

Chapter 8

Children and young people on renal replacement therapy (RRT) for end-stage kidney disease (ESKD) in the UK in 2019

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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 2019 (figure 8.1). This included patients with a transplant (Tx) and patients on dialysis – in-centre haemodialysis (ICHHD), 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. Children (aged <16 years) and young people (aged 16 to <18 years) are reported separately. Data about young people also include those managed in adult centres, to provide a more complete epidemiological picture for this population.

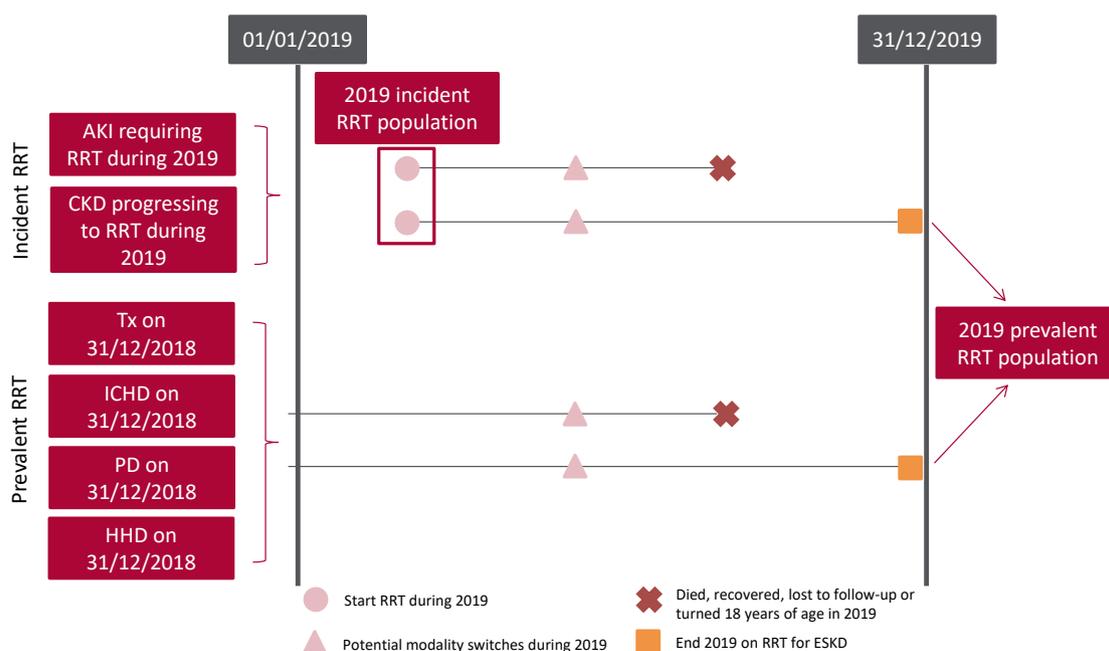


Figure 8.1 Pathways children and young people could follow to be included in the UK 2019 incident and/or prevalent RRT populations

Note that patients starting RRT in 2019 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 2019 and remained on RRT for at least 90 days.
- **Prevalent population:** patients who were on RRT at the end of 2019 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 2005–2009, 2010–2014 and 2015–2019.

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

- **Incident population:** patients who started RRT during 2019 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 2019 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 8.1):

- **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 2019 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 2019 is reported in this chapter (table 8.1). 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 8.1 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 8.6–8.13
	Blood pressure during PD or after HD to be maintained at <90 th percentile for age, sex and height.	Tables 8.14–8.15, figures 8.14–8.15
	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 8.17
	Serum bicarbonate concentrations should be 20–26 mmol/L	Table 8.17
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 8.17	
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 8.2–8.3, 8.15

Detail about the completeness of data returned to the UK Renal Registry (UKRR) is available through the UKRR data portal (renal.org/audit-research/data-portal). 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

- 101 patients aged <16 years started RRT for ESKD in the UK in 2019 compared to 115 patients in 2018
- RRT incidence in patients aged <16 years was 8.0 pmarp compared to 9.1 pmarp in 2018
- 832 patients aged <16 years were receiving RRT at UK paediatric renal centres on 31/12/2019, an increase from 826 patients in 2018
- RRT prevalence in patients aged <16 years was 65.5 pmarp. 78.4% had a functioning Tx (48.6% living donor and 29.8% deceased donor), 10.8% were receiving HD and 10.7% 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 2005 and 2019, 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, 78.7% of paediatric patients had a functioning kidney Tx
- The median height z-score for children on dialysis was -2.1 compared with -1.1 for those with a functioning Tx
- The median weight z-score for children on dialysis was -1.3 compared with -0.1 for those with a functioning Tx
- The overall median eGFR of the 652 children with a kidney transplant on 31/12/2019 was 61 mL/min/1.73m² and 6.6% had an eGFR of <30 mL/min/1.73m²
- Of those with complete data, 74.1% of the prevalent paediatric RRT population had 1 or more risk factors for cardiovascular disease; 3.7% had 3 risk factors
- 55.1% and 64.3% of prevalent HD patients achieved systolic blood pressure (SBP) and diastolic blood pressure (DBP) values <90th percentile, respectively
- 62.0% and 64.0% of prevalent PD patients achieved SBP and DBP values <90th percentile, respectively
- 74.4% and 78.6% of prevalent Tx patients achieved SBP and DBP values <90th percentile, respectively.

Young people

- 31 patients aged 16 to <18 years started RRT for ESKD in the UK in 2019
- RRT incidence in young people was 21.7 pmarp
- 219 patients aged 16 to <18 years were receiving RRT on 31/12/2019, of whom the majority (86.8%) were managed in paediatric renal centres
- RRT prevalence in patients aged 16 to <18 years was 153.6 pmarp
- Tubulointerstitial disease accounted for 49.8% of all PRDs in prevalent young people, followed by familial/hereditary nephropathies (18.5%) and glomerular disease (18.5%). Diabetic nephropathy was seen in 0.5%
- The overall median eGFR of young people with a kidney transplant on 31/12/2019 was 67 mL/min/1.73m² and 2.5% had an eGFR of <30 mL/min/1.73m²
- The proportion of young people prevalent to RRT on 31/12/2019 with a blood pressure within the 'normal' range (<130/80 mmHg) was 47.4% of dialysis and 72.1% 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 2019 are shown in tables 8.2 and 8.3, respectively, with further detail available through the UKRRR data portal (renal.org/audit-research/data-portal).

Table 8.2 Data completeness for paediatric patients (<16 years old) prevalent to Tx on 31/12/2019 by centre

Centre	N with Tx	Data completeness (%)														
		Height at start	Weight at start	BMI	SBP	DBP	Hb	Creat at start	GH	ESA	IV iron	Chol	Bicarb	PTH	Ca	Phos
Bham_P	67	91.0	95.5	97.0	97.0	97.0	98.5	91.0	0.0	0.0	0.0	92.5	97.0	9.0	98.5	97.0
Blfst_P	25	84.0	92.0	96.0	100.0	96.0	100.0	96.0	92.0	96.0	92.0	72.0	100.0	100.0	100.0	100.0
Brstl_P	41	85.4	95.1	97.6	95.1	75.6	100.0	100.0	0.0	100.0	0.0	26.8	97.6	82.9	100.0	100.0
Cardf_P	26	92.3	92.3	11.5	92.3	46.2	96.2	96.2	0.0	15.4	0.0	96.2	96.2	96.2	96.2	96.2
Glasg_P	43	95.4	97.7	97.7	97.7	97.7	100.0	97.7	97.7	100.0	95.4	27.9	100.0	97.7	100.0	100.0
L Eve_P	68	72.1	73.5	100.0	100.0	100.0	100.0	75.0	0.0	0.0	0.0	58.8	100.0	98.5	100.0	100.0
L GOSH_P	125	84.0	91.2	98.4	53.6	53.6	95.2	92.8	96.0	99.2	99.2	39.2	90.4	88.0	90.4	95.2
Leeds_P	45	91.1	97.8	100.0	100.0	93.3	100.0	97.8	100.0	100.0	100.0	13.3	100.0	100.0	100.0	100.0
Livpl_P	27	66.7	77.8	0.0	0.0	0.0	92.6	88.9	0.0	0.0	0.0	63.0	92.6	92.6	92.6	92.6
Manch_P	69	95.7	97.1	98.6	100.0	100.0	100.0	97.1	98.6	100.0	1.5	43.5	100.0	97.1	100.0	100.0
Newc_P	27	81.5	85.2	92.6	92.6	0.0	100.0	74.1	0.0	0.0	0.0	85.2	100.0	85.2	100.0	100.0
Nottm_P	65	80.0	98.5	90.8	86.2	84.6	93.9	98.5	0.0	98.5	98.5	89.2	93.9	92.3	93.9	93.9
Soton_P	24	75.0	75.0	100.0	100.0	100.0	100.0	87.5	83.3	100.0	100.0	79.2	100.0	100.0	100.0	100.0
UK	652	84.8	91.0	89.9	84.2	76.5	97.9	92.0	48.8	67.2	49.4	56.8	96.6	84.8	96.9	97.7

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

Table 8.3 Data completeness for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2019 by centre

Centre	N on dialysis	Data completeness (%)													
		Height at start	Weight at start	BMI	SBP	DBP	Hb	GH	ESA	IV iron	Chol	Bicarb	PTH	Ca	Phos
Bham_P	31	67.7	74.2	93.6	93.6	93.6	96.8	0.0	0.0	0.0	96.8	96.8	6.5	96.8	96.8
Blfst_P	4	100.0	100.0	75.0	75.0	0.0	100.0	75.0	100.0	100.0	75.0	100.0	100.0	100.0	100.0
Brstl_P	15	73.3	93.3	100.0	100.0	14.3	100.0	0.0	100.0	0.0	71.4	100.0	100.0	100.0	100.0
Cardf_P	6	66.7	50.0	0.0	83.3	0.0	83.3	0.0	0.0	0.0	50.0	83.3	83.3	83.3	83.3
Glasg_P	12	91.7	91.7	100.0	100.0	100.0	100.0	100.0	100.0	100.0	75.0	100.0	100.0	100.0	100.0
L Eve_P	11	90.9	90.9	100.0	100.0	100.0	100.0	0.0	0.0	0.0	9.1	100.0	100.0	100.0	100.0
L GOSH_P	30	66.7	70.0	100.0	83.3	83.3	96.7	23.3	23.3	23.3	43.3	56.7	96.7	56.7	96.7
Leeds_P	10	80.0	100.0	60.0	100.0	80.0	100.0	60.0	100.0	100.0	50.0	100.0	100.0	90.0	100.0
Livpl_P	10	80.0	80.0	0.0	0.0	0.0	80.0	0.0	0.0	0.0	20.0	80.0	80.0	80.0	80.0
Manch_P	20	100.0	100.0	95.0	95.0	45.0	100.0	95.0	95.0	0.0	55.0	100.0	90.0	100.0	100.0
Newc_P	10	70.0	70.0	50.0	50.0	0.0	100.0	0.0	0.0	0.0	30.0	100.0	100.0	100.0	100.0
Nottm_P	16	75.0	81.3	87.5	81.3	62.5	100.0	0.0	100.0	100.0	62.5	100.0	100.0	100.0	100.0
Soton_P	5	100.0	100.0	100.0	100.0	80.0	100.0	80.0	100.0	100.0	60.0	100.0	100.0	100.0	100.0
UK	180	78.3	82.8	82.7	84.4	61.5	97.2	28.3	48.6	30.2	57.5	90.5	80.5	89.9	97.2

Bicarb – bicarbonate; BMI – body mass index; Ca – calcium; Chol – cholesterol; DBP – diastolic blood pressure; ESA – erythropoiesis stimulating agent; GH – growth hormone; 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 8.4 Paediatric patients (<16 years old) incident to RRT in 2019 by age and sex

Age group (yrs)	All patients		Male		Female	
	N	pmarp	N	pmarp	N	pmarp
0-<2	14	9.5	5	6.6	9	12.5
2-<4	12	7.6	7	8.6	5	6.5
4-<8	16	4.9	10	5.9	6	3.7
8-<12	27	8.2	11	6.5	16	10.0
12-<16	32	10.5	19	12.1	13	8.7
<16 yrs	101	8.0	52	8.0	49	7.9

pmarp – per million age-related population

Table 8.5 Paediatric patients (<16 years old) incident to RRT by age and 5 year time period

Age group (yrs)	2005-2009		2010-2014		2015-2019	
	N	pmarp	N	pmarp	N	pmarp
0-<2	104	14.0	99	12.2	103	13.3
2-<4	45	6.3	74	9.4	63	7.9
4-<8	100	7.4	91	6.0	117	7.1
8-<12	127	8.8	128	9.2	128	8.1
12-<16	221	14.6	174	11.7	173	12.0
<16 yrs	597	10.4	566	9.4	584	9.3

pmarp – per million age-related population

Table 8.6 Paediatric patients (<16 years old) incident to RRT by ethnicity and 5 year time period

Ethnicity	2005-2009		2010-2014		2015-2019	
	N	%	N	%	N	%
White	443	75.2	400	70.7	376	67.1
Asian	101	17.1	101	17.8	110	19.6
Black	26	4.4	26	4.6	37	6.6
Other	19	3.2	39	6.9	37	6.6
<16 yrs	589	100.0	566	100.0	560	100.0

8 children in 2005–2009, 0 in 2010–2014 and 24 in 2015–2019 with no ethnicity recorded were excluded.

Table 8.7 Paediatric patients (<16 years old) incident to RRT by centre and 5 year time period

Centre	2005-2009		2010-2014		2015-2019	
	N	%	N	%	N	%
Blfst_P	17	2.8	21	3.7	10	1.7
Bham_P	66	11.1	62	11.0	81	13.9
Brstl_P	32	5.4	38	6.7	30	5.1
Cardf_P	21	3.5	21	3.7	20	3.4
Glasg_P	49	8.2	33	5.8	47	8.0
L Eve_P	65	10.9	56	9.9	65	11.1
L GOSH_P	121	20.3	104	18.4	103	17.6
Leeds_P	56	9.4	52	9.2	41	7.0
Livpl_P	26	4.4	30	5.3	23	3.9
Manch_P	47	7.9	56	9.9	63	10.8
Newc_P	23	3.9	22	3.9	32	5.5
Nottm_P	61	10.2	51	9.0	47	8.0
Soton_P	13	2.2	20	3.5	22	3.8
<16 yrs	597	100.0	566	100.0	584	100.0

PRDs were grouped into categories as shown in table 8.8, with the mapping of disease codes into groups explained in more detail in appendix A.

Table 8.8 Paediatric patients (<16 years old) incident to RRT by primary renal disease (PRD) and 5 year time period

PRD	2005-2009		2010-2014		2015-2019	
	N	%	N	%	N	%
Tubulointerstitial disease	282	47.8	303	53.6	263	48.0
- CAKUT	260	44.1	286	50.6	256	46.7
- Non-CAKUT	22	3.7	17	3.0	7	1.3
Glomerular disease	128	21.7	93	16.5	109	19.9
Familial/hereditary nephropathies	95	16.1	98	17.3	78	14.2
Systemic diseases affecting the kidney	28	4.7	21	3.7	22	4.0
Miscellaneous renal disorders	57	9.7	50	8.8	76	13.9

7 children in 2005–2009, 1 in 2010–2014 and 36 in 2015–2019 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 2005 and 2019 was grouped by five year time periods.

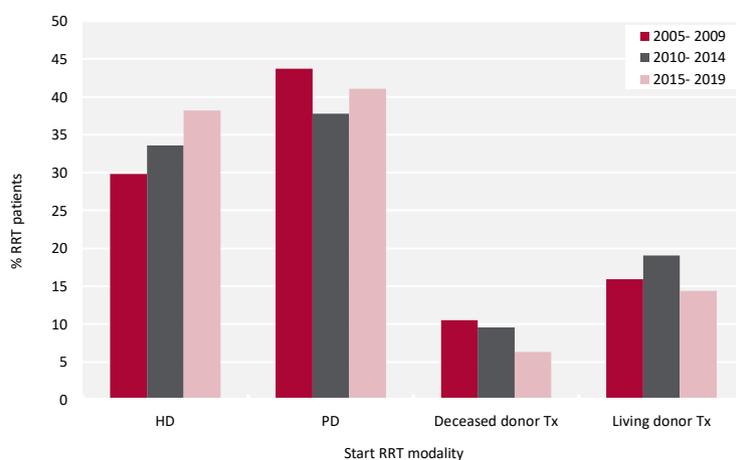


Figure 8.2 Start RRT modality for paediatric patients (<16 years old) incident to RRT by 5 year time period

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 8.9 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)

	N on RRT	N (%) with pre-emptive Tx
Total cohort analysed (2005-2019)	1,277	416 (32.6)
Time period		
2005-2009	422	151 (35.8)
2010-2014	419	153 (36.5)
2015-2019	436	112 (25.7)
Sex		
Male	812	287 (35.3)
Female	465	129 (27.7)
Ethnicity		
White	887	329 (37.1)
Asian	235	49 (20.9)
Black	61	9 (14.8)
Other	68	19 (28.0)
Age at start of RRT (yrs)		
3 mths-<2	146	6 (4.1)
2-<4	157	45 (28.7)
4-<8	248	104 (42)
8-<12	294	102 (34.7)
12-<16	432	159 (36.8)
PRD		
Tubulointerstitial disease	676	285 (42.2)
Glomerular disease	237	14 (5.9)
Familial/hereditary nephropathies	190	64 (33.7)
Miscellaneous renal disorders	98	28 (28.6)
Systemic diseases affecting the kidney	39	16 (41)

98 children were excluded because they were aged <3 months; 372 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 8.10 Age and sex breakdown of paediatric patients (<16 years old) prevalent to RRT on 31/12/2019

Age group (yrs)	All patients		Male		Female		M/F ratio
	N	pmarp	N	pmarp	N	pmarp	
0-<2	15	10.2	6	7.9	9	12.5	0.6
2-<4	53	33.6	33	40.7	20	26.0	1.6
4-<8	160	48.6	113	67.0	47	29.3	2.3
8-<12	258	78.3	159	94.2	99	61.6	1.5
12-<16	346	113.2	207	132.1	139	93.3	1.4
<16 yrs	832	65.5	518	79.6	314	50.7	1.6

pmarp – per million age-related population

Table 8.11 Age and ethnicity breakdown of paediatric patients (<16 years old) prevalent to RRT on 31/12/2019

Age group (yrs)	N			
	White	Asian	Black	Other
0-<4	49	5	4	6
4-<8	105	30	10	13
8-<12	178	48	9	17
12-<16	238	66	18	17
<16 yrs	570	149	41	53

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 2019.

19 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 8.3 and 8.4, respectively. Table 8.12 breaks down current modality for prevalent patients by age group.

Table 8.12 RRT modality used by paediatric patients (<16 years old) prevalent to RRT on 31/12/2019 by age group

Age group (yrs)	Total N	HD		PD		Living donor Tx		Deceased donor Tx	
		N	%	N	%	N	%	N	%
0-<2	15	6	40.0	9	60.0	0	0.0	0	0.0
2-<4	53	15	28.3	20	37.7	13	24.5	5	9.4
4-<8	160	21	13.1	22	13.8	82	51.3	35	21.9
8-<12	258	17	6.6	15	5.8	147	57.0	79	30.6
12-<16	345	31	9.0	23	6.7	162	47.0	129	37.4
<16 yrs	831	90	10.8	89	10.7	404	48.6	248	29.8

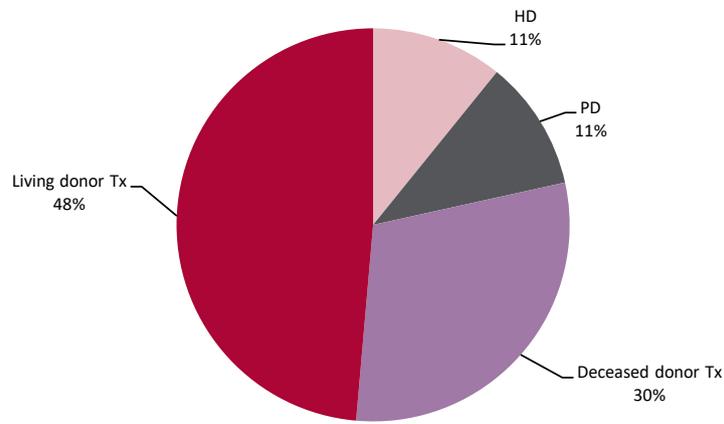


Figure 8.3 RRT modality used by paediatric patients (<16 years old) prevalent to RRT on 31/12/2019

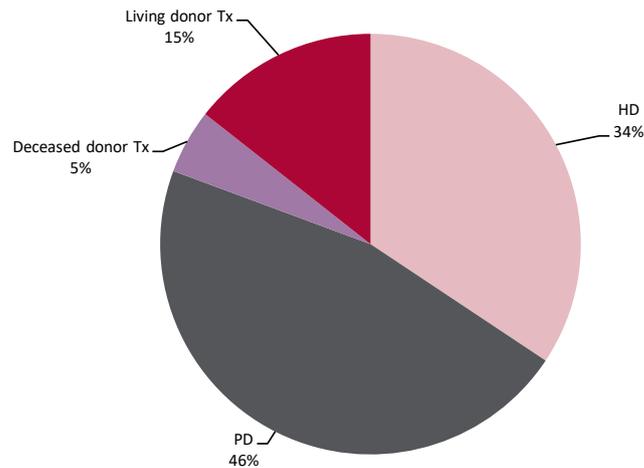


Figure 8.4 RRT modality used at the start of RRT by paediatric patients (<16 years old) prevalent to RRT on 31/12/2019

Causes of ESKD in prevalent paediatric RRT patients

PRDs were grouped into categories as shown in table 8.13.

Table 8.13 Primary renal diseases (PRDs) of paediatric patients (<16 years old) prevalent to RRT on 31/12/2019 by sex and ethnicity

PRD	N	%	N male	N female	% non-White
Tubulointerstitial disease	425	53.1	326	99	28.2
- CAKUT	415	51.8	320	95	27.6
- Non-CAKUT	10	1.2	6	4	40.0
Glomerular disease	155	19.4	83	72	34.0
Familial/hereditary nephropathies	105	13.1	38	67	38.8
Systemic diseases affecting the kidney	38	4.7	17	21	10.5
Miscellaneous renal disorders	78	9.7	42	36	25.6
Total (with data)	801	100.0	506	295	29.4
Missing	31	3.9	12	19	47.6

CAKUT – congenital anomalies of the kidneys and urinary tract

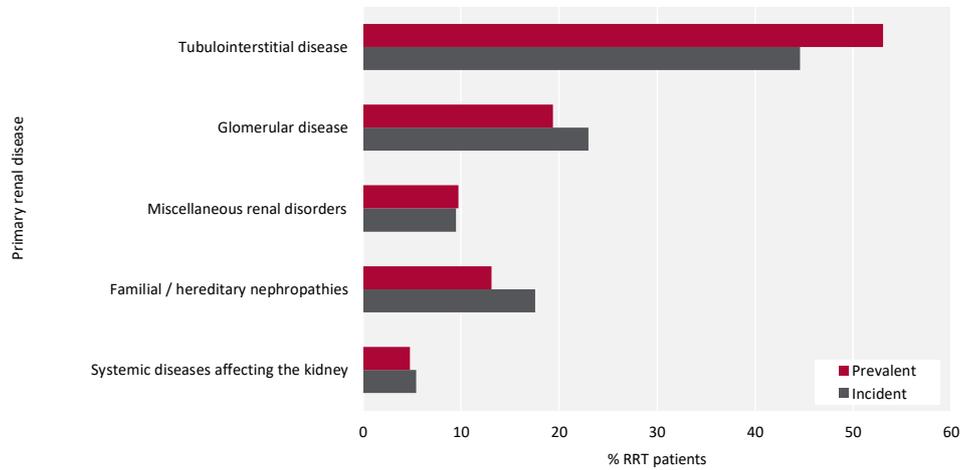


Figure 8.5 Comparison of primary renal diseases for paediatric patients (<16 years old) incident and prevalent to RRT in 2019 with no missing data

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

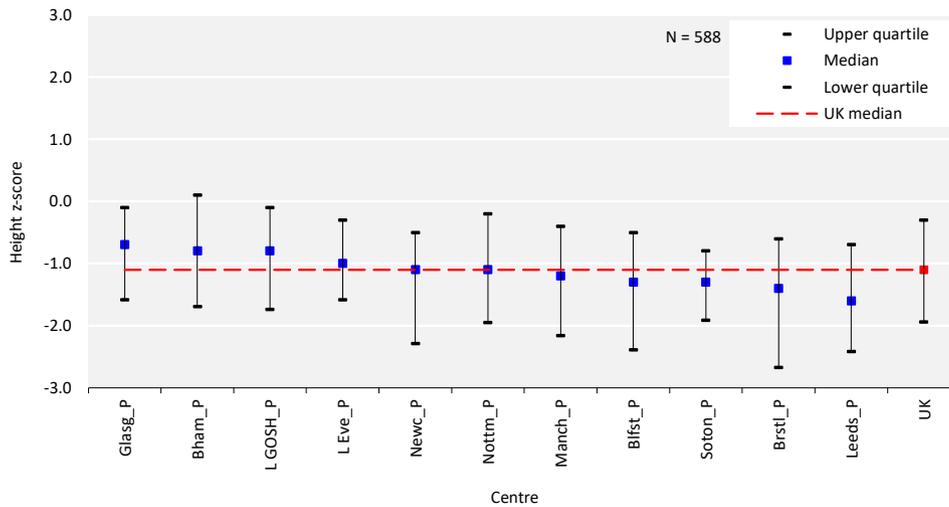


Figure 8.6 Median height z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2019 by centre

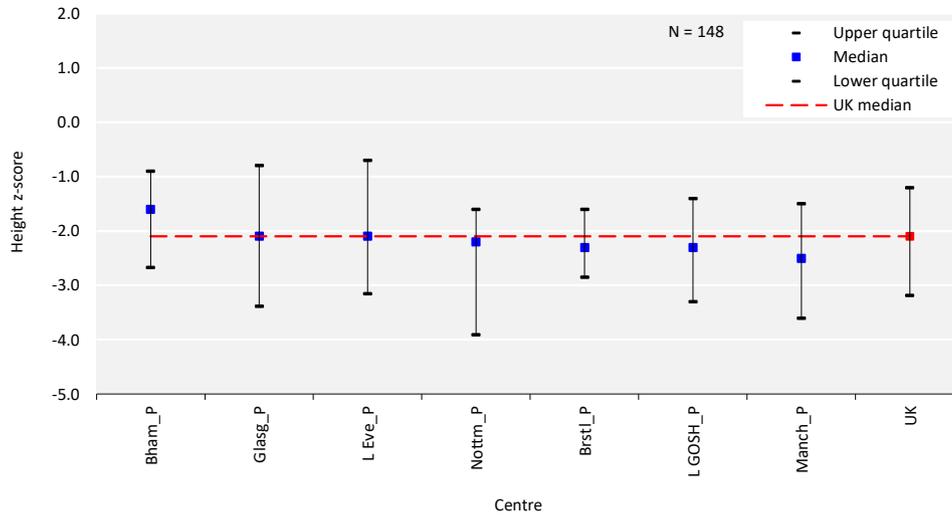


Figure 8.7 Median height z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2019 by centre

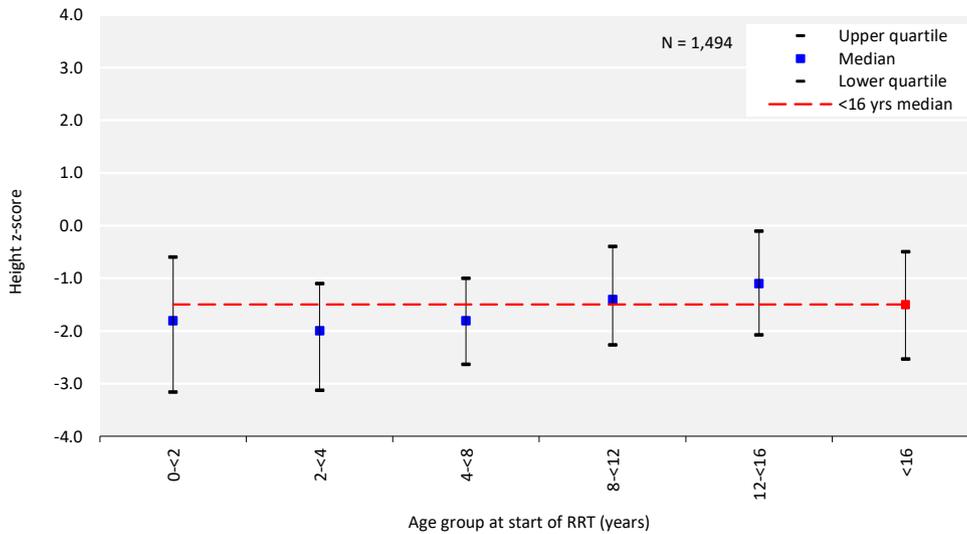


Figure 8.8 Median height z-scores at start of RRT for incident paediatric RRT patients (<16 years old) between 2005 and 2019 by age group at start of RRT

Weight of paediatric RRT patients

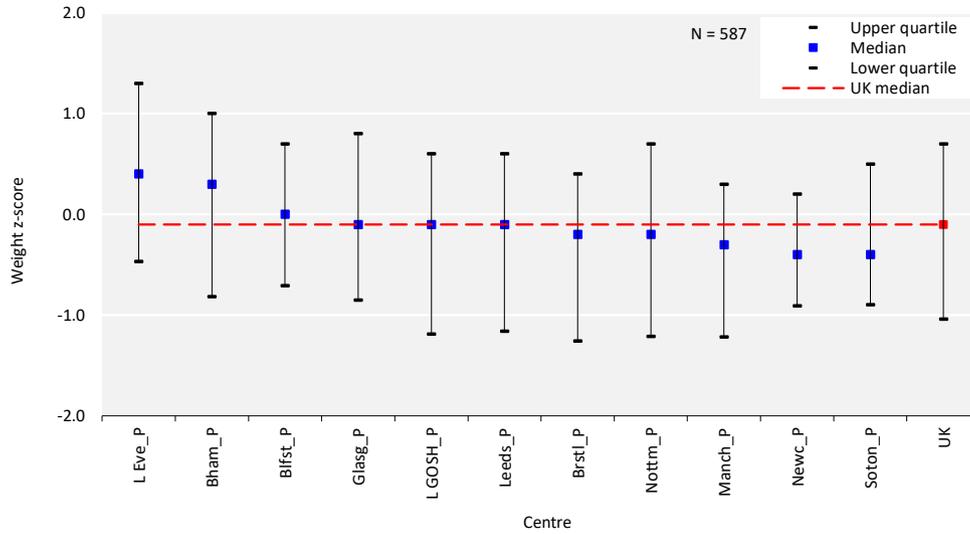


Figure 8.9 Median weight z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2019 by centre

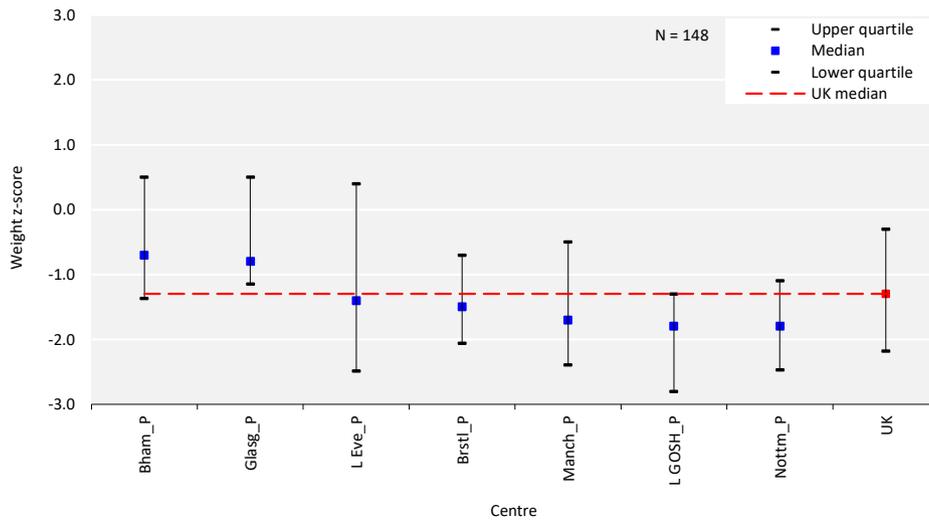


Figure 8.10 Median weight z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2019 by centre

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.

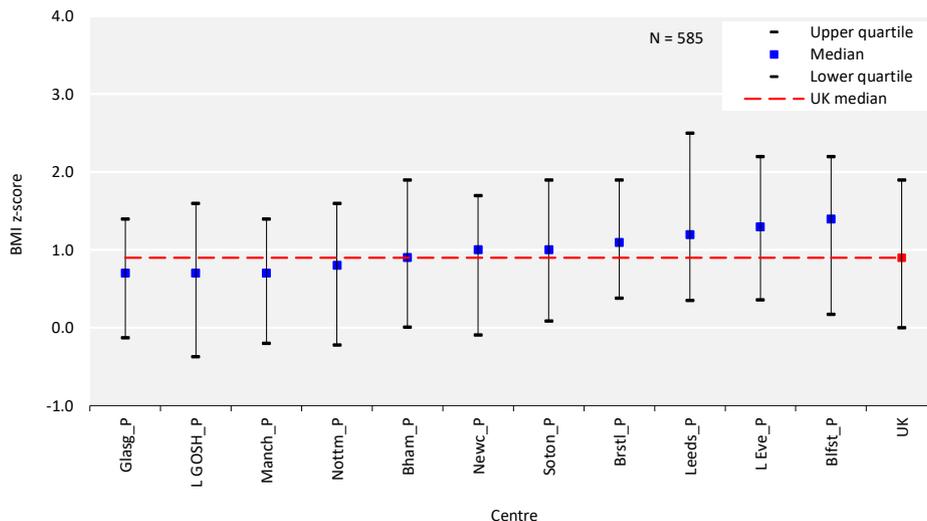


Figure 8.11 Median body mass index (BMI) z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2019 by centre

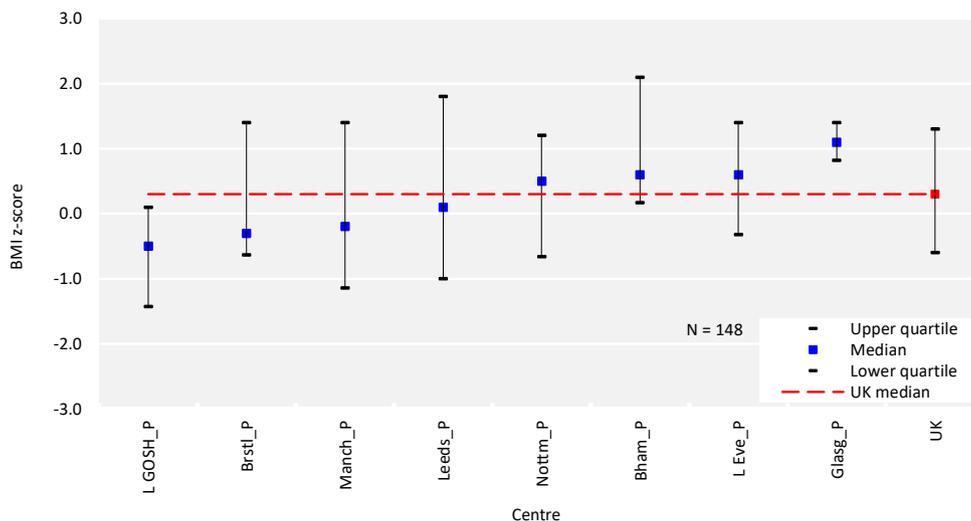


Figure 8.12 Median body mass index (BMI) z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2019 by centre

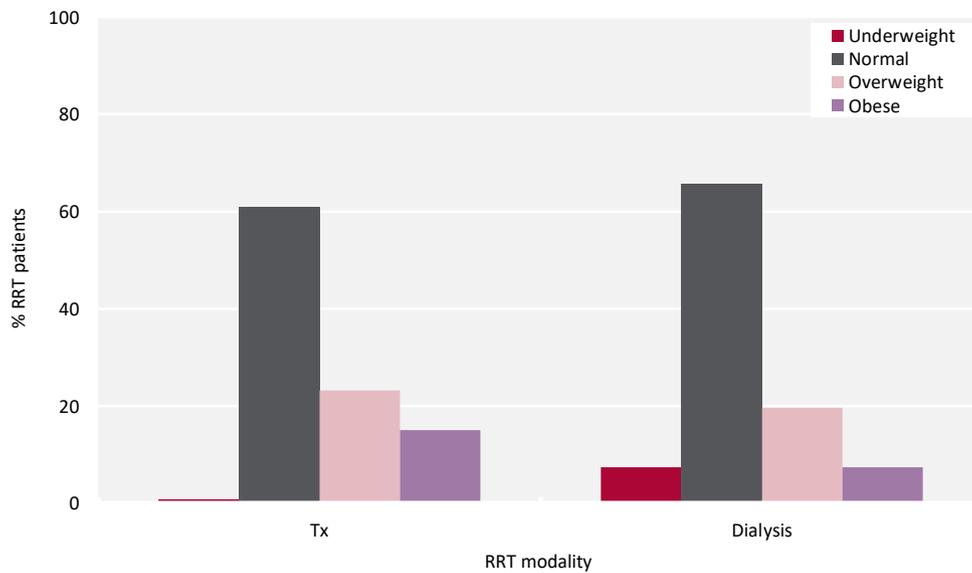


Figure 8.13 Body mass index categorisation of paediatric patients (<16 years old) prevalent to RRT on 31/12/2019 by RRT modality

Hypertension in paediatric RRT patients

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

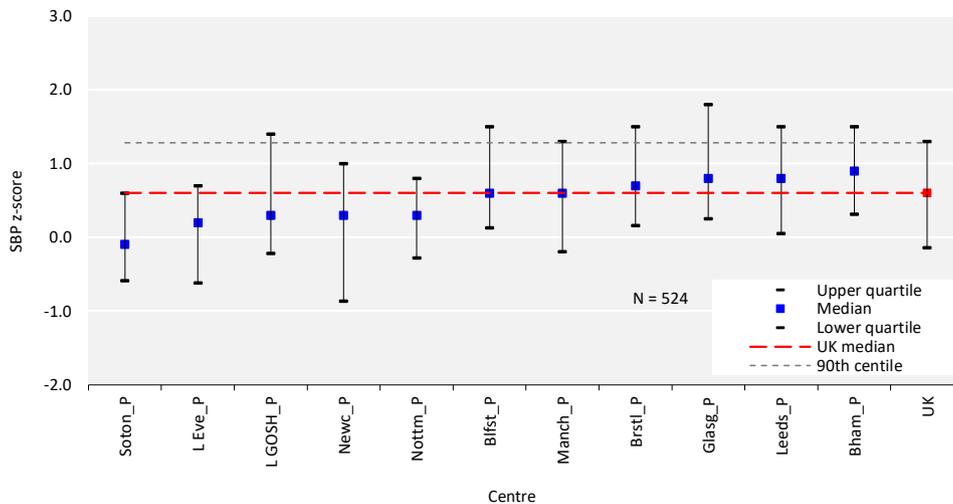


Figure 8.14 Median systolic blood pressure (SBP) z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2019 by centre

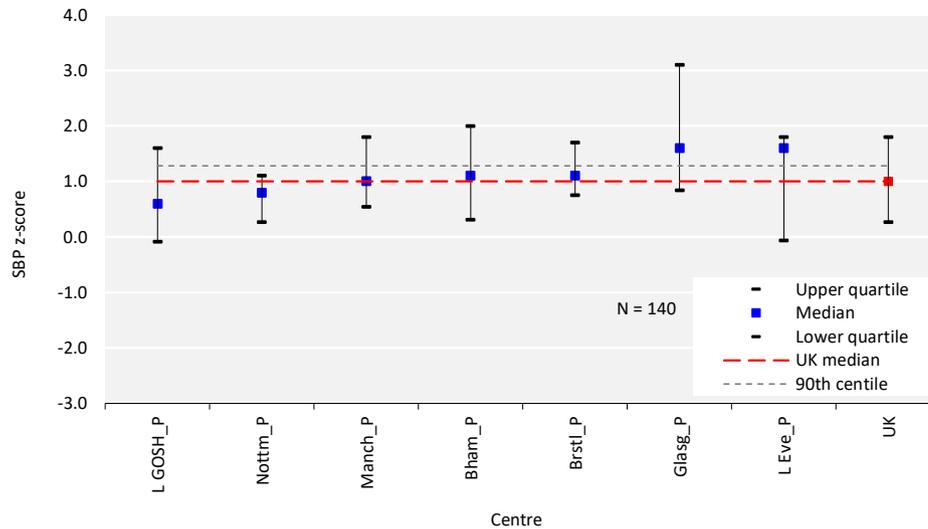


Figure 8.15 Median systolic blood pressure (SBP) z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2019 by centre

Table 8.14 Percentage of paediatric patients (<16 years old) prevalent to RRT on 31/12/2019 achieving the standards for blood pressures

Characteristic	SBP		DBP	
	N	% <90th percentile	N	% <90th percentile
Total	665	71.1	584	76.0
Age group (yrs)				
0-<5	82	64.6	58	70.7
5-<12	314	68.5	278	75.9
12-<16	269	76.2	248	77.4
Sex				
Male	415	70.6	369	74.0
Female	250	72.0	215	79.5
Ethnicity				
White	447	73.4	389	78.9
Asian	126	62.7	116	68.1
Black	37	70.3	33	75.8
Other	41	78.1	36	80.6
Modality				
HD	69	55.1	56	64.3
PD	71	62.0	50	64.0
Tx	524	74.4	477	78.6

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 402 of the 832 patients (48.3%) with data for all three risk factors.

Table 8.15 Frequency of number of cardiovascular risk factors in paediatric patients (<16 years old) prevalent to RRT on 31/12/2019

N cardiovascular risk factors	Hypertensive	Overweight/Obese	Hypercholesterolaemic	N	%	Total %
0	No	No	No	104	25.9	25.9
1	Yes	No	No	61	15.2	43.8
	No	Yes	No	67	16.7	
	No	No	Yes	48	11.9	
2	Yes	Yes	No	45	11.2	26.6
	Yes	No	Yes	31	7.7	
	No	Yes	Yes	31	7.7	
3	Yes	Yes	Yes	15	3.7	3.7
Total N	152	158	125	402		
Total %	37.8	39.3	31.1			100.0

Biochemistry parameters in prevalent paediatric RRT patients

The median values and the percentage with eGFR <30 mL/min/1.73m² for prevalent 2019 paediatric Tx patients are presented in table 8.16.

Table 8.16 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 31/12/2019 by centre

Centre	N with Tx	Median eGFR (mL/min/1.73m ²)	% eGFR <30 mL/ min/1.73m ²	% data completeness
Bham_P	67	55	9.2	97.0
Blfst_P	25	75	8.3	96.0
Brstl_P	41	64	2.6	92.7
Cardf_P ¹	26			15.4
Glasg_P	43	87	0.0	97.7
L Eve_P	68	56	4.4	100.0
L GOSH_P	125			68.0
Leeds_P	45	72	2.2	100.0
Livpl_P ¹	27			0.0
Manch_P	69	67	5.9	98.6
Newc_P	27	79	0.0	88.9
Nottm_P	65	50	8.5	90.8
Soton_P	24	68	4.2	100.0
UK	652	61	6.6	83.7

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

¹Although completeness of creatinine data was good, height data completeness was very low – heights are needed to calculate eGFRs from creatinine.

Table 8.17 Attainment of targets for haemoglobin, calcium, phosphate, parathyroid hormone and bicarbonate in paediatric patients (<16 years old) (a) prevalent to dialysis on 31/12/2019 by centre and (b) prevalent to Tx on 31/12/2019 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	31	3.3	60.0	0.0	73.3	10.0	63.3		0.0	80.0
Blfst_P	4									
Brstl_P	15	28.6	57.1	0.0	78.6	21.4	50.0	42.9	7.1	71.4
Cardf_P	6									
Glasg_P	12	8.3	50.0	8.3	83.3	41.7	41.7	16.7	0.0	75.0
L Eve_P	11	18.2	63.6	0.0	90.9	0.0	45.5	36.4	9.1	90.9
L GOSH_P	30	20.7	34.5			0.0	58.6	62.1		
Leeds_P	10	50.0	40.0	0.0	77.8	10.0	50.0	30.0	0.0	70.0
Livpl_P	10	12.5	62.5	0.0	50.0	25.0	37.5	50.0	0.0	50.0
Manch_P	20	20.0	50.0	10.0	55.0	20.0	40.0	44.4	5.0	75.0
Newc_P	10	30.0	60.0	0.0	70.0	30.0	30.0	60.0	0.0	90.0
Nottm_P	16	31.3	37.5	0.0	81.3	6.3	25.0	25.0	0.0	81.3
Soton_P	5									
UK	180	20.1	49.4	4.4	70.2	13.8	47.1	44.4	3.1	75.9
TX PATIENTS WITH EGFR <30 ML/MIN/1.73 M²										
UK	36	41.7	58.3	4.0	84.0	11.1	69.4	54.2	47.2	52.8

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 8.18 Median estimated glomerular filtration rate (eGFR) in paediatric patients (<16 years old) prevalent to Tx on 31/12/2019 by time since transplantation and age group

Time since transplantation	Age group (yrs)					
	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	12	92	20	67	22	66
1 yr	16	74	35	72	23	59
3 yrs	12	83	73	68	46	65
5 yrs	0	0	98	61	55	55
≥7 yrs	0	0	48	56	86	54
Total (IQR)	40	87 (64-110)	274	64 (47-83)	232	56 (44-73)

IQR – interquartile range

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

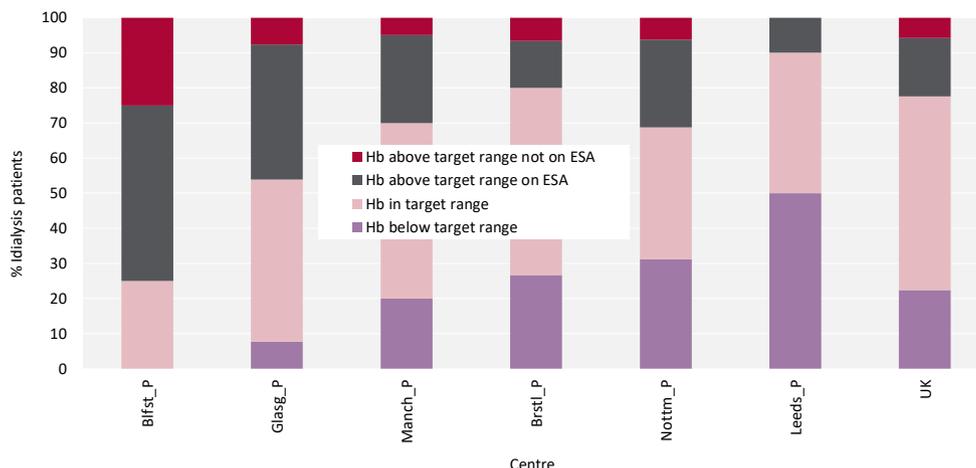


Figure 8.16 Proportion of paediatric patients (<16 years old) prevalent to dialysis on 31/12/2019 with haemoglobin (Hb) below, within and above target by centre; for those above target the proportion on erythropoiesis stimulating agent (ESA) therapy is shown

Transfer to adult renal services for prevalent paediatric RRT patients

Seventy-five paediatric patients transitioned to adult renal centres in 2019. The median age of patients at transfer was 17.8 years with an IQR of 17.4–18.2 years. Overall, the demographics of this population reflected those of the prevalent paediatric RRT population.

Survival in paediatric RRT patients

Of patients aged <16 years, 1,616 started RRT between 2005 and 2018 at paediatric renal centres and were included in survival analyses, to allow at least one year follow-up. At the end of 2019, 90 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 3.8 years (range three days to 14.7 years).

Table 8.19 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 (%)	93.8	98.2	98.6	99.4	99.2
95% CI	90.4-96.1	94.6-99.4	96.4-99.5	97.8-99.9	97.5-99.7
Survival at 2 years (%)	92.4	96.3	95.3	98.5	97.6
95% CI	88.6-94.9	92-98.3	92.1-97.3	96.5-99.4	95-98.9
Survival at 3 years (%)	90.0	94.9	94.6	97.9	97.6
95% CI	85.8-93	90.1-97.4	91.1-96.7	95.6-99	95-98.9
Survival at 4 years (%)	87.9	94.2	94.6	97.2	
95% CI	83.3-91.2	89-96.9	91.1-96.7	94.7-98.5	
Survival at 5 years (%)	86.9	93.3	93.5	96.7	
95% CI	82.2-90.5	87.8-96.4	89.8-96	93.9-98.2	

CI – confidence interval

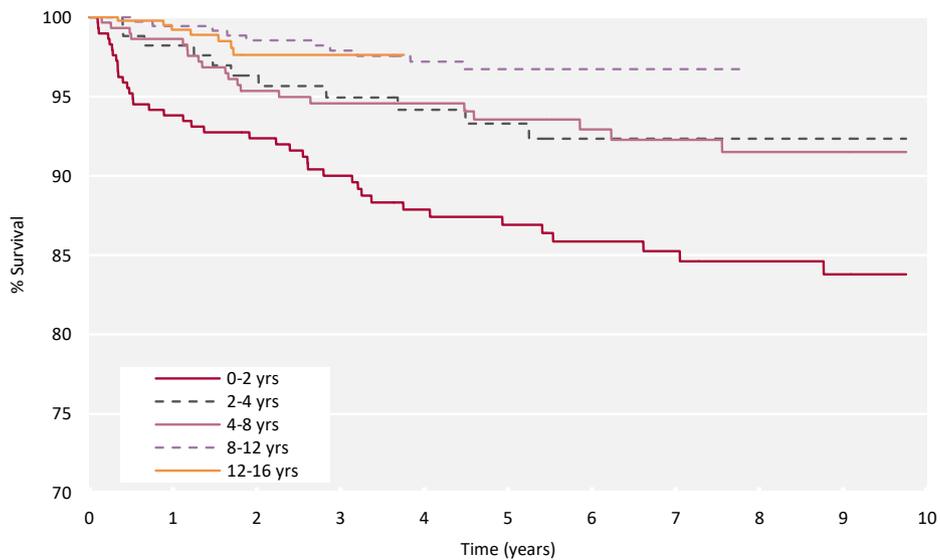


Figure 8.17 Unadjusted Kaplan-Meier survival (from day 90) of incident paediatric RRT patients (<16 years old) between 2005 and 2018 by age group at start of RRT

The 8–12 yrs and 12–16 yrs lines stop before 10 years, because the analysis was censored at age 16 years. The UKRR is combining the paediatric and adult databases and so in future will be able to report survival extended into adulthood.

Analyses – young people

RRT incidence and prevalence in young people

Table 8.20 reports the numbers of young people who started RRT in 2019 (incidence) as well as those on RRT as of 31/12/2019 (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 8.20 Demographics of young people (16–<18 years) incident to RRT in 2019 and/or prevalent to RRT on 31/12/2019, by care setting

Characteristic	Incident			Prevalent		
	Paediatric centres	Adult centres	All	Paediatric centres	Adult centres	All
N	21	10	31	190	29	219
pmarp			21.7			153.6
Median age (yrs)	16.7	17.5	17.0	16.9	17.7	17.0
% male	57.1	60.0	58.1	61.6	72.4	63.0
Ethnicity¹ (%)						
White	52.9	77.8	61.5	65.2	65.4	65.2
Asian	23.5	11.1	19.2	21.0	11.5	19.8
Black	11.8	11.1	11.5	9.4	15.4	10.1
Other	11.8	0.0	7.7	4.4	7.7	4.8
Missing	19.0	10.0	16.1	4.7	10.3	5.5
PRD¹ (%)						
Tubulointerstitial disease	35.3	33.3	34.6	50.6	44.0	49.8
Glomerular disease	29.4	44.4	34.6	18.9	16.0	18.5
Familial/hereditary nephropathies	23.5	11.1	19.2	17.8	24.0	18.5
Systemic diseases affecting the kidney	0.0	0.0	0.0	1.7	4.0	2.0
Diabetes	0.0	0.0	0.0	0.0	4.0	0.5
Miscellaneous renal disorders	11.8	11.1	11.5	11.1	8.0	10.7
Missing	19.0	10.0	16.1	5.3	13.8	6.4
Modality (%)						
HD	42.9	60.0	48.4	12.1	31.0	14.6
PD	38.1	30.0	35.5	6.8	10.3	7.3
Tx	19.1	10.0	16.1	81.1	58.6	78.1

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 8.21 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 8.21 Number of centres that submitted data for young people (16–<18 years) incident to RRT in 2019 and/or prevalent to RRT on 31/12/2019, by care setting

Setting	Incident	Prevalent
Paediatric centres	10 out of 13	13 out of 13
Adult centres	10 out of 70	18 out of 70

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 31/12/2019 are presented by care setting (adult or paediatric centre).

Table 8.22 Measures of graft function in young people (16–<18 years) prevalent to Tx on 31/12/2019, by care setting

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	154	16.9	141	107	67	2.1	94.1
Adult centres	17	17.8	16	122	60	6.3	91.6

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

Table 8.23 reports the median eGFR for all young people prevalent to Tx on 31/12/2019 by time since transplantation. Small numbers preclude further analysis by care setting (adult or paediatric centre).

Table 8.23 Estimated glomerular filtration rate (eGFR) in young people (16–<18 years) prevalent to Tx on 31/12/2019 by time since transplantation

Time since transplantation	N	Median FAS-eGFR (mL/min/1.73m ²)
3 months	12	55
1 year	25	70
3 years	33	65
5 years	30	71
≥7 years	57	68
Total (IQR)	157	67 (52-83)

FAS – Full Age Spectrum; IQR – interquartile range

Biochemical and blood pressure measures in young people

Table 8.24 shows attainment of biochemical and blood pressure measures for young people prevalent to dialysis and transplant on 31/12/2019 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 8.24 Attainment of biochemical and blood pressure measures in young people (16–<18 years) prevalent to RRT on 31/12/2019, by modality and care setting

Characteristic	Dialysis			Tx		
	Paediatric centres	Adult centres	All	Paediatric centres	Adult centres	All
N	36	12	48	154	17	171
Median (IQR) Hb (g/L)	118 (103-126)	117 (104-126)	117 (103-126)	122 (112-135)	122 (116-149)	122 (112-135)
% Hb <100g/L	16.7	9.1	14.9	11.3	0.0	10.2
Median (IQR) Ca (mmol/L)	2.4 (2.3-2.6)	2.4 (2.3-2.5)	2.4 (2.3-2.5)	2.4 (2.3-2.5)	2.3 (2.3-2.5)	2.4 (2.3-2.5)
% Ca in range	60.0	88.9	65.9	87.1	93.8	87.7
Median (IQR) Phos (mmol/L)	1.7 (1.2-2.0)	1.7 (1.3-2.3)	1.7 (1.3-2.1)	1.2 (1.0-1.3)	1.1 (1.0-1.4)	1.1 (1.0-1.3)
% phos in range	44.4	54.6	46.8	71.3	37.5	68.1
Median (IQR) bicarb (mmol/L)	25 (23-29)	24 (23-27)	25 (23-29)	24 (22-26)	24 (22-26)	24 (22-26)
% bicarb in range	54.3	66.7	56.8	72.1	86.7	73.5
Median (IQR) SBP (mmHg)	118 (113-128)	126 (117-139)	121 (113-130)	117 (108-122)	126 (118-135)	117 (108-125)
Median (IQR) DBP (mmHg)	76 (70-80)	80 (76-82)	77 (70-82)	71 (61-78)	74 (69-83)	71 (62-79)
% 'normal' BP range (<130/80 mmHg)	55.2	22.2	47.4	73.7	54.6	72.1
% high BP (≥140/90 mmHg)	10.3	22.2	13.2	9.3	18.2	10.1

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