UK Kidney Association
UK Renal Registry

Chapter 8

Children and young people with chronic kidney disease (CKD) and on kidney replacement therapy (KRT) for end-stage kidney disease (ESKD) in the UK in 2023

Contents

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 2023 (figure 8.1). This included patients with a kidney 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. For the first time, this report includes a dedicated section on children and young people (<18 years) with chronic kidney disease, outside the context of KRT or AKI. The content of this section is expected to evolve as data submission and completeness become more complete.

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.

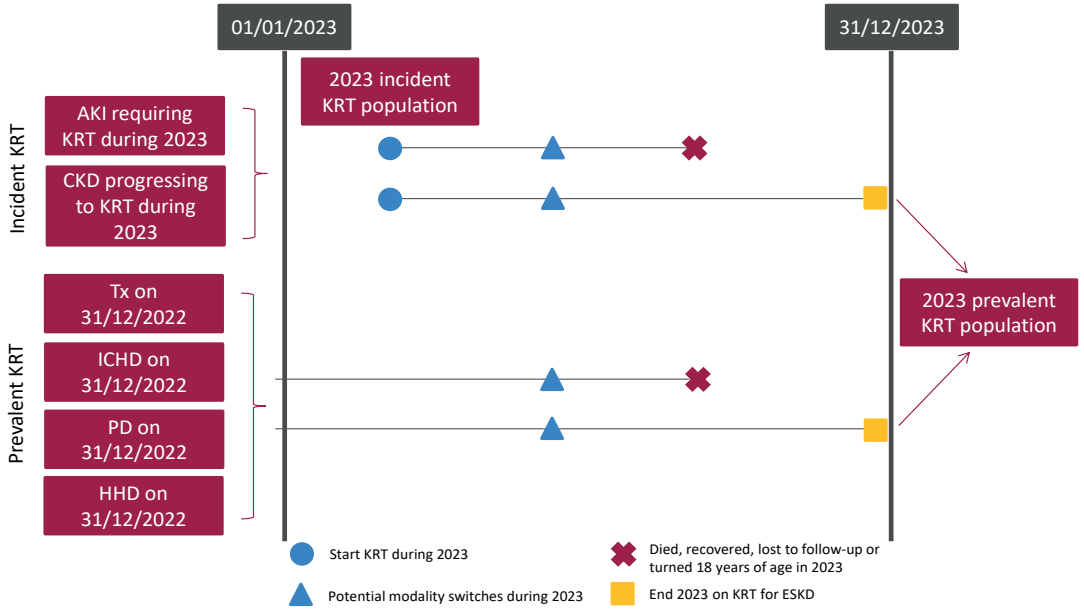

Figure 8.1 Pathways children and young people could follow to be included in the UK 2023 incident and/or prevalent KRT populations

Note that patients who recovered kidney function before 90 days on dialysis are not included in the KRT population
CKD – chronic kidney disease

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

- **Incident population:** patients who started KRT during 2023 and remained on KRT for at least 90 days.
- **Prevalent population:** patients who were on KRT at the end of 2023 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 2009-2013, 2014-2018 and 2019-2023.

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

- **Incident population:** patients who started KRT during 2023 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 2023 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 8.3 and 8.4) use a restricted prevalent cohort. Children who have moved centre, or changed or started treatment in the quarter are not included for consistency of measurements.

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.

For children and young people aged <18 years with CKD not on KRT, the following population is included in the chapter:

A 2023 prevalent CKD population is described, comprising individuals who:

- were reported by a paediatric kidney centre as receiving treatment for CKD at the end of 2023, and
- had an eGFR of <30mL/min/1.73m2 on their last recorded creatinine measurement.

Individuals are categorised as having CKD stage G5 (estimated glomerular filtration rate [eGFR] <15 mL/min/1.73m2) or CKD stage G4 (eGFR 15–29 mL/min/1.73m2). Further categorisation, e.g. by eGFR trend or albuminuria is not possible using UK Renal Registry (UKRR) data.

Possible pathways that a child could follow to be included in the 2023 prevalent CKD children population can be seen in figure 1.1 of Chapter 1 on the adult CKD population.

It is important to highlight that the individuals described in this chapter represent a sub-population of those with CKD in the UK. Many individuals with diagnosed CKD, particularly those with earlier stages, may receive care outside specialist kidney centres and are therefore not captured here. In addition, not all paediatric kidney centres are currently submitting CKD data to the UKRR.

Rationale for analyses

For both the children and young people sections, the analyses begin with a description of the 2023 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 2023 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 <90th percentile for age, sex and height. Blood pressure in Tx patients to be maintained at <90th percentile for age, sex and height	Tables 8.15–8.16, 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 8.18
	Serum bicarbonate concentrations should be 20–26 mmol/L	Table 8.18
	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 8.18
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 8.3-8.4, 8.16

Detail about the completeness of data returned to the 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 exluded 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

- In 2023, 118 patients aged under 16 years commenced KRT for ESKD in the UK, an increase from 109 patients in 2022. This corresponds to an incidence rate of 9.5 pmarp up from 8.8 pmarp in 2022.
- 861 patients aged under 16 years were receiving KRT at UK paediatric kidney centres on 31/12/2023, a number similar to 2022. The prevalence was 69.0 pmarp, with 77.6% having a functioning transplant (52.5% from living donors and 25.1% from deceased donors), 11.5% on haemodialysis, and 10.8% on peritoneal dialysis.
- Tubulointerstitial disease accounted for approximately 50% of all primary renal diseases (PRDs) in prevalent paediatric patients, with a high male:female ratio (3:1).
- At the time of transfer to adult services, 81.5% of paediatric patients had a functioning kidney Tx.
- The median height z-score for children on dialysis was -1.8 compared with -1.0 for those with a functioning Tx.
- The median weight z-score for children on dialysis was -1.1 compared with -0.2 for those with a functioning Tx.
- The median eGFR of children with a kidney transplant on 31/12/2023 was 61 mL/min/1.73m^2 and 7.8% had eGFR <30 mL/min/1.73m^2.
- Of those with complete data, 71.1% of the prevalent paediatric KRT population had 1 or more risk factors for cardiovascular disease; 4.4% had 3 risk factors.
- 53.9% and 61.1% of prevalent HD patients achieved systolic blood pressure (SBP) and diastolic blood pressure (DBP) values <90th percentile, respectively.
- 77.8% and 90.9% of prevalent PD patients achieved SBP and DBP values <90th percentile, respectively.
- 83.7% and 82.6% of prevalent Tx patients achieved SBP and DBP values <90th percentile, respectively.

Young people

- In 2023, 24 patients aged 16 to <18 years started KRT for ESKD in the UK, corresponding to an incidence rate of 15.1 pmarp.
- In young people (16–18 years), KRT prevalence was 141.6 pmarp , with 225 patients receiving KRT (excluding Manchester Children's Hospital), 80.4% of whom were managed in paediatric kidney centres.
- Tubulointerstital disease accounted for 44.1% of all PRDs in prevalent young people, followed by familial/hereditary nephropathies (15.6%) and glomerular disease (13.7%).
- The overall median eGFR of young people with a kidney transplant on 31/12/2023 was 67 mL/min/1.73m^2 and 4.8% had an eGFR of <30 mL/min/1.73m^2.
- 47.4% of young people on dialysis and 69.1% of those transplanted had a blood pressure in the 'normal' range (<130/80 mmHg).

CKD

- In 2023, 173 patients aged under 18 years had CKD 4/5 stage across six paediatric centres, with a crude prevalence rate of 20.1 pmarp with majority (74%) classified as CKD stage 4. The median age was 9.9 years (Interquartile range (IQR) 6.0 - 14.1) and 67.6% were male.

Analyses – children

Changes to the prevalent paediatric KRT population

For the 13 paediatric kidney centres, the number of prevalent children on KRT was calculated as a proportion of the estimated centre catchment population (calculated as detailed in appendix A).

Table 8.2 Number of prevalent paediatric KRT patients by year and by centre; number of KRT patients as a proportion of the catchment population

	N on KRT					Estimated catchment population <16 (millions)	2023 crude rate (pmarp)
Centre	2019	2020	2021	2022	2023		
Bham_P	87	105	98	103	94	1.23	77
Blfst_P	29	27	25	25	22	0.39	56
Brstl_P	53	49	52	48	45	0.91	49
Cardf_P	30	29	28	26	29	0.39	75
Glasg_P	54	58	56	58	54	0.90	60
L Eve_P	77	80	82	83	79	1.55	51
L GOSH_P	150	157	157	158	169	2.56	66
Leeds_P	56	57	59	58	59	0.79	75
Livpl_P	30	39	42	47	54	0.59	92
Manch_P	87	87	86	82	96	0.94	102
Newc_P	37	35	34	30	31	0.53	59
Nottm_P	73	85	83	79	83	1.25	66
Soton_P	30	34	44	45	46	0.46	101
UK	**793**	**842**	**846**	**842**	**861**	**12.48**	**69**

pmarp – per million age-related population

Manch_P was unable to provide data for 2023 but did provide a total prevalent number for <16s. This has been used in this table but not elsewhere in this chapter (except where noted)

Data completeness for prevalent paediatric KRT patients

Data returns of key variables for Tx and dialysis patients <16 years old at the end of 2023 are shown in tables 8.3 and 8.4, respectively, with further detail available through the UKRR data portal (ukkidney.org/audit-research/data-portals).

Table 8.3 Data completeness for paediatric patients (<16 years old) prevalent to Tx on 31/12/2023 by centre

Centre	N with Tx	Data completeness (%)											
		Height	Weight	BMI	SBP	DBP	Hb	Creat	Chol	Bicarb	PTH	Ca	Phos
Bham_P	71	25.4	28.2	25.4	28.2	28.2	100.0	100.0	97.2	100.0	98.6	100.0	100.0
Blfst_P	20	5.0	5.0	5.0	0.0	0.0	100.0	100.0	60.0	100.0	90.0	100.0	100.0
Brstl_P	36	0.0	97.2	0.0	97.2	80.6	97.2	94.4	16.7	94.4	75.0	94.4	94.4
Cardf_P	23	82.6	82.6	82.6	82.6	8.7	87.0	87.0	8.7	87.0	21.7	87.0	87.0
Glasg_P	45	100.0	100.0	100.0	97.8	97.8	100.0	100.0	22.2	100.0	84.4	100.0	100.0
L Eve_P	60	1.7	96.7	0.0	96.7	96.7	96.7	96.7	35.0	96.7	95.0	96.7	96.7
L GOSH_P	125	24.0	26.4	24.0	14.4	14.4	99.2	99.2	78.4	2.4	92.8	0.0	99.2
Leeds_P	44	75.0	100.0	75.0	100.0	43.2	100.0	100.0	95.5	100.0	100.0	100.0	100.0
Livpl_P	35	0.0	0.0	0.0	2.9	0.0	97.1	97.1	54.3	97.1	94.3	97.1	97.1
Newc_P	23	0.0	0.0	0.0	100.0	0.0	100.0	100.0	87.0	100.0	87.0	100.0	100.0
Nottm_P	51	92.2	94.1	92.2	92.2	92.2	100.0	98.0	72.6	98.0	90.2	98.0	98.0
Soton_P	39	100.0	100.0	100.0	76.9	61.5	94.9	94.9	41.0	94.9	92.3	94.9	94.9
UK	**572**	**40.7**	**59.8**	**40.6**	**59.3**	**45.6**	**98.3**	**97.9**	**61.5**	**76.8**	**89.2**	**76.2**	**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
Children who have moved centre, or changed or started treatment in the quarter are not included

Table 8.4 Data completeness for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2023 by centre

Centre	N on dialysis	Data completeness (%)										
		Height	Weight	BMI	SBP	DBP	Hb	Chol	Bicarb	PTH	Ca	Phos
Bham_P	18	11.1	27.8	11.1	16.7	11.1	83.3	83.3	83.3	83.3	83.3	83.3
Blfst_P	1	0.0	0.0	0.0	0.0	0.0	100.0	100.0	100.0	100.0	100.0	100.0
Brstl_P	4	0.0	100.0	0.0	100.0	75.0	100.0	25.0	100.0	100.0	100.0	100.0
Cardf_P	6	83.3	83.3	83.3	33.3	0.0	100.0	66.7	100.0	100.0	100.0	100.0
Glasg_P	8	100.0	100.0	100.0	100.0	75.0	100.0	62.5	100.0	100.0	100.0	100.0
L Eve_P	15	0.0	86.7	0.0	86.7	86.7	86.7	66.7	86.7	80.0	86.7	86.7
L GOSH_P	28	46.4	71.4	42.9	64.3	64.3	100.0	42.9	7.1	100.0	0.0	100.0
Leeds_P	13	61.5	61.5	46.2	23.1	23.1	100.0	76.9	100.0	100.0	100.0	100.0
Livpl_P	17	0.0	0.0	0.0	0.0	0.0	100.0	41.2	100.0	94.1	100.0	100.0
Newc_P	6	0.0	0.0	0.0	83.3	0.0	100.0	16.7	100.0	100.0	100.0	100.0
Nottm_P	27	92.6	92.6	92.6	92.6	63.0	96.3	85.2	96.3	96.3	96.3	96.3
Soton_P	4	100.0	100.0	100.0	100.0	75.0	100.0	75.0	100.0	100.0	100.0	100.0
UK	**147**	**44.2**	**62.6**	**42.2**	**57.8**	**44.2**	**95.9**	**62.6**	**78.2**	**94.6**	**76.9**	**95.9**

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
Children who have moved centre, or changed or started treatment in the quarter are not included

Changes to the incident paediatric KRT population

The number of incident patients on KRT <16 years old was used to calculate age-related rates per million population and were grouped by age, sex, five year time period, ethnicity, centre and PRD.

Table 8.5 Paediatric patients (<16 years old) incident to KRT in 2023 by age and sex

	All patients		Male		Female	
Age group (yrs)	N	pmarp	N	pmarp	N	pmarp
0-<2	20	14.5	13	18.4	7	10.4
2-<4	9	6.2	7	9.5	2	2.8
4-<8	14	4.5	10	6.3	4	2.7
8-<12	24	7.4	13	7.8	11	6.9
12-<16	39	11.7	18	10.6	21	12.9
<16 yrs	**106**	**8.5**	**61**	**9.5**	**45**	**7.4**

pmarp – per million age-related population

Including Manch_P the overall N was 118 and pmarp 9.5

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

	2009-2013		2014-2018		2019-2023	
Age group (yrs)	N	pmarp	N	pmarp	N	pmarp
0-<2	102	12.8	113	14.4	86	12.5
2-<4	65	8.3	70	8.7	52	7.2
4-<8	89	6.1	127	7.7	76	4.9
8-<12	119	8.6	131	8.5	152	9.4
12-<16	188	12.5	178	12.6	190	12.0
<16 yrs	**563**	**9.5**	**619**	**10.0**	**556**	**9.0**

pmarp – per million age-related population

Including Manch_P the overall N for 2019-2023 was 568 and pmarp 9.2

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

	2009-2013		2014-2018		2019-2023	
Ethnicity	N	%	N	%	N	%
White	395	70.7	425	69.0	352	66.4
Asian	103	18.4	118	19.2	108	20.4
Black	23	4.1	37	6.0	33	6.2
Other	38	6.8	36	5.8	37	7.0
<16 yrs	**559**	**100.0**	**616**	**100.0**	**530**	**100.0**

4 children in 2009-2013, 3 in 2014-2018 and 26 in 2019-2023 with no ethnicity recorded were excluded

Table 8.8 Paediatric patients (<16 years old) incident to KRT by centre and 5 year time period

	2009-2013		2014-2018		2019-2023	
Centre	N	%	N	%	N	%
Bham_P	63	11.2	81	13.1	65	11.4
Blfst_P	25	4.4	13	2.1	8	1.4
Brstl_P	36	6.4	31	5.0	24	4.2
Cardf_P	16	2.8	26	4.2	18	3.2
Glasg_P	35	6.2	48	7.8	33	5.8
L Eve_P	60	10.7	68	11.0	61	10.7
L GOSH_P	115	20.4	87	14.1	120	21.1
Leeds_P	43	7.6	46	7.4	38	6.7
Livpl_P	19	3.4	36	5.8	43	7.6
Manch_P	60	10.7	70	11.3	52	9.2
Newc_P	17	3.0	37	6.0	15	2.6
Nottm_P	55	9.8	52	8.4	61	10.7
Soton_P	19	3.4	24	3.9	30	5.3
<16 yrs	**563**	**100.0**	**619**	**100.0**	**568**	**100.0**

Manch_P was unable to provide data for 2023 but did provide a total incident number for <16s. This has been used in this table but not elsewhere in this chapter (except where noted)

PRDs were grouped into categories as shown in table 8.9, with the mapping of disease codes into groups explained in more detail in appendix A.

Table 8.9 Paediatric patients (<16 years old) incident to KRT by primary renal disease (PRD) and 5 year time period

	2009-2013		2014-2018		2019-2023	
PRD	N	%	N	%	N	%
Tubulointerstitial disease	274	49.1	307	49.7	197	41.8
- CAKUT	267	47.8	296	47.9	186	39.5
- Non-CAKUT	7	1.3	11	1.8	11	2.3
Glomerular disease	67	12.0	103	16.7	96	20.4
Familial/hereditary nephropathies	109	19.5	93	15.0	84	17.8
Systemic diseases affecting the kidney	29	5.2	22	3.6	18	3.8
Miscellaneous renal disorders	79	14.2	93	15.0	76	16.1

5 children in 2009-2013, 1 in 2014-2018 and 85 in 2019-2023 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 2009 and 2023 was grouped by five year time periods.

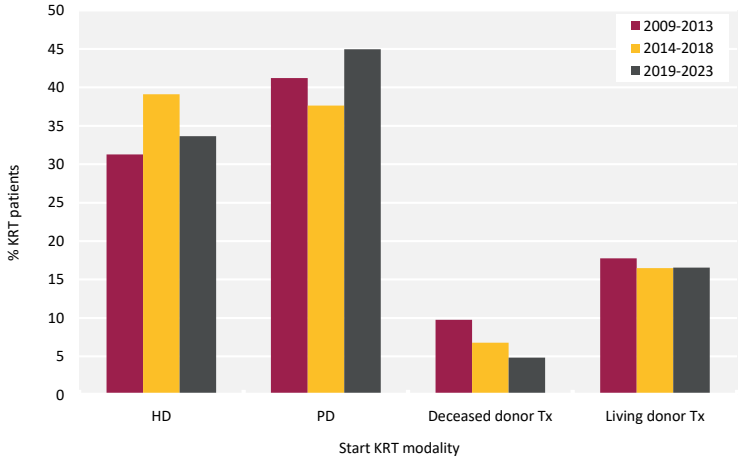

Figure 8.2 Start KRT modality for paediatric patients (<16 years old) incident to KRT by 5 year time period

Pre-emptive transplantation in incident paediatric KRT patients

The analysis of pre-emptive transplantation excluded patients starting KRT aged <3 months and patients known to have presented late.

Table 8.10 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 (2009-2023)	1,311	412 (31.4)
Time period		
2009-2013	409	154 (37.7)
2014-2018	461	140 (30.4)
2019-2023	441	118 (26.8)
Sex		
Male	832	285 (34.3)
Female	479	127 (26.5)
Ethnicity		
White	883	324 (36.7)
Asian	257	46 (17.9)
Black	65	13 (20.0)
Other	82	22 (26.8)
Age at start of RRT (yrs)		
3 mths-<2	163	6 (3.7)
2-<4	163	51 (31.3)
4-<8	237	101 (42.6)
8-<12	318	103 (32.4)
12-<16	430	151 (35.1)
PRD		
Tubulointerstitial disease	646	274 (42.4)
Glomerular disease	190	8 (4.2)
Familial/hereditary nephropathies	215	56 (26.0)
Miscellaneous renal disorders	148	36 (24.3)
Systemic diseases affecting the kidney	43	17 (39.5)

81 children were excluded because they were aged <3 months; 346 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 were grouped by age, sex and ethnicity.

Table 8.11 Age and sex breakdown of paediatric patients (<16 years old) prevalent to KRT on 31/12/2023

	All patients		Male		Female		M/F pmarp
Age group (yrs)	N	pmarp	N	pmarp	N	pmarp	ratio
0-<2	18	13.0	13	18.4	5	7.4	2.5
2-<4	36	24.9	22	29.8	14	19.9	1.5
4-<8	121	39.2	74	46.9	47	31.2	1.5
8-<12	212	65.3	138	83.0	74	46.7	1.8
12-<16	378	113.7	221	129.8	157	96.8	1.3
<16 yrs	**765**	**61.3**	**468**	**73.2**	**297**	**48.8**	**1.5**

pmarp – per million age-related population
Including Manch_P the overall N was 861 and pmarp 69.0

Table 8.12 Age and ethnicity breakdown of paediatric patients (<16 years old) prevalent to KRT on 31/12/2023

	N			
Age group (yrs)	White	Asian	Black	Other
0-<4	35	5	2	4
4-<8	80	22	8	8
8-<12	139	37	14	20
12-<16	246	72	19	31
<16 yrs	**500**	**136**	**43**	**63**

23 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 8.13 breaks down current modality for prevalent patients by age group.

Table 8.13 KRT modality used by paediatric patients (<16 years old) prevalent to KRT on 31/12/2023 by age group

		HD		PD		Living donor Tx		Deceased donor Tx	
Age group (yrs)	Total N	N	%	N	%	N	%	N	%
0-<2	18	5	27.8	13	72.2	0	0.0	0	0.0
2-<4	36	8	22.2	13	36.1	11	30.6	4	11.1
4-<8	121	16	13.2	15	12.4	68	56.2	22	18.2
8-<12	212	19	9.0	18	8.5	122	57.5	53	25.0
12-<16	378	40	10.6	24	6.3	201	53.2	113	29.9
<16 yrs	**765**	**88**	**11.5**	**83**	**10.8**	**402**	**52.5**	**192**	**25.1**

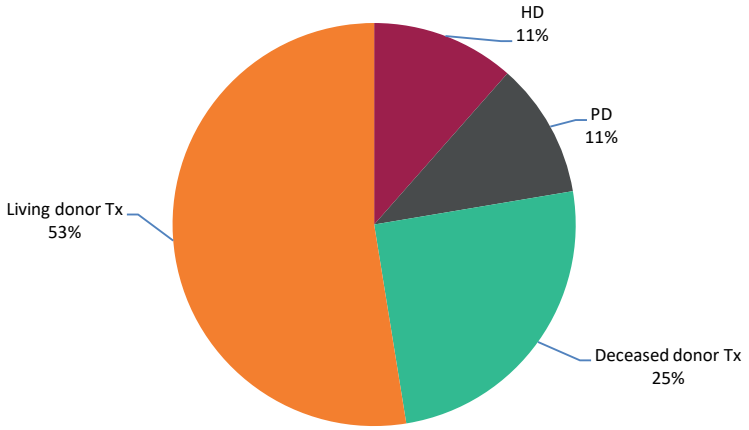

Figure 8.3 KRT modality used by paediatric patients (<16 years old) prevalent to KRT on 31/12/2023

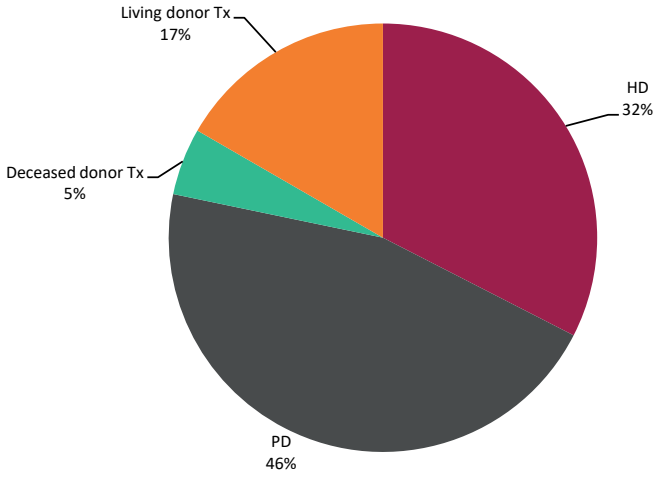

Figure 8.4 KRT modality used at the start of KRT by paediatric patients (<16 years old) prevalent to KRT on 31/12/2023

Causes of ESKD in prevalent paediatric KRT patients

PRDs were grouped into categories as shown in table 8.14.

Table 8.14 Primary renal diseases (PRDs) of paediatric patients (<16 years old) prevalent to KRT on 31/12/2023 by sex and ethnicity

PRD	N	%	N male	N female	% White
Tubulointerstitial disease	346	49.9	259	87	70.1
- CAKUT	338	48.7	254	84	70.9
- Non-CAKUT	8	1.2	5	3	37.5
Glomerular disease	118	17.0	52	66	62.9
Familial/hereditary nephropathies	115	16.6	58	57	72.6
Systemic diseases affecting the kidney	31	4.5	17	14	80.6
Miscellaneous renal disorders	84	12.1	40	44	64.6
Total (with data)	**694**	**100.0**	**426**	**268**	**69.1**
Missing	71	9.3	42	29	48.4

CAKUT – congenital anomalies of the kidneys and urinary tract

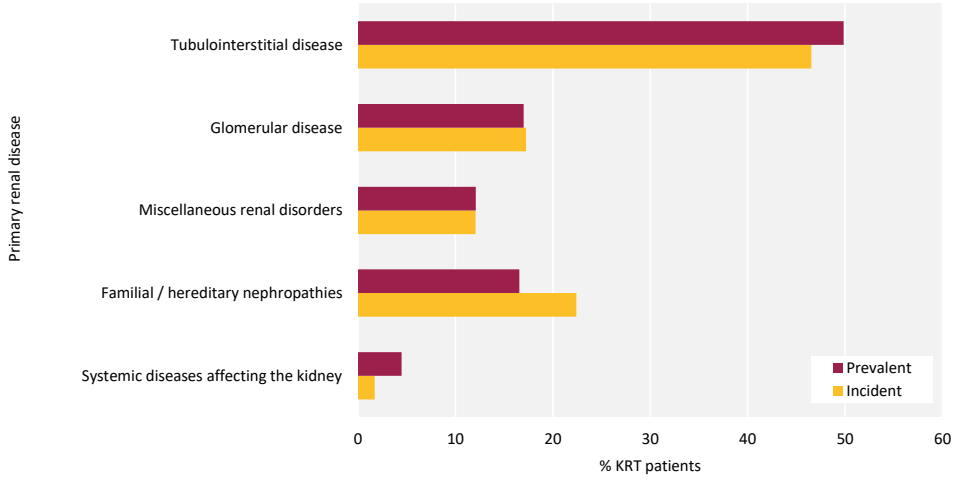

Figure 8.5 Comparison of primary renal diseases for paediatric patients (<16 years old) incident and prevalent to KRT in 2023 excluding missing data

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

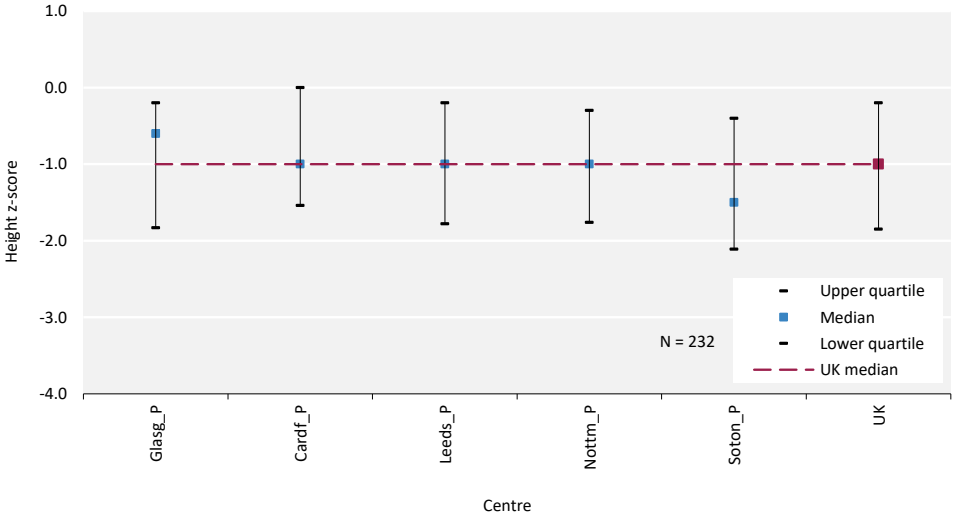

Figure 8.6 Median height z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2023 by centre

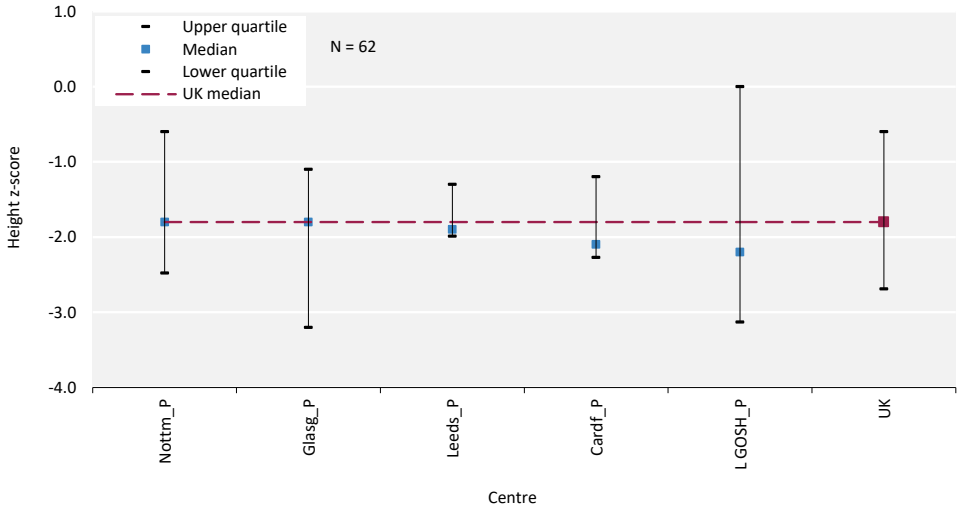

Figure 8.7 Median height z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2023 by centre (the usual centre exclusion criteria have been relaxed here)

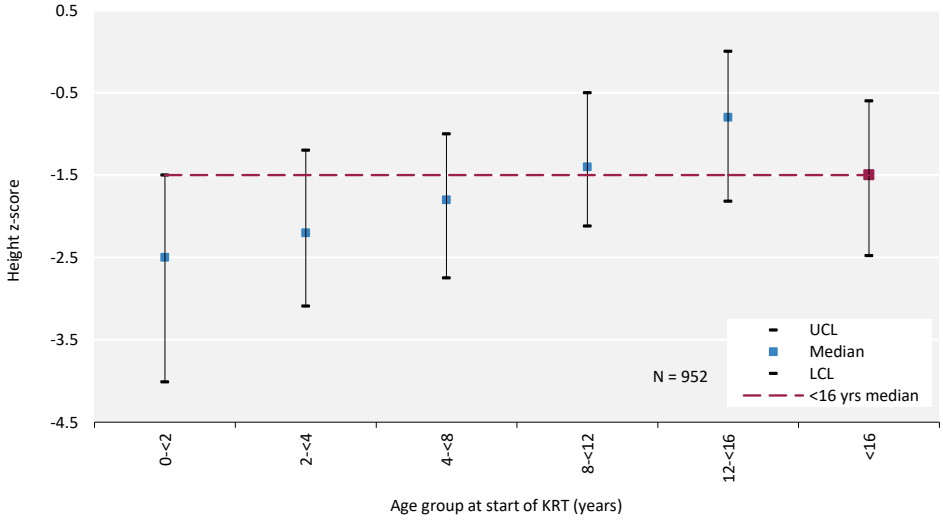

Figure 8.8 Median height z-scores at start of KRT for incident paediatric KRT patients (<16 years old) between 2009 and 2023 by age group at start of KRT

Weight of paediatric KRT patients

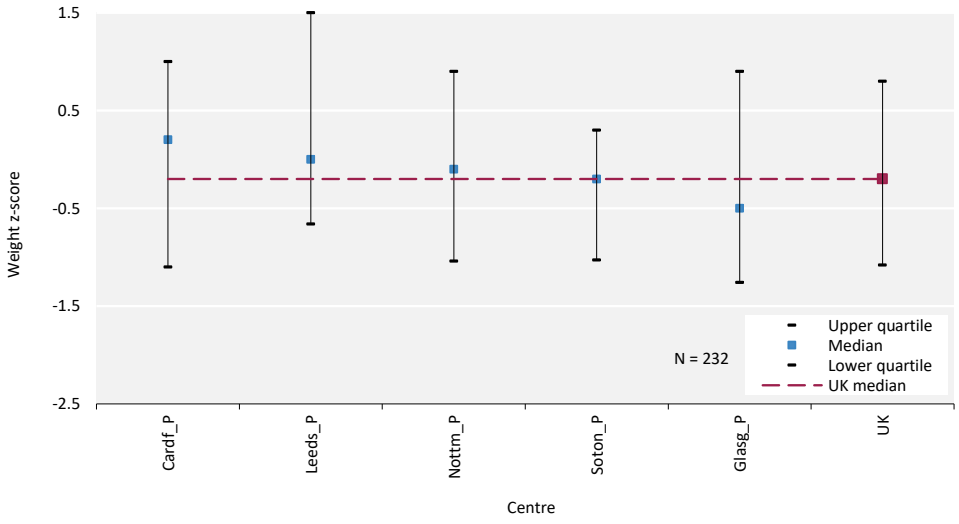

Figure 8.9 Median weight z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2023 by centre

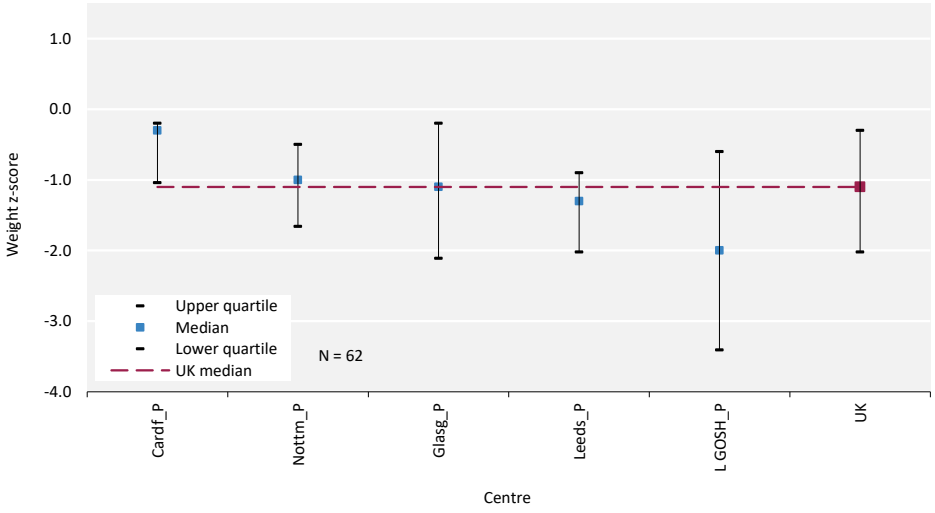

Figure 8.10 Median weight z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2023 by centre (the usual centre exclusion criteria have been relaxed here)

Cardiovascular risk factor evaluation in prevalent paediatric KRT patients

Obesity in paediatric KRT patients

BMI was calculated using the formula BMI = weight (kg)/height^2 (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.

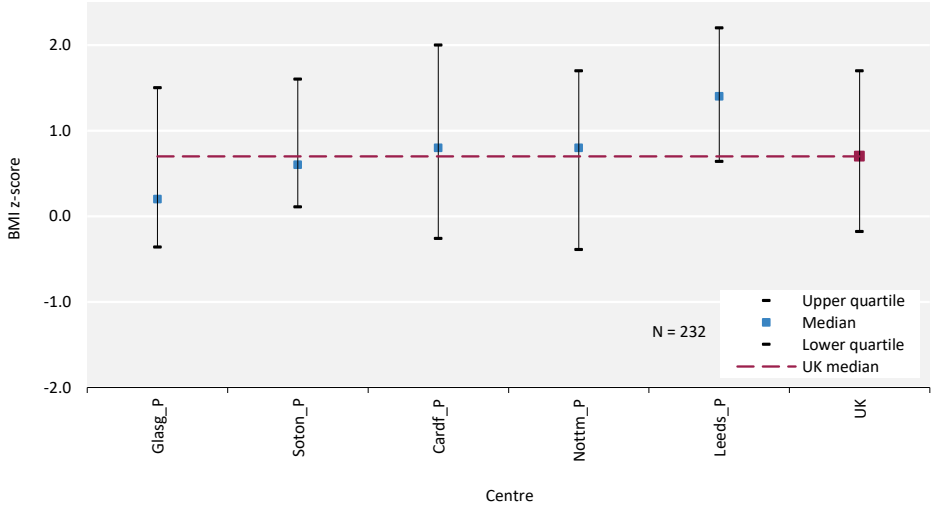

Figure 8.11 Median body mass index (BMI) z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2023 by centre

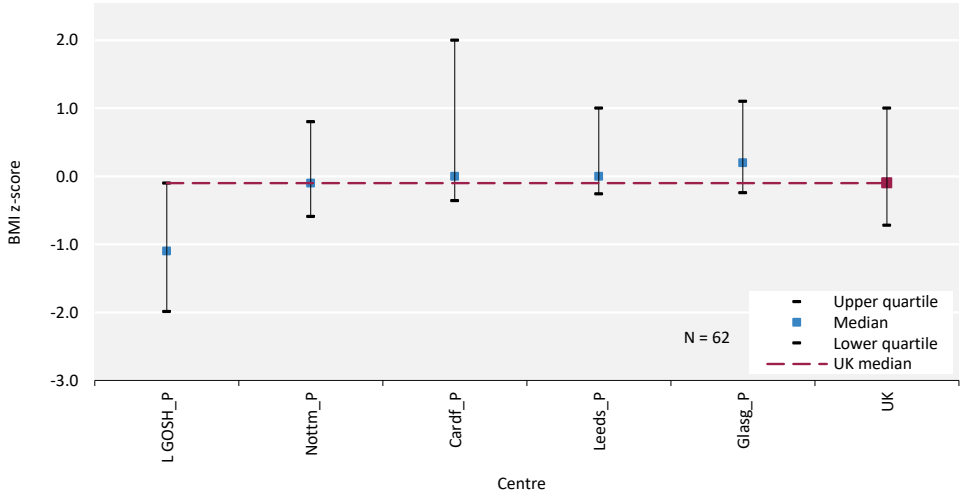

Figure 8.12 Median body mass index (BMI) z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2023 by centre (the usual centre exclusion criteria have been relaxed here)

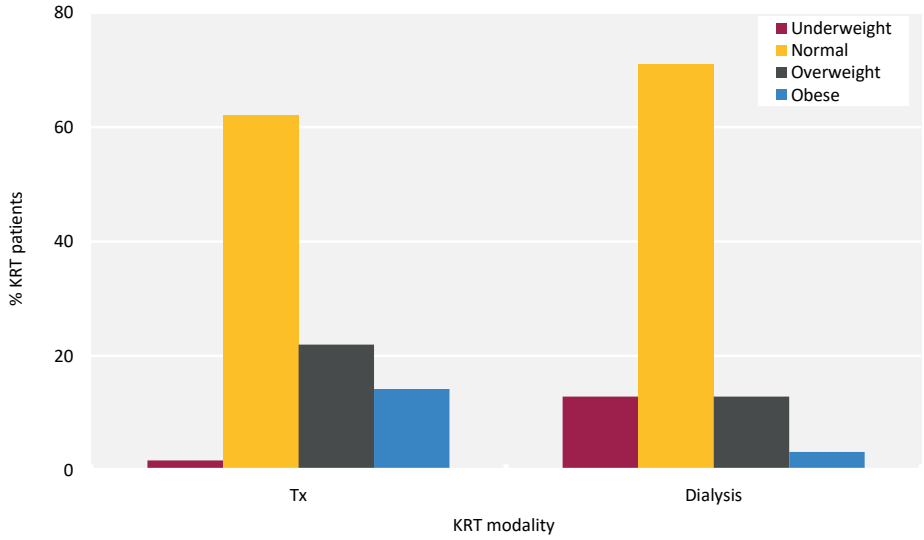

Figure 8.13 Body mass index categorisation of paediatric patients (<16 years old) prevalent to KRT on 31/12/2023 by KRT modality

Hypertension in paediatric KRT patients

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

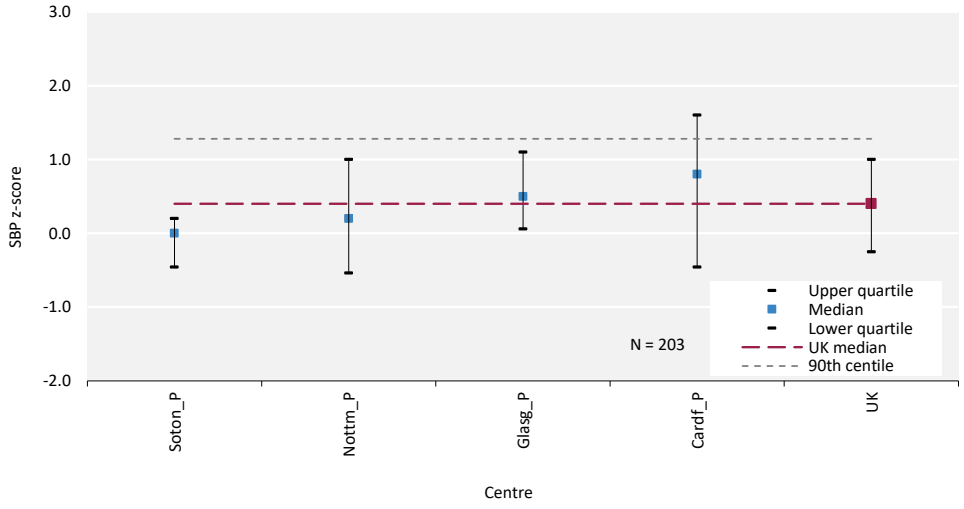

Figure 8.14 Median systolic blood pressure (SBP) z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2023 by centre

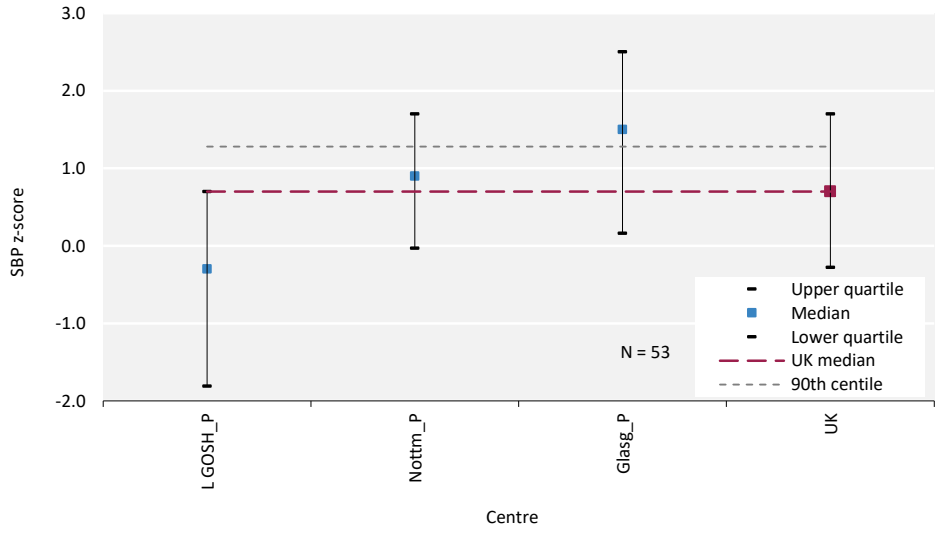

Figure 8.15 Median systolic blood pressure (SBP) z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2023 by centre (the usual centre exclusion criteria have been relaxed here)

Table 8.15 Percentage of paediatric patients (<16 years old) prevalent to KRT on 31/12/2023 achieving the standards for blood pressures

	SBP		DBP	
Characteristic	N	% <90th percentile	N	% <90th percentile
Total	256	80.08	195	81.5
Age group (yrs)				
0-<5	27	66.7	11	81.8
5-<12	93	76.3	77	81.8
12-<16	136	85.3	107	81.3
Sex				
Male	164	79.9	123	79.7
Female	92	80.4	72	84.7
Ethnicity				
White	175	78.3	137	81.8
Asian	41	85.4	26	76.9
Black	14	85.7	11	81.8
Other	20	80.0	16	81.3
Modality				
HD	26	53.9	18	61.1
PD	27	77.8	22	90.9
Tx	203	83.7	155	82.6

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 159 of the 719 patients (22.1%) with data for all three risk factors.

Table 8.16 Frequency of number of cardiovascular risk factors in paediatric patients (<16 years old) prevalent to KRT on 31/12/2023

N cardiovascular risk factors	Hypertensive	Overweight/Obese	Hypercholesterolaemic	N	%	Total %
0	No	No	No	46	28.9	28.9
1	Yes	No	No	13	8.2	
	No	Yes	No	19	11.9	39.6
	No	No	Yes	31	19.5	
2	Yes	Yes	No	10	6.3	
	Yes	No	Yes	16	10.1	27.0
	No	Yes	Yes	17	10.7	
3	Yes	Yes	Yes	7	4.4	4.4
				159		**100.0**
Total N with the risk factor	**46**	**53**	**71**			
Total % with the risk factor	**28.9**	**33.3**	**44.7**			

Biochemistry parameters in prevalent paediatric KRT patients

The median values and the percentage with eGFR <30 mL/min/1.73m^2 for prevalent 2023 paediatric Tx patients are presented in table 8.17.

Table 8.17 Median estimated glomerular filtration rate (eGFR) and percentage with eGFR <30 mL/min/1.73m^2 in paediatric patients (<16 years old) prevalent to Tx on 31/12/2023 by centre

Centre	N with Tx	Median eGFR (mL/min/1.73m^2)	% eGFR <30 mL/min/1.73m^2	% data completeness
Bham_P	71			23.9
Blfst_P	20			5.0
Brstl_P	36			0.0
Cardf_P	23	64	0.0	82.6
Glasg_P	45	66	0.0	100.0
L Eve_P	60			1.7
L GOSH_P	125			24.0
Leeds_P	44	80	9.1	75.0
Livpl_P	35			0.0
Newc_P	23			0.0
Nottm_P	51	45	10.6	92.2
Soton_P	39	63	5.3	97.4
UK	**572**	**61**	**7.8**	**40.4**

Blank cells – centres with <70% data completeness or <10 patients
For the centres with missing data, completeness of creatinine data was good but completeness of height was low (heights are needed to calculate eGFRs from creatinine)

Table 8.18 Attainment of targets for haemoglobin, calcium, phosphate, parathyroid hormone and bicarbonate in paediatric patients (<16 years old) (a) prevalent to dialysis on 31/12/2023 by centre and (b) prevalent to Tx on 31/12/2023 with estimated glomerular filtration rate (eGFR) <30 mL/min/1.73 m^2 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	18	13.3	60.0	0.0	80.0	6.7	53.3	6.7	6.7	66.7
Blfst_P	1									
Brstl_P	4									
Cardf_P	6									
Glasg_P	8									
L Eve_P	15	30.8	30.8	0.0	53.9	7.7	46.2	25.0	38.5	61.5
L GOSH_P	28	10.7	39.3			14.3	50.0	60.7		
Leeds_P	13	7.7	46.2	7.7	76.9	0.0	30.8	15.4	15.4	76.9
Livpl_P	17	23.5	47.1	5.9	64.7	0.0	47.1	43.8	0.0	94.1
Newc_P	6									
Nottm_P	27	19.2	50.0	3.9	69.2	7.7	46.2	19.2	0.0	84.6
Soton_P	4									
UK	**147**	**17.7**	**45.4**	**3.5**	**71.7**	**9.9**	**46.8**	**33.1**	**8.7**	**79.1**
TX PATIENTS WITH EGFR <30 ML/MIN/1.73 M^2										
UK	**18**	**16.7**	**83.3**	**6.3**	**87.5**	**5.6**	**83.3**	**20.0**	**12.5**	**81.3**

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 8.19 Median estimated glomerular filtration rate (eGFR) in paediatric patients (<16 years old) prevalent to Tx on 31/12/2023 by time since transplantation and age group

	Age group (yrs)					
	0-<5		5-<12		12-<16	
Time since transplantation	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						
0.25–<2 years	14	88	30	69	30	66
2–<4 years	2		21	65	18	65
4–<7 years			33	59	24	59
≥ 7 years			7	60	50	45
Total (IQR)	**16**	**92 (71-112)**	**91**	**62 (47-84)**	**122**	**56 (42-72)**

IQR – interquartile range
As seen in table 8.17, completeness of eGFR is 40% of N=572

Transfer to adult kidney services for prevalent paediatric KRT patients

One-hundred and thirty-five paediatric patients transitioned to adult kidney centres in 2023. The median age of patients at transfer was 17.9 years with an IQR of 17.5-18.1 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, 1,612 started KRT between 2009 and 2022 at paediatric kidney centres and were included in survival analyses, to allow at least one year follow-up. At the end of 2023, 107 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 7.3 years (range 1 day to 14.8 years).

Table 8.20 Unadjusted Kaplan-Meier survival (from day 90) of incident paediatric KRT patients (<16 years old) between 2009 and 2022 by age group at start of KRT

	Age group (yrs)				
	0-<2	2-<4	4-<8	8-<12	12-<16
Survival at 1 year (%)	94.9	97.7	98.9	99.2	99.6
95% CI	91.5-96.9	93.9-99.1	96.6-99.6	97.5-99.7	98.4-99.9
Survival at 2 years (%)	93.0	96.5	96.3	98.0	98.8
95% CI	89.3-95.5	92.3-98.4	93.2-98.0	95.8-99.0	97.3-99.5
Survival at 3 years (%)	89.8	95.8	95.4	97.7	97.9
95% CI	85.4-92.9	91.4-98.0	92.1-97.4	95.4-98.8	96.1-98.9
Survival at 5 years (%)	86.2	95.1	94.5	96.1	96.8
95% CI	81.2-89.9	90.4-97.5	90.9-96.7	93.2-97.8	94.7-98.1
Survival at 10 years (%)	84.3	95.1	91.6	94.1	94.2
95% CI	79.0-88.4	90.4-97.5	86.5-94.8	90.1-96.6	90.9-96.3

CI – confidence interval

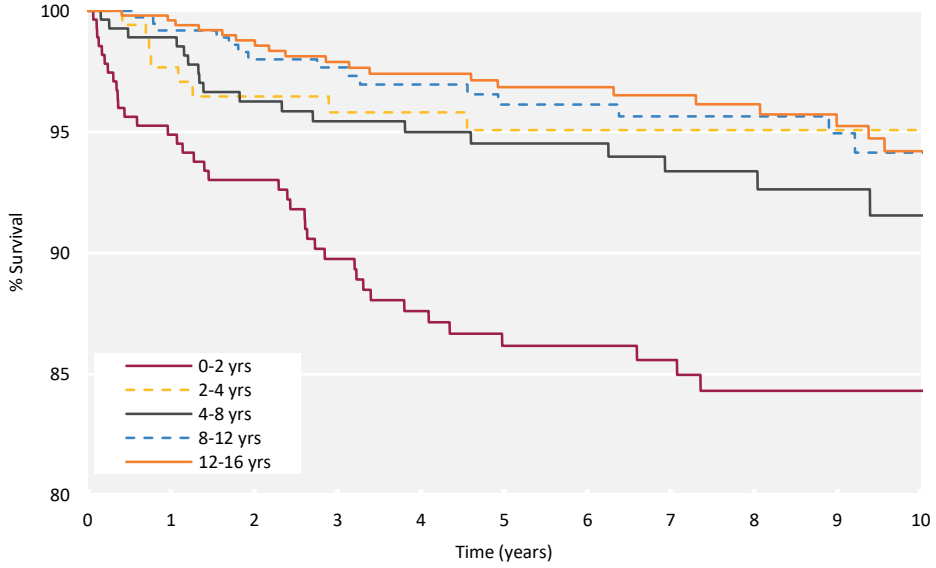

Figure 8.16 Unadjusted Kaplan-Meier survival (from day 90) of incident paediatric KRT patients (<16 years old) between 2009 and 2022 by age group at start of KRT

Analyses – young people

KRT incidence and prevalence in young people

Table 8.21 reports the numbers of young people (16-<18 years old) who started KRT in 2023 (incidence) as well as those on KRT as of 31/12/2023 (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 8.21 Demographics of young people (16-<18 years) incident to KRT in 2023 and/or prevalent to KRT on 31/12/2023, by care setting

	Incident			Prevalent		
Characteristic	Paediatric centres	Adult centres	All	Paediatric centres	Adult centres	All
N	11	13	24	181	44	225
pmarp			15.1			141.6
Median age (yrs)	16.8	17.1	17.1	16.9	17.5	17.0
% male	54.6	38.5	45.8	54.1	56.8	54.7
Ethnicity[1] (%)						
White	63.6	66.7	65.0	67.8	66.7	67.6
Asian	27.3	11.1	20.0	17.2	23.1	18.3
Black	0.0	11.1	5.0	7.2	5.1	6.9
Other	9.1	11.1	10.0	7.8	5.1	7.3
Missing ethnicity	0.0	30.8	16.7	0.6	11.4	2.7
PRD[1] (%)						
Tubulointerstitial disease	33.3	22.2	26.7	44.4	42.5	44.1
Glomerular disease	0.0	11.1	6.7	13.5	15.0	13.7
Familial/hereditary nephropathies	0.0	0.0	0.0	15.2	17.5	15.6
Systemic diseases affecting the kidney	16.7	33.3	26.7	2.9	5.0	3.3
Diabetes	0.0	0.0	0.0	0.0	0.0	0.0
Miscellaneous renal disorders	50.0	33.3	40.0	24.0	20.0	23.2
Missing PRD	45.5	30.8	37.5	5.5	9.1	6.2
Modality (%)						
HD	27.3	76.9	54.2	13.8	31.8	17.3
PD	54.6	15.4	33.3	6.6	13.6	8.0
Tx	18.2	7.7	12.5	79.6	54.6	74.7

[1]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 8.22 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 8.22 Number of centres that submitted data for young people (16-<18 years) incident to KRT in 2023 and/or prevalent to KRT on 31/12/2023, by care setting

	Incident	Prevalent
Paediatric centres	7 out of 13	12 out of 13
Adult centres	9 out of 67	22 out of 67

Transplant parameters in young people

The median values for age, creatinine and eGFR, and the proportion with an eGFR <30 mL/min/1.73m^2 for young people prevalent to Tx on 31/12/2023 are presented by care setting (adult or paediatric centre).

Table 8.23 Measures of graft function in young people (16–<18 years) prevalent to Tx on 31/12/2023, by care setting

	N on Tx	Median age (yrs)	N with creatinine data	Median creatinine (µmol/L)	Median FAS-eGFR (mL/min/1.73m^2)	% FAS-eGFR <30 mL/min/1.73m^2	% creatinine completeness
Paediatric centres	144	17.0	144	110	69	4.9	100.0
Adult centres	24	17.5	24	130	58	4.2	100.0

Table 8.24 reports the median eGFR for all young people prevalent to Tx on 31/12/2023 by time since transplantation. Small numbers preclude further analysis by care setting (adult or paediatric centre).

Table 8.24 Estimated glomerular filtration rate (eGFR) in young people (16-<18 years) prevalent to Tx on 31/12/2023 by time since transplantation

Time since transplantation	N	Median FAS-eGFR (mL/min/1.73m^2)
< 3 months	5	
3 months–<2 years	37	75
2–<4 years	24	69
4–<7 years	36	60
≥ 7 years	64	63
Total (IQR)	**166**	**67 (53-81)**

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

Biochemical and blood pressure measures in young people

Table 8.25 shows attainment of biochemical and blood pressure measures for young people prevalent to dialysis and transplant on 31/12/2023 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 8.25 Attainment of biochemical and blood pressure measures in young people (16-<18 years) prevalent to KRT on 31/12/2023, by modality and care setting

	Dialysis			Tx		
Characteristic	Paediatric centres	Adult centres	All	Paediatric centres	Adult centres	All
N	37	20	57	144	24	168
Median (IQR) Hb (g/L)	116 (103-124)	100 (94-117)	109 (97-124)	127 (114-139)	120.5 (104-134)	126 (113-139)
% Hb <100g/L	19.4	47.4	29.1	7.0	8.3	7.2
Median (IQR) Ca (mmol/L)	2.5 (2.4-2.6)	2.3 (2.2-2.4)	2.4 (2.3-2.5)	2.4 (2.4-2.5)	2.4 (2.3-2.5)	2.4 (2.4-2.5)
% Ca in range	70.4	84.2	76.1	90.4	86.4	89.8
Median (IQR) Phos (mmol/L)	1.7 (1.4-2.2)	2 (1.6-2.1)	1.8 (1.5-2.2)	1.1 (1-1.2)	1.1 (0.9-1.3)	1.1 (1-1.3)
% phos in range	52.8	31.6	45.5	64.3	54.2	62.9
Median (IQR) bicarb (mmol/L)	24 (21-27)	22 (18-25)	23 (20-26)	23 (21-25)	22 (20-26)	23 (21-25)
% bicarb in range	60.7	50.0	56.5	77.9	52.4	74.1
Median (IQR) SBP (mmHg)	128 (117-138)	125 (117-140)	126 (117-138)	116 (110-123)	124.5 (111-137)	116 (110-125)
Median (IQR) DBP (mmHg)	72 (65-89)	77.5 (67-86)	72 (65-88)	69 (60-78)	77 (70-83)	70 (60-79)
% 'normal' BP range (<130/80 mmHg)	41.7	57.1	47.4	72.3	50.0	69.1
% high BP (≥140/90 mmHg)	33.3	28.6	31.6	4.8	21.4	7.2

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

Analyses - Under 18 yrs old with CKD

For the 6 paediatric centres that were able to submit data on their CKD population, the number of prevalent patients with CKD is presented as crude rate per million age-related population (PMARP).

Table 8.26 Demographics and CKD stage of under 18's on 31/12/23

Centre	N with CKD <18yrs old	Median (IQR) age in yrs	% male	% stage G4	% stage G5	CKD 2023 crude rate (pmarp)
Brstl_P	22	10.6 (4.7-13.2)	72.7	90.9	9.1	21.4
Glasg_P	11	10.6 (3.1-14.4)	63.6	90.9	9.1	10.9
L Eve_P	63	10.3 (6.0-13.9)	65.1	76.2	23.8	36.1
L GOSH_P	49	11.0 (6.8-14.3)	71.4	65.3	34.7	16.9
Nottm_P	13	8.9 (6.0-14.6)	61.5	61.5	38.5	9.2
Soton_P	15	6.7 (4.4-10.5)	66.7	66.7	33.3	29.1
Total	**173**	**9.9 (6.0-14.1)**	**67.6**	**74.0**	**26.0**	**20.1**

pmarp - per million age-related population