UK Renal Registry 17th Annual Report: Chapter 9 Clinical, Haematological and Biochemical Parameters in Patients Receiving Renal Replacement Therapy in Paediatric Centres in the UK in 2013: National and Centre-specific Analyses

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Key Words
Biochemical variables · Blood pressure · BMI · Children · Dialysis · ERF · Growth · Haemoglobin · Height · Paediatric · Quality improvement · Transplant · Weight

Summary

- The median height z-score for children on dialysis was −2.0 and for children with a functioning transplant −1.3. Children transplanted before the age of 11 years improved their height z-score over the subsequent three years, whereas those older than 11 maintained their height z-score, with all transplanted patients having a similar height z-score after three years of starting renal replacement therapy (RRT).
- The median weight z-score for children on dialysis was −1.2 whereas children with a functioning transplant had a near normal weight with a median z-score of −0.2.
- Of those with data, 75% of the prevalent paediatric RRT population had one or more risk factors for cardiovascular disease, with 1 in 10 having all three risk factors evaluated.
- For transplant patients, 76% achieved the systolic blood pressure (SBP) standard and 91% achieved the haemoglobin standard.
- For haemodialysis patients, 53% achieved the SBP standard, 66% achieved the haemoglobin standard, 84% achieved the calcium standard, 43% achieved the phosphate standard and 43% achieved the parathyroid hormone (PTH) standard.
- For peritoneal dialysis patients, 61% achieved the SBP standard, 83% achieved the haemoglobin standard, 71% achieved the calcium standard, 56% achieved the phosphate standard and 36% achieved the PTH standard.

Introduction

This report focuses on the following variables for the prevalent paediatric dialysis and transplantation cohort on the 31st December 2013:

1. The completeness of data returns to the UK Renal Registry (UKRR)
2. Anthropometric characteristics and growth in children with established renal failure (ERF)
3. Cardiovascular risk factors (CVRFs) in children with ERF
4. Laboratory and clinical indices including anaemia control and biochemical findings in children with ERF

Analyses of prevalent paediatric patients aged <16 years receiving renal replacement therapy (RRT) for the year 2013 and for the period 2002 to 2013 inclusive are reported. A single dataset was collected for each patient per year during this time period. Where possible, analysis of incident cohorts has been undertaken with centre specific data for each paediatric nephrology centre in the UK also being provided.

Methods

There were 13 paediatric nephrology centres managing children on RRT in the UK in 2013. Ten of these centres provided surgical renal transplant services, and all centres offered outpatient and inpatient follow up for children who had received kidney transplants. Centres and abbreviations are listed in appendix K.

Data collection

The data presented in this report relate to the annual census date of 31st December 2013. Data submission to the UKRR in previous years has been electronic in most cases and paper-based in a minority. These data items are then checked, validated and manually entered into the current paediatric UKRR database.

Standards and standardisation

Standards are in bold text and are from the 'Treatment of adults and children with renal failure', Renal Association standards third edition (2002) [1] unless otherwise stated.

Where the value of clinical parameters in childhood varies with age and size, data are presented as z-scores.

Anthropometry

'Measures of supine length or standing height and weight should be monitored at each clinic visit. All measurements should be plotted on European reference growth charts for healthy children.'

The reference range for height (Ht), weight (Wt) and body mass index (BMI) in childhood varies with gender and age. BMI was calculated using the formula BMI = Wt (kg)/Ht^2 (m). Height and weight were adjusted for age. To account for discrepancies in linear growth secondary to renal disease, BMI was expressed according to height-age, rather than chronological age. The International Obesity Taskforce definition [2] was used to define overweight and obesity; z-scores were calculated based on the British 1990 reference data for height and weight [3].

Blood pressure

'Blood pressure varies throughout childhood and should be maintained within two standard deviations of the mean for normal children of the same height and sex. The systolic blood pressure during peritoneal dialysis or after haemodialysis should be maintained at <90th centile for age, gender and height.'

'In paediatric renal transplant patients, the systolic blood pressure should be maintained at <90th percentile for age, gender and height.'

The analyses of systolic blood pressure (SBP) in this report present the achievement of SBPs at or below the 90th percentile. Guidance for blood pressure in paediatric renal transplant patients was based on 2011 British Association for Paediatric Nephrology (BAPN) recommendations [4].

The reference range for SBP varies with gender, age and height. The data is therefore presented as z-scores based on data from the fourth report of the National High Blood Pressure Education Programme working group in the United States [5].

Cholesterol

The National Heart Lung and Blood Institute recommends screening for dyslipidaemias in children with chronic renal disease/end-stage renal disease/post renal transplant (deemed high risk) between the ages of 2 and 17, and defines high total cholesterol as $\geqslant$5.2 mmol/L [6]. This cut-off has been adopted for this report.

Haemoglobin and Ferritin

Guidance on the management of anaemia in adults and children with chronic kidney disease was updated and published by the National Institute for Health and Care Excellence (NICE) in February 2011 (Clinical Guideline 114) [7].

'Typically maintain the aspirational Hb range between 100 and 120 g/L for young people and children aged 2 years and older, and between 95 and 115 g/L for children younger than 2 years of age, reflecting the lower normal range in that age group.'

Haemoglobin and ferritin were analysed using age related laboratory reference ranges as in table 9.1.

Calcium, phosphate and parathyroid hormone (PTH)

'Serum phosphate and calcium should be kept within the normal range. PTH levels should be maintained within twice the upper limit of the normal range but, contrary to adult standards, may be kept within the normal range if growth is normal.'

Table 9.1. Summary of relevant biochemical clinical audit measures

Parameter	Age			
	<1 year	1–<5 years	6–12 years	>12 years
Haemoglobin (g/L), NICE guideline CG 114	Maintain 95–115 for <2 years	Maintain 100–120 for >2 years	100–120	100–120
Ferritin (μg/L)	200–500	200–500	200–500	200–500
Corrected calcium (mmol/L)	2.24–2.74	2.19–2.69	2.19–2.69	2.15–2.55
Phosphate (mmol/L)	1.10–1.95	1.05–1.75	1.05–1.75	1.05–1.75
Parathyroid hormone (individual centre units)	Within twice the normal range Levels may be maintained within normal range if growing appropriately			
Bicarbonate (mmol/L)	Reported as either within or outside centre reference range			

Calcium, phosphate and PTH were analysed using age related laboratory reference ranges as in table 9.1. Individual variable data analysis has been performed per centre and nationally. It should be noted that 'normal' growth is difficult to determine in the setting of paediatric RRT.

Bicarbonate

'Serum bicarbonate concentrations should be between 20 and 26 mmol/l.'

Bicarbonate reference ranges vary by centre, and are reported as within or outside the reference range as given in table 9.1.

Cardiovascular risk factors

This year a cross-sectional evaluation of the prevalence of traditional risk factors for cardiovascular disease, including hypertension, overweight/obesity and hypercholesterolaemia in children with ERF was undertaken. In this initial analysis, the prevalence of one or more CVRFs in children with ERF in the UK is shown. Evidence for the use of total cholesterol and the relationship of childhood CVRFs with adult CVRFs is available from The National Heart Lung and Blood Institute [6].

Statistical analyses

Data were analysed to calculate summary statistics (maximum, minimum, mean and median values in addition to standard deviation and quartile ranges). Where applicable, the percentage achieving the audit standard was also calculated. If a patient had missing data, they were excluded from the relevant analyses.

Longitudinal analyses of attainment of standards were also performed. These were based on a single data point per ERF patient per year collected as described previously. Caution should be exercised in the interpretation of analyses based on data items from a single annual measurement per patient. This is due to changing audit standards over time and variable data returns for previous years. Furthermore, for biochemical variables there are not only differences between assays used at different centres, but also differences in the timing of the result between modalities to take into account. All analyses were performed using SAS 9.3.

Results

Data completeness

Tables 9.2 and 9.3 show the completeness of data returns for transplant and dialysis patients for 2013.

Overall, completeness was excellent for height, weight, SBP, haemoglobin, creatinine, bicarbonate, calcium and phosphate in both groups. Variability in the use of certain parameters limits the completeness of these items. In 2013 completeness remained similar to the previous year [8]. For the first time this year total cholesterol data is presented in the cardiovascular risk section. Inter-centre reporting of this remained inconsistent, with completeness from five centres less than 50% for transplant patients. It is hoped that reporting this data will encourage improved data returns for this item in subsequent years.

Growth

Height

Figures 9.1 and 9.2 show that children receiving RRT were short for their age; those on dialysis were significantly shorter that those with renal transplants. The overall median z-score was −1.3 in the transplanted group and −2.0 in the dialysis group, $p < 0.0001$. Figure 9.3 demonstrates that by the time of RRT start, children are already short for their age with an overall median height z-score of −1.4 (shown by the dotted line) with younger children aged 2–8 most affected. Figure 9.4 shows that the subset of children who improved height z-scores were those transplanted before the age of 11 years. In contrast, all those commencing RRT over the age of 11 started at the same z-score of

Table 9.2. Percentage data completeness for transplant patients <16 years old by centre for each variable and total number of patients per centre in 2013

Centre	Transplant patients *N*	Height	Weight	BMI	SBP	Hb	Creat	Ferr	ESA	IV iron	Chol	Bicarb	PTH	Ca	Phos
Bham_P	63	98.4	98.4	98.4	98.4	93.7	98.4	52.5			93.6	98.4	91.9	98.4	98.4
Blfst_P[a]	16	93.8	100.0	93.8	100.0	100.0	100.0	25.0	100.0	87.5	43.8	100.0	6.3	93.8	93.8
Brstl_P	32	93.8	96.9	93.8	93.8	100.0	100.0	59.4	100.0	100.0	62.5	100.0	65.6	100.0	100.0
Cardf_P[b]	16	94.1	100.0	94.1	100.0	100.0	100.0	93.8	93.8	93.8	100.0	100.0	100.0	100.0	100.0
Glasg_P	29	100.0	100.0	100.0	100.0	100.0	100.0	44.8	100.0	100.0	34.5	96.6	86.2	96.6	100.0
L Eve_P	62	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	85.5	100.0	100.0	100.0	100.0
L GOSH_P	119	96.6	96.6	96.6	93.3	96.6	96.6	96.6	42.9	28.6	5.0	96.6	96.6	96.6	96.6
Leeds_P	53	90.6	90.6	88.7	90.6	100.0	100.0	79.3	100.0	100.0	94.3	98.1	83.0	100.0	96.2
Livpl_P[b]	27	84.6	84.6	84.6	80.8	84.6	84.6	73.1	80.8	61.5	69.2	84.6	40.0	80.8	84.6
Manch_P	36	97.2	97.2	97.2	97.2	100.0	100.0	80.6	100.0	100.0	47.2	100.0	100.0	100.0	100.0
Newc_P	21	90.5	90.5	90.5	90.5	85.7	76.2	76.2	100.0	100.0	66.7	81.0	52.4	85.7	85.7
Nottm_P	58	94.8	96.6	94.8	94.8	98.3	98.3	41.4	98.3	96.6	1.7	98.3	44.8	100.0	100.0
Soton_P[b]	18	88.2	94.1	88.2	94.1	100.0	100.0	93.8	94.1	94.1	100.0	100.0	93.8	100.0	100.0
UK	**550**	**95.3**	**96.2**	**95.1**	**94.9**	**97.1**	**97.3**	**74.3**	**70.3**	**65.7**	**52.6**	**97.1**	**80.6**	**97.3**	**97.3**

Abbreviations: BMI – body mass index; SBP – systolic blood pressure; Hb – haemoglobin; Creat – creatinine; Ferr – ferritin; ESA – erythropoietin stimulating agent; IV – intravenous; Chol – cholesterol; Bicarb – bicarbonate; PTH – parathyroid hormone; Ca – calcium; Phos – phosphate
Blank cells represent data items that could not be submitted due to technical reasons
[a]Belfast does not measure PTH in transplanted patients
[b]Non-transplant surgery centre

approximately −1.1, but whilst those who were transplanted maintained their height, the height z-score continued to worsen for those who received dialysis. For dialysis patients across all age groups their height z-score tended to worsen over time. It should be noted that due to changes in modality, groups are not strictly sequential in this analysis.

The proportion of patients aged 2–16 years with a height less than two standard deviations in 2013 was much higher for those on dialysis (46.8% for

Table 9.3. Percentage data completeness for dialysis patients <16 years old by centre for each variable and total number of patients per centre in 2013

Centre	Dialysis patients *N*	Height	Weight	BMI	SBP	Hb	Ferr	ESA	IV iron	Chol	Bicarb	PTH	Ca	Phos
Bham_P	20	90.0	95.0	90.0	95.0	95.0	95.5			95.2	90.0	95.2	95.0	95.0
Blfst_P	5	60.0	100.0	60.0	100.0	100.0	100.0	100.0	100.0		100.0	100.0	100.0	100.0
Brstl_P	7	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	85.7	100.0	100.0	100.0	100.0
Cardf_P	3	100.0	100.0	100.0	100.0	100.0	100.0		100.0	33.3	100.0	100.0	100.0	100.0
Glasg_P	12	91.7	100.0	91.7	100.0	100.0	91.7	100.0	100.0	58.3	100.0	100.0	100.0	100.0
L Eve_P	14	57.1	64.3	57.1	64.3	100.0	100.0	92.9	92.9	7.1	100.0	100.0	100.0	100.0
L GOSH_P	30	100.0	100.0	100.0	96.7	100.0	96.7	86.7	80.0	72.0	100.0	100.0	100.0	100.0
Leeds_P	12	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Livpl_P	5	66.7	100.0	66.7	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Manch_P	25	92.0	92.0	92.0	92.0	100.0	100.0	100.0	96.0	4.0	100.0	100.0	100.0	100.0
Newc_P	2	50.0	50.0	50.0	50.0	100.0	100.0	100.0	100.0	50.0	100.0	100.0	100.0	100.0
Nottm_P	12	83.3	91.7	91.7	50.0	100.0	91.7	91.7	91.7		100.0	91.7	100.0	100.0
Soton_P	5	100.0	100.0	100.0	100.0	80.0	85.7	100.0	100.0	80.0	80.0	71.4	80.0	80.0
UK	**152**	**88.2**	**93.5**	**88.9**	**89.5**	**98.7**	**96.8**	**76.6**	**74.7**	**50.0**	**98.0**	**97.5**	**98.7**	**98.7**

Abbreviations: BMI – body mass index; SBP – systolic blood pressure; Hb – haemoglobin; Ferr – ferritin; ESA – erythropoietin stimulating agent; IV – intravenous; Chol – cholesterol; Bicarb – bicarbonate; PTH – parathyroid hormone; Ca – calcium; Phos – phosphate
Blank cells represent data items that could not be submitted due to technical reasons

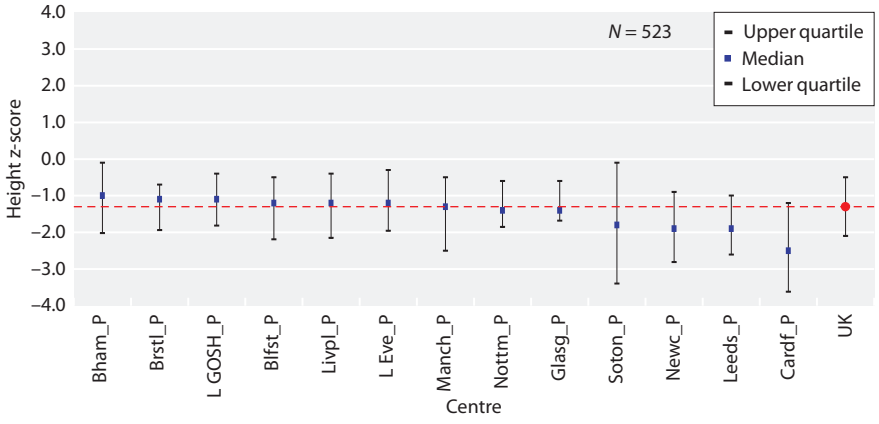

Fig. 9.1. Median height z-scores for transplant patients <16 years old in 2013, centre specific and national averages.

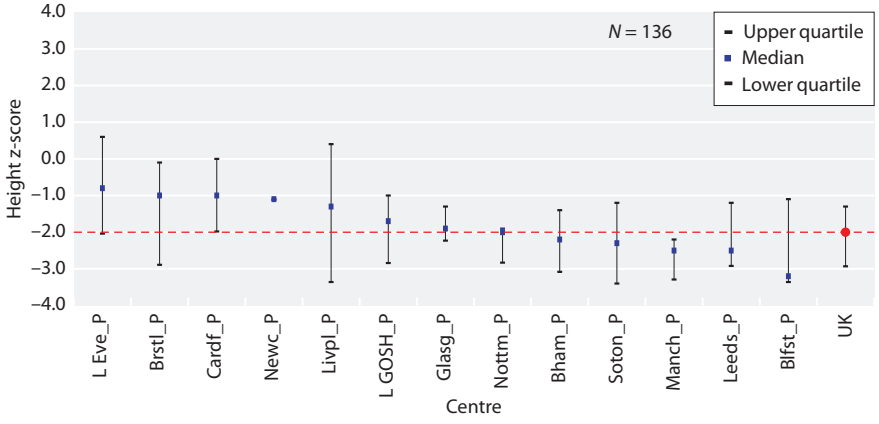

Fig. 9.2. Median height z-scores for dialysis patients <16 years old in 2013, centre specific and national averages.

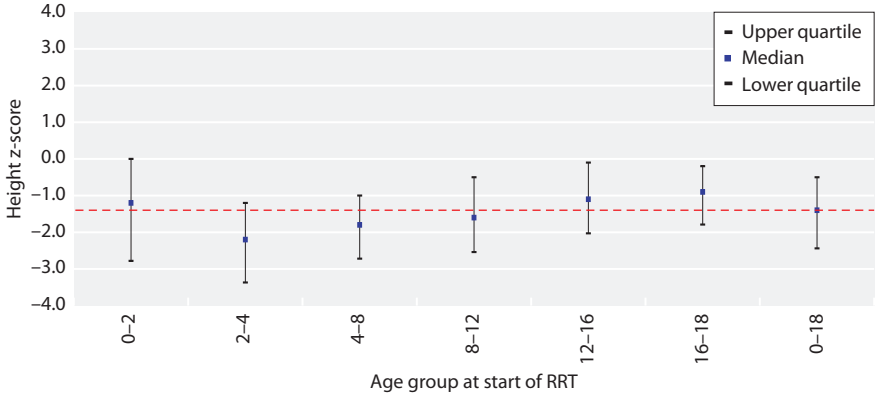

Fig. 9.3. Median height z-scores at start of RRT for patients <18 years old between 2002 and 2013, by age of start

haemodialysis (HD) and 43.2% for peritoneal dialysis (PD)) compared to those with a functioning transplant (25.7%), excluding situations where growth might be compromised (patients with syndromes and those born prematurely). Individual centre data has not been shown due to very small numbers per modality per centre. Figure 9.5 displays temporal fluctuations in use of growth hormone in those with a height less than two standard deviations; whilst it appears use of growth hormone was falling, reporting of this has been poor over the last three years. Average use of growth hormone for under 16s with a height less than two standard deviations since 2002 is 27.2% for dialysis patients and 10.3% for transplant patients.

Weight

Figures 9.6 and 9.7 show that children receiving dialysis were significantly more underweight than those

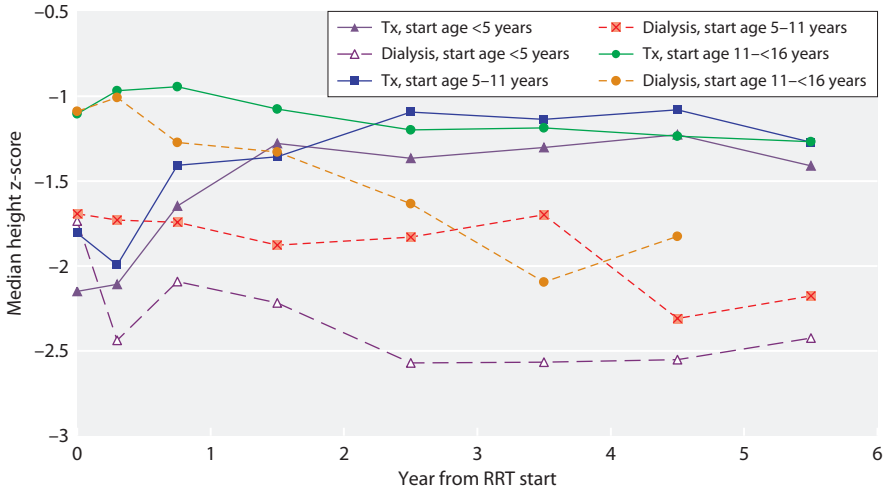

Fig. 9.4. Median height z-scores for patients <16 years old by time on RRT and treatment modality

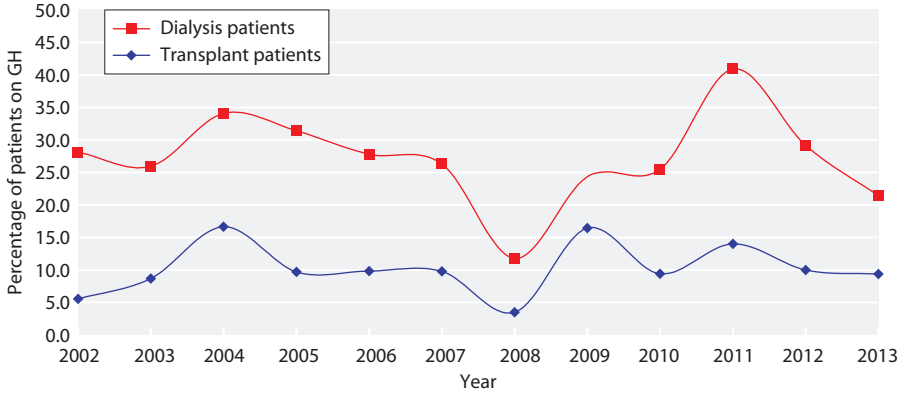

Fig. 9.5. Use of growth hormone in children <16 years old with a height under 2SD between 2002 and 2013

with renal transplants. The overall median z-score was −0.2 in the transplanted group and −1.2 in the dialysis group, $p < 0.0001$.

Cardiovascular risk factor evaluation

Obesity

Figures 9.8 and 9.9 show that children with renal transplants had a significantly higher body mass index than those receiving dialysis. The overall median z-score was 0.9 in the transplanted group and 0.2 in the dialysis group, $p < 0.0001$.

Figure 9.10 demonstrates higher proportions of overweight and obese children (41.4%) in those with renal transplants compared to those receiving dialysis (25.9%). There was a higher proportion of underweight children in the dialysis group (8.9%) compared to those with renal transplants (0.6%). There was a highly significant difference in proportions of those underweight or with a normal BMI and those overweight/obese between age groups; older children aged 12 to <16 years had a higher body mass index than younger children aged under five years, $p < 0.0001$. Of those aged 12 to <16 years, 44.2% were overweight or obese compared to 40.0% of those aged 5 to <12 years and only 17.2% of those aged 0 to <5 years. Looking only at the proportions of those underweight, just 0.8% of those aged 12 to <16 years were underweight compared to 1.3% of those aged 5 to <12 years and 9.1% of those aged 0 to <5 years. There were no statistically significant differences between proportions of those underweight, normal, overweight or obese in terms of sex, ethnicity or donor source (deceased or living).

Hypertension

Figures 9.11 and 9.12 show children receiving RRT are hypertensive compared to the healthy population, and those receiving dialysis had a significantly higher median SBP than those with renal transplants. There was wide inter-centre variability in median SBP z-score. The median SBP z-score was maintained at or below the 90th centile by all centres for children with transplants

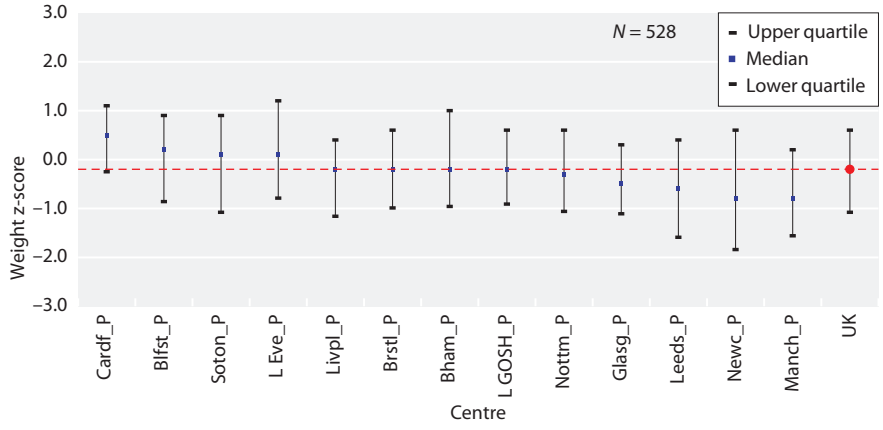

Fig. 9.6. Median weight z-scores for transplant patients <16 years old in 2013, centre specific and national averages

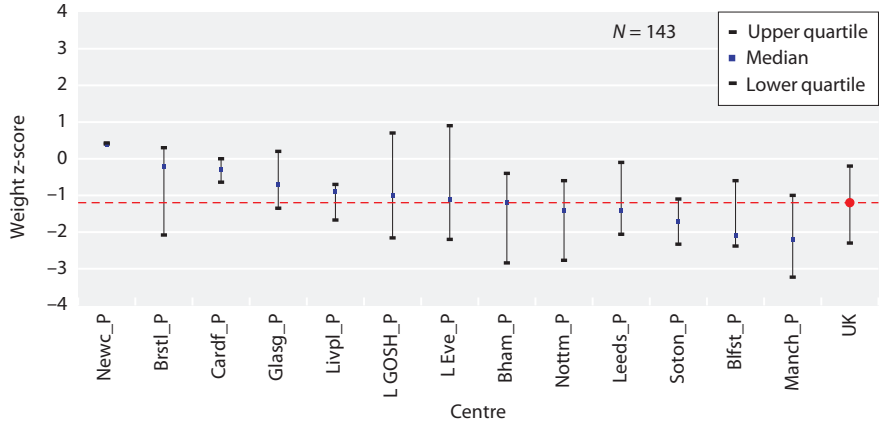

Fig. 9.7. Median weight z-scores for dialysis patients <16 years old in 2013, centre specific and national averages

whereas six centres were above the 90th centile for median SBP z-score for children receiving dialysis. The overall median z-score was 0.6 in the transplanted group and 1.0 in the dialysis group, $p = 0.002$. Of those aged <16, 76.1% of children with a functioning kidney transplant, 53.4% of those receiving HD, and 60.7% of those receiving PD had a SBP <90th percentile in 2013. Individual centre data showing percentages achieving the SBP standard by modality has not been shown due to very small numbers per modality per centre. Table 9.4 shows that there was a highly significant difference in the percentage <90th percentile for SBP between RRT modalities, whereas there was no difference with age, gender or ethnicity. Nor was there any statistically significant difference in SBP between living and deceased donor transplants.

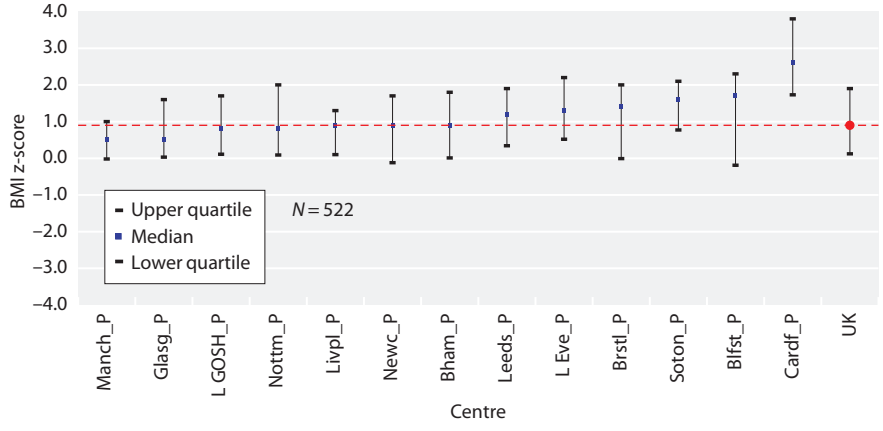

Fig. 9.8. Median BMI z-scores for transplant patients <16 years old in 2013, centre specific and national averages

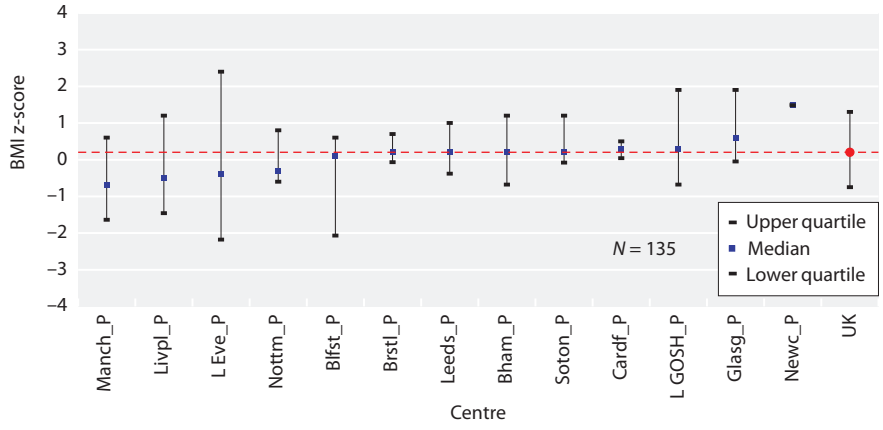

Fig. 9.9. Median BMI z-scores for dialysis patients <16 years old in 2013, centre specific and national averages

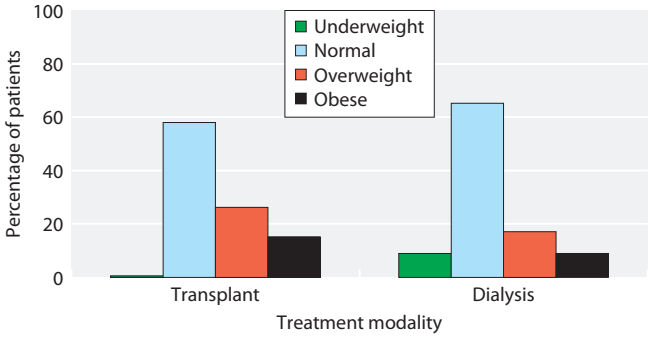

Fig. 9.10. BMI categorisation in children <16 years old by modality in 2013

Cardiovascular risk factor prevalence

Table 9.5 shows that the percentage of patients with no CVRFs was 26%, one CVRF was 35%, two CVRFs was 27% and the percentage of those with all evaluated CVRFs was 12%. This analysis is restricted to the 353 of 702 (50.3%) patients with complete data for all three items. Thus of the included prevalent paediatric RRT population, 75% had one or more risk factors for cardiovascular disease, with 1 in 10 having all three risk factors evaluated. Of those included in this analyses, 170 (48%) had hypertension, 150 (43%) were overweight/obese and 125 (35%) had hypercholesterolaemia. Treatment modality influenced the number of CVRFs, with transplants being associated with more CVRFs ($p = 0.007$). There were no statistically significant differences in number of CVRFs according to age, gender or ethnicity.

Laboratory and clinical indices

Haemoglobin and ferritin

The percentage of patients aged <16 on dialysis achieving the haemoglobin standard in 2013 was 65.5% for those on HD and 82.5% for those on PD, compared to 91.2% for those with a renal transplant. Individual centre data has not been shown due to very small numbers per modality per centre. During 2011–2013, 73.2% of dialysis patients and 91.8% of transplant patients achieved the standard for haemoglobin, which has remained consistent since 2002–2004. The proportion of patients with a ferritin in range during 2011–2013

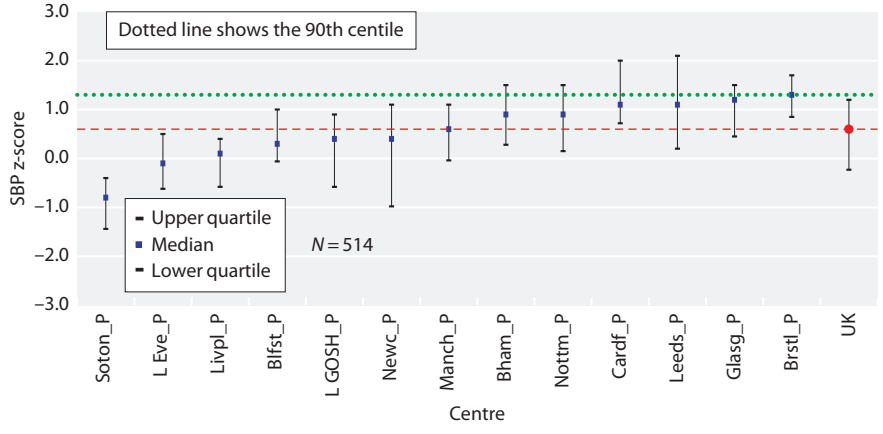

Fig. 9.11. Median systolic blood pressure z-scores for transplant patients <16 years in 2013, centre specific and national averages

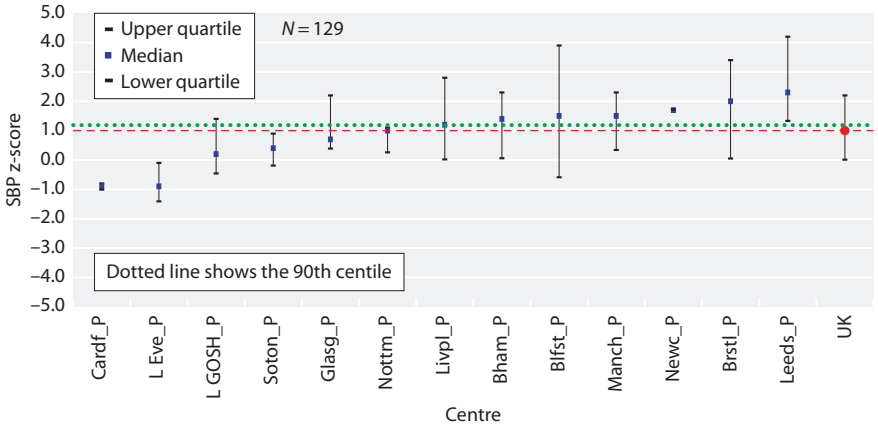

Fig. 9.12. Median systolic blood pressure z-scores for dialysis patients <16 years in 2013, centre specific and national averages

Table 9.4. Percentage of patients <16 years old achieving the standards for systolic blood pressure in 2013

	N	% below 90th percentile	*p* value
Total	643	72.2	
Age group			0.13
0–<5 years	94	66.0	
5–<12 years	301	70.8	
12–16 years	248	76.2	
Gender			0.06
Male	393	74.8	
Female	250	68.0	
Ethnicity			0.3
Black	23	60.9	
Other	44	75.0	
South Asian	101	66.3	
White	446	73.5	
RRT modality			<0.0001
Dialysis	129	56.6	
Transplant	514	76.1	

was 33.3% for dialysis patients and 14.8% for transplant patients. It is not possible to comment on trends for ferritin due to historical missing data, although this has substantially improved more recently.

Whilst table 9.6 suggests that fewer anaemic dialysis patients were receiving erythropoietin stimulating agents (ESAs) in the 2011–2013 period, it must be considered that the data completeness of ESA usage has fallen considerably in the last five years, and therefore reliability of the data is questionable.

Figure 9.13 demonstrates fluctuations in usage of ESAs for dialysis patients according to haemoglobin standard, with an erratic picture largely since 2009 when data completeness reduced. Prior to 2009, trends were more stable. Usage appears smoother for the transplant groups, where completeness is marginally better. Figure 9.14 shows that similar to figure 9.13, attainment of the haemoglobin standard and use of intravenous iron was also subject to alterations, with completeness also being inconsistent. More meaningful conclusions might be evident from these graphs if this data could be better provided by centres.

Table 9.5. Frequency of number of cardiovascular risk factors in prevalent RRT patients <16 years in 2013

Number of CV risk factors	Hypertensive	OW/Obese	Hypercholesterolaemic	*N*	%	Total %
0	No	No	No	90	25.5	**25.5**
1	Yes	No	No	55	15.6	
	No	Yes	No	45	12.7	**35.1**
	No	No	Yes	24	6.8	
2	Yes	Yes	No	38	10.8	
	Yes	No	Yes	34	9.6	**27.2**
	No	Yes	Yes	24	6.8	
3	Yes	Yes	Yes	43	12.2	**12.2**
N	**170**	**150**	**125**			
Total %	**48.2**	**42.5**	**35.4**			

Table 9.6. Proportion of paediatric RRT patients on ESA, by haemoglobin attainment, across time

Time period	Haemoglobin below standard % on ESA	Haemoglobin above standard % on ESA
Transplant patients		
2002–2004	17.5	4.2
2005–2007	22.5	4.1
2008–2010	24.7	8.1
2011–2013	20.0	5.8
Dialysis patients		
2002–2004	95.5	90.6
2005–2007	95.8	96.3
2008–2010	93.9	88.1
2011–2013	78.3	88.8

Calcium

The percentage of patients aged <16 on HD ($n = 88$) achieving the calcium standard in 2013 was 84.1%, with 5.7% of patients being hypocalcaemic, and 10.2% being hypercalcaemic. The percentage of patients aged <16 on PD ($n = 63$) achieving the calcium standard in 2013 was 71.4%, with 4.8% of patients being hypocalcaemic, and 23.8% being hypercalcaemic. Individual centre data has not been shown due to very small numbers per modality per centre.

Analysis by age demonstrated that for HD in the 0 to <5 group ($n = 27$), 22.2% were hypercalcaemic and 3.7% hypocalcaemic, with the remainder (74.1%) being within the age related reference range. In the 5 to <12 group ($n = 32$), 0% were hypercalcaemic, 3.1% were hypocalcaemic and the vast majority (96.9%) were within the age related reference range. In the 12 to <16 group ($n = 29$), 10.3% were hypercalcaemic, 10.3% were hypocalcaemic and the remainder (79.3%) were within the age related reference range. For PD, analysis by age was less reliable due to small group numbers; the majority of the hypercalcaemia came from 13 patients in the 12 to <16 year group, where 46.2% were hypercalcaemic.

Phosphate

The percentage of patients aged <16 on HD ($n = 88$) achieving the phosphate standard in 2013 was 43.2%, with 27.3% of patients being hypophosphataemic, and 29.6% being hyperphosphataemic. The percentage of patients aged <16 on PD ($n = 63$) achieving the phosphate standard in 2013 was 55.6%, with 4.8% of patients being hypophosphataemic, and 39.7% being hyperphosphataemic. Individual centre data has not been shown due to very small numbers per modality per centre.

Analysis by age for both HD and PD demonstrated no particular differences between age groups of proportions within, above or below the age related reference range.

Parathyroid hormone

The percentage of patients aged <16 with a renal transplant ($n = 439$) achieving the PTH standard in 2013 was 80.2%, with 19.8% having hyperparathyroidism. The percentage of patients aged <16 on HD ($n = 87$) achieving the PTH standard in 2013 was 42.5%, with 57.5% having hyperparathyroidism. The percentage of patients aged <16 on PD ($n = 66$) achieving the PTH standard in 2013 was 36.4%, with 63.6% having hyperparathyroidism.

Individual centre data has not been shown due to very small numbers per modality per unit, and low

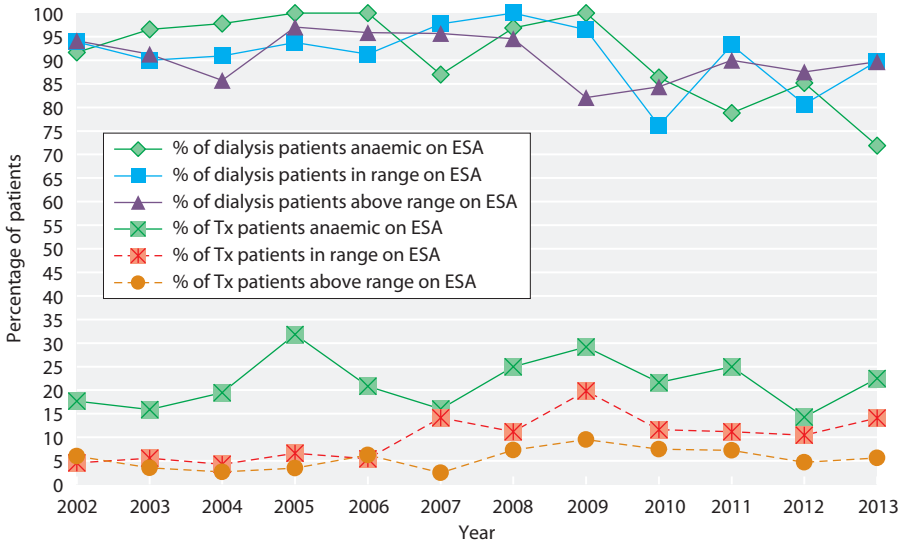

Fig. 9.13. The use of ESA by haemoglobin standard and treatment modality between 2002 and 2013 in prevalent RRT patients <16 years old

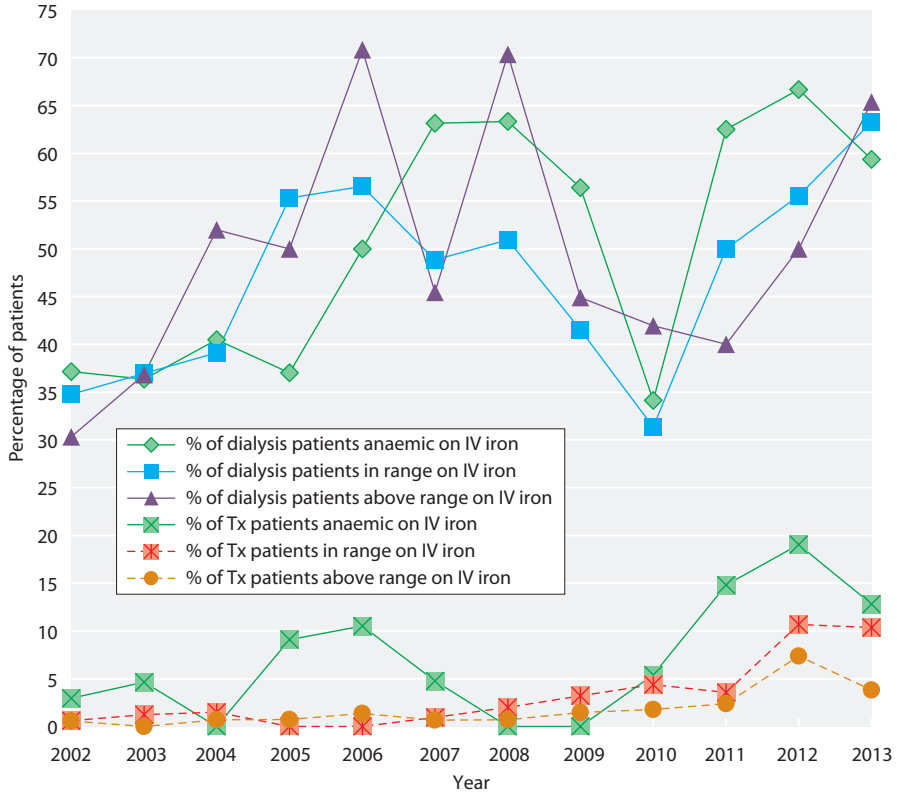

Fig. 9.14. The use of intravenous iron by haemoglobin standard and treatment modality between 2002 and 2013 in prevalent RRT patients <16 years old

completeness for some centres for transplant patients. Analysis by age for all groups demonstrated no particular differences between age groups of proportions within or above the standard.

Bicarbonate

Table 9.7 demonstrates that more than 80% of both transplant and dialysis patients achieved the bicarbonate standard in 2013, with reasonably similar proportions

Table 9.7. Centre analysis of bicarbonate levels (mmol/L) in patients under 16 years old by treatment modality, in 2013

	Transplant patients				Dialysis patients			
Centre	*N*	% below standard	% within standard	% above standard	*N*	% below standard	% within standard	% above standard
Bham_P	62	1.6	82.3	16.1	18	0.0	77.8	22.2
Blfst_P	16	68.8	31.3	0.0	5	0.0	100.0	0.0
Brstl_P	32	18.8	81.3	0.0	7	10.0	90.0	0.0
Cardf_P	16	6.3	93.8	0.0	3	33.3	66.7	0.0
Glasg_P	28	14.3	82.1	3.6	12	17.1	82.9	0.0
L Eve_P	62	24.2	75.8	0.0	14	25.0	75.0	0.0
L GOSH_P	115	0.9	98.3	0.9	30	7.1	88.1	4.8
Leeds_P	52	3.9	90.4	5.8	12	0.0	83.3	16.7
Livpl_P	22	27.3	72.7	0.0	6	0.0	100.0	0.0
Manch_P	36	8.3	88.9	2.8	25	22.2	71.5	6.3
Newc_P	17	17.7	82.4	0.0	2	0.0	100.0	0.0
Nottm_P	57	3.5	87.7	8.8	12	0.0	58.6	41.4
Soton_P	18	5.6	94.4	0.0	4	0.0	100.0	0.0
UK	**533**	**10.5**	**85.6**	**3.9**	**150**	**8.8**	**80.4**	**10.8**
Age group								
0–<5 years	50	16.0	82.0	2.0	58	11.2	75.6	13.2
5–<12 years	267	12.4	84.3	3.4	50	6.3	83.5	10.2
12–<16 years	216	6.9	88.0	5.1	42	8.6	83.7	7.7

between modalities. Here individual centre data has been combined for HD and PD in order to provide limited comparison, but despite this, numbers remain small. There were no statistical differences between age groups on the achievement of the bicarbonate standard.

Conclusions

Registry data

The Paediatric Renal Registry is a valuable resource for describing the paediatric ERF population and assessing how outcome data compares against national standards. It provides a means of benchmarking and improving the quality of the care provided to children on RRT in the UK.

There are some important limitations to the data provided to the Registry. Unlike the adult Registry, data collection is only performed once per year; one must be wary of over analysing items where a single annual measurement is submitted to the Registry, especially if the variable can vary widely from day to day. The Paediatric Registry also includes far fewer patients. These limitations restrict the quality of the analysis and ability to make comparisons between centres. In order to address these restrictions, patients are grouped into cohorts by time period to ameliorate the problem of reduced numbers. Moving to a quarterly data return would greatly improve the accuracy of the report, as well as resolve some of the issues with completeness. The lack of completeness of certain data items described in this report such as the use of growth hormone, ESAs and intravenous iron and transplant immunosuppression do provide a challenge in drawing meaningful conclusions from the data. A concerted effort from all centres to regularly provide this information could lead to a much more accurate assessment of how paediatric ERF patients are managed. In addition, more cohesiveness between centres with the items reported to the Registry would be valuable, however it is accepted that information technology, practice and services differ.

Changes to the chapter

This year the paediatric biochemistry chapter has been restructured, with the objective to provide new ways of looking at the data and to improve reporting. Insights from the literature and from other national registries are welcomed to provide novel data presentation and processing to aid better management of children on RRT. For the first time, cholesterol data which has now passed 50% completeness is reported and has enabled the presentation of the prevalence of some of the commonest CVRFs in children on RRT. It is hoped that by reporting on items with lower completeness, clinicians will be inspired to improve their returns to fully realise the potential of the Registry.

Standards

The Renal Association guidelines that are reported against are now over ten years old with guidelines in development or being updated by the BAPN. These new standards are welcomed in order to ensure that the report is current and relevant.

Growth

Previous Registry reports [8] and data from the ESPN/ERA-EDTA [9] have established that the UK ERF population are shorter than healthy children. UK paediatric transplant patients had a near normal z-score for weight, whereas dialysis patients are underweight. The BMI findings in this report are influenced by the reduced height of RRT patients, so although transplant patients' weights were comparable to the healthy population, they were overweight for their height.

A new analysis in this report suggests that there were important differences in growth trends between cohorts of children according to age of commencement of RRT. Children transplanted under 11 years of age improved their height z-score, and children transplanted over 11 years maintain height z-scores, with all transplanted patients having a similar height z-score after three years of starting RRT. As a healthy child with a normal pubertal growth spurt will have a static height z-score and the Registry dataset does not collect information regarding puberty, it is difficult to comment on growth patterns any further. This new analysis thus shows patterns of growth trend over the first few years following commencement of RRT by modality and adds to the recent European Registry data where an older age at RRT start, the cumulative time with a functioning graft, more recent RRT vintage and greater height z-score at RRT start were associated with higher final height z-score [9]. Although the proportion of those receiving growth hormone in those under 16 with a height z-score <2 standard deviations is reported, it is accepted that growth hormone use would not be recommended in newly transplanted patients and in those demonstrating catch up growth.

Work is being undertaken to investigate the number of patients with a final adult height recorded at age 18. Difficulties in such an analysis include the representation of patients who may be managed in paediatric or adult

centres and the low data completeness of height reporting to the adult Registry, as well as continued growth past the age of 18 years. More detailed analyses of the effect of different steroid regimes on growth were not possible for inclusion in this report due to a lack of power.

Cardiovascular risk factor evaluation

Novel analyses in this report highlight that of those with data, 75% of paediatric RRT patients had one or more risk factors, and that 1 in 10 had three risk factors for cardiovascular disease including hypertension, obesity and hypercholesterolaemia. As the assessment of all three risk factors only used data from half the population, the proportions of hypertension and obesity without cholesterol data were also tested and found to be the same as when taking into account all three variables. It is accepted that using total cholesterol alone may have limitations in the assessment of dyslipidaemia, but Registry data for other lipid measures is sub-optimal and thus this makes best use of the data available. An annual full lipid screen for children on RRT would enhance the Registry's ability to assess dyslipidaemia in the paediatric ERF population.

The analyses highlight that hypertension remained the most prevalent 'traditional' CVRF in this paediatric RRT cohort. These findings are similar to previous reports including pre-dialysis CKD cohorts [10]. These data should encourage clinicians to develop strategies to reduce current rates of hypertension and excess weight in childhood populations on RRT in the UK.

Laboratory and clinical indices

Haemoglobin standard achievement was broadly similar to previous years. Completeness for ferritin has improved in recent years but unfortunately reduced for ESA data. Improving data returns on usage of ESAs and intravenous iron would help more comprehensive commentary regarding anaemia management. The results of the national audit on anaemia in the UK paediatric ERF population may provide further insights.

This year comparison between centres has not been reported for bone biochemistry parameters. The small numbers per modality at each centre allow for limited comparison, and therefore data for all patients and by age groups are instead provided.

Bicarbonate data, an important aspect in the growing child, has been merged for the dialysis groups in order to compare with children with renal transplants. Standard achievement remained stable for this variable.

Future work

A strategy under discussion is a move to consider 'double counting' patients. If a patient changes modality half way through the year, their results currently can only be reported against one modality. Double counting would correct for potential data lost in a modality. This may provide a suitable stopgap until quarterly data returns are in place for children receiving RRT.

The ongoing work to merge the paediatric and adult registries will allow the reporting of data for 16–18 year olds, who may be managed in either care setting. Uniting the registries will also allow the linkage of longer term outcomes such as graft lifespan and cardiovascular comorbidity.

The full integration of the NEW paediatric dataset (version 10.0) should provide more uniformity in the data items collected which may aid completeness.

An exciting development for nephrology in general is the formation of the UK Renal Data Collaboration (of which the BAPN is a member) and the creation of a data warehouse [11]. Such an advance has the possibility to revolutionise future reporting by facilitating the collection of data and allowing increased frequency of data collection. Potentially this will also allow the expansion of range of electronic data items that are reported. This could remove many of the current limitations associated with the Paediatric Renal Registry.

Conflicts of interest: none

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