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P079 -Changes at the UK Renal Registry: new annual report, new data access application process and new research ready dataset

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Introduction

The UK Renal Registry (UKRR) collects a wide range of data items about patients with kidney disease to conduct audit and, where permissions allow, research. Recently, the legal basis for collecting data was expanded to include patients with acute kidney injury and patients with advanced chronic kidney disease not on dialysis. In another exciting development, NHS Digital permitted the UKRR dataset to be linked to the Hospital Episode Statistics and Civil Registration datasets for audit work. With additional data come opportunities and challenges.

Methods

The UKRR recently undertook a major review of its operations around reporting, managing and sharing data, which included seeking the feedback of clinicians, researchers and patients. The UKRR continues to consult with The Renal Association trustees and UKRR Patient Council to decide how best to implement these changes.

Results

1) Annual report

The 21st annual report – analyses of 2017 patient data – will be released in a new, leaner, predominantly online format, with the following key changes:

- analyses will be directly linked to the Renal Association Clinical Guideline Standards
- chapters will reflect treatment types and stages, rather than biomedical parameters
- there will be less commentary, making it easier to find information
- two report summaries will be published in a medical journal – one for adult data and one for paediatric data
- novel analyses will be published outside the report – forthcoming publications include diabetes and ethnicity
- a booklet of plain English summaries and infographics for every chapter (see figure 1) will be co-produced with the UKRR Patient Council to improve accessibility to the report.

Figure 1. An example of an infographic summarising key statistics about the in-centre haemodialysis population in 2016

These changes will speed up the production of the annual report, giving the renal community more timely access to UKRR data. Timeliness will be further enhanced through the development of a data portal.

2) Applying to access UKRR data

The process for researchers and clinicians to apply to access UKRR data is being amended:

- all applications will go through the same process – this includes applications that wish to use the UKRR's data permissions and those that have their own data permissions
- all successful applications will be listed on a new UKRR website along with associated outputs.

3) Audit/research ready dataset

A data completeness review is underway at the UKRR to identify which data items are of a sufficient quality and completeness to be suitable for audit and research analyses. Making this reduced dataset publicly available will increase transparency of data availability.

Discussion

These changes will enable a greater breadth of analyses to be conducted at the UKRR, without compromising the UKRR's core audit role. Furthermore, a diverse and dynamic communication strategy will ensure the wide dissemination of UKRR work. We very much welcome feedback to make our annual report, data and other outputs as usable and useful to the renal community as possible (ukrr-research@renalregistry.nhs.uk).