

# Paediatric Patient Reported Experience Measure (PPREM) Pilot

## 2024 Report

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## Foreword

Understanding the experiences of the children and young people with kidney disease and their parents and carers is essential to delivering truly patient-centred care. This report presents the third pilot of the Paediatric Kidney Patient Reported Experience Measure (pPPREM), reflecting current practice and acting as a guide towards meaningful improvement.

This is only possible with the support of health care professionals from all 13 UK paediatric nephrology centres in the UK but also children, young people and their parents and carers who contribute to the PREM each year.

These pilots are also supporting the development of a more comprehensive, validated measure encompassing all ages through a research study led by the University of Hertfordshire. I am very grateful to them for their dedication and expertise in gathering information through workshops and interviews that are an essential part of the study. I am also deeply grateful to every child, young person, parent, carer and health care professional who shared their experiences.

The Paediatric Kidney PREM in 2025 will be part of the validation stage of the process following which we will have a validated measure that can be used in future years. This will help us achieve our aim of capturing the experience of those with kidney disease, regardless of their age, to be used to develop and improve kidney care in the UK for children, young people and adults.



Andrew Lunn  
Chief Investigator of the Paediatric Patient Reported Experience Measure Study

### Acknowledgments

We would like to express a huge thank you to all who have contributed to the 2024 pilot Paediatric PREM without whom this would not have been possible:

- The children and young people who experience the healthcare we provide and their families who completed the pilot Paediatric PREM,
- Every health professional working in Paediatric Nephrology that has made this a truly nationally representative Paediatric Kidney PREM,
- The members of the British Association of Paediatric Nephrology (BAPN)<sup>1</sup> Patient Experience Quality Improvement Working Group,
- The UK Kidney Association (UKKA) and Kidney Care UK,
- The University of Hertfordshire who analysed the Kidney PREM data and led the production of this report.

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<sup>1</sup> <https://ukkidney.org/bapn/about-bapn>

## Statistical Glossary

**Range:** When a group of scores are calculated, such as theme scores for each centre, the *range* is the difference between the largest (maximum) and smallest (minimum) score. The range provides useful information about the spread, or *variability*, of scores across centres.

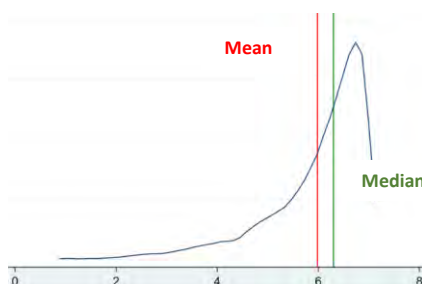
**Mean:** The *mean* centre score is calculated across patient scores by adding them together and dividing by the number of scores used, giving the mathematical average value.

**95% Confidence Interval:** When patient scores are combined to calculate the mean centre score, there is a 95% chance that the *95% confidence interval* would contain the true mean centre score that would be obtained if all patients were included. Higher *variability* and/or a small number of patient scores can result in wider 95% confidence intervals.

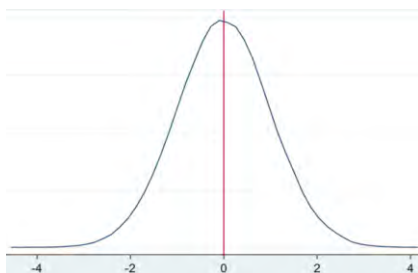
**Median:** If patient scores for a particular centre were listed in order, the *median* is the middle value separating the high scoring (top half) from the low scoring (bottom half).

**Lower/Upper Quartiles and Interquartile Range:** If patient scores were again listed in order and divided into four groups of equal size, the *lower quartile* (or 25<sup>th</sup> centile) would be the value below which the bottom quarter of scores lies. Conversely, the *upper quartile* (or 75<sup>th</sup> centile) is the value above which lie the top quarter of scores. The difference between the upper and lower quartiles is the *interquartile range*, which contains the middle 50% of scores and is a measure of *variability* of scores.

**Left-Skewed:** Scores are *left-skewed* (or negatively skewed) if there are lots of high value scores (e.g., 6s and 7s) and few low value scores (1s, 2s and 3s). For left-skewed data, the median score is always larger than the mean.



**Normal Distribution:** Scores are *normally distributed* if the mean and median are equal, with the scores distributed symmetrically around them.



## Executive Summary

In 2024, the pilot Paediatric PREM (pPPREM) was held alongside the adult Kidney PREM for the third consecutive year. Questions remained unchanged from its inception, using items based on those in the validated Kidney PREM. Children and young people aged 12 to 16 years could complete the pPPREM, either by themselves or with help from a trusted adult. Parents/carers of children and young people of any age (0 to 16 years) could participate, reporting their own experiences of their child's care.

### Response numbers and patient characteristics

A total of 363 responses were received from 13 UK centres, representing a 16.3% increase from 312 in 2023 and building on the 285 received in the initial pPPREM of 2022. A total of 312 responses were received from parents/carers and 51 from children/young people. Response numbers from each centre were wide ranging, from 1 to 98, with analysis at centre level possible for all but one of the thirteen UK paediatric centres.

Although the pPPREM was designed to capture experiences of children and young people aged 12 to 16 years (alongside parents/carers of children and young people of ages 0 to 16), two individuals aged  $\geq 17$  years completed the adult Kidney PREM but reported attending paediatric centres and were included in pPPREM analysis. Kidney patients of every age (from 0 to 17) were represented in the pPPREM, with most responses relating to White children and young people (80.4%), an increase from 77.2% in 2023. Asian children and young people accounted for 10.5% of responses and Black children and young people for just 3.3% of responses, each a decrease from 2023. However, amongst children and young people participating in the pPPREM themselves, 21.6% were Asian and 5.9% Black.

Around half of responses (50.1%) related to children and young people with chronic kidney disease who were not receiving kidney replacement therapy and 30.9% were about those with functioning kidney transplants. Forty-one responses (11.3%) were for children and young people receiving haemodialysis, of which six received treatment at home.

### Notes for interpretation

As the UK Renal Registry (UKRR) primarily collects data about individuals who are receiving kidney replacement therapy, demographic comparisons cannot easily be made between pPPREM respondents and the UK paediatric kidney population given the large proportion who attend clinic for monitoring. Caution is also advised when considering demographic representation as individuals may be double counted if both the children and young people and their parent(s)/carer(s) have submitted a response. Although a reasonable proportion of paediatric responses have been collated, the absolute numbers are small, particularly when analysing by centre. This results in low data precision, so caution is advised when making inferences or comparisons by centre.

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## Key findings from the pilot Paediatric PREM

The pPPREM achieved a total participation of 363 responses in 2024, an increase from 312 in 2023.

The themes scored most highly in 2023 remained the same in 2024: *Privacy & Dignity* (6.73), *Patient Information* (6.52) and *Access to the Kidney Team* (6.51).

Additionally, the three lowest scoring pPPREM themes were unchanged from 2023: *Communication* (5.85), *The Environment* (5.81) and *Support* (5.79).

*Privacy & Dignity* remained the highest reported theme by all response groups. Children and young people reported an improvement of +0.33 (from 6.29 to 6.62), while parents/carers of <12s reported a reduction of -0.12 (6.72 to 6.84) in comparison to 2023.

Across all participants combined, theme scores demonstrated little change when compared to 2023, with differences ranging from -0.10 to +0.02.

Scores for parents/carers of <12s reduced across all themes. The largest change was seen in *Sharing Decisions* which was scored at 5.97 out of 7, a reduction of 0.27 from 2023.

For children and young people completing the pPPREM themselves, theme scores increased in all but two themes: *Patient Information* (6.51 in 2024 vs 6.53 in 2023) and *Communication* (5.81 in 2024 vs 5.89 in 2023). The largest increase for children and young people was in *Support*, up by +0.66 compared to 2023 (5.69 vs 5.03).

Total pPPREM scale scores (calculated across the entire survey) increased for children and young people by +0.19. All three response groups reported similar total experiences of care: 6.13 for parents/carers of <12s, 6.14 for parents/carers of 12+ and 6.11 for children and young people.

At a question-level, *Support* when accessing patient support groups (Q6), *Communication* between the kidney team and school (P02) and parking (Q38) within *Environment* theme continued to be poorly scored, as in 2023, although with apparent variation in responses between children and young people and parents/carers. *Communication* between the GP and kidney team (Q9) and between the kidney team and non-healthcare services (Q11) were also reported less positively.



## Introduction

In 2022 the British Association of Paediatric Nephrology (BAPN), as part of a wider Kidney Quality Improvement Partnership (KQIP) programme, implemented a Paediatric Patient Experience working group, with contribution from all 13 Specialist Paediatric Nephrology Centres in the UK. Preliminary work from members within the group, particularly Dr Ben Reynolds<sup>2</sup> and Ms Suzanne Turton<sup>3</sup> in Glasgow, demonstrated that development of specific measures for children and young people with CKD was feasible, that parents/carers wanted to give feedback and that they also wanted their children to be able to give their own feedback.

The Paediatric Patient Experience group subsequently began working with the UK Kidney Association and Kidney Care UK, in partnership with the University of Hertfordshire, on this pilot measure as part of the steps towards a vision of having an all-age Kidney PREM. Using the established methodology and technology of the adult Kidney patient reported experience measure (PREM) and making minor adaptations to the already validated questions and themes a specific set of questions was developed for those 12 years of age or over and for parents/carers of children and young people of all ages.

In 2024 a NIHR funding bid to develop and validate questions that can be used for children under 12 years of age and improve the measure for parents/carers and young people 12 years and over was successful. We have been working on the development of this Kidney PREM that will guide quality improvement and improve patient care and experience. There are three key parts of this process; developing a validated measure, ensuring national use of the measure and developing quality improvement projects based on the results from the measure. We really value the support of everyone who so far has contributed to the study and are grateful in advance to those of you who will continue to support us in the final stages of the project.

We are very grateful that the ongoing support of the BAPN, UK Kidney Association (UKKA) and Kidney Care UK (KCUK) has meant that we have been able to repeat the pilot measure and now have three years of data for comparison. This report highlights those findings.

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<sup>2</sup> Consultant Paediatric Nephrologist at NHS Greater Glasgow and Clyde

<sup>3</sup> Expert kidney patient

## Methodology

### The pilot Paediatric PREM

The pPPREM contains 41 questions across 13 themes of patient care and a further question on *Overall Experience*. A large portion of the questions were taken directly from the 39 questions in the validated national Kidney PREM for adults. In collaboration with the Paediatric Patient Experience group, some changes to the structure were made; the *Needling* theme was removed, whilst a *Medication* theme was added. Additional questions within themes were also inserted: one relating to communication between the kidney team and school, and another to the child-friendliness of the kidney care environment.

Respondents stated whether they were a child/young person aged 12-16 years receiving care or if they were responding as a parent/carer in relation to the care their child receives. Depending on their response, amended versions of some questions were presented as appropriate.

For each question, participants scored their experience of kidney care from worst (1) to best (7), generally using a scale of 'Never' to 'Always'. As with the national adult Kidney PREM, patient characteristics were collected including treating centre, treatment type and location (for people receiving haemodialysis), age, sex, ethnicity and use of Patients Know Best. In addition to this, participants were asked to provide information about any help received to complete the questionnaire and to rate how their experience of care has changed over the last year (from 'much worse' to 'much better').

A free-text question at the end of the questionnaire allowed individuals to provide suggested improvements to the questions and highlight aspects of care that are important to them that may have been missed.

In addition, at the end of the pPPREM 2024, participants were asked whether they had received any feedback about the previous year's Kidney PREM findings, in alignment with the adult Kidney PREM.

**Commented [LM1]:** The paed questionnaire did not include a question on diabetes or medication

### Data collection

Online access to the pPPREM lasted eight weeks, from 16<sup>th</sup> September until 11<sup>th</sup> November 2024, alongside the annual Kidney PREM for adults. Collection of data was publicised as an online survey, with links available on both the UKKA and KCUK websites. Numbers of online respondents were monitored and circulated to centres throughout the collection period.

Respondents were asked to select their treating centre from a drop-down list, or to type the name of the centre in a free text box. Individuals whose treating centre could not be identified were excluded from centre scores but included in the national analysis.

### Analysis and reporting

Responses to questions were used to calculate scores for each theme, as well as the total pilot Paediatric PREM score across all themes, excluding the Overall question. For further detail, including

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data processing, please refer to the Kidney PREM Technical Report<sup>4</sup>, which will contain technical detail for both the Kidney PREM and the pilot Paediatric PREM.

Throughout this report, the total number of responses used to estimate individual statistics may vary since not all questions were answered by all participants. To preserve anonymity, in cases where a group average would be calculated on less than seven respondents the data are withheld. People with kidney disease who are not receiving Kidney Replacement Therapy (KRT) are referred to as CKD (non-KRT) patients.

**Commented [DW2]:** Is this accurate - is the technical report sufficient for interpretation this year?

**Commented [LM3R2]:** Last year (2023) the technical report did include PPREM analysis

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<sup>4</sup> <https://ukkidney.org/kidney-patient-reported-experience-measure>

## Results

### Chapter 1: Profile of Paediatric PREM respondents

#### Response profile

In total, across the 13 UK paediatric renal centres, 363 responses were received for the 2024 pPPREM (Table 1.1); an increase from the 312 responses received in 2023 (16.3%).

Table 1.1: 2024 responses by Treating Centre

Centre	Responses 2024		Responses 2023	Change from 2023		Proportion of KRT patients at each centre <sup>1</sup>
	N	% of returns		N	%	
Alder Hey Children's Hospital	48	13.2%	8	+40	500.0%	5.68%
Birmingham Children's Hospital	34	9.4%	9	+25	277.8%	11.17%
Bristol Royal Hospital for Children	19	5.2%	19	0	0.0%	5.87%
Children's Hospital for Wales, Cardiff	12	3.3%	11	+1	9.1%	3.54%
Evelina London Children's Hospital	1	0.3%	13	-12	-92.3%	10.71%
Great North Children's Hospital	17	4.7%	6	+11	183.3%	3.72%
Great Ormond Street Hospital	22	6.1%	43	-21	-48.8%	18.25%
Leeds Children's Hospital	41	11.3%	21	+20	95.2%	6.98%
Nottingham Children's Hospital	35	9.6%	52	-17	-32.7%	9.87%
Royal Belfast Hospital for Sick Children	14	3.9%	14	0	0.0%	2.89%
Royal Hospital for Children, Glasgow	98	27.0%	90	+8	8.9%	6.70%
Royal Manchester Children's Hospital	9	2.5%	9	0	0.0%	9.96%
Southampton Children's Hospital	13	3.6%	12	+1	8.3%	4.66%
<b>UK Total</b>	<b>363</b>	<b>-</b>	<b>312</b>	<b>+51</b>	<b>16.3%</b>	<b>1074</b>

<sup>1</sup>Data from the UK Renal Registry as at end of 2022. Information is presented to give an indication of the relative size of each centre and can be used to compare to the proportion of pPPREM returns per centre.

#### Participant characteristics

##### Age

The majority of responses (86%) were completed by parents/carers of children and young people, and there was an increase in the responses provided by parents of 8–11-year-olds (25.6% from 20.8% in 2023) but a decrease in those provided by parents of 4–7 year-olds (17.0% from 22.7%) the previous year.

Table 1.2: Age of patient receiving care

Age (years)	Year	Parent/Carer (% of total)	Child/Young Person (% of total)	Total (% of total)
0-3	2023	46 (17.4%)	-	46 (14.7%)
	2024	53 (17.0%)	-	53 (14.6%)
4-7	2023	60 (22.7%)	-	60 (19.2%)
	2024	53 (17.0%)	-	53 (14.6%)
8-11	2023	55 (20.8%)	-	55 (17.6%)
	2024	80 (25.6%)	-	80 (22.0%)
12-16	2023	103 (39.0%)	44 (91.7%)	147 (47.1%)
	2024	126 (40.4%)	49 (96.1%)	175 (48.2%)
17+ <sup>2</sup>	2023	-	4 (8.3%)	4 (1.3%)
	2024	-	2 (3.9%)	2 (0.6%)
Total	2023	264 (84.6%)	48 (15.4%)	312
	2024	312 (86.0%)	51 (14.0%)	363

<sup>2</sup>The children and young people respondents, two individuals aged 17-21 years who received kidney care in paediatric centres were included in this analysis, despite completing the adult Kidney PREM.

## Gender

A slightly higher proportion of male participants (51.0%) in children and young people aged 12 years and over responded compared to females (43.1%, Table 1.3), which differs to responses for the previous year (41.5% and 55.4% respectively). A small number of individuals identify as non-binary or other gender, with 0.8% of total responses provided across all groups. Overall, the 2024 data continue to show a higher response rate for male patients across all respondent groups. The representation of female participants (36.1%) has decreased compared to 2023 (40.7%).

Table 1.3: Gender of patient receiving care

	Year	Parent/Carer <12 years (% of total)	Parent/Carer 12+ years (% of total)	Child/Young Person (% of total)	Total (% of total)
<b>Gender</b>					
Male	2023	102 (64.6%)	36 (58.1%)	27 (41.5%)	165 (57.9%)
	<b>2024</b>	<b>126 (67.7%)</b>	<b>75 (59.5%)</b>	<b>26 (51.0%)</b>	<b>227 (62.5%)</b>
Female	2023	56 (35.4%)	24 (38.7%)	36 (55.4%)	116 (40.7%)
	<b>2024</b>	<b>60 (32.3%)</b>	<b>49 (38.9%)</b>	<b>22 (43.1%)</b>	<b>131 (36.1%)</b>
Other/Non-binary	2023	-	-	-	-
	<b>2024</b>	-	<b>1 (0.8%)</b>	<b>2 (3.9%)</b>	<b>3 (0.8%)</b>
Rather not say	2023	-	-	-	-
	<b>2024</b>	-	<b>1 (0.8%)</b>	<b>1 (2.0%)</b>	<b>2 (0.6%)</b>
<b>Total</b>	2023	161	103	48	312
	<b>2024</b>	<b>186</b>	<b>126</b>	<b>51</b>	<b>363</b>

### Ethnicity

The relative proportion of different ethnic groups stayed largely consistent across respondent groups as in the previous year (Table 1.4).

The majority of responses across all response groups reported White ethnicity (80.4%). Representation of White children and young people decreased from 75.0% in 2023 to 66.7% in 2024. However, the proportion of White patients reported by parents/carers of under 12s increased from 76.4% in 2023 to 83.9% in 2024.

Asian representation increased this year amongst children and young people aged 12 years and over, with responses from Asian participants accounting for 21.6% of the total, an increase from 10.4% in 2023. However, amongst parents/carers of children under 12 years, the proportion decreased from 13.7% in 2023 to 8.6% in 2024.

The number of respondents identifying as Black stayed low across all groups, with 3.3% of total responses compared to 4.2% in 2023. Similarly, respondents identifying as Mixed/Other accounted for 5.0% of responses in 2024, similar to 5.4% in 2023.

Table 1.4: Ethnicity of patient receiving care

<i>Ethnicity</i>	<i>Year</i>	<i>Parent/Carer &lt;12 years (% of total)</i>	<i>Parent/Carer 12+ years (% of total)</i>	<i>Child/Young Person (% of total)</i>	<i>Total (% of total)</i>
Asian	2023	22 (13.7%)	12 (11.7%)	5 (10.4%)	39 (12.5%)
	<b>2024</b>	<b>16 (8.6%)</b>	<b>11 (8.7%)</b>	<b>11 (21.6%)</b>	<b>38 (10.5%)</b>
Black	2023	4 (2.5%)	5 (4.9%)	4 (8.3%)	13 (4.2%)
	<b>2024</b>	<b>2 (1.1%)</b>	<b>7 (5.6%)</b>	<b>3 (5.9%)</b>	<b>12 (3.3%)</b>
White	2023	123 (76.4%)	82 (79.6%)	36 (75.0%)	241 (77.2%)
	<b>2024</b>	<b>156 (83.9%)</b>	<b>102 (81.0%)</b>	<b>34 (66.7%)</b>	<b>292 (80.4%)</b>
Mixed/ Other	2023	10 (6.2%)	4 (3.9%)	3 (6.3%)	17 (5.4%)
	<b>2024</b>	<b>10 (5.4%)</b>	<b>5 (4.0%)</b>	<b>3 (5.9%)</b>	<b>18 (5.0%)</b>
Rather not say	2023	2 (1.2%)	-	-	2 (0.6%)
	<b>2024</b>	<b>2 (1.1%)</b>	<b>1 (0.8%)</b>	<b>0 (0.0%)</b>	<b>3 (0.8%)</b>
<b>Total</b>	2023	161	103	48	312
	<b>2024</b>	<b>186</b>	<b>126</b>	<b>51</b>	<b>363</b>

#### Treatment modalities for patients receiving care

Just over half of the survey responses are related to non-KRT treatment, with 50.1% indicating CKD (non-KRT, Table 1.5). UKRR does not report data on non-KRT paediatric patients, therefore, the data must be interpreted with caution.

Of those who received KRT, functioning kidney transplant recipients made up 30.9% of responses, up from 21.5% in 2023. Nevertheless, transplant patients remain underrepresented compared to UKRR data in 2022<sup>4</sup>, where 77.7% of paediatric KRT patients are reported as having received a transplant.

Children and young people receiving haemodialysis decreased to 19.6% (from 33.3% in 2023), while parent/carer response stayed similar. Overall, there was a slight decrease in those who selected peritoneal dialysis this year (7.7% vs. 10.9%) compared to the previous year.

<sup>4</sup> <https://www.ukkidney.org/audit-research/annual-report/26th-annual-report-data-31122022>

Table 1.5: Treatment modality of patient receiving care

	Year	Parent/Carer <12 years (% of total)	Parent/Carer 12+ years (% of total)	Child/Young Person (% of total)	Total (% of total)	UK KRT Population 2022
Transplant	2023	29 (18.0%)	26 (25.2%)	12 (25.0%)	67 (21.5%)	<b>77.7%</b>
	<b>2024</b>	<b>49 (26.3%)</b>	<b>45 (35.7%)</b>	<b>18 (35.3%)</b>	<b>112 (30.9%)</b>	
Haemodialysis	2023	13 (8.1%)	14 (13.6%)	16 (33.3%)	43 (13.8%)	<b>11.7%</b>
	<b>2024</b>	<b>15 (8.1%)</b>	<b>16 (12.7%)</b>	<b>10 (19.6%)</b>	<b>41 (11.3%)</b>	
Peritoneal dialysis	2023	18 (11.2%)	12 (11.7%)	4 (8.3%)	34 (10.9%)	<b>10.6%</b>
	<b>2024</b>	<b>18 (9.7%)</b>	<b>5 (4.0%)</b>	<b>5 (9.8%)</b>	<b>28 (7.7%)</b>	
CKD (non-KRT)	2023	101 (62.7%)	51 (49.5%)	16 (33.3%)	168 (53.8%)	-
	<b>2024</b>	<b>104 (55.9%)</b>	<b>60 (47.6%)</b>	<b>18 (35.3%)</b>	<b>182 (50.1%)</b>	
<b>Total</b>	2023	158	62	65	312	
	<b>2024</b>	<b>186</b>	<b>126</b>	<b>51</b>	<b>363</b>	

#### Patients receiving haemodialysis

The UKRR reports that there were 101 children and young people under 16 years old in the UK were receiving haemodialysis at the end of 2022. In the pPPREM, 41 responses related to those receiving haemodialysis. It should be noted that 10 are from children and young people and 16 from parents/carers of those aged 12 years and over, so some could relate to the same individual receiving care. This, however, still represents a significant proportion of the UK paediatric haemodialysis population.

Table 1.6: Participation in shared care by those receiving haemodialysis in centres

	Year	Parent/Carer <12 years (% of total)	Parent/Carer 12+ years (% of total)	Child/Young Person (% of total)	Total (% of total)
Participating	2023	2 (15.4%)	3 (23.1%)	3 (20.0%)	8 (19.5%)
	<b>2024</b>	<b>4 (28.6%)</b>	<b>2 (15.4%)</b>	<b>1 (12.5%)</b>	<b>7 (20.0%)</b>
Declined	2023	-	1 (7.7%)	3 (20.0%)	4 (9.8%)
	<b>2024</b>	<b>1 (7.1%)</b>	<b>1 (7.7%)</b>	<b>0 (0.0%)</b>	<b>2 (5.7%)</b>
Not invited	2023	7 (53.8%)	5 (38.5%)	5 (33.3%)	17 (41.5%)
	<b>2024</b>	<b>4 (28.6%)</b>	<b>6 (46.2%)</b>	<b>1 (12.5%)</b>	<b>11 (31.4%)</b>
Don't know	2023	7 (53.8%)	5 (38.5%)	5 (33.3%)	17 (41.5%)
	<b>2024</b>	<b>5 (35.7%)</b>	<b>4 (30.8%)</b>	<b>6 (75.0%)</b>	<b>15 (42.9%)</b>
<b>Total</b>	2023	13	13	15	42
	<b>2024</b>	<b>14</b>	<b>13</b>	<b>8</b>	<b>35</b>

One in five respondents (20%) reported participation in shared care (Table 1.6). The proportion of participants aware of shared care remained low, with 42.9% unsure whether themselves or their children and young people were participating, and this is the case for the majority of the children and young people respondents (75%). Respondents who reported not being invited to engage in shared care decreased from 41.5% in 2023 to 31.4% this year.



#### Patients attending clinic but not receiving kidney replacement therapy

Most respondents (78.6%) reported attending clinic for monitoring only (Table 1.7), across all respondent groups, with 85.0% of parents/carers of children and young people aged 12 and above. Similarly, 77.9% of parents/carers of under 12s, and 61.1% of children and young people respondents reported being in this group. A small proportion (17.0%) reported attending due to approaching end-stage kidney disease, similar to 14.3% in 2023.

Table 1.7: Reason for attending clinic for patients not receiving kidney replacement therapy

	Year	Parent/Carer <12 years (% of total)	Parent/Carer 12+ years (% of total)	Child/Young Person (% of total)	Total (% of total)
Attending for monitoring only	2023	78 (77.2%)	41 (80.4%)	14 (87.5%)	133 (79.2%)
	2024	81 (77.9%)	51 (85.0%)	11 (61.1%)	143 (78.6%)
Approaching end stage kidney disease	2023	14 (13.9%)	8 (15.7%)	2 (12.5%)	24 (14.3%)
	2024	19 (18.3%)	8 (13.3%)	4 (22.2%)	31 (17.0%)
Don't know CKD type	2023	9 (8.9%)	2 (3.9%)	-	11 (6.5%)
	2024	4 (3.9%)	1 (1.7%)	3 (16.7%)	8 (4.4%)
<b>Total CKD (non-KRT)</b>	2023	101	51	16	168
	2024	104	60	18	182

#### Help to participate in pilot pPREM

Twenty-four (6.9%) respondents reported receiving help to complete the survey, with two-thirds (n=16, 66.7%) being children and young people. The majority reported needing help due to age (n=15). Other reasons include English language, Health, Haemodialysis, and eyesight. Of parents/carers, 2.9% of respondents required assistance to complete the survey, a decrease from 3.8% in 2023. Most respondents reported that they received help from a friend, relative or carer.

#### English as first language

Twenty participants (5.5%) reported a first language other than English. Overall, there were 16 languages reported to be spoken: Arabic (2), Bulgarian (1), Farsi (1), Greek (1), Kurdish (1), Panjabi (1), Pashtu (1), Polish (2), Romanian (1), Russian (1), Somali (3), Telugu (1), Turkish (1), Urdu (2). These twenty individuals were receiving care from six centres, with five from Birmingham Children's Hospital; four from Royal Hospital for Children, Glasgow and Great Ormond Street Hospital respectively; three from Alder Hey Children's Hospital and Leeds Children's Hospital respectively; one from Nottingham Children's Hospital.

## Paediatric Patient Reported Experience of Kidney Care in the UK 2024

### Use of Patients Know Best

Less than half of respondents (44.9%) reported using Patients Know Best<sup>5</sup> (PKB). The highest uptake was among parents/carers of children and young people aged 12 and above (50.0%, Table 1.8), and the lowest among children and young people (25.5%). Among those who didn't use PKB (47.7%), not knowing what PKB is (70.5%) was the main reason, particularly among children and young people (78.6%).

<sup>5</sup> <https://patientsknowbest.com/>

Table 1.8: Participant use of Patients Know Best

	Parent/Carer <12 years (% of total)	Parent/Carer 12+ years (% of total)	Child/Young Person (% of total)	Total (% of total)
<b>Yes, using PKB</b>	<b>87 (46.8%)</b>	<b>63 (50.0%)</b>	<b>13 (25.5%)</b>	<b>163 (44.9%)</b>
<b>No, not using PKB because:</b>	<b>90 (48.4%)</b>	<b>55 (43.7%)</b>	<b>28 (54.9%)</b>	<b>173 (47.7%)</b>
It's unavailable	4 (4.4%)	7 (12.7%)	2 (7.1%)	13 (7.5%)
Don't know what it is	65 (72.2%)	35 (63.6%)	22 (78.6%)	122 (70.5%)
Another reason	21 (23.3%)	13 (23.6%)	4 (14.3%)	38 (22.0%)
<b>Don't know</b>	<b>9 (4.8%)</b>	<b>8 (6.3%)</b>	<b>10 (19.6%)</b>	<b>27 (7.4%)</b>

PKB: Patients Know Best

### Medication

Overall, the hospital pharmacy was the most selected option for medication provider (31.4% of the total) across all groups (Table 1.9). The GP was second most selected (24.9% of the total) and "Delivered to me" was the option that was least selected across groups.

Table 1.9: Medication provider

	Parent/Carer <12 years (% of total)	Parent/Carer 12+ years (% of total)	Child/Young Person (% of total)	Total (% of total)
General Practitioner (GP)	39 (23.1%)	30 (26.3%)	14 (27.5%)	83 (24.9%)
Hospital pharmacy	56 (33.1%)	32 (28.1%)	17 (33.3%)	105 (31.4%)
Community pharmacy	29 (17.2%)	20 (17.5%)	7 (13.7%)	56 (16.8%)
Delivered to me	6 (3.6%)	9 (7.9%)	5 (9.8%)	20 (6.0%)
Mixture of above	38 (22.5%)	23 (20.2%)	8 (15.7%)	69 (20.7%)
Other	1 (0.6%)	-	-	1 (0.3%)
<b>Total</b>	<b>169</b>	<b>114</b>	<b>51</b>	<b>334</b>

## Chapter 2: Additional questions

Each year, the additional questions included in the national Kidney PREM are developed by the Kidney PREM working group, in collaboration with service users. Topics that the group recognise as important are determined to better understand current practices at a local level and from a patient perspective in order to drive improvements. The questions are included at the end of the survey, but before participants were asked to provide any comments.

Table 2.1 Young people starting treatment in the previous 12 months.

	Started treatment in the past 12 months		Completed PREM 2023	
	Frequency	%	Frequency	%
Birmingham	16	51.6%	2	12.5%
Belfast	3	21.4%	2	18.2%
Bristol	2	12.5%	7	53.8%
Cardiff	4	22.2%	0	0.0%
Glasgow	24	32.0%	24	33.3%
Evelina	0	0.0%	0	0.0%
GOSH	8	61.5%	1	7.7%
Leeds	13	46.4%	13	46.4%
Liverpool	15	48.4%	5	16.1%
Manchester	3	50.0%	1	16.7%
Newcastle	3	23.1%	3	23.1%
Nottingham	10	43.5%	9	39.1%
Southampton	3	30.0%	2	20.0%
<b>Total</b>	<b>104</b>	<b>29.8%</b>	<b>69</b>	<b>28.2%</b>

On average 30% of respondents started treatment in the last year, but that ranged from 0 to 51.6%. The proportion of respondents who completed the survey last year was lower (28.2%) also ranging widely from 0 to 53.8%.

Notably only 10% of respondents recall being told about the pPPREM results from the previous year, with 4 centres having no respondents, and 4 less than 10% reporting that they had been told.

Paediatric Patient Reported Experience of Kidney Care in the UK 2024

Table 2.2: Participants who were spoken to about the previous year's PPREM

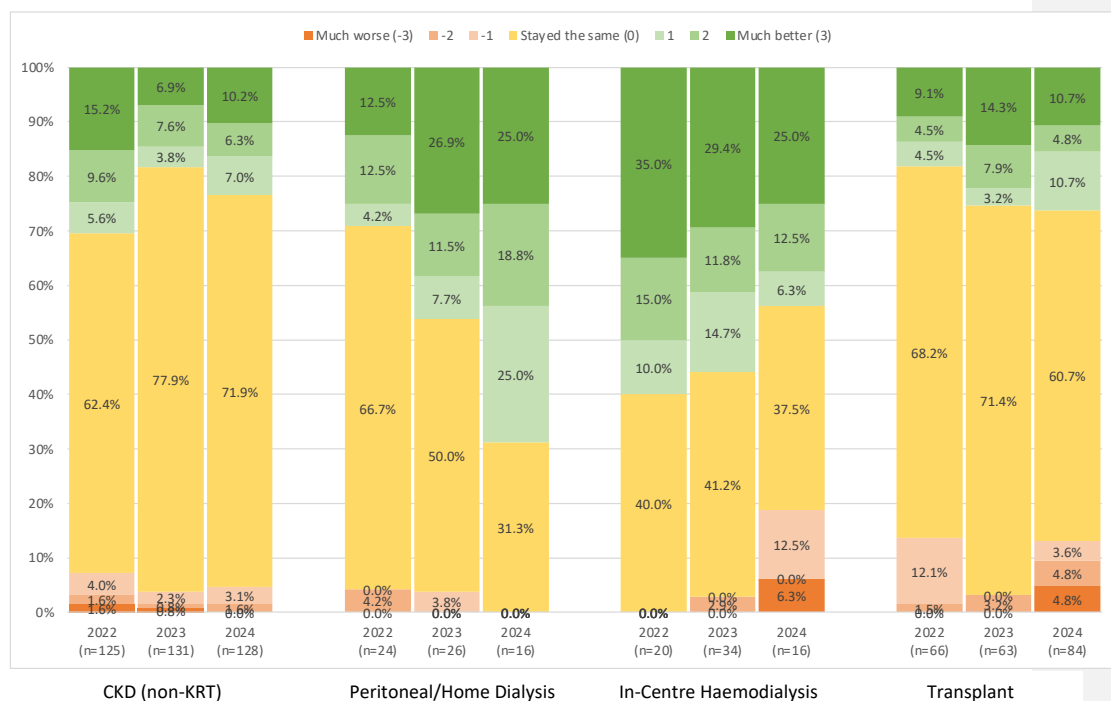
	Responses 2024		Responses 2023	
	Frequency	%	Frequency	%
Birmingham	6	18.8%	1	11.1%
Belfast	1	7.1%	4	28.6%
Bristol	0	0.0%	1	5.9%
Cardiff	0	0.0%	0	0.0%
Glasgow	10	10.4%	5	5.7%
Evelina	0	0.0%	1	7.7%
GOSH	1	4.8%	4	10.3%
Leeds	6	14.6%	4	19.0%
Liverpool	10	21.7%	2	25.0%
Manchester	0	0.0%	3	33.3%
Newcastle	1	6.7%	1	16.7%
Nottingham	8	24.2%	1	1.9%
Southampton	1	7.7%	2	16.7%
<b>Total</b>	<b>44</b>	<b>12.6%</b>	<b>29</b>	<b>9.6%</b>

## Chapter 3: Change in patient experience

*'Overall, how much better or worse was your kidney care experience during the last year?'*

Participants were asked to rate how their experience of care has changed over the previous year. Responses each year were recorded using a 7-point Likert scale from -3 (much worse) through 0 (no change) to +3 (much better), with an additional option to indicate they had not been receiving care a year ago.

Figure 3.1: Changes in patient experience over past year for 2022 and 2023 and 2024, by treatment



### In 2024

Notably this year there is a remarkable increase in positive responses from young people receiving Peritoneal or Home Dialysis. This is balanced by an increase in more negative responses from young people receiving In-centre haemodialysis or those with a transplant (18.8% and 13.2% respectively). In general, respondents report either no change, or an improvement over the last year.

## Chapter 4: Pilot Paediatric PREM theme results

### Pilot Paediatric PREM theme scores

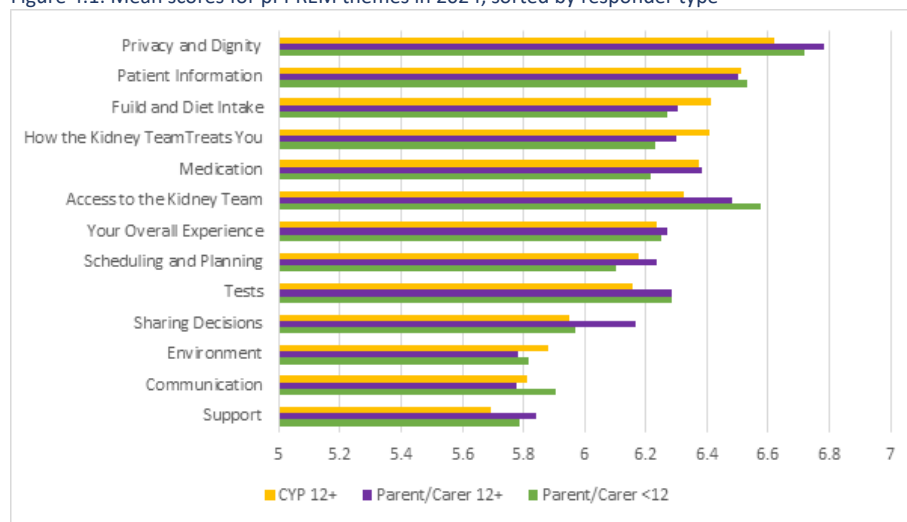
Responses for questions within each theme were combined to obtain theme scores for each pPPREM participant, summarised by respondent type (parent/carer of under 12s, parent/carer of over 12s, children and young people), (Figure 4.1). Appendix Table A1 contains a table of mean scores and 95% confidence intervals for 2024 for each response group.

The highest scoring themes for 2024 were Privacy and Dignity (6.73) and Patient Information (6.52). The lowest scoring themes were the Support (5.79), Environment (5.81) and Communication (5.85).

Children and young people provided lower scores for over half of themes in comparison to other response groups including Access to the Team (6.33), Tests (6.16) and Privacy and Dignity (6.62).

In comparison to the previous year, scores provided by parents/carers for under 12s across all themes were lower, with the greatest difference seen in Sharing Decisions (6.24 in 2023, 5.97 in 2024) and Scheduling (6.28 in 2023, 6.10 in 2024). In contrast, the majority of scores provided by children and young people increased from 2023, with some of the greatest differences shown in The Environment (5.55 in 2023, 5.88 in 2024) and Privacy and Dignity (6.29 in 2023, 6.62 in 2024).

Figure 4.1: Mean scores for pPPREM themes in 2024, sorted by responder type



Graph does not include responses for themes which received <7 responses

# Paediatric Patient Reported Experience of Kidney Care in the UK 2024

Table 4.1 Means for each pPPREM theme, by response group, sorted from highest to lowest

	Parent/Carer <12			Parent/Carer 12+			Children and young people 12+			Total		
	2024	2023	Change	2024	2023	Change	2024	2023	Change	2024	2023	Change
Privacy & Dignity	6.72	6.84	-0.12	6.78	6.77	0.01	6.62	6.29	0.33	6.73	6.73	0.00
Patient Information	6.53	6.58	-0.05	6.50	6.48	0.02	6.51	6.53	-0.02	6.52	6.54	-0.02
Access to Team	6.58	6.60	-0.02	6.48	6.52	-0.04	6.33	6.04	0.29	6.51	6.49	0.02
Fluid & Diet	6.27	6.31	-0.04	6.31	6.35	-0.05	6.41	6.13	0.28	6.30	6.30	0.01
Medication	6.22	6.37	-0.15	6.38	6.46	-0.08	6.38	6.31	0.06	6.30	6.39	-0.09
Treats	6.23	6.35	-0.12	6.30	6.32	-0.02	6.41	6.30	0.11	6.28	6.33	-0.05
Tests	6.28	6.36	-0.08	6.28	6.39	-0.11	6.16	6.09	0.07	6.27	6.33	-0.06
Overall Experience	6.25	6.37	-0.12	6.27	6.40	-0.13	6.23	6.02	0.21	6.26	6.33	-0.07
Scheduling	6.10	6.28	-0.18	6.24	6.23	0.01	6.17	6.03	0.14	6.16	6.23	-0.07
Sharing Decisions	5.97	6.24	-0.27	6.17	6.13	0.04	5.95	5.73	0.22	6.04	6.12	-0.09
Communication	5.90	6.02	-0.12	5.78	5.85	-0.07	5.81	5.89	-0.08	5.85	5.94	-0.10
The Environment	5.82	5.93	-0.11	5.78	5.97	-0.19	5.88	5.55	0.33	5.81	5.88	-0.07
Support	5.79	5.98	-0.19	5.84	5.78	0.06	5.69	5.03	0.66	5.79	5.77	0.02
Transport	-	-	-	-	-	-	-	6.06	-	-	6.06	-
pPPREM Scale Score	6.13	6.24	-0.11	6.14	6.20	-0.05	6.11	5.92	0.19	6.13	6.18	-0.05

Table does not include responses for themes which received <7 responses.

## Centre scores for pPPREM themes

Overall, the ranges of centre mean score were narrow, with the greatest difference of 1.4 between the highest and lowest scoring centre across all themes. It is notable that Environment has the largest variation between centres. In addition, Support has a small range, and is also poorly endorsed, indicating that most centres score poorly for Support.

Table 4.2: Summary of centre scores across all participant types, sorted from highest to lowest:

Theme	2024			2023		
	Range	Mean range	Mean	Range	Mean range	Mean
Privacy & Dignity	0.5	6.5 - 7.0	6.7	0.5	6.4 - 6.9	6.7
Patient Information	0.9	6.0 - 6.9	6.6	1.1	5.7 - 6.8	6.5
Access	0.8	6.1 - 6.9	6.5	0.9	6.0 - 6.9	6.5
Tests	0.8	5.8 - 6.6	6.3	0.3	6.2 - 6.5	6.4
Fluid & Diet	0.9	5.7 - 6.6	6.3	0.9	5.9 - 6.8	6.3
Medication	1.1	5.6 - 6.8	6.3	1.1	5.9 - 7.0	6.4
How the Team Treats You	1.2	5.6 - 6.8	6.3	0.8	5.9 - 6.7	6.3
Overall	1.2	5.6 - 6.8	6.2	0.5	6.1 - 6.6	6.3
Scheduling	1.1	5.5 - 6.6	6.1	1.0	5.7 - 6.7	6.2
Sharing Decisions	1.3	5.3 - 6.6	6.1	1.2	5.5 - 6.6	6.1
Support	1.0	5.2 - 6.2	5.8	1.1	5.3 - 6.4	5.7
Communication	1.4	5.0 - 6.4	5.8	1.0	5.5 - 6.5	5.9
Environment	1.3	5.1 - 6.4	5.7	1.3	5.1 - 6.5	5.8
Mean ≤5.8	Mean ≥6.3					

## Paediatric Patient Reported Experience of Kidney Care in the UK 2024

## Overall Experience of Care

The final question of the pPPREM asks individuals to rate their *Overall Experience* of care:

*'How well would you grade your overall experience of the service provided by your kidney unit on a scale from 1 (worst it can be) to 7 (best it can be)?'*

As this question aims to capture the overall experience of kidney care, it is not used when calculating the total pPPREM score (described on page 28). Unlike other pPPREM questions, 'Don't know' and 'not applicable' options are not available responses. *Overall Experience* scores well at 6.33, with centre scores ranging from 6.08 to 6.57). Figure 4.2 shows the percentage distribution of respondent scores for each paediatric kidney centre, showing the variability across centres.

*Notes for interpretation:*

The number of people providing a response to the *Overall Experience* question from each centre is shown in brackets next to each centre name. These values range from 8 to 88. It is important to keep in mind these numbers when interpreting the figure. For example:

A centre with 10 responses means that if five individuals scored '1' for *Overall Experience*, 50% of the bar would be dark red.

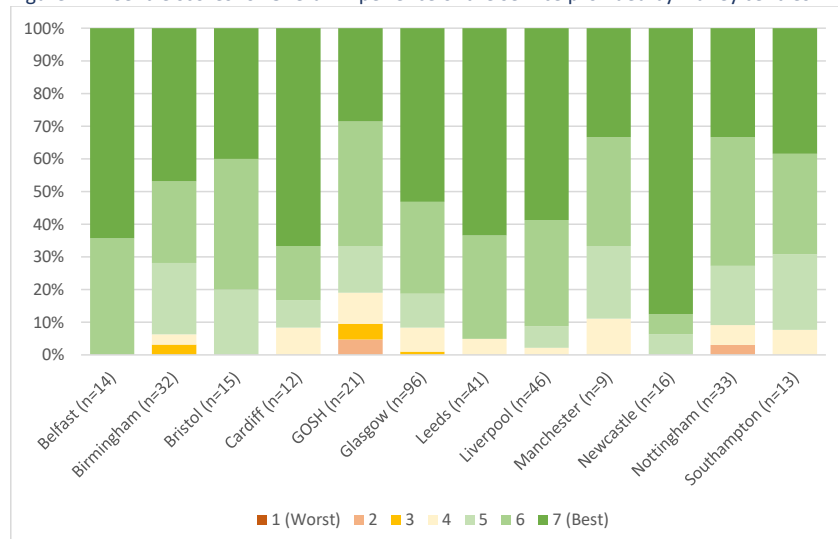
A centre with 80 responses means that if five individuals scored '1', just 6.25% of the bar would be dark red.

As in previous years, similar to the Adult Kidney PREM, the large majority of participants report their *Overall Experience* to be positive. Only four centres received scores of 3 or below. Although it is clear that variation exists within each centre with a mixture of scores received, it should be noted that no centre received a rating of 1 (worst it can be). Twelve out of thirteen centres are displayed, the other not achieving the minimum number of responses (seven) required for reporting.



## Paediatric Patient Reported Experience of Kidney Care in the UK 2024

Figure 4.2: Centre scores for Overall Experience of the service provided by kidney centres



## Chapter 5: Paediatric PREM theme results by treatment

### Theme mean scores by treatment

Those reporting Non-KRT scored Support the least of all treatment modalities (5.7) while those reporting in-centre HD score Privacy and Dignity the lowest of all treatment types (6.44). For positive scoring, those reporting Peritoneal Dialysis or Home Dialysis scored medication the highest (6.35) while Transplant reported Privacy and Dignity the highest (6.79).

PD patients scored all but one theme (Support) more negatively than 2023, as did transplant patients (Privacy and Dignity). However, non-KRT patients scored the majority of themes more positively than

Table 5.1: Comparison of mean Kidney PREM scores by treatment group for 2024 and 2023

	Chronic Kidney Disease (non-KRT)					Peritoneal Dialysis/Home Haemodialysis				
	2024 (n=176)		2023 (n=163)		2024 vs 2023	2024 (n=32)		2023 (n=35)		2024 vs 2023
	Mean	95% CI	Mean	95% CI		Mean	95% CI	Mean	95% CI	
Access	6.46	6.32 - 6.60	6.43	6.27 - 6.60	0.03	6.52	6.16 - 6.87	6.75	6.52 - 6.98	-0.24
Support	5.70	5.47 - 5.92	5.79	5.54 - 6.04	-0.09	6.14	5.77 - 6.50	6.12	5.71 - 6.53	0.02
Communication	5.84	5.64 - 6.05	5.77	5.56 - 5.99	0.07	6.03	5.62 - 6.45	6.27	5.92 - 6.62	-0.24
Patient Information	6.45	6.31 - 6.60	6.48	6.33 - 6.63	-0.02	6.64	6.41 - 6.88	6.89	6.75 - 7.02	-0.25
Fluid & Diet	6.09	5.88 - 6.30	6.05	5.81 - 6.30	0.04	6.67	6.43 - 6.92	6.7	6.47 - 6.93	-0.03
Medication	6.33	6.17 - 6.49	6.29	6.10 - 6.47	0.04	6.35	6.00 - 6.70	6.62	6.36 - 6.87	-0.27
Tests	6.26	6.12 - 6.40	6.23	6.08 - 6.38	0.03	6.30	6.00 - 6.60	6.56	6.34 - 6.78	-0.27
Sharing Decisions	6.03	5.83 - 6.22	5.98	5.76 - 6.19	0.05	6.40	6.12 - 6.67	6.48	6.15 - 6.82	-0.09
Privacy & Dignity	6.75	6.65 - 6.85	6.79	6.69 - 6.89	-0.04	6.69	6.46 - 6.92	6.74	6.51 - 6.98	-0.06
Scheduling	6.18	6.01 - 6.34	6.11	5.92 - 6.30	0.07	6.11	5.75 - 6.47	6.48	6.16 - 6.80	-0.37
How Team Treats you	6.25	6.08 - 6.42	6.24	6.05 - 6.42	0.01	6.39	6.07 - 6.70	6.64	6.38 - 6.90	-0.25
Transport	-	-	-	-	-	-	-	-	-	-
Environment	5.89	5.75 - 6.04	5.86	5.70 - 6.01	0.04	5.89	5.58 - 6.19	6.11	5.78 - 6.44	-0.22
Overall	6.30	6.16 - 6.44	6.20	6.04 - 6.37	0.10	6.31	5.96 - 6.66	6.63	6.42 - 6.83	-0.32
PREM Scale Score	6.12	6.00 - 6.25	6.09	5.95 - 6.24	0.03	6.26	6.00 - 6.52	6.46	6.25 - 6.66	-0.20

KRT: kidney replacement therapy 95% CI: 95% confidence interval

Table 5.1: Comparison of mean Kidney PREM scores by treatment group for 2024 and 2023 (cont.)

	In-Centre Haemodialysis					Transplant				
	2024 (n=32)		2023 (n=39)		2024 vs 2023	2024 (n=109)		2023(n=64)		2024 vs 2023
	Mean	95% CI	Mean	95% CI		Mean	95% CI	Mean	95% CI	
Access	6.58	6.31 - 6.85	6.32	5.90 - 6.75	0.26	6.57	6.43 - 6.72	6.58	6.33 - 6.83	-0.01
Support	6.02	5.55 - 6.49	5.11	4.44 - 5.78	0.91	5.77	5.51 - 6.03	5.92	5.56 - 6.28	-0.15
Communication	5.97	5.50 - 6.44	6.08	5.64 - 6.53	-0.11	5.76	5.53 - 5.99	6.11	5.85 - 6.36	-0.35
Patient Information	6.67	6.41 - 6.93	6.35	5.94 - 6.75	0.33	6.55	6.38 - 6.71	6.64	6.44 - 6.84	-0.09
Fluid & Diet	6.69	6.45 - 6.94	6.49	6.19 - 6.78	0.21	6.40	6.20 - 6.60	6.54	6.29 - 6.79	-0.14
Medication	6.31	5.90 - 6.73	6.59	6.33 - 6.86	-0.28	6.23	6.06 - 6.40	6.38	6.13 - 6.62	-0.15
Tests	6.14	5.71 - 6.56	6.21	5.84 - 6.57	-0.07	6.31	6.15 - 6.46	6.54	6.40 - 6.69	-0.23
Sharing Decisions	5.85	5.36 - 6.34	6.01	5.57 - 6.46	-0.16	6.00	5.78 - 6.21	6.35	6.05 - 6.66	-0.36
Privacy & Dignity	6.44	6.01 - 6.87	6.42	6.04 - 6.81	0.01	6.79	6.71 - 6.88	6.77	6.57 - 6.98	0.02
Scheduling	6.14	5.73 - 6.55	6.45	6.16 - 6.74	-0.31	6.15	5.96 - 6.34	6.25	6.02 - 6.49	-0.10
How Team Treats you	6.45	6.08 - 6.82	6.28	5.91 - 6.65	0.17	6.24	6.03 - 6.46	6.43	6.19 - 6.67	-0.19
Transport			6.06	5.64 - 6.47	-0.46	-	-	-	-	-
Environment	5.93	5.50 - 6.37	5.94	5.54 - 6.34	-0.01	5.63	5.43 - 5.83	5.80	5.51 - 6.09	-0.17
Overall	6.09	5.64 - 6.55	6.35	5.98 - 6.72	-0.26	6.21	6.03 - 6.39	6.47	6.29 - 6.65	-0.26
PREM Scale Score	6.18	5.87 - 6.48	6.13	5.87 - 6.40	0.04	6.10	5.95 - 6.25	6.27	6.08 - 6.47	-0.17

KRT: kidney replacement therapy 95% CI: 95% confidence interval

## Chapter 6: Patient experience of kidney care across the service

On each of pages 29 to 43 two types of figures are presented:

### **1. Mean centre scores and confidence intervals: Caterpillar plots (left-hand figure)**

These are displayed on the left of each page, showing centre mean scores and 95% confidence intervals for each theme of the 2024 pPPREM. Vertical green lines on the charts denote the lower quartile, median and upper quartile of these scores. The size of the confidence interval usually relates to the number of responses for each centre, with an increasing level of uncertainty if few surveys were received, or if there was variation in responses within a centre.

Centre mean scores were estimated if at least 7 responses were received. The number of responses used to calculate the scores are in brackets after each centre name. Each chart shows how many participants from each centre completed the minimum number of questions such that a theme score could be calculated, rather than the number of respondents completing the entire pPPREM. This is particularly important where questions are filtered and bases for analyses become smaller.

### **2. Question-level responses by respondent group (right-hand figure)**

A second figure is presented for each pPPREM theme, showing the proportion of respondent scores (from 1 to 7) allocated to each of the questions within those themes, by response group (children and young people, parents/carers of under 12s, parents/carers of over 12s). Again, the number of participants of each type responding is shown in brackets after the question label and varies across each question. Bars total 100%, so that the distribution of scores is clear. This is reflected in the width of segments from dark red (1, negative), through yellow (4, neutral) to dark green (7, positive). The number of participants responding with values of 1 to 7 varies. Again, 'don't know', 'not applicable' and missing responses have been excluded.

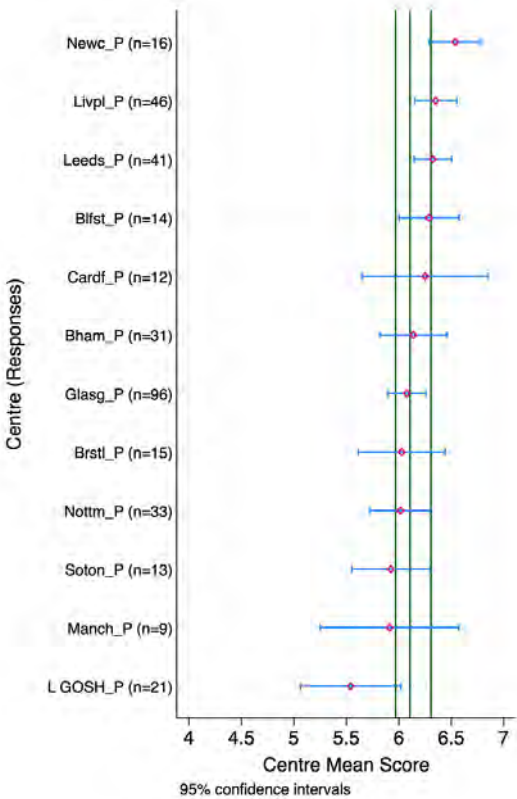
Results shown in this section may help to provide greater insights into the issues driving the theme scores at a national level and thus provide a guide to steer local quality improvement initiatives. Paediatric centres are encouraged to view this information alongside their centre-level data to assess their results in the context of national figures.

Paediatric Patient Reported Experience of Kidney Care in the UK 2024

The pPPREM scale score is calculated across all questions included in the survey, except for Q39 (Overall Experience) and is the total measure of patient experience across all themes.

Pilot Paediatric PREM scale score

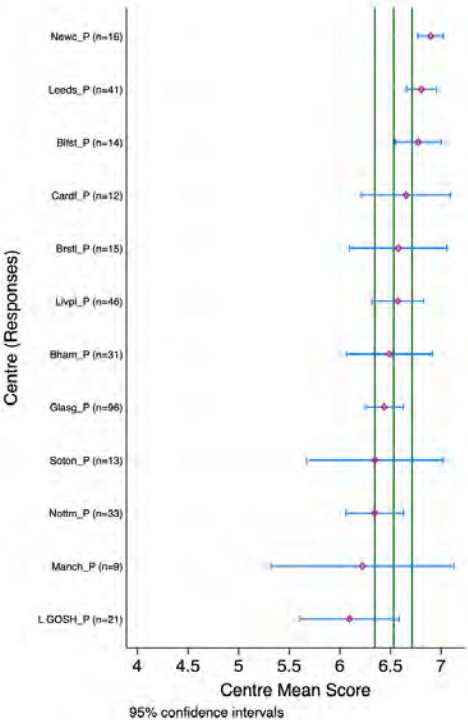
Mean of centre scores: 6.12, range: 5.54 to 6.54.



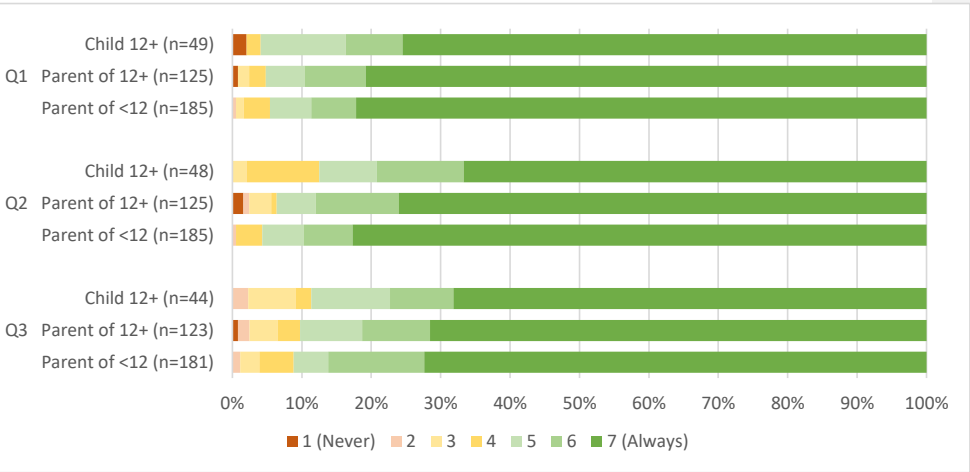
Paediatric Patient Reported Experience of Kidney Care in the UK 2024

Theme 1: Access to Kidney Team

Mean of centre scores: 6.52, range: 6.10 to 6.90.



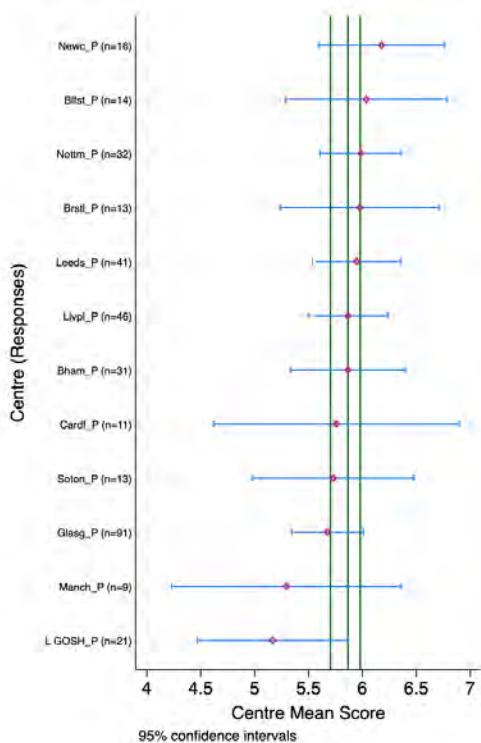
- Q1. Does the kidney team take time to answer your questions about your kidney disease or treatment?
- Q2. Would you feel comfortable to contact the unit from home if you were anxious or worried?
- Q3. Would you feel able to ask for an additional appointment with your kidney doctor if you wanted to?



CYP: Children and Young People, P/C: Parents/Carers

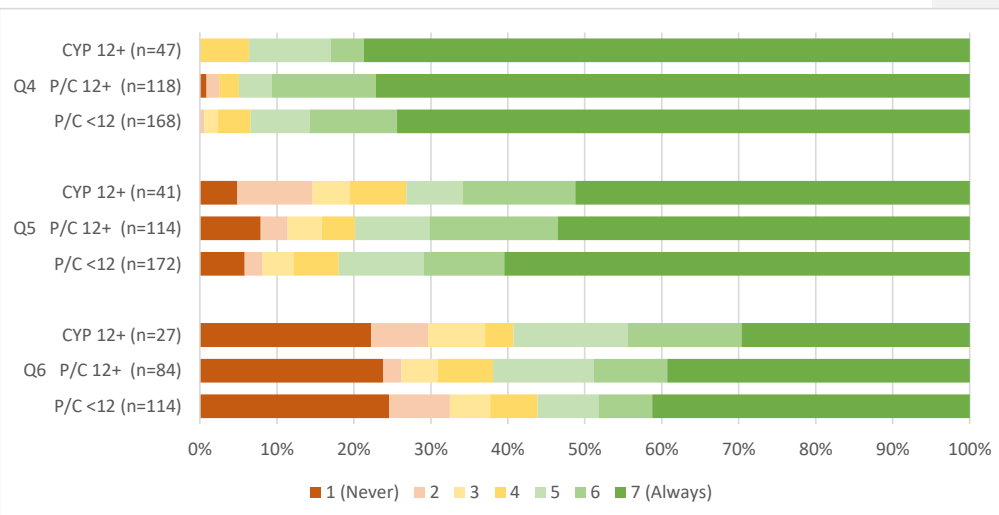
Theme 2: Support

Mean of centre scores: 5.79, range: 5.17 to 6.18.



Does the kidney team help you to get the support you want with:

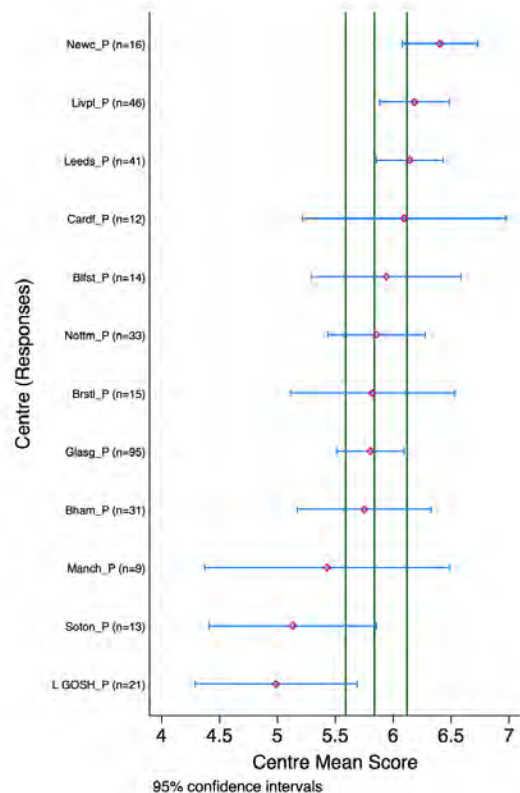
- Q4. Medical issues resulting from your kidney disease?  
Q5. Any other concerns or anxieties resulting from your kidney disease or treatment?  
Q6. Accessing patient support groups such as Kidney Patient Associations (KPA)?



CYP: Children and Young People, P/C: Parents/Carers

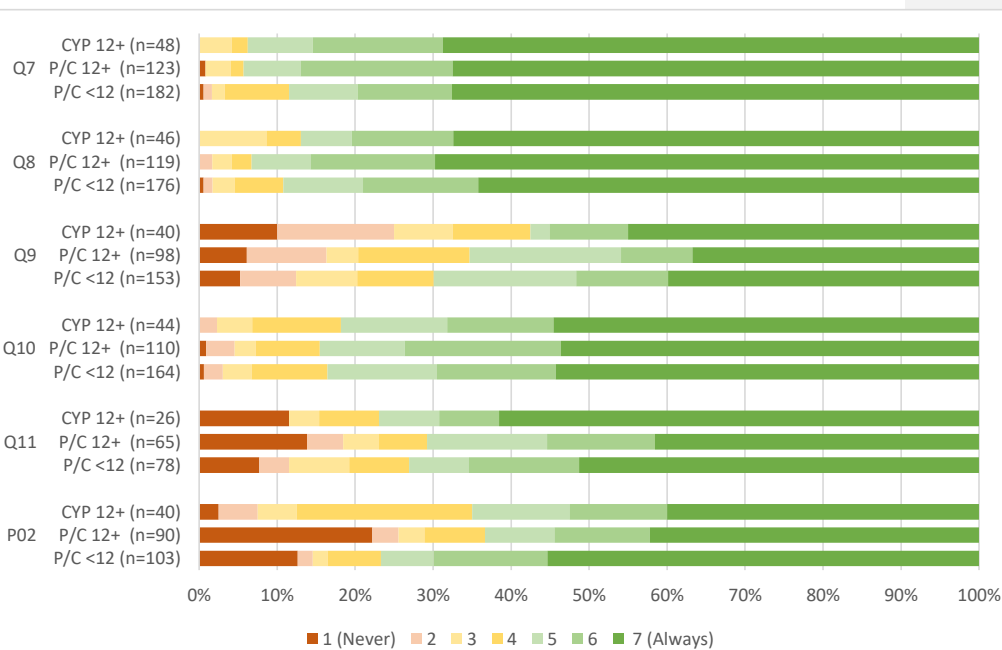
Theme 3: Communication

Mean of centre scores: 5.80, range: 4.99 to 6.40.



**Do you think there is good communication between:**

- Q7. You and your kidney team?  
Q8. Members of the kidney team?  
Q9. Your GP and the kidney team?  
Q10. The kidney team and other medical specialists?  
Q11. The kidney team and other non-healthcare services if you need them, such as social work or housing?

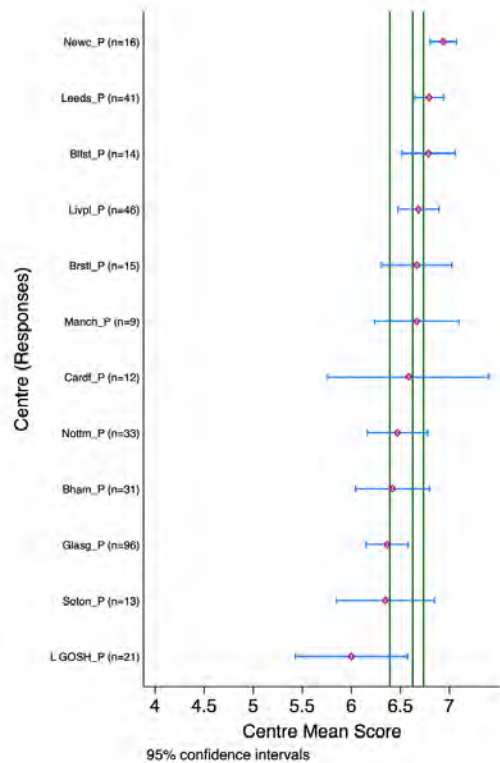


CYP: Children and Young People, P/C: Parents/Carers



Theme 4: Patient Information

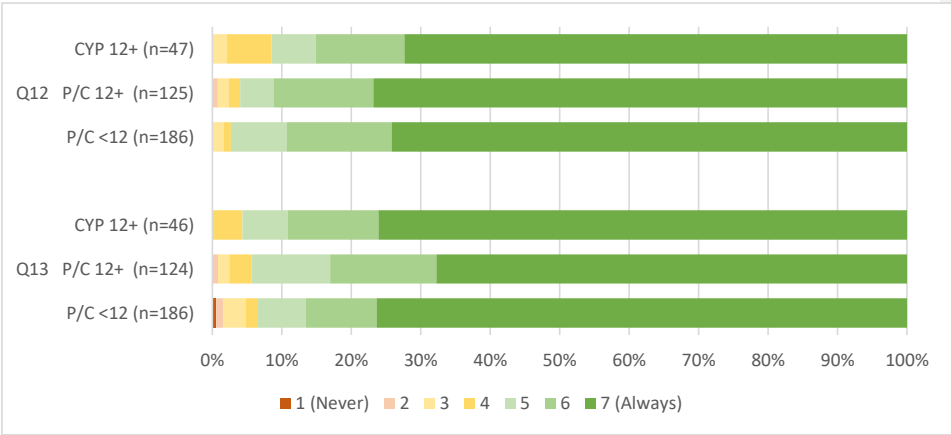
Mean of centre scores: 6.56, range: 6.00 to 6.94.



**Does the kidney team:**

Q12. Explain things to you in a way that is easy to understand?

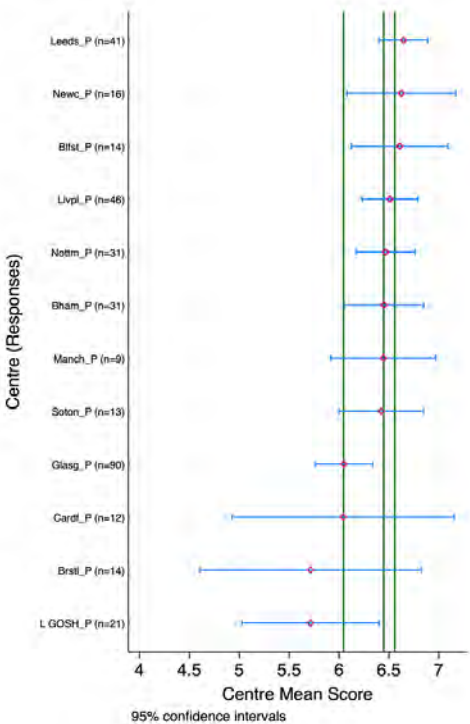
Q13. Give you as much information about your kidney disease or treatment as you want?



CYP: Children and Young People, P/C: Parents/Carers

Theme 5: Fluid & Diet

Mean of centre scores: 6.31, range: 5.71 to 6.65.

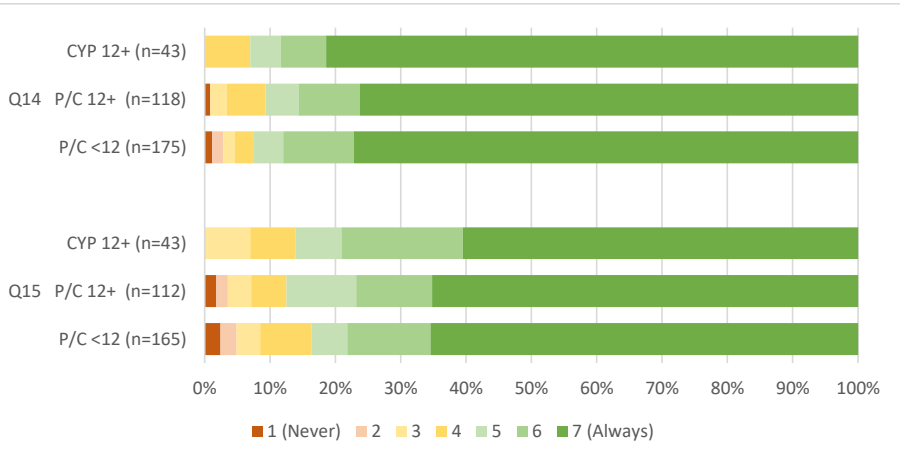


Thinking about the advice you are given about **fluid intake**:

Q14. Does the kidney team give you clear advice on your fluid intake?

Thinking about the advice you are given about **diet**:

Q15. Does the kidney team give you clear advice on your diet?

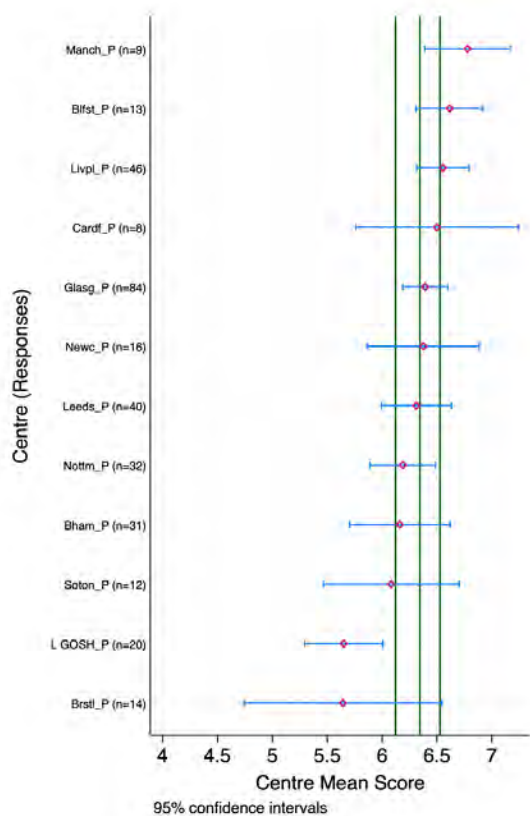


CYP: Children and Young People, P/C: Parents/Carers

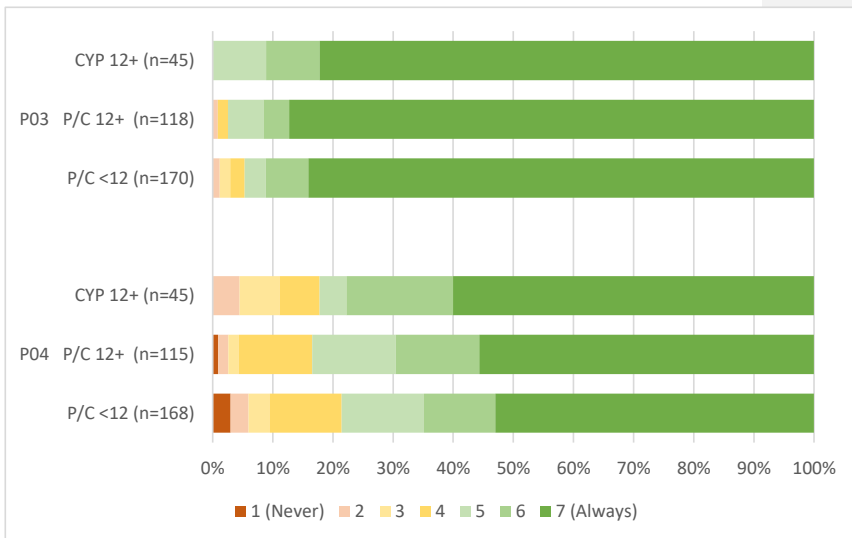
Paediatric Patient Reported Experience of Kidney Care in the UK 2024

Theme 6: Medication

Mean of centre scores: 6.27, range: 5.64 to 6.78.



- P03. Does the kidney team give you clear advice on your/your child's medications?  
P04. Getting a repeat prescription for my kidney care medicines is easy.

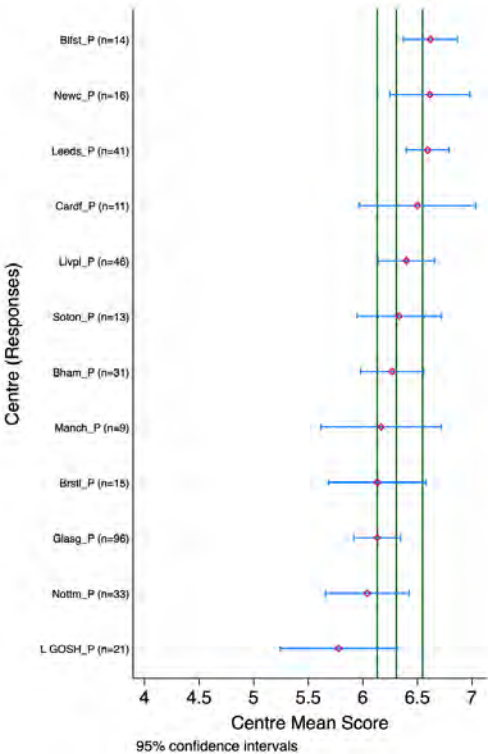


CYP: Children and Young People, P/C: Parents/Carers

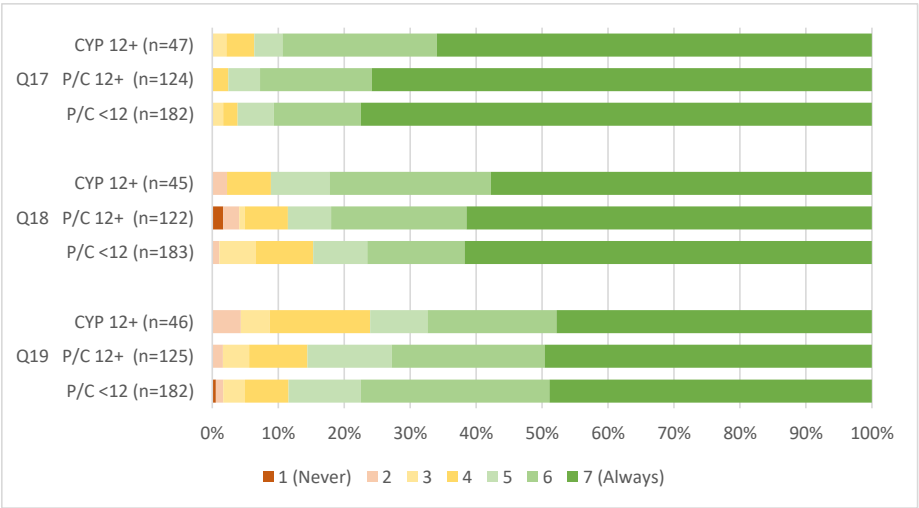
Paediatric Patient Reported Experience of Kidney Care in the UK 2024

Theme 7: Tests

Mean of centre scores: 6.30, range: 5.78 to 6.62.



- Q17. Do you understand the reasons for your tests?  
Q18. Do you get your test results back within an acceptable time period?  
Q19. Do you understand the results of your tests?

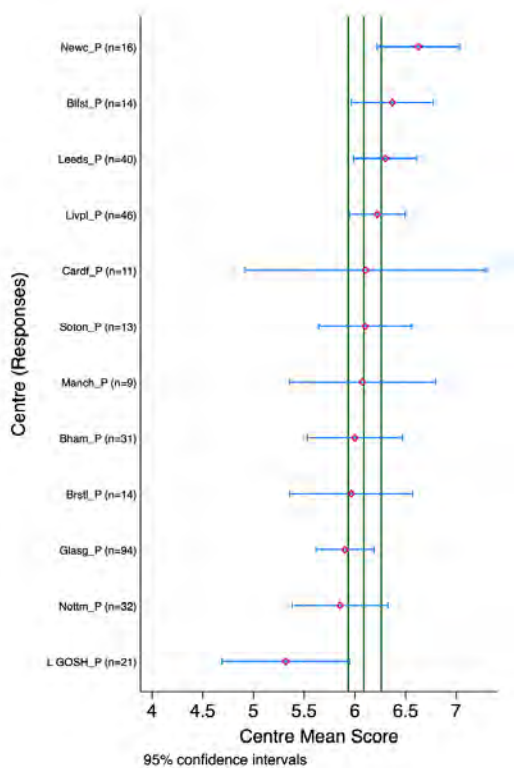


CYP: Children and Young People, P/C: Parents/Carers

Paediatric Patient Reported Experience of Kidney Care in the UK 2024

Theme 8: Sharing Decisions

Mean of centre scores: 6.07, range: 5.32 to 6.63

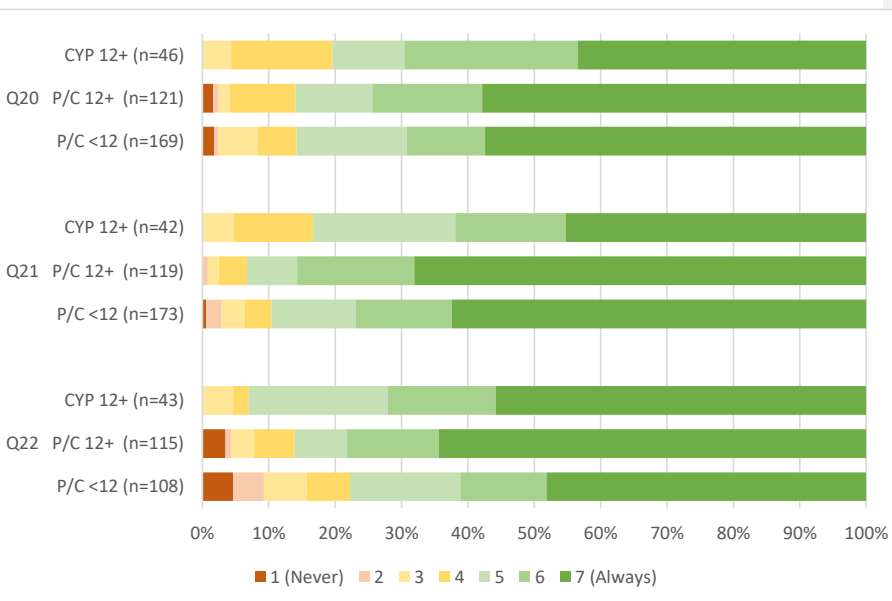


Does the kidney team:

Q20. Talk with you about your treatment and life goals?

Q21. Enable you to participate in decisions about your kidney care as much as you want?

Q22. Talk to you about taking a more active role in managing your own kidney care?



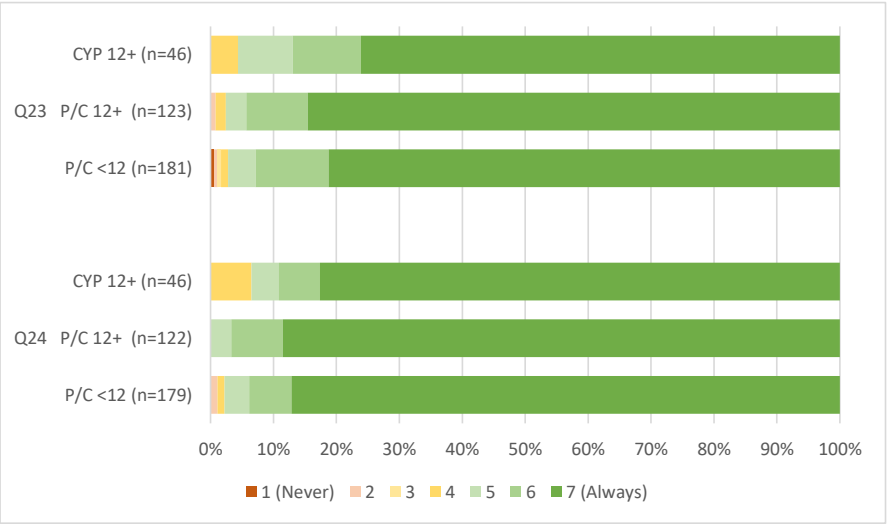
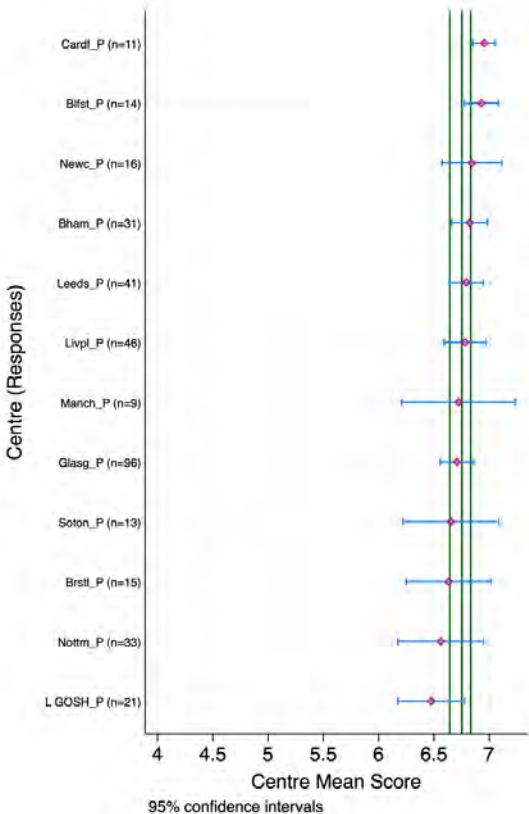
CYP: Children and Young People, P/C: Parents/Carers

Paediatric Patient Reported Experience of Kidney Care in the UK 2024

Theme 9: Privacy & Dignity

Mean of centre scores: 6.74, range: 6.48 to 6.95.

- Q23. Are you given enough privacy when discussing your condition or treatment?  
Q24. Is your dignity respected during visits and clinical examinations?

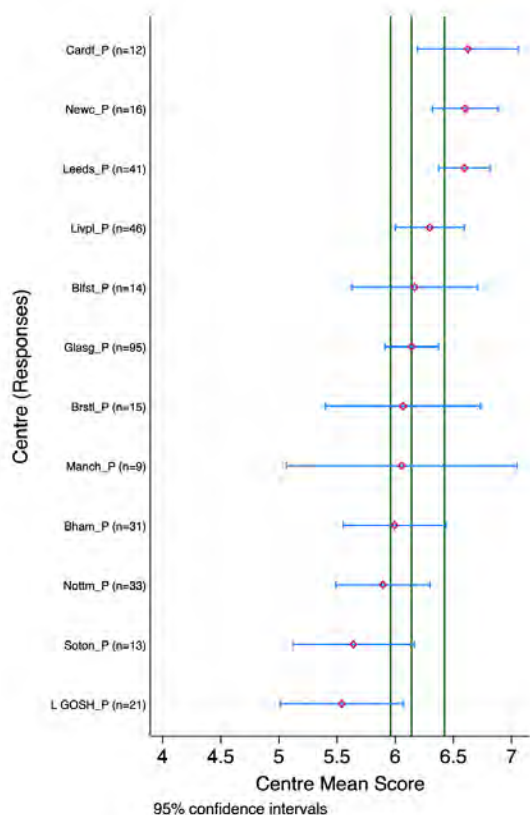


CYP: Children and Young People, P/C: Parents/Carers

Paediatric Patient Reported Experience of Kidney Care in the UK 2024

Theme 10: Scheduling and Planning

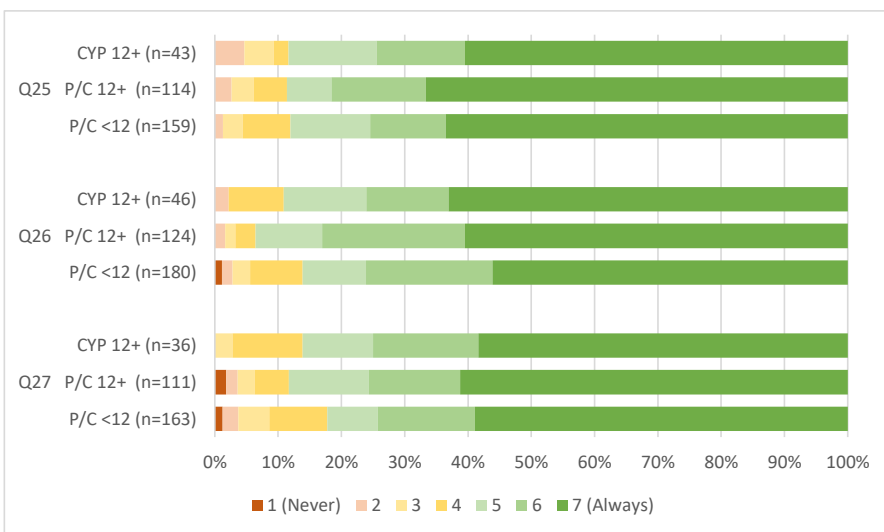
Mean of centre scores: 6.14, range: 5.54 to 6.63.



- Q25. Can you change your appointment times if they are not suitable for you?  
Q26. Do you feel your time is used well at your appointments relating to your kidneys?

*If you have blood tests done at an outpatient clinic or GP surgery (not those on in centre or in satellite haemodialysis):*

- Q27. Are the arrangements for your blood tests convenient for you?

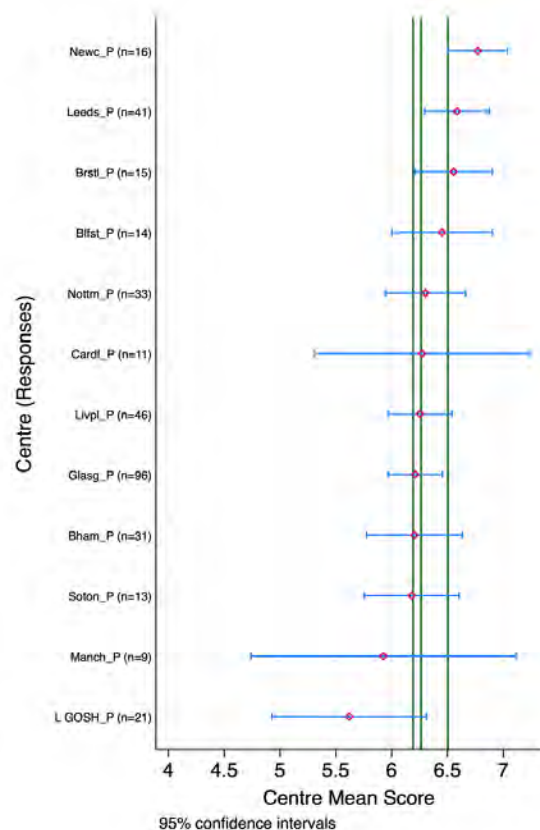


CYP: Children and Young People, P/C: Parents/Carers

Paediatric Patient Reported Experience of Kidney Care in the UK 2024

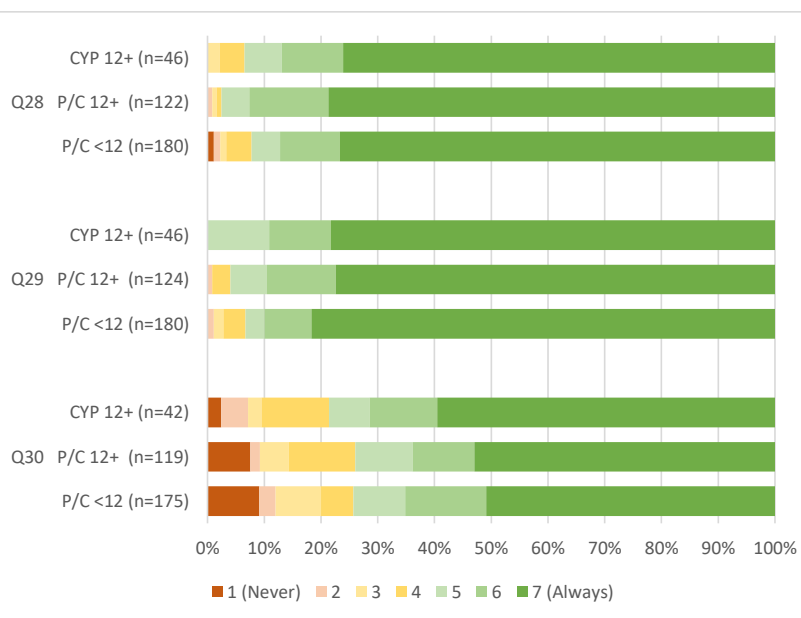
Theme 11: How the Kidney Team Treats You

Mean of centre scores: 6.28, range: 5.62 to 6.77.



Thinking about how the kidney team treats you, do they:

- Q28. Take you seriously?  
Q29. Show a caring attitude towards you?  
Q30. Ask you about your emotional feelings?



CYP: Children and Young People, P/C: Parents/Carers



## Theme 12: Transport (NOT Included in 2024)

Questions about *Transport* were only asked of those receiving in-centre haemodialysis for whom hospital transport was arranged, applicable for just 12 participants (all children and young people). As a minimum of seven responses were required to estimate centre scores, centre-level results could therefore not be calculated.

- Q31. Is the vehicle provided suitable for you?

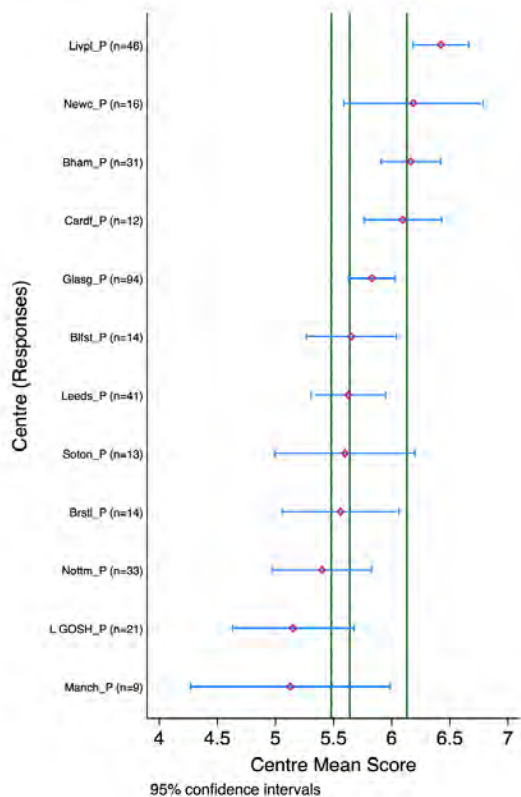
Q32. Is the time it takes to travel between your home and the kidney unit acceptable to you?

Q33. Once your visit to the kidney unit is finished and you are ready to leave, are you able to leave within less than 30 minutes?

Paediatric Patient Reported Experience of Kidney Care in the UK 2024

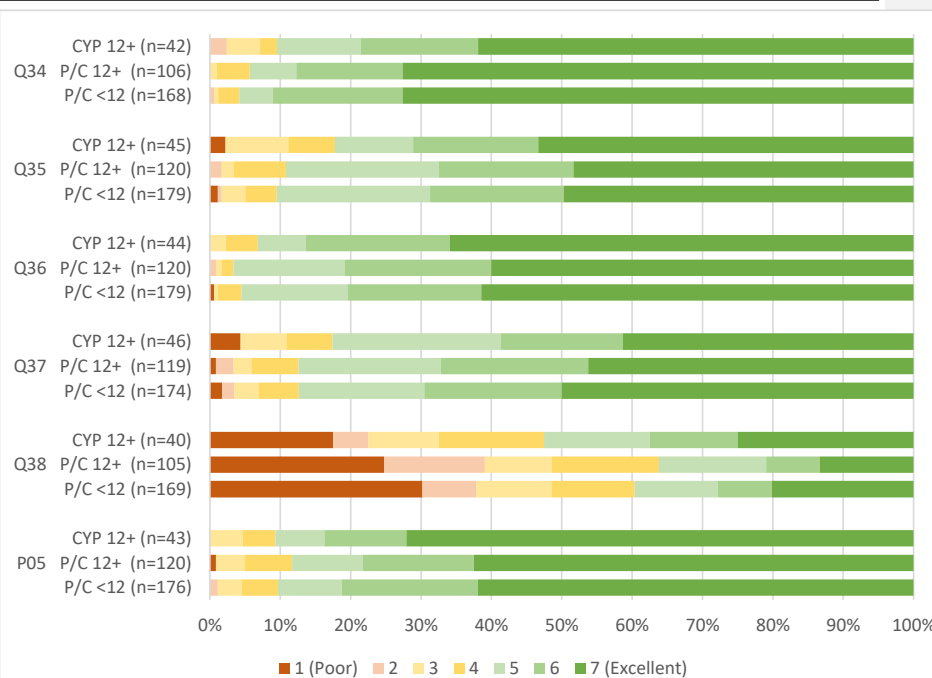
Theme 13: The Environment

Mean of centre scores: 5.74, range: 5.13 to 6.42.



When you attend the kidney unit, how would you grade:

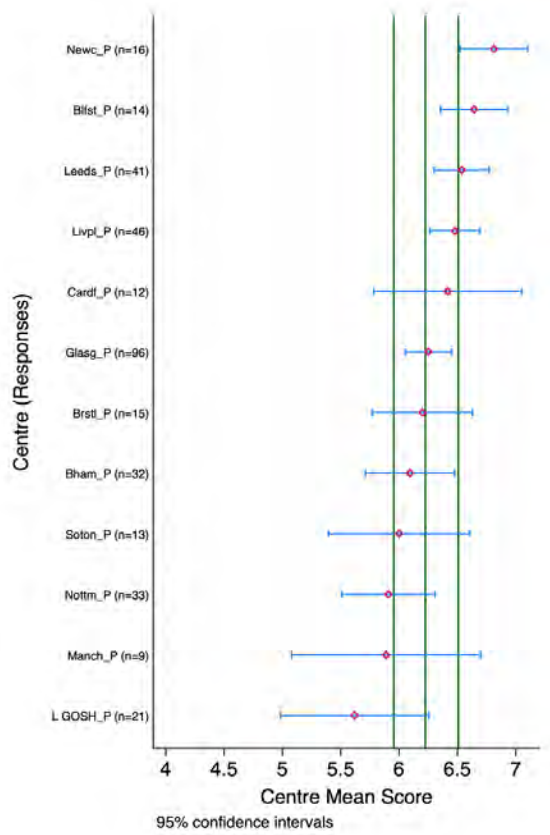
- Q34. Accessibility (e.g., lifts, ramps, auto doors)? Q35. Comfort?  
Q36. Cleanliness? Q37. Waiting area?  
Q38. Parking? P05. Child-friendliness?



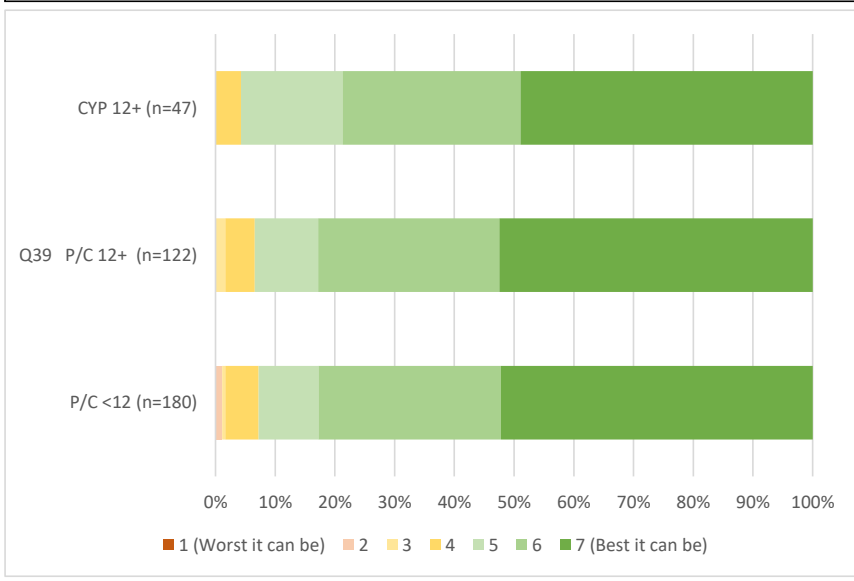
CYP: Children and Young People, P/C: Parents/Carers

Theme 14: Overall Experience

Mean of centre scores: 6.24, range: 5.62 to 6.81.



Q39. How well would you grade your overall experience of the service provided by your kidney unit on a scale from 1 (worst it can be) to 7 (best it can be)?



CYP: Children and Young People, P/C: Parents/Carers

#### What's next for the pPREM?

The pPPREM has now been tested over three PREM cycles, giving valuable information about the feasibility of routine data collection from parents/carers and children and young people aged 12 years and over. This is a fantastic step forward towards our aim of developing a validated, reliable PREM for use with children and young people under 18 years of age who receive specialist kidney care for CKD, so that people of all ages can receive the benefits of a national Kidney PREM.

The other significant step forward has been securing NIHR funding<sup>6</sup> to further develop the measure, in collaboration with young people and their parents/carers, to ensure that all appropriate themes are included. Additionally, the funding enables us to determine whether children and young people younger than 12 are able to meaningfully report their own patient experiences using appropriate measures.

The objective is that on completion of the study the Paediatric PREM will provide validated, age-appropriate measures focussed on key areas of patient care which are important to children and young people, their families and health care professionals. This will then inform ongoing quality improvement work through the BAPN Paediatric Patient Experience working group. Once the measure is finalised, the collection of the Paediatric PREM will be included as part of the annual Kidney PREM process.

The NIHR funded work is expected to last for two years, with the 2025 PPREM being used as part of the validation phase, with reporting due in 2026. For further information, please contact the research team on [kidneyresearch@herts.ac.uk](mailto:kidneyresearch@herts.ac.uk).

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<sup>6</sup> NIHR206218: Paediatric Kidney Patient Reported Experience Measure - developing and validating an experience measure for under 18-year

Appendix

Table A1: Mean theme scores and 95% confidence intervals, by response group

	Parent/carer <12 years		Parent/carer 12+ years		Young person 12+ years		Total	
	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)
Access to Kidney Team	180	6.58 (6.46, 6.69)	122	6.48 (6.31, 6.65)	46	6.33 (6.03, 6.62)	348	6.51 (6.42, 6.60)
Support	175	5.79 (5.57, 6.00)	118	5.84 (5.60, 6.08)	46	5.69 (5.31, 6.08)	339	5.79 (5.64, 5.94)
Communication	179	5.90 (5.72, 6.09)	122	5.78 (5.54, 6.02)	46	5.81 (5.43, 6.20)	347	5.85 (5.71, 5.98)
Patient Information	180	6.53 (6.39, 6.67)	122	6.50 (6.35, 6.66)	46	6.51 (6.27, 6.75)	348	6.52 (6.43, 6.61)
Fluid & Diet	173	6.27 (6.08, 6.46)	121	6.31 (6.10, 6.51)	45	6.41 (6.15, 6.68)	339	6.30 (6.17, 6.43)
Medication	166	6.22 (6.06, 6.38)	116	6.38 (6.22, 6.55)	44	6.38 (6.09, 6.66)	326	6.30 (6.19, 6.40)
Tests	179	6.28 (6.15, 6.42)	122	6.28 (6.12, 6.45)	46	6.16 (5.87, 6.45)	347	6.27 (6.17, 6.36)
Sharing Decisions	176	5.97 (5.78, 6.16)	120	6.17 (5.96, 6.38)	46	5.95 (5.65, 6.25)	342	6.04 (5.91, 6.17)
Privacy & Dignity	179	6.72 (6.61, 6.83)	122	6.78 (6.69, 6.87)	46	6.62 (6.38, 6.85)	347	6.73 (6.66, 6.80)
Scheduling	179	6.10 (5.94, 6.27)	122	6.24 (6.06, 6.41)	46	6.17 (5.85, 6.50)	347	6.16 (6.05, 6.27)
How Team Treats you	179	6.23 (6.06, 6.40)	122	6.30 (6.11, 6.49)	46	6.41 (6.14, 6.67)	347	6.28 (6.16, 6.39)
The Environment	179	5.82 (5.67, 5.96)	120	5.78 (5.60, 5.96)	46	5.88 (5.54, 6.22)	345	5.81 (5.71, 5.92)
Overall Experience	180	6.25 (6.10, 6.40)	122	6.27 (6.10, 6.44)	47	6.23 (5.97, 6.50)	349	6.26 (6.15, 6.36)
pPPREM Scale Score	180	6.13 (6.01, 6.25)	122	6.14 (6.00, 6.29)	46	6.11 (5.88, 6.35)	348	6.13 (6.05, 6.22)

Table does not include responses for themes which received <7 responses.

Paediatric Patient Reported Experience of Kidney Care in the UK 2024

Table A2: Mean theme scores and 95% confidence intervals, by centre theme scores and 95% confidence intervals, by centre

Centre	Scale		Access to Team		Support		Communication		Patient Information		Fluid & Diet		Medication	
	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)
Bham_P	31	6.14 (5.82, 6.46)	31	6.49 (6.06, 6.91)	31	5.87 (5.34, 6.40)	31	5.75 (5.17, 6.33)	31	6.42 (6.04, 6.80)	31	6.45 (6.05, 6.85)	31	6.16 (5.70, 6.62)
Blfst_P	14	6.29 (6.00, 6.57)	14	6.77 (6.55, 7.00)	14	6.04 (5.29, 6.79)	14	5.94 (5.30, 6.58)	14	6.79 (6.52, 7.06)	14	6.61 (6.12, 7.09)	13	6.62 (6.31, 6.92)
Brstl_P	15	6.03 (5.61, 6.44)	15	6.58 (6.10, 7.06)	13	5.97 (5.24, 6.71)	15	5.82 (5.11, 6.53)	15	6.67 (6.31, 7.02)	14	5.71 (4.61, 6.82)	14	5.64 (4.74, 6.54)
Cardf_P	12	6.25 (5.65, 6.85)	12	6.65 (6.21, 7.09)	11	5.76 (4.62, 6.90)	12	6.09 (5.22, 6.97)	12	6.58 (5.76, 7.41)	12	6.04 (4.93, 7.15)	8	6.50 (5.76, 7.24)
Glasg_P	96	6.08 (5.90, 6.26)	96	6.44 (6.25, 6.63)	91	5.68 (5.34, 6.01)	95	5.81 (5.51, 6.10)	96	6.36 (6.15, 6.58)	90	6.05 (5.76, 6.34)	84	6.39 (6.19, 6.60)
LGOSH_P	21	5.54 (5.06, 6.02)	21	6.10 (5.61, 6.58)	21	5.17 (4.47, 5.86)	21	4.99 (4.29, 5.69)	21	6.00 (5.43, 6.57)	21	5.71 (5.03, 6.40)	20	5.65 (5.29, 6.01)
Leeds_P	41	6.32 (6.15, 6.50)	41	6.80 (6.66, 6.95)	41	5.95 (5.54, 6.36)	41	6.14 (5.86, 6.43)	41	6.79 (6.65, 6.94)	41	6.65 (6.40, 6.89)	40	6.31 (5.99, 6.63)
Livpl_P	46	6.35 (6.15, 6.55)	46	6.57 (6.32, 6.83)	46	5.87 (5.49, 6.24)	46	6.18 (5.88, 6.48)	46	6.68 (6.48, 6.89)	46	6.51 (6.23, 6.79)	46	6.55 (6.32, 6.79)
Manch_P	9	5.91 (5.25, 6.57)	9	6.22 (5.32, 7.13)	9	5.30 (4.23, 6.36)	9	5.43 (4.37, 6.49)	9	6.67 (6.24, 7.10)	9	6.44 (5.92, 6.97)	9	6.78 (6.39, 7.17)
Newc_P	16	6.54 (6.29, 6.78)	16	6.90 (6.77, 7.02)	16	6.18 (5.59, 6.76)	16	6.40 (6.08, 6.73)	16	6.94 (6.80, 7.07)	16	6.62 (6.08, 7.17)	16	6.38 (5.86, 6.89)
Nottm_P	33	6.01 (5.73, 6.30)	33	6.34 (6.06, 6.63)	32	5.98 (5.61, 6.36)	33	5.86 (5.43, 6.28)	33	6.47 (6.16, 6.78)	31	6.47 (6.17, 6.76)	32	6.19 (5.89, 6.49)
Soton_P	13	5.92 (5.55, 6.30)	13	6.35 (5.67, 7.02)	13	5.73 (4.98, 6.48)	13	5.13 (4.41, 5.85)	13	6.35 (5.85, 6.85)	13	6.42 (6.00, 6.85)	12	6.08 (5.47, 6.70)

Centre	Tests		Sharing Decisions		Privacy & Dignity		Scheduling		How Team Treats		The Environment		Overall Experience	
	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)
Bham_P	31	6.27 (5.98, 6.56)	31	6.00 (5.53, 6.47)	31	6.82 (6.66, 6.98)	31	5.99 (5.55, 6.44)	31	6.20 (5.78, 6.63)	31	6.16 (5.91, 6.42)	32	6.09 (5.71, 6.48)
Blfst_P	14	6.62 (6.37, 6.87)	14	6.37 (5.97, 6.77)	14	6.93 (6.77, 7.08)	14	6.17 (5.62, 6.71)	14	6.45 (6.00, 6.90)	14	5.65 (5.27, 6.04)	14	6.64 (6.36, 6.93)
Brstl_P	15	6.13 (5.69, 6.58)	14	5.96 (5.36, 6.57)	15	6.63 (6.25, 7.02)	15	6.07 (5.40, 6.73)	15	6.56 (6.21, 6.90)	14	5.56 (5.06, 6.06)	15	6.20 (5.77, 6.63)
Cardf_P	11	6.50 (5.97, 7.03)	11	6.11 (4.92, 7.30)	11	6.95 (6.85, 7.06)	12	6.62 (6.19, 7.06)	11	6.27 (5.31, 7.24)	12	6.10 (5.76, 6.43)	12	6.42 (5.78, 7.05)
Glasg_P	96	6.13 (5.92, 6.35)	94	5.90 (5.62, 6.19)	96	6.71 (6.56, 6.86)	95	6.14 (5.91, 6.37)	96	6.21 (5.97, 6.46)	94	5.83 (5.63, 6.03)	96	6.25 (6.05, 6.45)
LGOSH_P	21	5.78 (5.24, 6.31)	21	5.32 (4.69, 5.95)	21	6.48 (6.18, 6.78)	21	5.54 (5.01, 6.07)	21	5.62 (4.93, 6.31)	21	5.15 (4.63, 5.68)	21	5.62 (4.98, 6.25)
Leeds_P	41	6.59 (6.40, 6.79)	40	6.30 (5.99, 6.61)	41	6.79 (6.64, 6.95)	41	6.59 (6.37, 6.81)	41	6.59 (6.30, 6.87)	41	5.63 (5.31, 5.95)	41	6.54 (6.30, 6.77)
Livpl_P	46	6.40 (6.14, 6.66)	46	6.22 (5.95, 6.50)	46	6.78 (6.59, 6.97)	46	6.30 (6.00, 6.59)	46	6.25 (5.97, 6.54)	46	6.42 (6.18, 6.66)	46	6.48 (6.26, 6.69)
Manch_P	9	6.17 (5.62, 6.72)	9	6.07 (5.35, 6.80)	9	6.72 (6.21, 7.23)	9	6.06 (5.06, 7.05)	9	5.93 (4.74, 7.11)	9	5.13 (4.27, 5.99)	9	5.89 (5.08, 6.70)
Newc_P	16	6.61 (6.25, 6.98)	16	6.62 (6.22, 7.03)	16	6.84 (6.57, 7.11)	16	6.60 (6.32, 6.89)	16	6.77 (6.51, 7.04)	16	6.19 (5.59, 6.79)	16	6.81 (6.52, 7.10)
Nottm_P	33	6.04 (5.66, 6.42)	32	5.85 (5.38, 6.33)	33	6.56 (6.17, 6.95)	33	5.89 (5.49, 6.30)	33	6.30 (5.94, 6.66)	33	5.40 (4.98, 5.83)	33	5.91 (5.51, 6.31)
Soton_P	13	6.33 (5.95, 6.72)	13	6.10 (5.64, 6.56)	13	6.65 (6.22, 7.09)	13	5.64 (5.12, 6.16)	13	6.18 (5.76, 6.60)	13	5.60 (5.00, 6.20)	13	6.00 (5.40, 6.60)

Table A3: Median theme scores and interquartile ranges, by treatment group

	Chronic Kidney Disease (non-KRT)					Peritoneal Dialysis/Home Haemodialysis				
	2024 (n=176)		2023 (n=163)		2024 vs 2023	2024 (n=32)		2023 (n=35)		2024 vs 2023
	Median	IQR	Median	IQR		Median	IQR	Median	IQR	
Access to Team	7.00	6.33 – 7.00	7.00	6.33 – 7.00	0.00	7.00	6.50 – 7.00	7.00	7.00 – 7.00	0.00
Support	6.33	4.50 – 7.00	6.67	4.67 – 7.00	-0.34	6.42	5.58 – 7.00	6.67	6.00 – 7.00	-0.25
Communication	6.25	5.17 – 7.00	6.20	5.00 – 7.00	0.05	6.60	5.18 – 7.00	7.00	5.67 – 7.00	-0.40
Patient Information	7.00	6.00 – 7.00	7.00	6.00 – 7.00	0.00	7.00	6.50 – 7.00	7.00	7.00 – 7.00	0.00
Fluid & Diet	7.00	5.50 – 7.00	7.00	6.00 – 7.00	0.00	7.00	6.50 – 7.00	7.00	7.00 – 7.00	0.00
Medication	7.00	6.00 – 7.00	7.00	6.00 – 7.00	0.00	7.00	6.00 – 7.00	7.00	6.50 – 7.00	0.00
Tests	6.67	6.00 – 7.00	6.67	5.67 – 7.00	0.00	6.67	6.00 – 7.00	7.00	6.33 – 7.00	-0.33
Sharing Decisions	6.50	5.33 – 7.00	6.58	5.33 – 7.00	-0.08	6.83	5.83 – 7.00	7.00	6.33 – 7.00	-0.17
Privacy & Dignity	7.00	7.00 – 7.00	7.00	7.00 – 7.00	0.00	7.00	6.75 – 7.00	7.00	7.00 – 7.00	0.00
Scheduling	6.67	5.67 – 7.00	6.58	5.67 – 7.00	0.09	6.33	5.33 – 7.00	7.00	6.33 – 7.00	-0.67
How Team Treats you	7.00	5.67 – 7.00	7.00	6.00 – 7.00	0.00	7.00	5.83 – 7.00	7.00	6.67 – 7.00	0.00
The Environment	6.00	5.20 – 6.67	6.00	5.40 – 6.67	0.00	6.00	5.33 – 6.50	6.17	5.83 – 7.00	-0.17
Overall Experience	7.00	6.00 – 7.00	7.00	6.00 – 7.00	0.00	7.00	6.00 – 7.00	7.00	6.00 – 7.00	0.00
Pilot PPREM Scale Score	6.37	5.74 – 6.77	6.41	5.80 – 6.76	-0.04	6.53	5.83 – 6.80	6.69	6.09 – 6.86	-0.16

Paediatric Patient Reported Experience of Kidney Care in the UK 2024

Table A3: Median theme scores and interquartile ranges, by treatment group (cont.)

	In-Centre Haemodialysis					Transplant				
	2024 (n=32)		2023 (n=39)		2024 vs 2023	2024 (n=109)		2023 (n=64)		2024 vs 2023
	Median	IQR	Median	IQR		Median	IQR	Median	IQR	
Access to Team	7.00	6.50 – 7.00	7.00	6.33 – 7.00	0.00	7.00	6.33 – 7.00	7.00	6.67 – 7.00	0.00
Support	6.58	4.83 – 7.00	5.75	4.00 – 7.00	0.83	6.33	5.00 – 7.00	6.67	5.00 – 7.00	-0.34
Communication	6.50	5.40 – 7.00	6.37	5.83 – 7.00	0.13	6.00	5.10 – 6.80	6.27	5.82 – 7.00	-0.27
Patient Information	7.00	6.75 – 7.00	7.00	6.00 – 7.00	0.00	7.00	6.50 – 7.00	7.00	6.75 – 7.00	0.00
Fluid & Diet	7.00	6.50 – 7.00	7.00	6.00 – 7.00	0.00	7.00	6.00 – 7.00	7.00	6.50 – 7.00	0.00
Medication	7.00	6.00 – 7.00	7.00	6.50 – 7.00	0.00	6.50	5.50 – 7.00	7.00	6.00 – 7.00	-0.50
Tests	6.67	5.50 – 7.00	6.67	6.00 – 7.00	0.00	6.42	6.00 – 7.00	6.67	6.33 – 7.00	-0.25
Sharing Decisions	6.33	5.00 – 7.00	6.67	5.00 – 7.00	-0.34	6.33	5.33 – 7.00	7.00	6.33 – 7.00	-0.67
Privacy & Dignity	7.00	6.50 – 7.00	7.00	6.50 – 7.00	0.00	7.00	7.00 – 7.00	7.00	7.00 – 7.00	0.00
Scheduling	6.50	5.75 – 7.00	7.00	6.00 – 7.00	-0.50	6.33	5.67 – 7.00	6.58	5.67 – 7.00	-0.25
How Team Treats you	7.00	6.33 – 7.00	7.00	6.00 – 7.00	0.00	6.83	6.00 – 7.00	7.00	6.00 – 7.00	-0.17
The Environment	6.33	5.65 – 6.73	6.33	5.60 – 7.00	0.00	5.82	5.00 – 6.45	6.08	5.45 – 6.50	-0.26
Overall Experience	6.50	6.00 – 7.00	7.00	6.00 – 7.00	-0.50	6.00	6.00 – 7.00	7.00	6.00 – 7.00	-1.00
Pilot PPREM Scale Score	6.55	5.75 – 6.77	6.46	5.89 – 6.68	0.09	6.32	5.72 – 6.62	6.59	6.07 – 6.77	-0.27