

The Renal Association
UK Renal Registry

Southmead Hospital
Southmead Rd
Bristol
BS10 5NB
UK

Telephone

0117 959 5665

Fax

0117 959 5664

Email

Renalreg@renalreg.com

Web site

www.renalreg.com

General Manager

Hilary Doxford

Clinical Data Managers

Fran Benoy-Deeney

Paul Dawson

Systems Manager

David Bull

Programmer

Matthew Brealey

Secretary / PA

Eve Marangon

Editors

Dr D Ansell, Prof T Feest

Editorial Support

Dr A Ahmad, Dr A V R Rao

Editorial Consultation

Dr J Harper, Dr P Naish, Dr E Will, Dr A J Williams

Contributors

In addition to contributions from the editorial team (Dr D Ansell, Prof T Feest, Dr A Ahmad, Dr A V R Rao), specific contributions have been received towards the following chapters by:

	Chapters
Mr A Bakran	11
Dr R Burden	4, 5
Dr C Burton	7
Dr C Byrne	15
Prof S Davies	9
Dr J Harper	10
Dr E Lamb	9
Dr M Lewis	13
Dr J Nicholas	16
Dr P Roderick	4, 5
Dr D Thomas	6
Dr D Throssell	8
Dr E Will	2

Additional Proof Reading

Mrs F Benoy-Deeney

Ms H Doxford

UK Renal Registry

Director: Dr D Ansell

Accounts: Triangle 3 Ltd

The UK Renal Registry Subcommittee

Chairman: Prof T Feest

Secretary: Dr E Will

Members: Dr R Burden
Prof S Davies
Dr J Harper
Dr P Roderick
Dr P Stevens
Mrs N Thomas
Dr A Williams

Ex Officio Renal Association:

Prof J Feehally (President), Dr D O'Donoghue (Secretary)
Prof A Rees (Management Board Chair)

Scotland: Dr K Simpson

Wales: Dr R Moore

Northern Ireland: Dr J Woods

British Association of Paediatric Nephrology: Dr C Reid

British Transplantation Society: Mr A Bakran, Dr C Dudley

Association of Clinical Biochemists: Dr E Lamb

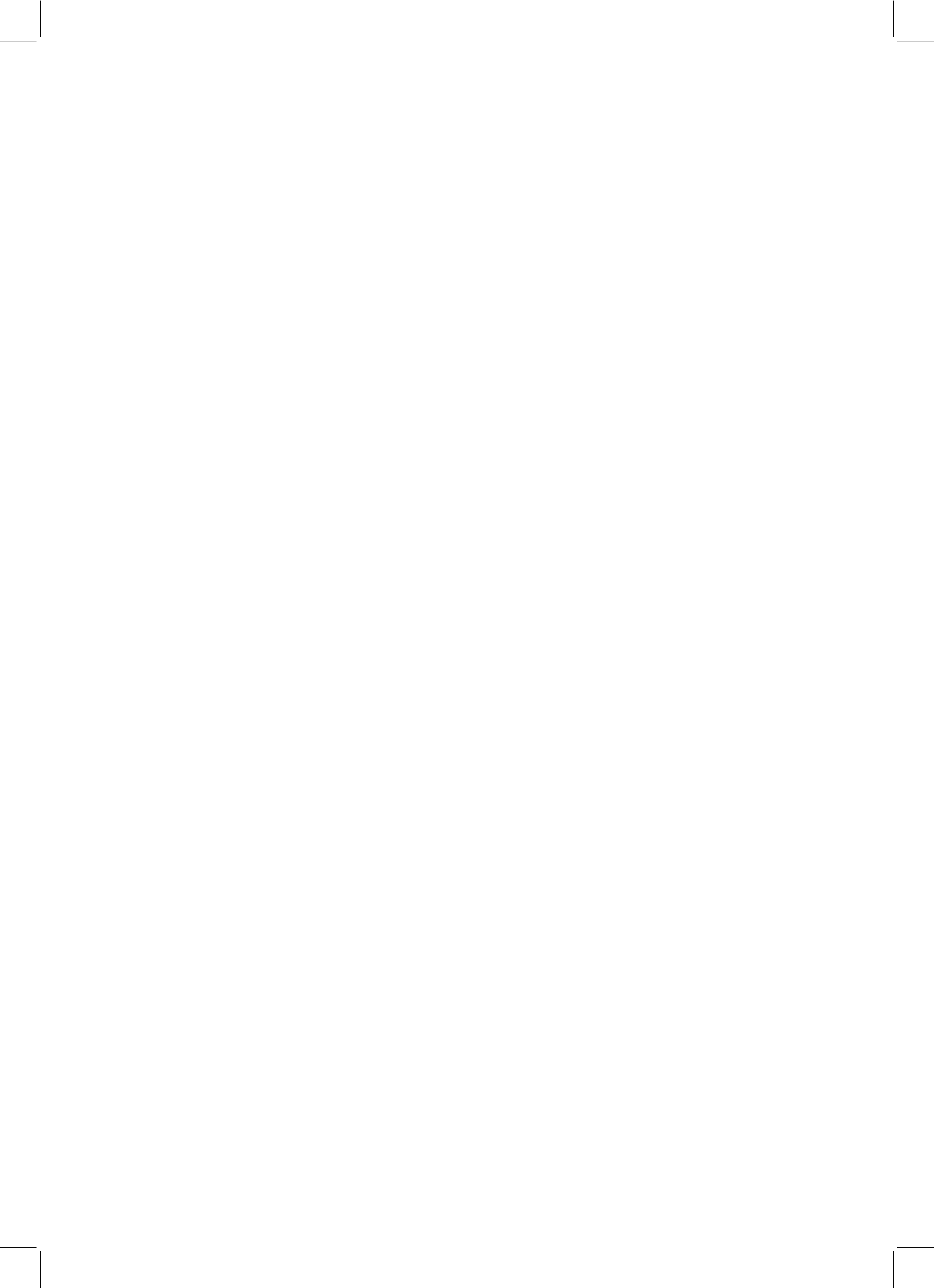
Department of Health: Mr D Gilbert, Ms J Verity

Royal College of Nursing: Ms A Redmond

Health Commissioners: To be appointed

National Kidney Federation (patient rep): Mr A Ramnarine

Retired Members 2004: Prof A Woolf, Dr J Tizard



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Chapter 1: Summary of Findings

All acronyms can be found in appendix G.

- A UK survey of CKD patients under the care of nephrologists estimates that there are about 140,000 CKD patients under the care of nephrologists from UK renal units, of whom approximately 23,000 are CKD stage 4 and 5 (not on dialysis).
- In the CKD survey the median CKD/prevalent RRT ratio was calculated as 3.7 and the median CKD stage 4 and 5/prevalent RRT ratio was 0.6.
- In 2003, the minimum estimated adult acceptance rate for RRT in the UK is 104 pmp (6,069 patients). In addition 88 children started RRT.
- Of the 2003 patient cohort, the established modality at 90 days was haemodialysis in 67.5% and peritoneal dialysis in 29.2%; only 3.3% had received a transplant.
- After 3 years, of patients first established on PD, 29% remain on PD, 23% converted to HD, 21% were transplanted and 25% had died. These results were similar in centres with both large and small PD programmes.
- The minimum estimated prevalence of RRT in the UK at the end of 2003 was 632 pmp. The local authority prevalence varies considerably from 227 to 950 pmp.
- The annual increase in prevalence in the 27 English and Welsh units participating in the Registry since 2000 is around 5%.
- In men the RRT prevalence peaked at 1,837 pmp in the 80–85 year band; this contrasts with a peak prevalence for women in the 65–74 year age band of 985 pmp.
- From 1998–2003 the median age of prevalent patients on HD increased, the median age of those on PD decreased.
- Twenty-two percent of new patients starting RRT are ≥ 75 years old and 12% of all prevalent patients are ≥ 75 years old.
- 84% of HD and 88% of PD patients had an Hb of >10 g/dl. In total, 85% of all dialysis patients achieved an Hb ≥ 10 g/dl. Only 6% of prevalent HD patients and 4% of PD patients had an Hb <9 g/dl.
- More patients were treated with EPO than in 2001 for both HD (91% vs 83%) and PD (77% vs 65%). EPO doses were higher in patients on HD (mean 9,197 units/wk; median 8,000 units/wk) than in PD (mean 5,831 units/wk; median 5,000 units/wk).
- An analysis to assess the contribution of inter-laboratory variation to the ‘between-centre performance’ indicates that there is no evidence to suggest that laboratory variation influences Registry data for serum phosphate or calcium, but there is an influence on serum albumin.
- Achievement of the phosphate target of <1.8 mmol/L is better on PD (68% of patients) compared with HD (59% of patients). Using KDOQI guidelines for calcium phosphate product (<4.4 mmol²/L²), 67% of dialysis patients achieve this target, although control is better on PD (75%) than on HD (64%).
- A lower percentage of younger dialysis patients achieved a serum phosphate <1.8 mmol/L than of the elderly age groups (<65 years – 54%, 65–74 years – 67%, ≥ 75 years – 73%; $p < 0.0001$), with the most elderly significantly the highest in achievement. Achievement of the serum calcium Standard was similar in all ages.
- Interpretation of iPTH data is complicated by large analytical differences between centres. There is large between-centre variation in the apparent ability of renal centres to achieve the RA Standard of <32 pmol/L (48% to 88%) with an average for E&W of 66%.

- Over the last 7 years there has been no significant change in systolic or diastolic blood pressure achievement.
 - Serum cholesterol continues to improve. In E&W, 77% of HD patients achieved a cholesterol <5mmol/L compared with 64% on PD and 53% of transplant patients.
-
- The age adjusted (60years) survival for the 1 year after 90 day period is 86%.
 - The one year prevalent transplant patient survival was 97.5% and the prevalent dialysis patient survival was 83.4%.
 - The hazard of death does not increase with length of time on dialysis, at least in the first 6 years. The 'vintage effect' of increasing hazard of death with length of time on RRT, noted in the US, is not apparent in UK survival data.
-
- Transplant function analysed by CKD stage 1–2 (eGFR <60), 3 (eGFR 30–59), 4 (eGFR 15–29) and 5 (eGFR <15), shows that these categories account for 26%, 57%, 15% and 2.7% of patients respectively. With over 17% of prevalent transplant recipients being classified as CKD stage 4–5; this has implications in the planning of services for these patients.
- In transplant patients Hb falls with decreasing eGFR, such that of the 2.7% of transplant patients with an eGFR <15ml/min, 30% had an Hb <10g/dl and 41% <11g/dl.
-
- The increase of the paediatric ERF population has plateaued. There remains a high incidence and prevalence of ERF in South Asian children, accounted for by an increased incidence of genetic diseases with autosomal recessive inheritance.
 - Blood pressure control in the paediatric renal transplant population was sub-optimal; many were also overweight, or had hyperlipidaemia and 38% were anaemic.
-
- Comparisons of national registries show that age distribution of dialysis patients in the UK and the USA is similar.
 - In the UK, history of a previous MI is found in 50% more patients starting RRT over age 65 years than in the USA. In the UK, patients starting RRT have a much higher incidence of cerebrovascular disease than the USA (18% v 12% in patients aged 75+). The incidence of peripheral vascular disease and COPD is similar in the UK and the USA, across all age bands.
-

Chapter 2: Introduction to the 2004 Report

The UK 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. Almost 98% of the income for the Registry is derived from this capitation fee.

Topics covered in this chapter

A full list of the issues covered in this chapter is included below.

- Areas covered by the UK Renal Registry
- Centres in the 2004 Report
- Centres submitting 2004 data
- Centres submitting 2005 data
- Centres submitting 2006 data
- Centres in discussion with the Registry
- Future coverage by the Registry
- Software and links to the Registry
- Paediatric Renal Registry links
- Links with other organisations
- Commissioning of renal services
- The Registry and clinical governance
- Anonymity and confidentiality
- The 'Health and Social Care Act 2001': section 60 exemption
- Support for renal services in the National Programme for IT
- Support for renal systems managers
- Interpretation of the data within the Report
- Future potential
- Support for Renal Specialist Registrars undertaking a non-clinical secondment
- New data collection and analysis
- The Challenge
- Distribution of the Registry Report

Areas covered by the UK Renal Registry

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

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

Centres in the 2004 Registry Report

All the above renal units in England & Wales run the CCL Proton software, except: – Ipswich and Bangor (Baxter system), Hammersmith (own system), Newcastle (CCL clinical vision), Kings (own system – Renalware), Stevenage (Lister's own system Renalplus) and Hope Hospital (own system).

Centres submitting 2004 data

The following additional centres have submitted data from 2004 and will be included in the next report (Table 2.2).

Centres submitting 2005 data

The renal units shown in Table 2.3 plan to have their IT systems setup and running in time to submit 2005 data.

Centres submitting 2006 data

It is hoped to include the following centre in 2006 (Table 2.4).

Centres in discussion with the Registry

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.

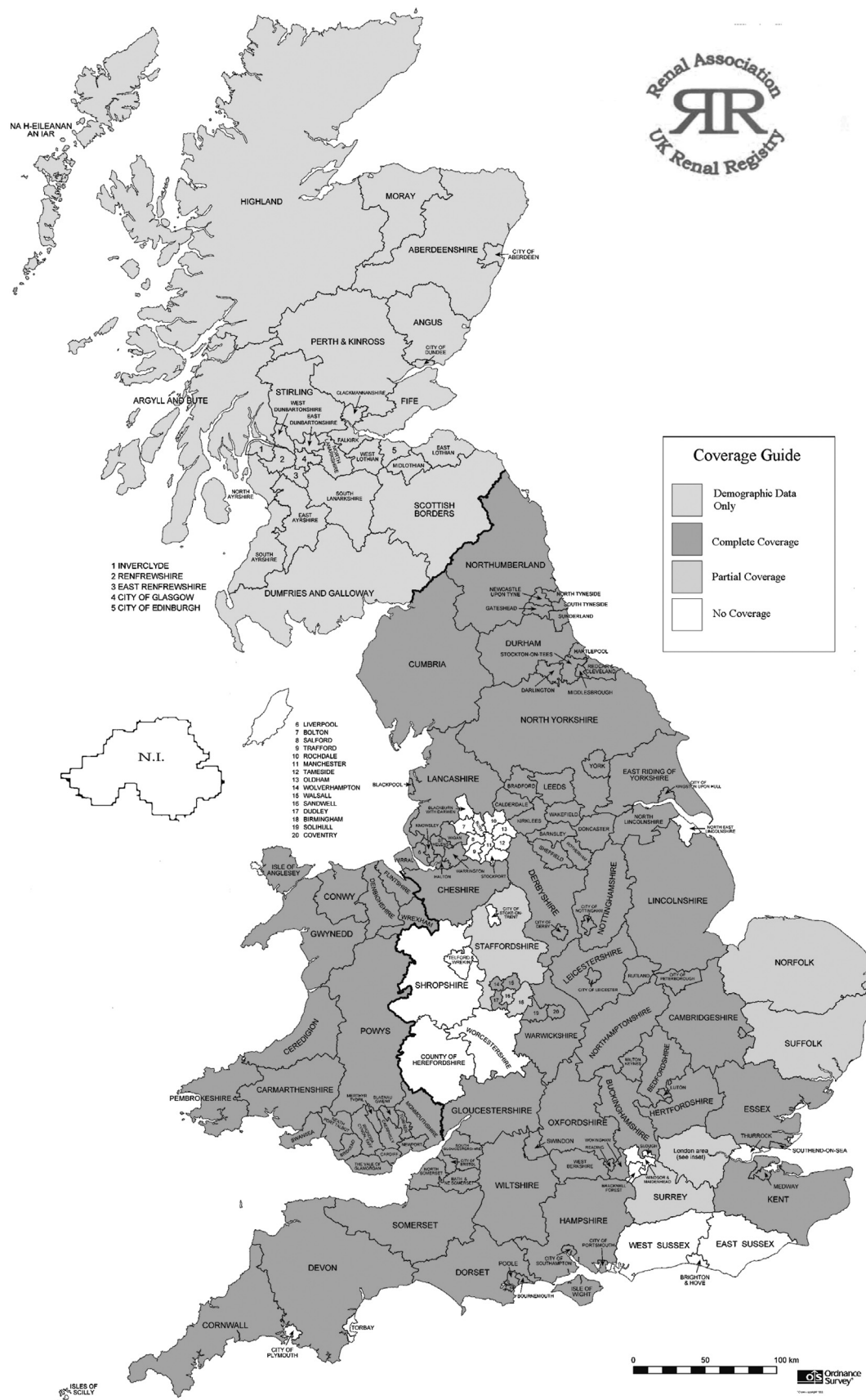


Figure 2.1: Areas covered by the Renal Registry

Table 2.1: Centres in the 2004 Registry Report

		Estimated population (millions)
England & Wales		39.85
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
Clwyd	Ysbyty Clwyd	0.15
Derby	Derby City Hospital	0.48
Exeter	Royal Devon and Exeter Hospital	0.75
Gloucester	Gloucester Royal Hospital	0.55
Hull	Hull Royal Infirmary	1.04
Ipswich	Ipswich Hospital	0.33
Leeds	St James's Hospital & Leeds General Infirmary	2.20
Leicester	Leicester General Hospital	1.80
Liverpool	Royal Infirmary	1.35
London	Guys & St Thomas' Hospital	1.70
London	Hammersmith & Charing Cross Hospitals	1.30
London	Kings College Hospital	1.01
*Manchester	Hope Hospital	0.94
Middlesbrough	James Cook University Hospital	1.00
Newcastle	Freeman Hospital	1.31
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
Sheffield	Northern General Hospital	1.75
Stevenage	Lister Hospital	1.25
Southend	Southend Hospital	0.35
Sunderland	Sunderland Royal Hospital	0.34
Swansea	Morrison Hospital	0.70
Truro	Royal Cornwall Hospital	0.36
Wirral	Arrowe Park Hospital	0.53
Wolverhampton	New Cross Hospital	0.49
Wordsley	Wordsley Hospital	0.42
Wrexham	Maelor General Hospital	0.32
York	York District Hospital	0.39
Northern Ireland	Summary demographic data from all centres	1.69
Scotland	Summary demographic data from all centres via the Scottish Renal Registry	5.06

*This unit is included in the report for the first time.

Table 2.2: Additional centres submitting 2004 data

	(Indicates IT system used by hospital)	Estimated population (millions)
Basildon	Basildon Hospital (Mediqal)	0.50
Birmingham	Queen Elizabeth Hospital (own system)	1.82
Brighton	Royal Sussex County Hospital– (CCL Windows)	0.98
Chelmsford	Broomfield Hospital (Mediqal)	0.50
Dorset	Dorchester Hospital (Mediqal)	0.71
London	Barts/Royal London (King’s system)	1.79
Shrewsbury	Royal Shrewsbury Hospital (Lister system)	0.40
Norwich	James Paget Hospital (Mediqal system)	0.84
	Total	7.54

Table 2.3: Further centres planning to submit 2005 data

	(Indicates IT system used by hospital)	Estimated population (millions)
Canterbury	Kent & Canterbury (Velos system) possibly	0.91
London	Royal Free (King’s system)	0.67
Northern Ireland	Belfast + all 4 NI renal units (Mediqal system)	1.69
Stoke	North Staffs (Cybernius system)	0.70
	Total	3.97

Table 2.4: Centres hoping to submit data in 2006

	(Indicates IT system used by hospital)	Estimated population (millions)
London	Middlesex / UCLH – amalgamating with Royal Free in 2005 (Kings system)	0.75

Table 2.5: Centres without Registry-compatible IT

	(Indicates IT system used by hospital)	Estimated population (millions)
Manchester	Royal Infirmary	2.51
London	St George’s (own system)	
London	St Mary’s Paddington (Proton) due to no agreement on funding Registry capitation fee	0.81

Future coverage by the Registry

From the data presented here, it can be seen that the report on the 2003 data covers nearly 80% of the UK for some items and that by the end of 2004 some 90% of the UK will be covered by the Registry. With the recommendation in the Renal National Service Framework (NSF) that all units should participate in audit through the Registry, complete coverage of the UK should be accelerated. The Health Care Commission (HCC) wishes to use the Registry as one vehicle

for monitoring implementation of the NSF. Commissioners of renal services will thus be encouraged to enable the provision of adequate data systems for all units to join the Registry.

Software and links to the Registry

From the above information, it is evident that there are now 13 systems in use by renal units, some of these are commercial and some in-house systems. The Registry is working with

the relevant companies to help them provide appropriate software links to the Registry.

Paediatric Renal Registry links

In the UK there are 780 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 on a partially manual basis. As in previous years, this report includes a chapter of analyses from these data (chapter 13). In order to integrate them with the adult Registry and also provide funded resources for data management, the BAPN has asked the adult Registry to develop ways of collecting the paediatric data. This process of integration of paediatric data is proceeding slowly.

Links with other organisations

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

Close collaboration has developed with the UK Transplant Authority to produce analyses utilising the strengths of both databases, some of which are included in this report. It is hoped to further develop these ties.

Support has been given to the Department of Health (DoH) in acquiring the basic data necessary for the future planning of renal services. The Registry participated in providing data to formulate the advice to ministers for the Renal NSF. It is also working with the DoH Data Standards Board on the Information Strategy to support the Renal NSF and in developing a Renal Dataset for the national (Connecting for Health) IT spine. The Registry is part of the Kidney Alliance. Discussions are taking place on forging closer links with the Health Care Commission.

The Renal Association UK Registry sends fully anonymised data to the European Renal

Association Registry. Several representatives have participated in discussions regarding the ERA QUEST initiative. There has been contact with the International Federation of Renal Registries, but patient data are not sent to this organisation.

Commissioning of renal services

In April 2002, the 95 existing health authorities in England were reformed as 28 Strategic Health Authorities (SHAs). 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 is assisting specialised commissioning consortia and individual Primary Care Trusts (PCTs) with appropriate data and analyses.

The Registry and clinical governance

There has been considerable debate within the Renal Association Trustee and Executive Committees, the Clinical Affairs Board, the Registry Board and 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 inform the President of the Renal Association who may 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 Executives of all Trusts in which a renal unit is situated, since the responsibility for clinical governance within the Trust lies formally with the Chief Executive. For the anonymised parts of the report, the Chief Executive is informed of the code of the relevant 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 aids the development of comparative audit and may assist learning from best practice, as well as allowing public accountability. This was discussed in the Renal Registry Committee and at the Renal Association Executive Committee. 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 appeared to provoke 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 of patient survival between renal units requires at least the ability to correct for case mix, which needs robust initial comorbidity data: these are not yet provided by many units. In some of the analyses in this report, it has been possible to study the influence of initial co-morbidities. However, as is evident in chapter 16, reporting of initial comorbidity remains incomplete and is still insufficient for meaningful adjustments to outcome data. For this reason, survival data are still reported anonymously. The Renal NSF encourages reporting of comorbidity and ethnicity data and it is hoped this will encourage more renal units to collect these data so that anonymity can be removed. An analysis of comparative patient survival is possible that confirms the range of outcome being achieved nationally (Chapter 11).

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 managers and statisticians are able to identify the centres. This identification is necessary so that the Registry can discuss with the relevant centres any discrepancies in the data or analyses.

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

The Registry has been granted a section 60 exemption by the Secretary of State under the Health and Social Care Act. This exemption allows the registration of identifiable patient information from renal units without first asking the consent of each individual patient, avoiding a breach of the Common Law on confidentiality.

This exemption is temporary and is reviewed annually. The progress towards collection of anonymised data or obtaining permission of the individual patient is monitored by the Patient Information Advisory Group (PIAG). The Registry is progressing towards anonymisation of data as two recent medical studies of patient consent^{1,2} showed that only 33% of patients provided consent. It could be confirmed in these studies that outcomes in the consented group were different from those patients where consent was not given. Such behaviour would render many of the Registry analyses invalid.

The first annual report on progress by the Registry towards anonymisation has been submitted to PIAG and a more detailed discussion is provided in Chapter 18.

Support for renal services in the National Programme for IT (NPfIT)

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

Support for renal systems managers

This year the Registry has provided a forum for a renal informatics meeting supporting development of renal IS & IT staff. Topics included; a discussion on current informatics, health informatics professionalism (eg UKCHIP), agenda for change and informatics related job profiles. A detailed report on these presentations is available on the Registry web site.

Interpretation of the data within the report

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

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

To assess whether there is an overall significant difference in the percentage reaching the Standard between centres, a Chi-squared test has been used. Caution should be used when interpreting 'no overlap' of 95% confidence intervals between centres in these presentations. When comparing data between many centres, it is not necessarily correct to conclude that two centres are significantly different if their 95% confidence intervals do not overlap. In this process, the eye compares centre X with the other 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. In several chapters "Z" plots are used to identify significant outliers (see Chapters 5 and 14). The Registry is investigating further methods of performing such comparisons.

In Chapters 4 and 5 charts are presented to allow PCTs and other organisations representing relatively small populations to assess whether their incidence and prevalence rates for renal failure are significantly different from the average UK performance.

Future potential

Support for Renal Specialist Registrars undertaking a non-clinical secondment

Through links with the Universities of Southampton and Bristol some training is available in both epidemiology and statistics. Dr Az Ahmad and Dr Raman Rao are currently working as Registry registrars, with Dr Ahmad also completing his MD. Dr Catherine Byrne has completed two years working as a Registry registrar and returned to finish her specialist training. It is hoped that their positive experiences will encourage other registrars who are also interested in undertaking epidemiological work, to consider working with the Registry.

Dr Fergus Caskey has organised a secondment in Berlin with the German Renal Registry and is undertaking a comparative analysis between the UK and Germany on the variation in the percentage of patients treated on renal replacement therapy.

New data collection and analysis

Surveys of facilities

After consultation with the Clinical Affairs Board and the Renal Clinical Directors Forum the Registry has carried out three surveys. There has been a further review of renal facilities within the UK and of basic data from non-participating units. The Registry is collaborating with the British Renal Society to collect data on non-medical staffing and with the National Kidney Research Fund to collect data on vascular access. It is hoped these will all be reported late in 2005. Some of the basic elements of these surveys may be needed on an annual basis, but this will only be performed with agreement of the Renal Unit Clinical Directors Forum.

The Survey on Pre-dialysis care

This report contains preliminary results from a survey and analysis conducted by Dr Az Ahmad of facilities available for pre-dialysis care (Chapter 3). This is the first report available in such detail and should be invaluable as a base line for monitoring implementation of the Renal NSF and in identifying the obstructions to progress.

There is considerable interest in collecting further data on cohorts of renal patients with chronic renal impairment: many renal units already hold such data in their systems. 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.

The challenge

With the re-presentation of these Registry data to the renal community, the challenge to UK Nephrology is to find effective and creative ways of using the data to improve clinical practice. As yet, not all the necessary formal structures are in place to allow full value to be

derived from the opportunities suggested by the Registry data. The Renal Association is currently considering structures to promote the use of Registry data to facilitate closing the audit loops of nephrological practice. It has set up the Clinical Affairs Board partly with this in mind. In some cases, the Registry itself has been able to conduct enquiries to understand the factors underlying good performance (eg see Chapters 6 and 9) and is taking a lead to make a start in that process.

Other insights are also possible and quantifiable. For example, this year sees a new analysis of transplant patients by chronic kidney disease category. With over 22% of prevalent transplant recipients being classified as CKD Stage 5 (eGFR <15mls/min), this has major implications in the commissioning of specific services (eg anaemia and phosphate management) for these patients.

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 £15 cost of printing and postage will be requested. The full report may be seen on the Registry website – www.renalreg.com

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Chapter 3: National Survey on the Prevalence and Management of Patients with Chronic Kidney Disease under the care of Nephrologists in the UK

Introduction

There is increasing awareness and focus on the management of patients with chronic kidney disease (CKD). Parts of the recently published National Service Framework Parts 1 and 2^{1,2} and the soon to be published guidelines on CKD jointly developed by the Renal Association, Royal College of Physicians of London Specialty Committee on Renal Disease and the Royal College of General Practitioners are evidence of this and will stimulate even more interest. Indeed most nephrologists believe these documents will lead to an increase in the referral of patients with CKD to nephrology services. Planning for this growth area in renal care is difficult as there are few data available on the number of patients who are approaching established renal failure, both in the UK and other countries and there is very little information on the facilities available for such patients and organisation of their care. This contrasts with the situation for patients already on renal replacement therapy in the UK, about whom data are widely collected and analysed.

With this in mind, the idea for the CKD survey was conceived. The main aim was to investigate the current working practices and management models of CKD patients across all the renal units in the country and also to gather some information regarding the number of prevalent patients with CKD under the care of UK nephrologists.

Background

There are robust systems for collecting data on patients on RRT. For such patients in 2004 the UK Renal Registry had electronic linkage with 36 of the 53 renal units in England (73% coverage); all 5 renal units in Wales (100% coverage); had links with the Scottish Renal Registry and will soon cover the whole UK. In addition, since 1992, the Department of Health in

England has conducted three national surveys on the provision of renal replacement therapy in the UK, collecting data on the incident and prevalent patients, the number of renal units and dialysis stations being utilised and the facilities available in terms of the number of medical and some non-medical personnel involved³. From 2004, similar surveys will be conducted annually by the UK Renal Registry, on behalf of the Renal Association and the British Renal Society.

The situation for chronic kidney disease is very different. This has been partly due to the lack of definition of the 'pre-dialysis' phase. Several terminologies were used interchangeably to describe this group of patients, which included chronic renal failure, chronic renal impairment, chronic renal disease and chronic renal insufficiency⁴. The publication in 2002 of NKF-KDOQI guidelines⁵ defining this group of patients as 'Chronic Kidney Disease (CKD)' and outlining the definition and classification of CKD and estimating prevalence in the USA (Tables 3.1 and 3.2) is welcomed as it facilitates performance of comparative studies and analysis on this subject.

In the USA, data from 15,625 participants in the Third National Health and Nutrition Examination Survey (NHANES III) estimated that 11% (19.2 million) of the adult population in the US suffers from CKD, with 4.7% (8.3 million) in stages 3–5, with a much higher prevalence in the older age groups, diabetics and hypertensives⁶. More recently, in the UK, work by the NeoErica (New Opportunities for Early Renal Intervention by Computerised Assessment) project involving analysis of records of 22,819 patients from databases of general practitioners in East Kent, West Surrey and Salford showed an estimated prevalence of stages 3–5 CKD of 5.1% in the general population⁷. In Australia, the Australian Diabetes, Obesity and Lifestyle (AusDiab) study showed a prevalence of 11.2% of CKD stages 3–5 in

Table 3.1: Definition of Chronic Kidney Disease according to NKF-KDOQI guidelines⁵

Criteria
Kidney damage for ≥ 3 months, defined by structural or functional abnormalities of the kidney with or without decreased GFR, manifest by either
Pathological abnormalities
Markers of kidney damage, including abnormalities of blood or urine or abnormalities in imaging tests
GFR < 60 ml/min/1.73 m ² for ≥ 3 months, with or without kidney damage

Table 3.2: Stages of Chronic Kidney Disease, Prevalence in the USA and Recommended Action Plan⁵

Stage	Description	GFR (ml/min/1.73 m ²)	Prevalence %	Actions
–	At increased risk eg known diabetes or hypertension	≥ 60 (with CKD risk factors)		Screening; chronic kidney disease risk reduction
1	Kidney damage with normal or increased GFR	≥ 90	3.3%	Diagnosis and treatment; treatment of co-morbid conditions; slowing progression; cardiovascular risk reduction
2	Kidney damage with mild decreased GFR	60–89	3.0%	Estimating progression
3	Moderately decreased GFR	30–59	4.3%	Evaluating and treating complications
4	Severely decreased GFR	15–29	0.2%	Preparation for kidney replacement therapy
5	Kidney failure	< 15 (or dialysis)	0.1%	Kidney replacement (if uraemia present)

the 10,949 patients of the cohort. Unfortunately, there was no estimation for the general population in Australia made from the available data⁸.

Although there were differences in terms of the study cohort and the study methods, the data from NeoRica, NHANES III and Aus-Diab studies clearly show the magnitude of the problem of CKD in the general population. For each patient with CKD known to nephrologists, there are many others not referred. John *et al*⁹ analysed the biochemical results from 2 laboratories in East Kent, identifying patients with chronic kidney disease using the criteria of serum creatinine ≥ 180 $\mu\text{mol/L}$ in men or ≥ 135 $\mu\text{mol/L}$ in women. Between October 2000 and September 2001, 3,822 patients fulfilled the

criteria for chronic kidney disease, equivalent to a prevalence of 5,554 patients pmp. When cross-referenced with the renal unit database, only 15% (582 patients) were known to the renal team. The non-referred group were mainly elderly with a median age of 83 years, with 66% aged 80 or older and another 23% aged 70–79. When analysed according to estimated GFR (MDRD), the percentages of patients with stage 4 and 5 chronic kidney disease known to the renal team were poor (34.7% and 16.2% respectively), even when those aged 80 and over were excluded from the analysis (63.6% and 38.5%) (Table 3.3). If all these un-referred patients were to be assessed by nephrologists, it is calculated that an extra 300 consultant sessions/pmp/year would be needed to cope with the extra workload.

Table 3.3: Percentage of CKD Stage 4–5 patients known to renal units (adapted from John *et al*⁹)

eGFR	Including patients age 80+			Excluding patients 80+		
	Men (%)	Women (%)	All (%)	Men (%)	Women (%)	All (%)
< 15	42.6	29.0	34.7	71.4	57.1	63.6
15–30	21.3	12.1	16.2	39.1	32.4	38.5
30–42.8	13.7	7.0	9.6	24.2	14.8	19.0
All	20.4	11.4	15.2	36.1	26.9	31.2

The CKD Survey

With the high prevalence of CKD and the lack of information on facilities and organisation of care in mind, the CKD survey was conceived. As stated earlier the main aim is to investigate the current working practices and management models of CKD patients across all the renal units in the country, highlighting the positive points of how the care of the multi skilled renal team is being delivered but also to identify aspects of care which renal units feel are important, but still inadequate and need to be improved. From the survey it is hoped to produce the first national data for the UK in terms of the number of patients with CKD currently under nephrological care; previous studies have focused on prevalence of CKD in the community. The data collection has been limited to patients with CKD stage 4 and 5*, as these are the patients who are most likely to progress towards established renal failure requiring RRT.

Methods

The questionnaire was developed within the Demographic study group of the Renal Registry with valuable assistance from Dr Michael Ward (Freeman Hospital, Newcastle) and Dr Donal O'Donoghue (Hope Hospital, Salford). The questionnaire was piloted at several renal units – St Helier Hospital (Carshalton), Birmingham Heartlands Hospital, New Cross Hospital (Wolverhampton), Southampton General Hospital and Morrision Hospital (Swansea) – before being sent out to the rest of the country.

The initial plan was to circulate the questionnaire to all the renal units with RRT facilities in the UK and also to general physicians with an interest in nephrology working in other district general hospitals without RRT facilities. The DGH Society was approached for assistance but was unfortunately unable to provide a complete listing of general physicians with an

*For this report, CKD Stage 5 refers only to patients with estimated glomerular filtration rate <15ml/min who are not on dialysis

interest in nephrology currently working in district general hospitals in the UK. Therefore the circulation was limited to the renal units in the UK. The questionnaire was sent out to all 72 renal units in the UK in June 2004 and refers to the situation in June 2004.

Data were entered and stored in a Microsoft Access database by a single operator and data were then checked by another operator to ensure correct data transfer from the paper version. Any queries from the responses were then followed up with the relevant contact person for the renal unit concerned. Data were then analysed using the SAS statistics package. Where data on RRT are used, these are either from the 2002 National Renal Survey or the Renal Registry's own database.

Results

Number of patients

Of the 72 units, 70 (97%) responded to the survey; 35 centres were able to provide data on the number of CKD patients under nephrological follow up and 25 of these centres were able to provide estimated glomerular filtration rate (eGFR) for these patients. In 21 of the units, details of all CKD patients are kept in the same database as RRT patients.

In these 35 centres, there were a total of 78,000 patients with CKD, giving a median number of 2,000 patients per renal unit (range 275–5,685). In the 25 centres with eGFR data, there were a total of 8,912 CKD stage 4 and 5 patients; a median of 321 CKD stage 4 and 5 (range 53–819).

Using data from the National Renal Survey 2002, the median CKD/prevalent RRT ratio was calculated as 3.7 and the median CKD stage 4 and 5/prevalent RRT ratio was 0.6.

Using these ratios and applying them to the total number of prevalent RRT patients in the UK in 2002 (estimated to be 37,000), it is therefore estimated that there are about 140,000 CKD patients under the care of UK nephrologists of whom 23,000 are CKD stage 4 and 5 patients.

Multi-skilled renal (MSR) team

Few renal units have a full complement MSR team. All but 1 unit who responded have a dietitian for CKD patients. 72% of the units have a renal pharmacist and 64% have a social worker working for the unit. 87% of units have a specific person providing dialysis education and 76% and 53% of the units have anaemia and access co-ordinators respectively. Only 33% have a counsellor and just 24% a psychologist. Some units are creating more specific nursing roles for nurses such as diabetic nurse (29%) and 9% have a blood pressure nurse (Table 3.4).

In renal units that did not have the various MSR personnel in post at the time of the survey, social workers lead the list of MSR personnel needed by renal units with 91% of the centres expressing their need to have one. This is followed by dialysis education providers (89%), counsellors (78%), access coordinators (75%) and psychologists (67%).

Dietitians and dialysis education providers are the main MSR personnel attending CKD clinics in over 95% of the renal units that have one.

There are regular MSR team meetings in 47 of the 70 renal units. The frequency of the meetings varies between the units from 1 meeting per week to 1 meeting every 13 weeks, with the majority of the units either having a weekly

(49%) or a monthly (36%) meeting. In 36 of the 47 units (77%), the regular MSR meetings have been in place for more than 1 year.

In 49 of the 70 renal units there are clinics for CKD patients in neighbouring district general hospitals (DGH), averaging 3 other DGHs per main renal unit. In 15 of these 49 units, CKD patients from the peripheral DGHs have to be reviewed in the main unit because the MSR team's services are only available in the main unit and not in the peripheral hospital.

Low Clearance Clinic

One model for management of patients with CKD stage 4 and 5 is the "low clearance clinic", although there are other models which provide a co-ordinated care pathway through the MSR team. In early June 2004, of the 70 units, 50 (71%) held pre-RRT clinics or low clearance clinics for managing patients approaching RRT. A further 10 centres (15%) were planning to set up similar clinics with 5 of these clinics due to start in the second half of 2004. In 10 of the 50 units with such clinics, not all the consultants were using the facilities. The median number of patients under the care of these clinics was 118, however this ranged from 25 to 850 patients. This was partly due to the different size of the centres, but may also reflect the differing criteria for referring patients to the service.

Table 3.4: Multi skilled renal team composition within renal centres

	Units with the following MSR personnel for CKD patients %		Units without the following MSR personnel that feel they are needed %		Units where MSR personnel attends clinics where CKD patients are seen %	
	Yes	No	Yes	No	Yes	No
Dietitian	99	1	0	100	94	6
Pharmacist	72	28	60	40	15	85
Social worker	64	36	91	9	47	53
Physiotherapist	22	78	27	73	21	79
Occupational Therapist	28	72	40	60	22	78
Counsellor	33	67	78	22	52	48
Psychologist	25	75	67	33	53	47
Anaemia Coordinator	76	24	31	69	76	24
Access Coordinator	53	47	75	25	66	34
Dialysis Education Provider	87	13	89	11	93	7
Diabetic nurse	29	71	58	42	33	67
BP nurse	9	91	30	70	67	33

The frequency of these clinics ranged from 1 to 3 clinics per week. The majority of these clinics (86%) have been running for more than 1 year. In 84% of these units, there is a renal nurse specialist involved in the organisation and running of the clinics. The amount of responsibility entrusted to the renal nurse specialist varies between units. From the collective survey responses, facilitating clear and efficient communication with other personnel involved in the care of CKD patients appears to be the main role of the renal nurse specialist. Some of these nurses are also involved in the delivery of CKD education, counselling, transplant assessments and prescribing and altering prescription under medical supervision. In some units, patients are reviewed by the nephrologist and the nurse specialist on an alternate basis.

Pre-dialysis education

Apart from specific dialysis education providers, education was also delivered by a variety of other professionals such as dialysis nurses, transplant co-ordinators, dietitians and pharmacists.

While subjects such as types of dialysis, dietary restrictions, fluid balance, CKD related anaemia, renal bone disease were very well covered, aspects of CVD risk factors, sexual matters and psychological support were not necessarily reported to be covered in the programme.

In various units there were education materials available in audio and Braille for the blind, and translated into Bengali, Cantonese, Gujarati, Hindi, Punjabi, Somali, Urdu and Welsh (Table 3.5).

Dialysis Access services

Fifty-five renal units (76%) had a dedicated vascular access surgical team, with 41 (59%) providing clinics for pre-access assessments and 27 (39%) providing post-access follow-up. In the 55 units with a dedicated vascular access team, the median waiting time for elective fistula surgery was 6 weeks (range 1–36 weeks), compared with 12 weeks (range 4–26 weeks) in the 14 units without a dedicated team. There were 51 units with dedicated theatre sessions for access formation and the number of sessions range between 1 session per month to 6 sessions per week.

Tenckhoff catheter insertions were performed by nephrologists in 28 renal units. In these centres the median waiting time for catheter insertion was 2 weeks (range ‘within same week’ – 8 weeks), compared with a median of 4 weeks (range ‘within same week’ – 12 weeks) in centres where nephrologists do not perform insertions. Forty units (57%) have a renal interventional radiologist.

Access coordinators were employed in 37 centres (53%) to organise and prioritise the waiting list. In 32 units (46%), information regarding access formation and problems were entered into a database.

Relating MSR team with patients’ outcome

For centres participating with the Registry’s activity, analysis was performed to relate the clinical variables at the start of dialysis with the presence or absence of members of the MSR team and also the presence or absence of a low

Table 3.5: Education materials available in other languages

Language	Hospitals where leaflets are available in the language
Bengali	Middlesex, Sheffield
Cantonese	Glasgow, Sheffield
Gujarati	Leicester, Sheffield, Preston, Queen Elizabeth – Birmingham
Hindi	Leicester, Middlesbrough, Sheffield, Preston, Queen Elizabeth – Birmingham
Punjabi	Coventry, Leicester, Queen Elizabeth – Birmingham, Stoke-on-Trent
Somali	Sheffield
Urdu	Glasgow, Reading, Sheffield, Queen Elizabeth – Birmingham
Welsh	Bangor, Cardiff, Rhyl, Swansea, Wrexham

Table 3.6: Comparison of haemoglobin and biochemistry results between centres with anaemia coordinators, diabetic nurses or low clearance clinic

		Median values end of quarter 1				
		Hb g/dl at start	Corrected Ca mmol/L	Phosphate mmol/L	iPTH pmol/L	HbA1c %
Anaemia coordinator	Yes	10.1	N/A	N/A	N/A	N/A
	No	10.1	N/A	N/A	N/A	N/A
Low clearance clinic	Yes	10.2	2.38	1.58	19.1	N/A
	No	9.9	2.36	1.60	22.3	N/A
Diabetic nurse	Yes	N/A	N/A	N/A	N/A	6.5
	No	N/A	N/A	N/A	N/A	6.8

clearance clinic. The Registry's data used were from 2003; therefore one major assumption here is that the situation at June 2004 largely applied in 2003.

In terms of anaemia management, the median haemoglobin at the start of dialysis was identical in centres that did or did not employ an anaemia coordinator. However the median haemoglobin appears to be slightly higher in centres utilising a low clearance clinic compared to those which did not (median Hb 10.2 v 9.9; $p=0.001$), although the clinical relevance of this is unclear (Table 3.6).

Apart from serum creatinine, the Registry is not yet collecting other biochemical variables at the start of dialysis, therefore values at the end of the first quarter following the start of RRT have been used as a surrogate instead. Data in table 3.6 show that there were no marked differences between those centres with and without a low clearance clinic in terms of the median value for corrected calcium, phosphate and serum iPTH at the end of the first quarter.

The median HbA1c was lower in centres with a diabetic nurse compared to those without (6.5% v 6.8%; $p=0.044$), although like the haemoglobin data, the clinical relevance of this is unclear.

Discussion

This is the first national survey in the UK to attempt to document the prevalence of patients with CKD under the care of a nephrologist and also to assess the available services for their management.

From this survey, it is estimated that there are about 140,000 CKD patients under the care of nephrologists from UK renal units, of whom approximately 23,000 are CKD stage 4 and 5 (not on dialysis). This is an approximate estimate as only 50% of centres were able to provide these data and there is at present no way of validating the data which were returned. In terms of workload for the NHS this is an underestimate, as many known CKD patients are looked after by nephrologists working in district general hospitals not attached to a renal unit and also by other specialists such as cardiologists, diabetologists and urologists. Other patients are managed solely within primary care.

Ifudu *et al*¹⁰ showed that in the USA, receiving care from nephrologists prior to starting dialysis is associated with improved short term morbidity, a lower level of serum creatinine at the start of dialysis, needing to use less temporary access and spending a much shorter period in hospital compared to those receiving care from non-nephrologists or no medical care.

However, data on the best model for management of CKD patients are still limited. Harris *et al*¹¹ concluded that an intensive multi-disciplinary management approach did not offer any significant advantage in terms of progression of renal disease nor mortality rate. In contrast, the studies by Binik *et al*¹² and Devins *et al*¹³, suggested that a more enhanced intensive education programme for pre-ERF patients may delay the start of RRT by at least 3 months and in a paper by Levin *et al*¹⁴, patients who were attending a pre-dialysis clinic programme had better clinical variables at the start of dialysis and were less likely to have a problem with

symptomatic uraemia, less likely to start dialysis in an emergency manner and less likely to start dialysis as an inpatient.

Nevertheless, it is almost universally accepted that the multi disciplinary approach is the best way forward in managing the complex needs of this group of patients. The NSF for Renal Services Part 1 and 2 emphasised that the management of patients approaching dialysis should involve a multi skilled renal team rather than just nephrologists^{1,2}.

The report *The Renal Team: A Multi Professional Renal Workforce Plan for Adults and Children with Renal Disease*¹⁵, 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 recommended by the NSF. Notably lacking are social workers, psychologists and counsellors suggesting that such emotional and psychological support frequently appears to be a relatively low priority, especially in a financially constrained environment. There is no indication whether this prioritisation is driven by the perceptions of the renal team or the commissioners.

It is fashionable at present to have a low clearance clinic to streamline the management of patients approaching dialysis: 71% of the units are using this approach. From the analysis of biochemical variables in the first quarter following commencement of RRT, the potential benefit is still unclear although there is a suggestion that the median haemoglobin at the start of dialysis to be higher in patients from centres with a low clearance clinic. This highlights the need for further research to identify the most effective methods for organising care for CKD patients approaching dialysis.

Rather surprisingly not all centres have a specific dialysis education provider. This is perhaps an area that needs to be improved, as it is important to enable patients to choose the appropriate modality at the start of their RRT journey. Preparation for dialysis in terms of timely provision of vascular or peritoneal access is still not optimum, with some centres lacking a dedicated surgical team to perform these procedures.

Conclusion

Management of patients with CKD is an important issue, as increasing emphasis and awareness due to recent publication of the NSF for Renal Services and the imminent CKD guidelines developed by the Renal Association, Royal College Specialty Committee on Renal Disease, the Royal College of General Practitioners and Royal College of Physicians, will undoubtedly lead to an increase of referral to nephrologists. At present the provision of services is variable across the country with dialysis access services and socio-psychological support possibly being the two main aspects which need to be addressed. These data from this survey will serve as a good baseline to gauge the impact of the implementation of the recommendations from the National Service Framework on the service delivery both locally and nationally.

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Chapter 4: New Adult Patients Starting Renal Replacement Therapy in the UK in 2003

Summary

- In 2003, the total estimated acceptance rate for RRT in the UK is 104 pmp. This is compiled from complete data for adults from Northern Ireland, Scotland and Wales and an extrapolation from the 73% of the English population covered, giving a total population acceptance rate of 103 pmp if only adult cases are included (6,069 patients). In addition 88 children started RRT (see Chapter 13).
- The estimated acceptance rate is an underestimate due to under-representation of ethnic minorities in the areas covered by the English units compared with the population as a whole.
- In England and Wales, for adults in 2003, the crude acceptance rates in local authorities varied from 14 to 231 pmp; the standardised rate-ratios for acceptance varied from 0.14 to 2.21.
- In the 27 units submitting data since 2000, there has been a 15% rise in the acceptance numbers over this period, with wide variations between different units.
- Between 1999 and 2003, in incident patients with known primary renal diagnosis, the proportion of diabetic nephropathy as the cause of ERF has remained unchanged at 19–20%. However, with the continuing increase of overall acceptance rate the annual diabetic acceptance rate has increased from 17 pmp in 1999 to 19 pmp in 2003.
- Of the 2003 patient cohort, the established modality at 90 days was haemodialysis in 67.5% and peritoneal dialysis in 19.2%: only 3.3% had received a transplant.
- After 3 years, of patients first established on HD, 42% remain on HD, 3% had changed to PD, 12% had been transplanted and 40% had died.
- After 3 years, of patients first established on PD, 29% remain on PD, 23% converted to HD, 21% were transplanted and 25% had died. These results were similar in both large and small PD programmes and in those units who established both high and small proportions of new patients on PD.

Introduction

In 2003, the UK Renal Registry covered an estimated 73% of England and 100% of Wales. Data on incident and prevalent patients in Scotland were obtained from the Scottish Renal Registry and data for Northern Ireland were obtained from the renal unit in the Royal Belfast Hospital which coordinates the renal service provision in Northern Ireland.

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. The proportion of the population aged over 65 years was similar in the fully covered population (defined below, ie based on Local Authority (LA) areas whose population was thought to be fully covered by participating units) compared with the general population of England and Wales. The proportion from an ethnic minority group was lower in the covered population at 6.7% compared with 8.7% 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 South Asian and African-Caribbean ethnic minority populations.

For comparisons between renal units and between local areas fully covered by the Renal Registry, the data from the Registry are fully valid.

Paediatric data, which are not included in this Chapter, can be found in Chapter 13.

Adult patients accepted for renal replacement therapy in the UK, 2003

There were estimated to be over 6,000 adult patients accepted for RRT in the whole of the UK for the year 2003, which is equivalent to a total population acceptance rate of 103 pmp (Table 4.1). The acceptance rate was calculated using an overall total for England derived from the data available for the renal units in England participating in the Registry's activity which cover an estimated 39.1 million

people. The acceptance rate in 2002 was 101 pmp.

Data returned directly to the UK Renal Registry – England and Wales

In 2003, 36 of the 53 renal units in England and all 5 units in Wales, returned data directly to the UK Renal Registry on new patients accepted for RRT (Table 4.2). The estimated catchment population for the units was 39.1 million, representing 73% of the population of England and all of Wales. These units recorded 3,953 new patients for 2003. The majority of the following detailed analyses are based on data from these units.

Rates per million, per annum, accepted by renal units have not been calculated, as renal unit catchment populations are not precisely defined. Estimates of renal unit catchment populations are unreliable; in general they are usually overestimated.

Table 4.1: Number of new patients accepted in the UK in 2003

	England	Wales	Scotland	N. Ireland	UK
No of renal units	36/53	5	10	5	73
Patient numbers	3,566 (4,886)*	387	582	214	6,069*
Population (millions)	49.6	2.9	5.0	1.7	59.2
Acceptance rate pmp	99*	133	116	126	103*
(95% CI)	(96–102)	(121–146)	(107–126)	(110–142)	(101–106)

*Extrapolated – is an underestimate due to under-representation of ethnic minorities in the areas covered by the English units participating in the Registry compared with the population as a whole.

Table 4.2: Number of new patients accepted by individual renal units reporting to the UK Renal Registry 1998–2003

Treatment centre	No of new patients					
	1998	1999	2000	2001	2002	2003
Bangor	N/A	N/A	N/A	N/A	29	38
Bradford	N/A	N/A	N/A	61	60	75
Bristol	122	119	151	151	125	168
Cambridge	N/A	N/A	N/A	84	75	104
Carlisle	40	26	27	25	29	30
Carshalton	141	108	117	120	173	203
Clwyd	N/A	N/A	N/A	N/A	19	28
Coventry	87	92	89	103	97	76
Cardiff	137	138	137	142	142	154
Derby	N/A	N/A	26	49	N/A	62
Exeter	74	82	71	99	82	98
Gloucester	49	59	46	49	57	55
Guys	N/A	N/A	122	109	140	95
Hammersmith and Charing Cross	N/A	N/A	N/A	N/A	174	152
Heartlands	71	71	77	85	59	103
Hull	73	65	81	75	105	78
Ipswich	N/A	N/A	N/A	N/A	21	35
Kings	N/A	N/A	N/A	N/A	117	114
Leeds*	N/A	N/A	N/A	N/A	N/A	169
Leeds General Infirmary*	N/A	N/A	68	74	63	N/A
Leeds St James*	71	79	89	87	80	N/A
Leicester	181	161	177	182	151	168
Liverpool	N/A	N/A	N/A	182	150	119
ManWst	N/A	N/A	N/A	N/A	N/A	141
Middlesbrough	109	92	90	82	112	104
Newcastle	N/A	N/A	N/A	N/A	105	91
Nottingham	129	128	113	121	87	114
Oxford	146	139	144	168	160	179
Plymouth	71	67	63	63	86	69
Portsmouth	N/A	N/A	N/A	144	143	137
Preston	79	105	118	135	113	99
Reading	N/A	N/A	54	71	43	69
Sheffield	129	134	136	152	156	158
Stevenage	116	105	N/A	125	97	114
Southend	N/A	43	39	35	35	43
Sunderland	41	45	46	35	56	57
Swansea	N/A	23	61	110	111	133
Truro	N/A	N/A	N/A	35	58	48
Wirral	N/A	N/A	N/A	N/A	40	49
Wolverhampton	N/A	75	77	76	99	93
Wordsley	46	43	40	34	25	41
Wrexham	N/A	51	58	36	42	34
York	N/A	N/A	40	36	67	56
E&W	1,912	2,050	2,357	3,135	3,583	3,953

*For 2003, Leeds General Infirmary and St James have been combined under Leeds.
N/A – No data returned to the Registry for that year.

Geographical variation in acceptance rates in England and Wales

Introduction

Geographical equity of access to RRT is an important goal of renal service provision. However different areas will have different needs for RRT depending on demographic composition particularly age, gender, social deprivation and ethnic minority status. Comparison of crude acceptance rates onto RRT by geographical area alone can be misleading without taking account of such factors. This section uses age and gender standardisation as in the 2002 Report to compare RRT incident rates and tries to relate these to the ethnic minority profile. The impact of social deprivation on the acceptance rate has not been re-analysed for

this year's report but is recorded in the 2002 report. The total population used for the standardisation is the combination of all Local Authority areas for which the Registry had complete coverage in 2003. This analysis is restricted to England and Wales.

Methods

The methods of calculating the standardised acceptance rate ratio are described in detail in Appendix D.

In summary, age and gender specific acceptance rates were first calculated using the available registry data on the number of incident patients for the covered area in England and Wales and the data on the age and gender breakdown of the population of each Local Authority (LA) area obtained from the 2001

Table 4.3: Age/gender specific acceptance rates in the covered population

		N (estimated population)	N (cases in estimated population)	Crude rate per million estimated population in age and gender group
16-19	Men	862,382	15	17.4
	Women	827,246	6	7.3
20-24	Men	1,011,524	46	45.5
	Women	1,007,674	24	23.8
25-29	Men	1,060,351	57	53.8
	Women	1,097,126	37	33.7
30-34	Men	1,248,816	72	57.7
	Women	1,300,041	41	31.5
35-39	Men	1,307,889	89	68.0
	Women	1,342,029	69	51.4
40-44	Men	1,188,636	90	75.7
	Women	1,207,214	67	55.5
45-49	Men	1,076,433	144	133.8
	Women	1,092,413	78	71.4
50-54	Men	1,177,531	149	126.5
	Women	1,189,607	94	79.0
55-59	Men	969,583	183	188.7
	Women	982,151	112	114.0
60-64	Men	826,600	176	212.9
	Women	854,226	140	163.9
65-74	Men	1,347,444	564	418.6
	Women	1,529,782	348	227.5
75-79	Men	481,784	258	535.5
	Women	669,364	166	248.0
80-84	Men	280,317	159	567.2
	Women	483,629	91	188.2
85-89	Men	129,904	39	300.2
	Women	302,094	25	82.8
90+	Men	47,819	11	230.0
	Women	165,370	4	24.2

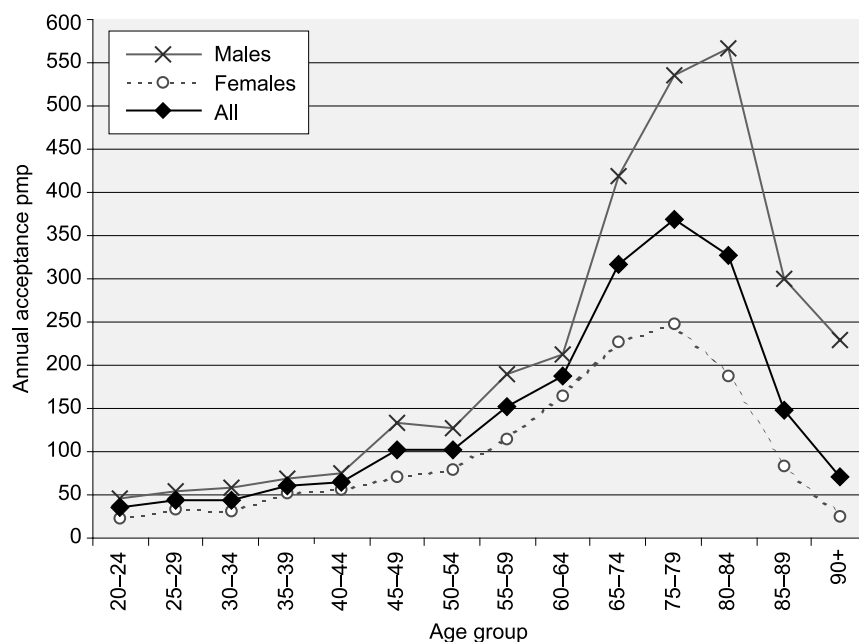


Figure 4.1: Acceptance rates in each gender in different age bands

Census data from the Office for National Statistics (ONS). These age and gender specific rates were then used to calculate the expected acceptance numbers for each LA area. The age and gender standardised acceptance rate ratio is therefore equal to the observed acceptance rate/expected numbers accepted.

A ratio of 1 indicates that the LA area's acceptance rate was as expected if the age/gender rates found in the total covered population applied to the LA area's population structure; a ratio 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.

Results

Age and Gender

The estimated population in England and Wales covered by the Registry in 2003 was 39.1 million, representing all of Wales and 73% of the English population. The overall adult acceptance rate for these parts of the UK was 99 pmp

(158 pmp in men and 93 pmp in women). The rates of acceptance in this population increased with age up to around age 80 and were higher in men in all age groups (Table 4.3 and Figure 4.1). The age specific rates were highest in the 80-84 age group in men and the 75-79 age group in women. In all age groups between 60% and 65% of new patients were male (Figure 4.2).

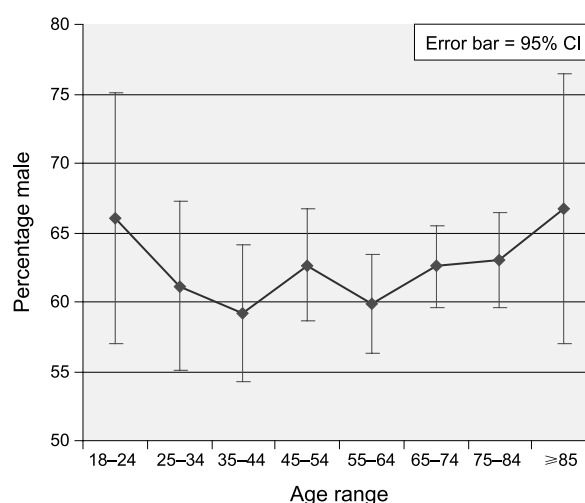


Figure 4.2: Percentage males accepted in age bands

Local Authority acceptance rates

Acceptance rates in Local Authorities with complete coverage by the Registry are shown in Table 4.4.

With the current commissioning arrangements in the UK, groups such as primary care trusts which represent relatively small populations of 30,000 to 250,000 often wish to assess their performance. When assessing a relatively infrequent occurrence such as acceptance for renal replacement therapy in such small populations there are wide confidence intervals for any observed frequency. To enable assessment of whether an observed acceptance rate is likely to be significantly different from the national average, Figures 4.3 and 4.4 have been included in the report. From these, for any size of population

(X axis) the upper and lower 95% confidence intervals around the national average acceptance rate (dotted lines) can be read from the Y axis. Any observed acceptance rate for renal failure must be outside these limits for the given population to be statistically significantly different from the national average. Thus for a population of 50,000 the observed take-on would have to be outside the limits of 10 per million population per year to 180 per million population per year. However for a population of 300,000 these limits are from 65 per million population per year to 135 per million population per year.

Standardised acceptance rate ratios

The standardised acceptance rate ratios for local authorities with complete coverage by the

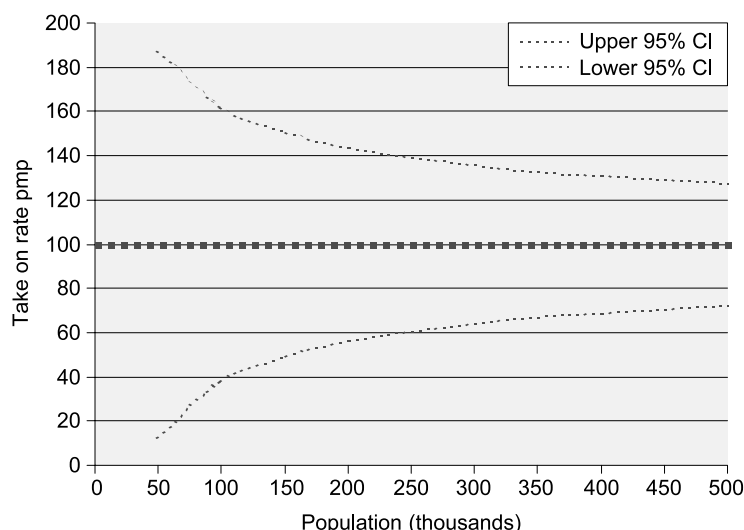


Figure 4.3: 95% Confidence limits for take on rate of 100 pmp for population size 50,000–500,000

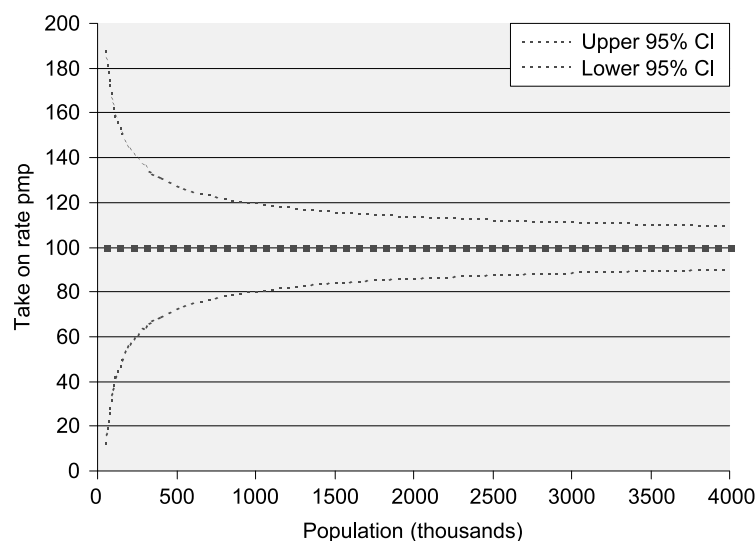


Figure 4.4: 95% Confidence limits for take on rate of 100 pmp for population size up to 4 million

Table 4.4: Crude adult acceptance rates and standardised rate-ratios for 2003 and combined years 2001–2003

Areas with significantly low acceptance ratios over 3 years are italicised in greyed areas, those with significantly high ones are bold in greyed areas.

Ratio = observed/expected acceptance rate.

Ethnicity = % South Asian and Black from 2001 Census.

UK Area	SHA	Name	Tot Pop	2003				Combined years				Ethnicity %
				Ratio	L 95% CL	U 95% CL	Crude rate pmp	Ratio	L 95% CL	U 95% CL	Crude rate pmp	
North East	County Durham & Tees Valley	Darlington	97,838	1.00	0.54	1.87	102.21	0.90	0.62	1.32	91.99	2.1
		<i>Durham</i>	<i>493,469</i>	<i>0.81</i>	<i>0.60</i>	<i>1.10</i>	<i>83.09</i>	<i>0.77</i>	<i>0.65</i>	<i>0.93</i>	<i>79.03</i>	<i>1.0</i>
		Hartlepool	88,610	1.36	0.77	2.40	135.42	0.99	0.67	1.45	97.81	1.2
		Middlesbrough	134,855	1.20	0.72	1.98	111.23	1.09	0.80	1.48	101.34	6.3
		Redcar and Cleveland	139,132	1.26	0.79	2.00	129.37	1.33	1.02	1.72	136.56	1.1
	Northumberland, Tyne & Wear	Stockton-on-Tees	178,408	0.94	0.57	1.53	89.68	0.94	0.71	1.24	89.68	2.8
		Gateshead	191,151	0.76	0.46	1.25	78.47	0.98	0.72	1.35	102.01	1.6
		Newcastle upon Tyne	259,536	0.89	0.58	1.35	84.77	0.93	0.70	1.24	88.62	6.9
		North Tyneside	191,658	0.55	0.30	0.99	57.39	0.75	0.52	1.07	78.26	1.9
		Northumberland	307,190	0.85	0.59	1.23	91.15	0.80	0.61	1.05	86.27	1.0
		South Tyneside	152,785	0.75	0.43	1.33	78.54	0.82	0.56	1.20	85.09	2.7
Sunderland	280,807	1.20	0.85	1.69	117.52	0.96	0.77	1.20	93.78	1.9		
North West	Cheshire & Merseyside	Halton	118,209	1.29	0.76	2.18	118.43	1.20	0.87	1.64	109.97	1.2
		Knowsley	150,459	1.22	0.76	1.97	112.99	0.89	0.64	1.22	81.97	1.6
		Liverpool	439,471	0.87	0.63	1.21	81.92	1.20	1.02	1.41	112.26	5.7
		Sefton	282,958	0.76	0.51	1.15	81.28	0.86	0.69	1.08	91.89	1.6
		St. Helens	176,843	0.57	0.31	1.06	56.55	0.80	0.59	1.08	79.17	1.2
		Warrington	191,080	0.72	0.42	1.23	68.03	0.84	0.63	1.13	80.25	2.1
	<i>Wirral</i>	<i>312,293</i>	<i>1.05</i>	<i>0.75</i>	<i>1.47</i>	<i>108.87</i>	<i>0.76</i>	<i>0.61</i>	<i>0.96</i>	<i>78.99</i>	<i>1.7</i>	
	Cumbria and Lancashire	Blackburn with Darwen	137,470	1.52	0.96	2.41	130.94	1.32	0.99	1.76	113.96	22.1
		Blackpool	142,283	0.38	0.17	0.85	42.17	0.72	0.52	1.01	79.65	1.6
		<i>Cumbria</i>	<i>487,607</i>	<i>0.80</i>	<i>0.59</i>	<i>1.08</i>	<i>86.13</i>	<i>0.78</i>	<i>0.66</i>	<i>0.94</i>	<i>84.77</i>	<i>0.7</i>
		<i>Lancashire</i>	<i>1,134,975</i>	<i>0.60</i>	<i>0.47</i>	<i>0.76</i>	<i>59.91</i>	<i>0.71</i>	<i>0.63</i>	<i>0.81</i>	<i>71.66</i>	<i>5.3</i>
	Greater Manchester	Bolton	261,037	0.97	0.65	1.45	91.94	0.97	0.65	1.45	91.94	11.0
		Bury	180,607	0.58	0.31	1.08	55.37	0.58	0.31	1.08	55.37	6.1
		Oldham	217,276	0.75	0.45	1.24	69.04	0.75	0.45	1.24	69.04	13.9
		Rochdale	205,357	1.06	0.68	1.64	97.39	1.06	0.68	1.64	97.39	11.4
		Salford	216,105	1.33	0.92	1.93	129.57	1.33	0.92	1.93	129.57	3.9
		Wigan	301,415	0.86	0.58	1.28	82.94	0.86	0.58	1.28	82.94	1.3
Yorkshire and the Humber	North and East Yorkshire and Northern Lincolnshire	East Riding of Yorkshire	314,113	1.02	0.73	1.42	111.42	0.89	0.73	1.10	97.63	1.2
		Kingston upon Hull, City of	243,588	0.96	0.64	1.46	90.32	0.98	0.77	1.24	91.68	2.3
		North East Lincolnshire	157,981	0.70	0.39	1.27	69.63	0.72	0.52	1.01	71.74	1.4
		North Lincolnshire	152,848	0.63	0.34	1.18	65.42	0.76	0.55	1.05	78.51	2.5
		North Yorkshire	569,660	1.03	0.81	1.32	110.59	1.02	0.88	1.18	109.42	1.1
		York	181,096	1.53	1.06	2.22	154.61	1.28	1.01	1.61	128.85	2.2
	South Yorkshire	Barnsley	218,063	0.73	0.45	1.19	73.37	0.85	0.66	1.11	85.60	0.9
		Doncaster	286,865	0.97	0.67	1.40	97.61	0.93	0.75	1.16	94.12	2.3
		Rotherham	248,175	1.02	0.69	1.51	100.74	1.12	0.90	1.39	110.14	3.1
		Sheffield	513,234	0.97	0.73	1.29	95.47	0.98	0.83	1.15	96.12	8.8
	West Yorkshire	Bradford	467,664	1.59	1.25	2.02	143.27	1.45	1.25	1.68	130.44	21.7
		Calderdale	192,405	0.96	0.61	1.53	93.55	0.93	0.71	1.22	90.09	7.0
		Kirklees	388,567	1.21	0.90	1.63	113.24	1.10	0.92	1.32	102.94	14.4
		Leeds	715,403	1.07	0.85	1.34	100.64	0.97	0.85	1.12	91.79	8.2
		Wakefield	315,172	0.87	0.60	1.27	85.67	0.80	0.64	1.00	78.26	2.3

Table 4.4: (continued)

UK Area	SHA	Name	Tot Pop	2003				Combined years				Ethnicity %
				Ratio	L 95% CL	U 95% CL	Crude rate pmp	Ratio	L 95% CL	U 95% CL	Crude rate pmp	
East Midlands	Leicestershire, Northamptonshire and Rutland	Leicester	279,920	1.66	1.22	2.27	142.90	1.50	1.24	1.81	128.61	36.1
		Leicestershire	609,578	0.85	0.65	1.12	85.30	0.92	0.79	1.07	92.41	5.3
		<i>Northamptonshire</i>	<i>629,676</i>	<i>0.76</i>	<i>0.57</i>	<i>1.01</i>	<i>71.47</i>	<i>0.85</i>	<i>0.72</i>	<i>0.99</i>	<i>79.94</i>	4.9
		Rutland	34,563	1.67	0.75	3.72	173.60	0.83	0.43	1.60	86.80	1.9
	Trent	Derby	221,709	0.93	0.60	1.44	90.21	0.93	0.60	1.44	90.21	12.6
		<i>Derbyshire</i>	<i>734,585</i>	<i>0.89</i>	<i>0.70</i>	<i>1.13</i>	<i>92.57</i>	<i>0.63</i>	<i>0.54</i>	<i>0.74</i>	<i>65.34</i>	1.5
		<i>Lincolnshire</i>	<i>646,644</i>	<i>0.62</i>	<i>0.46</i>	<i>0.83</i>	<i>68.04</i>	<i>0.63</i>	<i>0.53</i>	<i>0.74</i>	<i>69.07</i>	1.3
		Nottingham	266,988	0.88	0.58	1.35	78.66	1.06	0.85	1.33	94.89	15.1
	Nottinghamshire	748,508	1.11	0.90	1.37	113.56	0.94	0.82	1.07	96.19	2.6	
	West Midlands	Birmingham and the Black Country	<i>Dudley</i>	<i>305,153</i>	<i>0.83</i>	<i>0.56</i>	<i>1.22</i>	<i>85.20</i>	<i>0.66</i>	<i>0.51</i>	<i>0.85</i>	<i>67.73</i>
Solihull			199,515	1.61	1.14	2.26	165.40	1.12	0.89	1.42	115.28	5.4
Walsall			253,498	1.27	0.90	1.80	126.23	1.21	0.98	1.48	119.66	13.6
Wolverhampton			236,582	1.82	1.35	2.45	181.76	1.56	1.30	1.88	156.39	22.2
Coventry, Warwickshire, Herefordshire & Worcestershire		Coventry	300,849	1.17	0.83	1.64	109.69	1.39	1.16	1.67	130.74	16.0
Warwickshire		505,858	0.81	0.60	1.10	83.03	0.94	0.80	1.11	96.21	4.4	
East of England	Bedfordshire and Hertfordshire	Bedfordshire	381,572	0.98	0.70	1.36	91.73	0.88	0.72	1.08	82.99	6.7
		<i>Hertfordshire</i>	<i>1,033,978</i>	<i>0.63</i>	<i>0.50</i>	<i>0.81</i>	<i>60.93</i>	<i>0.67</i>	<i>0.58</i>	<i>0.77</i>	<i>64.15</i>	6.3
		Luton	184,373	1.86	1.29	2.68	157.29	1.35	1.05	1.72	113.90	28.1
	Essex	Southend-on-Sea	160,259	1.44	0.96	2.14	149.76	1.22	0.95	1.56	126.88	4.2
	Norfolk, Suffolk & Cambridgeshire	<i>Cambridgeshire</i>	<i>552,659</i>	<i>0.79</i>	<i>0.58</i>	<i>1.07</i>	<i>76.00</i>	<i>0.78</i>	<i>0.66</i>	<i>0.93</i>	<i>75.39</i>	4.1
		Peterborough	156,061	1.18	0.74	1.90	108.93	1.07	0.80	1.43	98.25	10.3
	North West London	Ealing	300,948	1.63	1.20	2.21	136.24	1.65	1.33	2.04	137.90	41.3
		Hammersmith and Fulham	165,244	1.96	1.34	2.88	157.34	1.85	1.40	2.45	148.27	22.2
	South East London	Bexley	218,307	0.99	0.64	1.51	96.19	1.03	0.81	1.32	100.78	8.6
		Bromley	295,532	1.11	0.79	1.56	111.66	0.85	0.68	1.07	85.72	8.4
		Greenwich	214,404	1.32	0.88	1.97	111.94	1.43	1.09	1.87	121.27	22.9
		Lambeth	266,169	1.41	0.97	2.04	105.20	1.25	1.00	1.57	93.93	37.6
		Lewisham	248,923	1.22	0.82	1.81	96.42	1.28	1.03	1.61	101.77	34.1
Southwark	244,866	1.58	1.10	2.25	122.52	1.63	1.27	2.09	126.60	37.0		
South West London	Croydon	330,588	1.35	0.98	1.84	117.97	1.17	0.97	1.42	102.85	29.8	
South East	Hampshire and Isle of Wight	<i>Hampshire</i>	<i>1,240,102</i>	<i>0.70</i>	<i>0.57</i>	<i>0.86</i>	<i>70.16</i>	<i>0.68</i>	<i>0.60</i>	<i>0.77</i>	<i>68.27</i>	2.2
		<i>Isle of Wight</i>	<i>132,731</i>	<i>0.64</i>	<i>0.34</i>	<i>1.18</i>	<i>75.34</i>	<i>0.61</i>	<i>0.43</i>	<i>0.88</i>	<i>72.83</i>	1.3
		Portsmouth	186,700	1.09	0.70	1.71	101.77	0.98	0.74	1.29	91.06	5.3
		Southampton	217,444	0.91	0.57	1.44	82.78	0.79	0.60	1.05	72.05	7.6
	Thames Valley	<i>Buckinghamshire</i>	<i>479,026</i>	<i>0.72</i>	<i>0.51</i>	<i>1.01</i>	<i>68.89</i>	<i>0.78</i>	<i>0.64</i>	<i>0.94</i>	<i>74.46</i>	7.9
		Milton Keynes	207,057	1.49	1.01	2.21	120.74	1.05	0.80	1.38	85.32	9.3
		Oxfordshire	605,489	1.17	0.92	1.49	110.65	0.98	0.84	1.14	92.49	4.9
		Reading	143,096	1.06	0.62	1.83	90.85	0.93	0.66	1.30	79.20	13.2
		Slough	119,064	1.73	1.07	2.78	142.78	1.42	1.05	1.93	117.58	36.3
		West Berkshire	144,485	0.90	0.51	1.58	83.05	0.80	0.56	1.13	73.83	2.6
		Wokingham	150,231	1.19	0.73	1.95	106.50	0.85	0.60	1.18	75.44	6.1

Table 4.4: (continued)

UK Area	SHA	Name	Tot Pop	2003				Combined years				Ethnicity %
				Ratio	L 95% CL	U 95% CL	Crude rate pmp	Ratio	L 95% CL	U 95% CL	Crude rate pmp	
South West	Avon, Gloucestershire and Wiltshire	<i>Bath and North East Somerset</i>	169,040	0.79	0.47	1.34	82.82	0.66	0.48	0.92	69.02	2.8
		Bristol, City of	380,616	1.45	1.10	1.91	133.99	1.32	1.12	1.56	121.73	8.2
		Gloucestershire	564,559	0.91	0.69	1.19	93.88	0.87	0.74	1.02	89.75	2.8
		North Somerset	188,564	1.39	0.97	2.01	153.79	1.12	0.89	1.42	123.74	1.4
		South Gloucestershire	245,641	1.19	0.82	1.72	113.99	1.12	0.90	1.39	107.20	2.4
		Swindon	180,051	1.02	0.64	1.65	94.42	0.88	0.66	1.19	81.46	4.8
		<i>Wiltshire</i>	432,972	0.62	0.42	0.90	62.36	0.59	0.47	0.73	59.28	1.6
	Dorset & Somerset	<i>Somerset</i>	498,095	0.84	0.63	1.12	92.35	0.84	0.71	0.99	91.68	1.2
	South West Peninsula	Cornwall and Isles of Scilly	501,267	1.23	0.97	1.55	139.65	1.22	1.07	1.40	138.98	1.0
		<i>Devon</i>	704,491	0.88	0.70	1.11	100.78	0.86	0.75	0.99	98.89	1.1
Plymouth		240,722	1.36	0.97	1.93	132.93	1.39	1.14	1.70	135.70	1.6	
Torbay		129,706	1.18	0.75	1.88	138.78	0.94	0.70	1.27	110.51	1.2	
Wales	Bro Taf	Cardiff	305,353	1.41	1.03	1.93	127.72	1.24	1.02	1.51	112.44	8.4
		Merthyr Tydfil	55,979	1.81	0.97	3.36	178.64	1.57	1.07	2.30	154.82	1.0
		Rhondda, Cynon, Taff	231,947	0.91	0.59	1.40	90.54	1.10	0.88	1.38	109.22	1.2
	Dyfed Powys	The Vale of Glamorgan	119,292	1.07	0.62	1.85	108.98	0.99	0.71	1.37	100.59	2.2
		Carmarthenshire	172,842	1.51	1.05	2.18	167.78	1.20	0.95	1.52	133.07	0.9
		Ceredigion	74,941	0.61	0.25	1.47	66.72	1.06	0.72	1.56	115.65	1.4
		Pembrokeshire	114,131	1.27	0.78	2.07	140.19	1.11	0.82	1.50	122.67	0.9
	Gwent	<i>Powys</i>	126,353	0.35	0.14	0.83	39.57	0.55	0.37	0.83	63.31	0.9
		Blaenau Gwent	70,064	0.14	0.02	1.00	14.27	0.89	0.57	1.40	90.39	0.8
		Caerphilly	169,519	1.10	0.69	1.74	106.18	1.07	0.82	1.41	104.22	0.9
		Monmouthshire	84,885	0.87	0.44	1.75	94.25	1.27	0.91	1.77	137.44	1.1
		Newport	137,012	1.49	0.96	2.32	145.97	1.24	0.94	1.64	121.64	4.8
	Morgannwg	Torfaen	90,949	1.41	0.82	2.43	142.94	1.23	0.88	1.72	124.61	0.9
		Bridgend	128,645	1.68	1.11	2.56	171.01	1.33	1.01	1.74	134.74	1.4
		Neath Port Talbot	134,468	1.61	1.07	2.42	171.04	1.40	1.09	1.80	148.73	1.1
	North Wales	Swansea	223,300	1.74	1.28	2.36	183.61	1.68	1.41	2.02	177.64	2.2
Conwy		109,596	0.69	0.36	1.33	82.12	0.92	0.62	1.37	109.49	1.1	
<i>Denbighshire</i>		93,065	0.19	0.05	0.78	21.49	0.32	0.17	0.60	35.82	1.2	
Flintshire		148,594	2.21	1.56	3.12	215.35	1.83	1.40	2.39	178.34	0.8	
Gwynedd		116,843	2.15	1.47	3.13	231.08	1.95	1.47	2.58	209.68	1.2	
Isle of Anglesey		66,829	1.50	0.83	2.70	164.60	1.16	0.72	1.86	127.19	0.7	
Wrexham	128,476	1.33	0.83	2.14	132.32	1.10	0.81	1.48	108.97	1.1		

Registry for the year 2003 and the combined years 2001–2003 are shown in Table 4.4. The combined three-year analysis is reported because the incidence of RRT is low and authorities with small populations will have wide confidence limits for the acceptance rate such that the interpretation of an individual year is extremely difficult. Combining 3 years gives a

higher incidence rate and reduces the confidence intervals. This is well illustrated by Blaenau Gwent, population 70,064, whose acceptance ratio in 2003 was only 0.14, but 95% confidence intervals were 0.02–1.00, ie the ratio of 0.14 is not significantly different from the mean. The sustained ratio over 3 years is 0.89, range 0.57 to 1.40.

Discussion

There is substantial variation in the crude LA area acceptance rates from 14 to 231 pmp in 2003. 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. Some areas have significantly high ratios. These are often areas with a high ethnic minority population and/or a socially deprived population, factors which were shown to be important in the 2003 Registry report. Good examples where these factors are likely to be important are Leicester and Wolverhampton. However, the ethnicity and social deprivation factors do not explain the higher ratios in areas such as Bristol, Cornwall and York, where the catchment areas are relatively affluent with a low proportion of ethnic minorities. There are still unexplained reasons why these areas have higher acceptance rates. Figure 4.5 illustrates that in areas with about 10% ethnic minorities, the standardised rate ratio tends to be more than 1.0, but the reverse argument that areas with lower proportion of ethnic minorities have lower standardised rate ratio is not necessarily true.

Some LA areas have significantly low rate ratios. In some, this is consistent with low ethnic minority numbers and lower social deprivation eg Wiltshire, Wirral and Bath, but the explanation is less apparent in other areas. These standardised rates are all relative to an overall acceptance rate that may not meet population need for RRT.

Local changes in acceptance rate

Changes in acceptance by renal units

The number of patients accepted by each renal unit in England and Wales is shown in Table 4.2. There is variation in time trends between units which may reflect chance fluctuation, completeness of reporting, rising incidence of ERF, changes in referral patterns or catchment populations and areas and the introduction of conservative care teams. In the 27 units submitting data since 2000 (counting Leeds as 1 unit), there has been a 15% rise in the acceptance numbers over this period, with wide variations between different units.

Ethnicity

There is substantial variation in the completeness of ethnicity data (Table 4.5). In England and Wales, 18 units now provide over 90% complete data. In contrast 9 provide less than 30%. Such levels of incompleteness make it difficult to reliably assess 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 2002 (see Registry Report 2003), showing that the Registry units are not totally representative of the whole UK.

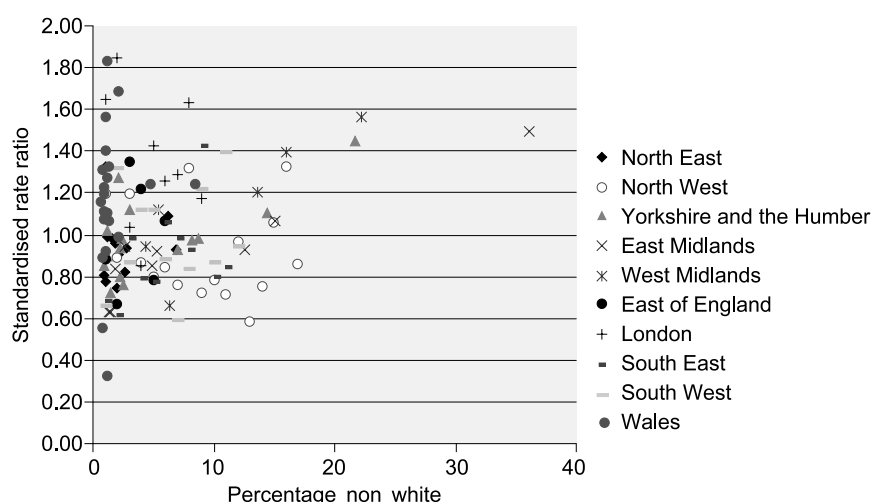


Figure 4.5: Percentage of population non White and standardised acceptance rate ratio

Table 4.5: Percentage of patients in different ethnic groups, by centre

Treatment Centre	% returns	% White	% Black	% Asian	% Chinese	% Other
Nottm	100	86.8	6.1	6.1	0.0	0.9
Glouc	100	100.0	0.0	0.0	0.0	0.0
Sheff	100	91.8	1.9	5.7	0.6	0.0
Heart	100	72.8	6.8	17.5	1.0	1.9
Words	100	95.1	2.4	2.4	0.0	0.0
H&CX	100	46.1	11.2	19.1	0.7	23.0
Stevng	99.1	83.2	2.7	13.3	0.0	0.9
Wolve	98.9	80.4	8.7	10.9	0.0	0.0
Redng	98.6	73.5	8.8	14.7	0.0	2.9
York	98.2	98.2	0.0	0.0	0.0	1.8
Ports	97.1	98.5	0.8	0.8	0.0	0.0
Bristol	97.0	96.3	1.8	1.2	0.0	0.6
Newc	96.7	94.3	1.1	4.5	0.0	0.0
Swmse	96.2	100.0	0.0	0.0	0.0	0.0
Leic	95.2	80.0	1.3	16.3	0.6	1.9
Oxford	94.4	91.1	3.0	4.7	0.6	0.6
Carls	93.3	100.0	0.0	0.0	0.0	0.0
Sund	91.2	100.0	0.0	0.0	0.0	0.0
ManWst	88.7	89.6	0.8	8.0	0.0	1.6
Prstn	87.9	85.1	0.0	14.9	0.0	0.0
Plym	85.5	100.0	0.0	0.0	0.0	0.0
Covnt	82.9	79.4	3.2	17.5	0.0	0.0
Livrpl	79.8	97.9	0.0	0.0	1.1	1.1
Middlbr	79.8	97.6	0.0	2.4	0.0	0.0
Bradf	69.3	63.5	0.0	36.5	0.0	0.0
Derby	66.1	87.8	2.4	4.9	0.0	4.9
Leeds	59.2	84.0	5.0	11.0	0.0	0.0
Guys	56.8	59.3	35.2	3.7	1.9	0.0
Carsh	42.9	69.0	12.6	16.1	1.1	1.1
Wirrl	40.8	100.0	0.0	0.0	0.0	0.0
Hull	33.3	100.0	0.0	0.0	0.0	0.0
Sthend	25.6	100.0	0.0	0.0	0.0	0.0
Truro	25.0	91.7	8.3	0.0	0.0	0.0
Extr	21.4	95.2	0.0	4.8	0.0	0.0
Bangr	21.1	100.0	0.0	0.0	0.0	0.0
Clwyd	11.1	100.0	0.0	0.0	0.0	0.0
Camb	8.7	100.0	0.0	0.0	0.0	0.0
Wrexm	5.9	100.0	0.0	0.0	0.0	0.0
Kings	3.5	50.0	25.0	25.0	0.0	0.0
Crdff	2.6	100.0	0.0	0.0	0.0	0.0
Eng	75.5	85.4	3.9	8.4	0.3	2.0
Wales	38.9	100.0	0.0	0.0	0.0	0.0
E&W	72.1	86.2	3.7	8.0	0.3	1.9
E&W for units > 90% returns	97.6	86.6	3.2	7.6	0.3	2.3

Within the units with over 90% returns there is significant variation in the percentages of new patients from the ethnic minorities known to have high rates of ERF ie South Asian and Black, ranging from 0% to 30%.

Table 4.6 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 (eg 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 2002 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 in older groups amongst ethnic minorities.

Age

The median age of patients starting renal replacement therapy has risen from 63.0 in 1998 to 64.8 in 2001 although there has been no

Table 4.6: Median age of ethnic groups accepted for RRT

Centre	Median age of incident patients	
	Ethnic minority	All
Bradf	62.8	67.1
Bristl	44.2	67.0
Carsh	52.3	63.8
Covnt	53.3	64.0
Derby	67.2	66.5
Extr	54.8	68.8
Guys	44.0	54.9
H&CX	61.8	62.1
Heart	62.4	70.9
Kings	30.8	63.4
Leeds	49.7	61.1
Leic	65.3	65.9
Livrpl	67.7	62.6
ManWst	56.0	60.2
Middlbr	64.9	63.8
Newc	36.6	58.1
Nottm	57.6	66.0
Oxfrd	59.5	65.1
Ports	36.1	63.0
Prstn	51.8	65.6
Redng	64.5	67.5
Sheff	63.9	63.9
Stevng	64.3	64.2
Truro	75.7	69.5
Wolve	55.3	65.6
Words	54.3	68.7
York	57.5	68.0
E&W	58.8	64.8

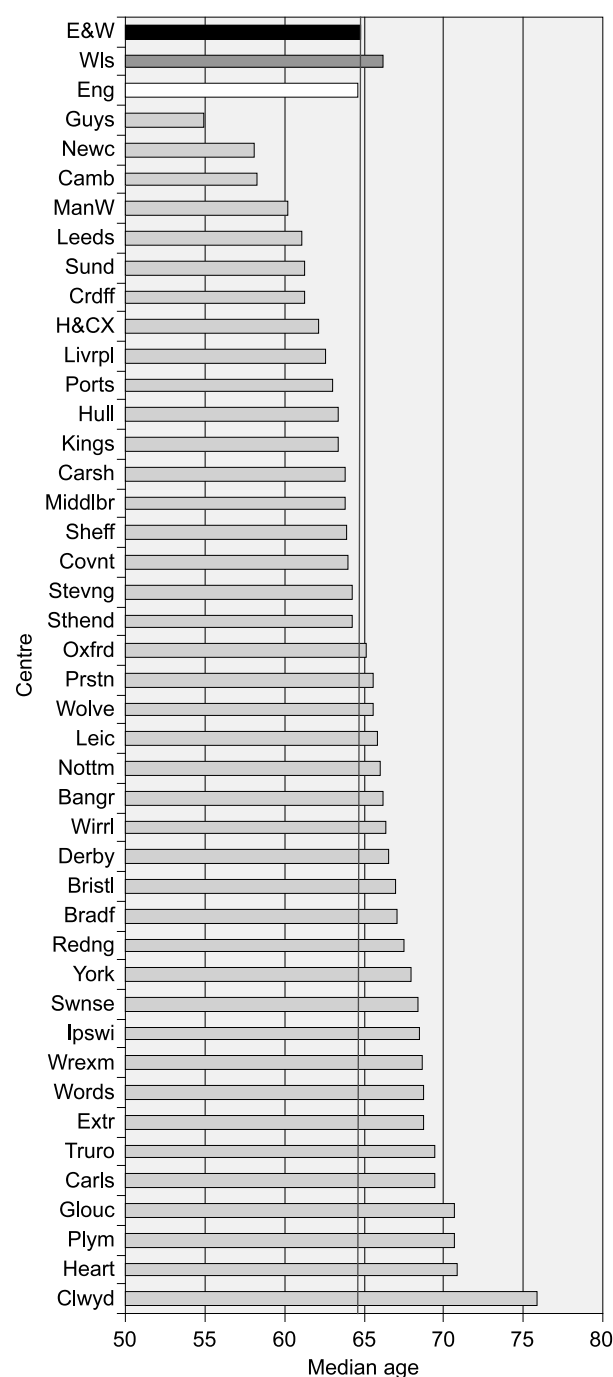


Figure 4.6: Median age of new patients in each centre

Table 4.7: Median age and percentage of incident patients over 75 in England and Wales 1998–2003

Year	Median age	% over 75
1998	63.0	17.6
1999	63.0	18.3
2000	64.0	21.2
2001	64.8	21.0
2002	65.5	23.5
2003	64.8	22.3

increase in the last 3 years. The proportion of incident patients aged over 75 has also increased from 17.6% in 1998 to 22.3% in 2003 (Table 4.7).

The large variation in median age by centre is shown in Figure 4.6. A few units have a median age under age 60: in contrast some have median age over 70.

Gender

Gender specific acceptance rates for the contiguous population covered by the UK Renal Registry 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). There was an excess of males starting RRT in all age groups in the 2003 cohort (Figure 4.1), as in previous years.

Table 4.8: Percentage of males, by age, 1998–2003

	1998	1999	2000	2001	2002	2003
England & Wales	62.8	62.2	59.3	63.2	61.8	61.9

Primary renal diagnosis

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

The male:female ratio is over one, as expected for most types of kidney disease. This is somewhat surprising for Adult Polycystic Disease (APKD), as the APKD gene is distributed equally amongst the general population: the excess of males may relate to factors more common in males which may influence the rate of progress of renal failure, such as hypertension and reno-vascular disease. There is also a gender imbalance in patients with diabetic nephropathy, this may be for a similar reason.

The aetiology uncertain/glomerulonephritis not proven group is the most common group overall, due to the high incidence in the elderly.

Diabetes is the most common specific cause overall. This is especially due to the very high incidence in those under 65; apart from aetiology uncertain it is also the most common cause in elderly patients. 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). After excluding patients with a missing diagnosis, the proportion of patients with diabetic nephropathy as the cause of ERF has remained unchanged between 1999 and 2003 at 19–20% (19.0% in 1999 and 19.3% in 2003). However with the continuing increase of overall

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

Diagnosis	E&W <65	E&W >65	E&W All	M:F
Aetiology unc./GN NP*	19.7	29.6	24.6	1.5
Glomerulonephritis	12.9	5.9	9.4	2.4
Pyelonephritis	7.8	7.4	7.6	1.4
Diabetes	20.9	14.9	17.9	1.6
Renal Vascular disease	2.4	13.2	7.7	1.6
Hypertension	4.7	5.6	5.1	2.3
Polycystic Kidney	9.4	2.7	6.1	1.3
Other	15.7	13.4	14.6	1.4
Not sent	6.6	7.3	6.9	2.4
No of patients	1,992	1,942	3,953	

*GN NP, glomerulonephritis not proven

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

Unit	Not sent	Aetiology unc./GN NP	Diabetes	GN	Polycystic kidney	Hypertn	Reno- vascular	Pyelo- nephritis	Other
Bangr	2.6	39.5	13.2	10.5	2.6	13.2	0.0	5.3	13.2
Bradf	17.3	14.7	14.7	10.7	4.0	5.3	12.0	10.7	10.7
Bristol	3.6	22.6	14.9	11.3	10.1	3.0	10.1	9.5	14.9
Camb	3.8	36.5	21.2	10.6	6.7	1.0	3.8	6.7	9.6
Carls	0.0	23.3	13.3	6.7	13.3	0.0	20.0	10.0	13.3
Carsh	0.5	25.1	25.1	8.9	2.0	3.9	9.9	5.4	19.2
Clwyd	0.0	77.8	22.2	0.0	0.0	0.0	0.0	0.0	0.0
Covnt	0.0	15.8	27.6	11.8	3.9	5.3	7.9	11.8	15.8
Crdff	2.6	37.7	22.7	9.1	3.9	2.6	1.3	9.1	11.0
Derby	45.2	6.5	19.4	6.5	3.2	0.0	4.8	9.7	4.8
Extr	43.9	12.2	6.1	6.1	7.1	0.0	3.1	4.1	17.3
Glouc	1.8	27.3	7.3	12.7	3.6	0.0	14.5	7.3	25.5
Guys	0.0	14.7	21.1	7.4	9.5	11.6	5.3	6.3	24.2
H&CX	0.7	12.5	30.3	8.6	5.3	15.1	3.3	4.6	19.7
Heart	0.0	26.2	30.1	3.9	6.8	1.9	12.6	5.8	12.6
Hull	21.8	19.2	15.4	9.0	10.3	3.8	3.8	7.7	9.0
Ipswi	0.0	48.6	17.1	14.3	8.6	2.9	2.9	2.9	2.9
Kings	2.6	15.8	28.9	10.5	2.6	14.0	3.5	10.5	11.4
Leeds	30.2	8.9	13.0	9.5	7.1	3.6	7.7	10.1	10.1
Leic	3.0	16.7	23.8	13.1	8.9	3.6	13.1	8.3	9.5
Livrpl	0.8	39.5	15.1	8.4	5.0	11.8	3.4	3.4	12.6
ManWst	0.0	68.8	7.1	4.3	3.5	2.1	2.8	3.5	7.8
Middlbr	5.8	27.9	20.2	7.7	7.7	2.9	10.6	5.8	11.5
Newc	2.2	15.4	9.9	16.5	12.1	3.3	5.5	9.9	25.3
Nottm	2.6	25.4	21.1	6.1	5.3	6.1	4.4	12.3	16.7
Oxfrd	2.2	19.6	17.9	12.3	5.6	3.9	8.9	8.9	20.7
Plym	1.4	15.9	20.3	8.7	4.3	1.4	13.0	4.3	30.4
Ports	8.8	18.2	16.8	9.5	4.4	3.6	8.0	9.5	21.2
Prstn	3.0	30.3	9.1	12.1	14.1	6.1	3.0	11.1	11.1
Redng	0.0	23.2	15.9	7.2	7.2	1.4	14.5	17.4	13.0
Sheff	0.0	13.3	17.7	13.3	6.3	10.8	13.3	8.9	16.5
Stevng	0.0	41.2	11.4	4.4	7.0	2.6	3.5	2.6	27.2
Sthend	20.9	27.9	23.3	4.7	7.0	0.0	7.0	4.7	4.7
Sund	0.0	10.5	12.3	22.8	8.8	19.3	8.8	7.0	10.5
Swmse	6.0	18.0	15.0	9.8	2.3	4.5	17.3	6.8	20.3
Truro	8.3	37.5	18.8	16.7	4.2	0.0	6.3	8.3	0.0
Wirrl	0.0	98.0	0.0	0.0	2.0	0.0	0.0	0.0	0.0
Wolve	1.1	19.4	23.7	8.6	3.2	7.5	17.2	9.7	9.7
Words	0.0	24.4	19.5	14.6	12.2	12.2	2.4	2.4	12.2
Wrexm*	38.2	14.7	20.6	0.0	2.9	0.0	5.9	5.9	11.8
York	50.0	7.1	5.4	3.6	7.1	7.1	7.1	7.1	5.4
Eng	6.9	24.1	17.9	9.5	6.4	5.2	7.8	7.6	14.6
Wales	7.1	29.6	18.8	8.4	3.0	4.1	7.3	7.3	14.4
E&W**	6.9	24.6	17.9	9.4	6.1	5.1	7.7	7.6	14.6

*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	Renovascular	Pyelonephritis	Other
E&W	26.4	19.3	10.1	6.6	5.5	8.3	8.1	15.7

acceptance rate the diabetic acceptance rate has increased from 17 pmp to 19 pmp.

In the absence of firm definitions for certain diagnostic categories eg hypertensive disease and reno-vascular disease, some centre variation in cause is likely to reflect differences in classification rather than geographical differences in underlying disease. Reno-vascular disease is a common reported cause in the elderly.

First established treatment modality

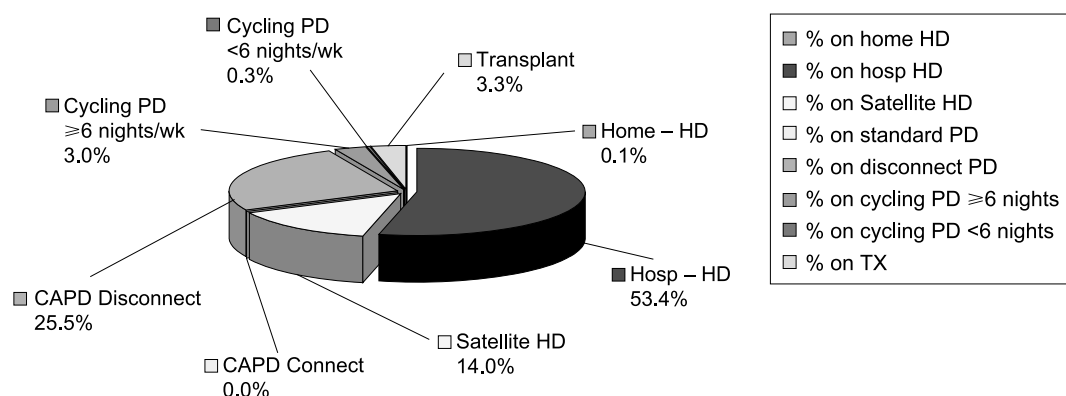
In 2003, haemodialysis was the very first modality of RRT in 68.6% of patients in England and Wales, with 29.1% using PD and 2.2% receiving pre-emptive transplants. However, many patients, especially those being referred late to renal units, undergo a brief period of haemodialysis before being established on peritoneal dialysis. As an indication of the elective treatment modality, the established modality at 90 days is a more clearly defined and representative figure (Figure 4.7). Of the 90.4% of the 2003 patient cohort alive on day 90 of treatment (ie

those starting therapy 1/10/2002–30/9/2003), 67.5% were on HD, 29.2% on PD and 3.3% had received a transplant.

There were significant differences between individual units within England and Wales in the percentage of new patients established on haemodialysis ($p < 0.0001$). There is a wide variation between units in the percentage of patients on HD at day 90 (Figure 4.8) from 2 units with fewer than 40% on HD to 4 units with over 80%.

Peritoneal dialysis patients have a lower median age than HD patients (58 years and 67 years respectively, $p < 0.0001$). The comparison of HD usage in the under and over 65 age group is shown in Figure 4.9. In most units there are a substantially greater proportion of patients over age 65 years on HD compared with patients under age 65. In a few the proportions were similar or even reversed (eg Gloucester, Ipswich, and Derby).

When analysing modality by age <65 and $65+$, 63% and 78% of patients respectively were on HD at day 90 in England & Wales (Figure 4.9).

**Figure 4.7: RRT modality at day 90 – 2003 cohort**

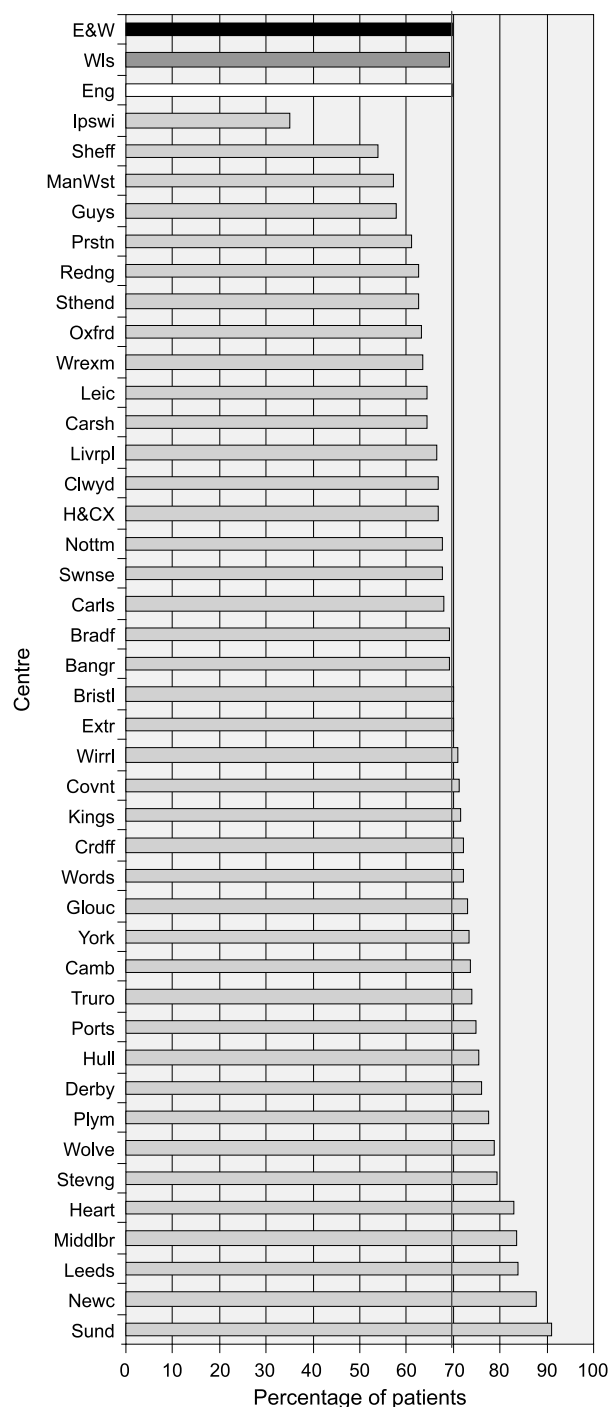


Figure 4.8: Percentage of incident dialysis patients in each centre on HD on day 90, 2003 cohort

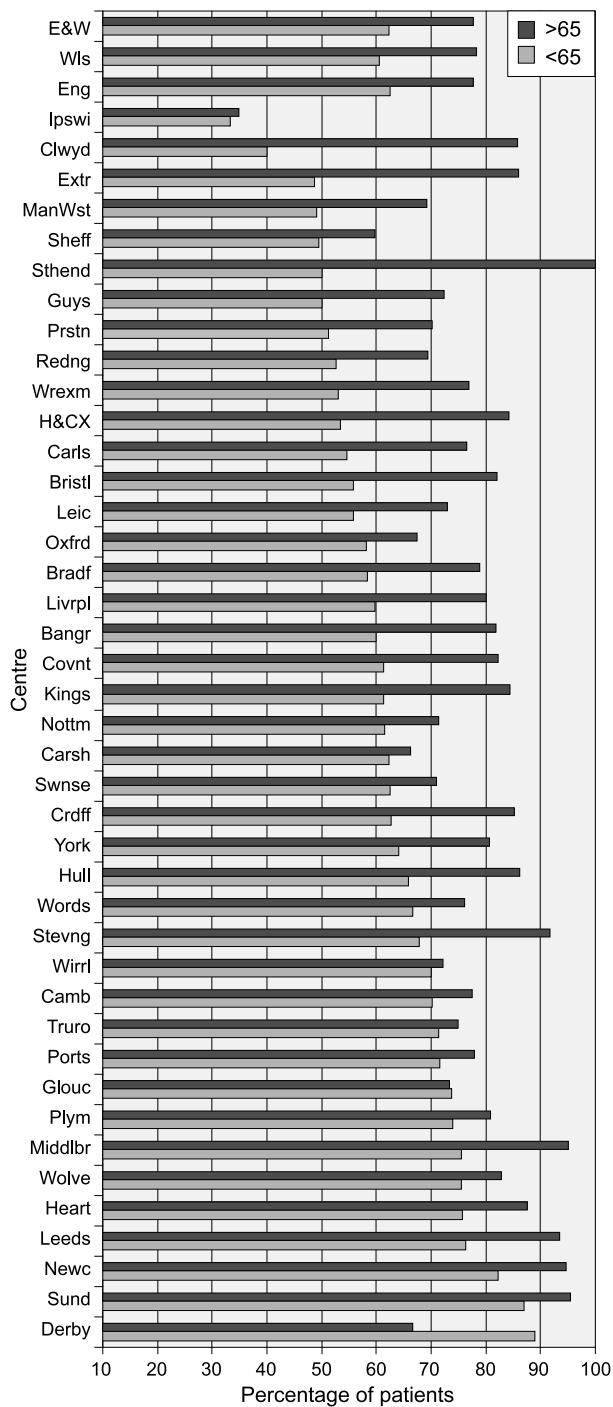


Figure 4.9: Percentage of incident dialysis patients on HD in each centre on day 90, by age, 2003

Changes in treatment modality in the first 3 years

Those established on haemodialysis

The modality changes in the first 3 years of those patients starting RRT in 1998–2000 were analysed for those patients established on haemodialysis on day 90 (n = 4,661 patients).

The sequential modality changes are shown in Table 4.12.

These are changes subsequent to the first 90 days after starting dialysis. As reported before, transfer to PD is negligible after the first year. This is an older group of patients than those established on PD and the patients have more co-morbidity, explaining the relatively higher

Table 4.12: 3 year sequential modality changes in patients established on HD 1998–2000

n = 4,661	Sequential modality changes over 3 years for patients established on HD at day 90, 1998–2000		
	End of yr 1	End of yr 2	End of yr 3
	%	%	%
Remained on HD	72	54	42
Changed to PD	3	3	3
Had a transplant	4	9	12
Stopped treatment	0	0	0
Unknown	0	1	1
Recovered	1	1	1
Died	20	31	40

death rate and lower transplant rate compared with PD patients.

Those established on peritoneal dialysis

The modality changes in the first 3 years of those patients starting RRT in 1998 and 1999 were analysed in detail for those patients established on peritoneal dialysis on day 90. The characteristics of this cohort of 1,281 patients are listed in Table 4.13.

The sequential annual changes in treatment modality are shown in Table 4.14. After 3 years less than 30% are still alive on peritoneal dialysis and 23% have changed to haemodialysis (defined as changing to haemodialysis for at least 3 months). The rate of change is constant with about 65% of those on PD at the beginning of each year remaining on it at the end and 11% at the beginning of each year changing to HD within the year.

Pure PD technique survival can be analysed by only considering those patients remaining

Table 4.13: General characteristics of PD survival study cohort

	General characteristics of PD survival study cohort (n = 1,281)	
	n	%
Male	780	61
Age 65+	433	34
Diabetic nephropathy	237	19

Table 4.14: 3 year sequential modality changes in patients established on PD 1998–1999

n = 1,281	Sequential modality changes over 3 years for patients established on PD at day 90, 1998–1999		
	End of yr 1	End of yr 2	End of yr 3
	%	%	%
Remains on PD	67	44	29
Changed to HD	11	18	23
Had a transplant	10	17	21
Other	1	2	2
Died	11	19	25

alive and on dialysis for 3 years and censoring transplants, deaths, and “other”. The attrition rate is then related to those whose PD fails and who have to convert to haemodialysis. After such censoring, the pure PD technique survival rates were 86% at the end of the first year, 74% at the end of the second year and 63% by the end of the third year after being established on PD (Table 4.15).

Factors affecting PD technique survival

Demographic

Table 4.16 shows the data on the demographic of the cohort as divided according to age groups, gender, primary diagnosis (diabetics or non-diabetics) and ethnicity. These factors were analysed for possible effect on the 3-year PD technique survival. There were no significant differences observed between the 3 different age groups, between gender, between those with primary diagnosis of diabetic nephropathy and non-diabetic nephropathy and also between the different ethnic groups.

Unit factors

The UK has a higher proportion of dialysis patients using PD than any other country

Table 4.15: Pure PD technique survival – Kaplan-Meier survival analysis

End of:	Overall PD technique survival	
	Survival	95% CI
Year 1	86%	84–88
Year 2	74%	71–77
Year 3	63%	60–66

Table 4.16: Demographic factors and relationship with 3-year PD technique survival

		Number of patients	3yr PD technique survival %	95% CI	p value
Age groups	18-44	319	62	55-69	0.75
	45-64	529	64	59-69	
	65+	433	62	56-68	
Gender	Male	780	64	60-68	0.77
	Female	501	62	57-67	
Primary diagnosis	Non diabetic	1,044	64	60-67	0.63
	Diabetic	237	61	53-68	
Ethnicity	Asian	73 (7%)	63	50-75	0.57
	Black	20 (2%)	66	43-89	
	White	930 (87%)	61	57-65	

within Europe and within the UK this Chapter has again demonstrated wide variations between units in the proportion using PD. There have been suggestions that in some cases this is due to lack of haemodialysis resources leading to inappropriate patients being coerced to accept PD: if this were the case one might expect a higher technique failure rate in those units due to an increased number of patients converting to haemodialysis. To examine this, the cohort was analysed to study the effect of unit preferences for modality, as judged by the percentage of new RRT patients established on PD, on PD technique survival rate. The cohort was also analysed to study the effect on PD technique survival rate of the size of the PD programme within a unit, as there have been suggestions from Europe that small PD programmes in terms of the actual number of patients on PD may have a higher failure rate than larger ones^{1,2}.

In this cohort, there was no significant relationship between the percentage started on PD and the size of the PD programme (Figure 4.10) or the annual number starting RRT (Figure 4.11). Therefore any influence of one factor on PD technique survival should not confound any influence of the other.

A scatter plot of the relationship between the percentage started on PD and PD technique survival (Figure 4.12) shows the data are not normally distributed and are not suitable for simple correlation analysis.

The same is true for the relationship between PD programme size and technique survival (Figure 4.13).

To further study the possible effects of modality preference on PD technique survival, the renal units were divided into three groups

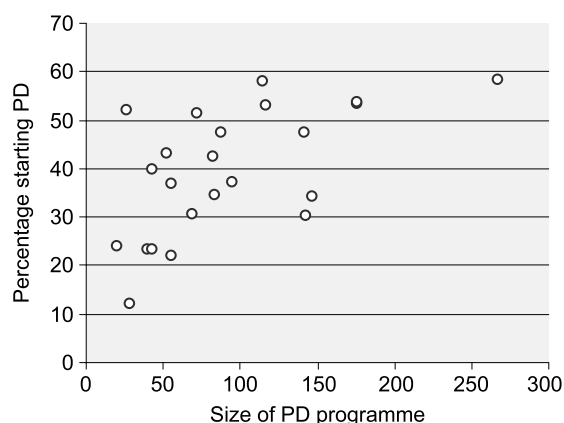


Figure 4.10: Relationship of percentage starting PD and size of PD programme

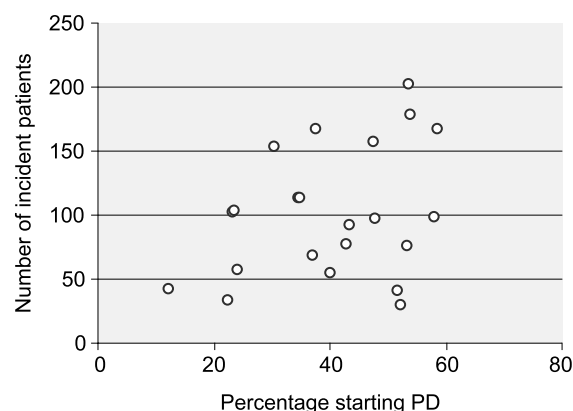


Figure 4.11: Relationship of percentage starting PD and annual number starting RRT

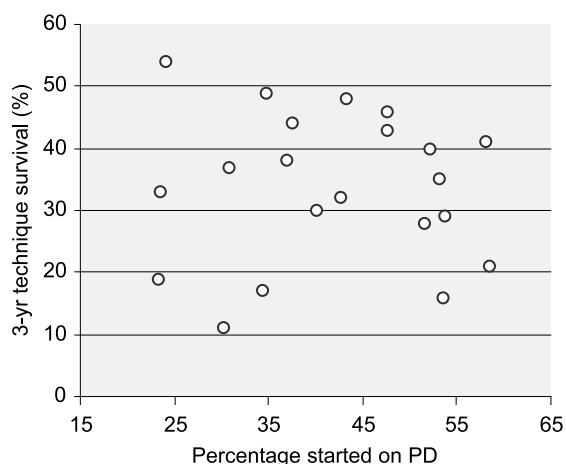


Figure 4.12: Relationship between percentage new RRT patients started on PD and 3 year technique survival

according to the percentage of new incident patients established on PD: low (less than 35% established on PD), intermediate (35–45%) and high (more than 45%) (Table 4.17).

The sequential modality changes showed similar percentages remaining on PD at the end of 3 years at about 30% in all three groups, although there was significant differences in terms of 3-year pure PD technique survival (68% in the high, 54% in the intermediate and 63% in low group; Chi-squared p value = 0.03). There is

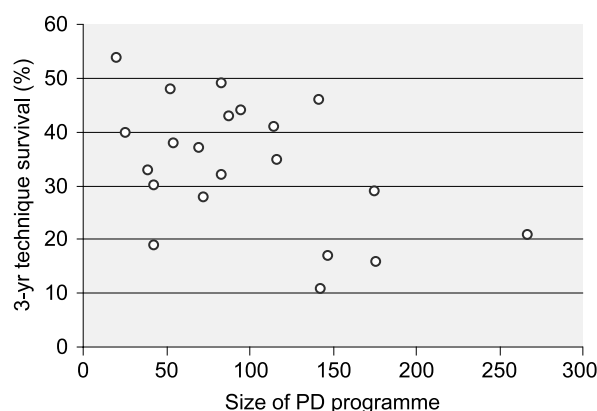


Figure 4.13: Relationship between size of PD programme and 3 year technique survival

therefore no suggestion in these analyses that units who place a large percentage of patients on PD are inappropriately selecting patients for this treatment who will quickly need to convert to haemodialysis, although there is a possibility that conversion to haemodialysis is limited by available facilities.

For the analysis of possible effects of PD programme size on PD technique survival, the units were divided into three groups according to the number of PD patients; large units (more than 100 patients), medium (50–100) and small (less than 50) (Table 4.18).

Table 4.17: Variation in 3 year modality changes and PD technique survival in centres with varying preference from use of PD

Groups	Number of			Sequential modality change at end of			% 3-year PD technique survival (95% CI)
	centres	patients		year 1 %	year 2 %	year 3 %	
High	7	649	Remained on PD	67	43	30	66 (61–71)
			Changed to HD	10	16	21	
			Had a transplant	10	18	20	
			Other	1	2	2	
			Died	12	21	28	
Intermediate	7	340	Remained on PD	68	46	27	54 (48–61)
			Changed to HD	11	21	29	
			Had a transplant	11	16	20	
			Other	0	1	1	
			Died	10	17	23	
Low	9	292	Remained on PD	67	43	29	68 (61–74)
			Changed to HD	12	19	22	
			Had a transplant	12	18	25	
			Other	1	2	2	
			Died	8	18	23	

Table 4.18: Variation in 3 year modality changes and PD technique survival in centres with varying size of PD programme

Groups	Number of			Sequential modality change at end of			% 3-year PD technique survival (95% CI)
	centres	patients		year 1 %	year 2 %	year 3 %	
Large	8	755	Remained on PD	68	44	30	68 (64–72)
			Changed to HD	10	16	20	
			Had a transplant	10	18	22	
			Other	1	2	2	
			Died	11	20	27	
Medium	9	378	Remained on PD	69	45	27	54 (47–60)
			Changed to HD	12	21	29	
			Had a transplant	10	14	19	
			Other	1	2	2	
			Died	8	17	23	
Small	6	148	Remained on PD	59	41	26	63 (53–73)
			Changed to HD	13	20	24	
			Had a transplant	13	19	24	
			Other	1	1	1	
			Died	14	20	26	

At the end of 3 years, the percentages of patients remaining on PD were again similar at around 30%. When analysed for 3-year pure PD technique survival, there were significantly higher survival rates in the large group at 68% compared to the other 2 groups; however the survival rate is higher in the small group (63%) compared to the medium group (54%) (Chi-squared p value 0.002).

From these results, PD technique survival appears to be as good in small programmes as large, although it should be noted that in European terms nearly all the UK programmes are large. The paper suggesting poorer technique survival in smaller units defined small as less than 20, a size virtually never seen in the UK. However units with intermediate usage of PD or of intermediate size seem to have a significantly shorter PD technique survival. The

reasons for this are not known and require further investigation, including studies at unit level of PD staffing and policies.

Survival of incident patients

This is considered in Chapter 15. International comparisons will be found in Chapter 17.

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Chapter 5: All Patients Receiving Renal Replacement Therapy in the United Kingdom in 2003

Summary

- The estimated prevalence of RRT in the UK at the end of 2003 was 632 pmp.
- The annual increase in prevalence in the 27 English and Welsh units participating in the Registry since 2000 is stable at around 5%.
- The Local Authority prevalence varies considerably from 227 to 950 pmp.
- In men the RRT prevalence peaked in the 80–85 year old population at 1,837 pmp and this contrasts with a peak prevalence for women in the 65–74 year age band of 985 pmp.
- Dialysis prevalence peaks in men at 1,755 pmp in the 80–85 year old population and for women at 699 pmp in the 65–74 year age band.
- The median age of all patients on RRT was 56 years: for HD, PD and transplant patients respectively it was 64, 58 and 49 years.
- From 1998–2003 the median age of prevalent patients on HD increased, the median age of those on PD decreased.
- In 2003, 46% of RRT patients in the UK had a functioning transplant, 40% were on HD and 14% on PD.
- The one year prevalent transplant patient and dialysis patient survival was 97.5% and 83.4% respectively.

Introduction

The UK Renal Registry in 2003 covered 73% of England and 100% of Wales. Data on incident and prevalent patients in Scotland were obtained from the Scottish Renal Registry and summary data for Northern Ireland were obtained from the renal unit in Royal Belfast

Hospital which coordinates the renal service provision.

Any assessment of the incidence and characteristics of patients receiving 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. The proportion of the population aged over 65 years was similar in the fully covered population (defined below, ie based on Local Authority (LA) areas whose population was thought to be fully covered by participating units). The proportion from an ethnic minority group was lower in the covered population at 6.7% compared with 8.7% 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 prevalence of RRT 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 South Asian and African-Caribbean ethnic minority populations.

For comparisons between renal units and between local areas fully covered by the Renal Registry, the data from the Registry are fully valid.

Analyses of paediatric data, which are not included in this Chapter, can be found in Chapter 13.

All adult patients receiving Renal Replacement Therapy in the UK, 2003

It is estimated there were over 37,000 adult patients receiving RRT in the whole of the UK for the year 2003, a total population prevalence of 632 pmp (Table 5.1). The prevalence was calculated using an overall total for England

Table 5.1: Prevalence of renal replacement therapy in the UK 2002 and 2003**2003**

	England	Wales	Scotland	N. Ireland	UK
No of renal units	36/53	5	10	5	73
Total RRT patients	22,356 (30,640)*	2,087	3,459	1,202	37,388
Rate pmp (95% CI)	621 (614–628)	718 (688–748)	692 (669–715)	707 (669–746)	632 (626–639)
In Registry centres:					
Haemodialysis	8,971 (40%)	788 (38%)	1,471 (42%)	552 (46%)	11,782 (40%)
Peritoneal dialysis	3,135 (14%)	355 (17%)	387 (11%)	85 (7%)	3,962 (14%)
Transplants	10,379 (46%)	815 (45%)	1,604 (46%)	565 (47%)	13,363 (46%)
% dialysis pts on HD	74%	69%	79%	87%	75%

*Extrapolated – is an underestimate due to under-representation of ethnic minorities in the areas covered by the English units participating in the Registry compared with the population as a whole.

2002

	England	Wales	Scotland	N. Ireland	UK
No of renal units	52	5	10	4	71
Total RRT patients	30,498	2,006	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)

derived from the data available for the renal units in England participating in the Registry's activity which cover an estimated 36.2 million people. As indicated above this is an underestimate, probably by 3–5% and neither this nor the total UK figure can be compared with the 2002 figure which was the result of the national survey which had a 100% response.

The percentage increase in prevalence from 2002 to 2003 was 4.0% in Wales, 1.1% in Scotland and 7.6% in Northern Ireland.

Data returned directly to the UK Renal Registry – England and Wales

Prevalent patients on 31/12/2003

The number of units participating in the UK Renal Registry activity has increased to 41, providing data for 24,468 prevalent RRT patients in England and Wales. The number of prevalent patients and distribution of treatments used in each of these units 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 and some renal units do not follow up any transplanted patients. Thus units with a transplant centre tend to have a higher proportion of transplant patients under follow up compared with units without a transplant centre. The Registry does not yet include two of the larger transplant centres, Queen Elizabeth Hospital in Birmingham (to be included in the next report) and the Manchester Royal Infirmary.

Changes in Prevalence 2000–2003

For the 27 units which have been participating in Registry activity since 2000, the prevalent number continues to increase year by year (Table 5.3). The increase averages 5% per year. For individual centres, the changes in total numbers are shown in Table 5.4.

Local Authority Prevalence

The prevalence of RRT in those Local Authorities with complete coverage in 2003 is shown in Table 5.5.

Table 5.2: Prevalent RRT patients in each unit, 31 December 2003

Centre	Total RRT	% HD	% PD	% transplant
Oxford*	1,398	28	11	62
Liverpool*	1,253	31	11	58
Leeds*	1,227	37	9	54
Guys*	1,200	30	11	59
Cardiff*	1,153	30	14	56
Leicester*	1,107	37	19	44
H&CX*	1,088	47	18	35
Sheffield*	1,087	45	16	39
Bristol*	1,060	36	7	57
Portsmouth*	1,059	31	10	59
Carshalton*	891	40	22	39
Nottm*	814	36	18	46
Newcastle*	783	27	6	67
Cambridge*	746	30	13	56
Preston	742	40	17	43
ManWst	605	35	23	42
Coventry*	581	40	14	46
Kings	574	41	16	43
Stevenage	568	63	10	27
Middlbr	552	43	4	53
Exeter	531	41	16	43
Hull	524	49	12	39
Heartlands	517	57	5	37
Swansea	438	50	23	27
Wolve	404	60	17	23
Plymouth*	390	34	14	52
Bradford	313	46	17	36
Derby	279	75	25	N/A
Sunderland	263	41	7	52
Gloucester	247	50	14	36
Wordsley	247	39	21	40
Ipswich	241	34	27	38
Truro	236	56	15	30
Reading	229	59	36	5
Wrexham	205	51	24	25
York	197	57	18	24
Southend	194	60	24	16
Carlisle	176	33	18	49
Wirral	162	88	12	N/A
Bangor	94	72	28	N/A
Clwyd	68	81	19	N/A

*Transplant centres

Table 5.4: Changes in number on RRT in each centre 2000–2003

Centre	Total number of RRT patients			
	2000	2001	2002	2003
Bangor			89	94
Bradford		252	280	313
Bristol	909	951	993	1,060
Cambridge		651	714	746
Carlisle	157	161	170	176
Carshalton	672	697	789	891
Clwyd			87	68
Coventry	519	552	571	581
Cardiff	970	1,047	1,113	1,153
Derby				279
Exeter	444	466	517	531
Gloucester	237	197	212	247
Guys	1,130	1,157	1,189	1,200
H&CX			1,081	1,089
Heartlands	455	477	484	517
Hull	437	459	519	524
Ipswich			239	241
Kings			572	577
Leeds	1,141	1,155	1,196	1,227
Leicester	976	1,030	1,071	1,107
Liverpool		970	1,162	1,253
ManWst				617
Middlbr	447	441	521	552
Newcastle			654	783
Nottm	787	831	812	814
Oxford	1,241	1,311	1,369	1,398
Plymouth	412	398	395	390
Portsmouth		1,016	1,037	1,059
Preston	529	550	594	742
Reading	179	206	202	229
Sheffield	868	944	1,026	1,087
Stevenage	459	462	528	572
Southend	160	165	176	194
Sunderland	245	237	255	263
Swansea	313	394	386	438
Truro		182	212	236
Wirral			140	162
Wolve	328	351	384	404
Wordsley	254	245	236	247
Wrexham	246	225	212	205
York	120	137	172	197
Total	14,635	18,317	22,359	24,463

Table 5.3: Number of patients in the same 27 centres on RRT, 2000–2003

End year	2000	2001	2002	2003
Total number of patients	14,635	15,246	16,092	16,946
% increase in year	N/A	5.5	4.2	5.5
Cumulative 3 year % increase				15.8

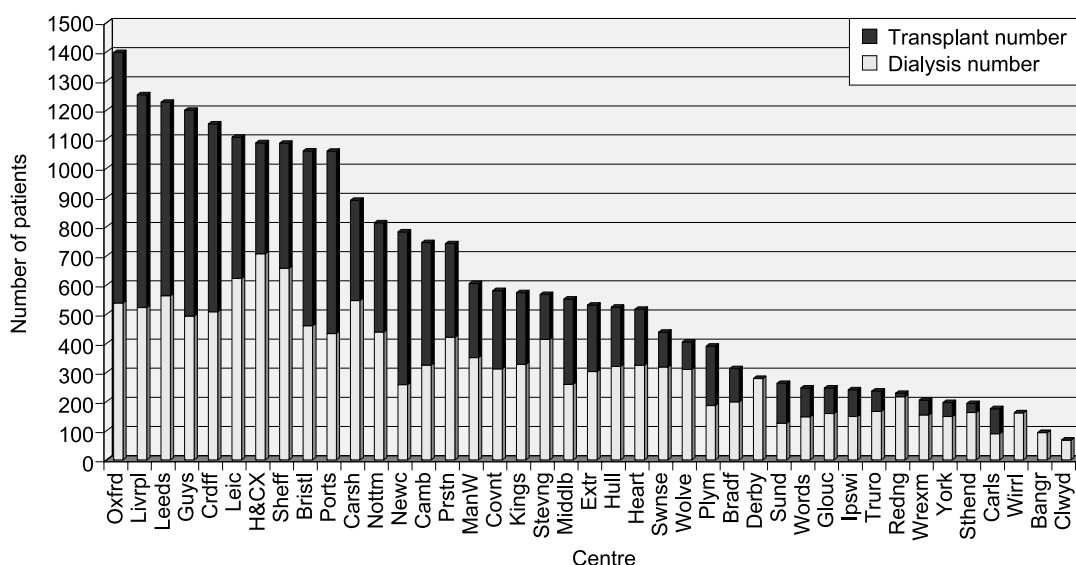


Figure 5.1: Distribution of dialysis and transplant patients in centres in England and Wales

Table 5.5: Local Authority prevalences and adjusted prevalence ratios 2003

Areas with a significantly high prevalence ratio have a grey infill.
 Areas with a significantly low prevalence ratio are in italics.

UK Area	SHA	Name	Tot Pop	2003				Ethnicity %
				Ratio	L 95% CL	U 95% CL	Crude rate pmp	
North East	County Durham & Tees Valley	Darlington	97,838	0.81	0.61	1.07	490.61	2.1
		<i>Durham</i>	493,469	0.77	0.68	0.88	476.22	1.0
		Hartlepool	88,610	0.97	0.73	1.27	575.56	1.2
		<i>Middlesbrough</i>	134,855	0.57	0.42	0.76	318.86	6.3
		<i>Redcar and Cleveland</i>	139,132	0.57	0.43	0.76	352.18	1.1
		<i>Stockton-on-Tees</i>	178,408	0.46	0.34	0.61	269.05	2.8
	Northumberland, Tyne & Wear	Gateshead	191,151	1.08	0.91	1.29	669.63	1.6
		Newcastle upon Tyne	259,536	0.98	0.83	1.16	558.69	6.9
		North Tyneside	191,658	1.01	0.84	1.21	626.12	1.9
		Northumberland	307,190	0.94	0.82	1.09	605.49	1.0
		South Tyneside	152,785	0.93	0.75	1.15	569.43	2.7
Sunderland	280,807	1.03	0.89	1.19	608.96	1.9		
North West	Cheshire & Merseyside	Halton	118,209	1.02	0.80	1.29	583.71	1.2
		Knowsley	150,459	1.26	1.04	1.52	711.16	1.6
		Liverpool	439,471	1.21	1.08	1.35	680.36	5.7
		Sefton	282,958	0.91	0.78	1.06	565.45	1.6
		St. Helens	176,843	0.85	0.69	1.04	508.93	1.2
		Warrington	191,080	0.90	0.74	1.10	533.81	2.1
		Wirral	312,293	1.11	0.97	1.27	678.85	1.7
	Cumbria and Lancashire	Blackburn with Darwen	137,470	1.07	0.85	1.33	567.40	22.1
		Blackpool	142,283	0.80	0.64	1.01	513.06	1.6
		<i>Cumbria</i>	487,607	0.83	0.74	0.94	531.17	0.7
		<i>Lancashire</i>	1,134,975	0.84	0.77	0.91	505.74	5.3
	Greater Manchester	<i>Bolton</i>	261,037	0.80	0.67	0.96	463.54	11.0
		<i>Bury</i>	180,607	0.39	0.29	0.53	227.01	6.1
		<i>Oldham</i>	217,276	0.55	0.43	0.69	308.36	13.9
		<i>Rochdale</i>	205,357	0.64	0.51	0.80	360.35	11.4
		<i>Salford</i>	216,105	0.76	0.63	0.93	444.23	3.9
		<i>Wigan</i>	301,415	0.65	0.54	0.78	388.17	1.3

Table 5.5: (continued)

UK Area	SHA	Name	Tot Pop	2003				Ethnicity %
				Ratio	L 95% CL	U 95% CL	Crude rate pmp	
Yorkshire and the Humber	North and East Yorkshire and Northern Lincolnshire	East Riding of Yorkshire	314,113	0.91	0.78	1.05	585.78	1.2
		Kingston upon Hull, City of	243,588	1.00	0.84	1.18	562.43	2.3
		North East Lincolnshire	157,981	0.99	0.81	1.22	588.68	1.4
		North Lincolnshire	152,848	0.96	0.78	1.18	595.36	2.5
		<i>North Yorkshire</i>	569,660	0.74	0.66	0.84	470.46	1.1
		York	181,096	1.08	0.90	1.29	646.07	2.2
	South Yorkshire	Barnsley	218,063	1.22	1.04	1.42	738.32	0.9
		Doncaster	286,865	1.11	0.97	1.28	672.79	2.3
		Rotherham	248,175	1.20	1.03	1.39	717.24	3.1
		Sheffield	513,234	1.07	0.96	1.19	623.50	8.8
	West Yorkshire	Bradford	467,664	1.34	1.21	1.49	735.57	21.7
		Calderdale	192,405	1.14	0.96	1.35	670.46	7.0
		Kirklees	388,567	1.25	1.11	1.40	712.88	14.4
		Leeds	715,403	1.06	0.97	1.17	602.46	8.2
Wakefield		315,172	0.90	0.77	1.04	536.22	2.3	
East Midlands	Leicestershire, Northamptonshire and Rutland	Leicester	279,920	1.82	1.61	2.05	950.27	36.1
		Leicestershire	609,578	0.97	0.87	1.07	590.57	5.3
		Northamptonshire	629,676	0.93	0.83	1.03	541.55	4.9
		Rutland	34,563	1.02	0.67	1.55	636.52	1.9
	Trent	Derby	221,709	1.32	1.14	1.54	762.26	12.6
		<i>Derbyshire</i>	734,585	0.88	0.80	0.97	549.97	1.5
		<i>Lincolnshire</i>	646,644	0.81	0.72	0.90	518.06	1.3
		Nottingham	266,988	1.34	1.17	1.55	715.39	15.1
Nottinghamshire	748,508	1.01	0.92	1.11	623.91	2.6		
West Midlands	Birmingham and the Black Country	<i>Dudley</i>	305,153	0.80	0.68	0.94	494.83	6.3
		Solihull	199,515	0.91	0.76	1.10	561.36	5.4
		Walsall	253,498	0.84	0.71	1.00	500.99	13.6
		Wolverhampton	236,582	1.27	1.10	1.47	748.15	22.2
	Coventry, Warwickshire, Herefordshire & Worcestershire	Coventry	300,849	1.38	1.21	1.57	771.15	16.0
Warwickshire	505,858	1.08	0.97	1.20	666.19	4.4		
East of England	Bedfordshire and Hertfordshire	Bedfordshire	381,572	0.97	0.85	1.11	566.08	6.7
		<i>Hertfordshire</i>	1,033,978	0.61	0.56	0.68	361.71	6.3
		Luton	184,373	1.26	1.05	1.50	667.13	28.1
	Essex	Southend-on-Sea	160,259	0.94	0.77	1.15	567.83	4.2
	Norfolk, Suffolk & Cambridgeshire	Cambridgeshire	552,659	0.89	0.79	1.00	524.74	4.1
		Peterborough	156,061	1.01	0.82	1.25	570.29	10.3
	North West London	Ealing	300,948	1.55	1.37	1.76	830.71	41.3
		Hammersmith and Fulham	165,244	1.56	1.32	1.85	810.92	22.2
	South East London	Bexley	218,307	1.22	1.04	1.43	719.17	8.6
		Bromley	295,532	0.97	0.84	1.13	585.39	8.4
		Greenwich	214,404	1.04	0.87	1.25	550.36	22.9
		Lambeth	266,169	1.37	1.18	1.58	676.26	37.6
Lewisham		248,923	1.64	1.44	1.88	843.63	34.1	
Southwark		244,866	1.74	1.52	1.99	878.03	37.0	
South West London	Croydon	330,588	1.14	1.00	1.31	629.18	29.8	

Table 5.5: (continued)

UK Area	SHA	Name	Tot Pop	2003				Ethnicity %
				Ratio	L 95% CL	U 95% CL	Crude rate pmp	
South East	Hampshire and Isle of Wight	<i>Hampshire</i>	1,240,102	0.79	0.73	0.86	480.61	2.2
		<i>Isle of Wight</i>	132,731	0.71	0.56	0.91	474.64	1.3
		Portsmouth	186,700	1.28	1.08	1.51	712.37	5.3
		Southampton	217,444	0.97	0.81	1.17	528.87	7.6
	Thames Valley	Buckinghamshire	479,026	1.00	0.89	1.12	592.87	7.9
		Milton Keynes	207,057	1.09	0.91	1.30	579.55	9.3
		Oxfordshire	605,489	1.13	1.02	1.25	654.02	4.9
		Reading	143,096	1.24	1.01	1.51	656.90	13.2
		Slough	119,064	1.76	1.46	2.13	923.87	36.3
		West Berkshire	144,485	0.93	0.75	1.16	546.77	2.6
		Wokingham	150,231	0.92	0.74	1.15	532.51	6.1
	South West	Avon, Gloucestershire and Wiltshire	<i>Bath and North East Somerset</i>	169,040	0.74	0.60	0.93	455.51
Bristol, City of			380,616	1.47	1.32	1.64	817.10	8.2
Gloucestershire			564,559	0.89	0.80	1.00	549.10	2.8
North Somerset			188,564	1.13	0.95	1.33	726.54	1.4
South Gloucestershire			245,641	1.12	0.96	1.31	667.64	2.4
Swindon			180,051	0.88	0.72	1.08	505.41	4.8
<i>Wiltshire</i>			432,972	0.74	0.65	0.86	452.69	1.6
Dorset & Somerset		Somerset	498,095	0.92	0.82	1.03	584.23	1.2
South West Peninsula		Cornwall and Isles of Scilly	501,267	1.09	0.98	1.21	718.18	1.0
		<i>Devon</i>	704,491	0.87	0.79	0.96	569.21	1.1
		Plymouth	240,722	1.11	0.95	1.30	652.20	1.6
		Torbay	129,706	0.98	0.79	1.22	647.62	1.2
Wales		Bro Taf	Cardiff	305,353	1.27	1.11	1.46	694.28
	Merthyr Tydfil		55,979	1.59	1.22	2.09	946.78	1.0
	Rhondda, Cynon, Taff		231,947	1.27	1.10	1.48	754.48	1.2
	The Vale of Glamorgan		119,292	1.13	0.91	1.41	687.39	2.2
	Dyfed Powys	Carmarthenshire	172,842	1.20	1.01	1.42	769.49	0.9
		Ceredigion	74,941	1.00	0.75	1.33	627.16	1.4
		Pembrokeshire	114,131	0.89	0.70	1.13	569.52	0.9
		<i>Powys</i>	126,353	0.43	0.31	0.60	284.92	0.9
	Gwent	Blaenau Gwent	70,064	1.23	0.94	1.62	742.18	0.8
		Caerphilly	169,519	1.13	0.94	1.36	666.59	0.9
		Monmouthshire	84,885	1.18	0.92	1.50	753.96	1.1
		Newport	137,012	1.31	1.08	1.59	766.36	4.8
		Torfaen	90,949	1.29	1.02	1.63	780.66	0.9
	Morgannwg	Bridgend	128,645	1.18	0.96	1.44	715.15	1.4
		Neath Port Talbot	134,468	1.24	1.02	1.50	773.42	1.1
		Swansea	223,300	1.38	1.20	1.60	850.87	2.2
	North Wales	Conwy	109,596	1.02	0.81	1.28	675.21	1.1
		Denbighshire	93,065	0.95	0.73	1.23	601.73	1.2
		Flintshire	148,594	1.22	1.01	1.48	733.54	0.8
		Gwynedd	116,843	1.35	1.11	1.64	838.73	1.2
Isle of Anglesey		66,829	1.05	0.78	1.40	673.36	0.7	
Wrexham		128,476	1.44	1.20	1.74	863.97	1.1	

Standardised prevalence ratios

Methods

The methods of calculating the standardised rate ratio are described in detail in Appendix D.

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

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

Results

The standardised prevalence rate ratios for Local Authorities with complete coverage by the Registry for the year 2003 are shown in Table 5.5. The prevalence of RRT is low and authorities with small populations have wide confidence limits for the prevalence such that the interpretation of an individual year is extremely difficult. As the prevalence is progressively rising a combined three-year figure has not been shown, as this may be misleading.

Significance of results in small populations

There is substantial variation in the crude LA area prevalences from 227 to 950 pmp in 2003. Relatively small numbers of cases mean that the confidence limits are often quite wide for most areas so that the standardised prevalence ratios usually include one. Some areas have significantly high ratios. These are often areas with a

high ethnic minority population and/or a socially deprived population, factors which were shown to be important in the 2003 Registry report. Good examples where both these factors are likely to be important are Wolverhampton, Leicester and Lewisham. Ethnicity is probably a major factor in Slough, but is not a factor in Merthyr Tydfil or Liverpool where social deprivation may play a major role. However the high prevalence in places like Bristol and Oxfordshire cannot be related to either of these factors where the catchment areas are relatively affluent with a low proportion of ethnic minorities. There are still unexplained reasons why these areas have a high prevalence.

The ethnic influence on prevalence is increased by the relatively greater survival of patients from the African-Caribbean and South Asian groups.

Groups such as primary care trusts, which represent relatively small populations of 30,000 to 250,000, often wish to assess their performance. When assessing a relatively infrequent occurrence such as prevalence of RRT in such small populations there are wide confidence intervals for any observed frequency. To enable assessment of whether an observed prevalence is likely to be significantly different from the national average, Figures 5.2 and 5.3 have been included in the report. From these, for any size of population (X axis) the upper and lower 1 in 20 confidence intervals around the national average prevalence (dotted lines) can be read from the Y axis. Any observed prevalence for renal failure must be outside these limits for the given population to be statistically significantly different from the national average. Thus for a population of 50,000 the observed prevalence would have to be outside the limits of 400 per million population to 850 per million population. However for a population of 500,000 these limits are from 560 per million population to 690 per million population.

Age

The overall age profile for prevalent patients is shown in Figure 5.4.

The prevalence rates by age band have been calculated from the Local Authority populations covered by the Registry. As described

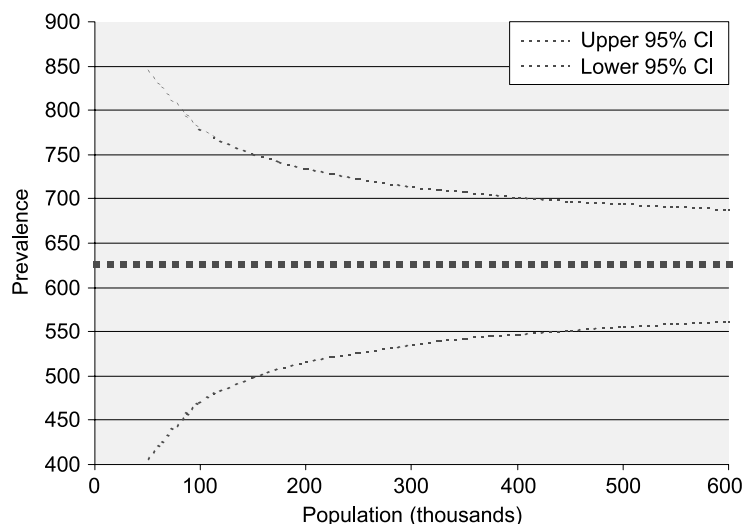


Figure 5.2: 95% confidence limits for prevalence of 625 pmp for population size 50,000–600,000

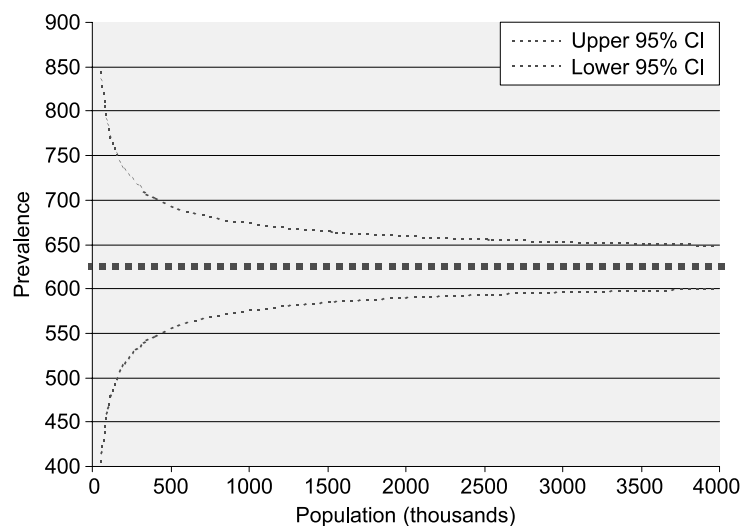


Figure 5.3: 95% confidence limits for prevalence of 625 pmp for population size 50,000–4,000,000

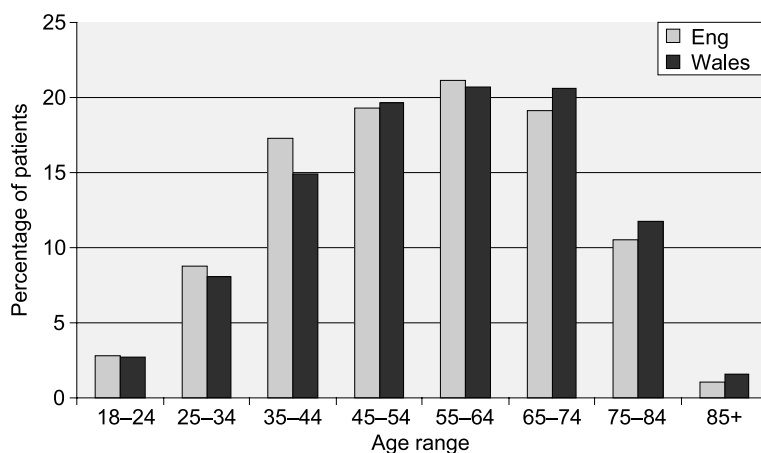


Figure 5.4: Age profile of prevalent patients

above, the age distribution for each LA has been derived from the 2001 census data. Figure 5.5 shows the prevalence rate pmp by age and gender on 31/12/2003 for all the renal replace-

ment therapy population. In men the RRT prevalence peaked in the 80–85 year old population at 1,837 pmp and this contrasts with a peak prevalence for women in the 65–74 year age band

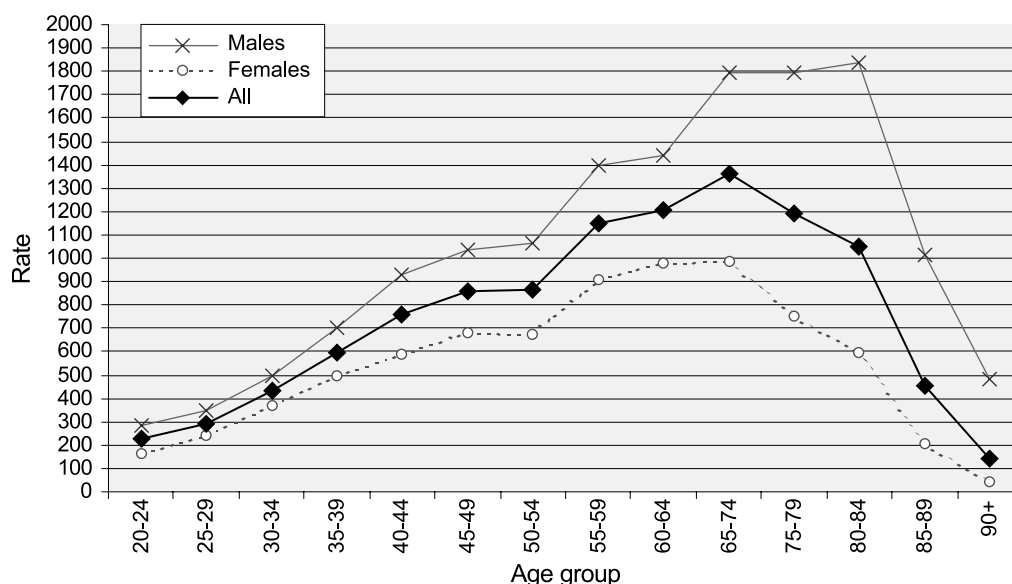


Figure 5.5: Prevalence rate pmp of RRT by age and gender on 31/12/2003

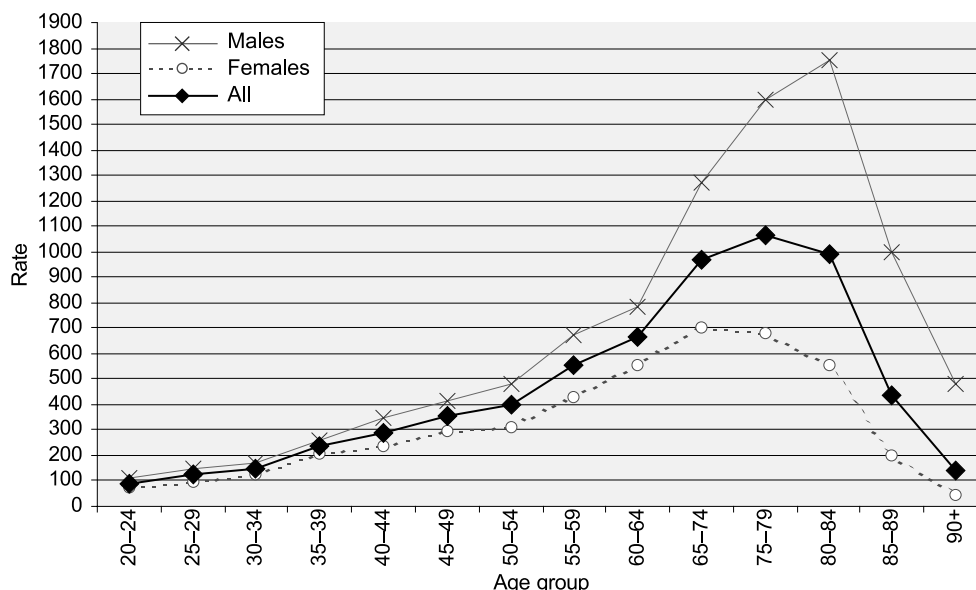


Figure 5.6: Prevalence rate pmp of dialysis patients by age and gender on 31/12/2003

of 985 pmp. Similarly dialysis prevalence peaks in men and women in these same age groups at 1,755 pmp and 699 pmp respectively (Figure 5.6).

Figure 5.7 shows the changes in renal replacement therapy prevalence rates during the period 2001–2003. Prevalence rates are increasing annually across all age bands with the largest increases in patient prevalence rates in the 65–85 year age bands.

The median age for all prevalent RRT patients has increased from 54.3 years in 1998 to 56.0 years in 2003. As expected, the median age is lowest for the transplant patients,

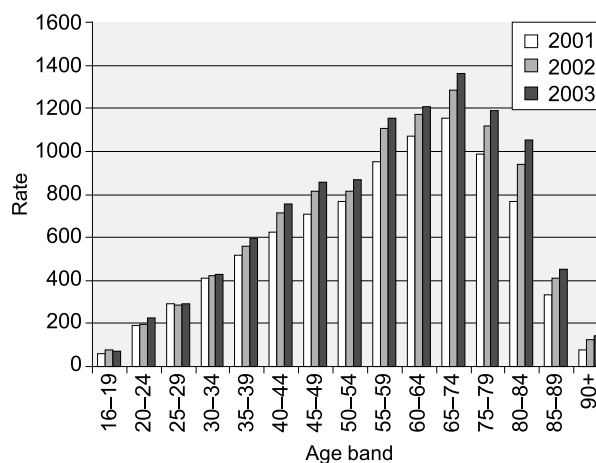


Figure 5.7: Change in prevalence rate pmp of RRT by age 2001–2003

Table 5.6: Median age of treatment modalities for England and Wales 1998–2003

	Transplants	PD	HD	All
Median age 2003	49.3	58.0	64.3	56.0
Interquartile range	39–60	45–69	50–74	43–68
Range between units	40–57	49–65	56–72	51–65
Median age 2002	49.6	58.3	64.5	55.9
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

followed by PD patients, with the HD patients having the highest median age. The median age for patients on PD has shown a trend to decrease whereas the median age for haemodialysis patients has increased from 62.6 years to 64.3 years (Table 5.6).

The wide variation in the median age of dialysis patients between each unit is shown in Figure 5.8. This may be due to differences in the demography of the local population, referral and acceptance policies, survival rates and facilities for service provision.

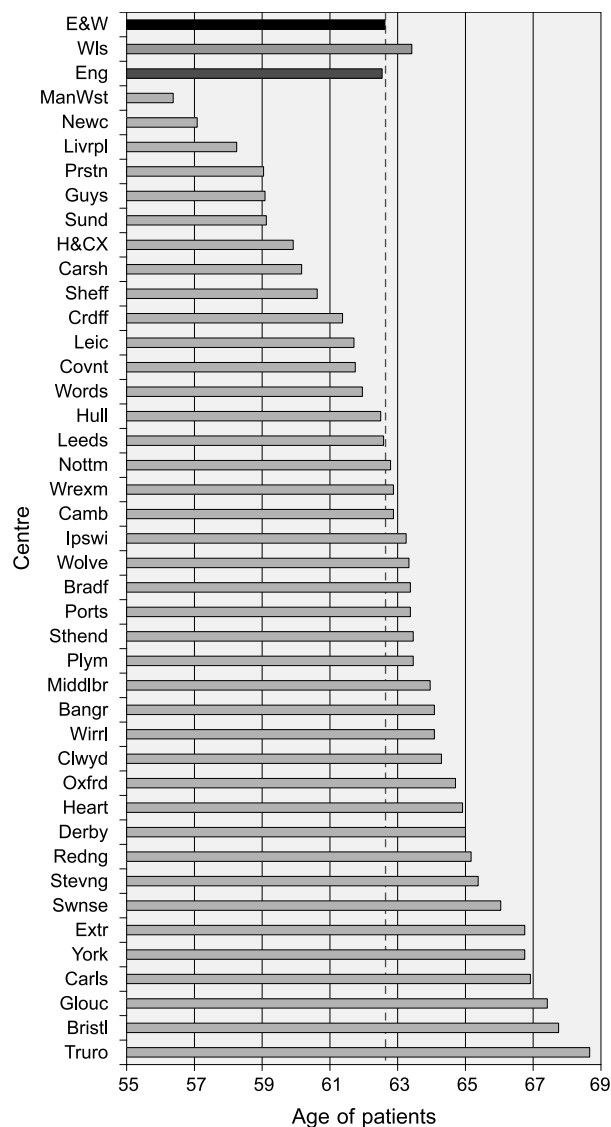


Figure 5.8: Median age of RRT patients on 31/12/2003 by centre

Gender

Of the prevalent patients 61% were male, this male preponderance was evident across all age groups (Figure 5.9). The difference in rates by gender per million population are shown above in Figure 5.5.

Ethnicity

There has been no marked change in the provision of ethnicity data in 2003 compared to 2002. Overall data return improved slightly from 77.5% in 2002 to 79.7% in 2003 whilst the number of centres returning at least 90% of ethnicity data has decreased from 22 to 21 (Table 5.7). This is disappointing as it was hoped that units would devise systems to

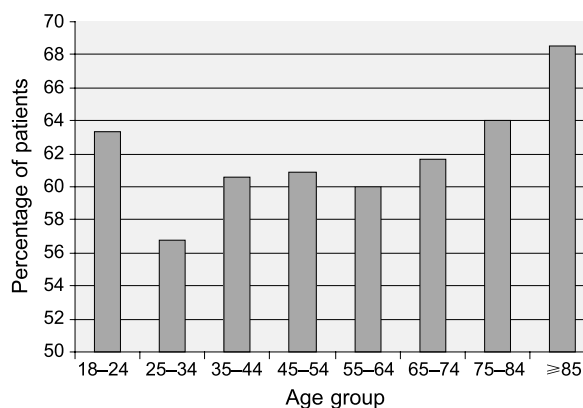


Figure 5.9: Percentage of male patients according to age

Table 5.7: Ethnicity of prevalent patients in each centre, 2003

Centre	% Return	% White	% Black	% Asian	% Chinese	% Other
Gloucester	100.0	98.4	0.8	0.0	0.8	0.0
Sheffield	100.0	93.4	1.7	3.5	0.8	0.6
H&CX	100.0	34.1	11.9	20.1	0.9	33.1
Stevenage	99.8	82.1	4.3	13.2	0.4	0.0
Heartlands	99.6	72.0	6.4	19.2	0.6	1.7
Wordsley	99.6	90.7	1.2	7.3	0.8	0.0
Newcastle	99.5	96.7	0.3	2.6	0.5	0.0
Wolve	99.0	78.1	6.3	15.1	0.5	0.0
Swansea	98.4	99.1	0.0	0.7	0.0	0.2
Bristol	98.2	93.9	2.9	2.0	0.3	0.9
Reading	97.4	69.5	12.6	16.1	0.4	1.3
Leicester	97.1	80.3	2.4	16.0	0.3	1.0
Carlisle	96.0	99.4	0.0	0.6	0.0	0.0
Nottm	95.7	88.4	4.7	5.8	0.0	1.0
Ports	95.7	96.9	0.5	2.1	0.3	0.2
Plymouth	95.6	96.0	2.7	0.5	0.3	0.5
Sunderland	94.7	98.4	0.4	0.4	0.4	0.4
Preston	94.6	86.7	1.1	11.4	0.0	0.7
Liverpool	92.9	97.0	1.2	0.5	0.9	0.4
York	91.9	98.3	0.0	1.1	0.0	0.6
Middlbr	90.2	96.0	0.0	3.2	0.8	0.0
Coventry	89.8	82.0	3.1	14.8	0.2	0.0
Guys	88.7	79.9	14.8	3.9	1.3	0.1
Derby	85.3	89.5	3.0	6.3	0.4	0.8
Hull	82.8	98.6	0.2	0.2	0.5	0.5
ManWst	81.4	89.7	1.0	8.7	0.0	0.6
Carshalton	79.0	72.3	9.2	9.4	1.0	8.1
Exeter	77.2	98.5	0.7	0.2	0.2	0.2
Bradford	71.9	64.0	1.8	33.3	0.0	0.9
Leeds	70.7	83.2	3.7	12.6	0.0	0.6
Southend	70.6	94.1	3.7	2.2	0.0	0.0
Wrexham	57.1	99.1	0.0	0.0	0.9	0.0
Bangor	56.4	100.0	0.0	0.0	0.0	0.0
Wirral	51.2	95.2	1.2	1.2	–	2.4
Truro	44.5	99.0	1.0	0.0	0.0	0.0
Clwyd	41.2	92.9	3.6	0.0	3.6	0.0
Cambridge	40.6	96.0	0.7	3.0	0.0	0.3
Oxford	34.9	91.7	1.7	5.6	0.8	0.2
Cardiff	30.4	96.0	1.1	2.0	0.3	0.6
Ipswich	6.2	92.9	0.0	0.0	0.0	7.1
Kings	4.5	69.6	17.4	13.0	0.0	0.0
E&W	79.7	86.3	3.6	7.2	0.5	2.5

provide this information, at least for new patients, in which case there should be a steady improvement in prevalent patient data. The available data are unlikely to be truly represen-

tative but they do indicate the wide variation across the country. Those units with a high local ethnic minority population will have an expansion rate much higher than average.

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

Primary Diagnosis	% all patients	Inter unit range %	% age <65	% age >65	M:F ratio
Aetiology unc./ glomer. NP*	23.1	5.5–74.1	21.3	29.0	1.6
Glomerulonephritis**	15.5	4.4–21.6	17.8	7.6	2.3
Pyelonephritis	12.9	4.3–19.5	13.8	9.8	1.1
Diabetes	11.8	4.1–23.2	11.5	13.3	1.6
Polycystic kidney	9.1	3.2–13.2	10.4	4.7	1.1
Hypertension	6.1	0.7–16.3	5.7	7.8	2.3
Renal vascular disease	3.6	0.5–10.3	1.7	10.9	2.0
Other	13.7	4.9–24.7	14.4	10.7	1.4
Not sent	4.2	0.2–37.3	3.5	6.2	1.8

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

**Biopsy proven.

Primary Renal Disease

Table 5.8 shows detail of the primary renal disease based on the original EDTA coding. Data completion ranged from 62.7% to 99.8%. There has been no difference in the pattern of diagnoses compared with last year. The most common identifiable diagnosis for those under 65 was glomerulonephritis (17.8%) and for those 65 and over diabetes (13.3%). Overall 11.8% 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.

Diabetes

Tables 5.9a and 5.9b show the median age and modalities of treatment for diabetic patients compared with other patients. The data are similar to previous years' data. For patients under 65 years old, only 18% of those with Type II diabetes has a functioning transplant compared to 43% in those with Type I diabetes and 60% in non-diabetics. For those over 65 years old, Type II diabetics again have the lowest percentage with functioning transplants at 7% compared to 9% in Type I diabetics and 24% in non-diabetics.

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

	Type I	Type II	All diabetes	Non-diabetics
Number	1,866	1,019	2,885	20,562
M:F ratio	1.52	1.60	1.55	1.55
Median age on 31.12.03	51	66	57	56
Median age started ESRF	46	63	53	47
Median years on RRT	3.2	2.0	2.7	5.7
% HD	43	67	51	38
% PD	20	22	21	13
% transplant	37	12	28	49

Table 5.9b: Age relationships of type of diabetes and modality

	Age less than 65			Age 65 or more		
	Type I	Type II	Non-diabetics	Type I	Type II	Non-diabetics
Total number	1,493	459	14,313	372	559	6,231
% HD	36	61	28	73	71	61
% PD	21	21	12	17	22	15
% transplant	43	18	60	9	7	24

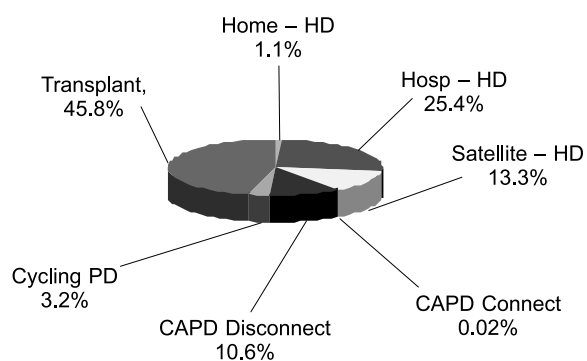


Figure 5.10: Percentage of patients on each treatment modality, 31 December 2003

Modalities of Treatment

Figure 5.10 shows the breakdown according to treatment modalities. Overall the most common treatment modality is transplantation (46%). The variations in patterns of treatment with age are shown in Figure 5.11. Transplantation is the predominant treatment modality in patients less than 65 years old whilst haemodialysis is in those 65 or older.

Of dialysis patients, haemodialysis is the main modality across all age groups, ranging from 65% in the 18–24 age group to 89% in the 85+ age group (Table 5.10).

Haemodialysis

The proportion of dialysis patients treated by haemodialysis varied widely between the units (Figure 5.12) and in almost every unit was higher in the elderly (Figure 5.13). The overall proportion of patients on HD in satellite units

Table 5.10: Dialysis modality percentages in different age groups

Age group	HD%	PD%
18–24	65	35
25–34	67	33
35–44	66	34
45–54	70	30
55–64	71	29
65–74	76	24
75–84	84	16
85+	89	11
All	74	26

was 33.6% (Figure 5.14) with wide variations between units. Despite recent NICE advice¹, very few units had significant home HD programmes (Figure 5.14).

Peritoneal dialysis

For units in the Registry, the percentages of patients on each of the main types of PD are shown in Figure 5.15. In a few units, over 50% of PD patients are using the automated PD technique.

Change in treatment modality 1997–2003

Although the figures from each year are not strictly comparable as the number of units contributing to the Registry has gradually increased year on year, Table 5.11 and Figure 5.16 suggest a trend from 1997 to 2003 towards an increasing number and proportion of patients

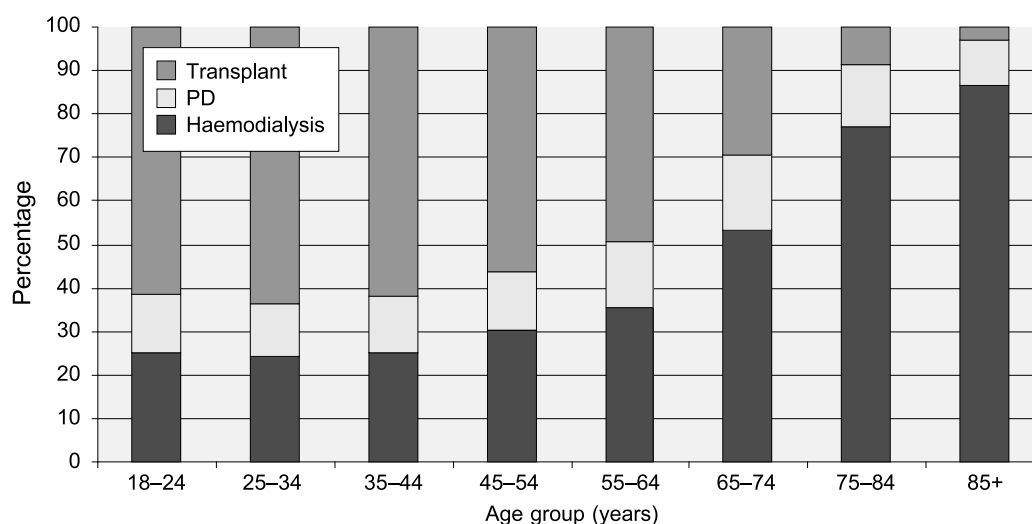


Figure 5.11: Patients on each modality in different age groups

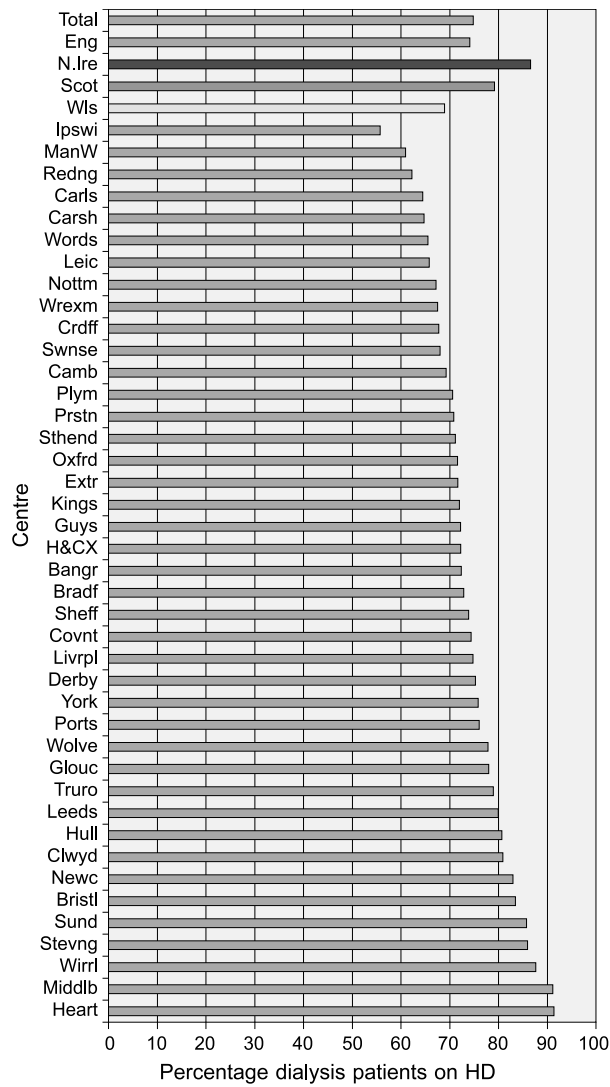


Figure 5.12: Proportion of patients on haemodialysis in each centre

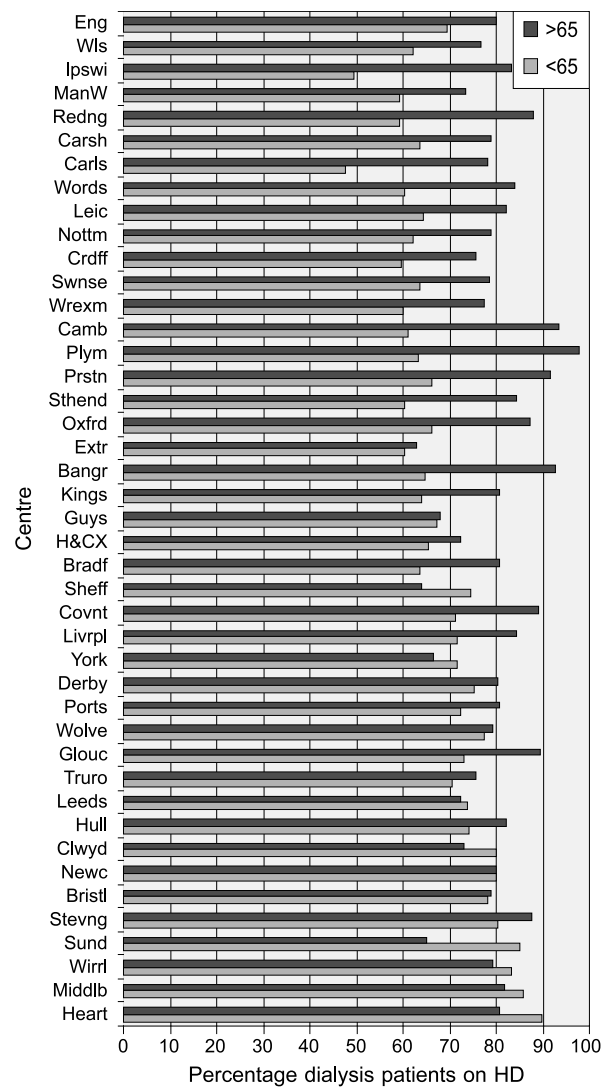


Figure 5.13: Proportion of older and younger patients on haemodialysis in each centre

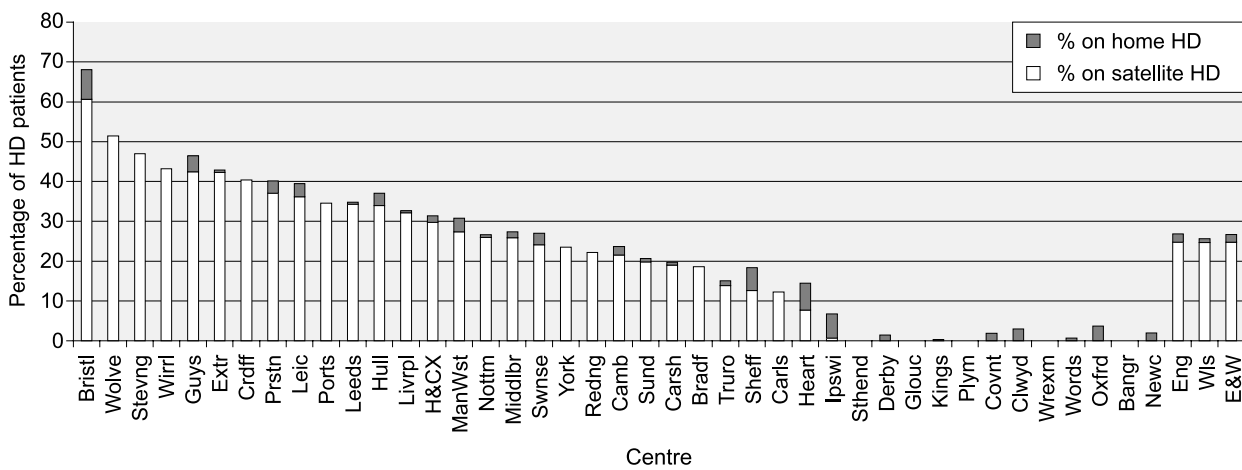


Figure 5.14: Percentage of HD patients treated at home and in satellite units

on haemodialysis (especially in satellite units). Whilst absolute numbers may not be falling, there is a decreasing proportion of peritoneal dialysis and transplant patients. The proportion

of patients using home haemodialysis remains very low and shows no recent rise despite the NICE guidance¹ (Table 5.11, Figure 5.17): the proportion on automated PD is fairly static.

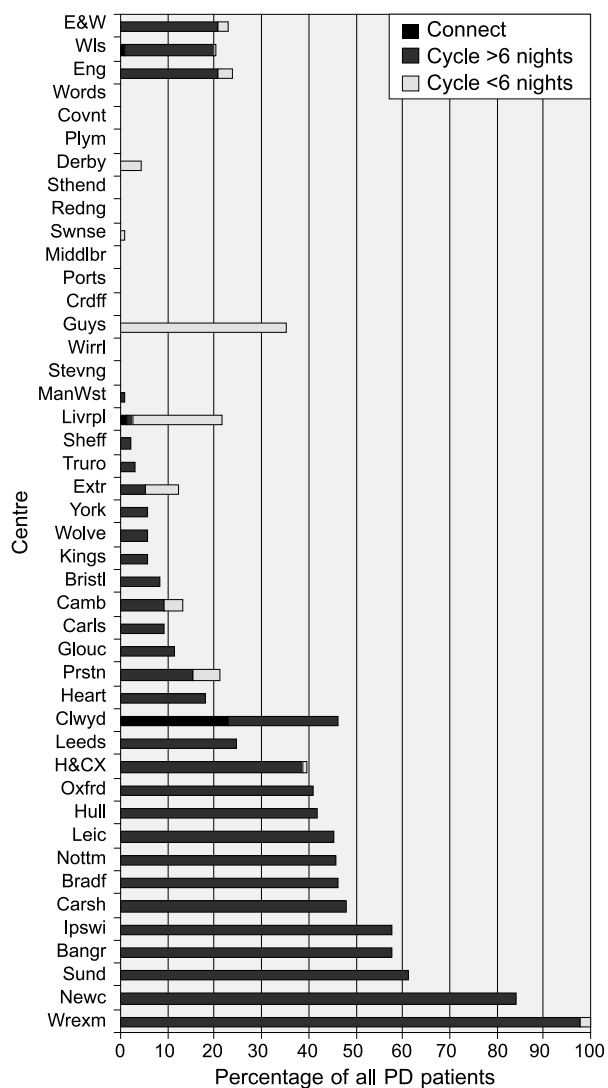


Figure 5.15: Use of connect and automated PD as a percentage of total PD

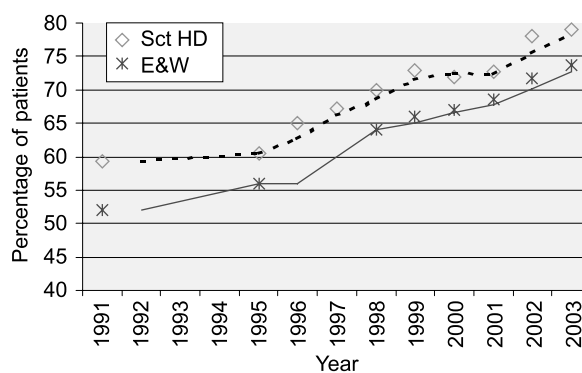


Figure 5.16: Proportion of patients on HD 1991–2003

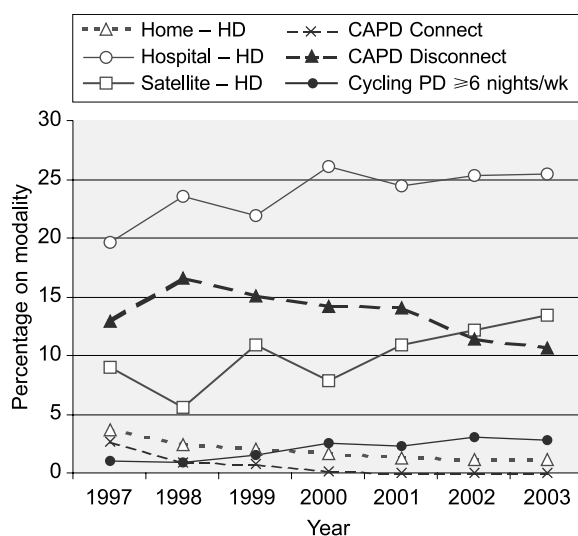


Figure 5.17: Changes in proportion of patients on different dialysis modalities 1997–2003

Table 5.11: Proportion of patients on different modalities of RRT, 1999–2003

	% HD home	% HD hospital	% HD satellite	% CAPD connect	% CAPD disconnect	% cycling PD ≥6 nights/wk	% cycling PD <6 nights/wk	% transplant
1997	3.7	19.7	9.0	2.7	12.9	1.0	0.0	51.0
1998	2.4	23.6	5.6	0.9	16.6	0.9	0.1	49.9
1999	2.0	21.9	10.9	0.7	15.0	1.6	0.5	47.3
2000	1.7	26.1	7.8	0.1	14.2	2.5	0.6	46.9
2001	1.3	24.5	10.9	0.0	14.0	2.3	0.4	46.6
2002	1.2	25.3	12.2	0.0	11.4	3.1	0.3	46.0
2003	1.1	25.4	13.4	0.0	10.6	2.8	0.4	45.8

Table 5.12: One year Kaplan-Meier survival of dialysis patients with and without censoring at transplantation (adjusted for age = 60)

Centre	Censoring transplant			Not censoring transplant			Difference (censoring – not censoring)
	Unadjusted 1 year survival	Lower 95% CI	Upper 95% CI	Unadjusted 1 year survival	Lower 95% CI	Upper 95% CI	
M0	88.5	85.8	91.3	87.9	85.1	90.9	0.6
M1	85.2	81.2	89.4	85.0	80.9	89.2	0.2
M2	89.6	87.0	92.4	89.3	86.5	92.1	0.4
M3	84.3	79.1	89.8	83.6	78.3	89.4	0.6
M4	89.1	85.7	92.6	88.8	85.4	92.4	0.3
M5	90.5	88.2	92.9	90.3	87.9	92.7	0.3
M6	75.9	68.8	83.7	75.1	67.8	83.1	0.8
M7	84.8	81.5	88.2	84.4	81.0	87.9	0.4
M8	93.3	87.8	99.1	92.9	87.2	99.0	0.4
M9	81.6	76.2	87.3	80.8	75.2	86.8	0.8
N0	82.1	77.9	86.5	82.0	77.7	86.5	0.1
N1	83.5	78.4	88.9	82.9	77.7	88.5	0.5
N2	81.7	78.2	85.5	80.6	77.2	84.1	1.1
N3	86.1	83.1	89.1	85.6	82.7	88.7	0.4
N4	84.2	79.2	89.6	84.3	79.0	90.0	-0.1
N5	83.2	76.7	90.2	82.6	75.9	89.8	0.6
N6	85.9	83.1	88.8	85.3	82.4	88.3	0.6
N7	90.9	86.7	95.2	90.5	86.1	95.0	0.4
N8	87.6	84.1	91.2	87.1	83.6	90.9	0.5
N9	85.8	80.4	91.6	85.6	80.1	91.5	0.2
O0	85.9	82.3	89.7	85.3	81.6	89.2	0.6
O1	87.9	85.4	90.6	87.6	84.9	90.3	0.4
O2	81.8	76.3	87.7	81.4	75.7	87.5	0.4
O3	84.2	80.0	88.5	83.4	79.1	87.9	0.8
O4	86.3	81.2	91.7	85.9	80.8	91.4	0.4
O6	79.2	75.0	83.7	78.5	74.1	83.1	0.7
O7	84.9	81.4	88.5	84.3	80.7	88.0	0.6
O8	87.2	83.8	90.7	86.6	83.1	90.3	0.6
O9	82.9	79.4	86.6	82.2	78.6	86.1	0.7
P0	85.6	80.8	90.8	85.0	80.0	90.4	0.6
P1	85.9	83.1	88.8	85.1	82.2	88.1	0.7
P2	83.6	80.7	86.5	83.1	80.2	86.1	0.4
P3	92.3	90.1	94.6	92.0	89.7	94.4	0.3
P5	78.3	70.2	87.4	77.2	68.8	86.7	1.1
P6	85.6	78.7	93.1	84.8	77.5	92.7	0.9
P7	89.1	86.8	91.5	88.7	86.3	91.2	0.4
P8	85.1	81.7	88.6	84.8	81.4	88.4	0.2
P9	81.6	77.1	86.3	80.6	75.9	85.5	1.0
Q0	85.5	81.9	89.4	84.9	81.2	88.9	0.6
Q1	87.0	83.4	90.8	86.7	83.0	90.5	0.3
Q2	87.1	82.2	92.4	86.7	81.6	92.2	0.4
Eng	86.1	85.4	86.8	85.7	84.9	86.4	0.5
Wales	84.2	82.1	86.3	83.2	81.1	85.3	1.0
E&W	86.0	85.3	86.7	85.4	84.7	86.2	0.5

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 2003. The patients in the transplant cohort have all been established with a transplant for at least 6 months.

Comparison of survival of prevalent dialysis patients between centres is complex. Survival of prevalent dialysis patients can be studied with or without censoring at transplant. When a patient is censored at transplantation, the patient is considered as alive up to the point of transplantation, but the patient's status post-transplant is not considered. Therefore a death following transplantation is not taken into account in calculating the survival figure. It could induce differences between those units with a high transplant rate and those with a low transplant rate, especially in younger patients where the transplant rate is highest. The differences are likely to be small due to the low post-transplantation mortality rate and the relatively small proportion of patients being

transplanted in a given year compared to the whole dialysis population (usually less than 15% of the total dialysis population). To estimate the potential differences the results for individual renal units were compared with or without censoring at transplant. The results are shown in Table 5.12. There is never more than a 2% difference in one year survival and the higher survival is usually in the censored data. With such small differences only the censored results have been quoted throughout the rest of this Chapter.

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

There were no significant differences between England and Wales so the combined data are presented. Transplanted patients had better survival than even the younger non-diabetic patients on dialysis and the data are shown in Table 5.13. The one year death rate for preva-

Table 5.13: One-year survival of established prevalent RRT patients in England and Wales (unadjusted unless stated otherwise)

Patient group	No. of patients	No. of deaths	KM survival	KM 95% CI
Transplant patients 2003				
Censored at dialysis	9,752	237	97.5	97.2–97.8
Not censored at dialysis	9,752	255	97.4	97.1–97.7
Dialysis patients 2003				
All 2003	12,103	1,934	83.4	82.7–84.1
All 2003 adjusted age = 60	12,103	1,934	86.0	85.3–86.7
2 year survival – Dialysis patients 2002				
All 1/1/2002 (2 year)	10,381	2,495	74.6	73.7–75.4
Dialysis patients 2003				
All age <65	6,633	610	90.2	89.4–90.9
All age 65+	5,470	1,324	75.6	74.4–76.7
Non-diabetic <55	3,429	176	94.4	93.6–95.2
Non-diabetic 55–64	1,814	223	87.1	85.5–88.7
Non-diabetic 65–74	2,315	441	80.6	79.0–82.3
Non-diabetic 75+	1,980	566	71.3	69.3–73.3
Non-Diabetic <65	5,243	399	91.8	91.1–92.6
Diabetic <65	1,078	179	82.6	80.3–84.9
Non-Diabetic 65+	4,295	1,007	76.3	75.0–77.6
Diabetic 65+	770	216	71.9	68.7–75.0

KM = Kaplan-Meier survival.

Cohorts of patients alive 1/1/2003 unless indicated otherwise.

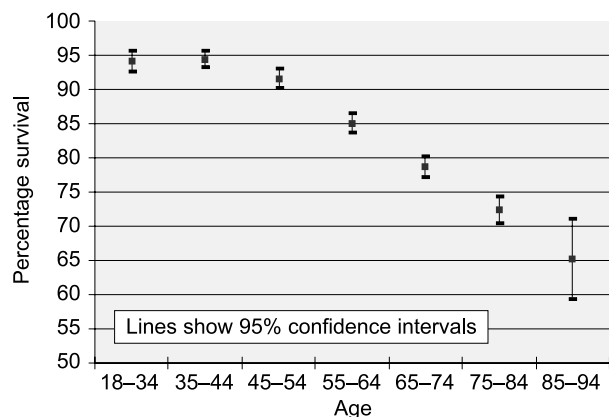


Figure 5.18: 1 year survival of prevalent dialysis patients in different age groups – 2003

lent dialysis patients is 15.0 per 100 patient years (95% CI 14.3–17.8). In Figure 5.18 the survival of prevalent dialysis patients for each age band is shown.

The one year survival of prevalent dialysis patients in each centre

The one year survival of dialysis patients in each centre is shown in Table 5.12 and is illustrated in Figures 5.19 and 5.20, dividing the data into those <65 years old and those 65 years old and over. There appeared to be significant differences in the survival rate between the centres, after adjusting for the differences in median age of patients at each centre (Figure 5.21). These findings require more detailed investigation by the Registry.

The one year survival of prevalent dialysis patients in England and Wales from 1997–2003

The one-year survival of prevalent dialysis patients in England and in Wales increased

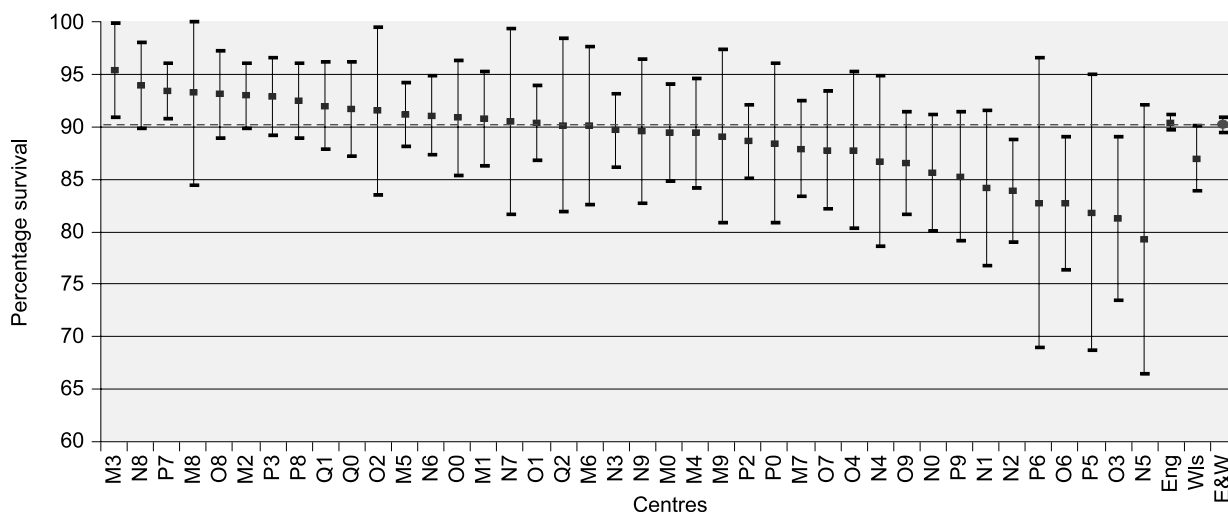


Figure 5.19: One year survival of prevalent dialysis patients aged under 65 in each centre

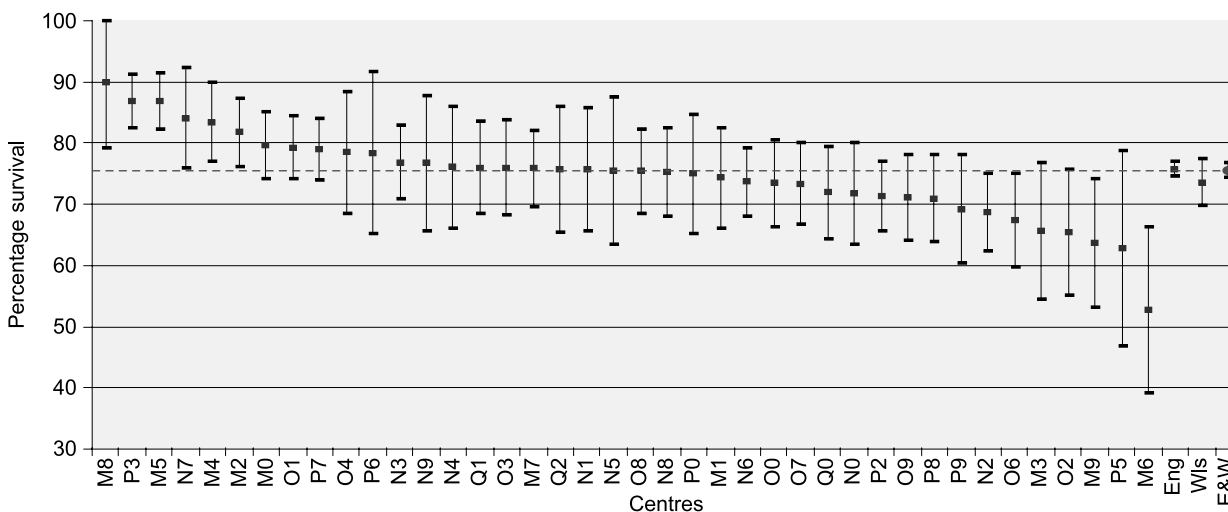


Figure 5.20: One year survival of prevalent dialysis patients aged 65 and over in each centre

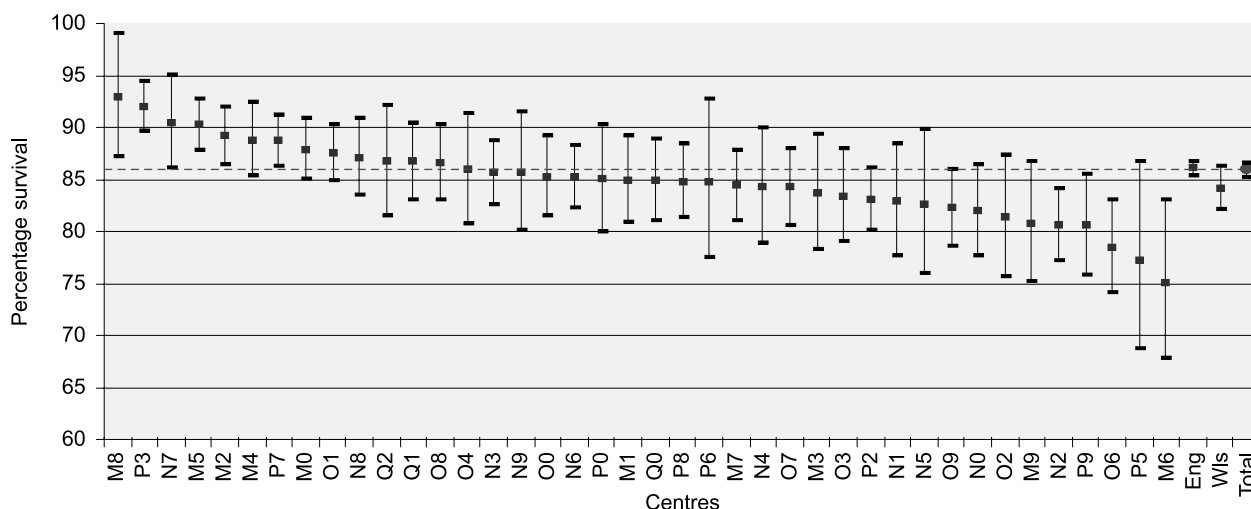


Figure 5.21: One year survival of prevalent dialysis patients in each centre adjusted to age 60

Table 5.14: Serial one year survival for dialysis patients in England and Wales from 1997–2003

Year	England		Wales	
	1 year survival %	95% CI	1 year survival %	95% CI
1997	83.3	81.7–84.8	N/A	
1998	84.2	83.0–85.5	78.2	73.4–83.2
1999	84.1	83.0–85.2	83.4	80.5–86.3
2000	85.3	84.4–86.3	85.4	82.9–88.0
2001	86.1	85.3–86.9	88.0	85.9–90.2
2002	87.5	86.9–88.1	87.4	85.5–89.3
2003	86.1	85.4–86.8	84.2	82.1–86.3

significantly from 1997 (83.3% and 78.2% respectively) to 2002 (87.5% and 87.4%), but has fallen marginally in 2003 (Table 5.14, Figure 5.22). The difference between England and Wales is not significant.

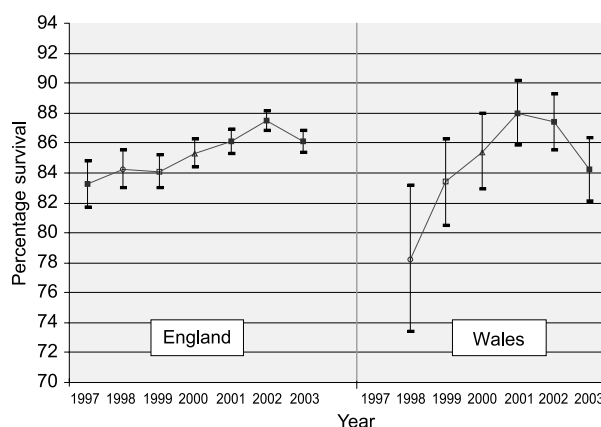
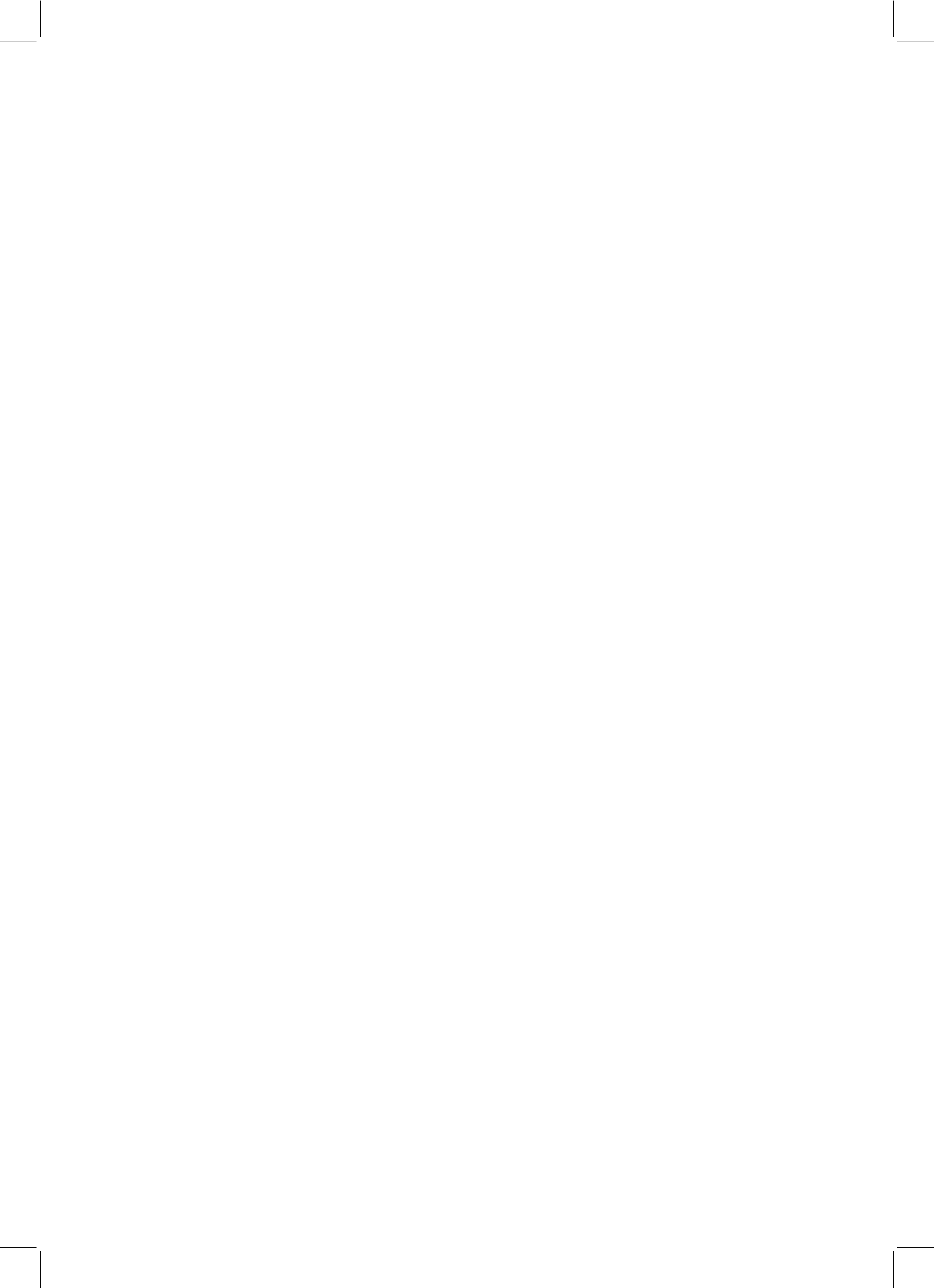


Figure 5.22: Serial one year survival for dialysis patients in England and Wales from 1997–2003

Reference

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



Chapter 6: Adequacy of Haemodialysis and Serum Bicarbonate

Summary

- Dialysis adequacy as measured by the urea reduction ratio (URR) continues to rise year on year.
- The URR rises further the longer an individual has been on dialysis.
- Concentrating on adequacy in the first few months after starting dialysis is likely to improve the median URR for a renal unit.
- Achievement of serum bicarbonate Standard is very variable between centres.
- A Registry survey of 8 renal units was unable to account for this variability in pre-haemodialysis serum bicarbonate.

Completeness of data

The Wirral renal unit does not have an automated biochemistry link into the IT renal system (at Liverpool) which accounts for their data being unavailable. The Registry extraction software at Proton sites either extracts the URR if found in the system or it attempts to calculate a URR from two blood samples taken on the same day within the quarter. The inability to identify two blood samples taken on the same day may account for the low levels of URR completeness at some of the sites.

At Cambridge, Coventry, Nottingham and Swansea there are significant differences in the frequency of bicarbonate measurement between HD and PD.

Table 6.1: Data completeness

Centre	URR HD	Bicarbonate HD	Bicarbonate PD	Centre	URR HD	Bicarbonate HD	Bicarbonate PD
Bangr	100	100	92	Middlbr	94	97	100
Bradf	99	100	98	Newc	N/A	97	95
Bristol	97	99	100	Nottm	95	75	47
Camb	37	68	100	Oxfrd	72	82	94
Carls	91	93	94	Plym	77	86	98
Carsh	68	83	95	Ports	83	92	80
Clwyd	75	94	100	Prstn	46	81	81
Covnt	98	17	56	Redng	98	98	100
Crdff	78	75	95	Sheff	98	100	100
Derby	85	89	93	Stevng	77	90	98
Extr	96	97	100	Sthend	90	95	100
Glouc	95	98	100	Sund	96	97	100
Guys	89	97	100	Swmse	36	72	99
H&CX	N/A	98	93	Truro	96	98	91
Heart	86	92	96	Wirrl	N/A	N/A	N/A
Hull	90	91	98	Wolve	93	99	98
Ipswi	100	100	98	Words	96	99	96
Kings	86	93	94	Wrexm	73	83	94
Leeds	96	99	98	York	90	92	100
Leic	97	98	99	Eng	77	87	87
Livrpl	79	84	96	Wls	68	79	96
ManWst	52	0	0	E&W	76	86	88

Dialysis adequacy

Introduction

Although the Renal Association guidelines offer both Kt/V and the URR as markers for the adequacy of dialysis, the Registry has chosen the URR for comparative audit. The Renal Association has endorsed more than one method of sampling for adequacy measurements. The last two Registry reports have confirmed and discussed variability in methodology between units and this is therefore not taken further in this report.

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

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

Every patient receiving thrice weekly HD should show:

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

Recommendations

Patients receiving twice weekly dialysis for reasons of geography should receive a higher sessional dose of dialysis, with a total Kt/V

urea (combined residual renal and HD) of >1.8. If this cannot be achieved, then it should be recognised that there is a compromise between the practicalities of dialysis and the patient's long-term health. (Good practice)

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)

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

Achieved URR

The median URR achieved by each unit is shown in figure 6.1. The variability is wide, ranging from over 75% to 62% with a median URR of 71%. This variability is reflected in the proportion of patients in each unit achieving the 65% URR target (figure 6.2) which ranged from 35% to 95% with a median of 77%. This appears not to be due to sampling methodology (early and late sampling methods are indicated on the graphs).

Figure 6.3 shows that the higher the median URR, the higher the percentage of patients whose URR is >65%, although this relationship plateaus once the median URR reaches 73%. To achieve 90% compliance with the RA Standard a median of over 73% is required.

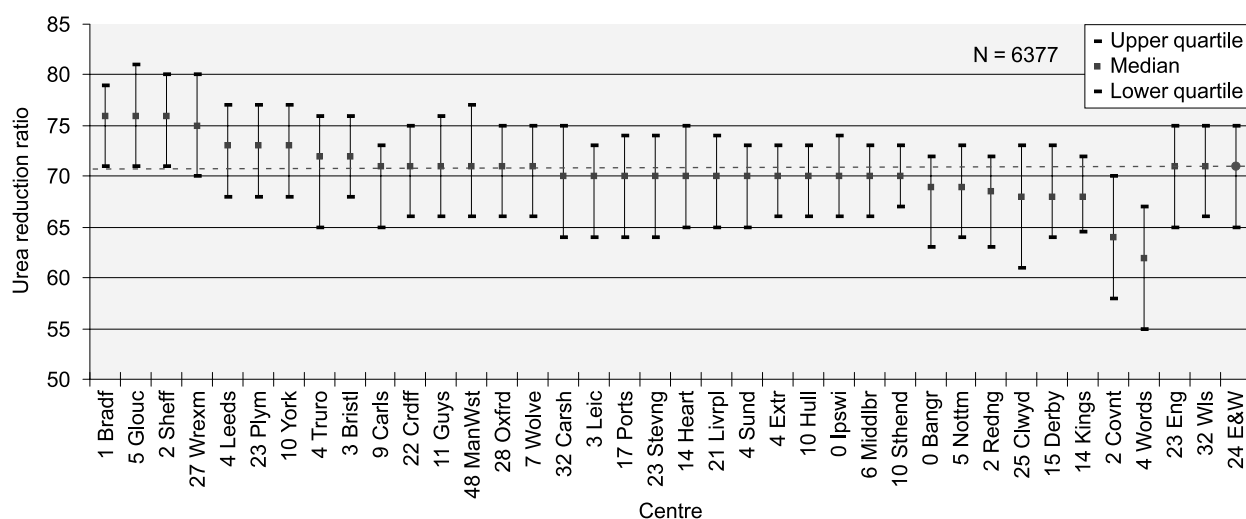


Figure 6.1: Median URR achieved in each renal unit

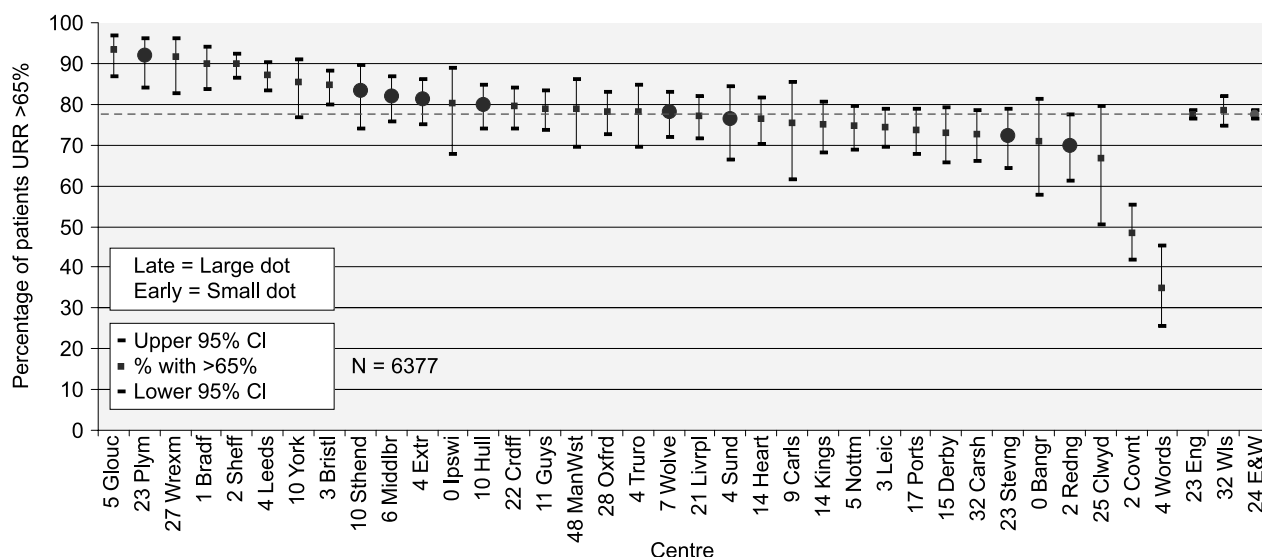


Figure 6.2: Percentage patients, by centre, with a URR of $\geq 65\%$ in the last quarter of 2003

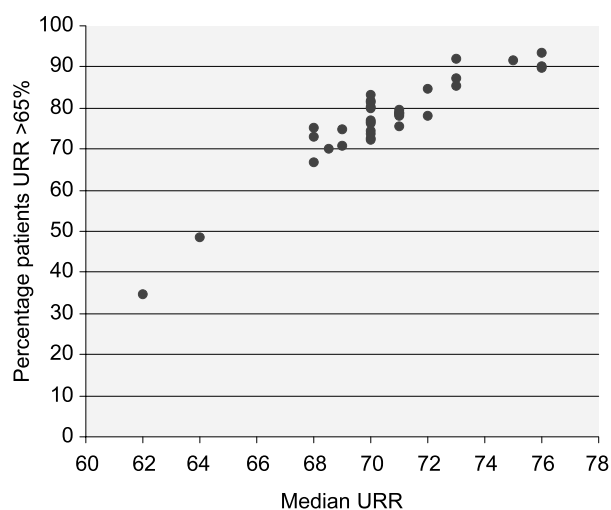


Figure 6.3: URR achievement and median URR at each renal unit

Changes in URR over time

The Registry has data on URR for up to six years (1998–2003), depending on when units joined the Registry. Almost all units have demonstrated an improvement in median URR and percentage compliance with the 65% standard over this time (figures 6.4 and 6.5).

The summary data for England and Wales are shown in figure 6.6 and demonstrate a clear improvement.

Even units starting with a high median URR of 70% such as Plymouth can demonstrate

improvement year on year. It is unclear how much the best units are going to be able to improve on current adequacy since the biggest constraint for the thrice weekly dialysed patient is likely to be the dialysis time deliverable or acceptable to patients. The Wordsley renal unit showed a decrease in the percentage of patients achieving RA standards from 52% in 2002 down to 29% in 2003. Informal enquiry has indicated that the unit was already aware of this problem. There had been a reduction in the percentage of patients dialysing through an AV fistula down to only 25% of all HD patients. Similar problems with commissioning vascular access services also affects many other renal units in the UK. At Wordsley, this has now been resolved through commissioning additional on site vascular access sessions.

Nevertheless it is apparent from figure 6.7 that patients in the earlier stages of their dialysis career are less well dialysed. There is wide variation in the URR of patients starting dialysis in different units (figure 6.8). This may be due to more than one factor, unsatisfactory access and possibly a belief in some units that it is necessary to build up to a big clearance working a patient up to the biggest dialyser. Concentrating on patients in the earlier months of dialysis could produce significant changes in median URR and percent compliance with the standard.

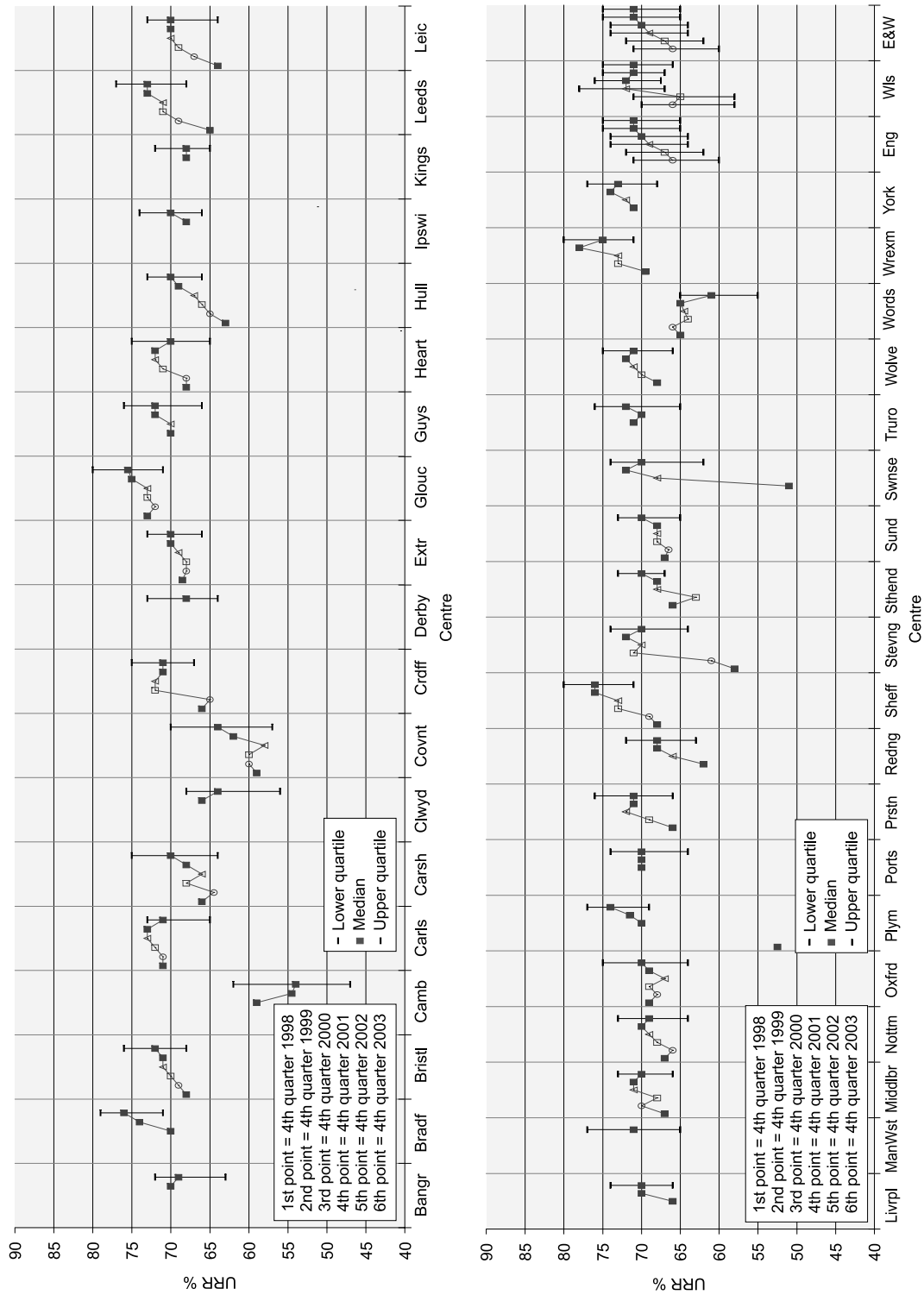


Figure 6.4: Change in meeting the median URR in 1998-2003

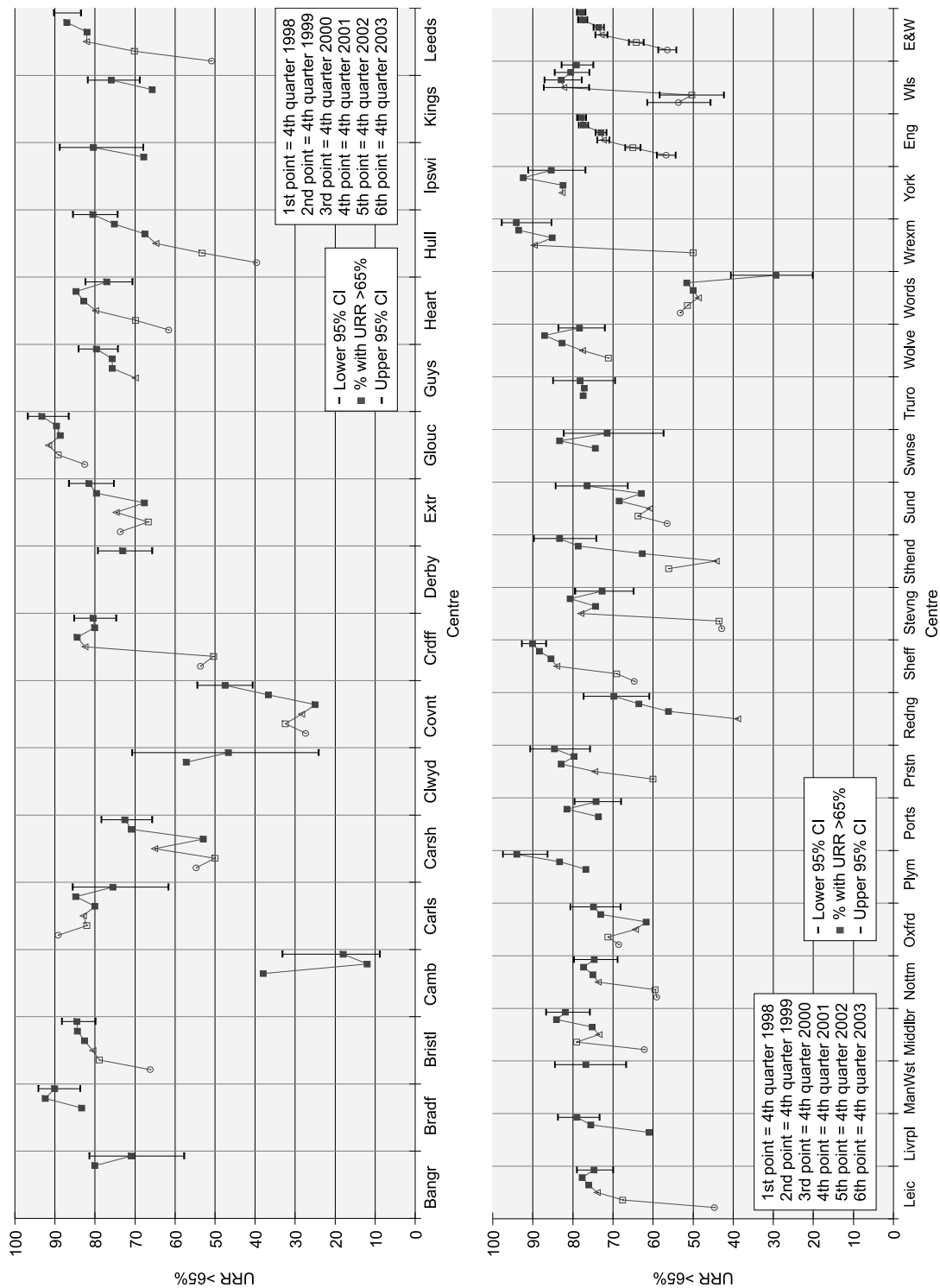


Figure 6.5: Change in meeting the URR Standard in 1998–2003

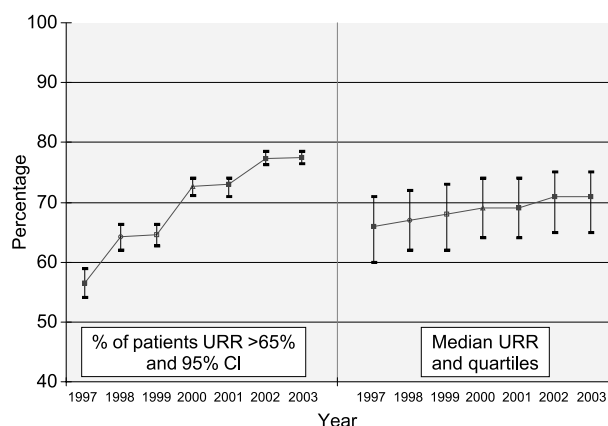


Figure 6.6: Percentage URR over 65% and change in median URR 1997–2003, England & Wales

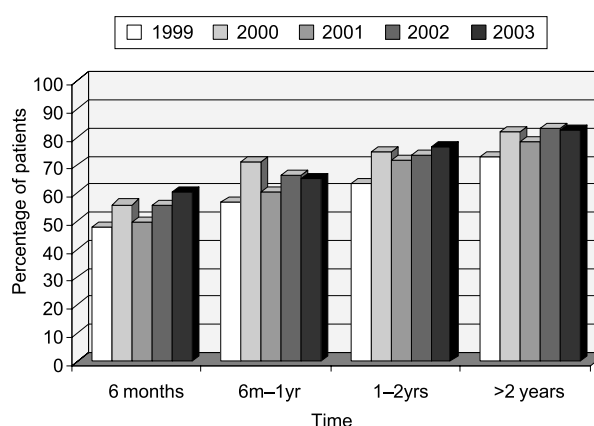


Figure 6.7: Percentage of patients with URR >65% by time on RRT

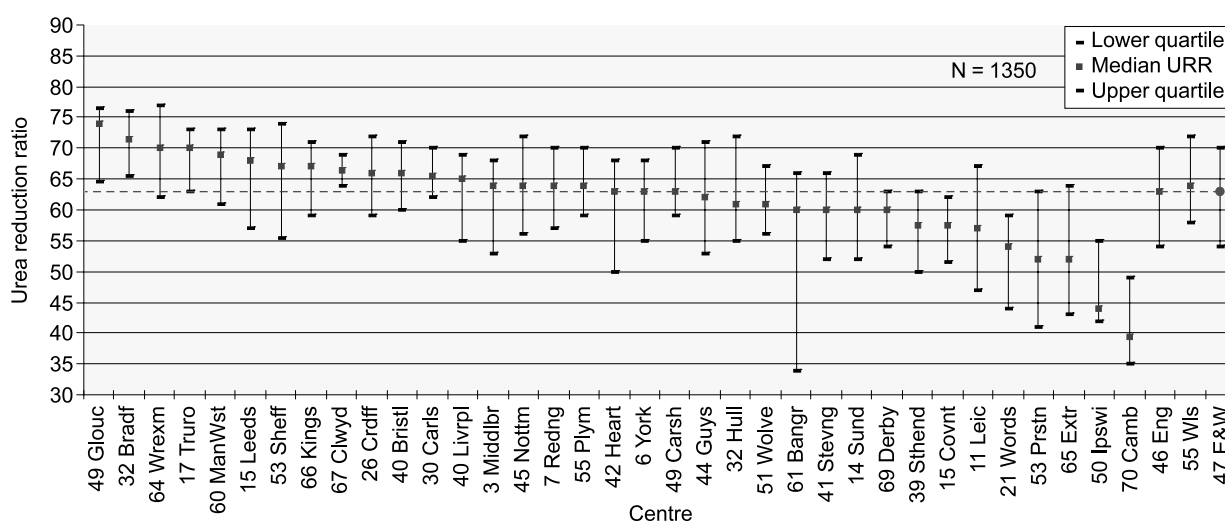


Figure 6.8: URR in patients starting dialysis, by centre

Serum bicarbonate

The current Renal Association guidelines recommend different standards for HD and for PD, based on level C and B evidence:

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

For CAPD patients serum bicarbonate, measured with minimal delay after venepuncture, should be between 25 and 29 mmol/L. (B)

Haemodialysis

Judged by the median bicarbonate results in figure 6.9, units would appear to be largely compliant with the bicarbonate standard. However the percentage compliance with the

standard shows very wide variability (figure 6.10) and this has been investigated further with a specific Registry study reported below.

Peritoneal Dialysis

In peritoneal dialysis patients, the median bicarbonate tends to be higher, 26 mmol/L compared with 23 mmol/L on HD, but there is still wide variability in this and the percentage compliance is shown in figures 6.11 and 6.12.

Change in modality of treatment and serum bicarbonate

The Registry is able to link biochemical data at patient level to details on changes of modality. Patients on PD develop progressively lower serum bicarbonate in the first six months following a switch to haemodialysis (figure 6.13).

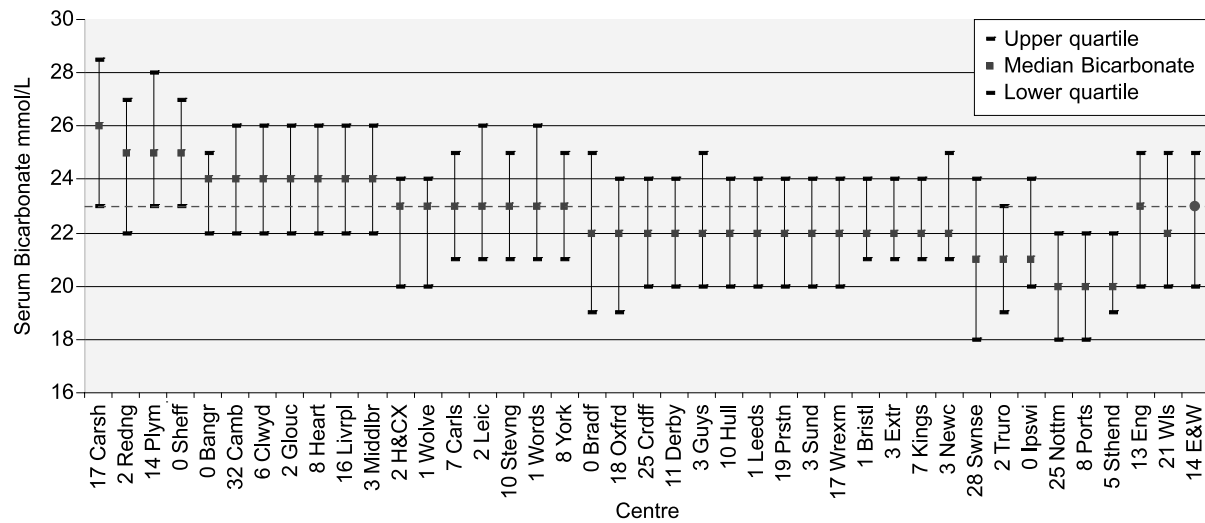


Figure 6.9: Median serum bicarbonate, haemodialysis

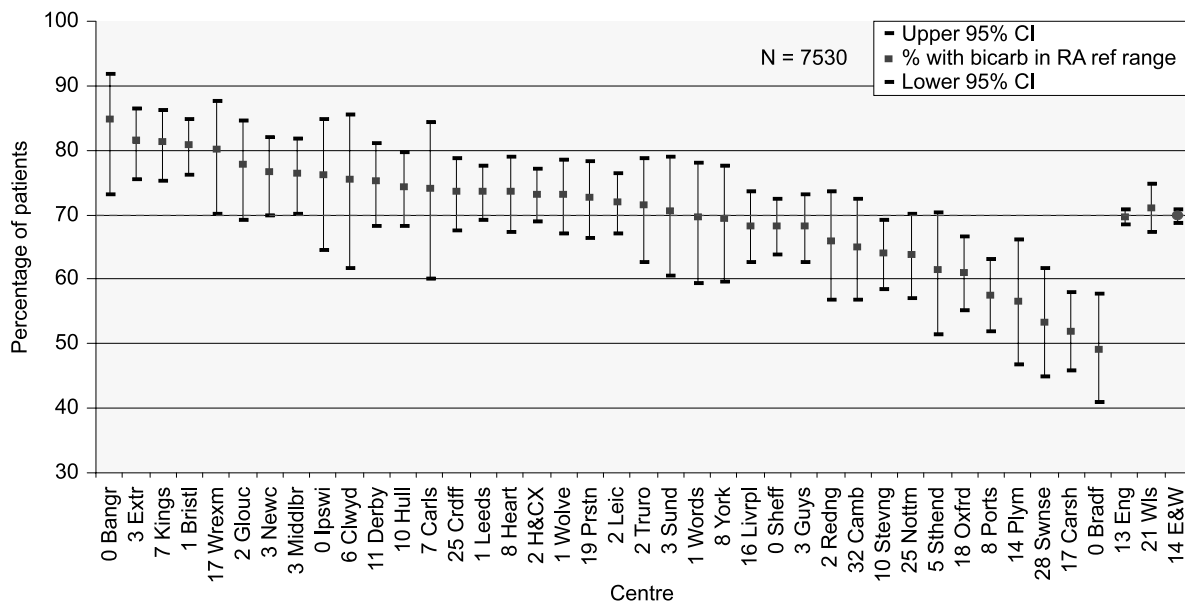


Figure 6.10: Percentage of patients with bicarbonate 20–26 mmol/L, HD

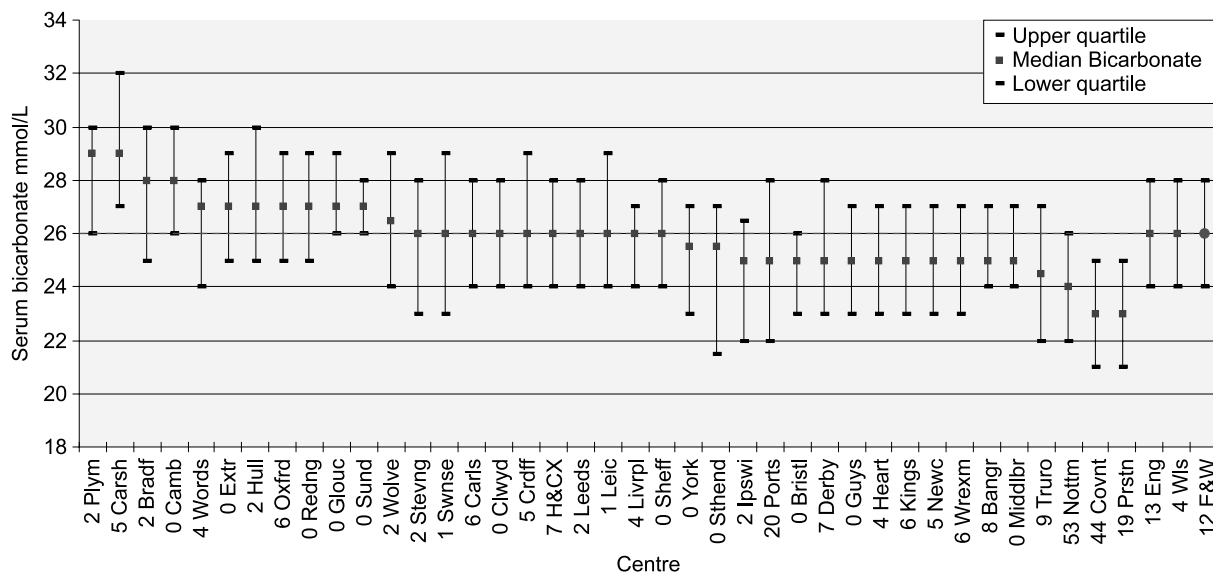


Figure 6.11: Median serum bicarbonate, PD

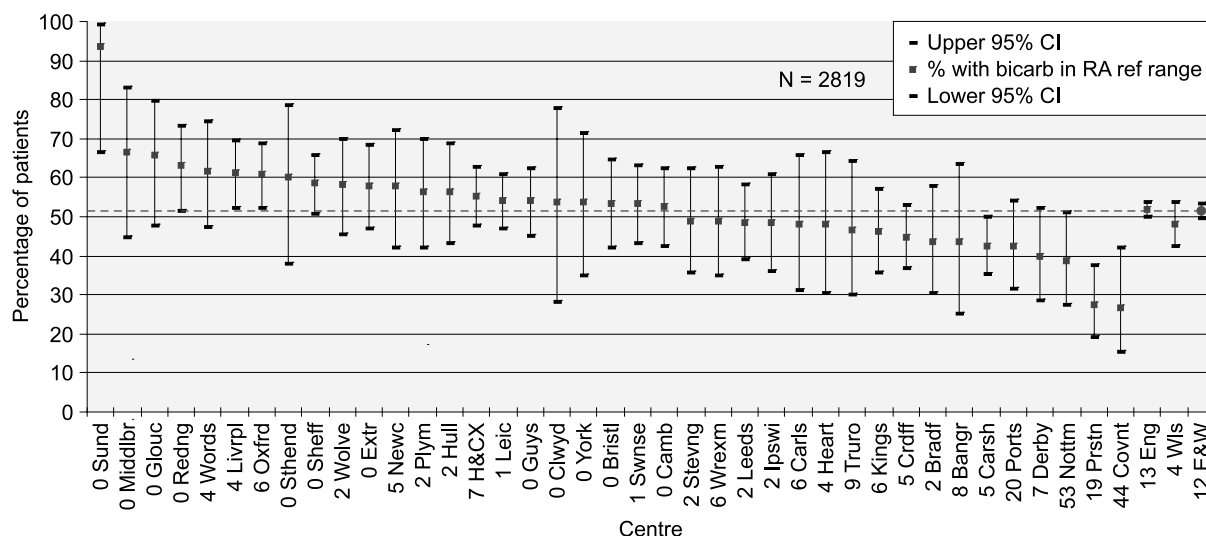


Figure 6.12: Percentage of patients with bicarbonate 25–29 mmol/L, PD

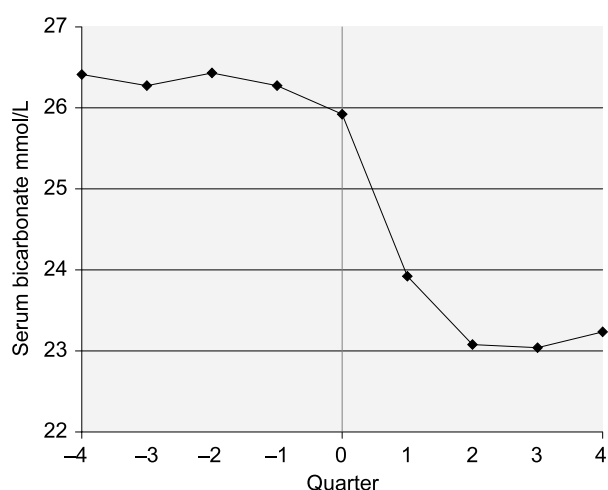


Figure 6.13: Serum bicarbonate after modality change, PD–HD

Inter-unit variability in serum bicarbonate – a Registry survey

Serum bicarbonate values are affected by various patient related and methodological factors. Some of the practical factors affecting bicarbonate measurement are the level of filling of the sample tube, storage of the sample after collection and transportation time to the laboratory. Delays in transport to the laboratories can lead to significant reductions in serum bicarbonate¹.

The Renal Registry has undertaken a survey to investigate the reasons for wide variation in

median bicarbonate values among the renal units.

Methods

A structured telephone survey was conducted of eight haemodialysis units, by selection of four centres at each end of the bicarbonate spectrum. The following data were collected

1. Time of sample collection (pre-haemodialysis or post-haemodialysis).
2. Method of filling the tubes (vacuum based tubes or manual syringe).
3. Approximate time delay after collection of sample to reaching the laboratory for analysis (time the blood samples remain in dialysis unit after collection from the patients, mode of transport to laboratory, time to reach laboratory).
4. Average dialysate bicarbonate concentration used.
5. Percentage of patients on thrice weekly HD.
6. Approximate percentage of patients with a neck line.
7. Day of collection of blood sample (long inter-dialytic intervals – Monday and Tuesday vs short inter-dialytic interval – Wednesday and Thursday or Friday and Saturday).

The Kruskal–Wallis non-parametric test was used to test for differences between the two groups (high bicarbonate and low bicarbonate).

Results

In the low bicarbonate group the median pre-HD bicarbonate was 19, 20, 21 and 21 mmol/L respectively compared with 25, 25, 26 and 27 mmol/L in the high bicarbonate group. The median bicarbonate values in the low group were below the normal range for their respective laboratories. Median bicarbonate values were within the laboratory reference range for centres in the high bicarbonate group.

All the samples were collected pre-haemodialysis and were handled by on-site hospital laboratories. Generally vacuum based systems were used for blood sampling, although in some centres manual syringes were used for patients dialysing through a temporary line. One centre in the low bicarbonate group collected the blood samples by syringe only.

The median time delay between collecting blood samples and the samples reaching the laboratory for analysis was 56 min for the low bicarbonate group and 72 min for the high bicarbonate group. This delay includes both the time during which blood samples remained in the dialysis unit after sampling and the time taken to reach the laboratory from the unit.

This time difference was not statistically different ($p = 0.38$).

Only one unit used 40 mmol/L bicarbonate dialysate, all the other units used 35 mmol/L bicarbonate as their principal dialysate.

The number of patients on twice a week dialysis differed significantly between the two groups (high group 2.7%, low group 10.2%; $p < 0.00001$).

The low bicarbonate group had 27.5% using neck lines whilst the high bicarbonate group had 12.5% on neck lines. This difference was not however statistically significant. ($p = 0.18$).

In a separate study using data from the Bristol renal unit, the effect of the length of time between dialysis (inter-dialytic interval) on serum bicarbonate was measured. Data were analysed from 559 samples taken after a long inter-dialytic interval (Mon/Tue samples) and 2,239 samples taken after a short interval (Wed/Thu samples). There was no significant difference in the median serum bicarbonate values between these two groups ($p = 0.09$).

Table 6.2: Results of bicarbonate survey

Groups	Low bicarbonate group				High bicarbonate group			
	Nottm	Covnt	Truro	Sthend	Sheff	Glouc	Bangor	Carsh
Lab ref	20–28	24–30	23–29	22–27	22–32	18–26	22–30	24–30
Median bicarb	19	20	21	21	25	25	26	27
Number	181	180	115	104	390	113	59	220
Sample method	Both	Syringe	Vac	Both	Vac	Both	Vac	Vac
Time in unit (min)*	90	60	30	40	60	60	60	45
Time in transit (min)**	1	2	1	10	15	30	10	10
Total time	91	62	30	50	75	90	70	55
Transport method***	Porter	Porter	Auto	Porter	Porter	Porter	Porter	Porter
Dialysate bicarb	35	35	35	35	40	35	35	35
% ×2/week	5	15	12	9	2	3	11	2
% neck line	60	15	25	30	15	10	10	40
Median URR	70	62	70	68	76	76	70	68
Sample interval****	Long	Short	Short	Long	Short	Long	Short	Long

*Time in unit: Approximate time (in minutes) sample remains in the renal unit after collection, before being picked up for transport to laboratory

**Time in transit: Time (in minutes) to reach lab after being picked up from dialysis unit

***Transport method: Auto = automated sample transfer method to lab

****Sample interval: Short = Wednesday or Thursday, Long = Monday or Tuesday

Discussion

The median serum bicarbonate value reflects the control of metabolic acidosis by a centre and methodological issues could confound the interpretation of the serum bicarbonate data. This may have clinical relevance since true metabolic acidosis is a catabolic state. Recently it has also been suggested that alkalosis after haemodialysis, increases the rate of vascular calcification.

This study was unable to demonstrate specific methodological reasons for the variability in serum bicarbonate between renal units. Although the number of patients on twice a week dialysis was different between the two groups, it is not possible for the small number of these patients to affect the median bicarbonate value to such a degree.

In particular, it might have been expected that time delays in specimen transportation would explain the differences in bicarbonate. This has not been shown, although it is

accepted that the time intervals were a crude estimate reported by nurses which may be inaccurate and that the Registry has not accounted for delays in processing the blood sample once it had reached the laboratory.

The Registry data aggregates the HD satellite unit data with the in-centre data and this may be a confounder in the analysis. There are considerable limitations to the interpretation of a small telephone survey and the numbers of centres in the study were small.

It has been shown that different laboratory assays produce different bicarbonate results². This has not been investigated in this study although it would also be of interest.

References

1. Kirschbaum B. Spurious metabolic acidosis in hemodialysis patients, *Am J Kidney Dis* 35:1068–1071.
2. Bray *et al.* The magnitude of metabolic acidosis is dependent on difference in bicarbonate assays, *Am J Kidney Dis* 1996 Nov;28(5):700–3.

Chapter 7: Haemoglobin

Summary

- Improvement in haemoglobin concentrations of patients receiving dialysis treatment continued in 2003. 84% of haemodialysis patients and 88% of peritoneal dialysis patients had a haemoglobin concentration above the Renal Association target of 10 g/dl. In total, 85% of all dialysis achieved an Hb \geq 10 g/dl.
- Only 6% of prevalent HD patients and 4% of PD patients had an Hb $<$ 9 g/dl.
- Haemoglobin in the first quarter of dialysis treatment has also continued to rise although 41% of individuals new to dialysis still had an Hb $<$ 10 g/dl in 2003 (cf 43% and 45% in 2002 and 2001 respectively). 19% had an Hb $<$ 9 g/dl in 2003.
- 65% of haemodialysis patients and 72% of peritoneal dialysis patients achieve a haemoglobin above the European guidelines of 11 g/dl. 67% of the 11,456 dialysis patients with haemoglobin returns had an Hb \geq 11 g/dl.
- Several centres appear to achieve a narrower control of haemoglobin concentration within their patient populations as evidenced by a smaller standard deviation of 1.0. This smaller sd is not related to centre size and either indicates a systematic approach, a difference within the patient cohort (eg comorbidity) or a random statistical variation.

Introduction

This chapter describes data reported to the Renal Registry at the end of 2003, relating to the management of anaemia. The third edition of the Renal Association Standards document has stated that:

individuals with chronic renal failure should achieve a haemoglobin of 10 g/dl within 6 months of being seen by a nephrologist

unless there is a specific reason why it could not be achieved.

To date the proportion of patients with chronic renal failure who cannot achieve a haemoglobin of 10 g/dl for clinical reasons is not known and so there is no longer a proportion stated as a standard. Renal centres will judge their performance by comparison with other centres through data submitted to the Renal Registry. United States and European clinical guidelines set the target for haemoglobin at 11 g/dl and some UK nephrologists may use protocols designed to achieve this higher target.

The UK Renal Registry collects data on patients receiving RRT and records the date that RRT starts. The Registry does not as yet have sufficient information on data pre-dialysis to allow analysis of the requirement to achieve the target haemoglobin within 6 months. Several renal units are achieving similar haemoglobin levels pre-dialysis to those post dialysis indicating a systematic approach to treating anaemia in patients with chronic kidney disease.

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

Inclusion criteria

Patients on dialysis during the last quarter of 2003 were included in the analysis 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 2003 was used in the analysis.

Completeness of data

The completeness of haemoglobin returns to the Registry are shown below in table 7.1. The Wirral renal unit does not have an automated lab link into the Liverpool renal system and this accounts for their low level of data return.

Table 7.1: Completeness of haemoglobin data

Centre	HD	PD
Bangr	100	100
Bradf	100	98
Bristol	100	100
Camb	71	100
Carls	93	94
Carsh	85	99
Clwyd	96	92
Covnt	99	96
Crdff	95	97
Derby	88	94
Extr	97	100
Glouc	98	100
Guys	96	100
H&CX	99	99
Heart	90	100
Hull	96	98
Ipswi	100	98
Kings	97	94
Leeds	99	98
Leic	98	99
Livrpl	87	94
ManWst	69	98
Middlbr	97	100
Newc	93	98
Nottm	97	100
Oxfrd	99	100
Plym	81	89
Ports	94	88
Prstn	95	99
Redng	98	100
Sheff	100	100
Stevng	93	100
Sthend	98	100
Sund	98	100
Swmse	74	99
Truro	98	94
Wirrl	11	13
Wolve	99	100
Words	100	100
Wrexm	85	94
York	93	100

Haemoglobin achievement by dialysis centres for all prevalent patients

The data describing the haemoglobin distribution in each centre is tabulated in table 7.2 for haemodialysis and table 7.3 for peritoneal dialysis and also shown in figures 7.1 and 7.2. The percentage of patients with haemoglobin ≥ 11 g/dl for each centre is also shown in the tables for the information of those centres that regard this as the most appropriate target. Once again, in 2003 there was an increase in the percentage of haemodialysis patients with haemoglobin ≥ 10 g/dl (84% in England and 85% in Wales compared to 82% and 84% respectively in 2002). For peritoneal dialysis patients the percentage with haemoglobin ≥ 10 g/dl stayed constant at 88% in England and 89% in Wales.

The percentage of patients with haemoglobin ≥ 11 g/dl has increased for both haemodialysis and peritoneal dialysis patients in both England and Wales (62% in 2002 increasing to 65% in 2003 for haemodialysis and 71% in 2002 increasing to 72% in 2003 for peritoneal dialysis). This increase could indicate that some centres are aiming to achieve the European target of haemoglobin 11 g/dl or that there is increased recognition that to achieve the Renal Association target of 10 g/dl in a high proportion of patients a median haemoglobin over 11 g/dl is required.

Figures 7.3, 7.4, 7.5, 7.6, 7.7 and 7.8 compare haemoglobins in dialysis centres by median haemoglobin, percentage with Hb ≥ 10 g/dl and percentage Hb ≥ 11 g/dl for patients on haemodialysis and peritoneal dialysis. As in previous years reports there is a broad spread of data across different dialysis centres for median haemoglobin and for percentage attainment of the Renal Association target. For haemodialysis the 90% range is unchanged compared to 2002. The quartile range for haemodialysis was 10.4–12.5 in 2002 and 10.5–12.6 in 2003. There is very little change between the ranges in 2002 compared with 2003 for peritoneal dialysis.

There is no obvious relationship between centre size and haemoglobin management. The 5 centres with the highest percentage of patients

Table 7.2: 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 \geq 10	% with Hb \geq 11
Bangr	100	11.8	9.4–14.9	10.7–12.9	11.8	1.5	86	64
Bradf	100	12.1	10.1–15.0	11.3–13.1	12.3	1.5	97	83
Bristol	99	11.8	8.8–14.3	10.7–12.5	11.7	1.5	88	71
Camb	71	11.1	7.7–14.1	10.1–12.4	11.2	1.9	76	54
Carls	93	11.2	9.2–12.6	10.5–11.7	11.1	1.0	84	62
Carsh	85	11.5	8.8–14.6	10.5–12.6	11.6	1.8	83	66
Clwyd	96	11.2	7.9–14.1	10.0–12.9	11.4	2.0	77	60
Covnt	99	11.4	8.7–13.9	10.4–12.4	11.4	1.6	83	60
Crdff	95	12.1	8.9–14.5	10.8–13.2	11.9	1.7	85	72
Derby	88	10.9	8.1–13.9	10.0–12.3	11.1	1.7	75	48
Extr	97	11.3	9.1–13.5	10.5–12.2	11.3	1.3	85	59
Glouc	98	11.7	8.8–13.8	10.7–12.5	11.6	1.5	86	73
Guys	96	11.3	9.2–13.7	10.4–12.4	11.4	1.5	84	59
H&CX	99	11.9	9.1–14.2	10.8–12.9	11.8	1.5	89	71
Heart	90	11.2	8.6–13.5	10.0–12.2	11.1	1.5	75	58
Hull	96	11.4	8.6–13.4	10.5–12.2	11.3	1.4	84	65
Ipswi	100	11.4	9.4–13.2	10.7–12.2	11.5	1.3	89	64
Kings	97	11.4	8.7–13.4	10.3–12.3	11.2	1.5	79	58
Leeds	99	11.8	9.2–14.0	10.9–12.6	11.7	1.5	89	74
Leic	98	10.9	8.8–13.6	10.0–12.0	11.1	1.5	76	49
Livrpl	87	12.0	9.2–15.1	10.7–13.4	12.0	1.9	87	71
ManWst	69	11.1	8.8–14.3	9.8–12.8	11.3	1.8	73	57
Middlbr	97	11.5	8.2–14.3	10.3–12.5	11.4	1.8	81	64
Newc	93	11.4	8.2–13.5	10.4–12.2	11.2	1.6	80	62
Nottm	97	11.6	9.1–14.3	10.4–12.6	11.6	1.6	86	66
Oxfrd	99	11.4	8.7–13.8	10.4–12.5	11.4	1.5	83	62
Plym	81	11.7	9.8–13.8	10.9–12.4	11.7	1.1	93	73
Ports	94	11.6	8.8–14.4	10.4–13.0	11.6	1.7	82	68
Prstn	95	11.8	8.7–14.2	10.5–12.9	11.7	1.7	85	66
Redng	98	11.7	8.9–14.5	10.6–12.8	11.7	1.6	86	68
Sheff	100	11.3	8.7–13.8	10.2–12.2	11.2	1.5	79	59
Stevng	93	11.7	9.4–14.0	10.6–12.6	11.7	1.5	89	67
Sthend	98	11.7	8.6–13.2	11.1–12.4	11.6	1.4	91	78
Sund	98	11.0	8.8–14.0	10.3–12.6	11.3	1.6	82	50
Swmse	74	11.6	8.9–14.4	10.3–13.0	11.6	1.8	82	65
Truro	98	11.1	9.4–12.7	10.4–11.5	11.0	1.0	82	57
Wolve	99	12.1	8.4–14.5	10.8–13.1	11.8	1.9	83	73
Words	100	11.1	8.9–14.1	10.2–12.2	11.2	1.5	80	54
Wrexm	85	12.7	9.6–14.5	11.6–13.5	12.4	1.5	94	82
York	93	11.9	9.1–14.2	10.9–12.8	11.8	1.6	88	72
Eng	93	11.5	8.8–14.1	10.4–12.5	11.5	1.6	84	64
Wls	89	12.0	8.9–14.5	10.7–13.1	11.9	1.7	85	70
E&W	93	11.5	8.8–14.1	10.5–12.6	11.5	1.6	84	65

with an Hb \geq 10 g/dl for haemodialysis are relatively small, each having fewer than 150 patients with data returned. However Hammer-smith & Charing Cross (H&CX) and Leeds are large centres (>400 patients) with good performance against the target. A number of smaller

units have a low percentage of patients with Hb \geq 10 g/dl.

Figures 7.9 and 7.10 indicate the relationship between median Hb in a centre and the percentage of patients with Hb \geq 10 g/dl or Hb

Table 7.3: 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	13.5	10.8–15.3	12.2–13.8	13.2	1.4	96	92
Bradf	98	12.8	9.8–15.0	11.7–13.8	12.7	1.7	94	85
Bristol	100	12.1	9.3–15.0	10.8–13.0	12.0	1.8	92	73
Camb	100	11.9	9.4–14.0	10.9–12.7	11.8	1.4	89	73
Carls	94	11.4	8.6–14.5	10.2–12.7	11.5	1.7	86	59
Carsh	99	12.2	9.4–14.8	11.2–13.1	12.1	1.6	93	78
Clwyd	92	12.2	8.8–14.3	9.9–12.5	11.7	1.8	75	67
Covnt	96	11.6	8.9–15.3	10.2–12.6	11.6	1.8	80	63
Crdff	97	12.3	9.3–14.8	11.0–13.1	12.1	1.7	90	75
Derby	94	11.7	8.6–14.5	10.7–12.8	11.8	1.7	84	70
Extr	100	11.7	9.7–13.8	11.0–12.5	11.7	1.3	91	75
Glouc	100	11.6	8.0–12.9	10.3–12.2	11.2	1.4	81	59
Guys	100	11.7	8.9–14.4	10.6–12.8	11.7	1.6	85	66
H&CX	99	11.9	9.2–14.6	11.0–13.1	12.0	1.7	91	77
Heart	100	11.8	8.9–14.0	10.7–12.5	11.6	1.5	86	71
Hull	98	11.5	9.3–14.3	10.7–12.8	11.6	1.5	82	69
Ipswi	98	12.3	9.7–14.4	11.2–13.0	12.2	1.5	95	78
Kings	94	12.3	8.7–14.9	11.0–13.1	12.0	1.8	86	75
Leeds	98	12.4	9.2–15.0	11.3–13.3	12.3	1.7	88	80
Leic	99	11.8	8.7–14.2	10.5–12.9	11.6	1.7	85	66
Livrpl	94	12.2	9.0–14.4	11.0–13.3	12.1	1.7	87	76
ManWst	98	11.2	8.9–14.0	10.1–12.4	11.3	1.6	81	54
Middlbr	100	12.5	9.0–14.3	11.5–13.3	12.1	1.9	86	76
Newc	98	12.0	8.8–14.1	10.5–12.9	11.8	1.7	82	72
Nottm	100	11.9	9.8–15.1	11.0–13.1	12.1	1.6	93	78
Oxfrd	100	12.2	8.9–14.6	11.1–13.1	12.1	1.6	89	79
Plym	89	12.0	10.2–14.7	11.2–12.6	12.1	1.3	95	83
Ports	88	12.0	9.2–15.7	10.7–13.2	12.1	2.0	85	70
Prstn	99	11.8	9.2–14.4	10.7–12.8	11.8	1.7	90	67
Redng	100	11.6	9.1–13.9	10.7–12.4	11.5	1.5	85	70
Sheff	100	11.4	8.4–13.9	10.3–12.6	11.4	1.7	81	60
Stevng	100	12.0	9.6–14.2	10.9–13.2	12.0	1.6	92	75
Sthend	62	12.0	10.0–16.3	10.9–12.8	12.2	1.8	96	65
Sund	100	11.3	9.6–14.2	10.5–12.5	11.5	1.4	88	63
Swmse	99	11.9	8.2–14.9	10.6–13.4	11.8	2.0	84	67
Truro	94	11.3	9.4–14.7	10.7–12.5	11.6	1.4	94	65
Wolve	100	12.5	9.6–15.5	11.2–13.4	12.4	1.7	93	80
Words	100	11.7	9.9–14.4	11.2–12.9	11.9	1.7	92	80
Wrexm	94	12.8	11.0–14.6	12.0–13.6	12.8	1.1	100	96
York	100	12.7	10.0–14.7	11.4–13.6	12.5	1.5	96	85
Eng	97	11.9	9.1–14.6	10.8–12.9	11.9	1.7	88	72
Wls	97	12.3	9.3–14.9	11.1–13.4	12.2	1.8	89	77
E&W	97	11.9	9.2–14.6	10.8–13.0	11.9	1.7	88	72

≥ 11 g/dl. For the first time this year there is a suggestion that a plateau may develop at higher median haemoglobins with little difference in percentage Hb ≥ 10 g/dl between centres with median haemoglobins ranging from 11.6 g/dl to

12.1 g/dl. The percentage Hb ≥ 10 g/dl in these centres is 85–90%. This may suggest that with current strategies it is not possible to achieve a higher proportion of haemodialysis patients with the target haemoglobin.

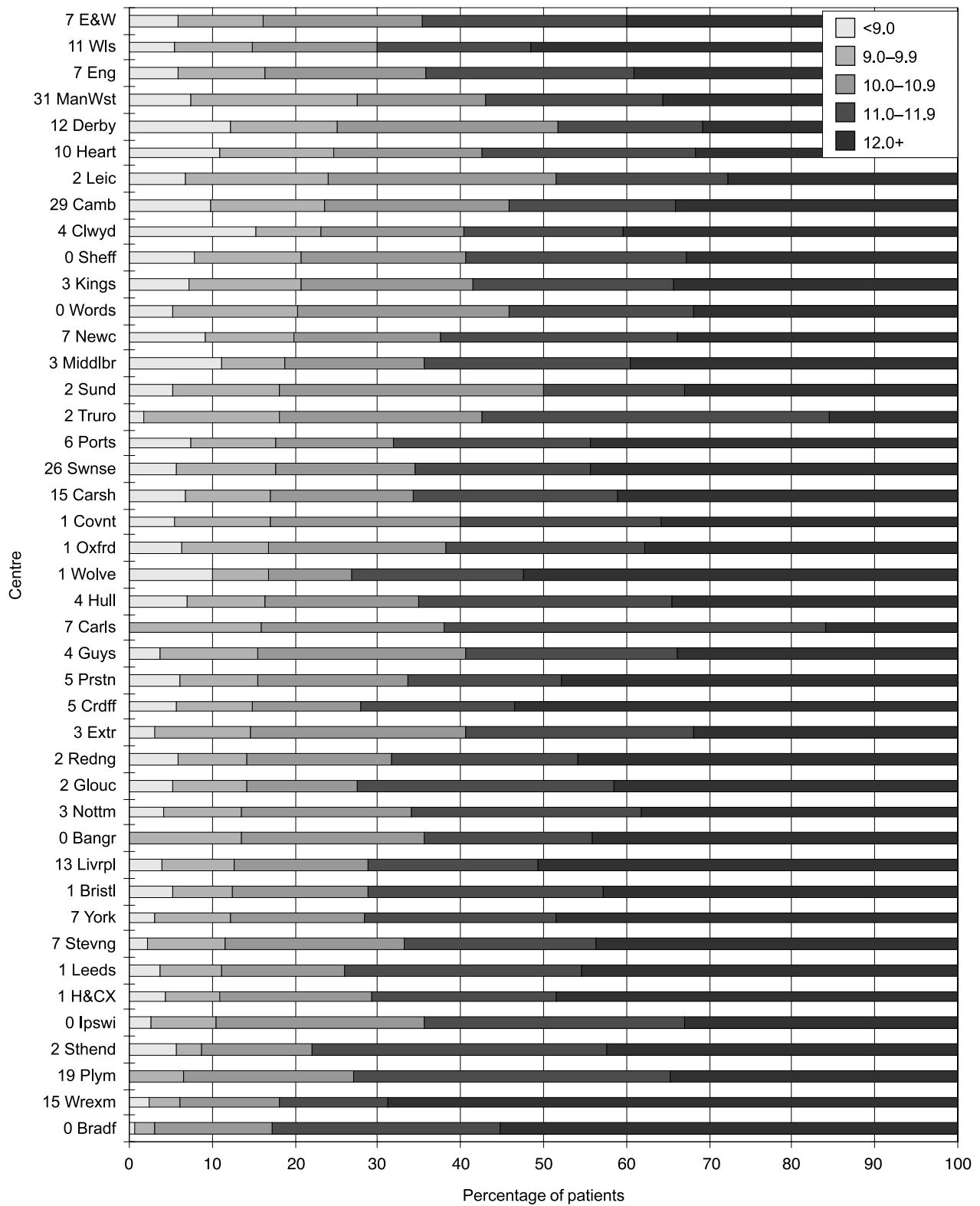


Figure 7.1: Distribution of haemoglobin in patients on HD

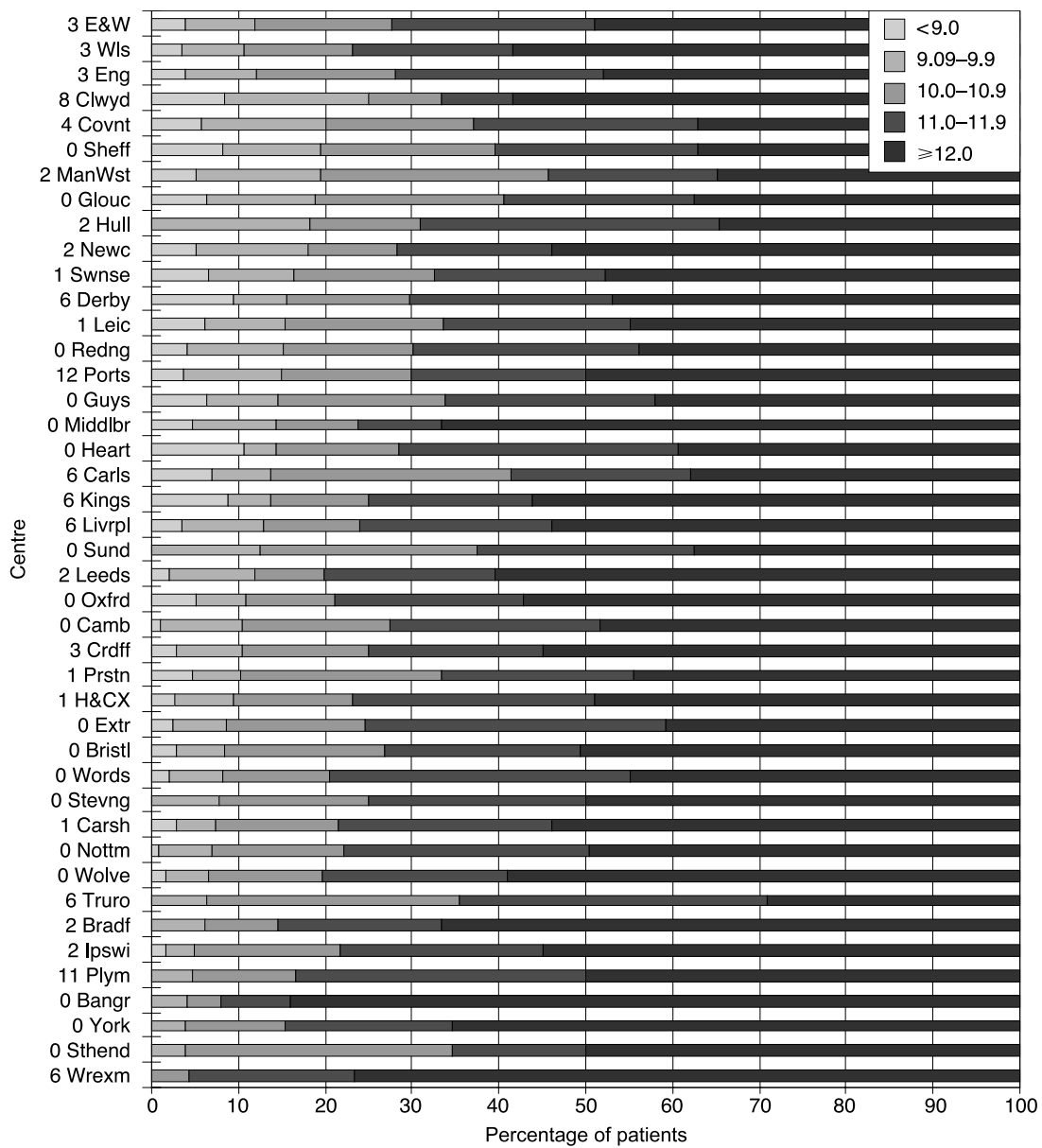


Figure 7.2: Distribution of haemoglobin in patients on PD

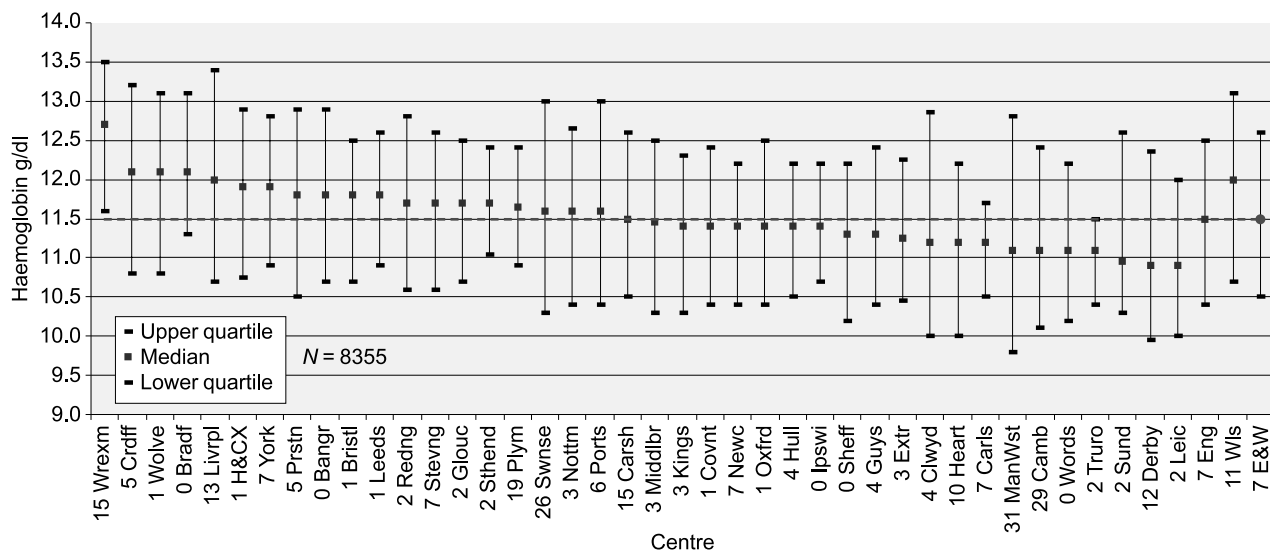


Figure 7.3: Haemoglobin and quartile ranges for HD patients

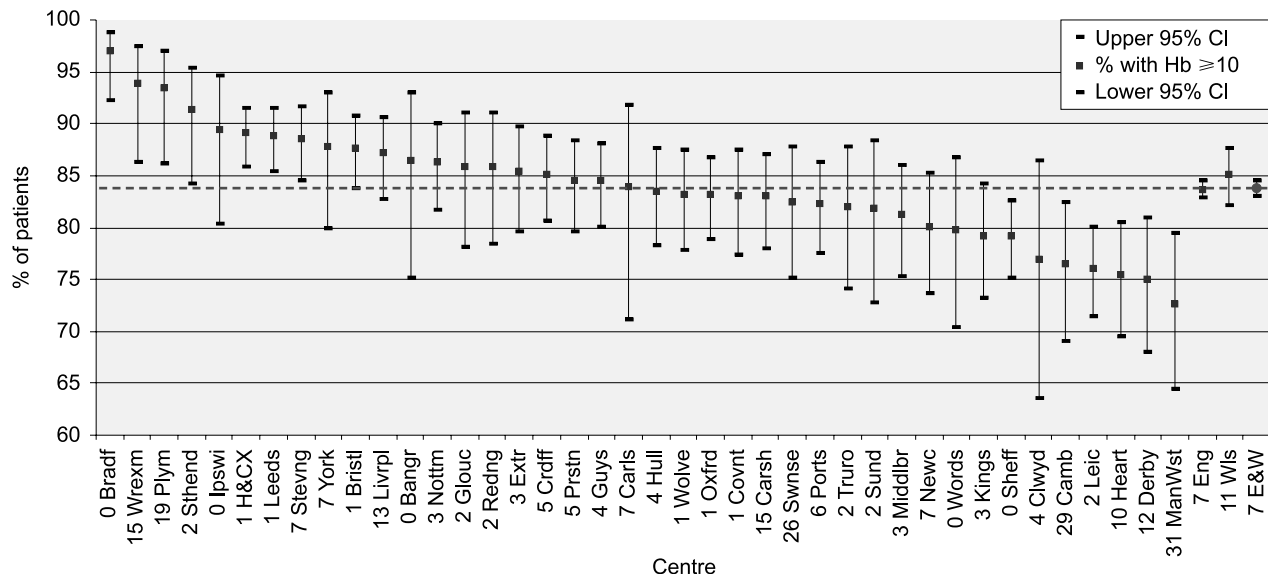


Figure 7.4: Percentage of HD patients, by centre, achieving RA target Hb

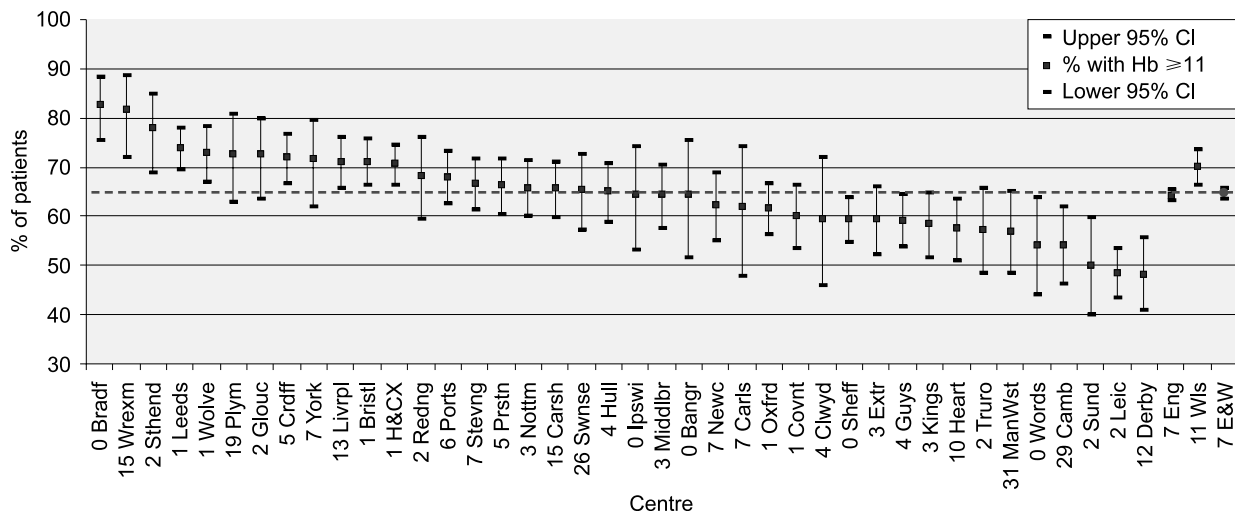


Figure 7.5: Percentage of HD patients with Hb > 11 g/dl

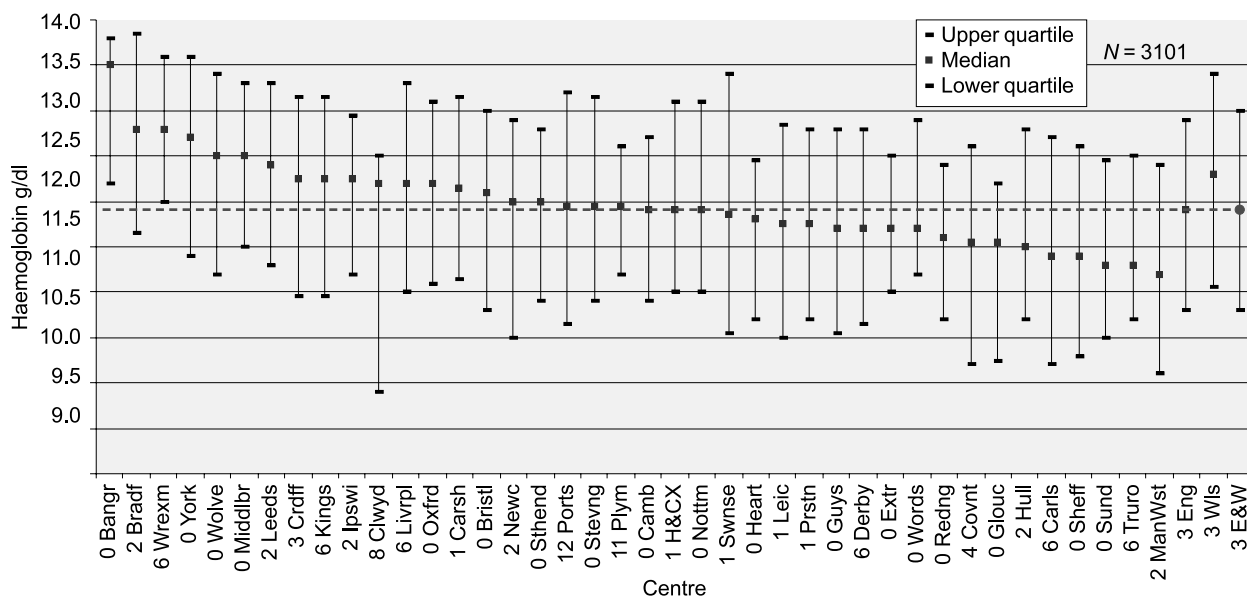


Figure 7.6: Haemoglobin and quartile ranges for PD patients

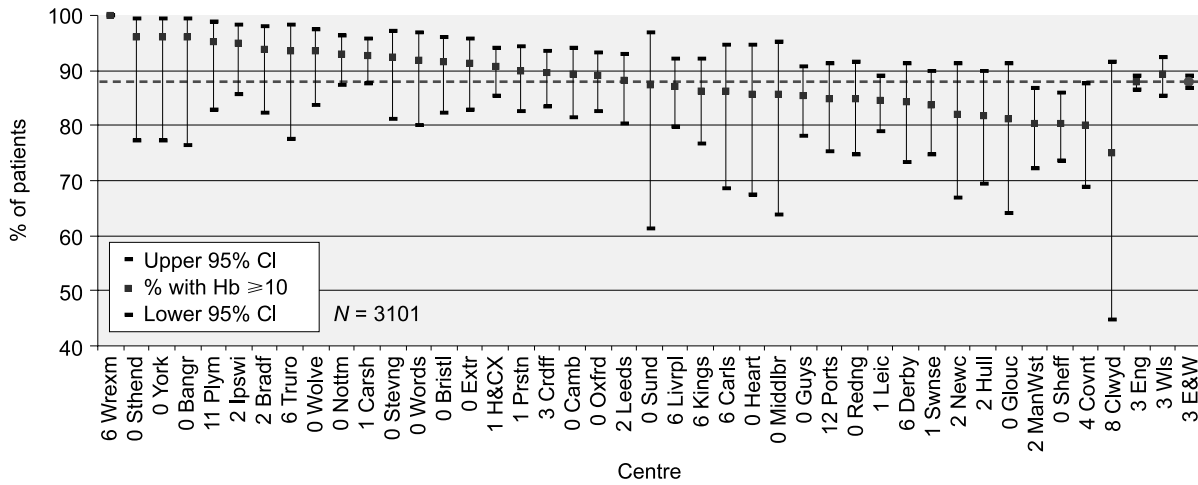


Figure 7.7: Percentage of PD patients, by centre, achieving RA target Hb

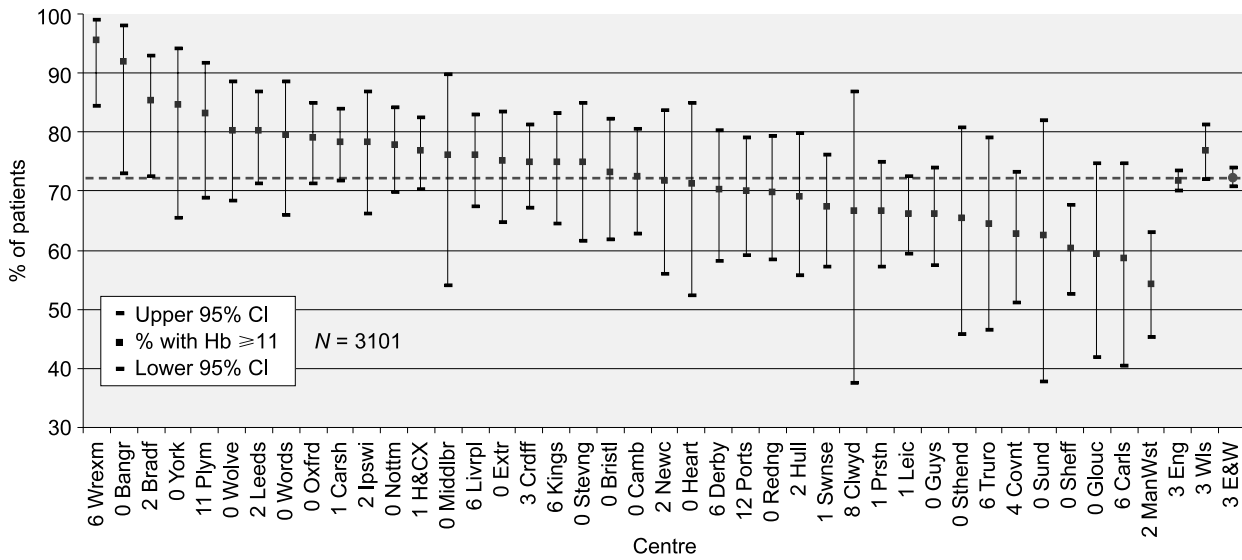


Figure 7.8: Percentage of PD patients with Hb > 11 g/dl

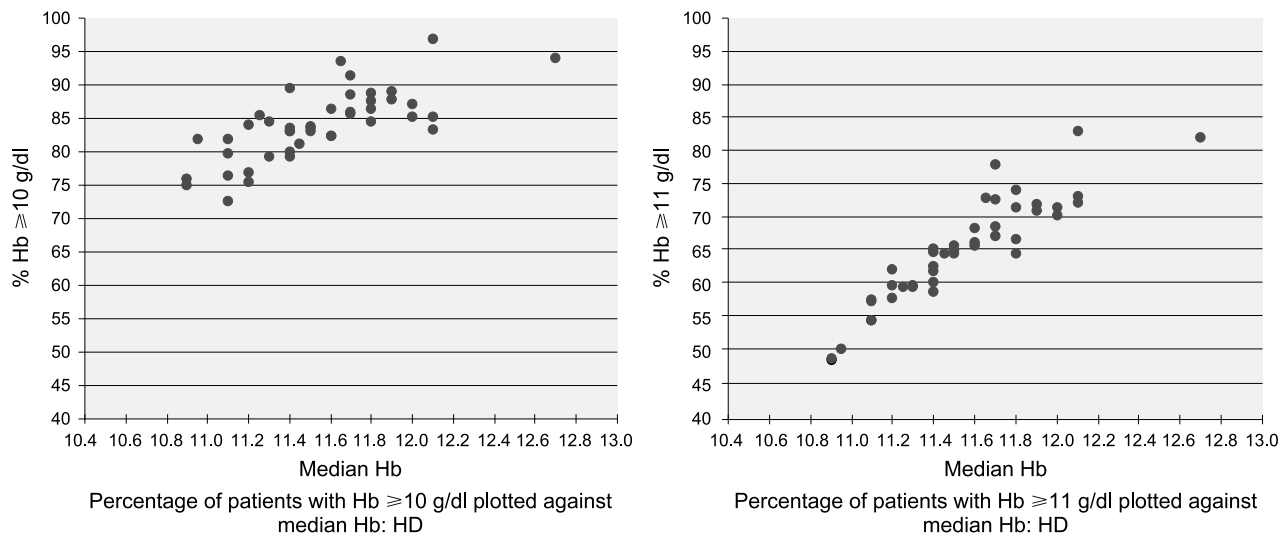


Figure 7.9

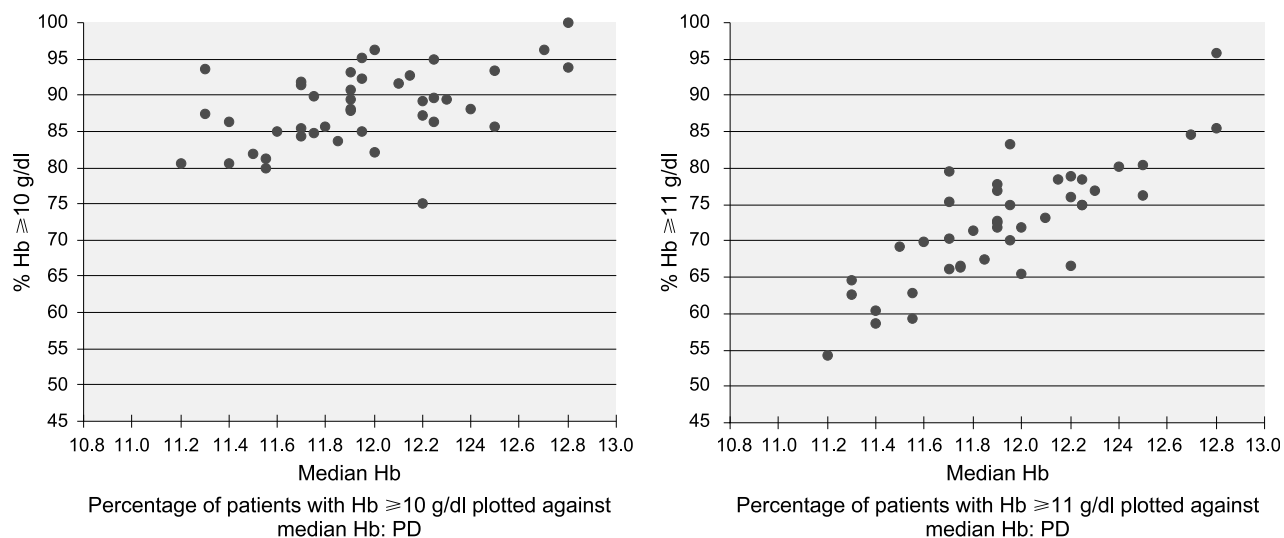


Figure 7.10

Haemoglobin concentrations in patients who have recently started RRT

The haemoglobin concentrations for the first quarter that individuals received dialysis in each centre are presented in table 7.4 and in figures 7.11, 7.12 and 7.13. These new patient data are compared to the data from prevalent dialysis patients in figure 7.14. The Renal Association haemoglobin target no longer distinguishes between patients with chronic renal failure who do or do not receive dialysis treatment.

There is a continuing increase in the percentage of new patients with Hb ≥ 10 g/dl (figure 7.15). The rate of increase has reduced in the past 2 years compared to previously, perhaps because of the proportion of patients who present as uraemic emergencies and have not had an opportunity for management of anaemia

prior to dialysis starting. Some units also experienced difficulties with prescription of erythropoietin to pre-dialysis patients. These factors no doubt also influence the variation in the difference in anaemia management between new and prevalent patients in centres.

Exeter for example, has the lowest percentage (41%) of new patients with Hb ≥ 10 g/dl but achieves 87% Hb ≥ 10 g/dl for prevalent patients. Guys, on the other hand, has 85% of prevalent patients with an Hb ≥ 10 g/dl and 73% of new patients. Figures 7.16 and 7.17 indicate the rate of increase of haemoglobin concentration of new patients over their first year of dialysis treatment. Median haemoglobin rises to 6 months and percentage Hb ≥ 10 g/dl may go on increasing up to 12 months. This data therefore supports the Renal Association standard that allows 6 months to achieve the target haemoglobin concentration.

Table 7.4: Haemoglobin levels for new patients starting dialysis

Centre	% data return	Median Hb g/dl	90% range	Quartile range	% Hb >10 g/dl
Bangr	97	10.2	8.0–15.1	9.4–11.4	61
Bradf	94	10.6	8.1–13.3	9.7–11.5	66
Bristol	100	10.4	8.0–13.3	9.3–11.3	60
Camb	89	10.5	7.7–14.0	9.3–11.7	64
Carls	97	10.6	7.2–13.8	9.4–11.6	61
Carsh	93	10.8	8.1–13.0	9.7–11.8	71
Clwyd	100	9.6	8.1–11.4	9.2–10.3	44
Covnt	93	10.4	8.3–13.4	9.6–11.4	67
Crdff	99	10.8	8.6–13.6	9.9–11.9	74
Derby	73	9.6	7.4–12.0	8.3–10.6	45
Extr	99	9.7	8.1–12.5	9.2–10.5	41
Glouc	100	10.2	7.9–12.9	9.1–10.9	59
Guys	85	10.8	8.6–13.1	9.9–11.7	73
H&CX	99	10.3	8.1–13.4	9.3–11.4	60
Heart	97	9.9	7.5–12.4	9.3–10.7	47
Hull	96	9.9	7.8–12.2	8.9–11.2	49
Ipswi	94	10.6	8.2–12.3	9.4–11.1	60
Kings	74	9.7	8.0–13.2	9.0–11.1	48
Leeds	94	10.3	7.7–13.6	9.3–11.2	64
Leic	99	10.1	7.8–12.9	9.1–11.2	54
Livrpl	99	10.4	8.2–13.4	9.2–11.4	61
ManWst	69	10.1	7.7–12.9	9.1–11.3	54
Middlbr	90	9.8	7.3–12.6	8.5–11.0	44
Newc	89	9.7	7.5–12.7	9.0–11.1	46
Nottm	100	10.1	8.1–13.5	9.1–11.4	51
Oxfrd	100	10.5	8.8–13.3	9.5–11.4	65
Plym	84	10.7	7.8–13.5	9.3–11.6	61
Ports	100	10.0	7.9–13.3	9.0–11.4	51
Prstn	98	9.9	7.8–13.0	9.0–11.4	48
Redng	100	10.5	8.3–13.4	9.5–11.6	65
Sheff	98	10.1	7.9–13.4	9.0–11.1	53
Stevng	99	10.4	8.2–13.6	9.2–11.3	63
Sthend	95	10.9	7.2–12.9	9.1–11.9	63
Sund	98	10.5	7.7–13.7	9.5–11.7	67
Swmse	95	9.9	7.6–12.7	8.8–11.1	45
Truro	100	10.6	7.9–12.8	9.5–11.5	67
Wolve	98	10.3	8.1–13.2	9.1–11.7	60
Words	100	10.0	8.4–14.0	8.8–11.2	50
Wrexm	81	10.4	8.6–12.5	9.8–11.1	68
York	96	10.8	7.7–13.6	10.1–11.7	77
Eng	93	10.3	8.0–13.2	9.2–11.4	58
Wls	96	10.3	8.1–13.3	9.3–11.5	61
E&W	93	10.3	8.0–13.3	9.2–11.4	59

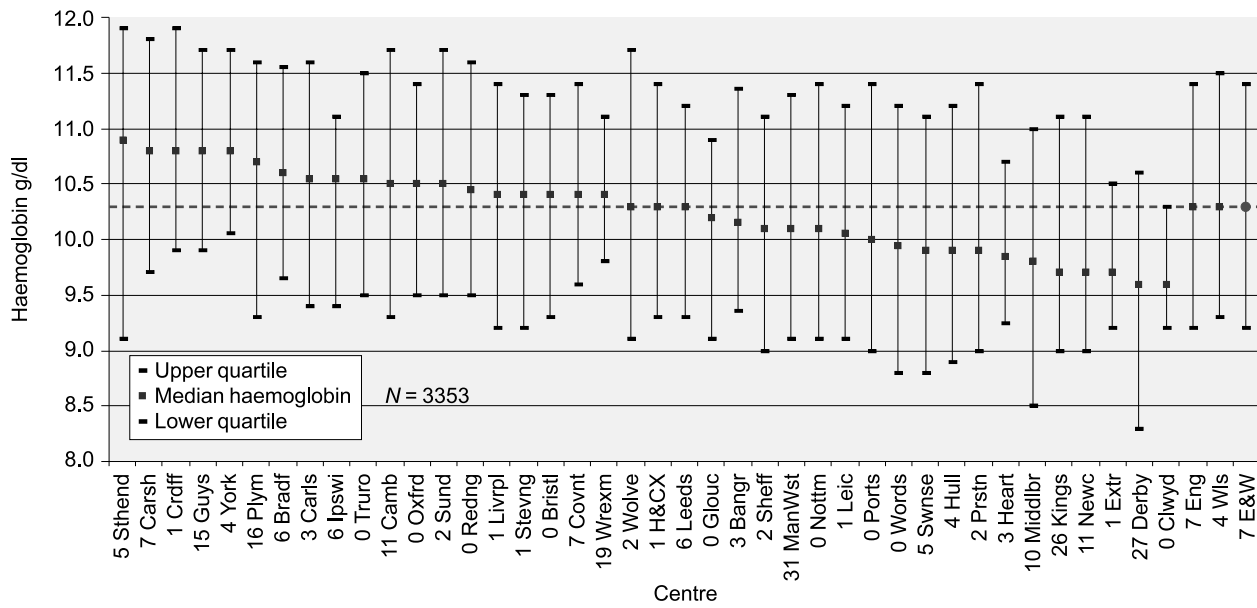


Figure 7.11: Haemoglobin median and quartile range for new patients

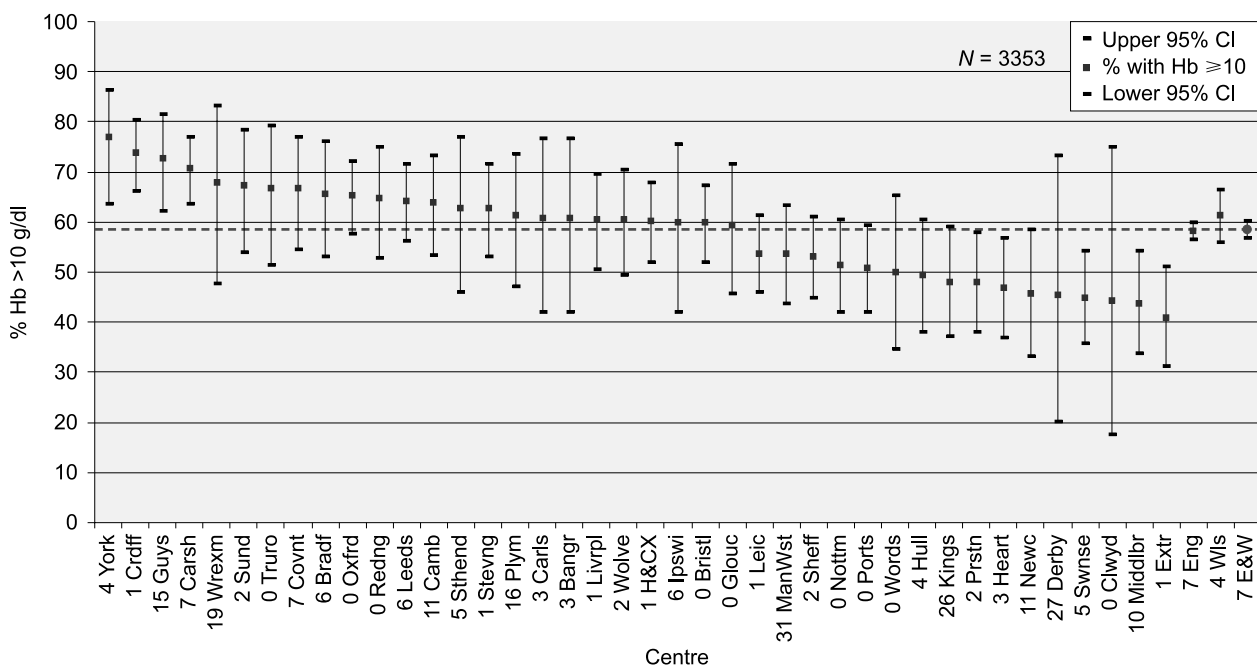


Figure 7.12: Percentage of new patients, by centre, achieving the RA target

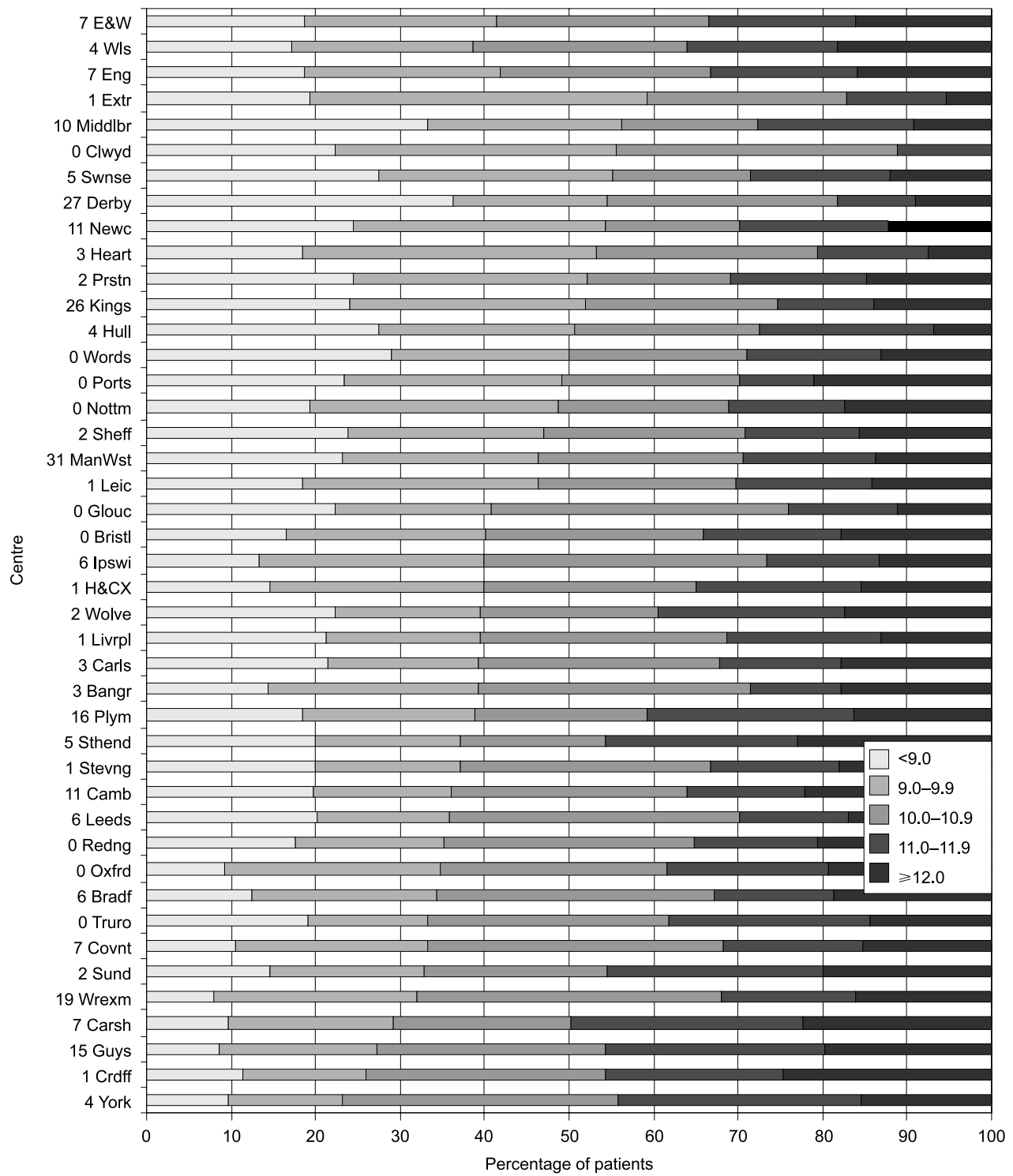


Figure 7.13: Distribution of haemoglobin for new patients

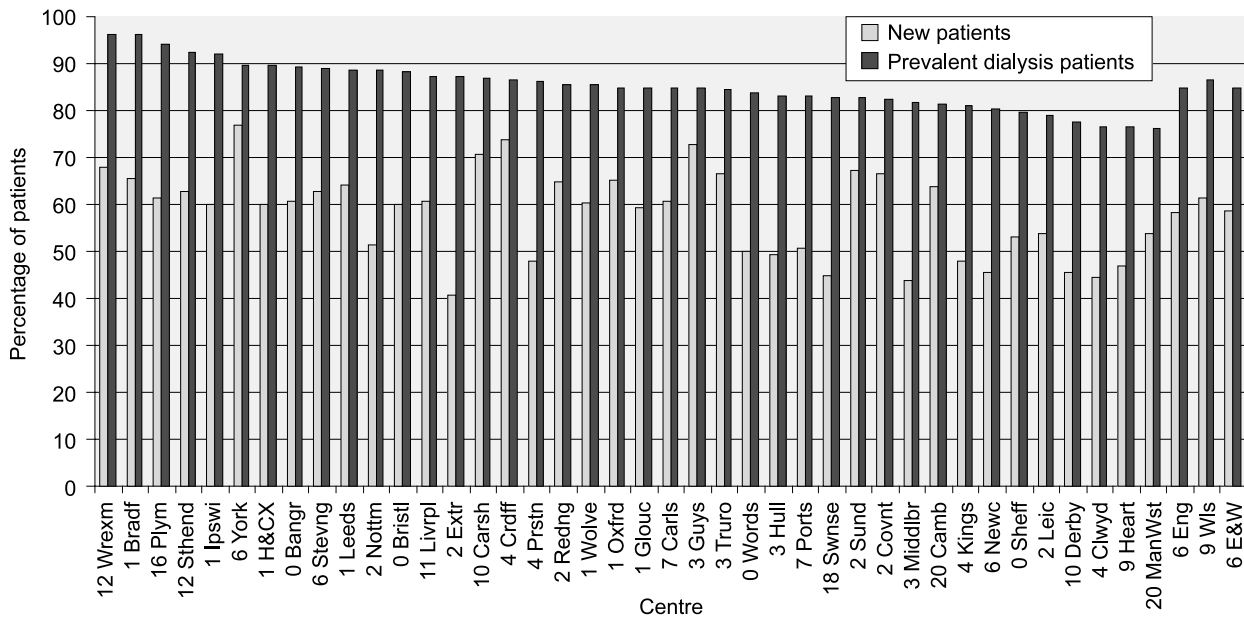


Figure 7.14: Percentage of new and prevalent patients with Hb ≥ 10 g/dl

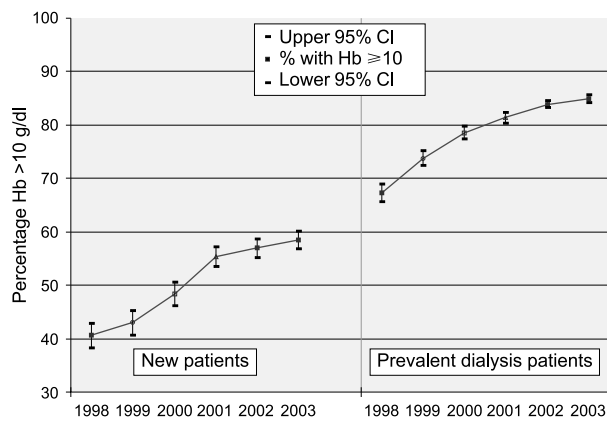


Figure 7.15: Change in percentage of patients starting RRT with Hb ≥ 10 g/dl in E&W 1998–2003

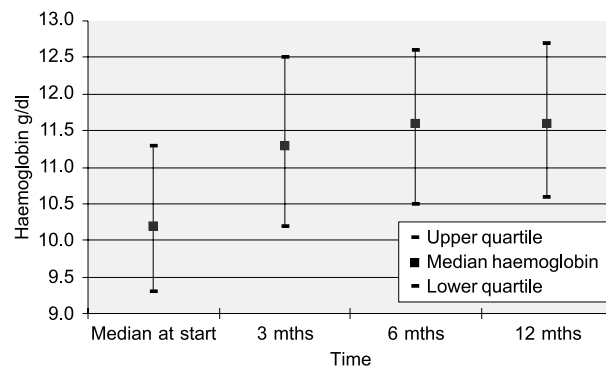


Figure 7.16: Serial median Hb for new patients in 2003

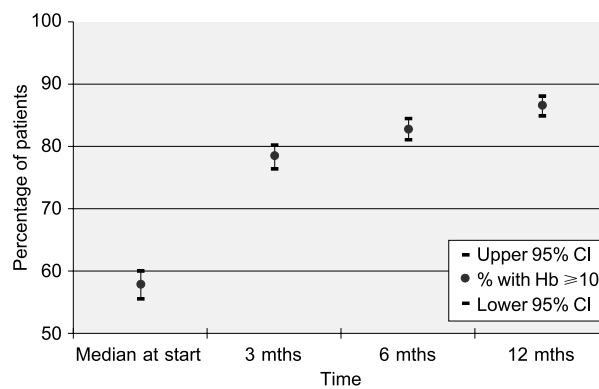


Figure 7.17: Serial percentage of new patients in 2003 with Hb ≥ 10 g/dl

Haemoglobin concentration and change of treatment modality

Figure 7.18 shows the effect on mean haemoglobin concentration of changing from peritoneal dialysis to haemodialysis. There is a sharp fall in haemoglobin concentration in the quarter following the change of dialysis modality. This will reflect the increased risk of anaemia on haemodialysis, failure of any remaining residual renal function after starting HD and also the effect of any illness that precipitated the change of treatment. It is of note that recovery of haemoglobin concentration may take as long as 9 months. Centres utilising algorithms for EPO prescribing may need to take modality data into account and EPO dose should be increased when changing modality.

Although patients on PD generally have a higher haemoglobin than those on HD (tables 7.3 and 7.2, 11.9 v 11.5 g/dl), it is of interest that those patients that change modality from PD have a below average haemoglobin of 11.5 g/dl. By one year post change this has risen back to 11.5 g/dl which is average for HD patients. This indicates that those patients remaining on PD are a separate medical group from those that change.

Dialysis patients who receive kidney transplants may experience a small fall in haemoglobin around the time of transplantation. There is a rapid rise post transplant such that the mean haemoglobin in the first quarter post transplant is substantially higher than the haemoglobin on dialysis. It may still take 6 to 9

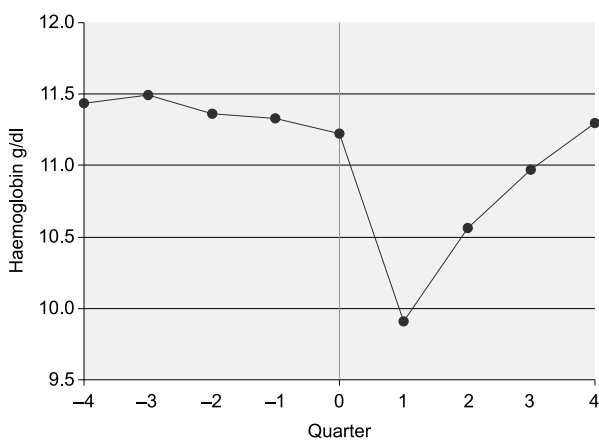


Figure 7.18: Haemoglobin by quarter before and after modality change PD to HD

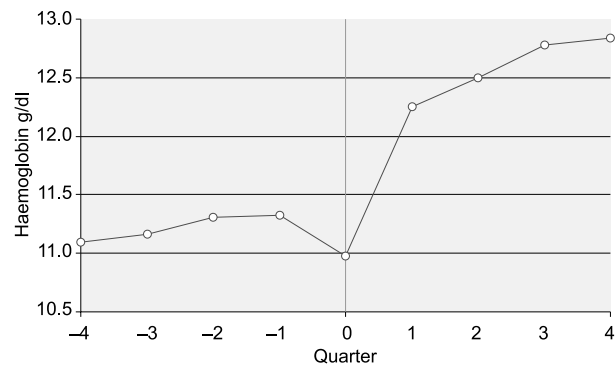


Figure 7.19: Haemoglobin by quarter before and after modality change dialysis to transplant

months post transplantation for haemoglobin to reach its long term level (figure 7.19).

Changes in anaemia management over time

Year on year the Registry data demonstrate an increase in the percentage of haemodialysis patients in England and Wales with haemoglobin ≥ 10 g/dl, this year reaching 82% (figure 7.20). The percentage of peritoneal dialysis patients reaching the target haemoglobin in 2003 was the same as in 2002 at 88%. This steady improvement of anaemia management nationally disguises considerable variability that occurs within single dialysis centres particularly those with relatively small numbers of patients (figures 7.21, 7.22, 7.23, 7.24). Many centres have small numbers of patients on peritoneal dialysis contributing to variability in these results. A single set of data for a particular centre must therefore be interpreted with caution.

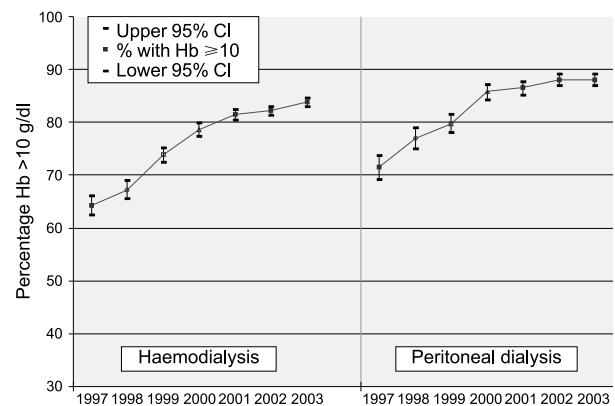


Figure 7.20: Percentage of dialysis patients with Hb ≥ 10 g/dl 1997–2003

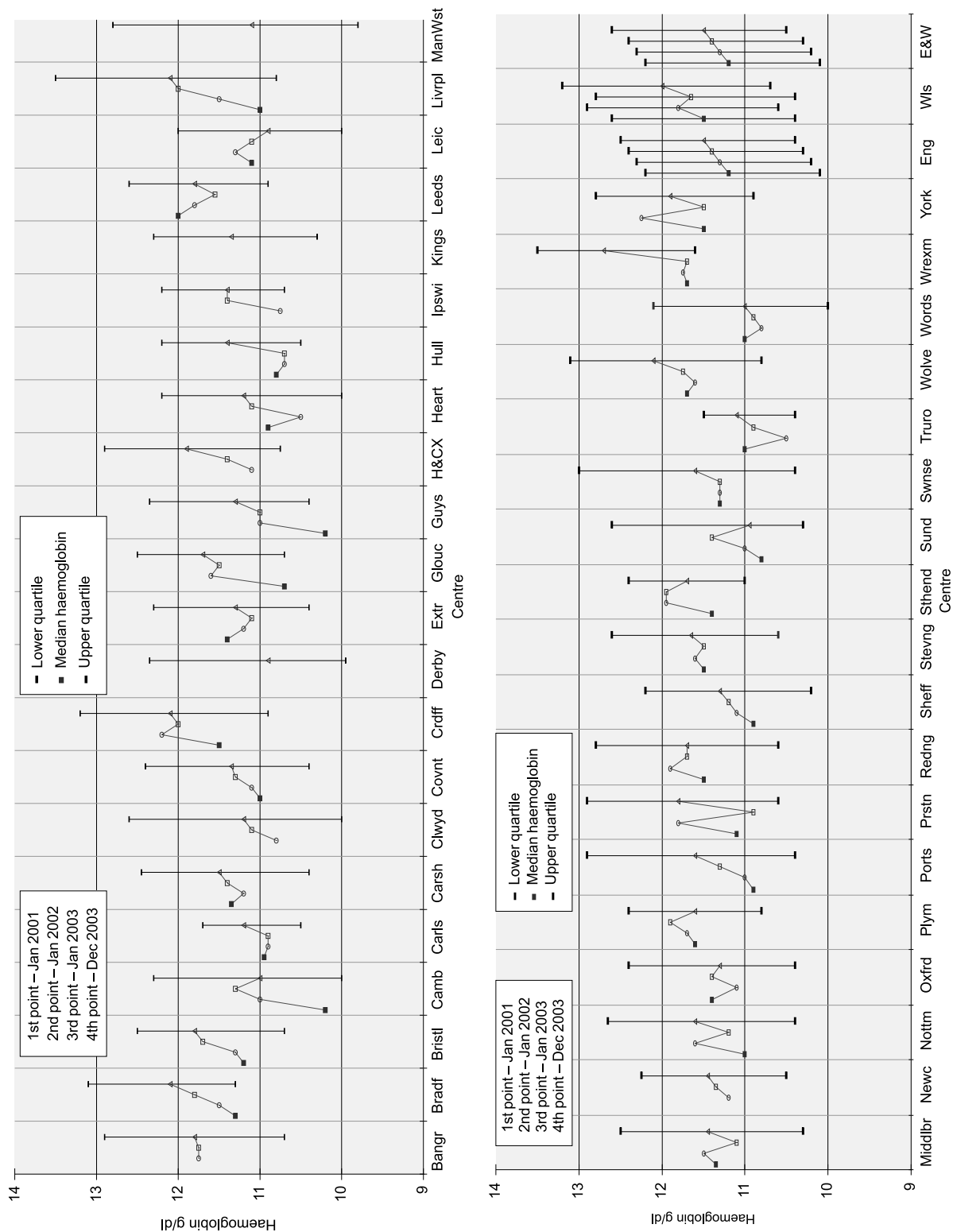


Figure 7.21: Median Hb from start of 2003 by centre: haemodialysis

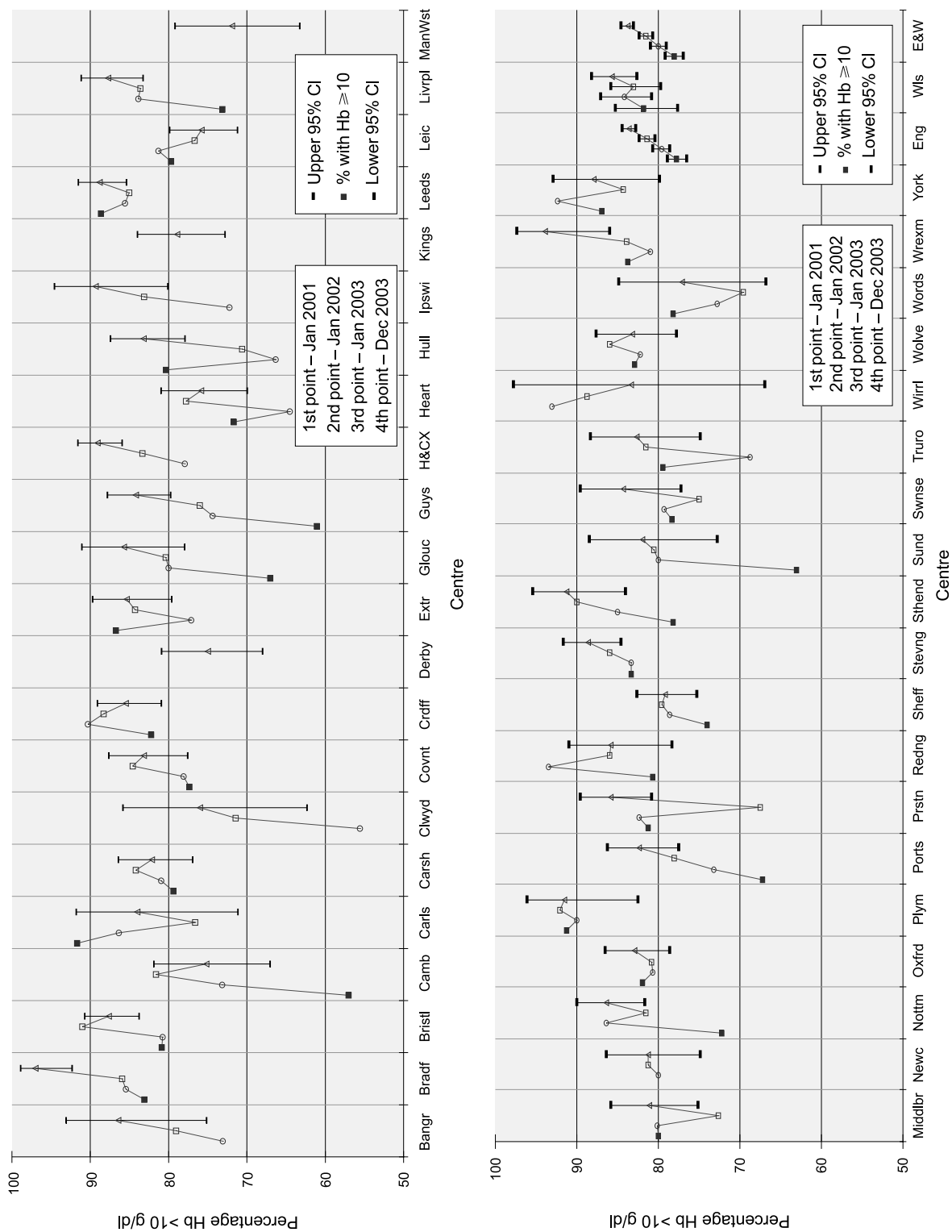


Figure 7.22: Hb ≥ 10 g/dl at start 2001 to end of 2003 by centre: haemodialysis

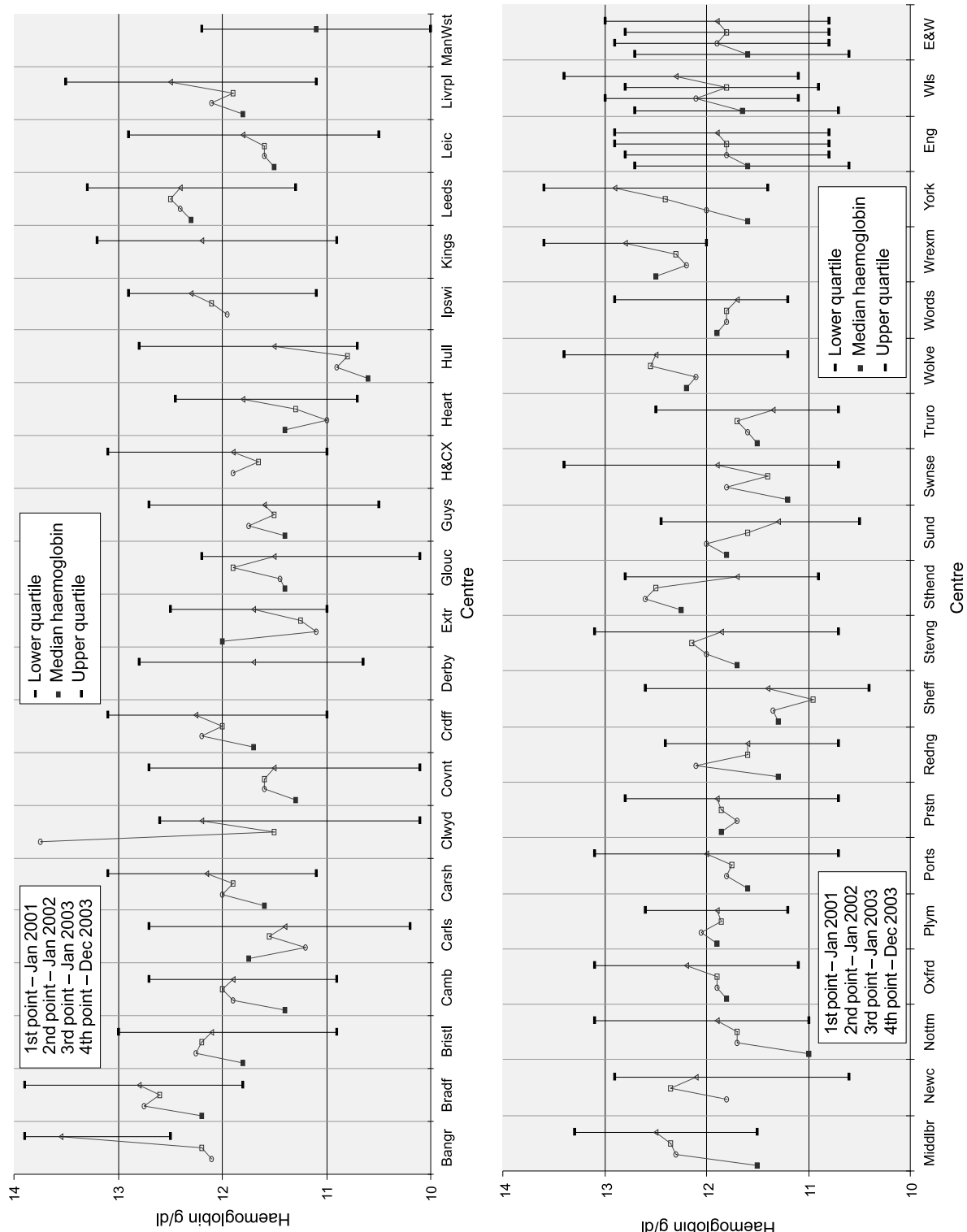


Figure 7.23: Median Hb from start 2001 to end of 2003 by centre: peritoneal dialysis

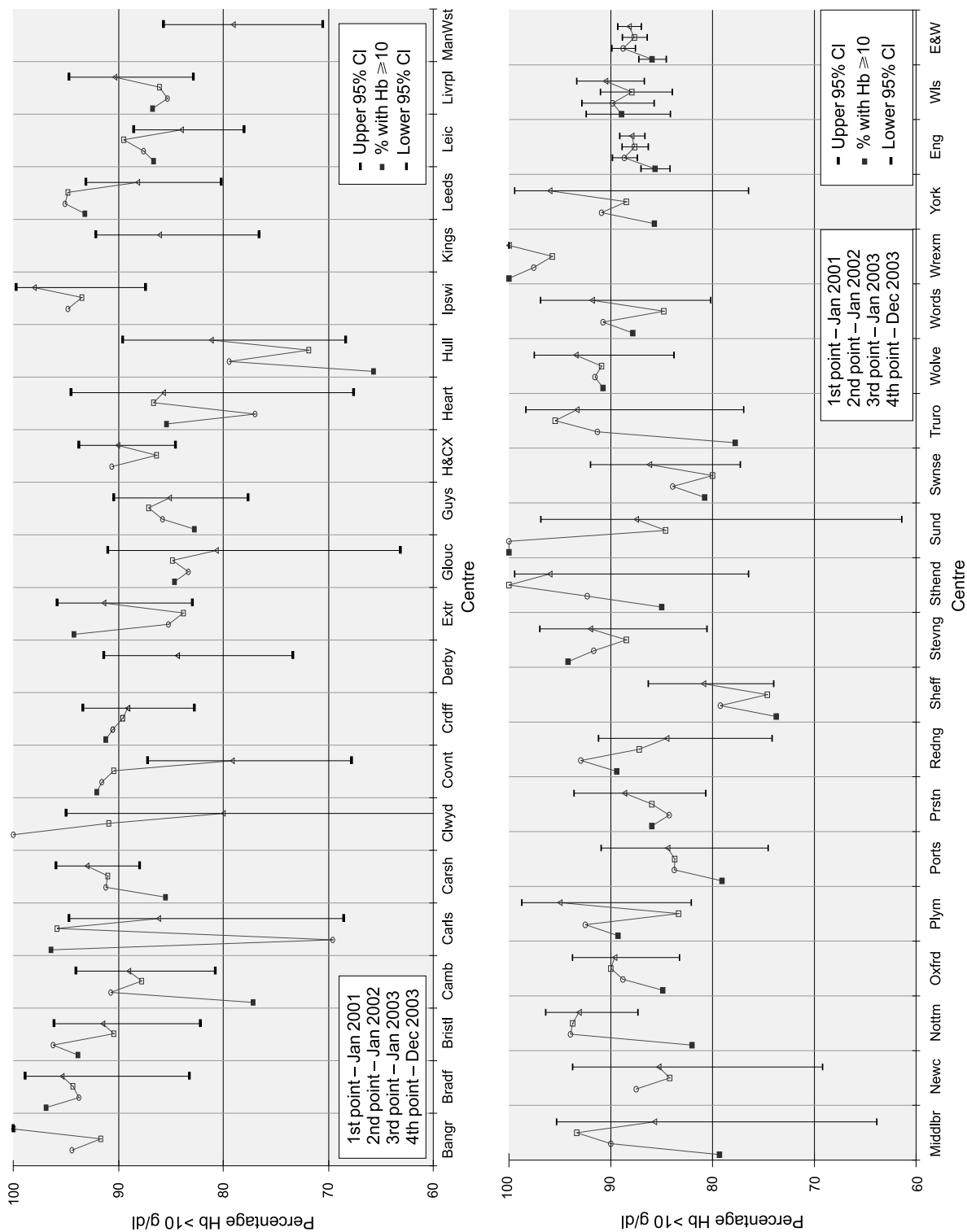


Figure 7.24: Hb ≥ 10 g/dl at start 2001 to end of 2003 by centre: peritoneal dialysis

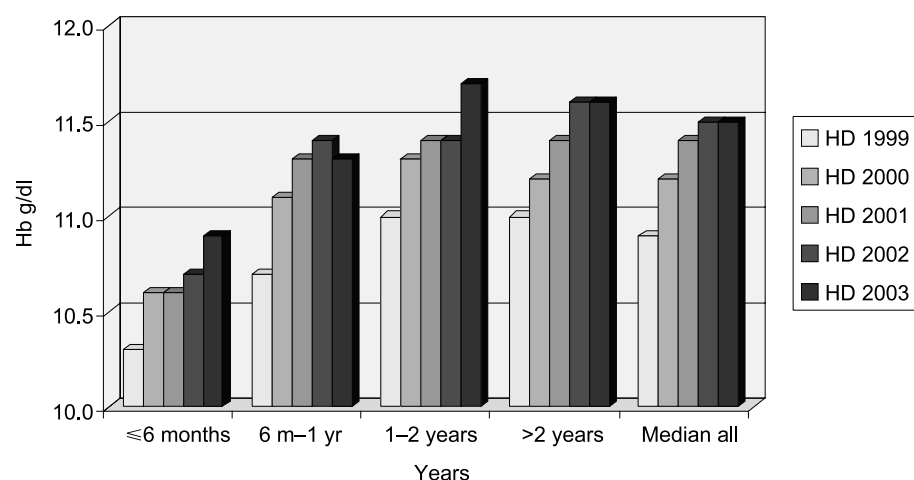


Figure 7.25: Change in median Hb by length of time on RRT HD

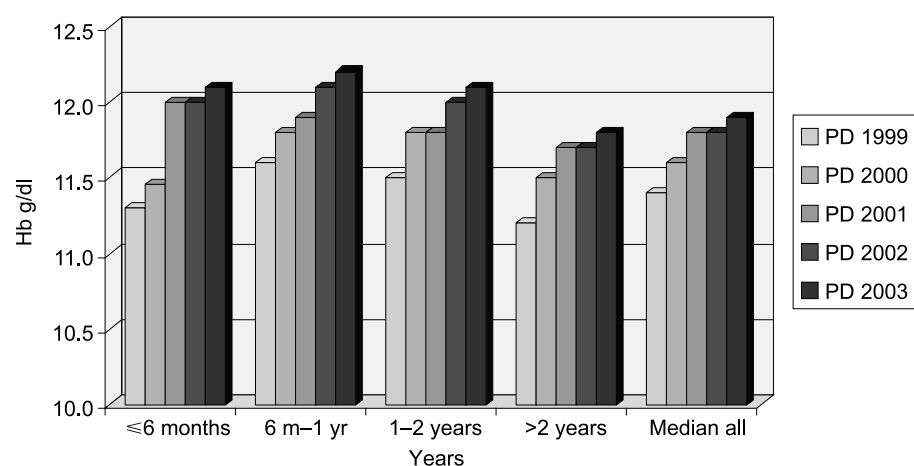


Figure 7.26: Change in median Hb by length of time on RRT PD

Several units that started from a low base in 2001 have made very major advances in anaemia management in subsequent years. Cambridge, Guys, Clwyd and Sunderland stand out as centres that have made significant improvements. A few centres have had declines in the percentage of patients achieving the target Hb and those units will no doubt wish to investigate the causes. Plymouth is interesting for sustaining a stable and very high percentage of patients meeting the target over the 3 years of study despite having a relatively small number of dialysis patients. There is insufficient information to show whether this is because Plymouth has an unusually stable patient group or particularly effective anaemia management.

Figure 7.25 shows that median haemoglobin for new patients within 6 months of starting

haemodialysis has risen from 10.3 g/dl in 1999 to 10.9 g/dl in 2003. Part of this is due to the increased use of EPO pre-dialysis, but there may also be a more rapid rise in haemoglobin.

Figure 7.26 shows that this change is even more striking in patients on PD, where the median haemoglobin has risen from 11.3 g/dl within the first 6 months in 1999 to 12.1 g/dl in 2003.

Conclusion

Anaemia management continues to improve in dialysis units across England and Wales. Pre-dialysis anaemia management remains an area where there is great variability between dialysis centres. Now that the Renal Association standard does not distinguish between dialysis and

pre-dialysis patients this variability should reduce in the future. There is some evidence of a plateau developing in the relationship between percentage of patients achieving the Renal Association target and median haemoglobin

concentration. This suggests that there may be a limit to the extent to which currently used anaemia management protocols can cope with the intrinsic variability in dialysis patients haemoglobin.

Chapter 8: Factors Influencing Haemoglobin

Summary

- The percentage of patients achieving a serum ferritin above 100 µg/L was greater than in 2002 for both haemodialysis (HD) (95% vs 94%) and peritoneal dialysis (PD) (87% vs 85%).
- For patients on HD, more than 90% of patients had a serum ferritin above 100 µg/L at 36 of 40 renal units in contrast to only 15 of 39 units for patients on PD.
- Median ferritin was higher for HD (440 µg/L; quartile range 279–637 µg/L) than for PD (267 µg/L; quartile range 158–436 µg/L).
- There remained large differences in achieved ferritin between different centres, and year-on-year changes in individual units' median ferritin did not always parallel national trends.
- The percentage of patients with serum ferritin >100 µg/L increased linearly with age for both HD and PD modality (linear trend $p < 0.001$).
- After change of modality from PD to HD, serum ferritin rises from 200 µg/L to 330 µg/L at the end of 12 months post switch and continues rising.
- More patients were treated with Erythropoietin Stimulating Agents (ESAs) than in 2001 for both HD (91% vs 83%) and PD (77% vs 65%).
- As in previous reports, the percentage of patients with haemoglobin (Hb) above 10 g/dl without ESA therapy was greater for PD (23%) than HD (7%).
- ESA doses were higher in patients on HD (mean 9,197 units/wk; median 8,000 units/wk) than in PD (mean 5,831 units/wk; median 5,000 units/wk).
- The percentage of patients treated with ESAs varied little with time on HD, but

progressively increased from the second year of PD treatment onwards.

- Age had little impact on the percentage of HD patients treated with ESAs, but in PD patients treatment rates were higher in 18–44 year olds than in older patients.
- A higher percentage of females than males received ESAs in both HD and PD modalities. For both modalities more males than females achieved a Hb above 10 g/dl without ESA treatment.

Introduction

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

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

SDIII and EBPGII also recommend:

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

in addition, EBPGII adds:

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

To achieve adequate iron status across a patient population, SDIII and EBPGII advocate population target medians for ferritin of 200–500 µg/L, for TSAT of 30–40%, for hypochromic red cells of <2.5% and CHr of =35 pg/cell. EBPGII comments that: a serum ferritin target for the treatment population of 200–250 µg/L ensures that 85–90% of patients attain a serum ferritin of 100 µg/L.

All guidelines advise that:

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

Serum ferritin has several disadvantages as an index of iron status. It measures storage iron rather than available iron; behaves as an acute phase reactant, and is therefore increased in inflammatory states, malignancy and liver disease; and may not accurately reflect iron stores if measured within a week of the administration of intravenous iron. Of the alternative measures of iron status available, HRC and CHr are generally considered superior to TSAT. Both however require specialised analysers to which few UK renal units have easy access. Since TSAT is measured infrequently in many centres, and most UK units continue to use serum ferritin for routine iron management, ferritin remains the chosen index of iron status for this report. The Registry will start collecting TSAT, HRC and CHr from those units measuring it.

Information on the use of ESAs was excluded from the 2003 report due to data collection problems. These problems have now been addressed, allowing ESA data from 23 units to be presented in this report. These data remain incomplete and work continues to establish more comprehensive ESA returns. Data are presented as total weekly erythropoietin dose. Doses of darbepoietin were harmonised with erythropoietin data by multiplying by 200 and correcting for any frequency of administration less than weekly.

Completeness of data returns

The completeness of serum ferritin returns to the Registry over 6 months is shown in table 8.1. Not all sites use serum ferritin as the sole indicator of iron status. The Wirral renal unit does not have an automated biochemistry link into the IT renal system which accounts for their very low rate of return. Some haemodialysis patients may be having serum ferritin measured at their satellite haemodialysis centre

Table 8.1: Completeness of serum ferritin returns

	Ferritin HD %	Ferritin PD %
Bangor	100	92
Bradford	100	100
Bristol	100	100
Cambridge	71	96
Carlisle	93	94
Carshalton	78	92
Clwyd	94	100
Coventry	99	93
Cardiff	96	96
Derby	87	91
Exeter	97	100
Gloucester	97	97
Guys	99	99
H&CX	98	97
Heartlands	93	100
Hull	96	96
Ipswich	99	70
Kings	99	94
Leeds	99	98
Leicester	97	99
Liverpool	85	95
ManWest	71	98
Middlesbrough	93	100
Newcastle	97	98
Nottingham	97	100
Oxford	91	99
Plymouth	84	98
Portsmouth	94	87
Preston	98	100
Reading	98	100
Sheffield	100	100
Stevenage	89	100
Southend	96	94
Sunderland	96	100
Swansea	70	99
Truro	98	91
Wolverhampton	17	19
Wordsley	99	100
Wrexham	97	96
York	85	90
England	92	96

and this data may not always be transferred to the main renal unit IT system. In other cases of missing data, renal units may need to address structural processes to ensure that serum ferritin is checked at the 3 monthly clinic visit.

Serum ferritin

Serum ferritin concentrations and interquartile ranges are presented in table 8.2 and figure 8.1

for haemodialysis and table 8.3 and figure 8.2 for peritoneal dialysis. The percentages of patients achieving a serum ferritin over 100 µg/L for each modality are shown in figures 8.3 and 8.4.

Table 8.2: Serum ferritin concentration in HD patients

Centre	% data return	Median ferritin	90% range	Quartile range	% ferritin >100 µg/L
Bangor	100	499	148–960	357–641	97
Bradford	100	351	145–949	260–493	99
Bristol	100	418	70–1304	210–683	91
Cambridge	71	160	11–658	75–306	66
Carlisle	93	379	190–956	262–507	98
Carshalton	78	379	131–998	251–519	97
Clwyd	94	264	107–687	222–408	96
Coventry	99	352	75–1467	196–501	92
Cardiff	96	602	155–1207	411–824	99
Derby	87	344	75–973	212–508	92
Exeter	97	335	133–678	256–432	97
Gloucester	97	310	44–848	190–414	88
Guys	99	444	94–1012	283–645	95
H&CX	98	586	191–1449	381–814	97
Heartlands	93	170	31–535	97–287	73
Hull	96	455	156–893	330–617	97
Ipswich	99	482	57–911	227–633	91
Kings	99	511	169–1107	360–680	98
Leeds	99	534	256–1044	446–650	99
Leicester	97	389	116–875	232–569	96
Liverpool	85	675	86–1714	407–1000	95
ManWest	71	481	81–1351	256–786	94
Middlesbrough	93	337	56–1301	187–674	87
Newcastle	97	464	206–933	355–600	98
Nottingham	97	553	226–1066	433–661	99
Oxford	91	313	91–799	213–438	94
Plymouth	84	554	148–1404	408–686	96
Portsmouth	94	358	121–820	264–492	97
Preston	98	530	136–1211	359–790	97
Reading	98	558	277–1174	429–803	100
Sheffield	100	523	113–1055	362–696	96
Stevenage	89	425	107.5–1169	288–629	96
Southend	96	360	190–671	285–437	99
Sunderland	96	472	154–1178	320–624	99
Swansea	70	360	93–952	225–532	94
Truro	98	513	254–935	387–640	99
Wolverhampton	99	463	186–798	347–568	98
Wordsley	97	451	126–1118	320–710	98
Wrexham	85	553	194–1084	418–864	96
York	92	556	238–908	432–656	100
England	92	436	97–1104	278–629	95
Wales	88	508	126–1095	305–732	97
Eng & Wales	92	440	98–1103	279–637	95

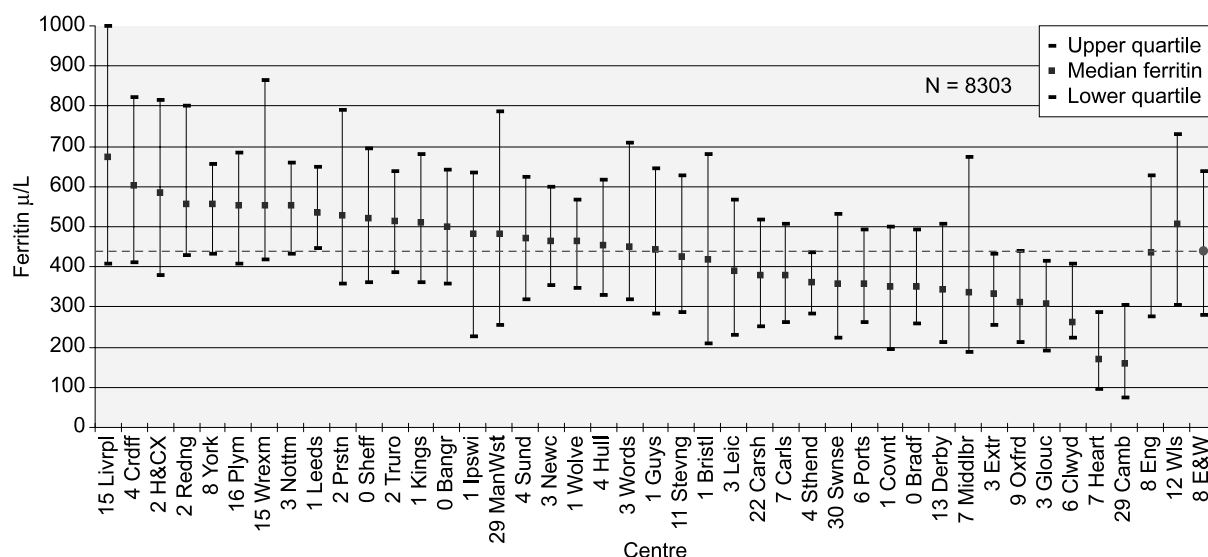


Figure 8.1: Median serum ferritin: haemodialysis

All centres achieved a median ferritin over 100 µg/L for both HD and PD, though as in previous reports the overall median was higher for HD (440 µg/L) than for PD (267 µg/L). Despite good overall achievement of targets for ferritin, there remained large variations in achieved ferritin between units. For HD patients, median ferritin ranged from 160 to 675 µg/L, and for PD from 140 to 712 µg/L, and whilst only four centres had fewer than 90% of HD patients with ferritin less than 100 µg/L, this applied to 24 units in respect of PD. This may reflect both variations in facilities and staff for the administration of intravenous iron (particularly for home dialysis patients) and differences in the ability of units to finance a large intravenous iron replacement programme.

Many centres showed marked differences in iron status between their HD and PD populations suggesting that iron replacement practices are different for the two modalities, either by design or because of logistical problems in providing intravenous iron to PD patients. The three centres with the highest median ferritin in HD (Liverpool, Cardiff and Hammersmith & Charing Cross) all had ferritin values near the national median in PD, suggesting either that they aspired to higher targets for HD than PD, or that PD patients had poorer access to intravenous iron. In contrast, Middlesbrough and Sunderland, who in last year's report had the highest median ferritin for PD, returned ferritin values near the national median for HD, implying intentional targeting of iron therapy to their PD population.

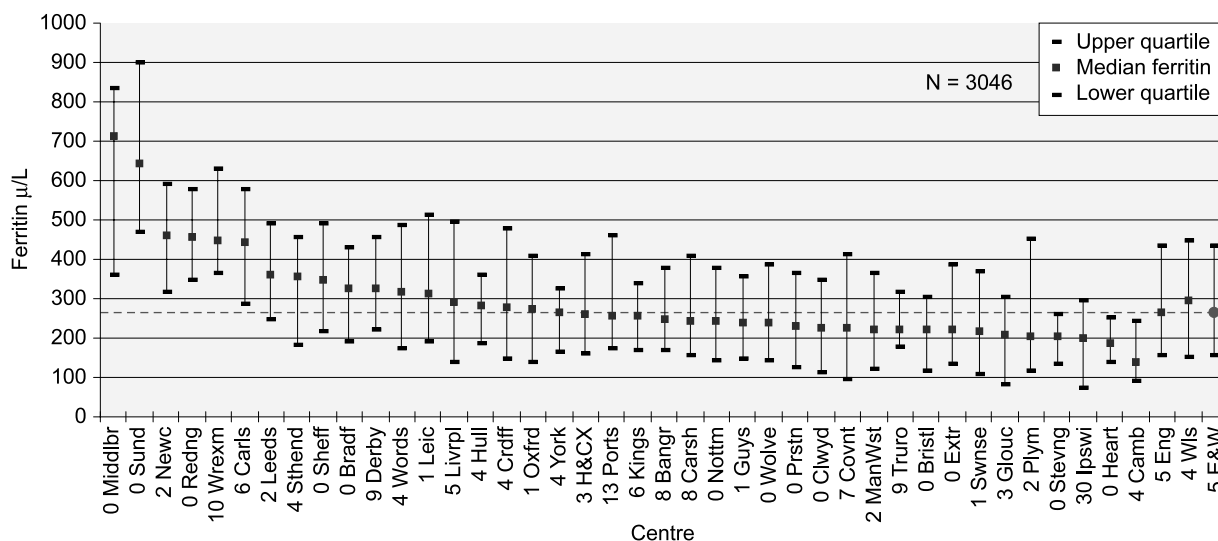


Figure 8.2: Median serum ferritin: peritoneal dialysis

Table 8.3: Serum ferritin concentration in PD patients

Centre	% data return	Median ferritin	90% range	Quartile range	% ferritin >100 µg/L
Bangor	92	250	120–474	168–380	96
Bradford	100	327	84–829	190–430	90
Bristol	100	221	35–521	117–305	77
Cambridge	96	140	29–564	91–243	70
Carlisle	94	445	230–1032	285–579	100
Carshalton	92	245	42–781	155–410	85
Clwyd	100	228	48–529	111–348	77
Coventry	93	226	33–1076	94–413	72
Cardiff	96	278	60–908	149–478	87
Derby	91	326	82–760	223–457	90
Exeter	100	221	56–722	136–389	81
Gloucester	97	207	10–693	82–306	71
Guys	99	241	57–838	150–355	86
H&CX	97	263	57–1150	159–412	89
Heartlands	100	186	24–478	138–253	86
Hull	96	282	107–664	185–361	96
Ipswich	70	199	22–496	75–296	72
Kings	94	255	85–746	171–337	93
Leeds	98	361	144–935	249–492	99
Leicester	99	315	49–879	192–511	89
Liverpool	95	290	49–966	138–497	87
ManWest	98	223	37–1111	120–367	81
Middlesbrough	100	712	187–1141	359–834	100
Newcastle	98	461	49–1029	317–593	95
Nottingham	100	243	72–746	143–378	90
Oxford	99	272	44–848	140–407	84
Plymouth	98	207	57–683	118–452	83
Portsmouth	87	258	62–1200	176–462	89
Preston	100	232	54–829	128–366	84
Reading	100	456	142–958	350–580	96
Sheffield	100	346	72–891	219–490	93
Southend	96	358	67–700	182–456	90
Stevenage	100	204	47–497	135–263	81
Sunderland	100	644	96–1141	469–900	94
Swansea	99	220	19–677	110–370	79
Truro	91	222	64–594	178–318	90
Wolverhampton	100	239	76–543	145–389	87
Wordsley	96	316	63–838	176–488	87
Wrexham	90	450	292–903	364–630	100
York	96	265	72–1025	166–325	84
England	95	266	53–872	158–434	87
Wales	96	296	51–874	152–450	87
Eng & Wales	95	267	53–872	158–436	87

Given that only two centres for HD and three centres for PD had a median serum ferritin less than 200 µg/L, it is unsurprising that no relationship exists for either modality

between the percentage of patients with serum ferritin above 200 µg/L and a haemoglobin level >10 g/dl (figures 8.5 and 8.6).

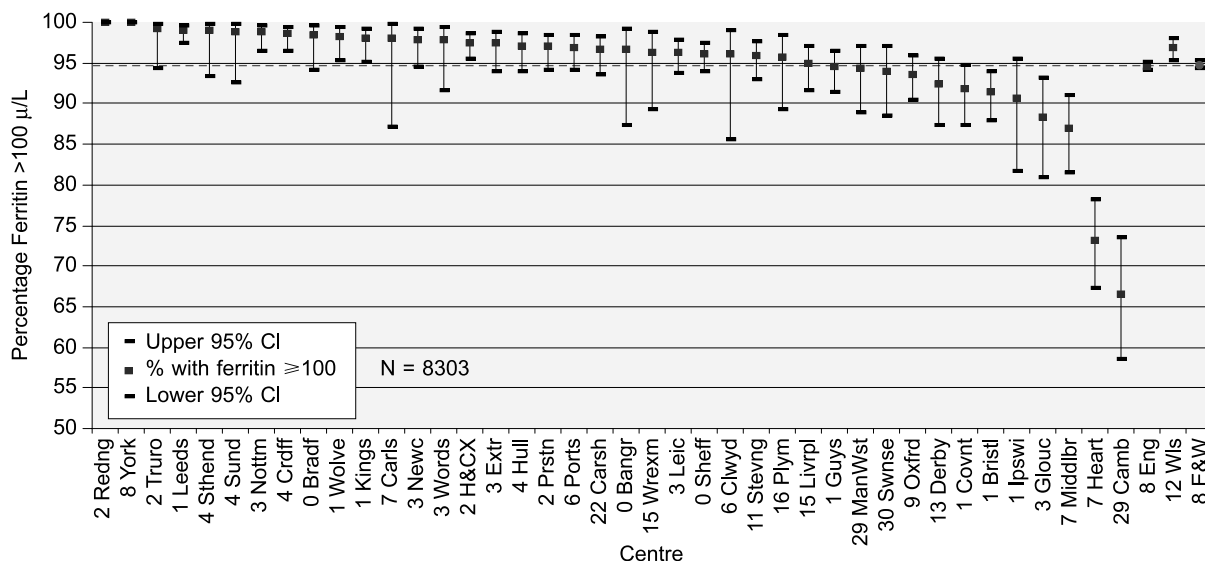


Figure 8.3: Percentage of HD patients with serum ferritin >100 µg/L

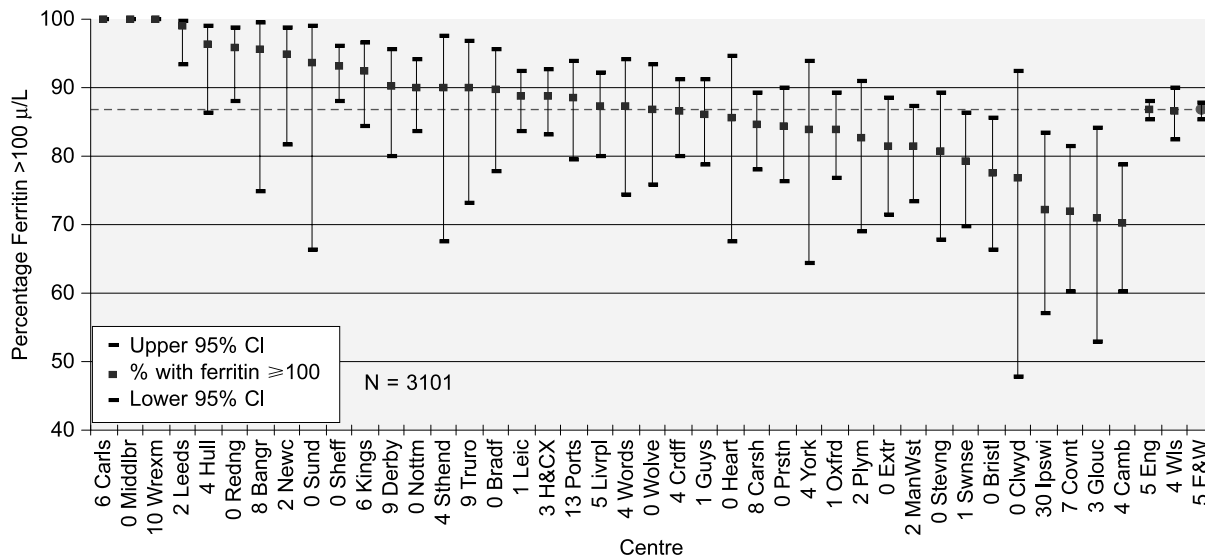


Figure 8.4: Percentage of PD patients with serum ferritin >100 µg/L

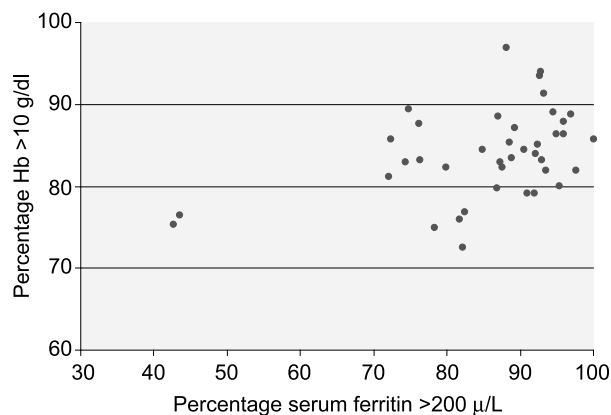


Figure 8.5: Percentage of patients with serum ferritin >200 µg/L and Hb >10 g/dl on HD

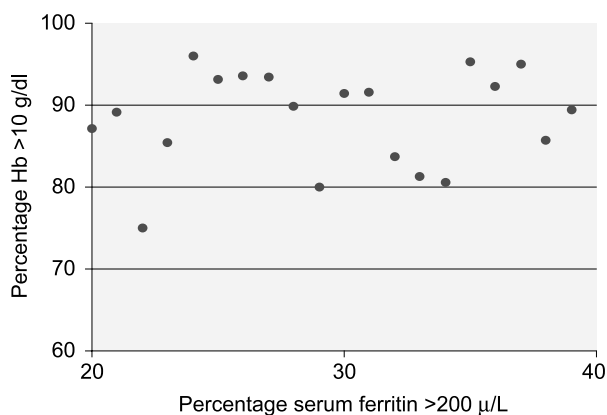


Figure 8.6: Percentage of patients with serum ferritin >200 µg/L and Hb >10 g/dl on PD

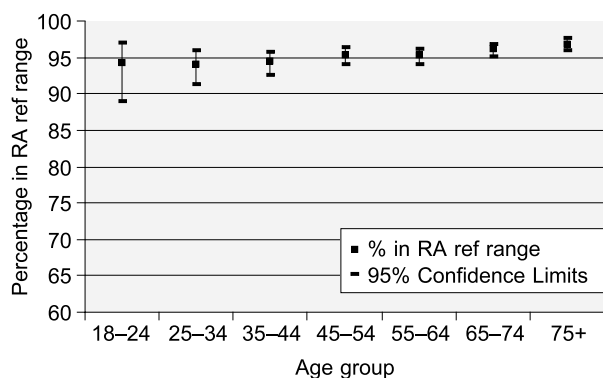


Figure 8.7: Percentage of HD patients with a serum ferritin >100 µg/L by age band

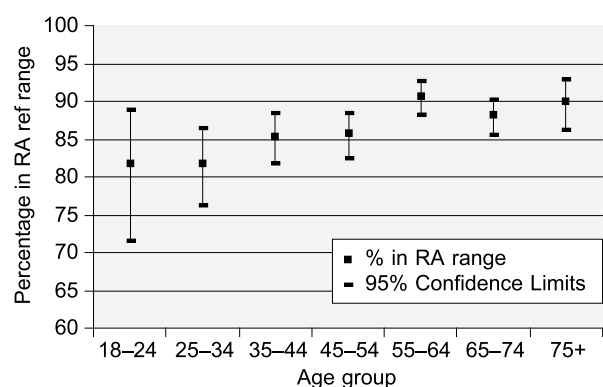


Figure 8.8: Percentage of PD patients with a serum ferritin >100 µg/L by age band

Achievement of serum ferritin and patient age

The achievement of serum ferritin >100 µg/L by age band has not been previously analysed by the Registry and is shown in figures 8.7 and 8.8.

The percentage of HD patients with a serum ferritin >100 µg/L was found to differ significantly between the age groups (χ^2 test, $p = 0.027$). The χ^2 test for linear trend was also significant ($p < 0.001$) and the test for deviation from non linearity was not significant.

The percentage of PD patients with a serum ferritin >100 µg/L was found to differ significantly between the age groups (χ^2 test, $p = 0.003$). The χ^2 test for linear trend was also significant ($p < 0.001$) and the test for deviation from non linearity was not significant.

Changes in serum ferritin 1999–2003 in England and Wales

Figure 8.9 shows that the percentage of HD and PD patients achieving a ferritin over

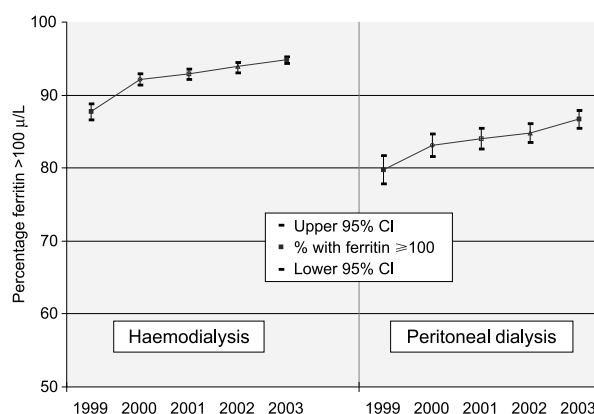


Figure 8.9: Percentage change in achievement of serum ferritin >100 µg/L, 1999–2003

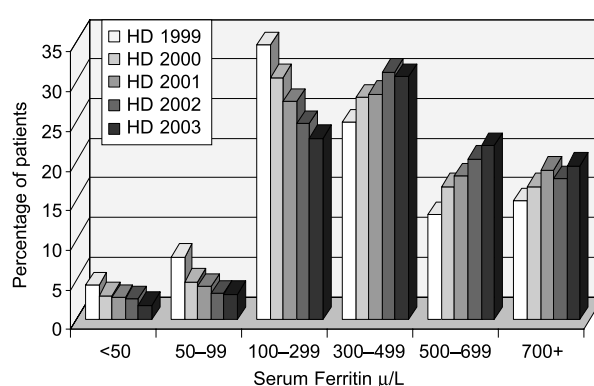


Figure 8.10: Serum ferritin distribution 1999–2003 haemodialysis

100 µg/L continued its year-on-year rise during 2003. For the first time, there was a fall in the percentage of HD patients with serum ferritin in the range 300–499 µg/L, and as expected given the overall rise in median ferritin, the percentage with ferritin over 500 µg/L correspondingly increased (figure 8.10). For PD, the percentage with ferritin 300–499 µg/L and above continued to increase (figure 8.11), showing a lag behind the trend for HD.

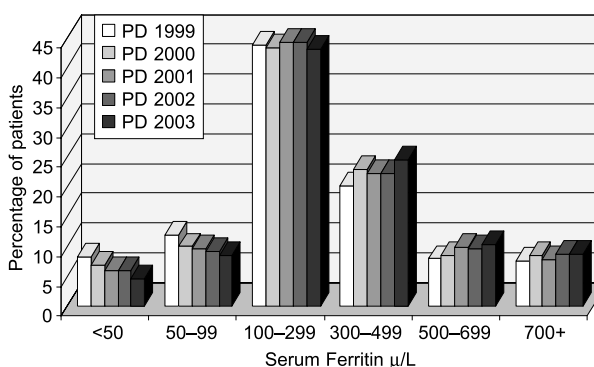


Figure 8.11: Serum ferritin distribution 1999–2003 peritoneal dialysis

Serum ferritin and length of time on renal replacement therapy

As in last year's report, the median and lower quartile values for serum ferritin were above 100 µg/L for both HD and PD by the sixth month on dialysis. As before however, median ferritin continued to increase beyond this time, reaching the respective modality median by two years after the start of dialysis (figures 8.12 and 8.13). For HD this paralleled a rise in Hb over the same period, though in PD haemoglobin fell from one year onwards in contrast to the continuing rise in ferritin. This observation implies that many units continue to drive up the serum ferritin in patients who on the basis of published guidelines would already be considered iron replete, again suggesting that local targets for serum ferritin may exceed published recommendations.

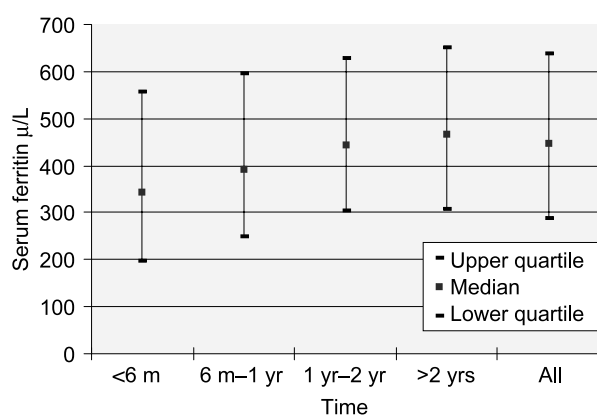


Figure 8.12: Median ferritin by length of time on RRT: HD

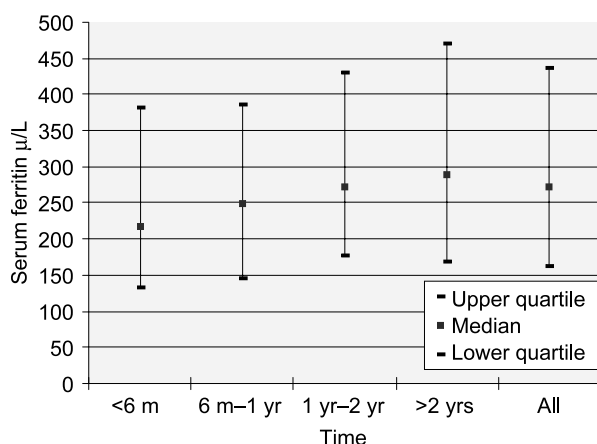


Figure 8.13: Median ferritin by length of time on RRT: PD

Changes in serum ferritin by centre 1999–2003

The continuing rise in median ferritin across England and Wales between 1999 and 2003 was not universally paralleled in individual renal units. In respect of HD, serial ferritin values from individual units broadly followed one of four patterns during this period (figure 8.14). Bristol, Leicester, Portsmouth, Stourbridge and Wrexham matched the national picture, showing a progressive and continuing rise in serum ferritin throughout the four year period. In all these centres except Wrexham (where the national median was exceeded in every year except 2000) this increased from a relatively low baseline in 1999 to values near to (or in Stourbridge exceeding) the national median by 2003. In Exeter, Gloucester, Preston, Nottingham and Southend, rising medians in earlier years were followed by a plateau, suggesting successful achievement of a local target. Guys, Leeds, Liverpool, Sheffield and Sunderland maintained a stable median ferritin between 1999 and 2003, and in every year this exceeded the respective national median. Finally, Carlisle and Swansea showed a falling trend, although both centres still returned a median ferritin within the recommended population target in 2003.

Year-on-year changes of median ferritin in PD patients were less pronounced than in the HD population, with more units maintaining stable levels than showing progressive change (figure 8.15). Several units did however, show serial increases, including Coventry, Guys, Liverpool, Reading and Wrexham. Of particular note are Middlesbrough and Sunderland, whose pronounced rise in ferritin in the PD population contrasted with stable levels in HD patients over the same period. This again suggests preferential targeting of iron replacement to PD patients in these units.

Change in serum ferritin after modality change

The change in serum ferritin before and after modality change has not been previously analysed. Patients who died within 12 months after change of modality were excluded from the analysis as they may have just changed from PD to HD due to inter-current illness prior to death.

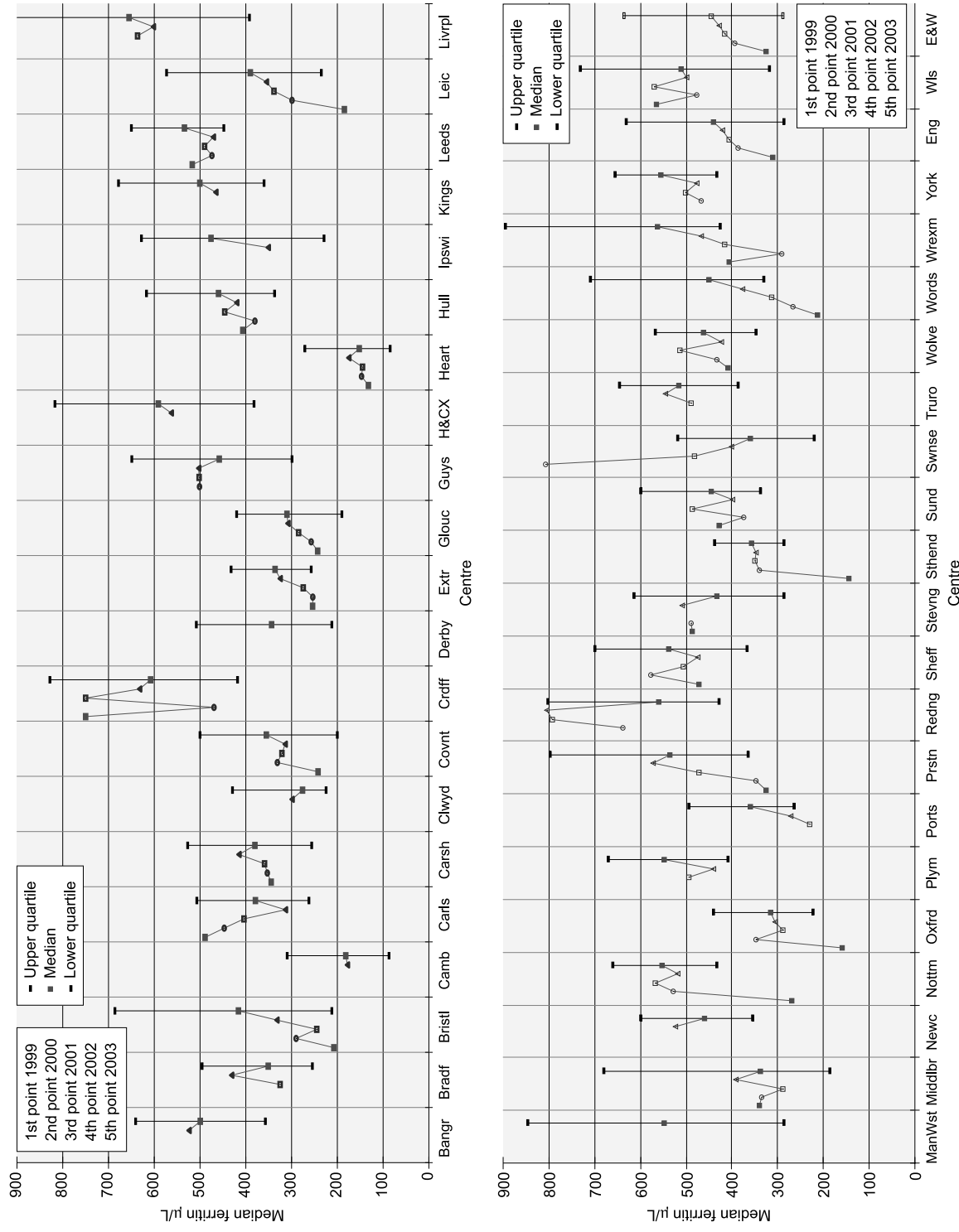


Figure 8.14: Serial ferritin concentration in haemodialysis patients

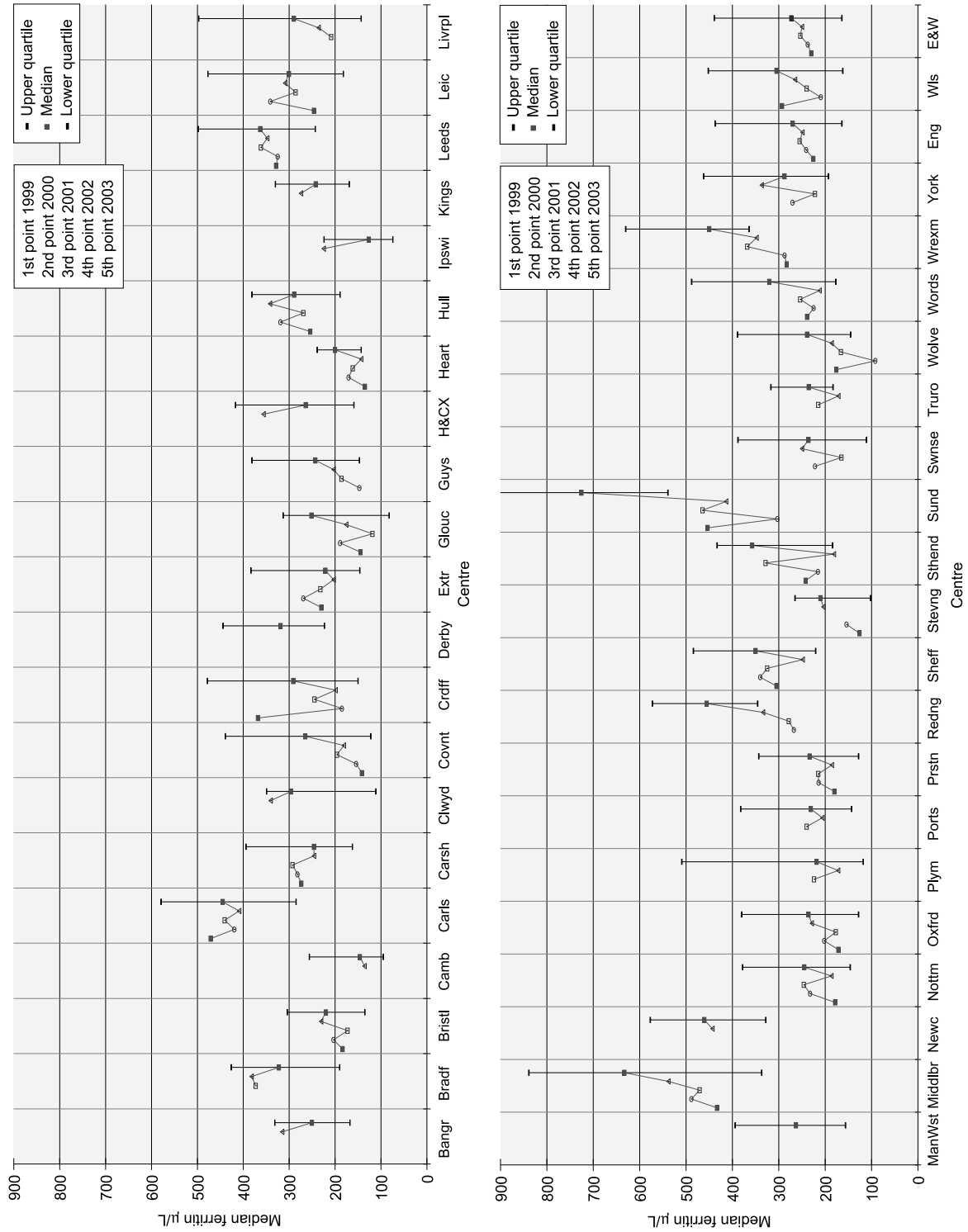


Figure 8.15: Serial ferritin concentration in peritoneal dialysis patients

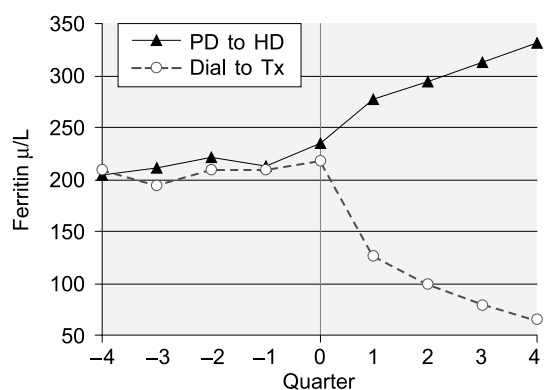


Figure 8.16: Change in serum ferritin before and after modality change

Figure 8.16 shows that after changing from PD to HD, serum ferritin increased from a median of 200 µg/L to 330 µg/L by the end of 12 months, although this was still below the average ferritin of 440 µg/L for HD patients in E&W. In contrast, dialysis patients receiving a transplant showed a marked fall in serum ferritin (associated with a rise in Hb to 13.5 g/dl). It is of note that median serum ferritin in the dialysis patients who were transplanted was lower than the median ferritin of all those on dialysis.

Erythropoietin stimulating agents

In the previous chapter there continues an annual increase in the haemoglobin achieved by renal units. For E&W, only 15% and 11% of HD and PD patients had an Hb <10 g/dl. This would leave a medium size renal unit (700,000 population), with approximately 200 patients on HD and 100 on PD, **with 30 and 11 patients respectively with a haemoglobin <10 g/dl**. These numbers are very small and interpretation of the variation in percentage of patients with an Hb <10 g/dl and not on ESAs MUST be viewed with caution.

In a similar way to the rest of the Registry data the ESA data is collected from renal IT systems, although in contrast to the automated laboratory links this relies on manual data entry. The reliability of these data depends on who is entering the data (doctor, EPO nurse, or data clerk), whether the renal unit is prescribing the ESA directly (within the renal unit budget) or whether ESAs are prescribed by the GP

(from the PCT budget). In the latter case, the data in the renal IT system may not always be updated with that of the GP letter or the GP may decline to prescribe ESAs at the higher dose advised by the nephrologist.

Patients treated and dose variation

ESA data were returned by 22 centres for HD (table 8.4) and 21 centres for PD (table 8.5), though for several centres data were available only for one modality. For both HD and PD, more patients were treated with ESAs than in the 2002 report (91% vs 83% for HD; 77% vs 65% for PD), though achieved haemoglobins were also higher. The percentage of patients receiving ESAs ranged from 82 to 97% (mean 91%) for HD and from 58–90% (mean 77%), for PD. Only one unit (Middlesbrough) prescribed ESAs to a higher percentage of PD than HD patients. In several other centres (notably Coventry, Guys and Leeds) strikingly fewer PD than HD patients received ESAs. It is of note, that the median haemoglobin of PD patients from these 3 centres was the same as or higher than that in the HD population. In addition, the percentage of PD patients with Hb <10 g/dl who were receiving ESAs was higher than the overall percentage of patients treated with ESAs. This suggests that the difference between modalities reflects lower ESA requirements in the PD population in these centres, rather than being due to problems in providing ESAs for this group.

As in previous reports, the percentage of patients achieving a haemoglobin over 10 g/dl without ESAs, was markedly higher for PD than HD, despite a higher median ferritin in the HD population of 440 µg/L compared with that of 267 µg/L in the PD population. This reflects the greater susceptibility of HD patients to anaemia and a probable offsetting effect of greater residual renal function in PD patients. In respect of patients with an Hb <10 g/dl, three centres (Gloucester, Plymouth and Sunderland) succeeded in prescribing ESAs for all patients in both modalities. Only Ipswich and Middlesbrough, who prescribed ESAs for all PD patients with an Hb <10 g/dl, treated a greater proportion of PD than HD patients in this category.

HD patients continued to receive larger doses of ESAs than their PD peers (median 8000 vs 5000 units/wk; mean 9197 vs 5831 units/week

Table 8.4: ESA prescribing in HD patients

Treatment Centre	% on ESA	Mean weekly dose for pts on ESA	Median dose for Hb pts on ESA	Hb <10 g/dl % on ESA	Hb ≥ 10 g/dl % not on ESA
Bangor	95	10021	8500	100	6
Bradford	93	7509	6000	75	6
Bristol	93	8209	6000	95	7
Coventry	85	10827	10000	76	12
Cardiff	96	9000	9000	95	2
Exeter	95	8288	7500	93	2
Gloucester	97	10568	9000	100	4
Guys	90	–	–	94	10
Ipswich	84	7595	8000	88	16
Kings	95	–	–	95	4
Leeds	94	10194	9000	98	6
Leicester	94	9627	8000	98	6
Liverpool	91	9780	9000	94	6
ManWest	82	9213	8000	97	6
Middlesbrough	88	6413	6000	90	9
Plymouth*	n/a	8488	7000	100	12
Sheffield	92	9713	8000	95	9
Stevenage	85	11370	10000	94	12
Southend	89	6065	4000	78	8
Sunderland	89	7424	6000	100	13
Truro	90	4786	4000	95	11
York	89	11537	10000	100	5
England	90	9186	8000	94	8
Wales	96	10000	9000	96	2
Eng & Wales	91	9197	8000	94	7

*data from Plymouth incomplete

respectively). For HD, two of the three units prescribing the highest median dose of 10000 units/wk (Stevenage and York) delivered haemoglobins above the national median, though the third (Coventry) which treated the same percentage of patients with ESAs as Stevenage, reported a median Hb slightly below the national median. In respect of PD, three of the five units prescribing a median dose of 6000 units/week or more (Coventry, Carlisle and Sheffield) reported a median haemoglobin near the bottom of the national range, though all three centres also treated a smaller percentage of PD patients than the national average. As in previous reports, centres prescribing higher doses of ESAs were not necessarily more successful in meeting haemoglobin targets, reflecting the importance of other influences on renal anaemia including iron status, residual renal function, case mix and dialysis adequacy.

ESAs and time on renal replacement therapy

From table 8.6, the percentage of HD patients receiving ESAs during their first year of dialysis corresponded exactly to the overall national median percentage for the HD population. This demonstrates that HD patients in need of ESAs commenced treatment before or soon after starting haemodialysis. For PD, the percentage treated with ESAs during the first year of dialysis was slightly below that of the overall national median, but subsequently exceeded this from 2–3 years onwards. This may reflect delay in the commencement of ESAs in PD patients, or more probably the effect of a progressive loss of residual renal function from the second year of RRT onwards, resulting in increasing anaemia and therefore ESA requirements.

Table 8.5: ESA prescribing in PD patients

Treatment Centre	% on ESA	Mean weekly dose for pts on ESA	Median dose for Hb pts on ESA	Hb <10 g/dl % on ESA	Hb ≥ 10 g/dl % not on ESA
Bangor	76	4000	4000	100	21
Bristol	75	5072	4000	83	26
Carlisle	71	7682	6000	100	28
Coventry	58	7048	7000	71	43
Cardiff	82	–	–	93	18
Exeter	85	6001	4500	86	15
Gloucester	78	4940	4000	100	27
Guys	69	3600	3600	83	33
Ipswich	74	5674	4000	100	26
Kings	86	–	–	82	7
Leeds	71	6337	4500	92	30
Leicester	76	4664	4000	80	24
Liverpool	85	6426	6000	93	15
ManWest	77	5326	5000	74	22
Middlesbrough	90	4842	4000	100	11
Plymouth	83	6000	6000	100	18
Sheffield	74	7802	6000	87	30
Stevenage	79	5317	4000	100	23
Sunderland	88	5071	4000	100	14
Truro	82	4038	4000	100	17
Wordsley	90	5477	4000	100	11
England	77	5863	5000	85	23
Wales	81	4000	4000	88	18
Eng & Wales	77	5831	5000	85	23

Table 8.6: ESA use and length of time on RRT

	Time on treatment (years)					
	<1 (%, no)	1–2 (%, no)	2–3 (%, no)	3–5 (%, no)	5–10 (%, no)	10+ (%, no)
Haemodialysis	91 (768)	92 (858)	94 (675)	92 (806)	89 (749)	86 (488)
Peritoneal dialysis	75 (275)	75 (246)	82 (216)	78 (235)	79 (169)	80 (99)

Age and ESA provision

Only minor variations were seen with age in the percentage of HD patients treated with ESAs, with slightly lower treatment rates in the 35–64 year age group (table 8.7). In comparison with 2002 data, fewer HD patients achieved an Hb ≥10 g/dl without ESAs, though this may simply reflect higher overall treatment rates in the current report. Treatment rates in PD patients showed more significant variations with age,

falling from 87% in the 18–34 age group to 74% in 45–64 age group (table 8.8). Consistent with this, was the higher percentage of PD patients aged 45–64 who achieved an Hb ≥10 g/dl without ESAs (figure 8.17).

ESA prescription and gender

As in previous reports, a greater percentage of females than males were treated with ESAs in

Table 8.7: Percentage use of ESAs, by Hb achievement and age, on HD

Age Group (years)	18–34	35–44	45–54	55–64	65–74	75+
% on EPO	92	88	89	91	92	91
% Hb <10 on ESA	97	93	93	95	94	94
% Hb >10 no ESA	7	12	9	8	7	5

Table 8.8: Percentage use of ESAs, by Hb achievement and age, on PD

Age Group (years)	18–34	35–44	45–54	55–64	65–74	75+
% on EPO	87	80	74	75	76	77
% HB <10 on ESA	90	90	90	87	70	92
% HB >10 no ESA	15	20	28	26	22	22

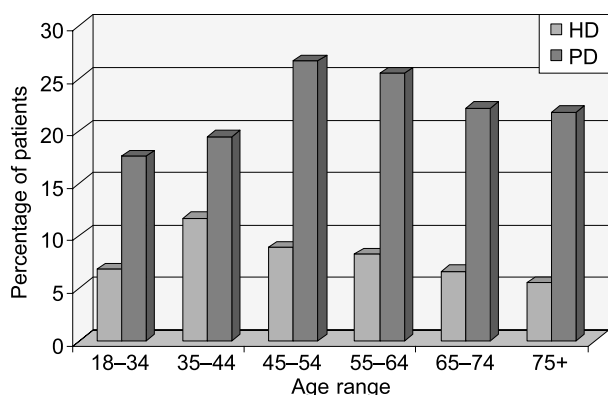


Figure 8.17: Percentage of patients with Hb ≥ 10 g/dl, by age group and modality

both dialysis modalities, despite a lower achieved haemoglobin in females (tables 8.9 and 8.10). For PD, this effect was particularly pronounced in the 35–64 age group, perhaps because the increased susceptibility to anaemia of women within this group is relatively more important than in HD where dialysis blood losses over-ride gender differences (figures 8.18 and 8.19). For both modalities, more males than females achieved a haemoglobin over 10 g/dl without ESAs, though this effect was more pronounced in PD (tables 8.9 and 8.10).

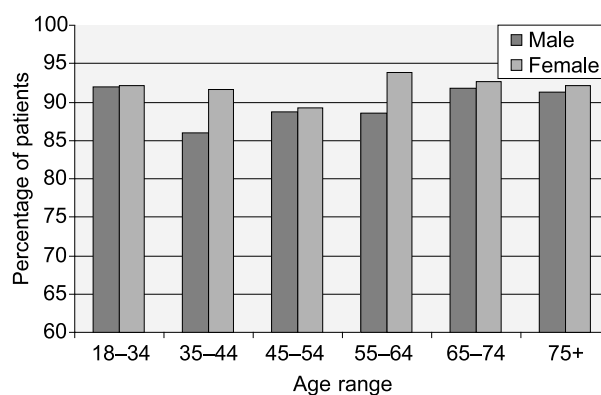


Figure 8.18: Percentage provision of ESAs by age and gender, for patients on HD

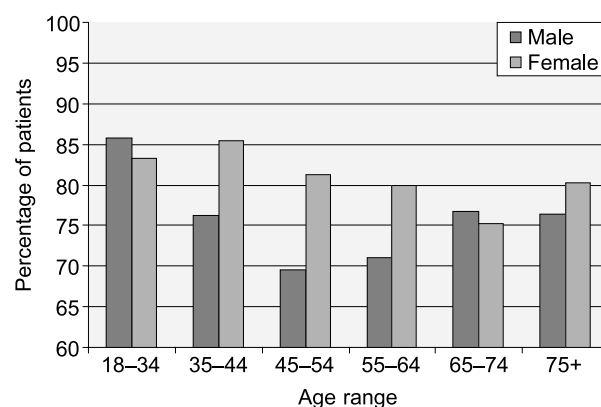


Figure 8.19: Percentage provision of ESAs by age and gender, for patients on PD

Table 8.9: ESA treatment, by gender, on HD

Gender	Mean Hb g/dl	Standard deviation	% on ESA	Hb <10 g/dl % on ESA	Hb ≥ 10 g/dl % without ESA
Male	11.6	1.6	90	93	8
Female	11.3	1.6	92	95	6

Table 8.10: ESA treatment, by gender, on PD

Gender	Mean Hb g/dl	Standard deviation	% on ESA	Hb <10 g/dl % on ESA	Hb ≥ 10 g/dl % without ESA
Male	12.1	1.7	74	82	26
Female	11.6	1.6	81	88	19

Conclusion

The continuing rise in median serum ferritin and the percentage of patients with serum ferritin greater than 100 $\mu\text{mol/L}$ seen in this year's report show that the provision of intravenous iron for UK dialysis patients continues to improve. Whilst there remain marked differences in achieved ferritin between centres, examination of serial data and comparison of the iron status of HD and PD patients in individual units suggest that this may be due to policy decisions about iron replacement therapy rather than simply to the superiority of some intravenous iron programmes over others.

Although the returns on ESA treatment remain incomplete, they show a continuing increase in the number of patients treated compared with 2001 data. The percentage of patients requiring ESAs and the doses they received, remained markedly higher in HD than PD, though in contrast to HD, the number of PD patients receiving ESAs increased with time on dialysis.

Overall, the data demonstrate that UK renal units continue to accord a high priority to the management of factors influencing haemoglobin, and suggest that iron and ESA therapy are increasingly monitored and modified to address local priorities in the treatment of renal anaemia.



Chapter 9: Serum Phosphate, Calcium, Parathyroid Hormone and Albumin

Summary

- An analysis to assess the contribution of inter-laboratory variation to the 'between-centre performance' indicates that there is no evidence to suggest that laboratory variation influences Registry data for serum phosphate or calcium but there is an influence on serum albumin. The current status of analytical methodology does not allow an accurate assessment of the contribution of inter-laboratory variability to between-centre iPTH differences.
- There has been a year on year improvement in control of serum phosphate in dialysis patients although control remains poor and the variation between units is wide and significant.
- Achievement of the RA phosphate target of <1.8 mmol/L is better on PD (68% of patients) compared to HD (59% of patients).
- The Kings renal unit achieves very good control of serum phosphate in HD patients (76% patients <1.8 mmol/L) through the use of a dietetic prescribing team with support from a pharmacist.
- The median corrected serum calcium for all dialysis patients is 2.42 mmol/L, with 63% of patients achieving a serum corrected calcium within the RA target range.
- There is no significant difference between PD patients and HD patients in terms of achieved serum calcium control.
- Comparative audit of serum calcium remains difficult due to methodological differences, especially in albumin measurement and the use of different correction formulae.
- Using KDOQI calcium phosphate product guidelines of <4.4 mmol²/L², 67% of dialysis patients achieve this target although control is better on PD (75%) than on HD (64%). There is wide variation between units.
- Interpretation of iPTH data is complicated by large analytical differences between centres. There is large between-centre variation in the apparent ability of renal centres to achieve the RA target (48% to 88% compliance with the standard).
- In dialysis patients the BCP method of measuring serum albumin gave lower median results than the BCG method.
- For HD patients, the median serum albumin was 38 g/L (BCG) and 34 g/L (BCP). For the BCG technique, 79% of the patients had a serum albumin above 35 g/L: for the BCP technique, 85% of the patients had a serum albumin above 30 g/L.
- PD patients had lower serum albumin compared with those on HD. The median serum albumin was 36 g/L using BCG and 30 g/L using BCP. For the BCG technique, 60% of the patients had a serum albumin above 35 g/L: for the BCP technique, 55% of the patients had a serum albumin above 30 g/L.

Introduction

Traditionally, control of phosphate, calcium and parathyroid hormone metabolism has been regarded as synonymous with control of renal bone disease: recently there has been a shift in emphasis with the increasing realisation that both serum calcium and phosphate control and their balance may also be important in preventing accelerated vascular disease. This chapter presents information relating calcium, phosphate and iPTH control to the RA standards.

For calcium, phosphate and iPTH no separate RA standards are set for different dialysis modalities. Nevertheless, different modalities offer different challenges in achieving metabolic control. Where appropriate, data for HD and PD are shown separately in addition to/instead of the pooled dialysis data.

Table 9.1: Table of data completeness by centre

	Albumin			Uncorrected calcium			Phosphate			iPTH		
	HD	PD	Tx	HD	PD	Tx	HD	PD	Tx	HD	PD	Tx
Bangor	100	100	N/A	100	100	N/A	100	100	N/A	98	92	N/A
Bradford	100	100	97	100	100	97	100	98	95	84	86	22
Bristol	99	100	98	99	100	97	99	100	98	94	99	82
Cambridge	71	100	80	71	100	80	71	100	80	65	95	13
Carlisle	93	94	94	93	94	94	93	94	83	91	94	24
Carshalton	85	99	90	85	99	90	85	99	89	67	77	10
Clwyd	94	100	N/A	94	100	N/A	94	100	N/A	89	31	N/A
Coventry	99	93	81	99	93	81	99	93	81	89	77	20
Cardiff	95	97	96	95	97	96	95	97	96	91	94	16
Derby	88	96	N/A	88	94	N/A	88	93	N/A	0	0	N/A
Exeter	97	100	96	43	5	0	97	100	94	96	100	11
Gloucester	98	100	98	98	100	98	98	100	95	98	94	33
Guys	92	100	81	96	100	92	96	100	92	95	98	18
H&CX	99	99	95	99	99	95	99	99	95	60	89	30
Heartlands	93	100	71	93	100	71	93	100	71	85	75	5
Hull	96	98	81	96	98	81	96	98	81	79	91	16
Ipswich	100	100	96	100	100	96	100	98	98	93	95	37
Kings	96	94	91	96	94	91	93	88	56	93	93	20
Leeds	99	98	94	99	98	93	99	98	93	97	97	23
Leicester	98	99	93	98	99	92	98	99	92	97	91	56
Liverpool	87	96	92	87	96	92	86	96	92	76	78	28
ManWst	69	98	72	69	98	72	69	98	72	64	93	70
Middlbr.	97	100	93	97	100	93	97	100	93	73	86	4
Newcastle	97	98	79	97	98	79	97	98	78	62	73	20
Nottingham	97	100	95	97	100	94	97	100	94	95	96	72
Oxford	99	100	95	99	100	95	95	100	95	84	91	32
Plymouth	86	98	84	86	98	82	86	98	83	73	79	13
Portsmouth	94	88	88	94	82	88	94	81	85	84	43	9
Preston	98	99	68	98	99	67	98	99	64	96	99	30
Reading	98	100	80	98	100	90	98	100	90	95	96	60
Sheffield	100	100	99	100	100	99	100	100	99	98	81	11
Stevenage	93	100	74	90	98	74	89	98	73	83	87	41
Southend	96	100	60	96	52	57	95	100	57	88	68	7
Sundrland	96	100	97	96	100	97	96	100	97	94	100	96
Swansea	72	99	91	72	99	90	72	98	89	63	91	25
Truro	98	97	97	98	94	96	98	94	96	96	91	38
Wirral	9	13	N/A	9	6	N/A	9	6	N/A	17	6	N/A
Wolve.	99	100	90	99	100	90	99	100	85	94	97	35
Words	99	100	89	98	98	89	99	98	89	0	0	0
Wrexham	86	92	98	86	92	92	86	92	92	71	86	57
York	93	100	95	82	88	32	92	100	95	91	81	20
England	N/A	N/A	N/A	92	94	87	93	97	88	81	83	30
Wales	N/A	N/A	N/A	88	97	95	88	97	95	81	89	20
Total	N/A	N/A	N/A	91	94	87	92	97	88	81	84	29

This Chapter also contains data relating to serum albumin concentrations in dialysis patients. These data have been included here in recognition of the inter-relationship between calcium and albumin measurement and the commonality of the problems that affect them.

This year an attempt has again been made to assess the contribution of inter-laboratory variation to the 'between-centre' comparison of renal unit performance. Laboratories in the UK participate in external quality assessment schemes in which their achieved result for a specified analyte is compared with the result from other laboratories. The predominant scheme in the UK is the UK National External Quality Assessment Scheme (UK NEQAS, www.ukneqas.org.uk). Although not all laboratories participate in this scheme, a comparable scheme based in Wales (WEQAS) is also widely used. The organisers of the UK NEQAS scheme have assisted the Registry by providing mean bias data for the laboratories that support renal centres. The bias data is expressed relative to an all laboratory trimmed mean (ALTM) and has been used to assess whether renal centre performance is related to between-laboratory differences. Analysis was undertaken using data from July-December 2002. The analysis is clearly fairly crude and there are important caveats which should be borne in mind when attempting any interpretation. For example, it has not been possible to account for satellite dialysis centres where the biochemical data may be generated from a different laboratory from that used in the main renal unit.

Completeness of data returns

Table 9.1 shows the data completeness for serum albumin, uncorrected calcium, phosphate and iPTH. Completeness of data returns were measured over 6 months for patients on dialysis and 12 months for transplant patients. The Wirral renal unit does not have an automated biochemistry link into the IT renal system (at Liverpool) which accounts for the data being unavailable. Bangor, Clwyd and Wirral do not look after transplant patients.

Serum Phosphate

The Renal Association Standard states:

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

There is no recommendation on the frequency of measurement. This contrasts with the KDOQI guidelines which also set a minimum range for serum phosphate of 1.13 mmol/L and specify that it should be measured monthly.

Although there has been a year on year improvement in serum phosphate control, it remains poor with only 61% of dialysis patients achieving serum phosphate concentrations <1.8 mmol/L and several units having median serum phosphate concentrations above the standard of 1.8 mmol/L. In general, the phosphate control is better on peritoneal dialysis. Overall, 59% of haemodialysis and 68% of peritoneal dialysis patients have serum phosphate under 1.8 mmol/L. The variation between units is wide (Figures 9.1 to 9.5). For both HD ($\chi^2 = 273$, $p < 0.001$) and PD ($\chi^2 = 107$, $p < 0.001$) modalities, the percentage of patients with a serum phosphate below 1.8 mmol/L differed significantly between centres.

The Kings renal unit managed to achieve 76% of HD patients with a serum phosphate <1.8 mmol/L compared with 60% in E&W. Figure 9.3 shows that this high achievement was associated with the smallest inter-quartile range of 0.45 mmol/L compared with 0.74 mmol/L for England and Wales. Enquiries to this renal unit indicate that this tight control of serum phosphate has been achieved through use of a dietician led prescribing and management team for control of serum phosphate. Within this renal unit, dieticians initiate prescribing of calcium based phosphate binders and are also allowed to alter dosing of non-calcium based agents. Calcium based phosphate binders are still used in the majority of patients at this renal unit. Although Figure 9.8 does not show the corrected serum calcium data for HD patients at the Kings renal unit, analysis of the uncorrected calcium data shows that the

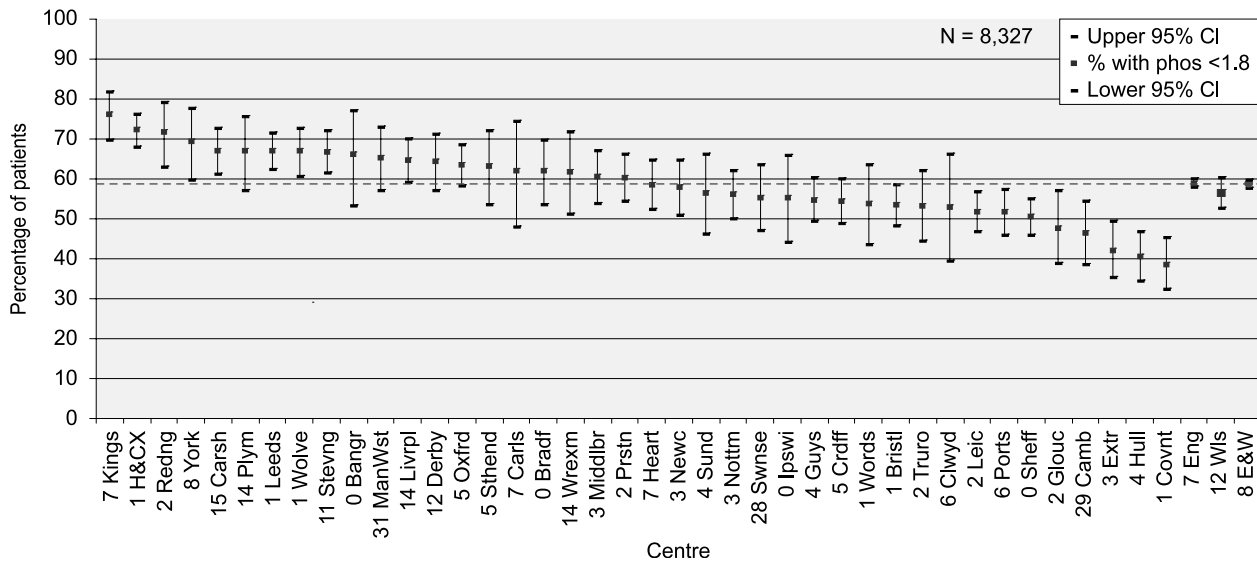


Figure 9.1: Percentage of HD patients in RA range for serum phosphate

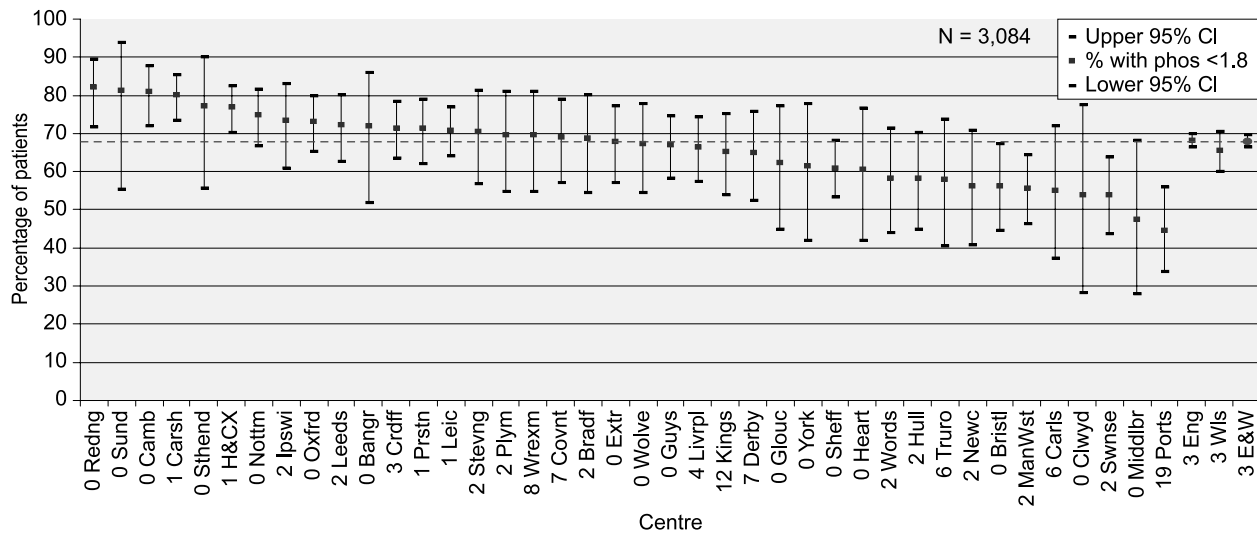


Figure 9.2: Percentage of PD patients in RA range for serum phosphate

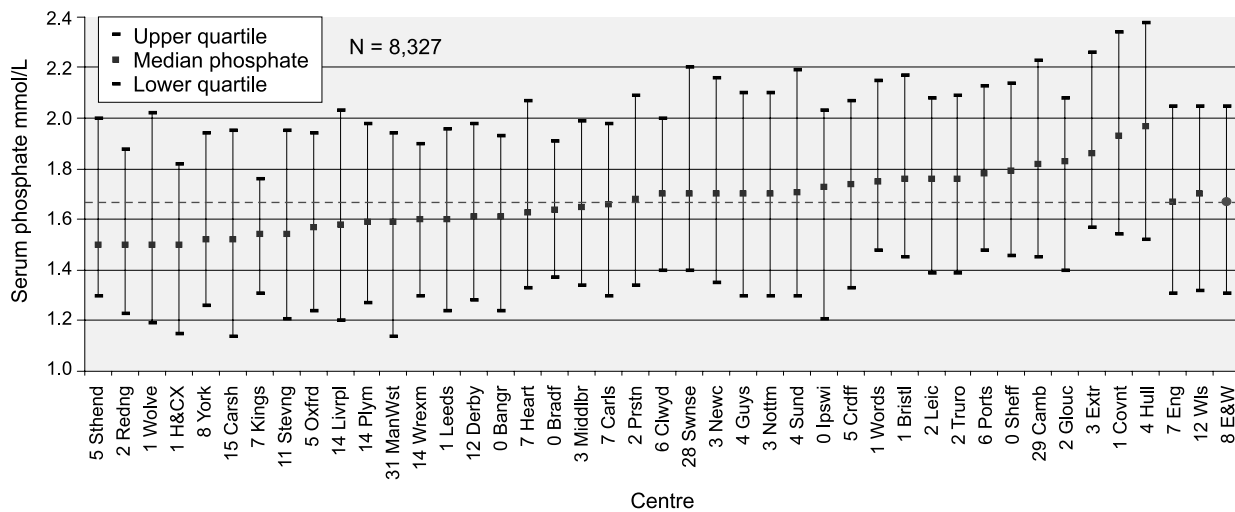


Figure 9.3: Median serum phosphate mmol/L: HD patients

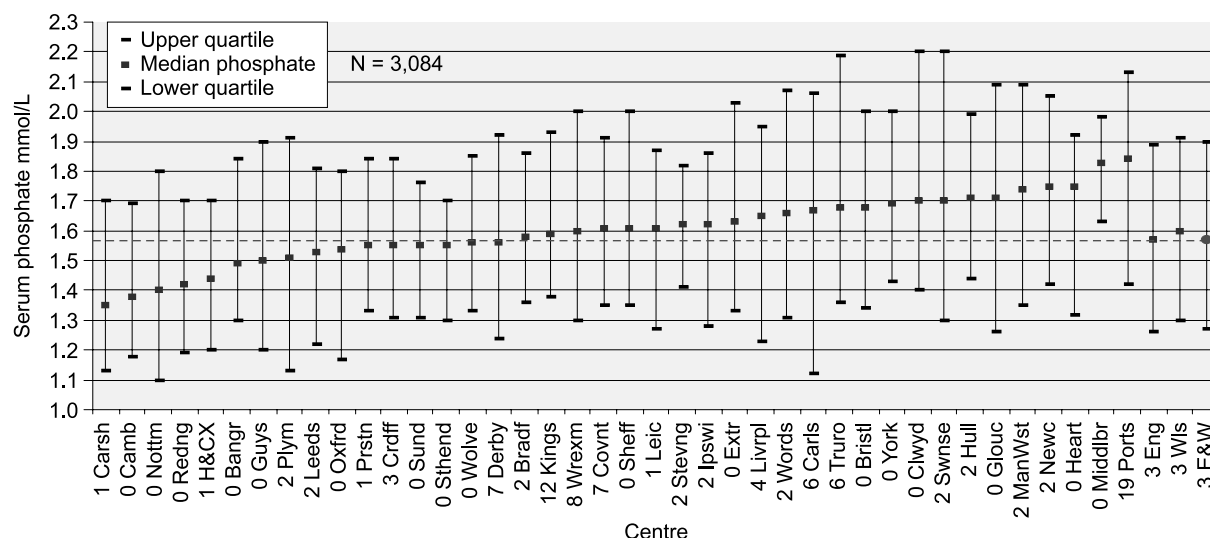


Figure 9.4: Median serum phosphate mmol/L: PD patients

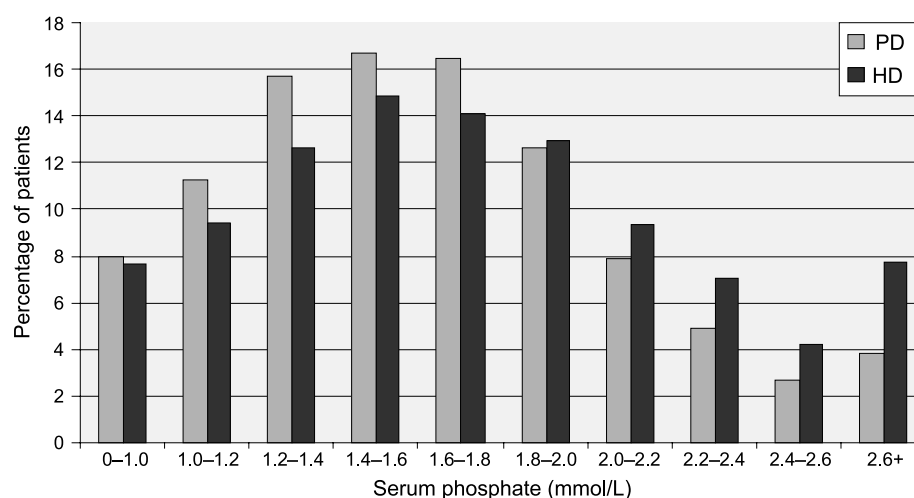


Figure 9.5: Distribution of serum phosphate by PD & HD

median uncorrected calcium at Kings is 2.33 mmol/L compared with 2.36 mmol/L for England and Wales. Achievement of low serum phosphate levels at the Kings renal unit has therefore not been at the expense of higher serum calcium results.

Figure 9.5 shows the difference in control of serum phosphate between HD and PD patients. Almost twice the percentage of HD patients (8%) have a serum phosphate above 2.6 mmol/L compared with 4% of patients on PD.

Analysis of the influence of laboratory bias

An analysis of the potential contribution of laboratory bias to between centre differences has been undertaken using data from the 2003

Registry Report and data supplied by UK NEQAS. No relationship ($p=0.124$) was observed between the renal centre median serum phosphate and percentage bias relative to the UK NEQAS ALTm using Spearman's rank correlation. The 'between centres' coefficient of variation (CV) for serum phosphate was 6.7% whereas the between-laboratory CV for serum phosphate for all participants in the UK NEQAS scheme using a range of different methods was 4.5%. Taken together, these data suggest that the differences seen between renal centres are greater than can be explained by inter-laboratory variation.

The variability seen therefore suggests that a clinical focus on phosphate control can bring biochemical benefits, which might be translated into future survival benefits.

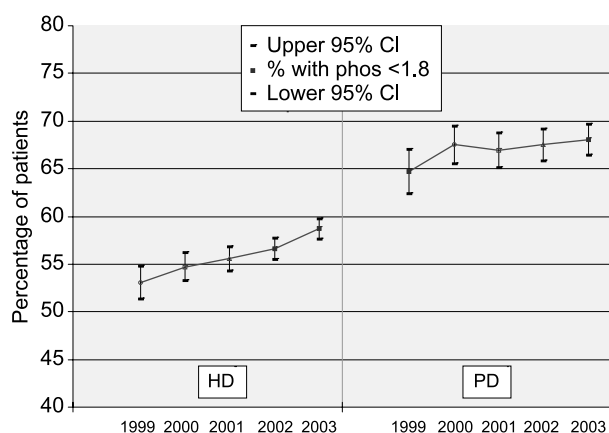


Figure 9.6: Change in percentage of patients achieving serum phosphate <1.8 mmol/L, 1999–2003

Change in achievement of serum phosphate 1999–2003

Figure 9.6 shows the change over 5 years in the percentage of patients achieving serum phosphate <1.8 mmol/L in patients in renal units in England and Wales who have contributed to the Registry throughout that time. Overall, there appears to have been a gradual improvement in the percentage of patients achieving this target for both HD (53.1 to 58.7%) and PD (64.7 to 68.1%).

Change in modality of treatment and effect on serum phosphate

The Registry is able to link biochemical data at individual patient level to changes of modality. Provision of a renal transplant produces a predictable improvement in serum phosphate control. Conversely, switching dialysis modality

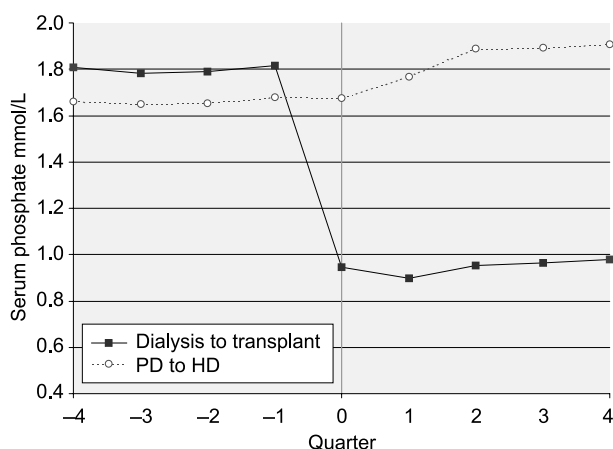


Figure 9.7: Serum phosphate, by quarter, in individual patients before and after modality change

from PD to HD appears to be associated with a worsening of phosphate control and median rise of 0.2 mmol/L (Figure 9.7).

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.

The KDOQI guidelines advise that serum levels of corrected total calcium should be maintained within the normal range for the laboratory used, preferably toward the lower end (2.10 to 2.37 mmol/L), although the evidence for this is opinion based.

Comparative audit in this area remains difficult due to differences in analytical methods between units, (and even between satellite units managed by one clinical team), different mathematical methods being applied to correct serum calcium for serum albumin concentration and 3 different methods for analysing serum albumin (BCG wet, BCG dry and BCP see the Registry reports 1999–2003). However, as discussed in last year's Registry report¹, since nephrologists in each unit will be making clinical decisions based on their local corrected calcium results, these data are in some sense the most valid and are illustrated in Figures 9.8 to 9.11.

The median corrected calcium is 2.42 mmol/L for HD patients and 2.44 mmol/L for PD patients. Overall, 63% of patients (64% HD, 63% PD) achieved a serum corrected calcium concentration within the RA target range. The variation between units is wide and the percentage of patients with a serum corrected calcium within the RA target range differed significantly between centres for both HD ($\chi^2 = 2023$, $p < 0.001$) and PD ($\chi^2 = 1179$, $p < 0.001$) modalities.

Analysis of the influence of laboratory bias

An analysis of the potential contribution of laboratory bias to between centre differences has been undertaken using data from the 2003 Registry Report and data supplied by UK

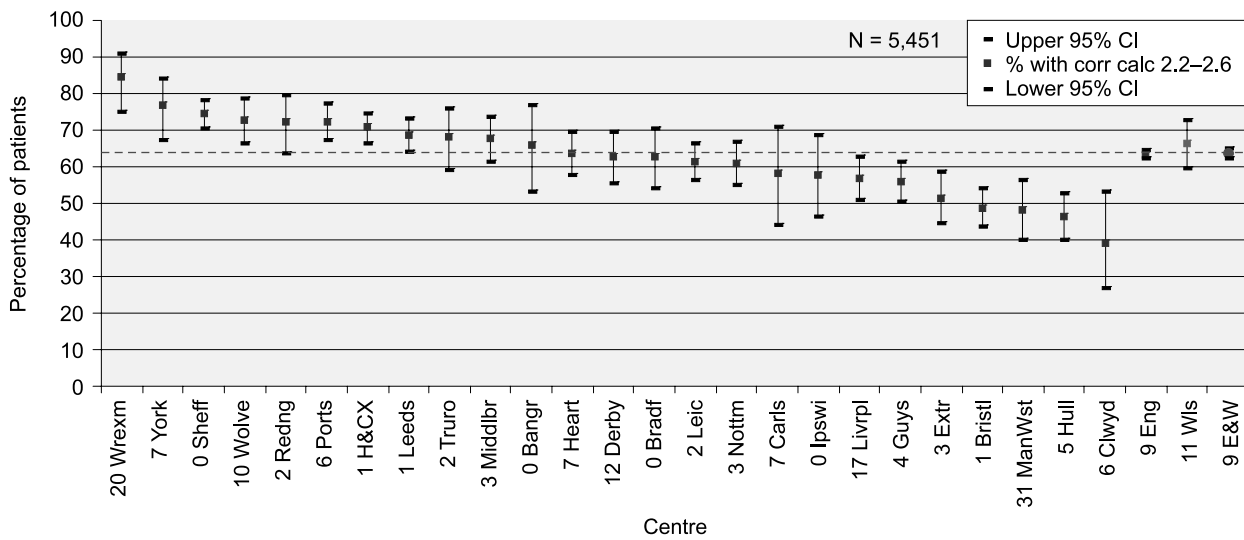


Figure 9.8: Percentage of patients with corrected calcium within 2.2 to 2.6 mmol/L: HD

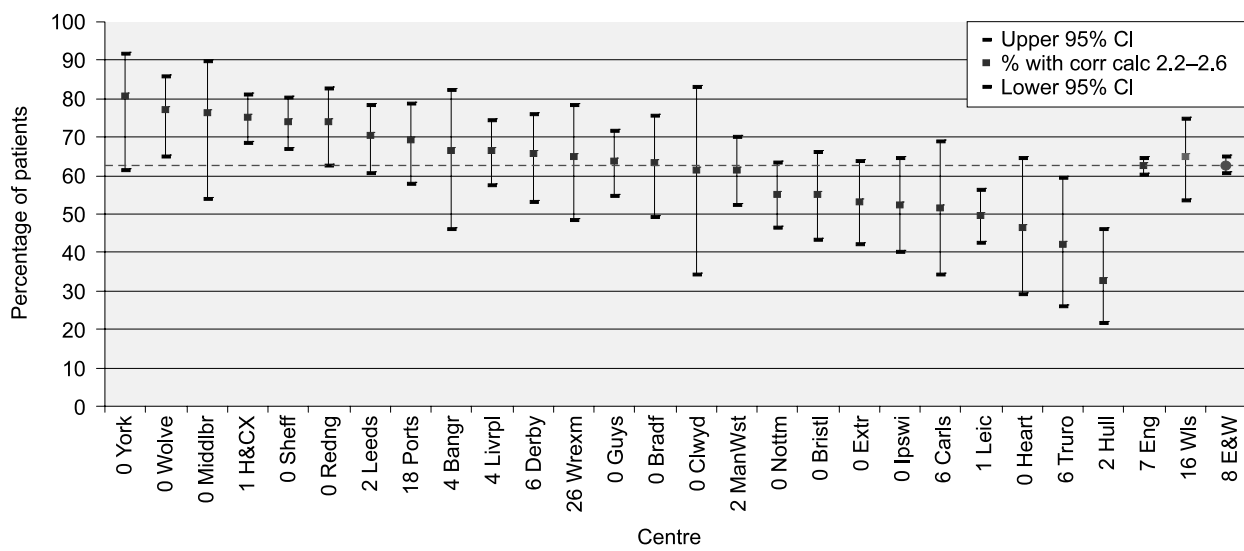


Figure 9.9: Percentage of patients with corrected calcium within 2.2 to 2.6 mmol/L: PD

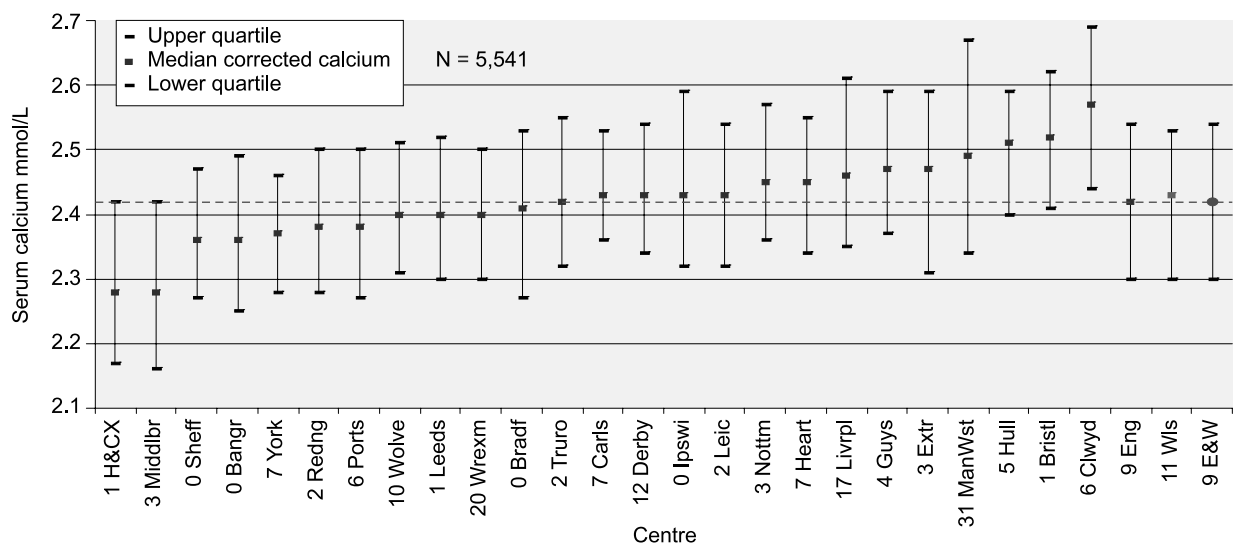


Figure 9.10: Median corrected calcium by centre: HD

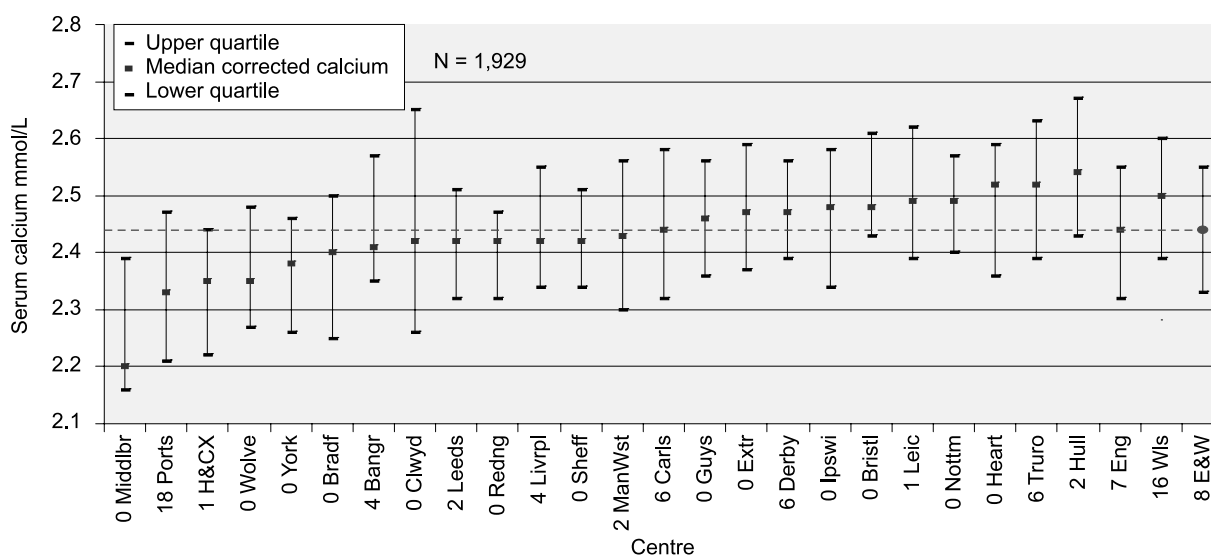


Figure 9.11: Median corrected calcium by centre: PD

NEQAS. No relationship ($p=0.748$) was observed between median serum corrected calcium and percentage bias of the calcium assay relative to the UK NEQAS ALTM using Spearman's rank correlation. The between centre coefficient of variation (CV) for serum corrected calcium was 2.5%, whereas the between-laboratory CV for serum calcium for all participants in the UK NEQAS scheme using a range of different methods was 3.0%.

Corrected calcium clearly depends on measurement of albumin in addition to calcium. Analysis is complicated by the existence of three different methods used for measurement of serum albumin (bromocresol green (BCG) wet and dry and bromocresol purple (BCP)). However, an earlier Registry report suggested that the correction formulae in use were not necessarily influenced by the choice of albumin method (3rd Registry Report, 2000). Therefore analysis was undertaken comparing median corrected calcium for the centres against the UK NEQAS bias relative to the ALTM data for albumin. This was available from 15 of the laboratories supporting renal centres and ranged from -7.7% to 5.8% (median 1.33%). No relationship ($p=0.5567$) was observed between median serum corrected calcium and percentage bias of the albumin assay using Spearman's rank correlation.

Taken together, these data suggest that the differences seen between renal centres for (corrected) calcium are not explained by inter-laboratory variation.

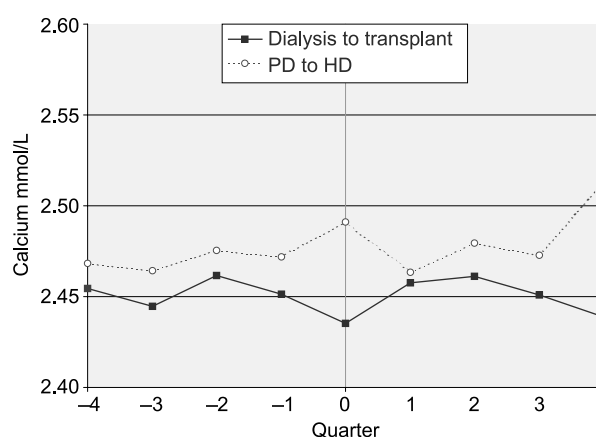


Figure 9.12: Serum corrected calcium, by quarter, before and after modality change

Change in modality of treatment and effect on serum calcium

Neither change in dialysis modality (PD to HD), nor the provision of a renal transplant appear to be associated with clear changes in serum corrected calcium concentration (Figure 9.12).

Calcium/phosphate product

The Renal Association has no standard for the serum calcium phosphate product, but the KDOQI guidelines recommend the product should be less than $4.4 \text{ mmol}^2/\text{L}^2$ ($=55 \text{ mg}^2/\text{dl}^2$). Calculating the product using non-corrected serum calcium, more than half (67%) of patients achieve this standard, but the range between units is wide (44% to 82%) (Figure 9.13).

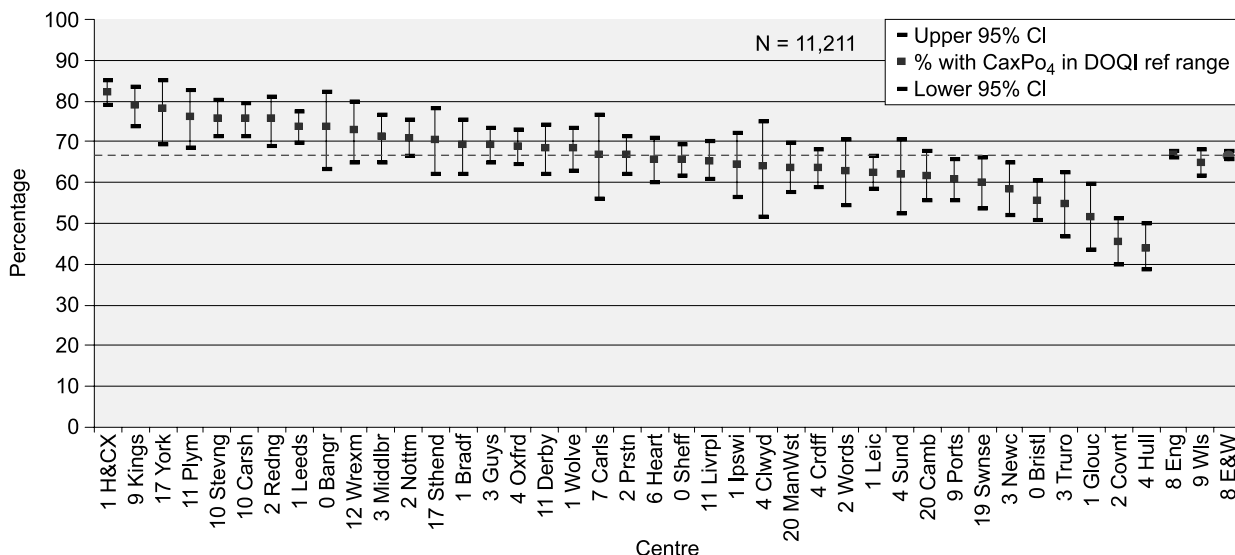


Figure 9.13: Percentage of dialysis patients with calcium phosphate product in the KDOQI recommended range

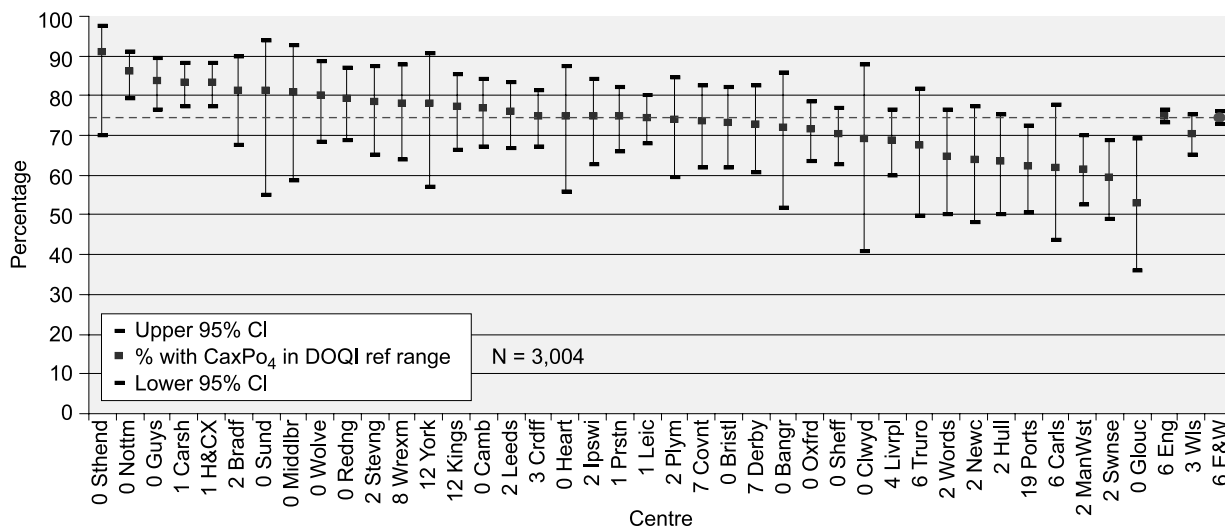


Figure 9.14: Percentage of PD patients with calcium phosphate product in the KDOQI recommended range

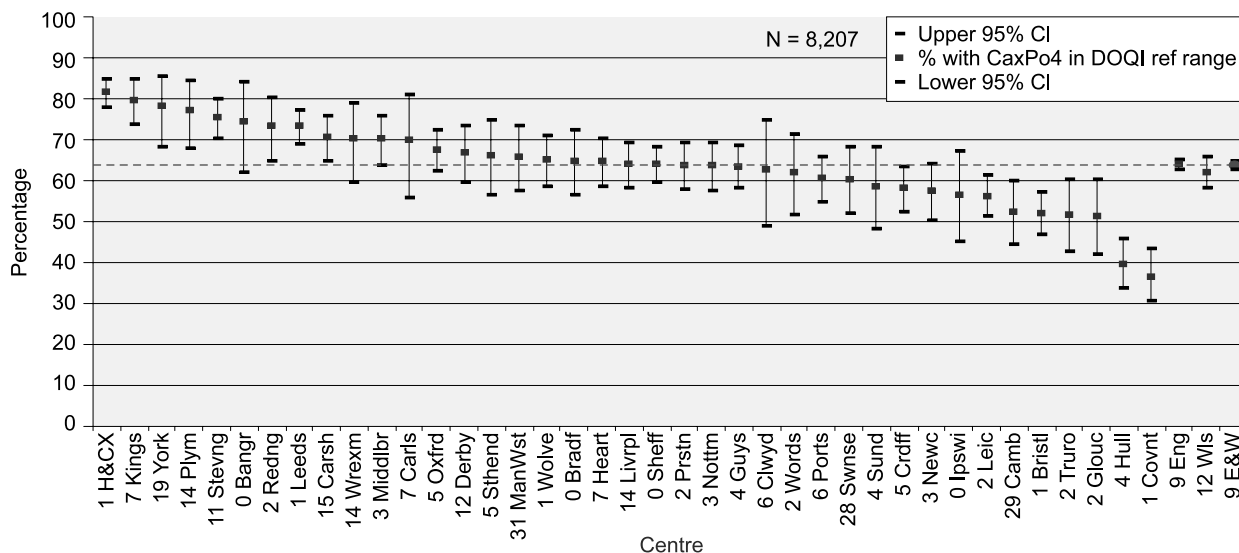


Figure 9.15: Percentage of HD patients with calcium phosphate product in the KDOQI recommended range

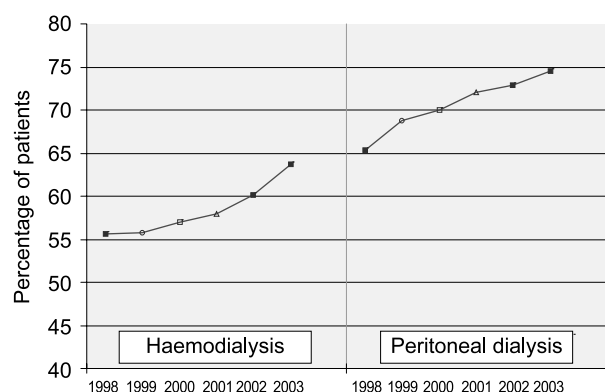


Figure 9.16: Percentage of patients with calcium phosphate product $<4.4 \text{ mmol}^2/\text{L}^2$ in 1999–2003

Control is better on PD, with 75% (range 53–91%) of patients achieving the standard, than on HD (64%, range 37–82%) (Figures 9.14–9.16). The variation between units was significant for both HD ($\chi^2 = 365, p < 0.001$) and PD ($\chi^2 = 94, p < 0.001$) modalities.

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 iPTH values from different units is difficult due to the variety of

methods and reference ranges in use. Laboratories commonly adopt the reference ranges suggested by the assay manufacturer’s product information, but for iPTH laboratories may not quote the same upper limit even when using the same methods². The lack of rigour with which some reference ranges have been derived is also an area of concern (ie no manufacturers appear to have established their reference ranges in proven vitamin D replete individuals)². The differing reactivity of the various iPTH methods with the PTH 7–84 fragment known to accumulate in uraemia (see below)³ is another confounding factor. To enable some form of comparative audit, the Registry has expressed all results in pmol/L and chosen an upper limit of four times the median upper lab value: this equates to 32 pmol/L.

The median iPTH for all dialysis patients (19 pmol/L) lies well within the Standard although the distribution between the centres was wide (6 to 34 pmol/L, Figure 9.17). There was little difference in median iPTH between PD patients (21, range 4 to 55 pmol/L) and HD patients (19, range 6 to 38 pmol/L). Overall, 66% of dialysis patients achieved the RA Standard, but the spread of data between centres was remarkable, ranging from 48% to 87% compliance with the standard (Figure 9.18).

Analysis of the influence of laboratory bias

An analysis of the potential contribution of laboratory bias to between centre differences in

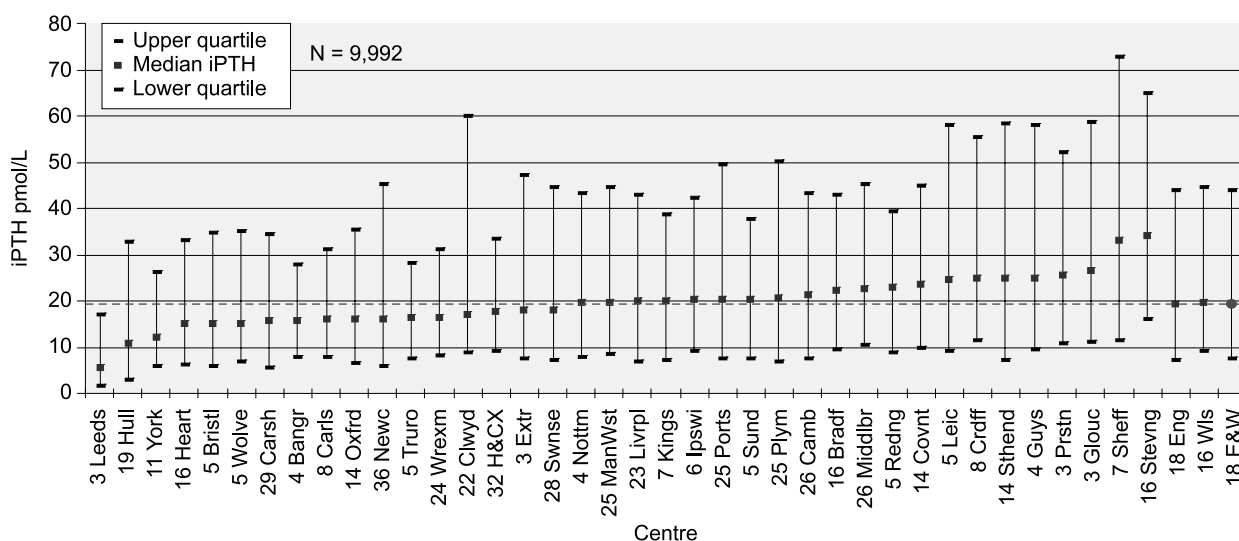


Figure 9.17: Median iPTH by centre: dialysis

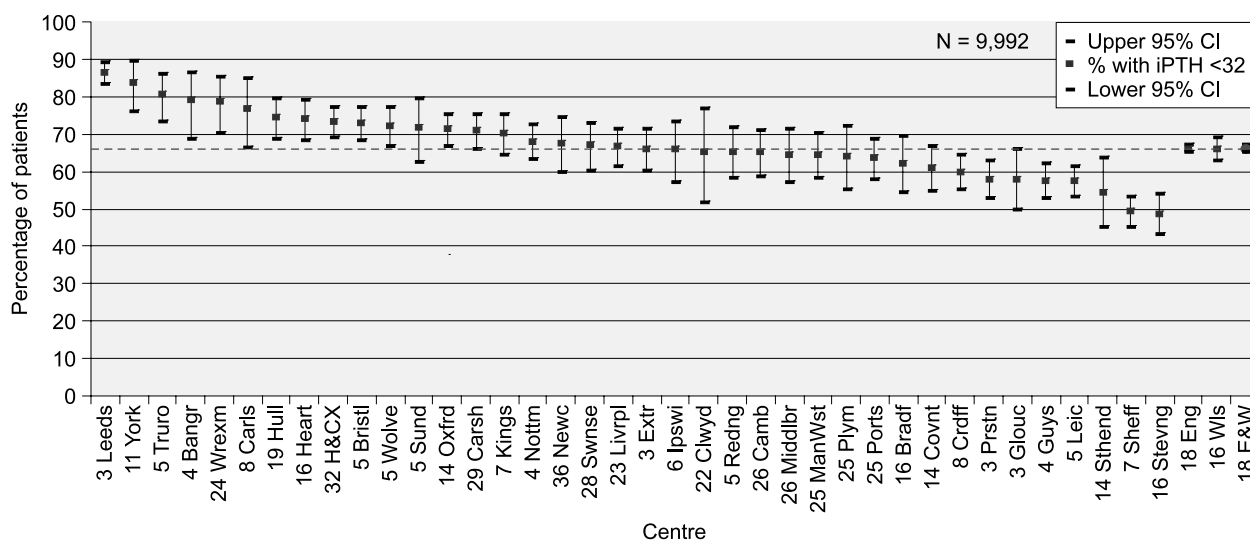


Figure 9.18: Percentage of patients with iPTH <32 pmol/L: dialysis

serum iPTH was undertaken using data from the 2003 Registry report and data supplied by UK NEQAS, which were available from 30 of the laboratories supporting the 35 renal centres which contributed data to the report. Although mean UK NEQAS bias relative to the ALTM varied widely (range -17.3% to 17.8%), this was unrelated ($p=0.3740$) to the renal centre median serum iPTH using Spearman's rank correlation. Median centre iPTHs for the PD and HD programmes rank in a very different order, despite using the same iPTH assay. Anecdotally, three centres all served by the same laboratory had median iPTHs of 20, 20 and 9 pmol/L. Taken together these observations tend to suggest that differences in patient management and/or case mix probably have a greater influence on centre median iPTH than analytical variation.

PTH measurement at the centres was dominated by three major method groups; DPC Immulite ($n=10$), Nicholl's Institute Advantage ($n=11$) and Roche Elecsys ($n=9$). It is known that fragments of PTH (predominantly 7–84) accumulate in uraemia and cross-react to varying extents in so-called 'intact' PTH immunoassays; typically these fragments account for about 50% of the PTH immunoreactivity reported by laboratories². UK NEQAS data have demonstrated differences in recovery of PTH 7–84 varying from 28% with the DPC method, to 53% with the Roche Elecsys method and 58% with the Nicholl's Advantage method (data supplied by UK NEQAS). Therefore the possibility that cross-reactivity with

PTH 7–84 was affecting renal centre performance was tested using one-way ANOVA. Mean centre median iPTH was 13.3, 14.8 and 18.5 pmol/L with the DPC, Nicholl's and Roche methods respectively ($p=0.1198$).

PTH variation between centres is large, as is analytical variation. However, the two do not seem to be obviously related to each other. Variation against the UK NEQAS ALTM may reflect a combination of differences in calibration (there is no international standard for iPTH), varying cross-reactivity with PTH 7–84 and the mixture of samples circulated in the UK NEQAS scheme (typically approximately half of the samples are spiked with uraemic serum). For example, although the DPC method demonstrates the lowest cross-reactivity with PTH 7–84, it typically demonstrates $>10\%$ positive bias compared to the UK NEQAS ALTM; the Nicholl's and Roche methods, by comparison, demonstrate $>10\%$ negative bias (UK NEQAS Annual Review 2001). This could suggest that the effects of calibration and non-specificity between the different assays are cancelling each other out. Until calibration, standardisation and specificity issues are resolved, it will remain difficult to ascertain the true contribution of analytical variation to centre performance.

The current understanding of renal parathyroid disease is likely to undergo a paradigm shift in the next few years. In addition to the advent of calcimimetic agents and increasing emphasis on reducing calcium phosphate product, the

recognition that so-called ‘intact’ iPTH assays are not specific for the whole molecule form of PTH may have profound influences on the approach of the nephrological community to renal osteodystrophy. At present it remains unclear whether PTH 7–84 has significant biological activity *in vivo*⁴. At the very least, given the high prevalence of this circulating truncated form in uraemic patients, the RA standards may require review to accommodate those centres using the third generation, bio-intact (1–84 specific) assays.

Serum Albumin

The Renal Association has no standard for serum albumin.

The RA Standards document 3rd edition⁵ recognises the importance of serum albumin as a marker of outcome, but does not recommend setting an audit standard for serum albumin, predominantly due to lack of standardisation of albumin assays between laboratories. Serum albumin concentration is influenced significantly by the dye used in the assay method; either bromocresol green (BCG) or bromocresol purple (BCP). For this report, centres have been separated both by methodology of albumin measurements and by dialysis modality. The difference between BCG and BCP methods in uraemic patients is widely known. In the current report, the influence of between-laboratory variation on centre performance within the BCG method group alone is explored. Too few

centres use the BCP method for meaningful analysis.

Haemodialysis

For centres supported by laboratories using BCG methods (n = 28) the median serum albumin was 38 g/L (range 35 to 41 g/L) (Figure 9.19). As anticipated, centres using the BCP method (n = 13) generally had lower albumin concentrations (median 34 g/L, range 33 to 40 g/L) (Figure 9.20). Overall, 79% of patients had serum albumin above 35 g/L for the BCG method (Figure 9.21) and 85% for BCP (Figure 9.22). For both BCG ($\chi^2 = 604$, $p < 0.001$) and BCP ($\chi^2 = 128$, $p < 0.001$) centres, the percentage of patients achieving serum albumin concentrations above these levels differed significantly between centres.

An analysis of the potential contribution of laboratory bias to between-centre differences has been undertaken using data from the 2003 Registry report and data supplied by UK NEQAS. UK NEQAS method group and laboratory bias data were available for 26 of the laboratories supporting these renal centres (17 BCG, 9 BCP). Given the small data available for the BCP group, analysis was only undertaken of the 17 haemodialysis centres with BCG data. Amongst these, there was a relationship between percentage bias relative to the UK NEQAS ALTM and median albumin ($r_s = 0.61$, $p = 0.0089$) using Spearman’s rank correlation. This was largely driven by two laboratories using a dry chemistry BCG

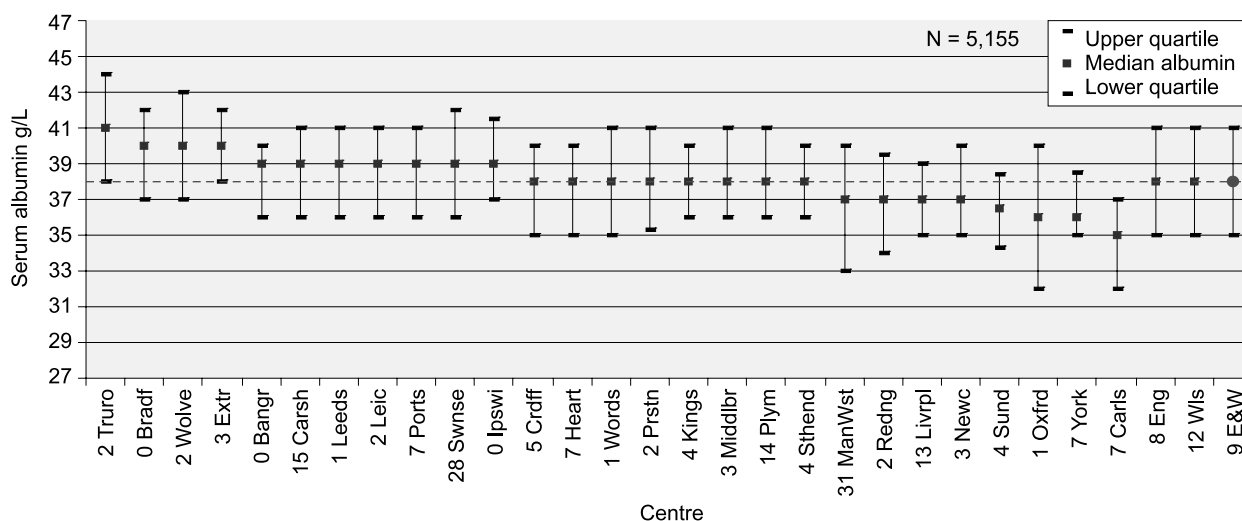


Figure 9.19: Median serum albumin in HD patients by centre: BCG method

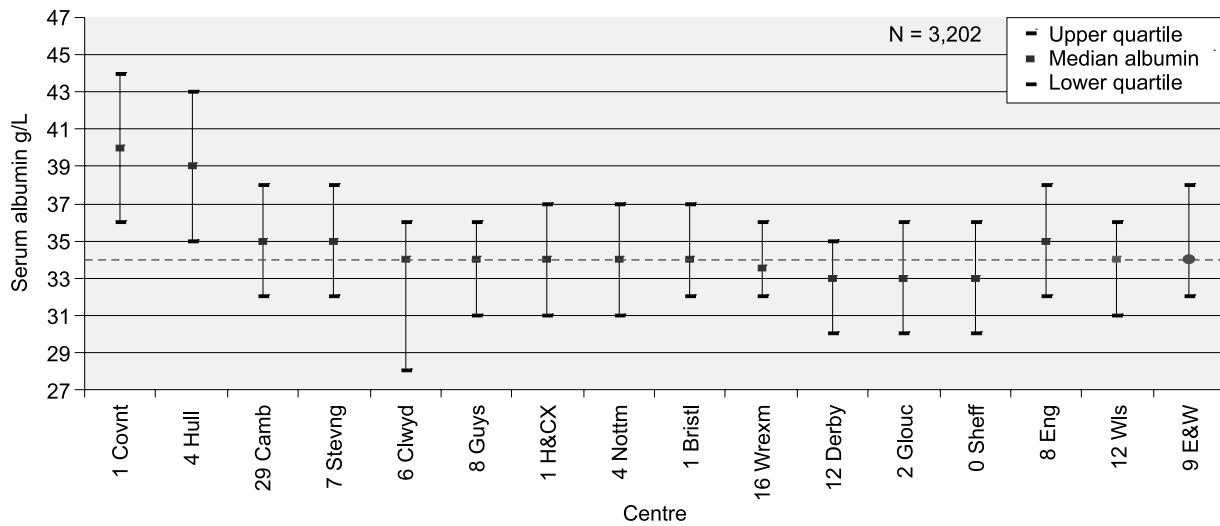


Figure 9.20: Median serum albumin in HD patients by centre: BCP method

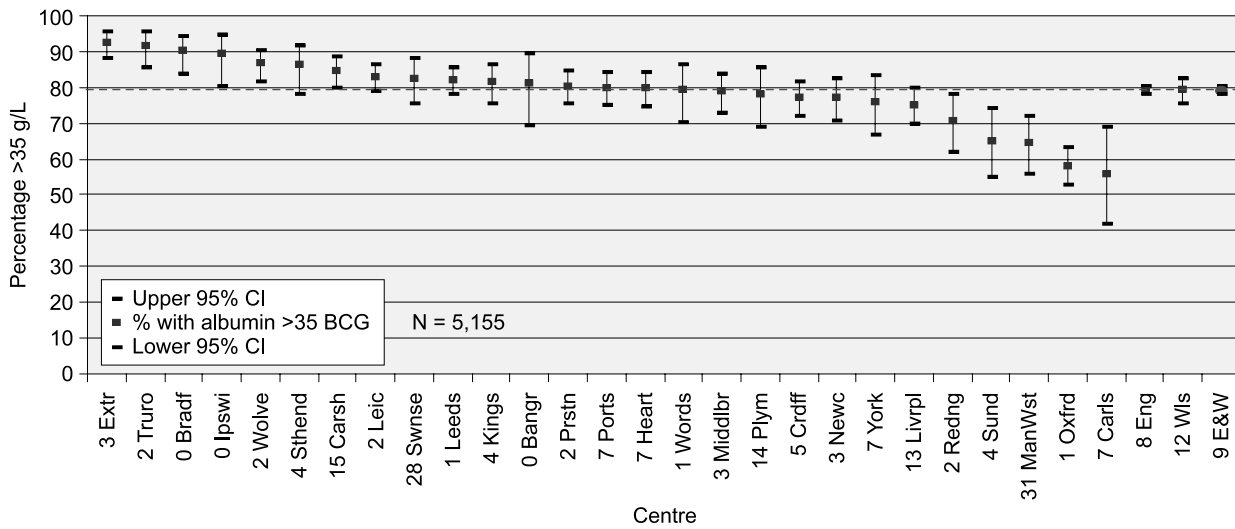


Figure 9.21: Percentage of HD patients by centre with serum albumin >35 g/L (BCG)

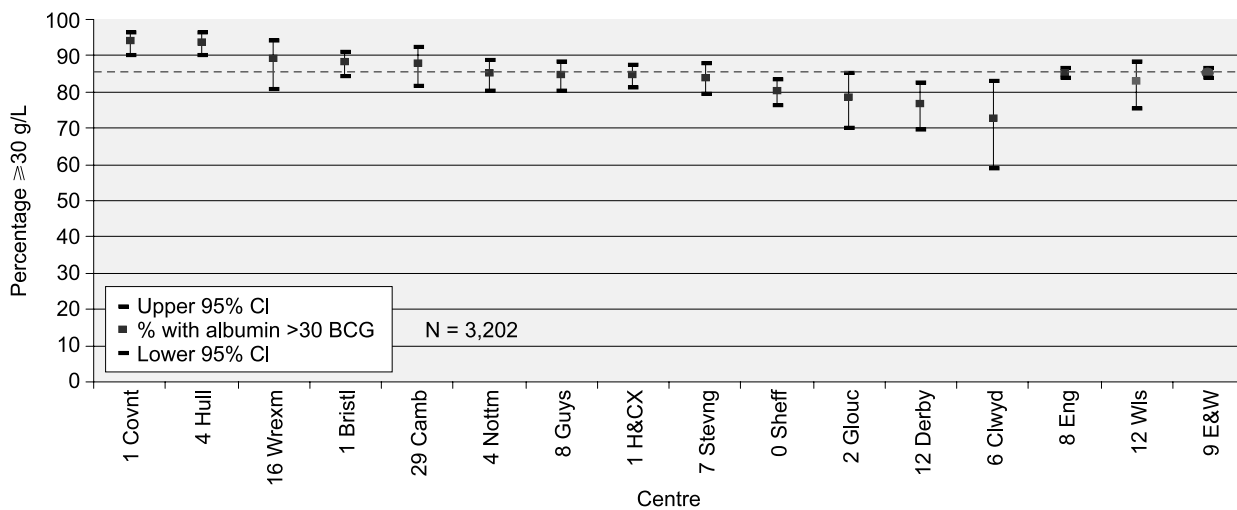


Figure 9.22: Percentage of HD patients by centre with serum albumin >30 g/L (BCP)

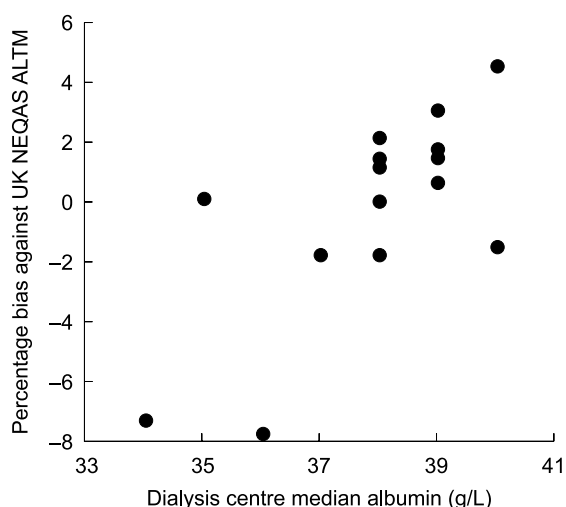


Figure 9.23: Analysis of percentage bias against UK NEQAS ALTM

method, which have low median patient serum albumin (Figure 9.23).

Peritoneal dialysis

Serum albumin is generally lower in PD patients than in HD patients, predominantly due to peritoneal protein losses⁶. Furthermore, peritoneal albumin clearance increases with time on treatment due to increasing effective peritoneal surface area⁷. For centres supported by laboratories using BCG methods (n = 27) the median serum albumin was 36 g/L (range 33 to 38 g/L) (Figure 9.24). As anticipated, centres using the BCP method (n = 13) generally had lower albumin concentrations (median 30 g/L, range 28 to 32 g/L) (Figure 9.25). Overall, 59% of patients had serum albumin above 35 g/L for

the BCG method (Figure 9.26) and 55% for BCP (Figure 9.27). For both BCG ($\chi^2 = 138$, $p < 0.001$) and BCP ($\chi^2 = 32$, $p = 0.0015$) centres, the percentage of patients achieving serum albumin concentrations above these levels differed significantly between centres. The data indicate how difficult it is to keep serum albumin above the recommended minimum in patients treated by peritoneal dialysis.

Analysis of the influence of laboratory bias

An analysis of the potential contribution of laboratory bias to between centre differences has been undertaken using data from the 2003 Registry report and data supplied by UK NEQAS. UK NEQAS method group and laboratory bias data was available for 26 of the laboratories supporting these renal centres (17 BCG, 9 BCP). Given the small amount of data available for the BCP group, analysis was undertaken of the 17 PD centres with BCG data only. Amongst these, there was no relationship between percentage bias relative to the UK NEQAS ALTM and median albumin ($r_s = 0.47$, $p = 0.0545$) using Spearman's rank correlation.

Although BCP results clearly demonstrate lower mean albumin concentrations in dialysis patients, in quality assessment samples generally there is no clear relationship between bias relative to the ALTM and method group. Indeed, amongst laboratories supporting renal centres, of the seven laboratories demonstrating the

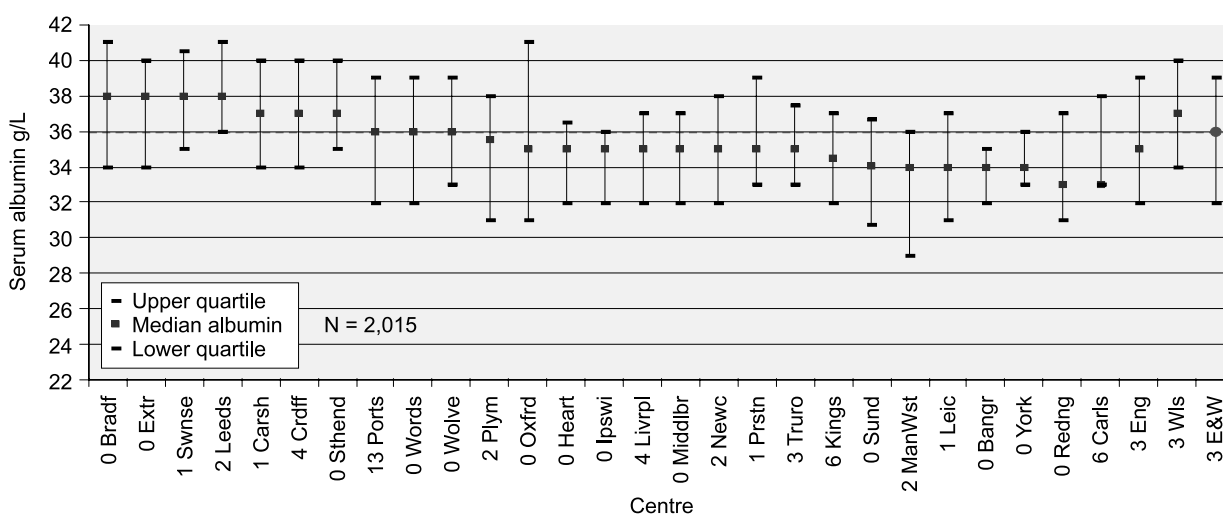


Figure 9.24: Median serum albumin in PD patients by centre: BCG method

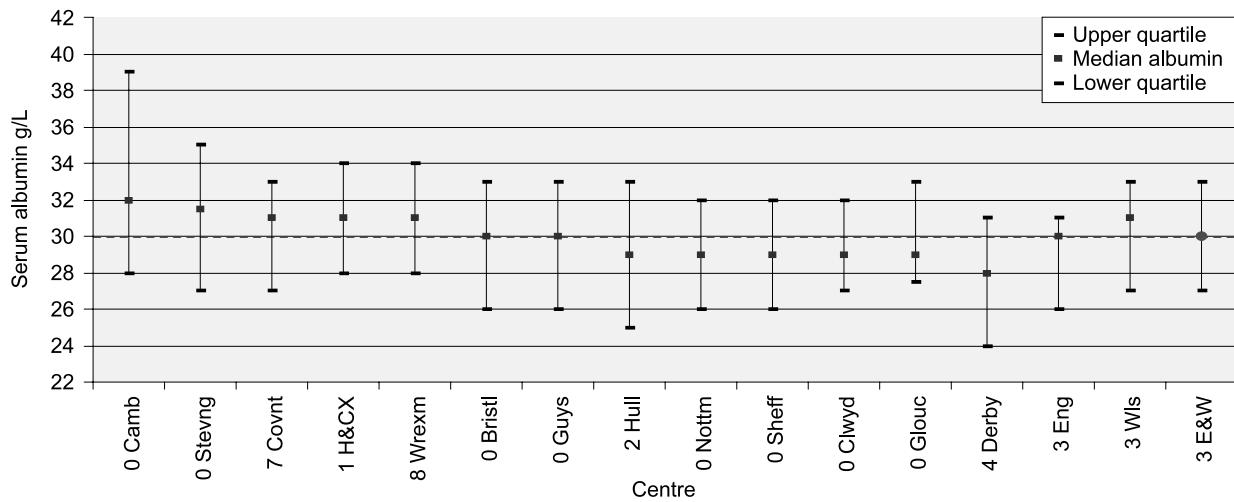


Figure 9.25: Median serum albumin in PD patients by centre: BCP method

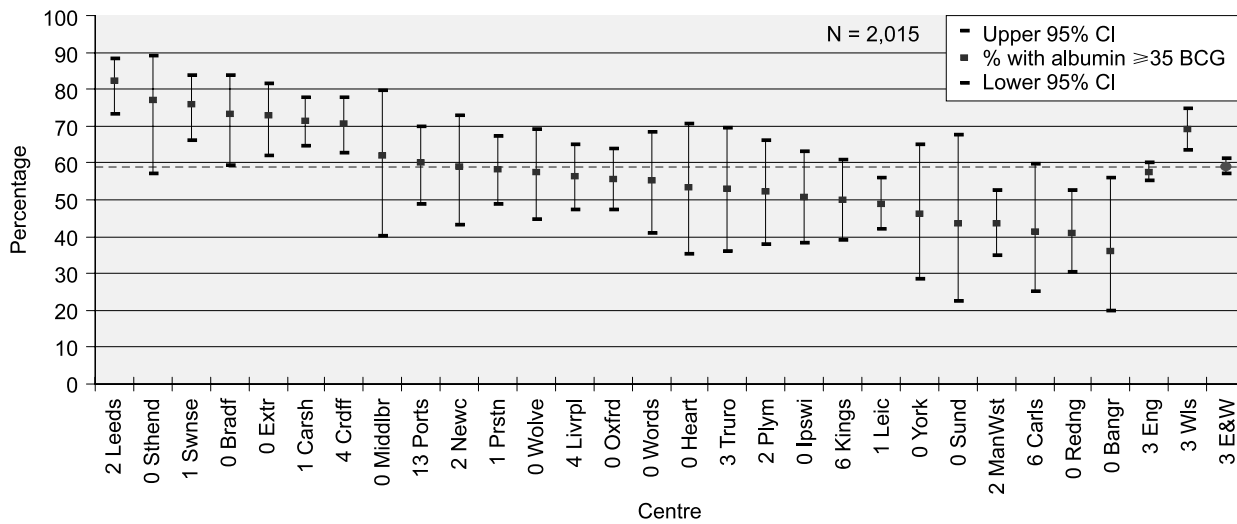


Figure 9.26: Percentage of PD patients by centre with serum albumin >35 g/L (BCG)

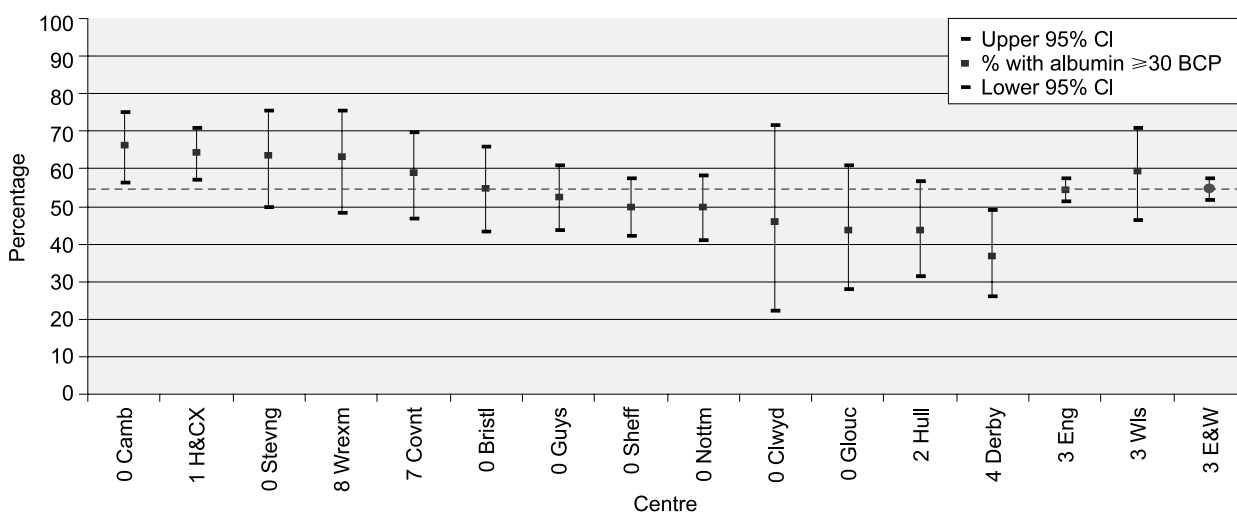


Figure 9.27: Percentage of PD patients by centre with serum albumin >30 g/L (BCP)

most positive bias compared with the UK NEQAS ALTM, five used BCP. This could reflect differing reactivity of the quality assessment material with the BCG/BCP methods compared with uraemic patient samples, or the relative paucity of 'low-range' albumin distributions in the UK NEQAS scheme. The situation is also confused by the use of dry-chemistry BCG methods, which appear to give lower results in dialysis patients. In December 2002, the between-laboratory CV for serum albumin for all participants in the UK NEQAS scheme using a range of different methods was 5.1%. When broken down into method groups, between-laboratory agreement was 3.2%, 3.9% and 3.7% for the BCG, BCP and dry-chemistry methods respectively. Overall, between-centre albumin variation does not greatly exceed laboratory variation and there is some evidence that laboratory variation may contribute to between-centre differences.

Effect of time on treatment

Figure 9.28 demonstrates the effect of time on treatment on the percentage of patients with serum albumin in the target range for both HD and PD. Over time, on HD, 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 PD, serum albumin tends to fall. Possible explanations are increasing peritoneal protein clearance associated with high peritoneal transport due to the cumulative effect of repeated peritonitis and glucose exposure and informative censoring (ie loss of 'fitter' patients to transplantation)⁷.

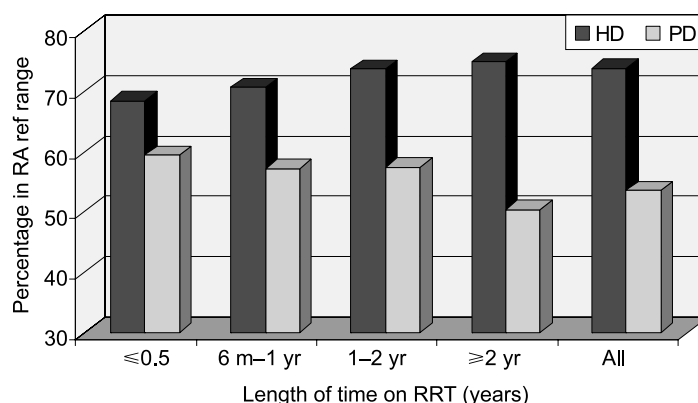


Figure 9.28: Changes over time on HD and PD in percentage of patients with serum albumin >35g/L (BCG) or >30g/L (BCP)

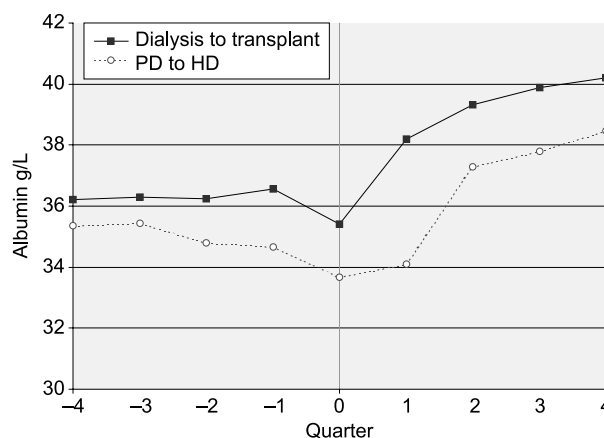


Figure 9.29: Serum albumin, by quarter, before and after modality change

Effect of modality change

Provision of a renal transplant or switching dialysis modality from PD to HD produces predictable increases in serum albumin concentration (Figure 9.29).

Serum Albumin – Discussion

Previous reports from the UK Renal Registry and other publications¹⁸ have recognised the difficulties in using serum albumin as an audit measure in patients with renal failure. BCG is the more commonly used method but tends to overestimate serum albumin when compared with (gold-standard) antibody based methods, especially at lower levels of serum albumin as are often seen in RRT patients. BCG is known to react non-specifically with other protein fractions (α 1, α 2 and β globulins) in serum, which tend to be over-represented in hypoalbuminaemic situations, eg in an acute phase reaction.

There have been calls for laboratories to switch to use of BCP⁹ but the situation is not straightforward. Not all BCG methods are equal, with the relative interference from non-albumin protein being in part dependent on the time period over which the reaction is monitored (non-albumin proteins react more slowly than albumin itself)^{10,11}. Further, dry-slide BCG methods have in fact been reported to show a slight negative bias (−1 g/L) when compared with immunological assays¹² and would appear from the present data to contribute significantly to differences between renal centres. Although some authors have demonstrated improved accuracy of BCP methods compared with BCG in uraemic patients⁸, others have shown significant underestimation of serum albumin by BCP methods in haemodialysis patients^{13,14}. This may relate to the presence of an inhibitor of the BCP dye-binding reaction¹⁵ which accumulates in haemodialysis patients but not in patients being treated with PD¹⁶. Other unexplored factors may be important: for example, HD is known to result in loss of cysteine from its mixed disulphide bond, so that the proportion of mercaptalbumin is higher after treatment¹⁷. It is known that mercaptalbumin is less reactive with BCP methods than its oxidised non-mercaptalbumin form¹⁸.

As reflected in the RA standards, it is widely accepted that BCG gives serum albumin results approximately 5 g/L higher on average than BCP in a renal patient population^{19,20}. The present Registry data give some credence to the equivalence of these two standards, with roughly equivalent numbers of dialysis patients achieving the RA minimum albumin concentration with BCG and BCP methods. However, the Registry data support the RA stance that it is not appropriate to set an audit standard for serum albumin. It is clear that analytical influences are significant, but there is no clear pointer as to which method is most appropriate in uraemic patients and whether they can be applied equally to PD and HD patients. There are almost certainly other confounding factors; for example the effect of social deprivation alluded to above. Further, at the individual patient level there is little that can be done to correct hypoalbuminaemia (apart from changing RRT modality).

As concluded in previous Registry reports, although serum albumin measurement is useful

clinically at the individual patient level, the value of between-centre comparative audit and continuing to present these data is questionable.

Acknowledgements

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Chapter 10: Factors which may influence cardiovascular disease – blood pressure and serum cholesterol

Summary

- Blood pressure returns to the Renal Registry continue to be poor from some centres.
- In England & 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%).
- Over the last 7 years there has been no significant change in systolic or diastolic blood pressure achievement.
- In England & Wales, the cholesterol standard was achieved in 77% of patients on haemodialysis (HD) (inter unit range 54–69%), 64% of peritoneal dialysis (PD) patients (range 41–84%) and 53% of transplant patients (Tx) (range 25–72%).
- Cholesterol levels are consistently lower in haemodialysis patients compared to peritoneal dialysis or transplant patients.
- Post-haemodialysis blood pressure, episodes of symptomatic hypotension during haemodialysis, C-reactive protein (CRP), beta blocker and statin use need to be recorded to help with the interpretation of Renal Registry data.

Introduction

Hypertension and hypercholesterolaemia are major risk factors for cardiac disease in the general population. Evidence from numerous randomised controlled trials indicate the lower the blood pressure or cholesterol level, the lower the cardiovascular risk, particularly for diabetics. There is no controlled trial data in this area for patients on renal replacement therapy (RRT). Until there is definitive evidence it is important to audit the effect of lowering blood pressure and cholesterol in the (HD), (PD) and (Tx) populations.

Hypertension plays a direct role in the development of heart disease and cardiac failure in renal impairment. The duration of hypertension before the start of dialysis correlates with mortality¹. Studies with a follow-up period exceeding 5 years show a positive correlation between hypertension and mortality. The U-shaped relationship evident in short term studies² highlights the risk of death is greatest for patients with established cardiac failure and relative hypotension. The evidence suggests a more aggressive approach to blood pressure control is needed in the early stages of chronic kidney disease (CKD) if patients are to survive longer on RRT.

Widening pulse pressure (systolic minus diastolic blood pressure) is a manifestation of arterial stiffening and is a potent predictor of cardiac mortality in both the general and dialysis populations³. In a cross sectional study PD patients had significantly stiffer arteries with blunted vasodilator responses compared with patients on HD. Both dialysis groups had stiffer arteries than Tx patients and essential hypertensive controls⁴. The effect of different treatment modalities on arterial function is likely to be an important area for future research. Pulse pressure is not the only important factor; both high systolic blood pressure and low diastolic blood pressure are independently associated with cardiovascular death^{5,6}. For HD, post-dialysis blood pressure correlates more closely with outcome^{2,7}.

The main cause of hypertension in the dialysis population is salt and water overload. Sodium also has an independent effect on left ventricular hypertrophy and dilatation⁸. A combination of dietary sodium restriction and increased sodium removal by long HD normalises blood pressure in 95% of patients and reduces mortality compared to conventional HD⁹. Also in PD, sodium restriction and enhanced sodium clearance achieves dry weight and blood pressure control in 90% of patients and is associated with improved survival^{10,11}. For PD patients with residual renal function, increased ultrafiltration often leads to decreased

Kt/V, necessitating an increase in dialysis dose or transfer to HD. Currently no unit in the UK takes an aggressive approach to sodium balance and indeed this would be a difficult area to audit. The development of hypertension after renal transplantation is independently correlated with graft function and use of drugs, particularly cyclosporin¹². The role of sodium balance has not been addressed in Tx patients.

Blood Pressure Control

Introduction

The Renal Association standards for control of hypertension were revised in August 2002. 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 on RRT. Diabetic guidelines for non-RRT patients with proteinuria advise a lower target BP (<125/75 mmHg) to reduce cardiovascular risk.

There are several other UK guidelines set for blood pressure achievement in diabetic patients, which cause confusion. The National Institute of Clinical Excellence (NICE) guidelines^{13,14} for non-RRT patients with Type 2 diabetes and proteinuria advise a BP <135/75 mmHg. The NICE guidelines for management of Type 1 diabetes in adults¹⁵ recommends a BP of <130/80 mmHg in patients with diabetic nephropathy and <125/75 mmHg in those with proteinuria. The above standards should not be confused with the blood pressure target set within the GP contract, which is a payment related target and not a clinical standard.

KDOQI have set a guideline for patients with CKD stages 1 and 2, diabetic patients and all transplant recipients (irrespective of creatinine clearance) of:

Blood pressure <130/80 mmHg

Completeness of Data Returns

Table 10.1 shows the data completeness of blood pressure values for each unit according to

Table 10.1: Percentage of patients with complete returns of blood pressure values by modality

	% completed data			
	Pre HD	Post HD	PD	Transplants
Bangor	99	99	92	–
Bradford	5	3	98	89
Bristol	99	98	100	50
Cambridge	12	0	95	73
Carlisle	93	93	38	3
Carshalton	0	0	1	0
Clwyd	11	0	85	–
Coventry	99	99	75	66
Cardiff	8	0	6	93
Derby	83	84	26	–
Exeter	93	91	100	11
Gloucester	97	0	6	35
Guys	69	67	5	1
H&CX	0	0	0	0
Heartlands	92	91	7	2
Hull	88	88	47	4
Ipswich	95	96	2	1
Kings	0	0	0	0
Leeds	97	96	52	70
Leicester	97	93	92	80
Liverpool	34	0	64	66
ManWest	0	0	0	0
Middlesbrough	95	94	100	52
Newcastle	0	0	0	0
Nottingham	96	95	100	96
Oxford	95	82	80	7
Plymouth	0	0	0	2
Portsmouth	0	0	0	0
Preston	0	0	0	0
Reading	92	1	95	17
Sheffield	100	98	97	97
Stevenage	87	0	7	4
Southend	95	1	9	3
Sunderland	96	96	6	4
Swansea	0	0	0	2
Truro	96	96	60	47
Wirral	4	0	5	–
Wolverhampton	99	93	17	4
Wordsley	95	91	90	62
Wrexham	1	0	0	0
York	91	91	89	98
England	62	51	46	33
Wales	13	9	13	77
E&W	58	48	42	36

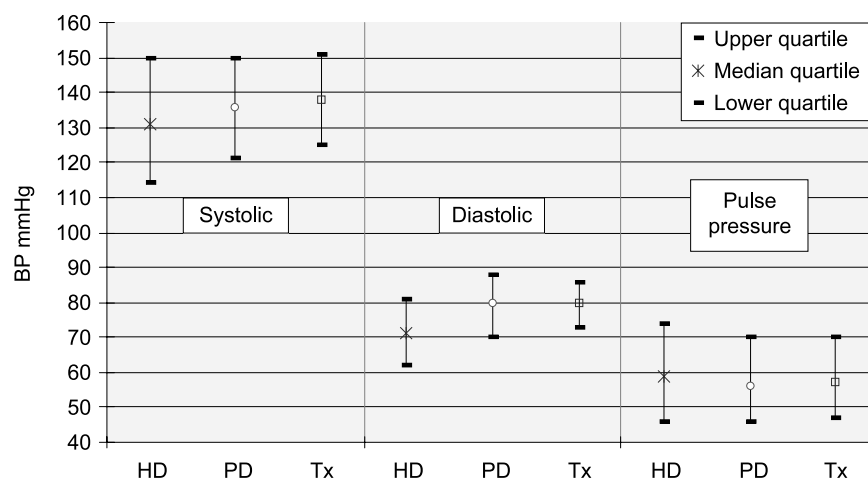


Figure 10.1: Summary of BP achievements

modalities. Patients need to have at least one blood pressure recording in the last 6 months of 2003 to be included in the analyses. Units with more than 50% missing data were excluded from the blood pressure analyses.

Sixteen centres had insufficient data for HD, 23 centres insufficient data for PD and 24 centres insufficient data for Tx. For the analyses, data were available for 4,052 Tx patients, 1,482 PD patients and 5,659 HD patients, but only 4,678 HD patients also had data on post-haemodialysis BP. Clearly a large proportion of units still have problems transferring data from all their clinical areas onto their renal IT systems. The renal NSF Information Strategy document highlights the need for an effective IT infrastructure.

Distribution of blood pressure by modality

Figure 10.1 indicates systolic, diastolic and pulse pressure distributions for each treatment modality (post-HD data is shown). The systolic/diastolic standard deviations for post HD, PD and Tx were 26/14, 24/13 and 20/11 respectively, with the widest spread for HD. The values have not changed substantially over the last few years and should be compared to 18/10 for a hypertensive population. A specified blood pressure target eg 130/80 typically becomes the mean blood pressure of the group. Diastolic blood pressure is significantly lower for HD and accounts for the wider pulse pressure in this group (Kruskal-Wallis test; $p < 0.0001$).

Achievement of combined systolic and diastolic standard

Figures 10.2–10.5 show a wide variation between units achieving the combined blood pressure standard for each modality. In England & Wales, the median percentage of HD patients achieving the standard pre-dialysis is 37% (range 9–54%) and post-dialysis 43% (range 30–54%). For PD patients, the median achieving the standard is 28% (range 4–47%) and 21% for Tx patients (range 16–26%). Chi squared testing indicates the variation between centres for each treatment modality is significant (HD and PD; $p < 0.0001$, Tx; $p = 0.0236$).

Systolic pressure alone

Figures 10.6–10.13 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 is 38% (range 9–56%) and post-dialysis is 48% (range 35–61%). 37% of PD patients achieve the standard (range 20–61%) and 31% of Tx patients (range 20–46%). Chi squared testing indicates the variation between centres for each treatment modality is significant (HD, PD and Tx; $p < 0.0001$). The median systolic blood pressure for pre-HD, post-HD, PD and Tx is 147, 131, 136 and 138 mmHg respectively.

Diastolic pressure alone

Figures 10.14–10.21 show wide variation between units achieving the diastolic blood pressure standard. In England & Wales, the

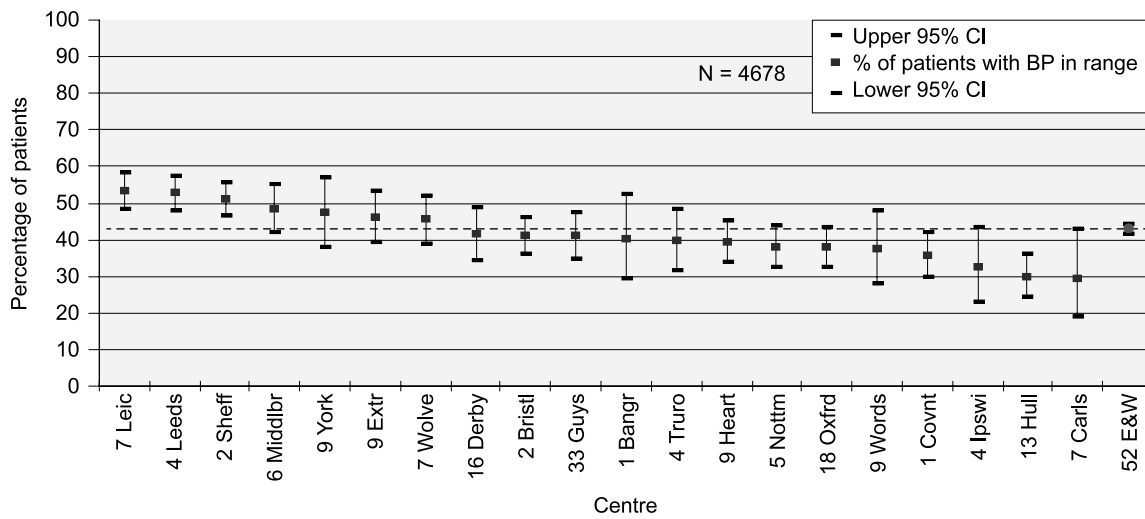


Figure 10.2: Percentage of patients with BP <130/80 mmHg: post-HD

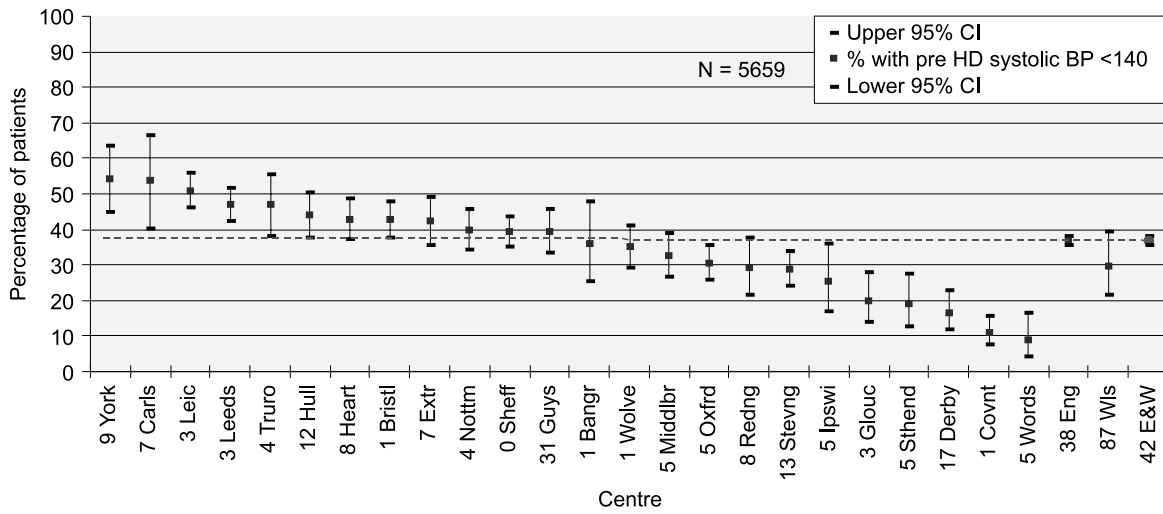


Figure 10.3: Percentage of patients with BP <140/90 mmHg: pre-HD

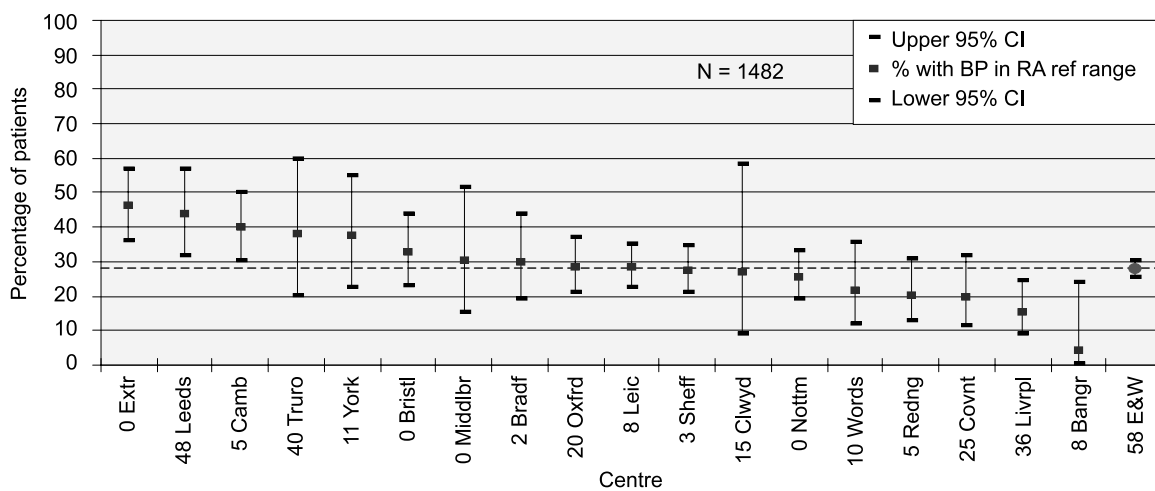


Figure 10.4: Percentage of patients with BP <130/80 mmHg: PD

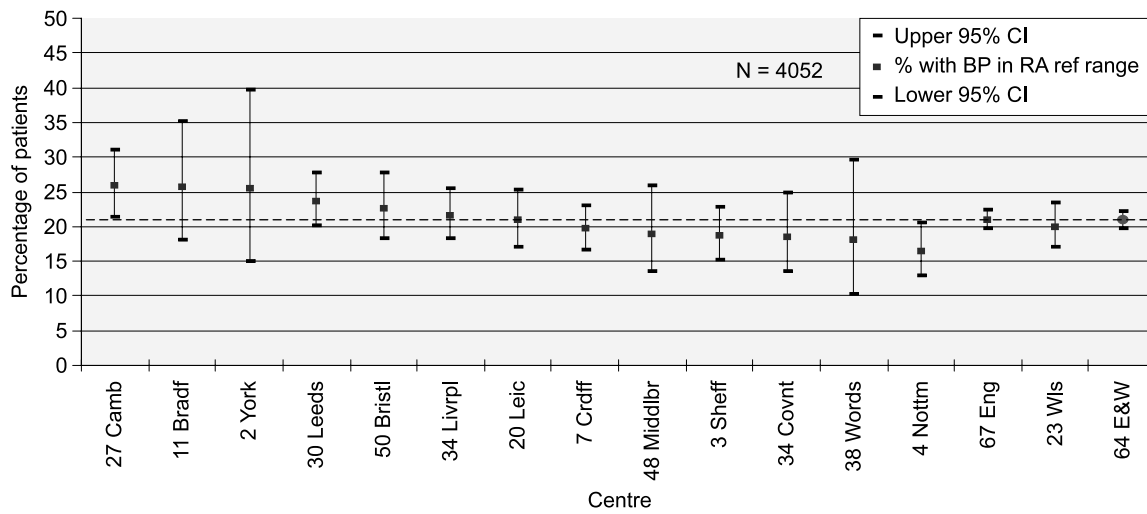


Figure 10.5: Percentage of patients with BP <130/80 mmHg: transplant

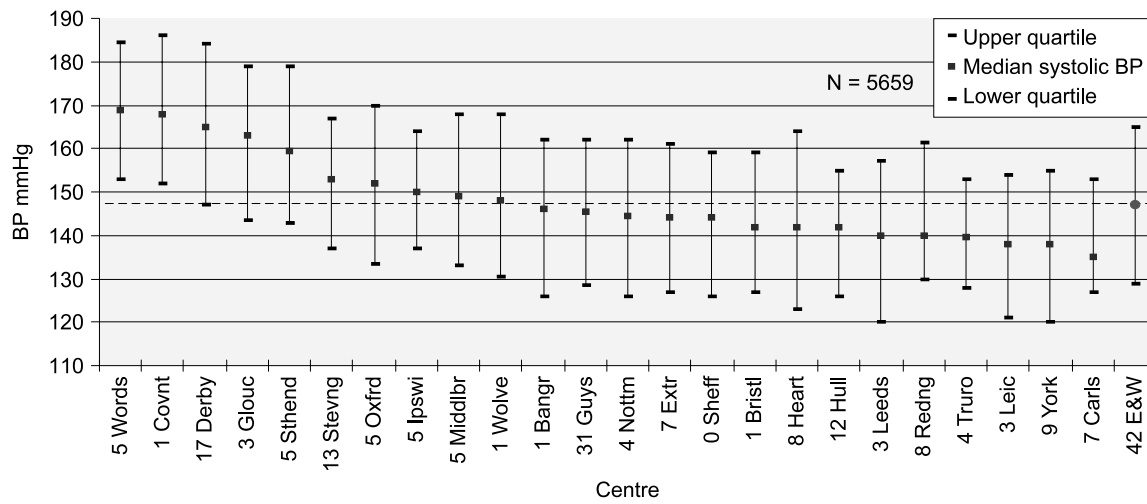


Figure 10.6: Median systolic BP: pre-HD

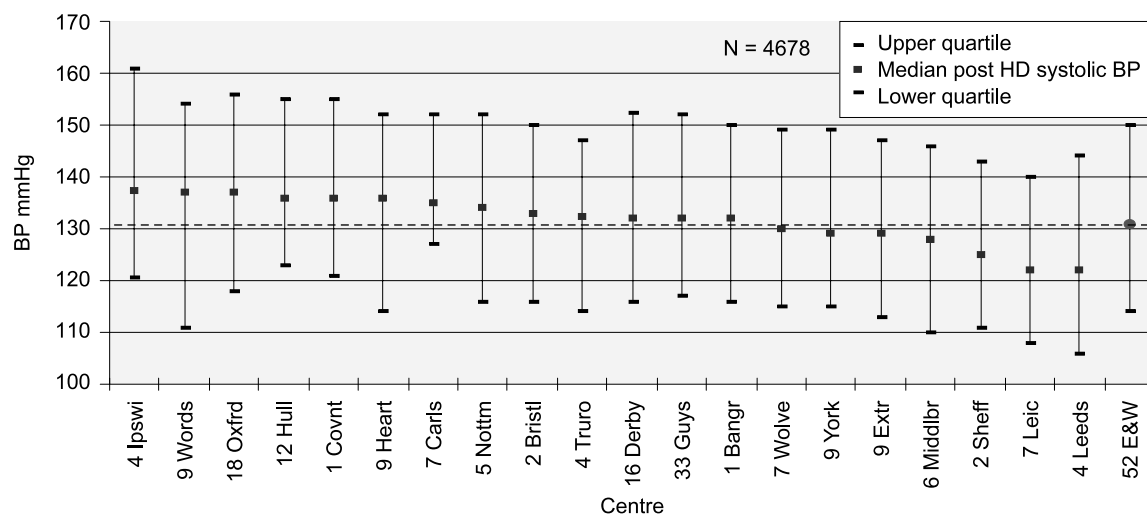


Figure 10.7: Median systolic BP: post-HD

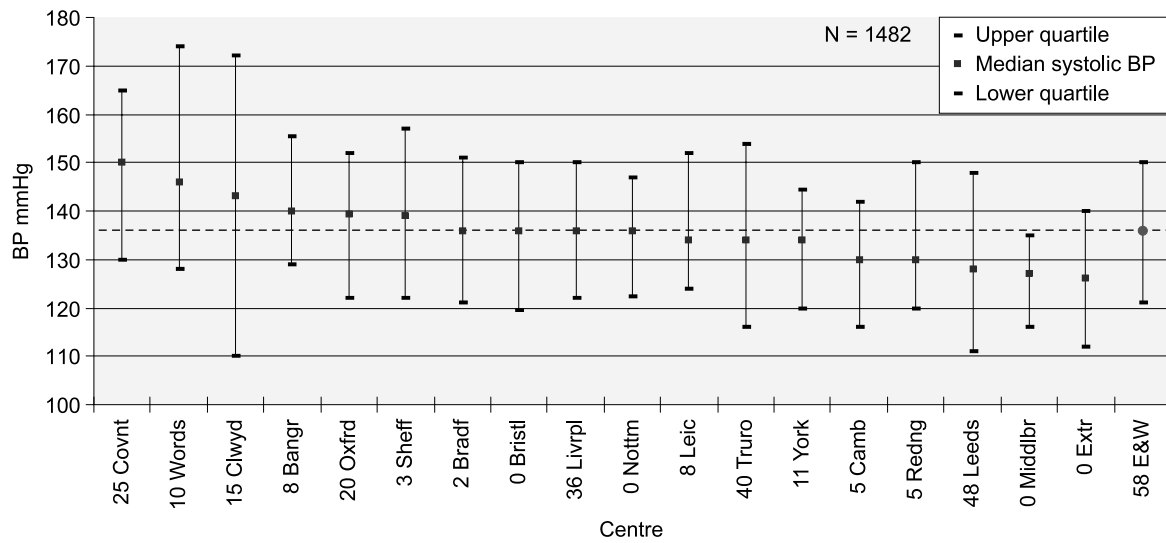


Figure 10.8: Median systolic BP: PD

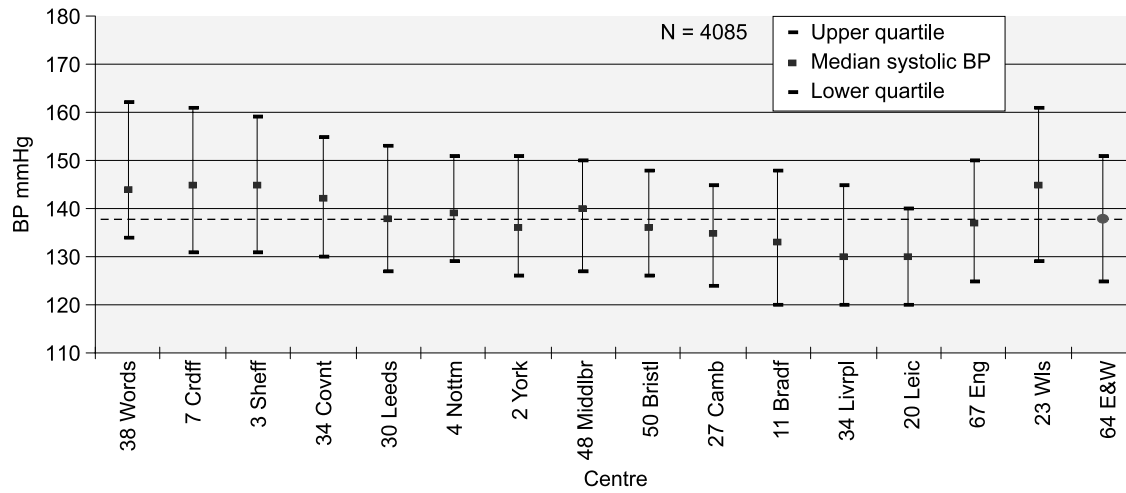


Figure 10.9: Median systolic BP: transplant

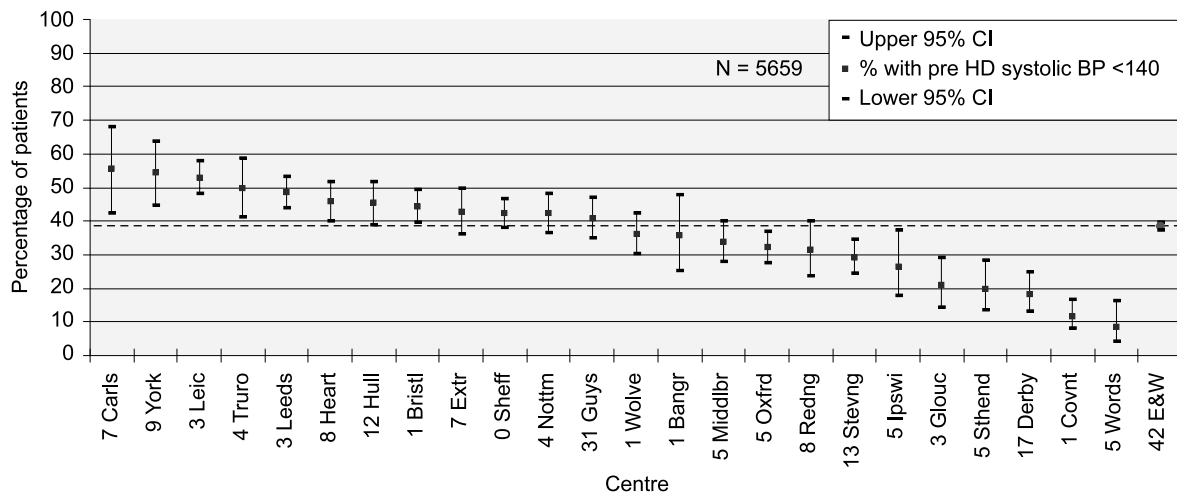


Figure 10.10: Percentage of patients with systolic BP <140 mmHg: pre-HD

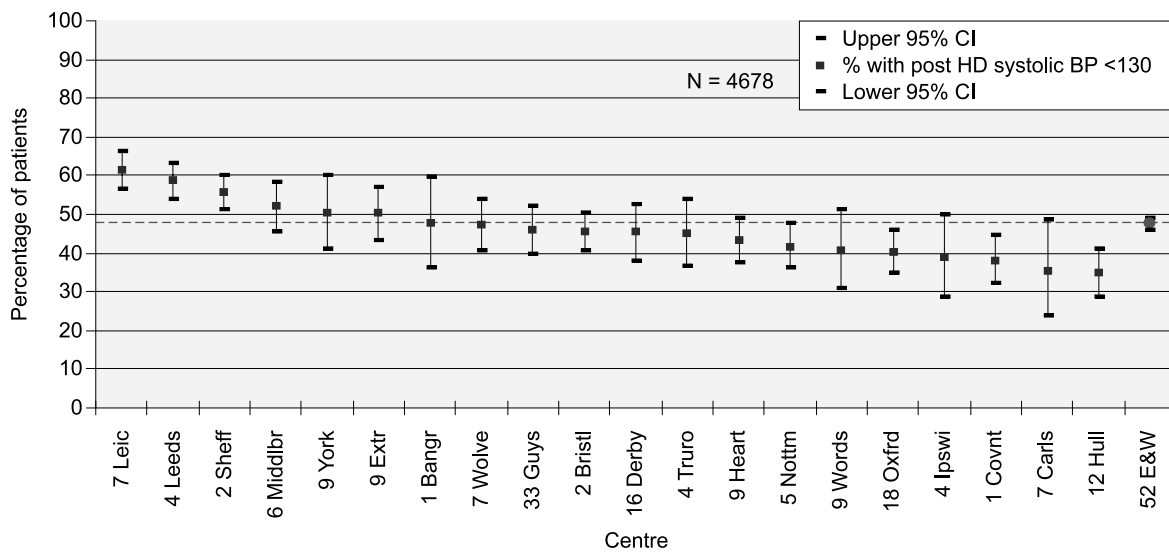


Figure 10.11: Percentage of patients with systolic BP <130 mmHg: post-HD

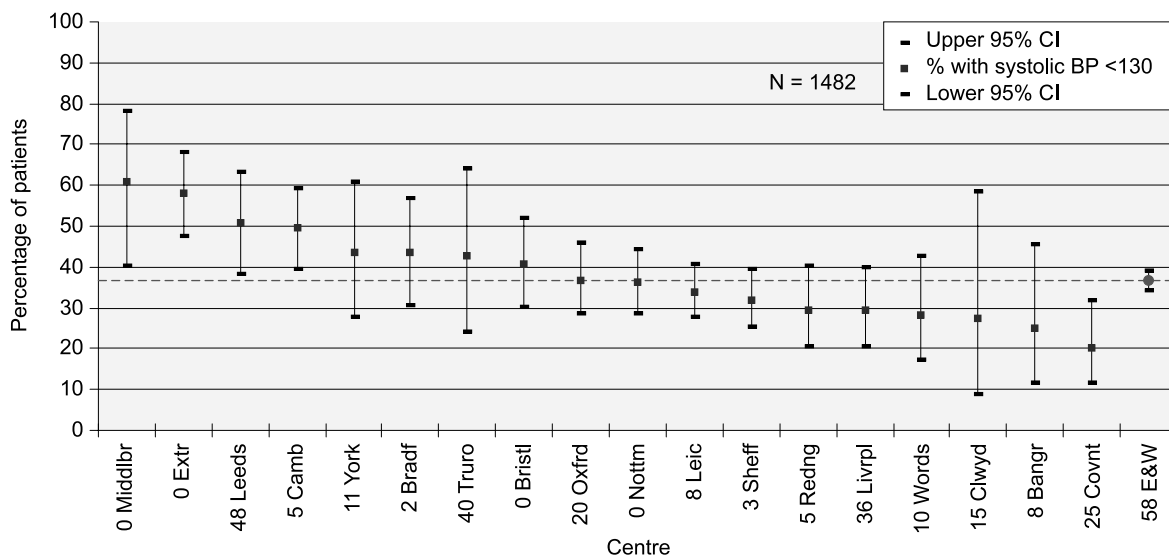


Figure 10.12: Percentage of patients with systolic BP <130 mmHg: PD

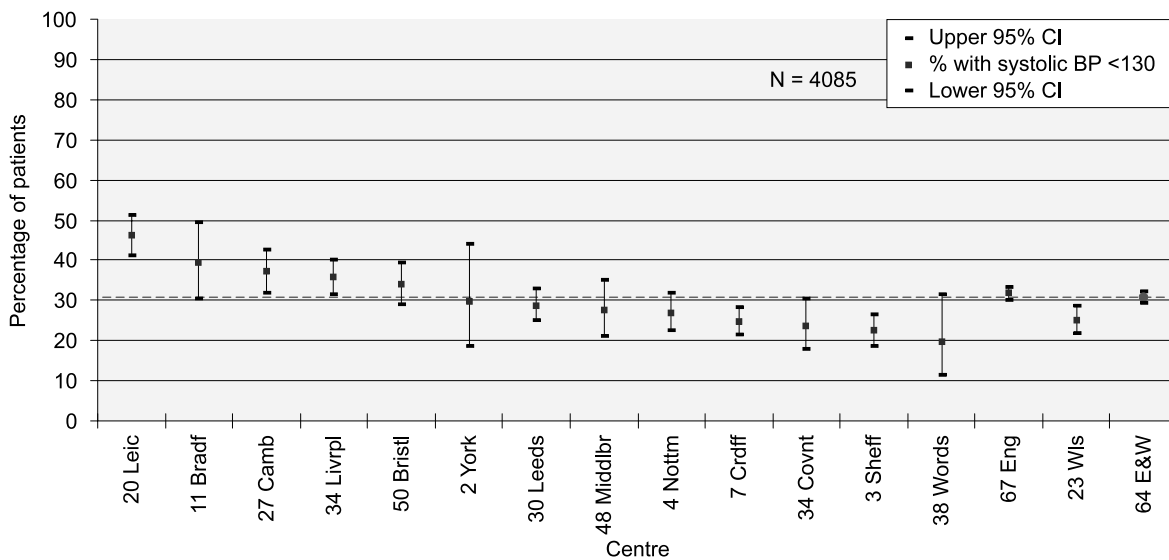


Figure 10.13: Percentage of patients with systolic BP <130 mmHg: transplant

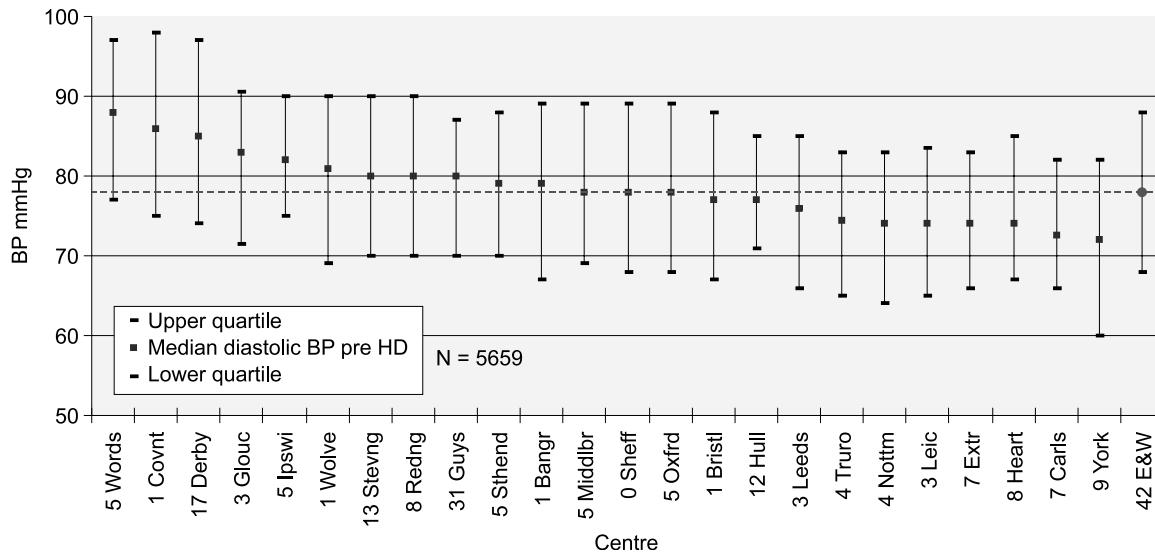


Figure 10.14: Median diastolic BP: pre-HD

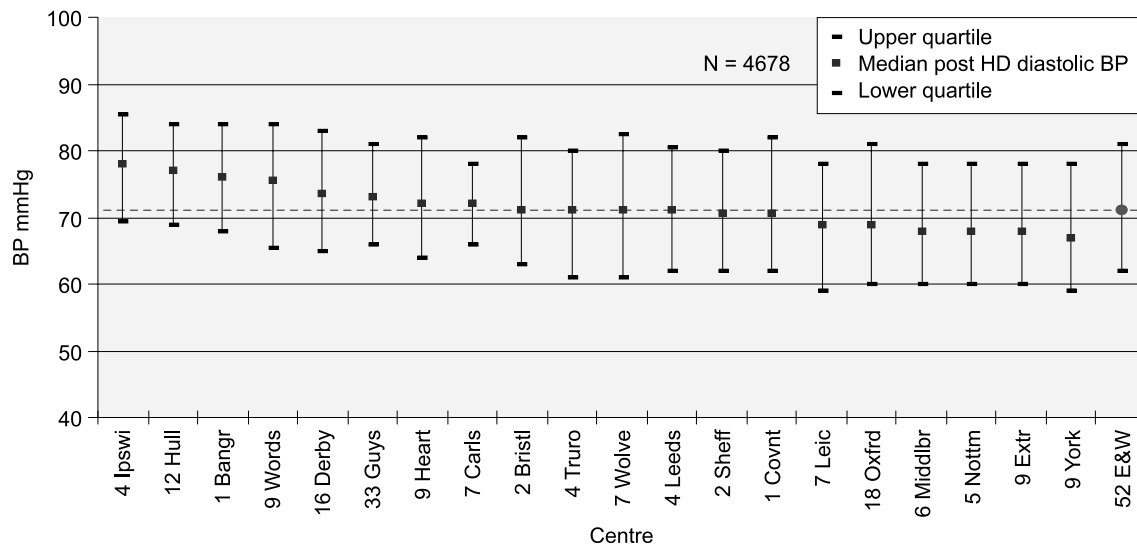


Figure 10.15: Median diastolic BP: post-HD

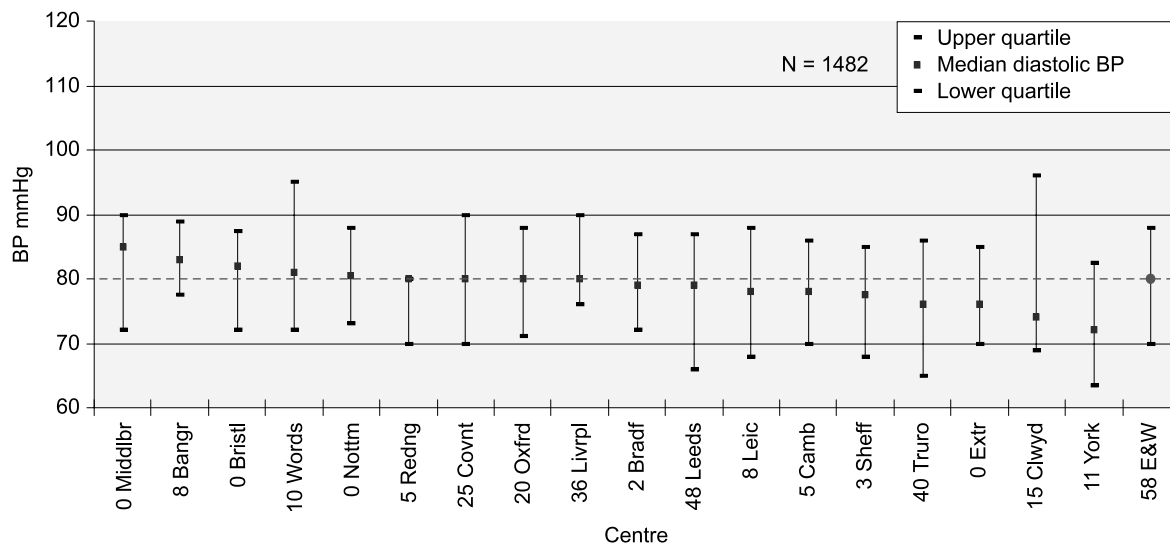


Figure 10.16: Median diastolic BP: PD

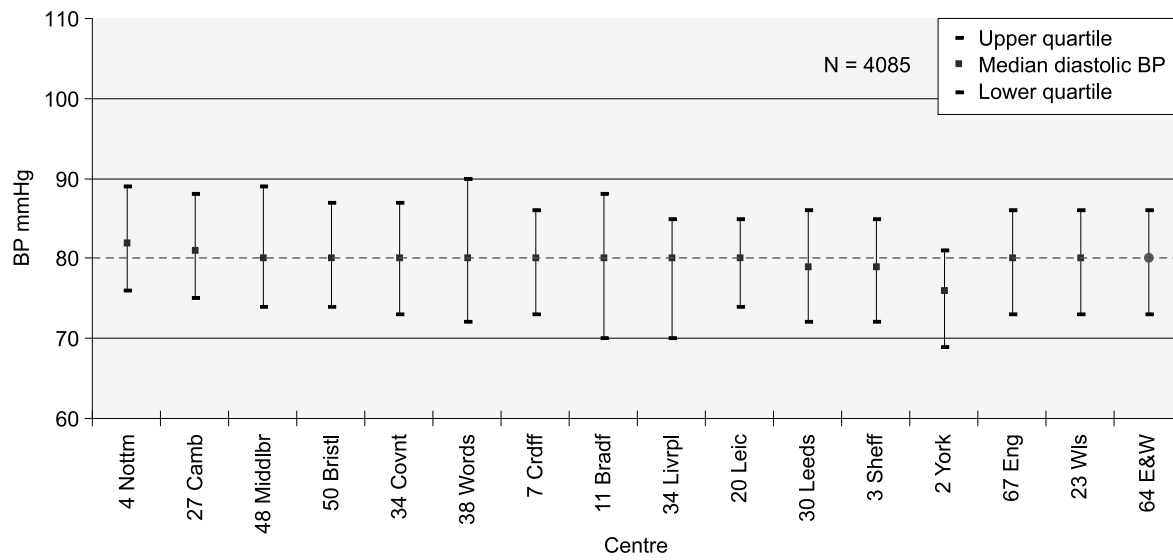


Figure 10.17: Median diastolic BP: transplant

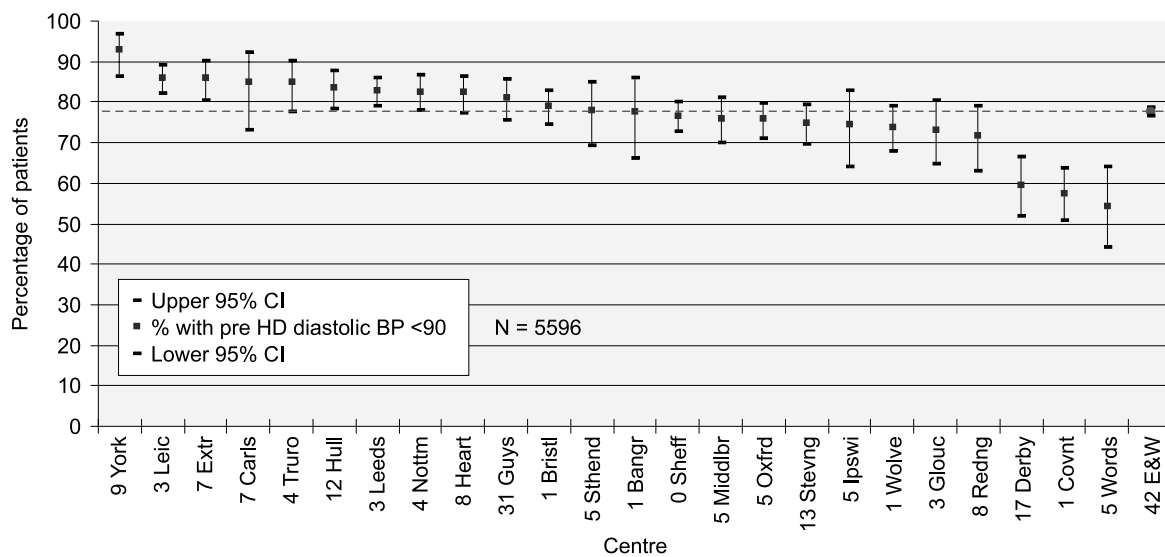


Figure 10.18: Percentage of patients with diastolic BP <90 mmHg: pre-HD

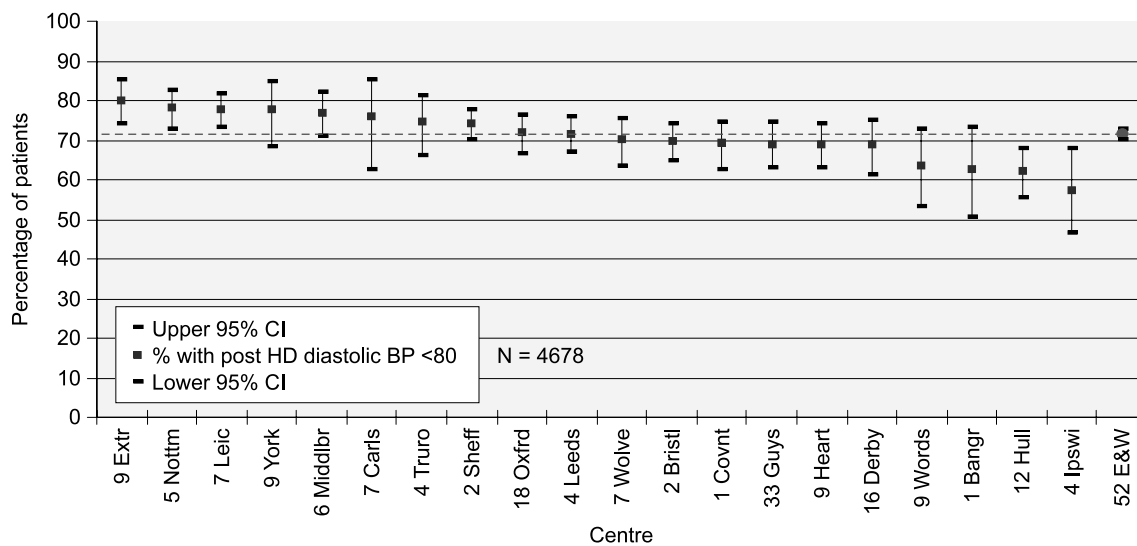


Figure 10.19: Percentage of patients with diastolic BP <80 mmHg: post-HD

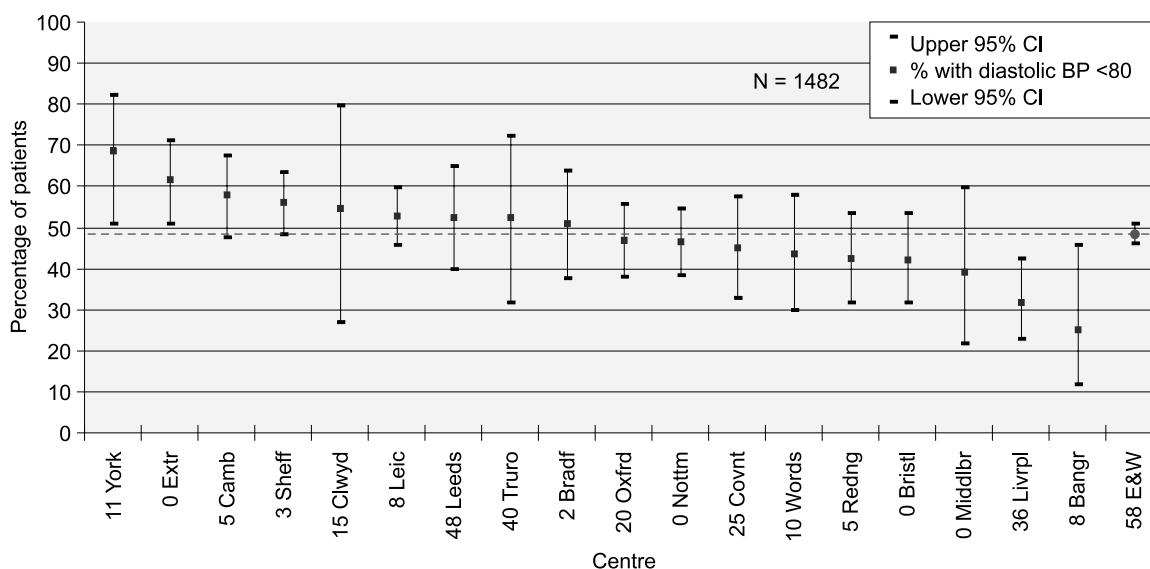


Figure 10.20: Percentage of patients with diastolic BP <80 mmHg: PD

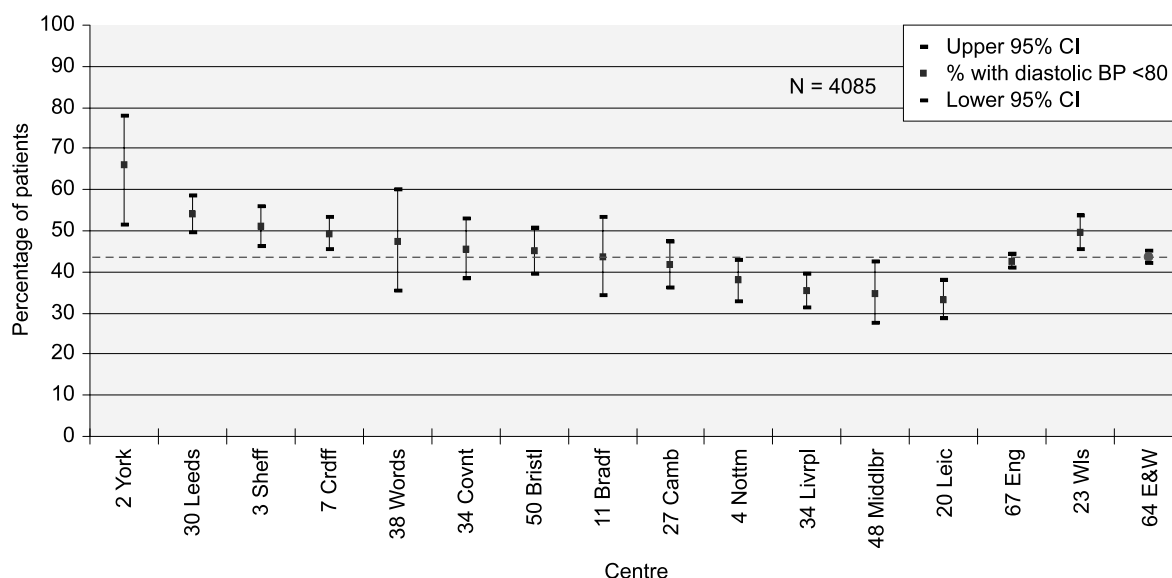


Figure 10.21: Percentage of patients with diastolic BP <80 mmHg: transplant

percentage of HD patients achieving the standard pre-dialysis is 78% (range 54–93%) and post-dialysis 71% (range 58–80%). 49% of PD patients achieve the standard (range 25–69%) and 44% of Tx patients (range 33–66%). Chi squared testing indicates the variation between centres for each treatment modality is significant (HD and Tx; $p < 0.0001$, PD; $p = 0.0093$). The median diastolic blood pressure for pre-HD, post-HD, PD and Tx is 78, 71, 80 and 80 mmHg respectively.

Mean arterial pressure (MAP)

Figures 10.22–10.29 show wide variation between units achieving the desired mean

arterial pressure. MAP is calculated as diastolic blood pressure plus one third of the pulse pressure. In England & Wales, the percentage of HD patients achieving the standard pre-dialysis average 64% (range 34–80%) and post-dialysis average 63% (range 47–73%). An average of 48% of PD patients achieve the standard (range 25–63%) and 43% of Tx patients (range 33–65%). Chi squared testing indicates the variation between centres for each treatment modality is significant (HD and Tx; $p < 0.0001$, PD; $p = 0.0245$). The median MAP for pre-HD, post-HD, PD and Tx is 101, 92, 98 and 99 mmHg respectively.

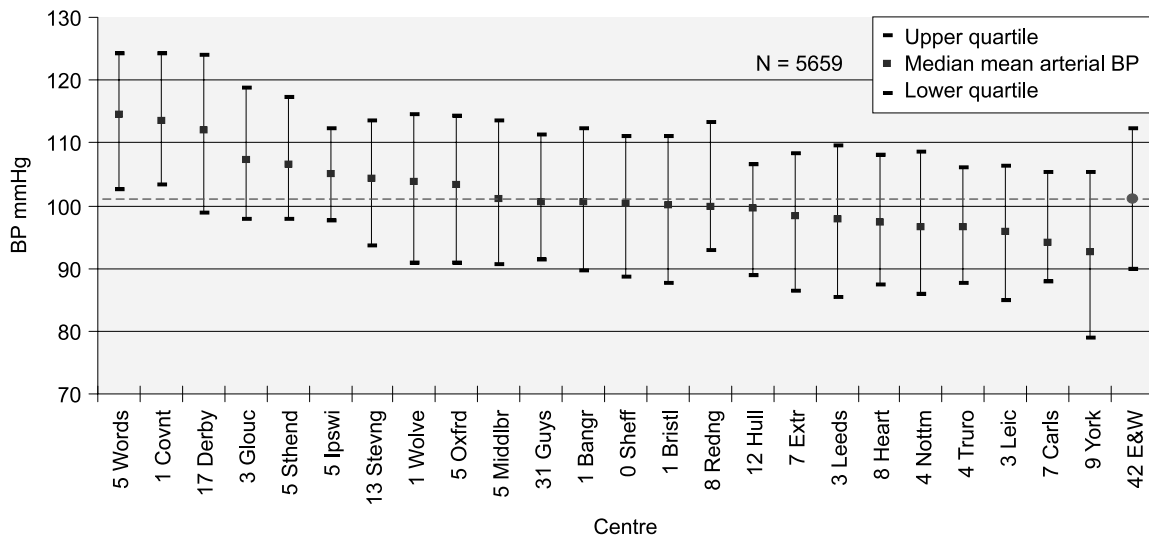


Figure 10.22: Median MAP: pre-HD

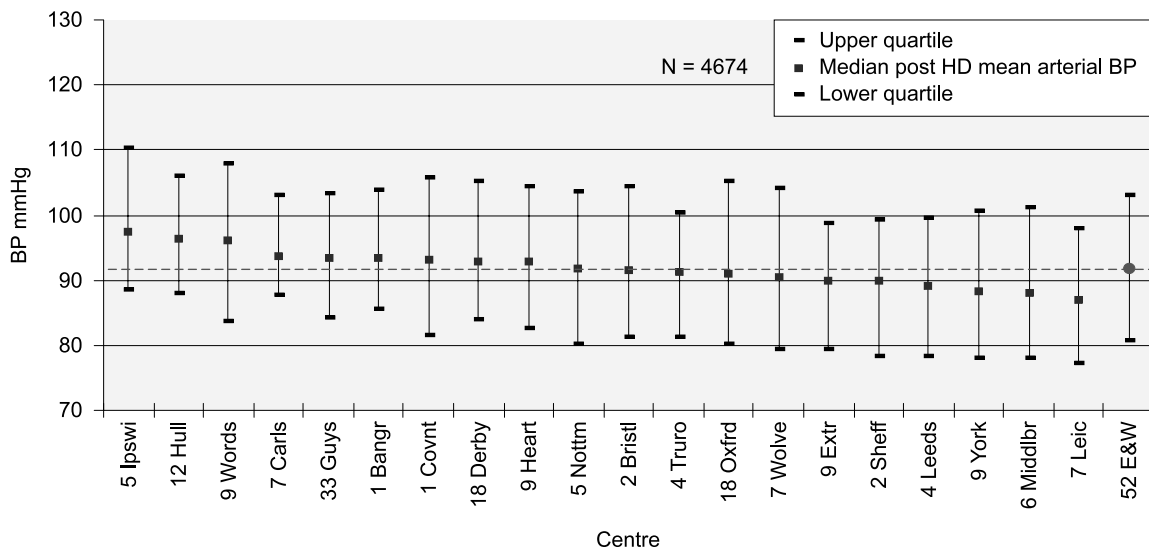


Figure 10.23: Median MAP: post-HD

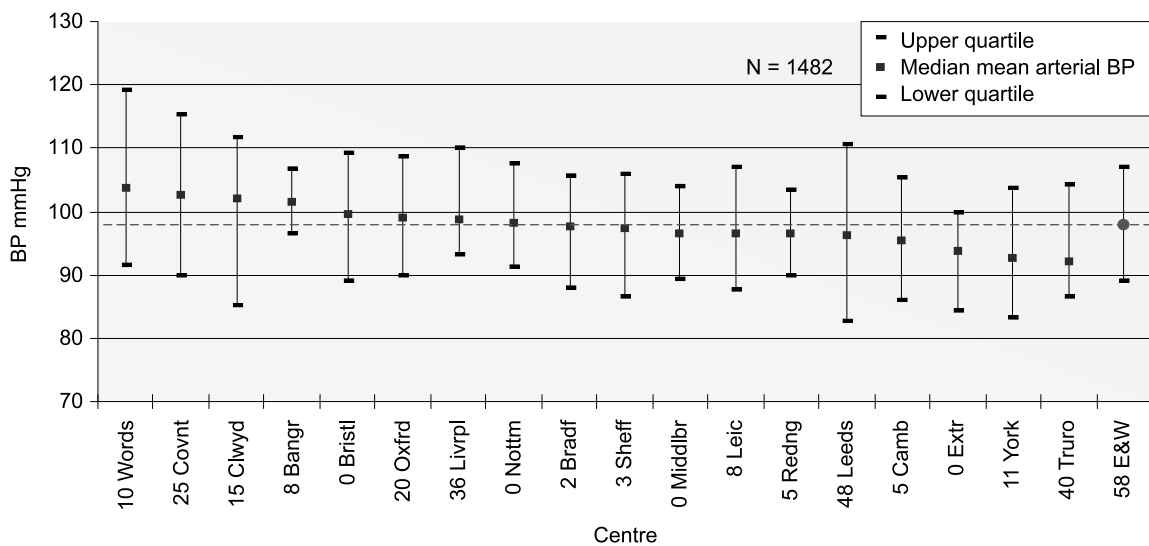


Figure 10.24: Median MAP: PD

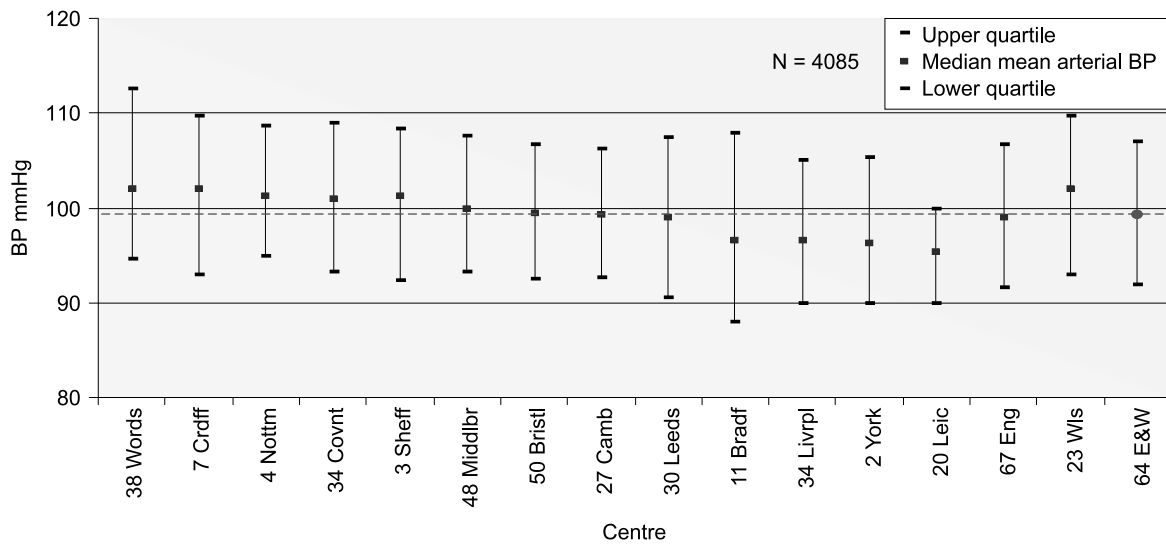


Figure 10.25: Median MAP: transplant

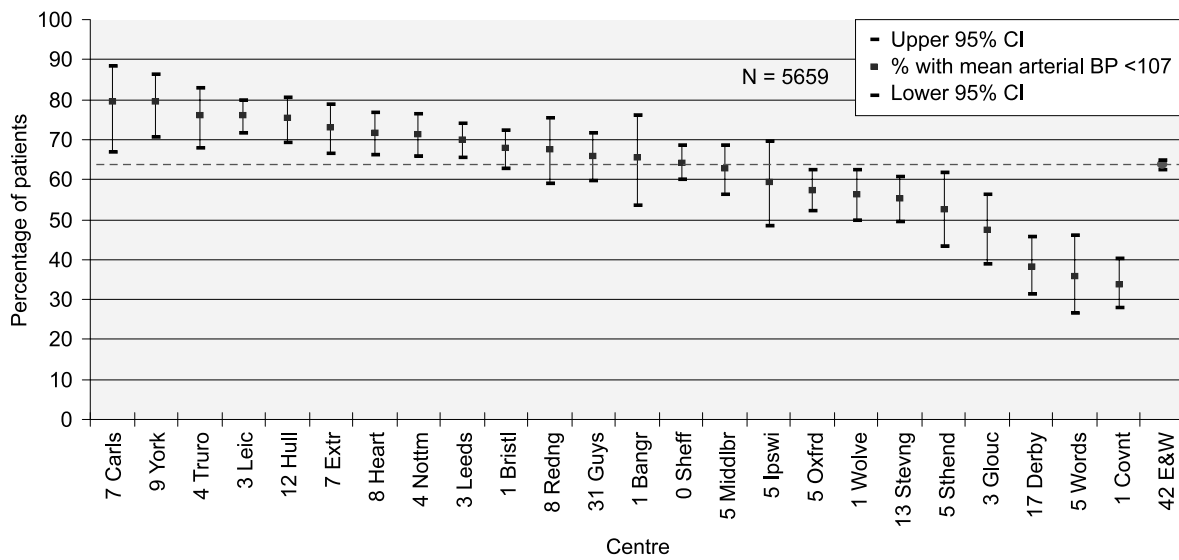


Figure 10.26: Percentage of patients with MAP <107 mmHg: pre-HD

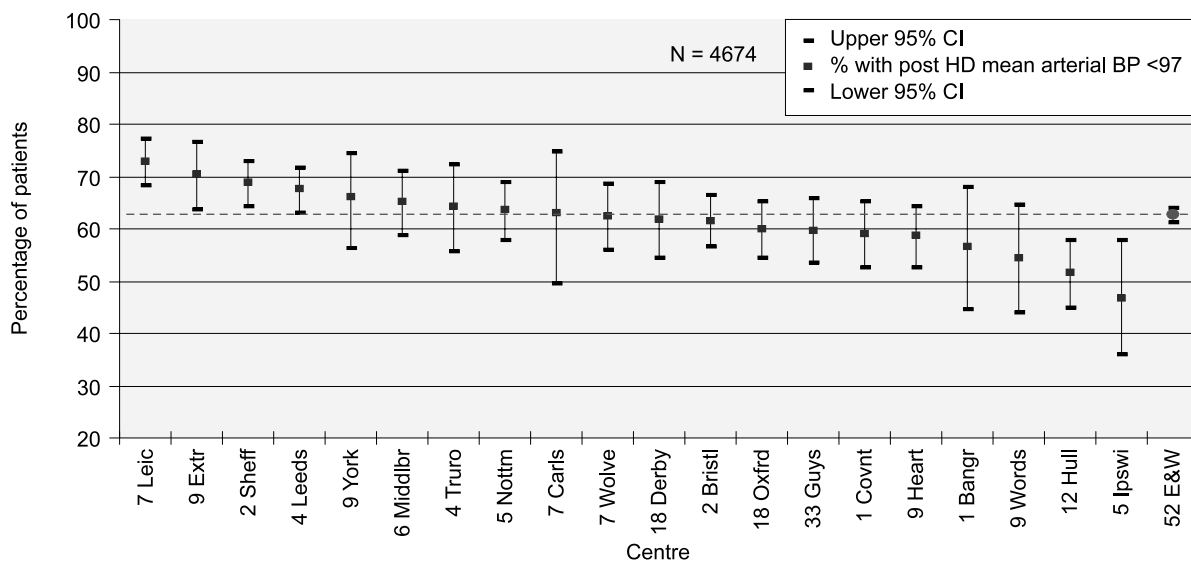


Figure 10.27: Percentage of patients with MAP <97 mmHg: post-HD

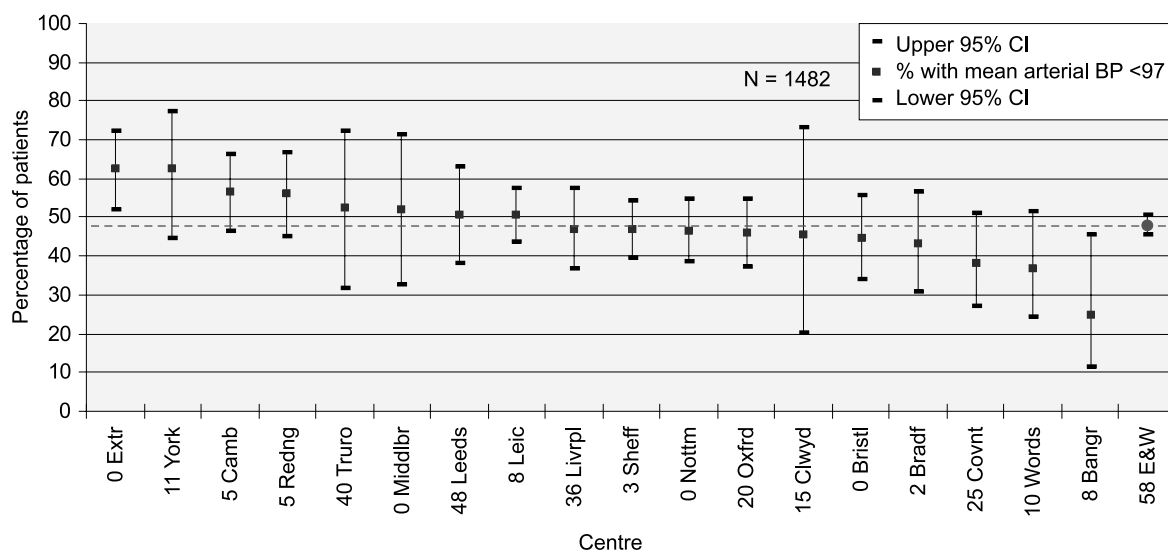


Figure 10.28: Percentage of patients with MAP <97 mmHg: PD

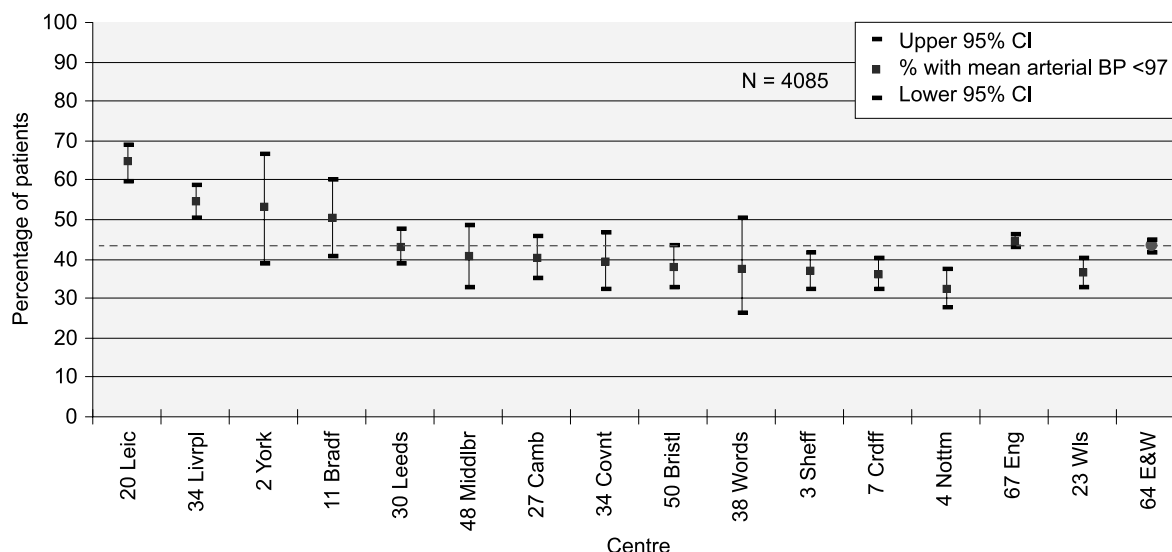


Figure 10.29: Percentage of patients with MAP <97 mmHg: transplant

Pulse pressure

Figures 10.30–10.33 show the variation between units for pulse pressure. The median pulse pressure for pre-HD, post-HD, PD and Tx is 68, 59, 56 and 57 mmHg respectively.

Blood pressure by primary diagnosis

Figures 10.34–10.41 show the variation in blood pressure control by primary diagnosis for each treatment modality (the HD data are post-haemodialysis data). The data show higher blood pressure levels for diabetics and reno-vascular disease; the median systolic pressure being higher

than for other groups by 10 mmHg and 6 mmHg respectively. Except for diabetics, blood pressure control is significantly better on HD for each of the diagnostic groups. Compared with PD and Tx, the median systolic blood pressure was lower on HD by 3–9 mmHg and 7–13 mmHg respectively. The reduction in median diastolic blood pressure was 5–8 mmHg and 6–9 mmHg respectively. In hypertension trials, a 10 mmHg lowering of systolic or 5 mmHg lowering of diastolic blood pressure for just a few years reduces death from stroke by 40% and ischaemic heart disease by 30%¹⁶. Excluding diabetics, the percentages of patients achieving the combined blood pressure standard were 40–48% for HD, 23–34% for PD and 18–23% for Tx. This probably reflects

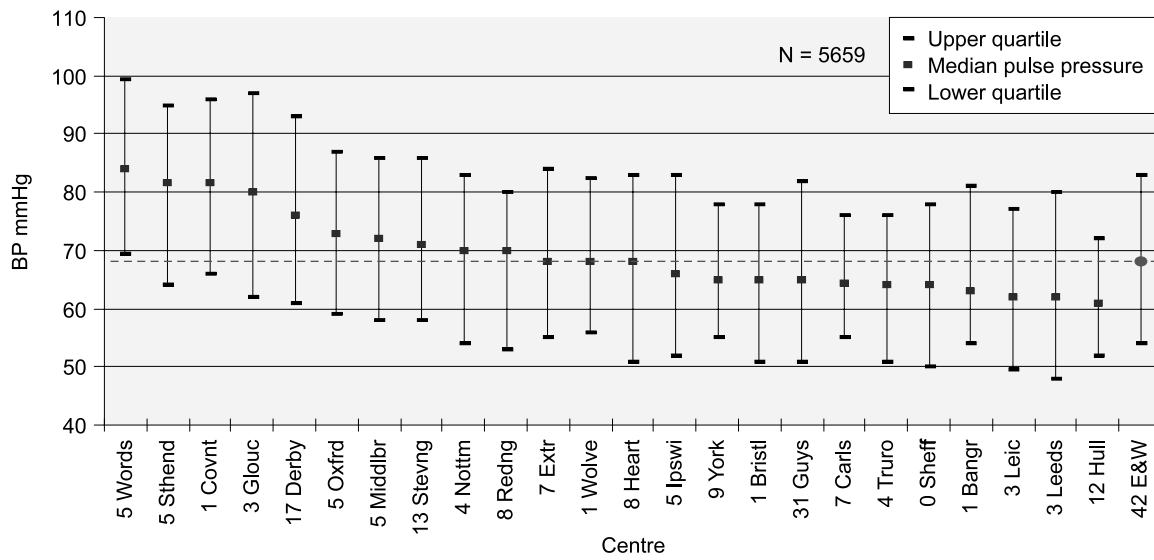


Figure 10.30: Median PP: pre-HD

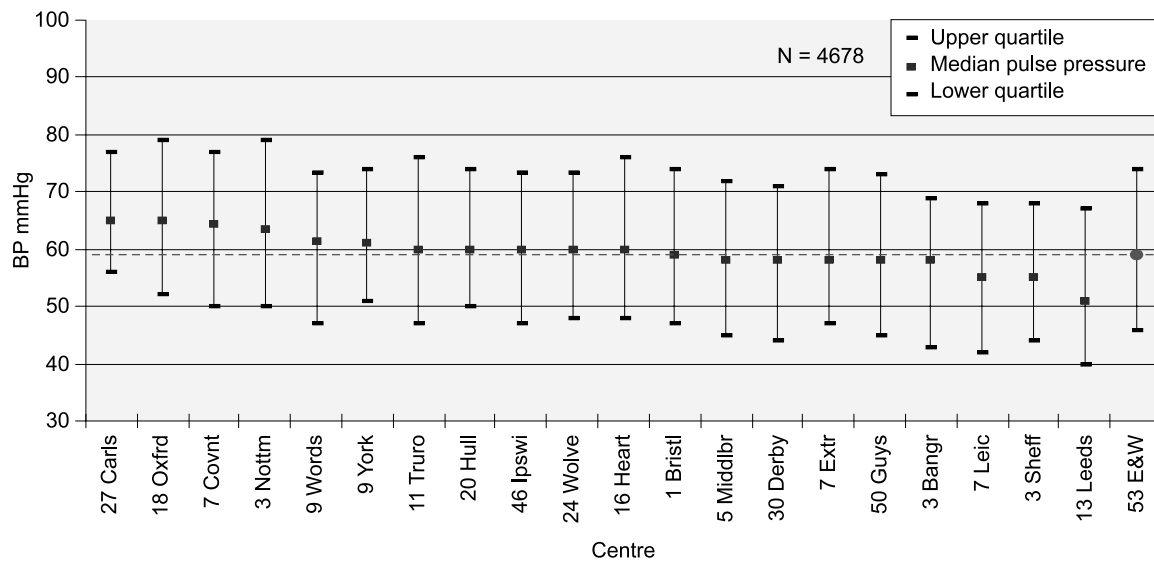


Figure 10.31: Median PP: post-HD

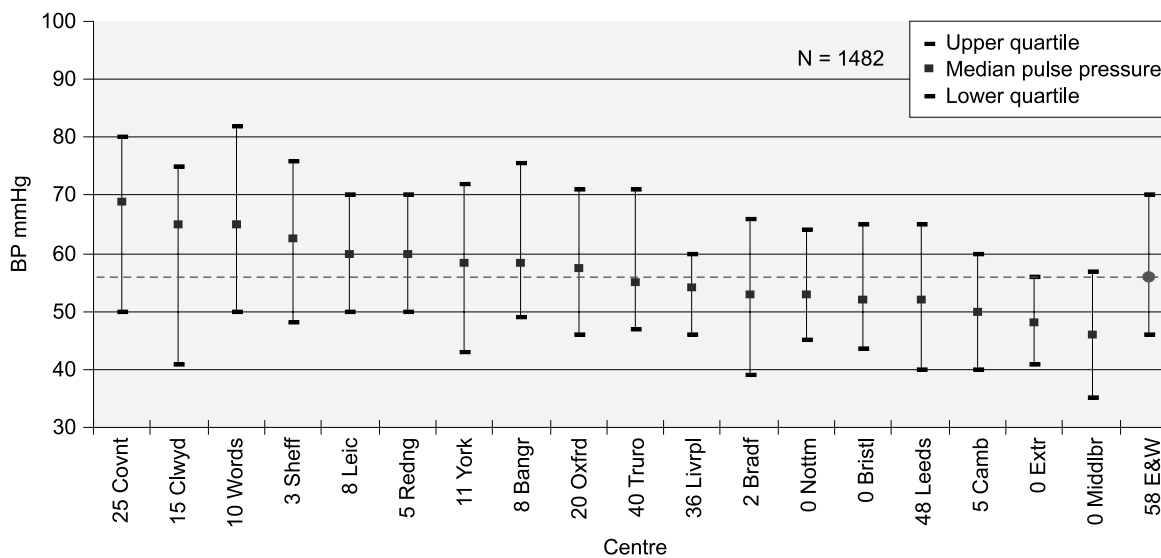


Figure 10.32: Median PP: PD

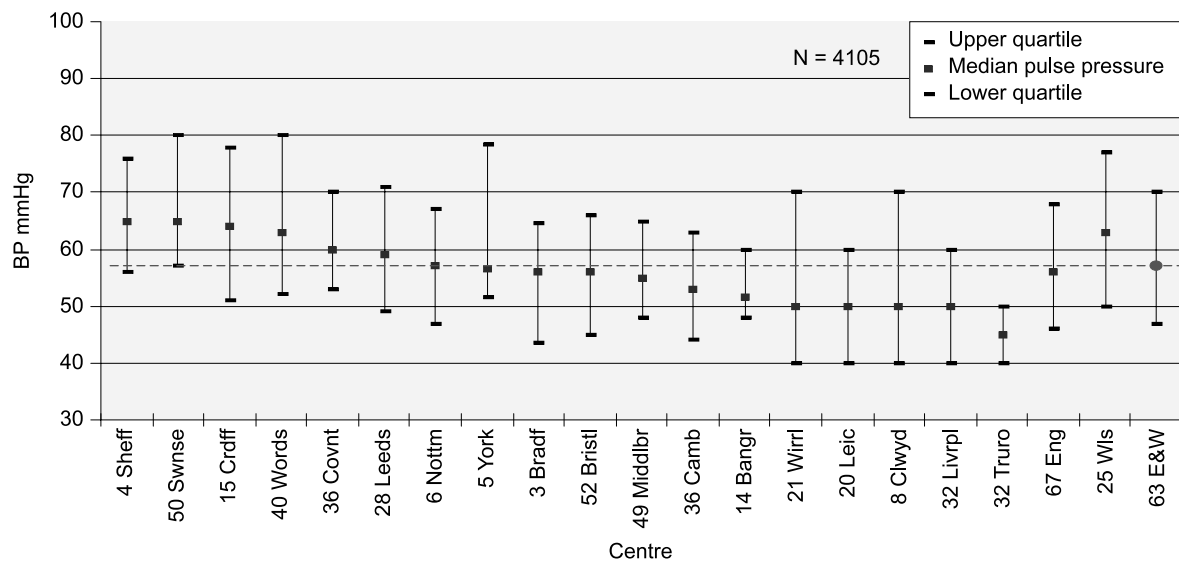


Figure 10.33: Median PP: transplant

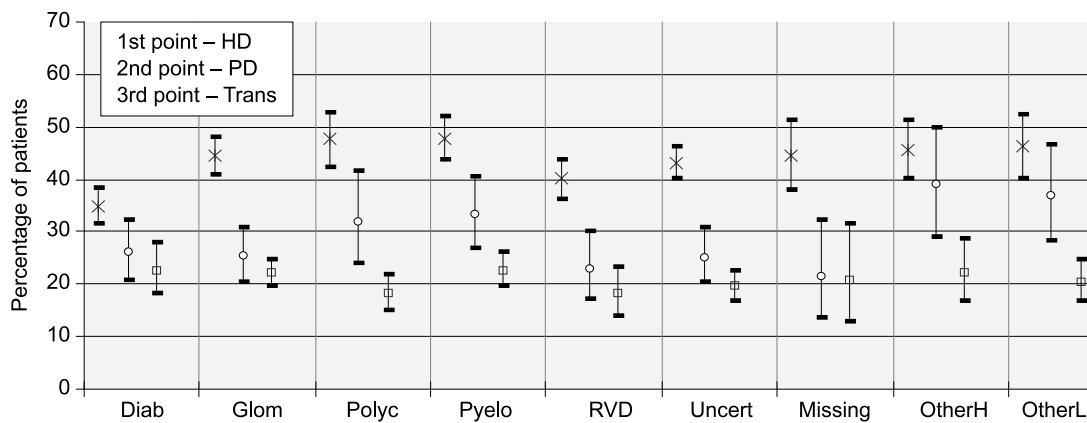


Figure 10.34: Percentage of patients with BP in standards by diagnosis

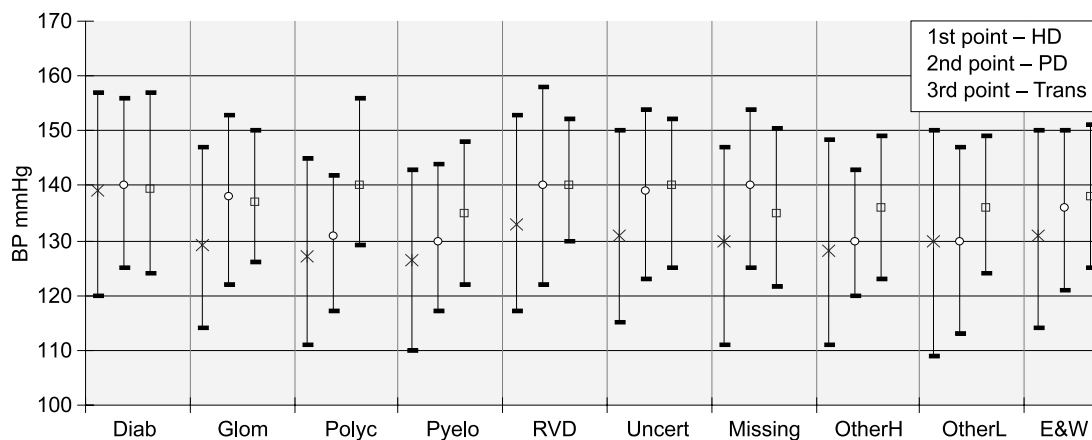


Figure 10.35: Median SBP by diagnosis

closer monitoring and supervision of fluid balance by HD nursing staff and suggests a more effective approach to blood pressure control is needed in the outpatient clinic setting. Poor

blood pressure control for diabetics remains a major concern with only 35%, 26% and 23% of them achieving the combined standard on HD, PD and Tx respectively.

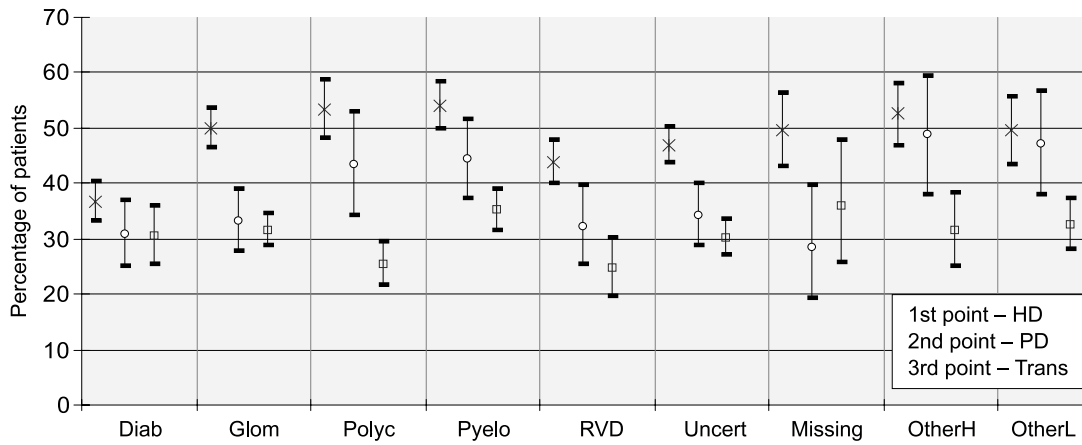


Figure 10.36: Percentage of patients with SBP in standards by diagnosis

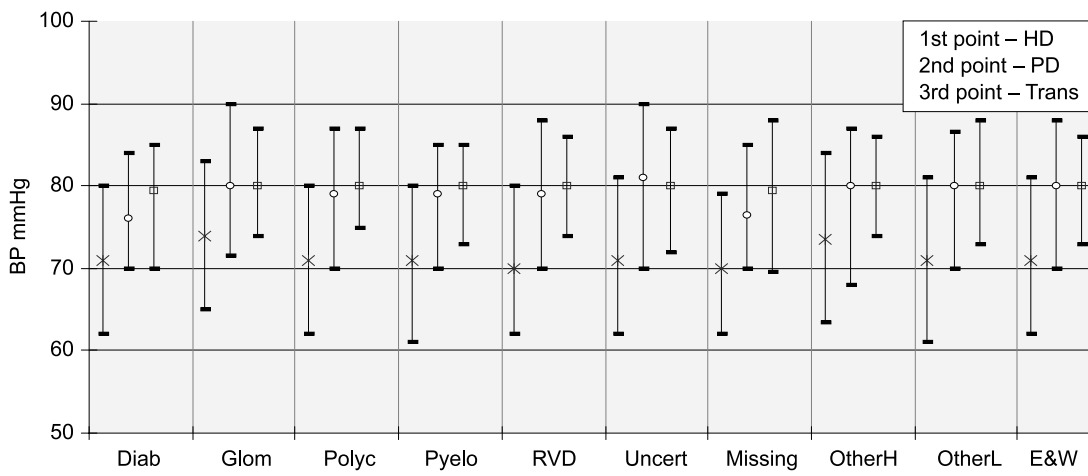


Figure 10.37: Median DBP by diagnosis

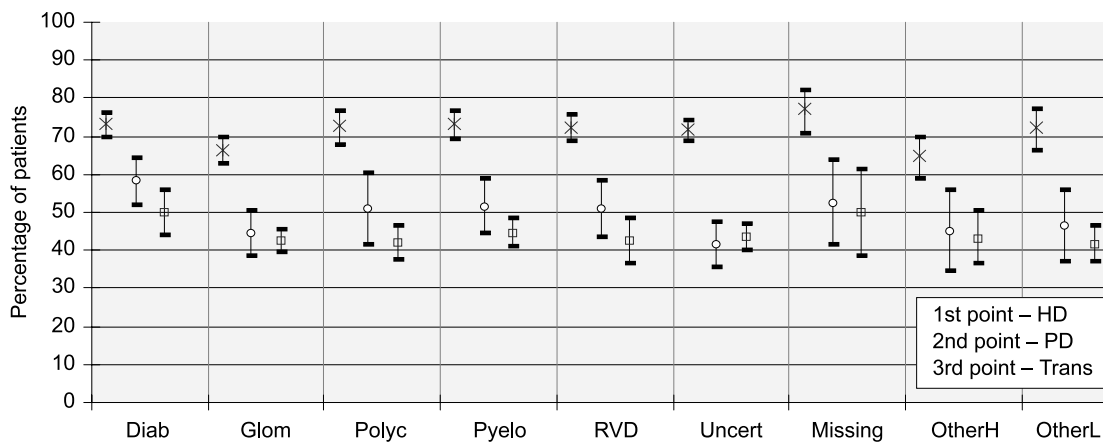


Figure 10.38: Percentage of patients with DBP in standards by diagnosis

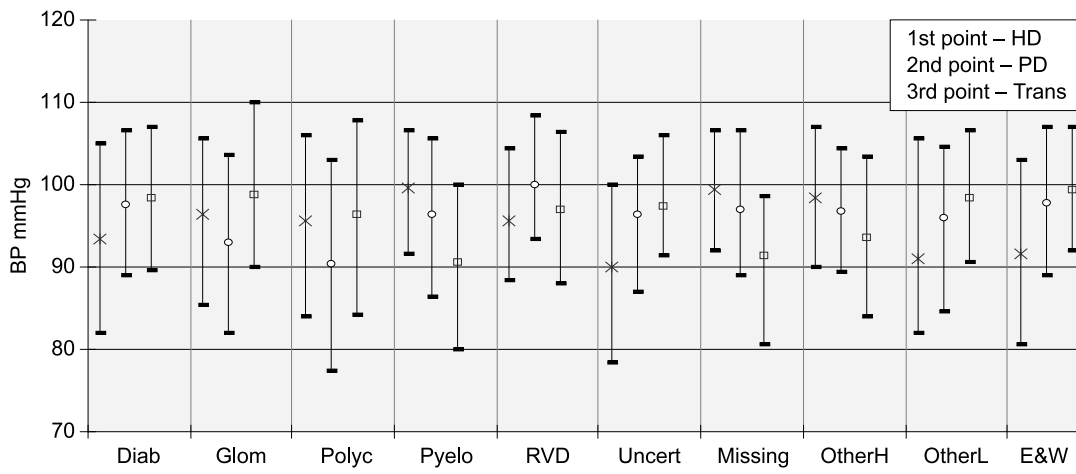


Figure 10.39: Median MAP by diagnosis

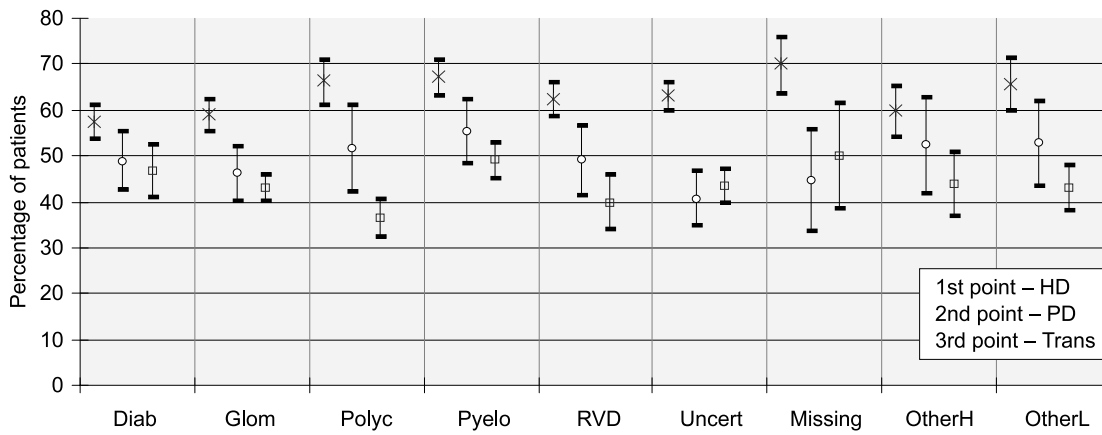


Figure 10.40: Percentage of patients with MAP in standards by diagnosis

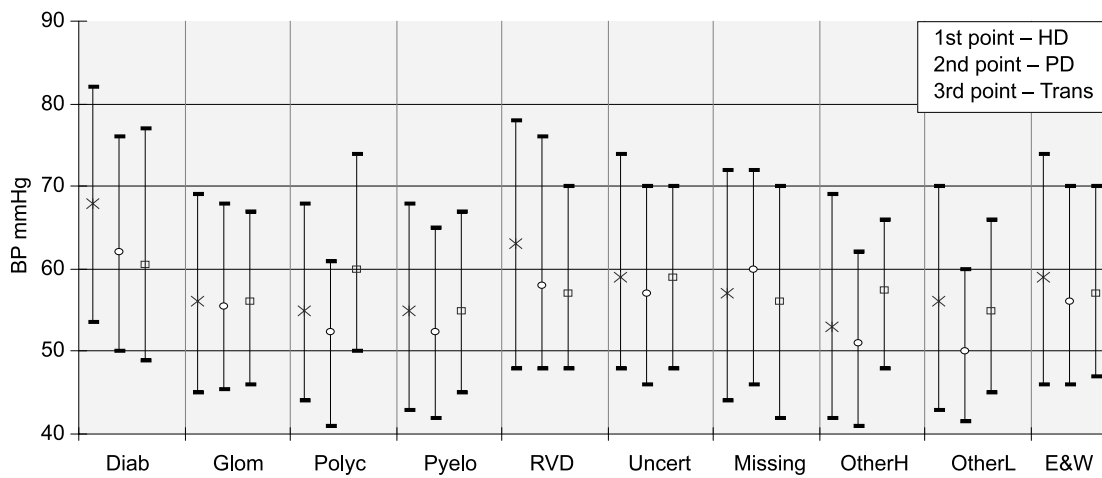


Figure 10.41: Median PP by diagnosis

Cholesterol and Achievement of the Standard

Introduction

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. Large randomised controlled trials in patients with existing coronary artery disease have demonstrated that lowering LDL-cholesterol by 1mmol/L for 4–5 years reduces the risk of myocardial infarction or stroke by 25%¹⁷.

There are still major uncertainties regarding the benefit of cholesterol lowering in CKD patients as less than a quarter of cardiac mortality is attributed to acute myocardial infarction. More common causes of cardiac death such as cardiac failure, cardiac arrest and arrhythmia may not be directly related to serum cholesterol concentration. The relationship between duration of hyperlipidaemia and mortality is unclear but the CRIB study is due to publish baseline cholesterol and 4 year mortality data for a cohort of 369 patients with CKD. A retrospective, single centre study showed patient survival was significantly increased if total cholesterol was less than 5.5mmol/L at the time of renal transplantation¹⁸. The J-shaped relationship between cholesterol and mortality in short term studies^{19,20} highlights the fact that the risk of death is greatest for patients with malnutrition, chronic disease and chronic inflammation. These conditions are all associated with low cholesterol levels and are major independent risk factors for death.

To date there is no convincing evidence that primary prevention with statins benefits patients with renal failure. The 4D study has just reported no benefit of atorvastatin 20mg vs placebo in 1255 HD patients with Type 2 diabetes for cardiac death, non-fatal myocardial infarction and stroke (abstract ASN). The ALERT study compared fluvastatin 40mg vs placebo in 2102 renal transplant patients. Although LDL fell on average by 1mmol/L the reduction in cardiac death and myocardial infarction was not significant over a 6 year period²¹.

There is more convincing evidence that statins offer effective secondary prevention. The CARE study showed pravastatin 40mg reduced further cardiac events in 1711 patients after myocardial infarction in patients with mild CKD²². The Renal Registry needs to collect data on statin use to audit the benefit of lowering cholesterol in patients on renal replacement therapy.

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-cholesterol²³. Neither the Framingham risk score nor the European SCORE system use CRP to calculate cardiovascular risk. A single CRP level using a high-sensitivity assay has been shown to have prognostic value for both haemodialysis and peritoneal dialysis populations^{24,25}. The Finnish Registry has shown no difference in CRP concentrations between these two dialysis modalities in recent years. CRP will now be collected 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. The current standards are:

Primary prevention:

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

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

Fasting LDL-cholesterol of <3 mmol/L

Secondary prevention:

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

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

European best practice guidelines suggest the dialysis standards should be applied to transplant patients²⁶. Lower targets are recommended for patients with established cardiovascular disease or diabetes (total cholesterol

<4.5 mmol/L and LDL-cholesterol 2.5 mmol/L)²⁷. Lipid profiles are advised annually for transplant patients and every 6 months for dialysis patients. Blood samples should be taken immediately before dialysis or at least 12 hours after, preferably with the patient in a fasting state.

The KDOQI guidelines are based round the ATPIII Guidelines²⁸ and recommend that:

Haemodialysis patients should have lipid profiles measured either before dialysis, or on days not receiving dialysis. (B)

Patients with LDL cholesterol >2.6 mmol/L should be treated to lower LDL cholesterol below this level.

The standard also includes treating triglycerides and is defined around monitoring LDL cholesterol and not total cholesterol as in the UK. KDOQI have also defined transplant recipients with normal function to be the same as for those patients with CKD, considering these patients as high risk:

For adult kidney transplant recipients with LDL \geq 2.6 mmol/L, treatment should be considered to reduce LDL to <2.6 mmol/L (evidence B).

For adult kidney transplant recipients with LDL <2.6 mmol/L, fasting triglycerides \geq 2.26 mmol/L, and non-HDL cholesterol (total cholesterol minus HDL) \geq 3.36 mmol/L, treatment should be considered to reduce non-HDL cholesterol to <3.36 mmol/L (evidence C).

The Renal Registry will present fasting lipid profiles if enough units start to collect this data. The current audit is based on random, non-fasting total cholesterol measurements only.

Completeness of data return

Table 10.2 shows the data completeness of cholesterol data for each centre by modality. There is a large variation of data completeness and the data is especially poorly captured for patients on peritoneal dialysis.

Serum cholesterol by modality

Figures 10.42–10.48 show wide variation between units achieving the cholesterol standard. In England & Wales, the number of patients achieving the standard for HD average

Table 10.2: Table of completion of cholesterol data by centre and modality

	% completed data		
	HD	PD	Transplants
Bangor	93	96	–
Bradford	47	98	90
Bristol	95	100	97
Cambridge	66	95	35
Carlisle	83	38	66
Carshalton	3	1	16
Clwyd	76	85	–
Coventry	0	75	0
Cardiff	89	6	86
Derby	79	26	–
Exeter	73	100	81
Gloucester	92	6	76
Guys	78	5	43
H&CX	98	0	97
Heartlands	69	7	27
Hull	73	47	38
Ipswich	93	2	88
Kings	47	0	88
Leeds	85	52	92
Leicester	92	92	96
Liverpool	5	64	19
ManWest	75	0	76
Middlesbrough	97	100	84
Newcastle	89	0	84
Nottingham	74	100	77
Oxford	89	80	71
Plymouth	82	0	84
Portsmouth	34	0	56
Preston	97	0	61
Reading	90	95	80
Sheffield	92	97	96
Stevenage	29	7	67
Southend	48	100	57
Sunderland	96	6	96
Swansea	69	0	86
Truro	88	60	84
Wirral	1	5	–
Wolverhampton	84	17	65
Wordsley	68	90	55
Wrexham	73	0	73
York	79	89	50
England	69	46	66
Wales	81	13	85
E&W	70	42	68

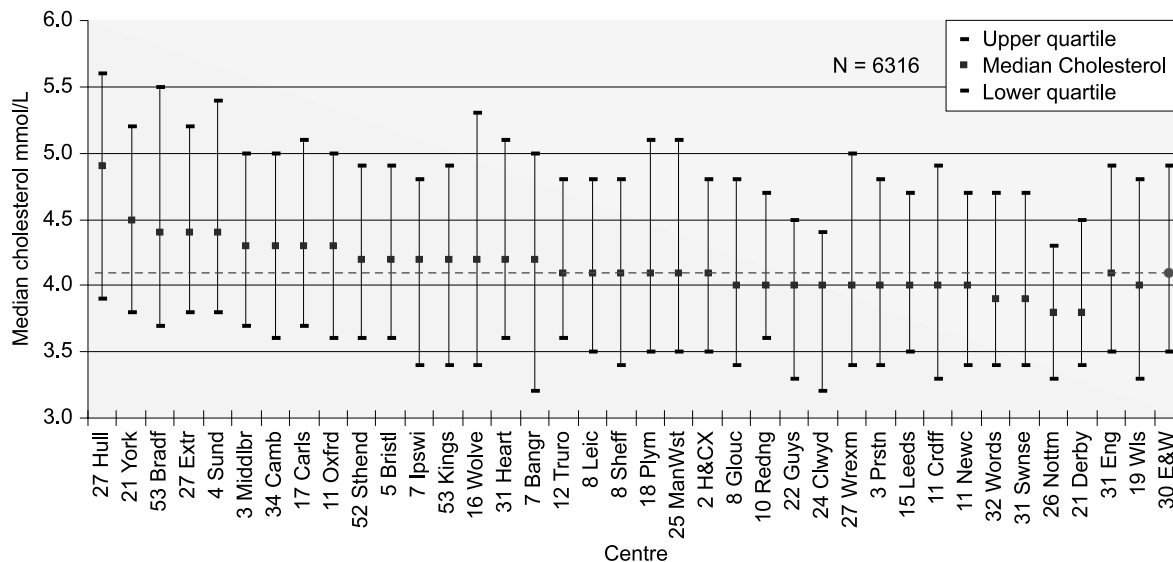


Figure 10.42: Median cholesterol: HD

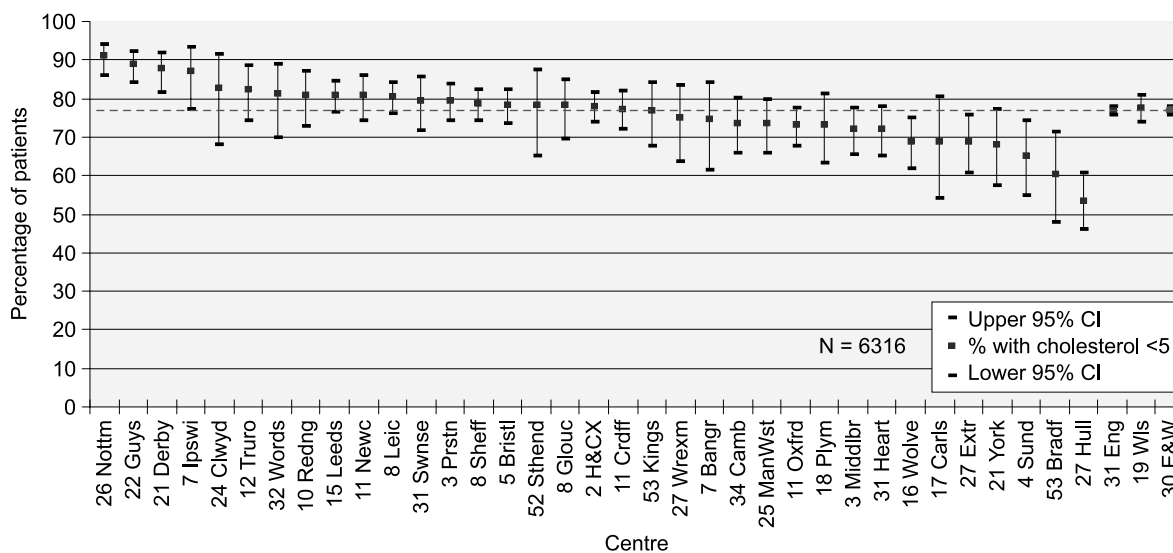


Figure 10.43: Percentage of patients with cholesterol <5 mmol/L: HD

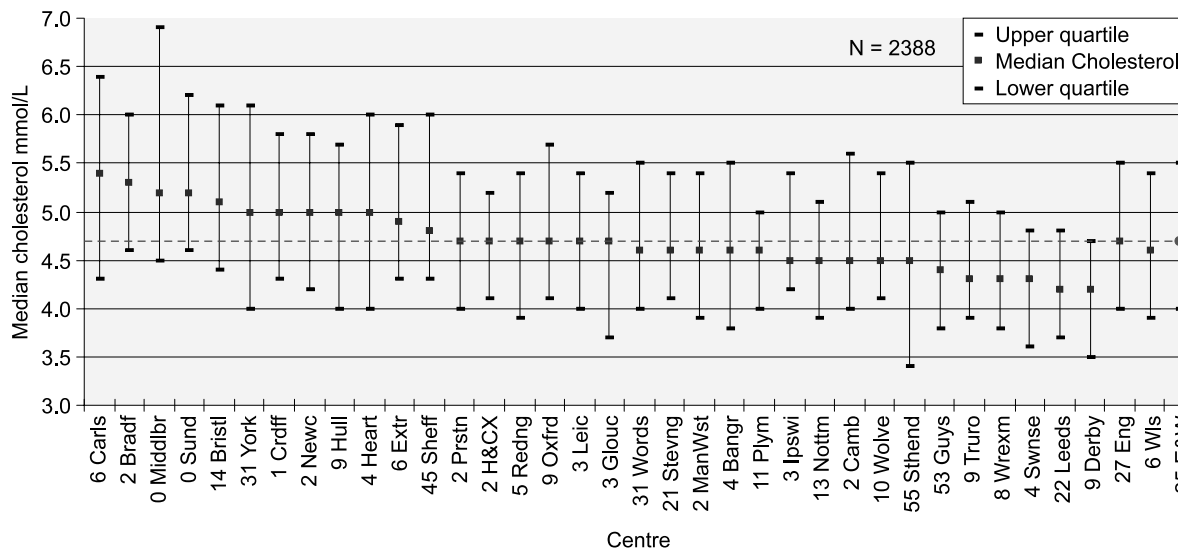


Figure 10.44: Median cholesterol: PD

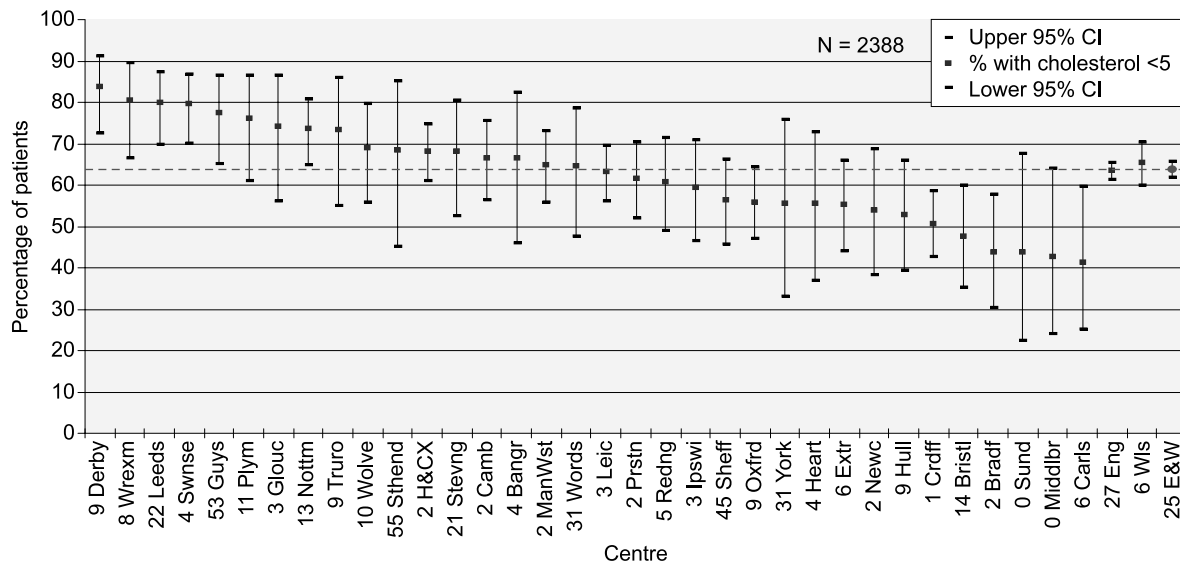


Figure 10.45: Percentage of patients with cholesterol <5 mmol/L: PD

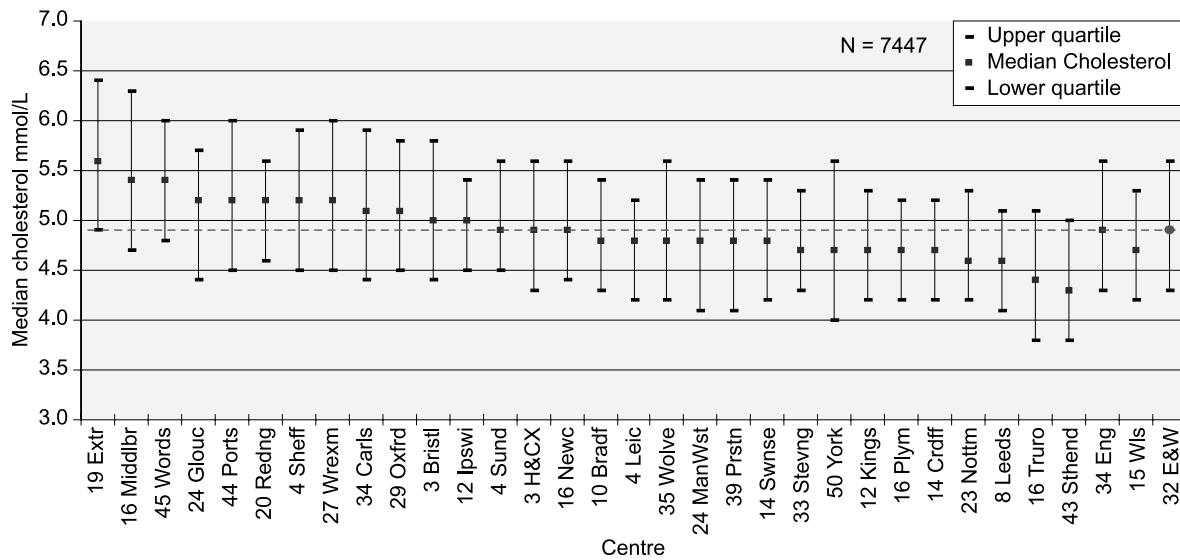


Figure 10.46: Median cholesterol: transplant

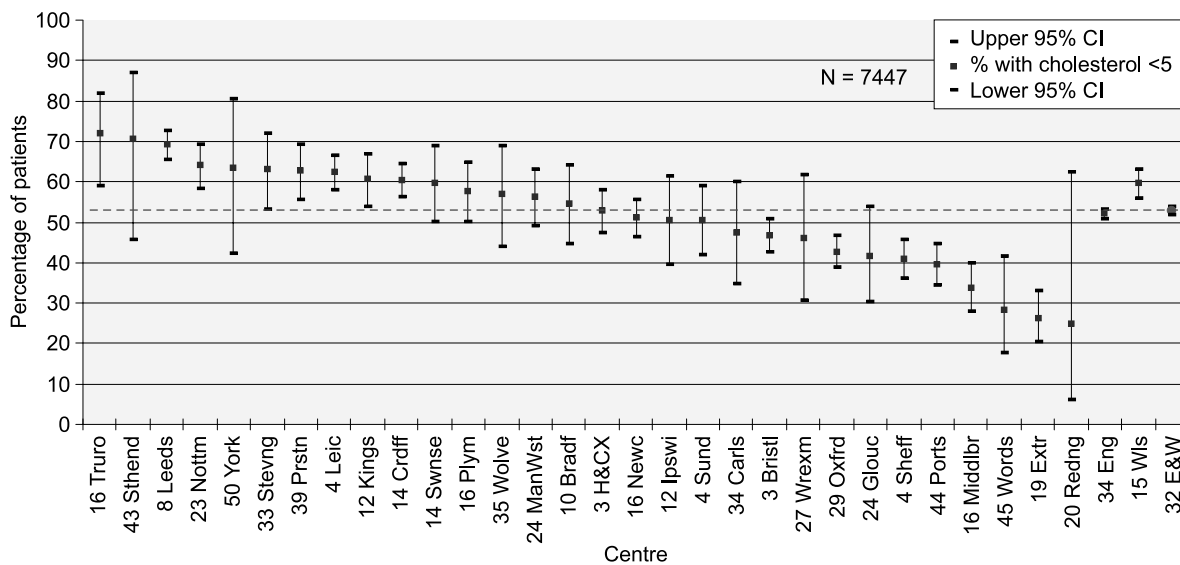


Figure 10.47: Percentage of patients with cholesterol <5 mmol/L: transplant

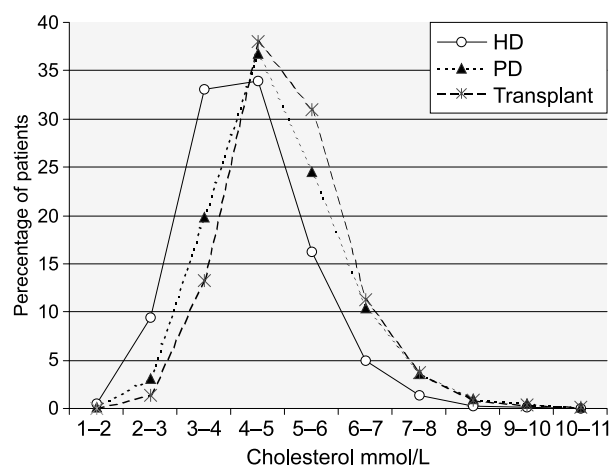


Figure 10.48: Serum cholesterol distribution by modality 31/12/2003

76.9% (range 54–91%), 63.8% for PD (range 41–84%) and 52.9% for transplant (range 25–72%). Chi squared testing indicates the variation between centres for each treatment modality is significant (HD, PD and TX; $p < 0.0001$).

Cholesterol levels are significantly lower in HD patients; the median cholesterol concentration for HD, PD and transplant is 4.1, 4.7 and 4.9 mmol/L respectively (Kruskal-Wallis test; $p < 0.0001$). It is not possible to correlate cholesterol levels with statin use as this drug data is not currently collected by the Renal Registry. Other factors to explain the differences

include inflammation, protein losses and nutritional status.

Change in Cholesterol achievement 1997–2002

Figure 10.49 shows the cholesterol data for all treatment modalities between 1997 and 2003. Figures 10.50–10.52 show these data by centre. Over 6 years cholesterol levels have fallen in all treatment groups. The percentage of patients currently achieving the standard for HD, PD and Tx is 77%, 64% and 53% respectively. The majority of units show an improvement in cholesterol control over this period. The units with the worst control initially show a fall in median cholesterol in excess of 1 mmol/L (data not shown). Finnish Registry data has shown the reduction in total cholesterol is mainly due to a fall in LDL-cholesterol in each treatment modality. In addition, triglycerides were highest in PD patients and HDL-cholesterol highest in Tx patients. Data from the SHARP trial should indicate whether lipid profiles of UK patients show similar trends.

Cholesterol levels following modality change

Figures 10.53 and 10.54 show the change in serum cholesterol when patients switch from

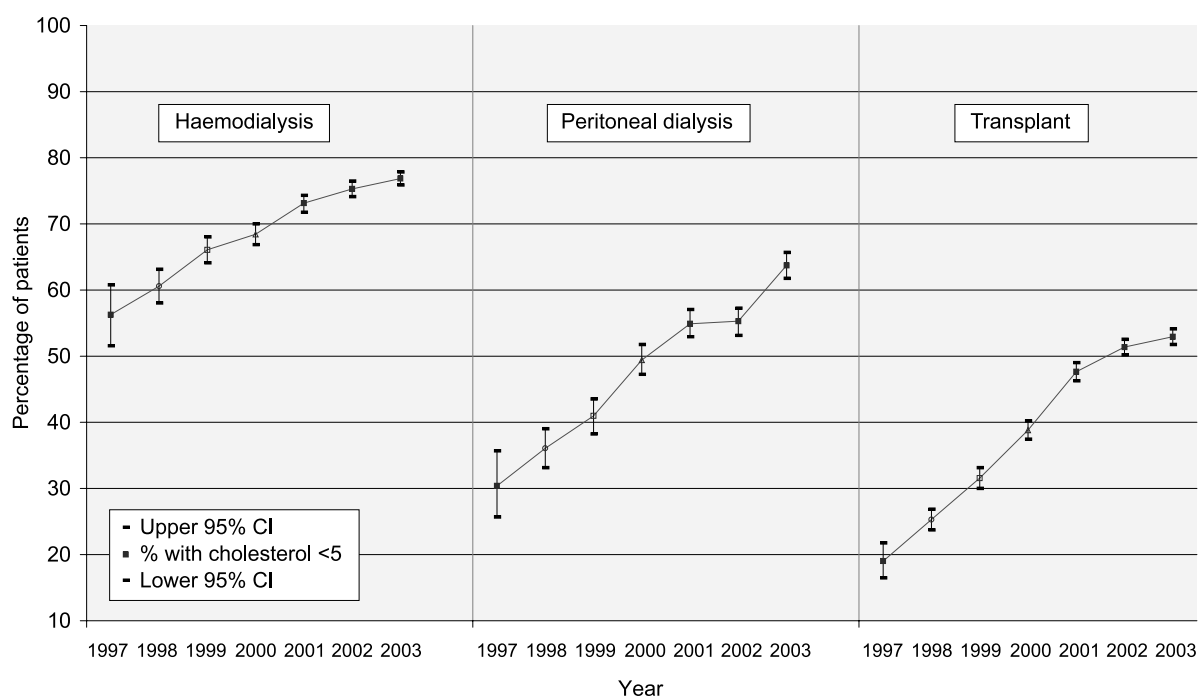


Figure 10.49: Percentage of patients with cholesterol <5 mmol/L HD vs PD vs Tx 1997–2003

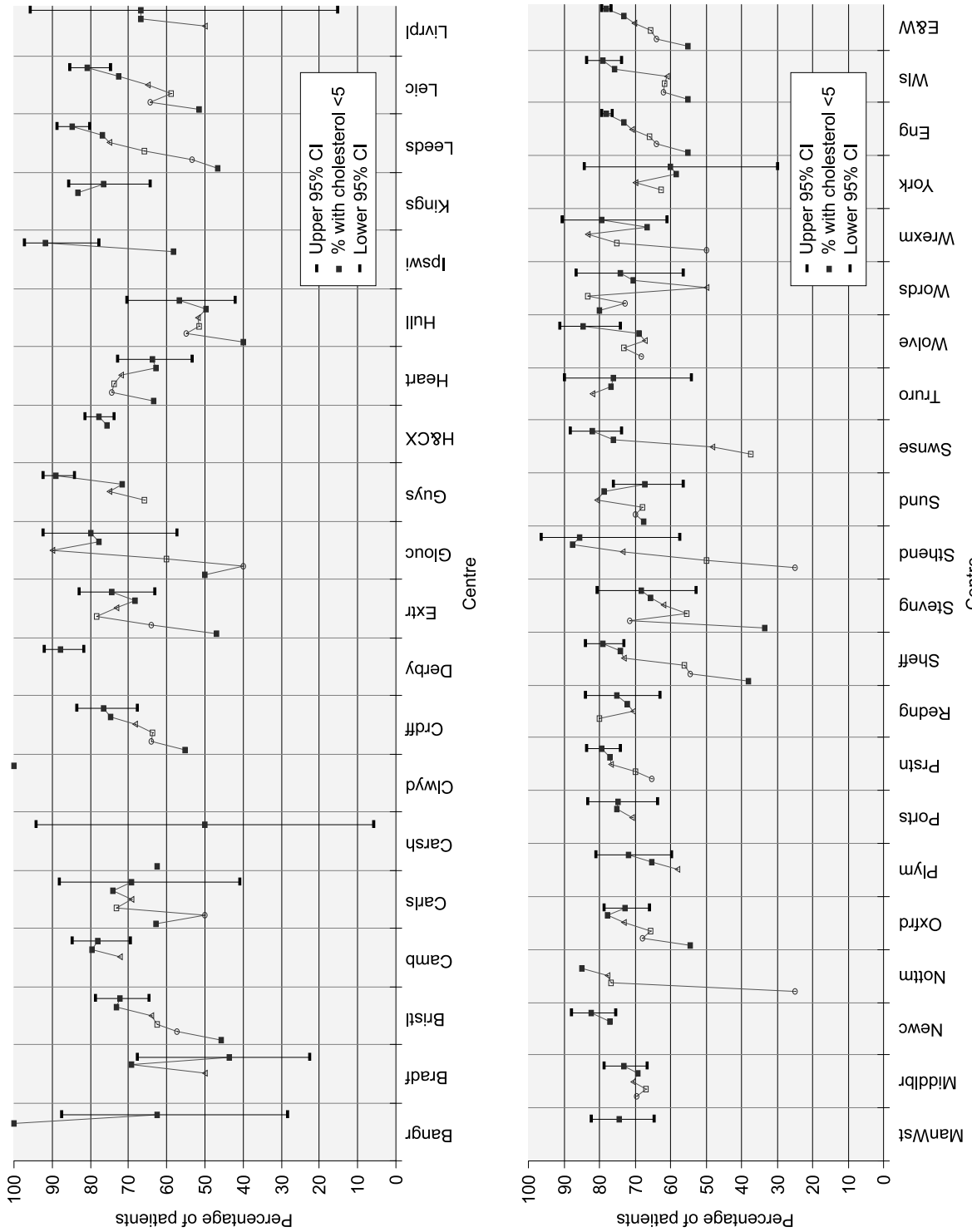


Figure 10.50: Change in % HD patients with cholesterol <5 mmol/L by centre 1998–2003

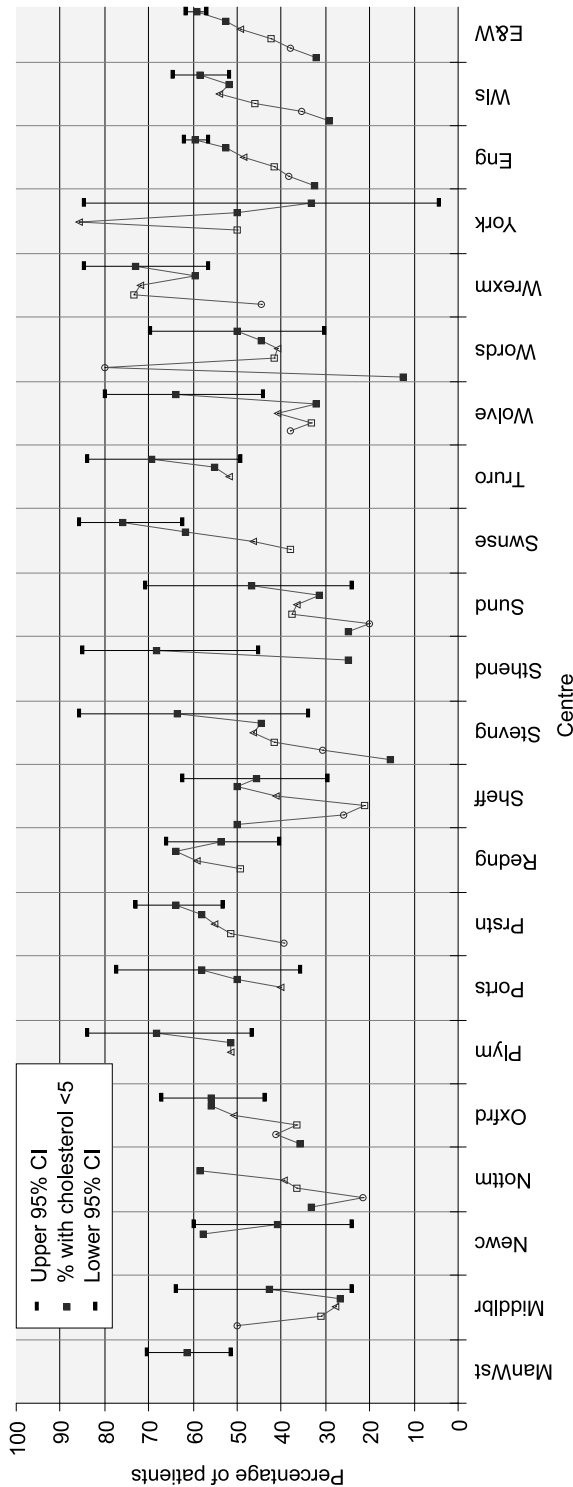
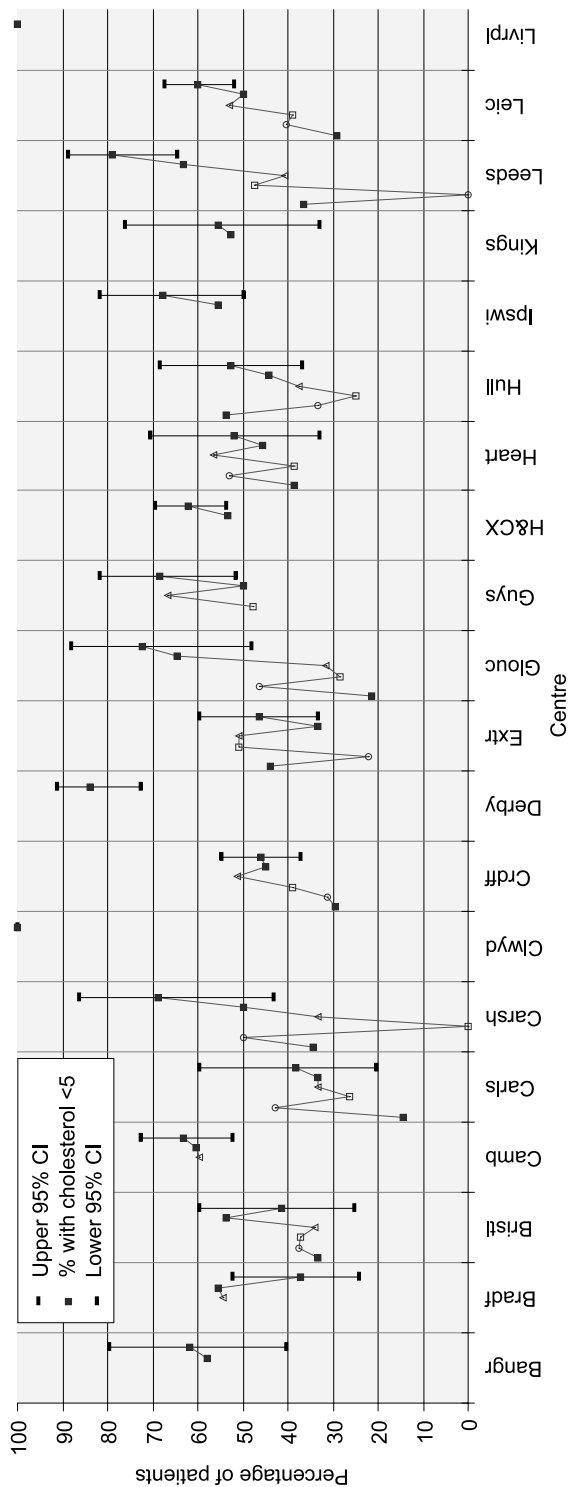


Figure 10.51: Change in % PD patients with cholesterol <5 mmol/L by centre 1998–2003

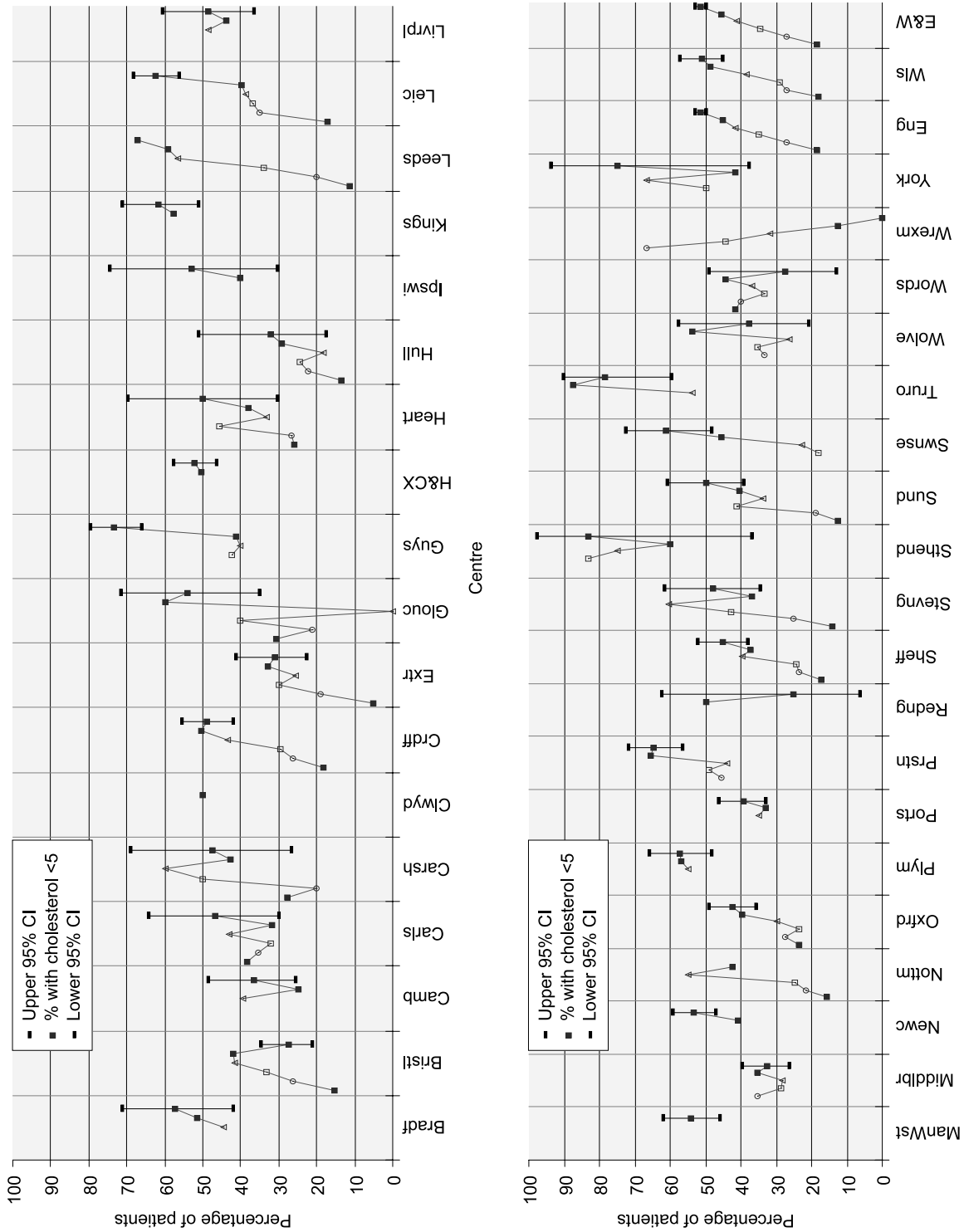


Figure 10.52: Change in % Tx patients with cholesterol <5 mmol/L by centre 1998–2003

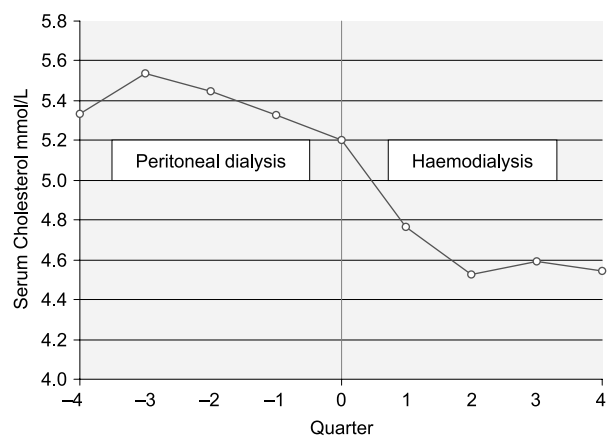


Figure 10.53: Serum cholesterol before and after modality change (PD to HD)

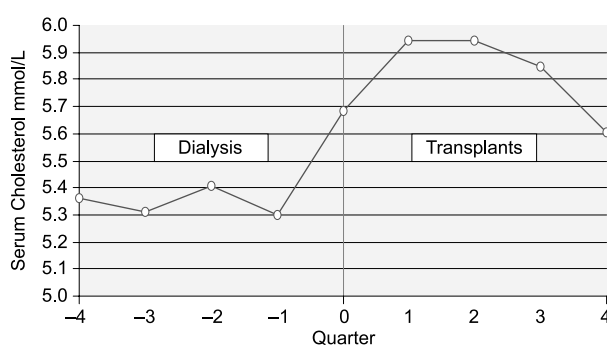


Figure 10.54: Serum cholesterol before and after modality change (dialysis to transplant)

one treatment modality to another. The means have been adjusted for the fall in cholesterol for each modality each year. The value at 'quarter zero' covers a period of three months around modality change. This represents a mix of cholesterol levels pre and post switch so can be ignored. When patients transfer from PD to HD the mean serum cholesterol falls by 0.8 mmol/L. The cholesterol falls during the first two quarters on HD and then the level plateaus for the rest of the year. It is not clear whether systemic inflammation induced by HD or withdrawal of PD solutions is responsible. Data regarding statin use is not available. By contrast when dialysis patients are transplanted the mean serum cholesterol rises within the first quarter by 0.64 mmol/L. These levels are sustained until the end of the first year when the mean cholesterol falls by 0.34 mmol/L. This may reflect hyperlipidaemia induced by immunosuppression as higher doses are used initially to prevent acute rejection. Alternatively the fall in cholesterol level towards the end of the year may be a direct result of therapeutic intervention with a statin.

The degree of change in serum cholesterol when patients switch treatment modalities is comparable to last year. The clinical significance, if any, will hopefully be established by long term follow up.

Ongoing Trials

The AURORA study is investigating rosuvastatin 10 mg vs. placebo in 2700 HD patients and results are expected in 2008. The SHARP trial is investigating ezetimibe 10 mg/simvastatin 20 mg vs. placebo in 9000 CKD patients (3000 on dialysis). Results are expected in 2009.

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Chapter 11: Renal Transplantation in Adults

(This chapter has been produced in collaboration with the British Transplant Society)

Summary

- This Chapter reports on data returned from 41 units of which 16 are renal transplant centres. Several large renal units remain outside the annual Registry data collection.
- The proportion of prevalent RRT patients of all ages made up by renal transplants was 46% in 2003, showing a continued decline.
- 26% of all transplant patients on the Registry database are managed by non-transplant centres.
- Treatment modality for prevalent RRT patients aged <65 years comprised of renal transplantation in 57%, HD in 30% and PD in 13%.
- 2.2% of all prevalent transplants failed in 2003.
- Annual death rate of patients with renal transplants was 2.4% excluding patients with failed grafts returning to dialysis and 2.6% if included.
- Renal transplant function (eGFR) varies significantly between centres.
- Haemoglobin and serum cholesterol achievement vary significantly between centres.
- Blood pressure reporting continues to be incomplete and point prevalent achieved blood pressure control falls well short of Renal Association Standards.
- Transplant function analysed by CKD stage 1–2 (eGFR <60), 3 (eGFR 30–59), 4 (eGFR 15–29), 5 (eGFR <15), shows that these categories account for 26%, 57%, 15% and 2.7% of patients respectively.
- Haemoglobin values fall with decreasing eGFR such that of the 2.7% of transplant patients with eGFR <15 ml/min, 30% had an Hb <10 g/dl and 51% <11 g/dl.
- Control of iPTH was poor in transplant recipients in CKD stages 4 and 5, with 27% and 48% of patients respectively having a PTH >32 pmol/L (=300 ng/L).
- An increase of systolic and diastolic BP was apparent with declining eGFR.
- 33% of transplant recipients in CKD stage 5 have a serum phosphate >1.8 mmol/L.
- With over 17% of prevalent transplant recipients being classified as CKD stage 4–5 this has implications in the planning of services for these patients.

Introduction

In England there are 14 centres outside of London performing renal transplantation in 2003 and one centre in Wales. In London, the eight transplant centres are gradually amalgamating to create five centres: St Helier (Carshalton) combining with St Georges, the Middlesex with the Royal Free Hospital, the Hammersmith & Charing Cross with St Mary's, Guy's Hospital and the London Hospital.

Notwithstanding these separate transplant centres, most centres have also amalgamated into alliances, of which there are six currently:

North Thames (Hammersmith & Charing Cross/St Mary's, The London, Royal Free Hospital/Middlesex),

South Thames (St Helier/St Georges and Guy's Hospital),

North of England (Leeds, Liverpool, Manchester and Newcastle),

Trent (Leicester, Nottingham, Sheffield),

South, South West & Wales (Bristol, Cardiff, Oxford, Plymouth, Portsmouth),

Scotland (Aberdeen, Edinburgh, Glasgow).

Belfast, Birmingham, Cambridge and Coventry were the only centres independent of an alliance. Over and above these transplant centres, much of the management follow-up of

transplant patients was performed in the original referring renal units. This Chapter reports data returned from 41 units, of which 16 perform renal transplantation.

National comprehensive data for incidence and survival of renal transplantation are available from UKTransplant (www.uktransplant.org.uk). The Renal Registry is undertaking combined analyses of data with UKTransplant and will report jointly on these analyses.

UKTransplant report that there were 1,386 cadaveric renal transplants and 450 live donor transplants in the period April 2003 to March 2004. In the same period in 2002–2003, there had been 1,399 cadaveric and 379 living related transplants, reflecting a rise in live donor transplants that compensates for a fall in cadaveric transplants undertaken. There continued to be a rise in the number of non-heart beating cadaveric donor organ retrievals, 70 in the year 2003–2004, up from 58 in 2002–2003. In total there were 1,836 renal transplants in 2003–2004, the largest number of renal transplants in a single year on record. The transplant waiting list at 31st March 2004 consisted of 5,074 patients compared to 5,020 at the same period in 2003, a rise of 1%. The number of patients waiting for a kidney transplant represents 86 patients per million population.

As in previous years, data on kidney disease leading to transplantation, demography of transplant recipients, ethnicity in transplantation, renal function, blood pressure, cholesterol, haemoglobin and the proportion of patients with diabetes receiving a transplant are all included in this Chapter.

Transplants performed in 2003

There were 1,021 renal transplants performed by centres contributing data to the Renal Registry,

Table 11.2: Number of new and prevalent transplant recipients in centres 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	1,581	Not available	517	5,433
2000	1,671	Not available	646	6,689
2001	1,691	Not available	830	8,688
2002	1,658	17,135	935	10,372
2003	1,697	Not available	1,021	11,194

Table 11.1: Median age of new transplant recipients in Registry units in E&W since 1998

Year	Median age	Number
1998	42.9	496
1999	41.6	517
2000	45.4	646
2001	43.7	830
2002	46.8	935
2003	44.9	1,021

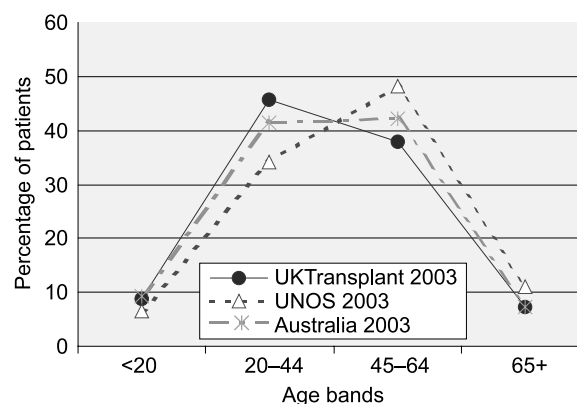


Figure 11.1: Age distribution of patients transplanted in 2003, UK, USA, and Australia

which represents 60% of renal transplants performed in the UK in 2003. The median age of the new transplant recipients in 2003 was 44.9 years, of which 60% were men and 40% women, reflecting the predominance of males in the dialysis population.

The median age of all transplant recipients in 2003 (including those from live donors) is shown in Figure 11.1. These data from the USA have been supplied by the UNOS database and the Australian data from the ANZDATA Registry. The median age of transplant recipients is slightly higher in the US and 11% of recipients are aged over 65 compared with 7.5% in the UK and 7.2% in Australia.

Table 11.2 shows the number of new and prevalent transplant patients in the UK and in

Table 11.3: Primary diagnosis transplant patients in the UK

	New transplants in 2003		Established transplants 1/1/03	
	%	No	%	No
Aetiology unc. /Glomer. NP*	17	170	16	1,627
Glomerulonephritis	22	221	25	2,581
Pyelonephritis	12	121	16	1,684
Diabetes	10	100	7	730
Renal vascular disease/ Hypert.	7	67	7	700
Polycystic kidney disease	14	138	11	1,184
Not sent	5	56	3	291
Other	14	148	15	1,506

*glomerulonephritis not biopsy proven.

Table 11.4: Incidence of co-morbidity in transplanted and not transplanted patients

Co-morbidity Total Patient number	Not transplanted 3707	Transplanted 425
Cardiovascular disease	26.5%	6.8%
Peripheral vascular disease	15.5%	2.1%
Cerebrovascular disease	12.3%	3.5%
Diabetes (not cause of ERF)	8.1%	2.6%
Diabetes (as primary diagnosis)	20.6%	10.7%
COPD	8.5%	1.4%
Liver disease	2.3%	0.7%
Malignancy	12.7%	1.9%
Smoking	17.9%	16.8%

the centres involved in Registry's activity from 1999–2003. UK data on new transplant recipients was supplied by UKTransplant and UK prevalent transplant data were derived from the National Renal Survey.

The primary renal disease in newly transplanted patients as well as in the established population are detailed in Table 11.3.

Renal transplantation and co-morbidity

Patients benefit significantly from renal transplantation and the characteristics of patients on the waiting list and receiving a transplant are of interest. Using information from centres with a high return of co-morbid information collected at the start of RRT (>75%), an analysis of patients who had been transplanted and those that remained on dialysis by the end of 2003 was performed. Of an incident cohort of 4,132 patients, just over 10% of patients (425) had been transplanted.

As expected there was a higher level of co-morbid conditions in those patients who remained on dialysis (Table 11.4). Although the prevalence of smoking was similar between the 2 groups this masks the fact that there is a higher prevalence of smoking (22%) in the younger patients starting RRT.

Prevalence of established renal transplants

At the end of 2003, there were 11,194 prevalent transplant patients in participating centres. The transplant prevalence rate by age group is shown in Figure 11.2. The prevalence rate is lower in women as the incidence of renal replacement therapy is higher in men by a ratio of approximately 3:2. The transplant prevalence rate peaks in both men and women in the 55–59 years age group, at 724 pmp and 429 pmp respectively.

Table 11.5 shows the number of prevalent transplant patients at each centre organised by

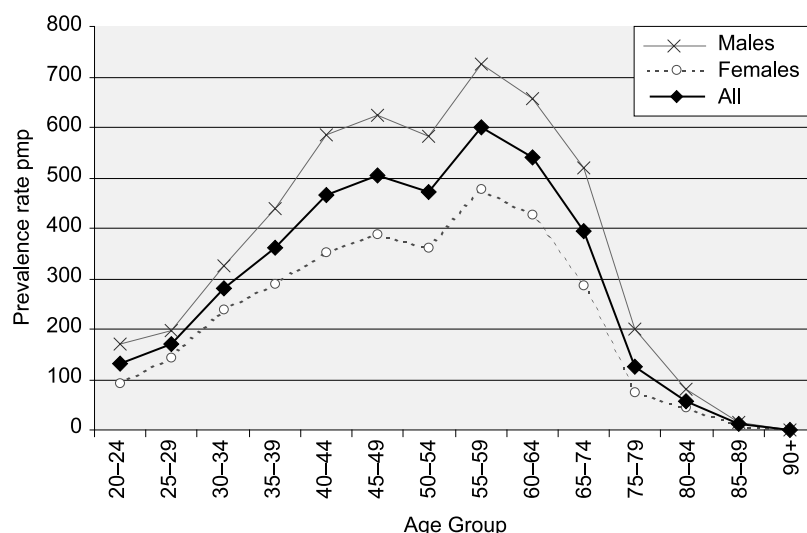


Figure 11.2: Transplant prevalence rate pmp by age and gender

whether the renal unit is a dialysis only centre or also a transplanting centre. Transplant centres transfer patients back to the referring dialysis centres at a variable time after transplantation,

Table 11.5: Number of prevalent transplant patients by renal unit

Dialysis centre	No of Tx	Transplanting centre	No of Tx
Bangr	N/A	Bristol	600
Bradf	114	Camb	421
Carls	86	Carsh	344
Clwyd	N/A	Covnt	269
Derby	N/A	Crdff	645
Extr	228	Guys	707
Glouc	88	H&CX	381
Heart	192	Leeds	664
Hull	203	Leic	484
Ipswi	92	Livrpl	730
Kings	246	Newc	525
ManWst	254	Nottm	375
Middlbr	293	Oxfrd	860
Prstn	321	Plym	203
Redng	12	Ports	625
Stevng	155	Sheff	429
Sthend	31		
Sund	137		
Swmse	119		
Truro	70		
Wirrl	N/A		
Wolve	93		
Words	99		
Wrexm	51	Eng Total	10,379
York	48	Wales Total	815

ranging from several weeks to not at all. This means that a prevalence rate cannot be produced by centre. The numbers in Table 11.5 provide an indication of workload. The totals for Wales in Table 11.5 are lower than the transplant prevalence totals shown in Chapter 4 as the data for Table 11.5 are calculated from patients under the care of Welsh renal units. About 100 transplant patients in North Wales are under the direct care of the Liverpool renal unit.

The transplant prevalence rate per million population by Shire and County of the recipient postcode is shown in Table 11.6. Several large transplant centres were not contributing data to the Registry in 2003 (Birmingham, Manchester and 4 London centres). This may account for some of the low prevalence rates in the Birmingham and Manchester area. In contrast, the Cumbria and Lancashire patients are all transferred back to the parent renal unit (Preston and Carlisle) post transplant. The low prevalence rate seen in Blackburn & Darwen may be due partly to the difficulty of matching HLA tissue types from cadaveric donors with those of patients from ethnic minority backgrounds. Cadaveric donation rates are lower in the ethnic minority groups and this compounds the problems for RRT, given the 4-6 times higher incidence of chronic renal failure within these groups.

With the current commissioning arrangements in the UK, groups such as primary care trusts which represent relatively small populations of 30,000 to 250,000 often wish to

Table 11.6: Prevalent transplant patients by local authority

UK Area	Shire, County	Name	Total pop	Rate pmp 2001	Rate pmp 2002	Rate pmp 2003	
North East	County Durham and Tees Valley	Darlington	97,838	235	245	235	
		Durham	493,469		271	281	
		Hartlepool	88,610	293	338	361	
		Middlesbrough	134,855	170	170	170	
		Redcar and Cleveland	139,132	237	237	215	
		Stockton-on-Tees	178,408	128	134	145	
	Northumberland, Tyne & Wear	Gateshead	191,151		392	423	
		Newcastle upon Tyne	259,536		327	339	
		North Tyneside	191,658		370	417	
		Northumberland	307,190		319	364	
		South Tyneside	152,785		301	359	
		Sunderland	280,807	245	348	366	
		North West	Cheshire & Merseyside	Halton	118,209	186	236
Knowsley	150,459			299	312	332	
Liverpool	439,471			266	263	307	
Sefton	282,958			190	208	236	
St. Helens	176,843			192	214	203	
Warrington	191,080			193	198	261	
Wirral	312,293			259	281	307	
Cumbria & Lancashire	Blackburn with Darwen		137,470	87	94	138	
	Blackpool		142,283	133	105	231	
	Cumbria		487,607	198	211	252	
	Lancashire		1,134,975	140	150	247	
	Greater Manchester						203
			Bolton	261,037			71
			Bury	180,607			110
			Oldham	217,276			116
			Rochdale	205,357			185
			Salford	216,105			162
			Wigan	301,415			
Yorkshire and the Humber	North & East Yorkshire, Northern Lincolnshire		East Riding of Yorkshire	314,113	194	213	232
		Kingston upon Hull, City of	243,588	209	234	242	
		North East Lincolnshire	157,981	208	240	240	
		North Lincolnshire	152,848	176	209	228	
		North Yorkshire	569,660	180	196	217	
		York	181,096	248	248	254	
	South Yorkshire	Barnsley	218,063	298	321	330	
		Doncaster	286,865	195	219	247	
		Rotherham	248,175	241	245	261	
		Sheffield	513,234	198	220	235	
	West Yorkshire	Bradford	467,664	273	290	322	
		Calderdale	192,405	301	343	353	
		Kirklees	388,567	301	324	355	
		Leeds	715,403	255	265	266	
		Wakefield	315,172	250	250	266	

Table 11.6: (continued)

UK Area	Shire, County	Name	Total pop	Rate pmp 2001	Rate pmp 2002	Rate pmp 2003	
East Midlands	Leicestershire, Northamptonshire, Rutland	Leicester	279,920	371	382	385	
		Leicestershire	609,578	246	267	277	
	Trent	Northamptonshire	629,676	252	255	266	
		Rutland	34,563	318	405	491	
		Derby	221,709			184	
		Derbyshire	734,585	197	206	205	
		Lincolnshire	646,644	219	228	236	
		Nottingham	266,988	250	273	262	
West Midlands	Birmingham & the Black Country	Nottinghamshire	748,508	232	247	249	
		Dudley	305,153	190	190	196	
		Solihull	199,515	145	160	170	
		Walsall	253,498	67	86	102	
	Coventry, Warwickshire, Herefordshire & Worcestershire	Wolverhampton	236,582	139	143	169	
		Coventry	300,849	262	289	295	
		Warwickshire	505,858	314	326	330	
		Bedfordshire & Hertfordshire	Bedfordshire	381,572	193	222	233
East of England	Hertfordshire	Hertfordshire	1,033,978		95	113	
		Luton	184,373	195	233	244	
	Essex	Southend-on-Sea	160,259	49	62	62	
		Norfolk, Suffolk & Cambridgeshire	Cambridgeshire	552,659	220	222	235
			Peterborough	156,061	160	173	192
London	North West London	Ealing	300,948		255	245	
		Hammersmith and Fulham	165,244		217	217	
	South East London	Bexley	218,307	242	334	366	
		Bromley	295,532	233	280	287	
		Greenwich	214,404		205	223	
		Lambeth	266,169	131	187	187	
		Lewisham	248,923	245	341	333	
		Southwark	244,866		371	400	
	South West London	Croydon	330,588	187	220	211	
	South East	Hampshire & Isle of Wight	Hampshire	1,240,102	256	265	279
Isle of Wight			132,731	271	293	286	
Portsmouth			186,700	348	358	380	
Southampton			217,444	280	280	308	
Thames Valley		Buckinghamshire	479,026	281	319	336	
		Milton Keynes	207,057	236	236	275	
		Oxfordshire	605,489	346	345	351	
		Reading	143,096	321	335	363	
		Slough	119,064		302	352	
		West Berkshire	144,485	339	352	366	
South West	Avon, Gloucestershire and Wiltshire	Wokingham	150,231	252	252	272	
		Bath and North East Somerset	169,040	242	236	224	
		Bristol, City of	380,616	359	375	399	
		Gloucestershire	564,559	212	249	281	
		North Somerset	188,564	355	381	403	
		South Gloucestershire	245,641	309	350	370	
		Swindon	180,051	277	283	288	
		Wiltshire	432,972	237	247	254	

Table 11.6: (continued)

UK Area	Shire, County	Name	Total pop	Rate pmp 2001	Rate pmp 2002	Rate pmp 2003	
South West	Dorset and Somerset	Somerset	498,095	228	254	287	
		South West Peninsula	Cornwall and Isles of Scilly	501,267	249	263	277
	Devon	Devon	704,491	227	241	255	
		Plymouth	240,722	324	332	328	
		Torbay	129,706	323	323	300	
Wales	Bro Taf	Cardiff	305,353	320	330	343	
		Merthyr Tydfil	55,979	428	464	428	
		Rhondda, Cynon, Taff	231,947	375	375	362	
		The Vale of Glamorgan	119,292	301	318	360	
		Dyfed Powys	Carmarthenshire	172,842	347	283	329
	Ceredigion	Ceredigion	74,941	240	280	333	
		Pembrokeshire	114,131	227	210	254	
		Powys	126,353	102	71	63	
		Gwent	Blaenau Gwent	70,064	413	385	442
			Caerphilly	169,519	312	312	342
	Monmouthshire		84,885	424	424	412	
	Newport		137,012	350	357	343	
	Morgannwg	Torfaen	90,949	472	461	439	
		Bridgend	128,645	334	334	342	
		Neath Port Talbot	134,468	327	275	334	
		Swansea	223,300	353	367	398	
	North Wales	Conwy	109,596		255	319	
		Denbighshire	93,065	107	204	268	
		Flintshire	148,594		275	296	
		Gwynedd	116,843		222	282	
Isle of Anglesey		66,829		164	179		
Wrexham		128,476	373	358	350		
ENGLAND			31,024,376			263	
WALES			2,903,083			329	
		Total	33,927,459			269	

assess their performance. When assessing a relatively infrequent occurrence, such as prevalence of renal transplantation in such small populations, there are wide confidence intervals for any observed frequency. To enable assessment of whether an observed acceptance rate is likely to be significantly different from the national average, Figure 11.3 has been included in the report. From this, for any size of population (X axis) the upper and lower 95% confidence intervals around the national average prevalence rate (dotted lines) can be read from the Y axis. Any observed acceptance rate for renal failure must be outside these limits for the given population to be statistically significantly different from the national average. Thus for a

population of 100,000 the observed transplant prevalence would have to be outside the limits of 170 per million population per year to 370 per million population per year. However for a population of 500,000 these limits are from 224 per million population per year to 315 per million population per year.

Figures 11.4 and 11.5 show the percentage of dialysis patients in 2003 under and above the age of 65 years at each centre who ever had a transplant in the past. Overall 21.5% (range 5.7–2.9%) of dialysis patients aged less than 65 years have ever had a transplant and considerably fewer, only 3.1% (range 0–9.1%) of dialysis patients above the age of 65 years have ever had a transplant in the past.

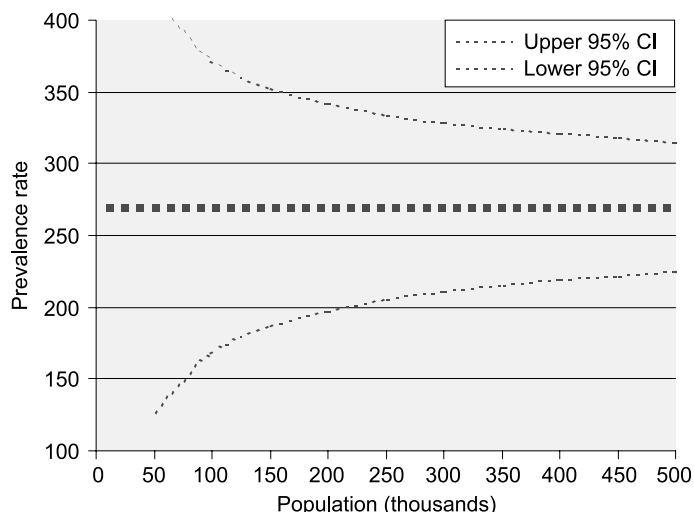


Figure 11.3: 95% Confidence limits for prevalence rate of 270 pmp for population size 50,000–500,000

In both figures, wide variations are seen in the proportion of patients receiving a transplant. There is no simple explanation for this wide variability and previous explanations, such

as the proportion of patients from non-transplant centres being followed up at the main transplant centre after transplantation may account for some of the inconsistency (this

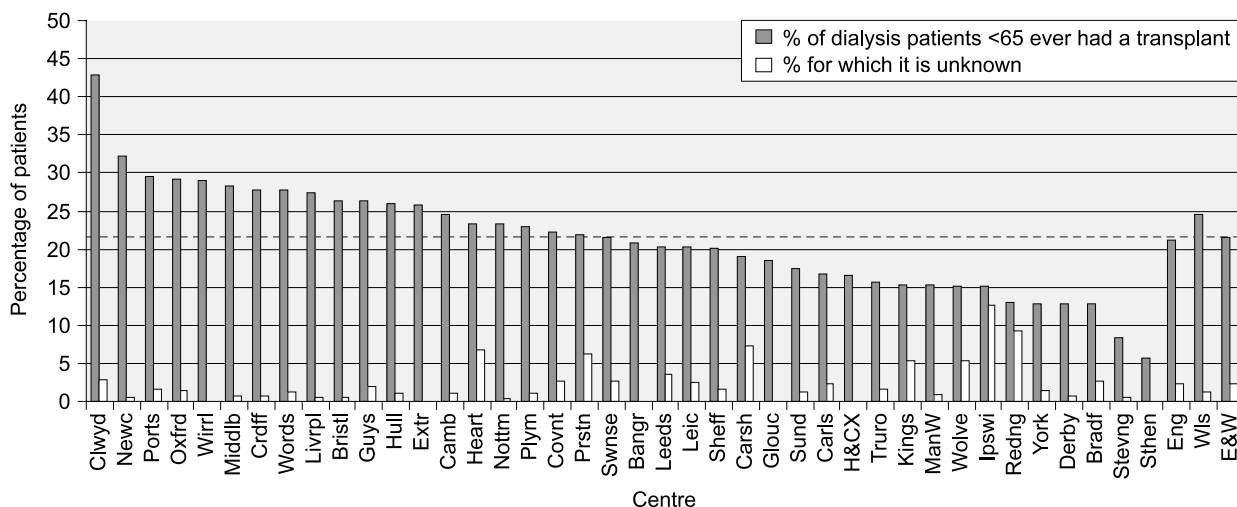


Figure 11.4: Percentage of dialysis patients <65 who ever had a transplant

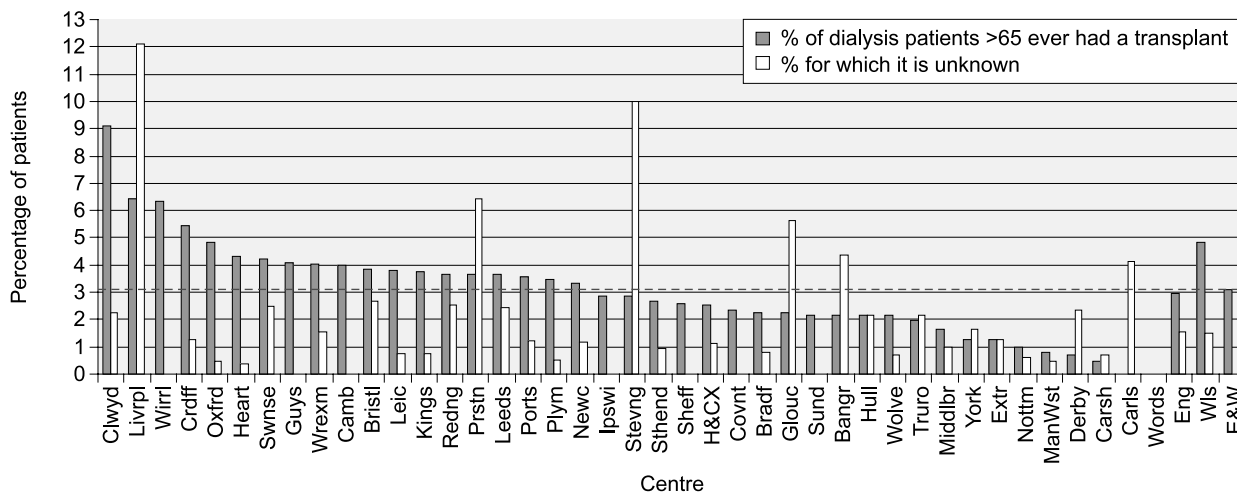


Figure 11.5: Percentage of dialysis patients 65+ who ever had a transplant

Table 11.7: Annual proportion of RRT patients with a functioning transplant, recipient median age and % aged >65 since 1997 (E&W)

Year	% all RRT with functioning transplant	Median age prevalent transplant recipients	% prevalent transplant recipients >65 yrs old
1997	51.0	N/A	11.2
1998	49.9	N/A	12.4
1999	47.3	N/A	12.4
2000	46.9	N/A	13.0
2001	46.6	49.0	13.2
2002	46.0	49.6	14.0
2003	45.8	49.6	14.3

analysis is shown later). There may however, be differences between transplant centres in acceptance criteria for listing on the transplant waiting list. Also, differences in the proportion of dialysis patients made up of ethnic minority groups, who have a high proportion of blood group B and more uncommon HLA typing and are more difficult to transplant, will be significant.

As the take on rate for dialysis continues to increase in the elderly population, so the overall proportion of RRT patients with a functioning transplant continues to fall from 51% in 1997 to 45.8% in reporting centres in 2003 (Table 11.7). Although the median age of new recipients in 2003 is 44.9 years, because of the large numbers of prevalent patients, the percentage of prevalent transplant recipients aged over 65 years is increasing annually and is now 14.3%.

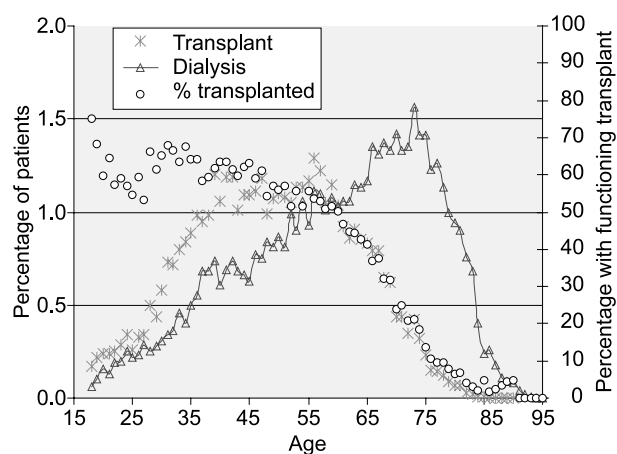
Age and prevalent transplant recipients

The age distribution of prevalent transplant and dialysis patients is shown in Figure 11.6. Within the RRT population there is a higher proportion of transplanted patients compared to dialysis at all ages up to 61 years of age and thereafter the reverse is true (right margin scale of Figure 11.6). The peaks of patients with transplants or on dialysis are 56 and 73 years respectively, a 17 year difference. This compares with a median age of patients with a transplant of 49.6 years and 62.6 years for those on dialysis. In the renal replacement therapy population aged over 65 years, 21.2% have a functioning transplant with 78.8% remaining on dialysis, in keeping with data from other

Registries. Of those aged over 65 years, this accounted for 14% of the total prevalent transplant population compared with 45% of the prevalent dialysis population.

The treatment modality of prevalent patients at each participating centre age <65 years and receiving renal replacement therapy is shown in Figure 11.7. The figure shows that transplant centres tend to have the largest proportion of transplant patients (range 42–73%) compared to dialysis patients with some dialysis centres seeing few or no transplant patients for follow-up.

For those patients aged under 65 years in England & Wales, RRT is provided as transplantation in 57% of patients, haemodialysis in 30% of patients and peritoneal dialysis in 13% of patients. When all patients receiving RRT are included then the proportion of transplanted patients falls to 46% as there is a low level of transplantation above the age of 65 years.

**Figure 11.6: Age distribution of prevalent dialysis and transplant patients**

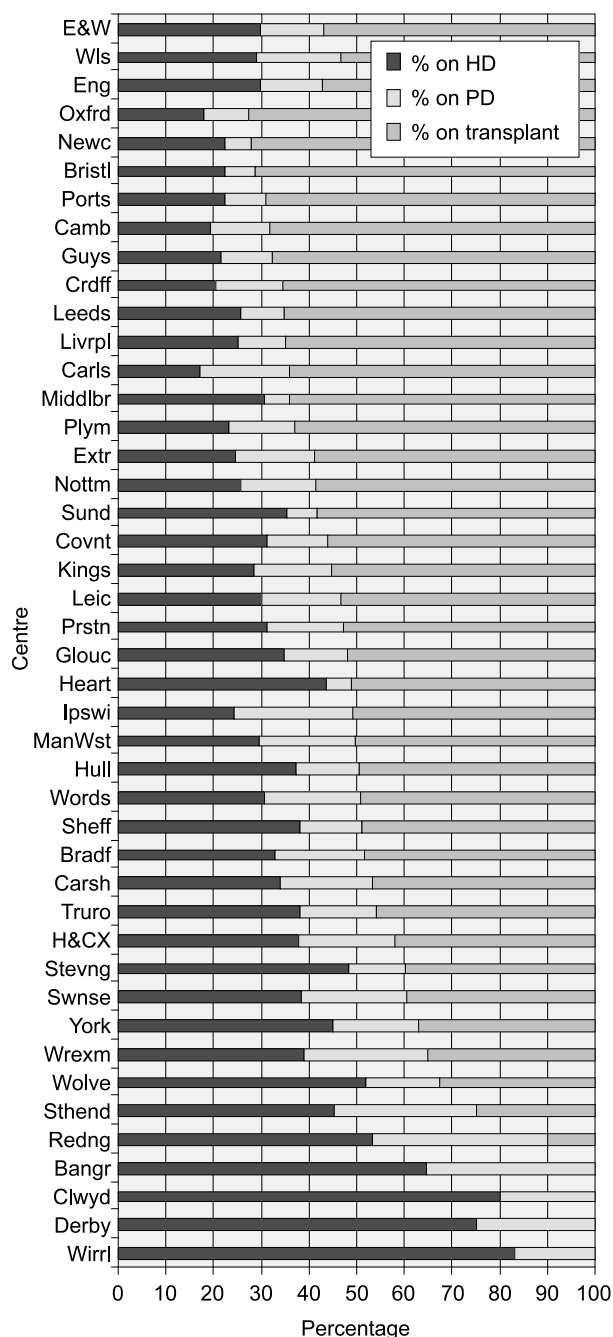


Figure 11.7: Treatment modality of prevalent patients <65 years old

In 2003, renal units contributing data to the Registry accounted for 11,194 transplanted patients, 9,759 on haemodialysis and 3,490 on peritoneal dialysis. The median age of these patients by modality was 50, 64 and 58 respectively. Patients with transplants in general are younger than those on peritoneal dialysis, who

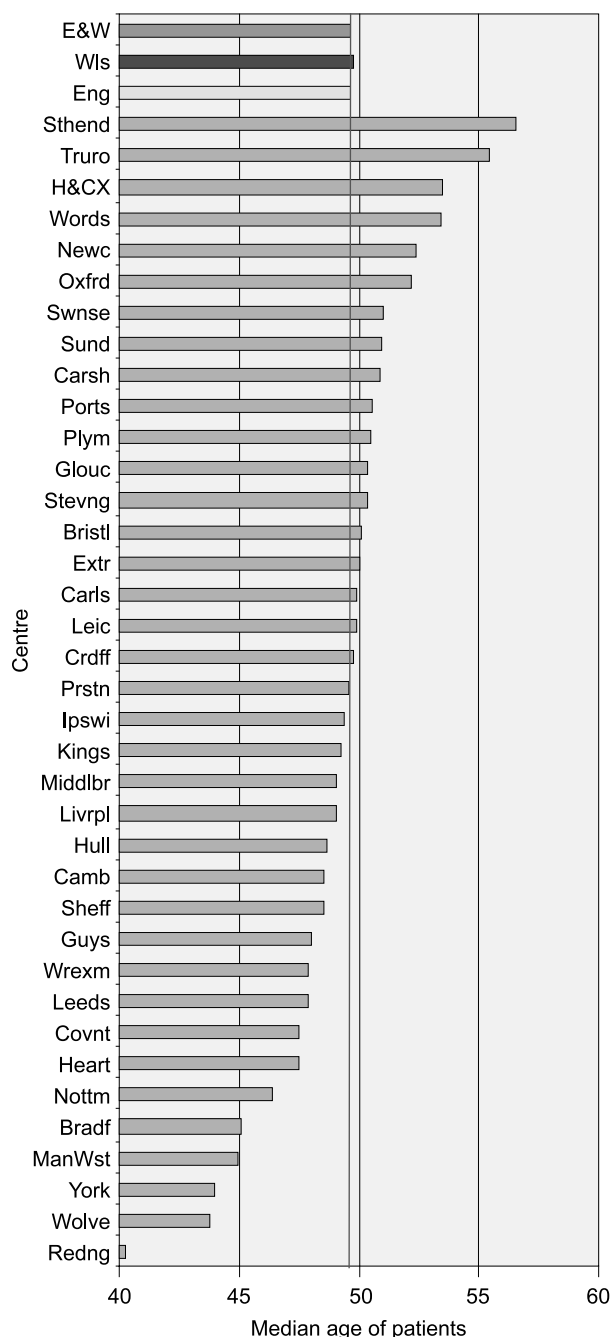


Figure 11.8: Median age of prevalent patients with a transplant

are younger than those on haemodialysis in all centres.

The median age of prevalent patients by centre with a functioning transplant is shown in Figure 11.8.

Ethnicity

The Registry continues to collect ethnicity data although it remains incomplete. The ethnicity of transplanted patients is shown in Figure 11.9. While the overall percentage of transplant patients aged <65 years who are White is 85.4%, African Caribbean 4.5%, South Asian 7.5%, Chinese 0.2%, and “other” 2.4%, there is marked variation in the proportion of different ethnic minority patients within and between centres. African Caribbean patients are predominantly drawn from the South-East of England while South Asians are more widespread but concentrated in London (H&CX, Reading, Stevenage), Midlands (Leicester, Wolverhampton, Coventry) and Bradford. Chinese patients comprise only a very small proportion of the transplant population.

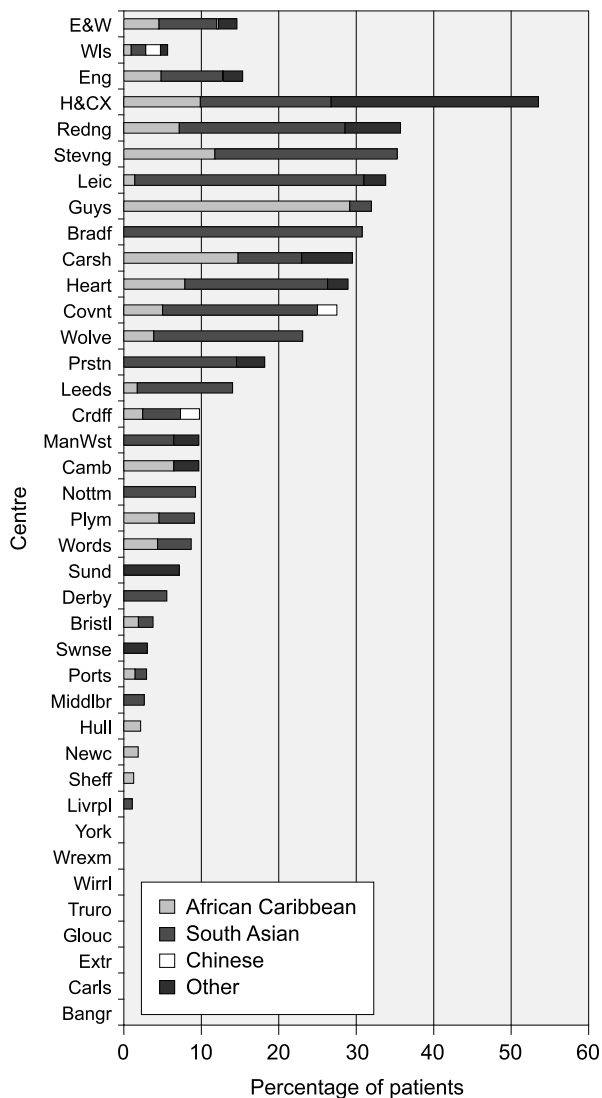


Figure 11.9: Ethnicity of dialysis patients under 65 who have ever had a transplant

Hammersmith & Charing Cross have an unusually high percentage of patients (26.8%) listed in the “other” category.

Table 11.8 shows the proportion of dialysis patients aged <65 years by ethnicity in each centre that has never had a transplant. Eight centres did not have any transplant patients from ethnic minorities. Donors from ethnic minorities comprise 2.7% of all cadaveric solid organ donors in the UK and they receive 15.6% of solid organ transplants (source UKTransplant).

Figure 11.10 shows the ethnic distribution of patients receiving RRT who have never received a renal transplant. 78.2% of the total are White patients, 6.6% Black patients, 11.1% South Asian, 0.6% Chinese and 3.5% “other” patients.

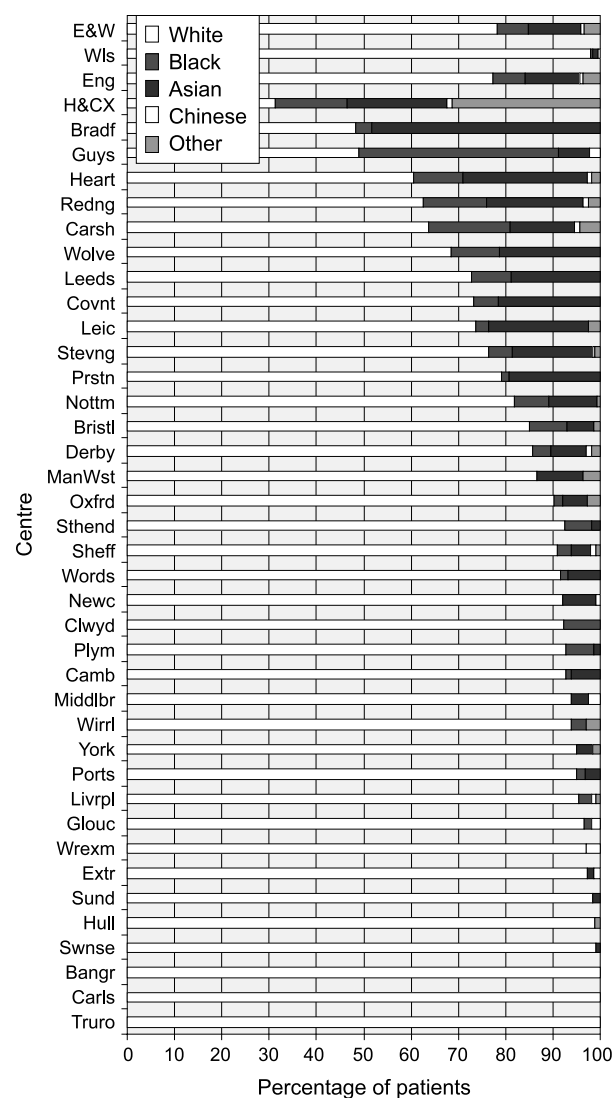


Figure 11.10: Ethnicity of dialysis patients under 65 who have never had a transplant

Table 11.8: Ethnicity of dialysis patients <65 who have never had a transplant

Centre	% White	% Black	% Asian	% Chinese	% Other
Bradf	48.4	3.2	48.4	0.0	0.0
Sthend	90.7	5.6	1.9	0.0	0.0
Stevng	76.5	4.9	16.9	0.6	1.1
Carsh	63.8	17.2	13.5	1.2	4.3
Wirrl	93.9	3.0	0.0	0.0	3.0
York	94.9	0.0	3.4	0.0	1.7
Middlbr	93.9	0.0	3.7	2.4	0.0
Nottm	81.8	7.4	10.2	0.0	0.6
Bristl	85.1	7.8	5.7	0.0	1.4
Truro	100.0	0.0	0.0	0.0	0.0
Hull	98.9	0.0	0.0	0.0	1.1
Leic	73.8	2.6	21.0	0.0	2.6
Derby	85.7	3.8	7.6	1.0	1.9
Ipswi	100.0	0.0	0.0	0.0	0.0
Camb	92.8	1.2	6.0	0.0	0.0
Glouc	96.5	1.8	0.0	1.8	0.0
Extr	97.2	0.0	1.4	1.4	0.0
Ports	95.0	1.9	3.1	0.0	0.0
Redng	62.7	13.3	20.5	1.2	2.4
Guys	48.9	42.2	6.7	2.2	0.0
Kings	0.0	50.0	50.0	0.0	0.0
Sheff	90.8	3.0	4.3	1.0	1.0
Plym	92.7	5.9	1.5	0.0	0.0
Covnt	73.3	5.2	21.6	0.0	0.0
Clwyd	92.3	7.7	0.0	0.0	0.0
Wrexm	97.0	0.0	0.0	3.0	0.0
Wolve	68.4	10.3	21.3	0.0	0.0
Heart	60.5	10.5	26.3	0.9	1.8
Carls	100.0	0.0	0.0	0.0	0.0
Sund	98.3	0.0	1.7	0.0	0.0
ManWst	86.7	0.0	9.7	0.0	3.6
Prstn	79.1	1.7	19.2	0.0	0.0
Words	91.5	1.7	6.8	0.0	0.0
Oxfrd	90.4	1.8	5.3	0.0	2.6
Leeds	72.9	8.4	18.7	0.0	0.0
Livrpl	95.5	2.7	0.0	0.9	0.9
Bangr	100.0	0.0	0.0	0.0	0.0
Swmse	99.1	0.0	0.9	0.0	0.0
H&CX	31.4	15.0	21.1	1.1	31.4
Crdff	94.4	0.0	5.6	0.0	0.0
Newc	92.0	0.0	7.1	0.9	0.0
Eng	77.3	6.9	11.6	0.6	3.6
Wls	98.0	0.5	1.0	0.5	0.0
E&W	78.2	6.6	11.1	0.6	3.5

Failed transplants 2003

In 2003, 2.2% of transplanted patients returned to dialysis (range 0–6.3%) which is unchanged from that reported in 2002.

UKTransplant calculates graft survival data by including death with a functioning graft as a transplant failure. Primary graft non-function (which accounts for the loss of 5% of all grafts) is also included within the graft failure figure. Some countries do not include primary non-function within the graft survival data and therefore one year graft survival rates may appear 5% lower in the UK when comparing data with those countries.

According to UKTransplant, in the period 1999–2002 year of transplant, there was a one

year graft survival of 87% (86–89%) for cadaveric heart beating donors and 93% (91–95%) for live donors. The 5 year survival for the 1996–1998 transplant cohorts are 71% and 84% for cadaveric and live donors respectively.

Quality of transplant function

Transplant function was assessed by the most recent serum creatinine within six months and by estimated GFR using the abbreviated MDRD equation.

There was variable collection of serum creatinine data in the centres but overall 91% of patients had a serum creatinine available for analysis. Figure 11.11 shows the median serum creatinine values in contributing centres with a

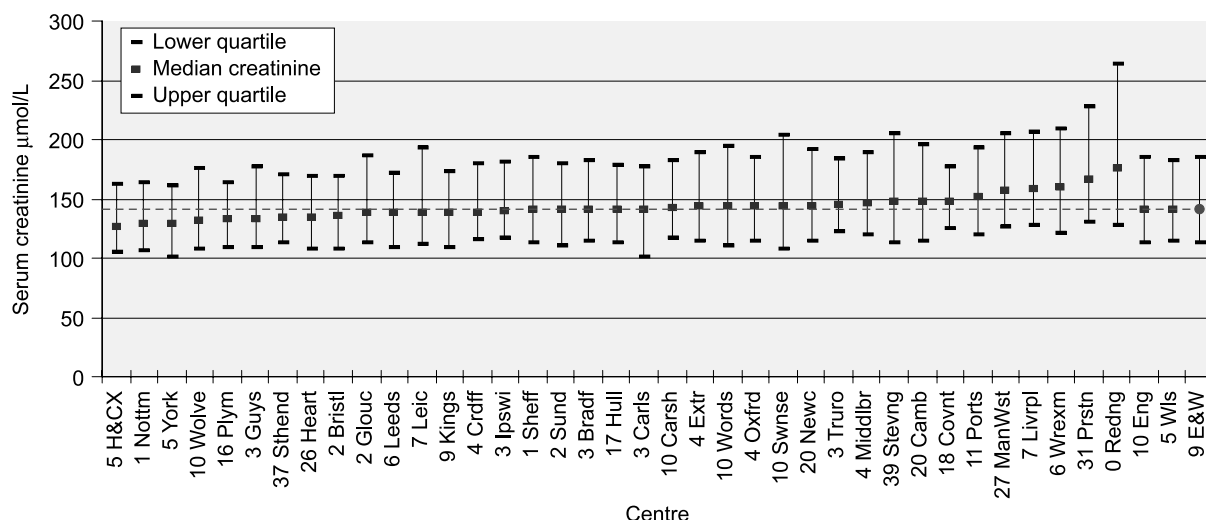


Figure 11.11: Median serum creatinine by centre

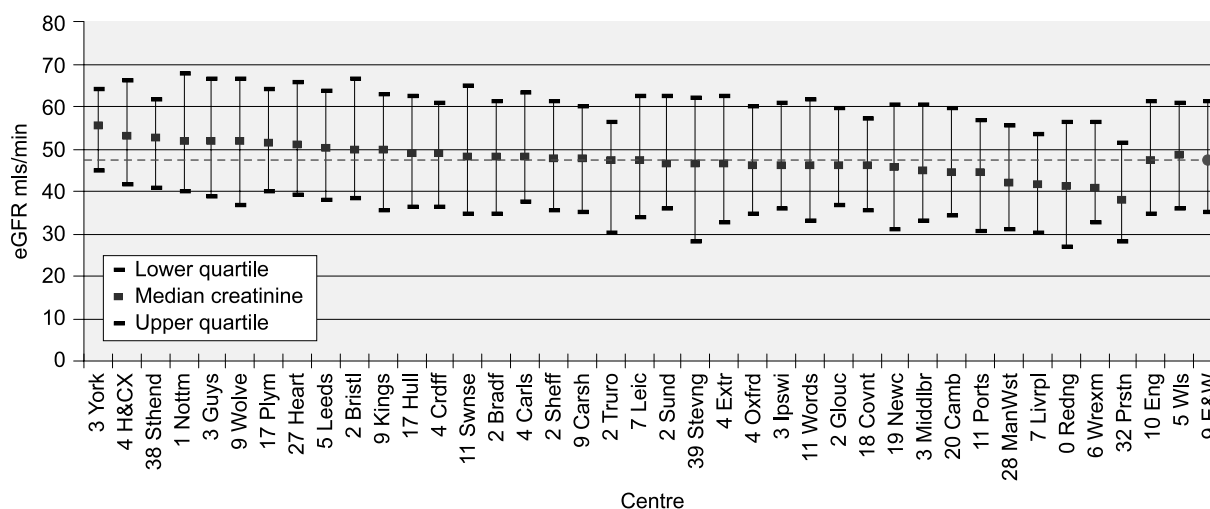


Figure 11.12: Median eGFR by centre

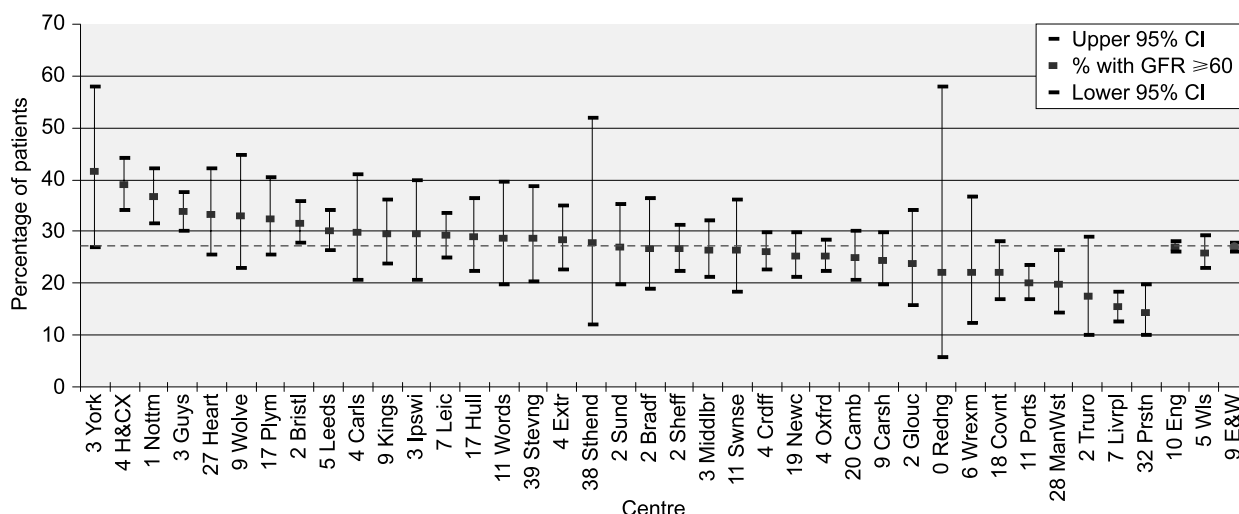


Figure 11.13: Percentage of patients with eGFR >60 mls/min by centre

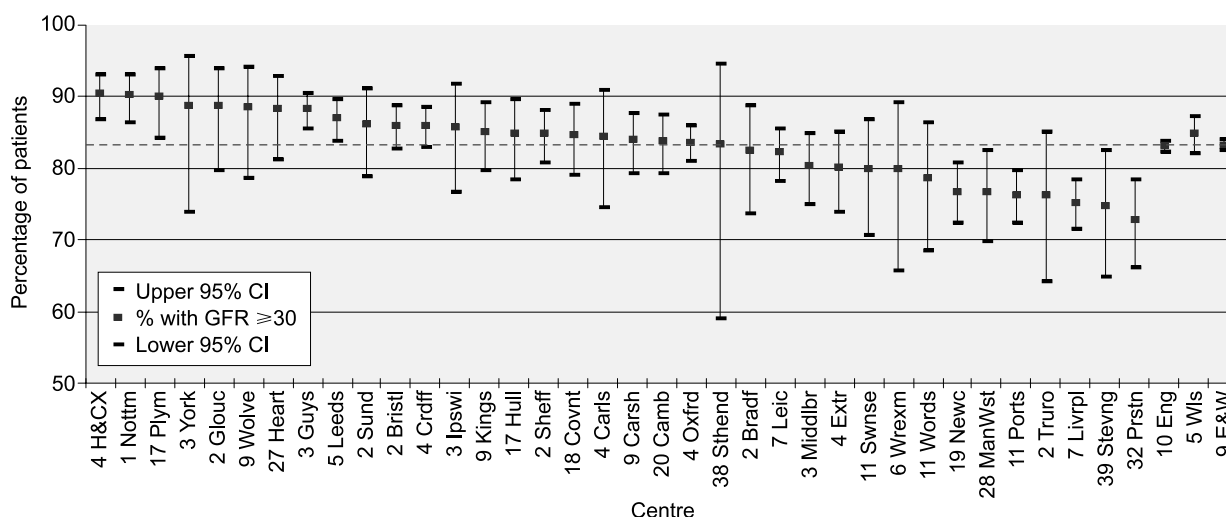


Figure 11.14: Percentage of patients with eGFR >30 mls/min by centre

median of 142 $\mu\text{mol/L}$ and range of 127 to 167 $\mu\text{mol/L}$ in 9,987 patients. The median eGFR (Figure 11.12) of prevalent transplant patients in England & Wales was 47.6 mls/min/ 1.73m^2 and median values ranged from 38.1–55.5 mls/min/ 1.73m^2 . The wide discrepancy in transplant function between centres is unexplained. Differences in immunosuppression policies, use of marginal donor kidneys, HLA matching policies and the number of acute rejection episodes patients undergo, may all have some influence. The relationship between creatinine/eGFR and long-term graft survival needs clarification using the UKTransplant database. Figures 11.13 and 11.14 show the percentage of patients in each centre with the calculated eGFR of greater than 60 and 30 mls/min/ 1.73m^2 respectively, the average for England & Wales being 27% and 83% respectively.

Analysis of transplant patients classed by CKD stages

This new analysis analyses the transplant patients as if they had chronic kidney disease and classes them by CKD stages 1–5 with stages 1 and 2 being grouped together. For conversion factors from SI units see Appendix H.

In Table 11.9, 2.7% of prevalent transplant patients have an eGFR of <15 mls/min and a further 15% an eGFR between 15–29 mls/min. The median eGFR in patients with CKD stages 1 and 2 has not been presented due to the inaccuracy inherent in the MDRD formula in calculating eGFRs >60 mls/min.

Lower eGFR is associated with a rise in both systolic and diastolic blood pressure. These data

Table 11.9: Analysis by CKD stage

	Stage 1–2 (≥60)	Stage 3 (30–59)	Stage 4 (15–29)	Stage 5 (<15)
Number of patients	2,123	4,658	1,212	225
% of patients	25.8	56.7	14.8	2.7
eGFR mean ± SD	Not calculated	44.9 ± 8.3	23.8 ± 4.1	11.4 ± 2.9
eGFR median	Not calculated	44.8	24.5	12.2
Systolic BP mean ± SD	138 ± 19	141 ± 21	143 ± 22	147 ± 22
Diastolic BP mean ± SD	80 ± 10	80 ± 11	81 ± 11	83 ± 14
Cholesterol mean ± SD	5.0 ± 1.0	5.1 ± 1.1	5.1 ± 1.2	5.0 ± 1.8
Cholesterol % ≥5 mmol/L	49	51	47	39
Haemoglobin mean	13.6 ± 1.6	12.8 ± 1.6	11.6 ± 1.6	11.0 ± 1.8
Haemoglobin % <10 g/dl	2	4	14	30
Haemoglobin % <11 g/dl	5	13	34	51
Ferritin median µg/L	89	111	168	212
Ferritin % <100 µg/L	53	46	33	16
Phosphate mean ± SD	0.9 ± 0.23	1.0 ± 0.23	1.2 ± 0.29	1.6 ± 0.42
Phosphate % >1.8 mmol/L	0.2	0.3	2.7	32.7
Corr calcium mean ± SD	2.45 ± 0.16	2.45 ± 0.15	2.41 ± 0.17	2.36 ± 0.21
Corr calcium % >2.6 mmol/L	9	9	7	7
Calcium % <2.2 mmol/L	4	3	8	16
iPTH median	9	10	16	31
iPTH % >32 pmol/L	5	9	27	48
Albumin mean ± SD	41 ± 4	40 ± 4	39 ± 5	37 ± 6
Albumin % <35 g/L	7	9	15	32
Bicarbonate mean ± SD	26 ± 3	25 ± 3	23 ± 4	22 ± 4
Bicarbonate % <22 mmol/L	8	14	32	49

are observational data from clinics and have not been adjusted for any increase in anti-hypertensive medications used within the groups. The percentage of patients with a serum cholesterol <5 mmol/L appears to increase with decreasing eGFR, which may be as a result of increased statin use in patients with poorer renal function rather than a direct fall related to renal function.

Haemoglobins fell with decreasing eGFR, such that of the 2.7% of transplant patients with eGFR <15 ml/min, 30% had an Hb <10 g/dl and 41% <11 g/dl. It is of interest that the standard deviation is constant at 1.6 g/dl across all groups until eGFR <15 ml/min and then it increases to 2.0 g/dl. This implies that centre factors may be coming into play with regard to variation in the management of these patients. The fall in haemoglobin contrasts with a rise in median serum ferritin from 89 to

206 µg/L with decreasing eGFR. The reasons for this may be multi-factorial including decreased utilisation of ferritin with lower erythropoietin levels, ferritin acting as an inflammatory marker (as albumin also fell) and iron infusions given for anaemia.

Of the 2.7% of transplant patients with eGFR <15 ml/min, 29% had a serum phosphate >1.8 mmol/L and 42% had an iPTH >32 pmol/L (=300 ng/L). PTH control was also poor in patients with CKD stage 4 with 27% of patients with iPTH values >32 pmol/L. These results appear worse than one would expect in non-transplant CKD patients in these groups. The contribution of poorer recognition and/or management of these patients, who may remain under transplant clinic follow up rather than under CKD clinic protocols, remains to be explored.

Re-allocation of transplant patients to parent dialysis centre

Each transplant centre serves a number of renal units and each transplant centre has a different policy of post-transplant patient management. In some transplant centres, patients are transferred back almost immediately to the referring dialysis unit while in other centres management of the patient remains in the transplant centre until the graft is failing. This is the reason why for Bangor, Clywd, Derby and Wirral, there appeared to be no transplant patients under their care and only those with poor graft function in other renal units. The transplant data have been reanalysed after re-allocating the patients to the original referring dialysis centre (Table 11.10). The transplant numbers remain low at the Wirral and Swansea renal units as they are a relatively new renal unit so patients transplanted in the 1980s would never have had dialysis at these units and in this analysis remain at their transplant centre.

After reallocation, the main exchanges were seen to be between Swansea and Cardiff, Oxford and Reading, Derby and Nottingham, Bangor, Clywd, Wirral, Wrexham and Liverpool.

Data on median age, median eGFR and median haemoglobin were analysed after re-allocation (Table 11.11). Apart from the changes in the data for Reading (median age increased by 6 years and the median eGFR increased by 6ml/min), there were no other large differences in these analyses of median age, median eGFR and median haemoglobin before and after centre re-allocation.

Table 11.10: Comparison of number of transplant patients before and after reallocation to original referring dialysis centre

Centre	Before reallocation	After reallocation	Difference
	Number of transplant		
Bangr	0	13	13
Bradf	114	119	5
Bristol	600	569	-31
Camb	421	390	-31
Carls	86	89	3
Carsh	344	341	-3
Clwyd	0	15	15
Covnt	269	257	-12
Crdff	645	586	-59
Derby	0	31	31
Extr	228	245	17
Glouc	88	117	29
Guys	707	696	-11
H&CX	381	379	-2
Heart	192	194	2
Hull	203	207	4
Ipswi	92	100	8
Kings	246	245	-1
Leeds	664	646	-18
Leic	484	484	0
Livrpl	730	651	-79
ManWst	254	254	0
Middlbr	293	304	11
Newc	525	416	-109
Nottm	375	339	-36
Oxfrd	860	788	-72
Plym	203	191	-12
Ports	625	622	-3
Prstn	321	322	1
Redng	12	77	65
Sheff	429	425	-4
Stevng	155	178	23
Sthend	31	21	-10
Sund	137	141	4
Swmse	119	178	59
Truro	70	73	3
Wirrl	0	13	13
Wolve	93	91	-2
Words	99	97	-2
Wrexm	51	83	32
York	48	56	8

Table 11.11: Comparing median age, eGFR and Hb before and after centre reallocation

Centre	Median age			Median eGFR			Median Hb		
	Before	After	Diff	Before	After	Diff	Before	After	Diff
Bangr	0.0	55.5	55.5	N/A	42.6	42.6	N/A	12.7	12.7
Bradf	45.1	45.0	-0.1	48.3	48.6	0.3	13.1	13.1	0.0
Bristol	50.1	50.4	0.3	49.9	49.8	-0.1	13.1	13.1	0.0
Camb	48.5	48.8	0.3	44.6	44.2	-0.4	12.3	12.3	0.0
Carls	49.9	49.3	-0.5	48.2	48.2	0.0	12.8	12.9	0.1
Carsh	50.9	50.9	0.0	47.6	47.6	0.0	12.9	12.9	0.0
Clwyd	0.0	53.3	53.3	N/A	45.2	45.2	N/A	13.4	13.4
Covnt	47.5	47.0	-0.5	46.0	46.0	0.0	12.8	12.9	0.1
Crdff	49.8	49.4	-0.4	48.9	48.6	-0.4	13.2	13.1	-0.1
Derby	0.0	43.5	43.5	N/A	54.2	54.2	N/A	12.9	12.9
Extr	50.0	49.7	-0.3	46.4	46.7	0.3	13.0	13.1	0.1
Glouc	50.4	50.3	0.0	46.2	48.4	2.2	12.7	12.8	0.1
Guys	48.0	48.0	0.0	51.9	51.9	0.0	12.9	12.9	0.0
H&CX	53.5	53.5	0.0	53.2	53.1	0.0	12.5	12.5	0.0
Heart	47.5	47.6	0.1	51.0	50.3	-0.7	13.3	13.2	-0.1
Hull	48.7	48.5	-0.2	49.1	49.1	0.0	13.2	13.2	0.0
Ipswi	49.4	49.4	0.0	46.3	46.3	0.0	12.5	12.5	0.0
Kings	49.2	49.5	0.3	49.9	49.9	0.0	12.0	12.0	0.0
Leeds	47.9	48.0	0.1	50.2	50.1	-0.1	13.0	13.0	0.0
Leic	49.9	49.9	0.0	47.3	47.3	0.0	12.9	12.9	0.0
Livrpl	49.1	49.1	0.0	41.6	40.7	-0.9	12.6	12.6	0.0
ManWst	45.0	45.0	0.0	42.2	42.2	0.0	12.7	12.7	0.0
Middlbr	49.1	49.0	-0.1	44.7	44.7	0.0	13.4	13.4	0.0
Newc	52.4	52.8	0.4	45.6	46.5	0.9	12.7	12.7	0.0
Nottm	46.4	46.7	0.2	52.0	51.6	-0.3	13.2	13.2	0.0
Oxford	52.2	52.7	0.5	46.3	46.2	-0.1	12.4	12.4	0.0
Plym	50.5	51.3	0.9	51.5	51.5	0.0	12.5	12.4	-0.1
Ports	50.5	50.6	0.0	44.4	44.4	0.0	12.4	12.4	0.0
Prstn	49.6	49.5	-0.1	38.1	38.1	0.0	12.7	12.7	0.0
Redng	40.3	46.4	6.2	41.2	47.2	6.1	12.4	12.5	0.1
Sheff	48.5	48.7	0.2	47.7	47.9	0.2	13.0	13.0	0.0
Stevng	50.4	49.8	-0.5	46.5	46.8	0.3	13.0	12.9	-0.1
Sthend	56.6	56.6	0.0	52.9	53.2	0.4	12.3	12.4	0.0
Sund	51.0	50.1	-0.9	46.6	46.6	0.0	13.2	13.2	0.0
Swlse	51.0	51.0	0.0	48.4	49.6	1.3	12.6	13.0	0.4
Truro	55.5	55.1	-0.4	47.5	46.1	-1.4	13.1	13.1	0.0
Wirrl	0.0	38.8	38.8	N/A	54.3	54.3	N/A	13.7	13.7
Wolve	43.8	45.5	1.7	51.8	51.0	-0.8	12.9	12.9	0.0
Words	53.4	53.4	0.0	46.2	46.2	0.0	12.8	12.8	0.0
Wrexm	47.9	48.8	0.9	40.9	44.1	3.2	12.7	12.6	-0.1
York	44.0	44.1	0.1	55.3	55.7	0.4	13.1	13.0	-0.1

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 >10 g/dl) should be applied for these patients.

Haemoglobin data are quite incomplete in many contributing centres and range from as low as 63.3% availability to 100%, with a mean of 90.1%.

Figure 11.15 shows the median haemoglobin values for all prevalent transplant patients at least six months following transplantation in

contributing centres with the median haemoglobin value of 12.8 g/dl (range 12.0–13.4 g/dl) not dissimilar to the 2002 Registry Report. Figure 11.16 shows the percentage of transplant patients in each unit with a haemoglobin <10 g/dl. In 2003, 5.1% of transplant patients who were at least six months following transplantation have haemoglobin below this figure, compared to 5.4% in 2002. Quality of graft function (eGFR), the use of bone marrow suppressants (azathioprine, mycophenolate mofetil, and sirolimus) and the variable use of erythropoietin in the failing graft population may provide some explanation. Analysis was performed to find the percentage of patients who had haemoglobin <11 g/dl and 14.5% of patients fell into this category. Figure 11.17 shows the median haemoglobin value achieved at each

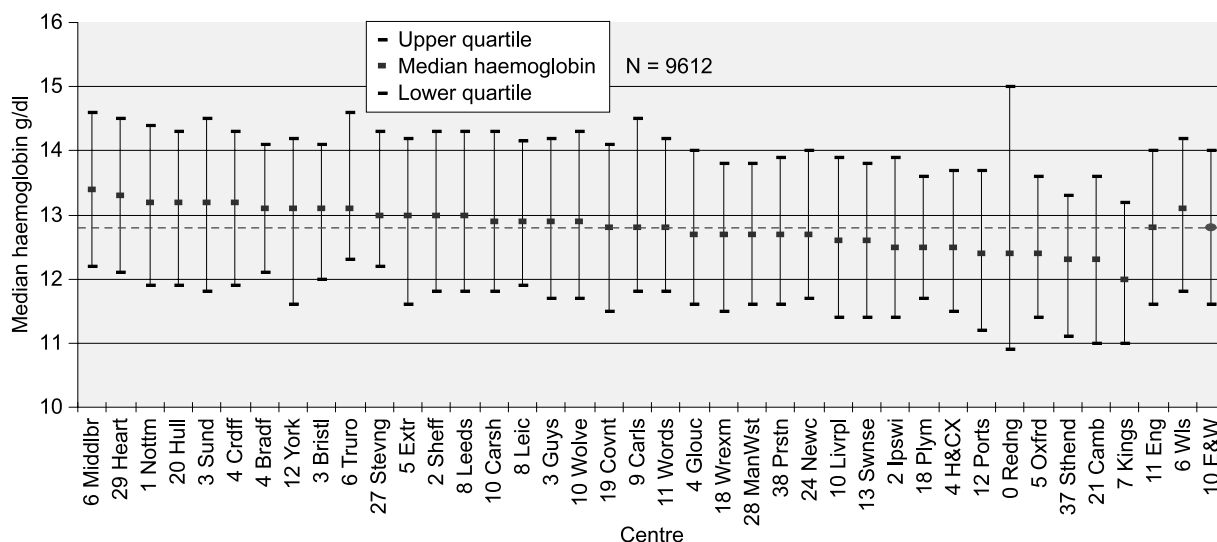


Figure 11.15: Median haemoglobin of prevalent transplant patients by centre

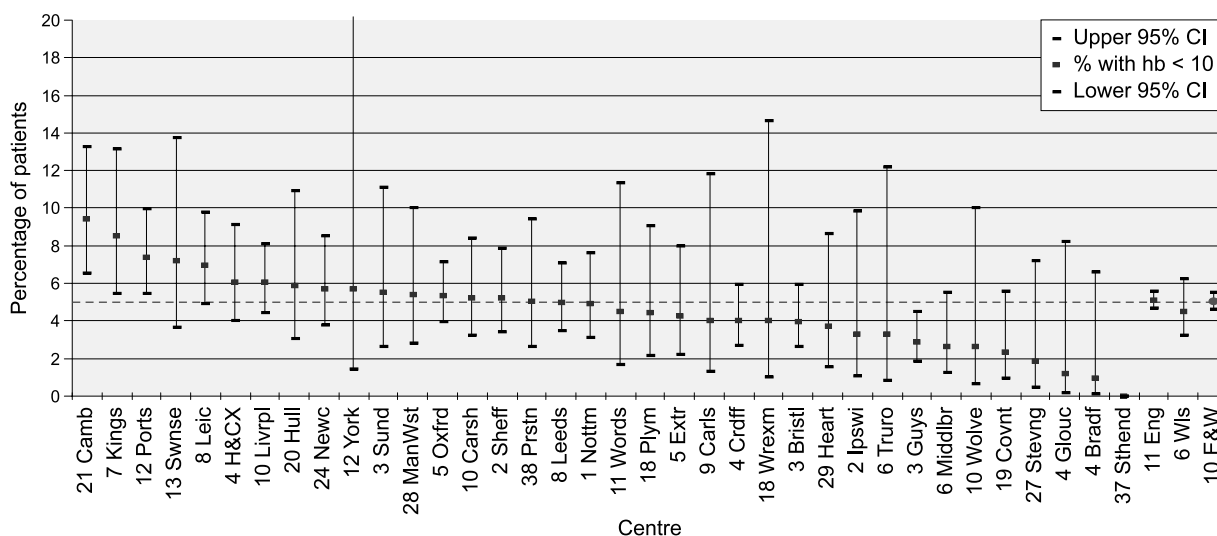


Figure 11.16: Percentage of patients Hb <10 g/dl by centre

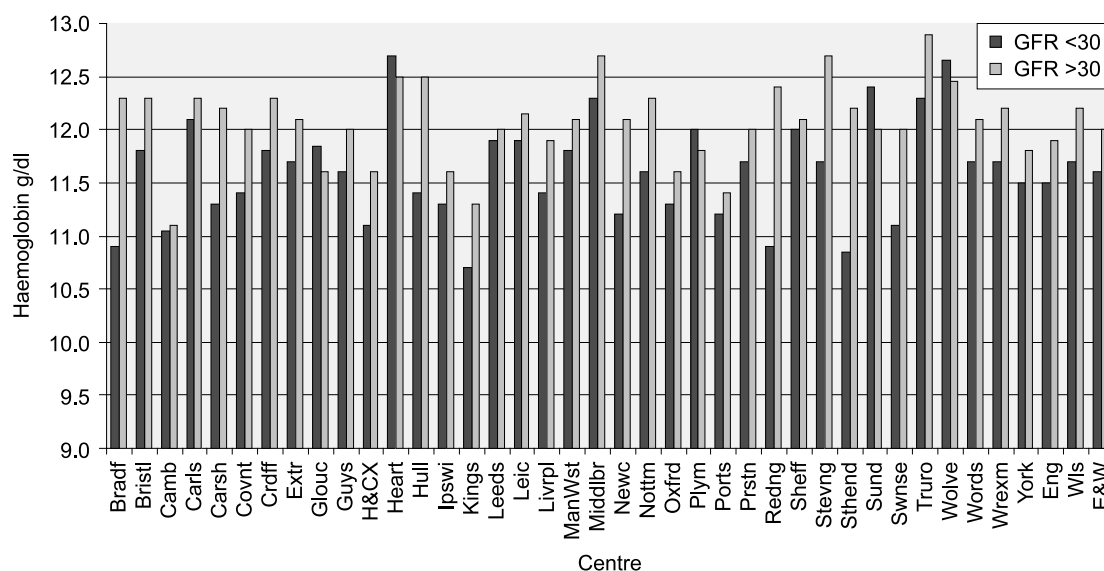


Figure 11.17: eGFR <30 and >30 with median Hb by centre

Table 11.12: Relationship between Hb, GFR and gender in transplant patients

Gender	eGFR mls/min	Mean Hb g/dl	Std dev	5th–95th centile	Median Hb	Quartile range	No. with data
Male	<30	11.8	1.7	9.1–14.7	11.7	10.7–12.9	646
Male	30+	13.4	1.6	10.7–16.0	13.5	12.4–14.5	3,645
Female	<30	11.3	1.5	8.6–13.7	11.3	10.3–12.4	600
Female	30+	12.5	1.5	10.1–15.0	12.5	11.5–13.5	2,133

centre by level of renal function (eGFR < or >30 mls/min). Not unexpectedly, the better the GFR, the higher the haemoglobin values.

As in the previous year's analysis, haemoglobin values are lower in women for the same level of eGFR than in men (Table 11.12).

Serum cholesterol

As in previous years, current analyses evaluate all transplant patients whose grafts have been functioning for at least a year. Returns on serum cholesterol data continue to improve, with 67.6% of patients from reporting centres producing data on 7,447 patients. As in previous years there are no recommendations in either the Renal Association or British Transplant Society Standards documents regarding a desirable cholesterol level in renal transplant recipients, so those data have been analysed as though patients are at a high cardiovascular risk.

The median cholesterol level was 4.9 mmol/L with a range between centres of 4.3–5.6 mmol/L (Figure 11.18). The percentage of patients in each centre with a cholesterol value within the Renal Association reference range varies between 25–72%, with a mean value of 53% in England & Wales (Figure 11.19). This continues to show a small annual improvement over previous years (Figure 11.20).

The Leeds renal unit has significantly lower serum cholesterol in transplanted patients than the average for England & Wales. This renal unit has seen an improvement from 33% to 66% of patients with a cholesterol <5 mmol/L after implementing software which provides an automated prompting system within the clinic visit. The software checks the serum cholesterol value and if required suggests atorvastatin and an appropriate dose. If the serum cholesterol has not been measured a prompt reminds the clinician to do so¹.

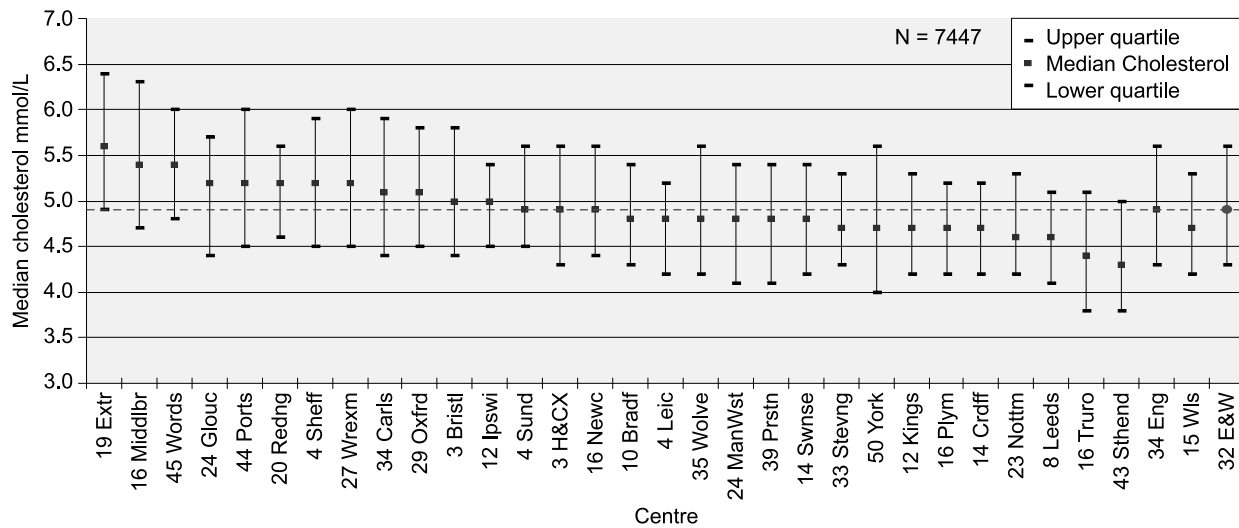


Figure 11.18: Median cholesterol in prevalent transplant patients by centre

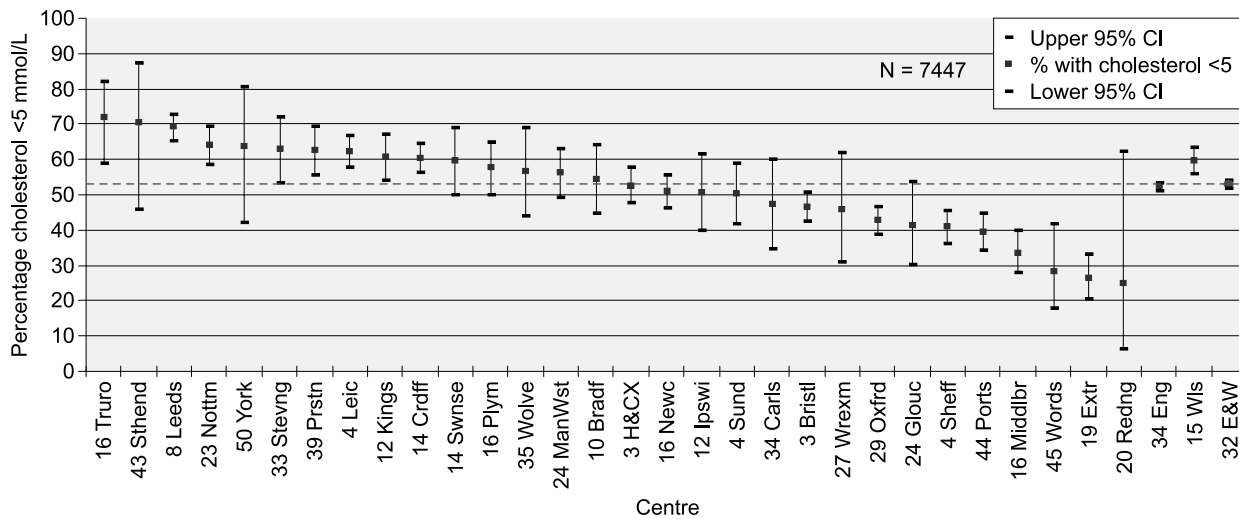


Figure 11.19: Percentage of transplant patients with cholesterol <5 mmol/L by centre

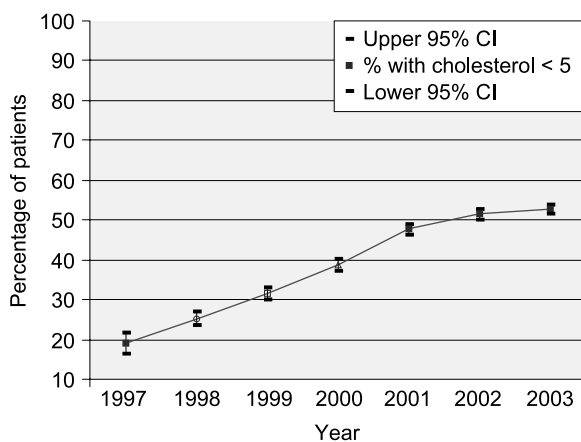


Figure 11.20: Percentage of transplant patients with cholesterol <5 mmol/L 1997-2003

Blood pressure

The third edition of the Renal Association's Standards and Audit Measures, published in August 2002, recommends:

Blood pressure targets for renal transplant recipients of less than 130 mmHg systolic blood pressure (SBP) and less than 80 mmHg diastolic blood pressure (DBP) (strength of recommendation B)

There continue to be incomplete blood pressure data returns, as shown in Table 11.13, despite the importance of this given by the Renal Association Standards. There needs to be

Table 11.13: Completeness of BP returns for transplant patients.

Centre	% BP return from last 6m 2003
York	97.2
Nottm	96.4
Sheff	96.3
Crdff	93.3
Bradf	85.9
Leic	77.7
Camb	73.7
Leeds	71.1
Livrpl	67.4
Covnt	63.5
Words	57.7
Middlbr	52.6
Bristl	49.6
Glouc	38.9
Truro	38.2
Wrexm	26.0
Redng	11.1
Extr	7.4
Oxfrd	6.6
Stevng	4.7
Sthend	4.4
Sund	4.3
Hull	4.0
Carls	3.8
Swmse	1.9
Guys	1.3
Heart	1.2
Plym	1.1
Carsh	0.3
Newc	0.2
H&CX	0.0
Ipswi	0.0
Kings	0.0
ManWst	0.0
Ports	0.0
Prstn	0.0
Wolve	0.0
Eng	33.0
Wls	76.0
E&W	36.3

greater efforts to capture these data automatically when measured in the clinic, for downloading to the Renal Registry. Currently, only 36% of patients have blood pressure data available.

Overall only 26% of transplant patients achieved both a systolic and diastolic BP within the RA Standard (Figure 11.21). Median systolic blood pressure in transplant patients was 138 mmHg (range 130–144 mmHg) as shown in Figure 11.22 and median diastolic BP was 80 mmHg (range 40–120 mmHg), Figure 11.23. The percentage of patients with a systolic blood pressure <130 mmHg is shown in Figure 11.24. Overall, only 31% of patients conformed to RA systolic BP criteria. Figure 11.25 reveals that only 44% of patients have a diastolic blood pressure within RA guidelines.

Clearly blood pressure recordings are subject to well-known biases and this was discussed in detail in Chapter 11 of the 2003 Registry Report. Such biases may be reduced if electronic measurement of blood pressure is undertaken, provided that the instruments used are appropriately validated and any necessary transcription is accurate. In addition, the clinic setting may not be the best place to undertake blood pressure measurements, although this remains a contentious area of debate.

The relationship between eGFR and systolic and diastolic blood pressure is shown earlier in Table 11.9. In the main, the higher the eGFR the lower the diastolic and systolic blood pressure.

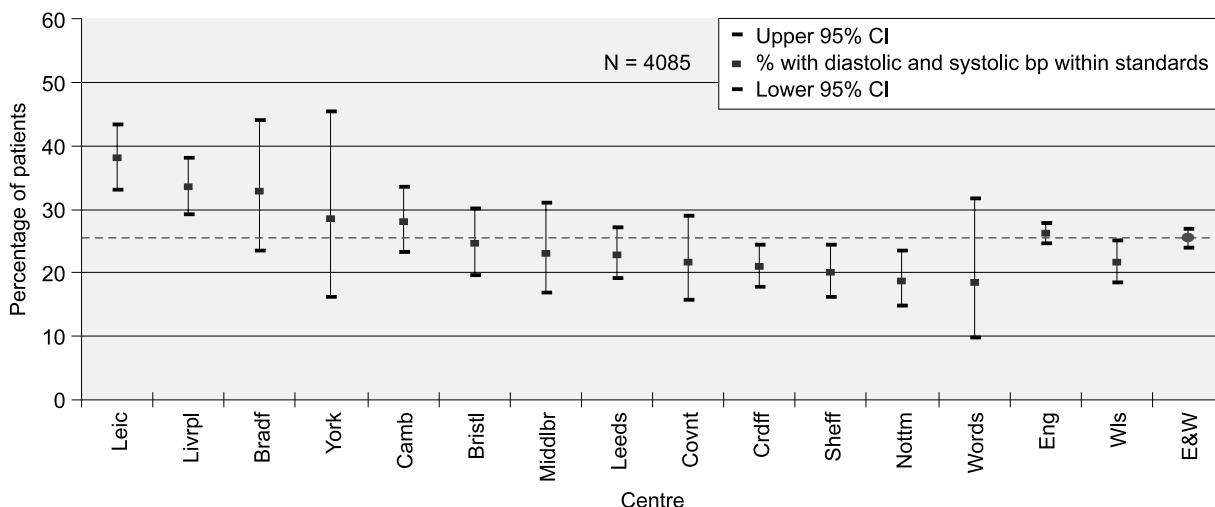


Figure 11.21: Percentage of patients with a BP below 130/80 mmHg

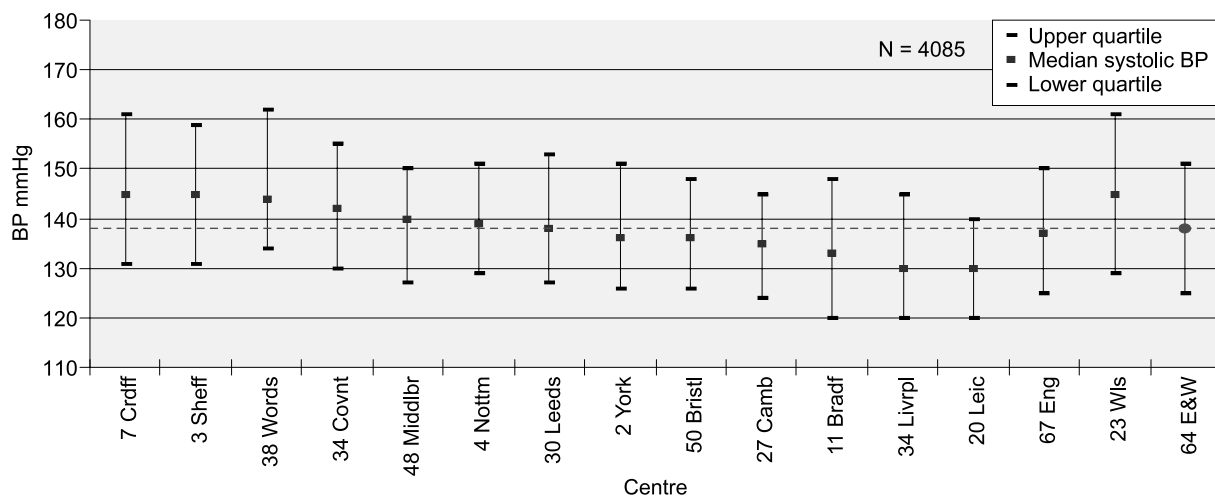


Figure 11.22: Median systolic BP by centre

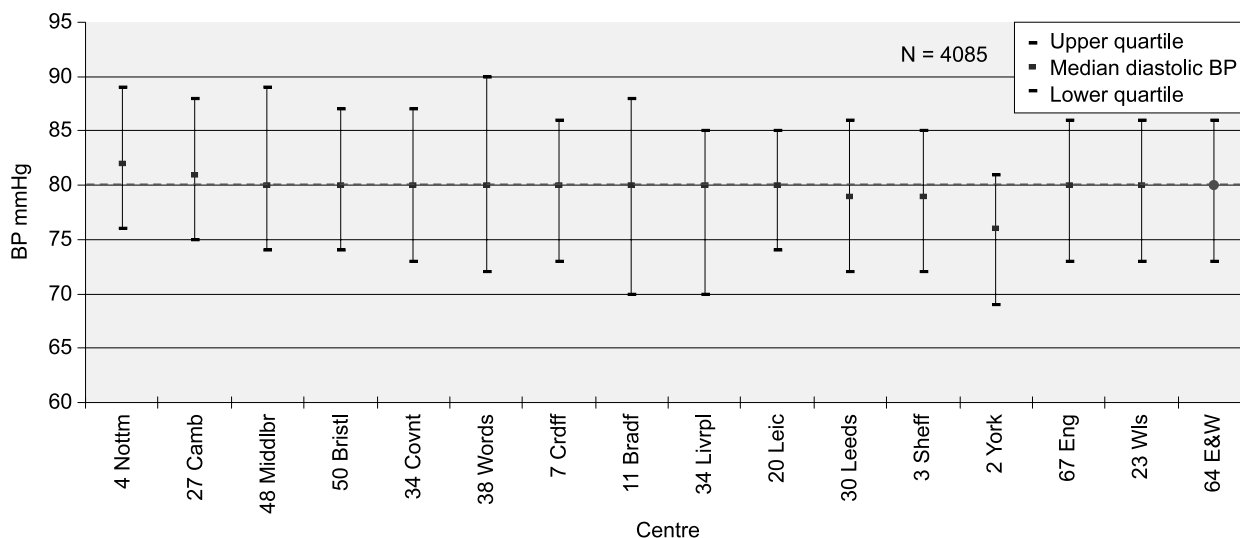


Figure 11.23: Median diastolic BP by centre

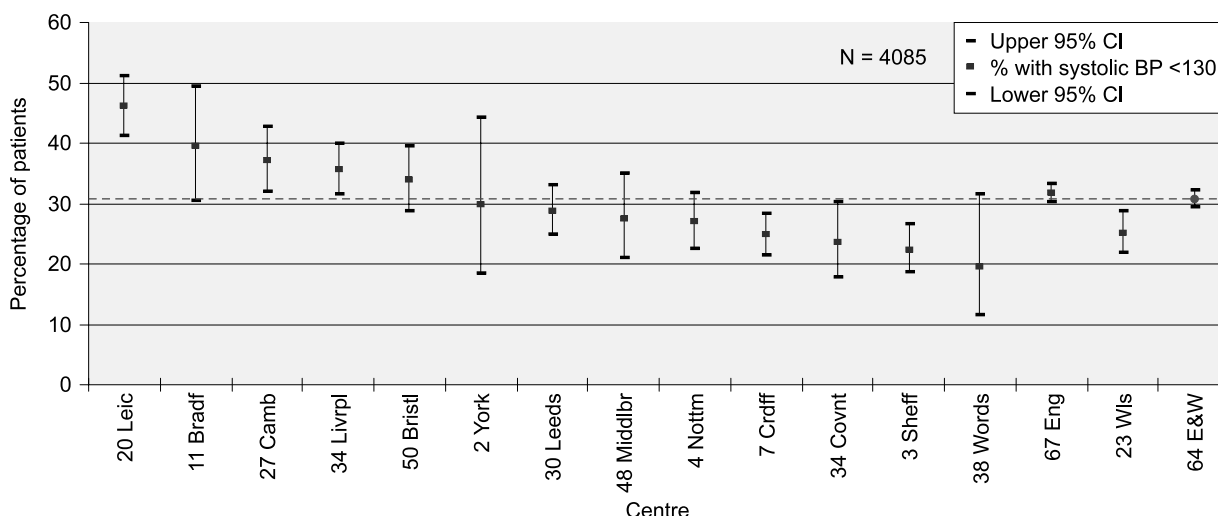


Figure 11.24: Percentage of patients with a systolic BP below 130 mmHg

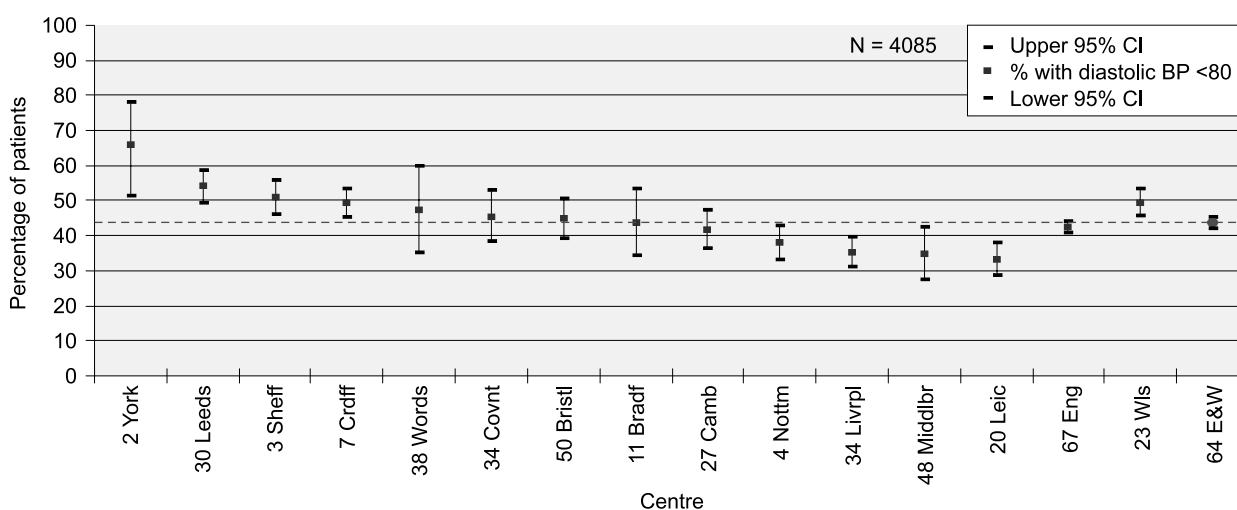


Figure 11.25: Percentage of patients with a diastolic BP below 80 mmHg

Transplant patient survival

Table 11.14 shows the survival of patients in 2003 with an established renal transplant. The one year survival of prevalent transplant

patients was 97.5% in England & Wales for patients in contributing centres censored at dialysis and 97.3% if patients returning to dialysis are included. This is unchanged from previous years.

Table 11.14: Survival during 2003 of established transplant patients alive on 1/1/2003

	Transplant censored at dialysis			Transplant including dialysis returns		
	Eng	Wales	E&W	Eng	Wales	E&W
No. of patients	8,992	758	9,750	8,994	758	9,752
No. of deaths	222	15	237	758	16	255
Death Rate	2.5	2.1	2.5	2.5	3.1	2.6
(95% CI)	2.2–2.9	1.1–3.3	2.2–2.9	2.2–2.9	2–4.7	2.3–2.9
K-M* 1 yr survival	97.4	97.9	97.5	97.3	98	97.3
(95% CI)	97.1–97.8	96.9–98.9	97.2–97.8	97.0–97.6	97.0–99.0	97.1–97.7

*Kaplan-Meier

Conclusions

This Chapter reports on data returned from 41 units, 37 of which follow prevalent transplant patients. Currently 16 units perform renal transplantation and follow-up 73.8% of the Registry prevalent transplant cohort. Data on 60.2% of all UK renal transplants performed in 2003 are presented. With the increase in the number of patients over the age of 65 years maintained on dialysis, the proportion of RRT provided by transplantation is declining progressively and stood at 45% in 2003. As pointed out in previous years, many unexplained variations exist between centres with respect to access for transplantation in patients receiving dialysis and patients whose underlying renal disease diagnosis is diabetes mellitus appear under-represented in the transplant cohort.

During 2003, 2.2% of all prevalent renal grafts failed and the annual death rate in prevalent patients with renal transplants was 2.4% (excluding patients with failed grafts returning to dialysis).

There remains considerable room for improvement in terms of data collection. Explanations are needed for the significant variations in haemoglobin, serum cholesterol and blood pressure in the different centre transplant cohorts. Nevertheless, with more centres contributing data to the Renal Registry the opportunities for comparative audit, clinical policy development and improved outcomes will increase. CKD Staging appears to provide a framework for this effort in regard to renal transplant patients. With 17% of prevalent transplant recipients being classified as CKD stage 4–5 this has organisational implications for structuring specific services (eg anaemia and phosphate management) for these patients.

References

1. Garthwaite EA, Will EJ, Bartlett C, Richardson D, Newstead CG. Patient-specific prompts in the cholesterol management of renal transplant outpatients: results and analysis of underperformance. *Transplantation* 2004 Oct 15;78(7):1042–7.

Chapter 12: 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, intact parathyroid hormone and blood pressure.

Introduction

The Standards Committee of the Renal Association has identified a number of laboratory and clinical variables that may relate to quality of care or outcomes and has recommended minimum Standards or target ranges that should be achieved in established dialysis patients. A revised document was published in autumn 2002 and these are shown in Table 1.

Data included on dialysis patients are from the last quarter of 2003 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 a 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.

In the following section, many figures use a common modified box-plot format, data being presented separately for haemodialysis (HD), peritoneal dialysis (PD) and transplantation.

Table 12.1: 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	<5 mmol/L	<5 mmol/L	
Dialysis adequacy	Urea reduction ratio >65%		
Ferritin	>100 mcg/L	>100 mcg/L	
Haemoglobin	≥ 10 g/dl	≥ 10 g/dl	
HbA1c	<7%	<7%	<7%
Parathyroid hormone	<4× upper local range	<4× upper local range	<4× upper local range
Phosphate	Pre-HD <1.8 mmol/L	<1.8 mmol/L	

- 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 G).
- These methods are the best way the Registry has found to convey the underlying data for the larger number of centres.

Haemoglobin

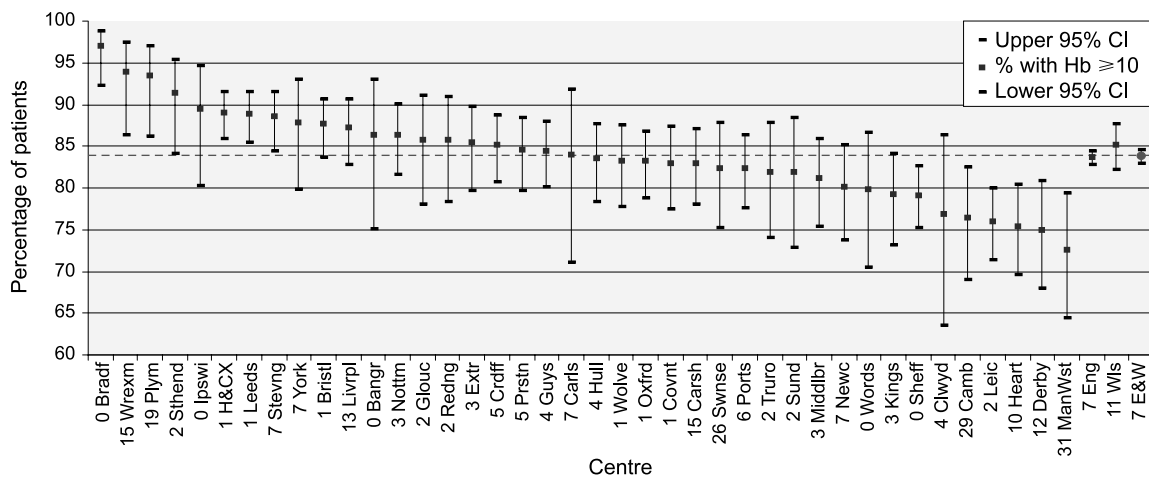


Figure 12.1: Percentage of HD patients achieving the RA Hb Standard by centre

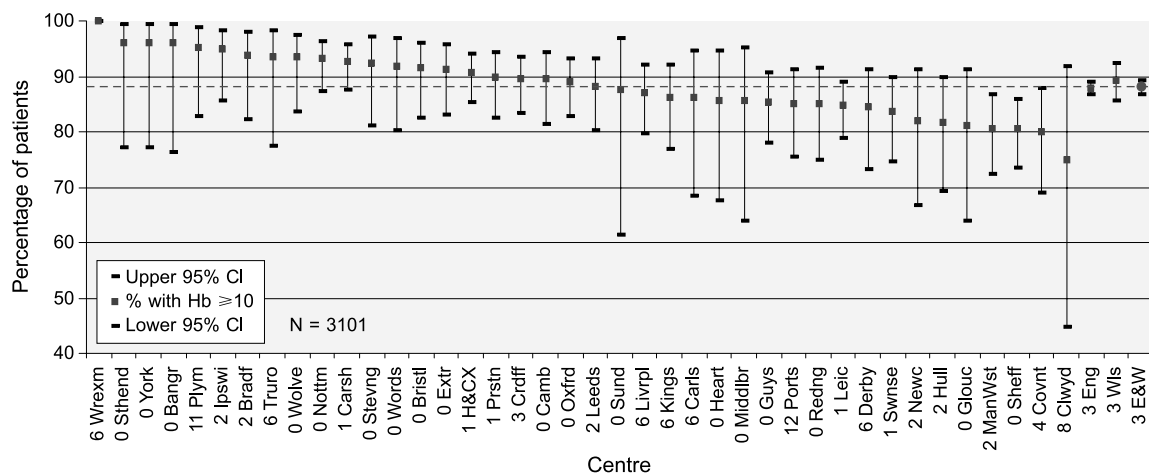


Figure 12.2: Percentage of PD patients achieving the RA Hb Standard by centre

Serum Ferritin

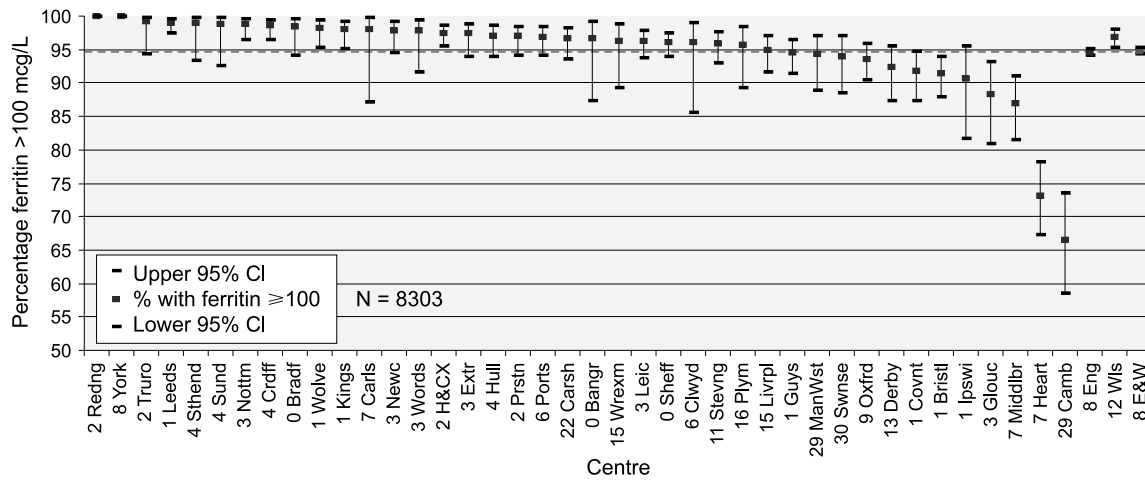


Figure 12.3: Percentage of HD patients achieving the RA Ferritin Standard by centre

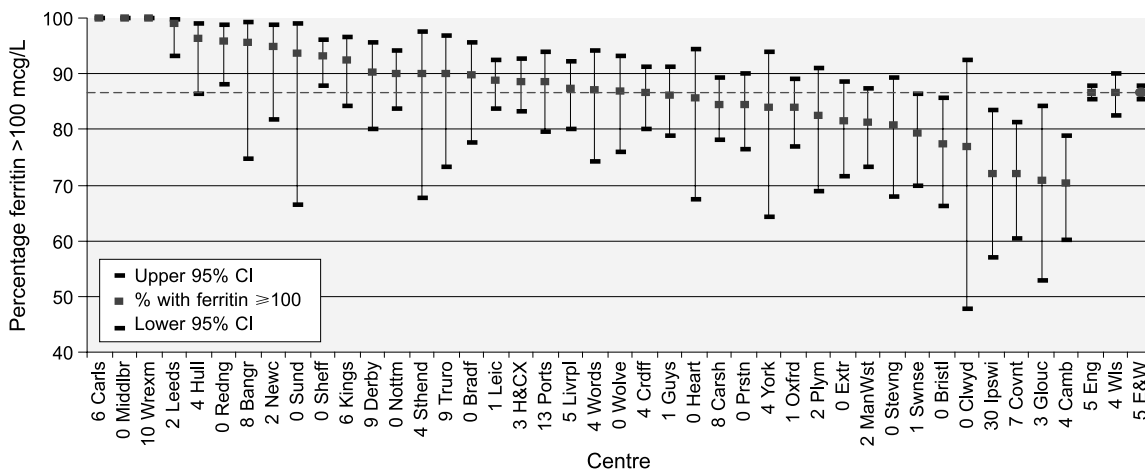


Figure 12.4: Percentage of PD patients achieving the RA Ferritin Standard by centre

Serum calcium

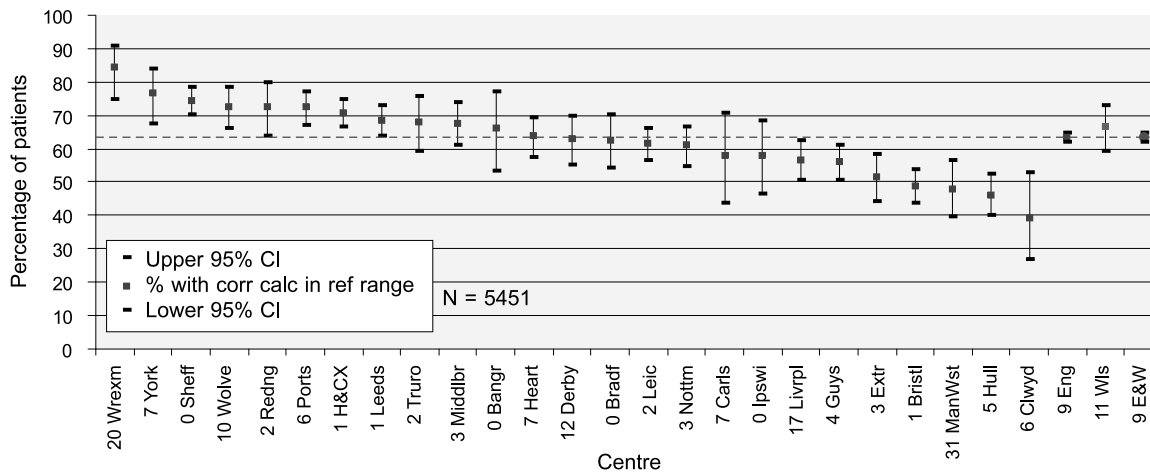


Figure 12.5: Percentage of HD patients achieving the RA calcium Standard by centre

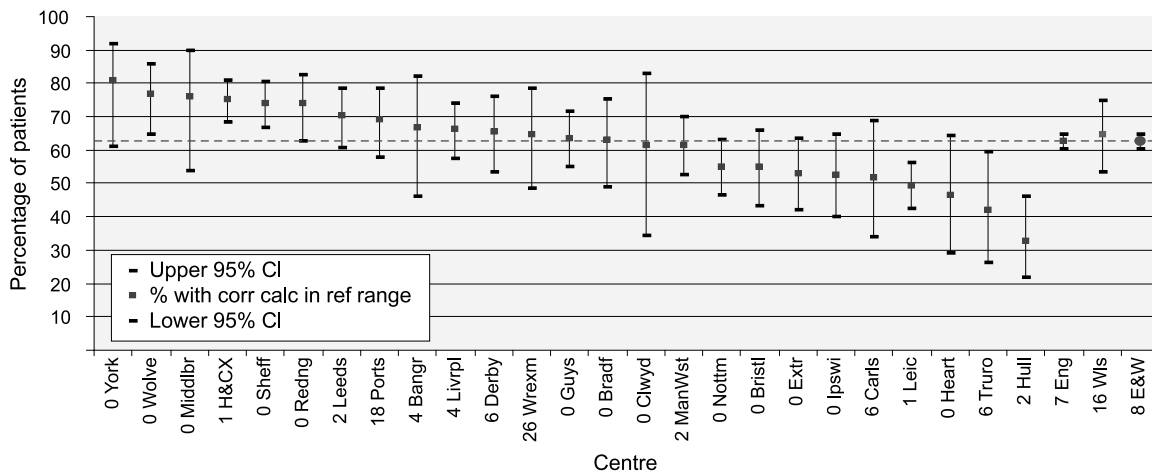


Figure 12.6: Percentage of PD patients achieving the RA calcium Standard by centre

Serum phosphate

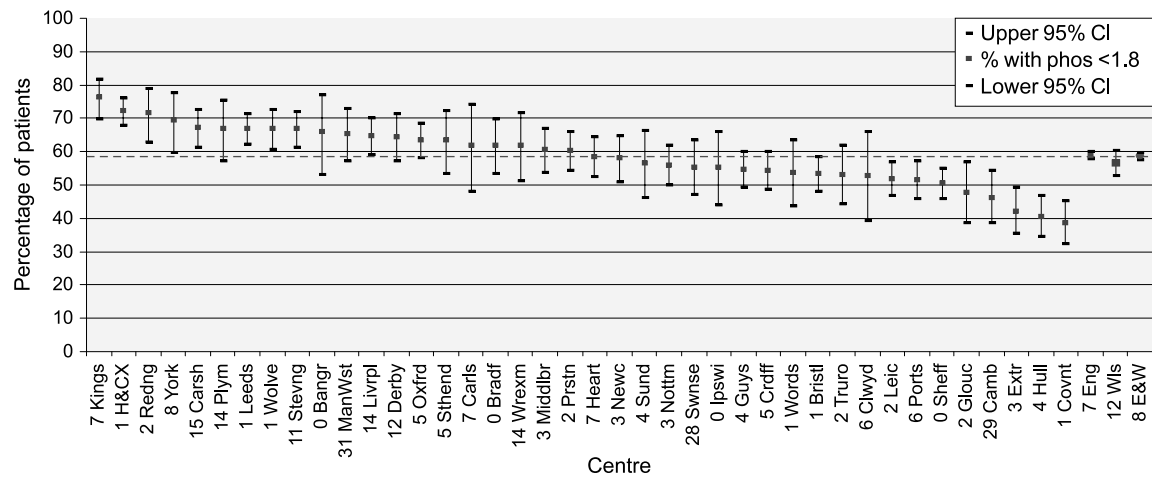


Figure 12.7: Percentage of HD patients achieving the RA phosphate Standard by centre

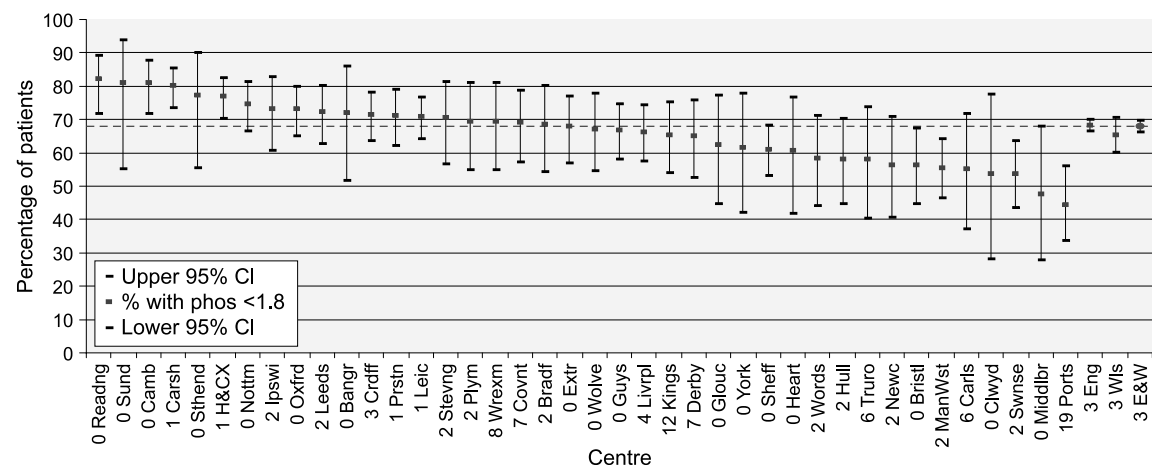


Figure 12.8: Percentage of PD patients achieving the RA phosphate Standard by centre

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 (8 pmol/L) and the recommended Standard of $< \times 4$ this limit.

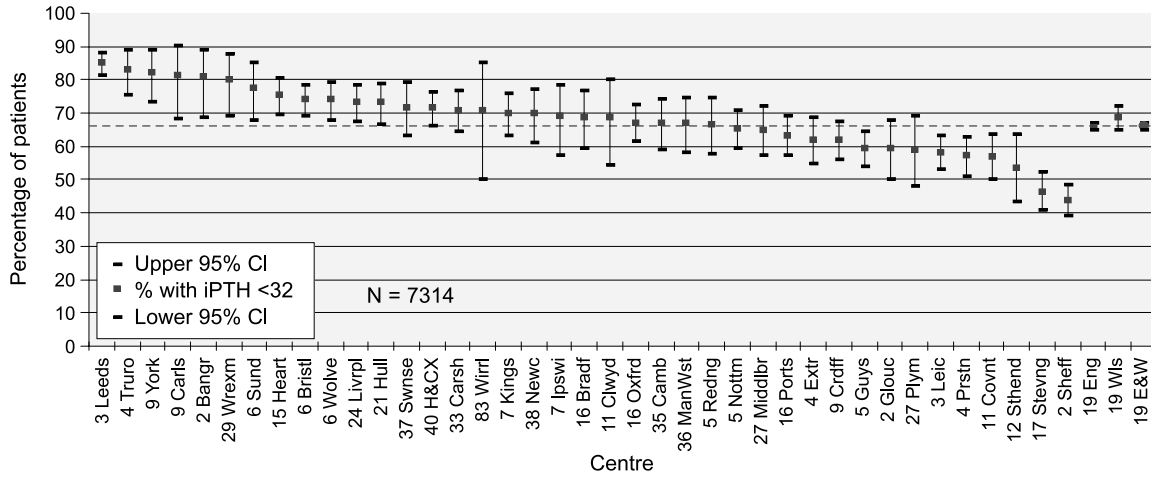


Figure 12.9: Percentage of HD patients achieving iPTH <32 pmol/L by centre

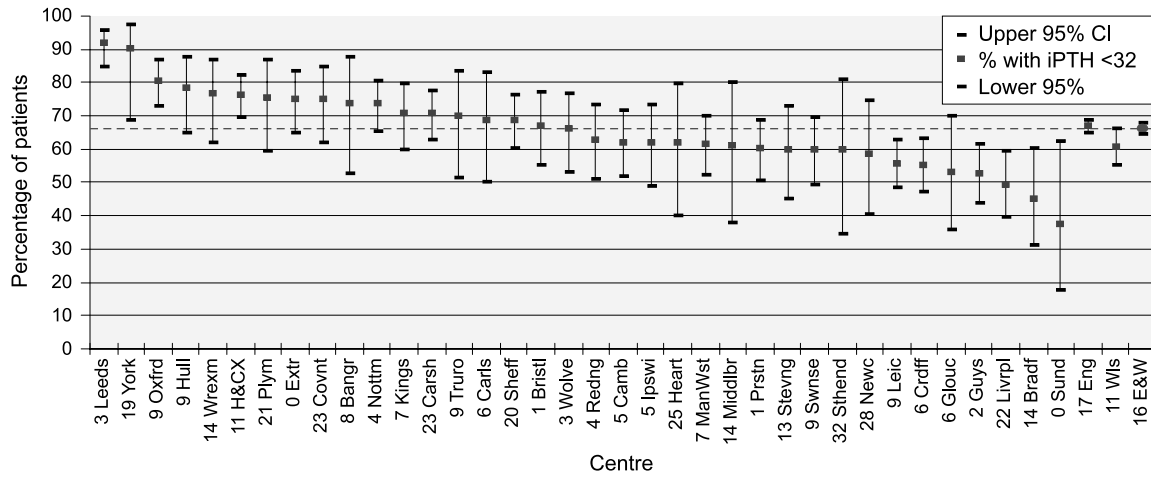


Figure 12.10: Percentage of PD patients achieving iPTH <32 pmol/L by centre

Dialysis adequacy

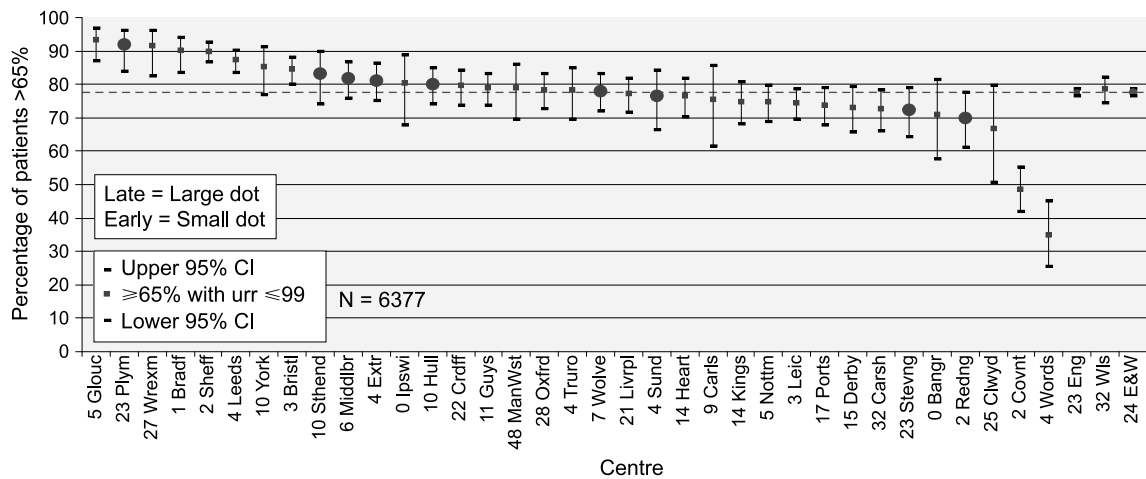


Figure 12.11: Percentage of HD patients with URR $\geq 65\%$ by centre

Serum bicarbonate

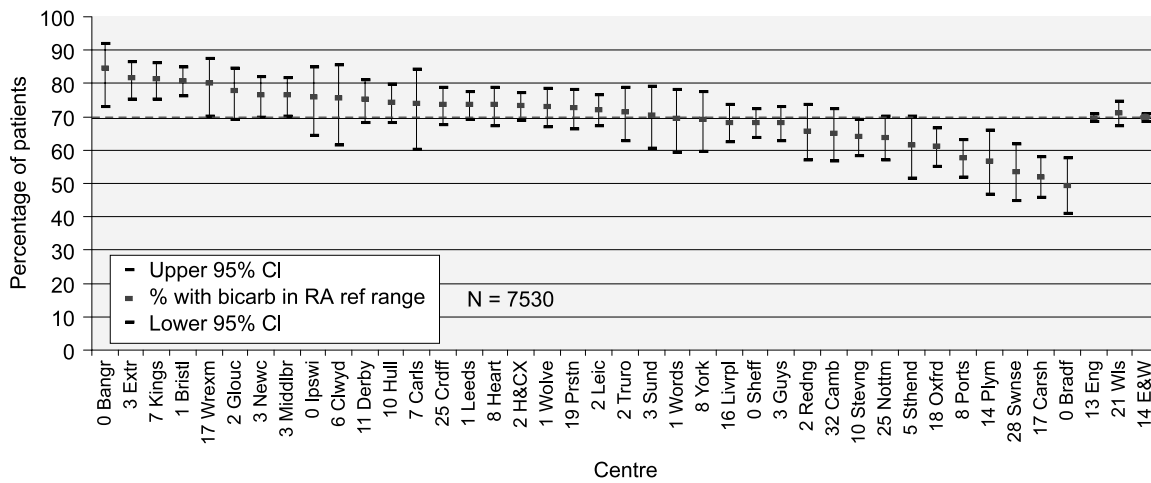


Figure 12.12: Percentage of HD patients achieving the RA bicarbonate Standard by centre

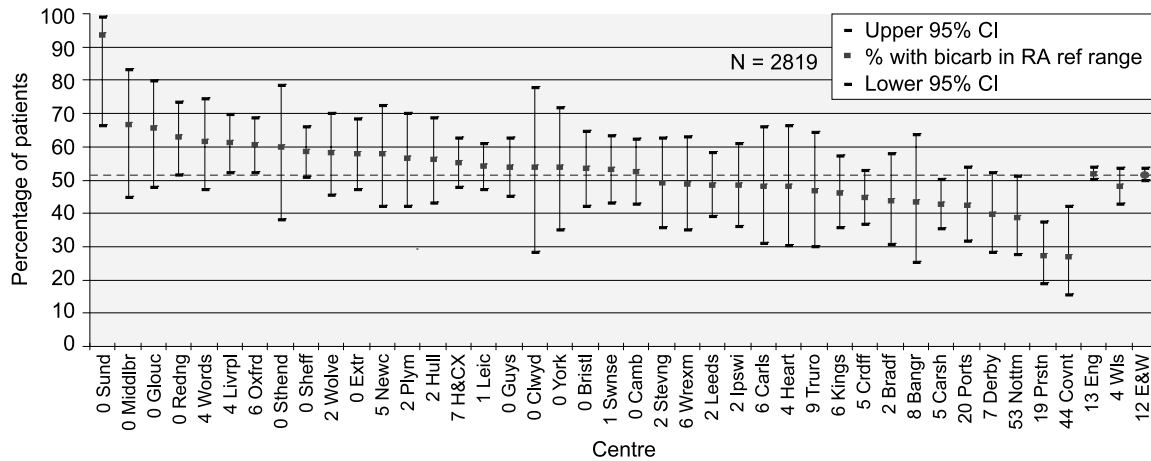


Figure 12.13: Percentage of PD patients achieving the RA bicarbonate Standard by centre

Serum albumin

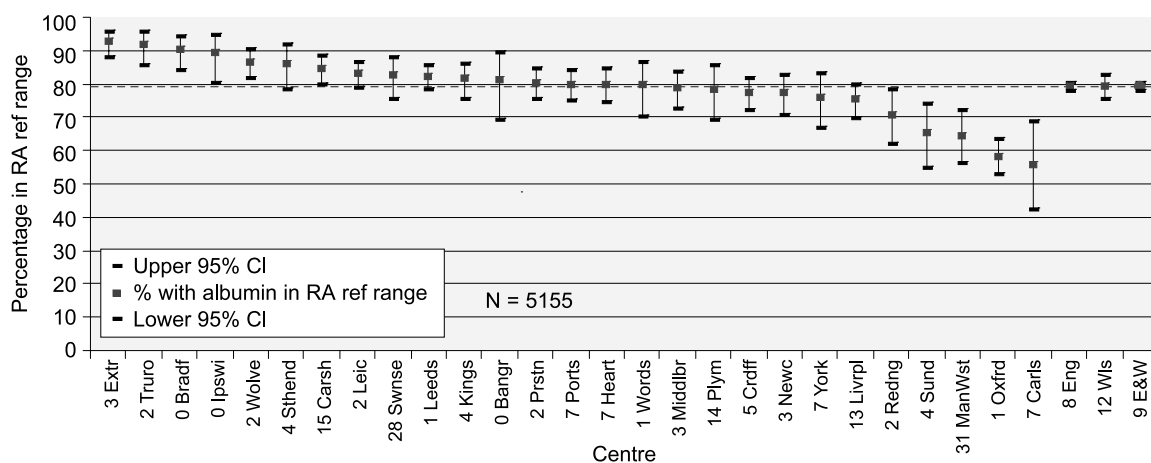


Figure 12.14: Percentage of HD patients achieving the RA albumin BCG Standard by centre

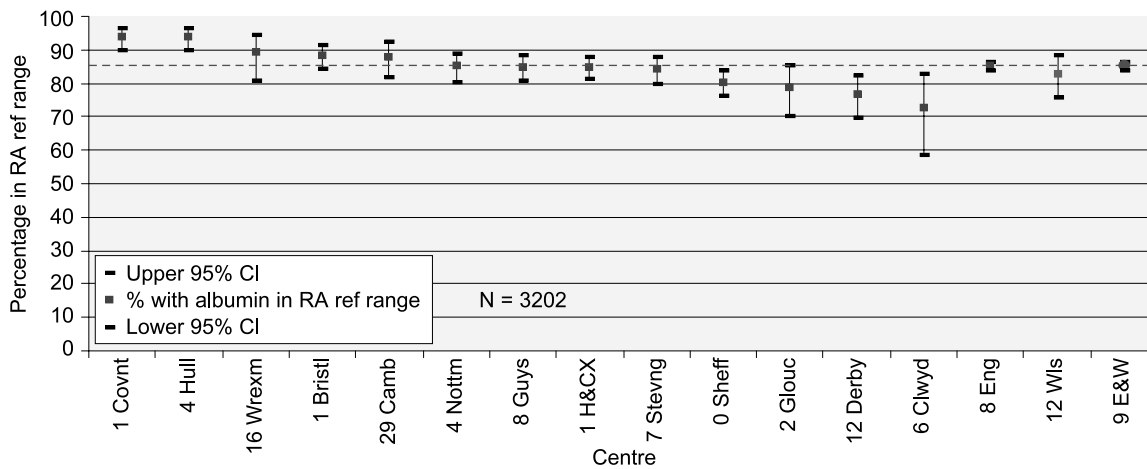


Figure 12.15: Percentage of HD patients achieving the RA albumin BCP Standard by centre

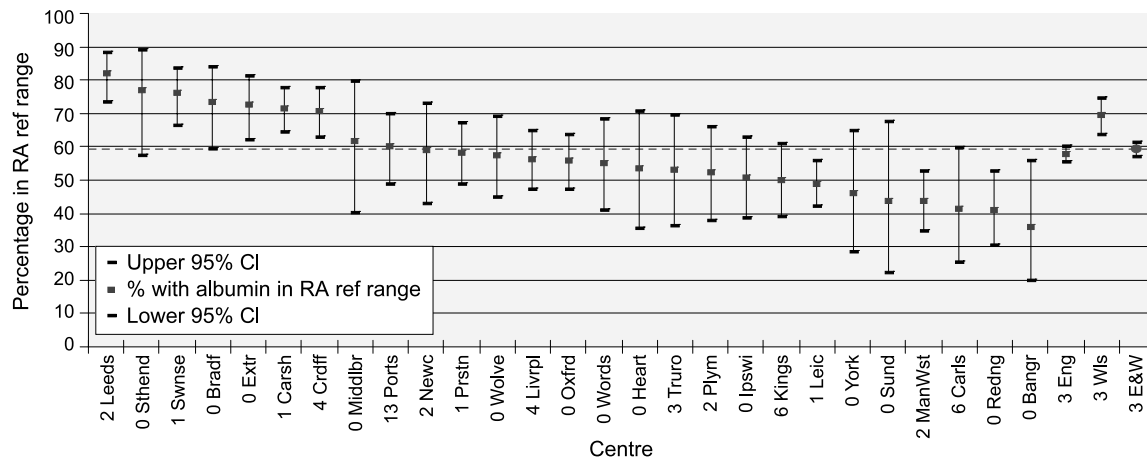


Figure 12.16: Percentage of PD patients achieving the RA albumin BCG Standard by centre

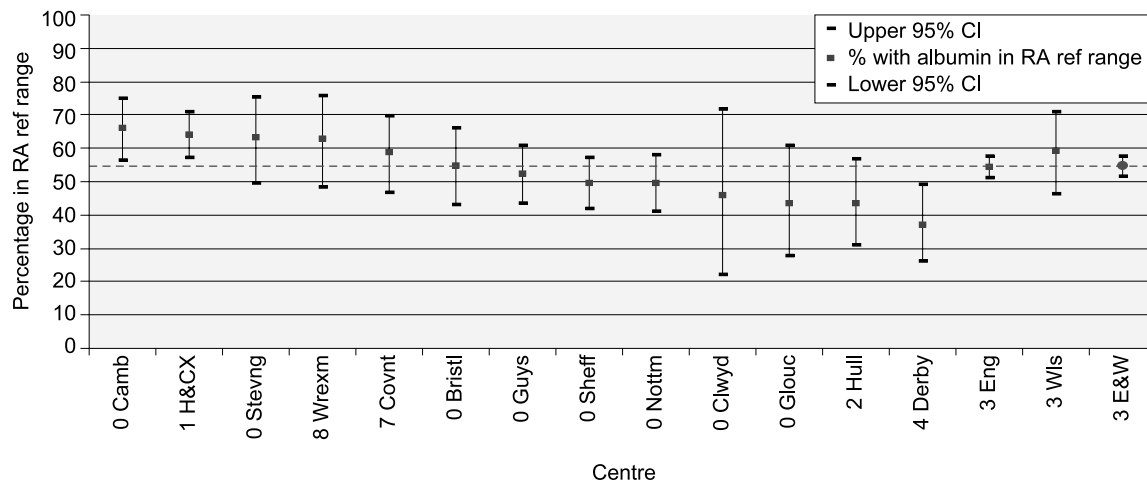


Figure 12.17: Percentage of PD patients achieving the RA albumin BCP Standard by centre

Blood Pressure

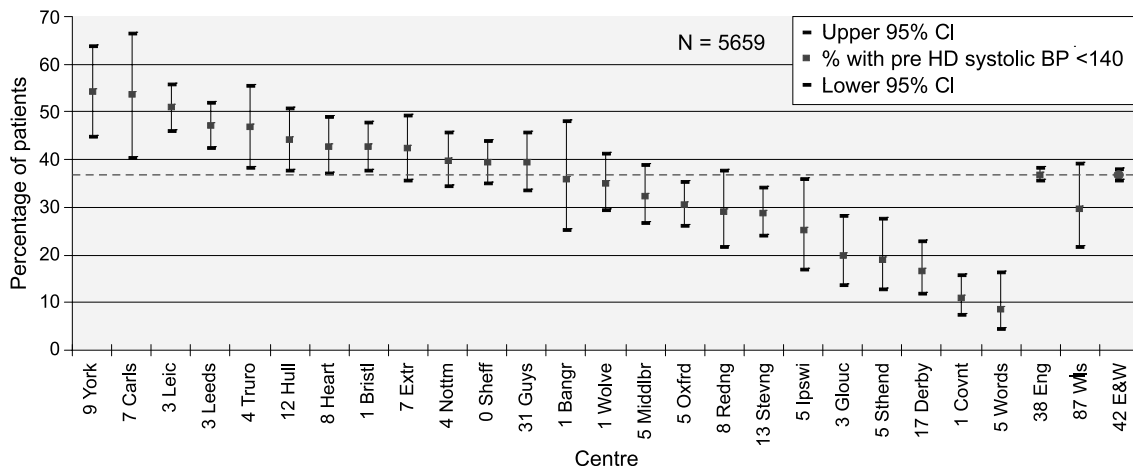


Figure 12.18: Percentage of HD patients achieving the RA BP Standard by centre

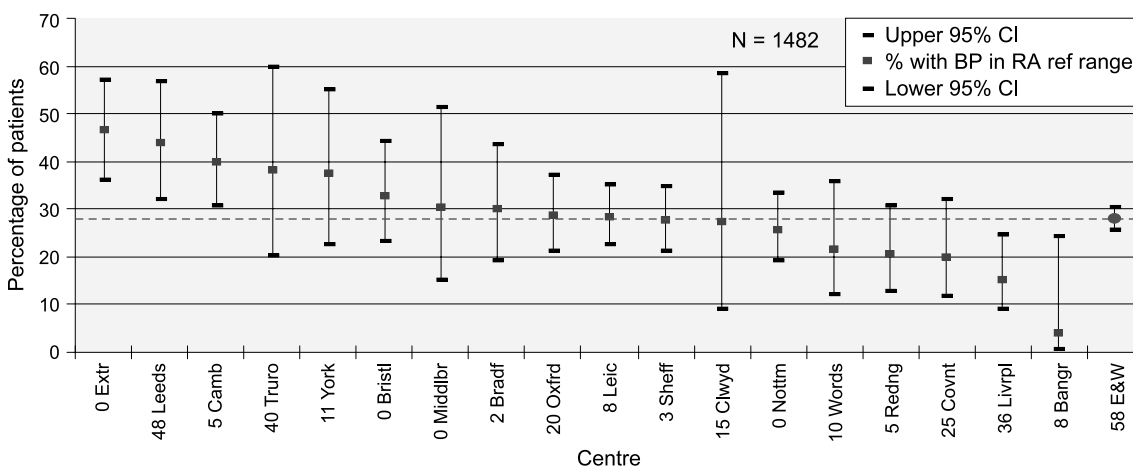


Figure 12.19: Percentage of PD patients achieving the RA BP Standard by centre

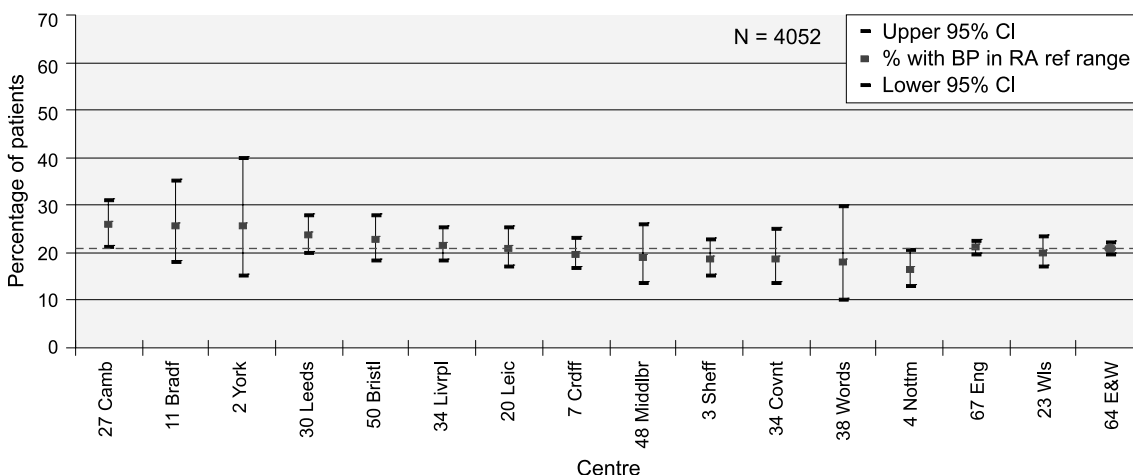


Figure 12.20: Percentage of transplant patients achieving the RA BP Standard by centre

Serum Cholesterol

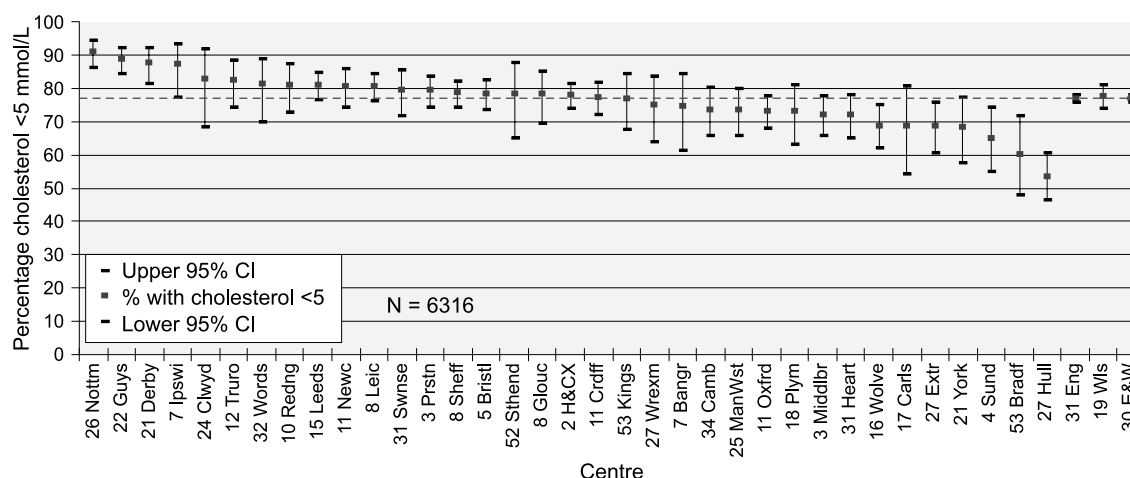


Figure 12.21: Percentage of HD patients achieving the RA cholesterol Standard by centre

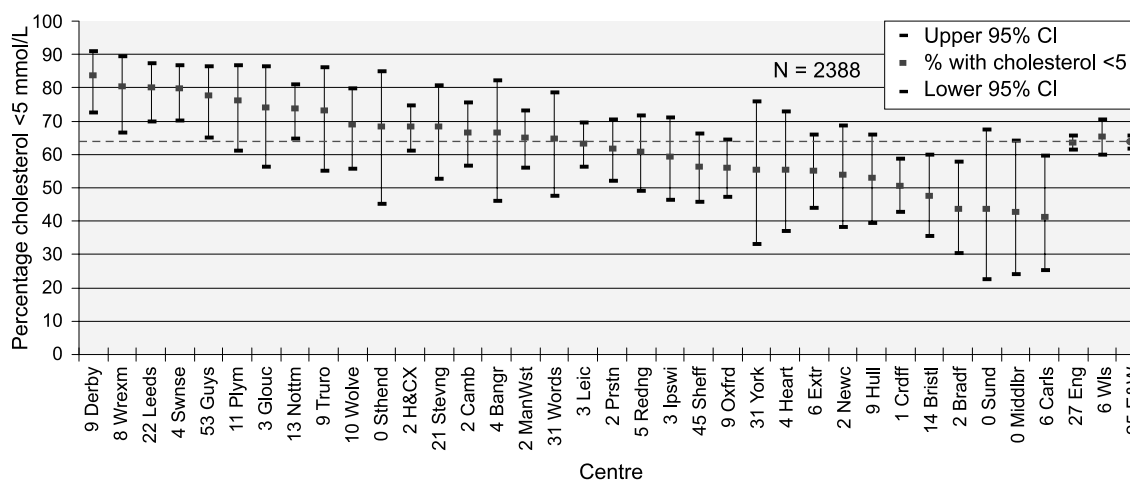


Figure 12.22: Percentage of PD patients achieving the RA cholesterol Standard by centre

Glycated Haemoglobin

Only patients with a primary diagnosis of diabetes as the cause of ERF were included in this analysis. Patients with post transplant diabetes or who developed diabetes post ERF were excluded from the analysis.

As discussed in Chapter 19 of the 2003 Registry Report, all centres except Birmingham Heartlands, Carshalton, Swansea and Wolverhampton use assays that are DCCT aligned.

Of the 45 kidney and pancreas transplants undertaken in the UK in the year, Guys performed 8, Liverpool 5 and Oxford 5. Diabetic patients who have received a pancreas transplant have not been excluded from the transplant analysis and may partially explain the lower HbA1c results seen at Guys & Liverpool.

Guys do not use a steroid sparing regime in transplanted patients so this cannot account for their better HbA1c results.

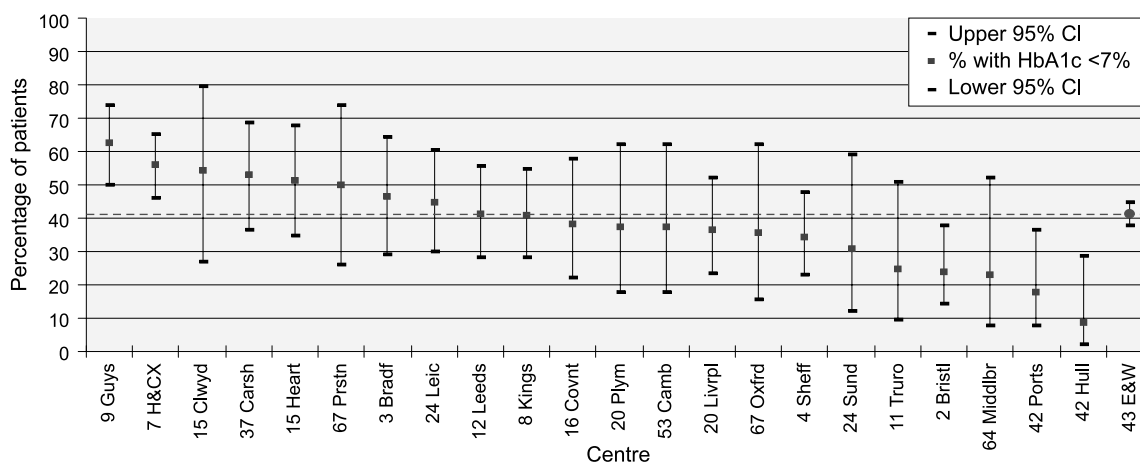


Figure 12.23: Percentage of diabetic HD patients achieving the RA HbA1c Standard by centre

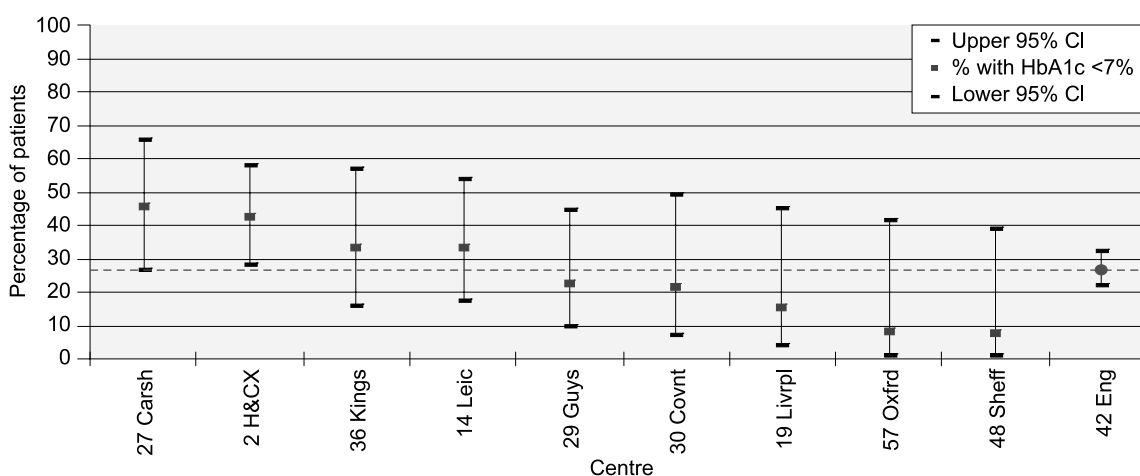


Figure 12.24: Percentage of diabetic PD patients achieving the RA HbA1c Standard by centre

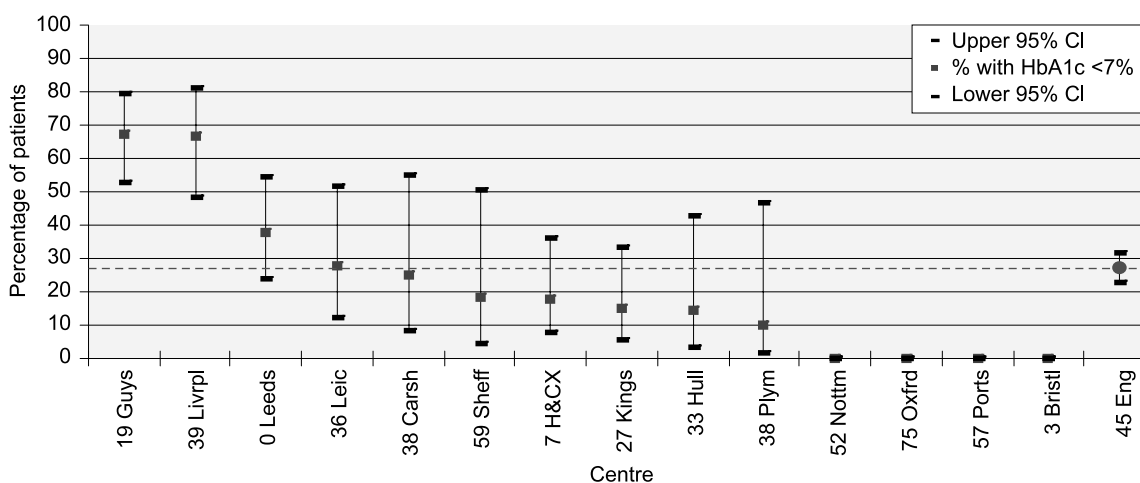


Figure 12.25: Percentage of diabetic transplant patients achieving the RA HbA1c Standard by centre

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 of data (who were included in the analysis) minus 1.

Due to the large number of statistical tests undertaken, significance levels used were $p < 0.01$ level.

Results

Haemoglobin

A chi squared test was used to determine whether the percentage of patients with a haemoglobin level of 10 g/dl or more differed between centres.

For patients on HD, the percentage of patients with a haemoglobin of 10 g/dl or more was found to differ significantly between centres ($\chi^2 = 158.2$, d.f. = 40, $p < 0.001$).

For patients on PD, the percentage of patients with a haemoglobin of 10 g/dl or more was found to differ significantly between centres ($\chi^2 = 73.5$, d.f. = 40, $p < 0.001$).

Ferritin

A chi squared test was used to determine whether the percentage of patients with a ferritin level of 100 mcg/L or more differed between centres.

For patients on HD, the percentage of patients with a ferritin of 100 mcg/L or over was found to differ significantly between centres ($\chi^2 = 422$, d.f. = 40, $p < 0.001$).

For patients on PD, the percentage of patients with a ferritin of 100 mcg/L or over was found to differ significantly between centres ($\chi^2 = 132$, d.f. = 40, $p < 0.001$).

Corrected Calcium

A chi squared test was used to determine whether the percentage of patients with a calcium level of 2.2 to 2.6 mmol/L differed between centres.

For patients on HD, the percentage of patients with a serum calcium of 2.2 to 2.6 mmol/L differed significantly between centres ($\chi^2 = 615$, d.f. = 50, $p < 0.001$).

For patients on PD, the percentage of patients with a serum calcium of 2.2 to 2.6 mmol/L differed significantly between centres ($\chi^2 = 189$, d.f. = 50, $p < 0.001$).

Phosphate

A chi squared test was used to determine whether the percentage of patients with a phosphate level of 1.8 mmol/L or less differed between centres.

For patients on HD, the percentage of patients with a serum phosphate of 1.8 mmol/L or less differed significantly between centres ($\chi^2 = 276$, d.f. = 40, $p < 0.001$).

For patients on PD, the percentage of patients with a serum phosphate of 1.8 mmol/L or less differed significantly between centres ($\chi^2 = 107$, d.f. = 40, $p < 0.001$).

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 ($\chi^2 = 366$, 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 ($\chi^2 = 149$, d.f. = 38, $p < 0.001$).

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 ($\chi^2 = 421$, d.f. = 38, $p < 0.001$).

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 between centres.

For patients on HD, the percentage of patients with a bicarbonate within 20–26 mmol/L differed significantly between centres ($\chi^2 = 219$, 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 ($\chi^2 = 100$, d.f. = 39, $p < 0.001$).

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 ($\chi^2 = 211$, d.f. = 27, $p < 0.001$) and >30 g/L measured by BCP differed significantly between centres ($\chi^2 = 65.4$, d.f. = 12, $p < 0.001$).

For patients on PD, the percentage of patients with a serum albumin ≥ 35 g/L measured by BCG differed significantly between centres ($\chi^2 = 124$, d.f. = 27, $p < 0.001$) and >30 g/L measured by BCP differed significantly between centres ($\chi^2 = 31.7$, d.f. = 12, $p = 0.0015$).

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 $\leq 140/90$ mmHg differed significantly between centres ($\chi^2 = 326$, d.f. = 33, $p < 0.001$).

For patients on PD, the percentage of patients with a blood pressure of $\leq 130/80$ mmHg

differed significantly between centres ($\chi^2 = 84.4$, d.f. = 31, $p < 0.001$).

For patients with a transplant, the percentage of patients with a blood pressure of $\leq 130/80$ mmHg differed significantly between centres ($\chi^2 = 53.2$, d.f. = 31, $p = 0.0079$).

Cholesterol

A chi squared test was used to determine whether the percentage of patients with a serum cholesterol level of 5 mmol/L or less differed between centres.

For patients on HD, the percentage of patients with a serum cholesterol of 5 mmol/L or less differed significantly between centres ($\chi^2 = 179$, d.f. = 39, $p < 0.001$).

For patients on PD, the percentage of patients with a serum cholesterol of 5 mmol/L or less differed significantly between centres ($\chi^2 = 115$, d.f. = 37, $p < 0.001$).

HbA1c

A chi squared test was used to determine whether the percentage of patients with a glycated haemoglobin level of less than 7% differed between centres.

For patients on HD, the percentage of patients with an HbA1c of $<7\%$ differed significantly between centres ($\chi^2 = 68.6$, d.f. = 30, $p < 0.001$).

For patients on PD, the percentage of patients with an HbA1c of $<7\%$ **did not** differ significantly between centres ($\chi^2 = 49.1$, d.f. = 31, $p = 0.0205$).

For patients with a transplant, the percentage of patients with an HbA1c of $<7\%$ differed significantly between centres ($\chi^2 = 137$, d.f. = 33, $p < 0.001$).

Chapter 13: Report of the Paediatric Renal Registry

Summary

Demography

- The growth of the paediatric ERF population has plateaued.
- Fifty percent of patients who presented to paediatric nephrology units and entered ERF had a GFR under 20 ml/min/1.73 m² at the time they were first seen.
- There remains a high incidence and prevalence of ERF in South Asian children.
- This is in part accounted for by an increased incidence of genetic diseases with autosomal recessive inheritance in the South Asian group ($p < 0.0001$).
- The South Asian patients are more likely to be on HD and less likely to have a functioning allograft than White patients.

Analysis of cardiovascular risk factors

- Blood pressure control in the paediatric renal transplant population was sub-optimal.
- A large proportion of the paediatric renal transplant population were overweight or obese.
- Many paediatric renal transplant patients had hyperlipidaemia.
- Longitudinal as well as cross-sectional analysis of the data in these areas suggest that these are real problems that may well have a significant impact upon patient health in the future.
- Blood pressure control in the paediatric dialysis population was sub-optimal.
- Anaemia was poorly controlled in the paediatric dialysis population with 38% remaining anaemic.
- Bone disease was poorly controlled in the paediatric dialysis population with 50%

having raised intact PTH and 36% serum phosphate above the RA Standard.

- Longitudinal as well as cross-sectional analysis of these data support these findings.

Although absolute mortality rate in children with ERF is low compared with adult patients, the presence of cardiovascular risk factors is a cause for concern. Whilst accepting that paediatric RRT patients are difficult to manage, failure to meet standards in these areas is potentially creating major problems in the future for these patients from cardiovascular co-morbidity.

Introduction

Whilst utilising existing renal unit databases in some regions and looking to the installation of new data management tools in others to allow the continuous collection of paediatric data for analysis, the paediatric arm of the Renal Registry continues to collect patient demographics together with annual patient status returns. The aim is to move to continuous data collection as soon as possible.

In this report, the demographics of established renal failure in childhood in the UK are described together with a focus on cardiovascular risk factors in the paediatric ERF population.

Paediatric RRT population

The paediatric arm of the Renal Registry contains data on a total of 1,421 patients. Of these, 869 patients are male and 552 patients are female giving a male to female ratio of 1.57:1. Ninety one of these patients (42 males and 49 females) are known to have died whilst under the care of paediatric units. Others have had their care transferred to adult services. Remaining with the paediatric units in April 2003 were 776 patients (475 males and 301 females, male to female ratio, 1.58:1). This is a fall from a total of 793 patients being cared for in paediatric units in 2002 and is the first time a fall in

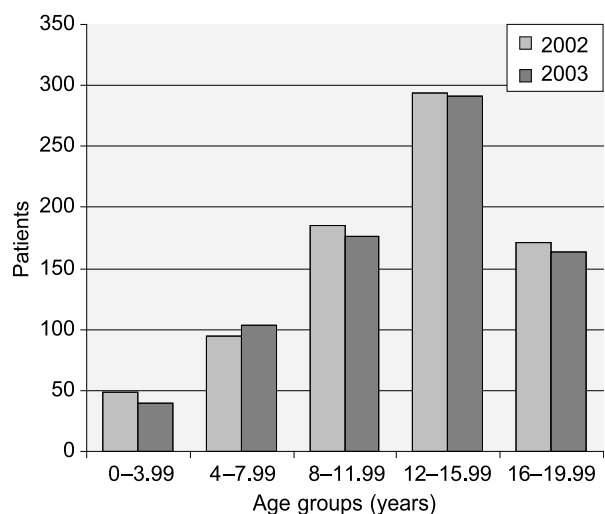


Figure 13.1: Paediatric ERF population in 2002 and 2003 by age group

the prevalent paediatric RRT population has been documented.

Figure 13.1 shows the population for 2002 and 2003 broken down according to age group. It is clear that the fall in numbers is related to small fluxes in each group rather than to a specific trend in one age band. Figure 13.2 shows the numbers of patients under the age of 15 years, allowing comparisons with data collected before the Registry began. Table 13.1 shows this data in greater detail. After a significant rise in the paediatric RRT population from 1986 until the millennium, it now appears to have reached a plateau.

The gender distribution of the population, broken down according to age, is shown in Figure 13.3. As before, it can be seen that males

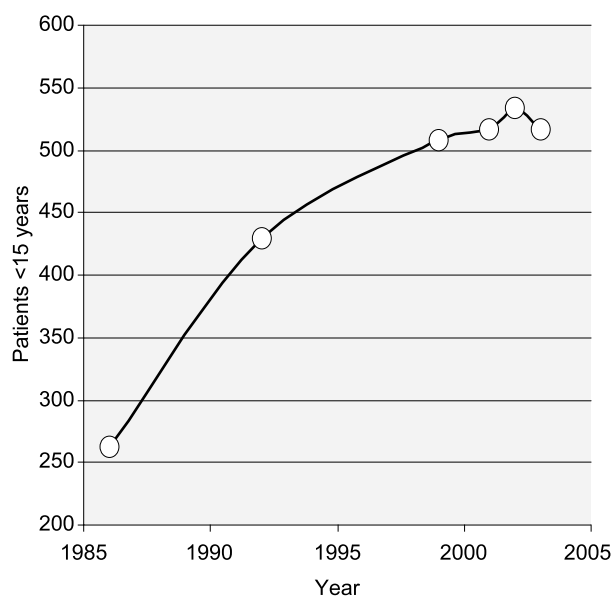


Figure 13.2: ERF patients below the age of 15 years by year of data

Table 13.1: Prevalent ERF population by age and year of data collection

Age group (yrs)	Patient prevalence data					
	1986	1992	1999	2001	2002	2003
0-1.99		16	18	13	14	10
2-4.99		55	46	56	58	56
5-9.99		150	151	146	147	141
10-14.99		208	293	301	315	310
15-19.99			253	274	259	256
Total <15	263	429	508	516	534	517
Total <20			761	790	793	773

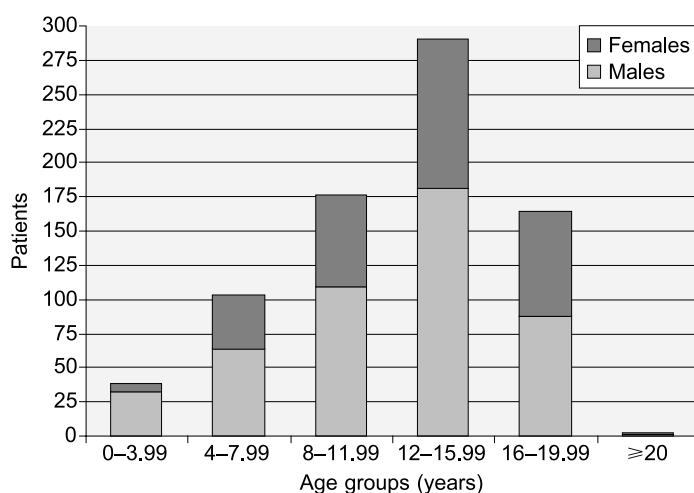


Figure 13.3: Paediatric ERF population by age and gender

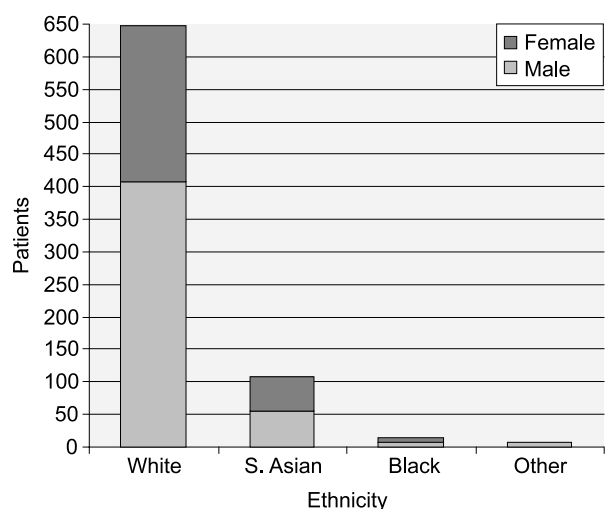


Figure 13.4: Paediatric ERF population by ethnicity and gender

predominate in the first 4 years of life and thereafter the proportion of females increases steadily but never exceeds 50%. The explanation for the gender distribution lies with the distribution of diagnoses and this is discussed below.

Figure 13.4 shows the patient distribution according to ethnicity, broken down by gender,

whilst Figure 13.5 shows the distribution according to age, broken down by ethnicity. As expected, the vast majority of patients are White and a significant minority are South Asian. The proportion of South Asians exceeds their proportion in the general population and as will be demonstrated below, this relates to a higher incidence of specific inherited diseases that cause renal failure. Another effect of this is that the gender distribution of the South Asian population is different to that of the White population with almost 50% of South Asian patients in ERF being female, whilst a little over a third of White patients are female.

Prevalence and take-on rate

The prevalence of ERF amongst children in the UK is shown in Table 13.2. Within this table, the prevalence is broken down into four age-bands between birth and 16 years of age as well as showing the total prevalence in under 16 year olds and that in the UK population as a whole. It is clear that the prevalence rises

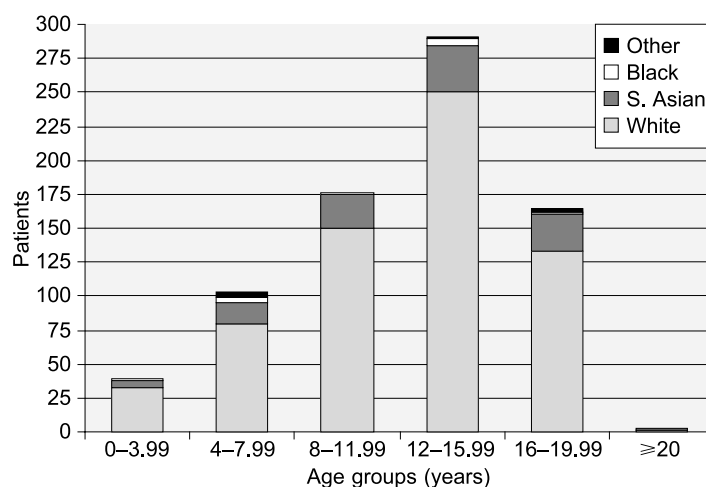


Figure 13.5: Paediatric ERF population by age and ethnicity

Table 13.2: Prevalence of ERF in the paediatric population

Age Group (yrs)	Prevalence (pmp)		
	Males	Females	Total
0-3.99	22.7	5.2	14.2
4-7.99	42.6	27.3	35.2
8-11.99	68.5	44.2	56.6
12-15.99	114.7	73.3	94.5
< 16	63.5	38.5	51.3
UK pop	13.5	7.4	10.4

Figures are pmp in each age band and per million total UK population

steadily throughout childhood. This is in part secondary to an increased take-on rate in later childhood (see below) but mainly secondary to the survival of patients with ERF throughout childhood.

Figure 13.6 shows the prevalence of RRT in the UK childhood population broken down according to ethnicity. Even taking into account the higher proportion of young people within the ethnic minority groups, the prevalence of RRT in the South Asian population is significantly greater than that of the White population, being a little over twice that of the White population. The prevalence of RRT in the Black population seems to be lower than that of the White population, but with the small numbers involved this does not reach statistical significance.

To calculate the take-on rate, the average of the number of children starting ERF treatment since data collection began 7 years ago, has been used. This allows for a more accurate calculation of take-on rate bearing in mind year-on-year fluctuations that can occur. Table 13.3 shows the take-on rate for each year from 1996 onwards. Although there are small fluctuations,

Table 13.3: Incidence rate for children age < 16 years, by year and gender

	1996	1997	1998	1999	2000	2001	2002	Total	Average
Male	47	64	66	47	50	73	51	398	56.9
Female	36	36	45	47	53	42	37	296	42.3

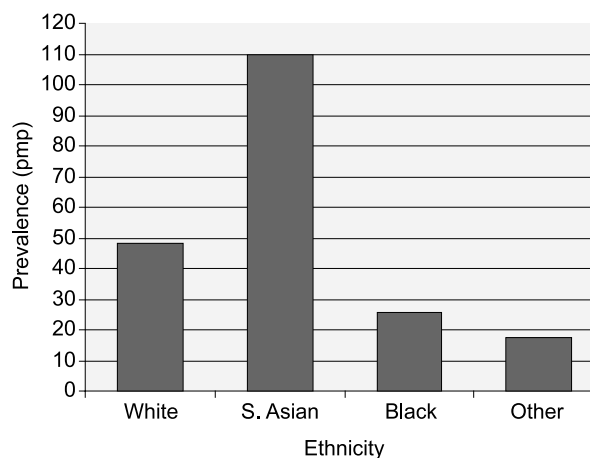


Figure 13.6: Prevalence of ERF in children by ethnicity

there are no trends for either the total number of children starting RRT or any one gender.

Table 13.4 shows the take-on rate for the UK population, broken down according to age-groups between birth and 16 years of age. As has been demonstrated in previous reports, the peak take-on rate is in young people between the ages of 12 and 16 years.

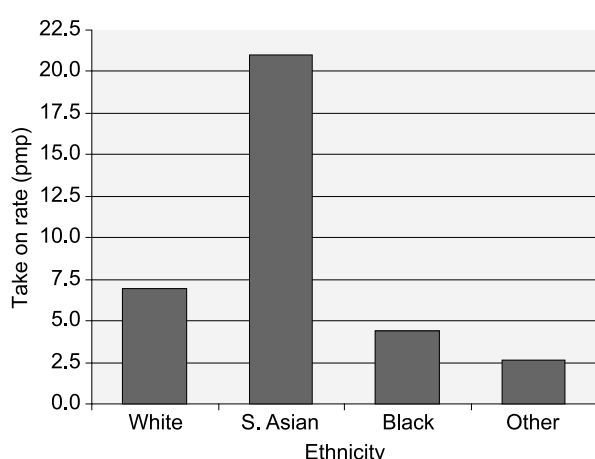
The take-on rate in the first 4 years of life, courtesy of the significant number of children with congenital diseases, is similar to that of children between the ages of 8 and 12 years, whilst there is a fall in presentation in ERF between the ages of 4 and 8 years. The number presenting with congenital diseases falls with age whilst the peak uptake for those with acquired diseases is in the older age group.

Figure 13.7 shows the average take-on rate of patients with ERF broken down according to ethnicity. Again, despite the high proportion of children in the South Asian population as a whole, the take-on rate per million of the childhood population in South Asians is a little over 3 times that of the White population.

Table 13.4: Take-on rate for children age < 16 years at start of RRT

Age group (yrs)	Take on rate (pmp)		
	Male	Female	Total
0–3.99	9.5	5.7	7.7
4–7.99	4.9	3.7	4.3
8–11.99	7.9	6.8	7.4
12–15.99	11.7	10.5	11.1
< 16	8.5	6.7	7.7
UK pop	1.8	1.3	1.5

Figures are per million childhood population in each age band and per million total UK population

**Figure 13.7: Take-on rate of children with ERF by ethnicity**

Causes of ERF in childhood

The primary cause of ERF was given for 1,303 of the 1,421 patients registered (91.7%). The diagnoses are listed alphabetically in Table 13.5 and the distribution of these diagnoses is not different to previous assessments. This distribution of diagnoses does not represent the true distribution in an unselected population. The causes of renal failure in children vary with age. Those patients presenting young are over represented since patients presenting under the age of 5 years will have at least a decade with paediatric services whilst patients presenting as teenagers are transferred to adult services within 5 years. To investigate this, we have compared the diagnostic distribution of patients starting RRT from 1996 until 2003 with those who started RRT before 1996. This is shown in Figure 13.8.

For the more recent patients, there is a lower prevalence of renal dysplasia and obstructive uropathy and a higher prevalence of glomerular diseases, reflux nephropathy, tubular and metabolic diseases. Similarly, there is an increase in the prevalence of patients with chronic renal failure of uncertain aetiology, a diagnosis that tends to be made in older rather than younger children. The difference between the distribu-

Table 13.5: ERF diagnosis for 1303 patients on the paediatric RRT Registry

Diagnosis	Male	Female	Total	% Total
Acquired obstructive uropathy	3	0	3	0.2
Alport's syndrome	15	4	19	1.5
Anti-GBM disease	0	5	5	0.4
Autosomal recessive PKD	14	15	29	2.2
Bartter's syndrome	2	1	3	0.2
Branchio-oto-renal syndrome	5	2	7	0.5
Chronic renal failure – uncertain aetiology	12	14	26	2.0
Cis-platinum nephrotoxicity	1	0	1	0.1
Congenital nephrotic syndrome (DMS)	8	2	10	0.8
Congenital nephrotic syndrome (Finnish)	14	14	28	2.1
Congenital nephrotic syndrome (FSGS)	4	7	11	0.8
Congenital nephrotic syndrome (unspecified)	8	23	31	2.4
Congenital obstructive uropathy – bladder outlet obstruction (not PUV)	11	6	17	1.3
Congenital obstructive uropathy (not bladder outlet obstruction)	11	5	16	1.2
Congenital obstructive uropathy – Posterior urethral valves	180	0	180	13.8
Cortical necrosis	13	11	24	1.8
Crescentic glomerulonephritis	5	6	11	0.8
Cyclosporin nephrotoxicity	9	3	12	0.9

Table 13.5: (continued)

Diagnosis	Male	Female	Total	% Total
Cystinosis	29	22	51	3.9
Diarrhoea positive haemolytic uraemic syndrome	14	22	36	2.8
Diarrhoea negative haemolytic uraemic syndrome	3	6	9	0.7
Drug nephrotoxicity (unspecified)	0	1	1	0.1
Glomerulonephritis (unspecified)	6	6	12	0.9
Henoch Schoenlein nephritis	10	13	23	1.8
IgA nephropathy	3	5	8	0.6
Lawrence Moon Biedl syndrome	2	3	5	0.4
Megacystis megaureter	3	0	3	0.2
Membranous nephropathy	0	1	1	0.1
Mesangio-capillary glomerulonephritis Type 1	7	3	10	0.8
Mesangio-capillary glomerulonephritis Type 2	2	6	8	0.6
Mesoblastic nephroma	1	0	1	0.1
Metabolic diseases (other)	3	0	3	0.2
Microscopic polyarteritis nodosa	1	2	3	0.2
Mitochondrial cytopathy	1	1	2	0.2
Multicystic dysplastic kidneys	9	6	15	1.2
Nephrocalcinosis	0	1	1	0.1
Nephronophthisis	33	32	65	5.0
Neuropathic bladder	9	13	22	1.7
Other cytotoxic drug nephrotoxicity	2	3	5	0.4
Polycystic kidney disease (other)	4	4	8	0.6
Primary focal segmental glomerulo-sclerosis	48	52	100	7.7
Primary hyperoxaluria type 1	4	3	7	0.5
Primary interstitial nephritis	8	5	13	1.0
Proliferative glomerulonephritis	3	4	7	0.5
Prune belly syndrome	22	0	22	1.7
Reflux nephropathy	45	49	94	7.2
Renal artery stenosis	3	1	4	0.3
Renal artery thrombosis	1	1	2	0.2
Renal dysplasia	173	84	257	19.7
Renal hypoplasia	8	13	21	1.6
Renal trauma	1	1	2	0.2
Renal tubular acidosis	3	0	3	0.2
Renal vein thrombosis	9	4	13	1.0
Systemic lupus erythematosus	1	4	5	0.4
Tuberous sclerosis PKD	0	1	1	0.1
Tubular disorders (other)	1	1	2	0.2
Vasculitis (unspecified)	0	3	3	0.2
Wegner's granulomatosis	1	1	2	0.2
Wilms' nephropathy	3	1	4	0.3
Wilms' tumour	8	8	16	1.2
Total	799	504	1,303	100.0

tion of diseases in the two patient groups was significant ($\chi^2 = 30.76$, $p = 0.0006$).

Over the period from 1996–2003, 694 patients were registered, of whom 677 (97.6%) had a primary cause of ERF noted. The return rate

for the recording of ERF diagnosis from the various units in the UK is detailed in Table 13.6.

With the relatively large number of patients now registered from the time of their commencement of ERF treatment, it has been

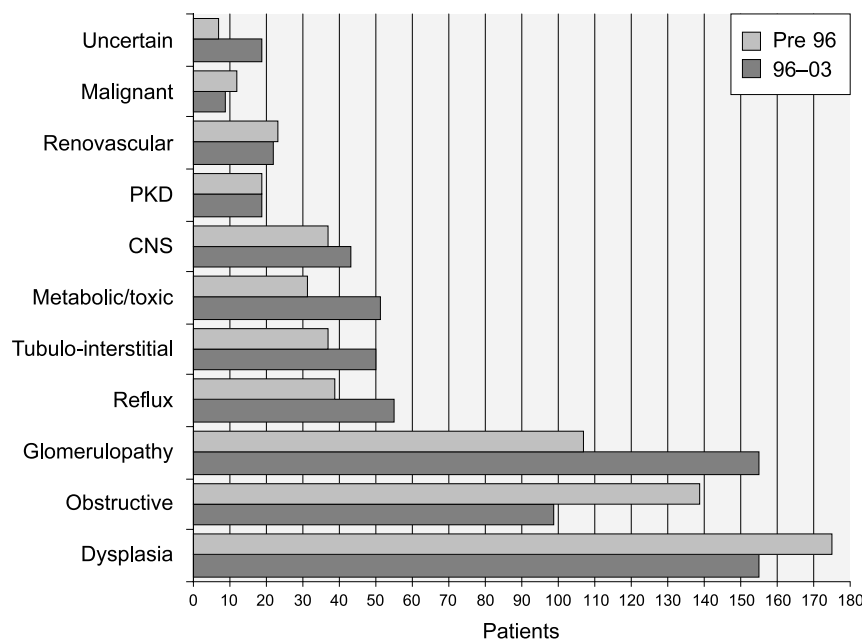


Figure 13.8: Distribution of ERF diagnoses for those starting RRT before and after 1996

possible to create a table giving an accurate breakdown of the frequency of different diagnoses. These are shown in a grouped fashion in Table 13.7. Renal dysplasia and glomerular diseases rank evenly as the major causes of ERF in children in the UK at present, these are followed by obstructive uropathy and then reflux nephropathy.

Malignancies, reno-vascular disease, metabolic disease, polycystic disease and congenital nephrotic syndrome tend to present early in

childhood. Dysplasia and obstructive uropathy, although congenital diseases, present with ERF throughout childhood. Glomerular diseases, reflux nephropathy, tubular diseases and chronic renal failure of uncertain aetiology present with ERF later in childhood. Again, the differences in the distributions of diagnosis with age at ERF commencement was highly significant ($\chi^2 = 107.4$, $p < 0.0001$).

Table 13.6: Data return rate for ERF diagnosis, by centre

Centre	ERF diagnosis data		
	Patients	Data available	% Return
Guys	82	82	100.0
Manchester	79	79	100.0
Bristol	58	58	100.0
Belfast	21	21	100.0
Nottingham	82	81	98.8
Leeds	65	64	98.5
Newcastle	38	37	97.4
Liverpool	32	31	96.9
Southampton	30	29	96.7
Birmingham	63	60	95.2
Glasgow	34	32	94.1
Cardiff	17	16	94.1
GOSH	93	87	93.5

One feature noted in the last report was the increased incidence of some inherited diseases in patients from the South Asian subcontinent. It was felt that the increased incidence of these conditions in the South Asian population would in part explain the increased prevalence and take-on rate of members of this ethnic group. To look at this further, all the diagnoses have been classified into those with recessive, dominant, sex-linked or no definite hereditary pattern. Diseases that sometimes, but not always, follow a hereditary pattern (eg reflux nephropathy) were classified as having no definite hereditary pattern. The result of comparing recessive disorders with other disorders, broken down according to ethnicity, is shown in Figure 13.9. It can be seen that autosomal recessive diseases are more than twice as common as the cause of RRT in the South Asian population than the White population. This difference was highly significant ($p < 0.0001$, Fisher's exact test).

Table 13.7: Grouped ERF diagnoses

Diagnosis	Male	Female	Total	% Group	% Total
Renal dysplasia and related conditions					
Renal dysplasia	79	44	123	79.4	18.2
Multicystic dysplastic kidneys	5	5	10	6.5	1.5
Prune belly syndrome	8	0	8	5.2	1.2
Renal hypoplasia	4	2	6	3.9	0.9
Branchio-oto-renal syndrome	3	0	3	1.9	0.4
Lawrence Moon Biedl syndrome	1	2	3	1.9	0.4
Megacystis megaureter	2	0	2	1.3	0.3
Total with primary renal dysplasia	102	53	155	100.0	22.9
Obstructive uropathy					
Posterior urethral valves	69	0	69	69.7	10.2
Congenital obstructive uropathy (not BOO)	4	3	7	7.1	1.0
Neuropathic bladder	3	9	12	12.1	1.8
Congenital bladder outlet obstruction (not PUV)	7	2	9	9.1	1.3
Acquired obstructive uropathy	2	0	2	2.0	0.3
Total with obstructive uropathy	85	14	99	100.0	14.6
Glomerulonephritis, vasculitis and glomerulopathy					
Primary focal segmental glomerulo-sclerosis	29	32	61	39.4	9.0
Diarrhoea positive haemolytic uraemic syndrome	9	9	18	11.6	2.7
Henoch Schoenlein nephritis	4	8	12	7.7	1.8
Glomerulonephritis (unspecified)	6	4	10	6.5	1.5
Alport's syndrome	7	1	8	5.2	1.2
Crescentic glomerulonephritis	3	4	7	4.5	1.0
IgA nephropathy	3	4	7	4.5	1.0
Diarrhoea negative haemolytic uraemic syndrome	1	5	6	3.9	0.9
Mesangio-capillary glomerulonephritis Type 1	2	3	5	3.2	0.7
Proliferative glomerulonephritis	2	3	5	3.2	0.7
Mesangio-capillary glomerulonephritis Type 2	0	4	4	2.6	0.6
Systemic lupus erythematosus	1	3	4	2.6	0.6
Microscopic polyarteritis nodosa	1	2	3	1.9	0.4
Anti-GBM disease	0	2	2	1.3	0.3
Wegner's granulomatosis	1	1	2	1.3	0.3
Vasculitis (unspecified)	0	1	1	0.6	0.1
Membranous nephropathy	0	0	0	0.0	0.0
Total with glomerular disease	69	86	155	100.0	22.9
Reflux nephropathy and CRF of uncertain aetiology					
Reflux nephropathy	28	27	55	74.3	8.1
Chronic renal failure – uncertain aetiology	9	10	19	25.7	2.8
Total with reflux nephropathy and CRF of uncertain aetiology	37	37	74	100.0	10.9
Primary tubular and interstitial disorders					
Nephronophthisis	19	20	39	78.0	5.8
Primary interstitial nephritis	4	2	6	12.0	0.9
Bartter's syndrome	1	1	2	4.0	0.3
Renal tubular acidosis	1	0	1	2.0	0.1
Nephrocalcinosis	0	1	1	2.0	0.1
Tubular disorders (other)	1	0	1	2.0	0.1
Total with primary tubular and interstitial disorders	26	24	50	100.0	7.4

Table 13.7: (continued)

	Male	Female	Total	% Group	% Total
Congenital nephrotic syndrome					
Congenital nephrotic syndrome (Finnish)	7	8	15	34.9	2.2
Congenital nephrotic syndrome (unspecified)	3	11	14	32.6	2.1
Congenital nephrotic syndrome (FSGS)	3	6	9	20.9	1.3
Congenital nephrotic syndrome (DMS)	4	1	5	11.6	0.7
Total with congenital nephrotic syndrome	17	26	43	100.0	6.4
Renal vascular disorders					
Cortical necrosis	7	5	12	54.5	1.8
Renal vein thrombosis	5	1	6	27.3	0.9
Renal artery stenosis	1	1	2	9.1	0.3
Renal trauma	1	1	2	9.1	0.3
Renal artery thrombosis	0	0	0	0.0	0.0
Total with renal vascular disorders	14	8	22	100.0	3.2
Metabolic diseases and drug nephrotoxicity					
Cystinosis	16	13	29	56.9	4.3
Cyclosporin nephrotoxicity	9	3	12	23.5	1.8
Primary hyperoxaluria type 1	2	1	3	5.9	0.4
Other cytotoxic drug nephrotoxicity	2	2	4	7.8	0.6
Metabolic diseases (other)	1	0	1	2.0	0.1
Mitochondrial cytopathy	1	1	2	3.9	0.3
Cis-platinum nephrotoxicity	0	0	0	0.0	0.0
Drug nephrotoxicity (unspecified)	0	0	0	0.0	0.0
Total with metabolic diseases and drug nephrotoxicity	31	20	51	100.0	7.5
Polycystic kidney disease (PKD)					
Autosomal recessive PKD	3	11	14	73.7	2.1
Polycystic kidney disease (other)	2	2	4	21.1	0.6
Tuberous sclerosis PKD	0	1	1	5.3	0.1
Total with PKD	5	14	19	100.0	2.8
Malignant and related diseases					
Wilms' tumour	3	4	7	77.8	1.0
Wilms' nephropathy	2	0	2	22.2	0.3
Mesoblastic nephroma	0	0	0	0.0	0.0
Total with malignant and related diseases	5	4	9	100.0	1.3

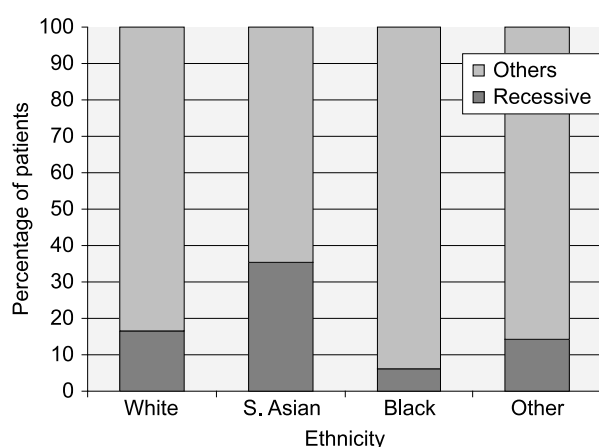


Figure 13.9: Recessive versus other diseases causing ERF by ethnicity

Presentation of patients to nephrology services

Data on the presentation of patients to renal services is important to determine the effectiveness of local referral networks in the early detection and treatment of disease, allowing the prevention of, or a delay in the onset of ERF. Currently, only a small data set around the time of presentation is collected. This data set consists of the date the patient was first seen by a paediatric nephrologist and the patients' height, weight and serum creatinine at that time. Early reports showed that the collection of this data was incomplete. Unfortunately,

Table 13.8: Return rate for presentation data by centre

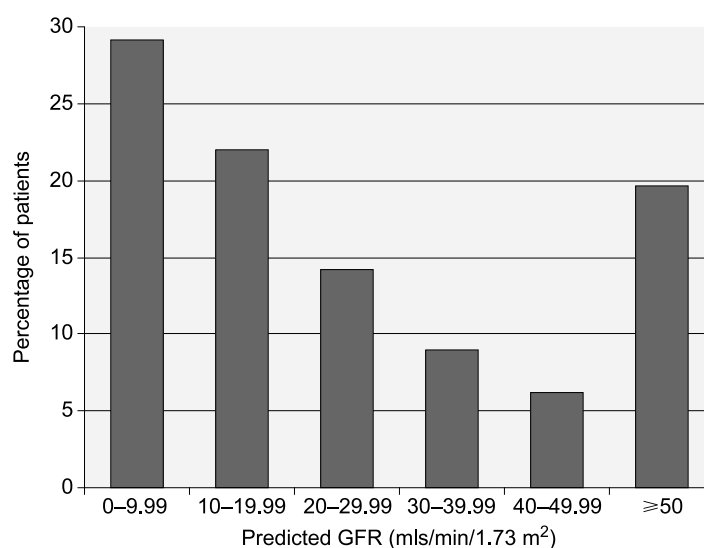
Centre	Patients	Complete data	% Complete return	Partial data	% Data return
Cardiff	17	17	100	0	100
Nottingham	82	74	90	5	96
Manchester	79	67	89	6	92
Newcastle	38	33	87	2	92
Bristol	58	49	85	4	91
Leeds	65	53	82	8	94
Belfast	21	16	76	4	95
Southampton	30	21	70	2	77
Guys	82	54	66	14	83
Birmingham	63	38	60	13	81
GOSH	93	55	59	20	81
Glasgow	34	19	56	7	77
Liverpool	32	16	50	12	88

even with prospective data collection the return for this data set is not as high as desired. Table 13.8 shows the return rate for presentation data for patients starting ERF treatment after 1st April 2003. A complete return indicates the return of date, height, weight and creatinine. Recognising that it is sometimes difficult to record all parameters (eg newborns, patients seen in district clinics where at the time, there is no indication to check a creatinine) partial returns were also recorded which include the date and any one of the other three parameters.

An estimate of predicted GFR from the height and serum creatinine ($k \times \text{Ht}/\text{Creat}$), using a constant of 40 at all ages, was available in 515 of the 694 patients (74%). These GFRs are demonstrated graphically in Figure 13.10. With 29% of patients having a predicted GFR

under $10 \text{ ml/min/1.73 m}^2$ and 21% having a predicted GFR of 10 to $20 \text{ ml/min/1.73 m}^2$, there is little opportunity for intervention in 50% of patients. In addition, a few of those with high predicted GFRs will have conditions such as malignancy or congenital nephrotic syndrome where early bilateral nephrectomy is planned. Earlier referral of patients, when renal impairment is mild or moderate, affords greater opportunities for secondary prevention (eg intensive feeding, growth hormone, erythropoietin, control of osteodystrophy, ACE inhibitors or angiotensin receptor blockers).

Data on height at presentation was available in 517 of the 645 patients presenting under the age of 16 years (80.2%). Height standard deviation score (SDS) at presentation is shown as a box and whisker plot (showing median,

**Figure 13.10: Predicted GFR at presentation to nephrology services**

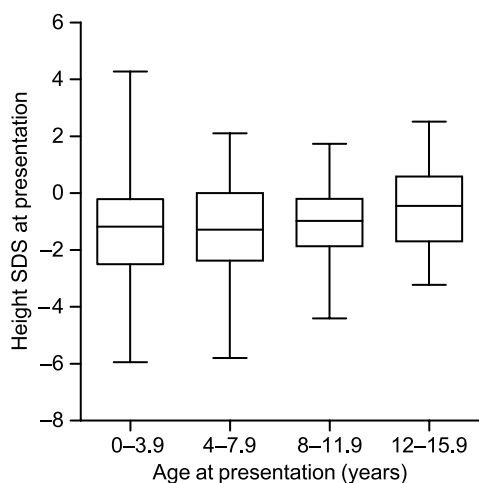


Figure 13.11: Predicted GFR at start of RRT
This includes peri-operative results on patients undergoing bilateral nephrectomy

inter-quartile range and range) in Figure 13.11. Non-parametric statistics have been used, as particularly in neonates, small errors in height measurement can lead to large changes in SDS. It is clear that the median height is below average in all groups. There is a trend for height SDS to increase with age of presentation (Kruskal–Wallis test, $p = 0.0013$).

Data on height SDS at presentation was available for 522 of 677 patients (77.1%). Median height varied significantly with the cause of ERF (Kruskal–Wallis test, $p < 0.0001$). Height SDS was lowest in patients with metabolic diseases such as cystinosis, whereas those presenting with a glomerulopathy had a distribution of heights more comparable with that of the general population (Figure 13.12).

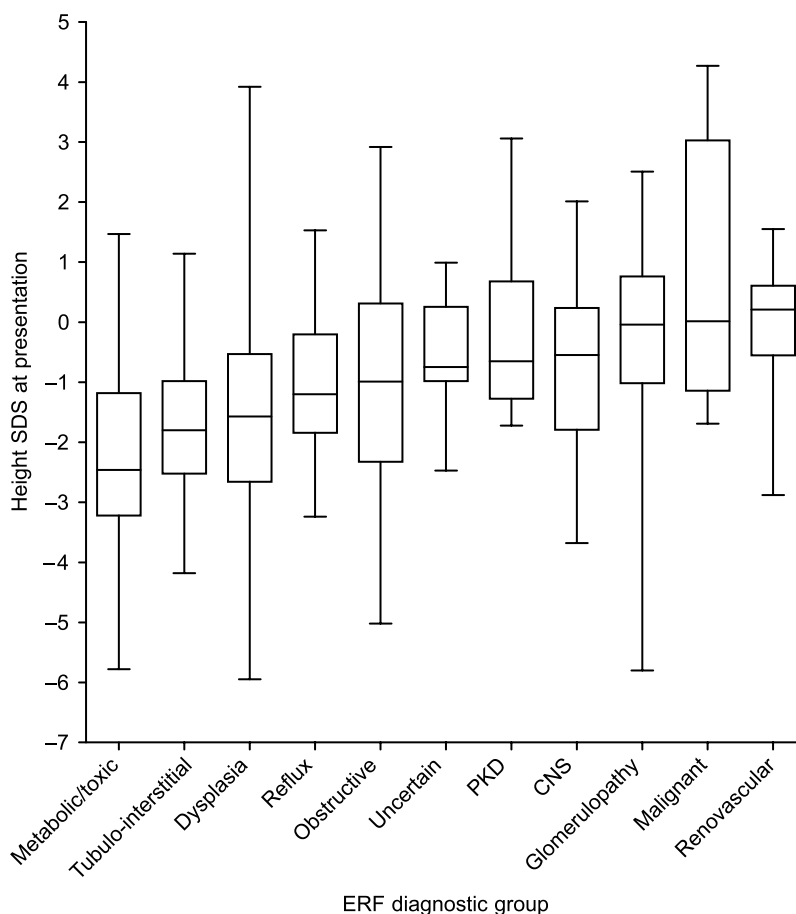


Figure 13.12: Height SDS at presentation by ERF diagnosis

eGFR, height and modality at commencement of RRT

In addition to diagnosis, which is dealt with above, the data set collected at the commencement of ERF treatment includes the date of commencement of therapy plus the patients' height, weight and creatinine at that time. Also required is the treatment modality being used 90 days after the commencement of ERF treatment. As with presentation data there are many reasons why complete data sets are not available and this particularly is the case where neonates are starting treatment. Data return rates from the different UK centres are detailed in Table 13.9.

Predicted GFR at the commencement of ERF treatment (calculated as detailed above) was available for 608 of the 694 patients (87.6%). These data are shown in Figure 13.13. As expected, the vast majority of patients have very poor renal function with a predicted GFR under 10mls/min/1.73m² in 61%. A further 34% have a predicted GFR between 10 and 20mls/min/1.73m². A small number of patients who started treatment at the time of bilateral nephrectomy for malignant or severe protein-losing conditions account for those with a higher predicted GFR.

Data on height at the commencement of ERF treatment were available for 562 of 636

Table 13.9: Return rate for ERF start data by centre

Centre	Patients	Data available	% Return
Nottingham	82	78	95
Cardiff	17	16	94
Newcastle	38	35	92
Belfast	21	19	91
Manchester	79	71	90
Leeds	65	58	89
Guys	82	71	87
Birmingham	63	53	84
Bristol	58	45	78
Liverpool	32	24	75
Southampton	30	22	73
GOSH	93	68	73
Glasgow	34	22	65

patients (88.4%) under the age of 16 years when they started treatment. These data have been subdivided by age of commencement of treatment and are presented in Figure 13.14. As with the data on presentation to nephrology services, overall height at the commencement of ERF management is below average. Median height SDS is lowest in the youngest age-group and there is a significant rise in median height SDS with increasing age at commencement of treatment (Kruskal–Wallis test, p < 0.0001).

Data on height SDS at presentation and ERF diagnosis were available for 612 patients. Again there was significant variation in median height

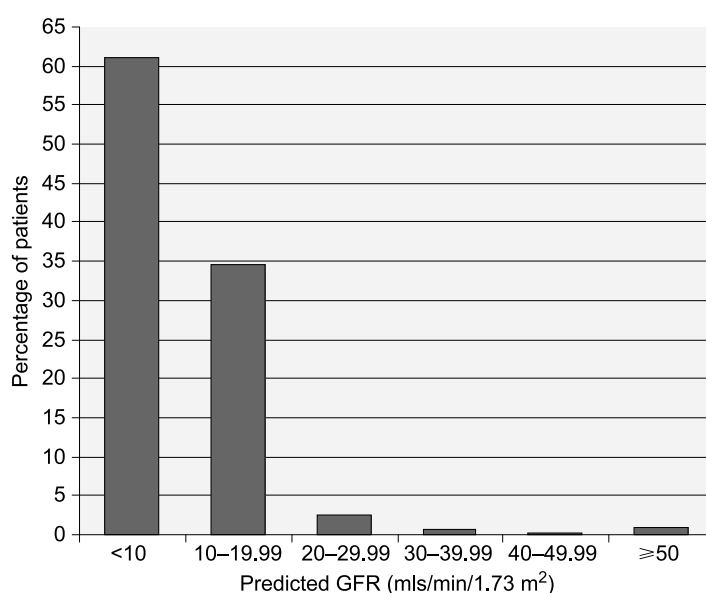


Figure 13.13: Predicted GFR at commencement of RRT
This includes peri-operative results on patients undergoing bilateral nephrectomy

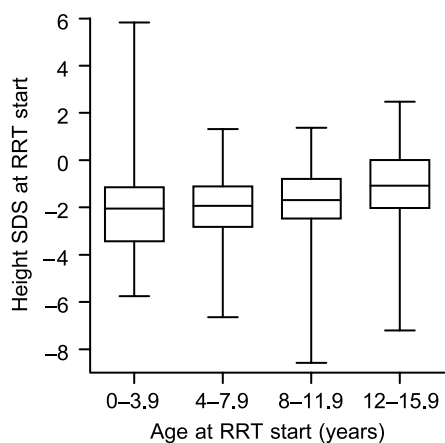


Figure 13.14: Height SDS at start of RRT by age

SDS according to diagnostic group with those groups associated with later and more acute onset disease being associated with better height at the commencement of ERF treatment (Kruskal–Wallis test, $p < 0.0001$) (Figure 13.15).

Recognising that growth is a problem in patients with chronic renal failure, it is important to assess not just the actual height SDS of patients at commencement of treatment but also the change in height SDS from presentation to ERF. Clearly, to make this assessment a reasonable period of time between presentation and ERF is required and so for this analysis only those members of the cohort of 694 patients presenting after April 1996 who came to nephrology services one or more years before the commencement of ERF treatment were

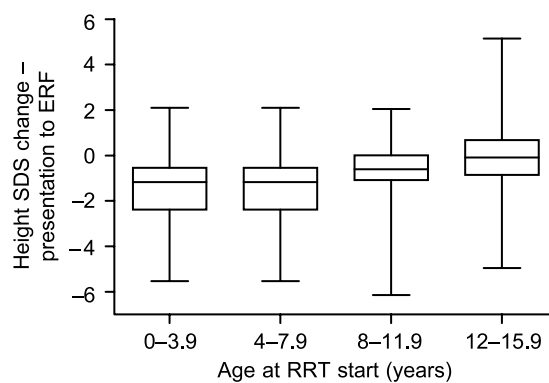


Figure 13.16: Change in height SDS from presentation to ERF by age at commencement of RRT

considered. Data on height, both at presentation and ERF commencement, were present in 252 of 351 patients (71.8%) who met the above criteria and who were under 16 years of age at the start of ERF treatment.

Figure 13.16 shows the change in height SDS divided according to the age of ERF treatment commencement. The overall tendency was for patients to fall behind with their growth between presentation and ERF. This was worse in those starting ERF treatment in the first 8 years of life. However, the median height change was a loss of just over 1.1 standard deviations in these patients. For those starting ERF treatment between 12 and 16 years the median height loss was 0.1 standard deviations. Pubertal staging and bone age data were not

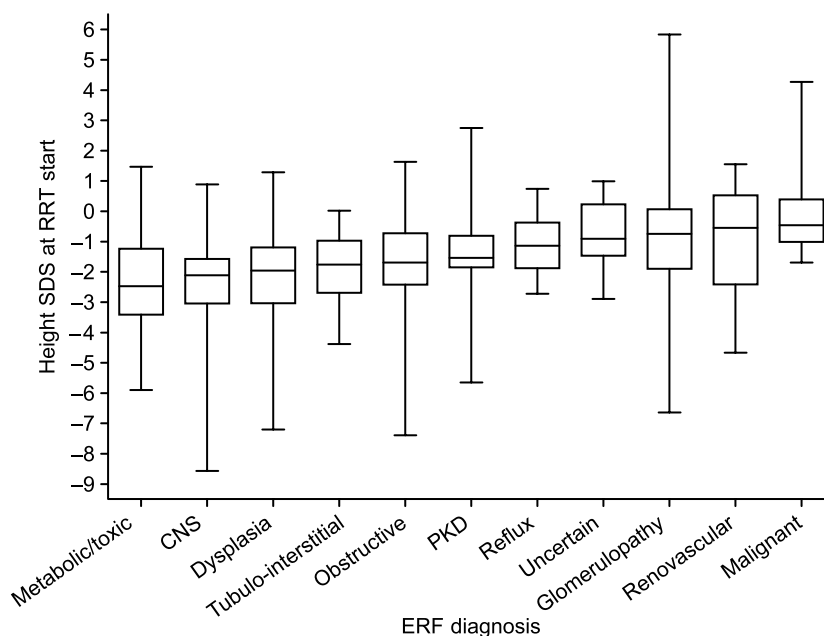


Figure 13.15: Height SDS at start of RRT by diagnosis

available for this analysis. The variation in the median height standard deviation change between age groups was significant (Kruskal-Wallis test, $p < 0.0001$).

Looking at the change in height SDS from presentation to ERF treatment starting, broken down according to the cause of renal failure, data was available for 266 patients. Of these, 5 patients were omitted as they were split between three diagnostic groups with a maximum of two in any one group. For the remaining 261 patients the change in height SDS is shown in Figure 13.17. It is interesting to note that patients with congenital nephrotic syndrome fared the worst with a median height loss of 1.24 standard deviations. The next worst group were those with a glomerulopathy who had a median height loss of 0.8 standard deviations. The other groups demonstrated little height loss. Of particular note are patients with metabolic disorders (the majority of whom have cystinosis) and tubulo-interstitial disorders (most of whom have nephronophthisis). Although these patients are generally small there was certainly no major loss of height as they progressed to RRT.

Data on treatment 90 days after entering an RRT programme were available for 667 of the 694 patients (96.1%). The most common treatment was peritoneal dialysis with 52% of the cohort being started on this. The majority of

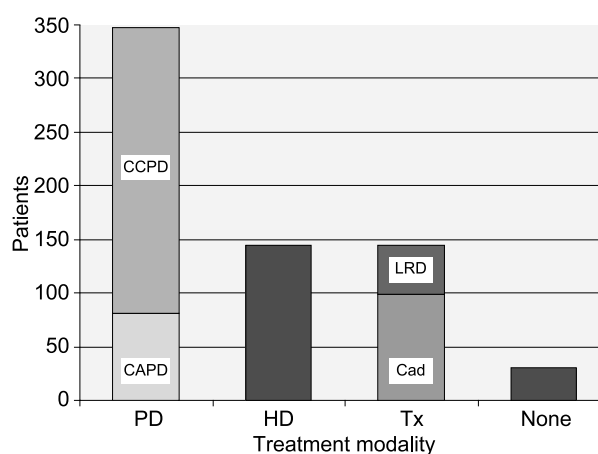


Figure 13.18: Distribution of RRT modalities at day 90

these patients were managed with cycling peritoneal dialysis whilst 20% were started on CAPD. Roughly equal numbers of patients were on haemodialysis or had received a transplant. Of the transplanted patients two thirds had received a cadaveric allograft and one third a graft from a living donor. Overall, 21% of patients had received a transplant by day 90. Approximately 95% of these were pre-emptive grafts but some will simply have been people fortunate enough to receive a graft within a short time of starting dialysis. Thirty one patients were on no treatment on day 90. These were patients who had problems with dialysis access or management and who were being managed conservatively on that particular day (Figure 13.18).

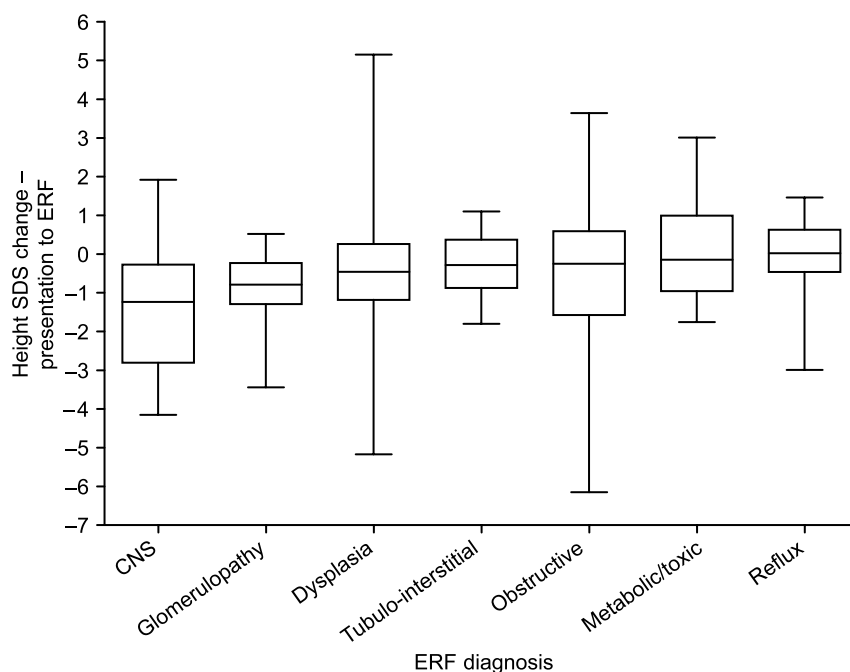


Figure 13.17: Change in height SDS from presentation to ERF by diagnosis

Current renal replacement therapy modality

Most units managed to supply a complete data set with regard to basic patient treatment in April 2003, though some units did have problems with data collection and return (Table 13.10). As a result, the treatment modality was known for 743 of 776 patients (95.7%). The distribution of treatments is shown in Figure 13.19. The vast majority of patients (76.9%) were living with a functioning allograft. Of these just over one fifth had an organ from a living donor and the remainder had cadaveric grafts. For the 173 patients on dialysis, 107 were on peritoneal dialysis and of these just 17 were on CAPD, the rest being treated with automated cycling dialysis. Sixty six patients were on hospital based haemodialysis.

There were significant differences between the South Asian and White patients with regard to current treatment modality. A greater proportion of the South Asian group were on dialysis rather than having a transplant ($p = 0.0027$). Of those on dialysis significantly more South

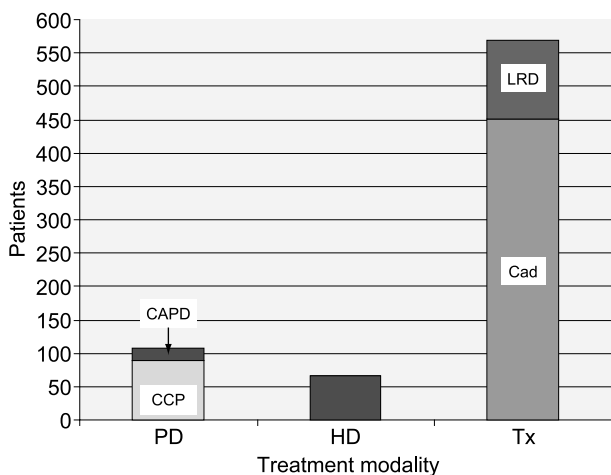


Figure 13.19: Distribution of current RRT modalities

Table 13.10: Return rate for current patient modality from UK centres

Centre	Patients	Data available	% Return
GOSH	136	136	100
Manchester	88	88	100
Guys	82	82	100
Nottingham	80	80	100
Birmingham	65	65	100
Liverpool	35	35	100
Belfast	30	30	100
Cardiff	22	22	100
Bristol	45	44	98
Leeds	73	69	95
Southampton	17	16	94
Glasgow	58	48	83
Newcastle	45	22	49

Asian children were on haemodialysis than peritoneal dialysis ($p = 0.0117$). These data are summarised in Figure 13.20. The higher prevalence of blood group B and HLA homozygosity in this population make it more difficult to find compatible organs.

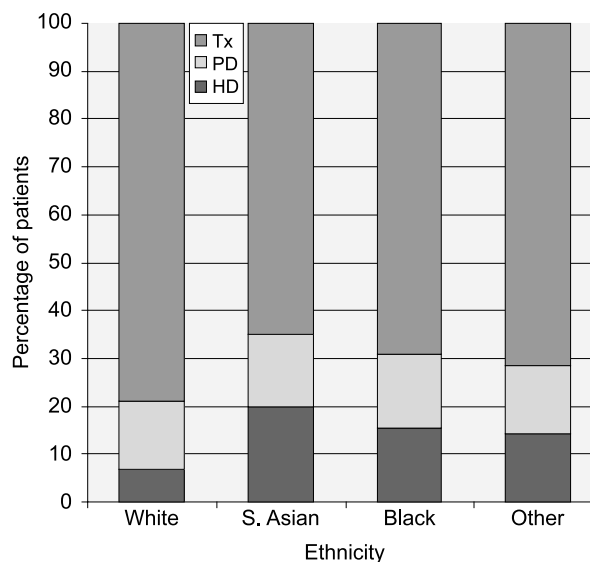


Figure 13.20: Distribution of current modalities by ethnicity

Focus on cardiovascular risk factors in paediatric ERF patients

Cardiovascular disease has been recognised as the most important cause of death in patients on renal replacement therapy. The risk of death from cardiovascular disease is elevated 30 fold for patients with ERF compared with the general population. The incidence of cardiovascular disease is also much increased after renal transplantation¹.

Young adults on renal replacement therapy die primarily of cardiac causes. The relative mortality risk from cardiac causes for a 25–34 year old on RRT is the same as that of a 75–80 year old without ERF. Amongst children with a renal transplant, cardiac disease is the single largest cause of death accounting for 35% of deaths in this age group.

The nature of cardiac disease differs from conventional ischaemic heart disease and includes a spectrum of disorders such as left ventricular hypertrophy, valvular calcification, cardiomyopathy and conduction disturbances. A study of young adults who had developed renal failure as a child, most of whom were transplanted, demonstrated that over 40% of patients had left ventricular hypertrophy and 19% had aortic valve calcification². Increased arterial stiffness is a risk factor for mortality in adults with established renal failure. Carotid artery wall stiffness is increased in young adult patients with established renal failure and hypertension is one of the main determinants of this³.

A controlled trial comparing children with chronic renal insufficiency with children on dialysis and controls demonstrated that even those with chronic renal insufficiency had evidence of impaired left ventricular diastolic function. There was an association between increased serum phosphate and calcium phosphate product and the development of left ventricular diastolic dysfunction and also between the presence of anaemia and left ventricular diastolic dysfunction⁴.

Cardiovascular risk factors in paediatric transplant patients

The majority of children with ERF have a renal transplant. Thus factors contributing to cardiovascular morbidity and mortality need to be analysed. Factors available for study in the Paediatric Renal Registry are blood pressure, body mass index (BMI), lipid status and anaemia. All of these have been associated with cardiovascular morbidity and standards for care have been described in the Renal Association Standards document.

Of the 570 patients known to have functioning renal transplants and under the care of a paediatric unit in 2003, complete data, including systolic blood pressure, diastolic blood pressure and the number of anti-hypertensive medications being taken were available for 417 patients (73.2%). Most of the missing data related to diastolic blood pressure values which can be more difficult to delineate in paediatric patients. Data on systolic blood pressure and anti-hypertensive medication were available for 520 patients (91.2%).

The distribution of systolic blood pressure values across the cohort is shown in Figure 13.21. It can be seen that the distribution is shifted significantly to the right of normal with the median standard deviation score being 0.72.

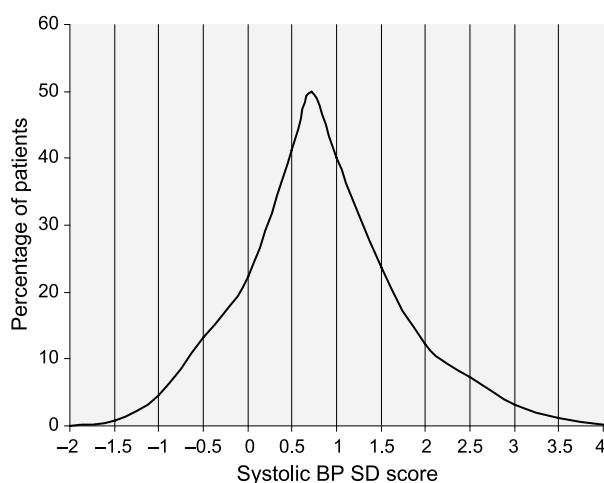


Figure 13.21: Distribution curve of systolic BP in transplant patients

The Renal Association Standard states that;

blood pressure should be kept at below 2 standard deviations (97.5th centile) from the mean for height and sex

Good practice suggest that the target systolic blood pressure should be below the 90th centile for height and sex. The standards used for this analysis are those given in the first American Task Force which relate to age and sex, rather than height and sex. The differences are in fact small but the use of these standards removes one disadvantage from renal patients in that a significant proportion are pathologically small and the use of height and sex standards can face the practitioner with unrealistically low target blood pressures in these patients. The other point that needs to be noted is that the Registry does not collect the method of blood pressure measurement. In many clinics, the norm is to use an automated oscillatory blood pressure monitor. The standards were generated using mercury sphygmomanometers. Oscillatory machines tend to give higher values for systolic blood pressures and lower values for diastolic blood pressures compared to the mercury sphygmomanometer. Although normal ranges for oscillatory machines for ambulatory blood pressure monitoring have been established, no such normal ranges have been established for casual blood pressure measurements using oscillatory machines.

Despite these caveats, it is quite clear that on this cross-sectional analysis, blood pressure control in the paediatric transplant population

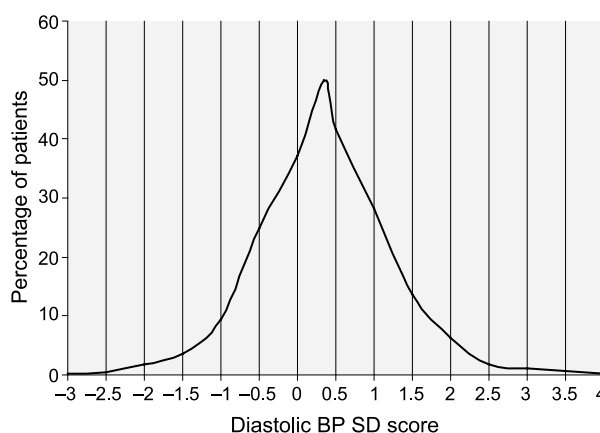


Figure 13.22: Distribution curve of diastolic BP in transplant patients

is poor. The median systolic blood pressure is shifted to the right by 0.72 standard deviations. 12.3% have a systolic blood pressure above the 97.5th centile and 20% have a systolic blood pressure in excess of the 95th centile.

The situation is similar for diastolic blood pressure (Figure 13.22). The median diastolic blood pressure is shifted to the right by 0.35 standard deviations with 6.2% having a diastolic blood pressure above the 97.5th centile and 11.3% having a diastolic measurement above the 95th centile.

The use of anti-hypertensive medication is shown in Figure 13.23. Overall, 59% of patients are on one or more anti-hypertensive medication. Just 177 patients (34%) have both a normal blood pressure and are on no anti-hypertensives, whilst 66% either have hypertension or are on anti-hypertensives to control

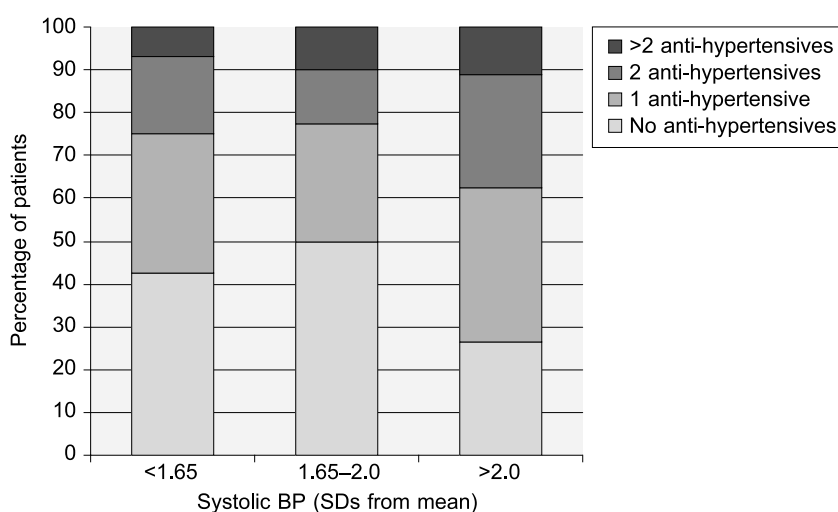


Figure 13.23: The use of anti-hypertensive medication in transplant patients by systolic BP

their blood pressure. Of those with a systolic blood pressure above the 97.5th centile, 26.5% were not on any anti-hypertensive medication at the time, whilst 50% of those with a blood pressure between the 95th centile and the 97.5th centile were not on any anti-hypertensive medication.

As data for the paediatric registry are only collected on an annual basis, it would clearly be possible to misinterpret blood pressure data as the picture faced by a clinician following a patient longitudinally might be very different from the single annual snap-shot obtained from the Registry. To study this further, all transplant patients who have had at least 3 consecutive years' of data recordings were analysed. There were 1,692 records with blood pressures available in a total of 419 patients. 193 recordings (11.4%) in 50 patients (11.9%) showed a systolic blood pressure more than the 97.5th centile. Of these, 27 patients (6.4%) had two or more years' (range 2–6) of consecutive systolic blood pressures more than the 97.5th centile. Looking at the 95th centile for systolic blood pressure, 325 recordings (19.2%) were above this value in 82 (19.5%) patients. Sixty five patients (15.5%) had 2 or more consecutive years' of systolic blood pressure above the 95th centile. Thus overall, blood pressure control in paediatric transplant patients appears to be sub-optimal.

The Registry has previously reported the problem of obesity in paediatric transplant recipients. Figure 13.24 shows the distribution

of BMI standard deviation scores amongst the paediatric renal transplant population. It has been suggested that judging obesity by centiles for BMI is not appropriate. Instead a projected BMI over 30 kg/m² at adulthood is taken as definition of obesity whilst a projected BMI over 25 kg/m² at adulthood is used to define overweight patients⁵. Values for BMI were available in 520 patients, of whom 503 also had blood pressure data and details of anti-hypertensive medication. It can be seen that the curve is significantly shifted to the right with the median BMI standard deviation score being 0.9, 41.7% of the transplant population were overweight on cross-sectional analysis whilst 18.3% were obese. There was no gender difference. Fifty five patients (10.9%) were both overweight and had a systolic blood pressure above the 95th centile for age. Of these, 28 patients (5.6%) were both obese and had a systolic blood pressure above the 95th centile for age.

Although data on lipids are part of the routine paediatric registry data set, submission of these data is poor with 3 of the 13 paediatric centres not submitting any lipid data and only partial returns from the other 10 units. For 2003, data on lipids were available for just 190 transplants of whom 183 also had data on blood pressure, 183 also had data on BMI and 178 had data on BMI and blood pressure. No standards for cholesterol in children exist, other than the recommendation within the standards document that cholesterol should be measured. Fifty seven patients (30%) had a cholesterol above 5 mmol/L (the current Renal Association

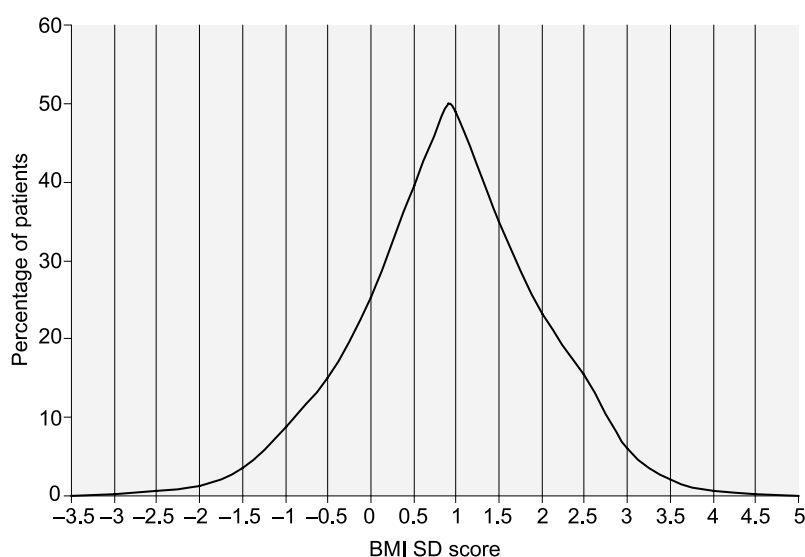


Figure 13.24: BMI SD score distribution for paediatric transplant patients

standard for adults). Of these, 17 (9.3%) also had a systolic blood pressure above the 95th centile and 29 (15.8%) were overweight, of whom 17 (9.3%) were obese. Nine patients (5.1%) had the triad of a high cholesterol, high systolic blood pressure and were overweight, whilst 5 of these patients (2.8%) were obese with this.

The final factor available to study that has been associated with cardiovascular morbidity is anaemia. This is difficult to study on a cross-sectional basis as it is chronic anaemia that leads to cardiovascular morbidity, whilst the snap-shot of haemoglobin obtained from the Registry will be affected by the patient's clinical status at the time. Data on haemoglobin were available in 542 (95.1%) patients.

The Renal Association Standard for haemoglobin advises that

for children of 2 years of age and above, the haemoglobin should be equal to or greater than 10.5 g/dl.

None of the patients in the study cohort was under 2 years of age. Ninety patients (16.6%) had a haemoglobin below 10.5 g/dl. Of these, a serum ferritin was available in only 26, of whom 9 had clearly inadequate iron stores. Three of the patients were documented to have received intravenous iron and 11 were documented to have been receiving erythropoietin.

Figure 13.25 shows the distribution of GFRs for those with a haemoglobin <10.5 g/dl and

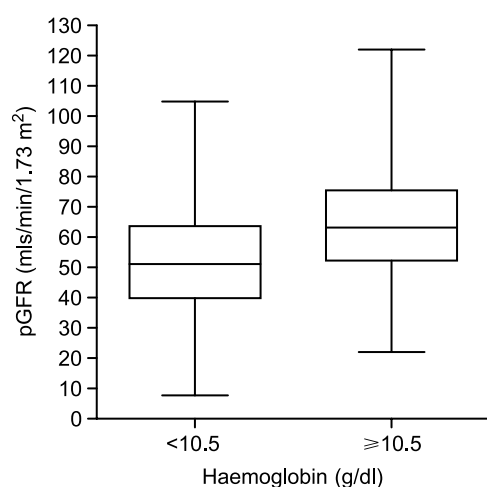


Figure 13.25: Distribution of predicted GFRs in transplant patients by Hb

those above this value. As one might expect, the predicted GFRs in the anaemic group were significantly less than the non-anaemic group ($p = <0.0001$), although the median and interquartile range for predicted GFR in the anaemic group is rather higher than one would expect with non-transplanted patients with chronic renal failure. Anaemia was not a common problem amongst those with other cardiovascular risk factors with just 2.6% having anaemia and hypertension, 5.0% anaemia and obesity and 0.6% anaemia together with hypertension and obesity. Just 39 of the 90 anaemic patients had had their cholesterol measured. Of these, 9 (23%) had a value above 5 mmol/L. Four of these patients were obese of whom 2 were also hypertensive.

Cardiovascular risk factors in peritoneal dialysis patients

Of the 107 patients known to be on peritoneal dialysis, dynamic records for 2003 were available for 103 patients. With regard to the study of cardiovascular risk factors, factors available for study were blood pressure, body mass index, lipids, haemoglobin and bone chemistry parameters.

Data on blood pressure was available in 98 patients. The distribution of the systolic and diastolic blood pressures are shown in Figure 13.26. For both systolic and diastolic pressure, the median value is shifted to the right, more so

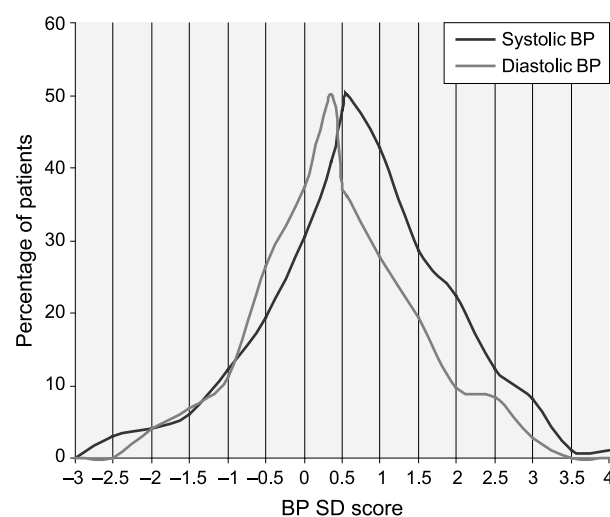


Figure 13.26: Distribution of systolic and diastolic BP in patients on PD

for systolic than diastolic values. 24.5% of PD patients had a systolic blood pressure above the 95th centile for their age, whilst 22.4% had a systolic pressure above the 97.5th centile. These values for diastolic pressures were 16.6% and 9.7% respectively. Thus, hypertension is clearly a significant problem in the paediatric dialysis population.

Data on body mass index were available in 96 patients (89.7%). The median BMI standard deviation score was very close to 0, though 17.7% of this group would be classified as being overweight whilst 5.2% fell into the obese category. Most of the patients however, did not appear to demonstrate an excessive weight for their age and the high BMI's related more to short stature in this group. Thus potentially, with improved growth, these patients would have a normal body habitus. Figure 13.27 shows the distribution of both BMI standard deviation scores and height standard deviation scores on the same axis. The height distribution is shifted markedly to the left with the median height SDS being slightly below the 5th centile for age. Despite this, only 11 patients were documented to be receiving growth hormone.

The measurement of lipids is clearly not routine in many units and only 33 patients (30.8%) had lipid measurements documented. Of these, 21 had a cholesterol level in excess of

5 mmol/L. Seven of these patients had a primary diagnosis of either congenital or acquired nephrotic syndrome. If any of these patients retained residual renal function, then this would predispose them to hyperlipidaemia. Even discounting all of these patients however, an incidence of hyperlipidaemia of 42% is concerning in a high risk group for cardiovascular morbidity.

Data on haemoglobin were available in 101 patients. At the time of data collection, none of these patients were below the age of 6 months, whilst 8 were between 6 months and 2 years and the rest were over 2 years. For those under the age of 2, all met the Renal Association Standard of having a haemoglobin over 10 g/dl. All of these patients were on erythropoietin and 3 of the 8 had also received intravenous iron therapy. For the 93 patients over the age of 2 years, 36 had a haemoglobin below the standard of 10.5 g/dl. Only 26 of these patients had a ferritin documented and this was low in 4. Nine of these patients had received intravenous iron and 32 of the 36 had been treated with erythropoietin. Amongst the 57 who met the Renal Association Standard, there were again 4 patients not on erythropoietin therapy, whilst 14 patients (a similar proportion to the anaemic group) had received intravenous iron. Forty eight of the 57 patients had a ferritin documented and of these 12 were iron-deficient according to the Renal Association Standard.

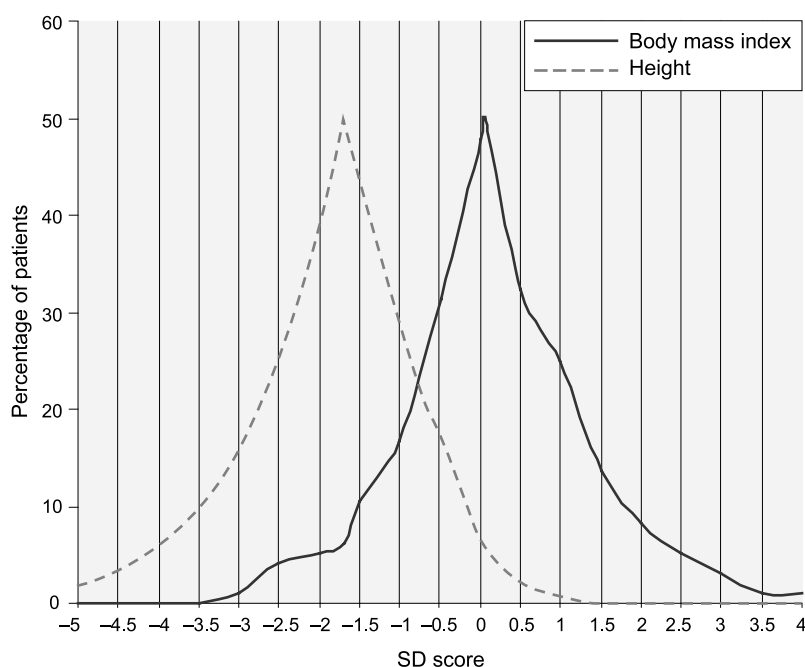


Figure 13.27: Distributions of BMI and Height SDS scores for patients on PD

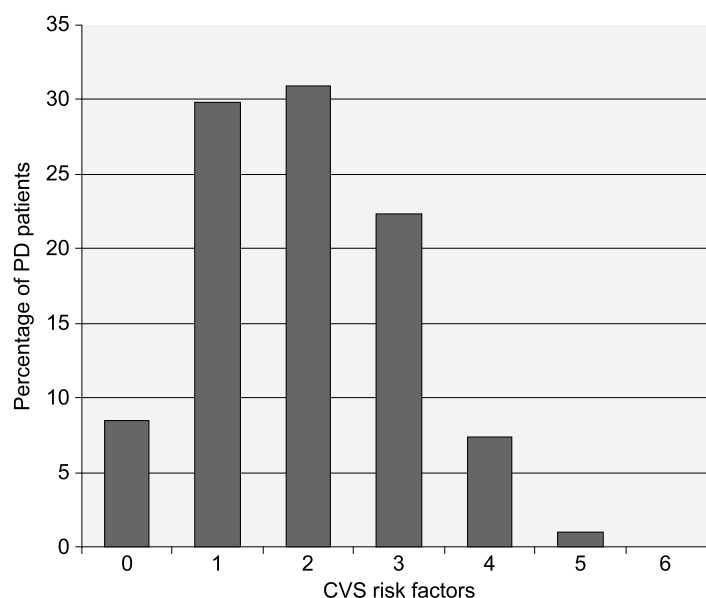


Figure 13.28: Number of cardiovascular morbidity risk factors present in PD

The Renal Association Standard for PTH states that;

PTH to be less than twice the upper limit of normal for the local laboratory

and for plasma phosphate;

plasma phosphate should be kept within the normal range for age

Measurement of PTH and phosphate levels were available in 101 and 102 of the 107 patients respectively. Fifty-one of the 101 patients had a PTH value more than twice the upper limit of normal for their laboratory, whilst 29 of these had a PTH value in excess of 4 times the upper limit of normal for their laboratory.

Phosphate is more complex to analyse as normal values for phosphate vary throughout childhood, being highest in infancy and falling to the adult normal range in early childhood. Interestingly, none of the 8 patients below the age of 2 years had a raised phosphate. For patients over the age of 2 years, 37 patients (36.3%) had a phosphate level above 1.8mmol/L, whilst 20 patients (20.1%) had a phosphate level above 2.0mmol/L.

Although this data only looks at a cross-section of the population rather than following the population longitudinally, it seems clear

that risk factors for cardiovascular morbidity are present in a significant proportion of the population. It is not clear what the effect of the presence of more than one risk factor is on the incidence of morbidity and this is complicated by the fact that some risk factors, such as high PTH values and anaemia or obesity and hypertension, tend to be closely linked. Figure 13.28 shows the number of patients undergoing peritoneal dialysis according to the number of cardiovascular morbidity risk factors they have shown on cross-sectional analysis. Over 60% of patients in this group have two or more risk factors for cardiovascular morbidity. This figure will be an under-estimate of the true prevalence of risk factors as only a minority of patients had their lipid levels measured.

Cardiovascular risk factors in haemodialysis patients

Data were available for 45 of the 66 patients receiving haemodialysis in 2003. Of these, data on systolic blood pressure were available in 38 and as with other modalities of therapy, the tendency was towards hypertension with a median systolic blood pressure 1.1 standard deviations above the mean. 36.8% of patients had a systolic blood pressure above the 95th centile with 28.9% being above the 97.5th centile for age. These figures are more dramatic than seen in other modalities of therapy. However, the quantity of missing data was greater in

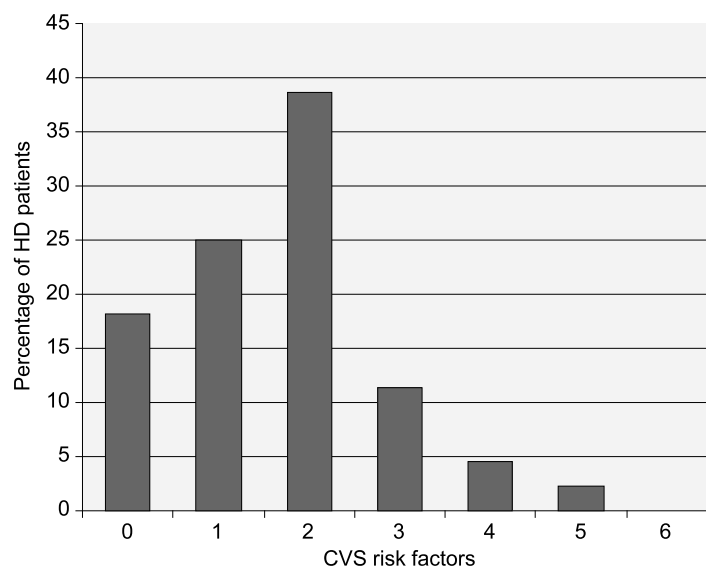


Figure 13.29: Number of cardiovascular morbidity risk factors present in HD patients

haemodialysis patients and many of these blood pressures will have been recorded prior to haemodialysis when the patients would have been at their most volume-overloaded state.

Data on body mass index were available for 36 patients, of whom 8 (22.2%) were overweight and 4 (11.1%) were obese. Lipid levels were only measured in 20 patients and 4 of these (2 of whom were patients with nephrotic syndrome as their primary diagnosis) had a cholesterol above 5 mmol/L.

Bone chemistry was recorded in 38 patients. Of these, 17 had a PTH greater than twice the upper limit of normal for the laboratory and 13 had a PTH more than 4 times the upper limit of normal for the laboratory. With regard to phosphate, 14 of the 38 patients had a phosphate level above the upper limit of normal for their age.

Data on haemoglobin were available for 44 patients, 4 of whom were under the age of 2 years (but over the age of 6 months) at the time of data entry. Two of these 4 failed to meet the Standard of a haemoglobin of 10 g/dl. All of these patients were receiving erythropoietin. One had received intravenous iron and 3 had appropriate iron stores according to their serum ferritin levels. For those over the age of 2 years, 15 of 40 patients failed to meet the target of 10.5 g/dl. Two of these patients had not yet received erythropoietin therapy and only 4 of the 15 were on intravenous iron therapy. Amongst those with a haemoglobin above

10.5 g/dl, all were receiving erythropoietin and 14 of the 25 patients were receiving erythropoietin therapy.

As with peritoneal dialysis patients, the cumulative number of risk factors in individual patients is shown in Figure 13.29. The figure shown here will be an under-estimate of the true incidence of these factors as data is incomplete in certain areas, particularly with regard to lipid levels. Even taking this into account, 56.8% of patients have at least 2 or more cardiovascular morbidity risk factors present on cross-sectional analysis.

Chronicity of cardiovascular risk factors in dialysis patients

Cardiovascular morbidity will be related to the presence of predisposing factors for prolonged periods of time. All the above assessments of dialysis patients are based on cross-sectional analyses. To investigate how persistent these risk factors were, all patients who have had 3 or more consecutive years' dialysis were analysed. 302 annual records were available for a total of 87 patients. For some parameters such as lipid levels too little data were recorded for meaningful analysis. As patients in the dialysis group do not have rapidly changing bodily proportions, data on BMI is the same as for cross-sectional analysis. This analysis has therefore been limited to looking at blood pressure control, anaemia and bone chemistry.

Data on systolic blood pressure were available from 278 records relating to 79 patients. Of these, 15 patients (18.9%) had a systolic blood pressure recorded at above the 95th centile for two or more consecutive years (range 2–5 years). The majority of these, 13 patients (16.4%), had a systolic blood pressure recorded at above the 97.5th centile for age for two or more consecutive years.

Data on anaemia were available from 295 records for 84 patients. Twenty one patients (25%) had a haemoglobin below the Renal Association Standard for two or more consecutive years. A number of adult studies have shown anaemia predicts morbidity and mortality in CRF even before dialysis has started⁶. Correction of anaemia in adult patients with CRF or on dialysis reduces morbidity and mortality^{7,8}. Adult studies have also shown that anaemia in CRF is an independent risk factor for left ventricular hypertrophy, whilst LVH is a predictor of cardiovascular mortality and early correction of anaemia can lead to regression of LVH. Changes in left ventricular mass are recognised as a frequent occurrence in paediatric dialysis patients⁹.

Information on the clinical effects of anaemia on paediatric ERF patients is relatively scarce. The 1996 and 2001 NAPRTCS reports revealed that in children and adolescents with CRF, a haematocrit <33% was found to be associated with accelerated progression to ERF^{10,11}. Warady and Ho used the NAPRTCS database to look specifically at morbidity and mortality attributable to anaemia in 1,942 paediatric dialysis patients starting dialysis in 1992 through to 2001¹². Overall, 68% of patients were anaemic (defined as haematocrit <33%) on day 30 after initiation of dialysis and 29.1% were severely anaemic (haematocrit <27%). Through the period 1992–2000, there was a fall in the percentage of patients anaemic at day 30 from 79.7% in 1992 to 50.6% in 2000. When compared with patients with haematocrit >33%, anaemic patients had a significantly higher mean number of days in hospital in the first year after initiation of dialysis. Anaemia was also associated with the risk of dying. There were 171 deaths in the 9 year period, giving 29 deaths per 1,000 patient years; the youngest patients aged 0–1 year at the start of dialysis had the highest mortality at 78 deaths

per 1,000 patient years. Looking at all ages, being anaemic at day 30 gave a relative risk (RR) of death of 1.52 (confidence interval 1.03–2.26). Compared to those with haematocrit 33–36%, those with haematocrit <27% had a RR death of 1.80 (confidence interval 1.04–3.12). This study confirms a correlation between anaemia and both morbidity as measured by length of hospitalisation and mortality. Thus, the findings that a significant proportion of the paediatric dialysis population are not only anaemic on cross-sectional but also on longitudinal analysis, is particularly concerning.

With regard to bone chemistry, data on PTH were available from 220 records in 52 of the 87 patients, whilst data on phosphate levels was available from 290 records in 80 patients. Thirteen patients (25%) had two or more consecutive years' recordings of a PTH more than twice the upper limit of normal for the laboratory concerned whilst 21 patients (29.6%) had high serum phosphate levels for two or more consecutive years.

Looking at combinations of risk factors, 6 patients (7.6%) had chronic hypertension and anaemia whilst 12 (15.1%) had chronic hypertension and bone disease. Four patients (5.1%) had a long term combination of all three problems.

Conclusions

The patient prevalence in paediatric renal units in April 2003 numbered 776 with a male to female ratio of 1.57:1. The previously documented growth in the paediatric ERF population appears to have plateaued. The gender and ethnic distribution of the population is unchanged from previous reports. Similarly, prevalence and take-on rate are not significantly different to before. The take-on rate for South Asian patients remains 3 times that of the White population. This appears to be related to a significantly higher incidence of diseases acquired through autosomal recessive inheritance in this group ($p < 0.0001$).

Fifty percent of patients who presented to paediatric nephrology units and entered ERF had a GFR under 20 ml/min/1.73 m² at the time they were first seen by a paediatric nephrologist.

Patients who develop ERF tend to be smaller than average at the time of presentation, this being most marked in patients with metabolic disease and congenital renal dysplasia. By the start of ERF treatment most patients had fallen further behind with regards to height, this was most marked in the younger patients. Treatment at day 90 after commencement of ERF therapy was peritoneal dialysis in 52% of patients. Twenty one percent had functioning renal allografts, with approximately 95% through pre-emptive engraftment. With regard to current therapy 76.9% of the paediatric ERF population had a functioning renal allograft. Of the others, 61.8% were on PD and the remainder on HD. Patients of South Asian ethnicity were significantly less likely to have a functioning allograft ($p = 0.0027$) and were significantly more likely to be on HD rather than PD ($p = 0.0117$).

Examining risk factors for the later development of cardiovascular morbidity and mortality, patients with functioning renal allografts showed a shift in the distribution of their blood pressure with 20% having a systolic and 11.3% a diastolic pressure above the 95th centile for age. On longitudinal analysis, 19.5% had a systolic blood pressure above the 95th centile for 2 or more years' consecutive readings. A high BMI in transplant patients was common with 41.7% being overweight and 18.3% obese. In 30% of those with a documented cholesterol level this was over 5 mmol/L. Using the Renal Association standards, 16.6% were anaemic though only 12.2% of these patients were receiving erythropoietin. Amongst patients on PD, 24.5% had a systolic and 16.6% a diastolic blood pressure above the 95th centile for age. BMI was high with 17.7% being overweight and 5.2% obese, though this was more related to short stature than excessive weight for age with 50% of patients having a height below the 5th centile for age. Using Renal Association standards, 38.7% were anaemic, 50.4% had a raised PTH and 36% were hyperphosphataemic. Figures for the small number of HD patients were similar. Looking at patients who had a minimum of 3 consecutive years' dialysis, 16.4% had a systolic blood pressure recorded at over the 95th centile for age, 25% were anaemic, 25% had a PTH above twice the upper limit of normal and 29% were hyperphosphataemic for two or more consecutive years.

Although absolute mortality rate in children with ERF is low compared with adult patients, the presence of cardiovascular risk factors is a cause for concern. Whilst accepting that paediatric RRT patients are difficult to manage, failure to meet standards in these areas is potentially creating major problems in the future for these patients from cardiovascular co-morbidity.

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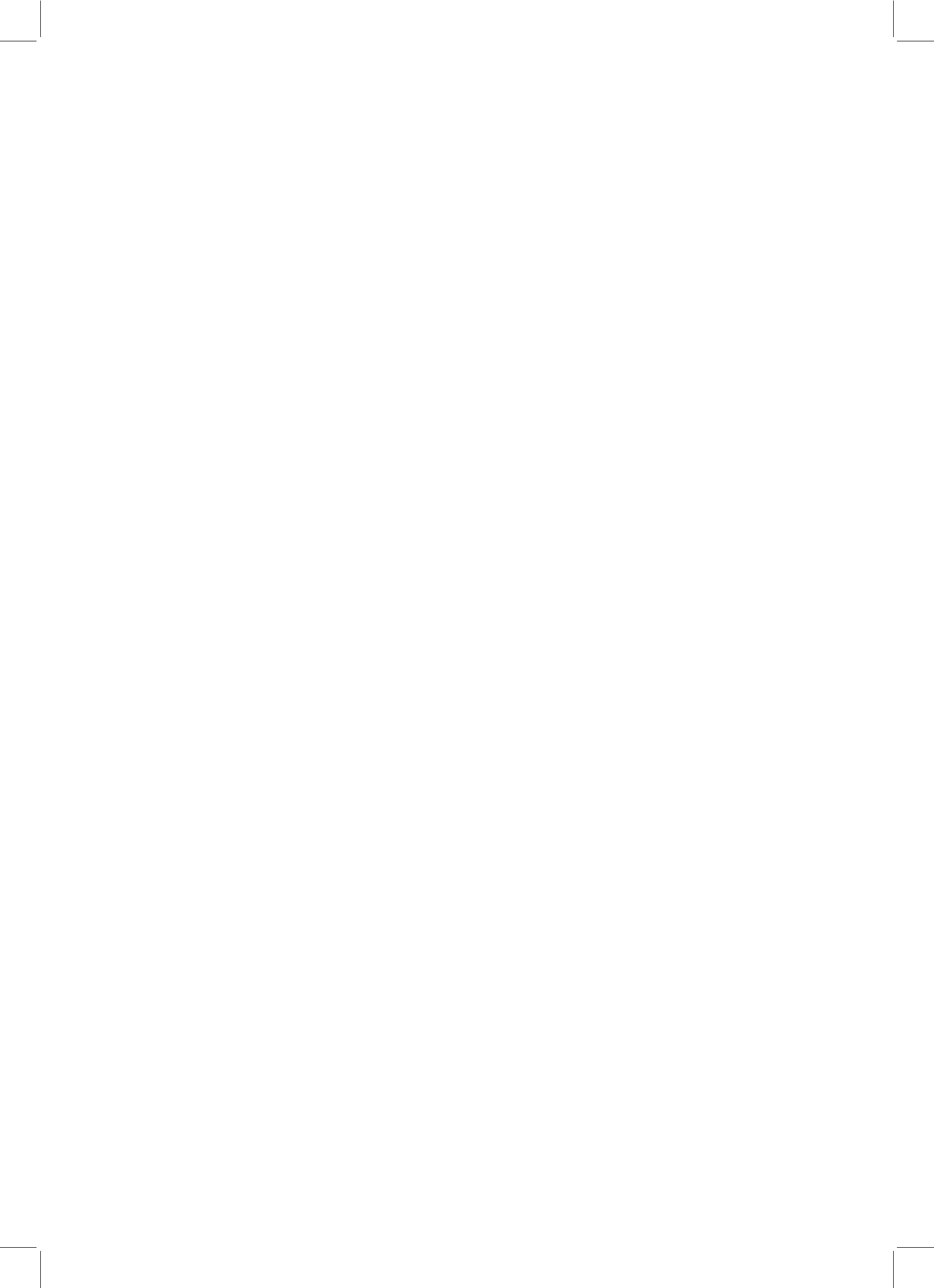
Acknowledgments

This report was compiled by Dr MA Lewis, Mrs J Shaw, Dr C Reid and Dr J Evans.

It was reviewed, revised and approved by the Paediatric Renal Registry subcommittee comprising:

Dr Kate Verrier-Jones
Dr Chris Reid
Dr Jonathon Evans
Dr Nicholas Webb
Dr Rodney Gilbert
Dr Malcolm Lewis

This report is presented on behalf of the BAPN.



Chapter 14: Survival of Incident Patients

Summary

- From the first RRT, the one year survival of all patients (unadjusted for age) is 78%. From the 90th day of RRT, the one year survival is 87%. The age adjusted (60 years) survival for the 1 year after 90 day period is 86%.
- There is a high death rate in the first 90 days of RRT, a period not included in reports by many registries and other studies.
- The 5 year survival (including deaths within the first 90 days) is 45%: 63% for patients aged less than 65 years and 24% for those aged 65 years and over.
- Several centres had a figure for the 1 year after 90 day survival which was outside 2 or 3 SDs from the mean for E&W: in some cases this was better survival, in others poor survival. Poor reporting by renal units of patient co-morbidity and ethnicity makes interpretation of these apparent differences in patient survival between centres difficult, and a relationship to clinical performance cannot yet be inferred.
- To adjust survival for case-mix requires improved data return by renal units: methodologies and structure at renal unit level need to improve, possibly with investment in informatics staff.
- The hazard of death does not increase with length of time on dialysis (in the first 6 years). The 'vintage effect' of increasing hazard of death with length of time on RRT noted in the US, is not apparent in UK survival data.

Introduction

The analyses presented in this chapter examine the survival from the start of renal replacement therapy (RRT), including pre-emptive

transplantation, of incident RRT patients. Patients returning to dialysis after a failed transplant are not included in this incident cohort. For individual renal units such analysis allows a comparison with experience in previous years and with other centres.

These analyses encompass the outcomes from the total incident UK dialysis population, including the 31% who start on peritoneal dialysis and the 3% who receive a pre-emptive transplant. The results therefore show a true reflection of the whole UK RRT population. The survivals reported here are better than those reported for the UK by the IDOPPS study, which only includes haemodialysis patients. As shown in Chapter 4, the haemodialysis patients are a selected group with increased co-morbidity and higher death rates than those selected for PD or pre-emptive transplant.

The one and two year survival figures quoted in this chapter are from the first day of renal replacement therapy unless stated otherwise, not from day 90 as quoted in the USRDS data from the USA and by many countries included in the IDOPPS study.

Death rates in different centres contributing to the UK Renal Registry are reported here. These are raw data that require interpretation if legitimate centre comparisons are to be attempted. The Registry can adjust for the effects of the different age distributions of the patients in different centres, but lacks sufficient data from many participating centres to enable adjustment for factors of co-morbidity and ethnic origin, which have been demonstrated to have a major impact on outcome. With this lack of information on case mix, no significance can currently be attributed to any apparent difference in survival between centres. It is for this reason that in this section the individual units are not identified. It is most important that participating centres send more comprehensive data on co-morbidity and ethnic origin.

Despite the uncertainty about any apparent differences in outcome, for centres which appear to be outliers, the Registry initiates discussions to see whether any factors can be identified which contribute to apparently “good” or “poor” results.

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. When comparing two groups, the hazard ratio is the ratio of the estimated hazards for group A relative to group B, where the hazard is the risk of dying at time t given that the individual has survived until this time. The underlying assumption of a proportional hazards model is that this ratio remains constant throughout the period under consideration. Whenever used, the proportional hazards model was tested for validity.

Funnel plot

To enable assessment of whether an observed survival is likely to be significantly different from the national average, Figure 14.7 has been included in the report. From this, for any size of incident cohort (X axis) one can identify whether any given survival rate (Y axis) falls within plus or minus 2 standard deviations

(SDs) from the national mean (solid lines, 95% confidence interval) or 3 standard deviations (dotted lines, 99.8% confidence interval). Thus for an incident cohort of 100 patients the observed survival would have to be outside the limits of 79% to 93% at 2 SDs. However for an incident cohort of 500 patients these limits are from 83% to 89% at 2 SDs.

Validity of the centre adjustment for proportional hazards

For the Cox model to be used to adjust centre survival to a specific age (eg 60 years), the assumption of constant proportionality means that the relationship of survival (hazard of death) to age is similar in all centres within the time period studied. If one centre had a relationship of survival with age different from the other centres, the adjustment would not be valid. Testing showed the relationship to be similar for all centres.

Survival of new patients on RRT

The revised Renal Standards document concluded that:

It is hard to set survival standards at present because these should be age, gender and co-morbidity adjusted and this is not yet possible from Registry data. The last Standards document recommended at least 90% one year survival for patients aged 18–55 years with standard primary renal disease. This may have been too low as the rate in participating centres in the Registry was 97%, though numbers were small

The Renal standard Document defines Standard Primary Renal Disease using the EDTA diagnosis codes (including only codes 0–49): this excludes patients with renal disease due to diabetes and other systemic diseases. It is more widespread practice to simply exclude diabetics, so these figures are included in this report to allow comparison with reports from other Registries. The results are shown in Table 14.1.

The UK data show the high death rate in the first 90 days and a steep age related decline in survival over all time periods. Table 14.2 contains 90 day and 1 year after 90-day adjusted

Table 14.1: One-year patient survival – patients aged 18–55, 2002 cohort

First treatment	Standard primary renal disease	All diseases except diabetes
All %	95.4	93.9
95% CI	93.7–97.1	92.2–95.5
HD %	93.4	91.6
95% CI	90.7–96.0	89.2–94.0
PD %	98.6	97.9
95% CI	71.1–100	96.3–99.6

patient survival for England and for Wales, showing the high initial death rate.

The age adjusted survival by first established treatment modality is shown in Table 14.3.

There appears to be better survival on PD compared with HD (Tables 14.1 and 14.3) after age adjustment, similar to data from theUSRDS and Australasian (ANZDATA) Registries. However a straightforward comparison of the modalities in this way is not valid, as there are significant factors in selection for the modalities and the patients in the two groups are not comparable (Chapter 4).

Tables 14.4 to 14.10 show survival of all patients and those above and below 65 years of age, for up to six years after initiation of renal replacement therapy.

If the survival data in Tables 14.5 to 14.10 were calculated from after day 90 (1 year after

Table 14.3: One-year survival by first established treatment modality (age adjusted)

	HD	PD
Adjusted 1 year after 90 days %	83.8	89.6
95% CI	82.0–85.5	87.6–91.7

Table 14.4: Unadjusted 90 day survival of new patients, 2002 cohort by age

Age	KM ¹ survival analysis (%)	KM 95% CI	N
18–64	95.2	94.1–96.2	1,663
≥65	85.8	84.2–87.4	1,806
All ages	90.3	89.3–91.3	3,469

¹KM = Kaplan-Meier.

Table 14.5: Unadjusted 1 year survival of new patients, 2002 cohort by age

Age	KM survival analysis (%)	KM 95% CI	N
18–64	88.9	87.4–90.4	1,663
≥65	67.0	64.9–69.2	1,806
All ages	77.6	76.3–79.0	3,469

day 90 survival, 2 years after 90 day survival, etc) this increases the survival in all cases by an additional 3%–4% across both age bands. For example in Table 14.9 the 5 year survival for patients aged <65 years becomes 65.2% (was 62.6%) and for those aged 65+ years becomes 27.9% (was 24.4%).

Table 14.2: Patient survival across England and Wales, 2002 cohort

	England	Wales	England & Wales
Adjusted (age 60) %	93.0	92.4	93.0
90 day, 95%CI	92.0–94.1	89.9–95.0	92.0–94.0
Adjusted (age 60) %	85.7	85.5	85.7
1 year after 90 days, 95%CI	84.2–87.2	81.8–89.4	84.3–87.1

Table 14.6: Unadjusted 2 year survival of new patients, 2001 cohort by age

Age	KM survival analysis (%)			N
	1 year	2 year	2 year 95% CI	
18–64	88.5	81.3	79.3–83.3	1,524
≥65	66.8	53.2	50.6–55.7	1,540
All ages	78.4	67.4	65.7–69.1	3,064

Table 14.7: Unadjusted 3 year survival of new patients, 2000 cohort by age

Age	KM survival analysis (%)			3 year 95% CI	N
	1 year	2 year	3 year		
18–64	89.6	82.3	75.4	73.0–77.9	1,211
≥65	68.1	54.8	41.4	38.3–44.0	1,156
All ages	79.1	68.7	58.5	56.5–60.5	2,367

Table 14.8: Unadjusted 4 year survival of new patients, 1999 cohort by age

Age	KM survival analysis (%)				4 year 95% CI	N
	1 year	2 year	3 year	4 year		
18–64	88.1	82.3	75.6	69.6	66.8–72.5	1,028
≥65	67.8	52.6	39.9	29.7	26.7–32.7	910
All ages	78.5	68.2	58.7	50.7	48.4–53.0	1,938

Table 14.9: Unadjusted 5 year survival of new patients, 1998 cohort by age

Age	KM survival analysis (%)					5 year 95% CI	N
	1 year	2 year	3 year	4 year	5 year		
18–64	87.1	80.8	74.5	69.2	62.5	59.3–65.6	872
≥65	65.1	50.7	30.7	31.8	24.4	21.3–27.4	767
All ages	76.9	66.9	58.9	51.2	44.8	42.5–47.2	1,639

Table 14.10: Unadjusted 6 year survival of new patients, 1997 cohort by age

Age	KM survival analysis (%)						6 year 95% CI	N
	1 year	2 year	3 year	4 year	5 year	6 year		
18–64	87.4	80.4	74.4	68.3	64.0	59.7	55.1–64.2	454
≥65	65.8	45.2	33.6	23.9	14.5	10.8	7.5–14.1	345
All ages	78.1	65.2	56.8	49.1	42.6	38.6	35.2–42.0	799

Survival of new patients and age

The incident cohort included in this analysis is all those patients starting RRT in 2002. Patients who recovered function within 90 days (ie patients with acute rather than chronic renal failure) have been excluded.

In Figure 14.1, the unadjusted survival has been shown for the first 90 days, the first year from day 0 of RRT and the first year after day 90. The last figure allows comparison with many other Registries, including the US Registry, which record data only from day 90 onwards.

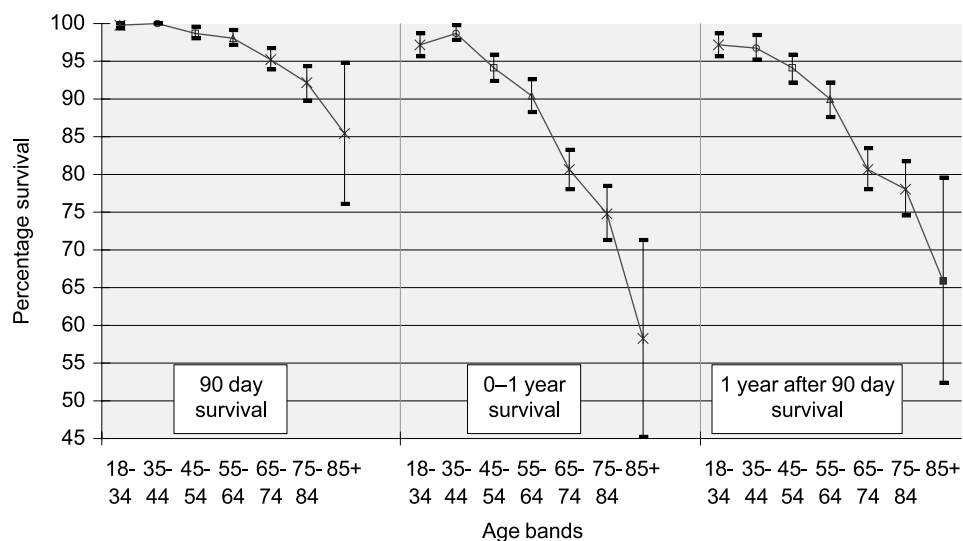


Figure 14.1: Unadjusted survival of all incident patients, by age band

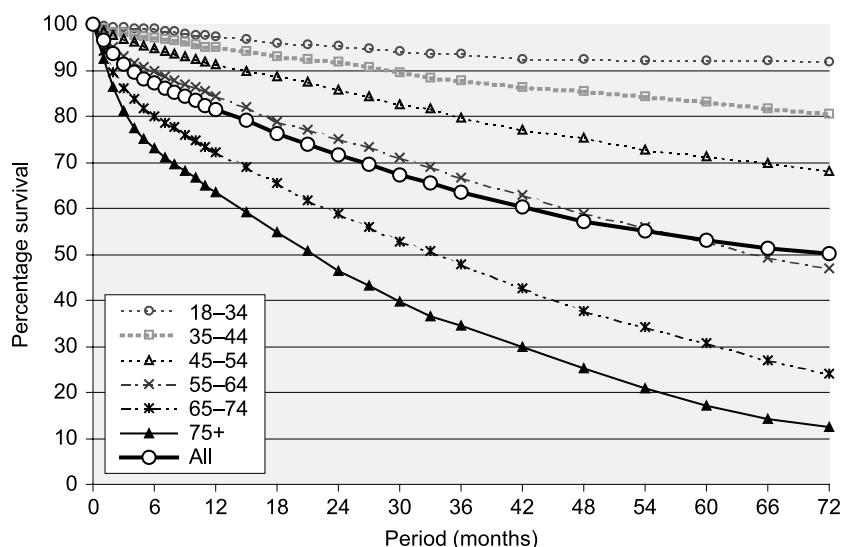


Figure 14.2: Kaplan-Meier 6-year survival of incident patients

The UK Registry has been collecting data on incident patients since its inception in 1997, enabling survival to be estimated for up to six years after starting renal replacement therapy. The Kaplan-Meier survival curves are shown in Figure 14.2.

Only the older groups reach 50% mortality in the 6 year period. For these the 50% survival times with 95% CI are: aged 55–64, 66 months $\pm 2.8m$; aged 65–74, 33 months $\pm 1.8m$; over 75, 21 months $\pm 2.1m$. 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 14.3). The hazard ratios for the differing age bands are not proportional across the ages for all the time periods. These data contrast with the ‘vintage effect’ seen in data from the USRDS Registry (USA) which demonstrates a rising hazard of death with increasing length of time on renal replacement therapy. Cross sectional analysis of the one year hazard of death in

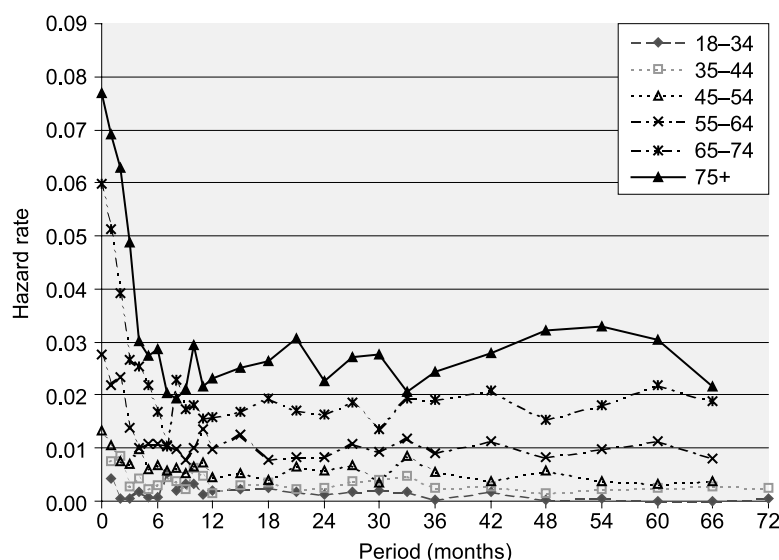


Figure 14.3: 6-year hazard of death ratios, by age band

The results beyond 36 months for patients aged 75+ are not reliable as the numbers were very small

prevalent UK patients also fails to show any effect of ‘vintage’.

Age adjustment of survival in the first 90 days and thereafter

Analysing all the patients starting RRT between 1997 and 2000, the proportional hazards for each 1-year increase in age of the patients for the two time intervals of the first 90 days and the subsequent 365 days are shown in Table 14.11.

These data show that there was, in the first 90 days, a greater risk of death for every 1 year increase in patient age than there was in the subsequent 1-year period. 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.

These data on their own would not invalidate the proportional hazards model for age

Table 14.11: Increase in proportional hazard of death for each year increase in age, at 90 days and for 1 year thereafter

Interval	Hazard of death	95% CI
First 90 days	1.058	1.050–1.065
1 year after first 90 days	1.041	1.035–1.047

adjustment between centres for the single time period of 0-365 days. Analysis has shown that there are centre variations in the hazards that invalidate the model for the 0-365 day time period but the model is valid if the period is divided into 0-90 days and any subsequent period. This is due to the change over period between these two hazards varying between centres, with some earlier at 80 days and others later at 110 days. When analysed within the periods the hazards remain proportional but when analysed for the 0-365 days they are not. Analysed over longer periods (eg 3 years) the effect is lost as it becomes very small.

Changes in incident patient survival, 1997–2002

In Figure 14.4, the right-hand graph shows the adjusted one-year after 90-day survival for all incident patients on the Registry in the years 1997–2002. More centres have joined the Registry since 1997 and these centres may have had varying survival rates. The left-hand graph shows the same analysis just for those centres that reported in 1997. It shows that in the years up to 2001 there appeared to be an overall improvement in survival from 84.0 to 88.0%, but the trend has since stopped or even reversed. These data also demonstrate that the survival profile of the 1997 centres is similar to that of the newer centres.

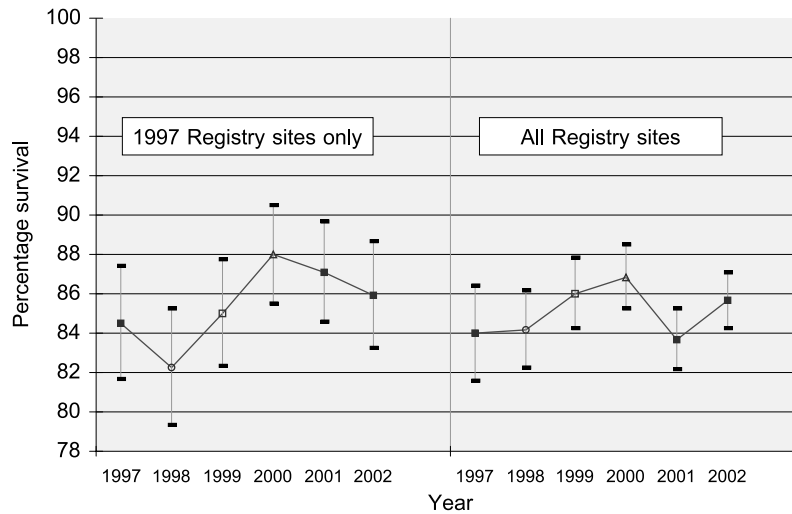


Figure 14.4: Change in one-year after 90 day adjusted (age 60) survival, 1997–2002

Survival of incident patients in 2002 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. The Registry has contacted units when apparent anomalies in data occur and it is clear there is

considerable variability between units in how these decisions are made, so one must be cautious when making comparative assessment of survival in the first 90 days. As the 1 year survival from day 0 of starting renal replacement therapy includes this time period, the more appropriate figure for comparing renal units is the 1 year after 90 days which can also be adjusted for age: results are shown in Figure 14.5 (adjusted to age 60), with their 95% confidence intervals.

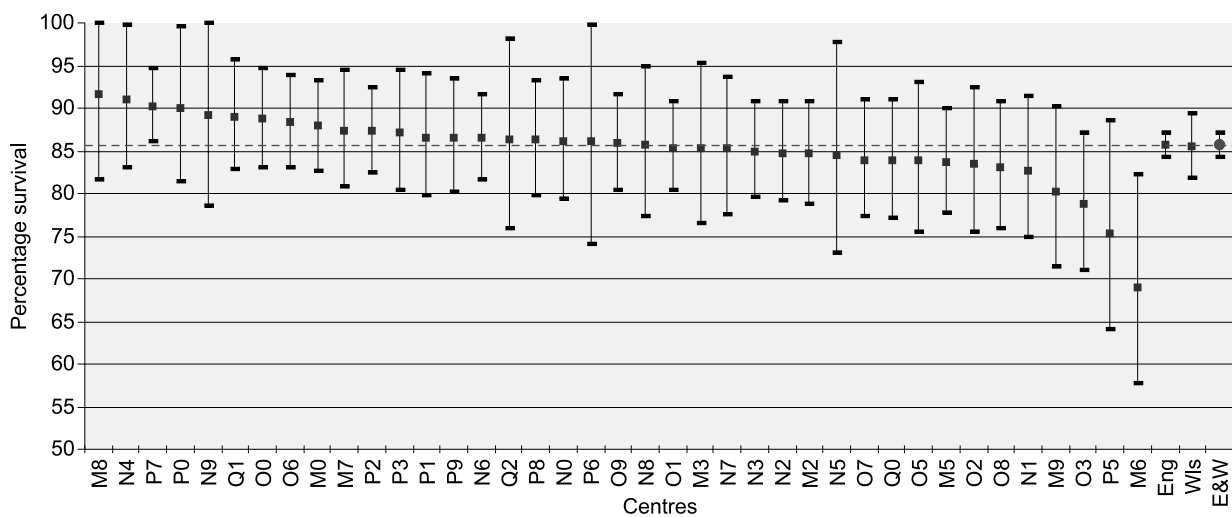


Figure 14.5: Adjusted survival 1 year after 90 days; 2002 cohort
Showing 95% confidence intervals

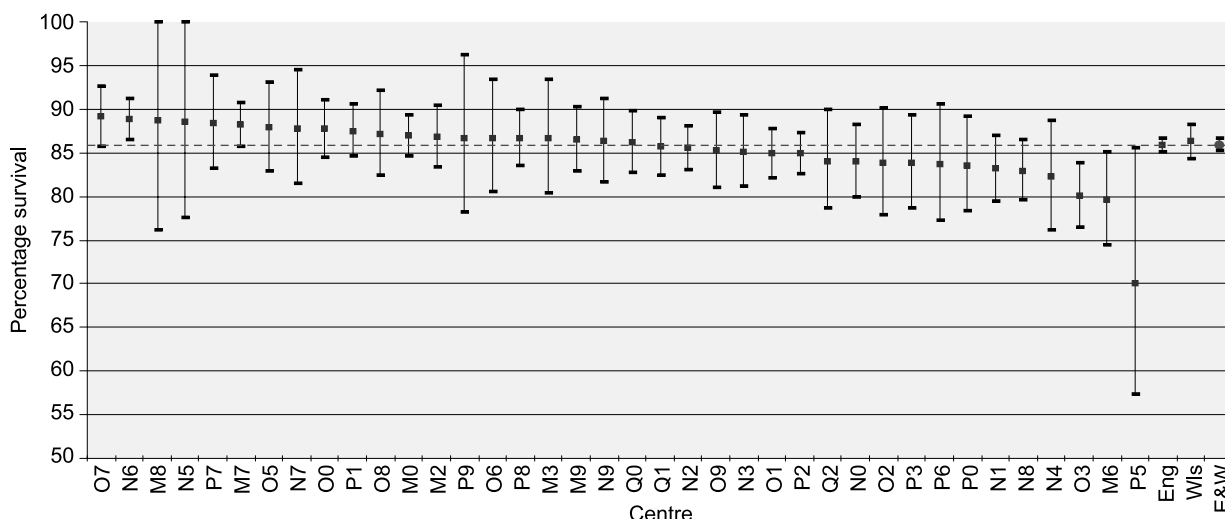


Figure 14.6: Adjusted survival 1 year after 90 days; 1997–2002 cohort
Showing 95% confidence intervals

Survival of incident patients 1997 – 2002 by centre

In the analysis of 2002 data alone, some of the smaller centres have wide confidence intervals. This can be addressed in part by including a larger cohort, including all patients starting RRT 1997–2002: this also assesses sustained performance. Figure 14.6 shows the adjusted survival for 1 year after 90 days in each centre for all new patients starting renal replacement therapy 1997–2002. Some centres have been contributing data to the Renal Registry for only part of this period so they will have fewer years included. The unadjusted data are shown in Table 14.12 at the end of this chapter.

Analysis of centre variability in survival in 1 year after 90 days

These data on survival are shown using funnel plots (see methods section) to identify possible outliers (Figure 14.7). To overcome the variability in centres with small numbers and to assess sustained performance, Figure 14.7 includes data from the 1997–2002 cohorts of patients. In this funnel plot analysis, 2 centres are above 2 standard deviations (SDs) from the national mean and 3 centres are below 2 SDs from the national mean: this requires more detailed investigation by the Registry. The Z-score (adjusted standard deviation) for each of the centres is shown in Table 14.12 at the end of this chapter.

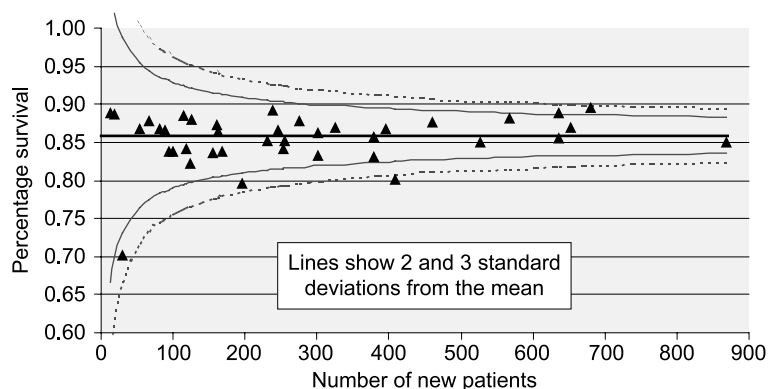


Figure 14.7: Funnel plot for age adjusted 1 year after 90 days survival; 1997–2002 cohorts

This analysis has not been adjusted for co-morbid conditions so it is not possible to conclude that any of these centres have better or worse survival. This highlights the importance of all renal units needing to return data on co-morbidity. In addition there is a wide scatter of results from the different units such that a variation from the mean of 2 standard deviations may not be large enough to indicate statistical significance: 3 standard deviations may be more appropriate.

To adjust survival for case-mix needs better data return from renal units and requires improved methodologies and structure at renal unit level. This is likely to include investment in informatics staff within renal units who would form part of the renal team.

Analysis of centre survival within the first 90 days

The age-adjusted 90-day survivals of patients incident in 2002 are shown in Figure 14.8. The unadjusted data are shown in Table 14.13 at the end of this chapter.

Figure 14.9 shows the age adjusted 90 day survival using a funnel plot for the 1997–2002 cohorts of patients starting on renal replacement therapy. The Z-score (adjusted standard deviation) for each of the centres is shown in Table 14.13 at the end of this chapter.

Although 2 centres are outside 3 SDs from the mean this may either be due to inclusion of patients with acute renal failure or case mix of

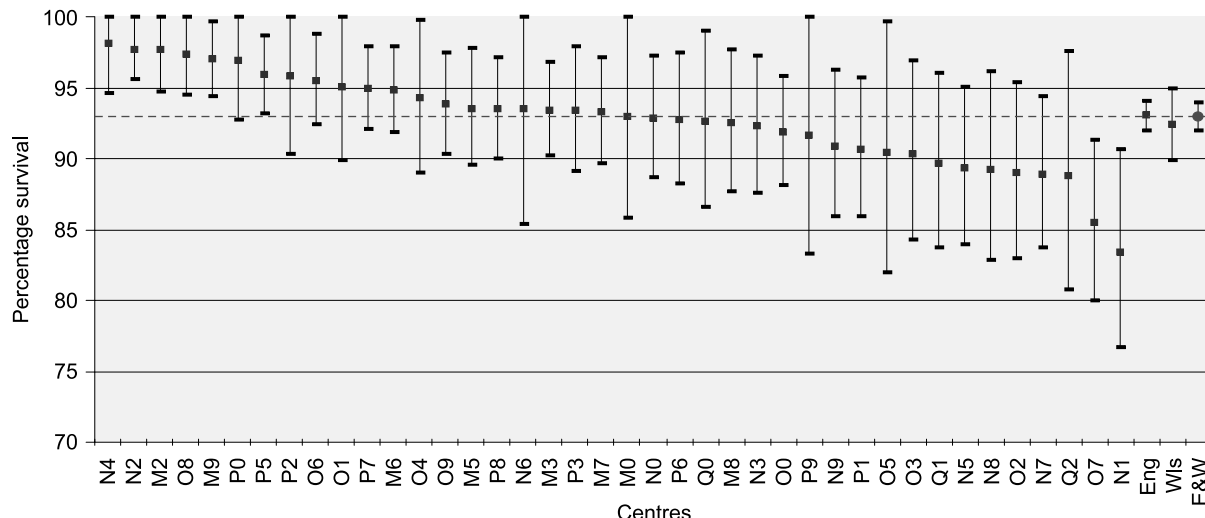


Figure 14.8: Age adjusted survival in the first 90 days; 2002 cohort
Showing 95% confidence intervals

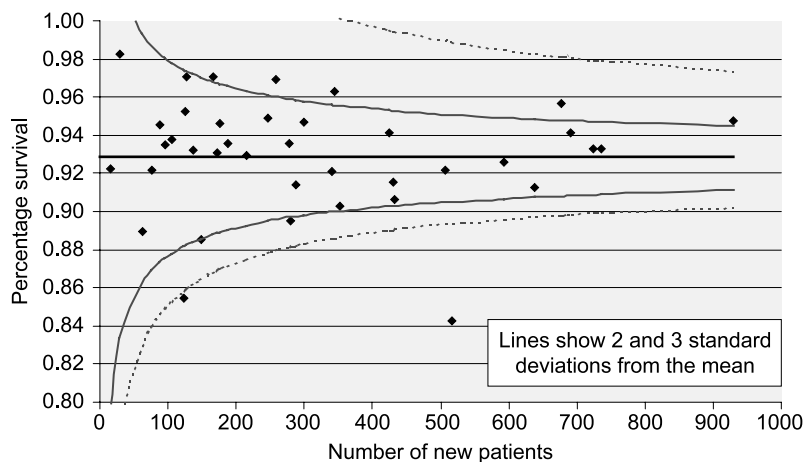


Figure 14.9: Funnel plot for age adjusted 90 days survival; 1997–2002 cohorts

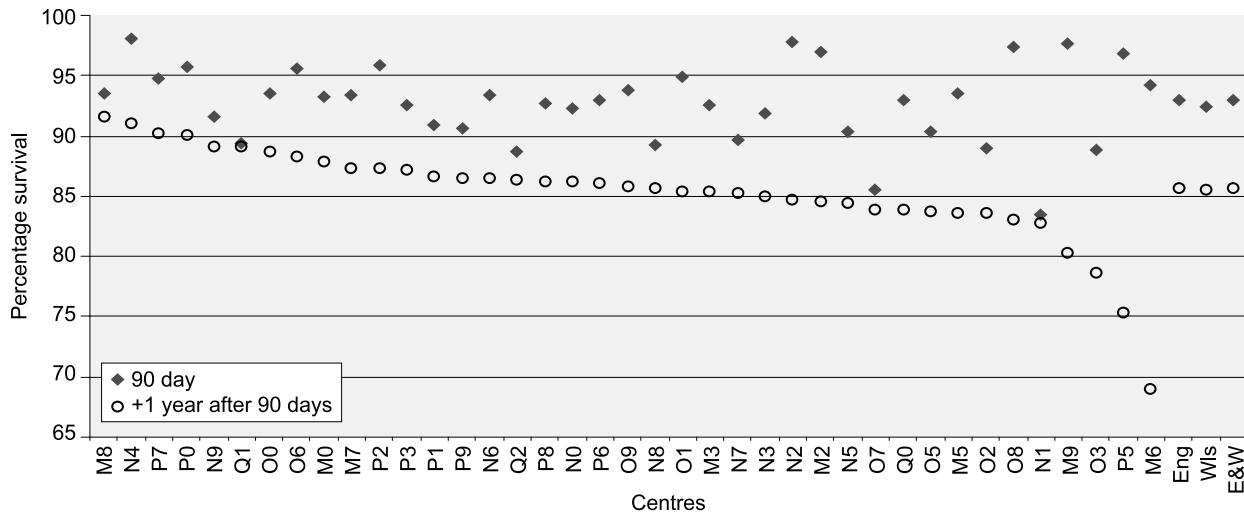


Figure 14.10: Adjusted survival of new patients, 90 day compared with 1 year after 90 days

those starting RRT. This will be investigated in further detail through consultation with these renal units.

Comparison of the 90 day and 1 year after 90 day survival

Similar to previous years, Figure 14.10 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. No consistency of better or worse than average performance can be inferred.

Changes in survival by centre 1997 – 2002

Annual changes in survival by individual renal units are shown in Figure 14.11.

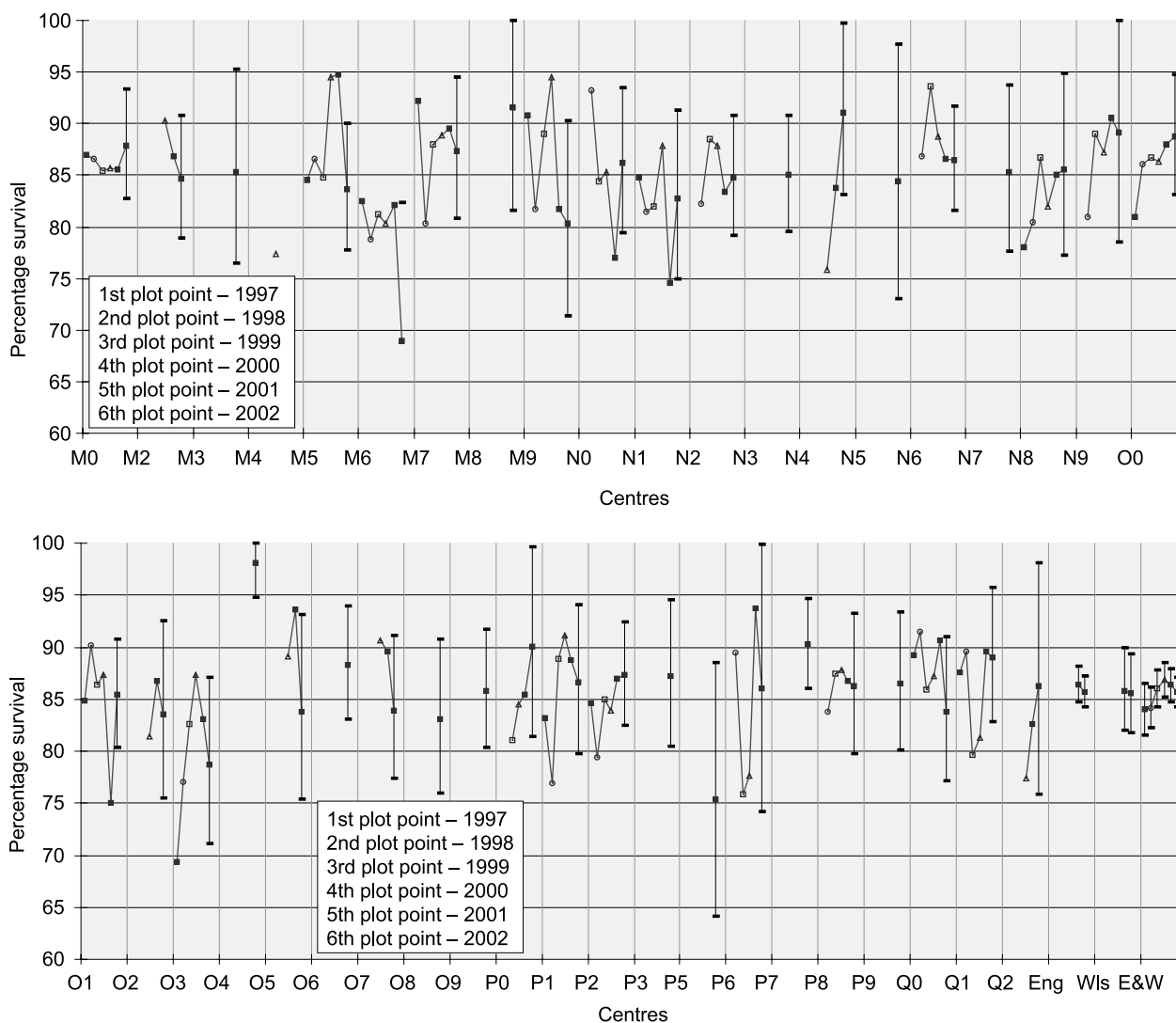


Figure 14.11: Age adjusted survival, 1 year after 90 days; 1997–2002 cohort

Appendix of survival tables

Z-scores

The Z-score expresses the divergence of a renal centre’s result from the most probable result (the mean of the Registry) as a number of standard deviations. Z-scores are especially informative when the distributions to which they refer, are normal.

The Z-score is useful when seeking to compare the relative standings of items (ie % survival in an individual centre) from distributions with different means and/or different standard deviations. Since the mean value and standard deviation for % survival depend upon the number and scatter of results from the individual centre, comparison between centres with differing numbers of patients is facilitated by standardising the result.

Mathematically $Z =$

$$\frac{\% \text{ survival in the centre} - \% \text{ survival for all patients}}{\text{Standard deviation of \% survival in the centre}}$$

As the standard deviation in the centre is determined by the number of patients and the scatter of values in the centre, the Z-score adjusts for the variation of patient numbers and the scatter in each centre. From the equation above it follows that a Z-score of 1 means the % survival observed is one standard deviation (for that centre) different from the mean for all centres.

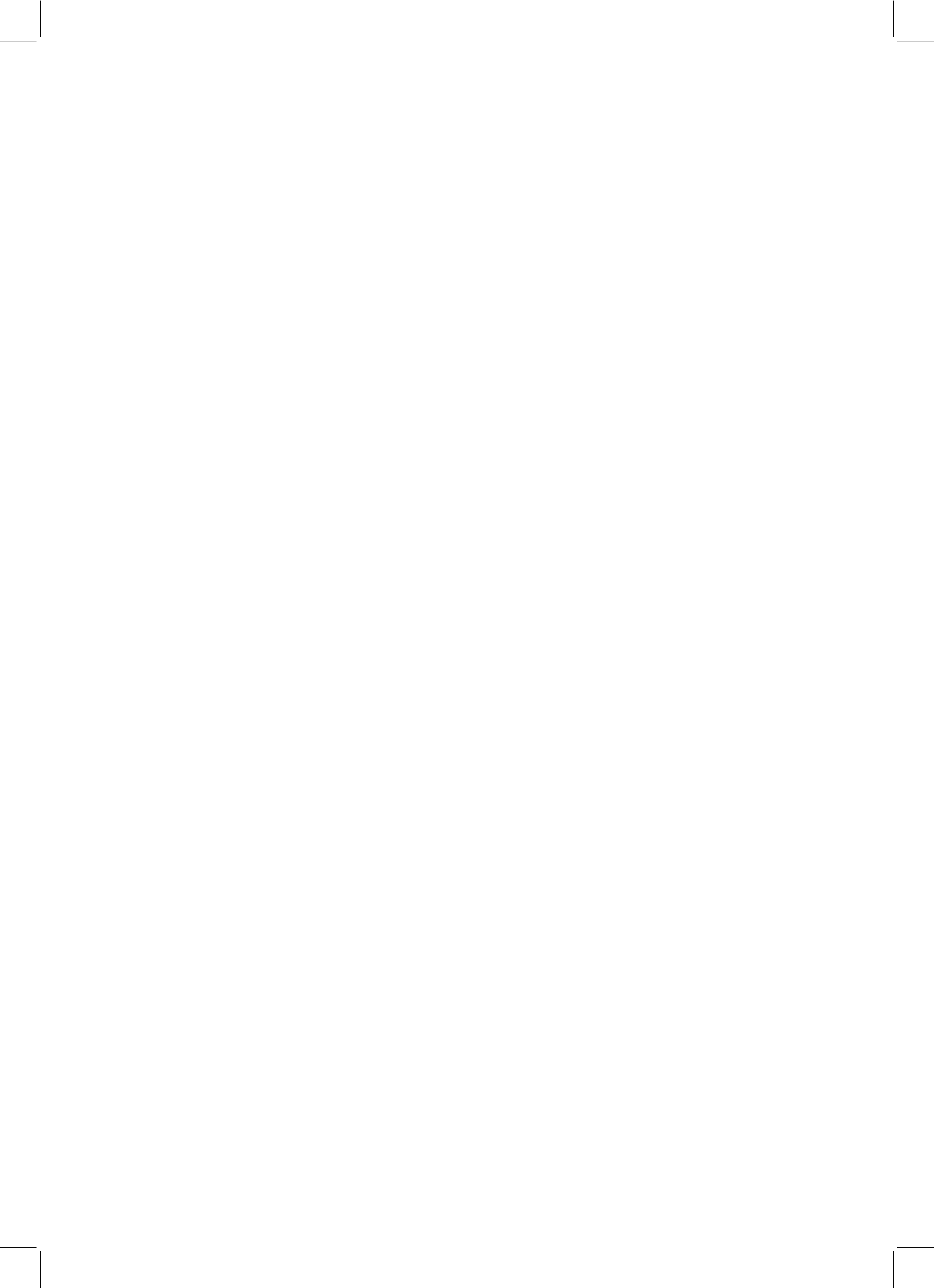
Thus a Z-score above 2 means the result is more than 2 standard deviations from the mean and thus outside the 95% probability: a Z-score above 3 means the result is more than 3 standard deviations from the mean and thus outside the 99.8% probability.

Tables of survival by centre and Z-scores**Table 14.12: 1 year after 90 day survival by centre for 1997–2002**

Centre	Unadjusted		Adjusted to age 60 years		Z-score
	1 year after 90 day survival & 95%CI		1 year after 90 day survival & 95%CI		
M0	83.9	81.1–86.7	87.0	84.6–89.4	0.84
M2	86.1	82.3–89.9	86.8	83.3–90.5	0.49
M3	84.1	76.4–91.7	86.6	80.4–93.4	0.21
M5	89.4	87.1–91.7	89.5	87.3–91.9	3.08
M6	76.9	71.0–82.8	79.6	74.5–85.1	–2.32
M7	86.6	83.8–89.4	88.2	85.7–90.7	1.76
M8	84.6	65.0–100.0	88.8	76.1–100.0	0.46
M9	81.2	76.2–86.1	86.5	82.9–90.3	0.32
N0	81.0	76.1–85.8	84.1	80.0–88.3	–0.89
N1	78.4	73.8–83.1	83.2	79.5–87.0	–1.43
N2	82.3	79.4–85.3	85.5	83.0–88.1	–0.31
N3	82.3	77.6–87.0	85.2	81.2–89.3	–0.38
N4	79.5	72.3–86.7	82.2	76.1–88.8	–1.15
N5	84.2	67.8–100.0	88.6	77.5–100.0	0.46
N6	87.2	84.6–89.8	88.8	86.5–91.2	2.43
N7	82.1	72.9–91.3	87.8	81.6–94.5	0.56
N8	78.5	74.4–82.7	83.0	79.6–86.5	–1.69
N9	83.2	77.4–89.0	86.4	81.7–91.3	0.18
O0	82.9	78.4–87.4	87.7	84.5–91.1	1.05
O1	81.9	78.7–85.2	85.0	82.2–87.8	–0.68
O2	75.4	66.7–84.2	83.8	78.0–90.1	–0.68
O3	77.3	73.2–81.3	80.1	76.5–83.8	–3.14
O5	84.8	78.5–91.1	87.9	82.9–93.1	0.75
O6	82.9	74.8–91.1	86.7	80.5–93.4	0.24
O7	86.1	81.7–90.5	89.1	85.7–92.7	1.78
O8	85.5	80.0–91.0	87.2	82.5–92.2	0.51
O9	83.0	78.2–87.9	85.2	81.0–89.6	–0.34
P0	81.1	74.9–87.3	83.6	78.3–89.2	–0.84
P1	86.9	83.8–90.0	87.5	84.6–90.5	1.05
P2	83.2	80.7–85.7	84.9	82.7–87.2	–0.88
P3	82.1	76.2–87.9	83.8	78.7–89.3	–0.78
P5	58.6	40.7–76.5	70.1	57.4–85.6	–2.20
P6	81.0	73.3–88.7	83.7	77.3–90.6	–0.66
P7	86.0	79.6–92.3	88.4	83.3–93.9	0.93
P8	85.6	82.1–89.0	86.7	83.6–90.0	0.48
P9	87.0	78.1–96.0	86.8	78.2–96.2	0.18
Q0	82.3	78.0–86.6	86.2	82.8–89.8	0.17
Q1	83.8	80.1–87.5	85.7	82.4–89.1	–0.15
Q2	77.6	70.0–85.2	84.1	78.6–89.9	–0.65
Eng	83.4	82.6–84.1	85.9	85.2–86.7	–0.10
Wales	83.1	80.8–85.3	86.3	84.4–88.2	0.36
E&W	83.4	82.7–84.1	85.9	85.2–86.7	Ref

Table 14.13: 90 day survival by centre for 1997–2002

Centre	Unadjusted		Adjusted to age 60 years		Z-score
	1yr after 90 day survival & 95%CI		1 year after 90 day survival & 95%CI		
M0	90.3	85.1–95.5	93.3	89.7–97.1	0.57
M2	96.3	93.2–99.5	97.0	94.4–99.6	3.69
M3	90.7	83.0–98.5	92.6	86.6–99.0	0.28
M5	92.0	87.7–96.3	93.5	90.0–97.1	0.51
M6	92.9	86.1–99.6	94.3	89.0–99.8	0.06
M7	90.4	84.0–96.7	93.5	89.2–98.0	–1.54
M8	89.5	75.7–100.0	93.5	85.4–100.0	–0.13
M9	95.8	90.2–100.0	97.7	94.7–100.0	4.83
N0	90.2	84.1–96.3	92.3	87.6–97.3	0.56
N1	77.9	69.1–86.7	83.4	76.8–90.6	–1.94
N2	96.9	93.9–99.9	97.7	95.6–100.0	4.15
N3	89.3	84.4–94.3	91.9	88.1–95.9	–0.99
N4	97.1	91.4–100.0	98.1	94.6–100.0	3.23
N5	84.6	70.7–98.5	90.4	82.0–99.7	
N6	90.8	86.4–95.2	93.5	90.2–96.8	1.58
N7	82.8	73.0–92.5	89.7	83.7–96.0	–0.30
N8	84.2	74.7–93.7	89.2	82.8–96.2	–1.12
N9	87.5	74.3–100.0	91.7	83.3–100.0	1.21
O0	89.2	82.5–95.8	93.6	89.5–97.8	1.76
O1	93.3	89.5–97.1	94.9	92.0–97.9	–0.27
O2	82.8	73.6–92.1	89.0	83.0–95.4	0.54
O3	86.4	80.0–92.8	88.9	83.7–94.4	–5.91
O4	92.3	83.9–100.0	95.1	89.9–100.0	
O5	86.7	78.1–95.3	90.4	84.2–97.0	–1.92
O6	93.9	89.5–98.3	95.5	92.4–98.8	0.83
O7	78.7	71.0–86.4	85.5	80.0–91.3	–2.13
O8	95.9	91.5–100.0	97.4	94.6–100.0	3.64
O9	92.2	87.8–96.6	93.8	90.4–97.4	1.66
P0	94.9	87.9–100.0	95.8	90.3–100.0	0.12
P1	87.1	79.9–94.2	90.9	85.9–96.2	–0.63
P2	94.7	91.1–98.3	95.9	93.1–98.7	2.84
P3	90.7	84.6–96.8	92.6	87.7–97.7	0.45
P5	94.7	87.6–100.0	96.9	92.8–100.0	4.16
P6	90.0	79.3–100.0	93.0	85.8–100.0	–2.63
P7	93.2	89.3–97.1	94.8	91.8–97.9	1.44
P8	91.2	85.7–96.7	92.7	88.3–97.4	1.24
P9	87.6	81.3–93.9	90.7	85.9–95.7	–1.07
Q0	89.6	83.5–95.7	92.9	88.7–97.3	–0.61
Q1	86.2	79.2–93.1	89.3	84.0–95.0	–1.76
Q2	82.4	69.5–95.2	88.8	80.7–97.6	0.21
Eng	90.4	89.4–91.4	93.0	92.0–94.1	–0.35
Wales	89.1	85.6–92.5	92.4	89.9–95.0	1.48
E&W	90.3	89.3–91.3	93.0	92.0–94.0	Ref



Chapter 15: Elderly Patients on Renal Replacement Therapy

Summary

- The median age of incident patients has risen in the last 20 years to 64.8 years, although there has been no increase in the last 3 years.
- Twenty-two percent of new patients starting RRT were ≥ 75 years old and 12% of all prevalent patients were ≥ 75 years old.
- In the elderly, reno-vascular disease (18%) was the most common identified cause of established renal failure. Diabetic nephropathy was the cause in only 8% of those over 74. 'Uncertain' diagnosis was frequent (22% in 65–74 yrs age group; 31% in ≥ 75 years).
- Older patients more often had co-morbidity present at the start of dialysis than those under 65 (67% and 54% respectively, $p < 0.0001$), but there was not an increased burden of co-morbidity in those of 75 and over compared with those of 65–74, indeed some co-morbidities were significantly less common in that age group.
- Survival falls progressively with increasing age: 1 year after 90 day survival in 75–79 year olds was 74% compared with 57% in those aged ≥ 85 ($p < 0.001$).
- At 1 year after 90 days, treatment withdrawal was the commonest cause of death in the very elderly patients (27%): it was twice as common as a cause of death in the older patients than those aged 65–74 years ($p < 0.05$). Otherwise in both the elderly age groups cardiac death was most common (65–74 – 27%; ≥ 75 – 22%), followed by infection.
- Only 8% of patients aged ≥ 75 have a functioning renal transplant compared with 29% of those in the 65–74 years age group and 57% of those < 65 years. 78% of patients aged ≥ 75 years were on HD compared with 30% < 65 years. PD usage was similar in the three age cohorts (14%, 17%, and 14%).
- Patients aged ≥ 75 years were significantly less likely to be in the highest quintile of Townsend scores, ie less likely to be deprived.
- In achievement of the Renal Association Standard for haemoglobin the elderly do at least as well as the young.
- Systolic BP Standards were achieved less often in the elderly but diastolic more often: there was little difference between the two elderly age groups.
- A lower percentage of younger dialysis patients achieved the RA Standards for serum phosphate than of the elderly age groups (< 65 years – 54%, 65–74 years – 67%, ≥ 75 years – 73%; $p < 0.0001$), with the most elderly significantly the highest in achievement. Achievement of the serum calcium Standard was similar in all ages.

Introduction

With increasing numbers of patients on renal replacement therapy (RRT), the median age of incident patients has risen in the last 20 years to 64.8 years, although there has been no increase in the last 3 years (Table 15.1). The proportion of incident patients aged over 75 increased from 17.6% in 1998 to 22.3% in 2003.

The median age for all prevalent RRT patients has increased from 54.3 years in 1998 to 56.0 years in 2003. As expected, the median age was lowest for the transplant patients, followed by PD patients, with the HD patients having the highest median age. The median age for patients on PD has shown a trend to decrease whereas the median age for haemodialysis patients has increased from 62.6 years to 64.3 years (Table 15.2).

With the aged general population increasing it was not surprising that the largest growth has been seen in the over 65 age group. Prevalent RRT patients were also surviving longer (see

Table 15.1: Median age and percentage of incident patients over 75 in England and Wales 1998–2003

Year	Median age	% over 75
1998	63.0	17.6
1999	63.0	18.3
2000	64.0	21.2
2001	64.8	21.0
2002	65.5	23.5
2003	64.8	22.3

Table 15.2: Median age of treatment modalities for England and Wales 1998–2003

	Transplants	PD	HD	All
Median age 2003	49.3	58.0	64.3	56.0
Interquartile range	39–60	45–69	50–74	43–68
Range between units	40–57	49–65	56–72	51–65
Median age 2002	49.6	58.3	64.5	55.9
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

Report 2003). The recent stability in incident patients of the median age and proportion aged over 75, while acceptance rates continue to increase, may in part be due to the recently increased provision of supportive care teams for those not wishing to undertake dialysis.

Increasingly elderly patients carry associated co-morbidity, in particular cardiac disease and as a consequence a need for more medical care and a potential for reduced survival. As many of the elderly patients are unfit for transplantation they remain on dialysis, usually haemodialysis, which brings with it issues regarding cost, vascular access difficulty, and hospitalisation.

In this chapter on older patients on RRT in the UK, 'elderly' was defined as 65 years and more: patients have been analysed in two groups, 65–74 years and ≥ 75 years. These elderly patients were also compared with those less than 65 years. Patients have been analysed by renal centre for primary renal diagnosis, ethnic origin, associated co-morbidity, treatment modality, dialysis adequacy, achievement of Renal Association standards, causes of death and survival. The incident and prevalent cohorts have been analysed separately.

Methods

The incident patient cohort included all those patients starting RRT since the beginning of 1997 until the end of 2003, while prevalent patients included all those alive on RRT on December 31st 2003. Chi-squared and Fisher's exact tests were used for statistical analyses, with Kaplan-Meier for survival.

Survival analysis of incident patients was at 90 days and 1 year after 90 days. Ninety-day survival analysis included all those patients starting RRT from 1997 to September 30th 2003 and one year after 90 days survival analysis included all those patients starting RRT from 1997 to September 30th 2002.

Incident Patients

The proportion of elderly patients starting RRT in each centre is shown in Table 15.3. As numbers were relatively small in each centre per year, they were aggregated for the last 3 years to give more meaningful figures (Table 15.3). In the last three years in E&W, the proportion of incident patients over 75 years remained stable (21% – 2001, 24% – 2002, 21% – 2003). In those centres with the last three years data available, the proportion of incident patients over 75 years varied from around 15% to 35%. This may be due to differences in the demography of the local population, referral and acceptance policies, or availability of treatment facilities.

Primary renal diagnosis

In contrast with patients under 65, in whom diabetes (DM) is the most common diagnosis (21%) and reno-vascular disease (RVD) relatively uncommon (8%), in the age group 65 to 74 years, reno-vascular disease (18%) was the most common identified cause of established renal failure, with diabetes 17% (Figure 15.1, Table 15.4). However in those aged 75 or more, RVD was the commonest identified cause of established renal failure (31%) with diabetes only 8% and polycystic disease (2%). These differences were all statistically significant ($p < 0.001$). In both older groups the majority of patients were of 'uncertain' diagnosis (22% in the 65–74 yrs age group; 31% in ≥ 75 years),

Table 15.3: Proportion of incident patients aged ≥ 75 in each unit in 2001–2003

Treatment centre	% ≥ 75 yrs	No ≥ 75 yrs
Bradford	15	30
Sheffield	16	73
Sunderland	17	25
Cambridge	18	51
Middlesbrough	18	53
Preston	18	62
Stevenage	18	58
Guys	19	64
Leicester	19	97
Portsmouth	19	81
Carshalton	21	103
Liverpool	21	91
Leeds	21	97
Wordsley	21	21
Nottingham	22	68
Wolverhampton	22	58
Wrexham	22	24
Cardiff	23	108
Reading	24	42
Carlisle	25	21
Hull	25	63
Oxford	25	126
Coventry	26	70
Heartlands	28	68
Swansea	29	102
Truro	29	41
Bristol	30	132
Southend	30	34
Gloucester	31	50
Plymouth	31	67
York	32	52
Exeter	35	97
H&CX**	17	55
Newcastle**	19	37
Kings**	20	46
Bangor**	25	17
Wirral**	29	25
Ipswich**	30	23
Clwyd**	36	10
Derby*	15	9
Hope*	16	23
England	22	2,113
Wales	25	261
E&W	22	2,374

*One year data (2003).

**Two year data (2002–03).

reflecting the large numbers who were referred with small kidneys.

Ethnicity

Considering only those centres with $\geq 75\%$ complete returns (all three age groups, $n = 10,859$), the ethnic distribution of incident patients by age was analysed in the three age groups (Table 15.5). In both elderly age groups the majority of patients were White (95% in ≥ 75 years, 89% in 65–74 years), but with significantly fewer ethnic minority patients in the ≥ 75 years cohort ($p < 0.001$): the difference was largely in the South-Asian and African-Caribbean cohorts.

It was known that the median age of South-Asians and African-Caribbeans starting RRT is lower than that of Caucasians (Chapter 4), reflecting the younger median age of the ethnic minority population within the UK as a whole. The potential need for RRT in the elderly in the ethnic minorities was not otherwise identified.

Co-morbidity

Considering only those centres with $\geq 75\%$ complete returns (all three age groups, $n = 4,122$), co-morbidity was compared in the three age groups. Not surprisingly, significantly more of the elderly had co-morbidity present at the start of dialysis than those under 65 (67% and 54% respectively, $p < 0.0001$).

Cardiac disease was the most common co-morbidity present in total, but in those under 65 smoking was the most common co-morbidity (Figure 15.2). Those aged < 65 years were significantly more likely to be current smokers at the start of RRT (20%) when compared with the other two groups (65–74 years – 16%; ≥ 75 years – 11.5%, $p < 0.0001$) but COPD was more common in the elderly (65–74 years – 11%; ≥ 75 years – 10%) than younger patients (7%, $p < 0.0001$), suggesting many older patients may be ex-smokers (Table 15.6). Diabetes as a co-morbidity in patients with other causes of renal failure was twice as common in the elderly than the younger group (10% compared with 5%, $p < 0.0001$).

Perhaps unexpectedly there was not an increased burden of co-morbidity in those of 75

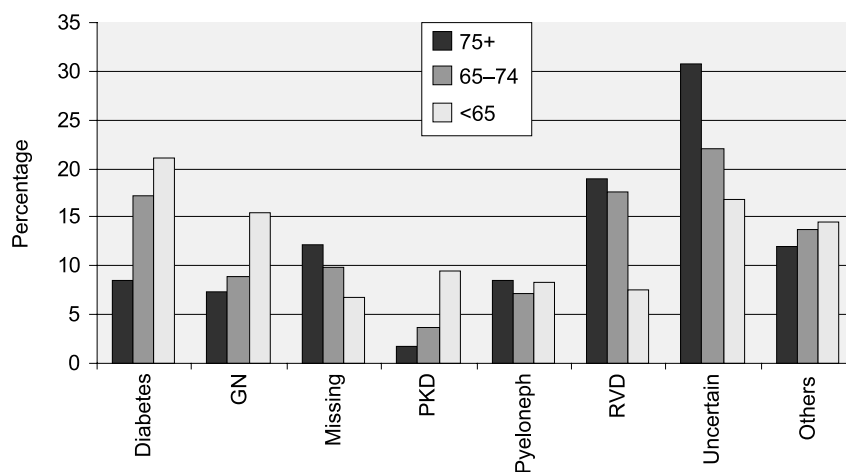


Figure 15.1: Primary renal diagnosis in incident patients in different age groups

Table 15.4: Primary renal diagnosis in incident patients in different age groups

Age	Diabetes	GN	PKD	Pyelonephritis	RVD	Uncertain
<65	21.2% (1,909)	15.4% (1,395)	9.4% (852)	8.2% (746)	7.6% (688)	16.8% (1,519)
65-74	17.1% (838)	8.8% (429)	3.8% (184)	4.1% (345)	17.5% (856)	22.1% (1,076)
≥75	8.4% (313)	7.2% (271)	1.8% (68)	8.5% (317)	31.3% (704)	30.8% (1,145)

() = number of patients.

Table 15.5: Ethnicity in incident patients by age

Age	South-Asian	African-Caribbean	Chinese	Other	White
≥75	2.6% (58)	1.2% (27)	0.3% (6)	1.3% (30)	94.5% (2,090)
65-74	5.9% (176)	3.5% (105)	0.4% (13)	1.3% (38)	88.8% (2,644)
<65	9.4% (538)	4.4% (248)	0.5% (27)	1.8% (102)	83.8% (4,757)

() = number of patients.

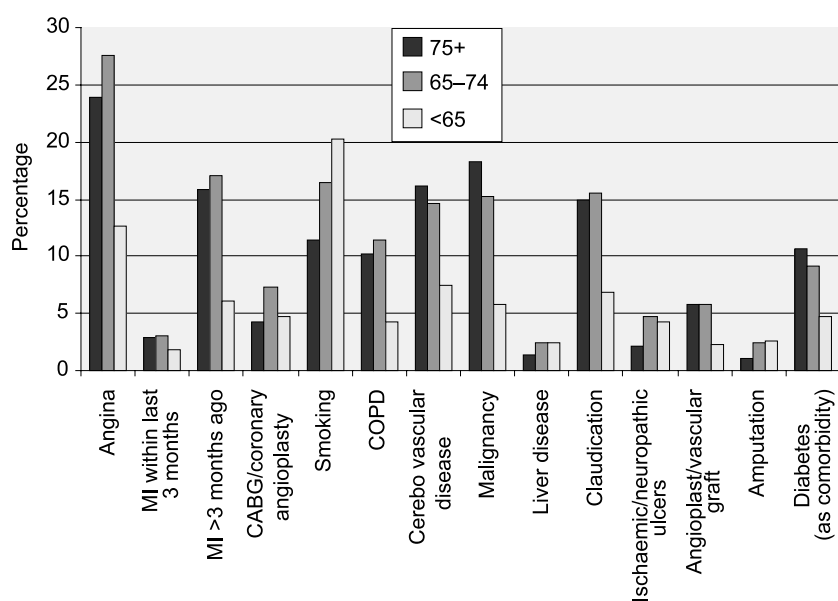


Figure 15.2: Co-morbidities in different age groups

Table 15.6: Co-morbidity by age group

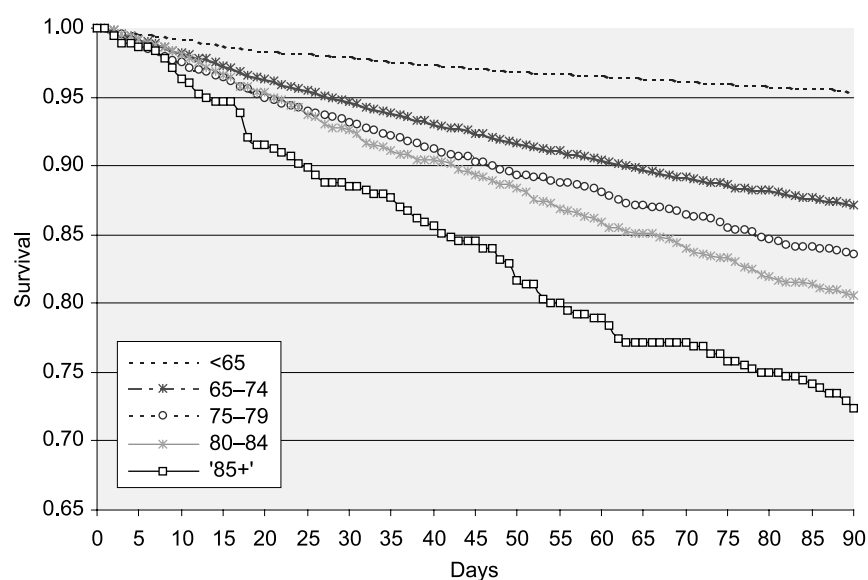
Co-morbidity	<65		65–74		75+		P-value
	No.	%	No.	%	No.	%	
Angina	266	13	323	28	200	24	<0.0001
MI within last 3 months	38	2	35	3	24	3	0.0559
MI >3 months ago	127	6	198	17	132	16	<0.0001
CABG/coronary angioplasty	89	5	78	7	31	4	0.0023
Smoking	406	20	183	16	92	11	<0.0001
COPD	89	4	134	11	85	10	<0.0001
Cerebro vascular disease	157	7	171	15	135	16	<0.0001
Malignancy	123	6	179	15	152	18	<0.0001
Liver disease	52	2	29	2	11	1	0.1343
Claudication	143	7	182	16	124	15	<0.0001
Ischaemic/neuropathic ulcers	89	4	56	5	18	2	0.0084
Angioplasty/vascular graft	48	2	68	6	48	6	<0.0001
Amputation	56	3	29	2	9	1	0.0311
Diabetes (as comorbidity)	97	5	106	9	89	11	<0.0001

and over compared with those of 65–74, indeed some co-morbidities were significantly less common in this age group, namely smoking ($p=0.002$), ischaemic ulcers ($p=0.002$), amputation ($p=0.02$) and previous CABG/coronary angioplasty ($p=0.005$). There were no co-morbidities significantly more common in this age group compared with the 65–74 group. This may reflect screening procedures for fitness for dialysis, or choice by many elderly and frail patients to take the supportive care option. There may be an increase in other co-morbidities not recorded by the Registry in the very elderly and the role of selection by survival to the start of RRT was unclear.

Survival

Using Kaplan-Meier methodology, survival was analysed at 90 days and for 1 year after 90 days (Figures 15.3 and 15.4). Incident patients aged <65 were compared with those aged 65–74 and ≥ 75 : the latter were split further into 5 year age bands.

Over the first 90 days, survival fell progressively with increasing age, such that those patients starting RRT aged ≥ 85 had a 72% chance of being alive compared with 83% in those aged 75–79. This was significantly lower than the survival of those aged <75 (65–74 years – 87%; <65 years – 95%). The survival

**Figure 15.3: Kaplan-Meier survival by age group (90 days)**

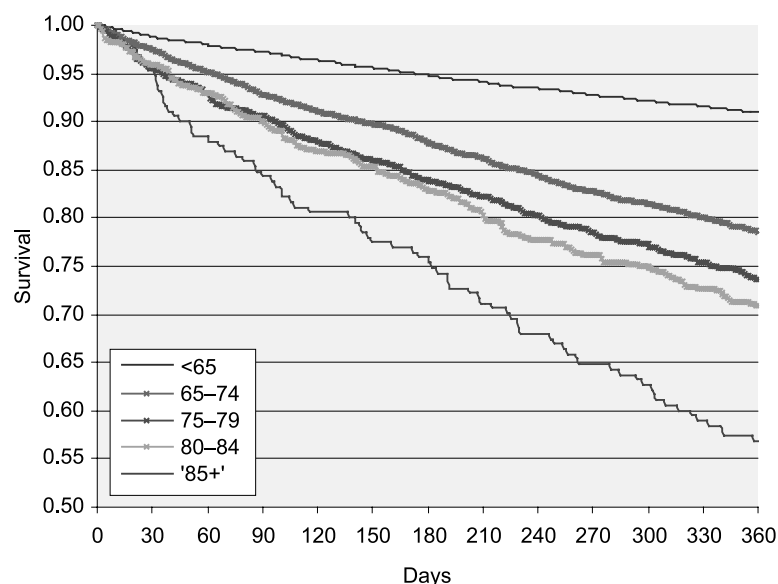


Figure 15.4: Kaplan-Meier survival by age group (1 year after 90 days)

advantage in patients aged 75–79 over those aged 80–84 was only 3% by the end of day 90 and 9% over those aged 85 or more.

This pattern was repeated during the year after 90 days (Figure 15.4). The patients aged 65–74 had a 78% chance of being alive at 1 year after 90 days compared with 73.5% in those aged 75–79, 71% in those aged 80–84 and 57% in those aged 85 or more ($p < 0.001$).

Cause of Death

The cause of death in those elderly patients where it had been recorded ($n = 660$) was analysed and grouped into the following categories:

cerebrovascular accident, treatment withdrawal, cardiac disease, infections, malignancy, uncertain/not determined and ‘other’. During the first 90 days, death from cardiac disease was the commonest cause in both elderly age groups (65–74 – 32%; ≥ 75 – 24%, Figure 15.5). Treatment withdrawal was almost twice as common as a cause of death in those aged ≥ 75 than in the other age groups, which were similar (19% v 10% and 9% respectively, $p < 0.05$). Infection was the second most common cause of death in both elderly groups (65–74 – 20%; ≥ 75 – 21%). Malignancy accounted for only 6% of deaths in those ≥ 75 years. This low percentage may be explained by the high percentage of treatment withdrawals in the same

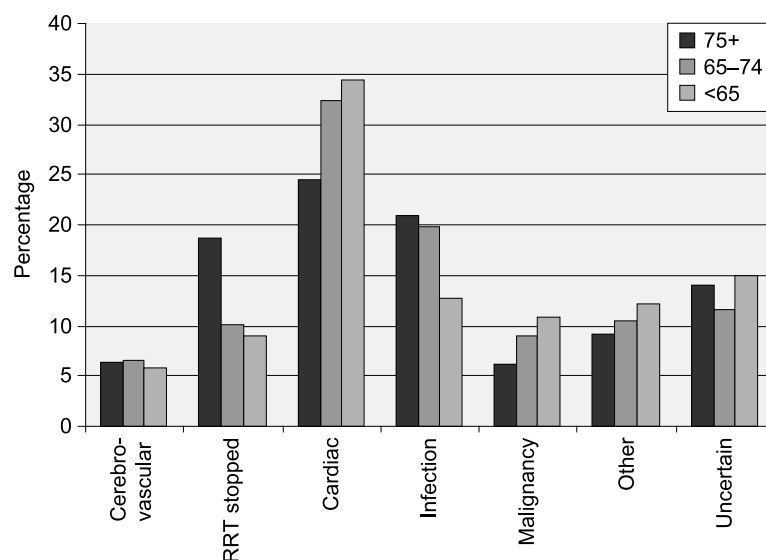


Figure 15.5: Cause of death at 90 days in three age groups

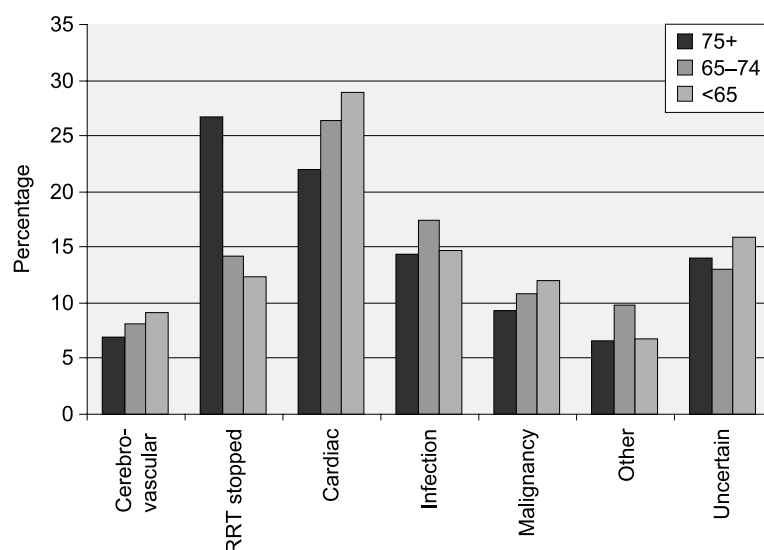


Figure 15.6: Cause of death in 1 year after 90 days in three age groups

group, where the factors prompting withdrawal are undeclared.

At 1 year after 90 days (Figure 15.6), the patterns were similar to those at 90 days, with large numbers of patients in both the elderly age groups dying from cardiac disease (65–74 – 27%; ≥ 75 – 22%), but treatment withdrawal became the commonest cause of death in the very elderly patients (27%). It was twice as common as a cause of death in the older patients than those aged 65–74 years ($p < 0.05$).

There was no difference in the causes of death up to 3 years compared with 3–5 years within the two elderly age groups. Treatment withdrawal remained more common in the very elderly at both up to 3 and 3–5 years (23% and 27% in those ≥ 75 ; 12% and 14% in those 65–74, $p < 0.0001$).

Prevalent Patients

The proportion of prevalent patients aged ≥ 75 has increased slowly over the last six years; although many patients of this age are starting RRT, they are of course dying more quickly than younger patients. The proportion of prevalent patients aged ≥ 75 years was 9% in England in 1998 and has risen to 12% in 2003 (Figure 15.9). In Wales from a lower start (7%) there has been a larger increase to 13%, but numbers are small. Guy's, Newcastle and Sunderland had the lowest proportion of

patients aged ≥ 75 years (7%) while York and the Wirral units had the highest (22%) (Table 15.7).

Treatment Modality

There were large differences in modality type between the age groups (Figure 15.8) with more elderly patients on haemodialysis (≥ 75 years – 78%, 65–74 years – 54% and < 65 years – 30%, $p < 0.0001$). Patients in the older age groups are not receiving transplants (≥ 75 years – 8%, 65–74 years – 30%, < 65 years – 57%; $p < 0.0001$), probably as a consequence of comorbidity making them unsuitable candidates. Within the two elderly age groups, the 65–74 years group had fewer patients on haemodialysis (53% vs. 78%) and more patients on

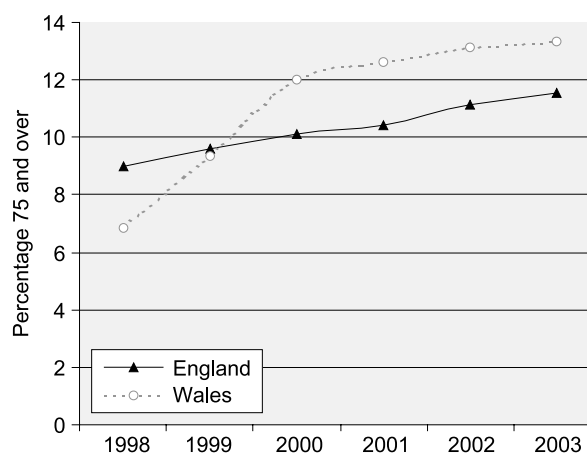
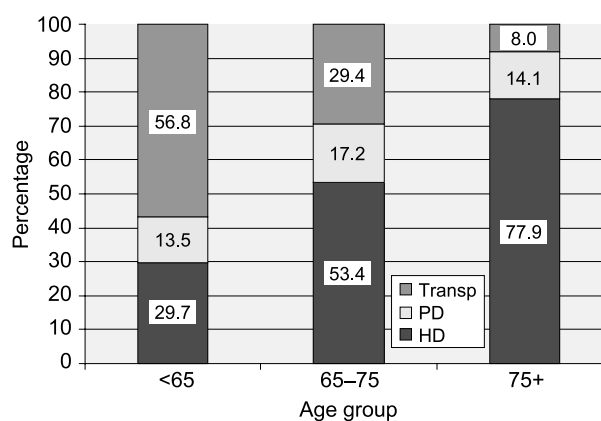


Figure 15.7: Percentage of prevalent RRT patients aged ≥ 75 , England and Wales 1998–2003

Table 15.7: Proportion of prevalent patients aged ≥ 75 in 2003

Centre	No. 75+	% 75+
Bangor	20	21
Bradford	29	9
Bristol	158	15
Cambridge	69	9
Carlisle	22	13
Carshalton	92	10
Clwyd	13	19
Coventry	65	11
Cardiff	128	11
Derby	59	21
Exeter	96	18
Gloucester	48	19
Guys	87	7
H&CX	117	11
Heartlands	86	17
Hope	52	9
Hull	77	15
Ipswich	35	15
Kings	66	11
Leicester	111	10
Liverpool	102	8
Middlesbrough	62	11
Newcastle	52	7
Nottingham	93	11
Oxford	153	11
Plymouth	52	13
Portsmouth	115	11
Preston	73	10
Leeds	116	9
Reading	43	19
Sheffield	103	9
Stevenage	83	15
Southend	41	21
Sunderland	19	7
Swansea	71	16
Truro	48	20
Wirral	35	22
Wolverhampton	63	16
Wordsley	33	13
Wrexham	29	14
York	44	22
England	2,599	12
Wales	261	13
E&W	2,860	12

peritoneal dialysis (PD) and transplants (Tx) (PD: 17% vs. 14%; Tx: 30% vs. 8%). These differences were statistically significant ($p < 0.0001$).

**Figure 15.8: Treatment modalities in three age groups**

Ethnicity

Ethnic breakdown in the prevalent population reflected patterns found in the incident cohort (Table 15.8). The majority of patients in both elderly age groups were White (≥ 75 years – 91%, 65–74 years – 85%). When compared with the 65–74 years age group, there were fewer ethnic minority patients in the ≥ 75 years cohort ($p < 0.0001$). This difference was largely seen in the South Asian (3.5%) and African-Caribbean cohorts (3%).

Within ethnic groups, the proportion aged ≥ 75 varied. Whilst 12% of Whites on RRT were aged ≥ 75 , only 6% of South Asians and 8% of African-Caribbeans were in this age group.

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 from the 2001 Census data) 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.

Using the Townsend score, social deprivation was analysed in the three age groups (Table 15.9) and the Townsend scores were grouped into quintiles. Using the Chi-squared test, a difference was seen between the three age groups and the Townsend score distribution ($p < 0.0001$).

Table 15.8: Ethnicity of prevalent patients on RRT in three age groups

Age	Ethnic Groups					Total
	South Asian	African-Caribbean	Chinese	Other	White	
≥75	3.5% (65)	3.0% (54)	0.4% (7)	2.6% (44)	91.0% (1,700)	1,870
65–74	7.0% (221)	5.0% (155)	0.5% (17)	2.0% (70)	85.0% (2,718)	3,181
<65	7.5% (872)	4.0% (501)	0.5% (60)	3.0% (367)	85.0% (9,795)	11,595

() = number of patients.

Table 15.9: Social deprivation score in three age groups

Age	Townsend quintile score					Total
	1	2	3	4	5	
≥75	19% (541)	21% (583)	20% (567)	22% (612)	18% (522)	2,825
65–74	19% (872)	21% (995)	19% (862)	21% (956)	20% (964)	4,649
<65	18% (2,940)	19% (3,212)	18% (3,042)	22% (3,644)	23% (3,755)	16,593

() = number of patients.

Renal Association Standards

The Renal Association sets standards for a number of laboratory variables against which the Registry audits the reporting renal units. This year a selection of variables were analysed to assess results in the elderly. Because of the small number of patients aged ≥75 years with a functioning renal transplant, only results from those on dialysis were analysed.

Haemoglobin

All established patients on RRT should achieve a haemoglobin of ≥10 g/dl. The elderly do at least as well as the young (Table 15.10). Between the two elderly groups there was no significant difference in the percentage of patients achieving the standard for haemoglobin ($p=0.39$). This was also true for both dialysis modalities ($p=0.25$ for HD and PD).

The median Hb was similar in both elderly groups on dialysis (11.5 g/dl) but was higher in those on PD (11.9 g/dl) than HD (11.4 g/dl).

Considering haemoglobin in those aged ≥75 years by 5-year age bands (75–79, 80–84, and 85+) there was no difference in the proportion achieving desirable levels on dialysis (85%, 84%, 87%, $p=0.5$). The same was true of HD and PD patients analysed separately.

Blood Pressure

The Renal Association blood pressure Standard for patients on PD and post HD is set at <130/80 mmHg.

For systolic BP, <50% of patients on dialysis achieved the Standard, irrespective of modality or age group. Comparing the three age groups, older dialysis patients had significantly worse performance rates ($p=0.009$), but within the two elderly groups no difference was seen (≥75 years – 45%, 65–74 years – 41%, $p=0.1$) (Table 15.11). For HD patients the trends were similar. In patients on PD, no difference was seen between the age groups (≥75 years – 32%, 65–74 years – 34%, <65 years – 38%; $p=0.13$).

Table 15.10: Percentage haemoglobin ≥10 g/dl by age and dialysis modality

Age	All dialysis		Haemodialysis		Peritoneal dialysis	
	<10	10+	<10	10+	<10	10+
≥75	15%	85%	16%	84%	9%	91%
65–74	16%	84%	18%	82%	11%	89%
<65	18%	82%	20%	80%	14%	86%

Table 15.11: Proportion achieving BP Standards by age and modality

Age	All dialysis		Haemodialysis		Peritoneal dialysis	
	Systolic <130	Diastolic <80	Systolic <130	Diastolic <80	Systolic <130	Diastolic <80
≥75	42%	79%	43%	81%	32%	63%
65–74	45%	74%	48%	79%	34%	55%
<65	47%	58%	50%	63%	39%	43%

Median systolic blood pressure readings were 131 mmHg, 132 mmHg and 134 mmHg respectively in three age groups (<65 years, 65–74 years and ≥75 years).

Diastolic control was better than systolic control in all age groups. Between the two elderly groups, the diastolic control was statistically better in the ≥75 years age group (≥75 years – 79%, 65–74 years – 74%; $p=0.002$). Median diastolic readings however were lower in those aged ≥75 years (67 mmHg) when compared with the other two groups (65–74 years – 69 mmHg, <65 years – 75 mmHg).

In those aged ≥75 years, blood pressure was further analysed to see if there were any differences with increasing age. In 5-year age band intervals, systolic and diastolic blood pressure control was no different with increasing age, irrespective of modality.

Serum Phosphate and Calcium

The Renal Association standards document recommends a serum phosphate level of <1.8 mmol/L. A lower percentage of younger

dialysis patients achieved the RA ideal values than in the elderly age groups (<65 years – 54%, 65–74 years – 67%, ≥75 years – 73%; $p < 0.0001$) (Figure 15.9). A similar pattern was seen in patients on HD (51%, 64% & 71% respectively, $p < 0.0001$) or PD (62%, 76% & 83% respectively, $p < 0.0001$). Significantly more of the most elderly population achieved the RA Standard in both treatment modalities ($p < 0.01$).

In the ≥75 years group, the cohort was further analysed in 5-year age bands (75–79, 80–84, 85+) to see if there were further differences in serum phosphate amongst the older patients. There was a suggestive trend towards lower serum phosphate with increasing age which did not reach statistical significance (Table 15.12) (Figure 15.10).

Phosphate control in the elderly may be better because of a reduced dietary intake since phosphate levels are known to mirror protein intake. The median phosphate fell with increasing age band, from 1.5 mmol/L in patients aged 75–79 to 1.39 mmol/L in those aged 85 or more on dialysis and was similar across modalities.

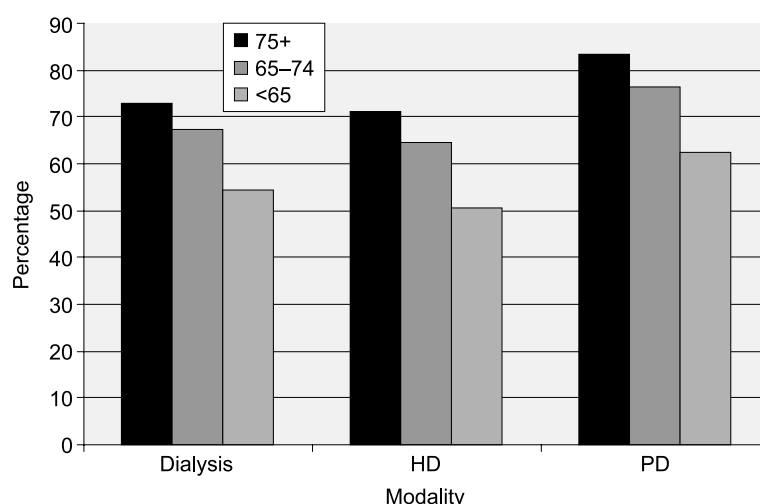
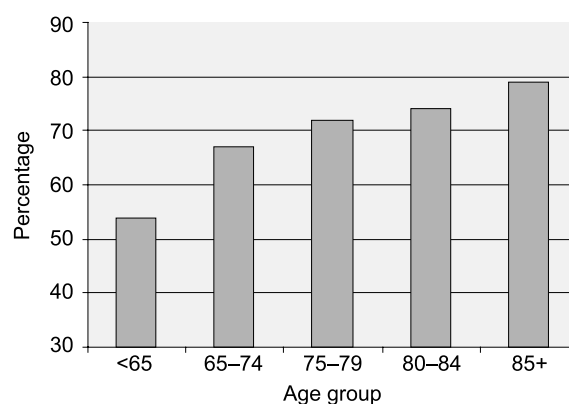
**Figure 15.9: Percentage achievement of serum phosphate Standard in three age groups: dialysis**

Table 15.12: Percentage achievement of serum phosphate <1.8mmol/L in the elderly

Age	Dialysis	HD	PD
<65	54%	51%	62%
65–74	67%	64%	76%
75–79	72%	70%	81%
80–84	74%	72%	87%
85+	79%	77%	96%

The RA standards document recommends that the corrected serum calcium should be kept between 2.2 and 2.6 mmol/L. This was analysed by age and methodology used to measure serum albumin for the correction of the raw calcium values (BCG or BCP). Neither the albumin assay method, modality, nor age group had an effect on the proportion of patients achieving RA standards (Table 15.13).

**Figure 15.10: Percentage achievement of serum phosphate <1.8 mmol/L by age****Table 15.13: Percentage achieving the RA Standard for corrected serum calcium in three age bands**

Age	Proportion of patients in range (2.2–2.6 mmol/L)					
	Dialysis		Haemodialysis		Peritoneal dialysis	
	BCG	BCP	BCG	BCP	BCG	BCP
<65	72%	73%	72%	71%	65%	77%
65–74	73%	76%	73%	75%	74%	80%
≥75	75%	77%	76%	76%	73%	82%

Discussion

Several countries have reported an increase in the proportion of elderly patients starting RRT¹. Of new patients starting treatment reported to the Registry, 22% are now aged ≥75 years, this has increased from 15% in 1997. Prior to 1980, few ERF patients over the age of 60 were dialysed, partly through reluctance to refer to nephrology departments, partly because of reservations about likely prognosis and quality of life on dialysis and partly because of a lack of resources². The reasons for the subsequent increase in numbers of elderly people commenced on RRT are multiple and include amongst others: an increased awareness of primary and secondary care physicians of the need to refer, technical advances leading to improved tolerance of dialysis, the development of PD programmes, an increase in treatment centres and the clinical demonstration of benefit to the elderly^{3,4}.

The small proportion of non-Whites among the elderly has been highlighted in the literature^{4,5} and explained by several factors. It is known that the median age of South Asians and African-Caribbeans starting RRT is lower than that of Caucasians (Registry Report 2002) suggesting a younger population reaching established renal failure (ERF). This partly reflects the generally younger age profile of the ethnic minority population within the UK as a whole. Within the general population of England and Wales, only 16% of those aged 65 or more are from a non-White ethnic group (www.statistics.gov.uk). There may be an overall decreased life span in the minority ethnic groups due to a greater prevalence of diabetes and cardiovascular risk factors.

There is also postulated, decreased awareness of and possibly limited access to nephrology services. With regard to referral patterns however, UK Renal Registry data do not show any

evidence of lack of referral from the ethnic minorities and have shown that South Asians are more likely to be referred more than one year prior to initiating RRT to nephrology services than Whites. This does not eliminate the possibility that there may be unmet need in the elderly of ethnic minorities.

The main cause of established renal failure in the ≥ 75 years age group was uncertain (31%), probably because of late presentation with small kidneys to nephrology services. The commonest identified cause in the very elderly was renovascular disease (19%), which is not surprising given the frequency of vascular comorbidity (peripheral, cardiac or cerebrovascular). The low frequency of diabetes as a primary renal diagnosis in the older age cohort may reflect selection bias, or that relatively few diabetic patients survive to this age.

The high proportion of older patients on haemodialysis as a modality partly reflects the low rate of transplantation in the elderly. Many of these older patients are medically unfit for listing because of co-morbidities and may be also unable to manage PD successfully.

Although 33% of patients aged ≥ 75 years had no reported co-morbidity on starting RRT, 67% had one or more conditions. In the literature the proportion of incident patients aged ≥ 75 with at least one co-morbidity is $\geq 90\%$ but the numbers studied were smaller⁴. Eighty percent of individuals over 65 years of age in the general population have one and 30% three or more chronic illnesses⁶ and increasing comorbidities have been shown to correlate with frequency of hospitalisation⁴. Cardiac disease was the commonest co-morbidity present in our cohort and this was reflected in the mortality of elderly patients on RRT; it was the commonest cause of death in the first 90 days and accounted for 22% of deaths in the year after 90 days.

The high proportion of elderly people achieving some standards such as serum phosphate, serum calcium and haemoglobin may reflect a more routine life style, more restrained appetites, or more respect for instruction/advice. The higher systolic BP is not surprising in view of the reduced compliance of the vascular tree in the elderly with susceptibility to dialysis-related

hypotension. There is no evidence of under treatment of anaemia in the elderly.

Early mortality (within 90 days) among the elderly on dialysis increased significantly with age, from 16% for those 75–79 years old to 28% for those ≥ 85 . The figures were 26% and 43% respectively for the year after 90 days. Treatment withdrawal became the commonest recorded cause of death in the year after 90 days in those aged ≥ 75 years. The Registry has no evidence of whether this was as a consequence of the quality of life, or the burden of current or chronic pathologies.

Some nephrologists offer a trial of dialysis to elderly patients and those with significant comorbidity, with reassessment of the quality of life and functional status once established on RRT. This may account partly for the large number of deaths in the first 90 days and subsequent high treatment withdrawal rates. The decision to withdraw once started is often a difficult one for patient, family and staff. There is now evidence that with a comprehensive conservative approach, elderly patients can have a satisfactory quality of life without dialysis during their final months and may survive as long as many of those who are dialysed⁷. Once RRT has been initiated, the time required for treatment, the reduction in urine output and other physiological changes may actually reduce quality of life, so that there is a growing reluctance to enter into trials of RRT.

The very elderly patients starting RRT may represent the tip of an iceberg with more either not referred or not accepted for RRT. However, if those selected for dialysis carry the least co-morbidity, as their longevity on treatment is unimpressive the outcome in terms of survival and quality of life of the unreferred may be much worse. One should not assume that dialysis is the best option for all these patients.

The laboratory reporting of serum creatinine rather than calculated creatinine clearance plays a part in the failure to recognise established renal failure in the community. This is most misleading in women, patients of small build and the elderly. There are recommendations pending that clinical chemistry departments should be reporting an estimated creatinine clearance derived from serum creatinine. The

challenge for nephrologists will be to help thus identified uraemic elderly patients and their families come to appropriate choices about renal replacement therapy, a specific example of the goal of 'adding life to years rather than years to life' in the management of the elderly.

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Chapter 16: Co-morbidity in Incident Patients

Summary

- Co-morbidity returns have improved and over 50% of renal units are submitting some information. 5,916 patients have had co-morbid data returns so far, which accounts for 39% of all incident dialysis patients.
- The incidence of co-morbidity increases with increasing age until age 75. In patients aged over 75, the percentage starting renal replacement therapy (RRT) with cardiovascular and cerebrovascular disease appears to reduce.
- 30% of diabetics were referred within 3 months of requiring dialysis.
- Diabetic patients starting RRT have a greater number of co-morbidities than non-diabetics and the majority were aged less than 65 years. Even after adjusting for co-morbidity in the Cox survival model, being diabetic was still a significant additional risk factor for impaired survival.
- HD patients were older and had more co-morbidity than those going onto PD.
- Most of the Registry co-morbid conditions influenced patient survival.
- In the multivariate analysis, diabetes was not a risk factor in the 90 day survival while as expected it is a risk factor in the longer term survival beyond day 90. Similarly smoking has a long term negative impact on survival rather than a short term impact.
- Comparisons of national registries show that age distribution of dialysis patients in the UK and the USA is similar. In the UK, history of a previous myocardial infarction (MI) is found in 50% more patients starting RRT over age 65 years than in the USA.
- In the USA the apparent higher rates of cardiac disease than the UK is misleading. It is due to the inclusion of congestive

cardiac failure and dysrhythmias, which are not collected by the UK Registry.

- In the UK, patients starting RRT have a much higher incidence of cerebrovascular disease (CVA) than the USA (18% v 12% in patients aged 75+).
- The incidence of peripheral vascular disease (PVD) and chronic obstructive pulmonary disease (COPD) is similar in the UK to the USA, across all age bands.
- In the UK the incidence of diabetes in the transplanted cohort is 20% which is marginally lower than that seen in the incident RRT cohort (24%).
- Since, together with age, weight of co-morbidity determines survival on RRT, the completeness of co-morbidity recording by renal units needs to increase.

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 16.1. A patient may therefore have a fully completed screen recording no co-morbid conditions to be present. Null entries are considered missing data rather than 'no'.

Beginning in 2004, the presence or absence of heart failure prior to the start of RRT was also recordable. Definitions for each co-morbidity are given at the end of this chapter.

Data on smoking at the time of starting RRT has been collected as a marker for vascular (cardiac, cerebral and peripheral) risk. It is not a co-morbid condition although for the purposes of these analyses, it has been treated as such.

Angina	Claudication
Previous MI within last 3 months	Ischaemic/neuropathic ulcers
Previous MI >3 months ago	Angioplasty vasc graft/aneurysm (non coronary)
Previous CABG or coronary angioplasty	Amputation for Periph Vasc disease
Heart failure	
Cerebrovascular disease	Smoking
Diabetes (not causing ESRF)	Malignancy
Chronic Obstructive Pulmonary Disease	
Liver Disease	

Figure 16.1: Co-morbidity entry screen for the CCL Proton system

Co-morbidity returns by renal units

15197 incident patients' details have been collected by the Renal Registry and the returns by renal units are shown in table 16.1. There are 41 renal units submitting information to the Registry, with an increasing number of patients with co-morbid information being available for analysis (table 16.2). The initial median co-morbid returns in 1999 were only 15%, but by 2003, it had risen to 57%. The proportion of renal units with a high return of co-morbidity (>67%) has increased from 25% in 1999 to 43% by 2003. The ideal situation would be to achieve co-morbid returns above 90% and the

proportion of units achieving such a standard started at 6% in 1999, rising to 29% in 2001 and falling to 18% in 2003.

Unfortunately, many renal units (49%) are returning less than 50% of co-morbid information and the Renal Registry will have to explore mechanisms by which data returns can be improved.

Some centres like Bradford, Bristol, Leeds, Sheffield and York are showing declining co-morbidity returns. This contrasts with Hammer-smith, Nottingham, Truro and Wolverhampton which show a sustained high return or improving return of co-morbidity.

Table 16.1: Co-morbidity data returns, by centre, at the start of RRT

Treatment centre	1999		2000		2001		2002		2003	
	No. incident patients	% returns co-morbidity	No. incident patients	% returns co-morbidity	No. incident patients	% returns co-morbidity	No. incident patients	% returns co-morbidity	No. incident patients	% returns co-morbidity
Bangor	–	–	–	–	–	–	29	55.2	38	39.5
Bradford	–	–	–	–	61	93.4	61	100.0	75	84.0
Bristol	118	89.8	149	94.0	152	91.4	123	79.7	168	67.9
Cambridge	–	–	–	–	103	4.9	75	4.0	104	–
Cardiff	137	0.7	139	0.7	153	–	157	–	154	1.3
Carlisle	26	46.2	27	40.7	26	3.8	29	20.7	30	–
Carshalton	111	9.9	119	11.8	119	15.1	172	2.9	203	2.5
Clwyd	–	–	–	–	–	–	19	–	9	–
Coventry	92	–	88	–	104	–	95	1.1	76	–
Derby	–	–	–	–	–	–	–	–	62	54.8
Exeter	82	31.7	72	36.1	98	30.6	82	47.6	98	43.9
Gloucester	59	1.7	48	97.9	50	98.0	57	66.7	55	87.3
Guys	–	–	126	0.8	111	–	141	–	95	–
Heartlands	82	–	86	–	85	–	60	–	103	–
HS & CX	–	–	–	–	–	–	177	99.4	152	100.0
Hull	64	1.6	81	2.5	74	–	105	4.8	78	88.5
Ipswich	–	–	–	–	–	–	42	38.1	35	28.6
Kings	–	–	–	–	–	–	117	86.3	114	94.7
Leeds	82	84.1	160	90.6	162	85.8	147	78.9	169	69.8
Leicester	164	79.9	177	75.7	184	90.2	152	88.2	168	83.9
Liverpool	–	–	–	–	186	55.9	150	46.0	119	52.9
Man-West	–	–	–	–	–	–	–	–	141	26.2
Middlesbrgh	92	1.1	86	69.8	81	90.1	111	100.0	104	–
Newcastle	–	–	–	–	–	–	105	1.0	91	3.3
Nottingham	128	24.2	114	71.1	121	66.1	87	98.9	114	97.4
Oxford	142	–	152	2.6	169	1.2	164	–	179	0.6
Plymouth	68	1.5	60	–	64	3.1	86	1.2	69	–
Portsmouth	–	–	–	–	144	56.3	142	45.1	137	30.7
Preston	106	0.9	117	0.9	136	0.7	112	–	99	1.0
Reading	–	–	49	–	63	–	42	–	69	–
Sheffield	133	20.3	137	81.0	152	85.5	156	57.7	158	51.9
Southend	43	2.3	39	7.7	37	24.3	35	45.7	43	37.2
Stevenage	103	–	101	–	125	0.8	89	1.1	114	–
Sunderland	46	–	46	–	38	5.3	56	46.4	57	59.6
Swansea	–	–	91	75.8	112	73.2	113	81.4	133	94.0
Truro	–	–	–	–	37	54.1	58	65.5	48	85.4
Wirral	–	–	–	–	–	–	38	–	49	–
Wolverhmpn	74	100.0	78	100.0	75	100.0	95	100.0	92	100.0
Wordsley	43	–	40	–	34	–	25	4.0	41	–
Wrexham	51	–	55	–	35	–	41	–	34	–
York	–	–	40	92.5	37	91.9	68	70.6	56	58.9
Totals	2046		2477		3128		3613		3933	

Table 16.2: Summary of the co-morbidity returns available for analysis

	Years					Totals
	1999	2000	2001	2002	2003	
Number of renal units	23	27	32	39	41	
Total number of new patients	2046	2477	3128	3613	3933	15197
Number of patients with co-morbid data entries	494	965	1300	1554	1603	5916
Percentage of co-morbid returns						
Mean of co-morbid returns for all centres (%)	24	39	41	43	41	39
Median of co-morbid returns per centre (%)	15	70	56	51	57	57

Frequency of co-morbidity returned

Of the 5,884 patients where co-morbid information was available by 90 days of RRT, table 16.3 outlines the total and age dependent incidence of co-morbidity. Cardiovascular diseases, COPD and malignancy were more common in patients aged over 65 years whilst diabetes, liver

disease and smoking were more common in the younger patients.

Registry analyses from previous years indicate that the Registry is underestimating co-morbidity. Patients who die within 90 days were less likely to have their co-morbidity recorded and these patients would therefore have been excluded from analyses.

Table 16.3: Frequency of co-morbidity at the time of starting RRT

Co-morbidity	Age <65 years		Age >65 years		Total % incidence
	No. pts	%	No. pts	%	
Cardiovascular disease	470	15.7	987	34.0	24.7
Angina	355	11.9	773	26.6	19.2
MI in past 3 months	58	1.9	102	3.5	2.7
MI >3 months ago	188	6.3	478	16.5	11.3
CABG/angioplasty	124	4.5	176	6.6	5.5
Cerebrovascular disease	210	7.0	481	16.6	11.7
Diabetes (not a cause of ERF)	145	4.9	287	10.0	7.4
Diabetes as primary disease	660	22.0	450	15.4	18.8
Diabetes of either category	805	26.8	737	25.3	26.1
COPD	139	4.7	313	10.9	7.7
Liver disease	91	3.1	50	1.7	2.4
Malignancy	192	6.4	482	16.7	11.5
Peripheral vascular disease	301	10.1	538	18.5	14.2
Claudication	197	6.6	434	15.0	10.8
Ischaemic/neuropathic ulcers	125	4.2	117	4.1	4.1
Angioplasty/vascular graft	66	2.2	142	4.9	3.5
Amputation	76	2.5	57	2.0	2.3
Smoking	609	21.4	423	15.2	18.4
No co-morbidity present	1354	49.0	796	28.6	38.7

Abbreviations: MI – myocardial infarction; CABG – coronary artery bypass grafting; COPD – chronic obstructive pulmonary disease; ERF – established renal failure.

Table 16.4: Cumulative co-morbidity present at the commencement of RRT

		Number of co-morbidities					
Totals	%	0	1	2	3	4	5+
		38.7	29.0	16.0	8.1	4.4	3.7

Co-morbidity totals

The presence of several co-morbid factors can influence patient survival^{1,2}. Using the 14 fields available, an analysis of cumulative co-morbidity was performed (table 16.4). Of the data available, 39% had no co-morbidity and only 16% of patients had 3 or more conditions.

Frequency of co-morbidities by age band

Figures 16.2 and 16.3 outline the frequency of cardiac and vascular co-morbidity segregated by age bands. Cardiac and cerebrovascular disease incidence increases with age up to the 65 to 74 years age band, with the majority of patients receiving RRT being in this age band. Of patients aged above 75 years, the incidence of patients on RRT as well as the incidence of cardiac and cerebrovascular co-morbidities reduce. As the incidence co-morbidities: such as cardiac; cerebrovascular disease and COPD increases in the general population, this reduction in incidence of these co-morbidities in the older dialysis patients must be due to either patients not being referred for RRT; or patients

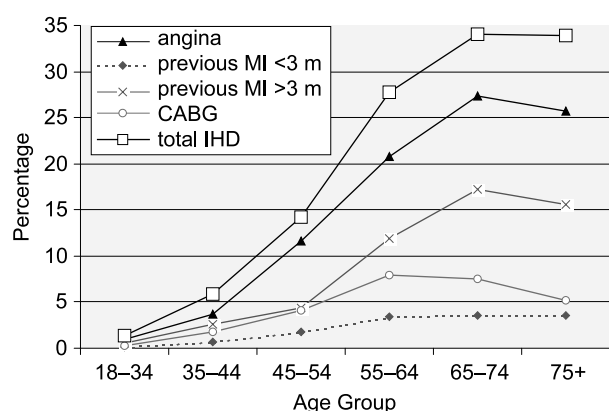


Figure 16.2: Frequency of cardiac co-morbidities in incident patients

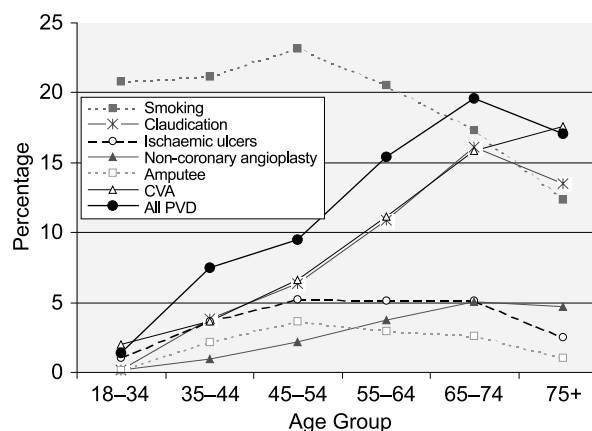


Figure 16.3: Frequency of vascular co-morbidity in incident dialysis patients

being managed in a conservative manner and not commencing RRT.

Figure 16.4 outlines the incidence of the conditions as COPD, diabetes not causing end stage renal failure, malignancy and liver disease. Smoking and liver disease incidence falls as patients age, whilst the incidence of malignancy rose. Diabetes as the primary cause of ERF starts to decline in those patients aged over 65 while diabetes as a co-morbidity continues to rise. This may be due to misclassification with 25% of patients classified with a primary diagnosis of ‘uncertain’ (EDTA diagnosis – 2 small kidneys) and a further 28% classified as renovascular disease. This highlights the potential for Registries to under record the incidence of diabetes unless collecting co-morbidity.

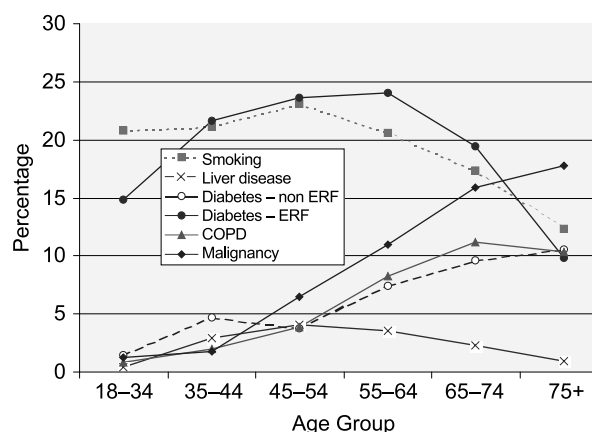


Figure 16.4: Frequency of other co-morbid conditions

Abbreviations: COPD – chronic obstructive pulmonary disease; non-ERF – not causing established renal failure

Table 16.5: Percentage of patients with and without diabetes and co-morbid conditions

	Non-diabetics	Diabetics
Cardiovascular disease	23.0	31.7
Cerebrovascular disease	10.6	16.5
Peripheral vascular disease	11.2	27.5
Smoking	18.4	18.2
COPD	8.1	6.3
Malignancy	13.3	4.4
Liver disease	2.4	2.2

Diabetes and co-morbidity

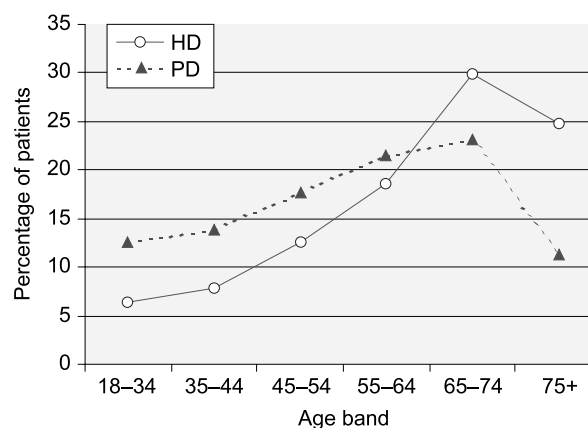
Using the available co-morbid data, patients with diabetes (1107) and those without diabetes (4648) were compared. Table 16.5 outlines the incidence of co-morbidity for patients with and without diabetes. Cardiac disease as a group including any case of angina; myocardial infarction; coronary artery angioplasty or bypass surgery was more common in diabetics even though diabetic patients were a younger age group than the non-diabetics (58% <65 years table 16.3). This was also similar for peripheral vascular disease (which included all cases of claudication; amputation; non coronary artery angioplasty, stenting or surgery) and for cerebrovascular disease.

It is disheartening to see that the incidence of smoking tobacco is similar in the diabetics to the non-diabetics, despite the well established increased risks in diabetics. Targeted smoking cessation programs may have a role to play.

The incidence of COPD and liver disease were similar in the two groups, whilst malignancy was more common in non diabetic patients.

Dialysis modality and co-morbidity

By 90 days after starting RRT (figure 16.5), those patients on PD were significantly younger than the HD patients (57 v 66 years respectively, $p < 0.0001$). The proportion of the PD patients aged 65 and over was 34.4% as compared with 54.7% in HD patients.

**Figure 16.5: Age distribution of patients within each modality at day 90**

Dialysis modality selection for patients is not wholly dependent upon co-morbidity and is more dependent upon practical issues of patient choice, in some centres the availability of haemodialysis slots, the provision of space at home for storage of PD fluid, in addition to patients' physical and mental capacity to perform PD.

Following analysis of dialysis modality with co-morbid conditions and age, it was noted that patients with previous CABG surgery were more likely to start on PD. This contrasts with COPD, diabetes, angina, liver disease, malignancy, limb amputees, cerebrovascular disease and ischaemic/neuropathic ulcers where patients were more likely to start on HD. (Table 16.6).

A history of myocardial infarction, non coronary artery angioplasty/surgery and smoking tobacco did not differ significantly between dialysis modalities.

The median age of patients starting RRT is shown in table 16.6 and this shows that there is a complex relationship of age, co-morbidity and modality which is difficult to disentangle. As highlighted above, patients on PD are generally younger, although when analysed by co-morbidity the median age of patients with a previous MI are similar across modalities. This may indicate a preference for PD in this co-morbidity group.

Table 16.6: Proportions of co-morbid conditions present in PD and HD patients

Co-morbidity	HD		PD		p value
	%	Median age	%	Median age	
Angina	15.2	70	14.8	67	<0.001
MI – more than 3 months ago	7.8	69	9.9	70	0.9
MI – within 3 months	2.3	70	1.9	68	0.4
CABG	4.4	67	5.8	65	0.003
Cerebrovascular disease	9.9	72	8.2	66	<0.001
Diabetes non-ERF	10.3	68	8.5	63	<0.001
COPD	6.5	70	4.2	64	<0.001
Smoking	19.7	63	19.0	55	0.4
Liver disease	3.1	58	1.3	57	<0.001
Malignancy	9.2	71	6.7	65	<0.001
Claudication	8.7	70	10.5	67	0.054
Ischaemic/neuropathic ulcers	4.0	65	2.7	53	0.02
Angioplasty of non coronary vessels	2.9	72	3.4	67	0.1
Amputations	2.6	65	1.9	53	0.003

Patient early referral and co-morbidity

Nephrological follow up in the pre-dialysis phase is important in; addressing and modifying cardiovascular risk factors, the prevention of malnutrition, it enables the preparation of patients for renal replacement as well as ensuring the placement of appropriate forms of dialysis/vascular access and the prevention of uraemic emergencies.

In the Registry Report 2003 analysis of late referral in chapter 16 (unrelated to whether a centre was sending co-morbidity data) showed that <3 months, 3–12 months and >1yr nephrological follow up was 30%, 21% and 49% respectively. Figure 16.6 shows that the younger and older patients were more likely to

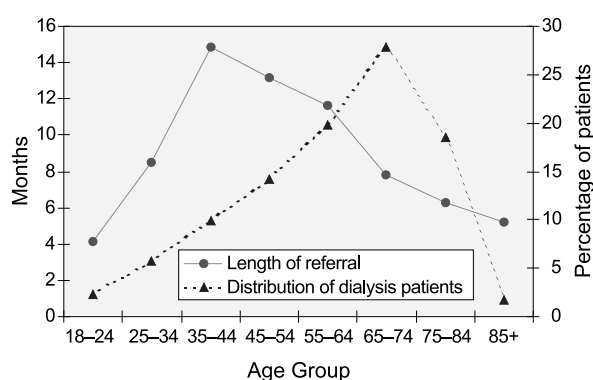


Figure 16.6: Duration of pre dialysis nephrological care and the proportions of the dialysis patients present per age band

present late with a short period of nephrological follow up.

Patients aged over 65 accounted for 48% of the total dialysis population and as expected, these individuals had a higher total co-morbidity in addition to the shorter period of nephrological follow up shown above.

Using information on co-morbidity and nephrological follow up from a cohort of 3981 patients, co-morbid conditions and referral were analysed (table 16.7). In the patients with specific co-morbid conditions, the referral pattern followed a similar trend: with 31% of

Table 16.7: Percentage of specific co-morbid conditions receiving pre dialysis follow up

	Referral period			
	3 m	3–6 m	6–12 m	>1 yr
Cardiovascular disease	27.7	8.7	11.3	52.3
Peripheral vascular disease	27.1	9.6	15.3	48.0
Cerebrovascular disease	27.3	9.7	13.5	49.6
Diabetes (not cause of ERF)	29.2	5.0	10.1	55.8
COPD	33.3	9.0	9.9	47.8
Liver disease	42.0	10.1	5.8	42.0
Malignancy	46.1	7.5	7.5	39.0
Smoking	32.9	10.3	13.1	43.7

Notes:

Heart disease included any instance of myocardial infarction, angina, coronary artery angioplasty or bypass surgery.

Peripheral vascular disease included any instance of claudication, the presence of ischaemic ulcers, limb amputation or angioplasty of non coronary vessels.

patients receiving less than 90 days of nephrological follow up and 49% receiving more than one year. In those patients with no co-morbidity present (who were also younger) 39% received less than 3 month nephrological follow up.

When analysed by number of co-morbid conditions present (either 1, 2, 3, 4+) the length of nephrological follow up was similar across the four groups. Only in those patients with three co-morbid conditions were patients likely to present >6 months prior to start of RRT.

In patients with diabetes, over 44% were referred within a year of requiring dialysis and 29% within 3 months, which is insufficient time to allow progression modifying treatment to have an effect or in the latter case to plan dialysis.

Frequency of co-morbidity by ethnicity

There were 4905 patients with data returns for both ethnicity and co-morbidity (table 16.8).

For this analysis cardiovascular disease included angina, myocardial infarction, coronary angioplasty or coronary artery bypass grafting. In addition, PVD included claudication, non coronary artery angioplasty/stenting, amputations and the presence of ischaemic/neuropathic ulcers. The incidence of cardiac disease was similar in the South Asian and White populations, whilst vascular diseases (CVA + PVD) and smoking were more common in the White population.

When diabetes as a factor leading to diabetic nephropathy or diabetes as a coexistent condition was considered, as expected figure 16.7 shows that the incidence of diabetes was significantly greater in the ethnic minorities (p < 0.0001).

Analysing the data by age (figure 16.8), there were fewer patients in the age 75+ from the ethnic minorities. This is due to the fact that the ethnic minority community in the UK is a much younger population than the established population.

Table 16.8: Frequency of co-morbidity by ethnic group

	South Asian	Black	Chinese*	Other	White
Number of patients	369	145	18	100	4273
Ethnicity (%)	7.5	3.0		2.0	87.1
Smoking (%)	8.6	7.7		3.7	20.4
CVA (%)	8.4	10.4		3.7	11.9
PVD (%)	11.4	3.4		6.5	14.9
Cardiovascular disease (%)	24.1	17.4		14.8	25.1
Liver disease (%)	3.5	0.7		2.8	2.3
COPD (%)	4.2	3.5		4.7	8.5
Malignancy (%)	3.5	4.9		1.9	12.0

*Due to small numbers no analysis has been performed on this data

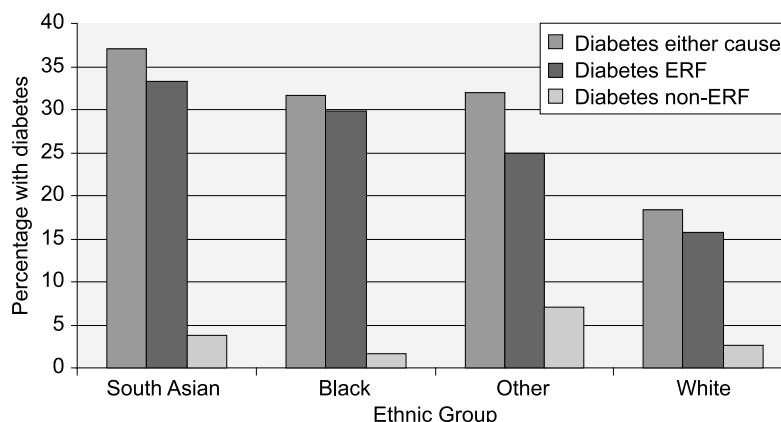


Figure 16.7: Frequency of diabetes by ethnic group

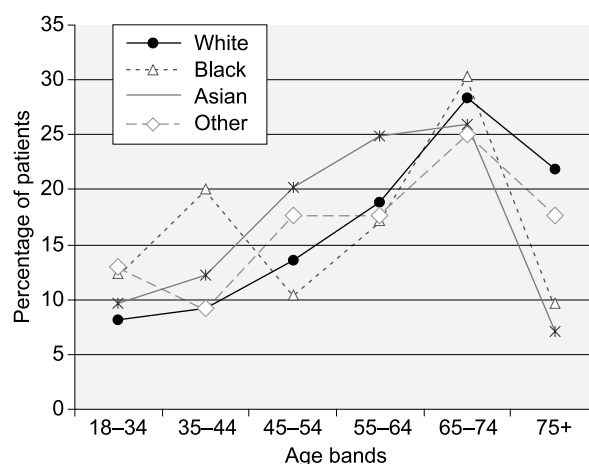


Figure 16.8: Age distribution of incident patients by ethnic group

Renal function at commencement of dialysis and co-morbidity

Using the abbreviated MDRD calculation, the eGFR of patients starting dialysis was calculated and is shown in table 16.9. The Tukey multiple comparison test was used to test the mean of those patients with the specific co-morbidity against those with none of the co-morbidities present. As many tests were being carried out, only a p value <0.01 was considered statistically significant. This should not imply that these differences imply a clinical

significance as they may be only small variations.

Patients with diabetes had a slightly higher eGFR at commencement of dialysis (table 16.9), although this may not be a clinically important difference. As diabetic patients had more co-morbidity (table 16.5) it is possible that factors such as heart disease, heart failure/resistant oedema may have prompted earlier dialysis initiation in these individuals.

This data is similar to that of the United States Renal Data System (USRDS) which shows a mean eGFR of 9.6 ml/min at the start of RRT.

Table 16.9: Mean eGFR and presence of co-morbidity

	Co-morbidity present		p value
	Mean	95% CI	
No co-morbidity	8.7	8.4-9.1	0.070
Angina	9.3	8.9-9.6	0.005
MI in past 3 months	9.9	8.5-11.3	0.055
MI >3 months ago	8.9	8.5-9.3	0.161
CABG/angioplasty	9.7	9.0-10.3	0.075
Cerebrovascular disease	9.0	8.6-9.4	0.178
Diabetes (not cause of ERF)	9.4	8.7-10.0	0.016
Diabetes as primary disease	10.2	9.6-10.7	<0.0001
Diabetes of either category	9.9	9.5-10.4	<0.0001
COPD	9.2	8.7-9.8	0.036
Liver disease	9.4	8.3-10.4	0.077
Malignancy	9.1	8.4-9.7	0.421
Claudication	9.5	9.0-10.0	0.010
Ischaemic/neuropathic ulcers	9.8	8.9-10.8	0.030
Angioplasty/vascular graft	9.5	8.6-10.5	0.050
Amputation	9.8	8.8-10.8	0.051
Smoking	8.4	8.1-8.7	0.516

Table 16.10: Mean haemoglobin by co-morbidity

	Mean	95% CI	p value
No co-morbidity	10.0	10.0–10.1	0.911
Angina	10.1	10.0–10.2	0.259
MI in past 3 months	10.2	9.9–10.5	0.675
MI >3 months ago	10.3	10.1–10.4	0.004
CABG/angioplasty	10.2	10.1–10.4	0.064
Cerebrovascular disease	10.0	9.8–10.1	0.998
Diabetes (not cause of ERF)	10.2	10.0–10.3	0.223
Diabetes as primary disease	9.9	9.8–10.0	0.265
Diabetes of either category	10.0	9.9–10.1	0.422
COPD	9.9	9.7–10.0	0.114
Liver disease	9.7	9.3–10.1	0.022
Malignancy	10.0	9.8–10.1	0.488
Claudication	10.0	9.9–10.2	0.349
Ischaemic/neuropathic ulcers	9.7	9.5–10.0	0.092
Angioplasty/vascular graft	10.2	9.9–10.5	0.048
Amputation	9.8	9.5–10.1	0.237
Smoking	10.0	9.8–10.1	0.594

Haemoglobin at commencement of dialysis and co-morbidity

The mean haemoglobin at commencement of dialysis was analysed (table 16.10) and median haemoglobin (1–14 days prior to RRT) for those without co-morbidity present was 10 g/dl. Only patients with a myocardial infarction >3 m previously had a slightly higher haemoglobin.

Renal transplantation and co-morbidity

Patients benefit significantly from renal transplantation and which patients are listed on the waiting list and receive a transplant is of interest. A more detailed analysis of access to the transplant waiting list is in chapter 11. Utilising information from centres with a high return of co-morbid information (>67%), an analysis of patients who had been transplanted (Tx) and those that remained on dialysis by the end of 2004 was performed. Of a cohort of 4,132 patients, just over 10% of patients (425) had been transplanted.

Renal transplant patients were significantly younger, however a small number of patients had been transplanted from the older age bands (figure 16.9). As expected there was a higher level of co-morbid conditions in those patients who remained on dialysis (table 16.11).

In the future, more detailed analysis of patient selection for transplant listing will be possible in conjunction with UKTransplant.

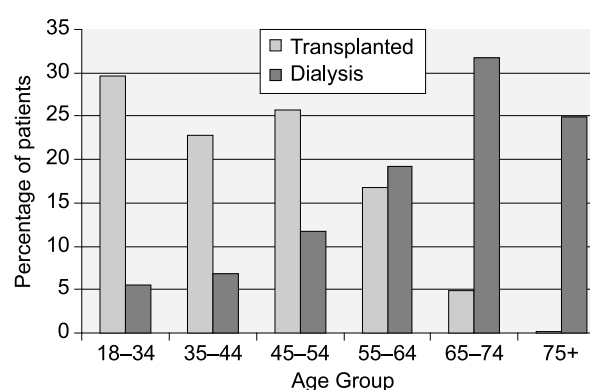


Figure 16.9: Distribution of incident RRT cohort that received a transplant and those that remained on dialysis

Table 16.11: Incidence of co-morbidity in transplanted and not transplanted patients

Co-morbidity	Not transplanted	Transplanted
Patient number	3707	425
Cardiovascular disease	26.5%	6.8%
Peripheral vascular disease	15.5%	2.1%
Cerebrovascular disease	12.3%	3.5%
Diabetes (not cause of ERF)	8.1%	2.6%
COPD	8.5%	1.4%
Liver disease	2.3%	0.7%
Malignancy	12.7%	1.9%
Smoking	17.9%	16.8%

Survival analysis and co-morbidity

Survival within 90 days of commencing dialysis

The univariate model (table 16.12), does not allow adjustment for age, so patients were first stratified by age group (less than 65 years and 65 years and above) to make some account for the increasing incidence of co-morbidity with age which would otherwise obscure the analysis.

Important risk factors for both age groups for survival in the first 90 days were malignancy and vascular disease: (which includes at least one of cerebrovascular disease; claudication; ischaemic/neuropathic ulcer; angioplasty/vascular graft; or amputation). As liver disease was more common in patients aged less than 65, it was noted as an

important risk factor in this group. Patients aged less than 65 with cardiovascular disease faced a significant risk as compared to others within this age group who did not have this co-morbid condition. Cardiovascular disease was not significant in those patients aged over 65 and this may indicate a clinical decision not to start RRT in older patients with severe cardiovascular disease who were thought unlikely to survive the first 3 months or patients who died before starting RRT.

The multivariate analysis using a Cox proportional hazards model for the first 90 days after dialysis initiation (table 16.13) was performed. The variables considered in the model were:

age, angina, myocardial infarction (MI) in previous 3 months, MI more than 3 months ago, CABG/angioplasty, cerebrovascular

Table 16.12: Univariate analysis, co-morbidity hazards of death by day 90

Co-morbidity	age <65		age 65+	
	Hazard ratio	p-value	Hazard ratio	p-value
Angina	2.3	0.003	1.0	0.744
Cardiovascular disease*	2.1	0.003	1.2	0.244
Vascular disease**	3.3	<0.0001	1.3	0.018
Diabetes (not as cause of ERF)	0.8	0.694	1.3	0.189
Diabetes as primary disease	1.5	0.131	0.8	0.138
Diabetes of either category	1.3	0.227	1.0	0.725
COPD	1.5	0.409	1.1	0.639
Liver disease	6.0	<0.0001	1.1	0.828
Malignancy	3.8	<0.0001	1.7	<0.000
Claudication	2.1	0.029	1.1	0.534
Ischaemic/neuropathic ulcers	4.9	<0.0001	2.0	0.002
Smoking	0.5	0.095	1.3	0.128

*At least one of angina, myocardial infarction at any time, angioplasty/vascular graft

**At least one of cerebrovascular disease, claudication, ischaemic/neuropathic ulcer, angioplasty/vascular graft, amputation

Table 16.13: Cox regression survival analysis of the first 90 days of RRT

Variable	p-value	Hazard ratio	95% CI
Age per 1 year increase	<0.0001	1.05	1.04–1.07
MI in past 3 months	0.033	1.76	1.05–2.97
Cerebrovascular disease	0.026	1.41	1.04–1.90
Malignancy	<0.0001	2.14	1.63–2.82
Liver disease	0.001	2.60	1.45–4.66
Ischaemic/neuropathic ulcers	<0.0001	2.58	1.72–3.86

disease, diabetes of either category, COPD, liver disease, malignancy, claudication, ischaemic/neuropathic ulcers, angioplasty/vascular graft, amputation and smoking.

The results showed that age as a linear variable, a history of a recent myocardial infarction in the previous 3 months, cerebrovascular disease, malignancy, liver disease and ischaemic ulcers were all significant factors associated with impaired survival.

Survival 1 yr after 90 days of commencing RRT

Many other countries are unable to collect data on survival within the first 90 days of starting RRT. For this reason a 1 year survival analysis has been performed excluding the first 90 day period.

Similar to the previous analysis, the univariate analysis was performed after stratifying the patients into 2 age bands (table 16.14). In the younger patients (<65 years): the presence of

heart disease; diabetes and liver disease were important risk factors within this age group compared to those without these co-morbidities. The lack of importance of cardiovascular disease in the older age group either indicates that other factors are more important or there is a selection bias through death prior to starting RRT or acceptance on to the program.

In the multivariate analysis (table 16.15), age, cerebrovascular disease and malignancy were important. Smoking and diabetes were added into the model only after first testing all the other co-morbidities because many co-morbid conditions will be correlated with these two factors. Smoking and diabetes remained an important prognostic factor even after adjusting for all the other co-morbid conditions.

In the multivariate analysis, the contrast between important risk factors in survival up to day 90 and the 1 year after 90 days period shows that diabetes is not a risk factor in the 90 day survival while as expected it is a risk factor in

Table 16.14: Univariate analysis, co-morbidity hazards of death by 1 year after 90 days

Co-morbidity	age <65		age 65+	
	Hazard ratio	p-value	Hazard ratio	p-value
Angina	1.6	0.027	0.9	0.577
Cardiovascular disease*	1.9	0.000	1.1	0.550
Vascular disease**	2.9	<0.0001	1.3	0.030
Diabetes (not as cause of ERF)	2.3	0.003	1.4	0.043
Diabetes as primary disease	2.5	<0.0001	1.2	0.236
Diabetes of either category	2.9	<0.0001	1.3	0.018
COPD	2.0	0.021	1.2	0.414
Liver disease	3.3	0.000	1.6	0.196
Malignancy	3.9	<0.0001	1.3	0.093
Claudication	2.8	<0.0001	1.3	0.099
Ischaemic/neuropathic ulcers	3.0	<0.0001	1.8	0.007
Smoking	1.5	0.030	1.3	0.111

*At least one of angina, myocardial infarction at any time, angioplasty/vascular graft

**At least one of cerebrovascular disease, claudication, ischaemic/neuropathic ulcer, angioplasty/vascular graft, amputation

Table 16.15: Cox regression survival analysis for the 1 year after 90 days

Variable	p-value	Hazard ratio	95% CI
Age per 1 year increase	<0.0001	1.04	1.04–1.05
Cerebrovascular disease	0.008	1.39	1.09–1.78
Liver disease	0.009	1.99	1.19–3.34
Malignancy	<0.0001	1.69	1.32–2.15
Ischaemic/neuropathic ulcers	0.002	1.75	1.23–2.49
Smoking	0.010	1.36	1.08–1.72
Diabetes of either category	<0.0001	1.65	1.35–2.02

the longer term. Whether this lack of importance in the first 90 days is due to the absence of a short term impact or that diabetic patients with a high co-morbidity load die prior to start of RRT is unknown. Similarly smoking has a long term negative impact on survival rather than a short term impact.

International comparisons of renal registries and co-morbidity

The number of national renal registries which produce a comprehensive list of co-morbid conditions of dialysis patients is small. A comparative analysis between countries, was available using publications from the USA, Australia/New Zealand and the Netherlands. As discussed earlier in this chapter, UK data is probably under reporting co-morbidity.

The USRDS generates a large amount of data which is easily accessible through its website (www.usrds.org). The Australian and New Zealand (ANZDATA) Registry had published co-morbid information in a paper discussing late referral and data is on their website (www.anzdata.org)³. The Necosad group⁴ discussing dialysis have published information of a prospective cohort of patients from the 36 renal units in the Netherlands. Using all this information, it was possible to make a number of observations regarding co-morbidity.

Analysis by the proportions of the incident UK and US RRT patients within specific age bands shows a similar distribution (figure 16.10).

Definitions of cardiac disease, peripheral vascular disease and diabetes vary between countries. **Methods of recording other co-morbidity may also be different within these Registries,**

therefore these comparisons should be interpreted cautiously.

Cardiac disease, cerebrovascular disease, peripheral vascular disease and COPD appear to be more common in Australia and New Zealand (table 16.16). Diabetes was most common in the USRDS population, followed by Australia and New Zealand. The USA was the only other country with data on smoking history and this was 1/3 the rate seen in the UK (5.2% v 18.4%).

The incidence of peripheral vascular disease, and COPD were similar in the USA, UK and Netherlands.

The Necosad data from the Netherlands shows a similarity to that in the UK for the incidence of diabetes, peripheral vascular disease, malignancy and COPD in the renal replacement therapy population. This may also relate to the similar incidence of RRT in the Netherlands in 2002 (100 p.m.p) to that of the UK (103 p.m.p). The Necosad data set is complete and this close agreement with the UK

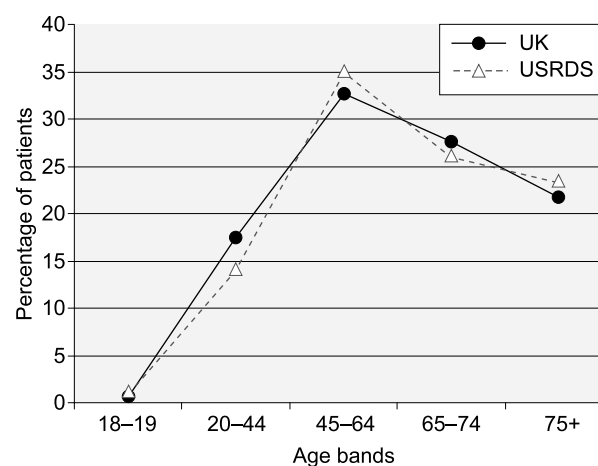


Figure 16.10: Percentage of patients on dialysis by age distribution, for UK and USA

Table 16.16: Summary of co-morbidity from differing national registries

Study period	National registries			
	ANZDATA Apr 1995–Mar 2000	USRDS 1995–2003	Renal Registry 1999–2003	Necosad 2 Jan 1997– Nov 2000
Number of patients	4243	696043	15197*	1041
Ischaemic heart disease inc MI	38.6%	23.8%	24.7%	11.1%
Cerebrovascular disease	15.1%	9.0%	11.7%	7.2%
Peripheral vascular disease	25.9%	14.3%	14.2%	13.0%
COPD	15.6%	7.1%	7.7%	7.2%
Diabetes**	30.7%	41.2%	18.8%	19.5%
Malignancy	–	5.3%	11.5%	10.1%
Smoking	not collected	5.2%	18.4%	not collected
Congestive cardiac failure	not collected	32.0%	not collected	12.3%
Patients with no co-morbidity at start of RRT***	39.0%	9.4%	38.7%	not collected

Notes:

*comprehensive co-morbid information was only available in 5916 patients.

**countries may sometimes include those patients who were diabetic not as a primary cause of renal failure in this total.

***US data includes hypertension (74%) and also congestive cardiac failure as a co-morbidity

data may suggest that while the Renal Registry data is badly incomplete it is reasonably representative of the UK.

The USRDS includes hypertension as a separate risk factor which is present in 74% of patients starting RRT and this explains why the percentage of patients in the USA reported as having no co-morbidity was low.

The incidence of cardiac co-morbidity was less in patients aged over 75 in the UK renal replacement therapy population than those in the 65–74 age band. A more detailed analysis of UK co-morbidity by age band, compared to the USA is shown in table 16.17.

In the UK, the incidence of previous myocardial infarction rises with age and falls slightly in

Table 16.17: Percentage of co-morbidity present, per age group, UK and USA populations

Registry	Conditions	Age bands			
		≤44	45–64	65–74	75+
UK	Myocardial infarction	1.9	10.8	19.5	18.4
USRDS	Myocardial infarction	1.8	7.6	11.7	12.4
UK	Ischaemic heart disease	3.8	22.1	34.0	33.9
USRDS	Ischaemic heart disease	4.1	19.8	32.1	35.2
USRDS	Cardiac dysrhythmia	1.0	3.6	7.7	10.8
USRDS	Congestive heart failure	11.7	28.5	39.2	43.8
UK	COPD	1.5	6.4	11.2	10.4
USRDS	COPD	1.3	5.7	10.2	10.4
UK	Smoking	21.0	21.7	17.3	12.4
USRDS	Smoking	7.5	6.9	4.4	2.3
UK	Malignancy	1.5	9.1	15.9	17.8
USRDS	Malignancy	1.3	3.9	7.0	9.0
UK	Cerebrovascular disease	2.9	9.2	15.9	17.6
USRDS	Cerebrovascular disease	2.5	8.1	11.8	12.3
UK	Peripheral vascular disease	4.6	13.0	19.6	17.1
USRDS	Peripheral vascular disease	4.0	13.1	18.8	18.3

those aged over 75 years. This contrasts with the USA, where the incidence of a previous myocardial infarction is much lower than the UK in patients starting renal replacement therapy. Although in the USA it continues to rise in patients aged over 75 (probably at less than the expected rate seen in the general population), the rate is still only 2/3 that seen in the UK (12% v 18%). This higher incidence of previous MI would have a detrimental effect on survival in the UK and partly accounts for the lower incidence rates, with many patients in the UK dying before reaching the stage of requiring RRT.

The incidence of ischaemic heart disease is similar between the UK and USA at 34% and 35% of patients aged over 75 years respectively. The apparent similar incidence of cardiac disease in the USA when compared to the UK (table 16.16) is due to the inclusion of cardiac dysrhythmia. Congestive cardiac failure is not collected in the UK which also accounts for the apparent higher co-morbidity rate in the USA.

Cerebrovascular disease in UK patients was more common than the USA across all age bands, rising to almost 50% higher in those aged over 75 years. In contrast the incidence of peripheral vascular disease was similar in the UK to that of the USA, across all age bands.

Discussion

Since 1999, 15,197 patients' details have been recorded by the Renal Registry and 39% of these individuals did have co-morbid returns. There are still difficulties with data returns from the majority of renal units, although a number of renal units have managed to submit a sustained high data return. It is likely that these renal units have invested in administrative and IT systems to aid data collection and the lessons learnt by these units need to be shared. This incompleteness of data returned leads to potential unreliability in analyses. Surprisingly therefore the incidence of several co-morbidities seemed to correlate closely with that of the USA and Netherlands.

The current datasets collected by the Renal Registry have been useful and a number of

analyses investigating patient survival as well as patient demography have been performed. There are a number of differing systems of co-morbid data collection^{1,2,4,5,6,7}. As mortality is associated with cardiac and vascular disease, all the differing methods do collect information associated with these topics. To date, co-morbidity has been used by the Registry to analyse the outcomes of dialysis and transplant patients. It has been noted that elderly patients (aged 75+) have less co-morbidity than patients aged 65 to 74 years.

The Renal Registry has advocated that all renal units should collect information on patients with severe renal disease managed conservatively, without dialysis. It is likely that this group will account for the apparent disparity in the incidence of co-morbidity in the elderly patients. In general, there are patients with severe renal failure who do not start dialysis as a consequence of multiple co-morbidity, age and disability. There is debate as to whether the current information collected by the Renal Registry will aid the analysis in this group of patients. It is likely that severity of individual or collective co-morbidities or entirely different factors such as dementia and mental illness, which are not collected by the Renal Registry, may influence the decision on whether to start on renal replacement therapy or opt for conservative management.

In the past, cardiac failure as a co-morbid condition was not collected by the Renal Registry, but its importance has been noted and the dataset has been adjusted to collect heart failure information. Similarly there may be a need to further adapt the current dataset to account for other co-morbid conditions that may prove to be of importance.

The functional ability of patients can influence patient survival¹, and the collection of Karnovsky scores may be useful in the long term, although it is unlikely that renal units would cope with this added burden of work.

In summary, an understanding of the co-morbidity burden faced by patients is necessary to support future analyses, and all renal units have been encouraged to submit a complete dataset of their patients.

Appendix to Chapter 16

Important changes to co-morbidity definitions in 2003

The non-coronary angioplasty group has been widened to include other vascular grafts and arterial stents. The new definitions are given below:

Angioplasty, stenting, vascular graft, aneurysm (all non-coronary)

This category now includes vascular grafts (e.g. aortic bifurcation grafts), arterial stents and aneurysms.

Episode of heart failure (right or left) prior to RRT

This is whether or not it was only the result of fluid overload.

Co-morbidity definitions

Angina

A history of chest pain on exercise with or without ECG changes, exercise tolerance test, radionucleotide imaging or angiography.

Previous MI within the past 3 months

The rise and fall of a biomarker (CK, CK-MB or Troponin) together with one of either ischaemic symptoms, pathologic Q waves, ischaemic ECG changes or a coronary intervention. This definition is from both the European Society of Cardiology and the American College of Cardiology.

Previous MI more than 3 months ago

From the time of the start of RRT.

Previous CABG or coronary angioplasty

Episode of heart failure (right or left)

This is whether or not it was only caused by fluid overload.

Cerebrovascular disease

Any history of strokes (of whatever cause) and including transient ischaemic attacks caused by carotid disease.

Diabetes (not causing established renal failure)

This includes diet-controlled diabetics.

Chronic obstructive pulmonary disease

This is defined as a slowly progressive airways disorder characterised by obstruction of the expiratory airflow, which does not change markedly over several months, it may be accompanied by airway hyper-reactivity and may be partially reversible.

N.B. Chronic bronchitis and emphysema may occur in the absence of airflow obstruction. Asthma patients may rarely develop airflow obstruction that does not improve with steroids.

Liver disease

Persistent enzyme evidence of hepatic dysfunction or biopsy evidence or hepatitis B e antigen or hepatitis C antigen (polymerase chain reaction) positive serology.

Malignancy

Defined as any history of malignancy (even if curative), for example the removal of a melanoma; excludes basal cell carcinoma.

Claudication

Current claudication based on a history, with or without Doppler or angiographic evidence.

Ischaemic/neuropathic ulcers

The current presence of these ulcers.

Angioplasty, stenting, vascular graft, vascular aneurysm (all non-coronary)

This category now includes vascular grafts (e.g. aortic bifurcation grafts) and renal artery stents.

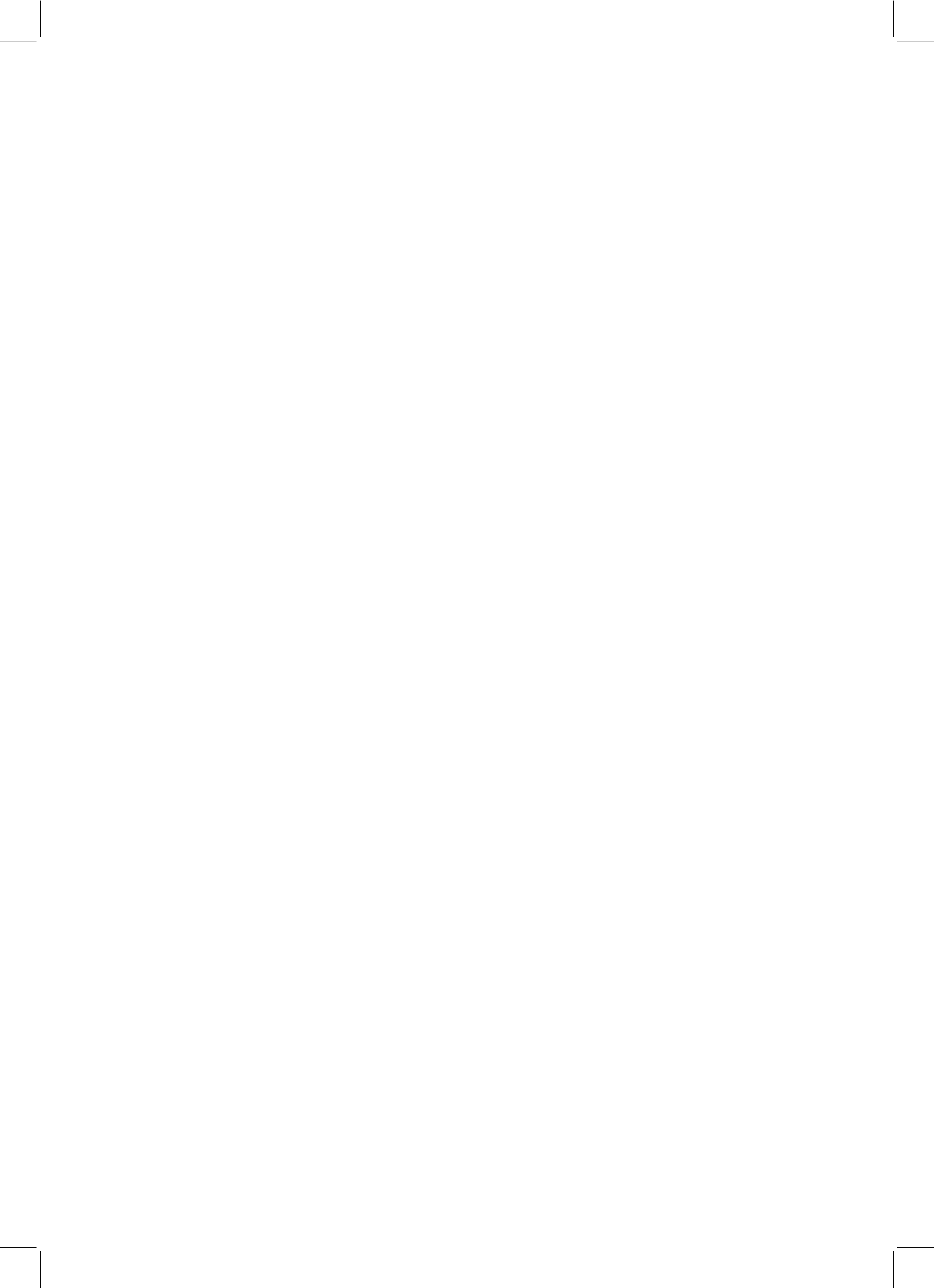
Amputation for peripheral vascular disease

Smoking

Being a current smoker or having a history of smoking within the previous year.

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Chapter 17: 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 UK achieves similar phosphate control in PD patients to that in Australia although phosphate control in HD patients is slightly worse in the UK.
- Two year survival of incident patients in the UK is around the European average.
- Comparisons of national registries show that age distribution of dialysis patients in the UK and the USA is similar. In the UK, history of a previous MI is found in 50% more patients starting RRT over age 65 years than in the USA.
- In the USA the apparent higher rates of cardiac disease than the UK is misleading. It is due to the inclusion of congestive cardiac failure and dysrhythmias, which are not collected by the UK Registry.
- In the UK, patients starting RRT have a much higher incidence of cerebrovascular disease than the USA (18% v 12% in patients aged 75+).
- The incidence of peripheral vascular disease and COPD is similar in the UK to the USA across all age bands.

Problems of international comparison

When making international comparisons of RRT, 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)¹. 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 (eg co-morbidity) and depend on the rigour of individual renal units to ensure the accuracy of the data. Not all renal units are 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 record detailed data, but are open to sampling errors which may be important when it comes to interpretation. iDOPPS only collect data on haemodialysis patients which in the UK would exclude 33% of the dialysis population who are on PD (and have less co-morbidity). In some UK centres, 60% of patients are on PD and iDOPPS sampling from HD patients in these centres would produce an even more biased subset of patients. This accounts for the apparent higher UK mortality published by iDOPPS which is not seen in the European Renal Registry analysis of UK data compared with other European countries (Table 17.7).

These data used for international comparisons in this chapter are all derived from large national or renal registries.

International comparative incidence data

International comparisons of incidence RRT data 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

Table 17.1: Annual incidence rates of RRT by country, per million population

Country	Incidence				% diabetic 2002/03
	2000	2001	2002	2003	
Taiwan	323	357	365	–	35
USA	325	328	336	–	44
Japan	252	252	262	265	41
Germany	175	184	174	186	36
Belgium (Dutch-speaking)	–	–	170	–	17
Greece	157	164	165	–	27
Czech Republic	151	163	157	–	35
Canada	143	152	154	–	34
Italy	131	136	142	–	16
Austria	133	136	132	141	33
Hungary	129	130	N/A	139	25
Uruguay	121	124	136	–	20
Denmark	–	–	130	129	22
Spain	132	127	126	–	22
Turkey	115	141	122	–	23
Sweden	126	124	125	121	24
New Zealand	110	119	115	112	40
UK	89	95	101	103	18
Netherlands	93	101	100	101	16
Poland	68	84	99	–	24
Bosnia and Herzegovina	–	–	77	95	–
Australia	92	97	94	98	26
Norway	89	95	92	95	16
Finland	90	91	94	93	39

mortality, as the initial 90-day high mortality will be lost.

The estimated UK annual acceptance rate has slowly risen to 103 pmp over the last 5 years (Table 17.1).

Some countries show a very similar pattern to the UK with a rate around 90–100 pmp, 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 17.1). 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.

Analysis by the proportions of the incident UK and US RRT patients within specific age bands shows a similar distribution (Figure 17.1).

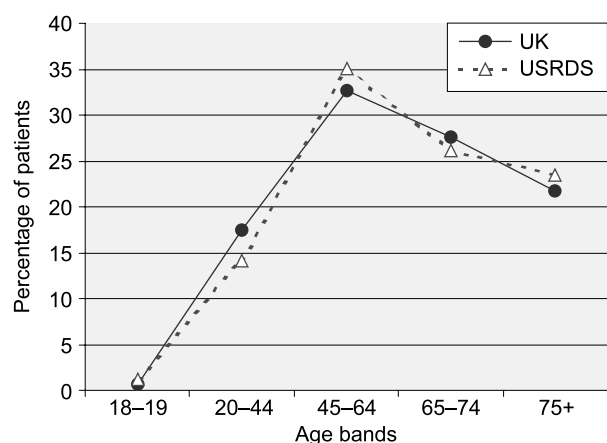


Figure 17.1: Percentage of patients on dialysis by age distribution, for UK and USA

Prevalent patients

The changing prevalence of RRT over three years in selected countries is shown in Table 17.2 and the distribution of modality for dialysis patients is in Table 17.3. The highest prevalence rates are observed in Taiwan, Japan and the USA. In Europe, Spain and Germany has the highest prevalence rate. The UK has one of the lowest prevalence rates amongst the European countries.

Haemodialysis is the main dialysis modality in all countries, with more than 90% of dialysis patients on HD in the majority of countries. New Zealand has an exceptionally high use of PD at 45%. PD use is also high in Australia, the UK, Canada and the Scandinavian countries. The 3 countries with the highest prevalence rates (Taiwan, Japan and the USA) have less than 10% of their dialysis patients on PD.

Table 17.2: Prevalence rates of RRT, pmp, by country

Country	Prevalence			
	2000	2001	2002	2003
Japan	1,576	1,642	1,726	1,862
Taiwan	1,483	1,557	1,548	–
USA	1,360	1,403	1,446	–
Spain	871	880	950	–
Germany	870	919	918	949
Canada	807	854	893	–
Belgium (Dutch-speaking)	–	–	877	–
Italy	804	835	864	–
Greece	797	815	841	–
Austria	712	748	781	814
Uruguay	737	763	807	–
Sweden	714	735	756	774
Denmark	638	679	699	732
Chile	611	672	726	–
New Zealand	611	652	685	710
Czech Republic	625	663	695	–
Australia	608	634	658	686
Netherlands	621	640	658	683
Norway	581	613	641	666
Finland	583	612	637	661
UK	–	–	626	632
Hungary	517	580	–	609
Bosnia and Herzegovina	–	–	417	432
Poland	316	353	390	–
Turkey	275	359	388	–

Table 17.3: Percentage dialysis modalities in prevalent patients

Country	Year	HD	PD	Home HD (% of HD patients)
New Zealand	2003	55	45	25.0
Netherlands	2003	72	28	2.0
United Kingdom	2002	73	27	3.0
Denmark	2003	74	26	1.3
Sweden	2002	76	24	3.0
Australia	2003	76	24	13.0
Finland	2003	79	21	4.0
Canada	2002	82	18	2.0
Norway	2003	84	16	0.3
Poland	2002	89	11	0.0
Spain	2002	90	10	–
Greece	2002	90	10	0.0
Hungary	2003	92	8	0.0
Italy	2002	92	8	1.0
Austria	2003	92	8	0.3
USA	2002	92	8	0.4
Taiwan	2002	93	7	0.0
Uruguay	2002	94	6	0.0
Belgium (Dutch-speaking)	2002	94	6	–
Germany	2003	95	5	0.9
Japan	2003	96	4	0.0
Bosnia and Herzegovina	2003	97	3	–

Comparison of biochemical and haematological results

Some comparative data on biochemical and haematological variables are shown in Table 17.4. These USA data are from the Centre for

Medicare & Medicaid Services, 2003 Annual Report of Clinical Performance Measures Project². The Australian and New Zealand data are from the Australia and New Zealand Dialysis and Transplant Registry Report, 2004⁴.

Table 17.4: Comparative data on indicators of quality of care – England & Wales, USA, Australia, and New Zealand

	E & W	USA	Australia	N. Zealand
Median URR	71.0%	71.5%	73.0%	68.0%
% patients with URR \geq 65%	78%	86%	88%	65%
% Hb \geq 10 g/dl	84% HD 88% PD	93% HD 94% PD	–	–
% Hb \geq 11 g/dl	65% HD 72% PD	79% HD 79% PD	66%	37%
Median ferritin μ g/L	440 HD 267 PD	599 HD 425 PD	–	–
% ferritin >100 μ g/L	95% HD 87% PD	92% HD 84% PD	90%	86%
Phosphate <1.8 mmol/L	59% HD 68% PD	–	66% HD 68% PD	52% HD 61% PD

Comparisons of co-morbidity

The number of national renal registries which produce a comprehensive list of co-morbid conditions of dialysis patients is small. A comparative analysis between countries, was available using publications from the USA, Australia/New Zealand and the Netherlands.

The USRDS (United States Renal Data System) generates a large amount of data which is easily accessible through its website (www.usrds.org)³. The Australian and New Zealand (ANZDATA) Registry had published co-morbid information in a paper discussing late referral and the data is on their website (www.anzdata.org)⁴. The Necosad group⁵ discussing dialysis have published information of a prospective cohort of patients from the 36 renal units in the Netherlands. Using all this information, it was possible to make a number of observations regarding co-morbidity.

Definitions of cardiac disease, peripheral vascular disease and diabetes vary between countries. **Methods of recording other co-morbidity may also be different within these Registries, therefore these comparisons should be interpreted cautiously.**

Cardiac disease, cerebrovascular disease, peripheral vascular disease and COPD appear

to be more common in Australia and New Zealand (Table 17.5). Diabetes was most common in the USRDS population, followed by Australia and New Zealand. The USA was the only other country with data on smoking history and this was 1/3 the rate seen in the UK (5.2% v 18.4%).

The incidence of peripheral vascular disease and COPD were similar in the USA, the UK and the Netherlands.

The Necosad data from the Netherlands shows a similarity to that in the UK for the incidence of diabetes, peripheral vascular disease, malignancy and COPD in the renal replacement therapy population. This may also relate to the similar incidence of RRT in the Netherlands in 2002 (100 pmp) to that of the UK (103 pmp).

The USRDS includes hypertension as a separate risk factor which is present in 74% of patients starting RRT and this explains why the percentage of patients in the USA reported as having no co-morbidity was low.

The incidence of cardiac co-morbidity was less in patients aged over 75 in the UK renal replacement therapy population than those in the 65–74 age band. A more detailed analysis of UK co-morbidity by age band, compared to the USA is shown in Table 17.6.

Table 17.5: Summary of co-morbidity from differing national registries

	National registries			
	ANZDATA	USRDS	UK RR	Necosad 2
Study period	2003	1995–2003	1999–2003	1997–2000
Number of patients	1,953	696,043	15,197*	1,041
Ischaemic heart disease incl MI	30.5%	23.8%	24.7%	11.1%
Cerebrovascular disease	11.0%	9.0%	11.7%	7.2%
Peripheral vascular disease	19.0%	14.3%	14.2%	13.0%
COPD	12.0%	7.1%	7.7%	7.2%
Diabetes**	35.0%	41.2%	18.8%	19.5%
Malignancy	not collected	5.3%	11.5%	10.1%
Smoking	11.0%	5.2%	18.4%	not collected
Congestive cardiac failure	not collected	32.0%	not collected	12.3%
Patients with no co-morbidity at start of RRT***	39.0%	9.4%	38.7%	not collected

Notes:

*Comprehensive co-morbid information was only available in 5,916 patients.

**Countries may sometimes include those patients who were diabetic not as a primary cause of renal failure in this total.

***US data includes hypertension (74%) and also congestive cardiac failure as a co-morbidity.

Table 17.6: Percentage of co-morbidity present, per age group, UK and USA populations

Registry	Conditions	Age bands			
		<44	45–64	65–74	75+
UK	Myocardial infarction	1.9	10.8	19.5	18.4
USRDS	Myocardial infarction	1.8	7.6	11.7	12.4
UK	Ischaemic heart disease	3.8	22.1	34.0	33.9
USRDS	Ischaemic heart disease	4.1	19.8	32.1	35.2
USRDS	Cardiac dysrhythmia	1.0	3.6	7.7	10.8
USRDS	Congestive heart failure	11.7	28.5	39.2	43.8
UK	COPD	1.5	6.4	11.2	10.4
USRDS	COPD	1.3	5.7	10.2	10.4
UK	Smoking	21.0	21.7	17.3	12.4
USRDS	Smoking	7.5	6.9	4.4	2.3
UK	Malignancy	1.5	9.1	15.9	17.8
USRDS	Malignancy	1.3	3.9	7.0	9.0
UK	Cerebrovascular disease	2.9	9.2	15.9	17.6
USRDS	Cerebrovascular disease	2.5	8.1	11.8	12.3
UK	Peripheral vascular disease	4.6	13.0	19.6	17.1
USRDS	Peripheral vascular disease	4.0	13.1	18.8	18.3

In the UK, the incidence of previous myocardial infarction rises with age and falls slightly in those aged over 75 years. This contrasts with the USA, where the incidence of a previous myocardial infarction is much lower than the UK in patients starting renal replacement therapy. Although in the USA it continues to rise in patients aged over 75 (probably at less than the expected rate seen in the general population), the rate is still only 2/3 that seen in the UK (12% v 18%). This higher incidence of previous MI would have a detrimental effect on survival in the UK and partly accounts for the lower incidence rates, with many patients in the UK dying before reaching the stage of requiring renal replacement therapy.

The incidence of ischaemic heart disease is similar between the UK and USA at 34% and 35% of patients aged over 75 years respectively. The apparent similar incidence of cardiac disease in the USA when compared to the UK (Table 17.5) is due to the inclusion of cardiac dysrhythmia. Congestive cardiac failure is not collected in the UK which also accounts for the apparent higher co-morbidity rate in the USA.

Cerebrovascular disease in UK patients was more common than in the USA across all age bands, rising to almost 50% higher in those aged over 75 years. In contrast the incidence of

peripheral vascular disease was similar in the UK to that of the USA, across all age bands.

Transplant recipients in 2003

The median age of all transplant recipients in 2003 (including those from live donors) is shown in Figure 17.2. These data from the USA have been supplied by the UNOS database and the Australian data from the ANZDATA Registry. The median age of transplant recipients is slightly higher in the US and 11% of recipients are aged over 65 compared with 7.5% in the UK and 7.2% in Australia.

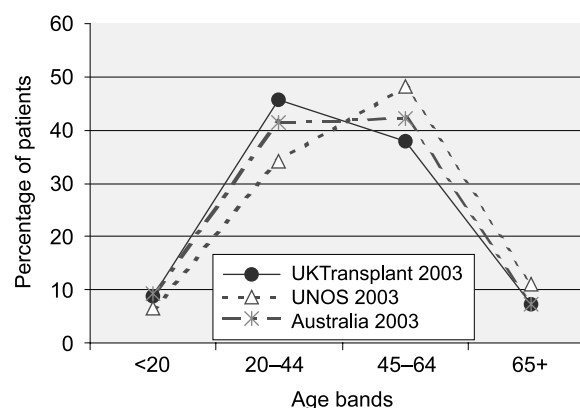


Figure 17.2: Age distribution of patients transplanted in 2003, UK, USA, and Australia

Table 17.7: All European Registry countries, adjusted survival of incident RRT patients

Adjusted for age, gender and primary diagnosis

	1 year survival from 90 days (95% CI)	2 year survival from 90 days (95% CI)
0–19 yrs	96.4 (95.1–97.8)	95.1 (93.5–96.6)
20–44 yrs	95.5 (95.1–96.0)	92.0 (91.4–92.7)
45–64 yrs	88.6 (88.1–89.1)	79.8 (79.2–80.4)
65–74 yrs	79.2 (78.5–79.9)	63.1 (62.3–64.0)
75+ yrs	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 diabetic	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)

One and two-year survival of incident patients

All European Registry Countries

These data are taken from the European Renal Registry report⁶.

The survival of incident patients in the first 2 years in the UK is very close to the European average (Tables 17.7 and 17.8). 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 period prevalent RRT patients – UK and USA

Death rates of point prevalent RRT patients in different age groups, established on RRT in the

Table 17.9: Death rates per 1,000 years exposed, period prevalent RRT patients (White patients only), USA and UK

Age group	No. died	Total	Sum of patient years	UK deaths per 1,000 years	95% CI	US deaths per 1,000 years
20–29	10	893	317,825	11.5	4.4–18.6	26.2
30–39	53	2,086	736,935	26.3	19.3–33.2	43.6
40–49	90	2,532	887,668	37.0	29.5–44.6	71.6
50–59	190	3,087	1,065,546	65.1	56.2–74.1	122.7
60–64	146	1,497	502,853	106.0	89.8–122.3	182.3
65–69	190	1,476	482,311	143.9	125.0–162.8	243.2
70–79	535	2,555	787,874	248.0	229.8–266.2	342.3
80+	226	740	211,803	389.7	350.0–429.4	504.3

Table 17.8: UK England & Wales adjusted survival of incident RRT patients

Adjusted for age, gender and primary diagnosis

	1 year survival from 90 days (95% CI)	2 year survival from 90 days (95% CI)
0–19 yrs	Not available	Not available
20–44 yrs	95.4 (94.0–96.8)	91.7 (89.9–93.6)
45–64 yrs	88.3 (86.8–89.9)	80.3 (78.4–82.3)
65–74 yrs	77.0 (74.6–79.5)	61.1 (58.3–64.0)
75+ yrs	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 diabetic	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)

UK and USA are shown in Table 17.9 and Figure 17.3. To eliminate the effect of ethnicity, the comparison of death rates in the UK and the USA was calculated for white patients only. The death rates in the UK are significantly

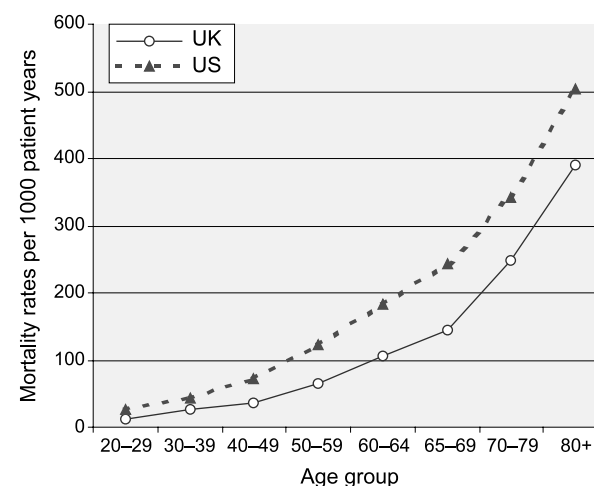


Figure 17.3: Death rates per 1,000 years exposed, period prevalent RRT patients (White patients only), USA and UK

better than in the USA. The USA data are from the USRDS Annual Report 2004³.

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Chapter 18: The 'Health and Social Care Act 2001': section 60 exemption

Summary

The Registry has been granted a section 60 exemption by the Secretary of State under the Health and Social Care Act. This exemption allows the registration of identifiable patient information from renal units without first asking the consent of each individual patient, avoiding a breach of the common law on confidentiality.

This exemption is temporary and is reviewed annually. The progress towards collection of anonymised data or obtaining permission of the individual patient is monitored by the Patient Information Advisory Group (PIAG).

The first annual report on progress by the Registry towards anonymisation has been submitted to PIAG.

Introduction

The Registry falls under Schedule 3 exemption from the Data Protection Act 1998. This section within the Act relates to the processing of sensitive personal information. In Section 8 of Schedule 3, access to personal information is allowed for necessary medical purposes, but must be undertaken by either a health professional or a person who owes a duty of confidentiality equivalent to that of a health professional (such as health researchers or statisticians). In regard to the Renal Registry, "medical purposes" includes preventative medicine, medical diagnosis, medical research, the provision of care and treatment and the management of healthcare services. Under common law individual consent to collect identifiable data is still required.

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 essential.
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 data where age is a factor.
2. To assess geographical equality of access to treatment eg 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 create a large and recurring workload. More importantly, it would lead to incomplete data collection, as some patients would refuse permission. In two recent medical studies^{1,2} only 33% of patients provided consent and it could be confirmed that outcomes in those groups were different from those patients where consent was not given. Such behaviour would render many of the Registry 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 Registry Committee has decided to take this course.

Path towards compliance

In the application to PIAG, the Registry set out a four-stage path towards full compliance.

It is government policy in England & Wales, that patient's NHS numbers will be used for all hospital episodes. The goal 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 and geographical area of residence such as local authority or health authority. It will then not be necessary to store the full postcode in the database.

1. 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 distribution in renal units. These communications will describe the extent of the information that is stored regarding patients with renal failure and the fact that patient identifiers are only accessible to a small number of skilled and conscientious staff. It will also explain how that information is used and that all outputs are anonymous. 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 is being 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 has altered its software to hold patient identifiable data items received from renal units in a separate database.

1.2.2. Where necessary data is incomplete, the Registry is using a 'postcode lookup application' to obtain a valid full postcode and then use the NHS

Strategic Tracing Service to obtain the NHS number. The Registry is advising renal units to update their patient demographic data to include the missing data.

1.2.3. The Registry will move towards deletion of 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.

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

2. 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. All other patient identifiable data will be deleted once this pre-analysis activity has been completed.

3. Stage 3 –

3.1. The National Programme for IT 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.

4. 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 dataset (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 Department of Health (DoH) Datasets Development Programme, the Registry is currently seeking approval for the National Renal Dataset.
- 4.3. The Registry will work with local service providers to implement the Renal NSF Core Service. That includes the requirement for LSPs 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.

It is acknowledged by PIAG that some of the timescales may not be achieved due to as yet unresolved technical issues/lack of progress with the NHS IT infrastructure. All these issues will be reviewed annually by PIAG.

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Appendix A: The Renal Registry Rationale

1. Executive summary
 2. Introduction
 3. Statement of intent
 4. Relationships of the Renal Registry
 5. The role of the Renal Registry for nephrologists
 6. The role of the Renal Registry for Trust managers
 7. The role of the Renal Registry for commissioning agencies
 8. The role of the Renal Registry national quality assurance schemes
 9. The role of the Renal Registry for patients
 10. Abbreviations
 11. References
- 1.5 Data will be collected quarterly to maintain unit level quality assurance, with an annual report
 - 1.6 Activity is 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: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.

A:2 Introduction

- 2.1 Registry based National Specialty Comparative Audit is one of the cornerstones of NHS development. The Renal *National Service Framework* (NSF), published in 2004, recommended the participation of all renal units in comparative audit through the Renal Registry¹. Chief Executives are now responsible for clinical governance and comparative audit at national level will be an essential part of this agenda². 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.
- 2.2 The need for careful comparative audit has been confirmed through the development of government agencies such as the National Institute for Clinical Excellence (NICE) and the Healthcare Commission. 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 ERA-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 ERA-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 four ad hoc national data collections from England & Wales were solicited from renal centres in 1992, 1996, 1999 and 2002. 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, the NHS has developed a need to underpin clinical activity more rigorously through the scientific evidence base (for example, the Cochrane Initiative) and by quality assurance activity through audit. These initiatives require comprehensive information about the structures, processes and outcomes of RRT, which go well beyond the detail previously compiled by the ERA-EDTA.
- 2.5 The Registry is recognised as one of the few high-quality clinical databases available for general use³.
- 2.6 The aspiration for renal services to be provided within the National Service Framework is underpinned by the development of the Renal Registry⁴.
- 2.7 Similar cultural pressures have more recently affected all clinical disciplines, so that Registries are implemented 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, PCT and health authority management, standard setting, audit and research. The opportunity for data gathering arises partly from improvements in information technology. Although it was possible to see the need for a national renal database 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

- 3.1 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 RRDS by automatic downloading from renal centre databases. There will be a core dataset, with optional elements of special interest that may be entered by agreement for defined periods. A report will be published annually to allow a comparative audit of facilities, patient demographics, quality of care and outcome measures. Participation is mandated through the recommendation in the Renal NSF. 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 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 Committee and Clinical Affairs Board. 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 Ireland data to the ERA Registry will be through the Renal Registry. The Scottish Renal Registry already sends data to the ERA Registry.
- 4.5 A paediatric database has been developed in collaboration with the Renal Registry and the two databases are compatible. These two databases are in the process of being integrated which will allow long-term studies of renal cohorts over a wide range of age.
- 4.6 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. The responsibilities of the unit and Registry are clarified in

the clauses of the Agreement, as well as the conditions of publication of data.

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 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. Centre data will be 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, PCTs, 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 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 Committee to conduct local or national audit and research using the database. All such projects will need the agreement of the Registry Committee and any costs involved 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 that 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 Review⁵ 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 £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 from 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 the Healthcare Commission will depend on decisions as to the roles of those agencies⁶.
- 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 on survival data 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 Committee.

A:9 The role of the Renal Registry for patients

- 9.1 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

BAPN	British Association of Paediatric Nephrology
BTS	British Transplantation Society
ERA-EDTA	European Renal Association-European Dialysis and Transplant Association
ERF	Established Renal Failure
NFKPA	National Federation of Kidney Patients' Associations
NHS	National Health Service
NICE	National Institute of Clinical Excellence
PCT	Primary Care Trust
RRDSS	Renal Registry Data Set Specification
RRT	Renal Replacement Therapy

A:11 References

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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 established renal failure (ERF)

Established renal failure (also known as end-stage renal failure/end-stage renal disease) is defined as the date of the first dialysis (or of pre-emptive transplant).

If a patient is started as ‘acute’ renal failure and does not recover, the date of start of renal replacement should be backdated to the start of acute dialysis.

If a patient is started on dialysis and dialysis is temporarily stopped for less than 90 days for any reason (including access failure and awaiting the formation of further access) except the recovery of renal function, the date of start of renal replacement therapy (RRT) remains the date of first dialysis. If the patient has stopped for longer than 90 days, he or she is classed as ‘recovered’.

Change of modality from PD to HD

Sites are requested to log in their timeline changes from PD to HD if the modality switch is for longer than 30 days.

Analyses that include PD technique survival, patients on peritoneal dialysis who changed to haemodialysis for less than 31 days before changing back to PD were classified as remaining on PD. Those remaining on haemodialysis for more than 30 days and then changing back to PD were classified as having changed to haemodialysis.

B:3 Analysis criteria

Definition of the take-on population (incidence)

The take-on population in a year included patients who later recovered from ERF after 90 days from the start of treatment. Patients newly transferred into a centre who were already on RRT were **excluded** from the take-on population for that centre. Patients restarting dialysis after a failed transplant were also excluded (unless they started RRT in that current year).

Since patients who restarted RRT after recovering from ERF are included in the take-on population, the following scenario can occur: a patient may start RRT in 2003, recover and then restart RRT in 2003. Such patients are counted twice in the analysis providing they have been receiving RRT for more than 90 days on each occasion.

Patients who started treatment at a centre and then transferred out soon after receiving treatment are counted at the original centre for all analyses of treatment on the 90th day.

Definition of the prevalent population

This is calculated as all patients who are alive on 31 December and includes the incident cohort for that year alive on that date.

Confidence Interval

The 95% confidence intervals have been calculated using the normal approximation of the Poisson.

Death rate calculation

The death rate per 100 patient years was calculated by counting the number of deaths and dividing by the person years exposed. This includes all patients, including those who died within the first 3 months of therapy. The person years at risk were calculated by adding up, for each patient, the number of days at risk (until they died or transferred out) and dividing by 365.

Odds ratio

The odds of dying is the:

$$\frac{\text{(Probability of dying for someone with a phosphate of 1.71–2.10 mmol/L)}}{\text{(Probability of surviving for someone with a phosphate of 1.71–2.10 mmol/L)}}$$

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

$$\frac{\text{(Probability of dying in the next interval for a phosphate of 1.71–2.10 mmol/L)}}{\text{(Probability of dying in the next interval for a phosphate in the reference range)}}$$

Z-Scores

The enquiry into the excess of paediatric cardiac deaths at the Bristol Royal Infirmary defined an outlier as lying beyond 3 standard deviations from the mean, using the statistical methodology of Shewhart's control theory. This analysis relies on the centre sizes, and hence their standard deviation, being very similar. Renal units in the UK vary greatly in size, catchment populations varying from 300,000 to over 2 million. There is a consequent variation in the total patient number on RRT so the figure for the standard deviation will vary greatly between centres. The standard deviation for the total RRT population is not an appropriate number as this will be very small. Therefore, the Shewhart methodology cannot be applied. The Registry has used the accepted statistical technique of Z-scores to identify any outliers.

Definition

Z-scores are sometimes called "standard scores". It is a measure of the distance in standard deviations of a sample from the mean.

The Z-score transformation is especially useful when seeking to compare the relative standings of items from distributions with different means and/or different standard deviations. The Z-score for an item indicates how far and in what direction, that item deviates from its distribution's mean, expressed in units of its distribution's standard deviation.

Mathematically:

the survival Z-score

$$= \frac{\text{Survival for centre X} - \text{survival for all centres}}{\text{Standard error for centre X}}$$

The Z-score is therefore an adjustment for the size of the centre and when comparing the different Z-scores for all the centres, they should be normally distributed. The observed Z value compared with the expected Z value (see explanation below) should be on a straight line.

Calculation of the expected Z value

Suppose there is a normally distributed population from which we repeatedly draw random samples of some specific size, say 10. These 10 values from each such random sample are sorted into increasing order, smallest value to largest value. When the sample data is sorted in this way, the individual numbers are called **order statistics**. The smallest value will vary somewhat from one such sample to another, but over the long run, the smallest values should tend to cluster around some average smallest value and produce a **mean** or **expected values of the order statistics**. These data have been compiled into tables so that for every specific total number of ordered samples (eg 38 centres with Registry survival data) there is an expected Z value for each ordered centre in that list.

Survival analyses of prevalent cohort

These analyses exclude the current year's incident cohort. Note some Renal Registries include these patients in the prevalent survival.

Criteria for analysis by treatment modality in a quarter

The following quarterly entries were included and excluded:

- Patients on haemodialysis with a treatment centre of 'elsewhere' were **removed**. It should be noted that there were some patients on transplant with a treatment centre of 'elsewhere'; these patients were **included**.
- Entries for which the hospital centre was not the primary treatment centre were removed from the analysis of data for that centre.
- Patients who had been on RRT for less than 90 days were removed (by definition of 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 2003 would, for example, be included for the quarter 1/03 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 example, the number of days on RRT would be calculated from 1 November 2003. The patient would be excluded from the analysis for quarter 4/03 since on 31 December 2003, he or she would have been on RRT for only 90 days. The patient would be included in the analysis from quarter 1/04 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 2003, 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 2002 and 31 September 2003 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 2003. 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 2002 and 31 December 2002. 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 2003.
2. Patients who had a transplant between 1 July 2002 and 31 December 2002 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 2002 and 31 December 2002.
4. The few patients who recovered renal function in 2003 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 2003 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.

Seasonal variation of deaths using circular data statistical technique

In a study with a cyclic time period, such as a year, it is possible to interpret these data as circular data. (Mardia, *Statistics of Directional Data*, 1972)¹. Circular analysis has advantages over linear analysis as circular data has no beginning or end. Circular data cannot be ordered for example, December is not 'larger' than January.

An example of the importance of circular data analysis over linear analysis would be looking at the observed angles in a data set, 15° and 354° , the arithmetic mean would be approximately 180° , and this is clearly not the average direction. This is illustrated in the figure B.1.

Hence, why it is better to use circular analysis, the mean direction is 0° and this would be the resultant date of death. Analyses carried out with this methodology need to be specific to circular data.

The patients included were an incident cohort of all those patients who died between 1997 and 2003. Data used are the Townsend score, age and additional data on the daily temperatures from 1997 to

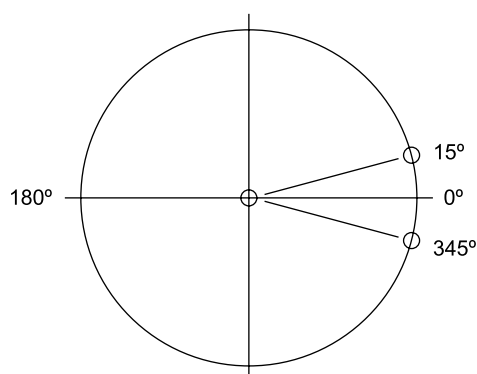


Figure B.1: Analysis of circular data

2003 are also included. The response variable of interest is the date of death. Each day in the year represented as an angle on a circle results in a set of circular data.

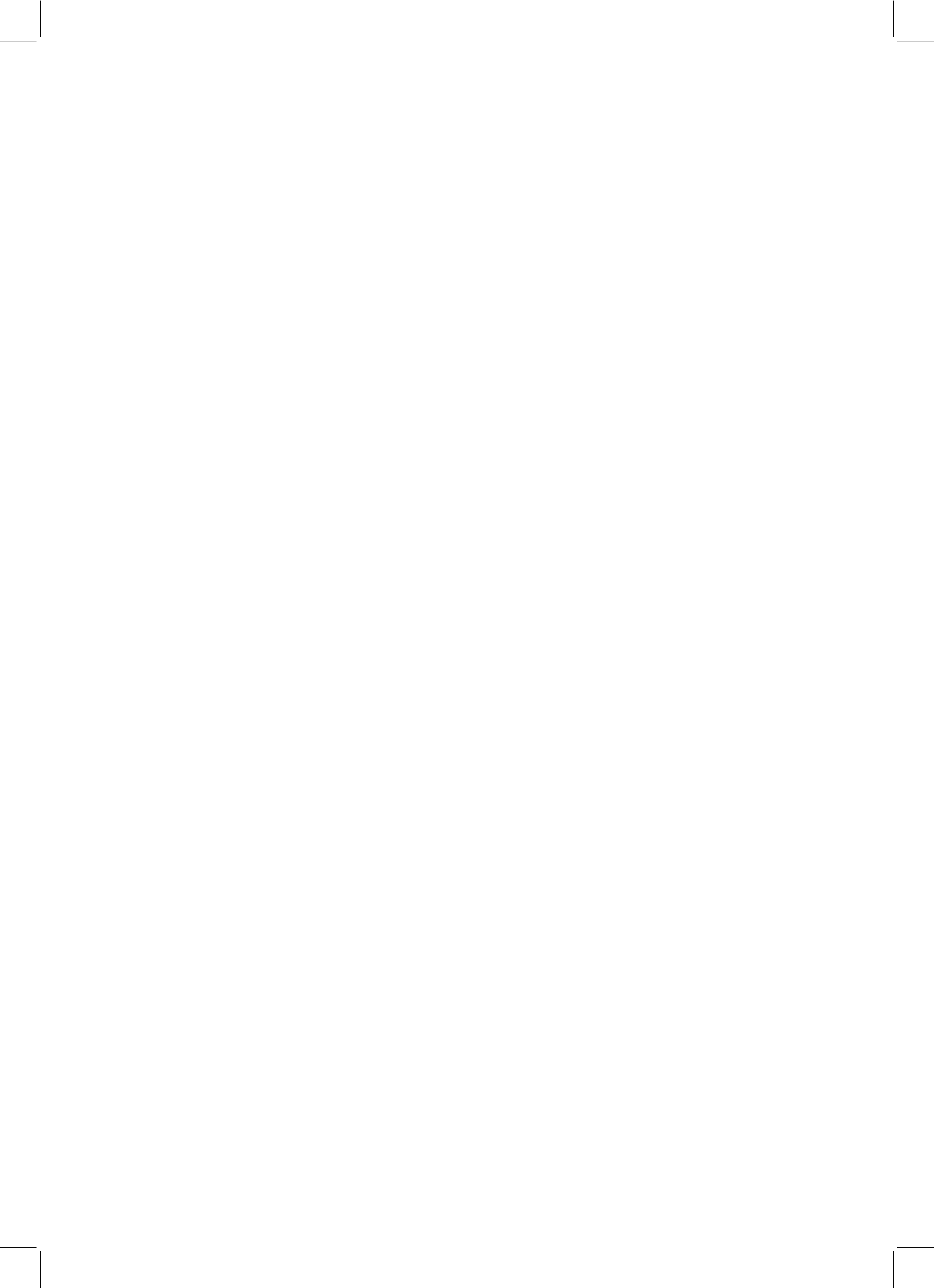
The seasonal variation in deaths were assessed using standard uniformity tests in the form of the Rayleigh Test. Rayleigh's test is a parametric test which assesses the significance of the mean resultant length which is the measure of strength of the mean direction. Any departure from uniformity and evidence of true seasonal variation would be shown

here. The mean direction gives the 'preferred' day of death for a patient on RRT.

Circular-regression analysis is carried out to assess the affect of different variables on the date of death. The response variable is the date of death and is a circular variable.

Reference

1. Mardia KV. (1972). *Statistics of Directional Data*. Academic Press: London.



Appendix C: Renal Services Described for Non-physicians

(Reproduced from the third edition of the Renal Association Standards document, August 2002)

This appendix provides information on the issues discussed in this Report, 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 (ERF)

- 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 Afro-Caribbean) than

in Whites, this is supported by national mortality statistics. People from the Indian subcontinent have a higher prevalence of non-insulin dependent diabetes, and those with diabetes are more likely than Whites to develop renal failure. This partly explains the higher acceptance rate of Asians on to renal replacement programmes.

Causes of Renal Failure

1.7 Most renal diseases that cause renal failure fall into 6 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 anti-hypertensives called angiotensin converting enzyme inhibitors (ACE-I) 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, eg diabetes may cause blindness and diseases of the nerves and blood vessels. Others, such as anaemia, bone disease and heart failure, are consequences of the renal failure. Coincidental disease such as chronic bronchitis and arthritis are particularly common in older patients with renal failure. In addition many patients with end stage renal disease have diseases affecting the heart and blood vessels 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 kidney 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 more common in transplant patients than in age-matched controls. During subsequent years there is a steady loss of transplanted kidneys owing to a process of chronic rejection; treatment of this is quite unsatisfactory at the moment, so many patients require a second or even third graft over several decades, with further periods of dialysis in between.

- 1.15 The main problem with expanding the transplantation service is the shortage of suitable kidneys to transplant. Although the situation can be improved it is now clear that whatever social and medical structures are present and whatever legislation is adopted, there will inevitably be a shortage of kidneys from humans. This remains the case even if kidneys from the newly dead (cadaver kidneys) are retrieved with the maximum efficiency, and living donors (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 specialities, 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 increases, and this may interrupt the regular care of patients already on renal replacement therapy, so increased resources may be required.
 3. Routine nephrology. A substantial workload is associated with the immunological and metabolic nature of renal disease which requires investigative procedures in an inpatient setting. It is estimated that 10 inpatient beds per million of the population are required for this work.
 4. Investigation and management of fluid and electrolyte disorders. This is a variable proportion of the nephrologists work, depending on the other expertise available in the hospital.

5. Outpatient work. The outpatient work in renal medicine consists of the majority of general nephrology together with clinics attended by dialysis and renal transplant patients.

Further Reading

Further details of renal services for renal failure, written for non-physicians, can be found in:

Cameron JS. *Kidney Failure – the Facts*. London: Oxford University Press, 1996.



Appendix D: Methodology of standardised acceptance rates calculation and administrative area geography and Registry population groups in England & Wales

Chapter 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. This methodology is also used in Chapter 5 for analysis of prevalent patients.

Patients

All new cases accepted onto RRT in each year recorded by the Registry were included. Each patient's postcode was matched to a 2001 Census output area. In 2003 there were only 14 patients with postcodes that had no match; there was no obvious clustering by renal unit.

Geography: Unitary Authorities, Counties and other areas

In contrast to 2002 contiguous 'county' areas were not derived by merging Unitary Authorities (UAs) with a bordering county. For example, Southampton UA and Portsmouth UA were kept separate from Hampshire county. The final areas used were Metropolitan counties, Greater London districts, Welsh areas, Shire counties and Unitary Authorities – these different types of area were called 'Local Authority (LA) areas'.

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

Administrative area geography in England and Wales

There are currently 46 unitary authorities in England, 34 shire counties and six metropolitan counties. Greater London forms a unique area type. Shire counties and metropolitan counties are subdivided into districts; unitary authorities are not subdivided.

Greater London is subdivided into the London Boroughs and the City of London.

Unitary Authorities

Table D.1: Unitary Authorities

Code	UA name
00EB	Hartlepool
00EC	Middlesbrough
00EE	Redcar and Cleveland
00EF	Stockton-on-Tees
00EH	Darlington
00ET	Halton
00EU	Warrington
00EX	Blackburn with Darwen
00EY	Blackpool
00FA	Kingston upon Hull, City of
00FB	East Riding of Yorkshire
00FC	North East Lincolnshire
00FD	North Lincolnshire
00FF	York
00FK	Derby
00FN	Leicester
00FP	Rutland
00FY	Nottingham
00GA	Herefordshire, County of
00GF	Telford and Wrekin
00GL	Stoke-on-Trent
00KF	Southend-on-Sea
00HA	Bath and North East Somerset
00HB	Bristol, City of
00HC	North Somerset
00HD	South Gloucestershire
00HG	Plymouth
00HH	Torbay
00HN	Bournemouth
00HP	Poole
00HX	Swindon
00JA	Peterborough
00KA	Luton
00KG	Thurrock
00LC	Medway
00MA	Bracknell Forest
00MB	West Berkshire
00MC	Reading

Table D.1: (continued)

Code	UA name
00MD	Slough
00ME	Windsor and Maidenhead
00MF	Wokingham
00MG	Milton Keynes
00ML	Brighton and Hove
00MR	Portsmouth
00MS	Southampton
00MW	Isle of Wight

Shire counties

There are 34 shire counties, subdivided into non-metropolitan districts.

Table D.2: Shire counties

Code	County name
09	Bedfordshire
11	Buckinghamshire
12	Cambridgeshire
13	Cheshire
15	Cornwall and Isles of Scilly
16	Cumbria
17	Derbyshire
18	Devon
19	Dorset
20	Durham
21	East Sussex
22	Essex
23	Gloucestershire
24	Hampshire
26	Hertfordshire
29	Kent
30	Lancashire
31	Leicestershire
32	Lincolnshire
33	Norfolk
34	Northamptonshire
35	Northumberland
36	North Yorkshire
37	Nottinghamshire
38	Oxfordshire
39	Shropshire
40	Somerset
41	Staffordshire
42	Suffolk
43	Surrey
44	Warwickshire
45	West Sussex
46	Wiltshire
47	Worcestershire

Metropolitan counties

There are six metropolitan counties, all in England and representing heavily built-up areas (other than Greater London). These are subdivided into metropolitan districts.

Table D.3: Metropolitan counties

Code	Area name	Metropolitan district
00BL	Greater Manchester	Bolton
00BM		Bury
00BN		Manchester
00BP		Oldham
00BQ		Rochdale
00BR		Salford
00BS		Stockport
00BT		Tameside
00BU		Trafford
00BW		Wigan
00BX	Merseyside	Knowsley
00BY		Liverpool
00BZ		St. Helens
00CA		Sefton
00CB		Wirral
00CC	South Yorkshire	Barnsley
00CE		Doncaster
00CF		Rotherham
00CG		Sheffield
00CH	Tyne and Wear	Gateshead
00CJ		Newcastle upon Tyne
00CK		North Tyneside
00CL		South Tyneside
00CM		Sunderland
00CN	West Midlands	Birmingham
00CQ		Coventry
00CR		Dudley
00CS		Sandwell
00CT		Solihull
00CU		Walsall
00CW		Wolverhampton
00CX	West Yorkshire	Bradford
00CY		Calderdale
00CZ		Kirklees
00DA		Leeds
00DB		Wakefield

Greater London

This is an administrative unit covering the London metropolis. There are 32 boroughs and also the City of London (a City Corporation).

Table D.4: London boroughs

Code	Area name	Borough name
00AA	Greater London	City of London
00AB		Barking and Dagenham
00AC		Barnet
00AD		Bexley
00AE		Brent
00AF		Bromley
00AG		Camden
00AH		Croydon
00AJ		Ealing
00AK		Enfield
00AL		Greenwich
00AM		Hackney
00AN		Hammersmith and Fulham
00AP		Haringey
00AQ		Harrow
00AR		Havering
00AS		Hillingdon
00AT		Hounslow
00AU		Islington
00AW		Kensington and Chelsea
00AX		Kingston upon Thames
00AY		Lambeth
00AZ		Lewisham
00BA		Merton
00BB		Newham
00BC		Redbridge
00BD		Richmond upon Thames
00BE		Southwark
00BF		Sutton
00BG		Tower Hamlets
00BH		Waltham Forest
00BJ		Wandsworth
00BK		Westminster

Welsh Local Authorities**Table D.5: Welsh Local Authorities**

Code	Area name	LA name
00PP	Gwent	Monmouthshire
00PK		Caerphilly
00PR		Newport
00PL		Blaenau Gwent
00PM		Torfaen
00PT	Bro Taf	Cardiff
00PF		Rhondda; Cynon; Taff
00PD		The Vale of Glamorgan
00PH		Merthyr Tydfil
00NS	Dyfed Powys	Pembrokeshire
00NQ		Ceredigion
00NU		Carmarthenshire
00NN		Powys
00NC	North Wales	Gwynedd
00NE		Conwy
00NA		Isle of Anglesey
00NL		Wrexham
00NJ		Flintshire
00NG		Denbighshire
00NZ	Morgannwg	Neath Port Talbot
00NX		Swansea
00PB		Bridgend

Areas included in Registry 'covered' population

The Renal Registry identified all areas in England and Wales for which they estimated to have complete coverage. Analysis was restricted to these areas.

In Table D.6 the right hand column indicates whether the area has been included in the incident population calculation. This is dependant on whether the renal unit in the area is sending data to the Registry and that there are no overlapping areas with renal units not yet connected to the Registry.

This has been grouped by the area in the UK, then Strategic Health Authority (SHA) for England and Area for Wales.

Table D.6: Renal Registry coverage of England and Wales

UK Area	SHA (Eng) /Area (Wales)	Name	Area Type	Code	Covered in 2003?
North East	County Durham and Tees Valley	Darlington	Unitary Authority	00EH	✓
		Durham	Shire County	20	✓
		Hartlepool	Unitary Authority	00EB	✓
		Middlesbrough	Unitary Authority	00EC	✓
		Redcar and Cleveland	Unitary Authority	00EE	✓
		Stockton-on-Tees	Unitary Authority	00EF	✓
	Northumberland, Tyne & Wear	Gateshead	Metropolitan District	00CH	✓
		Newcastle upon Tyne	Metropolitan District	00CJ	✓
		North Tyneside	Metropolitan District	00CK	✓
		Northumberland	Shire County	35	✓
		South Tyneside	Metropolitan District	00CL	✓
		Sunderland	Metropolitan District	00CM	✓
North West	Cheshire & Merseyside	Cheshire	Shire County	13	×
		Halton	Unitary Authority	00ET	✓
		Knowsley	Metropolitan District	00BX	✓
		Liverpool	Metropolitan District	00BY	✓
		Sefton	Metropolitan District	00CA	✓
		St. Helens	Metropolitan District	00BZ	✓
		Warrington	Unitary Authority	00EU	✓
		Wirral	Metropolitan District	00CB	✓
	Cumbria and Lancashire	Blackburn with Darwen	Unitary Authority	00EX	✓
		Blackpool	Unitary Authority	00EY	✓
		Cumbria	Shire County	16	✓
		Lancashire	Shire County	30	✓
	Greater Manchester	Bolton	Metropolitan District	00BL	✓
		Bury	Metropolitan District	00BM	✓
		Manchester	Metropolitan District	00BN	×
		Oldham	Metropolitan District	00BP	✓
		Rochdale	Metropolitan District	00BQ	✓
		Salford	Metropolitan District	00BR	✓
		Stockport	Metropolitan District	00BS	×
		Tameside	Metropolitan District	00BT	×
		Trafford	Metropolitan District	00BU	×
Wigan		Metropolitan District	00BW	✓	
Yorkshire and the Humber	North and East Yorkshire and Northern Lincolnshire	East Riding of Yorkshire	Unitary Authority	00FB	✓
		Kingston upon Hull, City of	Unitary Authority	00FA	✓
		North East Lincolnshire	Unitary Authority	00FC	✓
		North Lincolnshire	Unitary Authority	00FD	✓
		North Yorkshire	Shire County	36	✓
		York	Unitary Authority	00FF	✓
	South Yorkshire	Barnsley	Metropolitan District	00CC	✓
		Doncaster	Metropolitan District	00CE	✓
		Rotherham	Metropolitan District	00CF	✓
		Sheffield	Metropolitan District	00CG	✓
	West Yorkshire	Bradford	Metropolitan District	00CX	✓
		Calderdale	Metropolitan District	00CY	✓
		Kirklees	Metropolitan District	00CZ	✓
		Leeds	Metropolitan District	00DA	✓
Wakefield		Metropolitan District	00DB	✓	

Table D.6: (continued)

UK Area	SHA (Eng) /Area (Wales)	Name	Area Type	Code	Covered in 2003?	
East Midlands	Leicestershire, Northamptonshire and Rutland	Leicester	Unitary Authority	00FN	✓	
		Leicestershire	Shire County	31	✓	
		Northamptonshire	Shire County	34	✓	
		Rutland	Unitary Authority	00FP	✓	
	Trent	Derby	Unitary Authority	00FK	✓	
		Derbyshire	Shire County	17	✓	
		Lincolnshire	Shire County	32	✓	
		Nottingham	Unitary Authority	00FY	✓	
		Nottinghamshire	Shire County	37	✓	
	West Midlands	Birmingham and the Black Country	Birmingham	Metropolitan District	00CN	×
Dudley			Metropolitan District	00CR	✓	
Sandwell			Metropolitan District	00CS	×	
Solihull			Metropolitan District	00CT	✓	
Walsall			Metropolitan District	00CU	✓	
Wolverhampton			Metropolitan District	00CW	✓	
Coventry, Warwickshire, Herefordshire and Worcestershire		Coventry	Metropolitan District	00CQ	✓	
		Herefordshire, County of	Unitary Authority	00GA	×	
		Warwickshire	Shire County	44	✓	
Worcestershire		Worcestershire	Shire County	47	×	
		Shropshire and Staffordshire	Shropshire	Shire County	39	×
			Staffordshire	Shire County	41	×
			Stoke-on-Trent	Unitary Authority	00GL	×
Telford and Wrekin	Unitary Authority		00GF	×		
East of England	Bedfordshire and Hertfordshire	Bedfordshire	Shire County	9	✓	
		Hertfordshire	Shire County	26	✓	
		Luton	Unitary Authority	00KA	✓	
	Essex	Essex	Shire County	22	×	
		Southend-on-Sea	Unitary Authority	00KF	✓	
		Thurrock	Unitary Authority	00KG	×	
	Norfolk, Suffolk and Cambridgeshire	Cambridgeshire	Shire County	12	✓	
		Norfolk	Shire County	33	×	
		Peterborough	Unitary Authority	00JA	✓	
Suffolk		Shire County	42	×		
London	North Central London	Barnet	London Borough	00AC	×	
		Camden	London Borough	00AG	×	
		Enfield	London Borough	00AK	×	
		Haringey	London Borough	00AP	×	
		Islington	London Borough	00AU	×	
	North East London	Barking and Dagenham	London Borough	00AB	×	
		City of London	London Borough	00AA	×	
		Hackney	London Borough	00AM	×	
		Havering	London Borough	00AR	×	
		Newham	London Borough	00BB	×	
		Redbridge	London Borough	00BC	×	
		Tower Hamlets	London Borough	00BG	×	
		Waltham Forest	London Borough	00BH	×	

Table D.6: (continued)

UK Area	SHA (Eng) /Area (Wales)	Name	Area Type	Code	Covered in 2003?
London (continued)	North West London	Brent	London Borough	00AE	×
		Ealing	London Borough	00AJ	✓
		Hammersmith and Fulham	London Borough	00AN	✓
		Harrow	London Borough	00AQ	×
		Hillingdon	London Borough	00AS	×
		Hounslow	London Borough	00AT	×
		Kensington and Chelsea	London Borough	00AW	×
		Westminster	London Borough	00BK	×
	South East London	Bexley	London Borough	00AD	✓
		Bromley	London Borough	00AF	✓
		Greenwich	London Borough	00AL	✓
		Lambeth	London Borough	00AY	✓
		Lewisham	London Borough	00AZ	✓
		Southwark	London Borough	00BE	✓
	South West London	Croydon	London Borough	00AH	✓
Kingston upon Thames		London Borough	00AX	×	
Merton		London Borough	00BA	×	
Richmond upon Thames		London Borough	00BD	×	
Sutton		London Borough	00BF	×	
Wandsworth		London Borough	00BJ	×	
South East	Hampshire and Isle of Wight	Hampshire	Shire County	24	✓
		Isle of Wight	Unitary Authority	00MW	✓
		Portsmouth	Unitary Authority	00MR	✓
		Southampton	Unitary Authority	00MS	✓
	Kent and Medway	Kent	Shire County	29	×
		Medway	Unitary Authority	00LC	×
	Surrey and Sussex	Brighton and Hove	Unitary Authority	00ML	×
		East Sussex	Shire County	21	×
		Surrey	Shire County	43	×
		West Sussex	Shire County	45	×
	Thames Valley	Bracknell Forest	Unitary Authority	00MA	×
		Buckinghamshire	Shire County	11	✓
		Milton Keynes	Unitary Authority	00MG	✓
		Oxfordshire	Shire County	38	✓
		Reading	Unitary Authority	00MC	✓
Slough		Unitary Authority	00MD	✓	
West Berkshire		Unitary Authority	00MB	✓	
Windsor and Maidenhead		Unitary Authority	00ME	×	
Wokingham	Unitary Authority	00MF	✓		
South West	Avon, Gloucestershire and Wiltshire	Bath and North East Somerset	Unitary Authority	00HA	✓
		Bristol, City of	Unitary Authority	00HB	✓
		Gloucestershire	Shire County	23	✓
		North Somerset	Unitary Authority	00HC	✓
		South Gloucestershire	Unitary Authority	00HD	✓
		Swindon	Unitary Authority	00HX	✓
		Wiltshire	Shire County	46	✓
		Dorset and Somerset	Bournemouth	Unitary Authority	00HN
	Dorset		Shire County	19	×
	Poole		Unitary Authority	00HP	×
	Somerset		Shire County	40	✓

Table D.6: (continued)

UK Area	SHA (Eng) /Area (Wales)	Name	Area Type	Code	Covered in 2003?
South West (continued)	South West Peninsula	Cornwall and Isles of Scilly	Shire County	15	✓
		Devon	Shire County	18	✓
		Plymouth	Unitary Authority	00HG	✓
		Torbay	Unitary Authority	00HH	✓
Wales	Bro Taf	Cardiff	Welsh LA	00PT	✓
		Merthyr Tydfil	Welsh LA	00PH	✓
		Rhondda, Cynon, Taff	Welsh LA	00PF	✓
		The Vale of Glamorgan	Welsh LA	00PD	✓
	Dyfed Powys	Carmarthenshire	Welsh LA	00NU	✓
		Ceredigion	Welsh LA	00NQ	✓
		Pembrokeshire	Welsh LA	00NS	✓
		Powys	Welsh LA	00NN	✓
	Gwent	Blaenau Gwent	Welsh LA	00PL	✓
		Caerphilly	Welsh LA	00PK	✓
		Monmouthshire	Welsh LA	00PP	✓
		Newport	Welsh LA	00PR	✓
		Torfaen	Welsh LA	00PM	✓
	Morgannwg	Bridgend	Welsh LA	00PB	✓
		Neath Port Talbot	Welsh LA	00NZ	✓
		Swansea	Welsh LA	00NX	✓
	North Wales	Conwy	Welsh LA	00NE	✓
		Denbighshire	Welsh LA	00NG	✓
		Flintshire	Welsh LA	00NJ	✓
		Gwynedd	Welsh LA	00NC	✓
Isle of Anglesey		Welsh LA	00NA	✓	
Wrexham		Welsh LA	00NL	✓	

Population

The populations and age/gender breakdown for the LA areas were taken from Casweb. Casweb is a web interface to statistics and related information from the United Kingdom Census of Population, developed at Manchester University for academic use.

Calculation of acceptance rates

Crude rate

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

$$\frac{\text{observed_cases}}{\text{population}} \times 1,000,000$$

per million population (pmp).

Standardised acceptance rate ratio (SARR)

The age/gender standardised rate ratio of acceptance onto RRT was calculated for each LA area for the year 2003:

$$\frac{\text{observed_cases}}{\text{expected_cases}}$$

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

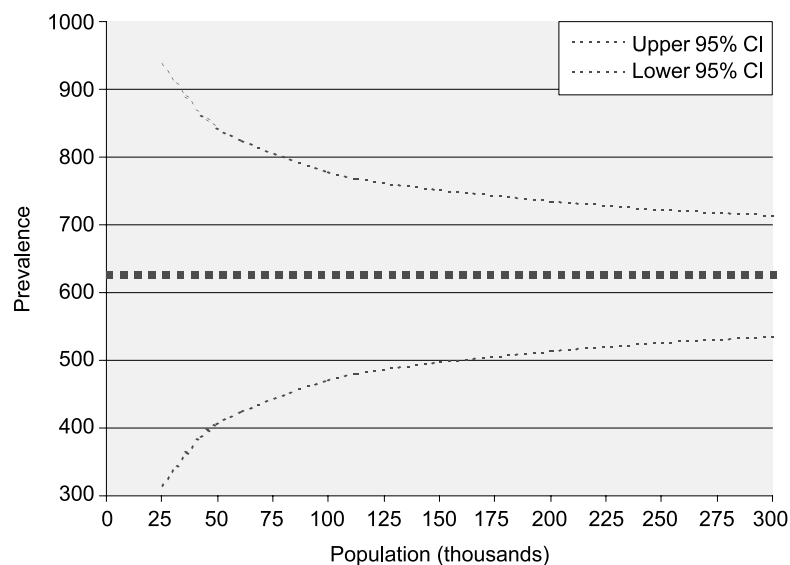


Figure D.1: 95% confidence limits for prevalence of 625 pmp for population size 50,000–300,000

expected cases were calculated for the 2003 data and then applied to the 2002 and 2001 data for the calculation of the age/gender standardised rate ratios.

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

Analysis of prevalent patients by PCT

Groups such as primary care trusts, which represent relatively small populations of 30,000 to 250,000, often wish to assess their performance. When assessing a relatively infrequent occurrence such as prevalence of RRT in such small populations there

are wide confidence intervals for any observed frequency.

To enable assessment of whether an observed prevalence is likely to be significantly different from the national average Figures 5.2 and 5.3 have been included in the report. From these, for any size of population (X axis) the upper and lower 1 in 20 confidence intervals around the national average prevalence (dotted lines) can be read from the Y axis. Any observed prevalence for renal failure must be outside these limits for the given population to be statistically significantly different from the national average. Thus for a population of 50,000 the observed prevalence would have to be outside the limits of 400 per million population to 850 per million population. However for a population of 300,000 these limits are from 535 per million population to 715 per million population.

These rates **have not** been adjusted for ethnicity. Much higher rates are expected in populations with a high percentage of patients from South Asian and African Caribbean backgrounds.

The PCT analysis uses the patient postcode and not the GP postcode

Table D.7: Prevalent renal replacement therapy patients by PCT

UK Area	SHA	Name of PCT	PCT Code	PCT population	Tot Expected	Tot Observed	O/E	L 95% CL	U 95% CL	rate pmp	
North East	County Durham and Tees Valley	Darlington PCT	5J9	79,370	59	48	0.82	0.62	1.09	605	
		Derwentside PCT	5KA	69,909	52	50	0.96	0.73	1.26	715	
		Durham and Chester-le-Street PCT	5KC	117,719	83	71	0.85	0.68	1.08	603	
		Durham Dales PCT	5J8	70,340	54	28	0.52	0.36	0.76	398	
		Easington PCT	5KD	75,827	56	44	0.78	0.58	1.05	580	
		Hartlepool PCT	5D9	70,773	52	51	0.98	0.74	1.29	721	
		Langbaugh PCT	5KN	79,021	60	45	0.75	0.56	1.01	569	
		Middlesbrough PCT	5KM	140,680	100	47	0.47	0.35	0.63	334	
		North Tees PCT	5E1	142,989	103	48	0.46	0.35	0.62	336	
	Sedgefield PCT	5KE	70,954	53	42	0.79	0.59	1.07	592		
	Northumberland, Tyne and Wear	Gateshead PCT	5KF	156,653	116	128	1.10	0.93	1.31	817	
		Newcastle PCT	5D7	214,102	145	145	1.00	0.85	1.17	677	
		North Tyneside PCT	5D8	157,632	117	120	1.02	0.85	1.22	761	
Northumberland Care Trust		TAC	251,735	193	186	0.96	0.83	1.11	739		
South Tyneside PCT		5KG	124,093	92	87	0.94	0.77	1.16	701		
Sunderland Teaching PCT	5KL	228,716	164	171	1.04	0.90	1.21	748			
North West	Cheshire and Merseyside	Bebington and West Wirral PCT	5F8	97,854	76	76	1.00	0.80	1.25	777	
		Birkenhead and Wallasey PCT	5H2	154,400	112	136	1.22	1.03	1.44	881	
		Central Cheshire PCT	5H4								
		Central Liverpool PCT	5HA	194,860	129	149	1.15	0.98	1.35	765	
		Cheshire West PCT	5H3	125,103	94	80	0.85	0.68	1.06	639	
		Eastern Cheshire PCT	5H5								
		Ellesmere Port and Neston PCT	5H6	65,625	49	54	1.10	0.84	1.44	823	
		Halton PCT	5J1	94,390	67	69	1.03	0.82	1.31	731	
		Knowsley PCT	5J4	118,553	84	107	1.27	1.05	1.54	903	
		North Liverpool PCT	5G9	80,837	56	68	1.21	0.95	1.53	841	
		South Liverpool PCT	5HC	80,727	58	82	1.41	1.14	1.76	1016	
		South Sefton PCT	5M5	135,191	99	96	0.97	0.79	1.18	710	
		Southport and Formby PCT	5F9	94,556	74	64	0.87	0.68	1.11	677	
		St Helens PCT	5J3	142,621	105	90	0.86	0.70	1.06	631	
	Warrington PCT	5J2	153,126	111	102	0.92	0.76	1.12	666		
	North West	Cumbria and Lancashire	Blackburn With Darwen PCT	5CC	105,113	72	78	1.08	0.87	1.35	742
			Blackpool PCT	5HP	117,147	89	73	0.82	0.65	1.03	623
Burnley, Pendle and Rossendale PCT			5G8	192,997	139	138	1.00	0.84	1.18	715	
Carlisle and District PCT			5D4	93,492	70	56	0.80	0.61	1.04	599	
Chorley and South Ribble PCT			5F2	165,084	122	73	0.60	0.48	0.75	442	
Eden Valley PCT			5D5	57,489	45	41	0.91	0.67	1.23	713	
Fylde PCT			5HE	60,689	48	34	0.70	0.50	0.99	560	
Hyndburn and Ribble Valley PCT			5G7	99,393	73	68	0.93	0.73	1.18	684	
Morecambe Bay PCT			5DD	254,533	189	150	0.79	0.68	0.93	589	
Preston PCT			5HD	112,778	78	79	1.01	0.81	1.26	700	
West Cumbria PCT	5D6	106,842	81	79	0.98	0.78	1.22	739			
West Lancashire PCT	5F3	88,020	65	52	0.80	0.61	1.05	591			
Wyre PCT	5HF	87,293	69	63	0.91	0.71	1.17	722			

Table D.7 (continued)

UK Area	SHA	Name of PCT	PCT Code	PCT population	Tot Expected	Tot Observed	O/E	L 95% CL	U 95% CL	rate pmp
North West (continued)	Greater Manchester	Ashton, Leigh and Wigan PCT	5HG	243,522	177	117	0.66	0.55	0.79	480
		Bolton PCT	5HQ	208,359	149	121	0.81	0.68	0.97	581
		Bury PCT	5JX	144,322	104	41	0.39	0.29	0.53	284
		Central Manchester PCT	5CL							
		Heywood and Middleton PCT	5F4							
		North Manchester PCT	5CR							
		Oldham PCT	5J5	170,694	121	67	0.55	0.44	0.70	393
		Rochdale PCT	5JY	102,737	73	61	0.84	0.65	1.08	594
		Salford PCT	5F5	174,854	124	96	0.78	0.64	0.95	549
		South Manchester PCT	5AA							
		Stockport PCT	5F7							
		Tameside and Glossop PCT	5LH							
		Trafford North PCT	5F6							
		Trafford South PCT	5CX							
Yorkshire and the Humber	North and East Yorkshire and Northern Lincolnshire	Craven, Harrogate and Rural District PCT	5KJ	166,066	126	105	0.83	0.69	1.01	632
		East Yorkshire PCT	5E3	139,648	106	99	0.94	0.77	1.14	709
		Eastern Hull PCT	5E5	88,531	63	66	1.05	0.83	1.34	745
		Hambleton and Richmondshire PCT	5KH	86,949	69	28	0.41	0.28	0.59	322
		North East Lincolnshire PCT	5AN	126,491	93	97	1.04	0.85	1.27	767
		North Lincolnshire PCT	5EF	120,809	91	73	0.80	0.64	1.01	604
		Scarborough, Whitby and Ryedale PCT	5KK	130,280	103	77	0.75	0.60	0.94	591
		Selby and York PCT	5E2	223,887	162	175	1.08	0.93	1.25	782
		West Hull PCT	5E6	105,282	72	71	0.98	0.78	1.24	674
		Yorkshire Wolds and Coast PCT	5E4	118,689	94	85	0.91	0.73	1.12	716
	South Yorkshire	Barnsley PCT	5JE	176,616	130	161	1.24	1.06	1.44	912
		Doncaster Central PCT	5CK	56,779	41	58	1.40	1.08	1.81	1022
		Doncaster East PCT	5EK	89,104	67	69	1.03	0.81	1.30	774
		Doncaster West PCT	5EL	83,832	62	66	1.07	0.84	1.36	787
		North Sheffield PCT	5EE	92,731	66	86	1.31	1.06	1.62	927
		Rotherham PCT	5H8	199,516	146	178	1.22	1.05	1.41	892
		Sheffield South West PCT	5EP	104,069	74	69	0.94	0.74	1.19	663
		Sheffield West PCT	5EN	91,888	60	46	0.77	0.58	1.03	501
	South East Sheffield PCT	5EQ	132,498	96	119	1.24	1.03	1.48	898	
	West Yorkshire	Airedale PCT	5AW	93,357	69	70	1.01	0.80	1.28	750
		Bradford City PCT	5CF	99,684	61	120	1.98	1.66	2.37	1204
		Bradford South and West PCT	5CG	104,485	73	99	1.35	1.11	1.64	948
		Calderdale PCT	5J6	153,977	112	129	1.15	0.97	1.37	838
		East Leeds PCT	5HK	128,264	92	104	1.13	0.93	1.37	811
		Eastern Wakefield PCT	5E7	138,071	101	92	0.91	0.74	1.12	666
		Huddersfield Central PCT	5LJ	111,141	78	102	1.30	1.07	1.58	918
		Leeds North East PCT	5HJ	90,354	66	86	1.29	1.05	1.60	952
		Leeds North West PCT	5HM	158,978	98	90	0.91	0.74	1.12	566
		Leeds West PCT	5HH	87,441	62	70	1.14	0.90	1.43	801
		North Bradford PCT	5CH	68,053	49	55	1.12	0.86	1.45	808
		North Kirklees PCT	5J7	133,372	93	136	1.46	1.23	1.73	1020
		South Huddersfield PCT	5LK	65,646	48	39	0.81	0.59	1.11	594
South Leeds PCT		5HL	115,827	81	81	1.00	0.80	1.24	699	
Wakefield West PCT	5E8	116,348	85	77	0.91	0.73	1.14	662		

Table D.7 (continued)

UK Area	SHA	Name of PCT	PCT Code	PCT population	Tot Expected	Tot Observed	O/E	L 95% CL	U 95% CL	rate pmp
East Midlands	Leicestershire, Northamptonshire and Rutland	Charnwood and North West Leicestershire PCT	5JC	188,810	136	147	1.08	0.92	1.27	779
		Daventry and South Northamptonshire PCT	5AC	80,823	60	49	0.82	0.62	1.08	606
		Eastern Leicester PCT	5EY	137,984	90	188	2.09	1.81	2.41	1362
		Hinckley and Bosworth PCT	5JA	94,038	70	58	0.83	0.64	1.07	617
		Leicester City West PCT	5EJ	83,534	54	78	1.44	1.15	1.79	934
		Melton, Rutland and Harborough PCT	5EH	111,966	85	87	1.02	0.83	1.26	777
		Northampton PCT	5LW	168,139	116	119	1.02	0.86	1.23	708
		Northamptonshire Heartlands PCT	5LV	227,281	165	159	0.96	0.82	1.12	700
	South Leicestershire PCT	5JD	128,630	95	90	0.94	0.77	1.16	700	
	Trent	Amber Valley PCT	5ED	95,279	72	74	1.03	0.82	1.30	777
		Ashfield PCT	5FA	66,349	49	53	1.08	0.83	1.42	799
		Bassetlaw PCT	5ET	87,266	66	57	0.87	0.67	1.13	653
		Broxtowe and Hucknall PCT	5EV	112,389	83	79	0.95	0.76	1.19	703
		Central Derby PCT	5AL	49,397	33	53	1.60	1.22	2.10	1073
		Chesterfield PCT	5EA	81,016	61	70	1.16	0.91	1.46	864
		Derbyshire Dales and South Derbyshire PCT	5H7	87,064	65	57	0.88	0.68	1.14	655
		East Lincolnshire PCT	5H9	220,623	178	143	0.80	0.68	0.95	648
		Erewash PCT	5ER	89,012	65	66	1.01	0.79	1.29	741
		Gedling PCT	5EC	91,918	69	74	1.07	0.85	1.35	805
		Greater Derby PCT	5EX	128,666	93	116	1.25	1.04	1.50	902
		High Peak and Dales PCT	5HN	82,218	64	25	0.39	0.27	0.58	304
		Lincolnshire South West PCT	5D3	129,627	98	74	0.75	0.60	0.95	571
		Mansfield District PCT	5AM	79,182	59	68	1.16	0.92	1.47	859
		Newark and Sherwood PCT	5AP	85,816	65	73	1.12	0.89	1.41	851
		North Eastern Derbyshire PCT	5EG	138,791	106	110	1.04	0.86	1.25	793
		Nottingham City PCT	5EM	217,321	140	191	1.36	1.18	1.57	879
		Rushcliffe PCT	5FC	86,215	64	63	0.99	0.77	1.26	731
	West Lincolnshire PCT	5D2	176,490	132	132	1.00	0.84	1.19	748	
West Midlands	Birmingham and The Black Country	Dudley Beacon and Castle PCT	5HV	90,283	67	62	0.93	0.72	1.19	687
		Dudley South PCT	5HT	157,967	119	89	0.75	0.61	0.92	563
		Eastern Birmingham PCT	5MY							
		Heart of Birmingham PCT	5MX							
		North Birmingham PCT	5MW							
		Oldbury and Smethwick PCT	5MG							
		Rowley, Regis and Tipton PCT	5MH							
		Solihull PCT	5D1	160,434	121	112	0.92	0.77	1.11	698
		South Birmingham PCT	5M1							
		Walsall PCT	5M3	201,862	148	127	0.86	0.72	1.02	629
	Wednesbury and West Bromwich PCT	5MJ								
	Wolverhampton City PCT	5MV	190,286	137	177	1.29	1.11	1.50	930	
	Coventry, Warwickshire, Herefordshire and Worcestershire	Coventry PCT	5MD	241,232	166	232	1.40	1.23	1.59	962
		Herefordshire PCT	5CN							
		North Warwickshire PCT	5MP	146,008	108	120	1.11	0.93	1.33	822
		Redditch and Bromsgrove PCT	5MR							
		Rugby PCT	5M9	70,854	53	79	1.50	1.20	1.87	1115
South Warwickshire PCT		5MQ	196,725	147	138	0.94	0.79	1.11	701	
South Worcestershire PCT		5MT								
Wyre Forest PCT	5DR									

Table D.7 (continued)

UK Area	SHA	Name of PCT	PCT Code	PCT population	Tot Expected	Tot Observed	O/E	L 95% CL	U 95% CL	rate pmp
West Midlands (continued)	Shropshire and Staffordshire	Burntwood, Lichfield and Tamworth PCT	5DQ	121,803	89	71	0.80	0.63	1.01	583
		Cannock Chase PCT	5MM	102,779	75	49	0.66	0.50	0.87	477
		East Staffordshire PCT	5ML							
		Newcastle-Under-Lyme PCT	5HW							
		North Stoke PCT	5ME							
		Shropshire County PCT	5M2							
		South Stoke PCT	5MF							
		South Western Staffordshire PCT	5MN							
		Staffordshire Moorlands PCT	5HR							
		Telford and Wrekin PCT	5MK							
		East of England	Bedfordshire and Hertfordshire	Bedford PCT	5GD	119,104	85	90	1.06	0.87
Bedfordshire Heartlands PCT	5GE			185,785	135	126	0.93	0.78	1.11	678
Dacorum PCT	5GW			110,049	80	68	0.85	0.67	1.08	618
Hertsmere PCT	5CP			75,732	55	11	0.20	0.11	0.36	145
Luton PCT	5GC			143,643	97	123	1.27	1.07	1.52	856
North Hertfordshire and Stevenage PCT	5GH			143,674	103	123	1.19	1.00	1.42	856
Royston, Buntingford and Bishops Stortford PCT	5GK			49,226	35	14	0.40	0.24	0.68	284
South East Hertfordshire PCT	5GJ			138,474	100	66	0.66	0.52	0.84	477
St Albans and Harpenden PCT	5GX			104,071	76	43	0.57	0.42	0.77	413
Watford and Three Rivers PCT	5GV			130,070	93	13	0.14	0.08	0.24	100
Welwyn Hatfield PCT	5GG			79,492	57	36	0.63	0.45	0.87	453
Essex	Basildon PCT		5GR							
	Billericay, Brentwood and Wickford PCT		5GP							
	Castle Point and Rochford PCT		5JP	135,111	103	64	0.62	0.49	0.79	474
	Chelmsford PCT		5JN							
	Colchester PCT		5GM							
	Epping Forest PCT		5AJ							
	Harlow PCT		5DC							
	Maldon and South Chelmsford PCT		5GL							
	Southend On Sea PCT		5AK	130,154	95	91	0.95	0.78	1.17	699
	Tendring PCT		5AH							
	Thurrock PCT		5GQ							
Uttlesford PCT	5GN									
Witham, Braintree & Halstead	TAG									
Norfolk, Suffolk and Cambridgeshire	Broadland PCT		5JL							
	Cambridge City PCT		5JH	93,553	56	51	0.91	0.69	1.20	545
	Central Suffolk PCT		5JT							
	East Cambridgeshire and Fenland PCT	5JK	110,866	85	64	0.76	0.59	0.96	577	
	Great Yarmouth PCT	5GT								
	Huntingdonshire PCT	5GF	111,458	81	81	0.99	0.80	1.24	727	
	Ipswich PCT	5JQ	114,092	82	80	0.97	0.78	1.21	701	
	North Norfolk PCT	5JM								
	North Peterborough PCT	5AF	78,235	54	64	1.18	0.92	1.51	818	
	Norwich PCT	5A2								
	South Cambridgeshire PCT	5JJ	104,839	78	69	0.88	0.70	1.12	658	
	South Peterborough PCT	5AG	69,727	51	50	0.99	0.75	1.30	717	
	Southern Norfolk PCT	5G1								
	Suffolk Coastal PCT	5JR								
	Suffolk West PCT	5JW								
Waveney PCT	5JV									
West Norfolk PCT	5CY									

Table D.7 (continued)

UK Area	SHA	Name of PCT	PCT Code	PCT population	Tot Expected	Tot Observed	O/E	L 95% CL	U 95% CL	rate pmp	
London	North Central London	Barnet PCT	5A9								
		Camden PCT	5K7								
		Enfield PCT	5C1								
		Haringey PCT	5C9								
		Islington PCT	5K8								
	North East London	Barking and Dagenham PCT	5C2								
		Chingford, Wanstead and Woodford PCT	5C7								
		City and Hackney PCT	5C3								
		Havering PCT	5A4								
		Newham PCT	5C5								
		Redbridge PCT	5C8								
		Tower Hamlets PCT	5C4								
		Walthamstow, Leyton and Leytonstone PCT	5C6								
	North West London	Brent PCT	5K5								
		Ealing PCT	5HX	245,475	159	250	1.57	1.39	1.78	1018	
		Hammersmith and Fulham PCT	5H1	139,124	85	134	1.58	1.33	1.87	963	
		Harrow PCT	5K6								
		Hillingdon PCT	5AT								
		Hounslow PCT	5HY								
		Kensington and Chelsea PCT	5LA								
	Westminster PCT	5LC									
	South East London	Bexley PCT	5AX	175,653	127	157	1.24	1.06	1.45	894	
		Bromley PCT	5A7	240,420	175	173	0.99	0.85	1.14	720	
		Greenwich PCT	5A8	170,649	112	118	1.05	0.88	1.26	691	
Lambeth PCT		5LD	218,178	130	180	1.38	1.19	1.60	825		
Lewisham PCT		5LF	199,926	126	210	1.66	1.45	1.90	1050		
Southwark PCT		5LE	198,395	123	215	1.75	1.53	2.00	1084		
South West London	Croydon PCT	5K9	263,219	180	208	1.15	1.01	1.32	790		
	Kingston PCT	5A5									
	Richmond and Twickenham PCT	5M6									
	Sutton and Merton PCT	5M7									
	Wandsworth PCT	5LG									
Hampshire and Isle Of Wight	East Hampshire PCT	5FD	137,109	105	105	1.00	0.83	1.21	766		
	Eastleigh and Test Valley South PCT	5LY	129,947	95	80	0.84	0.68	1.05	616		
	Fareham and Gosport PCT	5LX	145,696	109	99	0.91	0.75	1.11	679		
	Isle of Wight PCT	5DG	109,023	86	63	0.73	0.57	0.93	578		
	Mid-Hampshire PCT	5E9	137,573	102	82	0.80	0.65	1.00	596		
	New Forest PCT	5A1	140,046	112	69	0.62	0.49	0.78	493		
	North Hampshire PCT	5DF	164,936	118	99	0.84	0.69	1.02	600		
	Portsmouth City PCT	5FE	143,769	99	133	1.35	1.14	1.60	925		
	Blackwater Valley and Hart PCT	5G6	133,751	94	62	0.66	0.51	0.85	464		
	Southampton City PCT	5L1	180,002	117	115	0.99	0.82	1.18	639		
	Kent and Medway	Ashford PCT	5LL								
		Canterbury and Coastal PCT	5LM								
		Dartford, Gravesham and Swanley PCT	5CM								
East Kent Coastal PCT		5LN									
Maidstone Weald PCT		5L2									
Medway PCT		5L3									
Shepway PCT		5LP									
South West Kent PCT		5FF									
Swale PCT		5L4									

Table D.7 (continued)

UK Area	SHA	Name of PCT	PCT Code	PCT population	Tot Expected	Tot Observed	O/E	L 95% CL	U 95% CL	rate pmp	
South East (continued)	Surrey and Sussex	Adur, Arun and Worthing PCT	5L8	179,395	138	24	0.17	0.12	0.26	134	
		Bexhill and Rother PCT	5FH								
		Brighton and Hove City PCT	5LQ								
		Crawley PCT	5MA								
		East Elmbridge and Mid Surrey PCT	5KP	211,903	160	125	0.78	0.65	0.93	590	
		East Surrey PCT	5KQ	129,769	95	78	0.82	0.66	1.02	601	
		Eastbourne Downs PCT	5LR								
		Guildford and Waverley PCT	5L5	183,399	133	76	0.57	0.46	0.72	414	
		Hastings and St Leonards PCT	5FJ								
		Horsham and Chanctonbury PCT	5MC								
		Mid-Sussex PCT	5FK								
		North Surrey PCT	5L6								
		Sussex Downs and Weald PCT	5LT								
		Western Sussex PCT	5L9	172,723	136	97	0.71	0.58	0.87	562	
		Woking PCT	5L7	161,216	117	89	0.76	0.62	0.94	552	
	Thames Valley	Bracknell Forest PCT	5G2	85,306	58	48	0.83	0.63	1.11	563	
		Cherwell Vale PCT	5DV	97,650	71	65	0.91	0.71	1.16	666	
		Chiltern and South Buckinghamshire PCT	5G4	128,997	99	76	0.77	0.61	0.96	589	
		Milton Keynes PCT	5CQ	166,449	112	123	1.10	0.92	1.31	739	
		Newbury and Community PCT	5DK	75,071	54	47	0.88	0.66	1.17	626	
		North East Oxfordshire PCT	5DT	55,366	39	51	1.30	0.99	1.71	921	
		Oxford City PCT	5DW	131,116	81	105	1.29	1.06	1.56	801	
		Reading PCT	5DL	158,562	105	126	1.20	1.01	1.43	795	
		Slough PCT	5DM	94,156	62	110	1.79	1.48	2.15	1168	
		South East Oxfordshire PCT	5DX	75,744	57	57	1.00	0.77	1.29	753	
		South West Oxfordshire PCT	5DY	152,030	112	129	1.15	0.97	1.37	849	
		Vale of Aylesbury PCT	5DP	140,786	101	122	1.21	1.01	1.44	867	
		Windsor, Ascot and Maidenhead PCT	5G3								
		Wokingham PCT	5DN	119,283	85	80	0.94	0.76	1.17	671	
	Wycombe PCT	5G5	107,895	76	83	1.10	0.88	1.36	769		
	South West	Avon, Gloucestershire and Wiltshire	Bath and North East Somerset PCT	5FL	140,064	102	77	0.76	0.61	0.95	550
			Bristol North PCT	5JF	171,039	116	187	1.62	1.40	1.87	1093
			Bristol South and West PCT	5JG	141,548	93	124	1.34	1.12	1.59	876
			Cheltenham and Tewkesbury PCT	5KW	129,363	94	72	0.77	0.61	0.97	557
			Cotswold and Vale PCT	5KY	153,734	118	95	0.80	0.66	0.98	618
North Somerset PCT			5M8	155,300	120	137	1.14	0.97	1.35	882	
Kennet and North Wiltshire PCT			5K4	152,810	114	81	0.71	0.57	0.88	530	
South Gloucestershire PCT			5A3	196,855	144	164	1.14	0.98	1.33	833	
South Wiltshire PCT			5DJ	90,627	69	49	0.71	0.54	0.94	541	
Swindon PCT			5K3	147,086	104	94	0.91	0.74	1.11	639	
West Gloucestershire PCT		5KX	175,214	129	143	1.11	0.94	1.30	816		
West Wiltshire PCT		5DH	93,886	71	66	0.93	0.73	1.18	703		
Dorset and Somerset		Bournemouth PCT	5CE								
		Mendip PCT	5FX	86,301	64	58	0.90	0.70	1.16	672	
		North Dorset PCT	5CD								
		Poole PCT	5KV								
		Somerset Coast PCT	5FW	116,469	92	89	0.97	0.79	1.20	764	
		South and East Dorset PCT	5FN								
		South Somerset PCT	5K1	118,795	92	74	0.80	0.64	1.01	623	
South West Dorset PCT		5FP									
Taunton Deane PCT	5K2	83,613	63	70	1.12	0.88	1.41	837			

Table D.7 (continued)

UK Area	SHA	Name of PCT	PCT Code	PCT population	Tot Expected	Tot Observed	O/E	L 95% CL	U 95% CL	rate pmp
South West (continued)	South West Peninsula	Central Cornwall PCT	5KT	152,388	119	124	1.05	0.88	1.25	814
		East Devon PCT	5FT	99,639	81	63	0.77	0.60	0.99	632
		Exeter PCT	5FR	109,058	75	76	1.01	0.81	1.26	697
		Mid Devon PCT	5FV	75,411	59	64	1.09	0.85	1.39	849
		North and East Cornwall PCT	5KR	128,666	102	134	1.31	1.11	1.56	1041
		North Devon PCT	5FQ	120,592	95	70	0.73	0.58	0.93	580
		Plymouth PCT	5F1	190,543	136	157	1.15	0.99	1.35	824
		South Hams and West Devon PCT	5CV	90,772	73	63	0.87	0.68	1.11	694
		Teignbridge PCT	5FY	86,955	68	65	0.95	0.74	1.21	748
		Torbay PCT	5CW	108,098	84	84	1.00	0.81	1.24	777
		West of Cornwall PCT	5FM	128,935	102	102	1.00	0.83	1.22	791
Wales	Bro Taf	Cardiff	6A8	254,621	171	212	1.24	1.09	1.42	833
		Merthyr Tydfil	6B8	44,150	32	53	1.64	1.26	2.15	1200
		Rhondda, Cynon, Taff	6A9	179,351	130	175	1.34	1.16	1.56	976
		Vale of Glamorgan	6C3	93,529	70	71	1.02	0.81	1.28	759
	Dyfed Powys	Carmarthenshire	6B7	141,533	110	133	1.21	1.02	1.44	940
		Ceredigion	6A4	62,159	45	47	1.05	0.79	1.39	756
		Pembrokeshire	6A3	93,689	74	65	0.88	0.69	1.13	694
		Powys	6C4	102,263	81	36	0.44	0.32	0.62	352
	Gwent	Blaenau Gwent	6C2	54,846	41	52	1.28	0.98	1.68	948
		Caerphilly	6B2	135,760	99	113	1.14	0.95	1.38	832
		Monmouthshire	6A1	69,329	54	64	1.19	0.93	1.52	923
		Newport	6B9	109,925	80	105	1.31	1.08	1.58	955
		Torfaen	6B6	71,432	53	82	1.56	1.25	1.93	1148
	Morgannwg	Bridgend	6B3	103,441	77	92	1.19	0.97	1.46	889
		Neath Port Talbot	6A5	107,412	81	104	1.28	1.06	1.55	968
		Swansea	6A6	186,744	136	190	1.40	1.21	1.61	1017
	North Wales	Conwy	6A7	92,779	73	74	1.02	0.81	1.28	798
		Denbighshire	6C1	75,455	58	56	0.97	0.75	1.26	742
		Flintshire	6B5	119,680	88	109	1.23	1.02	1.49	911
		Gwynedd	6A2	95,521	71	98	1.38	1.13	1.69	1026
Isle of Anglesey		6B1	55,715	43	45	1.05	0.78	1.40	808	
Wrexham		6B4	101,868	74	111	1.50	1.24	1.80	1090	



Appendix E: Data Tables

E:1 Patients starting renal replacement in 2003

Table E.1.1: Take-on of new dialysis patients

Centre	Take-on figures for new patients on dialysis			
	Aged <65		Aged >65	
	% on HD	% on PD	% on HD	% on PD
Bangr	60	40	82	18
Bradf	58	42	79	21
Bristol	56	44	82	18
Camb	70	30	77	23
Carls	55	45	76	24
Carsh	62	38	66	34
Clwyd	40	60	86	14
Covnt	61	39	82	18
Crdff	63	37	85	15
Derby	89	11	67	33
Extr	49	51	86	14
Glouc	74	26	73	27
Guys	50	50	72	28
H&CX	53	47	84	16
Heart	76	24	88	13
Hull	66	34	86	14
Ipswi	33	67	35	65
Kings	61	39	84	16
Leeds	76	24	94	6
Leic	56	44	73	27
Livrpl	60	40	80	20
ManWst	49	51	69	31
Middlbr	75	25	95	5
Newc	82	18	95	5
Nottm	62	38	71	29
Oxfrd	58	42	68	32
Plym	74	26	81	19
Ports	72	28	78	22
Prstn	51	49	70	30
Redng	53	47	69	31
Sheff	49	51	60	40
Stevng	68	32	92	8
Sthend	50	50	100	–
Sund	87	13	95	5
Swnse	63	38	71	29
Truro	71	29	75	25
Wirrl	70	30	72	28
Wolve	76	24	83	17
Words	67	33	76	24
Wrexm	53	47	77	23
York	64	36	81	19
Eng	63	37	78	22
Wls	61	39	78	22
E&W	62	38	78	22

Table E.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	965	578	1,140	329
Wales	92	60	115	32
E&W	1,057	638	1,255	361

Table E.1.3: Treatment modalities at 90 days

Centre	Treatment modalities at 90 days					
	% on HD	% on PD	% on transplant	% transferred out	% stopped treatment	% died
Bangr	53	24	–	3	–	21
Bradf	62	28	–	–	–	11
Bristol	53	23	12	1	2	9
Camb	55	20	19	–	–	7
Carls	56	26	–	–	–	18
Carsh	57	32	3	1	–	7
Clwyd	67	33	–	–	–	–
Covnt	55	22	9	–	3	12
Crdff	62	24	3	1	1	10
Derby	70	22	–	–	–	9
Extr	61	26	–	–	–	13
Glouc	64	24	4	–	–	9
Guys	55	40	3	–	1	1
H&CX	59	30	–	2	1	9
Heart	74	15	–	–	–	11
Hull	69	23	–	1	–	7
Ipswi	33	60	3	–	–	5
Kings	66	26	3	–	1	4
Leeds	73	14	3	1	–	9
Leic	57	32	5	–	–	7
Livrpl	57	29	4	–	–	10
ManWst	53	40	–	–	–	8
Middlbr	70	14	3	–	–	12
Newc	69	10	8	–	2	12
Nottm	63	30	1	–	1	5
Oxfrd	51	30	5	2	1	11
Plym	60	17	–	–	2	21
Ports	63	21	4	–	1	10
Prstn	56	35	2	–	1	6
Redng	53	32	2	2	–	12
Sheff	51	43	1	–	1	5
Stevng	73	19	–	1	–	7
Sthend	54	32	–	–	–	14
Sund	82	8	2	–	–	8
Swmse	56	27	1	–	–	16
Truro	64	23	–	–	2	11
Wirrl	60	24	–	–	2	13
Wolve	65	18	–	–	1	16
Words	65	25	–	–	–	10
Wrexm	54	31	–	3	–	11
York	62	23	–	–	–	15
Eng	61	26	3	0	1	9
Wls	58	26	2	1	0	13
E&W	60	26	3	0	1	10

Table E.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	2,107	909	108	14	20	320
Wales	207	92	6	3	1	46
E&W	2,314	1,001	114	17	21	366

Table E.1.5: First treatment modality

Centre	First treatment modality		
	% on HD	% on PD	% on transplant
Bangr	79	21	0
Bradf	68	32	0
Bristol	62	26	11
Camb	58	24	18
Carls	59	41	0
Carsh	63	34	2
Clwyd	67	33	0
Covnt	68	26	6
Crdff	72	26	2
Derby	76	24	0
Extr	73	27	0
Glouc	73	27	0
Guys	52	45	2
H&CX	68	32	0
Heart	82	18	0
Hull	76	24	0
Ipswi	38	63	0
Kings	65	35	1
Leeds	81	16	3
Leic	62	35	4
Livrpl	63	33	3
ManWst	58	42	0
Middlbr	83	17	0
Newc	82	10	8
Nottm	68	31	1
Oxfrd	64	31	5
Plym	78	22	0
Ports	74	23	3
Prstn	60	40	0
Redng	63	37	0
Sheff	54	45	1
Stevng	79	21	0
Sthend	62	38	0
Sund	90	10	0
Swmse	70	30	0
Truro	74	26	0
Wirrl	73	27	0
Wolve	81	19	0
Words	73	28	0
Wrexm	66	34	0
York	68	32	0
Eng	68	29	2
Wls	71	28	1
E&W	69	29	2

Table E.1.6: First treatment modality – patient numbers

	First treatment modality		
	No on HD	No on PD	No on transplant
England	2,380	1,018	83
Wales	252	100	3
E&W	2,632	1,118	86

Table E.1.7: Treatment modalities by gender

Centre	Treatment by gender					
	Haemodialysis			Peritoneal Dialysis		
	% Male	% Female	M:F ratio	% Male	% Female	M:F ratio
Bangr	61	39	1.6	50	50	1.0
Bradf	53	47	1.1	68	32	2.1
Bristol	53	47	1.1	59	41	1.4
Camb	62	38	1.6	78	22	3.5
Carls	58	42	1.4	89	11	8.0
Carsh	70	30	2.4	66	34	1.9
Clwyd	75	25	3.0	75	25	3.0
Covnt	60	40	1.5	59	41	1.4
Crdff	59	41	1.4	64	36	1.8
Derby	56	44	1.3	70	30	2.3
Extr	57	43	1.3	65	35	1.9
Glouc	69	31	2.3	38	62	0.6
Guys	65	35	1.8	63	37	1.7
H&CX	55	45	1.2	75	25	3.0
Heart	64	36	1.8	64	36	1.8
Hull	59	41	1.4	53	47	1.1
Ipswi	67	33	2.0	70	30	2.3
Kings	67	33	2.0	48	52	0.9
Leeds	66	34	1.9	61	39	1.6
Leic	62	38	1.6	59	41	1.5
Livrpl	57	43	1.3	69	31	2.2
ManWst	61	39	1.5	60	40	1.5
Middlbr	67	33	2.0	69	31	2.2
Newc	53	47	1.1	60	40	1.5
Nottm	61	39	1.6	55	45	1.2
Oxfrd	70	30	2.4	53	47	1.1
Plym	58	42	1.4	73	27	2.7
Ports	61	39	1.5	73	27	2.7
Prstn	67	33	2.1	51	49	1.1
Redng	69	31	2.2	35	65	0.5
Sheff	71	29	2.5	61	39	1.5
Stevng	74	26	2.8	43	57	0.7
Sthend	70	30	2.3	33	67	0.5
Sund	63	37	1.7	75	25	3.0
Swmse	64	36	1.8	70	30	2.3
Truro	68	32	2.1	92	8	11.0
Wirrl	67	33	2.0	55	45	1.2
Wolve	63	37	1.7	59	41	1.4
Words	81	19	4.2	80	20	4.0
Wrexm	58	42	1.4	73	27	2.7
York	68	32	2.2	67	33	2.0
Eng	63	37	1.7	61	39	1.6
Wls	61	39	1.6	66	34	2.0
E&W	63	37	1.7	62	38	1.6

Table E.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	1,335	770	556	351
Wales	127	80	61	31
E&W	1,462	850	617	382

E:2 Current patients 2003**Table E.2.1: Treatment modalities for patients aged under 65 and over 65**

Centre	Treatment modalities by centre							
	Patients aged <65				Patients aged >65			
	% on HD	% on PD	% on transplant	HD:PD	% on HD	% on PD	% on transplant	HD:PD
Bangr	65	35	–	1.8	80	20	–	4.1
Bradf	33	19	48	1.7	75	14	11	5.4
Bristol	22	6	71	3.6	63	9	28	7.1
Camb	19	12	68	1.6	60	16	23	3.7
Carls	17	19	64	0.9	64	17	19	3.8
Carsh	34	19	47	1.7	53	27	20	2.0
Clwyd	80	20	–	4.0	82	18	–	4.5
Covnt	31	13	56	2.5	62	17	21	3.7
Crdff	20	14	66	1.5	54	15	31	3.7
Derby	75	25	–	3.0	76	24	–	3.1
Extr	25	16	59	1.5	72	16	13	4.5
Glouc	35	13	52	2.7	72	16	12	4.6
Guys	22	11	68	2.0	56	14	30	4.0
H&CX	38	20	42	1.9	66	14	20	4.9
Heart	44	5	51	8.6	83	6	11	13.7
Hull	37	13	50	2.9	76	9	15	8.3
Ipswi	24	25	51	1.0	55	33	13	1.7
Kings	29	16	55	1.8	65	16	19	4.1
Leeds	26	9	65	2.8	67	9	23	7.2
Leic	30	17	53	1.8	53	25	22	2.1
Livrpl	25	10	65	2.5	51	12	37	4.2
ManWst	29	20	50	1.5	52	29	18	1.8
Middlbr	31	5	64	5.9	70	2	28	39.3
Newc	22	6	72	3.9	44	5	51	8.0
Nottm	26	16	58	1.6	59	22	19	2.7
Oxfrd	18	9	73	1.9	50	15	35	3.4
Plym	23	14	63	1.7	58	15	28	3.8
Ports	22	9	69	2.6	54	13	33	4.2
Prstn	31	16	53	1.9	64	18	18	3.6
Redng	53	37	10	1.5	65	35	–	1.9
Sheff	38	13	49	2.9	60	22	18	2.7
Stevng	48	12	40	4.0	83	8	9	10.7
Sthend	45	30	25	1.5	82	16	3	5.3
Sund	35	6	58	5.7	56	8	35	6.7
Swkse	38	22	40	1.7	65	25	10	2.6
Truro	38	16	46	2.4	73	14	14	5.4
Wirrl	83	17	–	4.9	92	8	–	12.2
Wolve	52	15	33	3.4	73	20	7	3.7
Words	31	20	49	1.5	56	21	23	2.6
Wrexm	39	26	35	1.5	68	22	10	3.1
York	45	18	37	2.5	73	19	8	3.9
Eng	30	13	57	2.3	63	16	22	4.0
Wls	29	18	53	1.6	62	19	19	3.3
E&W	30	13	57	2.2	63	16	21	3.9

Table E.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 transplant	No on HD	No on PD	No on transplant
England	4,641	2,049	8,894	4,330	1,086	1,485
Wales	375	229	690	413	126	125
E&W	5,016	2,278	9,584	4,743	1,212	1,610

Table E.2.3: Treatment modality median ages by centre

Centre	Median ages and treatment modalities by centre			
	Median age on HD	Median age on PD	Median age on transplant	Median age for all
Bangr	67.5	58.6	46.4	54.5
Bradf	65.6	64.1	40.3	63.4
Bristl	69.6	58.8	50.9	56.9
Camb	66.1	63.7	50.4	61.0
Carls	69.7	56.3	50.4	60.3
Carsh	61.3	51.2	49.1	52.5
Clwyd	64.3	61.5	47.5	58.6
Covnt	62.7	58.9	45.0	51.2
Crdff	65.2	62.0	48.5	56.0
Derby	65.1	59.5	50.5	56.9
Extr	69.2	59.3	–	64.1
Glouc	70.0	58.5	56.6	61.3
Guys	62.4	60.0	53.4	58.4
H&CX	62.6	54.5	49.6	54.5
Heart	65.6	52.0	48.0	51.8
Hull	64.2	57.8	49.9	58.6
Ipswi	66.6	52.8	48.7	56.4
Kings	66.0	56.4	50.0	58.8
Leeds	64.4	60.3	43.8	59.9
Leic	62.4	59.7	52.2	56.2
Livrpl	60.4	55.9	–	64.1
ManWst	55.7	53.4	52.4	53.8
Middlbr	65.0	58.9	47.5	55.0
Newc	57.9	57.2	49.8	54.6
Nottm	65.3	58.6	49.2	55.3
Oxfrd	66.9	62.2	55.5	64.7
Plym	65.8	59.2	50.5	54.9
Ports	64.7	63.8	–	64.3
Prstn	61.5	52.6	47.9	53.3
Redng	66.1	58.2	48.5	53.9
Sheff	60.3	62.0	51.0	60.8
Stevng	66.5	64.8	–	65.0
Sthend	67.7	63.2	44.0	61.5
Sund	59.5	53.3	53.5	57.2
Swmse	66.5	61.0	49.9	56.1
Truro	71.8	54.7	45.1	54.7
Wirrl	66.1	54.2	49.4	55.8
Wolve	63.5	55.4	51.0	53.8
Words	64.7	57.9	47.9	59.0
Wrexm	67.2	59.9	50.1	56.9
York	67.6	49.3	49.1	56.3
Eng	64.2	58.0	49.6	55.9
Wls	66.2	58.1	49.8	56.7
E&W	64.3	58.0	49.6	56.0

Table E.2.4: Dialysis modalities for patients aged under 65

Dialysis modalities for patients aged under 65								
Centre	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ≥ 6 nights	% on cycling PD < 6 nights	% on unknown type of PD
Bangr	0	65	0	0	10	25	0	0
Bradf	0	46	17	0	19	17	0	0
Bristol	15	18	44	0	18	2	0	0
Camb	3	41	17	0	31	4	2	0
Carls	0	38	10	0	48	5	0	0
Carsh	1	44	19	0	18	19	0	0
Clwyd	3	77	0	0	14	6	0	0
Covnt	3	68	0	0	29	0	0	0
Crdff	0	28	31	0	41	0	0	0
Derby	3	72	0	0	24	0	1	0
Extr	1	24	34	0	26	3	3	0
Glouc	0	73	0	0	23	4	0	0
Guys	6	25	36	0	22	0	11	0
H&CX	3	35	28	0	21	13	0	0
Heart	11	72	6	0	8	2	0	0
Hull	4	43	27	0	15	11	0	0
Ipswi	11	38	0	0	18	33	0	0
Kings	0	64	0	0	32	1	0	0
Leeds	1	42	30	0	20	7	0	0
Leic	5	26	33	0	17	18	0	0
Livrpl	1	36	34	0	10	0	3	0
ManWst	5	28	26	0	39	0	0	0
Middlbr	3	59	24	0	14	0	0	0
Newc	3	77	0	0	3	17	0	0
Nottm	1	38	23	0	17	21	0	0
Oxfrd	6	60	0	0	15	19	0	0
Plym	0	63	0	0	27	0	0	0
Ports	0	39	33	0	28	0	0	0
Prstn	5	29	32	0	25	7	2	0
Redng	0	37	22	0	41	0	0	0
Sheff	10	53	12	0	25	1	0	0
Stevng	0	40	41	0	20	0	0	0
Sthend	0	60	0	0	40	0	0	0
Sund	1	66	18	0	5	10	0	0
Swmse	5	37	22	0	36	0	1	0
Truro	3	53	14	0	28	2	0	0
Wirrl	0	46	37	0	8	0	0	0
Wolve	0	29	48	0	22	1	0	0
Words	1	59	0	0	40	0	0	0
Wrexm	0	60	0	0	0	39	1	0
York	0	46	26	0	29	0	0	0
Eng	3	44	22	0	21	7	1	0
Wls	1	40	20	0	30	7	0	0
E&W	3	44	22	0	22	7	1	0

Table E.2.5: Dialysis modalities for patients aged over 65

Dialysis modalities for patients aged over 65								
Centre	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ≥ 6 nights	% on cycling PD < 6 nights	% on unknown type of PD
Bangr	0	80	0	0	13	7	0	0
Bradf	0	64	20	0	9	7	0	0
Bristol	1	13	73	0	11	1	0	0
Camb	1	51	27	0	20	1	0	0
Carls	0	65	15	0	19	2	0	0
Carsh	0	47	19	0	19	14	0	0
Clwyd	3	79	0	9	6	3	0	0
Covnt	1	78	0	0	21	0	0	0
Crdff	0	26	53	0	21	0	0	0
Derby	0	76	0	0	22	0	1	0
Extr	0	33	49	0	17	0	1	0
Glouc	0	82	0	0	17	1	0	0
Guys	1	27	53	0	13	0	7	0
H&CX	0	50	33	0	11	7	0	0
Heart	2	81	9	0	6	1	0	0
Hull	1	45	43	0	6	4	0	0
Ipswi	0	61	1	0	20	17	0	0
Kings	1	80	0	0	16	2	0	0
Leeds	0	49	39	0	9	3	0	0
Leic	1	26	41	0	20	12	0	0
Livrpl	0	52	28	0	13	1	2	1
ManWst	0	34	30	0	35	0	0	0
Middlbr	0	69	28	0	2	0	0	0
Newc	0	89	0	0	2	9	0	0
Nottm	0	44	29	0	19	8	0	0
Oxfrd	2	75	0	0	18	4	0	0
Plym	0	79	0	0	17	0	0	0
Ports	0	45	36	0	19	0	0	0
Prstn	1	33	45	0	19	1	1	0
Redng	0	43	22	0	35	0	0	0
Sheff	0	59	13	0	26	1	0	0
Stevng	0	38	53	0	9	0	0	0
Sthend	0	84	0	0	16	0	0	0
Sund	0	63	24	0	7	7	0	0
Swmse	1	45	27	0	28	0	0	0
Truro	0	71	14	0	15	0	0	0
Wirrl	0	43	49	0	8	0	0	0
Wolve	0	23	56	0	20	1	0	0
Words	0	72	0	0	28	0	0	0
Wrexm	0	76	0	0	0	24	0	0
York	0	58	22	0	18	3	0	0
Eng	0	52	28	0	16	3	0	0
Wls	0	47	30	1	19	4	0	0
E&W	0	51	28	0	16	3	0	0

Table E.2.6: Age ranges by centre

Centre	Patient age range by centre (%)							
	18–24	25–34	35–44	45–54	55–64	65–74	75–84	85+
Bangr	2	3	9	14	23	28	20	1
Bradf	5	10	17	18	18	23	9	–
Bristol	4	8	16	19	20	19	13	2
Camb	2	10	19	21	22	17	9	1
Carls	2	8	16	16	25	21	12	1
Carsh	2	10	20	15	24	20	10	1
Clwyd	4	6	9	19	13	29	18	1
Covnt	2	10	19	18	22	17	10	1
Crdff	3	10	17	21	21	16	9	2
Derby	1	6	10	16	17	29	18	3
Extr	2	7	15	18	24	16	16	2
Glouc	2	7	10	17	23	21	16	3
Guys	2	10	23	21	20	16	7	1
H&CX	1	7	15	22	23	21	10	1
Heart	3	9	15	16	22	19	15	1
Hull	4	9	16	18	22	17	13	2
Ipswi	3	6	20	21	18	19	14	1
Kings	1	8	19	21	17	23	11	1
Leeds	5	10	17	22	19	17	8	1
Leic	2	9	16	20	21	20	9	1
Livrpl	3	9	21	21	21	16	8	1
ManWst	3	14	20	19	18	17	8	0
Middlbr	3	8	21	16	21	19	11	0
Newc	4	8	19	23	23	17	6	0
Nottm	5	10	17	19	18	20	11	1
Oxfrd	2	9	18	19	23	19	10	1
Plym	2	9	15	18	25	17	13	1
Ports	4	8	19	19	22	17	10	1
Prstn	3	10	17	21	22	17	9	1
Redng	3	8	11	17	13	29	17	2
Sheff	3	8	16	21	22	21	9	0
Stevng	1	7	13	17	20	26	13	1
Sthend	3	6	9	13	29	19	17	4
Sund	2	13	17	21	21	20	7	0
Swmse	3	6	12	18	20	26	15	2
Truro	1	5	9	15	19	30	15	5
Wirrl	2	6	10	12	20	27	20	2
Wolve	3	7	15	15	22	22	15	1
Words	2	5	14	22	23	21	12	1
Wrexm	2	7	13	17	21	26	13	1
York	5	7	14	14	17	21	18	5
Eng	3	9	17	19	21	19	11	1
Wls	3	8	15	20	21	21	12	2
E&W	3	9	17	19	21	19	11	1

Table E.2.7: Dialysis modalities for non-diabetic patients (all ages)

Dialysis modalities for non-diabetic patients (all ages)								
Centre	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ≥ 6 nights	% on cycling PD < 6 nights	% on unknown type of PD
Bangr	0	70	0	0	13	17	0	0
Bradf	0	54	21	0	15	11	0	0
Bristol	8	14	61	0	14	1	0	0
Camb	2	46	20	0	26	3	1	0
Carls	0	51	9	0	36	4	0	0
Carsh	1	47	18	0	19	16	0	0
Clwyd	2	77	0	6	13	2	0	0
Covnt	2	75	0	0	23	0	0	0
Crdff	0	28	38	0	34	0	0	0
Derby	2	75	0	0	21	0	1	0
Extr	1	27	40	0	22	2	2	0
Glouc	0	81	0	0	18	1	0	0
Guys	5	26	43	0	18	0	9	0
H&CX	2	39	31	0	16	11	0	0
Heart	8	77	7	0	7	1	0	0
Hull	4	45	34	0	8	9	0	0
Ipswi	6	54	1	0	13	26	0	0
Kings	0	74	0	0	22	1	0	0
Leeds	1	41	39	0	13	5	0	0
Leic	4	26	37	0	18	16	0	0
Livrpl	1	40	34	0	11	0	2	0
ManWst	4	31	27	0	36	0	0	0
Middlbr	1	62	27	0	10	0	0	0
Newc	2	81	0	0	3	14	0	0
Nottm	1	39	29	0	18	13	0	0
Oxfrd	5	68	0	0	16	11	0	0
Plym	0	74	0	0	19	0	0	0
Ports	0	41	36	0	23	0	0	0
Prstn	4	29	38	0	23	5	1	0
Redng	0	41	23	0	36	0	0	0
Sheff	6	55	14	0	25	0	0	0
Stevng	0	39	47	0	14	0	0	0
Sthend	0	75	0	0	25	0	0	0
Sund	1	65	20	0	5	10	0	0
Swmse	3	41	25	0	31	0	0	0
Truro	1	66	12	0	20	1	0	0
Wirrl	0	44	43	0	8	0	0	0
Wolve	0	28	50	0	20	2	0	0
Words	1	65	0	0	34	0	0	0
Wrexm	0	71	0	0	0	28	1	0
York	0	52	33	0	14	1	0	0
Eng	3	47	26	0	18	5	1	0
Wls	1	42	25	0	27	4	0	0
E&W	2	46	26	0	19	5	1	0

Table E.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	7,201	2,391	9,311
Wales	599	279	763
E&W	7,800	2,670	10,074

Table E.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 hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ≥ 6 nights	% on cycling PD < 6 nights	% on unknown type of PD
Bradf	0	50	17	0	21	12	0	0
Sthend	0	67	0	0	33	0	0	0
Stevng	0	40	41	0	19	0	0	0
Carsh	1	46	18	0	17	18	0	0
Wirrl	0	45	37	0	9	0	0	0
York	0	42	40	0	18	0	0	0
Middlbr	2	57	26	0	16	0	0	0
Nottm	2	35	27	0	18	18	0	0
Bristl	18	15	44	0	19	1	0	0
Truro	2	55	11	0	30	2	0	0
Hull	6	46	25	0	10	13	0	0
Leic	6	26	33	0	16	19	0	0
Derby	4	73	0	0	23	0	0	0
Ipswi	13	44	0	0	10	33	0	0
Camb	3	40	17	0	31	4	3	0
Glouc	0	77	0	0	19	4	0	0
Extr	2	23	31	0	26	4	4	0
Ports	0	38	36	0	27	0	0	0
Redng	0	38	23	0	40	0	0	0
Guys	8	24	37	0	20	0	11	0
Kings	0	71	0	0	25	1	0	0
Sheff	11	52	13	0	24	0	0	0
Plym	0	68	0	0	22	0	0	0
Covnt	3	74	0	0	23	0	0	0
Clwyd	4	77	0	0	19	0	0	0
Wrexm	0	65	0	0	0	33	3	0
Wolve	0	32	45	0	22	2	0	0
Heart	14	70	6	0	8	2	0	0
Carls	0	38	5	0	51	5	0	0
Sund	2	66	18	0	3	11	0	0
ManWst	6	29	25	0	38	1	0	0
Prstn	6	28	32	0	26	7	1	0
Words	1	58	0	0	40	0	0	0
Oxfrd	7	60	0	0	14	19	0	0
Leeds	1	39	33	0	19	8	0	0
Livrpl	1	34	37	0	10	0	2	0
Bangr	0	64	0	0	11	25	0	0
Swmse	6	36	18	0	39	0	1	0
H&CX	3	33	29	0	20	14	1	0
Crdff	0	31	26	0	43	0	0	0
Newc	3	77	0	0	3	17	0	0
Eng	4	43	23	0	20	7	1	0
Wls	2	41	18	0	34	5	0	0
E&W	4	43	23	0	21	7	1	0

Table E.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	3,714	1,554	7,938
Wales	279	182	646
E&W	3,993	1,736	8,584

Table E.2.11: Dialysis modalities for non-diabetic patients aged over 65

Dialysis modalities for non-diabetic patients aged over 65								
Centre	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ≥ 6 nights	% on cycling PD < 6 nights	% on unknown type of PD
Bangr	0	77	0	0	15	8	0	0
Bradf	0	59	25	0	7	9	0	0
Bristol	1	13	74	0	10	1	0	0
Camb	1	53	24	0	21	2	0	0
Carls	0	63	12	0	22	2	0	0
Carsh	1	48	17	0	21	13	0	0
Clwyd	0	78	0	11	7	4	0	0
Covnt	1	76	0	0	23	0	0	0
Crdff	0	25	52	0	23	0	0	0
Derby	0	77	0	0	18	0	2	0
Extr	0	31	49	0	19	0	1	0
Glouc	0	83	0	0	17	0	0	0
Guys	1	28	51	0	13	0	6	0
H&CX	0	49	35	0	10	7	0	0
Heart	2	83	8	0	6	1	0	0
Hull	2	43	45	0	5	5	0	0
Ipswi	0	64	2	0	16	18	0	0
Kings	1	77	0	0	19	2	0	0
Leeds	0	45	48	0	6	2	0	0
Leic	1	26	41	0	20	12	0	0
Livrpl	0	52	28	0	13	1	3	1
ManWst	0	35	32	0	32	0	0	0
Middlbr	0	68	29	0	3	0	0	0
Newc	0	89	0	0	3	9	0	0
Nottm	0	43	31	0	17	9	0	0
Oxfrd	2	76	0	0	17	4	0	0
Plym	0	80	0	0	15	0	0	0
Ports	0	44	37	0	18	0	0	0
Prstn	1	31	47	0	19	1	1	0
Redng	0	44	23	0	33	0	0	0
Sheff	0	59	15	0	26	0	0	0
Stevng	0	38	53	0	9	0	0	0
Sthend	0	82	0	0	18	0	0	0
Sund	0	63	23	0	8	8	0	0
Swmse	1	45	30	0	25	0	0	0
Truro	0	72	13	0	14	0	0	0
Wirrl	0	43	49	0	8	0	0	0
Wolve	0	24	57	0	17	2	0	0
Words	0	74	0	0	26	0	0	0
Wrexm	0	79	0	0	0	21	0	0
York	0	60	28	0	10	2	0	0
Eng	1	51	29	0	16	3	0	0
Wls	0	44	33	1	20	2	0	0
E&W	0	50	29	0	16	3	0	0

Table E.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	3,487	837	1,373
Wales	320	97	117
E&W	3,807	934	1,490

Table E.2.13: Dialysis modalities for diabetic patients

Dialysis modalities for diabetic patients								
Centre	% on home HD	% on hospital HD	% on satellite HD	% on connect PD	% on disconnect PD	% on cycling PD ≥ 6 nights/wk	% on cycling PD < 6 nights/wk	% on unknown type of PD
Bangr	0	91	0	0	0	9	0	0
Bradf	0	63	13	0	13	13	0	0
Bristol	2	22	58	0	15	3	0	0
Camb	2	43	30	0	23	2	0	0
Carls	0	55	36	0	9	0	0	0
Carsh	0	48	17	0	20	15	0	0
Clwyd	7	80	0	0	0	13	0	0
Covnt	0	61	0	0	39	0	0	0
Crdff	0	22	53	0	25	0	0	0
Derby	0	80	0	0	17	0	2	0
Extr	0	23	55	0	14	0	0	0
Glouc	0	73	0	0	20	7	0	0
Guys	0	27	41	0	20	0	12	0
H&CX	0	48	25	0	18	9	0	0
Heart	0	79	11	0	9	2	0	0
Hull	0	38	38	0	21	4	0	0
Ipswi	4	24	0	0	48	24	0	0
Kings	0	66	0	0	28	2	0	0
Leeds	0	51	24	0	19	5	0	0
Leic	1	31	30	0	21	16	0	0
Livrpl	0	52	23	1	11	0	5	1
ManWst	0	24	29	0	46	0	0	0
Middlbr	5	67	21	0	7	0	0	0
Newc	0	71	0	0	0	29	0	0
Nottm	0	46	16	0	16	22	0	0
Oxfrd	0	62	0	0	22	16	0	0
Plym	0	65	0	0	29	0	0	0
Ports	0	43	30	0	26	0	0	0
Prstn	0	41	33	0	22	2	2	0
Redng	0	36	21	0	43	0	0	0
Sheff	2	61	5	0	29	3	0	0
Stevng	0	37	46	0	17	0	0	0
Sthend	0	67	0	0	33	0	0	0
Sund	0	65	20	0	10	5	0	0
Swnse	2	42	23	0	33	0	0	0
Truro	0	71	8	0	21	0	0	0
Wirrl	0	50	50	0	0	0	0	0
Wolve	0	18	56	0	26	0	0	0
Words	0	63	0	0	37	0	0	0
Wrexm	0	75	0	0	0	25	0	0
York	0	86	0	0	14	0	0	0
Eng	0	49	22	0	22	6	1	0
Wls	1	41	32	0	21	4	0	0
E&W	0	48	23	0	22	6	1	0

Table E.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	711	345	637
	Type II	635	209	116
Wales	Type I	93	35	44
	Type II	43	11	4
E&W	Type I	804	380	681
	Type II	678	220	120

Table E.2.15: Diabetics

Centre	M:F ratio	Median age on 31/12/2003	Median age at start of treatment	Median time on ESRF treatment	
				in days	in years
Bangr	5	68	66	532	1.5
Bradf	1	63	60	882	2.4
Bristol	2	57	51	1,010	2.8
Camb	2	51	45	927	2.5
Carls	1	62	58	1,358	3.7
Carsh	1	58	53	490	1.3
Clwyd	1	62	58	918	2.5
Covnt	2	56	52	1,095	3.0
Crdff	2	56	53	981	2.7
Derby	2	60	56	861	2.4
Extr	1	55	51	1,454	4.0
Glouc	1	60	55	1,311	3.6
Guys	1	54	50	1,228	3.4
H&CX	2	62	58	931	2.6
Heart	1	61	56	828	2.3
Hull	1	58	54	974	2.7
Ipswi	2	50	48	862	2.4
Kings	2	64	61	920	2.5
Leeds	2	55	51	1,185	3.2
Leic	2	59	54	774	2.1
Livrpl	2	52	46	1,404	3.8
ManWst	2	58	55	841	2.3
Middlbr	2	51	46	778	2.1
Newc	2	54	48	1,568	4.3
Nottm	1	58	53	1,389	3.8
Oxfrd	1	55	50	1,146	3.1
Plym	2	53	50	674	1.8
Ports	2	55	49	1,148	3.1
Prstn	1	57	54	919	2.5
Redng	2	62	58	713	2.0
Sheff	2	56	52	1,016	2.8
Stevng	2	57	53	839	2.3
Sthend	2	59	55	425	1.2
Sund	2	51	46	731	2.0
Swmse	2	60	56	792	2.2
Truro	2	62	65	743	2.0
Wirrl	3	61	59	752	2.1
Wolve	2	60	57	630	1.7
Words	2	63	58	1,029	2.8
Wrexm	2	55	49	1,233	3.4
York	2	50	49	668	1.8
Eng	2	57	53	987	2.7
Wls	2	59	54	905	2.5
E&W	2	57	53	974	2.7

Table E.2.16: Transplant gender ratios

	% of males	% of females	No of males	No of females	M:F ratio
England	60.8	39.2	6,315	4,064	1.6
Wales	64.3	35.7	524	291	1.8
E&W	61.1	38.9	6,839	4,355	1.6

E:3 EDTA Primary Diagnosis Groups

Table E.3.1: Collation of EDTA Primary Renal Diagnoses

CODE	TITLE	Group
0	Chronic renal failure; aetiology uncertain Unknown/Unavailable [0]	Uncertain
10	Glomerulonephritis; histologically NOT examined [10]	Uncertain
11	Focal segmental glomerulosclerosis 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 glomerulosclerosis 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 nephronoptosis [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

Table E.3.4. (continued)

CODE	TITLE	Group
83	Amyloid [83]	Amyloid
84	Lupus erythematosus [84]	Other
85	Henoch-Schoenlein purpura [85]	Other
86	Goodpasture's Syndrome [86]	Other
87	Systemic sclerosis (scleroderma) [87]	Other
88	Haemolytic Uraemic Syndrome (including Moschcowitz Syndrome) [88]	Other
89	Multi-system disease – other (not mentioned above) [89]	Other
90	Tubular necrosis (irreversible) or cortical necrosis (different from 88) [90]	Other
91	Tuberculosis [91]	Other
92	Gout nephropathy (urate) [92]	Other
93	Nephrocalcinosis and hypercalcaemic nephropathy [93]	Other
94	Balkan nephropathy [94]	Other
95	Kidney tumour [95]	Other
96	Traumatic or surgical loss of kidney [96]	Other
99	Other identified renal disorders [99]	Other
199	Code not sent [199]	Other

Appendix F: National Programme for IT Output Based Specification 167 – Renal Services

Introduction

The text of the Output Based Specification (OBS) contract for renal services is provided below. This is section 167 within the contract signed by the regionally based Local Service Providers (LSPs) as a component of the National Programme for IT (NPfIT).

This has been included in the Registry Report so that renal unit managers may reference this document in their negotiations within the Trust and with the LSPs.

OBS 167 – Renal Services

NSFs are not just about collecting data; this part of the specification will not substitute for each LSP making particular reference to the specific documents available to help in satisfying the policy and service requirements for the prevention of renal disease and management of people with renal failure.

It is recognised that every area of specialist activity will have variations in the data it uses and the way it operates the basic primary clinical (and other) activity. This part of the specification identifies that which, in terms of overall activity and monitoring, is specific to people with renal disease, particularly those with renal failure.

In February 2001, the Secretary of State announced his intention to establish a new set of national standards to improve services for 30,000 kidney patients.

The incidence and prevalence of kidney failure is increasing steadily and as such there is a real need to address issues of prevention and capacity to reduce incidence and increase choice and treatment options. This will be addressed through a number of processes:

- The development of improved preventative strategies based around well established risk factors and interventions.

- Reduction in the variation in treatment rates and quality of service, including referral to.
- Nephrologists and the development of care plans.
- Provision of sufficient capacity to ensure that patients consistently receive optimal care (ie choice of treatment and frequency of dialysis).
- Optimisation of access to and outcome of renal transplantation.

The new Renal Services NSF will be developed with the help of health and social care professionals and managers, patients, carers, partners, agencies and other advocates. It will be the blueprint for national standards and services that will improve treatment and care for the 30,000 patients in the UK on dialysis or living with a kidney transplant.

As with other published NSFs the Renal Services NSF standards will be supported by an information strategy, which will build on work already underway for existing national service frameworks to ensure that the specific renal issues can be addressed in an appropriate manner.

This will include (through close collaboration with the Renal Registry and UKT) the development of a nationally approved dataset. The dataset is expected to incorporate the two existing data sets and be developed to include those elements required that are not within the scope of the two current collections.

The Renal Services NSF is expected to be published later this year. Further information can be found at the URL, <<http://www.doh.gov.uk/nsf/renal.htm>> .

Scope

The Renal NSF has been developed in 4 modules to consider the whole patient journey. This starts with those at risk because of congenital, acquired or inherited renal disease or risk factors, through the process of diagnosis, progression to renal failure, dialysis and transplantation and supported care and decisions at the end of life.

Module 1 This is concerned with haemodialysis and peritoneal dialysis and includes the year prior to the start of renal replacement therapy and issues surrounding appropriate and timely access surgery.

Module 2 This is concerned with maximising the benefits of transplantation and includes key issues relating to live and cadaveric donors. Some donor issues are dealt with in the Transplant Framework, published by the Department of Health (DoH).

Module 3 This module is concerned with:

- Identification of people at risk of renal failure because of previously identified renal disease or congenital, inherited or acquired conditions predisposing to renal disease and renal disease.
- Detection of early progressive renal disease and early signs of renal failure by detection of proteinuria, hypertension or reduced or falling GFR.
- Prevention of renal failure by evidence based management of those identified.
- Lifestyle choices that reduce risk and increase longevity.

This module also addresses acute renal failure which is an important source of morbidity and mortality and also provides a source of patients who do not recover and therefore have unplanned acute onset chronic renal failure.

Module 4 End of life care is an important choice for people with ERF, a difficult condition from which there can be no recovery. Planned and supported care at the end of life is an important component of the services provided.

It should be noted that, at the time of publication of the OBS, modules 1 and 2 are further advanced than modules 3 and 4. As a consequence, the renal services requirements of ICRS address the needs within primary and secondary care settings. Further requirements relating to primary and palliative care settings are yet to be articulated.

Governance and audit

The ICRS spine and LSP must provide a facility for the direct care of the patient with renal disease, in primary, secondary and tertiary care and provide the functionality to deliver data for secondary purposes.

For the direct care of patients with renal failure the ICRS will ensure that the system will:

- Provide a continuous lifelong record of the patient's history, care, discussions and wellbeing;
- Have the ability to support serial online biochemical and other tests, X-rays and biopsies;
- Provide facilities for data transformation for assessing progress and adequacy of care (eg, estimated GFR using the Cockcroft and Galt formula or KT/V for dialysis adequacy);
- Enable the patient and health professionals to participate in the development and use of a personal care plan which enables the patient to have access to their own records and participate in their own management and joint decisions;
- Share information appropriately between health sectors, members of the multidisciplinary team and other specialists in an accurate and timely way with due regard to confidentiality and with the patient's consent;
- Provide the facility for prescribing information for patients with various levels of impaired renal function and with renal transplants;
- Enable patients waiting for a transplant to access their status on the transplant list;
- Provide decision support based on evidence;
- Provide access to the knowledge base for patients and health professionals;
- Provide functionality for decision support to clinicians at the point of care informed by evidence-based information such as that developed by the NeLH;
- Provide information to monitor the standards of the Renal Association, the British Transplantation Society and other relevant professional bodies and ICRS Output Based Specification;
- Provide information to monitor the standards outlined in the Renal National Service Framework for renal disease and other NSF's such as Diabetes, CHD and Children's & Maternity Services when published.

For the management of donors there should be facilities to support:

(For live donors)

- the needs of live donors as patients and organ donors;
- the ability of live donors to see the results of their tests and participate in shared decision making;
- the ability to provide statutory information about live donation to UK Transplant;
- the ability to provide follow up of the donor.

(For cadaveric donors)

- the needs of cadaveric donors, both heart beating and non-heart beating, including records that continue to function and are accessible after the death of the donor;
- functionality to support links for health professionals to the organ donor register in order to establish the status and wishes of a potential donor;
- functionality to enable health professionals to view the medical records of potential donors, both non-heart beating and heart beating donors to inform decisions about proceeding with organ donation;
- functionality to support UK Transplant in the process of organ allocation and statutory duties related to organ donation;
- functionality to enable health professionals to view the records of cadaveric kidney donors or if the recipient has a subsequent problem or to research newly identified problems and to identify the recipients if the donor is later found to have an unexpected problem (eg cancer found at post mortem or CJD);
- enable information to be transferred from donor to recipients and from one recipient to others from a common donor, when required, with appropriate levels of confidentiality;
- provide information required for organ allocation through UK Transplant; and

(For healthy people)

- those who wish to register on the organ donor register;
- data for secondary purposes.

In addition the data required for secondary purposes (epidemiology, incidence, prevalence, activity, outcome, treatment modalities, audit, benchmarking, management, clinical governance, planning commissioning and research) must be derived from the Patient Record.

Information about patients with renal failure:

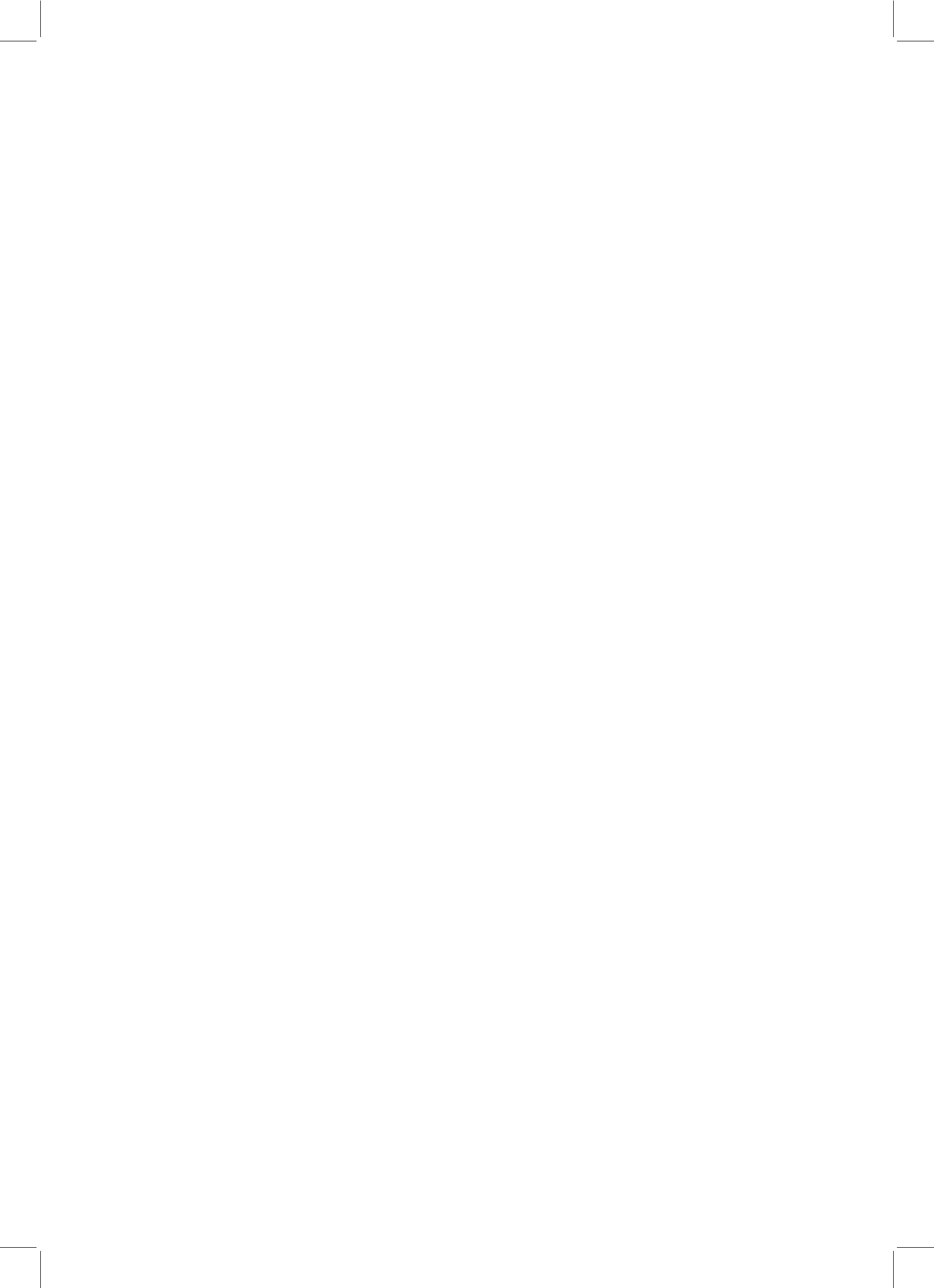
- information about patients with renal failure in primary secondary and tertiary care;
- data required for the renal registry and other key stakeholders. *(The details of the information required will be informed by a review of information to be undertaken by the NHSIA and commissioned by the DoH);*
- information on the waiting times and outcome of transplantation;

Information about donated organs:

- information required by UK transplant for statutory duties;
- information required to monitor the outcome of renal transplantation in relation to the type of organ, its condition and transfer;
- information about the organ allocation and transplantation process;

Information about donors:

- information on live donors, including follow up;
- information about cadaveric donors.



Appendix G: Acronyms and Abbreviations used in the Report

ACE (inhibitor)	Angiotensin converting enzyme (inhibitor)
APD	Automated peritoneal dialysis
ARF	Acute renal failure
AVF	Arteriovevous fistula
BAPN	British Association of Paediatric Nephrology
BCG	Bromocresol green
BCP	Bromocresol purple
BMI	Body mass index
BP	Blood pressure
BTS	British Transplant Society
CABG	Coronary artery bypass grafting
CAPD	Continuous ambulatory peritoneal dialysis
CCL	Clinical Computing Limited
CCPD	Cycling peritoneal dialysis
CI	Confidence interval
CIC	Clean intermittent catheterisation
CKD	Chronic kidney disease
CMMS	US Centre for Medicare and Medicaid Services
COPD	Chronic obstructive pulmonary disease
CRF	Chronic renal failure
CRP	C-reactive protein
CXR	Chest X Ray
DBP	Diastolic blood pressure
DCCT	Diabetes Control and Complications Trial
DFS	Date first seen
DM	Diabetes mellitus
DOH	Department of Health
DOPPS	Dialysis Outcomes and Practice Patterns Study
DOQI	Disease Outcomes Quality Initiative
E&W	England and Wales
EBPG	European Best Practice Guidelines
ERA-EDTA	European Renal Association – European Dialysis and Transplant Association
eGFR	Estimated GFR
EPO	Erythropoietin
EPR	Electronic patient record
ERA	European Renal Association
ER	Early referral
ERF	Established renal failure
FSGS	Focal segmental glomerulosclerosis
GB	Great Britain
GFR	Glomerular filtration rate
GN	Glomerulonephritis
HA	Health Authority
HbA1c	Glycated Haemoglobin
HCFA	USA Health Care Finance Administration – now replaced by CMMS
HD	Haemodialysis
HDL	High-density lipoprotein

Hb	Haemoglobin
HLA	Human Leucocyte Antigen
HR	Hazard ratio
ICRS	Integrated care records system
IHD	Ischaemic heart disease
IDOPPS	International Dialysis Outcomes and Practice Patterns Study
IFCC	International Federation of Clinical Chemistry & Laboratory Medicine
IM&T	Information management & technology
IPD	Intermittent peritoneal dialysis
iPTH	Intact parathyroid hormone
ITU	Intensive therapy unit
ISB	Information Standards Board
K/DOQI	KDOQI
KM	Kaplan-Meier
LA	local authorities
LDL	Low-density lipoprotein
LR	Late referral
LSPs	Local service providers
LV	Left ventricular
LVH	Left ventricular hypertrophy
MAP	Mean arterial blood pressure
MDRD study	Modified Diet in Renal Disease study
MI	Myocardial infarction
NAS	National Analytical Society
NASP	National application service Providers
NCRS	National care records service
NeLH	National electronic library for health
NEQAS	UK National External Quality Assessment Scheme
NFKPA	National Federation of Kidney Patients' Associations
NHS	National Health Service
NHID	National Health Informatics Development
NHSIA	NHS Information Agency
NICE	National Institute of Clinical Excellence
NpFIT	National Programme for Information Technology
NSF	National service framework
OA	Output area (Census)
OBSC	Output based specification contract
ONS	Office of National Statistics
PCT	Primary Care Trust
PD	Peritoneal dialysis
PIAG	Patient Information Advisory Group
PKD	Polycystic kidney disease
pmcp	Per million child population
pmp	Per million population
PP	Pulse pressure
PTH	Parathyroid hormone
PVD	Peripheral vascular disease
RA	Renal Association
RNSF	Renal national service framework (or NSF)
ROCR	Review of central information requirements
RR	Relative risk
RRDSS	Renal registry data set specification
RRT	Renal replacement therapy

SARR	Standardised acceptance rate ratio
SAS	Statistical Analysis System (statistical software used by the Registry)
SBP	Systolic blood pressure
SD	Standard deviation
SDS	Standard deviation score
SDII	Renal Standards document – second edition
SDIII	Renal Standards document – third edition
SES	Socio-economic status
SHARP	Study of Heart and Renal Protection
SI	System International (units)
SIRS	Study of Implementation of Renal Standards
SMR	Standardised mortality ratios
StHAs	Strategic health authorities
SUS	Secondary use service
TOR	Take-on rate
TSAT	Transferrin saturation
UA	Unitary Authorities
UKR	Urea kinetic modelling
UKRR	UK Renal Registry
UKT	UK Transplant
USRDS	United States Renal Data System
URR	Urea reduction ratio
WEQAS	Welsh External Quality Assurance Study
WTE	Whole time equivalent



Appendix H: Laboratory conversion factors

Conversion factors from SI units	
Albumin	$\text{g/dl} = \text{g/L} \times 0.1$
Bicarbonate	$\text{mg/dl} = \text{mmol/L} \times 6.1$
Calcium	$\text{mg/dl} = \text{mmol/L} \times 4$
Calcium \times phosphate	$\text{mg}^2/\text{dl}^2 = \text{mmol}^2/\text{L}^2 \times 12.4$
Cholesterol	$\text{mg/dl} = \text{mmol/L} \times 38.6$
Creatinine	$\text{mg/dl} = \text{micmol/L} \times 0.011$
Glucose	$\text{mg/dl} = \text{mmol/L} \times 18$
Haemoglobin	$\text{Hct} = \text{g/dl} \times 3.11$ (<i>NB this factor is variable</i>)
phosphate	$\text{mg/dl} = \text{mmol/L} \times 3.1$
PTH	$\text{ng/L} = \text{pmol/L} \times 9.5$
Urea	$\text{mg/dl} = \text{mmol/L} \times 2.8$

Appendix I: Abbreviations used for the renal unit 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	Bristol
Cambridge	Addenbrookes Hospital	Camb
Cardiff	University of Wales Hospital	Crdff
Carlisle	Cumberland Infirmary	Carls
Carshalton	St Helier Hospital	Carsh
Clwyd	Ysbyty Clwyd	Clwyd
Coventry	Walsgrave Hospital	Covnt
Derby	Derby City General Hospital	Derby
Exeter	Royal Devon and Exeter Hospital	Extr
Gloucester	Gloucester Royal Hospital	Glouc
Hull	Hull Royal Infirmary	Hull
Ipswich	Ipswich Hospital	Ipswi
Leeds	St James's Hospital and Leeds General Infirmary	Leeds
Leicester	Leicester General Hospital	Leic
Liverpool	Royal Liverpool University Hospital	Livrpl
London	Guys and St Thomas' Hospital	Guys
London	Hammersmith + Charing Cross	H&CX
London	Kings College Hospital	Kings
Manchester	Hope Hospital	ManWst
Middlesbrough	James Cook University Hospital	Middlbr
Newcastle	Freeman Hospital	Newc
Nottingham	Nottingham City Hospital	Nottm
Oxford	Churchill Hospital	Oxfrd
Plymouth	Derriford Hospital	Plym
Portsmouth	Queen Alexandra Hospital	Ports
Preston	Royal Preston Hospital	Prstn
Reading	Royal Berkshire Hospital	Redng
Sheffield	Northern General Hospital	Sheff
Stevenage	Lister Hospital	Stevn
Southend	Southend Hospital	Sthend
Sunderland	Sunderland Royal Hospital	Sund
Swansea	Morrison Hospital	Swnse
Truro	Royal Cornwall Hospital	Truro
Wirral	Arrowe Park Hospital	Wirrl
Wolverhampton	New Cross Hospital	Wolve
Wordsley	Wordsley Hospital	Words
Wrexham	Maelor General Hospital	Wrexm
York	York District Hospital	York