Chapter 8

Children and young people on kidney replacement therapy (KRT) for end-stage kidney disease (ESKD) in the UK in 2022

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 2022 (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.
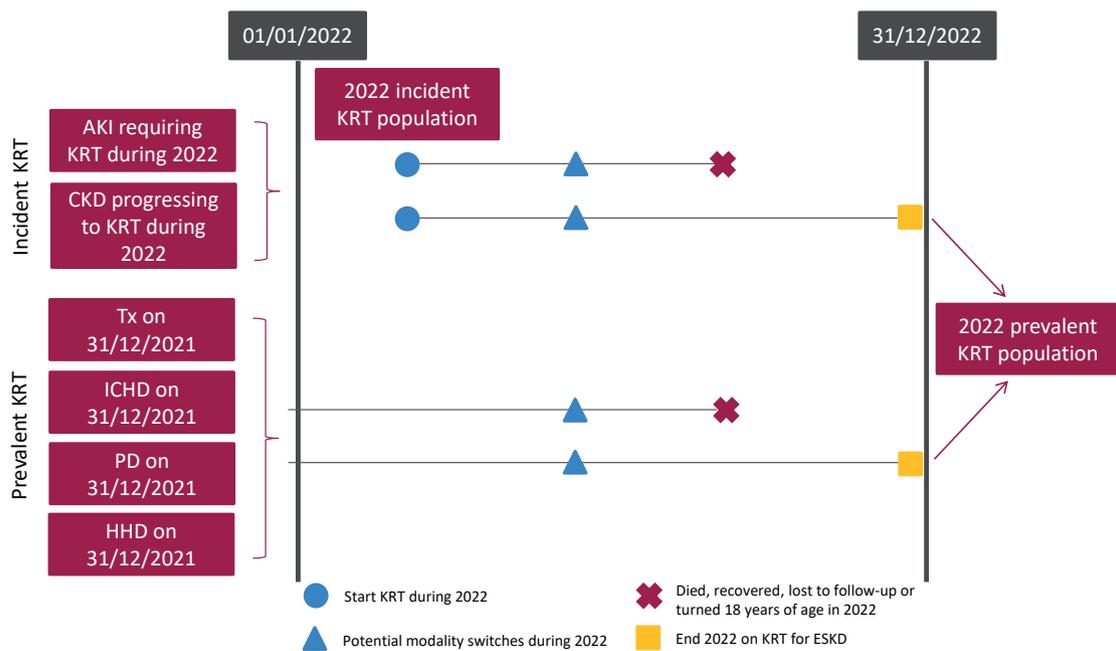
Figure 8.1 Pathways children and young people could follow to be included in the UK 2022 incident and/or prevalent KRT populations

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 2022 and remained on KRT for at least 90 days.
- **Prevalent population:** patients who were on KRT at the end of 2022 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 2008-2012, 2013-2017 and 2018-2022.

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

- **Incident population:** patients who started KRT during 2022 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 2022 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 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.

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Children and young people on KRT in the UK in 2022

Rationale for analyses

For both the children and young people sections, the analyses begin with a description of the 2022 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 2022 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

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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 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'.

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Key findings

Children

- 109 patients aged <16 years started KRT for ESKD in the UK in 2022 compared to 110 patients in 2021.

- KRT incidence in patients aged <16 years was 8.8 pmarp compared to 8.9 pmarp in 2021.

- 844 patients aged <16 years were receiving KRT at UK paediatric kidney centres on 31/12/2022, similar to the number in 2021.

- KRT prevalence in patients aged <16 years was 68.0 pmarp. 76.8% had a functioning Tx (50.4% living donor and 26.4% deceased donor), 12.0% were receiving HD and 11.3% 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 (3:1).

- Between 2008 and 2022, 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, 73.7% of paediatric patients had a functioning kidney Tx.

- The median height z-score for children on dialysis was -1.4 compared with -0.9 for those with a functioning Tx.

- The median weight z-score for children on dialysis was -0.7 compared with -0.2 for those with a functioning Tx.

- The overall median eGFR of the 628 children with a kidney transplant on 31/12/2022 was 61 mL/min/1.73m^2 and 6.6% had an eGFR of <30 mL/min/1.73m^2.

- Of those with complete data, 71.7% of the prevalent paediatric KRT population had 1 or more risk factors for cardiovascular disease; 7.1% had 3 risk factors.

- 57.1% and 58.6% of prevalent HD patients achieved systolic blood pressure (SBP) and diastolic blood pressure (DBP) values <90th percentile, respectively.

- 66.7% and 66.7% of prevalent PD patients achieved SBP and DBP values <90th percentile, respectively.

- 79.8% and 82.1% of prevalent Tx patients achieved SBP and DBP values <90th percentile, respectively.

Young people

- 28 patients aged 16 to <18 years started KRT for ESKD in the UK in 2022.

- KRT incidence in young people was 18.1 pmarp.

- 243 patients aged 16 to <18 years were receiving KRT on 31/12/2022, of whom the majority (85.6%) were managed in paediatric kidney centres.

- KRT prevalence in patients aged 16 to <18 years was 157.4 pmarp.

- Tubulointerstital disease accounted for 43.8% of all PRDs in prevalent young people, followed by familial/hereditary nephropathies (21.7%) and glomerular disease (15.0%).

- The overall median eGFR of young people with a kidney transplant on 31/12/2022 was 66 mL/min/1.73m^2 and 6.0% had an eGFR of <30 mL/min/1.73m^2.

- Of prevalent young people managed in paediatric kidney centres, 60.6% of those on dialysis and 72.4% of those transplanted had a blood pressure in the 'normal' range (<130/80 mmHg).

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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

Centre	N on KRT					Estimated catchment population <16 (millions)	2022 crude rate (pmarp)
	2018	2019	2020	2021	2022		
Bham_P	97	87	105	98	103	1.22	84
Blfst_P	29	29	27	25	25	0.39	64
Brstl_P	54	53	50	52	50	0.91	55
Cardf_P	28	30	29	28	26	0.39	67
Glasg_P	57	54	58	56	58	0.89	65
L Eve_P	80	77	78	82	86	1.54	56
L GOSH_P	148	150	155	157	159	2.55	62
Leeds_P	58	56	57	59	59	0.78	75
Livpl_P	40	30	39	42	46	0.59	79
Manch_P	82	87	87	86	82	0.94	88
Newc_P	36	37	35	34	30	0.52	57
Nottm_P	70	73	86	83	79	1.24	64
Soton_P	30	30	34	43	41	0.45	90
UK	**809**	**793**	**840**	**845**	**844**	**12.41**	**68**

pmarp – per million age-related population

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Data completeness for prevalent paediatric KRT patients

Data returns of key variables for Tx and dialysis patients <16 years old at the end of 2022 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 31/12/2022 by centre

| Centre | N with Tx | Data completeness (%) | | | | | | | | | | | |
		Height	Weight	BMI	SBP	DBP	Hb	Creat	Chol	Bicarb	PTH	Ca	Phos
Bham_P	72	97.2	98.6	97.2	97.2	95.8	98.6	98.6	98.6	98.6	97.2	98.6	98.6
Blfst_P	20	20.0	95.0	20.0	20.0	20.0	100.0	100.0	90.0	100.0	95.0	100.0	100.0
Brstl_P	35	0.0	97.1	0.0	94.3	82.9	97.1	97.1	31.4	97.1	71.4	97.1	97.1
Cardf_P	18	0.0	94.4	0.0	94.4	0.0	94.4	94.4	5.6	94.4	16.7	94.4	94.4
Glasg_P	44	100.0	100.0	100.0	97.7	97.7	88.6	90.9	56.8	97.7	86.4	90.9	90.9
L Eve_P	64	0.0	100.0	0.0	100.0	100.0	100.0	100.0	46.9	100.0	98.4	100.0	100.0
L GOSH_P	125	28.8	35.2	28.8	22.4	22.4	91.2	37.6	4.8	4.0	19.2	0.0	37.6
Leeds_P	43	97.7	100.0	97.7	100.0	65.1	100.0	100.0	7.0	100.0	97.7	100.0	100.0
Livpl_P	28	0.0	7.1	0.0	7.1	3.6	96.4	96.4	64.3	96.4	89.3	96.4	96.4
Manch_P	64	0.0	0.0	0.0	100.0	98.4	100.0	100.0	70.3	100.0	76.6	100.0	100.0
Newc_P	25	0.0	0.0	0.0	100.0	4.0	100.0	100.0	52.0	100.0	80.0	100.0	100.0
Nottm_P	54	90.7	98.2	90.7	92.6	83.3	98.2	100.0	64.8	100.0	74.1	100.0	100.0
Soton_P	36	100.0	100.0	100.0	86.1	75.0	88.9	88.9	0.0	88.9	86.1	88.9	88.9
UK	**628**	**44.8**	**68.0**	**44.8**	**75.5**	**64.0**	**96.0**	**85.7**	**44.0**	**79.5**	**71.5**	**78.2**	**85.7**

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 31/12/2022 by centre

| Centre | N on dialysis | Data completeness (%) | | | | | | | | | | | |
		Height	Weight	BMI	SBP	DBP	Hb	Chol	Bicarb	PTH	Ca	Phos
Bham_P	27	92.6	92.6	92.6	88.9	70.4	96.3	96.3	96.3	96.3	96.3	96.3
Blfst_P	3	33.3	66.7	33.3	33.3	33.3	66.7	0.0	66.7	66.7	66.7	66.7
Brstl_P	11	0.0	90.9	0.0	90.9	54.6	90.9	63.6	90.9	81.8	90.9	90.9
Cardf_P	6	0.0	66.7	0.0	33.3	0.0	100.0	33.3	100.0	100.0	100.0	100.0
Glasg_P	13	100.0	100.0	100.0	100.0	84.6	100.0	61.5	100.0	100.0	92.3	92.3
L Eve_P	15	0.0	100.0	0.0	100.0	100.0	93.3	73.3	93.3	93.3	93.3	93.3
L GOSH_P	22	72.7	86.4	72.7	77.3	77.3	90.9	45.5	18.2	72.7	0.0	81.8
Leeds_P	9	100.0	100.0	77.8	100.0	0.0	100.0	77.8	100.0	100.0	100.0	100.0
Livpl_P	14	0.0	0.0	0.0	0.0	0.0	92.9	35.7	92.9	92.9	92.9	92.9
Manch_P	15	0.0	33.3	0.0	100.0	26.7	93.3	60.0	93.3	93.3	93.3	93.3
Newc_P	5	0.0	0.0	0.0	100.0	0.0	100.0	40.0	100.0	80.0	100.0	100.0
Nottm_P	20	65.0	90.0	65.0	65.0	40.0	100.0	40.0	100.0	100.0	100.0	100.0
Soton_P	3	100.0	100.0	100.0	100.0	66.7	100.0	33.3	100.0	100.0	100.0	100.0
UK	**163**	**49.1**	**75.5**	**47.9**	**77.9**	**50.9**	**95.1**	**58.9**	**85.3**	**91.4**	**82.2**	**93.3**

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

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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 2022 by age and sex

Age group (yrs)	All patients		Male		Female	
	N	pmarp	N	pmarp	N	pmarp
0-<2	13	9.4	7	9.9	6	8.9
2-<4	10	6.9	6	8.1	4	5.6
4-<8	13	4.2	7	4.5	6	4.0
8-<12	36	11.1	17	10.2	19	12.0
12-<16	37	11.4	24	14.4	13	8.2
<16 yrs	**109**	**8.8**	**61**	**9.6**	**48**	**7.9**

pmarp – per million age-related population

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

Age group (yrs)	2008-2012		2013-2017		2018-2022	
	N	pmarp	N	pmarp	N	pmarp
0-<2	95	12.1	116	14.8	87	12.1
2-<4	59	7.6	74	9.0	56	7.3
4-<8	90	6.3	121	7.5	81	5.0
8-<12	121	8.6	134	9.0	157	9.4
12-<16	205	13.6	171	12.1	189	12.0
<16 yrs	**570**	**9.6**	**616**	**10.1**	**570**	**9.0**

pmarp – per million age-related population

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

Ethnicity	2008-2012		2013-2017		2018-2022	
	N	%	N	%	N	%
White	408	72.0	423	69.0	339	67.7
Asian	98	17.3	117	19.1	97	19.4
Black	26	4.6	33	5.4	32	6.4
Other	35	6.2	40	6.5	33	6.6
<16 yrs	**567**	**100.0**	**613**	**100.0**	**501**	**100.0**

3 children in 2008-2012, 3 in 2013-2017 and 69 in 2018-2022 with no ethnicity recorded were excluded

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

Centre	2008-2012		2013-2017		2018-2022	
	N	%	N	%	N	%
Bham_P	68	11.9	79	12.8	68	11.9
Blfst_P	27	4.7	12	1.9	10	1.8
Brstl_P	32	5.6	35	5.7	33	5.8
Cardf_P	16	2.8	21	3.4	20	3.5
Glasg_P	44	7.7	44	7.1	42	7.4
L Eve_P	62	10.9	70	11.4	64	11.2
L GOSH_P	113	19.8	100	16.2	94	16.5
Leeds_P	43	7.5	49	8.0	40	7.0
Livpl_P	18	3.2	32	5.2	43	7.5
Manch_P	51	8.9	71	11.5	55	9.6
Newc_P	21	3.7	32	5.2	19	3.3
Nottm_P	55	9.6	52	8.4	53	9.3
Soton_P	20	3.5	19	3.1	29	5.1
<16 yrs	**570**	**100.0**	**616**	**100.0**	**570**	**100.0**

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

PRD	2008-2012		2013-2017		2018-2022	
	N	%	N	%	N	%
Tubulointerstitial disease	271	48.0	300	48.8	201	42.1
- CAKUT	262	46.5	291	47.3	190	39.8
- Non-CAKUT	9	1.6	9	1.5	11	2.3
Glomerular disease	71	12.6	103	16.7	97	20.3
Familial/hereditary nephropathies	111	19.7	101	16.4	77	16.1
Systemic diseases affecting the kidney	33	5.9	17	2.8	23	4.8
Miscellaneous renal disorders	78	13.8	94	15.3	79	16.6

6 children in 2008-2012, 1 in 2013-2017 and 93 in 2018-2022 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 2008 and 2022 was grouped by five year time periods.
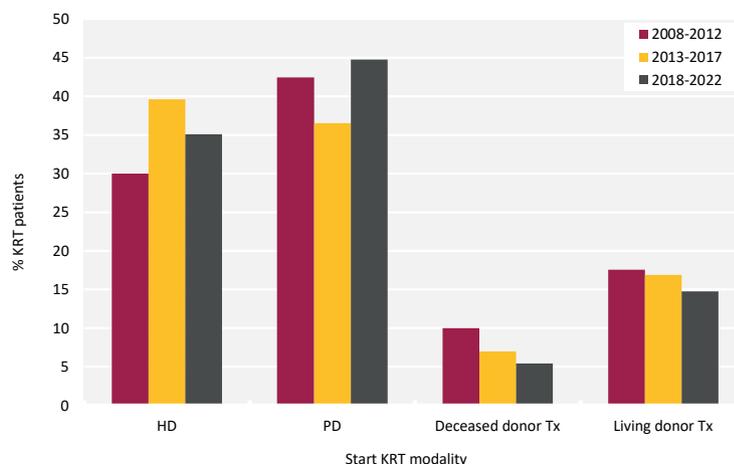
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Figure 8.2 Start KRT modality for paediatric patients (<16 years old) incident to KRT by 5 year time period

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 (2008-2022)	1,310	413 (31.5)
Time period		
2008-2012	413	156 (37.8)
2013-2017	456	143 (31.4)
2018-2022	441	114 (25.9)
Sex		
Male	833	288 (34.6)
Female	477	125 (26.2)
Ethnicity		
White	867	318 (36.7)
Asian	234	48 (20.5)
Black	63	10 (15.9)
Other	81	19 (23.5)
Age at start of KRT (yrs)		
3 mths-<2	156	6 (3.8)
2-<4	163	52 (31.9)
4-<8	231	99 (42.9)
8-<12	324	101 (31.2)
12-<16	436	155 (35.6)
PRD		
Tubulointerstitial disease	630	269 (42.7)
Glomerular disease	191	6 (3.1)
Familial/hereditary nephropathies	219	58 (26.5)
Miscellaneous renal disorders	143	38 (26.6)
Systemic diseases affecting the kidney	41	17 (41.5)

85 children were excluded because they were aged <3 months; 361 children were excluded because they presented late

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Children and young people on KRT in the UK in 2022

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 31/12/2022

Age group (yrs)	All patients		Male		Female		M/F pmarp ratio
	N	pmarp	N	pmarp	N	pmarp	
0-<2	18	13.0	10	14.1	8	11.8	1.2
2-<4	34	23.4	20	26.9	14	19.8	1.4
4-<8	141	45.9	92	58.5	49	32.7	1.8
8-<12	262	80.6	176	105.8	86	54.2	2.0
12-<16	389	119.8	222	133.5	167	105.4	1.3
<16 yrs	**844**	**68.0**	**520**	**81.9**	**324**	**53.5**	**1.5**

pmarp – per million age-related population

Table 8.12 Age and ethnicity breakdown of paediatric patients (<16 years old) prevalent to KRT on 31/12/2022

Age group (yrs)	N			
	White	Asian	Black	Other
0-<4	34	5	0	4
4-<8	91	22	12	8
8-<12	174	40	11	26
12-<16	234	78	20	29
<16 yrs	**533**	**145**	**43**	**67**

56 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 31/12/2022 by age group

Age group (yrs)	Total N	HD		PD		Living donor Tx		Deceased donor Tx	
		N	%	N	%	N	%	N	%
0-<2	18	4	22.2	14	77.8	0	0.0	0	0.0
2-<4	34	7	20.6	12	35.3	13	38.2	2	5.9
4-<8	141	17	12.1	13	9.2	85	60.3	26	18.4
8-<12	262	26	9.9	25	9.5	140	53.4	71	27.1
12-<16	389	47	12.1	31	8.0	187	48.1	124	31.9
<16 yrs	**844**	**101**	**12.0**	**95**	**11.3**	**425**	**50.4**	**223**	**26.4**
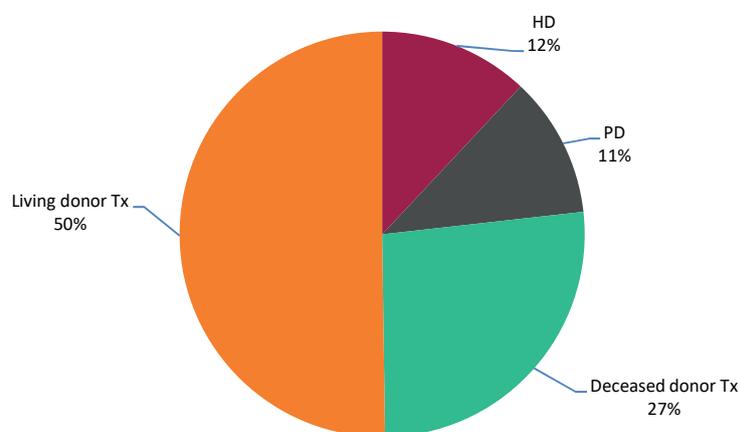
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Figure 8.3 KRT modality used by paediatric patients (<16 years old) prevalent to KRT on 31/12/2022
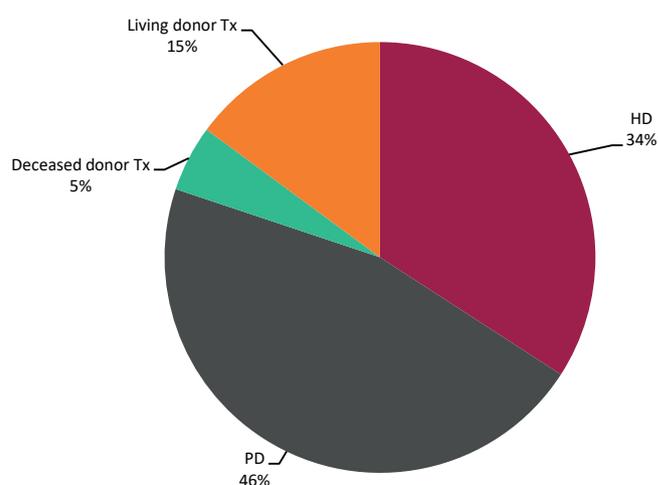

Figure 8.4 KRT modality used at the start of KRT by paediatric patients (<16 years old) prevalent to KRT on 31/12/2022

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 31/12/2022 by sex and ethnicity

PRD	N	%	N male	N female	% White
Tubulointerstitial disease	378	49.3	284	94	70.0
- CAKUT	369	48.1	278	91	70.6
- Non-CAKUT	9	1.2	6	3	44.4
Glomerular disease	128	16.7	60	68	62.9
Familial/hereditary nephropathies	117	15.3	55	62	64.9
Systemic diseases affecting the kidney	38	5.0	21	17	83.8
Miscellaneous renal disorders	106	13.8	51	55	66.3
Total (with data)	**767**	**100.0**	**471**	**296**	**68.2**
Missing	77	9.1	49	28	55.6

CAKUT – congenital anomalies of the kidneys and urinary tract

Children and young people on KRT in the UK in 2022
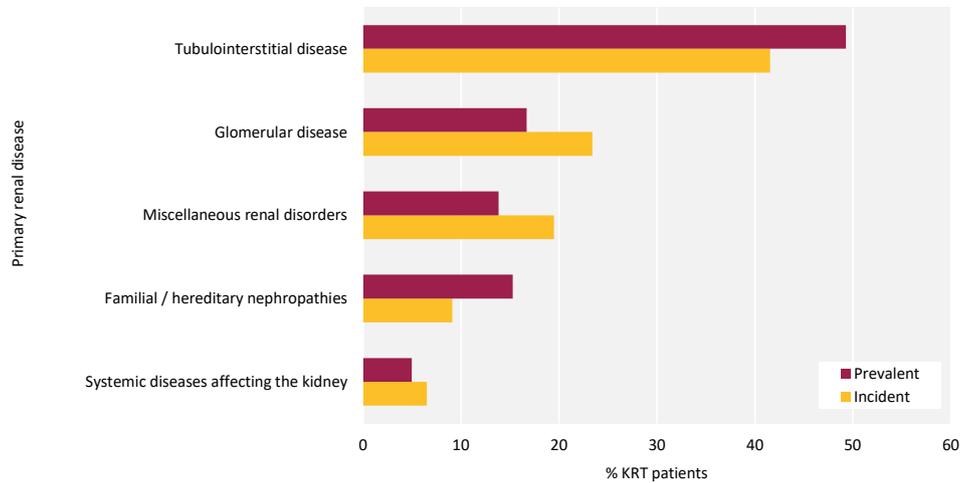
Figure 8.5 Comparison of primary renal diseases for paediatric patients (<16 years old) incident and prevalent to KRT in 2022 with no missing data

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
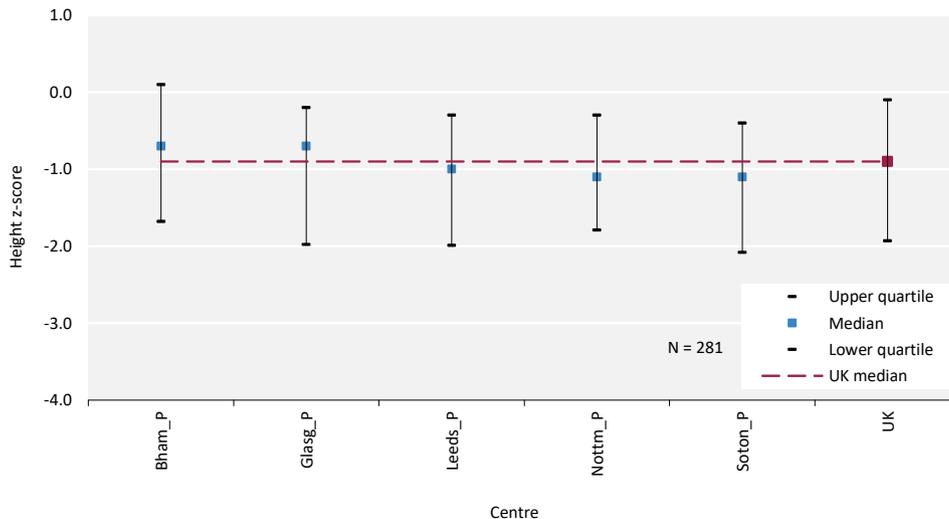
Figure 8.6 Median height z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2022 by centre

Paediatrics

Children and young people on KRT in the UK in 2022
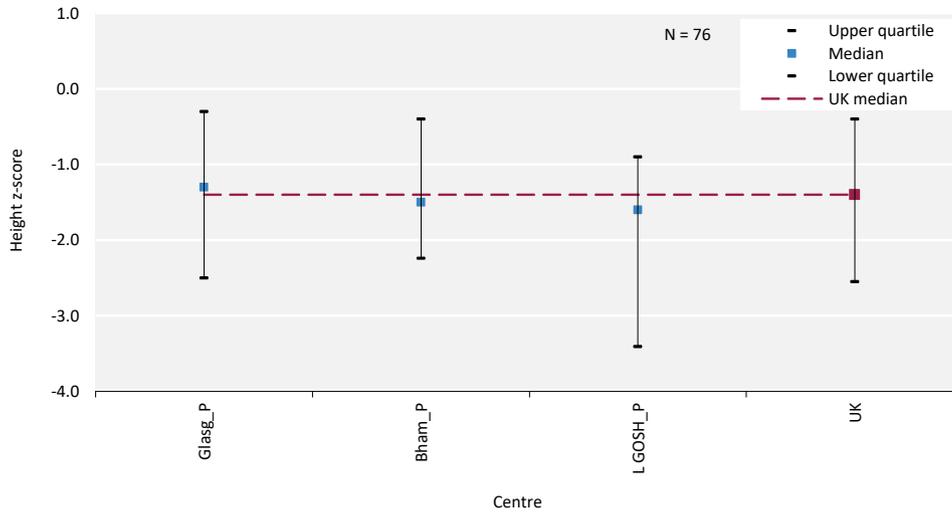
Figure 8.7 Median height z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2022 by centre
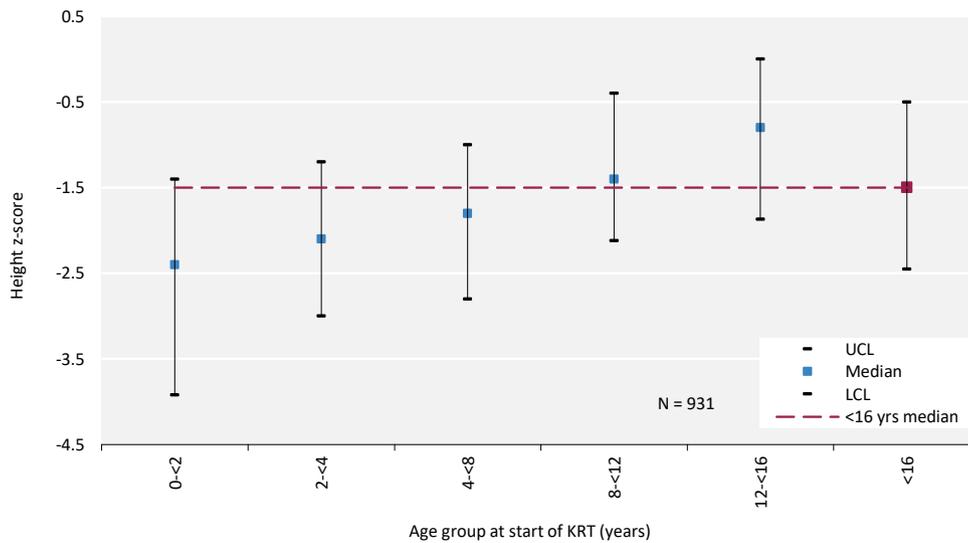
Figure 8.8 Median height z-scores at start of KRT for incident paediatric KRT patients (<16 years old) between 2008 and 2022 by age group at start of KRT

Children and young people on KRT in the UK in 2022

Paediatrics

Weight of paediatric KRT patients
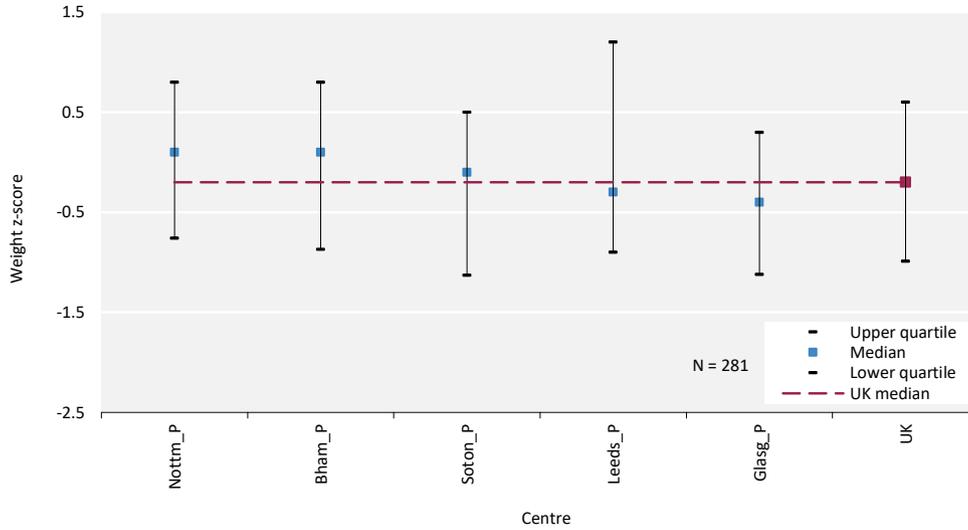
Figure 8.9 Median weight z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2022 by centre
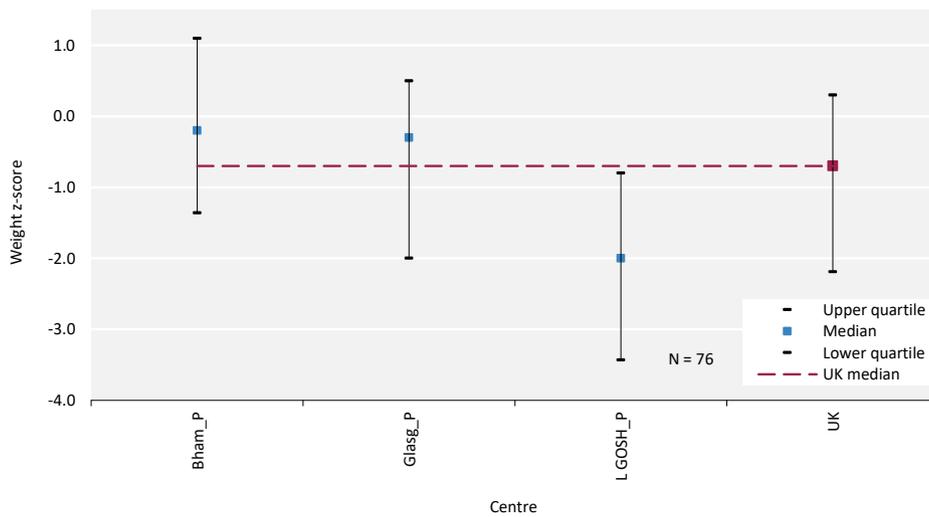
Figure 8.10 Median weight z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2022 by centre

Children and young people on KRT in the UK in 2022

Paediatrics

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.
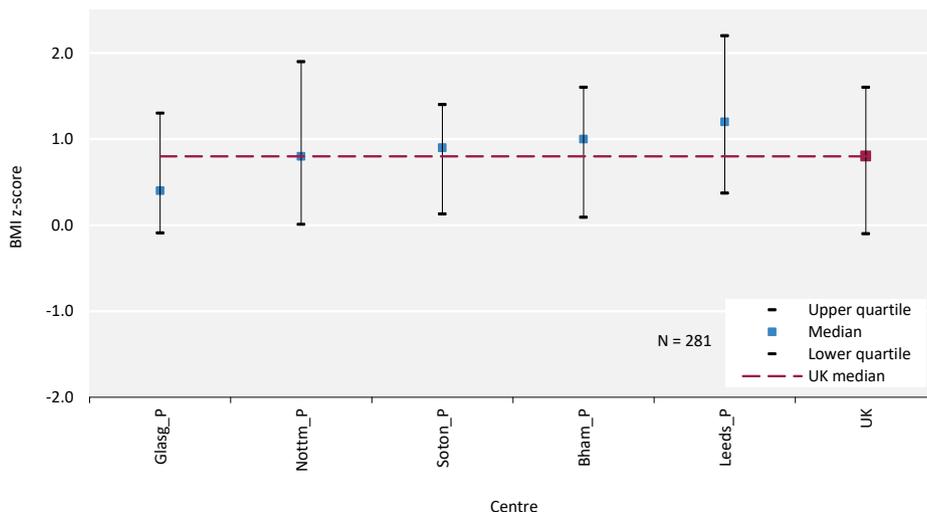
Figure 8.11 Median body mass index (BMI) z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2022 by centre
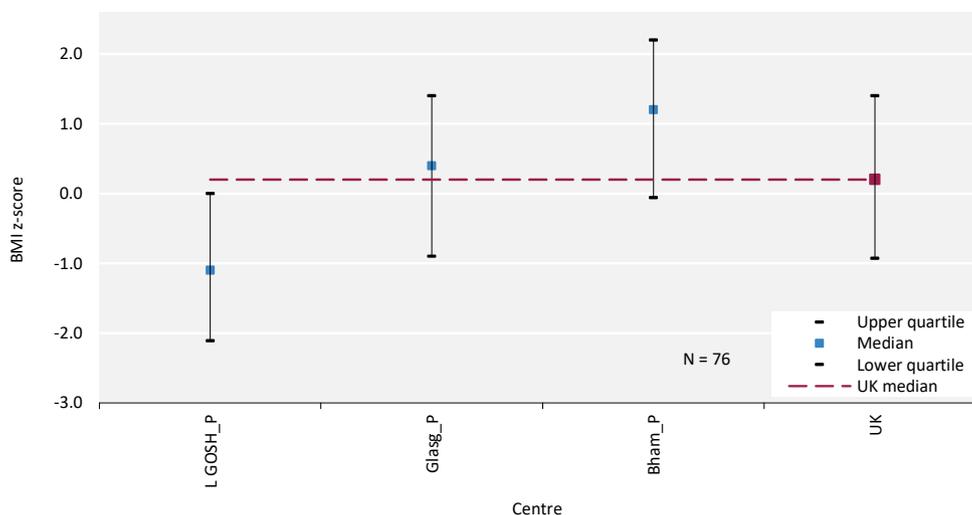
Figure 8.12 Median body mass index (BMI) z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2022 by centre

Children and young people on KRT in the UK in 2022
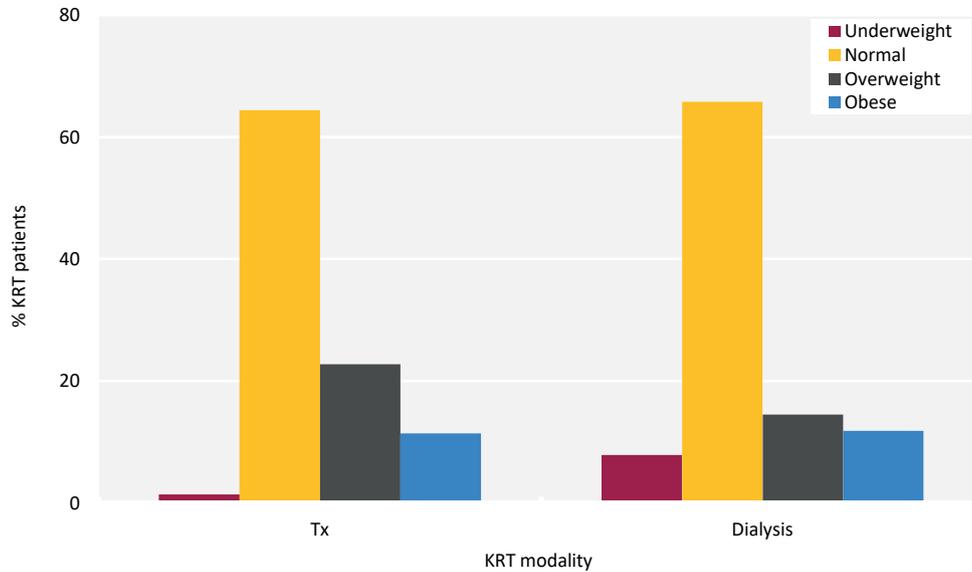
Paediatrics

Figure 8.13 Body mass index categorisation of paediatric patients (<16 years old) prevalent to KRT on 31/12/2022 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.
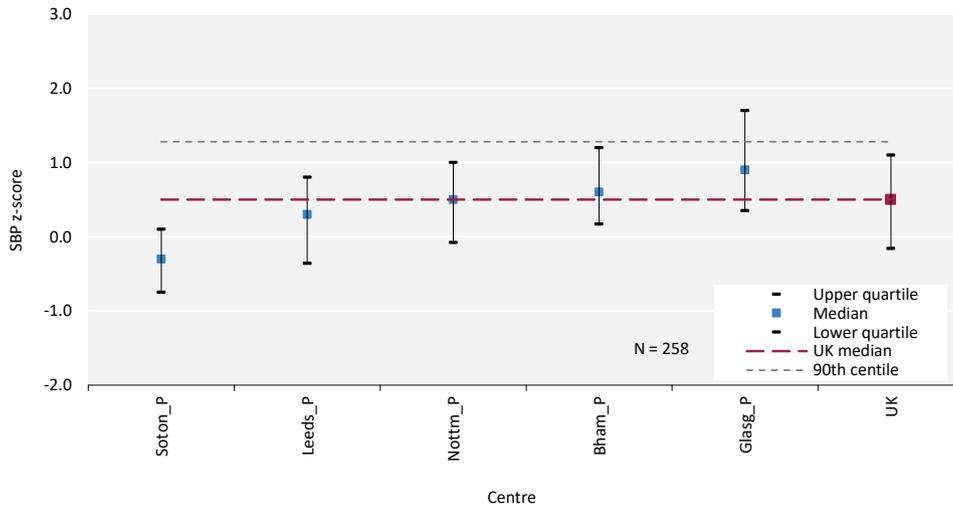
Figure 8.14 Median systolic blood pressure (SBP) z-scores for paediatric patients (<16 years old) prevalent to Tx on 31/12/2022 by centre
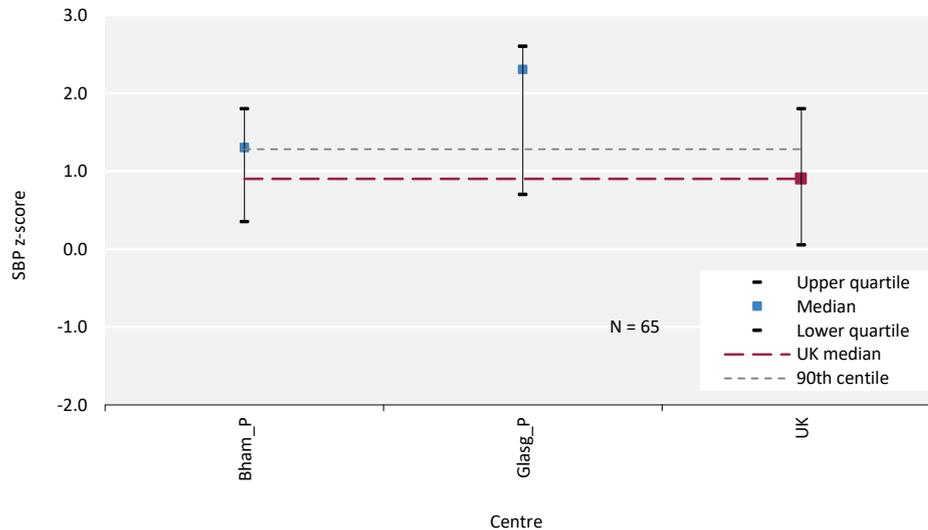
Paediatrics

Figure 8.15 Median systolic blood pressure (SBP) z-scores for paediatric patients (<16 years old) prevalent to dialysis on 31/12/2022 by centre

Table 8.15 Percentage of paediatric patients (<16 years old) prevalent to KRT on 31/12/2022 achieving the standards for blood pressures

	SBP		DBP	
Characteristic	N	% <90th percentile	N	% <90th percentile
Total	323	76.2	276	78.3
Age group (yrs)				
0-<5	28	71.4	16	87.5
5-<12	138	74.6	113	76.1
12-<16	157	78.3	147	78.9
Sex				
Male	208	77.9	180	78.3
Female	115	73.0	96	78.1
Ethnicity				
White	199	74.9	173	80.9
Asian	59	84.8	47	78.7
Black	11	81.8	10	70.0
Other	18	72.2	16	68.8
Modality				
HD	35	57.1	29	58.6
PD	30	66.7	24	66.7
Tx	258	79.8	223	82.1

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

Paediatrics

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 184 of the 791 patients (23.3%) 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 31/12/2022

N cardiovascular risk factors	Hypertensive	Overweight/Obese	Hypercholesterolaemic	N	%	Total %
0	No	No	No	52	28.3	28.3
1	Yes	No	No	32	17.4	
	No	Yes	No	26	14.1	42.4
	No	No	Yes	20	10.9	
2	Yes	Yes	No	11	6.0	
	Yes	No	Yes	15	8.2	22.3
	No	Yes	Yes	15	8.2	
3	Yes	Yes	Yes	13	7.1	7.1
				184		100.0
Total N with the risk factor	**71**	**65**	**63**			
Total % with the risk factor	**38.6**	**35.3**	**34.2**			

Biochemistry parameters in prevalent paediatric KRT patients

The median values and the percentage with eGFR <30 mL/min/1.73m^2 for prevalent 2022 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 31/12/2022 by centre

Centre	N with Tx	Median eGFR (mL/min/1.73m²)	% eGFR <30 mL/min/1.73m²	% data completeness
Bham_P	72	50	5.8	95.8
Blfst_P	20			20.0
Brstl_P	35			0.0
Cardf_P	18			0.0
Glasg_P	44	76	0.0	100.0
L Eve_P	64			0.0
L GOSH_P	125			28.0
Leeds_P	43	71	2.4	97.7
Livpl_P	28			0.0
Manch_P	64			0.0
Newc_P	25			0.0
Nottm_P	54	51	12.2	90.7
Soton_P	36	69	3.1	88.9
UK	**628**	**61**	**6.6**	**43.8**

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 8.18 Attainment of targets for haemoglobin, calcium, phosphate, parathyroid hormone and bicarbonate in paediatric patients (<16 years old) (a) prevalent to dialysis on 31/12/2022 by centre and (b) prevalent to Tx on 31/12/2022 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	27	11.5	50.0	0.0	57.7	0.0	46.2	46.2	7.7	73.1
Blfst_P	3									
Brstl_P	11	0.0	80.0	0.0	80.0	0.0	40.0		40.0	40.0
Cardf_P	6									
Glasg_P	13	0.0	46.2	0.0	91.7	50.0	33.3	30.8	0.0	84.6
L Eve_P	15	42.9	35.7	0.0	78.6	0.0	50.0	42.9	21.4	78.6
L GOSH_P	22	20.0	50.0			5.6	38.9	62.5		
Leeds_P	9									
Livpl_P	14	15.4	38.5	0.0	84.6	7.7	69.2	15.4	0.0	100.0
Manch_P	15	14.3	57.1	0.0	35.7	50.0	50.0	42.9	0.0	57.1
Newc_P	5									
Nottm_P	20	30.0	40.0	0.0	55.0	0.0	35.0	25.0	5.0	85.0
Soton_P	3									
UK	**163**	**17.4**	**47.7**	**0.0**	**66.4**	**11.8**	**44.7**	**40.3**	**9.4**	**77.0**
TX PATIENTS WITH EGFR <30 ML/MIN/1.73 M²										
UK	**18**	**27.8**	**72.2**	**0.0**	**100.0**	**0.0**	**100.0**	**30.8**	**8.3**	**91.7**

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 31/12/2022 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 m²)	N	Median eGFR (mL/min/1.73 m²)	N	Median eGFR (mL/min/1.73 m²)
<3 months						
0.25–<2 years	14	89	36	80	34	61
2–<4 years	1		31	65	16	59
4–<7 years			49	65	26	54
≥7 years			11	60	56	48
Total (IQR)	**15**	**87 (66-97)**	**127**	**66 (48-84)**	**132**	**52 (40-70)**

IQR – interquartile range
As seen in table 8.17, completeness of eGFR is 44% of N=628

Transfer to adult kidney services for prevalent paediatric KRT patients

One-hundred and sixteen paediatric patients transitioned to adult kidney centres in 2022. The median age of patients at transfer was 18.0 years with an IQR of 17.6-18.2 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, 1,628 started KRT between 2008 and 2021 at paediatric kidney centres and were included in survival analyses, to allow at least one year follow-up. At the end of 2022, 112 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 2008 and 2021 by age group at start of KRT

|	Age group (yrs)				
	0-<2	2-<4	4-<8	8-<12	12-<16
Survival at 1 year (%)	95.0	97.7	98.9	99.2	99.6
95% CI	91.6-97.0	94.0-99.1	96.7-99.6	97.5-99.7	98.5-99.9
Survival at 2 years (%)	93.1	96.5	95.9	98.0	98.8
95% CI	89.4-95.5	92.4-98.4	92.7-97.7	95.9-99.0	97.4-99.5
Survival at 3 years (%)	89.9	95.9	95.1	97.7	98.2
95% CI	85.5-92.9	91.6-98.0	91.7-97.1	95.4-98.8	96.5-99.0
Survival at 5 years (%)	86.3	95.2	93.7	95.9	96.9
95% CI	81.4-90.0	90.5-97.6	89.9-96.1	93.0-97.6	94.8-98.1
Survival at 10 years (%)	85.1	94.4	90.6	93.8	94.1
95% CI	79.9-89.0	89.4-97.0	85.3-94.0	89.7-96.3	90.9-96.2

CI – confidence interval
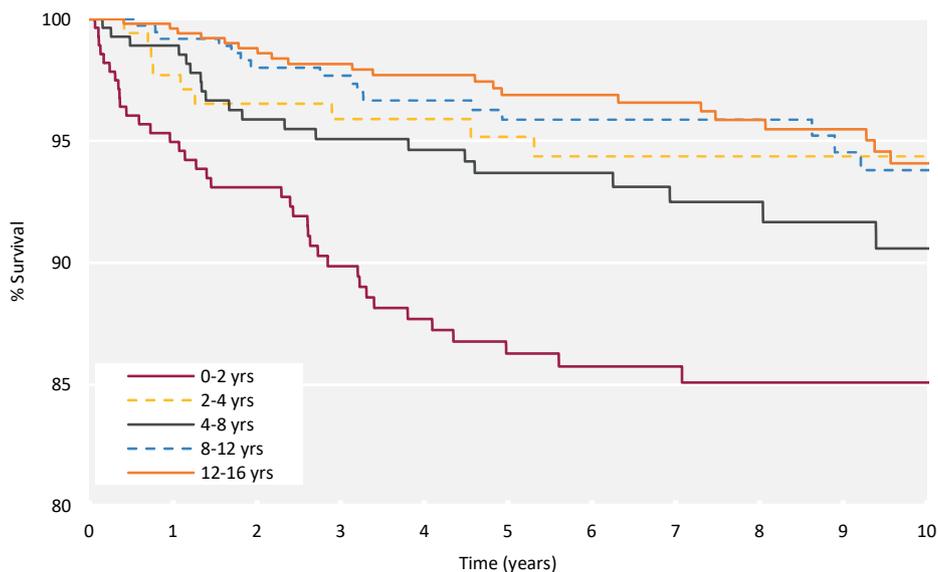
Figure 8.16 Unadjusted Kaplan-Meier survival (from day 90) of incident paediatric KRT patients (<16 years old) between 2008 and 2021 by age group at start of KRT

Children and young people on KRT in the UK in 2022

Paediatrics

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 2022 (incidence) as well as those on KRT as of 31/12/2022 (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 2022 and/or prevalent to KRT on 31/12/2022, by care setting

Characteristic	Incident			Prevalent		
	Paediatric centres	Adult centres	All	Paediatric centres	Adult centres	All
N	15	13	28	208	35	243
pmarp			18.1			157.4
Median age (yrs)	16.7	17.1	16.8	16.9	17.5	17.0
% male	80.0	46.2	64.3	60.6	71.4	62.1
Ethnicity[1] (%)						
White	57.1	54.6	56.0	67.0	67.7	67.1
Asian	28.6	18.2	24.0	21.8	17.7	21.2
Black	14.3	18.2	16.0	5.6	8.8	6.1
Other	0.0	9.1	4.0	5.6	5.9	5.6
Missing ethnicity	6.7	15.4	10.7	5.3	2.9	4.9
PRD[1] (%)						
Tubulointerstitial disease	42.9	18.2	32.0	43.6	45.2	43.8
Glomerular disease	14.3	27.3	20.0	15.4	12.9	15.0
Familial/hereditary nephropathies	7.1	18.2	12.0	19.5	35.5	21.7
Systemic diseases affecting the kidney	7.1	18.2	12.0	3.1	3.2	3.1
Diabetes	0.0	0.0	0.0	0.0	0.0	0.0
Miscellaneous renal disorders	28.6	18.2	24.0	18.5	3.2	16.4
Missing PRD	6.7	15.4	10.7	6.3	11.4	7.0
Modality (%)						
HD	60.0	46.2	53.6	12.0	20.0	13.2
PD	26.7	46.2	35.7	8.2	25.7	10.7
Tx	13.3	7.7	10.7	79.8	54.3	76.1

[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

Paediatrics

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 2022 and/or prevalent to KRT on 31/12/2022, by care setting

	Incident	Prevalent
Paediatric centres	7 out of 13	13 out of 13
Adult centres	10 out of 67	20 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/1.73 m^2 for young people prevalent to Tx on 31/12/2022 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 31/12/2022, by care setting

	N on Tx	Median age (yrs)	N with creatinine data	Median creatinine (μmol/L)	Median FAS-eGFR (mL/min/1.73m2)	% FAS-eGFR <30 mL/min/1.73m2	% creatinine completeness
Paediatric centres	166	17.0	150	109	67	5.3	90.4
Adult centres	19	17.5	17	134	59	11.8	89.5

Table 8.24 reports the median eGFR for all young people prevalent to Tx on 31/12/2022 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 31/12/2022 by time since transplantation

Time since transplantation	N	Median FAS-eGFR (mL/min/1.73m2)
< 3 months	6	
0.25–<2 years	34	63
2–<4 years	26	65
4–<7 years	37	74
≥ 7 years	62	65
Total (IQR)	**165**	**66 (53-81)**

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

Paediatrics

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 31/12/2022 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 31/12/2022, by modality and care setting

Characteristic	Dialysis			Tx		
	Paediatric centres	Adult centres	All	Paediatric centres	Adult centres	All
N	42	16	58	166	19	185
Median (IQR) Hb (g/L)	110 (95-127)	108 (97-124)	109 (96-126)	126 (114-138)	136 (118-147)	126.5 (114-139)
% Hb <100g/L	29.5	26.7	28.8	7.9	13.3	8.3
Median (IQR) Ca (mmol/L)	2.5 (2.4-2.6)	2.4 (2.2-2.5)	2.5 (2.3-2.6)	2.5 (2.4-2.5)	2.4 (2.4-2.5)	2.5 (2.4-2.5)
% Ca in range	69.4	62.5	67.3	87.5	87.5	87.5
Median (IQR) Phos (mmol/L)	1.8 (1.4-2.0)	2.2 (1.8-2.7)	1.8 (1.5-2.2)	1.1 (1.0-1.3)	1.1 (1.0-1.2)	1.1 (1.0-1.3)
% phos in range	43.9	13.3	35.7	61.6	50.0	60.6
Median (IQR) bicarb (mmol/L)	24 (22-27)	23 (19-25)	23 (21-26)	23 (21-25)	23 (20-25)	23 (21-25)
% bicarb in range	59.0	66.7	61.1	74.3	66.7	73.5
Median (IQR) SBP (mmHg)	121 (109-130)			118 (110-125)		
Median (IQR) DBP (mmHg)	74 (68-80)			70 (63-79)		
% 'normal' BP range (<130/80 mmHg)	60.6			72.4		
% high BP (≥140/90 mmHg)	15.2			4.1		

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

Paediatrics