# Chapter 2 Introduction to the UK Renal Registry report of July 1998.

#### 2:1 Data included in the analysis

This is the first substantive report from the UK Renal Registry. It is an analysis and presentation of data from the 9 units who participated throughout the calendar year 1997. In addition data from 4 pilot units for the calendar year 1996 are also studied. Only the units from whom the Registry received a complete set of data for 1997 are included in the analysis. They are listed in table 2.1. Many units have joined subsequently and will be included in the next annual report. The time periods for analysis of quarterly data are listed in appendix C.

Birmingham	Heartlands Hospital
Bristol	Richard Bright Renal Unit, Southmead Hospital
Gloucester	Gloucester Royal Infirmary
Leeds	St James Hospital (excluding Leeds General
	Infirmary)
Leicester	Leicester General Hospital
Middlesborough	South Cleveland Hospital
Nottingham	Nottingham City Hospital
Plymouth	Derriford Hospital
Sheffield	Northern General Hospital

Table 2.1 Renal units included in the subsequent report

Inevitably a first report is somewhat limited. One year is an inadequate time to follow changes in sequential data. Even simple outcome measures such as one year or even three month survival necessitate follow-up of patients into the next calendar year. This has limited the number of analyses possible. This year's material will therefore be somewhat cross-sectional in nature; subsequent reports will be better able to analyse outcomes and trends and look in more detail at the determinants of various outcomes.

All the units who reported throughout 1997 were from England. Software has recently been written to extract data from the Scottish Renal Registry, but we are unable to incorporate this until permission has been obtained from all the Scottish renal units. Scottish data are therefore not included in this report, but it is intended to include them in the future. Welsh units are now joining the Registry, and it is also hoped to have data from Northern Ireland shortly.

Although over 7,000 patients are currently registered, with over 5,000 available for this report,. this is still a relatively small number for detailed analysis, especially if stratifying patients by age, diagnosis, co-morbidity etc. Much of this report will therefore be descriptive, with little interpretation. As the Registry develops more detailed statistical analysis and interpretation will be possible.

Co-morbidity data were not available for the new patients starting dialysis in 1997, but this information is now being collected for 1998 and will be included in the next annual report.

#### 2:2 Biochemical and haematological data.

Quarterly biochemical and haematological data is extracted from local renal unit systems as the last data items stored for that quarter. For haemodialysis patients the last pre-dialysis blood value is extracted.

For comparative audit of this data, the Renal Association, Renal Standards document has been referenced (reference 1)

In attempting to compare clinical performance indicators such as serum bicarbonate, calcium, phosphate etc. a potential problem became apparent. While data from an individual laboratory are both appropriate and valid for use within that hospital environment with the use of local reference ranges, the results for a sample analysed in a particular laboratory using one analytical method may differ significantly from that generated by another laboratory using the same or another method. Such variations make the interpretations of a national standard difficult. As renal units' performances are being assessed and compared against these standards, and compared with one another, it is important to understand the variations within laboratory data. This is dealt with in detail in chapter 5, with an explanation of the attempts of the Registry at harmonisation of data to allow comparison. Such harmonisation has not been previously reported in the literature.

In the presentation of haematological and biochemical clinical performance measures, clear reference is made to the national recommended standards.

## 2:3 Main areas of emphasis of the report

This report will concentrate on four main areas:-

- 1. Analysis of new patients and the stock of patients receiving treatment. Comparisons are made with available statistics from previous surveys, and published reports from the USA, Australasia and Scotland (Chapters 3 and 4).
- 2. The difficulties encountered in attempting to compare biochemical results from different laboratories. Chapter (5) reports on the harmonisation of laboratory results in order to allow valid comparisons..
- 3. A comparison of adequacy of haemodialysis using urea reduction ratio (chapter 7).
- 4. An analysis of data of relationship of haemoglobin, serum ferritin, and use of erythropoeitin (chapter 8)

The comparative audit of biochemical indicators of clinical performance is in chapter 6, and blood pressure in chapter 9.

#### 2:4 Anonymity and confidentiality

Centre anonymity has been carefully 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 co-ordinator, 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 units.

Whilst relatively few centres are participating in the Registry it may be possible to identify a centre by the number of patients it returns. For this reason throughout this report the analyses which compare units quote percentages and not actual numbers of patients.

#### 2:5 Statistical analysis

The Renal Registry employs a full-time biostatistician. All the analyses in the subsequent report have been performed using the SAS statistical package. In addition Microsoft Excel and Powerpoint have been used to produce graphs, illustrations, and tables

Non-parametric tests have been used, except where the data has been found to be normally distributed.

The cumulative frequency distribution graphs for the biochemistry and haematology data have been smoothed using a cubic spline algorithm (reference 2). This may result in a discrepancy between reading a figure from the graph and the figure listed in the comparable table.

### 2:6 Comparison with other available data.

Throughout this document five major sources of data for comparison are frequently quoted. Data from England and Wales in 1995 are from the recently published renal specialty survey (reference 3); data from England in 1993 are from the National Renal Review (reference 4); data from the USA are from the USRDS data report 1997 which contains data up to and including 1995 (references 5,6); data from Australia is from the Australian and New Zealand Registry report 1997 (reference 7); data from Scotland from an abstract of a presentation to the European Renal Association in June 1998 (reference 8) and a report in Nephrology Dialysis and Transplantation 1997 (reference 9); and data from Europe from the European Renal Association annual report on the management of renal failure in Europe,XXVIII,1997, which contains data from 1995 (reference 10).

## 2:7 Distribution of this report.

One copy of this report will be sent to all renal units in the United Kingdom. Copies will be widely available to interested parties, and can be purchased from the Renal Registry price £9.95

Each renal unit will be able to purchase a specific data report in which its own figures and performance will be clearly identifiable compared with the national figure.