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Foreword

“It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness, it was the epoch of belief, it was the epoch of incredulity, it was the season of Light, it was the season of Darkness, it was the spring of hope, it was the winter of despair, we had everything before us, we had nothing before us, we were all going direct to Heaven, we were all going direct the other way.”

Charles Dickens, the opening of ‘A Tale of Two Cities’.

This may describe the feelings of those of us associated with the UK Renal Registry over the near twenty years of its existence – but now, certainly, is the best of times.

In the past there was excitement within the Registry. There was the thrill at producing the first report, followed in the last decade by achieving complete coverage of the United Kingdom. There was satisfaction when the statistics and audit produced by the Registry began to be recognised and used by clinicians, and more as the Registry came to work closely with patients and government to play significant roles in national planning and, importantly, in improving the quality of renal care. Today there are even more exciting opportunities.

Currently the Registry has a strong team delivering a service of increasing quality. There are now 22 employees. Some have given long loyal exceptional service, whilst newcomers have brought fresh ideas making important contributions. The data validation process has been radically revised and routine procedures automated, leaving the data managers more time to talk with renal units about the important things. The data completeness and quality have massively improved, the cycle of data collection and validation is much quicker and the Registry is on course to catch up and collect data in a timely fashion during 2013. In addition the Registry has moved into monitoring of vascular access data, is conducting a pilot on the audit of peritoneal access and will soon be fully integrated with the Paediatric Renal Registry. The Registry also acts as an umbrella organisation co-ordinating and supporting the growing number of Rare Disease Registries (RADAR) and liaises closely with Renal PatientView. Commissioners are engaged with the Registry, some are even considering making the provision of timely returns to the Registry part of the contract with dialysis units. Throughout, the Registry has remained independent of government and industry. All this provides the groundwork for the Registry of the future.

Looking to the future the Registry has many projects for patients, including facilitation of patient recorded data and production of patient decision aids. There are negotiations with the NHS Institute for qualitative research into dialysis decision making and the benefits of ‘activated’ patients. There are plans to begin to monitor Acute Kidney Injury and Chronic Kidney Disease. Research is growing; one most important project is the linkage with HES data. The Registry is exploring new technologies (the interactive data portal is one exciting current example) intending to radically change its techniques of data collection to improve speed and data quality, facilitate links with RADAR and other parts of Registry activities, and with their permission allow transfer of information as patients move unit to unit.

My association with the Registry is nearing its end. I will be leaving a great team at a Registry for which, I am convinced, this is the best of times with everything before it!

Terry Feest
UK Renal Registry Advisor and former Chairman
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