The UK Renal Registry: an overview

The UK Renal Registry (www.renalreg.org) performs national audits of the care of patients with established renal failure in the UK. Data from all patients receiving renal replacement therapy in each renal centre in England, Wales and Northern Ireland are analysed in the UK Renal Registry, and data on Scottish patients are sent by the Scottish Renal Registry, which is run independently.

The UK Renal Registry is a registered charity and part of the Renal Association. It is based in Bristol and employs 13 staff: a full-time medically qualified director, a general manager, a project manager, a secretary, three statisticians, three specialist registrars on out-of-programme experience, and three data managers. The Registry published its 10th Annual Report (on patients receiving renal replacement therapy in 2006) in March 2008 (Ansell et al, 2008a). Its primary purpose is to drive up the quality of care of patients with kidney failure.

How is it funded?

Renal centres pay an annual capitation fee, currently £17, for each patient (including children) on renal replacement therapy whose data are submitted. This fee represents less than 0.05% of the annual cost of treatment. Additional grants (for instance, from the Department of Health or the Information Centre) have been obtained to support new work, but the capitation fee gives the UK Renal Registry financial security and freedom from reliance on obtaining charitable grants or sponsorship. Submission of data is a requirement of the National Service Framework for Renal Services. Bequests have also been received for additional research activities.

How does it work?

Renal centre IT systems

The UK Renal Register is fully electronic, and – nearly uniquely – relies on data extracted directly from electronic patient records used in the day-to-day care of patients on renal replacement therapy. Renal medicine was among the first specialties in the UK to adopt clinical computing for routine care (Morgan and Will, 1983), and all UK renal centres now have computer systems that facilitate the care of their patients.

These systems vary widely (Simpson et al, 2006): the commonest system is the Proton system developed over 30 years ago by Clinical Computing Ltd, but a variety of systems have been developed more recently, some commercially provided and some developed by individual trusts in house. These systems allow clinicians to incorporate decision support systems and care pathways. All provide tabular and graphical display of sequential laboratory data (automatically transferred from the laboratory system), recording of the modality 'timeline' of a patient's renal replacement therapy (e.g. start and stop dates for each modality of treatment) and recording of the primary cause of renal disease. Nearly all allow recording of co-morbidity at the start of renal replacement therapy. The functionality of these systems continues to improve with time. Currently, all systems are being revised to allow recording of the type of vascular access used for haemodialysis. The ability of the UK Renal Registry to collect quarterly laboratory data is unique among national renal registries (Hodsman et al, 2007).

Quarterly extraction of data

Each quarter, an encrypted data extract is sent from each system to the UK Renal Registry. Validation, completeness and error checks are then performed to detect logical inconsistencies in the data and unexpected changes in data items compared to previous extracts. Some errors relate to changes made locally in the configuration of the renal centre IT system, requiring changes then to be made to the data item 'mapping' software. Others relate to human error, particular in entry of modality timeline items.

Errors are resolved by discussion between UK Renal Registry data managers and the IT managers in each centre, and revised data extracts are submitted. Following completion of this process, the database is 'locked' and prepared for statistical analysis. The statistical analyses are then interpreted by a team of clinicians and epidemiologists and prepared for publication.

Outputs

The main output from the UK Renal Registry is the annual report. This contains chapters on the demographics of renal replacement therapy (incidence and prevalence), late presentation and co-morbidity; chapters on achievement of clinical performance measures (e.g. dialysis dose, correction of anaemia, control of bone and mineral metabolism); access to, and outcome of, kidney transplantation (in collaboration with UK Transplant); survival (adjusted for age and, where the data are available, for co-morbidity); renal replacement therapy in children; and international comparisons.

Each of these chapters contains not only data on the UK population as a whole, but also named centre-specific analyses, so that each centre can compare its performance with every other centre in the UK. *Figure 1* shows a funnel plot of age-adjusted survival in each centre. Survival is measured in those patients who have already survived on renal replacement therapy for 90 days, excluding patients who die with acute renal failure and allowing comparison with other international registries. The centre can be identified by reference to the table in the full report (Ansell et al, 2008b). The fact that it is possible to identify each centre by name for this and all other analyses is evidence of the high level of trust that clinicians place in the UK Renal Registry's reports.

The wealth of high-quality data held by the UK Renal Registry has also enabled researchers to publish academic papers on a range of subjects (Roderick et al, 2004; Feest et al, 2005; Ahmad et al, 2006; Caskey et al, 2006; Ansell et al, 2007).

The future of the Registry under Connecting for Health

The UK Renal Registry has an interesting few years ahead, as the National Programme for Information Technology (NPfIT) takes shape. The flow of data from specialty-specific systems direct to disease-specific registries is not part of the strategy of NPfIT; instead, it is envisaged that all data will be extracted from the electronic care record and transmitted to the Secondary Uses Service, a 'data warehouse' housed by the

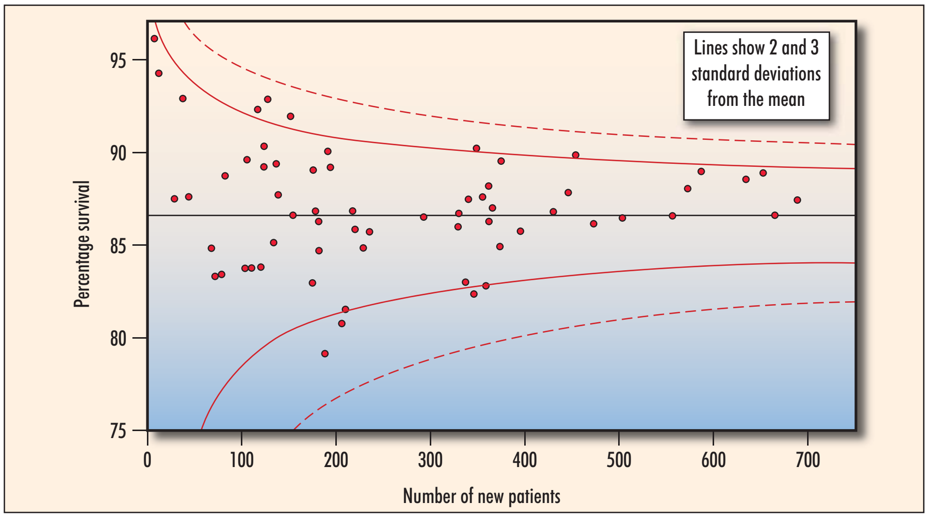

Figure 1. Funnel plot of age-adjusted 1-year after 90 days survival: 2002–2005 cohort.

Information Centre, which will then make selected data available to legitimate secondary users such as the UK Renal Registry.

A number of specialty-specific datasets are being prepared for approval by the Information Standards Board; following approval, collection of these data will be mandatory, obliging local service providers and trusts to ensure their collection. This may have many advantages, particularly in drastically reducing the number of different IT systems from which data will be extracted, and in allowing linkage to other datasets and sources of NHS information – for instance, on hospital admissions, discharge diagnoses and surgical operations.

The potential drawback is that there is no provision within NPfIT for the extensive data cleaning that the UK Renal Registry currently undertakes; once data are submitted from an individual trust, they will be deemed to be suitable for analysis. This makes trusts responsible for their own data quality; and undoubtedly, if a trust is named as an 'outlier' for a particular outcome, this will encourage the trust to double-check the data relating to that outcome. However, for 99.9% of analyses, trusts will (by definition) not be identified as outliers, and will not have this incentive to ensure high quality data.

For many purposes, including activity analysis and payment by results, this may well be good enough. However, for high-quality clinical audit, using complex case-mix adjustment models to allow valid comparisons between centres, with relatively low numbers of patients in each centre, a few inaccuracies (for instance, the inclusion of patients with acute renal failure in analysis of 1-year survival after initiation of maintenance haemodialysis) may result in misleading conclusions being drawn unless appropriate data checks have been undertaken.

Lessons for other specialties

The UK Renal Registry has benefited from being professionally led. The Renal Association's (2007) Clinical Practice Guidelines are the basis on which analyses of clinical performance by centre are designed. The use of electronic capture and transmission of data collected during the process of routine patient care has helped the UK Renal Registry collect a wide range of data with minimal additional workload to the clinical team. This has been testing the concept that NPfIT would like to follow for other specialties with the concept of Secondary Uses Service.

Open publication of each centre's data has helped promote active discussion within the renal community, sharing best practice and ways to improve patient outcomes. A yearly improvement in the major clinical quality indicators has also been documented. The agreement of a national speciality dataset guarantees the future. **BJHM**

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KEY POINTS

- The UK Renal Registry audits the care of all patients receiving renal replacement therapy in the UK.
- It is a fully electronic registry which receives quarterly data collections directly from electronic patient records on local renal IT systems.
- It is funded by an annual capitation fee for each patient whose data are submitted.
- It is a professionally-led registry as part of the Renal Association, with interpretation of the data analyses undertaken by a team of clinicians and epidemiologists.
- Connecting for Health promises an exciting future for the UK Renal Registry with the potential for additional sources of data, but it must remain under the guidance of clinicians to ensure appropriate interpretation of analyses.