

## Chapter 2: Introduction to the 2002 Report

### Area covered by the Renal Registry

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

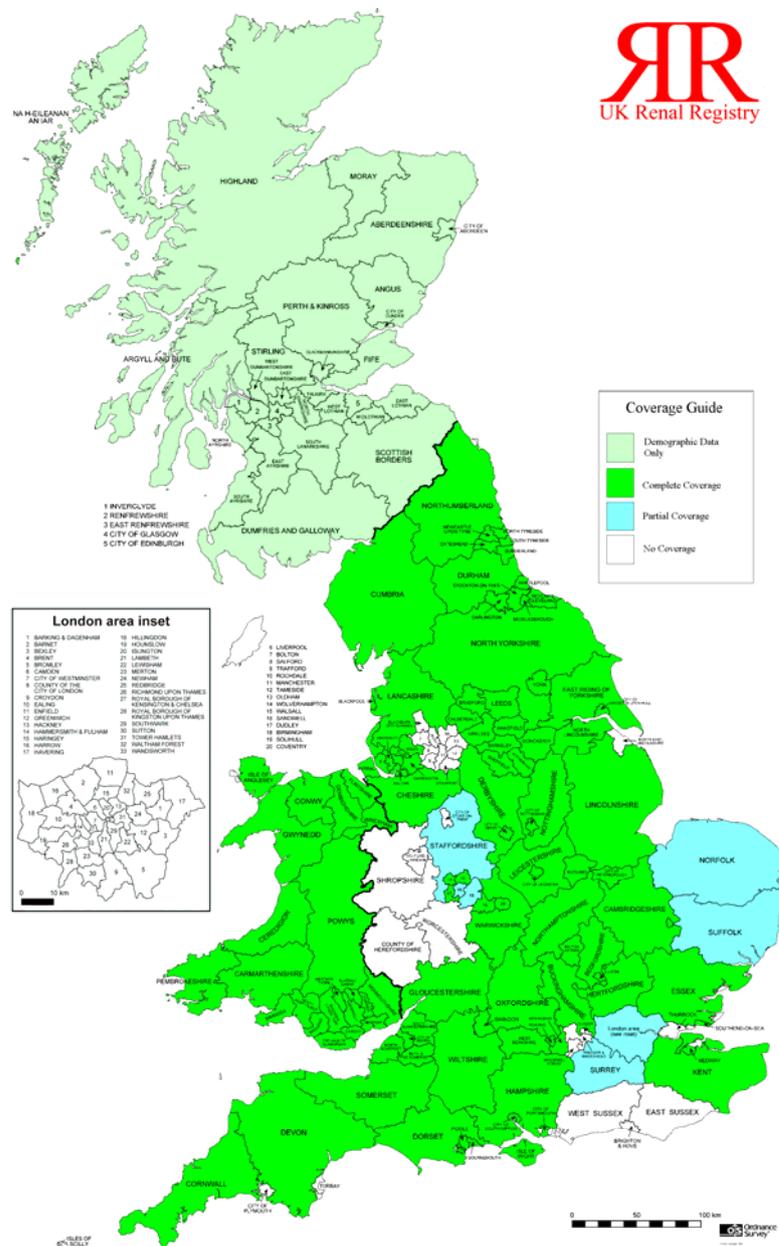


Figure 2.1: Area covered by the Renal Registry

## Centres in the 2002 Registry report

		Estimated population (millions)
<b>England &amp; Wales</b>		<b>33.01</b>
Birmingham	Heartlands Hospital	0.60
*Bradford	St Luke's Hospital	0.60
Bristol	Southmead Hospital	1.50
*Cambridge	Addenbrookes Hospital	1.42
Cardiff	University of Wales Hospital	1.30
Carlisle	Cumberland Infirmary	0.36
Carshalton	St Helier Hospital	1.80
Coventry	Walsgrave Hospital	0.85
Exeter	Royal Devon and Exeter Hospital	0.75
Gloucester	Gloucester Royal Hospital	0.55
Hull	Hull Royal Infirmary	1.02
Leeds	Leeds General Infirmary	0.90
Leeds	St James's Hospital	1.30
Leicester	Leicester General Hospital	1.80
*Liverpool	Royal Infirmary	1.35
London	Guys and St Thomas' Hospital	1.70
Middlesborough	James Cook University Hospital	1.00
Nottingham	Nottingham City Hospital	1.16
Oxford	Churchill Hospital	1.80
Plymouth	Derriford Hospital	0.55
*Portsmouth	St Mary's Hospital	2.00
Preston	Royal Preston Hospital	1.48
Reading	Royal Berkshire Hospital	0.60
*Rhyl	Ysbyty Clwyd	0.15
Sheffield	Northern General Hospital	1.75
Stevenage	Lister	1.25
Southend	Southend Hospital	0.35
Sunderland	Sunderland Royal Hospital	0.34
Swansea	Morrison Hospital	0.70
*Truro	Royal Cornwall Hospital	0.36
Wolverhampton	Newcross Hospital	0.49
Wordsley	Stourbridge Hospital	0.42
Wrexham	Maelor General Hospital	0.42
York	York District Hospital	0.39

**Table 2.1: Centres in the 2002 Registry**

\*These units are being reported by the Registry for the first time.

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

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

### **Exclusion of data from the report**

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

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

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

**Table 2.2: Excluded centres**

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

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

### ***Centres who have recently joined the Registry***

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

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

**Table 2.3: IT systems used by hospitals**

### ***Centres in the process of joining the Registry***

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

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

**Table 2.4: IT systems being implemented**

### ***Centres in discussion with the Registry***

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

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

**Table 2.5: Centres without Registry-compatible IT**

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

### ***Future coverage by the Registry***

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

### ***Software and links to the Registry***

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

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

### ***Paediatric Registry links***

There are in the UK an estimated 750 patients under 18 years old who are on renal replacement therapy. As most of the 13 UK paediatric renal units are small, the British Association of Paediatric Nephrology (BAPN) was able to set up its own database to collect data. As in previous years, this report includes a chapter of analyses from these data.

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

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

**Table 2.6: Paediatric renal unit plans**

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

### ***Links with other organisations***

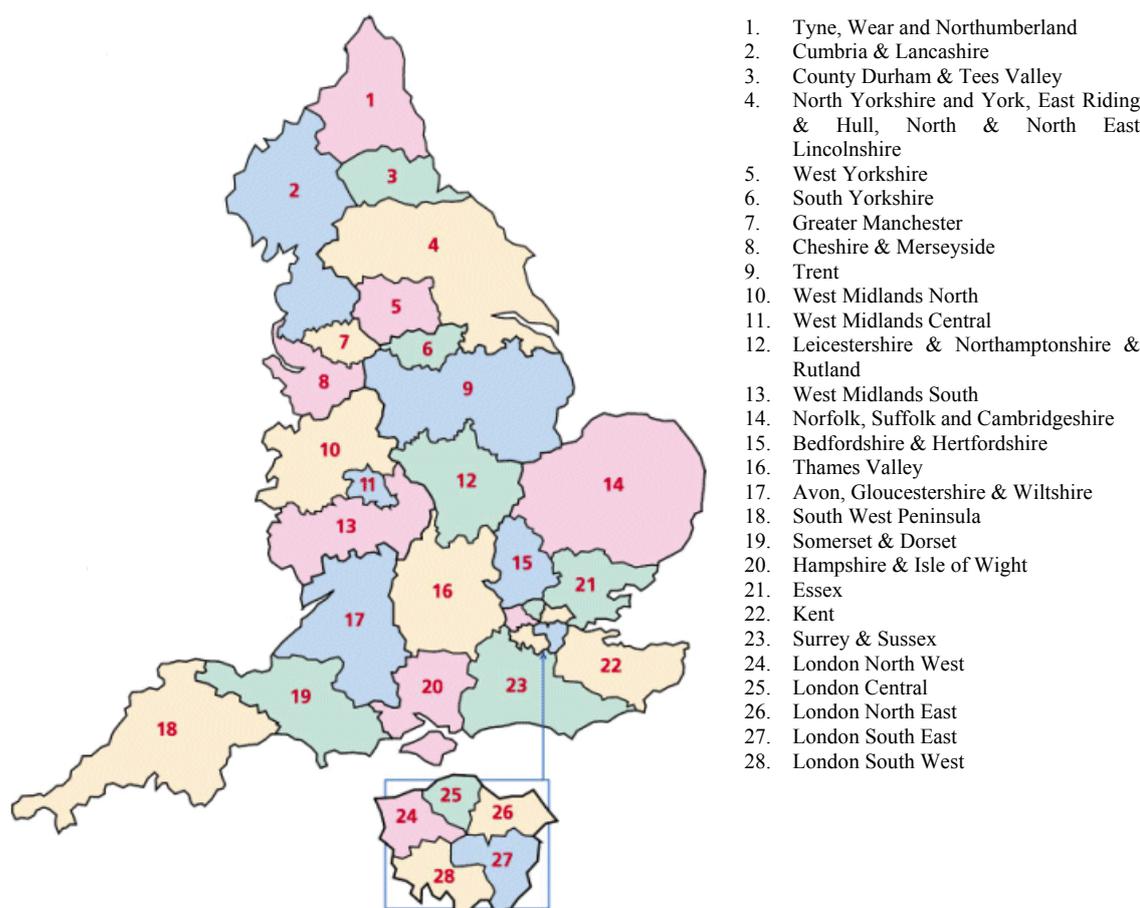
The UK Renal Registry has been active in supporting the the Renal Association Standards Sub-committee in the production of the new standards document. Support has been given to the Department of Health in gaining the basic data necessary for the future planning of renal services; the Registry has also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

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

### ***New methods of commissioning renal services***

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

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



**Figure 2.2: Map of new StHAs**

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

### ***The Registry and clinical governance***

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

## ***Anonymity and confidentiality***

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

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

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

Where anonymity has been retained in the report, neither the Chairman of the Registry nor the Sub-committee members are aware of the identity of the centres within the analysis; only the Renal Registry director, data manager and statistician are able to identify the centres. This identification is necessary so that any issues raised, and discrepancies in the analysis, can be discussed with the relevant centre.

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

## ***Interpretation of the data within the report***

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

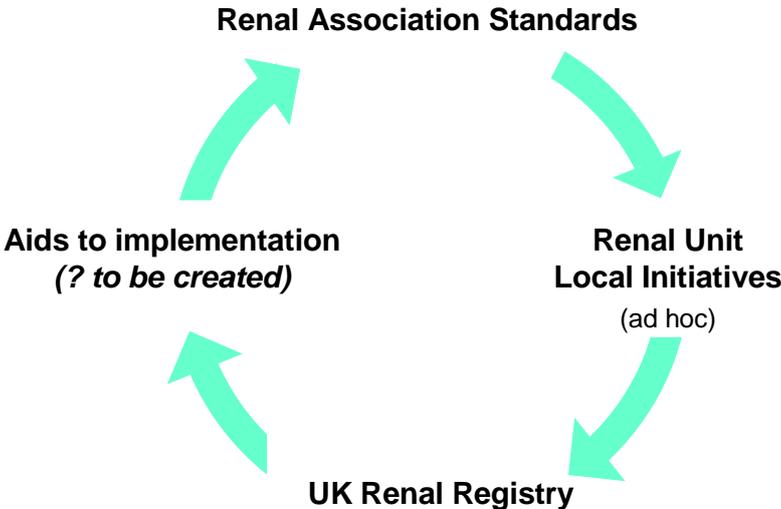
As in last year's report, the 95% confidence interval is shown for compliance with a Standard. The calculation of this confidence interval (based on the Poisson distribution), and the width of the confidence interval, depends on the number of patients within the Standard and the number of patients with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

To assess whether there is an overall significant difference in the percentage reaching the Standard between centres, a chi squared test has been used. Caution should be used when interpreting ‘no overlap’ of 95% confidence intervals between centres in these presentations. When comparing data between many centres, it is not necessarily correct to conclude that two centres are significantly different if their 95% confidence intervals do not overlap. In this process, the eye compares centre X with the other 40 centres and then centre Y with the other 39 centres. Thus, 79 comparisons have been made, and in any comparison at least four are likely to be ‘statistically significant’ by chance at the commonly accepted 1 in 20 level. If 41 centres were compared with each other, 860 individual comparisons would be made, and one would expect to find 42 ‘statistically significant’ differences. Thus, if the units with the highest and lowest achievement of a standard are selected and compared, it is probable that a ‘statistically significant result’ will be obtained. Such comparisons of units selected after reviewing the data are invalid in statistical terms. The Registry has therefore not tested for ‘significant difference’ between the highest achiever of a standard and the lowest achiever as these centres were not identifiable in advance of looking at the data.

The most appropriate way of testing for significance between individual centres to see where the differences lie is not clear. The commonly used Bonferroni test is not applicable to this kind of data as the individual comparisons are not independent. The Registry is investigating the most appropriate methods of performing such comparisons.

**Integration with the audit cycle**

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



**Figure 2.3: Renal Registry audit cycle**

With the presentation of these Registry data to the renal community, the challenge to nephrologists is to find effective and creative ways of using the data in the implementation part of the cycle in order to improve clinical practice. As yet, not all the necessary formal structures are in place to allow full value to be derived from the opportunities presented by the Registry data. The Renal Association is currently considering structures to use the Registry data to facilitate closing the audit loop.

## ***Future potential***

### ***National Service Framework***

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

### ***Scientific studies***

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

### ***Pre-'end-stage renal failure' cohorts***

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

### ***A move towards explanation***

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

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

## ***Distribution of the Registry Report***

The Renal Association has made a grant towards meeting part of the cost of the report so that it can be distributed to all members of the Association. The report will also be distributed to StHAs and all PCTs in England and Commissioners throughout the UK.

Further copies of the report will be sent to individuals or organisations on request: a donation towards the £12 cost of printing and postage would be appreciated

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