

Chapter 2: Introduction to the 2000 report

Introduction

The role of a clinical Registry may seem self-evident. The aggregation, analysis and presentation of information about any discipline have obvious benefits in enlarging scientific and technical understanding, demonstrating trends in management, and supporting planning and development. Historically, it also acts as a powerful mirror, to reflect the development of a Speciality. However, demographic trends develop only slowly, data change little from year to year, and lose interest to clinicians. In addition, improved IT now allows data analysis at Unit level. The interests of clinicians have broadened, to include the delivery of health care and quality assurance of clinical outcomes, and they want more from data collection and analysis. There is thus a need to re-assess the role of a Renal Registry. It is important to look for some 'added-value' for reported data, so as to reward and sustain the effort of data collection and transmission. It is appropriate to restate the potential value from the Renal Registry activity.

Demographic data collection. This data is still of vital importance for informed planning, prediction, purchasing decisions and contracting. In addition to standard estimates of acceptance rates, death rates transplant rates, etc., the large volumes of data in the Renal Registry allow more detailed analysis. Important examples for planning include the study of initial modalities of treatment and transfers of modality as discussed in chapter 4. Another example is the analysis of transplant failures, the subsequent modality of such patients, and the influence of this on haemodialysis demand as described in chapter 5 and 11.

Survival analysis. The large numbers of patients on the Registry allow stratification by age, gender, and diagnosis. Survival of populations can then be adjusted to a standard age and diagnosis mix. This permits some comparison of survival between renal units, presented here for the first time.

Clinical practice and survival. Standard adjustment of risk factors, together with the quarterly serial collection of intermediate markers of clinical outcome from all individuals on the Renal Registry, facilitate analysis of factors which may influence survival, such as haemoglobin concentration, serum phosphate control, blood pressure control. This will inform units where to focus their clinical activity to best advantage. Several such analyses are presented in this report

Audit and Quality Assurance. A major current issue is the quality assurance (QA) of clinical outcomes and the performance of Renal Units in clinical and cost effectiveness. With the collection of serial clinical data the Registry is in a unique position to contribute to such clinical and comparative audit.

The UKRR relies on large numbers (fifteen thousand patients) to achieve a rapid publication of 'good enough' material, sufficient at least to generate hypotheses, raise questions and display current trends. Experience has confirmed the practicality of near complete data capture on large patient numbers, with presentation as distributions that vary widely in absolute terms but, as is demonstrated in this report, that also show an impressive uniformity of range/dispersion. Distributions are generally stable unless a major effort has been made to influence clinical outcomes. The data are able to confirm improvement or deterioration

against a backdrop of random variation. They indicate the necessary scope of changes required to meet official standards and demonstrate de facto compliance or the possibility of compliance. They illustrate the gaps between desirable and achieved outcomes and indicate the likely cost and effort of bridging them.

UK Renal Registry focus on individuals. The need for the clinician to maintain a focus on the individual as well as the cohort is important to recognise in Registry work as well as in clinical practice. Serial data analysis of individuals may show marked oscillation of results, as demonstrated in the haemoglobin data, when the cohort may be apparently stable. The individual’s position in the cohort a diagnostic tool able to reveal otherwise covert needs for clinical attention.

Difficulties

There are difficulties. The UKRR data are of uncertain quality for Unit comparison because laboratory harmonisation is incomplete. Correction of values like serum calcium is controversial. Further exercises to validate the data collected are needed. More work is necessary to improve these issues, but at least the problems have been rendered apparent. The ‘maturity’ of Renal Unit patient cohorts must also vary, so that in most cases current data are indicative rather than definitive for comparative purposes. Data protection rules may yet threaten the exercise. Having said all of that, the comparison of different Units opens up the area of QA and prepares the ground for improvement.

Integration with the audit cycle.

The UK Renal Registry is part of the renal audit cycle as shown. With the presentation of this registry data to the renal community, the challenge to nephrologists is to find effective and creative ways to use the data in the implementation part of the cycle, in order to improve clinical practice

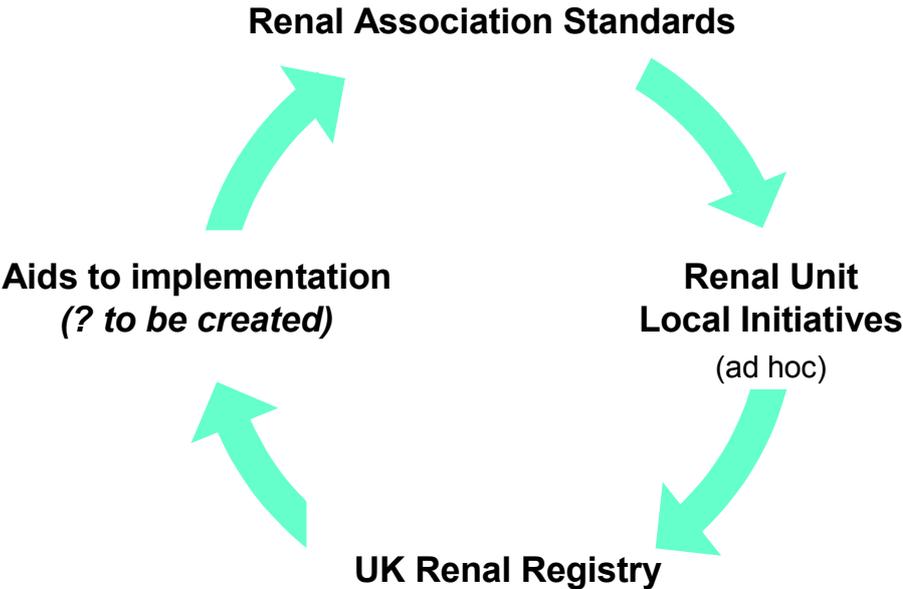


Figure 2.1 Renal Registry audit cycle

Area covered by the Renal Registry.

The 2000 UK Renal Registry report refers to activity in 1999 and covers 47% of the UK adult population, and all paediatric renal replacement activity. In total 35 renal units have contributed to the report, including all 11 adult renal units in Scotland and 23 of the 63 Units (37 %) in England and Wales (Table 2.1). The English and Welsh units cover 43% of the population of 52.2 million.

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

England & Wales		Population (millions)
	Total	22.5
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
Middlesbrough	South Cleveland Hospital	1.00
Nottingham	Nottingham City Hospital	.86
Oxford	Churchill Hospital	1.80
Plymouth	Derriford Hospital	.45
Preston	Royal Preston Hospital	1.6
Sheffield	Northern General Hospital	1.75
Stevenage	Lister Hospital	1.25
Stourbridge	Wordsley Hospital	.42
Southend	Southend Hospital	.35
Sunderland	Sunderland Royal Hospital	.34
Wolverhampton	Newcross Hospital	.35
Wrexham	Maelor General Hospital	.32
Scotland	Total	5.10
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 2.1 Participating adult centres

The 12 renal units in Table 2.2 have already joined the Registry (software completed) and a further 7 indicated in Table 2.3 are in the process of joining

Bradford	Bradford Royal Infirmary	.60
Canterbury	Kent and Canterbury -Velos system	
Liverpool	Royal Infirmary	1.75
Leeds	Leeds General Infirmary	.75
London	Guys and St Thomas Hospital	
London	St Mary's Hospital	.64
Portsmouth	St Mary's Hospital	2.00
Reading	Royal Berkshire Hospital	
Rhyl	Ysbyty Clwyd (via Liverpool)	
Swansea	Morrison hospital	.70
Truro	Royal Cornwall Hospital	
York	York District Hospital	.25

Tables 2.2 New units joined the Registry since the Report

The following centres are in the process of being connected

Bangor	Ysbyty Gwynedd -Baxter system	
Ipswich	Ipswich Hospital -Baxter system	
Derby	Derby City Hospital	
London	Kings College Hospital (own system)	.81
London	Royal Free (own system)	
London	St Georges (own system)	
Newcastle	New CCL system	

Tables 2.3 Renal 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.

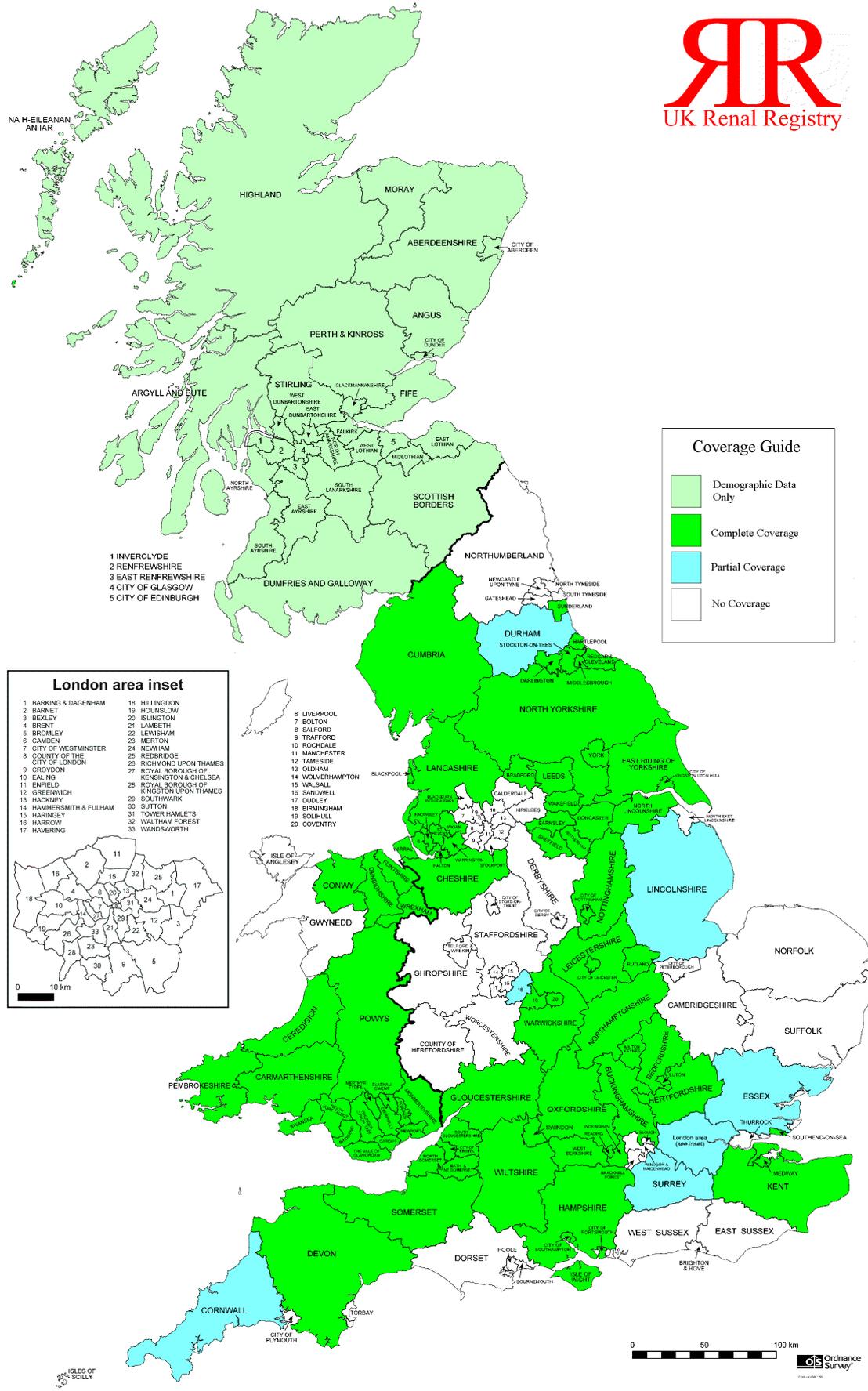


Figure 2.2 Coverage of the Renal Registry

The independence of the UK Renal Registry

The UK Renal Registry is managed by a sub-committee of the Renal Association. The Renal Association established the UK Renal Registry, with support from the Department of Health, the British Association for Paediatric Nephrology, and the British Transplantation Society. Each of these organisations has representatives on the Registry sub-committee. The Registry 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. The Department of Health and Industry continue to give additional generous support.

Participation in the Renal Registry is voluntary but the expectation is that all United Kingdom renal and transplant units will ultimately join. 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

It is the wish of some participating centres that centre anonymity is maintained. 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 treated there; for this reason throughout this report the analyses which compare centres do not show actual numbers of patients in each centre.

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.

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 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 interval 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 in any comparison 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

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: 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***