



Paediatric Patient Reported Experience Measure (PPREM) Pilot

2023 Report

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Foreword

We are delighted to present this 2nd national pilot Paediatric Patient Reported Experience Measure (pPPREM) report for children and young people with kidney disease in the UK. With continued support from the adult Kidney PREM and the University of Hertfordshire, and based on validated questions of the Kidney PREM, this report describes the experience of children and young people with kidney disease and that of their parents and carers.

The support from health professionals continues to have been fantastic, with all 13 UK paediatric nephrology centres contributing to the development of the data collection and ongoing development of the Paediatric PREM.

We are also very grateful for the support of children and young people with kidney disease and their parents and carers who have completed the questionnaire. This has resulted in this second pilot providing valuable information across all ages and all treatment groups within paediatric nephrology services, increasing on the number of responses from last year.

The aim of the Paediatric PREM is to help professionals and patients to work together to improve the quality of care and quality of lives for children and young people with kidney disease. The success of this and the previous pilot have helped us secure funding to develop a full Paediatric PREM. This will allow 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.



Dr Jan Dudley
President of the BAPN



Dr Andrew Lunn
Chair of the BAPN Patient Reported Experience Group

Acknowledgments

We would like to express a huge thank you to all who have contributed to the 2023 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 PREM,
- The members of the BAPN Patient Reported Experience 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.

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.

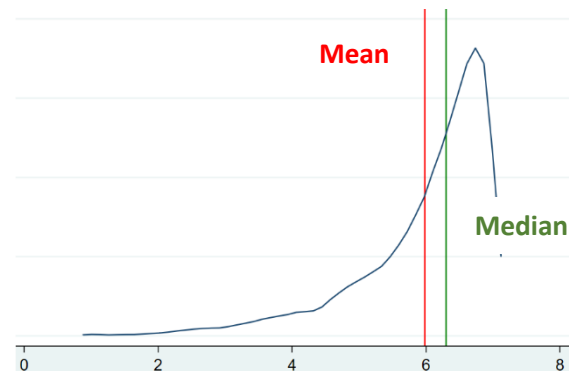
Mean: The *mean* centre score is calculated across patient scores by adding them together and dividing by the number of scores used, giving the mathematical average value.

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.

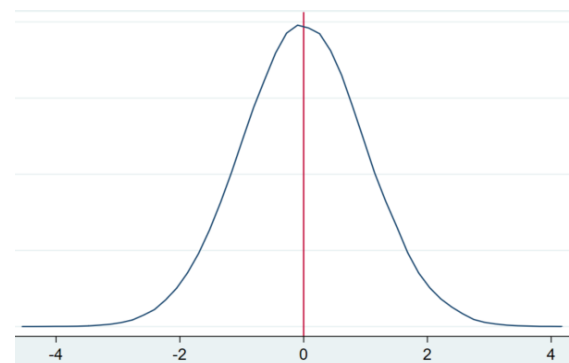
Median: If patient scores for a particular centre were listed in order, the *median* is the middle value separating the high scoring (top half) from the low scoring (bottom half).

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 25th centile) would be the value below which the bottom quarter of scores lies. Conversely, the *upper quartile* (or 75th 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

Following success of the initial survey in 2022, the pilot Paediatric PREM (pPPREM) was repeated in 2023 alongside the adult Kidney PREM¹. Questions were identical to the 2022 pPPREM, based on items from the validated Kidney PREM. Children and young people (CYP) aged 12 to 16 years could complete the pPPREM, either by themselves or with help from a trusted adult. Parents/carers of CYP of any age could participate and were asked to respond considering their experience as a parent/carer.

Response numbers and patient characteristics

A total of 312 responses were received from all 13 UK centres in 2023, a 9.5% increase from 285 valid surveys received in 2022. There were 264 responses from parents/carers and 48 from CYP themselves. Response numbers from each centre were variable, ranging from 6 to 90.

Although the pPPREM targeted CYP aged up to 16 years, some individuals aged 17 years or over continue to attend paediatric centres, and so were included in analysis. Kidney patients of all age groups were represented in the pPPREM, from 0 to 17 years. Individuals from many ethnic groups participated; notably there was a higher proportion of Asian respondents than in Kidney PREM (12.5% vs 9.5%), but a lower proportion of black patients (4.2% vs 9.0%). As seen in 2022, over half of responses related to CYP with chronic kidney disease (CKD) who were not receiving kidney replacement therapy (KRT). This reaffirms that CYP are more likely to have their CKD management in secondary care than via their GP.

Notes for interpretation

As the UK Renal Registry (UKRR) primarily collects data about individuals who are receiving KRT, demographic comparisons cannot easily be made between pPPREM respondents and the UK paediatric kidney population. Caution is also advised when considering demographic representation as individuals may be double counted if both the CYP 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.

¹ <https://ukkidney.org/kidney-patient-reported-experience-measure>

Key findings from the pilot Paediatric PREM

The pPPREM achieved a good response from parents/carers and children and young people with CKD, increasing in number from 285 in 2022 to 312 in 2023.

The highest scoring themes were *Privacy & Dignity* (6.73), *Patient Information* (6.54) and *Access to the Kidney Team* (6.49).

The lowest scoring pPPREM themes were *Communication* (5.94), *The Environment* (5.88) and *Support* (5.77).

Communication increased in score across all participants by 0.28 compared to 2022, from 5.67 to 5.94, with largest increase seen in parents/carers of under 12s (from 5.28 to 6.02).

Transport increased by 0.88 compared to 2022, from 5.18 to 6.06. However, only 12 participants reported using hospital transport this year (15 participants in 2022).

Young people rated the *Support* they experienced more poorly than parents/carers at 5.03 out of 7, compared to 5.98 and 5.78 for parents/carers of under 12s and over 12s respectively.

Across all themes, the range of centre scores was narrow, in contrast to the wide range seen in the adult Kidney PREM.

Privacy & Dignity was scored highly across all centres (range 6.41 to 6.94). However, young people rated the theme slightly less positively (6.29) than parents/carers (6.84 for under 12s and 6.77 for over 12s).

Reassuringly, pPPREM participants scored *Overall Experience* of their care positively at all centres, the average being 6.28 and ranging from 6.08 to 6.57.

At a question-level, *Support* when accessing patient support groups (Q6), *Communication* between the kidney team and school (P02) and, parking within *Environment* theme (Q38) were scored poorly (scores of 1-3 out of 7 by over 20% of participants).

Introduction

In 2022 the 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 Reynolds² and Ms Suzanne Turton³ 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 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.

This year, a successful NIHR funding bid was made 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. The aim is to provide a patient reported experience measure (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. There is confidence in achieving this through continued work with a community of children and young people with kidney disease, parents/carers, and healthcare professionals to achieve the long-term goal of an all-age Kidney PREM.

Whilst the NIHR bid was being developed, the Paediatric Patient Experience working group were committed to maintain the momentum from 2022, repeating the pilot measure in 2023 in partnership with the UK Kidney Association and Kidney Care UK. This report highlights those findings.

² Consultant Paediatric Nephrologist at NHS Greater Glasgow and Clyde

³ Expert kidney patient

Methodology

The pilot Paediatric PREM

The pilot Paediatric Kidney PREM 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 posed 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 (CYP) aged 12-16 years receiving care or if they were responding by proxy (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.

Three additional questions were asked at the end of the pilot Paediatric PREM 2023 concerning specific topics in alignment with the adult Kidney PREM. These were: whether the kidney team had asked about the participant's wellbeing, who their clinic letters were addressed to and whether their centre had discussed the previous year's Kidney PREM findings with the participant.

Data collection

Online access to the pilot Paediatric Kidney PREM lasted eight weeks, from 11th September until 6th November 2023, alongside the annual Kidney PREM for adults. Collection of data was publicised as an online survey, with links available on both the UK Kidney Association and Kidney Care UK 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 'pPPREM scale score' (the total pilot Paediatric PREM score) across all themes, excluding the Overall question. For further detail, including data processing, please refer to the Kidney PREM Technical Report⁴, 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.

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

Results

Chapter 1: Profile of Paediatric PREM respondents

Response profile

A total of 312 responses were received from the 13 UK centres in 2023 for the pilot Paediatric PREM (PPREM), Table 1.1, a 9.5% increase from the 285 surveys received in 2022. There were 264 responses from parents/carers of children and young people (CYP) and 48 from CYP aged 12 years and over, 15.4% of surveys received, Table 1.2. This year sees an increase in the proportion of parents/carers of CYP completing the survey; in 2022 they accounted for 77.2% of the responses. Four of the CYP were aged 17-21 years but receiving care from paediatric centres, so although they participated in the adult Kidney PREM, these individuals are reported here, included in the '12 years and over' category throughout this report, unless otherwise stated. As both parents/carers and CYP aged 12 and over were able to participate in the pilot PPREM, it should be noted that more than one response could have been submitted for a CYP, potentially double counting in terms of patient characteristics or demographics.

Table 1.1: Pilot Paediatric PREM 2023 Responses by Treating Centre

Centre	Responses 2023		Responses 2022	Change from 2022		Proportion of KRT patients at each centre ¹
	N	% of returns		N	%	
Alder Hey Children's Hospital	8	2.6%	14	-6	-42.9%	4.6%
Birmingham Children's Hospital	9	2.9%	28	-19	-67.9%	12.1%
Bristol Royal Hospital for Children	19	6.1%	21	-2	-9.5%	5.9%
Children's Hospital for Wales, Cardiff	11	3.5%	17	-6	-35.3%	3.7%
Evelina London Children's Hospital	13	4.2%	61	-48	-78.7%	9.6%
Great North Children's Hospital	6	1.9%	10	-4	-40.0%	3.8%
Great Ormand Street Hospital	43	13.8%	27	+16	59.3%	18.4%
Leeds Children's Hospital	21	6.7%	19	+2	10.5%	6.8%
Nottingham Children's Hospital	52	16.7%	32	+20	62.5%	10.3%
Royal Belfast Hospital for Sick Children	14	4.5%	10	+4	40.0%	3.1%
Royal Hospital for Children, Glasgow	90	28.8%	12	+78	650.0%	6.8%
Royal Manchester Children's Hospital	9	2.9%	8	+1	12.5%	10.1%
Southampton Children's Hospital	12	3.8%	22	-10	-45.5%	4.7%
UK Total	312	-	285	+27	9.5%	950

1. Data from the UK Renal Registry as at end of 2021. 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

Amongst parents/carers, over half of the responses (61.0%) related to a child under the age of 12 years, Table 1.2. Responses for parents/carers of CYP aged 0-3 and 8-11 years decreased slightly from the previous year, but overall, an additional 44 responses were received from parents/carers compared to 2022. Of the responses received relating to 12-16-year-olds, less than a third were CYP reporting their own experiences of care received (29.9%), with most responses coming from parents/carers for this age bracket (103 vs 44). Just 48 CYP participated in the pilot Paediatric PREM in 2023 compared to 65 in 2022.

Table 1.2: Pilot Paediatric PREM age of patient receiving care

Age (years)	Year	Parent/Carer (% of parent/carer)	Child/Young Person (% of CYP)	Total (% of total)
0-3	2022	51 (23.2%)	-	51 (17.9%)
	2023	46 (17.4%)	-	46 (14.7%)
4-7	2022	38 (17.3%)	-	38 (13.3%)
	2023	60 (22.7%)	-	60 (19.2%)
8-11	2022	69 (31.4%)	-	69 (24.2%)
	2023	55 (20.8%)	-	55 (17.6%)
12-16	2022	62 (28.2%)	52 (80.0%)	114 (40.0%)
	2023	103 (39.0%)	44 (91.7%)	147 (47.1%)
17+	2022	-	13 (20.0%)	13 (4.6%)
	2023	-	4 (8.3%)	4 (1.3%)
Total (% of total)	2022	220 (77.2%)	65 (22.8%)	285
	2023	264 (84.6%)	48 (15.4%)	312

Gender

Amongst CYP participants aged 12 years and over, fewer males than females responded (43.8%), Table 1.3. Conversely, participation was greater from parents/carers of male patients under 12 years (64.6%) and 12-16 years (58.3%). No participants selected non-binary or other gender. There are no marked differences when comparing with data from 2022, with the gender split from responses of each group remaining similar.

Table 1.3: Pilot Paediatric PREM gender of patient receiving care

Gender	Year	Parent / Carer <12 years (% of total)	Parent / Carer 12+ years (% of total)	Child/Young Person (% of total)	Total (% of total)
Male	2022	102 (64.6%)	36 (58.1%)	27 (41.5%)	165 (57.9%)
	2023	104 (64.6%)	60 (58.3%)	21 (43.8%)	185 (59.3%)
Female	2022	56 (35.4%)	24 (38.7%)	36 (55.4%)	116 (40.7%)
	2023	57 (35.4%)	43 (41.7%)	27 (56.3%)	127 (40.7%)
Rather not say	2022	-	2 (3.2%)	2 (3.1%)	4 (1.4%)
	2023	-	-	-	-
Total	2022	158	62	65	285
	2023	161	103	48	312

Ethnicity

The ethnic profile of patients receiving care was similar within each respondent group, Table 1.4. For CYP aged 12 years and over, three quarters of the respondents were white (75.0%). A total of 76.4% of parents/carers of under 12s and 79.6% of parents/carers of 12-16-year-olds stated that their CYP was white. There appeared to be a similar number of patients of Asian ethnicity reported by the parents/carers of the under 12s (13.7%) compared to the 12 years and over groups with 11.7% for parents/carers and 10.4% for CYP. Although the total number of responses for Asian respondent groups was similar to 2022, there was a decrease in the percentage of Asian CYP completing the survey (10.4% vs 16.9% in 2022). Just 13 participants reported black ethnicity, so comparisons cannot be made across the three response groups.

Table 1.4: Pilot Paediatric PREM ethnicity of patient receiving care

<i>Ethnicity</i>	Year	Parent / Carer	Parent / Carer	Child/Young	Total (% of total)
		<12 years (% of total)	12+ years (% of total)	Person (% of total)	
Asian	2022	17 (10.8%)	10 (16.1%)	11 (16.9%)	38 (13.3%)
	2023	22 (13.7%)	12 (11.7%)	5 (10.4%)	39 (12.5%)
Black	2022	4 (2.5%)	3 (4.8%)	8 (12.3%)	15 (5.3%)
	2023	4 (2.5%)	5 (4.9%)	4 (8.3%)	13 (4.2%)
White	2022	124 (78.5%)	41 (66.1%)	38 (58.5%)	203 (71.2%)
	2023	123 (76.4%)	82 (79.6%)	36 (75.0%)	241 (77.2%)
Mixed/ Other	2022	13 (8.2%)	5 (8.1%)	4 (6.1%)	22 (7.7%)
	2023	10 (6.2%)	4 (3.9%)	3 (6.3%)	17 (5.4%)
Rather not say	2022	-	-	-	7 (2.5%)
	2023	2 (1.2%)	-	-	2 (0.6%)
Total	2022	158	62	65	285
	2023	161	103	48	312

Treatment modalities for patients receiving care

Most participants reported that the patient being cared for was not receiving kidney replacement therapy, KRT (53.8%), with some variation by respondent type (62.7% of parents/carers of CYP under 12 years, 49.5% of parents/carers of CYP over 12 years and 33.3% of CYP), Table 1.5. Amongst CYP, numbers receiving each KRT type were almost unchanged from 2022, but those not receiving KRT decreased by half (34 to 16) compared to the previous year.

The percentage of parents/carers of CYP with functioning kidney transplants has decreased, to 18.0% (23.5% in 2022) for the under 12s and 25.2% (35.5% in 2022) for the over 12s. Of the 144 respondents who reported receiving KRT care, 73 (46.5%) had functioning transplants; by comparison, most children in the UK receiving KRT have transplants (76.3%, data from end of 2021, UKRR⁵) suggesting an under-representation of transplant recipients in this report. As the UKRR does not yet report data for patients not receiving KRT, and given that over half of responses related to this group, caution should be taken when making comparisons between treatment groups or to UKRR demographic numbers.

Table 1.5: Treatment modality of patient receiving care

	Year	Parent / Carer	Parent / Carer	Child/Young	Total (% of total)	UK KRT Population 2021
		<12 years (% of total)	12+ years (% of total)	Person (% of total)		
Transplant	2022	37 (23.5%)	22 (35.5%)	14 (21.5%)	73 (25.6%)	76.3%
	2023	29 (18.0%)	26 (25.2%)	12 (25.0%)	67 (21.5%)	
Haemodialysis	2022	14 (8.9%)	7 (11.3%)	13 (20.0%)	34 (11.9%)	11.5%
	2023	13 (8.1%)	14 (13.6%)	16 (33.3%)	43 (13.8%)	
Peritoneal dialysis	2022	14 (8.9%)	6 (9.7%)	4 (6.2%)	24 (8.4%)	12.2%
	2023	18 (11.2%)	12 (11.7%)	4 (8.3%)	34 (10.9%)	
CKD (non-KRT)	2022	93 (58.9%)	27 (43.6%)	34 (52.3%)	154 (54.0%)	-
	2023	101 (62.7%)	51 (49.5%)	16 (33.3%)	168 (53.8%)	
Total	2022	158	62	65	285	
	2023	161	103	48	312	

⁵ <https://ukkidney.org/audit-research/annual-report/25th-annual-report-data-31122021>

Patients receiving haemodialysis

The UKRR reports that there were around 200 CYP in the UK receiving dialysis (peritoneal dialysis or haemodialysis) at the end of 2021. In the pPPREM, 43 responses related to those receiving haemodialysis. It should be noted that 16 are from CYP and 14 from parents/carers of those aged 12 years and over, so some could relate to the same individual receiving care. Of those receiving haemodialysis, just two were at home. Although one was reported by a parent/carer of a CYP aged 12+ years and the other a CYP, the two were at different centres. The remainder received their care at their main centre.

Participation in shared care for individuals receiving haemodialysis

Almost 20% of all respondents across all groups stated they were participating in shared care, while nearly 10% across groups have declined participation, Table 1.6. Across all response groups, 41.5% stated they did not know whether they/their CYP was participating in shared care, though this was the case in over half of parents/carers of CYP under 12 (53.8%).

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

	Parent/Carer <12 years	Parent/Carer 12+ years	Child/Young Person	Total
Participating	2 (15.4%)	3 (23.1%)	3 (20.0%)	8 (19.5%)
Declined	-	1 (7.7%)	3 (20.0%)	4 (9.8%)
Not invited	4 (30.8%)	4 (30.8%)	4 (26.7%)	12 (29.3%)
Don't know	7 (53.8%)	5 (38.5%)	5 (33.3%)	17 (41.5%)
Total	13	13	15	42

Patients attending clinic but not receiving kidney replacement therapy

Amongst responses relating to patients not receiving KRT, almost 80% (79.2%) of all participants stated that they/their CYP were attending clinic for monitoring only in 2023, similar to the previous year (77.3%), Table 1.7. There also remained a similar proportion of individuals responding about patients approaching end stage kidney disease compared to the previous year (14.3% vs 15.6% in 2022). There remains a small group (6.5%) who do not know the CKD type of the patient, all of whom were parents/carers completing the pilot Paediatric PREM.

For patients approaching end stage kidney disease, nearly two-thirds (62.5%) of respondents had decided upon their/their CYP's KRT type. This contrasts to responses received in 2022, where this was the case for just 33.3%.

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	2022	71 (76.3%)	24 (88.9%)	24 (70.6%)	119 (77.3%)
	2023	78 (77.2%)	41 (80.4%)	14 (87.5%)	133 (79.2%)
Approaching end stage kidney disease	2022	15 (16.1%)	2 (7.4%)	7 (20.6%)	24 (15.6%)
	2023	14 (13.9%)	8 (15.7%)	2 (12.5%)	24 (14.3%)
Don't know CKD type	2022	7 (7.5%)	1 (3.7%)	3 (8.8%)	11 (7.1%)
	2023	9 (8.9%)	2 (3.9%)	0 (0.0%)	11 (6.5%)
Total CKD (non-KRT)	2022	93	27	34	154
	2023	101	51	16	168

Help to participate in pilot Paediatric PREM

Twenty-six (8.3%) of respondents reported receiving help to complete the survey, 16 of whom were CYP. Fifteen of those cited age as the reason for needing help and the other due to connection to the haemodialysis machine. Most parents/carers completed the pilot Paediatric PREM without assistance (96.2%). Three quarters (76.9%) of all respondents receiving help did so from a friend, relative or carer, in contrast to those completing the adult Kidney PREM who were more likely to receive help from a volunteer or staff member (66.2%).

English as first language

Twenty-eight participants (9.0%) reported that the patient receiving care had a first language other than English. A total of 19 languages were reported to be spoken: 1 Arabic, 1 Bengali, 1 Chichewa, 1 Croatian 2 Dari, 1 Farsi, 1 Hindi, 1 Igala, 1 Italian, 1 Lithuanian, 1 Pashtu, 3 Polish, 2 Portuguese, 1 Punjabi, 3 Romanian, 1 Russian, 1 Sinhalese, 2 Slovakian and 2 Urdu, with one patient reported to be non-verbal. These 28 individuals were receiving care from six centres, with 12 from Great Ormond Street Hospital and seven from Nottingham Children's Hospital.

Use of Patients Know Best

As most centres have transferred to the use of Patients Know Best⁶ (PKB) from the previous service, PatientView, the question relating to the use of online platforms to receive test results was reworded in both the pilot Paediatric PREM and the adult Kidney PREM. CYP completing the survey were less likely to report using PKB (29.2%) than parents/carers (42.2% under 12s, 47.6% over 12s), Table 1.8. Despite this, there is a slightly higher proportion of pPPREM respondents reporting PKB use than in the adult Kidney PREM (42.0% vs 36.9%).

Table 1.8: Pilot Paediatric PREM 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)
Yes, using PKB	68 (42.2%)	49 (47.6%)	14 (29.2%)	131 (42.0%)
No, not using PKB because:	80 (49.7%)	47 (45.6%)	25 (52.1%)	152 (48.7%)
It's unavailable	7 (8.8%)	2 (4.3%)	2 (8.0%)	11 (7.2%)
Don't know what it is	57 (71.3%)	32 (68.1%)	19 (76.0%)	108 (71.1%)
Another reason	16 (20.0%)	13 (27.7%)	4 (16.0%)	33 (21.7%)
Don't know	13 (8.1%)	7 (6.8%)	9 (18.8%)	29 (9.3%)

PKB: Patients Know Best

Medication

As with the previous year, a quarter of participants reported receiving their/their CYP's medication from a mixture of sources (26.7%), Table 1.9. There was an increase in proportion of those reportedly obtaining medication from their GP, from 27.3% in 2022 to 31.5% in 2023, and a corresponding decrease in those who received it from the hospital pharmacy (29.9% in 2022 to 23.7% in 2023). Thirty-eight (12.2%) participants reported that this question was not applicable to them as they/their CYP did not require medication.

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)	41 (30.1%)	34 (37.0%)	10 (23.8%)	85 (31.5%)
Hospital pharmacy	30 (22.1%)	15 (16.3%)	19 (45.2%)	64 (23.7%)
Community pharmacy	19 (14.0%)	11 (12.0%)	4 (9.5%)	34 (12.6%)
Delivered to me	5 (3.7%)	6 (6.5%)	1 (2.4%)	12 (4.4%)
Mixture of above	41 (30.1%)	24 (26.1%)	7 (16.7%)	72 (26.7%)
Other	0 (0.0%)	2 (2.2%)	1 (2.4%)	3 (1.1%)
Total receiving medication	136	92	42	270

⁶<https://patientsknowbest.com/>

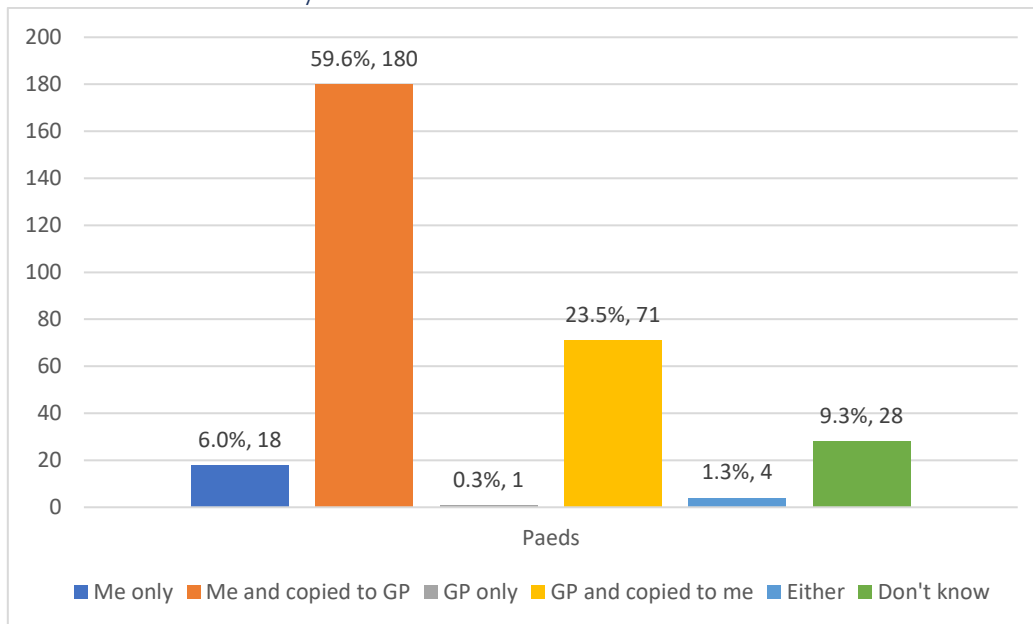
Chapter 2: Additional questions

The Kidney PREM working group, in collaboration with service users, developed three additional, one-off questions for Kidney PREM participants in 2023 which were also asked of pilot Paediatric PREM participants. These were designed to capture information on topics deemed important by the group to better understand current practices at a local level and from a patient perspective in order to drive improvements. The questions were added at the end of the survey so as not to interfere with the measure itself, but before participants were asked to provide any comments.

Question A: 'Who are your kidney clinic letters sent to?'

Best practice suggests that clinic letters should be addressed to patients/their parents/carers as well as to their primary care practitioners, using appropriate language so that they can be well understood. A total of 302 participants (96.8% of pilot Paediatric PREM respondents) provided a response, Figure 2.1. Over half (59.6%) reported that letters were sent to themselves and copied to their GPs, with a further 6.0% stating that they were sent only to themselves. A total of 23.8% responded that letters were sent either to the GP only, or to their GP and copied to themselves. Just under a tenth (9.3%) did not know who their clinic letters were sent to.

Figure 2.1: Results for 'Who are your clinic letters sent to?'



Question B: 'Have your kidney team talked to you about your wellbeing in the last year? For example: benefits/housing/mental health.'

This question also received 302 responses (96.8%), with nearly a half (48.0%) reporting that staff had spoken with them about their wellbeing in the previous year, Table 2.1. There was considerable variation by centre, with proportions ranging from 27.3% to 100.0%. However, small numbers at some centres mean that differences should be interpreted with caution.

Question C: 'Has anyone from your unit talked to you about last year's pPPREM report?'

This question was included to aid the understanding of if and how pilot Paediatric PREM results have been used by centres. A total of 302 (96.8% of respondents) provided an answer to this question, with just 9.6% of participants stating that someone had spoken to them about the previous year's results (Table 2.1). Again, there was some centre variation; 0.0% of individuals at Cardiff had discussed findings compared to 33.3% of those in Manchester.

Table 2.1: Pilot Paediatric PREM participants who have been spoken to about their wellbeing or previous year's report

	Question B: Spoken to about Wellbeing?		Question C: Spoken to about last year's pPPREM?	
	Frequency	%	Frequency	%
Birmingham	5	55.6%	1	11.1%
Belfast	9	64.3%	4	28.6%
Bristol	7	41.2%	1	5.9%
Cardiff	3	27.3%	0	0.0%
Glasgow	27	30.7%	5	5.7%
Evelina	5	38.5%	1	7.7%
GOSH	24	61.5%	4	10.3%
Leeds	15	71.4%	4	19.0%
Liverpool	5	62.5%	2	25.0%
Manchester	3	33.3%	3	33.3%
Newcastle	6	100.0%	1	16.7%
Nottingham	29	55.8%	1	1.9%
Southampton	5	41.7%	2	16.7%
<i>Unknown centre</i>	2	66.7%	0	0.0%
Total	145	48.0%	29	9.6%

Chapter 3: Change in patient experience

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

Participants of the pPPREM are asked to rate how their experience of care has changed over the previous year. This question is asked at the end of the scale (after question 39) prior to the additional questions and comments free-text box. 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.

In 2023

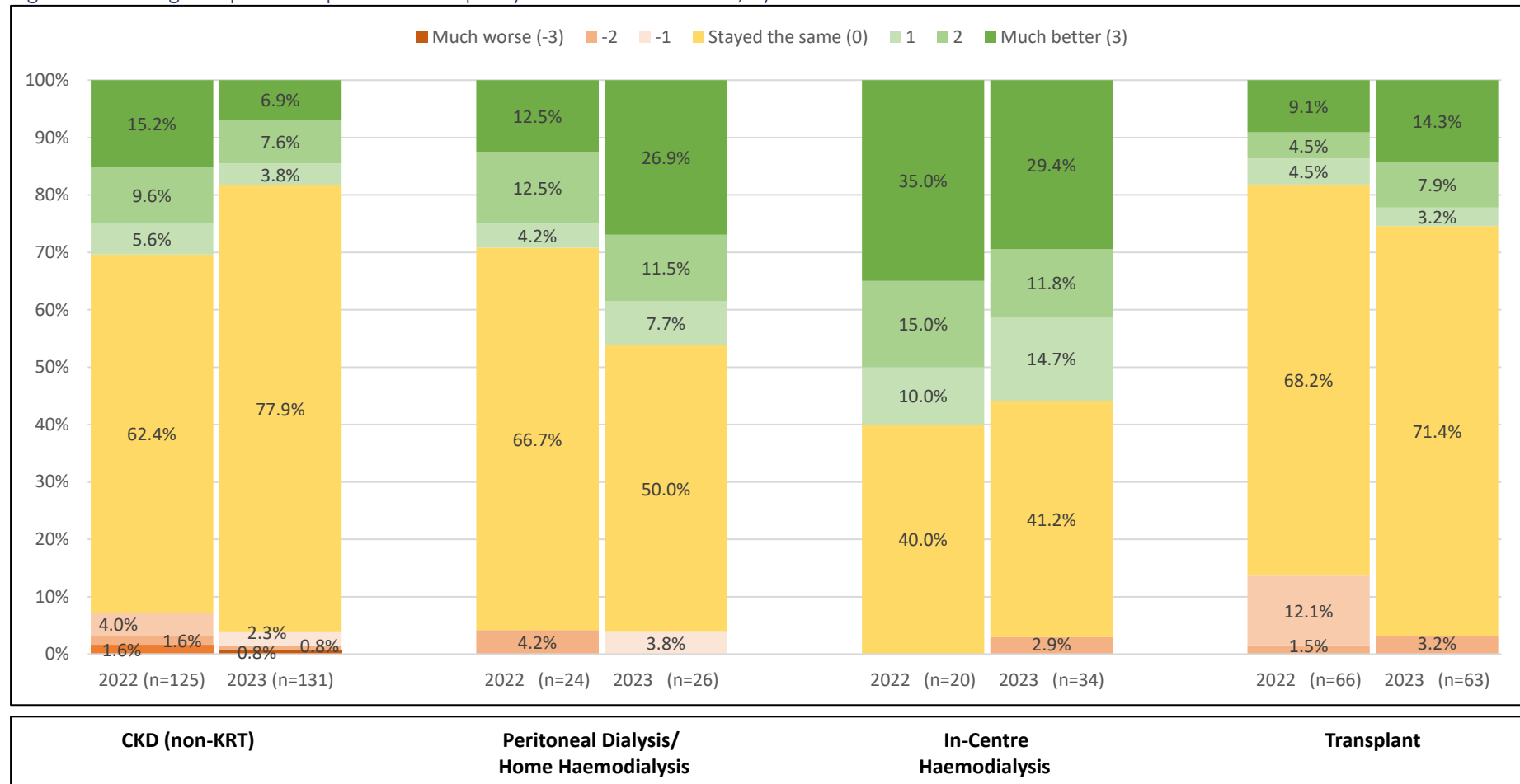
A total of 302 individuals (96.8% of all participants) provided an answer to this question, with 48 of those (15.9%) stating that they were not receiving care in the previous year. Amongst those who scored their change in experience, 68.5% stated that they had experienced no change over the previous year. Just 3.5% reported their experience worsening (-1, -2, or -3 ‘much worse’), with the remainder (28.0%) stating an improvement in their experience (+1, +2 or +3 ‘much better’).

There was some variation by treatment type (Figure 3.1), with 55.9% of those reporting on individuals receiving in-centre haemodialysis stating that care was better (+1, +2 or +3 ‘much better’) compared to just 18.3% of those relating to individuals not receiving KRT, with transplant (25.4%) and home therapies (home haemodialysis and peritoneal dialysis, 46.2%) in between. Encouragingly, at the lower end of the scale there was little difference between treatment modalities, the proportion of those reporting a worse experience (-1, -2, or -3 ‘much worse’) ranging from 2.9% to 3.8%.

Compared to previous years

With the exception of in-centre haemodialysis, those reporting on other treatment groups provided different response profiles in 2023 compared to 2022. For those not receiving KRT, the proportion of those reporting no change increased dramatically from 62.4% to 77.9%, with a corresponding decrease in better (+1, +2 or +3 ‘much better’) scores. In contrast, both transplant and home therapy (home haemodialysis, peritoneal dialysis) groups increased their better scores, but those answering on behalf of people with functioning kidney transplant also decreased the proportion of worse (-1, -2, or -3 ‘much worse’) scores from 13.6% to 3.2%.

Figure 3.1: Changes in patient experience over past year for 2022 and 2023, by treatment⁷



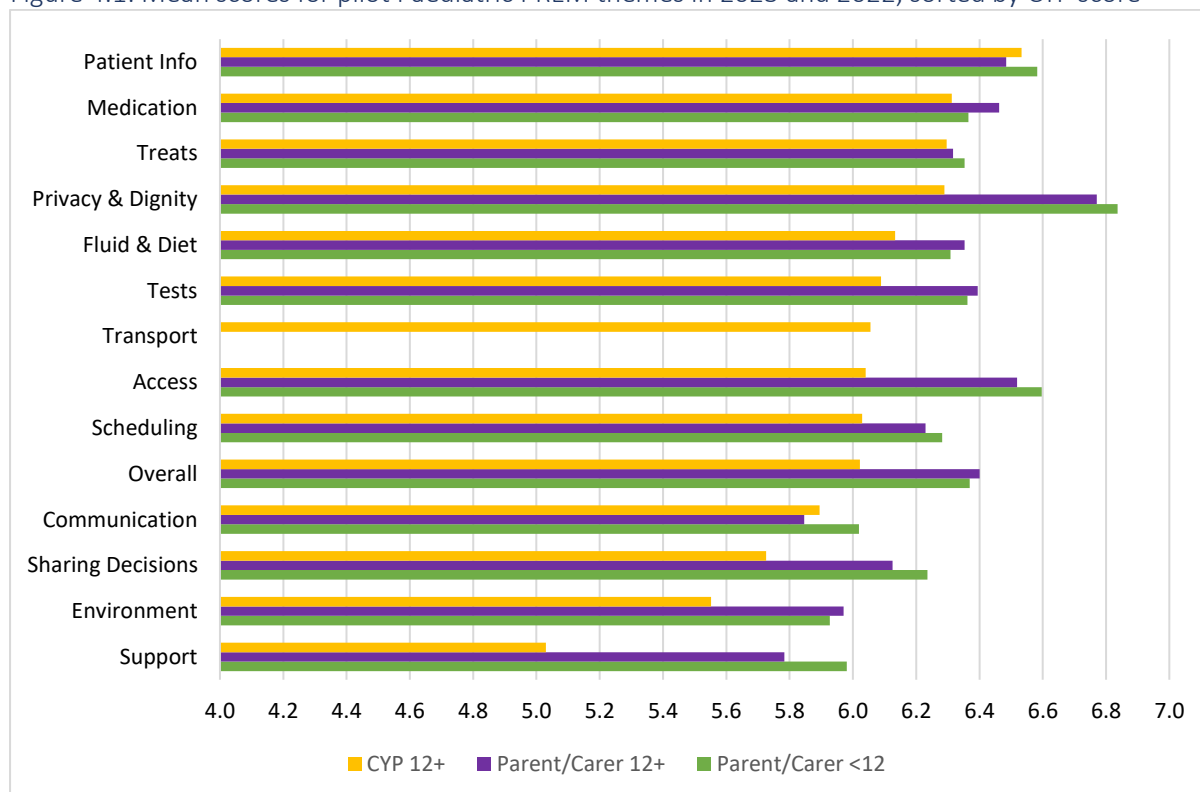
⁷ During analysis of 2023 pilot Paediatric PREM data, a coding error relating to 2022 results was revealed, where -3 and +3 values were inverted. Results published here have been updated using the correct figures.

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, CYP), Figure 4.1. Appendix Table A1 contains a table of mean scores and 95% confidence intervals for 2023 for each response group.

Figure 4.1: Mean scores for pilot Paediatric PREM themes in 2023 and 2022, sorted by CYP score



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

In 2023, the highest scoring themes were *Privacy & Dignity* (6.73), *Patient Information* (6.54) and *Access to the Kidney Team* (6.49), Table 4.1. The lowest scoring pPPREM themes were *Communication* (5.94), *The Environment* (5.88) and *Support* (5.77).

Communication increased in score across all participants by 0.28 compared to 2022, from 5.67 to 5.94, and increased amongst each respondent group, with the largest increase seen in parents/carers of under 12s, where the score increased by 0.74 (from 5.28 to 6.02). *Transport* saw the largest increase across all participants, increasing by 0.88 compared to 2022, from 5.18 to 6.06. However, only 12 participants reported using hospital transport this year (15 participants in 2022). CYP rated the *Support* they experienced more poorly than parents/carers, at 5.03 out of 7 compared to 5.98 and 5.78 for parents/carers of under 12s and over 12s respectively.

The largest decreases in theme scores in 2023 were from CYP; whilst remaining high at 6.29, *Privacy & Dignity* decreased by 0.31 from 6.59 in 2022. *Sharing Decisions* and *The Environment* decreased by a similar amount (0.29 and 0.24 respectively) amongst CYP, in each case resulting in scores which were much lower than each parent/carer group. In *Communication* and *Patient Information* themes, CYP provided similar scores to parents/carers, however, for all other themes, CYP's scores were the lowest of all respondent groups. In general, both parent groups scored themes similarly.

The largest increase from 2022 was in Transport, from 5.11 to 6.06 in CYP, but based on a small number of responses (n=9 in 2022, n=12 in 2023). However, there were too few participants using hospital transport to estimate scores from other groups.

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

	Parent/Carer <12			Parent/Carer 12+			CYP 12+			Total		
	2023	2022	Change	2023	2022	Change	2023	2022	Change	2023	2022	Change
Privacy & Dignity	6.84	6.82	0.02	6.77	6.58	0.19	6.29	6.59	-0.31	6.73	6.72	0.01
Patient Information	6.58	6.62	-0.04	6.48	6.36	0.13	6.53	6.34	0.20	6.54	6.50	0.04
Access to Team	6.60	6.59	0.01	6.52	6.46	0.06	6.04	6.16	-0.12	6.49	6.47	0.02
Medication	6.37	6.31	0.06	6.46	6.45	0.01	6.31	6.30	0.01	6.39	6.34	0.05
How Team Treats	6.35	6.36	-0.01	6.32	6.22	0.10	6.30	6.32	-0.02	6.33	6.32	0.01
Tests	6.36	6.30	0.07	6.39	6.30	0.10	6.09	6.11	-0.02	6.33	6.26	0.08
Overall Experience	6.37	6.34	0.03	6.40	6.34	0.06	6.02	6.02	0.01	6.33	6.27	0.06
Fluid & Diet	6.31	6.40	-0.10	6.35	6.46	-0.10	6.13	6.18	-0.05	6.30	6.37	-0.07
Scheduling	6.28	6.22	0.06	6.23	6.19	0.04	6.03	6.01	0.02	6.23	6.17	0.06
Sharing Decisions	6.24	6.11	0.13	6.13	6.22	-0.09	5.73	6.02	-0.29	6.12	6.11	0.01
Transport			0.00			0.00	6.06	5.11	0.94	6.06	5.18	0.88
Communication	6.02	5.28	0.74	5.85	5.48	0.36	5.89	5.63	0.26	5.94	5.67	0.28
The Environment	5.93	5.84	0.08	5.97	5.61	0.36	5.55	5.79	-0.24	5.88	5.78	0.10
Support	5.98	5.91	0.07	5.78	5.70	0.08	5.03	5.16	-0.13	5.77	5.70	0.07
pPPREM Scale Score	6.24	6.17	0.07	6.20	6.06	0.14	5.92	5.96	-0.04	6.18	6.10	0.08

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

Centre scores for pilot Paediatric PREM themes

Centre scores were calculated for each theme, available in the appendix Table A2. Using these values, centre mean scores were obtained for each theme, then compared to values from the previous year (Table 4.2). As in 2022, *Privacy & Dignity* (6.7), *Access to the Kidney Team* (6.5) and *Patient Information* (6.5) were the highest scoring themes for centres. The lowest were *Communication* (5.9), *The Environment* (5.8) and *Support* (5.7), again mirroring findings from 2022.

The ranges of centre mean score were generally narrow, the difference between the highest and lowest scoring centre being no more than 1.3 across all themes. This contrasts with results from the adult Kidney PREM, where just three themes had ranges below 1.3, the highest being 2.2 (for both *Sharing Decisions* and *Transport*). *Privacy & Dignity* was the highest scoring theme in both 2023 and 2022, replicating results from the adult Kidney PREM, though with a slightly higher score (6.7 for pPPREM vs 6.4). Just four Kidney PREM themes received scores of at least 6.3, but this was the case for over half (eight) pPPREM themes.

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

Theme	2023			2022		
	Range	Centre Mean range	Mean	Range	Centre Mean range	Mean
Privacy & Dignity	0.5	6.4 - 6.9	6.7	0.5	6.5 - 7.0	6.7
Access to Kidney Team	0.9	6.0 - 6.9	6.5	1.1	5.8 - 6.9	6.5
Patient Information	1.1	5.7 - 6.8	6.5	0.7	6.2 - 6.9	6.5
Tests	0.3	6.2 - 6.5	6.4	0.7	6.0 - 6.7	6.3
Medication	1.1	5.9 - 7.0	6.4	1.3	5.6 - 6.9	6.3
Fluid & Diet	0.9	5.9 - 6.8	6.3	1.0	5.7 - 6.7	6.4
How Team Treats You	0.8	5.9 - 6.7	6.3	0.8	5.8 - 6.6	6.3
Overall Experience	0.5	6.1 - 6.6	6.3	1.0	5.8 - 6.8	6.3
Scheduling	1.0	5.7 - 6.7	6.2	1.2	5.4 - 6.7	6.2
Sharing Decisions	1.2	5.5 - 6.6	6.1	0.8	5.7 - 6.6	6.2
Communication	1.0	5.5 - 6.5	5.9	1.5	5.0 - 6.5	5.8
The Environment	1.3	5.1 - 6.5	5.8	1.2	5.0 - 6.2	5.8
Support	1.1	5.3 - 6.4	5.7	0.7	5.4 - 6.1	5.7

Mean \leq 5.8 Mean \geq 6.3

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 32). 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.

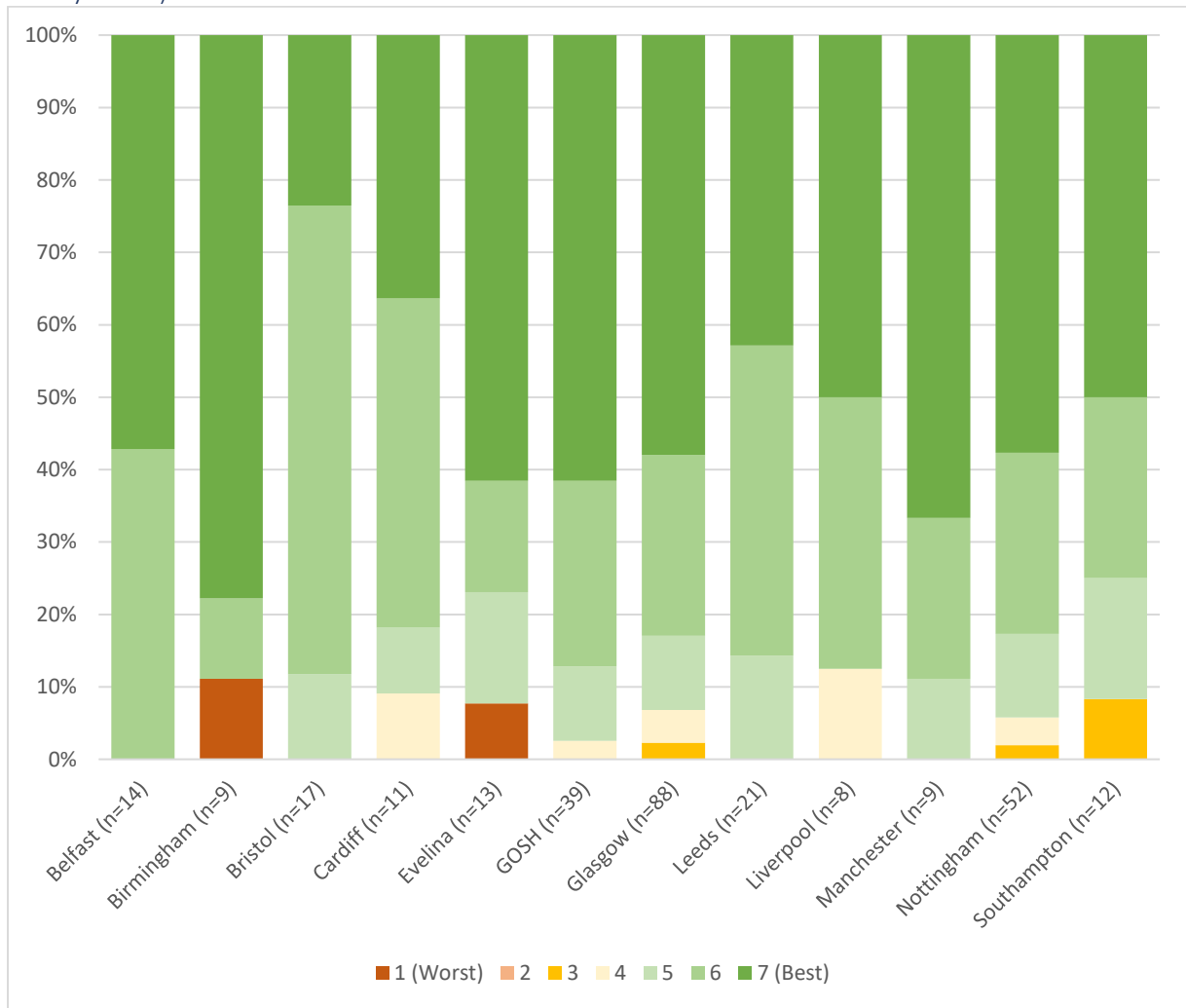
Notes for interpretation:

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 with the adult Kidney PREM, the vast majority of participants report their *Overall Experience* to be positive, with 95.0% giving a score of at least 5 out of 7. For four paediatric centres, 100% of participants gave scores between 5 and 7 and a further six received positive scores from over 90% of respondents. Although it is clear that variation exists within each centre with a mixture of scores received, it should be noted that for both centres displaying a dark red segment (score of 1, worst it can be) it related to scores from just one individual at each centre. Twelve out of 13 centres are displayed, the other not achieving the minimum number of responses (seven) required for reporting.

Figure 4.2: Centre scores for Overall Experience of the service provided by kidney centres (Q39 in Kidney PREM)



Chapter 5: Paediatric PREM theme results by treatment

Theme mean scores by treatment

Average scores for individuals were calculated according to their treatment modality, regardless of their treating paediatric centre, and compared with scores from 2022 (Table 5.1). As pPPREM data are negatively skewed (see Statistical Glossary of this report), with many participants giving high (≥ 5) scores, data can also be summarised using medians and interquartile ranges, which are available in appendix Table A3. Differences in medians are seen less often but can be more striking when they do occur.

Compared to other treatment modalities, those reporting about in-centre haemodialysis scored *Support* theme least positively at 5.11, compared to 5.79 for those not receiving KRT, 6.12 for those receiving home therapies (home haemodialysis or peritoneal dialysis) and 5.92 for those with a functioning kidney transplant. *Communication* was scored highly for those on home therapies at 6.27, in contrast with those not receiving KRT at 5.77, the lowest scoring theme of the treatment modality group. *Overall Experience* was scored highest by home therapies at 6.63, though with all treatment groups awarding a high score (6.20 for those not receiving KRT, 6.35 for those on in-centre haemodialysis, 6.47 for those with a functioning transplant).

Amongst those not receiving KRT, changes in scores from 2022 were small, generally <0.2 . For those receiving home therapies, all theme scores increased, with the largest difference seen in *Support* theme, increasing from 5.34 in 2022 to 6.12 in 2023. However, caution should be taken when interpreting these results due to relatively small numbers both years (35 in 2023, 24 in 2022). Theme scores for in-centre haemodialysis mostly decreased from the previous year, though with a large improvement in *Transport* theme from 5.18 to 6.06 in 2023. In contrast with those receiving home therapies, the largest decrease for in-centre haemodialysis was in *Support*, from 5.97 to 5.11. Again, caution is needed due to small numbers (39 in 2023, 29 in 2022). For those with functioning kidney transplants, all but one theme (*Access to Kidney Team*) increased in score. The largest increase was in *Communication*, from 5.70 in 2022 to 6.11, but all other increases were small (<0.2).

Fluid & Diet was scored more highly across all treatment modalities than in the adult Kidney PREM. Although it showed a similar pattern to the adults, with lower *Fluid & Diet* scores seen in those not receiving KRT, these were >6 out of 7 amongst all treatment groups. *Communication* was another theme where scores were higher amongst pPPREM respondents than the adult Kidney PREM for most treatment modalities, with the exception of those not receiving KRT. Notably, the pPPREM scale score (calculated across all themes) was higher throughout all groups than for Kidney PREM respondents.

Table 5.1: Comparison of mean Kidney PREM scores by treatment group for 2023 and 2022

	Chronic Kidney Disease (non-KRT)					Peritoneal Dialysis/Home Haemodialysis				
	2023 (n=163)		2022 (n=144)		2023 vs 2022	2023 (n=35)		2022 (n=24)		2023 vs 2022
	Mean	95% CI	Mean	95% CI		Mean	95% CI	Mean	95% CI	
Access to Kidney Team Support	6.43	6.27 - 6.60	6.29	6.10 - 6.49	0.14	6.75	6.52 - 6.98	6.75	6.52 - 6.98	0.00
Communication	5.77	5.56 - 5.99	5.57	5.33 - 5.80	0.21	6.27	5.92 - 6.62	5.68	5.19 - 6.16	0.60
Patient Information	6.48	6.33 - 6.63	6.47	6.30 - 6.65	0.01	6.89	6.75 - 7.02	6.61	6.30 - 6.92	0.28
Fluid & Diet	6.05	5.81 - 6.30	6.21	5.99 - 6.42	-0.16	6.70	6.47 - 6.93	6.66	6.43 - 6.89	0.04
Medication	6.29	6.10 - 6.47	6.28	6.09 - 6.47	0.00	6.62	6.36 - 6.87	6.28	5.85 - 6.70	0.34
Tests	6.23	6.08 - 6.38	6.17	5.99 - 6.34	0.06	6.56	6.34 - 6.78	6.32	6.02 - 6.63	0.24
Sharing Decisions	5.98	5.76 - 6.19	6.00	5.78 - 6.22	-0.02	6.48	6.15 - 6.82	6.25	5.83 - 6.67	0.23
Privacy & Dignity	6.79	6.69 - 6.89	6.78	6.68 - 6.88	0.01	6.74	6.51 - 6.98	6.59	6.14 - 7.04	0.15
Scheduling	6.11	5.92 - 6.30	6.10	5.89 - 6.30	0.01	6.48	6.16 - 6.80	6.43	6.02 - 6.84	0.05
How Team Treats you	6.24	6.05 - 6.42	6.28	6.11 - 6.46	-0.05	6.64	6.38 - 6.90	6.32	5.85 - 6.80	0.32
Transport	-	-	-	-	-	-	-	-	-	-
The Environment	5.86	5.70 - 6.01	5.86	5.69 - 6.03	0.00	6.11	5.78 - 6.44	5.62	5.24 - 6.01	0.49
Overall Experience	6.20	6.04 - 6.37	6.17	5.99 - 6.36	0.03	6.63	6.42 - 6.83	6.32	5.96 - 6.69	0.31
Pilot PPREM Scale Score	6.09	5.95 - 6.24	6.05	5.91 - 6.20	0.04	6.46	6.25 - 6.66	6.12	5.80 - 6.43	0.34

KRT: kidney replacement therapy

95% CI: 95% confidence interval

Table 5.1: Comparison of mean Kidney PREM scores by treatment group for 2023 and 2022 (cont.)

	In-Centre Haemodialysis					Transplant				
	2023 (n=39)		2022 (n=29)		2023 vs 2022	2023 (n=64)		2022 (n=70)		2023 vs 2022
	Mean	95% CI	Mean	95% CI		Mean	95% CI	Mean	95% CI	
Access to Kidney Team Support	6.32	5.90 - 6.75	6.60	6.26 - 6.94	-0.28	6.58	6.33 - 6.83	6.67	6.53 - 6.82	-0.09
Communication	5.11	4.44 - 5.78	5.97	5.39 - 6.56	-0.86	5.92	5.56 - 6.28	5.85	5.53 - 6.17	0.07
Patient Information	6.08	5.64 - 6.53	6.15	5.73 - 6.57	-0.07	6.11	5.85 - 6.36	5.70	5.39 - 6.00	0.41
Fluid & Diet	6.35	5.94 - 6.75	6.66	6.37 - 6.95	-0.31	6.64	6.44 - 6.84	6.46	6.25 - 6.68	0.18
Medication	6.49	6.19 - 6.78	6.58	6.23 - 6.93	-0.09	6.54	6.29 - 6.79	6.47	6.27 - 6.67	0.07
Tests	6.59	6.33 - 6.86	6.54	6.20 - 6.88	0.05	6.38	6.13 - 6.62	6.38	6.14 - 6.61	0.00
Sharing Decisions	6.21	5.84 - 6.57	6.47	6.19 - 6.74	-0.26	6.54	6.40 - 6.69	6.34	6.13 - 6.55	0.20
Privacy & Dignity	6.01	5.57 - 6.46	6.12	5.69 - 6.55	-0.11	6.35	6.05 - 6.66	6.29	6.05 - 6.53	0.07
Scheduling	6.42	6.04 - 6.81	6.58	6.32 - 6.84	-0.16	6.77	6.57 - 6.98	6.69	6.51 - 6.88	0.08
How Team Treats You	6.45	6.16 - 6.74	6.24	5.75 - 6.73	0.21	6.25	6.02 - 6.49	6.17	5.92 - 6.42	0.08
Transport	6.28	5.91 - 6.65	6.61	6.32 - 6.90	-0.33	6.43	6.19 - 6.67	6.29	6.05 - 6.53	0.14
The Environment	6.06	5.64 - 6.47	5.18	4.53 - 5.83	0.88	-	-	-	-	-
Overall Experience	5.94	5.54 - 6.34	5.95	5.55 - 6.36	-0.01	5.80	5.51 - 6.09	5.62	5.34 - 5.90	0.18
Pilot PPREM Scale Score	6.35	5.98 - 6.72	6.48	6.21 - 6.75	-0.13	6.47	6.29 - 6.65	6.37	6.16 - 6.58	0.10
	6.13	5.87 - 6.40	6.27	6.01 - 6.52	-0.13	6.27	6.08 - 6.47	6.13	5.94 - 6.31	0.15

KRT: kidney replacement therapy

95% CI: 95% confidence interval

Chapter 6: Patient experience of kidney care across the service

On each of pages 32 to 46, 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 2023 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.

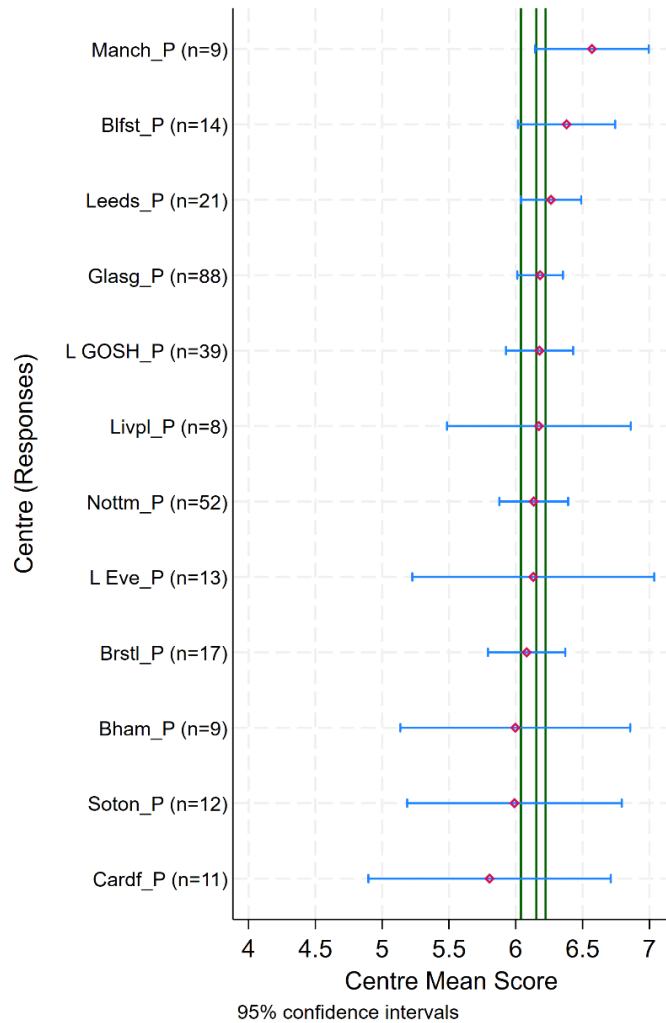
2. Question-level responses by respondent group (right-hand figure)

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 (CYP, 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.

Pilot Paediatric PREM scale score

Mean of centre scores: 6.16, range: 5.80 to 6.57.

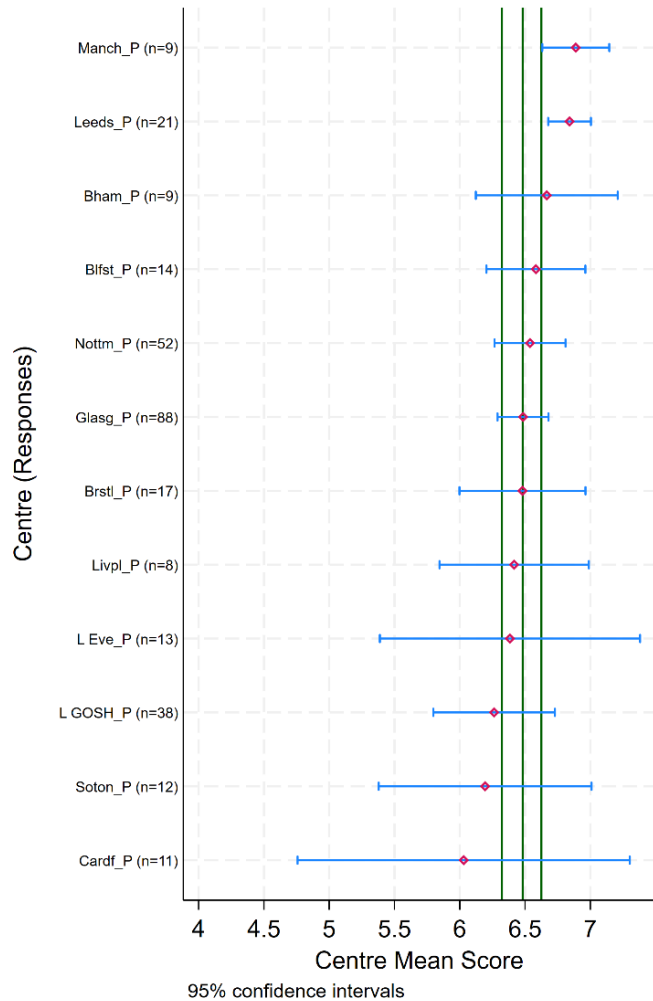


The pPPREM scale score is calculated across all question of the survey, with the exception of Q39 (Overall Experience) and is the total measure of patient experience across all themes.

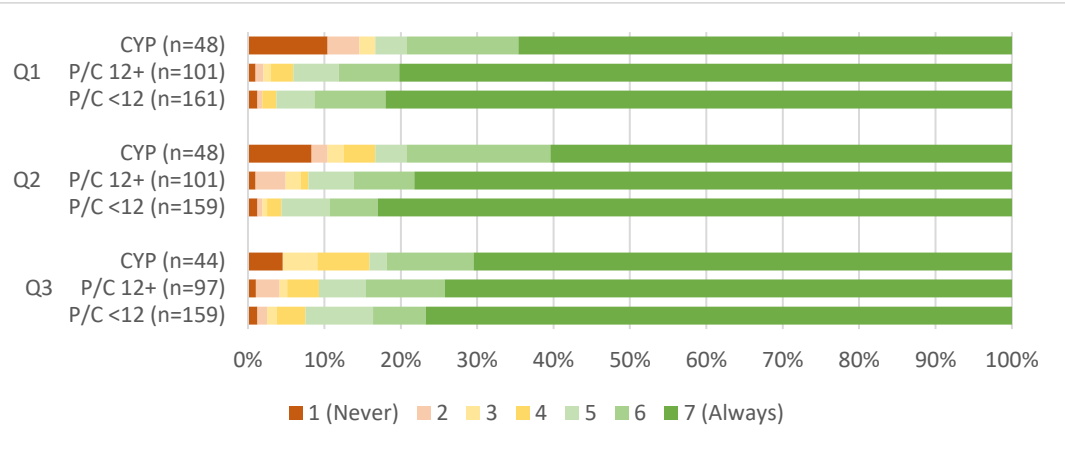
Centres scores ranged from 5.80 to 6.57, with no confidence intervals falling outside of the lower or upper quartiles. This suggests that no paediatric centres achieved scores outside of the average.

Theme 1: Access to Kidney Team

Mean of centre scores: 6.48, range: 6.03 to 6.89.



- 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?

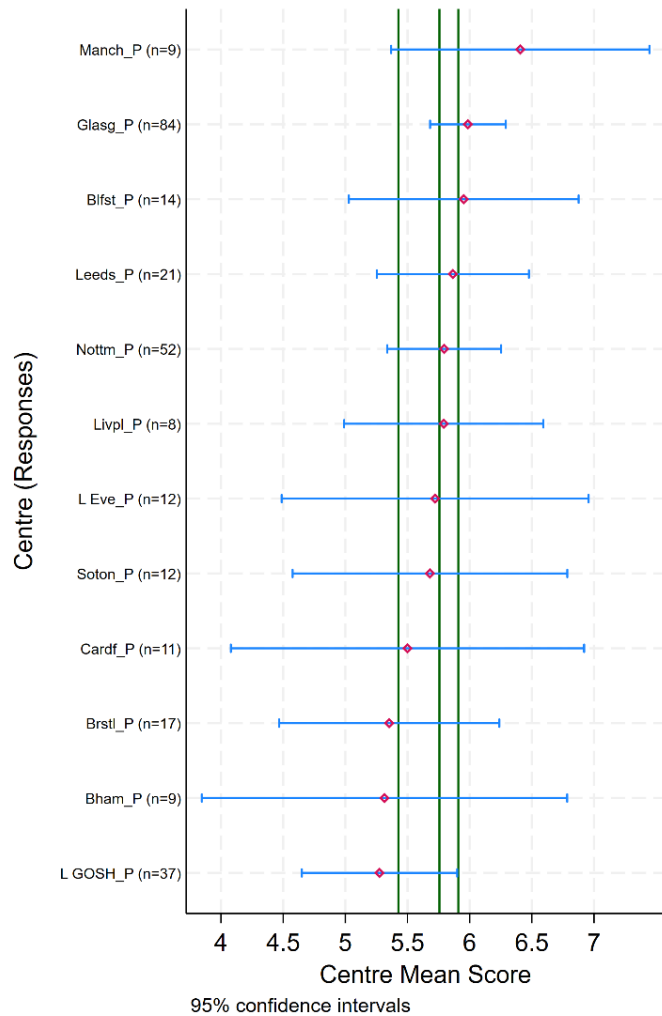


CYP: Children and Young People, P/C: Parents/Carers

Access to the Kidney Team was a high scoring theme, with slightly lower scores from CYP than parents/carers. This difference was driven by lower scores for CYP across all three questions, although notably with 16.7% of CYP awarding low scores (1 to 3) about taking time to answer questions (Q1), compared to 1.9% of parents/carers of under 12s and 3.0% of parents/carers of over 12s. Two paediatric centres achieved high scores for this theme, with relatively small confidence intervals, in contrast to lower scoring centres with wide confidence intervals indicative of in-centre variation. However, all centres received higher scores (>6 out of 7).

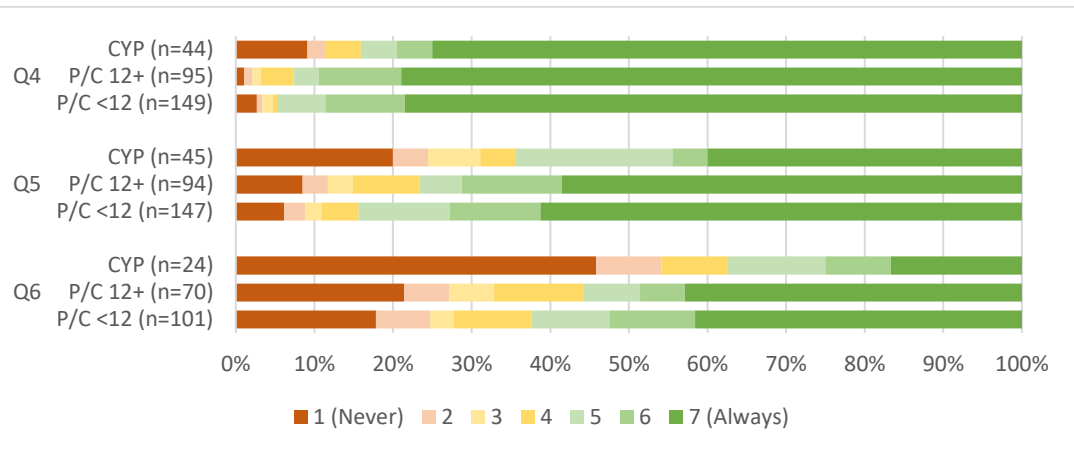
Theme 2: Support

Mean of centre scores: 5.72, range: 5.27 to 6.41.



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)?

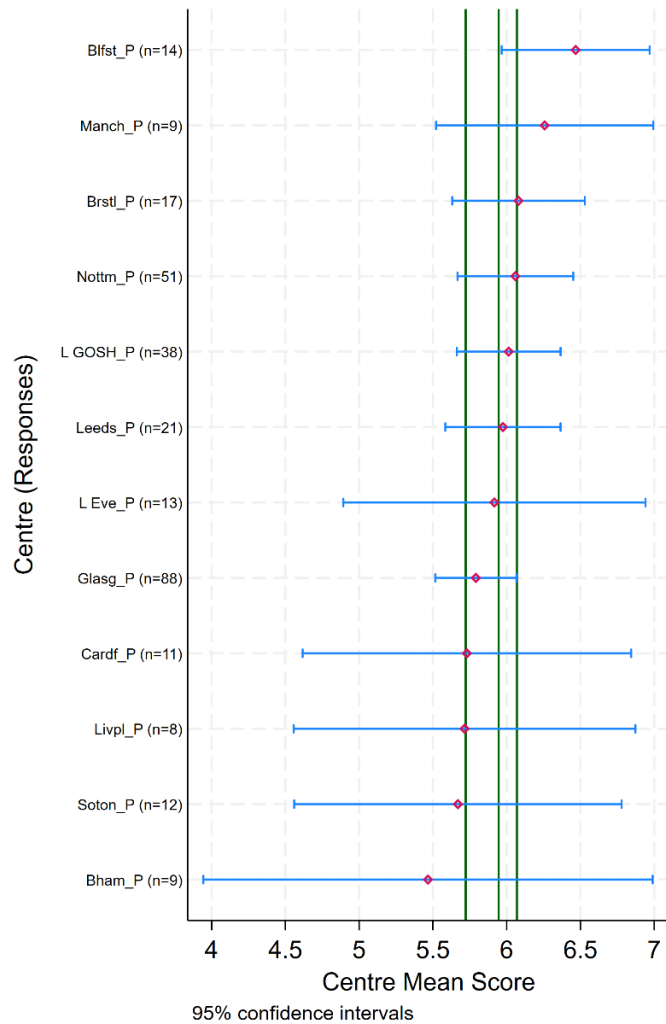


CYP: Children and Young People, P/C: Parents/Carers

Support was the lowest scoring theme of the pPPREM, again with CYP giving lower scores than parents/carers. Accessing patient support groups (Q6) was the lowest of the theme, mirroring adult Kidney PREM findings. Over half of CYP (54.2%) gave low scores (1-3), a higher proportion than either parent/carer groups (27.7% under 12s, 32.9% over 12s). Support with concerns/anxieties from disease/treatment (Q5) received low scores (1-3) from nearly a third of CYP (31.1%), more than double the proportion of either parent/carer group. There was a relatively wide range of centre scores, but with most displaying some within centre variation suggesting mixed experiences for patients.

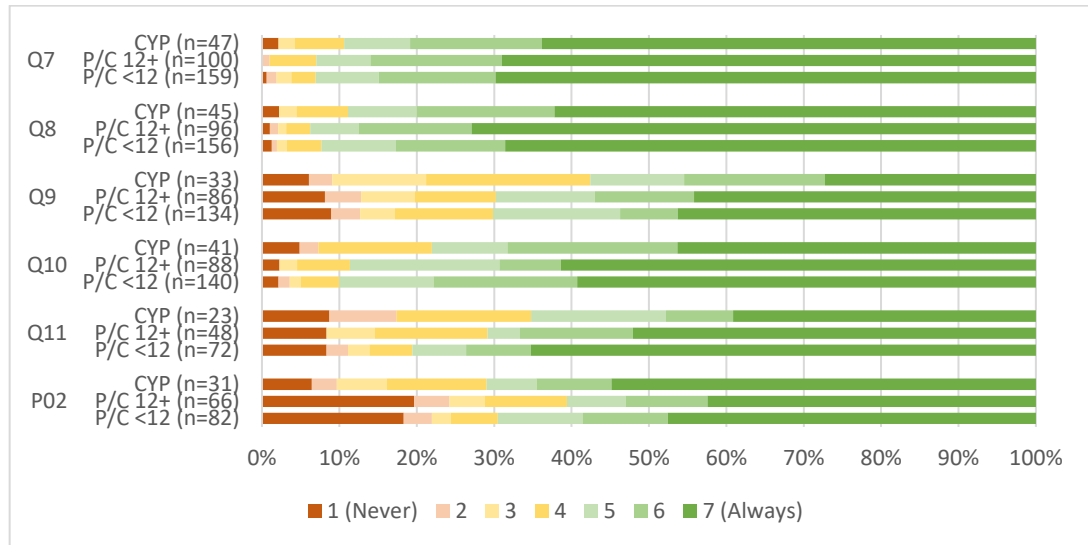
Theme 3: Communication

Mean of centre scores: 5.93, range: 5.47 to 6.47.



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?
- P02. The kidney team and your/your child's school?

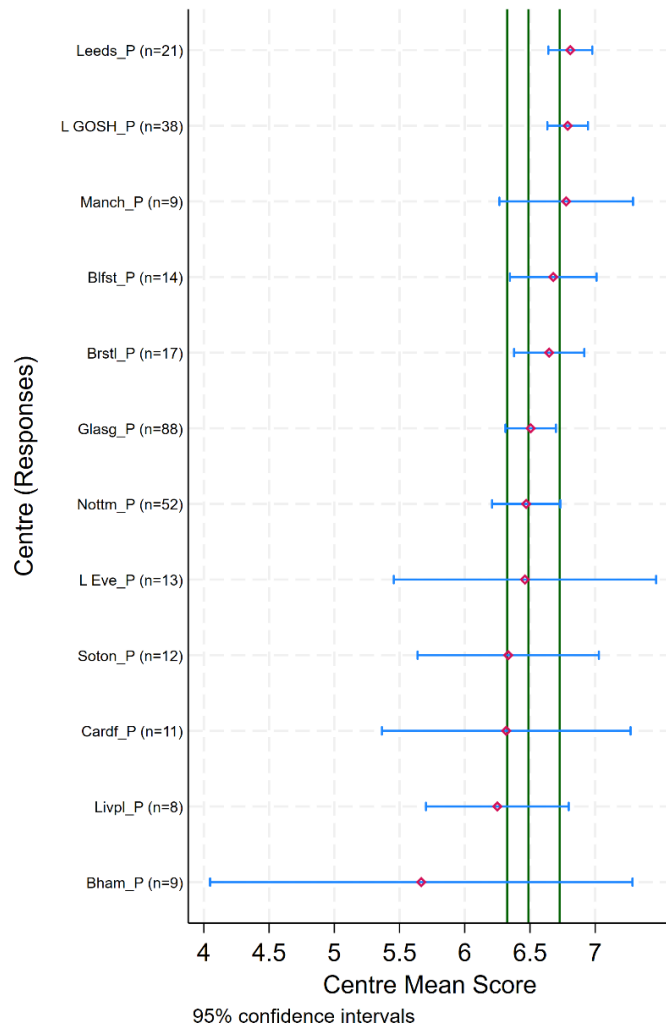


CYP: Children and Young People, P/C: Parents/Carers

Although *Communication* was one of the lower scoring themes, there was little difference between CYP and parents/carers. Interestingly, a smaller proportion of CYP (16.1%) gave low scores (1-3) for communication between the kidney team and school (P02) than parent/carer groups (24.4% under 12s, 28.8% over 12s). Centre scores were variable, again with substantial within centre differences amongst some.

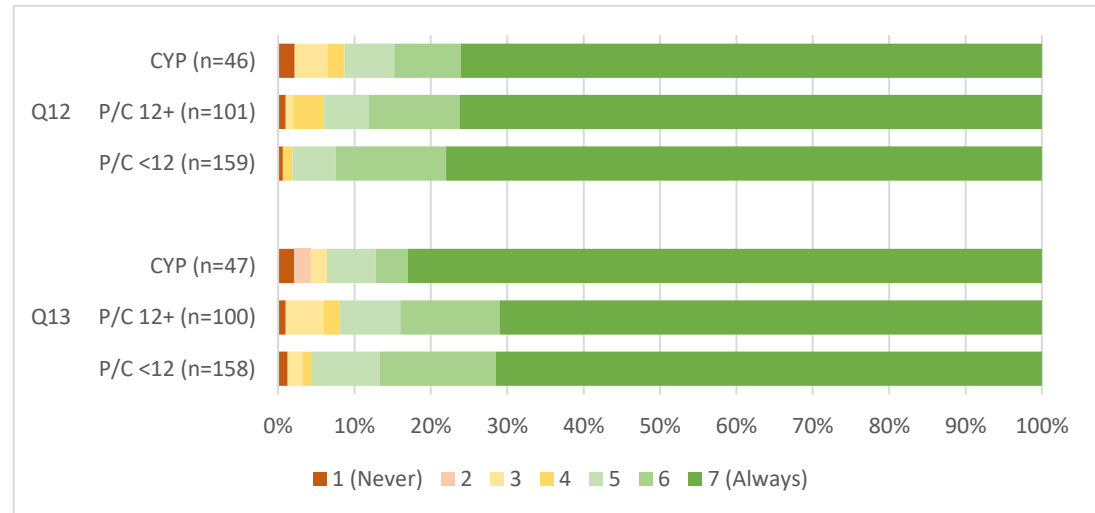
Theme 4: Patient Information

Mean of centre scores: 6.48, range: 5.67 to 6.81.



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?

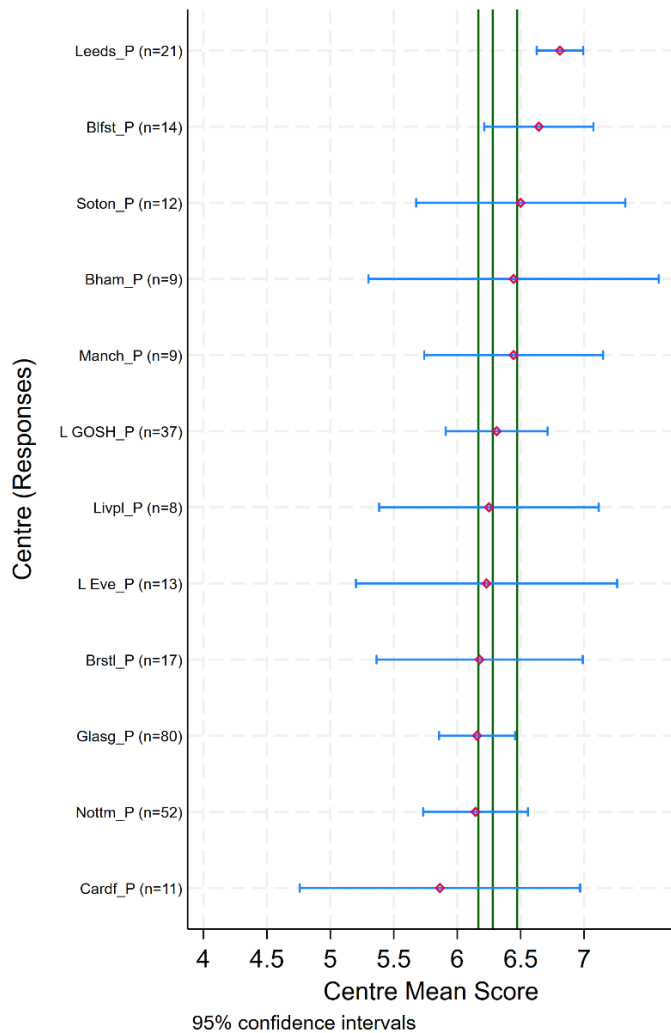


CYP: Children and Young People, P/C: Parents/Carers

Patient Information was a high-scoring theme for all participant groups, with very little difference in scores between them. Over 90% of all three groups gave high scores (5-7) for both questions, with 83.0% of CYP stating they were always (7 out of 7) given as much information about their kidney disease/treatment as they wanted (Q13). All but one paediatric centre received scores of at least 6.2 out of 7, with the lower scoring centre showing considerable variation amongst its participants.

Theme 5: Fluid & Diet

Mean of centre scores: 6.33, range: 5.86 to 6.81.

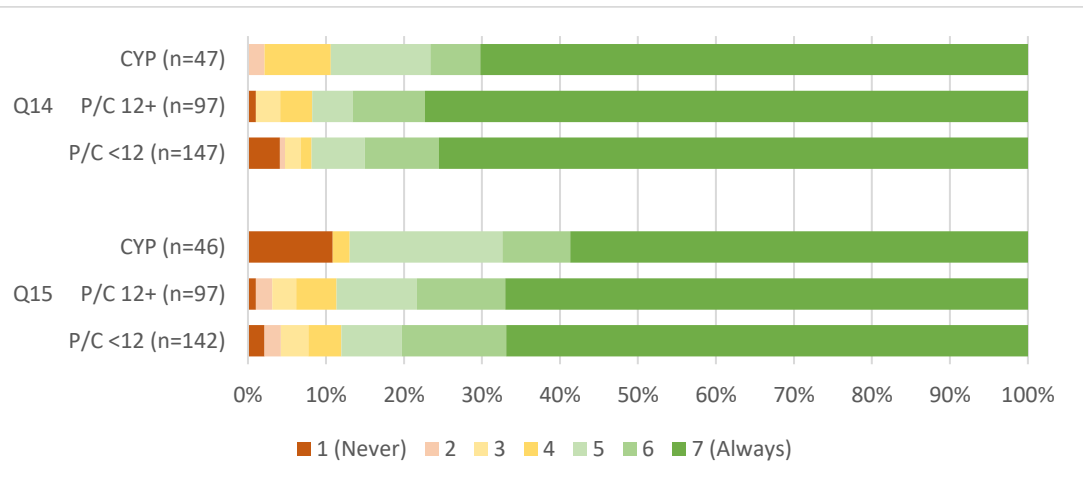


Thinking about the advice you are given about **fluid intake**:

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?

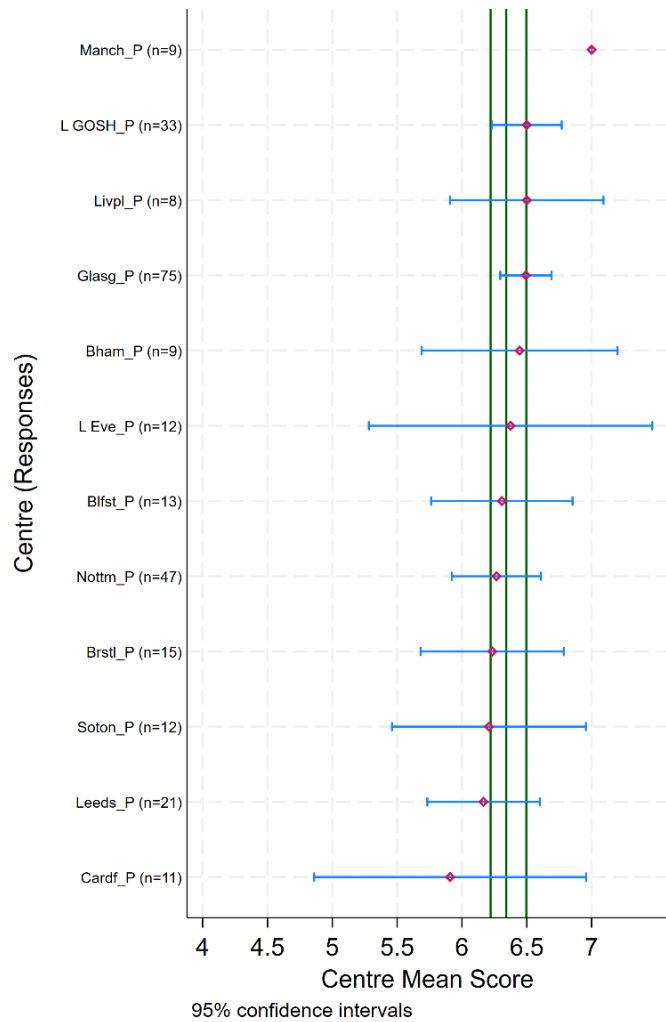


CYP: Children and Young People, P/C: Parents/Carers

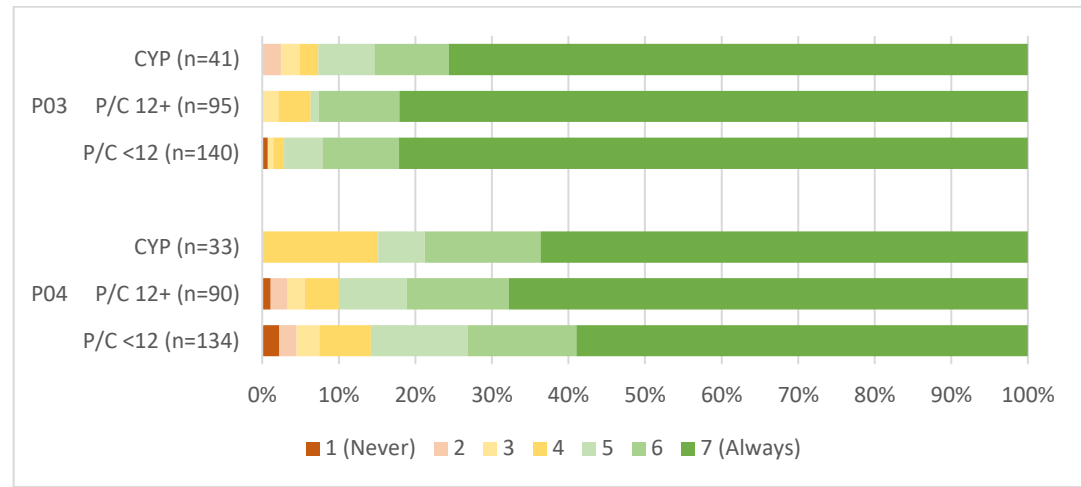
CYP gave low (1-3) scores for their diet advice (Q15) more than for their fluid advice (Q14), at 10.9% and 2.1% respectively. However, generally this theme was answered positively by all participant groups. Centres showed some variation in scores, with one centre performing particularly well.

Theme 6: Medication

Mean of centre scores: 6.37, range: 5.91 to 7.00.



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.

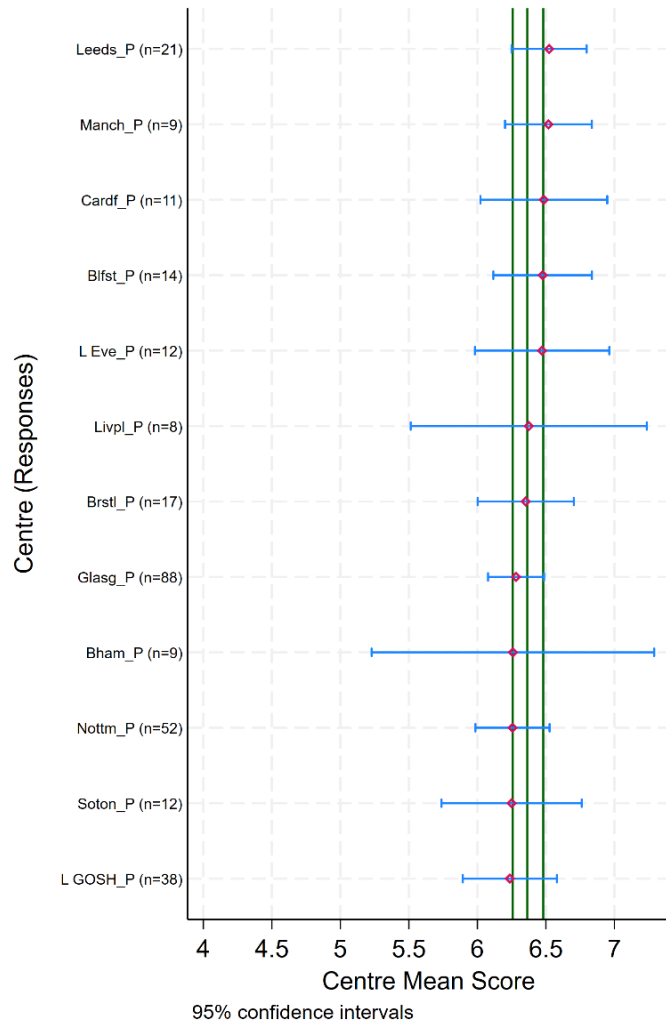


CYP: Children and Young People, P/C: Parents/Carers

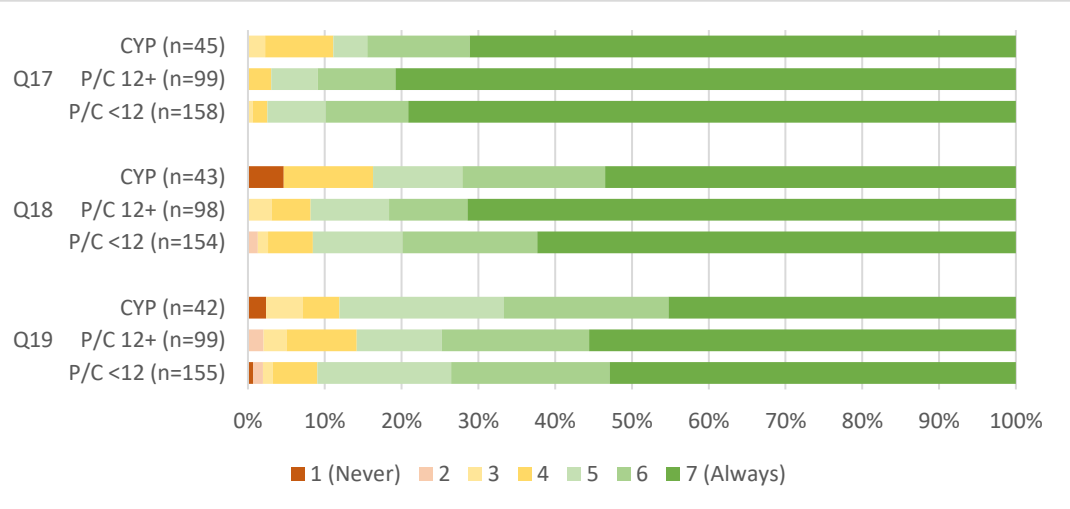
Medication theme was developed for the pPPREM, so does not feature in the adult Kidney PREM. CYP scored Medication particularly well, their second highest of all themes, with no CYP participants awarding low scores (1-3) for getting repeat prescriptions (P04). All participant groups were positive about medication advice (P03), each group having over 92% scoring the question highly (5-7). All centres achieved high scores, with 100% of participants at one centre giving scores of 7 (Always) for both questions within the theme.

Theme 7: Tests

Mean of centre scores: 6.37, range: 6.24 to 6.52.



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?

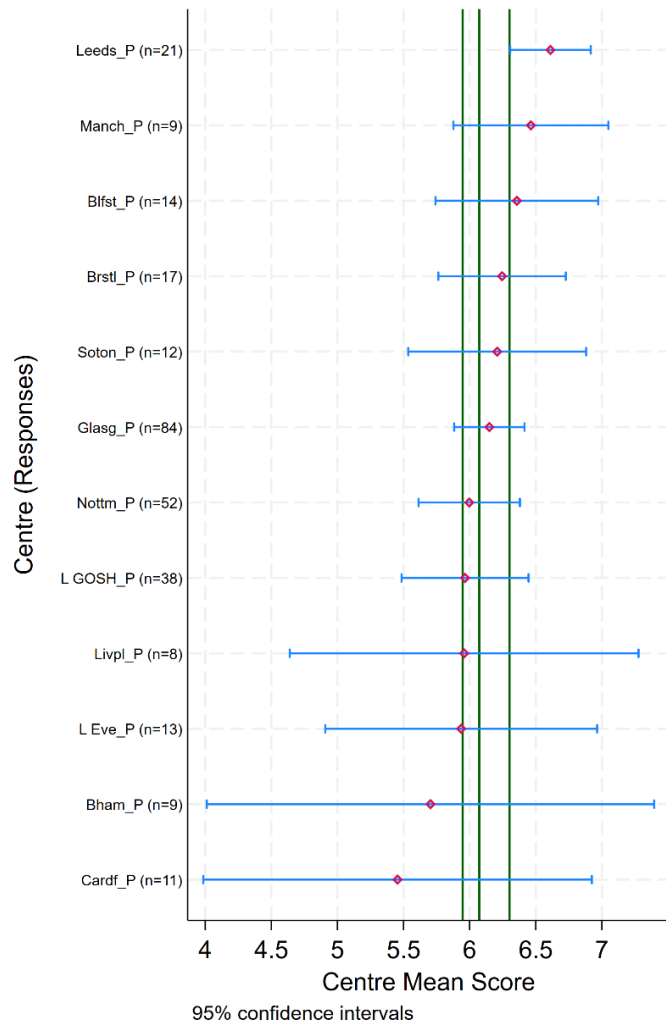


CYP: Children and Young People, P/C: Parents/Carers

Although this was a high-scoring theme, CYP scored *Tests* slightly lower than each of the parent/carer groups. A handful of CYP gave lower scores (1-3) for receiving test results within an acceptable time (Q18) and for understanding results of tests (Q19), but most scored the questions positively. Scores were high for all centres, with the lowest achieving 6.37 and with most demonstrating little within centre variation by their narrow confidence intervals.

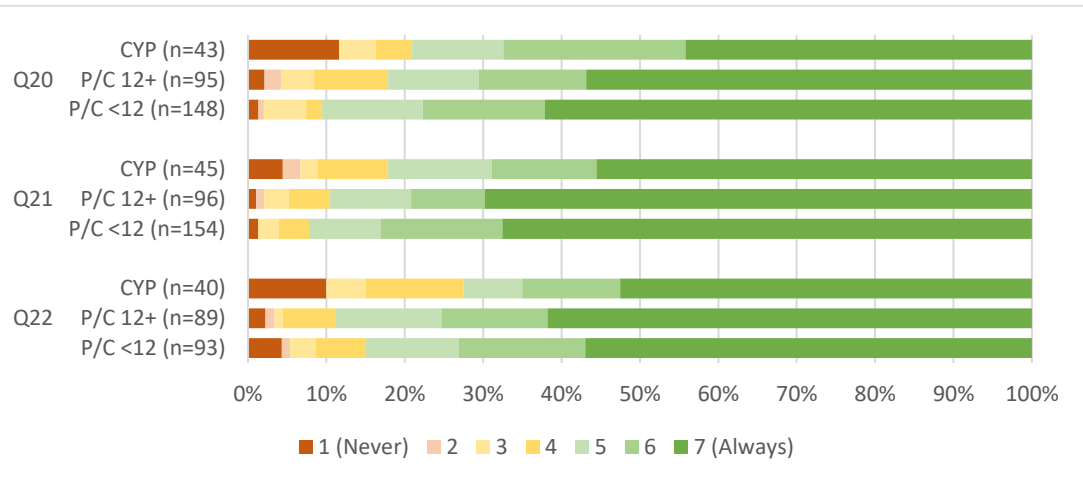
Theme 8: Sharing Decisions

Mean of centre scores: 6.09, range: 5.45 to 6.61.



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?

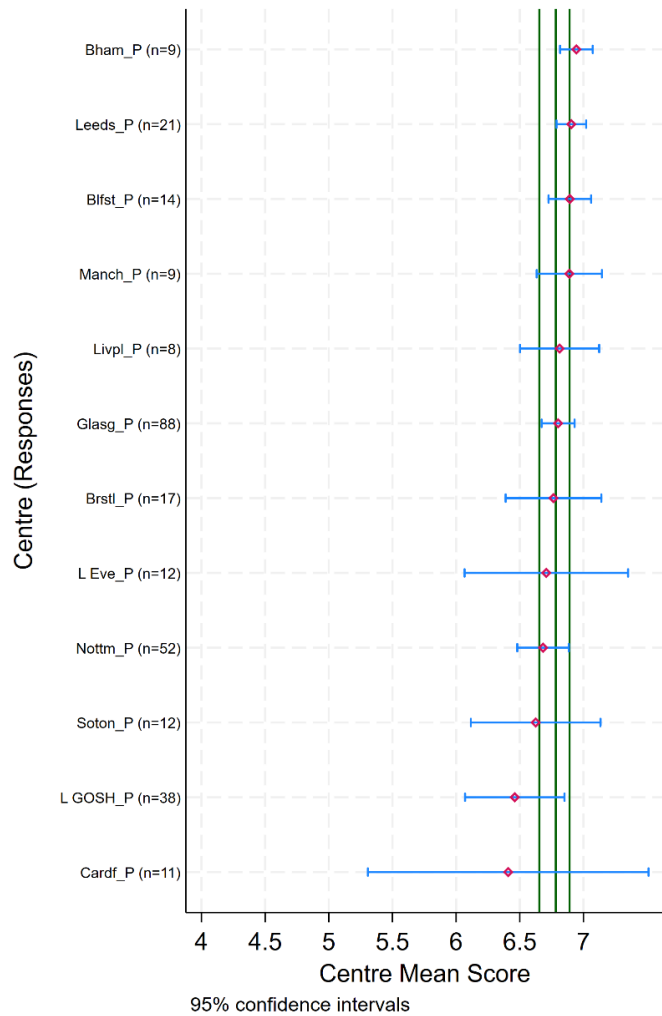


CYP: Children and Young People, P/C: Parents/Carers

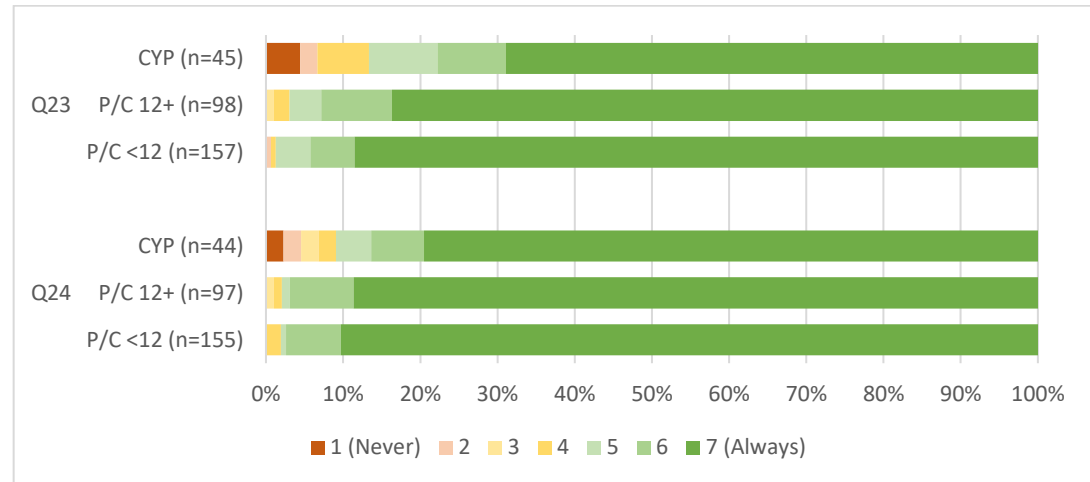
Sharing Decisions is one of the poorest scored themes of the adult Kidney PREM but is scored slightly more positively in the pPPREM. CYP scored all three questions more negatively than both parent/carer groups, particularly regarding the team discussing treatment and life goals (Q20), where 16.3% gave low scores (1-3), and discussing taking a more active role in managing their own care (Q22), given low scores by 15.0%. Centres achieving scores at the lower end of the range (<6) generally had wide confidence intervals, suggesting a degree of variation from participants within centres.

Theme 9: Privacy & Dignity

Mean of centre scores: 6.74, range: 6.41 to 6.94.



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

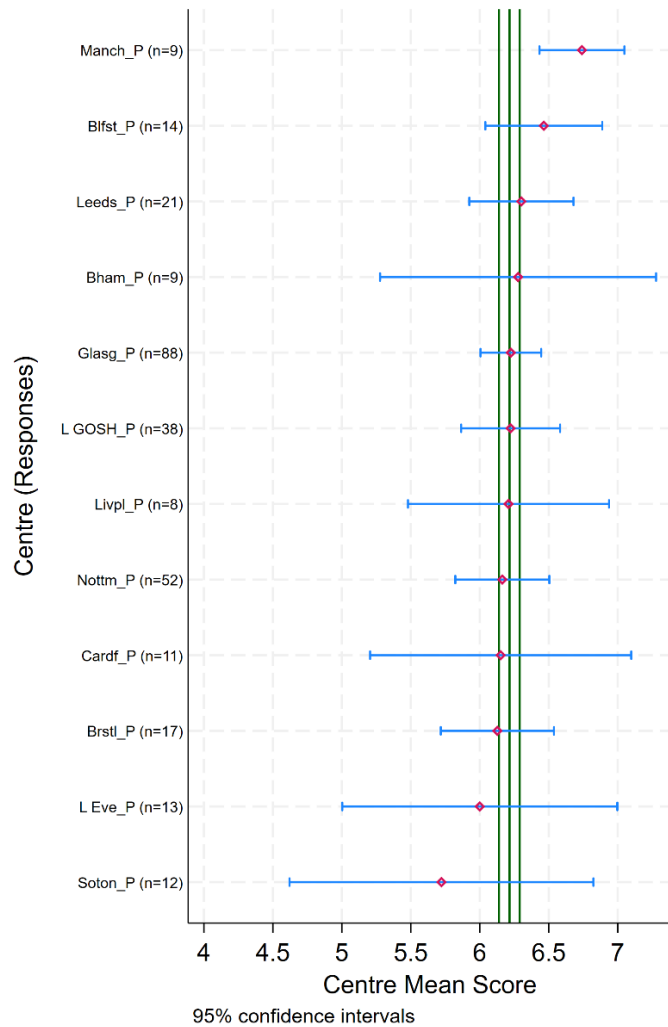


CYP: Children and Young People, P/C: Parents/Carers

Privacy & Dignity is the highest-scoring theme of the pPPREM as well as the adult Kidney PREM. High scores (5-7) were awarded by over 96% of each parent/carer group in both questions. Although there was a small group of CYP giving lower scores for privacy when discussing treatment (6.7%, Q23) and for dignity during visits and examinations (6.8%, Q24), the theme was still one of the highest for CYP. Centres scores were high, ranging from 6.41 to 6.94, with very little variation in participant scores within centres.

Theme 10: Scheduling and Planning

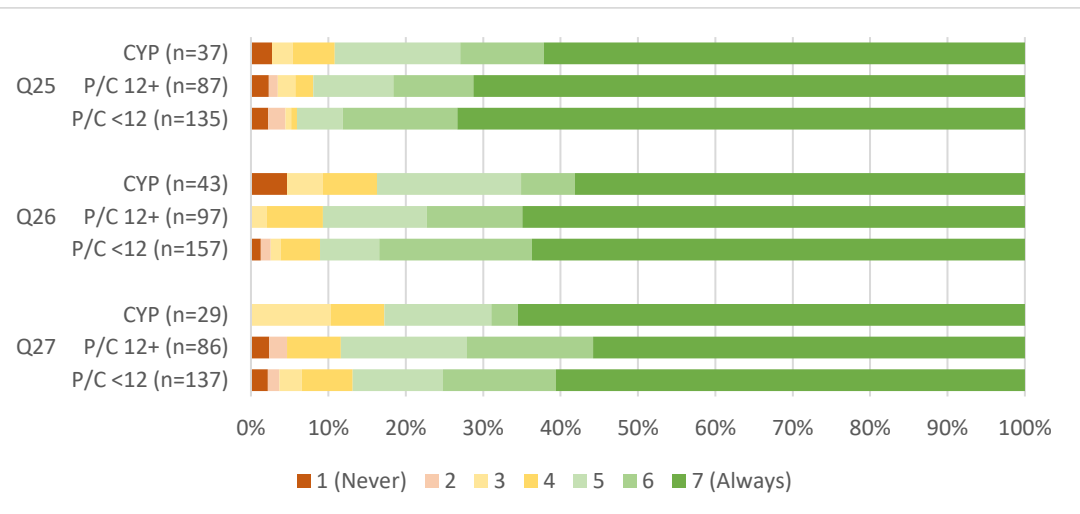
Mean of centre scores: 6.22, range: 5.72 to 6.74.



- 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?

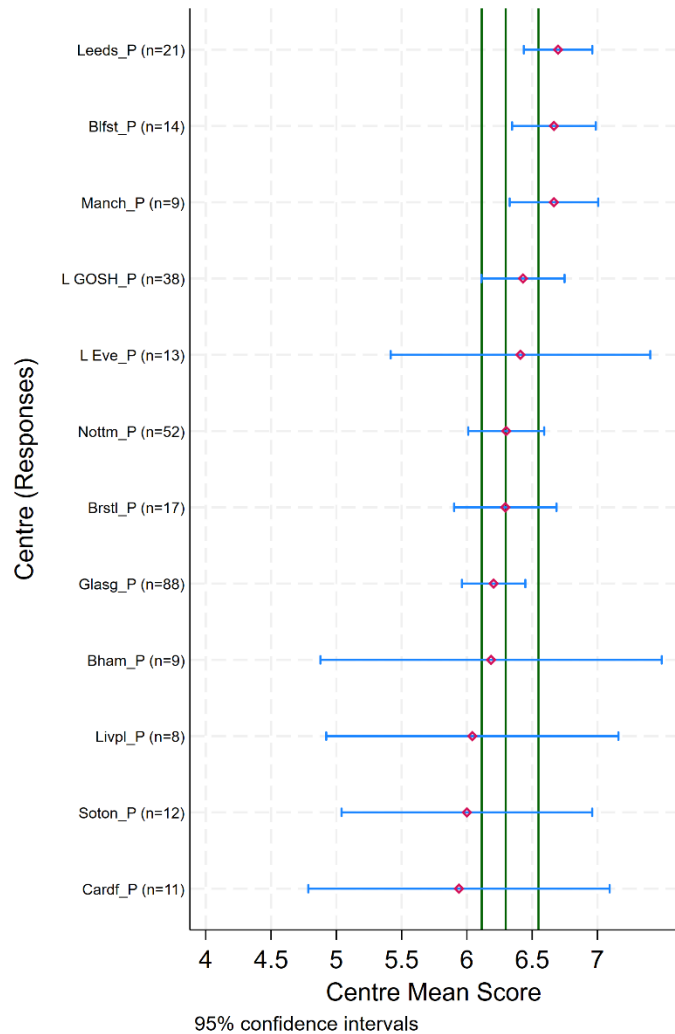


CYP: Children and Young People, P/C: Parents/Carers

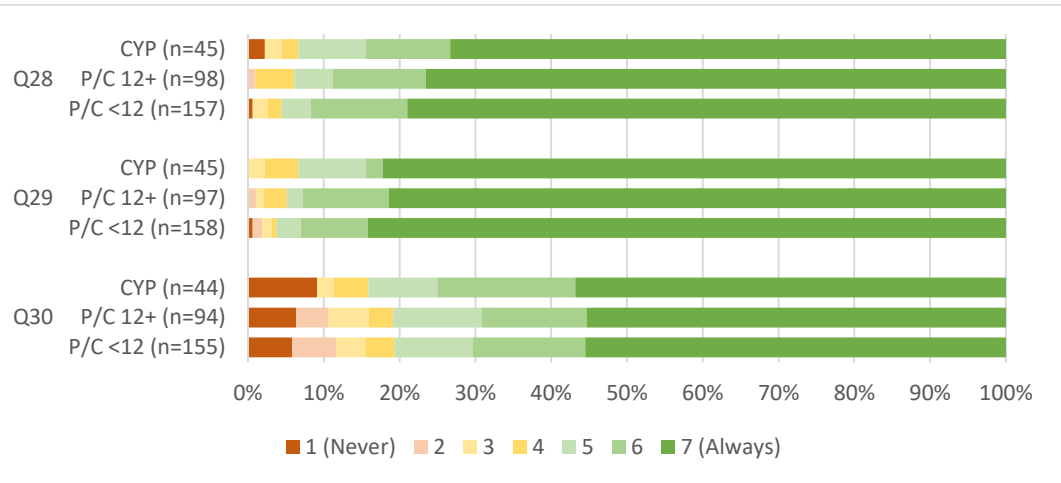
Scheduling & Planning scores reasonably well amongst the pPPREM themes, although with CYP scoring the theme slightly lower than the two parent/carer groups. Although arrangements for blood tests (Q27) was scored low (1-3) by a higher proportion of CYP (10.3% vs 6.6% [under 12s] and 4.7% [over 12s]), none of the CYP participants gave scores of 1 or 2. Scores across centres showed some variation, with lower centres demonstrating within centre variation with wider confidence intervals.

Theme 11: How the Kidney Team Treats You

Mean of centre scores: 6.32, range: 5.94 to 6.70.



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

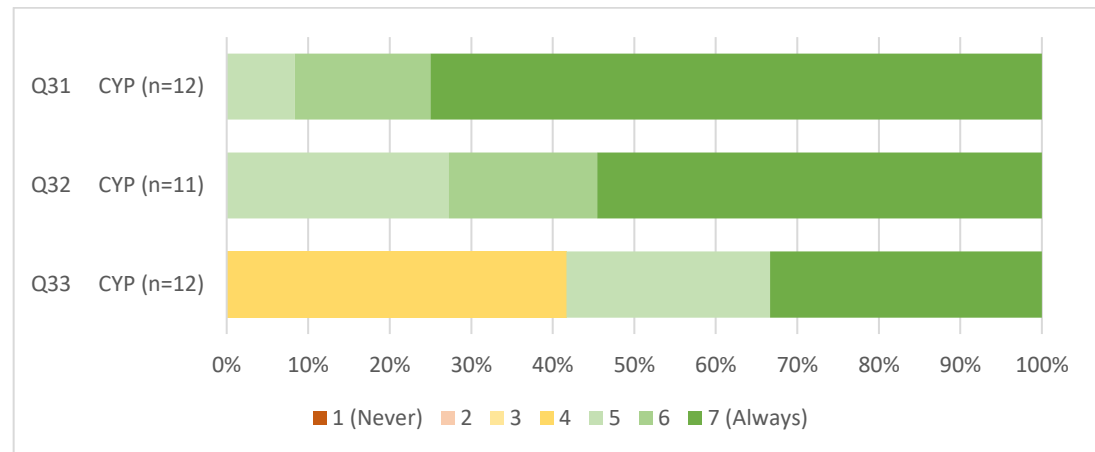
Scores for *How the Team Treats You* were similar in all response groups and tended to be high across paediatric centres. As seen with the adult Kidney PREM, the kidney team discussing emotions (Q30) was scored least favourably by all participant groups, though by fewer CYP (11.4% scoring 1-3) than parent/carers (15.5% under 12s, 16.0% over 12s). Being shown a caring attitude (Q29) was scored best of the theme; over 93% of all groups gave scores of 5-7 out of 7. As seen in other themes, lower scoring centres tended to have wider confidence intervals due to variation in participant scores.

Theme 12: Transport

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

Although limited to just 12 responses, a similar picture emerged as was seen in the adult Kidney PREM, with more positive responses regarding the suitability of the vehicle (Q31) and the acceptability of the time to travel between home and the kidney unit (Q32). Responses were less positive when asked whether participants could leave within 30 minutes of being ready (Q33), but no participants used the lowest (1-3) scores of the scale.

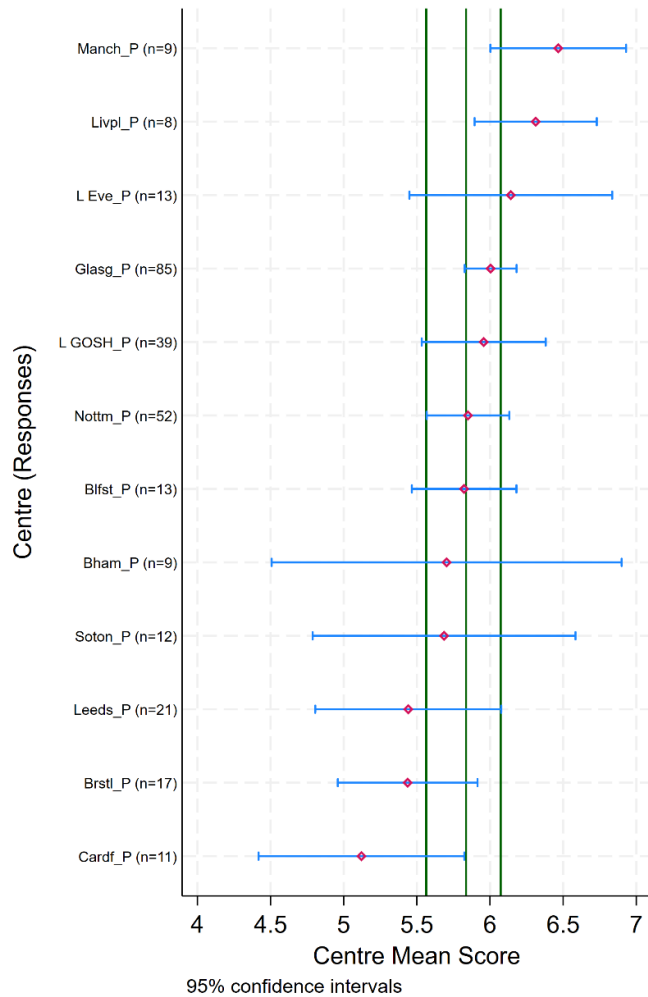
- Q31. Is the vehicle provided suitable for you?
- Q32. Is the time it takes to travel between your home and the kidney unit acceptable to you?
- Q33. Once your visit to the kidney unit is finished and you are ready to leave, are you able to leave within less than 30 minutes?



CYP: Children and Young People

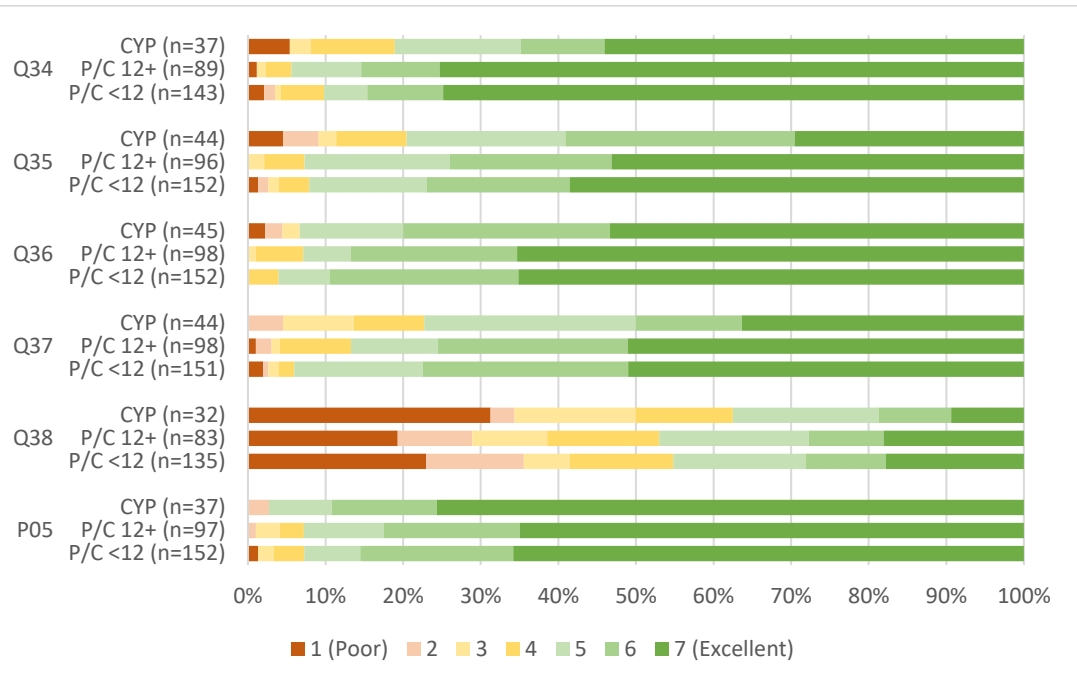
Theme 13: The Environment

Mean of centre scores: 5.83, range: 5.12 to 6.47.



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

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

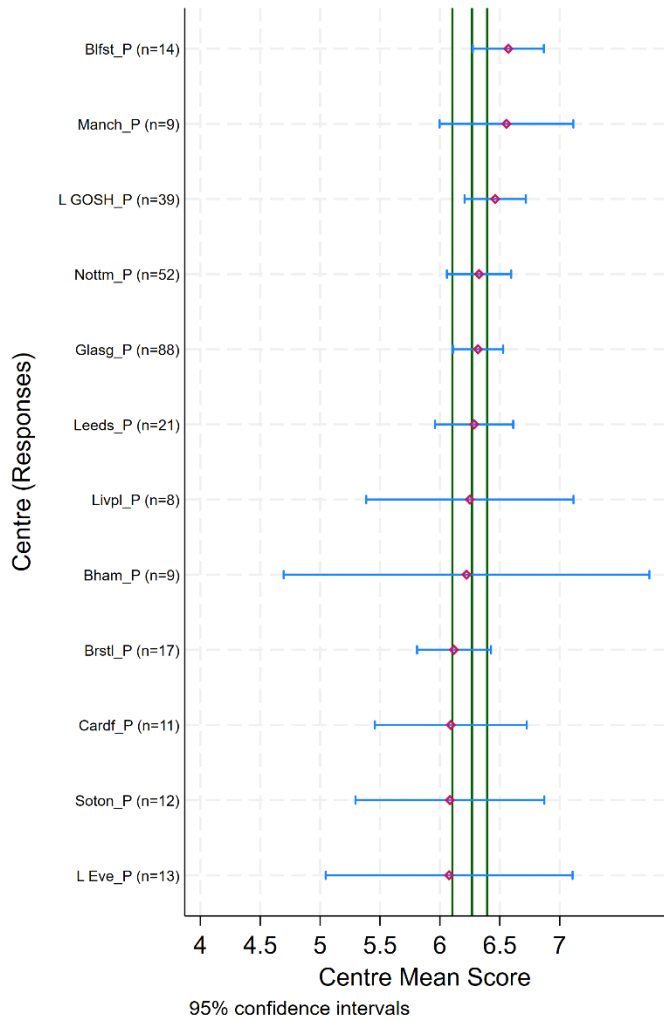


CYP: Children and Young People, P/C: Parents/Carers

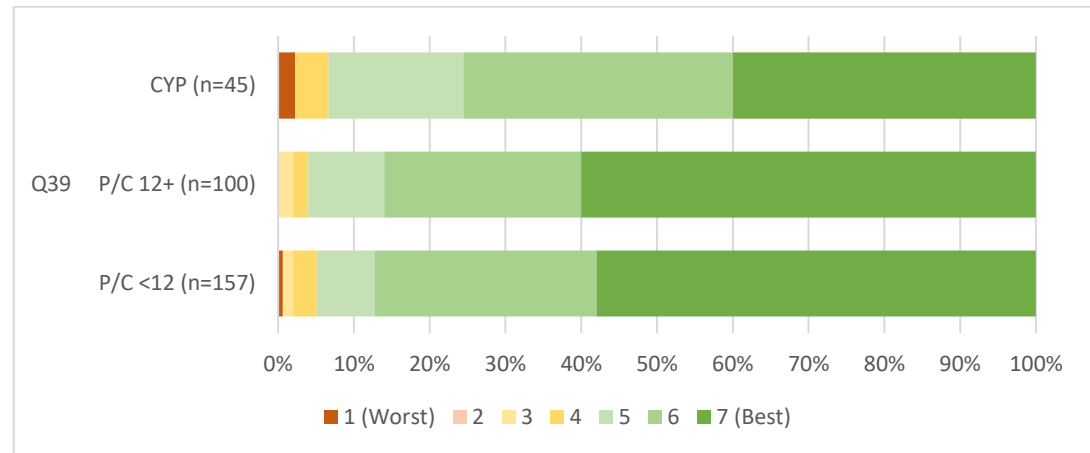
Questions relating to *The Environment* received mixed responses from participants. Cleanliness (Q36) and child-friendliness (P05) was scored highly (5-7) by over 92% of all response groups, but accessibility (Q34), comfort (Q35) and the waiting area (Q37) were each scored a little lower by CYP than parents/carers. Parking (Q38) was scored poorly by all groups, with less than half awarding high (5-7) scores and a significant proportion giving low (1-3) scores, more so than in the adult Kidney PREM.

Theme 14: Overall Experience

Mean of centre scores: 6.28, range: 6.08 to 6.57.



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

Encouragingly, *Overall Experience* was well scored, achieving >6 out of 7 for participants at all paediatric centres and for all response groups. Average scores for CYP were slightly lower than for parents/carers, mainly because due to the slightly lower proportion giving the maximum score of 7 (best it can be). Centre scores were all above 6 out of seven, though with no centre achieving maximum scores from all participants.

What's next for the pilot Paediatric PREM?

The pPPREM has now been tested over two PREM cycles, giving valuable information about the feasibility of routine data collection from parents/carers and CYP 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 funding⁸ 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 CYP 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 CYP, their families and health care professionals. This will then inform ongoing quality improvement work through the British Association for Paediatric Nephrology⁹ (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 reporting due in 2026. For further information, please contact Dr Andrew Lunn, Nottingham University Hospitals NHS Trust andrew.lunn@nuh.nhs.uk.

⁸ NIHR206218: Paediatric Kidney Patient Reported Experience Measure - developing and validating an experience measure for under 18-year-olds.

⁹ <https://ukkidney.org/bapn/about-bapn>

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 Support	157	6.60 (6.45, 6.74)	98	6.52 (6.33, 6.70)	45	6.04 (5.59, 6.49)	300	6.49 (6.37, 6.61)
Communication	152	5.98 (5.75, 6.21)	96	5.78 (5.47, 6.10)	45	5.03 (4.44, 5.62)	293	5.77 (5.59, 5.95)
Patient Information	155	6.02 (5.82, 6.22)	98	5.85 (5.58, 6.11)	45	5.89 (5.50, 6.28)	298	5.94 (5.80, 6.09)
Fluid & Diet	157	6.58 (6.45, 6.72)	98	6.48 (6.29, 6.68)	45	6.53 (6.18, 6.89)	300	6.54 (6.44, 6.65)
Medication	151	6.31 (6.09, 6.53)	95	6.35 (6.12, 6.59)	45	6.13 (5.71, 6.56)	291	6.30 (6.15, 6.45)
Tests	141	6.37 (6.20, 6.53)	92	6.46 (6.27, 6.65)	40	6.31 (5.93, 6.69)	273	6.39 (6.27, 6.51)
Sharing Decisions	156	6.36 (6.23, 6.50)	98	6.39 (6.23, 6.56)	45	6.09 (5.75, 6.43)	299	6.33 (6.23, 6.43)
Privacy & Dignity	154	6.24 (6.04, 6.43)	97	6.13 (5.87, 6.38)	45	5.73 (5.22, 6.23)	296	6.12 (5.97, 6.27)
Scheduling	156	6.84 (6.76, 6.92)	98	6.77 (6.64, 6.90)	45	6.29 (5.87, 6.71)	299	6.73 (6.64, 6.82)
How Team Treats you	157	6.28 (6.10, 6.46)	98	6.23 (6.02, 6.44)	45	6.03 (5.68, 6.38)	300	6.23 (6.10, 6.35)
Transport	157	6.35 (6.18, 6.53)	98	6.32 (6.10, 6.53)	45	6.30 (5.94, 6.65)	300	6.33 (6.21, 6.46)
The Environment	-	-	-	-	12	6.06 (5.64, 6.47)	12	6.06 (5.64, 6.47)
Overall Experience	154	5.93 (5.75, 6.10)	98	5.97 (5.78, 6.16)	45	5.55 (5.20, 5.91)	297	5.88 (5.76, 6.01)
pPPREM Scale Score	157	6.37 (6.22, 6.52)	100	6.40 (6.22, 6.58)	45	6.02 (5.67, 6.37)	302	6.33 (6.22, 6.44)
	157	6.24 (6.11, 6.38)	99	6.20 (6.03, 6.36)	45	5.92 (5.64, 6.20)	301	6.18 (6.08, 6.28)

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

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

Centre	pPPREM Scale Score		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	9	6.00 (5.14, 6.86)	9	6.67 (6.12, 7.21)	9	5.31 (3.85, 6.78)	9	5.47 (3.94, 6.99)	9	5.67 (4.05, 7.29)	9	6.44 (5.30, 7.59)	9	6.44 (5.69, 7.20)
Blfst_P	14	6.38 (6.02, 6.74)	14	6.58 (6.20, 6.96)	14	5.95 (5.03, 6.88)	14	6.47 (5.97, 6.97)	14	6.68 (6.35, 7.01)	14	6.64 (6.21, 7.07)	13	6.31 (5.76, 6.85)
Brstl_P	17	6.08 (5.79, 6.37)	17	6.48 (6.00, 6.96)	17	5.35 (4.47, 6.24)	17	6.08 (5.63, 6.53)	17	6.65 (6.38, 6.92)	17	6.18 (5.36, 6.99)	15	6.23 (5.68, 6.79)
Cardf_P	11	5.80 (4.90, 6.71)	11	6.03 (4.76, 7.30)	11	5.50 (4.08, 6.92)	11	5.73 (4.62, 6.84)	11	6.32 (5.36, 7.27)	11	5.86 (4.76, 6.97)	11	5.91 (4.86, 6.96)
Glasg_P	88	6.18 (6.01, 6.35)	88	6.48 (6.29, 6.68)	84	5.99 (5.68, 6.29)	88	5.79 (5.52, 6.07)	88	6.51 (6.31, 6.70)	80	6.16 (5.86, 6.46)	75	6.49 (6.30, 6.69)
L Eve_P	13	6.13 (5.23, 7.04)	13	6.38 (5.39, 7.38)	12	5.72 (4.49, 6.96)	13	5.92 (4.89, 6.94)	13	6.46 (5.46, 7.47)	13	6.23 (5.20, 7.26)	12	6.38 (5.28, 7.47)
L GOSH_P	39	6.18 (5.93, 6.43)	38	6.26 (5.80, 6.73)	37	5.27 (4.65, 5.90)	38	6.01 (5.66, 6.37)	38	6.79 (6.63, 6.95)	37	6.31 (5.91, 6.71)	33	6.50 (6.23, 6.77)
Leeds_P	21	6.26 (6.04, 6.49)	21	6.84 (6.68, 7.00)	21	5.87 (5.25, 6.48)	21	5.97 (5.58, 6.37)	21	6.81 (6.64, 6.98)	21	6.81 (6.63, 6.99)	21	6.17 (5.73, 6.60)
Livpl_P	8	6.17 (5.49, 6.86)	8	6.42 (5.84, 6.99)	8	5.79 (4.99, 6.59)	8	5.71 (4.56, 6.87)	8	6.25 (5.70, 6.80)	8	6.25 (5.38, 7.12)	8	6.50 (5.91, 7.09)
Manch_P	9	6.57 (6.14, 7.00)	9	6.89 (6.63, 7.15)	9	6.41 (5.37, 7.45)	9	6.26 (5.52, 6.99)	9	6.78 (6.27, 7.29)	9	6.44 (5.74, 7.15)	9	7.00 (7.00, 7.00)
Newc_P	6	0.00 (0.00, 0.00)	6	0.00 (0.00, 0.00)	6	0.00 (0.00, 0.00)	6	0.00 (0.00, 0.00)	6	0.00 (0.00, 0.00)	6	0.00 (0.00, 0.00)	6	0.00 (0.00, 0.00)
Nottm_P	52	6.13 (5.88, 6.39)	52	6.54 (6.27, 6.81)	52	5.79 (5.34, 6.25)	51	6.06 (5.67, 6.45)	52	6.47 (6.21, 6.73)	52	6.14 (5.73, 6.56)	47	6.27 (5.92, 6.61)
Soton_P	12	5.99 (5.19, 6.79)	12	6.19 (5.38, 7.01)	12	5.68 (4.58, 6.79)	12	5.67 (4.56, 6.78)	12	6.33 (5.64, 7.03)	12	6.50 (5.68, 7.32)	12	6.21 (5.46, 6.96)

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	9	6.26 (5.23, 7.29)	9	5.70 (4.01, 7.40)	9	6.94 (6.82, 7.07)	9	6.28 (5.28, 7.28)	9	6.19 (4.88, 7.49)	9	5.70 (4.51, 6.90)	9	6.22 (4.70, 7.75)
Blfst_P	14	6.48 (6.12, 6.84)	14	6.36 (5.74, 6.97)	14	6.89 (6.73, 7.06)	14	6.46 (6.04, 6.89)	14	6.67 (6.35, 6.99)	13	5.82 (5.47, 6.18)	14	6.57 (6.27, 6.87)
Brstl_P	17	6.35 (6.00, 6.70)	17	6.25 (5.76, 6.73)	17	6.76 (6.39, 7.14)	17	6.13 (5.72, 6.54)	17	6.29 (5.90, 6.69)	17	5.44 (4.96, 5.91)	17	6.12 (5.81, 6.43)
Cardf_P	11	6.48 (6.02, 6.95)	11	5.45 (3.99, 6.92)	11	6.41 (5.31, 7.51)	11	6.15 (5.20, 7.10)	11	5.94 (4.79, 7.09)	11	5.12 (4.42, 5.82)	11	6.09 (5.46, 6.73)
Glasg_P	88	6.28 (6.08, 6.49)	84	6.15 (5.88, 6.41)	88	6.80 (6.67, 6.93)	88	6.23 (6.01, 6.45)	88	6.20 (5.96, 6.45)	85	6.00 (5.83, 6.18)	88	6.32 (6.11, 6.53)
L Eve_P	12	6.47 (5.98, 6.96)	13	5.94 (4.91, 6.96)	12	6.71 (6.07, 7.35)	13	6.00 (5.00, 7.00)	13	6.41 (5.42, 7.40)	13	6.14 (5.45, 6.84)	13	6.08 (5.05, 7.11)
L GOSH_P	38	6.24 (5.89, 6.58)	38	5.96 (5.48, 6.45)	38	6.46 (6.07, 6.85)	38	6.22 (5.86, 6.58)	38	6.43 (6.11, 6.75)	39	5.96 (5.53, 6.38)	39	6.46 (6.21, 6.72)
Leeds_P	21	6.52 (6.25, 6.80)	21	6.61 (6.31, 6.92)	21	6.90 (6.79, 7.02)	21	6.30 (5.92, 6.68)	21	6.70 (6.44, 6.96)	21	5.44 (4.81, 6.08)	21	6.29 (5.96, 6.61)
Livpl_P	8	6.38 (5.51, 7.24)	8	5.96 (4.64, 7.28)	8	6.81 (6.50, 7.12)	8	6.21 (5.48, 6.94)	8	6.04 (4.92, 7.16)	8	6.31 (5.89, 6.73)	8	6.25 (5.38, 7.12)
Manch_P	9	6.52 (6.20, 6.84)	9	6.46 (5.88, 7.05)	9	6.89 (6.63, 7.15)	9	6.74 (6.43, 7.05)	9	6.67 (6.33, 7.01)	9	6.47 (6.00, 6.93)	9	6.56 (6.00, 7.11)
Newc_P	6	0.00 (0.00, 0.00)	6	0.00 (0.00, 0.00)	6	0.00 (0.00, 0.00)	6	0.00 (0.00, 0.00)	6	0.00 (0.00, 0.00)	6	0.00 (0.00, 0.00)	6	0.00 (0.00, 0.00)
Nottm_P	52	6.26 (5.99, 6.53)	52	6.00 (5.61, 6.38)	52	6.68 (6.48, 6.89)	52	6.16 (5.82, 6.50)	52	6.30 (6.01, 6.59)	52	5.85 (5.57, 6.13)	52	6.33 (6.06, 6.60)
Soton_P	12	6.25 (5.74, 6.76)	12	6.21 (5.54, 6.88)	12	6.63 (6.12, 7.13)	12	5.72 (4.62, 6.82)	12	6.00 (5.04, 6.96)	12	5.69 (4.79, 6.58)	12	6.08 (5.30, 6.87)

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

	Chronic Kidney Disease (non-KRT)					Peritoneal Dialysis/Home Haemodialysis				
	2023 (n=163)		2022 (n=144)		2023 vs 2022	2023 (n=35)		2022 (n=28)		2023 vs 2022
	Median	IQR	Median	IQR		Median	IQR	Median	IQR	
Access to Team Support	7.00	6.33 - 7.00	7.00	6.00 - 7.00	0.00	7.00	7.00 - 7.00	7.00	7.00 - 7.00	0.00
Communication	6.67	4.67 - 7.00	6.00	4.67 - 7.00	0.67	6.67	6.00 - 7.00	5.17	4.50 - 6.83	1.50
Patient Information	6.20	5.00 - 7.00	6.00	4.73 - 7.00	0.20	7.00	5.67 - 7.00	6.10	4.83 - 6.53	0.90
Fluid & Diet	7.00	6.00 - 7.00	7.00	6.00 - 7.00	0.00	7.00	7.00 - 7.00	7.00	6.25 - 7.00	0.00
Medication	7.00	6.00 - 7.00	7.00	6.00 - 7.00	0.00	7.00	6.50 - 7.00	7.00	6.00 - 7.00	0.00
Tests	6.67	5.67 - 7.00	6.67	5.67 - 7.00	0.00	7.00	6.33 - 7.00	6.67	5.67 - 7.00	0.33
Sharing Decisions	6.58	5.33 - 7.00	6.58	5.33 - 7.00	0.00	7.00	6.33 - 7.00	6.67	6.00 - 7.00	0.33
Privacy & Dignity	7.00	7.00 - 7.00	7.00	7.00 - 7.00	0.00	7.00	7.00 - 7.00	7.00	6.75 - 7.00	0.00
Scheduling	6.58	5.67 - 7.00	6.67	5.67 - 7.00	-0.09	7.00	6.33 - 7.00	7.00	6.33 - 7.00	0.00
How Team Treats you	7.00	6.00 - 7.00	6.67	6.00 - 7.00	0.33	7.00	6.67 - 7.00	7.00	6.00 - 7.00	0.00
Transport	-	-	-	-	-	-	-	-	-	-
The Environment	6.00	5.40 - 6.67	6.17	5.33 - 6.67	-0.17	6.17	5.83 - 7.00	5.92	4.83 - 6.17	0.25
Overall Experience	7.00	6.00 - 7.00	6.00	6.00 - 7.00	1.00	7.00	6.00 - 7.00	7.00	6.00 - 7.00	0.00
Pilot PPREM Scale Score	6.41	5.80 - 6.76	6.29	5.78 - 6.73	0.12	6.69	6.09 - 6.86	6.42	5.65 - 6.63	0.27

KRT: kidney replacement therapy

IQR: Interquartile range

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

	In-Centre Haemodialysis					Transplant				
	2023 (n=39)		2022 (n=25)		2023 vs 2022	2023 (n=64)		2022 (n=70)		2023 vs 2022
	Median	IQR	Median	IQR		Median	IQR	Median	IQR	
Access to Team Support	7.00	6.33 - 7.00	7.00	6.67 - 7.00	0.00	7.00	6.67 - 7.00	7.00	6.67 - 7.00	0.00
Communication	5.75	4.00 - 7.00	7.00	4.50 - 7.00	-1.25	6.67	5.00 - 7.00	6.50	4.67 - 7.00	0.17
Patient Information	6.37	5.83 - 7.00	6.40	6.00 - 7.00	-0.03	6.27	5.82 - 7.00	6.10	4.60 - 6.80	0.17
Fluid & Diet	7.00	6.00 - 7.00	7.00	6.50 - 7.00	0.00	7.00	6.75 - 7.00	7.00	6.00 - 7.00	0.00
Medication	7.00	6.00 - 7.00	7.00	6.50 - 7.00	0.00	7.00	6.00 - 7.00	7.00	6.00 - 7.00	0.00
Tests	7.00	6.00 - 7.00	7.00	6.00 - 7.00	0.00	6.67	6.00 - 7.00	6.67	6.00 - 7.00	0.00
Sharing Decisions	6.67	6.00 - 7.00	7.00	6.00 - 7.00	-0.33	6.67	6.33 - 7.00	6.67	6.00 - 7.00	0.00
Privacy & Dignity	6.67	5.00 - 7.00	6.67	5.33 - 7.00	0.00	7.00	6.33 - 7.00	7.00	5.67 - 7.00	0.00
Scheduling	7.00	6.50 - 7.00	7.00	6.00 - 7.00	0.00	7.00	7.00 - 7.00	7.00	7.00 - 7.00	0.00
How Team Treats you	7.00	6.00 - 7.00	7.00	6.00 - 7.00	0.00	6.58	5.67 - 7.00	6.58	5.67 - 7.00	0.00
Transport	7.00	6.00 - 7.00	7.00	6.67 - 7.00	0.00	7.00	6.00 - 7.00	6.67	6.00 - 7.00	0.33
The Environment	6.00	5.83 - 6.33	5.33	4.33 - 6.00	0.67	-	-	-	-	-
Overall Experience	6.33	5.60 - 7.00	6.00	5.33 - 6.80	0.33	6.08	5.45 - 6.50	5.92	5.17 - 6.33	0.16
Pilot PPREM Scale Score	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	6.46	5.89 - 6.68	6.48	6.11 - 6.77	-0.02	6.59	6.07 - 6.77	6.40	5.78 - 6.76	0.19

IQR: Interquartile range