

Introduction: Welcome to the UK Renal Registry's 21st Annual Report

The UK Renal Registry (UKRR) Annual Report is aimed primarily at health professionals with an interest in the health, care and outcomes of people with kidney disease in the UK. The main purpose of the report is to present information about the care provided to patients at each of the UK's 71 adult and 13 paediatric renal centres against national standards, in particular, The Renal Association's guidelines – <https://renal.org/guidelines/>.

As highlighted in the foreword, the format of this year's report is significantly different to previous years. In brief, there are fewer chapters, each representing either a stage or modality of end-stage kidney disease (ESKD) and all follow the same structure. Clinical summaries of the report – one for adult data and one for paediatric data – will be published in *Nephron*. Lastly, in partnership with The Renal Association Patient Council, a summary of the annual report for patients has been developed, in plain English and with infographics – <https://www.renalreg.org/patient-info/>.

The new report is simpler and faster to produce. Combined with the new data portal this will increase the clinical timeliness and relevance of UKRR data. It will also free up UKRR resources to conduct and facilitate a wider variety of audit and research work using UKRR data. The UKRR welcomes your comments on this annual report.

Data items collected by the UKRR

The UKRR was originally established as a registry for people with ESKD on renal replacement therapy (RRT) – recently, data permissions were expanded to include patients with acute kidney injury (AKI) in primary and secondary care (in England only) and all cases of chronic kidney disease (CKD) stages 2–5 in secondary care not on dialysis. For this year's report only patients with ESKD on RRT are reported.

The full list of data items that the UKRR aims to collect (dataset version 4.2) can be found at <https://www.renalreg.org/datasets/the-uk-renal-registry-dataset/>.

Work is underway to assess and improve the quality and completeness of the advanced CKD dataset, so that these data can be included in future annual reports. The AKI master patient index, established as part of the NHS England safety alert, is progressing well with 93% of laboratories submitting data. The UKRR produces quarterly AKI reports for clinical commissioning groups and laboratories, and will publish a separate AKI annual report later this year.

Mechanisms of data transfer to the UKRR

Most data items about adults are collected from renal centres via secure and automatic quarterly downloads from the renal centre IT system to the UKRR database. English, Welsh and Northern Irish renal centres send their data directly to the UKRR, where the data are cleaned and validated before analyses are conducted. Scottish data are collected, validated and published by the Scottish Renal Registry before they are shared with the UKRR. AKI data, in contrast, are collected from hospital laboratories via secure and automatic monthly downloads from the laboratory IT system to the UKRR database. The majority of patients in the AKI cohort are not under the care of renal centres.

Data items about children are collected from renal centres through a variety of mechanisms – from automated download to Excel spreadsheets – reflecting differences in how local IT systems handle paediatric renal data.

The continuing development of the UK Renal Data Collaboration (UKRDC) is leading to significant changes in both adult and paediatric data collection. Data will flow immediately to the UKRR data warehouse rather than through quarterly downloads, enabling much quicker feedback and analyses of up to date data. Furthermore, the new format will allow data to be extracted in more detail and with more metadata, which will improve interpretation of the data. Trials with King’s College Hospital renal centre are proceeding well.

Data completeness of UKRR held data items

The completeness and quality of data items submitted to the UKRR varies by renal centre, but continues to cause significant challenges, as detailed in each chapter. Throughout the report, each analysis includes only those renal centres that had submitted the data item for at least 70% of their patients.

Poor data completeness may result from failure to undertake a test or to accurately capture patient data. Data may also be lost during the transfer and validation processes. The UKRR dataset has evolved and expanded over time in response to audit guidelines, with an understandable variable lag in the ability of renal centre IT systems to respond to those changes. Data completeness is likely to improve with the development of the UKRDC and increasing uptake of version 4.2 of the UKRR dataset. The UKRR will prioritise greater transparency around data completeness to aid the planning of audit and research.

Completeness of comorbidity data from renal centres at the start of RRT remains poor. However, NHS Digital recently permitted the UKRR to link the UKRR dataset to the Hospital Episode Statistics (HES) and Civil Registration datasets, which, for the first time, will allow adjustment for comorbidity in survival analyses as a standalone piece of work to follow the publication of this report.

Information governance at the UKRR – the care of patient data

Issues surrounding information governance, data protection and information security remain a priority at the UKRR to ensure that the UKRR continues to process data fairly, transparently and securely. The UKRR remains clear and open with patients about how their data are used, publishing information describing the nature and scope of processing on the UKRR website and in patient information leaflets and posters, which are distributed to all renal centres.

The UKRR continues to receive support from the Department of Health’s Health Research Authority with their approval of the UKRR under section 251 of the NHS Act (2006) to collect data without individual patient consent. This helps to ensure the robustness and validity of analyses, while respecting the rights and freedoms of patients in relation to their data.

The Health Research Authority also continues to support the UKRR’s governance framework for assessing applications for others to use the UKRR’s data for audit and research purposes. The UKRR accepts applications to use its data all year round – <https://www.renalreg.org/about-us/working-with-us/>.

Each year the UKRR completes an assessment against the National Data Guardian's information governance standards. NHS Digital has updated the method of assessment this year, replacing the Information Governance Toolkit with the Data Security and Protection Toolkit. The UKRR achieved a positive outcome for the 2018/2019 assessment period.

Further information on information governance at the UKRR is available at <https://www.renalreg.org/patient-info/>.

How to interpret centre specific analyses and outlying centres

The UKRR continues to advise caution when comparing centre specific attainment of clinical audit measures provided in this report. For many of these analyses no adjustment can be made for the range of factors known to influence the measured variable. The UKRR does not test for significant differences between centres – arbitrary 95% and 99% confidence intervals are created from the data to show compliance with an audit standard. Centre comparisons will become more meaningful when more comorbidity data are included in analyses via the UKRR-HES data linkage and when advanced CKD data are included to understand differences in the transition of patients onto both RRT and conservative non-dialysis pathways.

Despite these shortcomings, for a number of years identifiable centre specific reports on the survival of RRT patients have been published in the annual report.

The UKRR has no statutory powers. However, because the UKRR provides centre specific analyses of important clinical outcomes, including survival, it is important to define how the UKRR responds to apparent under-performance. The UKRR senior management team communicates survival outlier status with the renal centres prior to publication. Centres are asked to report their outlying status internally at trust level and to follow-up with robust mortality and morbidity meetings. They are also asked to provide evidence that the clinical governance department and chief executive of the trust housing the service have been informed. In the event that no such evidence is provided, the chief executive officer or medical director of the UKRR informs the president of The Renal Association, who then takes action to ensure that the findings are properly investigated.

We hope you enjoy the new format of the annual report and as always we welcome your feedback on the outputs of the UKRR – renal@renal.org.