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The UK Renal Registry: making patient data matter

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The UK Renal Registry (UKRR) 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. It is therefore unlike many other national audits, which are run by the Healthcare Quality Improvement Partnership. Although originally limited to patients on renal replacement treatments – dialysis therapies and kidney transplant recipients – it now collects all cases of acute kidney injury (AKI) 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 activity passed over to the UKRR from 2009.

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

How does the UKRR collect data?

The Bristol-based UKRR team of about 25 data analysts, statisticians and researchers manage data collection on approximately 7,000 new patients and 55,000 existing patients on renal replacement treatments each year (Gilg et al., 2017, MacNeill and Ford, 2017). Data items collected are listed on the UKRR website (www.renalreg.org/data/). The UKRR has support under section 251 of the Health and Social Care Act to collect these data for audit and research purposes without individual patient consent (Caskey et al., 2017). 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 UKRR, 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 UKRR. The process of data collection is likely to change significantly in the future with the launch of the UK Renal Data Collaboration (UKRDC), which aims to standardise UK-wide data collection and storage, enabling more real time analyses and outputs from the UKRR (Caskey et al., 2017).

What are UKRR data used for?

The UKRR 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 through the *Think Kidneys* programme, and clinical informatics.

1. Audit

The 19th annual report was published in September 2017. While the majority of the 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 on the UKRR website

(<https://www.renalreg.org/publications-reports/>) and is used by health professionals, commissioners, patients and the public to view individual renal unit performance against national standards.

2. *Research*

The UKRR is open to requests from clinicians, researchers and statisticians (www.renalreg.org/about-us/working-with-us/). It provides large data sets for epidemiological and exploratory analyses and efficient outcome data for clinical trials. The UKRR is currently leading two NIHR-HTA funded randomised controlled trials: (i) the Prepare for Kidney Care study randomises older comorbid patients approaching end-stage kidney disease to either prepare for responsive management or prepare for dialysis (Caskey, 2017a); and (ii) the High-volume Haemodiafiltration vs High-flux Haemodialysis Registry Trial randomises patients to two different types of dialysis (Caskey, 2017b). Registry-based trials offer the potential to efficiently answer questions that could not only improve patient outcomes, but also standardise care nationally. By being nested within the entire patient population, they also help us understand any selection biases in recruitment to the trial, so that the generalisability of the results to routine practice can be fully understood. In addition, formal quality improvement evaluations (Gallagher et al., 2017) and research projects (Pruthi et al., 2016, Birnie et al., 2017) are undertaken by research fellows, statisticians and external researchers. The UKRR has also been a powerful tool for monitoring equity of access to dialysis (Judge et al., 2012) and transplantation (Udayaraj et al., 2012).

3. *Improvement and innovation through the Think Kidneys programme*

The UKRR has now worked together with NHS England on three national *Think Kidneys* programmes to improve the care of people with, or at risk of, kidney disease (<https://www.thinkkidneys.nhs.uk/>):

- (i) The AKI programme raised awareness of AKI 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 AKI data from primary and secondary care to the UKRR (figure 1). The focus of future work at the UKRR will be to combine these data with linked data on hospitalisation and mortality to facilitate ongoing surveillance of AKI outcomes.
- (ii) The Transforming Participation in Chronic Kidney Disease (TPCKD) 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.
- (iii) The Kidney Quality Improvement Partnership (KQuIP) works to improve the lives of people affected by kidney disease by supporting healthcare professionals, kidney units, renal networks and commissioners to achieve the highest quality of care for patients (figure 2).

4. *Clinical informatics*

- (i) The UKRDC is a new process for collecting data for kidney patients, whereby data will flow into a central data repository and flow out to various organisations with approved access to the data. Advantages of the UKRDC include real time data access and processing, standardised processing and nomenclature and the ability to link quickly with other databases.
- (ii) 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 UKRR 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.

- (iii) The National Registry of Rare Kidney Diseases (RaDaR) is a Renal Association initiative coordinated by the UKRR that brings data of patients with certain rare kidney diseases together (figure 1). RaDaR provides clinicians with an invaluable resource to accelerate research and presents patients with opportunities to participate in research.

What challenges does the UKRR 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 UKRR 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 developing world. Clearly many challenges lie ahead, but these are exciting times for national audits and registries.

Acknowledgements

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Key points

- The UKRR collects data on all patients receiving renal replacement therapy in the UK via automatic downloads from renal centres.
- The UKRR recently started to collect AKI and advanced CKD data, which will greatly improve our understanding of how patients progress to end-stage kidney disease.
- The UKRR 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 purposes, patient data are also used for research, quality improvement and innovation through the *Think Kidneys* programme, and clinical informatics.
- A future challenge for the UKRR 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.

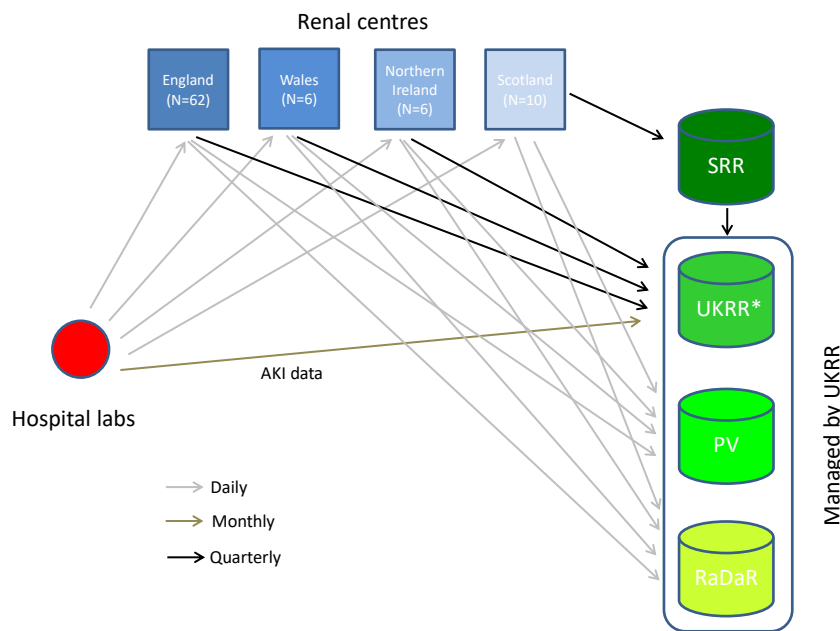


Figure 1 A schematic of data flows between hospital labs, renal centres and registry databases (SRR, Scottish Renal Registry; UKRR, UK Renal Registry; PV, PatientView; RaDaR, National Registry of Rare Kidney Diseases). *The UKRR collects data on paediatric patients for the British Association for Paediatric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

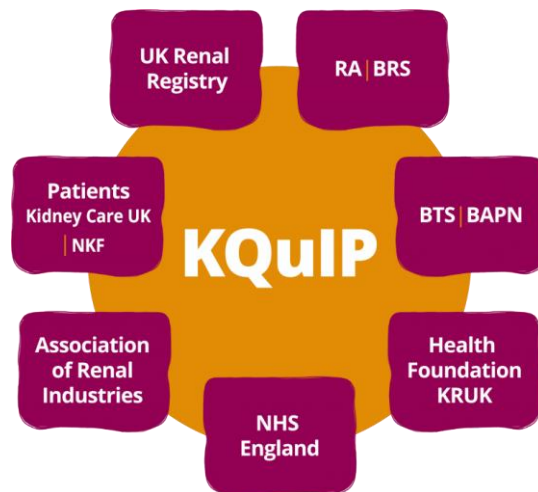


Figure 2 Founding members of the KQuIP (RA, Renal Association; BRS, British Renal Society; BTS, British Transplantation Society; BAPN, British Association for Paediatric Nephrology; KRUK, Kidney Research UK; NKF, National Kidney Federation)

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