



# Paediatric Kidney Patient Reported Experience Measure (PREM) Pilot

## 2022 Report

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## FOREWORD

The British Association for Paediatric Nephrology (BAPN) was formed in 1973 and one of the aims of the organisation has been to set standards and improve medical care for children and young people with kidney disease. At a similar time in 1975 the British Kidney Patient Association (BKPA) was established with the aim of improving the quality of life for kidney patients.

Although over the years the organisations have changed, with the BAPN now being a part of the UK Kidney Association and the BKPA re-launched in 2017 as Kidney Care UK, the ethos of both have remained constant.

It is a natural alliance for both groups to work together to find out more regarding the experience of care of children and young people with kidney disease in the UK. Building on the work done previously in the development of the adult Kidney PREM and supported by the University of Hertfordshire we are delighted that the opportunity arose for the organisations to work together to develop a pilot Paediatric PREM. Using the validated questions of the Kidney PREM, with minor modifications where necessary, this report is the first step in describing and understanding the experience of children and young people with kidney disease and the experience of their parents and carers.

The support from health professionals has been fantastic with all 13 UK paediatric nephrology centres contributing to the development of the pilot, data collection and development of this report.

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 a pilot providing valuable information across all ages and all treatment groups within paediatric nephrology services.

We have seen how the Kidney PREM has been developed as an invaluable resource helping professionals and patients to work together to improve the quality of care and quality of lives for adults with kidney disease. Although much work is still to be done, we are confident that the pilot reported here is an important step on the way to the development of 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 of all ages, young people and adults, supporting the aims of the two organisations that were started in the 1970s.



**Dr Jan Dudley**

President of the BAPN



**Mr Paul Bristow**

Chief Executive of Kidney Care UK

## ACKNOWLEDGEMENTS

We would like to express a huge thank you to all who have contributed to this project especially those from Kidney Quality Improvement Partnership (KQIP), the Paediatric Patient Experience working group, the University of Hertfordshire, The UK Kidney Association (UKKA), the UK Renal Registry and Kidney Care UK, without whom this would not have been possible.

We would also like to thank every health professional working in Paediatric Nephrology who has supported this by giving out a QR code, adding the website link to their letters, and inviting and supporting patients to respond to the pilot Paediatric PREM. It is that effort that makes this a truly nationally representative Paediatric PREM.

Our final thanks go to the children and young people who experience the healthcare we provide and their families. We strive to provide the best quality, patient centred-care we can, and it is only with your support and completion of the Paediatric PREM that we can work together to improve what we are doing.

## 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.

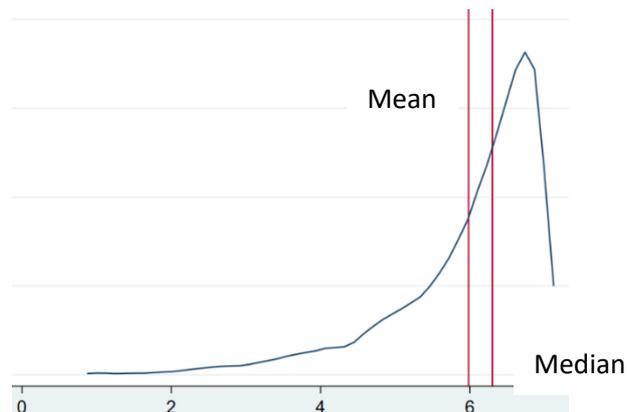
**Mean:** The *mean* centre score is calculated across patient scores by adding them together and dividing by the number of scores used, giving the mathematical average value.

**95% Confidence Interval:** When scores are combined to calculate the mean centre score, there is a 95% chance that the *95% confidence interval* would contain the true 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.

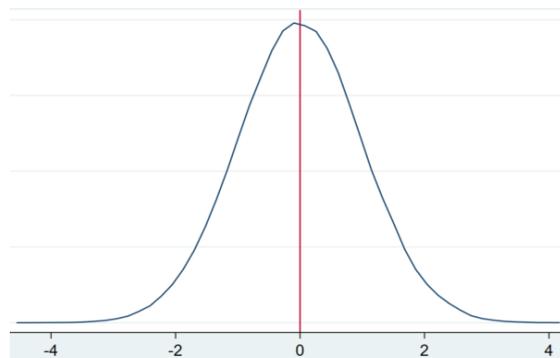
**Median:** If scores within a particular centre were listed in order, the *median* is the middle value separating the high scoring (top half) from the low scoring (bottom half).

**Lower/Upper Quartiles and Interquartile Range:** If 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 lie. 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

The Kidney PREM has been collecting data for over 6 years and has provided information from adult patients with kidney disease to healthcare professionals to guide how services can be improved. For the first year, as an initial pilot, we have extended this to include children and young people with chronic kidney disease (CKD) aged 12 or older and parent/ carers of children and young people of all ages, the pilot Paediatric PREM. The validated questions used in the Kidney PREM have been used with minor modifications if needed and all the data collection has been online.

The response has been fantastic with completed questionnaires from all 13 centres in the UK who treat children and young people with CKD. In contrast to adult respondents, over half (54%) of the responses were regarding children and young people with CKD who were not yet needing kidney replacement therapy. This represents a key difference between adult and paediatric care in that children with known kidney disease are more likely to be under the care of hospital specialists as opposed to being managed in primary care. The responses from those who are being treated with kidney replacement therapy represent at least one in 6 children and young people who are being treated in the UK, a significant proportion.

Overall, the responses include all age groups, a range of ethnic groups and a predominantly male population, which is often seen among children with kidney disease. We advise caution however in making direct comparisons of demographic data to known kidney populations as individuals may be over-represented if a young person and or parent/carer(s) submit a response. As with the Kidney PREM there is the ongoing need to support engagement from under-represented groups including those in minority ethnic groups, those that need assistance in completing the form and males who are 12 and over and completing the form themselves.

Although a reasonable proportion of paediatric responses have been collated, the absolute numbers are small, particularly when analysing data by centre. This will result in low precision of data and therefore we advise caution in making inferences or comparisons by centre.

The majority of responses are positive and reflect a high quality of care being received by children and young people in paediatric nephrology centres across the UK. In addition to identifying areas for improvement, it is important to recognise and celebrate areas where families are satisfied with the care they receive and ensure this continues.

## KEY MESSAGES

This pilot paediatric PREM has received responses from a significant proportion of children and young people with chronic kidney disease and their parents and carers.

The majority of responses are very positive with mean scores for the themes ranging from 5.18 to 6.72 (scores out of 7). This reflects a high quality of care being received by children and young people in paediatric nephrology centres across the UK.

The highest scores were given to questions regarding access to the renal team (mean 6.47), patient information (mean 6.5) and privacy and dignity (mean 6.72).

Shared decision making rated highly with a mean score of 6.11. This is in contrast to the Kidney PREM in adults where this is a consistent low scoring theme. This needs to be interpreted with caution given the small numbers but is something we will be exploring further.

The support theme (mean score 5.7), particularly knowledge of support groups, and communication (mean score 5.67) between the renal team and others e.g., schools and the GP were low scoring themes. In addition, the communication theme had the largest variation between centres with a difference in mean scores from 5.0 to 6.5.

In-hospital dialysis patients were more likely to report care was the same or worse than one year ago. Numbers are small but this may be linked with increasing dialysis numbers across England and Wales and increased pressure on this aspect of service provision.

The score for transport for patients treated with in-centre haemodialysis is a low scoring theme (mean 5.18). This was particularly with regards to the time taken waiting for transport at the end of dialysis. There were low numbers in this group so this must be interpreted with caution.

## How we plan to use this data to inform quality improvement

- Quality Improvement based on this data can only be as good as the quality of this data. Our first priority is to continue to improve the Paediatric PREM through development of an all age PREM, as well as increase the number of responses, overall and from under-represented groups. We will be asking each centre to identify what they did well and what they can do to improve responses and share this with other centres. We will also look at how we can improve responses from males aged 12+ and those from under-represented ethnic groups.
- Individual centre data and comments will be circulated to heads of service and members of the KQulP Paediatric Patient Experience group.
- We will also share this data with the BAPN lead for Quality Improvement so the information can be considered in national projects.

## Recommended actions

- We would recommend that each centre identifies one area that they feel they can focus on regarding improvement of patient experience. We would then ask that this is shared with the Paediatric Patient Experience group so we can all learn and improve together.
- We would recommend that themes for improvement nationally to be considered by the BAPN lead for Quality Improvement would be
  - Transport for those receiving in hospital haemodialysis; particularly the time waiting after completing dialysis
  - Communication with GPs, schools and other specialities – how can this be improved and variation reduced?
  - Support – particularly peer support. How can we improve awareness of existing groups and additional support available to young people and families?

## INTRODUCTION

In 2016, the Kidney Patient Reported Experience Measure (Kidney PREM), was developed to capture the experiences of specialist kidney care nationally for UK-based adult patients. Developed by the UK Kidney Association (UKKA) and Kidney Care UK (KCUK), and supported by the University of Hertfordshire, the Kidney PREM is a key measure helping kidney units understand more about patient experience of care and identify areas for improvement. With over 80,000 responses it is the largest measure of the experience of people with chronic kidney disease (CKD), providing a nationally representative picture of patient care. However, the existing Kidney PREM does not include paediatric patients. Experience of care can be difficult to rate by proxy as it is unclear whether respondents are rating the child's experience, how they think the child would respond, or providing their own perspective on the child's experience. Children present a range of different challenges for the national healthcare service compared to adults and need an appropriate measure to capture their own experience directly. The Royal College of Paediatrics and Child Health (RCPCH) has supported the development of experience measures in other paediatric specialties which demonstrated this is feasible and can shape the development of services.

It was in this context that the British Association for Paediatric Nephrology (BAPN), as part of a wider Kidney Quality Improvement Partnership (KQIP) programme, started 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 Ben Reynolds and Suzanne Turton in Glasgow, demonstrated that specific measures for children and young people with CKD were 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 began working with the UKKA and KCUK, 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 we were able to offer a specific set of questions for those 12 years of age or over and for parents / carers of children and young people of all ages.

This is the first year that the Paediatric PREM (PPREM) has been piloted, with every centre in the UK contributing. All treatment modalities and all ages are represented, and the number of responses is comparable to the same stage of the adult Kidney PREM relative to the size of the population under study.

This is, however, only the first step. As a Paediatric Patient Experience group, we are working on developing and validating questions that can be used for children under 12 years of age as well as improving the measure for parents / carers and young people 12 years and over. Locally, we can all work to improve our collection methods and response rates. With the support of the BAPN, UKKA and KCUK, we need to embed the process in our national quality improvement work and demonstrate the benefit of this to our patients. In other words, the hard work starts now; however, we are confident of achieving this as we continue to work together as a community of children and young people with kidney disease, parents / carers, and healthcare professionals to achieve our long-term goal of an all-age Kidney PREM.

## METHODOLOGY

### The Paediatric Kidney PREM pilot

The Pilot Paediatric Kidney PREM (PPREM) 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 national Kidney PREM for adults. Some changes to the structure were made; the 'Needling' theme was removed, while a 'Medication' theme was added. Additional questions within themes were also inserted: one relating to communication between the kidney team and school, and the child-friendliness of the kidney care environment.

Respondents selected whether they were a child/young person (CYP) aged 12-16 years receiving care or if they were rating by proxy (as a parent or carer) in relation to the care their child receives. Depending on their response to this, 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 Kidney PREM for ages 17 and over, participant characteristics were collected including treating centre, treatment type and location (for people receiving haemodialysis), age, sex, ethnicity and use of PatientView/Patients Know Best. In addition to this, participants were asked to provide information about any help received to complete the questionnaire.

There is a free-text question at the end of the survey where individuals were asked to give suggestions for questions that they feel should be asked regarding aspects of their experience deemed important to them. Although 59 comments were received, all related to specific aspects of care. Therefore, these will be anonymised and included in the information given to individual centres, with no further analysis in this report.

### Data collection

The pilot paediatric PREM ran for six weeks from 1st October to 12th November 2022, alongside the annual Kidney PREM for adults. The collection of the data was publicised as an online survey, with links available on both the UK Kidney Association and Kidney Care UK websites. It was also advertised via social media through the BAPN twitter handle. 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.

## Analysis and reporting

Responses to questions were used to calculate scores for each theme, as well as the '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 Report, which will be published online later in 2023.

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: dialysis or kidney transplantation) are referred to as CKD (non-KRT) participants.

## RESULTS

### Response Profile

In 2022, a total of 285 valid surveys were received for the pilot Paediatric PREM (PPREM): 220 (77.2%) from parents/carers and 65 (22.8%) from children/young people (CYP). Thirteen of the CYP were aged 17-21 years and receiving care from paediatric centres, so although they participated in the adult Kidney PREM, they are reported here. These participants have been included in the '12 years and over' category throughout this report, unless otherwise stated. Responses were received from all 13 paediatric kidney centres in the UK, Table 1. As both parents/carers and CYP aged 12 years and over were able to participate in the pilot PPREM, it should be noted that more than one response could have been submitted for CYP, potentially double counting in terms of participant characteristics or treatment types.

**Table 1: Frequency of returns from centres completing PPREM Pilot 2022**

Centre	No. of returns	% of returns	% of UK KRT patients under 17 years <sup>1</sup>
Alder Hey Children's Hospital	14	5.0%	4.6%
Birmingham Children's Hospital	28	10.0%	12.1%
Bristol Royal Hospital for Children	21	7.5%	5.9%
Children's Hospital for Wales, Cardiff	17	6.0%	3.7%
Evelina London Children's Hospital	61	21.7%	9.6%
Great North Children's Hospital	10	3.6%	3.8%
Great Ormond Street Hospital	27	9.6%	18.4%
Leeds Children's Hospital	19	6.8%	6.8%
Nottingham Children's Hospital	32	11.4%	10.3%
Royal Belfast Hospital for Sick Children	10	3.6%	3.1%
Royal Hospital for Children, Glasgow	12	4.3%	6.8%
Royal Manchester Children's Hospital	8	2.8%	10.1%
Southampton Children's Hospital	22	7.8%	4.7%
<i>Missing</i>	4	-	-
<b>UK Total</b>	<b>285</b>	<b>-</b>	<b>950</b>

*KRT: Kidney Replacement Therapy*

### Patient Characteristics

Over half of the responses (55.4%) were provided by parents/carers for a child under the age of 12 years, Table 2. Fewest responses were received for patients aged 4-7 years (13.3%), followed by patients aged 0-3 (17.9%) and those aged 8-11 (24.2%).

Of the responses received relating to 12-16-year-olds, less than half were CYP reporting their own experiences of care received (45.6%), with the majority coming from parents/carers.

<sup>1</sup> Data from the UK Renal Registry. This includes only patients receiving kidney replacement therapy.

**Table 2: Pilot PPREM 2022 Patient age**

	Number (%) of returns
<b>Total</b>	285
<b>Age (years)</b>	
0-3	51 (17.9%)
4-7	38 (13.3%)
8-11	69 (24.2%)
12-16	114 (40.0%)
Child/Young Person	52 (45.6%)
Parent/Carer	62 (54.4%)
<sup>2</sup> 17-21	13 (4.6%)

For CYP participants aged 12 years and over, fewer males than females responded (41.5%), Table 3. Conversely, participation was greater from parents/carers of male patients amongst under 12 years (64.6%) and 12-16 years (58.1%), more closely reflecting the number of CYP receiving KRT recorded by the UK Renal Registry (UKRR) in 2021 (62.2% male).

The ethnic profile of patients varied according to each respondent group. For CYP aged 12 years and over, just over half of the respondents were white (58.5%), whereas 78.5% of parents/carers of under 12s and 66.1% of parents/carers of 12-16-year-olds stated that their CYP was white. Just 15 participants reported black ethnicity, so comparisons across the three response groups are not practical. However, there seemed to be fewer patients of Asian ethnicity reported by the parents/carers of the under 12s (10.8%) than for either of the 12 years and over groups (16.1% for parents/carers, 16.9% for CYP).

**Table 3: Pilot PPREM 2022 Patient characteristics by completion group**

	Parent/Carer under 12 years (% of total)	Parent/Carer 12 years and over (% of total)	Child/Young Person 12 years and over (% of total)	Total (% of total)
<b>Total</b>	158	62	65	285
<b>Gender</b>				
Female	56 (35.4%)	24 (38.7%)	36 (55.4%)	116 (40.7%)
Male	102 (64.6%)	36 (58.1%)	27 (41.5%)	165 (57.9%)
Rather not say	0 (0.0%)	2 (3.2%)	2 (3.1%)	4 (1.4%)
<b>Ethnicity</b>				
Asian	17 (10.8%)	10 (16.1%)	11 (16.9%)	38 (13.3%)
Black	4 (2.5%)	3 (4.8%)	8 (12.3%)	15 (5.3%)
White	124 (78.5%)	41 (66.1%)	38 (58.5%)	203 (71.2%)
Other	13 (8.2%)	5 (8.1%)	4 (6.1%)	22 (7.7%)
Rather not say	0 (0.0%)	3 (4.8%)	4 (6.2%)	7 (2.5%)

<sup>2</sup> These patients receive their care in paediatric centres but are aged 17 and over, so completed the adult Kidney PREM, but are included in these results.

## Help to Participate

Respondents were asked whether they had help completing the questionnaire.

Of those CYP aged 12 years and over completing the pilot PPREM, over half did so independently (60%). For those who did receive help, a large proportion were helped by a friend or relative (88.5%). Over three quarters (76.9%) of participants cited 'I am aged 12-16 and need someone to help me' as the reason for receiving help.

The vast majority of parents/carers of a patient under 12 years completed the pilot PPREM alone without assistance (96.2%), as did parents/carers of a patient over 12 years (95.2%).

## Treatment profile

Across all response types, over half of patients were not receiving KRT (54.0%), Table 4. Over a quarter (25.6%) of responses related to CYP with a functioning kidney transplant, while a comparatively smaller number were receiving peritoneal dialysis (8.4%). Most CYP receiving haemodialysis had treatment in centre (88.2%).

**Table 4: Pilot PPREM 2022 Treatment modality by response group**

	Parent/Carer under 12 years (% of total)	Parent/Carer 12 years and over (% of total)	Child/Young Person 12 years and over (% of total)	Total (% of total)	% of UK KRT Population 2021 <sup>3</sup>
<b>Total</b>	158	62	65	285	950
Transplant	37 (23.5%)	22 (35.5%)	14 (21.5%)	73 (25.6%)	10.1%
Peritoneal	14 (8.9%)	6 (9.7%)	4 (6.2%)	24 (8.4%)	20.7%
Haemodialysis	14 (8.9%)	7 (11.3%)	13 (20.0%)	34 (11.9%)	31.2%
<i>At Home</i>	2 (14.3%)	1 (14.29%)	1 (7.7%)	4 (11.7%)	
<i>Hospital</i>	12 (85.7%)	6 (85.7%)	12 (92.3%)	30 (88.2%)	
CKD (non-KRT)	93 (58.9%)	27 (43.6%)	34 (52.3%)	154 (54.0%)	
Attend for monitoring	71 (76.3%)	24 (88.9%)	24 (70.6%)	119 (77.3%)	
Approaching ESKD:	15 (16.1%)	2 (7.4%)	7 (20.6%)	24 (15.6%)	
<i>Chosen KRT</i>	7 (46.7%)	2 (100.0%)	7 (100.0%)	16 (66.7%)	
<i>Undecided</i>	8 (53.3%)	0 (0.0%)	0 (0.0%)	8 (33.3%)	
Don't know	7 (7.5%)	1 (3.7%)	3 (8.8%)	11 (7.1%)	

CKD: Chronic Kidney Disease  
KRT: Kidney Replacement Therapy  
ESKD: End-stage Kidney Disease

<sup>3</sup> Responses by proportion of each treatment modality according to UKRR data (2021).

## Use of Online Platforms

Pilot PPREM participants were asked about their use of PatientView/Patients Know Best; results shown in Table 5. A higher proportion of responding CYP used such a platform (33.8%) than parents/carers (28.5% for those with under 12s, 29.0% for 12-16-year-olds). Most of those who were not using these systems did not know what they were.

**Table 5: Pilot PPREM 2022 participant use of PatientView/Patients Know Best**

	Parent/Carer under 12 years (% of total)	Parent/Carer 12 years and over (% of total)	Child/Young Person 12 years and over (% of total)	Total (% of total)
Yes, using PV/PKB	45 (28.5%)	18 (29.0%)	22 (33.8%)	85 (29.8%)
No, not using	97 (61.4%)	42 (67.7%)	33 (50.8%)	172 (60.4%)
Unavailable	6 (6.2%)	6 (14.3%)	2 (6.1%)	14 (8.1%)
Don't know what it is	79 (81.4%)	34 (81.0%)	30 (90.9%)	143 (83.1%)
Other reason	12 (12.4%)	2 (4.8%)	1 (3.0%)	15 (8.7%)
Don't know	16 (10.1%)	2 (3.2%)	10 (15.4%)	28 (9.8%)

## Medication

Participants of pilot PPREM were asked how they obtained medication. Data are missing for the thirteen CYP age 17-21 years, since they completed the adult Kidney PREM and so were not shown this question. A further 30 participants (16 parents/carers of under 12s, 9 parents/carers of 12–16-year-olds, 5 CYP) stated that they did not know, or that the question was not applicable. Just over a quarter of participants reported obtaining medication from their GP, nearly a third from the hospital pharmacy and a further quarter from a mixture of sources, Table 6.

**Table 6: Pilot PPREM 2022 participant medication source**

	Parent/Carer under 12 years (% of total)	Parent/Carer 12 years and over (% of total)	Child/Young Person 12 years and over (% of total)	Total (% of total)
GP	37 (26.1%)	16 (30.2%)	13 (27.7%)	66 (27.3%)
Hospital pharmacy	41 (28.9%)	14 (26.4%)	17 (36.2%)	72 (29.8%)
Community pharmacy	19 (13.4%)	2 (3.8%)	5 (10.6%)	26 (10.7%)
Delivered to me	6 (4.2%)	5 (9.4%)	4 (8.5%)	15 (6.2%)
Mixture of above	39 (27.5%)	16 (30.2%)	8 (17.0%)	63 (26.0%)
<b>Total</b>	<b>142</b>	<b>53</b>	<b>47</b>	<b>242</b>

## English as First Language

Eighteen participants (6.3%) advised that the kidney patient's first language was something other than English (11 European, 4 Asian, 1 African, 1 Arabic and 1 British Sign Language). In five centres, English was the first language spoken by all individuals being described, and 10 of those with an alternative first language were treated at just two centres.

## Patient Experience of Kidney Care

Patient experience of paediatric kidney care in 2022 is presented in the following five sections:

1. The participant view of how their experience of care has changed over the past year, according to treatment modality,
2. An overview of patient experience scores across the 13 pilot PPREM themes at a national level,
3. Centre-level scores for overall experience (final question of the pilot PPREM), and for other pilot PPREM themes,
4. Comparison of treatment-level scores for pilot PPREM themes using medians and interquartile ranges (IQR),
5. A detailed look at each theme of the pilot PPREM.

**The themes of the 2022 pilot Paediatric PREM are:**

- 1) Access to the Kidney Team
- 2) Support
- 3) Communication
- 4) Patient Information
- 5) Fluid Intake and Diet
- 6) Medication
- 7) Tests
- 8) Sharing Decisions About Your Care
- 9) Privacy and Dignity
- 10) Scheduling and Planning
- 11) How the Kidney Team Treats You
- 12) Transport
- 13) The Environment
- 14) Overall

## 1. Change in Experience of Care Over the Past Year

Participants were asked ‘Overall, how much better or worse was your kidney care experience during the last year?’, using a scale from -3 (much worse) to +3 (much better), where 0 related to ‘no change’. A total of 235 (82.5%) respondents reported receiving treatment at least a year ago. Those responding on behalf of CYP with a transplant, on home therapies (peritoneal dialysis/home haemodialysis) and CYP not receiving KRT reported a similar amount of change, with most (68.2% transplant, 66.7% peritoneal/home haemodialysis, 62.4% CKD) reporting no change in their experience of care in the past 12 months, Table 7, Figure 1. In contrast, the reported experiences of in-centre haemodialysis recipients/their carers seem less stable, with ‘no change’ given by just 40.0%. However, both the peritoneal and haemodialysis groups receiving treatment a year ago are small (<20), so results should be interpreted with caution.

**Table 7: Reported change in experience during the last year**

	CKD (non-KRT)	PD/HHD	ICHD	Transplant	Total
<b>Worse</b>	26 (20.8%)	4 (16.7%)	7 (35.0%)	15 (22.7%)	52 (22.1%)
<b>No change</b>	78 (62.4%)	16 (66.7%)	8 (40.0%)	45 (68.2%)	147 (62.6%)
<b>Better</b>	21 (16.8%)	4 (16.7%)	5 (25.0%)	6 (9.1%)	36 (15.3%)
<b>Not having treatment a year ago</b>	20	4	6	3	33
<b>Total</b>	145	28	26	69	268

Worse: -3 (much worse) to -1, No change: 0, Better: +1 to +3 (much better)

CKD: Chronic Kidney Disease

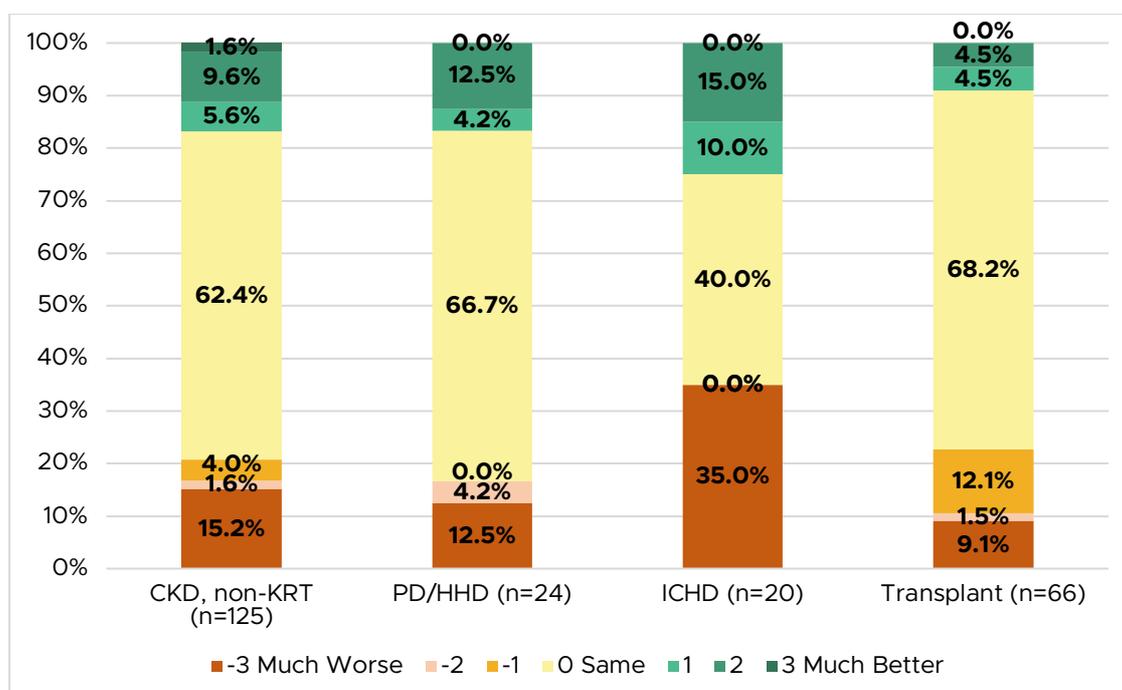
KRT: Kidney Replacement Therapy

PD: Peritoneal dialysis

HHD: Home haemodialysis

ICHD: In centre haemodialysis

**Figure 1: Patient experience change over the last year by treatment**



## 2. Patient Experience Scores by Theme

Figure 2 displays pilot PPREM scores for each theme according to response group, with possible values ranging from 1 to 7. Transport theme did not receive sufficient responses for all response group scores to be estimated, so only CYP values are shown.

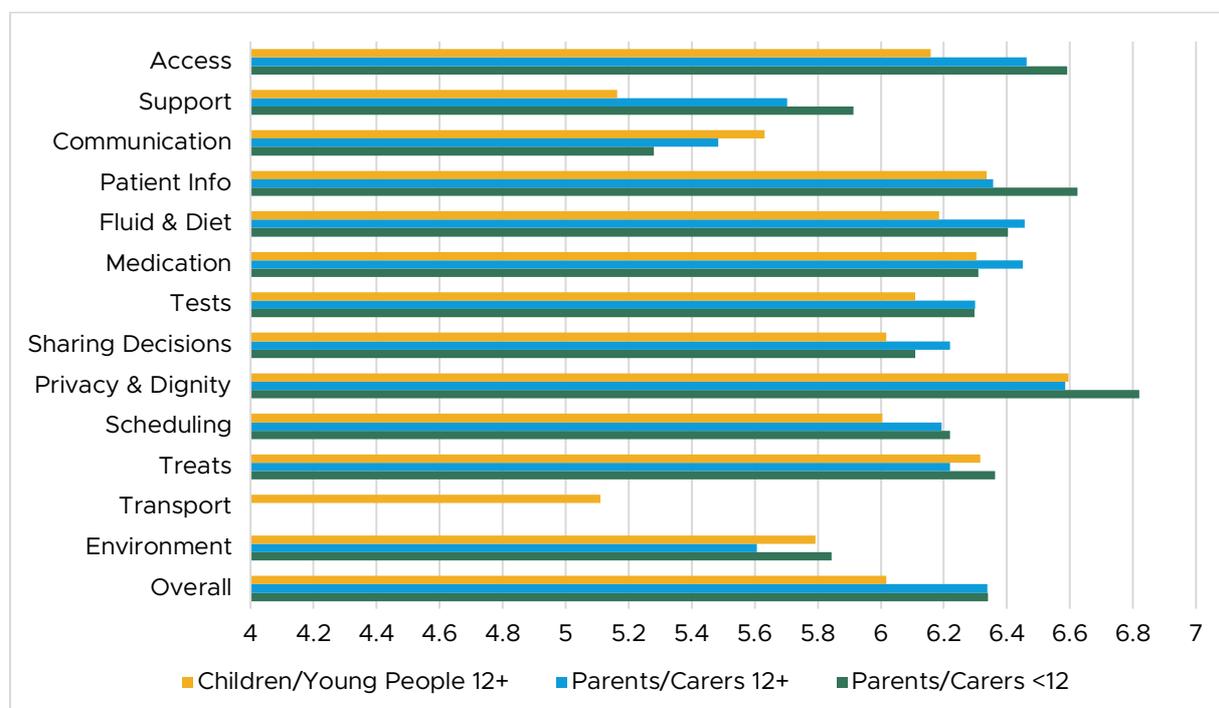
Parents/carers of all age groups scored some themes more highly than CYP to a varying degree, notably Access (parents/carers <12: 6.59, parents/carers 12+: 6.46, CYP: 6.16), Support (parents/carers <12: 5.91, parents/carers: 12+ 5.70, CYP 5.16) and Overall (parents/carers <12: 6.34, parents/carers: 12+ 6.34, CYP 6.02).

Privacy & Dignity was the highest scoring theme across all response groups, (parents/carers <12: 6.82, parents/carers: 12+ 6.58, CYP 6.59). In contrast, Sharing Decisions was the most poorly rated theme of the adult Kidney PREM (5.54) but scored more highly amongst all pilot PPREM response groups (parents/carers <12: 6.11, parents/carers: 12+ 6.22, CYP 6.02).

Support, Environment and Communication were scored most poorly of the themes across all response groups. CYP gave the lowest scores to Support (5.16), notably lower than both parent/carer groups (parents/carers <12: 5.91, parents/carers 12+: 5.70). Conversely, CYP scored Communication more highly than the parent/carer respondents (parents/carers <12: 5.28, parents/carers 12+: 5.48, CYP 5.63). Scores for Transport theme were only estimated for CYP, receiving in-centre haemodialysis, obtaining the lowest value across all themes at 5.11.

Mean values and 95% confidence intervals for each group can be seen in the appendix, Table A1.

**Figure 2: Mean scores for Kidney PREM themes and the Overall experience question by respondent type<sup>4</sup>**



<sup>4</sup> Graph does not include responses for themes which received <7 responses.

### 3. Experience of Care by Centre

The final question of pilot PPREM asks, ‘How well would you grade your overall experience of the service provided by your kidney unit?’ and is answered on a scale from 1 (worst it can be) to 7 (best it can be). Overall experience is scored highly at 6.27 across all response groups, with centre scores ranging from 5.79 to 6.80.

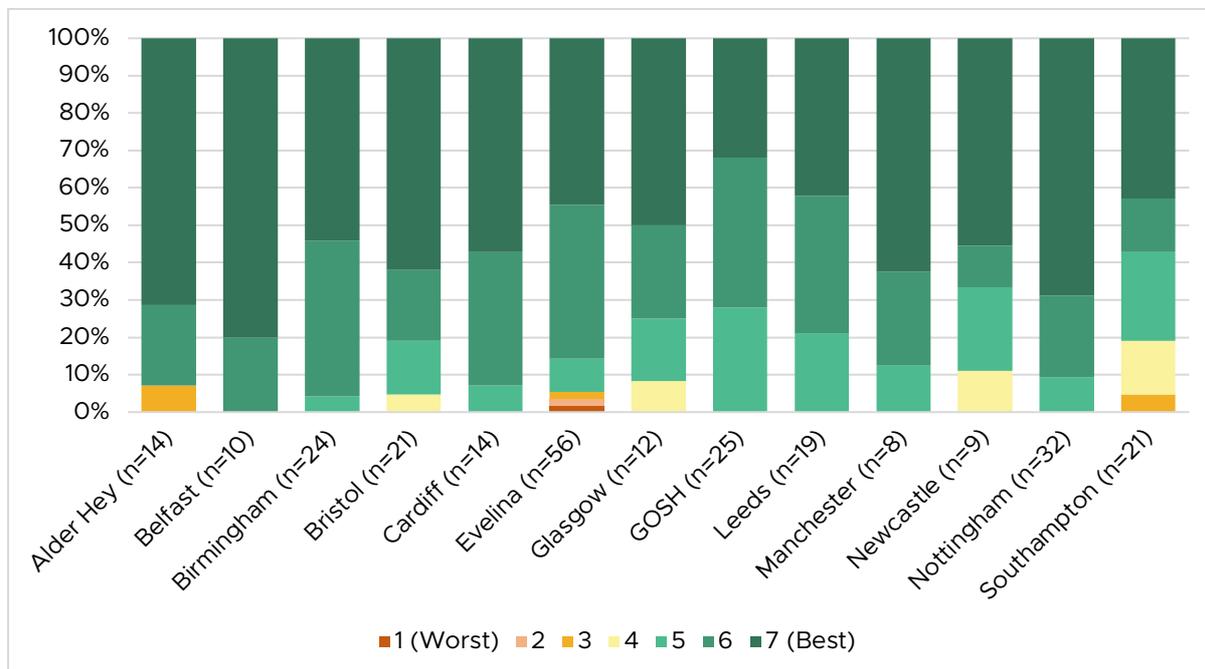
Mean scores were calculated for each of the 13 paediatric centres, shown in Figure 3. Most centres’ participants score their overall experience highly, with seven centres receiving entirely positive (scores 5-7) values. Very few participants graded their overall experience poorly (scores 1-3).

Figure 3 should be interpreted with caution, recognising low numbers of participants at some units.

The value in brackets next to centre names on the chart represents the number of people responding to this question at each centre, ranging from eight to 56. These numbers are vital for reading the figure accurately:

- 1) for a centre with 10 responses, one person scoring ‘1’ for overall experience shows as red for 10% of the sample,
- 2) for a centre with 50 responses, a single person scoring ‘1’ would be barely visible on the chart, representing 2% of the sample.

**Figure 3: Centre scores for Overall Experience of the service provided by renal centres (Q39 in Pilot Paediatric PREM)**



Centre (mean) scores were calculated for each theme. The average and range of the centre scores are summarised in appendix Table A2, with individual centre scores and 95% confidence intervals displayed in Table A3.

## 4. How Patient Experience Compares in pilot PPREM Themes Across Treatment Groups

In this section, medians and interquartile ranges (IQR) have been used because they are a good way to measure changes in scores across most individuals within each group<sup>5</sup>.

### Consistency:

Access, Patient Information, Fluid & Diet and Privacy & Dignity themes received the highest possible median scores across all treatment groups at 7.0 (out of 7.0), with Tests receiving median scores of 6.67 throughout modalities, although with slightly different interquartile ranges, see Table 8.

### Variation:

Support, Communication and Overall themes displayed the widest variation in centre scores, ranges 1.67, 0.75 and 1.00 respectively.

The lowest scoring theme was Transport at 5.33, applicable only for individuals receiving haemodialysis. Notably, CKD (non-KRT) was the only treatment group where the median Overall centre score was 6.00, with each other receiving the maximum 7.0.

**Table 8: Comparison of median pilot PPREM scores by treatment group**

	CKD (Non-KRT)		Peritoneal/Home Haemodialysis		In-Centre Haemodialysis		Transplant	
	Median	IQR	Median	IQR	Median	IQR	Median	IQR
Scale	6.29	5.78 - 6.73	6.42	5.65 - 6.63	6.48	6.11 - 6.77	6.40	5.78 - 6.76
Access	7.00	6.00 - 7.00	7.00	7.00 - 7.00	7.00	6.67 - 7.00	7.00	6.67 - 7.00
Support	6.00	4.67 - 7.00	5.17	4.50 - 6.83	7.00	4.50 - 7.00	6.50	4.67 - 7.00
Communication	6.00	4.73 - 7.00	6.10	4.83 - 6.53	6.40	6.00 - 7.00	6.10	4.60 - 6.80
Patient Information	7.00	6.50 - 7.00	7.00	6.50 - 7.00	7.00	6.50 - 7.00	7.00	6.00 - 7.00
Fluid & Diet	7.00	6.00 - 7.00	7.00	6.25 - 7.00	7.00	6.50 - 7.00	7.00	6.00 - 7.00
Medication	7.00	6.00 - 7.00	7.00	6.00 - 7.00	7.00	6.00 - 7.00	7.00	6.00 - 7.00
Tests	6.67	5.67 - 7.00	6.67	5.67 - 7.00	7.00	6.00 - 7.00	6.67	6.00 - 7.00
Sharing Decisions	6.58	5.33 - 7.00	6.67	6.00 - 7.00	6.67	5.33 - 7.00	7.00	5.67 - 7.00
Privacy & Dignity	7.00	7.00 - 7.00	7.00	6.75 - 7.00	7.00	6.00 - 7.00	7.00	7.00 - 7.00
Scheduling	6.67	5.67 - 7.00	7.00	6.33 - 7.00	7.00	6.00 - 7.00	6.58	5.67 - 7.00
Treats	6.67	6.00 - 7.00	7.00	6.00 - 7.00	7.00	6.67 - 7.00	6.67	6.00 - 7.00
Transport	-	-	-	-	5.33	4.33 - 6.00	-	-
Environment	6.17	5.33 - 6.67	5.92	4.83 - 6.17	6.00	5.33 - 6.80	5.92	5.17 - 6.33
Overall	6.00	6.00 - 7.00	7.00	6.00 - 7.00	7.00	6.00 - 7.00	7.00	6.00 - 7.00

CKD: Chronic Kidney Disease  
KRT: Kidney Replacement Therapy  
IQR: Inter-quartile range

<sup>5</sup> This is particularly the case for pilot PPREM, as theme scores at a national level are heavily left skewed (most individuals have selected high values [5/6/7] with very few low scores chosen [1/2/3]). Other sections and charts within this report use means to describe centre scores, which is appropriate because these, local, values are approximately normally distributed.

## 5. Patient experience of kidney care across the service

This section of the report presents overall scores for all questions in the 2022 pilot Paediatric PREM.

The graphs on the left show centre scores and 95% confidence intervals (95% CIs) for each theme of the 2022 pilot PPREM. Vertical lines show the median, lower quartile and upper quartile of these centre scores. Generally, the size of the confidence interval usually relates to the number of responses for each centre, with an increasing level of uncertainty if fewer surveys were received. Centre scores could be estimated for each theme if at least 7 responses were recorded.

Graphs could not be produced for the Transport theme since these questions are only applicable to those receiving haemodialysis in-centre, and no centres achieved the minimum requirement of 7 responses.

The number of responses used to calculate the scores are in brackets after each centre name. Each chart shows how many individuals from each centre completed the questions being reported, as opposed to the number of participants from each centre who completed the pilot PPREM. There is variability in these numbers across themes, since it excludes those for whom theme scores could not be estimated; usually respondents selected 'don't know' or 'not applicable'.

A second figure is presented for each pilot PPREM theme, showing the proportion of 1.0 - 7.0 scores awarded to each of the questions within those themes, separated into response group (i.e., CYP 12+ years, Parents/Carers 12+ years, Parents/Carers <12 years). The number of participants responding 1.0 - 7.0 is shown in brackets after the question label. Bars total 100%, so the distribution of scores is clear, reflected in the width of segments from dark red (1.0; negative), through orange (4.0; neutral) to dark green (7.0; positive).

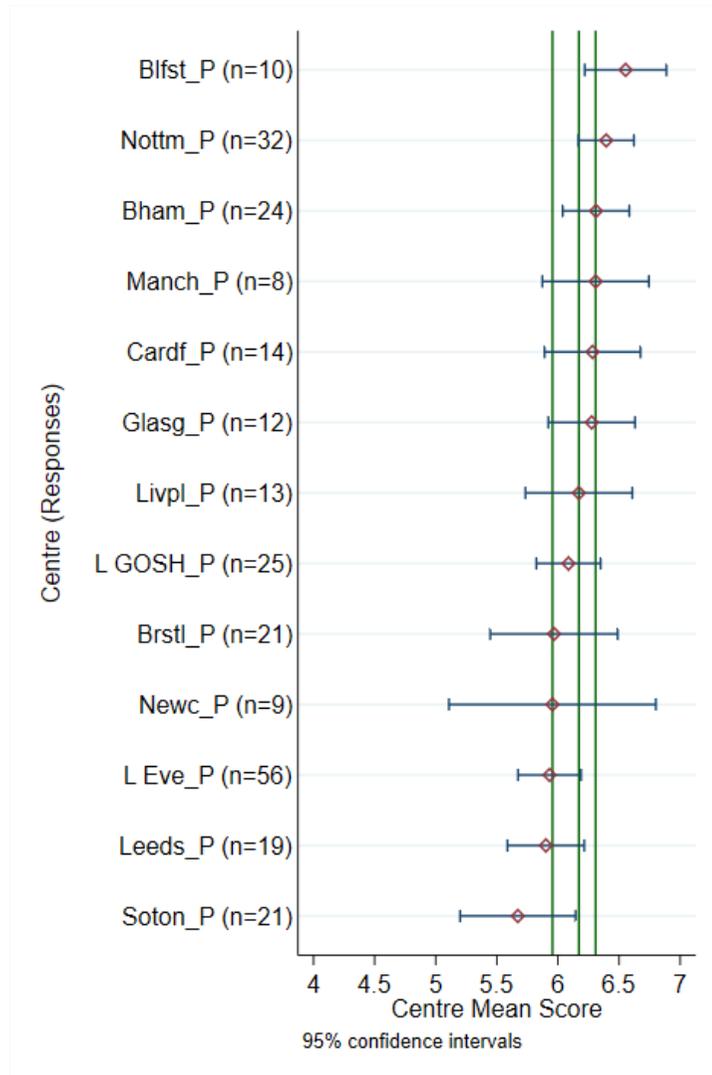
The number of individuals responding with a 1.0 - 7.0 out of 7.0 varies, as some questions are only applicable to certain participants, with some giving a valid response of 'don't know' or 'not applicable' as described above.

As the pilot PPREM has been derived from the adult Kidney PREM, the question numbering reflects the initial survey, with additional questions given a 'P' prefix, to aide comparisons with the adult survey.

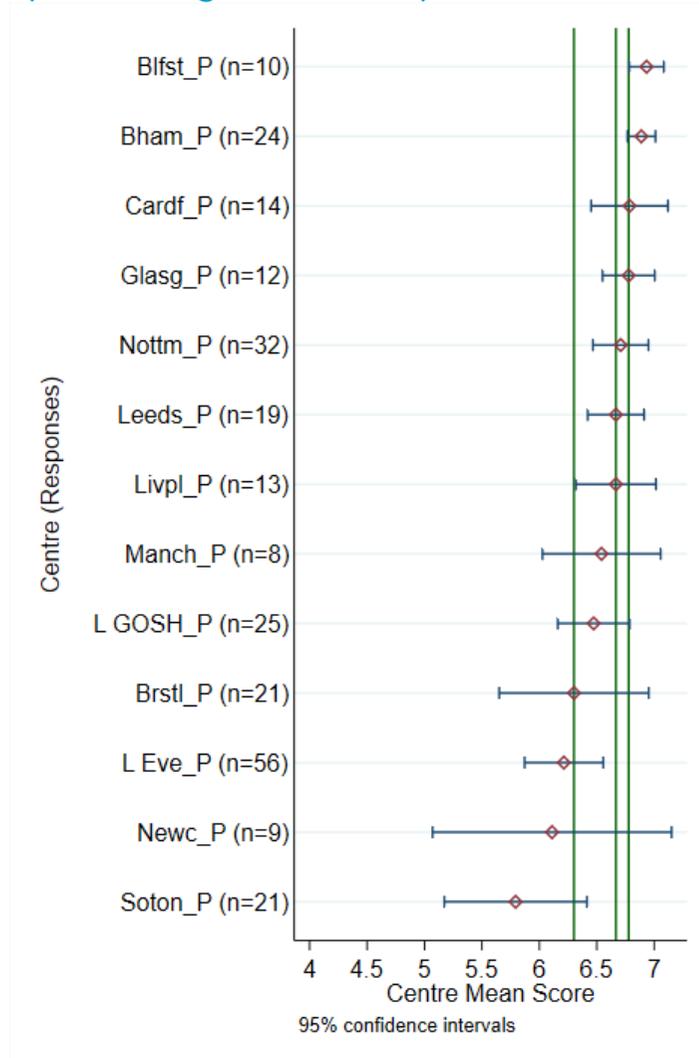
Data in this section may help to provide greater insights into the issues driving the theme scores and thus provide a guide to steer local quality improvement initiatives.

**Scale Score: Mean score of 6.14 (centre range 5.67–6.55)**

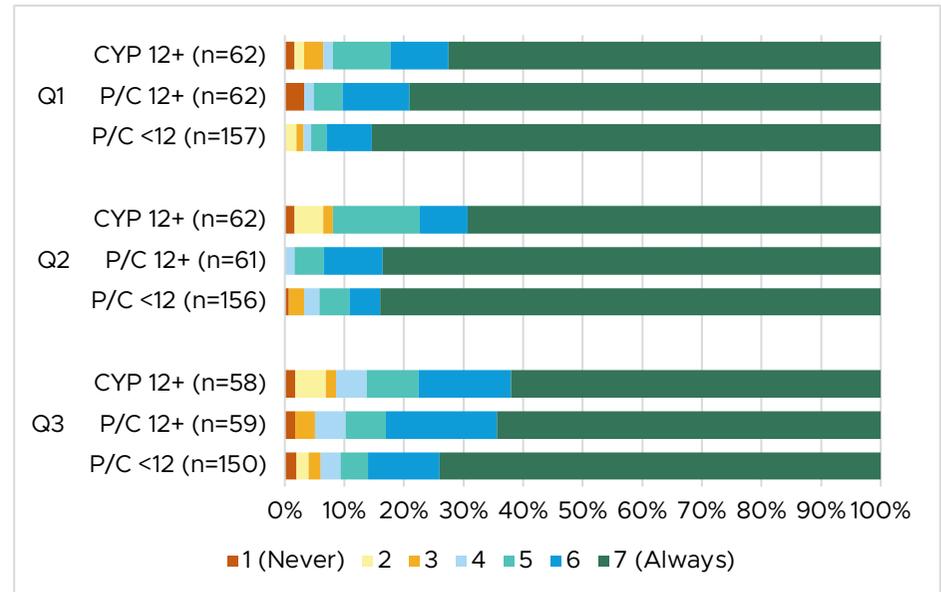
This is the total score across all questions of the Pilot PPREM, excluding the Overall question (Q39). Centre scores ranged from 5.67 to 6.55, with no centres with confidence intervals either side of the inter-quartile range.



**Section 1 Access to the Kidney Team: Mean score of 6.53 (centre range 5.79 – 6.93)**



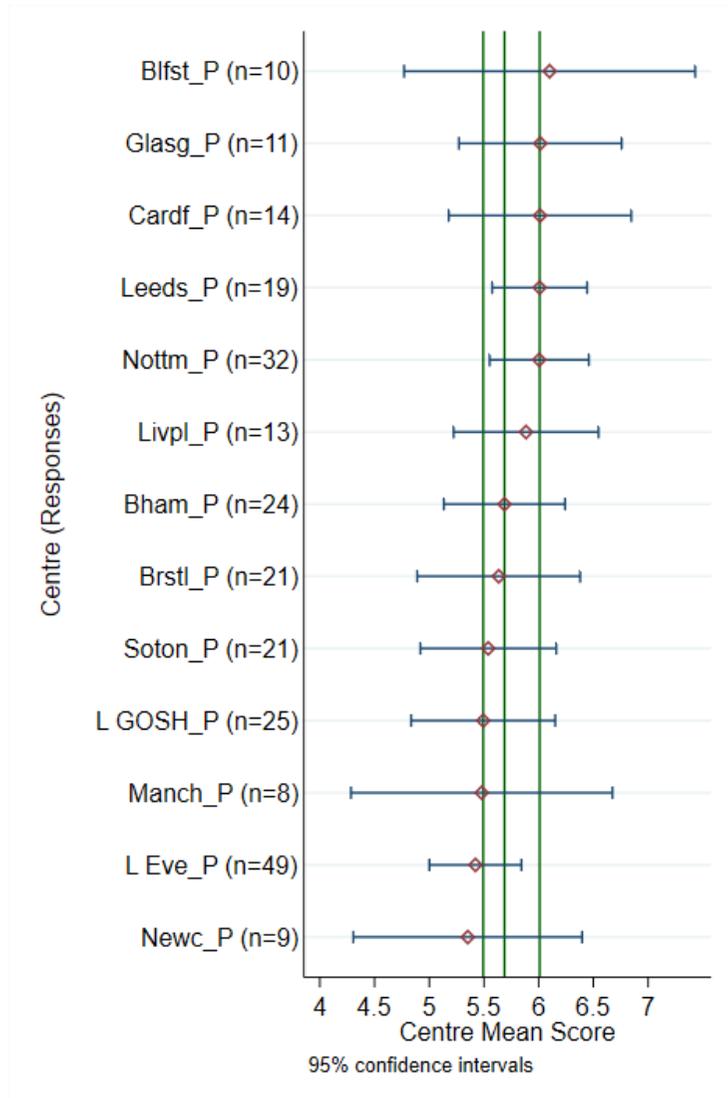
**Q1.** Does the Kidney team take time to answer your questions about your kidney disease or treatment?  
**Q2.** Would you feel comfortable to contact the unit from home if you were anxious or worried?  
**Q3.** Would you feel able to ask for an additional appointment with your kidney doctor if you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



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

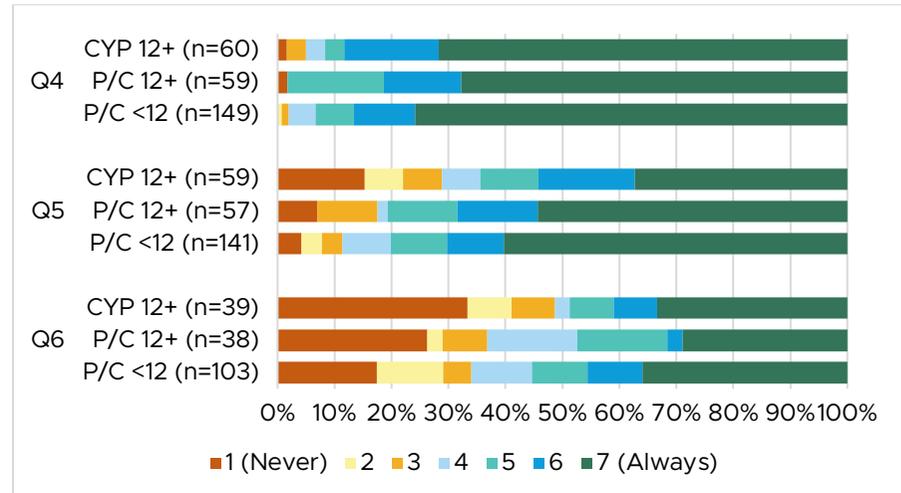
Access was one of the more highly scoring themes, with fewer than 15% rating experience as 4 or lower across all questions. Notably, parents/carers of under 12s awarded more scores of 7 than the other response groups throughout the theme.

**Section 2 Support: Mean score of 5.74 (centre range 5.35 – 6.10)**



**Does the renal team help you to get the support you want with:**

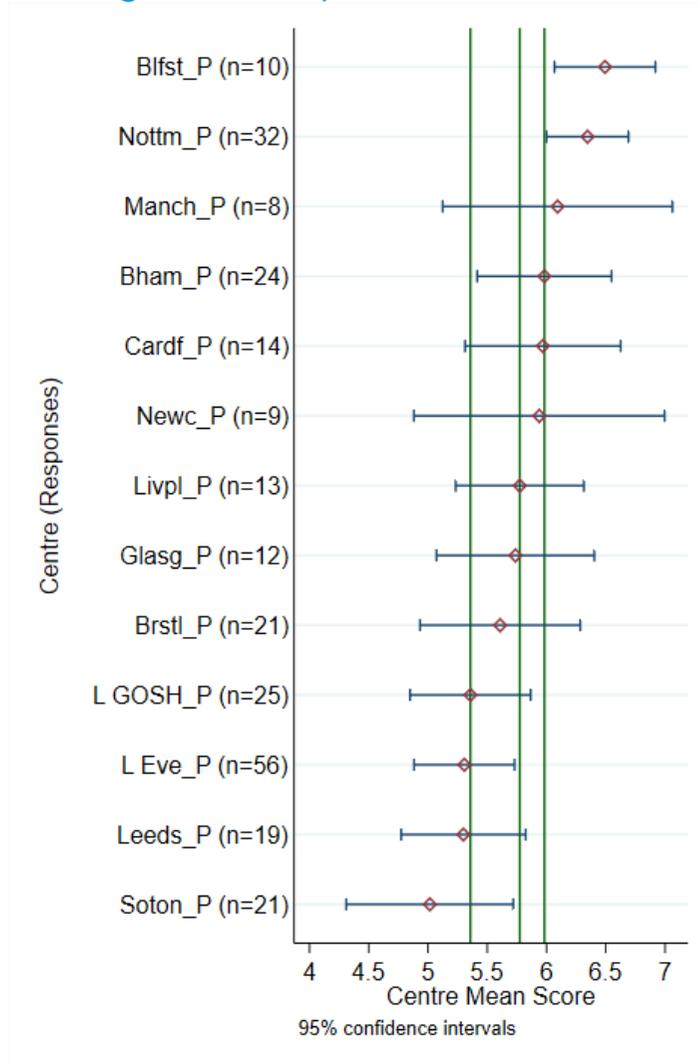
- Q4.** Medical issues resulting from your kidney disease?
- Q5.** Any other concerns or anxieties resulting from your kidney disease or treatment?
- Q6.** Accessing patient support groups such as Kidney Patient Associations (KPA)?



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

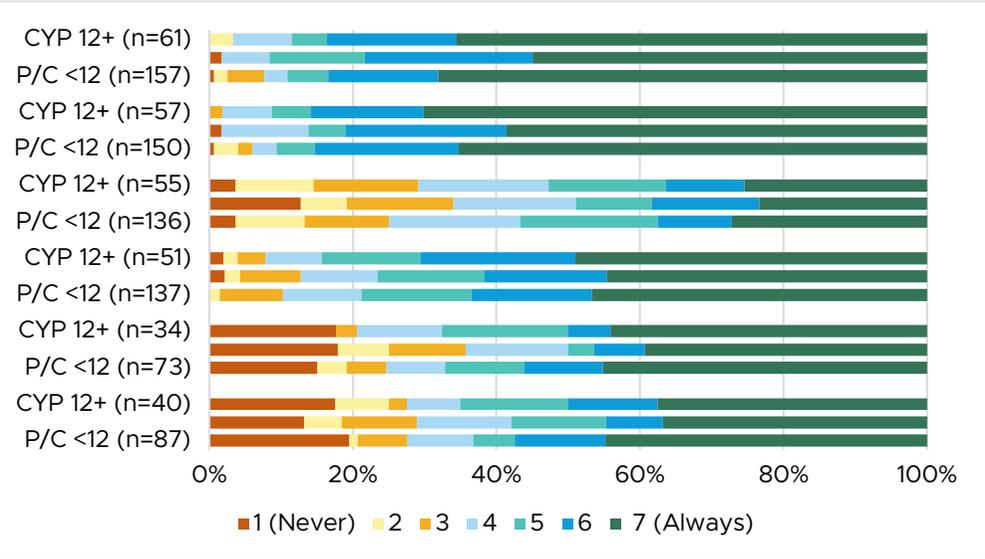
Across the Support theme, variation was apparent between the individual questions. Question 4 (support with medical issues) was well-scored, with over 90% of participants providing a rating of at least 5. However, question 5 (support with other concerns) was scored less favourably, mainly owing to a handful of individuals giving ‘1, never’ ratings. Question 6 (support to access patient support groups) received less than 50% of 5-7 scores for CYP and parents/carers of 12-16-year-olds, with parents/carers of under 12s marginally better at just over 50%. However, this question was applicable to fewer participants, with fewer responses received across response groups.

**Section 3 Communication: Mean score of 5.76 (centre range 5.02-6.49)**



Do you think there is good communication between:

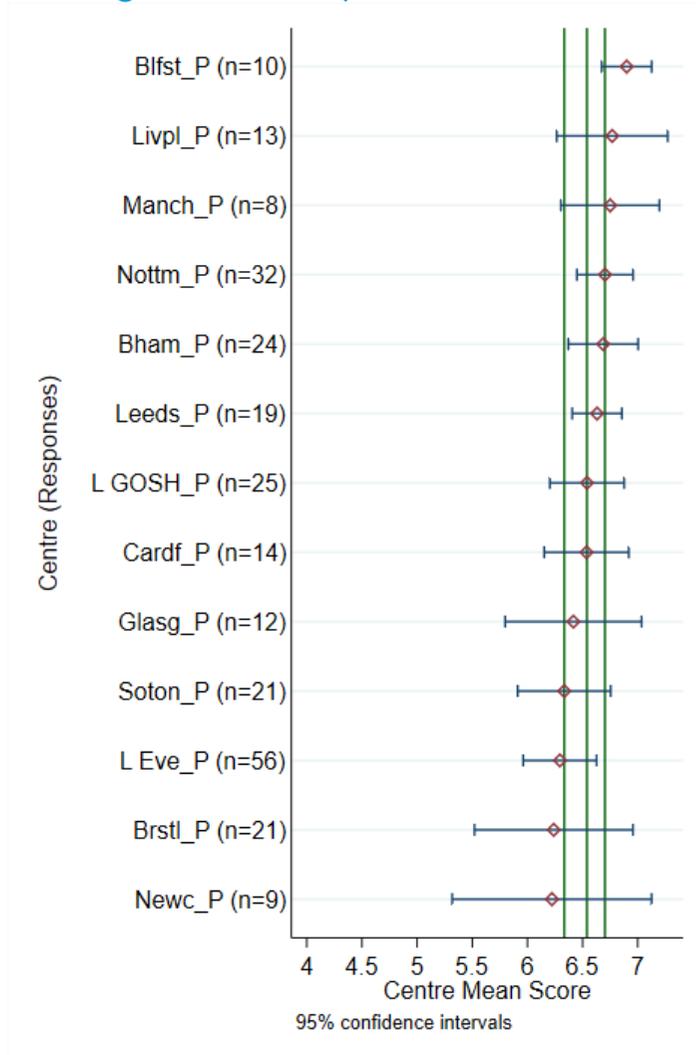
- Q7.** You and your renal team?
- Q8.** Members of the renal team?
- Q9.** Your GP and the renal team?
- Q10.** The renal team and other medical specialists?
- Q11.** The renal team and other non-healthcare services if you need them, such as social work or housing?
- P02.** The kidney team and your school?



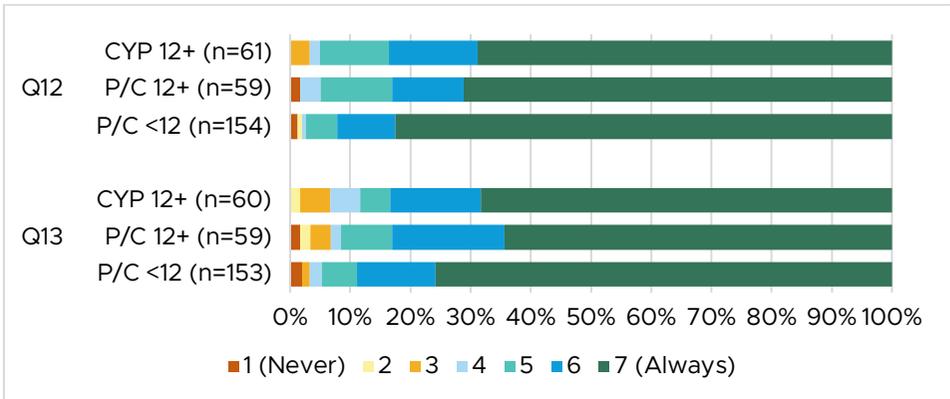
CYP: Children and Young People, P/C: Parents/Carers

In Communication, the response profile is similar across groups. Questions 11 and P02 (communication with non-healthcare services and school) performed least well, with over 20% scoring 1s or 2s across groups. Communication was the theme with the most variation across centre scores, with mean scores ranging from 5.02 to 6.49.

**Section 4 Patient Information: Mean score of 6.54 (centre range 6.22 – 6.90)**



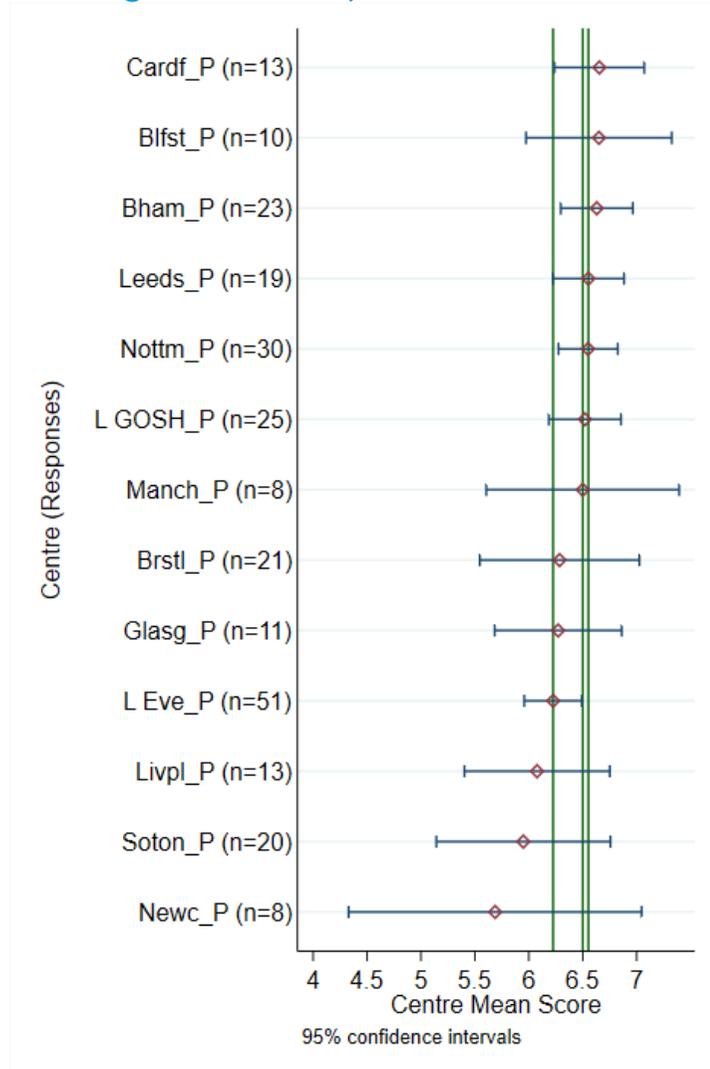
Does the kidney team:  
**Q12.** Explain things to you in a way that is easy to understand?  
**Q13.** Give you as much information about your kidney disease or treatment as you want?



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

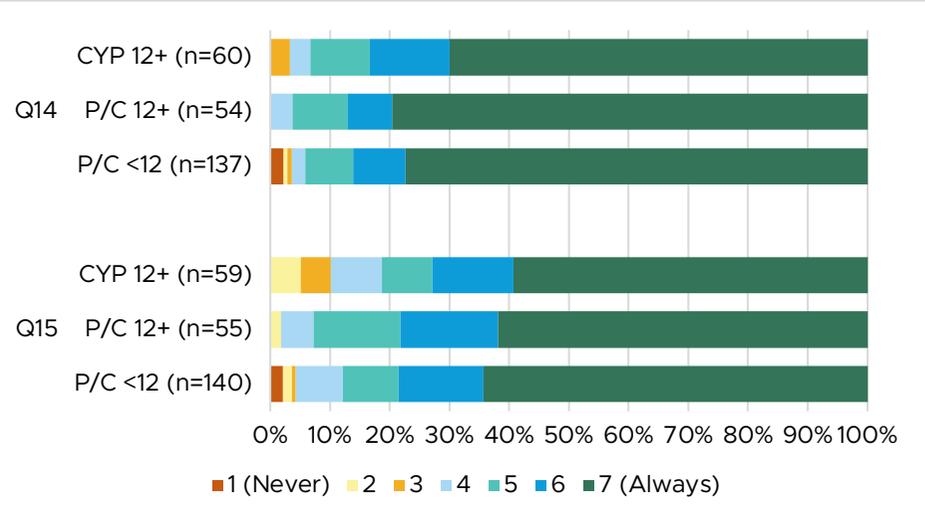
Patient Information was one of the more highly performing themes of the pilot PPREM. Very few participants scored either question with 1s or 2s, with over 85% of each response group giving positive values of 5 to 7. There was little variation across centres, with all high mean scores across all sites.

**Section 5 Fluid Intake and Diet: Mean score of 6.35 (centre range 5.69 – 6.65)**



**Thinking about the advice you are given about fluid intake:**  
Q14. Does the renal team give you clear advice on your fluid intake?

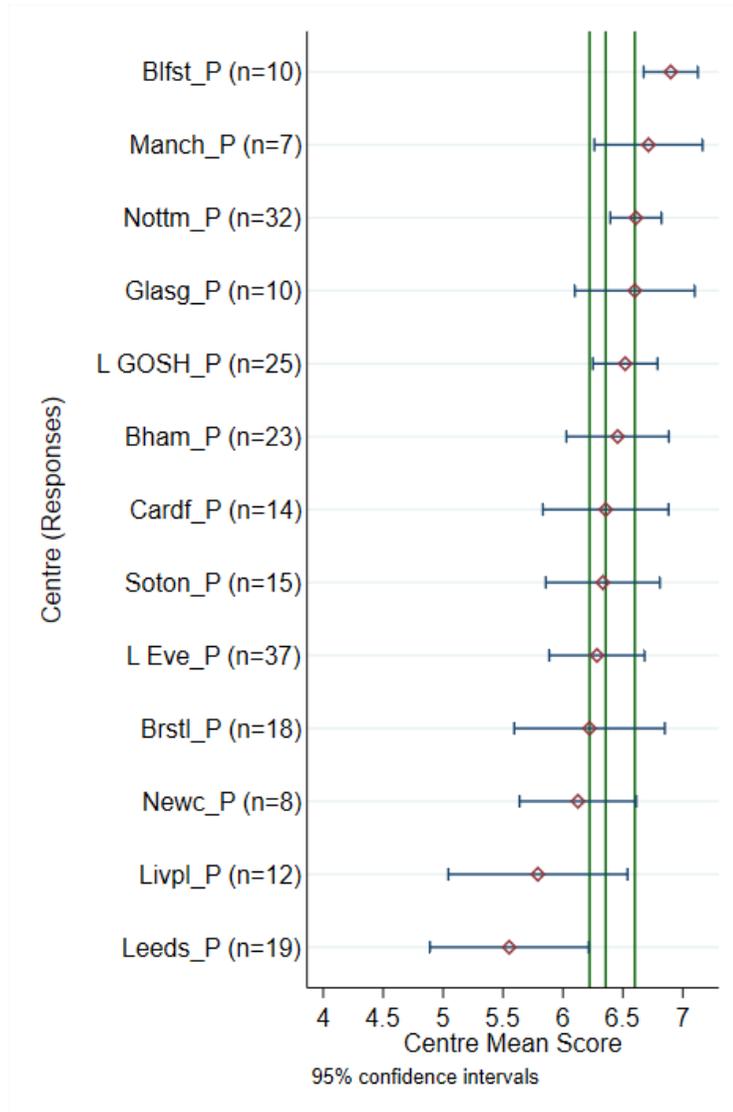
**Thinking about the advice you are given about diet:**  
Q15. Does the renal team give you clear advice on your diet?



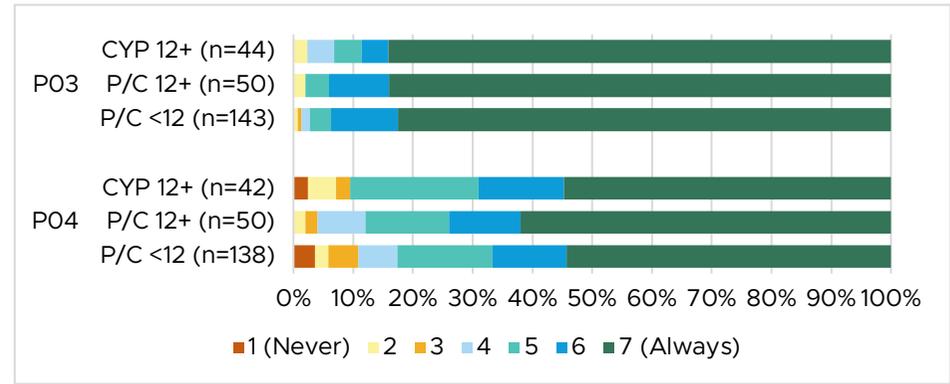
CYP: Children and Young People, P/C: Parents/Carers

Question 14 (advice on fluid intake) performed slightly better than question 15 (advice on diet), although high scores were given across the response groups for both questions.

**Section 6 Medication: Mean score of 6.34 (centre range 5.55 – 6.90)**



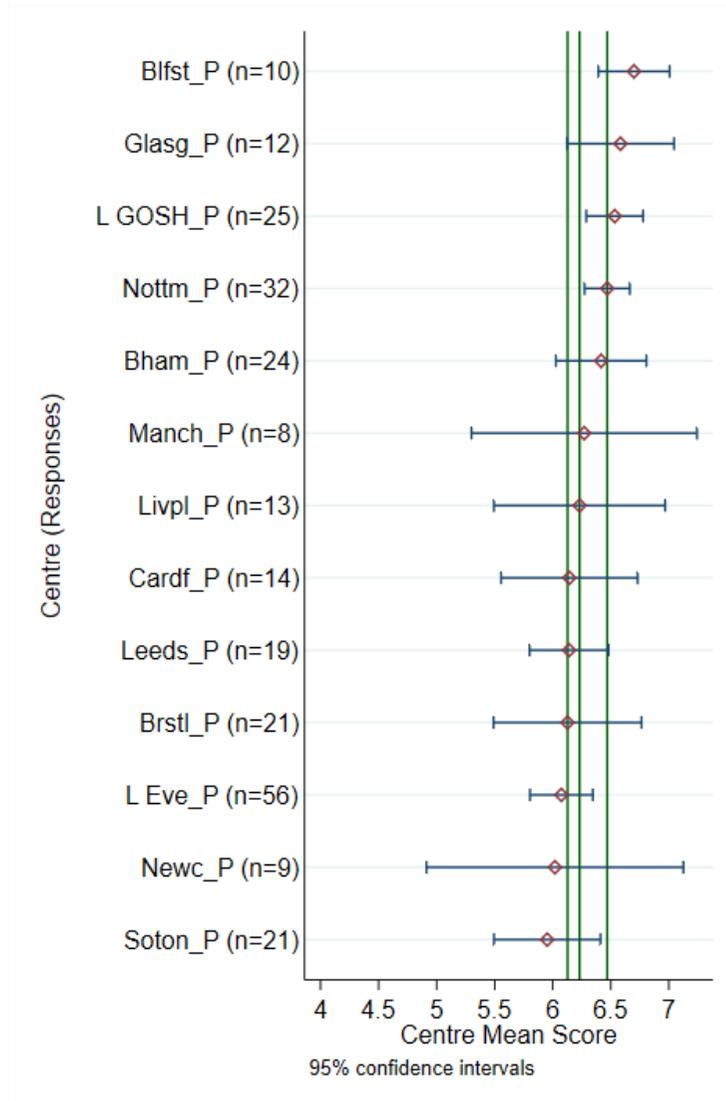
**P03.** Does the kidney team give you clear advice on your medications?  
**P04.** Getting a repeat prescription for my kidney care medicines is easy



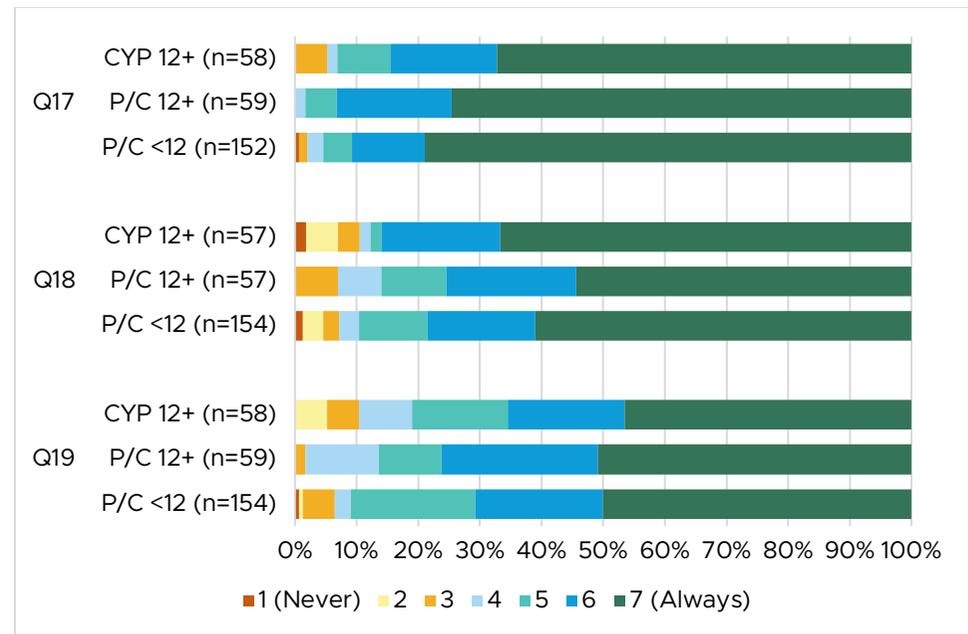
CYP: Children and Young People, P/C: Parents/Carers

Medication theme is unique to the pilot PPREM. Question P03 (medication advice) was extremely well scored. Over 90% of participants giving 5-7s, with over 80% of these being 7s. There were more lower scores given for question P04 (getting repeat prescriptions) but overall was still positive, with parents/carers of under 12s reporting this slightly less favourably than other response groups. Variation between sites was notable, with mean centre scores ranging from 6.34 to 6.90.

**Section 7 Tests: Mean score of 6.28 (centre range 5.95 – 6.70)**



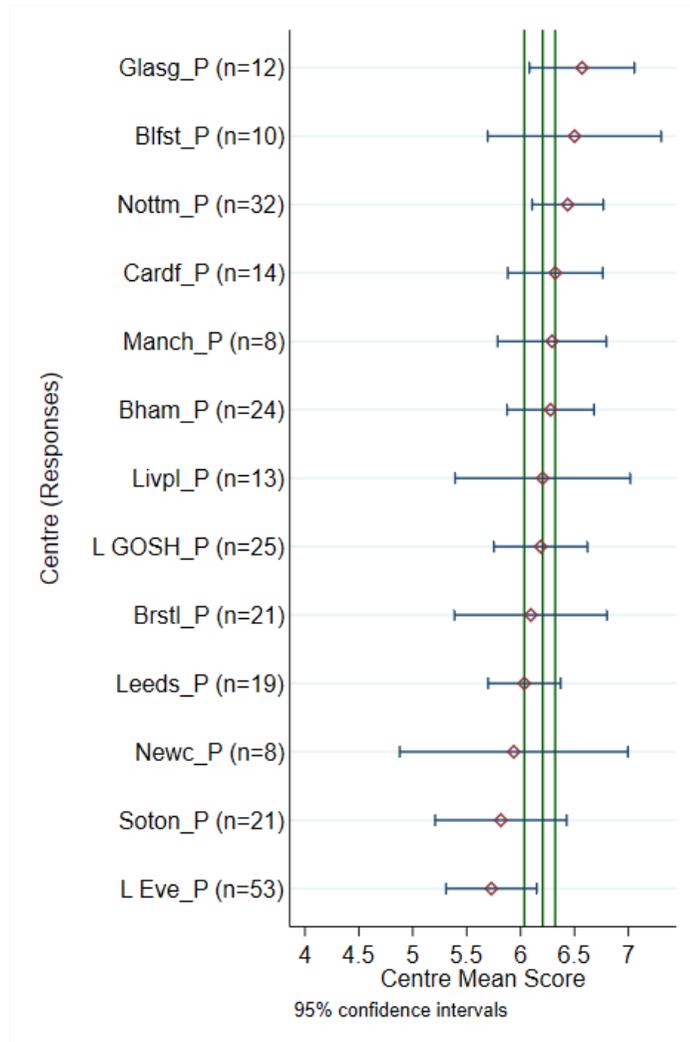
**Q17.** Do you understand the **reasons** for your tests?  
**Q18.** Do you get your test results back within an acceptable time period?  
**Q19.** Do you understand the **results** of your tests?



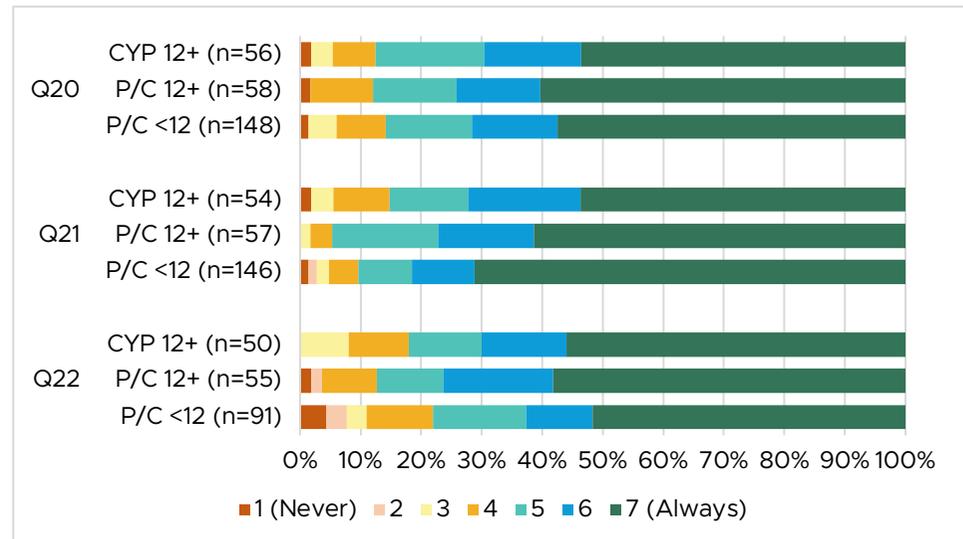
CYP: Children and Young People, P/C: Parents/Carers

Tests was another high-scoring theme, with all nearly all centres having a mean score of over 6 out of 7. Profiles across response profiles were similar for each question, with question 17 (understanding reasons for tests) the best performing question of the three.

**Section 8 Sharing Decisions About Your Care: Mean score of 6.18 (centre range 5.73 – 6.57)**



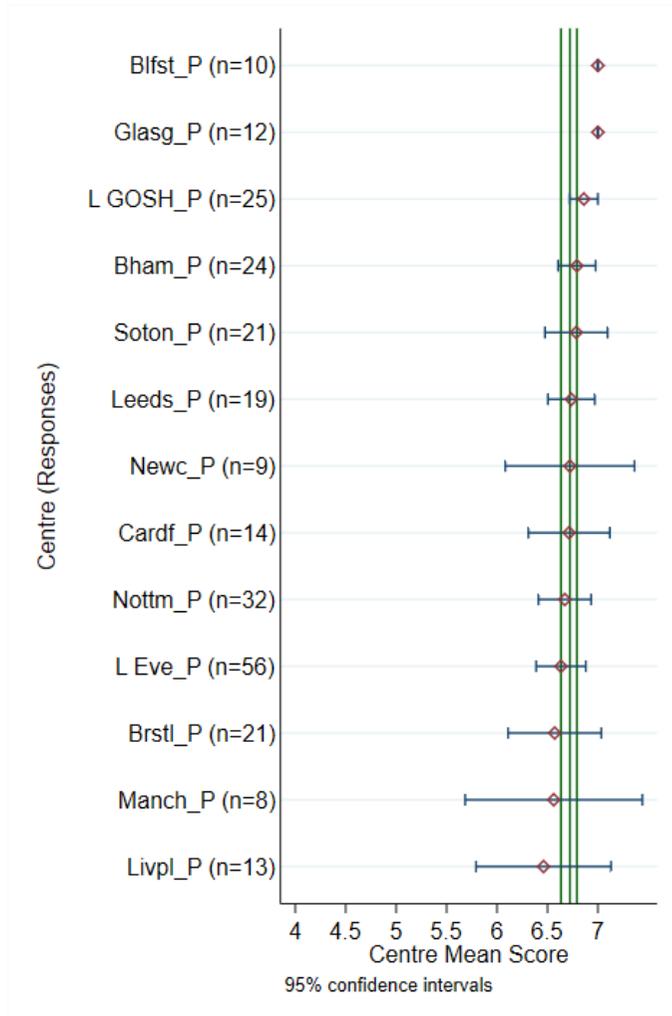
Does the kidney team:  
**Q20.** Talk with you about your treatment and life goals?  
**Q21.** Enable you to participate in decisions about your kidney care as much as you want?  
**Q22.** Talk to you about taking a more active role in managing your own kidney care?



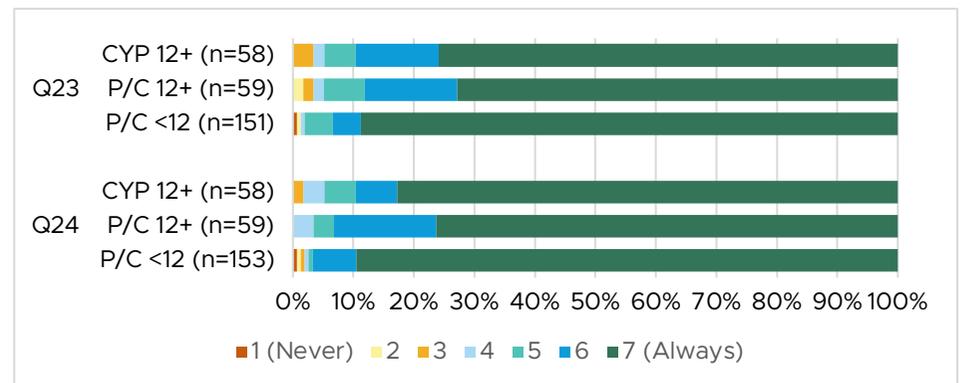
CYP: Children and Young People, P/C: Parents/Carers

Sharing Decisions theme is similar in profile across response groups, although parents/carers of 12-16-year-olds seem to rate slightly higher than other groups. There is little variation in centre scores, with centre mean scores ranging from 5.73 to 6.57 out of 7.

**Section 9 Privacy and Dignity: Mean score of 6.73 (centre range 6.46 – 7.00)**



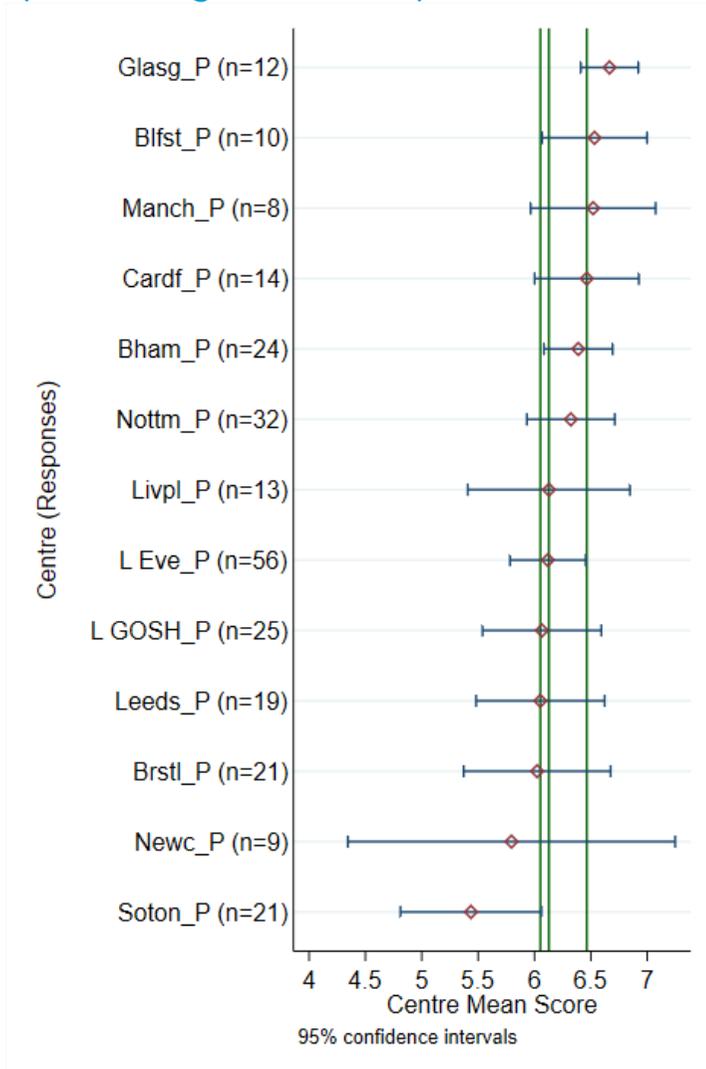
**Q23.** Are you given enough privacy when discussing your condition or treatment?  
**Q24.** Is your dignity respected during visits and clinical examinations?



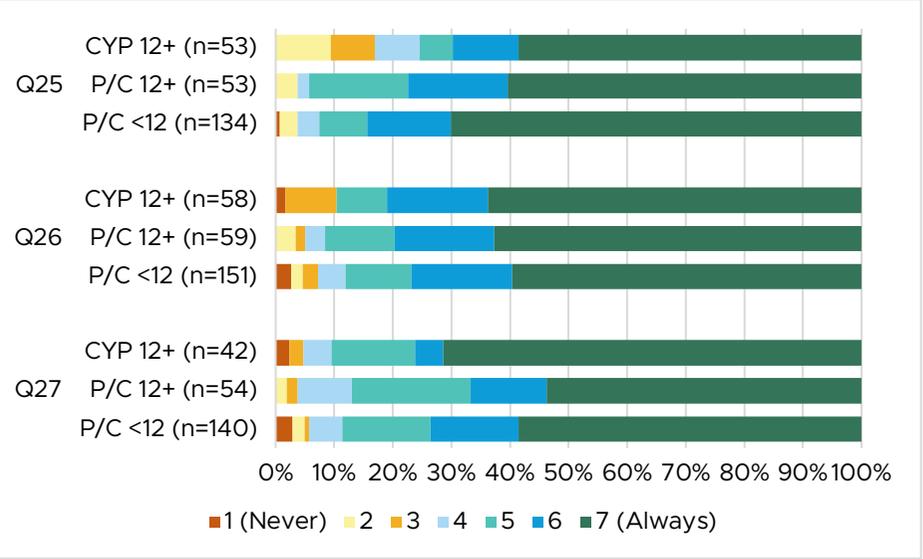
CYP: Children and Young People, P/C: Parents/Carers

Privacy and Dignity was the highest scoring theme in pilot PPREM, reflected in the high scores across all centres. Parents/carers of under 12s were the most positive, with nearly 90% of respondents giving each question 7 out of 7. This area of patient experience had the least variation across centres, all scores being within 0.54 of each other.

**Section 10 Scheduling and Planning: Mean score of 6.19 (centre range 5.44 – 6.67)**



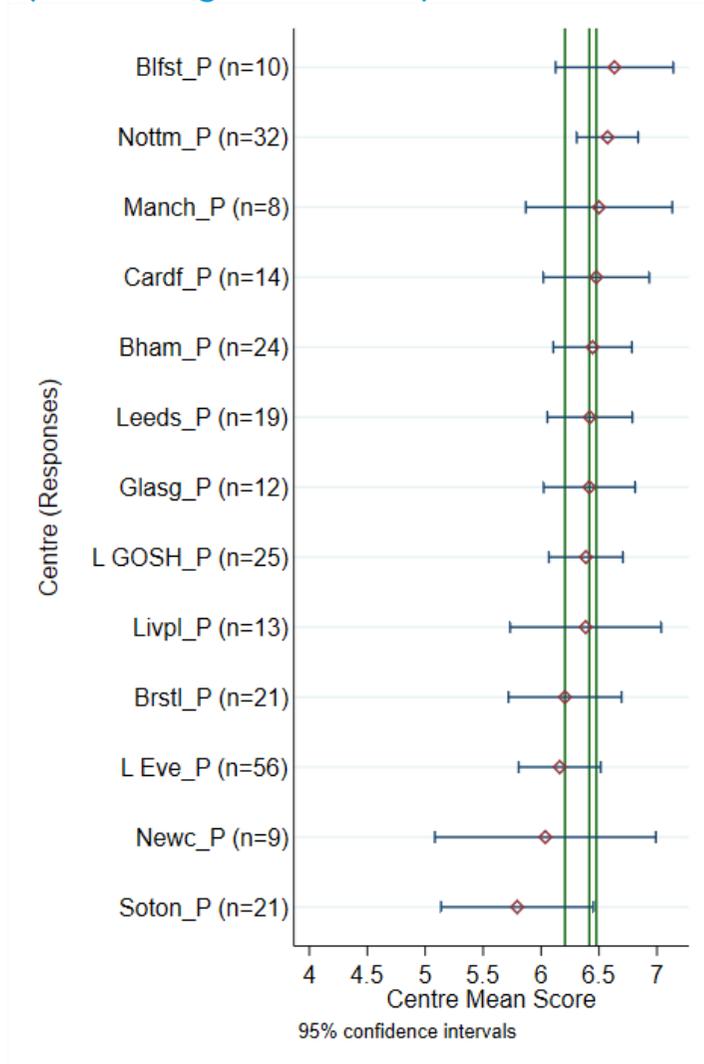
**Q25.** Can you change your appointment times if they are not suitable for you?  
**Q26.** Do you feel your time is used well at your appointments relating to your kidneys?  
*Not for those on in-centre or in-satellite haemodialysis:*  
**Q27.** Are the arrangements for your blood tests convenient for you?



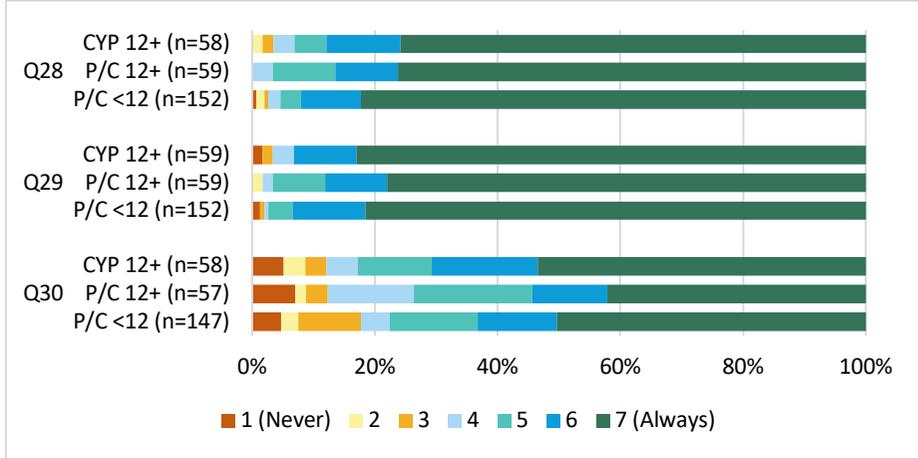
CYP: Children and Young People, P/C: Parents/Carers

Within Scheduling and Planning, question 25 (changing appointment times) showed a different response profile across groups, with CYP providing 75% positive scores (5-7) compared to both parent/carer groups at over 90%. Conversely, other questions in the theme were similar across all three groups.

**Section 11 How the Team Treats You: Mean score of 6.34 (centre range 5.79 – 6.63)**



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

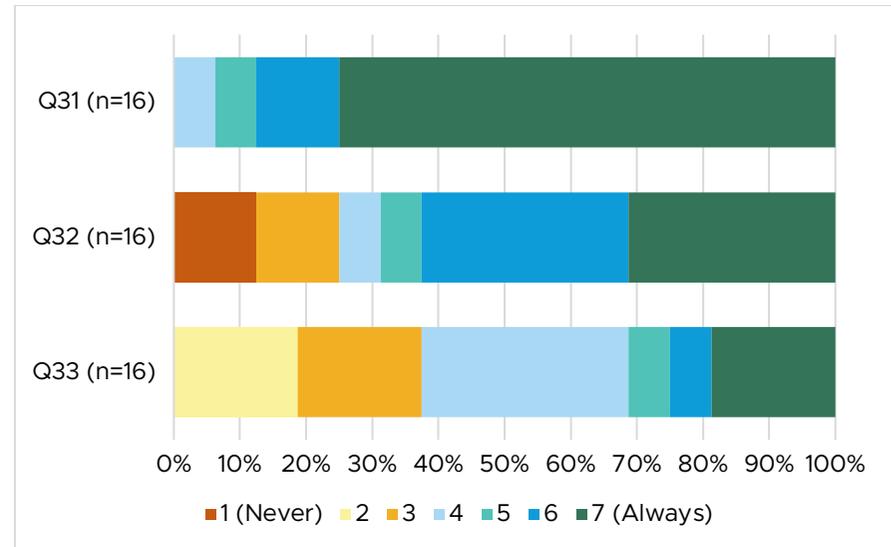
There was some variation between questions for this theme, with question 30 (asking about your feelings) performing most poorly. Once again, all three response groups provided a similar profile of scores.

**Section 12 Transport: Mean score 5.18**

Transport theme was applicable only when the CYP patient received haemodialysis at hospital and used hospital transport. Therefore, responses were provided by just 16 participants. No sites achieved the minimum 7 responses required to estimate centre scores, so the centre-level graph is not applicable.

Similarly, it is not appropriate to report response profile by group, so the total response profile is shown here.

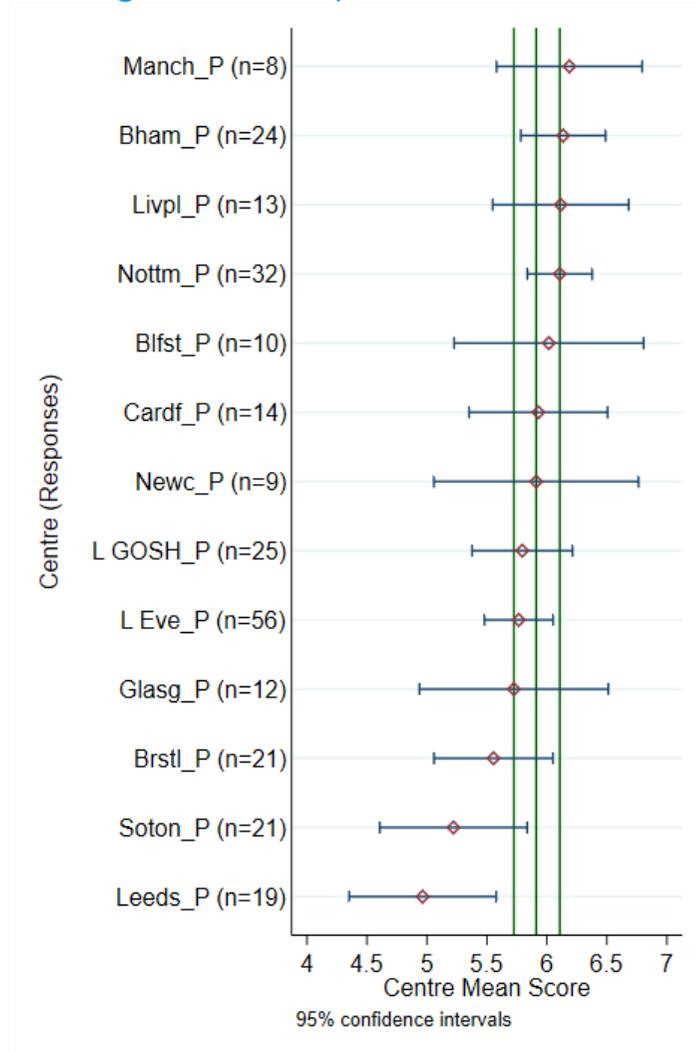
- Q31.** Is the vehicle provided suitable for you?
- Q32.** Is the time it takes to travel between your home and the Kidney unit acceptable to you?
- Q33.** Once your visit to the Kidney unit is finished and you are ready to leave, are you able to leave within less than 30 minutes?



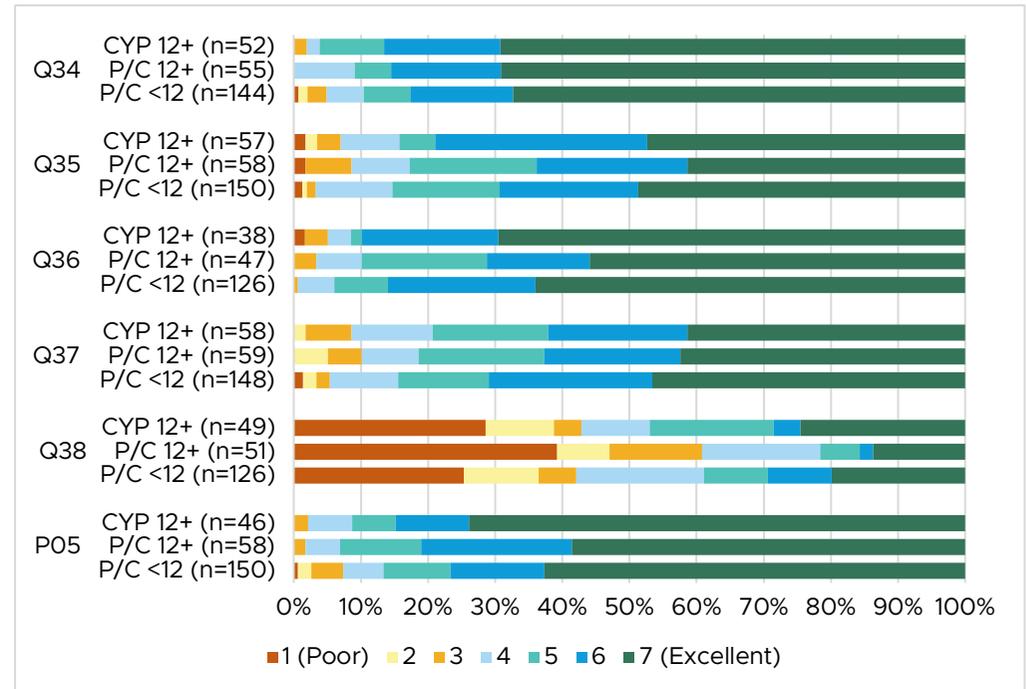
CYP: Children and Young People, P/C: Parents/Carers

Over 90% of respondents felt that the provided vehicle was suitable (question 31), but there was less positivity regarding the time to travel between home and the kidney unit (question 32), with fewer than 70% of participants giving scores of 5, 6 or 7. Question 33 (leaving within 30 minutes of being ready) was rated most negatively of the theme, just over 30% gave positive (5-7) responses.

**Section 13 Environment: Mean score of 5.80 (centre range 4.96 – 6.19)**



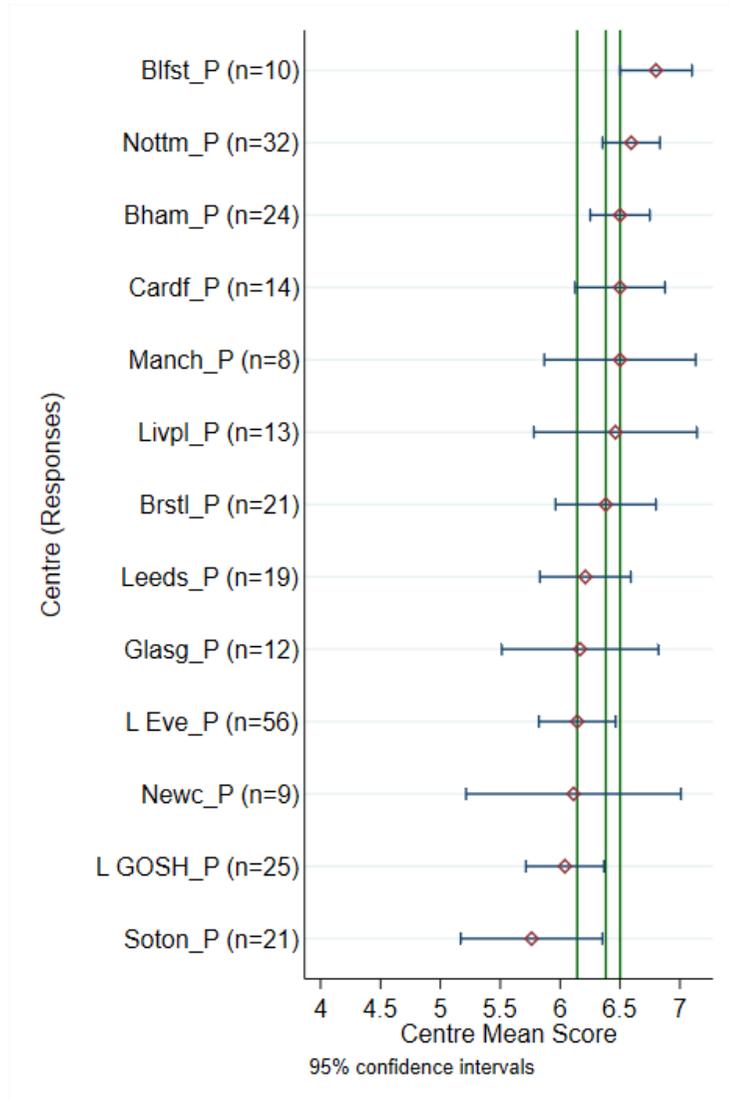
When you attend the Kidney unit, how would you grade:  
**Q34.** Accessibility (e.g., lifts, ramps, automatic doors)?  
**Q35.** Comfort? **Q36.** Cleanliness?  
**Q37.** Waiting Area? **Q38.** Parking?  
**P05.** Child-friendliness?



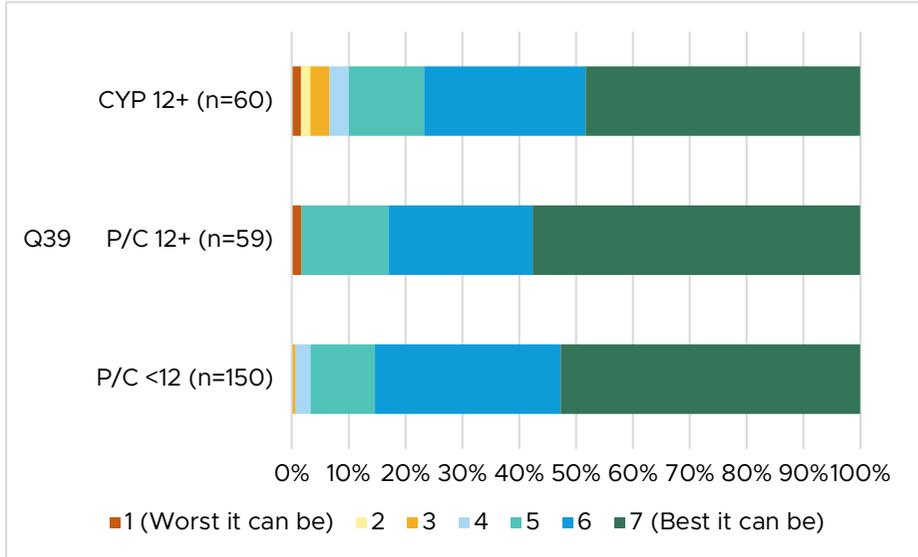
CYP: Children and Young People, P/C: Parents/Carers

Question 38 (parking) was the lowest scoring question across all three response groups, with parents/carers of over 12s the least positive. Other aspects of Environment were mostly rated positively, with little variation between response groups.

**Section 14 Overall: Mean score of 5.80  
(centre range 5.76 – 6.80)**



**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*

The Overall question was mostly responded to positively, with very few participants giving scores of 1 or 2. CYP were slightly less positive than the other response groups, although 90% gave scores of at least 5 out of 7. Centre scores were high, with little variation between them.

## APPENDICES

**Table A1: Mean and 95% Confidence intervals for each Pilot PPREM theme, by response group**

	Parents/Carers under 12 years		Parents/Carers 12 years and over		Children/Young People 12 years and over		Total	
	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)
Scale	150	6.17 (6.04, 6.30)	59	6.06 (5.84, 6.27)	58	5.96 (5.72, 6.20)	267	6.10 (6.00, 6.20)
Access	150	6.59 (6.45, 6.73)	59	6.46 (6.19, 6.73)	58	6.16 (5.84, 6.48)	267	6.47 (6.35, 6.59)
Support	145	5.91 (5.70, 6.12)	57	5.70 (5.36, 6.04)	57	5.16 (4.73, 5.60)	259	5.70 (5.53, 5.87)
Communication	150	5.72 (5.51, 5.93)	59	5.61 (5.24, 5.98)	58	5.60 (5.25, 5.95)	267	5.67 (5.51, 5.83)
Patient Information	150	6.62 (6.49, 6.76)	59	6.36 (6.05, 6.66)	58	6.34 (6.06, 6.61)	267	6.50 (6.38, 6.62)
Fluid & Diet	140	6.40 (6.22, 6.59)	57	6.46 (6.24, 6.68)	57	6.18 (5.87, 6.50)	254	6.37 (6.23, 6.50)
Medication	139	6.31 (6.15, 6.47)	50	6.45 (6.19, 6.71)	43	6.30 (5.96, 6.64)	232	6.34 (6.21, 6.47)
Tests	150	6.30 (6.15, 6.45)	59	6.30 (6.09, 6.51)	58	6.11 (5.80, 6.42)	267	6.26 (6.14, 6.37)
Sharing Decisions	147	6.11 (5.90, 6.31)	59	6.22 (5.95, 6.49)	57	6.02 (5.70, 6.33)	263	6.11 (5.97, 6.26)
Privacy & Dignity	150	6.82 (6.72, 6.92)	59	6.58 (6.37, 6.79)	58	6.59 (6.36, 6.83)	267	6.72 (6.63, 6.81)
Scheduling & Planning	150	6.22 (6.04, 6.40)	59	6.19 (5.94, 6.44)	58	6.01 (5.62, 6.39)	267	6.17 (6.03, 6.31)
How the team Treats you	150	6.36 (6.20, 6.52)	59	6.22 (5.96, 6.48)	58	6.32 (6.01, 6.62)	267	6.32 (6.20, 6.44)
Transport	3	-	3	-	9	5.11 (4.27, 5.95)	15	5.18 (4.53, 5.83)
Environment	150	5.84 (5.68, 6.01)	59	5.61 (5.32, 5.89)	58	5.79 (5.49, 6.09)	267	5.78 (5.65, 5.91)
Overall	150	6.34 (6.21, 6.47)	59	6.34 (6.07, 6.61)	59	6.02 (5.67, 6.36)	268	6.27 (6.15, 6.39)

**Table A2: Pilot PPREM Centre score summaries for each pilot PPREM theme**

Theme	Across all centres		
	Range	Mean range	Mean
Scale	0.9	5.7-6.6	6.1
Access	1.1	5.8-6.9	6.5
Support	0.8	5.4-6.1	5.7
Communication	1.5	5.0-6.5	5.8
Patient Information	0.7	6.2-6.9	6.5
Fluid & Diet	1.0	5.7-6.7	6.4
Medication	1.4	5.6-6.9	6.3
Tests	0.8	6.0-6.7	6.3
Sharing Decisions	0.8	5.7-6.6	6.2
Privacy & Dignity	0.5	6.5-7.0	6.7
Scheduling	1.2	5.4-6.7	6.2
Treats	0.8	5.8-6.6	6.3
Environment	1.2	5.0-6.2	5.8
Overall	1.0	5.8-6.8	6.3

**Table A3: Pilot PPREM Theme Scores (95% Confidence Intervals) by Centre**

Centre	Scale Score		Access		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	24	6.31 (6.04, 6.58)	24	6.89 (6.77, 7.01)	24	5.69 (5.13, 6.24)	24	5.98 (5.42, 6.55)	24	6.69 (6.37, 7.00)	23	6.63 (6.30, 6.96)	23	6.46 (6.03, 6.88)
Blfst_P	10	6.55 (6.22, 6.89)	10	6.93 (6.78, 7.08)	10	6.10 (4.77, 7.43)	10	6.49 (6.07, 6.92)	10	6.90 (6.67, 7.13)	10	6.65 (5.97, 7.33)	10	6.90 (6.67, 7.13)
Brstl_P	21	5.97 (5.45, 6.49)	21	6.30 (5.65, 6.95)	21	5.63 (4.89, 6.38)	21	5.61 (4.93, 6.28)	21	6.24 (5.52, 6.96)	21	6.29 (5.55, 7.03)	18	6.22 (5.59, 6.85)
Cardf_P	14	6.28 (5.89, 6.68)	14	6.79 (6.45, 7.12)	14	6.01 (5.18, 6.85)	14	5.97 (5.31, 6.63)	14	6.54 (6.15, 6.92)	13	6.65 (6.24, 7.07)	14	6.36 (5.83, 6.88)
Glasg_P	12	6.28 (5.92, 6.63)	12	6.78 (6.55, 7.01)	11	6.02 (5.27, 6.76)	12	5.74 (5.07, 6.40)	12	6.42 (5.80, 7.03)	11	6.27 (5.68, 6.86)	10	6.60 (6.10, 7.10)
L Eve_P	56	5.93 (5.67, 6.19)	56	6.21 (5.87, 6.56)	49	5.42 (5.00, 5.84)	56	5.31 (4.88, 5.73)	56	6.29 (5.96, 6.63)	51	6.23 (5.96, 6.49)	37	6.28 (5.89, 6.68)
L GOSH_P	25	6.09 (5.82, 6.35)	25	6.47 (6.16, 6.79)	25	5.49 (4.83, 6.15)	25	5.36 (4.85, 5.87)	25	6.54 (6.20, 6.88)	25	6.52 (6.19, 6.85)	25	6.52 (6.25, 6.79)
Leeds_P	19	5.90 (5.59, 6.22)	19	6.67 (6.42, 6.91)	19	6.01 (5.57, 6.44)	19	5.30 (4.77, 5.82)	19	6.63 (6.41, 6.86)	19	6.55 (6.22, 6.88)	19	5.55 (4.89, 6.21)
Livpl_P	13	6.17 (5.73, 6.61)	13	6.67 (6.32, 7.02)	13	5.88 (5.22, 6.55)	13	5.77 (5.23, 6.32)	13	6.77 (6.27, 7.27)	13	6.08 (5.40, 6.75)	12	5.79 (5.04, 6.54)
Manch_P	8	6.31 (5.87, 6.74)	8	6.54 (6.03, 7.06)	8	5.48 (4.28, 6.67)	8	6.09 (5.12, 7.06)	8	6.75 (6.30, 7.20)	8	6.50 (5.61, 7.39)	7	6.71 (6.26, 7.17)
Newc_P	9	5.95 (5.11, 6.80)	9	6.11 (5.07, 7.15)	9	5.35 (4.31, 6.40)	9	5.94 (4.88, 7.00)	9	6.22 (5.32, 7.13)	8	5.69 (4.33, 7.05)	8	6.13 (5.64, 6.61)
Nottm_P	32	6.39 (6.17, 6.62)	32	6.71 (6.47, 6.95)	32	6.01 (5.55, 6.46)	32	6.35 (6.00, 6.69)	32	6.70 (6.45, 6.96)	30	6.55 (6.28, 6.82)	32	6.61 (6.40, 6.82)
Soton_P	21	5.67 (5.20, 6.14)	21	5.79 (5.17, 6.41)	21	5.54 (4.92, 6.16)	21	5.02 (4.31, 5.72)	21	6.33 (5.91, 6.76)	20	5.95 (5.14, 6.76)	15	6.33 (5.86, 6.81)

Centre	Tests		Sharing Decisions		Privacy & Dignity		Scheduling		Treats		Environment		Overall	
	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	24	6.42 (6.03, 6.81)	24	6.28 (5.87, 6.68)	24	6.79 (6.61, 6.98)	24	6.39 (6.08, 6.69)	24	6.44 (6.11, 6.78)	24	6.14 (5.78, 6.49)	24	6.50 (6.25, 6.75)
Blfst_P	10	6.70 (6.39, 7.01)	10	6.50 (5.70, 7.30)	10	7.00 (7.00, 7.00)	10	6.53 (6.07, 7.00)	10	6.63 (6.13, 7.14)	10	6.02 (5.23, 6.81)	10	6.80 (6.50, 7.10)
Brstl_P	21	6.13 (5.49, 6.76)	21	6.10 (5.39, 6.80)	21	6.57 (6.11, 7.03)	21	6.02 (5.37, 6.68)	21	6.21 (5.72, 6.69)	21	5.55 (5.06, 6.05)	21	6.38 (5.96, 6.80)
Cardf_P	14	6.14 (5.55, 6.73)	14	6.32 (5.88, 6.76)	14	6.71 (6.31, 7.12)	14	6.46 (6.00, 6.93)	14	6.48 (6.02, 6.93)	14	5.93 (5.35, 6.51)	14	6.50 (6.12, 6.88)
Glasg_P	12	6.58 (6.12, 7.04)	12	6.57 (6.08, 7.06)	12	7.00 (7.00, 7.00)	12	6.67 (6.41, 6.92)	12	6.42 (6.02, 6.81)	12	5.72 (4.94, 6.51)	12	6.17 (5.51, 6.82)
L Eve_P	56	6.07 (5.80, 6.34)	53	5.73 (5.31, 6.15)	56	6.63 (6.39, 6.88)	56	6.12 (5.78, 6.46)	56	6.16 (5.81, 6.51)	56	5.77 (5.48, 6.05)	56	6.14 (5.82, 6.46)
L GOSH_P	25	6.53 (6.29, 6.78)	25	6.19 (5.75, 6.62)	25	6.86 (6.72, 7.00)	25	6.07 (5.54, 6.59)	25	6.39 (6.07, 6.71)	25	5.80 (5.38, 6.21)	25	6.04 (5.71, 6.37)
Leeds_P	19	6.14 (5.80, 6.48)	19	6.04 (5.70, 6.37)	19	6.74 (6.50, 6.97)	19	6.05 (5.48, 6.62)	19	6.42 (6.05, 6.79)	19	4.96 (4.35, 5.58)	19	6.21 (5.83, 6.59)
Livpl_P	13	6.23 (5.49, 6.97)	13	6.21 (5.39, 7.02)	13	6.46 (5.79, 7.13)	13	6.13 (5.41, 6.85)	13	6.38 (5.73, 7.04)	13	6.12 (5.55, 6.68)	13	6.46 (5.78, 7.14)
Manch_P	8	6.27 (5.30, 7.24)	8	6.29 (5.79, 6.80)	8	6.56 (5.68, 7.44)	8	6.52 (5.97, 7.08)	8	6.50 (5.87, 7.13)	8	6.19 (5.58, 6.79)	8	6.50 (5.87, 7.13)
Newc_P	9	6.02 (4.91, 7.13)	8	5.94 (4.88, 7.00)	9	6.72 (6.08, 7.36)	9	5.80 (4.34, 7.25)	9	6.04 (5.08, 6.99)	9	5.91 (5.06, 6.76)	9	6.11 (5.21, 7.01)
Nottm_P	32	6.47 (6.27, 6.66)	32	6.44 (6.11, 6.77)	32	6.67 (6.41, 6.93)	32	6.32 (5.93, 6.71)	32	6.57 (6.31, 6.84)	32	6.11 (5.84, 6.38)	32	6.59 (6.35, 6.83)
Soton_P	21	5.95 (5.49, 6.41)	21	5.82 (5.21, 6.43)	21	6.79 (6.48, 7.10)	21	5.44 (4.81, 6.06)	21	5.79 (5.14, 6.45)	21	5.22 (4.61, 5.84)	21	5.76 (5.17, 6.35)