UK Renal Registry 13th Annual Report (December 2010): Introduction

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The UK Renal Registry (UKRR) provides independent audit and analysis of renal replacement therapy (RRT) in the UK. The Registry is part of the UK Renal Association and is funded directly by participating renal centres through an annual capitation fee per patient per annum. The UKRR remains unique amongst renal registries in publishing both centre-specific analyses of indicators of quality of care, such as haemoglobin and also age-adjusted survival statistics for each renal centre.

Data are provided from all renal centres in the UK. For adult patients the Registry receives quarterly electronic data extracts from information systems used for clinical and administrative purposes within each renal centre in England, Wales and Northern Ireland and receives data from Scotland via the Scottish Renal Registry. Details of how the Registry extracts, analyses and reports on data for patients on RRT have been described previously [1].

The UKRR has also taken on the role of collecting paediatric data. This task is somewhat different from the collection of data from adult centres as many paediatric centres do not have clinical information systems which are used for day-to-day patient care. This is a major project as it is necessary to prepare and amalgamate the existing paediatric data for inclusion in the Registry database and to develop methods of obtaining data from the paediatric centres: this project is well under way.

This report contains analyses of data related to patient care in 2009. The inclusion of laboratory data permits analyses not only of the incidence, prevalence and outcomes of RRT in the UK, but also the achievement of clinical performance measures as defined by the Renal Association's Clinical Practice Guidelines. These guidelines have been recently reviewed and thus present new audit targets for forthcoming years for centres and challenges for the software extraction routines (see www.renal.org).

Personnel changes

There were significant changes of personnel within the Registry in 2010. After 15 years service Dr David Ansell ceased working for the Registry. David had worked for the Registry from its early days and made an enormous contribution to the work of the Registry, to its publications and to its goal of improving patient care.

The deputy director, Prof Chris Maggs, retired early in 2011. Prof Terry Feest has returned to the Registry as Acting Director pending the appointment of a permanent Director before the end of 2011.

Completeness of data returns from UK renal centres

Data are still incomplete, particularly those data items that require clinical input, including primary renal disease and comorbidity at the start of RRT.

These deficiencies limit the Registry's ability to perform analyses that are fully adjusted for case-mix and it is of major importance that returns of these data items are improved.

Table 1 gives completeness of data returns on ethnic origin, primary renal diagnosis, date first seen by a nephrologist and comorbidity at the start of RRT, from each centre in the UK for 2009.

It is disappointing that whilst there have been some changes in the performance of individual centres this has been variable and there has been no significant improvement in the last year.

Data collection and validation

The Registry is conducting a major review of the processes used for collection and validation of data and of its communications with renal centres. This review has demonstrated that the processes used until now had not kept abreast of developments in technology and were no longer fully fit for purpose. For some 4 months these have been examined in detail and new more automated processes developed which will reduce the time taken to collect and validate data, will provide more consistency in data validation and should therefore facilitate provision of more accurate data. Communications with renal centres concerning the data files obtained have been revised and it is hoped that centres will now find the feedback helpful and informative.

Inevitably this review has led to some delay in starting to process the data files for 2010 but this delay was necessary in order to produce a process which will enable faster data collection and validation and timely production of the Registry Reports in the future.

The Registry is also planning a pilot project of radical new ways of retrieving data from renal centres, perhaps on a daily basis. This project will work with Renal Patient

Table 1. Percentage completeness of data returns for ethnicity, primary renal diagnosis, date first seen by a nephrologist and comorbidity at the start of RRT (incident patients 2009)

Centre	Ethnicity	Primary diagnosis	Date 1st seen	Comorbidity	Average completeness	Country
Newry	100.0	100.0	100.0	100.0	100.0	N Ireland
Ulster	100.0	100.0	100.0	100.0	100.0	N Ireland
L Kings	96.1	100.0	98.4	100.0	98.6	England
Wolve	98.5	98.5	98.5	98.5	98.5	England
Nottm	100.0	100.0	98.3	94.4	98.2	England
Bradfd	90.7	98.1	90.6	96.3	93.9	England
Oxford	97.1	94.1	91.0	91.2	93.4	England
Derby	84.6	100.0	97.4	91.0	93.3	England
Stevng	100.0	100.0	96.9	74.2	92.8	England
Wrexm	100.0	100.0	89.5	79.0	92.1	Wales
Tyrone	100.0	100.0	100.0	68.4	92.1	N Ireland
Dorset	100.0	100.0	88.4	80.0	92.1	England
Carlis	95.8	100.0	83.3	83.3	90.6	England
Middlbr	89.5	89.5	96.8	85.3	90.3	England
Leeds	94.9	84.0	92.9	86.5	89.6	England
Kent	88.3	99.2	97.7	60.2	86.3	England
Bristol	96.8	88.5	71.3	79.6	84.1	England
Derry	93.8	100.0	[a]	56.3	83.3	N Ireland
Donc	95.0	100.0	95.0	42.5	83.1	England
Antrim	100.0	100.0	100.0	31.6	82.9	N Ireland
Ports	86.8	99.3	96.0	40.4	80.6	England
Leic	95.0	87.8	68.8	66.7	79.6	England
Chelms	76.3	97.4	97.4	44.7	79.0	England
York	93.5	71.7	82.6	67.4	78.8	England
Shrew	93.6	95.7	100.0	17.0	76.6	England
Sheff	52.1	97.9	97.9	52.1	75.0	England
Swanse	100.0	100.0	0.9	97.4	74.6	Wales

Table 1. Continued

Centre	Ethnicity	Primary diagnosis	Date 1st seen	Comorbidity	Average completeness	Country
Belfast	75.5	100.0	81.1	37.7	73.6	N Ireland
Sund	98.4	100.0	0.0	95.3	73.4	England
Basldn	96.2	96.1	[c] 0.0	88.5	70.2	England
Bangor	10.0	100.0	93.1	76.7	69.9	Wales
L Barts	97.0	96.6	0.0	81.6	68.8	England
Glouc	16.5	98.7	93.4	64.6	68.3	England
M RI	94.7	87.3	41.2	44.0	66.8	England
Sthend	82.6	100.0	0.0	82.6	66.3	England
Norwch	54.2	100.0	85.4	22.9	65.6	England
Carsh	85.0	95.2	1.0	68.1	62.3	England
Camb	95.7	[b] 99.3	38.4	0.7	58.5	England
L St.G	83.3	79.6	6.5	54.6	56.0	England
Prestn	75.5	93.9	0.0	49.0	54.6	England
B Heart	99.0	99.0	1.0	16.2	53.8	England
Liv RI	58.8	[b] 100.0	0.0	45.6	51.1	England
Redng	100.0	99.0	[c] 0.0	2.0	50.3	England
Ipswi	2.6	97.4	92.1	2.6	48.7	England
M Hope	100.0	94.1	0.0	0.0	48.5	England
B QEH	98.8	92.9	0.4	0.8	48.2	England
Dudley	92.4	100.0	0.0	0.0	48.1	England
Newc	100.0	91.0	[c] 0.0	0.0	47.8	England
Wirral	98.4	17.7	71.7	0.0	46.9	England
Plymth	11.7	91.7	3.3	76.7	45.8	England
Covnt	89.9	92.4	0.0	0.0	45.6	England
Liv Ain	22.2	91.7	0.0	66.7	45.1	England
Clwyd	23.5	100.0	0.0	52.9	44.1	Wales
L Guys	62.0	98.9	4.0	3.4	42.1	England
Exeter	95.7	47.1	19.4	0.7	40.7	England
Truro	45.1	45.1	23.5	45.1	39.7	England
Stoke	19.3	99.1	37.6	0.0	39.0	England
Brightn	58.3	95.8	0.0	0.0	38.5	England
Hull	10.8	68.6	0.0	71.6	37.7	England
Cardff	48.3	82.8	0.0	0.6	32.9	Wales
L West	3.1	100.0	0.0	2.0	26.3	England
L Rfree	89.7	0.6	0.0	0.0	22.6	England
Colchr	13.3	6.7	0.0	0.0	5.0	England
Airdrie	2.1	100.0				Scotland
D & Gall	0.0	100.0				Scotland
Dundee	0.0	100.0				Scotland
Dunfn	0.0	100.0				Scotland
Edinb	0.0	100.0				Scotland
Inverns	0.0	100.0				Scotland
Klmarnk	0.0	100.0				Scotland
Glasgw	0.6	97.7				Scotland
Abrdn	0.0	98.1				Scotland

[a]Centre excluded due to small patient numbers
[b]Data from these centres included a high proportion of patients whose primary renal diagnosis was 'uncertain'. This appears to have been largely because software in these centres was defaulting missing values to 'uncertain'
[c]As in previous Reports, all 'first seen' dates have been set to 'missing' because at least 10% of the dates returned were identical to the date of start of RRT. Whilst it is possible to start RRT on the day of presentation, comparison with the data returned from other centres raises the possibility, requiring further investigation, of incorrect data entry or extraction from these centres

View. If successful this would facilitate the production of timely interim audit reports pending publication of the detailed annual analysis of the present.

Interpretation of centre-specific comparisons

The Registry continues to advise caution in the interpretation of the comparisons of centre-specific attainment of clinical performance measures provided in this Report. As in previous reports, the 95% confidence interval is shown for compliance with a Guideline. The calculation of this confidence interval (based on the binomial distribution) and the width of the confidence interval depends on the number of values falling within the Standard and the number of patients with reported data.

To assess whether there is an overall significant difference in the percentage reaching the Standard between centres, a Chi-squared test has been used. Caution should be used when interpreting 'no overlap' of 95% confidence intervals between centres in these presentations. When comparing data between many centres, it is not necessarily correct to conclude that two centres are significantly different if their 95% confidence intervals do not overlap. If 72 centres were compared with each other, 2,556 such individual comparisons would be made (centre X with the other 71 centres and then centre Y with the other 70 centres etc.) and one would expect to find 127 apparently 'statistically significant' differences at the $p = 0.05$ level and still 25 at the $p = 0.01$ level. Thus, if the renal centres with the highest and lowest achievement of a standard are selected and compared, it is probable that an apparently 'statistically significant result' will be obtained. Such comparisons of renal centres selected after reviewing the data are statistically invalid. The UKRR has therefore not tested for 'significant difference' between the highest achiever of a standard and the lowest achiever, as these centres were not identified in advance of looking at the data.

Furthermore all differences between centres need to be interpreted in light of measured and unmeasured variables that may account for these differences, the clinical impact of the differences and trend in these variables over time. For instance the 1 year survival of a centre may be in the lowest quartile of centres but be improving faster than others and may reflect excellent care given the case-mix and socio-demographic population base of the region.

The role of the UKRR in improvement and the identification of underperformance

The Registry is part of the Renal Association. The Chair of the Registry is appointed by the Renal Association and reports to the Registry Management Board, which comprises the Trustees of the Renal Association and is chaired by the immediate past President. The UKRR has no statutory powers. However, the fact that the UKRR provides centre-specific analyses of important clinical outcomes, including survival, makes it important to define how the UKRR responds to apparent underperformance. Open publication of the analyses, together with an Executive Summary for Commissioners, should by itself drive up the quality of care provided. The UKRR also ensures that the Clinical Director of any service that is identified as an 'outlier' for age-adjusted survival is informed in advance of publication of this finding and asked to provide evidence that the Clinical Governance department and Chief Executive of the Trust housing the service are informed. In the event that no such evidence is provided, the Chair of the UKRR would inform the President of the Renal Association, who would then take action to ensure that the findings were properly investigated. These procedures are followed even if there is evidence that further adjustment, for instance for comorbidity, might explain outlier status.

Information governance

The UKRR operates within a comprehensive governance framework which concerns data handling, reporting and research, including data linkages and sharing agreements. The Chair of the UKRR Management Board is appointed as the Lead for Governance, with the UKRR Director responsible for day to day management of governance compliance. The Framework is based on good practice, as described in the Information Governance Framework:

(http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/igap/igaf)

and the Research Governance Framework for Health and Social Care (2005):

(http://www.dh.gov.uk/en/Aboutus/Researchanddevelopment/A-Z/Researchgovernance/DH_4002112).

The Registry has temporary exemption, granted by the Secretary of State under section 251 of The National Health Service Act (2006), to hold patient identifiable data. This exemption is reviewed annually.

The Registry and the National Renal Dataset

The National Renal Dataset (NRD) was designed to enable a detailed description and audit of renal services. It was developed at a time when it was envisaged that hospitals would be acquiring clinical information systems which would then send data to the Secondary Users Service (SUS) through Connecting for Health. It was 'mandated' for use, which means that the suppliers of clinical information systems are obliged to provide the capacity for these data to be recorded in those systems.

The NRD dataset was to be collected from a variety of sources including hospital theatre systems, renal centre IT systems, primary care IT systems, pathology IT systems and many others. It was not envisaged that it would be the responsibility of renal centres to assemble and enter all these data into their own systems.

Sadly the investment envisaged in hospital clinical information systems and the development of Connecting for Health has not taken place and the NRD does not have the envisaged support. This leaves a situation whereby most renal centres do not have IT systems capable of collecting the whole dataset and have not received the investment to purchase such systems or to provide staff to assemble the data.

In many quarters there is an expectation that the UK Renal Registry, together with UK Transplant, will be collecting these data, as is shown in the following extract from the NHS Information Centre website:

'The dataset extends the existing collections of the UK Renal Registry, UK Transplant and the British Association of Paediatric Nephrologists. Data collection and submission of the NRD will be included within these existing collection mechanisms'.

This is not strictly correct, as it is not the primary responsibility of the Renal Registry to collect these data and it is certainly not the role of the Registry to pass such data on to any other body. The Registry can easily provide the capacity within its database to store the data items from the NRD for subsequent audit, but the Registry has not been resourced for the enormous workload of validating and cleaning such data and furthermore, it can only collect data which are being stored on renal centre IT systems; most of these data items are not yet available on these systems.

Nevertheless the NRD is a valuable potential tool for good audit and the Registry will be working with the renal community to evaluate which items will be most important for critical audits and will then work with renal centres to find ways of assembling those data, extracting them and performing the chosen audits.

Vascular access

The problems of the NRD are well demonstrated by the recent Vascular Access Audit exercise. The Registry installed a large number of data items onto its database which were related to vascular access and were derived from the NRD. It soon became evident that relatively few renal centres had IT systems with the capacity to store the relevant vascular access data items from the NRD. Extraction routines were developed and the Registry did extract data from those centres with the capacity to store the data in their systems, but it was soon clear that in many of those centres only very few vascular access data items were actually in their systems and available. As a result the NHS Information Centre had to resort to sending spreadsheets to renal centres to fill in information, which provided useful cross-sectional access information but did not move forward existing means for the continuing collection of vascular access audit data. The Registry is working with renal centres, NHS Kidney Care and the Department of Health to define which items are both important and available for collection for audit of vascular access and then to find ways of resourcing and enabling centres to collect the data.

Linkage with Hospital Episode Statistics (HES) database

To date, the Registry's analyses of the quality of care have largely been confined to clinical and surrogate outcomes and have not included costs or hospitalisation. The UKRR is working with academic colleagues in Sheffield on a major two year project to explore the benefits of linkage with the Hospital Episode Statistics

database, which holds information not only on hospital admissions but on discharge diagnoses and procedure codes. This project was funded by Kidney Research UK and the DH Research Capability Programme and will help understanding of the health care burden and variation thereof for patients in receipt of renal replacement therapy.

Peer-reviewed publications since the last annual report

The UKRR's primary role is to use data to develop high-quality analyses to drive a cycle of continuous improvement in the care of patients with kidney disease in the UK. Research is an important part of improving the quality of existing analyses and developing new ones. Research from the Registry appears in peer-reviewed journals [2–12] in addition to articles published in collaboration with the EDTA-ERA Registry [13–17]. A list of publications involving analyses of UKRR data is available on the UKRR website at www.renalreg.org.

The future

With the progressive improvement in survival of patients on RRT documented in this report it seems inevitable that the prevalence of RRT will continue to increase, even with continuing improvements in preventive care, earlier referral of patients with advanced CKD and where appropriate, provision of supportive care in place of RRT for those who wish for it. RRT is a high cost therapy and this will pose a challenge to the NHS and to the UK renal community. This will make it more important than ever to submit high quality data on the outcomes of RRT and to develop reliable analyses of the epidemiology and outcomes of conservative management of advanced CKD.

Conflicts of interest: none

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