

Chapter 8

Children and young people on kidney replacement therapy (KRT) for end-stage kidney disease (ESKD) in the UK in 2020

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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 kidney replacement therapy (KRT) in the UK for at least 90 days in 2020 (figure 8.1). 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 recovered within the first 90 days of KRT were excluded from the analyses.

There are 13 paediatric kidney 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.

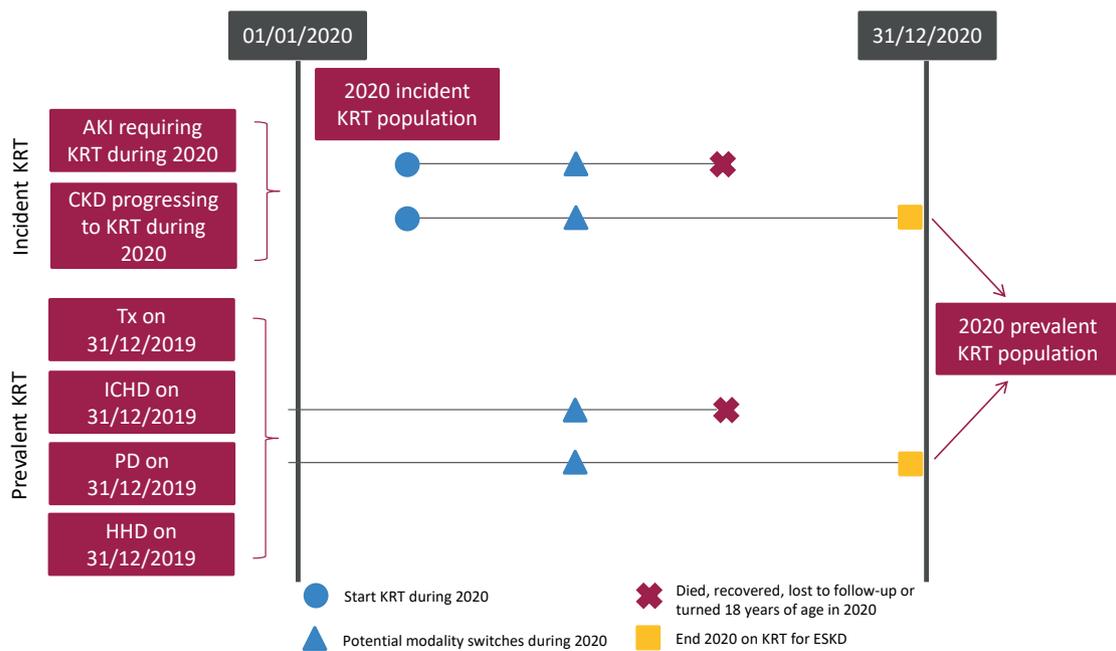


Figure 8.1 Pathways children and young people could follow to be included in the UK 2020 incident and/or prevalent KRT populations

Note that patients who recovered kidney function before 90 days on dialysis are not included in this chapter.

CKD – chronic kidney disease

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

- **Incident population:** patients who started KRT during 2020 and remained on KRT for at least 90 days.
- **Prevalent population:** patients who were on KRT at the end of 2020 and still under the care of a paediatric kidney centre.
- **Five-year populations:** patients who started KRT and remained on KRT for at least 90 days in the periods 2006–2010, 2011–2015 and 2016–2020.

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

- **Incident population:** patients who started KRT during 2020 in either an adult or paediatric centre and remained on KRT for at least 90 days.
- **Prevalent population:** patients who were on KRT at the end of 2020 in either an adult or paediatric centre.

This chapter addresses the following key aspects of the care of children incident to or on KRT 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 KRT:** 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 KRT:** 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 2020 incident and prevalent KRT populations, including the number on KRT 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 KRT and, where data permit, their attainment by UK paediatric kidney centres in 2020 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 KRT incidence and prevalence that are reported in this chapter

Audit guideline	Audit criteria	Related analysis/analyses
The UK Kidney Association: Treatment of adults and children with kidney 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. Blood pressure in Tx patients to be maintained at <90 th percentile for age, sex and height	Tables 8.14–8.15, figures 8.14–8.15
	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 (ukkidney.org/audit-research/data-portals). 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 kidney services within 90 days of starting KRT for ESKD is defined as a 'late presentation'. In this report 'late presentation' is used interchangeably with 'late referral'.

Key findings

Children

- 106 patients aged <16 years started KRT for ESKD in the UK in 2020 compared to 101 patients in 2019.
- KRT incidence in patients aged <16 years was 8.3 pmarp compared to 8.0 pmarp in 2019.
- 812 patients aged <16 years were receiving KRT at UK paediatric kidney centres on 31/12/2020, a decrease from 832 patients in 2019.
- KRT prevalence in patients aged <16 years was 63.8 pmarp. 76.2% had a functioning Tx (48.9% living donor and 27.3% deceased donor), 11.3% were receiving HD and 12.4% were receiving PD.
- Tubulointerstitial disease accounted for >50% of all primary renal diseases (PRDs) in prevalent paediatric patients, with a high male:female ratio (3:1).
- Between 2006 and 2020, 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, 85.5% of paediatric patients had a functioning kidney Tx.
- The median height z-score for children on dialysis was -1.7 compared with -1.0 for those with a functioning Tx.
- The median weight z-score for children on dialysis was -1.0 compared with 0.1 for those with a functioning Tx.
- The overall median eGFR of the 619 children with a kidney transplant on 31/12/2020 was 60 mL/min/1.73m² and 9.9% had an eGFR of <30 mL/min/1.73m².
- Of those with complete data, 76.8% of the prevalent paediatric KRT population had 1 or more risk factors for cardiovascular disease; 6.3% had 3 risk factors.
- 66.7% and 79.3% of prevalent HD patients achieved systolic blood pressure (SBP) and diastolic blood pressure (DBP) values <90th percentile, respectively.
- 63.8% and 66.0% of prevalent PD patients achieved SBP and DBP values <90th percentile, respectively.
- 72.3% and 76.5% of prevalent Tx patients achieved SBP and DBP values <90th percentile, respectively.

Young people

- 26 patients aged 16 to <18 years started KRT for ESKD in the UK in 2020.
- KRT incidence in young people was 17.8 pmarp.
- 208 patients aged 16 to <18 years were receiving KRT on 31/12/2020, of whom the majority (88.5%) were managed in paediatric kidney centres.
- KRT prevalence in patients aged 16 to <18 years was 142.1 pmarp.
- Tubulointerstitial disease accounted for 46.6% of all PRDs in prevalent young people, followed by familial/hereditary nephropathies (17.1%) and glomerular disease (18.7%).
- The overall median eGFR of young people with a kidney transplant on 31/12/2020 was 68 mL/min/1.73m² and 3.1% had an eGFR of <30 mL/min/1.73m².
- The proportion of young people prevalent to KRT on 31/12/2020 with a blood pressure within the 'normal' range (<130/80 mmHg) was 41.9% of dialysis and 66.7% of transplanted patients.

Analyses – children

Data completeness for prevalent paediatric KRT patients

Data returns of key variables for Tx and dialysis patients <16 years old at the end of 2020 are shown in tables 8.2 and 8.3, respectively, with further detail available through the UKRRR data portal (ukkidney.org/audit-research/data-portals).

Table 8.2 Data completeness for paediatric patients (<16 years old) prevalent to Tx on 31/12/2020 by centre

Centre	N with Tx	Data completeness (%)											
		Height	Weight	BMI	SBP	DBP	Hb	Creat	Chol	Bicarb	PTH	Ca	Phos
Bham_P	65	98.5	98.5	98.5	96.9	96.9	98.5	100.0	92.3	100.0	50.8	100.0	100.0
Blfst_P	26	23.1	92.3	23.1	30.8	30.8	100.0	100.0	69.2	100.0	92.3	100.0	100.0
Brstl_P	35	0.0	94.3	0.0	94.3	71.4	100.0	97.1	25.7	100.0	74.3	100.0	97.1
Cardf_P	22	0.0	100.0	0.0	100.0	22.7	100.0	100.0	4.6	100.0	31.8	100.0	100.0
Glasg_P	45	100.0	100.0	100.0	100.0	100.0	80.0	80.0	73.3	80.0	80.0	80.0	80.0
L Eve_P	63	100.0	100.0	100.0	100.0	100.0	100.0	100.0	60.3	100.0	93.7	100.0	100.0
L GOSH_P	119	100.0	100.0	100.0	62.2	62.2	100.0	100.0	58.8	16.8	99.2	100.0	100.0
Leeds_P	45	100.0	100.0	100.0	100.0	93.3	100.0	100.0	13.3	100.0	97.8	100.0	100.0
Livpl_P	21	0.0	14.3	0.0	9.5	4.8	95.2	95.2	57.1	95.2	90.5	95.2	95.2
Manch_P	66	0.0	0.0	0.0	98.5	95.5	100.0	100.0	84.9	100.0	97.0	100.0	100.0
Newc_P	27	0.0	0.0	0.0	100.0	3.7	100.0	100.0	85.2	100.0	85.2	100.0	100.0
Nottm_P	58	96.6	98.3	96.6	94.8	94.8	98.3	98.3	44.8	89.7	84.5	98.3	98.3
Soton_P	27	100.0	100.0	100.0	88.9	85.2	96.3	96.3	51.9	96.3	96.3	96.3	96.3
UK	619	68.7	81.1	68.7	85.0	75.6	97.9	97.9	59.1	81.3	85.3	98.1	97.9

Bicarb – bicarbonate; BMI – body mass index; Ca – calcium; Chol – cholesterol; Creat – creatinine; DBP – diastolic blood pressure; Hb – haemoglobin; Phos – phosphate; PTH – parathyroid hormone; SBP – systolic blood pressure

Table 8.3 Data completeness for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2020 by centre

Centre	N on dialysis	Data completeness (%)										
		Height	Weight	BMI	SBP	DBP	Hb	Chol	Bicarb	PTH	Ca	Phos
Bham_P	34	85.3	88.2	85.3	88.2	76.5	91.2	85.3	97.1	88.2	97.1	97.1
Blfst_P	1	100.0	100.0	100.0	0.0	0.0	100.0	0.0	100.0	100.0	100.0	100.0
Brstl_P	12	0.0	100.0	0.0	100.0	58.3	100.0	83.3	100.0	100.0	100.0	100.0
Cardf_P	7	0.0	85.7	0.0	85.7	28.6	100.0	71.4	100.0	100.0	100.0	100.0
Glasg_P	12	100.0	100.0	100.0	100.0	100.0	100.0	66.7	100.0	100.0	91.7	91.7
L Eve_P	18	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
L GOSH_P	33	97.0	97.0	97.0	81.8	81.8	100.0	66.7	24.2	100.0	100.0	100.0
Leeds_P	12	83.3	100.0	83.3	100.0	75.0	100.0	66.7	100.0	100.0	100.0	100.0
Livpl_P	8	0.0	0.0	0.0	0.0	0.0	100.0	0.0	100.0	100.0	100.0	100.0
Manch_P	23	0.0	0.0	0.0	100.0	47.8	100.0	43.5	100.0	100.0	100.0	100.0
Newc_P	8	0.0	0.0	0.0	62.5	0.0	100.0	12.5	100.0	100.0	100.0	100.0
Nottm_P	21	95.2	95.2	95.2	95.2	61.9	100.0	33.3	100.0	100.0	100.0	100.0
Soton_P	4	100.0	100.0	100.0	75.0	50.0	100.0	50.0	100.0	100.0	100.0	100.0
UK	193	65.3	76.2	65.3	87.1	65.8	98.5	62.2	86.5	97.9	99.0	99.0

Bicarb – bicarbonate; BMI – body mass index; Ca – calcium; Chol – cholesterol; DBP – diastolic blood pressure; Hb – haemoglobin; Phos – phosphate; PTH – parathyroid hormone; SBP – systolic blood pressure

Changes to the incident paediatric KRT population

The number of incident patients on KRT <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 KRT in 2020 by age and sex

Age group (yrs)	All patients		Male		Female	
	N	pmarp	N	pmarp	N	pmarp
0-<2	17	11.9	9	12.2	8	11.5
2-<4	7	4.5	4	5.1	3	4.0
4-<8	15	4.6	9	5.4	6	3.8
8-<12	31	9.3	19	11.1	12	7.4
12-<16	36	11.4	23	14.2	13	8.5
<16 yrs	106	8.3	64	9.8	42	6.8

pmarp – per million age-related population

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

Age group (yrs)	2006-2010		2011-2015		2016-2020	
	N	pmarp	N	pmarp	N	pmarp
0-<2	96	12.4	107	13.3	99	13.1
2-<4	49	6.7	77	9.6	61	7.7
4-<8	95	6.9	109	7.0	95	5.7
8-<12	122	8.4	138	9.8	131	8.1
12-<16	214	14.0	174	12.0	183	12.3
<16 yrs	576	9.8	605	10.0	569	9.0

pmarp – per million age-related population

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

Ethnicity	2006-2010		2011-2015		2016-2020	
	N	%	N	%	N	%
White	428	75.0	422	69.9	338	65.4
Asian	95	16.6	119	19.7	108	20.9
Black	25	4.4	28	4.6	36	7.0
Other	23	4.0	35	5.8	35	6.8
<16 yrs	571	100.0	604	100.0	517	100.0

5 children in 2006–2010, 13 in 2011–2015 and 52 in 2016–2020 with no ethnicity recorded were excluded.

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

Centre	2006-2010		2011-2015		2016-2020	
	N	%	N	%	N	%
Bham_P	66	11.5	73	12.1	81	14.2
Blfst_P	24	4.2	12	2.0	12	2.1
Brstl_P	35	6.1	37	6.1	27	4.7
Cardf_P	16	2.8	20	3.3	19	3.3
Glasg_P	44	7.6	40	6.6	44	7.7
L Eve_P	51	8.9	52	8.6	39	6.9
L GOSH_P	19	3.3	34	5.6	24	4.2
Leeds_P	64	11.1	69	11.4	60	10.5
Livpl_P	115	20.0	99	16.4	103	18.1
Manch_P	46	8.0	81	13.4	57	10.0
Newc_P	25	4.3	19	3.1	29	5.1
Nottm_P	58	10.1	49	8.1	56	9.8
Soton_P	13	2.3	20	3.3	18	3.2
<16 yrs	576	100.0	605	100.0	569	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 KRT by primary renal disease (PRD) and 5 year time period

PRD	2006-2010		2011-2015		2016-2020	
	N	%	N	%	N	%
Tubulointerstitial disease	275	48.7	289	48.8	235	46.8
- CAKUT	263	46.5	277	46.8	227	45.2
- Non-CAKUT	12	2.1	12	2.0	8	1.6
Glomerular disease	77	13.6	86	14.5	94	18.7
Familial/hereditary nephropathies	112	19.8	114	19.3	76	15.1
Systemic diseases affecting the kidney	32	5.7	16	2.7	24	4.8
Miscellaneous kidney disorders	69	12.2	87	14.7	73	14.5

11 children in 2006–2010, 13 in 2011–2015 and 67 in 2016–2020 with no PRD recorded were excluded.

CAKUT – congenital anomalies of the kidneys and urinary tract

Start modality of incident paediatric KRT patients

Start modality used by patients <16 years old starting KRT between 2006 and 2020 was grouped by five year time periods.

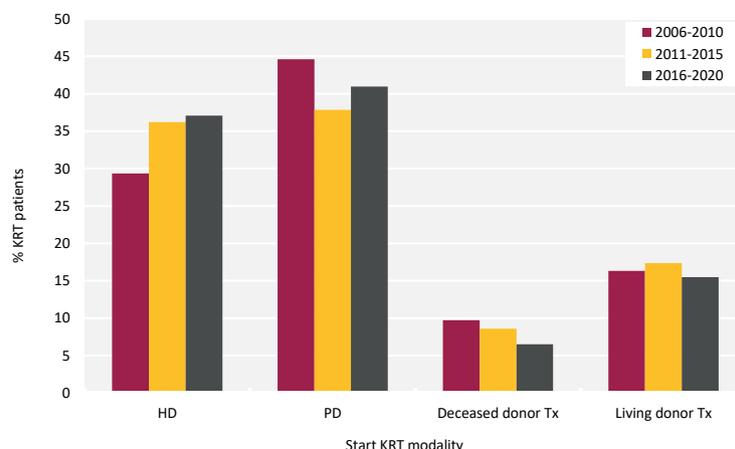


Figure 8.2 Start KRT modality for paediatric patients (<16 years old) incident to KRT by 5 year time period

Pre-emptive transplantation in incident paediatric KRT patients

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

Table 8.9 Pre-emptive transplantation in the incident paediatric KRT population aged 3 months to 16 years by 5 year time period, sex, ethnicity, age at start of KRT and primary renal disease (PRD)

	N on KRT	N (%) with pre-emptive Tx
Total cohort analysed (2006-2020)	1,300	426 (32.8)
Time period		
2006-2010	415	148 (35.7)
2011-2015	446	155 (34.8)
2016-2020	439	123 (28)
Sex		
Male	841	297 (35.3)
Female	459	129 (28.1)
Ethnicity		
White	881	335 (38)
Asian	244	52 (21.3)
Black	60	10 (16.7)
Other	68	15 (22.1)
Age at start of KRT (yrs)		
3 mths-<2	152	6 (3.9)
2-<4	161	49 (30.4)
4-<8	243	104 (42.8)
8-<12	304	101 (33.2)
12-<16	440	166 (37.7)
PRD		
Tubulointerstitial disease	650	286 (44)
Glomerular disease	181	6 (3.3)
Familial/hereditary nephropathies	223	61 (27.4)
Miscellaneous kidney disorders	130	35 (26.9)
Systemic diseases affecting the kidney	39	15 (38.5)

91 children were excluded because they were aged <3 months; 359 children were excluded because they presented late.

Demographics of prevalent paediatric KRT patients

The number of prevalent patients on KRT <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 KRT on 31/12/2020

Age group (yrs)	All patients		Male		Female		M/F ratio
	N	pmarp	N	pmarp	N	pmarp	
0-<2	15	10.5	7	9.5	8	11.5	0.8
2-<4	47	30.5	27	34.1	20	26.6	1.3
4-<8	151	46.3	102	61.0	49	30.9	2.0
8-<12	261	78.1	170	99.3	91	55.9	1.8
12-<16	338	107.1	198	122.4	140	91.1	1.3
<16 yrs	812	63.8	504	77.2	308	49.7	1.6

pmarp – per million age-related population

Table 8.11 Age and ethnicity breakdown of paediatric patients (<16 years old) prevalent to KRT on 31/12/2020

Age group (yrs)	N			
	White	Asian	Black	Other
0-<4	39	8	4	3
4-<8	97	26	7	16
8-<12	166	49	11	20
12-<16	213	69	19	18
<16 yrs	515	152	41	57

47 children with no ethnicity recorded were excluded

Treatment modality in prevalent paediatric KRT patients

The current and start KRT modalities for prevalent KRT 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 KRT modality used by paediatric patients (<16 years old) prevalent to KRT on 31/12/2020 by age group

Age group (yrs)	Total N	HD		PD		Living donor Tx		Deceased donor Tx	
		N	%	N	%	N	%	N	%
0-<2	15	2	13.3	13	86.7	0	0.0	0	0.0
2-<4	47	13	27.7	18	38.3	14	29.8	2	4.3
4-<8	151	16	10.6	15	9.9	87	57.6	33	21.9
8-<12	261	24	9.2	29	11.1	137	52.5	71	27.2
12-<16	338	37	10.9	26	7.7	159	47.0	116	34.3
<16 yrs	812	92	11.3	101	12.4	397	48.9	222	27.3

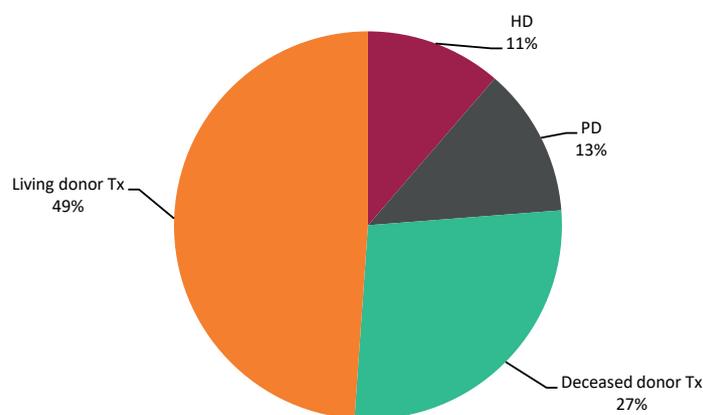


Figure 8.3 KRT modality used by paediatric patients (<16 years old) prevalent to KRT on 31/12/2020

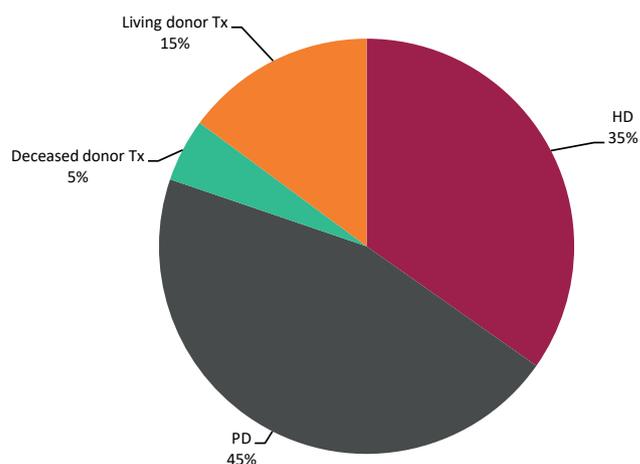


Figure 8.4 KRT modality used at the start of KRT by paediatric patients (<16 years old) prevalent to KRT on 31/12/2020

Causes of ESKD in prevalent paediatric KRT 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 KRT on 31/12/2020 by sex and ethnicity

PRD	N	%	N male	N female	% non-White
Tubulointerstitial disease	379	50.9	284	95	28.2
- CAKUT	370	49.7	278	92	28.8
- Non-CAKUT	9	1.2	6	3	44.4
Glomerular disease	112	15.0	59	53	35.5
Familial/hereditary nephropathies	124	16.6	60	64	40.3
Systemic diseases affecting the kidney	35	4.7	19	16	12.1
Miscellaneous kidney disorders	95	12.8	44	51	27.2
Total (with data)	745	100.0	466	279	30.9
Missing	67	8.3	38	29	63.4

CAKUT – congenital anomalies of the kidneys and urinary tract

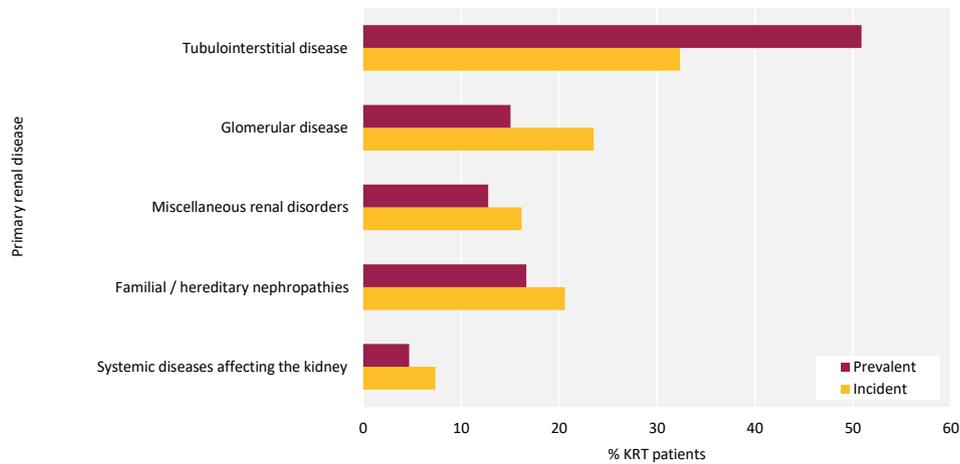


Figure 8.5 Comparison of primary renal diseases for paediatric patients (<16 years old) incident and prevalent to KRT in 2020 with no missing data

Growth of prevalent paediatric KRT patients

The height and weight of children receiving KRT 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 KRT patients

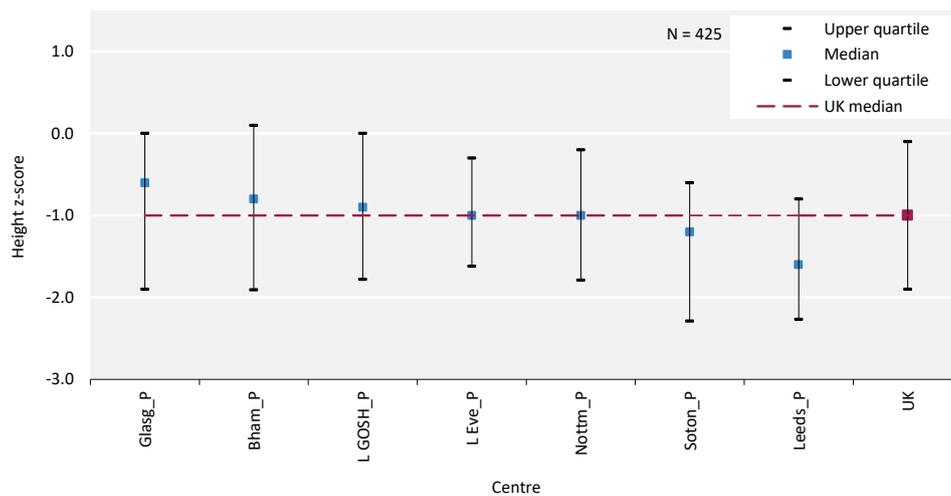


Figure 8.6 Median height z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2020 by centre

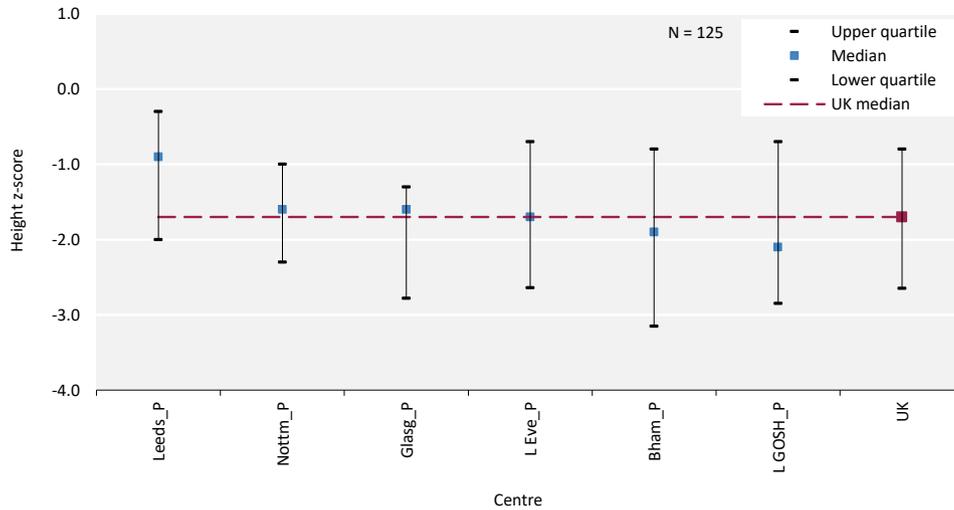


Figure 8.7 Median height z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2020 by centre

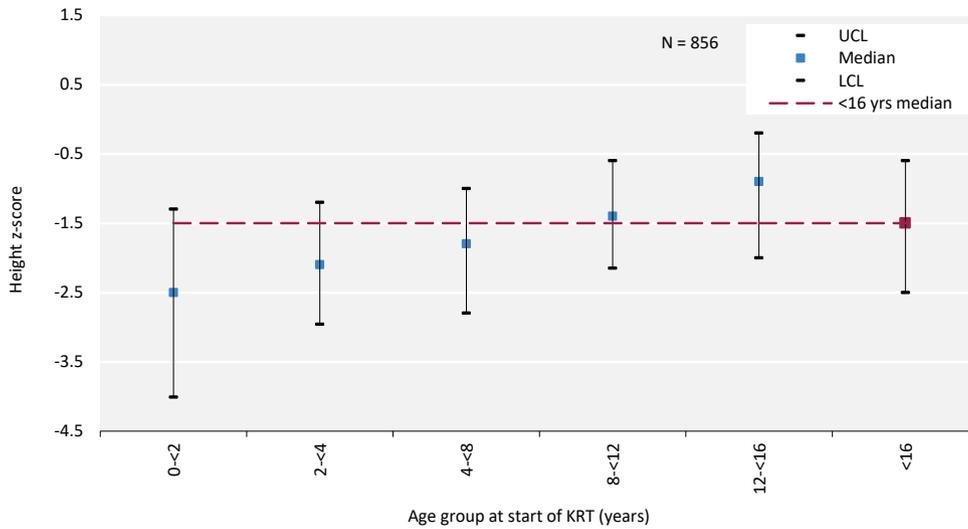


Figure 8.8 Median height z-scores at start of KRT for incident paediatric KRT patients (<16 years old) between 2006 and 2020 by age group at start of KRT

Weight of paediatric KRT patients

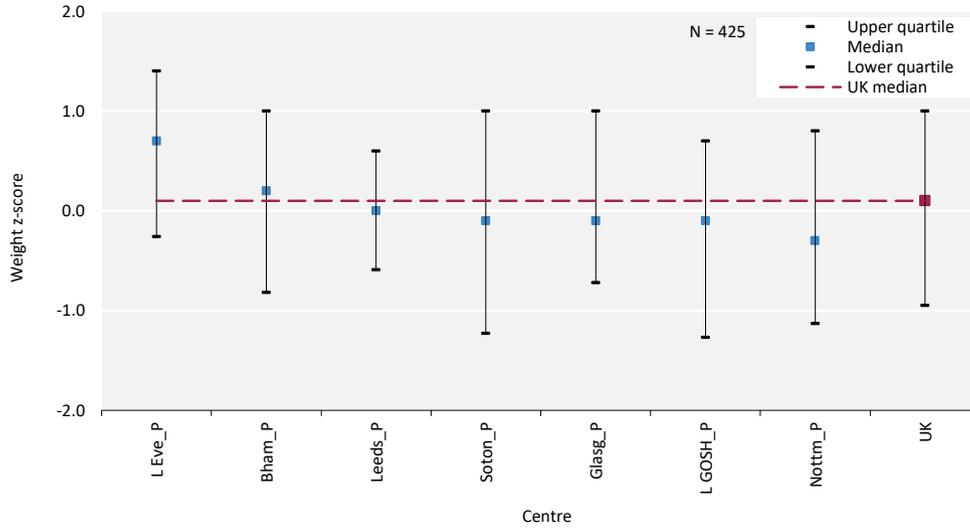


Figure 8.9 Median weight z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2020 by centre

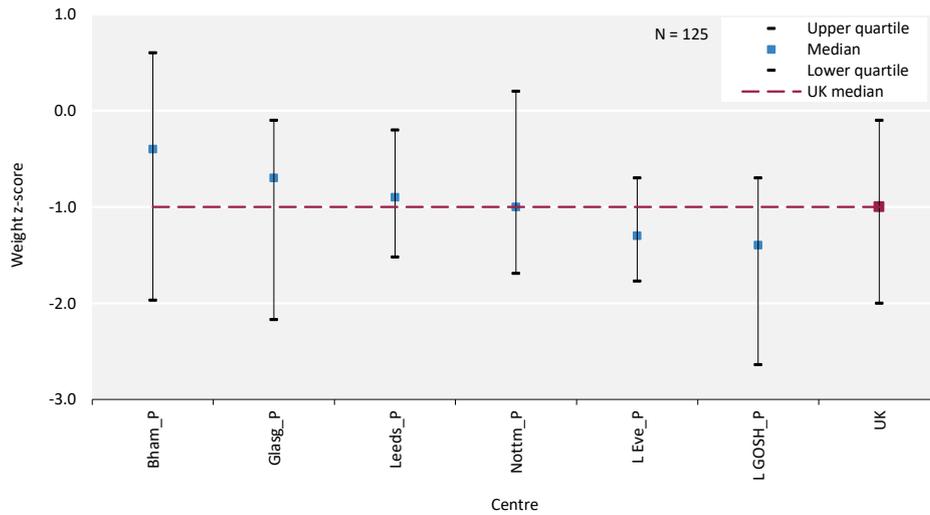


Figure 8.10 Median weight z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2020 by centre

Cardiovascular risk factor evaluation in prevalent paediatric KRT patients

Obesity in paediatric KRT 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 kidney 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.

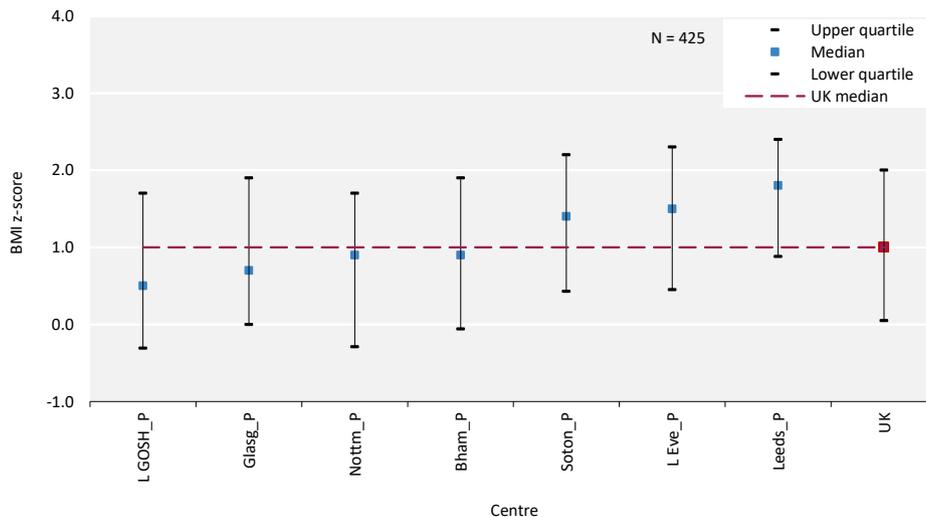


Figure 8.11 Median body mass index (BMI) z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2020 by centre

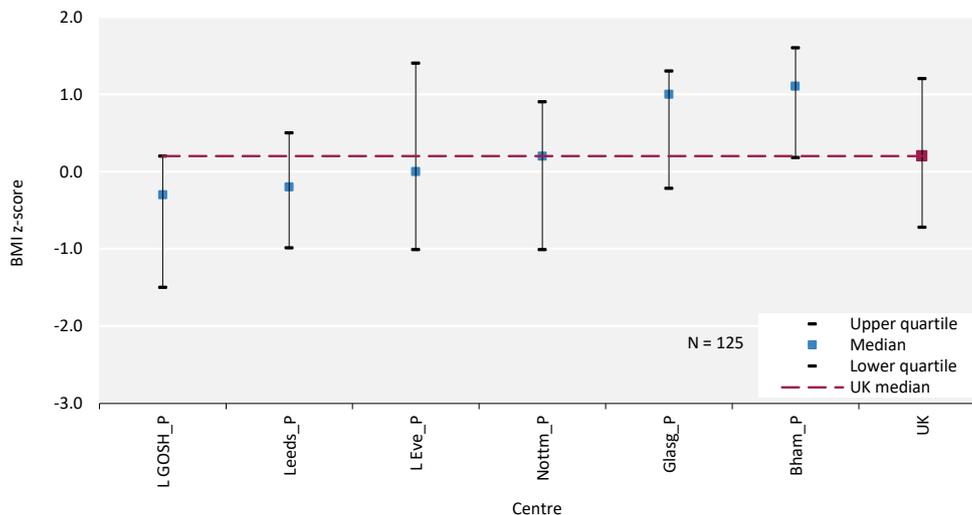


Figure 8.12 Median body mass index (BMI) z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2020 by centre

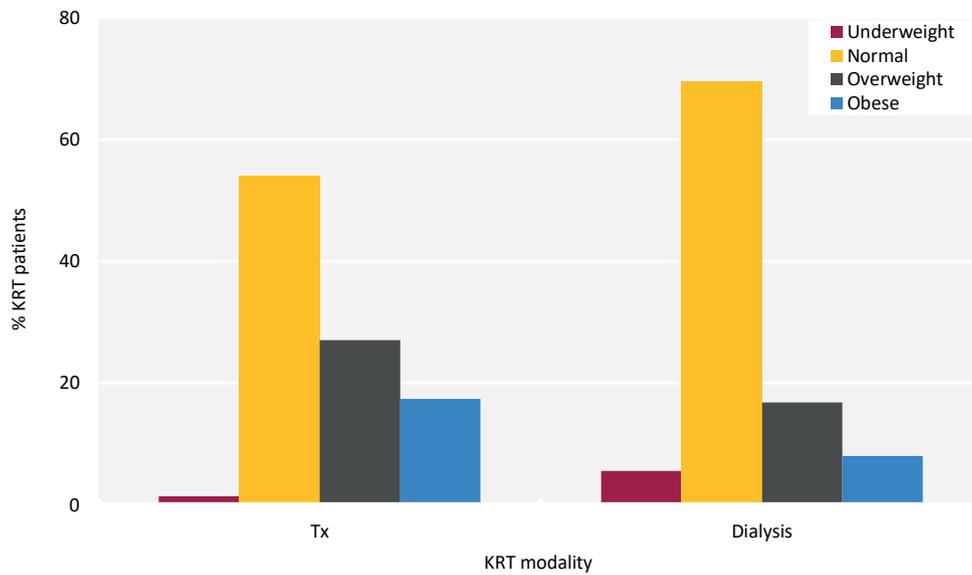


Figure 8.13 Body mass index categorisation of paediatric patients (<16 years old) prevalent to KRT on 31/12/2020 by KRT modality

Hypertension in paediatric KRT patients

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

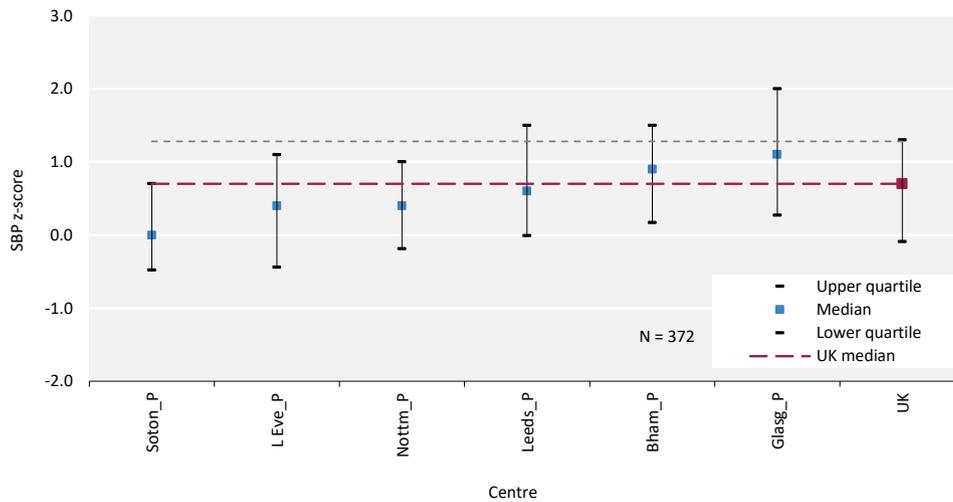


Figure 8.14 Median systolic blood pressure (SBP) z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2020 by centre

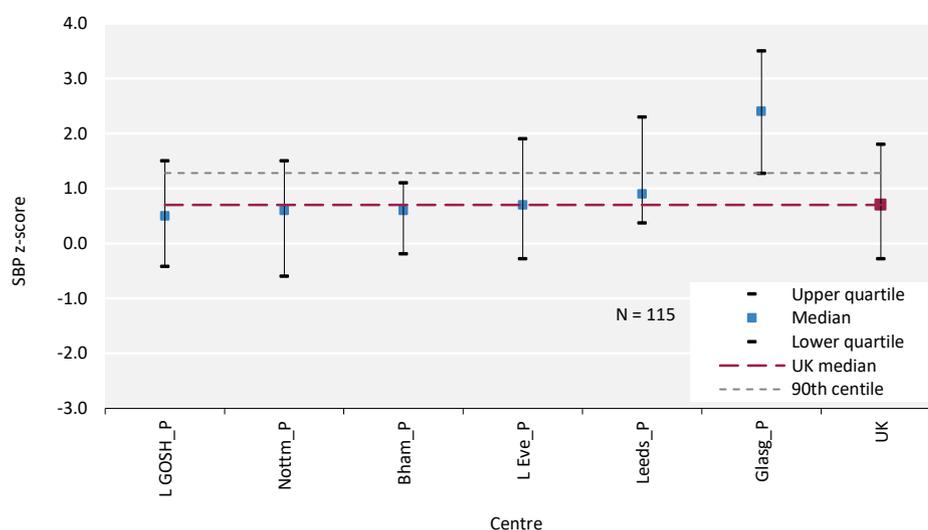


Figure 8.15 Median systolic blood pressure (SBP) z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2020 by centre

Table 8.14 Percentage of paediatric patients (<16 years old) prevalent to KRT on 31/12/2020 achieving the standards for blood pressures

Characteristic	SBP		DBP	
	N	% <90th percentile	N	% <90th percentile
Total	487	70.6	441	75.7
Age group (yrs)				
0-<5	49	67.4	39	64.1
5-<12	229	66.4	202	76.7
12-<16	209	76.1	200	77.0
Sex				
Male	299	70.6	273	76.9
Female	188	70.7	168	73.8
Ethnicity				
White	284	71.5	257	79.0
Asian	100	74.0	88	71.6
Black	33	72.7	32	71.9
Other	41	53.7	38	63.2
Modality				
HD	57	66.7	53	79.3
PD	58	63.8	47	66.0
Tx	372	72.3	341	76.5

DBP – diastolic blood pressure; SBP – systolic blood pressure

Cardiovascular risk factors in paediatric KRT patients

The analysis of the percentage of prevalent KRT patients with identified cardiovascular risk factors was restricted to the 315 of the 812 patients (38.8%) 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 KRT on 31/12/2020

N cardiovascular risk factors	Hypertensive	Overweight/Obese	Hypercholesterolaemic	N	%	Total %
0	No	No	No	73	23.2	23.2
1	Yes	No	No	42	13.3	44.1
	No	Yes	No	49	15.6	
	No	No	Yes	48	15.2	
2	Yes	Yes	No	28	8.9	26.3
	Yes	No	Yes	31	9.8	
	No	Yes	Yes	24	7.6	
3	Yes	Yes	Yes	20	6.3	6.3
				315		
Total N with the risk factor	121	121	123			
Total % with the risk factor	38.4	38.4	39.0			

Biochemistry parameters in prevalent paediatric KRT patients

The median values and the percentage with eGFR <30 mL/min/1.73m² for prevalent 2020 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 31/12/2020 by centre

Centre	N with Tx	Median eGFR (mL/min/1.73m ²)	% eGFR <30 mL/min/1.73m ²	% data completeness
Bham_P	65	54	10.9	98.5
Blfst_P	26			23.1
Brstl_P	35			0.0
Cardf_P	22			0.0
Glasg_P	45	79	8.3	80.0
L Eve_P	63	60	6.4	100.0
L GOSH_P	119	54	16.8	100.0
Leeds_P	45	78	2.2	100.0
Livpl_P	21			0.0
Manch_P	66			0.0
Newc_P	27			0.0
Nottm_P	58	55	7.1	96.6
Soton_P	27	66	7.7	96.3
UK	619	60	9.9	67.0

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

Although 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 31/12/2020 by centre and (b) prevalent to Tx on 31/12/2020 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	34	9.7	51.6	0.0	87.9	6.1	60.6	23.3	2.9	70.6
Blfst_P	1									
Brstl_P	12	0.0	66.7	0.0	91.7	0.0	100.0	50.0	33.3	58.3
Cardf_P	7									
Glasg_P	12	8.3	66.7	18.2	81.8	72.7	27.3	33.3	0.0	66.7
L Eve_P	18	27.8	38.9	0.0	77.8	0.0	55.6	38.9	5.6	88.9
L GOSH_P	33	24.2	33.3	0.0	90.9	18.2	48.5	42.4		
Leeds_P	12	16.7	50.0	0.0	75.0	16.7	58.3	41.7	8.3	66.7
Livpl_P	8									
Manch_P	23	43.5	30.4	4.4	69.6	26.1	47.8	39.1	4.4	78.3
Newc_P	8									
Nottm_P	21	28.6	38.1	0.0	66.7	4.8	19.1	38.1	4.8	81.0
Soton_P	4									
UK	193	20.0	43.7	2.1	81.2	13.6	53.4	37.6	18.7	66.3
TX PATIENTS WITH EGFR <30 ML/MIN/1.73 M²										
UK	41	22.0	78.1	2.4	85.4	4.9	65.9	65.8	58.5	39.0

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 31/12/2020 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	2		9		3	
0.25-<2 years	16	75	36	63	35	61
2-<4 years	4		54	72	32	63
4-<7 years			68	61	44	55
≥ 7 years			31	53	74	49
Total (IQR)	22	71 (59-83)	201	61 (47-79)	192	56 (41-67)

IQR – interquartile range

Transfer to adult kidney services for prevalent paediatric KRT patients

Seventy-six paediatric patients transitioned to adult kidney centres in 2020. The median age of patients at transfer was 18.0 years with an IQR of 17.6–18.4 years. Overall, the demographics of this population reflected those of the prevalent paediatric KRT population.

Survival in paediatric KRT patients

Of patients aged <16 years, 1,596 started KRT between 2006 and 2019 at paediatric kidney centres and were included in survival analyses, to allow at least one year follow-up. At the end of 2020, 86 deaths had been reported in these children before they reached 16 years of age and when still under the care of a paediatric kidney centre. Patients included in the analysis must have been alive on KRT for 90 days. The median follow-up time (beyond day 90) was 3.84 years (range 8 days to 14.7 years).

Table 8.19 Survival of incident paediatric KRT patients (<16 years old) at 1 year intervals of KRT by age at start of KRT

Survival	Age group (yrs)				
	0-<2	2-<4	4-<8	8-<12	12-<16
Survival at 1 year (%)	94.3	98.3	98.2	99.4	99.5
95% CI	90.8-96.5	94.8-99.5	95.8-99.3	97.8-99.9	97.9-99.9
Survival at 2 years (%)	92.4	97.7	95.6	98.5	97.9
95% CI	88.6-95	94-99.1	92.4-97.5	96.5-99.4	95.4-99.1
Survival at 3 years (%)	90.0	97.0	94.8	97.9	97.9
95% CI	85.7-93	93-98.8	91.4-96.9	95.6-99	95.4-99.1
Survival at 4 years (%)	87.4	96.3	94.8	96.8	
95% CI	82.7-90.9	91.8-98.3	91.4-96.9	94.2-98.3	
Survival at 5 years (%)	86.4	95.5	93.8	95.8	
95% CI	81.5-90.1	90.6-97.8	90.1-96.2	92.5-97.6	

CI – confidence interval

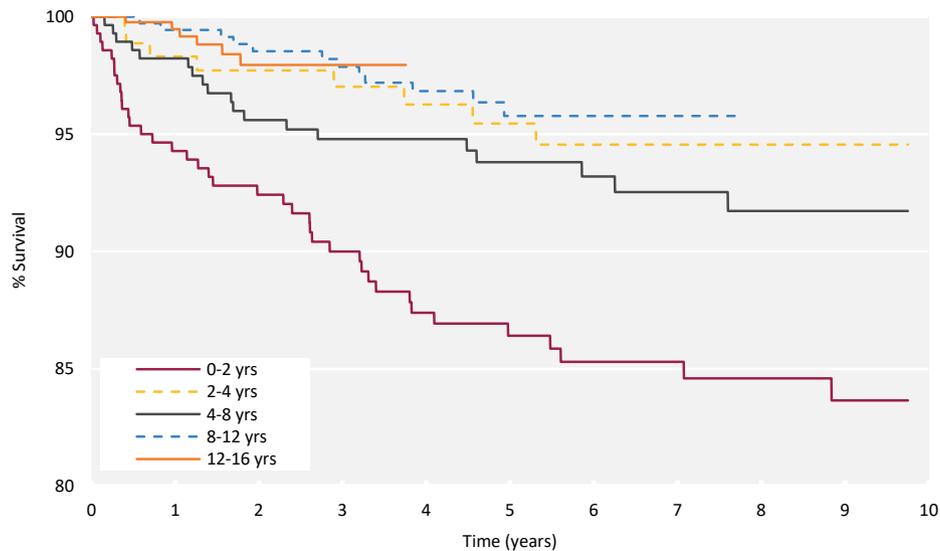


Figure 8.16 Unadjusted Kaplan-Meier survival (from day 90) of incident paediatric KRT patients (<16 years old) between 2006 and 2019 by age group at start of KRT

The 8–12 yrs and 12–16 yrs lines stop before 10 years, because the analysis was censored at age 16 years.

Analyses – young people

KRT incidence and prevalence in young people

Table 8.20 reports the numbers of young people who started KRT in 2020 (incidence) as well as those on KRT as of 31/12/2020 (prevalence) in both paediatric and adult centres, as an estimated total pmarp and grouped by sex, ethnicity and PRD. 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 KRT in 2020 and/or prevalent to KRT on 31/12/2020, by care setting

Characteristic	Incident			Prevalent		
	Paediatric centres	Adult centres	All	Paediatric centres	Adult centres	All
N	13	13	26	184	24	208
pmarp			17.8			142.1
Median age (yrs)	16.4	16.9	16.6	17.0	17.7	17.1
% male	53.9	53.9	53.9	63.0	75.0	64.4
Ethnicity¹ (%)						
White	58.3	63.6	60.9	67.0	57.1	65.2
Asian	25.0	9.1	17.4	18.4	23.8	19.8
Black	0.0	27.3	13.0	7.8	19.1	10.1
Other	16.7	0.0	8.7	6.7	0.0	4.8
Missing	7.7	15.4	11.5	2.7	12.5	3.8
PRD¹ (%)						
Tubulointerstitial disease	25.0	30.0	27.8	46.8	45.0	46.6
Glomerular disease	37.5	10.0	22.2	19.7	10.0	18.7
Familial/hereditary nephropathies	12.5	10.0	11.1	17.9	10.0	17.1
Systemic diseases affecting the kidney	12.5	10.0	11.1	4.6	5.0	4.7
Miscellaneous kidney disorders	12.5	40.0	27.8	11.0	30.0	13.0
Missing	38.6	23.1	30.8	6.0	16.7	7.2
Modality (%)						
HD	38.5	76.9	57.7	10.9	29.2	13.0
PD	46.2	15.4	30.8	7.1	20.8	8.7
Tx	15.4	7.7	11.5	82.1	50.0	78.4

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 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 KRT in 2020 and/or prevalent to KRT on 31/12/2020, by care setting

	Incident	Prevalent
Paediatric centres	7 out of 13	13 out of 13
Adult centres	12 out of 68	16 out of 68

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 31/12/2020 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 31/12/2020, 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	151	17.0	151	111	68	3.3	100.0
Adult centres	12	18.0	11	121	63	0.0	91.7

Table 8.23 reports the median eGFR for all young people prevalent to Tx on 31/12/2020 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 31/12/2020 by time since transplantation

Time since transplantation	N	Median FAS-eGFR (mL/min/1.73m ²)
< 3 months	1	
0.25–<2 years	33	75
2–<4 years	26	73
4–<7 years	32	68
≥ 7 years	65	60
Total (IQR)	157	68 (54-85)

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

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 31/12/2020 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 the majority of biochemical parameters, although a higher proportion of incomplete blood pressure data was noted among young people managed in adult centres.

Table 8.24 Attainment of biochemical and blood pressure measures in young people (16–<18 years) prevalent to KRT on 31/12/2020, by modality and care setting

Characteristic	Dialysis			Tx		
	Paediatric centres	Adult centres	All	Paediatric centres	Adult centres	All
N	33	12	45	151	12	163
Median (IQR) Hb (g/L)	111 (100-123)	112 (103-118)	111 (100-123)	130 (116-141)		129 (116-141)
% Hb <100g/L	24.2	20	23.3	5.8		5.6
Median (IQR) Ca (mmol/L)	2.5 (2.4-2.6)	2.5 (2.2-2.6)	2.5 (2.3-2.6)	2.4 (2.3-2.5)	2.4 (2.4-2.5)	2.4 (2.3-2.5)
% Ca in range	69.7	58.3	66.7	92.7	90.9	92.6
Median (IQR) Phos (mmol/L)	1.8 (1.4-2.1)	1.7 (1.4-2.1)	1.8 (1.4-2.1)	1.2 (1-1.3)	1.1 (1-1.2)	1.2 (1-1.3)
% phos in range	30.3	33.3	31.1	71.3	54.5	70.2
Median (IQR) bicarb (mmol/L)	26 (24-28)	24.5 (23-27)	25 (24-27)	23 (21-25)	26 (25-29)	24 (21-26)
% bicarb in range	66.7	58.3	64.1	71.7	60	70.8
Median (IQR) SBP (mmHg)	120 (112-131)		126 (112-135)	118 (110-124)		118 (110-125)
Median (IQR) DBP (mmHg)	79 (69-89)		75 (67-88)	72 (66-79)		72 (66-79)
% 'normal' BP range (<130/80 mmHg)	45.8		41.9	68.1		66.7
% high BP (≥140/90 mmHg)	33.3		35.5	3.4		4.9

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