UK Renal Registry 14th Annual Report: Introduction

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Introduction

The UK Renal Registry (UKRR) provides independent audit and analysis of renal replacement therapy (RRT) in the UK. The UKRR 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 relatively 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 UKRR receives quarterly electronic data extracts from information systems used for clinical and administrative purposes within each renal centre in England, Wales and Northern Ireland. Data from Scotland is received via the Scottish Renal Registry. Details of how the UKRR 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 UKRR 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 2010. 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 present 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 UKRR in 2011. Ron Cullen was appointed as Director of the Renal Registry. Ron's background is in quality improvement and policy development having worked extensively on both the clinical governance agenda and as Head of Healthcare, Quality and Standards within the Department of Health. Prof Terry Feest remains within the Registry as a Medical Advisor. Two data managers (Shaun Mannings and Jo Wilson), a statistician (David Pitcher), a programmer (George Swinnerton) whose main work has been to refine our validation steps and help with systems in general and secretary (Laura Woodward) have joined the Registry.

Data collection and validation

The UKRR has conducted a major review of the processes used for collection and validation of data and

of its communications with renal centres. This review demonstrated that the processes used had not kept abreast of developments in technology and were no longer fully fit for purpose. For some four months these have been examined in detail and new more automated processes developed which will reduce the time taken to collect and validate data. This will result in 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 led to some delay in starting to process the data files for 2010. This delay was necessary in order to produce a process which will enable faster data collection, validation and timely production of the Registry Reports in the future. It is expected the data for 2011 will be validated by November 2012 and the 2012 data by June 2013. It is the intention of the UKRR to publish data following an initial validation on a quarterly basis via the data portal (www.renalreg.com).

The UKRR 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 PatientView and RADAR to produce a single extraction routine. If successful this would facilitate the production of timely interim audit reports pending publication of the detailed annual analysis of the present.

Completeness of data returns from UK renal centres

Data completeness has generally improved this year, partly because of the improved feedback to centres and other improvements mentioned above. Table 1 shows the completeness of some key items over four years. In contrast to elsewhere in this Report, the first three rows of the table show the percentages as they were published in previous reports rather than as the data stands now. This is because the work on improving data collection and validation has also improved the 'historical' completeness, e.g. more information on date first seen for incident patients in 2009 is now available than when it was published in last year's report. Large improvements can be seen for ethnicity, date first seen and cause of death and these improvements will enable better and more comprehensive analyses. However, data are still incomplete, particularly for those data items that require clinical input, for example comorbidity at the start of RRT. These deficiencies limit the UKRR's ability to perform analyses that are fully adjusted for case-mix; it is of major importance that returns of these data items are improved.

Table 1. Percentage completeness of data returns for ethnicity, date first seen by a nephrologist and comorbidity (all for incident patients, E, W & NI) and cause of death (for deaths in 2010 amongst incident or existing patients, UK)

	2007	2008	2009	2010
Ethnicity	75.9	73.2	77.0	94.3
Date first seen	34.7	42.3	39.9	76.9
Comorbidity	40.0	40.0	44.4	49.1
Cause of death	35.7	38.4	42.2	60.1

Table 2 gives completeness of data returns on ethnic origin, primary renal diagnosis, date first seen by a nephrologist and comorbidity at the start of RRT in 2010, and also for cause of death for deaths in 2010, by centre. This shows that there are still some centres where improvements could be made.

Interpretation of centre-specific comparisons

The UKRR 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 (generally 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, Chi-squared tests have sometimes been used. Caution should be used when interpreting 'no overlap' of 95% confidence intervals between centres. 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

Table 2. 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 2010) and for cause of death (for deaths in 2010 amongst incident or existing patients)

Centre	Ethnicity	Primary diagnosis	Date first seen	Comorbidity	Cause of death	Average completeness	Country
Tyrone	100.0	100.0	100.0	100.0	100.0	100.0	N Ireland
Ulster	100.0	100.0	100.0	95.0	100.0	98.8	N Ireland
Nottm	100.0	100.0	97.3	96.5	98.8	98.1	England
Antrim	100.0	95.1	100.0	95.1	100.0	97.6	N Ireland
L Kings	93.2	100.0	93.9	99.3	96.1	97.3	England
Wolve	100.0	99.1	99.0	92.5	96.9	96.9	England
Wrexm	100.0	95.8	95.8	100.0	95.7	96.8	Wales
Kent	89.6	97.8	100.0	100.0	89.0	96.7	England
Newry	100.0	100.0	95.2	95.2	95.2	96.4	N Ireland
Leeds	98.5	99.2	100.0	89.2	95.9	96.1	England
Middlbr	100.0	100.0	96.9	95.9	88.2	95.2	England
Stevng	100.0	100.0	96.4	98.2	84.9	94.9	England
Bristol	100.0	99.4	97.6	92.3	89.4	94.7	England
Bradfd	93.8	98.4	100.0	92.2	87.9	94.6	England
York	94.4	100.0	94.4	91.7	88.9	93.7	England
Swanse	100.0	98.5	99.2	78.5	96.9	93.3	Wales
Derry	100.0	100.0	100.0	72.2	100.0	93.1	N Ireland
Oxford	99.4	94.6	95.8	94.6	84.6	92.4	England
Bangor	100.0	100.0	96.0	96.2	73.9	91.5	Wales
Derby	87.5	97.5	98.8	85.0	84.2	91.4	England
B Heart	100.0	99.0	95.8	73.7	96.6	91.3	England
Basldn	100.0	100.0	93.8	90.6	71.0	88.8	England
Sund	100.0	94.6	89.1	78.2	93.5	88.8	England
Truro	100.0	97.7	95.3	67.4	93.3	88.4	England
Donc	100.0	100.0	95.5	61.4	90.9	86.9	England
Shrew	100.0	100.0	100.0	100.0	46.0	86.5	England
Dorset	100.0	95.8	87.5	65.3	95.7	86.1	England
Sthend	96.7	90.0	90.0	70.0	92.3	85.6	England
Prestn	98.4	95.1	96.7	45.9	95.7	83.3	England
Hull	97.7	92.1	64.8	84.1	90.9	83.0	England
Glouc	98.3	100.0	91.4	43.1	97.3	82.9	England
Belfast	97.2	98.6	93.0	46.5	82.8	80.2	N Ireland
Leic	95.6	81.2	98.0	64.0	70.1	78.3	England
Chelms	88.1	95.2	97.6	28.6	86.7	77.0	England
Ports	98.7	96.7	98.0	45.3	67.0	76.7	England
Redng	100.0	95.5	97.8	0.0	97.3	72.7	England
Norwch	88.2	91.8	77.4	38.8	77.0	71.3	England
Dudley	100.0	97.6	90.0	0.0	94.3	70.5	England
L St.G	94.0	95.2	75.9	54.2	53.1	69.6	England
Sheff	99.3	91.7	98.6	78.5	3.0	67.9	England
Carlis	100.0	100.0	[b] 0.0	61.9	100.0	65.5	England
Newc	100.0	97.9	93.7	51.6	14.3	64.4	England
Exeter	86.8	96.3	61.8	4.4	89.5	63.0	England
Plymth	94.5	92.7	0.0	72.7	78.7	61.0	England
Carsh	85.5	81.0	86.8	67.9	6.7	60.6	England
Stoke	98.9	83.9	100.0	0.0	53.9	59.5	England
L Barts	97.6	89.9	[b] 0.0	72.0	73.9	58.9	England
Colchr	81.3	81.3	84.4	0.0	69.6	58.8	England
L Guys	95.1	77.1	86.7	2.1	67.3	58.3	England
Ipswi	100.0	[a] 44.1	93.9	8.8	70.0	54.2	England
Cardff	98.4	99.5	95.7	16.0	2.0	53.3	Wales
Wirral	96.2	69.2	82.4	0.0	54.1	51.4	England

Table 2. Continued

Centre	Ethnicity	Primary diagnosis	Date first seen	Comorbidity	Cause of death	Average completeness	Country
Clwyd	84.6	[a] 34.0	69.2	0.0	100.0	50.8	Wales
Covnt	99.2	97.5	95.7	0.9	0.0	48.5	England
M RI	96.9	82.2	62.3	40.5	4.7	47.4	England
B QEH	100.0	100.0	88.3	0.0	0.6	47.2	England
Liv RI	71.6	[a] 28.0	47.5	20.6	71.6	41.9	England
Camb	99.1	[a] 46.3	99.1	0.9	10.4	39.2	England
L Rfree	94.1	21.7	89.6	0.5	1.7	28.4	England
L West	98.9	98.9	0.0	0.8	0.5	25.0	England
Liv Ain	34.7	[a] 2.0	[b] 0.0	4.1	80.0	21.5	England
M Hope	100.0	48.6	1.4	0.0	0.0	12.5	England
Brightn	1.9	28.0	1.9	5.6	2.4	9.5	England
Abrdn		100.0			89.2		Scotland
Airdrie		100.0			96.8		Scotland
D & Gall		100.0			100.0		Scotland
Dundee		100.0			85.7		Scotland
Dunfn		100.0			72.4		Scotland
Edinb		100.0			98.3		Scotland
Glasgw		100.0			66.4		Scotland
Inverns		100.0			91.7		Scotland
Klmarnk		100.0			93.9		Scotland

[a]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'. For these centres the value given is the percentage with a specific diagnosis

[b]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

$p = 0.01$ 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 one 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. Furthermore the interpretation of survival in RRT patients needs to be seen in the context of the total population with advanced CKD (symptomatic stage 5 CKD) that may merit RRT. Since conservative care is used for many patients in whom there is a choice not to start dialysis the selection of sicker (and/or) older patients in one centre versus the practice in another centre may result in differences in survival due to this potential selection bias. For this important reason and the need to understand the quality of conservative care it is hoped to expand the Registry remit (technically and with appropriate information governance) to capture routine data on those patients with CKD stage 5.

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

The UKRR is part of the Renal Association. The Chair of the UKRR is appointed by the Renal Association and reports to the Renal 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 under-performance. 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' (below two standard deviations from the mean) for age-adjusted survival is informed 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 UKRR 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. This framework has been further strengthened this year with Dr Afzal Chaudhry (Chair of the Registry Committee) appointed as the Caldicott guardian and David Bull appointed as information governance lead. The UKRR has successfully completed the Connecting for Health information governance toolkit to a satisfactory standard.

The UKRR and the National Renal Dataset

The National Renal Dataset (NRD) was designed, with the support of the Department of Health, 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 Uses Service (SUS) through Connecting for Health. It was 'mandated' for use, which meant that the suppliers of clinical information systems are obliged to provide the capacity for these data to be recorded in those systems, and hospital Trusts to collect and submit the data.

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 never envisaged that it would be the responsibility of renal centres to assemble and enter all these data into their own systems, rather that they would be collected in these other systems as part of routine care.

Sadly the investment envisaged in hospital clinical information systems and the development of Connecting for Health has not taken place and the current information strategy is focused instead on sharing information between existing systems to improve access to information. 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 NHS Blood and 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 UKRR to collect these data and it

is certainly not the role of the UKRR to pass such data onto any other body. The UKRR can easily provide the capacity within its database to store the data items from the NRD for subsequent audit, but the UKRR has not been resourced for the significant workload of validating and cleaning such data; furthermore it can only collect data which are being stored on renal centre IT systems and most of these data items are not yet available on these systems. More fundamentally there has been a realisation that the whole of the NHS needs to reduce the scale of the burden of data-collection. Only key information with direct evidence of improvement of outcomes is likely to be a priority for centralised collection in the future. Nationally agreed data standards such as the NRD, reflecting the opinions of the wider renal community (including the UKRR and NHSBT) help direct where that collection effort should be focused. Encouragingly in many cases prioritising data item collection can effectively be done with little or no effect on the proven benefits of reflecting variation in performance to clinicians. Whilst centres that have systems and processes to effectively submit complete datasets should be congratulated, it is likely that there will be increasing focus on collecting a smaller number of items well. In this regard the goals of both the UKRR and the NRD remain the same.

Nevertheless going forward, the NRD is still a valuable potential tool for good audit and the UKRR 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. The UKRR will also continue to work to refine and influence the continued development of the NRD and provide data where it is available.

Vascular access

Over the last few years the Vascular Access Audit was funded by the Healthcare Quality Improvement Partnership (HQIP) and run by the NHS Information Centre. The funding for this project came to an end with the expectation that centres would have established systems and processes that record the access for all incident dialysis patients. The Renal Association and the UKRR always considered that this project should fall to its systems and electronic renal patient records. Therefore earlier this year and with support from renal centres, NHS Kidney Care and the Department of Health the UKRR refined which items are both important and available for collection for audit of vascular access. Since some systems were not ready to submit electronically the UKRR agreed that undertaking a spreadsheet exercise again this year was prudent and at the same time are assessing site readiness to collect future data electronically. This year the exercise was combined with an audit of peritoneal dialysis to provide richer information.

Linkage with Hospital Episode Statistics (HES) database

To date, the UKRR'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 has worked successfully with academic colleagues in Sheffield on a three 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 (see Chapter 13 The Linkage of Incident Renal Replacement Therapy Patients in England (2002–2006) to Hospital Episodes and National Mortality Data) for further information. This project, funded by Kidney Research UK and the Department of Health Research Capability Programme has been highly successful and has paved the way for regular linkage with hospital episode data. Furthermore, the recent amalgamation of the General Practice Research Database with the HES data (now called Clinical Practice Research Datalink, www.CPRD.com) means that the potential to assess many aspects of care for RRT patients for that proportion of the population covered by the CPRD is possible.

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 UK Renal Registry appears in peer-reviewed journals [2–10] in addition to articles

published in collaboration with the EDTA-ERA Registry [11–12].

Conclusion

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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