

Chapter 1 Introduction To The UK Renal Registry

1:1 The purpose of the Renal Registry

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.

1:2 UK National Registries

The Department of Health has recognised the desirability of developing national registries which will identify the cost and effectiveness of both medical and surgical treatments. Within the United Kingdom registries have been planned and implemented in cardiac surgery, intensive care, and diabetes. A Renal Registry was initiated in Scotland in 1992. The data contained in these registries will be used for national comparative speciality audits and identification of good practice in patient care. This activity is especially important in high cost, low volume services such as renal replacement therapy.

1:3 The need for a Renal Registry

The number of patients in the UK who enter endstage renal failure (ESRF) and subsequently require renal replacement therapy (RRT) continues to grow. Renal replacement therapy consumes nearly 2% of the NHS budget at an approximate cost of £25,000 per patient per annum. This is forecast to rise towards 3% of the total NHS budget within five years.

At the last survey of renal services in England and Wales in 1995 (Ref 1) there were 23,115 patients undergoing renal replacement therapy. The numbers in England had risen by 3,900 since the National Review of 1993, an increase of 20%. Only 5,500 of these patients, less than 25%, were registered on the National Organ Matching waiting list for a renal transplant. It is clearly essential for the National Health Service that the quality and efficiency of a service which is both expensive and expanding rapidly is monitored carefully. Until 10 years ago some information useful for management of the service was collected and analysed by the European Dialysis and Transplant Association (EDTA) registry. This registry is based on paper returns and the data collected from the UK in recent years has not been sufficiently complete to be of great value. The data set collected is also small, with little clinical information of help in monitoring the processes of care.

1:4 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 in the treatment of adult patients with renal failure. The Renal Registry will act as a source of comparative data for audit of compliance with the standards.

The Registry Subcommittee will maintain close links with the Renal Association Standards Subcommittee to support the further development of the Standards document and to monitor implementation.

1:5 Summary of the 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 Transplant Society. It is intended to be a resource in the development of patient care in renal disease. The Registry provides a focus for the collection and analysis of standardised data relating to the incidence, clinical management and outcome of renal disease. It will thus act as a source of comparative data for audit/benchmarking, planning and research. The UK Renal Registry will monitor indicators of the quality as well as quantity of care, with the aim of improving the standard of care. There will be an early concentration on data concerning renal replacement therapy, including transplantation. At a later date there will be an extension to other forms of treatment of renal disease..

There are a number of renal registries abroad which provide data on the acceptance of patients for renal replacement therapy, the stock of patients, treatment modalities and survival. However the regular collection and analysis of biochemical and haematological information is a unique feature of the UK Registry. This has been attempted before by very few groups

Data will be collected quarterly by automatic downloading from renal unit databases. Reports will be published twice yearly to allow comparative audit of facilities, patient demographics, quality of care and outcome measures.

The Registry will provide data for participating renal units, NHS Trusts, district health authorities and regional offices. It will also be in a position to submit data to the EDTA Registry, and other registries, if requested. The development of the Registry will be open to influence by all interested parties including clinicians, trusts, primary care groups, district health and other commissioning authorities, and patients organisations.

The initial development of the Registry has been financed by grants from the Department of Health and from industry. However its continuing activity will have to be 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.

A more full explanation of the Registry is contained in the document ‘The Registry Rationale’ in Appendix A. The outline composition of the Renal Registry subcommittee is illustrated in Figure 1.1. A summary of the functions of the Renal Registry is contained in table 1.1

Functions of the UK Renal Registry
<ul style="list-style-type: none"> • To collect demographic and descriptive data for comparison of equity of care and planning of service development • To facilitate comparative audit by means of a carefully defined data set • To collect data on indicators of quality of care to facilitate: Audit of the effectiveness of care against recommended national standards Improved care by identification of good practice • To produce national and local outcome data, having regard to case mix • To be a resource for research studies

Table 1.1 Functions of the UK Renal Registry

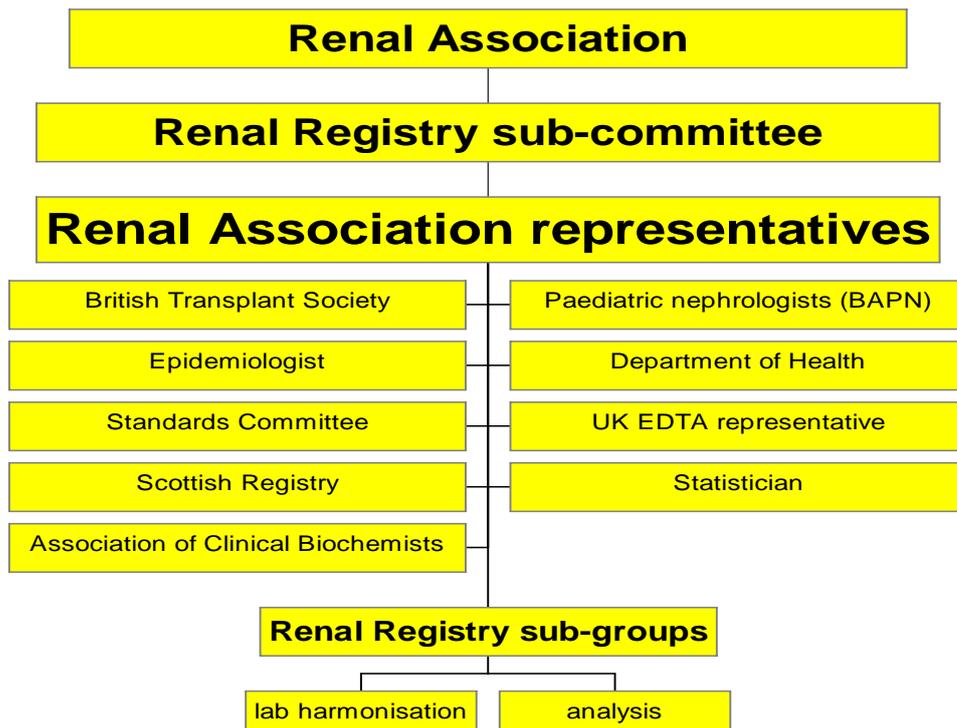


Figure 1.1 Composition of the Renal Registry Subcommittee

1:6 The question of nationwide participation in the Renal Registry

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 unit's information technology and data quality.

The ultimate aim is participation by all renal centres. Renal registries traditionally collect demographic data on patients receiving renal replacement therapy, giving information on acceptance rates, treatment types and patient characteristics. This needs a relatively small data set, often only 40 items, but demands countrywide coverage to be most useful. It allows the monitoring of trends, comparison between centres and countries, and planning. The Renal Registry will continuously evaluate the characteristics of the registered patients to check how representative they are of what is known of the country as a whole. It will also carry out simple surveys to collect demographic data from the whole of the UK.

To monitor indicators of quality of care and improve practice needs a large data set - the Registry is currently collecting 200 data items per patient quarterly, but does not need nationwide coverage. The data are useful as long as they are complete for each participating unit. The current database allows preliminary conclusions on national activity.

1:7 The development of the Renal Registry

A two year pilot project was started in April 1995. The first task of the Registry subcommittee was to specify a data set and then to commission the writing of a database. The software was originally written to run on a VAX cluster at the United Kingdom Transplant Service Special Authority (UKTSSA). Due to lack of space at UKTSSA, the Registry relocated to rented premises at Southmead Hospital in May 1997. The move delayed development, but forced the Registry to become fully independent. It now employs its own staff, runs its own payroll and purchases its own computer equipment and software licences.

Part of the initial specification of the database was portability. At the time of relocation the database was transferred to run on the Registry's own hardware. The database is on a Dec Alpha with 128 megabytes ram and 10 gigabytes of hard disk storage. The operating system runs Digital's open VMS, with a multi-user licence, and the database uses Oracles RDB file structure. This was sponsored by Oracle without charge to the Registry. All the database validation routines and screen handling have been written in Powerhouse (by Cognos), a 4GL language.

By March 1997 it had been demonstrated that the database was sufficient for the task and that the rigorous data validation routines developed were functioning. In April 1997 the Registry started to enrol further renal units and by July 1998 11 units, within

England and one in Wales were participating. They cover a combined population of at least 13 million, which includes 22% of the population of England.

Close links have been maintained with the Scottish Renal Registry and software has been successfully written to enable transfer of data from the Scottish Registry to the UK Registry. This will be facilitated when once all the Scottish renal units have given permission for this transfer. During 1998 many more of the Welsh units will enrol with the Registry. The participating units, and those currently planning to join are listed on the inside cover of this report.

1:8 Data transfer and management

There are no paper returns to the UK Renal Registry. Data extraction and transfer is electronic. For units to participate it is simply necessary that they have an Information Technology system storing required patient data. When a unit intends to join the Registry, staff from the Registry visit to study the local database. They then load software to extract the Registry data items from the unit database. The software prepares a file with identifiers for each data item. Data extraction is quarterly and file transfer is via modem over the NHS Healthnet. This is a secure system approved by the Department of Health. The data transfer on 1,000 patients takes less than 10 minutes.

On receipt of the file, the Registry holds data in a buffer area until staff are ready to process it. Validation routines are run to identify missing data, inconsistencies and unexpected changes. The Registry data manager discusses these problems with the local nominated Registry representative and will not load the data on the definitive database until the data are considered complete and accurate. Data transfer and management are summarised in tables 1.2 and 1.3

UK Renal Registry - data collection
<ul style="list-style-type: none">• Initial visits to unit for:<ul style="list-style-type: none">- Standardisation of local system- Installation of extraction routines• Quarterly local extraction carried out:<ul style="list-style-type: none">- File produced with identifiers for each data item- Transfer by NHS Healthnet- Data transfer - 200 items per patient - 1000 patients in 10 minutes- File held at Registry until staff ready to process

Table 1.2 Data extraction and transfer

UK Renal Registry - data management
<ul style="list-style-type: none">• Load unit file to database• Validation routine generates a report<ul style="list-style-type: none">- e.g. duplications, omissions, inconsistent patient transfer date• Data manager:<ul style="list-style-type: none">- Returns report by BT Healthnet- Telephone nominated contact in unit to discuss- Receives new revised report- Loads data to database when satisfied• Statistical routines - half day<ul style="list-style-type: none">- Finds inconsistencies, unexpected changes, out of range results, etc- Further checks with unit on accuracy• Data report finally accepted

Table 1.3 Data management

It is only with electronic extraction and transfer of data that quarterly returns can be achieved. Such frequent returns allow for close monitoring of change. The most useful interval is yet to be explored and established. With electronic transfer the UK Renal Registry is able to provide reports to units on data not more than six months old. Most other major renal registries are unable to report more quickly than eighteen months to two years, largely because they accept paper returns. This is a slow process needing transcription on receipt into a database.

1:9 Definitions

In order to allow meaningful comparative audit it was necessary for the Registry subcommittee to make clear definitions of the data collected. This was completed through a process of wide consultation. The definitions used by the Renal Registry are shown in appendix B. Further refinement and standardisation of these is likely in the future.

1:10 Registry funding

The initial development of the UK Renal Registry has been financed by grants from the Department of Health and from industry. Continuing activity will have to be 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. It is intended to make an annual charge per patient registered, which in the first phase will be £10.00 per patient per annum. This is 0.05% of the annual patient treatment cost and is considerably less than that charged by registries within other specialities in the United Kingdom.

The registry income will therefore be dependent on the number of patients registered, and thus the number of renal units participating. It is important that renal units put these charges into their Business Plans. They may need to help commissioning health

authorities to recognise the significance of the Renal Registry and the fact that it is the only vehicle for comparative audit of the provision of renal care, including DHA acceptance and patient stock rates, quality of renal care, outcomes of renal care, and identification of best practice.

In the intermediate term, until more patients are registered, further support will be sought both from the Department of Health and from industry. It is hoped that the Registry will become self-financing within two years.

The Renal Registry is non profit making and as part of the Renal Association is recognised as a charitable activity by the Charity Commission.

1:11 Other activities of the Renal Registry

The Registry has been commissioned by the Renal Association to maintain a database of medical staff in renal units within the United Kingdom.

Funding has been provided by the Department of Health to Professor Feest, Dr. Ansell, and Dr. Roderick to work with the UK Renal Registry to repeat a survey of UK renal services similar to those carried out in 1993 and 1995. In the future, as the number of units participating in the Registry grows these data will be available for most of the country from within the Renal Registry database. These surveys collect only a small proportion of the data routinely collected by the Renal Registry. Such surveys will however help the Renal Registry in the short term to compare some of the characteristics of the patients on the Registry (age, sex, underlying diagnosis, modalities of therapy) with the national picture, thus enabling an assessment of the reflection in the Registry database of the country as a whole.

Professor Feest and Dr. Roderick are negotiating for further funding to carry with the Renal Registry a retrospective study of the outcomes of cohorts of patients starting renal replacement therapy in the UK over the last ten years. This will be combined with some data available until 1988. The prognosis of patients starting renal replacement therapy in successive years in the United Kingdom, with allowances for age and underlying diagnosis, is not known. Whether outcomes have improved over the last ten years is uncertain. The provision of these data will provide a baseline for an assessment of the effect on patient outcomes of the introduction of the Renal Standards document and the Renal Registry.

Further ideas for studies will be welcome. If individuals wish to work with the Registry in audit or research they should apply through the Chairman or Secretary of the Renal Registry Subcommittee. No access to the Registry data, or additional activity within the Registry, will be allowed without approval by the subcommittee. Any additional costs will have to be met by the applicant.

By the end of 1998 the Registry hopes to be able to submit data returns to the EDTA database for the participating units, should they so require.