Chapter 2
Introduction

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Key Words
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Abstract
The 12th Annual Report from the UK Renal Registry (UKRR) contains analyses of data submitted from every centre providing clinical supervision of renal replacement therapy (RRT) in England, Wales, Northern Ireland and (via the Scottish Renal Registry) Scotland. The data are largely extracted direct from clinical information systems used for direct clinical care [1] and the inclusion of laboratory data permit 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. The UKRR remains unique amongst renal registries in not only publishing centre-specific analyses of outcomes, including laboratory variables but also including age-adjusted survival statistics. Data are still incomplete, particularly on those data items that require clinical input, including primary renal disease and comorbidity at the start of RRT, and these deficiencies limit the Registry's ability to perform analyses that are fully adjusted for case-mix. In England, the issue of a Dataset Change Notice [2] has made submission of a defined dataset on each patient undergoing RRT mandatory, but how quickly this will accelerate improvement in data returns remains to be determined.

National developments

The National Health Service has seen unprecedented increases in funding over the past 10 years, and in renal medicine this has removed restrictions on the availability of dialysis places that may have led in the past, to covert 'rationing' of RRT. There can now be more confidence that the incidence of RRT now reflects true clinical need for RRT, whilst recognising that some patients opt (usually for reasons of advanced age or comorbidity) for maximal conservative care in preference to dialysis. However, regional variation in RRT acceptance rates remains unexplained, and could reflect differences at the level of primary care or renal centre, particularly relating to initiation of RRT in elderly patients and those with significant comorbidity. The publication of guidelines on the management of chronic kidney disease (CKD) in the UK [3, 4] has also led to an increase in referral rate to renal services, resulting in reductions in the rate of late referral of patients who subsequently require RRT. Despite these advances, the analyses in this Report still show marked variations in the use of peritoneal dialysis and home haemodialysis. These variations are the subject of continuing research and have prompted the production of Renal Association working party reports [5, 6].

As a result of the global recession and the massive public debt in the UK, the NHS now faces a period in which continued growth in funding is very unlikely; most commentators anticipate that, at most, the NHS will receive 'flat cash' funding over the next 5 years. 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 patients with CKD5 with significant comorbidity, it is inevitable that the prevalence of RRT will continue to increase. Given the cost of RRT, this

combination of circumstances will create major challenges for the UK renal community. It will be 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.

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 to develop linkages with both the Hospital Episode Statistics database (which holds information not only on hospital admissions but on discharge diagnoses and procedure codes) and with the Programme Budgeting Atlas (that provides estimates of expenditure in secondary care according to specialty).

The UK government's document 'High Quality Care for All' [7] established quality (in three domains – safety, effectiveness, and patient experience) as the 'organising principle of the NHS'. Following the publication of this Report, the Department of Health commissioned the Information Centre to develop a set of 'Indicators for Quality Improvement' for use across the NHS. The indicators include several that are relevant to the renal community: measures of the quality of care of CKD patients in primary care (derived from the Quality Analysis and Management System, and based on the Quality and Outcomes Framework [8]); a number of markers relating to organ donation; markers relating to MRSA infection amongst patients on dialysis; and a number of markers directly derived from UKRR analyses. A list of markers, together with 'metadata' supporting their use, can be downloaded from the Information Centre's website [9].

Clinical information systems used in UK renal centres

As described elsewhere [1], the Registry obtains data extracts direct from information systems used for direct patient care. This minimises the requirements for data entry, but means that information is derived from a variety of different information systems with differing functionality. At present, of centres in England, Wales and Northern Ireland that submit data directly to the UKRR, 30 centres are using a CCL Proton system, 11 Mediqal, 4 RenalPlus, 3 VitalData, 3 CCL ClinicalVision, 2 B Braun, 1 CCL Windows, 1 Cybernius, 1 Fresenius, 1 iSoft, and 6 centres are using 'in-house' systems that are not commercially available or an integral part of a main hospital IT system.

Completeness of returns from UK renal centres

Table 2.1 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.

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 Standard. 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. In this process, the eye compares centre X with the other 71 centres and then centre Y with the other 70 centres. Thus, 141 comparisons have been made and at the commonly accepted 1 in 20 level at least 7 are likely to appear 'statistically significant' by chance. If 72 centres were compared with each other, 2,556 such individual comparisons would be made 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

Table 2.1. 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 2008)

Centre	Ethnicity	Primary diagnosis	Date 1st seen	Comorbidity	Average completeness	Country
L Kings	98.0	100.0	96.7	100.0	98.7	England
Newry	85.0	100.0	100.0	100.0	96.3	N Ireland
Dorset	100.0	98.8	98.8	83.3	95.2	England
Basldn	92.5	100.0	90.0	97.5	95.0	England
Ulster	84.6	100.0	92.3	100.0	94.2	N Ireland
Derby	90.2	98.9	95.7	91.3	94.0	England
Wolve	98.9	100.0	96.5	75.9	92.8	England
Swanse	95.8	95.8	93.2	85.8	92.7	Wales
Carlis	96.8	96.8	77.4	96.8	91.9	England
Bradfd	89.8	98.3	79.7	91.5	89.8	England
Middlbr	77.4	100.0	93.5	80.7	87.9	England
Chelms	72.7	100.0	97.0	78.8	87.1	England
Wrexm	100.0	100.0	100.0	45.5	86.4	Wales
Nottm	99.1	100.0	96.5	44.4	85.0	England
Derry	83.3	100.0	83.3	66.7	83.3	N Ireland
Tyrone	84.0	100.0	96.0	52.0	83.0	N Ireland
Leic	95.8	90.2	72.4	73.0	82.9	England
Stevng	98.0	99.0	94.0	38.6	82.4	England
Antrim	70.7	100.0	70.7	73.2	78.7	N Ireland
Oxford	89.0	98.0	99.3	28.1	78.6	England
Donc	92.0	100.0	92.0	28.0	78.0	England
Shrew	100.0	100.0	98.4	12.9	77.8	England
Kent	84.1	100.0	97.0	28.8	77.5	England
Ipswi	76.3	100.0	97.3	34.2	77.0	England
Newc	98.0	99.0	100.0	2.0	74.8	England
Bristol	91.7	81.2	61.6	61.9	74.1	England
Sheff	51.1	98.9	97.7	45.0	73.2	England
York	87.9	72.7	93.5	36.4	72.6	England
Glouc	22.2	91.1	84.4	91.1	72.2	England
Ports	71.0	98.2	85.0	34.3	72.1	England
Sund	84.1	100.0	[b] 0.0	100.0	71.0	England
Belfast	70.6	100.0	63.2	45.6	69.8	N Ireland
Leeds	76.1	54.2	69.1	65.2	66.1	England
L Barts	80.1	100.0	0.5	68.7	62.3	England
Wirral	97.6	61.0	82.1	4.9	61.4	England
Carsh	80.7	100.0	0.0	61.3	60.5	England
Norwch	54.3	93.5	12.0	76.1	59.0	England
L St.G	75.3	97.8	0.0	57.3	57.6	England
Redng	99.0	100.0	7.1	1.0	51.8	England
M RI	91.9	48.5	27.2	33.8	50.4	England
Camb	91.3	[a] 33.3	72.5	1.5	49.6	England
B Heart	99.1	99.1	0.0	0.0	49.5	England
L West	48.3	100.0	[b] 0.0	48.3	49.1	England
B QEH	97.8	97.4	0.0	0.0	48.8	England
Sthend	22.9	100.0	0.0	68.6	47.9	England
Dudley	83.7	100.0	0.0	0.0	45.9	England
Prestn	87.5	92.0	0.0	0.0	44.9	England
Hull	4.3	90.6	0.0	82.9	44.4	England
Covnt	72.6	100.0	0.0	0.0	43.1	England
Cardff	66.7	100.0	0.0	1.3	42.0	Wales
L Guys	59.8	100.0	2.4	1.2	40.8	England
Bangor	4.8	100.0	[b] 0.0	57.1	40.5	Wales
M Hope	99.1	[a] 0.9	48.6	0.9	37.4	England
Plymth	14.3	100.0	2.9	31.4	37.2	England

Table 2.1. Continued

Centre	Ethnicity	Primary diagnosis	Date 1st seen	Comorbidity	Average completeness	Country
Brightn	55.2	92.2	0.0	0.9	37.1	England
L Rfree	93.1	20.0	0.6	0.6	28.6	England
Liv RI	44.7	[a] 31.1	0.0	32.0	26.9	England
Truro	30.8	38.5	[b] 0.0	35.9	26.3	England
Stoke	2.4	100.0	[b] 0.0	[c] 0.0	25.6	England
Exeter	10.4	33.6	11.4	3.0	14.6	England
Clwyd	23.1	[a] 30.8	0.0	0.0	13.5	Wales
Liv Ain	19.0	[a] 0.0	0.0	0.0	4.8	England
Colchr	11.3	0.0	0.0	[c] 0.0	2.8	England
Airdrie	5.1	100.0				Scotland
Edinb	0.0	99.0				Scotland
Dunfn	0.0	96.7				Scotland
D & Gall	0.0	94.7				Scotland
Glasgw	0.0	94.4				Scotland
Abrdn	0.0	89.1				Scotland
Inverns	0.0	68.0				Scotland
Dundee	1.5	60.0				Scotland
Klmarnk	0.0	41.2				Scotland

[a] data from these centres included a high proportion of patients whose primary renal diagnosis was 'uncertain'. As discussed in chapter 3, this appears to have been largely because software in these centres was defaulting missing values to 'uncertain'
[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
[c] comorbidity data were available in some patients reported by these centres, but the distribution of different comorbidities was judged statistically highly unlikely, raising concerns about incorrect data entry or extraction from these centres

were not identified in advance of looking at the data. The uncertainty surrounding ranking of centres can be illustrated by Monte Carlo simulation [10].

In chapters 3 and 4, tables are presented to allow Primary Care Trusts and other organisations representing relatively small populations to assess whether their incident and prevalent rates for renal failure are significantly different from that expected from the age and gender breakdown of the population they serve.

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 Management Board, comprising the Trustees of the Renal Association plus the Director, Deputy Director, and Manager of the UKRR. 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 Deputy 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).

Details of how the Registry extracts, analyses and reports on data for patients on RRT have been described previously [1].

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.

Paediatric Registry

The British Association for Paediatric Nephrology Registry Committee has previously collected data on children under the care of paediatric nephrology centres using paper census returns. During 2009, all data held on the paediatric registry were transferred to the UKRR and data from most of the 13 paediatric centres was returned electronically. Some paediatric centres use renal IT systems for routine clinical care, whilst others currently only use these systems for the purpose of data submission. Those paediatric centres not currently submitting data electronically all have plans to do so.

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 however, is an important part of improving the quality of existing analyses and developing new ones. A number of articles have been published in peer-reviewed journals since the publication of the last Report [11–18] in addition to articles published in collaboration with the EDTA-ERA Registry [19–22]. A full list of publications involving analyses of UKRR data is available on the UKRR website at www.renalreg.org.

Conflict of interest: none

References

1 Ansell D, Tomson CRV. UK Renal Registry 11th Annual Report (December 2008): Chapter 15. The UK Renal Registry, UKRR database, validation, and methodology. Nephron Clinical Practice 2009;111(Suppl 1): c277–c285.

2 Information Standards Board. Dataset Change Notice 27/2008, issued December 2008. http://www.ic.nhs.uk/services/datasets/dataset-list/renal. Last accessed 1 Feb 2010.

3 Joint Specialty Committee on Renal Medicine of the Royal College of Physicians of London and the Renal Association. Chronic Kidney Disease in Adults. UK guidelines for identification, management, and referral. Royal College of Physicians, London: March 2006. http://www.renal.org/CKDguide/ckd2005.html. Last accessed 2 Feb 2010.

4 National Institute for Health and Clinical Excellence. Chronic Kidney Disease. Early identification and management of chronic kidney disease in adults in primary and secondary care. NICE Clinical Guideline 73. www.nice.org.uk

5 Renal Association Working Party on Peritoneal Dialysis. Final Report 18.11.09. http://www.renal.org/whatwedo/Publications.aspx. Last accessed 1 Feb 2010.

6 Renal Association Working Party on Home Haemodialysis. Final Draft Report 02.12.09. http://www.renal.org/Libraries/Publications/RA_Home_HD_Working_Party_Report_January_2010.sflb.ashx. Last accessed 1 Feb 2010.

7 Professor the Lord Darzi of Denham. High quality care for all: NHS Next Stage Review final report. Department of Health 30 June 2008. http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085825. Last accessed 1 Feb 2010.

8 The Information Centre. Quality and Outcomes Framework. http://www.qof.ic.nhs.uk/ Last accessed 1 Feb 2010.

9 The Information Centre. Measuring for Quality Improvement. http://www.ic.nhs.uk/services/measuring-for-quality-improvement. Last accessed 1 Feb 2010.

10 Hodsman A, Gilg J, Ben-Shlomo Y, Roderick P, Ansell D, Tomson C. Variation between dialysis centre achievement of audit measures for serum phosphate. Data from UK Renal Registry. Abstract presented at the Annual Meeting of the Renal Association, British Renal Society, and Scottish Renal Association, Glasgow, May 2008. https://registrations-online.com/Renal2008/docs/Uploaded/Posters/P148.doc

11 Karamadoukis L, Ansell D, Foley RN, McDonald SP, Tomson CR, Trpeski L, Caskey FJ. Towards case-mix-adjusted international renal registry comparisons: how can we improve data collection practice? Nephrol Dial Transplant 2009 Aug;24(8):2306–11. Epub 2009 Mar 4.

12 Rao R, Ansell D, Gilg JA, Davies SJ, Lamb EJ, Tomson CR. Effect of change in renal replacement therapy modality on laboratory variables: a cohort study from the UK Renal Registry. Nephrol Dial Transplant. 2009 Sep;24(9):2877–82. Epub 2009 Apr 8.

13 Udayaraj UP, Ben-Shlomo Y, Roderick P, Steenkamp R, Ansell D, Tomson CR, Caskey FJ. Ethnicity, socioeconomic status, and attainment of clinical practice guideline standards in dialysis patients in the United Kingdom. Clin J Am Soc Nephrol. 2009 May;4(5):979–87. Epub 2009 Apr 8.
14 Roderick P, Byrne C, Casula A, Steenkamp R, Ansell D, Burden R, Nitsch D, Feest T. Survival of patients from South Asian and Black populations starting renal replacement therapy in England and Wales. Nephrol Dial Transplant. 2009 Dec;24(12):3774–82. Epub 2009 Jul 21.
15 Dudley CR, Johnson RJ, Thomas HL, Ravanan R, Ansell D. Factors that influence access to the national renal transplant waiting list. Transplantation. 2009 Jul 15;88(1):96–102.
16 Nitsch D, Kadalayil L, Mangtani P, Steenkamp R, Ansell D, Tomson C, Dos Santos Silva I, Roderick P. Validation and utility of a computerized South Asian names and group recognition algorithm in ascertaining South Asian ethnicity in the national renal registry. QJM. 2009 Dec;102(12):865–72. Epub 2009 Oct 14.
17 Udayaraj UP, Ben-Shlomo Y, Roderick P, Casula A, Ansell D, Tomson C, Caskey F. Socioeconomic status, ethnicity and geographical variations in acceptance rates for renal replacement therapy in England and Wales – an ecological study. J Epidemiol Community Health. 2009 Oct 23. [Epub ahead of print]
18 Macdougall IC, Tomson CR, Steenkamp M, Ansell D. Relative risk of death in UK haemodialysis patients in relation to achieved haemoglobin from 1999 to 2005: an observational study using UK Renal Registry data incorporating 30,040 patient-years of follow-up. Nephrol Dial Transplant. 2009 Nov 23. [Epub ahead of print]
19 Couchoud C, Jager KJ, Tomson C, Cabanne JF, Collart F, Finne P, de Francisco A, Frimat L, Garneata L, Leivestad T, Lemaitre V, Limido A, Ots M, Resic H, Stojceva-Taneva O, Kooman J; QUEST working group on dialysis adequacy. Assessment of urea removal in haemodialysis and the impact of the European Best Practice Guidelines. Nephrol Dial Transplant 2009 Apr;24(4):1267–74. Epub 2008 Nov 27.
20 de Jager DJ, Grootendorst DC, Jager KJ, van Dijk PC, Tomas LM, Ansell D, Collart F, Finne P, Heaf JG, De Meester J, Wetzels JF, Rosendaal FR, Dekker FW. Cardiovascular and noncardiovascular mortality among patients starting dialysis. JAMA. 2009 Oct 28;302(16):1782–9.
21 Kramer A, Stel V, Zoccali C, Heaf J, Ansell D, Grönhagen-Riska C, Leivestad T, Simpson K, Pálsson R, Postorino M, Jager K; ERA-EDTA Registry. An update on renal replacement therapy in Europe: ERA-EDTA Registry data from 1997 to 2006. Nephrol Dial Transplant 2009 Dec;24(12):3557–66. Epub 2009 Oct 9.
22 Stel VS, Dekker FW, Ansell D, Augustijn H, Casino FG, Collart F, Finne P, Ioannidis GA, Salomone M, Traynor JP, Zurriaga O, Verrina E, Jager KJ. Residual renal function at the start of dialysis and clinical outcomes. Nephrol Dial Transplant 2009 Oct;24(10):3175–82. Epub 2009 Jun 10.