

The UK Renal Registry: making patient data matter

The UK Renal Registry was established by the Renal Association in 1995 with the primary aim of collating data centrally from all adult UK renal centres to improve the care of patients with end-stage kidney disease. Although originally limited to patients on renal replacement treatments – dialysis therapies and kidney transplant recipients – it now collects all cases of acute kidney injury in primary and secondary care and all cases of advanced chronic kidney disease in secondary care not on dialysis. Children on renal replacement treatments were initially captured by a separate registry established by the British Association for Paediatric Nephrology, but this passed over to the UK Renal Registry from 2009.

The UK Renal Registry is funded mainly through an annual capitation fee levied on renal centres for each dialysis and transplant patient. The main output of the UK Renal Registry is an annual quality assurance report that is distributed to the wider renal community with patient-friendly plain English summaries also available. Data are also used with appropriate permissions for research.

How does the UK Renal Registry collect data?

The UK Renal Registry team manages data collection on about 7000 new patients and 55000 existing patients on renal replacement treatments each year. The UK Renal Registry website (www.renalreg.org) lists data items

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collected. The UK Renal Registry has support under section 251 of the NHS Act 2006 to collect these data for audit and research purposes without individual patient consent.

Data are collected on a quarterly basis from all renal centres via automatic downloads (*Figure 1*). English, Welsh and Northern Irish renal centres send their data directly to the UK Renal Registry, where much work is undertaken to identify and resolve errors and inconsistencies before detailed statistical analyses are conducted. Scottish data are collected, validated and published by the Scottish Renal Registry before they are shared with the UK Renal Registry. The process of data collection is likely to change significantly in the future with the launch of the UK Renal Data Collaboration, which aims to standardize UK-wide data collection and storage, enabling more real-time analyses and outputs from the UK Renal Registry.

What are these data used for?

The UK Renal Registry has entered an exciting phase of its development with data now used not only for audit purposes, but also for research, quality improvement and innovation, and clinical informatics.

Audit

The 19th annual report was published in September 2017 (Byrne et al, 2017). While most chapters report long-term data, new or revised chapters are written each year that focus on novel ways of analysing and presenting the data. The report is available at www.renalreg.org and is used by health professionals, commissioners, patients and the public to view individual renal unit performance against national standards.

Research

The UK Renal Registry is open to requests from clinicians, researchers and statisticians. It provides large data sets for epidemiological and exploratory analyses and efficient outcome data for clinical trials. The UK Renal Registry is currently leading two National Institute for Health Research-Health Technology Assessment funded randomized controlled trials: the Prepare for Kidney Care study randomizes older comorbid patients approaching end-stage kidney disease to either prepare for responsive management or prepare for dialysis, and the High-volume Haemodiafiltration *vs* High-flux

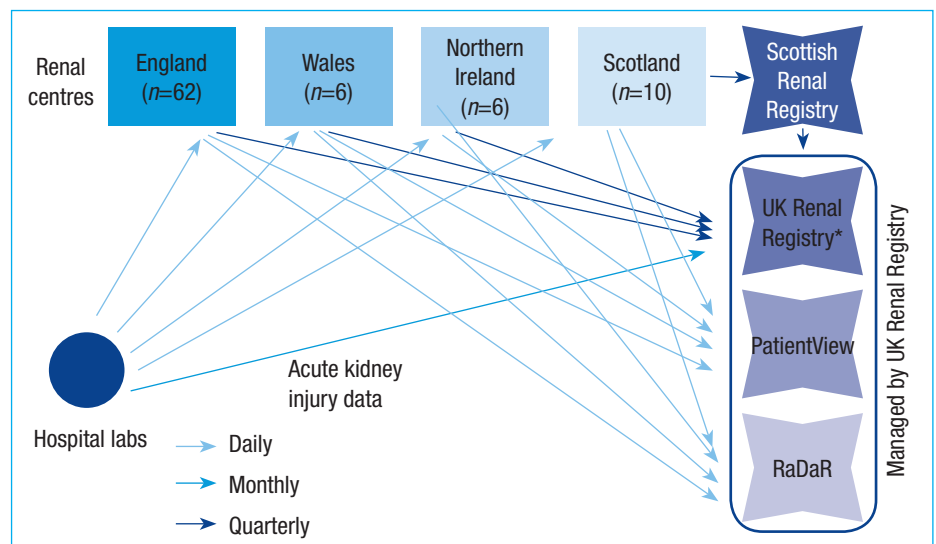


Figure 1. A schematic of data flows between hospital labs, renal centres and registry databases. RaDaR = National Registry of Rare Kidney Diseases. *The UK Renal Registry collects data on paediatric patients for the British Association for Paediatric Nephrology.

Haemodialysis Registry Trial randomizes patients to two different types of dialysis. Registry-based trials offer the potential to efficiently answer questions that could not only improve patient outcomes, but also standardize care nationally.

In addition, formal quality improvement evaluations and research projects (Birnie et al, 2017; Gallagher et al, 2017) are undertaken by research fellows, statisticians and external researchers. The UK Renal Registry has also been a powerful tool for monitoring equity of access to dialysis (Judge et al, 2012) and transplantation (Udayaraj et al, 2012).

Improvement and innovation through the Think Kidneys programme

The UK Renal Registry has worked with NHS England on three national Think Kidneys programmes (www.thinkkidneys.nhs.uk/) to improve the care of people with, or at risk of, kidney disease:

1. The acute kidney injury programme raised awareness of acute kidney injury by improving access to education, developing effective resources and sharing best practice across the NHS and beyond. More than 80% of laboratories in England now submit acute kidney injury data from primary and secondary care to the UK Renal Registry (Figure 1). The focus of future work will be to combine these data with linked data on hospitalization and mortality to facilitate ongoing surveillance of acute kidney injury outcomes.
2. The Transforming Participation in Chronic Kidney Disease programme supported people with kidney disease to make decisions about their health that improve their quality of life. Patient-reported outcome measures and levels of patient activation have been successfully collected in 14 renal centres. Work continues to test interventions that may improve an individual's outcome.
3. The Kidney Quality Improvement Partnership works to improve the lives of people affected by kidney disease by supporting health-care professionals, kidney units, renal networks and commissioners to achieve the highest quality of care for patients.

Clinical informatics

1. The UK Renal Data Collaboration is a new process for collecting data for kidney patients, whereby data will flow into a

central data repository and flow out to various organizations with approved access to the data. Advantages include real-time data access and processing, standardized processing and nomenclature, and the ability to link quickly with other databases.

2. PatientView is a mobile-friendly platform that gives patients real-time access to much of the information in their renal electronic health record. Daily updates including blood results, medication lists and letters on the local renal IT systems flow securely through the UK Renal Registry to a website that patients can log onto (Figure 1). Exciting developments are the ability of patients to contact their kidney team directly, as well as being able to feedback important information on how their kidney disease is impacting their lives.
3. The National Registry of Rare Kidney Diseases is a Renal Association initiative coordinated by the UK Renal Registry that brings together data of patients with certain rare kidney diseases (Figure 1). This provides clinicians with an invaluable resource to accelerate research and presents patients with opportunities to participate in research.

What challenges does the UK Renal Registry face?

Medicine is evolving rapidly, as is the technology that clinicians and patients have become accustomed to using in their day-to-day lives. The challenge is to process, analyse and report data as quickly as possible to ensure outputs are clinically meaningful and help engage patients in the ongoing management of their kidney conditions. Combining improved data processing with external data linkages to Hospital Episode Statistics and the Office for National Statistics will allow much more detailed analyses and help the UK Renal Registry remain an integral part of research into the many unanswered questions in nephrology. Opportunities include post-marketing surveillance of drugs and monitoring patient quality of life as they transition onto and change modalities of renal replacement treatments. Patient engagement is vital and the evolution of patients' involvement in their own care such as with PatientView is likely to be rapid. The guardianship of patient data will also continue to be a major challenge. Collaboration across national borders is likely to accelerate, as will the sharing of best practice with the

KEY POINTS

- The UK Renal Registry collects data on all patients receiving renal replacement therapy in the UK via automatic downloads from renal centres.
- The registry recently started to collect acute kidney injury and advanced chronic kidney disease data, which will greatly improve our understanding of how patients progress to end-stage kidney disease.
- The UK Renal Registry produces an annual report that health professionals, commissioners, patients and the public can use to view individual renal unit performance against national standards.
- In addition to audit, patient data are also used for research, quality improvement and innovation, and clinical informatics.
- A future challenge for the registry is to process, analyse and report data more quickly to ensure outputs are clinically meaningful and help engage patients in the ongoing management of their kidney conditions.

developing world. Clearly many challenges lie ahead, but these are exciting times for national audits and registries. **BJHM**

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