Chapter 19: The Registry and use of 2002 Report

The 2002 Report dealing with data from 2001 explores the demographic and treatment variables of the renal replacement programmes in England and Wales in a timely and increasingly comprehensive way. Summary demographic data are presented for Scotland and Northern Ireland.

This is the first year that units have been identified within the report. Renal unit anonymity has been maintained only for mortality analyses as the data cannot be standardised enough for case mix to make interpretation reliable and therefore useful. It is essential that comorbidity data are as complete and accurate as possible for this purpose, as for others. The responsibility of the Registry to the nephrology community and patients is shown by the extensive chapter on data validation. This year, there has been far more feedback to units, and subsequent dialogue, in order to improve the quality and accuracy of data.

These data are longitudinal rather than cross-sectional, and therefore represent a different perspective from reports from the Center for Medicare and Medicaid Services, which is the successor to the US Health Care Finance Administration annual sampling review, and from the International Dialysis Outcomes and Practice Patterns Study (IDOPPS) exercises. Comparison with other studies should be carried out with caution as patient cohorts are not always comparable. The UK data start, for example, from the first day of dialysis. Many countries do not record this information: in the USA, data are captured from day 90. The pattern within Europe is highly variable and not always consistent within a country. This makes the interpretation of outcome data subject to error.

Furthermore, patient cohorts may be selected for analysis in different ways. IDOPPS, for example, is a comprehensive study not of dialysis practice, but of haemodialysis (HD) practice. In most participating countries, peritoneal dialysis (PD) is little used, but in the UK there is a large contribution of PD to dialysis and involves typically younger, fitter patients. For this reason, the UK cohort on HD, in particular, is a 'selected' group of patients who are older and less fit. The cohort cannot be compared without reservation to a cohort of HD patients from a country where PD is rarely used. Sampling strategies developed for purposes such as IDOPPS offer useful experience and frameworks for future Registry studies, in which more detail is required than might be expected from a routine clinical database.

The UK Renal Registry holds data that would allow the identification of individual patients. These data allow complete follow-up despite unit transfers, which are especially common across transplantation. A failure to be able to follow patients as they moved centres was the Achilles heel of previous large-scale Registry data collection (e.g. the European Dialysis and Transplant Association). Identification is essential for the validation of sequential data with renal units and for many of the functions of the Registry, such as epidemiological studies, the assessment of equity of access to treatment, outcomes adjusted for age and all long-term analyses. Patients are never identified in any output. These data are securely held and accessible only by the handful of Registry staff members responsible for the characterisation of unit patient cohorts. The Registry is in discussion with Patient Information Advisory Group and other organisations concerning its ability to continue in this way within the data protection laws. Meanwhile, permission has been given to continue as at present, pending further discussion. These problems are not unique to the Renal Registry, other clinical Registries also joining in discussion.

The Report includes an analysis funded by the National Kidney Research Fund of causes of death and comorbidity. The data on paediatric established renal failure were provided by the Paediatric Registry, which is in the process of merging with the UK Renal Registry. A subset of the data on renal transplantation were provided and analysed in collaboration with UK Transplant.

The hypothesis – that regular, timely electronic data capture from clinical databases is feasible and productive – is under rigorous examination. The Registry has demonstrated that it is possible technically. Exactly how reliable and useful it can be remains to be seen, and the Registry is keenly aware of the need to sustain a pattern of IT and clinical improvement that will allow a further exploration of the approach. The signs are that the exercise will be able to underpin the Renal National Service Framework, generate hypotheses and support the systematic improvement of patient management.

This year also sees the beginning of attempts to move beyond the analysis and presentation of outcome data, towards explaining the results being achieved, for example the role of sampling methods in dialysis adequacy and the context of renal anaemia management with regard to serum ferritin level and erythropoietin dosage. More work is required to extend these analyses and to make them more comprehensive and reliable. This will need to be followed by effort at unit level to standardise management policies where appropriate.

The Renal Registry dataset is incomplete. In particular, there is a need extend into vascular access registration and data. For this to happen, however, individual units will need to have a systematic record of vascular access, something that has proved difficult in many centres. It is also hoped to collect more data on pre-dialysis management. The Registry has the capacity to collect a much greater dataset but can only work with data that are accurately and reliably recorded on an electronic database by the units themselves. The scale of any exercise that will be required to establish a higher standard of peripheral data registration is currently uncertain.

The UK Renal Registry is one of the very few sources world-wide of clinical as well as demographic data in renal replacement therapy, but this has yet to be put to full use by the nephrology community in a national renal audit cycle. With declared Standards, and the outcome data from UK Renal Registry, a plan–do–check–act sequence is almost complete. The scope for improvement is apparent, and it should be possible to bring a repertoire of resources to bear, both financial and clinical, where outcomes are less than desirable. The variation in consistency from centre to centre hints at a variety of renal unit policies and processes that might be improved. How far this should be further formulated is being explored by the Renal Association, which has set up a group to explore the relationship between the declared Standards and monitoring and audit by the Registry. This is likely to involve both the implementation of changes in practice and the dissemination of good practice.

Finally, the effort of the renal ‘constituency’ has been substantial. There could be no Registry without the efforts of individual renal centres and the personnel who have contributed to it, and they thoroughly deserve any reward that the 2002 Report may generate for them in their efforts to improve patient management.