

Chapter 7

Children and young people on renal replacement therapy (RRT) for end-stage kidney disease (ESKD) in the UK in 2018

Contents

Introduction	3
Rationale for analyses	5
Key findings	7
Children.....	7
Young people.....	7
Analyses – children	8
Data completeness for prevalent paediatric RRT patients.....	8
Changes to the incident paediatric RRT population	9
Start modality of incident paediatric RRT patients	10
Pre-emptive transplantation in incident paediatric RRT patients.....	11
Demographics of prevalent paediatric RRT patients	12
Treatment modality in prevalent paediatric RRT patients	12
Causes of ESKD in prevalent paediatric RRT patients	13
Growth of prevalent paediatric RRT patients.....	14
Cardiovascular risk factor evaluation in prevalent paediatric RRT patients.....	17
Biochemistry parameters in prevalent paediatric RRT patients.....	20
Transfer to adult renal services for prevalent paediatric RRT patients.....	22
Survival in paediatric RRT patients.....	23
Analyses – young people	24
RRT incidence and prevalence in young people	24
Transplant parameters in young people.....	25
Biochemical and blood pressure measures in young people.....	26

Introduction

This chapter describes the population of children and young people aged <18 years with end-stage kidney disease (ESKD) who were on renal replacement therapy (RRT) in the UK for at least 90 days in 2018 (figure 7.1). This included patients with a transplant (Tx) and patients on dialysis – in-centre haemodialysis (ICHD), home haemodialysis (HHD) and peritoneal dialysis (PD). Patients coded as acute kidney injury (AKI) or ESKD who died or recovered within the first 90 days of RRT were excluded from the analyses.

There are 13 paediatric renal centres in the UK, all of which are equipped to provide both haemodialysis (HD) and PD. Ten of these centres also perform kidney transplantation. Children aged 16 to <18 years may be managed in either paediatric or adult services. This is variable across the UK and dependent on local practices, social factors and patient/family wishes. This year, and in contrast to previous reports, children (aged <16 years) and young people (aged 16 to <18 years) are reported separately. Data about young people also includes those managed in adult centres, to provide a more complete epidemiological picture for this population.

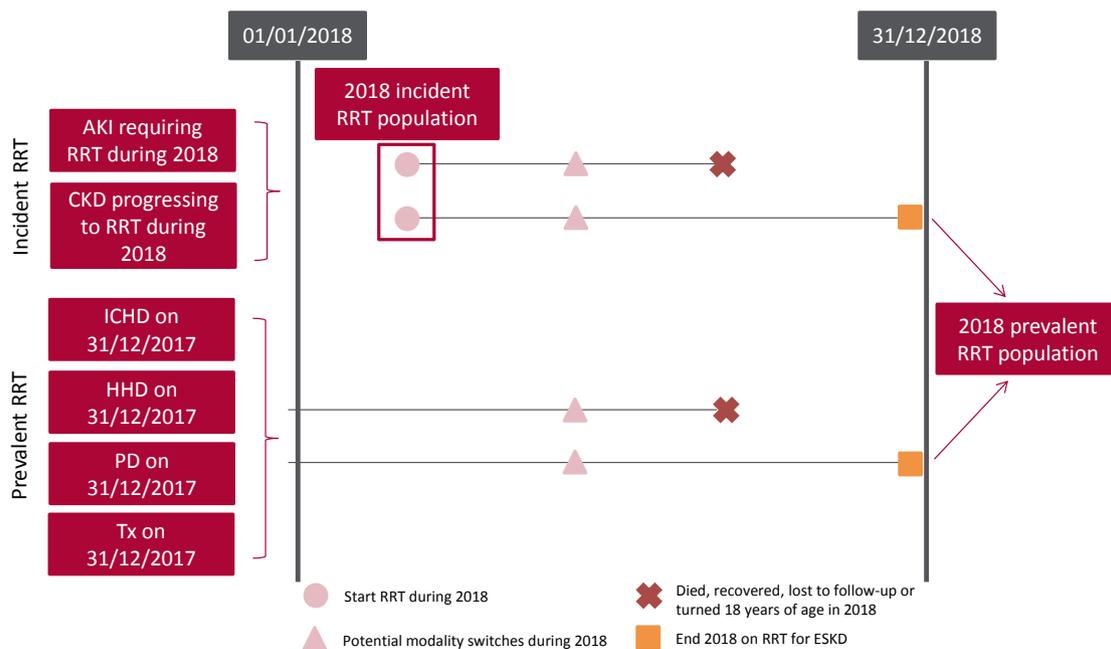


Figure 7.1 Pathways children and young people could follow to be included in the UK 2018 incident and/or prevalent RRT populations

Note that patients starting RRT in 2018 are only included in this chapter if they remained on RRT for ≥ 90 days.

CKD – chronic kidney disease

For children aged <16 years, the following populations included in this chapter are:

- Incident population: patients who started RRT during 2018 and remained on RRT for at least 90 days.
- Prevalent population: patients who were on RRT at the end of 2018 and still under the care of a paediatric renal centre.
- Five-year populations: patients who started RRT and remained on RRT for at least 90 days in the periods 2004–2008, 2009–2013 and 2014–2018.

For young people aged 16 to <18 years, the following populations included in this chapter are:

- **Incident population:** patients who started RRT during 2018 in either an adult or paediatric centre and remained on RRT for at least 90 days.
- **Prevalent population:** patients who were on RRT at the end of 2018 in either an adult or paediatric centre.

This chapter addresses the following key aspects of the care of children incident to or on RRT for which there are evidence-based guidelines (table 7.1):

- **Growth:** this includes age- and sex-adjusted heights and weights
- **Cardiovascular risk factors:** these include age-adjusted blood pressure, cholesterol and body mass index (BMI)
- **Complications associated with RRT:** these include anaemia and mineral and bone disorders.

For young people, the following aspects of care are addressed:

- **Cardiovascular risk factors:** these include blood pressure using raw systolic and diastolic values which are audited against European Society of Hypertension guidelines for the management of high blood pressure in children and adolescents (2016)
- **Complications associated with RRT:** these include anaemia and mineral and bone disorders. Paediatric reference ranges for children and young people up to 18 years are used as the standard measure.

Rationale for analyses

For both the children and young people sections, the analyses begin with a description of the 2018 incident and prevalent RRT populations, including the number on RRT per million age-related population (pmarp).

For children, height and weight are measures of healthy growth, which may be affected by kidney disease as well as its treatment. These measures are therefore presented for each centre in comparison to the UK median for this cohort.

The published guidelines listed below provide audit measures relevant to the care of children and young people on RRT and, where data permit, their attainment by UK paediatric renal centres in 2018 is reported in this chapter (table 7.1). Due to the small numbers of young people identified, we have omitted reporting by centre for this population.

For children, reporting estimated glomerular filtration rate (eGFR) is dependent on the completeness of both creatinine and height data. For young people, the Full Age Spectrum (FAS) equation was used to calculate eGFR – height data for young people managed in adult centres were incomplete and therefore a height-free calculation was used to standardise reporting and enable direct comparison within this population.

Table 7.1 Audit measures relevant to RRT incidence and prevalence that are reported in this chapter

Audit guideline	Audit criteria	Related analysis/analyses
The Renal Association: Treatment of adults and children with renal failure: standards and audit measures (2002)	Height and weight to be monitored at each clinic visit and plotted on the growth charts of healthy children and adolescents	Figures 7.6–7.13
	Blood pressure during PD or after HD to be maintained at <90 th percentile for age, sex and height.	Tables 7.14, 7.15, figures 7.14, 7.15
	Blood pressure in Tx patients to be maintained at <90 th percentile for age, sex and height	
	Serum phosphate and calcium should be kept within the normal range. Parathyroid hormone (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 7.17
	Serum bicarbonate concentrations should be 20–26 mmol/L	Table 7.17
Typically maintain the aspirational haemoglobin range 100–120 g/L for young people and children aged ≥2 years and 95–115 g/L for children <2 years, reflecting the lower normal range in that age group	Table 7.17	
National Heart Lung and Blood Institute and Kidney Disease Improving Global Outcomes (KDIGO) (2013)	Screening children at risk of secondary dyslipidaemias including those with CKD is recommended	Tables 7.2, 7.3, 7.15

Detail about the completeness of data returned to the UK Renal Registry (UKRR) is available through the UKRR data completeness portal (renal.org/audit-research/data-portal/completeness). The completeness of both transferrin saturation and percentage hypochromic red cells was too low to be reported as measures of iron stores. Audit measures that cannot be reported because the required data items were not collected by the UKRR are omitted – this includes reticulocyte haemoglobin content.

For children, data for height, weight, BMI and blood pressure vary with age, sex and size and are therefore presented as z-scores. Z-scores are a way of expressing the deviation of a given measurement from the age and size-specific population mean. This relies on the completeness of height data during the period in question.

For definitions and methods relating to this chapter see appendix A. Centres were excluded from caterpillar plots and cells were blanked in tables where data completeness for a biochemical variable was <70% and/or the number of patients reported was <10. This suppression of small numbers to minimise risk of patient re-identification limits in-depth analysis of centre-level data. A patient first seen by renal services within 90 days of starting RRT for ESKD is defined as a 'late presentation'. In this report 'late presentation' is used interchangeably with 'late referral'.

Key findings

Children

- 115 patients aged <16 years started RRT for ESKD in the UK in 2018 compared to 99 patients in 2017
- RRT incidence in patients aged <16 years was 9.1 pmarp compared to 7.9 pmarp in 2017
- 826 patients aged <16 years were receiving RRT at UK paediatric renal centres on 31/12/2018, an increase from 810 patients in 2017
- RRT prevalence in patients aged <16 years was 65.4 pmarp. 77.8% had a functioning Tx (47.2% living donor and 30.6% deceased donor), 11.4% were receiving HD and 10.8% were receiving PD
- Tubulointerstitial disease accounted for >50% of all primary renal diseases (PRDs) in prevalent paediatric patients, with a high male:female ratio (3.4:1)
- Between 2004 and 2018, about a third of patients aged <16 years who were referred early received a pre-emptive Tx
- At the time of transfer to adult services, 86.4% of paediatric patients had a functioning kidney Tx
- The median height z-score for children on dialysis was -1.8 compared with -1.1 for those with a functioning Tx
- The median weight z-score for children on dialysis was -0.8 compared with -0.1 for those with a functioning Tx
- Of those with complete data, 73.1% of the prevalent paediatric RRT population had 1 or more risk factors for cardiovascular disease; 6.1% had 3 risk factors
- 50.7% and 56.5% of prevalent HD patients achieved systolic blood pressure (SBP) and diastolic blood pressure (DBP) values <90th percentile, respectively
- 55.0% and 71.2% of prevalent PD patients achieved SBP and DBP values <90th percentile, respectively
- 80.4% and 75.2% of prevalent Tx patients achieved SBP and DBP values <90th percentile, respectively.

Young people

- 18 patients aged 16 to <18 years started RRT for ESKD in the UK in 2018
- RRT incidence in young people was 12.6 pmarp
- 199 patients aged 16 to <18 years were receiving RRT on 31/12/2018, of whom the majority (79.4%) were managed in paediatric renal centres
- RRT prevalence in patients aged 16 to <18 years was 139.4 pmarp
- Tubulointerstitial disease accounted for 51.3% of all PRDs in prevalent young people, followed by familial/hereditary nephropathies (18.9%) and glomerular disease (16.8%). Diabetic nephropathy was seen in 0.5%
- The overall median eGFR of young people with a kidney transplant on 31/12/2018 was 72 mL/min/1.73m² (IQR 57–90 mL/min/1.73m²)
- The proportion of young people prevalent to RRT on 31/12/2018 with a blood pressure within the 'normal' range (<130/80 mmHg) was 56.0% of dialysis and 69.8% of transplanted patients.

Analyses – children

Data completeness for prevalent paediatric RRT patients

Data returns of key variables for Tx and dialysis patients <16 years old at the end of 2018 are shown in tables 7.2 and 7.3, respectively, with further detail available through the UKRR data completeness portal (renal.org/audit-research/data-portal/completeness).

Table 7.2 Data completeness for paediatric patients (<16 years old) prevalent to Tx on 31/12/2018 by centre

Centre	N with Tx	Data completeness (%)														
		Height at start	Weight at start	BMI	SBP	DBP	Hb	Creat at start	Ferr	ESA	IV iron	Chol	Bicarb	PTH	Ca	Phos
Bham_P	66	93.9	97.0	95.5	95.5	95.5	98.5	95.5	65.2	0.0	0.0	90.9	97.0	1.5	98.5	97.0
Blfst_P	26	76.9	84.6	84.6	84.6	84.6	92.3	88.5	84.6	92.3	3.9	76.9	92.3	88.5	92.3	92.3
Brstl_P	41	90.2	97.6	92.7	92.7	82.9	97.6	100.0	73.2	100.0	46.3	51.2	100.0	82.9	100.0	100.0
Cardf_P	23	95.7	95.7	82.6	78.3	26.1	87.0	95.7	65.2	8.7	0.0	65.2	87.0	73.9	87.0	87.0
Glasg_P	44	95.5	97.7	100.0	100.0	100.0	100.0	97.7	90.9	100.0	100.0	38.6	100.0	100.0	100.0	100.0
L Eve_P	65	73.9	76.9	98.5	98.5	98.5	98.5	78.5	63.1	0.0	0.0	73.9	98.5	98.5	98.5	98.5
L GOSH_P	122	86.9	94.3	98.4	97.5	2.5	99.2	93.4	79.5	93.4	0.0	74.6	99.2	95.1	99.2	99.2
Leeds_P	47	93.6	100.0	93.6	100.0	95.7	100.0	100.0	70.2	100.0	100.0	46.8	100.0	97.9	100.0	100.0
Livpl_P	31	71.0	80.7	96.8	96.8	93.6	100.0	90.3	96.8	100.0	3.2	67.7	100.0	3.2	100.0	100.0
Manch_P	63	95.2	96.8	98.4	100.0	98.4	98.4	96.8	87.3	100.0	0.0	44.4	98.4	96.8	98.4	98.4
Newc_P	25	76.0	80.0	0.0	96.0	0.0	100.0	84.0	88.0	0.0	0.0	72.0	100.0	80.0	100.0	100.0
Nottm_P	63	79.4	98.4	90.5	88.9	85.7	96.8	96.8	90.5	98.4	98.4	88.9	95.2	90.5	95.2	95.2
Soton_P	27	74.1	74.1	100.0	100.0	100.0	100.0	85.2	100.0	100.0	100.0	48.2	100.0	100.0	100.0	100.0
UK	643	85.9	91.9	91.8	95.7	70.5	98.1	93.0	79.6	70.8	31.3	66.9	98.0	79.5	98.1	98.0

Bicarb – bicarbonate; BMI – body mass index; Ca – calcium; Chol – cholesterol; Creat – creatinine; DBP – diastolic blood pressure; ESA – erythropoiesis stimulating agent; Ferr – ferritin; Hb – haemoglobin; IV – intravenous; Phos – phosphate; PTH – parathyroid hormone; SBP – systolic blood pressure

Table 7.3 Data completeness for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2018 by centre

Centre	N on dialysis	Data completeness (%)													
		Height at start	Weight at start	BMI	SBP	DBP	Hb	Ferr	ESA	IV iron	Chol	Bicarb	PTH	Ca	Phos
Bham_P	33	90.9	93.9	90.9	93.9	93.9	97.0	90.9	0.0	0.0	87.9	97.0	3.0	97.0	97.0
Blfst_P	6	83.3	83.3	66.7	83.3	0.0	100.0	100.0	100.0	0.0	83.3	100.0	100.0	100.0	100.0
Brstl_P	14	50.0	85.7	85.7	100.0	50.0	100.0	100.0	100.0	64.3	71.4	100.0	92.9	100.0	100.0
Cardf_P	10	70.0	70.0	90.0	100.0	0.0	100.0	100.0	30.0	30.0	50.0	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	100.0	69.2	100.0	100.0	100.0	100.0
L Eve_P	15	80.0	80.0	100.0	100.0	93.3	100.0	100.0	0.0	0.0	6.7	100.0	100.0	100.0	100.0
L GOSH_P	26	76.9	84.6	80.8	100.0	3.9	100.0	80.8	100.0	0.0	80.8	100.0	100.0	100.0	100.0
Leeds_P	11	81.8	90.9	81.8	90.9	90.9	100.0	100.0	100.0	100.0	72.7	100.0	90.9	90.9	90.9
Livpl_P	11	45.5	45.5	90.9	90.9	54.6	100.0	100.0	100.0	0.0	9.1	100.0	0.0	100.0	100.0
Manch_P	16	100.0	100.0	100.0	100.0	75.0	100.0	75.0	100.0	0.0	68.8	100.0	93.8	100.0	100.0
Newc_P	11	27.3	27.3	0.0	81.8	0.0	90.9	90.9	0.0	0.0	81.8	90.9	90.9	90.9	90.9
Nottm_P	14	92.9	100.0	85.7	92.9	64.3	100.0	100.0	100.0	100.0	71.4	100.0	100.0	100.0	100.0
Soton_P	3	100.0	100.0	100.0	100.0	66.7	100.0	100.0	100.0	100.0	33.3	100.0	100.0	100.0	100.0
UK	183	78.1	83.6	84.2	95.6	57.4	98.9	92.9	63.9	29.0	65.6	98.9	74.3	98.4	98.4

Bicarb – bicarbonate; BMI – body mass index; Ca – calcium; Chol – cholesterol; DBP – diastolic blood pressure; ESA – erythropoiesis stimulating agent; Ferr – ferritin; Hb – haemoglobin; IV – intravenous; Phos – phosphate; PTH – parathyroid hormone; SBP – systolic blood pressure

Changes to the incident paediatric RRT population

The number of incident patients on RRT <16 years old was calculated as an estimated age-related rate per million population (calculated as detailed in appendix A) and grouped by age, sex, five year time period, ethnicity, centre and PRD.

Table 7.4 Paediatric patients (<16 years old) incident to RRT in 2018 by age and sex

Age group (yrs)	All patients		Male		Female	
	N	pmarp	N	pmarp	N	pmarp
0-<2	18	11.9	10	12.9	8	10.8
2-<4	13	8.2	9	11.0	4	5.2
4-<8	22	6.6	16	9.4	6	3.7
8-<12	25	7.7	11	6.6	14	8.9
12-<16	37	12.5	23	15.1	14	9.7
<16 yrs	115	9.1	69	10.7	46	7.5

pmarp – per million age-related population

Table 7.5 Paediatric patients (<16 years old) incident to RRT by age and 5 year time period

Age group (yrs)	2004-2008		2009-2013		2014-2018	
	N	pmarp	N	pmarp	N	pmarp
0-<2	94	13.0	100	12.6	106	13.5
2-<4	44	6.4	66	8.4	70	8.7
4-<8	93	6.8	83	5.6	129	7.9
8-<12	121	8.2	122	8.8	128	8.3
12-<16	211	13.5	186	12.3	172	12.1
<16 yrs	563	9.6	557	9.4	605	9.8

pmarp – per million age-related population

Table 7.6 Paediatric patients (<16 years old) incident to RRT by ethnicity and 5 year time period

Ethnicity	2004-2008		2009-2013		2014-2018	
	N	%	N	%	N	%
White	423	75.8	392	70.9	410	69.3
South Asian	88	15.8	103	18.6	102	17.2
Black	25	4.5	20	3.6	37	6.3
Other	22	3.9	38	6.9	43	7.3
<16 yrs	558	100.0	553	100.0	592	100.0

5 children in 2004–2008, 4 in 2009–2013 and 13 in 2014–2018 with no ethnicity recorded were excluded.

Table 7.7 Paediatric patients (<16 years old) incident to RRT by centre and 5 year time period

Centre	2004-2008		2009-2013		2014-2018	
	N	%	N	%	N	%
Blfst_P	13	2.3	24	4.3	13	2.1
Bham_P	63	11.2	62	11.1	81	13.4
Brstl_P	34	6.0	34	6.1	31	5.1
Cardf_P	21	3.7	16	2.9	25	4.1
Glasg_P	46	8.2	33	5.9	50	8.3
L Eve_P	55	9.8	58	10.4	68	11.2
L GOSH_P	113	20.1	120	21.5	88	14.5
Leeds_P	60	10.7	44	7.9	46	7.6
Livpl_P	26	4.6	20	3.6	33	5.5
Manch_P	42	7.5	55	9.9	62	10.2
Newc_P	24	4.3	17	3.1	35	5.8
Nottm_P	54	9.6	54	9.7	51	8.4
Soton_P	12	2.1	20	3.6	22	3.6
<16 yrs	563	100.0	557	100.0	605	100.0

PRDs were grouped into categories as shown in table 7.8, with the mapping of disease codes into groups explained in more detail in appendix A.

Table 7.8 Paediatric patients (<16 years old) incident to RRT by primary renal disease (PRD) and 5 year time period

PRD	2004-2008		2009-2013		2014-2018	
	N	%	N	%	N	%
Tubulointerstitial disease	266	47.8	294	52.9	296	49.5
- CAKUT	245	44.1	276	49.6	287	48.0
- Non-CAKUT	21	3.8	18	3.2	9	1.5
Glomerular disease	122	21.9	98	17.6	110	18.4
Familial/hereditary nephropathies	92	16.5	92	16.5	84	14.0
Systemic diseases affecting the kidney	19	3.4	29	5.2	23	3.8
Miscellaneous renal disorders	57	10.3	43	7.7	85	14.2

7 children in 2004–2008, 1 in 2009–2013 and 7 in 2014–2018 with no PRD recorded were excluded.

CAKUT – congenital anomalies of the kidneys and urinary tract

Start modality of incident paediatric RRT patients

Start modality used by patients <16 years old starting RRT between 2004 and 2018 was grouped by five year time periods.

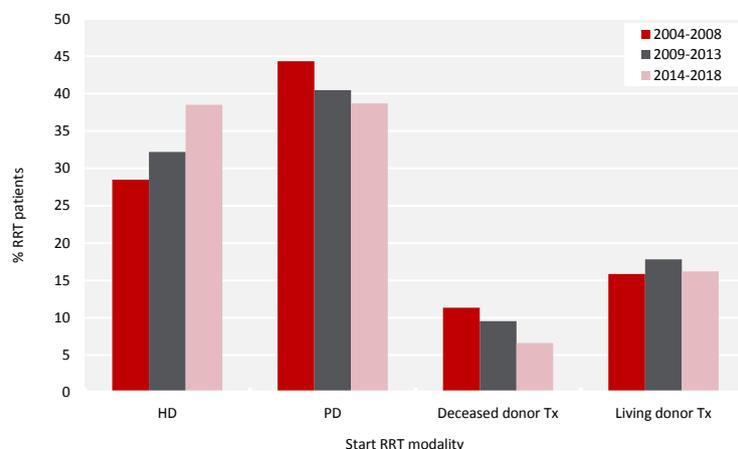


Figure 7.2 Start RRT modality for paediatric patients (<16 years old) incident to RRT by 5 year time period

Pre-emptive transplantation in incident paediatric RRT patients

The analysis of pre-emptive transplantation excluded patients starting RRT aged <3 months and patients presenting late.

Table 7.9 Pre-emptive transplantation in the incident paediatric RRT population aged 3 months to 16 years by 5 year time period, sex, ethnicity, age at start of RRT and primary renal disease (PRD)

Characteristic	N on RRT	N (%) with pre-emptive Tx
Total cohort analysed (2004-2018)	1,247	418 (33.5)
Time period		
2004-2008	398	145 (36.4)
2009-2013	400	145 (36.3)
2014-2018	449	128 (28.5)
Sex		
Male	801	290 (36.2)
Female	446	128 (28.7)
Ethnicity		
White	884	333 (37.7)
South Asian	221	50 (22.6)
Black	57	8 (14.0)
Other	70	20 (28.6)
Age at start of RRT (yrs)		
3 mths-<2	138	6 (4.4)
2-<4	155	43 (27.7)
4-<8	248	107 (43.2)
8-<12	283	104 (37.0)
12-<16	423	158 (37.4)
PRD		
Tubulointerstitial disease	679	293 (43.2)
Glomerular disease	233	15 (6.4)
Familial/hereditary nephropathies	187	64 (34.2)
Miscellaneous renal disorders	99	27 (27.3)
Systemic diseases affecting the kidney	38	16 (42.1)

100 children were excluded because they were aged <3 months; 378 children were excluded because they presented late.

Demographics of prevalent paediatric RRT patients

The number of prevalent patients on RRT <16 years old was calculated as an estimated age-related rate per million population (calculated as detailed in appendix A) and grouped by age, sex and ethnicity.

Table 7.10 Age and sex breakdown of paediatric patients (<16 years old) prevalent to RRT on 31/12/2018

Age group (yrs)	All patients		Male		Female		M/F ratio
	N	pmarp	N	pmarp	N	pmarp	
0-<2	20	13.2	13	16.7	7	9.5	1.8
2-<4	50	31.4	36	44.0	14	18.0	2.4
4-<8	173	52.2	125	73.7	48	29.7	2.5
8-<12	250	77.2	148	89.3	102	64.6	1.4
12-<16	333	112.3	212	139.6	121	83.7	1.7
<16 yrs	826	65.4	534	82.5	292	47.4	1.7

pmarp – per million age-related population

Table 7.11 Age and ethnicity breakdown of paediatric patients (<16 years old) prevalent to RRT on 31/12/2018

Age group (yrs)	N			
	White	South Asian	Black	Other
0-<4	53	4	3	6
4-<8	116	28	10	16
8-<12	170	47	8	21
12-<16	230	64	22	15
<16 years	569	143	43	58
pmarp <16 years	55.9	132.3	77.9	72.0

The 2011 Office for National Statistics census was used to estimate the proportion of White, South Asian, Black and Other ethnicity which was then applied to the population estimate for 2018.

13 children with no ethnicity recorded were excluded.

pmarp – per million age-related population

Treatment modality in prevalent paediatric RRT patients

The current and start RRT modalities for prevalent RRT patients aged <16 years are shown in figures 7.3 and 7.4, respectively. Table 7.12 breaks down current modality for prevalent patients by age group.

Table 7.12 RRT modality used by paediatric patients (<16 years old) prevalent to RRT on 31/12/2018 by age group

Age group (yrs)	Total N	HD		PD		Living donor Tx		Deceased donor Tx	
		N	%	N	%	N	%	N	%
0-<2	20	6	30.0	14	70.0	0	0.0	0	0.0
2-<4	50	11	22.0	17	34.0	20	40.0	2	4.0
4-<8	173	28	16.2	17	9.8	81	46.8	47	27.2
8-<12	250	17	6.8	13	5.2	140	56.0	80	32.0
12-<16	333	32	9.6	28	8.4	149	44.7	124	37.2
<16 years	826	94	11.4	89	10.8	390	47.2	253	30.6

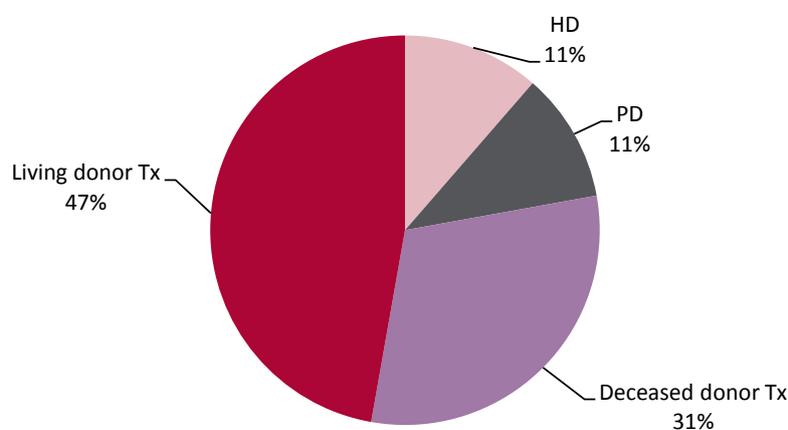


Figure 7.3 RRT modality used by paediatric patients (<16 years old) prevalent to RRT on 31/12/2018

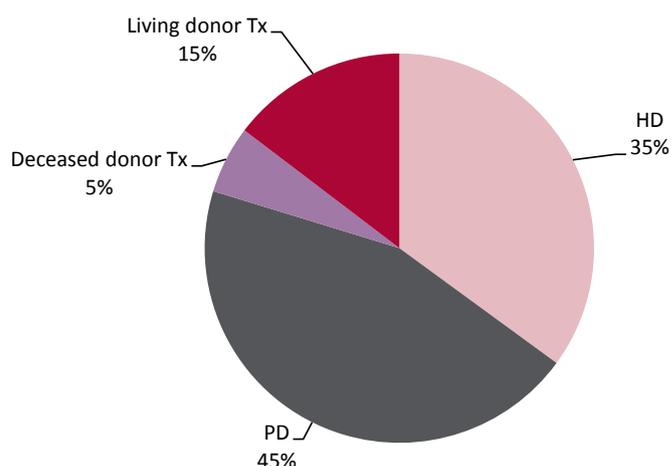


Figure 7.4 RRT modality used at the start of RRT by paediatric patients (<16 years old) prevalent to RRT on 31/12/2018

Causes of ESKD in prevalent paediatric RRT patients

PRDs were grouped into categories as shown in table 7.13.

Table 7.13 Primary renal diseases (PRDs) of paediatric patients (<16 years old) prevalent to RRT on 31/12/2018 by sex and ethnicity

PRD	N	%	N male	N female	% non-White
Tubulointerstitial disease	437	53.4	338	99	28.2
- CAKUT	426	52.0	330	96	28.0
- Non-CAKUT	11	1.3	8	3	40.0
Glomerular disease	156	19.0	82	74	32.5
Familial/hereditary nephropathies	106	12.9	45	61	41.3
Systemic diseases affecting the kidney	36	4.4	16	20	13.9
Miscellaneous renal disorders	84	10.3	49	35	28.4
Total (with data)	826	100.0	534	292	30.0
Missing	7	0.9	4	3	16.7

CAKUT – congenital anomalies of the kidneys and urinary tract

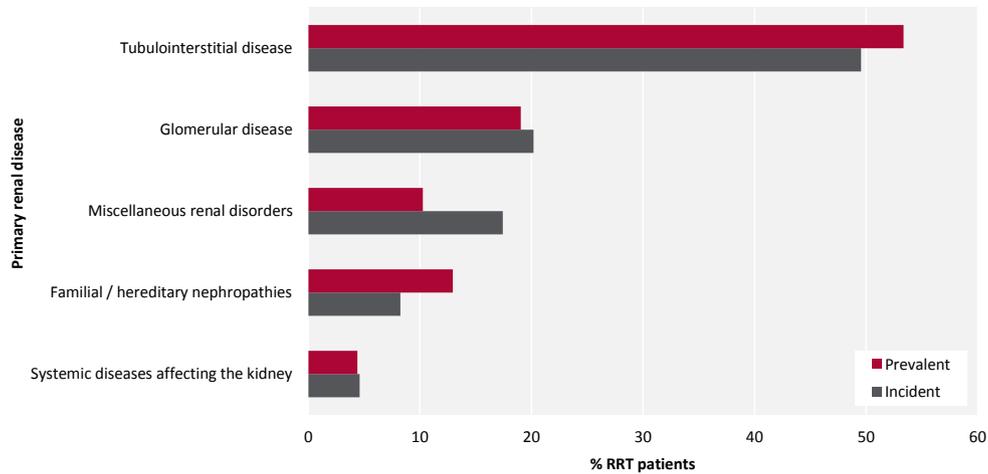


Figure 7.5 Comparison of primary renal diseases for paediatric patients (<16 years old) incident and prevalent to RRT in 2018 with no missing data

Growth of prevalent paediatric RRT patients

The height and weight of children receiving RRT were compared to the age- and sex-matched general childhood population. The UK median score for each measure is represented by a red dotted line.

Height of paediatric RRT patients

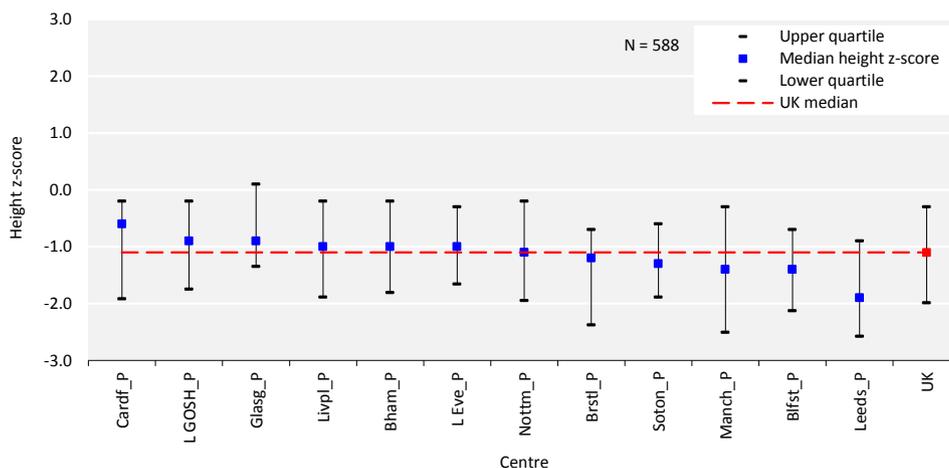


Figure 7.6 Median height z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2018 by centre

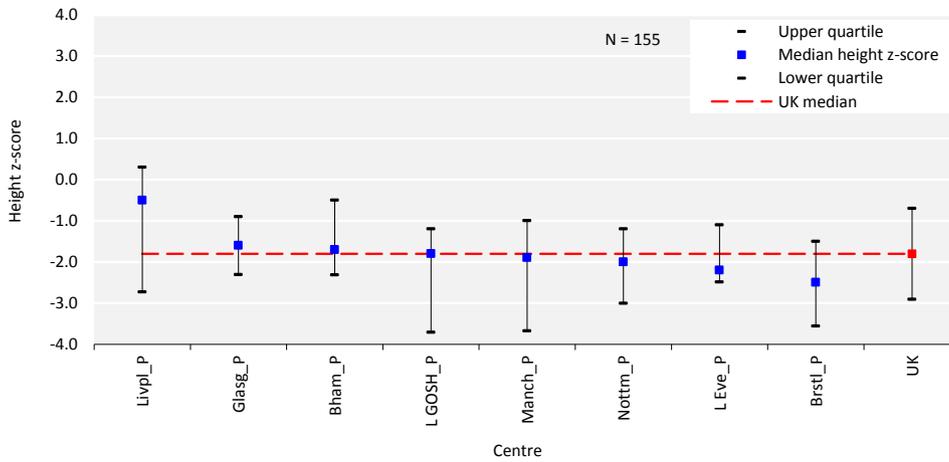


Figure 7.7 Median height z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2018 by centre

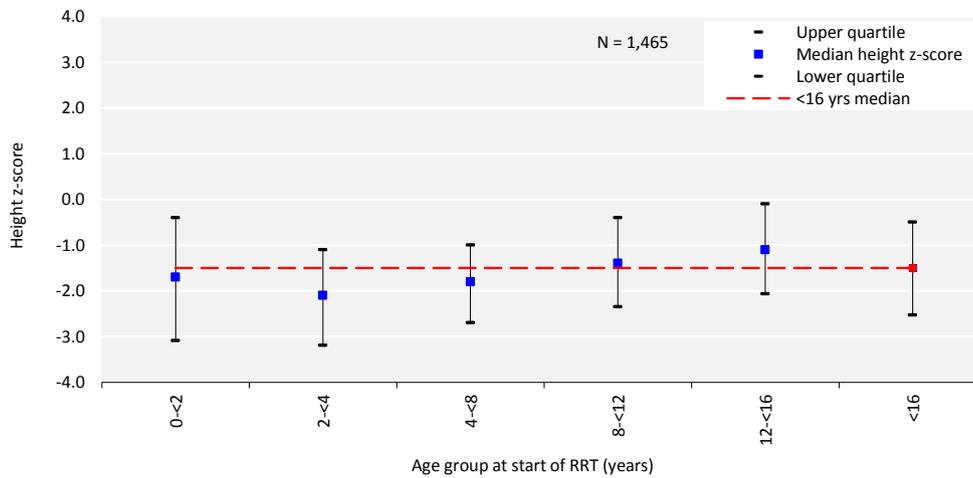


Figure 7.8 Median height z-scores at start of RRT for incident paediatric RRT patients (<16 years old) between 2004 and 2018 by age group at start of RRT

Weight of paediatric RRT patients

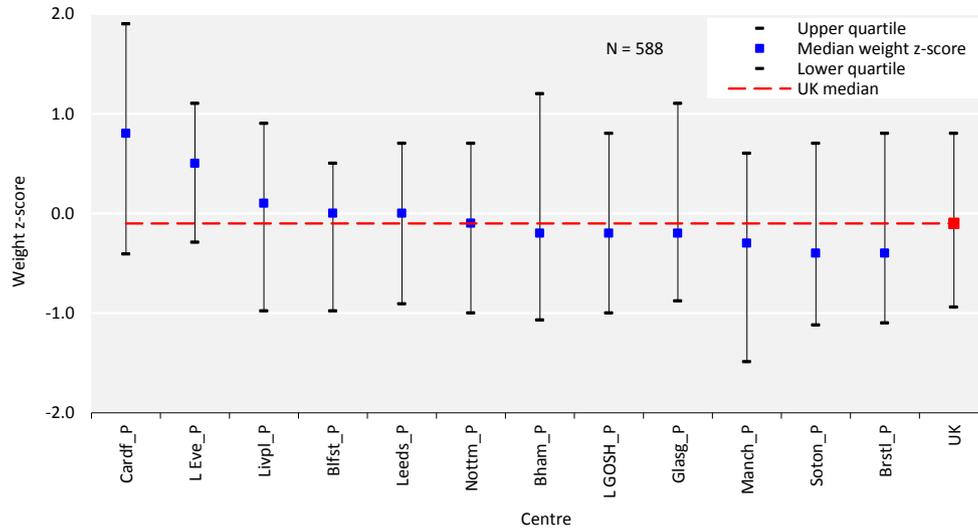


Figure 7.9 Median weight z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2018 by centre

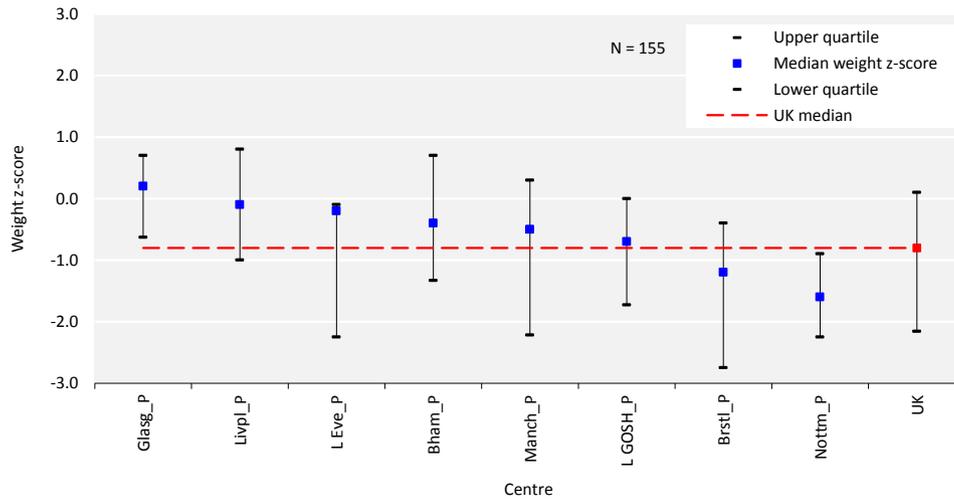


Figure 7.10 Median weight z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2018 by centre

Cardiovascular risk factor evaluation in prevalent paediatric RRT patients

Obesity in paediatric RRT patients

BMI was calculated using the formula $BMI = \text{weight (kg)} / \text{height}^2 \text{ (m)}$. 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. Height age corresponds to the age when a child's height is plotted at the 50th percentile on a UK growth chart.

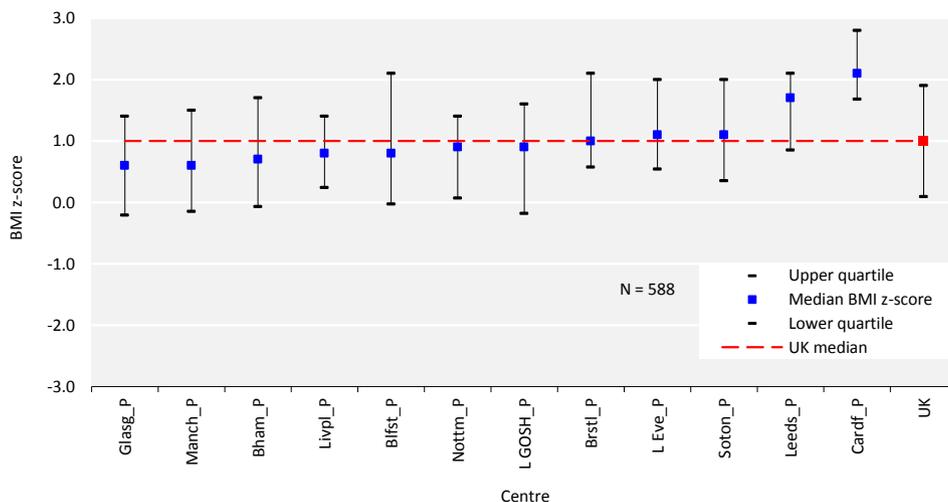


Figure 7.11 Median body mass index (BMI) z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2018 by centre

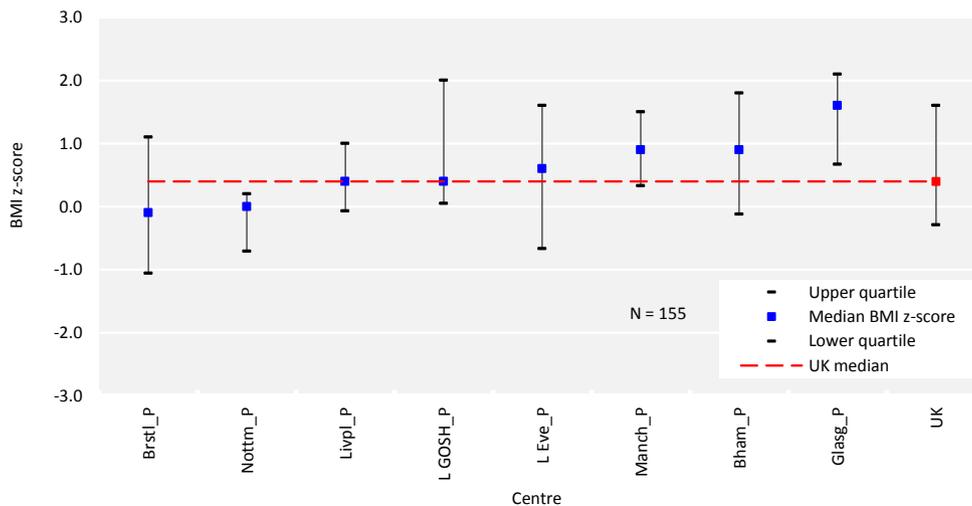


Figure 7.12 Median body mass index (BMI) z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2018 by centre

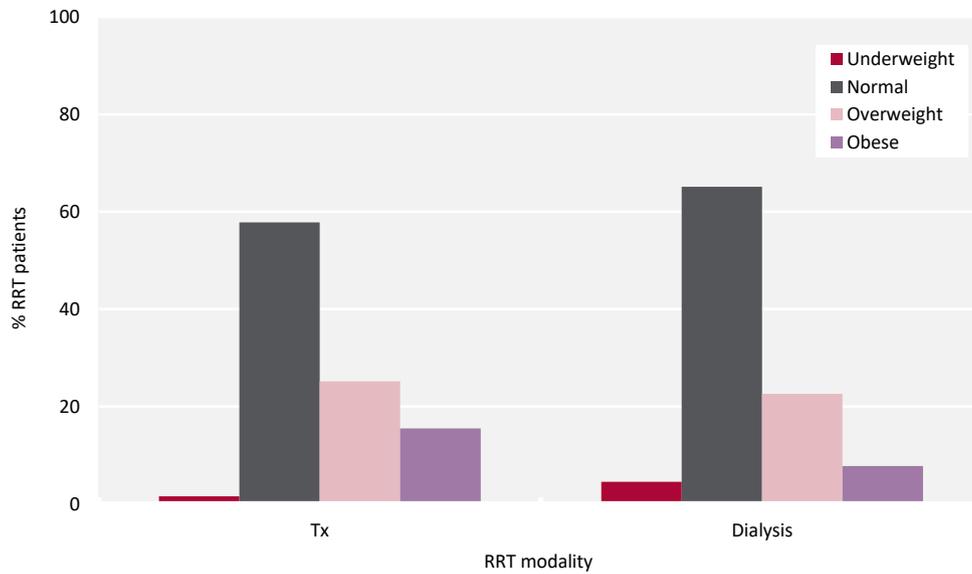


Figure 7.13 Body mass index categorisation of paediatric patients (<16 years old) prevalent to RRT on 31/12/2018 by RRT modality

Hypertension in paediatric RRT patients

In paediatric RRT patients, the systolic blood pressure should be maintained at <90th percentile for age, sex and height.

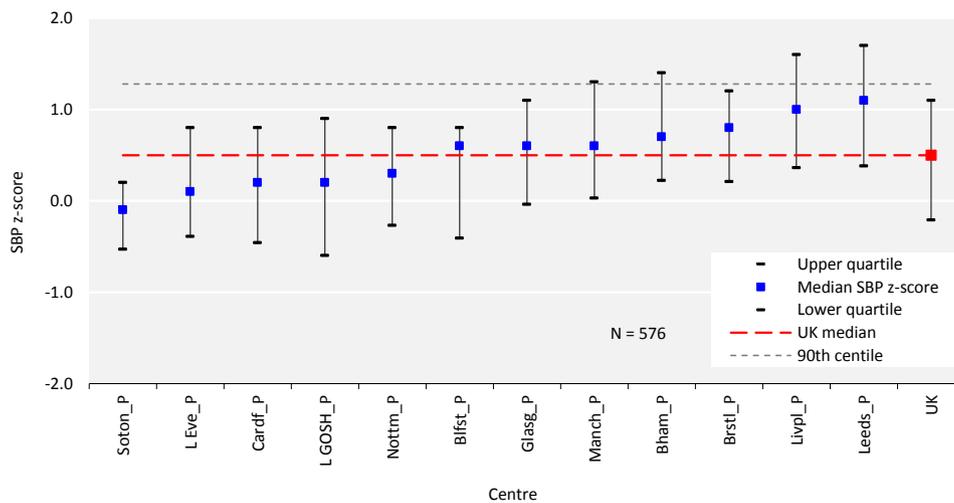


Figure 7.14 Median systolic blood pressure (SBP) z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2018 by centre

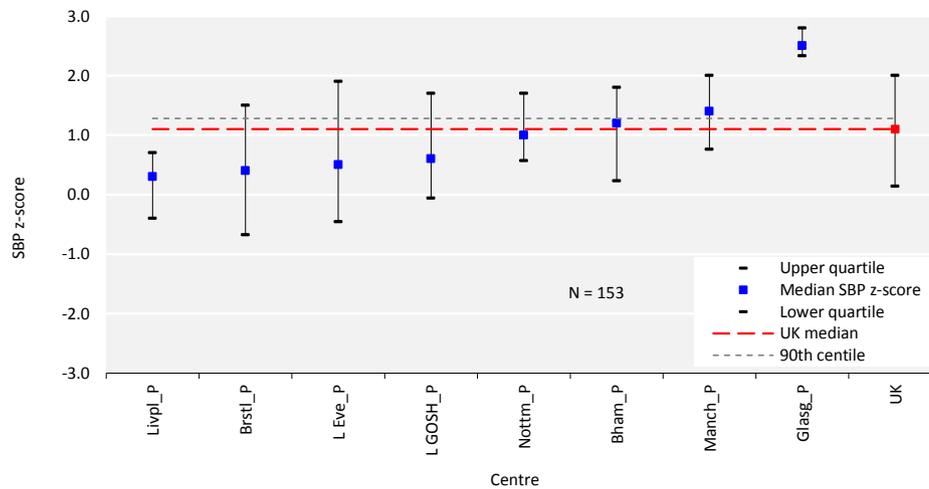


Figure 7.15 Median systolic blood pressure (SBP) z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2018 by centre

Table 7.14 Percentage of paediatric patients (<16 years old) prevalent to RRT on 31/12/2018 achieving the standards for blood pressures

Characteristic	SBP		DBP	
	N	% <90th percentile	N	% <90th percentile
Total	729	74.6	530	73.2
Age group (yrs)				
0-<5	92	57.6	56	66.1
5-<12	342	72.8	248	74.6
12-<16	295	82.0	226	73.5
Sex				
Male	479	76.4	346	74.3
Female	250	71.2	184	71.2
Ethnicity				
White	498	75.9	380	73.7
South Asian	131	71.0	93	67.7
Black	39	74.4	23	73.9
Other	54	75.9	33	81.2
Modality				
HD	73	50.7	46	56.5
PD	80	55.0	52	71.2
Tx	576	80.4	432	75.2

DBP – diastolic blood pressure; SBP – systolic blood pressure

Cardiovascular risk factors in paediatric RRT patients

The analysis of the percentage of prevalent RRT patients with identified cardiovascular risk factors was restricted to the 490 of the 826 patients (59.3%) with data for all three risk factors.

Table 7.15 Frequency of number of cardiovascular risk factors in paediatric patients (<16 years old) prevalent to RRT on 31/12/2018

N cardiovascular risk factors	Hypertensive	Overweight/Obese	Hypercholesterolaemic	N	%	Total %
0	No	No	No	132	26.9	26.9
1	Yes	No	No	59	12.0	37.3
	No	Yes	No	69	14.1	
	No	No	Yes	55	11.2	
2	Yes	Yes	No	55	11.2	29.6
	Yes	No	Yes	45	9.2	
	No	Yes	Yes	45	9.2	
3	Yes	Yes	Yes	30	6.1	6.1
Total N	189	199	175	490		
Total %	38.6	40.6	35.7			100.0

Biochemistry parameters in prevalent paediatric RRT patients

The median values and the percentage with eGFR <30 mL/min/1.73m² for prevalent 2018 paediatric Tx patients are presented in table 7.16.

Table 7.16 Median estimated glomerular filtration rate (eGFR) and percentage with eGFR <30 mL/min/1.73m² in paediatric patients (<16 years old) prevalent to Tx on 31/12/2018 by centre

Centre	N with Tx	Median eGFR (mL/min/1.73m ²)	% eGFR <30 mL/ min/1.73m ²	% data completeness
Bham_P	66	54	6.4	95.5
Blfst_P	26	79	9.1	84.6
Brstl_P	41	66	0.0	92.7
Cardf_P	23	75	0.0	78.3
Glasg_P	44	80	2.3	100.0
L Eve_P	65	55	4.7	98.5
L GOSH_P	122	58	8.5	96.7
Leeds_P	47	74	2.3	93.6
Livpl_P	31	76	0.0	96.8
Manch_P	63	65	1.6	96.8
Newc_P ¹	25			
Nottm_P	63	56	9.1	87.3
Soton_P	27	70	3.7	100.0
UK	643	63	4.8	90.8

Blank cells – centres with <70% data completeness or <10 patients.

¹Although completeness of creatinine data was good, no height data were returned – heights are needed to calculate eGFRs from creatinine.

Table 7.17 Attainment of targets for haemoglobin, calcium, phosphate, parathyroid hormone and bicarbonate in paediatric patients (<16 years old) (a) prevalent to dialysis on 31/12/2018 by centre and (b) prevalent to Tx on 31/12/2018 with estimated glomerular filtration rate (eGFR) <30 mL/min/1.73 m² in the UK

Centre	N	% Hb below target	% Hb within target	% Ca below target	% Ca within target	% phos below target	% phos within target	% PTH within target	% bicarb below target	% bicarb within target
DIALYSIS PATIENTS										
Bham_P	33	18.8	50.0	6.3	65.6	9.4	59.4		0.0	78.1
Blfst_P	6									
Brstl_P	14	7.1	71.4	0.0	78.6	35.7	42.9	38.5	0.0	57.1
Cardf_P	10	0.0	60.0	0.0	60.0	10.0	70.0	10.0	40.0	60.0
Glasg_P	13	15.4	46.2	7.7	76.9	46.2	30.8	38.5	7.7	84.6
L Eve_P	15	20.0	66.7	0.0	80.0	6.7	40.0	46.7	20.0	80.0
L GOSH_P	26	19.2	38.5	3.9	61.5	0.0	53.9	53.9	3.9	92.3
Leeds_P	11	27.3	63.6	20.0	60.0	0.0	40.0	40.0	0.0	72.7
Livpl_P	11	18.2	63.6	0.0	90.9	18.2	45.5		9.1	72.7
Manch_P	16	37.5	31.3	12.5	50.0	25.0	37.5	66.7	6.3	75.0
Newc_P	11	10.0	50.0	0.0	90.0	40.0	40.0	70.0	0.0	90.0
Nottm_P	14	21.4	64.3	0.0	50.0	7.1	50.0	50.0	0.0	57.1
Soton_P	3									
UK	183	18.8	50.8	4.4	67.8	16.1	47.8	51.5	6.1	75.7
TX PATIENTS WITH eGFR <30 mL/min/1.73 m²										
UK	28	32.1	46.4	14.3	78.6	14.3	75.0	60.0	17.9	82.1

Blank cells – centres with <70% data completeness or <10 patients.

See appendix A for biochemical target ranges.

Bicarb – bicarbonate; Ca – calcium; Hb – haemoglobin; Phos – phosphate; PTH – parathyroid hormone

Table 7.18 Median estimated glomerular filtration rate (eGFR) in paediatric patients (<16 years old) prevalent to Tx on 31/12/2018 by time since transplantation and age group

Time since transplantation	Age group (years)					
	0-<5		5-<12		12-<16	
	N	Median eGFR (mL/min/1.73 m ²)	N	Median eGFR (mL/min/1.73 m ²)	N	Median eGFR (mL/min/1.73 m ²)
3 mths	17	76	28	82	19	64
1 yr	16	88	37	70	25	64
3 yrs	5	90	83	64	49	63
5 yrs	0	0	107	59	62	60
≥7 yrs	0	0	41	53	95	56
Total (IQR)	38	84 (69-109)	296	64 (50-80)	250	61 (46-75)

IQR – interquartile range

The percentage of patients with haemoglobin above target range on ESA is shown by renal centre.

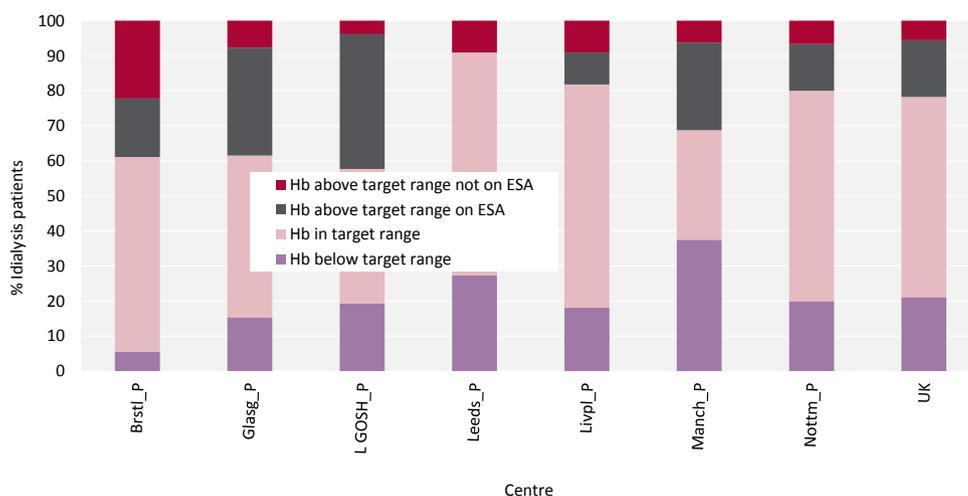


Figure 7.16 Proportion of paediatric patients (<16 years old) prevalent to dialysis on 31/12/2018 with haemoglobin (Hb) below, within and above target by centre; for those above target the proportion on erythropoiesis stimulating agent (ESA) therapy is shown

Transfer to adult renal services for prevalent paediatric RRT patients

Ninety-five paediatric patients transitioned to adult renal centres in 2018. The median age of patients at transfer was 18.0 years with an IQR of 17.5–18.4 years. Overall, the demographics of this population reflected those of the prevalent paediatric RRT population, but with a higher proportion having a functioning Tx (86.4% versus 76.3%).

Survival in paediatric RRT patients

Of patients aged <16 years, 1,583 started RRT between 2004 and 2017 at paediatric renal centres and were included in survival analyses, to allow at least one year follow-up. At the end of 2018, 88 deaths had been reported in these children before they reached 16 years of age and when still under the care of a paediatric renal centre. Patients included in the analysis must have been alive on RRT for 90 days. The median follow-up time (beyond day 90) was 3.6 years (range three days to 14.7 years).

Table 7.19 Survival of incident paediatric RRT patients (<16 years old) at 1 year intervals of RRT by age at start of RRT

Survival	Age group (yrs)				
	0-<2	2-<4	4-<8	8-<12	12-<16
Survival at 1 year (%)	93.6	98.2	98.6	99.7	99.0
95% CI	90.0-95.9	94.5-99.4	96.3-99.5	98.0-100	97.2-99.6
Survival at 2 years (%)	92.5	96.2	95.2	98.8	97.4
95% CI	88.7-95.0	91.8-98.3	91.9-97.2	96.8-99.5	94.8-98.7
Survival at 3 years (%)	90.0	94.8	94.8	98.1	97.4
95% CI	85.7-93.0	89.9-97.4	91.4-96.9	95.9-99.2	94.8-98.7
Survival at 4 years (%)	88.6	94.0	94.8	97.4	
95% CI	84.1-91.9	88.8-96.9	91.4-96.9	94.8-98.7	
Survival at 5 years (%)	87.1	93.1	93.7	96.9	
95% CI	82.2-90.7	87.5-96.3	89.9-96.1	94.1-98.4	

CI – confidence interval

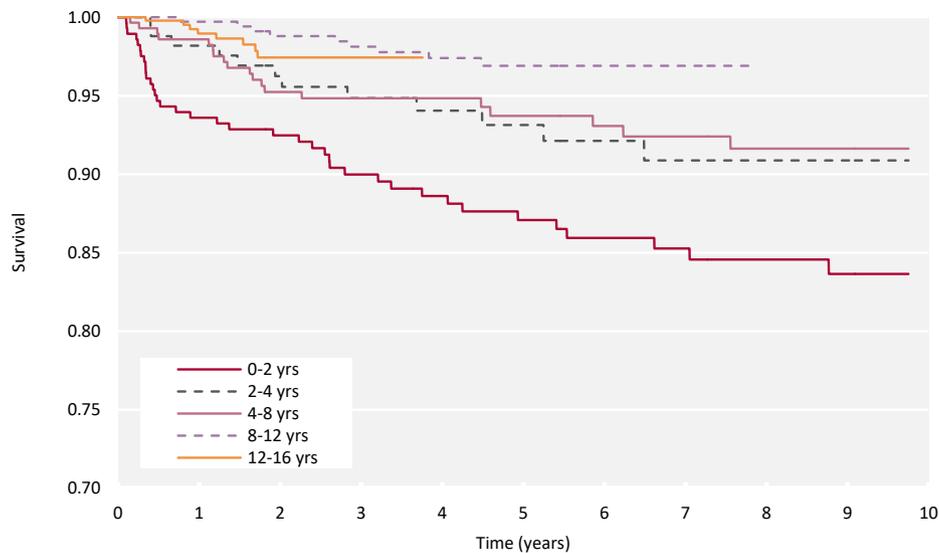


Figure 7.17 Unadjusted Kaplan-Meier survival (from day 90) of incident paediatric RRT patients (<16 years old) between 2004 and 2017 by age group at start of RRT

Analyses – young people

RRT incidence and prevalence in young people

Table 7.20 reports the numbers of young people who started RRT in 2018 (incidence) as well as those on RRT as of 31/12/2018 (prevalence) in both paediatric and adult centres, as an estimated total pmarp and grouped by sex, ethnicity and PRD. Diabetes is reported as a separate disease entity. For incident young people, start modality is reported; current treatment modality is reported for prevalent patients.

Table 7.20 Demographics of young people (16–<18 years) incident to RRT in 2018 and/or prevalent to RRT on 31/12/2018, by care setting

Characteristic	Incident			Prevalent		
	Paediatric centres	Adult centres	All	Paediatric centres	Adult centres	All
N	6	12	18	158	41	199
pmarp			12.6			139.4
Median age (yrs)	17.0	17.4	17.3	16.8	17.8	17.0
% male	16.7	50.0	38.9	57.6	75.6	61.3
Ethnicity¹ (%)						
White	33.3	50.0	43.8	74.5	55.3	70.8
South Asian	0.0	40.0	25.0	15.3	29.0	18.0
Black	33.3	0.0	12.5	5.1	7.9	5.6
Other	33.3	10.0	18.8	5.1	7.9	5.6
Missing	0.0	16.7	11.1	0.6	7.3	2.0
PRD¹ (%)						
Tubulointerstitial disease	33.3	25.0	27.8	53.5	41.2	51.3
Glomerular disease	16.7	50.0	38.9	17.2	14.7	16.8
Familial/hereditary nephropathies	33.3	8.3	16.7	19.1	17.7	18.9
Systemic diseases affecting the kidney	0.0	8.3	5.6	2.6	5.9	3.1
Diabetes	0.0	0.0	0.0	0.0	2.9	0.5
Miscellaneous renal disorders	16.7	8.3	11.1	7.6	17.7	9.4
Missing	0.0	0.0	0.0	0.6	17.1	4.0
Modality (%)						
HD	50.0	41.7	44.4	9.5	17.1	11.1
PD	33.3	50.0	44.4	7.6	17.1	9.5
Tx	16.7	8.3	11.1	82.9	65.9	79.4

¹Percentages by ethnicity and PRD were calculated for those with data (excluding patients with missing data).

pmarp – per million age-related population; PRD – primary renal disease

Table 7.21 details the number and type of centres (adult or paediatric) that have contributed to the incident and prevalent numbers reported. The small proportion of adult centres identified may reflect that young people are often directed to centres with an established transition programme for early adult care; however, under-reporting of young people may also account for this finding.

Table 7.21 Number of centres that submitted data for young people (16–<18 years) incident to RRT in 2018 and/or prevalent to RRT on 31/12/2018, by care setting

	Incident	Prevalent
Paediatric centres	5 out of 13	13 out of 13
Adult centres	11 out of 70*	21 out of 70*

*Cambridge did not submit patient-level data for 2018.

Transplant parameters in young people

The median values for age, creatinine and eGFR, and the proportion with an eGFR <30 mL/min/1.73 m² for young people prevalent to Tx on 31/12/2018 are presented by care setting (adult or paediatric centre).

Table 7.22 Measures of graft function in young people (16–<18 years) prevalent to Tx on 31/12/2018, by care setting

	N on Tx	Median age (yrs)	N with creatinine data	Creatinine (µmol/L)	Median FAS-eGFR (mL/min/1.73m ²)	% FAS-eGFR <30 mL/min/1.73m ²	% creatinine completeness
Paediatric centres	131	16.8	130	102	73	5.4	99.2
Adult centres	27	17.9	26	120	68	15.4	96.3

eGFR – estimated glomerular filtration rate; FAS – Full Age Spectrum

Table 7.23 reports the median eGFR for all young people prevalent to Tx on 31/12/2018 by time since transplantation. Small numbers preclude further analysis by care setting (adult or paediatric centre).

Table 7.23 Estimated glomerular filtration rate (eGFR) in young people (16–<18 years) prevalent to Tx on 31/12/2018 by time since transplantation

Time since transplantation	N	Median FAS-eGFR (mL/min/1.73m ²)
3 months	11	90
1 year	20	66
3 years	26	80
5 years	31	78
≥7 years	68	71
Total (IQR)	156	72 (57-90)

FAS – Full Age Spectrum; IQR – interquartile range

Biochemical and blood pressure measures in young people

Table 7.24 shows attainment of biochemical and blood pressure measures for young people prevalent to dialysis and transplant on 31/12/2018 for the total population and by care setting (adult or paediatric). Attainment of targets including haemoglobin, calcium, phosphate and bicarbonate are shown; median systolic and diastolic blood pressure values and the percentage of young people with blood pressure values within 'normal' range or that are 'high' are also reported. Data completeness was satisfactory (>70%) for all biochemical parameters, although a higher proportion of incomplete blood pressure data was noted among young people managed in adult centres. As a result, we advise caution when making inferences from the unadjusted data.

Table 7.24 Attainment of biochemical and blood pressure measures in young people (16–<18 years) prevalent to RRT on 31/12/2018, by modality and care setting

Characteristic	Dialysis			Tx		
	Paediatric centres	Adult centres	All	Paediatric centres	Adult centres	All
N	27	14	41	131	27	158
Median (IQR) Hb (g/L)	114 (101-124)	101 (99-121)	111 (100-124)	126 (116-137)	130 (116-147)	126 (116-138)
% Hb <100g/L	11.5	33.3	17.1	3.1	4.6	3.3
Median (IQR) Ca (mmol/L)	2.5 (2.4-2.6)	2.4 (2.3-2.5)	2.5 (2.4-2.6)	2.4 (2.3-2.5)	2.4 (2.3-2.5)	2.4 (2.3-2.5)
% Ca in range	53.9	90.9	64.9	92.3	84.6	91
Median (IQR) Phos (mmol/L)	1.7 (1.4-1.9)	2.1 (1.3-2.3)	1.7 (1.4-2.1)	1.1 (1.0-1.3)	1.1 (1.0-1.3)	1.1 (1.0-1.3)
% phos in range	53.9	36.4	48.7	59.7	61.5	60.0
Median (IQR) bicarb (mmol/L)	25 (23-27)	26 (21-26)	25 (22-27)	24 (22-26)	25 (23-26)	24 (22-26)
% bicarb in range	57.7	72.7	62.2	79.8	72	78.6
Median (IQR) SBP (mmHg)	114 (108-118)	142 (118-158)	116 (110-132)	117 (110-124)	123 (112-134)	118 (110-126)
Median (IQR) DBP (mmHg)	69 (63-80)	81 (56-82)	70 (63-81)	70 (64-77)	77 (70-81)	70 (65-78)
% 'normal' BP range (<130/80 mmHg)	66.7	28.6	56.0	73.8	47.4	69.8
% high BP (≥140/90 mmHg)	11.1	57.1	24.0	4.7	10.5	5.6

bicarb – bicarbonate; BP – blood pressure; Ca – calcium; DBP – diastolic blood pressure; Hb – haemoglobin; IQR – inter-quartile range; phos – phosphate; SBP – systolic blood pressure