

Patient Reported Experience of Kidney Care in the UK 2023



Table of Contents

Foreword	4
Acknowledgments	5
Statistical Glossary	6
Executive Summary	7
Pilot Paediatric PREM	12
Introduction	15
Methodology	16
The Kidney PREM	16
Data collection	16
Analysis and reporting	17
Results	18
Chapter 1: Profile of Kidney PREM respondents	18
Regional profile	18
Participant characteristics	19
Widening participation in Kidney PREM study	21
Treatment modalities of participants	23
Participants receiving haemodialysis	24
How results from the Kidney PREM shape care: Development of the needling patient reported experience measure (NPREM)	26
Participants attending clinic but not receiving kidney replacement therapy	27
Help to participate in Kidney PREM	28
English as first language	29
Measuring participant deprivation using partial postcodes	30
Use of Patients Know Best	34
Chapter 2: Additional questions	35
Question A: 'Who are your kidney clinic letters sent to?'	35
Question B: 'Have your kidney team talked to you about your wellbeing in the last year? For example: benefits/housing/mental health.'	35
Question C: 'Has anyone from your unit talked to you about last year's Kidney PREM report?'	36
Using Kidney PREM to drive local improvement	37
Chapter 3: Changes in patient experience	38
In 2023	38
Compared to previous years	38
Comments about experiences of care	40

Chapter 4: Kidney PREM theme results	42
Kidney PREM themes	42
Overall Experience of care	44
Chapter 5: Kidney PREM theme results by treatment and by question	46
Theme mean scores by treatment	46
Theme breakdown by question	48
Chapter 6: Patient experience of kidney care across the service	64
Kidney PREM Score	65
Theme 1: <i>Access to Kidney Team</i>	66
Theme 2: <i>Support</i>	67
Theme 3: <i>Communication</i>	68
Theme 4: <i>Patient Information</i>	69
Theme 5: <i>Fluid and Diet</i>	70
Theme 6: <i>Needling</i>	71
Theme 7: <i>Tests</i>	72
Theme 8: <i>Sharing Decisions</i>	73
Theme 9: <i>Privacy and Dignity</i>	74
Theme 10: <i>Scheduling and Planning</i>	75
Theme 11: <i>How the Kidney Team Treats You</i>	76
Theme 12: <i>Transport</i>	77
Theme 13: <i>The Environment</i>	78
Theme 14: <i>Overall Experience</i>	79

Foreword

Now in its eighth year, the Kidney (PREM) aims to accurately understand patient experience and views, providing evidence of where improvements are needed and reflecting patients' perspectives across the UK. The collaboration between Kidney Care UK and the UK Kidney Association produces an important tool for the whole community, with results that, if used correctly, can focus minds to deliver improvement.

It's superb the response rate has increased by over 5% this year, to 11,647 respondents but this report highlights work still to be done to reach more, particularly involving patient voices from the diverse ethnicities that make-up the patient community. Enabling these patient voices should be a priority, capturing credible, diverse views to support the evolution of kidney treatment care for all.

I have experienced various treatment modalities over the last 27 years from out-patients and pre-dialysis to satellite dialysis and transplants, returning to dialysis at home six years ago undertaking nocturnal for the last five. For me, taking control (of treatment) is fundamental to reclaiming your life particularly when you're on dialysis but important in other aspects of your treatment journey too. So, it's really heartening to see the growth in respondents who are involved in Shared Care at 35.8%. It certainly provides patients with a springboard, through sensitive and tailored learning and a nurturing culture, with potential to graduate to home dialysis and opportunity for increased transformational care that nocturnal provides. A real opportunity is evident to grow this work further to those patients who aren't lucky enough to be benefitting from Shared Care.

Unfortunately, it's no surprise to see Transport or Needling as two of the lowest scoring themes. It's of some comfort though to know that on the back of Kidney PREM further measures have been developed to help assess and hopefully contribute to future improvements around experience here.

Transport to and from haemodialysis adds hours to treatment days each week and the difficulties encountered are widely reported particularly around NHS England's 'universal commitment' to haemodialysis transport which has yet to bear any fruit. I hope over the next 12 months with a Northwest pathfinder in place and best practice shared elsewhere, there may be signs of improvement evident in future surveys. Access to timely, efficient, equitable haemodialysis transport plays a fundamental part in a dialysis patient's quality of life.

It's really important that Kidney PREM's results are fed-back through different routes to reach as many patients as possible including the impact the survey is making on service improvements. Valuing the patient voice is essential to sustain involvement and fend off any threat of survey fatigue and invigorate future involvement.

Nick Palmer

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Kidney Care UK

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

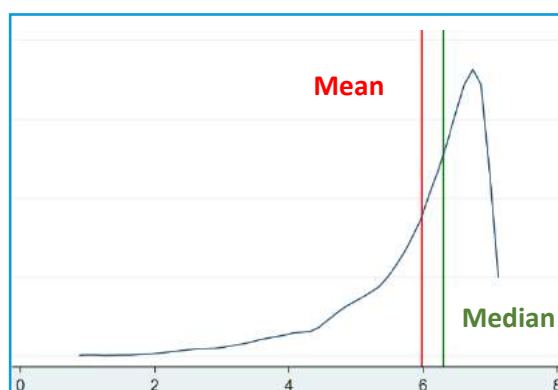
Mean: The mean centre score is calculated across patient scores by adding them together and dividing by the number of scores used, giving the mathematical average value.

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.

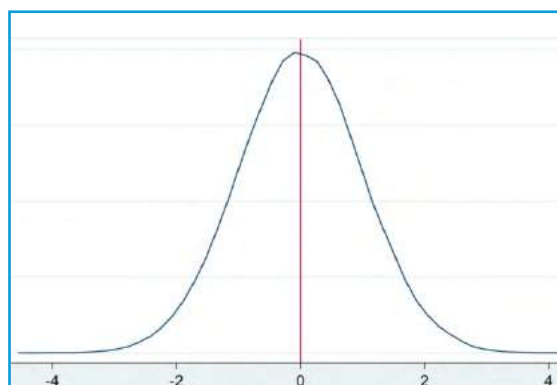
Median: If patient scores for a particular centre were listed in order, the median is the middle value separating the high scoring (top half) from the low scoring (bottom half).

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

1: Profile of Kidney PREM respondents

The eighth year of Kidney PREM saw the survey move to online-only data collection. As a result, responses were generally more complete, particularly with regards to demographic information. A total of 11,647 responses were received, an increase of 5.3% compared to 2022. Although there was a drop in responses from those aged over 75 years, this group remain overrepresented compared to figures from the UK Renal Registry (UKRR) of the population receiving kidney replacement therapy. As with previous years, Asian individuals living with kidney disease remain underrepresented in the Kidney PREM, at 9% compared to the 14% recorded by the UKRR.

Across all participants, 31.1% received help to complete Kidney PREM, with a higher proportion of staff/other (from 38.2% to 41.3%) and volunteer helpers (from 15.2% to 25.3%) in 2023, compared to 2022. Participants reported a need for increased help due to difficulties with technology and their connection to haemodialysis.

Haemodialysis remains the most common treatment modality amongst participants, increasing from 61.1% 2022 to 64.4% in 2023. Although the UKRR reports that 5.3% of those receiving haemodialysis do so at home, this was the case for just 2.8% of Kidney PREM haemodialysis respondents. Amongst those receiving treatment in kidney centres or satellite units, participation in shared care increased to 35.8% compared to 29.2% in 2022, with an increase seen across all age groups. However, 31.4% report not being invited to participate in aspects of shared care and a further 16.0% did not know if they had been invited.

Approximately one-tenth of respondents stated having a first language other than English. Urdu and Gujarati were the most common, although these translated versions of Kidney PREM were not widely used (2 Gujarati, 1 Urdu, 1 Welsh). Patients Know Best (PKB) was used by 36.9% of Kidney PREM respondents and unavailable for 4.3%. Those with a functioning kidney transplant or receiving haemodialysis at home reported using PKB most often, each over 60%.

2: Additional questions in 2023

Three additional, one-off questions were developed for Kidney PREM in 2023, designed to capture information on important topics, using the scale and reach of the Kidney PREM collection to better understand current practices to drive improvements. The questions and key findings were:

Where clinic letters are sent:

Over half (51.4%) said letters were sent to themselves, with a copy sent to their GPs.

Wellbeing discussed with staff:

A third (36.8%) reported that the kidney team had discussed their wellbeing over the previous year, though with substantial regional variation (between 27.9% and 59.4%).

Last year's Kidney PREM discussed:

Just 11.9% of participants said that someone had spoken with them about the previous year's Kidney PREM results. Again, there was regional variation (7.5% to 19.4%).

3: Changes in patient experience

Most participants stated that there had been no change in their experience of care over the previous year (57.2%), with a fifth (20.5%) reporting their care to be 'much better'. Low scores (-3 to -1) were given by 6.3% of all respondents. Some differences by treatment modality were apparent, with those receiving haemodialysis in satellite dialysis units providing the highest proportion of 'much better' scores (26.1%). Around 20% of individuals receiving peritoneal dialysis, haemodialysis at home or haemodialysis in centres reported that their experience was 'much better', whereas those with a functioning kidney transplant or not receiving kidney replacement therapy reported this less often (14.6% and 13.6% respectively). The proportion of those indicating that their care had worsened was relatively high in both 2020 and 2021 for all modalities except those receiving haemodialysis in centres and satellite units. However, this reduced in 2022 in a potential 'levelling-out' effect post-pandemic, remaining low in 2023.

4: Kidney PREM theme results

The 13 Kidney PREM themes covering aspects of experience such as *Support*, *Transport* and *Communication*, can be found on page 42 of this report. Although most theme scores (out of a maximum score of 7) have remained relatively stable year on year, these averages mask the variation in scores seen across centres.

Overall Experience scores perform well at 6.26, although with considerable variation in scores across centres (5.43 to 6.81) and many centres having a small but notable proportion of participants giving poorer scores (1-3 out of 7). Most Kidney PREM participants rated their *Overall Experience* highly, with 92.4% scoring at least 5 out of 7. For three centres, all respondents gave scores of 5-7, and 52 out of 67 centres received positive scores from more than 90% of participants.

High scoring themes

Privacy & Dignity (6.38), *Patient Information* (6.37) and *Access to the Kidney Team* (6.34). *Overall Experience* remains high scoring (6.26), highlighting the continued high quality of care reported by participants.

Low scoring themes

Transport (5.54), *Sharing Decisions* (5.59), *Needling* (5.83) and *Communication* (5.84).

5: Key Kidney PREM theme results by treatment and question

Kidney PREM themes across treatment modalities:

- Scores for those not receiving kidney replacement therapy showed small negative differences compared to 2022 for all but one theme. The largest decrease was in *Support*, decreasing by 0.13 to 5.56, the lowest score for a theme across all modalities.
- Individuals on peritoneal dialysis also reported a reduction in *Support* (-0.14) in 2023, although scored the theme slightly higher than those not receiving kidney replacement therapy at 5.82.
- For people receiving haemodialysis at home, some decreases in scores compared to the previous year were larger. For example, *Environment* decreased by 0.43 to make it the lowest scoring theme for this treatment type at 5.73.
- Although the score for *Sharing Decisions* increased by 0.16 in 2023 for those receiving haemodialysis in centres, it remains the lowest scoring theme of all modalities, closely followed by those receiving haemodialysis in satellite units (5.41 and 5.45 respectively).
- Amongst those not receiving kidney replacement therapy, *Fluid & Diet* was unchanged, the score of 5.28 remaining the lowest of all treatment modalities (others ranging from 5.96 to 6.23).

Responses to Kidney PREM questions:

Most Kidney PREM themes are comprised of more than one question. This section highlights where there is variation in scores between the questions that make up each theme.

Support: Over a quarter (27.4%) of respondents scored accessing patient support groups (Q6) poorly at 1-3 out of 7.

Communication:

- *Communication* between the GP and kidney team (Q9) had the lowest proportion of participants scoring 7 out of 7 (38.1%) of the theme and was scored 1-3 by 23.9% of participants.
- *Communication* between the kidney team and non-healthcare teams (Q11) was another poorly scored question of the theme and was scored 1-3 by over a quarter (27.4%) of participants.

How the kidney team treats you: Being asked about emotional feelings (Q30) was much less positively rated than other theme questions, with just 68% giving scores of 5-7 and nearly a quarter rating it poorly (scores of 1-3). Notably, 15% stated that they were never asked about their emotions, awarding scores of 1.

6: Patient experience of kidney care across the service

The final chapter of the Kidney PREM 2023 contains graphs showing centre scores and their 95% confidence intervals, often highlighting considerable centre variation in scores. Centres are encouraged to view these graphs alongside the portal and spreadsheet data to assess their results and to inform local quality improvement initiatives.

Patient comments from the Kidney PREM

In 2023, 4,202 (36%) Kidney PREM respondents provided a comment on their care. The number of individuals leaving a comment increased by 14.5% compared to 2022, likely contributed to by Kidney PREM being online only. The large number of comments contributes to our understanding of patient experience of kidney care and helps to explain the reasons for changes in theme scores in the national report from the previous year. Of those who left comments, 94.1% gave consent for them to be passed back to their kidney centre, meaning they can be used to help inform quality improvement. Generally, the profile of participants who left a free text comment matched that of the national Kidney PREM 2023; however, there was a higher representation in the comments from individuals of a Black ethnic heritage (+1.3%).

The full comments report follows the 13 themes of experience that comprise the Kidney PREM survey, as the free-text responses aligned with them well. Comments which do not fit the pre-existing Kidney PREM themes are presented under *Emerging Themes*. This year, in alignment with the Kidney PREM survey, two further themes of comments are included, *Overall Experience* and *Additional Questions*.

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

Kidney PREM development and impact:

The national Kidney PREM reports produced each year provide a high-level picture of national kidney care experience. However, they do not tell the whole story. Each year, the national report generates questions and areas that require further exploration. A number of new projects have been developed in response to the national Kidney PREM dataset, to extend understanding of how people living with kidney disease in the UK experience their care. The projects are briefly described below, with further details available in the Kidney PREM report:

Widening participation in Kidney PREM: this ongoing study aims to address consistent trends of underrepresentation from Asian participants in Kidney PREM. Preliminary findings include awareness of Kidney PREM, barriers to participating, Kidney PREM themes and suitability of questions.

Needling Patient Reported Experience Measure (NPREM): people receiving haemodialysis in centres and satellite units have consistently scored their experience of needling more poorly than most other Kidney PREM themes. In response, a measure has been developed to reliably assess people's experiences of needling in more detail. When finalised, the 28-item NPREM will offer individuals a way to score their experiences, helping kidney care teams identify where service improvements can be made.

Pilot Paediatric PREM (pPPREM): Now in its second year, the pPPREM received responses from 312 individuals in 2023, with a summary of results reported. NIHR-funded work is underway to further develop the measure and extend it to all children and young people receiving kidney care.

Driving local improvement: the Kidney Quality Improvement Partnership (KQIP) are holding a series of regional virtual events with kidney teams and patients, sharing Kidney PREM findings. The partnership aims to map out where local activity around improving experience of kidney care is happening, facilitating the spread of successful initiatives and developments.

Impact of Kidney PREM: a new study is underway assessing the impact of Kidney PREM data collection. This aims to gather evidence about the use of Kidney PREM results as a catalyst for action or change to service delivery, with results due summer 2024.

Pilot Paediatric PREM

Following success of the initial survey in 2022, the pilot Paediatric PREM (pPPREM) was repeated in 2023 alongside the adult Kidney PREM. Questions were identical to the 2022 pPPREM, based on items from the validated Kidney PREM. Children and young people (CYP) aged 12 to 16 years could complete the pPPREM, either by themselves or with help from a trusted adult. Parents/carers of CYP of any age could participate and were asked to respond considering their experience as a parent/carer. A summary of findings is shown here, with the full report available online¹.

Response numbers and patient characteristics

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

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

Notes for interpretation

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

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

Key findings from the pilot Paediatric PREM

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

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

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

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

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

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

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

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

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

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

What's next for the pilot Paediatric PREM?

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

The other significant step forward has been securing National Institute for Health and Care Research (NIHR) funding² to further develop the measure, in collaboration with young people and their parents/carers, to ensure that all appropriate themes are included. Additionally, the funding enables us to determine whether CYP younger than 12 are able to meaningfully report their own patient experiences using appropriate measures.

The objective is that on completion of the study the PPREM will provide validated, age-appropriate measures focussed on key areas of patient care which are important to CYP, their families and health care professionals. This will then inform ongoing quality improvement work through the British Association for Paediatric Nephrology³ (BAPN) Paediatric Patient Experience working group. Once the measure is finalised, the collection of the PPREM will be included as part of the annual Kidney PREM process.

The NIHR funded work is expected to last for two years, with reporting due in 2026. For further information, please contact Dr Andrew Lunn, Nottingham University Hospitals NHS Trust andrew.lunn@nuh.nhs.uk.

² NIHR206218: Paediatric Kidney Patient Reported Experience Measure - developing and validating an experience measure for under 18-year-olds.

³ <https://ukkidney.org/bapn/about-bapn>

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 2017¹. 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 2023, the survey was conducted almost entirely online², with one centre offering paper surveys which were input online by patient volunteers. Shifting collection to digital only 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 give written feedback.

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

- theme results for each centre by age, ethnicity, haemodialysis location 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 question at the end of the survey,
- 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>

¹ 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>

² 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 on 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 and repeated in 2023, participants were 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.

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. Its scope was widened in 2022 to capture any changes to experiences of care over the previous 12 months.

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

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

Data collection

Online access to the Kidney PREM in 2023 lasted eight weeks, from 11th September until 6th 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 2023. 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.

As a pilot, one centre was provided with a printable copy of the survey in response to their concerns around digital exclusion. Data collected using these paper versions were manually input by volunteers at the centre 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 2023, with comparisons to the previous two years. Reports, data and other results from earlier years are available online³. 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 but are shown as centre “Missing” in graphs in this document. 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.

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

Results

Chapter 1: Profile of Kidney PREM respondents

Regional profile

In 2023, a total of 11,647 individuals participated in Kidney PREM. Despite moving to online only data collection, this was an increase of 5.3% compared to returns received in 2022 (Table 1.1). Responses for the North East and North Cumbria, the South West and Wales were each more than 20% of their most recently recorded KRT populations, as recorded by the UK Renal Registry (UKRR) at the end of 2022. Most other regions had responses from over 10% of their patients, with the exception of centres in Scotland which had responses from just 7.1% of their populations. Regional variation was also apparent in differences between responses in 2023 compared to 2022, with four regions decreasing in participant numbers (East of England, London, Northern Ireland and Scotland) and the rest increasing or remaining broadly the same.

Appendix A contains response numbers for each kidney centre, along with a comparison against returns received in 2022. In 2023, there was a reduction in number of responses where centre names could not be identified, at 407 compared to 888 in 2022, returning to a similar number seen in 2021 (411). This decrease corresponds with the absence of paper surveys, which accounted for over 600 missing centre names in the previous year. However, recognising that this is an ongoing issue, plans are underway to simplify centre name options for Kidney PREM participants for future collections, so that participants can select their centre more easily.

Table 1.1: Kidney PREM 2023 responses by region

	Responses 2023		Responses 2022	Change from 2022		% of 2022 KRT ¹ Population
	N ²	% of returns		N	%	
England						
East of England	744	6.4%	858	-114	-13.3%	15.0%
London	2,568	22.0%	2,667	-99	-3.7%	16.7%
Midlands	1,782	15.3%	1,405	+377	26.8%	15.4%
North East & N Cumbria	751	6.4%	694	+57	8.2%	24.5%
North West	798	6.9%	448	+350	78.1%	12.0%
South East	1,420	12.2%	1,211	+209	17.3%	19.4%
South West ³	1,211	10.4%	935	+276	29.5%	24.3%
Yorkshire & Humber	631	5.4%	612	+19	3.1%	10.5%
England Total	10,265	88.1%	9,063	+1,202	13.3%	17.4%
Northern Ireland						
Northern Ireland Total	239	2.1%	319	-78	-25.1%	11.8%
Scotland						
Scotland Total	382	3.3%	420	-34	-9.0%	7.1%
Wales						
Wales Total	760	6.5%	625	+148	21.6%	23.2%
UK Total	11,647	-	11,063	+584	5.3%	16.8%

1. 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.
2. Totals include 407 respondents who gave their country of treatment but not their centre and one who did not provide any geographical information.
3. KRT population figure for Exeter unavailable for 2022. 2020 data used instead.

Participant characteristics

Age

The age profile of Kidney PREM participants in 2023 was similar to previous years (Table 1.2). Responses from those aged ≤ 30 years was slightly lower than the expected population (3.7% compared to 4.7%), based on KRT population figures from the UKRR, although with an absolute increase in numbers compared to both 2022 and 2021 (3.4% and 3.1% respectively). However, it should be noted that individuals with CKD not receiving KRT tend to be older compared to the KRT only population. Therefore, a smaller proportion from younger ages with a corresponding larger proportion of older patients is expected amongst the Kidney PREM population.

Responses from individuals aged 31 to 55 years remained low compared to expected proportions, at just 27.5% compared to 35.4%. The number of over 75s was similar to previous years, although representing a slightly smaller proportion due to the larger total number of submitted surveys. Although this was equivalent to a drop in proportion to 22.9%, this group remain overrepresented when compared to UKRR figures (15.7%). Contrary to the previous year when almost 400 individuals did not provide their age, this information was provided in full for 2023 due to online data collection.

Age profiles by treatment modality are available in Appendix B. Interestingly, there is little difference across ages between 2023 and 2022 amongst participants receiving satellite and in centre haemodialysis, despite anticipating an effect from switching to online only surveys. Similarly, there was little difference in age profiles of other modalities in 2023 compared to the previous year, although there appeared to be a reduction in participation amongst those individuals over 75 years with CKD who were not receiving KRT.

Gender

The proportion of responses by gender has remained stable over the past three years, with approximately 58% male. In 2023, there was a slight increase in those identifying as non-binary or other, or not disclosing their gender compared to previous years, but remaining at less than 1%. The small increase may be explained in part by the reduction in missing data as participants are required to provide a response using the online data collection platform.

Ethnicity

Detailed ethnicity options were retained in 2023 so that participants were able select the option that most closely matched their heritage. There was very little change in proportions in 2023, even at the detailed ethnicity level. Asian participants continue to be underrepresented in the Kidney PREM, around 9% in each of the last few years compared to 14% as reported by the UKRR. As described in last year's Kidney PREM report, the UK Kidney Association and Kidney Care UK collaborated with the Health Inequalities Unit at the University of Hertfordshire to consider potential disparities in Kidney PREM awareness and/or further barriers to participation. Initial findings are summarised on page 21 of this report, with full results due to be published later in 2024.

Ethnicity information for Kidney PREM participants receiving KRT at each centre is displayed in Appendix C alongside UKRR figures.

Table 1.2: Respondent characteristics for Kidney PREM in 2023, 2022 and 2021

	Kidney PREM 2023	Kidney PREM 2022	Kidney PREM 2021	UK KRT Patients as of end of 2022 ¹
Age (years)				
≤30	447 (3.8%)	363 (3.4%)	376 (3.1%)	4.7%
31-55	3,200 (27.5%)	2,731 (25.6%)	3,261 (26.6%)	35.4%
56-74	5,329 (45.8%)	4,895 (45.9%)	5,763 (47.0%)	44.3%
≥75	2,671 (22.9%)	2,680 (25.1%)	2,868 (23.4%)	15.7%
Missing Age	-	394	148	-
Gender²				
Female	4,743 (40.7%)	4,328 (40.3%)	5,038 (41.6%)	38.7%
Male	6,793 (58.3%)	6,346 (59.1%)	6,986 (57.7%)	61.3%
Non-binary/other	27 (0.2%)	11 (0.1%)	-	-
Rather not say	84 (0.7%)	59 (0.5%)	86 (0.7%)	-
Missing Gender	-	319	306	-
Ethnicity				
Asian Total	1,110 (9.5%)	1,008 (9.3%)	1,137 (9.3%)	14.5%
Indian	479 (4.1%)	462 (4.2%)	-	
Pakistani	289 (2.5%)	231 (2.1%)	-	
Bangladeshi	134 (1.2%)	85 (0.8%)	-	
Chinese	33 (0.3%)	39 (0.4%)	-	
Any other Asian background	173 (1.5%)	190 (1.7%)	-	
Black Total	939 (8.1%)	903 (8.4%)	1,005 (8.3%)	9.0%
Caribbean	356 (3.1%)	322 (3.0%)	-	
African	477 (4.1%)	462 (4.2%)	-	
Any other Black background	106 (0.9%)	119 (1.1%)	-	
Mixed or multiple Total	146 (1.3%)	154 (1.4%)	-	1.5%
White & Black Caribbean	32 (0.3%)	46 (0.4%)	-	
White & Black African	17 (0.1%)	27 (0.2%)	-	
White & Asian	32 (0.3%)	33 (0.3%)	-	
Any other Mixed background	65 (0.6%)	48 (0.4%)	-	
White Total	9,079 (78.0%)	8,579 (79.6%)	9,358 (76.9%)	73.1%
English/Welsh/Scottish/N Irish/British	8,580 (73.7%)	8,142 (74.6%)	-	
Irish	164 (1.4%)	153 (1.4%)	-	
Gypsy/Irish Traveller/Roma	13 (0.1%)	14 (0.1%)	-	
Any other white background	320 (2.7%)	269 (2.5%)	-	
Other ethnic groups Total	169 (1.5%)	269 (2.5%)	402 (3.3%)	1.9%
Arab	31 (0.3%)	27 (0.2%)	-	
Any other ethnic group	138 (1.2%)	113 (1.0%)	-	
Rather not say	204 (1.8%)	127 (1.2%)	260 (2.1%)	
Missing Ethnicity	-	152	254	
Total	11,647	11,063	12,416	

1. UKRR Ethnicity data does not include Scottish centres and has additional missing data for 2,168 individuals.

2. Non-binary and Other categories added to gender options for Kidney PREM 2022 and not collected by UKRR.

Widening participation in Kidney PREM study

Aims

There are consistent trends of under-representation from South Asian patient communities in the Kidney PREM. The study aimed to explore whether in this group of patients:

1. There are disparities in Kidney PREM awareness and barriers to participation,
2. The themes and questions of the Kidney PREM address relevant concerns.

Methods

Participants were recruited via the community or NHS sites. Individuals took part in semi-structured interviews in English or Urdu, with questions framed around the main themes of the Kidney PREM questionnaire. In addition, they were asked about their familiarity with Kidney PREM, their willingness to take part in it in the future, why they have or have not taken part in the past and what might prevent others from taking part.

Preliminary findings

Community recruitment has been completed and is reported here. It included interviews with eight minority ethnic kidney patients (six of Pakistani heritage). Recruitment from NHS sites continues. Patients were aged from 33 to 73 years and included three individuals with functioning transplants, with the rest of the individuals receiving in centre haemodialysis, some of whom had history with other modalities such as transplants and peritoneal dialysis.

Awareness of Kidney PREM

Two participants had completed Kidney PREM before. Both were confident English speakers and skilled with the required technology. Four expressed some awareness of Kidney PREM, though had either never been approached or never completed. Amongst these participants, there was generally a willingness to participate in the future. The rest displayed no awareness of Kidney PREM.

Barriers to participating

Barriers included language and understanding (not just limited to available language, but sometimes literacy, jargon or misunderstanding of what was being asked of them), a lack of awareness and advertising, lack of confidence or skills with technology, and a lack of time or motivation to complete it, especially true of transplant patients and those in work. It has been noted by interviewers that, especially amongst older participants, individuals do not really question their care, often taking doctor advice and words as gospel. Even if they are unhappy about something, many will not challenge it. In addition, they may worry about answering questions ‘incorrectly’, even when it is stressed that there are no right or wrong answers.

Main Kidney PREM themes

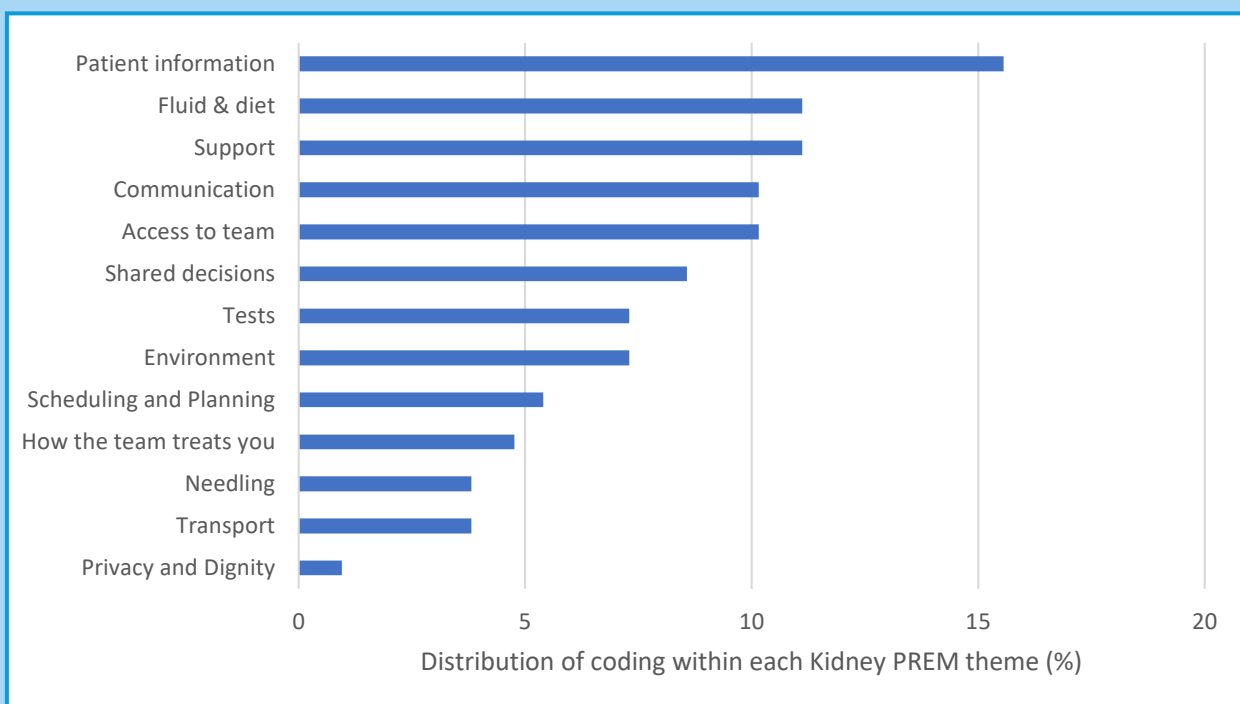
The figure below shows the distribution of coding within each theme of the Kidney PREM. Themes which elicited the most comments and feedback were *Patient Information, Fluid and Diet, Access to the Kidney Team* and *Support*. Indicative quotes to highlight key elements of the most commonly discussed themes are shown below.

Patient Information

“I think the clinicians think a lot of stuff is common sense. I put my hand up and say when it comes to medical stuff, I feel like I have no common sense. So they shouldn’t assume stuff, they should make it really explicit.”

Fluid and Diet

“they should have kind of [a] chart [of] diet for food, because information is not available everywhere. So it should be based people on Bengal based on their, you know, where they are from...”



Access to the Kidney Team

“No because I know they are busy, and I know I don’t always articulate my questions well. So I just think try again next time. If it is still a question then, umm, yeah, I don’t feel fobbed off.”

Support

“No, I am just there to do my dialysis and go home to be honest.”

Suitability of Kidney PREM questions

Most said the above themes and questions addressed the key aspects of their care and concerns. Particular highlights of what was lacking in their care and what was most important to these patients included: information (especially about diet), kindness and treatment by the kidney team, accessibility and being asked about their wellbeing.

Treatment modalities of participants

Haemodialysis remains relatively common amongst those participating in the Kidney PREM, increasing to 64.4% in 2023 (Table 1.3). UKRR figures suggest that this remains a larger proportion than would be expected based on the UK KRT population (38.3%). The number of Kidney PREM participants with a functioning kidney transplant remains low, with a slight drop in proportion to 15.9%, although a small increase in absolute numbers. Participant numbers have increased compared to 2022 across all treatment modalities (with the exception of those receiving peritoneal dialysis) but decreased in comparison to 2021 overall. Appendix D shows the proportion of people who participated in Kidney PREM receiving each KRT type by centre compared with aggregate national data. UKRR records show that there are over 39,000 people living with kidney transplants in the UK, of which fewer than 5% have participated in Kidney PREM. This contrasts with Kidney PREM participation of nearly 30% of those receiving haemodialysis in centres or satellite units.

Table 1.3: Treatment modality for Kidney PREM participants in 2023, 2022 and 2021

	Kidney PREM 2023	Kidney PREM 2022	Kidney PREM 2021	UK KRT Patients at end of 2022
Transplant	1,849 (15.9%)	1,780 (16.8%)	2,148 (17.7%)	56.3%
Haemodialysis	7,500 (64.4%)	6,469 (61.1%)	7,497 (61.8%)	38.3%
Peritoneal dialysis	620 (5.3%)	725 (6.9%)	772 (6.4%)	5.3%
CKD (non-KRT)	1,678 (14.4%)	1,605 (15.2%)	1,710 (14.1%)	- ¹
<i>Missing treatment</i>	-	484	289	-
Total	11,647	11,063	12,416	

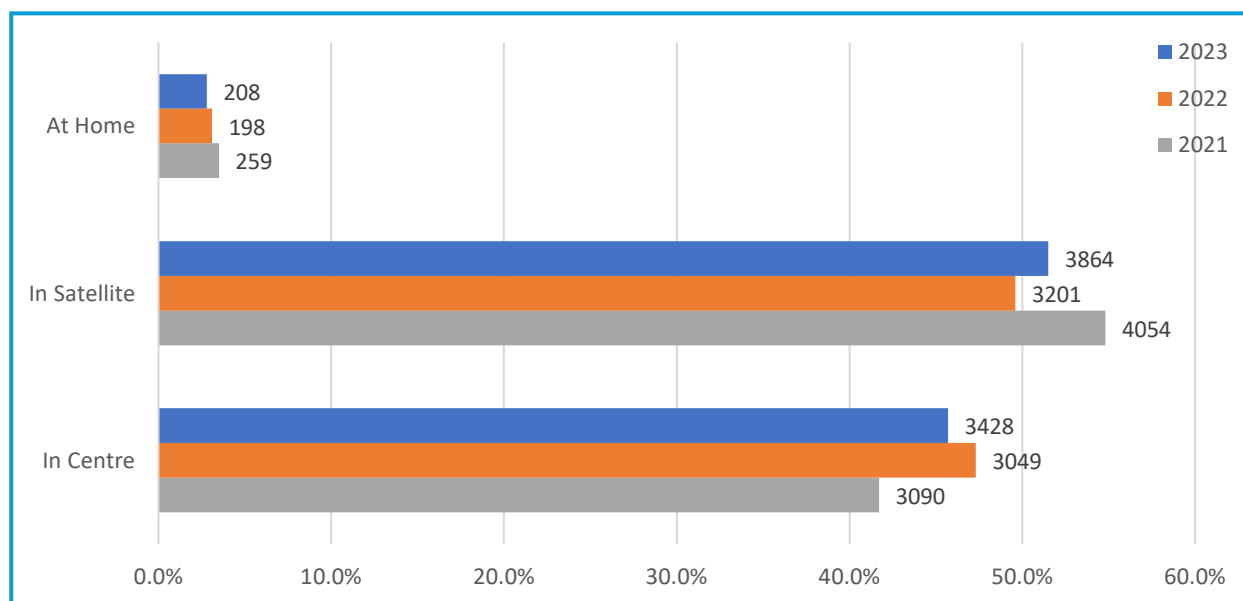
1. UKRR collects limited data for CKD patients not receiving KRT

Participants receiving haemodialysis

Haemodialysis location

According to UKRR figures, 5.3% of people receiving haemodialysis do so at home. However, home haemodialysis was reported in just 2.8% of Kidney PREM respondents receiving haemodialysis, Figure 1.2, a decrease from 3.5% in 2021. Over half of haemodialysis recipients receive treatment in satellite units (51.5%), a slight increase from 2022 (49.6%) but fewer than in 2021 (54.8%).

Figure 1.2: Haemodialysis location of Kidney PREM participants in 2023, 2022 and 2021



Participation in shared care for individuals receiving haemodialysis

People receiving haemodialysis in centres or satellite units were asked, “Have you been invited to participate in any tasks of your haemodialysis care (shared care)?”. Of the 7,292 respondents receiving in centre haemodialysis, 16.0% did not know if they had been invited to participate in shared care (Table 1.4), a similar proportion to 2022 (16.8%). Participation in shared care increased to 35.8% in 2023 from 29.2% in 2022, with an increase seen across all age groups. Individuals aged 75 years and over were still least likely to participate and were more likely to say they were not invited (36.0% compared to 24.5% of those aged 30 years and under).

Shared care participation remained higher in satellite units than in main centres (41.8% vs 29.1%), although both have increased since 2022.

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

	N	Participating	Declined	Not Invited	Don't Know
Age (years)					
≤30	257	96 (37.4%)	42 (16.3%)	63 (24.5%)	56 (21.8%)
31-55	1,809	717 (39.6%)	305 (16.9%)	483 (26.7%)	304 (16.8%)
56-74	3,247	1,181 (36.4%)	543 (16.7%)	1,035 (31.9%)	487 (15.0%)
75+	1,979	619 (31.3%)	327 (16.5%)	712 (36.0%)	320 (16.2%)
Gender					
Male	4,427	1,588 (35.9%)	726 (16.4%)	1,437 (32.5%)	675 (15.2%)
Female	2,788	1,002 (35.9%)	468 (16.8%)	839 (30.1%)	478 (17.1%)
Non-binary/other	11	5 (45.5%)	2 (18.2%)	3 (27.3%)	1 (9.1%)
Rather Not Say	66	18 (27.3%)	21 (31.8%)	14 (21.2%)	13 (19.7%)
Ethnicity					
Asian	807	353 (43.7%)	100 (12.4%)	206 (25.5%)	147 (18.2%)
Black	714	315 (44.1%)	100 (14.0%)	197 (27.6%)	102 (14.3%)
Mixed	90	44 (48.9%)	14 (15.6%)	21 (23.3%)	11 (12.2%)
White	5,426	1,816 (33.5%)	941 (17.3%)	1,814 (33.4%)	854 (15.7%)
Other	109	46 (42.2%)	16 (14.7%)	24 (22.0%)	23 (21.1%)
Rather Not Say	146	39 (26.7%)	46 (31.5%)	31 (21.2%)	30 (20.5%)
Haemodialysis location					
Main centres	3,428	999 (29.1%)	573 (16.7%)	1,256 (36.6%)	600 (17.5%)
Satellite units	3,864	1,614 (41.8%)	644 (16.7%)	1,037 (26.8%)	567 (14.7%)
Total	7,292	2,613 (35.8%)	1,217 (16.7%)	2,293 (31.4%)	1,167 (16.0%)

N: number of respondents

How results from the Kidney PREM shape care: Development of the needling patient reported experience measure (NPREM)

Since 2017, the Kidney PREM has shown that people using in centre and satellite haemodialysis consistently scored their experience of needling more poorly than other themes (yearly average ranging from 5.7-5.9) and that experience varies widely within and between centres (1.8-2.0 range). These results concerned the kidney community, and a group of researchers, clinicians, and people with lived experience of needling applied for funding⁴ to address this. In 2020, they began developing a measure (questionnaire) that can reliably assess people's experiences of needling for haemodialysis.

The research was carried out over multiple stages in eight kidney centres across England, with various needling practices and patient populations. First, to better understand needling, the team interviewed people on haemodialysis with a broad range of experience (for example, people on home haemodialysis who self-needle, people with fistulas or grafts). Second, the team and a group of people with lived experience of needling created questions derived from the interviews which were initially tested in further interviews and a pilot survey. Third, a larger sample of people on haemodialysis completed the questionnaire, allowing the team to assess its validity.

The result is a 28-item Needling Patient Reported Experience Measure (NPREM) which covers areas of care that patients said were important to needling. When it is finalised this year, it will be free to use and suitable for anyone with a fistula or graft that is currently used for haemodialysis. It offers all people who are needled for haemodialysis a way to score their experience and will show kidney care teams where improvements can be made, both at the centre-level and for individuals.

A QUESTIONNAIRE TO BETTER UNDERSTAND
YOUR EXPERIENCE OF NEEDLING

Needling Patient Reported Experience Measure

NPREM

Patients shared what makes haemodialysis needling go well and not so well. We turned these into questions. Then we tested them with lots of patients to make sure they made sense.

Helping patients and dialysis teams see where improvements can be made.



28 questions on key topics:

- My fistula/graft and needling
- Steps in needling
- Communicating with the team
- Working together
- My personal experience
- Overall needling experience

It gives us a great opportunity to **work together** as **patients and professionals** to see where **improvements** can be made in needling, where **needling** can be **made easier** for the patient, **making us all** feel more **comfortable and confident** in the process of needling.

University of Hertfordshire **UH**

NIHR | National Institute for Health Research



Fez Awan
Patient advocate
NPREM Patient Group

⁴ This project was funded by the National Institute for Health and Care Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number NIHR/PB-PG-0418-20047). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care

Participants attending clinic but not receiving kidney replacement therapy

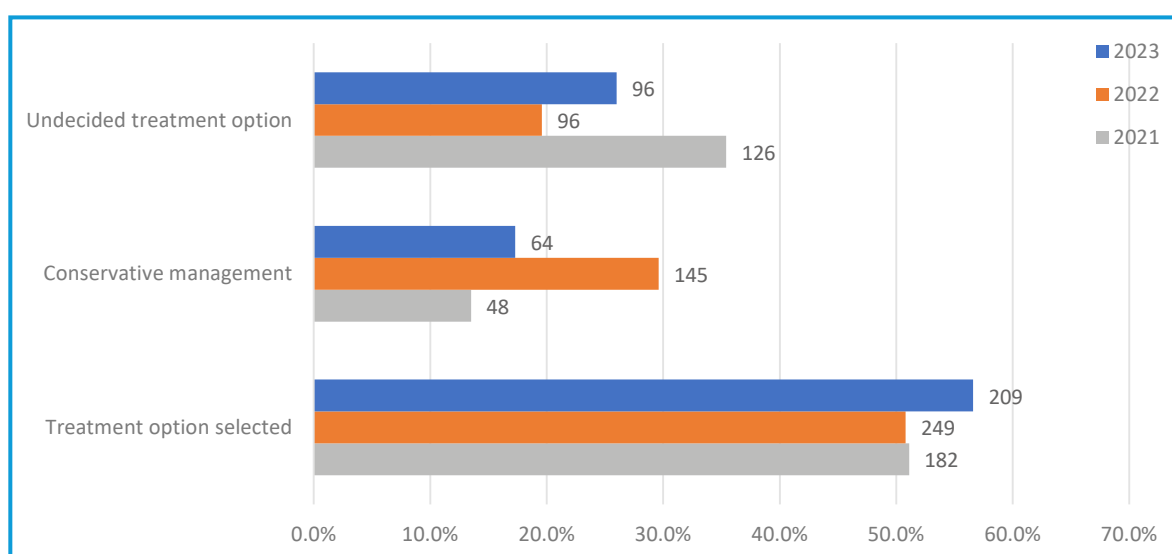
A similar number of Kidney PREM respondents reported attending clinic without receiving kidney replacement therapy in 2023 as in 2022. However, a larger proportion of these stated that they were attending for monitoring only (70.6%, Table 1.5). There remains a small group who do not know their CKD type and reason for attending clinic (7.4%). Although most data relating to participant treatment modalities were complete, CKD type was missing for one participant who completed a translated version of the Kidney PREM, where this question was unavailable.

Table 1.5: Reason for attending clinic for participants not receiving kidney replacement therapy

	Kidney PREM 2023	Kidney PREM 2022	Kidney PREM 2021
Attending for monitoring only	1,184 (70.6%)	982 (62.5%)	1,130 (66.1%)
Approaching end stage kidney disease	369 (22.0%)	490 (31.2%)	356 (22.0%)
Don't know CKD type	124 (7.4%)	99 (6.3%)	132 (8.2%)
<i>Missing CKD type</i>	1	34	92
Total CKD (non-KRT)	1,678	1,605	1,710

Of those approaching end stage kidney disease, over half (56.6%) had chosen their kidney replacement therapy option, Figure 1.3, a slight increase from 2022 and 2021. There was an increase in the proportion of those who have not yet decided a treatment option (from 19.6% to 26.0%), and a decrease in respondents who have chosen conservative management (from 29.6% to 17.3%).

Figure 1.3: Treatment option for individuals approaching end stage kidney disease



Help to participate in Kidney PREM

A total of 3,618 (31.1%) participants indicated that they received help to complete Kidney PREM, a small increase from 27.0% the previous year. There was a higher proportion of staff/other helpers supporting completion of the survey (Table 1.6), increasing from 38.2% to 41.3%, mirrored by a proportionately larger increase in volunteer helpers, from 15.2% to 25.3%. This corresponded with a drop in friends and relatives supporting participation in Kidney PREM.

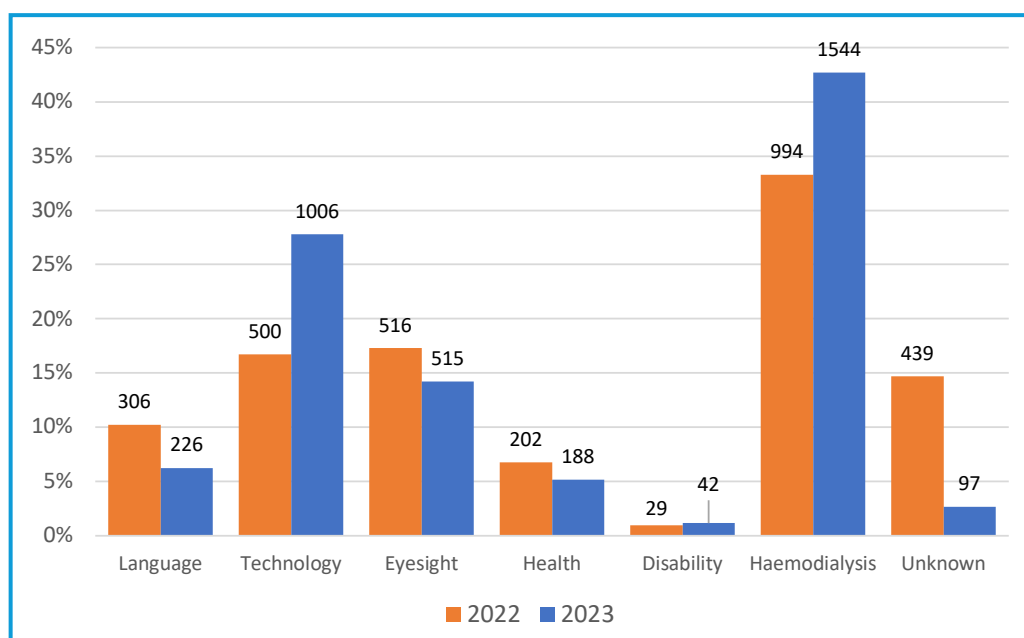
Table 1.6: Helpers for Kidney PREM completion in 2023 and 2022

	Kidney PREM 2023	Kidney PREM 2022
Friend/relative/carer	1,206 (33.3%)	1,437 (49.3%)
Volunteer	917 (25.3%)	442 (15.2%)
Staff/other	1,495 (41.3%)	1,036 (38.2%)
Total	3,618	2,986

Appendix Table E1 displays the number and proportion of participants who received help completing Kidney PREM by their characteristics and treatment modality. Notably, nearly half (49.1%) of participants aged 75 years and over received help. White participants received help least often (39.7%) and Asian participants the most often (42.6%), when compared with other ethnic groups. Of those people receiving haemodialysis, 42.7% received help with completion. This differed by treatment site, 45.0% at satellite units compared with 41.9% in main centres, perhaps suggesting a higher availability of help in satellite units.

There was an almost two-fold increase in the proportion of those receiving help to complete Kidney PREM because of difficulties with the technology, from 16.7% in 2022 to 27.8% in 2023 (Figure 1.4). Requiring support due to connection to the haemodialysis machine rose from 33.3% to 42.7%. Appendix Table E2 shows reasons for help by treatment modality.

Figure 1.4: Reason for receiving help to participate in Kidney PREM



English as first language

For the second year, participants were asked to report whether English was their first language, with an option to provide their first language if different. A tenth of Kidney PREM respondents (10.8%) stated that they first used a language other than English (Table 1.7). As with 2022, regional variation was seen; over a fifth (21.0%) of London-based participants indicated a language other than English, ten-fold higher than in the South West where the figure was just 2.1%.

Very few individuals at centres in Northern Ireland and Scotland did not have English as their first language, just 1.3% and 1.9% respectively. There was a larger proportion in Wales (11.2%), predominantly consisting of those with Welsh as their first language (48 out of 81, 59.3%).

Table 1.7: English as first language for Kidney PREM participants by region

Region	Other first language	English first language
England		
East of England	94 (12.6%)	650 (87.4%)
London	540 (21.0%)	2,028 (79.0%)
Midlands	200 (11.2%)	1,581 (88.8%)
North East & N Cumbria	18 (2.6%)	680 (97.4%)
North West	50 (6.3%)	748 (93.7%)
South East	124 (8.7%)	1,296 (91.3%)
South West	26 (2.1%)	1,185 (97.9%)
Yorkshire & Humber	49 (7.8%)	582 (92.2%)
Northern Ireland	3 (1.3%)	230 (98.7%)
Scotland	7 (1.9%)	367 (98.1%)
Wales	81 (11.2%)	644 (88.8%)
<i>Missing centre</i>	62 (15.2%)	345 (84.8%)
Total	1,254 (10.8%)	10,336 (89.2%)

Table 1.8 shows the wide range of languages spoken by Kidney PREM respondents, displaying those where the frequency was ≥ 10 . Urdu and Gujarati remain the most common, supporting the translation of the Kidney PREM into these languages. Despite this, just four translated surveys were completed: two in Gujarati, one in Urdu and one in Welsh. Punjabi (84) and Bengali (99) were also frequently selected, notably featuring more often than Welsh, one of the Kidney PREM translations. Over 100 languages were indicated, reflecting the cultural diversity of the CKD population. A full list of languages is available in Appendix F.

Table 1.8: Primary languages spoken by those for whom English is not their first language

Language	Frequency	Language	Frequency
Akan Fante/Twi	22	Albanian	10
Igbo	10	French	34
Somali	30	Greek	13
Yoruba	21	Italian	16
Other African	76	Polish	33
Bengali	99	Portuguese	31
Chinese	27	Romanian	35
Gujarati	118	Spanish	22
Hindi	32	Turkish	23
Malayalam	13	Welsh	54
Nepali	17	Other European	64
Punjabi	84	Arabic	40
Sinhala	12	Other	14
Tagalog/Filipino	34	<i>Unidentified</i>	<i>22</i>
Tamil	37	Total	1,254
Urdu	138		
Other Asian	73		

Measuring participant deprivation using partial postcodes

Introduced in 2022, Kidney PREM respondents were again asked to provide the first half of their postcodes, so that any differences in experience by location could be assessed. Participants were asked to enter information using a free-text box and were also given the option to select “no” if they preferred not to provide this data. There were 399 participants who selected “no” and additionally entered text; these were removed from analysis, resulting in 8,249 participants with partial postcodes (70.8% of the total Kidney PREM responses). There was some variation across regions (Table 1.9), ranging from 61.3% (East of England) to 83.4% (Scotland).

Table 1.9: Partial postcodes provided by region

	Postcode provided	
	Frequency	%
East of England	456	61.3%
London	1,819	70.8%
Midlands	1,263	70.9%
N Ireland	147	63.1%
North East & N Cumbria	527	70.2%
North West	523	65.5%
Scotland	312	83.4%
South East	1,104	77.7%
South West	870	71.8%
Wales	510	70.2%
Yorkshire & Humber	459	72.7%
<i>Unknown Centre</i>	<i>259</i>	<i>63.5%</i>
Total	8,249	70.8%

The first half of a postcode can usually identify which local authority (LA) each participant resides in. However, sometimes a postcode could map to more than one LA, the maximum being seven. Therefore, the most likely LA was selected for each participant, with methodological details provided in the technical report. A total of 759 partial postcodes could not be attributed to a LA, resulting in 7,315 (62.8% of all Kidney PREM respondents) being matched.

Indices of multiple deprivation (IMD) are calculated and reported separately for each nation in the UK⁵, by ranking lower layer super outer areas (LSOA), comprising between 400 and 1,200 people, according to their levels of deprivation. Limited information is reported at LA level, but a measure which could be compared across all four nations was required. Therefore, the proportion of LSOAs ranked as being in the most deprived 30% of the respective nation's IMD was used. Amongst those LAs matched to participant postcode, the proportion of LSOAs in the most deprived 30% ranged from 0% (least deprived) to 82.7% (most deprived), though mostly at the lower end (median 27.8%, interquartile range 13.2% to 44.4%).

For each theme, the association between scores and deprivation was measured using regression models. When deprivation of the area was higher, most themes had lower theme scores, Appendix Table G1, with the exception of *Fluid & Diet* and *The Environment* where the association was reversed. However, differences across all themes were small in either direction, less than 0.1 change in score per 10% increase in proportion of deprived LSOAs. Table 1.10 demonstrates the impact of these differences on each theme's scores. For example, for *Overall Experience*, individuals living in LAs with the smallest proportion of deprived areas scored 6.32 (95% CI 6.27 to 6.37), whereas those living in areas with the highest proportion of deprived areas scored slightly lower at 6.19 (95% CI 6.14 to 6.24).

⁵ <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).

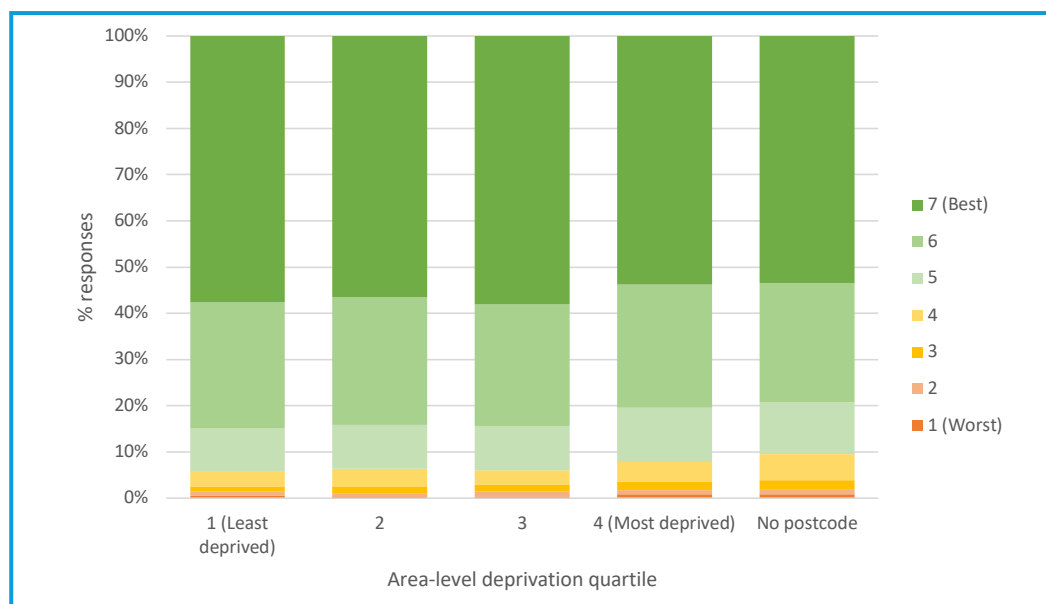
Table 1.10: Mean theme scores by deprivation

	Area-level deprivation ¹ : Mean score (95% CI)				No postcode provided N=3,737
	Least Deprived Quartile N=1,951	Quartile 2 N=1,939	Quartile 3 N=1,950	Most Deprived Quartile N=1,972	
Kidney PREM Score	6.08 (6.03, 6.12)	6.06 (6.02, 6.10)	6.06 (6.02, 6.11)	6.01 (5.96, 6.05)	5.96 (5.92, 5.99)
Access	6.45 (6.40, 6.49)	6.39 (6.35, 6.44)	6.36 (6.31, 6.41)	6.28 (6.23, 6.33)	6.24 (6.20, 6.28)
Support	5.85 (5.78, 5.91)	5.76 (5.68, 5.83)	5.77 (5.70, 5.84)	5.66 (5.59, 5.73)	5.63 (5.58, 5.69)
Communication	5.89 (5.83, 5.95)	5.85 (5.78, 5.91)	5.89 (5.83, 5.95)	5.83 (5.76, 5.89)	5.86 (5.82, 5.90)
Patient Information	6.48 (6.43, 6.52)	6.43 (6.38, 6.48)	6.40 (6.35, 6.45)	6.35 (6.29, 6.40)	6.25 (6.21, 6.29)
Fluid & Diet	5.90 (5.83, 5.98)	5.97 (5.90, 6.04)	6.04 (5.97, 6.10)	5.99 (5.92, 6.06)	6.03 (5.98, 6.08)
Needling	5.85 (5.73, 5.96)	5.90 (5.79, 6.01)	5.81 (5.70, 5.92)	5.64 (5.52, 5.76)	5.76 (5.70, 5.83)
Tests	6.22 (6.17, 6.27)	6.18 (6.13, 6.23)	6.16 (6.11, 6.21)	6.12 (6.06, 6.18)	6.05 (6.01, 6.10)
Sharing Decisions	5.67 (5.59, 5.74)	5.65 (5.57, 5.72)	5.67 (5.60, 5.75)	5.54 (5.46, 5.62)	5.47 (5.41, 5.53)
Privacy & Dignity	6.54 (6.50, 6.59)	6.50 (6.46, 6.55)	6.46 (6.41, 6.51)	6.43 (6.38, 6.48)	6.29 (6.25, 6.33)
Scheduling	6.23 (6.18, 6.28)	6.28 (6.23, 6.33)	6.27 (6.22, 6.32)	6.20 (6.14, 6.25)	6.17 (6.13, 6.21)
How Team Treats You	6.13 (6.08, 6.18)	6.13 (6.08, 6.19)	6.15 (6.10, 6.20)	6.08 (6.02, 6.13)	6.01 (5.97, 6.06)
Transport	5.49 (5.37, 5.61)	5.71 (5.60, 5.81)	5.53 (5.42, 5.64)	5.51 (5.41, 5.61)	5.52 (5.46, 5.58)
Environment	6.01 (5.96, 6.06)	6.07 (6.03, 6.12)	6.08 (6.04, 6.13)	6.13 (6.08, 6.18)	6.11 (6.07, 6.14)
Overall Experience	6.32 (6.27, 6.37)	6.30 (6.25, 6.34)	6.32 (6.27, 6.36)	6.19 (6.14, 6.24)	6.17 (6.13, 6.20)

¹ Local authorities of patient residence were divided into quartiles based on the percentage of LSOAs in most deprived 30% across nations.

The percentage distribution of respondent scores for each deprivation quartile is illustrated in Figure 1.5, demonstrating that those living in the most deprived areas selected 6-7 out of 7 for *Overall Experience* less often. Differences at the lower end of the response scale are smaller; 1-3 was selected by 3.9% of those in the most deprived area compared to 2.5% of those in the least deprived area.

Figure 1.5: Overall Experience scores by area-level deprivation quartile



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 which are not recorded in the Kidney PREM may prove more helpful when considering how people may experience their care. In addition, although care has been taken to provide a comparison across nations, the ranks are calculated

independently. An LSOA 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.

Although there appear to be some variation in scores according to deprivation levels, these differences are small in all themes. Measuring deprivation is important, particularly given the known impact of kidney health inequalities in the UK⁶. However, given the limitations of measuring deprivation based on partial postcode, this approach will be reviewed, with the aim of improving data collection and relevance of reporting for future Kidney PREM collection cycles.

⁶ <https://ukkidney.org/audit-research/disparities-report>

Use of Patients Know Best

As most centres have transitioned to the use of Patients Know Best⁷ (PKB) from the previous service, PatientView, the question relating to the use of online platforms to receive test results was reworded. There was a slight drop in the proportion of respondents using PKB to 36.9%, down from 38.1% in 2022 (Table 1.11). This remains lower than in 2020, when Kidney PREM was held online only, where 41.6% reported using PKB or PatientView. A large group of participants are unaware of PKB (31.5%). A small number of individuals (503, 4.3%) stated that PKB was unavailable in their centre, a third of which were treated at just five centres. PKB is currently unavailable at centres in Northern Ireland, yet 26 participants based there stated that they used the platform. There remains wide variation in usage of PKB by treatment modality, mirroring previous years. Transplant recipients (67.7%) and those receiving haemodialysis at home (60.6%) continue to be the biggest users of the platform. Those receiving haemodialysis in centres or satellites report using PKB less (centre haemodialysis 27.1%, satellite haemodialysis 25.4%) and are more likely to report that they did not know whether they used the platform (centre haemodialysis 16.8%, satellite haemodialysis 19.6%).

Table 1.11: Kidney PREM participant use of Patients Know Best, by treatment

	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	1,251 (67.7%)	85 (4.6%)	231 (12.5%)	198 (10.7%)	83 (4.5%)	1,848
Centre HD	928 (27.1%)	204 (6.0%)	1,195 (34.9%)	524 (15.3%)	576 (16.8%)	3,427
Satellite HD	982 (25.4%)	128 (3.3%)	1,414 (36.6%)	581 (15.0%)	757 (19.6%)	3,862
Home HD	126 (60.6%)	18 (8.7%)	25 (12.0%)	29 (13.9%)	10 (4.8%)	208
Peritoneal	252 (40.6%)	22 (3.5%)	199 (32.1%)	74 (11.9%)	73 (11.8%)	620
CKD (non-KRT)	761 (45.4%)	46 (2.7%)	604 (36.0%)	136 (8.1%)	130 (7.8%)	1,677
Total	4,300 (36.9%)	503 (4.3%)	3,668 (31.5%)	1,542 (13.2%)	1,629 (14.0%)	11,642

HD: Haemodialysis

CKD: Chronic kidney disease

⁷ <https://patientsknowbest.com/>

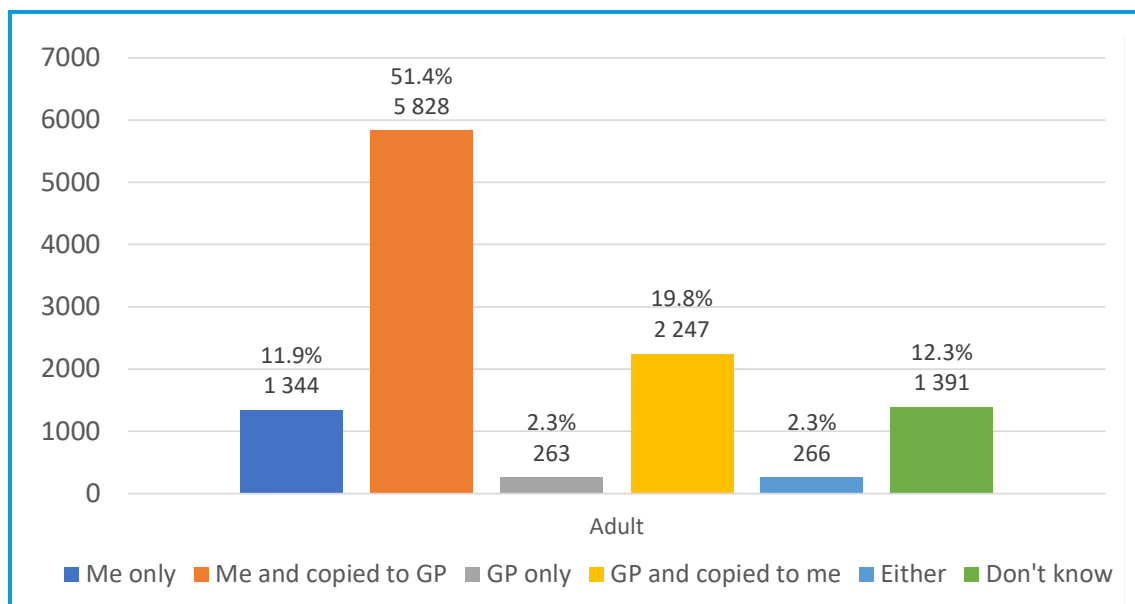
Chapter 2: Additional questions

The Kidney PREM working group, in collaboration with service users, developed three additional, one-off questions for Kidney PREM participants in 2023. These were designed to capture information on topics deemed important by the group, using the scale and reach of the Kidney PREM collection to better understand current practices at a local level and from a patient perspective, in order to drive improvements. The questions were added at the end of Kidney PREM so as not to interfere with the measure itself, but before participants were asked to provide any comments. The additional questions had a high rate of response at over 97%. Results are presented here at national and regional level, but are available for each centre in Appendix H.

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

Best practice suggests that clinic letters should be addressed to patients as well as to their primary care practitioners, using appropriate language so that they can be well understood. A total of 11,339 participants (97.4% of Kidney PREM respondents) provided a response, Figure 2.1. Over half (51.4%) reported that letters were sent to themselves and copied to their GPs, with a further 11.9% stating that they were sent only to themselves. A total of 22.2% responded that letters were sent either to the GP only, or to their GP and copied to themselves. Over a tenth (12.3%) did not know who their clinic letters were sent to.

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



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

Responses to this question were received from 11,344 individuals (97.4% of Kidney PREM respondents). Just over a third of all respondents (36.8%) stated that they had spoken with staff about their wellbeing in the previous year (Table 2.1). However, there was considerable regional variation; a higher proportion of those attending centres in Northern Ireland have had these conversations (59.5%), where centres are mostly small, compared to individuals at London centres (27.9%), which tend to be larger. It

should be noted, however, that the Midlands region contains some large centres and yet had one of the highest proportions reporting that their wellbeing was discussed (45.7%), so there are likely to be other contributing factors.

Results for each centre are shown in Appendix Table H2, where the wide variation of responses is evidenced; between 14.3% and 81.8% of participants report having discussed their wellbeing with staff at each centre.

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

This question was included to aid the understanding of if and how Kidney PREM results are used by centres. A total of 11,336 (97.3% of respondents) provided an answer to this question, with just 11.9% of participants stating that someone had spoken to them about Kidney PREM 2022 results (Table 2.1). Again, there was some regional variation; 7.5% of individuals at centres in Scotland had discussed findings compared to 19.4% of those at sites in the Midlands. There was variation across centres (Appendix Table H3), ranging from 0.0% (five centres) to 38.7%.

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

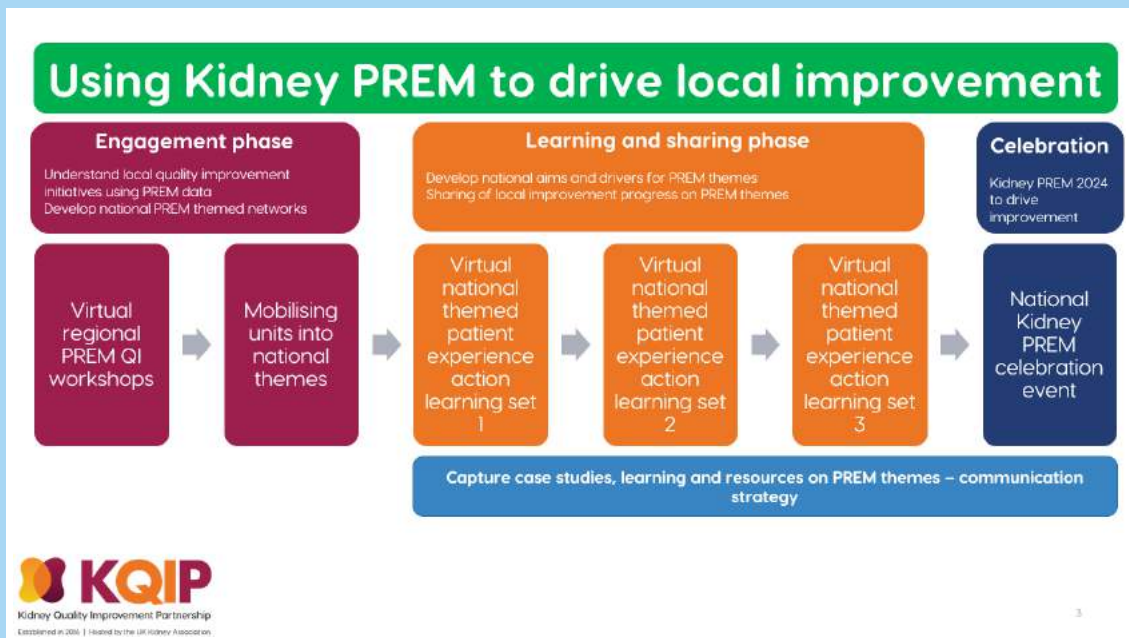
	Question B: Spoken to about Wellbeing Frequency (%)	Question C: Spoken to about last year's Kidney PREM Frequency (%)
England		
East of England	303 (41.5%)	96 (13.2%)
London	689 (27.9%)	258 (10.5%)
Midlands	802 (45.7%)	340 (19.4%)
North East & N Cumbria	284 (38.8%)	77 (10.5%)
North West	318 (40.3%)	66 (8.4%)
South East	428 (30.8%)	115 (8.3%)
South West	402 (33.7%)	113 (9.5%)
Yorkshire & Humber	221 (35.8%)	79 (12.8%)
Northern Ireland	135 (59.5%)	33 (14.6%)
Scotland	148 (41.1%)	27 (7.5%)
Wales	314 (44.5%)	88 (12.5%)
<i>Unknown centre</i>	127 (34.0%)	57 (15.2%)
Total	4,171 (36.8%)	1,349 (11.9%)

A new study is underway to look at the impact of Kidney PREM data collection at local and regional level. The work will be delivered by the University of Hertfordshire and the UK Kidney Association, comprising an online survey and centre interviews with staff and patients. The overall aim of the study is to gather evidence about if and how Kidney PREM results are used locally, either as a catalyst for action or change within service delivery, or in planning, identifying training needs or taking a more person-centred approach. Results from this study will be published in late 2024 and disseminated across centres and through kidney networks.

Using Kidney PREM to drive local improvement

The Kidney Quality Improvement Partnership are holding a series of regional virtual events with kidney teams and patients, sharing what Kidney PREM data is available, how to access the data, and discussing how to use the data to drive quality improvement.

From these events the partnership hopes to map out where local activity around improving experience of kidney care is happening. Attendees who are engaged in improvement locally will be invited to join national learning sets, based on themes of experience or treatment types, with the aim of sharing ideas, resources and learning and facilitating the spread of successful initiatives and developments. We look forward to reporting more fully on this activity as part of the Kidney PREM 2024 report.



Chapter 3: Changes in patient experience

Since 2020, Kidney PREM participants have been asked to rate how their experience of care has changed over the previous year. Initially focussed on pandemic-related changes in care, since 2022 this has been expanded to include all aspects of experience, beyond those related to COVID-19.

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

As with previous years, the question was placed at the end of the Kidney PREM scale (after question 39), prior to the additional questions and comments free-text box. Responses each year were recorded using a 7-point Likert scale from -3 (much worse) through 0 (no change) to +3 (much better), with an additional option to indicate they had not been receiving care a year ago.

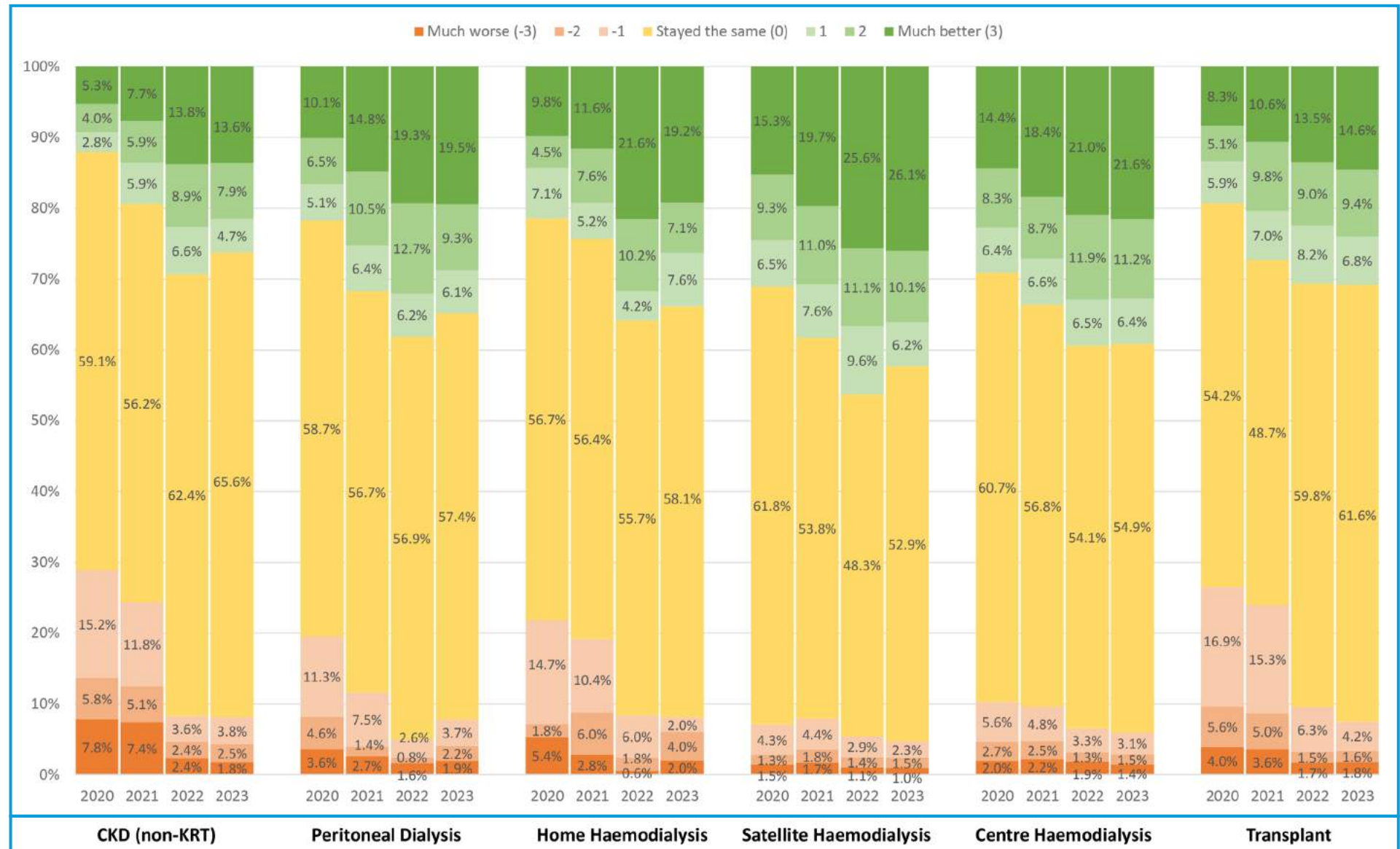
In 2023

A total of 11,346 (97.4% of Kidney PREM respondents) provided an answer, of which 1,861 (16.4%) stated that they were not receiving care a year ago. Of those receiving care, most stated that there had been no change in their experience (57.2%), with little difference seen by treatment modality (Figure 3.1). Just over a fifth (20.5%) of all respondents stated that their care was ‘much better’ than in the previous year. Those receiving haemodialysis in satellite units had the highest proportion of ‘much better’ scores at 26.1%, with those receiving peritoneal dialysis, haemodialysis at home or in main centres closer to one fifth (19.5%, 19.2% and 21.6% respectively). Individuals not receiving kidney replacement therapy and transplant recipients gave the top score less frequently (13.6% and 14.6%). Encouragingly, low scores (-3 ‘much worse’, -2 and -1) were given by just 6.3% of all participants and totalled less than 10% in each individual treatment modality.

Compared to previous years

Results for participants of all treatment modalities were broadly similar to those of 2022, although small decreases in the proportion of those awarding positive scores (+1, +2 and +3 ‘much better’) were seen in some modalities (those not receiving KRT, peritoneal dialysis, home haemodialysis, satellite haemodialysis). The proportion of those indicating that their care had worsened was relatively high in both 2020 and 2021 for all modalities except those receiving haemodialysis in centres and satellite units but reduced in 2022 in a potential ‘levelling-out’ effect of the pandemic, remaining low in 2023.

Figure 3.1: Changes in patient experience over past year for 2023, 2022, 2021 and 2020, by treatment⁸



⁸ During analysis of 2023 Kidney PREM data, a coding error relating to 2022 results was revealed, where -3 and +3 values were inverted for those completing Kidney PREM online. Results published here have been updated using the correct figures.

Comments about experiences of care

In 2023, the Kidney PREM was available online only, with all those responding to Kidney PREM having access 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”.

There were 11,647 individuals with kidney disease who took part, with 4,202 (36% of responses) providing a further comment on their care. The number of individuals responding to Kidney PREM increased slightly (5.3%) from 2022, with the number of respondents leaving a comment increasing by 14.5% in part undoubtedly due to the nature of Kidney PREM being online only. This increase in the number of comments has improved understanding of patient experience of kidney care and helps to explain the reasons for changes in theme scores in the national report from the previous year.

Additionally, 94.1% of responders gave consent for their comments to be passed back to their kidney centre which can be used to help support quality improvement. Generally, the profile of responders who left a free text comment matched that of the national Kidney PREM 2023; however, there was a higher representation in the comments from individuals of a Black ethnic heritage (+1.3%). Compared to Kidney PREM 2022 the profile of responders remained consistent.

Majority of the free-text responses align with the 13 Kidney PREM themes with *How the Kidney Team Treats You* receiving the highest number of comments (2,283), with 66% of comments under this theme were positive. This theme focused on positive comments about staff, thanking them for their care and dedication, as well as mentioning role specific staff members positively.

Access to the Kidney Team was the second most common theme to emerge from the comments and was predominantly negative (69%). Respondents commented on wanting to see a consultant more frequently, as well as having appointments scheduled with the dietician, social worker and psychologist. Additionally, respondents mentioned the need for better access to the kidney team outside of dialysis sessions.

Environment (649 comments), *Scheduling and Planning* (546 comments) and *Transport* (525 comments) received comments from individuals wanting better parking facilities, food to be offered during dialysis sessions and for appointments to be more frequent and better organised with no last-minute cancellations. Appointments via the telephone had mixed reviews with some finding them more convenient and a better use of time, whilst others feel they are less person-centred. Waiting times for transport following dialysis sessions continues to be an issue with individuals having to wait longer than an hour on most occasions.

Aspects of care such as *Needling*, *Privacy* and *Dignity* and *Sharing Decisions* received fewer comments but should still be considered as important areas of care for

improvement. Individuals receiving treatment would like more opportunities to discuss what they would like from their care, needling to be performed by competent members of staff, so as to be less painful and for conversations with consultants and nurses to be conducted in private, with those who identify as female having a separate space to dialyse to maintain dignity.

Emerging Themes (494 comments) contain comments which do not fit the pre-existing Kidney PREM themes, covering aspects of care such as medication and prescriptions, information about diagnosis or specific treatment issues, and questions about booking 'holiday dialysis'. This year, to align with the Kidney PREM, two new themes were introduced, *Overall Experience* and *Additional Questions*. There were 255 responses (98% positive) about overall experience of care, and 353 comments which covered the additional questions of Kidney PREM such as the change to Patient Knows Best, language barriers and feedback from last year's Kidney PREM report. The additional questions provide further insights into specific aspects of kidney care to support quality improvement in service delivery.

Respondents' characteristics were also reflected in comments: for instance, younger individuals tended to focus on *Environment* and older individuals on *How the Kidney Team Treats You* and *Access to the Kidney Team*. Those receiving haemodialysis in-centre or at a satellite unit were more likely to comment about *Environment* and *Transport*, with those yet to receive Kidney Replacement Therapy (KRT) or who have received a functioning transplant focused on *Scheduling* and *Planning*, and *Access to the Kidney Team*.

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 2023 and complement efforts to improve the care of people living with kidney disease.

The full 2023 Kidney PREM Comments Report and a detailed summary document can be accessed at:

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

Chapter 4: Kidney PREM theme results

Kidney PREM themes

Centre scores were calculated for each theme and can be viewed online⁹. Using these values, theme scores were obtained, and compared to values from the previous two years (Figure 4.1).

High scoring themes

As in recent years, the top scoring themes are *Privacy & Dignity* (6.38), *Patient Information* (6.37) and *Access to the Kidney Team* (6.34), where there continues to be little variation. Although small, the increase in *Patient Information* score means the theme is now the second highest of Kidney PREM themes in place of *Access to the Kidney Team*.

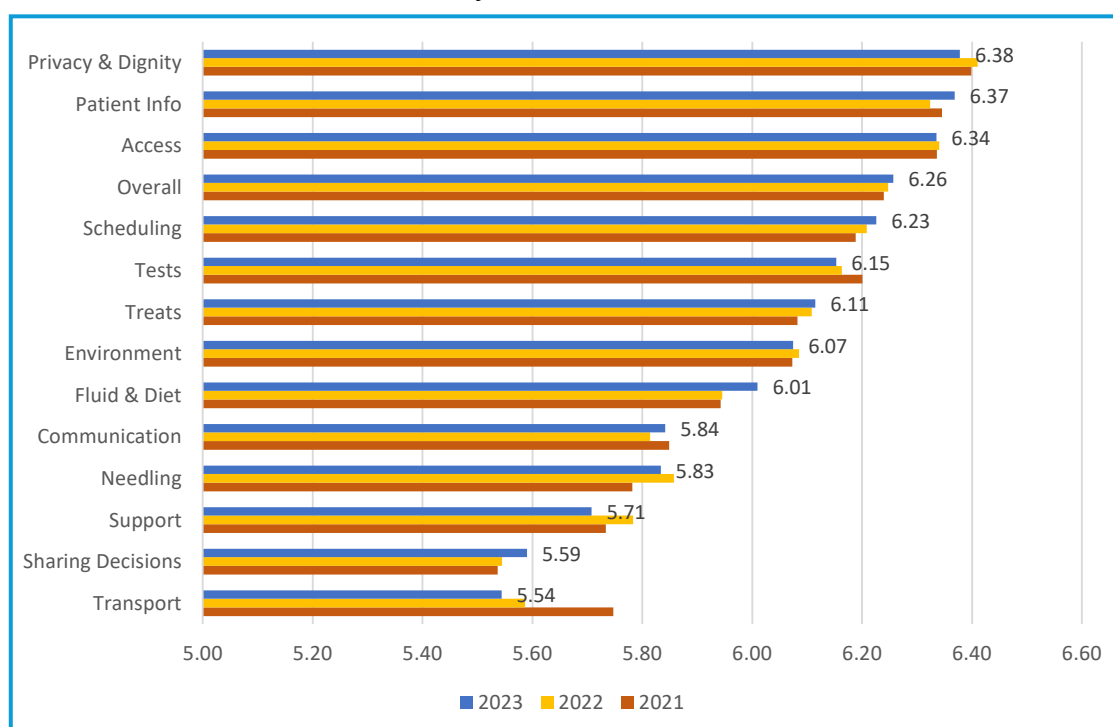
Overall Experience remains high scoring (6.26), highlighting the continued high quality of care received by participants.

Low scoring themes

Sharing Decisions (5.59) and *Transport* (5.54) remain low scoring. Despite improvements seen in 2020 which continued through 2021, these gains were not sustained resulting in *Transport* now scoring most poorly of all Kidney PREM themes having swapped with *Sharing Decisions*.

A small increase in score for *Communication* (5.84) and a small decrease for *Needling* (5.83) has resulted in these themes swapping order when ranking themes, although with almost no difference between values.

Figure 4.1: Mean centre scores for Kidney PREM themes in 2023, 2022 and 2021



⁹ <https://ukkidney.org/sites/renal.org/files/Centre%20and%20Satellite%20Means%20FORMATTED.xlsx>

Although most theme scores have remained relatively stable year on year, these averages mask the variation in scores seen across centres. Chapter 6 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 4.1). However, in 2023 five themes have narrow variation in centre scores, with values with ranges of ≤ 1.4 , equivalent to 20% of the total scale. Two of these themes have high means of ≥ 6.3 (to the nearest decimal point), equivalent to 90% of the scale: *Patient Information* (6.4) and *Overall Experience* (6.3). The decrease in range of *Overall Experience* was caused by an increase in score at the lower end of the scale, with the minimum centre score now 5.4 compared to 5.1 over the past two years. This suggests that centres who have performed less well in previous years have increased their *Overall Experience* scores in 2023.

The range for *Needling* was wider in 2023 than in recent years (2.0) with a maximum centre mean average score of 7. However, this was achieved by just one centre that had a low response rate for this question (n=7) with no in centre variation (i.e., all participants scored their experience of needling 7 - best it could be). *Fluid & Diet* had a relatively high mean (6.0), but a fairly wide range caused by two centres with lower scores.

Table 4.1: A summary of mean scores by centre, to nearest decimal point, sorted from highest to lowest theme

Theme	2023			2022			2021		
	Range	Mean range	Mean	Range	Mean range	Mean	Range	Mean range	Mean
Privacy & Dignity	1.6	5.3 - 6.9	6.4	1.2	5.7 - 6.9	6.4	1.7	5.1 - 6.8	6.4
Patient Information	1.1	5.8 - 6.8	6.4	1.7	5.2 - 6.8	6.3	1.5	5.5 - 7.0	6.3
Access to Kidney Team	1.5	5.4 - 6.9	6.3	1.8	5.2 - 7.0	6.3	1.5	5.5 - 7.0	6.3
Overall Experience	1.4	5.4 - 6.8	6.3	1.8	5.1 - 6.8	6.2	1.8	5.1 - 6.9	6.2
Scheduling & Planning	1.3	5.5 - 6.8	6.2	1.6	5.3 - 6.9	6.2	1.4	5.5 - 6.9	6.2
Tests	1.0	5.6 - 6.6	6.2	1.5	5.3 - 6.8	6.2	1.4	5.5 - 6.9	6.2
How Team Treats you	1.2	5.5 - 6.7	6.1	1.8	5.0 - 6.8	6.1	1.9	5.0 - 6.9	6.1
The Environment	1.3	5.5 - 6.8	6.1	1.8	5.0 - 6.9	6.1	1.6	5.2 - 6.8	6.1
Fluid & Diet	1.9	5.0 - 6.8	6.0	2.0	4.6 - 6.5	5.9	2.4	4.4 - 6.9	5.9
Communication	1.7	4.9 - 6.6	5.8	2.9	3.8 - 6.7	5.8	1.9	4.9 - 6.8	5.8
Needling	2.0	5.0 - 7.0	5.8	1.8	5.0 - 6.8	5.9	1.8	4.8 - 6.5	5.8
Support	1.6	4.8 - 6.4	5.7	2.0	4.6 - 6.6	5.8	2.4	4.5 - 6.9	5.7
Sharing Decisions	2.2	4.3 - 6.5	5.6	2.5	4.1 - 6.6	5.5	2.5	4.4 - 6.9	5.5
Transport	2.2	4.5 - 6.6	5.5	2.5	4.4 - 6.9	5.6	2.3	4.5 - 6.7	5.7

Mean ≤ 5.8	Mean ≥ 6.3	Range ≥ 2.0	Range ≤ 1.4
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Centre scores are available on the UKKA website, alongside satellite-level scores and a breakdown by participant age, ethnicity and treatment modality:

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

Overall Experience of care

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

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

As this question aims to capture the overall experience of kidney care, it is not used when calculating the total Kidney PREM score (described on page 49). Unlike other Kidney PREM questions, 'Don't know' and 'not applicable' options are not available responses. *Overall Experience* scores well at 6.26 (range of centre scores 5.43 to 6.81). Figure 4.2 shows the percentage distribution of respondent scores for each kidney centre, overlaid with the centre mean score and 95% confidence interval.

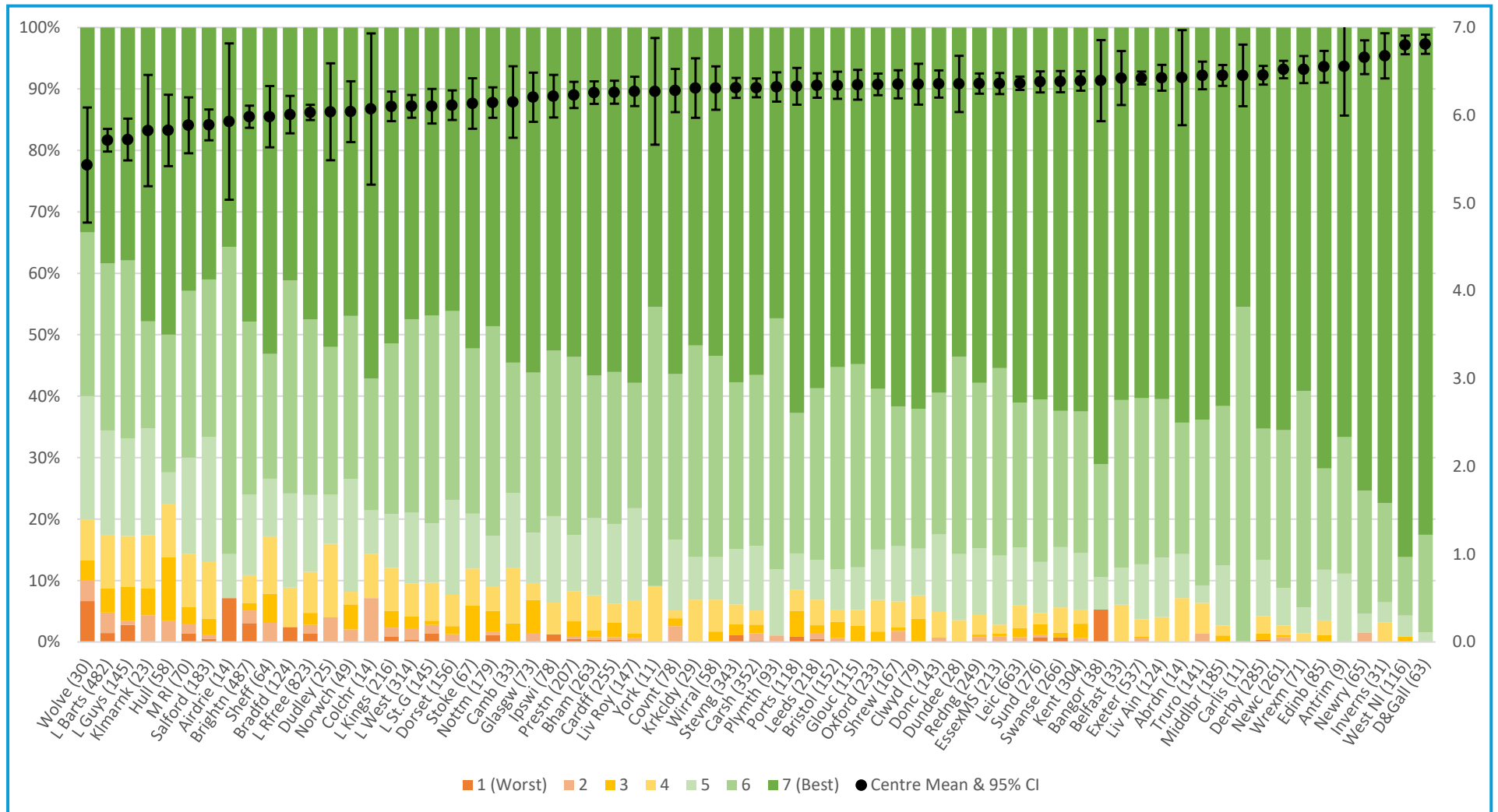
Notes for interpretation:

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 9 to 823. 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 dark red.
- A centre with 500 responses means that if five individuals scored '1', just 1.0% of the bar would be dark 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 92.4% of all respondents give a score of at least 5 out of 7. In three centres, 100% of respondents gave scores of between 5-7, and 52 out of 67 centres displayed received positive scores over 90% of the time. However, it is clear that variation exists within each centre, with many having a small but notable proportion of participants giving poorer scores (1-3 out of 7).

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



Chapter 5: Kidney PREM theme results by treatment and by question

Theme mean scores by treatment

Average scores for individuals were calculated according to their treatment modality, regardless of their treating centre, and compared with scores from 2022 (Table 5.1). 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 (≥ 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 for each theme are displayed later in this report for 2023 results and provide a useful visual summary of differences between treatment modalities.

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

	Chronic Kidney Disease (non-KRT)					Peritoneal Dialysis					Home Haemodialysis				
	2023 (n=1,617)		2022 (n=1,343)		2023 vs 2022	2023 (n=603)		2022 (n=574)		2023 vs 2022	2023 (n=204)		2022 (n=35)		2023 vs 2022
Mean	95% CI	Mean	95% CI	Mean		95% CI	Mean	95% CI	Mean		95% CI	Mean	95% CI	Mean	
Access	6.25	6.19 - 6.31	6.30	6.24 - 6.37	-0.05	6.42	6.33 - 6.50	6.45	6.36 - 6.53	-0.03	6.54	6.42 - 6.65	6.56	6.35 - 6.77	-0.02
Support	5.56	5.48 - 5.65	5.70	5.60 - 5.79	-0.13	5.82	5.70 - 5.94	5.96	5.84 - 6.07	-0.14	5.87	5.67 - 6.07	5.97	5.54 - 6.40	-0.10
Communication	5.75	5.67 - 5.82	5.82	5.74 - 5.90	-0.07	5.98	5.88 - 6.08	5.96	5.86 - 6.07	0.02	5.75	5.57 - 5.93	5.72	5.33 - 6.11	0.03
Patient Information	6.41	6.35 - 6.46	6.38	6.32 - 6.45	0.02	6.44	6.35 - 6.53	6.47	6.38 - 6.57	-0.03	6.48	6.34 - 6.61	6.51	6.23 - 6.80	-0.04
Fluid & Diet	5.28	5.17 - 5.38	5.28	5.17 - 5.39	0.00	6.01	5.90 - 6.13	6.05	5.93 - 6.16	-0.03	6.23	6.07 - 6.39	6.16	5.77 - 6.54	0.07
Needling	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Tests	6.08	6.02 - 6.14	6.17	6.10 - 6.23	-0.09	6.11	6.01 - 6.21	6.17	6.07 - 6.26	-0.06	6.25	6.10 - 6.39	6.40	6.14 - 6.66	-0.15
Sharing Decisions	5.70	5.61 - 5.78	5.73	5.64 - 5.82	-0.03	5.85	5.73 - 5.98	5.91	5.79 - 6.03	-0.06	5.97	5.77 - 6.17	6.15	5.74 - 6.56	-0.18
Privacy & Dignity	6.74	6.70 - 6.78	6.75	6.71 - 6.79	-0.01	6.53	6.44 - 6.62	6.59	6.51 - 6.67	-0.06	6.53	6.39 - 6.66	6.76	6.59 - 6.93	-0.23
Scheduling & Planning	6.24	6.18 - 6.29	6.27	6.21 - 6.33	-0.03	6.32	6.23 - 6.41	6.37	6.29 - 6.46	-0.05	6.32	6.16 - 6.48	6.50	6.26 - 6.74	-0.18
How the Team Treats	6.06	5.99 - 6.12	6.08	6.01 - 6.15	-0.02	6.23	6.13 - 6.32	6.24	6.14 - 6.33	-0.01	6.08	5.91 - 6.26	6.36	6.07 - 6.65	-0.28
Transport	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
The Environment	5.85	5.80 - 5.91	5.89	5.83 - 5.95	-0.04	5.98	5.89 - 6.07	6.02	5.93 - 6.11	-0.04	5.73	5.57 - 5.90	6.16	5.84 - 6.48	-0.43
Overall Experience	6.16	6.10 - 6.22	6.19	6.12 - 6.25	-0.03	6.32	6.23 - 6.41	6.36	6.27 - 6.45	-0.04	6.21	6.05 - 6.37	6.06	5.61 - 6.51	0.15
Kidney PREM Score	5.97	5.91 - 6.02	6.01	5.96 - 6.07	-0.05	6.12	6.04 - 6.20	6.16	6.08 - 6.23	-0.04	6.08	5.96 - 6.21	6.25	6.02 - 6.48	-0.17

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

Amongst those not receiving KRT, all but one theme showed a small negative difference compared to 2022. The largest decrease was in *Support* (-0.13), the average score now 5.56, the lowest score for *Support* of all modalities. Similarly, for people receiving peritoneal dialysis *Support* decreased by 0.14, although remained slightly higher at 5.82. Most theme scores decreased for those receiving haemodialysis at home, but differences were not always as small: *The Environment* -0.43 (now lowest score for this treatment type at 5.73), *How the Kidney Team Treats you* -0.28 (score now 6.08, but a high scoring theme across modalities), *Privacy & Dignity* -0.23 (although scoring 6.53 in another high-scoring theme). For those receiving haemodialysis in satellite units, most theme scores increased compared to 2022. Just three themes saw negative changes, and all were small (<0.1). The largest increase for this treatment type was seen in *Transport* at +0.23 to 5.63. Similarly, for those receiving haemodialysis in centre, most themes showed an increase in score; although six themes had small decreases across years, all were <0.1. The largest increase for this treatment type was in *Sharing Decisions* at +0.16, resulting in similar scores as those receiving satellite haemodialysis (5.41 centre and 5.45 satellite). However, these two modalities remain much lower scoring than other treatment groups in this theme. There was very little variation seen in scores across years for transplant recipients, with all changes between -0.1 and +0.1.

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

	Satellite HD					Centre HD					Transplant				
	2023 (n=3,806)		2022 (n=3,067)		2023 vs 2022	2023 (n=3,354)		2022 (n=2,872)		2023 vs 2022	2023 (n=1,776)		2022 (n=1,606)		2023 vs 2022
	Mean	95% CI	Mean	95% CI		Mean	95% CI	Mean	95% CI		Mean	95% CI	Mean	95% CI	
Access	6.32	6.28 - 6.35	6.32	6.28 - 6.35	0.00	6.25	6.21 - 6.30	6.25	6.21 - 6.29	0.00	6.51	6.46 - 6.55	6.46	6.41 - 6.51	0.04
Support	5.74	5.70 - 5.79	5.78	5.73 - 5.83	-0.03	5.59	5.54 - 5.65	5.67	5.61 - 5.73	-0.07	5.96	5.90 - 6.03	5.90	5.83 - 5.97	0.06
Communication	5.94	5.90 - 5.98	5.87	5.82 - 5.91	0.07	5.80	5.75 - 5.84	5.80	5.75 - 5.86	-0.01	5.91	5.85 - 5.96	5.84	5.77 - 5.90	0.07
Patient Information	6.33	6.30 - 6.37	6.31	6.27 - 6.35	0.02	6.22	6.17 - 6.27	6.18	6.13 - 6.23	0.04	6.59	6.55 - 6.63	6.56	6.51 - 6.60	0.03
Fluid & Diet	6.16	6.12 - 6.20	6.08	6.03 - 6.13	0.08	6.11	6.06 - 6.16	6.02	5.96 - 6.07	0.09	5.96	5.88 - 6.03	5.91	5.83 - 6.00	0.04
Needling	5.78	5.72 - 5.84	5.86	5.80 - 5.92	-0.08	5.78	5.72 - 5.85	5.76	5.70 - 5.83	0.02	-	-	-	-	-
Tests	6.15	6.11 - 6.19	6.11	6.07 - 6.15	0.04	5.99	5.94 - 6.04	5.96	5.91 - 6.01	0.03	6.40	6.36 - 6.44	6.45	6.40 - 6.49	-0.05
Sharing Decisions	5.45	5.40 - 5.51	5.44	5.37 - 5.50	0.02	5.41	5.35 - 5.47	5.25	5.18 - 5.32	0.16	5.93	5.86 - 6.00	5.95	5.88 - 6.02	-0.02
Privacy & Dignity	6.29	6.25 - 6.33	6.25	6.21 - 6.30	0.04	6.21	6.16 - 6.25	6.17	6.12 - 6.22	0.04	6.77	6.74 - 6.80	6.78	6.75 - 6.82	-0.01
Scheduling & Planning	6.23	6.19 - 6.27	6.16	6.12 - 6.21	0.06	6.14	6.10 - 6.19	6.11	6.06 - 6.16	0.03	6.29	6.24 - 6.34	6.26	6.21 - 6.32	0.03
How the Team Treats	6.09	6.05 - 6.12	6.15	6.11 - 6.19	-0.06	6.04	6.00 - 6.09	6.08	6.04 - 6.13	-0.04	6.15	6.10 - 6.21	6.15	6.09 - 6.20	0.01
Transport	5.63	5.58 - 5.69	5.41	5.34 - 5.47	0.23	5.44	5.38 - 5.50	5.51	5.45 - 5.58	-0.07	-	-	-	-	-
The Environment	6.33	6.30 - 6.36	6.28	6.25 - 6.32	0.05	6.09	6.06 - 6.13	6.11	6.07 - 6.15	-0.01	5.81	5.77 - 5.86	5.81	5.75 - 5.86	0.01
Overall Experience	6.30	6.26 - 6.33	6.26	6.22 - 6.30	0.03	6.18	6.14 - 6.22	6.21	6.16 - 6.25	-0.02	6.31	6.26 - 6.35	6.31	6.26 - 6.36	0.00
Kidney PREM Score	6.05	6.02 - 6.08	6.01	5.98 - 6.05	0.03	5.92	5.89 - 5.96	5.91	5.88 - 5.95	0.01	6.16	6.12 - 6.20	6.14	6.10 - 6.18	0.02

95% CI: 95% confidence interval

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 following pages gives information about a theme. The mean and range of the centre scores is displayed first, to provide a summary of the centre variation seen. Graphs showing centre scores and 95% confidence intervals for each theme are displayed in chapter 6.

The first figure in each section shows the mean score and 95% confidence interval (CI) for that theme by treatment modality. The number of participants used to calculate the scores for each treatment group is shown in brackets after the treatment name. These numbers vary, as '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.

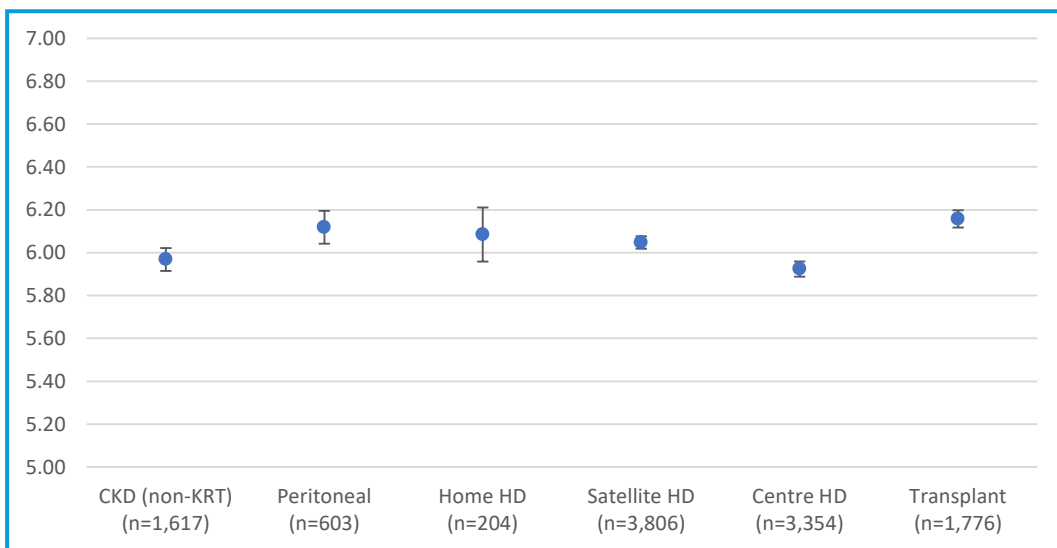
Questions for each theme have been abbreviated in this report for brevity but can be viewed in full online.

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: 6.02, range: 5.37 to 6.60.

Figure 5.0: Kidney PREM scale score means and 95% confidence intervals by treatment modality



The Kidney PREM score is calculated using results from questions 1 to 38 for each participant. As with previous years, there was little variation between treatment modalities, ranging from 5.92 (95% CI 5.89 to 5.96) for those receiving haemodialysis in centre, to 6.16 (95% CI 6.12 to 6.20) for individuals with a kidney transplant. Although these differences are statistically significant, there is little actual difference with just 0.23 between the top and bottom scoring modalities.

Theme 1: Access to Kidney Team

Mean of centre scores: 6.34, range: 5.42 to 6.94.

Figure 5.1A: Access to the Kidney Team theme means and 95% confidence intervals by treatment modality

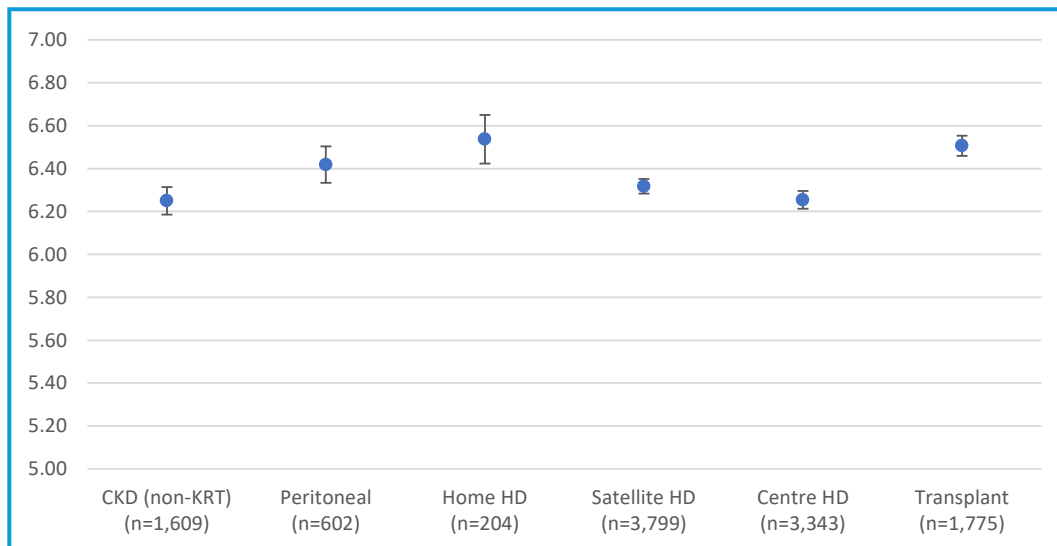
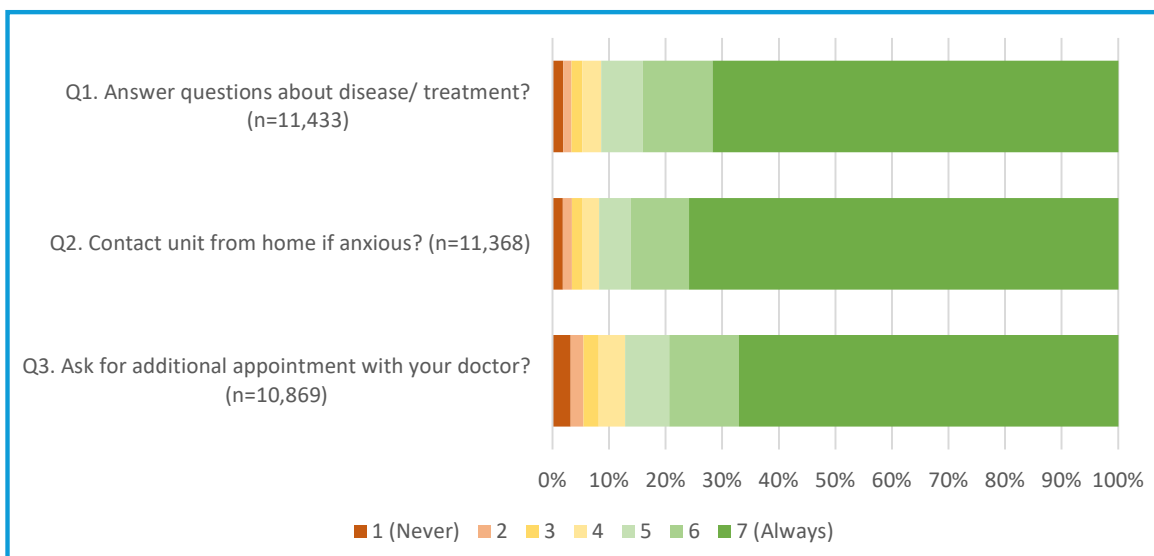


Figure 5.1B: Response frequencies for Access to the Kidney Team theme questions



Access to the Kidney Team is consistently one of the highest scoring themes of the Kidney PREM. In all three theme questions, over 85% of participants gave scores of 5 or above, with the values 1-3 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). All treatment modalities scored highly with little variation between them, ranging from 6.25 (CKD non-KRT) to 6.54 (home haemodialysis).

Theme 2: Support

Mean of centre scores: 5.71, range: 4.83 to 6.43.

Figure 5.2A: Support theme means and 95% confidence intervals by treatment modality

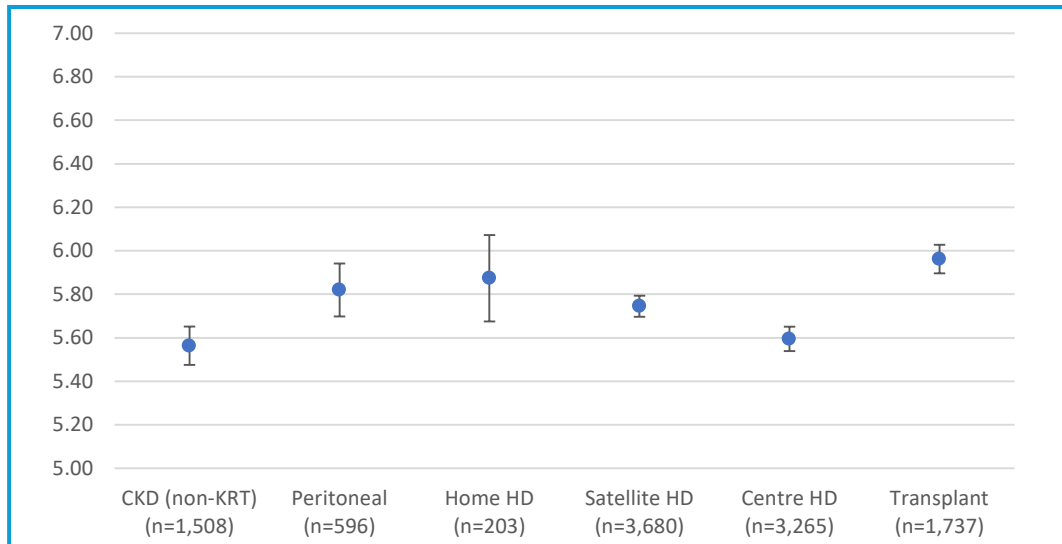
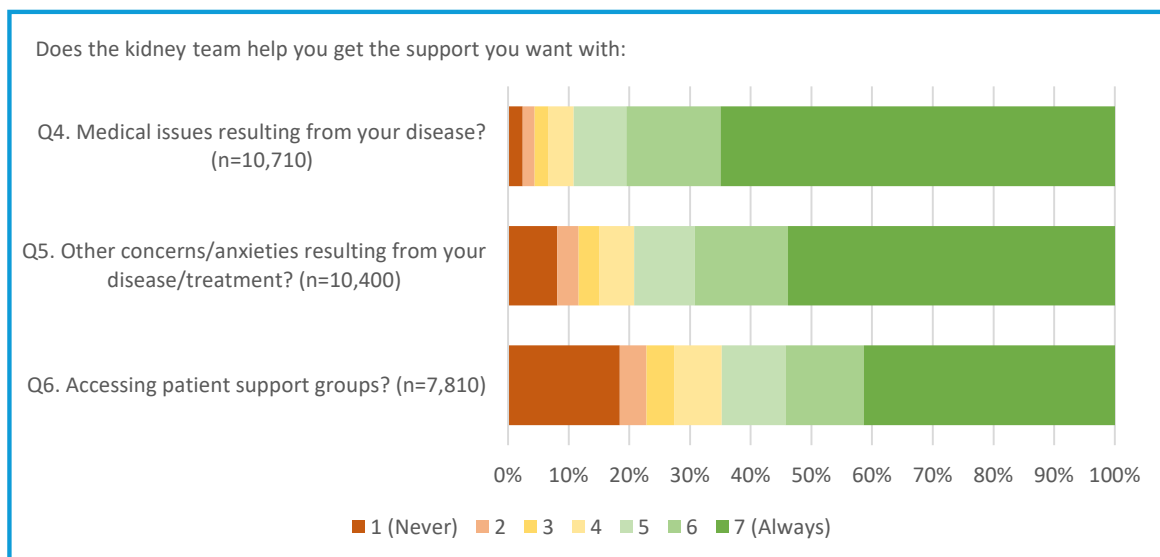


Figure 5.2B: Response frequencies for *Support* theme questions



Scores for *Support* varied between centres, with a difference of 1.60 ($\geq 20\%$ of the scale) between the top and bottom scoring centres. The mean score for all treatment modalities was less than 6 out of 7, with variation less marked than between centres. CKD (non-KRT) participants again scored most poorly at 5.56, whereas transplant recipients scored most highly with 5.96. *Support* when accessing patient support groups (Q6) was answered less often using the 1-7 scale than the two other theme questions (7,810 compared to >10,000), and was scored more poorly, with over a quarter of participants (27.4%) scoring 1-3. Although *Support* with other concerns/anxieties (Q5) was answered more positively in general, approximately 15% of participants gave low (1-3) scores.

Theme 3: Communication

Mean of centre scores: 5.84, range: 4.87 to 6.58.

Figure 5.3A: Communication theme means and 95% confidence intervals by treatment modality

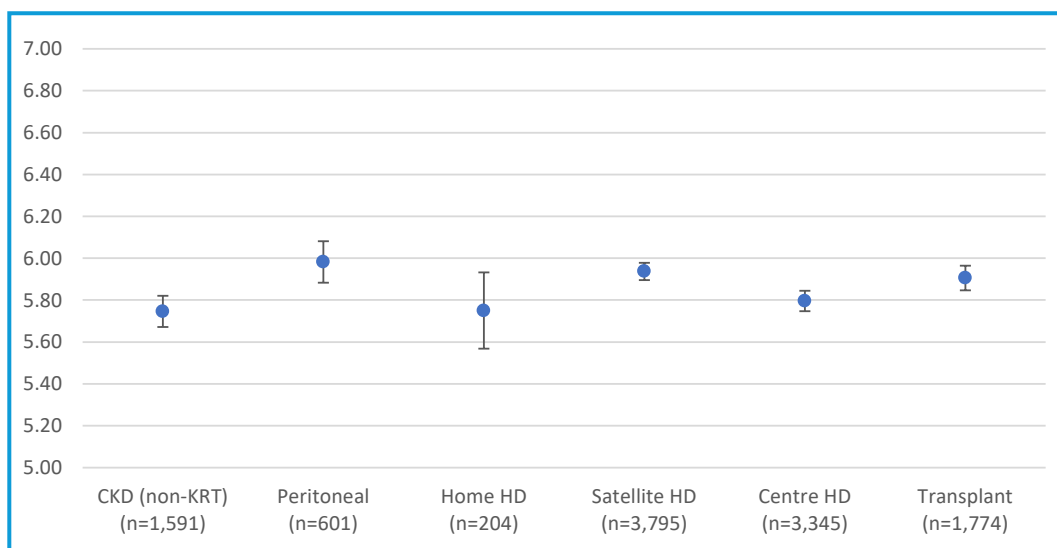
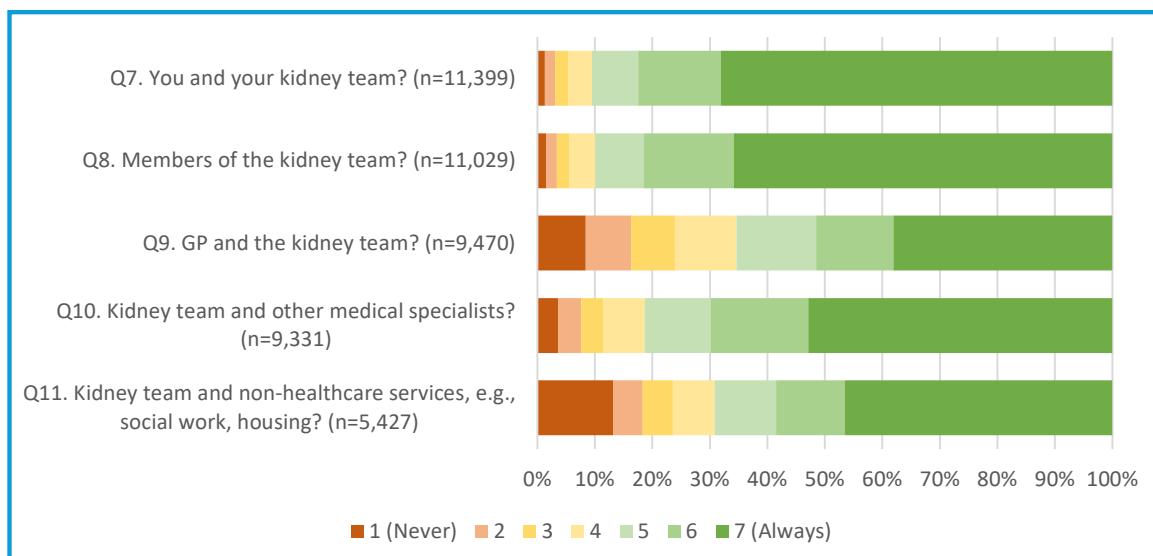


Figure 5.3B: Response frequencies for Communication theme questions



Communication was one of the lower scoring themes, with all treatment modalities having mean scores below 6; from 5.75 (CKD, non-KRT) to 5.98 (peritoneal dialysis). Encouragingly, *Communication* between participants and their kidney teams (Q7) and between members of the kidney team (Q8) were each rated highly, with around 90% of respondents selecting 5 or above. Experience of *Communication* between the kidney team and other medical specialists (Q10) was mixed; although 80% rated it highly, >10% gave 1-3 scores. However, *Communication* between the kidney team and GPs (Q9), and between the kidney team and non-healthcare teams (Q11) continue to be scored most poorly of the theme, given scores of ≤ 3 by around 23% of participants.

Theme 4: Patient Information

Mean of centre scores: 6.37, range: 5.77 to 6.85.

Figure 5.4A: Patient Information theme means and 95% confidence intervals by treatment modality

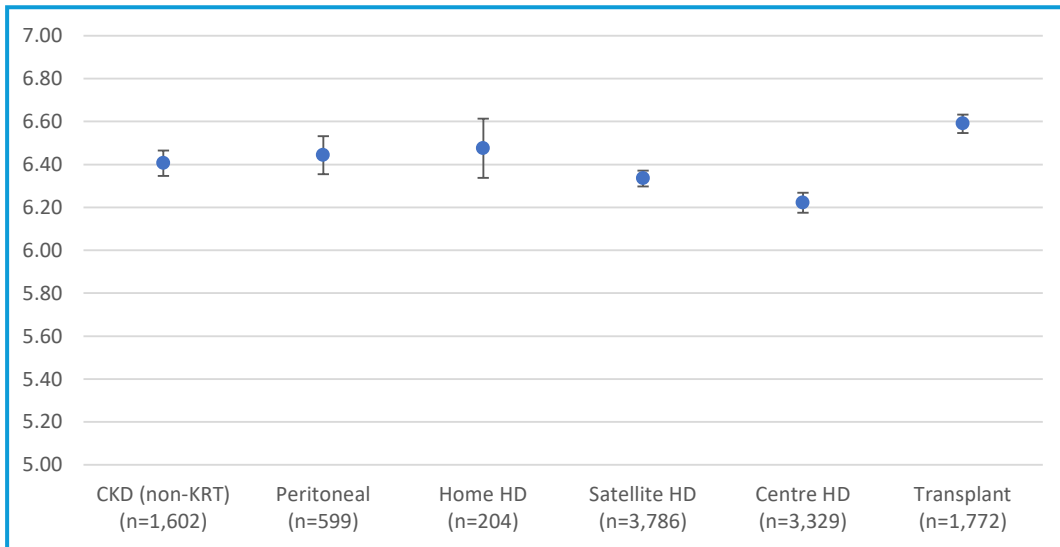
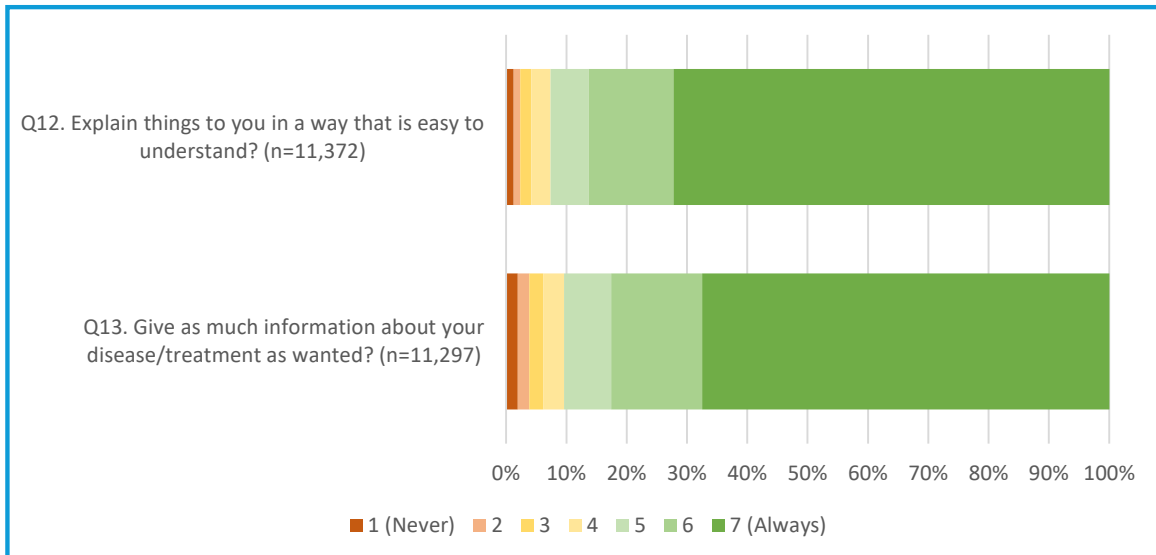


Figure 5.4B: Response frequencies for Patient Information theme questions



In recent years of the Kidney PREM, *Patient Information* has been one of the highest scoring themes, a trend which continues in 2023 with a relatively narrow range of scores across centres. Across all treatment modalities, scores were ≥ 6.2 , with transplant recipients most positive at 6.59. The response profile for each of the theme’s two questions was similar, scoring positively (5-7) in more than 90% of cases.

Theme 5: Fluid and Diet

Mean of centre scores: 6.01, range: 4.97 to 6.83.

Figure 5.5A: *Fluid and Diet* theme means and 95% confidence intervals by treatment modality

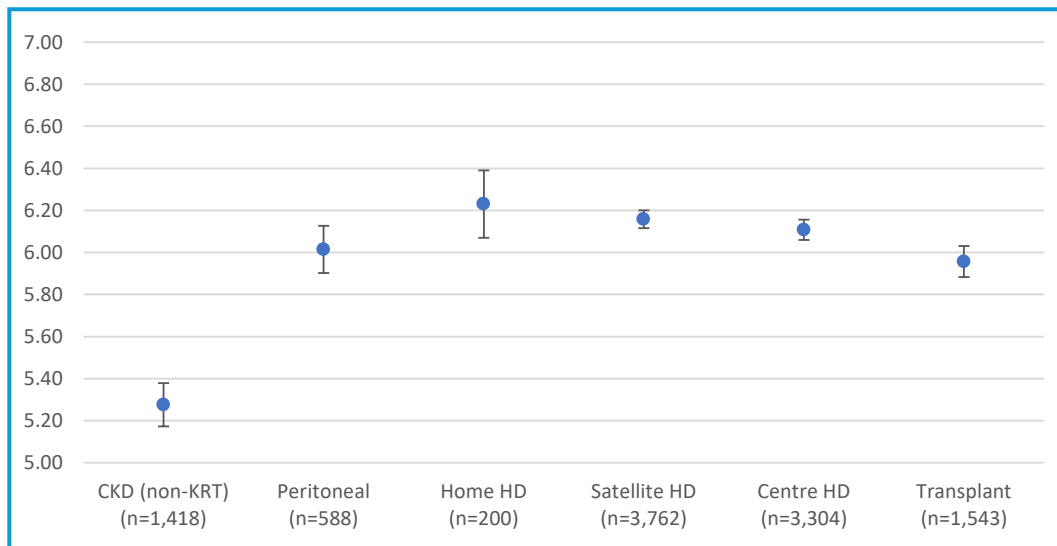
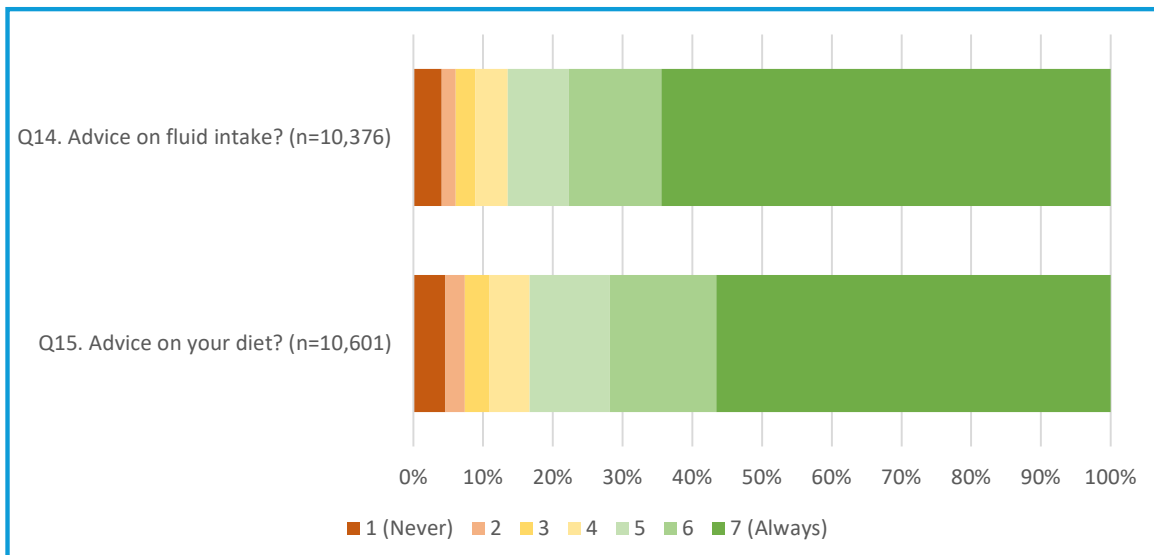


Figure 5.5B: Response frequencies for *Fluid and Diet* theme questions



Fluid & Diet usually features in the middle of themes by score and has a moderately wide range of scores; 1.86 between the highest and lowest centres. However, *Fluid & Diet* scores display some differences by treatment modality, with participants with CKD not receiving KRT scoring significantly lower (5.28) than other modalities (range 5.96 to 6.23). The two questions in this theme had similar response patterns, though with advice on fluid (Q14) receiving a slightly higher proportion of 5-7 scores than advice on diet (Q15); 86% vs 83%.

Theme 6: Needling

Mean of centre scores: 5.83, range: 4.96 to 7.00.

Figure 5.6A: *Needling* theme means and 95% confidence intervals by treatment modality

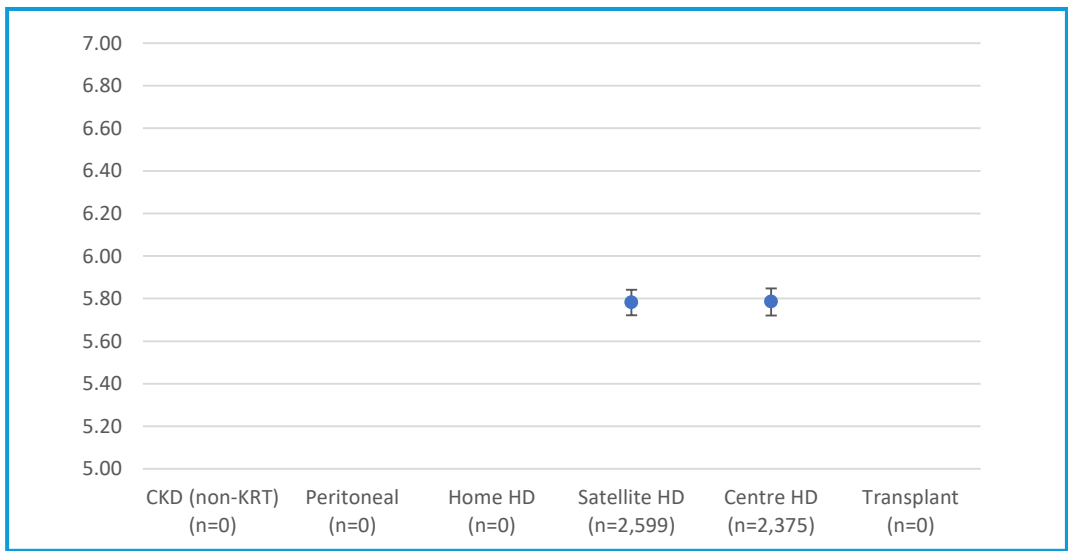
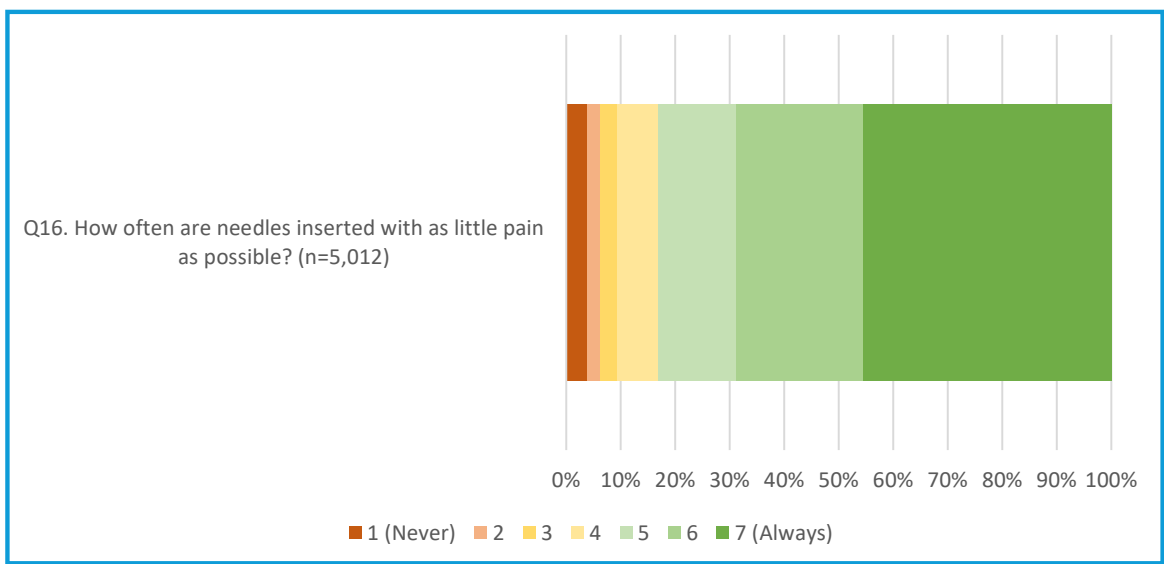


Figure 5.6B: Response frequencies for *Needling* theme questions



The *Needling* theme contains just one question and is applicable only to those receiving haemodialysis in satellite units or main centres. Scores were almost identical for each of the two treatment locations, at around 5.80 out of 7. Approximately 45% of participants stated that their needles were always inserted with as little pain as possible, giving a score of 7, with scores of 1-3 selected by just under 10% of respondents.

Theme 7: Tests

Mean of centre scores: 6.15, range: 5.63 to 6.65.

Figure 5.7A: Tests theme means and 95% confidence intervals by treatment modality

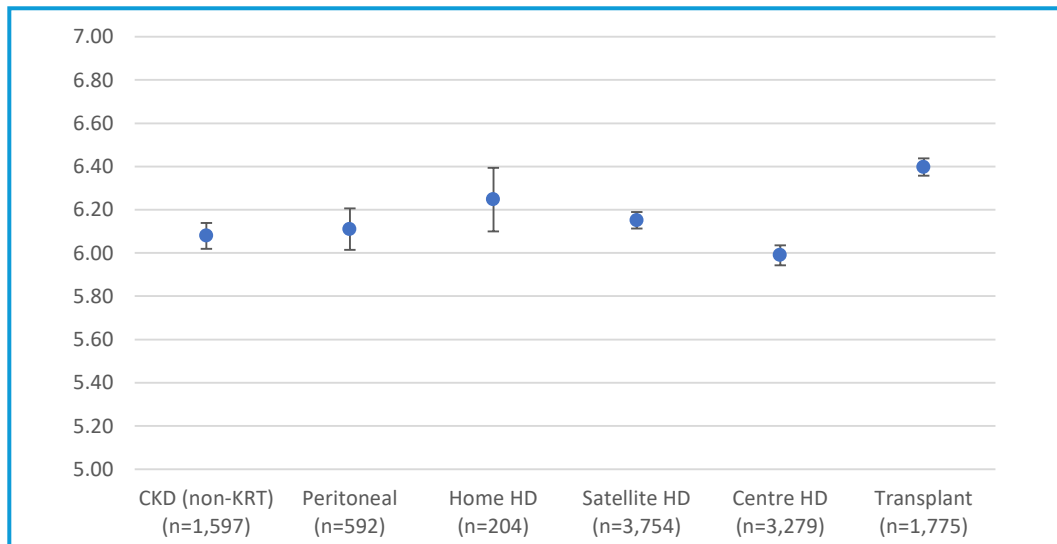
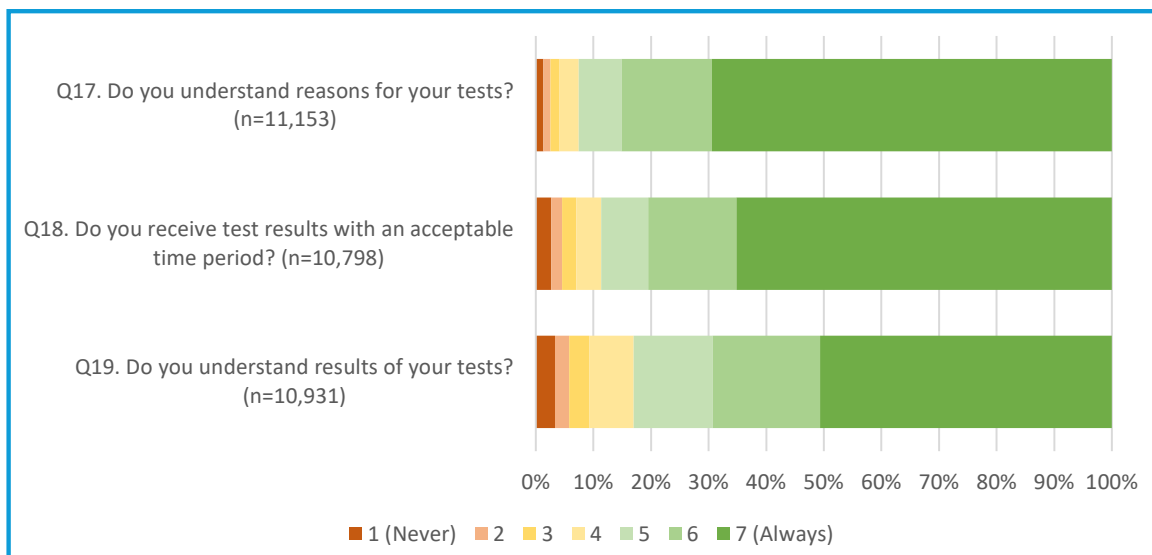


Figure 5.7B: Response frequencies for Tests theme questions



Kidney PREM participants mostly gave positive scores for *Tests*, regardless of treatment modality, though transplant recipients scored slightly higher at 6.40 compared to scores ranging from 5.99 (centre haemodialysis) to 6.25 (home haemodialysis) for the other treatment groups. Although all three questions performed well, understanding results of your tests (Q19) received a slightly lower proportion of high (5-7) responses; 83% compared to 89% for receiving results within an acceptable time period (Q18) and 93% for understanding reasons for tests (Q17).

Theme 8: Sharing Decisions

Mean of centre scores: 5.59, range: 4.27 to 6.52.

Figure 5.8A: *Sharing Decisions* theme means and 95% confidence intervals by treatment modality

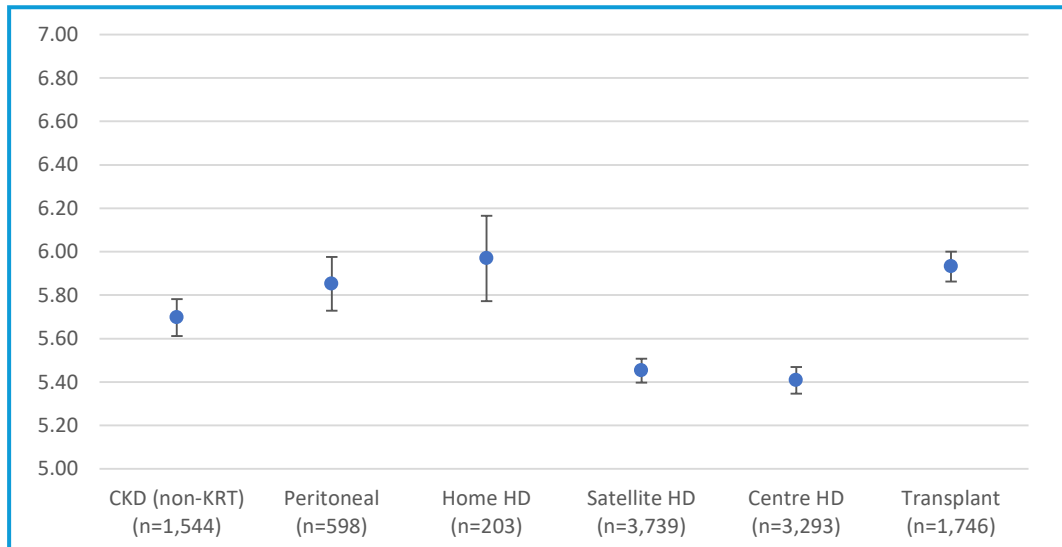
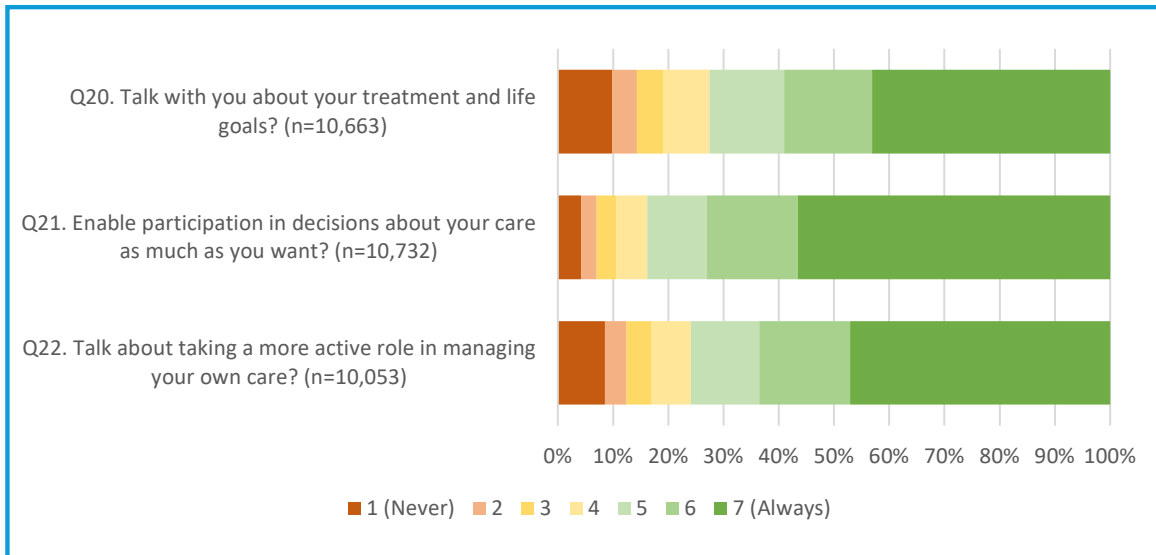


Figure 5.8B: Response frequencies for *Sharing Decisions* theme questions



In 2021 and 2022, *Sharing Decisions* was the poorest scoring theme, but a small increase means that it has now moved up a position, in place of Transport. At 4.27, the lower end of the centre score range was the lowest across all themes. Individuals receiving satellite and centre haemodialysis consistently score *Sharing Decisions* theme most poorly (5.45 and 5.41 respectively), slightly lower than participants in other treatment groups which range from 5.70 (CKD non-KRT) to 5.97 (home haemodialysis). All three questions had a notable proportion selecting scores of 1-3, with participation in decisions about care (Q21) the best performing at 11%. Discussing a more active role in managing care (Q22) received 17% of 1-3 scores and talking about treatment and life goals 19%.

Theme 9: Privacy and Dignity

Mean of centre scores: 6.38, range: 5.25 to 6.86.

Figure 5.9A: *Privacy and Dignity* theme means and 95% confidence intervals by treatment modality

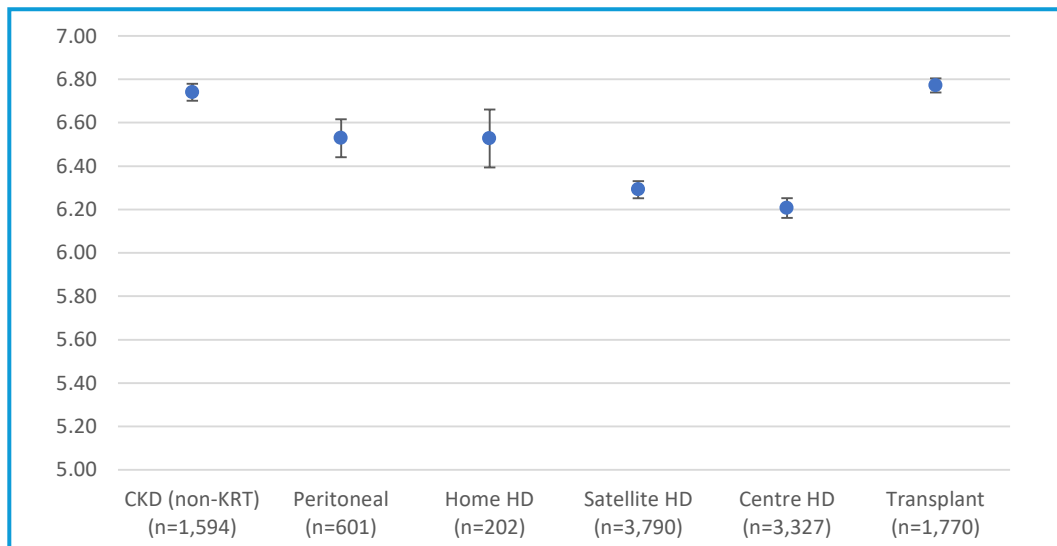
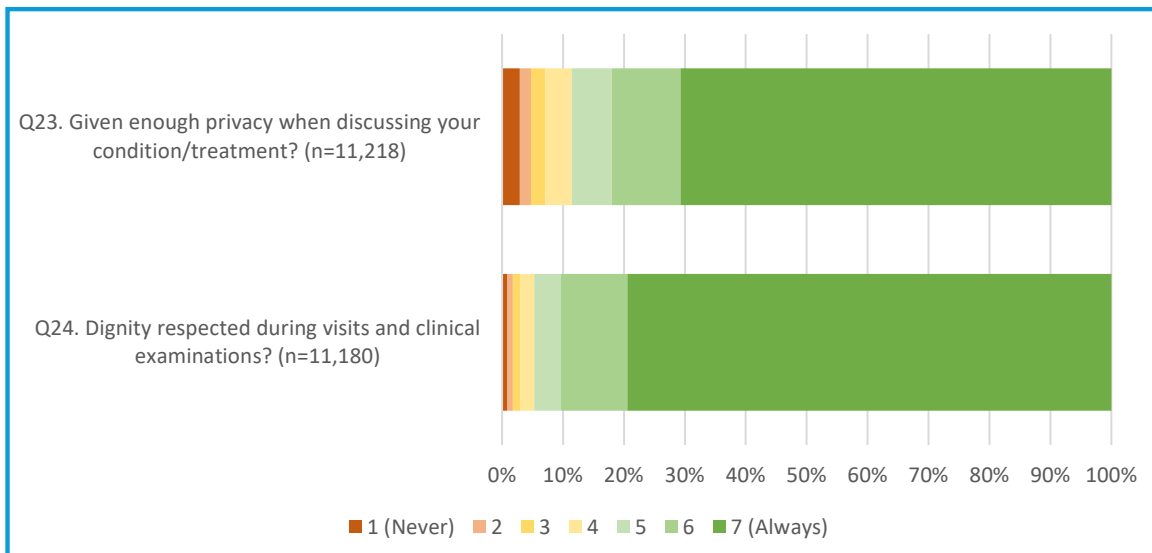


Figure 5.9B: Response frequencies for *Privacy and Dignity* theme questions



Privacy & Dignity has been the top performer of Kidney PREM for the past five years, although with some range in centre scores. Some differences between treatment groups were apparent, with those attending for haemodialysis scoring slightly lower (6.21 centre haemodialysis, 6.29 satellite haemodialysis) than other treatment modalities (range 6.53 to 6.77). However, it should be noted that scores were high for all treatment groups. Individuals reported that their dignity was respected (Q24), with 95% selecting scores of 5-7.

Theme 10: Scheduling and Planning

Mean of centre scores: 6.23, range: 5.47 to 6.76.

Figure 5.10A: *Scheduling and Planning* theme means and 95% confidence intervals by treatment modality

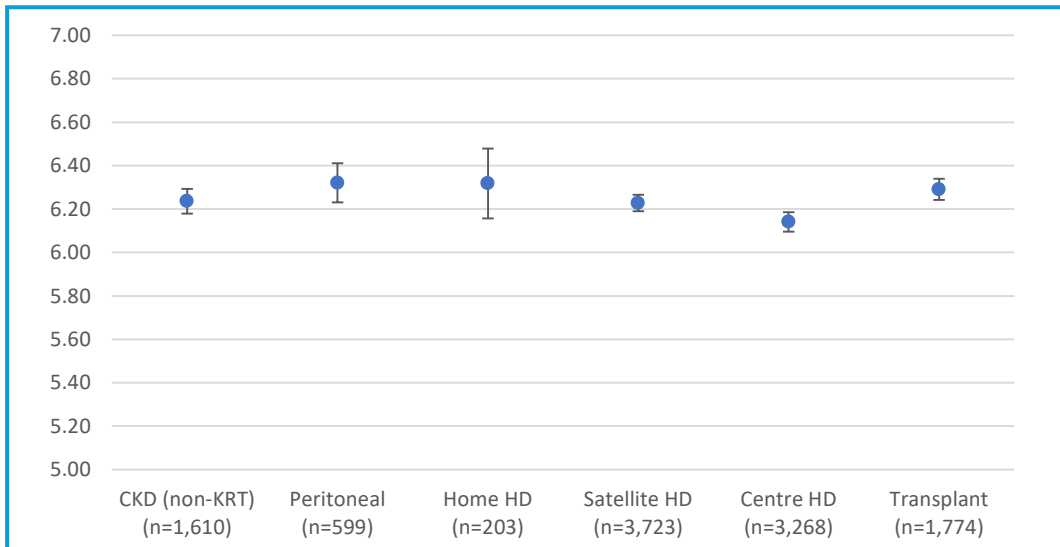
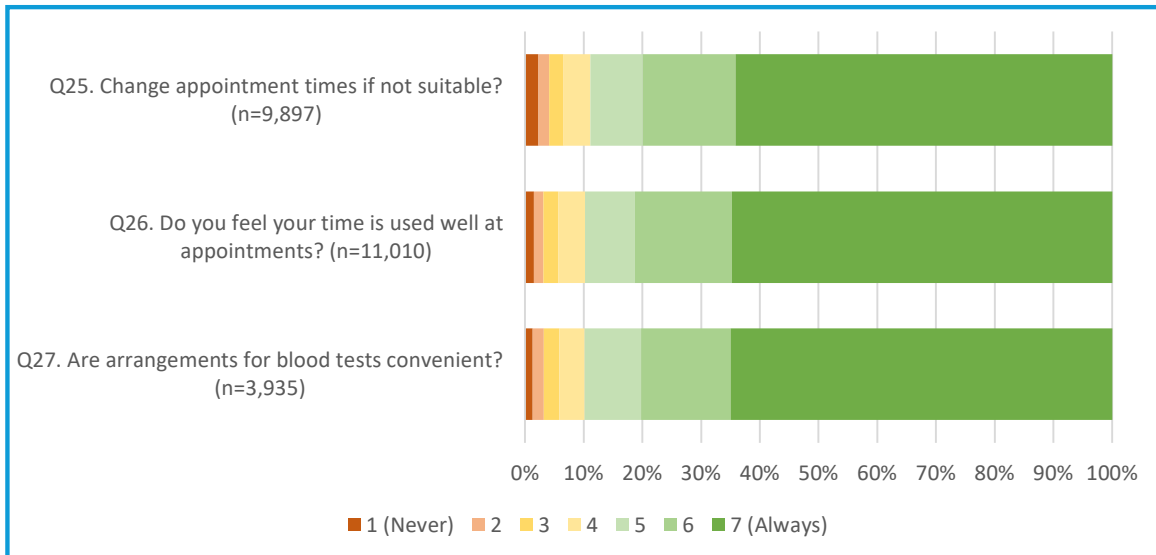


Figure 5.10B: Response frequencies for *Scheduling and Planning* theme questions



Scheduling & Planning was the theme with the least variation, with little difference seen by centre, by treatment or between questions. The mean score was relatively high at 6.23, with all treatment groups scoring around that number (6.14 to 6.32). Across all three questions, participants selected 5-7 nearly 90% of the time.

Theme 11: How the Kidney Team Treats You

Mean of centre scores: 6.11, range: 5.49 to 6.69.

Figure 5.11A: *How the Kidney Team Treats You* theme means and 95% confidence intervals by treatment modality

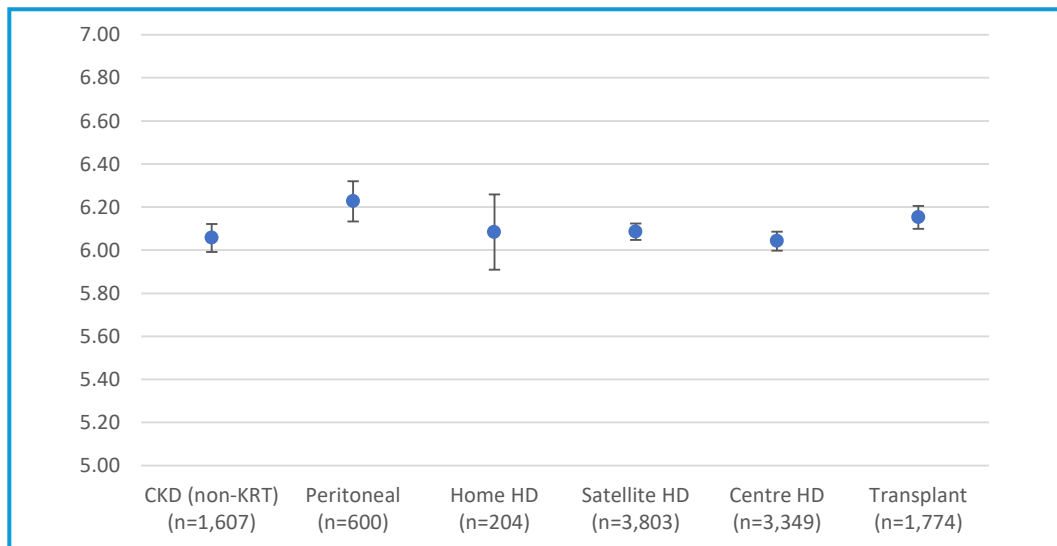
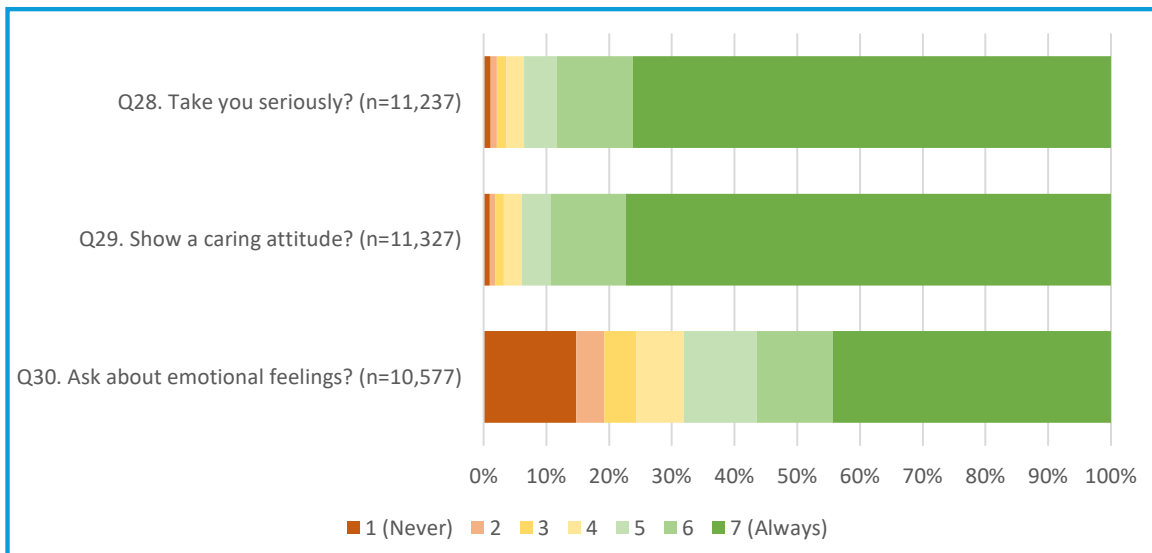


Figure 5.11B: Response frequencies for *How the Kidney Team Treats You* theme questions



Another high scoring theme, *How the Kidney Team Treats You* received a narrow range of scores between centres. All treatment groups gave scores of ≥ 6.0 , with little difference between them. Some differences were seen between questions, however, with participants reporting positively for being taken seriously (Q28) and being shown a caring attitude (Q29), with approximately 94% of individuals giving scores of 5-7. Being asked about emotional feelings (Q30) was much less positively rated as just 68% gave 5-7 values, and nearly a quarter rated it poorly using scores of 1-3. Notably, 15% stated that they were never asked about their emotions, awarding scores of 1.

Theme 12: Transport

Mean of centre scores: 5.54, range: 4.46 to 6.63.

Figure 5.12A: *Transport* theme means and 95% confidence intervals by treatment modality

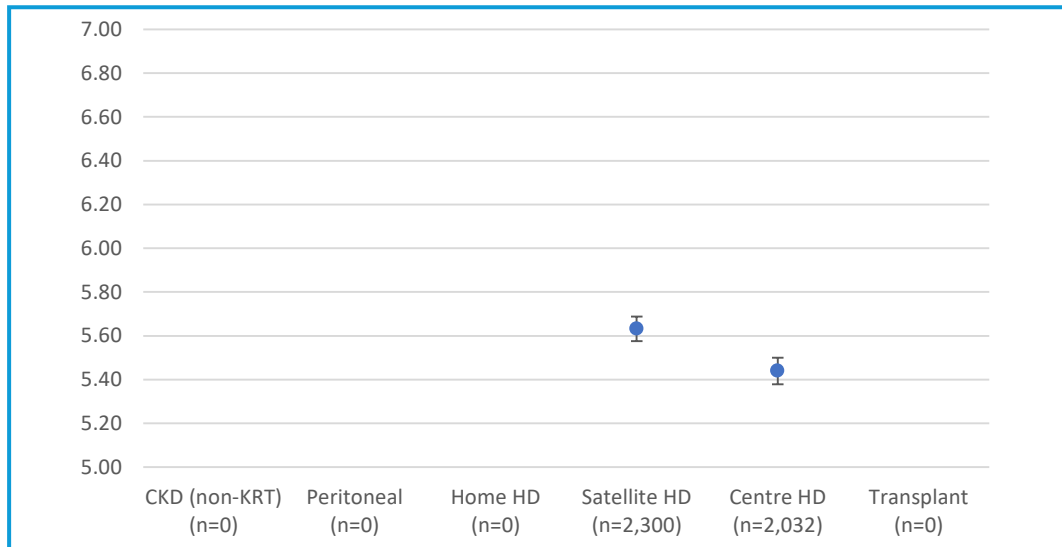
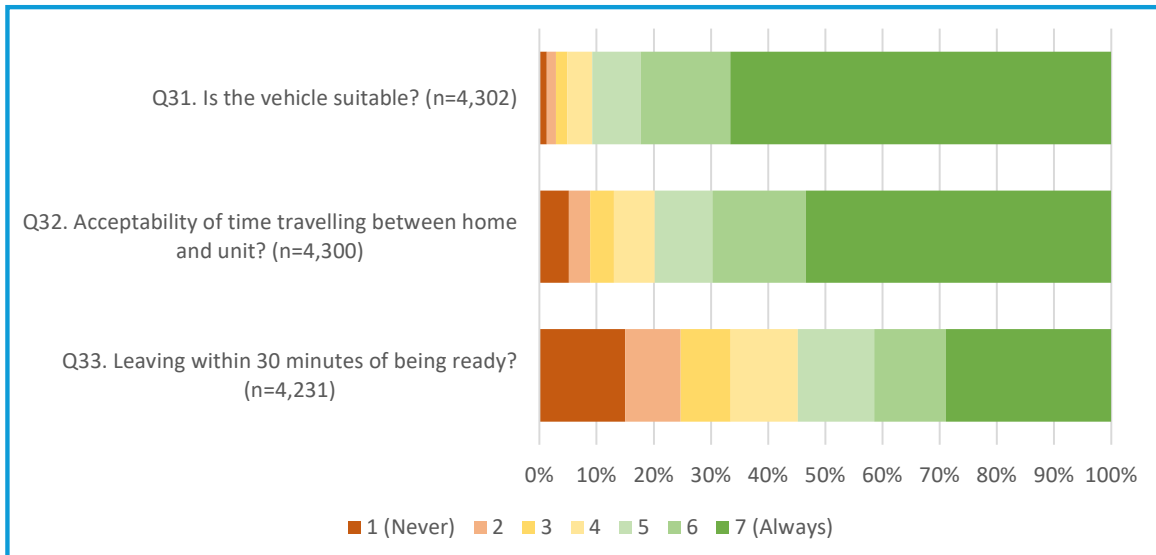


Figure 5.12B: Response frequencies for *Transport* theme questions



Transport is another theme in which the questions only apply to individuals receiving haemodialysis in centres or satellite units. Those at main centres rated *Transport* slightly lower than those at satellites, but with only a small difference between them. Nearly all participants felt that their provided vehicle was suitable (Q31), with 91% selecting 5-7. However, they were less positive regarding time travelling between home and the unit (Q32) with 80% issuing one of the top three scores. Leaving within 30 minutes of being ready (Q33) received the smallest proportion of 5-7 scores across the entirety of the Kidney PREM (55%).

Theme 13: The Environment

Mean of centre scores: 6.07, range: 5.46 to 6.77.

Figure 5.13A: *The Environment* theme means and 95% confidence intervals by treatment modality

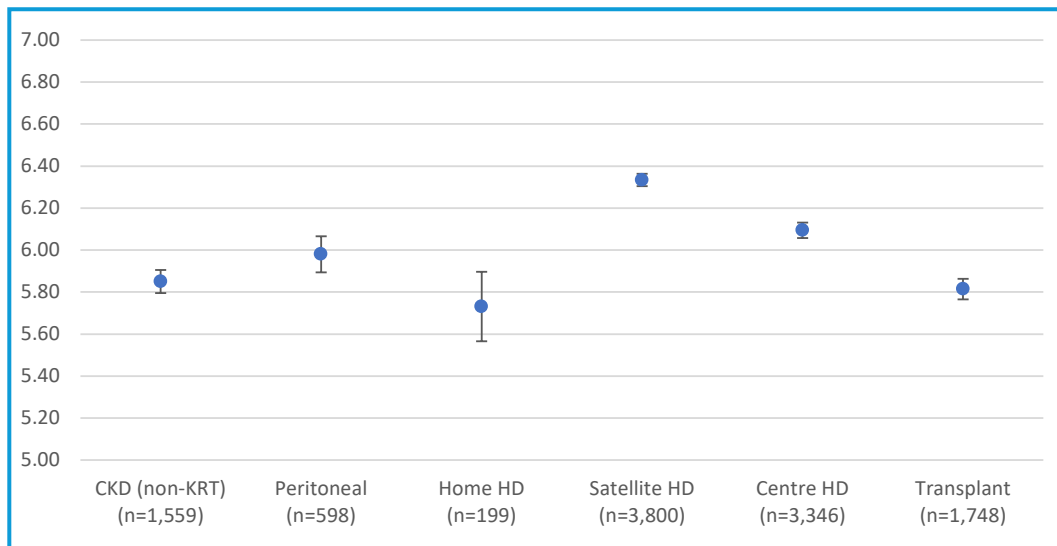
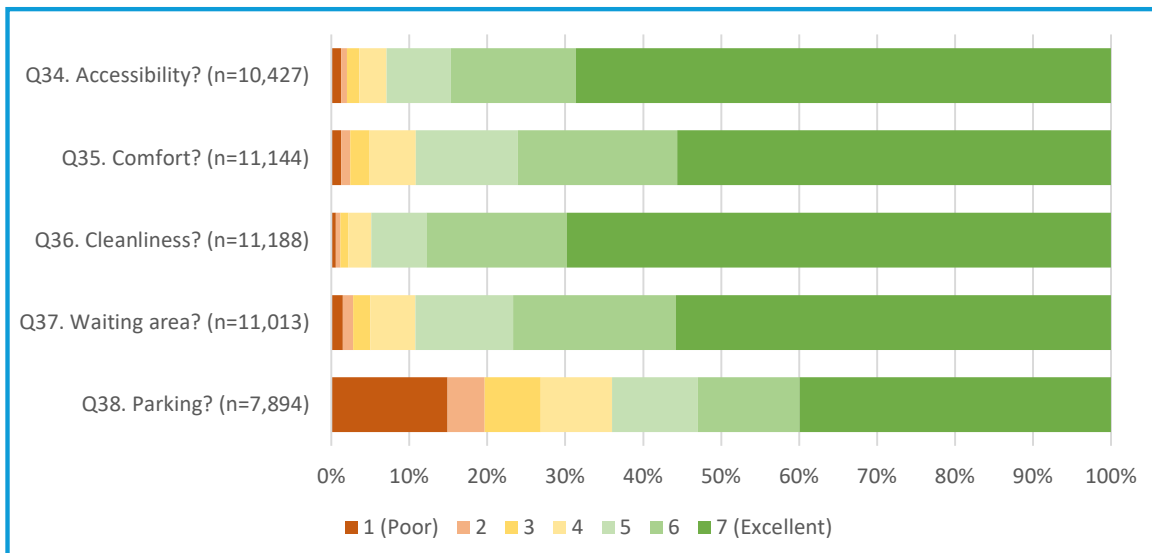


Figure 5.13B: Response frequencies for *The Environment* theme questions



The Environment had a relatively narrow range of scores between centres, with some variation seen between treatment types. Those receiving haemodialysis in satellite scored most highly (6.33) and those receiving it at home least positively (5.73). Most theme questions scored well, with scores of 5-7 given by ≥89% of participants regarding accessibility (Q34), comfort (Q35), cleanliness (Q36) and waiting area (Q37). Parking (Q38) remains an issue for some and was poorly scored (1-3) by 27% of respondents.

Theme 14: Overall Experience

Mean of centre scores: 6.26, range: 5.43 to 6.81.

Figure 5.14A: Overall Experience theme means and 95% confidence intervals by treatment modality

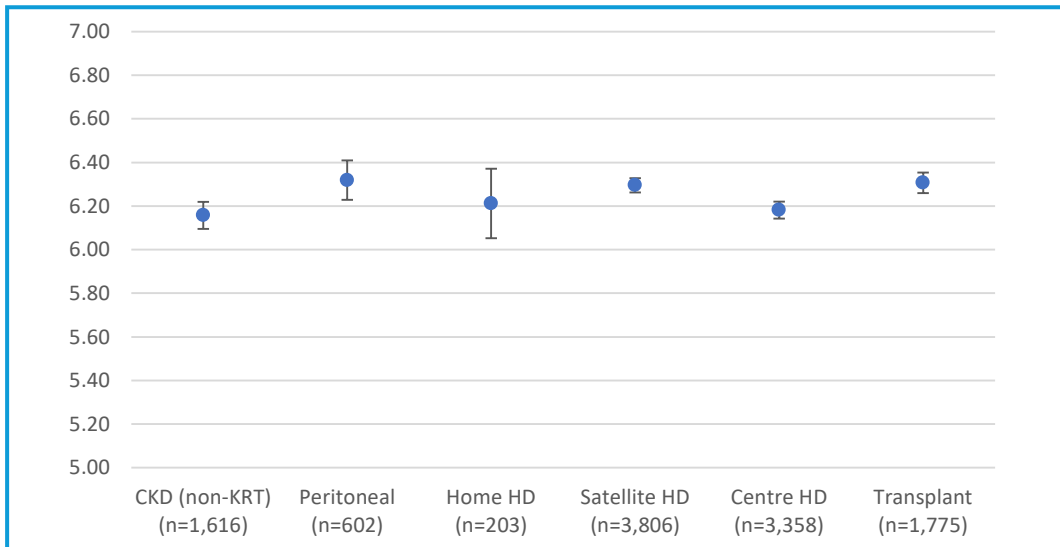
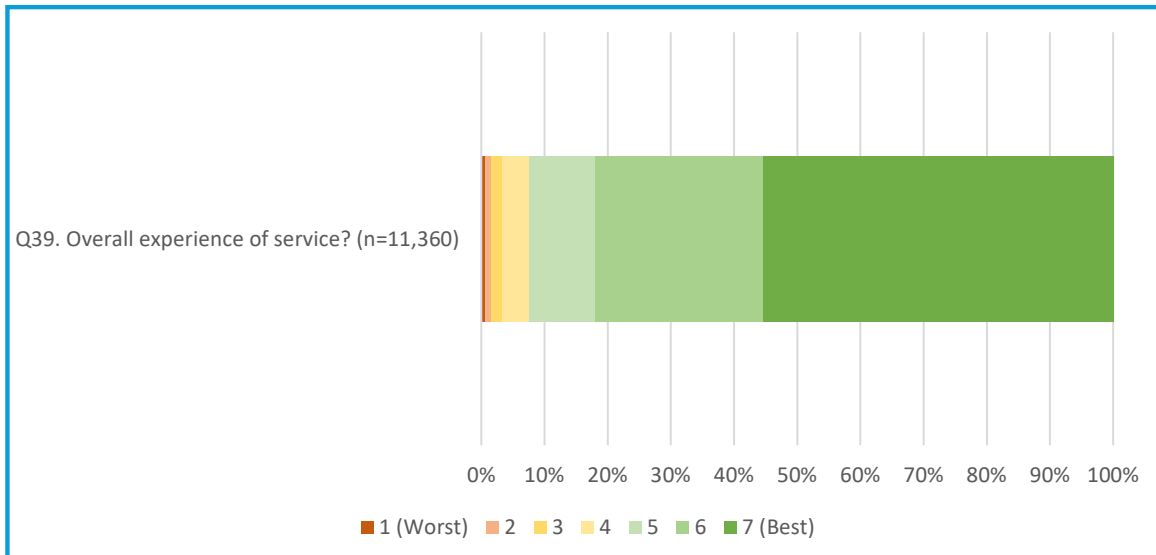


Figure 5.14B: Response frequencies for Overall Experience theme questions



Reassuringly, *Overall Experience* of kidney care remains a high scoring theme, with minimal variation between centres or treatment modalities. Most Kidney PREM participants score the theme highly, with 92% awarding 5-7 scores. Notably, over half of all respondents provide the top rating of 7 out of 7, and less than 1% give a score of 1 (worst it can be).

Chapter 6: Patient experience of kidney care across the service

This chapter presents mean scores for each theme in the 2023 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 of pages 65 to 79, two types of figures are presented.

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

These are displayed on the left of each page, showing centre mean scores and 95% confidence intervals for each theme of the 2023 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. Those participants for whom a centre could not be attributed are grouped under 'Missing'. These usually scored in the middle of the centre averages, suggesting no apparent differences between these individuals and those who provided a legible treating centre.

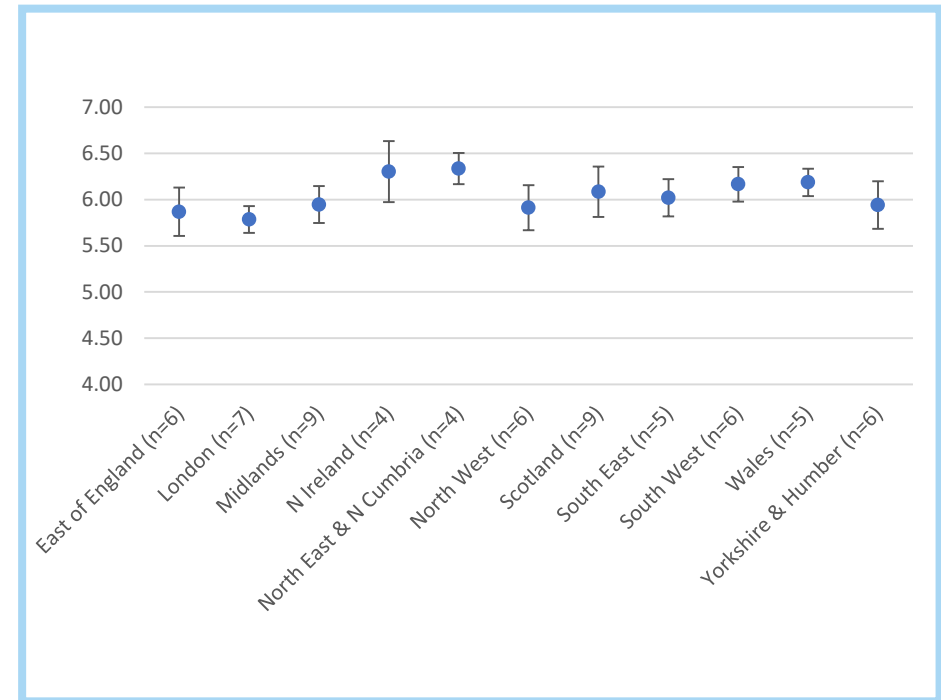
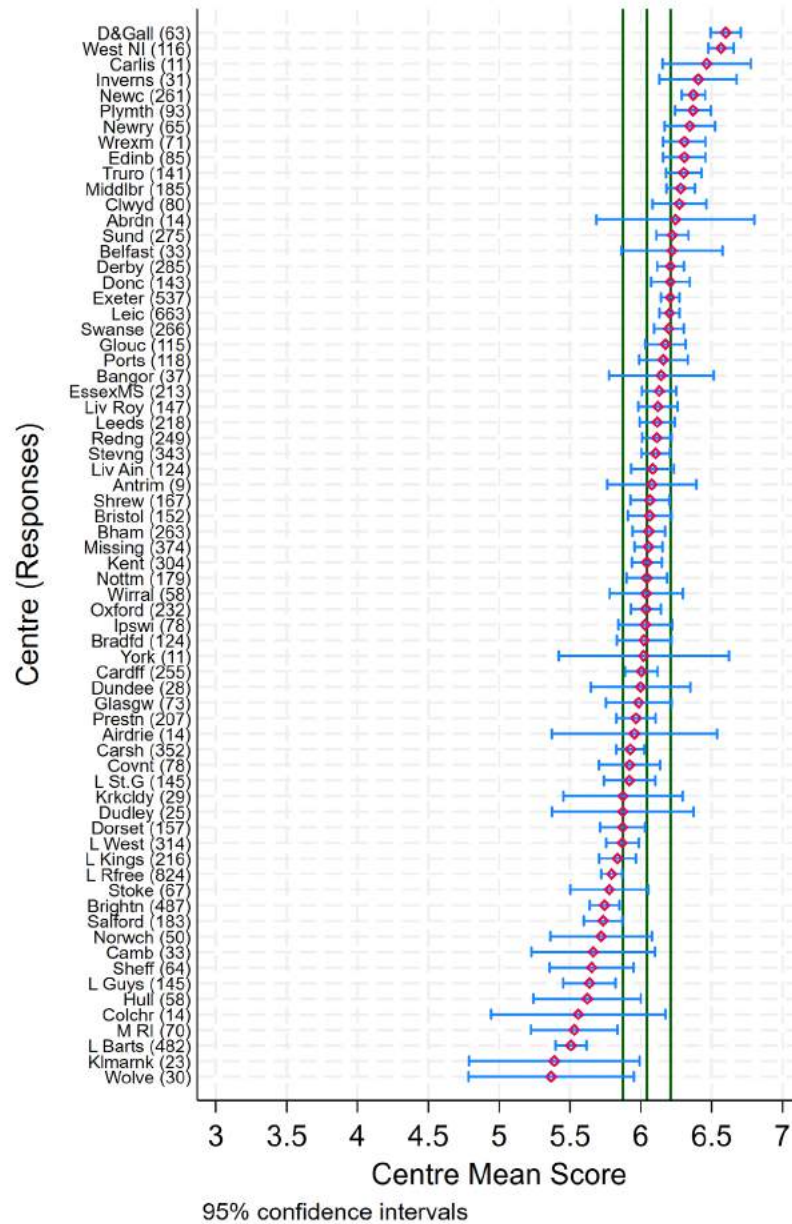
The number of responses used to calculate the scores are in brackets after each centre name. Each chart shows how many participants from each centre completed the minimum number of questions such that a theme score could be calculated, rather than the number of respondents completing the whole Kidney PREM. This is particularly important where questions are filtered and bases for analysis become smaller (e.g., 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, a minimum of seven responses were needed to calculate these to maintain anonymity.

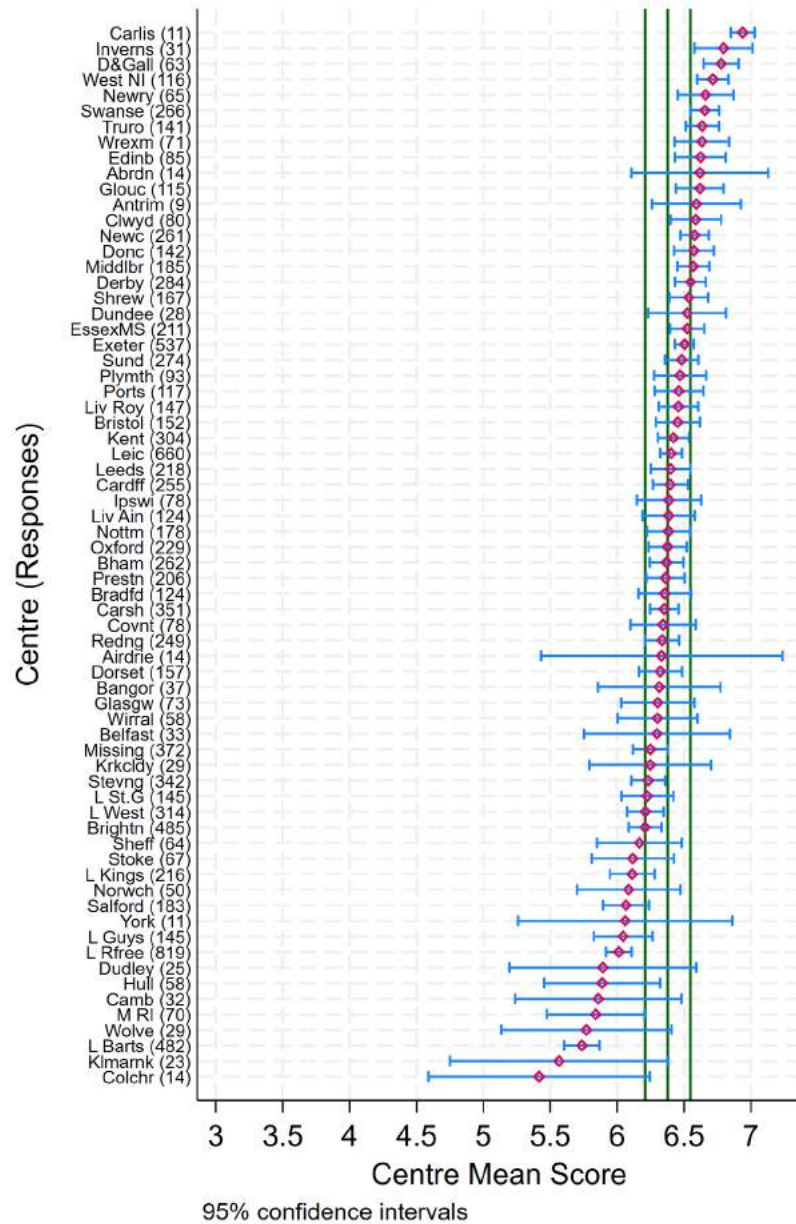
2. Regional means and confidence intervals of centre scores (right-hand figure)

Figures on the right of each page show the mean score and 95% confidence interval (CI) of centre mean scores within each geographical region of the UK, with the number of centres used to calculate each value displayed in brackets after the region name.

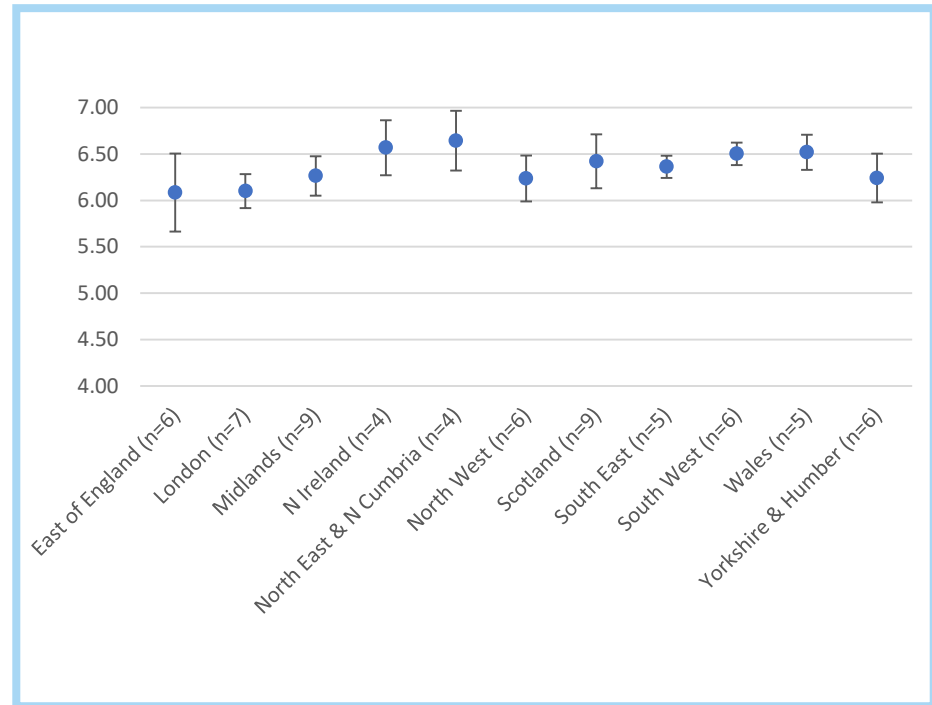
Kidney PREM Score



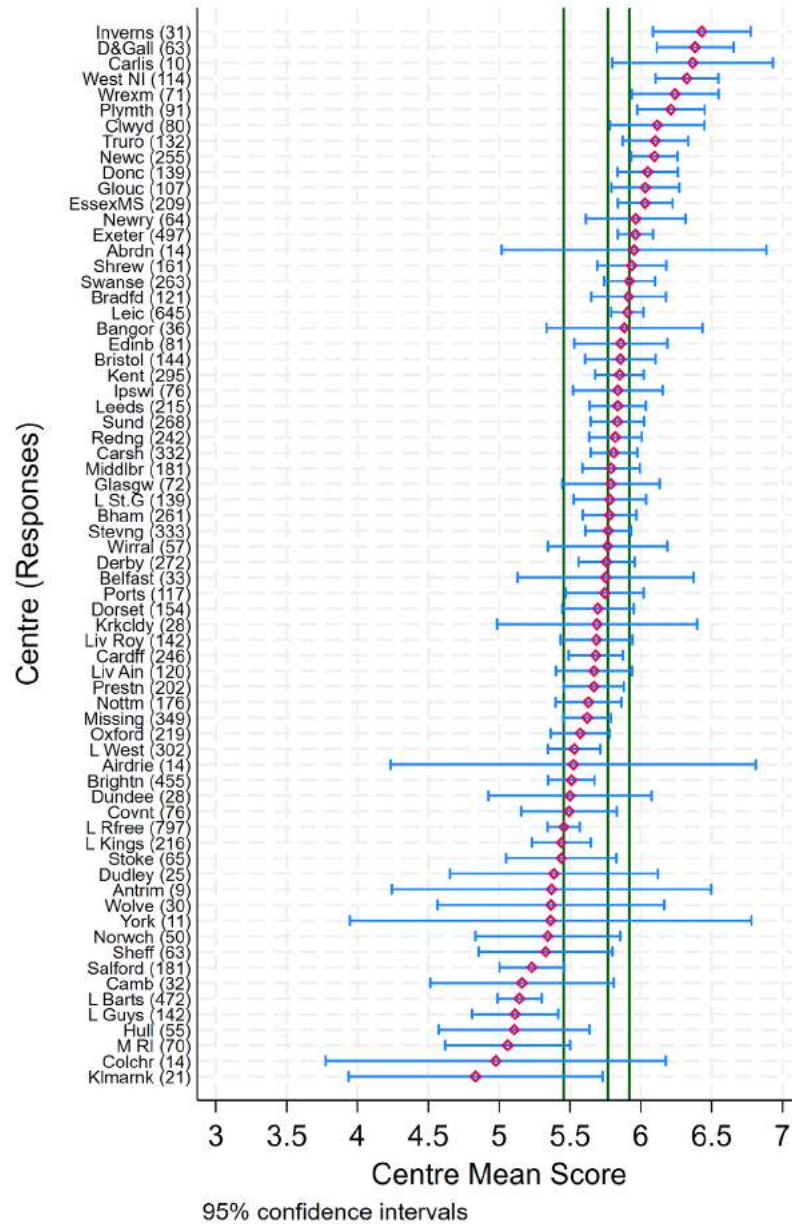
Theme 1: Access to Kidney Team



- 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?

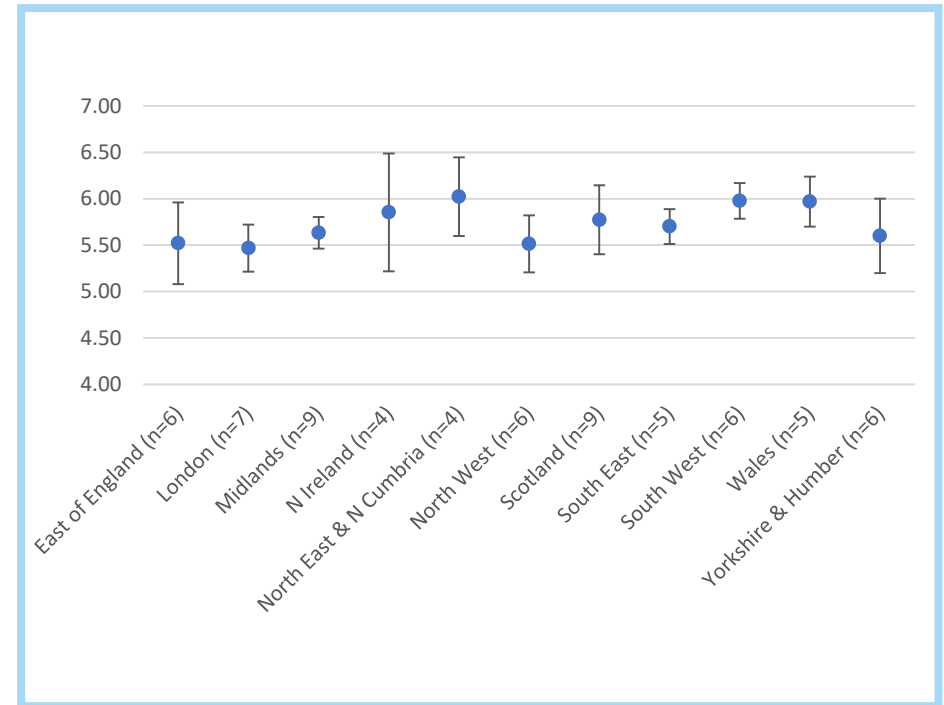


Theme 2: Support

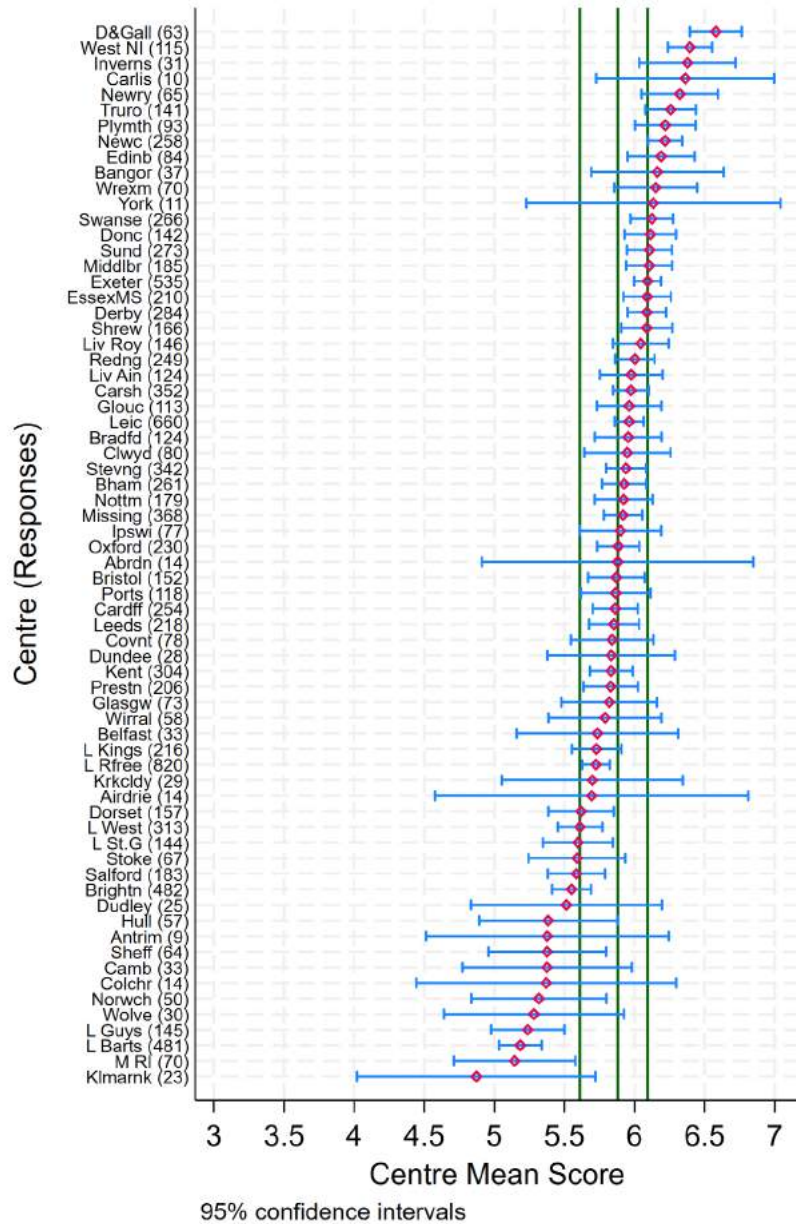


Does the kidney team help you to get the support you want with:

- 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)?

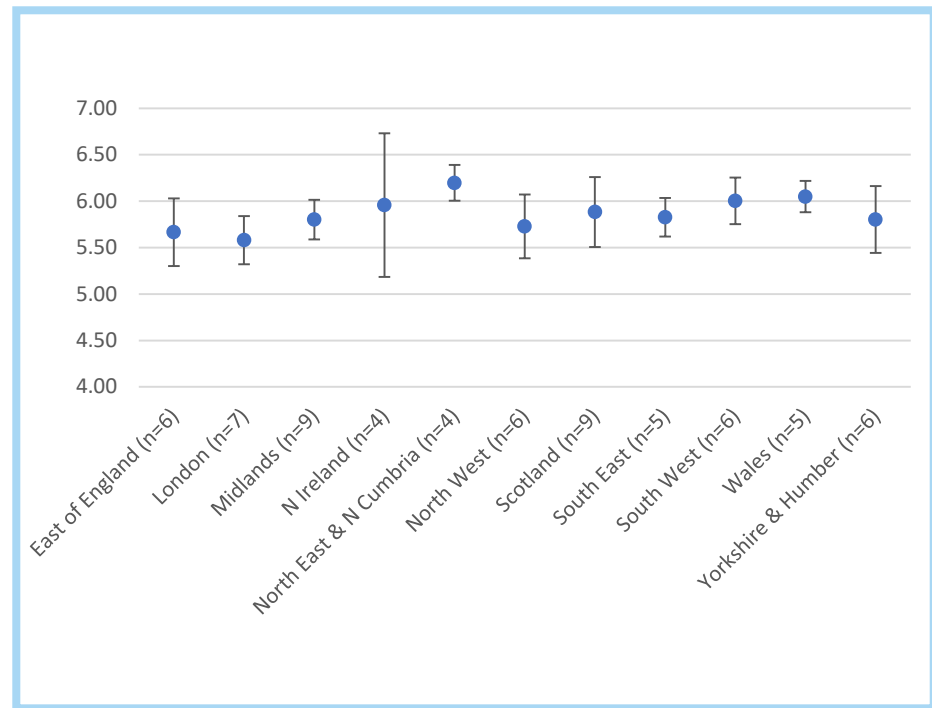


Theme 3: Communication

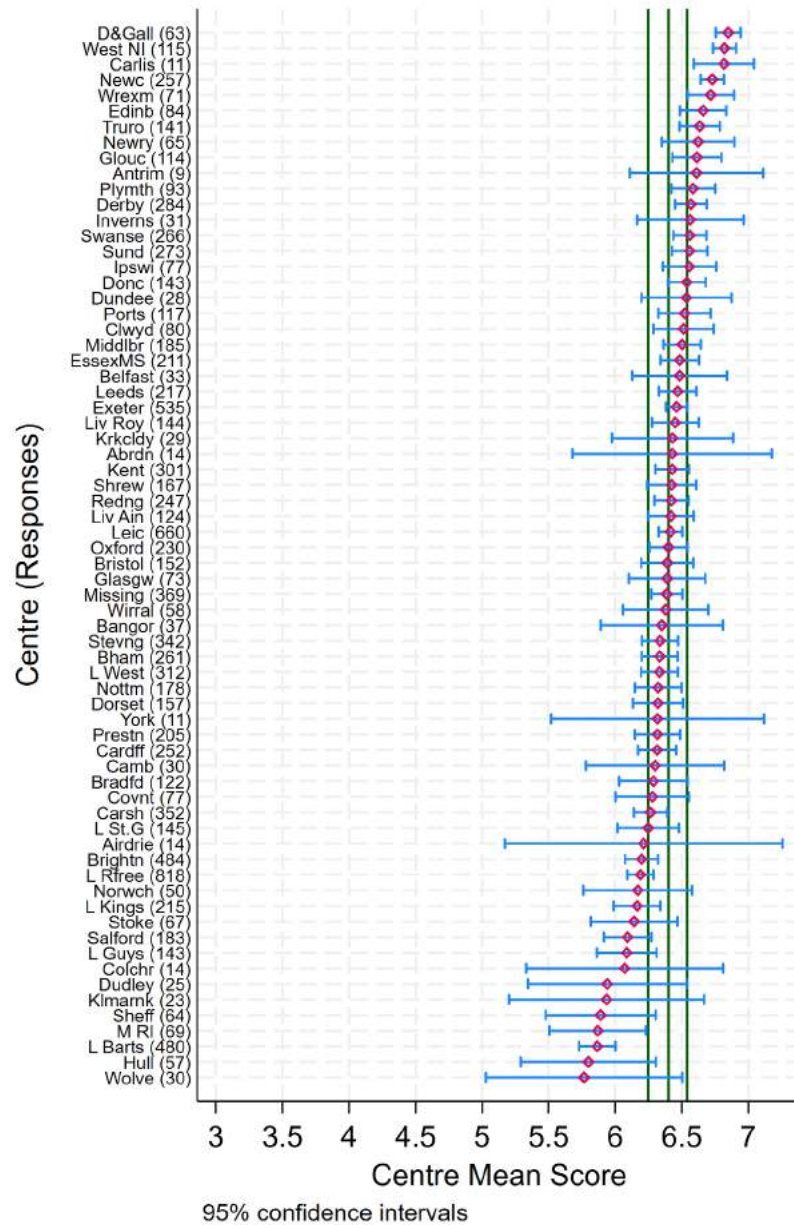


Do you think there is good communication between:

- 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?



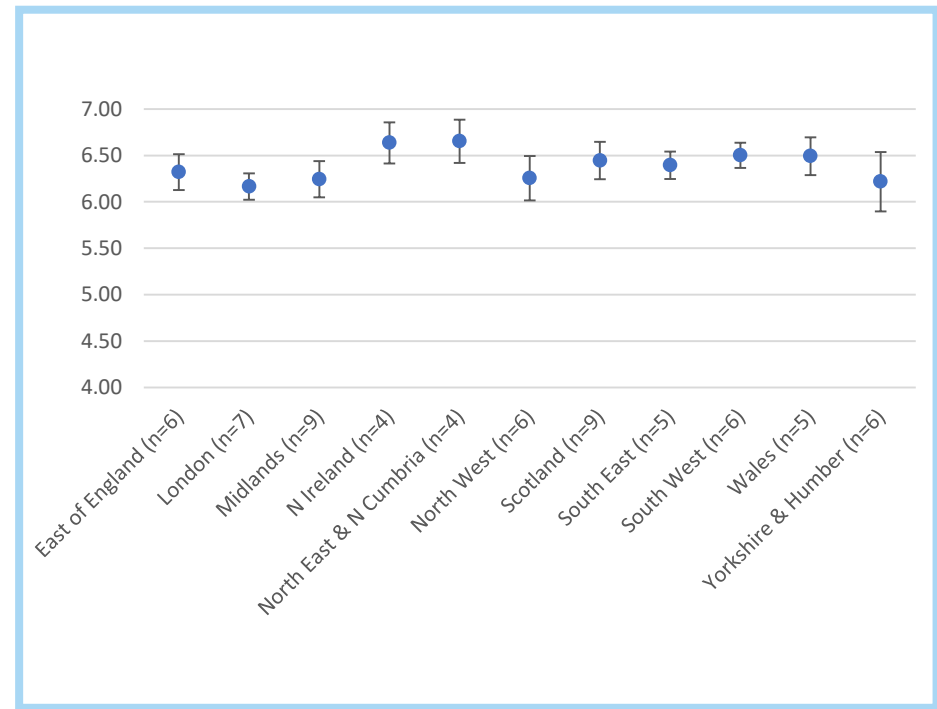
Theme 4: Patient Information



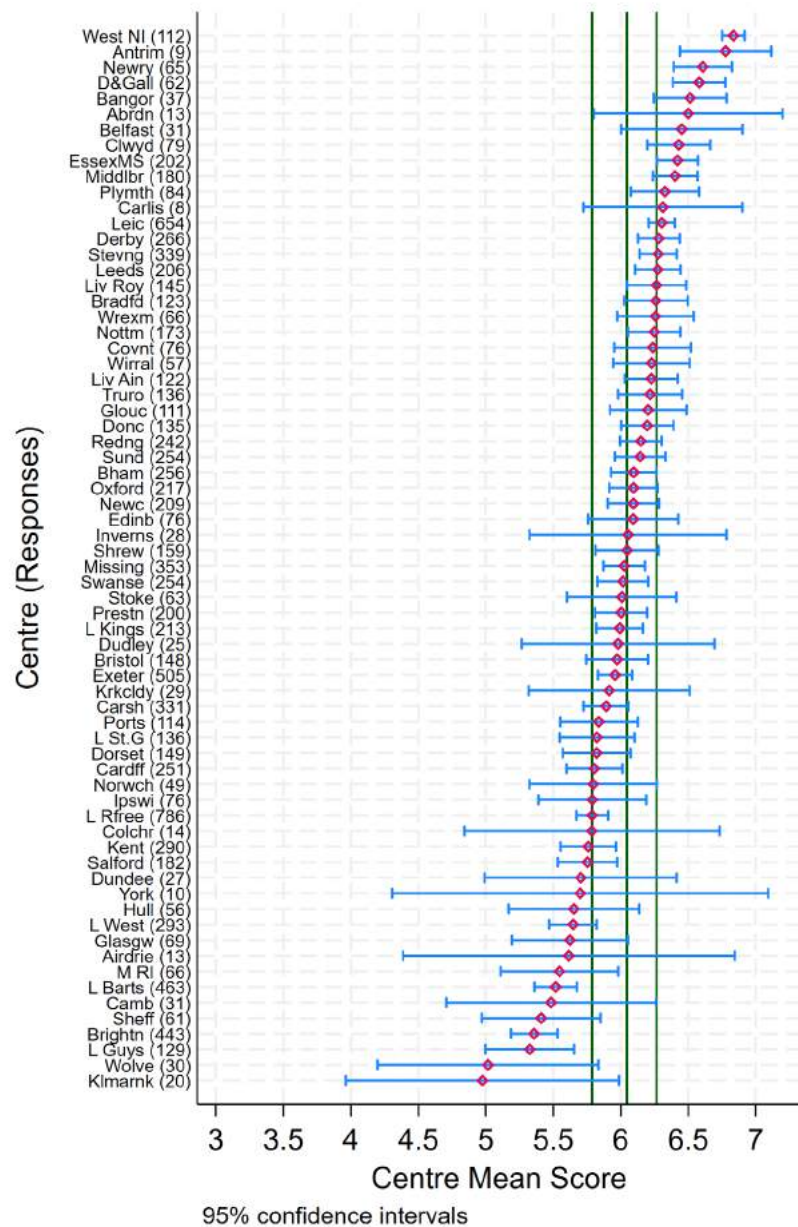
Does the kidney team:

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 and Diet

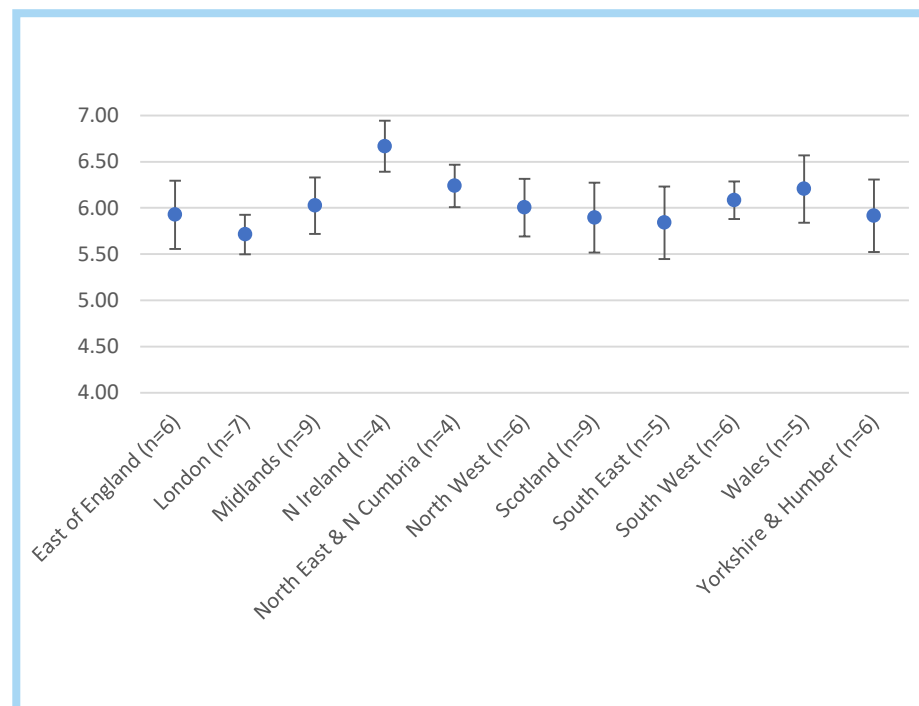


Thinking about the advice you are given about fluid intake:

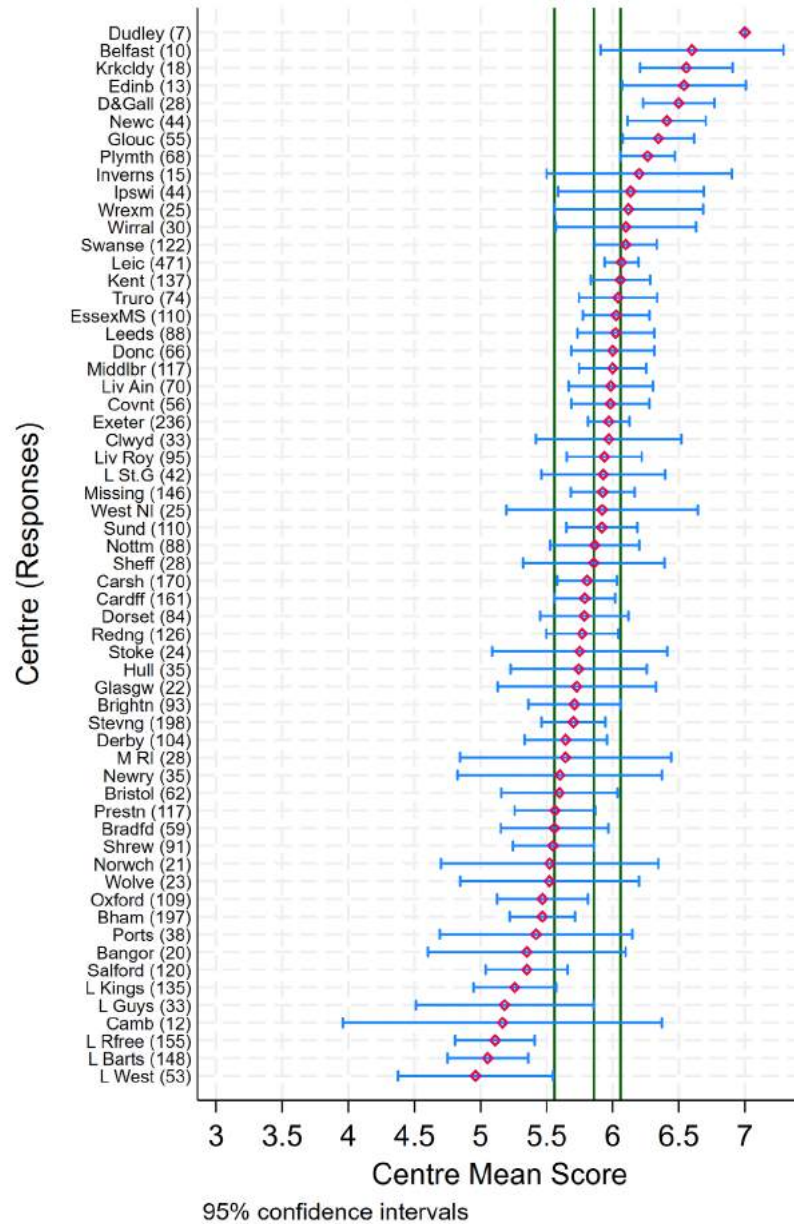
Q14. Does the kidney team give you clear advice on your fluid intake?

Thinking about the advice you are given about diet:

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

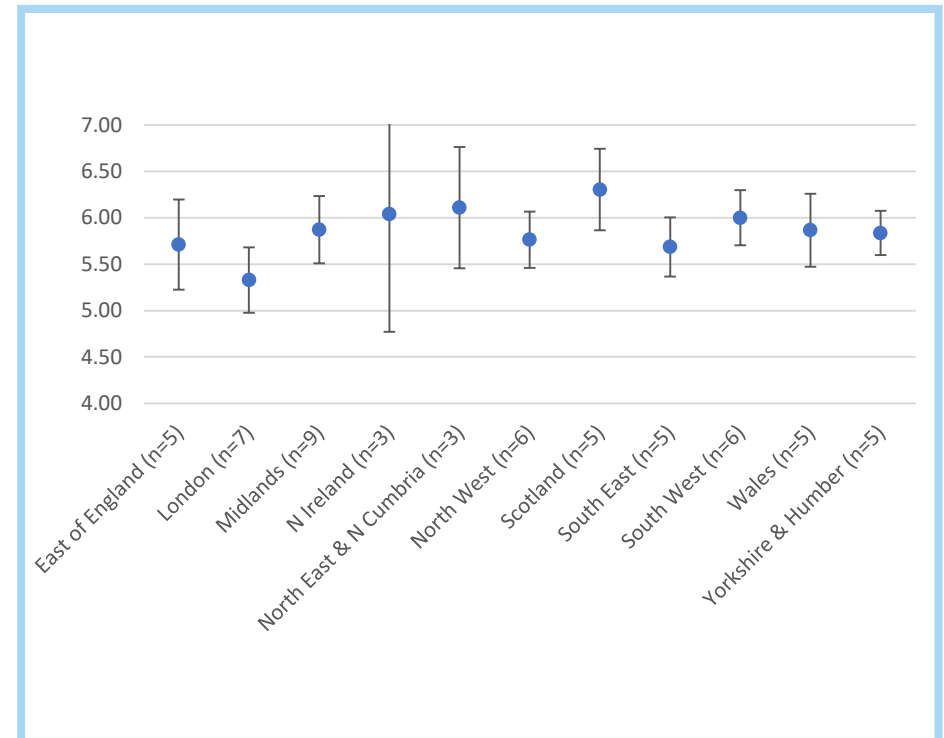


Theme 6: Needling

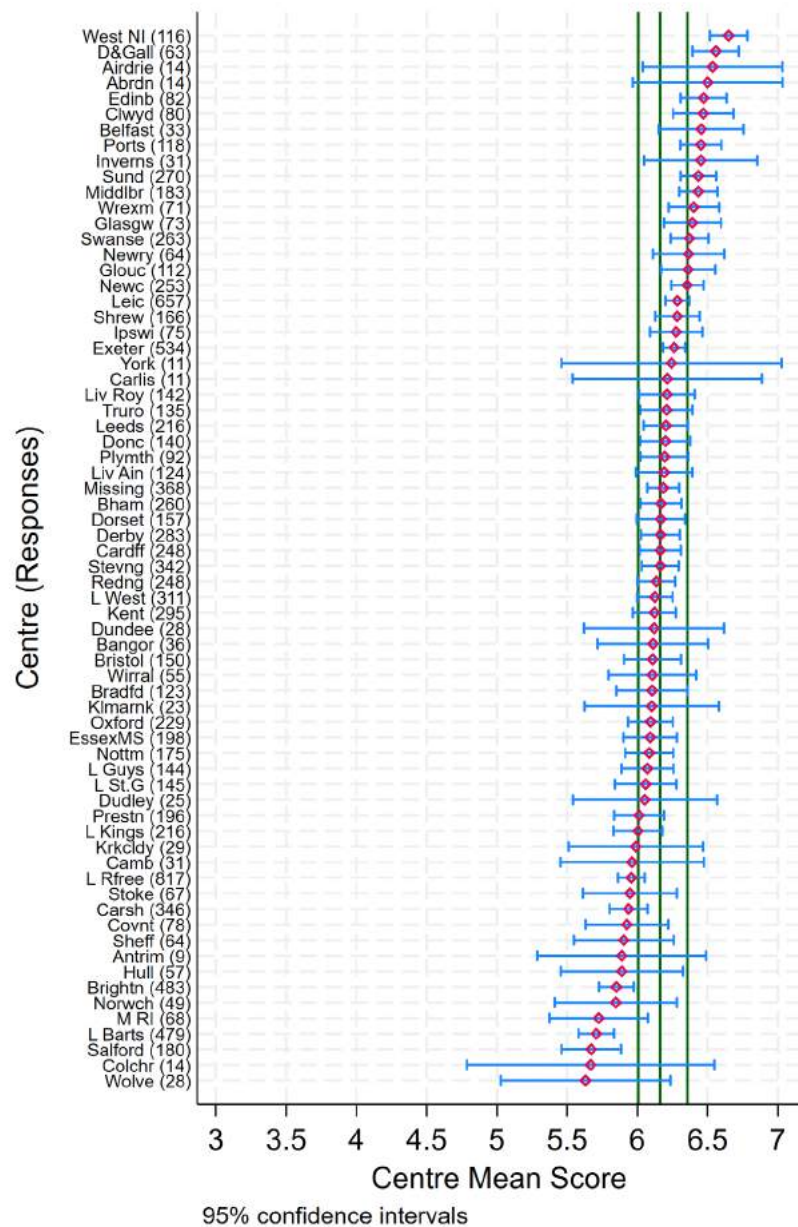


Q16. How often do the kidney team insert your needles with as little pain as possible?

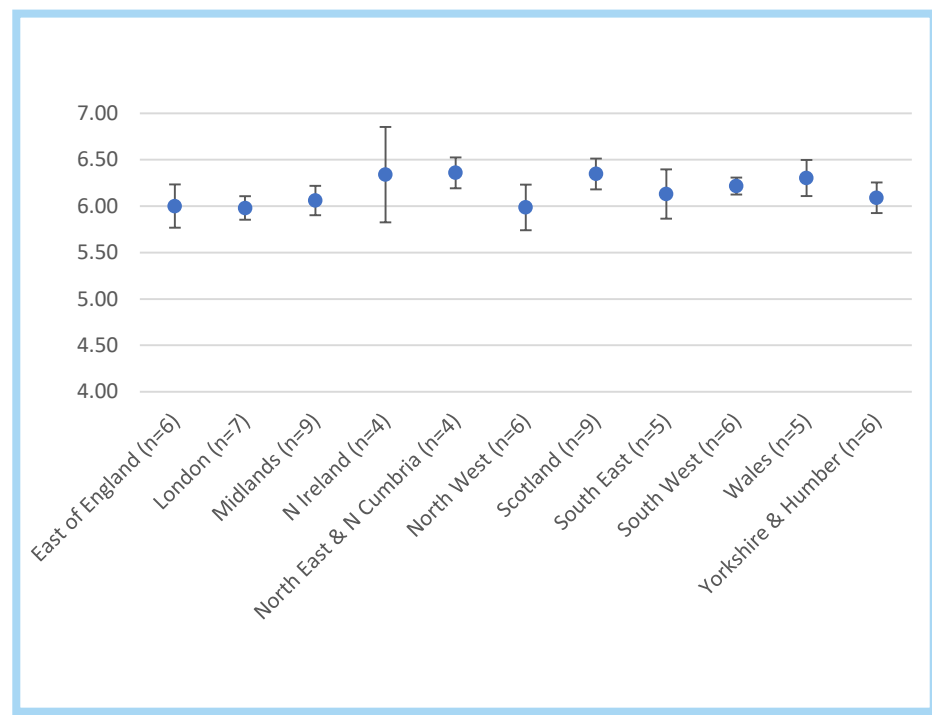
(in centre haemodialysis only)



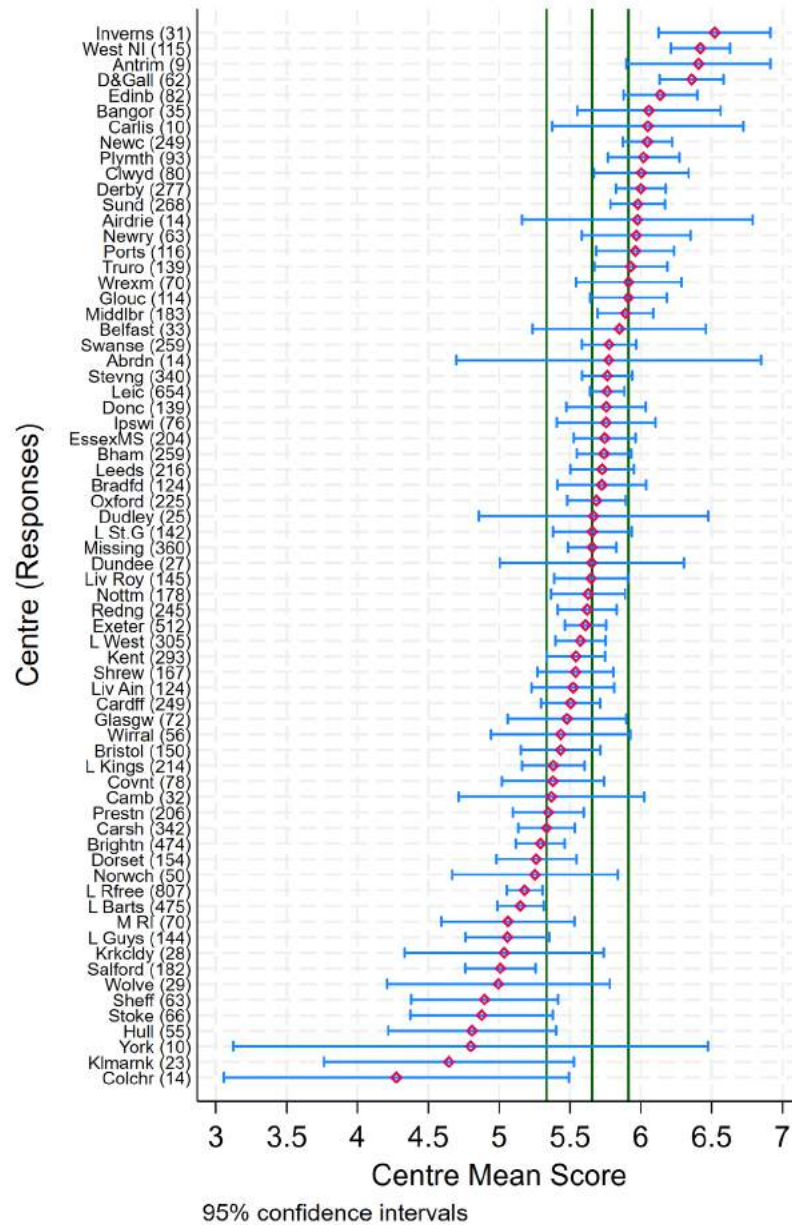
Theme 7: Tests



- 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?

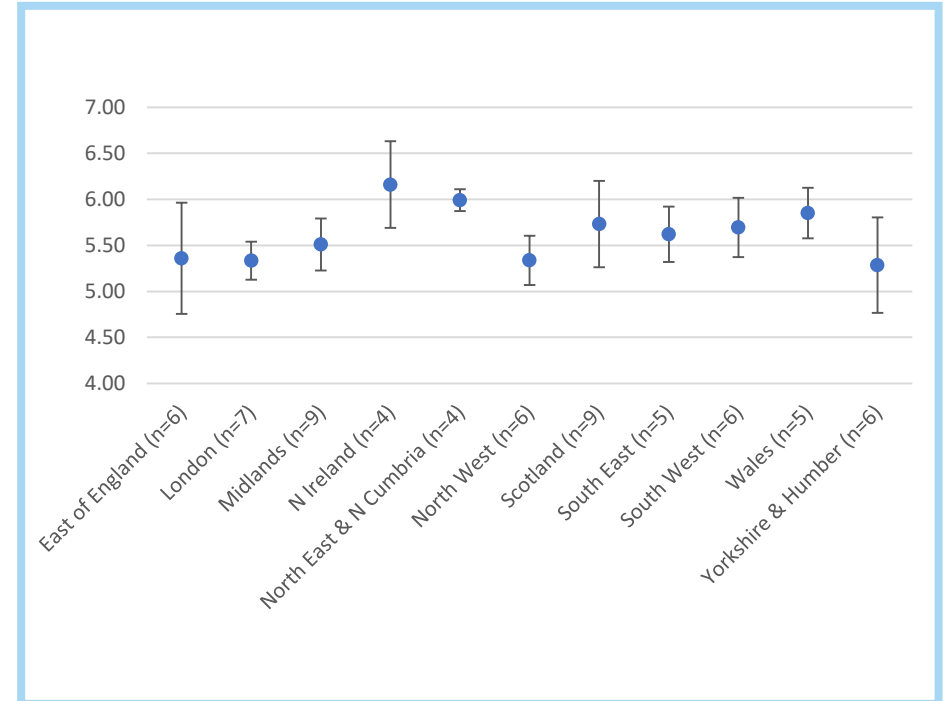


Theme 8: Sharing Decisions

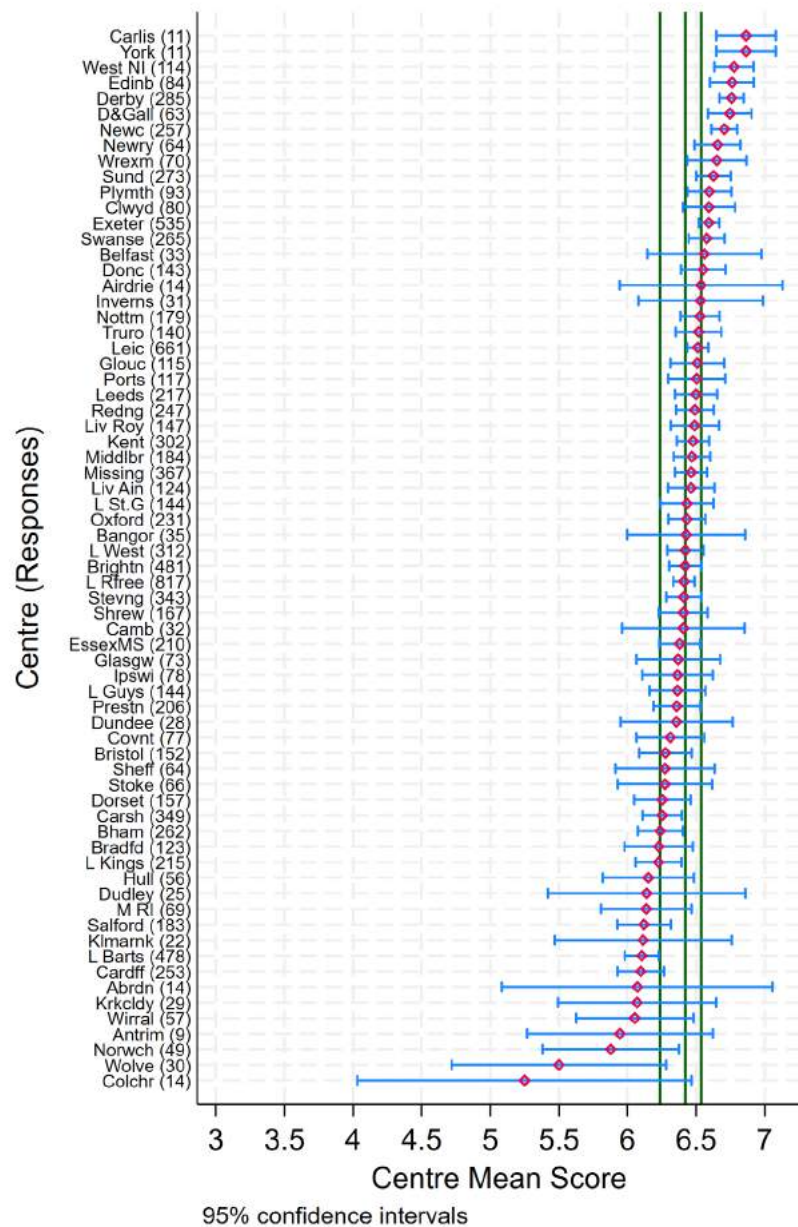


Does the kidney team:

- 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?

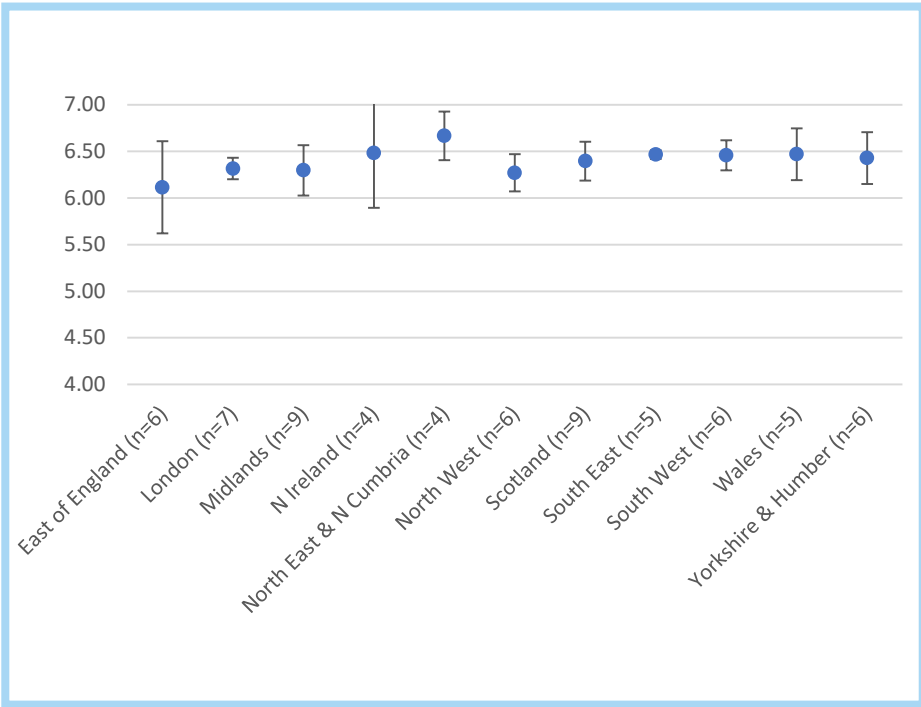


Theme 9: Privacy and Dignity

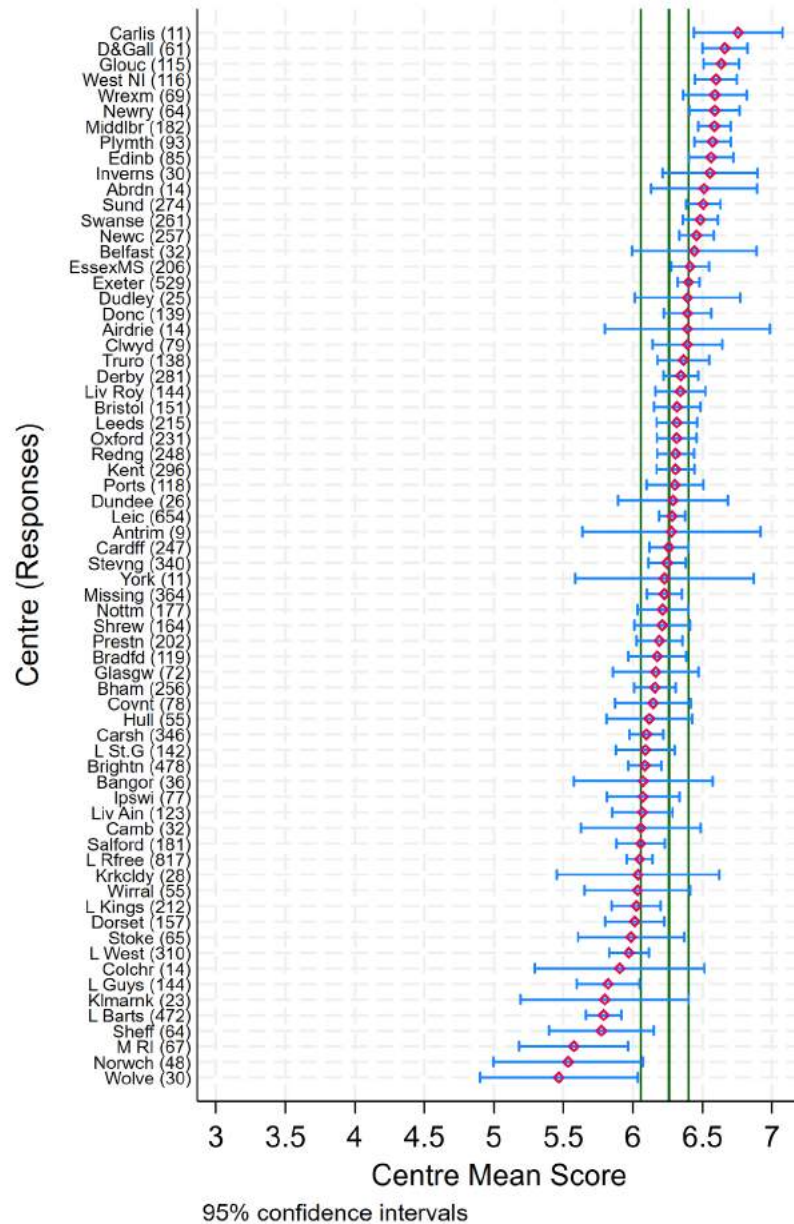


Q23. Are you given enough privacy when discussing your condition or treatment?

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



Theme 10: Scheduling and Planning

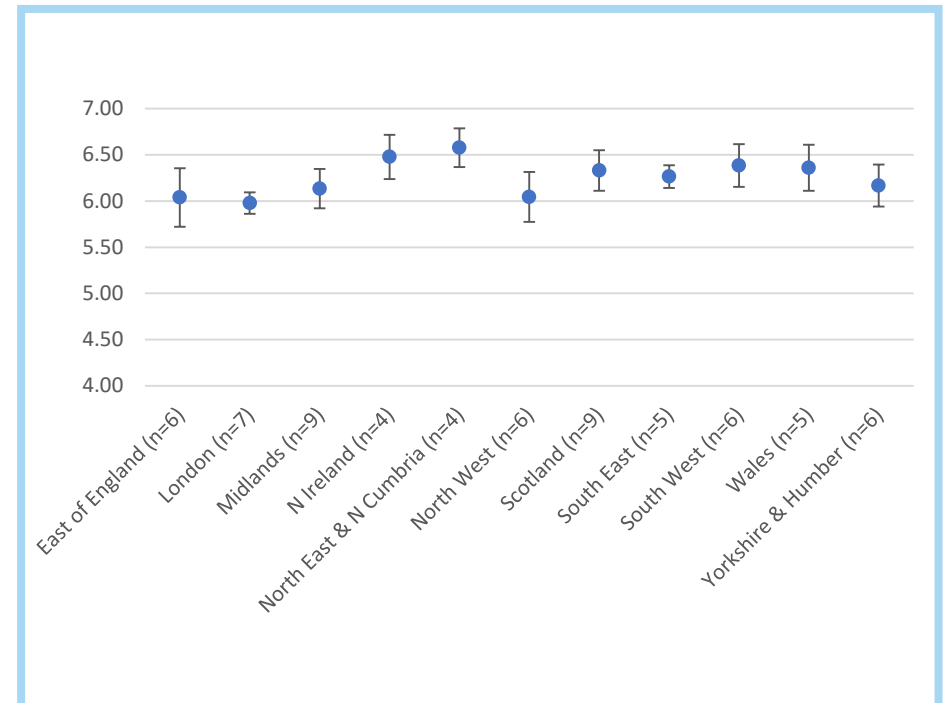


Q25. Can you change your appointment times if they are not suitable for you?

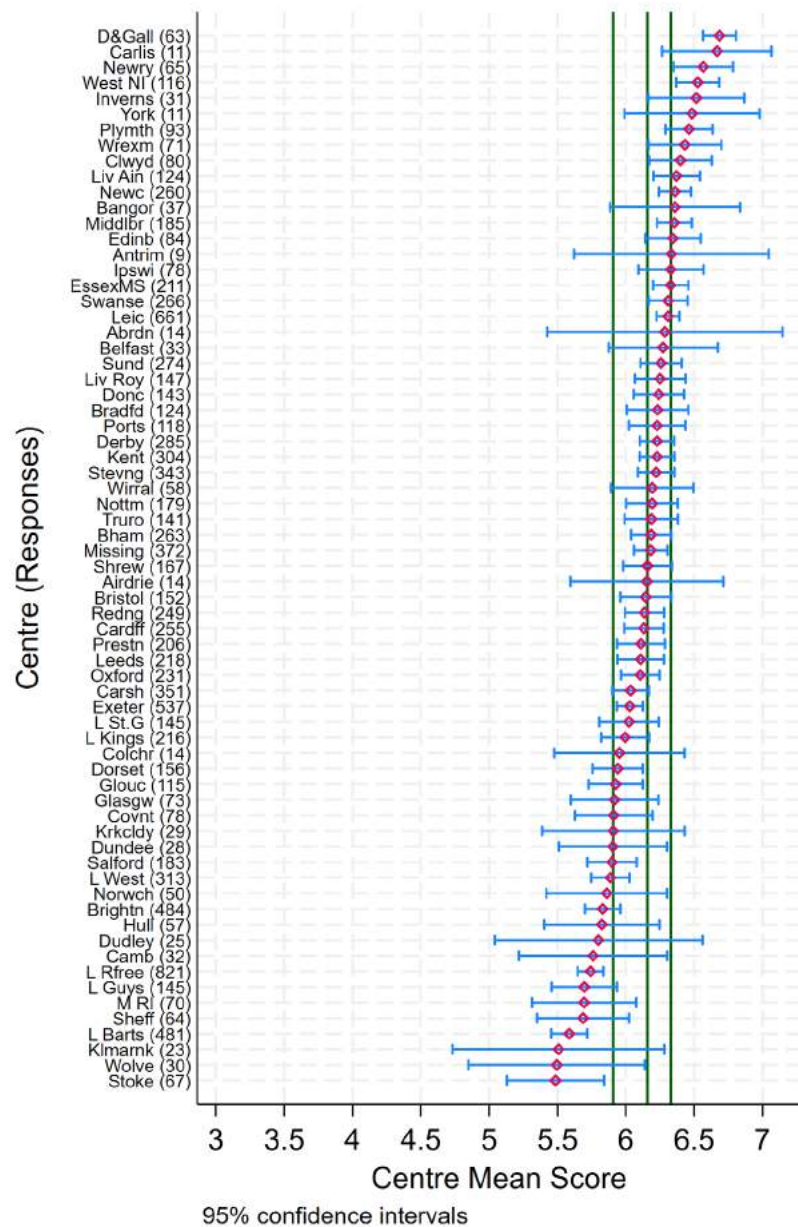
Q26. Do you feel your time is used well at your appointments relating to your kidneys?

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?

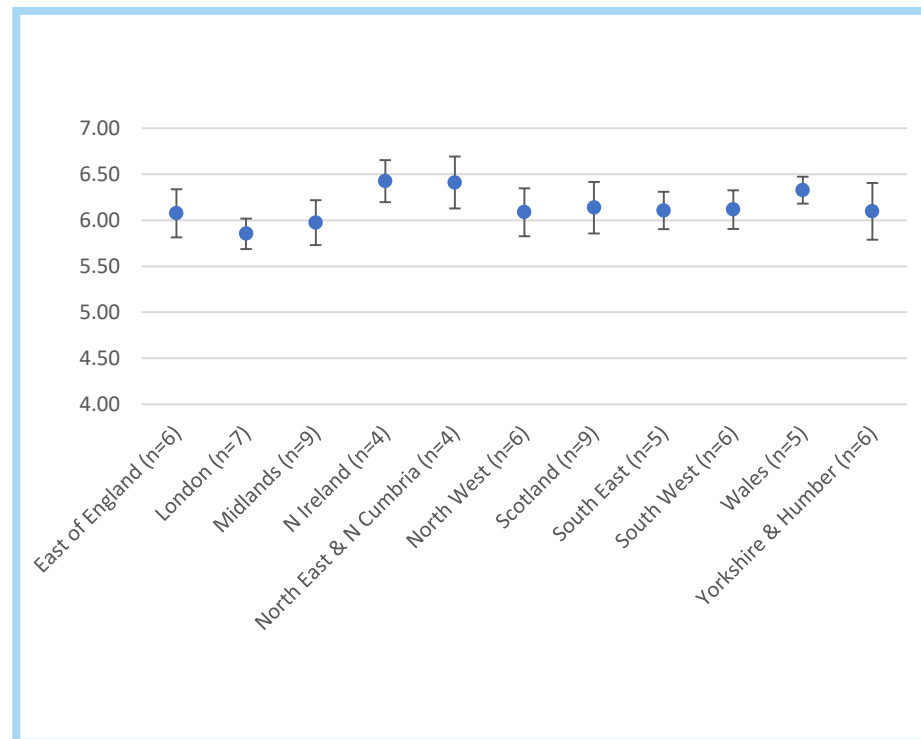


Theme 11: How the Kidney Team Treats You

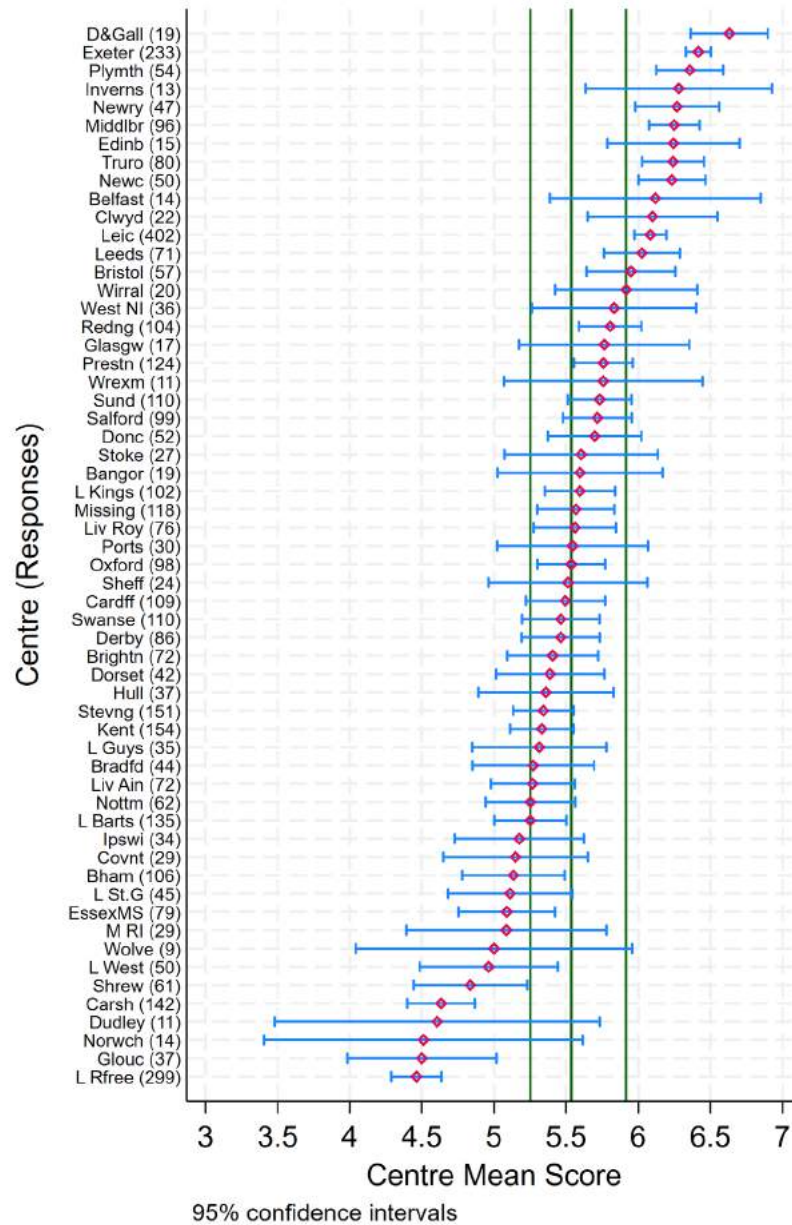


Thinking about how the kidney team treats you, do they:

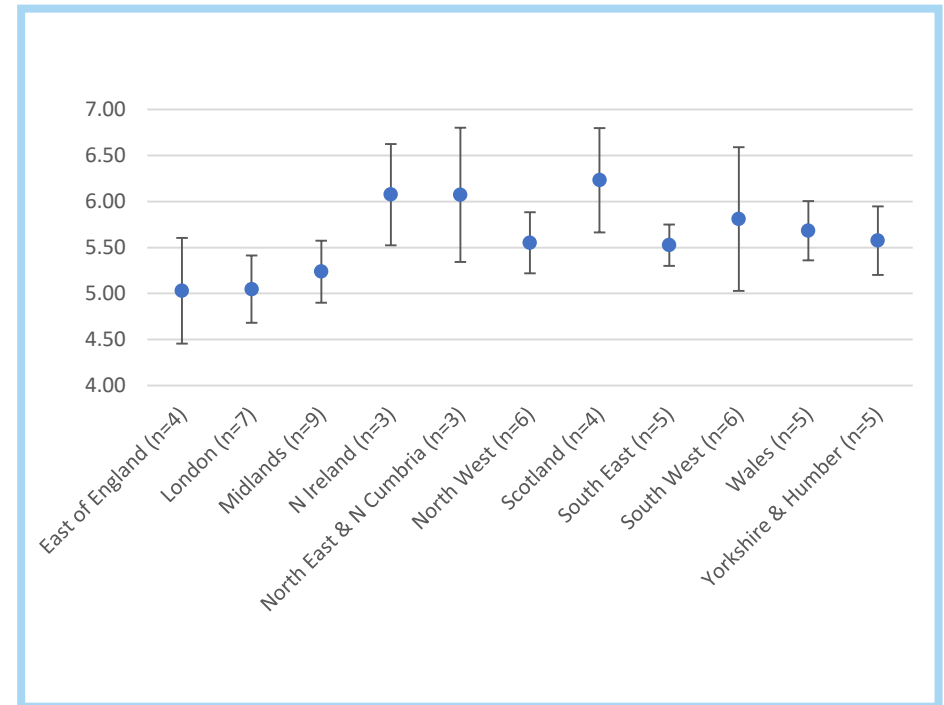
- Q28. Take you seriously?
- Q29. Show a caring attitude towards you?
- Q30. Ask you about your emotional feelings?



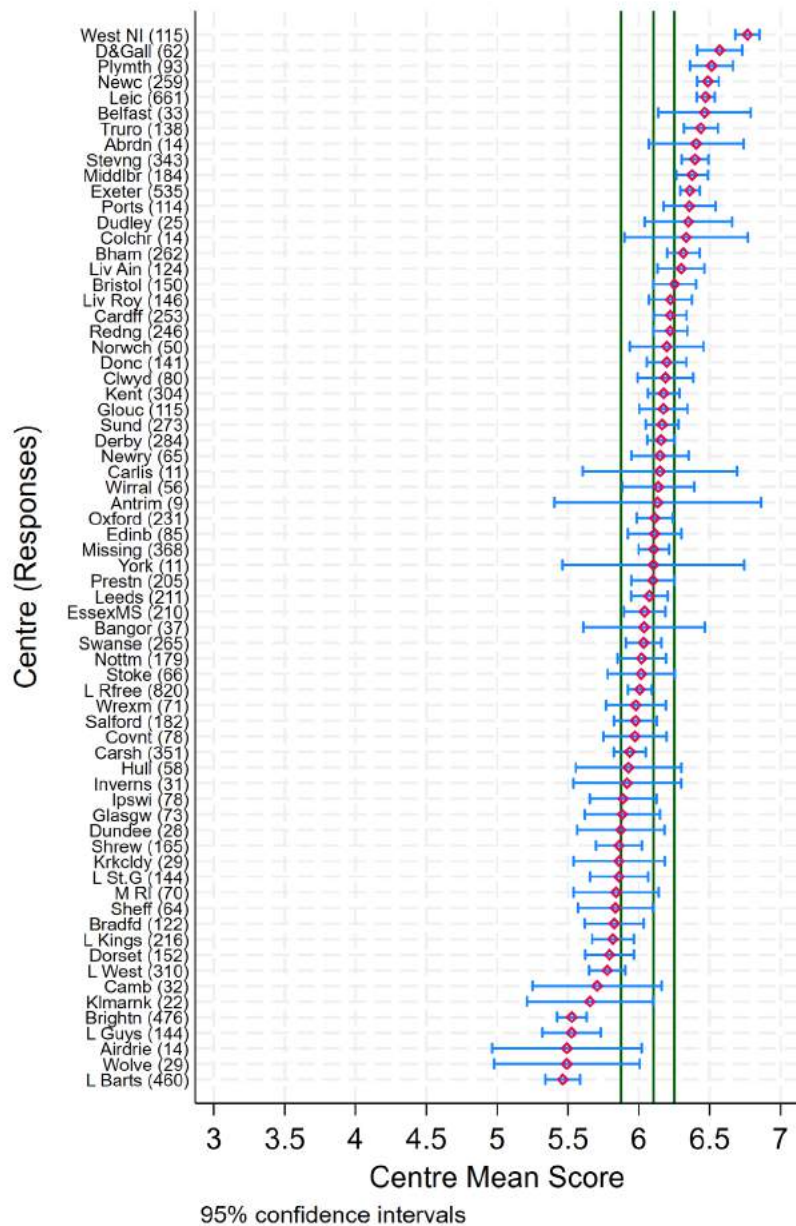
Theme 12: Transport



- 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?

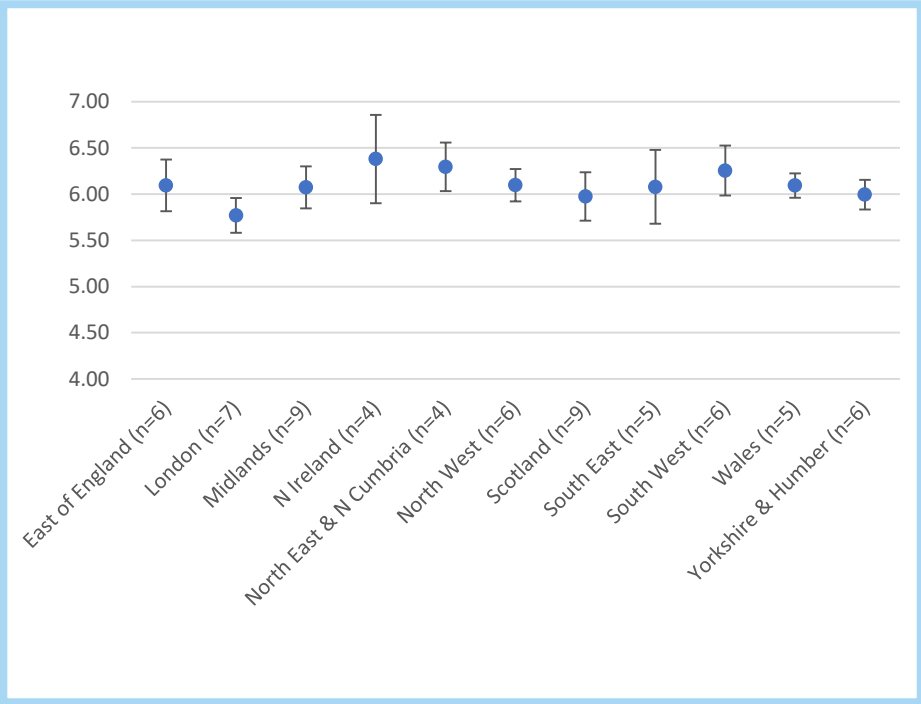


Theme 13: *The Environment*

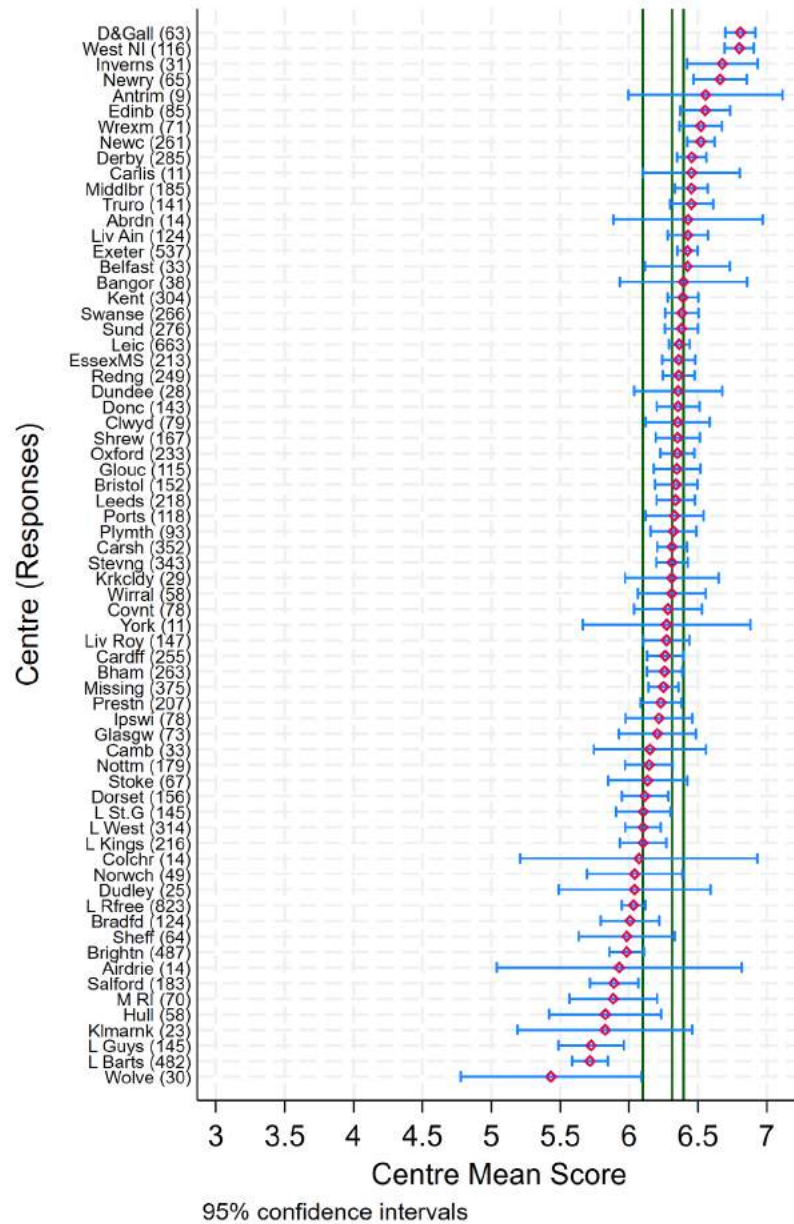


When you attend the kidney unit, how would you grade:

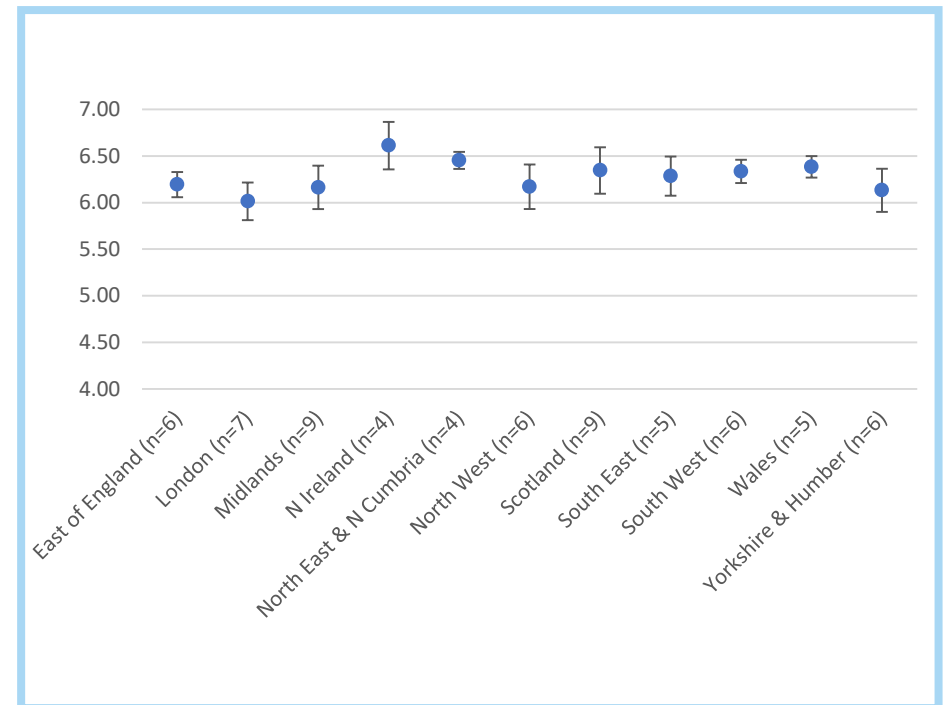
- Q34. Accessibility (e.g., lifts, ramps, automatic doors)?
- Q35. Comfort?
- Q36. Cleanliness?
- Q37. Waiting Area?
- Q38. Parking?



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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