Chapter 13
The UK Renal Registry Advanced CKD Study: frequency of incorrect reporting of date of start of RRT

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Key Words

Chronic kidney disease · Completeness · Dialysis · End stage renal disease · End stage renal failure · national registry · Renal replacement therapy · Validation

Abstract

Background: A preliminary review of the UK Renal Registry (UKRR) pre-RRT study data revealed results suggesting that, for some patients, the date of start of renal replacement therapy (RRT), as reported to the UKRR, was incorrect and often significantly later than the true date of start. A more detailed study then aimed to validate a set of criteria to identify patients with an incorrect start date. *Methods:* Pre-RRT laboratory data were electronically extracted from 8,810 incident RRT patients from 9 UK renal centres. Any patient with a low urea (<15 mmol/L) at the start of RRT or with a substantial improvement in kidney function (either a fall in urea >10 mmol/L or rise in eGFR >2 ml/min/1.73 m) within the two months prior to RRT were considered to potentially have an incorrect date of start. In 4 selected centres, the electronic patient records of all patients flagged were reviewed to validate these criteria. *Results:* Of 8,810 patients, 1,616 (18.3%) were flagged by the identification criteria as having a potentially incorrect date of start of RRT, although a single centre accounted for 41% of the total flagged cohort. Of these flagged patients, 61.7% had been assigned an incorrect date of start of haemodialysis (HD), 5.7% had evidence of acute RRT being given before the reported date of start of HD and 9.2% had evidence of starting peritoneal dialysis exchanges prior to the reported date of start. Of those flagged, 10.7% had a correct date of start of RRT. *Conclusions:* Accurate reporting of RRT episodes is vital for the analysis of time dependent studies such as survival or time to transplantation. A proportion of patients starting RRT were assigned an incorrect start date. In order to improve the accuracy of this reporting the UK Renal Registry must work with renal centres and clinical staff on improving data input for the start of RRT.

Introduction

The term established renal failure (ERF) used within this chapter is synonymous with the terms end stage renal failure (ESRF) and end stage renal disease

(ESRD), which are in more widespread international usage. Within the UK, patient groups have disliked the term 'end stage' which formerly reflected the inevitable outcome of this disease.

The epidemiology and management of patients with ERF in the United Kingdom has been well described in this, and previous, UKRR reports. However, the UKRR has not previously had access to data on patients prior to starting renal replacement therapy (RRT). The epidemiology and management of patients with advanced chronic kidney disease (CKD) prior to RRT has not been well described in large observational studies.

The increasing prevalence of patients being treated for ERF (a 40% rise in the UK in eight years [1]) has been described by commentators as a public health problem [2]. The National Institute for Clinical Excellence (NICE) guidelines for CKD emphasise a strategy to reduce the rise in ERF by retarding the progression of disease in patients with CKD [3]. The UK National Service Framework for Renal Services emphasises the importance of good pre-dialysis preparation in the final year before RRT is required [4]. A greater understanding about patients with advanced CKD, their progression of disease, the CKD complications they experience and their response to management is therefore essential.

The UK Renal Registry therefore sought to undertake a study of this population by extracting additional laboratory and clinical data at a number of predetermined time points during the year prior to starting RRT in all incident patients on the UKRR database from nine selected UK renal centres. Part of this work was funded by a grant from the Edith Murphy foundation (Registered Charity No. 1026062) through Kidney Research UK as part of a larger project funded by the Health Foundation, the Quality Improvement in Chronic Kidney Disease project.

The preliminary analysis of these laboratory eGFR data revealed an unexpected anomaly. When the median eGFR at each time point pre-RRT for two of the centres was plotted, the overall decline in eGFR was linear, with the exception of the final data time point (1 to 15 days prior to the start of RRT – month zero) which was higher than the previous time point (month minus 1) (figure 13.1). One of the possible explanations for the rise in eGFR at this time point was that there were a number of patients in whom the date of start of RRT, as reported in the dataset extracted from the local IT system and submitted to the UKRR was incorrect and whose
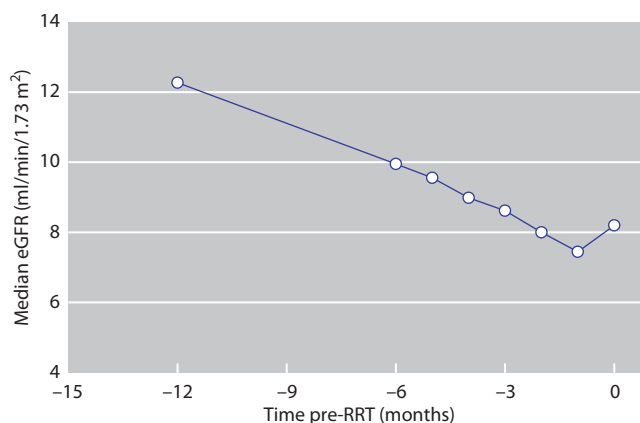

Fig. 13.1. Median eGFR at each time point pre-RRT for Centre D

laboratory results at the 'month zero time-point' were actually taken once RRT had already commenced. If this hypothesis was correct this would mean that a percentage of the final eGFR results at the start of RRT were artificially high.

A preliminary data validation exercise in a small sample of patients at one of the centres confirmed that there were indeed some patients with an incorrect RRT start date recorded in the renal IT system and therefore a falsely low serum creatinine extracted which was after the true start of RRT. It was therefore decided to undertake a more systematic data validation exercise at four of the renal centres to test the hypothesis that there were a number of patients in the cohort with an incorrect date of start of RRT.

Methods

UKRR pre-RRT study methods

All adult patients who had been reported to the UKRR as having commenced RRT (either on dialysis or with a pre-emptive transplant) at nine selected UK renal centres were included in the pre-RRT data extraction. The nine centres were selected for this pilot for a number of reasons. Firstly, they all used a common renal IT system (Proton, Clinical Computing Ltd). Secondly, they were historically some of the more reliable centres at providing complete data for prevalent RRT patients. Thirdly, they were known to register all the general nephrology patients on the renal IT system at earlier stages of CKD, rather than only at the start of RRT, making it more likely that the results of biochemical tests prior to the start of RRT would be available for extraction from the IT system. The study period was from 1997 when the first centres began reporting incident patients to the UKRR, until December 2006.

Patients were excluded if they were younger than 18 years at the start of RRT. Some of the centres did not start reporting

patients to the UKRR until 2001. Only patients starting RRT for the first time were included. Episodes of re-commencement of dialysis or second or subsequent transplants were not counted as 'incident' episodes.

The date of start of RRT was taken from the first modality 'timeline' entry on the renal IT system. This date may have been ascribed by the clinician, PD or HD nurse and responsibility for this would vary between centres. The RRT timeline options (both acute and chronic) are listed in appendix G on the UKRR website [www.renalreg.org].

During the study period, the UKRR definition of the date of start of RRT was:

> *Established renal failure is defined as the date of the first dialysis (or of pre-emptive transplant). If a patient started as 'acute' renal failure and did not recover function, the date of start of renal replacement therapy should be backdated to the start of acute haemodialysis.*

This definition required that clinicians should retrospectively change the timeline from acute to chronic dialysis once it became apparent that a patient who had started dialysis in supposedly acute circumstances was unlikely to recover function. The reason for this request was that the UKRR extraction software used the date of chronic RRT to flag patients, ignoring episodes of acute dialysis. This was to ensure that patients with acute renal failure were not analysed in the UKRR ERF cohorts. There was no specific definition for the date of start of peritoneal dialysis. This definition was published in appendix B of the UKRR annual report and has been available on-line only since 2005 [5]; hence, many nephrologists may have been unaware of the definition of the date of start used by the registry, and as a result may not have entered data on the timeline in a consistent manner.

In addition to the demographic, clinical and laboratory information held on the UKRR database for these patients, laboratory data were extracted according to a predetermined dataset for the final 12 months before the onset of RRT. The closest serum creatinine to time points: 0, 1, 2, 3, 4, 5, 6 and 12 months pre-RRT were extracted where present.

Estimated glomerular filtration rate was calculated from each serum creatinine measurement using the 4-variable Modification of Diet in Renal Disease (MDRD) equation [6]. In addition to serum creatinine, this equation requires age, gender and ethnicity. A correction factor of 1.21 was applied to patients of Black ethnicity. No correction factor was required for South Asian or other ethnicities. Where evidence of ethnicity was missing, it was presumed to be non-Black for the purpose of eGFR estimation. During the period of this study, standardisation of creatinine assay to that used in the MDRD study, was not available. The UKRR used the original '186-constant' in the MDRD formula to calculate eGFR. In 2009 most UK laboratories were using the '175-constant' formula with an IDMS-aligned serum creatinine assay. It has been shown that there is little inter-laboratory variation at more advanced stages of CKD [7].

Timeline validation study methods
Three arbitrary criteria were adopted for identifying patients with unexpectedly good kidney function prior to RRT after discussion with clinicians and following the single-centre preliminary validation exercise. These criteria were:

1. A serum urea below 15 mmol/L at month 0
2. A fall in serum urea greater than 10 mmol/L within the final two months pre-RRT
3. A rise in eGFR greater than 2 ml/min/1.73 m^2 within the final two months pre-RRT

The purpose of the validation exercise was firstly to test the hypothesis that the reason for the apparently good kidney function was that the majority of these patients had been assigned an inaccurate date of start of RRT, and secondly to confirm the validity of these arbitrary identification criteria to see if they could be subsequently used as exclusion criteria for further analyses.

After obtaining permission from the four renal centres to conduct the data validation exercise by interrogating the electronic records on the local renal IT systems, the above identification criteria were used to create a list of patients at each centre for review. A single investigator reviewed the electronic records of all identified patients to see if there was evidence of earlier renal replacement therapy than that reported to the registry. The IT system screens reviewed included: the haemodialysis (HD) event screen, the blood pressure (BP) record screen, the biochemistry screen, the clinical summary screen and the clinic letter and discharge summary screen. An entry in the HD event screen was taken as evidence that HD had occurred on a particular date, as was an entry of 'pre' and 'post' BP on the same day. An entry of 'pre-HD' and 'post-HD' serum urea on the same day in order to calculate a urea-reduction-ratio (URR) was also taken as evidence that HD had occurred. The free text entries from the summary screen and letters were searched for documented evidence that earlier RRT had occurred. For example, documentation that a patient had been transferred from an intensive care unit with compatible biochemistry was considered evidence that prior haemofiltration had probably occurred. Finally, documentation that a peritoneal dialysis (PD) catheter had been inserted and intermittent PD undertaken prior to the reported date of start was considered evidence that the reported date was incorrect.

Patients were divided into four categories: incorrect date of start of HD, incorrect date of start of PD, correct date of start and details unknown. These categories are summarised in table 13.1 and the possible causes are listed below and discussed in depth in the results section.

Results

After applying the RRT start identification criteria to all patients' results, there were 1,616 patients (18.3%) who met one or more of the identification criteria. There was a significant difference in the proportion of patients meeting these criteria in the nine centres (table 13.2, chi-squared test p < 0.0001).

Haemodialysis patients with incorrect dates
Table 13.3 shows a summary of the results of the 4 centre validation exercise. Of the patients starting haemodialysis with an incorrect date, 512 (61.7% of

Table 13.1. Circumstances resulting in apparently good kidney function prior to the start of renal replacement therapy

Coding	Summary	Definition
HD		**Patients with incorrect date of start who started RRT on haemodialysis**
HD-1	Incorrect date	The patient had been allocated an incorrect date, no other obvious cause
HD-2	Previous acute HD/CVVH	Evidence that the patient had received previous acute HD or CVVH
HD-3	Possible previous acute HD/CVVH	Circumstantial evidence that the patient probably underwent previous acute RRT
HD-4	Transfer in on HD/CVVH	Transfer of a patient from another renal centre or ICU without documentation of previous RRT on the timeline
HD-5	Probable incorrect date	Improbable acute fall in urea or creatinine which was unlikely to be caused by circumstances other than acute RRT, but no documentary evidence of this occurrence
HD-6	Spurious result	Isolated spurious biochemistry result e.g. compatible with a drip-arm sample
PD		**Patients with incorrect date of start who started RRT on peritoneal dialysis**
PD-1	Incorrect date	The patient had been allocated an incorrect date, no other obvious cause
PD-2	Previous acute HD/CVVH	A patient starting PD, but with evidence of previous acute HD or CVVH
PD-3	IPD prior to PD training	Evidence that the patient received intermittent PD exchanges prior to the documented date of start of PD
PD-4	Probable IPD prior to PD training	Circumstantial evidence that the patient probably had additional PD exchanges prior to the documented start date
Correct		**Patients starting either HD or PD who were flagged according to the identification criteria, but whose start date was actually correct**
C-1	Bilateral/2nd nephrectomy	Patients undergoing a bilateral or second nephrectomy
C-2	Natural fall in CR/urea prior to RRT	Apparent natural improvement in kidney function with evidence that the date of start of RRT was correct
C-3	Fall in CR/urea because of specific therapy	Specific therapy such as cessation of ACE inhibitor or appropriate fluid therapy in a fluid deplete patient resulting in an improvement in biochemistry
C-4	Urea <15 – elderly/frail	Commencement of RRT with an appropriately low urea in a patient known to be elderly or frail, without evidence of a significant improvement in kidney function which could be caused by acute HD
C-5	Urea <15 – other	Commencement of RRT for appropriate reasons with a low urea without evidence of a significant improvement in kidney function which could be caused by acute HD
Uncertain		**Lack of evidence in the electronic patient record to place patient in any of the above categories**
U	Uncertain	

CVVH = continuous veno-venous haemofiltration (or other continuous renal replacement therapy, usually undertaken in an intensive care unit)
Cr = serum creatinine

the total validation cohort) were found to simply have been allocated an incorrect date of start (code HD-1), with the majority of these patients all at one centre (centre D). This centre systematically allocated a later (incorrect) HD start date for reasons related to local arrangements for financial reimbursement of haemodialysis costs. The date of start of HD for established renal failure was reported as the date a patient started chronic HD at a satellite dialysis unit even if they had been receiving hospital or ward-based dialysis prior to this.

In 47 patients, there was evidence of receipt of acute RRT (either acute haemodialysis or acute continuous RRT in an ICU setting) prior to their reported date of starting HD, and that the date of start had not been retrospectively changed by the clinician when it became clear that the patient had established renal failure, as required by the UKRR definition.

A further 5 patients had an acute fall in urea (code HD-5) and creatinine which could only have been explained by acute RRT. Two patients had a spurious set of results which were markedly different to other biochemistry results at the time and were likely to represent venesection from the same arm as an intra-venous infusion.

Peritoneal dialysis patients with incorrect dates

In 79 patients who had peritoneal dialysis as their first recorded chronic dialysis modality (code PD-2) there was evidence that they had received one or more episodes of either acute HD or acute haemofiltration or similar continuous RRT in an ICU setting.

Table 13.2. Percentage of patients meeting identification criteria by renal centre

Centre	Number of patients meeting identification criteria	Total number of incident patients	Percentage of patients meeting identification criteria
A	128	1,400	9.1
B	78	825	9.5
C	130	795	16.4
D	660	1,755	37.6
E	56	844	6.6
F	216	769	28.1
G	246	1,447	17.0
H	33	298	11.1
J	69	677	10.2
Total	**1,616**	**8,810**	**18.3**
Total (excluding centre D)	*956*	*7,055*	*13.6*

In another 76 patients who started chronic RRT on PD there was evidence (codes PD-3, PD-4) that they had received additional PD exchanges prior to the reported date of start of chronic PD. Some of these were documented as overnight intermittent PD, whilst others were documented as having low-volume continuous PD. Others had no detailed documentation of the circumstances but had an otherwise unexplained improvement in renal biochemistry between the date of PD catheter insertion and documented date of start of PD.

Patients with a correct date of start of RRT despite anomalous results

In 89 patients (10.7% of the validation cohort) the start date appears to have been correctly assigned, despite having unexpectedly good kidney biochemistry as

Table 13.3. Results of the analysis of local electronic patient records of patients meeting the identification criteria

Code	Description	Centre A	Centre B	Centre D	Centre H	Total	%
C-1	Bilateral/2nd nephrectomy	3	3	1	2	9	1.1%
C-2	Cr/Ur fall pre-RRT	19	12	12	6	49	5.9%
C-3	Cr/Ur fall because of specific therapy	9	3	3	0	15	1.8%
C-4	U<15 – elderly/frail	4	2	1	0	7	0.8%
C-5	U<15 – other	2	5	0	2	9	1.1%
		37	**25**	**17**	**10**	**89**	**10.7%**
HD-1	Incorrect date	8	8	491	5	512	61.7%
HD-2	Previous acute HD/CVVH	8	16	4	10	38	4.6%
HD-3	Possible previous HD/CVVH	2	0	2	1	5	0.6%
HD-4	Transfer in on HD/CVVH	4	0	0	0	4	0.5%
HD-5	Probable incorrect date-improbable fall in U/Cr	1	0	4	0	5	0.6%
HD-6	Spurious result	1	0	1	0	2	0.2%
		24	**24**	**502**	**16**	**566**	**68.2%**
PD-1	Incorrect date	1	0	1	0	2	0.2%
PD-2	Previous acute HD/CVVH (<3 m)	5	2	72	0	79	9.5%
PD-3	IPD prior to training	8	0	0	0	8	1.0%
PD-4	Probable IPD	26	9	30	3	68	8.2%
		40	**11**	**103**	**3**	**157**	**18.9%**
U	Uncertain	0	10	6	2	18	2.2%
		0	**10**	**6**	**2**	**18**	**2.2%**
	Total	**101**	**70**	**628**	**31**	**830**	

Cr = serum creatinine, Ur = serum urea, RRT = renal replacement therapy, HD = haemodialysis, CVVH = continuous veno-venous haemofiltration (or other continuous renal replacement therapy, usually based in an intensive-care unit), IPD = intermittent peritoneal dialysis (or other methods of peritoneal dialysis fluid exchange)

defined by the identification criteria. There were 9 patients in this category (code C-1) who had undergone a bilateral or 2nd nephrectomy and would therefore have had reasonable kidney function until the time of the procedure.

A further 64 patients were flagged because of a fall in serum urea and/or an improvement in eGFR (codes C-2, C-3) in the two months prior to starting RRT. In 15 of these patients there was evidence of a specific intervention (code C-3) causing this improvement. For example, an episode of acute kidney injury secondary to fluid depletion followed by appropriate fluid therapy would appear as an improvement in kidney function if the circumstances were not known. Similarly, a patient with deteriorating function on an angiotensin converting enzyme (ACE) inhibitor may have shown a temporary improvement in kidney function on cessation of this drug [8]. In 49 patients there was a similar improvement in kidney function prior to RRT (code C-2) although the exact circumstances of the improvement could not be established.

Another 16 patients were flagged by the identification criteria (codes C-4, C-5) because the urea immediately prior to RRT was below 15 mmol/L, with 7 of these being elderly or frail (code C-4) (whose circumstances otherwise fitted with an appropriate reason for starting dialysis). In 9 patients (code C-5) there was no evidence of frailty but they were thought to have had appropriate indications for starting dialysis despite the low serum urea.

In 18 patients in the cohort it was not possible from the electronic records to establish whether the date of start was correct or not.

Discussion

These results highlight several key points. Firstly that the reported date of start of RRT can be highly dependent on local clinical requirements and reporting. The UKRR electronic data extraction methods are highly reliant on this correct date to extract the correct pre-RRT laboratory variables.

Using the identification criteria stated above, 18.3% of the original cohort of 8,810 patients had unexpectedly good kidney function at the reported date of start of RRT. It should be noted that a single centre (centre D) contributed 41% (660) of these 'flagged' patients (table 13.2). If this centre is excluded from the analysis, the proportion of flagged patients in the remaining 8 centres falls to 13.6%. However, it remains unknown whether the

systematic reporting issue in centre D is the exception in the UK, or whether it may also occur in other centres.

The validation exercise suggests that about 10% of the patients flagged by the identification criteria will actually have been assigned a correct date of start. If it is assumed that the systematic errors at centre D are unique to that centre, then the proportion of patients reported to the UKRR with an incorrect date of start may be as low as 12%. The authors are only aware of two other studies looking at the concordance of reported start dates: In a study from the Danish National Registry, 22.5% of the 3,020 incident cohort were found to have a wrong year of entry in the database. A random sample of 118 of these 3,020 patients found that the accuracy of start-date was regarded by the authors as having complete concordance with the day in 46% of patients and overall 87% of reported start dates fell within a range of −30 to +30 days of the actual date recorded in the case notes [9]. These data are not directly comparable to ours, but imply that in the small Danish study possibly up to 30–40% of patients were misallocated to a later start date, which compares to 12–18% in this study (12% after excluding one centre's data). In a 1987 study by the USRDS using a random sample of 1,692 patients, perfect concordance of RRT start-date with the case notes derived start date was described in only 64% of patients [10]. This only rose to 94% of records showing concordance of RRT start date when using a range of ±60 days, with 13% of patients showing a much later start date. These data are closer to those found in this study.

The second key point is that this study highlighted three causes for the majority of the incorrectly reported start dates.

The first cause related to the single centre that only entered patients on the RRT timeline at the time they started HD at a satellite unit. When the reason for this practice was sought it was stated that it was for billing purposes rather than for Registry reporting. The centre informed the UKRR that at the time of inquiry the practice had already ceased, although the change in practice had been made after the end of the study period. The UKRR cannot enforce a change in an individual centre's practice although it can highlight issues such as this and emphasise the importance of reporting RRT episodes accurately on the Registry timeline in renal IT systems.

The second cause for incorrect date reporting was the inability to recognise patients reported as starting on 'acute' HD before it was accepted there was to be no recovery of function. The way in which these

patients are reported to the UKRR has been subject to further discussions in the UKRR steering group, summarised as:

- The existing practice of asking clinicians to retrospectively change the modality from 'acute' HD to 'chronic' HD in patients who were initially thought to have a potentially reversible episode was not practicable.
- The current definition and recommendations for reporting the date of RRT start may have been inadequately publicised and notification of any future changes should be circulated to a wider renal audience.
- The specification for the software that reports these patients to the UKRR should be modified to reflect current clinical practice. If a patient is believed to have a potentially reversible episode of acute kidney injury, this should continue to be recorded locally as 'acute' HD. If a clinician then decides that they are not going to recover function, the RRT modality should be changed to 'chronic' HD at the time when this becomes apparent. At the start of chronic RRT, the software should include in the data transmission any prior recorded episode of 'acute' haemodialysis or haemofiltration.
- Registry analyses will backdate the start of RRT to that of the acute date (provided there has been less than 90 days recovery between 'acute' episodes).

These definitions and suggestions were published in the 2008 UKRR Annual Report [11] and a commentary circulated to the Renal Association membership. The definitions continue to be published in the UKRR Annual Report appendix B.

The third cause for incorrect data was the lack of a definition for the date of start of peritoneal dialysis. This study has highlighted the fact that a percentage of patients had some evidence of PD exchanges taking place at an earlier date than was being reported as the start of RRT. Discussions with the UK PD working party group revealed that there was also no international definition for the date of PD start. The UKRR undertook a small survey of clinicians who indicated that there were at least four different definitions considered to be the date of start of PD. These included: the date of insertion of PD catheter, the date of first PD fluid exchange, the date of start of PD training and the date of PD training completion and independence. These definitions were discussed by the UKRR steering group and UK PD working party and a definition was agreed as:

'the date of start of peritoneal dialysis is defined as the date of first PD fluid exchange given with the intention of causing solute or fluid clearance'.

This clarified that the situation of a fluid flush solely for the confirmation or maintenance of catheter patency is not the start of PD. This definition was first published in the 2008 Annual Report [11] and is now found in appendix B.

The third key point is that other registry analyses that rely upon the accuracy of the date of start of RRT (survival analysis of incident dialysis patients, the estimation of eGFR at the start of RRT and time to listing for renal transplantation) may be inaccurate in 12–18% of patients.

The UKRR has reported the eGFR at the start of RRT, both in the UK incident population [12] and as a contribution to European studies [13]. A small proportion of these eGFR results would be artificially high and it is probable that similar results may be found at other registries if equivalent evaluation exercises were undertaken. In the Danish and American studies mentioned earlier [9, 10], only 46% and 64% of patients respectively, had perfectly accurate start dates. A similar analysis of the eGFR at the start of RRT in these countries would therefore include 54% and 36% respectively of patients who did not start RRT on the day reported. This analysis shows that an incorrect late start date, even by only a few days, would result in the extraction of a serum creatinine result which was not pre-RRT and therefore produce a falsely high eGFR at start. In the UK cohort, the small number of patients affected (in the centres not showing the systematic data reporting error) would only have an almost undetectable effect on median eGFR at the start of RRT (under $0.5 \, ml/min/1.73 \, m^2$). This bias would be consistent across centres and also across all years. The slow annual rise seen in the UK of the eGFR at the start of RRT is unlikely to be an artefact of this error.

The results of this validation exercise also have implications for the analysis of the pre-RRT data collection. If the study was to include all the patients whose date of start was confirmed to be incorrect, analyses such as rate of decline of RRT and haemoglobin pre-RRT would yield inaccurate results. It was therefore decided to use the identification criteria to exclude patients with anomalous pre-RRT results, on the evidence from the validation study that these criteria correctly identified 87% of patients with incorrect timelines. During the validation exercise, a number of other

exclusion criteria were trialled including more complex models incorporating first treatment modality, primary renal disease and the absolute or percentage improvement in urea, creatinine and eGFR in the final two months pre-RRT. None of these models improved the predictive value of the original identification criteria.

In addition to excluding patients meeting the above criteria from UKRR future analyses on outcomes using pre-RRT data, it was also decided to completely exclude all the data from Centre D. It was felt that including this centre would introduce a systematic selection bias to the study cohort. Data from Centre F, which had the second highest proportion of flagged patients (28.1%), was then also excluded for similar reasons.

A limitation of this validation exercise is that only four renal centres were sampled and these were not randomly selected. One centre was chosen specifically to investigate the reason for the apparent high error rate. After excluding this one centre, it remains uncertain whether these results are representative of other UK renal centres.

Despite these limitations, it is felt that the study has revealed a number of important issues regarding the mechanism of reporting the date of start of RRT which have not previously been recognised by the UKRR and to our knowledge, have not previously been reported elsewhere in the renal literature. Although this study is not directly comparable with the two other validation studies [8, 9], the proportion of patients found to have inaccurate start dates in the UKRR database was much lower than the Danish study and may be similar to the USRDS study. It is likely that start date errors also affect all other national renal registries.

This study illustrates the emphasis and the attention to detail that the UKRR places on the data validation process. There is a large amount of data validation undertaken by the UKRR data management team in conjunction with the renal centres, some of which is automated, the remainder requiring additional human intervention and corroboration with renal centre staff. The publication of this study has resulted in changes in UK guidelines and practices and is evidence of the continuing efforts at the UKRR to improve the quality of the data analysed and interpreted in each Annual Report.

Conflict of interest: none

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