Chapter 10 Commentary

This first substantive report from the Renal Registry allows some preliminary conclusions to be drawn.

The pilot study has been completed and the Registry is now in a phase of development. The software and methodology has been vindicated , and this report demonstrates the ability of the Registry to collect quarterly data and analyse it. The low percentage returns on some areas of data indicate that a major limitation in this audit and research exercise will be the quantity and quality of the data held by each unit. The Registry will work with units to facilitate improvement in their data collection and quality.

The patient demographic information may have provided few surprises, although the variation in the basic features of case mix, such as age, is important. The data on co-morbidity anticipated in the next round of data collection will further characterise the clinical task undertaken by each centre, and will be important in assessing outcomes, although it will be three years at least before the Registry has enough sequential data on new patients to begin to produce survival data.

The unit preferences for renal replacement therapy modalities show significant differentiation. Each unit is working in a particular historical and contemporary context: the Registry hopes to be able to provide further description of the factors determining and/or restricting choice of treatment modality, and will eventually relate this to outcome measures.

The comparison of clinical performance data with the recommendations of the Renal Association Standards document was always going to be of interest. The exercise immediately brought into focus the problems of data harmonisation, and the use and derivation of local "normal" ranges. Although a start has been made in addressing these problems they need further discussion and exploration, and have implications for those setting the recommended standards. These difficulties imply that the comparative data must be considered with great care and without judgement at this stage. Nevertheless individual units will be able to draw conclusions and start to act on them.

In many areas current practice is adrift from the recommended standards. The inability to comply with the recommendations regarding serum phosphate may not be surprising, but it raises questions on the achievability of the standard. The data on haemoglobin demonstrate that the restatement of the recommendation in terms of an acceptable minimum (10 g/dl), rather than a range (10 - 12 g/dl) was wise. The data confirm that compliance with the guidelines will only be achieved with a median haemoglobin well over 11 g/dl, and a range of individual values greater than originally recommended. Whether it is possible to narrow the range of values within each unit and thus achieve compliance with the current standard without a significant number of patients having a haemoglobin above 12 g/dl is uncertain. The desirability of the 12 g/dl upper limit is currently under debate.

The homogeneity of much of the data suggests that most units represented take similar approaches to therapy in many areas. With some exceptions there is little evidence for wide variation in medical practice. The exceptions include the outstanding urea reduction ratio and haemoglobin results from one centre, and these deserve further study. This is an example of how the Registry can help to identify and disseminate good practice. It is also anticipated the report will enable individual units to identify areas where their practice appears to be less successful than other units, and so address possible reasons and means of improvement.

A number of questions of methodology have been raised. Standardisation of sampling technique will be important for further assessment of urea reduction ratio and KT/V. Discussion is needed with regard to appropriate sampling intervals for each variable and on quality control.

The Registry is collecting large volumes of data. This first report is inevitably somewhat exploratory and experimental. The act of producing it is a stimulus to discussion on the most appropriate analyses to perform. Having presented this report in the frame of the Renal standards document is still unclear what role it is anticipated that the Registry should have in providing a commentary, drawing conclusions, and facilitating changes in practice. A continuing dialogue with the Standards Sub-committee and within the Renal Association itself will help to resolve some of these issues and be essential to the development of the Registry as an effective agent for audit, research, and improvement in the quality of renal care.