

Notes for Interpretation – Completeness portal

The Completeness data portal has been developed by the UK Renal Registry to help clinicians and researchers to understand data completeness for key data items held in the wider UKRR dataset. It is worth noting that poor data completeness may result from failure to undertake a test or to accurately capture patient data. We envisage that data completeness is likely to improve with the development of the UK Renal Data Collaboration (UKRDC).

How are the data presented?

For adults, we present annual completeness for the last 5 years. The data are shown at the satellite unit level, and then grouped into centres, regions and then countries; in addition data are presented by modality. Completeness of ethnicity, date of presentation, body mass index (BMI) and primary renal diagnosis (PRD) are presented for the incident cohort. Completeness data on biochemistry variables are shown for the prevalent cohort, and considered complete if there is at least one measurement in the year. Regarding the paediatric patients, we present completeness for three fiveyear cohorts due to the small numbers in some units.

FAQs

1. Why do the numbers in the portal differ from what is presented in the latest annual report?

There are several reasons why numbers may not match exactly with those in the annual report. Firstly, the way in which we calculate data completeness in the annual report is different to the portal. We look for any values across all quarters in the portal to determine completeness for biochemistry variables for instance. In the annual report, we only look at whether data are present in the 3rd and 4th quarter for biochemistry measures. Thus, the completeness figures in the report are generally lower although the difference is small.

Second, year upon year, the completeness for any given variable presented in the portal can be improved if the units send this data to the registry in the latest returns. So it may be that what was published in previous annual reports is not exactly the same as what is presented in the portal due to improvements in data completeness.

Third, there are some ways in which we process the data in the annual report that might differ to the portal. For example, sometimes small changes are made to make the data presented in the report more accurate, but these changes are not made to the underlying database, and are therefore not reflected in the portal.

2. Is the completeness data for incident patients a reflection of what we know now about the patients or what we knew at the time (i.e. up to 5 years ago)?

This is a reflection of what we know now about the patients, so it will be more complete than it was at the time as centres fill in data retrospectively. This explains some apparent decrease in reporting of incident data with time.

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3. What are the prevalent and incident cohorts?

The incident population is defined as all patients who started renal replacement therapy (RRT) at UK renal centres, with the exclusion of patients that recovered their renal function for more than 90 days after having had only a short spell of RRT. The adult prevalent population for a year is defined as all RRT patients being treated at centres returning data to the UKRR for that year and who were alive on 31 December of that year.

Functionality

1. How do I collapse or expand the rows to view data at different geographical levels?

If you would like to view the data at a 'lower level' i.e. the satellite unit, you need to hover over the higher level (centre in this case) and click on the plus sign that is displayed when the cursor is placed on the right hand side of the name 'centre'. This expands the table to the right and displays the results of the lower level. To return to the higher level, hover over "centre" again but instead click on the minus sign that is displayed (see demo below). Viewing in full screen mode (icon at the bottom right of the Tableau window) will make the data easier to see and navigate.



2. Why are no data displayed when I change options?

Data may not be available for certain combinations of filters (for example paediatric data at the satellite level, or completeness of biochemistry data for incident patients). Selecting from the available options will display the relevant data. If you still find you cannot get a filter combination to show any data use the "refresh" icon in your browser address bar to reset all the filters back to their starting state. It is also possible that there is no data for that combination of filters (for example – there is no paediatric dialysis access data).

3. If I have any further queries on the portal data, who should I contact?

Please send your query to renalregistry@renalregistry.nhs.uk



Abbreviations and definitions

| BMI | body mass index at dialysis start (incident patients only) |
|-----------------------|--|
| BP | blood pressure (pre-dialysis unless otherwise specified) |
| date first seen | date first seen by renal services |
| Hba1c | glycated haemoglobin |
| HD | haemodialysis |
| ICHD | in-centre haemodialysis |
| no. sessions per week | number of dialysis sessions per week |
| PD | peritoneal dialysis |
| PRD | primary renal disease |
| Presentation | presentation time (between date first seen and starting RRT) |
| Time on dialysis | length of dialysis session |