UK Kidney Association

Kidney Care UK

Patient Reported Experience of Kidney Care in the UK
2022

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Foreword

The Kidney PREM 2022 report is the 7th annual report produced by the UK Kidney Association and Kidney Care UK. Much has changed since the initial report in 2015 when data was collected on paper and not all units were able to contribute. Since then, the Kidney PREM has continued to evolve and this year the opportunity to share kidney care experience was extended to our paediatric centres. This is an important development as we cannot assume that the experiences of adults are the same as those of children and young adults.

When Kidney PREM was launched in 2015, I was a Clinical Director at an adult renal service. It was the first time we were able to compare the reported experiences of our patients with other units across the country. This valuable data highlighted the opportunities to improve our services and directly influence the way we designed our transport services. We were not alone in using the Kidney PREM data to try and improve aspects of our services, and many units embarked on improvement projects e.g. fistula needling. For the first time we were able to identify units that were doing well and share their learning. In 2023, we have even more opportunities to share good practice across the United Kingdom. NHS England regional renal networks have been re-established and they are keen to support renal units in reducing variation in care across a range of areas. They will be supported by the Renal Service Transformation Programme (RSTP) which has worked with the kidney community to develop improvement toolkits and a data dashboard. The combination of Kidney PREM, toolkits and clinical metrics provides an opportunity to address some of the health inequalities our patients are subjected to, as well as improving care quality. I would encourage care providers and networks to ensure that the Kidney PREM is embedded within improvement plans.

At a local level, the Kidney PREM also provides an opportunity to strengthen engagement between care providers and patient and public voice representatives. I think many of us would agree that these are challenging times but working towards improving something that actually matters to our patients can be rewarding. The information in this Kidney PREM 2022 report really is important and I would encourage all teams to share good practice across the country.

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National Clinical Director Renal Medicine, NHS England

Acknowledgements

Kidney Care UK and the UK Kidney Association would like to thank the following people, without whom the Kidney PREM 2022 would not have been possible:

- People living with kidney disease who completed the 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.

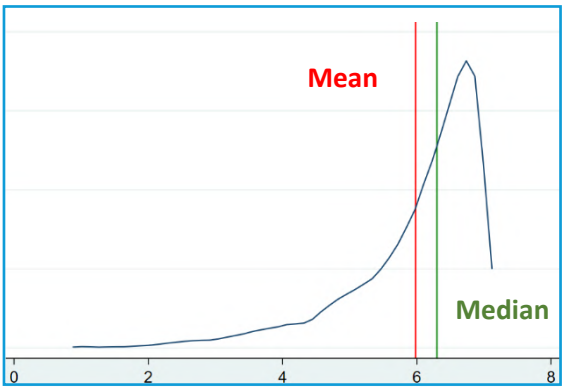
Mean: The mean centre score is calculated across patient scores by adding them together and dividing by the number of scores used, giving the mathematical average value.

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.

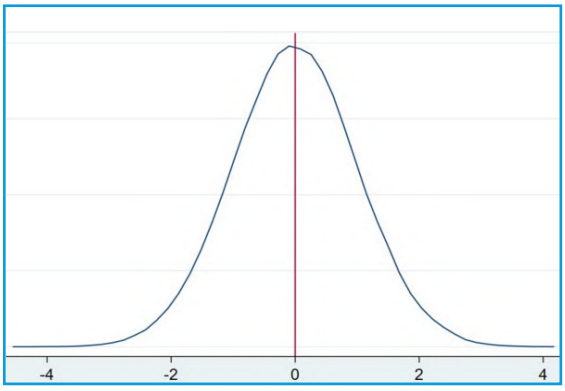
Median: If patient scores for a particular centre were listed in order, the median is the middle value separating the high scoring (top half) from the low scoring (bottom half).

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

This is the seventh annual report of the national Kidney PREM which is a measure of kidney patients' self-reported experience of the care they receive from kidney centres. It provides people living with kidney disease with the opportunity to feed into service improvement by sharing what matters most to them. Data collection for this report took place for six weeks between 1st October and 11th November 2022.

A total of 11,063 valid responses (7,030 online, 4,033 paper) were received, slightly fewer than in previous years. It is noteworthy that 15,210 paper surveys were sent to centres with only 26.5% being returned. Missing data were more common in paper returns. These issues have considerable resource implications. Older people and those receiving haemodialysis were more likely to use paper though the majority in both groups responded online.

The proportion of responders aged over 75 (25.1%) was higher than previous years and this group was over-represented in the sample compared to the proportion in this age category in the UK Renal Registry returns for those receiving kidney replacement therapy (KRT). Individuals of Asian ethnic background remain under-represented on the same basis. Transplant recipients were again markedly under-represented (16.8% of returns) whilst those receiving centre and satellite-based haemodialysis (61.1%) were over-represented. The proportion with chronic kidney disease (not receiving KRT) has remained stable at 15.2%. 145 (9%) of these stated that they had chosen conservative management – more than double that in 2021. Overall, a high proportion of participants (27%) said they needed help to complete the survey – especially those over 75, those of Asian ethnic background, and those receiving dialysis. There has been a small increase in the proportion of haemodialysis recipients participating in shared care – though a significant proportion still reported not being asked to participate, especially older respondents (42.2% of those over 75) and those dialysed in-centre rather than in satellites (41.5%).

For the first time, participants were asked whether English was their primary spoken language. 1,235 (12.8%) said they had a language other than English. Almost 100 languages were reported, Asian languages being the most prominent. In another first, individuals were given the option to provide the first part of their postcode. 7,998 analysable values (72.3% of all responses) were returned. These data may allow assessment of participant deprivation.

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

Though scores for the majority have remained stable, experience seems to have improved slightly amongst those not receiving KRT, whilst for those receiving centre- and satellite-based haemodialysis experience seems to have deteriorated. This may reflect a reversal of service changes enforced by the pandemic. In 2020 non-KRT and, to a lesser extent, transplanted individuals experienced reduced outpatient provision and reduced access to specialist nursing, whilst those receiving centre- and satellite-based haemodialysis experienced some benefits, notably changes in transport arrangement. The trends described may reflect a 'levelling-out' effect.

There was little change from previous years across the 13 Kidney PREM themes. *Access to the Renal Team, Privacy & Dignity* and *Patient Information* remain the highest scoring themes and *Sharing Decisions About Your Care* and *Transport* continue to be scored poorly. The gains made in the *Transport* theme in 2020 have dwindled. Scores for *Support, Communication* and *Needling* remain just above the lowest two themes, although *Support* and *Needling* continue their slight year on year improvement. These low scoring themes also tended to have the widest ranges of centre mean values.

There were major differences in some theme scores by treatment modality. Notably scores for *Fluid Intake and Diet* were markedly low in those not receiving KRT and *Sharing Decisions* and *Privacy & Dignity* amongst in centre-based and satellite haemodialysis recipients. Low scores in *Communication* were largely driven by scores on questions related to communication with GPs and non-healthcare services; in *Transport* by not being able to leave the haemodialysis unit within 30 minutes of being ready to leave; and in *Environment* by parking. Scores on H*ow the Renal Team Treats You* were generally good though perhaps reduced by low scores on the question of being asked about emotional feelings. Those centres with the lowest theme scores tended to be those with fewest responses.

Though there are a number of areas highlighted above in which there is potential for improvement, it is encouraging that the *Overall* experience question continues to be scored well with only minor differences across modalities.

Comments about experiences of care - a summary

At the end of the Kidney PREM, when accessed online, there is a 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, during COVID-19 or another time, please tell us below".

In 2022, 2,376 respondents (21.5% of those completing Kidney PREM) supplied written comments, 1,861 of which (78.3%) were coded under a theme covering an aspect of kidney care – the remainder stating that no further comments were necessary. 92.9% of participants gave consent for their comments to be passed back to their kidney centre. Generally, the profile of individuals providing comments matched that of Kidney PREM 2022, however, there were noticeably a higher representation from individuals who have received a functioning transplant (+5.2%). Compared to Kidney PREM 2021 the participant characteristics profile remained consistent.

The 2022 Kidney PREM Comments report follows the 13 Kidney PREM themes, with *How the Renal Team Treats You* receiving the highest number of comments (1,136). A total of 64% of comments under this theme were positive, focusing on comments about staff and thanking them for their care and dedication, as well as mentioning role-specific staff members positively. Comments containing examples of good experiences of care featured highly.

Environment was the second most common theme to emerge from the comments and was predominantly negative (82.9%). Respondents commented on issues with parking, such as the cost of parking and availability of spaces, the temperature of the unit being too cold, and the quality of the food offered.

Scheduling and Planning (330 comments), *Access to the Renal Team* (325 comments) and *Support* (278 comments) received several comments, with individuals wanting more face-to-face contact with the kidney team, wanting better access to the kidney team (particularly consultants), better availability of consultant appointments, more focussed support for home life and the impact of treatment. However, support throughout the COVID-19 pandemic was commented on positively.

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

Participants would like more opportunities to discuss what they would like from their care, needling to be less rushed so as to be less painful, and for conversations with consultants and nurses to be conducted in private. *Other Themes* contain comments which do not fit the pre-existing Kidney PREM themes. A total of 338 comments fell under *Other Themes* and subthemes headings, with prominent topics including mental health, psychological provision, self-care and medication. In addition to these, comments related directly to participant experience of their treatment, and some comments regarding the COVID-19 pandemic.

Respondent characteristics were reflected in comments. For instance, younger individuals tended to focus on *Support* and older participants, often receiving haemodialysis in-centre or at a satellite unit, on *Environment* and *Transport*. Those not receiving KRT or who are in receipt of a functioning kidney transplant focused on *Scheduling and Planning*, *Sharing Decisions About Your Care,* and *Tests*. Those receiving home therapies were more likely to comment outside of the Kidney PREM themes, instead commenting within *Other Themes.*

The 2022 Kidney PREM Comments Report also shows the comparison between free-text responses from Kidney PREM 2021 and Kidney PREM 2022. Only 21.5% of those completing the measure left a free-text response in 2022, compared to 40% in the previous year. In both years, positive comments about staff received the greatest number of comments, with comments regarding *Environment* being mostly negative. Comments in 2021 regarding *Support* included wanting more psychological support and mentioning the apparent lack of provision for this. This remained the same in 2022, though this year included an additional code, 'support with COVID-19', which received the most comments within this theme and were mostly positive (64%). In both years, issues with *Communication*, particularly participants wanting better Communication, featured as a negative aspect of patient care. Additionally, lack of information was an issue, particularly in relation to adequate updates about treatment, progress, and transplant prospects. More access to advice about diet, fluid intake and exercise was also requested.

We hope this summary provides some insight into what Kidney PREM participants think is important about their care and that the depth of these comments will enhance the findings of Kidney PREM 2022, complementing efforts to improve the care of people living with kidney disease.

The full 2022 Kidney PREM Comments Report and a detailed summary document can be accessed at:

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

Pilot Paediatric PREM - a summary

The Kidney PREM has been collecting data for over six years, providing healthcare professionals with information from adult patients with kidney disease to guide how services can be improved. For the first year, as an initial pilot, the 2022 survey was extended to include children and young people with chronic kidney disease (CKD) aged 12 years or older, and parent/carers of children and young people of all ages; the **pilot Paediatric PREM.** The validated questions of the adult Kidney PREM were used, with minor modifications if needed, and data collection entirely online.

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

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

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

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

Key messages from the Pilot Paediatric PREM

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

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

The highest scores were given to questions regarding Access to the *Renal Team* (mean 6.47), *Patient Information* (mean 6.5) and *Privacy & Dignity* (mean 6.72).

Sharing Decisions About Your Care rated highly with a mean score of 6.11. This is in contrast to the Kidney PREM in adults where this is a consistent low-scoring theme. This needs to be interpreted with caution given the small numbers but will be further explored.

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

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

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

Using this data to inform quality improvement

- Quality Improvement can only be as good as the quality of data. The first priority is to continue to improve the Paediatric PREM through development of an all-age Kidney PREM, as well as to increase the number of responses, overall and particularly from under-represented groups.
    - Centres will be asked to identify what they did well and what they can do to improve responses, and to share this with other centres.
    - The Paediatric PREM working group will also look at how to improve responses from males aged 12 years and over, and those from under-represented ethnic groups.
- Individual centre data and comments will be circulated to heads of service and members of the Kidney Quality Improvement Partnership Paediatric PREM working group.
- The pilot Paediatric PREM data will be shared with the British Association for Paediatric Nephrology lead for Quality Improvement so that the information can be considered in national projects.

Recommended actions for paediatric centres

- Centres have been asked to identify one area that they feel they can focus on regarding improvement of patient experience. This will be shared with the Paediatric Patient Experience group so we can all learn and improve together.
- The Paediatric PREM working group recommends that the BAPN lead for Quality Improvement should focus on the following themes for improvement nationally:
    - *Transport* for those receiving in hospital haemodialysis; particularly the time waiting after completing dialysis,
    - *Communication* with GPs, schools and other specialities; how this can be improved and variation reduced,
    - *Support*, with a focus on peer support; how to improve awareness of existing groups and additional support available to young people and their families.

Kidney PREM 2022

Introduction

The UK Kidney Association (UKKA) and Kidney Care UK are committed to improving the experience of care for all people living with kidney disease in the UK. This was the seventh year in which individuals, of all stages and treatment types, could have their say about their experience via the annual Kidney Patient Reported Experience Measure (Kidney PREM).

The Kidney PREM aims to:

- help teams understand how patients feel about their experience of care,
- show where improvement can be made,
- provide the UK Renal Registry (UKRR) with a national dataset on patient experience for audit and research.

The Kidney PREM is the only national measure of kidney patient experience, providing people with the opportunity to feed into service improvement by sharing what matters most to them. In this report we, focus on a range of aspects of kidney care and delve into variations by centres and participant characteristics. We present the national picture and encourage commissioners, kidney networks, people living with kidney disease, and their local multi-disciplinary teams to work together to understand what is good about local provision of care, and where improvements can be made.

To unpick experience of care, we have reported on patient experience of the 13 themes of care as well as the 39 aspects of kidney services covered by the individual questions. This provides an indication of where efforts may best be focussed.

Additional information available online:

- analysis of free text responses to the 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, during COVID-19 or another time, please tell us below”,
- graphs showing the centre scores for each theme comparing 2022 to 2021,
- centre scores for each theme by treatment groups,
- centre and satellite level results by question via the Kidney PREM portal,
- technical report
- the full Kidney PREM 2022 survey,
- appendices A-J.

Full Kidney PREM 2022 reporting, as well as for previous years, is available at:

www.ukkidney.org/kidney-patient-reported-experience-measure

Methodology

The Kidney PREM

Validated in 2017, the Kidney PREM contains 39 questions across 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 online version of the Kidney PREM, where individuals can comment on any aspect of care that has not already been covered. Participant characteristics are collected (age, gender, ethnicity) along with treating centre, treatment type, treatment detail (e.g., participation in shared care, reason for attending clinic if not receiving KRT, haemodialysis location), the type and nature of help received to complete the survey, and use of online platforms (PatientView, Patients Know Best). New for 2022, participants were asked to provide a partial postcode for their home address, and whether English was their first language, with an option to provide their primary language if appropriate. Respondents completing Kidney PREM online were asked to select their treating centre from a drop-down list filtered by country and region, or to type the name of the centre in a free text box. Similarly, staff at centres were asked to write UKRR renal unit codes onto paper copies prior to issuing them to participants.

The question about experience of care during COVID-19, introduced in 2020, was repeated this year, but rephrased to capture changes to care over the previous 12 months whether related to the pandemic or not.

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

Data collection

Kidney PREM ran for six weeks from 1st October to 11th November 2022. Kidney PREM was primarily publicised as an online survey, with links available on both the UK Kidney Association and Kidney Care UK websites. Centres were given paper surveys for distribution to individuals for whom online completion may be difficult. Centres were provided with packs of paper surveys and pre-paid return envelopes.

The number of paper surveys issued was calculated at 25% of centres' KRT populations, with extra copies provided for some centres based on their 2020 and 2021 returns, or if additional paper copies had been requested during Kidney PREM 2021. Some centres requested additional surveys during the collection window. In total, 15,210 paper copies were distributed, with just 4,033 (26.5%) returned.

Alongside the paper surveys, promotional materials including posters were distributed to centres in September 2022, and some centres were able to send the link to the Kidney PREM 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.

Analysis and reporting

The validated Kidney PREM has been used for annual data collection since 2018. This report presents results across the last three years from 2020 onwards. Reports and data from previous years are available online[1].

Responses to questions were used to calculate scores for each theme, as well as the 'scale score' (the total Kidney PREM score) across all themes (questions 1-38). For further detail, including data processing, please refer to the online Kidney PREM Technical Report.

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 kidney disease who are not receiving kidney replacement therapy are referred to as CKD (non-KRT) for the purpose of this report.

[1] www.ukkidney.org/kidney-patient-reported-experience-measure

Results

1. Profile of Kidney PREM Respondents

A total of 11,063 valid responses were received in the 2022 Kidney PREM, equivalent to 15.4% of the KRT population, slightly fewer responses than in previous years. Just two participants completed a translated version of the measure, one in Welsh and one in Gujarati. All regions of the UK were represented, although with regional variation (Table 1.1). London received the most returns at almost a quarter, reflecting the larger population receiving treatment. Of the English regions, the North East & North Cumbria had the highest increase in response rate as a proportion of their KRT population, from 19.3% to 22.9%. Other English areas received approximately the same or lower response rate than in 2021. The North West region, followed closely by Scotland, had a disproportionately lower response return compared to their KRT population (6.8% and 7.8% respectively), with Scotland returning over 100 fewer than in 2021. Northern Ireland responses increased from 2021, their return rate up to 15.8% from 13.3%.

Wales saw a decrease of nearly 300 participants, although at 19.1% of their KRT population were still one of the regions with the highest rate of participation. Appendix A contains response numbers for each kidney centre, along with a comparison with 2021 returns and the split between online and paper completion. Notably, this year saw a higher proportion of participants not completing centre names, with 888 unidentified in 2022, compared to 411 missing centres in 2021.

Regional Profile

Table 1.1: Frequency of Kidney PREM 2022 returns by region

	No. of returns	% of returns	% of 2021 Kidney Replacement Population[2] Therapy
England			
East of England	858	7.8%	17.6%
London	2,667	24.1%	17.6%
Midlands	1,405	12.7%	12.4%
North East & N Cumbria	694	6.3%	22.9%
North West	448	4.0%	6.8%
South East	1,211	10.9%	17.0%
South West	935	8.5%	18.9%[3]
Yorkshire & Humber	612	5.5%	10.5%
England Total	9,063	81.9%	15.4%
Northern Ireland			
N Ireland Total	319	2.9%	15.8%
Scotland			
Scotland Total	420	3.8%	7.8%
Wales			
Wales Total	625	5.6%	19.1%
UK Total[4]	11,063	-	15.9%

[2] The UK Renal Registry only collects data for those receiving KRT. Kidney PREM is completed by those not on KRT (15% of Kidney PREM respondents), so percentages are not directly comparable.

[3] Figures for Exeter unavailable in 2021. 2020 data used instead.

[4] Totals include those where respondents gave their country of treatment but not their centre (252) or did not provide any geographical information (636).

Participant Characteristics

Age

Individuals participating in Kidney PREM 2022 were similar in age profile to 2021, Table 1.2. A quarter were aged 75 years and over, considerably higher than the proportion amongst those receiving KRT recorded by the UKRR in that age group. Age profiles across treatments were as expected (online Appendix Table B); over two thirds of those with transplants and receiving haemodialysis at home were under 65 years of age (69.6% and 70.5% respectively). Conversely, over 50% of people receiving peritoneal dialysis, in-centre haemodialysis, in-satellite haemodialysis or not receiving KRT were at least 65 years old.

Gender

'Non-binary' and 'other' were introduced as gender options this year, with 0.1% of individuals selecting one of these. This corresponded with a reduction in participants answering, 'prefer not to say', since they were able to choose a response which more closely reflected their self-identity.

Ethnicity

More detailed ethnicity options were provided in 2022, adopting categories used in the UK Census[5]. This has corresponded with an increase in the proportion of participants providing ethnicity information, with a reduction in those selecting 'rather not say' or missing the question altogether. A separate category for 'Mixed' ethnicity was added alongside the existing 'Other' option, selected by 154 individuals (1.4% of those who responded). There were 9.3% of participants who described themselves as Asian, still somewhat below UKRR figures for the KRT population (14.1%).

Recognising that there has been a consistent trend in under-representation from South Asian patient communities, despite effort to make the PREM available in two relevant languages, UKKA has already engaged on a parallel project to advance strategies aimed at addressing involvement barriers. Led by the Inequalities in Health Unit at the University of Hertfordshire, this work will consider whether there are disparities in Kidney PREM awareness and/or further barriers to participation.

[5] https://www.ethnicity-facts-figures.service.gov.uk/style-guide/ethnic-groups

Table 1.2: Participant characteristics for Kidney PREM 2022, 2021 and 2020

	Kidney PREM 2022	Kidney PREM 2021	Kidney PREM 2020[6]	UK KRT Patients as at end of 2021
Total	11,063	12,416	9,645	
Age (years)				
≤ 30	363 (3.4%)	376 (3.1%)	400 (4.1%)	4.7%
31-55	2,731 (25.6%)	3,261 (26.6%)	2,929 (30.4%)	35.6%
56-74	4,895 (45.9%)	5,763 (47.0%)	4,537 (47.0%)	44.2%
≥ 75	2,680 (25.1%)	2,868 (23.4%)	1,779 (18.4%)	15.4%
Missing	394	148	-	-
Gender[7]				
Female	4,328 (40.3%)	5,038 (41.6%)	4,177 (43.3%)	38.7%
Male	6,346 (59.1%)	6,986 (57.7%)	5,404 (56.0%)	61.3%
Non-binary/other	11 (0.1%)	-	-	-
Rather not say	59 (0.5%)	86 (0.7%)	64 (0.7%)	-
Missing	319	306	-	-
Ethnicity[8]				
Asian Total	1,008 (9.3%)	1,137 (9.3%)	743 (7.7%)	14.1%
Indian	462 (4.2%)	-	-	
Pakistani	231 (2.1%)	-	-	
Bangladeshi	85 (0.8%)	-	-	
Chinese	39 (0.4%)	-	-	
Other	190 (1.7%)	-	-	
Black Total	903 (8.4%)	1,005 (8.3%)	613 (6.4%)	8.7%
Caribbean	322 (3.0%)	-	-	
African	462 (4.2%)	-	-	
Other	119 (1.1%)	-	-	
Mixed Total	154 (1.4%)	-	-	1.5%
White & Black Caribbean	46 (0.4%)	-	-	
White & Black African	27 (0.2%)	-	-	
White & Asian	33 (0.3%)	-	-	
Other	48 (0.4%)	-	-	
White Total	8,579 (79.6%)	9,358 (76.9%)	7,896 (81.9%)	73.8%
British	8,142 (74.6%)	-	-	
White	153 (1.4%)	-	-	
Gypsy/Roma	6 (0.1%)	-	-	
Other	8 (0.1%)	-	-	
Other Total	269 (2.5%)	402 (3.3%)	203 (2.1%)	1.9%
Arab	27 (0.2%)	-	-	
Other	113 (1.0%)	-	-	
Rather not say	127 (1.2%)	260 (2.1%)	190 (2.0%)	
Missing	152	254	-	

[6] No missing data in 2020 due to online-only collection.

[7] Separate 'Non-binary' and 'Other' categories added to Gender options for 2022 and combined for reporting purposes. Sex rather than gender data collected by the UKRR, with only 'male' and 'female' options currently available.

[8] More detailed Ethnicity options available in 2022. UKRR Ethnicity data does not include Scottish centres and has additional missing data for 1,777 individuals (2.8% of total).

Help to Participate

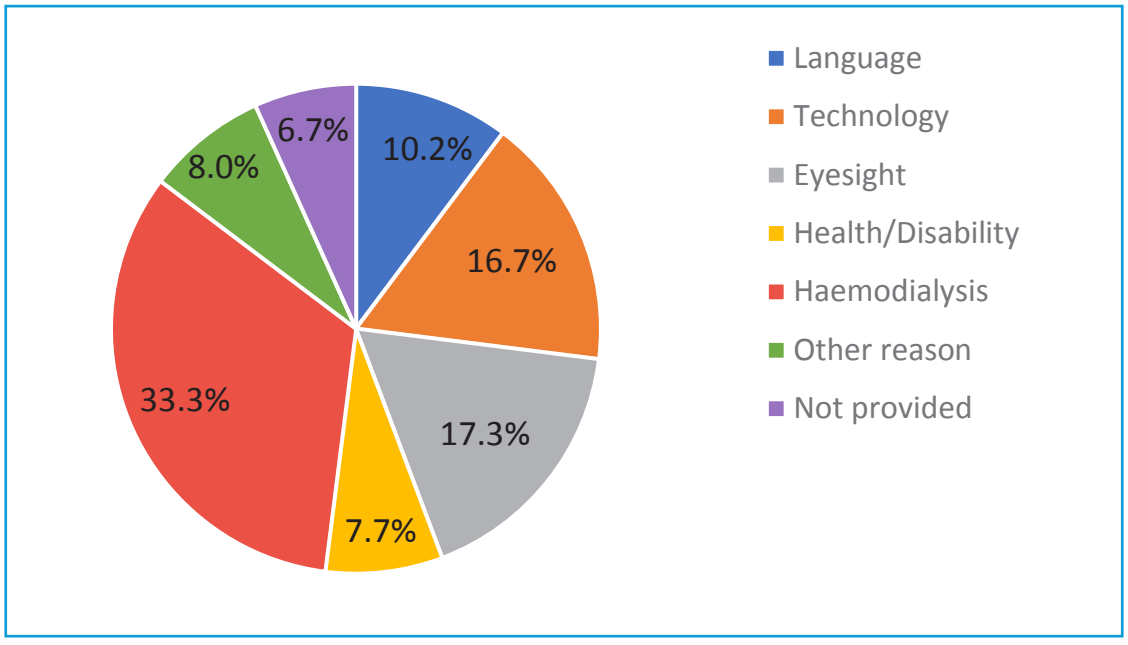
Individuals completing Kidney PREM were asked whether they had received any help to do so, with 2,986 (27.0%) stating that they had. Appendix Table C1 shows the characteristics of those who received help; notably 40.1% of the over 75s required assistance, compared to less than 20% of both the under 30s and 31-55 years age groups. A higher proportion of Asian ethnicity participants (46.3%) received help than other ethnic groups, despite over 75s comprising just 18.1% of Asian respondents, similar to those of black (14.1%) and mixed (16.1%) ethnicities, and a much smaller proportion than in white (27.6%) participants.

Over a third of individuals receiving haemodialysis had support to complete the Kidney PREM, which does not appear to be attributable to a difference in age profile; there were similar proportions of the over 75s amongst haemodialysis recipients (28.0%), peritoneal dialysis recipients (29.8%) and those not receiving KRT (28.3%). However, a much lower proportion of those with functioning transplants received help to complete (6.2%), potentially reflecting the much younger age profile of these individuals (6.9% over 75 years), Appendix Table B1.

Volunteers helped more respondents completing online rather than using paper, with relatives/friends providing more assistance to those using paper surveys, Appendix Table C2.

A third of those receiving help stated that they did so because the Kidney PREM was completed whilst they were receiving haemodialysis, Appendix Table C3. Eyesight issues (17.3%), difficulties with technology (16.7%) and language challenges (10.2%) were other common reasons given for needing help.

Figure 1.1: Reasons given for receiving help to complete Kidney PREM



Treatment modalities for participants

A similar proportion of individuals receiving haemodialysis participated in Kidney PREM 2022 as in 2021 (61.1%), although with slightly fewer of those being treated at satellite units (49.6% compared to 54.8% in 2021). The number of people treated with peritoneal dialysis was similar (725 vs 772), but conversely fewer transplant recipients participated in 2022 (1,780 vs 2,148 in 2021).

Of those not receiving KRT, most were attending clinic for monitoring (62.5%). More participants were approaching end-stage kidney disease (ESKD) than last year (490 vs 356), and of those a higher proportion had chosen conservative management (CM) than previously (29.6% vs 13.5%).

A larger number of individuals completing Kidney PREM failed to provide their treatment modality this year (484 vs 289 in 2021), potentially as a result of an increase in paper surveys, where questions could be skipped.

Table 1.3: Kidney PREM treatment modality in 2022, 2021 and 2020

	Kidney PREM 2022	Kidney PREM 2021	Kidney PREM 2020	UK KRT Patients as of end of 2021
Total	**11,063**	**12,416**	**9,645**	
Transplant	1,780 (16.8%)	2,148 (17.7%)	2,172 (22.5%)	56.5%
Haemodialysis	6,469 (61.1%)	7,497 (61.8%)	4,959 (51.4%)	37.9%
At Home	*198 (3.1%)*	*259 (3.5%)*	*239 (4.8%)*	*5.3%*
In-Satellite	*3,201 (49.6%)*	*4,054 (54.8%)*	*2,748 (55.4%)*	*94.7%*[9]
In-Centre	*3,049 (47.3%)*	*3,090 (41.7%)*	*1,972 (39.8%)*	
Missing location	*21*	*94*	-	-
Peritoneal dialysis	725 (6.9%)	772 (6.4%)	632 (6.6%)	5.6%
CKD (non-KRT)	1,605 (15.2%)	1,710 (14.1%)	1,882 (19.5%)	-[10]
Attending for monitoring	*982 (62.5%)*	*1,130 (66.1%)*		
Approaching ESKD	*490 (31.2%)*	*356 (22.0%)*		
KRT chosen	249 (50.8%)	182 (51.1%)		
CM chosen	145 (29.6%)	48 (13.5%)		
Undecided	96 (19.6%)	126 (35.4%)		
Don't know CKD type	*99 (6.3%)*	*132 (8.2%)*		
Missing CKD type	*34*	*92*		
Missing Treatment	484	289	-	-

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

[9] Distinction between in-centre and in-satellite haemodialysis patients unavailable
[10] UKRR collects limited data for CKD patients not receiving KRT

Participation in Shared Care for Individuals Receiving Haemodialysis

At 29.2%, shared care participation was higher than in 2021, where 26.3% of those receiving haemodialysis in-centre or in-satellite reported participating. A further 16.9% reported that they had been invited to participate in shared care tasks but had declined. However, 37.1% stated that they had not been invited and 16.8% did not know.

Shared care involvement was greatest amongst those aged 30 years and under, and 31-55 years (33.3% and 34.7% respectively) and least in the over 75s (25.1%), Table 1.4. Some variation was seen amongst ethnicity groups; notably 39.5% of Black respondents indicating their participation compared to just 27.5% of White individuals.

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

	N	Participating	Declined	Not Invited	Don't Know
Age (years)					
≤ 31	174	58 (33.3%)	23 (13.2%)	52 (29.9%)	41 (23.6%)
31-55	1,353	469 (34.7%)	217 (16.0%)	449 (33.2%)	218 (16.1%)
56-74	2,643	765 (28.9%)	479 (18.1%)	952 (36.0%)	447 (16.9%)
75+	1,613	405 (25.1%)	258 (16.0%)	680 (42.2%)	270 (16.7%)
Missing	203	51 (25.1%)	36 (17.7%)	86 (42.4%)	30 (14.8%)
Gender					
Male	3,609	1,033 (28.6%)	589 (16.3%)	1,387 (38.4%)	600 (16.6%)
Female	2,171	669 (30.8%)	385 (17.7%)	750 (34.5%)	367 (16.9%)
Non-binary/other	9	3 (33.3%)	1 (11.1%)	4 (44.4%)	1 (11.1%)
Not Say	41	13 (31.7%)	7 (17.1%)	10 (24.4%)	11 (26.8%)
Missing	156	30 (19.2%)	31 (19.9%)	68 (43.6%)	27 (17.3%)
Ethnicity					
Asian	625	198 (31.7%)	93 (14.9%)	201 (32.2%)	133 (21.3%)
Black	600	237 (39.5%)	77 (12.8%)	190 (31.7%)	96 (16.0%)
Mixed	82	24 (29.3%)	16 (19.5%)	28 (34.1%)	14 (17.1%)
White	4,466	1,227 (27.5%)	789 (17.7%)	1,737 (38.9%)	713 (16.0%)
Other	73	23 (31.5%)	11 (15.1%)	23 (31.5%)	16 (21.9%)
Not Say	83	29 (34.9%)	15 (18.1%)	21 (25.3%)	18 (21.7%)
Missing	57	10 (17.5%)	12 (21.1%)	19 (33.3%)	16 (28.1%)
Haemodialysis Location					
Hospital	2,865	711 (24.8%)	426 (14.9%)	1,188 (41.5%)	540 (18.8%)
Satellite	3,108	1,035 (33.3%)	585 (18.8%)	1,027 (33.0%)	461 (14.8%)
Unknown location	13	2 (15.4%)	2 (15.4%)	4 (30.8%)	5 (38.5%)
Total	**5,986**[11]	**1,748 (29.2%)**	**1,013 (16.9%)**	**2,219 (37.1%)**	**1,006 (16.8%)**

[11] Responses provided by 5986 in-centre, in-satellite or unknown location haemodialysis patients out of possible 6,271.

English as First Language

For the first time in 2022, participants were asked whether English was their primary spoken language. A total of 10,884 (98.4%) provided answers, of which 1,235 (12.8%) said they had a language other than English. Variation was seen across regions, with over a quarter in London and at least 10% in East of England, Midlands and Wales stating an alternative first language, Table 1.5. Notably, 48 of those in Wales declared Welsh as their first. Of those who did not provide a centre, nearly a fifth stated English not to be their first language.

Table 1.5: English as First Language for Kidney PREM Participants by Region

	Other First Language N (%)	English First Language N (%)
England		
East of England	92 (12.1%)	760 (89.2%)
London	542 (26.0%)	2,087 (79.4%)
Midlands	190 (15.9%)	1,192 (86.3%)
North East & N Cumbria	17 (2.6%)	666 (97.5%)
North West	7 (1.6%)	431 (98.4%)
South East	105 (9.6%)	1,089 (91.2%)
South West	26 (2.9%)	903 (97.2%)
Yorkshire & Humber	44 (8.0%)	551 (92.6%)
Northern Ireland	8 (2.6%)	302 (97.4%)
Scotland	6 (1.5%)	404 (98.5%)
Wales	64 (11.8%)	542 (89.4%)
Missing Centre	134 (18.6%)	722 (84.3%)
Total	**1,235 (12.8%)**	**9,649 (88.7%)**

Nearly 100 languages were listed, shown in Table 1.6 for those languages which were mentioned by at least 10 individuals. Appendix Table D1 displays a full list of languages spoken. Four participants entered two languages, both of which have been included. Additionally, 236 individuals, all of whom completed paper surveys, indicated that English was not their first language but did not provide what was. Three languages could not be identified from text entered, and in 15 cases only the country/continent could be identified (these have been included in ‘other African’, ‘other Asian’, ‘other European’ as appropriate).

Table 1.6: Primary languages spoken by those for whom English is not their first language

Language	Frequency	Language	Frequency
Akan	12	French	34
Igbo	14	Greek	15
Shona	10	Italian	27
Somali	34	Polish	22
Other African	63	Portuguese	24
Bengali	38	Romanian	21
Chinese/Mandarin/Cantonese	34	Spanish	32
Gujarati	93	Turkish	14
Hindi	39	Welsh	53
Nepali	20	Other European	55
Punjabi	86	Arabic	34
Tagalog/Filipino	24	British Sign Language	1
Tamil	16	Other	10
Urdu	108	*Unidentified*	3
Other Asian	67		

Participant Partial Postcodes

Another first for 2022 was that individuals completing Kidney PREM were asked to provide the first part of their postcode, with the aim of using these to determine a proxy measure of deprivation. This question was optional, with participants being asked to select a check box if they were unwilling to provide this information.

A total of 8,454 participants entered something in the postcode field, with a further 1,982 explicitly refusing to provide this information and the remaining respondents leaving the field blank. Of those who provided information, 237 entered something which could not be identified or analysed. A further 219 entered something in the postcode field, but selected the box stating that they did not give permission for this data to be used and were removed from analyses. This meant a total of 7,998 analysable values (72.3% of total Kidney PREM responses) were collected.

Some differences in willingness to provide this information were seen by region, with the East of England and the Midlands regions completing partial postcodes less often than other areas, Table 1.7.

Work to analyse these data is ongoing, alongside a review of the feasibility of using such a measure to assess participant deprivation.

Table 1.7: Number of partial postcodes provided by region

	Postcode Provided N (%)	Postcode Not Provided N (%)
England		
East of England	564 (65.7%)	294 (34.3%)
London	1,997 (74.9%)	670 (25.1%)
Midlands	929 (66.1%)	476 (33.9%)
North East & N Cumbria	567 (81.7%)	127 (18.3%)
North West	328 (73.2%)	120 (26.8%)
South East	964 (79.6%)	247 (20.4%)
South West	744 (79.6%)	191 (20.4%)
Yorkshire & Humber	467 (76.3%)	145 (23.7%)
Northern Ireland	232 (73.2%)	85 (26.8%)
Scotland	306 (73.6%)	110 (26.4%)
Wales	491 (80.2%)	121 (19.8%)
Missing Centre	646 (72.7%)	242 (27.3%)
Total	**8,235 (74.4%)**	**2,828 (25.6%)**

Use of Online Platforms

In previous years, participants were asked about their use of PatientView, but in 2022 the platform Patients Know Best was also included. Even with this, just a small increase was seen in those saying that they use an online platform (38.1%, up from 35.5% in 2021), not yet returning to the proportion reported in 2020 (41.6%) when Kidney PREM was held entirely online.

Where applicable, participants were also asked the reason for not utilising an online platform, with 35.8% of those responding doing so because they did not know what they were (Table 1.8). The use of PatientView or Patients Know Best varied according to treatment type. Individuals with a functioning transplant and those receiving haemodialysis at home were the biggest groups of users (69.9% and 68.7% respectively). Just 36.4% of participants receiving peritoneal dialysis reported using an online platform; somewhat surprising given the high proportion of home haemodialysis users.

Table 1.8: Kidney PREM participant use of PatientView/Patients Know Best, by treatment

	Yes, using PV/PKB	No, not using PV/PKB because:			Don't know	Total
		It's unavailable	Don't know what it is	Another reason		
Transplant	1,236 (69.9%)	38 (2.1%)	268 (15.2%)	178 (10.1%)	48 (2.7%)	1,780
Centre HD	928 (31.1%)	93 (3.1%)	1,220 (40.9%)	342 (11.5%)	400 (13.4%)	3,049
Satellite HD	899 (28.6%)	105 (3.3%)	1,121 (35.6%)	552 (17.5%)	471 (15.0%)	3,201
Home HD	134 (68.7%)	5 (2.6%)	34 (17.4%)	18 (9.2%)	4 (2.1%)	198
Peritoneal	257 (36.4%)	19 (2.7%)	292 (41.4%)	55 (7.8%)	83 (11.8%)	725
CKD (non-KRT)	590 (37.5%)	36 (2.3%)	694 (44.1%)	123 (7.8%)	132 (8.4%)	1,605
Total	**4,115 (38.1%)**	**309 (2.9%)**	**3,864 (35.8%)**	**1,294 (12.0%)**	**1,207 (11.2%)**	**10,789**

CKD: Chronic Kidney Disease
HD: Haemodialysis

2. Kidney PREM Completion Method: Online vs Paper

Prior to 2020, Kidney PREM was completed predominantly using paper surveys, albeit with an online version available. Completed surveys were collected at each centre and returned in bulk via courier to the UKKA for processing. The pandemic year required a shift to online-only for infection control purposes and to reduce the burden on staff in centres and satellite units. In subsequent years, there has been a focus on promoting the benefits of online completion, with paper surveys remaining available to ensure equity of access for all people with chronic kidney disease. In 2022, the UKKA sent a total of 15,210 to centres across the UK, with just 4,033 (26.5%) of these returned and included in analyses.

In 2021, nearly 80% of participants utilised the online option, but in 2022 this dropped to just 63.5%. Table 2.1 provides a summary of paper vs online submissions for each UK region, demonstrating considerable variation across the country. Notably, online was more popular in the south of England, receiving over 70% in each of East of England (75.6%), London (73.6%), South East (73.8%) and South West (71.8%). Respondents in Northern Ireland demonstrated the opposite pattern, with just 27.8% completing Kidney PREM online.

There was considerable variation in completion method by centre, shown in Appendix A Tables A1-A4 and illustrated in Appendix Figure A1.

Table 2.1: Regional summaries by completion

UK Total	Paper Survey 4,033 (36.5%)	Online Survey 7,030 (63.5%)
Region		
England		
East of England	209 (24.4%)	649 (75.6%)
London	703 (26.4%)	1,964 (73.6%)
Midlands	547 (38.9%)	858 (61.1%)
North East & N Cumbria	318 (45.8%)	376 (54.2%)
North West	168 (37.5%)	280 (62.5%)
South East	317 (26.2%)	894 (73.8%)
South West	264 (28.2%)	671 (71.8%)
Yorkshire & Humber	296 (48.4%)	316 (51.6%)
England Total	2,822 (32.0%)	6,008 (68.0%)
Northern Ireland		
N Ireland Total	229 (72.2%)	88 (27.8%)
England		
Scotland Total	131 (31.5%)	285 (68.5%)
Wales		
Wales Total	215 (35.1%)	397 (64.9%)
Missing[12]	636	252

[12] Online missing includes those who selected a country but not a centre.

Some differences were seen in participant characteristics according to completion method, Table 2.2. Perhaps as expected, fewer of those over 75 years completed Kidney PREM online than the younger age groups, but it should be noted that over half (54.6%) were able to do so. Three quarters of people using paper were 56 years and over (77.5%) compared to two thirds of online participants (67.6%). Nearly 10% of age data was missing for those using paper copies, whereas all online entries were complete. Kidney PREM online employs 'forced response' questions, where participants are unable to move to the next section before responding, thus minimising missing data.

Little variation was seen in completion method by those in minority ethnicity groups, suggesting that equity of access amongst these groups is not a major concern when considering the mode of participation. Appendix Table E1 shows the distribution of respondent characteristics (age, gender, and ethnicity) according to completion method, along with the distribution of the recorded UK KRT population to enable comparison.

Table 2.2: Participant characteristics by completion method

	Paper Survey	Online Survey
UK Total	**4,033 (36.5%)**	**7,030 (63.5%)**
Age (years)		
≤ 30	103 (28.4%)	260 (71.6%)
31-55	714 (26.1%)	2,017 (73.9%)
56-74	1,605 (32.8%)	3,290 (67.2%)
≥ 75	1,217 (45.4%)	1,463 (54.6%)
Missing	394	-
Gender		
Female	1,475 (34.1%)	2,853 (65.9%)
Male	2,218 (35.0%)	4,128 (65.0%)
Non-binary/other	7 (63.6%)	4 (36.4%)
Rather not say	14 (23.7%)	45 (76.3%)
Missing	319	-
Ethnicity		
Asian	367 (36.4%)	641 (63.6%)
Black	301 (33.3%)	602 (66.7%)
Mixed	64 (41.6%)	90 (58.4%)
White	3,130 (36.5%)	5,449 (63.5%)
Other	19 (13.6%)	121 (86.4%)
Rather not say[13]	-	127 (100.0%)
Missing	152	-

A vast difference in completion method was seen across treatment modalities, with a much higher proportion of transplant recipients accessing Kidney PREM online (83.5%) than other treatment modalities (haemodialysis 62.5%, peritoneal dialysis 58.3%, CKD 67.0%), Table 2.3. A higher proportion of individuals completed Kidney PREM online amongst all treatment groups, with the notable exception of those receiving conservative management, at just 29.7%.

[13] Option omitted from paper survey in error.

Those receiving haemodialysis and participating in shared care favoured online Kidney PREM (75.0%), considerably higher than those who were invited but declined (67.2%), not invited (58.7%) and didn't know (61.1%). There were proportionally more online users at satellite units than at centres (68.4% vs 56.1%), and yet more receiving haemodialysis at home (71.7%).

Respondents completing without help more often did so online (66.7%), compared to those who received help (61.9%).

Table 2.3: Treatment by completion method

UK Total	Paper Survey 4,033 (36.5%)	Online Survey[14] 7,030 (63.5%)
Treatment		
Transplant	293 (16.5%)	1,487 (83.5%)
Haemodialysis	2,425 (37.5%)	4,044 (62.5%)
At Home	56 (28.3%)	142 (71.7%)
In-Satellite	1,011 (31.6%)	2,190 (68.4%)
In-Centre	1,337 (43.9%)	1,712 (56.1%)
Missing HD Location	21	-
Peritoneal	302 (41.7%)	423 (58.3%)
CKD (non-KRT)	529 (33.0%)	1,076 (67.0%)
Attend for monitoring	265 (27.0%)	717 (73.0%)
Approaching ESKD:	208 (42.4%)	282 (57.6%)
KRT chosen	70 (28.1%)	179 (71.9%)
CM chosen	102 (70.3%)	43 (29.7%)
Undecided	36 (37.5%)	60 (62.5%)
Don't know	22 (22.2%)	77 (77.8%)
Missing CKD type	34	-
Missing Treatment	484	-
Shared Care		
Yes, Participating	436 (25.0%)	1,310 (75.0%)
No, Declined	332 (32.8%)	679 (67.2%)
No, Not Invited	915 (41.3%)	1,300 (58.7%)
Don't Know	389 (38.9%)	612 (61.1%)
Missing Shared Care	276	1
Help to Complete		
Alone	2,589 (33.3%)	5,179 (66.7%)
With Help	1,137 (38.1%)	1,849 (61.9%)
Missing Help	307	2

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

[14] Online values missing (Shared Care and Help to Complete) due to answering translated questionnaire.

3. Changes in Patient Experience

In 2020, Kidney PREM respondents were asked to rate the impact that the COVID-19 pandemic had on their experience of care, with the question repeated in 2021. Although the impact of the pandemic on healthcare has lessened over time, retaining this additional question was considered valuable in order to capture how participants felt that their care had changed over the previous year. The question was reframed as follows to capture all aspects of change, not just those enforced as a result of the pandemic:

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

Responses were recorded using a 7-point Likert scale from -3 (much worse) through 0 (no change) to +3 (much better). In addition, participants could indicate that they were not receiving care a year ago.

In 2022

Across treatment modalities in general, participants indicated that their care was at least the same (54.8%) or better (23.5%, scores of +1 to +3) during the previous year (Table 3.1). A higher proportion of haemodialysis recipients rated their care as worse (23.9%, scores of -1 to -3) than participants of other treatment modalities, with many of these poor scores being in the '-3, much worse' category (Figure 3.1). This is in notable contrast to both 2021 and 2020, when haemodialysis recipients had a considerably smaller proportion of 'worse' scores than for participants in other groups.

Compared to previous years

Participants of all treatment groups improved their proportion of 'better' scores in 2021, reversing that trend in 2022. However, those not receiving KRT were a notable exception as the only group showing an increased proportion of those stating that care had improved in 2022 than in 2021. It should be noted, however, that those not receiving KRT remained one of the groups providing the smallest proportion of 'better' ratings, second only to respondents with a kidney transplant. In 2020, individuals with CKD (not receiving KRT) submitted the highest proportion of 'worse' scores than any KRT groups. This proportion has decreased each year since, coinciding with a corresponding increase in 'better scores', potentially as kidney services have been able to return to pre-pandemic levels.

A smaller proportion of participants receiving haemodialysis in centres or at satellite units rated their experience as 'worse' in 2020, with the largest proportion of 'better' scores across all treatment groups. There was an increase in 'better' ratings in 2021, with 'worse' scores remaining stable from 2020 to 2021 amongst in-centre/in-satellite haemodialysis recipients. However, this trend reversed in 2022; the proportion of 'worse' scores increasing amongst those receiving in-centre (from 9.6% in 2021 to 20.1% in 2022) and in-satellite haemodialysis (from 7.9% in 2021 to 27.1% in 2022), higher than for those not receiving KRT (16.8%) for the first time. Again, this could potentially be attributed to a return of pre-pandemic service provision.

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

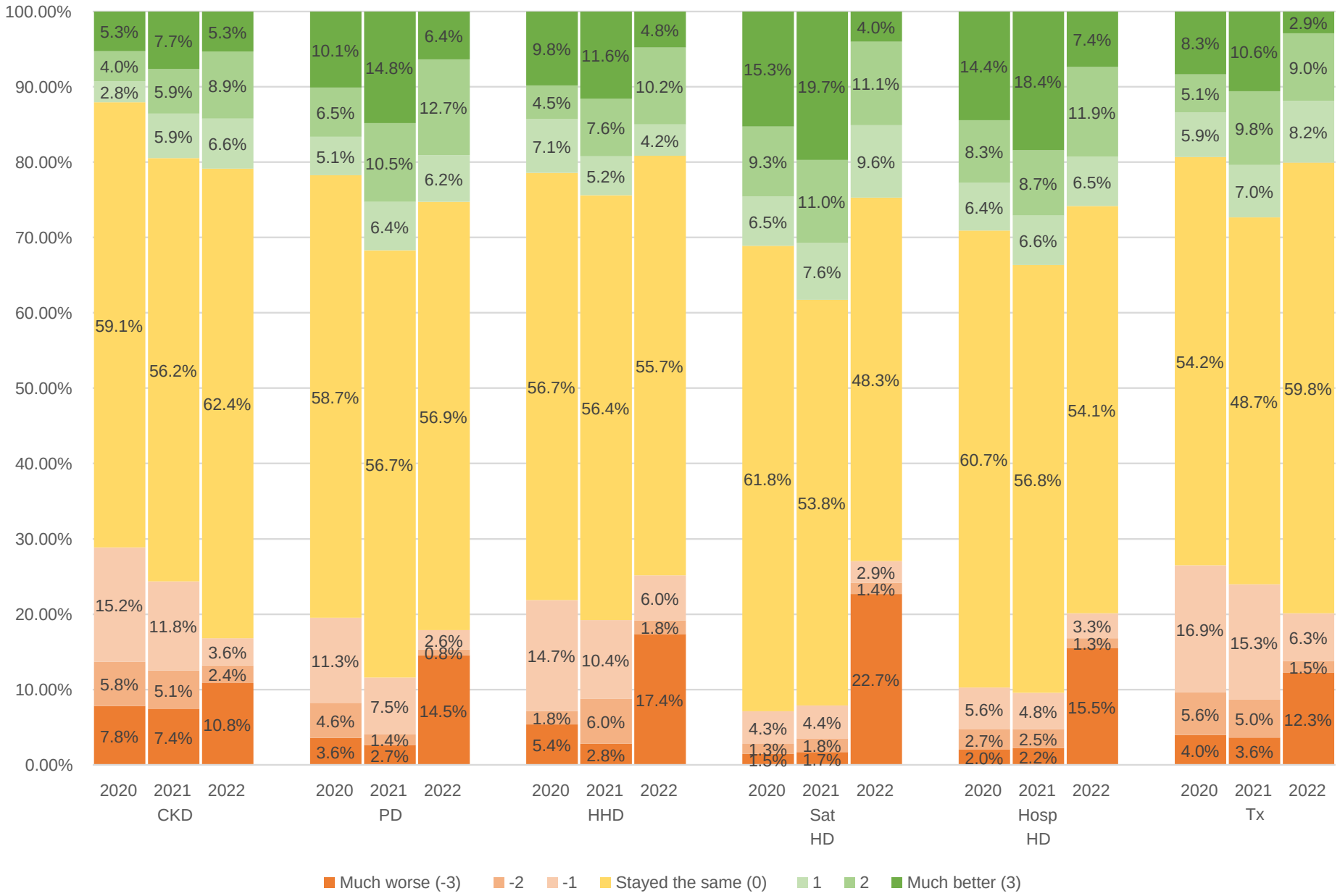


Table 3.1: Change in patient experience over the past year by treatment type: 2022, 2021, 2020

		N	Worse	Same	Better	Not receiving care a year ago[15]
CKD (non KRT)	**2022**	1,190	200 (16.8%)	742 (62.4%)	248 (20.8%)	108
	2021	1,594	388 (24.3%)	896 (56.2%)	310 (19.4%)	-
	2020	1,711	494 (28.9%)	1,011 (59.1%)	206 (12.0%)	-
Peritoneal Dialysis	**2022**	503	90 (17.9%)	286 (56.9%)	127 (25.2%)	66
	2021	716	83 (11.6%)	406 (56.7%)	227 (31.7%)	-
	2020	584	114 (19.5%)	343 (58.7%)	127 (21.7%)	-
Haemodialysis	**2022**	4,801	1,146 (23.9%)	2,452 (51.1%)	1,203 (25.1%)	501
	2021	7,209	647 (9.0%)	3,976 (55.2%)	2,586 (35.9%)	-
	2020	4,765	430 (9.0%)	2,912 (61.1%)	1,423 (29.9%)	-
Transplant	**2022**	1,551	312 (20.1%)	928 (59.8%)	311 (20.1%)	24
	2021	2,043	490 (24.0%)	995 (48.7%)	558 (27.3%)	-
	2020	2,038	540 (26.5%)	1,104 (54.2%)	394 (19.3%)	-
Total	**2022**	8,045	1,748 (21.7%)	4,408 (54.8%)	1,889 (23.5%)	699
	2021	11,562	1,608 (13.9%)	6,273 (54.3%)	3,681 (31.8%)	-
	2020	9,098	1,578 (17.3%)	5,370 (59.0%)	2,150 (23.6%)	-

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

[15] 2022 was the first year that participants were asked to indicate if they were not receiving care a year ago.

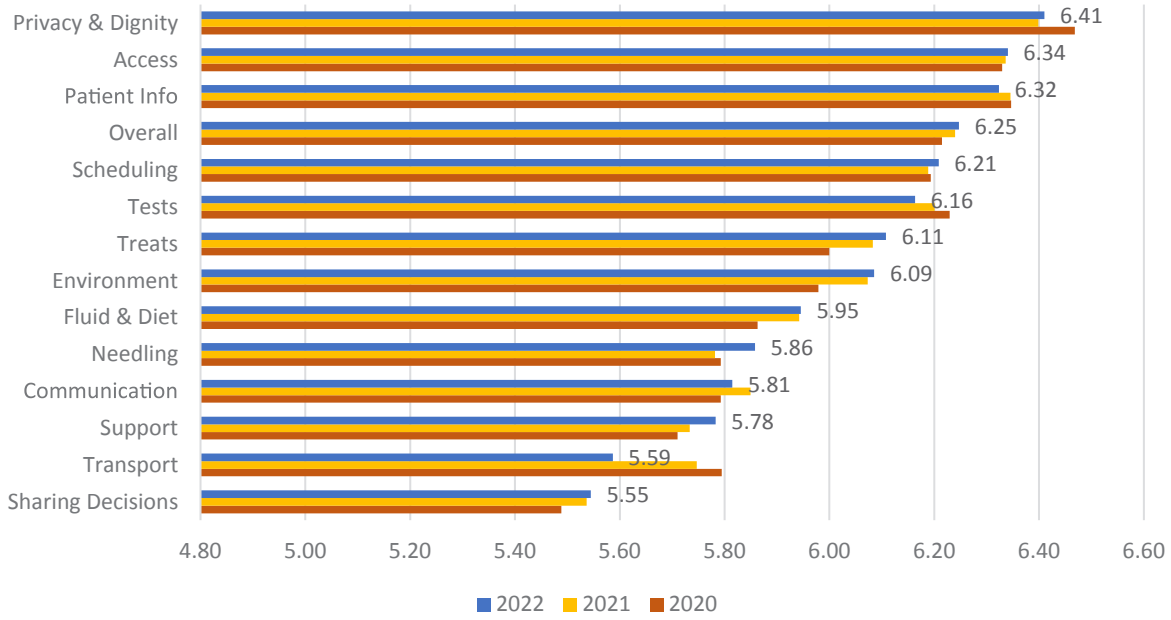
4. Kidney PREM Theme Results

Kidney PREM Themes

The mean of the centre scores were calculated for each theme of Kidney PREM, Figure 4.1. Values for 2022, 2021 and 2020 are shown in Appendix Table F1, along with the range of centre scores within each theme.

High Scoring Themes
Privacy & Dignity (6.41), Access (6.34) and Patient Information (6.32) remain the highest scoring themes, as in 2021 and 2020, with little variation seen year on year. Encouragingly, the *Overall* question remains strong (6.25).
Low Scoring Themes
Sharing Decisions (5.55) and *Transport* (5.59) continue to be scored poorly. The gains made in the *Transport* theme in 2020 have since dwindled, reducing by 0.2 over the two years. *Support* (5.78) and *Communication* (5.81) are just above the lowest two themes, although *Support* has seen a very small improvement each year.

Figure 4.1: Mean centre scores for Kidney PREM themes, 2022, 2021 and 2020



In 2022, there are fewer themes with narrow centre score ranges than in previous years; just *Privacy & Dignity* with centre score range ≤1.4 (5.7 to 6.9 out of 7), although this is the highest scoring theme, Appendix Table F1. Conversely, five themes have centre scores with a range of ≥2.0 (*Support, Communication, Fluid & Diet, Sharing Decisions* and *Transport*).

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)?'

Overall experience is rated highly at 6.25 (centre range 5.06 to 6.84). Figure 4.2 shows the percentage distribution of respondent scores for each kidney centre, overlaid with that centre's mean score and 95% confidence interval.

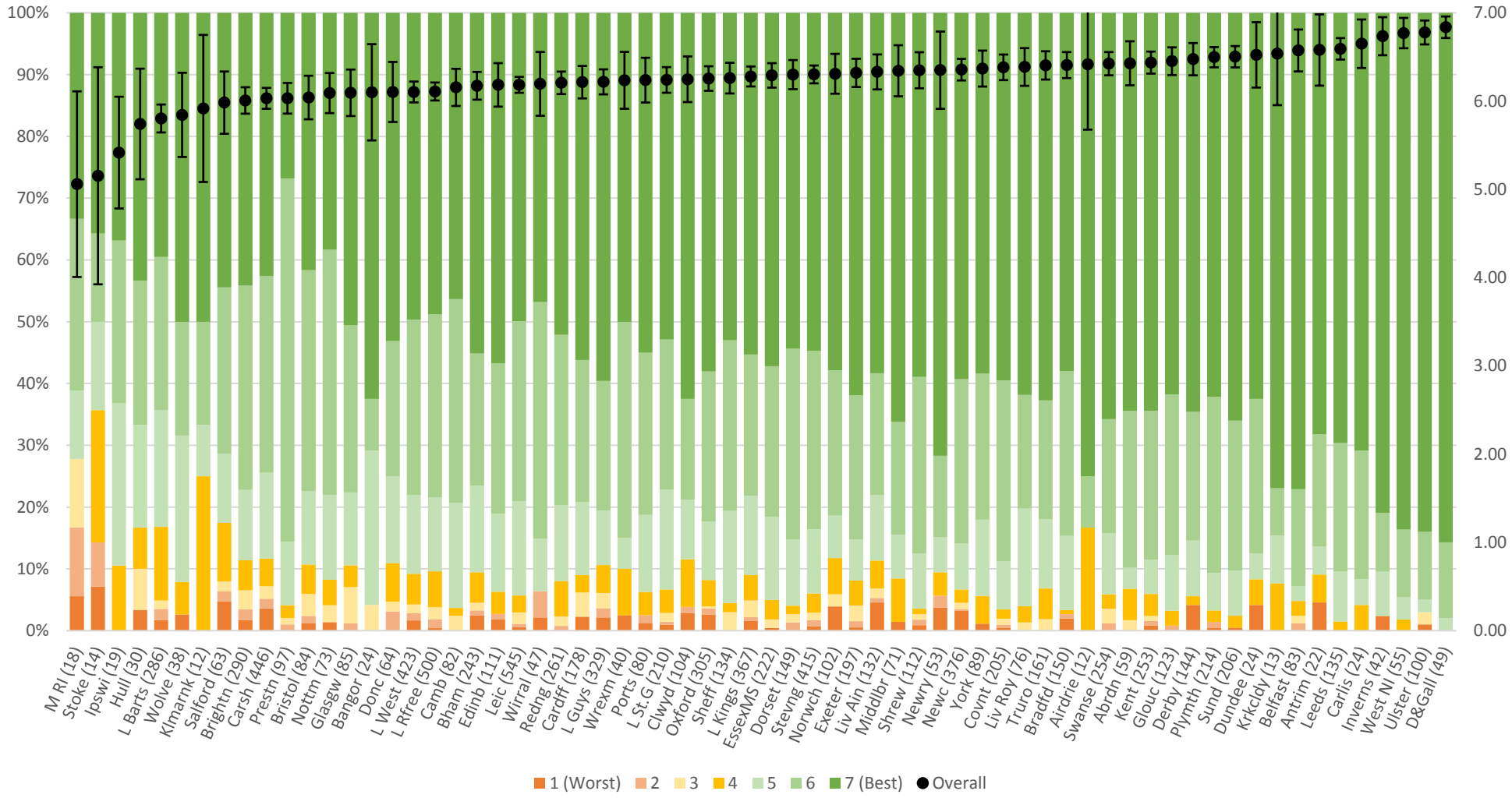
The number in brackets next to each centre name is the amount of people providing a response to the *Overall* experience question from that centre, with values ranging from 12 to 545. It is important to keep these numbers in mind when interpreting the figure accurately. For example:

- A centre with 20 responses means that one individual scoring '1' for *Overall* experience, would be illustrated with 5% of the bar dark red.
- A centre with 500 responses means that one individual scoring '1' means that just 0.2% of the bar would be dark red and so would not be visible.

Most Kidney PREM participants score their *Overall* experience highly, with 92.3% giving scores of at least 5 out of 7. There is some variation across centres, with just one centre receiving entirely positive scores. Many centres have a small but significant proportion of individuals scoring overall experience poorly (1 to 3).

Centre-level mean scores are available on the UKKA website, alongside satellite-level scores and a breakdown by age and treatment modality (https://ukkidney.org/kidney-patient-reported-experience-measure).

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



Overall (mean) centre scores and 95% confidence intervals displayed in black.

5. Kidney PREM Theme Results by Treatment and by Question

Theme Mean Scores by Treatment

Theme scores were calculated for participants of each treatment modality, Table 5.1. Whilst 198 individuals receiving haemodialysis at home participated in Kidney PREM, just 35 of these answered enough questions to enable analysis. Although year on year differences were small across most treatment groups, they are predominantly positive amongst those not receiving KRT and individuals with a functioning kidney transplant. They are mainly negative for participants receiving haemodialysis in centres or at satellite units and with home therapies (peritoneal dialysis and home haemodialysis) displaying more mixed changes across themes. Although differences are small at a theme level, these patterns support those seen when asking participants about change in their experience over the past year, highlighted in Table 3.1 and Figure 3.1.

Table 5.1: Comparison of mean Kidney PREM scores by treatment group for 2022 and 2021

	CKD (non-KRT)					Peritoneal Dialysis					Home Haemodialysis				
	2022 (n=1343)		2021 (n=1535)		2022 vs	2022 (n=574)		2021 (n=636)		2022 vs	2022 (n=35)		2021 (n=230)		2022 vs
	Mean	95% CI	Mean	95% CI	2021	Mean	95% CI	Mean	95% CI	2021	Mean	95% CI	Mean	95% CI	2021
Access	6.30	6.24 - 6.37	6.11	6.03 - 6.18	0.19	6.45	6.36 - 6.53	6.47	6.40 - 6.55	-0.02	6.56	6.35 - 6.77	6.52	6.40 - 6.64	0.04
Support	5.70	5.60 - 5.79	5.40	5.30 - 5.49	0.30	5.96	5.84 - 6.07	5.88	5.77 - 6.00	0.08	5.97	5.54 - 6.40	5.80	5.60 - 6.00	0.17
Communication	5.82	5.74 - 5.90	5.54	5.46 - 5.62	0.28	5.96	5.86 - 6.07	5.97	5.87 - 6.07	-0.01	5.72	5.33 - 6.11	5.73	5.55 - 5.90	-0.01
Patient Info	6.38	6.32 - 6.45	6.20	6.13 - 6.27	0.18	6.47	6.38 - 6.57	6.46	6.38 - 6.55	0.01	6.51	6.23 - 6.80	6.48	6.35 - 6.61	0.03
Fluid & Diet	5.28	5.17 - 5.39	4.97	4.86 - 5.08	0.31	6.05	5.93 - 6.16	6.08	5.97 - 6.18	-0.03	6.16	5.77 - 6.54	6.27	6.10 - 6.43	-0.11
Needling	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Tests	6.17	6.10 - 6.23	6.07	6.01 - 6.13	0.10	6.17	6.07 - 6.26	6.21	6.13 - 6.30	-0.04	6.40	6.14 - 6.66	6.42	6.31 - 6.53	-0.02
Sharing Decisions	5.73	5.64 - 5.82	5.45	5.35 - 5.54	0.28	5.91	5.79 - 6.03	5.90	5.79 - 6.02	0.01	6.15	5.74 - 6.56	6.07	5.88 - 6.25	0.08
Privacy & Dignity	6.75	6.71 - 6.79	6.71	6.66 - 6.75	0.04	6.59	6.51 - 6.67	6.60	6.53 - 6.68	-0.01	6.76	6.59 - 6.93	6.63	6.53 - 6.73	0.13
Scheduling	6.27	6.21 - 6.33	6.11	6.05 - 6.17	0.16	6.37	6.29 - 6.46	6.37	6.30 - 6.45	0.00	6.50	6.26 - 6.74	6.31	6.18 - 6.45	0.19
Treats	6.08	6.01 - 6.15	5.84	5.77 - 5.91	0.24	6.24	6.14 - 6.33	6.24	6.15 - 6.33	0.00	6.36	6.07 - 6.65	6.13	5.98 - 6.28	0.23
Transport	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Environment	5.89	5.83 - 5.95	5.78	5.72 - 5.84	0.11	6.02	5.93 - 6.11	6.03	5.96 - 6.11	-0.01	6.16	5.84 - 6.48	5.81	5.66 - 5.96	0.35
Overall	6.19	6.12 - 6.25	5.99	5.93 - 6.06	0.20	6.36	6.27 - 6.45	6.38	6.30 - 6.46	-0.02	6.06	5.61 - 6.51	6.24	6.11 - 6.38	-0.18
Scale scores	6.01	5.96 - 6.07	5.81	5.75 - 5.87	0.20	6.16	6.08 - 6.23	6.17	6.10 - 6.24	-0.01	6.25	6.02 - 6.48	6.13	6.02 - 6.25	0.12

Individuals receiving peritoneal dialysis and haemodialysis in-centre demonstrated changes of less than 0.1 (positive or negative) across all themes. Those in satellite haemodialysis and transplant groups each reported changes of <0.1 in all but one theme (satellite haemodialysis: *Transport* -0.17, transplant: *Sharing Decisions* +0.11). Participants not receiving KRT reported higher experience of care across all themes in 2022 compared to 2021, with increases ranging from 0.04 *(Privacy & Dignity)* to 0.31 *(Fluid & Diet)*, although they were still the lowest scoring treatment group across the *Fluid & Diet* theme. Home haemodialysis recipients displayed a mixed pattern in 2022 compared to 2021, increasing scores across some themes (notably, *Environment* +0.35, *How the Team Treats You* +0.23, *Scheduling & Planning* +0.19), but decreasing in others (*Fluid & Diet* -0.11, Overall -0.18).

In 2021, those not receiving KRT reported lower scores in *Access, Support, Fluid & Diet, Sharing Decisions, Overall* and *Scale* scores compared to other modalities, with 95% confidence intervals lying completely below the other treatment groups. Alongside these individuals, those with a functioning transplant also had low *Fluid & Diet* scores in 2021, but this continues to be the case only for CKD (non-KRT) respondents in 2022. *Sharing Decisions* and *Privacy & Dignity* themes were lower for those receiving in-satellite and in-centre haemodialysis last year, remaining the case in 2022.

Table 5.1 (cont.): Comparison of mean Kidney PREM scores by treatment group for 2022 and 2021

	Satellite Haemodialysis					Centre Haemodialysis					Transplant				
	2022 (n=3067)		2021 (n=3913)		2022 vs 2021	2022 (n=2872)		2021 (n=2893)		2022 vs 2021	2022 (n=1606)		2021 (n=1987)		2022 vs 2021
	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 - 6.29	6.29	6.25 - 6.34	**-0.04**	6.46	6.41 - 6.51	6.42	6.37 - 6.46	**0.04**
Support	5.78	5.73 - 5.83	5.73	5.68 - 5.78	**0.05**	5.67	5.61 - 5.73	5.64	5.58 - 5.70	**0.03**	5.90	5.83 - 5.97	5.85	5.78 - 5.91	**0.05**
Communication	5.87	5.82 - 5.91	5.92	5.88 - 5.96	**-0.05**	5.80	5.75 - 5.86	5.88	5.83 - 5.92	**-0.08**	5.84	5.77 - 5.90	5.76	5.70 - 5.81	**0.08**
Patient Info	6.31	6.27 - 6.35	6.30	6.26 - 6.34	**0.01**	6.18	6.13 - 6.23	6.24	6.19 - 6.29	**-0.06**	6.56	6.51 - 6.60	6.55	6.51 - 6.59	**0.01**
Fluid & Diet	6.08	6.03 - 6.13	6.15	6.11 - 6.20	**-0.07**	6.02	5.96 - 6.07	6.08	6.03 - 6.14	**-0.06**	5.91	5.83 - 6.00	5.82	5.74 - 5.90	**0.09**
Needling	5.86	5.80 - 5.92	5.80	5.74 - 5.86	**0.06**	5.76	5.70 - 5.83	5.72	5.65 - 5.79	**0.04**	-	-	-	-	-
Tests	6.11	6.07 - 6.15	6.12	6.09 - 6.16	**-0.01**	5.96	5.91 - 6.01	5.98	5.93 - 6.03	**-0.02**	6.45	6.40 - 6.49	6.42	6.38 - 6.46	**0.03**
Sharing Decisions	5.44	5.37 - 5.50	5.48	5.42 - 5.53	**-0.04**	5.25	5.18 - 5.32	5.29	5.22 - 5.36	**-0.04**	5.95	5.88 - 6.02	5.84	5.78 - 5.91	**0.11**
Privacy & Dignity	6.25	6.21 - 6.30	6.26	6.22 - 6.30	**-0.01**	6.17	6.12 - 6.22	6.22	6.17 - 6.27	**-0.05**	6.78	6.75 - 6.82	6.78	6.75 - 6.81	**0.00**
Scheduling	6.16	6.12 - 6.21	6.20	6.17 - 6.24	**-0.04**	6.11	6.06 - 6.16	6.12	6.07 - 6.17	**-0.01**	6.26	6.21 - 6.32	6.26	6.22 - 6.31	**0.00**
Treats	6.15	6.11 - 6.19	6.16	6.12 - 6.20	**-0.01**	6.08	6.04 - 6.13	6.09	6.04 - 6.13	**-0.01**	6.15	6.09 - 6.20	6.06	6.01 - 6.12	**0.09**
Transport	5.41	5.34 - 5.47	5.58	5.52 - 5.64	**-0.17**	5.51	5.45 - 5.58	5.58	5.51 - 5.64	**-0.07**	-	-	-	-	-
Environment	6.28	6.25 - 6.32	6.26	6.23 - 6.29	**0.02**	6.11	6.07 - 6.15	6.11	6.07 - 6.14	**0.00**	5.81	5.75 - 5.86	5.75	5.70 - 5.79	**0.06**
Overall	6.26	6.22 - 6.30	6.27	6.24 - 6.30	**-0.01**	6.21	6.16 - 6.25	6.27	6.23 - 6.31	**-0.06**	6.31	6.26 - 6.36	6.27	6.22 - 6.31	**0.04**
Scale scores	6.01	5.98 - 6.05	6.04	6.01 - 6.07	**-0.03**	5.91	5.88 - 5.95	5.94	5.91 - 5.98	**-0.03**	6.14	6.10 - 6.18	6.09	6.05 - 6.13	**0.05**

Theme Breakdown by Question

Detailed information is presented here for each of the Kidney PREM themes, at a national level.

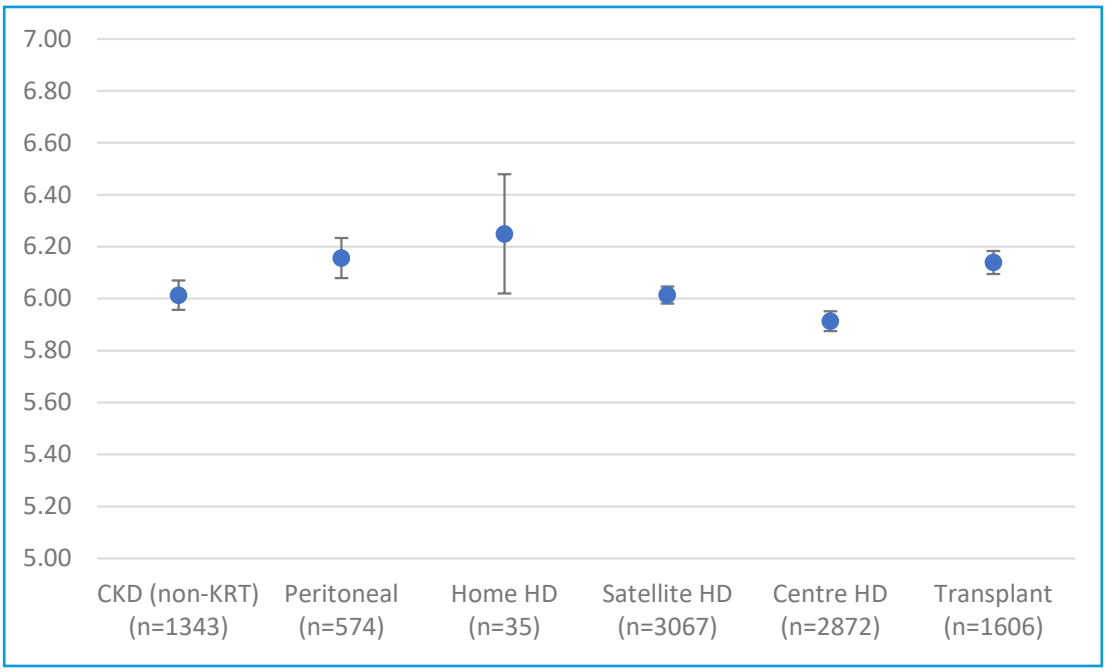
The first figure in each section shows the mean score and 95% confidence interval (CI) for that theme by treatment modality. The number of participants used to calculate the scores for each treatment group is shown in brackets after the treatment name. A second figure is presented for each Kidney PREM theme, showing the proportion of 1.0 - 7.0 scores awarded to each of the questions within those themes. The number of participants is shown in brackets after the question label. Bars total 100%, so the distribution of scores is clear, reflected in the width of segments from dark red (1.0; negative), through orange (4.0; neutral) to dark green (7.0; positive). The number of participants responding with a 1.0 – 7.0 out of 7.0 varies, as some questions are only applicable to certain participants (e.g., Transport and Needling). Some participants have a valid response of ‘don’t know’ or ‘not applicable’, and some completing Kidney PREM on paper choose not to respond to all the questions.

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

Scale Score

Mean centre score 6.02, range 4.98 to 6.71

Figure 5.0: Scale score; means and 95% confidence intervals by treatment modality



The scale score is calculated across questions 1 to 38 of the Kidney PREM. There is little variation in scores by treatment modality, with a range of just 0.34 (5.91 to 6.25). However, scores for those with a kidney transplant were higher (6.14, 95% CI 6.10 to 6.18) than for individuals receiving haemodialysis in a main centre (5.91, 95% CI 5.88 to 5.95) or at a satellite unit (6.01, 95% CI 5.98 to 6.05). Although these differences are statistically significant, they are small in absolute terms, which should be acknowledged when interpreting the practical relevance of such variation.

It should be noted that although 198 individuals receiving haemodialysis at home participated in the 2022 Kidney PREM, only 35 people answered a sufficient number of questions to contribute to the scale scores. This low number is reflected in the size of the 95% confidence interval, for this score and for the following individual themes, reflecting the increased uncertainty in scores compared to those for the other treatment groups.

Theme 1: Access to the Renal Team

Mean centre score 6.34, range 5.20 to 6.98

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

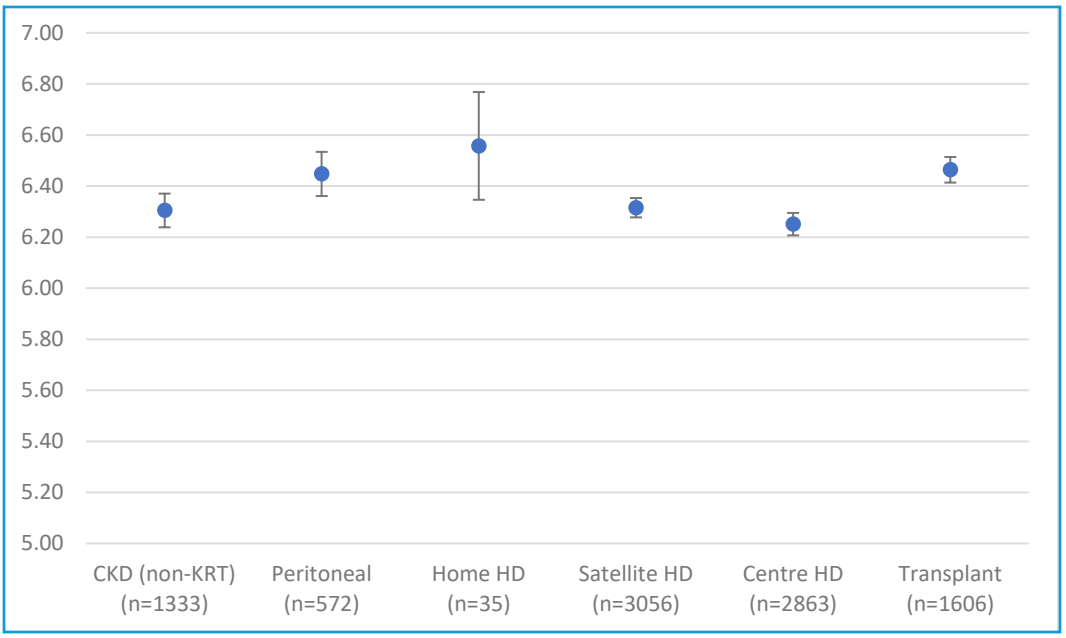
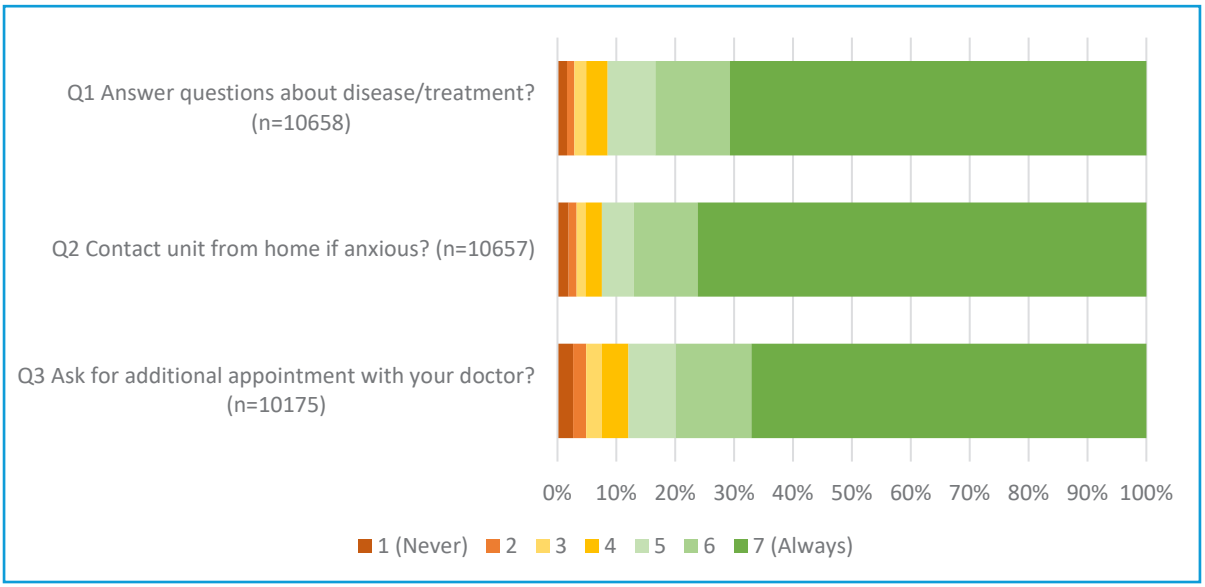


Figure 5.1B: Response frequencies for Access to the Renal Team theme questions



Access to the Renal Team was one of the top scoring themes, with over 85% of participants providing positive (5/6/7) responses for all three questions. Question 3 (asking for an additional appointment if wanted) was slightly less positively rated out of the three.

As with the scale score, little variation was seen across treatment groups, with a narrow range of values (0.31, 6.25 to 6.56). Additionally, all modalities awarded scores of at least 6.20 out of 7.0.

Theme 2: Support

Mean centre score 5.78, range 4.60 to 6.56

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

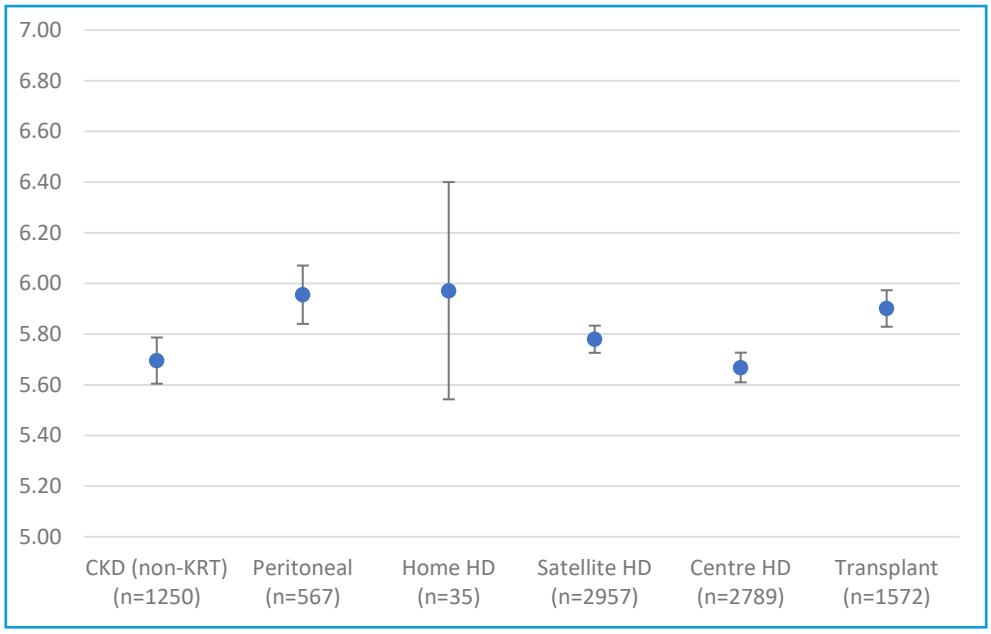
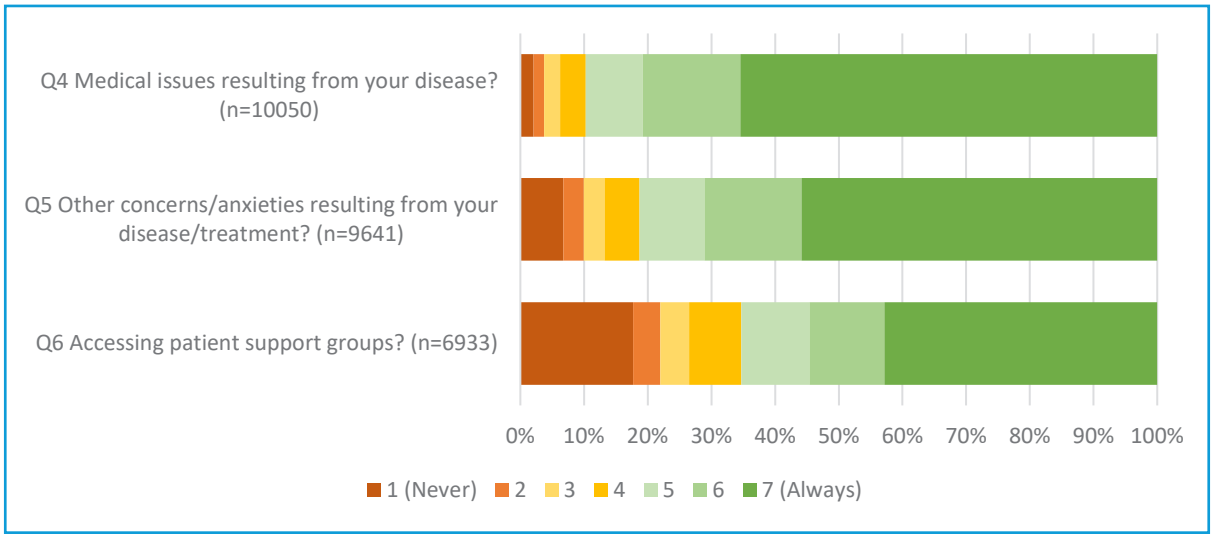


Figure 5.2B: Response frequencies for Support theme questions



Support was one of the lower scoring themes of Kidney PREM, with some differences in response profile across each question. Support with medical issues (Q4) was highly rated, 90% scoring at least 5 out of 7, but a slightly lower proportion (81%) of participants did so for support with other concerns or anxieties arising from treatment (Q5). Just 65% of respondents rated support with accessing patient support groups positively, with a large group (18%) providing a score of 1 (never) in this respect.

Little variation was seen between treatment modalities, with scores ranging between 5.67 (centre haemodialysis) to 5.97 (home haemodialysis).

Theme 3: Communication

Mean centre score 5.81, range 3.83 to 6.69

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

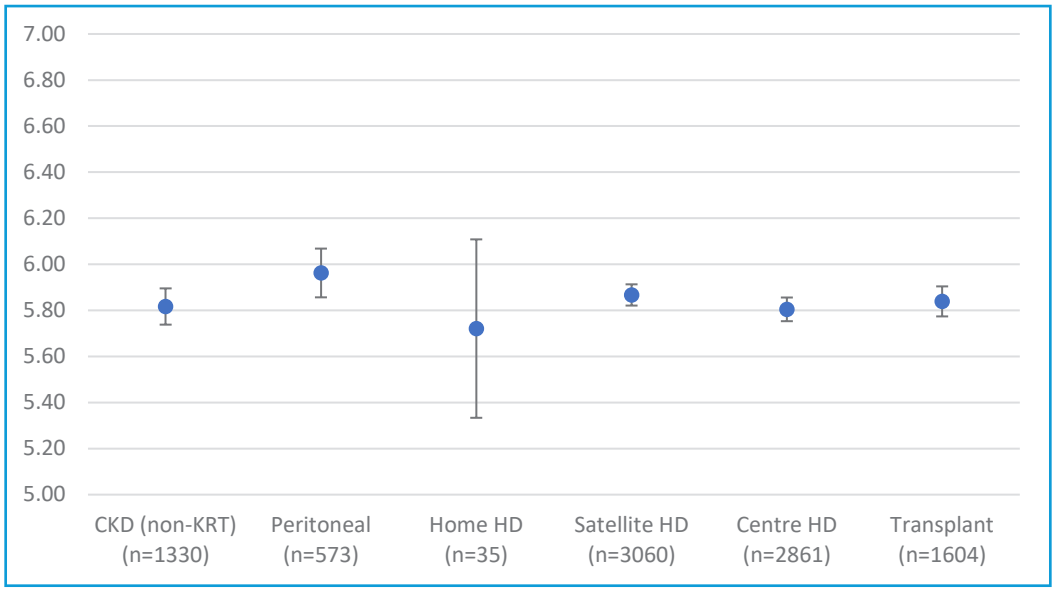
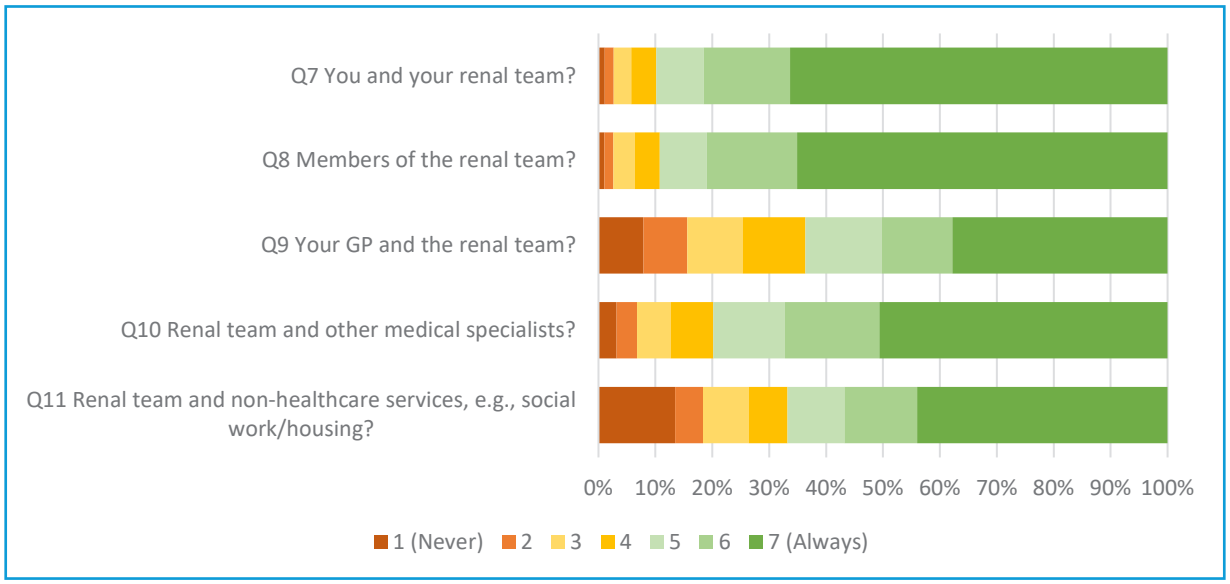


Figure 5.3B: Response frequencies for Communication theme questions



Communication theme had a similar mean score as *Support*, displaying the widest range of scores across centre out of all Kidney PREM themes. Participants generally awarded high scores for communication between individuals and the renal team (Q7, 90%), between members of the renal team (Q8, 89%) and between the renal team and other medical specialists (Q10, 80%). However, fewer scores of 5 to 7 were awarded regarding communication between GPs and the renal team (Q9, 64%) and between the renal team and other non-healthcare services, such as social work or housing (Q11, 67%). Similarly to *Support*, little variation was seen between treatment modalities.

Theme 4: Patient Information

Mean centre score 6.32, range 5.15 to 6.85

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

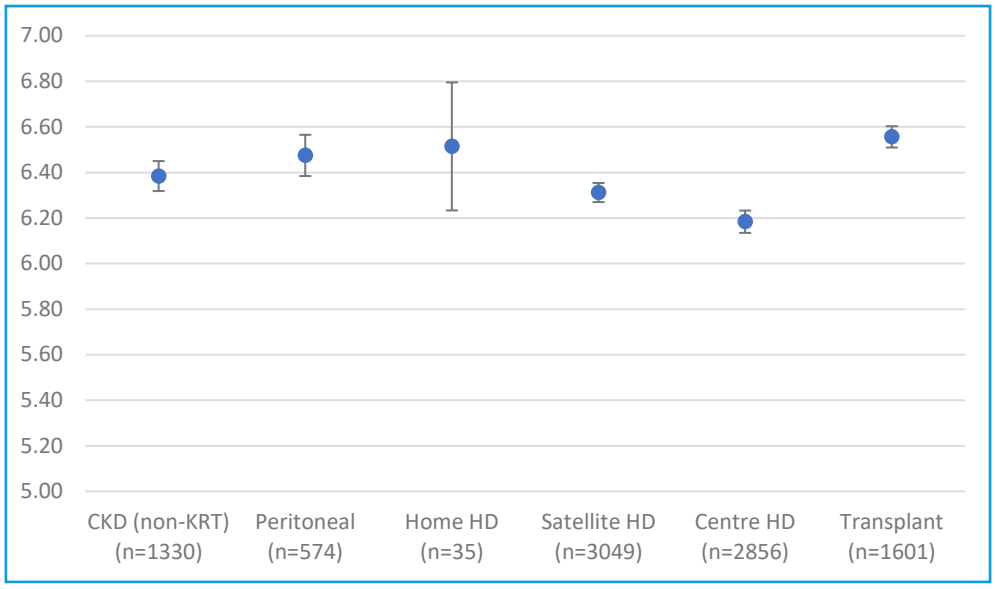
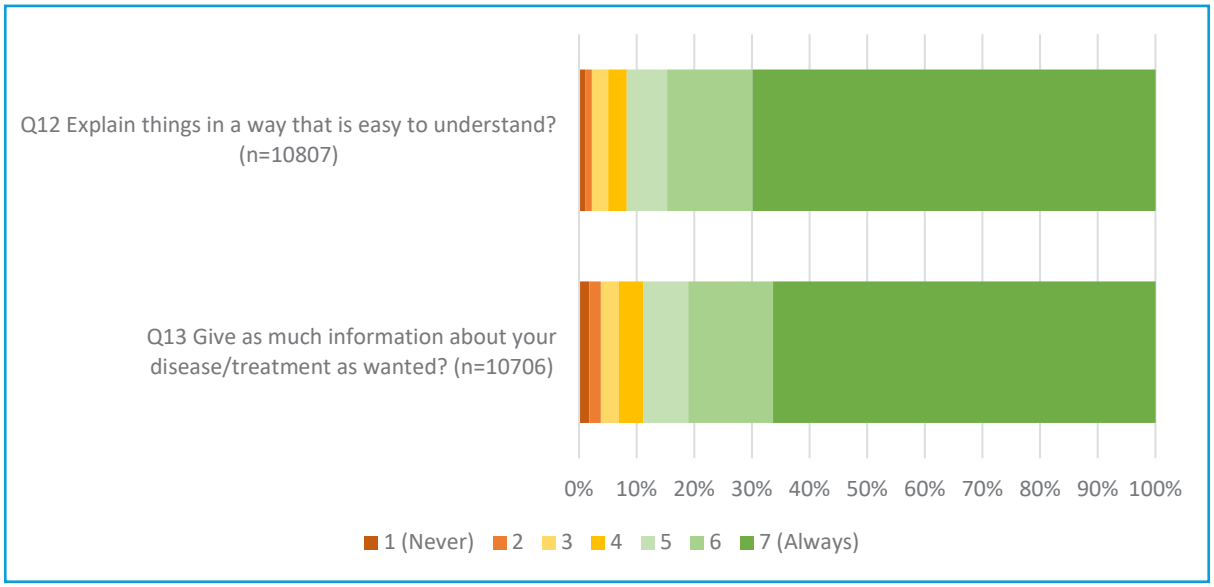


Figure 5.4B: Response frequencies for Patient Information theme questions



Patient Information remains a high scoring theme of Kidney PREM, reflected by the high proportion of individuals providing both theme questions with scores of at least 5 out of 7. Participants are largely positive about how things are explained to them (Q12, 92%) and that they are given as much information about their disease or treatment as they want (Q13, 89%).

Those with a kidney transplant scored *Patient Information* more highly (6.56) than those receiving haemodialysis at a centre (6.18) or satellite unit (6.31).

Theme 5: Fluid Intake and Diet

Mean centre score 5.95, range 4.56 to 6.53

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

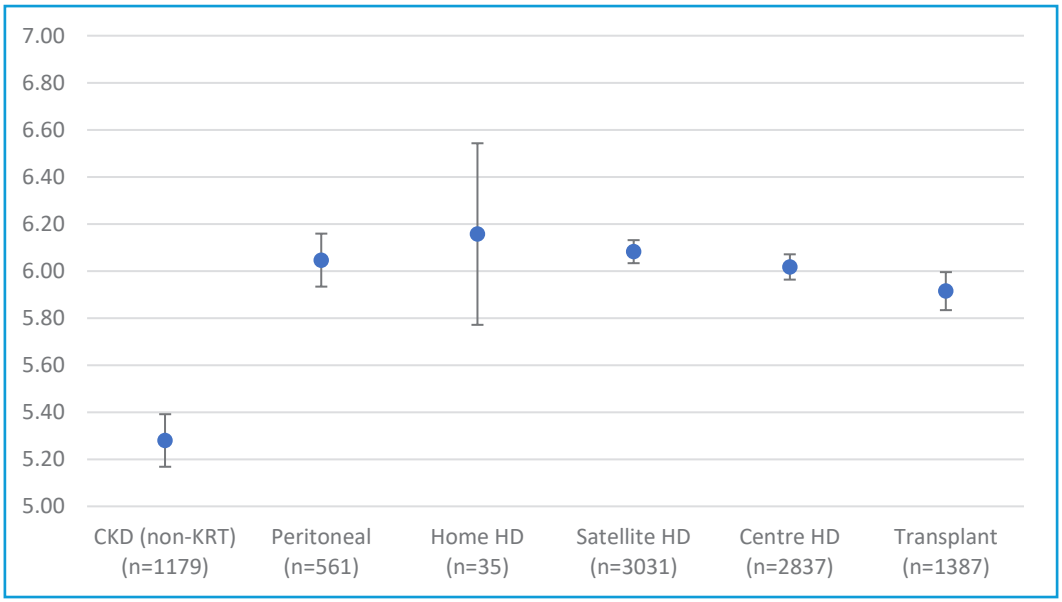
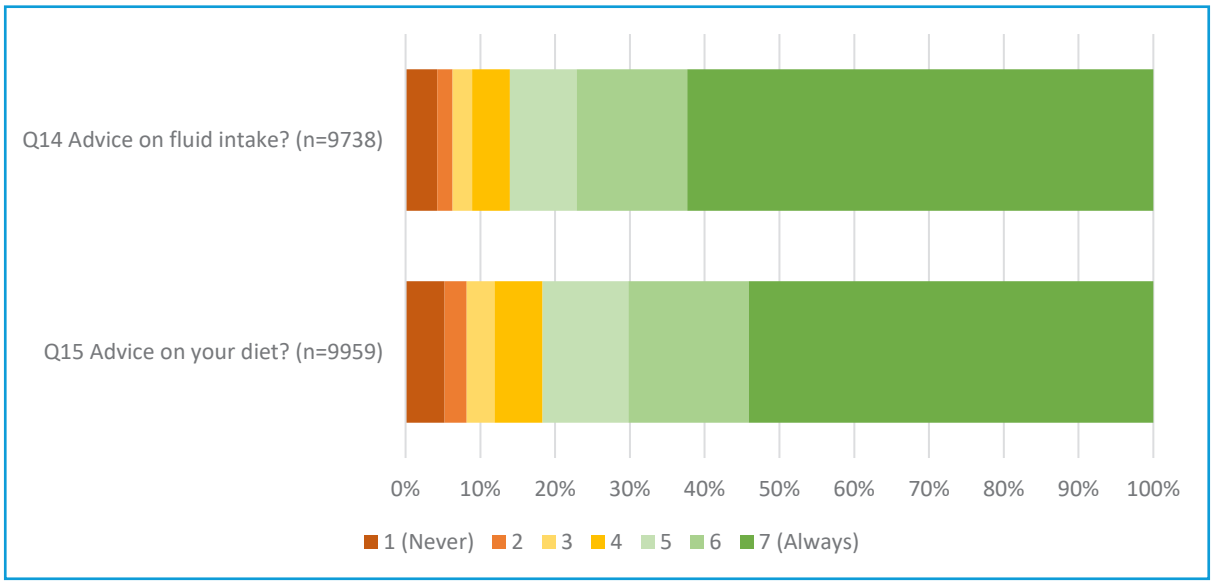


Figure 5.5B: Response frequencies for Fluid Intake and Diet theme questions



Fluid Intake and Diet was another theme demonstrating a wide range of scores across centres, with values ranging from 4.67 to 6.53. Advice on fluid intake (Q14) was rated slightly more positively, with 86% giving scores of 5 to 7, than advice on diet, which achieved 82%. Scores for individuals with CKD not receiving KRT was noticeably lower (5.28) than for those receiving KRT (ranging from 5.91 to 6.16), suggesting that a focus on providing advice for this patient group is warranted.

Theme 6: Needling

Mean centre score 5.86, range 4.96 to 6.78

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

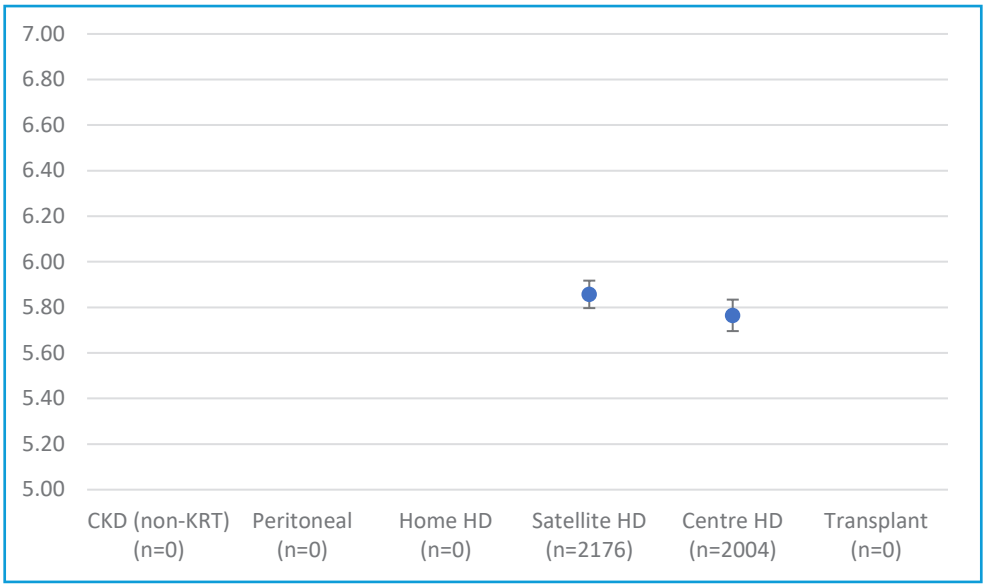
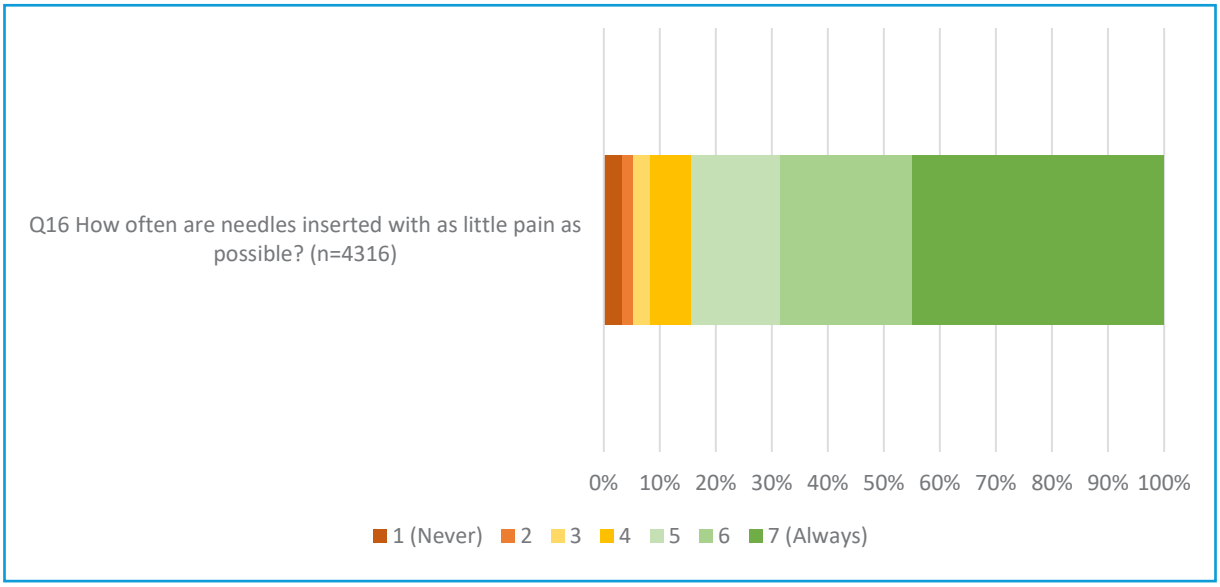


Figure 5.6B: Response frequencies for Needling theme questions



The *Needling* question applied only to those individuals who receive haemodialysis at a centre or satellite unit. Generally, participants answered positively, with 84% agreeing that needles are inserted with as little pain as possible. Scores were similar for each haemodialysis location type, 5.76 for those receiving treatment in-centre and 5.86 for those in-satellite.

Theme 7: Tests

Mean centre score 6.16, range 5.27 to 6.78

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

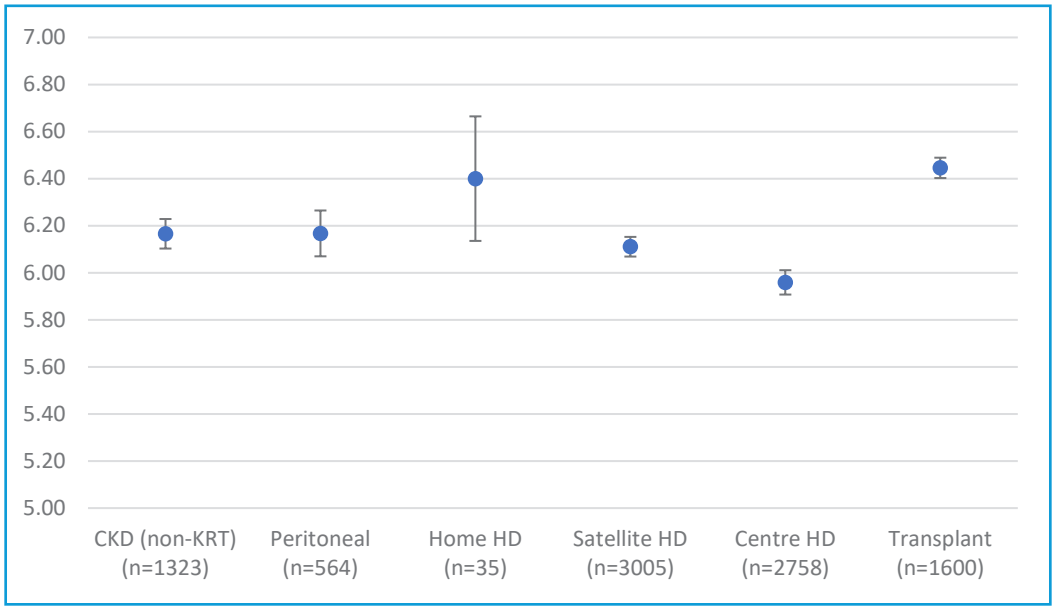
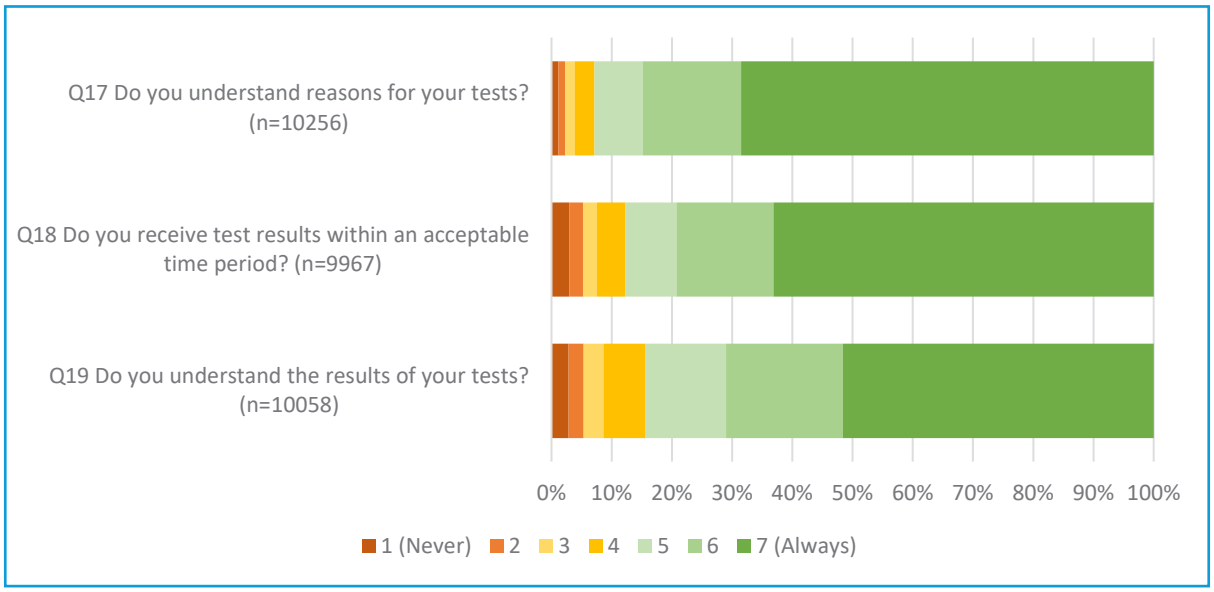


Figure 5.7B: Response frequencies for Tests theme questions



Respondents were mostly positive in their assessment of the *Tests* theme, with the range of centre scores amongst the lowest of the Kidney PREM themes in 2022. Understanding the results of tests was slightly less positively rated (Q19, 84% scoring 5 to 7) than understanding the reasons for tests (Q17, 93%).

Individuals receiving haemodialysis in centres scored slightly lower for the *Tests* theme than other treatment modalities (5.96) and those who have a kidney transplant slightly higher compared to others (6.45).

Theme 8: Sharing Decisions About Your Care

Mean centre score 5.55, range 4.07 to 6.58

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

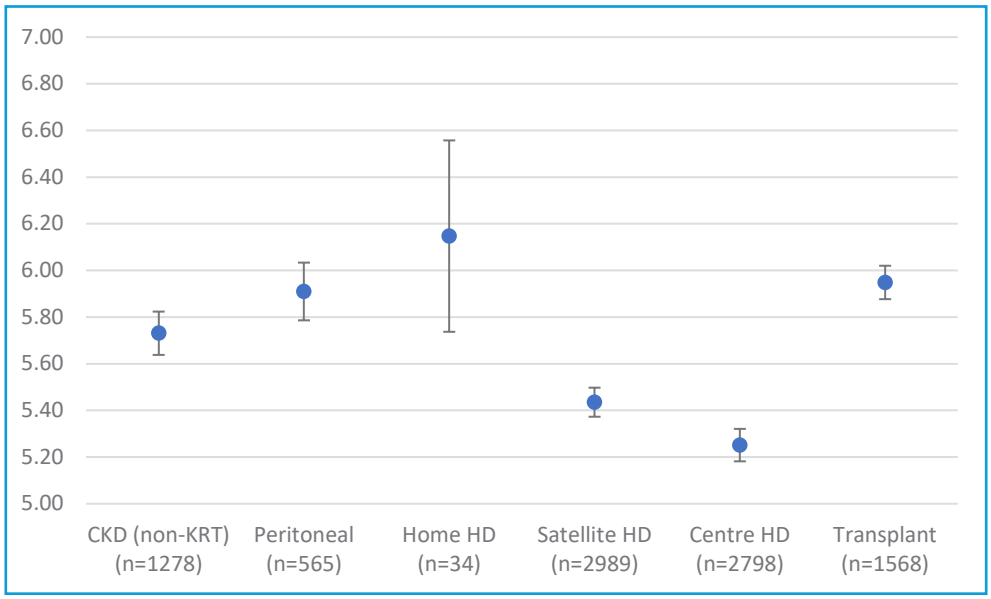
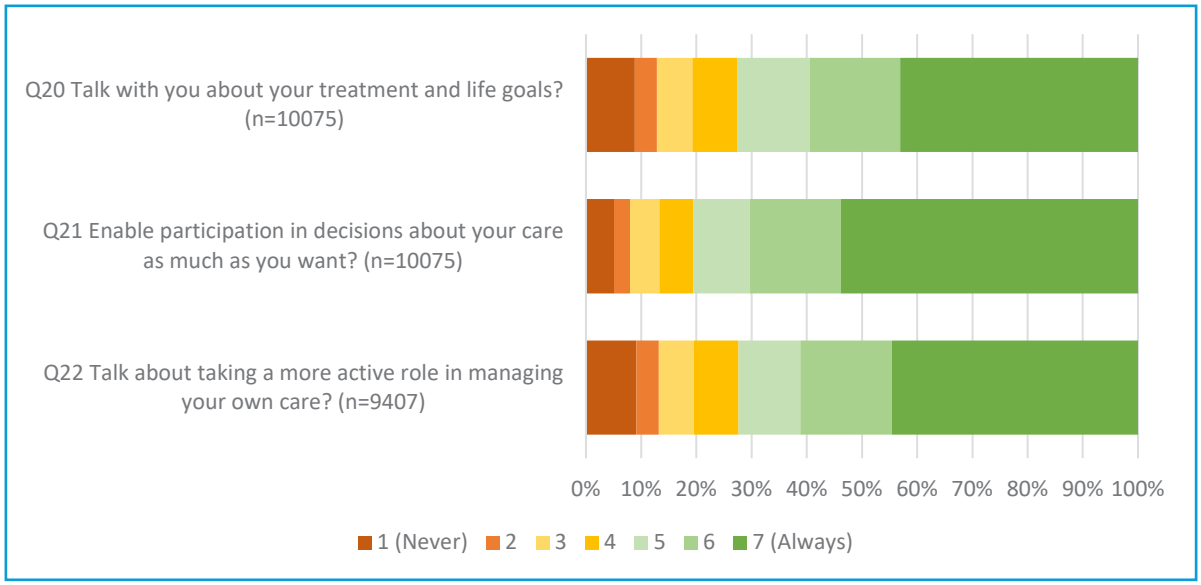


Figure 5.8B: Response frequencies for Sharing Decisions theme questions



Sharing Decisions About your Care remains the lowest scoring theme of Kidney PREM, with poorer proportions of respondents giving 5 to 7 scores. Participation in decisions about care was the highest of the three questions (Q21, 81%), with lower results for talking about treatment and life goals (Q20, 73%) and taking a more active role in managing care (Q22, 72%).

Differences were seen according to treatment group, with in-centre and in-satellite haemodialysis recipients rating *Sharing Decisions* much more poorly (5.25 and 5.44 respectively). Participants with transplants or receiving peritoneal dialysis provided similar scores, 5.95 and 5.91. The low average score for this theme reflects that there is a large proportion of participants who receive centre/satellite haemodialysis (56.5%) amongst all Kidney PREM participants.

Theme 9: Privacy and Dignity

Mean centre score 6.41, range 5.67 to 6.88

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

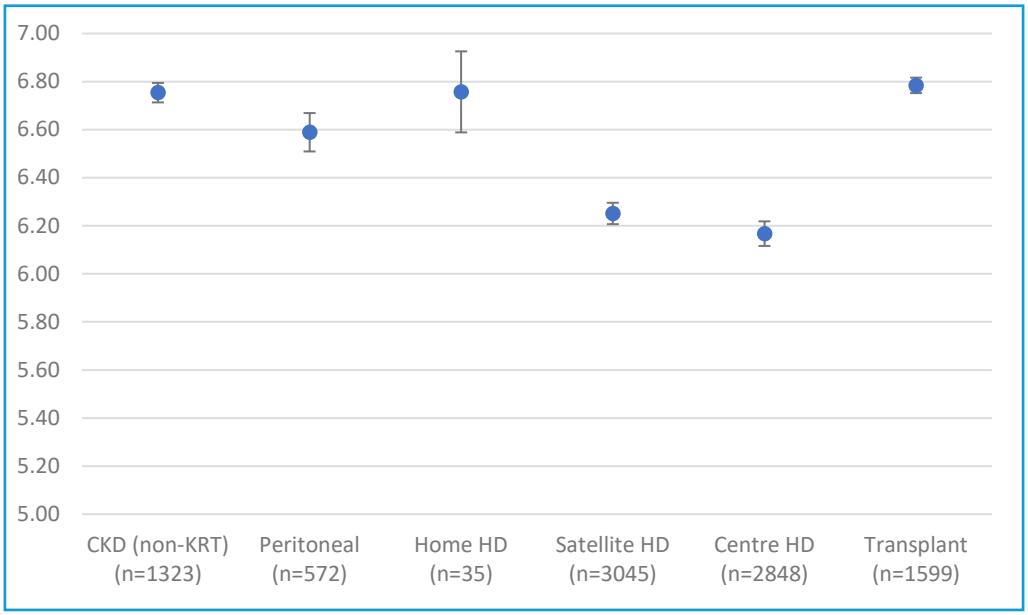
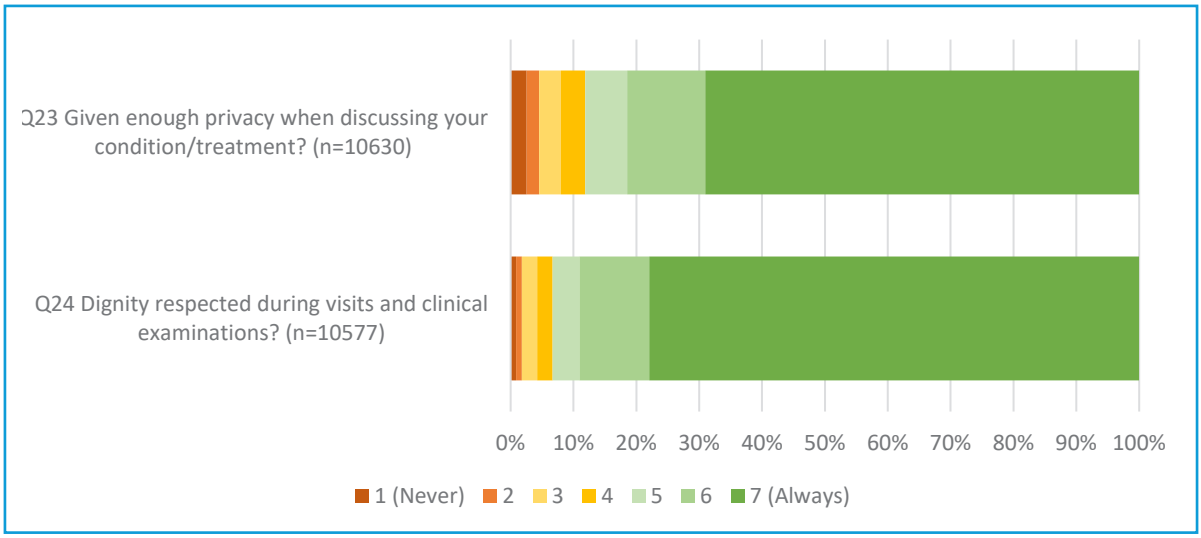


Figure 5.9B: Response frequencies for Privacy and Dignity theme questions



Privacy and Dignity continues to be the highest scoring Kidney PREM theme, with the lowest range of scores between centres (1.2, 5.7 to 6.9). Participants are more positive when asked to rate how their dignity is respected during visits and clinical examinations (Q24, 93% scoring 5 to 7), although privacy when discussing conditions or treatment is also positively regarded (Q23, 88%). Although high across all treatment modalities, *Privacy and Dignity* scores are lower for those receiving haemodialysis at satellite units (6.25) and in centres (6.17), perhaps as a result of the higher frequency of contact with clinicians, often in open wards rather than enclosed clinic rooms. This highlights the need to ensure that individuals are given choice about where to have conversations with clinicians, with suitable areas provided for this purpose.

Theme 10: Scheduling and Planning

Mean centre score 6.21, range 5.28 to 6.87

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

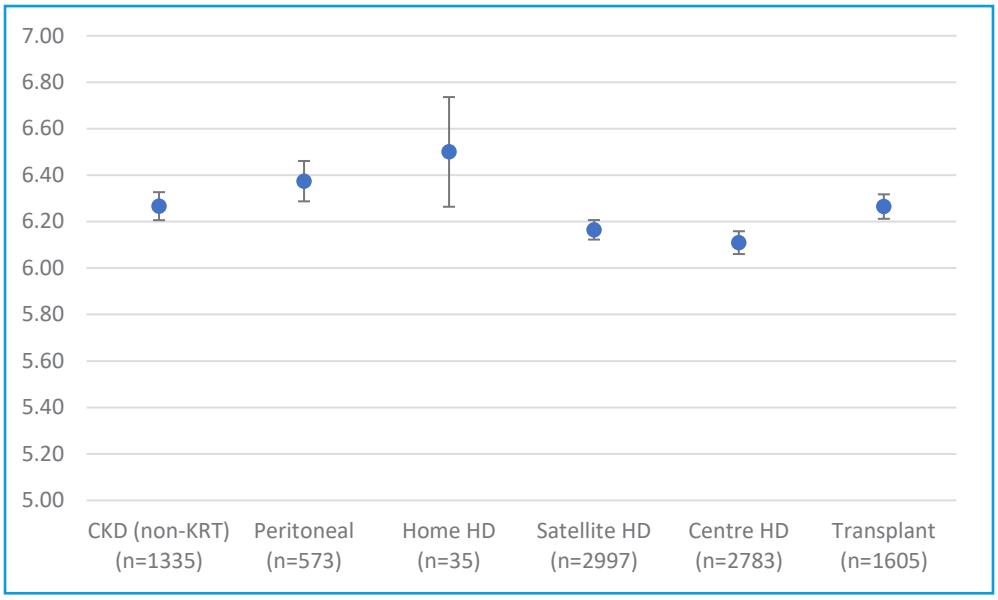
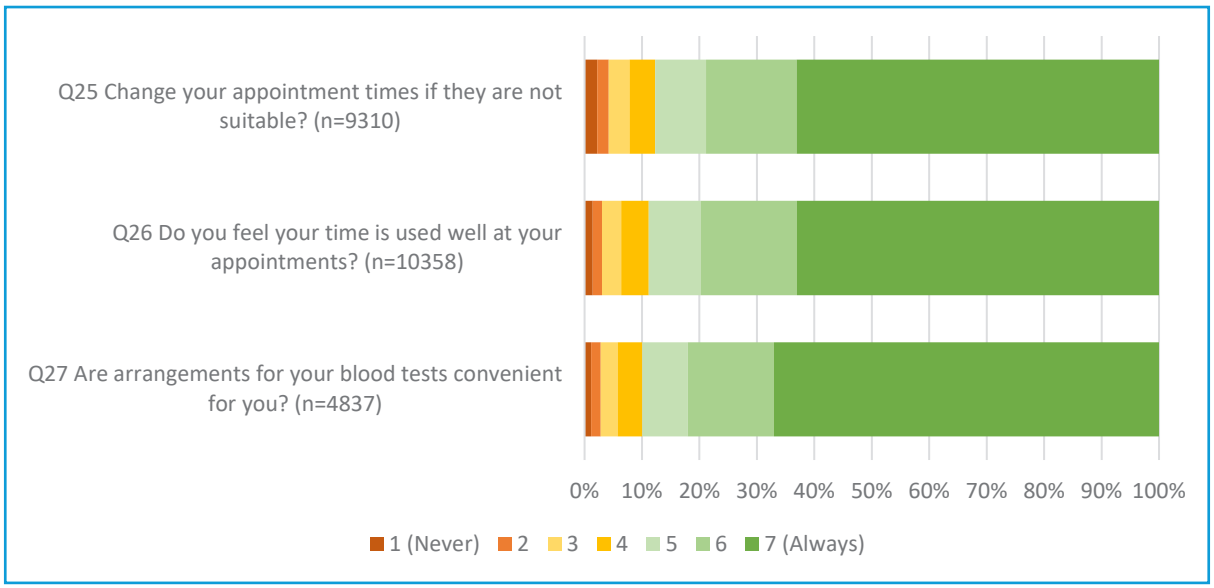


Figure 5.10B: Response frequencies for Scheduling and Planning theme questions



Within the *Scheduling and Planning* theme, little difference was seen in the proportion of respondents scoring at least 5 out of 7 for each question; changing appointment times (Q25) 88%, use of time at appointments (Q26) 89%, arrangements for blood tests (Q27) 90%. There was little variation seen between participant treatment groups, scores ranging between 6.11 (in-centre haemodialysis) and 6.50 (home haemodialysis).

Theme 11: How the Renal Team Treats You

Mean centre score 6.11, range 5.02 to 6.80

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

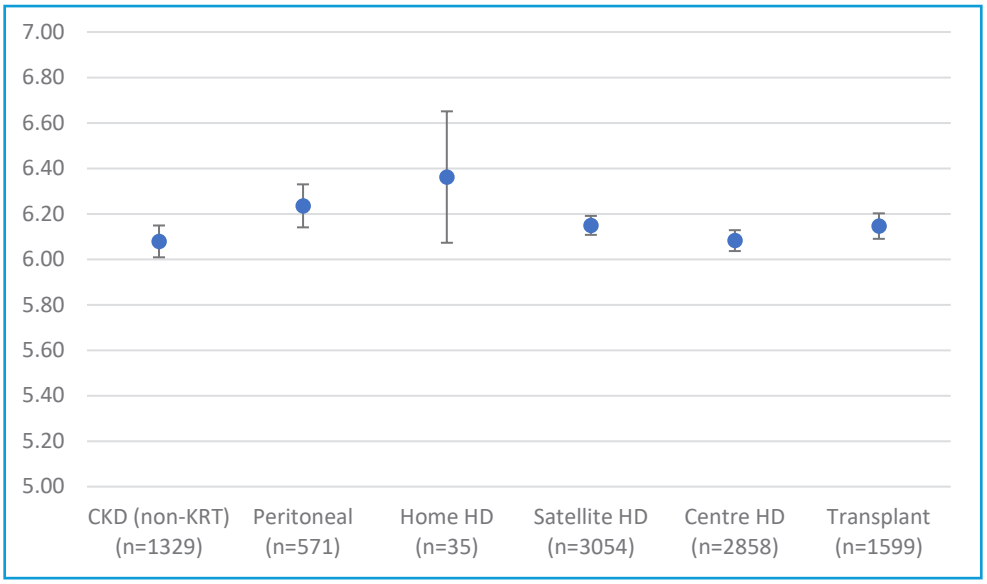
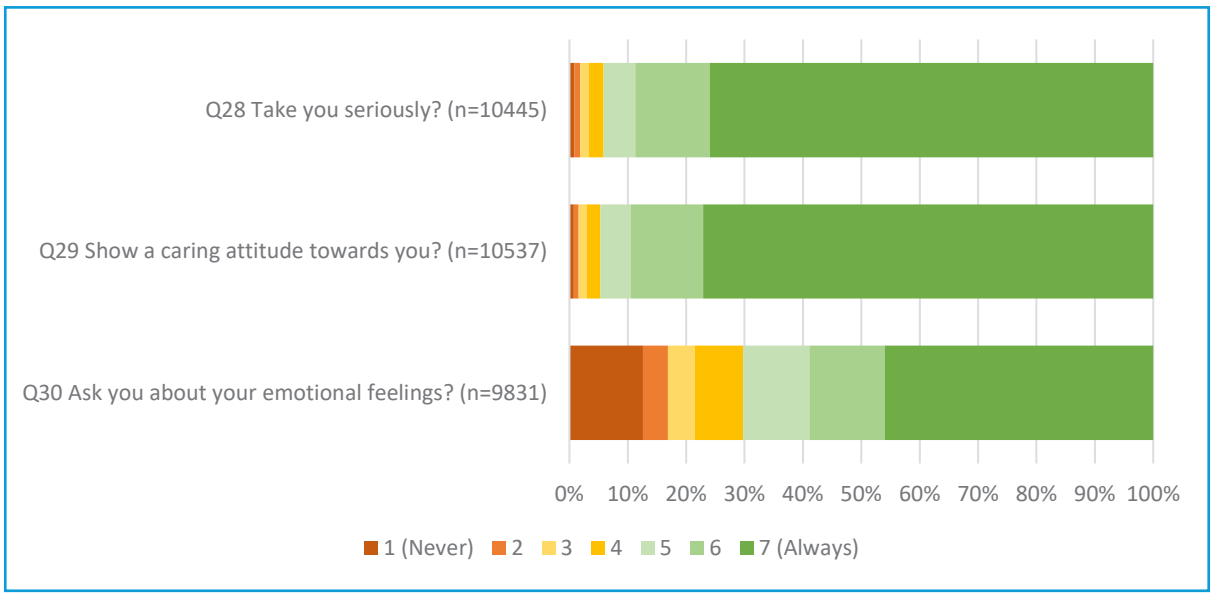


Figure 5.11B: Response frequencies for How the Renal Team Treats You theme questions



How the Renal Team Treats You was another theme with little variation, both according to treatment type (range 6.08 to 6.36) and across centres (5.02 to 6.80). Participants were overwhelmingly positive in rating whether the team took them seriously (Q28, 94% rating 5 to 7) and if the team showed a caring attitude (Q29, 95%). However, respondents were less concordant when asked whether the team asked about their emotional feelings (Q30), with just 70% stating that this was the case, and 13% indicating that this never happened (providing a score of 1 out of 7).

Theme 12: Transport

Mean centre score 5.59, range 4.39 to 6.87

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

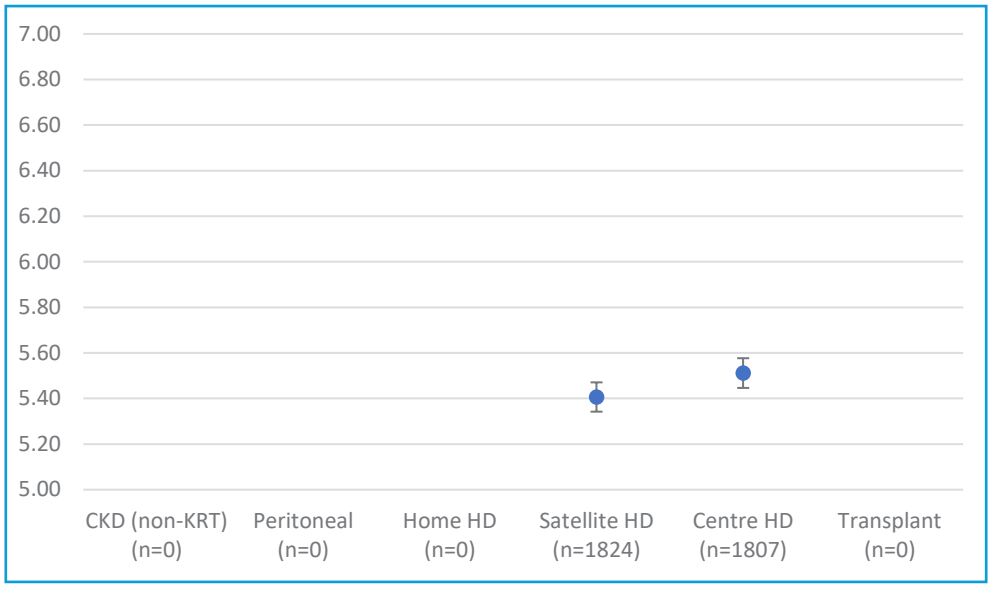
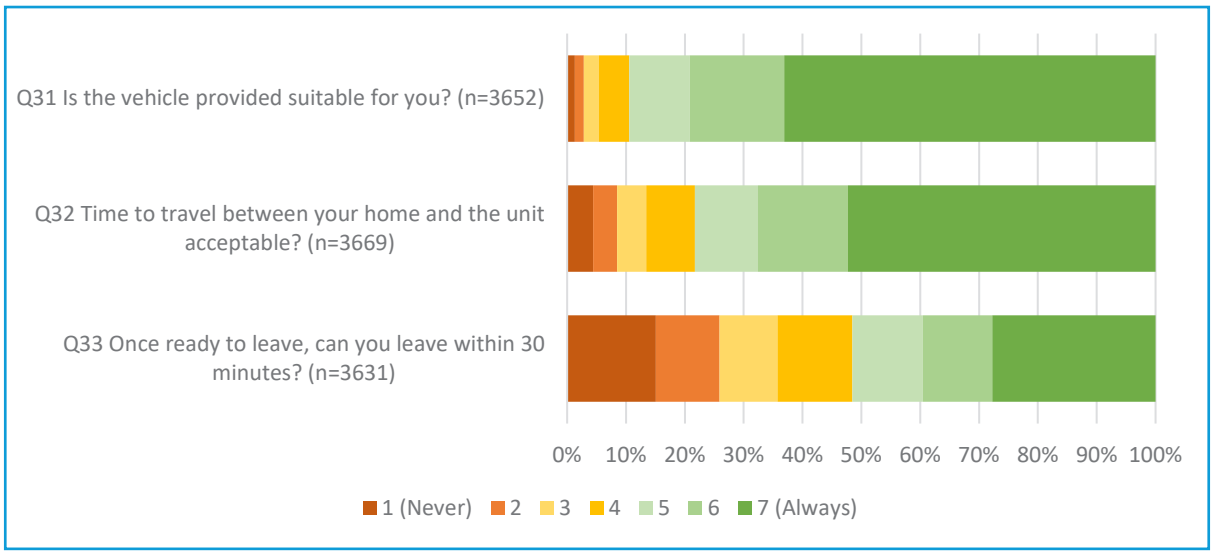


Figure 5.12B: Response frequencies for Transport theme questions



The *Transport* theme was applicable to those receiving haemodialysis in centre or at a satellite unit, with little difference in scores between those receiving treatment at the two location types. However, of the other Kidney PREM themes, scores are lower only for *Sharing Decisions*. In addition to this, centre scores were wide ranging (4.39 to 6.87), suggesting that *Transport* is a key theme to focus on to improve experience of care. Most respondents felt that the vehicle provided was suitable (Q31, 89% scoring 5 to 7), with fewer stating that the travel time between home and the haemodialysis location was acceptable (Q32, 78%). Just over half (52%) said that they were able to leave the unit within 30 minutes of completing dialysis (Q33), and 15% stated that this was never the case (rating 1 out of 7).

Theme 13: The Environment

Mean centre score 6.09, range 5.05 to 6.86

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

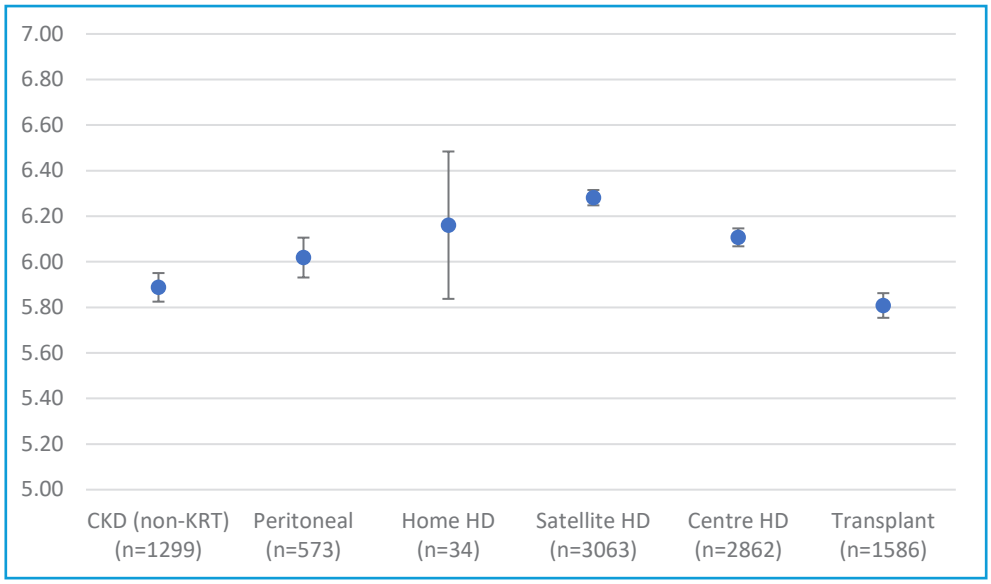
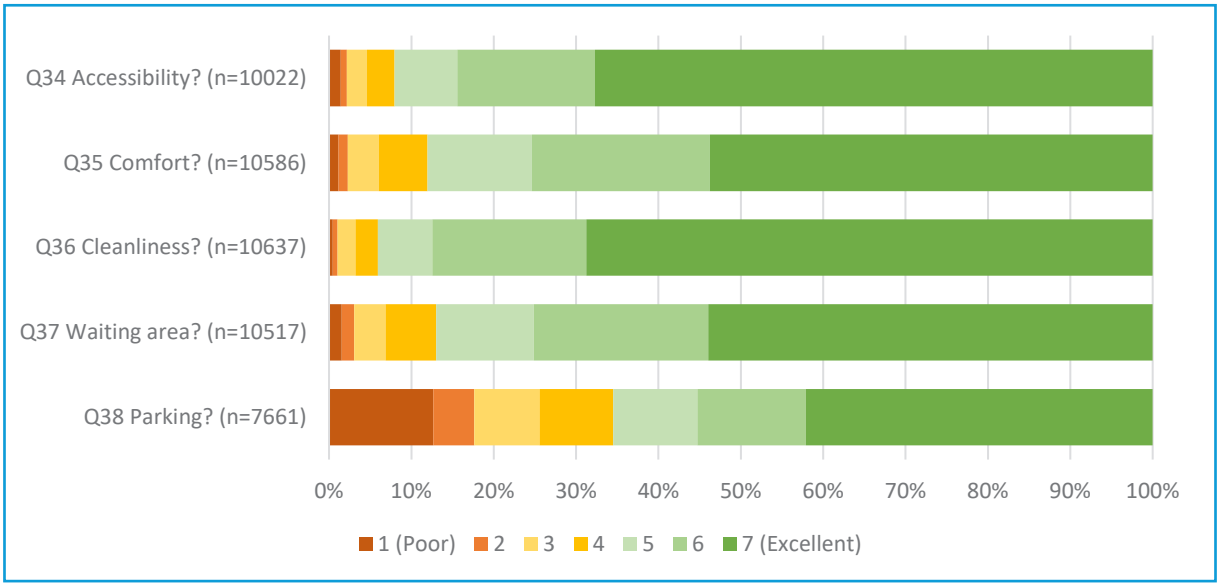


Figure 5.13B: Response frequencies for Environment theme questions



The *Environment* theme shows some variation by treatment modality, notably with transplant recipients scoring more poorly (5.81) than those receiving haemodialysis in centre (6.11) or at a satellite unit (6.28). There was some variety in response profile across *Environment* theme questions, with high proportions of 5 to 7 scores provided for accessibility (Q34, 92%), comfort (Q35, 88%), cleanliness (Q36, 94%) and the waiting area (Q37, 87%). However, as in previous years, the parking environment (Q38) was rated less well, with just 66% giving scores of 5 to 7 and 13% providing a score of 1 (poor).

Theme 14: Your Overall Experience

Mean centre score 6.25, range 5.06 to 6.84

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

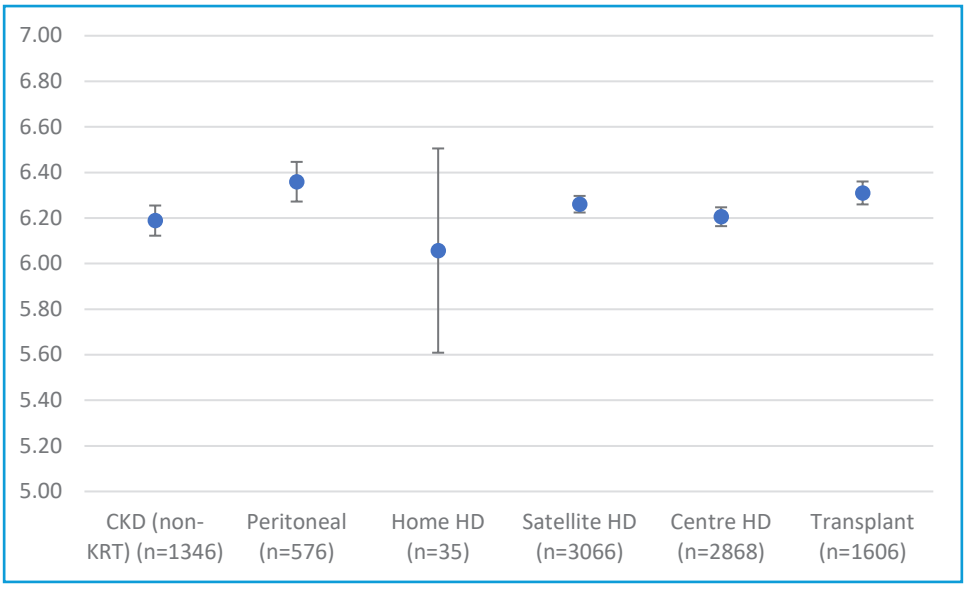
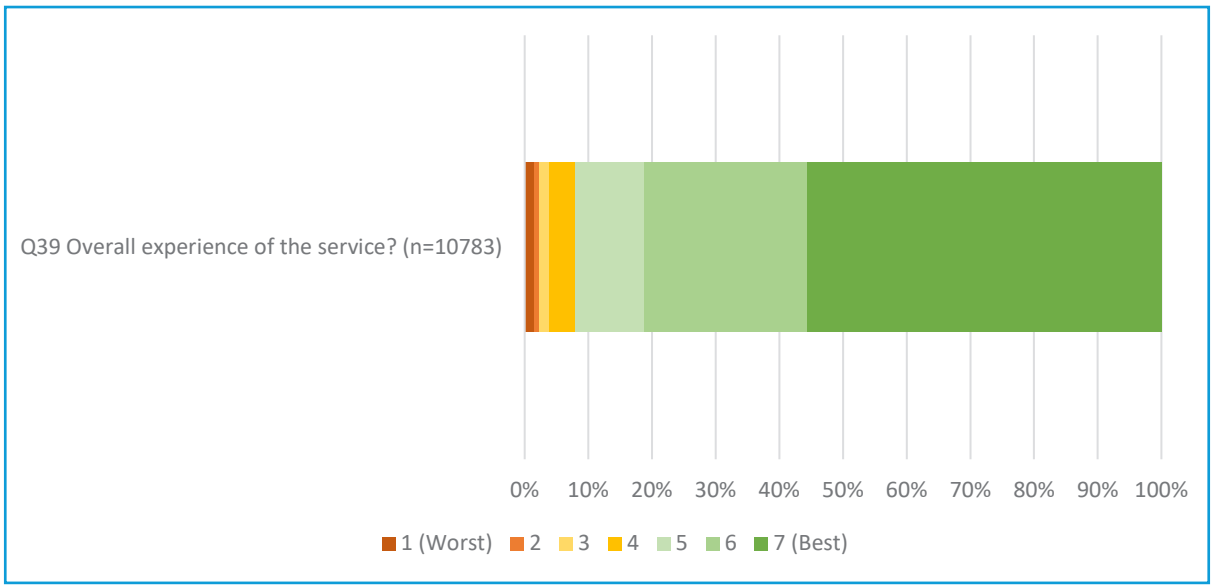


Figure 5.14B: Response frequencies for Overall Experience theme questions



Encouragingly, participants continue to rate their *Overall* experience of kidney care highly, with 92% scoring Q39 at least 5 out of 7. Just 1% of all Kidney PREM respondents provided a score of 1 (worst it can be). Very little variation between treatment modalities was seen, ranging from 6.06 to 6.36, with variation in centre scores minimal.

6. Patient experience of kidney care across the service

This chapter presents mean scores for each theme in the 2022 Kidney PREM, by centre and by 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 viewed at: **https://ukkidney.org/audit-research/data-portal/prem**

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 2022 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.

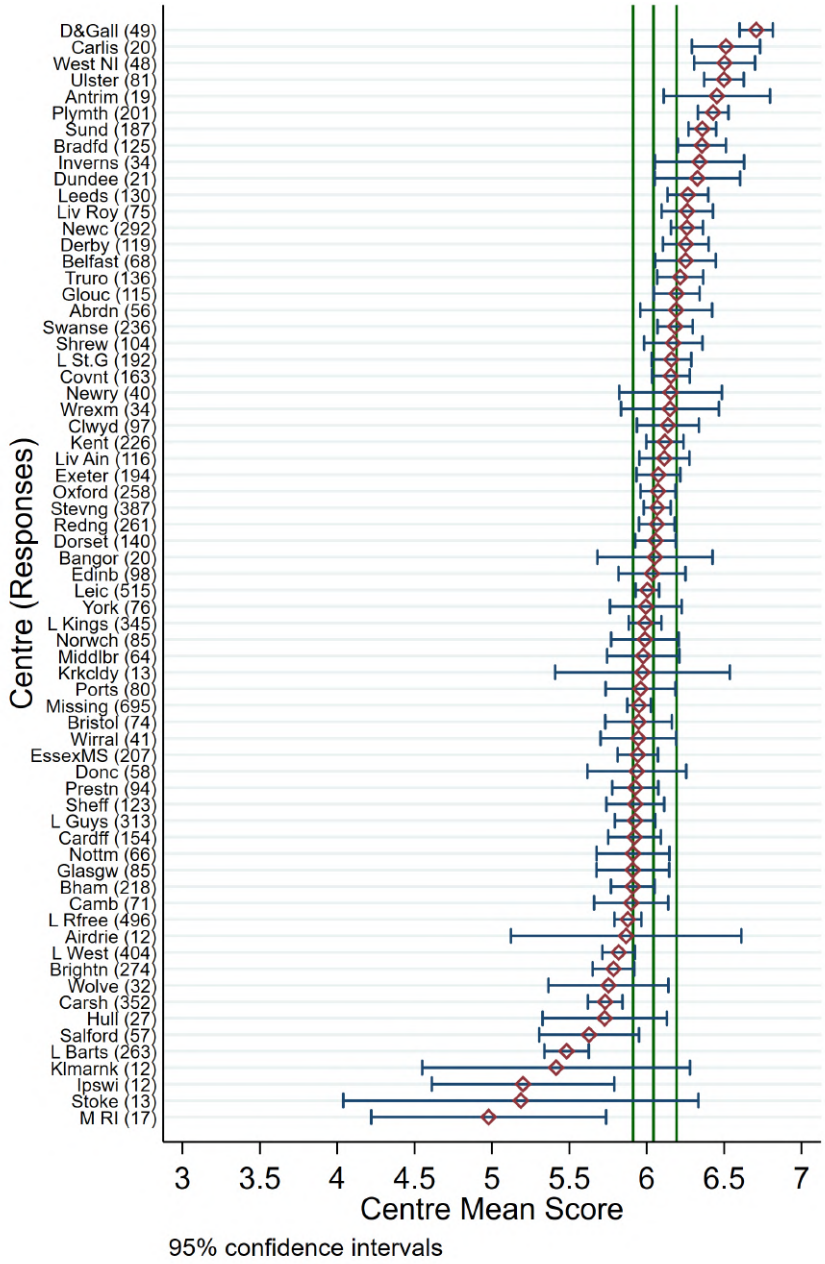
The number of responses used to calculate the scores are in brackets after each centre name. Each chart shows how many participants from each centre completed a sufficient number of questions such that a theme score could be calculated, as opposed to the number of individuals from each centre who completed the 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 individuals receiving in-centre/in-satellite haemodialysis).

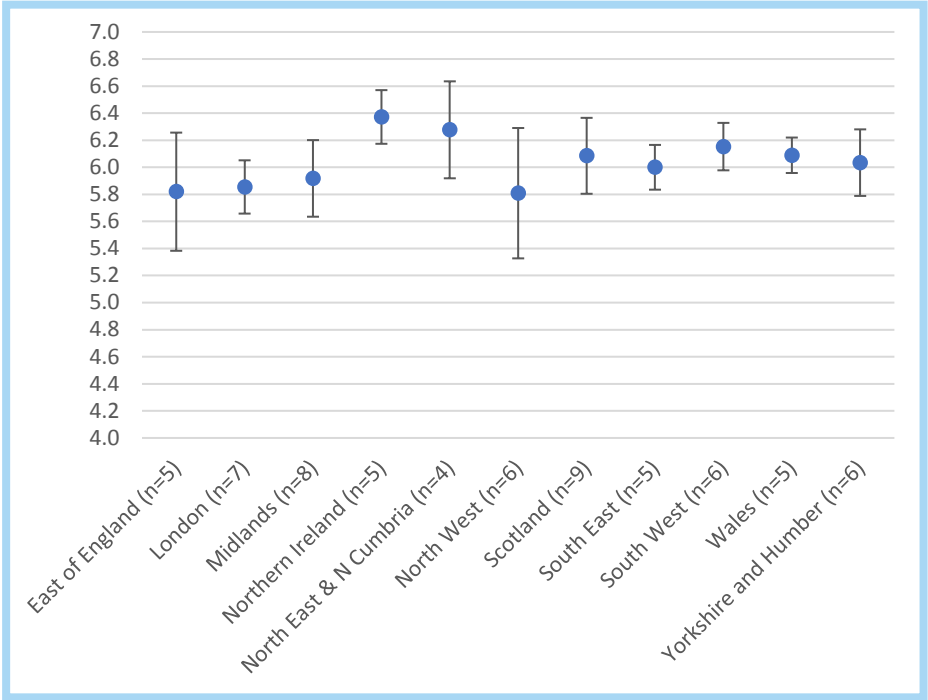
For most themes, centre scores are within a small range. However, each theme's graph shows a tail of outliers at the bottom, where centre scores were lower than others. *Transport* and *Needling* themes are only applicable to in-satellite and in-centre haemodialysis recipients. These themes therefore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

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

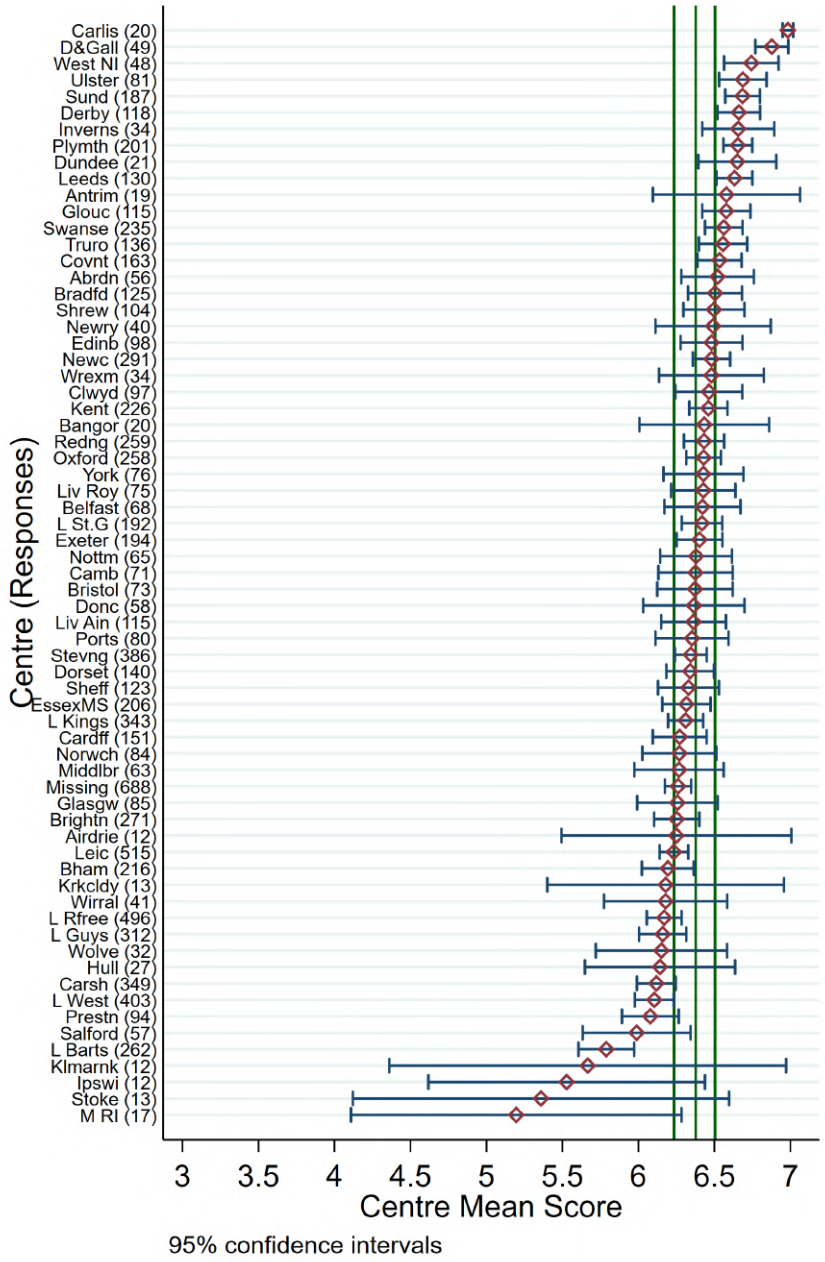
Figures on the right of each page show the mean score and 95% confidence interval (CI) of all centres mean scores within each geographical region of the UK, with the number of centres used to calculate each value displayed in brackets after the region name.

Scale Score


D&Gall (49)
Carlis (20)
West NI (48)
Ulster (81)
Antrim (19)
Plymth (201)
Sund (187)
Bradfd (125)
Inverns (34)
Dundee (21)
Leeds (130)
Liv Roy (75)
Newc (292)
Derby (119)
Belfast (68)
Truro (136)
Glouc (115)
Abrdn (56)
Swanse (236)
Shrew (104)
L St.G (192)
Covnt (163)
Newry (40)
Wrexm (34)
Clwyd (97)
Kent (226)
Liv Ain (116)
Exeter (194)
Oxford (258)
Stevng (387)
Redng (261)
Dorset (140)
Bangor (20)
Edinb (98)
Leic (515)
York (76)
L Kings (345)
Norwch (85)
Middlbr (64)
Krkcldy (13)
Ports (80)
Missing (695)
Bristol (74)
Wirral (41)
EssexMS (207)
Donc (58)
Prestn (94)
Sheff (123)
L Guys (313)
Cardff (154)
Nottm (66)
Glasgw (85)
Bham (218)
Camb (71)
L Rfree (496)
Airdrie (12)
L West (404)
Brightn (274)
Wolve (32)
Carsh (352)
Hull (27)
Salford (57)
L Barts (263)
Klmarnk (12)
Ipswi (12)
Stoke (13)
M RI (17)
Centre (Responses)
3
3.5
4
4.5
5
5.5
6
6.5
7
Centre Mean Score
95% confidence intervals


7.0
6.8
6.6
6.4
6.2
6.0
5.8
5.6
5.4
5.2
5.0
4.8
4.6
4.4
4.2
4.0
East of England (n=5)
London (n=7)
Midlands (n=8)
Northern Ireland (n=5)
North East & N Cumbria (n=4)
North West (n=6)
Scotland (n=9)
South East (n=5)
South West (n=6)
Wales (n=5)
Yorkshire and Humber (n=6)

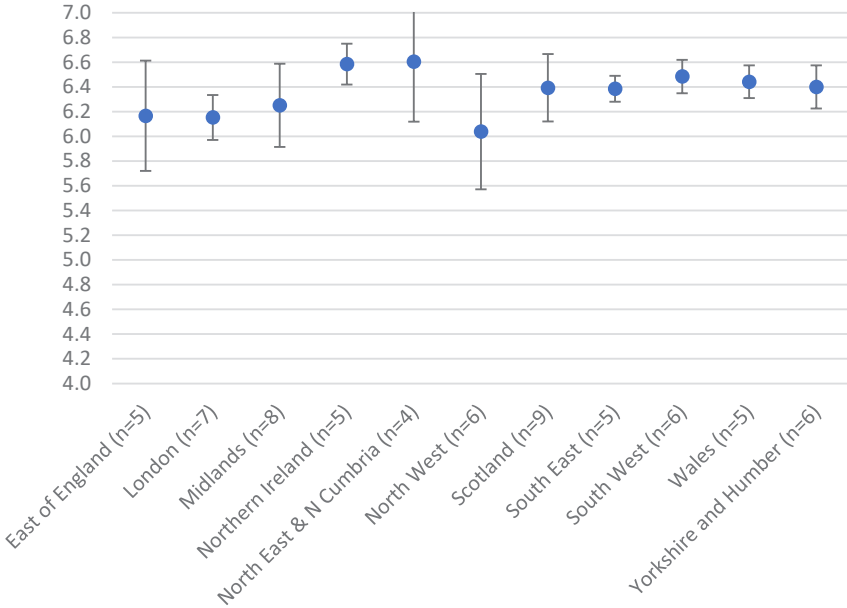
Theme 1: Access to the Renal Team



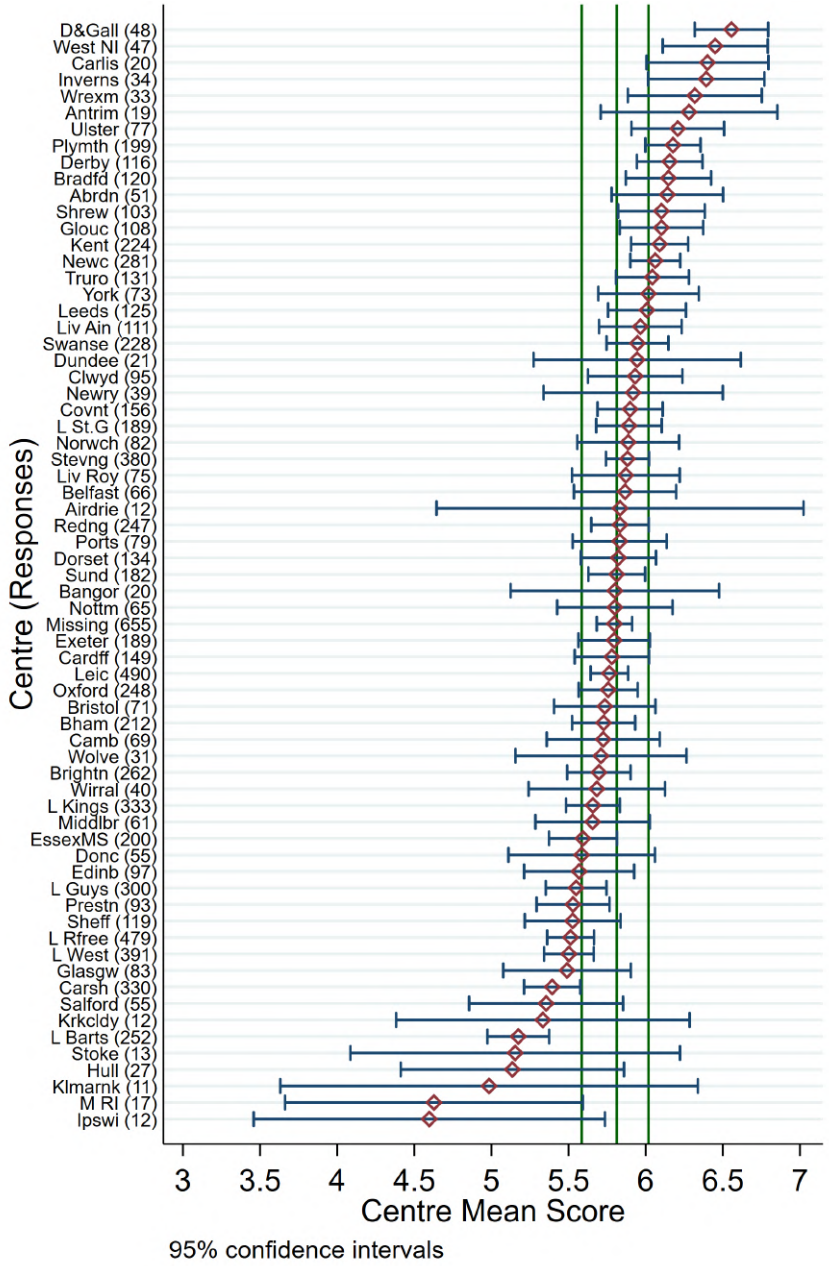
Q1. Does the renal team take time to answer your questions about your kidney disease or treatment?

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

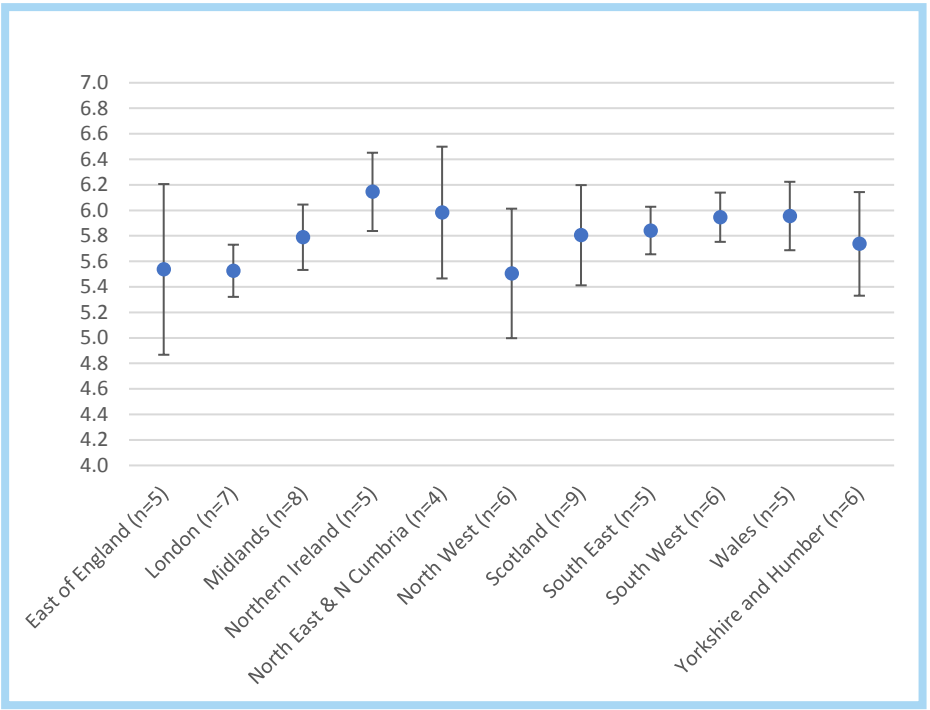


Does the renal team help you to get the support you want with:

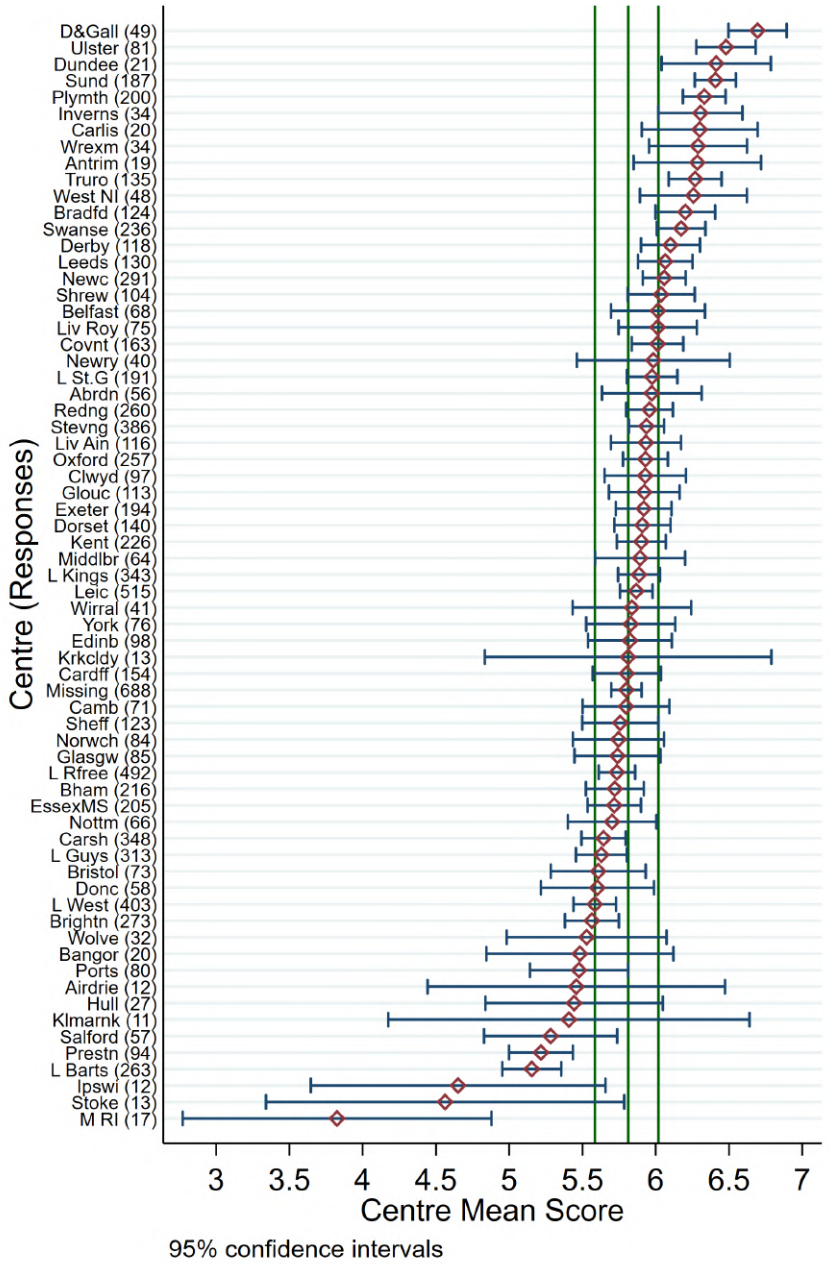
Q4. Medical issues resulting from your kidney disease?

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

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



Theme 3: Communication



Do you think there is good communication between:

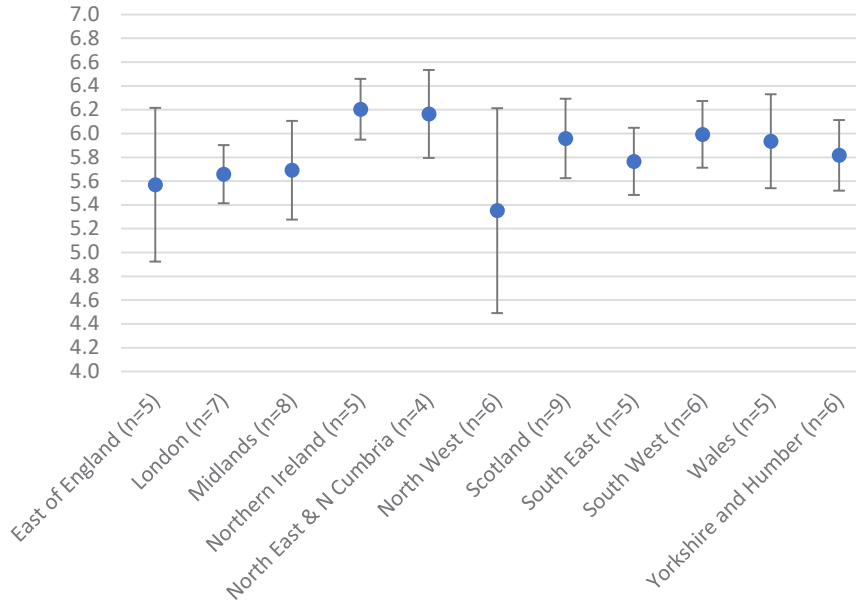
Q7. You and your renal team?

Q8. Members of the renal team?

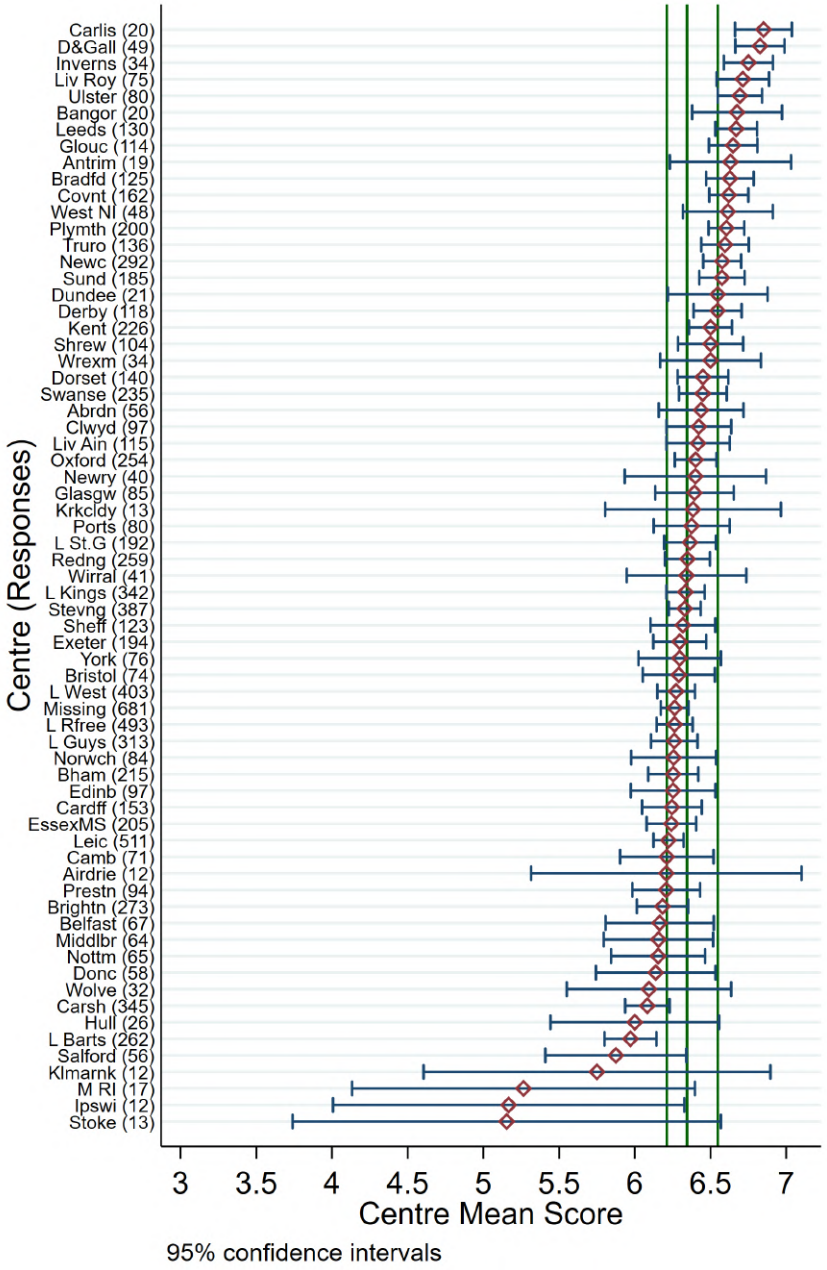
Q9. Your GP and the renal team?

Q10. The renal team and other medical specialists?

Q11. The renal team and other non-healthcare services if you need them, such as social work or housing?

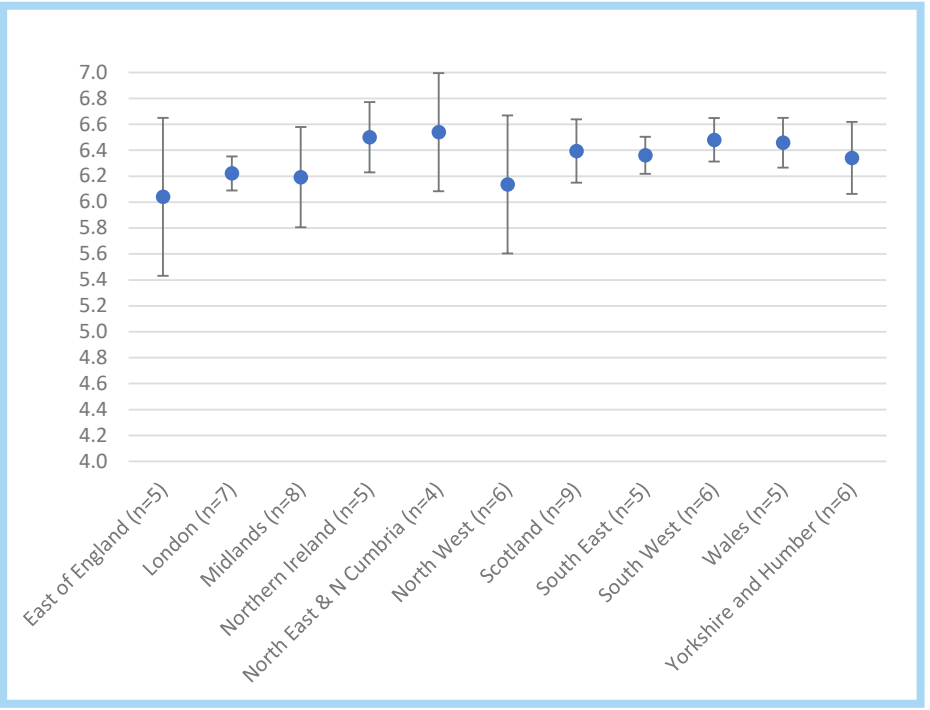


Theme 4: Patient Information

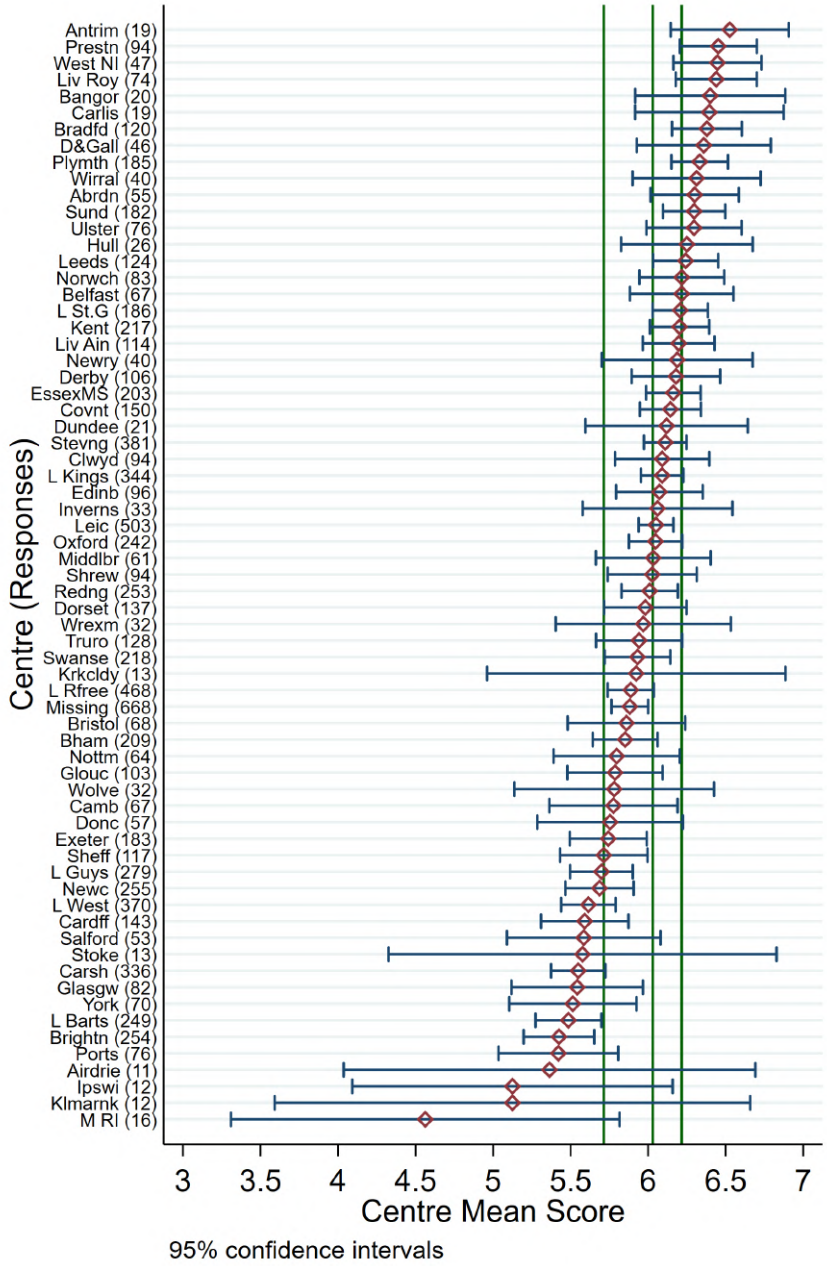


Does the kidney team:

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 Intake and Diet

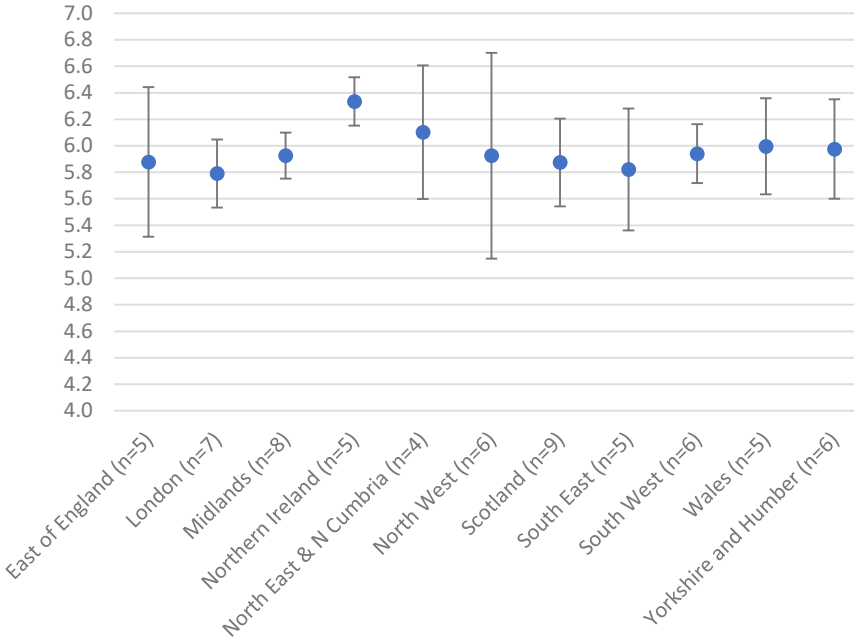


Thinking about the advice you are given about <u>fluid intake:</u>

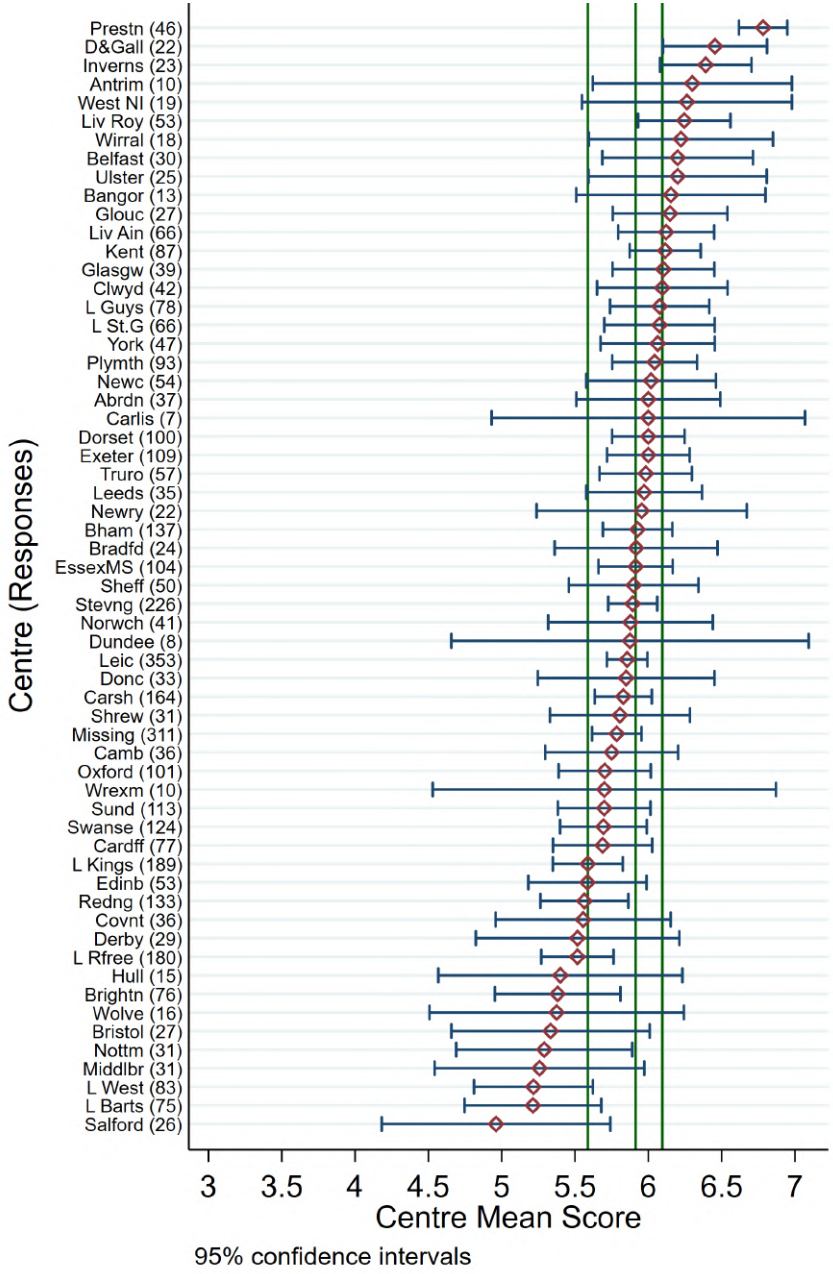
Q14. Does the renal team give you clear advice on your fluid intake?

Thinking about the advice you are given about <u>diet:</u>

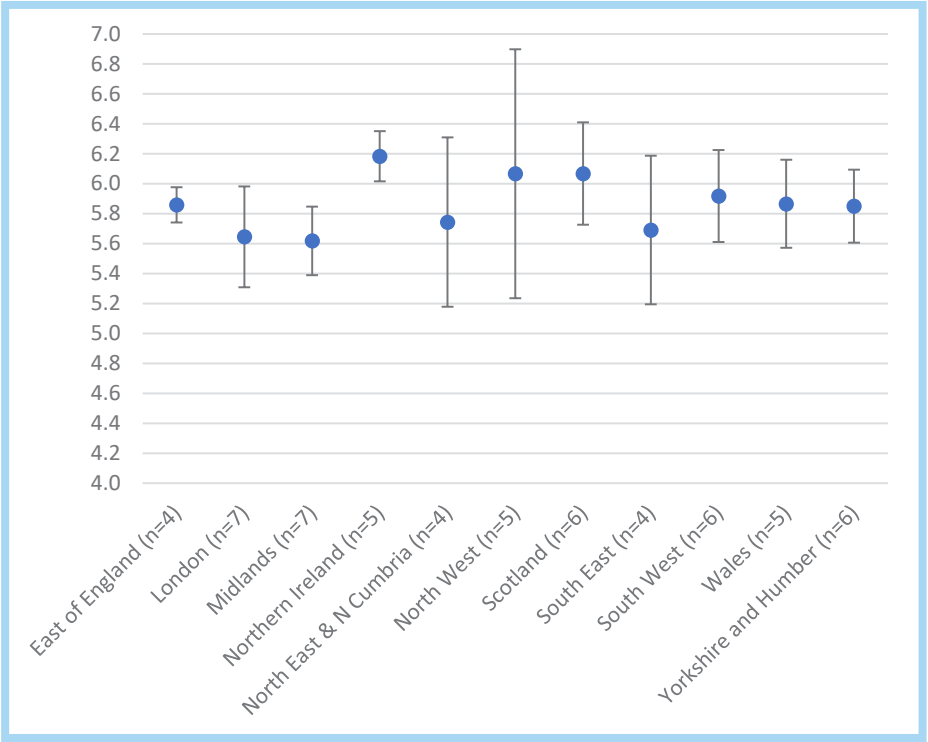
Q15. Does the renal team give you clear advice on your diet?



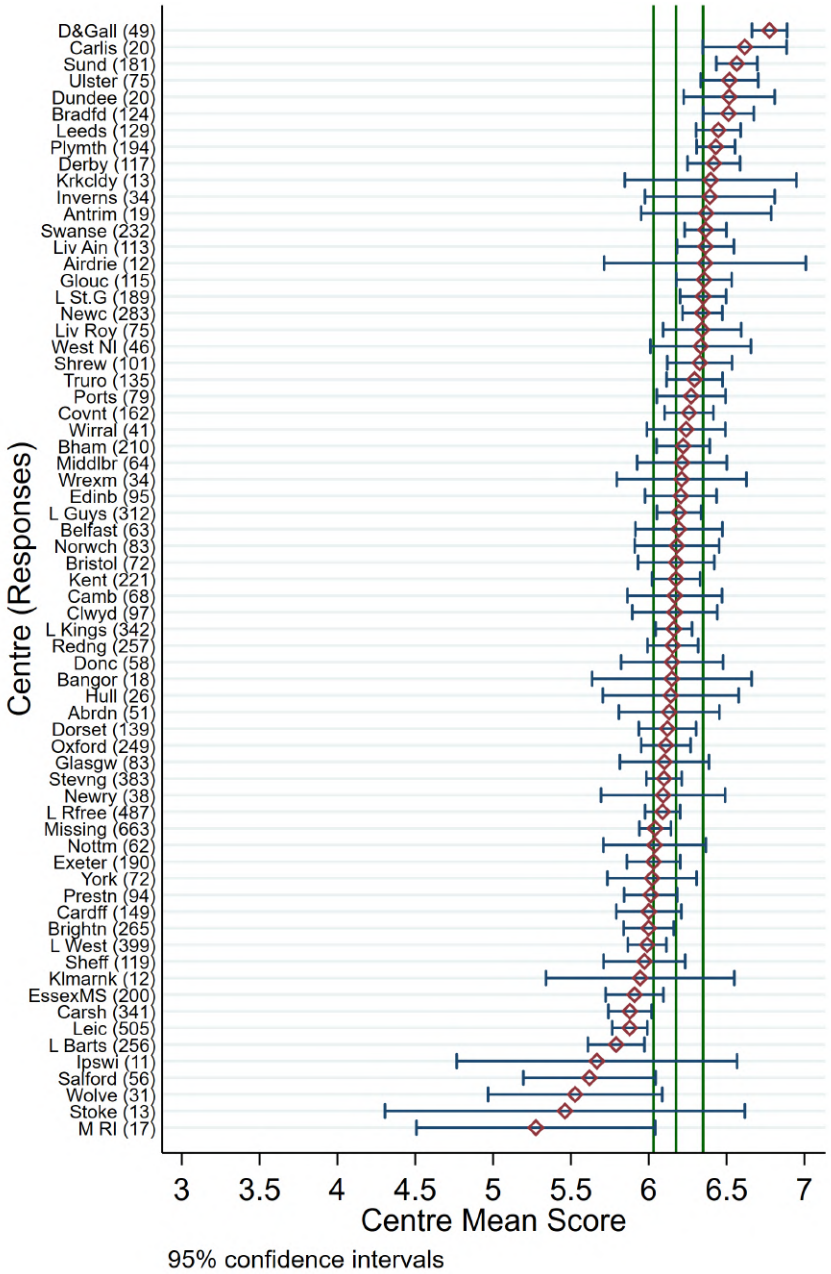
Theme 6: Needling



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



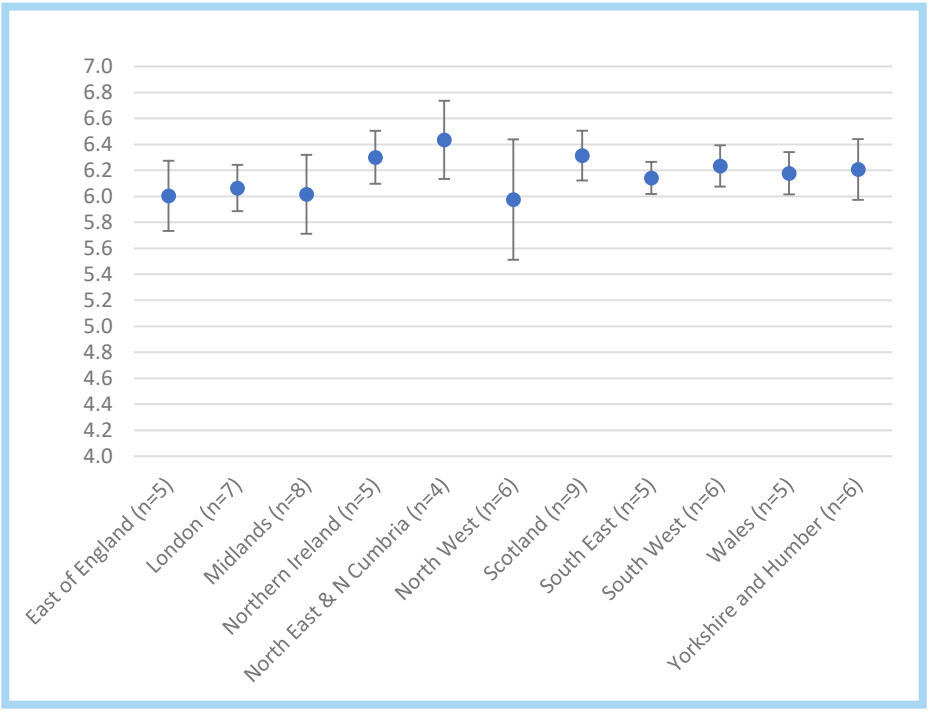
Theme 7: Tests



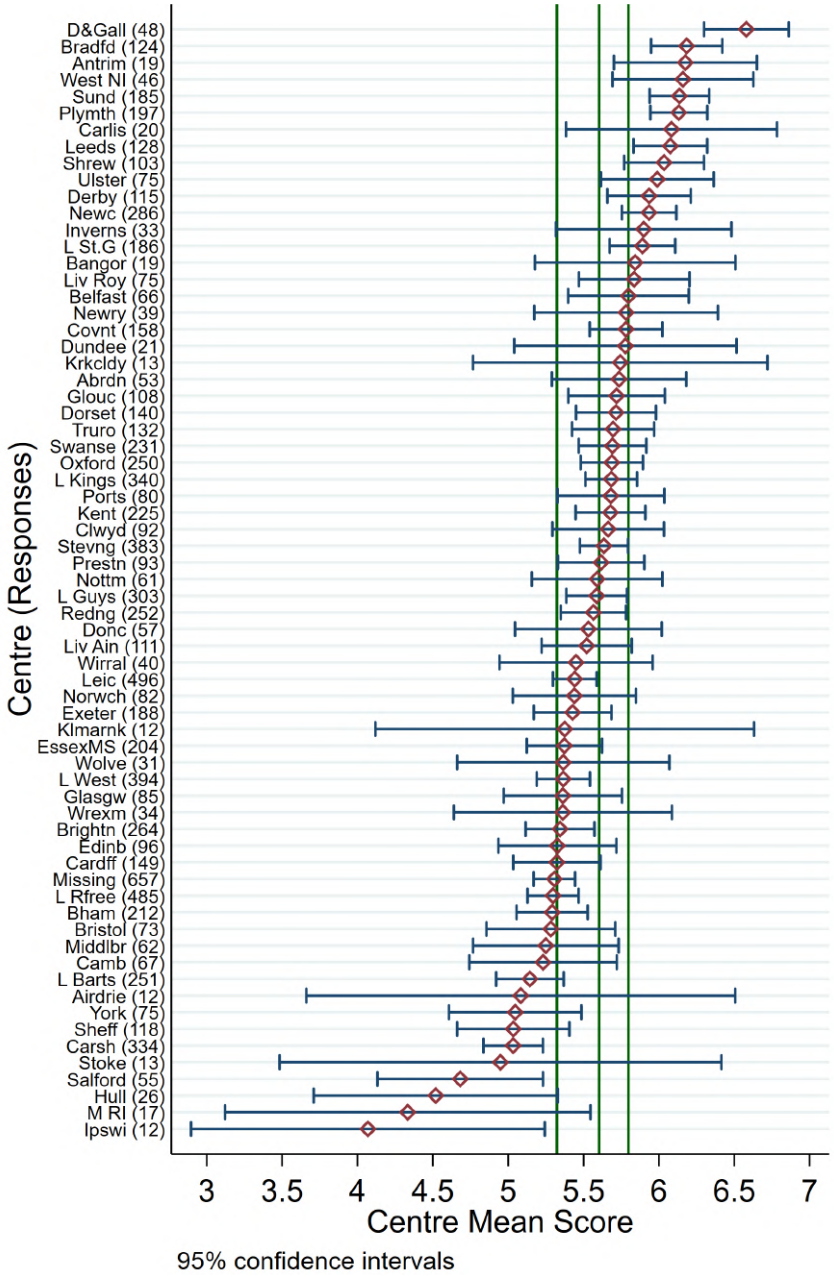
Q17. Do you understand the reasons for your tests?

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

Q19. Do you understand the results of your tests?

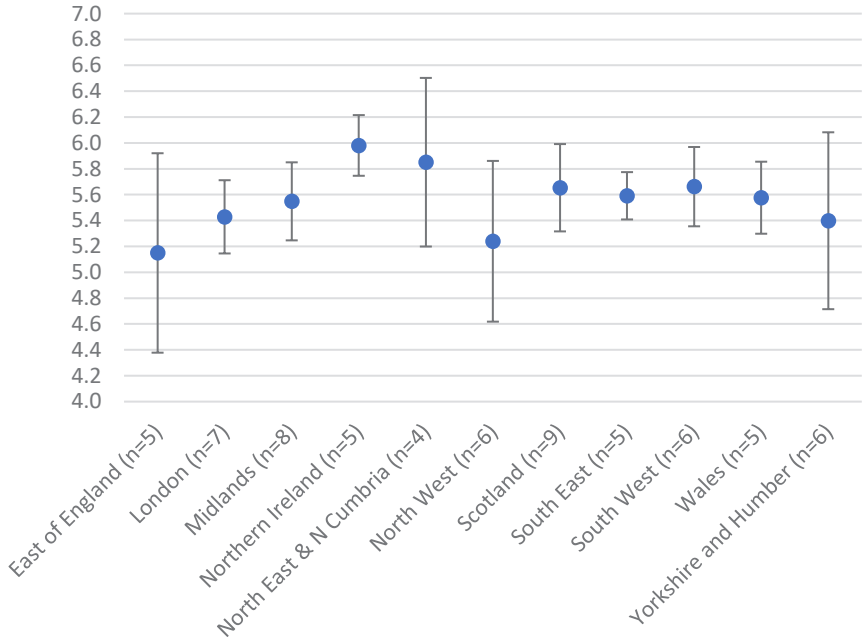


Theme 8: Sharing Decisions About Your Care

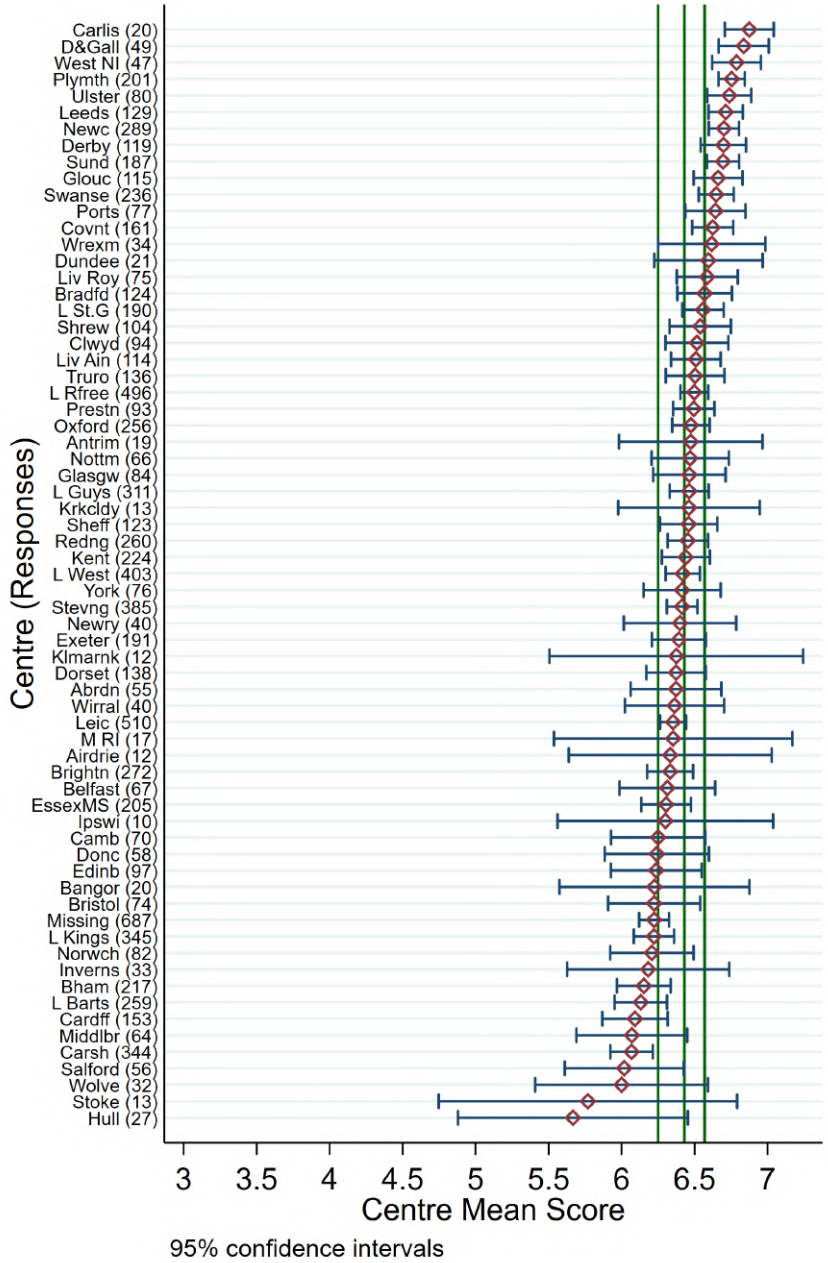


Does the renal team:

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?

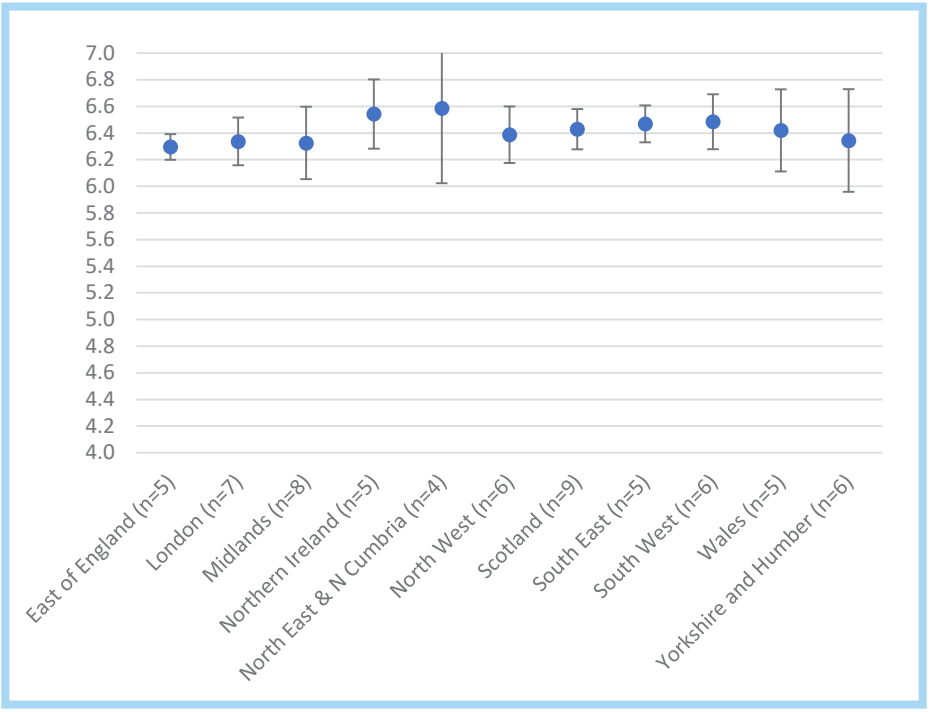


Theme 9: Privacy and Dignity

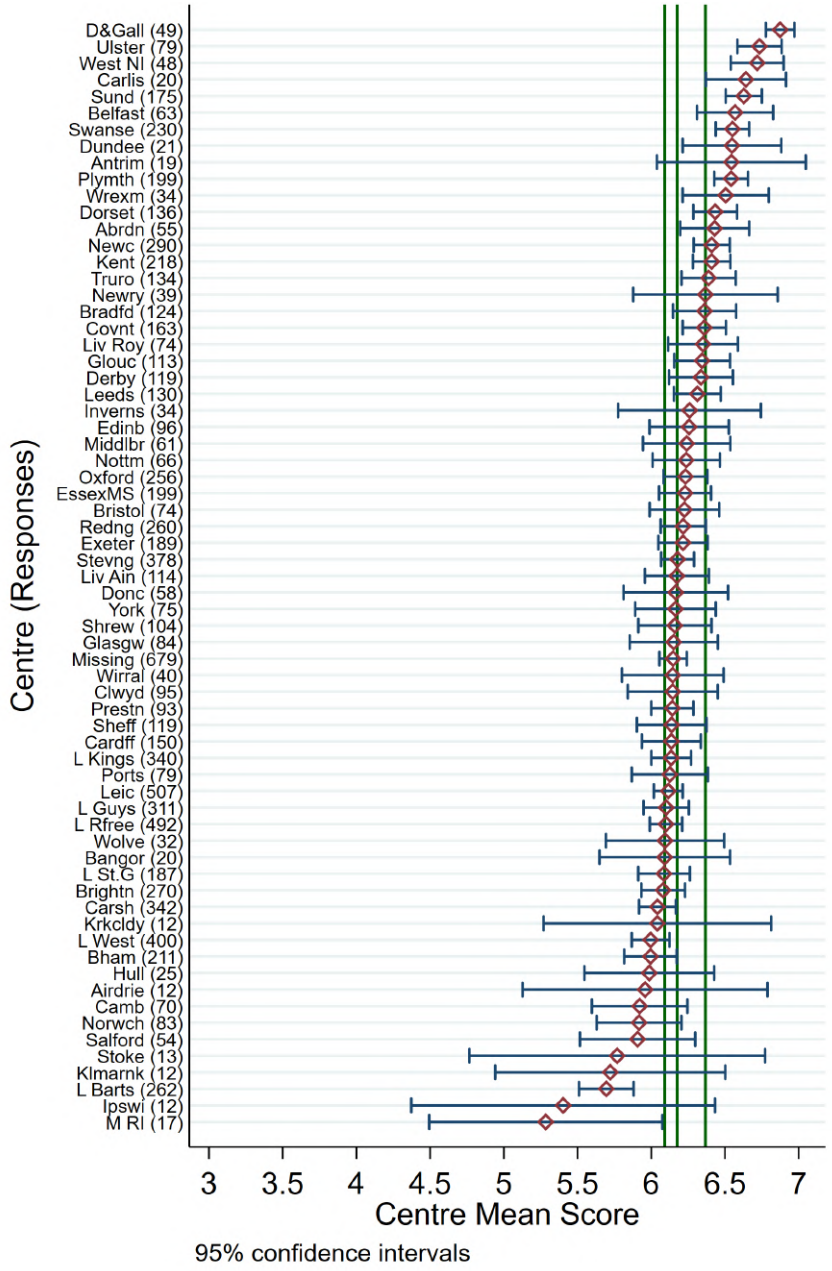


Q23. Are you given enough privacy when discussing your condition or treatment?

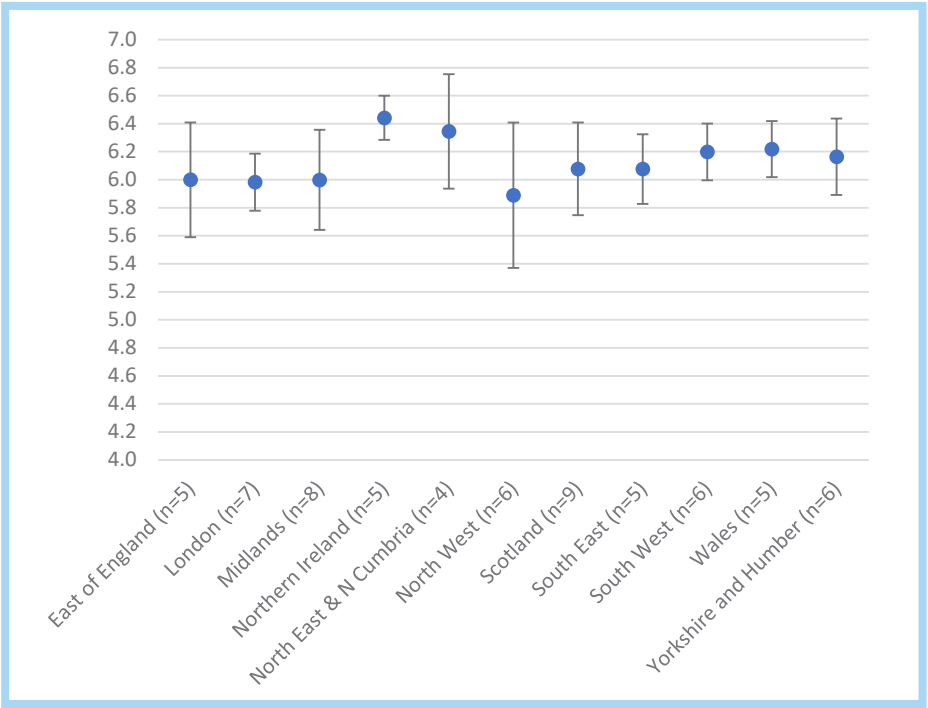
Q24. Is your dignity respected during visits and clinical examinations?



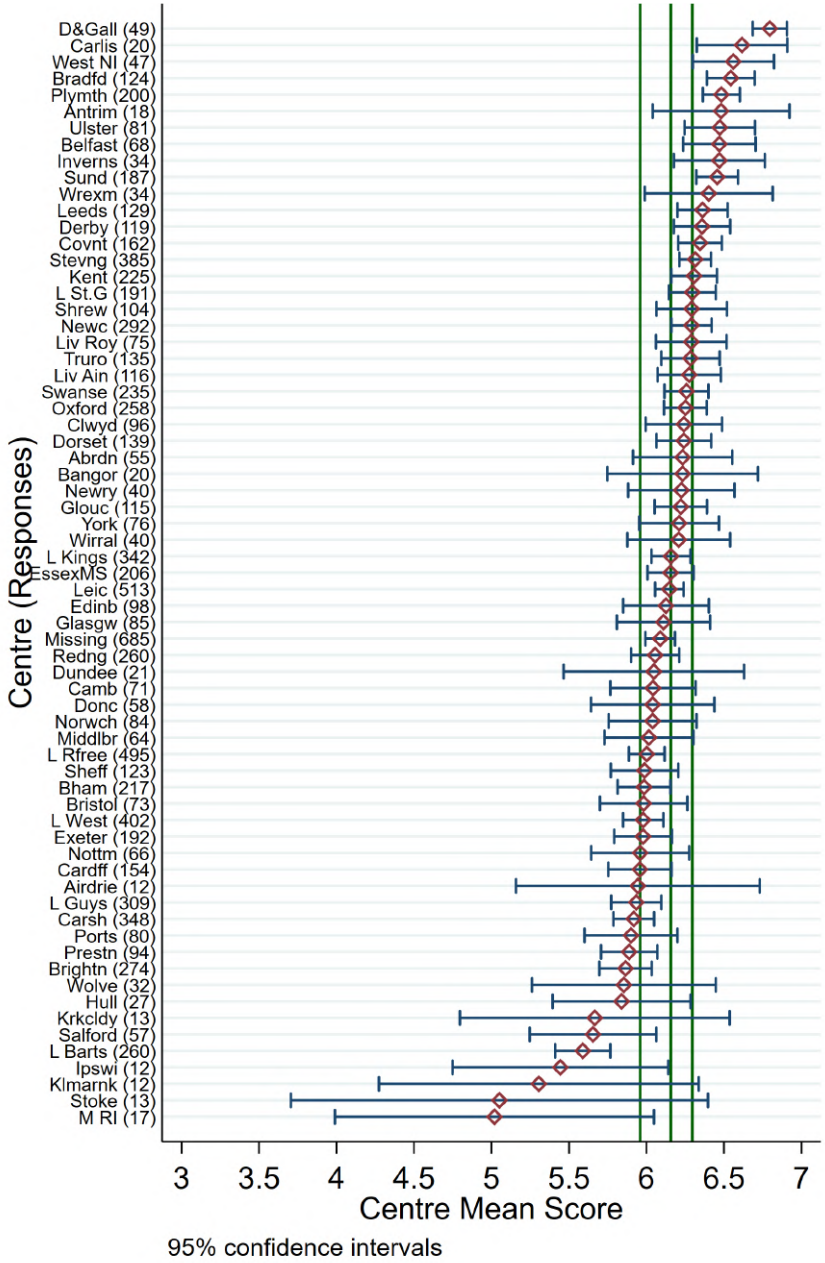
Theme 10: Scheduling and Planning



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 Renal Team Treats You

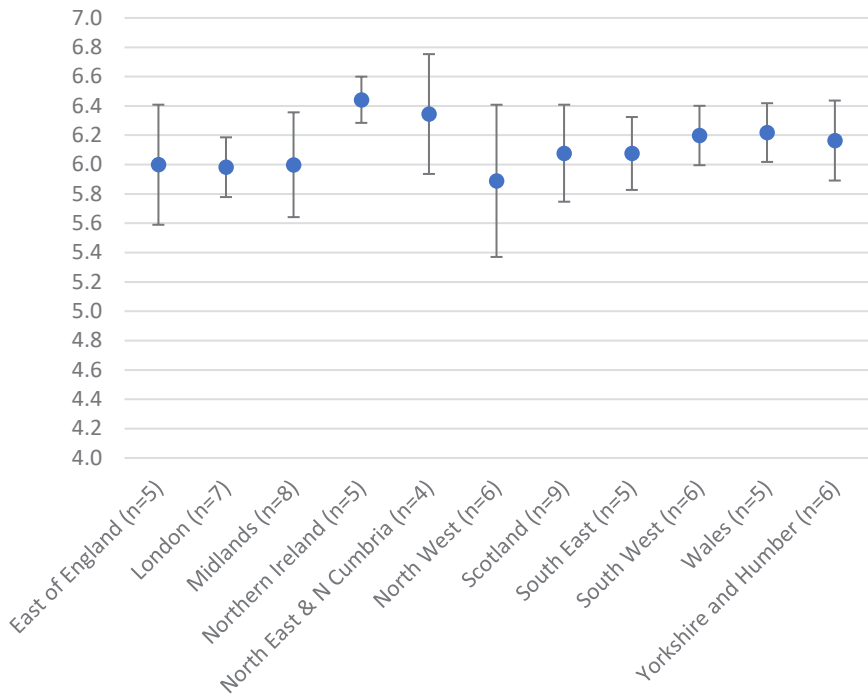


Thinking about how the renal team treats you, do they:

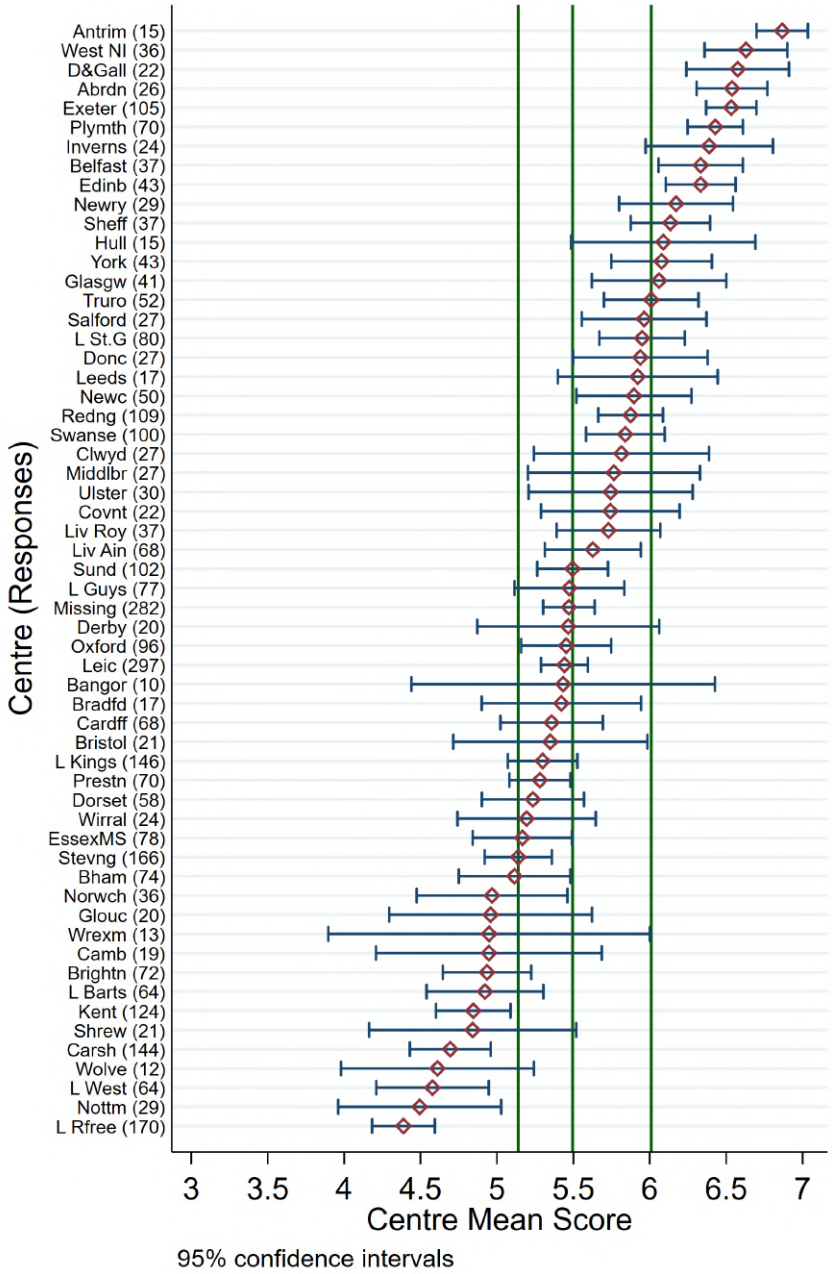
Q28. Take you seriously?

Q29. Show a caring attitude towards you?

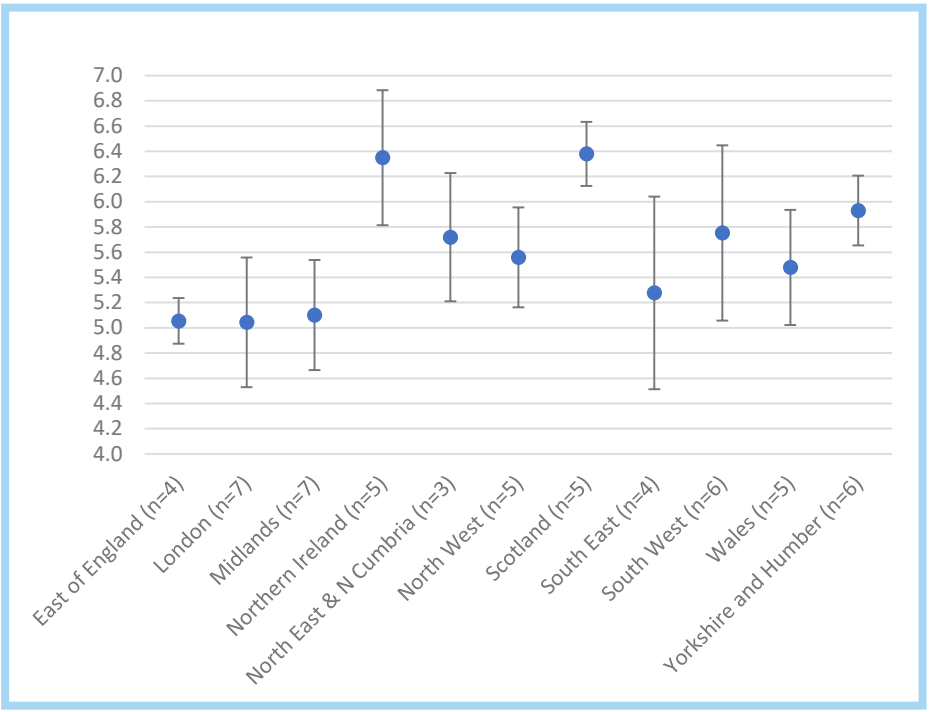
Q30. Ask you about your emotional feelings?



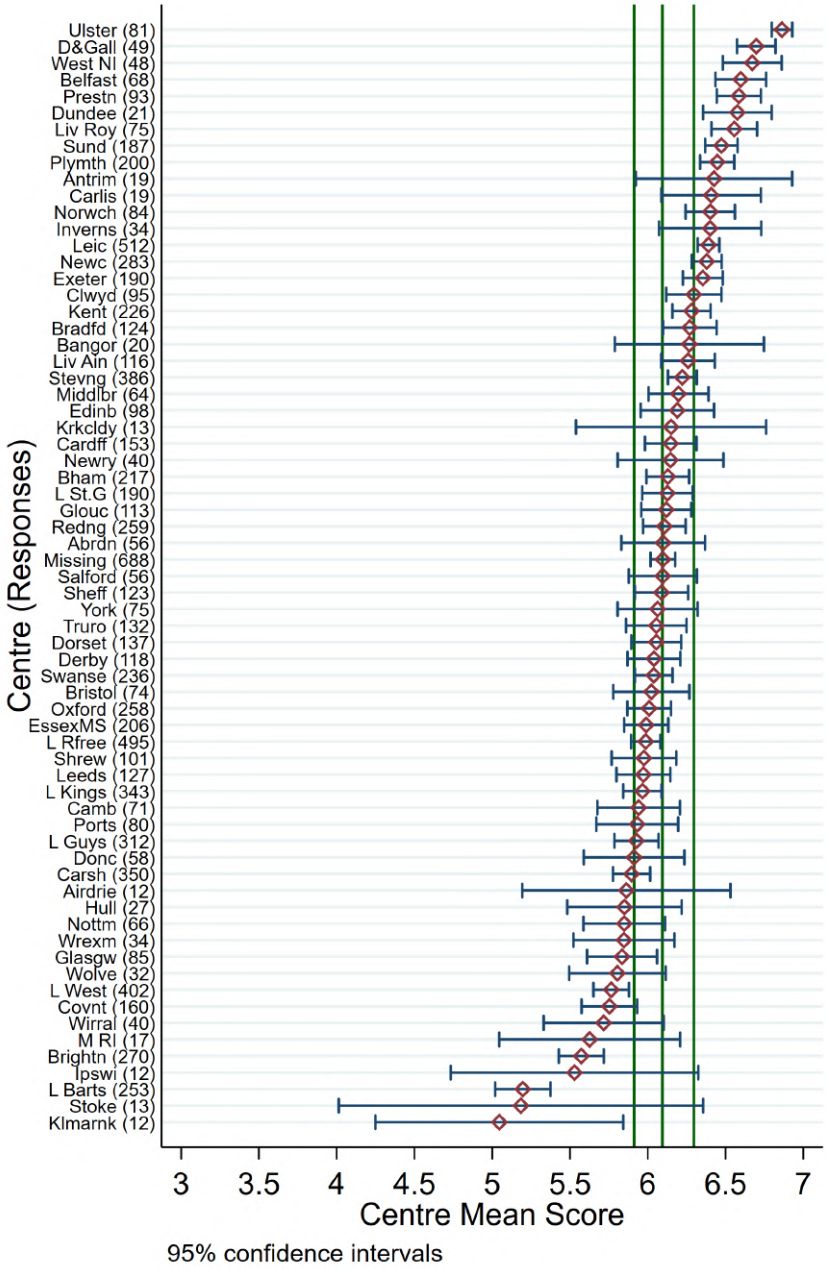
Theme 12: Transport



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?

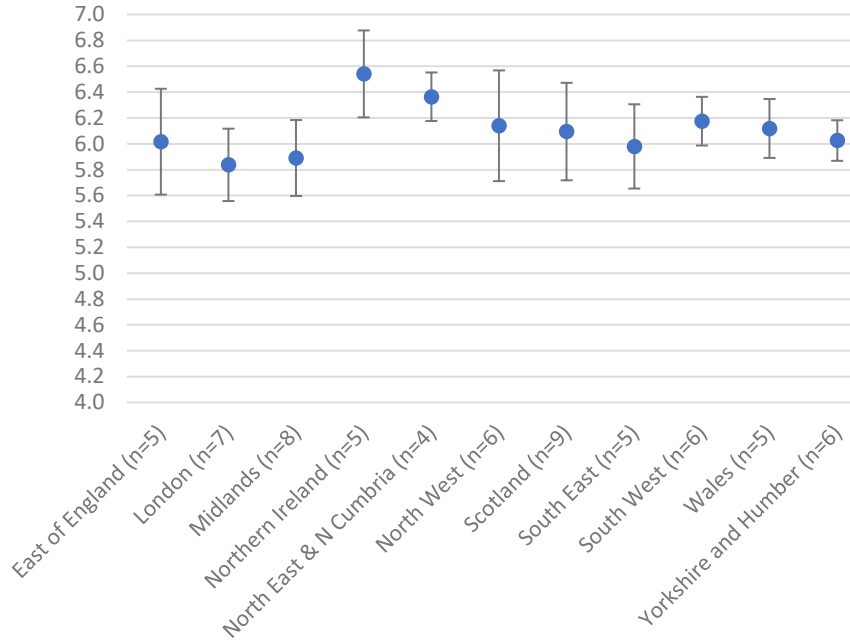


Theme 13: The Environment

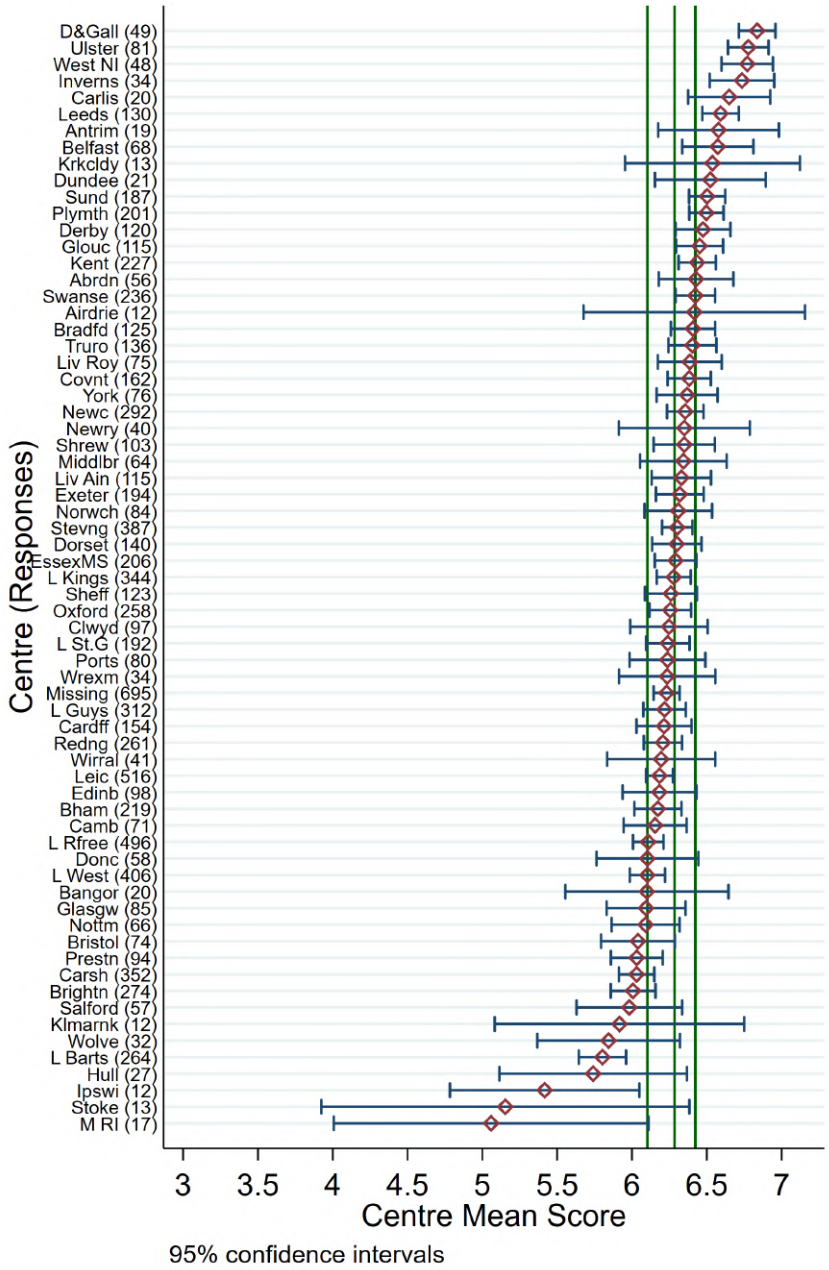


When you attend the renal unit, how would you grade:

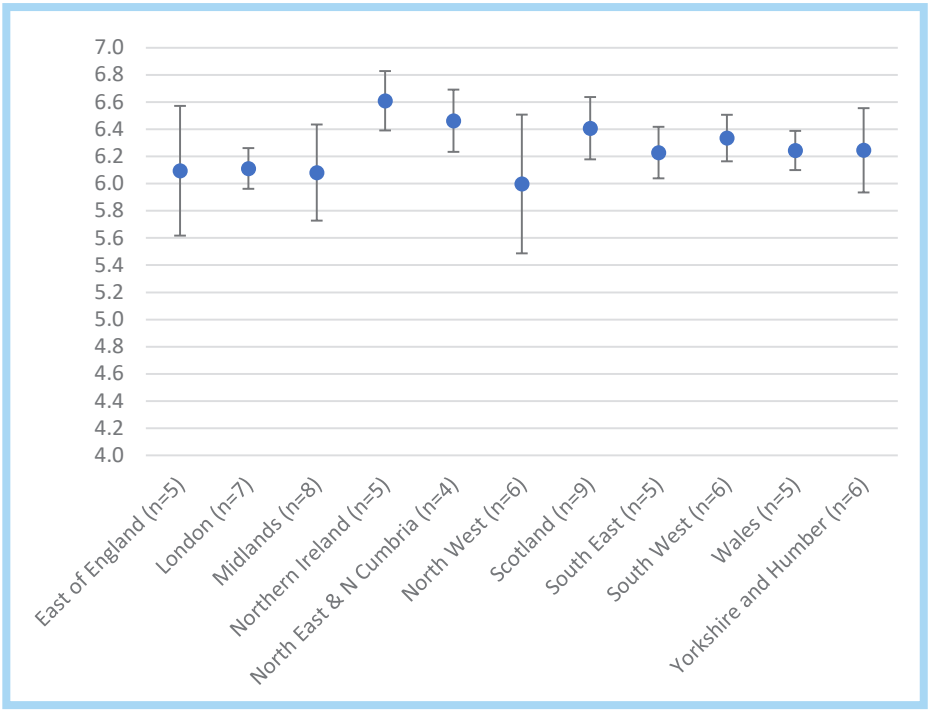
Q34. Accessibility (e.g., lifts, ramps, automatic doors)?
Q35. Comfort?
Q36. Cleanliness?
Q37. Waiting Area?
Q38. Parking?



Theme 14: Your Overall Experience



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



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