

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
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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 (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.

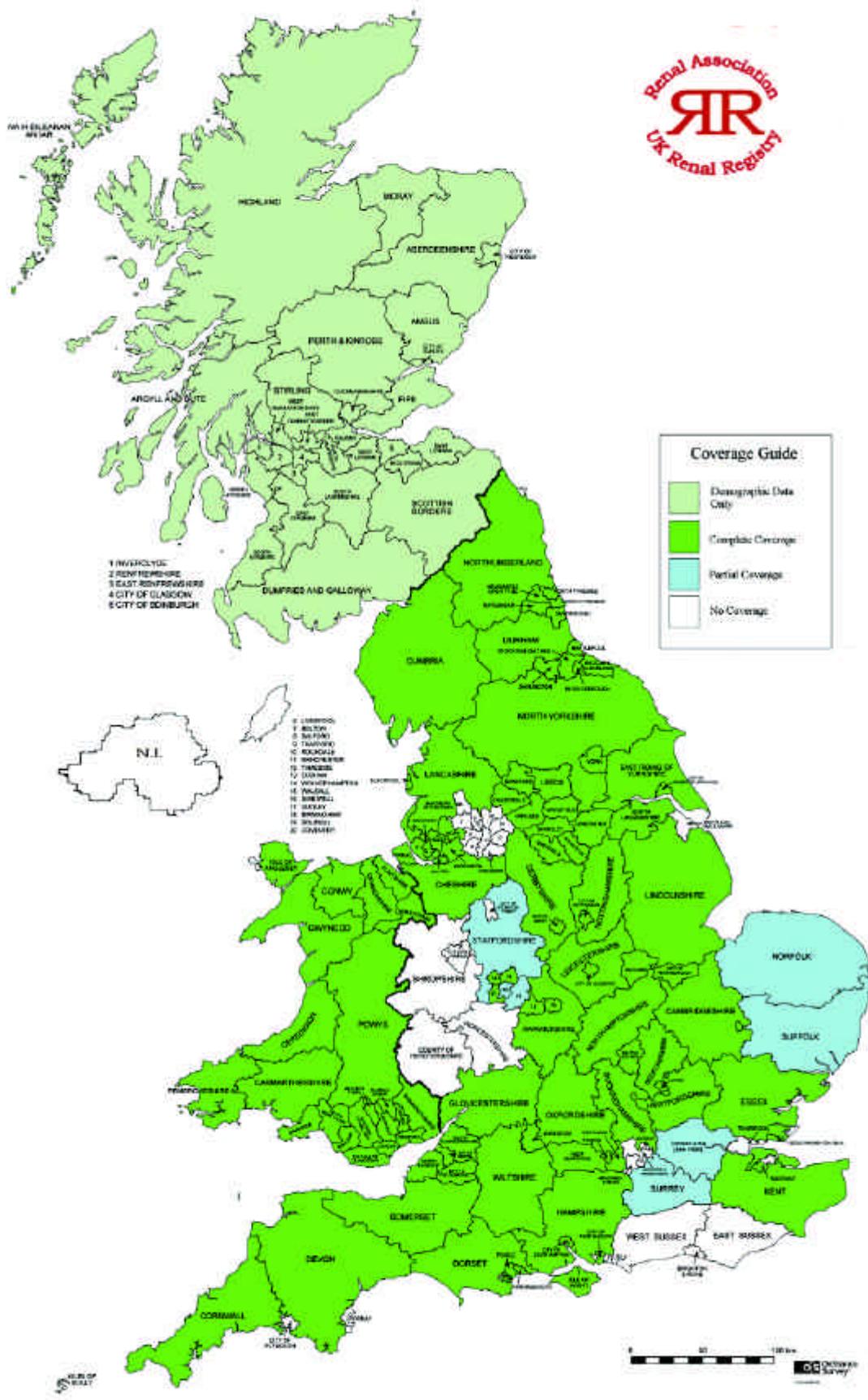


Figure 2.1: Areas covered by the Renal Registry

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 (Russell's Hall Hospital, Dudley)	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 (Mediqual)	0.50
Birmingham	Queen Elizabeth Hospital (own system)	1.82
Brighton	Royal Sussex County Hospital– (CCL Windows)	0.98
Chelmsford	Broomfield Hospital (Mediqual)	0.50
Dorset	Dorchester Hospital (Mediqual)	0.71
London	Barts/Royal London (King’s system)	1.79
Shrewsbury	Royal Shrewsbury Hospital (Renalplus system)	0.40
Norwich	James Paget Hospital (Mediqual 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 (Mediqual 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 <15 mls/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

References

1. Tu JV, Willison DJ, Silver FL, Fang J, Richards JA, Laupacis A, Kapral MK; Impracticability of informed consent in the Registry of the Canadian Stroke Network. *N Engl J Med.* 2004 Apr 1;350(14):1414–21.
2. McKinney PA, Jones S, Parslow R, Davey N, Darowski M, Chaudhry B, Stack C, Parry G, Draper ES; A feasibility study of signed consent for the collection of patient identifiable information for a national paediatric clinical audit database. *BMJ.* 2005 Apr 16; 330(7496):877–9.