	3015	821	1238
Wales	295	98	108
E&W	3310	919	1346

Table F.2.13. Dialysis modalities for diabetic patients

	Dialysis modalities for diabetic patients							
Centre	% on home HD	% on hosp HD	% on Satellite HD	% on connect PD	% on disconnect PD	% on cycling PD >=6 nights	% on cycling PD < 6 nights	% on unknown type of PD
Bangr	0	75	0	0	0	25	0	0
Bradf	0	70	0	0	11	19	0	0
Bristl	4	26	58	0	11	2	0	0
Camb	2	55	14	0	24	2	2	0
Carls	0	55	27	0	9	9	0	0
Carsh	0	32	24	0	24	19	0	0
Clwyd	0	92	0	0	0	8	0	0
Covnt	0	63	0	0	36	2	0	0
Crdff	0	32	49	0	19	0	0	0
Extr	0	29	50	0	17	0	0	0
Glouc	0	67	0	0	13	20	0	0
Guys	0	46	16	0	26	0	11	0
H&C	0	43	25	0	24	8	0	0
Heart	0	69	13	0	18	0	0	0
Hull	0	39	34	0	15	12	0	0
Ipswi	5	40	0	10	25	15	0	0
Kings	0	33	33	0	31	4	0	0
Leic	1	34	25	0	23	17	0	0
LGI	0	45	0	0	50	5	0	0
Livrpl	0	55	19	0	15	0	0	0
Middlbr	2	65	16	0	16	0	0	0
Newc	0	67	0	0	5	29	0	0
Notts	0	53	9	0	24	14	0	0
Oxfrd	0	59	0	0	26	14	0	0
Plym	0	59	0	0	37	0	0	0
Ports	0	53	22	0	25	0	0	0
Prstn	0	45	26	0	28	0	2	0
Redng	0	43	0	0	57	0	0	0
Sheff	4	63	6	0	27	0	0	0
Stevn	0	43	41	0	15	0	0	0
Sthend	0	78	0	0	22	0	0	0
StJms	0	31	45	0	17	7	0	0
Sund	0	82	9	0	5	5	0	0
Swnse	2	35	11	0	52	0	0	0
Truro	0	86	0	0	14	0	0	0
Wirrl	0	50	50	0	0	0	0	0
Wolve	0	19	41	0	39	2	0	0
Words	0	55	0	0	45	0	0	0
Wrex	0	72	0	0	0	28	0	0
York	0	86	0	0	14	0	0	0
Eng	1	48	20	0	24	6	1	0
Wls	1	45	23	0	25	6	0	0
E&W	1	48	20	0	24	6	1	0

Table F.2.14. Number of diabetic patients by treatment modalities

		Treatment modalities of diabetic patients		
	Type of Diabetes	No. on HD	No. on PD	No. on Transplant
England	Type I	623	343	565
	Type II	546	193	110
Wales	Type I	64	31	44
	Type II	34	12	1
E&W	Type I	687	374	609
	Type II	580	205	111

Table F.2.15. Diabetics

Centre	M:F ratio	Median age on 31.12.2002	Median age at start of treatment	Median time on ESRF treatment in days	Median time on ESRF treatment in years
Bangr	7.0	68	62	220	0.6
Bradf	1.3	62	60	477	1.3
Bristl	1.6	58	53	1161	3.2
Camb	1.5	53	44	1091	3.0
Carls	1.4	60	58	1607	4.4
Carsh	1.4	57	50	1267	3.5
Clwyd	0.4	60	55	1823	5.0
Covnt	1.5	55	52	1065	2.9
Crdff	2.4	58	54	1401	3.8
Extr	1.6	59	54	1281	3.5
Glouc	1.3	59	55	819	2.2
Guys	1.1	54	52	1014	2.8
H&C	1.6	63	59	910	2.5
Heart	1.4	60	56	992	2.7
Hull	1.1	59	56	798	2.2
Ipswi	1.4	60	56	1305	3.6
Kings	1.5	62	59	1055	2.9
Leic	1.9	55	51	1042	2.9
LGI	1.6	51	44	1050	2.9
Livrpl	2.0	55	50	1087	3.0
Middlbr	1.3	53	52	602	1.6
Newc	2.5	56	49	1415	3.9
Notts	1.0	58	53	1359	3.7
Oxfrd	1.2	54	49	1193	3.3
Plym	1.8	53	50	815	2.2
Ports	1.5	55	51	1115	3.1
Prstn	1.3	62	61	585	1.6
Redng	1.8	56	54	594	1.6
Sheff	2.3	55	49	934	2.6
Stevn	1.4	57	54	786	2.2
Sthend	2.3	60	56	1156	3.2
StJms	1.4	59	53	1110	3.0
Sund	2.2	51	49	857	2.3
Swnse	1.7	56	56	749	2.1
Truro	1.3	59	64	974	2.7
Wirrl	3.0	56	55	536	1.5
Wolve	1.6	59	56	776	2.1
Words	2.5	62	58	1459	4.0
Wrex	1.4	55	51	1676	4.6
York	0.6	53	52	518	1.4
England	1.5	57	54	995	2.7
Wales	1.9	58	55	1135	3.1
E&W	1.5	57	54	1006	2.8

Table F.2.16. Transplant gender ratios

	% of males	% of females	No of males	No of females	M:F ratio
Eng	60.7	39.3	5778	3743	1.5
Wls	63.8	36.2	506	287	1.8
E&W	60.9	39.1	6284	4030	1.6

F:3 Cause of Death Data Tables

Table F.3.1. Causes of Death by EDTA Code in Dialysis Patients

DIALYSIS	Count			Percent		
	<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%
Cerebro-vascular accident, other cause or unspecified [22]	159	239	398	9.0%	7.6%	8.1%
Gastro-intestinal 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%
Hameorrhage 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%
Tuberculosis (elsewhere) [37]	3	1	4	0.2%	0.0%	0.1%
Generalized 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 (Aplosia) [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.3.2. Cause of Death by Primary Renal Diagnosis

	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

	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
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
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

	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
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
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 Syndrome) [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

	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 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
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

	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
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 Ureaemic 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
Multi-system 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.3.3. Cause of Death by EDTA Code in Transplant Patients

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%
Cerebro-vascular accident, other cause or unspecified [22]	41	46	87	6.9%	6.4%	6.6%
Gastro-intestinal 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%
Generalized 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 (Aplosia) [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.3.4. Collation of EDTA Primary Renal Diagnoses

OLD 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
76	Glomerulonephritis related to liver cirrhosis [76]	Other
78	Cryoglobulinemic glomerulonephritis [78]	Other
79	Renal vascular disease - due to other cause (not given above and not code 84-88) [79]	Renal Vascular Disease
80	Type 1 diabetes with diabetic nephropathy [80]	Diabetes
81	Type 2 diabetes with diabetic nephropathy [81]	Diabetes
82	Myelomatosis/light chain deposit disease [82]	Malignancy
83	Amyloid [83]	Amyloid
84	Lupus erythematosus [84]	Other
85	Henoch-Schoenlein purpura [85]	Other
86	Goodpasture's Syndrome [86]	Other
87	Systemic sclerosis (scleroderma) [87]	Other
88	Haemolytic Ureaemic Syndrome (including Moschcowitz Syndrome) [88]	Other
89	Multi-system disease - other (not mentioned above) [89]	Other
90	Tubular necrosis (irreversible) or cortical necrosis (different from 88) [90]	Other
91	Tuberculosis [91]	Other
92	Gout nephropathy (urate) [92]	Other
93	Nephrocalcinosis and hypercalcaemic nephropathy [93]	Other
94	Balkan nephropathy [94]	Other
95	Kidney tumour [95]	Other
96	Traumatic or surgical loss of kidney [96]	Other
99	Other identified renal disorders [99]	Other
199	Code not sent [199]	Other

Appendix G: Laboratory conversion factors

	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
PTH	ng/L = pmol/L × 9.5
Urea	mg/dl = mmol/L × 2.8
Haemoglobin	Hct = g/dl × 3.11 (*NB this factor is variable*)

Appendix H: Abbreviations used for the renal units names in the figures and data tables

City	Hospital	Abbreviation
Bangor	Ysbyty Gwynedd	Bangr
Birmingham	Heartlands Hospital	Heart
Bradford	St Luke's Hospital	Bradf
Bristol	Southmead Hospital	Bristl
Cambridge	Addenbrookes Hospital	Camb
Cardiff	University of Wales Hospital	Crdff
Carlisle	Cumberland Infirmary	Carls
Carshalton	St Helier Hospital	Carsh
Coventry	Walsgrave Hospital	Covnt
Exeter	Royal Devon and Exeter Hospital	Extr
Gloucester	Gloucester Royal Hospital	Glouc
Hull	Hull Royal Infirmary	Hull
Ipswich	Ipswich Hospital	Ipswi
Leeds	Leeds General Infirmary	LGI
Leeds	St James's Hospital	StJms
Leicester	Leicester General Hospital	Leic
Liverpool	Royal Infirmary	Livrpl
London	Guys and St Thomas' Hospital	Guys
London	Hammersmith + Charing Cross	H&C
London	Kings College Hospital	Kings
Middlesborough	James Cook University Hospital	Middlbr
Newcastle	Freeman Hospital	Newc
Nottingham	Nottingham City Hospital	Notts
Oxford	Churchill Hospital	Oxfrd
Plymouth	Derriford Hospital	Plym
Portsmouth	Queen Alexandra Hospital	Ports
Preston	Royal Preston Hospital	Prstn
Reading	Royal Berkshire Hospital	Redng
Rhyl	Ysbyty Clwyd	Clwyd
Sheffield	Northern General Hospital	Sheff
Stevenage	Lister	Stevn
Southend	Southend Hospital	Sthend
Sunderland	Sunderland Royal Hospital	Sund
Swansea	Morriston Hospital	Swnse
Truro	Royal Cornwall Hospital	Truro
Wirral	Arrowe Park Hospital	Wirrl
Wolverhampton	Newcross Hospital	Wolve
Wordsley	Stourbridge Hospital	Words
Wrexham	Maelor General Hospital	Wrex
York	York District Hospital	York

The Renal Registry is an independent organisation which is part of the Renal Association and is funded directly by participating renal units through an annual fee per patient registered.

The Renal Registry would like to thank
the Department of Health in England
for commissioning and funding
the UK National Renal Review

Charitable donations were also received from the following commercial companies
Amgen
Novartis
Roche
Wyeth

Addendum to Report 2003

Page	Error	Correction
49	Data analysed by Local Authorities	Note these are Registry 'grouped' local authorities see appendix D for methodology
53	Table 4.5 HA populations for 14 HAs are incorrect (shifted down). The pmp calculations are correct (calculated before error)	See list below
55	Figure 4.3 wrong figure included	The figure shown was for prevalent patients. The correct figure is given below
61	Table 4.14 3 year HD technique survival Title of 1st column 1st 2nd row	Should read Remains on HD Remains on PD
257	Social deprivation summary point 5	The summary should read : *Social deprivation was a significant factor associated with long term survival on RRT after adjusting for age and primary renal diagnosis, but it was not significant after adjusting for cardiovascular co-morbidity* The wording of the text within the chapter is correct
336	Table 21.3 Mean eGFR by comorbidity The median values of eGFR were shown with 95% CI for the **mean** value	See correct table using the mean eGFR & 95% CI is shown below

Corrections

Table 4.5 Corrections

HA	population
Sunderland	292,300
Tees	556,300
Wakefield	318,800
Barnsley	228,100
Doncaster	290,500
Leicestershire	928,700
Lincolnshire	623,100
North Derbyshire	370,200
North Nottinghamshire	388,900
Nottingham	642,700
Rotherham	254,400
Sheffield	531,100
South Humber	308,600
Coventry	304,300

Figure 4.3 Correction

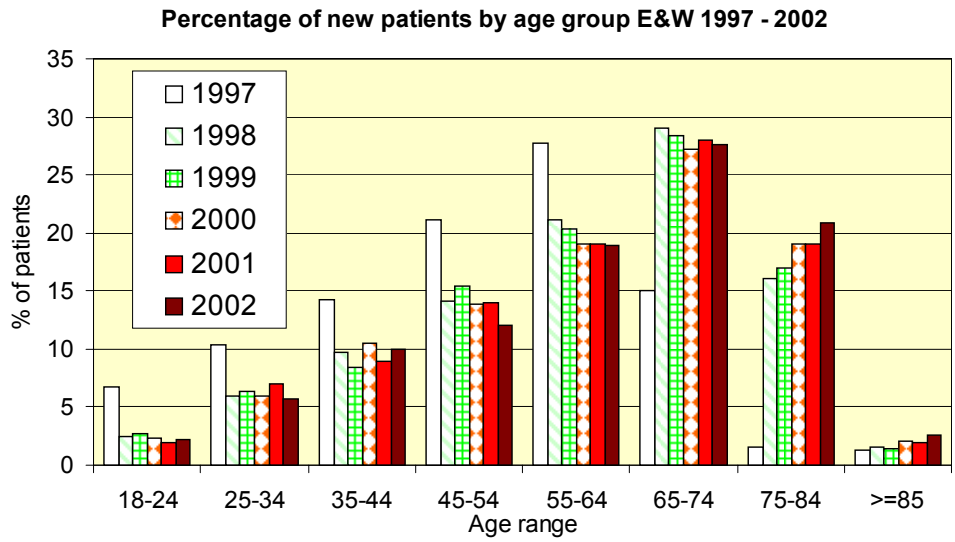

Table 21.3 mean eGFR and presence or absence of co-morbidity - Correction

	Present (95%CI)	Absent (95%CI)
Angina	8.3 (8.0 – 8.6)	7.4 (7.2 – 7.5)
MI in past 3 months	8.4 (7.3 – 9.5)	7.6 (7.4 – 7.7)
MI >3 months ago	8.0 (7.6 – 8.4)	7.5 (7.4 – 7.7)
CABG/angioplasty	8.4 (7.7 – 9.1)	7.5 (7.4 – 7.7)
Cerebrovascular disease	8.3 (7.9 – 8.8)	7.5 (7.3 – 7.6)
Diabetes (not as cause of ERF)	8.0 (7.4 – 8.7)	7.5 (7.4 – 7.7)
Diabetes as primary disease	8.5 (8.3 – 8.6)	7.5 (7.5 – 7.6)
Diabetes of either category		
COPD	8.2 (7.7 – 8.8)	7.5 (7.4 – 7.7)
Liver disease	8.1 (7.2 – 8.9)	7.6 (7.4 – 7.7)
Malignancy	7.6 (7.1 – 8.1)	7.6 (7.4 – 7.7)
Claudication	8.4 (7.9 – 8.8)	7.5 (7.3 – 7.6)
Ischaemic/neuropathic ulcers	8.5 (7.7 – 9.2)	7.5 (7.4 – 7.7)
Angioplasty/vascular graft	8.5 (7.5 – 9.4)	7.5 (7.4 – 7.7)
Amputation	9.6 (8.5 – 10.8)	7.5 (7.4 – 7.7)
Smoking	7.6 (7.3 – 8.0)	7.5 (7.4 – 7.7)