UK Renal Registry 14th Annual Report: Chapter 13 The Linkage of Incident Renal Replacement Therapy Patients in England (2002–2006) to Hospital Episodes and National Mortality Data: improved demography and hospitalisation data in patients undergoing renal replacement therapy

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Key Words
Routine data · Hospitalisation · Comorbidity · Coding

Summary

- Analysis of UK Renal Registry (UKRR) data is often hampered by missing demographical and clinical data including ethnicity, time of referral and co-existing medical conditions (comorbidity). Currently the UKRR has no method of collecting morbidity data once the patient has started renal replacement therapy (RRT).
- By linking UKRR data to Hospital Episode Statistics and Office of National Statistics data, information on demography and hospitalisation could be robustly explored in 98.3% of the 21,633 patients starting RRT between 2002 and 2006.
- For individual centres, there was variation in the mean number of diagnoses coded per admission (3.92–7.22) and the proportion of admissions with discharges the same day (range 6.6–42.8%).
- Linkage allowed successful determination of ethnicity, deprivation score and comorbid conditions in over 96% of patients suitable for analysis, whereas 39% of patients had these three data items complete from the UKRR dataset alone. However using admissions in the six months pre and post start of RRT only determined primary renal disease in an additional 6.5% of patients. Where data was available from both sources, concordance between UKRR and HES for comorbid conditions was 93%.
- Approximately 50% of incident RRT patients died during follow up and in these 65.0% of patients died in hospital with acute services, with an additional 14.2% of patients having been discharged from an acute provider in the preceding 30 days and the remaining 20.8% dying with no hospitalisation in the preceding 30 days.

Introduction

Since 1998 the UK Renal Registry (UKRR) has reported on the demography of incident renal replacement therapy (RRT) patients using data provided by renal centres. The quality of this data has varied between centres making it impossible for more extensive adjustment for important measures such as incident survival. The UKRR dataset has evolved over more than thirteen years to allow the collection of data that the nephrology community recognises as important; however completion rates for these items remain variable [1], and morbidity data after initiating RRT remain uncollected.

Morbidity, more specifically the development of a new condition is often associated with hospitalisation. The burden of hospitalisation in incident RRT patients has been highlighted in other renal disease registries using linkage to hospitalisation records [2, 3]. In the United States rates of admission in transplant and peritoneal dialysis patients have gradually decreased in the last five years but admissions associated with infection remain high in haemodialysis patients [2]. Hospitalisation data, in conjunction with information supplied for payment when a patient starts RRT, is used to enhance comorbidity information [4] and perform additional analyses such as cost evaluations by the United States Renal Data Service (USRDS).

The linkage of registry data to hospitalisation data will allow the reporting of new measures of centre performance, better adjustment of existing measures and allow the study of practice patterns associated with admissions to hospital. In England, hospitalisation is captured by the Hospital Episode Statistics (HES) dataset [5]. Designed to capture all admitted care and more recently outpatient care delivered in English hospitals, data are routinely available from 1998. HES is a rich source of information on inpatient delivered care, detailing demographical information on age, sex, ethnicity and postcode/geographical data including deprivation. Admission information includes the date, type and origin of admission, primary reason for admission, secondary diagnoses (other conditions/comorbidity). Operations and procedures performed whilst an inpatient are recorded along with the location of care, specialty and clinician providing care and in addition to location and length of stay. This chapter describes the linkage of incident patients starting RRT between 2002 and 2006 to the HES and Office of National Statistics datasets, and how this linked dataset can be used to enhance existing variables and derive new measures for renal centres in England.

Methods

Datasets, linkage and cohort

Due to the strict information governance surrounding HES data, this study utilised the Research Capability Programme (RCP), formed to allow researchers access to a wide range of healthcare data. They function in an honest broker role, accessing non-anonymised data sources, linking them using sensitive items and then stripping the dataset of these items. The RCP was functioning in pilot form, having agreed to link data for 12 studies, of which four were finally delivered. They had already taken receipt of the HES dataset from April 1996 to February 2011 and the Office of National Statistics death registrations over a similar period.

Incident patients in English centres starting renal replacement therapy between 1st January 2002 and 31st December 2006 were identified from the UKRR dataset. Demographic, treatment and laboratory data from the start of RRT until the end of 2009 were extracted, encrypted and transferred to the RCP. Data sources were linked by validating NHS numbers where possible using the NHS Personal Demographics Service (PDS) then linked on NHS number and date of birth. In situations where the NHS number existed in the datasets but could not be traced additional checks against patient details were performed. The combined dataset was anonymised, encrypted and returned to the UKRR and the University of Sheffield for analysis.

HES reflect care delivered by a particular consultant, and therefore activity is captured per consulting episode. An admission to one hospital (often referred to as a spell) may contain several episodes and if the patient is transferred a continuous inpatient admission may contain several spells. These records were collapsed for various measures where appropriate using existing data processing guidance [6], factoring patient movement for elective haemodialysis where possible. Elective haemodialysis sessions and admissions for assisted peritoneal dialysis were excluded from frequency analyses. In addition, from April 2003 HES began recording outpatient attendances and these episodes were also supplied. Outpatient HES identifies provider speciality and location but healthcare providers are yet to embrace diagnosis and procedural coding available in this dataset.

For the purposes of modelling frequency of admission and comorbidity, patients who had no linked HES data or who at any point had postcode data suggesting residence outside of England were excluded from analysis.

Variables

Comorbidity prior to starting renal replacement therapy was determined from comorbid conditions as coded by International Classification of Disease version 10 (ICD10) from hospitalisations prior to starting RRT. If the date of first RRT provided by the UKRR was during an admission, the primary reason for admission was excluded from comorbidity as this was technically morbidity. The established UKRR comorbid conditions were translated into ICD10 codes by reviewing codes using the Charlson comorbidity index [7] and the Elixhauser measure [8] taken from existing literature [9]. Conditions collected by the UKRR that did not exist in the Charlson or Elixhauser schemes were converted to ICD10 codes using the NHS Information Centre HRG grouping document which includes all ICD10 and Office of Population Censuses & Surveys (OPCS) procedural codes currently employed.

The ethnicity scheme employed by the UKRR was mapped into that used by HES when collection began in 1996 and further simplified for reporting. As ethnicity in HES is patient reported, this source was used as the primary source with the UKRR dataset queried in situations when ethnicity was coded 'missing'.

Socioeconomic status was determined using the index of multiple deprivation (IMD) version 2004 which is provided for every HES admission and was computed for UKRR postcode data using Lower Super Output Area and existing lookup tables [10]. Admissions or UKRR postcodes returned in the six months pre and post the date of first RRT were used to determine the patient's lower super output area of residence. These geographical areas were ranked according to deprivation by the office of national statistics in 2004, with those ranked 1 the most deprived and 32,482 the least deprived. Summary results were converted to a score out of 100 where 100 was the most deprived for ease of interpretation.

ICD10 diagnoses associated with primary renal disease (PRD) were determined from admissions in the six months pre and post start date of RRT in patients with PRD completed in the UKRR dataset. Non-specific codes such as those spanning several PRD groups were excluded. In patients surviving over 90 days with PRD coded as missing or unknown, a HES-derived PRD was assigned if an appropriate ICD10 code was identified over the same period.

In patients starting RRT in an era when the HES outpatient dataset had been collected for at least six months, HES inpatient and outpatient episodes were examined for nephrology speciality codes (code 361) in the treatment or main speciality fields. If these were earlier than the *date first seen by a nephrologist* reported by UKRR this new data would replace the existing value. The admitting speciality from the first episode was used to determine the speciality delivering care per admission for the first 12 months of RRT in patients who survived beyond 90 days.

Location of death was assigned by comparing the date of death from the ONS and NHS-tracing provided by the UKRR to hospitalisations in NHS trusts that are recognised acute providers in performance measures produced by the NHS information centre [11]. If a patient died whilst in hospital or within 30 days from discharge from an acute provider they were included in the 30 day mortality measure, with deaths outside this period reported separately.

Statistical Analyses

Patients who survived beyond 90 days from the start of RRT were included in analyses of comorbidity, speciality of care, late referral and location of death. Modality was determined at 90 days from the UKRR timeline for modality specific analyses. Funnel plots where used to identify outliers in outcomes measured as proportions with control lines derived from the binomial distribution. Proportions of patients with individual comorbid conditions determined by HES in those patients with and without UKRR comorbidity completed were compared with the Chi-squared test. A Cox proportional hazards model was used to determine the hazard ratio for death for the presence of a comorbidity compared to the absence of that comorbidity, modelled to three years follow-up. Cases were not censored for transplantation to ensure fair comparison between centres as per previous registry reports.

For calculating an overall comorbid score, weights for the presence of individual conditions were determined from a Cox regression model factoring age, sex and the presence or absence of comorbidities from the UKRR scheme, predicting death to three years. Following previously reported methods [12], multivariate hazard ratios for the presence of conditions were converted into scores to create an overall score using the following bandings: a score of 1 for hazard ratio of $\geqslant 1.2$ and <1.5, a score of 2 for hazard ratio of $\geqslant 1.5$ and <2.

Results

Linkage

Figure 13.1 details the data returned from the RCP, including the number of records from each data source

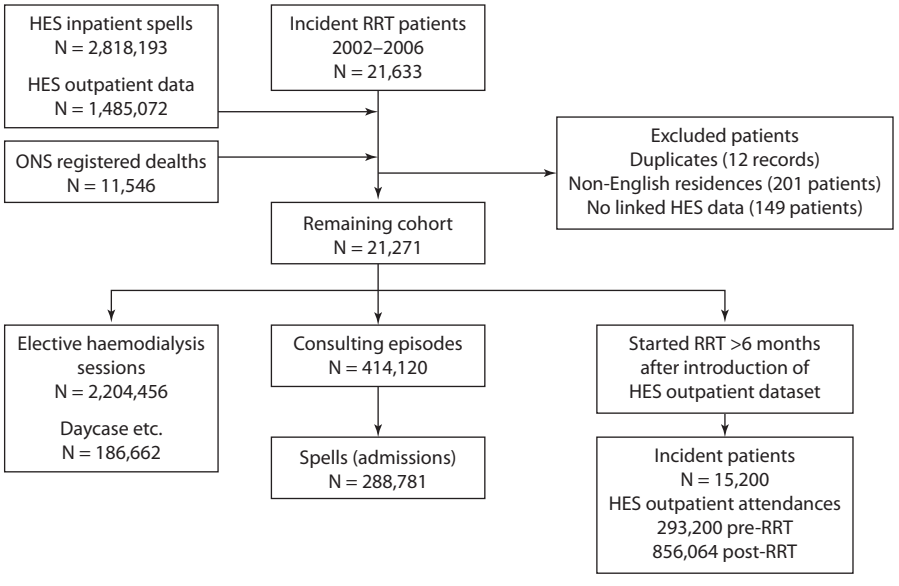

Fig. 13.1. Consort diagram detailing incident RRT patients 2002–2006, HES admissions and ONS records included in the analysis

and patients excluded from subsequent analysis. 98.3% of patients were suitable for continued analysis, with a total of 362 patients excluded. Ninety-seven percent of incident patients were supplied by the UKRR with NHS number. Linkage reports provided by the RCP identified 504 patients that could not have their NHS number traced by the PDS, some of whom would have had NHS numbers provided by the UKRR.

Table 13.1. Number of admissions, coding depth and proportion of admissions being discharged on the same day per centre

Centre	Admission frequency, N	Diagnosis code depth Mean number of codes (95% CI)	Procedure code depth Mean number of codes (95%CI)	Zero length of stays Frequency zero length admission, % (95% CI)
Basildon	2,073	3.9 (3.8–4.0)	0.8 (0.8–0.9)	14.4 (12.9–15.9)
B Heartlands	5,812	4.5 (3.8–4.0)	1.1 (1.0–1.1)	14.0 (13.1–14.9)
B QEH	7,138	4.8 (4.8–4.9)	1.3 (1.3–1.3)	10.9 (10.2–11.7)
Bradford	3,676	4.3 (4.2–4.3)	1.1 (1.0–1.1)	8.3 (7.4–9.2)
Brighton	4,794	5.1 (5.0–5.1)	1.4 (1.4–1.5)	13.0 (12.0–13.9)
Bristol	9,381	6.4 (6.3–6.4)	2.2 (2.1–2.3)	11.3 (10.6–11.9)
Cambridge	5,689	4.7 (4.7–4.8)	1.6 (1.5–1.6)	10.4 (9.6–11.1)
Carlisle	2,543	3.9 (3.8–4.0)	1.2 (1.1–1.2)	33.4 (31.6–35.3)
Carshalton	12,418	4.4 (4.3–4.4)	1.4 (1.4–1.5)	15.7 (15.1–16.4)
Chelmsford	1,398	5.1 (4.9–5.2)	1.5 (1.4–1.6)	9.5 (8.0–11.1)
Coventry	4,697	3.6 (3.5–3.6)	0.9 (0.9–1.0)	11.1 (10.2–12)
Derby	3,302	4.8 (4.7–4.8)	1.5 (1.4–1.5)	14.4 (13.2–15.6)
Dorchester	2,889	4.3 (4.2–4.4)	1.0 (1.0–1.1)	11.0 (9.9–12.1)
Dudley	2,074	4.7 (4.6–4.8)	2.0 (1.9–2.1)	7.8 (6.6–8.9)
Exeter	6,641	7.2 (7.1–7.3)	1.4 (1.3–1.4)	9.6 (8.9–10.3)
Gloucester	3,850	4.3 (4.2–4.3)	1.1 (1.0–1.1)	12.1 (11.0–13.1)
Hull	6,941	4.5 (4.4–4.5)	1.2 (1.1–1.2)	8.8 (8.2–9.5)
Ipswich	3,468	5.1 (5.0–5.2)	1.1 (1.1–1.2)	6.6 (5.7–7.4)
Leeds	11,132	4.2 (4.1–4.2)	1.5 (1.4–1.5)	9.2 (8.7–9.8)
Leicester	11,674	5.1 (5.0–5.1)	1.3 (1.2–1.3)	10.0 (9.5–10.5)
Liverpool – Aintree	1,282	4.7 (4.5–4.8)	1.2 (1.1–1.3)	14.4 (12.5–16.4)
Liverpool – RI	9,146	4.5 (4.5–4.6)	1.4 (1.3–1.4)	9.1 (8.5–9.7)
London – Barts	7,128	4.8 (4.7–4.9)	1.2 (1.1–1.3)	10.4 (9.7–11.1)
London – Guys	8,488	4.2 (4.1–4.2)	1.1 (1.0–1.1)	11.9 (11.2–12.6)
London – Kings	7,665	5.4 (5.3–5.5)	1.8 (1.8–1.9)	11.8 (11.1–12.5)
London – RFree	5,910	4.1 (4.0–4.1)	1.3 (1.3–1.4)	42.8 (41.5–44.1)
London – West	18,043	5.4 (5.4–5.4)	1.5 (1.4–1.5)	13.5 (13.0–14.0)
Middlesbrough	6,922	4.6 (4.6–4.7)	1.1 (1.0–1.1)	12.3 (11.5–13.0)
Newcastle-upon-Tyne	7,561	6.0 (6.0–6.1)	1.6 (1.6–1.7)	10.9 (10.2–11.6)
Norwich	4,394	4.6 (4.5–4.7)	1.0 (0.9–1.0)	13.2 (12.2–14.2)
Nottingham	8,304	6.8 (6.7–6.8)	1.7 (1.6–1.7)	15.3 (14.5–16.1)
Oxford	11,890	4.1 (4.0–4.1)	1.2 (1.2–1.2)	18.6 (17.9–19.3)
Plymouth	4,014	5.4 (5.3–5.4)	1.3 (1.3–1.4)	7.1 (6.3–7.9)
Portsmouth	11,280	4.3 (4.3–4.4)	1.2 (1.2–1.2)	28.3 (27.5–29.2)
Preston	9,304	5.3 (5.2–5.3)	1.3 (1.3–1.3)	16.7 (15.9–17.4)
Reading	4,423	4.1 (4.0–4.2)	1.3 (1.3–1.4)	13.8 (12.8–14.8)
Salford	10,002	4.6 (4.5–4.7)	1.2 (1.2–1.3)	32.4 (31.5–33.4)
Sheffield	10,991	4.5 (4.5–4.5)	1.2 (1.2–1.3)	10.6 (10.1–11.2)
Shrewsbury	1,243	4.6 (4.5–4.8)	1.5 (1.4–1.6)	10.0 (8.3–11.6)
Southend-on-Sea	2,131	5.5 (5.4–5.6)	1.7 (1.6–1.7)	11.0 (9.7–12.3)
Stevenage	5,757	4.0 (3.9–4.1)	1.0 (0.9–1.0)	12.3 (11.4–13.1)
Sunderland	3,821	4.8 (4.7–4.8)	1.7 (1.7–1.8)	12.6 (11.6–13.7)
Truro	3,817	5.1 (5.0–5.2)	1.0 (0.9–1.0)	22.5 (21.2–23.8)
Wirral	4,280	3.6 (3.5–3.6)	1.0 (0.9–1.0)	17.2 (16.1–18.4)
Wolverhampton	6,312	4.0 (4.0–4.1)	0.9 (0.8–0.9)	13.0 (12.2–13.9)
York	3,083	5.0 (4.9–5.1)	1.1 (1.1–1.2)	10.4 (9.3–11.5)
Total	**288,781**	**4.8 (4.8–4.8)**	**1.3 (1.3–1.3)**	**14.5 (14.3–14.6)**

Coding

The coding depth (how many diagnosis codes were utilised to code the first episode of a spell) varied between centres and over time. Table 13.1 details the number of admissions, coding depth for both diagnoses and procedures, and the frequency with which patients were discharged on the same day (zero length of stay admissions). Some centres had a high proportion of zero length of stay admissions (range 6.6%–42.8%), suggesting mis-coding of haemodialysis attendances. Excluding these admissions increased coding depth from 4.81 (95% CI 4.79–4.83) codes per admission to 4.99 (95% CI 4.97–5.01) codes per admission.

Coding depth increased over time at a rate of approximately 0.25 codes per year, as highlighted in figure 13.2.

Enhancement of Existing Variables

Enhanced variables for centres contributing to the cohort are summarised in table 13.2. Sufficient information was available for 20,968 patients (98.6% of analysis cohort) to derive IMD data from the six months pre and post the start of RRT, with 72% provided by the UKRR and a further 26.6% provided by HES. In the 15,165 patients where both sources could provide an IMD rank, ranks differed in 1,061 patients (7%), with an average difference of 6,054 or 19% of the range of IMD scores. When IMD was grouped into fifths across the combined dataset, concordance between sources for those with data for both was 95.5%.

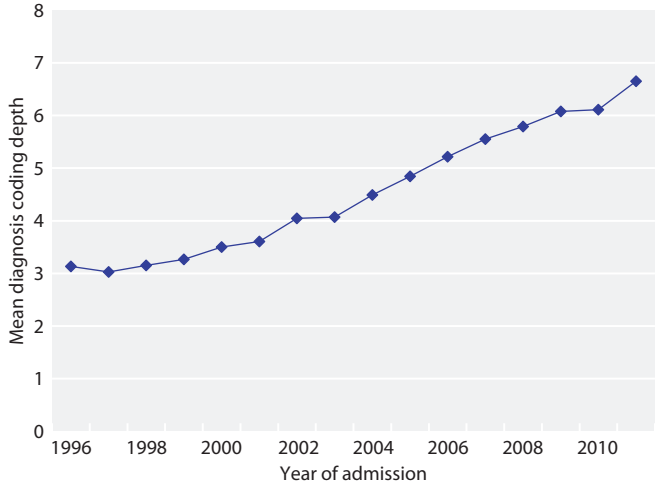

Fig. 13.2. Mean diagnosis coding depth according to date of admission

An additional 23.4% of patients had ethnicity derived bringing the total to 21,027 patients (98.9%). Disagreements in classification between sources were predominantly between Indian, Pakistani or Bangladeshi groups or Black Caribbean, Black African or Black Other groups (1,830 patients, 8.5%). Further re-grouping reduced the disagreement to 246 patients (1.2%). As expected there was a large variation in ethnicity across centres as demonstrated by the funnel plot in figure 13.3.

In patients with suitable HES outpatient data (N = 15,200) the number of patients with no documented contact with a nephrologist before starting RRT decreased from 8,330 to 2,216. New dates were derived in place of UKRR supplied data for 8,920 patients, including 608 patients with UKRR reported date first seen previously matching the date of first dialysis. However, 206 patients were documented as having no contact with renal services and 1,540 patients had still had no contact at 30 days from starting RRT.

For eight centres, the proportion of inpatient and outpatient care for RRT patients delivered by nephrology changed significantly during the follow-up period, suggesting changes in coding practices within the hospitals providing HES data. These centres are excluded from late referral analyses. As previously described in more select cohorts [13] the proportion of patients being seen as a late presentation has decreased over time, with the sharpest decline in the first 12 months of this analysis as demonstrated in figure 13.4, however residual variation between centres regarding timely referral persisted beyond this time, as detailed in table 13.3.

Primary renal disease was coded missing or uncertain in the UKRR dataset for 26.0% (4,978/19,525) of patients surviving over 90 days. Seventy one ICD10 codes that were routinely employed in HES to describe primary renal disease were identified from 67,210 admissions in the 12 month HES observation window and computed primary renal disease in 451 additional patients. Allowing the presence of diabetes to infer primary renal disease yielded 798 additional primary diagnoses, however after this process 3,729 patients (19.5%) were still without a primary renal disease (table 13.5).

Comorbidity

In patients who had UKRR comorbidity completed (53.7%), correlation between HES and UKRR datasets was reasonable, with an overall concordance between individual comorbidities of 93% excluding diabetes, amputation for peripheral vascular disease and

Table 13.2. Patient demography enhanced by HES in 21,271 patients

Centre	Incident patients N	Suitable for analysis %	Ethnicity			Deprivation centile	
			White %	Black %	S Asian %	Mean	95% CI
Basildon	176	98.9	93.7	*	*	48	44–52
Birmingham – Heartlands	512	98.8	70.8	7.1	17.4	66	63–69
Birmingham – QEH	571	97.9	69.6	8.9	14.5	64	62–66
Bradford	313	98.7	59.5	1.9	27.5	71	68–74
Brighton	361	99.4	85.0	1.4	1.4	45	42–48
Bristol	792	98.5	93.5	2.7	1.5	42	40–44
Cambridge	535	97.2	89.6	*	2.1	35	33–37
Carlisle	142	95.8	99.3	*	*	59	55–63
Carshalton	902	98.8	72.1	8.9	5.8	31	29–33
Chelmsford	139	100.0	93.5	*	*	33	30–37
Coventry	436	97.5	80.7	3.1	12.2	48	45–51
Derby	265	99.2	84.0	3.8	5.3	51	48–55
Dorchester	231	100.0	84.4	*	*	39	36–42
Dudley	203	99.0	91.5	3.5	4.5	58	55–62
Exeter	501	99.6	98.4	*	*	49	47–51
Gloucester	296	98.6	96.2	1.7	*	38	35–41
Hull	525	99.4	94.4	*	*	59	57–61
Ipswich	225	96.9	91.3	3.2	*	42	39–45
Leeds	871	99.2	81.0	2.2	9.3	61	60–63
Leicester	943	99.6	82.4	2.8	10.9	48	46–50
Liverpool – Aintree	67	100.0	94.0	*	*	69	63–76
Liverpool – RI	653	92.8	94.1	1	*	71	69–73
London – Barts	560	99.6	41.8	21.5	21.9	69	67–71
London – Guys	669	95.5	66.7	21.9	2.2	55	53–57
London – Kings	581	99.1	55.2	24.7	5.2	59	57–61
London – RFree	326	99.7	46.8	21.5	9.5	63	60–66
London – West	1,411	98.1	43.1	15.8	14.3	56	54–57
Middlesbrough	509	98.8	95.8	*	1.6	66	63–68
Newcastle-upon-Tyne	513	98.8	94.1	*	2.8	65	62–67
Norwich	324	99.7	97.8	*	*	44	42–47
Nottingham	579	99.5	90.5	3.5	2.4	60	58–62
Oxford	831	98.9	87.8	2.8	3.5	31	29–32
Plymouth	348	99.7	95.7	*	*	56	54–59
Portsmouth	718	98.5	94.2	0.8	1.1	38	36–40
Preston	536	99.3	83.1	2.6	10.0	59	57–62
Reading	361	99.4	76.9	7.2	10.3	34	32–37
Salford	497	99.8	81.7	*	9.7	68	66–70
Sheffield	801	99.4	91.5	1.8	3.6	65	63–67
Shrewsbury	151	84.8	89.8	3.9	*	52	49–56
Southend-on-Sea	202	97.5	84.3	2.5	3.0	44	40–47
Stevenage	517	96.5	74.7	10.4	9.6	39	37–41
Sunderland	279	97.8	98.5	*	*	71	68–74
Truro	263	97.7	94.6	*	*	61	60–63
Wirral	271	92.3	91.2	*	*	58	54–62
Wolverhampton	464	98.7	80.3	5.7	10.5	65	62–67
York	261	99.2	92.3	*	*	35	32–38
Total	**21,631**	**98.3**	**80.4**	**5.6**	**6.4**	**53**	

* Counts of less than five patients censored as per ONS recommendations
Note: two patients from a non-English centre excluded from total cohort

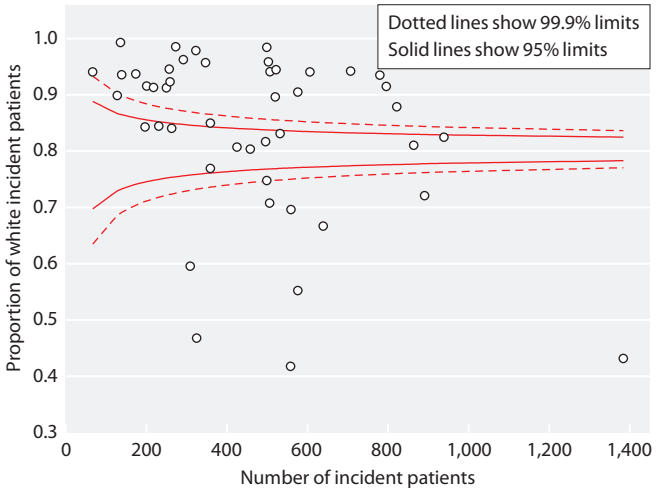

Fig. 13.3. Funnel plot detailing the proportion of white incident patients in England by centre

congestive cardiac failure (figure 13.5). Congestive cardiac failure as a comorbidity was introduced into the UKRR dataset in 2003, but centres do not appear to have used it during the recruitment period. Amputation is coded in HES as a procedure, but the reason for amputation is not part of this procedure code. Hazard ratios for survival censored at three years for the UKRR comorbidities derived from HES in 19,119 patients surviving beyond 90 days with admissions prior to starting RRT are detailed in table 13.6, including race stratified effect estimates for patients coded White and South Asian and comorbidity scores assigned to the presence of these conditions. There was no statistically significant difference in the incidence of individual comorbid conditions as derived by HES, between those with or without a UKRR comorbidity score.

Converting the multivariate hazard ratios into weighted scores, some conditions had statistically significant associated hazard for mortality but insufficient effect size to assign a score (table 13.6). The overall mean comorbid score per patient was 0.88 (95% CI 0.86–0.89) with haemodialysis patients scoring higher when compared to peritoneal dialysis patients (0.96, 95% CI 0.95–0.98 vs. 0.65, 95% CI 0.63–0.68). 48.3% of patients had a combined comorbid score based on UKRR conditions of zero. Comorbidity score increased linearly with age but reduced over the age of seventy (figure 13.6). The comorbid score did progressively increase over the years incident patients were sampled from (figure 13.7), with statistically significant differences between years (ANOVA $p < 0.001$) although the differences between scores were small.

Centre-based comorbidity scores for UKRR conditions were surprisingly uniform overall as detailed in figure 13.8a, however there were differences in the distribution of comorbidity per modality in peritoneal dialysis and haemodialysis for centres (figure 13.8b). Correlation of per centre mean comorbid scores for haemodialysis and peritoneal dialysis per centre was 0.223 ($p = 0.141$). Centres with deeper coding generally had higher comorbidity scores (Spearman's correlation 0.313, $p = 0.034$).

Location of Death

Table 13.4 highlights that there were differences between centres when comparing outcomes by the

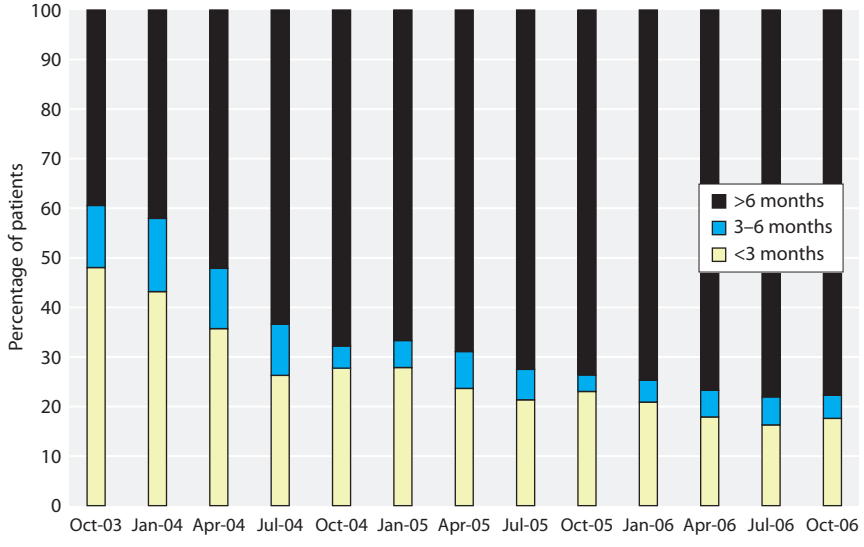

Fig. 13.4. Late presentation over time determined from HES speciality coding for 38 centres with consistent HES coding between October 2003 and October 2006

Table 13.3. Admissions under nephrology and presentation time

Centre	Admissions under nephrology in first 12 months		Incident patients Oct 2003–Dec 2006 (N)	Time from first seen by a nephrologist to starting RRT		
	Total admissions (N)	Proportion under nephrology (%)		Seen <90 days (%)	90 days–6 months (%)	>6 months (%)
Basildon	326	3.7	132	22.7	5.3	72.0
Birmingham – Heartlands	1,029	56.0	365	32.3	12.3	55.3
Birmingham – QEH	1,290	45.7	559	32.6	8.1	59.4
Bradford	663	38.9	188	19.1	5.3	75.5
Brighton	893	69.4	359	26.7	12.8	60.4
Bristol	1,931	77.4	545	21.1	4.0	74.9
Cambridge	922	31.7	377	35.5	9.5	54.9
Carlisle	645	64.5	85	27.1	9.4	63.5
Carshalton	2,239	60.6	574	31.9	8.5	59.6
Chelmsford						
Coventry	817	54.0	276	25.4	8.3	66.3
Derby	524	57.6	221	21.7	10.4	67.9
Dorchester	565	42.5	179	13.4	7.3	79.3
Dudley						
Exeter						
Gloucester	744	69.9	195	22.6	8.7	68.7
Hull	1,314	52.1	352	33.8	7.1	59.1
Ipswich	633	52.6	150	28.0	7.3	64.7
Leeds	1,929	64.0	578	24.6	5.7	69.7
Leicester	2,261	41.1	662	18.3	5.7	76.0
Liverpool – Aintree	211	65.4	67	20.9	9.0	70.1
Liverpool – RI	2,017	72.6	395	28.9	8.4	62.8
London – Barts	1,145	71.3	558	30.8	7.7	61.5
London – Guys	1,447	76.9	425	34.1	6.1	59.8
London – Kings	1,315	76.1	385	33.0	8.3	58.7
London – RFree	677	49.2	325	22.8	5.2	72.0
London – West	2,700	67.2	952	33.8	6.9	59.2
Middlesbrough	1,377	68.1	307	16.0	5.9	78.2
Newcastle-upon-Tyne	1,619	60.7	348	23.0	5.5	71.6
Norwich	937	51.2	323	24.5	4.3	71.2
Nottingham	1,345	60.7	407	21.6	5.7	72.7
Oxford	2,269	61.9	524	21.6	6.9	71.6
Plymouth	752	64.5	234	30.8	11.1	58.1
Portsmouth	2,279	71.8	462	16.9	8.2	74.9
Preston	2,422	62.4	195	22.6	8.7	68.7
Reading						
Salford	3,129	81.3	389	22.6	8.5	68.9
Sheffield	2,080	77.1	524	17.2	5.7	77.1
Shrewsbury						
Southend-on-Sea						
Stevenage	931	63.6	317	16.1	3.8	80.1
Sunderland	896	56.9	181	28.7	7.7	63.5
Truro	653	47.0	157	19.7	10.2	70.1
Wirral	551	34.5	170	37.1	4.7	58.2
Wolverhampton						
York						
Total	**49,477**	**62.6**	**13,598**	**26.2**	**7.2**	**66.6**

Centres with no statistics: variation in HES speciality coding over the follow-up period

Table 13.4. Location of death in patients surviving over 90 days

Centre	Patients surviving over 90 days N	Deaths in hospital %	Deaths in hospital and 30 days post-discharge %	Deaths with no contact within 30 days %
Basildon	159	66.2	77.5	22.5
Birmingham – Heartlds	450	64.1	76.2	23.8
Birmingham – QEH	521	65.8	80.9	19.1
Bradford	281	68.2	77.5	22.5
Brighton	333	*50.3**	*65.6**	**34.4****
Bristol	695	66.5	79.9	20.1
Cambridge	473	59.5	73.6	26.4
Carlisle	128	66.3	78.3	21.7
Carshalton	820	66.4	80.4	19.6
Chelmsford	121	72.4	85.5	14.5
Coventry	382	66.7	76.6	23.4
Derby	239	64.1	76.9	23.1
Dorchester	214	58.3	75.7	24.3
Dudley	176	78.6	84.7	15.3
Exeter	450	59.9	78.7	21.3
Gloucester	274	67.5	76.8	23.2
Hull	466	64.1	81.3	18.7
Ipswich	197	64.4	78.8	21.2
Leeds	778	66.8	83.4	16.6
Leicester	871	69.7	81.7	18.3
Liverpool – Aintree	62	75.9	86.2	13.8
Liverpool – RI	542	64.7	86.0	14.0
London – Barts	535	62.5	77.6	22.4
London – Guys	619	60.7	74.8	25.2
London – Kings	550	*46.8**	*64.4**	35.6**
London – RFree	314	64.3	78.6	21.4
London – West	1,325	64.9	76.1	23.9
Middlesbrough	444	70.9	84.1	*15.9**
Newcastle-upon-Tyne	459	75.5**	86.5	13.5
Norwich	278	60.8	74.5	25.5
Nottingham	520	71.6	83.8	16.2
Oxford	764	60.5	76.0	24.0
Plymouth	288	64.7	82.7	17.3
Portsmouth	642	63.6	80.4	19.6
Preston	506	61.2	77.2	22.8
Reading	334	63.4	72.7	27.3
Salford	468	67.4	82.4	*17.6**
Sheffield	739	70.4	84.3	15.7
Shrewsbury	114	49.1	75.4	24.6
Southend-on-Sea	172	72.9	81.2	18.8
Stevenage	459	62.2	76.8	23.2
Sunderland	254	71.4	84.4	*15.6**
Truro	239	71.2	88.5	11.5
Wirral	230	71.4	85.7	14.3
Wolverhampton	407	64.8	77.2	22.8
York	233	62.4	80.1	19.9
Total	**19,525**	**65.0**	**79.2**	**20.8**

* italics, lower than expected
** bold, higher than expected

Table 13.5. Primary renal disease before and after augmentation with 12 months HES data around the start of RRT

Primary renal disease	Before HES enhancement %	After HES enhancement, excluding diabetes %	After HES enhancement, including diabetes %
Missing	3.4	2.8	1.9
Diabetes	20.8	20.8	25.0
GN	10.9	11.0	11.0
Hypertension	5.9	5.9	5.9
PKD	6.9	7.7	7.7
Pyelonephritis	7.7	8.1	8.1
Reno-Vascular Disease	6.8	6.9	6.9
Other	15.1	16.0	16.0
Uncertain	22.6	20.9	17.6

GN – glomerulonephritis; PKD – polycystic kidney disease

location of death. Overall, 65.0% of patients died in a hospital classed as an acute provider (range 46.8–78.0%), with an additional 14.2% of patients having been discharged from an acute provider in the preceding 30 days (range 6.1–26.3 %) and the remaining 20.8% dying with no hospitalisation with an acute provider in the preceding 30 days (range 11.5–35.6%). Two centres were outliers for the proportion of deaths occurring outside hospital with no inpatient contact in the last 30 days, however no outliers were identified comparing in-hospital and 30-day mortality. Location of death per centre is summarised in table 13.4 with outliers highlighted.

Discussion

An essential function of any chronic disease registry is to accurately compare across provider centres the hard outcomes such as survival and hospitalisation. Patients maintained on renal replacement therapy have high morbidity and mortality and the outcomes mentioned need adequate adjustment particularly for comorbid diseases, ethnicity and socioeconomic factors. In response to the problem of missing data and the absence of morbidity and hospitalisation data within the UK Renal Registry dataset, it was possible to link 21,633 UKRR incident patients to HES data. Subsequent

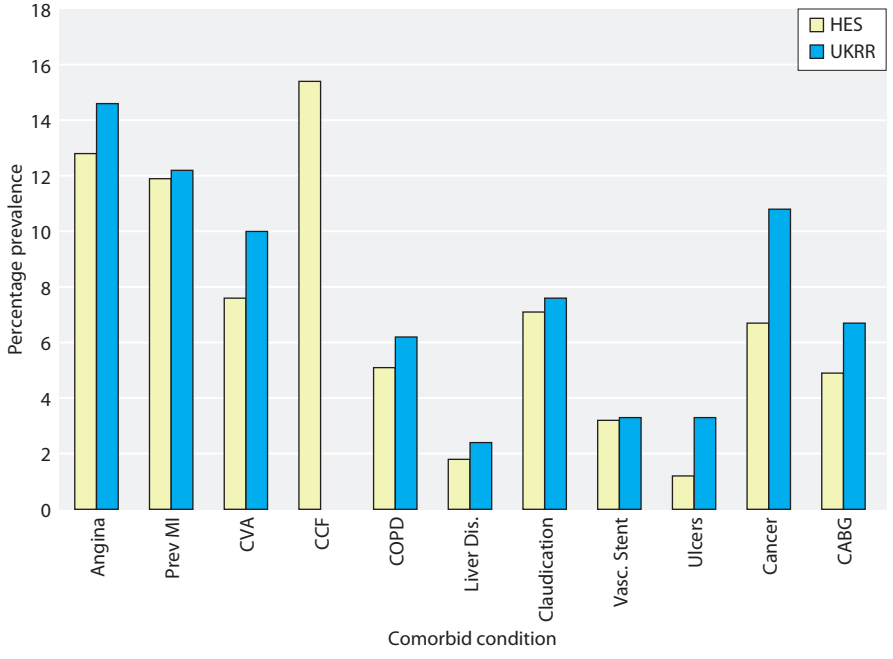

Fig. 13.5. Prevalence of comorbid conditions at the time of starting RRT derived from UKRR and HES in 10,276 patients with data from both sources
Prev MI – previous myocardial infarction
CVA – cerebrovascular accident
CCF – congestive cardiac failure
CABG – coronary artery bypass graft

Table 13.6. Hazard ratios for UKRR comorbidities with greater than 2% prevalence adjusted for age in patients surviving 90 days from starting renal replacement therapy

Condition	Univariate HR (95%CI)	Multivariate HR (95%CI)	Score	Caucasian (95%CI)	South Asian (95%CI)
Angina	1.75 (1.64–1.87)*	1.05 (0.98–1.14)	0	1.04 (0.96–1.13)	1.25 (0.90–1.75)
Myocardial Infarction	1.94 (1.81–2.07)*	1.20 (1.11–1.3)*	1	1.18 (1.08–1.28)*	1.57 (1.09–2.26)**
Heart Failure	2.24 (2.11–2.37)*	1.41 (1.32–1.51)*	1	1.46 (1.36–1.57)*	1.04 (0.75–1.43)
Stroke	1.77 (1.63–1.92)*	1.28 (1.18–1.39)*	1	1.25 (1.14–1.36)*	1.71 (1.21–2.43)*
Diabetes	1.44 (1.37–1.52)*	1.28 (1.21–1.35)*	1	1.38 (1.3–1.47)*	1.69 (1.28–2.24)*
COPD	2.22 (2.03–2.43)*	1.45 (1.32–1.58)*	1	1.45 (1.32–1.59)*	0.54 (0.26–1.11)
Claudication	2.04 (1.88–2.21)*	1.21 (1.11–1.33)*	1	1.24 (1.13–1.36)*	1.02 (0.57–1.82)
Cancer	2.00 (1.84–2.17)*	1.43 (1.32–1.55)*	1	1.33 (1.22–1.46)*	1.16 (0.57–2.37)
CABG	1.21 (1.08–1.35)*	0.76 (0.67–0.86)*	0	0.80 (0.7–0.92)*	0.44 (0.26–0.74)*
Vascular Stent	2.10 (1.88–2.34)*	1.18 (1.05–1.33)*	0	1.17 (1.04–1.32)*	1.16 (0.43–3.13)

* $p < 0.01$
** $p < 0.05$
COPD – chronic obstructive pulmonary disease
CABG – coronary artery bypass graft
Note: diabetes can also reflect primary renal disease in addition to comorbidity

analysis was possible in 98.3% of patients, with ethnicity, socioeconomic data and comorbidity derived for more than 98% of this cohort, representing the most complete description of a UKRR incident cohort to date.

Dataset linkage represents a growth industry in medical research, and the UKRR were fortunate to be included in the panel of datasets included in the RCP pilot. This study has demonstrated that linkage with HES is possible and there are benefits. It allows reporting and research analysis on a greater proportion of patients recorded by the registry and allows more robust comparison between centres. It highlights that information routinely collected but found missing by the UKRR is recorded elsewhere within the health system to a level sufficient to derive information on the majority of patients.

These early findings do allow comparisons to other international registries. Previously reported hazard ratios for death for the presence of atherosclerotic heart disease, congestive cardiac failure, cerebrovascular disease, peripheral vascular disease, COPD, cancer and diabetes are similar to incident USRDS patients in 2000 [4]. To circumvent poor Medicare coverage of

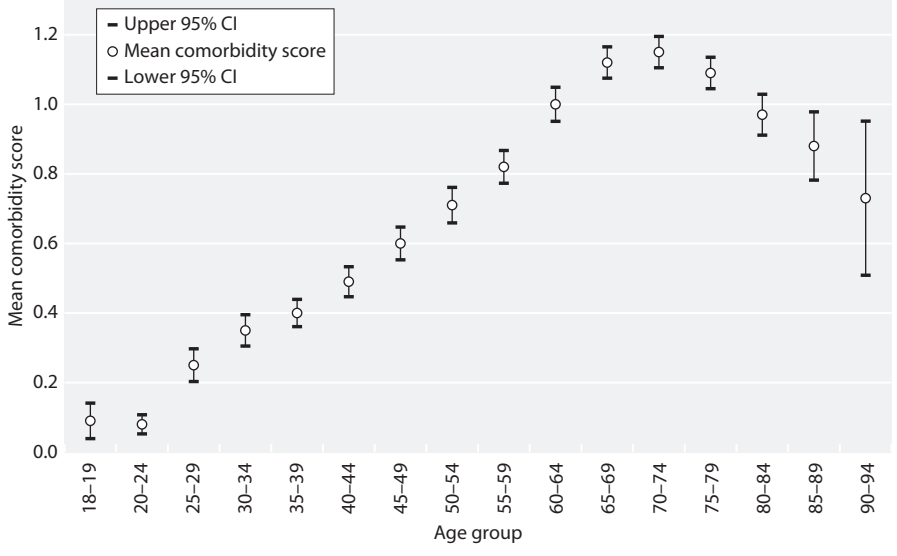

Fig. 13.6. Mean comorbidity score by age group

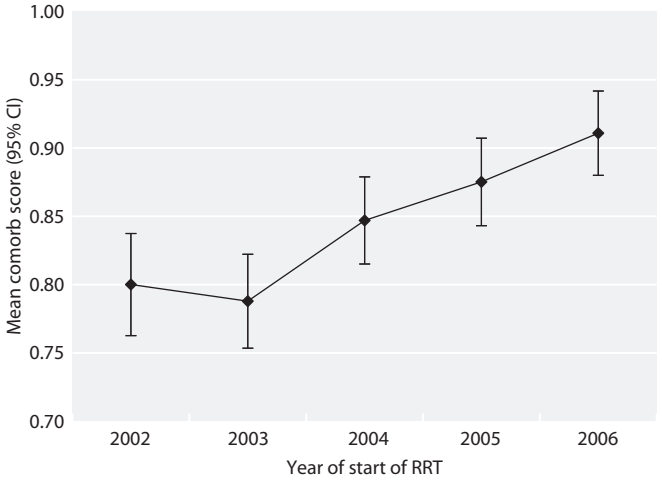

Fig. 13.7. Mean comorbid score derived from HES according to year of start of RRT

admissions prior to start of RRT, in addition to the Medical Evidence Report form admissions from the first nine months of RRT inform the comorbidity scoring performed by the USRDS. The prevalence of individual conditions in a 2001–2005 US white incident cohort is generally twice that reported here [2], and early accrued morbidity may explain some of this increase.

The difference in hazard ratios for different ethnic groups should not be over-interpreted as the confidence intervals for the comorbid conditions in South Asian patients are wide due to their smaller numbers. If scored separately South Asian patients would score higher for myocardial infarction and stroke but less for the remaining conditions. Comorbidity-adjusted centre survival may need to factor the ethnicity-specific impact of comorbid conditions.

The similar prevalence of comorbid conditions in those patients with and without UKRR comorbidity completed implies that missing UKRR comorbidity data may be random, or that comorbidity is similar between centres as demonstrated in figure 13.7. Previous registry reports in fact give us the answer, that in general, poor comorbidity returns are often a characteristic of a centre. The HES and UKRR comorbidity correlation is reasonable at 93%, but it may not be reasonable to assume the same in those patients who have missing comorbidity or that their comorbidity burden is similar to those with it completed. Previous UKRR research highlighted worse survival in patients who had no comorbidity coded [14], and an excess burden of unmeasured comorbid disease, or centre specific effects associated with poor data collection may explain this.

This study demonstrates a high rate of linkage, with only 149 patients (0.07%) resident in England having no linked HES data. There are theoretical reasons why an English RRT patient may have no HES data, but the employed linkage method is strongest when the NHS

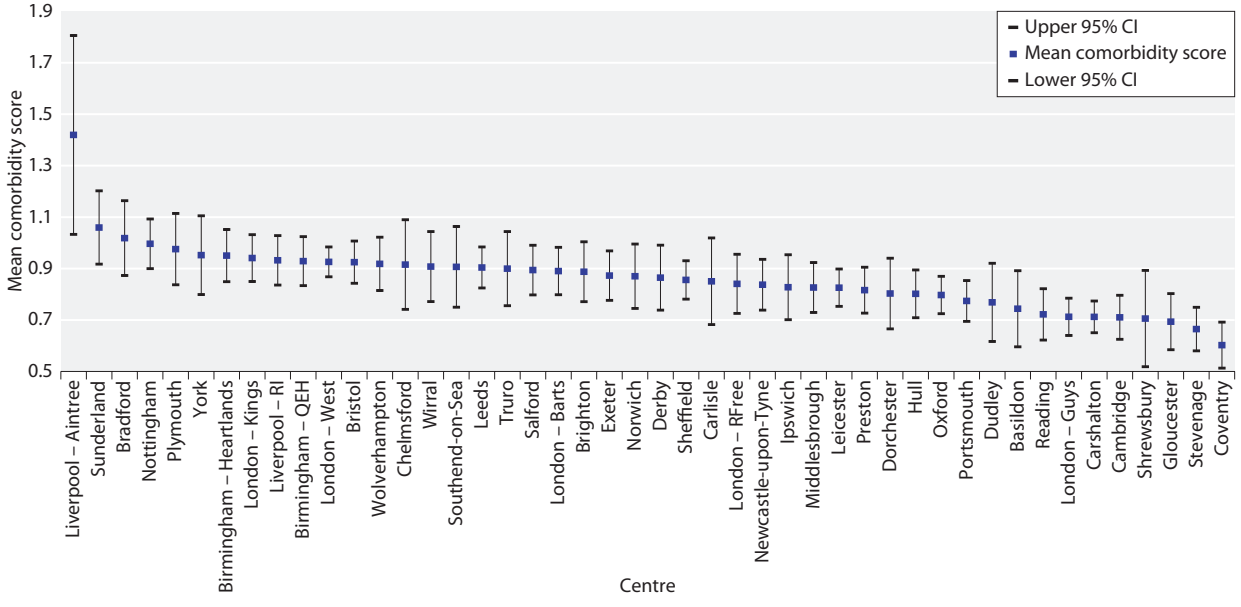

Fig. 13.8a. Mean comorbidity score per centre for patients surviving beyond 90 days, determined from UKRR comorbid conditions identified from admissions prior to starting RRT

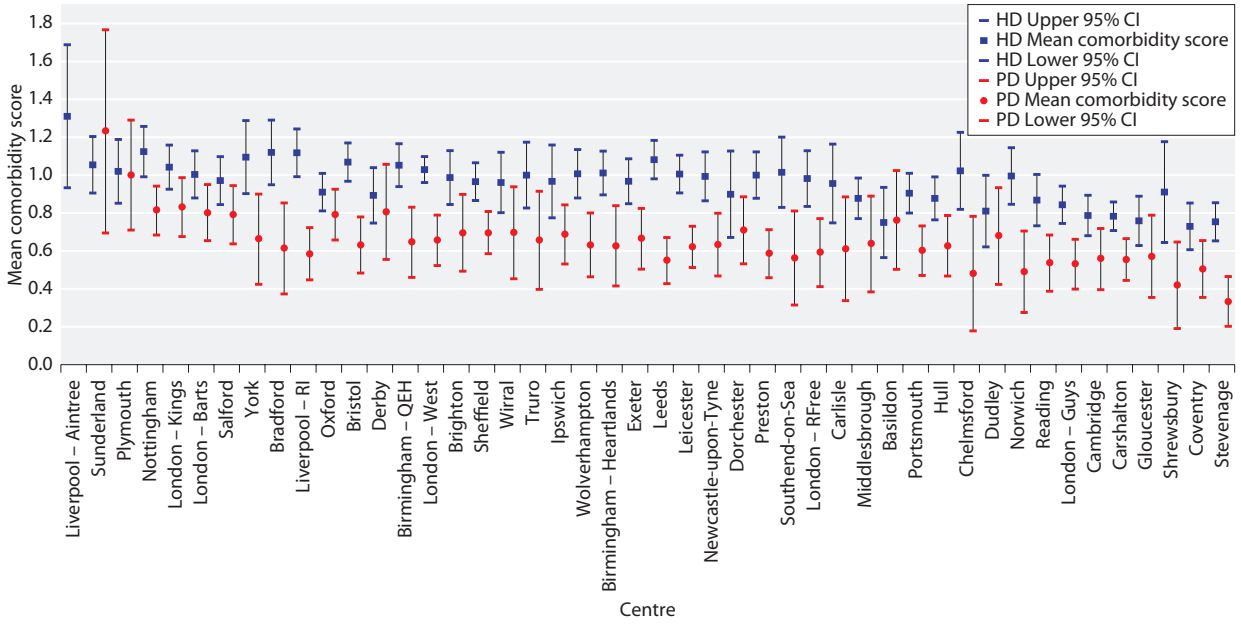

Fig. 13.8b. Mean comorbidity score per centre for patients surviving beyond 90 days stratified by RRT modality at 90 days, determined from UKRR comorbid conditions identified from admissions prior to starting RRT

number is complete and ensuring this would facilitate future linkages. Beyond the linkage validity, routine data has limitations. Issues relating to incorrect data may persist and even be masked by the use of HES data. Morbid or comorbid conditions cannot be classed as missing in the HES dataset, but simply that there are no comorbid conditions, unlike the UKRR dataset. Differences in how NHS trusts code admissions may hamper cause specific admission reporting. Since these data were collected, guidance has been issued on how activity in renal centres should be captured with HES [15]. Standardisation and consensus are needed to allow the greatest utility from a HES-UKRR combined dataset.

Coding practice has been shown elsewhere to have improved over the period in question at a similar rate [16]. Coding depth is around two codes greater for RRT patients than the national average and it is no surprise that there are centres who code deeper than others. The finding that comorbid scores for centres that code deeper are higher is logical, but the clinical significance of this when evaluating centre specific outcomes should be explored. Centres that code well may be doing other processes well leading to better outcomes, and this may dilute the impact comorbidity might have on performance measures.

HES data allows a more detailed and novel analysis than that previously hampered by missing data. Centre and modality specific admission rates and length of stay can be determined, reflecting varying practice patterns and patient experience. Cause specific admissions and related morbidity can be analysed, along with comprehensively adjusted centre-specific incident survival. Hospital standardised mortality rates allows a more direct measure of in-hospital care, both at centre and trust level. Combined with ONS data to determine 30-day mortality following discharge they allow a more complete reporting of hospital associated death [11]. A range of centre-specific performance measures based around hospitalisation and comorbidity will be delivered as part of this project in the coming years.

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Conflicts of interest: none

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