

Introduction: Welcome to the UK Renal Registry's 22nd Annual Report

The UK Renal Registry (UKRR) collects and reports data annually on approximately 70,000 kidney patients on renal replacement therapy (RRT) in the UK. The annual report is an audit of the care provided to these patients at each of the 71 adult and 13 paediatric centres against national standards, in particular, the Renal Association's guidelines – renal.org/health-professionals/guidelines/guidelines-commentaries.

The 22nd Annual Report includes the 8,000 patients who commenced RRT in 2018, as well as all 67,000 patients who were on RRT at the end of 2018. The chapters are split by treatment modality (transplant, in-centre haemodialysis, peritoneal dialysis and home haemodialysis), as well as by adults and children.

The online appendices cover the methodologies, including how data are collected and coded (appendix A) and include basic analyses at clinical commissioning group and health board level (appendix B) – renal.org/audit-research/annual-report.

Plain English summaries of the annual report have been developed in partnership with the Renal Association's Patient Council – renal.org/audit-research/annual-report.

Finally, all graphs used in the report are available for use in presentations – renal.org/audit-research/annual-report.

What's new?

This is the first report where the UKRR derived the audit variables for a renal centre (King's College Hospital) from the UK Renal Data Collaboration (UKRDC) database. Although only one centre provided data via this route, it proves the principle that the current audit standards can be monitored using this daily data flow. For King's College Hospital we could now report measures back to them in 'real time' and we are working on tools that can message renal centres regarding the quality and completeness of their data, and that can be used to visualise audit measures and patient numbers in a much more timely manner.

For the first time, people on home haemodialysis (HHD) were analysed separately from other haemodialysis patients. The numbers of people on HHD are much smaller than in-centre haemodialysis, but the differences in patient characteristics, and in particular their common dialysis regimens mean it is important that they are considered separately.

Also, for the first time, Hospital Episode Statistics (HES – England) and Patient Episode Database for Wales (PEDW) data were used in combination with UKRR data to adjust survival for case-mix. Using this adjustment, which will now form a routine analysis, there were no centres with significantly poorer patient survival.

Whilst the full report is a great resource for clinicians in renal centres, it is quite dense for a first understanding of key messages. Building on last year's co-production of a series of infographics summarising the adult data, this year we now have a separate summary of the paediatric data.

This is also the first time that we have entirely produced the report in-house.

Next steps?

Work is underway to assess and improve the quality and completeness of the advanced chronic kidney disease (CKD) dataset, so that these data can be included in future annual reports. Several analyses of these data were to be presented at UK Kidney Week in June to allow the analysis and conclusions to be debated and challenged. Some of this will still be available later in the year, and from next year we plan to include at least summary statistics in a chapter of the annual report.

Next year several other centres will be using UKRDC to send data for audit.

The completeness and quality of data items submitted to the UKRR varies by renal centre, but continues to cause significant challenges. Throughout the report, each analysis includes only those renal centres that submitted the data item for at least 70% of their patients. In the next year we will look carefully at the data we want to collect and the route by which we collect them. We need to be clearer about which data are essential to produce reliable comparisons and which data are desirable, but less commonly used. The NHS and the Renal Association standards are not static and changes in evidence and clinical practice need to be included. 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 in the validation processes. Once we have consulted on the data to collect we will need to help centres understand why they have gaps. We hope the new data completeness portal (renal.org/audit-research/data-portal/completeness) will be a valuable tool for renal centres and researchers.

Completeness of comorbidity data at the start of RRT has been a challenge to collect since the beginning of the UKRR 25 years ago, and the change to version 4.2 of the dataset did not improve this. We will increasingly use linkage between the UKRR and HES and PEDW to adjust for comorbidity in survival analyses and, after consultation, may reduce the amount of comorbidity data we ask centres to provide.

How to interpret centre 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 illustrate variability between centres and the outlying status of centres. Centre comparisons will become more meaningful when more comorbidity data are included in analyses via the data linkages 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 analyses 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.