



Patient Reported Experience of Kidney Care in the UK 2018

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Foreword

The Renal Association Renal Registry and Kidney Care UK are proud to publish the third Kidney Patient Reported Experience Measure report for 2018. The report is a significant and unique achievement driven by a wide collaboration which has grown to include over 13,000 patient responses from across 71 Adult Renal Units, including for the first time, Scotland and Northern Ireland. It meets the critical need for kidney disease-specific measures of patient experience and puts the patient voice at the forefront of quality improvement for Commissioners and those who deliver kidney services. The Kidney PREM has already been adopted as a key element of service review by the NHS England's Getting it Right First Time process.

The report reminds us that the drive towards patients and clinicians working together as equals and using people's expertise and knowledge of their own health is instrumental in achieving real, person centred care. We should celebrate the increasing involvement of renal units, our teams and patients working together through the Kidney PREM to make high quality care across the board a constant and make change happen.

We learnt that overall patients rate their care highly, although there are some clear messages for the renal community to work on as a whole. Reporting of centre-specific PREMs highlights variation between units and provides a focus on which to build bold local and national improvement, adding a perspective on what real quality means and how we measure it, giving us the confidence to know we're working on the right things.

Nationally we need to continue to work on the themes that have the widest variation in experience and which patients themselves are telling us need attention. In particular these include:

- Shared decision making
- Patient transport
- Vascular access needling in patients treated by haemodialysis.

Going forward we need to encourage even greater patient involvement. This is particularly important for those from ethnically diverse communities who have a disproportionate burden of kidney disease so that we may adequately address their needs. We urge health professionals, patients, and patient groups, to come together, discuss the results and agree collaborative plans for improvement. The Kidney PREM was designed to be an active tool, providing patient insight that informs and supports even better kidney care.

With this in mind, this year's Kidney PREM included the opportunity for participants to add free text for the first time. This adds another dimension to the results and renal units will be pleased to hear much of this was positive.

Finally, we would like to give our thanks to everyone who participated in Kidney PREM in 2018. The renal community is leading the way in working with patients to develop their care and we should be justifiably proud of this achievement.



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Introduction

The Renal Association and Kidney Care UK are committed to improving the patient experience of kidney care, to have a positive impact on patient quality of life. In 2016, a group of patients, clinicians and academics taking part in the Transforming Participation in Chronic Kidney Disease quality improvement programme, co-designed the Kidney Patient Reported Experience Measure (Kidney PREM), recognising the need for a disease specific measure of patient experience. The UK Renal Registry and Kidney Care UK together made it available nationally on an annual basis, to give patients the opportunity to feed into service improvement by sharing what matters most to them.

Kidney PREM has continued to grow: from just over 8,000 responses from centres in England in 2016; 11,027 from centres in England and Wales in 2017; to more than 13,000 from across the United Kingdom (UK) in 2018, with centres in Scotland and Northern Ireland participating for the first time this year. The annual measure continues to be made available in hard copy and online, in English, Welsh, Urdu and Gujarati to encourage participation from a wide range of patients. This year for the first time, in response to feedback from patients, a free text comments box was provided online giving kidney patients the opportunity to share aspects of their patient experience that are not covered within the Kidney PREM. These comments have given new insights that complement the Kidney PREM findings. Key themes from these comments are described within this report.

Executive Summary

Key Findings

Overall response

- 71 adult renal centres across the UK participated in Kidney PREM 2018, providing 13,770 valid responses, 2,742 more than 2017. This is a positive result, and testament to the UK renal community's commitment to measuring and understanding patient experience
- The findings from the two validated Kidney PREM collections – 2017 and 2018 – show a remarkably similar national picture; evidence of the robustness of Kidney PREM as a measure and therefore a solid baseline for informing and measuring quality improvement
- Whilst the national picture is similar across the last two years, there are marked changes in some renal centres, providing credible evidence of the potential for improvement
- As in 2017, differences between centres are more important to patient experience than any other single difference captured by the Kidney PREM. Issues such as the person's age, treatment type, location of treatment, ethnicity, or whether the person is male or female does not appear to be important in determining the experience that is reported

Kidney PREM results

- Patient rating of their Overall Experience remained high (6.3 out of 7.0 in both 2017 and 2018)
- As in 2017 however, there are some clear messages for the renal community to work together on, to address the issues impacting most negatively on patient experience: The lowest scoring themes remain Sharing Decisions About Your Care, Transport and Needling
- Nationally, there has been no improvement in these three key areas, which also continue to report the highest variation in scores between centres
- Support and Communication are closely related to Sharing Decisions About Your Care, and continue to be the fourth and fifth lowest rated aspects of renal patient experience

Kidney PREM comments

- The themes emerging from 317 written comments online fell mostly within the existing 13 themes of the Kidney PREM, but give further insight into how renal care can best be provided so that patients have a positive experience of kidney services
- There were two emerging themes that arose from the comments and fell outside the existing 13 themes of the Kidney PREM. These were PatientView, which was generally described positively with patients describing how this helps them to manage their condition, and Continuity of Care. This was a significant theme for many patients, who tended to hold a negative view of being seen by different professionals at their regular kidney care appointments.

Recommendations

Interpreting the Kidney PREM results

- Differences in response rates and respondent profile between centres mean that direct centre comparisons should not be assumed to be informative. Centre scores falling above or below the quartiles are likely to indicate patient experience outside of the normal range
- There are significant variations between centres, indicating the opportunity for centres to use their own data to identify areas for improvement
- The Kidney PREM will have the greatest impact when renal centres act on their local findings, and make improvements to care identified as necessary by their own patients
- There is however an opportunity for those units performing well in an area to share knowledge and ideas with those performing less well

Acting on the Kidney PREM results

- The consistent and unchanged national findings provide a strong case for change, and a call to action from kidney patients in the UK to address as a priority the three aspects of kidney care that impact most negatively on their experience: Sharing Decisions About Your Care; Transport and Needling
- Many of the areas for improvement are behavioural and cultural, which are challenging to address. It will be important for centres to maintain the high patient ratings of the fundamentals of service provision (access, scheduling, information, privacy & dignity) whilst identifying and resolving challenges in support, communication and shared decision making
- For the findings to be addressed and acted upon, the Kidney PREM data should be widely accessible to all, in order to encourage awareness and discussion between patients, staff and centres

Improving the Kidney PREM

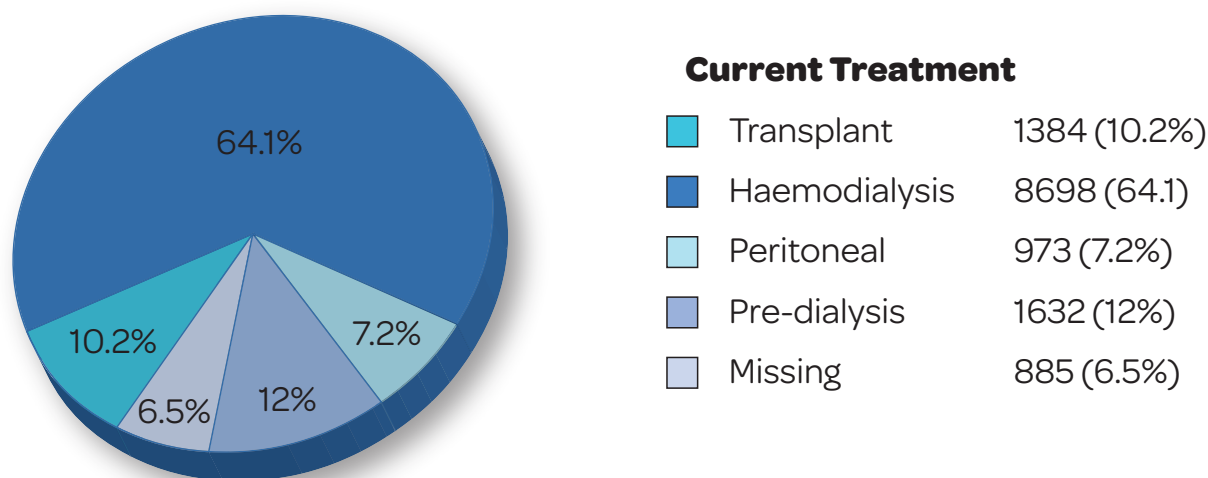
- To reflect a more representative picture of kidney patient experience in the UK, Kidney Care UK and the UK Renal Registry, in partnership with participating renal centres, should work to improve engagement across the whole patient community, in particular working to increase participation from under-represented groups
- There appears to be varying degrees of engagement with the Kidney PREM across centres, with response rates of patients on renal replacement therapy ranging from less than one percent, to over 60 percent. Whilst the response overall from the renal community is impressive there is some way to go to ensure every centre is represented in the Kidney PREM

Respondent Profile

71 adult renal centres across the UK participated in Kidney PREM 2018, providing 13,770 valid responses, 2,743 more than 2017.

The profile of patients responding to Kidney PREM 2018 was similar to 2017, with more men (53%) than women (36%) taking part, the largest age group being 56-74 (44%) and the majority being of white ethnicity (75%).

The proportion of patients on haemodialysis increased in 2018 (64% compared to 56%), with correspondingly fewer responses from transplanted (10% vs 14%) and pre-dialysis (12% vs 15%) patients.



Patient rating of renal services

Patient rating of their Overall Experience remained high (6.3 out of 7.0 in both 2017 and 2018).

The aspects of renal care which patients rate most highly, the core elements of service delivery, are unchanged from 2017: Privacy & Dignity; Access to the Team; Patient Information and Scheduling & Planning (all awarded mean scores of 6.2-6.3). As in 2017, Sharing Decisions About Your Care (awarded a mean of 5.4 out of 7.0), Transport (5.6) and Needling (5.7) perform less well.

There is considerable variation in overall experience of kidney care according to which renal unit a patient attends, as the range of mean scores awarded to centres increased from 1.0 point in 2017 to 1.4 points between the lowest (5.4) and highest (6.8) scoring centres in 2018.

The greatest differences between highest and lowest performing centres continue to be in scores awarded for Sharing Decisions About Your Care (a range of 3.1 points between the lowest (3.6) and highest (6.6) scores), Transport (2.6 point difference) and Needling (1.9).

Patient ratings of their experience of Support, Communication, Fluid & Diet and Environment are stable across 2017 to 2018; means have changed by just +/- 0.1. Table 1 shows the mean scores and ranges for all themes in the Kidney PREM in 2018 and the difference in scores between 2017 and 2018.

Table 1: Kidney PREM 2018 theme means and ranges and change from 2017 (centre scores).

	2018 Mean Score	Standard Deviation	Min score	Max score	Range	Change compared to 2017
Access to the Renal Team	6.4	0.2	5.9	6.9	1.0	0.0*
Support	5.9	0.3	4.9	6.6	1.7	-0.1
Communication	6.0	0.3	5.0	6.6	1.6	0.1
Patient Information	6.3	0.3	5.5	6.9	1.4	0.0
Fluid and Diet	6.1	0.3	5.3	6.9	1.5	0.1
Needling	5.8	0.3	4.5	6.4	1.9	0.0
Tests	6.2	0.2	5.7	6.6	0.9	0.0
Sharing Decisions About Your Care	5.5	0.4	3.6	6.6	3.1	-0.1
Privacy and Dignity	6.3	0.3	5.4	6.8	1.4	-0.1
Scheduling and Planning	6.2	0.3	5.3	6.8	1.6	0.0*
How the Renal Team Treats You	6.2	0.3	4.9	6.8	1.9	0.1
Transport	5.7	0.5	4.2	6.8	2.6	0.1
The Environment	6.1	0.3	5.6	6.7	1.2	0.1
Your Overall Experience	6.3	0.2	5.4	6.8	1.4	0.1*

*Differences of +/- 0.1 due to rounding

Comments from patients on their experience of renal services in the UK

A free text comments box was added to the end of the online version of the 2018 Kidney PREM, with patients informed that this was a trial run, and invited to comment about any aspect of their kidney care that had not been covered in the questionnaire.

317 patients, across a range of ages and modalities, provided a comment, with the strongest themes being Support, How the Team Treats You and Overall Experience. Comments on these themes were largely positive, with praise and thanks provided for caring and supportive teams.

How the Team Treats You

It was common for patients to have praise for the renal team, who were described as caring, approachable and patient focussed. Some commented that one or two negative individuals can make for a very variable experience of the team.

A strong sub-theme within How The Team Treats You was not being treated as an individual, which could impact strongly on how patients experienced their care, or how actively they participate in their care and decision making, as a result of not feeling understood.

Support

Where teams were not experienced as caring and supportive, patients were clear about the types of support needed, and commented that there can be a lack of emotional support specifically, although also citing lack of support at certain times in the care pathway. Despite being clear about the kind of support they need, some patients describe not knowing where to get support, be that from peers or professionals. A cornerstone of good support appears to be positive and receptive peers and staff, who are able to offer the individualised support a patient needs.

The patient definitions of good support, provided by staff receptive to patients as individuals, have the potential to impact on many aspects of kidney care and improve one of the poorest performing themes of the Kidney PREM in 2018 – Sharing Decisions About Your Care.

There were two **emerging themes** that arose from the comments and fell outside the existing 13 themes of the Kidney PREM. These were **PatientView**, which was generally described positively with patients describing how this helps them to manage their condition, and **Continuity of care**. This was a significant theme for many patients, who tended to hold a negative view of being seen by different professionals at kidney care appointments.

The themes emerging from the written comments give additional insight into how renal care can best be provided so that patients have a positive experience of kidney services.

Data interpretation

As outlined in 2017 the scale range is 7 points, a difference of 10% (or 0.7 points) or more between mean values, is likely to indicate a difference that is significant in terms of patient experience.

The number of responses from some centres, and units within centres, is still low and not necessarily representative of the patient population. This means that direct comparison of results between centres, or from year-to-year should not be assumed to be informative. Low response rates can be inferred from the charts in Appendix 4; normally the wider the confidence intervals, the smaller the number of responses from the centre.

Small changes were made to the Kidney PREM in 2018 compared to 2017 to allow for the number of questions to be reduced (from 50 to 39) and to make the meaning of two questions clearer. Comparison between the means scores from 2017 to 2018 will generally be possible but may be influenced where there is a substantial difference in the number of responders in 2017 compared to 2018. Comparison to the 2016 data is more challenging to interpret due to more substantial changes to the Kidney PREM made as a result of the 2016-2017 validation.

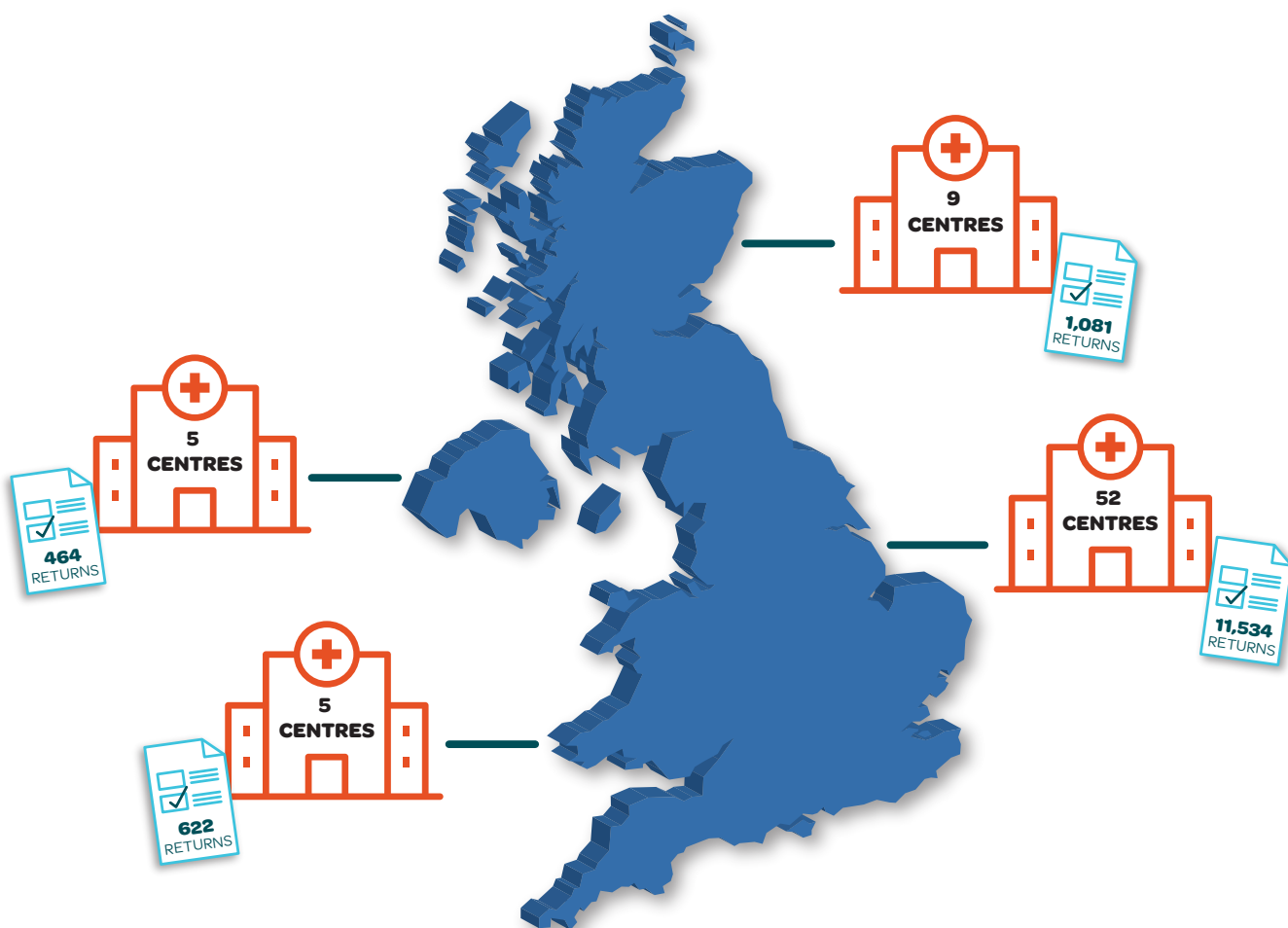
Kidney PREM 2018

Response profile

Paper copies of the Kidney PREM were made available to patients via their renal centres, and online in English, Gujarati, Urdu and Welsh, with publicity in participating units and on PatientView.

In 2018 a total of 71 adult renal centres across the UK participated in Kidney PREM, with patients from 281 units providing 13,770¹ valid responses. Participation has increased since 2017, with responses from 15 additional renal centres and 2,743 more patients (Table 2). Patients from centres in Scotland and Northern Ireland took part for the first time.

Returns by country



Created by Iconic from Noun Project

¹ When estimating individual statistics the total may be less than 13,770 as often patients did not respond to all the questions, and in cases where estimation of a group mean is based on fewer than 7 patients the data is withheld to preserve anonymity.

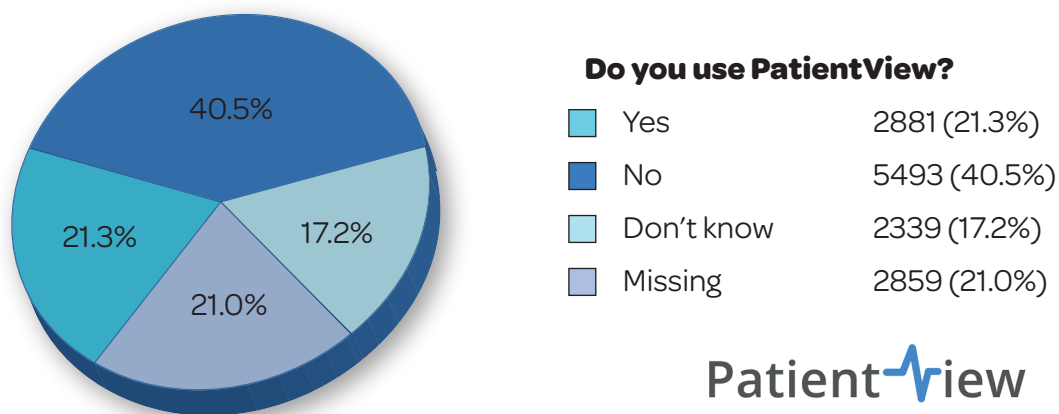
As in previous years, the largest age group participating in Kidney PREM was the 56-74 age range (44%), but with an increasing proportion of people over 56 (73% in 2018 compared to 69% in 2017). The proportions of men and women responding were similar to 2017, with more men taking part in Kidney PREM (53% to 36%, with 11% choosing not to say).

Patients on haemodialysis continued to be the predominant group, with more responding this year than in 2017 (64% compared to 56%²), and slightly smaller proportions in the transplant (10% vs 14%) and pre-dialysis (12% vs 15%) groups.

Reflecting treatment patterns, the proportions of younger patients in the transplant and pre-dialysis groups were larger than for other treatment groups. There is a much higher proportion of older patients (>75) in the peritoneal group this year than expected (37% compared to 31% overall).

The ethnic profile of patients in 2018 was very similar to 2017, with the majority being white (74.6% vs 74.2%). Whilst there was very little change to the proportions of patients of Asian (9.3%; 9.5%) or other (2.6%; 2.4%) ethnicity, slightly fewer Black patients responded this year (6.0% vs 7.0%).

The proportion of patients who used PatientView has reduced to 21.3% from 24.1% in 2017. There were still significant proportions of patients who either don't know whether they use PatientView (17.2%) or chose not to answer this question (21.0%).



For more information on PatientView, visit www.patientview.org.

² Renal centres in Scotland actively promoted Kidney PREM to haemodialysis patients, boosting the Kidney PREM 2018 haemodialysis sub-sample by over 1,000 responses.

Table 2: Characteristics of the people who completed the Kidney PREM in 2018 and 2017

Characteristic	PREM 2018	PREM 2017
Total	13,770	11,027
Age		
≤30	391 (2.8%)	353 (3.2%)
31-55	3,095 (22.5%)	2,797 (25.4%)
56-74	6,042 (43.9%)	4,731 (42.9%)
≥75	3,970 (28.8%)	2,902 (26.3%)
Missing	272 (2.0%)	244 (2.2%)
Gender		
Female	4,891 (35.5%)	4,031 (36.6%)
Male	7,295 (53.0%)	5,907 (53.6%)
Rather not say	57 (0.4%)	39 (0.4%)
Missing	1,527 (11.1%)	1,050 (9.5%)
Ethnicity		
Asian	1,275 (9.3%)	1,048 (9.5%)
Black	829 (6.0%)	774 (7.0%)
White	10,267 (74.6%)	8,184 (74.2%)
Rather Not Say	202 (1.5%)	155 (1.4%)
Other	355 (2.6%)	265 (2.4%)
Missing	842 (6.1%)	601 (5.5%)
Current Treatment		
Transplant	1,399 (10.2%)	1,545 (14.0%)
Haemodialysis	8,834 (64.2%)	6,194 (56.2%)
Peritoneal	982 (7.1%)	808 (7.3%)
Pre-dialysis	1,659 (12.0%)	1,671 (15.2%)
Missing	896 (6.5%)	809 (7.3%)
Haemodialysis Location		
At Home	299 (3.4%)	276 (4.5%)
In-centre	3,843 (43.5%)	2,671 (43.1%)
In-satellite	4,412 (49.9%)	3,036 (49.0%)
Missing	280 (3.2%)	211 (3.4%)
Use PatientView		
Yes	2,928 (21.3%)	2,658 (24.1%)
No	5,583 (40.5%)	4,321 (39.2%)
Don't Know	2,364 (17.2%)	1,824 (16.5%)
Missing	2,895 (21.0%)	2,224 (20.2%)

Overall patient experience

As in 2017, the mean score awarded for overall experience of the service provided by renal units is high; the same score of 6.3 out of 7 giving a good overall endorsement of renal services in the UK.

The range of scores across centres has grown from 1 point (5.7 to 6.7) in 2017 to 1.4 points (5.4 to 6.8) in 2018, indicating a considerable variation in experience across centres. Figure 1 shows clearly that a number of centres fall above and below the upper and lower quartiles, performing better or worse than the majority.

Figure 1: Centre mean scores for overall experience of the service provided by renal units (Question 39 in the 2018 Kidney PREM)

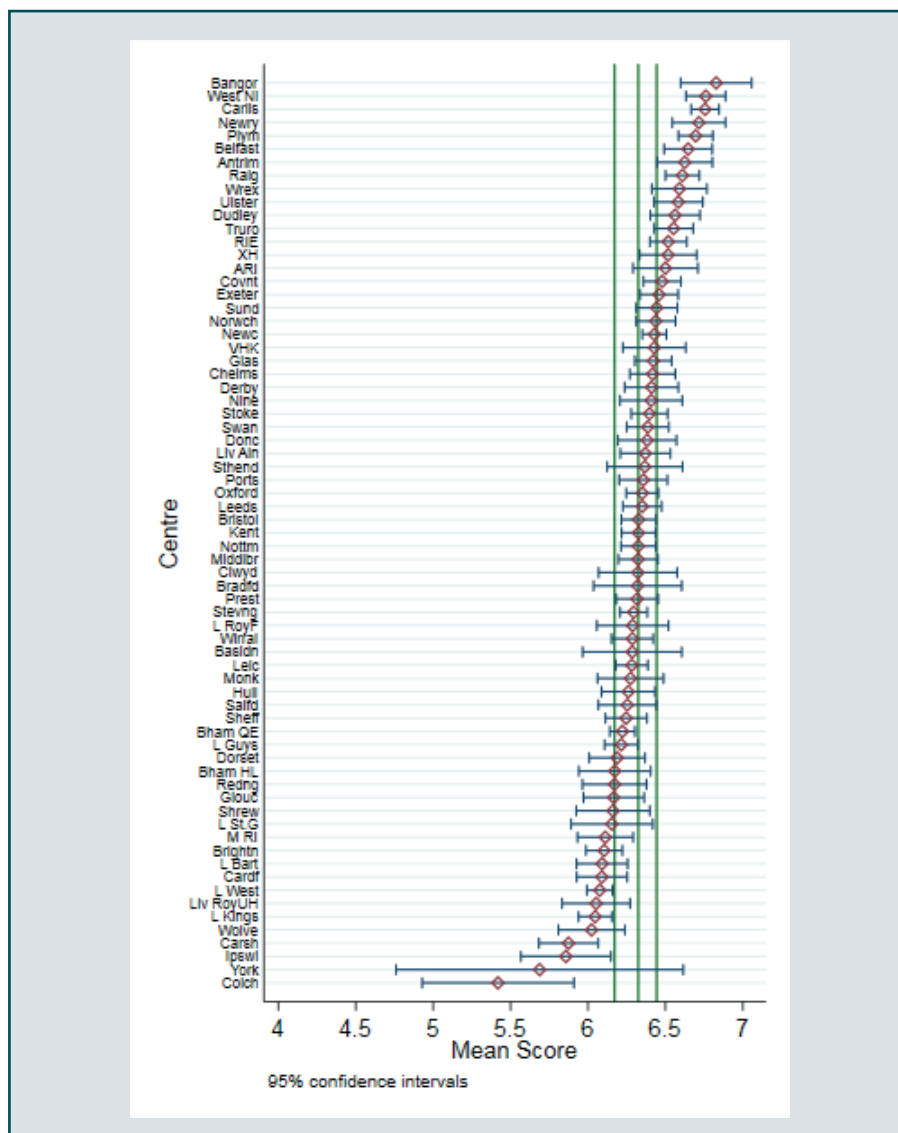
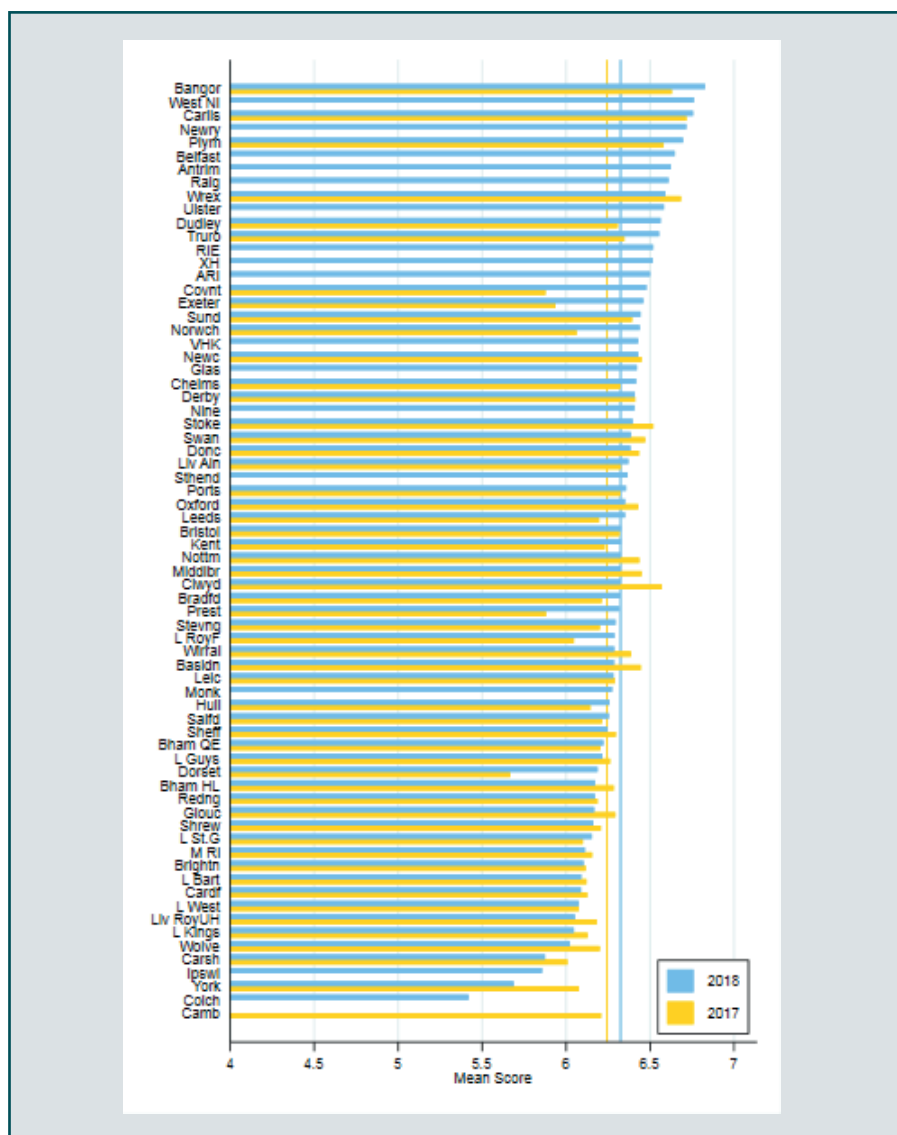


Figure 2 shows that whilst the mean score (6.3) for overall experience does not change, there has been considerable movement between centre scores from 2017 to 2018. Whilst some of this may reflect local quality improvement initiatives, large changes in patient experience from year to year would not be expected without a significant change in service delivery. Changes in ratings between 2017 and 2018 may reflect a change in the number of responding patients within some centres. Figure 2 also shows a notably positive overall experience for patients from renal centres in Northern Ireland.

Figure 2: 2018 and 2017 centre mean scores for overall experience of the service provided by renal units (Question 39 in the 2018 Kidney PREM)

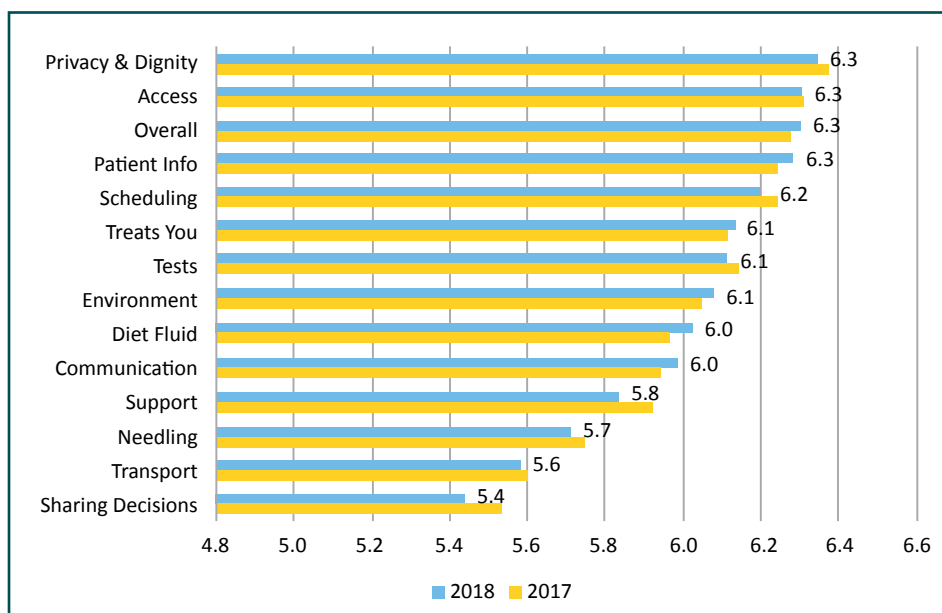


How patients experience renal services

The Kidney PREM measures kidney experience over 13 themes. Figure 3 shows the mean scores for each theme in both 2017 and 2018. Many similarities between 2017 and 2018 remain: Privacy & Dignity (6.3), Access to the Team (6.3), Patient Information (6.3) and Scheduling & Planning (6.2) continue to provide high overall mean scores (scoring 6.2-6.4 in 2017), and continue to be the aspects of renal care in which patient experience is most positive.

As in 2017, Sharing Decisions (5.4) Transport (5.6), and Needling (5.7) provide the lowest overall means in 2018, and are the aspects of renal care in which patient experience is in most need of improvement. Communication (6.0) and Support (5.8) are closely related to Sharing Decisions About Your Care, and continue to be the fourth and fifth lowest rated aspects of renal patient experience.

Figure 3: Mean scores for the 13 Kidney PREM themes and the overall experience question, showing values from 2017 and 2018.



Note: Some of the means for 2017 vary slightly compared to the data published last year due to changes in the way the figures have been calculated (centres with small numbers [<7] are now excluded).

Variation in patient experience between renal centres

Table 3 shows the overall mean for each theme, the minimum and maximum centre mean and the difference between the means (range).

As in 2017, there is considerable variation in patient experience of renal services between centres. Sharing Decisions About Your Care (3.1), Transport (2.6) and Needling (1.9) continue to provide the widest range of mean scores, this year joined by How the Team Treats You (also 1.9). The mean ranges for Sharing Decisions About Your Care and How The Team Treats you are made particularly large by a centre with noticeably low mean ratings in these areas.

The most consistent patient experience comes from Tests (0.9) and Access to the Team (1.0), both of which report a small range of centre means and high overall mean values, indicating consistently good practice across renal centres. Privacy and Dignity also has a fairly low range (1.4) and a high mean (6.3) indicating good consistency across the UK.

Patient ratings of their experience of Support, Communication, Fluid & Diet and Environment are stable across 2017 to 2018; means have changed by just +/- 0.1.

Table 3: A summary of the highest and lowest mean scores by centre, with the range in scores.

Theme	Topic	2017			2018		
		Range*	Mean range	Mean	Range	Mean range	Mean
1	Access to the Renal Team	0.9 [¥]	5.9 - 6.8 [¥]	6.3 [*]	1.0 [¥]	5.9 - 6.9 [¥]	6.4 [*]
2 ⁱ	Support	1.1	5.4 - 6.6	6.0 [#]	1.7	4.9 - 6.6	5.9 [#]
3 ⁱ	Communication	1.4	5.1 - 6.5	5.9	1.6	5.0 - 6.6	6.0
4 ⁱ	Patient Information	1.1	5.7 - 6.8	6.3 [*]	1.4	5.5 - 6.9	6.3 [*]
5 ⁱ	Fluid and Diet	1.6 ^o	5.0 - 6.7 ^o	6.0	1.5	5.3 - 6.9	6.1
6	Needling	1.4 ^o	5.3 - 6.6 ^o	5.8 [#]	1.9 ^o	4.5 - 6.4 ^o	5.8 [#]
7	Tests	1.1	5.6 - 6.7	6.2	0.9 [¥]	5.7 - 6.6 [¥]	6.2
8 ⁱ	Sharing Decisions About Your Care	1.5 ^o	4.9 - 6.4 ^o	5.6 [#]	3.1 ^o	3.6 - 6.6 ^o	5.5 [#]
9	Privacy and Dignity	0.9 [¥]	6.0 - 6.9 [¥]	6.4 [*]	1.4	5.4 - 6.8	6.3 [*]
10	Scheduling and Planning	0.8 [¥]	5.8 - 6.7 [¥]	6.3 [*]	1.6	5.3 - 6.8	6.2 [*]
11 ⁱ	How the Renal Team Treats You	1.1	5.5 - 6.6	6.1	1.9 ^o	4.9 - 6.8 ^o	6.2
12	Transport	2.5 ^o	4.2 - 6.7 ^o	5.6 [#]	2.6 ^o	4.2 - 6.8 ^o	5.7 [#]
13	Environment	1.2	5.3 - 6.5	6.0	1.2 [¥]	5.6 - 6.7 [¥]	6.1
14	Overall Experience	1.0	5.7 - 6.7	6.3	1.4	5.4 - 6.8	6.3

i indicates themes where questions were removed. Fluid and Diet also included changes to the questions.

*indicates the highest mean scores overall, and # indicates the lowest mean scores.

o indicates the largest ranges across themes

¥indicates the smallest ranges across themes.

Note: Some of the means and ranges for 2017 vary slightly compared to the data published last year due to changes in the way the figures have been calculated (centres with small numbers [<7] are now excluded).

Appendices 4 and 5 provide figures illustrating variation in mean scores across centres. In Appendix 4, the charts provide the mean score and 95% confidence intervals for each centre for the 2018 Kidney PREM (where there were more than 7 responses per centre), along with the median and quartile scores for centre means. Means where the confidence intervals fall beyond the 25th or 75th percentiles are worse than or better than the majority of centres in that theme. The charts in Appendix 5 provide the same data with mean scores plotted as bars in descending order.

Changes to the Kidney PREM between 2017 to 2018

The Kidney PREM was modified for 2018 to reduce its length (from 50 to 39 questions), with the aim of maintaining the overall mean scores, while increasing the overall response variation between people responding. The intention was to try to maximise any apparent differences within the 13 themes so that the questionnaire would become more sensitive to

those differences. There is a remarkable consistency in the overall mean scores from 2017 to 2018 that is not affected by an increase in the score ranges for all but three questions.

Where the range does fall (Fluid and Diet, Tests and Environment) the differences were not large. This indicates that the changes to the design of the questionnaire have worked as intended, providing further confirmation that the Kidney PREM is a valid and reliable measure of patient experience.

Differences between patients and their experience

The characteristics of the people responding are not the principle characteristic that determines the difference in patient experience in the Kidney PREM. It remains the case that differences between centres are more important to patient experience than any other single difference. Issues such as the person's age, treatment type, location of treatment, ethnicity, or whether the person is male or female do not appear to be important in determining the experience that is reported. Age does show a consistent increase in reported experience from the youngest to oldest age group (most likely in three groups: <30, 30-64, >64), but the range is small (5.8 to 6.1), indicating that the effect is very limited.

There is a small group of patients (<200; 1.4%) who are unwilling to provide information about their gender or ethnicity ("Not say" response) who do report a particularly poor experience (<5.4). This indicates a pool of patients who wish to protect their identity while reporting worse than average experience. However, there are also a considerable number of patients who have provided this information but also report a poor experience, indicating that this group are not exceptional within the overall pool of patients responding to the Kidney PREM.

Comments from patients on their experience of renal services in the UK

Following the 2017 Kidney PREM, patients suggested that a comments box would be useful, so this was piloted in the 2018 online English survey to test whether it was feasible to collect free text from patients and process and analyse it in a meaningful way. The comments box was optional, with patients informed that this was a pilot, and an opportunity for them to tell the Renal Association and Kidney Care UK about an aspect of their kidney care experience that had not already been covered in the Kidney PREM. A full report on the comments from patients on their experience of renal services can be found on the Renal Association website www.renalreg.org/projects/prem/.

Just under half (317) of patients completing the Kidney PREM online provided a written comment. Broadly even numbers of men and women responded to this section, and most were white (91%; 3% Black; 3% South Asian). Comments came from a good mix of patients on different treatment modalities (36% transplant; 31% haemodialysis; 27% pre-dialysis; 7% peritoneal dialysis).

Two researchers coded and themed the comments. Many comments fell into one or more of the 13 themes within the Kidney PREM, and so this was used as the starting frame, with other codes and themes added as analysis progressed.

Support and How The Team Treats You

These themes are closely related and were raised by many patients. Those providing comments were quite specific about the type of support needed, including financial, social, specialist, treatment specific and emotional. The sub-theme of lack of emotional support was strong, with some describing an absence of emotional support having a great impact on them, or their experience of care.

In my experience there is very little if any easy access psychological support at all to be found from this unit when it is needed by the patients and in particular, their families who often suffer just as much as the patients.

Linked to this, patients were very specific about the lack of support at certain times in the care pathway, with examples from early diagnosis or unplanned start on dialysis through to post-transplant discharge.

Some patients describe not knowing where to get support, some of which could potentially be met through Kidney Patient Associations. Patients commenting had a clear idea of the type of support they were looking for, be that patient networks or one on one support from experienced patients or professionals.

There is a need for a support network for patients, carers and family members, to meet with other kidney patients for support, sharing ideas, experiences etc.

Positively, patients were clear when they were in receipt of good support, including for non-renal issues, largely through positive and receptive staff and peers.

The team show interest and support regarding other family members. They are consistently kind and caring and treat me with respect and consideration, both as an out patient and as an inpatient, as a PD patient, as a haemo patient and also as a transplant patient.

When referring to How The Team Treats You, it was common for patients to have praise for the renal team, and wider staff, who were described as caring, approachable and patient focussed. Some describe generally caring teams over-shadowed by one or two negative individuals, making for a variable experience of the team.

I guess all my answers could be positive if it were not for one doctor and one staff nurse in whom I have no trust and who have between them caused life changing negative results.

The sub-theme to emerge most strongly with regards How The Team Treats You was not being treated as an individual, which for some patients impacted heavily on how they felt about their care. This was sometimes couched by an appreciation that staff are under pressure.

Sometimes more often than not the Kidney specialist makes me feel rushed and I feel he doesn't actually hear what I have to say, they know the science of Kidney disease but they have no idea what it is like to live with it and the effect it has ...they seem to lack empathy, the

nurses are lovely and do what they can but the specialists are totally different and I think need to be more considerate.

Overall Experience

This was a considerable theme, with largely very positive comments praising committed staff and excellent service. Words like fantastic, lucky and first class came up often. There was often a sense of gratitude, and comments that patients would recommend their centre to others in the same position.

Nurses are fabulous at treating us week to week and the consultants, doctors have guided my treatment excellently. Thank you.

My experience of the [centre] is; that the nursing and medical staff are very kind and attentive, there is excellent social worker support and the transport service using the cars is friendly and efficient. Overall I would highly recommend the service provided.

Comments on specific aspects of care

- Access To The Team was generally described negatively due to lack of staff engagement or staff availability out of hours
- Comments on Communication tended to be at two extremes, often incredibly positive, with examples of good communication within teams and across organisations, or described as lacking, with detail of how this impacts negatively on patient experience
- Patient Information can be lacking, be that in content, format or timing, and relates closely to the theme of support
- Reflecting the respondent profile, many comments on Fluid Intake & Diet focussed on the lack of ongoing information for patients who have received a transplant. Other patients described poor timing of dietary consultations and poor quality dietary advice or information
- The few patients commenting on Needling had varied concerns including staff skills and constructive feedback
- Patient comments on Tests were wide ranging; the desire for more blood tests or better access to test results as well as issues with the timing of tests
- Some patients described how they would like greater involvement in their care in the guise of Shared Decision Making, with some positive comments where this already happens
- The few comments on Privacy & Dignity related mainly to confidentiality
- Waiting times were an issue for some patients, both for in-centre haemodialysis and outpatient clinics, with other comments on Scheduling & Planning detailing system issues with booking appointments or receiving unreliable confirmations
- Transport was raised in a pragmatic way, with patients often suggesting solutions to ineffective transport rounds or excessive waiting times

- An aspect of Environment, Parking, was a strong sub-theme, largely because of excessive costs or lack of availability. Other comments focussed on hygiene and the quality of furniture in renal centres, both of which were largely seen as substandard.

Emerging themes

- Emerging themes included PatientView, which was generally described positively with patients describing how this helps them to manage their condition. Some focussed on functionality and improvements, largely extending the range of information available on the system

I would like to see more of the letters relating to my treatment on patient view, particularly non renal issues

- Continuity of care was a significant theme for many patients, who tended to hold a negative view of being seen by different professionals at kidney care appointments. Some find the perceived lack of consistency anxiety-inducing

I would like to see a regular doctor when attending appointments but instead I often meet somebody new at every appointment. This can be frustrating as they will only have a short time to read my notes before meeting me and don't actually know me.

- Those mentioning Pharmacy were divided on whether prescriptions would more sensibly be issued by renal centres or GP surgeries; a very individual issue
- There were several comments on questions that should be added to Kidney PREM in the future, often relating to specific treatment pathways or stages of kidney disease.

What's next?

Ongoing improvements to the Kidney PREM process

The results of Kidney PREM 2018 by unit will be made available online via the UK Renal Registry and Kidney Care UK's website. The results are presented as raw data scores. In addition, mean scores for each of the 13 Kidney PREM themes, by modality and centre are made available to all centres (where more than 10 patients responded)³.

On patient request we included a comments box at the end of the online Kidney PREM, which provided a great deal of insight and was well received by patients. We will include this again in the 2019 online Kidney PREM and are looking into the feasibility of including this in the paper version, or making it clearer to patients that if they complete Kidney PREM online, there is an opportunity to provide comments on their experience.

Patients from ethnic minorities are under-represented in the Kidney PREM and we are actively engaging patients from the South Asian community especially, to understand how to better reach these groups and measure their experience.

Whilst we are delighted at the engagement from haemodialysis patients, we will work closer with renal units in the run up to the 2019 Kidney PREM to ensure that we optimise participation from patients who are pre-renal replacement therapy, those who have received a transplant, or are on peritoneal dialysis. At the very least, we want to reverse the 2017-2018 decline in participation seen in some of these groups.

Renal centres have let us know that writing the renal unit codes on Kidney PREMs is an arduous process, although necessary in order to link patients to their treating centre. We are reviewing the feasibility of pre-printing the front sheets to include unit code.

In 2017, the Kidney PREM data was shared to Clinical Directors via the UK Renal Registry online Clinical Directors Forum. We recognise the difficulty wider staff and patients had in accessing the Kidney PREM 2017 data and therefore this year, we will be making this openly accessible and public via the Kidney Care UK and UK Renal Registry websites. This was supported by those attending the presentation of the 2017 Kidney PREM results at the 2018 Renal Clinical Directors Forum.

In time we hope this data will be presented in a more interactive format to allow centre level results to be interrogated by patients, staff and the public, and its use increased.

³ Whilst <7 is the limit for calculating scale scores across Kidney PREM themes, we have used <10 as the limit for reporting individual PREM items, to be sure of preserving patient identities.

Acting on the results of the Kidney PREM

The robustness of the measure has enabled the Kidney PREM data-set to be more widely adopted and used for national projects such as the renal Getting it Right First Time initiative, and has provided a patient-focussed data resource that is now available to the renal community.

One of the key findings of the Kidney PREM in both 2017 and 2018 is that renal patient experience is driven by the quality of service provided at the local renal centre, with a patients' characteristics having little bearing; for example being better or worse for older or younger people, or for people who have early stage kidney disease compared to those who have been on dialysis for some time. Put more simply, the quality of a patients' experience is dependent on the renal centre they attend for their kidney care.

Positively, this means that the full range of a unit's patients may benefit from a quality improvement initiative that is targeted at an aspect of the service that local patients have indicated needs improving. It also suggests that initiating improvements across the patient pathway will be beneficial.

The aspects of renal services that the Kidney PREM 2018 has shown vary most between centres across the UK are the same as 2017: Sharing Decisions About Your Care; Transport; Needling; with the addition in 2018 of How the Renal Team Treats You. UK Renal Registry and Kidney Care UK recommend that centres should review and address their performance in these areas when pursuing improvements in patient experience.

The UK Renal Registry and Kidney Care UK are keen to support centres and their units to act on findings to improve patient experience by focussing on what is shown to drive variations in experience locally. We are supporting this by:

- Support with publicising your Kidney PREM results locally to patients, colleagues and your local community to celebrate successes and any actions taken in response to the Kidney PREM;
- Supporting local Kidney Patient Associations to review the Kidney PREM results and work in partnership with hospitals and Quality Improvement leads to respond to areas in need of improvement;
- Sharing good practice – gathering case studies of good practice and sharing these on the UK Renal Registry and Kidney Care UK's website;
- Encouraging further local investigation;
- Offering advice – we are keen to talk with you to see how local action can best be focussed to achieve patient experience improvements. In the medium term we hope to be able to broker communications between those who can learn from each other, where one has successfully made changes aspired to by another.

Finally, the UK Renal Registry and Kidney Care UK have successfully partnered with University of Hertfordshire on a British Renal Society / Kidney Care UK research funding application: *Does measuring patient experience of kidney care benefit patients?* The study will investigate

whether Kidney PREM inspired, small-scale quality improvement work is associated with meaningful improvement in kidney patient experience. We will be surveying renal centres about their Kidney PREM results and plans for improvements in Spring 2019, and interviewing staff and patients in the Autumn, investigating changes in 2018-19 Kidney PREM results which may be attributable to locally inspired interventions. Early in 2020 we will share case studies of good practice on the UK Renal Registry and Kidney Care UK websites, with the aim that centres can learn from each other how improvements based on Kidney PREM patient experience data can be made.

Case Study Evidence

The UK Renal Registry and Kidney Care UK would like to hear how you have been using Kidney PREM findings locally, actions you have planned or things you have achieved as a result of action based on your unit or centre's results. If you would like to share your story with us, please do so by completing the template in Appendix 7 and returning it to catherine.stannard@renalregistry.nhs.uk. We will not share your details or story outside of the UK Renal Registry and Kidney Care UK without your prior permission.

The results of the Kidney PREM provides data to accompany the biochemical data gathered routinely by renal units and collated by the UK Renal Registry in the UK Renal Registry Annual Report.

The Annual Report is accessible to anyone and is a vital source of information for the renal community, used by a variety of stakeholders to improve patient care, and to show how well their hospital is managing kidney failure in clinical terms.

UK Renal Registry Annual Report Plain English summary:

<https://www.renalreg.org/patient-info/plain-english-summaries-2017-20th-annual-report/>

Annual Report Infographics:

<https://www.renalreg.org/patient-info/infographics/>

Full Annual Report:

www.renalreg.org/publications-reports

Glossary

Sample:	<p>When information is collected about a group of people, the group is referred to as a sample. Describing the “sample” (age, gender) is a useful way of understanding how representative that sample of people is compared to all the people in that group, known as the population (in this case all people, or population with Chronic Kidney Disease).</p>
Mean:	<p>When collecting information about a quantity (in this case patient experience) which will vary from one person to another, it is useful to have a way to summarise the central value which is common across those people. In this case the mean is the central value of patient experience in people living with CKD, and is calculated as the mathematical average.</p>
Confidence interval:	<p>A confidence interval provides a way of giving information about the error involved in estimating a value, for example a mean from a sample of people. Just as the values for each person might be different, so the mean value for different samples of people can also be different. In this report the confidence interval gives the values between which the mean value is likely to fall in 95 cases out of 100 (or in 95% of samples).</p>
Range:	<p>When information is collected about a group of people, the mean (or central value) is useful, but it is also useful to have information about the highest and lowest value. The range is the difference between the highest and lowest values in the sample, and gives useful information about the spread of values within a group.</p>
Quartile:	<p>The quartile is another useful way to provide information about the range of values within a sample of people. If the sample is ordered from the lowest to the highest value, the lowest and highest quarter of the sample can be excluded. The quartile is the difference between the highest and lowest value in the remaining middle (50%) of the sample. This allows people in the sample with exceptionally high and low values to be excluded when considering what the range of values might be.</p>

Plain English Guide to the Kidney PREM

The UK Renal Registry and Kidney Care UK work in partnership to give kidney patients in the UK the opportunity to provide feedback about their experience of treatment and care and to shape the services they use.

The Kidney Patient Reported Experience Measure (Kidney PREM) is made up of 38 questions on aspects of kidney care which patients have said are important to them, and a final question on overall experience of care. Kidney PREM is offered to people living with chronic kidney disease on an annual basis, in Spring each year.

Paper copies of the Kidney PREM were made available to patients via their renal centres, and online in English, Gujarati, Urdu and Welsh, with publicity in participating units and on Patient View.

The detailed results are made available on the UK Renal Registry and Kidney Care UK websites, allowing patients and staff to review their results and take action to improve patient experiences. In 2018 a total of 71 adult renal centres across the UK participated in Kidney PREM providing 13,770 responses.

New to the Kidney PREM for 2018:

- Patients from centres in Scotland and Northern Ireland participated for the first time
- The Kidney PREM was shortened from 50 to 39 questions, without compromising on the information collected
- Patients completing the Kidney PREM online were able to provide more detailed comments on their experience of care.

The UK Renal Registry and Kidney Care UK are keen to support patients to ensure they understand and can interpret the results.

If you are living with chronic kidney disease in the UK you can:

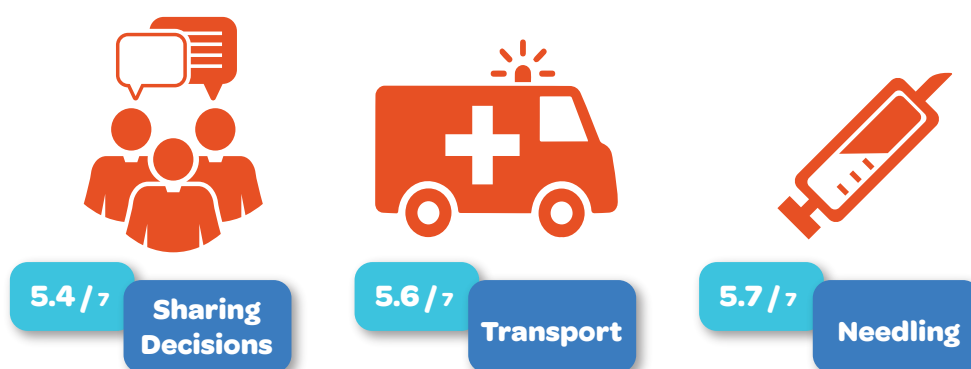
- Use the information to feel more informed about the care experienced nationally for kidney patients
- Understand how the care experienced at your centre compares to the national average by looking at Appendices 4 and 5, use our guide to help you
- Encourage other kidney patients to have a voice by participating in the 2019 Kidney PREM
- Contact your local Kidney Patient Association or centre officer if you need help understanding or want to discuss improvement ideas at your centre.

Summary of results:

Overall the results are considered to be very reliable and are consistent with previous years. The findings are all presented as the mean number, which is another way of saying average score.

The 39 questions covered in the Kidney PREM are grouped into thirteen ‘themes’ of renal care which patients have said are important, including Access to the Renal Team, Support, Communication, Patient information, Fluid Intake and Diet, and an ‘Overall Experience’ question. Only results by centre are presented here but centres have been provided with more in depth data at centre and satellite unit level.

- 1) Patient rating of their Overall Experience remained high (6.3 out of 7.0 in both 2017 and 2018).
- 2) Overall the most positively scored aspects of care were Privacy & Dignity (6.3/7), Access to the Team (6.3/7), Patient Information (6.3/7) and Scheduling & Planning (6.2/7)
- 3) The aspects of care requiring most improvement are Sharing Decisions About Your Care (5.4 / 7.0), Transport (5.6/7) and Needling (5.7/7).



When reviewing the results in more detail it is important to be aware that the number of responses from some centres is still low. The more responses a centre received, the more reliable the mean score is. Centres with fewer responses often have more extreme responses and this can have an impact in raising or lowering the mean score.

The results show that a patients’ reported experience was not affected by age, sex, ethnicity or treatment type. What it did show was the patient’s experience varied at a local level, with the difference in experience being determined largely by the renal centre they attend.

How do I use the mean score charts by centre in Appendix 4?

First find your centre’s name in Appendix 3. You can now check the mean score for your centre for each of the 13 themes.

	Mean score
	Mean score and confidence interval
	Left line = lower quartile Middle line = median Right line = upper quartile

Find your centre using the abbreviation, they are ordered from the highest to lowest mean score.

You will see the mean score for each centre as well as the confidence interval around the scores reported by patients.

To help you understand how your centre is performing against the national average, each graph has 3 lines that divide into four equal parts.

The first line (called the lower quartile) is the number below which marks the bottom 25 percent of the data.

The second line (the median) marks the middle of the range and has 50 percent of the data below it and 50 percent above it.

The third line (called the upper quartile) has the top 25 percent of the data above it.

Where centre means fall above or below the lower or upper lines, patients have reported to have a better (above the higher line) or worse (below the lower line) than average patient experience.

Please note that if fewer than 7 patients from a centre responded to a theme, the results from that centre for that theme are not included in the report.

How do I use the 2017 /18 theme comparison charts in Appendix 5?

These graphs show mean centre scores from results in 2017 and 2018.

Find your centre using the abbreviation, they are ordered from the highest to lowest mean 2018 score.

You can firstly compare performance results for your centre between 2017 and 2018.

A difference of 0.7 is equivalent to a 10% change which is likely to indicate significance in terms of patient experience. Large differences between years are worth investigating; however they could be a result of a significant increase or decrease in the number of patient responses from a centre, rather than a change in patient experience.

You can then compare your centre performance against the overall mean (average) score for both 2017 and 2018. The mean lines run vertically and are colour coded for each year.

How will the Kidney PREM be improved in 2019?

We will be working to actively engage groups that were under represented in the 2018 Kidney PREM. These include more patients from ethnic minorities, particularly those from South Asian background, and more patients who have received a transplant, or are pre-renal replacement therapy.

Following the successful trial in 2018 we will once again include a comments section in the online version of the 2019 Kidney PREM.

We will also be extending the review of the scores to 3 years in 2019.

These responses are all collected voluntarily to give people living with chronic kidney disease an opportunity to provide feedback about their experience of treatment and care and shape the services they use.

Thank you for your support and please continue to help raise awareness of the Kidney PREM locally and with your Kidney Patient Association.

Acknowledgements

The Renal Association and Kidney Care UK would like to thank the following people, without whom PREM 2018 would not have been possible.

- The patients who completed the Kidney PREM;
- The clinical directors, their staff and volunteers in the renal units in the UK who participated;
- Think Kidneys 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 Renal Registry Patient Council; and,
- Dr Janine Hawkins, Dr David Wellsted and Amanda Busby at the University of Hertfordshire who analysed the PREM 2018 data and led the production of this report.

Appendix One: The Kidney PREM 2018



The Annual Survey of Patient Reported Experience Measures (PREM)

The annual PREM survey has been designed by patients and professionals working together to find out how you feel about the services your kidney unit provides. The survey gives us feedback on renal services both locally for your unit, and nationally, and ensures that the views of kidney patients are heard. From this information, we can see what we are doing well and where we can do better. Your views matter and we act on them to help us improve services. We will provide you with feedback on the results. Information on the national results can be obtained from the UK Renal Registry or Kidney Care UK websites, along with the previous year’s results.

The survey is completely anonymous, your name will not appear anywhere on the survey.

Completing the survey

The survey should take about 15 minutes to complete. Please only tick one box for each question or statement, otherwise your answer will not count.

If you prefer you can complete the survey online at www.renalreg.org/projects/prem. The online survey is available in English, Welsh, Urdu and Gujarati. Please only complete one paper PREM or one online, not both.

You can ask your partner, a friend or family member to help you complete the survey. Choosing not to take part will not affect your care in any way. When you complete the survey think about your experience of care during the last few times that you have attended. Please fill in the survey as truthfully as possible.

On completion

Please place the completed questionnaire in the envelope provided, seal it, and post it in the post box or hand it to a staff member. By completing the questionnaire you are consenting to your answers being sent to and held by the UK Renal Registry and your renal unit.

If you have any questions or concerns about the survey please contact the UK Renal Registry by emailing Catherine.stannard@renalregistry.nhs.uk or by calling 0117 414 8151.

Please complete the name of the renal/satellite unit where you are completing this survey from.

UKRR Code

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 (To be filled in by a member of staff)

Renal Unit

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Current treatment Peritoneal dialysis Haemodialysis Transplant Attending kidney clinic but not on dialysis or transplantation

If you currently receive Haemodialysis, do you receive this...

At Home In-Hospital In - Satellite

Age 17-21 22-30 31-40 41-55
 56-64 65-74 75-84 85+

Gender Male Female I would rather not say

Ethnicity Asian Black White Other I would rather not say

Do you use PatientView? Yes No Don't Know

The following questions ask you about your experience with the renal unit, your kidney disease and treatment.

All the questions are answered on a scale of 1 to 7 where 1 is negative and 7 is positive.

For each question there's also a 'don't know' and 'not applicable' option.

SECTION 1: ACCESS TO THE RENAL TEAM

	Never					Always		Don't know	Not Applicable
	1	2	3	4	5	6	7		
1. Does the renal team take time to answer your questions about your kidney disease or treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Would you feel comfortable to contact the unit from home if you were anxious or worried?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Would you feel able to ask for an additional appointment with your kidney doctor if you wanted to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 2: SUPPORT

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

	Never							Always	Don't know	Not Applicable
	1	2	3	4	5	6	7			
4. Medical issues resulting from your kidney disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Any other concerns or anxieties resulting from your kidney disease or treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Accessing patient support groups such as Kidney Patient Associations (KPA)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 3: COMMUNICATION

Do you think there is good communication between:

	Never							Always	Don't know	Not Applicable
	1	2	3	4	5	6	7			
7. You and your renal team?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Members of the renal team?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Your GP and the renal team?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. The renal team and other medical specialists?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. The renal team and other non-healthcare services if you need them, such as social work or housing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 4: PATIENT INFORMATION

Does the renal team:

	Never							Always		Don't know	Not Applicable
	1	2	3	4	5	6	7				
12. Explain things to you in a way that is easy to understand?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Give you as much information about your kidney disease or treatment as you want?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 5: FLUID INTAKE AND DIET

Thinking about the advice you are given about **fluid intake**:

	Never							Always		Don't know	Not Applicable
	1	2	3	4	5	6	7				
14. Does the renal team give you clear advice on your fluid intake ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thinking about the advice you are given about **diet**:

	Never							Always		Don't know	Not Applicable
	1	2	3	4	5	6	7				
15. Does the renal team give you clear advice on your diet ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 6: NEEDLING

If you are on in-hospital or in-satellite haemodialysis please answer question 16, otherwise please go to SECTION 7: TESTS

	Never							Always		Don't know	Not Applicable
	1	2	3	4	5	6	7				
16. How often do the renal team insert your needles with as little pain as possible?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 7: TESTS

	Never						Always			
	1	2	3	4	5	6	7	Don't know	Not Applicable	
17. Do you understand the reasons for your tests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Do you get your test results back within an acceptable time period?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Do you understand the results of your tests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 8: SHARING DECISIONS ABOUT YOUR CARE

Does the renal team:

	Never						Always			
	1	2	3	4	5	6	7	Don't know	Not Applicable	
20. Talk with you about your treatment and life goals?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Enable you to participate in decisions about your kidney care as much as you want?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Talk to you about taking a more active role in managing your own kidney care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 9: PRIVACY AND DIGNITY

	Never						Always			
	1	2	3	4	5	6	7	Don't know	Not Applicable	
23. Are you given enough privacy when discussing your condition or treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Is your dignity respected during visits and clinical examinations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 10: SCHEDULING AND PLANNING

	Never							Always		Don't know	Not Applicable
	1	2	3	4	5	6	7				
25. Can you change your appointment times if they are not suitable for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Do you feel your time is used well at your appointments relating to your kidneys?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are on in-hospital or in-satellite haemodialysis, please move on to SECTION 11: HOW THE RENAL TEAM TREATS YOU. If you have blood tests done at an outpatient clinic or GP surgery, please answer question 27.

	Never							Always		Don't know	Not Applicable
	1	2	3	4	5	6	7				
27. Are the arrangements for your blood tests convenient for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 11: HOW THE RENAL TEAM TREATS YOU

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

	Never							Always		Don't know	Not Applicable
	1	2	3	4	5	6	7				
28. Take you seriously?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Show a caring attitude towards you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Ask you about your emotional feelings?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 12: TRANSPORT

If the renal unit arranges your transport, please answer these questions.

If the unit **does not** arrange your transport then please move on to SECTION 13: THE ENVIRONMENT.

	Never						Always		
	1	2	3	4	5	6	7	Don't know	Not Applicable
31. Is the vehicle provided suitable for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Is the time it takes to travel between your home and the renal unit acceptable to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 13: THE ENVIRONMENT

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

	Poor						Excellent		
	1	2	3	4	5	6	7	Don't know	Not Applicable
34. Accessibility (e.g., lifts, ramps, automatic doors)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Comfort?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Cleanliness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Waiting area?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Parking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 14: YOUR OVERALL EXPERIENCE

	Worst it can be			Best it can be			
	1	2	3	4	5	6	7
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)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for completing this questionnaire.
For further information please visit www.renalreg.org/projects/prem

Appendix Two: Age ranges across the different modalities

Age	Total		Transplant		Haemodialysis		Peritoneal		Pre-dialysis		Missing	
	Total	%	Total	%	Total	%	Total	%	Total	%	Total	%
17-21	72	0.5%	13	0.9%	31	0.4%	2	0.2%	21	1.3%	5	0.6%
22-30	319	2.3%	56	4.0%	168	1.9%	19	1.9%	68	4.1%	8	0.9%
31-40	688	5.0%	148	10.6%	333	3.8%	28	2.9%	146	8.8%	33	3.7%
41-55	2,407	17.5%	411	29.4%	1,372	15.5%	143	14.6%	369	22.2%	112	12.5%
56-64	2,523	18.3%	319	22.8%	1,636	18.5%	158	16.1%	280	16.9%	130	14.5%
65-74	3,519	25.6%	281	20.1%	2,390	27.1%	260	26.5%	381	23.0%	207	23.1%
75-84	3,189	23.2%	128	9.1%	2,207	25.0%	296	30.1%	268	16.2%	290	32.4%
85+	781	5.7%	22	1.6%	534	6.0%	63	6.4%	95	5.7%	67	7.5%
Missing	272	2.0%	21	1.5%	163	1.8%	13	1.3%	31	1.9%	44	4.9%
Total	13,770		1,399		8,834		982		1,659		896	

Note: Peritoneal patients do have a similar age distribution to haemodialysis patients, but this year there is a considerable increase in the proportion of peritoneal patients over 75 (37% compared to 31% haemodialysis). This may reflect a focus on encouraging responses from peritoneal patients this year compared to last in some centres.

Appendix Three: Unit abbreviations and response rates

Numbers in brackets in the 'Unit' column show the number of Kidney PREMs returned per unit (for reasons of anonymity, not including any units returning less than 10).

Numbers in brackets in the 'Centre' column shows the number of completed PREMs per centre, which is the basis for this report.

In centres marked with an asterisk, unit responses do not add up to centre responses, because at least one unit returned less than 10 Kidney PREMs, and so is/are not identified in the unit level data, but is/are included in the centre level data.

Main Centre	Unit / Satellite Location	Centre abbreviation
Aberdeen Royal Infirmary*	Banff (10) Inverurie (15) Elgin (19)	ARI (68)
Addenbrookes Hospital		Camb (3)
Aintree University Hospital	Aintree (26) Liverpool - Main Unit (80) Southport (51) Waterloo (28)	Liv Ain (185)
Arrowe Park Hospital	Chester (61) Clatterbridge (103) Wirral - Main Unit (61)	Wirral (225)
Barts and the London Hospital	King George (18) London - Main Unit (14) Newham (61) Queen's Hospital (15) Whipps Cross (61)	L Bart (169)
Basildon Hospital	Basildon - Main Unit (62) Orsett (14)	Basldn (76)
Belfast City Hospital	Belfast City Hospital - Main Unit (91)	Belfast (91)
Broomfield Hospital	Chelmsford - Main Unit (151)	Chelms (151)
Colchester General Hospital	Colchester - Main Unit (34)	Colch (34)
Cumberland Infirmary	Carlisle - Main Unit (96) Whitehaven (49)	Carlis (145)
Derriford Hospital*	Kingsbridge (11) Launceston (11) Plymouth - Main Unit (106)	Plym (137)

Main Centre	Unit / Satellite Location	Centre abbreviation
Doncaster Royal Infirmary	Bassetlaw (23) Dearne Valley (28) Doncaster - Main Unit (96)	Donc (147)
Dorset County Hospital	Bournemouth (37) Dorchester - Main Unit (30) Poole (20) Yeovil (34)	Dorset (121)
Dumfries and Galloway Royal Infirmary		DGRI (1)
Freeman Hospital	Alnwick (11) Newcastle-upon-Tyne - Main Unit (587) North Tyneside (38)	Newc (636)
Gloucester Royal Hospital*	Gloucester - Main Unit (75) Severn (37)	Glouc (119)
Guy's and St Thomas's Hospital	Borough (63) Camberwell (65) Forest Hill (13) London - Main Unit (87) New Cross Gate (35) Sidcup (29) Tunbridge Wells (88)	L Guys (380)
Heartlands Hospital	Balsall Heath (24) Birmingham - Main Unit (45) Lichfield (27) Solihull District General (26)	Bham HL (122)
Hull Royal Infirmary	Bridlington (20) Grimsby (35) Hull - Main Unit (67) Scunthorpe (39)	Hull (161)
Ipswich Hospital	Aldeburgh (11) Ipswich - Main Unit (52)	Ipswi (63)
James Cook University Hospital	Darlington (51) Middlesbrough - Main Unit (68) North Ormesby (49) Stockton (58)	Middlbr (226)
John Radcliffe and Churchill*	Aylesbury (64) John Radcliffe & Churchill - Main Unit (109) Milton Keynes (64) Swindon (89) Wycombe (82)	Oxford (409)

Main Centre	Unit / Satellite Location	Centre abbreviation
Kent & Canterbury Hospital	Canterbury - Main Unit (157) Dover (34) Maidstone (74) Margate (18) Medway (49) William Harvey (31)	Kent (363)
Kings College Hospital*	Bromley (71) Dartford (42) Dulwich (58) London - Main Unit (242) Sydenham (95) Woolwich (36)	L Kings (551)
Leicester General Hospital*	Chandra Mistry (32) Grantham (16) Hamilton (47) Kettering (70) Leicester - Main Unit (88) Lincoln (42) Loughborough (42) Northampton (30) Peterborough (59)	Leic (433)
Lister Hospital	Bedford (40) Harlow (99) Luton & Dunstable (108) St Albans City (30) Stevenage - Main Unit (199)	Stevng (476)
Manchester Royal Infirmary*	Altrincham (53) Manchester - Main Unit (60) Stockport (40) Tameside (26)	M RI (188)
Monklands Hospital	Monklands Hospital - Main Unit (96)	Monk (96)
Morrison Hospital	Aberystwyth (7) Swansea - Main Unit (140) West Wales (33) Withybush (28)	Swan (208)
New Cross Hospital	Cannock (38) Pond Lane (15) Walsall (43) Wolverhampton - Main Unit (47)	Wolve (143)

Main Centre	Unit / Satellite Location	Centre abbreviation
Ninewells Hospital	Arbroath (14) Ninewells Hospital - Main Unit (42) Perth (24)	Nine (80)
Norfolk & Norwich University Hospital	Cromer (25) James Paget (31) Norwich - Main Unit (149)	Norwch (205)
Northern General Hospital*	Barnsley (18) Heeley (44) Rotherham (51) Sheffield - Main Unit (96) Sheffield - Peter Moorhead (63)	Sheff (281)
Northern Trust	Northern Trust - Main Unit (75)	NI Nrth (75)
Nottingham City Hospital*	Ilkeston (10) Kings Mill (25) Lings Bar (28) Nottingham - Main Unit (240)	Nottm (308)
Queen Alexandra Hospital*	Bognor Regis (24) Isle of Wight (34) Milford-on-Sea (15) Totton (30) Portsmouth - Main Unit (37)	Ports (148)
Queen Elizabeth Hospital*	Aston Cross (63) Birmingham - Main Unit (233) Great Bridge (22) Hereford (33) Kings Norton (38) Redditch (26) Smethwick (98) Sparkhill (64) Woodgate Valley (50) Worcester (56)	Bham QE (691)
Queen Elizabeth University Hospital Glasgow*	Glasgow Royal Infirmary (128) Inverclyde (14) Glasgow - Main Unit (59) Stobhill (32) Victoria (59)	Glas (298)

Main Centre	Unit / Satellite Location	Centre abbreviation
Raigmore Hospital	Fort William (13) Raigmore - Main Unit (125) Stornoway (21) Wick (16)	Raig (175)
Royal Berkshire Hospital	Bracknell (17) Reading - Main Unit (80) Windsor (16)	Redng (113)
Royal Cornwall Hospital	Aubrey Williams (26) Bodmin (31) Truro - Main Unit (88)	Truro (145)
Royal Derby Hospital	Derby - Main Unit (142)	Derby (142)
Royal Devon and Exeter Hospital*	Barnstaple (33) Exeter - Main Unit (105) Heavitree (42) Honiton (25) Taunton (56)	Exeter (262)
Royal Free Hospital	Edgware (10) London - Main Unit (10) Mary Rankin / St Pancras (33) Tottenham Hale (19)	L RoyF (72)
Royal Infirmary of Edinburgh*	Edinburgh - Main Unit (92) St John's (52) Western General (31)	RIE (176)
Royal Liverpool University Hospital	Broadgreen (18) Halton (14) Liverpool - Main Unit (41) St Helens (36) Warrington (18)	Liv RoyUH (127)
Royal Preston Hospital	Accrington Victoria (18) Blackburn (16) Burnley (24) Chorley & District (59) Clifton (23) Preston - Main Unit (32) Westmorland General (47)	Prest (219)
Royal Shrewsbury Hospital	Shrewsbury - Main Unit (75) Telford (31)	Shrew (106)




Main Centre	Unit / Satellite Location	Centre abbreviation
Royal Sussex County Hospital	Bexhill (34) Brighton - Main Unit (201) Crawley (25) Eastbourne (52) Worthing (49)	Brightn (361)
Russell's Hall Hospital	Dudley - Main Unit (106)	Dudley (106)
Salford Royal Hospital	Bolton (14) Oldham (14) Rochdale (13) Salford - Main Unit (64) Wigan (22)	Salfd (127)
Southend University Hospital	Southend - Main Unit (84)	Sthend (84)
Southern Trust	Southern Trust - Main Unit (94)	NI Sth (94)
Southmead Hospital	Bath (25) Bristol - Main Unit (68) Brunel / Bright (51) Cossham (40) Frome (37) South Bristol (37) Weston-Super-Mare (45)	Bristol (303)
St George's Hospital*	London - Main Unit (71)	L St.G (78)
St Helier Hospital*	Carshalton - Main Unit (10) Crawley (19) Epsom (25) Farnborough (58) Kingston (30) West Byfleet (55)	Carsh (198)
St James's University Hospital	Beeston (14) Calderdale (14) Dewsbury (22) Huddersfield (34) Leeds - Main Unit (110) Pontefract (37) Seacroft - R & S (30) Seacroft - Ward B (15)	Leeds (276)
St Luke's Hospital	Bradford - Main Unit (41) Skipton (19)	Bradfd (60)
Sunderland Royal Hospital	Durham Dryburn (48) Sunderland - Main Unit (101) Washington (24)	Sund (173)

Main Centre	Unit / Satellite Location	Centre abbreviation
UHCW*	Main Unit (114) Walsgrave Hospital - Rugby (24) Walsgrave Hospital - Stratford (13)	Covnt (152)
Ulster Hospital	Main Unit (105)	Ulster (105)
University Hospital Crosshouse	Ayr (21) Crosshouse - Main Unit (72)	XH (93)
University Hospital of Wales	Cardiff North (46) Cardiff South (13) Llantrisant (38) Wales - Main Unit (21) Merthyr (46) Newport (54) Pontypool (33)	Cardf (251)
University Hospitals of North Midlands	County Hospital (24) Crewe (81) RSUH Stoke-on-Trent - Main Unit (173)	Stoke (278)
Victoria Hospital Kirkcaldy	Kirkcaldy - Main Unit (36) Queen Margaret (45) St Andrews (13)	VHK (94)
West London*	Charing Cross (61) Ealing (99) Hammersmith (43) Hayes (62) Ladbroke Grove (188) Northwick Park (174) Watford (72) West Middlesex (51) Central Middlesex (83)	L West (839)
Western Trust	Londonderry (39) Western Trust - Main Unit (60)	NI West (99)
Wrexham Maelor Hospital	Welshpool (19) Wrexham - Main Unit (50)	Wrex (69)
York Hospital*	York - Main Unit (15)	York (17)
Ysbyty Glan Clwyd*	Rhyl - Main Unit (56)	Clwyd (64)
Ysbyty Gwynedd	Bangor - Main Unit (30)	Bangor (30)

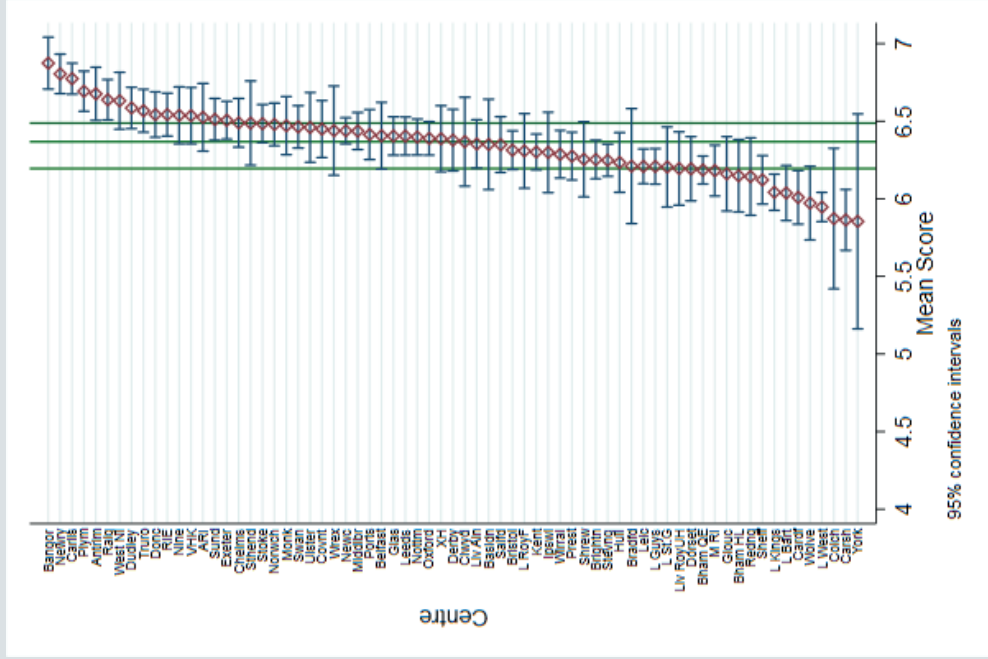
Appendix Four: Mean 2018 theme scores by centre

These charts give the centre mean score for each theme, with the 95% confidence interval (where there were more than 7 responses in a theme). Each chart also shows the overall median and quartile scores of the centre means. This gives an indication of how each centre compares to the overall mean scores. Where centre means fall above or below the 25th or 75th quartiles, centres clearly have better or worse patient experience within that theme.

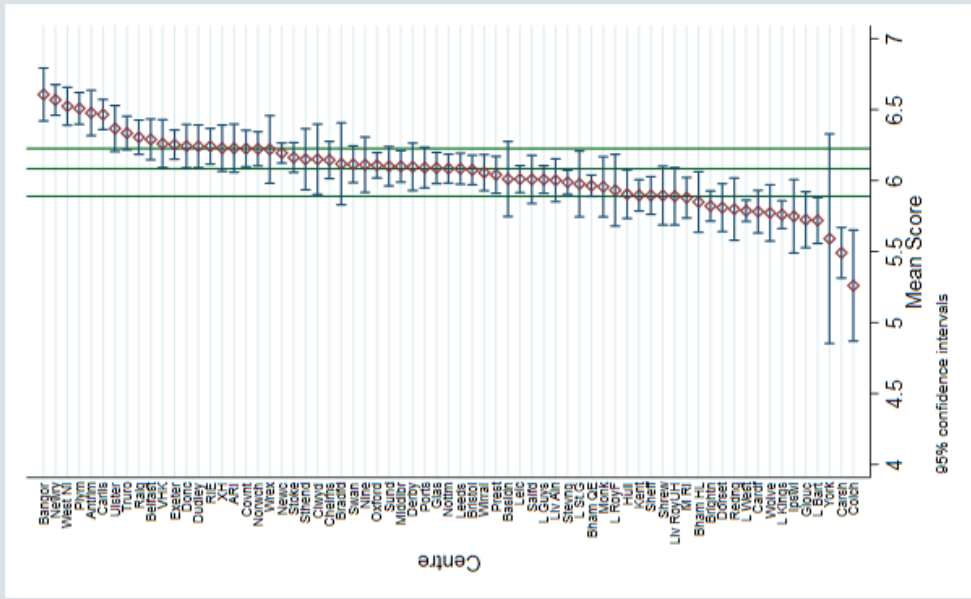
Confidence intervals that are clearly above or below the median score should be interpreted with more caution. The number of responding people from each centre will influence the size of the interval for that centre, with fewer responses leading to larger intervals.

	Mean score
	Mean score and confidence interval
	Left line = lower quartile Middle line = median Right line = upper quartile

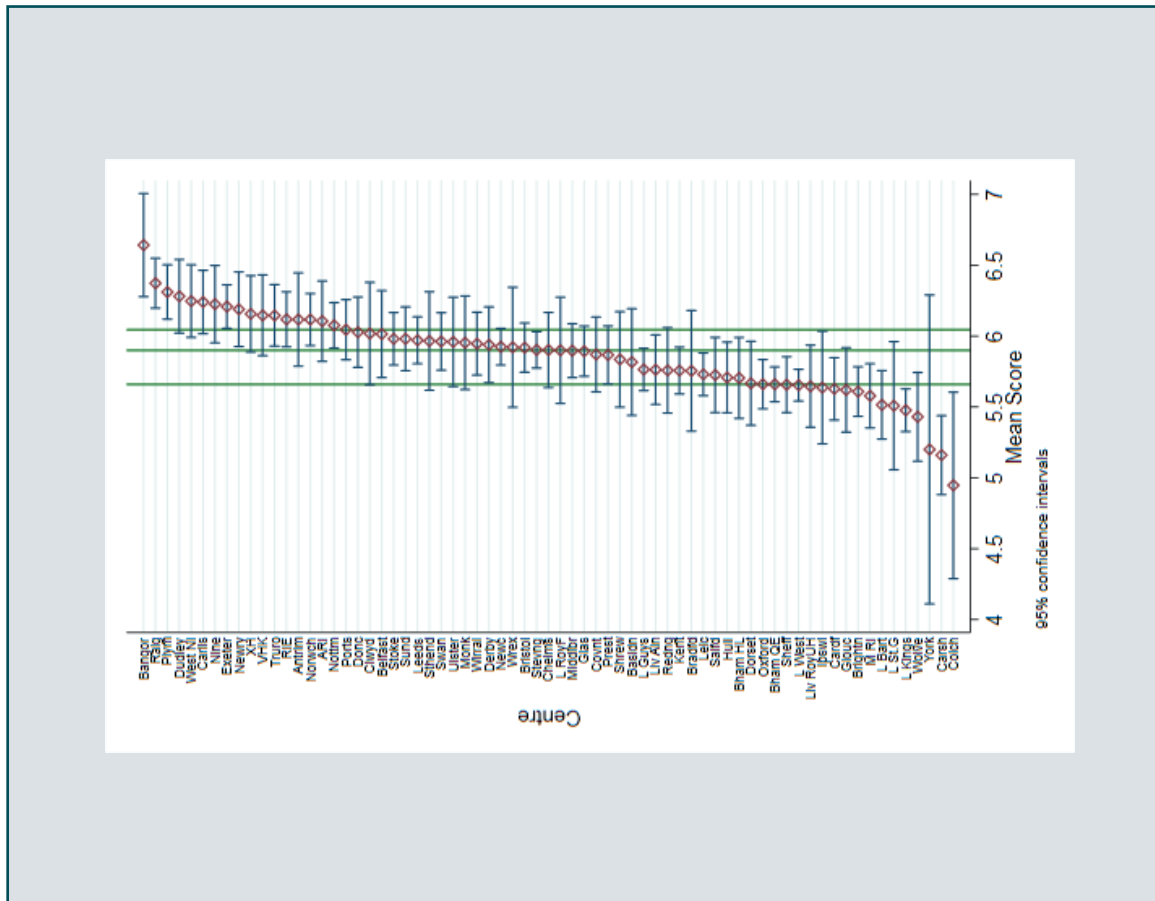
Section 1. Access to the Renal Team



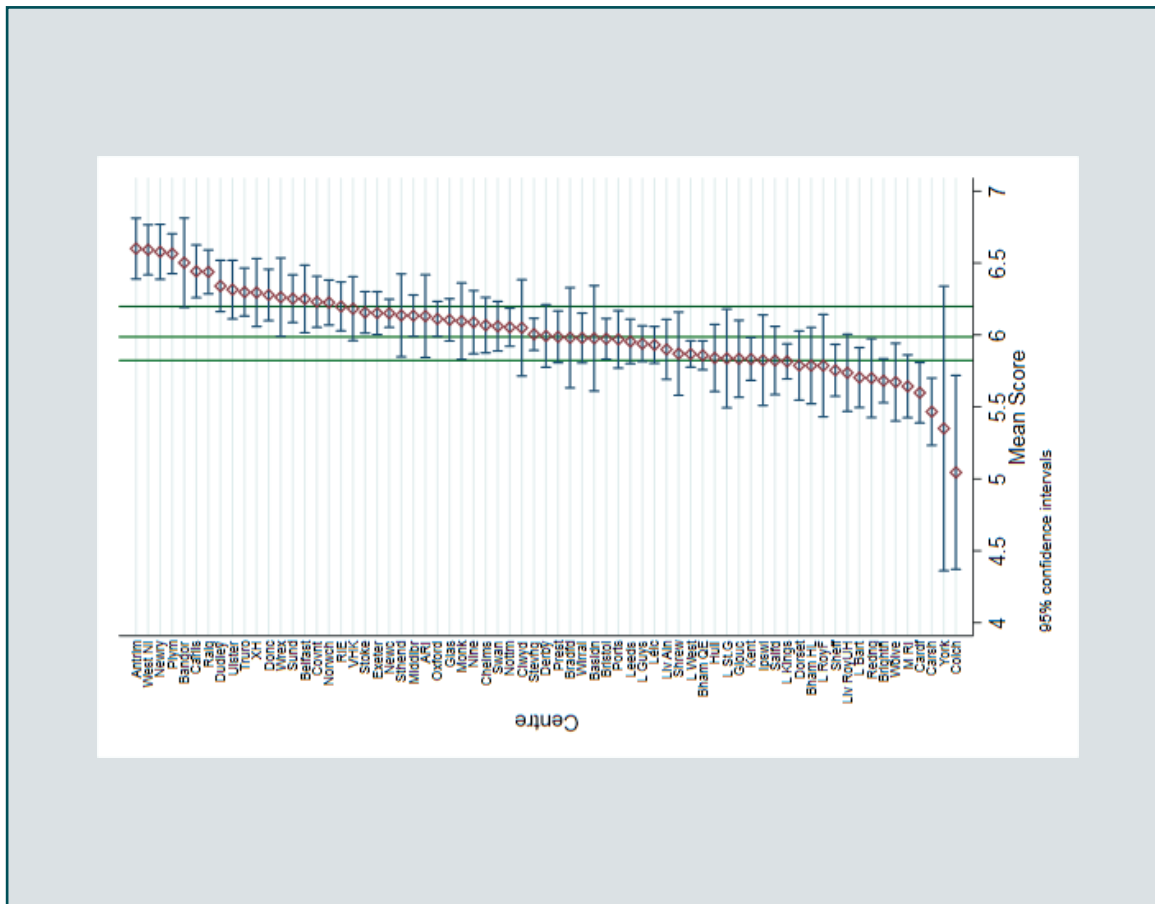
Scale Total. Responses across all themes



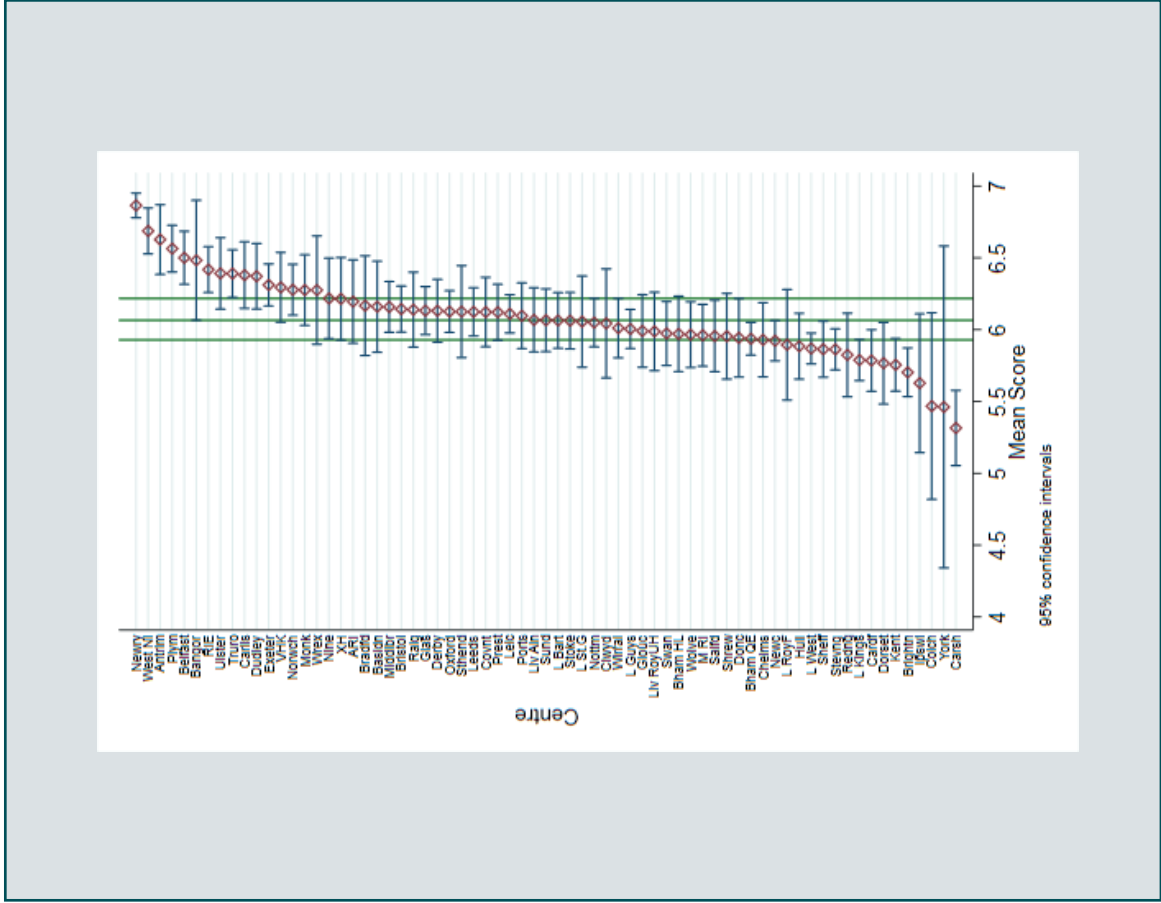
Section 2. Support



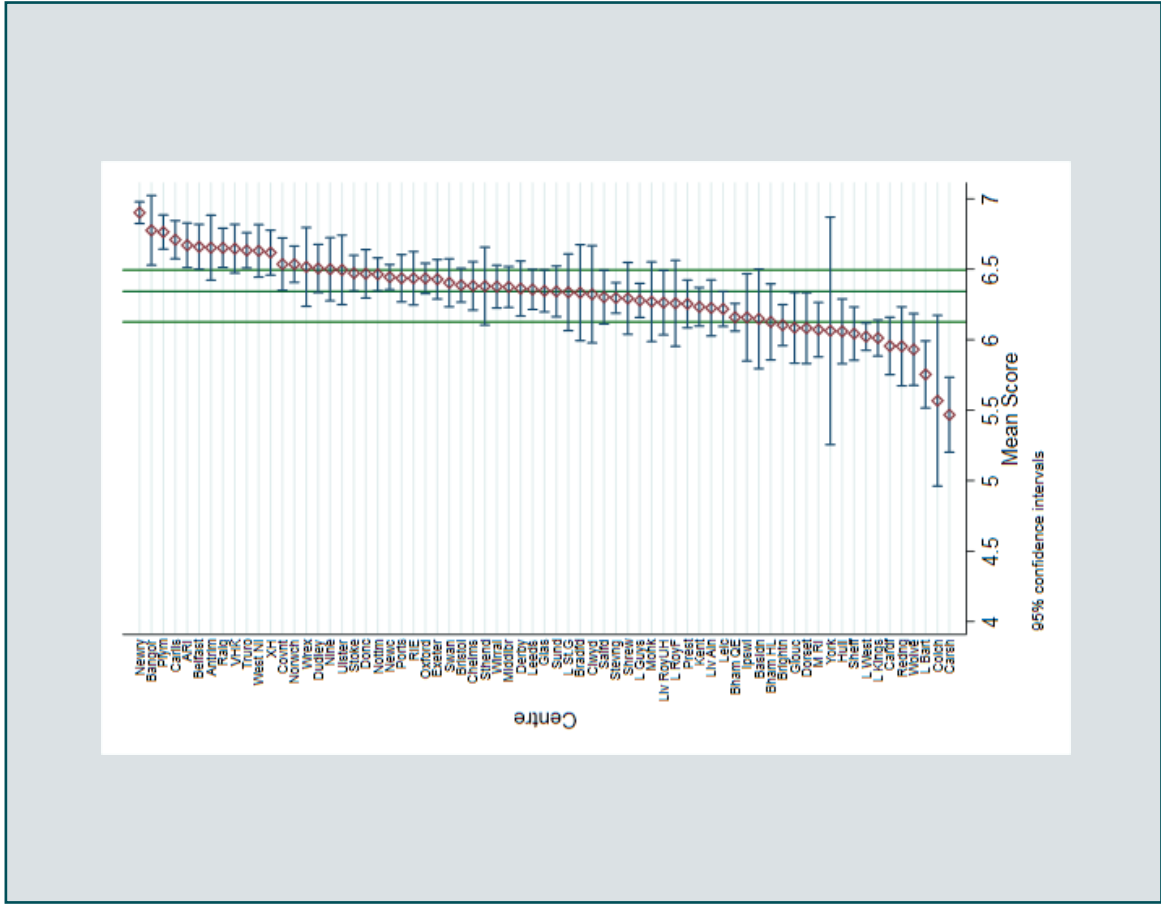
Section 3. Communication



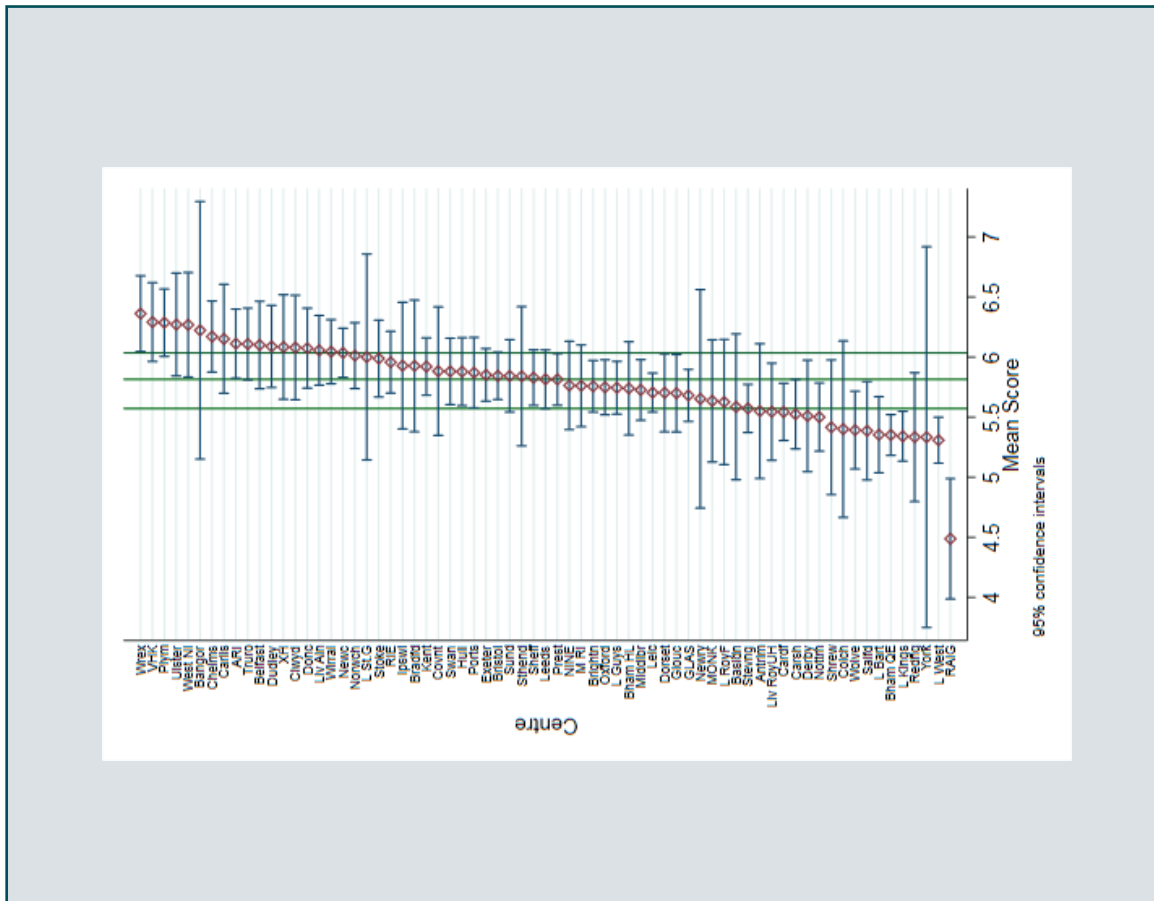
Section 5. Fluid Intake and Diet



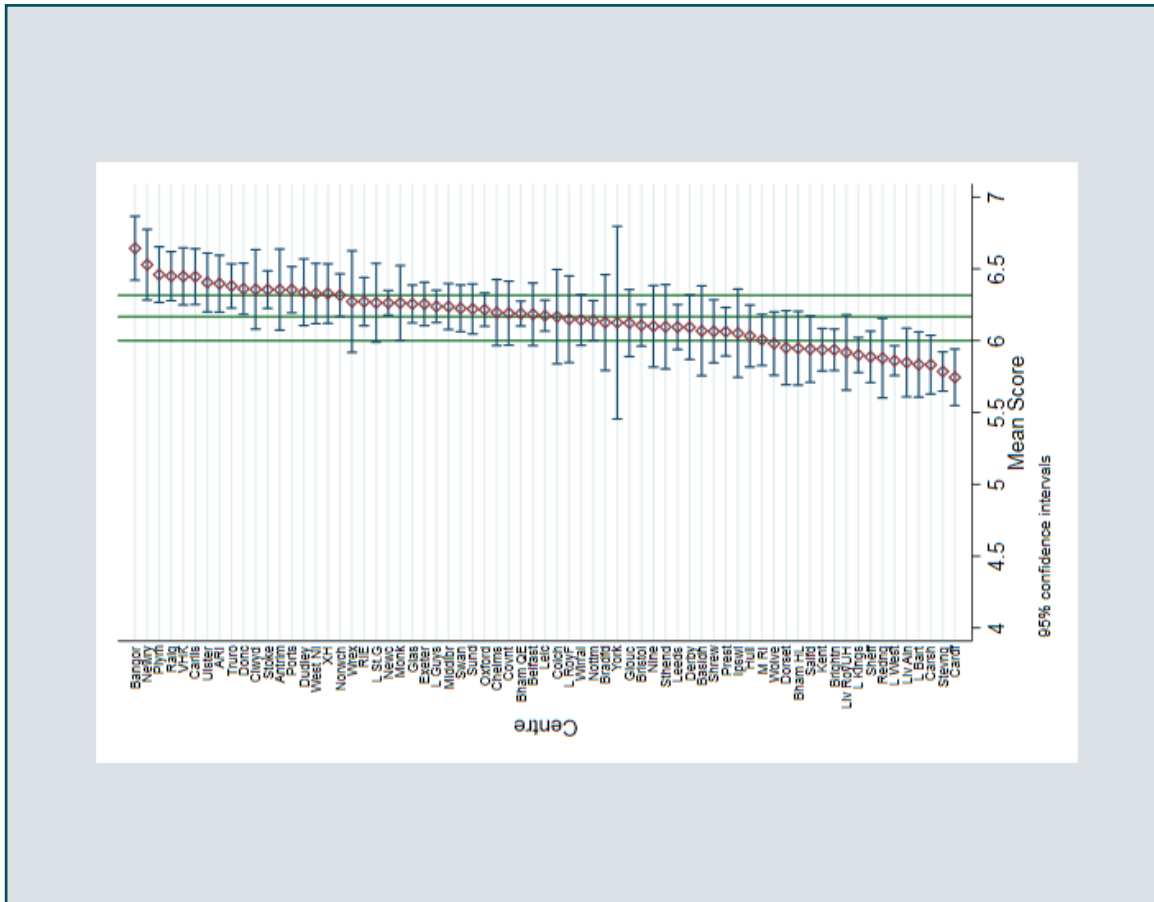
Section 4. Patient Information



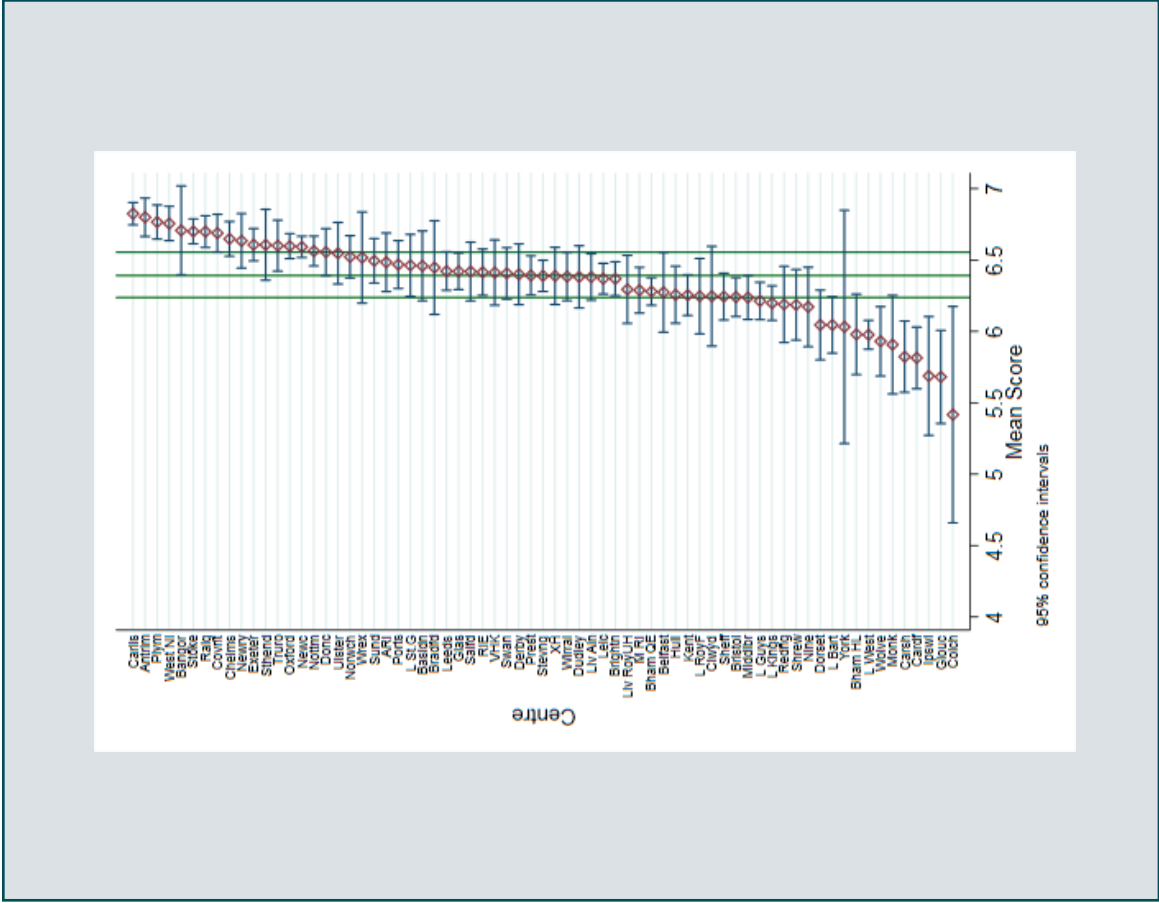
Section 6. Needing



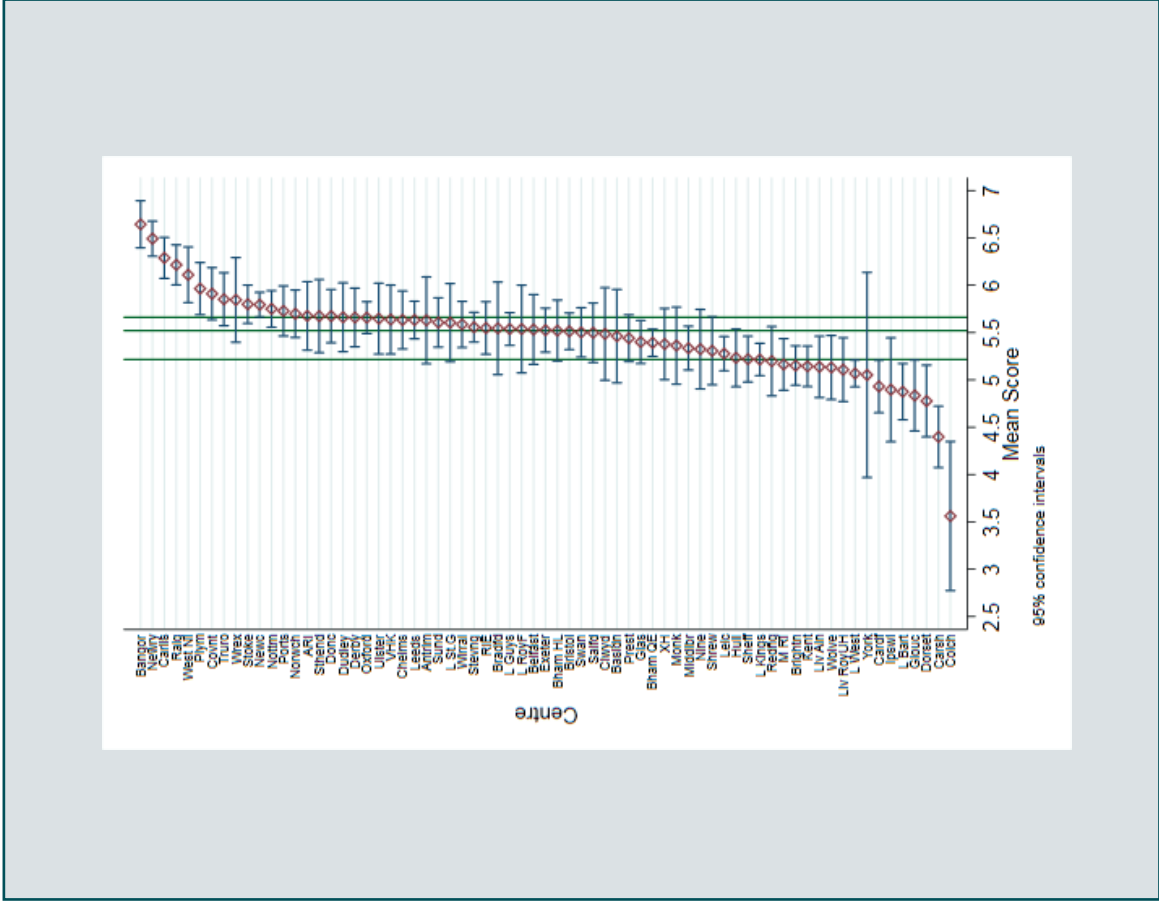
Section 7. Tests



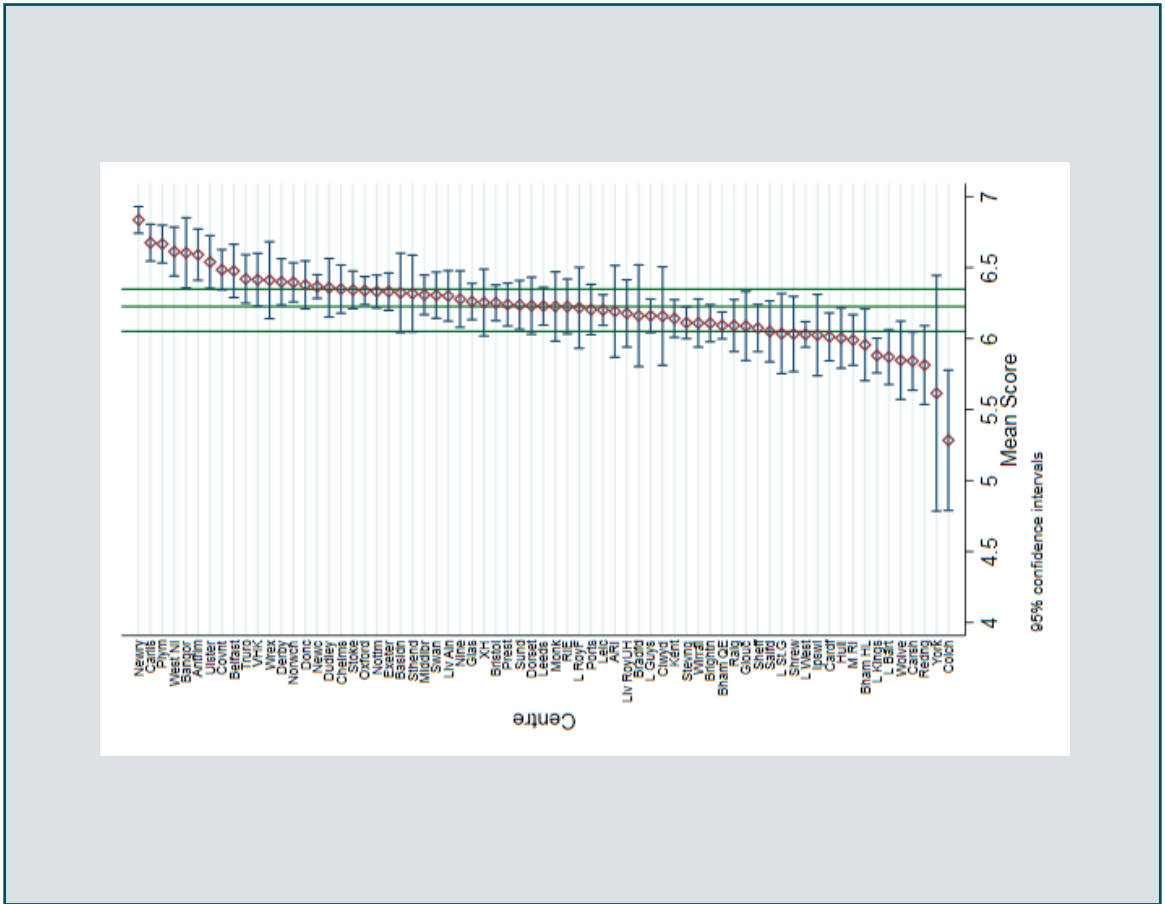
Section 9. Privacy and Dignity



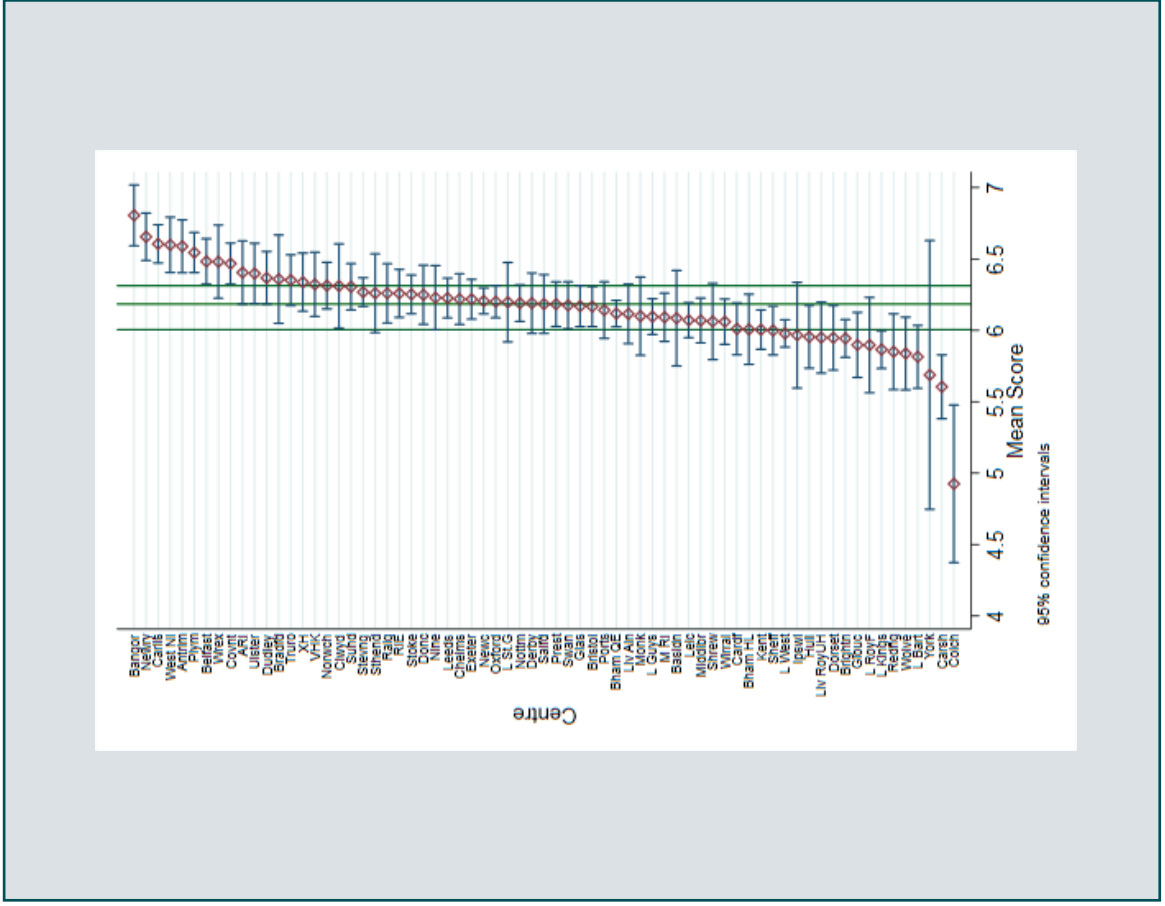
Section 8. Sharing Decisions About Your Care



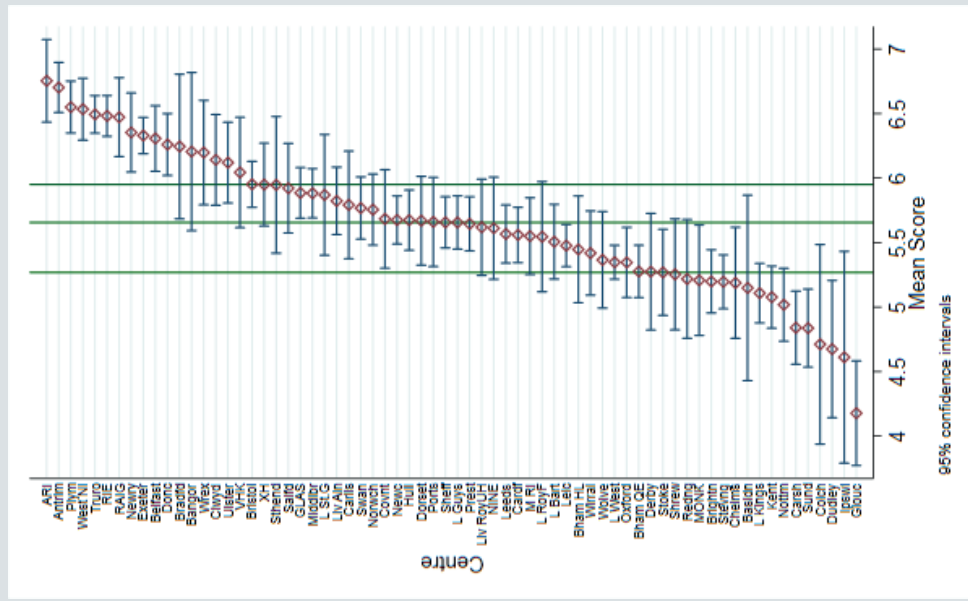
Section 10. Scheduling and Planning



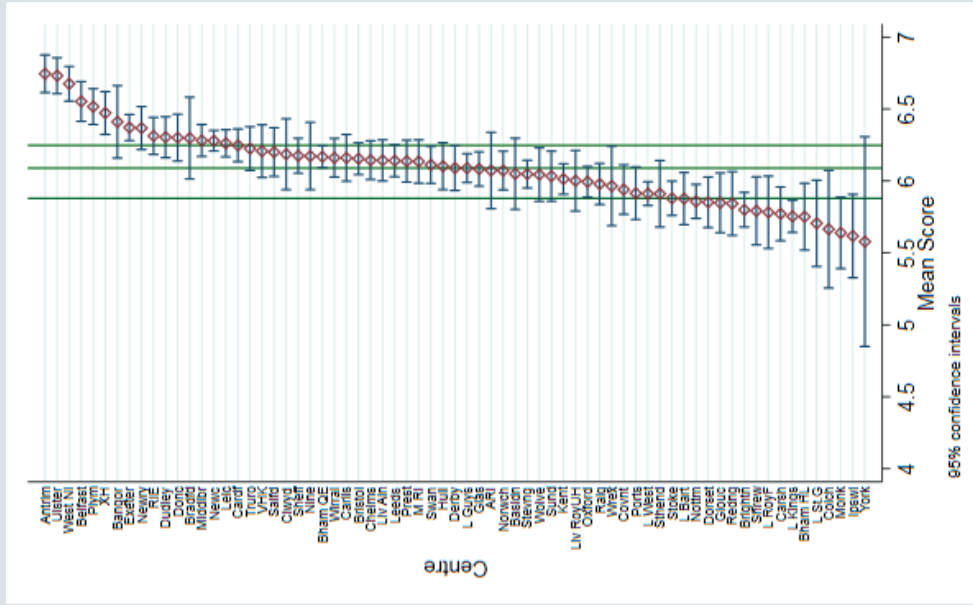
Section 11. How the Renal Team Treats You



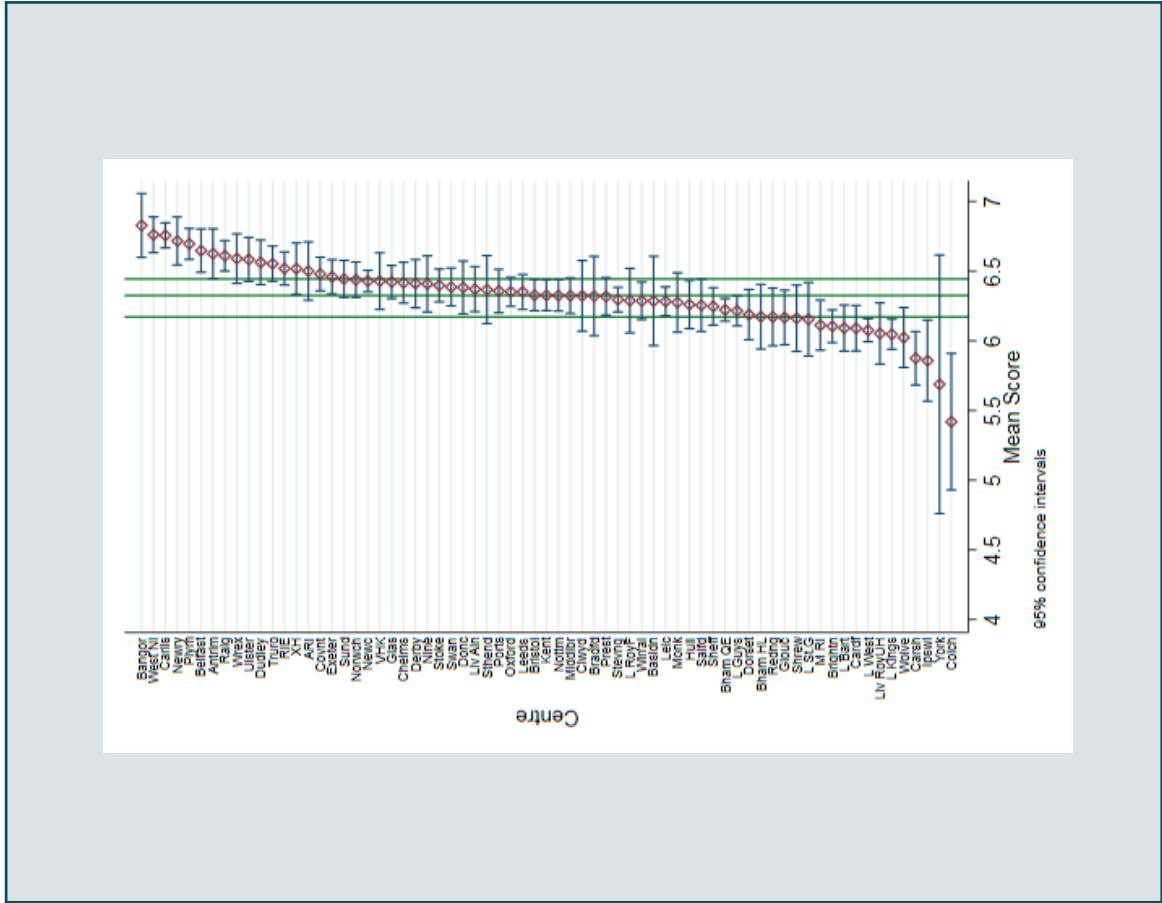
Section 12. Transport



Section 13. The Environment



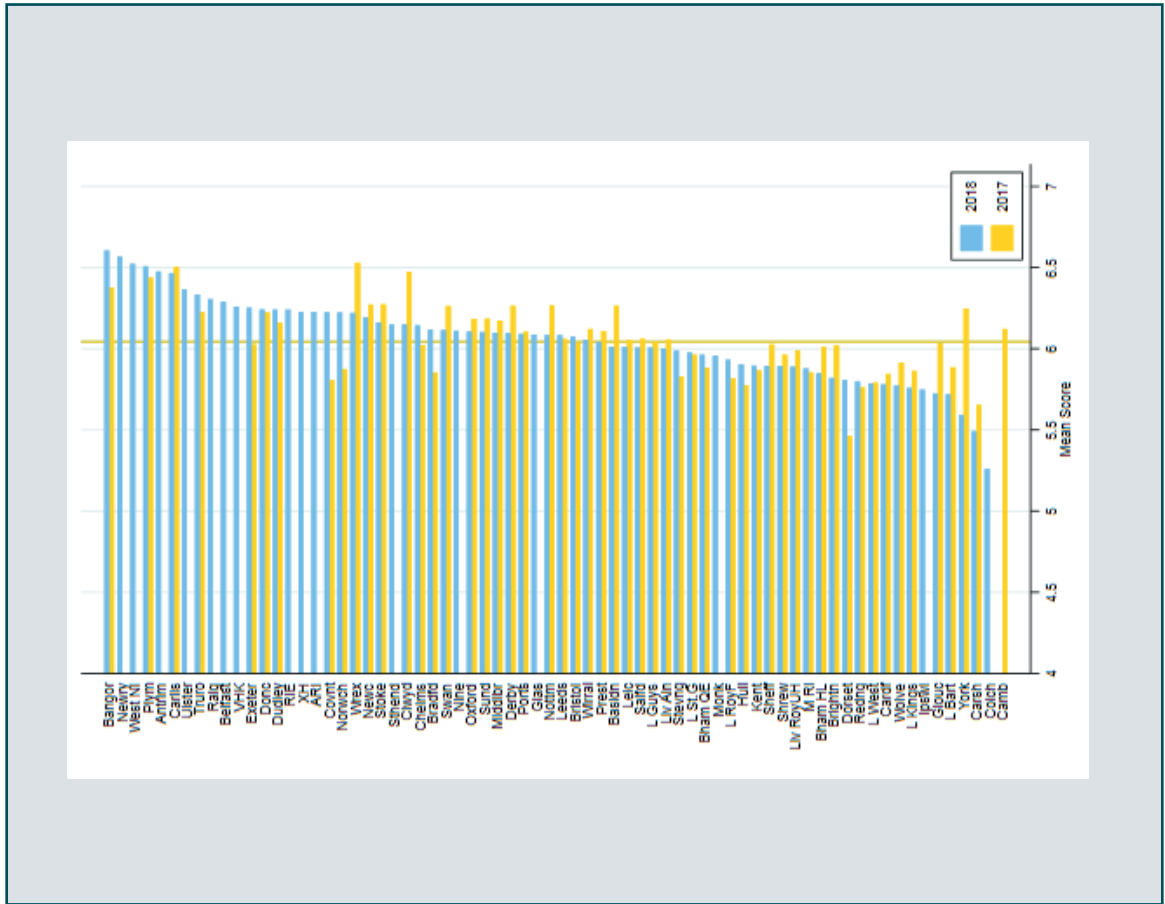
Section 14. Your Overall Experience



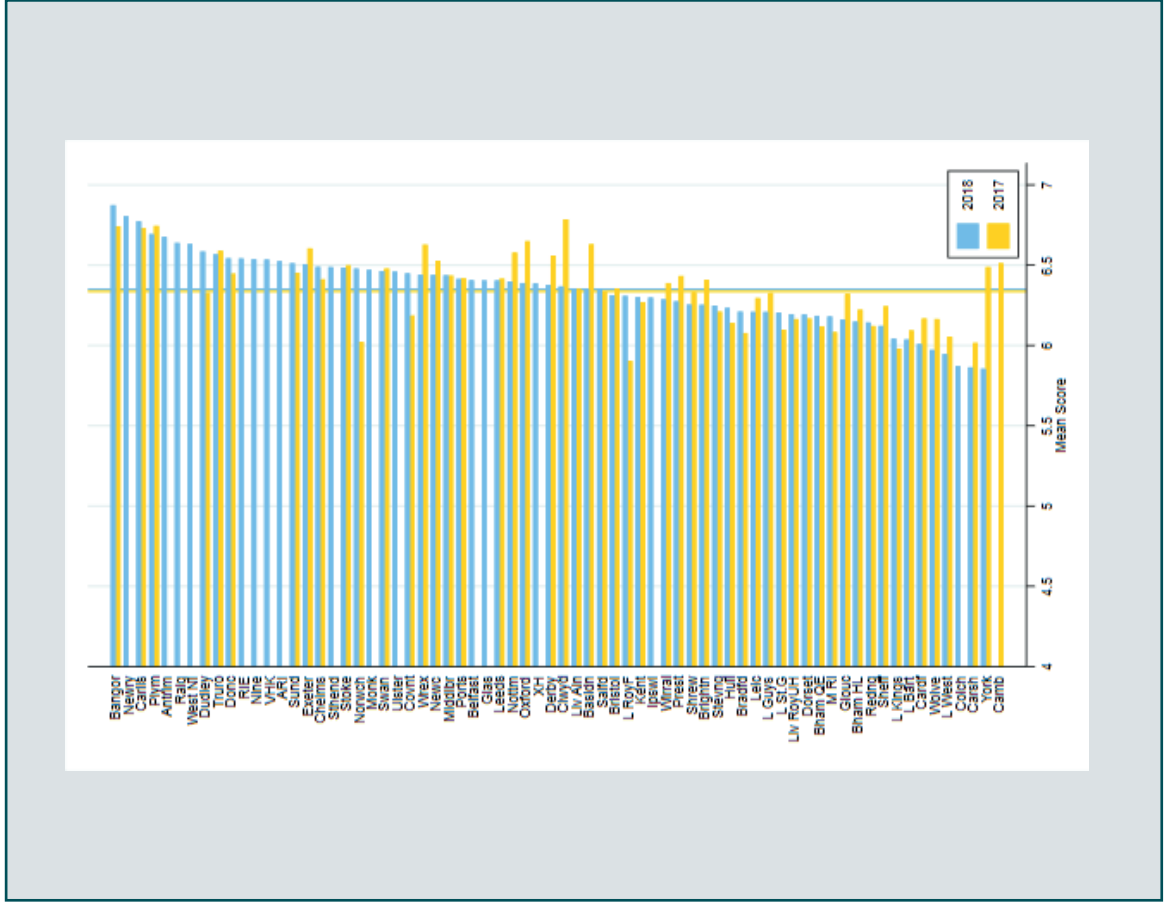
Appendix Five: 2017/18 Theme comparisons

These plots show mean centre scores in 2017 and 2018, with the vertical lines showing the overall mean of the centre scores for each year. Differences between 2017 and 2018 need to be interpreted with reference to the table in Appendix 6, which identifies changes made to the Kidney PREM between 2017 and 2018. Some differences may be attributable to these changes and not to changes in the experience of respondents. Other differences may be due to variation of people responding, or to the number of people responding in each year.

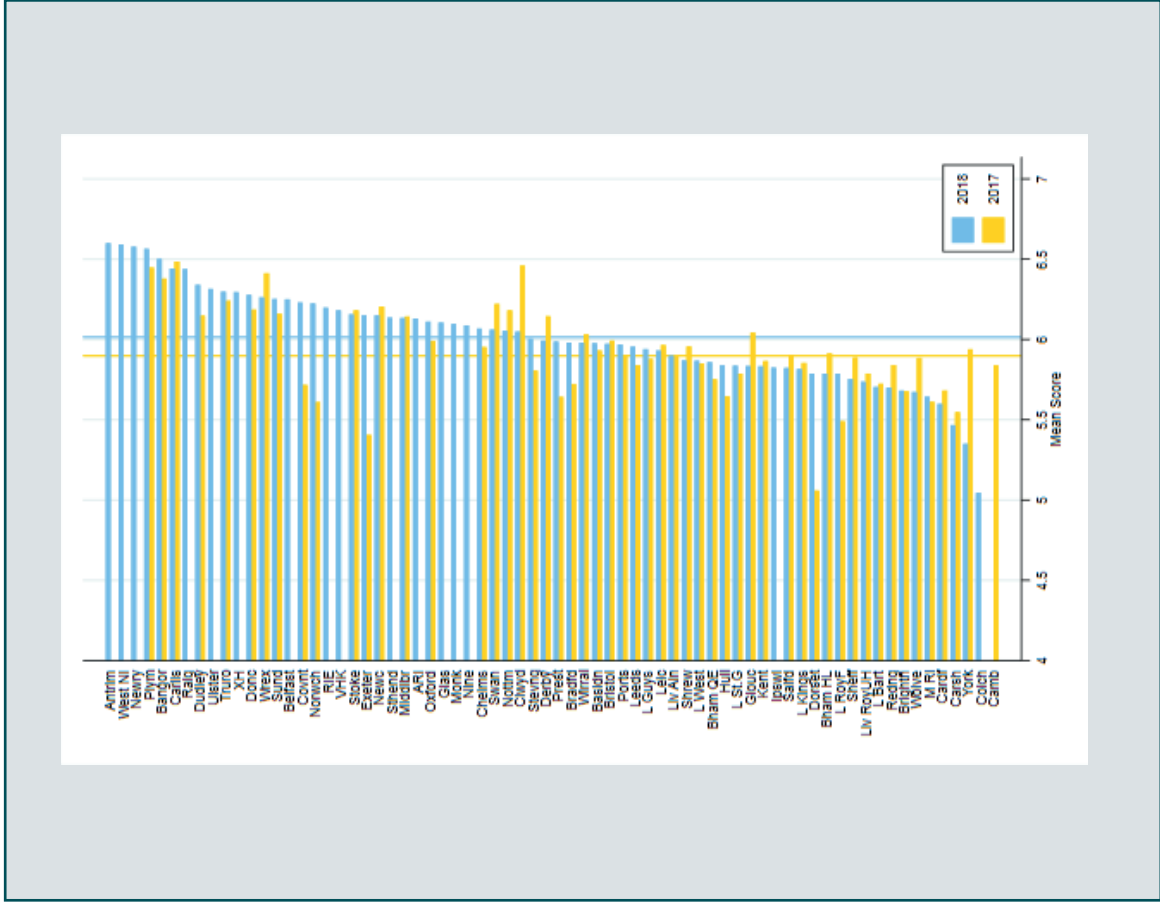
Scale Total. Responses across all themes



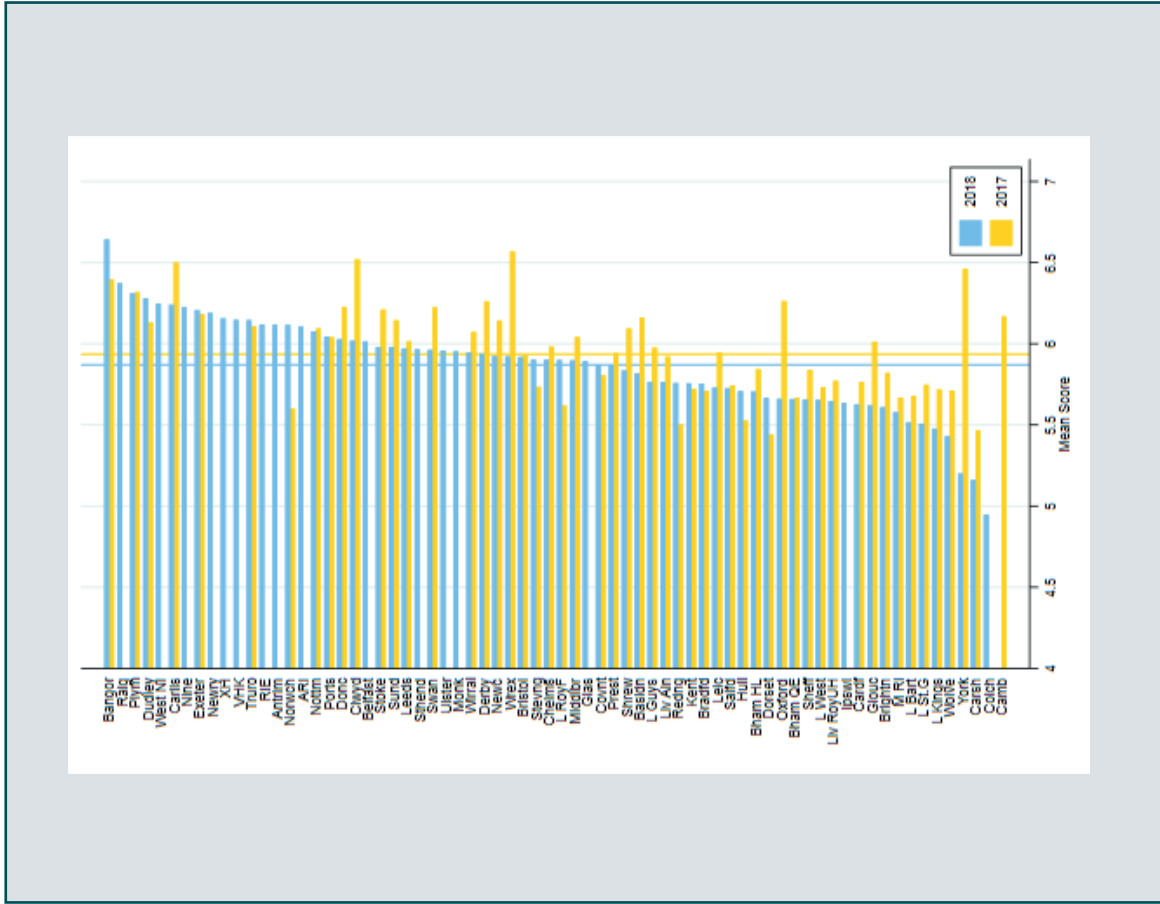
Session 1. Access to the Renal Team



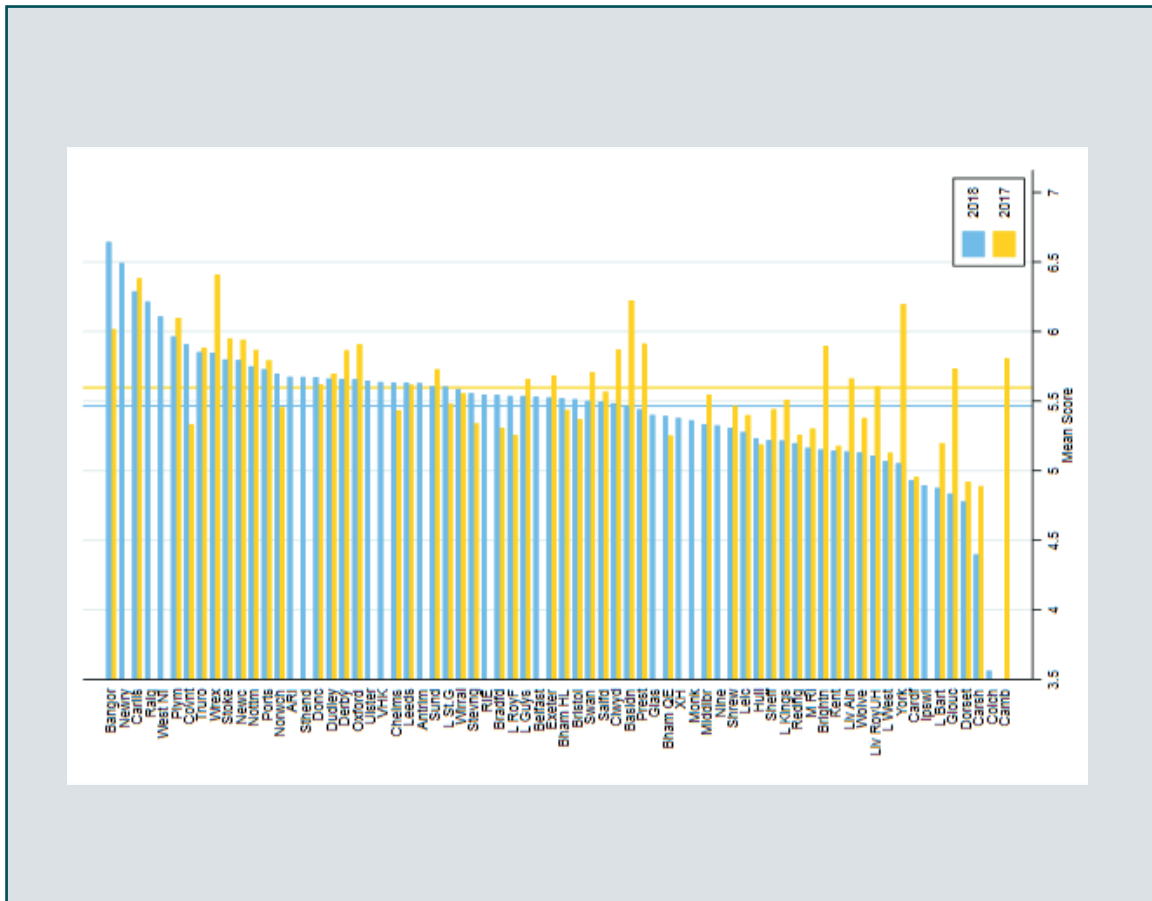
Session 3. Communication



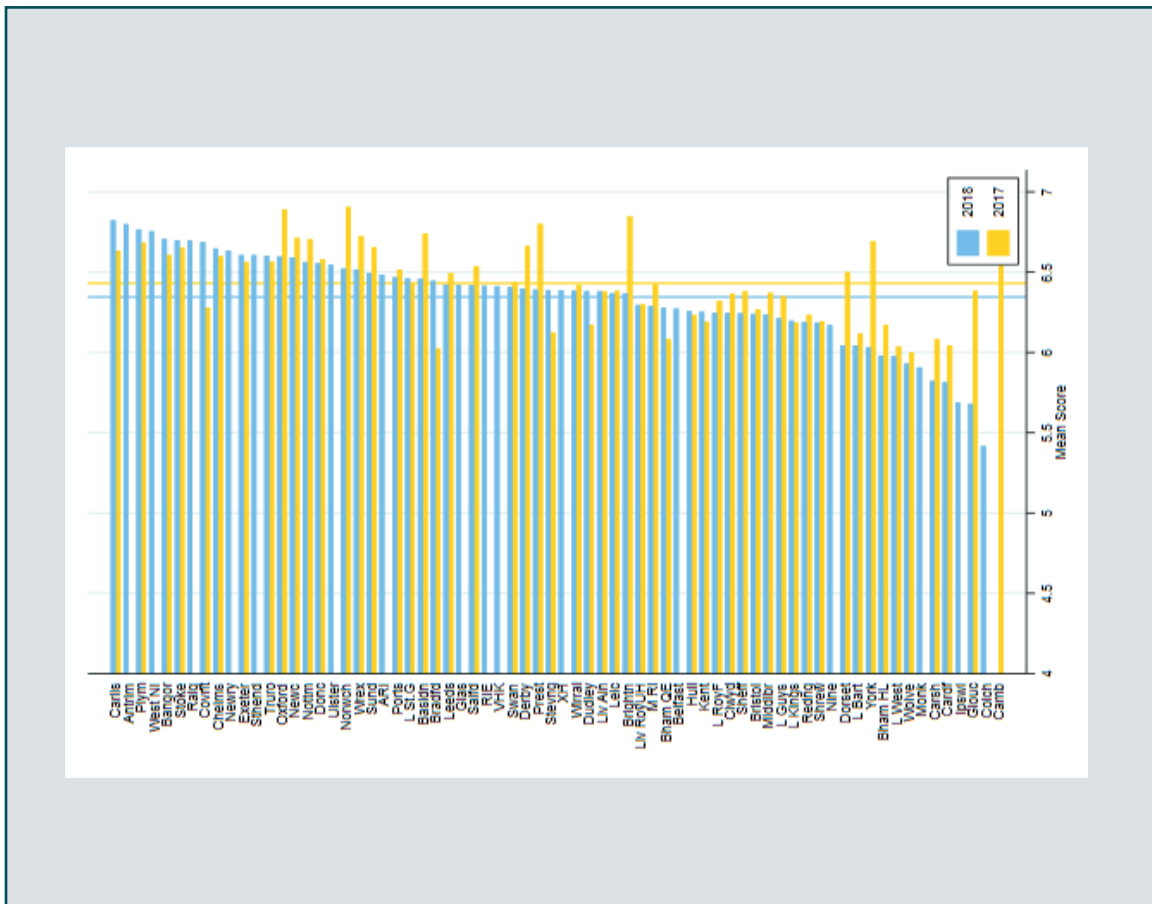
Session 2. Support



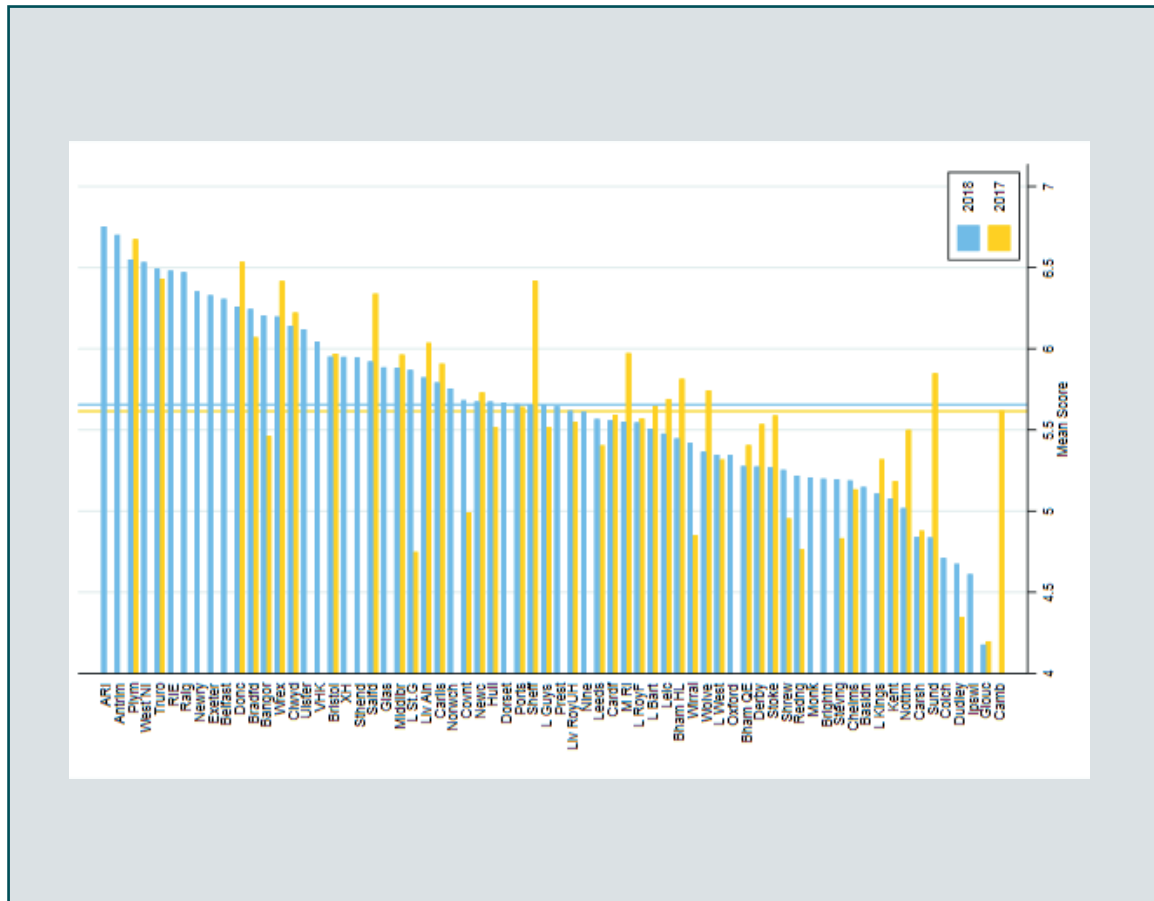
Session 8. Sharing Decisions About Your Care



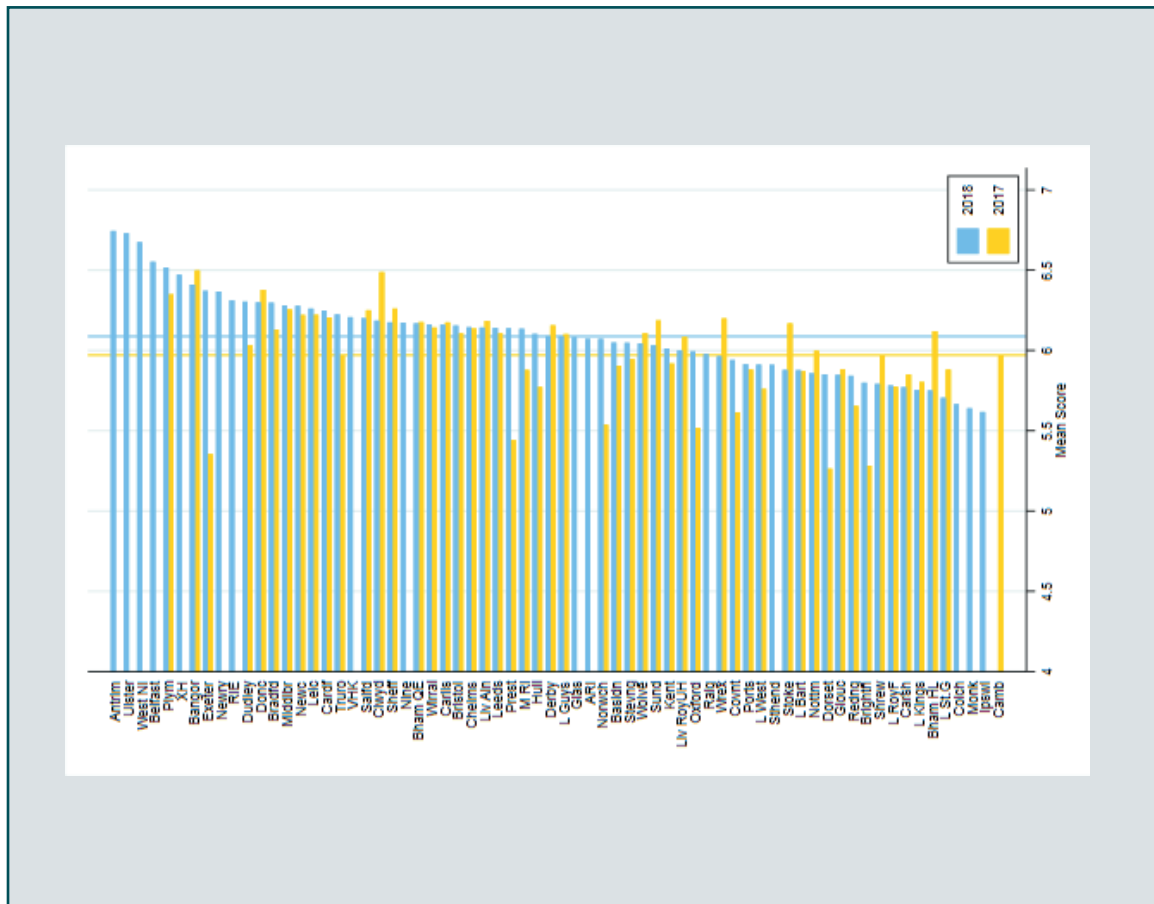
Session 9. Privacy and Dignity



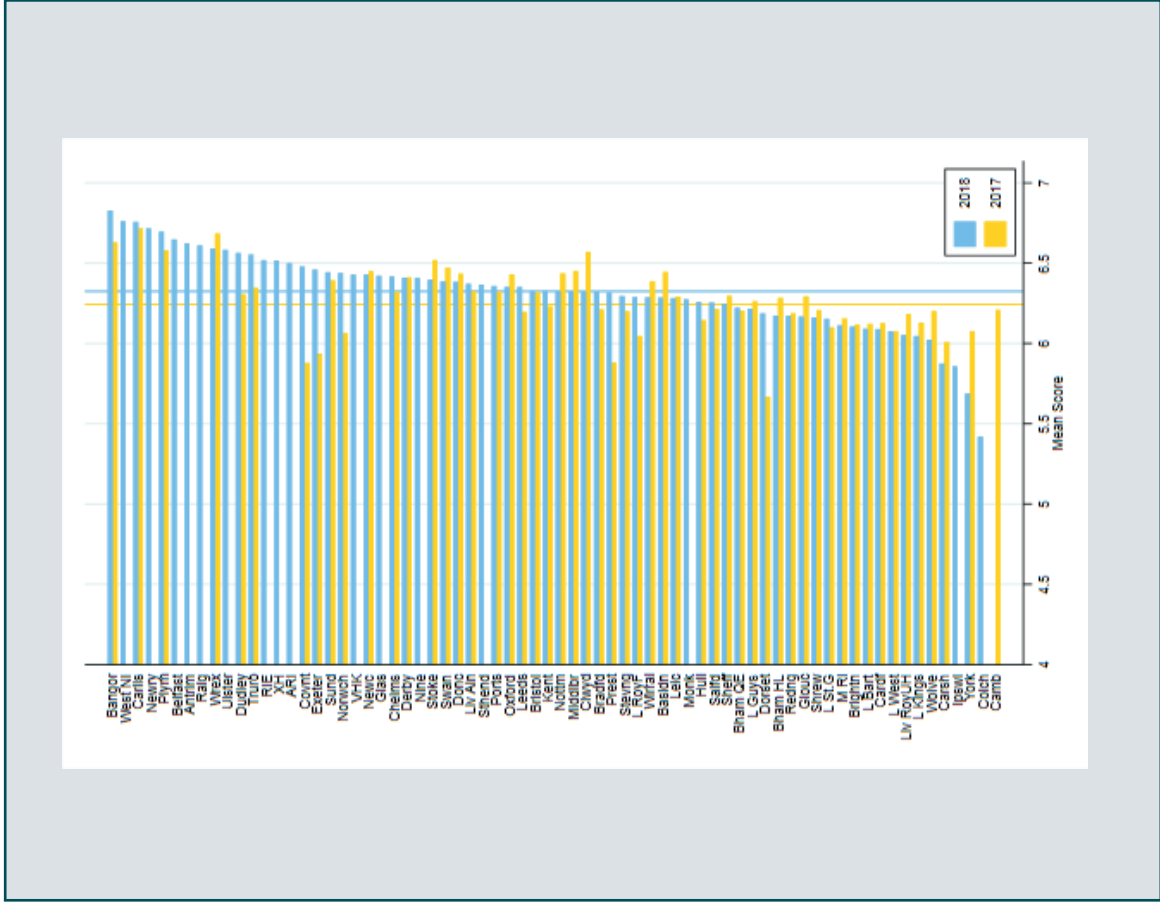
Session 12. Transport



Session 13. The Environment



Session 14. Your Overall Experience



Appendix Six: Changes to Kidney PREM between 2016-18

Theme	2018		2017 N		Changes 2017 to 2018		2016		N
	Section	N	Section	N	Changes	Section	N		
Access to the Renal Team	Section 1	3		3	No changes		Section 2	3	
Support	Section 2	3		4	Removed 1 question		Section 3	5	
	Section 3	5		6	Removed 1 question		Section 4	4	
Patient Information	Section 4	2		4	Removed 2 questions		Section 5	4	
Fluid Intake and Diet	Section 5	2		6	Removed 3 questions and clarified wording		Section 6	2	
Needling	Section 6	1		1	No changes		Section added 2017		
Tests	Section 7	3		3	No changes		Section 7	3	
Sharing Decisions About Your Care	Section 8	3		4	Removed 1 question		Section 8	4	
Privacy and Dignity	Section 9	2		2	No change		Section 9	2	
Scheduling and Planning	Section 10	3		3	No change		Section 10	3	
	Section 11	3		5	Removed 2 questions		Section 1	4	
Transport	Section 12	3		3	No change		Section 11	3	
Environment	Section 13	5		5	No change		Section 12	5	
Your Overall Experience	Section 14	1		1	No change		Section 13	1	
	Total number of questions	39		50				43	

Appendix Seven: Case Study Template



Patient Reported Experience Measure
Results and what's next – a case study



What action we took and how we did it:
What steps did you take to address the areas identified?

How we involved patients:
*Did you share your unit's PREM results with your patients?
How did you involve patients in PREM follow-up decisions?
How did you involve patients in the improvement initiative/s you put in place?*

For further information and resources on the PREM, please visit www.renalreg.org/projects/prem



Patient Reported Experience Measure
Results and what's next – a case study



The PREM process: *Provide some background to your participation in the PREM and how you went about engaging staff and patients*

Responding to PREM results

About our unit: *Unit name, size, staff / patient profile*

Area/s we wanted to improve on:
When looking at your PREM results what areas did you identify that needed improvement?

If you would like to share your case study with others, please complete this template and return to Catherine Stannard on Catherine.stannard@renalregistry.nhs.uk

Appendix Eight: Technical annex

About the Kidney PREM 2018 data

The Kidney PREM data consisted of 38 questions covering 13 themes and an overall experience question. Patients responded to each question on a scale from 1-7. All questions had the option of “don’t know” and “not applicable”, with the exception of question 39 “Your Overall Experience”. The themes and related questions with the response scale can be seen in Table A:

Table A: Themes in the 2018 Kidney PREM, with the response scale.

Section	Theme	Questions	Response scale
1	Access to the Renal Team	Q1-Q3	1 Never – 7 Always
2	Support	Q4-Q6	
3	Communication	Q7-Q11	
4	Patient Information	Q12-Q13	
5	Fluid Intake and Diet	Q14-Q15	
6	Needling	Q16	
7	Tests	Q17-Q19	
8	Sharing Decisions About Your Care	Q20-Q22	
9	Privacy and Dignity	Q23-Q24 ^a	
10	Scheduling and Planning	Q25-Q26, Q27 ^a	
11	How the Renal Team Treats You	Q28-Q30	
12	Transport	Q31-Q33	
13	The Environment	Q34-Q38	1 Poor – 7 Excellent
	Your Overall Experience	Q39 ^b	1 Worst it can be – 7 Best it can be

Those questions marked (a) referred to filtered questions, where only a subset of patients were required to answer. Question 39 (b) was a question about patients’ overall experiences. In addition to the survey data, information about patient characteristics was collected for current treatment (including pre-dialysis and transplant, and location of haemodialysis), age category, gender, ethnicity, and use of PatientView.

Data collection process

Online data collection was over a period of 8 weeks throughout June and July. Collection of paper copy data was advertised over a period of 4 weeks, from 1st to 30th June. Whilst the online survey was closed on 31st July, Kidney PREMs were returned to UK Renal Registry up until 31st August, and so may have been completed outside of this window.

Paper questionnaires

Each centre across England, Wales, Scotland and Northern Ireland was invited to take part in the Kidney PREM, with some units collecting data from a larger proportion of patients than others. Paper questionnaires were made available in units for patients to complete, with a member of staff inputting their UK Renal Registry renal unit code on the paper questionnaire. In the main, Scotland focussed their collection on their in centre haemodialysis population which will account for some of the increased representation of haemodialysis patients in the overall sample.

Completed questionnaires were sent to the UK Renal Registry where they were scanned. UKRR scanned 13,293 paper questionnaires, but of these 203 had 0 questions answered and a further 11 had only 1 question answered (assumed to be a scanning error). Therefore, 212 questionnaires were removed from the data, resulting in a dataset of 13,081.

Online questionnaires

The Kidney PREM was also made available online via the UK Renal Registry website (<https://www.renalreg.org/projects/prem>), with patients able to select their renal unit from a drop down list. Space was given to type a renal unit name if patients were unable to find the correct unit. Communication about the availability of the online survey was not applied consistently across units, and some patients may have found the Kidney PREM online without being told it was available. 810 patients submitted an online questionnaire, but of these 121 had answered 0 questions. These Kidney PREMs were removed from the data, resulting in a dataset of 689. In addition to English, the online questionnaire was available in Welsh, Gujarati and Urdu, with two Kidney PREMs completed in Gujarati.

The number of total valid responses to the Kidney PREM 2018 was 13,770 (13,081 paper and 689 online).

Data cleansing

All data analysis was done using either Excel or Stata/IC version 15.1. UK Renal Registry renal unit codes were added to the online data based on the unit selected by the patient from the drop down list. 93 records had entries in the "Unit Free Text" box either in addition to the unit selected or instead. UK Renal Registry checked these records; 60 were subsequently updated. The paper Kidney PREM results were appended to the online Kidney PREM results, with a variable created to identify the origin of each record (paper or online).

Patient characteristic variables (treatment, treatment location, age, sex, ethnicity and PatientView use) were encoded to allow for analysis. UK Renal Registry codes and hospital/unit names were checked and amended where appropriate for consistency. The patient summary characteristics table was produced based on all patients who provided valid responses and percentages were calculated across each characteristic (age, gender, ethnicity, treatment and haemodialysis location).

Estimation of scale/sub-scale scores

Sub-scale scores were estimated for each theme, for each patient. This was to give a score for each theme, with equal weight given to every question. If questions were not answered then theme sub-scale scores could still be estimated, so long as there was no more than one question missed. For themes containing just one question a score could not be estimated.

Themes 6 (Needling) and 10

(Transport) were filtered and so fewer scores were estimated. Theme 10 (Scheduling and Planning) contained one filtered question out of three, so scores were estimated using the unfiltered questions if applicable.

The overall scale score was estimated excluding question 39 (Your Overall Experience).

This left 38 questions, of which five were filtered leaving 33 for inclusion. Scale scores were estimated if there were less than four missed questions from the 33 (approximately 12%).

Questions which had been answered “Don’t Know” or “N/A” were not counted as missing.

Sub-scale and scale scores were not estimated for patients with missing centres.

Sub-scale and scale score were each calculated for each person using the following algorithm:

- “Don’t Know” and “Not Applicable” responses were recoded as missing
- Number of missed responses from each theme and the overall score was calculated (from unfiltered questions) (M)
- Total score for each theme and the overall scale was calculated (R)
- The scale or subscale average score was calculated (if number of missed responses ≤ 1 for each theme or ≤ 4 for overall score): $= \frac{R}{Q-M}$ where Q is the number of questions being evaluated, and M is the number of missing responses.

Mean scores by centre

Mean sub-scale and scale scores were calculated across each centre. Scores were only reported when there were seven or more responses per centre. Two centres had fewer than seven responses throughout, plus an additional centre had insufficient responses for the Needling theme and two for the Transport theme. The means estimated in this way were used for reporting in the following tables in the main body of the report and appendices:

- Table 1, comparing 2018 data with 2017 data (for those centres with seven or more responses);
- Table 3, a summary of the highest and lowest mean scores by centre, with the range in scores;
- Appendix 4 (Mean 2018 theme scores by centre); and
- Appendix 5 (2017/18 theme comparisons).

In the 2017 report some of the estimated means may vary due to differences in the exact method used to select cases.

The caterpillar plots in Appendix 4 (Mean 2018 theme scores by centre) provide a visual guide to variation between centres across the 13 themes, and for the overall experience question. Each plot (one per theme) shows the median, lower quartile and upper quartile for all centres as a vertical line. For each theme, the data was sorted in descending order by centre, and the mean value for each centre, with the 95% confidence intervals are shown. Any centres with less than seven responses for each theme were excluded from the graphs.

For the waterfall plots in Appendix 5 (2017/18 theme comparisons), mean scores across centres were calculated for each theme. 2017 mean scores were also calculated (excluding centres with fewer than 7 responses). The data was sorted in descending order for the 2018 means, and by centre. The plots show the 2017 and 2018 means for each centre and theme, with the overall mean value for 2017 and 2018 as vertical lines.

Question response centre/unit data

In addition to this report, question response data was made available to centres. Some relabelling or recoding was done to improve the readability of the dataset. The name of any unit or centre with less than 10 responses was removed to ensure that the anonymity of individual patients can be preserved (note the plots exclude centres with 7 or fewer responses).

Pivot tables and pivot charts were used in Excel to arrange the data by theme. Separate workbooks were produced at (1.) Centre level, (2.) Unit level and (3.) Overall. Two tables were generated for each theme; both containing that theme's questions. One includes the count of each response option for a question (i.e. 1-7, don't know, not applicable or missing), and the other includes the percentage of responses for each response option. A pivot table slicer was inserted so that the selection of a centre or unit and be selected to allow for different sets of data to be examined.

In addition to the excel spreadsheet with the data, tables were produced giving the theme scale scores displaying:

- Means of each theme by treatment modality (overall)

For each centre:

- Means and 95% confidence intervals of each theme by treatment modality
- Means of each theme by treatment modality for 2018, 2017 and 2016.

For each item under consideration, data was removed if there were fewer than 7 responses, to limit the potential of patient identification.

Limitations and caveats for interpreting the plots and data tables:

Presenting data to the community to allow for meaningful interpretation is always a challenge. In 2018, to improve the way units can interrogate their local data, additional tables have been provided for each renal centre providing means and confidence intervals for each of the 13 Kidney PREM themes, and for each treatment modality, adding to the information provided

by the caterpillar and waterfall plots. Any summary of data (means, intervals) leads to loss of information but increases the ability to make sense of trends across different groups.

The Kidney PREM 2018 data is challenging as the distribution of responses across the response options (1-7) does not follow a “normal” distribution. People tend to use the 5,6 and 7 response options much more than 4 or less, although a considerable number of people do wish to report a poor experience (referred to as a skewed distribution). A common way to deal with a skewed distribution is to use a median with quartiles to display the distribution of the data. However, if the median is estimated for the Kidney PREM data most questions and themes have a median of 7, and sometimes 6, meaning that the median as a way of communicating the central tendency is not sensitive to variation between questions or themes.

In addition, we are in the happy position of having a very large number of responses from the Kidney PREM. This means that the statistical reasons for reporting the median and quartiles is less important, and the mean and 95% confidence interval provides a robust picture of the responses for most people at the top end of the scale and makes it much easier to compare different groups. By examining the mean and confidence intervals we can have a high level of confidence that the intervals capture the responses of the majority of any group.

We can therefore be comfortable that if the interval for a particular group falls below, or above the 25th or below the 75th percentile for the group as a whole, then the majority of people responding group will be within that range, and the group can be considered to fall below or above the relevant percentile.

However, the choice of a mean and 95% confidence interval does mean that the confidence interval gives us less information about the “tail” of responses in the lower parts of the response scale. This should be borne in mind when making interpretations of the data. The width of confidence intervals are sensitive to sample size. A confidence interval is inversely proportional to the square root of the sample size (the confidence interval is produced by dividing by the square root of the sample size). This means that as the sample size increases the confidence interval gets smaller. If everything else is the same, the confidence interval for a sample size of 15 will be twice as big as a sample size of 60 (e.g. $\text{interval}/\sqrt{4}$). This is critical for small sample sizes of less than 30 where the confidence interval is likely to be very large. In a very real sense a large confidence interval indicates uncertainty which is reflected in the idea that a small sample size is not representative of the population. On-the-other-hand, a very small confidence interval may simply reflect a very large sample size and give the false impression of difference where the clinical or psychosocial meaning is less obvious.

Calculation of Kidney PREM responses received per centre

Tables B1 - C below display the number of Kidney PREM responses received as a proportion of those patients registered at each centre for each treatment group. UKRR does not hold data for pre-dialysis patients, so they have been excluded. The Kidney PREM data was

collected over the summer of 2018, whereas the UKRR patient numbers were recorded at the end of 2016. To account for this, these numbers were increased by 2.5%; broadly the increase in patients expected each year.

In a survey of this type, 10-30% response is generally expected, so any responses in excess of 30% are remarkable, and less than 10% indicates a poor response. The higher rate of return for haemodialysis patients is presumably because of their frequent attendance at clinic in comparison with peritoneal and transplant patients.

Caution should be used when interpreting statistics where the absolute number of responses is less than 20 within any particular group.

Table B1: Proportion of Kidney PREM responses for each treatment group by centre - ENGLAND

Renal Unit	Haemodialysis		Peritoneal Dialysis		Transplant		Total	
	N	Proportion (%)	N	Proportion (%)	N	Proportion (%)	N	Proportion (%)
Basldn	58	34.9%	10	28.7%	4	4.9%	72	25.5%
Bham HL	101	24.9%	21	23.3%	-	0.0%	122	18.2%
Bham QE	409	39.5%	39	26.6%	108	8.5%	556	22.7%
Bradfd	35	13.7%	7	27.3%	11	3.0%	53	8.1%
Brightn	203	43.1%	45	67.5%	35	7.2%	283	27.7%
Bristol	217	41.5%	31	57.1%	28	3.0%	276	18.3%
Camb	-	0.0%	-	0.0%	2	0.2%	2	0.1%
Carlis	43	44.6%	27	75.3%	12	7.8%	82	28.7%
Carsh	156	17.9%	8	6.9%	18	2.6%	182	10.8%
Chelms	62	45.5%	16	47.3%	15	13.1%	93	32.6%
Colch	28	22.0%	2	N/A	-	0.0%	30	23.6%
Covnt	44	11.4%	3	4.4%	15	2.7%	62	6.2%
Derby	62	25.1%	29	36.7%	11	4.8%	102	18.3%
Donc	69	34.7%	17	61.4%	16	14.3%	102	30.2%
Dorset	96	33.3%	4	10.5%	10	2.6%	110	15.6%
Dudley	81	38.9%	23	44.9%	2	2.1%	106	29.9%
Exeter	156	33.4%	45	52.3%	31	6.3%	232	22.3%
Glouc	88	35.2%	6	13.9%	9	4.8%	103	21.4%
Hull	119	35.3%	9	12.2%	15	3.2%	143	16.3%
Ipswi	49	32.7%	7	19.0%	-	0.0%	56	13.3%
Kent	223	50.6%	13	22.6%	35	5.8%	271	24.7%
L Bart	143	13.5%	7	3.4%	10	0.9%	160	6.6%
L Guys	232	32.7%	12	30.0%	61	4.4%	305	14.2%
L Kings	324	54.4%	35	37.5%	57	12.8%	416	36.6%
L RoyF	47	6.3%	2	1.2%	10	0.8%	59	2.6%
L St.G	11	3.0%	4	8.7%	10	2.1%	25	2.8%
L West	763	50.6%	12	11.6%	31	1.6%	806	23.0%
Leeds	183	34.0%	6	12.2%	57	5.7%	246	15.5%
Leic	367	37.1%	17	18.6%	19	1.5%	403	17.0%

Liv Ain	120	62.6%	18	67.5%	1	7.0%	139	59.7%
Liv RoyUH	97	25.9%	5	6.8%	15	1.9%	117	9.3%
M RI	138	25.6%	10	15.7%	20	1.4%	168	8.2%
Middlbr	203	59.7%	12	43.4%	4	0.7%	219	24.0%
Newc	247	75.3%	30	55.2%	119	17.1%	396	36.7%
Norwch	127	37.4%	20	39.8%	37	9.2%	184	23.2%
Nottm	113	28.1%	41	48.8%	64	9.2%	218	18.5%
Oxford	210	45.5%	45	46.2%	32	2.6%	287	15.8%
Plym	72	48.8%	7	17.1%	18	5.3%	97	18.4%
Ports	103	15.8%	16	20.8%	16	1.6%	135	7.8%
Prest	157	27.2%	16	39.0%	16	2.6%	189	15.3%
Redng	53	17.1%	7	12.2%	18	4.0%	78	9.6%
Sald	59	14.3%	36	32.8%	12	2.3%	107	10.2%
Sheff	252	39.9%	25	44.3%	1	0.1%	278	19.0%
Shrew	63	30.0%	22	55.0%	7	5.2%	92	23.9%
Stevng	344	63.1%	18	79.8%	54	15.1%	416	44.9%
Sthend	27	23.1%	11	35.8%	15	15.7%	53	21.8%
Stoke	92	25.9%	23	28.4%	43	10.4%	158	18.6%
Sund	117	45.5%	11	63.1%	16	6.5%	144	27.7%
Truro	81	46.5%	17	92.1%	23	9.3%	121	27.6%
Wirral	89	43.6%	13	57.6%	30	25.2%	132	38.2%
Wolve	103	32.0%	4	5.6%	17	9.0%	124	21.3%
York	9	4.4%	1	3.0%	-	0.0%	10	1.8%

Table B2: Proportion of Kidney PREM responses for each treatment group by centre - SCOTLAND

Renal Unit	Haemodialysis		Peritoneal Dialysis		Transplant		Total	
	N	Proportion (%)	N	Proportion (%)	N	Proportion (%)	N	Proportion (%)
ARI	52	22.0%	3	13.9%	6	1.9%	61	10.7%
DGRI	-	0.0%	-	0.0%	1	1.4%	1	0.7%
Glas	265	43.6%	1	1.8%	14	1.2%	280	15.6%
Monk	88	46.4%	2	8.1%	3	1.3%	93	20.6%
Nine	70	38.2%	2	9.3%	2	0.9%	74	17.2%
Raig	60	62.9%	5	44.3%	48	30.0%	113	42.4%
RIE	154	52.0%	3	7.9%	14	3.0%	171	21.4%
VHK	84	56.9%	1	5.4%	2	1.5%	87	28.8%
XH	84	58.1%	-	0.0%	6	4.1%	90	27.6%

Table B3: Proportion of Kidney PREM responses for each treatment group by centre – NORTHERN IRELAND

Renal Unit	Haemodialysis		Peritoneal Dialysis		Transplant		Total	
	N	Proportion (%)	N	Proportion (%)	N	Proportion (%)	N	Proportion (%)
Antrim	61	48.4%	1	6.1%	4	3.8%	66	26.7%
Belfast	72	36.2%	-	0.0%	10	1.6%	82	9.7%
Newry	47	52.7%	12	55.7%	8	6.1%	67	27.6%
Ulster	56	53.6%	6	97.6%	2	3.4%	64	37.6%
West NI	59	45.0%	3	29.3%	10	5.8%	72	22.9%

Table B4: Proportion of Kidney PREM responses for each treatment group by centre - WALES

Renal Unit	Haemodialysis		Peritoneal Dialysis		Transplant		Total	
	N	Proportion (%)	N	Proportion (%)	N	Proportion (%)	N	Proportion (%)
Bangor	13	16.9%	5	30.5%	4	4.4%	22	11.9%
Cardf	173	32.6%	14	18.2%	19	1.8%	206	12.3%
Clwyd	52	69.5%	3	19.5%	4	4.3%	59	32.3%
Swan	123	32.2%	28	40.8%	18	5.4%	169	21.5%
Wrex	51	40.1%	12	35.5%	-	0.0%	63	19.8%

Table C: Proportion of Kidney PREM responses for each treatment group by country

Renal Unit	Haemodialysis		Peritoneal Dialysis		Transplant		Total	
	N	Proportion (%)	N	Proportion (%)	N	Proportion (%)	N	Proportion (%)
England	7245	32.8%	865	27.2%	1210	2.2%	9320	17.0%
N Ireland	295	45.4%	22	27.9%	34	1.9%	351	19.2%
Scotland	857	43.9%	17	7.2%	96	1.9%	970	19.1%
Wales	412	34.6%	62	29.4%	45	1.4%	519	11.9%
Unknown		25		16		14		55
UK	8834	34.1%	982	26.5%	1399	4.0%	11215	17.3%



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