

Chapter 23: Afterword

Content

The 2003 Report contains information and analysis from data on patients from 2002. In addition to presenting the demographic information and studies of quality of care seen in previous reports, the Report contains many new analyses, particularly the standardised acceptance ratios, work on seasonal variation in mortality, analysis of the calcium phosphate product, new work on hypertension, study of the date of first referral and initiation of RRT, study of the influence of social deprivation, and some consideration of the problems of international comparisons in relation to Registry data as compared to sample studies. There is included a summary of the National Renal Review commissioned by the Department of Health, which also includes data on facilities and staffing of renal units. The Report is otherwise based on data from England and Wales, with some summary demographic data from Scotland and Northern Ireland. It is hoped that in the 2004 Report there will be detailed data from Northern Ireland.

The need for better quality data

Renal unit anonymity has been discarded apart from the survival analyses. The quality and completeness of data regarding co-morbidity and ethnicity are not yet good enough from many units to allow for appropriate adjustment of survival figures. Without such adjustment, comparison between units would be misleading. It is recognised that it is time-consuming, and often inconvenient, to record some of these data, but for future audit they will be essential. The Registry is keen to encourage the nephrology community to find ways to capture this material more completely and reliably.

The need for dedicated and trained IT staff has been identified by many renal units.

They will be important in improving the collection and quality of data. The sections in this report pertaining to calcium and phosphate, hypertension, ethnicity and co-morbidity all demonstrate the need for better data validation at renal unit level. In addition, it is acknowledged that the Renal Registry dataset is incomplete. There is a particular need to collect vascular access data. The Registry has the capacity to include such data and could propose a much bigger dataset. The limitation is largely in the data which can be reliably recorded on electronic databases within the Renal Units themselves. Vascular access data, which involve collation of activity in several parts of any hospital, can be difficult to capture without staff employed for the purpose and carefully designed procedures.

The NSF and its information strategy

Collection of co-morbidity, vascular access, and other data may be facilitated as a result of the recently published Renal National Service Framework. This strongly recommended that all renal units should participate in comparative audit through the Renal Association UK Renal Registry. This should help renal units to negotiate appropriate resources and staff for data capture, in particular dedicated trained IT staff. This is underlined by the carefully considered Renal NSF Information Strategy, which is in Appendix E.

The Data Protection Act

The decision by the Patient Information Advisory Group to grant the UK Renal Registry exemption from the Data Protection Act under section 60 of the Health and Social Care Act 2001, was a critical step for the future of the Registry. Currently the

Registry is unable to avoid duplicate registration of patients or to follow sequential data on individual patients without holding some patient identifiable data. The Registry outlined its plans to develop systems which will avoid the need for specific patient identification and yet avoid duplication and allow serial follow up. This will be possible within planned developments of the National Programme for Information Technology (NpFIT). The exemption from Section 60 is temporary, until these plans are implemented successfully.

The potential of the Registry

The Renal Association UK Renal Registry is one of the very few sources worldwide of clinical as well as demographic data on renal replacement therapy. Whilst the reports published so far are interesting and may have contributed to the improvements in renal care that they document, the data are nowhere near being put to full use. The wide variations between renal units in many aspects of care are highlighted by the Report. The Report does not explain these variations, nor identify where there is a serious lack of resources. It does not automatically identify and help to spread good practice. The Renal Association in the last year set up a Working Party to recommend changes to improve coordination of its activities in clinical areas. As a result, a Clinical Affairs Board has been instituted under the chairmanship of a Clinical Vice President. Amongst others, the Registry, the Standards subcommittee, and the Clinical Directors subcommittee will be represented on this board. This focused effort should enable increasing use of the Registry data in bringing about improvements in clinical care.

Monitoring the NSF

The Renal Association UK Renal Registry is working closely with CHAI, the NHS Information Agency, and the Department of Health. All these agencies believe that the Renal Registry will be an essential part of monitoring the implementation of the NSF. This places the Registry in a unique and exciting position as an independent organisation working with official agencies in this way. The relationship will give the clinical renal community an important and influential role in the development of renal services.

Conclusion

The renal community should be proud that it has taken the lead in developing a Registry, unique in its detail, which has become a component of clinical practice in many renal units, and a nationally and internationally respected tool for national collaborative renal audit. It is only through the efforts of individual renal centres together with the personnel who work within them, and the enthusiastic support of the Renal Association, that this has been achieved, and we are pleased to present the 2003 Report as a testament to that joint effort.