UK Renal Registry 16th Annual Report: Chapter 13 Clinical, Haematological and Biochemical Parameters in Patients Receiving Renal Replacement Therapy in Paediatric Centres in the UK in 2012: National and Centre-specific Analyses

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Key Words
Biochemical variables · Children · Dialysis · ERF · Haemoglobin · Height · Quality improvement · Transplant · Weight

Summary

- Median weight z-score for children on dialysis was −1.1 whereas children with a functioning transplant had a near normal weight (median z-score 0.1).
- Median height z-score for children on dialysis was −2.0 and for children with a functioning transplant −1.3.
- 76% of transplant patients, 57% of haemodialysis patients and 56% of peritoneal dialysis patients had a systolic blood pressure within the 90th percentile standard.
- 92% of transplant patients, 74% of HD patients and 83% of PD patients had a haemoglobin within or above the age appropriate standard.
- 50% of HD patients and 56% of PD patients achieved the audit standard for phosphate.

Introduction

This report focuses on the following variables for the prevalent paediatric dialysis and transplantation cohort on 31st December 2012:

1. The completeness of data returns to the renal registry
2. The anthropometric characteristics in children with established renal failure (ERF)
3. Blood pressure control in children with ERF
4. Anaemia control in children with ERF
5. Key biochemical findings in this population.

Analyses of prevalent paediatric patients aged <16 years receiving renal replacement therapy for the year 2012 and for the period 2001 to 2012 inclusive are reported. A single dataset was collected for each patient per year during this time period. Due to low numbers of patients in each cohort, no incident cohort analyses have been undertaken. Centre specific data for each paediatric nephrology centre in the UK has also been provided.

Methods

There were 13 centres providing care for children requiring renal replacement therapy in the UK, ten of which also provided surgical renal transplant services. All 13 centres provided outpatient and inpatient follow up for children who had received kidney transplants. Centres are listed in table 13.1 and appendix K.

Table 13.1. Paediatric renal centres, their abbreviations and IT systems

Paediatric centre	Abbreviation	Renal IT system
Belfast*	Blfst_P	Mediqal
Birmingham	Bham_P	Proton
Bristol	Brstl_P	Proton
Cardiff	Cardf_P	Proton
Glasgow	Glasg_P	Filemaker
Leeds	Leeds_P	Proton
Liverpool	Livpl_P	None
London Evelina	L Eve_P	Filemaker
London Great Ormond Street	L GOSH_P	Filemaker
Manchester	Manch_P	Filemaker
Newcastle	Newc_P	Clinical Vision
Nottingham	Nottm_P	Proton
Southampton	Soton_P	Bespoke

*New system installed, although paper submission received in 2012

Data collection

The data presented in this report relate to the annual census date of 31st December 2012.

Those paediatric centres with access to renal IT systems submitted encrypted electronic data directly to the UK Renal Registry (UKRR). Those centres without access, sent paper (Belfast and Liverpool) or electronic returns (Filemaker systems in table 13.1) in the original BAPN database format which were then entered into the original BAPN database as in previous years. Complete transfer to the UKRR encrypted database is still awaited.

Governance, reporting and standardisation

Information governance, reporting and standardisation were all performed in an identical manner to previous analyses to allow comparison [1]. Where the value of clinical parameters in childhood varies with age and size, data are presented as z-scores.

Anthropometry

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 $(m)^2$. 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 (IOTF) definition proposed by Cole *et al* [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 (BP)

The reference range for blood pressure 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 (NHBPEP) working group in the United States [4].

Laboratory values

Haemoglobin (Hb), ferritin (Ferr), calcium (Ca) and phosphate (Phos) were analysed using age related laboratory reference ranges as in table 13.2. Data analysis is presented for each centre individually and at a national level for each variable.

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 over time were also performed. These were based on a single data point per ERF patient per year collected as described previously. Cautious interpretation of these analyses is required due to changing audit standards over time and

Table 13.2. Summary of relevant biochemical clinical audit measures

	Age			
Parameter	<1 year	1–<6 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
eGFR ml/min/1.73 m^2 (transplant patients)	Estimated GFR (eGFR) as per Schwartz formula: (height × k)/ plasma creatinine The value for k is that in use at the reporting centre			
Parathyroid hormone (individual centre units)	Within twice the normal range Levels may be maintained within normal range if growing appropriately			

variable data returns for previous years. All analyses were done using SAS 9.3.

Standards

Standards are from the treatment of adults and children with renal failure, Renal Association 2002 guidelines [5] unless otherwise stated.

Anthropometry

'Height and weight should be monitored at each clinic visit. Measures of supine length or standing head circumference should be measured during each visit up to two years of age and 6 monthly up to 5 years of age. All measurements should be plotted on European reference growth charts for healthy children.'

Blood pressure

'Blood pressure varies throughout childhood and should be maintained within 2 standard deviations of the mean for normal children of the same height and sex. Systolic blood pressure during PD or post-HD should be maintained at <90th percentile for age, gender and height.'

The analyses of blood pressure in this report present the achievement of blood pressures at or below the 90th percentile.

Anaemia

Guidance on the management of anaemia in adults and children with chronic kidney disease was updated and published by the National Institute for Clinical Excellence (NICE) in February 2011 (Clinical Guideline 114) [6]. The recommendation in this guidance is that in children with chronic kidney disease, treatment should maintain stable haemoglobin levels between 100 and 120 g/L in children above 2 years of age and between 95 and 115 g/L in children below 2 years of age. These NICE standards have been adopted for this report.

Calcium, phosphate and parathyroid hormone (PTH) levels

Phosphate and calcium should be kept within the normal range [5]. For analyses of calcium and phosphate, the age related ranges as described previously have been used [1]. PTH levels should be kept less than twice the upper limit of normal.

Results

Data completeness

Tables 13.3 and 13.4 show the completeness of data returns for transplant and dialysis patients for 2012.

In 2012, overall completeness was good, with virtually all data variables showing a significant rise in completeness compared to 2011, maintaining the improvement noted in data returns over recent years. The only exception were data returns for cholesterol which continued to remain poor with four centres reporting on data for <50% patients, it is planned that analysis of this data will be included in next year's report.

Height, weight and BMI

Figures 13.1 and 13.4 show that children receiving renal replacement therapy 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, $p < 0.0001$.

Children with a functioning kidney transplant had a median weight z-score of 0.1, (figure 13.2), whilst those on dialysis had a significantly lower weight z-score than

Table 13.3. Percentage data completeness for transplant patients <16 years old by centre for each variable and total number of patients per centre in 2012

Centre	Transplant patients *N*	Height	Weight	BMI	Systolic BP	Hb	Creat	Ferr	EPO	IV iron	Chol	HCO_3	PTH	Ca	Phos
Bham_P	59	100.0	100.0	100.0	100.0	100.0	100.0	50.9	8.5	8.5	78.0	100.0	88.1	100.0	100.0
Blfst_P*	21	95.2	100.0	95.2	100.0	100.0	100.0	19.1	100.0	76.2	61.9	100.0	9.5	100.0	100.0
Brstl_P	35	94.3	97.1	94.3	97.1	100.0	100.0	68.6	100.0	100.0	74.3	100.0	80.0	100.0	100.0
Cardf_P	17	100.0	100.0	100.0	100.0	100.0	100.0	94.1	100.0	100.0	47.1	100.0	100.0	100.0	100.0
Glasg_P	27	100.0	100.0	100.0	100.0	100.0	100.0	85.2	100.0	100.0	37.0	100.0	100.0	100.0	100.0
L Eve_P	62	98.4	100.0	98.4	100.0	100.0	100.0	100.0	100.0	100.0	75.8	100.0	96.8	100.0	100.0
L GOSH_P	113	93.8	96.5	93.8	93.8	100.0	94.7	99.1	94.7	97.4	8.9	98.2	96.5	100.0	100.0
Leeds_P	57	96.5	98.3	96.5	98.3	100.0	100.0	35.1	96.5	96.5	93.0	93.0	35.1	98.3	93.0
Livpl_P	21	95.2	95.2	95.2	95.2	95.2	95.2	81.0	90.5	90.5	85.7	95.2	85.7	95.2	95.2
Manch_P	30	96.7	100.0	96.7	100.0	100.0	100.0	80.0	100.0	100.0	73.3	100.0	100.0	100.0	100.0
Newc_P	24	100.0	100.0	100.0	100.0	100.0	100.0	87.5	100.0	100.0	83.3	100.0	91.7	100.0	100.0
Nottm_P	54	92.6	96.3	92.6	94.4	98.2	98.2	85.2	100.0	100.0	24.1	98.2	57.4	98.2	98.2
Soton_P	14	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	100.0
UK	**534**	**96.4**	**98.3**	**96.4**	**97.6**	**99.6**	**98.5**	**77.3**	**88.0**	**87.6**	**56.2**	**98.5**	**80.5**	**99.4**	**98.9**

*Belfast do not routinely measure PTH in transplant patients

that of healthy children with a median of −1.1 (figure 13.5), $p < 0.0001$.

Body mass index in children, reported here based on 'height age', with a functioning transplant in 2012 showed inter-centre variation with a median z-score of 1.0 (figure 13.3) which was significantly higher than the median BMI z-score in those on dialysis which was 0.40 (figure 13.6), $p = <0.0001$. This is also highlighted in figure 13.7 which shows that 42.3% of transplanted children are either overweight or obese, compared to 25.7% of children on dialysis.

An analysis was performed excluding patients with syndromes and those born prematurely whose growth might be compromised. Table 13.5 shows that 27.7% of patients with a functioning transplant had a height <2SD, whilst the proportion below the normal range was even greater amongst those on haemodialysis (50.0%) and those on peritoneal dialysis (41.2%),

Table 13.4. Percentage data completeness for dialysis patients <16 years old by centre for each variable and total number of patients per centre in 2012

Centre	Dialysis patients *N*	Height	Weight	BMI	Systolic BP	Hb	Ferr	EPO	IV iron	Chol	HCO_3	PTH	Ca	Phos
Bham_P	21	100.0	100.0	100.0	100.0	100.0	90.5	4.8	4.8	90.5	100.0	100.0	100.0	100.0
Blfst_P	6	83.3	100.0	83.3	83.3	100.0	66.7	100.0	100.0	50.0	83.3	100.0	100.0	100.0
Brstl_P	5	100.0	100.0	100.0	100.0	100.0	100.0	100.0	80.0	80.0	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	100.0	100.0	100.0	100.0	100.0
Glasg_P	13	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	53.9	100.0	100.0	100.0	100.0
L Eve_P	12	91.7	91.7	91.7	91.7	100.0	91.7	100.0	100.0	25.0	100.0	100.0	100.0	100.0
L GOSH_P	25	100.0	100.0	100.0	100.0	100.0	88.0	96.0	100.0	72.0	100.0	100.0	100.0	100.0
Leeds_P	8	87.5	100.0	87.5	100.0	100.0	100.0	100.0	100.0	87.5	100.0	100.0	100.0	100.0
Livpl_P	4	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	75.0	100.0	100.0	100.0	100.0
Manch_P	22	95.5	100.0	95.5	95.5	100.0	95.5	100.0	100.0	13.6	95.5	100.0	100.0	100.0
Newc_P	3	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
Nottm_P	15	93.3	100.0	93.3	100.0	100.0	93.3	100.0	100.0	66.7	100.0	100.0	100.0	100.0
Soton_P	8	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	62.5	100.0	87.5	100.0	100.0
UK	**145**	**96.6**	**99.3**	**96.6**	**97.9**	**100.0**	**93.1**	**85.5**	**85.5**	**50.0**	**98.6**	**99.3**	**100.0**	**100.0**

Blank cell denotes data items which could not be sent by centre due to technical reasons

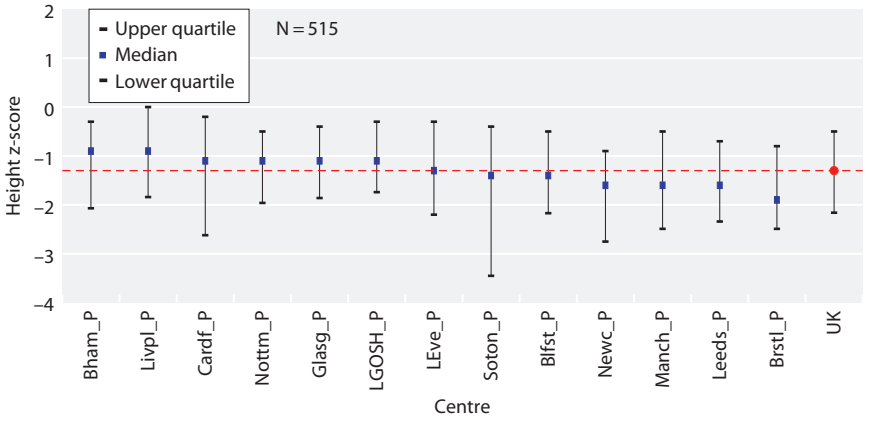

Fig. 13.1. Median height z-scores for transplant patients <16 years in 2012

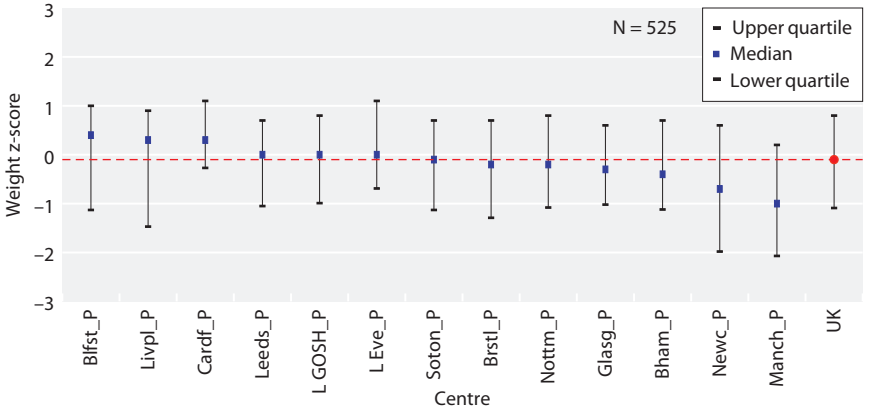

Fig. 13.2. Median weight z-scores for transplant patients <16 years in 2012

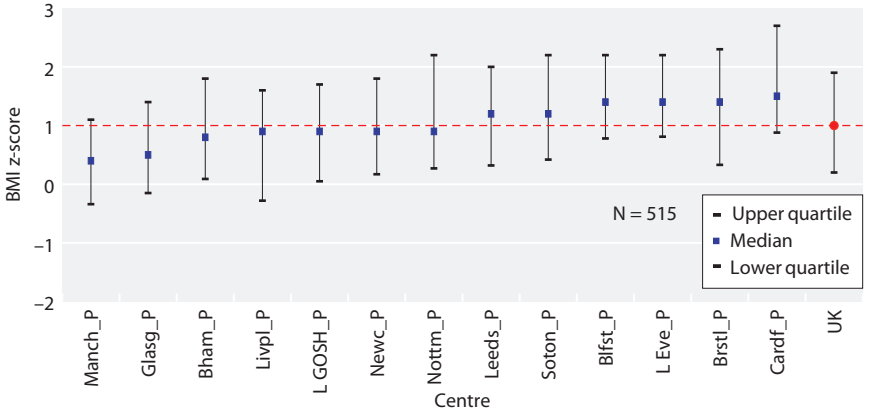

Fig. 13.3. Median BMI z-scores for transplant patients <16 years in 2012

$p < 0.01$. Analysis by age showed that amongst dialysis and transplanted patients the greatest proportion of children with a height <2SD was in the 2–4.99 years age group.

Figure 13.8 shows the use of growth hormone in all ERF children under 16 years with a height under 2SD in the UK between 2001 and 2012. There has been little change during this time in the overall use of growth hormone with a significant proportion of children under 16 years with a height under 2SD not receiving growth hormone. Only 29.2% of dialysis patients with a height below the normal range and 11.9% with a functioning transplant who were short received growth hormone treatment.

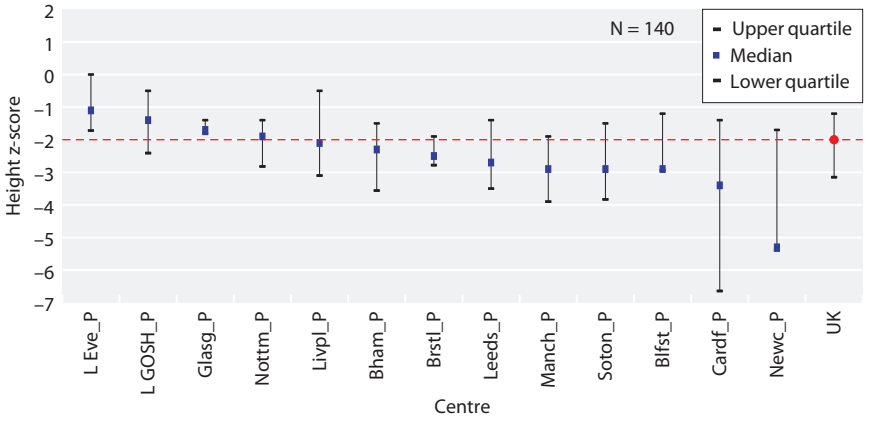

Fig. 13.4. Median height z-scores for dialysis patients <16 years in 2012

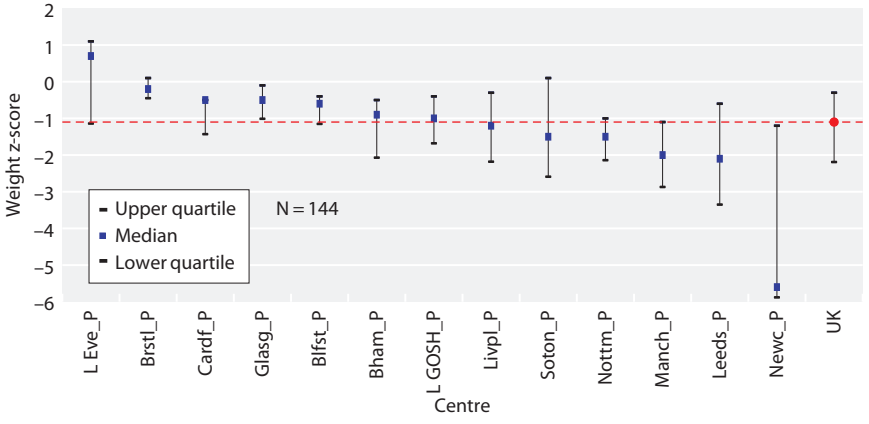

Fig. 13.5. Median weight z-scores for dialysis patients <16 years in 2012

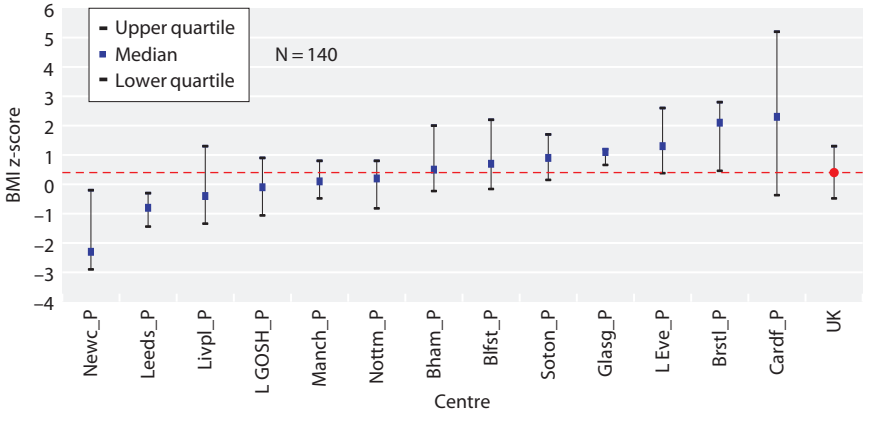

Fig. 13.6. Median BMI z-scores for dialysis patients <16 years in 2012

Blood pressure

Analyses of blood pressure levels have shown that blood pressure was higher in children receiving renal replacement therapy than in healthy children (figures 13.9, 13.10). There was wide inter-centre variation in systolic blood pressure, particularly in dialysis patients. The UK median z-score was 1.0 for dialysis patients and 0.40 for transplant patients.

For children with a functioning kidney transplant, 76.3% had a systolic BP <90th percentile which was slightly lower than last year when 81.1% of such children achieved the target (table 13.6). In comparison, 56.7% of children on haemodialysis had a systolic BP <90th percentile whilst 56.2% of children receiving peritoneal dialysis achieved this (table 13.6). The results for haemodialysis and peritoneal dialysis were slightly worse than

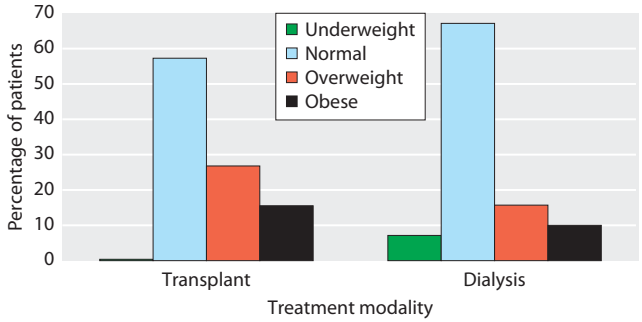

Fig. 13.7. BMI categorisation in children <16 years by modality in 2012

those achieved in the previous year (66.7% and 66.2% respectively) although absolute numbers were small. When analysing data by age, blood pressure control was slightly worse in the 0–4.99 year age group for dialysis patients with little difference noted amongst transplanted age groups.

Haemoglobin

The analyses in this report show that many children receiving dialysis were anaemic, with 25.7% of haemodialysis and 17.3% of peritoneal dialysis patients having a haemoglobin level below the standard (table 13.7).

Table 13.5. Percentage of patients aged 2–16 years old with height under 2SDs in 2012*

	Transplant patients		Haemodialysis patients		Peritoneal dialysis patients	
Centre	Patients with data (*N*)	% <2SD	Patients with data (*N*)	% <2SD	Patients with data (*N*)	% <2SD
Bham_P	57	26.3	10	80.0	10	40.0
Blfst_P	14	42.9	2	50.0	2	50.0
Brstl_P	24	41.7	2	50.0	2	50.0
Cardf_P	16	37.5	1	100.0	1	0.0
Glasg_P	25	8.0	3	33.3	6	33.3
L Eve_P	54	27.8	5	0.0	4	50.0
L GOSH_P	95	21.1	10	40.0	5	20.0
Leeds_P	40	27.5	2	50.0	3	33.3
Livpl_P	18	22.2	2	50.0	1	100.0
Manch_P	20	35.0	5	80.0	7	42.9
Newc_P	21	33.3	1	100.0	1	0.0
Nottm_P	39	30.8	4	25.0	6	50.0
Soton_P	10	50.0	3	33.3	3	66.7
UK	**433**	**27.7**	**50**	**50.0**	**51**	**41.2**
Age group						
2–4.99 years	40	35.0	9	77.8	11	54.6
5–11.99 years	203	30.05	23	47.83	20	45.0
12–15.99 years	190	23.68	18	38.89	20	30.0

*Preterm children and patients with a syndromic diagnosis were excluded from analyses

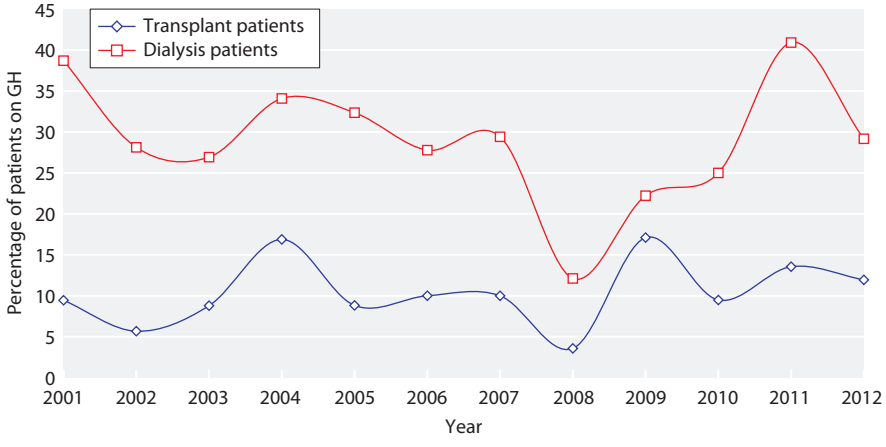

Fig. 13.8. Use of growth hormone in children <16 years with a height under 2SD in the UK between 2001 and 2012

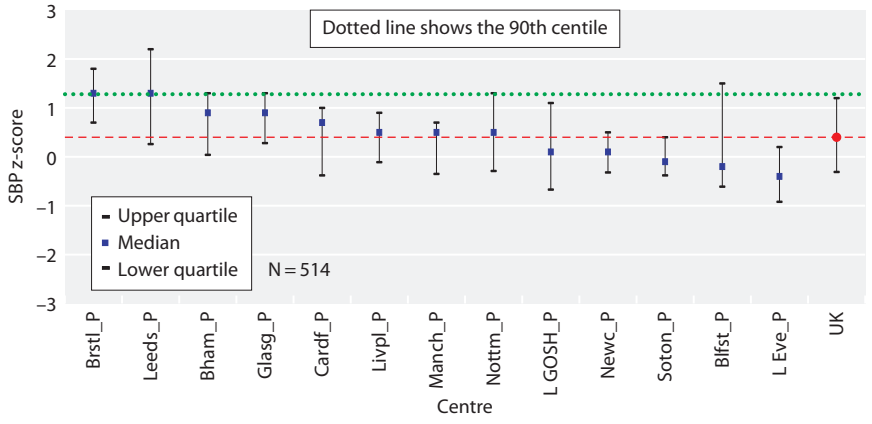

Fig. 13.9. Median systolic blood pressure z-scores for transplant patients <16 years in 2012

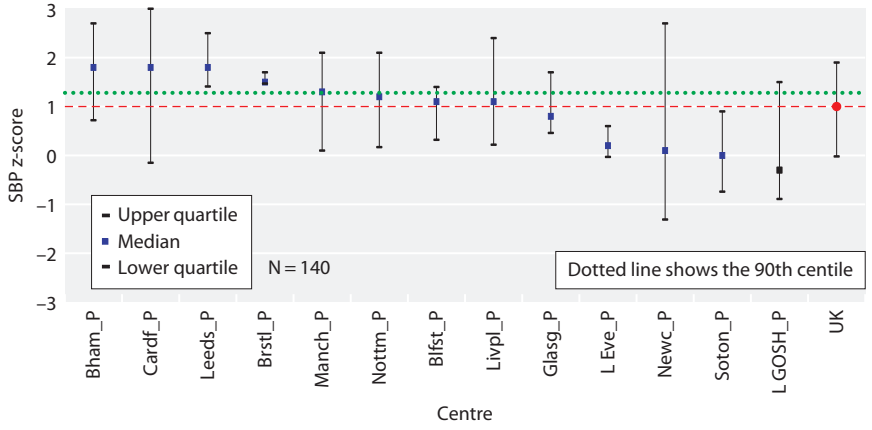

Fig. 13.10. Median systolic blood pressure z-scores for dialysis patients <16 years in 2012

Table 13.6. Percentage of patients <16 years achieving the standards for systolic blood pressure in 2012

	Transplant patients		Haemodialysis patients		Peritoneal dialysis patients	
Centre	Patients with data (*N*)	Below 90th percentile	Patients with data (*N*)	Below 90th percentile	Patients with data (*N*)	Below 90th percentile
Bham_P	59	67.8	11	54.6	10	20.0
Blfst_P	20	75.0	2	50.0	3	66.7
Brstl_P	33	57.6	3	33.3	2	0.0
Cardf_P	17	76.5	2	0.0	1	100.0
Glasg_P	27	74.1	4	50.0	9	77.8
L Eve_P	61	95.1	7	100.0	4	75.0
L GOSH_P	106	84.0	15	66.7	10	80.0
Leeds_P	55	49.1	3	33.3	4	0.0
Livpl_P	20	85.0	2	50.0	2	50.0
Manch_P	29	79.3	7	57.1	14	42.9
Newc_P	24	87.5	2	50.0	1	100.0
Nottm_P	49	75.5	4	0.0	10	70.0
Soton_P	14	92.9	5	80.0	3	100.0
UK	**514**	**76.3**	**67**	**56.7**	**73**	**56.2**
Age group						
0–4.99 years	49	73.5	20	45.0	29	51.7
5–11.99 years	239	73.6	28	53.6	23	52.2
12–15.99 years	226	79.7	19	73.7	21	66.7

Table 13.7. Percentage of patients <16 years old achieving the haemoglobin standard in 2012

Centre	Transplant patients			Haemodialysis patients			Peritoneal dialysis patients		
	Patients with data (*N*)	% achieving standard	% lower then standard	Patients with data (*N*)	% achieving standard	% lower then standard	Patients with data (*N*)	% achieving standard	% lower then standard
Bham_P	59	91.5	8.5	11	72.7	27.3	10	80.0	20.0
Blfst_P	21	90.5	9.5	3	100.0	0.0	3	100.0	0.0
Brstl_P	35	94.3	5.7	3	33.3	66.7	2	50.0	50.0
Cardf_P	17	94.1	5.9	2	50.0	50.0	1	100.0	0.0
Glasg_P	27	96.3	3.7	4	100.0	0.0	9	88.9	11.1
L Eve_P	62	95.2	4.8	8	100.0	0.0	4	75.0	25.0
L GOSH_P	113	90.3	9.7	15	93.3	6.7	10	90.0	10.0
Leeds_P	57	87.7	12.3	3	33.3	66.7	5	40.0	60.0
Livpl_P	20	95.0	5.0	2	50.0	50.0	2	100.0	0.0
Manch_P	30	93.3	6.7	7	71.4	28.6	15	86.7	13.3
Newc_P	24	91.7	8.3	2	0.0	100.0	1	100.0	0.0
Nottm_P	53	88.7	11.3	5	80.0	20.0	10	80.0	0.0
Soton_P	14	92.9	7.1	5	40.0	60.0	3	100.0	0.0
UK	**532**	**91.7**	**8.3**	**70**	**74.3**	**25.7**	**75**	**82.7**	**17.3**
Age group									
0–4.99 years	50	88.0	12.0	22	54.6	45.5	29	86.2	13.8
5–11.99 years	245	91.4	8.6	28	75.0	25.0	24	83.3	16.7
12–15.99 years	237	92.8	7.2	20	95.0	5.0	22	77.3	22.7

This compared to only 8.3% of patients with a functioning transplant having haemoglobin below the standard.

Analysis by age showed that the proportion of children on haemodialysis with haemoglobin below the standard was greatest for those under five years although this was not statistically significant.

Figure 13.11 shows that the percentage of dialysis patients achieving or exceeding the treatment standards for haemoglobin has increased over the last decade, with little change noted in transplanted patients. Attainment of ferritin standards are more difficult to interpret because of a higher proportion of historical missing data.

The attainment of the haemoglobin standard in transplant patients was assessed for different levels of graft function (figure 13.12) and with the use of MMF as immunosuppressant therapy (figure 13.13). Figure 13.12 demonstrates that haemoglobin standard attainment was worse for patients with transplant dysfunction with only 79.5% of patients with an eGFR of <45 achieving or exceeding the standard for haemoglobin compared to 95.4% of patients with an eGFR of >60. As for the impact of MMF, figure 13.12 shows that patients using

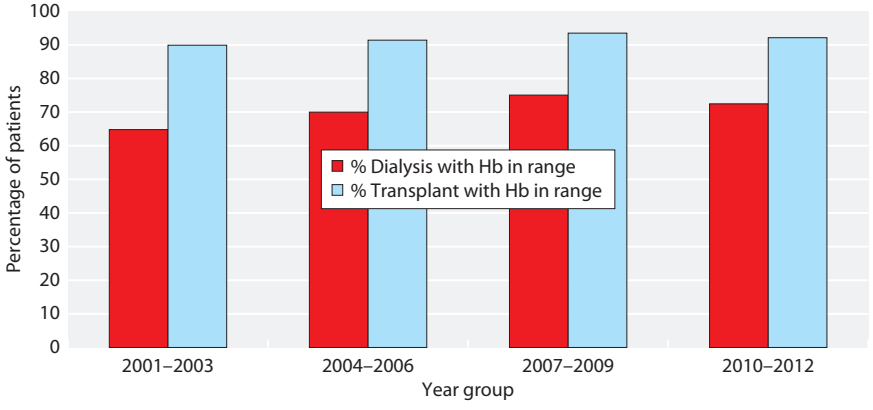

Fig. 13.11. The percentage of patients <16 years achieving the treatment standard for haemoglobin between 2001–2012, by treatment modality

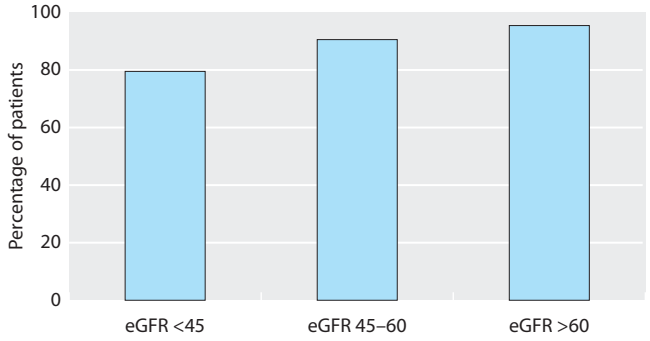

Fig. 13.12. The achievement of haemoglobin treatment standards in paediatric transplant patients <16 years, by the level of graft function
This figures combines all data from 2001–2012.

MMF as immunosuppressant therapy were more likely to have haemoglobin concentrations below the standard, which was statistically significant $p < 0.001$. Whilst this was noted between 2001–2006, this was not seen between 2007–2012, although during this time period there was a marked rise in missing data for MMF (48% missing data, compared to 14% during earlier years) making it difficult to draw any significant conclusions.

Regarding the use of erythropoietin (ESA) and IV iron, figure 13.14 shows that there has been little change in the use of these agents in transplanted patients over the last decade; in dialysis patients the use of ESA appears to have stabilised following the initial fall below 90% first observed in 2009. The use of IV iron in dialysis patients showed a small increase over last year. Table 13.8 shows that the majority of patients on dialysis (with a haemoglobin above or below range) were on ESA with little change over time.

Phosphate, calcium, PTH and bicarbonate

In 2012 in the UK as a whole, 50% of haemodialysis patients and 56% of peritoneal dialysis patients had a phosphate within the target range (table 13.9). The

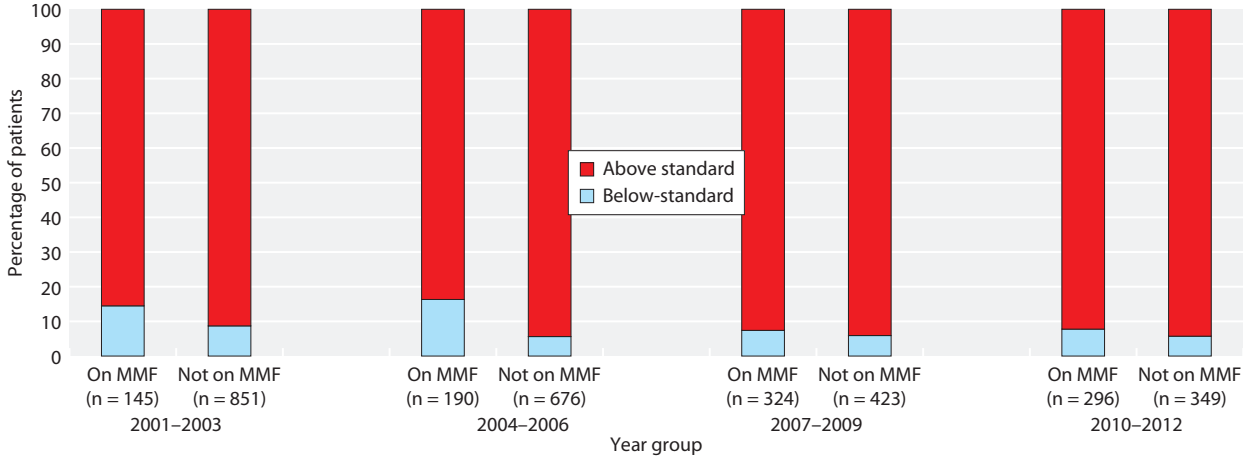

Fig. 13.13. The achievement of haemoglobin treatment standards in paediatric transplant patients <16 years, by use of MMF between 2001–2012

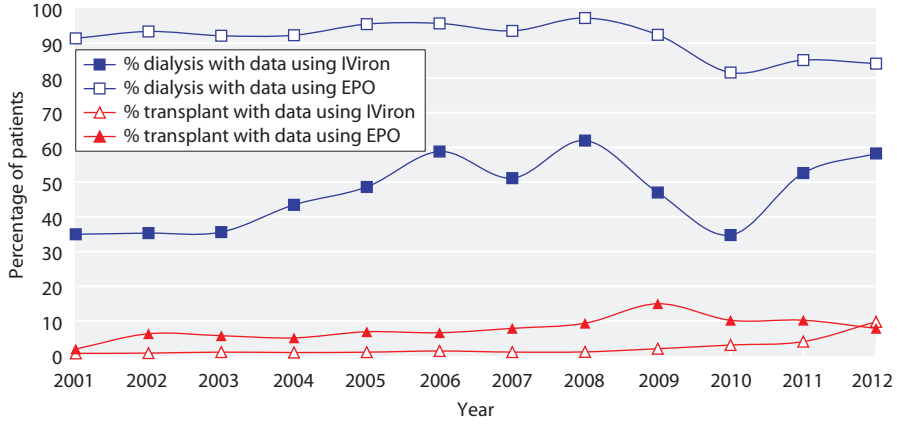

Fig. 13.14. The use of erythropoietin and IV iron in paediatric patients <16 years between 2001 and 2012 by treatment modality

Table 13.8. Proportion of paediatric RRT patients on ESA, by haemoglobin attainment, across time

Time period	Hb below standard % on ESA	Hb above standard % on ESA
Transplant patients		
2001–2003	15.2	3.8
2004–2006	23.2	4.2
2007–2009	23.2	6.6
2010–2012	21.3	6.4
Dialysis patients		
2001–2003	92.7	89.9
2004–2006	98.9	93.0
2007–2009	95.7	90.6
2010–2012	82.0	86.8

achievement of the standard for calcium was better with 80% of children on dialysis (haemodialysis and peritoneal dialysis) having a calcium level within the target range (table 13.10). As for PTH, only 43.5% of children on HD and 30.7% on PD had a PTH within the target range with wide inter-centre variation (table 13.11). In comparison, 84.2% of patients with a functioning transplant achieved a PTH within the target range. Caution should be exercised in the interpretation of these analyses as these analyses represent measurements performed once per year per patient. Further, there are differences between assays used at different centres which may further complicate interpretation of results. No significant age related differences were observed.

For the first time this year, data are presented on the bicarbonate levels achieved in children on dialysis and those transplanted (table 13.12). It is important to highlight that some centres reported having normal ranges extending below 20 mmol/L. It was observed that more children were acidotic (bicarbonate level <20 mmol/L) on haemodialysis (18.8%) as compared to peritoneal dialysis (2.7%), this perhaps reflects the timing of blood testing performed. Transplanted patients had the highest percentage (92.1%) of patients with a bicarbonate in range (20–30 mmol/L) with 7.2% of patients having a bicarbonate <20 mmol/L. No significant age related differences were observed.

Discussion

This year 92% of data returns were submitted electronically with most centres now having electronic systems, albeit currently without the facility for automatic data extraction. As this is developed over the coming years, it will allow downloads of data at multiple time points

Table 13.9. Achievement of the phosphate standard in dialysis patients <16 years in 2012

	Haemodialysis patients				Peritoneal dialysis patients			
Centre	Patients with data (*N*)	% within standard	% below standard	% above standard	Patients with data (*N*)	% within standard	% below standard	% above standard
Bham_P	11	36.4	18.2	45.5	10	50.0	0.0	50.0
Blfst_P	3	33.3	33.3	33.3	3	0.0	33.3	66.7
Brstl_P	3	33.3	66.7	0.0	2	50.0	0.0	50.0
Cardf_P	2	0.0	50.0	50.0	1	100.0	0.0	0.0
Glasg_P	4	25.0	0.0	75.0	9	55.6	0.0	44.4
L Eve_P	8	25.0	12.5	62.5	4	100.0	0.0	0.0
L GOSH_P	15	66.7	13.3	20.0	10	50.0	20.0	30.0
Leeds_P	3	66.7	0.0	33.3	5	60.0	0.0	40.0
Livpl_P	2	100.0	0.0	0.0	2	50.0	0.0	50.0
Manch_P	7	57.1	14.3	28.6	15	66.7	0.0	33.3
Newc_P	2	100.0	0.0	0.0	1	100.0	0.0	0.0
Nottm_P	5	80.0	20.0	0.0	10	50.0	0.0	50.0
Soton_P	5	40.0	20.0	40.0	3	33.3	0.0	66.7
UK	**70**	**50.0**	**17.1**	**32.9**	**75**	**56.0**	**4.0**	**40.0**
Age group								
0–4.99 years	22	54.6	22.7	22.7	29	55.2	0.0	44.8
5–11.99 years	28	50.0	17.9	32.1	24	50.0	8.3	41.7
12–15.99 years	20	45.0	10.0	45.0	22	63.6	4.6	31.8

Table 13.10. Achievement of the adjusted calcium standard in dialysis patients <16 years in 2012

	Haemodialysis patients				Peritoneal dialysis patients			
Centre	Patients with data (*N*)	% within standard	% below standard	% above standard	Patients with data (*N*)	% within standard	% below standard	% above standard
Bham_P	11	54.6	0.0	45.5	10	80.0	0.0	20.0
Blfst_P	3	66.7	0.0	33.3	3	33.3	0.0	66.7
Brstl_P	3	66.7	0.0	33.3	2	100.0	0.0	0.0
Cardf_P	2	100.0	0.0	0.0	1	100.0	0.0	0.0
Glasg_P	4	50.0	25.0	25.0	9	66.7	0.0	33.3
L Eve_P	8	87.5	12.5	0.0	4	75.0	0.0	25.0
L GOSH_P	15	100.0	0.0	0.0	10	90.0	0.0	10.0
Leeds_P	3	66.7	33.3	0.0	5	100.0	0.0	0.0
Livpl_P	2	100.0	0.0	0.0	2	50.0	0.0	50.0
Manch_P	7	71.4	14.3	14.3	15	80.0	13.3	6.7
Newc_P	2	100.0	0.0	0.0	1	100.0	0.0	0.0
Nottm_P	5	100.0	0.0	0.0	10	80.0	0.0	20.0
Soton_P	5	80.0	20.0	0.0	3	100.0	0.0	0.0
UK	**70**	**80.0**	**7.1**	**12.9**	**75**	**80.0**	**2.7**	**17.3**
Age group								
0–4.99 years	22	86.4	9.1	4.6	29	79.3	3.5	17.2
5–11.99 years	28	85.7	3.6	10.7	24	83.3	0.0	16.7
12–15.99 years	20	65.0	10.0	25.0	22	77.3	4.6	18.2

per year for each patient allowing more meaningful analyses. The recently updated NEW paediatric dataset is now being issued to system providers so that it can be incorporated in software upgrades.

The data for each section are discussed below, but often the results throw up as many questions as they answer. There are several areas where more detailed analysis may help to identify obstacles as to why there

Table 13.11. Percentage of patients <16 years achieving the PTH standard in 2012

	Transplant patients			Haemodialysis patients			Peritoneal dialysis patients		
Centre	Patients with data (*N*)	% achieving standard	% above standard	Patients with data (*N*)	% achieving standard	% above standard	Patients with data (*N*)	% achieving standard	% above standard
Bham_P	52	61.5	38.5	11	36.4	63.6	10	20.0	80.0
Blfst_P				3	33.3	66.7	3	100.0	0.0
Brstl_P	28	82.1	17.9	3	100.0	0.0	2	50.0	50.0
Cardf_P	17	82.4	17.7	2	50.0	50.0	1	0.0	100.0
Glasg_P	27	96.3	3.7	4	0.0	100.0	9	33.3	66.7
L Eve_P	60	90.0	10.0	8	50.0	50.0	4	25.0	75.0
L GOSH_P	109	84.4	15.6	15	53.3	46.7	10	50.0	50.0
Leeds_P				3	33.3	66.7	5	40.0	60.0
Livpl_P	18	100.0	0.0	2	50.0	50.0	2	100.0	0.0
Manch_P	30	93.3	6.7	7	42.9	57.1	15	6.7	93.3
Newc_P	22	100.0	0.0	2	0.0	100.0	1	0.0	100.0
Nottm_P	31	83.9	16.1	5	60.0	40.0	10	30.0	70.0
UK	**430**	**84.2**	**15.8**	**69**	**43.5**	**56.5**	**75**	**30.7**	**69.3**
Age group									
0–4.99 years	45	91.1	8.9	22	22.7	77.3	29	37.9	62.1
5–11.99 years	192	83.9	16.2	27	63.0	37.0	24	33.3	66.7
12–15.99 years	193	82.9	17.1	20	40.0	60.0	22	18.2	81.8

*Blank cells denote modalities where data completeness was <50%

Table 13.12. Centre analysis of bicarbonate levels (mmol/L) in patients under 16years old by treatment modality, in 2012

	Transplant patients				Haemodialysis patients				Peritoneal dialysis patients			
Centre	Patients with data (*N*)	% <20	% 20–30	% >30	Patients with data (*N*)	% <20	% 20–30	% >30	Patients with data (*N*)	% <20	% 20–30	% >30
Bham_P	59	8.5	89.8	1.7	11	18.2	81.8	0.0	10	0.0	80.0	20.0
Blfst_P	21	0.0	100.0	0.0	2	0.0	100.0	0.0	3	0.0	100.0	0.0
Brstl_P	35	2.9	97.1	0.0	3	33.3	66.7	0.0	2	0.0	100.0	0.0
Cardf_P	17	23.5	76.5	0.0	2	0.0	100.0	0.0	1	0.0	100.0	0.0
Glasg_P	27	37.0	63.0	0.0	4	100.0	0.0	0.0	9	22.2	66.7	11.1
L Eve_P	62	6.5	93.6	0.0	8	25.0	75.0	0.0	4	0.0	100.0	0.0
L GOSH_P	113	2.7	96.5	0.9	15	13.3	80.0	6.7	10	0.0	90.0	10.0
Leeds_P	53	0.0	100.0	0.0	3	0.0	100.0	0.0	5	0.0	80.0	20.0
Livpl_P	20	40.0	60.0	0.0	2	0.0	100.0	0.0	2	0.0	100.0	0.0
Manch_P	30	3.3	93.3	3.3	7	28.6	71.4	0.0	14	0.0	85.7	14.3
Newc_P	24	8.3	91.7	0.0	2	0.0	100.0	0.0	1	0.0	100.0	0.0
Nottm_P	53	0.0	98.1	1.9	5	0.0	80.0	20.0	10	0.0	70.0	30.0
Soton_P	14	0.0	100.0	0.0	5	0.0	100.0	0.0	3	0.0	100.0	0.0
UK	**528**	**7.2**	**92.1**	**0.8**	**69**	**18.8**	**78.3**	**2.9**	**74**	**2.7**	**83.8**	**13.5**
Age group												
0–4.99 years	50	12.0	88.0	0.0	22	13.6	86.4	0.0	29	3.5	72.4	24.1
5–11.99 years	244	6.6	92.2	1.2	27	18.5	77.8	3.7	23	4.4	87.0	8.7
12–15.99 years	234	6.8	92.7	0.4	20	25.0	70.0	5.0	22	0.0	95.5	4.6

<20 mmol/L was defined as being acidotic, although it is worth noting some centres report having normal ranges extending below 20

has been little apparent change in the attainment of many standards over the last few years.

Anthropometry

Children on renal replacement therapy are short for their age. Excluding children and young people with syndromes and those born prematurely, who are more likely to be short, just over a quarter of transplant patients, 50% of HD patients and 41% of PD patients had a height that was below the normal range. The figures would be lower if all children on RRT were included. Children aged less than five years who were on dialysis seemed to be most affected. Growth in the pre-school years is faster than in later years and so it is not surprising that dialysis at this age can have a deleterious effect on growth. It is a sobering thought that nearly half of children on dialysis have a height below the normal range. Whilst transplantation improves the situation, a quarter remain short.

The cross-sectional data presented here are little different from previous reports; indeed there appears to have been little change since 1999 which is disappointing [7]. There may be a number of reasons for this. Over the last few years, there has been an increase in the number of infants and young children receiving RRT. Children with ERF for a significant part of their childhood are more likely to have impaired growth than those who have had better health for part of their childhood and may be part of the explanation.

There have been initiatives to try and improve growth, such as using rhGH, improved nutrition and avoiding the use of steroids post transplant. Just under a third of dialysis patients, and 11.9% of transplant patients, who were short for their age, were on growth hormone treatment. The low uptake of rhGH within the UK ERF population where overall 32.8% of patients have a height below the normal range, remains disappointing. However in the transplant group it is important to remember that these data are cross-sectional and although some children are short, they may be growing at a rate above normal and therefore would not fall into the category for whom rhGH is appropriate.

The use of steroids post-transplant can affect growth and varies from centre to centre. It would be interesting to compare those centres which avoid steroids to those where steroids are used as standard post-transplant. Furthermore, it may be that many different factors not included here have an influence on growth and that further in depth studies will highlight these. There is therefore scope to increase the use of rhGH in these

patients. An analysis evaluating final adult height may add to our understanding. The proportion of short transplanted children varied by centre and it would be interesting to see if this relates to the centres' likelihood of using steroids post transplant.

In this report for the first time, BMI based on height-age as opposed to their chronological age is reported which is more appropriate given a cohort of children who have growth restriction. Overweight and obesity are also defined as per IOTF definitions. These definitions are different to those used in previous reports and likely to account for the small differences in reported data. Overall, little change in weight SDs and BMI SDs since 1999 in both transplanted children and those on dialysis were observed. Recent reports from the ERA-EDTA Registry [8] highlight the high prevalence rates of excess weight in UK children following renal transplantation. Furthermore, a report from the BAPN analysing the longitudinal change in BMI following transplantation highlights rates of excessive weight (overweight and obese) significantly worse than the background UK childhood population [9]. These data together highlight the need for urgent work to understand factors that lead to excess weight gain in this high risk cohort for adverse cardiovascular outcomes.

Blood pressure

There is an increasing body of evidence supporting the role of optimal blood pressure control in the management of CKD [10, 11]. There is also an increasing awareness of the importance of cardiovascular morbidity in paediatric patients with CKD and ERF. Despite this, there remains scope for improvement in BP control. As BP changes during childhood, it is important to manage blood pressure using percentiles in the clinic rather than using the absolute measurements alone. The authors hope that it may be possible at some point to include the degree of proteinuria for transplant patients in the analysis.

There was a wide range of median systolic BP scores in different centres and it might be helpful to reflect on the different strategies in each centre and their effect on outcomes. It is hoped that the clinical application of recently developed guidelines by the BAPN for the management of hypertension following transplantation would help in improving blood pressure control [12]. Once again the authors would highlight that these data reflect single measurements per year often performed using BP instruments that employ different techniques.

Anaemia

A significant proportion of dialysis patients (25.7% HD, 17.3% PD) were anaemic; this is little changed from previous reports. The proportion of transplant patients with a haemoglobin within the recommended range however has improved and is due to the change in standard used.

For transplant patients, the chances of a haemoglobin level below the standard were greater with reduced GFR and with the use of MMF. This highlights the importance of calculating GFR for transplant patients, rather than using creatinine alone. A lower GFR should highlight the need to check that the haemoglobin is within the recommended range. Since 2000, the proportion of patients with a haemoglobin within range who were on MMF has increased and remained stable in this year's report.

Whilst there are indicators to help identify those transplant patients at risk of anaemia, it is more difficult to highlight those at risk within the dialysis populations. As expected patients on HD seem more at risk and the risk of anaemia may be higher for those aged less than five years. Of those with a haemoglobin below range, over 90% of patients were on ESAs, although the proportion on IV iron or with a low ferritin was less clear. Of transplant patients with a low haemoglobin, 21% were on ESAs compared with 15% between 2001–2003.

It is important to highlight here that it is beyond the scope of the registry to be able to report on dose adjustments that would likely improve understanding of these data. It would be helpful to study dialysis patients in more detail to see if there are any factors which help identify those children at highest risk of anaemia. Detailed data on ferritin and IV iron would be needed for this subgroup of patients. The results of the national audit on anaemia in the UK paediatric ERF population may help to shed some further light on this.

Biochemistry

The numbers of paediatric patients on dialysis were small but phosphate control appears to be worse in patients on HD than in patients on PD. Results for calcium were little different between the dialysis groups, whilst patients on PD had worse PTH concentrations than those on haemodialysis. Data were less complete for PTH in the transplant group which might imply that the complications of reduced GFR might sometimes be overlooked in this group of patients. It would be useful to include vitamin D (calcidiol) concentrations in the parameters studied. Moving to multiple time point

reporting of data in future reports will allow better interpretation of biochemistry results. A higher proportion of subjects on HD were acidotic compared to those on PD, with the best results in transplanted patients.

Summary

In summary, continued efforts are being made to move towards universal electronic reporting from UK paediatric centres. Whilst this is ongoing, most centres are moving to using electronic systems which incorporate an electronic patient record. These improved electronic platforms have the additional potential to display percentiles and SDs and it may be that these functionalities will help make clinicians aware of patient's results and achievement of targeted clinical standards. Automatic calculations of e.g. eGFR in transplant patients may help to point out that some patients have lower GFRs that make them susceptible to anaemia. The likelihood of complete electronic reporting in the near future with plans for quarterly reporting in the format of the recently finalised NEW paediatric dataset will undoubtedly improve quality of data and their reporting, allowing improvements in patient care.

Conflicts of interest: none

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