

Patient Reported Experience of Kidney Care in the UK 2021



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Foreword

The Kidney PREM report for 2021 is based on the responses of 12,416 kidney patients across the United Kingdom (UK) to the annual Kidney PREM survey. I was one of them (I received a transplant in 2018, donated by my wife). I was also a new arrival on the Kidney PREM working group, which supports the survey and the analysis of its results. In this foreword, I have been invited to give an impression of the work of the group and of the Kidney PREM experience from the perspective of a novice group member.

The Kidney PREM working group is a balanced mix of clinicians, researchers, charities and patients in which each has equal status. To find out more about its work, and the conclusions drawn from earlier Kidney PREM surveys, I looked at some of the more recent reports. I found a clear progression in attempting to widen and deepen our understanding of patient experience through kidney patients' own eyes. In 2018, the working group pressed for more co-decision making and greater patient involvement; in 2019, it asked whether the Kidney PREM was a driver for change at the local level? Does the Kidney PREM result in an improvement in patient experience? If so, can this improvement be translated to different settings? The message was that the Kidney PREM should not stand still.

By the following year the need to evolve was very clear as the 2020 report acknowledged that it had been a year like no other. Both patients and professionals were hugely affected by COVID-19 and the working group concluded that it was a testament to the value of these reports and the hard work of the whole community that the Kidney PREM had been completed (entirely digitally for the first time) by every one of the UK renal centres.

The 2021 report, again largely based on online responses, takes up the same theme, still overshadowed by the ongoing impact of COVID-19. Restrictions were easing as the vaccination programme gathered momentum, but for many kidney patients the anxiety that is never far from their minds remained, or even intensified, because of immuno-suppression and the threat of long COVID-19. The impact of the last 18 months on staff and patient resilience was evident, through delayed appointments for other conditions, transplant delays and re-starts.

All this led to more questions, more detailed and more difficult to explore. Trying to confront them led to innovations in methodology, including the necessity to adapt to, and benefit from, online methods. The survey was reviewed and some additional questions added. There is a greater emphasis on qualitative methods, to try to glean information which reflects patient experience better and provides a better basis for analysis. There is also a strong conviction that findings should be accessible, in formats which suit their audiences.

The original mission of the Kidney PREM was to help renal unit teams understand how patients feel about their care and show where improvements can be made. The Kidney PREM working group has approached this task over the years by exploring and analysing patient experience in a variety of ways, always looking to dig deeper, with better understanding. I believe that the Kidney PREM is an invaluable, possibly unique resource, which has proved itself to be flexible, innovative and focussed on the quality of life of kidney patients.



Dr. Alan Hancock

Kidney Patient and Representative

Acknowledgements

Kidney Care UK and the UK Kidney Association would like to thank the following people, without whom the Kidney PREM 2021 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; and,
- 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 a centre.

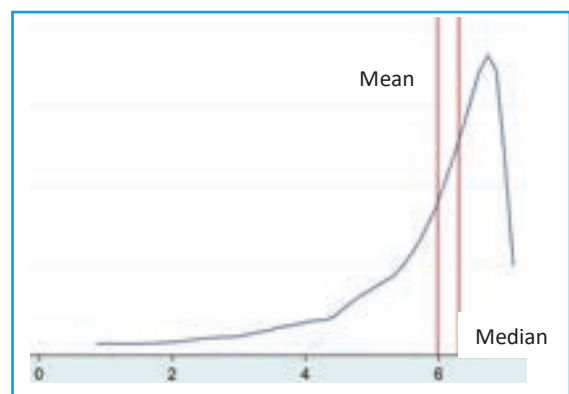
Mean: The mean centre score is calculated across patient scores by adding them together and dividing by the number of scores used, giving the mathematical average value.

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 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.

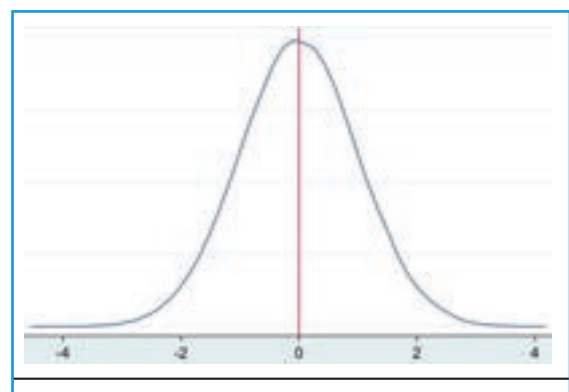
Median: If patient scores for a particular centre were listed in order, the median is the middle value separating the high scoring (top half) from the low scoring (bottom half).

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 fifth round of Kidney PREM data collection, following validation of the measure in 2017/18¹. The UK Kidney Association and Kidney Care UK present this as the most comprehensive report to date, drawing fully on the range of questions asked within each theme of care. This, supported by a qualitative analysis of written comments, provides a holistic view of patient experience of care as reported in 2021.

The Kidney PREM was available for completion online and on paper for six weeks through November and early December 2021. The 2021 questionnaire was the same as that used in 2020, with three additional patient characteristic questions.

A total of 12,416 valid surveys were submitted by people attending all 68 kidney centres in the UK. Most were from people treated in centres in England (85.4%), with 7.3%, 4.3% and 2.1% respectively from those in Wales, Scotland and Northern Ireland. Reflecting the profile of those treated for kidney disease, 58% of respondents are male.

The age profile of people completing Kidney PREM is similar to that of 2019, after a younger profile of respondents in 2020. This year, 47% are aged 56-74, 23% aged over 75.

Most respondents are White (76.9%), with a greater proportion of people with a Black ethnic heritage taking part in 2021 (8.3%) than 2020 (6.3%). Whilst participation amongst people of an Asian ethnicity is greater than last year (9.3% in 2021; 7.7% in 2020), these patients remain an underrepresented group compared to the UK Renal Registry figures (12.5%).

When looking at the current treatment of respondents, 14.1% of people have CKD (attending kidney clinic but not on dialysis or transplantation). Most people taking part in Kidney PREM are receiving haemodialysis (61.8%). Approaching one in five have had a transplant (17.7%), 6.4% are currently receiving peritoneal dialysis. The smallest group are those receiving home haemodialysis (2.1% of the total).

¹Hawkins, J., Wellsted, D., Corps, C., Fluck, R., Gair, R., Hall, N., Busby, A., Rider, B., Farrington, K., Sharma, S. & Van Der Veer, S. (2022). Measuring patients' experience with renal services in the UK: development and validation of the Kidney PREM. *Nephrology Dialysis Transplantation*.

Headline findings

- 12,416 people with kidney disease, from all 68 treating centres in the UK, took part in Kidney PREM this year, largely online.
- Overall experience of kidney care continues to be rated highly, with many patients who provided a written comment thanking staff for their commitment and efforts.
- For four in five participants, overall experience of kidney care stayed the same or was better during the last year of COVID-19. People with a transplant and those with CKD are more likely than those receiving dialysis to report a worse experience of kidney care over the last year.
- **Privacy and Dignity, Patient Information** and **Access to the Renal Team** continue to be high scoring and are the most consistent regardless of treatment.
- Experience of **Communication** between members of the renal unit team and people with kidney disease was scored far higher than communication between members of the renal team and GPs.
- Patient reported experience of **Sharing Decisions About Your Care** is particularly low scoring, with greater variability in experience between centres and across treatment types. More than half of those on haemodialysis have not been invited to take part in tasks of haemodialysis care, or do not know if they have.
- Broadly half of those receiving in-centre or in-satellite haemodialysis say that staff always **Needle** their fistula or graft with as little pain as possible; this remains a low scoring area with considerable range between centres.
- People receiving peritoneal dialysis and home haemodialysis report improved experience of **Support** from the renal unit team with treatment this year, compared to those receiving in-centre haemodialysis. Support in general continues to be a low scoring theme, notably lower than in 2019.
- Experience of **Advice on Fluid Intake** scores higher than **Advice on Diet**, and both are rated higher by those receiving dialysis than people with CKD or in receipt of a transplant.
- People receiving peritoneal dialysis report improved experience of **Tests**, with results being returned more quickly; this has worsened for those with a transplant and remains relatively low for people receiving in-centre haemodialysis. Half of respondents do not always understand their test results.
- Patient reported experience of **Transport** continues to be scored better compared to scores in 2019. As in previous years, Transport is one of the lowest scoring aspects of kidney care experience.
- People with CKD report relatively poorer experiences than people on kidney replacement therapy; the median (middle) score awarded for overall experience decreased to 6.0 from 7.0 in 2020 and remains there this year.

Recommendations to improve care in your unit using findings from the Kidney PREM

This report provides a national overview, the next stage is for data to be looked at in a local context, via the Kidney PREM portal hosted by UK Renal Registry. There, centres can see the areas of experience by region, centre and unit, and compare this to previous years' responses.

Written comments made by patients who wish to share their views with their treating centres, are already with Clinical Directors. These reveal on a centre level what matters to patients, and often, how they think experience of care could be improved.

This, shared between the multi-disciplinary team, people with kidney disease and their carers, as well as regionally and with commissioners, can provide focus for efforts to improve patient experience of care, from the 'little gems' (suggestions from patients for improvements to experience that would take little or no resource to implement) to the medium, and longer-term quality improvement suggestions.

Having reviewed the report and national data, the Kidney PREM working group have suggested some areas for centres to consider, to stimulate ideas and improvements in response to the data:

- Find out more about the Advanced Kidney Care population and their experiences of clinic
- Investigate the experiences of people with a working transplant, to understand where aspects of that pathway could best be improved
- Raise awareness about peer and kidney support groups and how to get in touch with them
- Work with local primary care providers to improve communication where this is known to be particularly poor; similarly with other professionals, including medical specialists where liaison and communication impacts negatively on patient experience
- Ask people with CKD coming into clinic how informed they feel about fluid intake and diet, and act to fill the gaps
- Reiterate to people the reasons for their tests, and check to see if they have understood them
- Reiterate how people can communicate with the renal team outside of appointments for the range of queries and concerns that may arise, and consider patient expectations about additional kidney doctor appointments
- Consider how people with kidney disease perceive the emotional support available at various stages of the pathway, and work in partnership with patients to improve access to emotional support where gaps are found
- Choose some 'little gems' to implement quickly and with little resource. The written comments show how patients can identify things which are very important to their experience of care that may go unnoticed to the kidney care team.

Summary of comments on experiences of care

“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 2021, 3,877 people completing Kidney PREM online provided comment on their experience of kidney care. Nine in ten (90.2%) gave consent for their comment to be passed back to their treating centre.

For the analysis and interpretation, comments were coded and grouped into themes, some of which align to the 13 areas of care covered by the Kidney PREM, some of which are new. A similar analysis was performed in 2020; both reports are available on the UK Kidney Association Kidney PREM website.

- People with transplants and those receiving in-satellite haemodialysis are more likely than others completing Kidney PREM to provide an additional comment on their experience of care.
- Positive comments about the renal unit team are by far the most common this year, as was the case in 2020. These tend to be short with clear sentiment:

*Nursing staff and support staff are top notch
(56-74, White, Sat HD)*

*Many thanks to all the kidney staff.
(65-74, Asian, CKD)*

*The home dialysis unit is always excellent great staff.
(75+, White, HHD)*

*.... everything is covered by the excellent staff.
(31-55, Other, Transplant)*

*All staff have shown a considerate and caring approach to my situation. They are a fantastic group of people.
(56-74, [ethnicity not provided], HHD)*

*The nurses are very caring friendly and approachable.
(56-74, Black, PD)*

- In 2021 younger patients tended to comment on the need for **Support** including general support for young people with CKD, and also financial support. People who are older commented on **Environment**, including the need for more comfortable chairs, and the suitability of hospital provided **Transport**.

- Whilst people with CKD commented on their positive experience of **Appointments** including the use of telephone calls, **Communication** was raised as an issue, including wanting more frequent communication with consultants and better methods of contacting the renal team. People with a transplant raised similar issues about communication, and also commented on **COVID-19**, with concerns over vaccinations and safety.
- People receiving peritoneal dialysis commented mainly on **Staff** and **Environment** (accessibility of the unit), as did those receiving in-centre haemodialysis, for whom **Transport** was a recurring theme (reflecting the age profile). People receiving home haemodialysis commented on **Support** and **COVID-19**, wanting more information regarding the pandemic and other options for support e.g. support groups.
- Comments relating to **Environment** featured highly in both 2021 and 2020 and were mostly negative; related to comfort, temperature control, and waiting areas.
- **Support** accounts for a far greater proportion of comments in 2021 compared to last year, particularly psychological support and how this is lacking.
- Issues with **Communication** feature highly and are generally negative, with comments in 2021 relating to issues with communication within the renal unit team, rather than communication between the renal unit team and those with kidney disease, which was the focus in 2020.
- In both 2021 and 2020, patients commented on lack of **Information**, particularly updates about treatment, kidney disease progression, and transplant prospects. People also want more access to advice about diet, fluid intake and exercise.
- In 2021, people have continued to provide feedback on ‘**little gems**’, areas of care where experience could be improved with relatively little effort, or where ‘small’ things impact negatively on care which might be easily changed.

Both reports are available on the UK Kidney Association Kidney PREM website.

Kidney PREM 2021

Introduction

UK Kidney Association and Kidney Care UK are committed to improving the experience of care for people with kidney disease. 2021 was the fifth year in which patients, 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 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.

Whilst COVID-19 is very much still with us, we have not made it the story of 2021, or the reason for differences between now and 2020. We provide our usual focus on several aspects of kidney care and delve into variations by centres and patient characteristics. In this way, we present the national picture, and encourage commissioners, renal networks, patients 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”***
- Analysis of free text responses to the questions on experience of care during COVID-19
- Graphs showing the centre scores for each theme comparing 2021 to 2019
- 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 2021 survey
- Appendices A-E

Full Kidney PREM 2021 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 a further question on overall experience. Patients 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 patients can comment on any aspect of care that has not already been covered. Patient characteristics are collected including treating centre, treatment type and location, age, sex, ethnicity and use of PatientView².

In the 2021 Kidney PREM questions were added to collect: in-centre haemodialysis patient participation in shared care; the treatment status of patients not currently on kidney replacement therapy (KRT); and the type and nature of help patients have, to complete the Kidney PREM.

The 2020 question on experience of care during COVID-19 was repeated this year, with minor changes to the wording in terms of the pandemic being something we live with rather than a new concern.

Data collection

Kidney PREM 2021 ran for six weeks from 1st November to 12th December. The collection of the data was primarily publicised as an online survey, with links available on both the UK Kidney Association and Kidney Care UK websites. As well as English, the online Kidney PREM was available in Welsh, Urdu and Gujarati. To encourage equity of access, centres were given paper surveys for distribution to patients 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 those centres whose response numbers had decreased in 2020 compared to 2019. Some centres requested additional surveys during the collection window. In total, 8,353 paper copies were distributed to centres, 2,566 returned.

Promotional materials including posters were distributed to centres in September 2021, and some centres were able to send the Kidney PREM link to patients via text message or email. Online numbers were monitored and circulated to centres throughout the collection period. The survey was promoted via adverts on Facebook, targeting kidney patients in geographical areas where response rates and awareness appeared low.

²[Patient Knows Best]

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 UK Renal Registry renal unit codes onto paper copies prior to issuing them to patients. Individuals whose treating centre could not be identified were excluded from centre scores but are shown as centre “Missing” in graphs.

Analysis and reporting

The validated Kidney PREM has been used for annual data collection since 2017/18. This report presents results across the last three years from 2019; some amendments to the calculation of Needling and Scheduling & Planning scores were made that year, and so caution should be taken when comparing 2019 results of these themes to 2020 and 2021.

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 Kidney PREM Technical Report.

Throughout this report, the total number of responses used to estimate individual statistics may vary since not all questions were answered by all patients. To preserve patient anonymity, in cases where a group average would be calculated on less than seven respondents, the data is withheld. People with kidney disease who are not receiving kidney replacement therapy are referred to as CKD patients.

Participation

For the first time when both paper and online options have been available, people taking part in Kidney PREM 2021 did so primarily online; with just one in five participants completing paper versions (20.7%). The figure in Appendix A shows the proportions of patients completing Kidney PREM 2021 online or on paper, presented by treating centre. Seven patients responded online in a language other than English; five in Welsh, and one in each case in Urdu and Gujarati.

Four in every five
patients completed the
Kidney PREM online



This year, respondents were asked whether they had help completing the Kidney PREM. One in four (27.3%) did, more likely amongst the over 75's, patients who are of Asian, Black or Other ethnicity, and those receiving in-centre or in-satellite haemodialysis (Appendix B, Table 1).

³Please only complete one paper PREM or one online, not both. You can ask a friend or family member or a volunteer to help you complete the survey.

The main reason for having help to complete the Kidney PREM is connection to haemodialysis machine (51.2%), or another issue (34.5%) not including language or frailty (Appendix B, Table 3). Language is a reason for having help to complete the Kidney PREM for 7.4% of patients, frailty for 6.9%, particularly people on peritoneal dialysis, those who have a transplant or with CKD.

Response profile

12,416 valid surveys were submitted as part of Kidney PREM 2021, an increase of 2,771 on 2020, with the name of the treating centre completed legibly in most cases (96.7%). Responses were received from patients at all 68 kidney centres in the UK, across 301 satellites (Appendix C shows participation in 2020 and 2021, by treating centre).

Patients from centres in England completed a greater proportion of surveys this year (85.4% of the UK total; 83% in 2020; Table 4). Whilst there were slightly fewer responses from patients receiving care in Wales and Scotland, the increase in responses from patients receiving care in Northern Ireland was approaching three-fold (266 in 2021; 94 in 2020).

Table 4: Regional profile of people completing Kidney PREM 2021*

	Freq (% of returns)	% of KRT population
England		
East of England	880 (8.5%)	18.5%
London	3,281 (31.7%)	22.3%
Midlands	1,660 (16.1%)	15.0%
North East	580 (5.6%)	19.3%
North West	770 (7.5%)	12.1%
South East	1,651 (16.0%)	23.5%
South West	926 (9.0%)	18.9%
Yorkshire & Humber	587 (5.7%)	10.1%
England Total	10,606 (85.4%)	18.4%
Northern Ireland		
N Ireland Total	266 (2.1%)	13.3%
Scotland		
Scotland Total	530 (4.3%)	9.9%
Wales		
Wales Total	902 (7.3%)	27.6%
UK Total	12,416	18.2%

* 1. The UK Renal Registry collects data about those receiving KRT only, although PREM returns include people with CKD not on KRT, so percentages are not directly comparable to the whole CKD population

2. Totals include those where respondents gave their country of treatment but not their centre (299), or did not provide any geographical information (112)

Patient characteristics

The profile of people completing Kidney PREM in 2021 was closer to 2019 than the pandemic year of 2020. This includes a greater proportion of responses from people receiving haemodialysis treatment than is true of the KRT population. Tables 5a and 5b show how the 2021 Kidney PREM respondent profile compares to data collated by The UK Renal Registry for patients receiving KRT.

Gender, age and ethnicity

As in previous years, more males (57.7%) than females (41.6%) completed Kidney PREM, reflecting the greater number of males in the KRT population (61.3%) (Table 5a).

Most respondents were aged 56-74 (44.1%). A minority were aged under 30 (3.1%), with most of the remaining participants being a broadly even split, aged 31-55 (26.6%) or over 75 (23.4%). This sees the age profile return to that of 2019, following 2020, where a greater proportion were 31-55 (30.4%) than over 75 (18.4%), likely reflecting the online-only data collection in 2020.

Age profiles across treatment types were as expected (Appendix E); over 65's making up over half of the peritoneal, in-centre and in-satellite haemodialysis populations, with the transplant and home haemodialysis populations including the greater number of 41-64 year olds'.

Responses from patients who are Asian (9.3%) and Black (8.3%) increased compared to 2020, although those from an Asian background remain under-represented compared to the KRT population (12.5%) and the proportion participating in 2019 (10.1%). There was a smaller proportion of White participants than in previous years (76.9%,) who remain over-represented compared to the population profile (70.4%).

Table 5a: Characteristics of the people who completed the Kidney PREM in 2021, 2020 and 2019 [Age, gender and ethnicity]

	2021	Kidney PREM 2020	2019	UK KRT Patients as of end of 2020
Total	12,416	9,645	16,469	68,249
Age				
≤30	376 (3.1%)	400 (4.1%)	514 (3.2%)	4.8%
31-55	3,261 (26.6%)	2,929 (30.4%)	3,892 (24.3%)	36.0%
56-74	5,763 (47.0%)	4,537 (47.0%)	7,198 (44.9%)	44.1%
≥75	2,868 (23.4%)	1,779 (18.4%)	4,416 (27.6%)	15.2%
Missing	148	-	449	-
Gender				
Female	5,038 (41.6%)	4,177 (43.3%)	5,937 (40.6%)	38.7% ⁴
Male	6,986 (57.7%)	5,404 (56.0%)	8,629 (58.9%)	61.3%
Rather not say	86 (0.7%)	64 (0.7%)	74 (0.5%)	-
Missing	306	-	1829	-
Ethnicity				
Asian	1,137 (9.3%)	743 (7.7%)	1,558 (10.1%)	12.5% ⁵
Black	1,005 (8.3%)	613 (6.4%)	1,137 (7.4%)	7.6%
White	9,358 (76.9%)	7,896 (81.9%)	12,010 (78.2%)	70.4%
Other	402 (3.3%)	203 (2.1%)	401 (2.6%)	2.9%
Rather Not Say	260 (2.1%)	190 (2.0%)	246 (1.6%)	-
Missing ⁶	254	-	1,117	6.6%

⁴ Currently, patients only able to select Male or Female⁵ Ethnicity data from England, Wales and Northern Ireland only.⁶ There is no missing data in 2020 as Kidney PREM was online only. The online version is set up so that each question must be answered to progress through the survey. Paper surveys were available in 2019 and 2021, where patients can leave questions blank, resulting in missing responses.

Treatment profile

Similar numbers of patients who are transplanted, not on KRT or receiving peritoneal dialysis took part in Kidney PREM in 2020 and 2021, providing good year on year data. The significant increase in haemodialysis patient participation this year has reduced the proportionate contribution of others.

Table 5b shows that haemodialysis patients continue to be most likely to take part in the Kidney PREM (61.8% of this year's responses). The next largest groups are transplant (17.7%) and CKD patients (14.1%), with 6.4% receiving peritoneal dialysis, and the smallest group were those receiving home haemodialysis (3.5% of participating haemodialysis patients, 2.1% of total).

In comparison with Kidney PREM 2020, the age profile of people with CKD (attending clinic but not in receipt of KRT) has shifted to include more over 75's, potentially due to the increase in paper survey use this year.

Most patients with CKD who are not receiving KRT, attend clinic regularly for monitoring of their kidney function only (69.8%). Others are considering treatment options as kidney failure approaches (n=356), of these, half have chosen a form of dialysis (51.1%), a third have not decided (35.4%) and the remainder have chosen conservative⁷ management (13.5%). This leaves a group who are not on KRT, and do not know whether their current care plan is monitoring renal function or considering treatment for end stage renal disease (8.2%).

⁷ In the Kidney PREM as 'conservative / supportive / medical management'

Table 5b: Treatment profile of the people who completed the Kidney PREM in 2021, 2020 and 2019

	Kidney PREM			UK KRT Patients as of end of 2020
	2021	2020	2019	
Total	12,416	9,645	16,469	68,249
<i>Treatment</i>				
Transplant	2,148 (17.7%)	2,172 (22.5%)	2,183 (14.2%)	57.0%
Haemodialysis	7,497 (61.8%)	4,959 (51.4%)	9,618 (62.4%)	37.4%
Peritoneal	772 (6.4%)	632 (6.6%)	1,166 (7.6%)	5.6%
CKD	1,710 (14.1%)	1,882 (19.5%)	2,437 (15.8%)	Unknown
Missing	289	-	1,065	-
<i>Haemodialysis Location</i>				
At Home	259 (3.5%)	239 (4.8%)	337 (3.6%)	5.4%
In-Satellite	4,054 (54.8%)	2,748 (55.4%)	4,557 (49.0%)	53.4%
In-Centre	3,090 (41.7%)	1,972 (39.8%)	4,400 (47.3%)	41.2%
Missing	94	-	324	-
<i>Status – not on KRT⁸</i>				
Attend for monitoring	1,130 (66.1%)			
Approaching ESRD:	356 (22.0%)			
Don't know	132 (8.2%)			
Missing	92			
Approaching ESRD:				
(a) KRT chosen	182 (51.1%)			
(b) CM chosen	48 (13.5%)			
(c) Not decided	126 (35.4%)			

Participation in shared care (those on haemodialysis treatments only)

One in four of those on in-centre or in-satellite haemodialysis participating in Kidney PREM participate in shared care (26.3%), notably those who are younger and / or who dialyse in satellite units (Table 6). Many have not been invited to participate in any tasks of their haemodialysis care (39.7%) or don't know (15.9%), particularly the over 75's. Positively, people who have been invited to take part in shared care are more likely to participate than to decline.

⁸ Question filtered – those attending kidney clinic but not on dialysis or transplantation. ESRD (End Stage Renal Disease), CM (Conservative Management)

Table 6: Participation in shared care by those receiving haemodialysis

	N	Participating	Declined	Not Invited	Don't Know
Age					
≤30	182	51 (2.8%)	34 (2.7%)	60 (2.2%)	37 (3.4%)
31-55	1,645	547 (30.1%)	263 (21.0%)	546 (20.0%)	289 (26.3%)
56-74	3,174	816 (44.9%)	625 (50.0%)	1,262 (46.1%)	471 (42.9%)
≥75	1,901	405 (22.3%)	328 (26.2%)	867 (31.7%)	301 (27.4%)
Missing	63	14	7	32	10
Gender					
Female	2,554	667 (37.0%)	476 (38.4%)	1,015 (37.5%)	396 (36.4%)
Male	4,219	1,122 (62.3%)	753 (60.8%)	1,673 (61.8%)	671 (61.7%)
Rather not say	59	12 (0.7%)	9 (0.7%)	18 (0.7%)	20 (1.8%)
Missing	133	32	19	61	21
Ethnicity					
Asian	764	181 (10.0%)	141 (11.3%)	268 (9.9%)	174 (16.0%)
Black	703	205 (11.3%)	113 (9.1%)	250 (9.2%)	135 (12.4%)
White	4,987	1,321 (72.7%)	926 (74.3%)	2,043 (75.3%)	697 (64.0%)
Other	242	73 (4.0%)	32 (2.6%)	91 (3.4%)	46 (4.2%)
Rather Not Say	171	38 (2.1%)	34 (2.7%)	62 (2.3%)	37 (3.4%)
Missing	98	15	11	53	19
Haemodialysis Location					
In-Satellite	3,963	1,150 (63.2%)	783 (19.8%)	1,427 (52.0%)	603 (54.9%)
In-Centre	2,947	669 (36.8%)	464 (15.7%)	1,319 (48.0%)	495 (45.1%)
Unknown HD	55	14	10	21	10
Total	6,728	1,833 (26.3%)	1,257 (18.0%)	2,767 (38.7%)	1,108 (15.9%)



Use of PatientView

The number of people participating in Kidney PREM and using PatientView (where available) has risen annually to 4,211 in 2021, but as a proportion this has declined this year (35.5% in 2020; 41.6% in 2021; Table 7). This may be a result of Kidney PREM being entirely online last year, when a greater proportion of participants would have been comfortable with online access.

As in previous years, some do not know whether they use PatientView (14.5%). A further 541 completing Kidney PREM on paper did not answer this question.

The Kidney PREM refers only to PatientView, although this has now become Patient Knows Best and alternative patient record systems are used in some centres. Future surveys will aim to capture information about the usage of all such available apps, to reflect their usage in the whole UK kidney community.

Table 7: Kidney PREM participant use of PatientView: 2021, 2020 and 2019

	Kidney PREM		
	2021	2020	2019
Total	1,2416	9,645	16,469
<i>PatientView</i>			
Yes	4,211 (35.5%)	4,012 (41.6%)	3,866 (30.2%)
No	5,946 (50.1%)	4,300 (44.6%)	6,523 (51.0%)
Don't Know	1,718 (14.5%)	1,333 (13.8%)	2,411 (18.8%)
Missing	541	-	3,669

Patient experience of kidney care

Patient experience of kidney care in 2021 and compared to previous years is presented here in three sections, opening with the participant view of how much COVID-19 continues to impact on their experience of care. This is followed by an overview of patient experience scores across the 13 Kidney PREM themes at a national level, and then overall experience at centre level:

The 13 Kidney PREM themes:

- | | |
|--------------------------|-----------------------------------|
| Access to the Renal Team | Sharing Decisions About Your Care |
| Support | Privacy and Dignity |
| Communication | Scheduling and Planning |
| Patient Information | How the Renal Team Treats You |
| Fluid Intake and Diet | Transport |
| Needling | The Environment |
| Tests | |

As in previous years, there is variation in experience according to which centre a patient attends for treatment, which is then examined in detail across each of the 13 themes of care by centre, treatment type and region, including a breakdown of scores per question. This shows which aspect of each theme of care experience are performing well and less well and provides a sense of direction for local quality improvement work.

Impact of COVID-19 on patient experience of care

Overall, people's experience of kidney care was more likely to have been better (31.8%) than worse (13.9%) during the last year of the pandemic (Table 8). This is an encouraging picture compared to 2020 when there was less distinction (23.6% reporting better experience, 17.3% worse). 54.3% of participants felt that their care during the last 12 months has stayed the same, slightly fewer than in 2020 (59.0% in 2020).

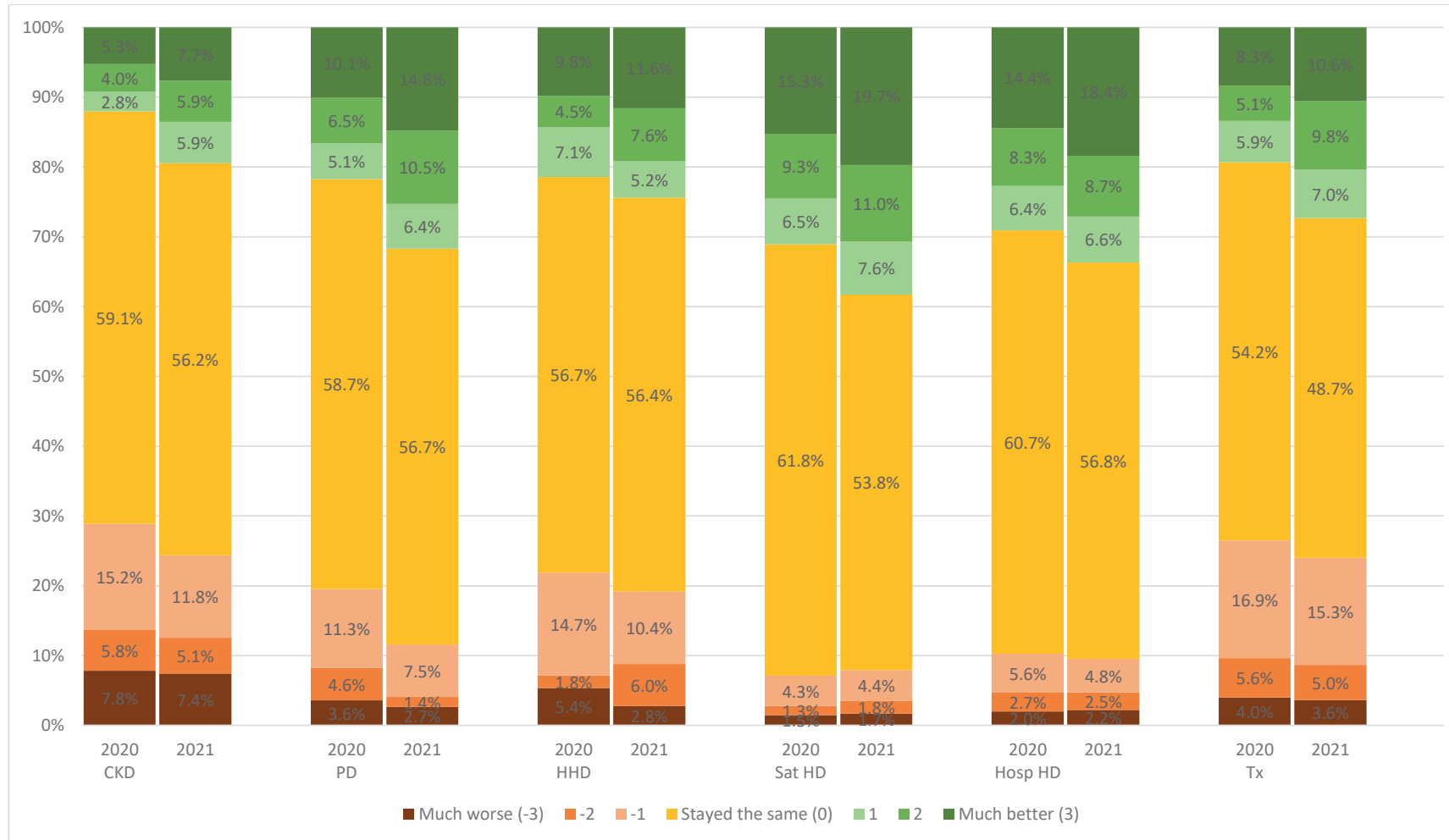
Whilst sizeable proportions of people on peritoneal dialysis and who have been transplanted say their experience of care has been better in the last year, one in four of those with a transplant report that experience has got worse (24.0%).

As shown in Figure 1, people receiving in-satellite and in-centre haemodialysis remain far more likely than others to feel that experience of care has stayed the same or improved. In turn, those on home therapies or with a transplant report a generally better experience than people with CKD not receiving KRT.

Table 8: Summary: Impact of COVID-19 patient experience - 2021 and 2020 by treatment

	CKD		Peritoneal		Haemodialysis		Transplant		Total	
	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020
Worse	388 (24.3%)	494 (28.9%)	83 (11.6%)	114 (19.5%)	647 (9.0%)	430 (9.0%)	490 (24.0%)	540 (26.5%)	1,608 (13.9%)	1,578 (17.3%)
Same	896 (56.2%)	1,011 (59.1%)	406 (56.7%)	343 (58.7%)	3,976 (55.2%)	2,912 (61.1%)	995 (48.7%)	1,104 (54.2%)	6,273 (54.3%)	5,370 (59.0%)
Better	310 (19.4%)	206 (12.0%)	227 (31.7%)	127 (21.7%)	2,586 (35.9%)	1,423 (29.9%)	558 (27.3%)	394 (19.3%)	3,681 (31.8%)	2,150 (23.6%)
Total	1,594	1,711	716	584	7,209	4,765	2,043	2,038	11,562	9,098

Figure 1: Impact of COVID-19 patient experience - 2021 and 2020 by treatment



National patient experience of kidney care by theme

Mean scores for each theme of the Kidney PREM were calculated from centre scores and are shown in Figure 2.

High Scoring Themes:

- As in previous years, **Privacy and Dignity** (6.40), **Patient Information** (6.35) and **Access to the Renal Team** (6.34) are high scoring themes of patient experience of kidney care.
- Scores for experience of **Privacy and Dignity** are lower than 2020 but improved on 2019.
- **Overall Experience** has seen a slight increase in score in 2021 and remains high at 6.24.
- Patients continue to report positive experience for **Tests** (6.20) and **Scheduling & Planning** (6.19).

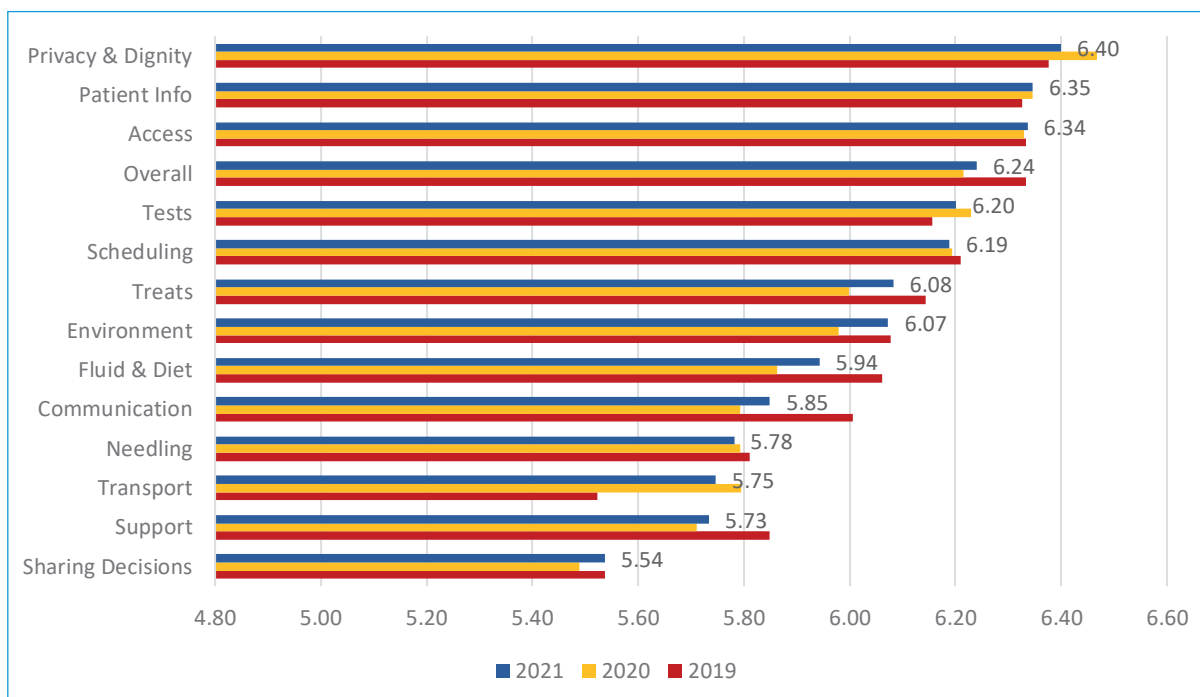
Low Scoring Themes:

- Whilst improved in the last 12 months, patient scores for experience of **Sharing Decisions About Your Care** (5.54) are still relatively low.
- Patient experience of the **Support** received from the renal team has also improved this year (5.73) but remains some way short of scores in 2019.
- Experience of unit-arranged **Transport** remains low (5.75), but is still significantly higher than in 2019, and a notable area where the pandemic may have made a positive impact.
- In-hospital and in-satellite haemodialysis patient experience of **Needling** (5.78) shows a slight year on year decline.

How the Team Treats You (6.08), **Environment** (6.07), **Fluid and Diet** (5.94) and **Communication** (5.85) have all seen improved patient experience scores in the last 12 months, however, all remain mid-range compared to experience of other aspects of care.

Where scores for both **Communication** and **Environment** fell noticeably in 2020, patient rating of the unit environment has broadly returned to 2019 scores.

Figure 2: Mean scores for the 13 Kidney PREM themes and the Overall experience question, showing values from 2021, 2020 and 2019



Patient scores for overall experience of care by centre

The summary question, “How well would you grade your overall experience of the service provided by your renal unit?” is answered on a scale from 1 (worst it can be) to 7 (best it can be). Overall experience is scored highly at 6.24, with centre scores ranging from 5.10 to 6.89.

Mean scores were calculated for each of the 68 renal centres, shown in Figure 3, overlaid on a chart showing the distribution of patient scores for each centre.

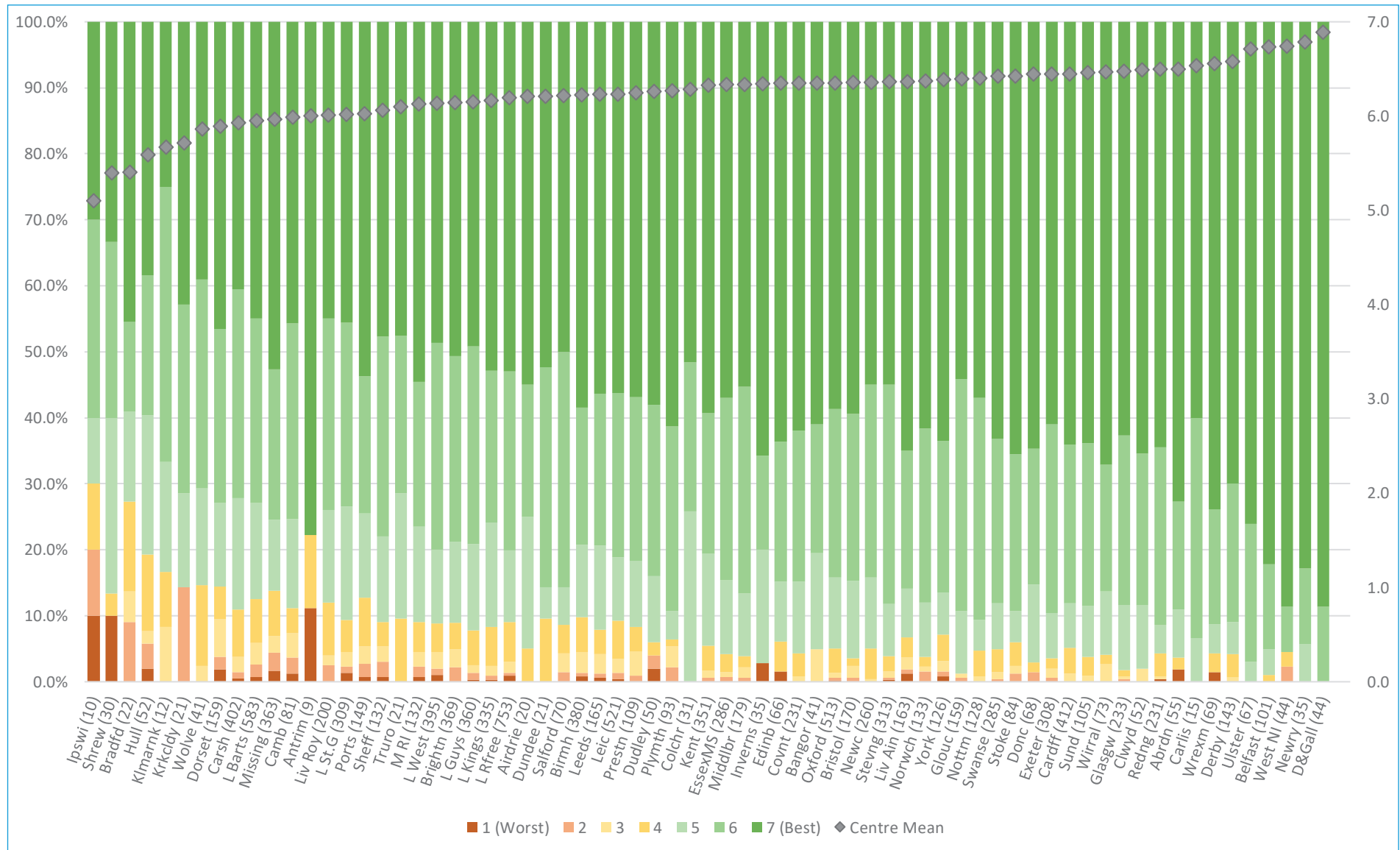
In Figure 3, the number in brackets next to centre names is the number of people responding to this question at each centre, ranging from nine to 753. These numbers are vital for reading the figure accurately:

- for a centre with 10 responses, one patient scoring ‘1’ for overall experience shows as red for 10% of the sample
- for a centre with 400 responses, a single patient scoring ‘1’ would not show on the chart.

Most centres’ participants score their overall experience highly (5-7), with five centres receiving entirely positive scores. Many centres have a small but significant proportion of patients scoring overall experience poorly (1-3).

Appendix E shows centre means with confidence intervals, medians and centre quartiles.

Figure 3: Centre scores for overall experience of the service provided by renal centres (Q39 in Kidney PREM)



Patient experience across Kidney PREM themes by treatment

In this section, medians and interquartile ranges (IQR) have been used because they are a good way to measure changes in scores across most patients within each group⁹.

Total scale scores showed little difference across treatment groups, but variation in experience according to treatment groups has increased this year, as median scores range from 6.19 to 6.47; twice that of 2020 (range of 0.28 compared to 0.14).

How experience changed between 2020 and 2021 – by treatment group:

CKD (non KRT)

There is little difference in scores compared to 2020, other than negative change for Communication and Sharing Decisions, which have seen decreases in scores of -0.20 and -0.33.

Peritoneal Dialysis

Scores improved or were stable across all areas of kidney care experience, notably Support and Tests which both increased by +0.34. Environment, Communication and Shared Decision Making saw increases of +0.20, +0.15 and +0.09 respectively.

Home Haemodialysis

As with those on peritoneal dialysis, scores awarded by those on home haemodialysis were the same or improved on 2020. Notably, increases were seen in Support (+0.34), Shared Decision Making (+0.33) and Communication (+0.15).

In Centre and In Satellite Haemodialysis

As in 2020, scores are similar across people who attend for haemodialysis treatment; generally slightly higher for those in-satellite compared to in-centre. Both saw increases in scores for Environment and Communication compared to last year (broadly +0.1).

Whilst in-satellite patient scores for Support and Tests are stable compared to 2020, these have decreased for in-centre patients, by -0.33 for Support and -0.17 for Tests.

Transplant

Scores awarded for Tests and Communication have decreased (-0.33 and -0.25); most others are stable, apart from Shared Decision Making which has seen positive change (+0.09).

⁹This is particularly the case for Kidney PREM, as theme scores at a national level are heavily left-skewed (most patients have selected high values (5/6/7) with very few low scores chosen (1/2/3)). Other sections and charts within this report use means to describe centre scores, which is appropriate because these, local, values are approximately normally distributed.

Areas which saw the greatest variation in scores in the last 12 months, by treatment types:

Shared Decision Making: stable for some, a change of +0.33 for people on home haemodialysis compared to -0.33 for those with CKD.

Support: largely stable but with a positive difference in score for patients on peritoneal dialysis or home haemodialysis (+0.34) a negative one for people on in-centre haemodialysis (-0.33).

Communication: Variation across the board, with scores changing by up to +0.15 for those on peritoneal dialysis and all forms of haemodialysis; falling for those with CKD (-0.20) and who have had a transplant (-0.25).

Scheduling: An increase in score of +0.50 for those on in-centre haemodialysis.

Tests: Year-on-year stability for most groups, with change of +0.34 for people on peritoneal dialysis, compared to decreases for those on in-centre haemodialysis (-0.17) and who have had a transplant (-0.33)

How experience in 2021 compares across treatment groups

Consistency:

Scores awarded to Access, Patient information and Privacy & Dignity are the highest possible amongst all treatment groups at 7.0. In-centre and in-satellite haemodialysis patients are consistent in their scoring of Needling and Transport (median score of 6.0).

Variation:

Median scores for Fluid & Diet, Shared Decision Making and Overall Experience show the most variation, +/- 1.0.

Scores for advice given on Fluid intake & Diet range from 6.0 for people with CKD not on KRT; to 6.50 for patients who have had a transplant or are on peritoneal dialysis, 7.0 for patients on haemodialysis.

Scores for Shared Decision Making are lowest amongst those with CKD and who attend centre or satellite haemodialysis (6.0), higher for transplant and peritoneal dialysis (6.42), and highest for those who have haemodialysis at home (7.0).

Overall Experience: For the last three years, all KRT groups have scored a median of 7.0 for overall experience. The median overall experience score for those with CKD decreased from 7.0 to 6.0 in 2020 and has stayed there in 2021.

Scores for Environment vary across a range of 0.80: increasing from 5.80 for those with a transplant, to 6.50 and 6.60 for those on in-centre and in-satellite haemodialysis.

Table 9: Comparison of median Kidney PREM scores by treatment group for 2021 and 2020

	CKD (non-KRT)					Peritoneal Dialysis					Home Haemodialysis				
	2021 (n=1535)		2020 (n=1739)		21v20	2021 (n=636)		2020 (n=595)		21v20	2021 (n=230)		2020 (n=227)		21v20
	Median	IQR	Median	IQR		Median	IQR	Median	IQR		Median	IQR	Median	IQR	
Access	7.00	5.67-7	7.00	6 - 7	0	7.00	6.33-7	7.00	6.33-7	0	7.00	6.33-7	7.00	6.33-7	0
Support	6.00	4-7	6.00	4 - 7	0	6.67	5.-7	6.33	5.-7	0.34	6.67	5-7	6.33	5-7	0.34
Communication	6.00	4.75-7	6.20	5 - 7	-0.20	6.40	5.5-7	6.25	5.-7	0.15	6.10	5-7	6.00	5-7	0.1
Patient Info	7.00	6-7	7.00	6 - 7	0	7.00	6.5-7	7.00	6 - 7	0	7.00	6-7	7.00	6-7	0
Fluid & Diet	6.00	3.5-7	6.00	3.5 - 7	0	6.50	5.5-7	6.50	5.5 - 7	0	7.00	6-7	7.00	6-7	0
Needling	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Tests	6.67	5.67-7	6.67	5.67 - 7	0	6.67	6-7	6.33	5.5 - 7	0.34	6.67	6-7	6.67	6-7	0.33
Sharing Decisions	6.00	4.67-7	6.33	4.5 - 7	-0.33	6.42	5.33-7	6.33	5 - 7	0.09	7.00	5.67-7	6.67	5.33 - 7	0
Privacy & Dignity	7.00	7-7	7.00	7 - 7	0	7.00	7-7	7.00	6.5 - 7	0	7.00	6.5-7	7.00	7 - 7	0
Scheduling	6.67	5.67-7	6.67	6 - 7	0	7.00	6-7	7.00	6 - 7	0	7.00	6-7	7.00	6-7	0
Treats	6.33	5-7	6.33	5 - 7	0	6.67	6-7	6.67	5.33 - 7	0	6.67	5.67-7	6.67	5.33 - 7	0
Transport	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Environment	6.00	5.2-6.8	6.00	5.2 - 6.6	0	6.20	5.5-7	6.00	5.2 - 6.8	0.2	6.00	5.2-6.78	6.00	4.8 - 6.6	0
Overall	6.00	6-7	6.00	6 - 7	0	7.00	6-7	7.00	6 - 7	0	7.00	6-7	7.00	6-7	0
Scale scores	6.19	5.38-6.71	6.23	5.38 - 6.69	-0.04	6.47	5.87-6.79	6.33	5.62 - 6.75	0.14	6.40	5.70-6.81	6.34	5.79 - 6.72	0.06

Table 9 contd.: Comparison of median Kidney PREM scores by treatment group for 2021 and 2020

	Satellite Haemodialysis					Centre Haemodialysis					Transplant				
	2021 (n=3913)		2020 (n=2706)		21v20	2021 (n=2893)		2020 (n=1887)		21v20	2021 (n=1987)		2020 (n=2065)		21v20
	Median	IQR	Median	IQR		Median	IQR	Median	IQR		Median	IQR	Median	IQR	
Access	7.00	6-7	7.00	6 - 7	0	7.00	6-7	7.00	6 - 7	0	7.00	6.33-7	7.00	6.33-7	0
Support	6.33	5-7	6.33	5 - 7	0	6.00	4.67-7	6.33	4.67 - 7	-0.33	6.33	5-7	6.33	5-7	0
Communication	6.40	5-7	6.33	5.25 - 7	0.07	6.33	5.25-7	6.25	5.2 - 7	0.08	6.00	5-7	6.25	5.25 - 7	-0.25
Patient Info	7.00	6-7	7.00	6 - 7	0	7.00	6-7	7.00	6 - 7	0	7.00	6.5-7	7.00	6.5 - 7	0
Fluid & Diet	7.00	6-7	7.00	5.5 - 7	0	7.00	5.5-7	7.00	5.5 - 7	0	6.50	5-7	6.50	5.5 - 7	0
Needling	6.00	5-7	6.00	5 - 7	0	6.00	5-7	6.00	5 - 7	0	-	-	-	-	-
Tests	6.67	5.67-7	6.67	5.67 - 7	0	6.50	5.33-7	6.67	5.67 - 7	-0.17	6.67	6-7	7.00	6.33 - 7	-0.33
Sharing Decisions	6.00	4.67-7	6.00	4.33 - 7	0	6.00	4-7	6.00	4 - 7	0	6.42	5.33-7	6.33	5.33 - 7	0.09
Privacy & Dignity	7.00	6-7	7.00	6 - 7	0	7.00	6-7	7.00	6 - 7	0	7.00	7-7	7.00	7 - 7	0
Scheduling	7.00	6-7	7.00	6 - 7	0	7.00	5.5-7	6.50	4.5 - 7	0.5	6.67	6-7	6.67	6-7	0
Treats	6.67	5.67-7	6.67	5.33 - 7	0	6.67	5.33-7	6.67	5.33 - 7	0	6.33	5.67-7	6.33	5.5 - 7	0
Transport	6.00	5-6.67	6.00	5.33 - 7	0	6.00	5-7	6.00	5 - 6.67	0	-	-	-	-	-
Environment	6.60	5.8-7	6.50	5.8 - 7	0.10	6.50	5.6-7	6.040	5 - 7	0.1	5.80	5.2-6	5.80	5.2 - 6.6	0
Overall	7.00	6-7	7.00	6 - 7	0	7.00	6-7	7.00	6 - 7	0	7.00	6-7	7.00	6-7	0
Scale scores	6.34	5.63-6.75	6.29	5.58 - 6.71	0.05	6.24	5.5-6.69	6.27	5.44 - 6.69	-0.03	6.34	5.77-6.72	6.38	5.81 - 6.71	-0.04

Patient experience of kidney care across the service

This section of the report presents overall scores for all questions in the 2021 Kidney PREM.

The first figure in each section shows the mean score and 95% confidence interval (CI) for that theme by treatment type. The number of patients used to calculate the scores for each treatment group is shown in brackets after the treatment name.

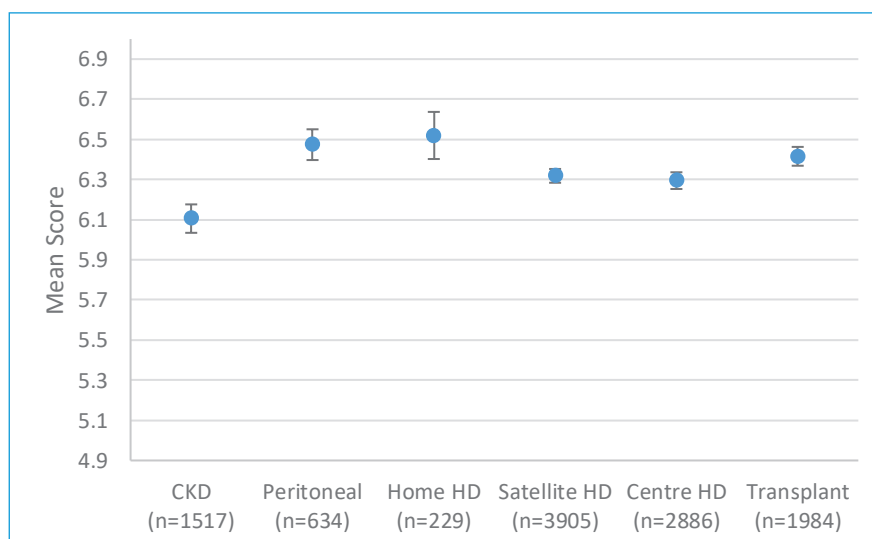
A second figure is presented for each Kidney PREM theme, showing the proportion of 1.0 - 7.0 scores awarded to each of the questions within those themes. The number of patients responding 1.0 - 7.0 is shown in brackets after the question label. Bars total 100%, so the distribution of scores is clear, reflected in the width of segments from dark red (1.0; negative), through orange (4.0; neutral) to dark green (7.0; positive).

The number of patients responding with a 1.0 – 7.0 out of 7.0 varies, as some questions are only applicable to certain patients (eg transport and needling), some patients have a valid response of ‘don’t know’ or ‘not applicable’, and some completing Kidney PREM on paper choose not to respond to all of 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.

Section One: Access to the Renal Team

Mean score 6.34 (centre range 5.50 – 6.98)



Access to the renal team is high scoring, with more than 80% scoring each question at or above 5.0 out of 7.0.

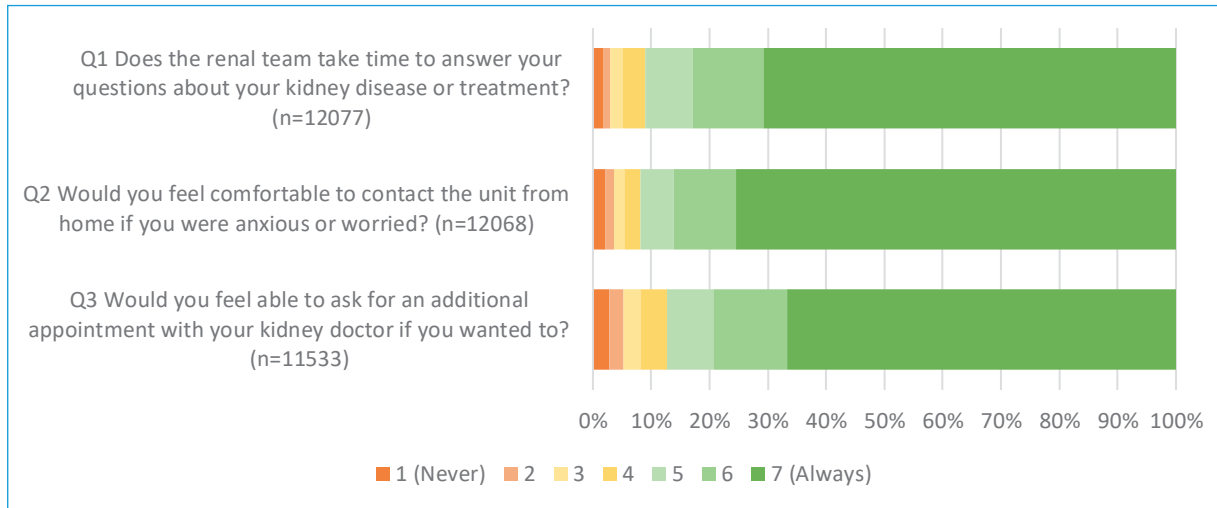
People with CKD are less positive than others about access.

Patients receiving home therapies than those receiving haemodialysis in-centre/satellite.

At least nine in ten people have a positive experience of the renal team taking time to answer their kidney related questions and similarly, of feeling comfortable to contact the team from home if they were anxious or worried.

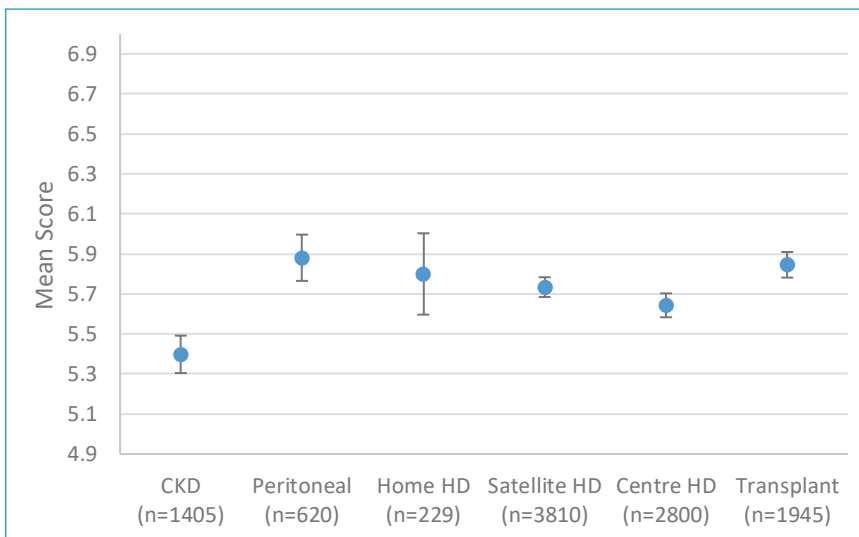
Whilst on a national level, fewer are sure of being able to ask for an additional appointment with their kidney doctor, this would benefit from the local context of what patients are advised to do with the various concerns which might come up between consults.

Figure 4: Access to the Renal Team



Section Two: Support

Mean score of 5.74 (centre range 4.45 – 6.88)



People receiving kidney replacement therapy are more likely to feel supported than those with CKD.

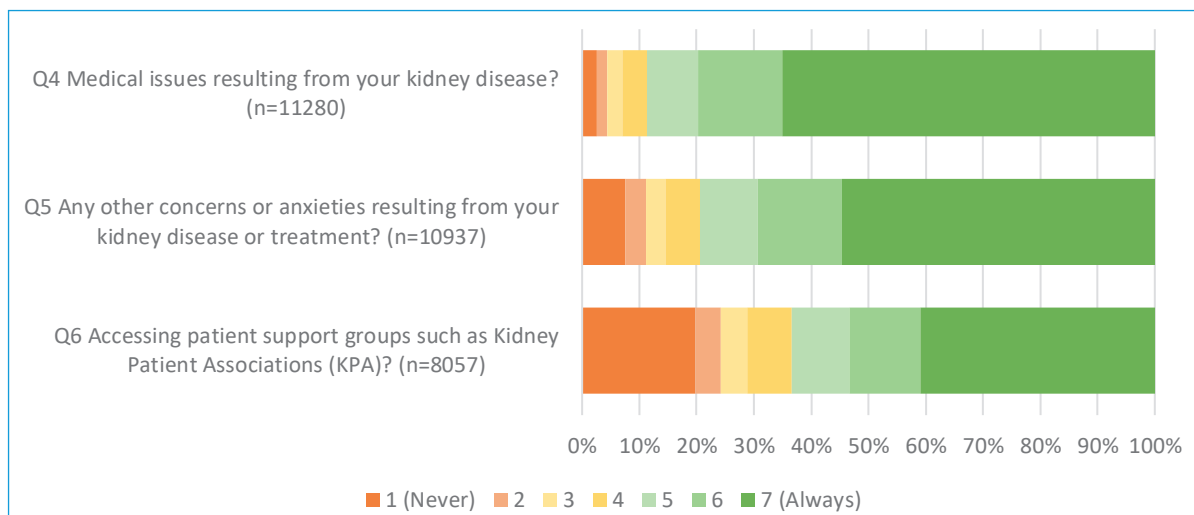
Those receiving peritoneal dialysis and with transplants are more positive about support than those attending units for haemodialysis.

Patient experience of renal team support is most positive when related to medical issues resulting from kidney disease. Patients are less positive about the support they get from the team for other kidney disease related concerns or anxieties, with one in ten scoring this at 2.0 or below. As with ‘Access’ above, centre data may indicate local patterns in how patients experience Support from their renal team.

Help in accessing patient support groups such as Kidney Patient Associations is the area most open to improvement, with 36.5% scoring this at 4.0 or below. Kidney PREM gives patients the opportunity to respond ‘Don’t Know’ or ‘Not Applicable’ if a question is not relevant to them, and so the 28.8% of patients scoring this as a 1.0 to 3.0 out of 7.0 may well be interested in help to access support groups.

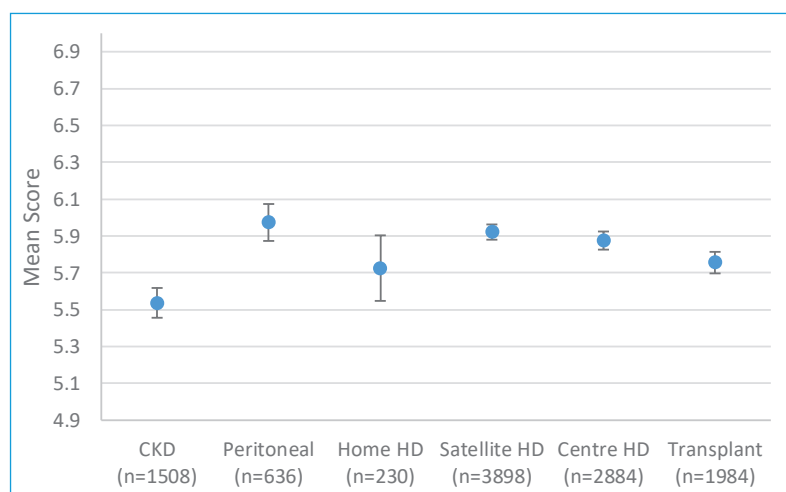
Figure 5: Support

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



Section Three: Communication

Mean patient experience score of 5.85 (centre range 4.92 - 6.85)



The range in mean scores and the variation in scores awarded for different types of communication (below) warrant deeper investigation than national means across treatment types can offer.

Nonetheless, the poorer experience of people with CKD compared to those on

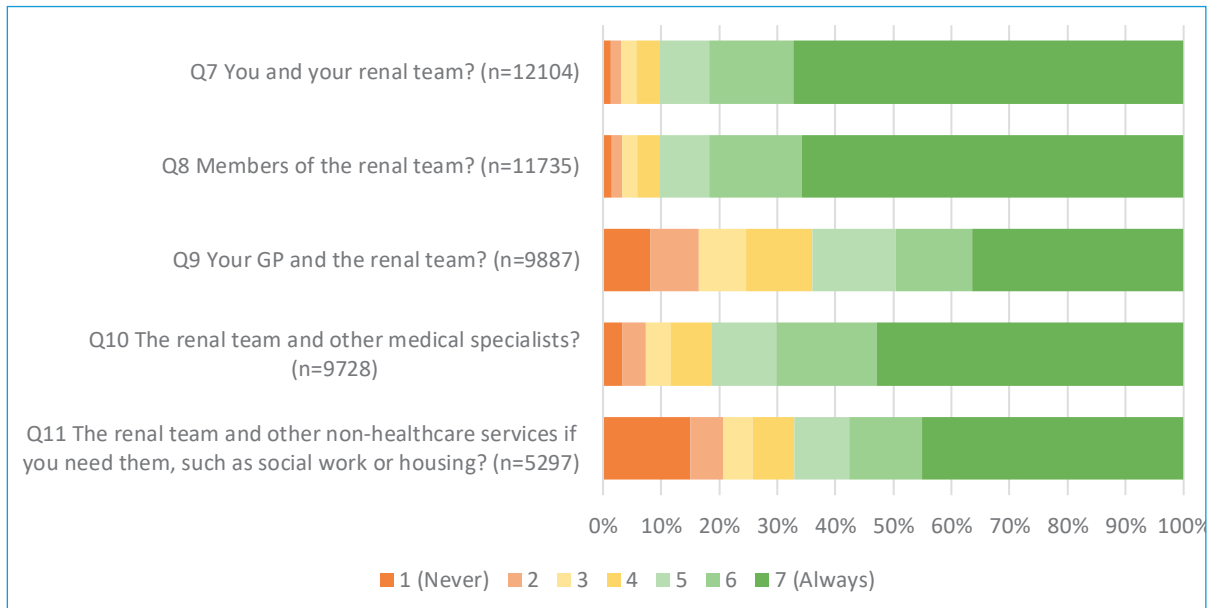
most types of dialysis is consistent. People who have had a transplant report poorer experience with communication than many other aspects of care

Nine in ten patients report a positive experience of communication between them and their renal team, and similarly, between members of their renal team (scoring at least 5.0 out of 7.0). The distribution of scores here is very similar, so it is possible that patients experience communication between them and the renal team, and between members of the renal team, as inextricably linked.

Communications outside of the renal team are experienced less positively: with higher proportions of patients scoring 3.0 or below for the quality of communication between the renal team and other medical specialists (11.6%), the GP and the renal team (24.7%) and the renal team and other non-healthcare services (25.8%).

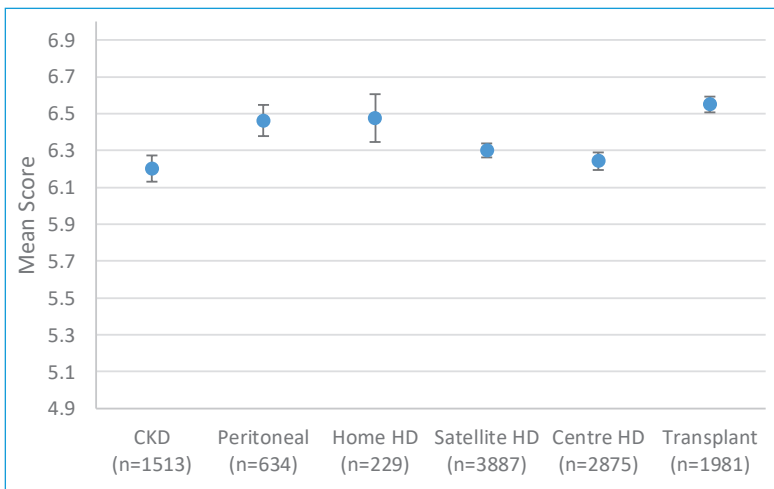
Figure 6: Communication

Do you think there is good communication between:



Section Four: Patient Information

Mean patient experience score of 6.35 (centre range 5.46 – 6.97)

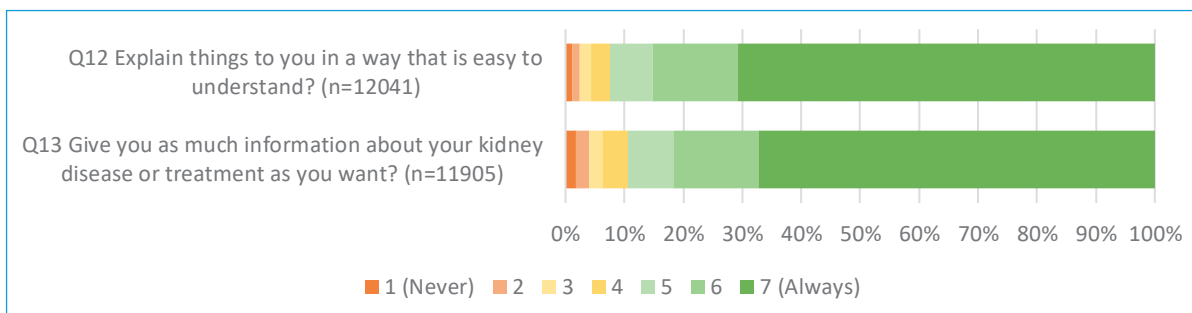


Patient experience of information (sufficient and understandable) is better for people who have had a transplant than those who are on in-centre or in-satellite haemodialysis or who have CKD.

Patient information is one of the highest scoring themes in the Kidney PREM, patients are largely positive that the renal team explains things to them in a way that is easy to understand and are given as much information about their kidney disease or treatment as they want.

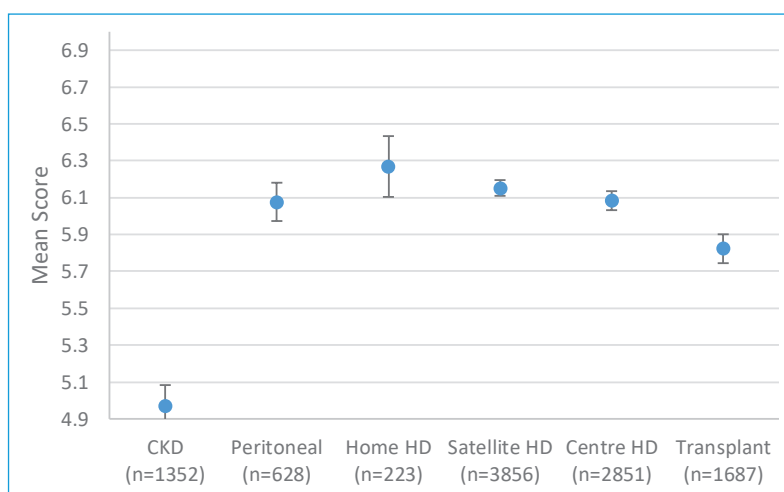
Figure 7: Patient Information

Does the renal team:



Section Five: Fluid Intake and Diet

Mean patient experience score of 5.95 (centre range 4.45 - 6.87)

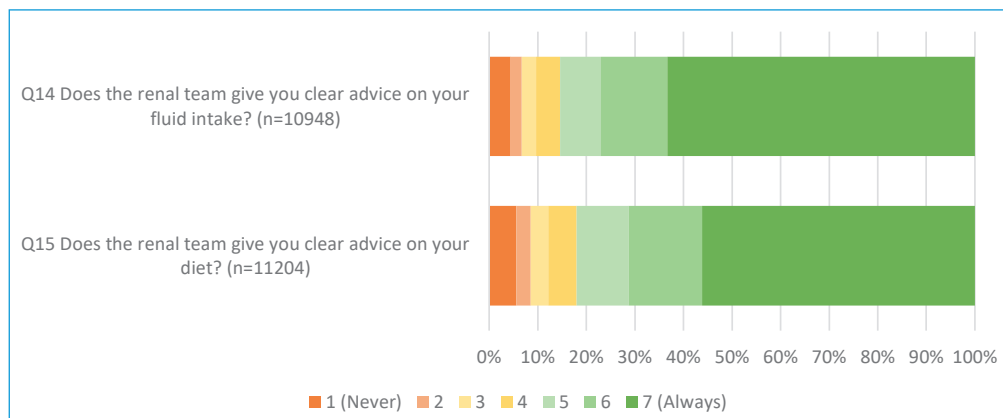


Experience with renal team advice on fluid intake and diet is markedly poorer for people with CKD than for those on kidney replacement therapies.

This is one of the lowest performing aspects of care for people with a transplant.

Patients are more likely to have a positive experience of renal team advice on fluid intake than diet; with 85.4% scoring clarity of advice on fluids at 5.0 or higher. These questions prompt fullest use of the range of scores on the scale, and so centres will find it useful to investigate this locally, particularly with regards to differences for people with CKD not on KRT, and others by treatment type.

Figure 8: Fluid Intake and Diet



Section Six: Needling

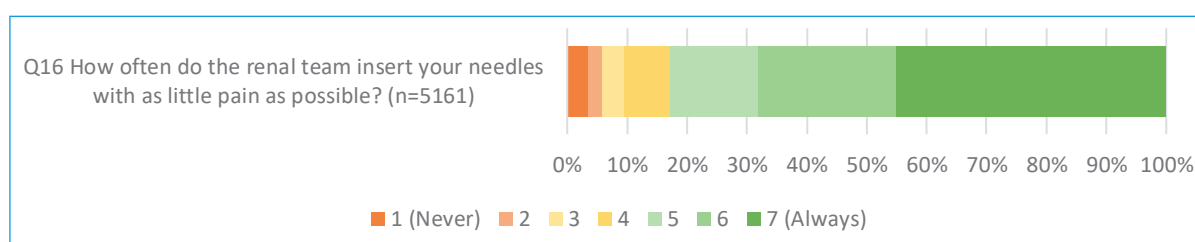
Mean patient experience score of 5.78 (centre range 4.75 - 6.50)

Overall, there is little difference between patients attending in-centre and satellite (means of 5.80 and 5.72). Approaching half of Kidney PREM respondents on in-hospital or in-satellite haemodialysis report that the renal team always insert their needles with as little pain as possible (45.1%),

With almost one in ten rating their experience as 3.0 or less out of 7.0 (9.6%) and there being significant range between centres, this is an area ripe for local investigation.

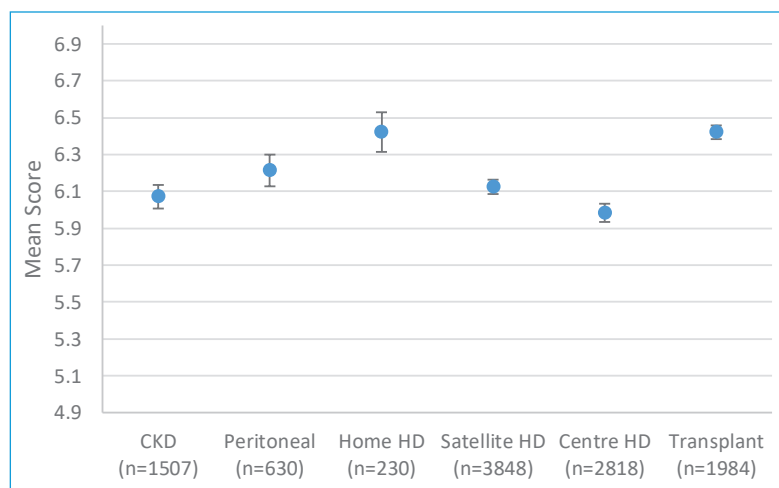
Figure 9 Needling

If you are receiving in-hospital or in-satellite haemodialysis



Section Seven: Tests

Mean patient experience score of 6.20 (centre range 5.52 - 6.93)



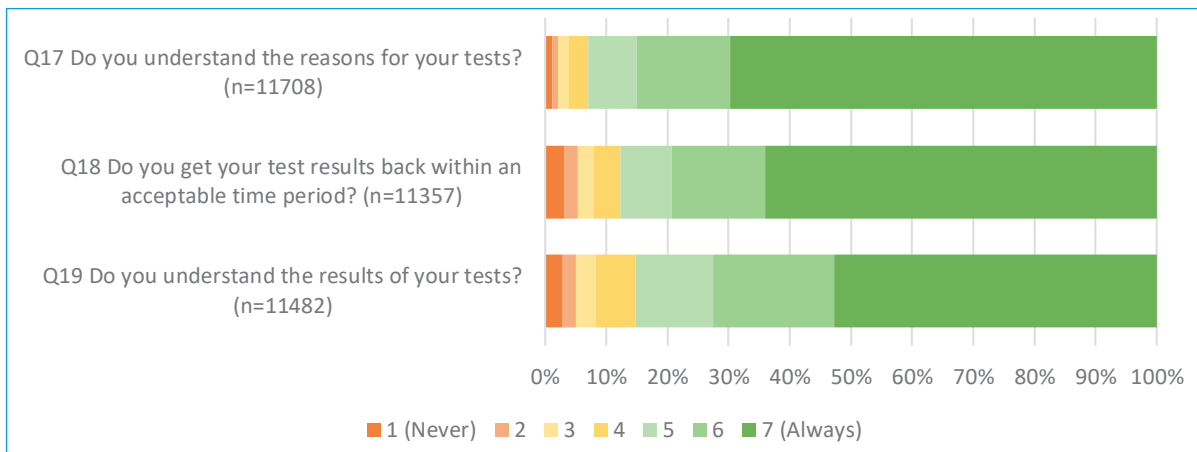
People receiving in-centre haemodialysis are less likely to have positive experience of tests (why they have them, what the results tell them and how long it takes to hear) than all other treatments.

The extent to which people with CKD feel informed about tests is markedly better than how informed they feel about fluid intake and diet.

Patients are more likely to understand the reasons for their tests (Q17), than to feel that they get their results back within an acceptable time-period (Q18), and more likely to feel that the time period is acceptable, than to understand the results (Q19).

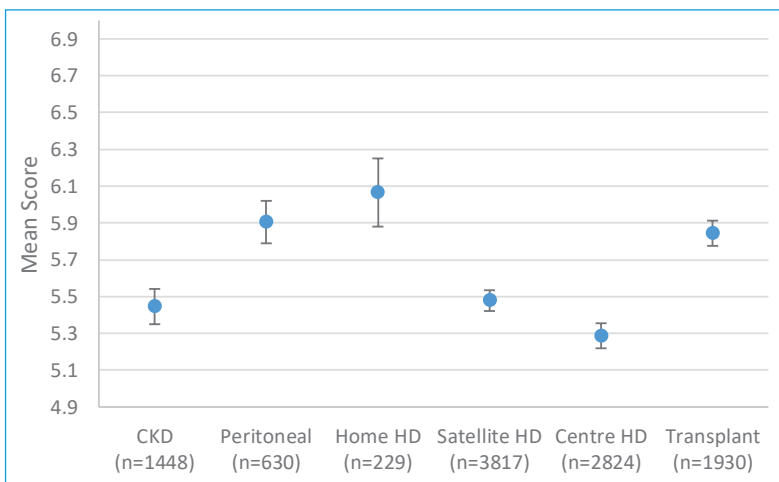
Whilst responses to Q19 are mainly positive, half of those responding to this question do not always understand the results of their tests, and one in ten rarely or never do.

Figure 10: Tests



Section Eight: Sharing Decisions About Your Care

Mean patient experience score of 5.54 (centre range 4.37 - 6.90)



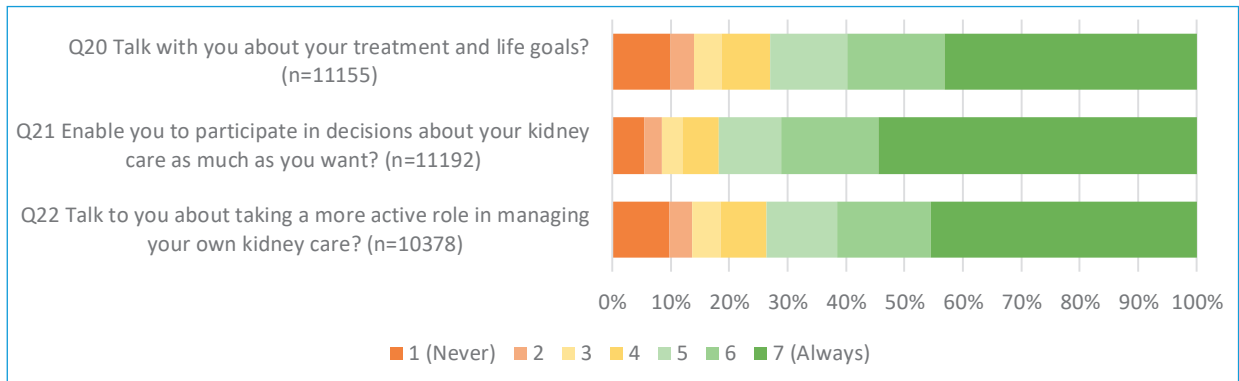
There is a marked difference in the experience of Shared Decision making amongst those on home therapies compared to people on in-unit haemodialysis and people with CKD.

Sharing Decisions About Your Care has been the poorest scoring aspect of the Kidney PREM for the last three years. Whilst most report a positive experience of shared decision making, 12.1% score this as 3.0 or lower, a significant minority who are not as involved as they wish to be.

The range of scores patients award for their experience of the renal team talking with them about their treatment and life goals (Q20), and about taking a more active role in managing their own kidney care (Q21) are highly similar, with large proportions scoring 4.0 or below.

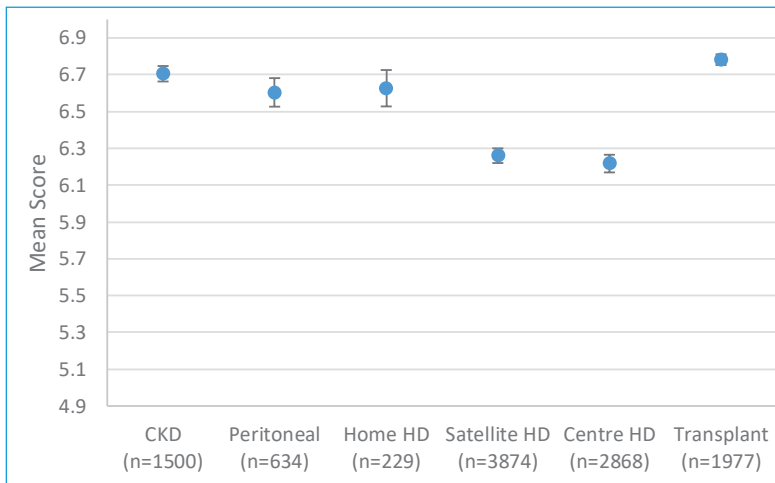
Figure 11: Sharing Decisions About Your Care

Does the renal team:



Section Nine: Privacy and Dignity

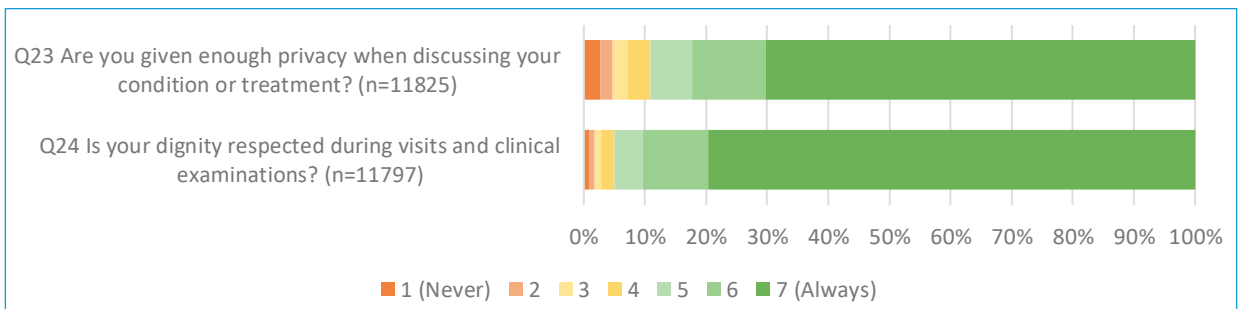
Mean patient experience score of 6.41 (centre range 5.09 - 6.83)



People receiving in-unit haemodialysis, having treatment in close proximity to others, are less positive about privacy and dignity than people on other treatments or not on KRT.

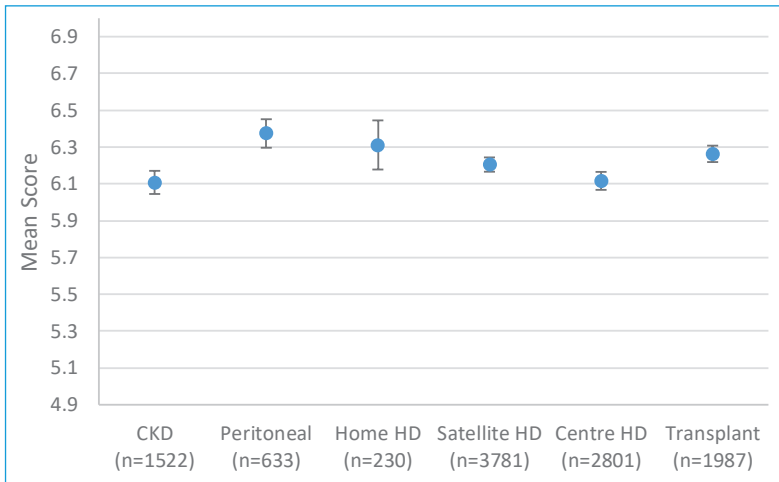
Whilst most patients report a good experience of being afforded privacy during clinical discussions, and having dignity respected during visits and examinations, there are minorities reporting poor experience in either or both cases.

Figure 12: Privacy and Dignity



Section Ten: Scheduling and Planning

Mean patient experience score of 6.19 (centre range 5.54 - 6.91)



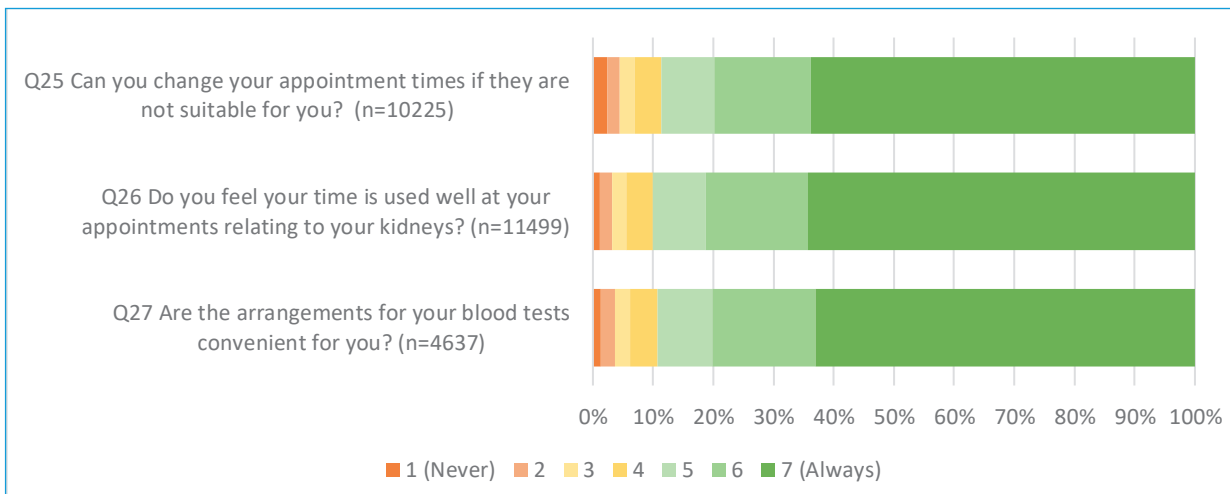
Patient experience of scheduling and planning is less clearly variable than other areas of care when looked at by treatment type.

Those receiving peritoneal dialysis and with transplants are generally more positive than people on in-centre haemodialysis and people with CKD.

Patient experience of scheduling

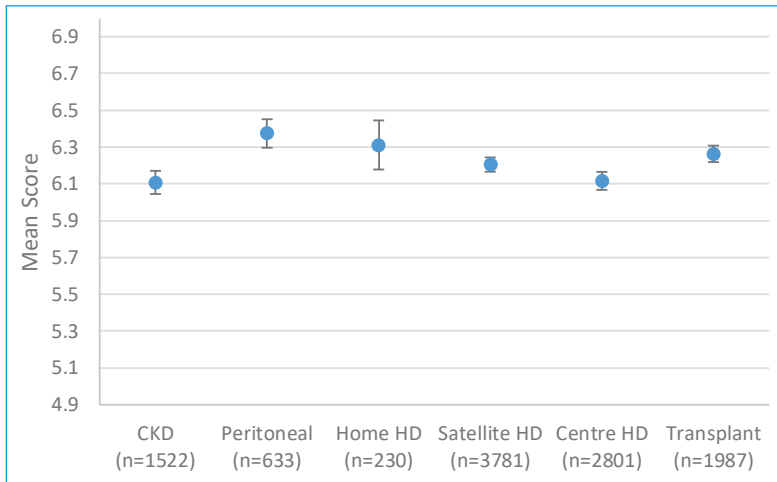
and planning has been static since 2019 and is neither high nor low performing in relation to the other areas of kidney care measured by the PREM. Most individuals award a positive score of 5.0 or higher for being able to change unsuitable appointment times, feeling that their time is well used at kidney related appointments, and having blood tests that are convenient for them.

Figure 13: Scheduling and Planning



Section Eleven: How The Renal Team Treats You

Mean patient experience score of 6.08 (centre range 5.00 - 6.94)



Whilst again less variable than other areas of care, people with CKD are less positive than patients on other treatment types about how the renal team treats them.

Local investigation may be particularly helpful in understanding this, given the range of areas covered within the theme.

When thinking about how the renal team treats them, 95% of patients responding in each case give scores of 5.0 or above to the team taking them seriously and showing a caring attitude.

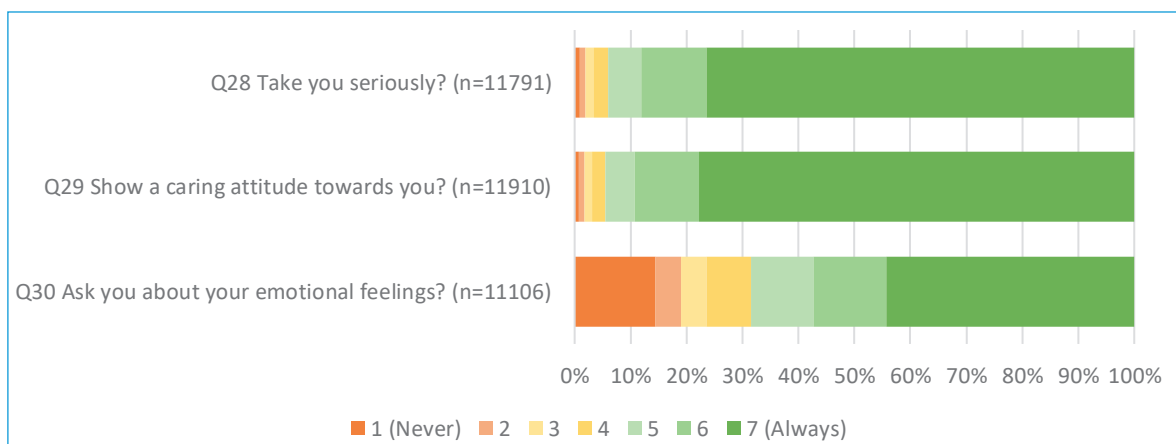
In contrast, one in four give a poor score of 1.0 -3.0 for the team asking them about their emotional feelings (23.6%), with one in six (14.4%) scoring this as something the team never does.

As the largest proportion of patients score being asked about their feelings as 7.0 out of 7.0, finding and exemplifying this practice would be a good place for centres to start to identify how to build this into everyday conversations with patients.

Alternatively, emotional support was one of the themes to come out of the national analysis of patient comments, and centres may wish to look at their local comments' files for insight into what patients feel is missing from their renal teams.

Figure 14: How The Renal Team Treats You

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



Section Twelve: Transport

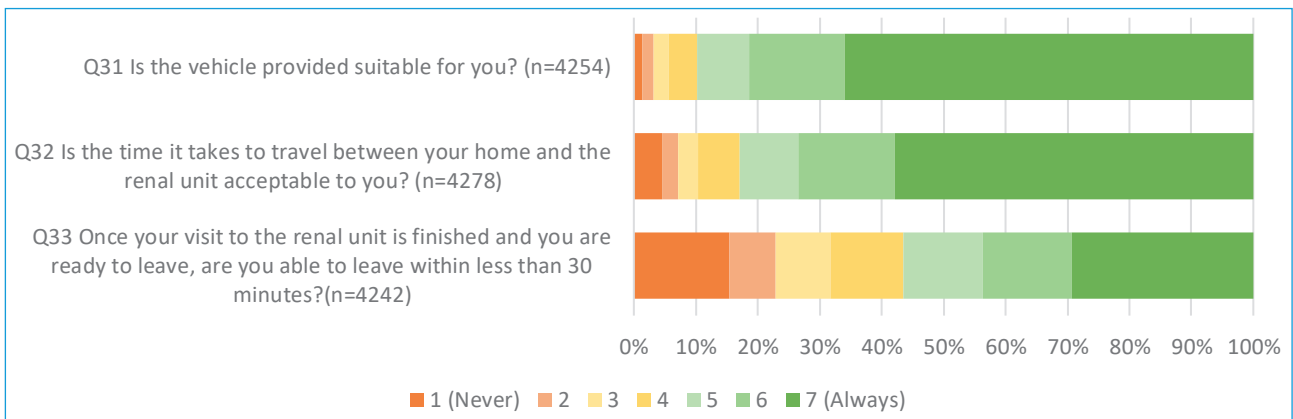
Mean patient experience score of 5.74 (centre range 4.49 - 6.74)

This section is completed by those receiving in-centre and in-satellite haemodialysis who have transport arranged for them by the unit; experience of in-satellite and in-centre patients is the same (mean of 5.8). Individuals are largely positive that the vehicle provided is suitable for them, although only two in three believe this is always the case (66.0%). There is less agreement that the time taken between home and the unit is acceptable.

One in three of those using unit transport to attend for haemodialysis score leaving within 30 minutes of being ready as poor, at 1.0 – 3.0 out of 7.0, with one in six (15.3%) never experiencing timely transport home.

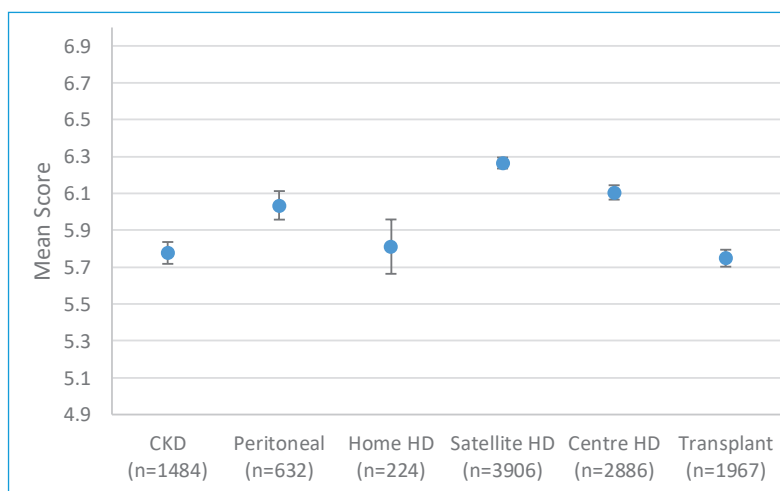
Figure 15 Transport

If the renal unit arranges your transport:



Section Thirteen: The Environment

Mean patient experience score of 6.07 (centre range 5.20 - 6.84)



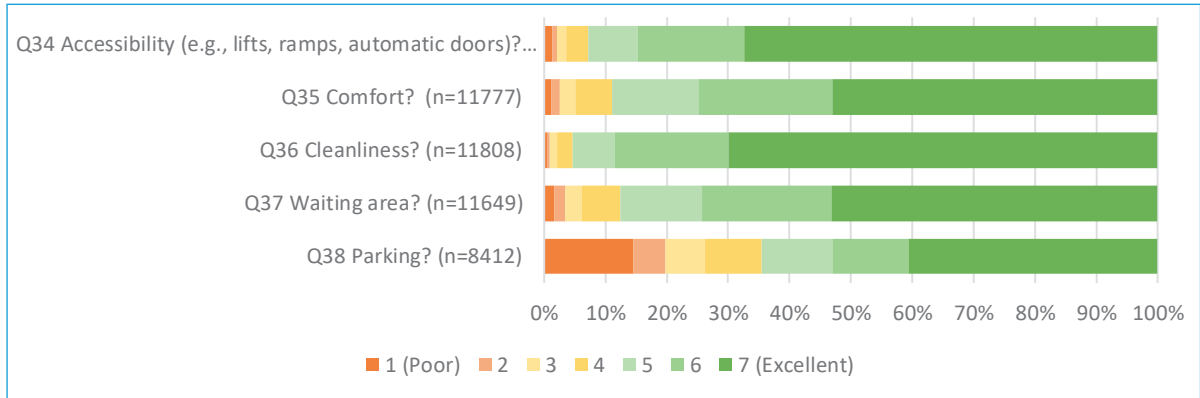
Environment is scored particularly poorly by people with a transplant, which may be exacerbated by a proportion of people who are treated by one centre and have their transplant at another.

People receiving in-unit haemodialysis report a better experience of environment than most others.

Patient experience of the renal unit environment broadly divides into three: accessibility and cleanliness are generally scored highly; comfort and the waiting area slightly less so; parking proving a poor experience for 26.2% of those responding (scoring 1.0 – 3.0).

Figure 16: The Environment

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



Patient experience of kidney care across the service

This section of the report presents mean and frequency scores for all themes in the 2021 Kidney PREM, by centre and treatment type.

Graphs show centre scores and 95% confidence intervals for each theme of the 2021 Kidney PREM. Vertical lines show the median, lower quartile and upper quartile. 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 scores could be estimated if at least 7 responses were received. The variable 'missing', comprises patients for whom a centre could not be attributed). This usually scored in the middle of the centre averages, suggesting no difference between these patients and those who provided a legible treating centre.

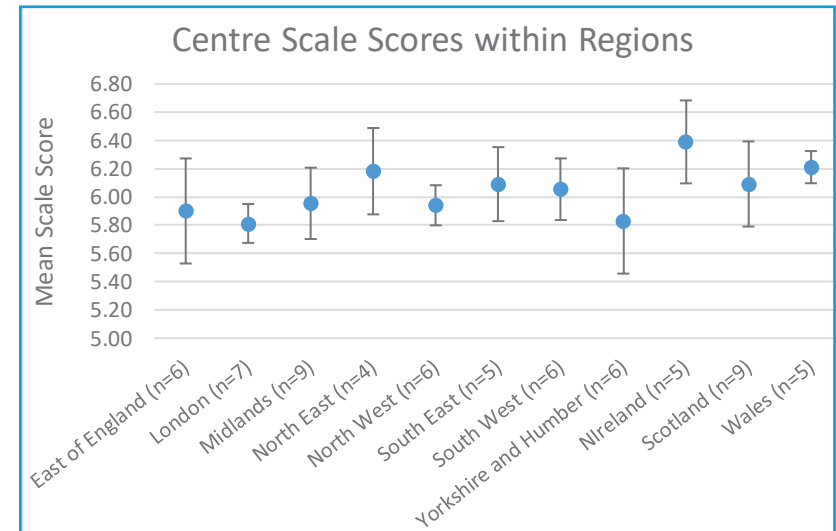
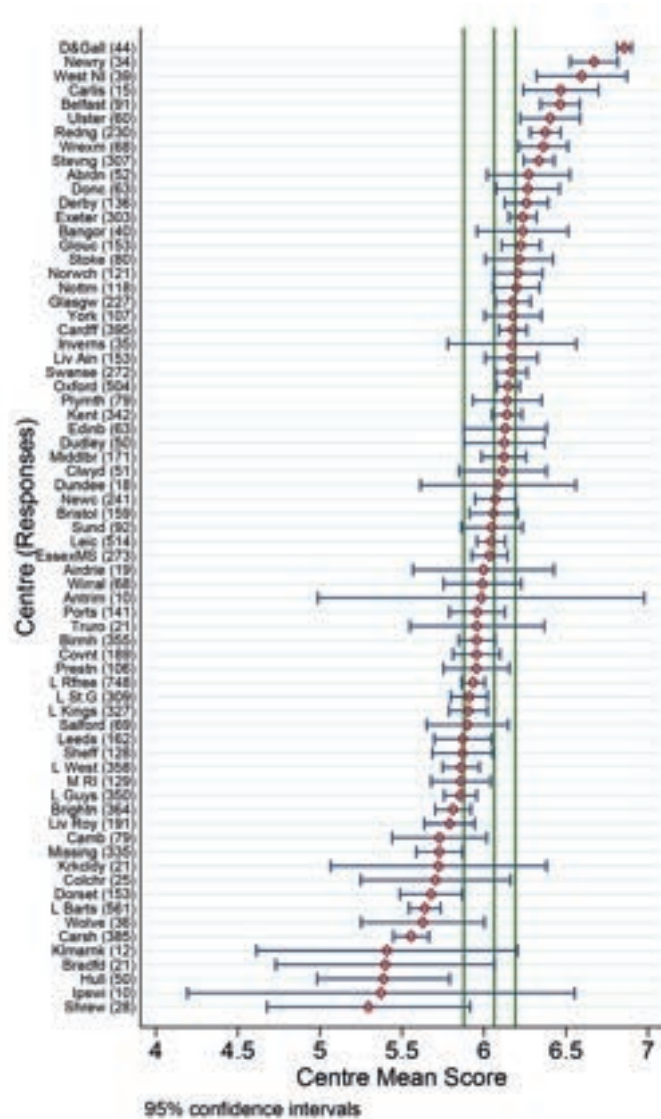
The number of responses used to calculate the scores are in brackets after each centre name. Each chart shows how many patients from each centre completed the questions being reported, as opposed to the number of patients from each centre who completed the Kidney PREM. This is particularly important where questions are filtered and bases for analysis become smaller (e.g., only 200/300 of a centre's respondents might complete the question on Needling, as this is only relevant to patients on haemodialysis).

For most themes, centre scores are mostly within a small range. However, each theme's graph shows a tail of outliers at the bottom, where centre scores were lower than others.

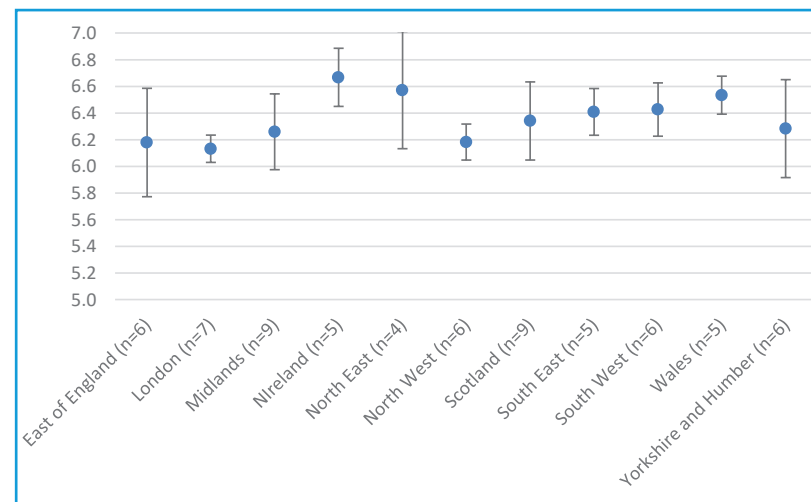
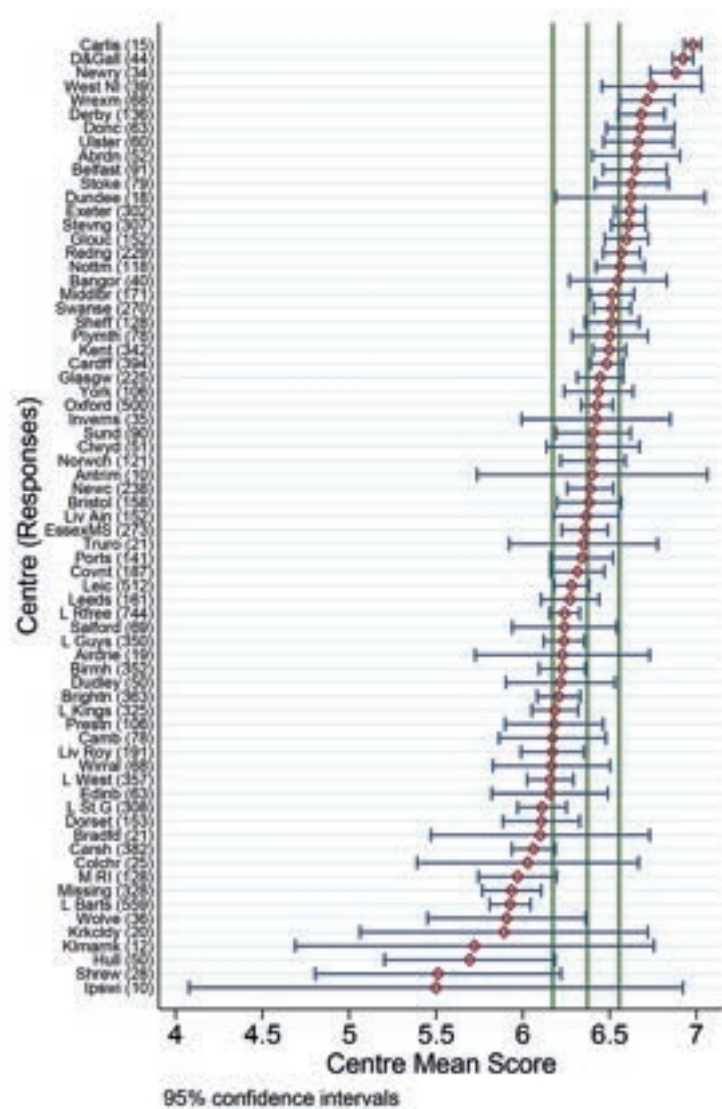
Transport and Needling themes are only applicable to in-satellite and in-centre haemodialysis patients. These themes therefore have fewer centre scores, as a minimum of seven patients were needed to calculate these to preserve patient anonymity.

Figures show the mean score and 95% confidence interval (CI) for centres within geographical regions, with the number of centres shown in brackets after the region name.

Scale Total: Responses across all themes



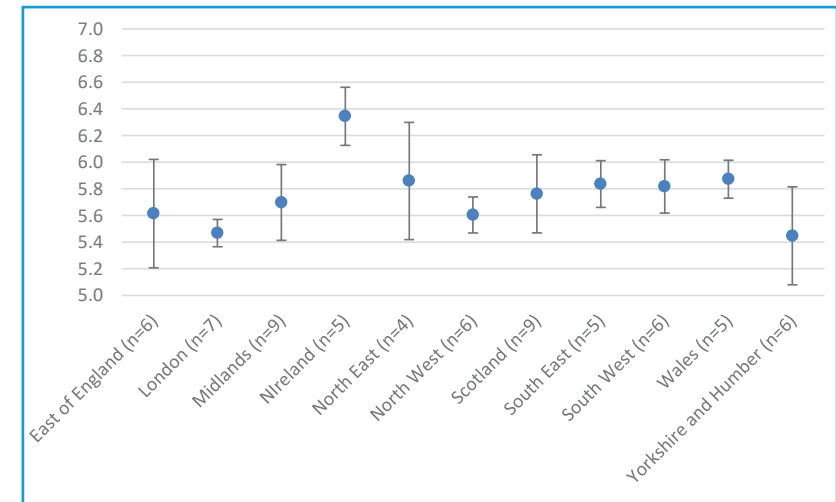
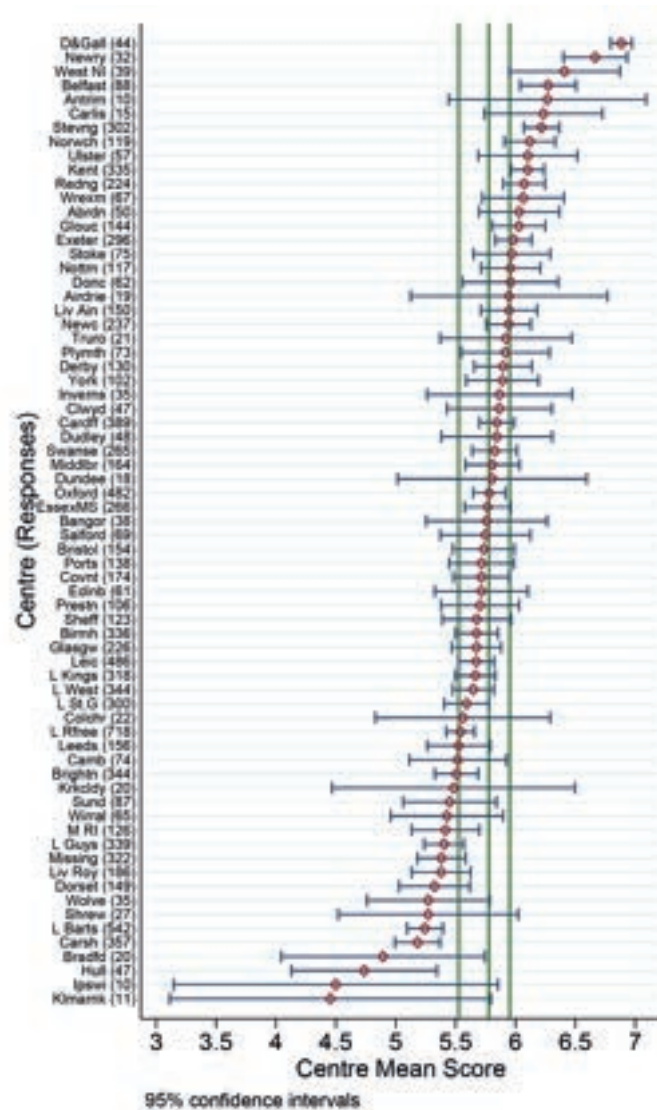
Section One: Access to the Renal Team



Theme questions

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

Section Two: Support

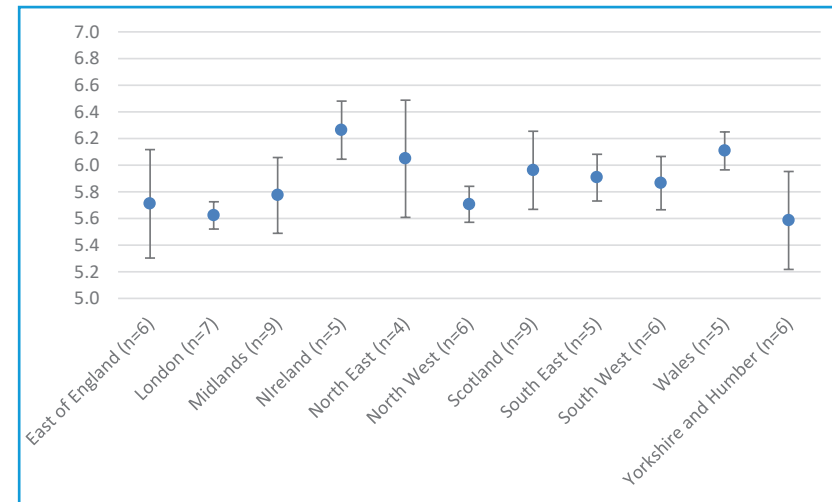
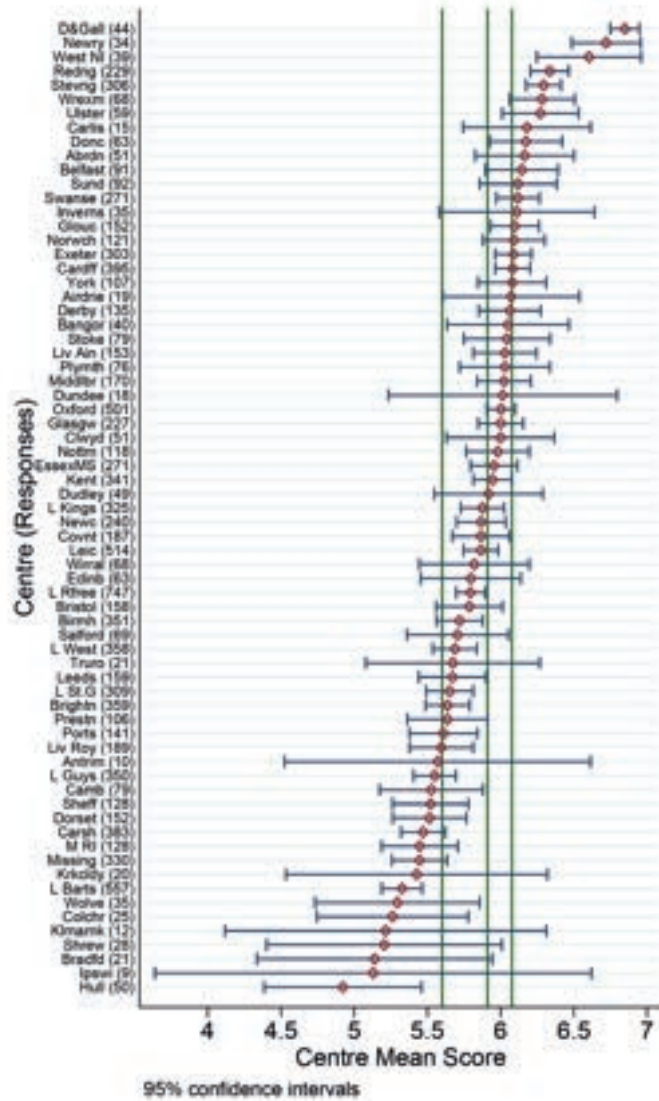


Theme questions

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

4. Medical issues resulting from your kidney disease?
5. Any other concerns or anxieties resulting from your kidney disease or treatment?
6. Accessing patient support groups such as Kidney Patient Associations (KPA)?

Section Three: Communication

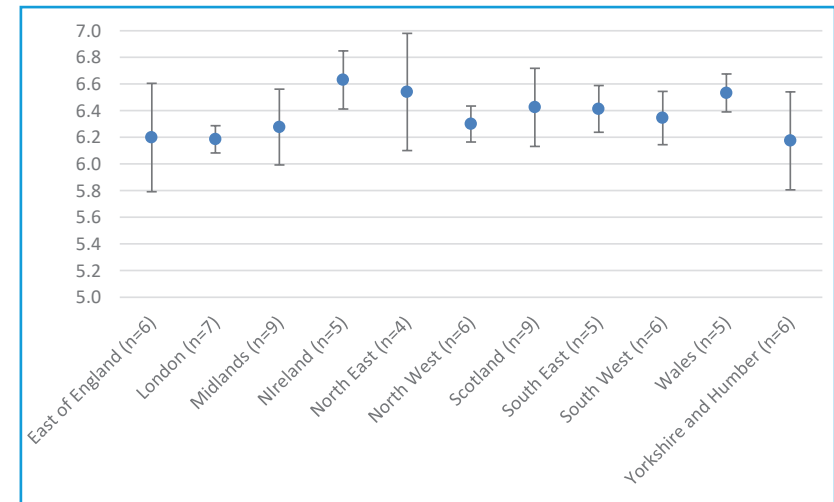
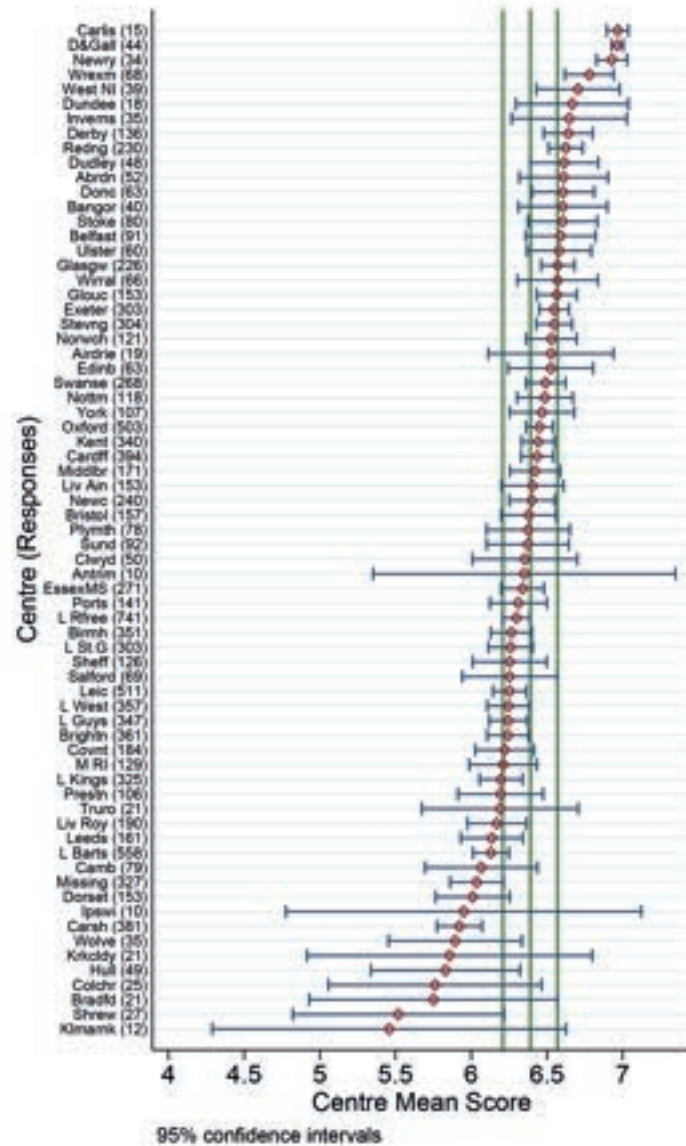


Theme questions

Do you think there is good communication between:

7. You and your renal team?
8. Members of the renal team?
9. Your GP and the renal team?
10. The renal team and other medical specialists?
11. The renal team and other non-healthcare services if you need them, such as social work or housing?

Section Four: Patient Information

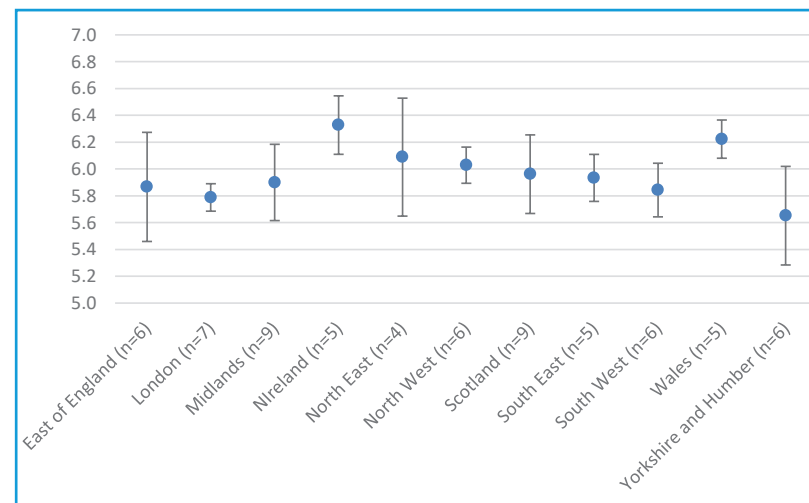
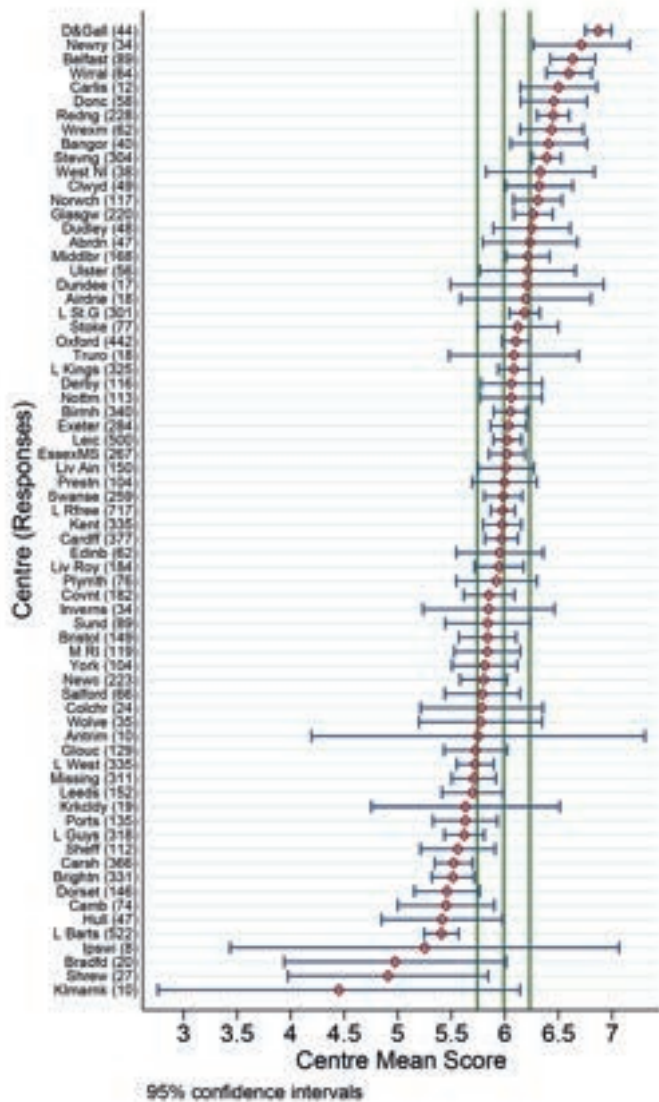


Theme questions

Does the renal team:

12. Explain things to you in a way that is easy to understand?
13. Give you as much information about your kidney disease or treatment as you want?

Section Five: Fluid Intake and Diet



Theme questions

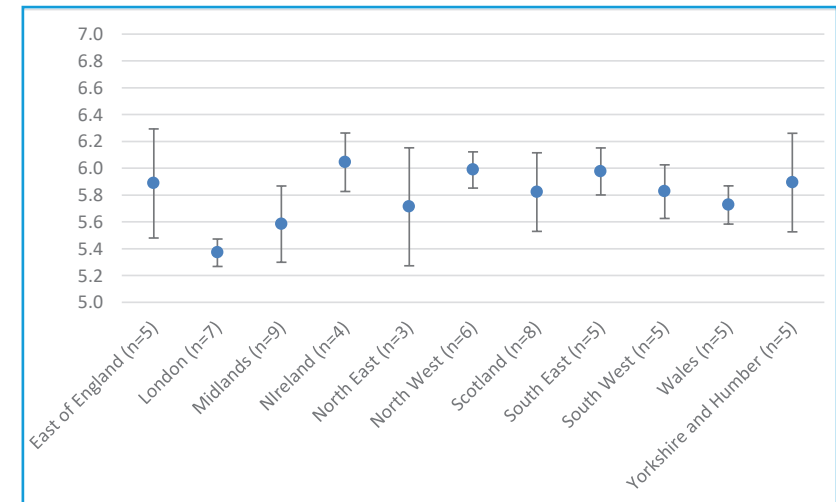
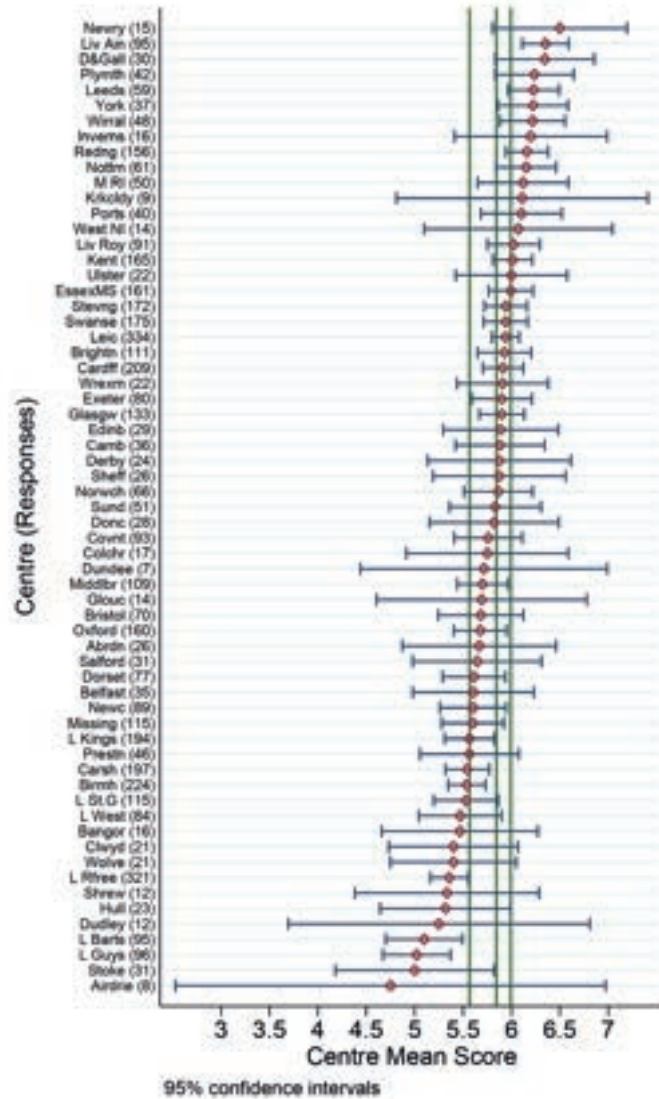
Thinking about the advice you are given about fluid intake:

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

Thinking about the advice you are given about diet:

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

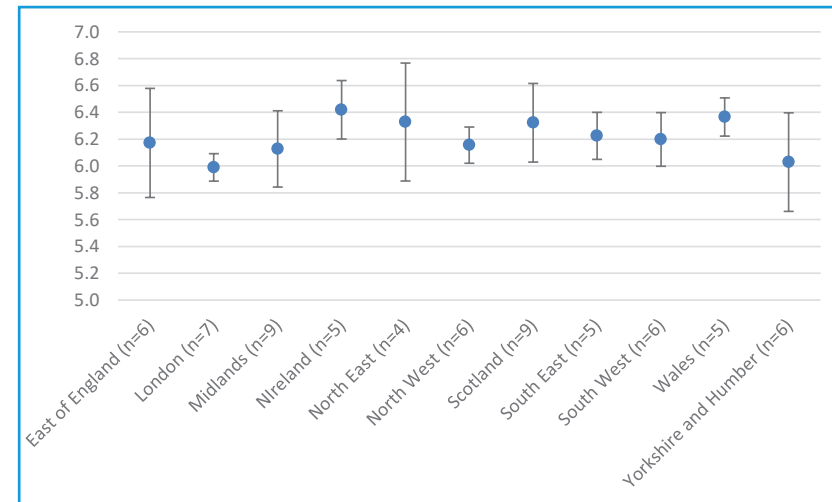
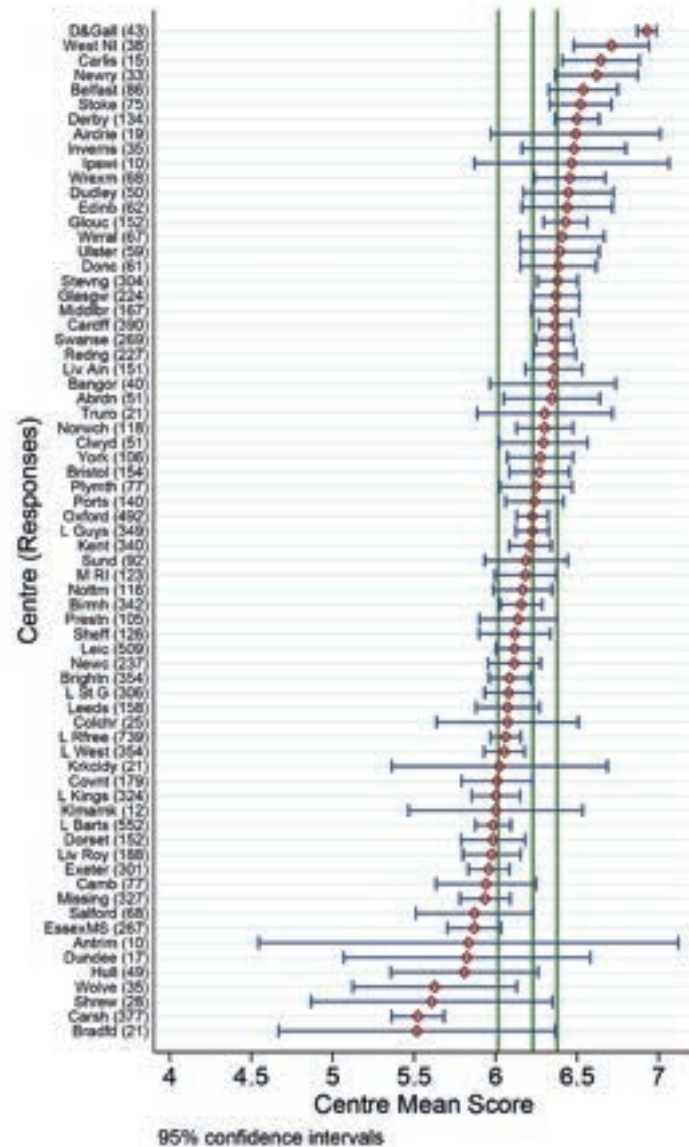
Section Six: Needling



Theme questions

If you are on in-hospital or in-satellite haemodialysis:
 16. How often do the renal team insert your needles with as little pain as possible?

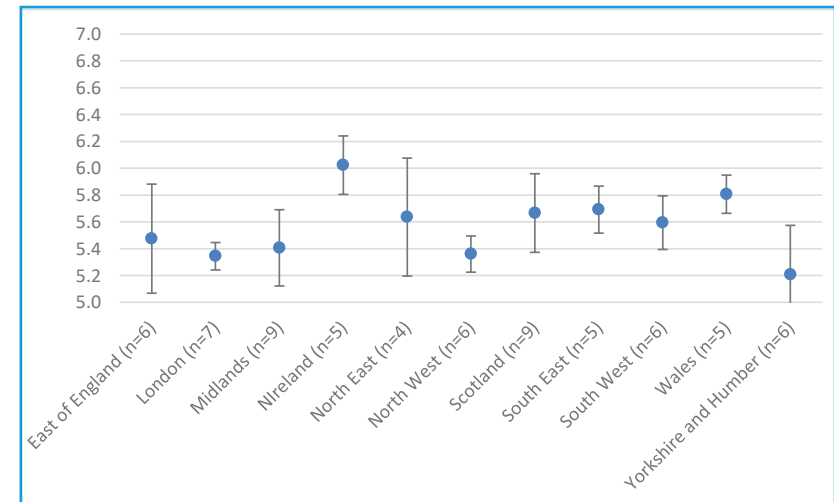
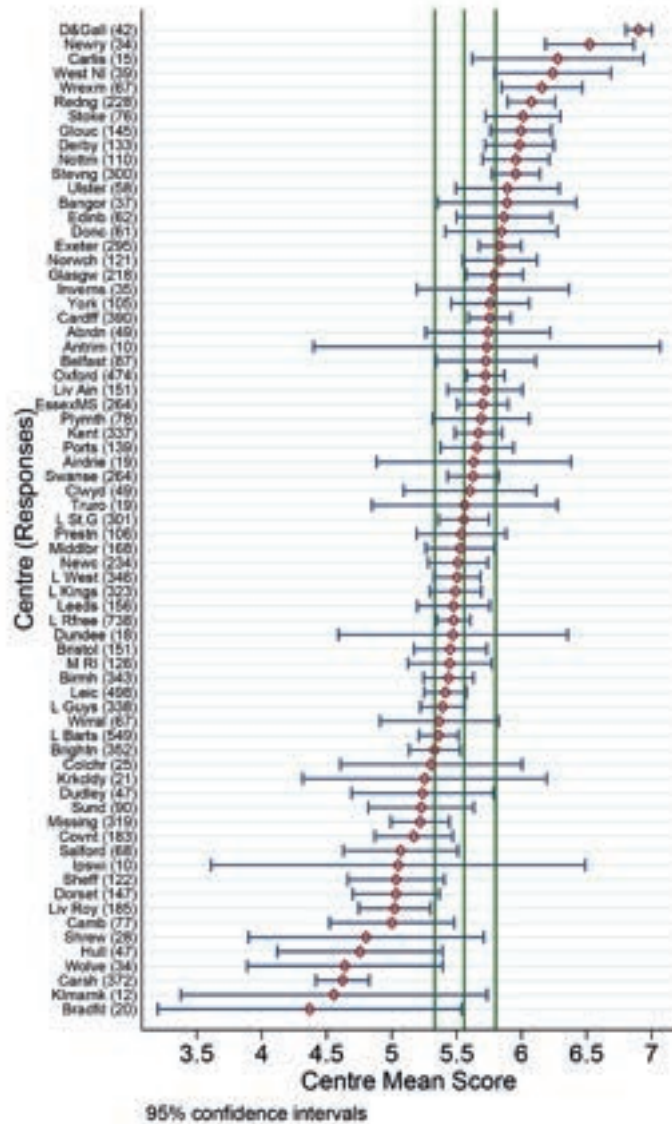
Section Seven: Tests



Theme questions

- 17. Do you understand the reasons for your tests?
- 18. Do you get your test results back within an acceptable time period?
- 19. Do you understand the results of your tests?

Section Eight: Sharing Decisions about your Care

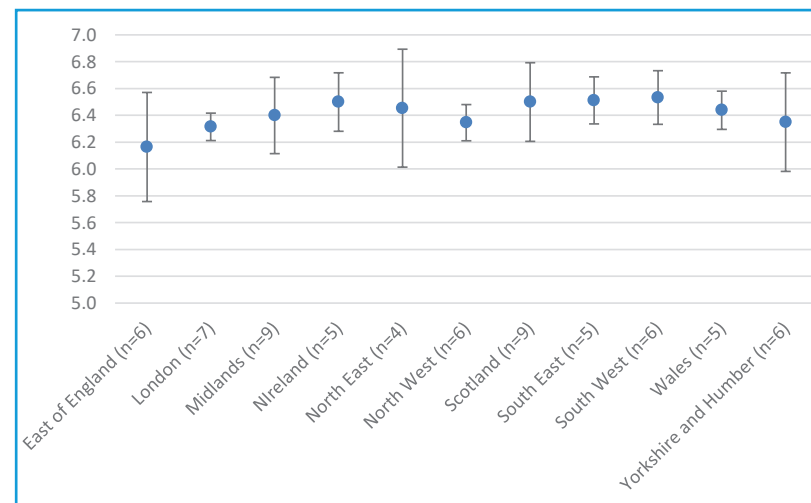
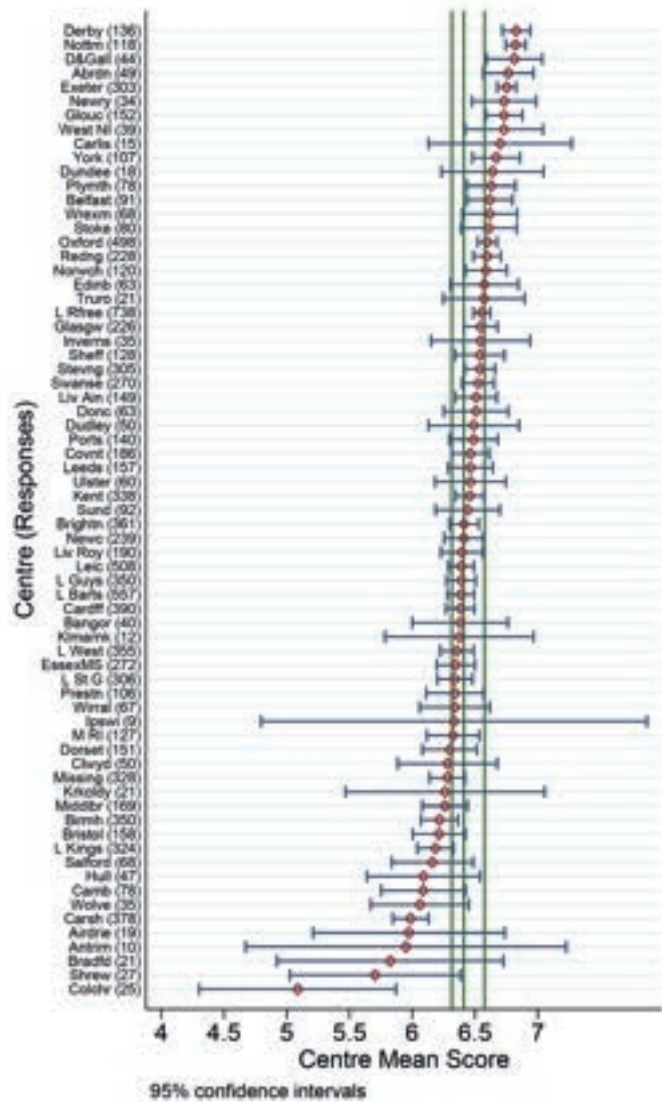


Theme questions

Does the renal team:

- 20. Talk with you about your treatment and life goals?
- 21. Enable you to participate in decisions about your kidney care as much as you want?
- 22. Talk to you about taking a more active role in managing your own kidney care?

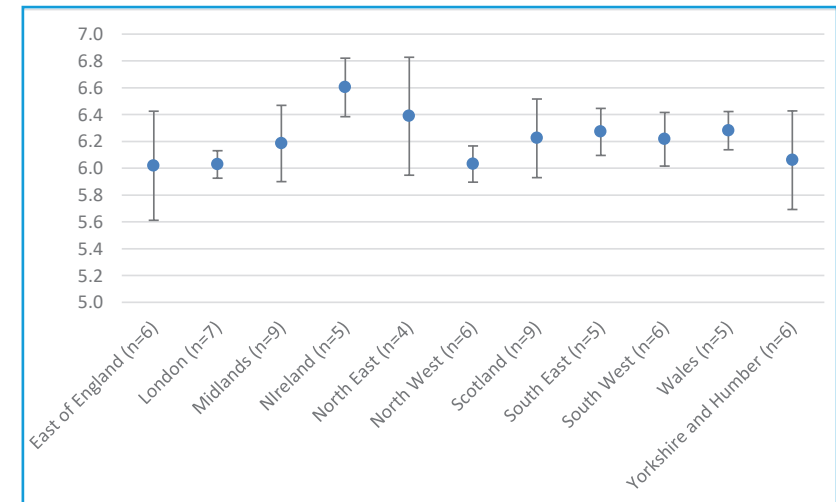
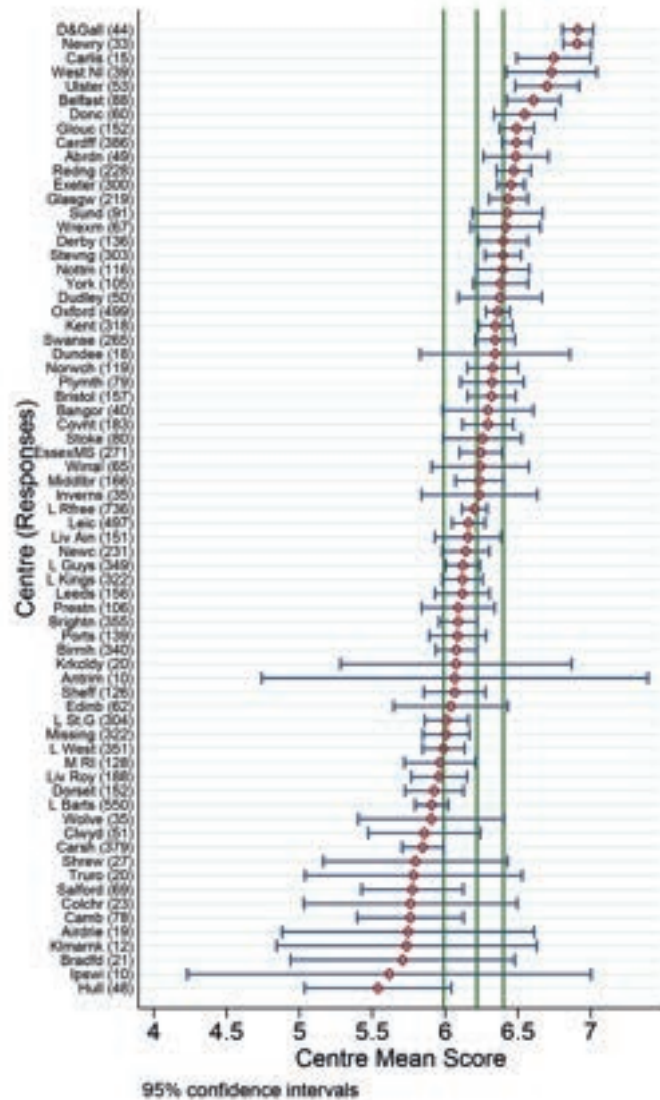
Section Nine: Privacy and Dignity



Theme questions

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

Section Ten: Scheduling and Planning



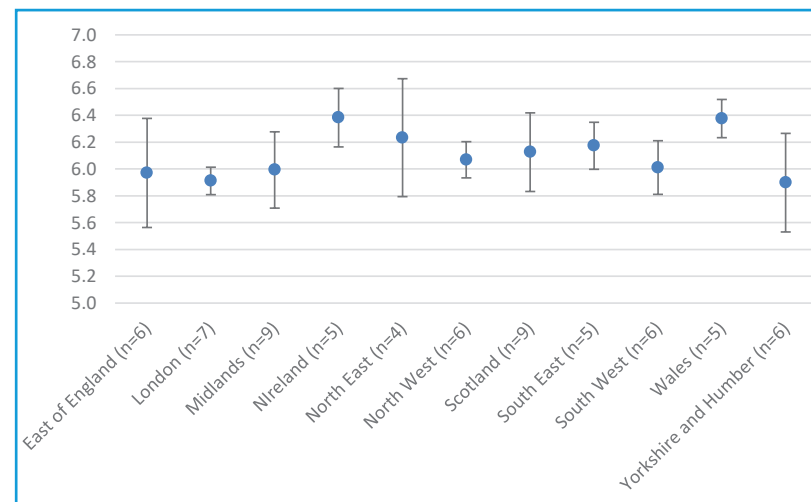
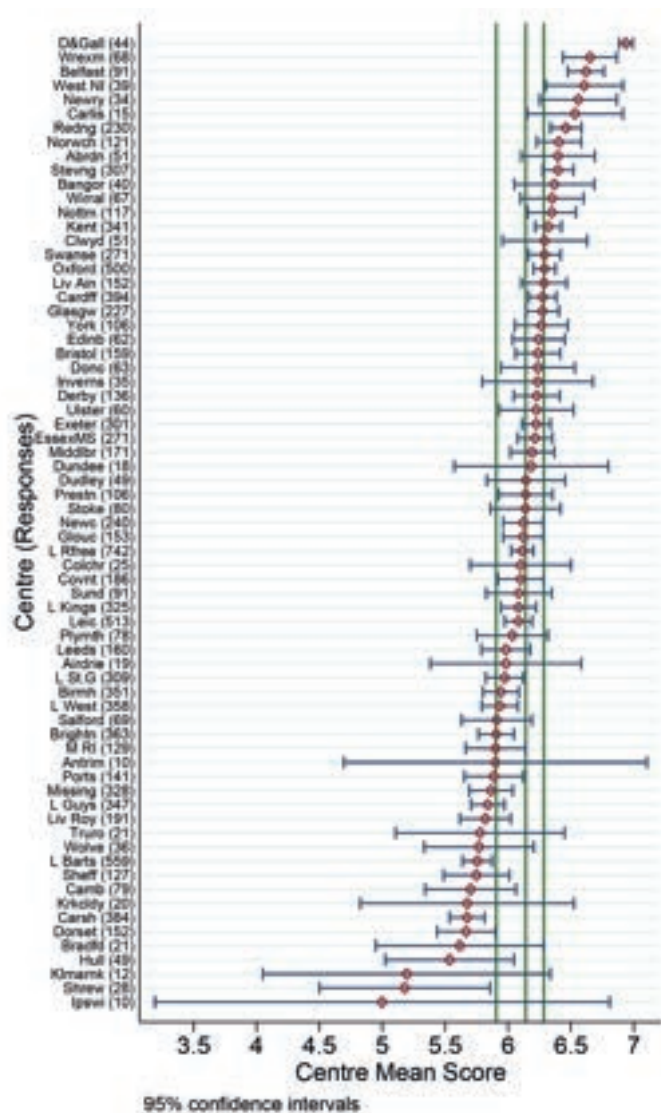
Theme questions

- 25. Can you change your appointment times if they are not suitable for you?
- 26. 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:

- 27. Are the arrangements for your blood tests convenient for you?

Section Eleven: How the Renal Team Treats You

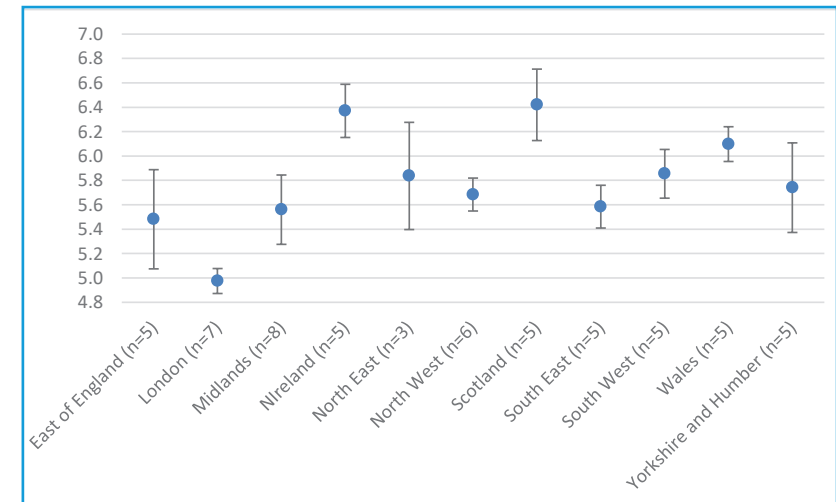
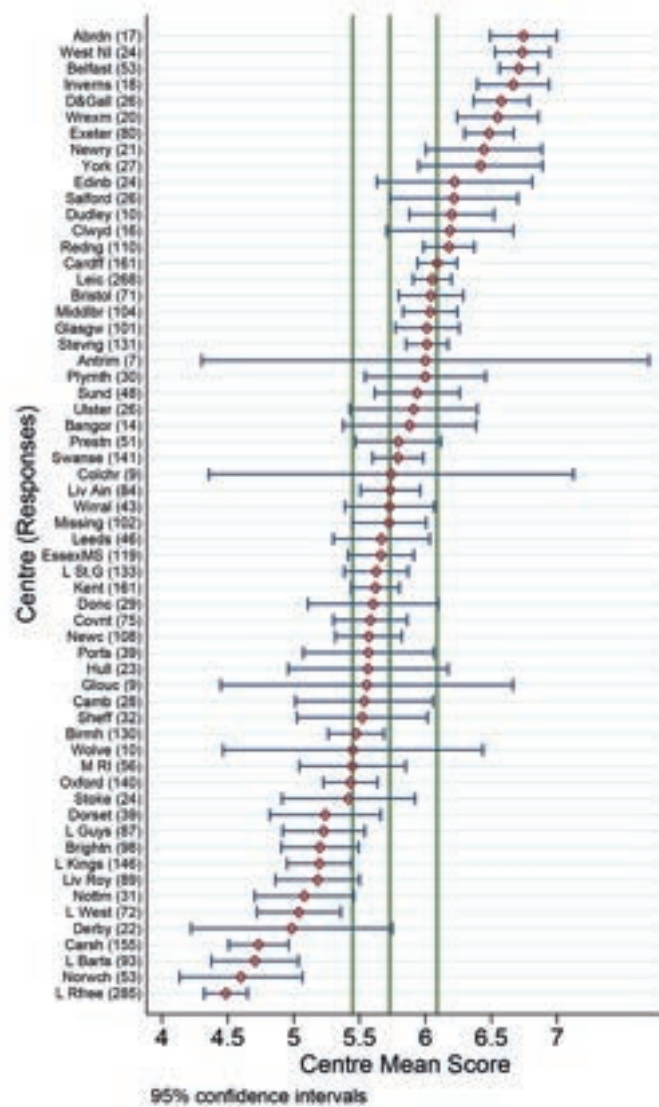


Theme questions

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

- 28. Take you seriously?
- 29. Show a caring attitude towards you?
- 30. Ask you about your emotional feelings?

Section Twelve: Transport

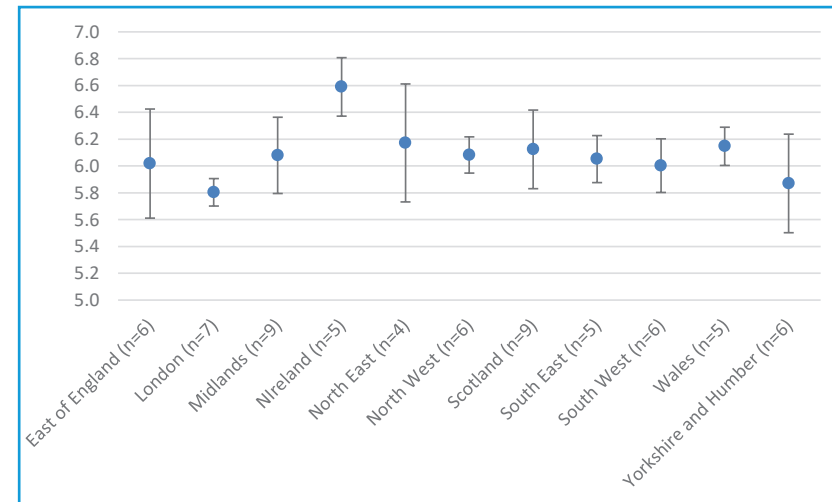
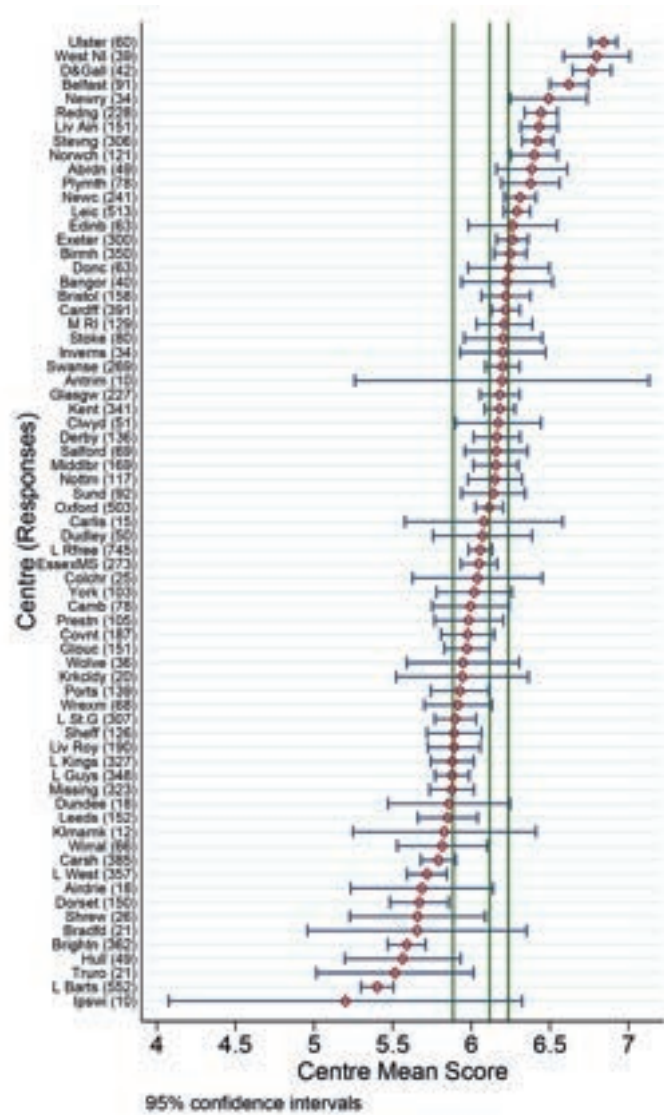


Theme questions

If the renal unit arranges your transport:

31. Is the vehicle provided suitable for you?
32. Is the time it takes to travel between your home and the renal unit acceptable to you?
33. Once your visit to the renal unit is finished and you are ready to leave, are you able to leave within less than 30 minutes?

Section Thirteen: The Environment

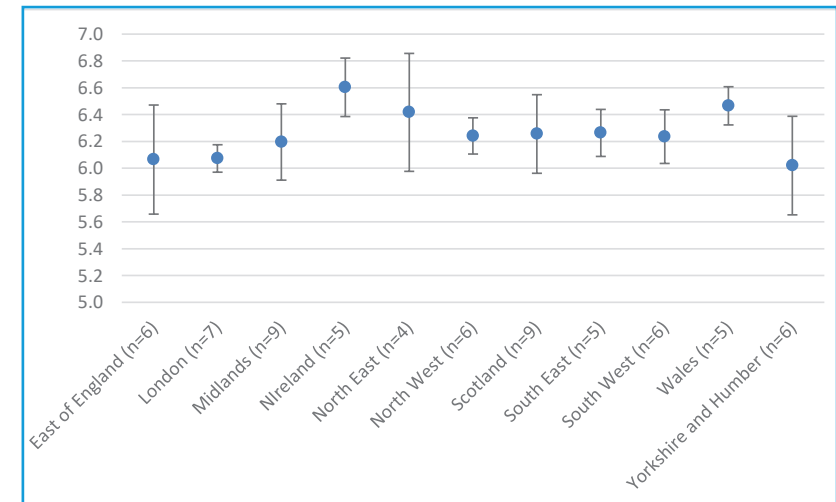
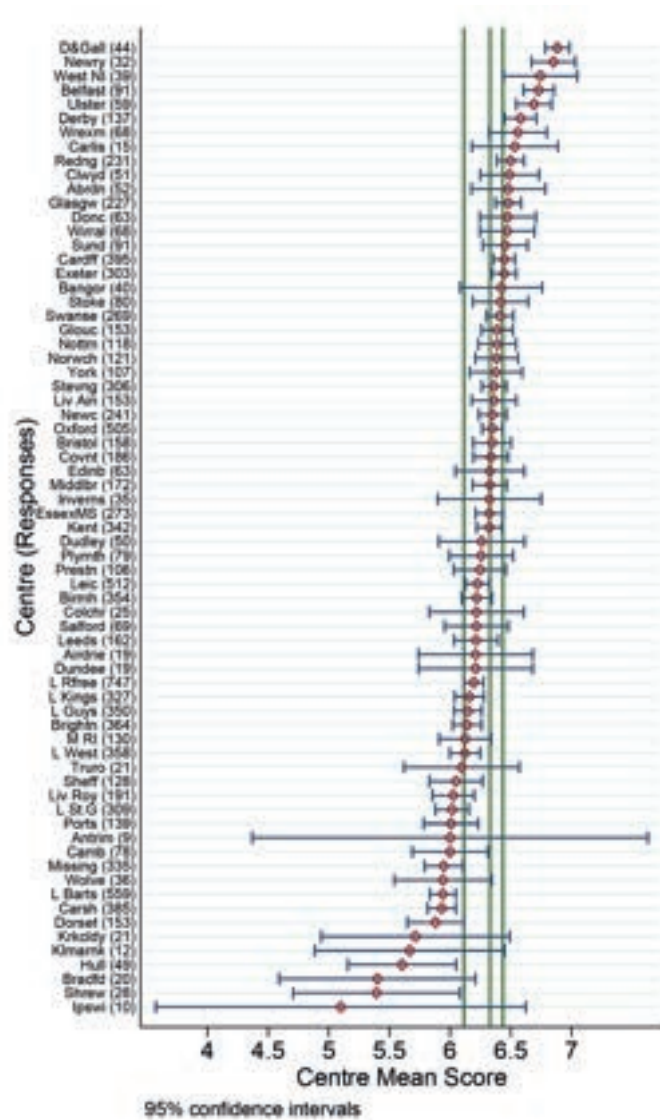


Theme questions

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

- 34. Accessibility (e.g., lifts, ramps, automatic doors)?
- 35. Comfort?
- 36. Cleanliness?
- 37. Waiting area?
- 38. Parking?

Section Fourteen: Your Overall Experience



Theme questions

39. 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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