

## *Chapter 8*

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# **Children and young people on kidney replacement therapy (KRT) for end-stage kidney disease (ESKD) in the UK in 2021**

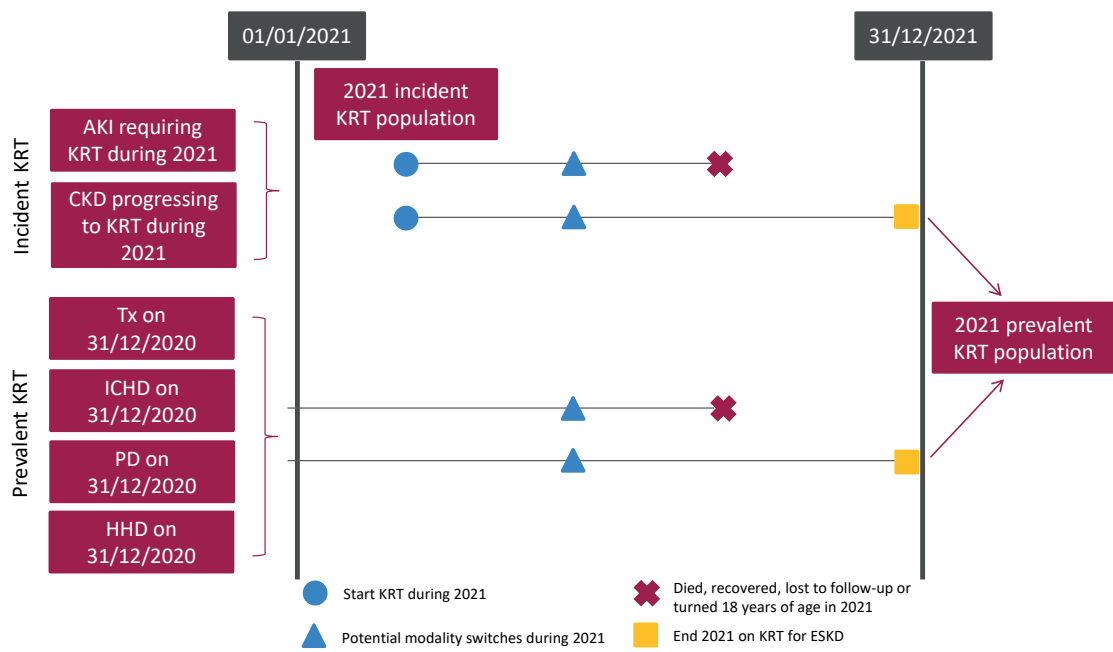
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# Introduction

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 2021 (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 2021 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 2021 and remained on KRT for at least 90 days.
- **Prevalent population:** patients who were on KRT at the end of 2021 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 2007–2011, 2012–2016 and 2017–2021.

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

- **Incident population:** patients who started KRT during 2021 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 2021 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.

The sections for these aspects (and tables 8.2 and 8.3) use a restricted prevalent cohort. Children who have moved centre, changed or started treatment in the quarter are not included.

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 2021 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 2021 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	<a href="#">Figures 8.6–8.13</a>
	Blood pressure during PD or after HD to be maintained at <90 <sup>th</sup> percentile for age, sex and height. Blood pressure in Tx patients to be maintained at <90 <sup>th</sup> percentile for age, sex and height	<a href="#">Tables 8.14–8.15, figures 8.14–8.15</a>
	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	<a href="#">Table 8.17</a>
	Serum bicarbonate concentrations should be 20–26 mmol/L	<a href="#">Table 8.17</a>
	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	<a href="#">Table 8.17</a>
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	<a href="#">Tables 8.2–8.3, 8.15</a>

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](http://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. 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

- 110 patients aged <16 years started KRT for ESKD in the UK in 2021 compared to 106 patients in 2020.
- KRT incidence in patients aged <16 years was 8.9 pmarp compared to 8.3 pmarp in 2020.
- 842 patients aged <16 years were receiving KRT at UK paediatric kidney centres on 31/12/2021, an increase from 812 patients in 2020.
- KRT prevalence in patients aged <16 years was 68.4 pmarp. 76.4% had a functioning Tx (49.8% living donor and 26.6% deceased donor), 11.0% were receiving HD and 12.6% were receiving PD.
- Tubulointerstitial disease accounted for approximately 50% of all primary renal diseases (PRDs) in prevalent paediatric patients, with a high male:female ratio (2.8:1).
- Between 2007 and 2021, 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, 84.2% of paediatric patients had a functioning kidney Tx.
- The median height z-score for children on dialysis was -1.5 compared with -0.9 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 611 children with a kidney transplant on 31/12/2021 was 61 mL/min/1.73m<sup>2</sup> and 5.6% had an eGFR of <30 mL/min/1.73m<sup>2</sup>.
- Of those with complete data, 74.9% of the prevalent paediatric KRT population had 1 or more risk factors for cardiovascular disease; 4.6% had 3 risk factors.
- 59.6% and 63.4% of prevalent HD patients achieved systolic blood pressure (SBP) and diastolic blood pressure (DBP) values <90th percentile, respectively.
- 60.4% and 65.9% of prevalent PD patients achieved SBP and DBP values <90th percentile, respectively.
- 77.0% and 80.8% 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 2021.
- KRT incidence in young people was 17.1 pmarp.
- 225 patients aged 16 to <18 years were receiving KRT on 31/12/2021, of whom the majority (83.6%) were managed in paediatric kidney centres.
- KRT prevalence in patients aged 16 to <18 years was 147.7 pmarp.
- Tubulointerstitial disease accounted for 42.0% of all PRDs in prevalent young people, followed by familial/hereditary nephropathies (22.6%) and glomerular disease (16.5%).
- The overall median eGFR of young people with a kidney transplant on 31/12/2021 was 71 mL/min/1.73m<sup>2</sup> and 6.1% had an eGFR of <30 mL/min/1.73m<sup>2</sup>.
- The proportion of young people prevalent to KRT on 31/12/2021 with a blood pressure within the 'normal' range (<130/80 mmHg) was 50.0% of dialysis and 66.4% 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 2021 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](http://ukkidney.org/audit-research/data-portals)).

**Table 8.2** Data completeness for paediatric patients (<16 years old) prevalent to Tx on 31/12/2021 by centre

Centre	N with Tx	Data completeness (%)											
		Height	Weight	BMI	SBP	DBP	Hb	Creat	Chol	Bicarb	PTH	Ca	Phos
Bham_P	69	98.6	100.0	98.6	100.0	98.6	100.0	100.0	95.7	100.0	65.2	100.0	100.0
Blfst_P	23	34.8	95.7	34.8	34.8	34.8	100.0	100.0	87.0	100.0	100.0	100.0	100.0
Brstl_P	36	0.0	94.4	0.0	91.7	80.6	100.0	100.0	36.1	100.0	86.1	100.0	100.0
Cardf_P	20	0.0	100.0	0.0	100.0	5.0	100.0	100.0	90.0	100.0	75.0	100.0	100.0
Glasg_P	41	100.0	100.0	100.0	100.0	100.0	82.9	82.9	26.8	87.8	78.1	82.9	82.9
L Eve_P	65	100.0	100.0	100.0	100.0	100.0	100.0	100.0	58.5	100.0	98.5	100.0	100.0
L GOSH_P	110	93.6	100.0	93.6	50.9	50.9	40.0	42.7	10.0	6.4	19.1	0.0	42.7
Leeds_P	42	100.0	100.0	100.0	100.0	88.1	100.0	100.0	7.1	100.0	100.0	100.0	100.0
Livpl_P	26	0.0	11.5	0.0	7.7	3.9	0.0	96.2	69.2	96.2	92.3	96.2	96.2
Manch_P	65	0.0	0.0	0.0	100.0	98.5	100.0	100.0	89.2	100.0	93.9	100.0	100.0
Newc_P	25	0.0	0.0	0.0	100.0	4.0	100.0	100.0	80.0	100.0	88.0	100.0	100.0
Nottm_P	59	86.4	94.9	86.4	89.8	86.4	98.3	98.3	44.1	98.3	83.1	98.3	98.3
Soton_P	30	100.0	100.0	100.0	86.7	73.3	100.0	100.0	3.3	100.0	100.0	100.0	100.0
<b>UK</b>	<b>611</b>	<b>66.8</b>	<b>80.5</b>	<b>66.8</b>	<b>82.7</b>	<b>72.7</b>	<b>83.6</b>	<b>88.2</b>	<b>49.6</b>	<b>82.0</b>	<b>75.1</b>	<b>80.5</b>	<b>88.2</b>

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 31/12/2021 by centre

Centre	N on dialysis	Data completeness (%)											
		Height	Weight	BMI	SBP	DBP	Hb	Chol	Bicarb	PTH	Ca	Phos	
Bham_P	22	95.5	95.5	95.5	95.5	90.9	95.5	95.5	95.5	95.5	95.5	95.5	95.5
Blfst_P	1	0.0	100.0	0.0	0.0	0.0	100.0	0.0	100.0	100.0	100.0	100.0	100.0
Brstl_P	9	0.0	100.0	0.0	100.0	33.3	100.0	88.9	100.0	100.0	100.0	100.0	100.0
Cardf_P	6	0.0	100.0	0.0	66.7	16.7	100.0	33.3	100.0	100.0	100.0	100.0	100.0
Glasg_P	12	100.0	100.0	100.0	91.7	91.7	100.0	50.0	100.0	100.0	100.0	100.0	100.0
L Eve_P	11	100.0	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	32	90.6	100.0	90.6	81.3	81.3	93.8	50.0	34.4	84.4	0.0	96.9	96.9
Leeds_P	13	76.9	100.0	76.9	100.0	46.2	100.0	53.9	100.0	100.0	100.0	100.0	100.0
Livpl_P	12	0.0	0.0	0.0	0.0	0.0	33.3	41.7	100.0	100.0	100.0	100.0	100.0
Manch_P	15	0.0	33.3	0.0	93.3	33.3	100.0	40.0	100.0	93.3	100.0	100.0	100.0
Newc_P	8	0.0	0.0	0.0	75.0	12.5	100.0	50.0	100.0	100.0	100.0	100.0	100.0
Nottm_P	23	91.3	91.3	91.3	87.0	60.9	100.0	30.4	100.0	100.0	100.0	100.0	100.0
Soton_P	11	100.0	100.0	100.0	81.8	72.7	90.9	45.5	90.9	90.9	90.9	90.9	90.9
<b>UK</b>	<b>175</b>	<b>65.7</b>	<b>81.1</b>	<b>65.7</b>	<b>82.3</b>	<b>60.6</b>	<b>93.1</b>	<b>56.0</b>	<b>86.9</b>	<b>95.4</b>	<b>80.6</b>	<b>98.3</b>	<b>98.3</b>

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 used to calculate age-related rate per million population 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 2021 by age and sex

Age group (yrs)	All patients		Male		Female	
	N	pmarp	N	pmarp	N	pmarp
0-<2	16	11.6	11	15.6	5	7.4
2-<4	11	7.6	9	12.1	2	2.8
4-<8	16	5.2	10	6.4	6	4.0
8-<12	29	8.9	18	10.8	11	6.9
12-<16	38	12.0	20	12.3	18	11.7
<b>&lt;16 yrs</b>	<b>110</b>	<b>8.9</b>	<b>68</b>	<b>10.8</b>	<b>42</b>	<b>7.0</b>

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)	2007-2011		2012-2016		2017-2021	
	N	pmarp	N	pmarp	N	pmarp
0-<2	94	12.0	118	15.0	93	12.6
2-<4	55	7.3	75	9.1	58	7.3
4-<8	89	6.4	119	7.5	90	5.5
8-<12	124	8.7	137	9.5	140	8.5
12-<16	217	14.2	181	12.7	181	11.8
<b>&lt;16 yrs</b>	<b>579</b>	<b>9.8</b>	<b>630</b>	<b>10.4</b>	<b>562</b>	<b>8.9</b>

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	2007-2011		2012-2016		2017-2021	
	N	%	N	%	N	%
White	423	73.4	434	69.2	329	65.1
Asian	94	16.3	123	19.6	110	21.8
Black	28	4.9	30	4.8	33	6.5
Other	31	5.4	40	6.4	33	6.5
<b>&lt;16 yrs</b>	<b>576</b>	<b>100.0</b>	<b>627</b>	<b>100.0</b>	<b>505</b>	<b>100.0</b>

3 children in 2007–2011, 3 in 2012–2016 and 57 in 2017–2021 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	2007-2011		2012-2016		2017-2021	
	N	%	N	%	N	%
Bham_P	62	10.7	73	11.6	75	13.3
Blfst_P	29	5.0	15	2.4	9	1.6
Brstl_P	36	6.2	30	4.8	34	6.0
Cardf_P	14	2.4	26	4.1	21	3.7
Glasg_P	48	8.3	40	6.3	45	8.0
L Eve_P	65	11.2	70	11.1	55	9.8
L GOSH_P	107	18.5	110	17.5	97	17.3
Leeds_P	47	8.1	54	8.6	38	6.8
Livpl_P	22	3.8	34	5.4	34	6.0
Manch_P	48	8.3	72	11.4	57	10.1
Newc_P	24	4.1	26	4.1	22	3.9
Nottm_P	59	10.2	59	9.4	47	8.4
Soton_P	18	3.1	21	3.3	28	5.0
<b>&lt;16 yrs</b>	<b>579</b>	<b>100.0</b>	<b>630</b>	<b>100.0</b>	<b>562</b>	<b>100.0</b>

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.

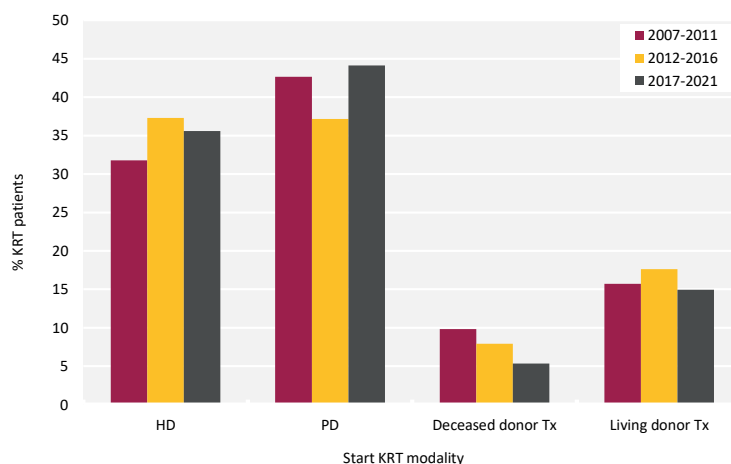
**Table 8.8** Paediatric patients (<16 years old) incident to KRT by primary renal disease (PRD) and 5 year time period

PRD	2007-2011		2012-2016		2017-2021	
	N	%	N	%	N	%
Tubulointerstitial disease	263	45.9	299	48.0	223	45.2
- CAKUT	254	44.3	290	46.5	206	41.8
- Non-CAKUT	9	1.6	9	1.4	17	3.4
Glomerular disease	78	13.6	99	15.9	91	18.5
Familial/hereditary nephropathies	122	21.3	102	16.4	87	17.6
Systemic diseases affecting the kidney	33	5.8	19	3.0	22	4.5
Miscellaneous renal disorders	77	13.4	104	16.7	70	14.2

6 children in 2007–2011, 7 in 2012–2016 and 69 in 2017–2021 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 2007 and 2021 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 (2007-2021)	1,330	418 (31.4)
<b>Time period</b>		
2007-2011	414	147 (35.5)
2012-2016	468	157 (33.5)
2017-2021	448	114 (25.4)
<b>Sex</b>		
Male	847	291 (34.4)
Female	483	127 (26.3)
<b>Ethnicity</b>		
White	890	320 (36.0)
Asian	245	49 (20.0)
Black	63	12 (19.0)
Other	79	20 (25.3)
<b>Age at start of KRT (yrs)</b>		
3 mths-<2	162	6 (3.7)
2-<4	163	50 (30.7)
4-<8	240	100 (41.7)
8-<12	316	104 (32.9)
12-<16	449	158 (35.2)
<b>PRD</b>		
Tubulointerstitial disease	647	276 (42.7)
Glomerular disease	191	7 (3.7)
Familial/hereditary nephropathies	232	63 (27.2)
Miscellaneous renal disorders	148	37 (25.0)
Systemic diseases affecting the kidney	42	16 (38.1)

86 children were excluded because they were aged <3 months; 355 children were excluded because they presented late

## Demographics of prevalent paediatric KRT patients

The number of prevalent patients on KRT <16 years old was used to calculate age-related rates per million population and grouped by age, sex and ethnicity.

**Table 8.10** Age and sex breakdown of paediatric patients (<16 years old) prevalent to KRT on 31/12/2021

Age group (yrs)	All patients		Male		Female		M/F pmarp ratio
	N	pmarp	N	pmarp	N	pmarp	
0-<2	17	12.3	11	15.6	6	8.9	1.7
2-<4	44	30.3	27	36.3	17	24.0	1.5
4-<8	151	49.2	98	62.3	53	35.4	1.8
8-<12	261	80.4	179	107.6	82	51.8	2.1
12-<16	369	116.5	203	125.1	166	107.5	1.2
<b>&lt;16 yrs</b>	<b>842</b>	<b>68.4</b>	<b>518</b>	<b>82.1</b>	<b>324</b>	<b>53.9</b>	<b>1.5</b>

pmarp – per million age-related population

**Table 8.11** Age and ethnicity breakdown of paediatric patients (<16 years old) prevalent to KRT on 31/12/2021

Age group (yrs)	N			
	White	Asian	Black	Other
0-<4	39	7	4	3
4-<8	96	28	10	10
8-<12	177	40	10	25
12-<16	220	78	20	26
<b>&lt;16 yrs</b>	<b>532</b>	<b>153</b>	<b>44</b>	<b>64</b>

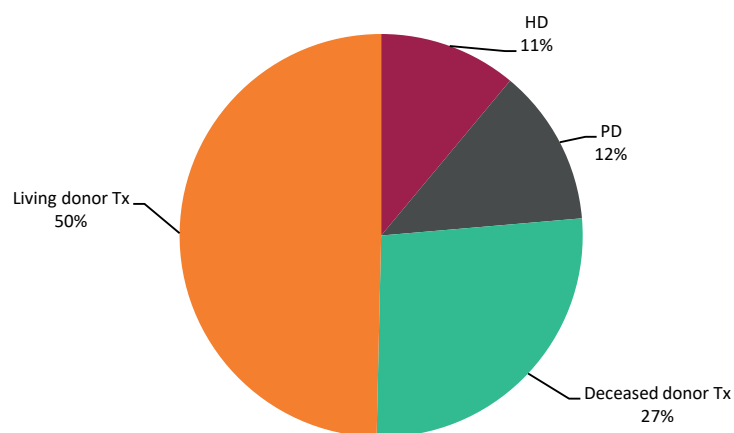
49 children with no ethnicity recorded were excluded

## Treatment modality in prevalent paediatric KRT patients

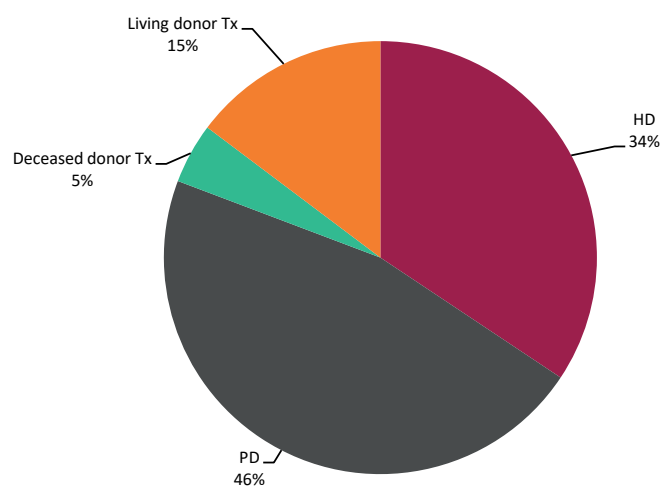
The current and start KRT modalities for prevalent KRT patients aged <16 years are shown in figures 8.3 and 8.4, respectively. Table 8.12 breaks down current modality for prevalent patients by age group.

**Table 8.12** KRT modality used by paediatric patients (<16 years old) prevalent to KRT on 31/12/2021 by age group

Age group (yrs)	Total N	HD		PD		Living donor Tx		Deceased donor Tx	
		N	%	N	%	N	%	N	%
0-<2	17	2	11.8	15	88.2	0	0.0	0	0.0
2-<4	44	9	20.5	17	38.6	14	31.8	4	9.1
4-<8	151	17	11.3	16	10.6	90	59.6	28	18.5
8-<12	261	26	10.0	21	8.0	139	53.3	75	28.7
12-<16	369	39	10.6	37	10.0	176	47.7	117	31.7
<b>&lt;16 yrs</b>	<b>842</b>	<b>93</b>	<b>11.0</b>	<b>106</b>	<b>12.6</b>	<b>419</b>	<b>49.8</b>	<b>224</b>	<b>26.6</b>



**Figure 8.3** KRT modality used by paediatric patients (<16 years old) prevalent to KRT on 31/12/2021



**Figure 8.4** KRT modality used at the start of KRT by paediatric patients (<16 years old) prevalent to KRT on 31/12/2021

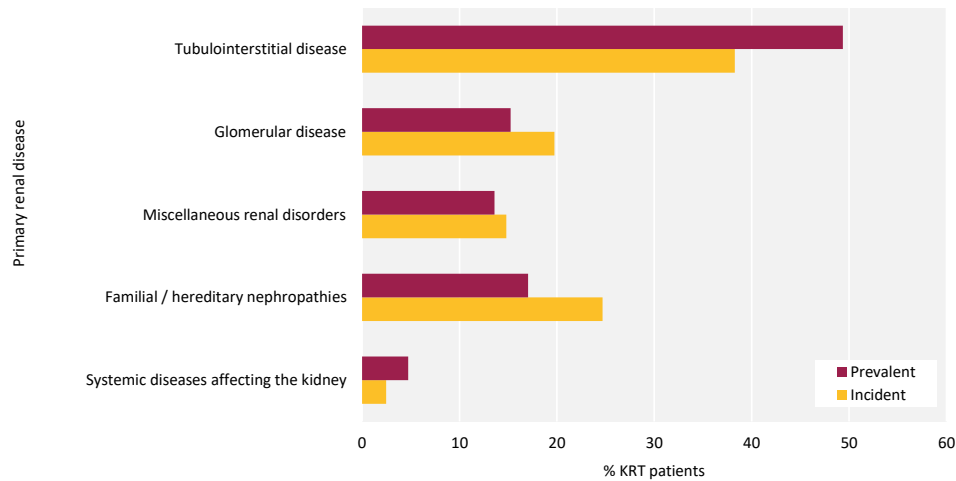
## Causes of ESKD in prevalent paediatric KRT patients

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 31/12/2021 by sex and ethnicity

PRD	N	%	N male	N female	% non-White
Tubulointerstitial disease	385	49.4	284	101	29.2
- CAKUT	370	47.4	277	93	28.8
- Non-CAKUT	15	1.9	7	8	40.0
Glomerular disease	119	15.3	60	59	35.9
Familial/hereditary nephropathies	133	17.1	60	73	39.8
Systemic diseases affecting the kidney	37	4.7	20	17	16.7
Miscellaneous renal disorders	106	13.6	53	53	34.0
<b>Total (with data)</b>	<b>780</b>	<b>100.0</b>	<b>477</b>	<b>303</b>	<b>32.1</b>
Missing	62	7.4	41	21	55.2

CAKUT – congenital anomalies of the kidneys and urinary tract

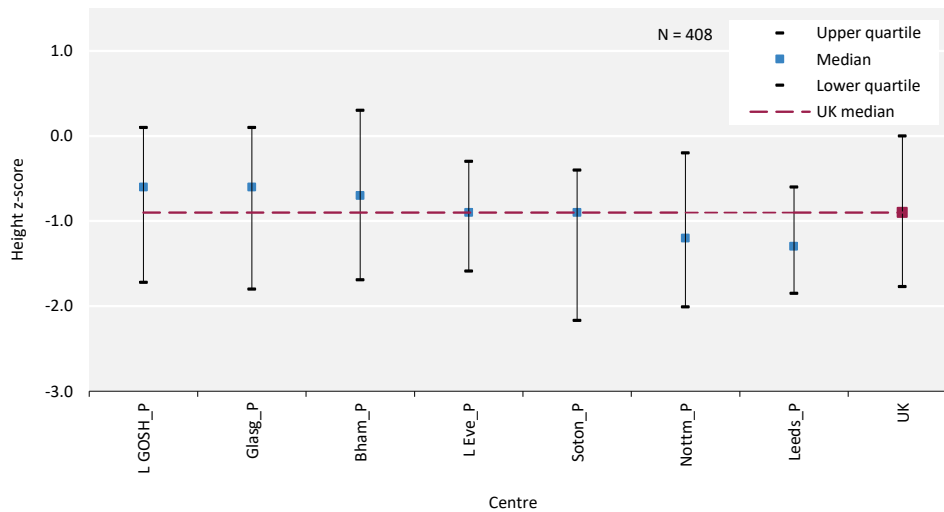


**Figure 8.5** Comparison of primary renal diseases for paediatric patients (<16 years old) incident and prevalent to KRT in 2021 with no missing data

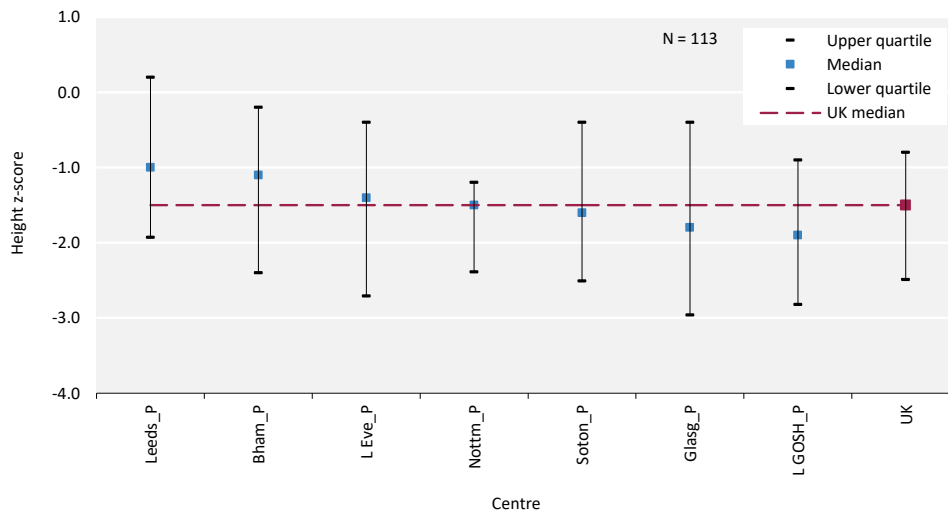
## Growth of prevalent paediatric KRT patients

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.

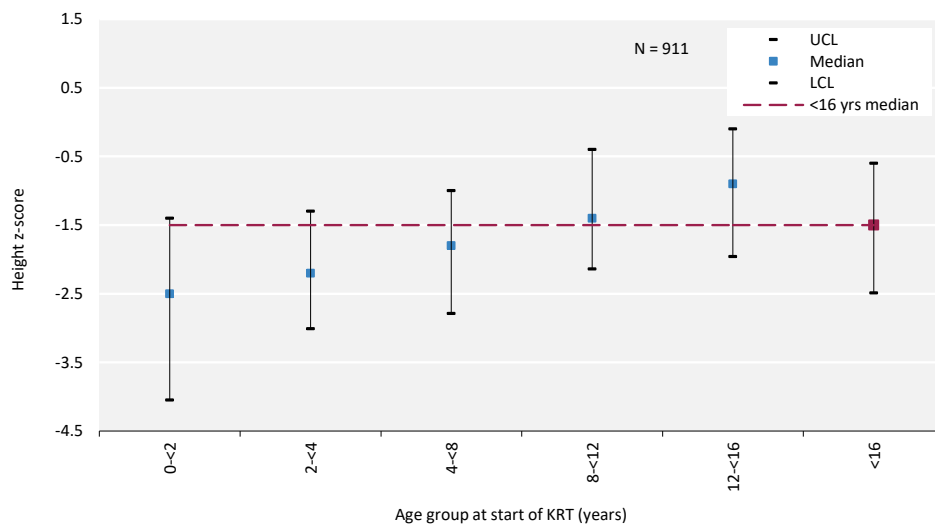
### Height of paediatric KRT patients



**Figure 8.6** Median height z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2021 by centre

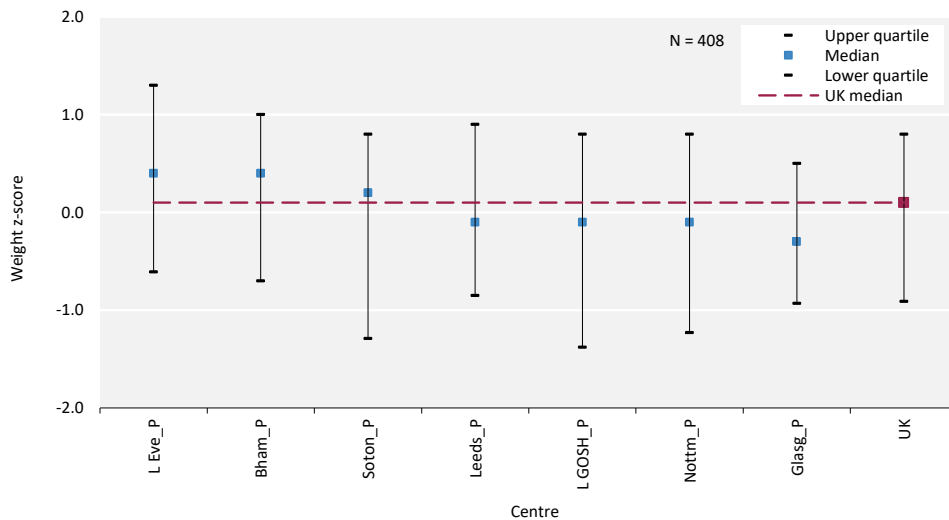


**Figure 8.7** Median height z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2021 by centre

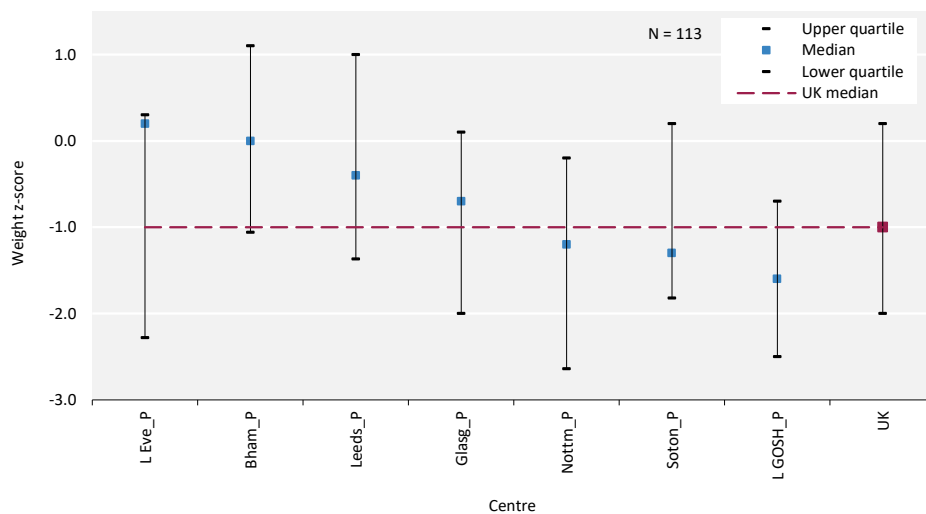


**Figure 8.8** Median height z-scores at start of KRT for incident paediatric KRT patients (<16 years old) between 2007 and 2021 by age group at start of KRT

## Weight of paediatric KRT patients



**Figure 8.9** Median weight z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2021 by centre



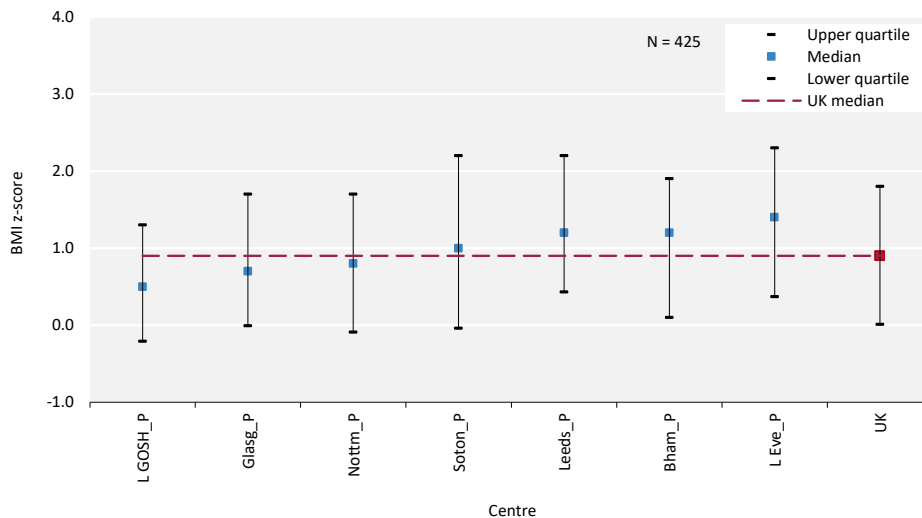
**Figure 8.10** Median weight z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2021 by centre



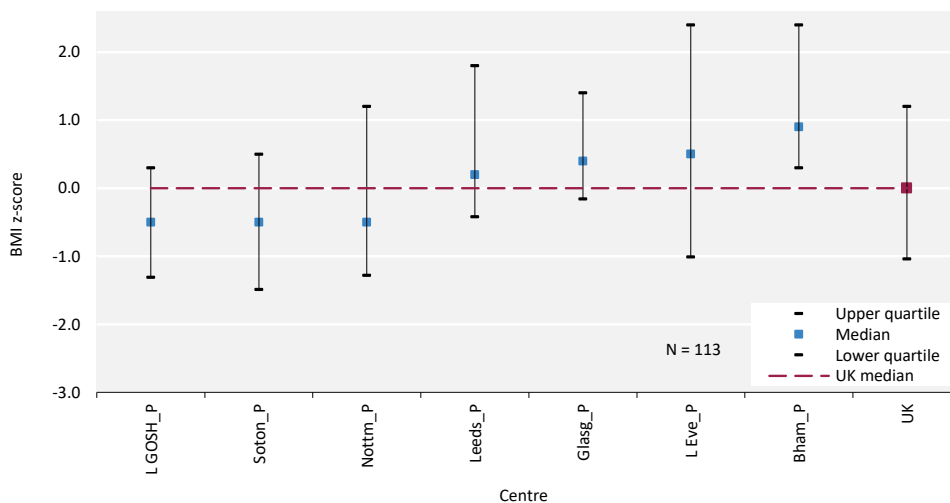
## Cardiovascular risk factor evaluation in prevalent paediatric KRT patients

### Obesity in paediatric KRT patients

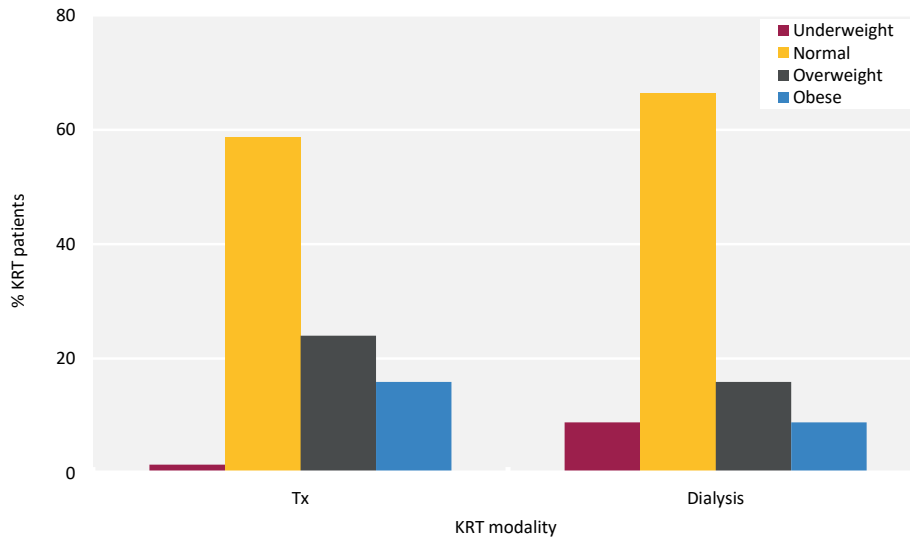
BMI was calculated using the formula  $BMI = \text{weight (kg)} / \text{height}^2 \text{ (m)}$ . Height and weight were adjusted for age. To account for discrepancies in linear growth secondary to kidney disease, BMI was expressed according to height age, rather than chronological age. Height age corresponds 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 31/12/2021 by centre



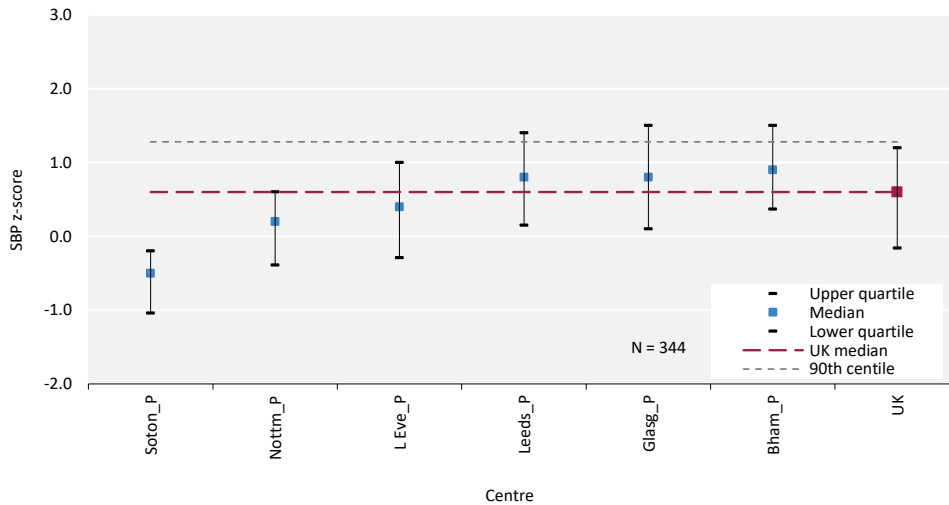
**Figure 8.12** Median body mass index (BMI) z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2021 by centre



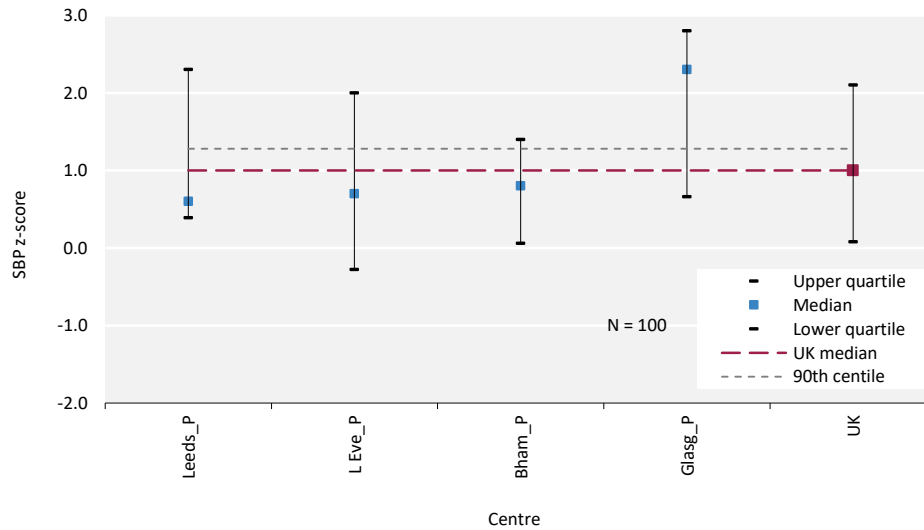
**Figure 8.13** Body mass index categorisation of paediatric patients (<16 years old) prevalent to KRT on 31/12/2021 by KRT modality

**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 31/12/2021 by centre



**Figure 8.15** Median systolic blood pressure (SBP) z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2021 by centre

**Table 8.14** Percentage of paediatric patients (<16 years old) prevalent to KRT on 31/12/2021 achieving the standards for blood pressures

Characteristic	SBP		DBP	
	N	% <90th percentile	N	% <90th percentile
<b>Total</b>	444	73.2	398	77.4
<b>Age group (yrs)</b>				
0-<5	40	70.0	29	65.5
5-<12	201	73.6	177	77.4
12-<16	203	73.4	192	79.2
<b>Sex</b>				
Male	265	74.3	236	79.2
Female	179	71.5	162	74.7
<b>Ethnicity</b>				
White	261	74.3	234	79.9
Asian	95	66.3	81	72.8
Black	26	73.1	25	76.0
Other	37	75.7	35	74.3
<b>Modality</b>				
HD	47	59.6	41	63.4
PD	53	60.4	44	65.9
Tx	344	77.0	313	80.8

DBP – diastolic blood pressure; SBP – systolic blood pressure  
 HD – haemodialysis; PD – peritoneal dialysis; Tx – transplant

### 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 223 of the 786 patients (28.4%) 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 31/12/2021

N cardiovascular risk factors	Hypertensive	Overweight/Obese	Hypercholesterolaemic	N	%	Total %
0	No	No	No	56	25.1	25.1
1	Yes	No	No	43	19.3	48.4
	No	Yes	No	42	18.8	
	No	No	Yes	23	10.3	
2	Yes	Yes	No	18	8.1	22.0
	Yes	No	Yes	12	5.4	
	No	Yes	Yes	19	8.5	
3	Yes	Yes	Yes	10	4.5	4.5
				<b>223</b>		
<b>Total N with the risk factor</b>	<b>83</b>	<b>89</b>	<b>64</b>			
<b>Total % with the risk factor</b>	<b>37.2</b>	<b>39.9</b>	<b>28.7</b>			

### Biochemistry parameters in prevalent paediatric KRT patients

The median values and the percentage with eGFR <30 mL/min/1.73m<sup>2</sup> for prevalent 2021 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/1.73m<sup>2</sup> in paediatric patients (<16 years old) prevalent to Tx on 31/12/2021 by centre

Centre	N with Tx	Median eGFR (mL/min/1.73m <sup>2</sup> )	% eGFR <30 mL/ min/1.73m <sup>2</sup>	% data completeness
Bham_P	69	52	7.4	98.6
Blfst_P	23			34.8
Brstl_P	36			0.0
Cardf_P	20			0.0
Glasg_P	41	74	0.0	100.0
L Eve_P	65	56	3.1	100.0
L GOSH_P	110			33.6
Leeds_P	42	75	0.0	100.0
Livpl_P	26			0.0
Manch_P	65			0.0
Newc_P	25			0.0
Nottm_P	59	51	13.7	86.4
Soton_P	30	73	3.3	100.0
<b>UK</b>	<b>611</b>	<b>61</b>	<b>5.6</b>	<b>56.0</b>

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

For most of the centres with missing data, 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 31/12/2021 by centre and (b) prevalent to Tx on 31/12/2021 with estimated glomerular filtration rate (eGFR) <30 mL/min/1.73 m<sup>2</sup> 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
<b>DIALYSIS PATIENTS</b>										
Bham_P	22	4.8	57.1	0.0	71.4	4.8	38.1	47.6	0.0	66.7
Blfst_P	1									
Brstl_P	9									
Cardf_P	6									
Glasg_P	12	8.3	50.0	0.0	100.0	33.3	33.3	16.7	0.0	83.3
L Eve_P	11	45.5	36.4	9.1	45.5	0.0	54.6	18.2	27.3	72.7
L GOSH_P	32	16.7	50.0			16.1	45.2	66.7		
Leeds_P	13	7.7	69.2	0.0	84.6	0.0	38.5	15.4	7.7	84.6
Livpl_P	12			0.0	66.7	8.3	41.7	25.0	8.3	58.3
Manch_P	15	6.7	60.0	0.0	26.7	26.7	53.3	42.9	0.0	86.7
Newc_P	8									
Nottm_P	23	17.4	47.8	0.0	82.6	0.0	47.8	26.1	0.0	78.3
Soton_P	11	20.0	70.0	0.0	50.0	0.0	60.0	70.0	0.0	70.0
<b>UK</b>	<b>175</b>	<b>16.6</b>	<b>50.9</b>	<b>0.7</b>	<b>68.8</b>	<b>9.3</b>	<b>47.7</b>	<b>40.1</b>	<b>8.6</b>	<b>73.7</b>
<b>TX PATIENTS WITH EGFR &lt;30 ML/MIN/1.73 M<sup>2</sup></b>										
<b>UK</b>	<b>19</b>	<b>22.2</b>	<b>77.8</b>	<b>6.7</b>	<b>93.3</b>	<b>5.3</b>	<b>79.0</b>	<b>50.0</b>	<b>26.7</b>	<b>73.3</b>

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 31/12/2021 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 <sup>2</sup> )	N	Median eGFR (mL/min/1.73 m <sup>2</sup> )	N	Median eGFR (mL/min/1.73 m <sup>2</sup> )
< 3 mths					1	
0.25-<2 years	17	75	38	68	29	64
2-<4 years	3		50	72	24	59
4-<7 years			57	60	36	54
≥ 7 years			19	57	65	49
<b>Total (IQR)</b>	<b>20</b>	<b>79 (68-99)</b>	<b>166</b>	<b>62 (47-81)</b>	<b>156</b>	<b>55 (40-70)</b>

IQR – interquartile range

This table includes 342 individuals with eGFR (as seen in table 8.16, completeness is 56% of N=611)

## Transfer to adult kidney services for prevalent paediatric KRT patients

One-hundred and forty-six paediatric patients transitioned to adult kidney centres in 2021. 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

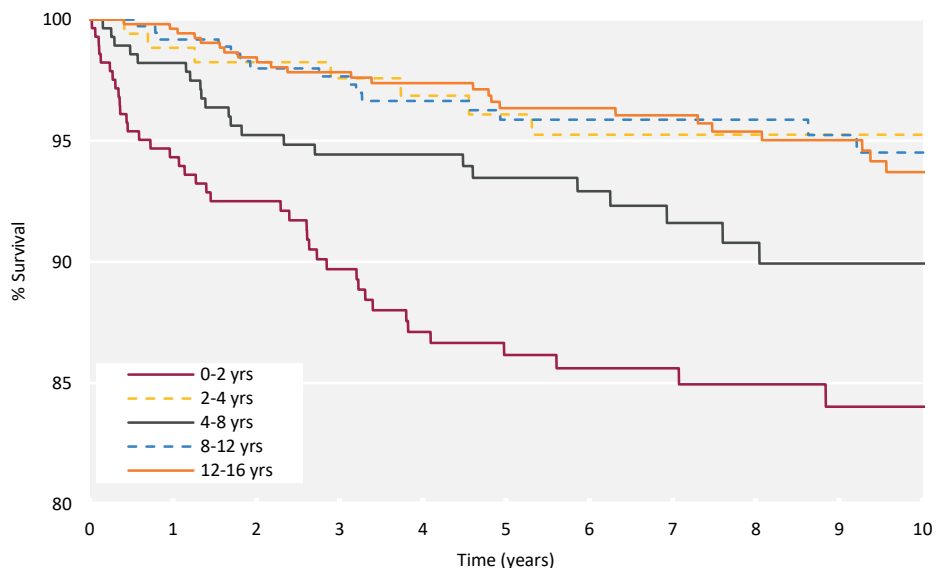
Of patients aged <16 years, 1,643 started KRT between 2007 and 2020 at paediatric kidney centres and were included in survival analyses, to allow at least one year follow-up. At the end of 2021, 119 deaths had been reported in these children. Patients included in the analysis must have been alive on KRT for 90 days. The median follow-up time (beyond day 90) was 7.1 years (range 9 days to 14.8 years).

**Table 8.19** Unadjusted Kaplan-Meier survival (from day 90) of incident paediatric KRT patients (<16 years old) between

	Age group (yrs)				
	0-<2	2-<4	4-<8	8-<12	12-<16
Survival at 1 year (%)	94.3	98.8	98.2	99.2	99.6
95% CI	90.9-96.5	95.4-99.7	95.8-99.3	97.5-99.7	98.5-99.9
Survival at 2 years (%)	92.5	98.2	95.2	98.0	98.4
95% CI	88.7-95	94.6-99.4	91.9-97.2	95.8-99	96.9-99.2
Survival at 3 years (%)	89.7	97.6	94.4	97.7	97.8
95% CI	85.4-92.8	93.7-99.1	90.9-96.6	95.4-98.8	96.1-98.8
Survival at 5 years (%)	86.2	96.1	93.5	95.9	96.3
95% CI	81.3-89.8	91.4-98.2	89.7-95.9	93-97.6	94.2-97.7
Survival at 10 years (%)	84.0	95.3	89.9	94.5	93.7
95% CI	78.5-88.2	90.2-97.7	84.7-93.4	90.8-96.8	90.6-95.8

CI – confidence interval

2007 and 2020 by age group at start of KRT



**Figure 8.16** Unadjusted Kaplan-Meier survival (from day 90) of incident paediatric KRT patients (<16 years old) between 2007 and 2020 by age group at start of KRT

# Analyses – young people

## KRT incidence and prevalence in young people

Table 8.20 reports the numbers of young people who started KRT in 2021 (incidence) as well as those on KRT as of 31/12/2021 (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 2021 and/or prevalent to KRT on 31/12/2021, by care setting

Characteristic	Incident			Prevalent		
	Paediatric centres	Adult centres	All	Paediatric centres	Adult centres	All
N	12	14	26	188	37	225
pmarp			17.1			147.7
Median age (yrs)	16.6	16.8	16.7	16.8	17.6	17.0
% male	66.7	50.0	57.7	62.8	67.6	63.6
<b>Ethnicity<sup>1</sup> (%)</b>						
White	70.0	64.3	66.7	71.8	58.3	69.6
Asian	20.0	28.6	25.0	18.8	25.0	19.8
Black	0.0	0.0	0.0	3.9	8.3	4.6
Other	10.0	7.1	8.3	5.5	8.3	6.0
Missing ethnicity	16.7	0.0	7.7	3.7	2.7	3.6
<b>PRD<sup>1</sup> (%)</b>						
Tubulointerstitial disease	30.0	9.1	19.1	41.0	47.1	42.0
Glomerular disease	0.0	27.3	14.3	17.4	11.8	16.5
Familial/hereditary nephropathies	40.0	36.4	38.1	21.9	26.5	22.6
Systemic diseases affecting the kidney	10.0	0.0	4.8	3.4	2.9	3.3
Diabetes	0.0	0.0	0.0	0.0	0.0	0.0
Miscellaneous renal disorders	20.0	27.3	23.8	16.3	11.8	15.6
Missing PRD	16.7	21.4	19.2	5.3	8.1	5.8
<b>Modality (%)</b>						
HD	33.3	71.4	53.9	15.4	13.5	15.1
PD	25.0	28.6	26.9	9.0	18.9	10.7
Tx	41.7	0.0	19.2	75.5	67.6	74.2

<sup>1</sup>Percentages 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

HD – haemodialysis; PD – peritoneal dialysis; Tx – transplant

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 2021 and/or prevalent to KRT on 31/12/2021, by care setting

	Incident	Prevalent
Paediatric centres	6 out of 13	13 out of 13
Adult centres	10 out of 68	21 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 m<sup>2</sup> for young people prevalent to Tx on 31/12/2021 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 31/12/2021, by care setting

	N on Tx	Median age (yrs)	N with creatinine data	Median creatinine (µmol/L)	Median FAS-eGFR (mL/min/1.73m <sup>2</sup> )	% FAS-eGFR <30 mL/min/1.73m <sup>2</sup>	% creatinine completeness
Paediatric centres	142	16.8	127	105	70	4.7	89.4
Adult centres	25	17.7	21	107	73	14.3	84.0

Table 8.23 reports the median eGFR for all young people prevalent to Tx on 31/12/2021 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 31/12/2021 by time since transplantation

Time since transplantation	N	Median FAS-eGFR (mL/min/1.73m <sup>2</sup> )
< 3 months	4	
0.25–<2 years	23	73
2–<4 years	25	78
4–<7 years	30	73
≥ 7 years	62	64
<b>Total (IQR)</b>	<b>144</b>	<b>71 (54-85)</b>

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 31/12/2021 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.

**Table 8.24** Attainment of biochemical and blood pressure measures in young people (16–<18 years) prevalent to KRT on 31/12/2021, by modality and care setting

Characteristic	Dialysis			Tx		
	Paediatric centres	Adult centres	All	Paediatric centres	Adult centres	All
N	46	12	58	142	25	167
Median (IQR) Hb (g/L)	114 (103-121)	99 (88-109.5)	110 (102-121)	126 (115.5-137)	134 (111-139)	126 (114-137)
% Hb <100g/L	9.1	50.0	17.9	9.2	9.1	9.2
Median (IQR) Ca (mmol/L)	2.5 (2.4-2.6)	2.4 (2.3-2.6)	2.5 (2.4-2.6)	2.4 (2.4-2.5)	2.4 (2.4-2.5)	2.4 (2.4-2.5)
% Ca in range	56.8	66.7	59.2	86.7	86.4	86.7
Median (IQR) Phos (mmol/L)	1.7 (1.4-2.0)	1.9 (1.6-2.0)	1.7 (1.5-2.0)	1.2 (1.0-1.3)	1.2 (0.9-1.4)	1.2 (1.0-1.3)
% phos in range	46.7	41.7	45.6	70.4	57.1	68.5
Median (IQR) bicarb (mmol/L)	24 (22-26)	24 (22-25)	24 (22-26)	23 (21-25)	24 (21-25)	23 (21-25)
% bicarb in range	62.2	81.8	66.7	73.9	68.2	72.9
Median (IQR) SBP (mmHg)	118 (112-132)	127 (121-135)	121 (113-134)	118 (110-125)	122 (116-126)	118 (110-125)
Median (IQR) DBP (mmHg)	72 (62-81)	81 (79-89)	78 (65-83)	70 (64-80)	76 (70-81)	71 (64-80)
% 'normal' BP range (<130/80 mmHg)	54.1	33.3	50.0	67.4	58.3	66.4
% high BP (≥140/90 mmHg)	13.5	22.2	15.2	10.5	8.3	10.3

See appendix A for biochemical target ranges

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