

## Chapter 2: Introduction to the 1999 report

### *Introduction*

The primary intention of the UK Renal Registry is to carefully monitor the quantity and quality of renal care in the UK, and thus to improve the quality and efficiency of this care. This report is provided to facilitate that process. It will enable internal audit within renal centres, support comparative audit, and provide information to stimulate and inform the process of improving protocols of care.

The UK Renal Registry is part of the pioneering work of the Renal Association in support of clinical governance. The process was initiated by the Renal Association with the publication of the document on “recommended standards and audit measures for the treatment of adults with renal care”. The audit and research work of the registry is essential for closing the audit loop and implementing those recommendations.

The 1999 UK Renal Registry report refers to activity in 1998 and covers 43% of the UK adult population. Many more renal units have joined the Registry since then. In total 31 Renal Units have contributed to the report, including all 12 Units in Scotland and 19 of the 63 Units (30 %) in England and Wales (Table 2.1). The English and Welsh units cover 38% of the population of 52.2 million.

	<b>Included in the Renal Registry</b>		
	<b>England &amp; Wales</b>	<b>Scotland</b>	<b>Total</b>
No. of units	19	12	31
No. of patients (31/12/99)	10,510	2,956	13,466
Population (m)	19.9 (of 52.2m)	5.1	25.0
Patients (pmp)	528	580	539
Patients per unit	553	246	434

**Table 2.1 Summary of adult patients registered and total population covered**

The participating centres are listed in Table 2.2; the areas represented are shown in Figure 2.1.

<b>England &amp; Wales</b>	<b>Total</b>	<b>Population (millions)</b>
		<b>19.9</b>
Birmingham	Heartlands Hospital	.60
Bristol	Southmead Hospital	1.50
Carlisle	Cumberland Infirmary	.32
Carshalton	St Helier Hospital	1.80
Cardiff	University of Wales Hospital	1.30
Coventry	Walsgrave Hospital	.85
Exeter	Royal Devon and Exeter Hospital	.85
Gloucester	Gloucester Royal Hospital	.55
Hull	Hull Royal Infirmary	1.02
Leeds	St James’s Hospital	1.45

Leicester	Leicester General Hospital	1.80
Middlesborough	South Cleveland Hospital	1.00
Nottingham	Nottingham City Hospital	.86
Oxford	Churchill Hospital	1.80
Plymouth	Derriford Hospital	.45
Sheffield	Northern General Hospital	1.75
Stevenage	Lister Hospital	1.25
Sunderland	Sunderland Royal Hospital	.34
Wordsley	Stourbridge Hospital	.42
<b>Scotland</b>		<b>Total 5.10</b>
Aberdeen	Aberdeen Royal Infirmary	
Airdrie	Monklands District General Hospital	
Dunfermline	Queen Margaret Hospital	
Dumfries	Dumfries & Galloway Royal Infirmary	
Dundee	Ninewells Hospital	
Edinburgh	Royal Infirmary	
Glasgow	Glasgow Royal Infirmary	
	Stobhill General Hospital	
	Western Infirmary	
Kilmarnock	Crosshouse Hospital	
Inverness	Raigmore Hospital	

**Table 2.2 Participating adult centres**

Most of this report concerns adults on renal replacement therapy. All the paediatric renal units in the country participate in a paediatric registry which is linked with the adult registry. A separate paediatric chapter is included.

The following centres have since joined the Registry, or are in the process of doing so.

Bradford	Bradford Royal Infirmary	.60
Liverpool	Royal Infirmary	1.75
London	Guys and St Thomas Hospital	
London	Kings College Hospital	.81
London	St Mary's Hospital	.64
Leeds	Leeds General Infirmary	.75
Preston	Royal Preston Hospital	.95
Portsmouth		2.00
Rhyl		
Southend		.35
Swansea	Morrison Hospital	1.00
Wolverhampton	Newcross Hospital	
Wrexham	Maelor General Hospital	.32
York		.25

**Tables 2.3 New units joining the Registry**

The catchment populations quoted are estimates provided by each individual unit, and only include areas for which a total renal replacement therapy service is provided. For the transplant units providing a transplant service to other renal units the additional transplant population is not included in the population served. As the Registry grows and covers large contiguous areas, errors due to cross-boundary flow of patients will become insignificant. It will then be possible to estimate prevalence and incidence of

renal replacement therapy by geographical areas, such as Health Authorities, using postcodes of individual patients.

It is difficult to estimate the growth of the UK renal replacement therapy program. Some indication is given by the fact that at the end of 1997 the Registry had data from 9 units, all in England, on 5,057 live patients. In the subsequent 12 months the number of patients receiving all forms of renal replacement therapy in these units has increased by 5.6 %.

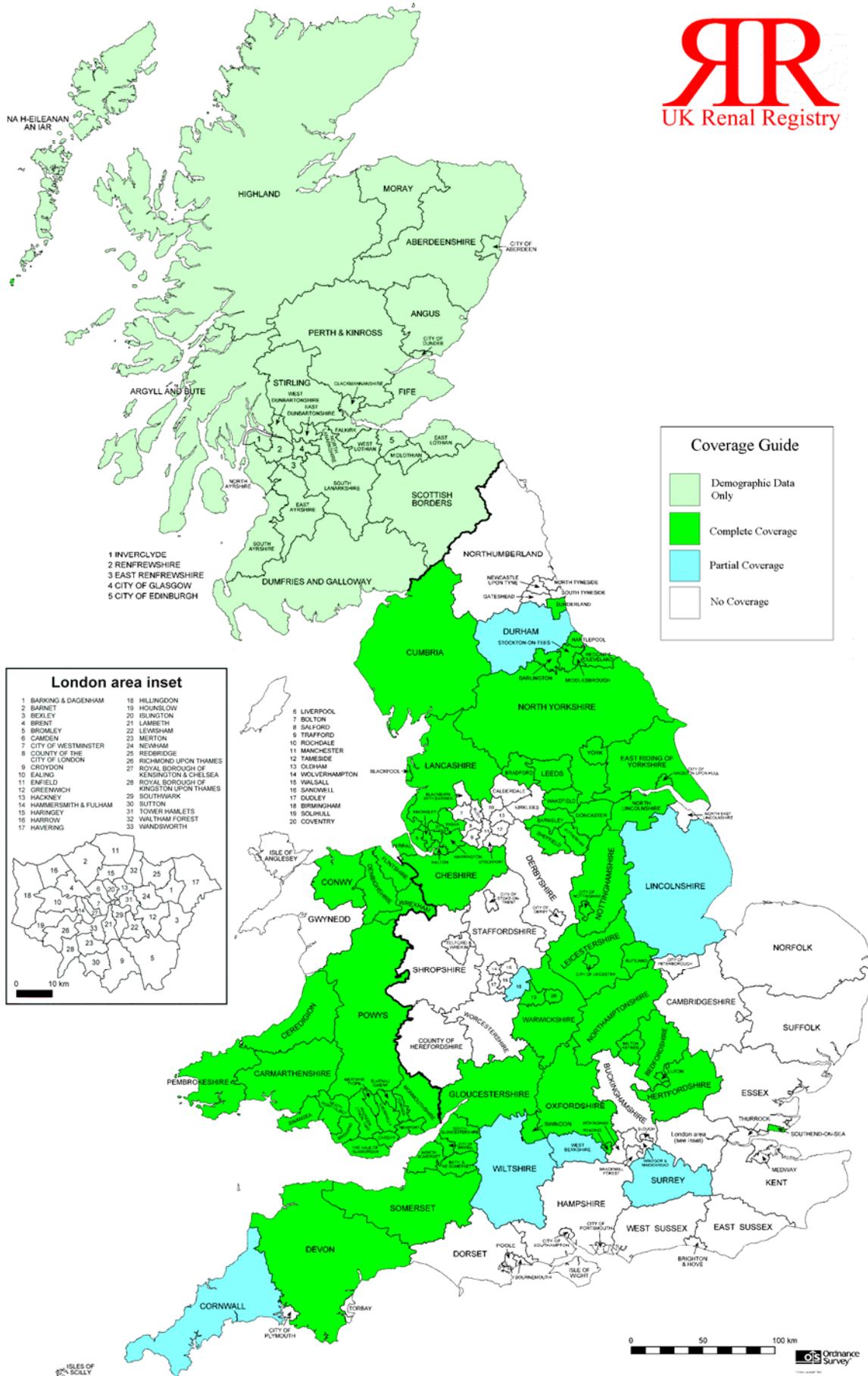


Figure 2.1 Geographical location of Units contributing to the Renal Registry

## ***Recommended Standards of renal care and the Renal Registry***

The UK Renal Association, together with the Royal College of Physicians of London, has produced a comprehensive document of recommended standards and audit measures for the treatment of adult patients with renal failure. Much of this report will assess compliance with these standards and guidelines.

Many national and regional renal registries provide data on the acceptance of patients for renal replacement therapy, the stock of patients, treatment modalities and survival. The unusual feature of the UK Registry is the collection of sequential quarterly data on all patients related to the quality of care. Such data include adequacy of dialysis, haemoglobin, blood pressure, and many biochemical variables such as serum albumin, phosphate and cholesterol. It is the collection of this data which allows audit against the national recommended standards.

### ***The UK Renal Registry***

The UK Renal Registry was established by the Renal Association, with support from the Department of Health, the British Association for Paediatric Nephrology, and the British Transplantation Society. It has close links with the Scottish Renal Registry.

The initial development of the Registry was financed by grants from the Department of Health and from industry. Continuing activity is largely funded through payment by participating renal units of an annual fee per patient registered. In this way the Registry will be able to remain an independent source of data and analysis on national activity in renal disease.

Participation in the Renal Registry is voluntary but the expectation is that all United Kingdom renal and transplant units will ultimately take advantage of the opportunities offered by the Renal Registry database. Ability to participate could be limited by the individual centre's information technology and data quality.

A more full explanation of the Registry is contained in the document 'The Registry Rationale' in Appendix A.

### ***Anonymity and confidentiality***

Centre anonymity has been carefully maintained, in accordance with the wishes of some participants. Neither the Chairman of the Registry nor the subcommittee 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.

It may be possible to identify a centre by the number of patients; for this reason throughout this report the analyses which compare centres do not show actual numbers of patients in each centre.

## ***Outline of Report***

This report will concentrate on the following areas :-

1. Analysis of new patients and all other patients receiving renal replacement therapy, and their short term survival
2. A comparison of adequacy of haemodialysis, using urea reduction ratio.
3. Analysis of haemoglobin, serum ferritin, and use of erythropoietin, including analysis of sequential changes in individuals
4. Analysis of biochemical indicators of quality of care
5. Blood pressure control
6. Renal transplantation
7. Paediatric renal replacement therapy
8. A summary of comparative standards of care measured against the Renal Associations Standards Document.

## ***Statistical Interpretation of the Report***

In this years report the 95% confidence interval is shown for compliance within a Standard. Calculation of this confidence interval takes into account the number of patients within the Standard and the number of patients with data. The 95% confidence interval provides an indication of how the result might vary if the measurement was repeated a short time later, or if patients with missing data were included.

Although the results have been ranked according to their achievement of the Standard, the 95% confidence interval indicates that their positions may vary if the measurement was repeated or patients with missing data included. It is possible to provide the 95% confidence interval on prediction of the rank order for each centre, though this has not been included this year.

To assess whether there is overall significant variation among 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 interval between centres in the 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 18 centres and then centre Y with the other 17 centres. Thus 35 comparisons have been made and if using a hypothesis test at least 2 are likely to be “statistically significant” by chance, at the commonly accepted 1 in 20 level. If 19 centres were compared with one another, then 171 individual comparisons would be made, and one would expect to find 9 “statistically significant” differences. To test for significance between individual centres to see where the differences lie would require multiple testing in this way and therefore was not performed by the Registry.

In addition, the Registry has not tested for significant difference between the highest achiever of the Standard and the lowest achiever, as these centres were not known in advance of looking at the data, which then invalidates the test.

## **References**

Essential references have been included at the end of each chapter of this report.

## **Distribution of Report**

The Renal Association has made a grant towards part of the report cost to allow distribution to all members of the Association. The report will also be distributed to Health Authorities.

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

The full report will also appear on the Registry web site – [\*www.renalreg.com\*](http://www.renalreg.com)