The Renal Association

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The UK Renal Registry

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Established in 1995 by the Renal Association, the UK Renal Registry (UKRR) currently collects data from 71 adult and 13 paediatric kidney centres. The annual report, funded by a small capitation fee, provides a snapshot of centre performance across the UK and is used as a source document for audit and benchmarking against quality of care standards. The collection, validation, analysis and publication of these data requires a great deal of work by the UKRR team and we are indebted to all the staff for their contributions to this 18th Annual Report. This report primarily covers activities in 2014, with centre comparisons including survival data de-anonymised.

When I last wrote the introduction for the UKRR report four years ago, I commented on the growing range of activities that the UKRR was supporting, including the National Registry for Rare Diseases (RaDaR), PatientView (PV), the Acute Kidney Injury Programme ('Think Kidneys') and The UK Renal Data Collaboration (UK RDC). These projects have continued to develop under the watchful eye of Ron Cullen, Chief Executive with support and strategic input from Fergus Caskey, Medical Director, Hilary Doxford, Head of Business and Development and Karen Thomas, Head of Programmes. This growth beyond the ‘core business’ continues apace with the UKRR now contributing to research studies such as the Surveying People Experiencing young Adult Kidney failure (SPEAK) project. There are also plans for the UKRR to provide follow-up data on patients recruited into cohort studies and clinical trials in the near future.

Having made an important contribution to data collection over the last 20 years, it seems logical that the UKRR should become involved in the Kidney Quality Improvement Partnership (KQuIP). This multi-professional initiative, agreed by the whole renal community in the Kidney Health: Delivering Excellence document, aims to improve the quality of care delivered, reduce variation and improve patient outcomes by spreading best practice. As a key partner, the UKRR will act as the data and analysis resource, providing logistic support and a learning platform.

Although the UKRR has secured grant funding for some of these additional activities, long-term sustainability will require an increase in regular income from capitation fees. For the past five years the capitation fee has been £21.50 per patient, levied as separate fees for the UKRR and PatientView on dialysis and transplant patients and representing less than 0.08% of the average annual cost of treating these patients. An increase to £30 per patient has recently been proposed and agreed by NHS England, thus securing the UKRR’s contribution to these important projects into the future.

David Wheeler
Chair, UK Renal Registry Renal Information Governance Board
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