



**Patient Reported Experience
of Kidney Care in the UK
2019**

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Foreword

We are pleased to present the 2019 Kidney Patient Reported Experience Measure report (Kidney PREM). Following the initial pilot in 2016, involving over 8,000 people living with kidney disease, participation has continued to grow and the measure is now collected right across the UK and the number of responses has doubled with over 16,000 patients giving their views on their care experience.

This unique source of data has been recognised and used throughout the renal community as the international drive for person-centred outcome data across the healthcare system gains momentum. The UK Kidney community is proud to be a part of this international work towards better understanding and improving patient experience.

More importantly, our vision of the Kidney PREM is that it is used as a driver for change at a local level. We know the top-level scores are not the full story and that improvement, particularly around the three lower scoring themes - shared decision making, transport and needling - is complicated. There are no easy answers, however, there are some centres who are getting it right and we would like to better understand why this is and what they are doing that could be shared.

The working group behind delivering the Kidney PREM continues to work hard to gain a better understanding of the many questions that the Kidney PREM throws up - What is it about a centre that causes it to have the biggest impact on patient experience compared to the other variables collected? Does the Kidney PREM result in an improvement in patient experience? If so, can this improvement be translated to different settings? We do not want the Kidney PREM to stand still.

Through research projects, consultation and our own quality improvement, we hope the data and community response to the Kidney PREM will continue to evolve so that it remains meaningful, embedded across the system, and improves the experience and outcomes of people living with Kidney disease, as well as those who care for them in the UK. Thank you for being a part of it.



Ron Cullen
Chief Executive
The Renal Association



Paul Bristow
Acting Chief Executive
Kidney Care UK

Glossary

Sample: *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).

Mean: 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.

Confidence interval: 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).

Range: 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.

Standard Deviation: Like the range, **the standard deviation helps to describe the variation of scores** around the mean score. A low standard deviation implies that scores are closer to the mean, while a high standard deviation indicates a wider spread of scores. Unlike the range which can be affected by unusually high or low scores, the standard deviation is focused on a central cluster of scores.

Quartile: 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.

Executive summary

Key findings

- 70 adult renal centres across the UK participated in Kidney PREM 2019, providing 16,469 valid responses, an increase of 2,699 from 2018
- The national picture remains similar across the past three years, but there are some changes amongst renal centres, suggesting potential for improvement
- As found in previous Kidney PREMs, centre differences are more closely related to patient experience than any other characteristic. A patient's age, treatment type, treatment location, ethnicity and gender have a small effect but are much less important than the treating centre when determining a patient's experience of renal services
- Patient rating of their Overall Experience remained high, at 6.3 out of 7 for the third consecutive year
- Privacy & Dignity, Access to the Team, Patient Information and Scheduling & Planning continued to be those areas which scored highly
- The issues which continue to impact most negatively on patient experience are Transport, Sharing Decisions About Your Care, Needling and Support, although patients now report the lowest experience within Transport
- There remains no improvement to these areas, which also report the highest variation in scores across centres
- Both Support and Communication are related to Sharing Decisions About Your Care. These areas continue to be the fourth and fifth lowest scored aspects of patient experience

The mean scores for all areas in the 2019 Kidney PREM were unchanged compared to 2018, with differences of just +/-0.1, as shown in table 1.

Table 1: Kidney PREM 2019 themes: Centre means, range of centre scores and change from 2018

	Mean Score	Standard Deviation of Centre Means	Min Centre Score	Max Centre Score	Range	Change compared to 2018
Access to the Renal Team	6.3	0.2	5.8	6.8	1.0	0.0
Support	5.8	0.3	5.2	6.7	1.5	0.0
Communication	6.0	0.3	4.9	6.6	1.7	0.0
Patient Information	6.3	0.2	5.7	6.8	1.1	0.0
Fluid and Diet	6.1	0.3	5.1	6.7	1.6	0.0
Needling	5.8	0.3	4.8	6.6	1.8	0.0
Tests	6.2	0.2	5.8	6.6	0.9	0.0
Sharing Decisions About Your Care	5.5	0.4	4.8	6.6	1.8	0.1
Privacy and Dignity	6.4	0.2	5.8	6.8	1.0	0.0
Scheduling and Planning	6.2	0.2	5.7	6.7	1.1	0.0
How the Renal Team Treats You	6.1	0.3	5.0	6.8	1.8	0.0
Transport	5.5	0.6	4.2	6.6	2.5	-0.1
The Environment	6.1	0.2	5.3	6.8	1.4	0.0
Your Overall Experience	6.3	0.2	5.5	6.8	1.3	0.0

Recommendations

The Kidney PREM is a signal for change, but does not tell the whole story.

- The Kidney PREM will have the greatest impact when renal centres further investigate and act on their local findings in partnership with patients and make improvements to care identified as necessary by their own patients
- There are significant variations between centres, indicating the opportunity for centres performing well in an area to share knowledge and ideas with those performing less well
- Differences in response rates and respondent profile between centres however, 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
- 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 aspects of kidney care that impact most negatively on their experience: Transport, Sharing Decisions About Your Care, Needling and Support
- 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
- Renal teams and patients are encouraged to look at, discuss and share their unit level results which are openly available via the PREM portal at www.renalreg.org/datasets/prem-portal/

Comments

- 508 patients provided a written comment on the online Kidney PREM
- These comments could be categorised into the existing Kidney PREM themes and three additional themes of PatientView, Continuity of Care and Pharmacy
- Positive comments were provided about patients' overall experience of care, the caring attitude of staff, and PatientView
- There were negative comments about difficulty in contacting the renal team, a lack of psychological support, transport, the environment, waiting times, timings of tests and appointments, staff shortages and poor continuity of care
- Suggestions for improvement were made by patients relating to a range of issues, including the dialysis environment, the option for telephone or Skype appointments and provision of psychological and emotional support

Data interpretation

A difference of at least 10% (0.7 points) 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 low and not necessarily representative of the patient population. This means that direct comparison of results between centres or across years should not be assumed to be informative. Low response rates can be inferred from the charts on pages 18-32 in this report; 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 reduce the number of questions from 50 to 39, but no further changes were made in 2019. Therefore, comparison between the mean scores from 2017 to 2019 is generally possible but may be influenced where there is a substantial difference in the number of responders. Some differences were made in the way that mean scores for Needling and Scheduling & Planning themes were estimated in 2019 to improve the interpretability of the results. Previously, all patients who had answered those questions were included in the analysis. For this year's results, answers were cross-referenced with each patient's treatment type so that scores for Needling were only estimated for in-hospital and in-satellite haemodialysis patients. Questions about blood tests (in the Scheduling & Planning theme) were analysed for all other patients. The comparison between 2019 and previous years' results may be influenced by this change for these areas.

Kidney PREM 2019

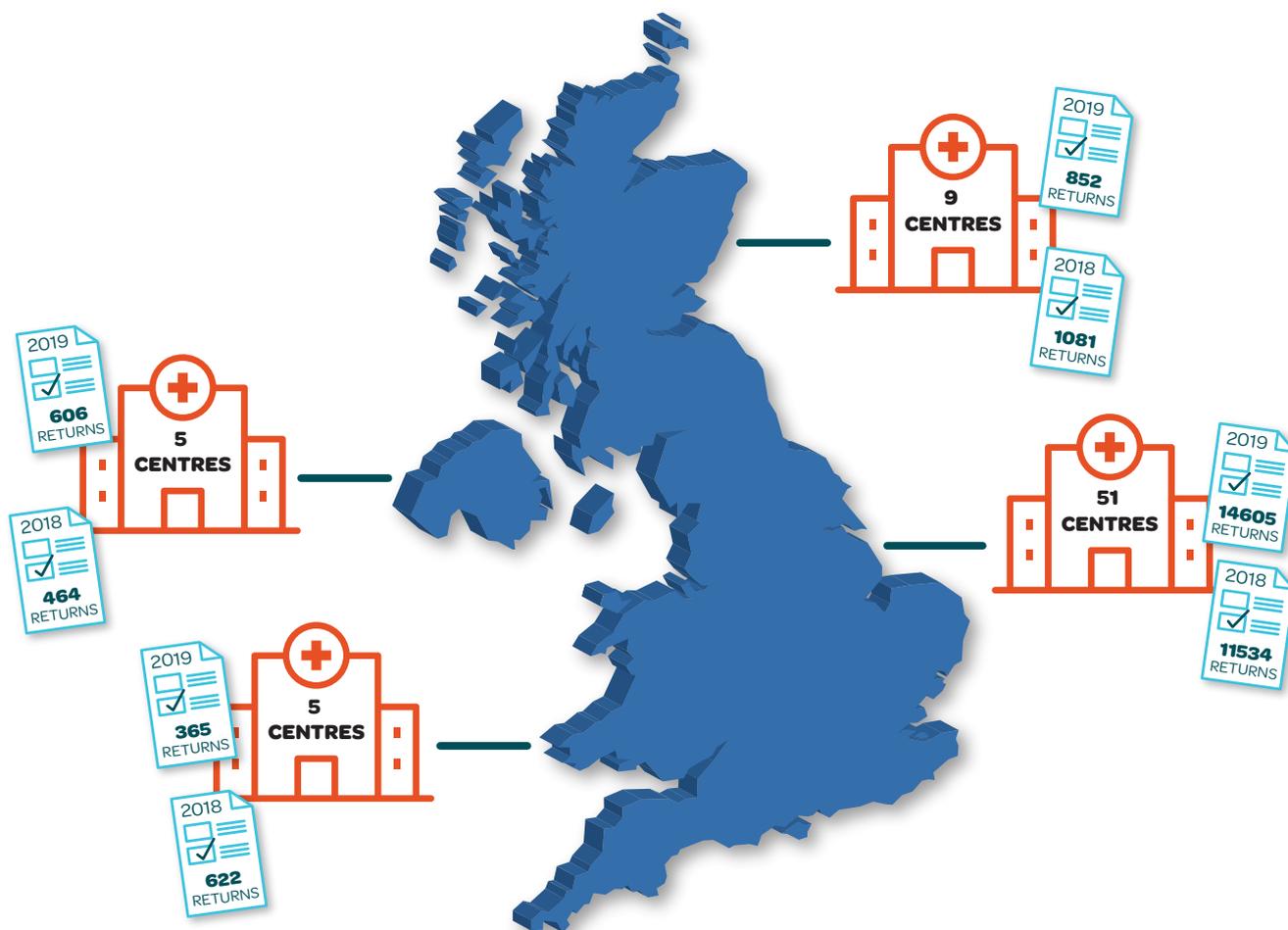
Response profile

As with previous years, paper copies of the Kidney PREM were available to patients through the renal centres. Online surveys could be taken in English, Gujarati, Urdu or Welsh, and were publicised in participating units and via PatientView.

A total of 70 adult renal centres participated in Kidney PREM in 2019 across the UK, with patients from 297 units providing 16,469¹ valid responses. Participation continues to increase year on year, with an additional 2,699 patient responses received compared to 2018 (Table 3). This builds upon the previous increase of 2,743 patients from 2017 to 2018.

Returns by country

Centres in England and Northern Ireland (NI) showed an increase in patient responses from 2018 at 3,071 (27%) and 142 (31%) respectively. However, responses received from Wales and Scotland were 257 (41%) and 229 (21%) lower than in 2018. 41 patients did not provide their centre.



¹ When estimating individual statistics the total may be less than 16,469 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.

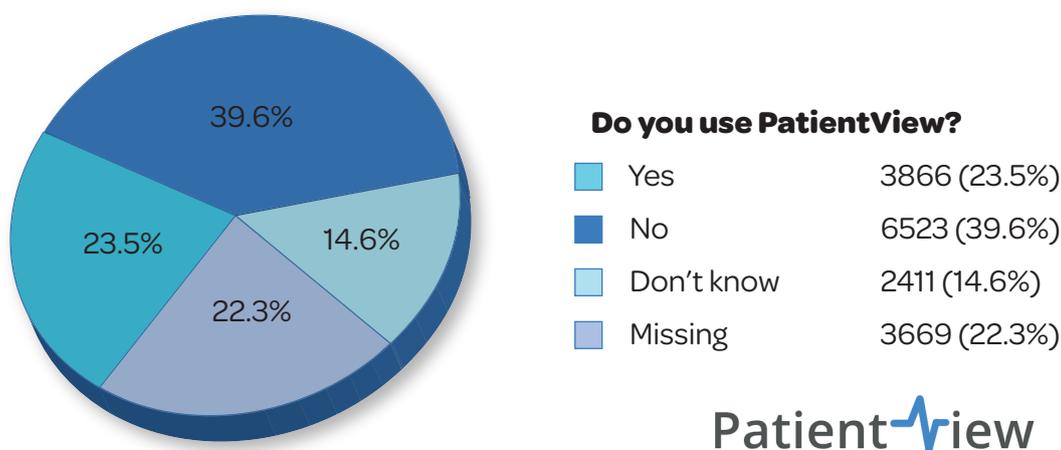
The proportion of patients over 65 years is larger in the haemodialysis and peritoneal groups than in the CKD² and transplant groups (Table 2), which reflects treatment patterns. The proportion of older patients (≥ 75 years) on peritoneal dialysis continues to be high (34%) compared to haemodialysis (31%).

Once again, the majority of respondents were aged from 56-74 (44%) (Table 3). There was a slight drop in responses from patients over 56 at 71% compared to 73%, but this was still an increase compared to 2017 where 69% of patients were over 56 years. There were more men than women responding to the PREM (52% to 36%, with 11% not providing this information), similar to the proportions in 2018.

The number of patients responding has increased across all treatment modalities, with a larger increase from 2018 to 2019 in the proportion of transplanted (from 10% to 13%) and CKD (12% to 15%) compared to a reduction in proportion of haemodialysis patients (from 64% to 58%). Haemodialysis therefore remains the predominant treatment type of Kidney PREM responders.

The ethnic profile of patients has remained stable from 2017 to 2019, with the majority being white (73%). There was little change in proportion of Asian patients, but a slight increase in black patients from 6% to 7%. There remains 8% of patients who choose not to disclose their ethnicity when completing the Kidney PREM. This reflects the national picture, as shown in table 3, where 6.7% of patients on a renal replacement therapy (RRT) in 2017 did not disclose their ethnicity.

The proportion of patients reporting the use of PatientView remained broadly the same at 23% in 2019 compared to 21% in 2018. There remains a significant group of patients who either reported they don't know if they use PatientView (15%) or chose not to answer (22%).



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

² Those patients attending kidney clinic but not in receipt of dialysis or a transplant are referred to as CKD throughout this report.

Table 2: Age ranges across the different modalities

Age (years)	Total		Transplant		Haemodialysis		Peritoneal		CKD		Missing	
	Total	%	Total	%	Total	%	Total	%	Total	%	Total	%
17-21	107	0.6%	18	0.8%	37	0.4%	6	0.5%	40	1.6%	6	0.6%
22-30	407	2.5%	94	4.3%	182	1.9%	29	2.5%	92	3.8%	10	0.9%
31-40	917	5.6%	209	9.6%	444	4.6%	49	4.2%	182	7.5%	33	3.1%
41-55	2975	18.1%	640	29.3%	1522	15.8%	176	15.1%	528	21.7%	109	10.2%
56-64	3093	18.8%	524	24.0%	1765	18.4%	212	18.2%	435	17.8%	157	14.7%
65-74	4105	24.9%	463	21.2%	2515	26.1%	281	24.1%	561	23.0%	285	26.8%
75-84	3522	21.4%	167	7.7%	2362	24.6%	320	27.4%	385	15.8%	288	27.0%
85+	894	5.4%	25	1.1%	575	6.0%	74	6.3%	140	5.7%	80	7.5%
Missing	449	2.7%	43	2.0%	216	2.2%	19	1.6%	74	3.0%	97	9.1%
Total	16469		2183		9618		1166		2437		1065	

Table 3: Characteristics of the people who completed the Kidney PREM in 2019, 2018 and 2017

Characteristic	PREM 2019	PREM 2018	PREM 2017	UK RRT Patients as of end of 2017 ³
Total	16469	13770	11027	63467
Age				
≤30	514 (3.1%)	391 (2.8%)	353 (3.2%)	4.4%
31-55	3892 (23.6%)	3095 (22.5%)	2797 (25.4%)	35.3%
56-74	7198 (43.7%)	6042 (43.9%)	4731 (42.9%)	44.6%
≥75	4416 (26.8%)	3970 (28.8%)	2902 (26.3%)	15.8%
Missing	449 (2.7%)	272 (2.0%)	244 (2.2%)	-
Gender				
Female	5937 (36.0%)	4891 (35.5%)	4031 (36.6%)	38.9%
Male	8629 (52.4%)	7295 (53.0%)	5907 (53.6%)	61.1% ⁴
Rather not say	74 (0.4%)	57 (0.4%)	39 (0.4%)	-
Missing	1829 (11.1%)	1527 (11.1%)	1050 (9.5%)	-
Ethnicity				
Asian	1558 (9.5%)	1275 (9.3%)	1048 (9.5%)	11.6%
Black	1137 (6.9%)	829 (6.0%)	774 (7.0%)	7.3%
White	12010 (72.9%)	10267 (74.6%)	8184 (74.2%)	70.9%
Other	401 (2.4%)	355 (2.6%)	265 (2.4%)	2.8%
Rather Not Say	246 (1.5%)	202 (1.5%)	155 (1.4%)	-
Missing	1117 (6.8%)	842 (6.1%)	601 (5.5%)	6.8%
Current Treatment				
Transplant	2183 (13.3%)	1399 (10.2%)	1545 (14.0%)	54.8%
Haemodialysis	9618 (58.4%)	8834 (64.2%)	6194 (56.2%)	39.7%
Peritoneal	1166 (7.1%)	982 (7.1%)	808 (7.3%)	5.5%
CKD	2437 (14.8%)	1659 (12.0%)	1671 (15.2%)	Unknown
Missing	1065 (6.5%)	896 (6.5%)	809 (7.3%)	-
Haemodialysis Location				
At Home	337 (3.5%)	299 (3.4%)	276 (4.5%)	5.2%
In-centre	4400 (45.7%)	3843 (43.5%)	2671 (43.1%)	43.1%
In-satellite	4557 (47.4%)	4412 (49.9%)	3036 (49.0%)	51.7%
Missing	324 (3.4%)	280 (3.2%)	211 (3.4%)	-
Patient View				
Yes	3866 (23.5%)	2928 (21.3%)	2658 (24.1%)	54.6%
No	6523 (39.6%)	5583 (40.5%)	4321 (39.2%)	45.4% ⁵
Don't Know	2411 (14.6%)	2364 (17.2%)	1824 (16.5%)	-
Missing	3669 (22.3%)	2,895 (21.0%)	2224 (20.2%)	-

³ Data only available for patients on a renal replacement therapy and excludes Cambridge⁴ Currently patients can only select male or female, although this is under review⁵ Based only on patients in England. Data unavailable for Scotland, NI and Wales

Overall patient experience

Patients continued to report a high overall experience with a mean of 6.3 out of 7, equal to 2018 and 2017 mean scores, which shows that patients report a consistently good overall experience of UK renal services.

The range of centre means was slightly narrower and higher in 2019 (5.5 - 6.8 compared to 5.4 - 6.8 in 2018). This demonstrates a considerable variation in experience between centres compared to any other measurable feature of patients. From figure 1 it is clear that there are a number of centres that fall either above the upper quartile or below the lower quartile of centre means.

Figure 1: Centre mean scores for overall experience of the service provided by renal units (Question 39 in the 2019 Kidney PREM)

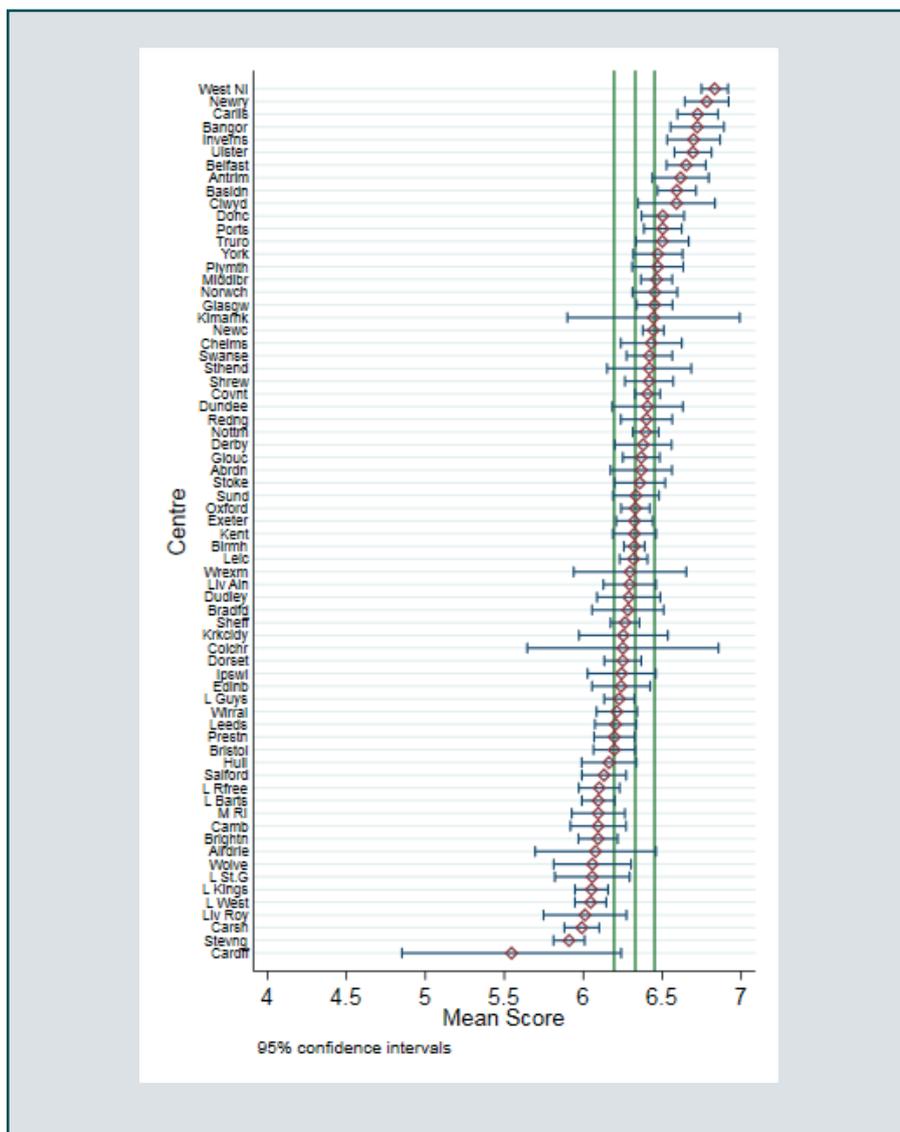
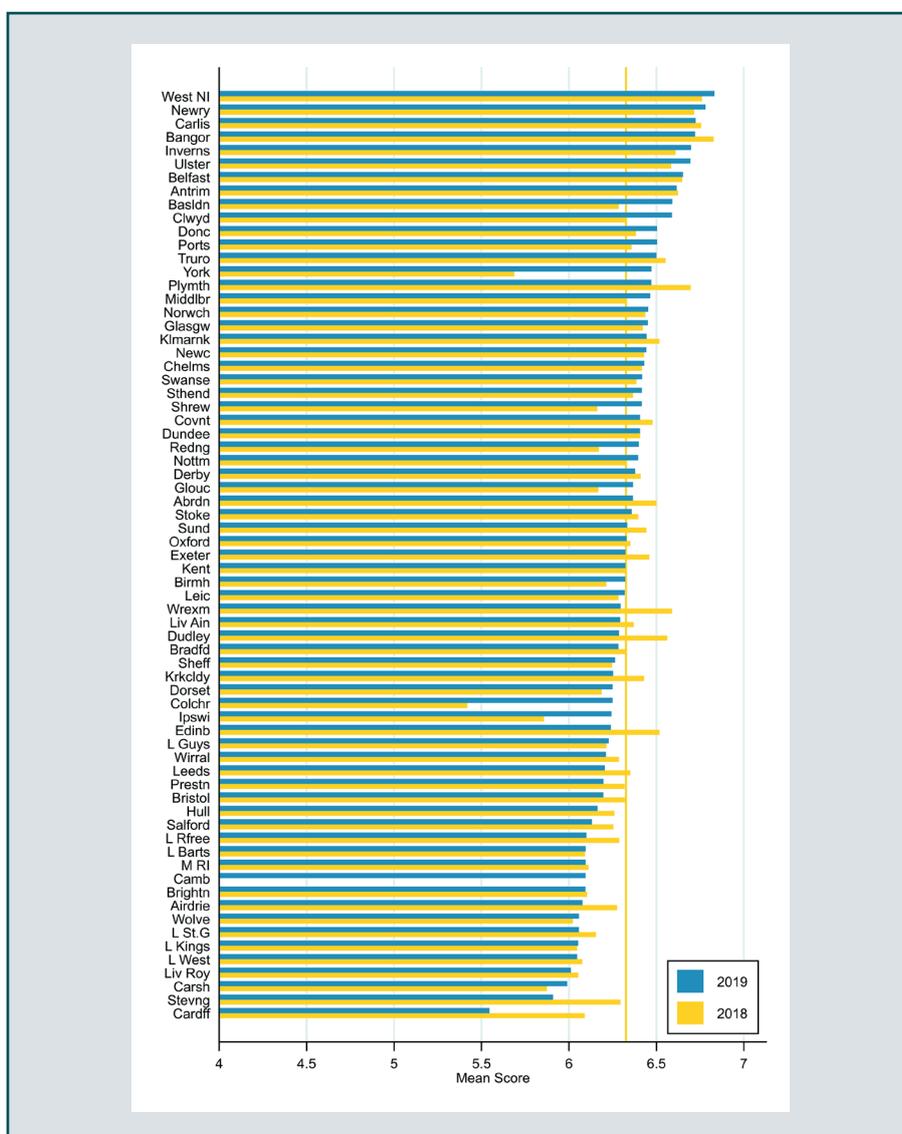


Figure 2 shows that, although the national mean of the overall score has remained static (6.3) there has been some movement between centre mean scores from 2018 to 2019. While relatively small numbers of patients responding (e.g. Cardiff, Colchester) may explain large year on year changes, in other centres the change may be due to either an increase in the number of patients responding this year (e.g. York), or due to other changes local to the centre that are having an impact on the patients experience. As in 2018, patients from NI report a notably positive overall experience, with the five centres featuring in the top 8 for overall experience.

Figure 2: 2019 and 2018 centre mean scores for overall experience of the service provided by renal units (Question 39 in the 2019 Kidney PREM)



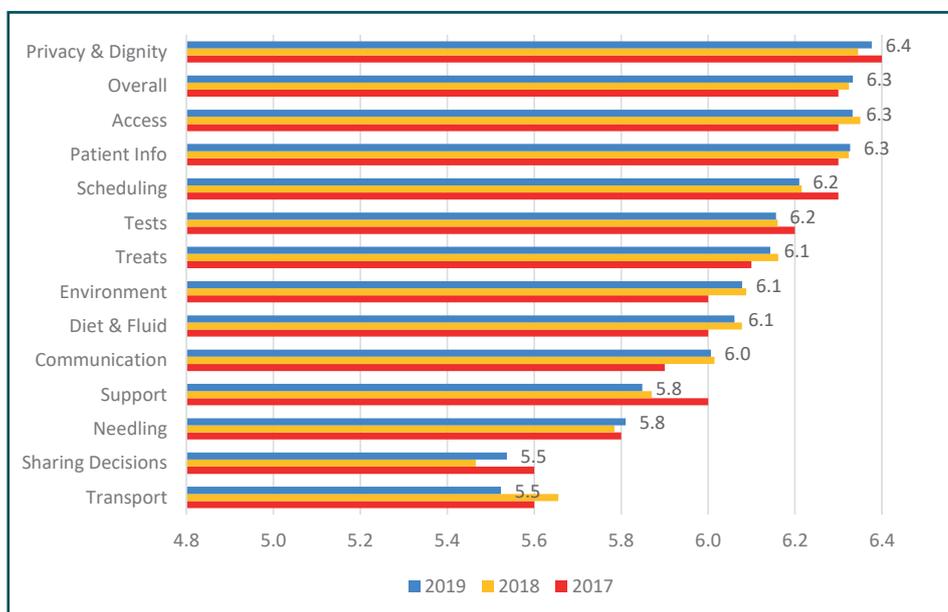
Variation in patient experience between centres

Table 4 shows the average centre means, the minimum and maximum centre mean and the difference (range) between the centre means for each theme. These means are shown in figure 3, for 2019, 2018 and 2017.

Each year, the Kidney PREM has shown considerable variation between centre means. Access to the Team, Privacy & Dignity and Patient Information are areas in which centre means are high, with each of these themes having a small range of centre means. This demonstrates consistently good practice across centres. Tests and Scheduling & Planning also have a narrow range of centre means and each score well at 6.2.

Similarly, Transport, Sharing Decisions and Needling have had consistently poor experiences reported each year. Each of these have wide ranges of centre means, suggesting that the overall means are reduced by the centres with patients who report worse experience within those themes. Support has dropped slightly to a mean value of 5.8, down from 6.0 in 2017. It is also notable that How the team treats you (1.8), Fluid & Diet (1.6), and Communication (1.7) have consistently wide ranges of centre means, indicating that these areas could benefit from a focus on understanding this variation between centres.

Figure 3: Mean scores for the 13 Kidney PREM themes and the overall experience question, showing values from 2019, 2018 and 2017⁶



⁶ This year the approach is to compare means at centre-level for greater clarity and interpretability. Means calculated over all patients were either the same or differed by just 0.1.

Table 4: A summary of the highest and lowest mean scores by centre, with the range in scores

Theme	Topic	2019			2018			2017		
		Range	Mean range	Mean	Range	Mean range	Mean	Range	Mean range	Mean
1	Access to the team	1.0	5.8 - 6.8	6.3	1.0	5.9 - 6.9	6.4	0.9	5.9 - 6.8	6.3
2	Support	1.5	5.2 - 6.7	5.8	1.7	4.9 - 6.6	5.9	1.1	5.4 - 6.6	6.0
3	Communication	1.7	4.9 - 6.6	6.0	1.6	5.0 - 6.6	6.0	1.4	5.1 - 6.5	5.9
4	Patient Information	1.1	5.7 - 6.8	6.3	1.4	5.5 - 6.9	6.3	1.1	5.7 - 6.8	6.3
5	Fluid and Diet	1.6	5.1 - 6.7	6.1	1.5	5.3 - 6.9	6.1	1.6	5.0 - 6.7	6.0
6	Needling	1.8	4.8 - 6.6	5.8	1.9	4.5 - 6.4	5.8	1.4	5.3 - 6.6	5.8
7	Tests	0.9	5.8 - 6.6	6.2	0.9	5.7 - 6.6	6.2	1.1	5.6 - 6.7	6.2
8	Sharing Decisions	1.8	4.8 - 6.6	5.5	3.1	3.6 - 6.6	5.5	1.5	4.9 - 6.4	5.6
9	Privacy & Dignity	1.0	5.8 - 6.8	6.4	1.4	5.4 - 6.8	6.3	0.9	6.0 - 6.9	6.4
10	Scheduling & Planning	1.1	5.7 - 6.7	6.2	1.6	5.3 - 6.8	6.2	0.8	5.8 - 6.7	6.3
11	How the team treats you	1.8	5.0 - 6.8	6.1	1.9	4.9 - 6.8	6.2	1.1	5.5 - 6.6	6.1
12	Transport	2.5	4.2 - 6.6	5.5	2.6	4.2 - 6.8	5.7	2.5	4.2 - 6.7	5.6
13	Environment	1.4	5.3 - 6.8	6.1	1.2	5.6 - 6.7	6.1	1.2	5.3 - 6.5	6.0
14	Overall experience	1.3	5.5 - 6.8	6.3	1.4	5.4 - 6.8	6.3	1.0	5.7 - 6.7	6.3

High average score
Low average score
Wide range of scores
Narrow range of scores

As engagement in the PREM across centres increases over time, there are fewer centres with very small numbers of patients contributing, so fewer outlying scores. The themes with the largest and smallest variations between centres are those with the highest and lowest overall mean scores respectively. This provides more confidence in the data and an additional emphasis to focus on the areas where poorer patient experience is reported, since these are the areas where there are greater opportunities for learning. Similarly, there is less variation between centres for themes where patients report better experiences.

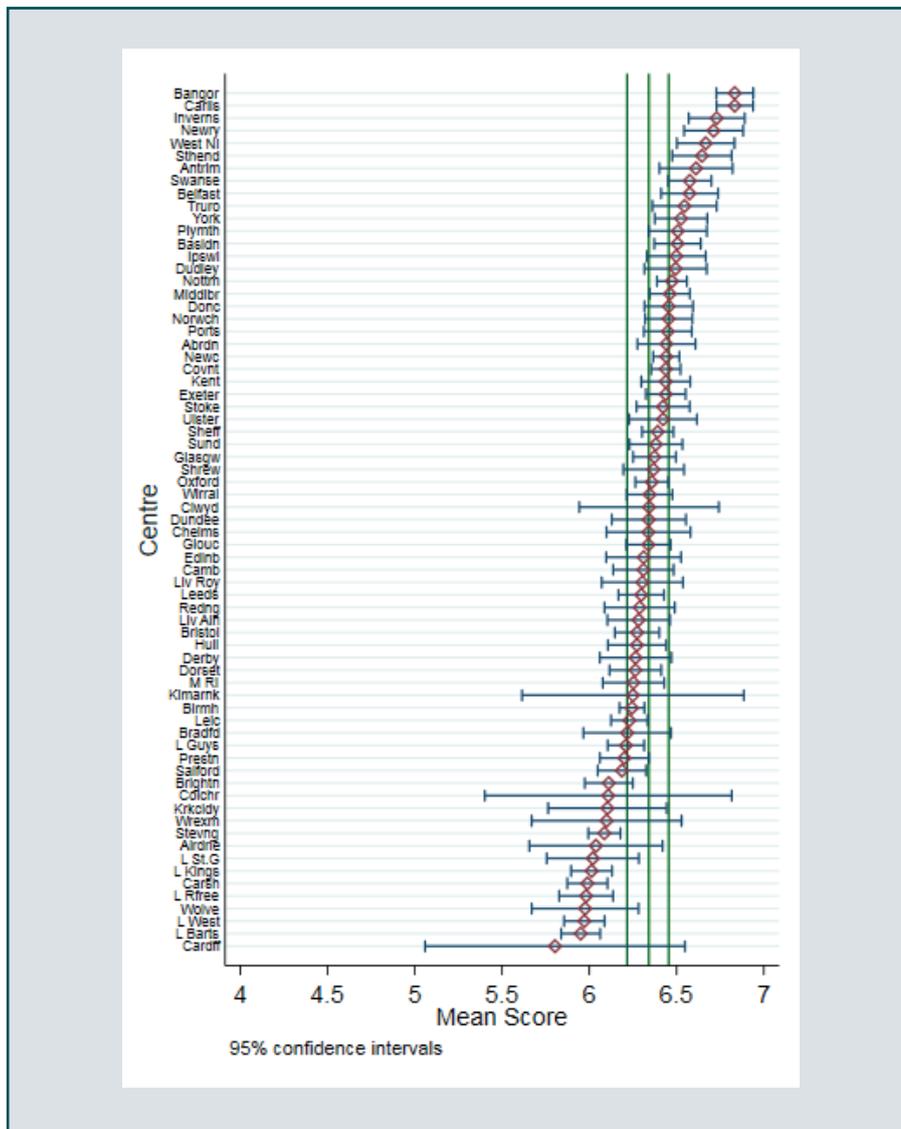
Mean 2019 theme scores by centre

The following graphs show the mean scores and 95% confidence intervals for each centre for the 2019 Kidney PREM (when a minimum of 7 responses per centre were received) along with the median and quartile scores for centre means. Means where the confidence interval falls entirely beyond the 25th or 75th percentiles are worse than or better than most centres in that theme.

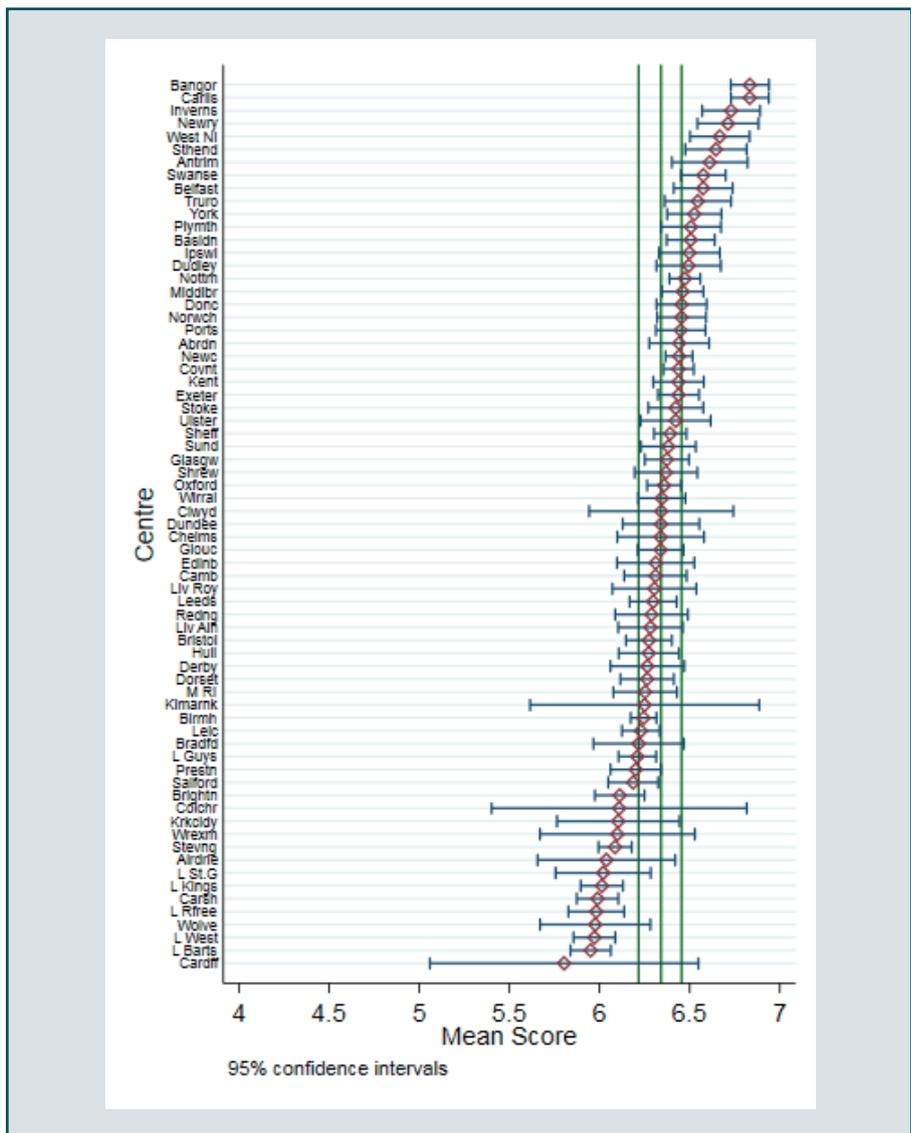
Additional results and information is available at www.renalreg.org/projects/prem/ including:

- Graphs showing the overall mean and the mean for each of the 13 themes by centre for both 2018 and 2019 (when a minimum of 7 responses per centre were received).
- Centre means by treatment type for each theme
- Comments analysis report
- Unit level results by question via the PREM portal
- Technical annex
- The full Kidney PREM 2019 survey

Scale Total: Responses across all themes



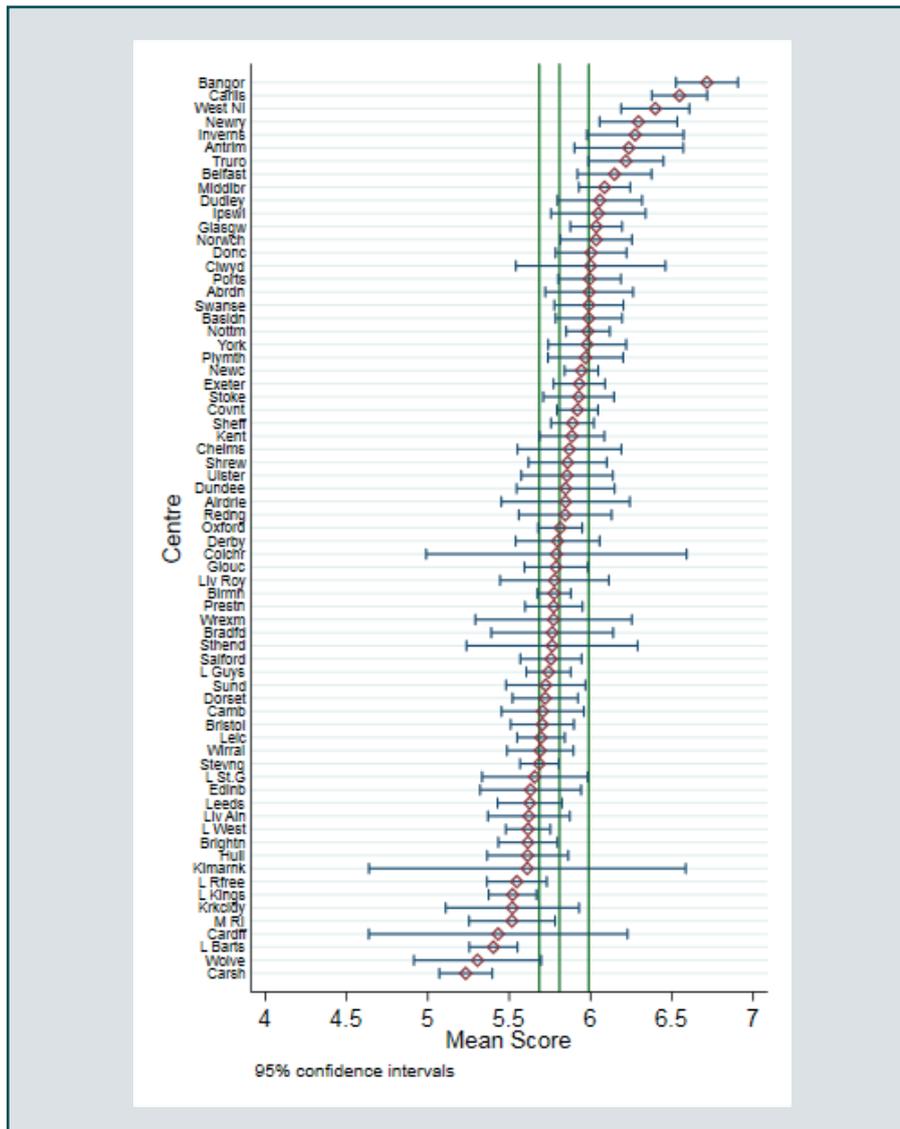
Section 1: Access to the renal team



Theme mean calculated from patient scores for the following items:

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

Section 2: Support

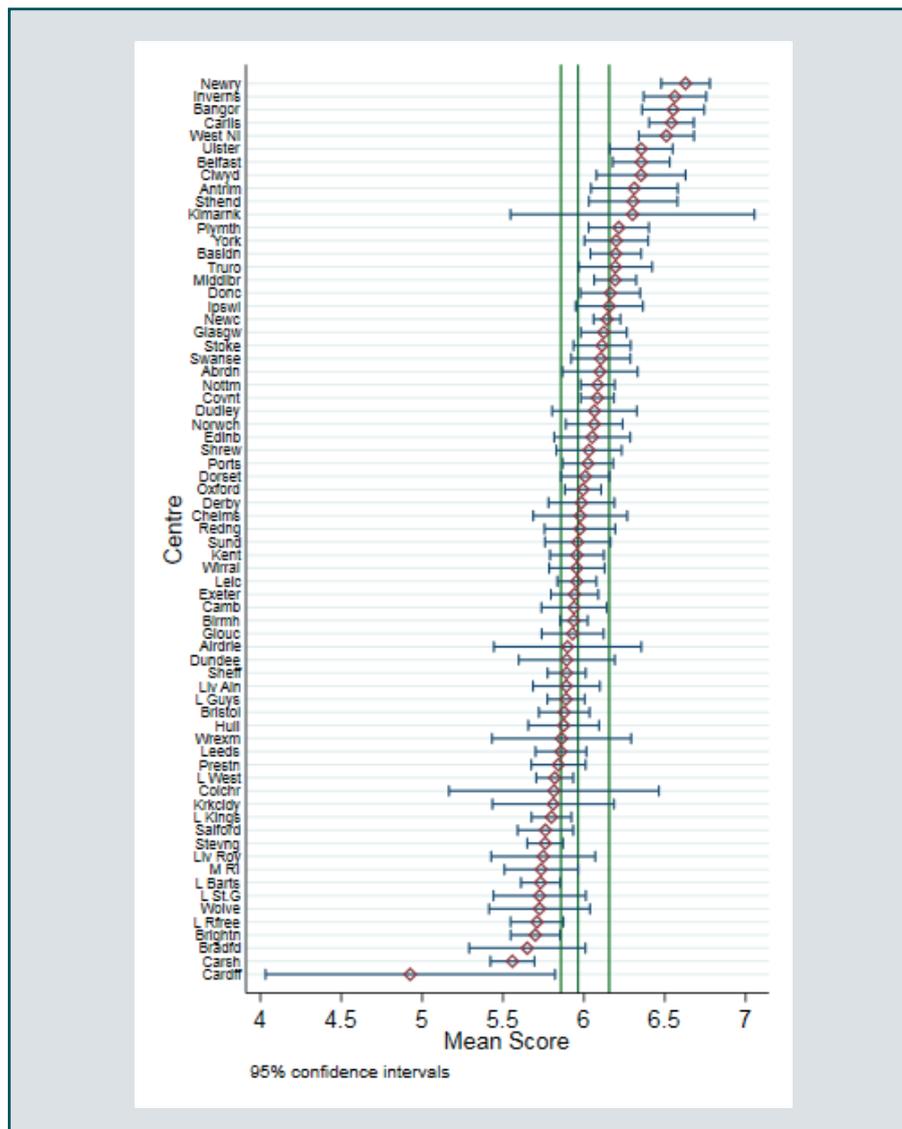


The mean calculated from patient scores for the following items:

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

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

Section 3: Communication



Theme mean calculated from patient scores for the following items:

Do you think there is good communication between:

7. You and your renal team?

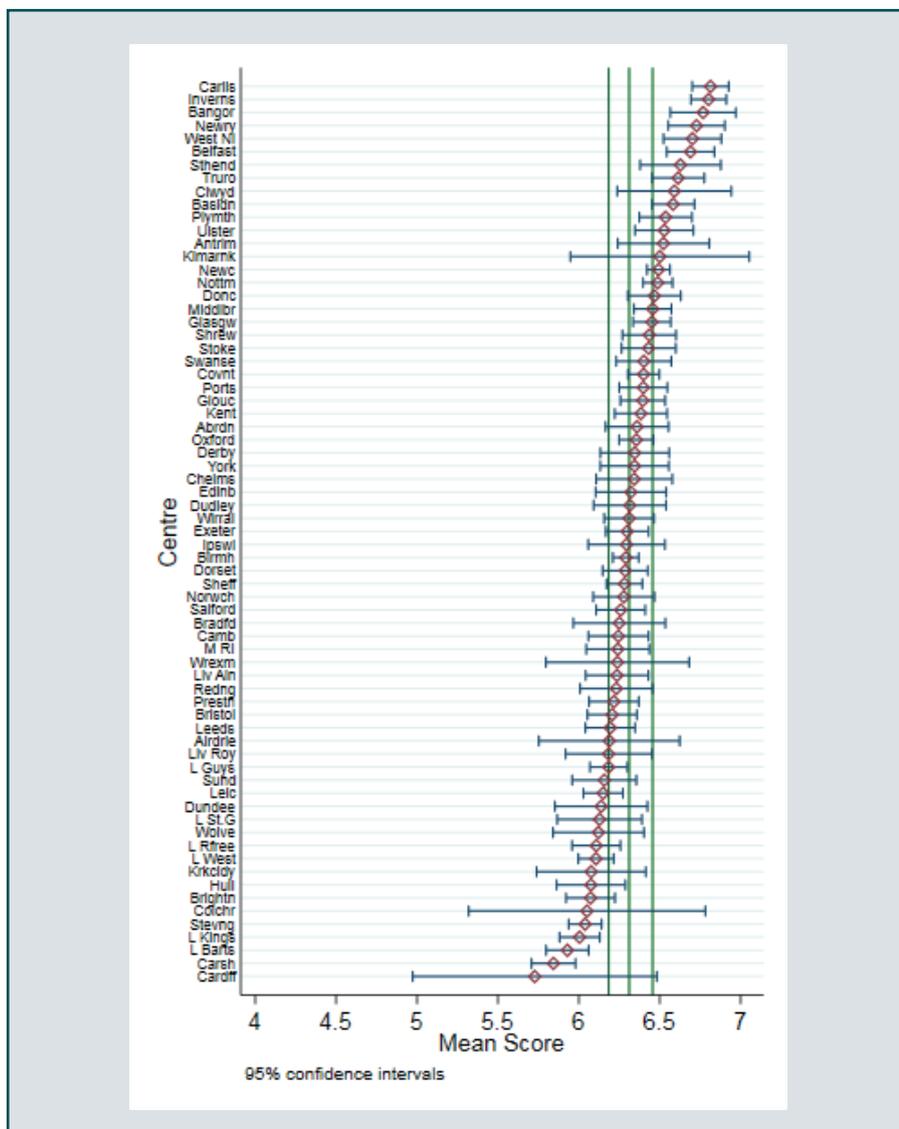
8. Members of the renal team?

9. Your GP and the renal team?

10. The renal team and other medical specialists?

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

Section 4: Patient information



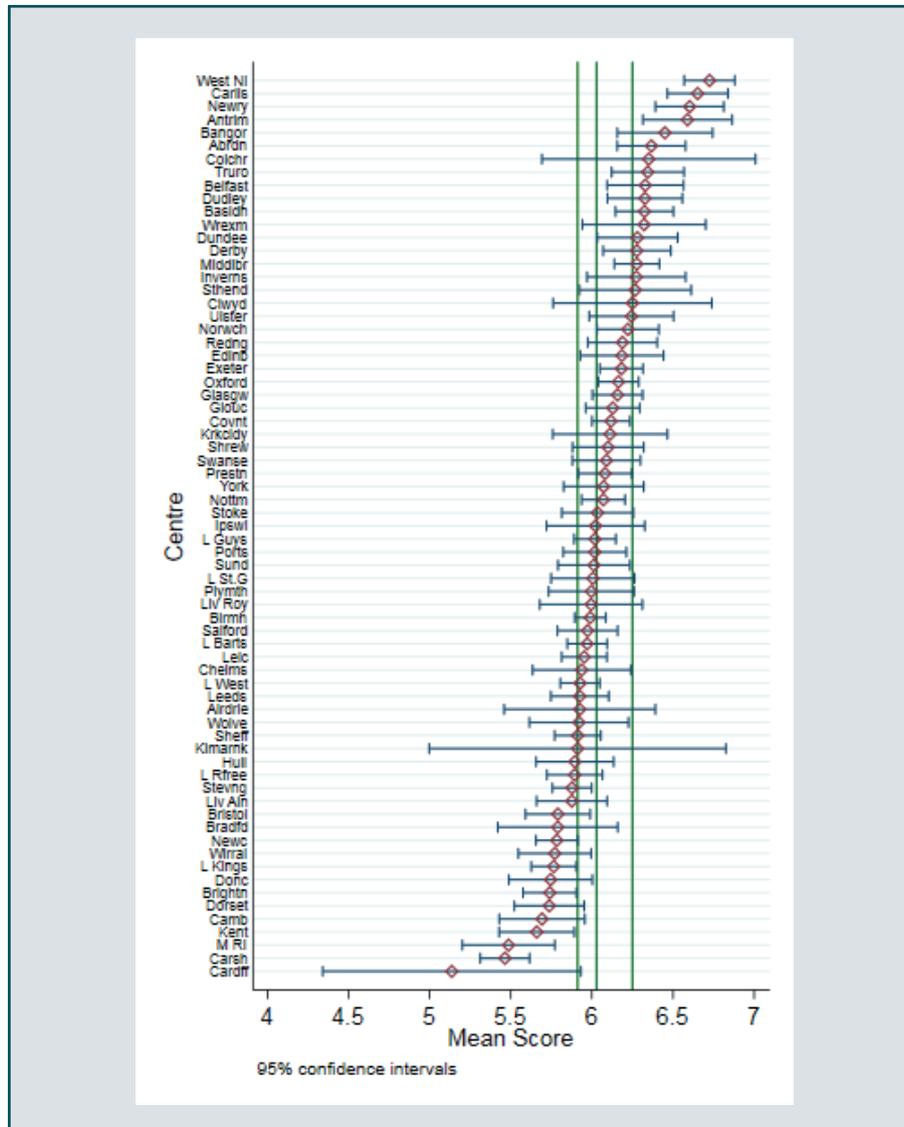
The mean calculated from patient scores for the following items:

Does the renal team:

12. Explain things to you in a way that is easy to understand?

13. Give you as much information about your kidney disease or treatment as you want?

Section 5: Fluid intake and diet



Theme mean calculated from patient scores for the following items:

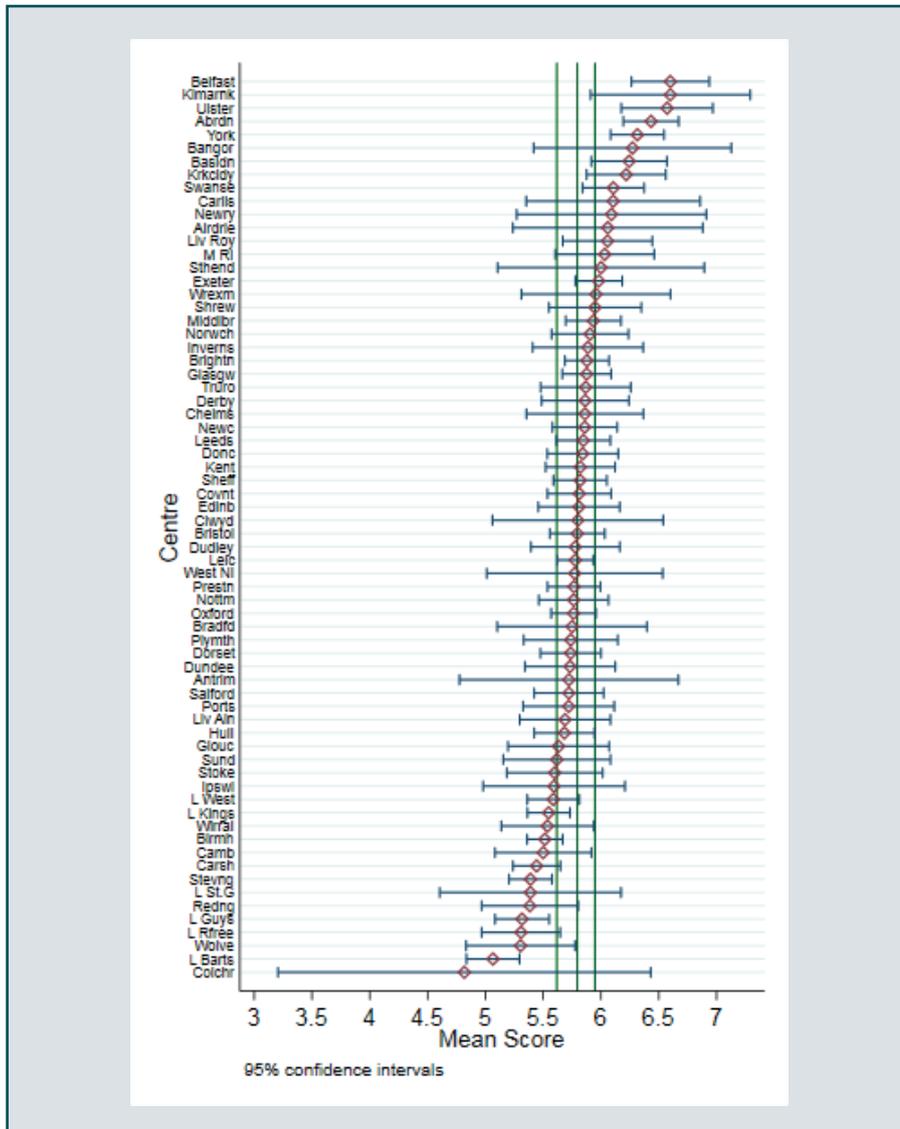
Thinking about the advice you are given about fluid intake:

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

Thinking about the advice you are given about diet:

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

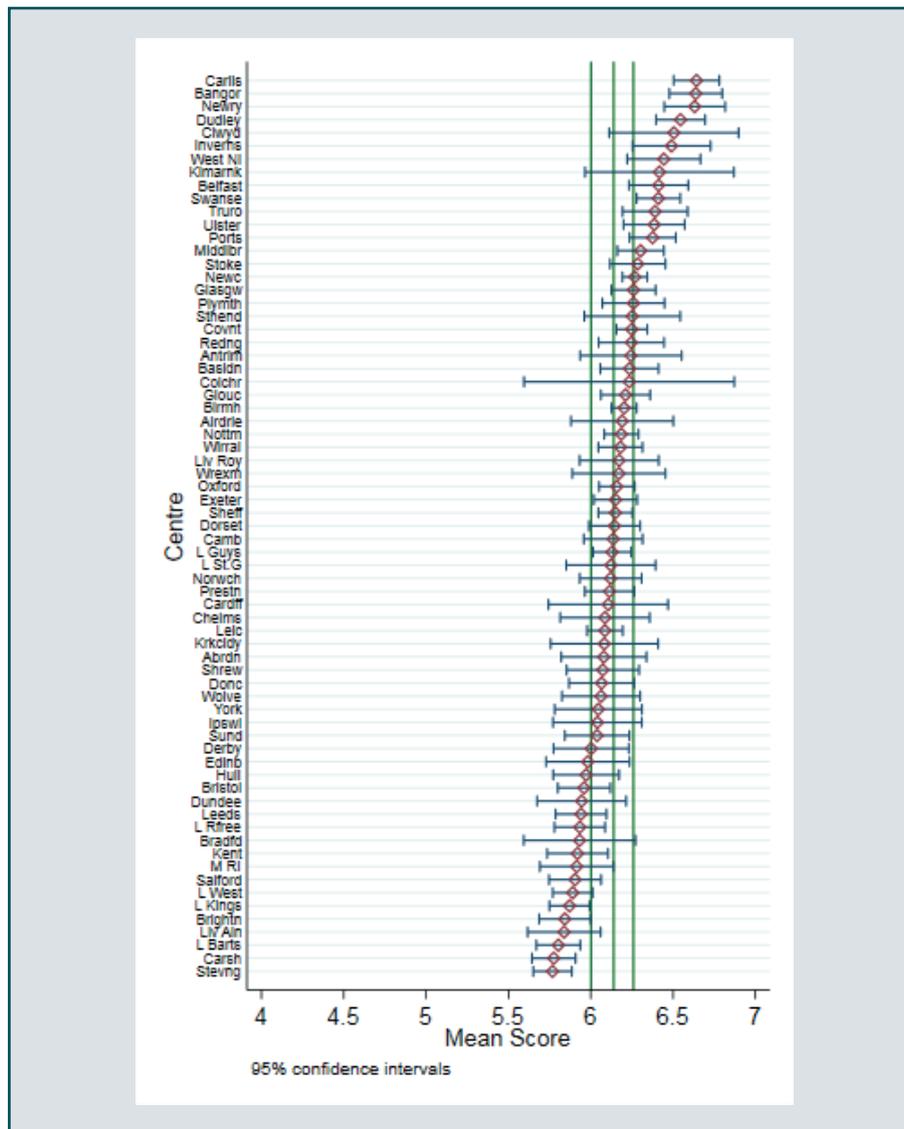
Section 6: Needling



If you are on in-hospital or in-satellite haemodialysis:

16. How often do the renal team insert your needles with as little pain as possible?

Section 7: Tests



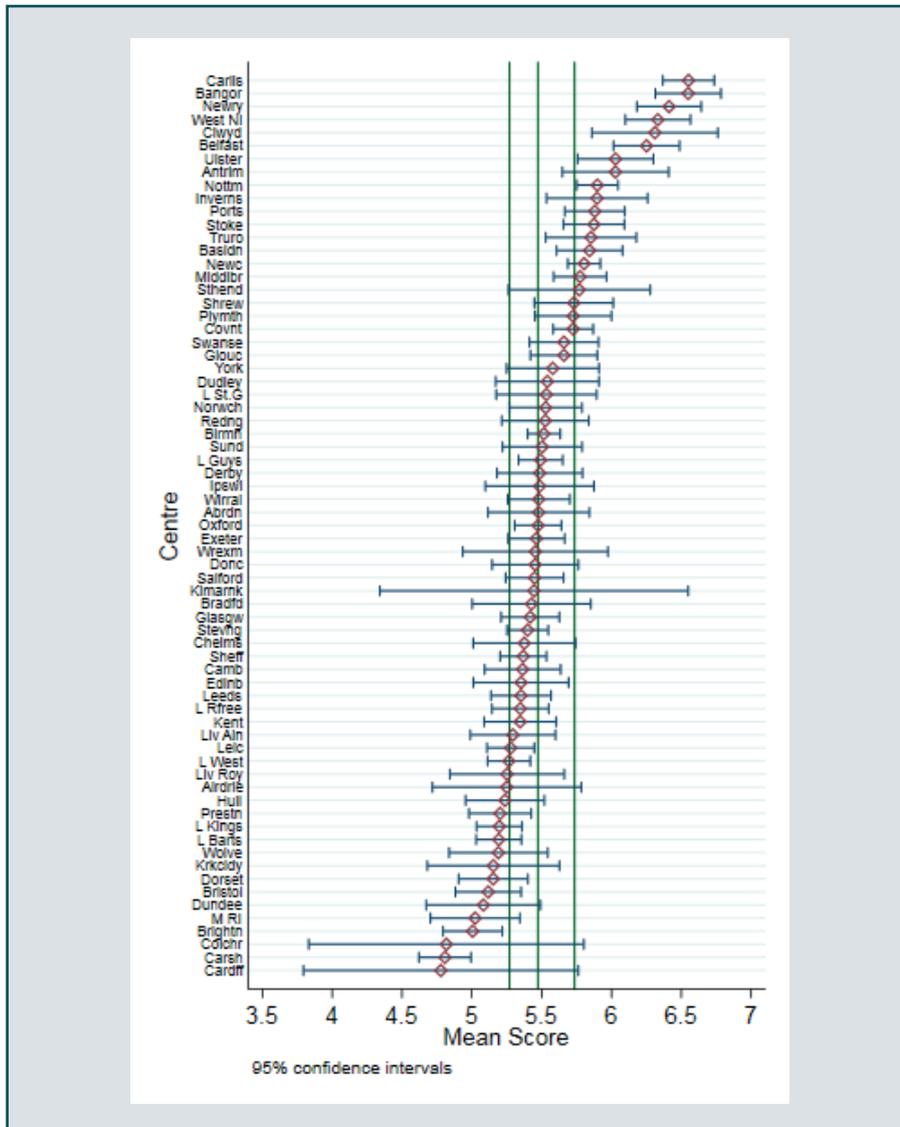
Theme mean calculated from patient scores for the following items:

17. Do you understand the reasons for your tests?

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

19. Do you understand the results of your tests?

Section 8: Sharing decisions about your care



Theme mean calculated from patient scores for the following items:

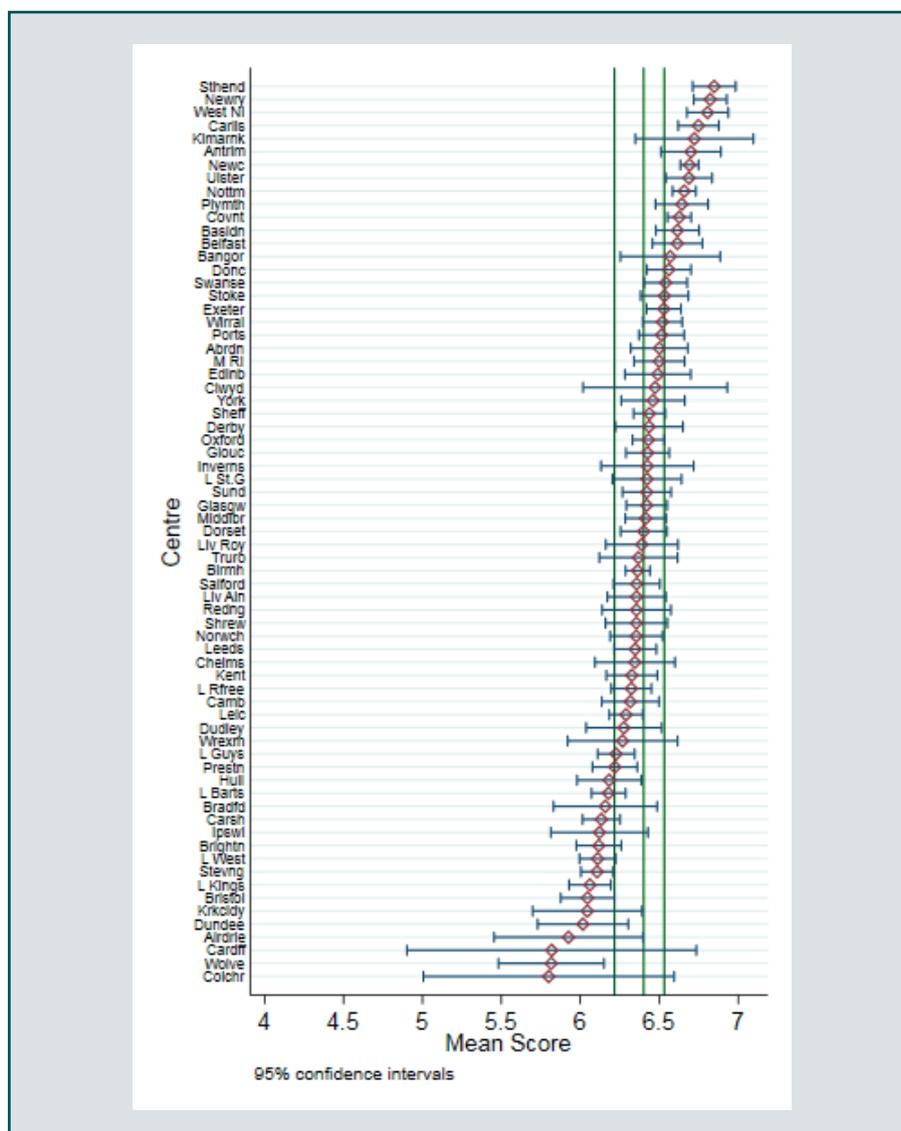
Does the renal team:

20. Talk with you about your treatment and life goals?

21. Enable you to participate in decisions about your kidney care as much as you want?

22. Talk to you about taking a more active role in managing your own kidney care?

Section 9: Privacy and dignity

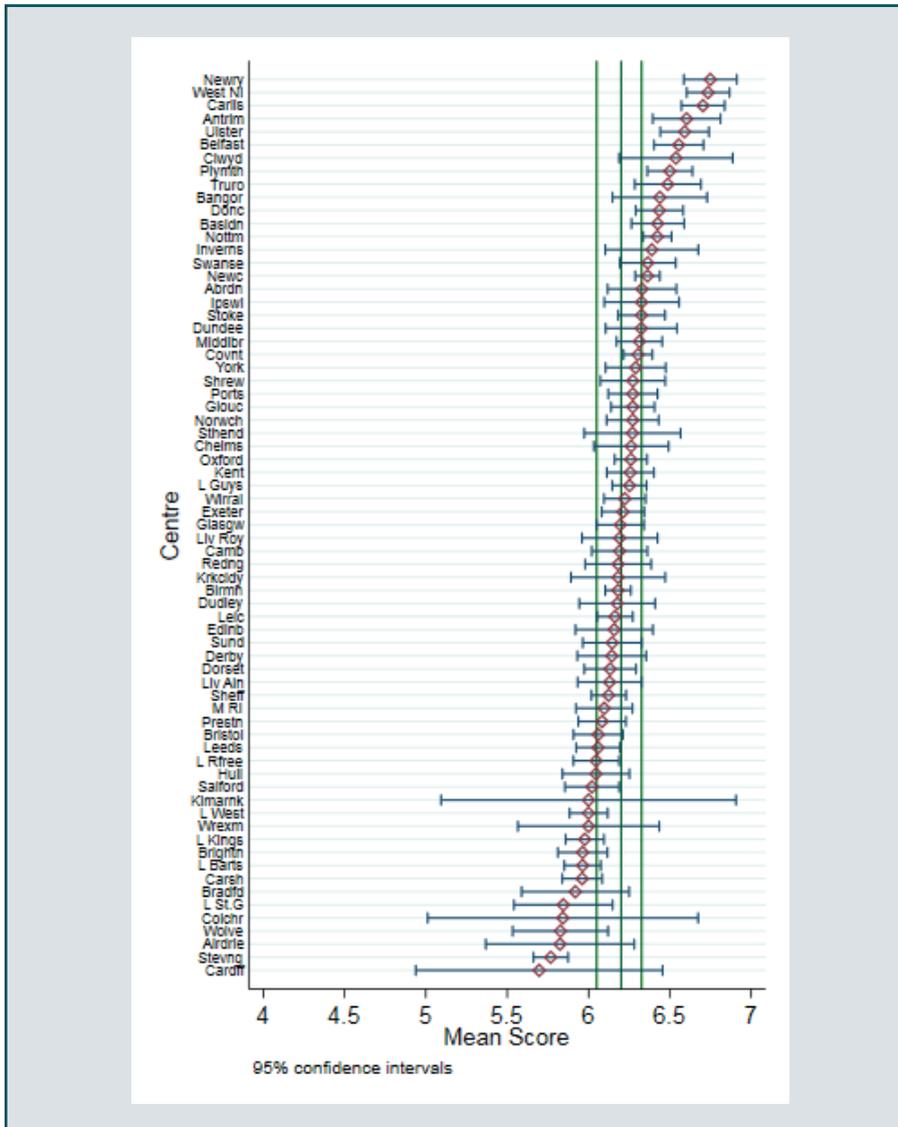


Theme mean calculated from patient scores for the following items:

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

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

Section 10: Scheduling and planning



Theme mean calculated from patient scores for the following items:

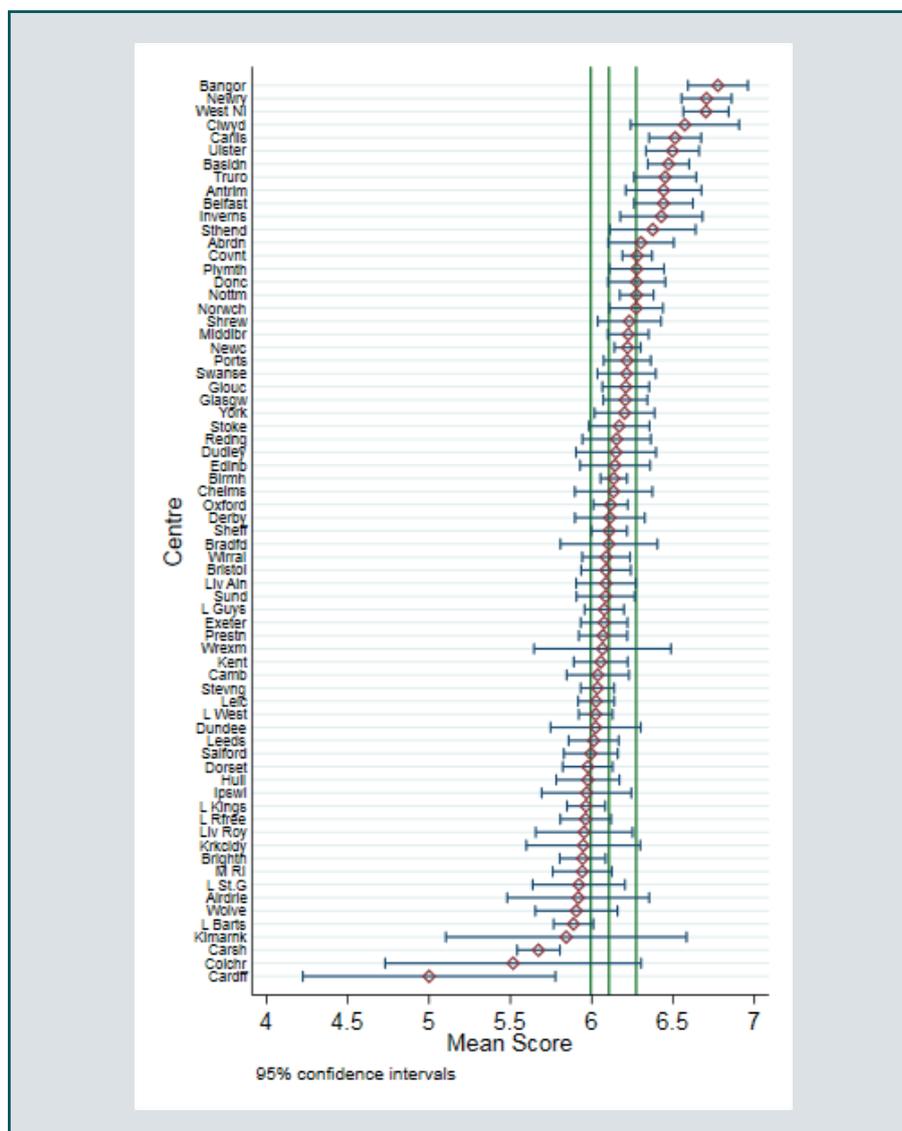
25. Can you change your appointment times if they are not suitable for you?

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

If you have blood tests done at an outpatient clinic or GP surgery:

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

Section 11: How the renal team treats you



Theme mean calculated from patient scores for the following items:

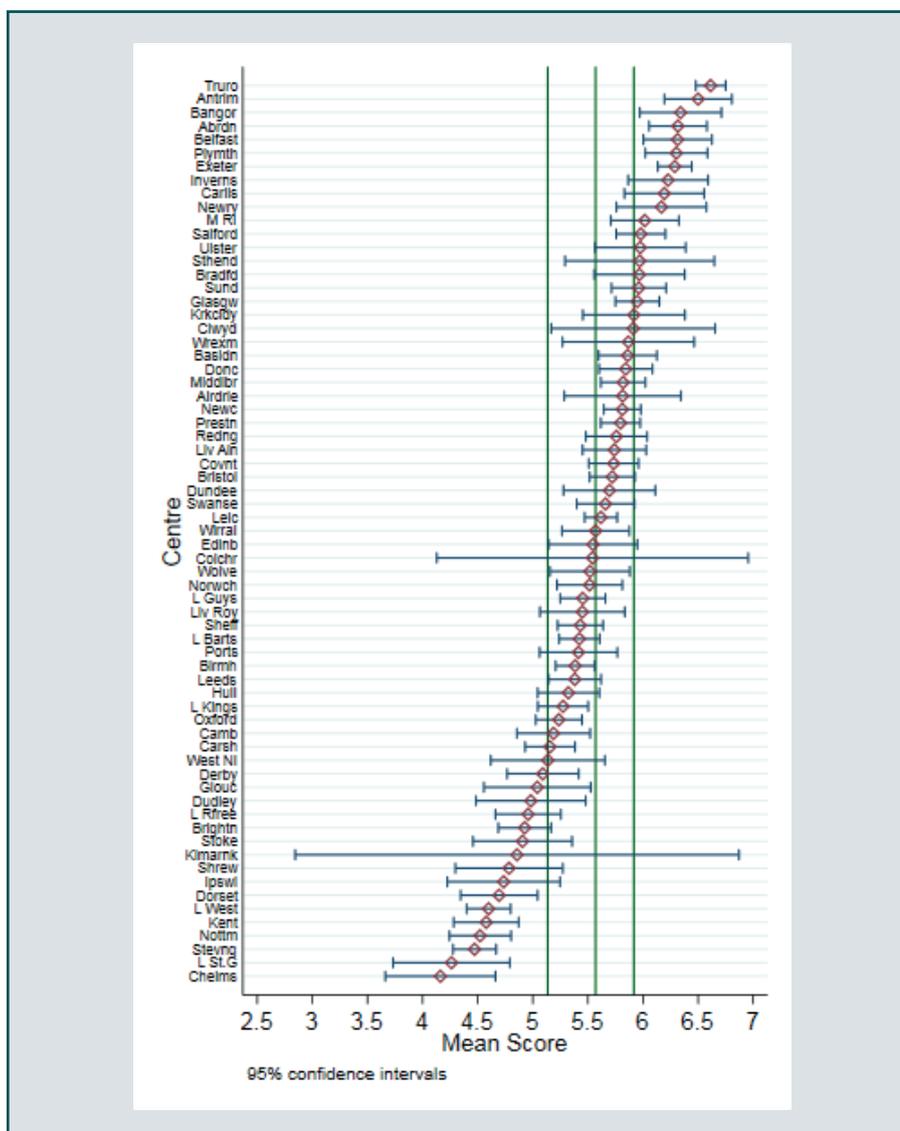
Thinking about how the renal team treats you, do they:

28. Take you seriously?

29. Show a caring attitude towards you?

30. Ask you about your emotional feelings?

Section 12: Transport



The mean calculated from patient scores for the following items:

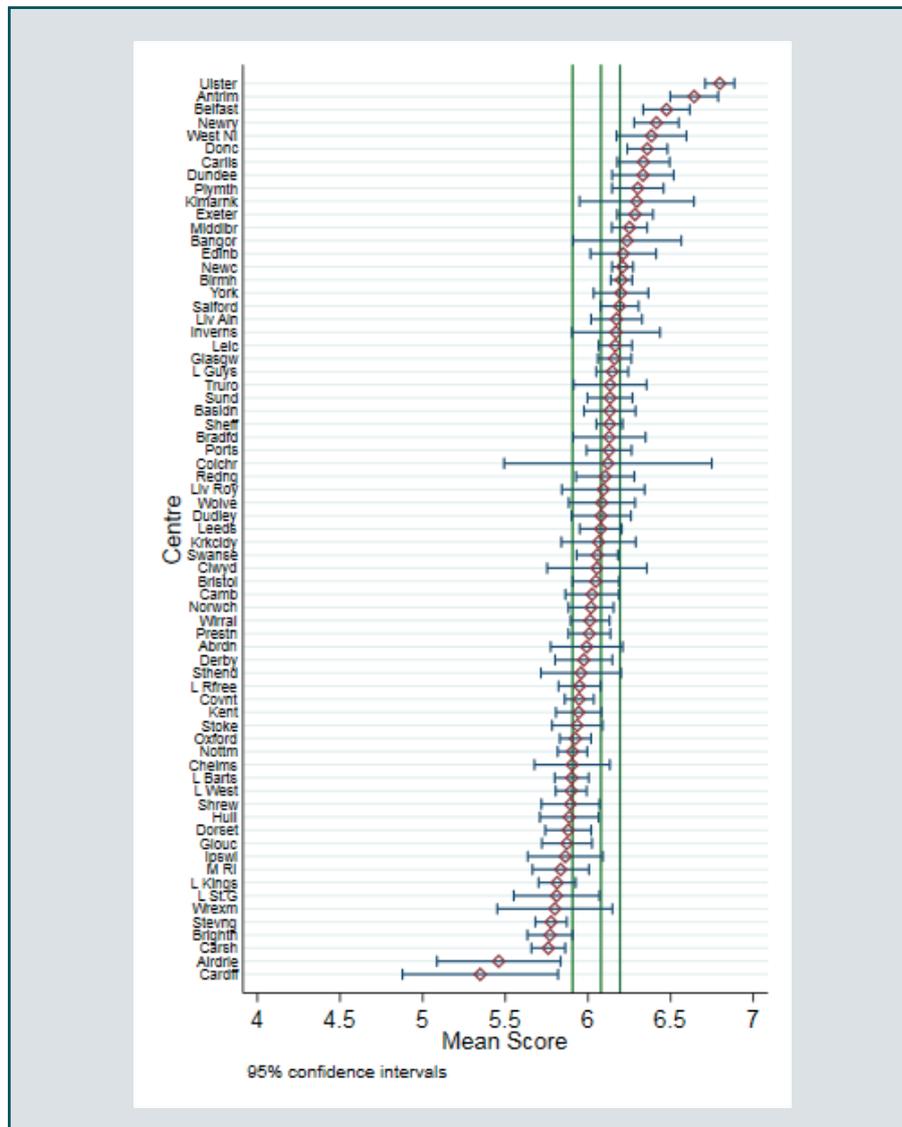
If the renal unit arranges your transport:

31. Is the vehicle provided suitable for you?

32. Is the time it takes to travel between your home and the renal unit acceptable to you?

33. Once your visit to the renal unit is finished and you are ready to leave, are you able to leave within less than 30 minutes?

Section 13: The environment



Theme mean calculated from patient scores for the following items:

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

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

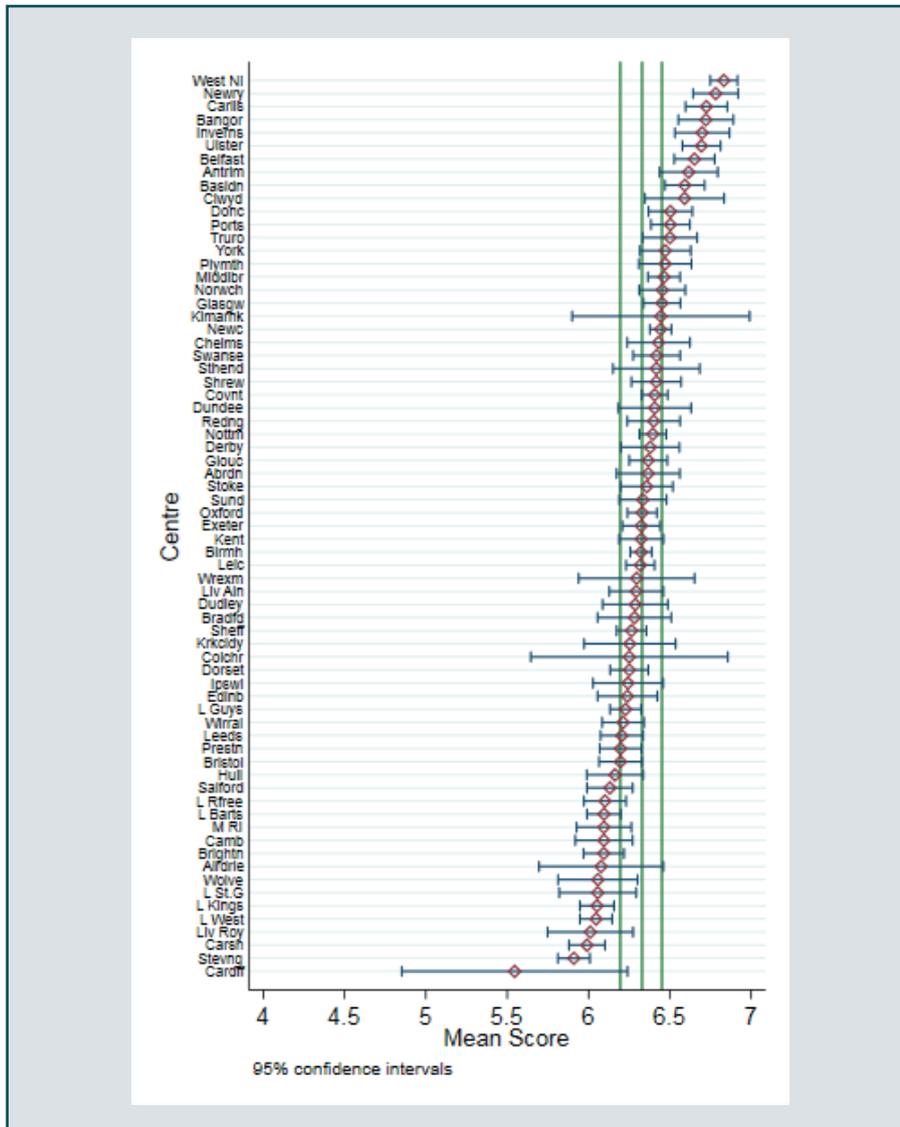
35. Comfort?

36. Cleanliness?

37. Waiting area?

38. Parking?

Section 14: Your overall experience



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)?

Changes to the Kidney PREM from 2018 to 2019

The same Kidney PREM has been used in 2018 and 2019 (see www.renalreg.org/projects/prem/), but some changes were made to the Kidney PREM in 2018 compared to 2017, and more substantial changes were made in 2017 compared to 2016. Some differences were also made in the way that the mean scores for the themes Needling and Scheduling & Planning were estimated in 2019, meaning that for some questions, comparison between 2018 and 2019 may be influenced by this change.

In 2019 there were 2,699 more valid responses than in 2018 (see table 3). In general comparison in scores between the years is possible from 2017 to 2019, but caution must be taken where the number of responses per centre changed from year to year.

Differences between patients and their experience

It remains the case that the single most important feature related to patients' experience is the centre in which the patient is treated. The variation across centres is far more widely marked than for any other feature that is recorded in the PREM survey.

Where the data has been evaluated for all the other patient related characteristics, the differences are present and reliable, but are small by comparison. These include features which have been noted previously in published works, such as age (the youngest patients report experience approximately 0.2 worse than the oldest) and ethnicity (white patients reporting scores of an average of 0.2 better than other ethnic groups). This compares with differences between centres of, for example, 2.5 (for transport), and 1.8 (for needling).

There remains a small group of patients (<800, approximately 4.8% of the dataset) who are unwilling to provide information about their gender or ethnicity and report particularly poor experiences. This group as a whole remain small, at approximately 3% of those with scores, however they may present an opportunity to understand why some patients report a poorer experience than others.

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

Of the 1,218 patients completing Kidney PREM online in English, 508 provided a written comment. Broadly even numbers of men and women responded. More of the patients who provided a comment fell into the younger age groups compared to the overall sample: 34% of respondents aged 55 years or under, 52% aged 56-74 years, and 10% aged over 75 years.

A large proportion of respondents were white (89%; 3% black; 3% Asian; 3% did not say; 1% other). Thirty-nine percent of patients were on dialysis (44% satellite unit; 35% hospital; 12% peritoneal dialysis; 9% home), 35% had received a transplant and 26% were CKD patients.

A mixed inductive and deductive approach to thematic analysis was used. The 14 Kidney PREM themes were used as a starting framework for comments, as were the additional emerging themes identified in the 2018 Kidney PREM report of Continuity of Care, PatientView and Pharmacy. Here we report a summary of comments by theme, which largely mirrors the findings reported in the 2018 report. A full report on the comments from patients on their experience of renal services will be published on The Renal Association website www.renalreg.org/projects/prem.

Access to the renal team: Patients highlighted issues related to difficulty accessing the renal team outside of appointments, lack of information around how to contact the renal team, and the renal team seldom having time to answer patients' questions.

Support: Support was mentioned frequently, with predominantly negative comments. Patients described needing social, emotional, specialist, personalised and treatment-specific support. Lack of emotional or psychological support was highlighted, with several reporting a *'serious lack of emotional support'*.

Communication: Most comments under the theme of Communication related to a perceived lack of communication within the renal team itself, or between the renal team and other medical professionals, and the detrimental effect on patients' care.

Patient information: Patients often reported feeling that they wanted more and/or higher-quality information, particularly at diagnosis or at the start of treatment. Some described having to source information and answers for themselves.

Fluid intake and diet: Most patients who commented on fluid intake and diet said that they had *'never been given dietary or fluid intake advice'* or that the information they had received was poor. There was a desire from patients to receive information and to see a renal dietician where possible.

Needling: Patients commented on the pain of needling, sometimes as a result of poor technique, and staff not using different sites. Comments also alluded to the high turnover of staff and how this caused anxiety relating to needling.

Tests: Many comments about tests related to the delay in getting results. Patients also noted that their most recent blood tests results were sometimes not available to the consultant during their appointment.

Sharing decisions about your care: Some patients reported that treatment decisions were a *'one way conversation'*, and although they wanted to be more actively involved, they were not asked about managing their own condition.

Privacy and dignity: Only a small number of patients referred to privacy and dignity. Those that did, spoke about lack of privacy during appointments.

Scheduling and planning: Issues commonly reported under this theme were waiting times in clinics, waiting for their dialysis session to start, timing of blood tests, travelling to different sites and a lack of flexibility with appointments.

How the renal team treats you: Many patients commented on this theme, both positively and negatively. Many patients praised staff, reporting that they felt *'cared about'* and that *'nothing was too much trouble for them.'* One patient stated that despite being *'overburdened'* the staff were *'brilliant'*. In contrast, many patients commented that they were never taken seriously and that there was inadequate staffing. Patients felt that staff were so busy, this often led to appointments being rushed or running late, e.g. *'Because of the shortages of staff, nurses have to rush and mistakes are made.'*

Transport: Transport was a big concern for many patients and had a real impact on their lives. Comments related to the waiting times and availability of suitable transport.

The environment: Parking was a strong sub-theme, with comments around lack of availability and the high costs. Patients also commented on uncomfortable facilities (chairs, beds and pillows) and temperature.

Overall experience: There were a considerable number of positive responses within this theme. Patients commented on how *'wonderful'* the staff are and how *'fantastic'* their treatment and care are.

Continuity of care: There was a lot of concern from patients around inconsistency of care, including being seen by a different member of the renal team at each visit, inconsistent advice, lack of continuity between different trusts and issues with transitions from child to adult services.

PatientView: Generally, PatientView was well reviewed, with a number of patients reporting that they found it *'useful'* and *'very helpful.'* However, some patients would have liked more detail about their blood test results and noted that PatientView was not always updated in time for appointments.

Pharmacy issues: Many patients reported that changing medication or collecting a prescription was challenging, time-consuming and involved travelling to a hospital pharmacy, rather than collection from local pharmacies.

Suggestions for improvements: Some patients also provided suggestions for improvements to care. These were varied and included improvements in the dialysis environment, the option for telephone or Skype appointments, and a desire for more holistic care, including support for emotional and psychological well-being.

What's next?

The Kidney PREM provides a unique source of data which has been recognised and used throughout the renal community as the international drive for person-centred outcome data across the healthcare system gains momentum. The Kidney PREM dataset has been included in the national renal Getting it Right First Time programme, within the Kidney Quality Improvement Programme, as well as within local trust audit meetings, service reviews and governance settings. It is now being reported alongside the bio-medical data via the UK Renal Registry's online data portal.

International interest in the UK Kidney PREM has come from countries such as Canada, Jordan, Malaysia and New Zealand. People have got in touch and are keen to collaborate, share ideas and learn from each other. The UK Kidney community should be proud to be a part of this international work towards better understanding and improving patient experience.

Better understanding the results of the Kidney PREM

That being said, there are many questions that the Kidney PREM throws up, and things that we still do not understand. Just some of the questions we are thinking about as a Kidney PREM working group include:

- What is behind the 'centre effect'? What is it about a centre that causes it to have the biggest impact on patient experience over any of the other variables collected?
- Does the Kidney PREM result in an improvement in patient experience? If so, can this improvement be translated to different settings?
- Could we get information from the Kidney PREM that is just as rich by sampling the patient population – or do more responses equal better data?
- How can we engage better with people who have received a transplant, or who have chronic kidney disease but are not on a renal replacement therapy or transplanted?

We do not want the Kidney PREM to stand still. Through research projects, consultation and our own quality improvement, we hope the data and response to the Kidney PREM will continue to evolve so that it is meaningful, embedded across the system, and improves the experience of people living with Kidney disease and those who care for them in the UK.

Acting on the results of the Kidney PREM

Our vision of the Kidney PREM is that it is used as a driver for change. We know the top-level scores are not the full story and that improvement, particularly around the three lower scoring themes - shared decision making, transport and needling - is complicated. There are no silver bullets or easy answers, however, there are some centres who are getting it right and we would like to better understand why this is and what they are doing that could be shared.

We also recognise that many centres and local units have been working hard to review and discuss their local data, and act to improve people's experience of kidney care across these themes. To show measurable improvement takes time, and we are keen to share stories of improvement-work inspired by the Kidney PREM from across the kidney community from all centres, regardless of the Kidney PREM results.

The University of Hertfordshire will shortly be undertaking a study investigating whether Kidney PREM inspired, small-scale quality improvement work is associated with meaningful improvement in kidney patient experience. From January 2020, renal units from across the UK will be invited to complete a short survey on their Kidney PREM results and quality improvement work, with some also participating in follow up qualitative interviews. This study will produce case studies of good practice, with the aim that centres can learn from each other how improvements based on Kidney PREM patient experience data can be made.

"I picked up the kidney PREM because I am interested in making improvements for my health on dialysis. It is only patients themselves who can speak for what treatment they are getting - taking part means you can express your feeling, emotions and opinion.

For me, just a few simple changes would make a difference, for example, a definite start time for dialysis patients in the mornings with a rota system that patients could understand. This would empower patients as they would know what was going on, rather than sitting in a waiting room being puzzled as to what time you will be treated.

Transport home within half an hour would also make all the difference. As a dialysis patient coming off the machine, I often have cramp in my hands, legs and feet and my neck, shoulder and back are stiff and sore. The last thing you need is to have to wait one and a half hours for transport home as you are exhausted and tired with a nine hour day.

I hope the results of the PREM are acted on by the renal team and that they and the patients make changes or improvements to make life better for people on dialysis."

Ann, Dialysis patient

Case study

Using the Kidney PREM to improve the experience of transport provision for haemodialysis patients at Kings College hospital

Helen Cronin- Matron for satellite services, Kings College Hospital

I meet with patients regularly at the satellite units and keep them updated on transport developments whilst addressing any individual issues they may have; it is the main area of concern for most patients and is an ongoing agenda item at our patient forum meetings.

When the Kidney PREM results came out for 2018, we shared the results locally at these patient meetings. We also discussed it at our dialysis Quality Improvement, Renal Care Group and Performance meetings where transport is always a key agenda item.

With the support of one of our haemodialysis consultants, who is also Corporate Medical Director for Quality, Governance and Risk, we presented renal transport updates at the Trust Patient Experience and Patient Safety Committees throughout the year. We had helpful steers from the Trust Governors. We work together at addressing transport provision and this joint working has played a huge part in the success of this project.

What we did

Firstly, we set up monthly meetings with the transport providers in July 2018, ensuring patient experience and performance data was top of the agenda and created an ongoing action tracker to capture activity and progress. The transport companies provided the data to review monthly.

We then rolled out clear escalation policies for each transport company and ensured that both transport providers met with relevant patient groups on a rolling basis to hear feedback and discuss plans for quality improvement.

Joining the South London Renal Operational Delivery Network for transport provided the opportunity to swap patients with Guy's and St Thomas' and improved patient journeys by enabling patients to dialyse closer to home.

There was a fresh focus on Cleric training (transport booking system) and engagement and we set up a system that allowed us to capture weekly data on transport issues from each unit.

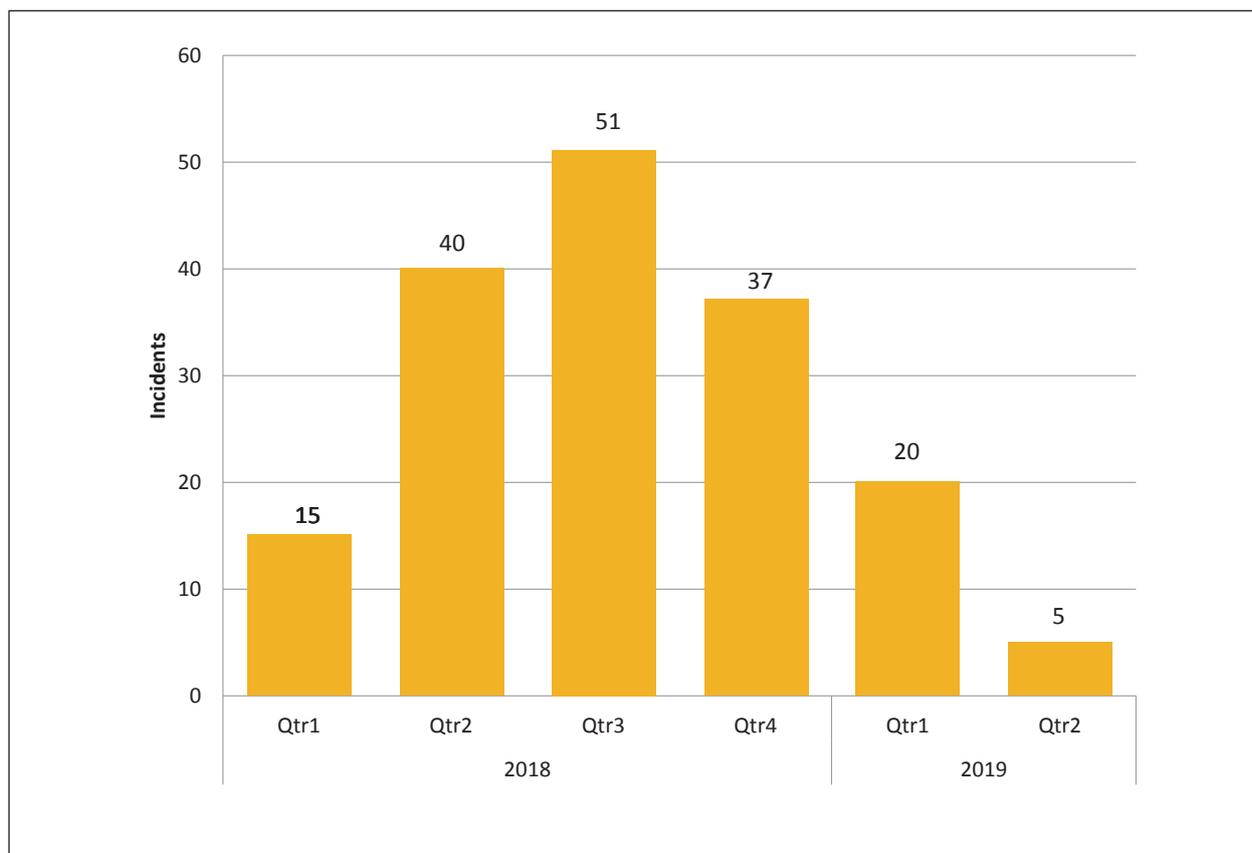
We created transport champions at each of our units and some of these staff members have excelled in their roles and have received recognition from the trust for their contribution to transport provision.

We undertook a large mapping exercise and focused on improved patient placement by identifying patients with transport challenges and giving them the opportunity to dialyse in a unit closer to where they lived.

We tracked adverse incident and complaint rates, including time to respond. We created flow diagrams of how both would be managed between Trust and provider.

We obtained line by line lists of escort-requiring patients and aborted journeys, to maximise efficiency and reduce unnecessary wasted journeys.

Figure 4: Renal transport adverse Incidents at Kings College Hospital, Jan 2018 - May 2019



The outcome

We managed to significantly reduce adverse incidents related to transport, as shown in the table above, and we work much more closely with Transport providers. We have reached a point where we can review individual patient journeys and work proactively at improving those that are problematic. Overall, we have improved the transport experience considerably from where it was when we set out on our journey in 2018.

Whilst we appreciate that this work is an ongoing project; the work to date has been a real team effort and we feel proud of what we have achieved for our patients.

Further information

A comprehensive kidney patient transport guidance report was launched in June 2019 – to find out more and to read the full document, go to www.kidneycareuk.org/transport.

Acknowledgements

The Renal Association and Kidney Care UK would like to thank the following people, without whom PREM 2019 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;
- The members of the Kidney PREM working group;
- The 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,
- The University of Hertfordshire who analysed the PREM 2019 data and led the production of this report.

Appendix A: Unit abbreviations and response rates

Numbers in brackets in the “Unit/Satellite Location” 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 Abbreviation” column show the number of completed Kidney 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 are not identified in the unit level data but are included in the centre level data.

Table A1: English Centres

Main Centre	Unit / Satellite Location	Centre abbreviation
Basildon Hospital	Basildon - Main Unit (171) Orsett (40)	Basldn (211)
Birmingham*	Aston Cross (47) Balsall Heath (15) Birmingham Heartlands - Main Unit (30) Birmingham Queen Elizabeth - Main Unit (309) Castle Vale (60) Great Bridge (38) Hereford (52) Kings Norton (28) Llandridod Wells (10) Redditch (32) Smethwick (77) Sparkhill (82) Woodgate Valley (40) Worcester (67)	Birmh (890)
Bradford	Bradford - Main Unit (53) Skipton (33)	Bradfd (86)
Brighton	Bexhill (27) Brighton - Main Unit (180) Crawley (24) Eastbourne (57) Worthing (50)	Brightn (338)

Main Centre	Unit / Satellite Location	Centre abbreviation
Bristol*	Bath (37) Bristol - Main Unit (82) Cossham (49) South Bristol (52) Weston-super-Mare (42)	Bristol (270)
Cambridge*	Cambridge - Main Unit (131) Hinchingsbrooke (28) Kings Lynn (32)	Camb (192)
Carlisle*	Carlisle - Main Unit (130)	Carlis (135)
Carshalton*	Carshalton - Main Unit (124) Crawley (41) Croydon (34) Epsom (37) Farnborough (41) Kingston (22) Purley (47) Sutton (50) West Byfleet (61)	Carsh (459)
Chelmsford	Chelmsford - Main Unit (101)	Chelms (101)
Colchester*	Colchester - Main Unit (16)	Colchr (20)
Coventry	Clay Lane (21) Coventry - Main Unit (430) Nuneaton (30) Rugby (37) Stratford (30) Whitnash (20)	Covnt (568)
Derby	Derby - Main Unit (153)	Derby (153)
Doncaster	Bassetlaw (34) Dearne Valley (31) Doncaster - Main Unit (117)	Donc (182)
Dorset	Bournemouth (41) Dorset - Main Unit (90) Poole (82) Yeovil (23)	Dorset (236)
Dudley*	Dudley - Main Unit (78) Tipton (33)	Dudley (113)

Main Centre	Unit / Satellite Location	Centre abbreviation
Exeter	Barnstaple (39) Exeter - Main Unit (127) Heavitree (60) Honiton (29) South Devon (Torquay) (54) Taunton (22)	Exeter (331)
Gloucester	Gloucester - Main Unit (182) Severn (41)	Glouc (223)
Hull	Bridlington (14) Grimsby (55) Hull - Main Unit (69) Scunthorpe (42)	Hull (180)
Ipswich*	Ipswich - Main Unit (98)	Ipswi (104)
Kent*	Kent - Main Unit (109) Dover (23) Maidstone (57) Margate (13) William Harvey (22)	Kent (225)
Leeds	Beeston (18) Calderdale (26) Dewsbury (29) Huddersfield (48) Leeds - Main Unit (90) Pontefract (29) Seacroft - R & S (62) Seacroft - Ward B (24)	Leeds (326)
Leicester	Boston (33) Chandra Mistry (29) Grantham (23) Hamilton (57) Kettering (84) Leicester - Main Unit (82) Lincoln (37) Loughborough (56) Northampton (52) Peterborough (44) Skegness (17)	Leic (514)

Main Centre	Unit / Satellite Location	Centre abbreviation
Liverpool Aintree*	Liverpool Aintree - Main Unit (106) Southport (50) Waterloo (32)	Liv Ain (192)
Liverpool Royal*	Broadgreen (15) Liverpool Royal - Main Unit (27) St Helens (35) Warrington (11)	Liv Roy (96)
London Barts	King George (43) London - Main Unit (318) Newham (60) Queen's Hospital (61) Whipps Cross (39)	L Barts (521)
London Guys	Borough (55) Camberwell (72) Lewisham Dialysis Centre (30) London - Main Unit (164) New Cross Gate (69) Sidcup (53) Tunbridge Wells (50)	L Guys (493)
London Kings*	Bromley (32) Dartford (55) Dulwich (44) London - Main Unit (175) Sydenham (76) Thamesmead (64) Woolwich (33)	L Kings (480)
London Royal Free	Barnet (32) Edgware (40) London - Main Unit (48) Mary Rankin / St Pancras (139) Tottenham Hale (65)	L Rfree (324)
London St George's	Colliers Wood (23) London St George's - Main Unit (69) North Wandsworth (21)	L St.G (113)

Main Centre	Unit / Satellite Location	Centre abbreviation
London West*	Central Middlesex (83) Charing Cross (17) Ealing (52) Hammersmith (114) Hayes (25) Ladbroke Grove (126) Northwick Park (77) Watford (60) West Middlesex (49)	L West (606)
Manchester*	Macclesfield (39) Manchester - Main Unit (96) Stockport (11) Tameside (34)	M RI (188)
Middlesbrough	Darlington (52) Middlesbrough - Main Unit (89) North Ormesby (50) Stockton (62)	Middlbr (253)
Newcastle	Alnwick (19) Newcastle - Main Unit (800) North Tyneside (38) Team Valley (13)	Newc (870)
Norwich	Cromer (28) James Paget (57) Norwich - Main Unit (101)	Norwch (186)
Nottingham	Ilkeston (21) Kings Mill (50) Lings Bar (24) Nottingham - Main Unit (428)	Nottm (523)
Oxford	Aylesbury (62) Horton (25) Milton Keynes (79) Oxford - Main Unit (186) Swindon (67) Wycombe (48)	Oxford (467)
Plymouth*	Launceston (10) Plymouth - Main Unit (148)	Plymth (171)

Main Centre	Unit / Satellite Location	Centre abbreviation
Portsmouth*	Basingstoke (10) Bognor Regis (37) Chandler's Ford (44) Portsmouth - Main Unit (80)	Ports (187)
Preston	Accrington Victoria (36) Blackburn (25) Burnley (33) Chorley & District (47) Clifton (53) Preston - Main Unit (91) Westmorland General (39)	Prestn (324)
Reading	Bracknell (16) Reading - Main Unit (98) Windsor (37)	Redng (151)
Salford	Bolton (54) Oldham (22) Rochdale (16) Salford - Main Unit (149) Wigan (50)	Salford (291)
Sheffield	Barnsley (25) Chesterfield (50) Heeley (48) Rotherham (49) Sheffield - Main Unit (328) Sheffield - Peter Moorhead (58)	Sheff (558)
Shrewsbury	Shrewsbury - Main Unit (119) Telford (39)	Shrew (158)
Southend	Southend - Main Unit (56)	Sthend (56)
Stevenage	Bedford (73) Harlow (151) Luton & Dunstable (23) St Albans City (56) Stevenage - Main Unit (179)	Stevng (482)
Stoke	County Hospital (22) Crewe (85) Stoke - Main Unit (102)	Stoke (209)

Main Centre	Unit / Satellite Location	Centre abbreviation
Sunderland	Durham Dryburn (36) Sunderland - Main Unit (119) Washington (41)	Sund (196)
Truro	Aubrey Williams (27) Bodmin (28) Truro - Main Unit (58)	Truro (113)
Wirral	Chester (96) Clatterbridge (138) Wirral - Main Unit (51)	Wirral (285)
Wolverhampton*	Cannock (28) Walsall (53) Wolverhampton - Main Unit (28)	Wolve (115)
York	Easingwold (33) Harrogate (39) Scarborough (19) York - Main Unit (49)	York (140)

Table A2: NI Centres

Main Centre	Unit / Satellite Location	Centre abbreviation
Antrim	Main Unit (70)	Antrim (70)
Belfast	Main Unit (147)	Belfast (147)
Newry	Main Unit (112)	Newry (112)
Ulster	Main Unit (168)	Ulster (168)
Western Trust*	Main Unit (108)	West NI (109)

Table A3: Welsh Centres

Main Centre	Unit / Satellite Location	Centre abbreviation
Bangor*	Bangor - Main Unit (38)	Bangor (45)
Cardiff*	Cardiff - Main Unit (14)	Cardff (23)
Clwyd	Clwyd - Main Unit (42)	Clwyd (42)
Swansea*	Swansea - Main Unit (147) West Wales (34) Withybush (21)	Swanse (210)
Wrexham	Welshpool (15) Wrexham - Main Unit (30)	Wrexm (45)

Table A4: Scottish Centres

Main Centre	Unit / Satellite Location	Centre abbreviation
Aberdeen*	Banff (11) Elgin (12) Inverurie (15) Aberdeen - Main Unit (41) Peterhead (16)	Abrdn (108)
Airdrie	Airdrie - Main Unit (43)	Airdrie (43)
Dumfries and Galloway*		D&Gall (4)
Dundee*	Dundee - Main Unit (53) Perth (34)	Dundee (96)
Edinburgh*	Borders General (24) Edinburgh - Main Unit (94)	Edinb (120)
Glasgow	Forth Valley (60) Glasgow Royal Infirmary (36) Inverclyde (24) Main Unit (64) Stobhill (63) Vale of Leven (27) Victoria (39)	Glasgw (313)
Inverness*	Inverness - Main Unit (38)	Inverns (60)
Kirkcaldy	Kirkcaldy - Main Unit (39) Queen Margaret (38) St Andrews (12)	Krkldy (89)
Kilmarnock*	Ayr (13)	Klmarnk (19)

Appendix B: Proportion of Kidney PREM responses for each treatment group by centre

Tables B1-B5 below display the number of Kidney PREM responses received as a proportion of those patients registered at each centre for each treatment group. The UK Renal Registry only holds data for those patients who have received a transplant, or who are treated with dialysis, so all others have been excluded. The Kidney PREM data was collected over the summer of 2019, whereas the UK Renal Registry patient numbers were recorded at the end of 2017. To account for this, patient numbers were increased by 2.5%, the expected increase each year.

In a survey of this type, 10-30% response is generally expected, so response levels above 30% are remarkable and below 10% are low. The higher rate of return for haemodialysis patients is presumably because of their frequent attendance at clinic in comparison with people on peritoneal dialysis or who have received a transplant.

Caution should be used when interpreting statistics where the absolute number of responses is less than 20 within any particular group, unless the centre is small such that the sample is less than one fifth of the patients in that centre.

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	142	79.2%	13	45.3%	21	20.9%	176	57.0%
Birmh	534	37.1%	41	16.0%	169	10.8%	744	22.8%
Bradfd	52	18.2%	8	39.0%	14	3.6%	74	10.7%
Brightn	254	53.3%	41	67.8%	11	2.2%	306	29.5%
Bristol	211	40.4%	8	13.7%	21	2.3%	240	15.9%
Camb	107	30.2%	5	15.7%	31	2.9%	143	9.8%
Carlis	39	38.8%	20	69.7%	47	29.6%	106	36.8%
Carsh	375	42.1%	54	54.9%	12	1.6%	441	25.6%
Chelms	56	41.7%	10	27.9%	10	8.3%	76	26.2%
Colchr ⁷	15	11.5%	3				18	13.8%
Covnt	184	52.3%	44	82.6%	69	11.9%	297	30.1%
Derby	96	38.5%	29	35.8%	7	2.9%	132	23.2%
Donc	102	53.2%	21	70.6%	26	21.7%	149	43.7%
Dorset	136	43.6%	25	69.7%	31	7.7%	192	25.5%
Dudley	73	32.8%	17	30.2%	13	13.2%	103	27.3%
Exeter	208	43.5%	43	55.9%	47	9.0%	298	27.6%
Glouc	76	29.9%	21	45.5%	21	9.7%	118	22.8%
Hull	119	32.8%	18	31.4%	21	4.4%	158	17.7%
Ipswi	56	35.5%	8	17.3%	25	10.5%	89	20.1%
Kent	144	31.6%	20	37.5%	22	3.6%	186	16.6%

Renal Unit	Haemodialysis		Peritoneal Dialysis		Transplant		Total	
	N	Proportion (%)	N	Proportion (%)	N	Proportion (%)	N	Proportion (%)
L Barts	395	36.4%	16	6.6%	43	3.5%	454	17.7%
L Guys	272	37.5%	22	55.0%	87	6.0%	381	17.2%
L Kings	337	55.6%	37	37.2%	37	7.9%	411	35.0%
L Rfree	148	20.6%	23	15.5%	30	2.2%	201	8.9%
L St.G	33	10.0%	6	15.8%	23	4.6%	62	7.2%
L West	509	34.0%	4	3.2%	68	3.5%	581	16.2%
Leeds	210	36.5%	31	52.1%	35	3.4%	276	16.6%
Leic	418	42.0%	13	13.1%	39	2.9%	470	19.3%
Liv Ain	102	55.3%	20	88.7%	10	69.7%	132	59.6%
Liv Roy	75	18.5%	1	1.4%	12	1.5%	88	6.8%
M RI	71	12.0%	6	8.4%	43	3.0%	120	5.7%
Middlbr	197	56.9%	16	74.3%	21	3.8%	234	25.4%
Newc	235	65.9%	39	64.5%	240	32.9%	514	44.9%
Norwch	120	37.0%	29	65.8%	19	4.4%	168	21.1%
Nottm	145	36.6%	40	55.7%	109	14.8%	294	24.4%
Oxford	293	61.1%	33	48.1%	60	4.4%	386	20.1%
Plymth	54	34.7%	20	39.8%	28	8.1%	102	18.4%
Ports	112	17.9%	30	34.8%	29	2.7%	171	9.6%
Prestn	235	40.5%	19	54.5%	29	4.2%	283	21.8%
Redng	85	26.9%	6	15.0%	41	8.9%	132	16.2%
Salford	189	43.1%	50	41.7%	23	3.9%	262	22.9%
Sheff	297	48.4%	21	37.3%	78	9.7%	396	26.8%
Shrew	80	37.9%	24	55.7%	18	13.7%	122	31.7%
Stevng	379	74.5%	35	148.5%	29	7.4%	443	48.0%
Sthend	9	7.2%	6	17.2%	10	10.2%	25	9.7%
Stoke	71	20.9%	18	24.1%	55	13.2%	144	17.3%
Sund	102	37.7%	13	79.3%	46	17.2%	161	29.0%
Truro	76	43.9%	14	91.1%	11	4.5%	101	23.3%
Wirral	75	34.5%	17	87.3%	36	22.5%	128	32.3%
Wolve	78	22.8%	8	14.5%	16	8.1%	102	17.1%
York	129	64.2%	2	5.6%	8	2.4%	139	24.5%

⁷ No peritoneal patients recorded at Colchester

Table B2: 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	46	37.1%	5	34.8%	10	8.6%	61	24.0%
Belfast	55	28.5%	8	45.9%	34	5.2%	97	11.2%
Newry	43	52.4%	11	46.7%	12	8.5%	66	26.7%
Ulster	43	38.1%	5	81.3%	13	18.7%	61	32.3%
West NI	41	34.5%	8	86.7%	16	8.3%	65	20.3%

Table B3: 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	19	22.1%	1	5.7%	7	7.3%	27	13.6%
Cardff	9	1.6%	1	1.4%	6	0.6%	16	0.9%
Clwyd	18	23.7%	7	56.9%	7	7.2%	32	17.2%
Swanse	126	32.2%	24	31.6%	28	8.2%	178	22.0%
Wrexm	30	24.0%	1	3.6%	9	5.2%	40	12.2%

Table B4: 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 (%)
Abrdn	89	38.3%			7	2.2%	96	16.6%
Airdrie	26	13.1%	1	6.1%	6	2.3%	33	6.9%
D&Gall	1	1.8%			2	2.6%	3	2.2%
Dundee	93	48.0%			2	0.8%	95	21.1%
Edinb	89	27.4%	3	8.6%	13	2.6%	105	12.2%
Glasgw	230	38.1%	16	32.5%	29	2.5%	275	15.1%
Inverns	58	64.3%			2	1.2%	60	22.3%
Klmarnk	15	9.5%			2	1.2%	17	4.9%
Krkldy	68	47.4%	3	29.3%	12	7.9%	83	27.1%

Table B5: 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	8510	37.8%	1068	33.7%	1951	6.4%	11529	20.5%
N Ireland	228	36.2%	37	51.6%	85	7.2%	350	18.7%
Wales	202	16.0%	34	16.3%	57	3.2%	293	9.0%
Scotland	669	33.4%	23	11.9%	75	2.5%	767	14.6%
Unknown	9		4		15		28	
UK	9618	36.4%	1166	32.0%	2183	6.0%	12967	19.5%



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