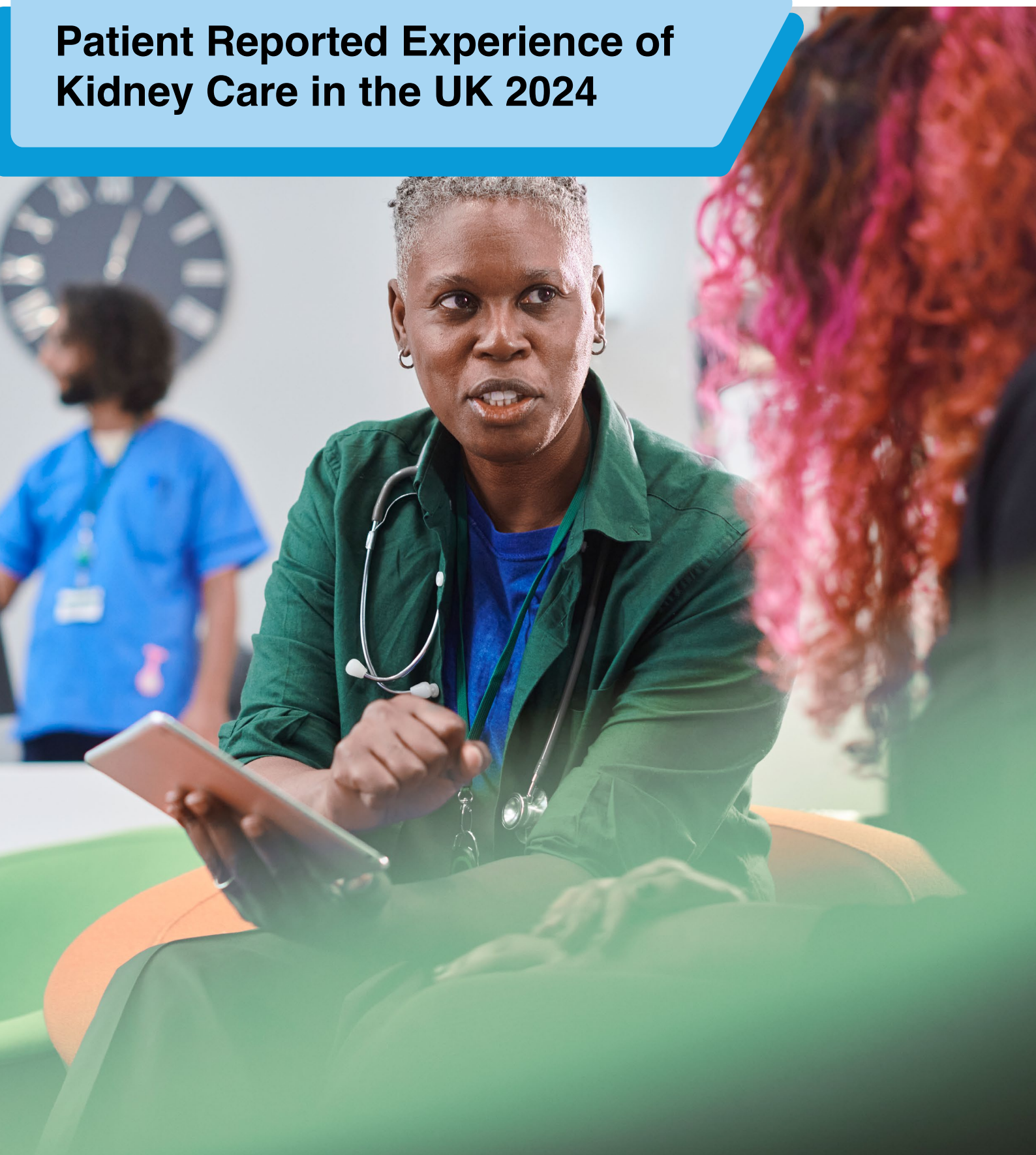


## Patient Reported Experience of Kidney Care in the UK 2024



# Contents

<b>Foreword</b>	3
<b>Acknowledgments</b>	4
<b>Statistical Glossary</b>	5
<b>Executive Summary</b>	6
<b>Pilot Paediatric PREM</b>	9
<b>Introduction</b>	12
<b>Methodology</b>	13
The Kidney PREM	13
Data collection	13
Analysis and reporting	14
<b>Results</b>	15
Chapter 1: Kidney PREM participants	15
Chapter 2: Accessing Kidney PREM	29
Chapter 3: Changes in patient experience	34
Chapter 4: Additional question results and comments about experience of care	36
Chapter 5: Kidney PREM theme results	44
Chapter 6: Kidney PREM theme results by treatment and deprivation	48
Chapter 7: Kidney PREM theme breakdown by question	53
Chapter 8: Patient experience of kidney care across the service	69

# Foreword

Living with kidney disease has a profound impact on multiple spheres of life. I know this from the generosity of patients and their families sharing lived experience in research settings. Why do we ask about experience of care specifically? Because it matters to everyday quality of life, and the efforts of healthcare professionals across the UK when planning, implementing, and evaluating care that responds to patient needs and preferences.

The Kidney PREM, now in its 9<sup>th</sup> year, is a partnership between the UK Kidney Association and Kidney Care UK. It provides a whole system approach to giving power to patient voice. It is clear that through collaborative effort, year-on-year more patients come forward to share, with a record 13,347 completions in 2024. It is essential that patients know how their perspectives make a difference, with further opportunity evident to close the feedback loop. This includes using methods of sharing that are meaningful for different patient communities. Afterall, knowing why is important to driving further motivation to take part.

This year, the Kidney PREM has deepened its effort to inform value-based care. This means care that achieves outcomes for all patients through sustainable, transparent, and equitable means. Patients were asked a new question about whether they have enough personal financial resources to meet their daily needs. I have always been encouraged by the Kidney PREM's emphasis on understanding patient circumstances from wider capture of gender, ethnicity, and language to now broader measures of deprivation. These are all factors that compromise outcomes with the Kidney PREM signposting where care can be adapted to need. The inclusion of this question has again emphasised the stark reality that individual experience of kidney care is closely related to wider social and structural disadvantage. Those who 'regularly go without' report the most negative perceptions of care. The data also highlight that disadvantage does not sit in isolation, for example, the clustering of lack of financial sufficiency with ethnicity. We know that there is more to be done to bring about purposive change, with this important data collection effort enabling targeted action.

In such a detailed report, it is important not to lose sight that overall patient experience remains favourable. Progress is also being made in areas such as perceptions of support, showing the impact of quality improvement endeavours. As the context in which healthcare teams operate becomes more complex, a sustained emphasis on partnership and co-creation is necessary to do justice to respondents. Together, we can work to address the ever-evolving issues that are experienced differentially by those navigating kidney care in the UK.



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# Acknowledgements

Kidney Care UK and the UK Kidney Association would like to thank the following people, without whom Kidney PREM 2024 would not have been possible:

- People living with kidney disease who completed Kidney PREM,
- The kidney care workforce and volunteers in all UK kidney centres, especially the Kidney PREM champions,
- The Kidney PREM working group, strategy group and equity group members,
- Transforming Participation in Chronic Kidney Disease Measurement Workstream members who developed the Kidney PREM and worked with the University of Hertfordshire on its validation,
- UK Kidney Association Patient Council,
- 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.

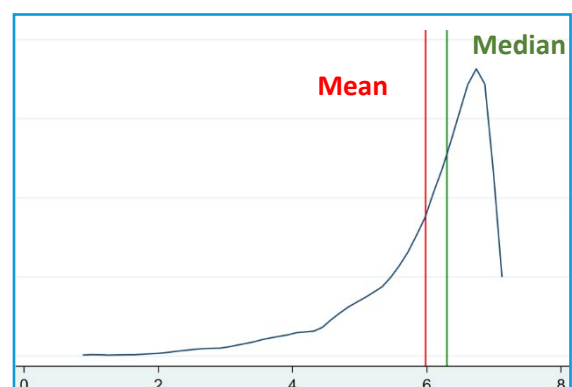
**Mean:** The *mean* centre score is calculated across patient scores by adding them together and dividing by the number of scores used, giving the mathematical average value.

**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.

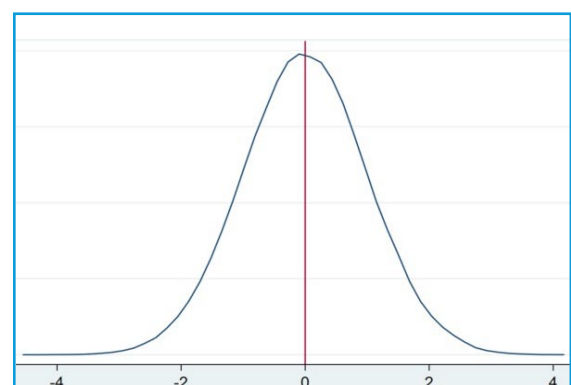
**Median:** If patient scores for a particular centre were listed in order, the *median* is the middle value separating the high scoring (top half) from the low scoring (bottom half).

**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

In its eighth year, 13,347 people living with kidney disease took part in the 2024 Kidney PREM. This was an increase of 1,700 from 2023, with participation increasing in most regions.

## Kidney PREM participants

Age and gender profiles were similar to those of previous years, but there was an increase in responses from Asian individuals at 11.4%, compared to around 9% in previous years.

Haemodialysis was the most common treatment, selected by 64.4% of Kidney PREM respondents, with 57.3% of those receiving their haemodialysis in satellite centres.

Of the respondents who had received care for their kidney disease for at least a year, 36.0% completed Kidney PREM in 2023, with some regional variation from 30.5% (Scotland) to 43.8% (South East).

Kidney PREM participants were invited to provide the first half of their postcodes so that the deprivation index for their residence could be determined. Of the three quarters (74.2%) of individuals willing to give this information, nearly half were found to reside in the two most deprived quintiles.

In addition, and new for 2024, respondents were asked about the sufficiency of their income to meet their daily needs. This was found to be more acceptable to participants than giving postcode information with just 7.2% declining to provide an answer. Over 60% stated that they had “enough” or “more than enough” income for their needs, with some small regional variation.

Unlike postcode-based deprivation, clear differences in participant characteristics were seen according to income sufficiency. This generally increased with age and was highest amongst White participants. Individuals receiving haemodialysis selected the two least sufficient income categories most often, regardless of the location of their treatment.

## Accessing Kidney PREM

A smaller proportion of individuals received help to complete the survey in 2024, 27.5% compared to 31.1% in 2023, with connection to haemodialysis remaining the most common reason for help.

All centres could offer potential participants paper surveys, following the successful pilot of paper data collection in 2023. Completed forms were input online by volunteers at centres, with a total of 11.7% Kidney PREM returns completed on paper. Two thirds of centres used paper surveys, with usage varying from 0.3% to 69.4%.

## Kidney PREM theme results

### Highest and lowest scoring themes

- Top scoring themes were *Privacy & Dignity* (6.40), *Patient Information* (6.40) and *Access to the Kidney Team* (6.38).
- *Overall Experience* remains high (6.29).
- Lowest scoring themes were *Sharing Decisions* (5.64) and *Transport* (5.54).

### Changes to national theme scores

- *How the team Treats You* (6.20) and *Tests* (6.16) reversed places in theme rankings.
- *Needling* was the only theme to reduce in score to 5.82.
- *Support* (also 5.82) saw the largest increase from 2023 scores.

### Theme scores by treatment groups

- Although four out of six treatment groups had the same top-scoring theme, *Privacy & Dignity*, each modality had a unique poorest theme.
- Those not receiving kidney replacement therapy reported the poorest *Fluid and Diet* experiences (5.34).
- Satellite haemodialysis participants reported an improved experience across most themes.
- In stark contrast, those on haemodialysis in main centres reported poorer experiences across most themes of care.

### Theme scores by income sufficiency

- There were substantial differences in scores according to the level of income sufficiency reported across all themes of care. Those who “regularly go without” reported the lowest scores in all themes whereas those with “enough” or “more than enough” income reported the most positive experience in all areas.
- The themes with the largest differences by income sufficiency were: *Sharing Decisions* (1.25), *Communication* (1.09) and *Tests* (1.09).

### Highest and lowest scoring questions

- Questions with the highest proportion of 5-7 scores were: *shown a caring attitude* (*How the Team Treats You*, Q29), *unit cleanliness* (*Environment*, Q36) and *dignity during visits* (*Privacy & Dignity*, Q24).
- Questions with the most use of 1-3 scores were: *being ready to leave within 30 minutes* (*Transport*, Q33), *parking* (*Environment*, Q38), *accessing patient support groups* (*Support*, Q6) and *communication between kidney team and non-healthcare services* (*Communication*, Q11).

## Changes in patient experience

Most Kidney PREM participants (61.6%) reported “no change” in their experience of care, though there was some variation by treatment from 54.3% (satellite haemodialysis) to 70.1% (those not receiving kidney replacement therapy). Just 9.5% of respondents reported that their care was “much better” than in the previous year, a large decrease from the 20.5% in 2023.

## Additional questions

Around a third of participants were diagnosed with diabetes. Of those, 72.7% have access to a diabetes specialist, with those on haemodialysis in satellites or at home the most likely to have access (78.9% and 79.4% respectively).

Individuals who have medication delivered or obtained it in hospitals generally reported more positive medication experiences, which contrasted with those who did not know their provider. A total of 16.6% of respondents said they had received feedback on results of Kidney PREM 2023; encouragingly this was an increase from 11.9% the previous year, although still with some regional variation.

The Kidney PREM continues to be an effective vehicle to better understand kidney patients' experiences of care. The digital format is improving the speed and accuracy of reporting and the sustainability of the programme. Kidney professionals in partnership with people living with kidney disease have an opportunity to use the results described here, alongside the free-text comments, to make impactful improvements to kidney care experience.

# Pilot Paediatric PREM

In 2024, the pilot Paediatric PREM (pPPREM) was held alongside the adult Kidney PREM for the third consecutive year. Questions remained unchanged from its inception, using items based on those in the validated Kidney PREM. Children and young people (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 (0 to 16 years) could participate, reporting their own experiences of their CYP's care.

## Response numbers and patient characteristics

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

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

Around half of responses (50.1%) related to CYP with chronic kidney disease who were not receiving kidney replacement therapy and 30.9% were about for those with functioning kidney transplants. Just 41 responses (11.3%) were for CYP receiving haemodialysis, of which six received treatment at home.

## Future plans

A paediatric report will be compiled giving the 13 UK centres more detailed information about the responses to help each centre consider how we can make improvements to our services. The development of a validated paediatric PREM is in progress and we are intending to complete this by the end of 2025.

## Notes for interpretation

As the UK Renal Registry (UKRR) primarily collects data about individuals who are receiving kidney replacement therapy, demographic comparisons cannot easily be



made between pPPREM respondents and the UK paediatric kidney population given the large proportion who attend clinic for monitoring. Caution is also advised when considering demographic representation as individuals may be double counted if both the 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.

## Key findings from the pilot Paediatric PREM

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

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

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

*Privacy & Dignity* remained the highest reported theme by all response groups. CYP reported an improvement of +0.33 (from 6.29 to 6.62), while parents/carers of under 12s reported a reduction of -0.12 (6.72 to 6.84).

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

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

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

Total pPPREM scale scores (calculated across the entire survey) increased for CYP by +0.19, meaning that all three response groups reported similar total experiences of care for the first time: 6.13 for parents/carers of under 12s, 6.14 for parents/carers of over 12s and 6.11 for CYP.

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

# Introduction

The Kidney Patient Reported Experience Measure (Kidney PREM) was developed in 2016 by an expert group consisting of clinicians, researchers and patients, with the validated measure in use since 2017<sup>1</sup>. This report marks the eighth year that the UK Kidney Association and Kidney Care UK have facilitated the Kidney PREM, showing the continued commitment to capturing and improving the experience of care of those living with kidney disease in the UK.

The Kidney PREM allows individuals treated at kidney centres in the UK to provide information across thirteen themes of care, such as *Communication* and *Access to the Kidney Team*. In 2024, the survey was mostly conducted online<sup>2</sup>, however centres were able to offer paper surveys which were printed locally and input online by volunteers where digital completion was not deemed possible. Shifting the central collection approach to digital has increased the quality of data collected by reducing the amount of missing information, improved the timeliness in issuing results to centres, and has provided all participants with the opportunity to add written comments.

In addition to this report, extra Kidney PREM results and findings are available for centres, including:

- Theme results for each centre by age, ethnicity, and treatment modality,
- Report appendices referred to throughout this report,
- Question-level results for each centre (and their satellite units) via the Kidney PREM portal,
- A full report detailing findings from the free text comments,
- The full Kidney PREM survey,
- A technical report describing the methodology,
- Previous years' Kidney PREM results.

All additional results can be accessed through the UK Kidney Association website:

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

<sup>1</sup> Measuring patients' experience with renal services in the UK: development and validation of the Kidney PREM, Nephrology Dialysis Transplantation. Hawkins J, Wellsted D, Corps C, Fluck R, Gair R, Hall N, Busby A, Rider B, Farrington K, Sharma S, van der Veer S. <https://doi.org/10.1093/ndt/gfac030>

<sup>2</sup> Annual Kidney Patient Reported Experience Measures survey goes digital, Journal of Kidney Care. Slevin J, Elson, K

# Methodology

## The Kidney PREM

Validated in 2017, the Kidney PREM contains 39 questions encompassing 13 themes of patient care and overall experience. Respondents score their experience of kidney care from worst (1) to best (7), generally on a scale of 'Never' to 'Always'. There is a free text question at the end of the Kidney PREM, where individuals can comment on any aspect of their experience of kidney care. Participant characteristics are collected (age, gender, ethnicity) along with treating centre. Treatment details are captured, including participation in shared care if receiving in centre haemodialysis, reason for attending clinic if not receiving kidney replacement therapy (KRT) and location of haemodialysis. In addition, participants are asked about the type and nature of any help received to complete the survey, and use of Patients Know Best to support their care. Introduced in 2022, participants are asked to provide a partial postcode for their home address, and to disclose whether English was their first language. Individuals could provide their primary language using a free text box, where appropriate. An additional question on income sufficiency was introduced in Kidney PREM 2024 as a proxy measure for deprivation at an individual level, based on participant perception rather than upon the location of the participant's home address.

Treating centres were selected using a drop-down list, filtered by country and region, or by typing into a free text box for review by the analysis team. A question relating to changes in experience of care during COVID-19 was introduced in 2020 and has since been repeated annually. It's scope was widened in 2022 to capture any changes to experiences of care over the previous 12 months.

A small number of additional questions were asked at the end of Kidney PREM 2024, concerning specific topics. These were: participants' access to specialist diabetes care, access to medication, and whether participants had received any feedback about the previous year's Kidney PREM findings.

In addition to English, Kidney PREM was available in Welsh, Urdu and Gujarati.

## Data collection

Online access to the Kidney PREM in 2024 lasted eight weeks, from 16<sup>th</sup> September until 11<sup>th</sup> November. Links to the survey were available on both the UK Kidney Association and Kidney Care UK websites.

Promotional materials including posters were distributed to centres in August 2024. Some centres sent the Kidney PREM link to patients via text message or email. Response

numbers were monitored throughout the collection period, with centres given weekly updates. The survey was also promoted across Kidney Care UK and UK Kidney Association social media platforms, in addition to the Kidney Care UK e-newsletter.

In response to concerns around digital exclusion, centres were this year able to request a digital version of the paper survey to print locally if required. Data collected using these paper versions were manually input by volunteers at centres into a bespoke online data capture system. Barriers to online completion were explored using an extra question about reasons for paper rather than digital completion.

## Analysis and reporting

This report presents results from 2024, with comparisons to the previous two years. Reports, data and other results from earlier years are available online<sup>3</sup>. Responses to questions were used to calculate scores for each theme, as well as the Kidney PREM scale score across all themes (questions 1-38). For further detail, including data processing, please refer to the Kidney PREM Technical Report online.

Throughout this report, the total used to estimate individual statistics may vary, since not all questions were answered by all participants. In cases where estimation of a group mean is based on fewer than seven responses, the data is withheld to preserve anonymity. Individuals whose treating centre could not be identified were excluded from centre scores. People with chronic kidney disease (CKD) who are not receiving kidney replacement therapy (KRT) are referred to as CKD (non-KRT) for the purpose of this report.

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<sup>3</sup> <https://ukkidney.org/kidney-patient-reported-experience-measure>



# Results

## Chapter 1: Kidney PREM participants

### Regional profile

Kidney PREM 2024 saw a total of 13,347 responses received, an increase of 1,700 from the previous year and the highest number of returns since taking a “digital first” approach to data collection. Most regions saw an increase in participation, with the Midlands increasing responses by 46.8%, an additional 1,782 responses from 2023, and Northern Ireland increasing by 40.6%, an additional 97 responses (Table 1.1). Just two regions, North West and Wales, saw a decrease in returns. Although the total number of people living in the UK with kidney disease is unknown, the UK Renal Registry<sup>4</sup> collects data from kidney centres about those on kidney replacement therapy (KRT). When considering Kidney PREM responses as a proportion of the KRT, participation ranged from 8.2% in Scotland to 30.0% in the North East & North Cumbria. Nearly a quarter of returns were from participants at London Kidney centres, reflecting

Table 1.1: Kidney PREM 2024 responses by region (column percentages)

	Response 2024		Responses 2023	Change from 2023		% of 2022 KRT Population <sup>5</sup>
	N	% of returns		N	%	
<b>England</b>						
East of England	901	6.8%	744	+157	21.1%	18.2%
London	3,202	24.0%	2,568	+634	24.7%	20.8%
Midlands	2,616	19.6%	1,782	+834	46.8%	22.5%
North East & N Cumbria	921	6.9%	751	+170	22.6%	30.0%
North West	723	5.4%	798	-75	-9.4%	10.9%
South East	1,636	12.3%	1,420	+216	15.2%	22.3%
South West <sup>6</sup>	1,218	9.1%	1,211	+7	0.6%	24.3%
Yorkshire & Humber	723	5.4%	631	+92	14.6%	12.0%
<b>England Total<sup>7</sup></b>	<b>11,950</b>	<b>89.5%</b>	<b>10,265</b>	<b>+1,685</b>	<b>16.4%</b>	<b>19.9%</b>
<b>Northern Ireland</b>						
<b>Northern Ireland Total</b>	<b>336</b>	<b>2.5%</b>	<b>239</b>	<b>+97</b>	<b>40.6%</b>	<b>16.3%</b>
<b>Scotland</b>						
<b>Scotland Total</b>	<b>450</b>	<b>3.4%</b>	<b>382</b>	<b>+68</b>	<b>17.8%</b>	<b>8.2%</b>
<b>Wales</b>						
<b>Wales Total</b>	<b>611</b>	<b>4.6%</b>	<b>760</b>	<b>-149</b>	<b>-19.6%</b>	<b>18.3%</b>
<b>UK Total</b>	<b>13,347</b>	<b>-</b>	<b>11,647</b>	<b>+1,700</b>	<b>14.6%</b>	<b>18.8%</b>

their larger population size. Changes to centre selection in the Kidney PREM survey resulted in just ten cases where the centre could not be identified after reviewing the free text entries, compared to 407 in 2023. Response numbers for each centre, how they differ from 2023 and the proportion of the KRT population are shown in Appendix A.

<sup>4</sup> <https://www.ukkidney.org/about-us/who-we-are/uk-renal-registry>

<sup>5</sup> Denominator data from the UK Renal Registry are available for those receiving KRT only, although Kidney PREM returns include people with CKD not receiving KRT, so percentages are not directly comparable to the whole CKD population.

<sup>6</sup> KRT population figure for Exeter unavailable for 2022. 2020 data used instead.

<sup>7</sup> England total includes 10 respondents who gave their country of treatment but not their centre.

## Participant characteristics

### Age

In 2024, the age profile of Kidney PREM participants has remained similar to recent years, with 46.0% aged 56-74 years (Table 1.2). The over 75s remain well-represented at 23.7%, although this age group accounted for just 15.7% of the KRT population in 2022. Conversely, there remains a smaller proportion of those aged 31-55 years (26.6%) than expected based on UKRR data (35.4%).

Age by treatment modality is available in Appendix B. As in 2023, there were no respondents aged 85 years and over receiving haemodialysis at home, and just six who were in this age group and with a functioning kidney transplant. Most proportions remained at similar levels compared to 2023, although of those not receiving KRT, the proportion of  $\geq 85$ s increased from 3.6% to 4.5%. Both home haemodialysis and transplant had higher proportions of those aged 41-55 years, at 28.9% and 28.3% respectively, than when considering Kidney PREM respondents as a whole (19.8%).

### Gender

Gender has remained largely unchanged in Kidney PREM participants over recent years, at around 58% male. There has been an increase in the proportion of those who would rather not provide their gender; 1.5% compared to 0.7%. This could be a feature of an increase in paper survey completion, since volunteers inputting were unable to skip the question if a response was not provided, or because individuals were reluctant to give their gender on paper due to the perceived reduction in confidentiality.

### Ethnicity

In previous Kidney PREM collections, Asian individuals have been underrepresented in Kidney PREM, usually around 9% compared to the UKRR's figures of 14.5%. However, in 2024, the proportion of participants of an Asian heritage increased to 11.4%.

As in previous years, ethnicity information for Kidney PREM participants receiving KRT at each centre is displayed in Appendix C, alongside figures reported from the UKRR.

Table 1.2: Respondent characteristics for Kidney PREM in 2024, 2023 and 2022 (column percentages)

	Kidney PREM 2024	Kidney PREM 2023	Kidney PREM 2022	UK KRT Patients as of end of 2022
<b>Age (years)</b>				
≤30	493 (3.7%)	447 (3.8%)	363 (3.4%)	4.7%
31-55	3,548 (26.6%)	3,200 (27.5%)	2,731 (25.6%)	35.4%
56-74	6,143 (46.0%)	5,329 (45.8%)	4,895 (45.9%)	44.3%
≥75	3,163 (23.7%)	2,671 (22.9%)	2,680 (25.1%)	15.7%
Missing	-	-	394	-
<b>Gender</b>				
Female	5,394 (40.4%)	4,743 (40.7%)	4,328 (40.3%)	38.7%
Male	7,713 (57.8%)	6,793 (58.3%)	6,346 (59.1%)	61.3%
Non-binary/other	35 (0.3%)	27 (0.2%)	11 (0.1%)	-
Rather not say	205 (1.5%)	84 (0.7%)	59 (0.5%)	-
Missing	-	-	319	-
<b>Ethnicity</b>				
<b>Asian Total</b>	<b>1,516 (11.4%)</b>	<b>1,110 (9.5%)</b>	<b>1,008 (9.3%)</b>	<b>14.5%</b>
Indian	674 (5.0%)	479 (4.1%)	462 (4.2%)	
Pakistani	358 (2.7%)	289 (2.5%)	231 (2.1%)	
Bangladeshi	139 (1.0%)	134 (1.2%)	85 (0.8%)	
Chinese	66 (0.5%)	33 (0.3%)	39 (0.4%)	
Any other Asian background	277 (2.1%)	173 (1.5%)	190 (1.7%)	
<b>Black Total</b>	<b>1,148 (8.6%)</b>	<b>939 (8.1%)</b>	<b>903 (8.4%)</b>	<b>9.0%</b>
Caribbean	439 (3.3%)	356 (3.1%)	322 (3.0%)	
African	575 (4.3%)	477 (4.1%)	462 (4.2%)	
Any other Black background	134 (1.0%)	106 (0.9%)	119 (1.1%)	
<b>Mixed or multiple Total</b>	<b>163 (1.2%)</b>	<b>146 (1.3%)</b>	<b>154 (1.4%)</b>	<b>1.5%</b>
White & Black Caribbean	33 (0.2%)	32 (0.3%)	46 (0.4%)	
White & Black African	20 (0.1%)	17 (0.1%)	27 (0.2%)	
White & Asian	37 (0.3%)	32 (0.3%)	33 (0.3%)	
Any other Mixed background	73 (0.5%)	65 (0.6%)	48 (0.4%)	
<b>White Total</b>	<b>10,003 (74.9%)</b>	<b>9,079 (78.0%)</b>	<b>8,579 (79.6%)</b>	<b>73.1%</b>
English, Welsh, Scottish, Northern Irish or British	9,463 (70.9%)	8,580 (73.7%)	8,142 (74.6%)	
Irish	177 (1.3%)	164 (1.4%)	153 (1.4%)	
Gypsy/Irish Traveller/Roma	11 (0.1%)	13 (0.1%)	14 (0.1%)	
Any other white background	351 (2.6%)	320 (2.7%)	269 (2.5%)	
<b>Other ethnic groups Total</b>	<b>229 (1.7%)</b>	<b>169 (1.5%)</b>	<b>269 (2.5%)</b>	<b>1.9%</b>
Arab	38 (0.3%)	31 (0.3%)	27 (0.2%)	
Any other ethnic group	191 (1.4%)	138 (1.2%)	113 (1.0%)	
<b>Rather not say</b>	<b>288 (2.2%)</b>	<b>204 (1.8%)</b>	<b>127 (1.2%)</b>	
Missing	-	-	152	
<b>Total</b>	<b>13,347</b>	<b>11,647</b>	<b>11,063</b>	

## Participant treatment modalities

Haemodialysis is the most common treatment of those completing Kidney PREM, the proportion increasing further this year to 66.1% from 64.4% in 2023 and 61.1% in 2022, (Table 1.3). Conversely, the proportion of respondents with a kidney transplant fell from 15.9% to 13.4%. Although total Kidney PREM responses increased in 2024, fewer people with transplants took part, from 1,849 to 1,786.

Table 1.3: Treatment modality for Kidney PREM participants in 2024, 2023 and 2022 (column percentages)

	Kidney PREM 2024	Kidney PREM 2023	Kidney PREM 2022	UK KRT Patients at end of 2022
Transplant	1,786 (13.4%)	1,849 (15.9%)	1,780 (16.8%)	56.3%
In-centre/satellite haemodialysis	8,599 (64.4%)	7,292 (62.6%)	6,250 (59.1%)	36.4%
Home haemodialysis	228 (1.7%)	208 (1.8%)	198 (1.9%)	2.0%
Peritoneal dialysis	635 (4.8%)	620 (5.3%)	725 (6.9%)	5.3%
Chronic kidney disease (non-KRT)	2,099 (15.7%)	1,678 (14.4%)	1,605 (15.2%)	-
Missing Treatment/HD location	-	-	505	-
<b>Total</b>	<b>13,347</b>	<b>11,647</b>	<b>11,063</b>	

*KRT: kidney replacement therapy*

The proportion of people who participated in Kidney PREM receiving each KRT type by centre and compared with aggregate national data is shown in Appendix D. UKRR records show that there were nearly 40,000 people living with kidney transplants in the UK at the end of 2022, of which 4.5% have participated in Kidney PREM. Of the approximately 26,000 individuals receiving haemodialysis in centres or satellite units, 34.2% completed Kidney PREM in 2024.

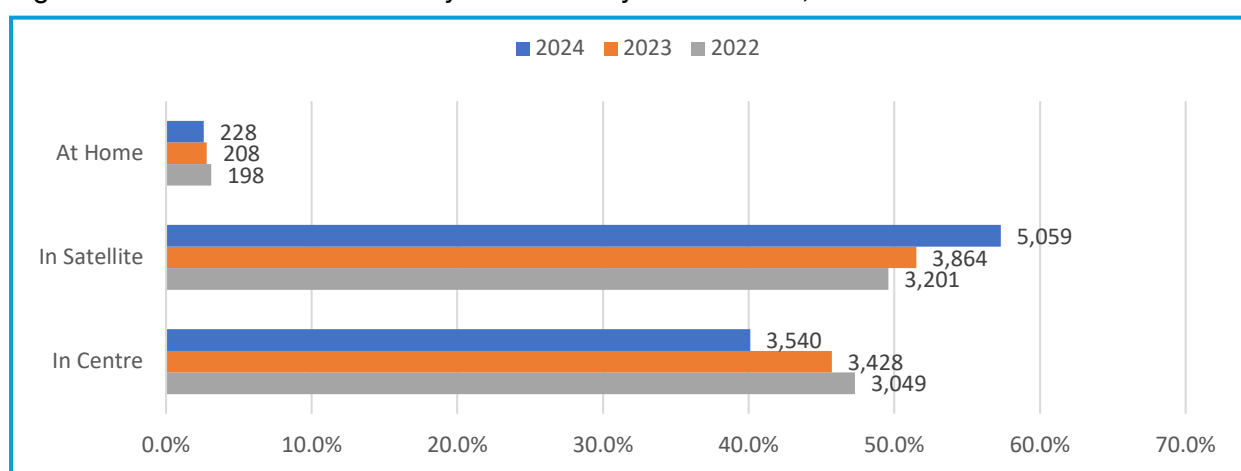
A total of 11,248 Kidney PREM participants were receiving KRT, equivalent to 15.9% of the UKRR recorded KRT population in 2022. This is slightly down from 16.2% in the previous year's Kidney PREM.

## Participants receiving haemodialysis

### *Haemodialysis location*

A total of 8,827 participants reported receiving haemodialysis, of which home haemodialysis was reported by just 2.6% despite accounting for 5.3% of the total UK haemodialysis population (Figure 1.1). The proportion of those receiving haemodialysis doing so in centres decreased to 40.1% from 45.7% in 2023, although the number was similar (3,428 in 2023, 3,540 in 2024). This is because of the large increase in responses from people having haemodialysis in satellites, an additional 1,195.

Figure 1.1: Location of haemodialysis for Kidney PREM 2024, 2023 and 2022



### *Participation in shared care for individuals receiving haemodialysis*

As in previous years, individuals receiving haemodialysis in a centre or unit were asked whether they participated in any aspects of their haemodialysis care. Of the 8,599 on haemodialysis at a center or unit, 30.2% reported participating in shared care, with a further 18.6% who were invited but declined to participate (Table 1.4). Although shared care participation had increased to 35.8% in 2023, the proportion returned to similar levels as in 2022. Participation increased slightly amongst those aged 30 years and under but reduced across all other age groups and for all ethnic groups. Those who chose not to provide their ethnicity had the highest proportion reporting participation in shared care at 36.1%. The proportion participating in satellites remained higher than in hospital dialysis (33.1% vs 26.0%), but this difference has significantly reduced from 2023 (satellites 41.8% vs hospital 29.1%). It remained the case that individuals aged 75 years and over participated least often (25.4%) and most often reported that they were not invited (36.0% compared to 24.0% of those aged 30 years and under).



Table 1.4: Participation in shared care by those receiving haemodialysis (row percentages)

	N	Participating	Declined	Not Invited	Don't Know
<b>Age (years)</b>					
≤30	263	106 (40.3%)	51 (19.4%)	63 (24.0%)	43 (16.3%)
31-55	2,087	701 (33.6%)	390 (18.7%)	622 (29.8%)	374 (17.9%)
56-74	3,915	1,197 (30.6%)	740 (18.9%)	1,271 (32.5%)	707 (18.1%)
75+	2,334	592 (25.4%)	421 (18.0%)	841 (36.0%)	480 (20.6%)
<b>Gender</b>					
Male	5,173	1,580 (30.5%)	963 (18.6%)	1,690 (32.7%)	940 (18.2%)
Female	3,238	971 (30.0%)	615 (19.0%)	1,039 (32.1%)	613 (18.9%)
Non-binary/other	23	10 (43.5%)	1 (4.3%)	6 (26.1%)	6 (26.1%)
Not Say	165	35 (21.2%)	23 (13.9%)	62 (37.6%)	45 (27.3%)
<b>Ethnicity</b>					
Asian	1,139	386 (33.9%)	201 (17.6%)	301 (26.4%)	251 (22.0%)
Black	839	270 (32.2%)	139 (16.6%)	245 (29.2%)	185 (22.1%)
Mixed	95	32 (33.7%)	21 (22.1%)	27 (28.4%)	15 (15.8%)
White	6,177	1,800 (29.1%)	1,200 (19.4%)	2,114 (34.2%)	1,063 (17.2%)
Other	141	33 (23.4%)	23 (16.3%)	48 (34.0%)	37 (26.2%)
Not Say	208	75 (36.1%)	18 (8.7%)	62 (29.8%)	53 (25.5%)
<b>Haemodialysis Location</b>					
Hospital	3,540	922 (26.0%)	561 (15.8%)	1,357 (38.3%)	700 (19.8%)
Satellite	5,059	1,674 (33.1%)	1,041 (20.6%)	1,440 (28.5%)	904 (17.9%)
<b>Total</b>	<b>8,599</b>	<b>2,596 (30.2%)</b>	<b>1,602 (18.6%)</b>	<b>2,797 (32.5%)</b>	<b>1,604 (18.7%)</b>

N: number of respondents

*Participants attending clinic but not receiving kidney replacement therapy*

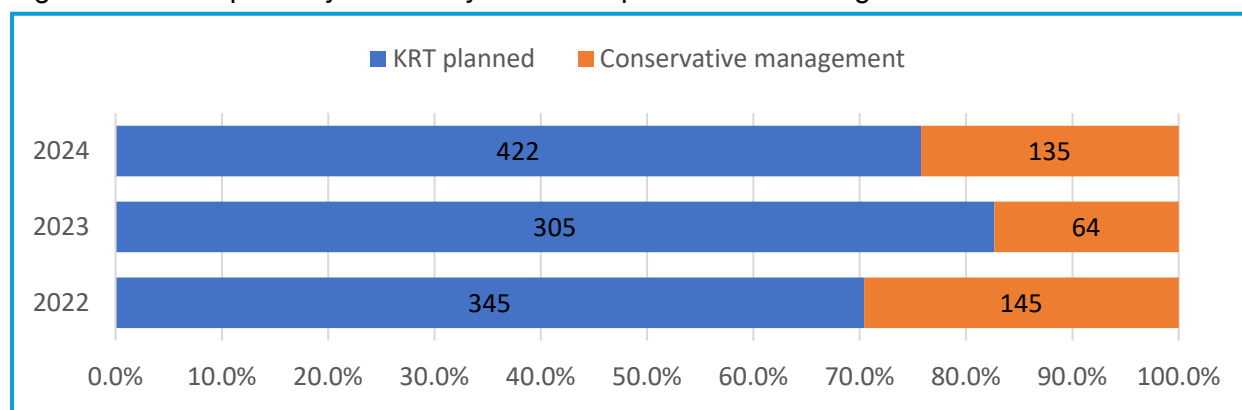
This year, there was a small increase in the number of Kidney PREM respondents who reported attending clinic without receiving kidney replacement therapy (Table 1.5). To better capture the reasons for individuals attending clinic, clinicians, patients and the Kidney PREM working group collaborated to amend the response options, combining those whose kidneys will fail, regardless of whether they had selected a treatment option. Subsequently, the proportion of those who do not know their CKD type has nearly doubled to 14.3%.

Table 1.5: Reason for attending clinic for individuals not receiving kidney replacement therapy (column percentages)

	Kidney PREM 2024	Kidney PREM 2023	Kidney PREM 2022
Attending for monitoring only	1,241 (59.1%)	1,184 (70.6%)	982 (62.5%)
Approaching end stage kidney disease	557 (26.5%)	369 (22.0%)	490 (31.2%)
Don't know CKD type	301 (14.3%)	124 (7.4%)	99 (6.3%)
Missing CKD type	-	1	34
<b>Total CKD (non-KRT)</b>	<b>2,099</b>	<b>1,678</b>	<b>1,605</b>

Of those approaching end stage kidney disease, nearly a quarter had chosen conservative management, (Figure 1.2) an increase from 2023 although lower than in 2022.

Figure 1.2: Care pathway for Kidney PREM respondents attending clinic but not on KRT



### English as additional language

There was an increase in proportion of those stating that their first language was something other than English, 12.8% compared to 10.8% in 2023. Regional variation remained, with a quarter (25.8%) of those attending centres in London with a non-English first language compared to just 1.8% in Northern Ireland (Table 1.6). Each region saw small increases in proportion, generally less than 1% with London showing the greatest change at 4.8%.

Table 1.6: English as additional language for Kidney PREM participants by region (column percentages)

Region	Other first language 2024	Other first language 2023	Change from 2023
<b>England</b>			
East of England	116 (12.9%)	94 (12.6%)	0.3%
London	826 (25.8%)	540 (21.0%)	4.8%
Midlands	331 (12.7%)	200 (11.2%)	1.5%
North East & N Cumbria	38 (4.1%)	18 (2.6%)	1.5%
North West	49 (6.8%)	50 (6.3%)	0.5%
South East	153 (9.4%)	124 (8.7%)	0.7%
South West	56 (4.6%)	26 (2.1%)	2.5%
Yorkshire & Humber	57 (7.9%)	49 (7.8%)	0.1%
<b>Northern Ireland</b>	6 (1.8%)	3 (1.3%)	0.5%
<b>Scotland</b>	13 (2.9%)	7 (1.9%)	1.0%
<b>Wales</b>	66 (10.9%)	81 (11.2%)	-0.3%
Missing centre	1 (10.0%)	62 (15.2%)	
<b>Total</b>	<b>1,712 (12.8%)</b>	<b>1,254 (10.8%)</b>	<b>2.0%</b>

Participants were able to state their first language if it was something other than English, with those selected at least 10 times shown in (Table 1.7). In previous years, Gujarati and Urdu have been the most common, but in 2024 there were more Punjabi speakers (152) than Gujarati (141). Alongside English, Kidney PREM is available in three other languages, Welsh, Gujarati and Urdu, all of which have high numbers of participants stating them to be their first languages. Despite this, just four translated Kidney PREM surveys were completed in 2024: one in Welsh, two in Gujarati and one in Urdu.

Kidney PREM participants specified a total of 126 languages, reflecting the cultural diversity of the chronic kidney disease population. A full list of languages is available in Appendix E.

It should be noted that participants with English as an additional language reported receiving help to complete Kidney PREM more often than those for whom English was their first language, 44.6% vs 24.9%. This highlights the importance of the availability of help to potential participants with English as an additional language and may explain in part the low uptake of translated Kidney PREM surveys.

Table 1.7: Primary languages spoken by those for whom English is not their first language

Language	Frequency	Language	Frequency
Akan Fante/Twi	30	Bulgarian	12
Igbo	10	French	44
Shona	17	Gaelic/Scottish	8
Somali	47	German	14
Swahili	11	Greek	21
Yoruba	21	Italian	31
Other African	80	Polish	33
Bengali	102	Portuguese	49
Chinese	59	Romanian	28
Farsi	13	Spanish	45
Gujarati	141	Turkish	30
Hindi	34	Welsh	56
Malayalam	15	Other European	79
Nepali	31	Arabic	69
Pakistani	10	BSL	3
Punjabi	152	Other	10
Tagalog/Filipino	69	Unidentified*	19
Tamil	54		
Urdu	178		
Other Asian	87	<b>Total</b>	<b>1,712</b>

\*Unidentified language: where a response was provided but the language could not be determined.

## Use of Patients Know Best

The proportion of participants using Patients Know Best (PKB) was almost unchanged from 2023 at 36.6% (Table 1.8). There remained a small group who said that PKB was unavailable (2.8%), though this was reduced from 2023 (4.3%). Around a third stated that they did not use PKB because they did not know what it was, almost unchanged from 2023. The use of PKB was highest amongst transplant recipients (68.3%), followed by those receiving haemodialysis at home (64.9%). Those receiving haemodialysis at centres or satellites reported the lowest use, 28.6% and 26.7% respectively.

Table 1.8: Kidney PREM participant use of Patients Know Best, by treatment (row percentages)

	Yes, using Patients Know Best	No, not using Patients Know Best because:			Don't know	Total
		It's unavailable	Don't know what it is	Another reason		
Transplant	1,219 (68.3%)	42 (2.4%)	239 (13.4%)	207 (11.6%)	78 (4.4%)	1,785
Centre HD	1,010 (28.6%)	126 (3.6%)	1,356 (38.3%)	481 (13.6%)	564 (15.9%)	3,537
Satellite HD	1,349 (26.7%)	139 (2.7%)	1,698 (33.6%)	706 (14.0%)	1,166 (23.1%)	5,058
Home HD	148 (64.9%)	7 (3.1%)	32 (14.0%)	28 (12.3%)	13 (5.7%)	228
Peritoneal	253 (39.8%)	19 (3.0%)	227 (35.7%)	73 (11.5%)	63 (9.9%)	635
CKD (non-KRT)	903 (43.0%)	46 (2.2%)	786 (37.5%)	178 (8.5%)	185 (8.8%)	2,098
<b>Total</b>	<b>4,882 (36.6%)</b>	<b>379 (2.8%)</b>	<b>4,338 (32.5%)</b>	<b>1,673 (12.5%)</b>	<b>2,069 (15.5%)</b>	<b>13,341</b>

HD: Haemodialysis, CKD: Chronic kidney disease, KRT: Kidney replacement therapy

## Measuring participant deprivation

### *Partial postcodes*

For the second year, Kidney PREM participants were asked to provide the first half of their postcodes in order to better understand domicile deprivation. Information could be entered using a free-text box, with respondents given the option to select “no” if they preferred not to provide this data. A total of 3,445 individuals chose not to provide their postcode and an additional 424 were removed from analysis since they selected “no” despite entering text. In total 9,902 participants provided postcode information, representing 74.2% of Kidney PREM participants, an increase from 70.8% in 2023. As seen in previous years, there was some regional variation in willingness to give this information (Table 1.9), the lowest proportion in the East of England (65.0%) and the highest in Scotland (84.7%), the same two regions as in 2023.

Table 1.9: Partial postcodes provided by region (column percentages)

	Postcode provided	
	2024	2023
East of England	586 (65.0%)	456 (61.3%)
London	2,332 (72.8%)	1,819 (70.8%)
Midlands	1,879 (71.8%)	1,263 (70.9%)
North East & N Cumbria	730 (79.3%)	527 (70.2%)
North West	532 (73.6%)	523 (65.5%)
South East	1,268 (77.5%)	1,104 (77.7%)
South West	950 (78.0%)	870 (71.8%)
Yorkshire & Humber	519 (71.8%)	459 (72.7%)
N Ireland	261 (77.7%)	147 (63.1%)
Scotland	381 (84.7%)	312 (83.4%)
Wales	456 (74.6%)	510 (70.2%)
<i>Unknown Centre</i>	8 (80.0%)	259 (63.5%)
<b>Total</b>	<b>9,902 (74.2%)</b>	<b>8,249 (70.8%)</b>

As described in detail in the Kidney PREM Technical Report, the first half of the postcode allows the local authority (LA) to be selected with reasonable accuracy. However, the LA could not be identified in 278 cases, so 9,624 (72.2% of the total Kidney PREM population) were included in analysis. LAs were ranked according to the proportion of smaller areas within the LA featuring in the most deprived 30% of the respective nation's Index of Multiple Deprivation (IMD)<sup>8</sup>. For ease of comparison, these were grouped into five groups (quintiles) ranging from 1 (most deprived) to 5 (least deprived). Although care has been taken to provide a comparison across nations, the ranks are calculated independently. An area in the most deprived 30% of one nation's IMD may not feature in the most deprived 30% of another, so caution should be taken when making comparisons.

Using full postcodes of patients from data submitted by centres, the UKRR assigned the IMD rank for patients attending each kidney centre. These were also grouped into quintiles and subsequently summarised across regions. Appendix Table F1 shows how data from Kidney PREM participants compares to this information from the wider kidney patient population receiving KRT as reported by the UKRR. In general, it seems that Kidney PREM has measured patient experience from a broad, representative range of the kidney population according to IMD, but with some regional variation.

Almost half of Kidney PREM respondents resided in the two most deprived quintiles (Table 1.10). Although there was some regional variation, broadly there seemed to be double the proportion of participants in the most deprived quintile (regional range 20.9% to 30.6%) than the least deprived (regional range 10.2% to 14.9%).

<sup>8</sup> <https://www.gov.uk/government/collections/english-indices-of-deprivation> (England),  
<https://www.nisra.gov.uk/statistics/deprivation/northern-ireland-multiple-deprivation-measure-2017-nimdm2017> (Northern Ireland),  
<https://www.gov.scot/collections/scottish-index-of-multiple-deprivation-2020/> (Scotland),  
<https://www.gov.wales/welsh-index-multiple-deprivation> (Wales).

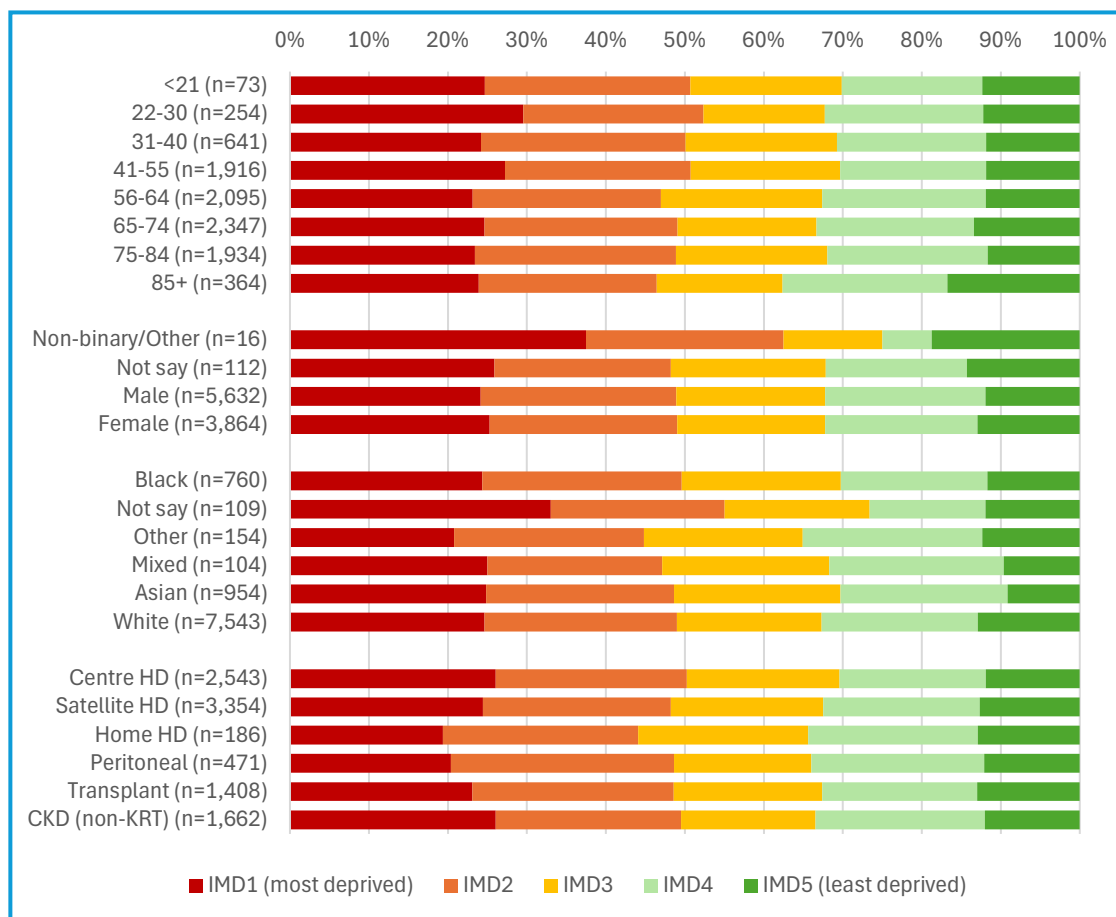


Table 1.10: IMD quintile, according to partial postcode, by region (row percentages)

	IMD Quintile					Not identified	Not provided
	1 Most deprived	2	3	4	5 Least deprived		
East of England	162 (28.5%)	147 (25.9%)	105 (18.5%)	96 (16.9%)	58 (10.2%)	18	315
London	558 (24.6%)	528 (23.3%)	436 (19.2%)	464 (20.4%)	283 (12.5%)	63	870
Midlands	451 (24.7%)	450 (24.7%)	346 (19.0%)	361 (19.8%)	217 (11.9%)	54	737
North East & N Cumbria	169 (23.9%)	154 (21.8%)	135 (19.1%)	157 (22.2%)	93 (13.1%)	22	191
North West	122 (23.7%)	129 (25.0%)	101 (19.6%)	99 (19.2%)	64 (12.4%)	17	191
South East	315 (25.6%)	319 (25.9%)	225 (18.3%)	225 (18.3%)	148 (12.0%)	36	368
South West	195 (20.9%)	234 (25.1%)	186 (19.9%)	198 (21.2%)	120 (12.9%)	17	268
Yorkshire & Humber	130 (25.9%)	107 (21.4%)	102 (20.4%)	103 (20.6%)	59 (11.8%)	18	204
N Ireland	77 (30.6%)	58 (23.0%)	38 (15.1%)	46 (18.3%)	33 (13.1%)	9	75
Scotland	84 (22.6%)	101 (27.2%)	57 (15.4%)	78 (21.0%)	51 (13.7%)	10	69
Wales	107 (24.2%)	109 (24.7%)	77 (17.4%)	83 (18.8%)	66 (14.9%)	14	155
Unknown centre	3 (37.5%)	4 (50.0%)	1 (12.5%)	0 (0.0%)	0 (0.0%)	0	2
<b>Total</b>	<b>2,373 (24.7%)</b>	<b>2,340 (24.3%)</b>	<b>1,809 (18.8%)</b>	<b>1,910 (19.8%)</b>	<b>1,192 (12.4%)</b>	<b>278</b>	<b>3,445</b>

In Figure 1.3, the distribution of IMD quintiles by participant characteristics is shown. No obvious patterns were apparent, with IMD quintile seemingly uncorrelated with age or treatment modality. There was a slightly higher proportion of non-binary/other gender participants in the more deprived IMD quintiles, but this was a small group with just 16 individuals providing postcode information. Similarly, a higher proportion of those not who did not provide their ethnicity resided in the most deprived two quintiles, but there was little difference when compared to other ethnicity groups. Appendix Table F2 contains the values used to produce Figure 1.3 alongside the frequencies of participants within each group.

Figure 1.3: IMD quintile by participant demographics



### Income sufficiency

An additional question, introduced in Kidney PREM 2024, asked participants about their income sufficiency. This was designed to be a proxy measure for deprivation at an individual level based on participant perception, rather than the location of their home address. The question asked:

*Does your household income meet your everyday need for things such as accommodation, food, clothing and other daily necessities?*

Answers were on a 5-point Likert scale: “I have more than enough money to meet my daily needs”, “I have enough money to meet my daily needs”, “I just about have enough money to meet my daily needs”, “I don’t have enough money to meet my daily needs”, “I regularly go without essentials”. “I don’t know” and “I’d rather not say” options were also available.

Responses are summarised at regional level in Table 1.11. In total, over 60% of participants stated that they had either “enough” or “more than enough”. Just 2.2% regularly go without essentials and a further 9.9% of respondents don’t have enough to meet their needs. There was a small amount of variation across regions.

Table 1.11: Sufficiency of income by region (row percentages)

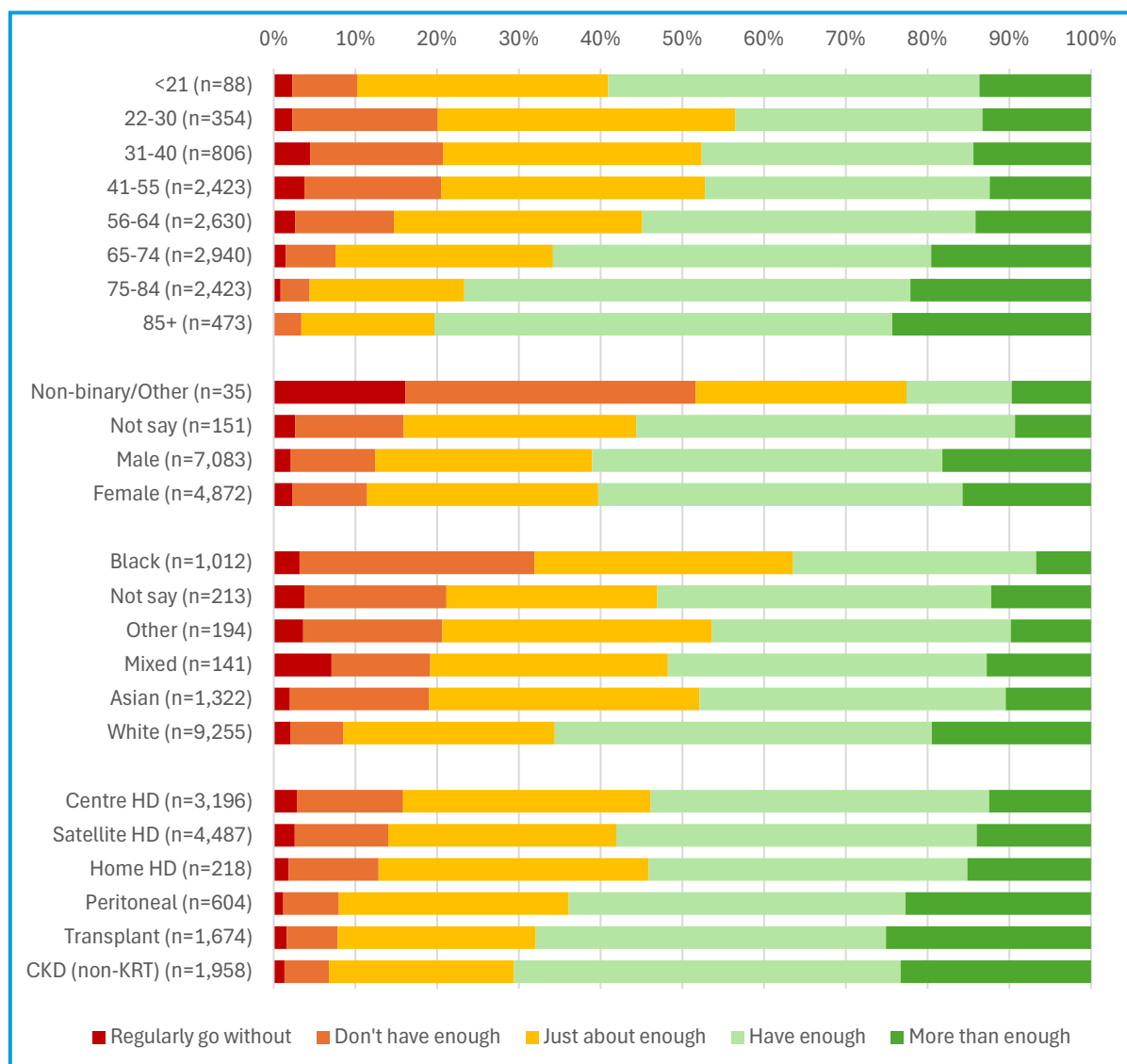
	Income					Rather not say	Don't know
	Regularly go without	Don't have enough	Just about enough	Have enough	More than enough		
East of England	13 (1.6%)	54 (6.8%)	235 (29.5%)	362 (45.5%)	132 (16.6%)	97	8
London	69 (2.4%)	412 (14.6%)	810 (28.7%)	1,063 (37.6%)	470 (16.6%)	268	108
Midlands	63 (2.7%)	237 (10.0%)	653 (27.5%)	1,101 (46.3%)	322 (13.6%)	193	47
NE & N Cumbria	14 (1.7%)	57 (6.7%)	246 (29.0%)	392 (46.3%)	138 (16.3%)	57	17
North West	13 (1.9%)	76 (11.3%)	187 (27.8%)	278 (41.4%)	118 (17.6%)	43	8
South East	28 (1.8%)	144 (9.4%)	356 (23.2%)	687 (44.8%)	317 (20.7%)	83	21
South West	29 (2.5%)	89 (7.7%)	290 (25.2%)	503 (43.6%)	242 (21.0%)	48	17
Yorks & Humber	17 (2.6%)	58 (8.9%)	208 (32.0%)	263 (40.5%)	103 (15.9%)	67	7
N Ireland	3 (1.1%)	18 (6.5%)	69 (24.8%)	147 (52.9%)	41 (14.7%)	53	5
Scotland	6 (1.4%)	29 (6.8%)	86 (20.2%)	194 (45.6%)	110 (25.9%)	21	4
Wales	15 (2.6%)	31 (5.4%)	165 (28.6%)	289 (50.2%)	76 (13.2%)	28	7
Unknown centre	0 (0.0%)	0 (0.0%)	6 (66.7%)	1 (11.1%)	2 (22.2%)	0	1
<b>Total</b>	<b>270 (2.2%)</b>	<b>1,205 (9.9%)</b>	<b>3,311 (27.3%)</b>	<b>5,280 (43.5%)</b>	<b>2,071 (17.1%)</b>	<b>958</b>	<b>250</b>

Although a quarter of people completing Kidney PREM chose not to provide their postcode, more were willing to answer questions about the sufficiency of their income. Just 958 (7.2%) chose not to provide an answer, whereas 3,869 (29.0%) did not enter a partial postcode.

Figure 1.4 shows how participants responded to the question on income according to their age, gender, ethnicity and treatment type, with frequencies and proportions reported in Appendix Table F3. With the exception of those 21 years and under, participants increasingly reported at least “having enough” as the age groups rose. Over 20% of those aged 22 to 55 years reported “not having enough” or “regularly going without essentials”. Although a small group at just 35 individuals, less than half of those identifying as non-binary or “other” gender have at least “just about enough” and had the largest proportion of those “regularly going without essentials” (16.1%). This group tended to be younger than the Kidney PREM population as a whole, with around 90% under the age of 55 years.

White participants had the lowest proportion of those “regularly going without” or “not having enough” (<10%) in contrast to Black participants where this was the case for >30%. Some differences were also seen by treatment modality, although differences were less stark. Those receiving haemodialysis, whether at a centre, in a satellite or at home, selected the two least sufficient income categories most often (15.8%, 14.0% and 12.8% respectively) whereas those receiving peritoneal dialysis, those with a kidney transplant and those not receiving kidney replacement therapy reported “regularly going without” or “not having enough” less often (7.9%, 7.8% and 6.8% respectively).

Figure 1.4: Income sufficiency by participant demographics



A comparison between IMD quintile and income sufficiency is shown in Appendix Table F4. For participants responding to both questions, the proportion of those in each IMD quintile was similar regardless of the response to the income sufficiency question, with no apparent relationship between the two measures.

Kidney PREM results according to income sufficiency are published in Chapter 6 of this report.

## Chapter 2: Accessing Kidney PREM

### Help to participate in Kidney PREM

In 2024, 3,665 participants received help to complete the survey, a similar value to 2023, though a reduction in proportion of overall responses from 31.1% to 27.5% (Table 2.1). There was a reduction in the proportion of volunteers assisting completion from 25.3% to 15.2%, and a corresponding increase in friends, relatives and carers (from 33.3% to 42.2%), reversing the change seen between 2022 and 2023.

Table 2.1: Helpers for Kidney PREM completion in 2024, 2023 and 2022 (column percentages)

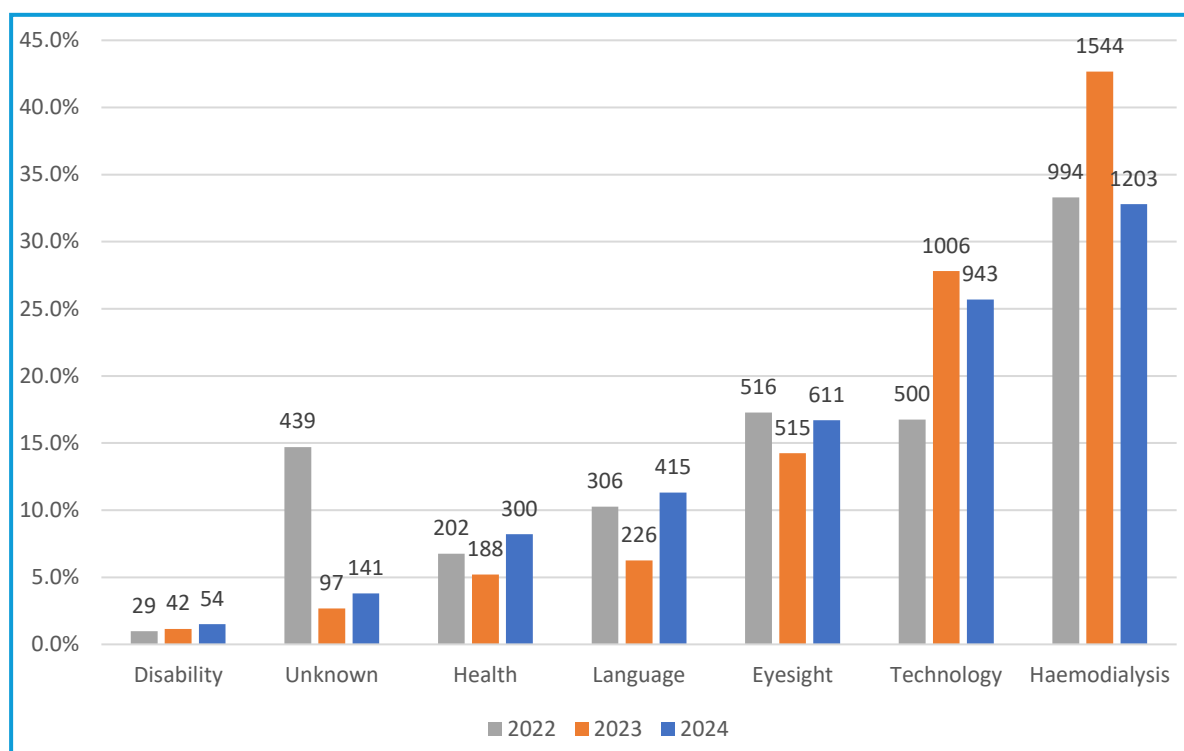
	Kidney PREM 2024	Kidney PREM 2023	Kidney PREM 2022
Friend/relative/carers	1,548 (42.2%)	1,206 (33.3%)	1,437 (49.3%)
Volunteer	557 (15.2%)	917 (25.3%)	442 (15.2%)
Staff/other	1,560 (42.6%)	1,495 (41.3%)	1,036 (38.2%)
<b>Total</b>	<b>3,665</b>	<b>3,618</b>	<b>2,986</b>

The number and proportion of participants who received help to complete Kidney PREM are shown in Appendix Table G1 by age, ethnicity and treatment modality. Over half (51.9%) of those aged 85 years and over received help, down from 60.5% in 2023, perhaps as a result of paper availability. Other than those under 21 years, the proportion being assisted decreased for each age group. Over a third of Asian participants (39.3%) received help compared to a quarter of White individuals (25.5%). More than a third of those receiving in-centre haemodialysis received help, slightly more so in satellites (37.7%) than centres (35.5%), with transplant recipients receiving help least often (5.6%).

There was a reduction in those stating that connection to a haemodialysis machine was the reason for receiving help to complete the Kidney PREM (32.7%), Figure 2.1, corresponding in part to the reduction in haemodialysis participants being helped. Technology remained the second largest reason (25.7%), followed by eyesight (16.7%). Appendix Table G2 provides details of the number and proportion of help reasons according to participants' treatment modality.

The number and proportion of individuals receiving help to complete Kidney PREM at each centre are shown in Appendix Table G3.

Figure 2.1: Reason for receiving help to participate in Kidney PREM

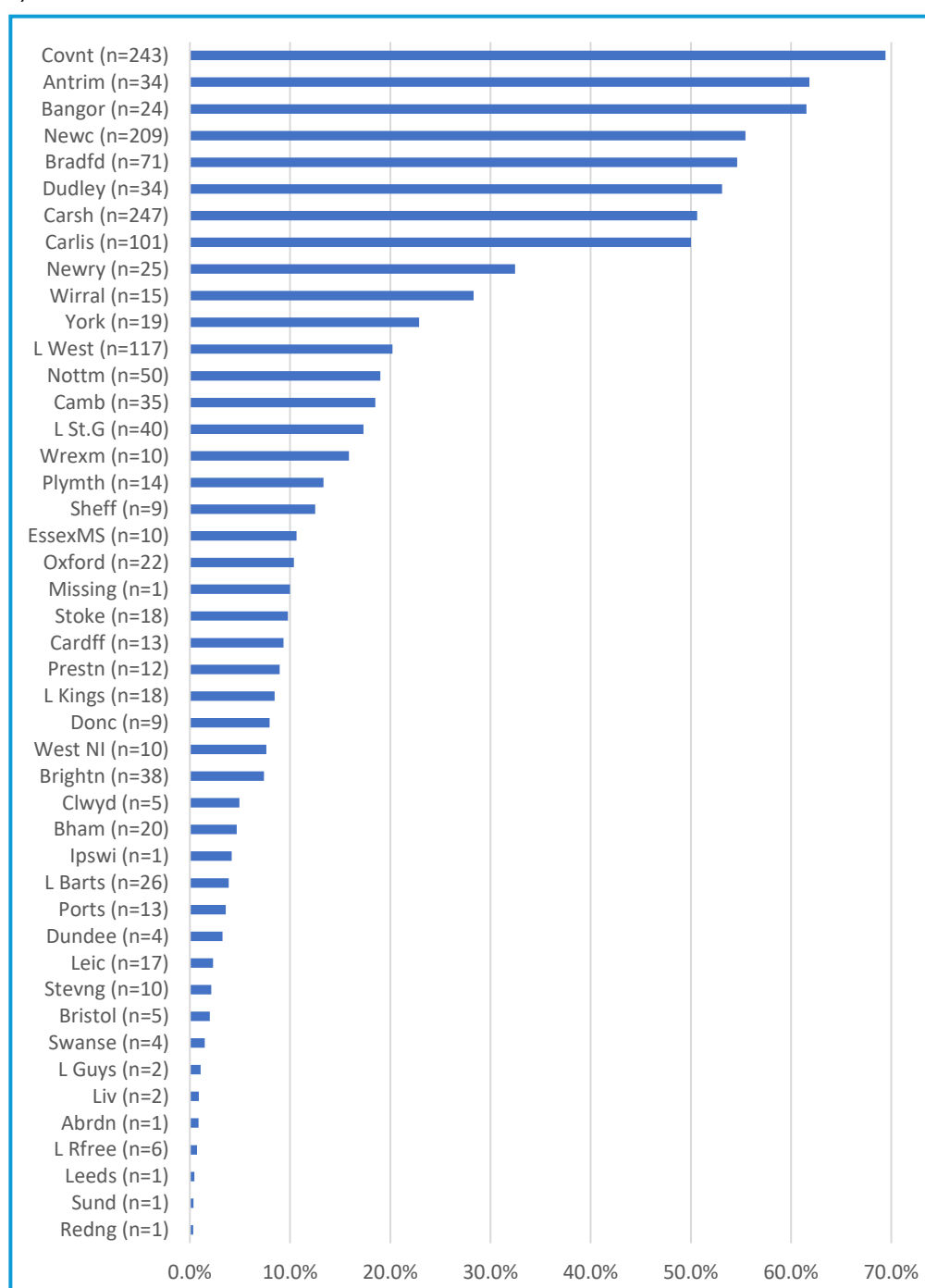


### Use of paper surveys

Following a successful pilot in one centre the previous year, all centres were given the option to offer paper Kidney PREM surveys in 2024, using volunteers to input the data to the online platform. A total of 1,567 paper surveys were submitted, 11.7% of all returns. Forty-five centres (66.2%) made use of the paper surveys, with uptake varying greatly, from 0.3% to 69.4% (Figure 2.2). Fifteen centres had fewer than 10 paper surveys returned. After data cleaning, the centre name could not be determined for one response. Coventry had the highest proportion of paper surveys and the largest increase in Kidney PREM responses. Appendix Table G3 also shows the number and proportion of returns for each centre.



Figure 2.2: Proportion of paper Kidney PREM returns by centre (number of paper returns in brackets)



In all age groups below 55 years, paper completion accounted for around 9% of returns (Table 2.2). However, each subsequent increase in age saw an increase in the proportion of paper surveys used, notably 16.7% of those aged 85 and older. Although there was no apparent difference between male and female participants, all but one individual identifying as non-binary/other completed the Kidney PREM online. Although the proportion of paper completion amongst those who answered the gender question with “Rather not say” seems high at 42.4%, it is possible that this question was sometimes missed in error, so “Rather not say” was selected by volunteers inputting responses in the absence of an answer.

Within ethnicity groups, Asian participants had the highest proportion of paper completion (16.2%), followed by Black individuals (13.8%). Of note, 15.5% of those with English as an additional language utilised paper surveys compared to 11.2% with English as a first language. This aspect, coupled with the increase in Asian participants compared to previous years, suggests that the widespread introduction of a paper option has helped increase the accessibility of Kidney PREM amongst groups who can face barriers to completion.

Those not receiving KRT had the highest proportion of paper completion (13.7%) of the treatment modality groups, closely followed by those receiving haemodialysis in satellites (13.1%) and centres (12.1%). Uptake was lowest amongst those on home haemodialysis, just 4.8%. Those on haemodialysis in centres or satellites tend to be older, so it is difficult to distinguish between those who preferred to complete a paper survey because of their age, or those whose preference was caused by limitations due to their treatment. Some centres may have promoted paper completion for operational reasons, especially those with an active volunteer group.

Table 2.2: Method of Kidney PREM completion by respondent characteristics (row percentages)

	Paper	Online
<b>Age (years)</b>		
≤21	10 (8.9%)	102 (91.1%)
22-30	37 (9.7%)	344 (90.3%)
31-40	77 (8.6%)	822 (91.4%)
41-55	235 (8.9%)	2,414 (91.1%)
56-64	325 (11.1%)	2,600 (88.9%)
65-74	406 (12.6%)	2,812 (87.4%)
75-84	389 (14.8%)	2,248 (85.2%)
85+	88 (16.7%)	438 (83.3%)
<b>Gender</b>		
Female	620 (11.5%)	4,774 (88.5%)
Male	859 (11.1%)	6,854 (88.9%)
Non-binary/other	1 (2.9%)	34 (97.1%)
Rather not say	87 (42.4%)	118 (57.6%)
<b>Ethnicity</b>		
Asian	245 (16.2%)	1,271 (83.8%)
Black	158 (13.8%)	990 (86.2%)
Mixed or multiple	15 (9.2%)	148 (90.8%)
White	1,092 (10.9%)	8,911 (89.1%)
Other ethnic groups	26 (11.4%)	203 (88.6%)
Rather not say	31 (10.8%)	257 (89.2%)
<b>First language</b>		
English	1,301 (11.2%)	10,324 (88.8%)
Other	266 (15.5%)	1,450 (84.5%)
<b>Treatment</b>		
Transplant	127 (7.1%)	1,659 (92.9%)
Centre haemodialysis	428 (12.1%)	3,112 (87.9%)
Satellite haemodialysis	662 (13.1%)	4,397 (86.9%)
Home haemodialysis	11 (4.8%)	217 (95.2%)
Peritoneal dialysis	52 (8.2%)	583 (91.8%)
CKD (non-KRT)	287 (13.7%)	1,812 (86.3%)
<b>Total</b>	<b>1,567</b>	<b>11,780</b>

There was a small difference in the proportion of those receiving help to complete Kidney PREM depending on survey completion method, with 29.9% of participants using paper surveys receiving help compared to 27.1% of online respondents. Friends, relatives or carers helped those completing on paper more often (59.2%), whereas staff were the group who assisted online returns the most (44.9%) (Table 2.3).

Table 2.3: Helper type by Kidney PREM completion method (column percentages)

	Paper	Online
Friend/relative/carers	277 (59.2%)	1,271 (39.8%)
Volunteer	79 (16.9%)	478 (15.0%)
Staff	100 (21.4%)	1,435 (44.9%)
Unknown	12 (2.6%)	13 (0.4%)
<b>Total</b>	<b>468</b>	<b>3,197</b>

## Chapter 3: Changes in patient experience

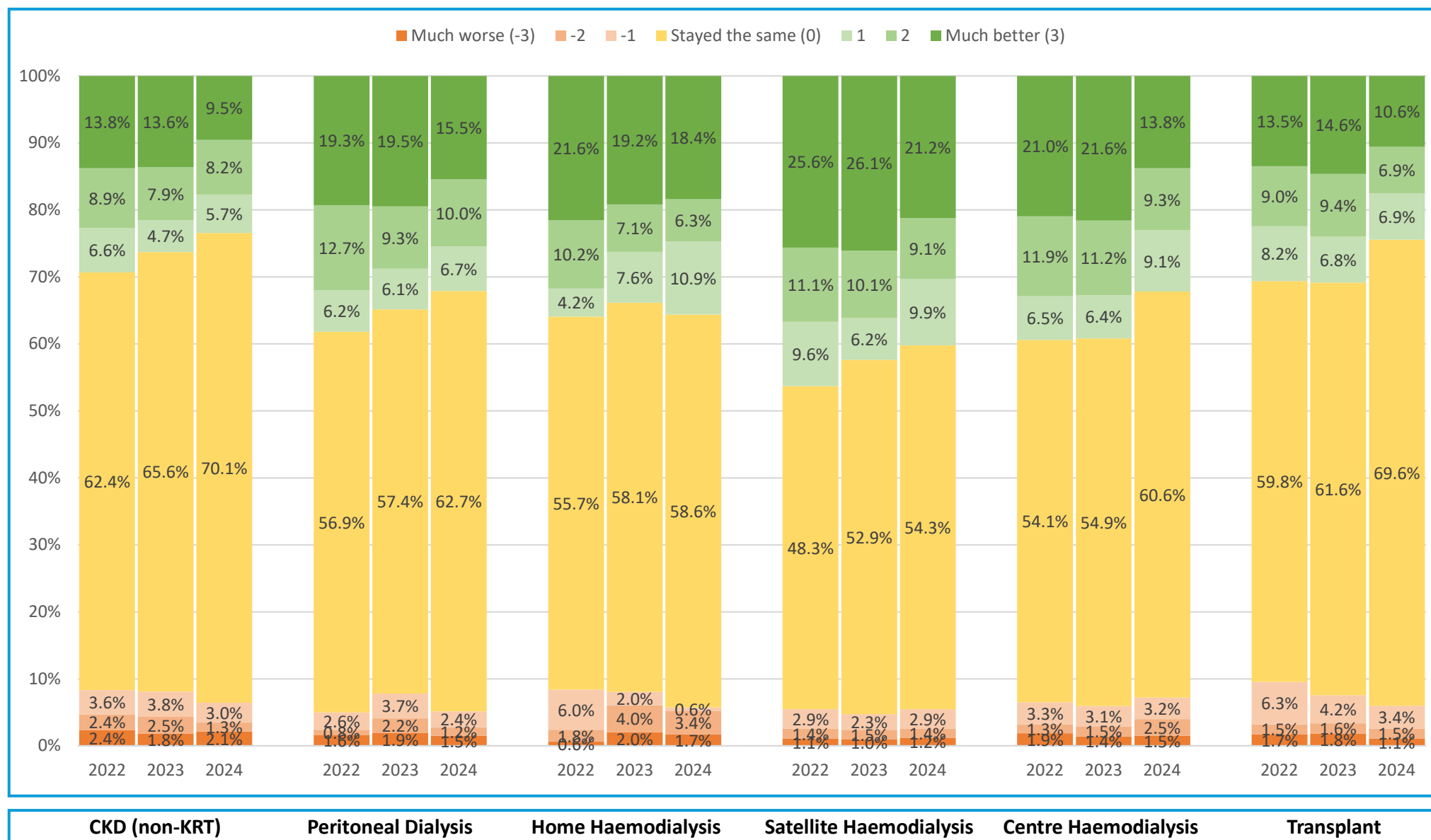
As in previous years, Kidney PREM participants were asked to rate how their experience of care has changed over the previous year:

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

As in previous years, responses were recorded using a 7-point Likert scale from -3 (much worse) through 0 (no change) to +3 (much better). The question was filtered and only shown to those who had indicated previously that they had not commenced kidney care within the previous 12 months.

A total of 8,470 participants responded (65.0%), the remaining stating that they had started receiving care within the previous 12 months, a reduction from 81.4% in 2023. Most stated there had been no change in their experience of care (61.6%, up from 57.2% in 2023), though this varied by treatment from 54.3% (satellite haemodialysis) to 70.1% (non-KRT) (Figure 3.1). Just 9.5% of all respondents reported that their care was “much better” than in the previous year, a large decrease from the 20.5% doing so in Kidney PREM 2023. The small proportion of poor scores (-3, -2 and -1) decreased slightly in most treatment groups with the exception of centre and satellite haemodialysis. Those receiving haemodialysis in satellites were once again the largest group to report “much better” experiences (21.2%), with centre haemodialysis not far behind at 18.4%. Individuals on in-satellite haemodialysis reported improvement (+1, +2 and +3 “much better”) most often (40.2%), with those not receiving KRT and those with a kidney transplant reporting improvement least often (23.4% and 24.5% respectively). Participants did not report worse experiences very often; all low scores combined (-3 “much worse”, -2 and -1) were given by just 6.1% of participants and ranged from 5.2% to 7.2% across treatment modality groups.

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



## Chapter 4: Additional question results and comments about experience of care

As in 2023, additional questions were included at the end of the Kidney PREM survey to collect information about a range of topics relevant to kidney care. Results are presented at overall and regional levels, with full centre-level results published in Appendix H.

### Kidney PREM 2023

Participants were asked about their completion of Kidney PREM 2023 using the following questions:

*Did you start receiving care for your kidney disease in the past 12 months?  
Did you complete the Kidney PREM in 2023?*

A total of 4,561 (35.0%) participants indicated that they started kidney care within the previous year (Table 4.1). There was some regional variation, 25.6% in Scotland compared to 40.1% in the Midlands, with more substantial differences between centres (43.1% to 93.3%).

Table 4.1 Kidney PREM respondents commencing care in previous year

	Started care in past 12 months
East of England	351 (39.4%)
London	1,056 (34.5%)
Midlands	1,033 (40.1%)
North East & N Cumbria	271 (29.8%)
North West	252 (35.5%)
South East	524 (32.8%)
South West	415 (34.6%)
Yorkshire & Humber	229 (32.0%)
N Ireland	95 (28.8%)
Scotland	112 (25.6%)
Wales	221 (36.6%)
Unknown centre	2 (22.2%)
<b>Total</b>	<b>4,561 (35.0%)</b>

A total of 8,474 (65.0%) participants started receiving care more than 12 months ago, from which a total of 3,047 (36.0%) stated they had completed the previous year's Kidney PREM survey (Table 4.2). Regional variation featured again, ranging from 30.5% (Scotland) to 43.8% (South East), with centre proportions ranging from 0% to 51.9%.

Table 4.2: Respondents completing Kidney PREM 2023 of those receiving care for  $\geq 12$  months

Completed Kidney PREM 2023	
East of England	206 (38.1%)
London	655 (32.7%)
Midlands	522 (33.9%)
North East & N Cumbria	210 (32.9%)
North West	173 (37.8%)
South East	469 (43.8%)
South West	292 (37.3%)
Yorkshire & Humber	159 (32.7%)
N Ireland	96 (40.9%)
Scotland	99 (30.5%)
Wales	164 (42.8%)
<i>Unknown centre</i>	2 (28.6%)
<b>Total</b>	<b>3,047 (36.0%)</b>

## Diabetes

The number of people with diabetes and kidney disease is increasing year on year, driving the significant growth in the dialysis population in the UK. Work has been undertaken demonstrating that people with diabetes receive suboptimal diabetes care once they reach end-stage kidney failure having commenced dialysis. They can be isolated from standard diabetes care, resulting in significant deficit in receiving regular screening for diabetes complications and receiving advice on the management of their diabetes.

There is a significant interest in improving the quality of care for people with diabetes on dialysis, so Kidney PREM participants with diabetes were asked about their current ability to access good quality diabetes care using the following questions:

*Have you been diagnosed with Diabetes?*

*Do you currently see, or have you access to, a member of a specialist diabetes team provided by the hospital (Diabetic Nurse specialist, dietician or Doctor)?*

In total, 4,369 (33.5%) of Kidney PREM participants have been diagnosed with diabetes, comparable to the 35.3% of the KRT population recorded as having diabetes either as primary kidney disease or as a comorbidity in 2022 (UKRR data)<sup>9</sup>. Of those Kidney PREM participants reporting diabetes, 3,178 (72.7%) have access to diabetes specialists, again varying by region from 62.7% (North East and North Cumbria) to 87.1% (Northern Ireland) (Table 4.3). Access to a specialist varied by centre, from 46.2% to 100%, with all participants from four centres confirming access to diabetes specialists.

<sup>9</sup>Note that this refers only to the 62% of the prevalent cohort with complete comorbidity data.



Table 4.3: Access to diabetes specialist by region

	Diabetes Specialist
East of England	262 (76.2%)
London	713 (68.8%)
Midlands	703 (77.3%)
North East & N Cumbria	193 (62.7%)
North West	169 (68.7%)
South East	328 (68.0%)
South West	297 (75.4%)
Yorkshire & Humber	174 (77.7%)
N Ireland	101 (87.1%)
Scotland	94 (76.4%)
Wales	142 (77.2%)
<i>Unknown centre</i>	2 (66.7%)
<b>Total</b>	<b>3,178 (72.7%)</b>

Kidney PREM respondents receiving haemodialysis in satellites or at home reported having access to diabetes specialists most often, 78.9% and 79.4% respectively (Table 4.4). Those not receiving kidney replacement therapy reported this least often 61.8%.

Table 4.4 Access to diabetes specialist by treatment modality

	Diabetes Specialist
Transplant	275 (66.3%)
Peritoneal dialysis	132 (69.8%)
Centre haemodialysis	913 (70.5%)
Satellite haemodialysis	1,476 (78.9%)
Home haemodialysis	50 (79.4%)
Chronic kidney disease (non-KRT)	332 (61.8%)

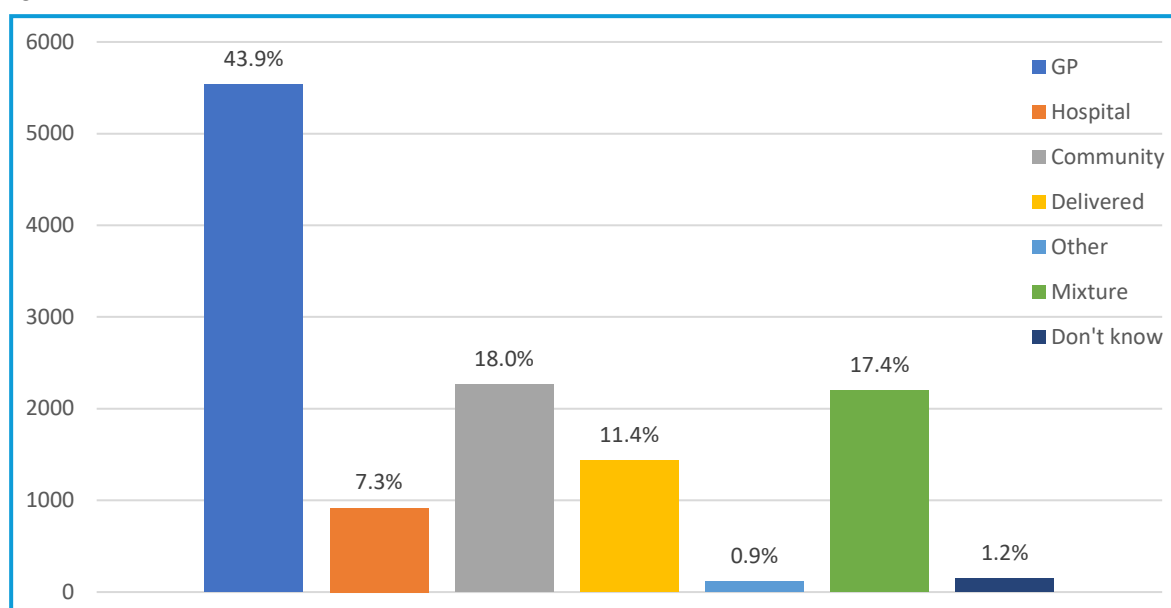
## Medication

In previous years' Kidney PREM surveys, participants have often commented about their medication, including the process to obtain it and its purpose. A short set of questions were introduced to capture these experiences more formally:

- *Does the kidney team give you clear advice on your medications?*
- *Getting a repeat prescription for my kidney care medicines is easy*
- *Do you know what each of your medications is for?*
- *Where do you usually get the medicines for your kidney disease from:*

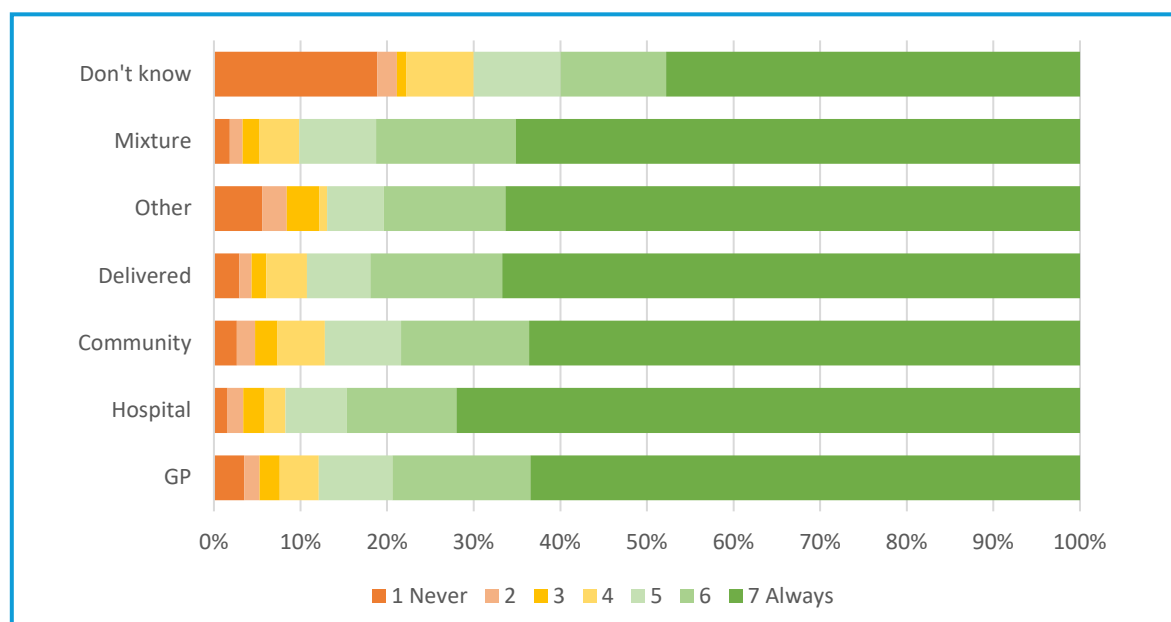
*GP, Hospital pharmacy, Community pharmacy, Delivered to me, Other, A mixture of the above, Don't know, Not applicable.*

Figure 4.1: Medication provider



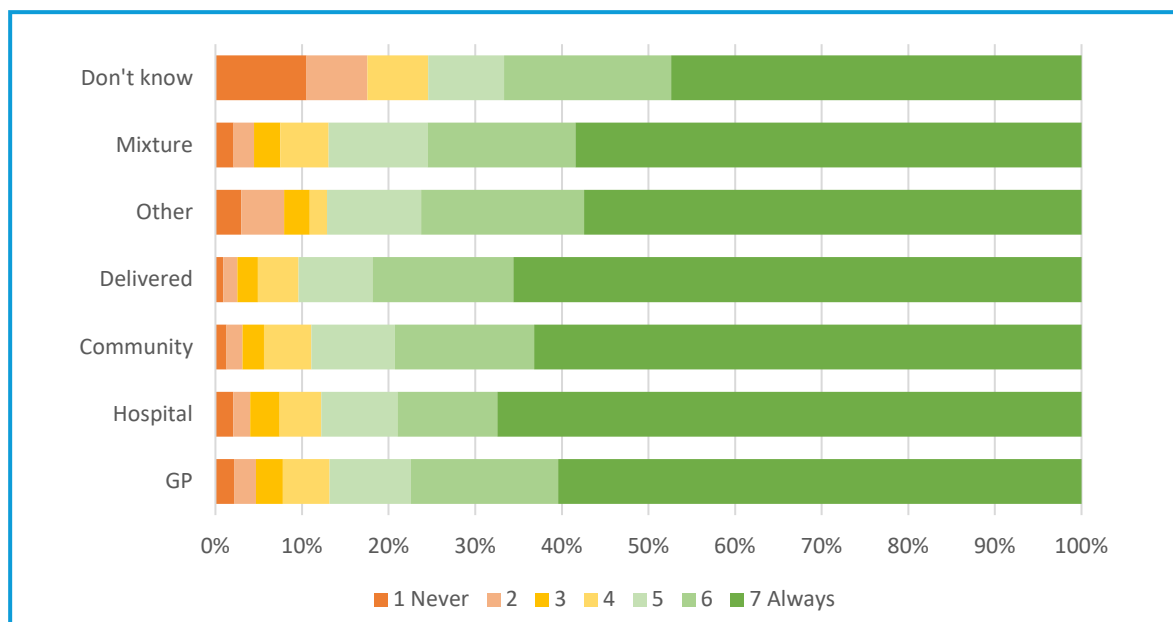
GP surgeries provided medication most often (43.9%) (Figure 4.1), although 17.4% of participants obtained medications from a mixture of places. There were 382 participants who selected “not applicable”, presumably because they are not prescribed medication for their kidney disease. Figures 4.2 to 4.4 show the responses to the medication experience questions, split out according to the medication provider.

Figure 4.2: Does the kidney team give you clear advice on your medications?



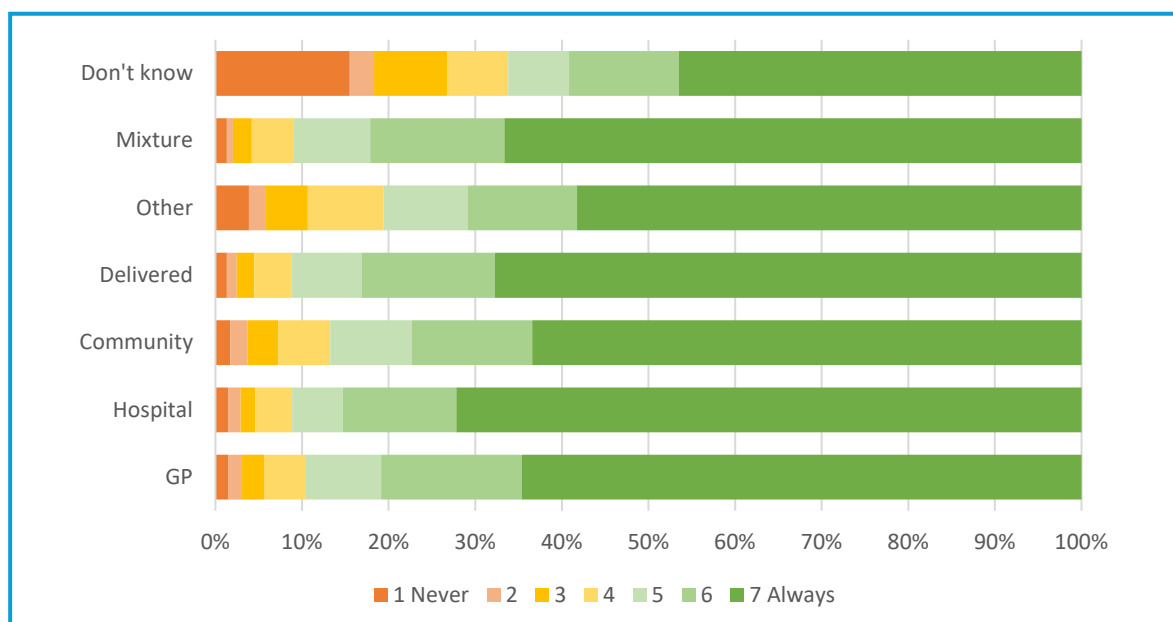
Those who obtain medication at the hospital reported the most positive experience around receiving clear advice, with over 90% selecting scores of 5-7 out of 7. Those who do not know where their medication comes from made up a small group of people (1.2% of the total) but nonetheless reported a less positive experience than those obtaining medication from known providers.

Figure 4.3 Getting a repeat prescription for my kidney care medicines is easy



Perhaps unsurprisingly, those having medication delivered reported the most positively when asked to consider the ease with which they obtain their repeat prescriptions, again more than 90% giving scores of 5-7 out of 7.

Figure 4.4 Do you know what each of your medications is for?



Once again, those who did not know where their medications came from reported the least positive experience, with more than 30% selecting 1-4 out of 7 when asked whether they knew what each of their medications was for. Individuals who selected “other” for their medication provider was also a small group, just 0.9% of those who responded, and additionally reported a less positive experience (nearly 20% selecting 1-4 out of 7).

## Feedback from Kidney PREM 2023

In 2023, participants were asked whether the previous year's Kidney PREM results had been communicated with them, a question which was slightly modified and repeated in 2024:

*Have you received any feedback about last year's Kidney PREM report results (for instance from a member of staff or from a unit poster or newsletter)?*

A total of 2,162 participants (16.6%) said they had received feedback, up from 11.9% in 2023 (Table 4.5). The Midlands and East of England had the highest proportion of participants, 22.2% and 22.0% respectively, with lowest proportions in the North East & North Cumbria (10.5%) and the North West (10.0%). Positively, most regions increased their feedback rates between 2023 and 2024, the East of England seeing the largest increase from 13.2% in 2023 to 22.0% in 2024.

Table 4.5: Results feedback received from previous years' Kidney PREMs

	2024	2023
East of England	196 (22.0%)	96 (13.2%)
London	449 (14.7%)	258 (10.5%)
Midlands	569 (22.2%)	340 (19.4%)
North East & N Cumbria	95 (10.5%)	77 (10.5%)
North West	71 (10.0%)	66 (8.4%)
South East	63 (14.5%)	115 (8.3%)
South West	228 (14.4%)	113 (9.5%)
Yorkshire & Humber	133 (18.6%)	79 (12.8%)
N Ireland	41 (12.4%)	33 (14.6%)
Scotland	63 (14.5%)	27 (7.5%)
Wales	97 (16.3%)	88 (12.5%)
<i>Unknown centre</i>	1 (11.1%)	57 (15.2%)
<b>Total</b>	<b>2162</b>	<b>1349</b>

## Comments about experiences of care

In 2024, the Kidney PREM received 13,347 responses from individuals with kidney disease, with 4,848 of those who took part (36% of responses) providing a further comment on their care in response to the free-text question.

*“If there is any other aspect of your experience of kidney care that you would like to comment on that has not already been covered, please tell us below”.*

The number of individuals responding to the Kidney PREM free text question increased slightly by 646 comments from 2023. As the number of free-text responses increases, our understanding of patient experience of kidney care improves and helps to explain the reasons for changes in theme scores in the national report from the previous year.

Additionally, 94.3% of responders gave consent for their comments to be passed back to their kidney centre which can be used to help support quality improvement. This has remained consistent with previous years. Generally, the profile of responders who left a free text comment matched that of the national Kidney PREM 2024. Compared to 2023, there has been an increase in the number of comments from individuals receiving haemodialysis at a satellite unit (+7.4%) and decrease from those with a functioning transplant (-3.6%).

The majority of the free-text responses align with the 13 Kidney PREM themes. There were 552 responses (11.4%) which said there was nothing further to add. Comments which do not fit the pre-existing Kidney PREM themes are grouped under *other aspects of care* and include comments on holiday treatment, integrated care for comorbidities and patients stating their current treatment. In addition, to align with the Kidney PREM, there are two themes, *Overall Experience* and *Additional Questions*, which cover responses on questions included in the survey. This year the additional questions asked were about medication and pharmacy, diabetes and feedback on the kidney PREM. The additional questions provide further insights into specific aspects of kidney care to support quality improvement and service delivery.

This year, a new theme was introduced, *Kidney PREM*, due to an increase in the number of comments about the measure itself. Responses include comments on the change to digital delivery, feedback from the Kidney PREM and suggestions to improve the survey.

*How the Kidney Team Treats You* received the highest number of comments, with the majority of comments under this theme being positive. This theme, alongside *overall experience*, are the only themes to receive a higher number of positive comments than negative. This theme focusses on positive comments about staff and the quality of care received.

*Access to the Kidney Team* included comments on the adequacy of staffing with patients noticing that the unit was understaffed and nurses overworked. Additionally,

individuals commented on the difficulties faced when trying to contact the kidney team, and wanting to see a consultant more frequently, which remains an issue from 2023.

*Environment* received comments from individuals wanting better parking facilities, complaints that the unit is too cold and that the beds and chairs provided for dialysis are uncomfortable. The lack of available food during dialysis has continued to feature prominently in the comments.

*Transport* waiting times for transport following dialysis sessions continues to be an issue with individuals having to wait longer than an hour on most occasions. However, kidney units who have switched transport providers have received positive comments for this change.

Aspects of care such as *Needling*, *Privacy* and *Dignity* and *Sharing Decisions* received the fewest comments again this year. It is essential that these themes should still be considered as important areas of care for improvement. This year, comments on *Needling*, include respondents wanting to change the method of needling used. For *privacy and dignity*, privacy during conversations with consultants during dialysis sessions, remains an issue. Lastly, respondents wanting to be involved in their care received a mix of negative and positive comments, with some stating that they were involved in their care and others feeling dismissed.

We hope this report will give some insight into what individuals with kidney disease think is important about their care and that their comments will help to illuminate the findings of Kidney PREM 2024 and complement efforts to improve the care of people living with kidney disease.

**The full 2024 Kidney PREM Comments Report and a detailed summary document can be accessed at:**

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

## Chapter 5: Kidney PREM theme results

### Kidney PREM themes

Centre scores were calculated for each theme and can be viewed online<sup>10</sup>. National theme scores were obtained using these, and compared to values from the previous two years (Figure 5.1).

#### High scoring themes

The top three scoring themes continue to be *Privacy & Dignity* (6.40), *Patient Information* (6.40) and *Access to the Kidney Team* (6.38), where there remains little variation year-on-year.

*Overall Experience* remains high scoring (6.29) with almost no change from previous years, highlighting the continued high quality of care received by participants.

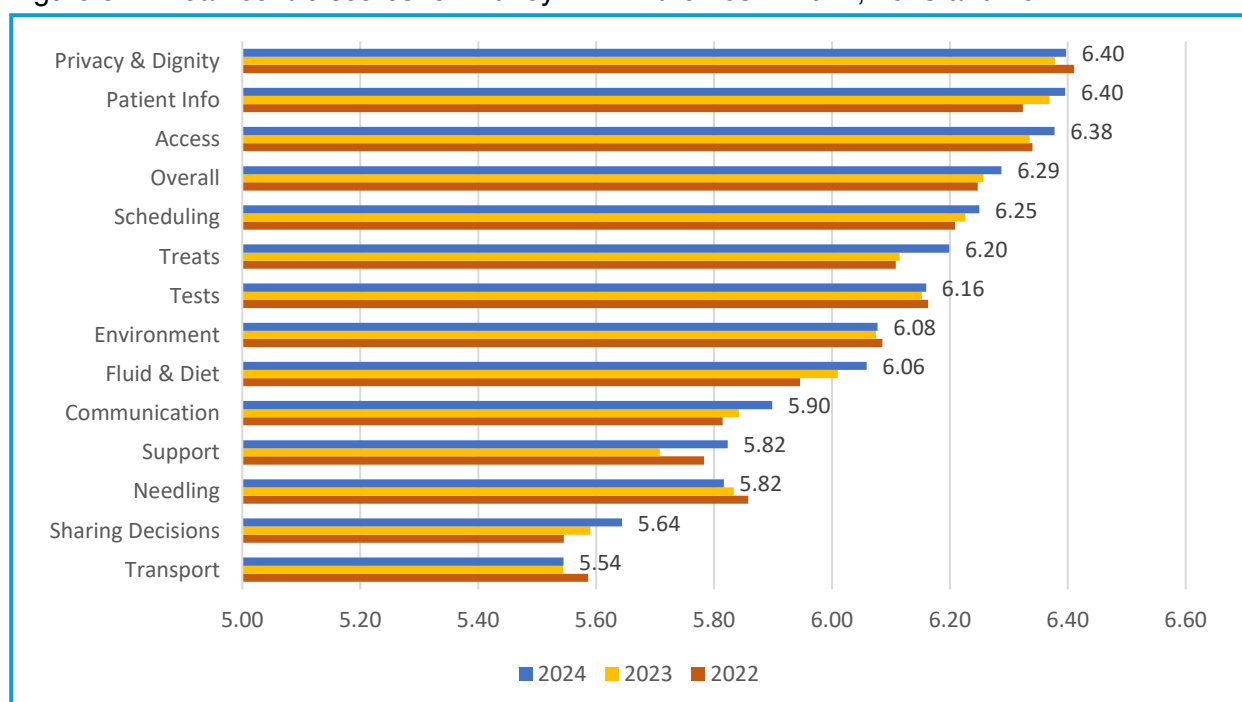
*How the Team Treats You* (6.20) increased in score from 2023; a small decrease for *Tests* (6.16) means that these themes have swapped order in the ranking.

#### Low scoring themes

*Sharing Decisions* (5.64) and *Transport* (5.54) remain the lowest scoring of all Kidney PREM themes. *Transport* continues to score most poorly of all themes, as improvements seen during the pandemic were not sustained, but has not reduced further in 2024.

*Needling* was the only theme to reduce in score, albeit only slightly, to 5.82. *Support* (5.82) saw the largest increase from 2023 scores, resulting in the two themes changing places.

Figure 5.1: Mean centre scores for Kidney PREM themes in 2024, 2023 and 2022



<sup>10</sup><https://www.ukkidney.org/sites/default/files/documents/Centre%20and%20Satellite%20Theme%20Means%20Jan25.xlsx>



Although most theme scores have remained relatively stable year on year, these averages mask the variation in scores seen across centres. Chapter 7 of this report shows variation via centre means and confidence intervals for each theme. In recent years, a small number of themes have had little variation amongst centre scores (Table 5.1). In 2024, this was the case for eight out of the 14 themes having ranges of  $\leq 1.4$ , equivalent to 20% of the total scale. Four of these had high means of  $\geq 6.3$  (to the nearest decimal point), equivalent to 90% of the scale: *Privacy & Dignity* (6.4), *Patient Information* (6.4), *Access to the Kidney Team* (6.4) and *Overall Experience* (6.3). Just two themes had wide ( $\geq 2.0$ ) ranges: *Needling* and *Transport*, both of which also had lower mean scores (5.8 and 5.5 respectively).

Table 5.1: A summary of mean scores by centre, to nearest decimal point, sorted from highest to lowest theme

Topic	2024				2023				2022		
	Range	Mean range	Mean		Range	Mean range	Mean		Range	Mean range	Mean
Privacy & Dignity	1.2	5.6 - 6.8	6.4		1.6	5.3 - 6.9	6.4		1.2	5.7 - 6.9	6.4
Patient Information	1.1	5.7 - 6.8	6.4		1.1	5.8 - 6.8	6.4		1.7	5.2 - 6.8	6.3
Access to Team	1.1	5.7 - 6.8	6.4		1.5	5.4 - 6.9	6.3		1.8	5.2 - 7.0	6.3
Overall	1.0	5.8 - 6.8	6.3		1.4	5.4 - 6.8	6.3		1.8	5.1 - 6.8	6.2
Scheduling	1.4	5.3 - 6.7	6.2		1.3	5.5 - 6.8	6.2		1.6	5.3 - 6.9	6.2
How Team Treats You	1.3	5.4 - 6.7	6.2		1.2	5.5 - 6.7	6.1		1.8	5.0 - 6.8	6.1
Tests	1.2	5.4 - 6.6	6.2		1.0	5.6 - 6.6	6.2		1.5	5.3 - 6.8	6.2
Environment	1.6	5.2 - 6.7	6.1		1.3	5.5 - 6.8	6.1		1.8	5.0 - 6.9	6.1
Fluid & Diet	1.6	5.1 - 6.7	6.1		1.9	5.0 - 6.8	6.0		2.0	4.6 - 6.5	5.9
Communication	1.6	4.9 - 6.5	5.9		1.7	4.9 - 6.6	5.8		2.9	3.8 - 6.7	5.8
Support	1.4	5.1 - 6.5	5.8		1.6	4.8 - 6.4	5.7		2.0	4.6 - 6.6	5.8
Needling	2.0	4.7 - 6.7	5.8		2.0	5.0 - 7.0	5.8		1.8	5.0 - 6.8	5.9
Sharing Decisions	1.7	4.7 - 6.4	5.6		2.2	4.3 - 6.5	5.6		2.5	4.1 - 6.6	5.5
Transport	2.1	4.5 - 6.6	5.5		2.2	4.5 - 6.6	5.5		2.5	4.4 - 6.9	5.6

Mean $\leq 5.8$	Mean $\geq 6.3$	Range $\geq 2.0$	Range $\leq 1.4$
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As well as centre scores, satellite-level scores and centre breakdown by participant age, ethnicity and treatment modality are available on the UKKA website at:

<https://ukkidney.org/kidneypatient-reported-experience-measure>.

## Overall Experience of care

The final question of Kidney PREM asks individuals to rate their *Overall Experience* of service:

*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 excluded when calculating the total Kidney PREM score. Unlike other Kidney PREM questions, 'Don't know' and 'not applicable' options are not available responses. *Overall Experience* scores well at 6.29 (range of centre scores 5.78 to 6.80). Figure 5.2 shows the percentage distribution of respondent scores for each kidney centre, overlaid with the centre mean score and 95% confidence interval.

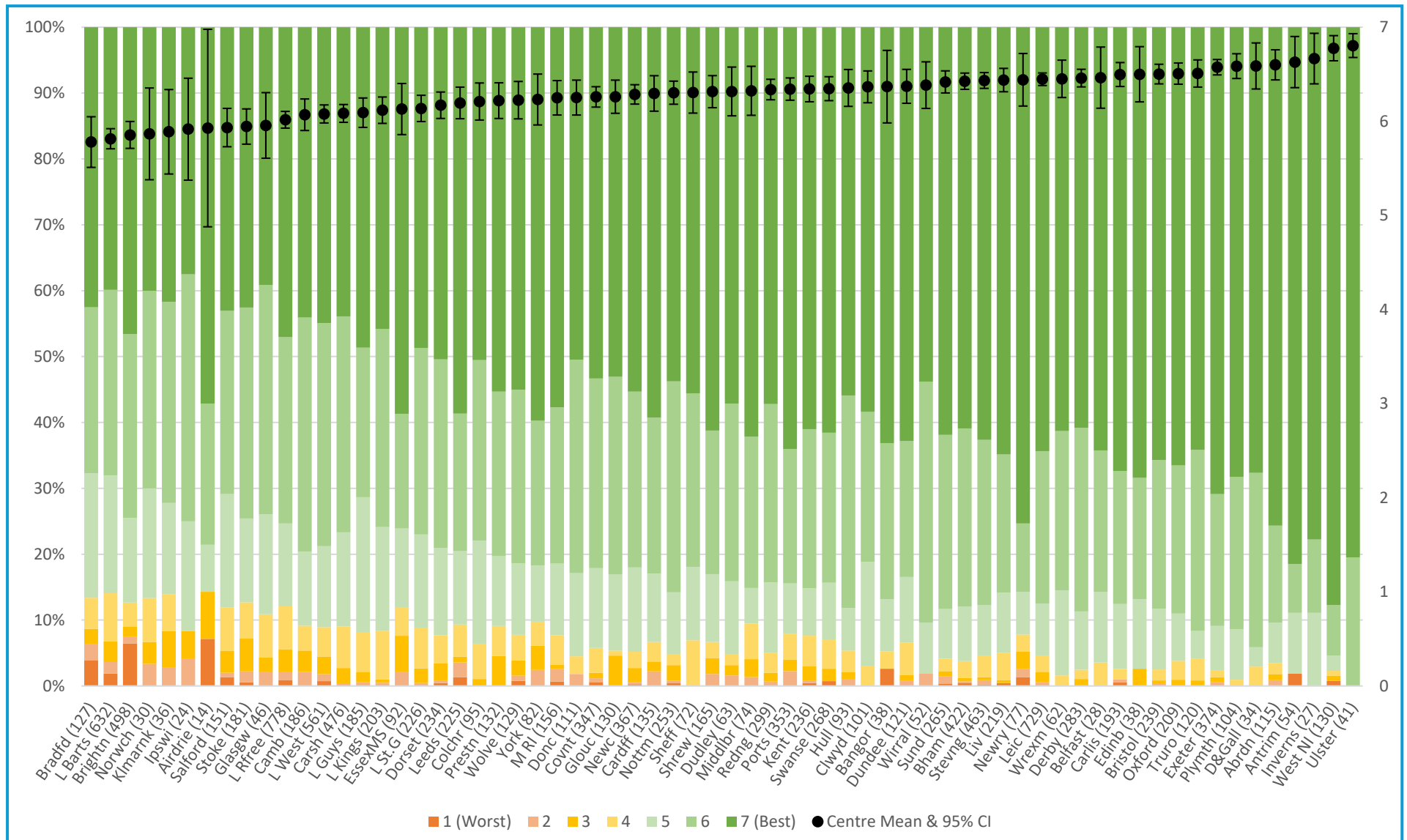
### Notes for interpretation:

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 14 to 778. It is important to keep in mind these numbers when interpreting the figure. For example:

- A centre with 20 responses means that if five individuals scored '1' for *Overall Experience*, 25% of the bar would be red.
- A centre with 500 responses means that if five individuals scored '1', just 1.0% of the bar would be red and so would not be visible.

It remains the case that the vast majority of Kidney PREM participants rate their *Overall Experience* highly, as 92.8% of all respondents give a score of at least 5 out of 7. One hundred percent of respondents at two centres gave scores of 5 to 7, and 55 out of 66 centres received these positive scores over 90% of the time. However, variation is apparent within each centre, with many having a small but notable proportion of participants giving poorer scores (1-3 out of 7), shown in red.

Figure 5.2: Centre scores for Overall Experience of the service provided by kidney centres (Q39 in Kidney PREM)



## Chapter 6: Kidney PREM theme results by treatment and deprivation

### Theme results by treatment

Average scores for individuals were calculated according to treatment modality, regardless of treating centre, and compared with scores from 2023 (Table 6.1). Given the large number of participants, changes in scores over time are expected to be small and hard to detect. As Kidney PREM data are negatively skewed (see Statistical Glossary of this report), with many participants giving high ( $\geq 5$ ) scores, data can also be summarised using medians and interquartile ranges, which are found in Appendix I. Differences in medians are seen less often but can be more striking when they do occur. Means and confidence intervals are displayed later in this report for each theme for 2024 results and provide a useful visual summary of differences between treatment modalities.

Table 6.1: Comparison of mean Kidney PREM scores by treatment group for 2024 and 2023

	Chronic kidney disease (non-KRT)					Peritoneal dialysis					Home haemodialysis				
	2024 (n=2,030)		2023 (n=1,617)		2024 vs 2023	2024 (n=603)		2023 (n=603)		2024 vs 2023	2024 (n=224)		2023 (n=204)		2024 vs 2023
	Mean	95% CI	Mean	95% CI		Mean	95% CI	Mean	95% CI		Mean	95% CI	Mean	95% CI	
Access	6.23	6.17 - 6.29	6.25	6.19 - 6.31	-0.02	6.39	6.29 - 6.49	6.42	6.33 - 6.50	-0.03	6.44	6.29 - 6.60	6.54	6.42 - 6.65	-0.09
Support	5.63	5.56 - 5.71	5.56	5.48 - 5.65	0.07	5.86	5.74 - 5.98	5.82	5.70 - 5.94	0.04	5.81	5.60 - 6.01	5.87	5.67 - 6.07	-0.06
Communication	5.77	5.70 - 5.83	5.75	5.67 - 5.82	0.02	5.90	5.80 - 6.01	5.98	5.88 - 6.08	-0.08	5.57	5.37 - 5.78	5.75	5.57 - 5.93	-0.18
Patient Information	6.37	6.31 - 6.42	6.41	6.35 - 6.46	-0.04	6.39	6.30 - 6.49	6.44	6.35 - 6.53	-0.05	6.43	6.28 - 6.57	6.48	6.34 - 6.61	-0.05
Fluid & Diet	5.34	5.25 - 5.43	5.28	5.17 - 5.38	0.07	6.09	5.98 - 6.19	6.01	5.90 - 6.13	0.07	6.11	5.93 - 6.29	6.23	6.07 - 6.39	-0.12
Needling	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Tests	6.08	6.02 - 6.13	6.08	6.02 - 6.14	0.00	6.08	5.99 - 6.18	6.11	6.01 - 6.21	-0.03	6.20	6.06 - 6.35	6.25	6.10 - 6.39	-0.05
Sharing Decisions	5.71	5.64 - 5.79	5.70	5.61 - 5.78	0.02	5.94	5.82 - 6.06	5.85	5.73 - 5.98	0.09	6.00	5.80 - 6.20	5.97	5.77 - 6.17	0.03
Privacy & Dignity	6.68	6.64 - 6.72	6.74	6.70 - 6.78	-0.06	6.53	6.44 - 6.62	6.53	6.44 - 6.62	0.00	6.46	6.31 - 6.61	6.53	6.39 - 6.66	-0.07
Scheduling & Planning	6.25	6.20 - 6.30	6.24	6.18 - 6.29	0.02	6.33	6.25 - 6.42	6.32	6.23 - 6.41	0.01	6.25	6.08 - 6.42	6.32	6.16 - 6.48	-0.07
How Team Treats you	6.07	6.01 - 6.13	6.06	5.99 - 6.12	0.02	6.29	6.20 - 6.39	6.23	6.13 - 6.32	0.07	6.11	5.94 - 6.28	6.08	5.91 - 6.26	0.03
Transport	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Environment	5.76	5.71 - 5.81	5.85	5.80 - 5.91	-0.09	5.93	5.84 - 6.02	5.98	5.89 - 6.07	-0.05	5.76	5.60 - 5.91	5.73	5.57 - 5.90	0.02
Overall Experience	6.12	6.06 - 6.18	6.16	6.10 - 6.22	-0.04	6.33	6.24 - 6.42	6.32	6.23 - 6.41	0.01	6.10	5.93 - 6.27	6.21	6.05 - 6.37	-0.11
PREM Score	5.96	5.91 - 6.01	5.97	5.91 - 6.02	-0.01	6.11	6.03 - 6.19	6.12	6.04 - 6.20	-0.01	6.03	5.89 - 6.16	6.08	5.96 - 6.21	-0.06

KRT: kidney replacement therapy, 95% CI: 95% confidence interval. Red highlighted = lowest theme mean, green highlighted = highest theme mean.

Those not receiving KRT continue to report poorest *Fluid and Diet* experiences (5.34) and highest *Privacy & Dignity* experiences (6.68). Peritoneal dialysis participants and those with transplants also report greatest experiences in *Privacy & Dignity* (6.53 and 6.76 respectively), the lowest themes being *Support* (5.86) and *The Environment* (5.74). Amongst participants not receiving KRT, those

on peritoneal dialysis and those with a functioning transplant, theme scores were similar to 2023, with all changes within  $\pm 0.1$  and an almost equal number of themes increasing and decreasing in score.

Most themes decreased in 2024 for those receiving home haemodialysis, the largest decrease in *Communication* (-0.18), now the lowest scoring theme within the modality group (5.57). *Privacy & Dignity* was the highest scored theme (6.46). Satellite haemodialysis participants reported an improved experience across most themes, the exceptions being *Transport* (-0.02) and *The Environment* (-0.03). *Sharing Decisions* had the largest increase (+0.20), followed closely by *How the Kidney Team Treats You* (0.18). *Patient Information* was the best scored theme for those in this group (6.38) and *Transport* the poorest (5.62). In stark contrast, those on haemodialysis in main centres reported poorer experiences across most themes, with the largest decreases seen in *Needling* (-0.16) and *Sharing Decisions* (-0.15). *Access* was scored best (6.24) and *Sharing Decisions* poorest (5.26), each of these scores the lowest “best” and “worst” themes across all treatment groups. Interestingly, although four out of six treatment groups had the same top-scoring theme, *Privacy & Dignity*, each modality had a unique poorest theme.

Table 6.1: Comparison of mean Kidney PREM scores by treatment group for 2024 and 2023 (cont.)

	Satellite haemodialysis					Centre haemodialysis					Transplant				
	2024 (n=5,002)		2023 (n=3,806)		2024 vs 2023	2024 (n=3,460)		2023 (n=3,354)		2024 vs 2023	2024 (n=1,722)		2023 (n=1,776)		2024 vs 2023
	Mean	95% CI	Mean	95% CI		Mean	95% CI	Mean	95% CI		Mean	95% CI	Mean	95% CI	
Access	6.36	6.33 - 6.39	6.32	6.28 - 6.35	0.04	6.24	6.20 - 6.28	6.25	6.21 - 6.30	-0.02	6.48	6.44 - 6.53	6.51	6.46 - 6.55	-0.02
Support	5.87	5.83 - 5.92	5.74	5.70 - 5.79	0.13	5.60	5.55 - 5.66	5.59	5.54 - 5.65	0.01	5.93	5.86 - 5.99	5.96	5.90 - 6.03	-0.03
Communication	5.96	5.93 - 6.00	5.94	5.90 - 5.98	0.03	5.74	5.69 - 5.79	5.80	5.75 - 5.84	-0.05	5.89	5.83 - 5.95	5.91	5.85 - 5.96	-0.01
Patient Information	6.38	6.35 - 6.41	6.33	6.30 - 6.37	0.04	6.19	6.14 - 6.23	6.22	6.17 - 6.27	-0.03	6.58	6.53 - 6.62	6.59	6.55 - 6.63	-0.01
Fluid & Diet	6.23	6.19 - 6.26	6.16	6.12 - 6.20	0.07	6.02	5.97 - 6.07	6.11	6.06 - 6.16	-0.09	5.97	5.89 - 6.04	5.96	5.88 - 6.03	0.01
Needling	5.88	5.83 - 5.93	5.78	5.72 - 5.84	0.10	5.63	5.56 - 5.70	5.78	5.72 - 5.85	-0.16	-	-	-	-	-
Tests	6.18	6.15 - 6.21	6.15	6.11 - 6.19	0.03	5.94	5.90 - 5.99	5.99	5.94 - 6.04	-0.05	6.41	6.37 - 6.45	6.40	6.36 - 6.44	0.01
Sharing Decisions	5.65	5.61 - 5.70	5.45	5.40 - 5.51	0.20	5.26	5.19 - 5.32	5.41	5.35 - 5.47	-0.15	5.98	5.92 - 6.05	5.93	5.86 - 6.00	0.05
Privacy & Dignity	6.34	6.31 - 6.37	6.29	6.25 - 6.33	0.05	6.16	6.11 - 6.20	6.21	6.16 - 6.25	-0.05	6.76	6.72 - 6.79	6.77	6.74 - 6.80	-0.02
Scheduling & Planning	6.27	6.23 - 6.30	6.23	6.19 - 6.27	0.04	6.06	6.01 - 6.11	6.14	6.10 - 6.19	-0.08	6.34	6.29 - 6.39	6.29	6.24 - 6.34	0.05
How Team Treats you	6.27	6.23 - 6.30	6.09	6.05 - 6.12	0.18	6.04	6.00 - 6.09	6.04	6.00 - 6.09	0.00	6.17	6.12 - 6.23	6.15	6.10 - 6.21	0.02
Transport	5.62	5.57 - 5.67	5.63	5.58 - 5.69	-0.02	5.43	5.37 - 5.49	5.44	5.38 - 5.50	-0.01	-	-	-	-	-
Environment	6.31	6.28 - 6.33	6.33	6.30 - 6.36	-0.03	6.02	5.98 - 6.06	6.09	6.06 - 6.13	-0.08	5.74	5.69 - 5.79	5.81	5.77 - 5.86	-0.08
Overall Experience	6.34	6.31 - 6.37	6.30	6.26 - 6.33	0.04	6.16	6.12 - 6.20	6.18	6.14 - 6.22	-0.02	6.32	6.27 - 6.37	6.31	6.26 - 6.35	0.02
PREM Score	6.11	6.08 - 6.14	6.05	6.02 - 6.08	0.06	5.87	5.84 - 5.91	5.92	5.89 - 5.96	-0.05	6.16	6.11 - 6.20	6.16	6.12 - 6.20	0.00

95% CI: 95% confidence interval. Red highlighted = lowest theme mean, green highlighted = highest theme mean.

Theme results by area and personal deprivation

Kidney PREM scores were calculated for participants within each Index of Multiple Deprivation quintile and according to how they had responded to the income sufficiency question described previously (Chapter 1). Figure 6.1 shows the distribution of responses to the Overall Experience question, comparing the postcode-derived IMD quintile to income sufficiency. The distribution of responses was similar across IMD quintiles, with very little variation in mean scores (6.21 to 6.31). In contrast, for the income sufficiency question, mean scores ranged from 5.49 to 6.38, a difference of more than 10% of the response scale. Those regularly going without necessities or not having enough reported poorest overall experiences, at 5.49 and 5.94 respectively, differences of 0.88 and 0.43 compared to those who reported more than enough. The difference between the findings for IMD and income sufficiency may be because there is only a weak association between these variables (Chapter 1). Affluent individuals can be found in areas of low IMD and vice versa.

Figure 6.1: Overall Experience scores by IMD quintile and income sufficiency

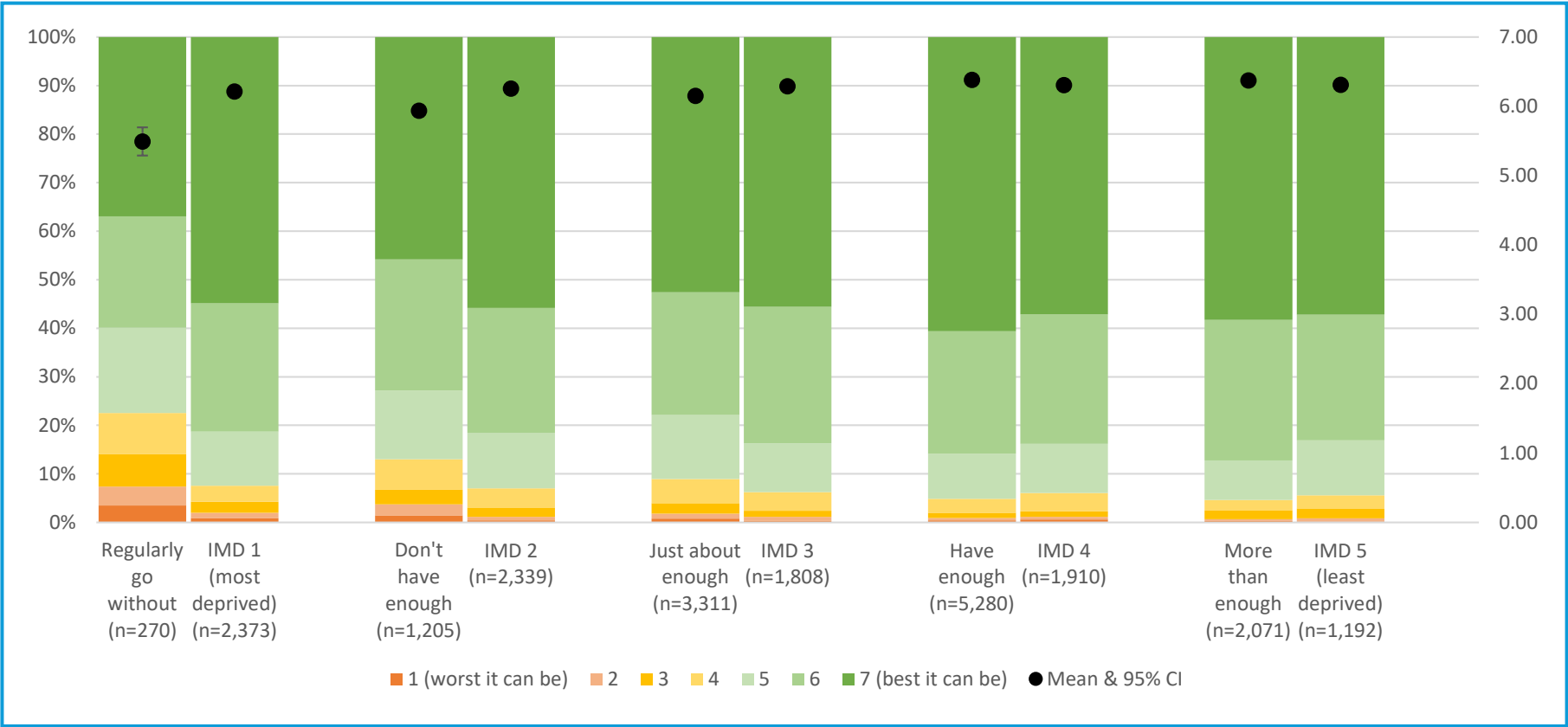


Table 6.2 Theme results by income sufficiency

	Regularly go without n=258	Don't have enough n=1,164	Just about enough n=3,224	Have enough n=5,194	More than enough n=2,031	Don't know n=236	Not say n=932
Access	5.61	5.92	6.23	6.45	6.54	6.23	6.21
Support	5.07	5.33	5.64	5.92	5.93	6.05	5.75
Communication	4.94	5.37	5.71	6.02	6.02	6.09	5.89
Patient Information	5.52	5.95	6.25	6.48	6.57	6.35	6.26
Fluid & Diet	5.28	5.77	5.96	6.10	6.00	6.19	6.06
Needling	4.99	5.34	5.68	5.99	5.96	5.68	5.61
Tests	5.28	5.78	6.02	6.24	6.37	6.07	6.01
Sharing Decisions	4.64	5.13	5.52	5.77	5.88	5.69	5.41
Privacy & Dignity	5.56	6.09	6.31	6.53	6.64	6.40	6.24
Scheduling & Planning	5.41	5.86	6.13	6.35	6.40	6.24	6.14
How Team Treats you	5.46	5.85	6.07	6.28	6.28	6.30	6.15
Transport	4.78	5.17	5.46	5.75	5.71	5.51	5.36
Environment	5.39	5.87	6.00	6.14	6.01	6.20	6.09
Overall Experience	5.49	5.94	6.15	6.38	6.37	6.11	6.23
PREM Score	5.22	5.65	5.93	6.16	6.19	6.10	5.97

Across themes, scores varied greatly according to participants' income sufficiency (Table 6.2), with those who "regularly go without" reporting the lowest scores in all themes. Scores were slightly higher from those who "do not have enough", and higher again for individuals with "just about enough". Respondents with "enough" or "more than enough" income reported the most positive experience in all areas. The themes with the largest differences were *Sharing Decisions* (1.25), *Communication* (1.09) and *Tests* (1.09). *The Environment* theme had the least variation, but still with a difference of 0.75, more than 10% of the response scale. Individuals who chose not to provide income sufficiency information tended to score relatively high, though generally slightly below those stating that they have "enough" or "more than enough". Interestingly, mean scores for those reporting "don't know" or who chose not to say were more closely aligned with those reporting "more than enough" than those stating they "regularly go without".

By IMD quintile, there was some indication of a similar pattern whereby those in the most deprived quintile reported the poorest experience in all themes with the exception of *Transport*, see Appendix Table F5. Individuals from the least deprived quintile reported the most positive experiences in all but three areas of care. However, these differences were much smaller, ranging from 0.08 in *Needling* to 0.13 in *Support*, *Fluid & Diet* and *Sharing Decisions*. The smaller differences may be because IMD is an area level measure which is less accurate than the individual level measure of income sufficiency.

IMD is a useful tool for assessing deprivation at a population level, providing information about the area where someone lives, however, it cannot account for someone's



individual circumstances. Therefore, whilst it is a useful proxy, individual-level measures of deprivation, such as income sufficiency, are likely to represent a more sensitive measure which may prove more helpful when considering different ways that people may experience their care. The higher response rate to this question also suggests a greater acceptability amongst Kidney PREM respondents than providing postcode information.

## Chapter 7: Kidney PREM theme breakdown by question

Detailed information on average scores by treatment type, and respondent scores for each of the questions within the Kidney PREM themes, is presented here for each of the Kidney PREM themes, shown at a national level.

Each of the pages of this chapter gives information about a theme. The mean and range of the centre scores is displayed first, to provide a summary of the centre variation. Graphs showing centre scores and 95% confidence intervals for each theme are displayed in Chapter 8.

The first figure in each section shows the mean score and 95% confidence interval (CI) for that theme by treatment modality for 2024 and 2023 for comparison. The number of participants used to calculate the scores for each treatment group is shown in brackets after the treatment name. These numbers vary, since 'not applicable', 'don't know' and missing responses have been excluded.

A second figure is presented for each Kidney PREM theme, showing the proportion of respondent scores (from 1 to 7) allocated to each of the questions within those themes. Again, the number of participants 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, since some questions are only applicable to certain participants (e.g., *Transport* and *Needling*). Again, 'don't know', 'not applicable' and missing responses have been excluded.

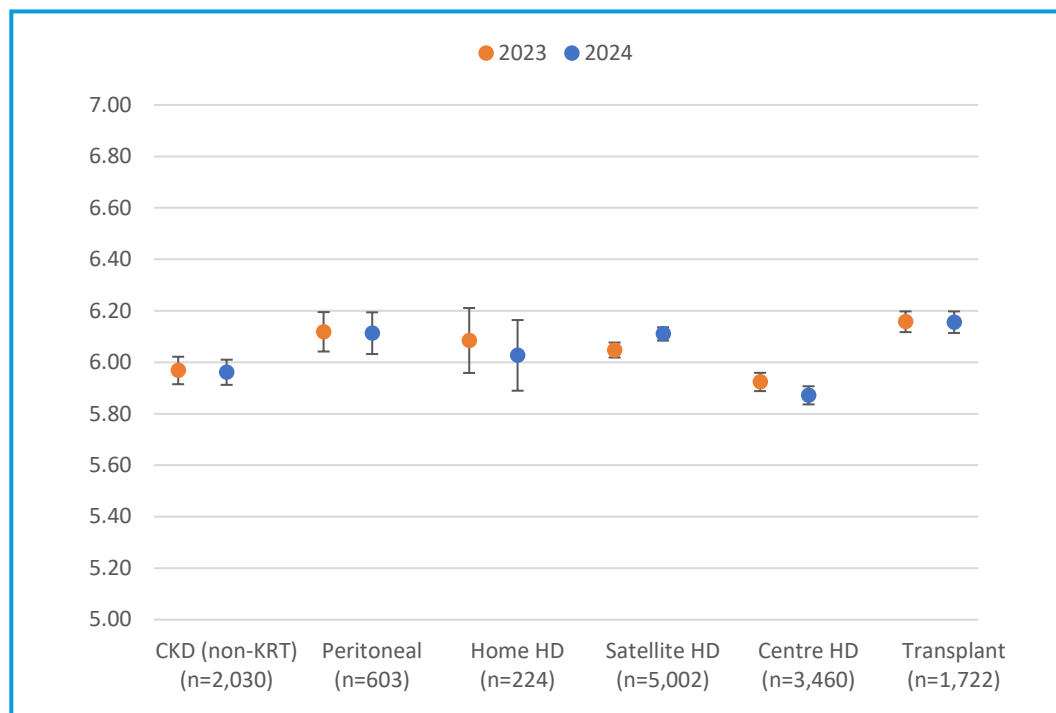
Questions for each theme have been abbreviated in this report but can be viewed in full online at the end of the Technical Report.

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.

## Kidney PREM score

Mean of centre scores: 6.07, range: 5.38 to 6.52.

Figure 7.0: Kidney PREM scale score means and 95% confidence intervals by treatment modality



The Kidney PREM score is calculated using each participant's results from questions 1 to 38. There was little variation between treatment modalities in line with results from previous years, scores ranging from 5.87 (95% CI 5.84 to 5.91) for those receiving haemodialysis in centre, to 6.16 (95% CI 6.11 to 6.20) for individuals with a kidney transplant, both modalities with similar scores to 2023. Although the confidence intervals for these two modalities do not overlap, the difference between scores is small, with just 0.28 between them. Notably, those on satellite haemodialysis reported a slightly increased patient experience whereas individuals receiving haemodialysis in centres saw a reduction, meaning that scores now differ by 0.24. This pattern was apparent in several themes throughout the survey.

## Theme 1: Access to Kidney Team

Mean of centre scores: 6.38, range: 5.72 to 6.78.

Figure 7.1A: *Access to the Kidney Team* theme means and 95% confidence intervals by treatment modality

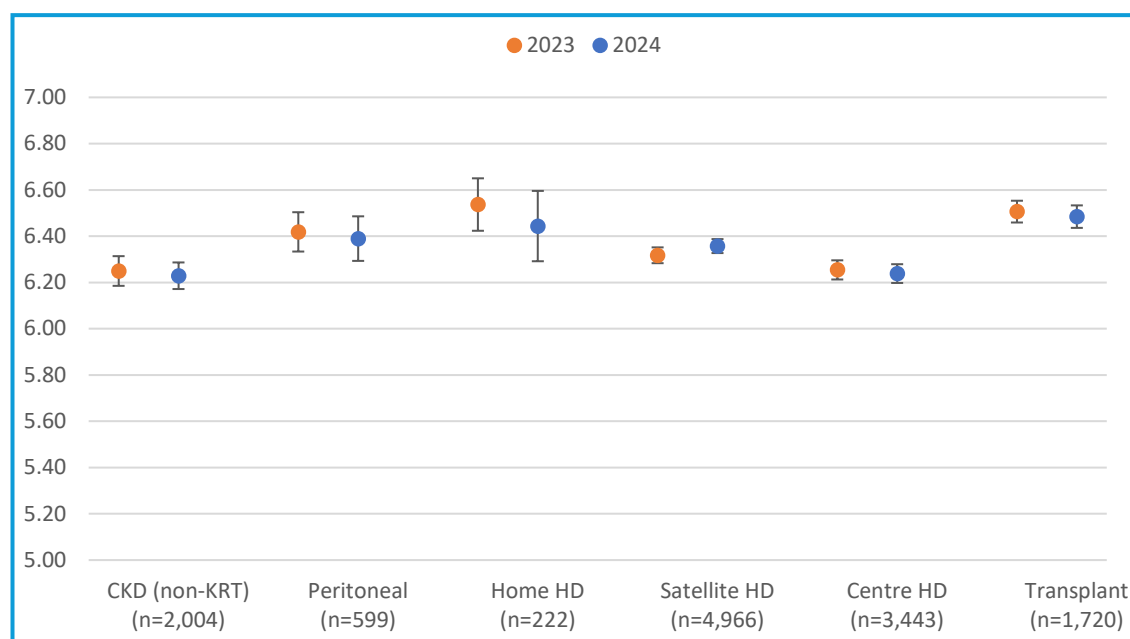
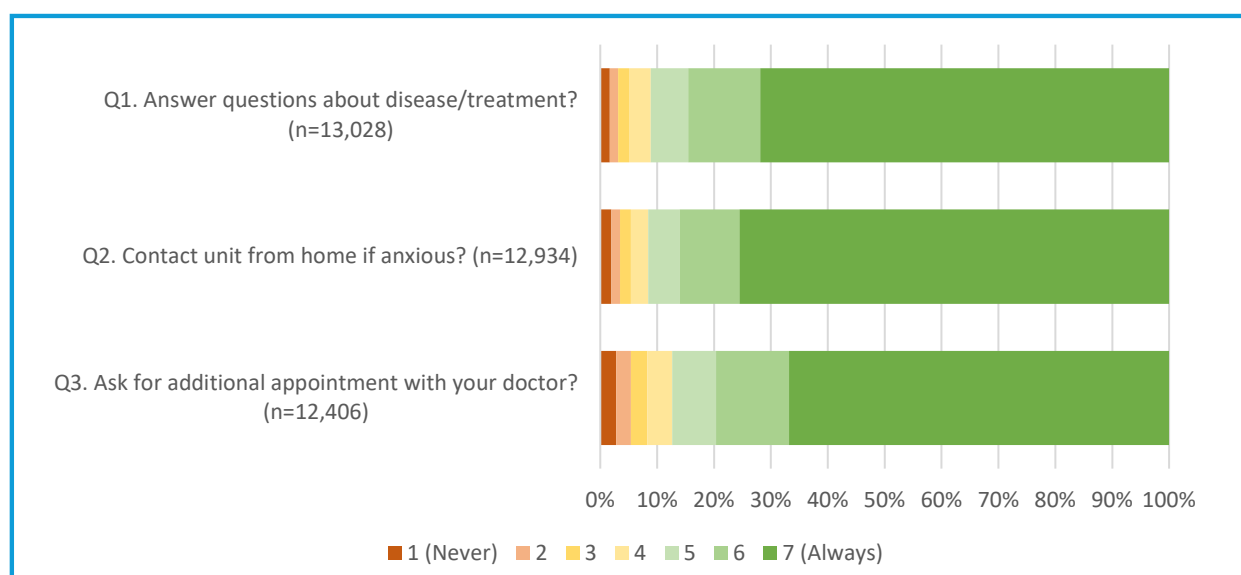


Figure 7.1B: Response frequencies for *Access to the Kidney Team* theme questions



*Access to the Kidney Team* continues to be scored well, the third highest of all Kidney PREM themes. For all three theme questions, more than 87% of participants scored their experience as 5 or above. Scores of 1-3 were used by around 5% of respondents when asked about *the team answering questions about their kidney disease or treatment* (Q1) and *feeling comfortable when contacting the unit from home* (Q2) but by 8.2% when asked about *additional appointments* (Q3). There was little variation between treatment modalities, with scores ranging from 6.23 (CKD non-KRT) to 6.48 (transplant).

## Theme 2: Support

Mean of centre scores: 5.82, range: 5.06 to 6.46.

Figure 7.2A: *Support* theme means and 95% confidence intervals by treatment modality

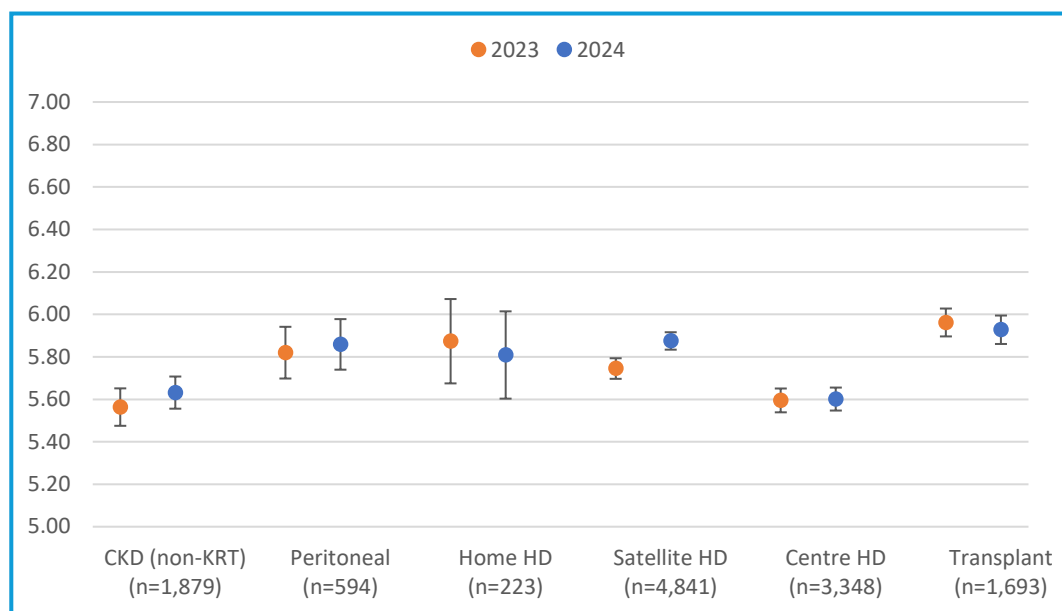
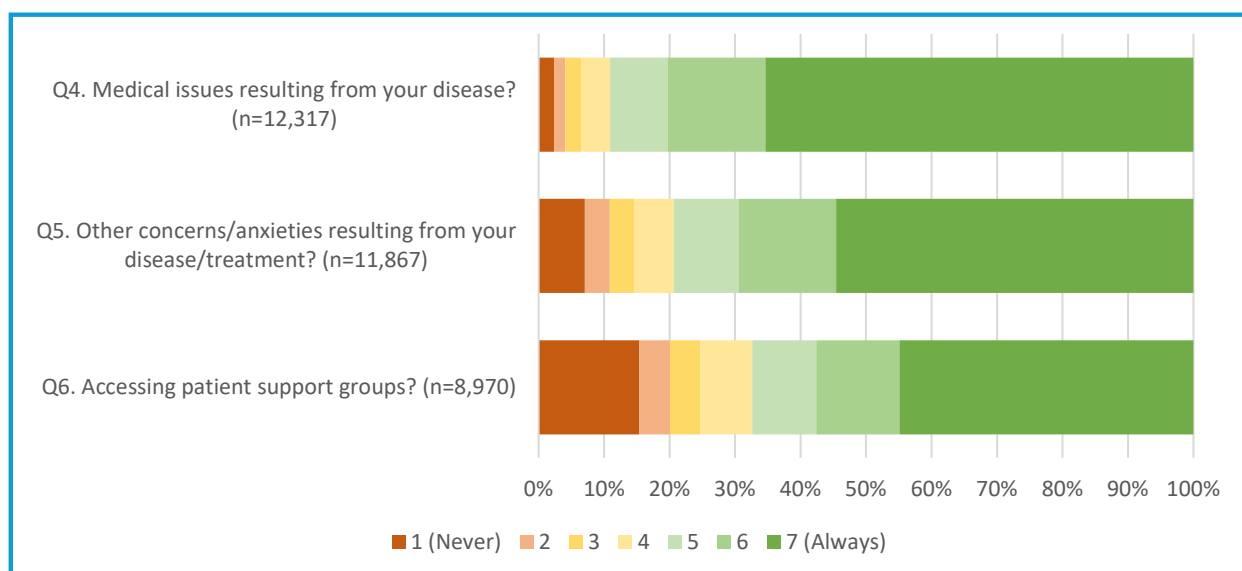


Figure 7.2B: Response frequencies for *Support* theme questions



*Support* theme routinely features at the lower end of Kidney PREM themes, although this year has increased from 5.71 to 5.82. Those receiving satellite haemodialysis reported an increase in experience, from 5.74 to 5.87, though scores for all modalities are below 6 out of 7. Variation remains at question level; although nearly 90% of participants report *support with medical issues* (Q4) with at least 5 out of 7, this is the case for around 80% of participants for *support with other concerns or anxieties* (Q5) and just 67% for *support accessing patient support groups* (Q6). Positively, 27.4% of participants awarded Q5 1 to 3 out of 7 in 2023, but this reduced to 24.7% in 2024.

### Theme 3: Communication

Mean of centre scores: 5.90, range: 4.88 to 6.48.

Figure 7.3A: *Communication* theme means and 95% confidence intervals by treatment modality

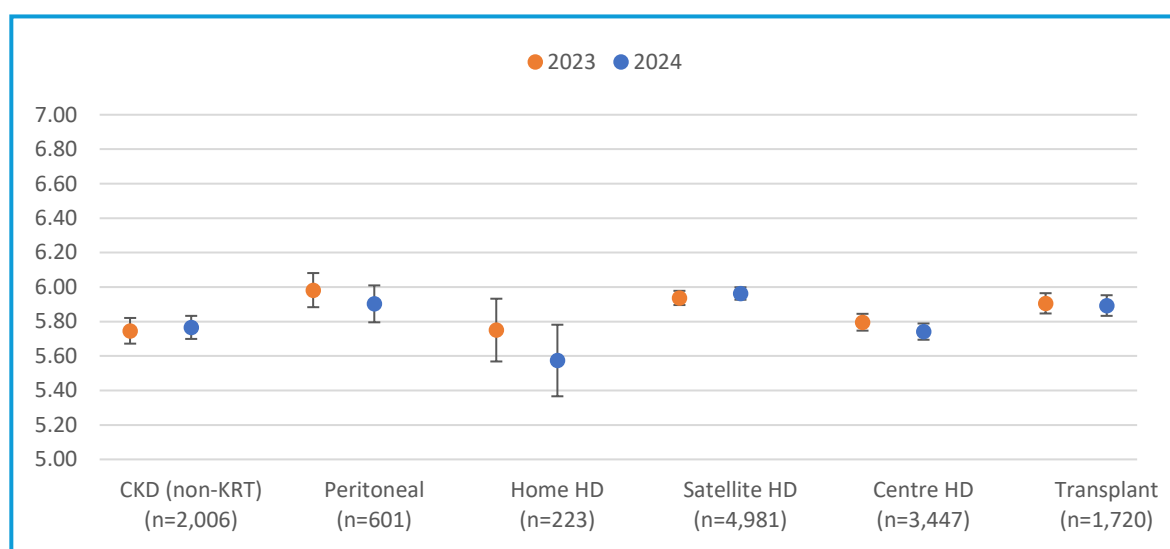
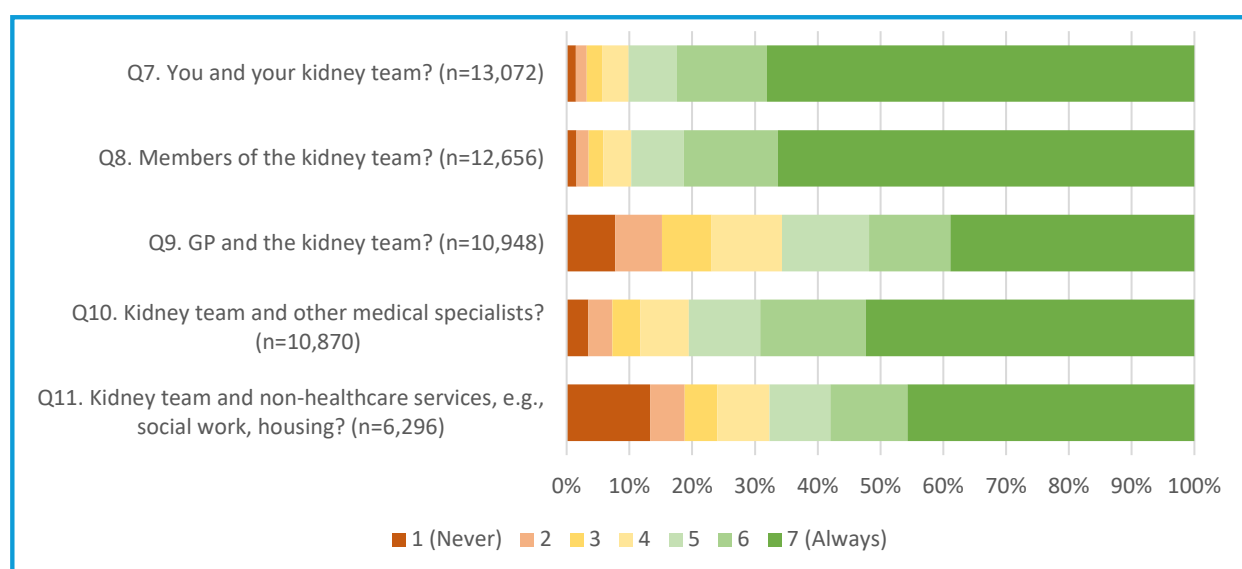


Figure 7.3B: Response frequencies for *Communication* theme questions



*Communication* continues to perform slightly lower than most themes, despite the small increase in score from 5.84 in 2023 to 5.90. As with *Support*, all treatment groups scored *Communication* below 6 out of 7. The largest change was seen in respondents receiving home haemodialysis, experience scores reducing from 5.75 to 5.57, widening the range of scores from 0.24 to 0.39 across modalities. At question level, the profile of responses was largely unchanged. Around 24% of participants gave 1 to 3 out of 7 scores to *communication between the GP and kidney team* (Q9) and *the kidney team and non-healthcare services* (Q11), similar to proportions seen in 2023. *Communication between patients and their kidney team* (Q7) and *between members of the kidney team* (Q8) remain positively reported, with around 90% awarding 5 to 7 out of 7.

## Theme 4: Patient Information

Mean of centre scores: 6.40, range: 5.69 to 6.85.

Figure 7.4A: *Patient Information* theme means and 95% confidence intervals by treatment modality

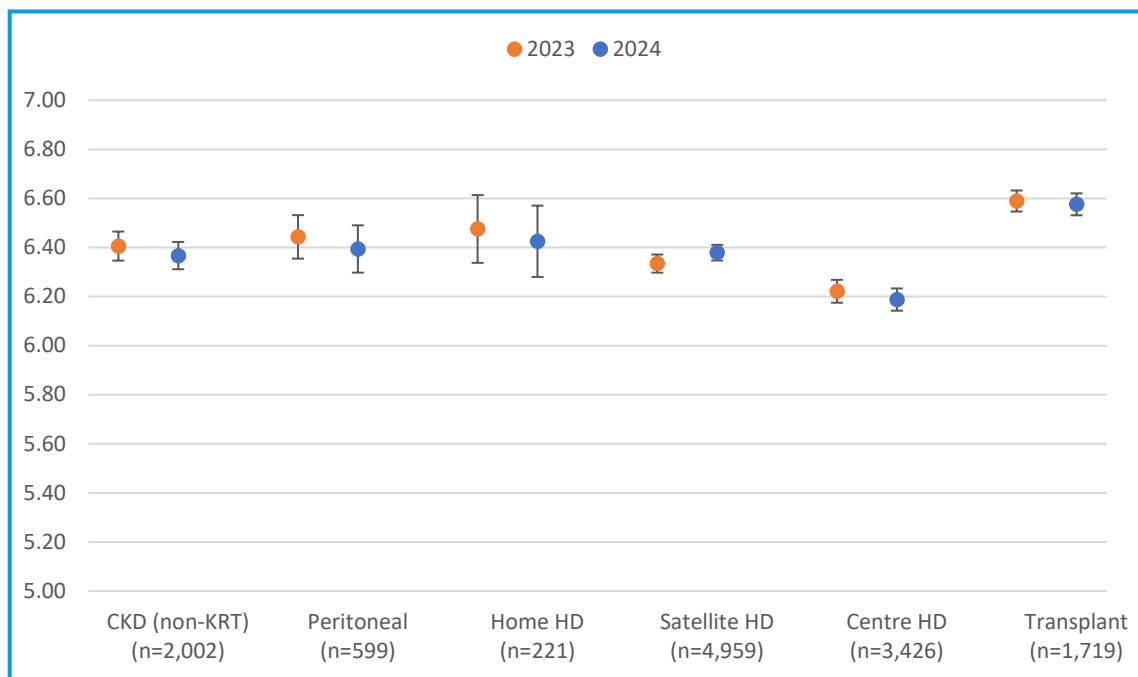
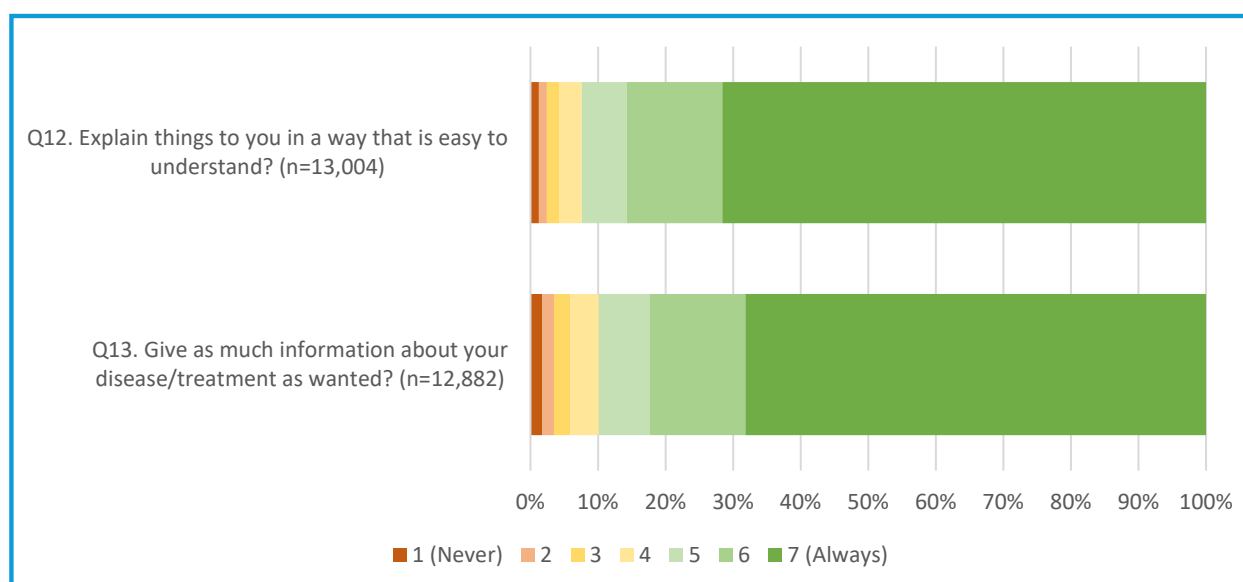


Figure 7.4B: Response frequencies for *Patient Information* theme questions



*Patient Information* remains one of the highest scoring themes of Kidney PREM, all treatment modalities averaging above 6 out of 7 for their experiences. Participants with transplants continue to report the highest scores at 6.58 and those receiving haemodialysis in centres the lowest at 6.19. Both questions are scored positively, with more than 90% scoring at least 5 out of 7.



## Theme 5: Fluid & Diet

Mean of centre scores: 6.06, range: 5.12 to 6.72.

Figure 7.5A: *Fluid & Diet* theme means and 95% confidence intervals by treatment modality

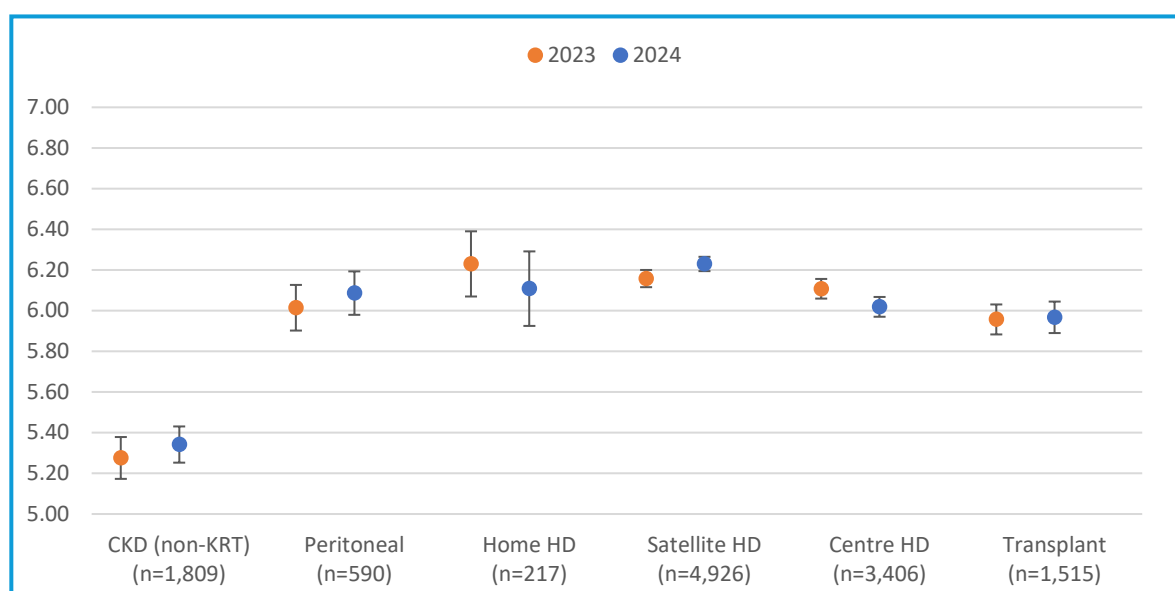
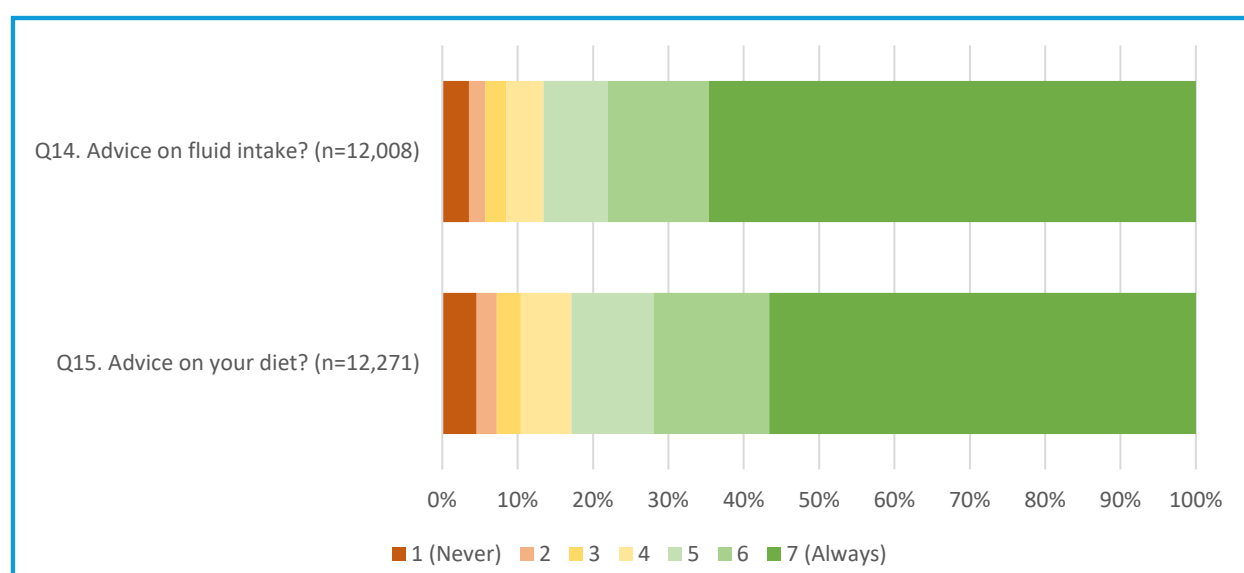


Figure 7.5B: Response frequencies for *Fluid & Diet* theme questions



Scores for *Fluid & Diet* have remained consistent as in previous years at just over 6 out of 7. Participants not receiving KRT continue to report a much lower experience (5.34) than all other groups. *Fluid & Diet* has the widest range of scores between treatment groups across all themes, with individuals receiving satellite haemodialysis reporting the best experience (6.23). Centre and satellite haemodialysis scores have been similar in the past, but those on satellite haemodialysis now report a slightly higher experience (6.23 vs 6.02). *Advice on fluid intake* (Q14) continues to be reported more positively than *diet* (Q15), in which more than 10% give scores of 1-3 out of 7.

## Theme 6: Needling

Mean of centre scores: 5.82, range: 4.70 to 6.69.

Figure 7.6A: *Needling* theme means and 95% confidence intervals by treatment modality

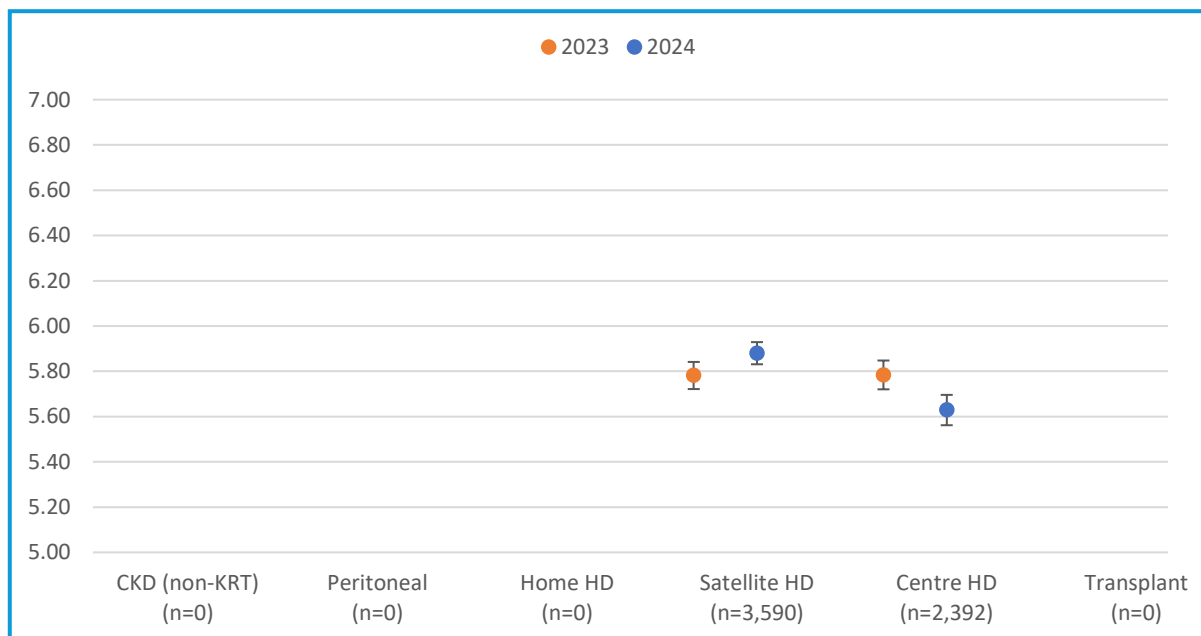
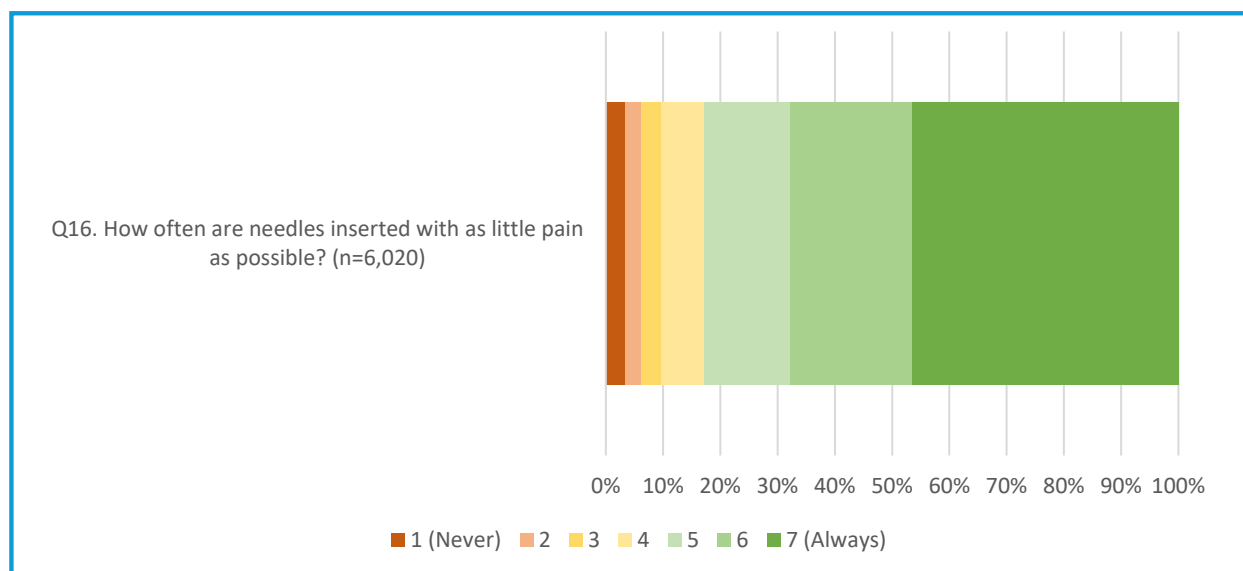


Figure 7.6B: Response frequencies for *Needling* theme questions



The *Needling* theme contains just one question and is applicable only to those receiving haemodialysis in satellite units or main centres. *Needling* remains one of the more poorly scored themes, now in the bottom three. The range of scores across centres is wide (4.7 to 6.7), suggesting variation in practices across the country. Historically, there has been little difference in experience between those receiving haemodialysis in satellites and centres, but in 2024 scores have increased for satellite participants to 5.88 and decreased for those at centres to 5.63, a difference of 0.25.

## Theme 7: Tests

Mean of centre scores: 6.16, range: 5.41 to 6.59.

Figure 7.7A: *Tests* theme means and 95% confidence intervals by treatment modality

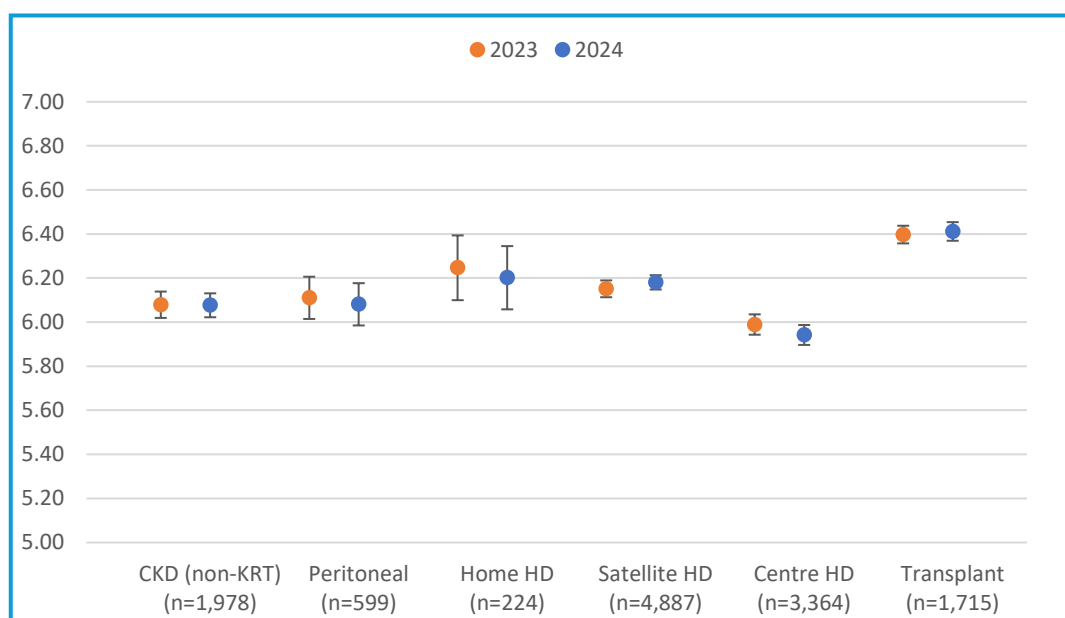
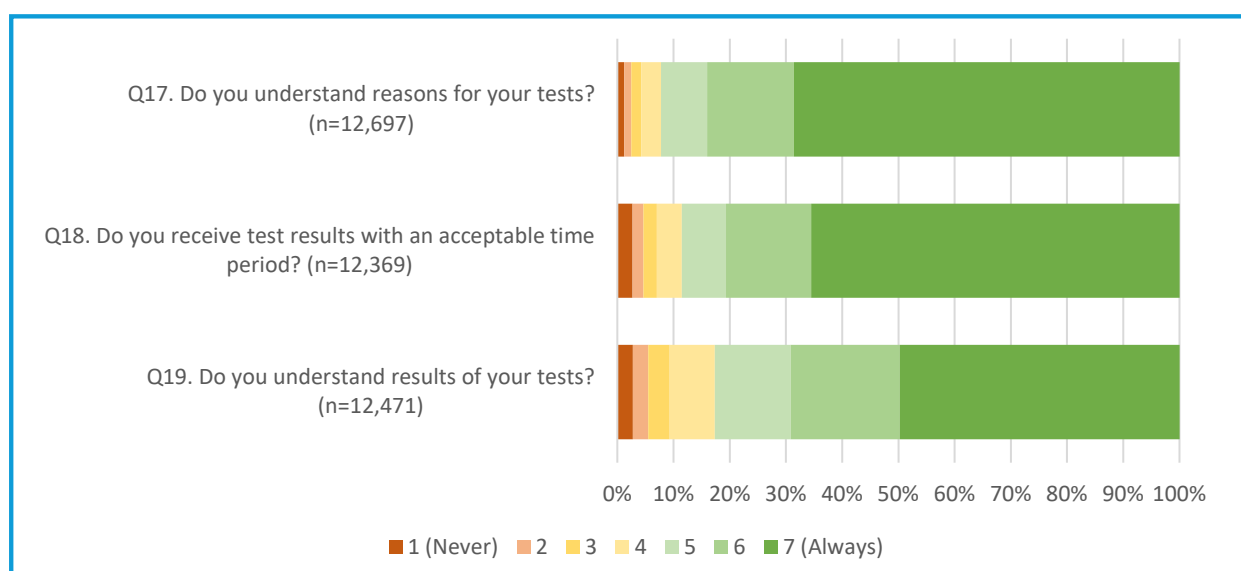


Figure 7.7B: Response frequencies for *Tests* theme questions



Scores for *Tests* are relatively high across all treatment modalities, although for those receiving haemodialysis in centres this has reduced to just below 6 out of 7 in 2024. For those with transplants, scores remain high at 6.41, 0.21 more than the next highest treatment group, home haemodialysis. Of the three questions comprising the theme, *understanding results of tests* (Q19) is the least positive with 9.3% of participants scoring experiences with 1-3 out of 7, compared to 7.0% for *receiving results within an acceptable time* (Q18) and 4.1% for *understanding reasons for tests* (Q17).

## Theme 8: Sharing Decisions

Mean of centre scores: 5.64, range: 4.71 to 6.36.

Figure 7.8A: *Sharing Decisions* theme means and 95% confidence intervals by treatment modality

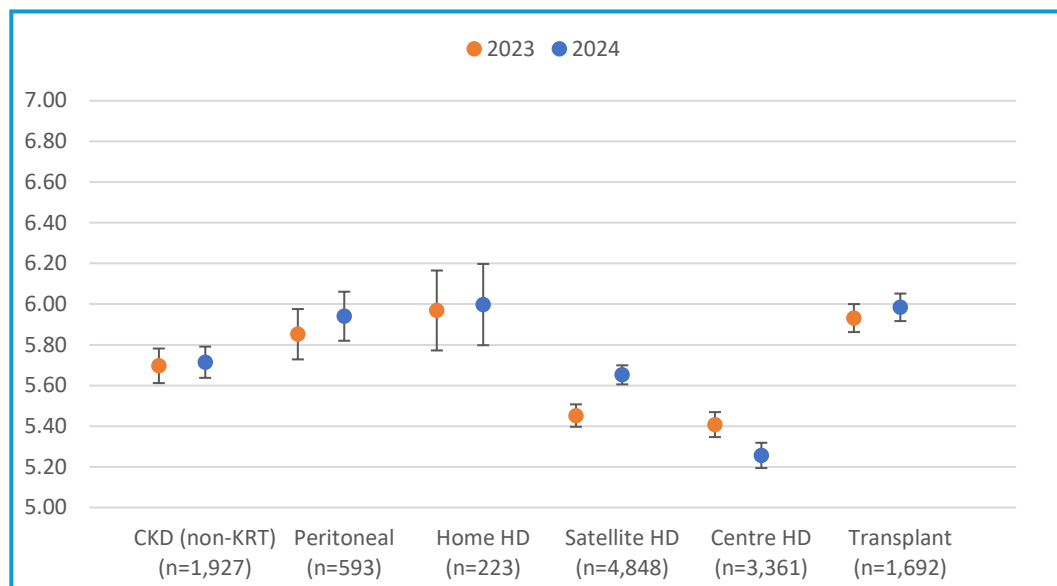
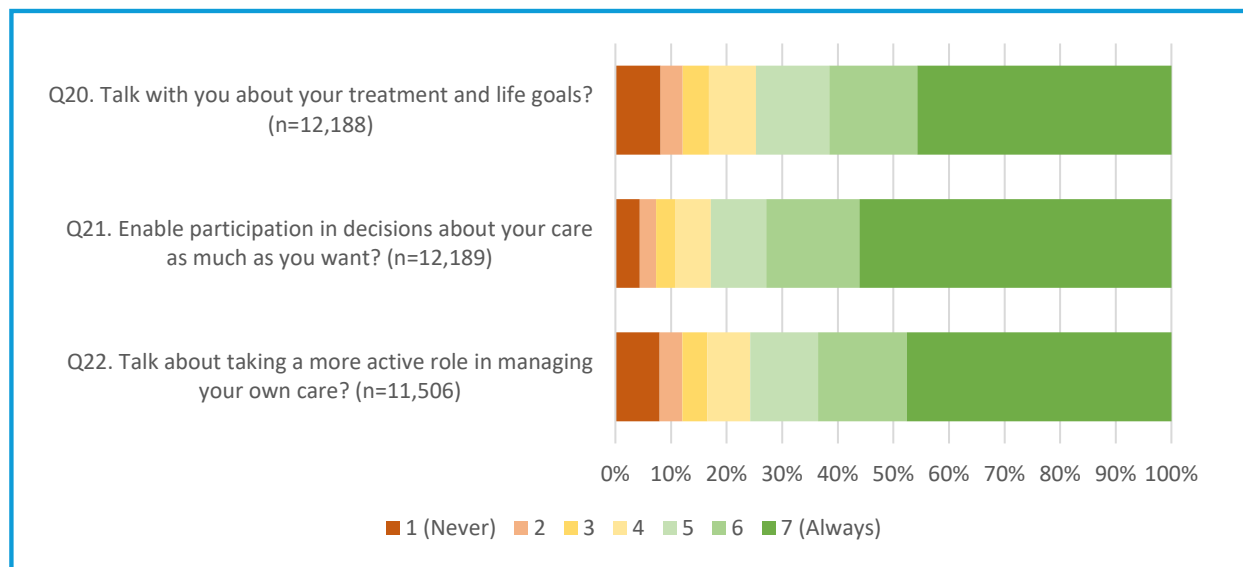


Figure 7.8B: Response frequencies for *Sharing Decisions* theme questions



As one of the poorer scoring themes, the small increase in score for *Sharing Decisions* from 5.59 to 5.64 is encouraging. Satellite and centre haemodialysis scores were similar in 2023 (5.45 and 5.41 respectively) but now differ by 0.40 at 5.65 (satellite) and 5.26 (centre). Home haemodialysis, peritoneal dialysis and transplant scores are similar at around 6 out of 7, whereas those not receiving KRT slightly lower at 5.71 out of 7. Unlike some themes where scores are affected by one poorer experience captured by one question, lower scores (1 to 3) are frequently reported across *Sharing Decisions*; discussing treatment and life goals (Q20) 16.8%, enabling participation in decisions (Q21) 10.8% and discussing active role in care (Q22) 16.5%.

## Theme 9: Privacy & Dignity

Mean of centre scores: 6.40, range: 5.56 to 6.79.

Figure 7.9A: *Privacy & Dignity* theme means and 95% confidence intervals by treatment modality

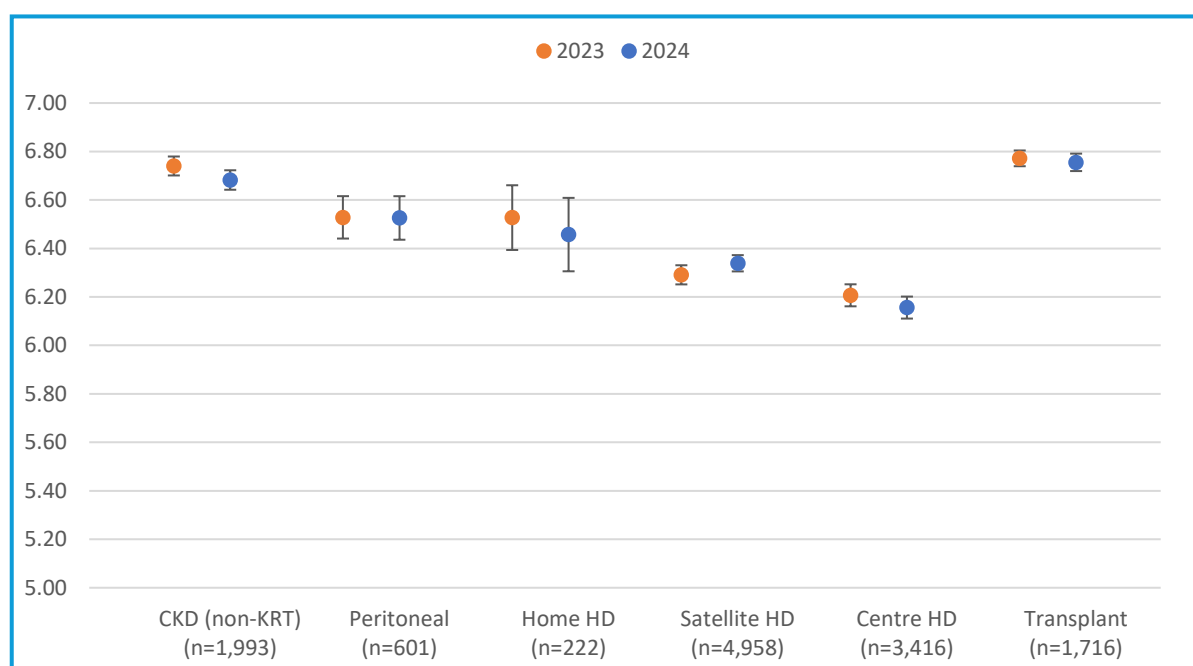
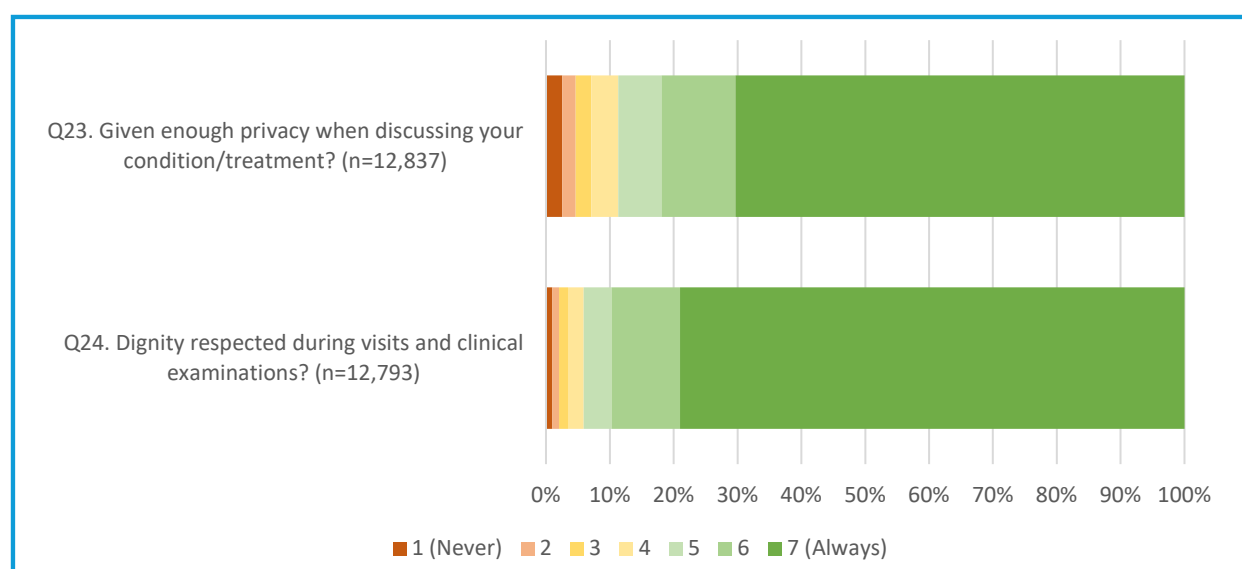


Figure 7.9B: Response frequencies for *Privacy & Dignity* theme questions



For the sixth consecutive year, *Privacy & Dignity* is Kidney PREM's top performer, rated top by four of the six treatment modality groups. As seen in other themes, satellite haemodialysis scores have slightly increased to 6.34 and have slightly decreased for centre haemodialysis to 6.16, though both remain relatively high at over 6 out of 7. *Respecting dignity* (Q24) is one of the highest scoring questions, 94.1% of participants awarding 5-7 out of 7 and just 3.4% selecting 1-3.

## Theme 10: Scheduling & Planning

Mean of centre scores: 6.25, range: 5.34 to 6.75.

Figure 7.10A: *Scheduling & Planning* theme means and 95% confidence intervals by treatment modality

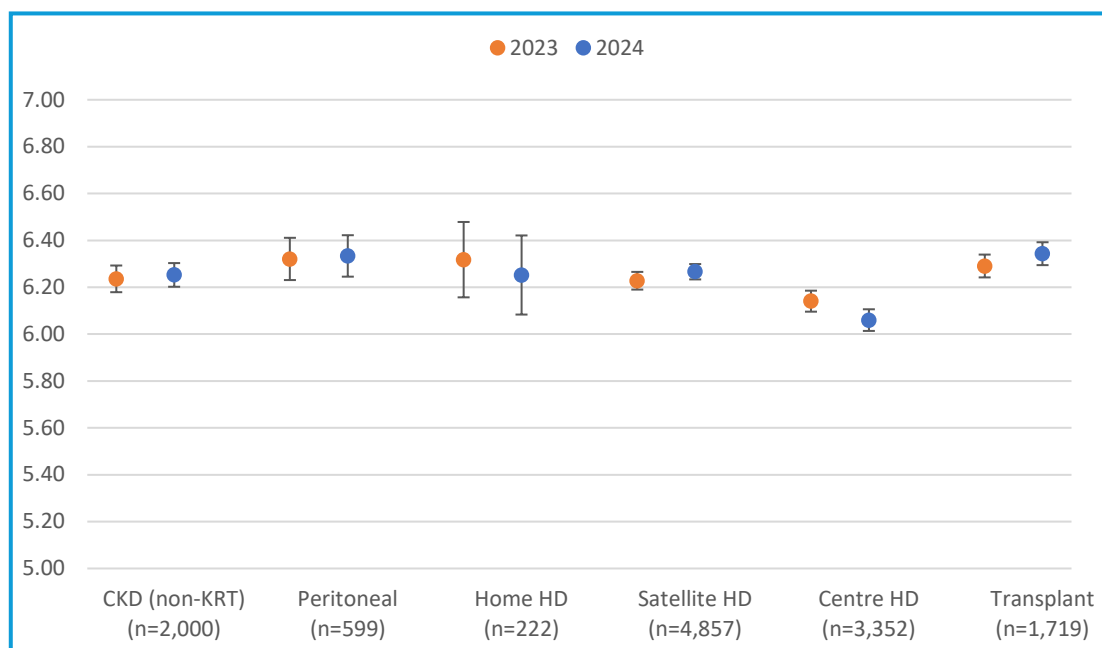
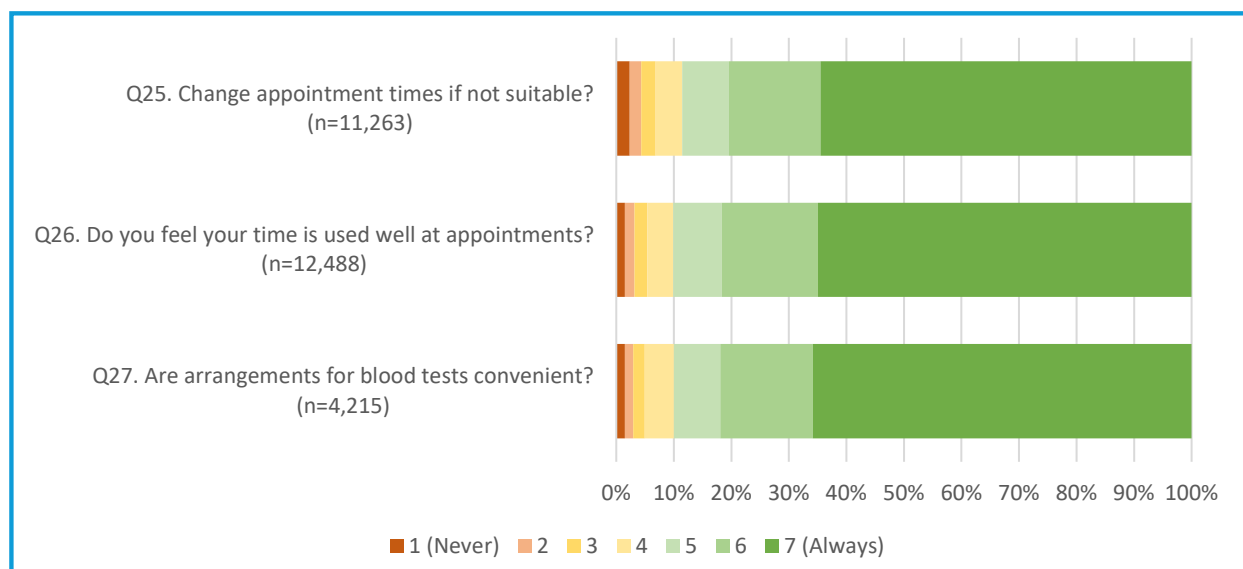


Figure 7.10B: Response frequencies for *Scheduling & Planning* theme questions



*Scheduling & Planning* scores were above 6 out of 7 for all treatment groups. Centre haemodialysis respondents scored the theme least positively in 2023, the score further decreasing to 6.06 in 2024. All three theme questions were scored positively, 88.5% of respondents scoring 5-7 for changing appointment times (Q25), 90% for both use of time in appointments (Q26) and blood test arrangements (Q27).

## Theme 11: How the Kidney Team Treats You

Mean of centre scores: 6.20, range: 5.36 to 6.69.

Figure 7.11A: *How the Kidney Team Treats You* theme means and 95% confidence intervals by treatment modality

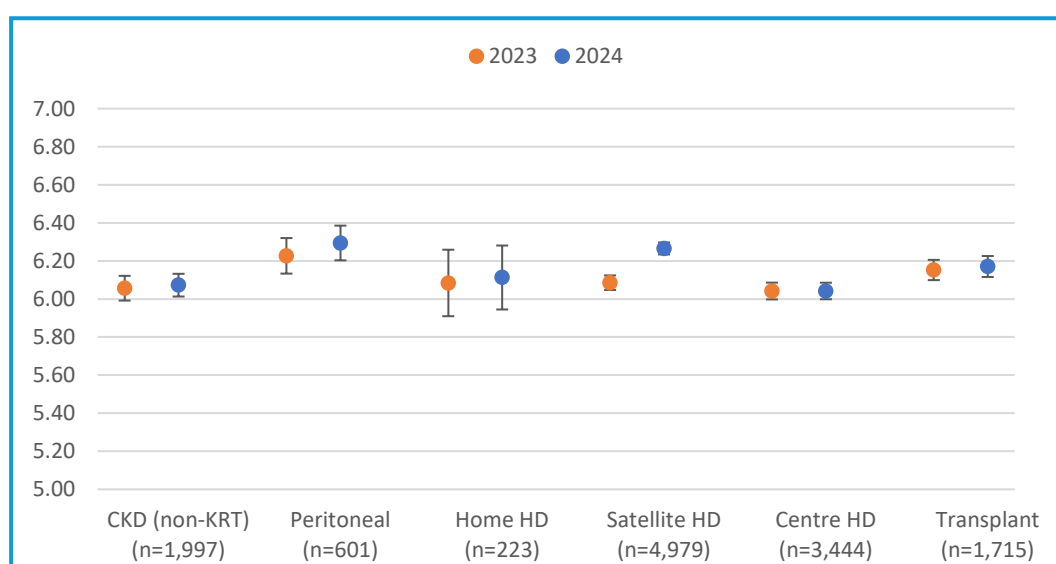
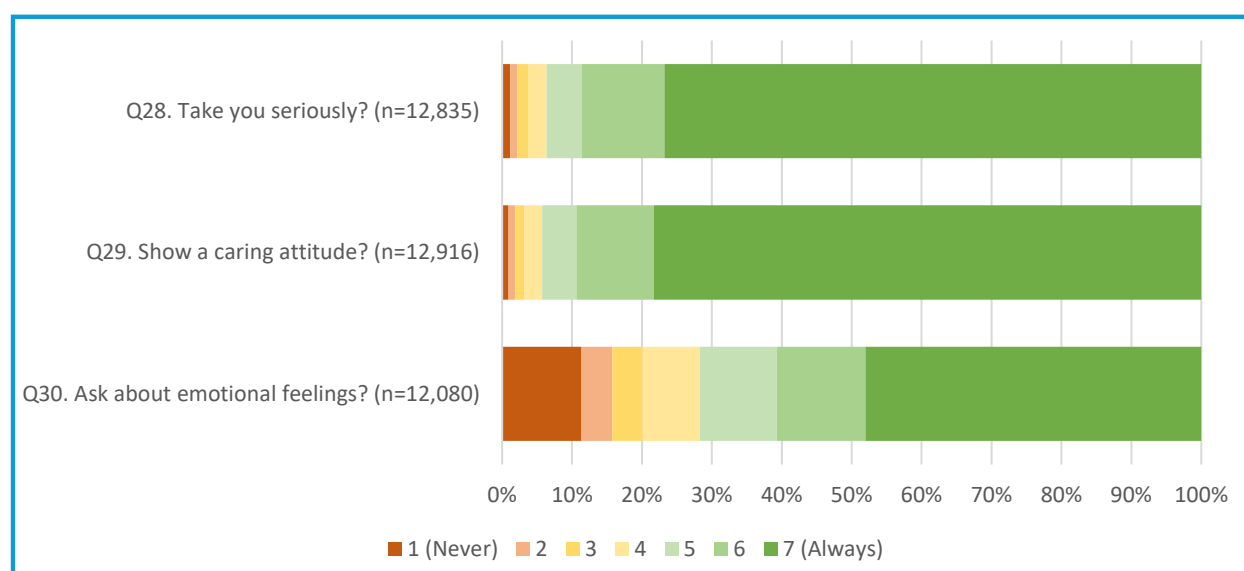


Figure 7.11B: Response frequencies for *How the Kidney Team Treats You* theme questions



*How the Kidney Team Treats You* was another theme where all treatment groups scored above 6 out of 7. Most had similar scores to 2023, with the exception of those receiving satellite haemodialysis; these increased from 6.09 to 6.27. Being asked about emotional feelings (Q30) was once again the poorest scoring question of the theme, 11.3% selecting 1 (never), and a fifth awarding 1-3 out of 7. However, being shown a caring attitude (Q29) had the highest proportion of participants selecting 5-7 (94.3%) across all Kidney PREM themes.

## Theme 12: Transport

Mean of centre scores: 5.54, range: 4.55 to 6.64.

Figure 7.12A: *Transport* theme means and 95% confidence intervals by treatment modality

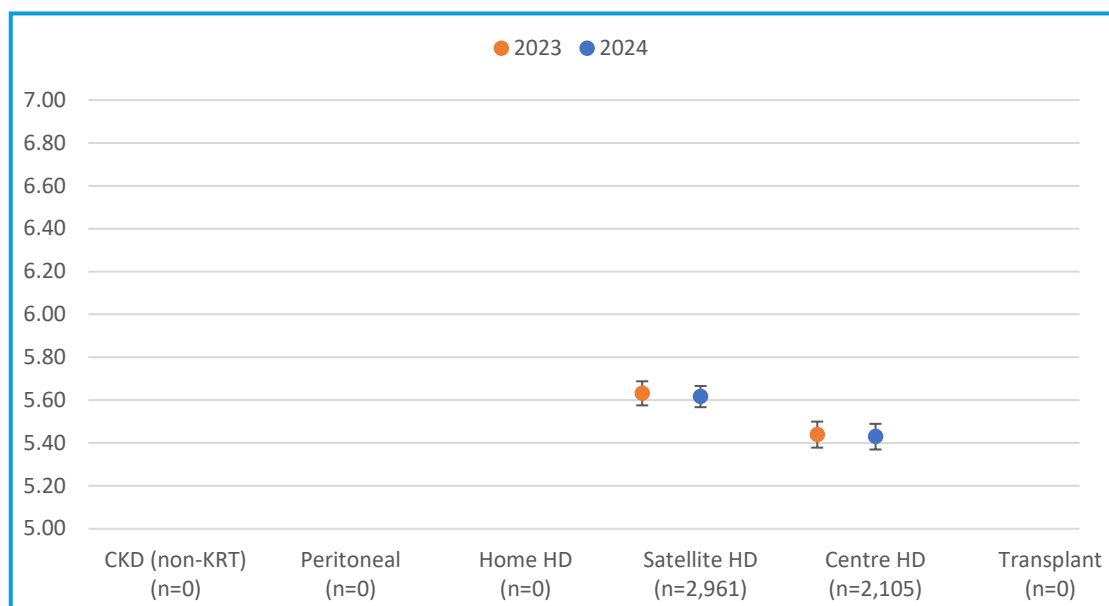
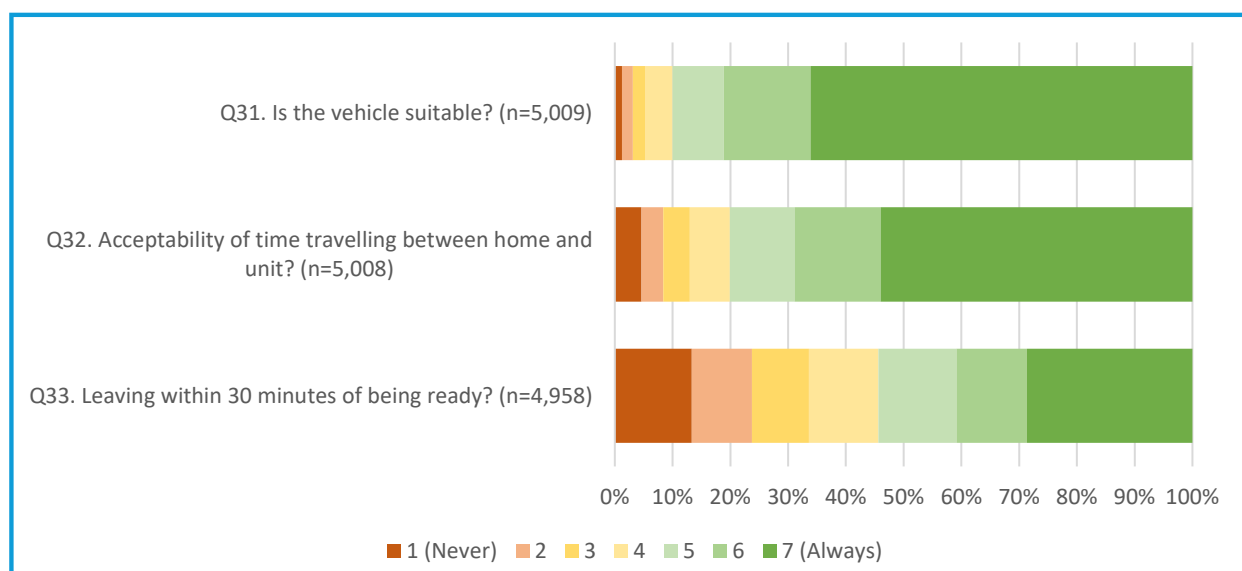


Figure 7.12B: Response frequencies for *Transport* theme questions



*Transport* theme is another in which the questions only apply to individuals receiving haemodialysis in centres or satellite units. Those attending centres continue to report slightly poorer experiences than those at satellites (5.43 vs 5.62), which is almost unchanged from 2023. *Leaving within 30 minutes of being ready* (Q33) remains the poorest scored question of the Kidney PREM, 1-3 out of 7 selected by 33.6% of respondents and 5-7 selected by just 54.4%.



## Theme 13: The Environment

Mean of centre scores: 6.08, range: 5.17 to 6.74.

Figure 7.13A: *The Environment* theme means and 95% confidence intervals by treatment modality

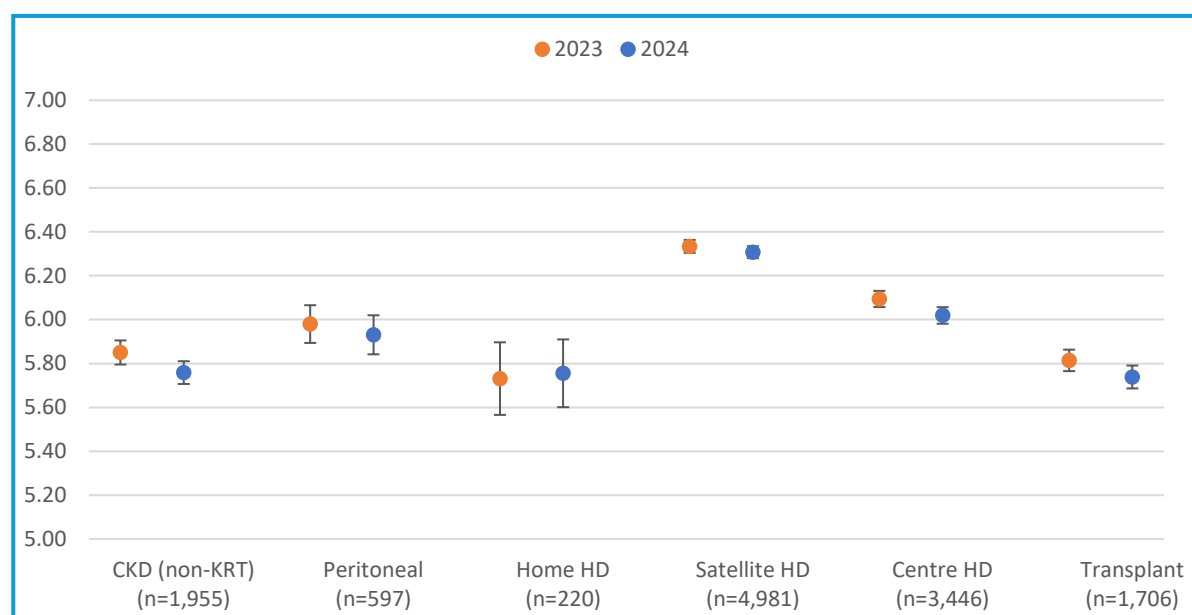
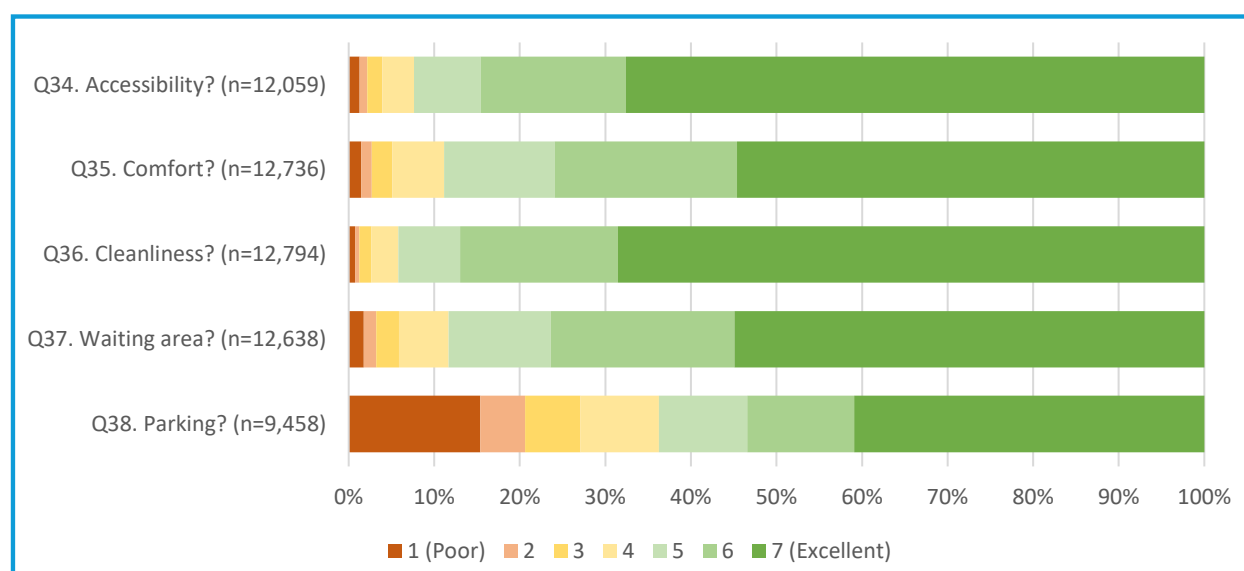


Figure 7.13B: Response frequencies for *The Environment* theme questions



There remains some variation in scores between treatment groups, with satellite haemodialysis scoring the most positively at 6.33 out of 7. Those not receiving KRT, individuals on home haemodialysis and those with transplants reported similar experiences, 5.76, 5.76 and 5.74 respectively. Over 90% of participants selected 5-7 out of 7 for both *comfort* (Q35) and *the waiting area* (Q37). *Parking* continues to be an issue, with over a quarter (27.1%) choosing 1-3 out of 7.

Theme 14: Overall Experience

Mean of centre scores: 6.29, range: 5.78 to 6.80.

Figure 7.14A: Overall Experience theme means and 95% confidence intervals by treatment modality

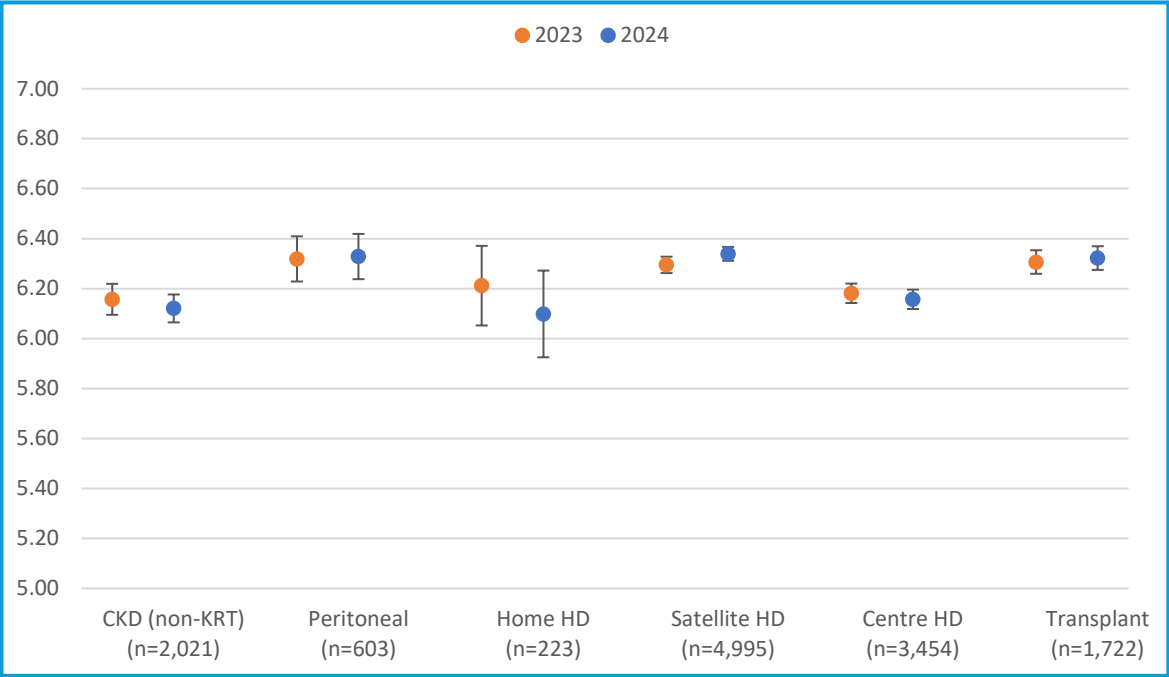
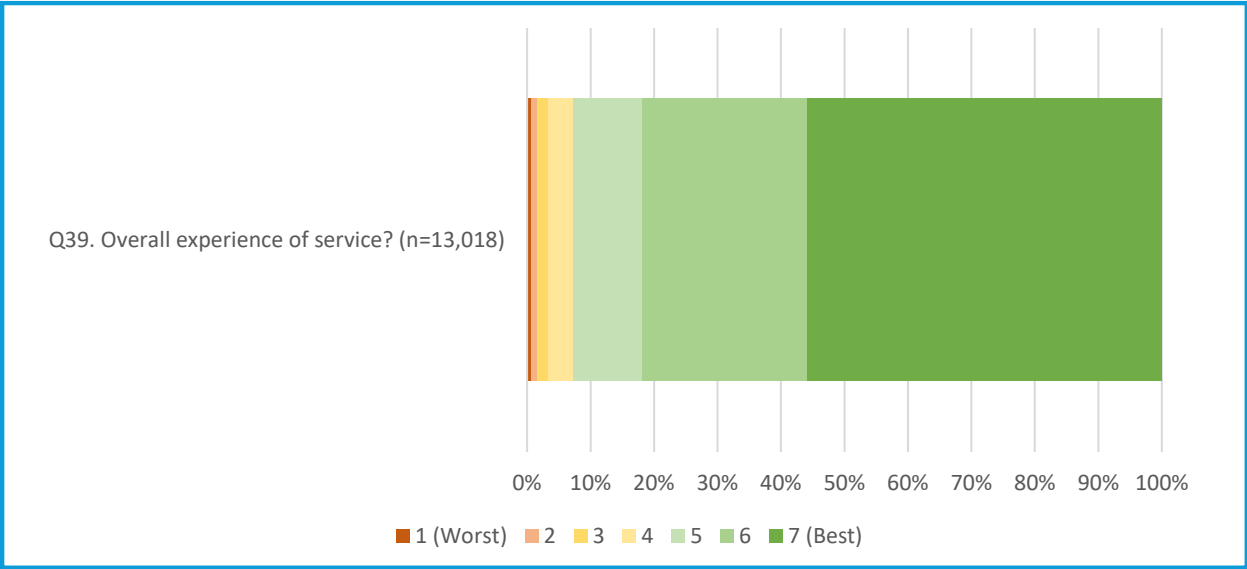


Figure 7.14B: Response frequencies for Overall Experience theme questions



Overall Experience continues to be well-reported, all treatment modalities scoring above 6 out of 7. Scores were similar to 2023, although those for home haemodialysis recipients reduced slightly by 0.11 to 6.10 out of 7. Over 90% of participants rated their Overall Experience positively (using 5-7 of the response scale), though with variation by centres as reported in chapter 5.

## Chapter 8: Patient experience of kidney care across the service

This chapter presents mean scores for each theme in the 2024 Kidney PREM, by centre and geographical region. Commentary has not been provided since centres are encouraged to view this information alongside their portal data to assess their results, which can be accessed here:

<https://ukkidney.org/audit-research/data-portal/prem>

### *Notes for interpretation:*

On each page of chapter 8, two types of figures are presented.

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

These are displayed on the left of each page, showing centre mean scores and 95% confidence intervals for each theme of the 2024 Kidney PREM. Vertical green lines on the charts denote the lower quartile, median and upper quartile of these scores. As before, 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.

Centre mean scores were estimated if at least 7 responses were received. Unlike the previous couple of years, those participants for whom a centre could not be attributed are not shown, since the change in centre selection methodology meant that this was too small a group to make any meaningful comparisons.

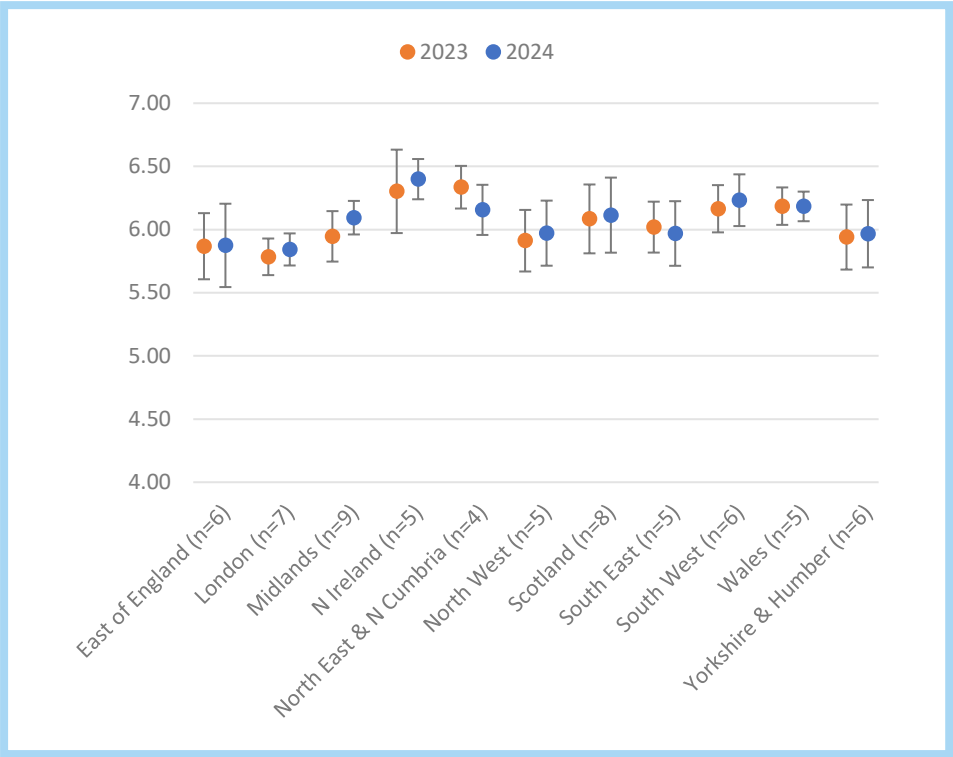
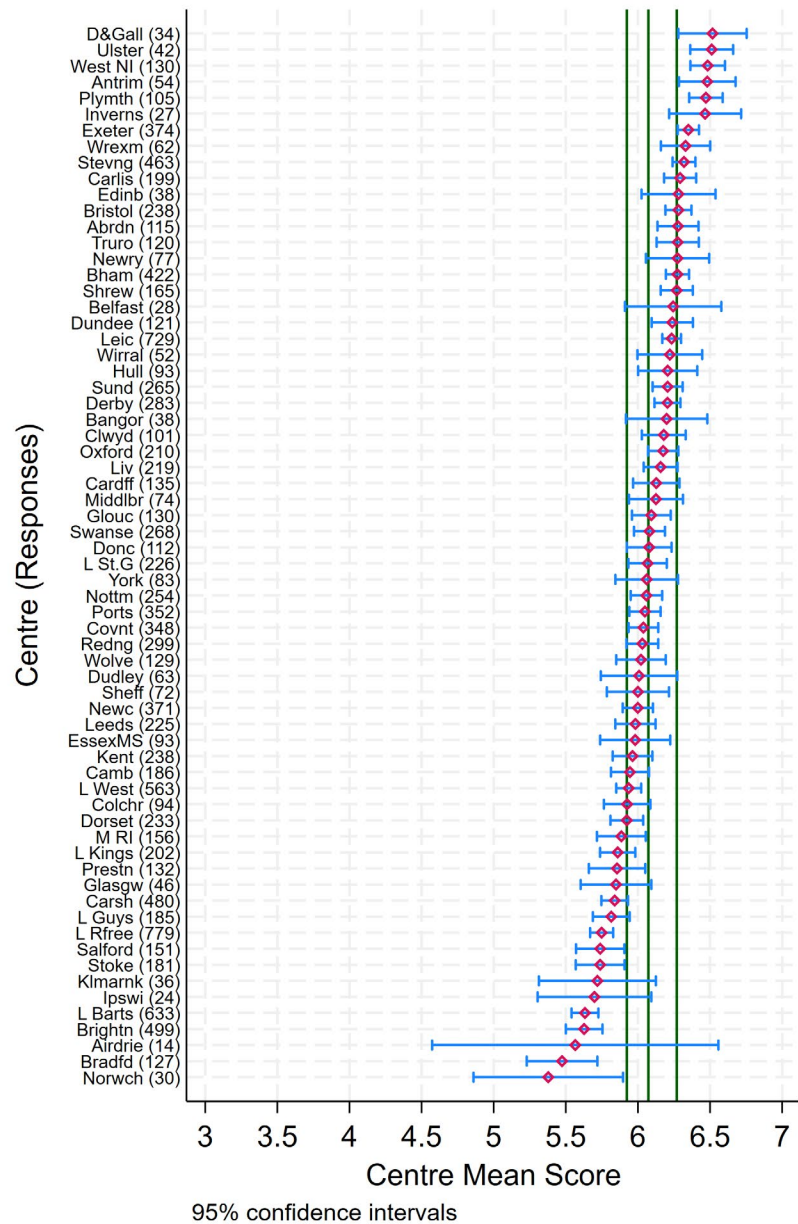
The numbers of responses used to calculate the scores are in brackets after each centre name. Each chart shows how many participants from each centre completed the minimum number of questions such that a theme score could be calculated, rather than the number of respondents completing the whole Kidney PREM. This is particularly important where questions are filtered and bases for analysis become smaller (For example, only 200 out of 300 of a centre's respondents might complete the question on *Needling*, since this is relevant only to those receiving in centre/in satellite haemodialysis).

For most themes, centre scores are within a small range. However, each theme's graph shows a tail of outliers at the bottom, where centre scores were lower than others. *Transport* and *Needling* themes are only applicable to in satellite and in centre haemodialysis recipients. These themes therefore have fewer centre scores, since a minimum of seven responses were needed to calculate these to maintain anonymity.

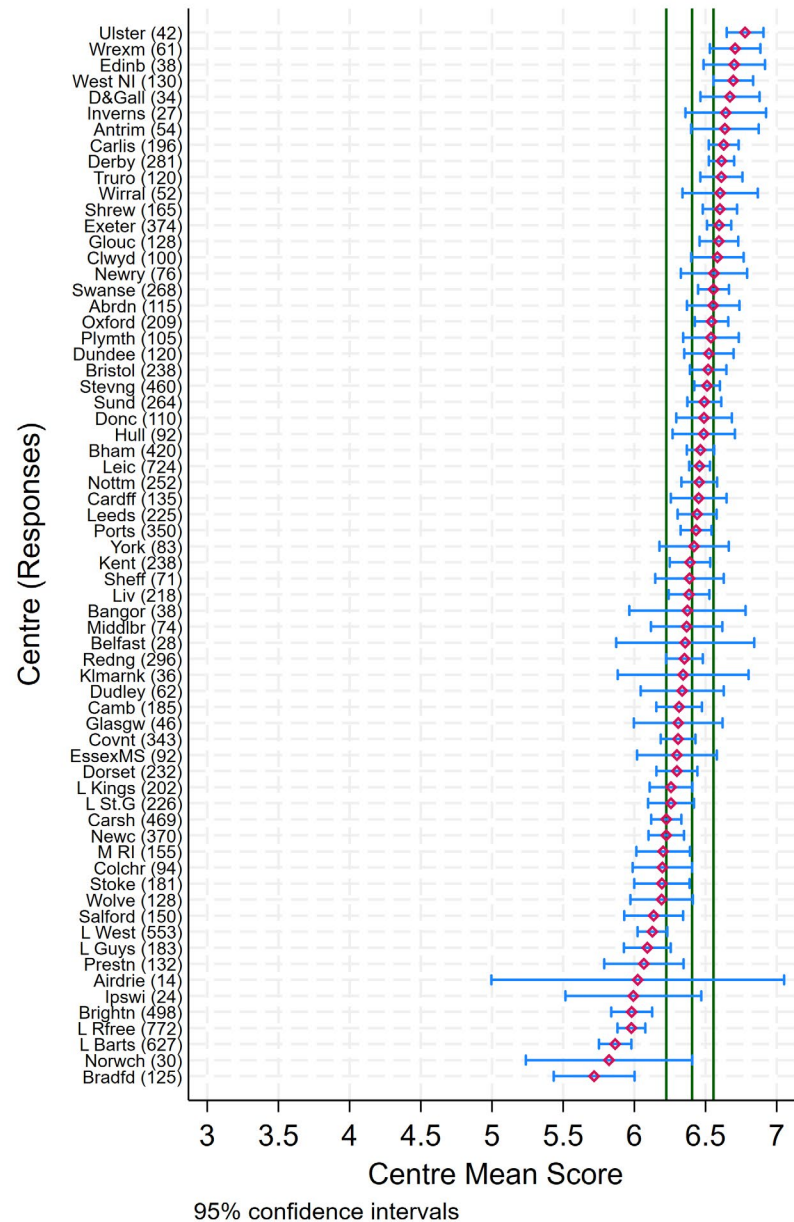
#### **2. Regional means and confidence intervals of centre scores (right-hand figure)**

Figures on the right of each page show the mean score and 95% confidence interval of centre mean scores within each geographical region of the UK and the comparison to 2023. The number of centres used to calculate each value is displayed in brackets after the region name.

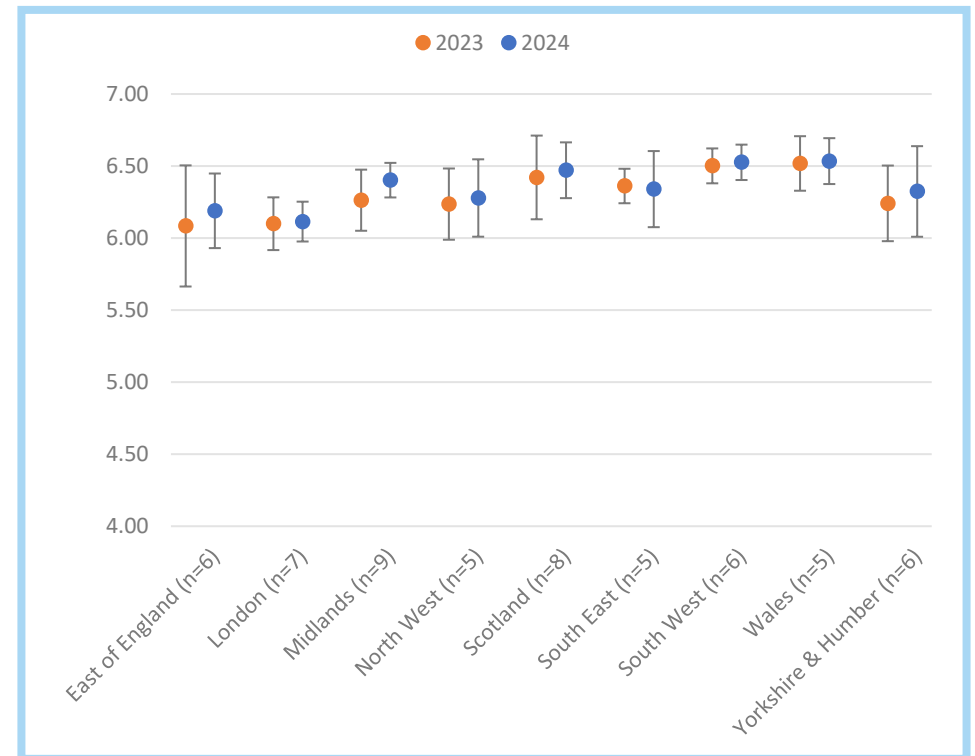
Kidney PREM Score



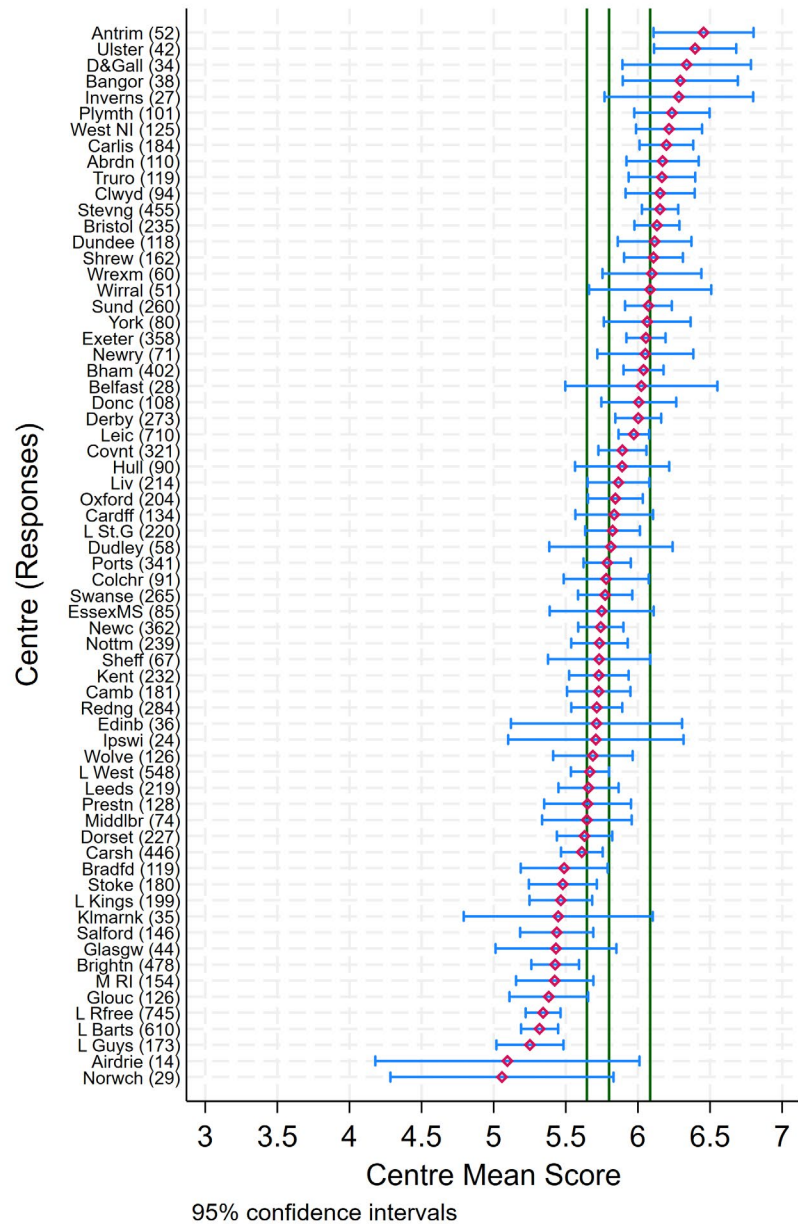
## Theme 1: Access to the Kidney Team



- 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?



Theme 2: Support

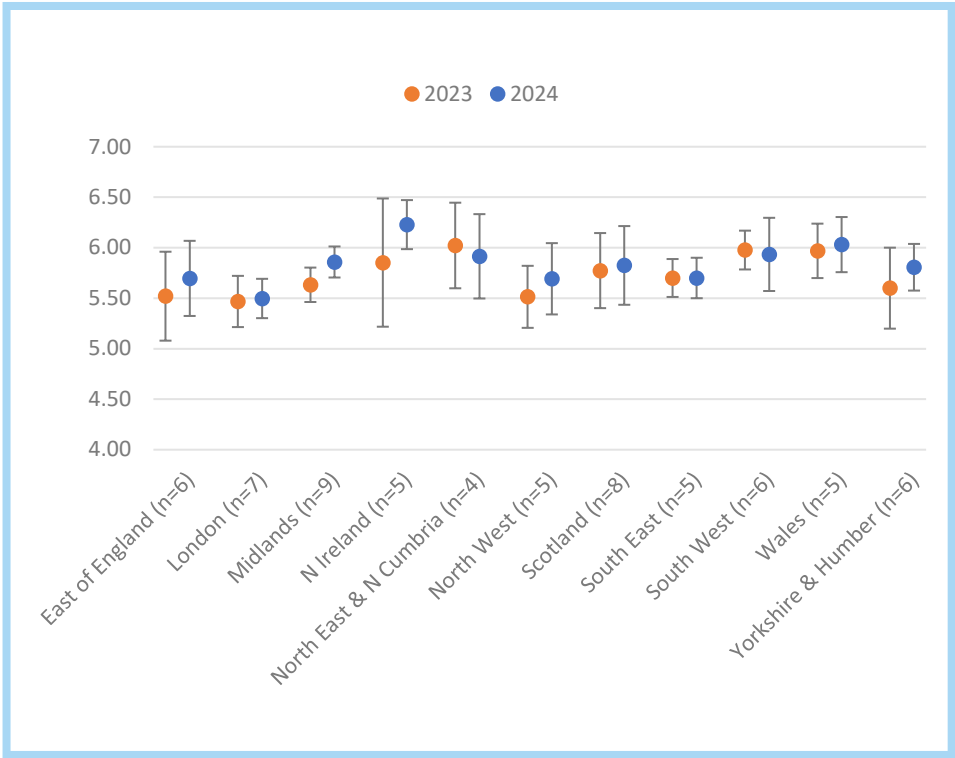


**Does the kidney team help you to get the support you want with:**

Q4. Medical issues resulting from your kidney disease?

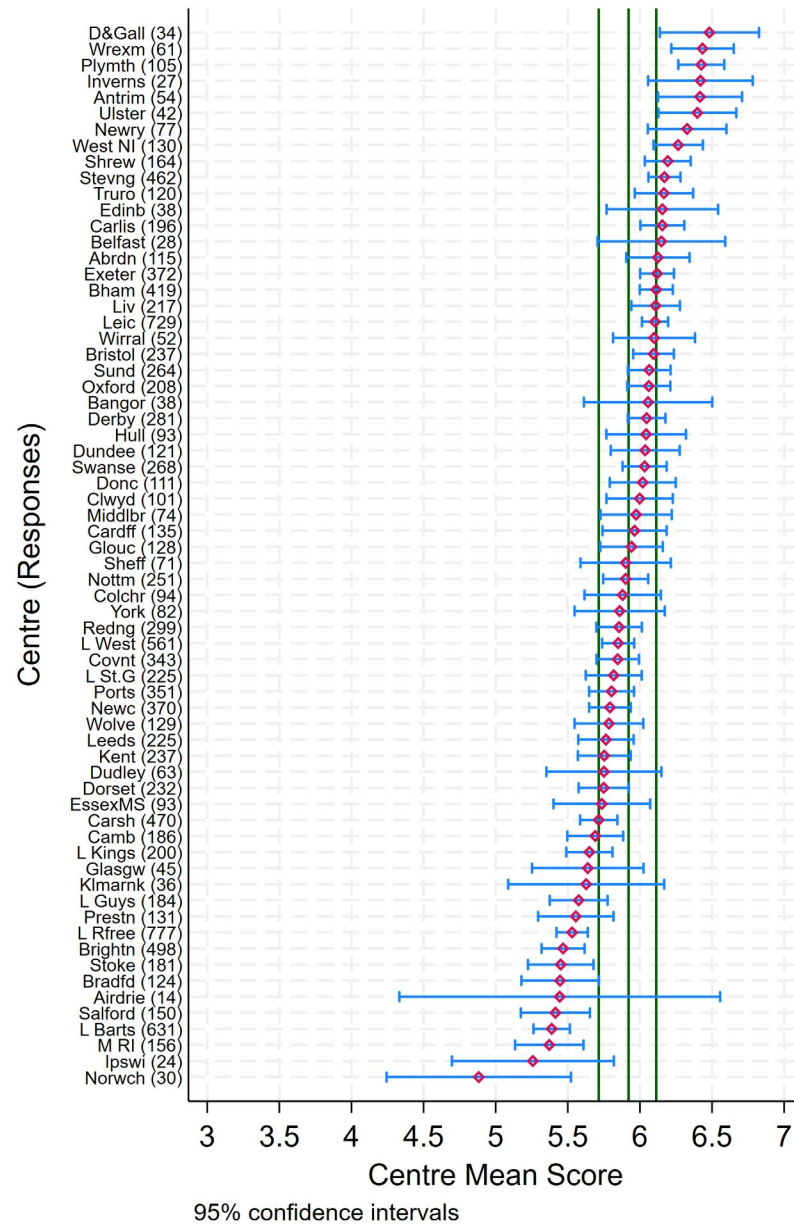
Q5. Any other concerns or anxieties resulting from your kidney disease or treatment?

Q6. Accessing patient support groups such as Kidney Patient Associations (KPA)?



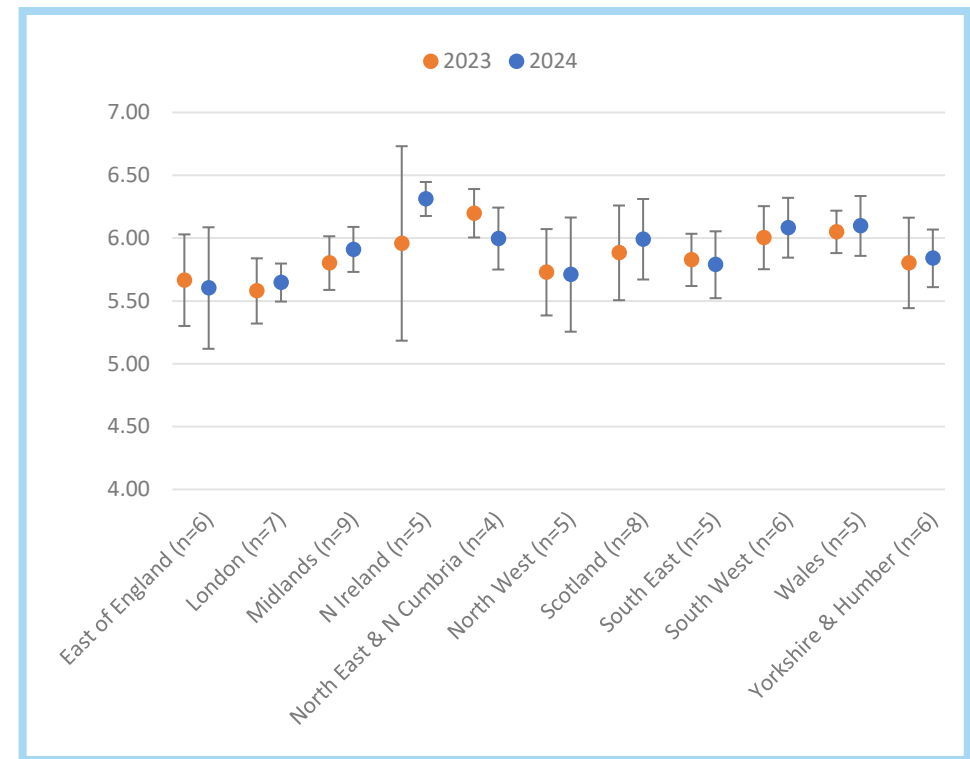


## Theme 3: Communication

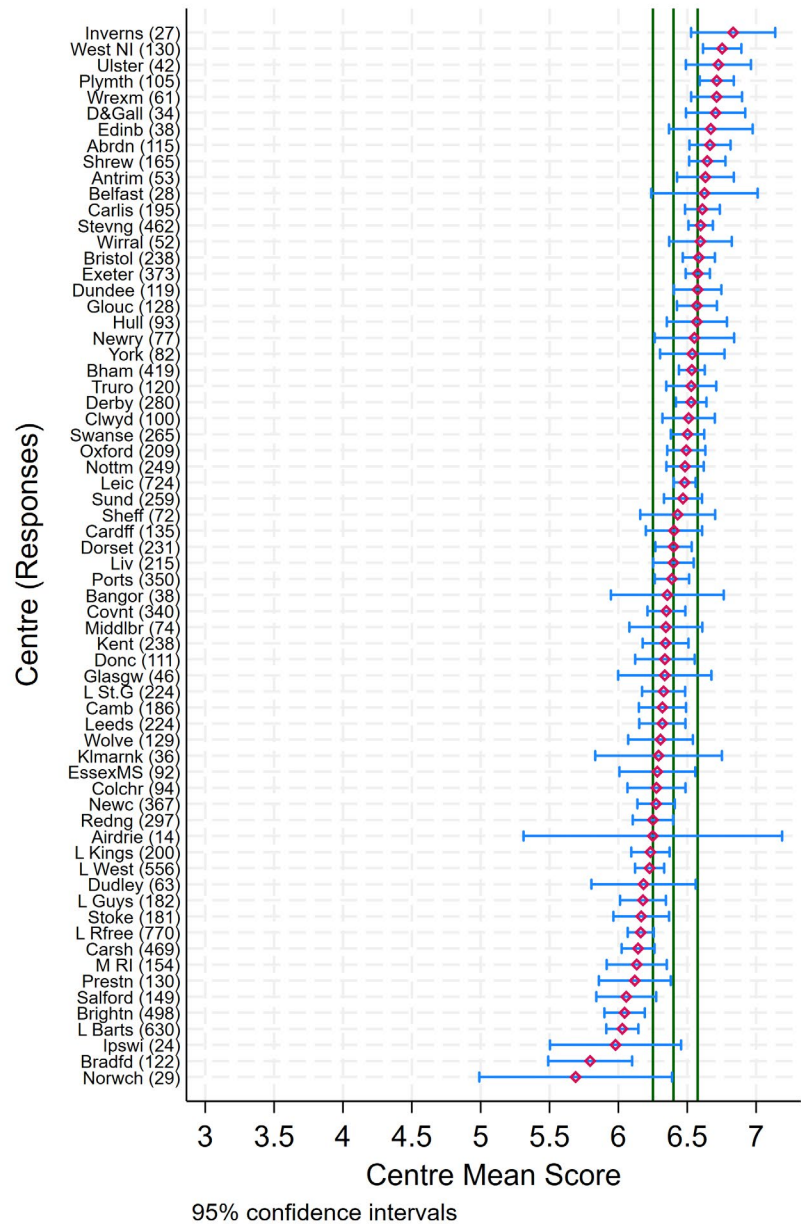


## Do you think there is good communication between:

- 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?

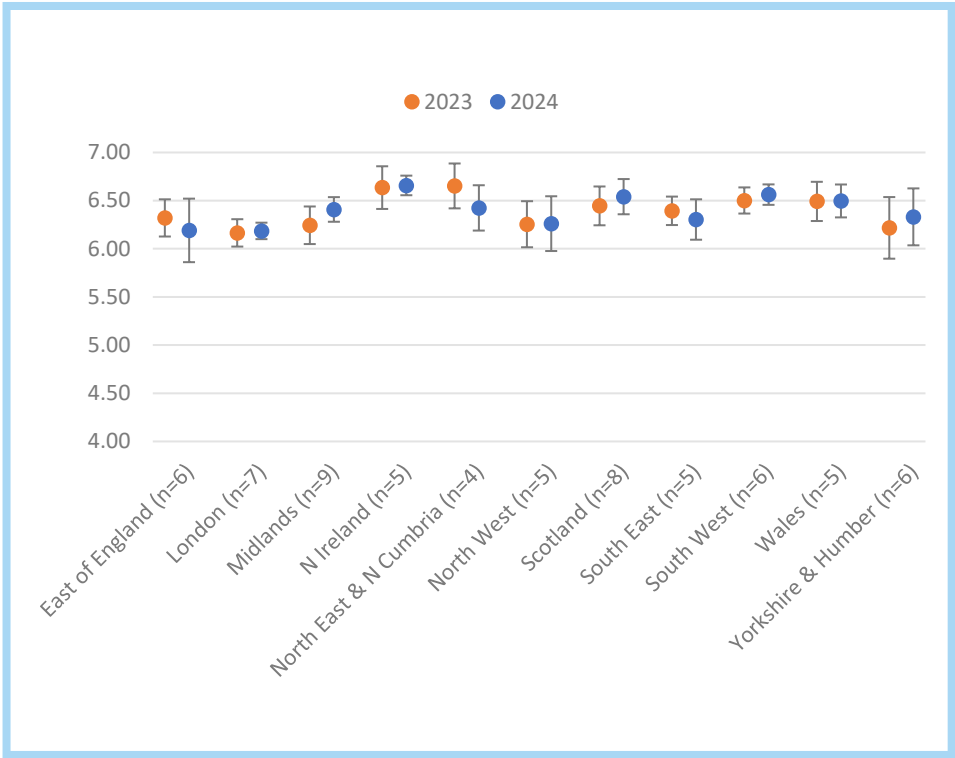


Theme 4: Patient Information



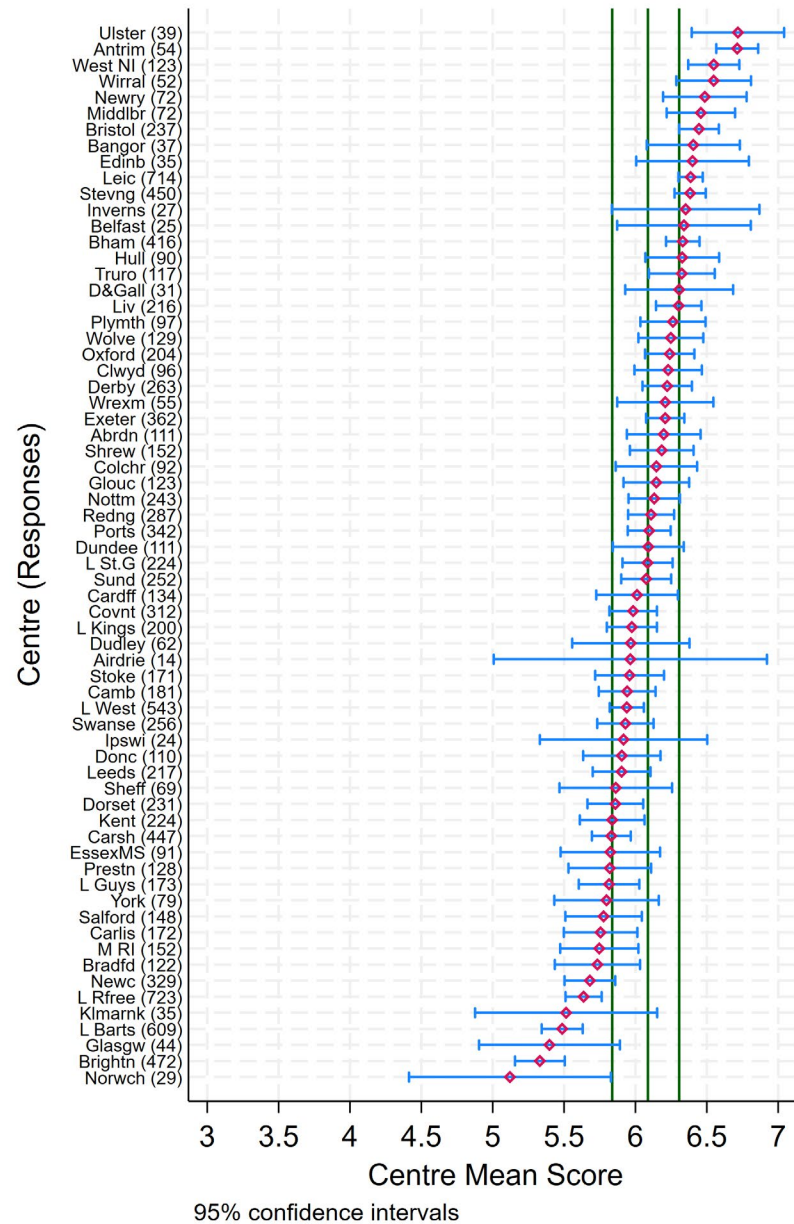
Does the kidney team:

- 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?





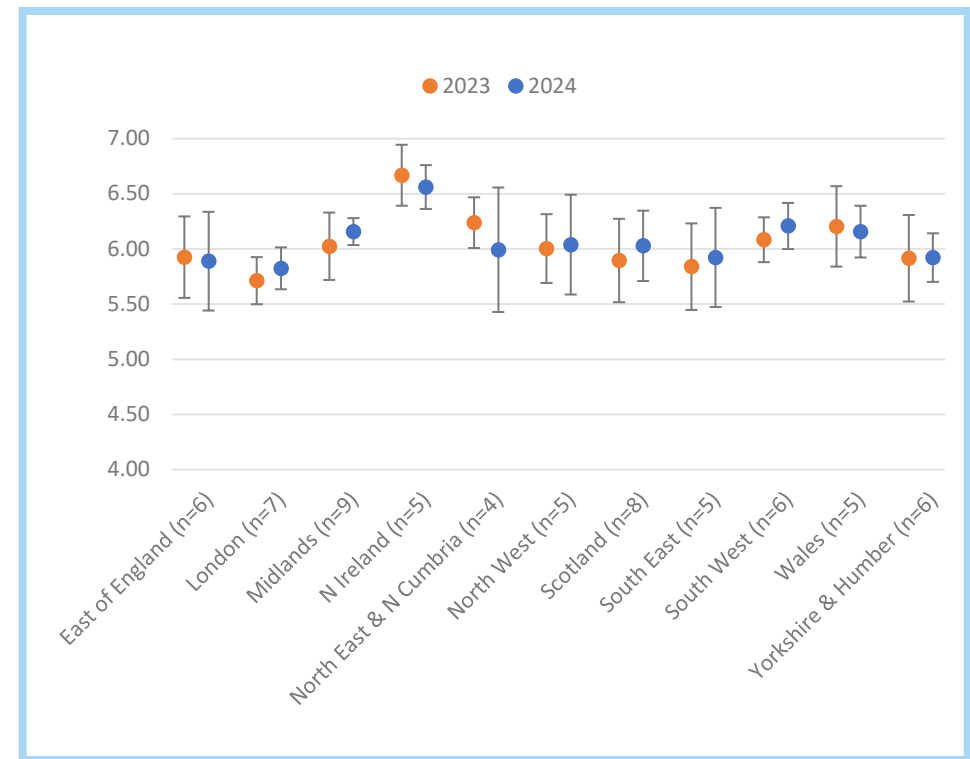
## Theme 5: Fluid &amp; Diet

Thinking about the advice you are given about fluid intake:

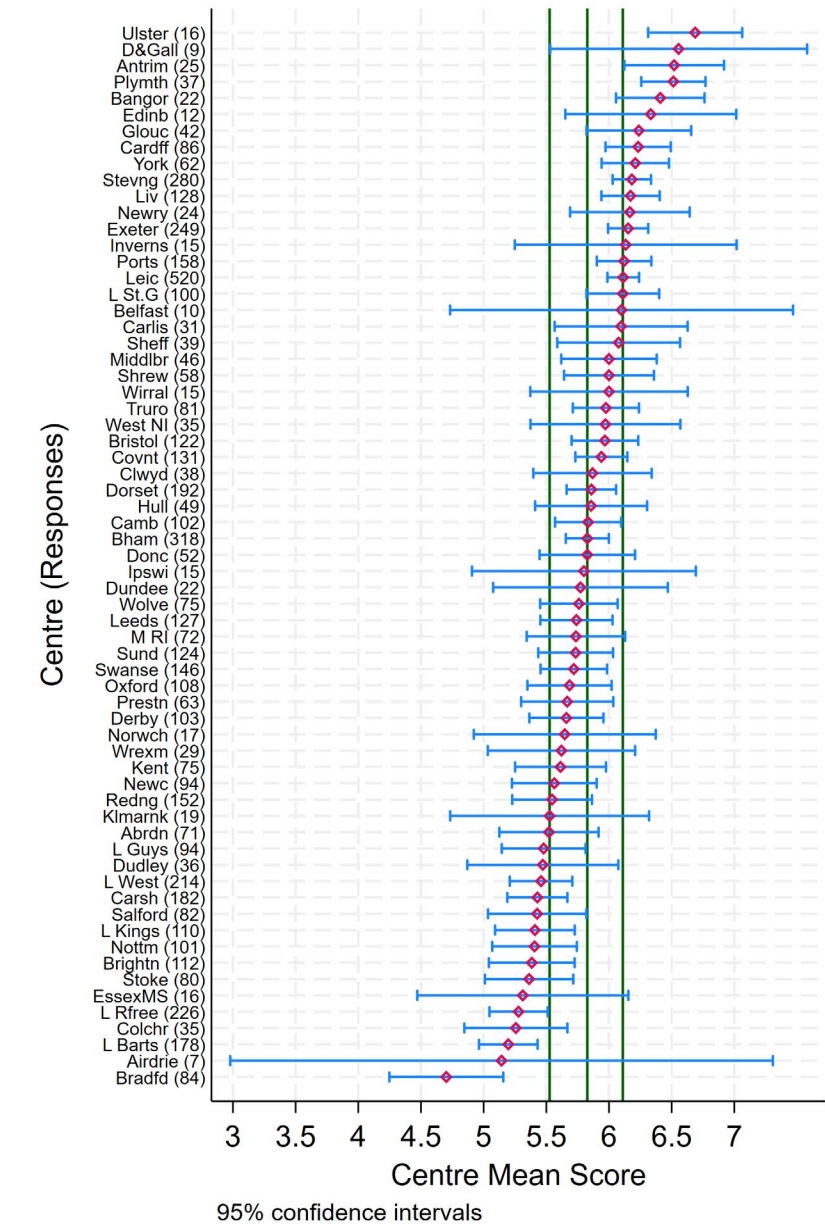
Q14. Does the kidney team give you clear advice on your fluid intake?

Thinking about the advice you are given about diet:

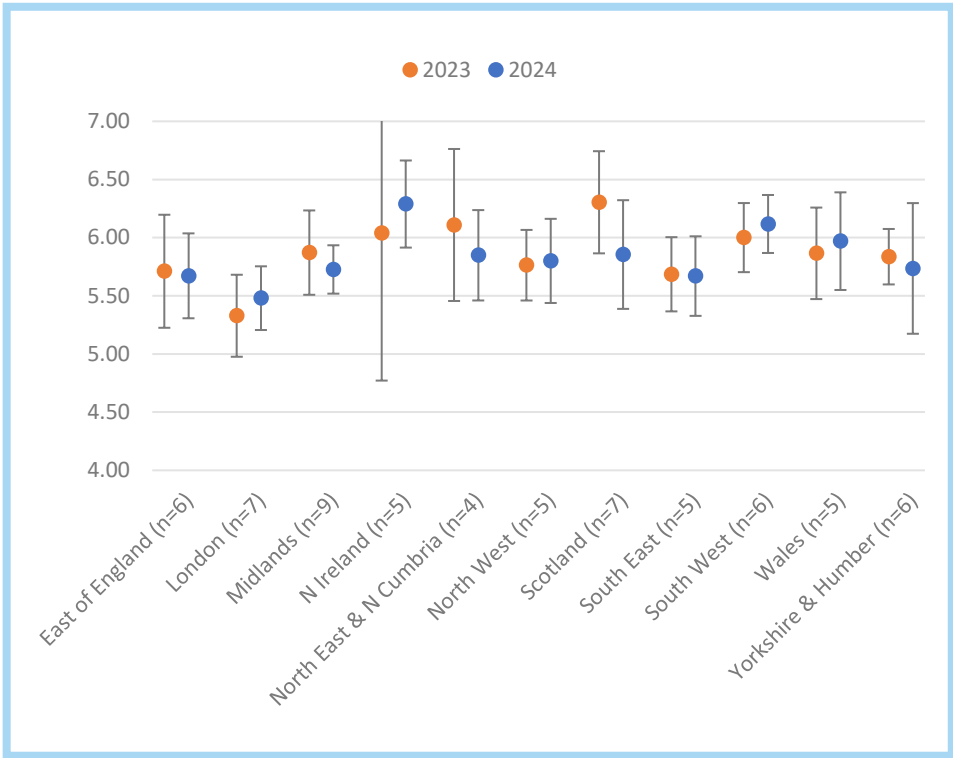
Q15. Does the kidney team give you clear advice on your diet?



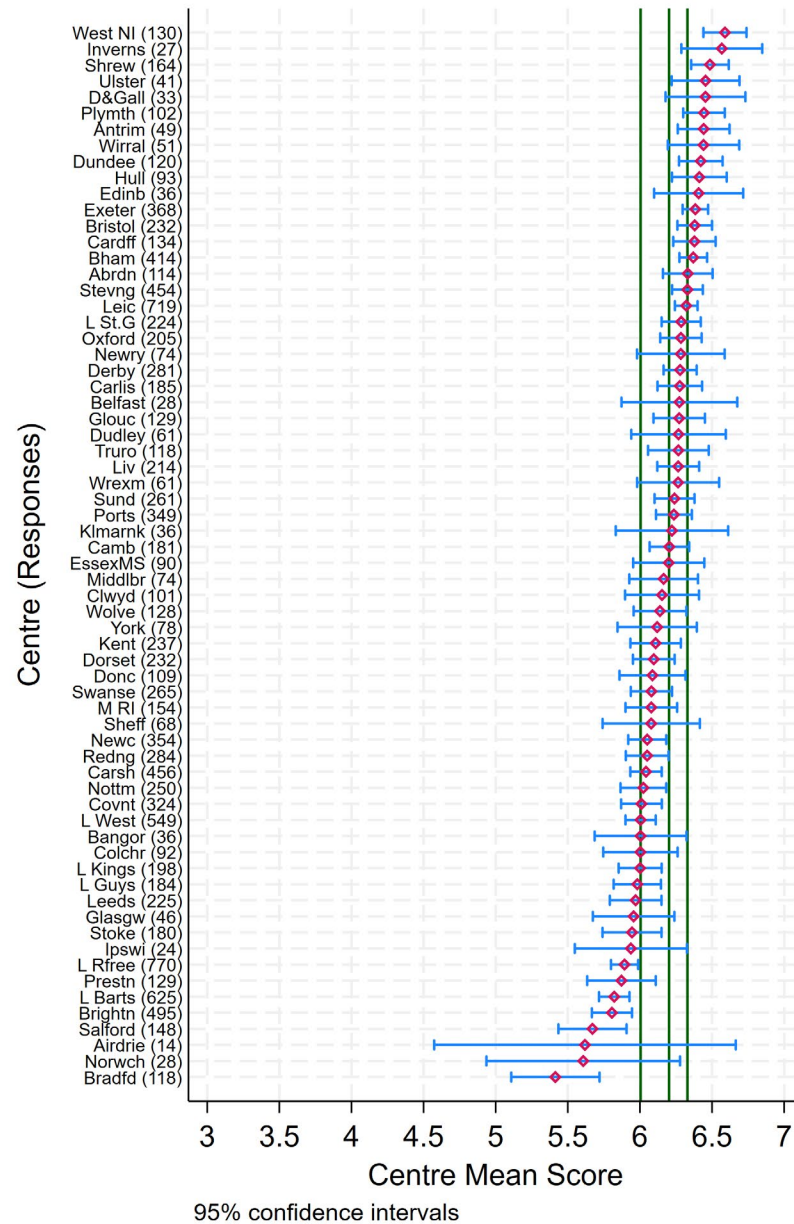
Theme 6: Needling



Q16. How often do the kidney team insert your needles with as little pain as possible?  
(in centre haemodialysis only)



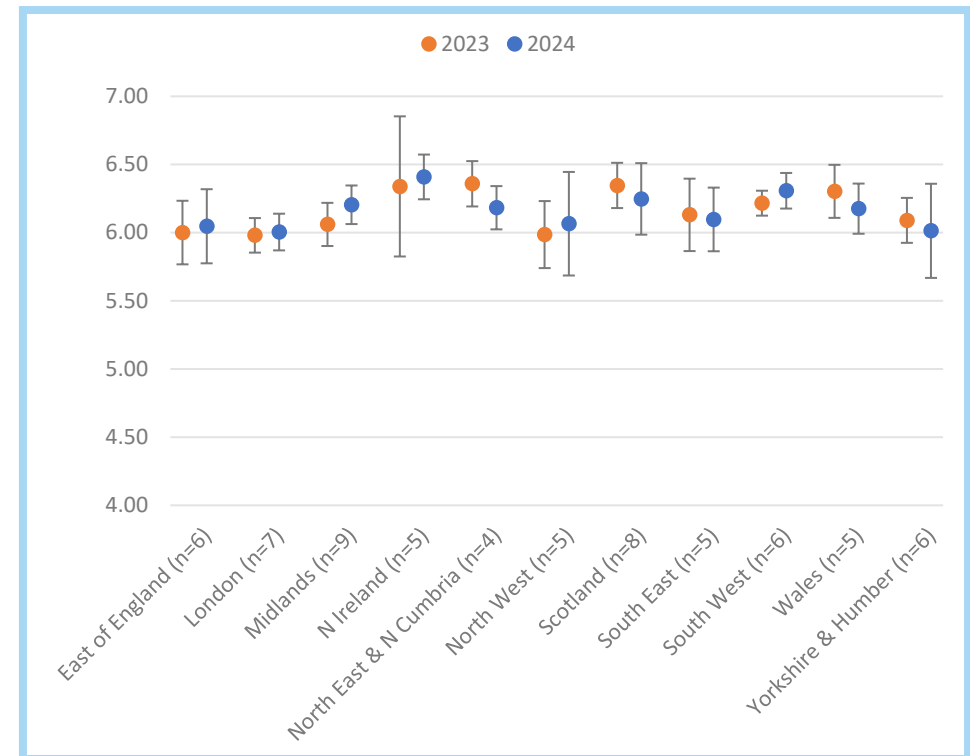
## Theme 7: Tests



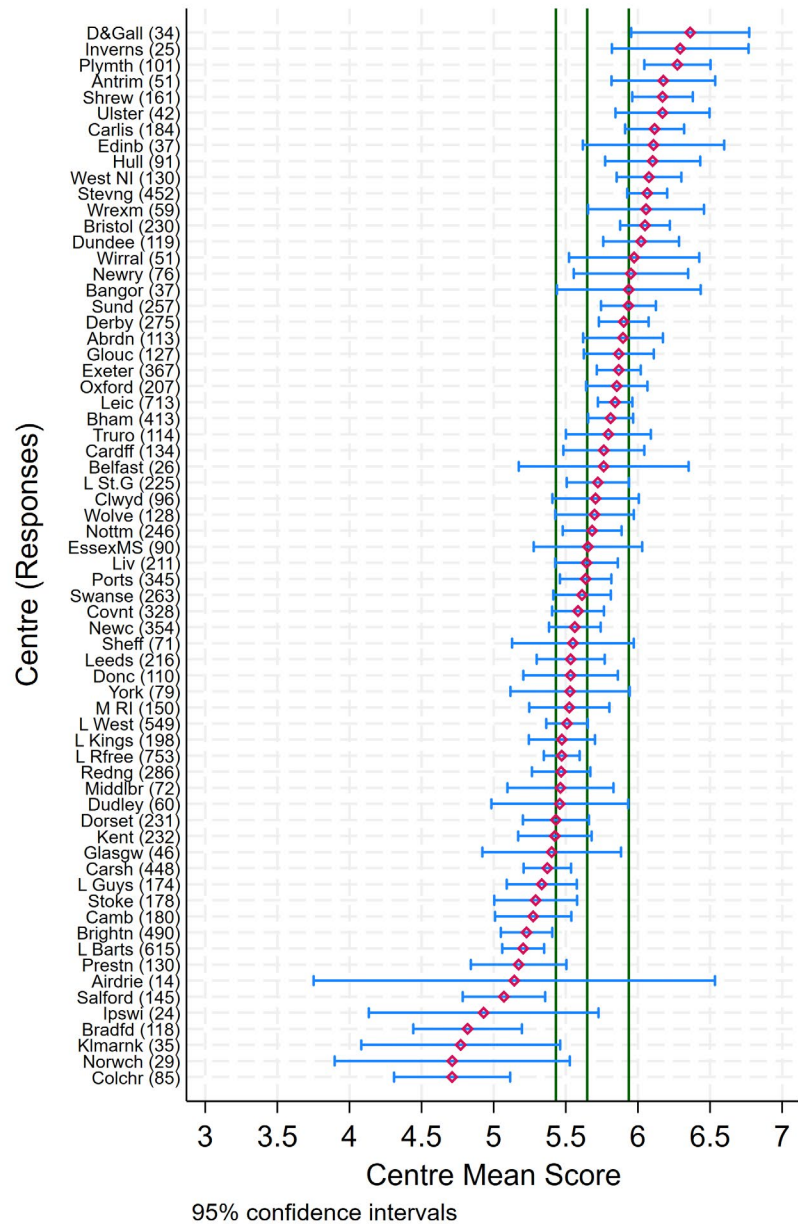
Q17. Do you understand the reasons for your tests?

Q18. Do you get your test results back within an acceptable time period?

Q19. Do you understand the results of your tests?

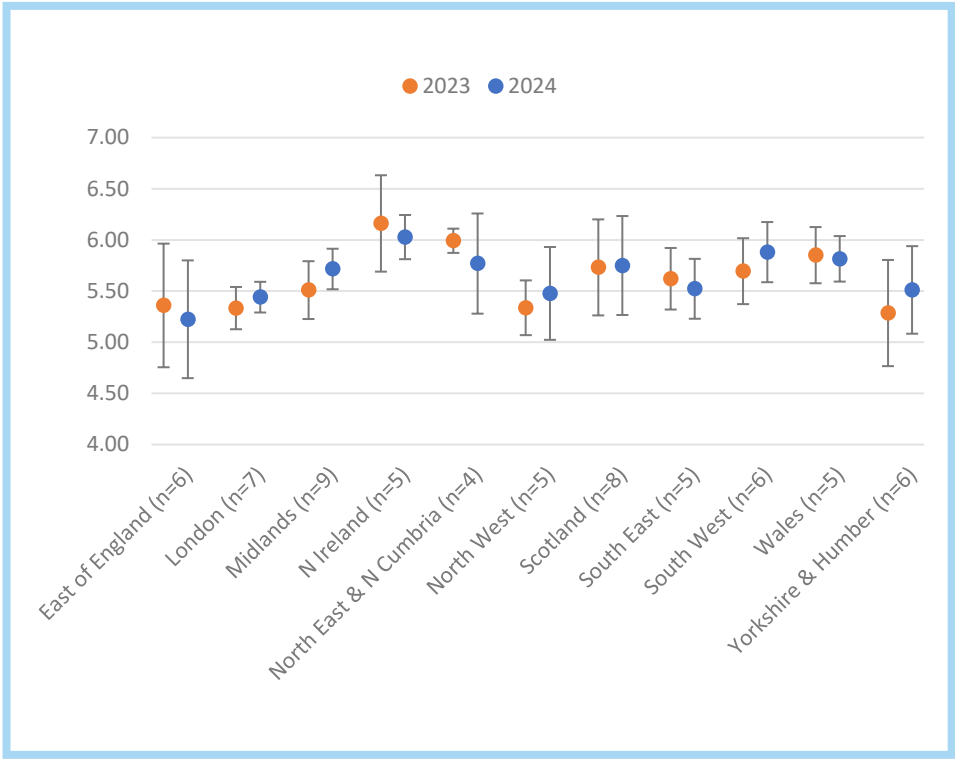


Theme 8: Sharing Decisions

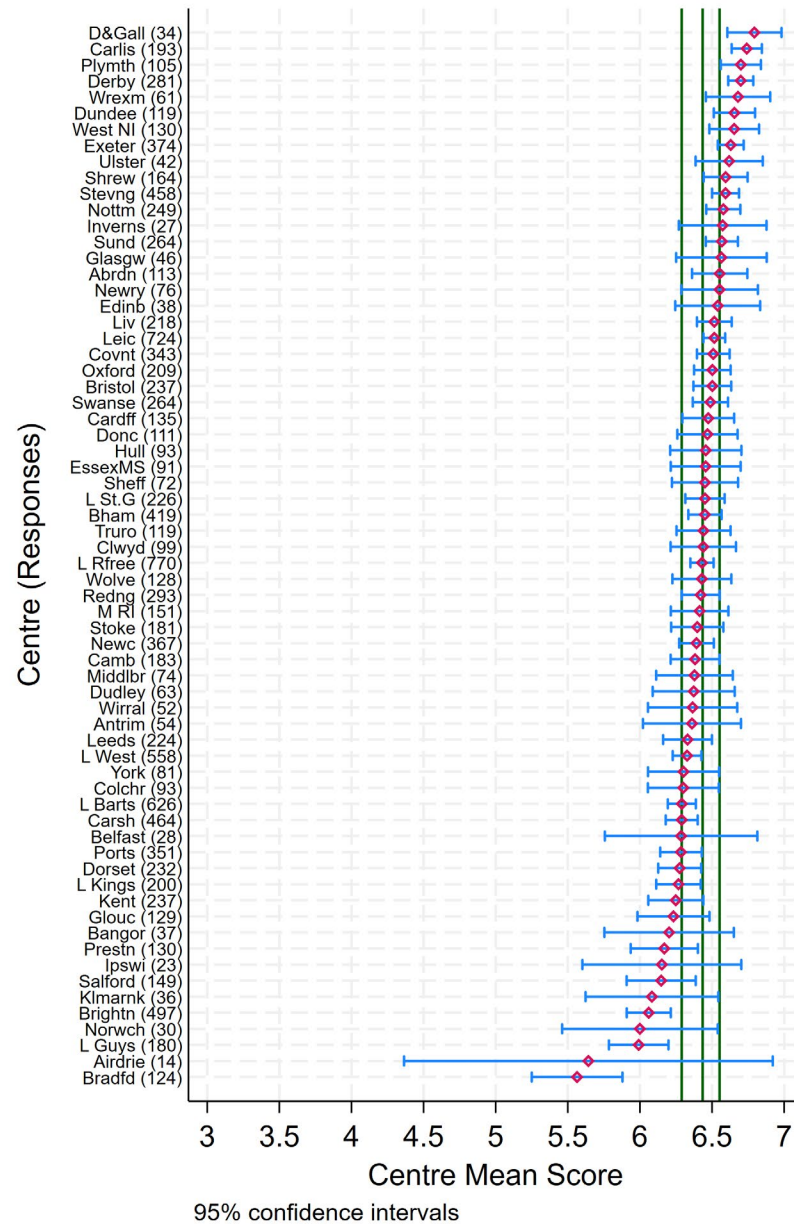


Does the kidney team:

- 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?

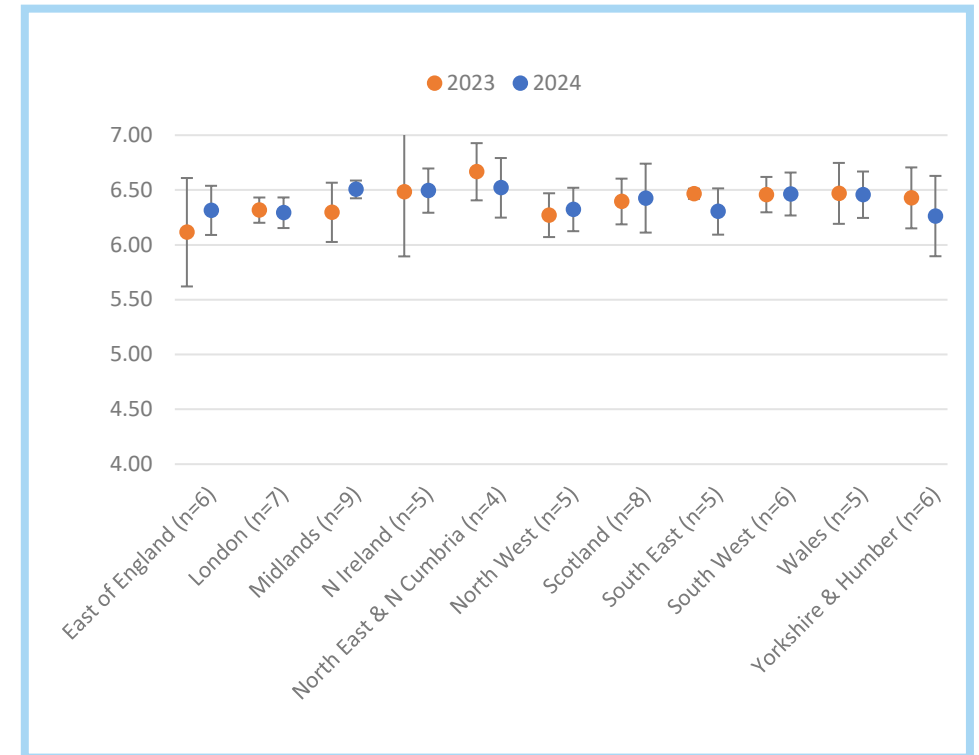


## Theme 9: Privacy and Dignity



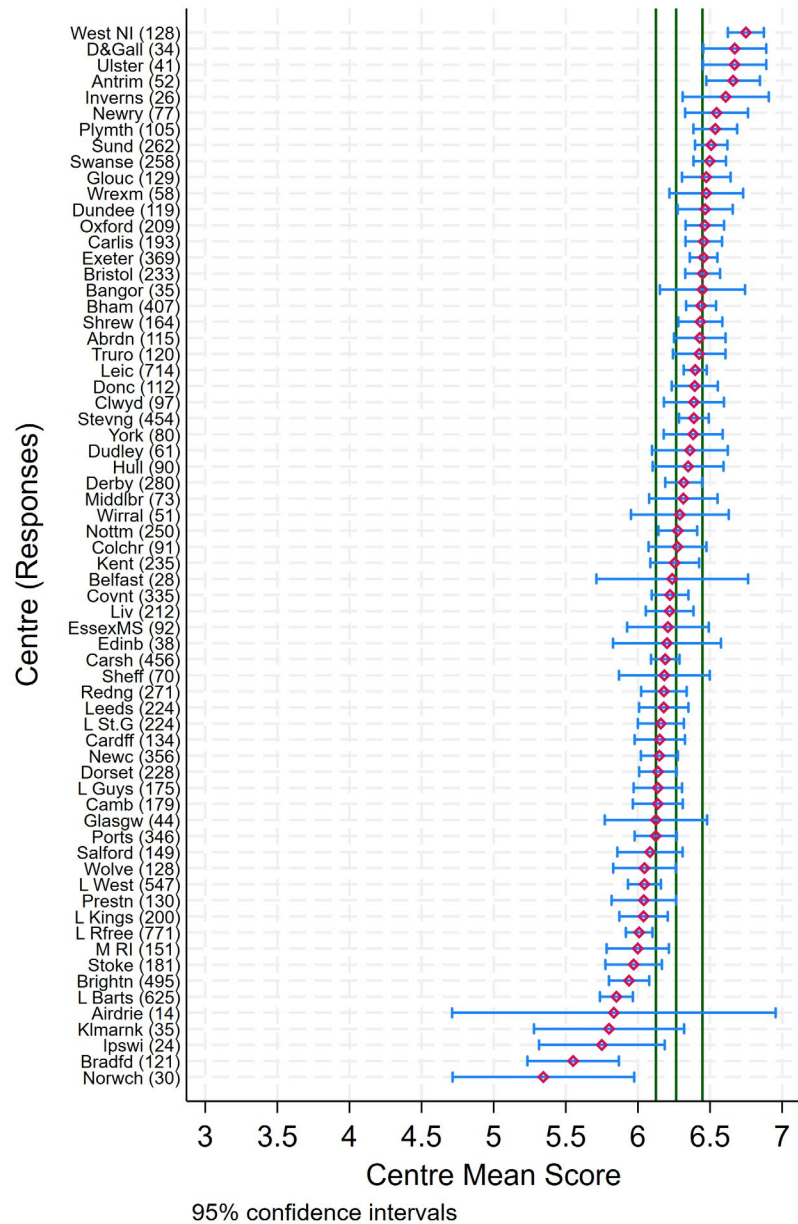
Q23. Are you given enough privacy when discussing your condition or treatment?

Q24. Is your dignity respected during visits and clinical examinations?

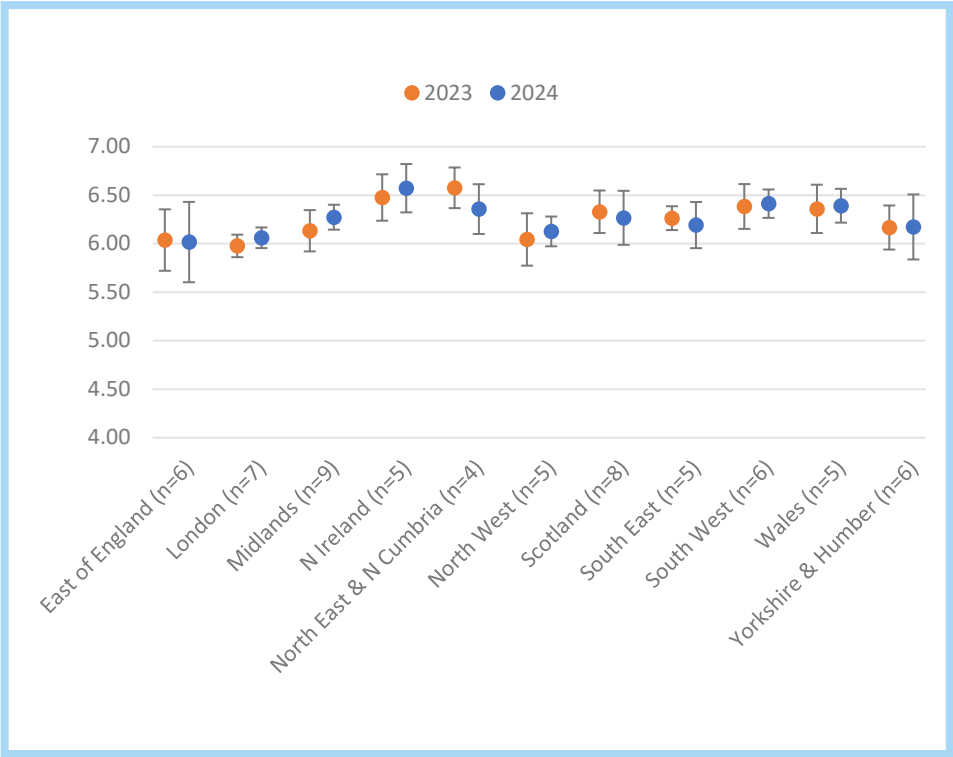


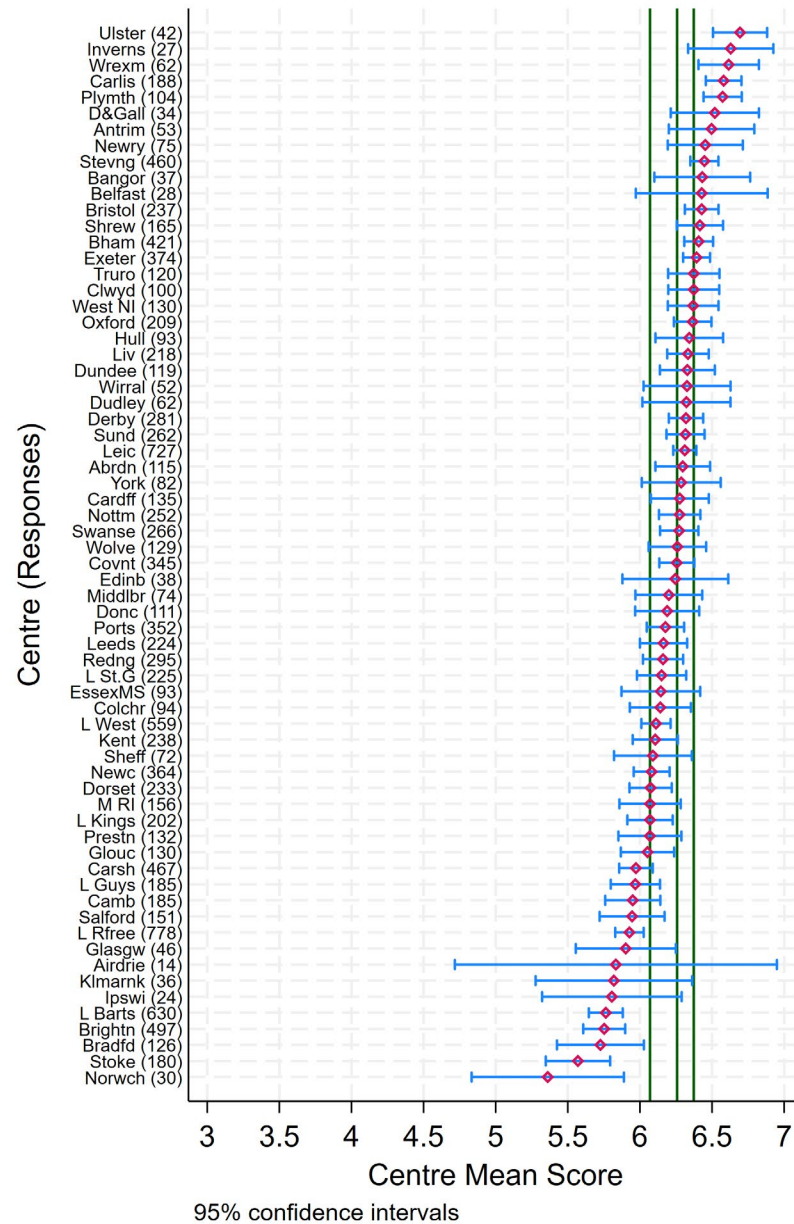


Theme 10: Scheduling and Planning



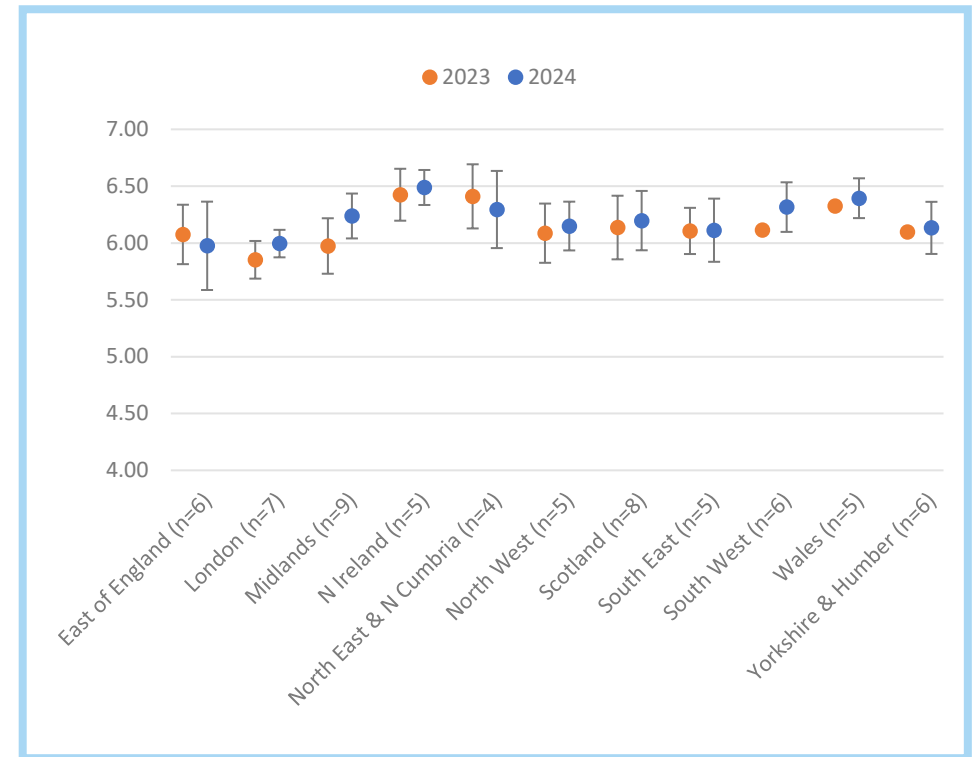
- Q25. Can you change your appointment times if they are not suitable for you?
- Q26. Do you feel your time is used well at your appointments relating to your kidneys?
- If you have blood tests done at an outpatient clinic or GP surgery (not those on in centre or in satellite haemodialysis):*
- Q27.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



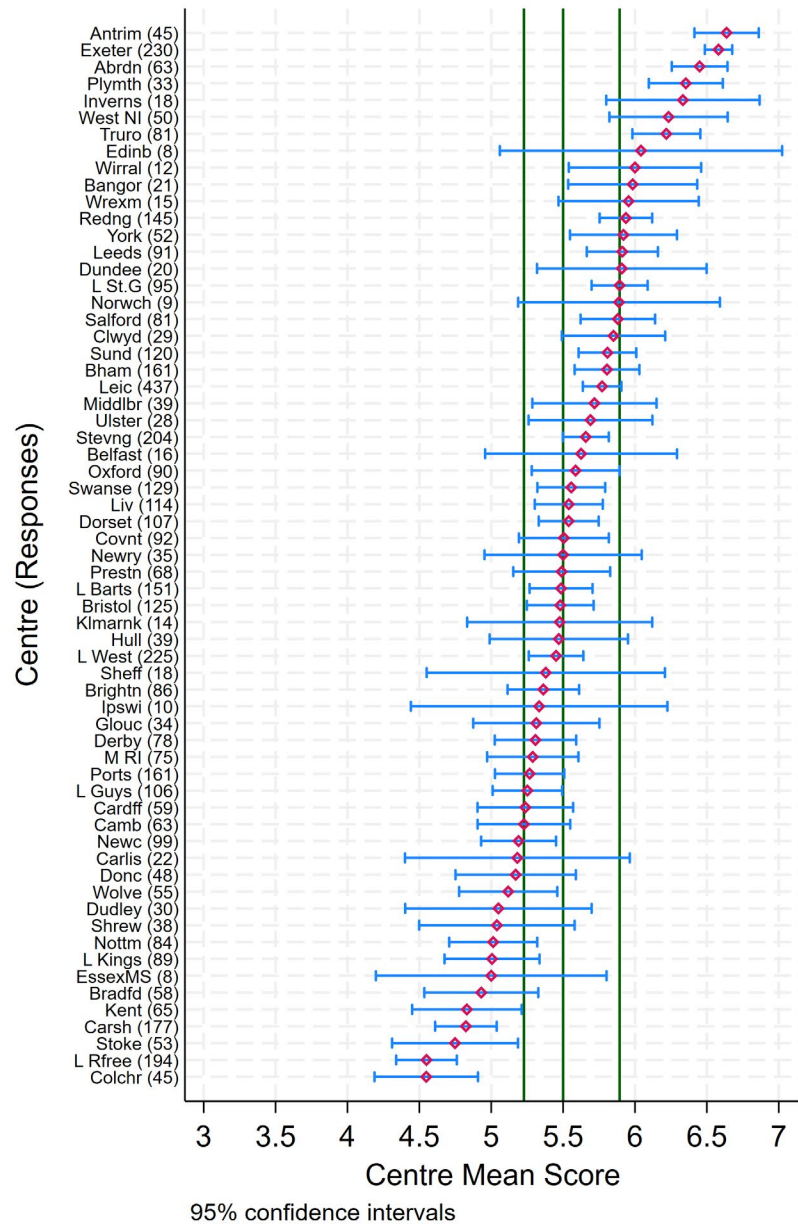
Theme 11: *How the Kidney Team Treats You*

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

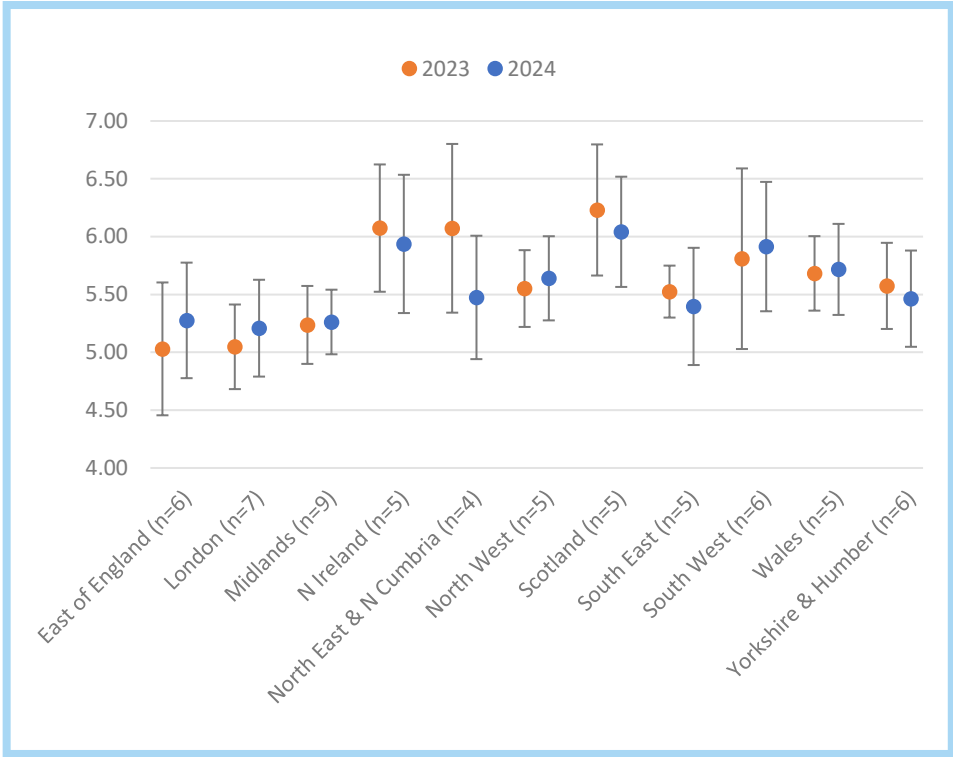
- Q28. Take you seriously?
- Q29. Show a caring attitude towards you?
- Q30. Ask you about your emotional feelings?



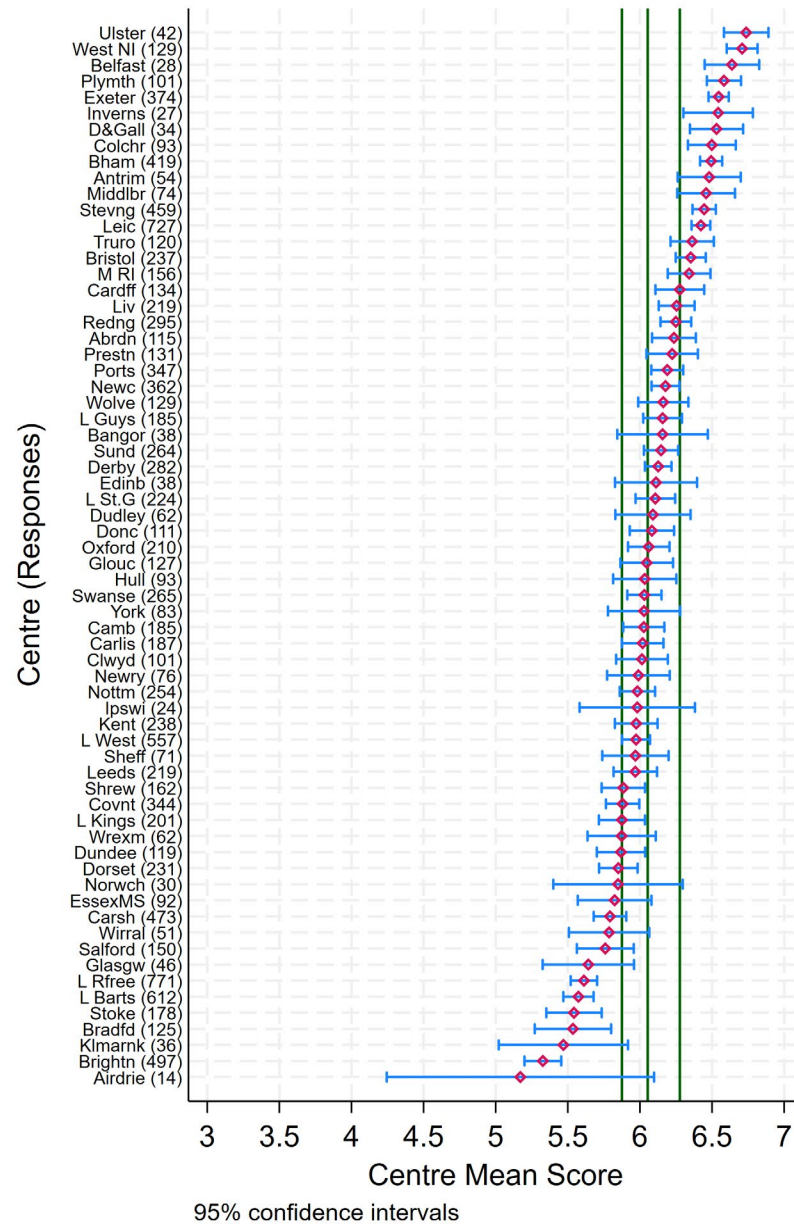
Theme 12: Transport



- 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?





Theme 13: *The Environment*

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

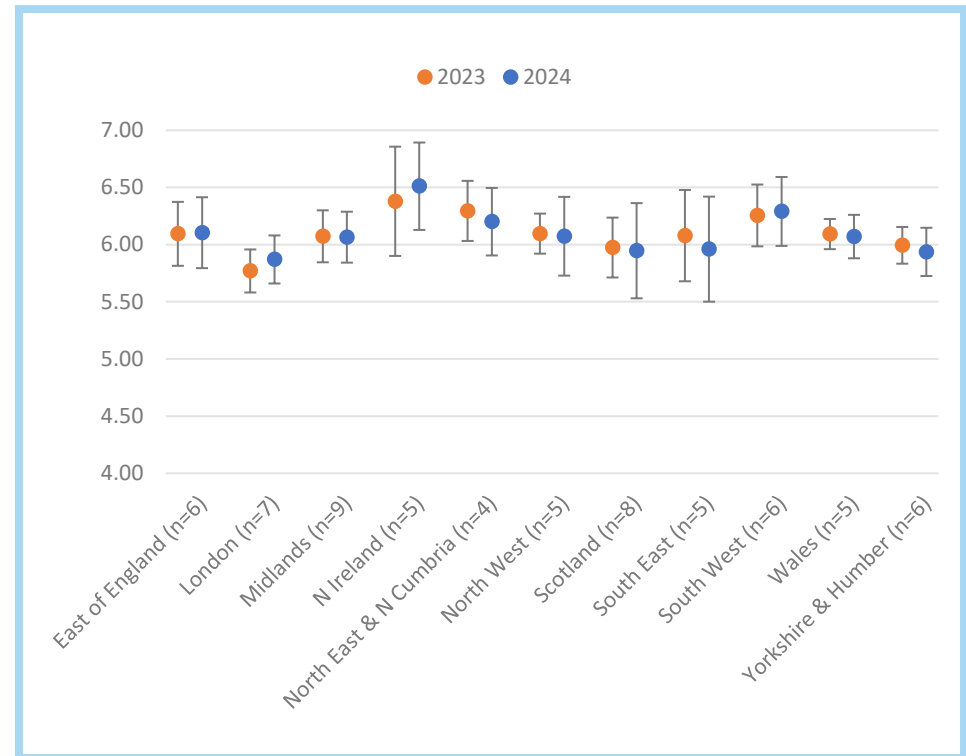
Q34. Accessibility (e.g., lifts, ramps, automatic doors)?

Q35. Comfort?

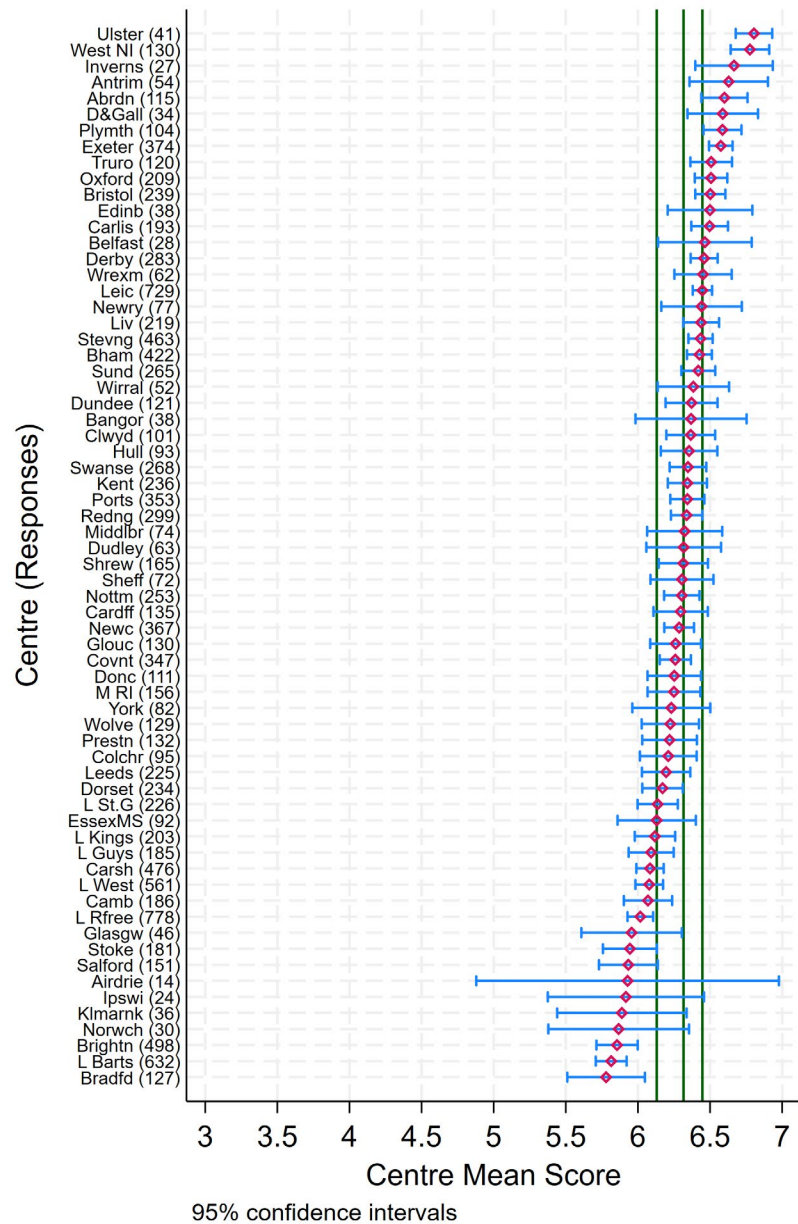
Q36. Cleanliness?

Q37. Waiting Area?

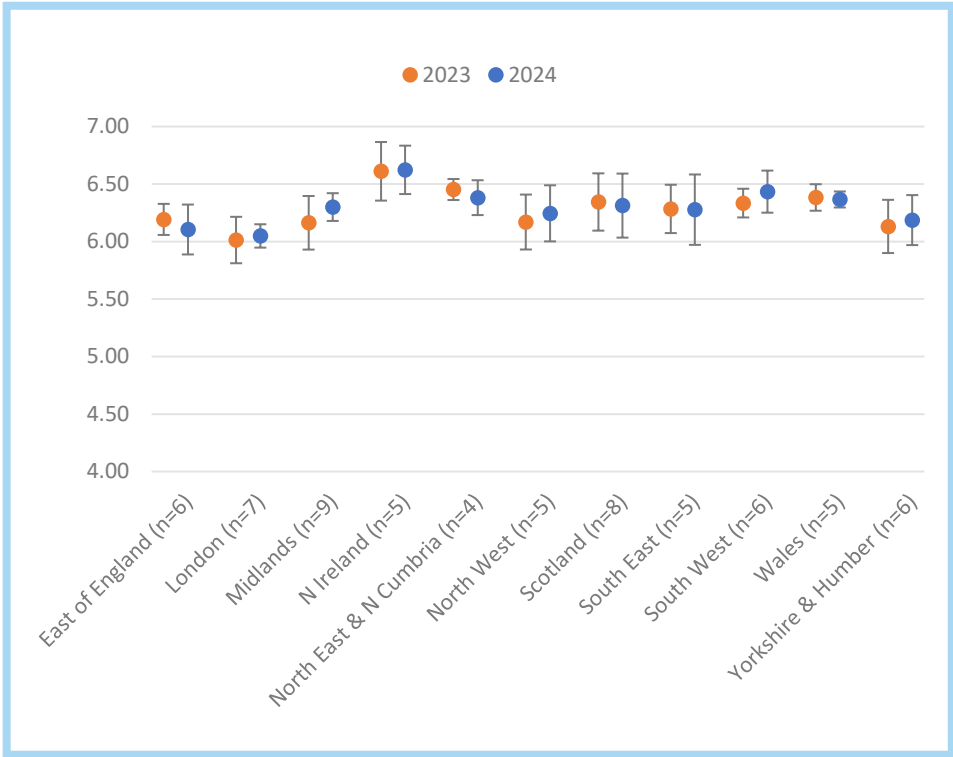
Q38. Parking?



Theme 14: Overall Experience



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)?





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