

Chapter 2: Introduction to the 2001 Report

Although this 2001 Renal Registry report is somewhat smaller than its immediate predecessor, it does contain the same basic data, from an increased number of renal units. The data are presented in a form to make it comparable with earlier reports. There is less commentary related to much of the core data, as the comments from last year remain valid for these data. There are also fewer chapters concerning activity somewhat peripheral to core Registry activity.

For the first time in this report, data are presented on acceptance rates for treatment by health authority. There are two other important additions. Chapter 3 contains details of the recently completed survey of satellite dialysis units in the UK, which was supported by the Renal Registry. Chapter 9 contains detailed statistical analysis not available before, on the survival of both incident and prevalent patients. Since 1999, there has been an improvement in reporting of data concerning ethnic origin and morbidity, although these areas still remain major concerns for the Registry.

This report on data from the year 2000 contains data from six renal units not previously included in the Renal Registry. During the year 2001 there has been a marked increase in the rate of new units joining the Renal Registry and there are now only 8 of the 75 renal units in the United Kingdom who are not linked to the Registry or in the process of being linked. These remaining 8 units are all in discussion with the Registry, and hope to join when once they have adequate electronic patient information systems.

Area covered by the Renal Registry.

The 2001 UK Renal Registry report refers to activity in 2000 and covers 54% of the UK adult population. In total 28 of the 63 adult units (45 %) in England and Wales (Table 2.1) have contributed to the report. The English and Welsh units cover 51% of the population of 52.2 million. One centre in England, included in the previous year's report, did not manage to submit all its data in time to be included in this report.

Although the 11 adult renal units in Scotland had submitted all their 2000 data to the Scottish Registry, due to a technical problem it was not possible to transfer the 2000 incident patient data, to the UK Registry in time for this report. It has though been possible to analyse the survival of the 1999 incident cohort from Scotland and also the prevalent cohort alive on 1st January 2000.

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

Centres in the 2001 Registry report

		Estimated Population (millions)
England & Wales		
Birmingham	Heartlands Hospital	.60
Bristol	Southmead Hospital	1.50
Cardiff	University of Wales Hospital	1.30
Carlisle	Cumberland Infirmary	.36
Carshalton	St Helier Hospital	1.80
Coventry	Walsgrave Hospital	.85
*Derby	Derby City Hospital	.48
Exeter	Royal Devon and Exeter Hospital	.75
Gloucester	Gloucester Royal Hospital	.55
Hull	Hull Royal Infirmary	1.02
*Leeds	Leeds General Infirmary	.90
Leeds	St James's Hospital	1.30
Leicester	Leicester General Hospital	1.80
*London	Guys and St Thomas Hospital	1.70
Middlesborough	South Cleveland Hospital	1.00
Nottingham	Nottingham City Hospital	1.16
Oxford	Churchill Hospital	1.80
Plymouth	Derriford Hospital	.55
Preston	Royal Preston Hospital	1.56
*Reading	Royal Berkshire Hospital	.60
Sheffield	Northern General Hospital	1.75
Southend	Southend Hospital	.35
Sunderland	Sunderland Royal Hospital	.34
*Swansea	Morrison hospital	.70
Wolverhampton	Newcross Hospital	.49
Wordsley	Stourbridge Hospital	.42
Wrexham	Maelor General Hospital	.42
*York	York District Hospital	.39
Total		26.44

* - these units are reported by the Registry for the first time

All the above renal units in England & Wales run the CCL proton software.

		Estimated Population (millions)
Scotland		
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	
Total		5.10

Centres recently joined the Registry

The following renal units 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.

	(indicates IT system used by hospital)	Estimated Population (millions)
Basildon	(Mediqal)	
Bradford	Bradford Royal Infirmary –(proton)	.60
Cambridge	Addenbrookes Hospital –(proton)	1.42
Liverpool	Royal Infirmary –(proton)	1.75
London	Kings College Hospital (Filemaker Pro own system)	1.01
London	St Mary’s Hospital –(proton)	.81
Newcastle	(New CCL Windows system)	1.31
Portsmouth	St Mary’s Hospital –(proton)	2.00
Rhyl	Ysbyty Clwyd (via Liverpool)	
Stevenage	Lister (was on previously but developed new system)	1.25
Truro	Royal Cornwall Hospital (proton)	.36
Wirral	Arrowe Park Hospital (proton)	

Centres in the process of joining the Registry

Work is in progress to connect the following centres to the Registry.

	(indicates IT system used by hospital)	Estimated Population (millions)
Bangor	Ysbyty Gwynedd –(Baxter system)	
Birmingham	Queen Elizabeth Hospital – (own system)	1.82
Dorset	Dorchester Hospital - (Mediqal)	.60
Ipswich	Ipswich Hospital –(Baxter system)	.33
Canterbury	Kent & Canterbury – (Velos system)	.91
London	Hammersmith + Charring Cross - (Own system)	1.3
London	Royal Free –(King’s system)	.67
London	Royal London – (King’s system)	
Manchester -Hope	Hope Hospital - (EDS hospital system)	
Norwich	Norfolk & Norwich Hospital –(Mediqal)	.84

Centres in discussion with the Registry

All the remaining renal units have made contact with the Registry and are considering how to facilitate joining. These are:

		Estimated Population (millions)
Northern Ireland	Belfast + 3 renal units – (Mediqual system)	
Brighton	(Buying new system)	.98
Chelmsford	Broomfield Hospital (Buying new system)	
London	St George’s – (Own system)	
Manchester –Royal	(Buying new system)	
Middlesex /UCLH	(Infoflex system – not adequate for Registry)	1.40
Shrewsbury	(Joining Bristol’s proton system)	
Stoke	(Buying Cybernius - new Canadian system)	.70

Software and links to the Registry

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

From the above lists 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 provide appropriate software links to the Registry.

In addition, the Lister renal unit in Stevenage has developed an in-house system, which 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

In the UK there are an estimated 750 patients aged under 18 on renal replacement therapy. As most of the 11 UK paediatric renal units are small, the British Association of Paediatric Nephrology (BAPN) was able to set up its own database to collect data. The last 2 UK Registry Reports have included a chapter of analyses from these data.

The paediatric registry has had difficulties with analysis of the paediatric data, and more recently with collection of data. There is a lack of direct funding of manpower resources to run the Paediatric Registry. Another problem has been the variable transfer of patients aged 15- 18 to adult units. 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 to collect this paediatric data. The Registry has obtained a grant from the English Department of Health to help automate data collection from the paediatric renal units, and will progress with this in 2002.

Anonymity and confidentiality

There is considerable pressure for the Renal Registry to cease reporting centres anonymously. Removal of anonymity would not only aid the development of comparative audit and assist learning from best practice, but also would also assure public accountability. This has been discussed in the Renal Registry Committee and at the Renal Association Executive Committee, with both in agreement of the importance of structuring a timescale for removal of anonymity. After consultation with the participating renal units, a phased programme towards removal of anonymity was agreed. This year the incidence and prevalence data in chapters 4 and 5 are identified by named renal unit. This move has been aided by the introduction of software enabling allocation of patient postcodes to health authorities, which have known population demographics. This provides more accurate incidence and prevalence rates than the estimated renal unit catchment populations provided by the units themselves. In subsequent reports there will be phased removal of anonymity from data related to the indicators of quality of care, such as KT/V, haemoglobin, serum phosphate.

Meaningful comparison of outcomes between renal units requires the ability to correct for case-mix. The co-morbidity data available to the Registry is not yet adequate for this. There also needs to be better standardisation of the definitions and coding of acute renal failure and endstage renal failure. Investigation by the Registry has shown that apparently high 90-day death rates in some units are due to inclusion of patients with acute renal failure. Until robust data are available that will permit correction for case-mix, the Registry wishes to maintain anonymity for outcome statistics.

Where anonymity has been retained in the Report, 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.

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

New methods of Commissioning Renal Services

In April 2002 the existing 95 Health Authorities in England will be reformed as 28 Strategic Health Authorities (StHAs). The proposed new boundaries and a list of the StHAs are shown below.

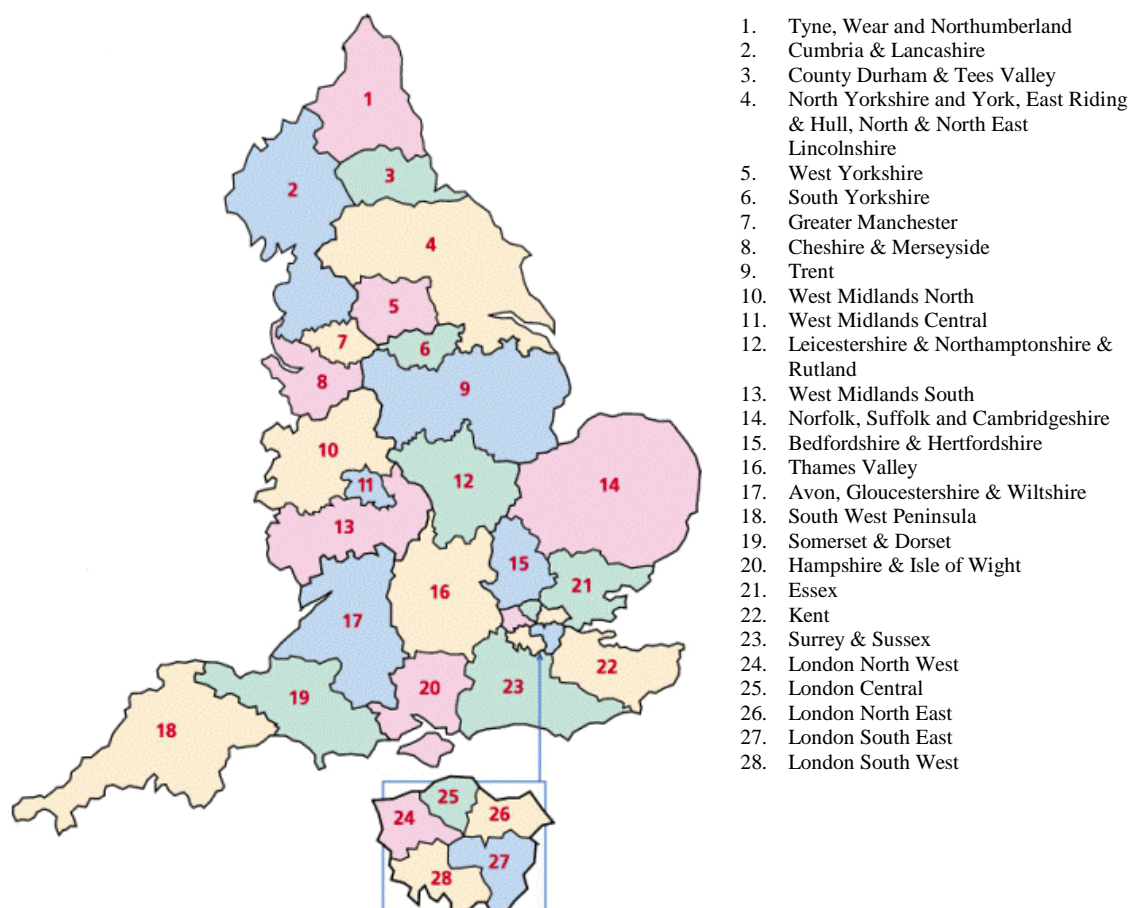


Figure 2.1 Map of new Strategic Health Authorities

Within this rearrangement is the devolvement of power to primary care trusts (PCTs). It was initially stated that these "will take responsibility for securing the full range of services for their local populations".

Since the consultation process, which started in mid 2001, there has been a considerable change in the wording of these proposals. The tertiary services that must be contracted for through a PCT consortium have now been defined in a 'National Specialised Services Definitions Set', and include renal services.

The following paragraph has been copied from the DOH document:- 'HARevenueResourceLimits2002-2003Annex8.doc' 28 November 2001

PCTs will work in consortia to ensure that specialised services (as defined in the National Specialised Services Definitions Set) continue to be effectively commissioned at StHA and supra StHA levels. The NHS must ensure that local arrangements maintain service continuity and allow co-ordinated service development, where appropriate, on a national scale. PCTs will be financially bound and organisationally committed to the decisions made through these

consortia. PCTs must honour existing agreements (financial and otherwise) negotiated by Regional Specialised Commissioning Groups and current specialised service commissioners.

In 2002-03, Regional Specialised Commissioning Groups (RSCGs) will have a specific role in developing PCT capacity to commission specialised services as part of a planned transition to successor arrangements. Ensuring that enough people with the right skills continue in their roles is particularly important in the context of specialised services

It is envisaged that StHAs will have a role in monitoring the performance of the specialised commissioning consortia.

The services included in the National Specialised Services Definitions Set can be found on the DOH website at: <http://www.doh.gov.uk/specialisedservicesdefinitions>

Renal Services definition

This definition of renal services has been copied from the above website.

Renal Services have been a national priority since 1993 when the National Renal Review was set up. In February 2000 the Department of Health announced that a Renal National Service Framework (NSF) would be developed. When the renal NSF is published, it will be the key reference document for commissioning renal services. This definition will therefore be updated at that stage to ensure consistency with the renal NSF. It is not anticipated that there will be any change in the identification of renal services as specialised services that require collective commissioning arrangements.

All nephrology should be considered as specialised, including:

*Treatment for End Stage Renal Failure (ESRF)
Treatment for acute renal failure
General nephrology (provided in a main nephrology unit)
Renal related surgery*

Interpretation of the data within the report

We again state that 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. 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 overall significant difference of 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 4 are likely to be “statistically significant” by chance at the commonly accepted 1 in 20 level. If 41 centres were compared with one another, then 860 individual comparisons would be made, and one would expect to find 42 “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.

The Registry has not tested for “significant difference” between the highest achiever of the standard and the lowest achiever, as these centres were not identifiable in advance of looking at the data, which renders the comparison invalid in statistical terms.

Integration with the audit cycle.

The UK Renal Registry is part of a national renal audit cycle as shown. With the presentation of this Registry data to the renal community, the challenge to nephrologists and the developing National Service Framework is to find effective and creative ways to use the data in the implementation part of the cycle, in order to improve clinical practice. The Renal Registry is at the forefront of speciality-based national developments in quality assurance/improvement, and not all the necessary formal structures are yet in place to allow full value to be derived from this opportunity.

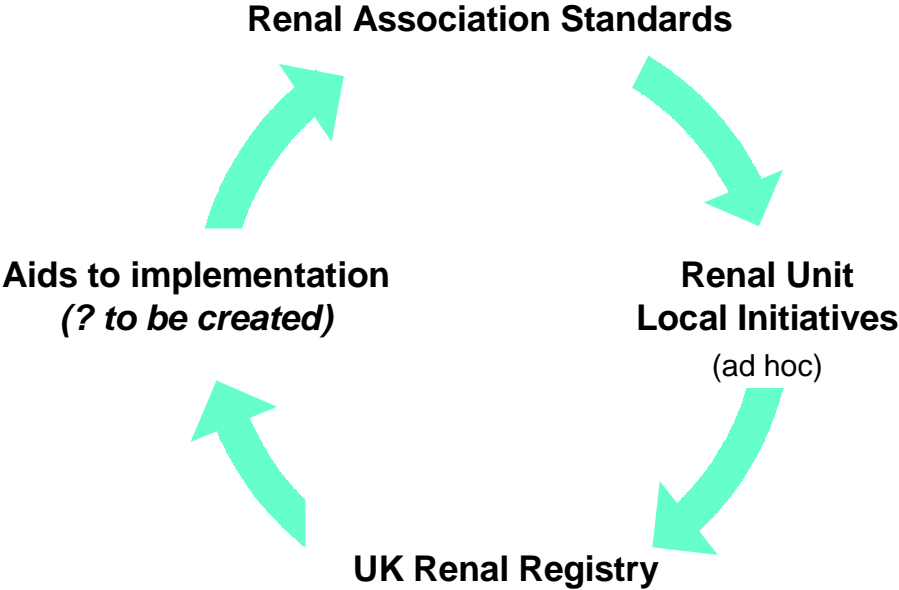


Figure 2.2 Renal Registry audit cycle

The Registry and Clinical Governance

There has been considerable debate within the Renal Association Trustee and Executive committees, and the Registry committee, about the Registry’s responsibilities under clinical governance, particularly if an individual renal unit appears to be under-performing in some areas of activity. . For apparently serious errors of under-performance, the Registry will

discuss this further with the renal unit and help check the validity of these data. The Registry Report is also sent to the Chief Executive of each 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 Trust's renal unit within the report. If, after such investigation, the problems persist, the Registry will recommend the renal unit seek an external peer review, and may need to inform the local commissioners.

Distribution of Report

The Renal Association has made a grant towards part of the report costs, 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

Future potential of the Registry

The Renal Registry has a unique data collection system with huge potential for the future. With almost complete coverage of the UK, the Registry is ideally situated to aid the implementation and monitoring of the National Service Framework.

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, and allowing easy addition of new data items, without requiring alterations 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 D.

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

