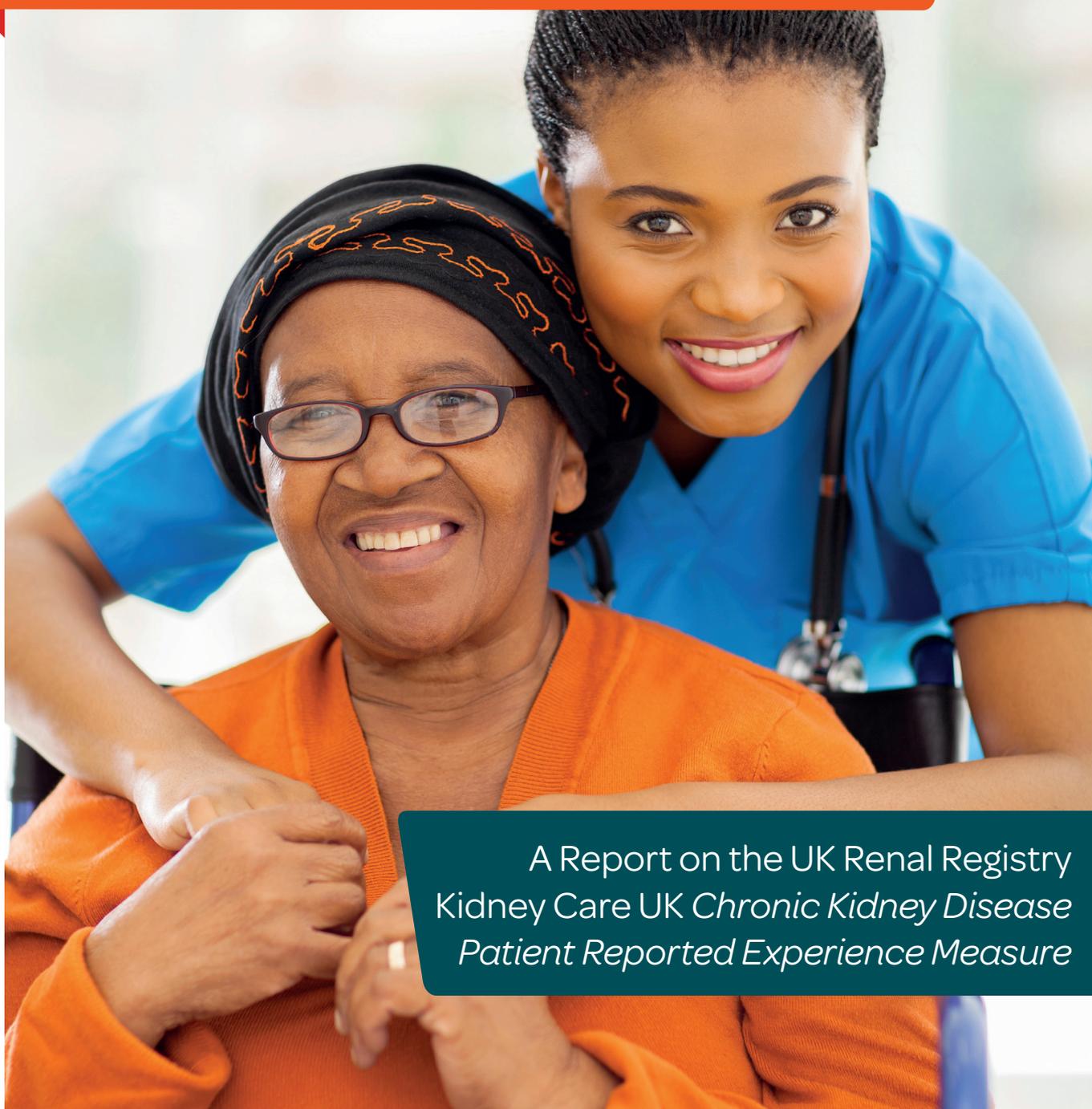




Patient Reported Experience of Kidney Care in England and Wales 2017



A Report on the UK Renal Registry
Kidney Care UK *Chronic Kidney Disease*
Patient Reported Experience Measure

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1. Foreword

I would like to congratulate the registry team for compiling another pioneering and illuminating report. The 2016 Patient Reported Experience Measures marked a watershed moment with the formal recognition of patient experience as a quality marker in renal care. This reflects a more general shift within healthcare systems away from paternalistic models and towards patient autonomy and empowerment.

The Clinical Reference Group for Renal Services joins the UK Renal Registry and Kidney Care UK in their commitment to improving the quality of life for patients living with renal disease. We also share the view that ensuring people have a positive experience of care is one of the key markers of quality in a healthcare system. It is essential that all providers of care for renal patients are aware of the perceptions of the people that they look after. Moreover, it is noteworthy that there appears to be a relationship between positive patient experience and improved patient safety.

The report itself has expanded slightly and now comprises 50 questions but it is still divided in to 13 themes. We welcome the decision to translate the questionnaire into Urdu and Gujarati to increase inclusivity and hope that future iterations will include further languages. The number of respondents has grown to more than 11,000 and it is encouraging that the majority of patients remain very positive about their overall experience. However, there are still a number of issues that clearly need addressing in certain geographic areas and these include transportation, needling practice and involvement in shared decision making.

It is a credit to the renal community that these responses are collected voluntarily and reveals a willingness to undergo candid reflection on the services that we provide. It also embodies a commitment to put the patient experience at the very heart of what we are trying to achieve. I hope that in the future these measures will be further refined and validated so that they can be used more formally in other quality measures.



Richard Baker, Chair, Renal Services Clinical Reference Group

2. How to interpret and use this report

The guidance in this section is intended to make the report more usable by everyone, not just those who are used to reading survey results.

This report presents the results of the 2017 Chronic Kidney Disease Patient Reported Experience Measure (PREM), the patient experience survey developed for renal patients in England and Wales. You can read a short summary of the important points in the Key Findings in the next section. The Results section presents the characteristics of the patients who took part in the survey, and provides more detail on how different aspects of renal services were assessed overall, and within and between centres.

Questions you might ask yourself as you read through the results include *How is my unit performing compared to last year?* *How do we compare with other units across England and Wales? Which areas of patient experience are most in need of attention in my unit?* The charts showing this data are in the Appendices at the end of the report.

The aspects of renal services which are covered in the 50 questions in the questionnaire are presented as thirteen ‘themes’. The questions making up each theme can be seen in Appendix 1. Examples include Access to the Renal Team, Patient Information, Support and Transport.

This report discusses the results of ‘centres’, meaning a main hospital centre including all its satellite units, unless otherwise stated. The PREM asks questions about a patient’s ‘unit’ which may be a satellite unit or main hospital centre. Unit level data has been made available to centre Clinical Directors.

The findings are presented as ‘means’ – another way of saying ‘averages’. This is a way of presenting the middle score given by a group of patients.

The ‘range’ around the mean is also important – the bigger the range, the more widely patient experience varies. If all the patient ratings are close to a mean score, then the range will be small, suggesting that patient experience is fairly consistent. If patient ratings vary widely, the range will be larger.

When you are reading the report and making comparisons, or looking at the ranges, look for differences of 0.7 or more. The questions in the PREM took answers on a 7 point scale (eg 1 = never, 7 = always). A difference of 10%, or 0.7, is likely to indicate a difference that is significant in terms of patient experience.

If fewer than 10 patients from a centre answered a particular question, the results from that centre for that question are not included in the report. This is to preserve anonymity as staff may know which few patients took part in the PREM.

The number of responses from some centres are low and not necessarily representative of the patient population (see number of returned PREMs by unit in Appendix 3). This means that direct comparison of results between centres, or from year-to-year should not be assumed to be informative.

Some centres did not actively take part in the PREM, however patients from their units completed the PREM online. Where this is the case, results are included, however, they may not be representative of the center's patient population.

When comparing PREM results between 2016 and 2017, you should bear in mind the changes made to the wording and sequence of questions in the PREM. For example, Section 10 'Scheduling and Planning', had substantial question amendment following the pilot in 2016, and the change in scores in 2017 may reflect these changes rather than patient experience.

3. Executive Summary

The UK Renal Registry and Kidney Care UK are organisations committed to improving the quality of life for patients living with renal disease. They are keen to encourage people to share their experience of care so that a strong patient voice is heard and acted on. The patient voice will help the kidney community understand and take account of patient experience and use it as the starting point for quality improvement and change in how renal care is delivered.

In its second year, the PREM proved to be a good platform for collecting information from patients to provide a local, regional and national perspective on renal services. This year, the PREM was extended to an online format and available in Urdu and Gujarati as well as English and Welsh, to facilitate wider participation.

Centres are starting to use PREM data to think about making service improvements. PREM results allow them to focus on tackling the issues which are of highest priority to their patients. Increasingly, centres will be able to use year on year PREM data to demonstrate the impact of what they have done to make changes and improve patient experience of renal care.

Key findings

The main factor affecting overall patient experience of renal services in England and Wales is the renal unit where the patient is treated. We analysed results question by question and by age, sex, treatment type and ethnicity and did not find any significant differences in experience according to these characteristics.

This means that the key factor to focus on in improving patient experience of renal services is the renal unit where the patient is treated. The results presented in this section of the report and in the charts in the appendices show where centres are performing particularly well or less well.

Privacy and Dignity and Access to The Renal Team are the areas which patients score most highly, with limited variation in experience across centres in England and Wales.

Transport, Needling and Sharing Decisions About Your Care are the three service areas which patients score lowest, with the most variation in experience across centres in England and Wales.

Patient experience of Communication and (Advice On) Fluid Intake and Diet also show significant variation in patient experience across different renal centres.

PatientView is used by 24.1% of patients. This may impact on a number of areas of experience including Patient Information, Tests and Sharing Decisions About Your Care.

Respondent profile

In total, 11,027 people completed the PREM in 2017, which is 2,865 more than in 2016. Patients from 56 of 57 adult renal centres took part, including five centres in Wales. In many ways, the profile of people responding to PREM 2017 is similar to the UK renal patient population, although there are more responses from people in the 56 to 74 age range on haemodialysis. Compared to 2016, there was an increase in representation from people within the pre-dialysis population.

Patient rating of renal services

Patient rating of their Overall Experience remains high (6.3), although this ranges across centres from 5.7 to 6.7 showing that a small number of units are performing above or below the majority.

Aspects of renal services which are rated most highly by patients include Privacy and Dignity (awarded a mean of 6.4 out of 7.0) and Access to the Renal Team (awarded a mean of 6.3). In contrast, Sharing Decisions About Your Care, Transport and Needling are performing less well (awarded means of 5.5, 5.6 and 5.7 out of 7.0).

Privacy and Dignity and Access to the Renal Team are also amongst the most consistent service elements across England and Wales, showing the smallest range in means (0.75 and 0.91 respectively). Table 1 shows the mean scores and ranges for all themes in the PREM in 2017, and the difference in scores between 2016 and 2017.

Variation in patient experience

Patient experience of Transport varies most between centres across England and Wales, with a range of 3.7 between highest (7.0) and lowest (3.3) centre mean scores. Haemodialysis patient experience of needling also varies widely, with a range of 2.0 between highest (7.0) and lowest (5.0) centre means. Other areas of experience which are variable include Sharing Decisions About Your Care (range of 1.5), Communication (range of 1.4) and Fluid Intake and Diet (also a mean range of 1.4).

In summary, Transport, Needling and Sharing Decisions About Your Care are the three renal service areas rated lowest for patient experience in England and Wales, both in terms of rating of experience and also in variation of experience between centres.

Advice on Diet and Fluid Intake was evaluated as one theme in PREM 2016. These were separated in 2017, resulting in improved data to show that the clarity and consistency of advice given by the renal team on diet is less consistent (mean less than 6.0) across centres than advice on fluid intake (mean more than 6.0). Similarly, for the 'Patient Information' theme, clarification to the questions has led to an increase in the best centre means (from 6.35 to 6.76), and an increase in the range of mean values (from 0.72 to 1.04) such that variation between centres is now more significant.

Table 1: PREM 2017 theme means and ranges, and change from 2016

Theme	2017 Mean Score	Standard Deviation	Min score	Max score	Range	Change compared to 2016
Access to the Renal Team	6.3	0.2	6.0	6.7	0.8 ¹	+0.3
Support	5.9	0.3	5.4	6.5	1.1	+0.3
Communication	5.9	0.3	5.1	6.5	1.4	+0.2
Patient Information	6.2	0.3	5.7	6.8	1.0	+0.2
Fluid and Diet	6.0	0.3	5.0	6.5	1.4	+0.0
Needling	5.7	0.4	5.0	7.0	2.0	-
Tests	6.1	0.2	5.6	6.7	1.1	+0.2
Sharing Decisions About Your Care	5.5	0.3	4.9	6.4	1.5	+0.3
Privacy and Dignity	6.4	0.2	6.0	6.9		+0.1
Scheduling and Planning	6.2	0.2	5.8	6.6	0.7	+0.6
How the Renal Team Treats You	6.1	0.2	5.5	6.6	1.1	-0.2
Transport	5.6	0.8	3.3	7.0	3.7	+0.2
The Environment	6.1	0.3	5.3	6.4	1.1	+0.8
Your Overall Experience	6.3	0.2	5.7	6.7	1.1	+0.2

¹ Ranges may differ by +/-0.1 due to rounding.

4. PREM Survey results and interpretation

Response profile

PREM was made available to patients in paper copy in English and online in English, Gujarati, Urdu and Welsh, with publicity via participating units and PatientView. The majority of responses were paper copy in English (91%).

Patients from 56 out of 57 adult renal centres in England and Wales took part in the 2017 PREM, providing 11,027 valid responses; 2,865 more respondents than in 2016 (see Table 2). The 56 centres comprised a total of 231 main centres and satellite units. The sample from Wales consisted of 554 patients from five renal centres.

Table 2 shows that the largest age group participating in the 2017 PREM was the 56 - 74 age range, which was also the case in 2016. The number of people from each age range participating in PREM in 2016 and 2017 is similar, with significantly fewer missing responses in 2017 (a more detailed analysis of age by type of treatment is given in Appendix 2). A greater proportion of men than women responded in 2017, but with more missing data than in 2016.

Information on ethnicity was not collected in 2016. In 2017 the majority of patients participating in PREM were White, with some representation from Asian and Black patients. 9% had another or an unknown ethnicity.

Awareness and use of PatientView is variable. As expected (given the profile of renal patients in England and Wales) respondents were predominantly on haemodialysis; similar proportions of home and in-centre dialysing patients responded across both years, with less missing data on current treatment in 2017. A greater proportion of pre-dialysis patients responded in 2017 (more than twice the number in 2016). Similar proportions of peritoneal, haemodialysis and transplant patients responded in both years.

Table 2: Characteristics of people who completed the PREM in 2017 and comparisons with 2016 where available

Characteristic	PREM 2017	PREM 2016
Total	11,027	8,162
Age		
≤30	353 (3.2%)	325 (4.0%)
31-55	2,797 (25.4%)	1,910 (23.4%)
56-74	4,731 (42.9%)	3,134 (38.4%)
≥75	2,902 (26.3%)	2,110 (25.9%)
Missing	244 (2.2%)	683 (8.4%)
Gender		
Male	5,907 (53.6%)	4,250 (52.1%)
Female	4,031 (36.6%)	3,652 (44.7%)
Rather not say	39 (.4%)	
Missing	1,050 (9.5%)	260 (3.2%)
Current Treatment		
Peritoneal dialysis	808 (7.3%)	738 (9%)
Haemodialysis	6,194 (56.3)	4,433 (54.3%)
Transplant	1,545 (14.0%)	1,070 (13.1%)
Pre-dialysis	1,671 (15.2%)	493 (6.0%)
Missing	809 (7.3%)	1,428 (17.6%)
Haemodialysis location²		
At home	276 (4.5%)	226 (5.1%)
In-centre	2,671 (43.1%)	3,353 (75.6%)
In-satellite	3,036 (49.0%)	
Missing		
Ethnicity		
Asian	1,048 (9.5%)	-
Black	774 (7.0%)	-
White	8,184 (74.2%)	-
Other	265 (2.4%)	-
Rather not say	155 (1.4%)	-
Missing	601 (5.5%)	-
Use PatientView		
Yes	2,658 (24.1%)	-
No	4,321 (39.2%)	-
Don't Know	1,824 (16.5%)	-
Missing	2,224 (20.2%)	-

² A distinction between in-centre and in-satellite patients was not made in 2016

Overall patient experience

Overall patient experience of the service provided by renal units remains high, with a mean of 6.3 out of 7, ranging across centres from 5.7 to 6.7. While a score of 5.7 indicates endorsement of overall patient experience, there remain significant differences between centres across England and Wales (see Figure 1), showing that a small number of centres are performing better or worse than the majority.

Figure 1: Centre mean scores for overall experience of the service provided by renal units (Question 50 in the 2017 PREM)

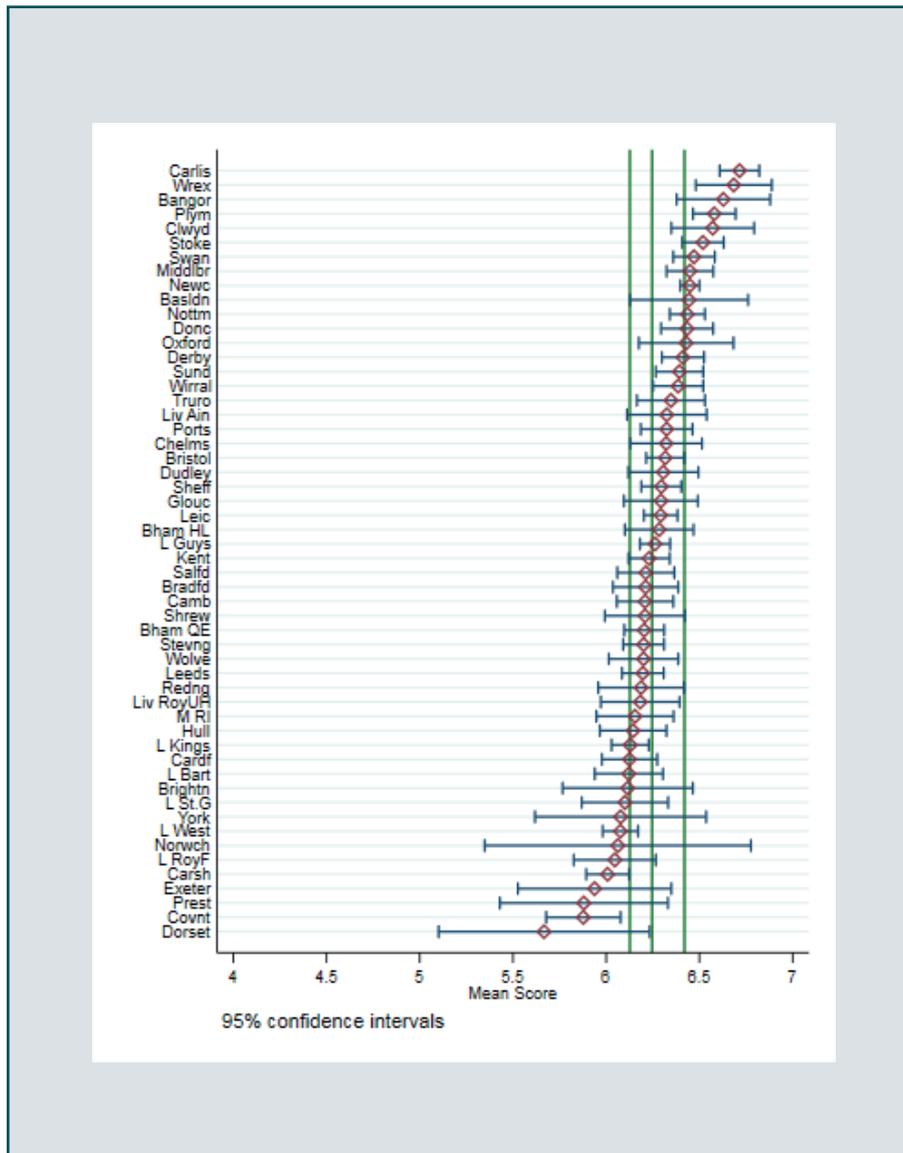
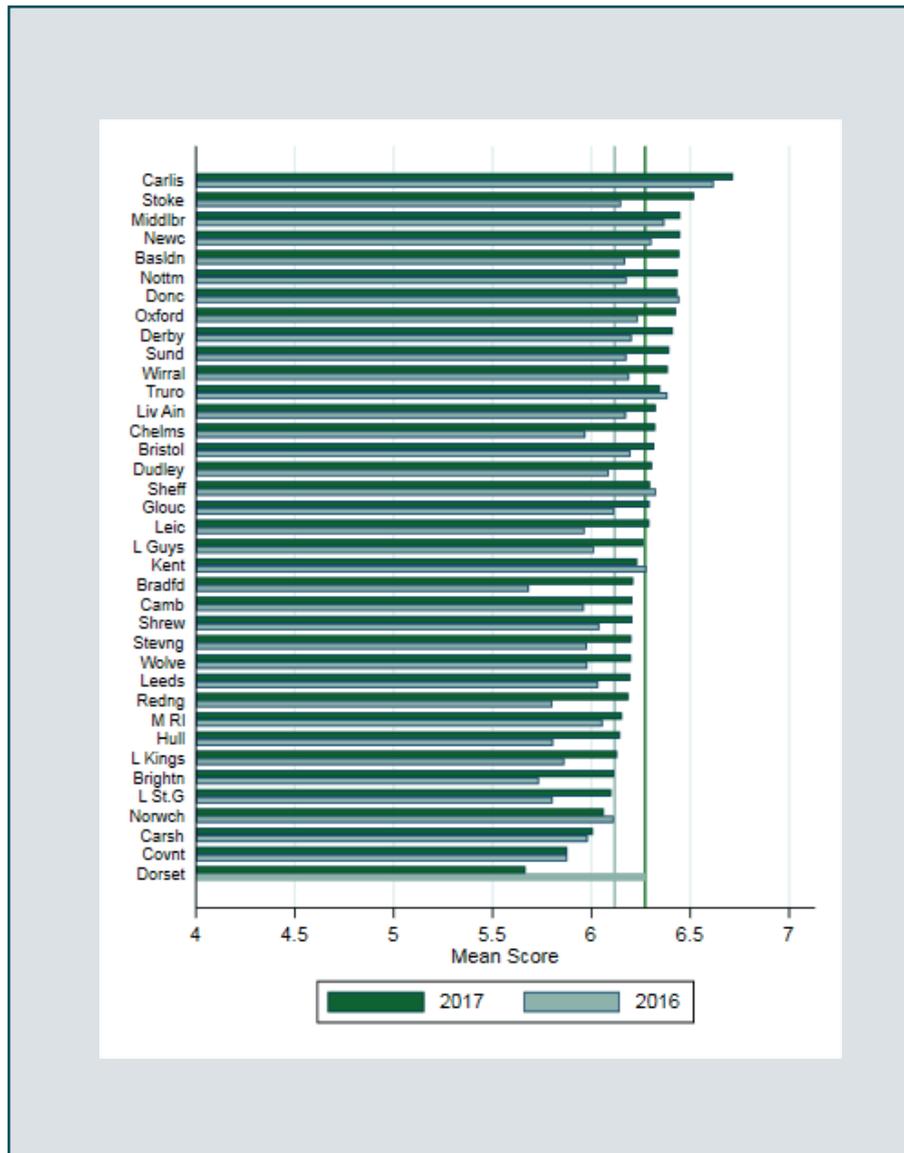


Figure 2 shows the year on year change across centres, indicating in most cases a small overall increase in patient experience. Such uniform movement may reflect changes in participation and to some degree the change in the format of the question.

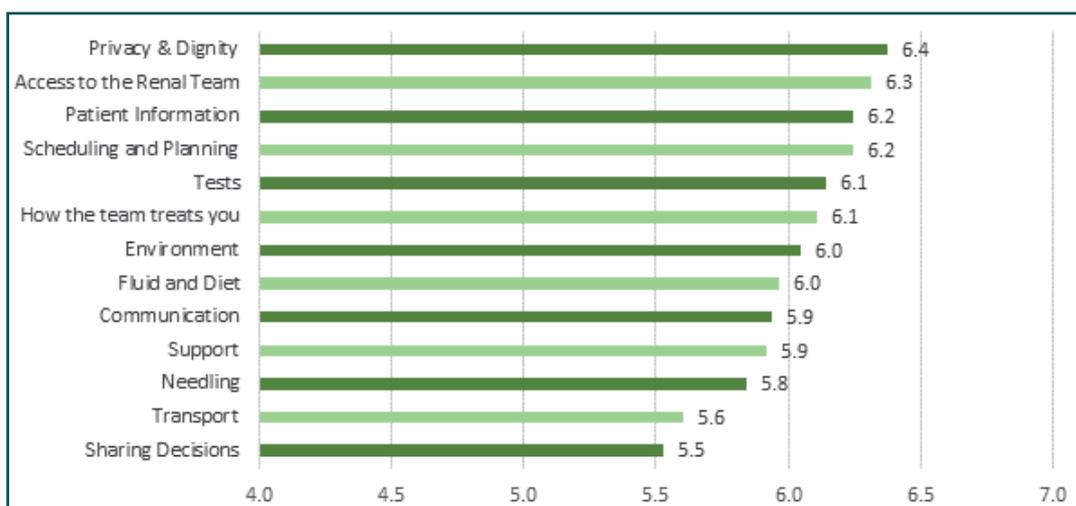
Figure 2: 2016 and 2017 centre mean scores for overall experience of the service provided by renal units (2016 scale adjusted from 10 point to 7 point)



How patients experience renal services

The PREM measures patient experience over 13 themes. Figure 3 shows the mean scores for each theme, based on the total sample of patients in England and Wales responding to the PREM in 2017. Privacy & Dignity (6.4) and Access to the Team (6.3) are rated most highly. In contrast, Sharing Decisions About Your Care (5.5) is rated lower, as is Transport, which is known to be an issue amongst many renal patients who rely on hospital provision (5.6).

Figure 3: Theme total sample means



Variation in patient experience between centres

There continues to be considerable variation in patient experience between centres. The aspects of renal service provision that vary the most between centres across England and Wales are Transport (3.7), Needling (2.0), Sharing Decisions (1.5), Fluid Intake & Diet (1.4) and Communication (1.4 see Table 3), as indicated by the large range in mean scores.

Whilst the large range observed for the variation in experience of **Transport** may reflect local arrangements, differences in organisation, management and delivery would still be important contributing factors.

Appendices 4 and 5 contain charts for each theme, illustrating variation in mean scores across centres, both 2017 data and comparison for 2016/17.

Table 3: A summary of the highest and lowest mean scores by centre, with the range in scores. Figures presenting the mean score for each centre is given in Appendix 4.

Theme	Topic	Range*	Mean Score**
1	Access to the team	0.75*	5.98 – 6.73¥
2	Support	1.06	5.44 – 6.50
3	Communication	1.42	5.06 – 6.48
4	Patient Information	1.04	5.72 – 6.76
5	Fluid and Diet	1.43#	5.04 – 6.47**
6	Needling	2.00#	5.00 – 7.00**
7	Tests	1.11	5.61 – 6.72
8	Sharing Decisions	1.49#	4.89 – 6.38**
9	Privacy and Dignity	0.91*	6.00 – 6.91¥
10	Scheduling and Planning	0.73*	5.83 – 6.56¥
11	How the team treats you	1.13	5.46 – 6.59
12	Transport	3.67#	3.33 – 7.00**
13	Environment	1.12	5.26 – 6.38
14	Overall experience	1.05	5.67 – 6.72

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

**Highlighted ranges indicate the largest and ¥ smallest ranges across themes.

Needling was a new PREM theme in 2017, consisting of a single question asked of in-centre haemodialysis patients: *How often do the renal team insert your needles with as little pain as possible?* This theme was added following comments from patients during evaluation of the 2016 PREM. The fact that it has the second largest range in centre means behind Transport indicates a considerable variation in patient experience by centre, as shown in Appendix 4.

The **Sharing Decisions About Your Care** theme has consistently low scores, and among the widest differences between centres. As a result of the pilot study in 2016, this section of the PREM has changed significantly to Does the renal team ... give you enough information so that you can understand what these decisions involve? This may explain the significantly modified response, increasing from 3.8 in 2016 to 5.7 in 2017³. Appendix 5 demonstrates the dramatic change in scores between 2016 and 2017. The number of responses remains high, but interpreting changes from 2016 to 2017 in this section is challenging, and should be treated with caution.

³ The scale in 2016 ran from 1 to 4. The 2016 mean scores have been transformed to be equivalent to the 1-7 scale used in 2017.

The questions for the **Fluid Intake and Diet** theme have changed considerably following patient feedback and pilot data analysis in 2016; separating two questions on the clarity and consistency of diet and fluid advice into six questions dealing with fluid and diet advice separately. In 2016 this section had one of the lowest variations between centres; in 2017 the range of scores has increased, with the lowest scores falling. The decision to split questions about fluid from diet has led to differentiation in responses with more negative responses to questions about diet (means 5.88, 5.97 and 5.88), than fluid (means 6.09, 6.17, 6.08). This suggests that the provision of information about fluid intake is consistent between centres, with greater variation in the provision of information about diet.

The **Communication** theme covers quality of communication between the patient and the renal team and then between the renal team and a number of other professionals, and has one of the largest mean ranges between the best and worst centres (Appendix 4). Questions about communication outside of the renal team still attract high levels of Not Applicable/Don't know responses, suggesting that this element of experience is not always visible to patients.

The lowest variation between centre means (suggesting greater consistency in services across England and Wales) is observed for Scheduling and Planning (0.73), Access to the Team (0.75), and Privacy and Dignity (0.91).

The **Scheduling and Planning** theme was changed considerably between 2016 and 2017, and inconsistency in questions in 2016 make it difficult to interpret changes. In 2017 the responses were vastly improved and differences between sites were reduced. Changing the tone of the question (number 34 in 2016), about time use during appointments to positive (question number 35 in 2017) has improved the response profile considerably, with the mean for this theme increasing between 2016 and 2017:

- 2016: Do you feel time is wasted on appointments relating to your kidneys? Eg waiting to be seen, repeating tests? (adjusted question mean 4.8)
- 2017: Do you feel your time is used well at your appointments relating to your kidneys? (mean 6.2)

Access to the Team remains a positive theme, with good consistency between centres. Clarification in the question about making additional kidney doctor appointments has reduced use of the Not Applicable response considerably, but otherwise changes to the theme and questions were minimal. **Privacy and Dignity** also had minimal changes made, and continues to show among the highest scores of any domain, and high response participation.

The **Patient Information** theme had low variation between centre means in 2016 (range 0.72), suggesting this is an element of renal patient experience which is most consistent across England and Wales. Whilst changes to the theme questions from 2016 to 2017 were about clarifying the meaning of the questions, this has led to a significant increase in the best centre means (from 6.35 to 6.76), and an increase in the range of mean values (from 0.72 to 1.04) such that variation between centres is now more significant.

Other notable changes in PREM from 2016 to 2017

The theme **How the Renal Team Treats You** was moved down the questionnaire, following indications from patient feedback that this question may be having a 'feel good' impact on responses to subsequent questions. Compared with 2016, the theme now includes five questions:

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

Q37 Listen carefully to you?

Q38 Spend enough time with you?

Q39 Take you seriously?

Q40 Show a caring attitude towards you?

Q41 Ask you about your emotional feelings?

Scores across the theme have reduced from 2016 to 2017; mean centre scores at the lower end have dropped considerably, increasing the differences between sites. The lower scores may reflect lower patient endorsement of the new question (Q41) about emotional support.

While scores for the **Environment** theme have improved from 2016 to 2017, differences between centres remains high, and mean centre scores are among the lowest and the highest across all questions. Parking continues to attract low mean scores.

5. What's Next?

Ongoing improvements to the PREM process

PREM asks patients about 'the services your renal unit provides', focussing on 'the renal team'. We have had feedback that patients and centres would find it useful to be able to differentiate between members of the renal team, being able to identify patient experience according to who they are dealing with within a multi-disciplinary team. We are looking into the best way of doing this without making it onerous for patients.

We have also had feedback from patients that a comments box would be useful. We do not want to collect free text from patients without being certain we can input, process and analyse it in a meaningful way. We are currently investigating ways of piloting this, potentially adding a free text box in the online survey in 2018, and will update patients and colleagues later in the year.

Acting on the results of the PREM 2017

A key finding of PREM 2017 is that renal patient experience is driven by the quality of service provided at the local renal unit; and does not vary by a patients' characteristics, for example being better or worse for older or younger people, or for people on dialysis compared to those who have had a transplant. Put more simply, patient experience varies according to the renal unit a patient attends for treatment.

Positively, this means that the full range of a unit's patients will potentially benefit from a quality improvement initiative that is targeted at an aspect of patient experience that patients have scored comparatively negatively. It also suggests that focussing on improvements across the patient pathway, from low clearance clinic to established replacement therapy, can be seamless, as a 'good service' means similar things to most patients.

The aspects of renal services that PREM 2017 has shown to vary most between centres across England and Wales are: Transport; Needling; Sharing Decisions About Your Care; (Advice on) Fluid Intake and Diet; and, Communication. UK Renal Registry and Kidney Care UK recommend that centres should review and address their performance in these areas in 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:

- Sharing good practice – gathering case studies of good practice and sharing these on the UK Renal Registry website;
- Encouraging further local investigation;
- Offering advice to centres – 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;
- Supporting local Kidney Patient Associations to review the PREM results and work in partnership with hospitals and Quality Improvement leads to respond to areas in need of improvement;
- Support with publicising your PREM results locally to patients, colleagues and your local community to celebrate successes and any actions taken in response to the PREM.

Case study evidence

The UK Renal Registry and Kidney Care UK would like to hear how you have been using 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 us at 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 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:

www.renalreg.org/patient-info/lay-summaries-2016-19th-annual-report

UK Renal Registry Annual Report Infographics:

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

UK Renal Registry Full Annual Report:

www.renalreg.org/publications-reports

6. Glossary

Sample:	<p>When information is collected about a group of people, the group is referred to as a sample.</p> <p>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>

7. Acknowledgement

The UK Renal Registry and Kidney Care UK would like to thank the following people, without whom PREM 2017 would not have been possible.

- Dr Janine Hawkins, Dr David Wellsted and the team at the University of Hertfordshire who analysed the PREM 2017 data and produced this report
- The patients who completed the PREM survey
- The clinical directors, their staff and volunteers in the renal units in England and Wales who participated
- Think Kidneys Transforming Participation in Chronic Kidney Disease Measurement Workstream members who developed the PREM and worked with the University of Hertfordshire on its validation
- Kidney Patient Association members
- UK Renal Registry Patient Council

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"/>									
5. Practical issues resulting from your kidney disease?	<input type="checkbox"/>									
6. Any other concerns or anxieties resulting from your kidney disease or treatment?	<input type="checkbox"/>									
7. Accessing patient support groups such as Kidney Patient Associations (KPA)?	<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			
8. You and your renal team?	<input type="checkbox"/>									
9. Members of the renal team?	<input type="checkbox"/>									
10. The renal team and your GP?	<input type="checkbox"/>									
11. Your GP and the renal team?	<input type="checkbox"/>									
12. The renal team and other medical specialists?	<input type="checkbox"/>									
13. The renal team and other non-healthcare services if you need them, such as social work or housing?	<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				
14. Explain things to you in a way that is easy to understand?	<input type="checkbox"/>										
15. Give you as much information about your kidney disease or treatment as you want?	<input type="checkbox"/>										
16. Give this information to you in a format that is suitable for you?	<input type="checkbox"/>										
17. Give this information to you at a time that is right for you?	<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				
18. Does the renal team give you the advice you want on your fluid intake ?	<input type="checkbox"/>										
19. Is that advice on your fluid intake clear?	<input type="checkbox"/>										
20. Is that advice on your fluid intake consistent?	<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				
21. Does the renal team give you the advice you want on your diet ?	<input type="checkbox"/>										
22. Is that advice on your diet clear?	<input type="checkbox"/>										
23. Is that advice on your diet consistent?	<input type="checkbox"/>										

SECTION 6: NEEDLING

If you are on in-hospital or in-satellite haemodialysis please answer question 24, otherwise please go to SECTION 7: TESTS

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

SECTION 7: TESTS

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

SECTION 8: SHARING DECISIONS ABOUT YOUR CARE

Does the renal team:

	Never							Always		Don't know	Not Applicable
	1	2	3	4	5	6	7				
28. Talk with you about your treatment and life goals?	<input type="checkbox"/>										
29. Enable you to participate in decisions about your kidney care as much as you want?	<input type="checkbox"/>										
30. Give you enough information so that you can understand what these decisions involve?	<input type="checkbox"/>										
31. Talk to you about taking a more active role in managing your own kidney care?	<input type="checkbox"/>										

SECTION 9: PRIVACY AND DIGNITY

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

SECTION 10: SCHEDULING AND PLANNING

	Never							Always		Don't know	Not Applicable
	1	2	3	4	5	6	7				
34. Can you change your appointment times if they are not suitable for you?	<input type="checkbox"/>										
35. Do you feel your time is used well at your appointments relating to your kidneys?	<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 36.

	Never							Always		Don't know	Not Applicable
	1	2	3	4	5	6	7				
36. Are the arrangements for your blood tests convenient for you?	<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				
37. Listen carefully to you?	<input type="checkbox"/>										
38. Spend enough time with you?	<input type="checkbox"/>										
39. Take you seriously?	<input type="checkbox"/>										
40. Show a caring attitude towards you?	<input type="checkbox"/>										
41. Ask you about your emotional feelings?	<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		Don't know	Not Applicable
	1	2	3	4	5	6	7				
42. Is the vehicle provided suitable for you?	<input type="checkbox"/>										
43. Is the time it takes to travel between your home and the renal unit acceptable to you?	<input type="checkbox"/>										
44. 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"/>										

SECTION 13: THE ENVIRONMENT

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

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

SECTION 14: YOUR OVERALL EXPERIENCE

	Worst it can be						Best it can be
	1	2	3	4	5	6	7
50. 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"/>						

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

Appendix 2: Patient age ranges across the different modalities

Age	Total		Haemodialysis		Peritoneal		Pre-dialysis		Transplant		Missing	
	Total	%	Total	%	Total	%	Total	%	Total	%	Total	%
17-21	66	0.6%	22	0.4%	4	0.5%	16	1.0%	15	1.0%	9	1.1%
22-30	287	2.6%	123	2.0%	16	2.0%	68	4.1%	68	4.4%	12	1.5%
31-40	616	5.6%	282	4.6%	36	4.5%	123	7.4%	152	9.8%	23	2.8%
41-55	2181	19.8%	1041	16.8%	134	16.6%	410	24.5%	484	31.3%	112	13.8%
56-64	2024	18.4%	1103	17.8%	153	18.9%	309	18.5%	353	22.8%	106	13.1%
65-74	2707	24.5%	1618	26.1%	200	24.8%	365	21.8%	320	20.7%	204	25.2%
75-84	2316	21.0%	1516	24.5%	191	23.6%	262	15.7%	112	7.2%	235	29.0%
85+	586	5.3%	360	5.8%	55	6.8%	86	5.1%	20	1.3%	65	8.0%
Missing	244	2.2%	129	2.1%	19	2.4%	32	1.9%	21	1.4%	43	5.3%
Total	11027		6194		808		1671		1545		809	

Note: The distribution of age ranges confirms what might be expected. Haemodialysis patients are predominantly in the 65 to 84 age range, pre-dialysis patients are spread largely from 41 to 74, with a similar profile for Transplant patients. Interestingly Peritoneal patients have a similar distribution of age to Haemodialysis patients with small differences, but represent only 7% compared to 56% of the population overall.

Appendix 3: Unit abbreviations and number of PREMs returned

Numbers in brackets in the 'Unit' column show the number of PREMs returned per unit, as reported in the Clinical Director dataset⁴ (ie, 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 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
*Ysbyty Gwynedd (Bangor)	Bangor - Main Unit (27)	Bangor (35)
*Basildon Hospital	Basildon - Main Unit (25)	Basldn (27)
Heartlands Hospital	Birmingham - Main Unit (12) Castle Vale (32) Solihull District General (34) Balsall Heath (24)	Bham HL (102)
Queen Elizabeth Hospital, Birmingham	Birmingham - Main Unit (48) Aston Cross (25) Hereford (32) Kings Norton (13) Worcester (54) Woodgate Valley (61) Smethwick (66) Sparkhill (41) Redditch (29) Great Bridge (46) Llandridod Wells (12)	Bham QE (427)
St Luke's Hospital	Bradford - Main Unit (115) Skipton (33)	Bradfd (148)
*Royal Sussex County Hospital	Brighton - Main Unit (21)	Brightn (27)

⁴ In December 2017 results of the survey by unit were made available to renal Clinical Directors, accessed through the UK Renal Registry website. The results were presented as raw data scores with no detailed analysis or narrative. Individual units were identified, provided there were more than 10 patients responding from the unit.

Main Centre	Unit / Satellite Location	Centre abbreviation
*Southmead Hospital	Bristol - Main Unit (86) Bath (42) South Bristol (64) Brunel / Bright (60) Weston-super-Mare (52) Cossham (61)	Bristol (368)
Addenbrooke's Hospital	Cambridge - Main Unit (150) Kings Lynn (27)	Camb (177)
University Hospital of Wales - Cardiff	Cardiff - Main Unit (35) Merthyr (45) Newport (49) Cardiff South (30) Llantrisant (32) Cardiff North (39)	Cardf (230)
Cumberland Infirmary	Carlisle - Main Unit (115) Whitehaven (33)	Carlis (148)
St Helier Hospital	Carshalton - Main Unit (93) Crawley (26) Croydon (44) Kingston - St Helier (14) Kingston - St George's (15) West Byfleet (52) Sutton (31) Purley (63) Epsom (32) Farnborough (51)	Carsh (421)
Broomfield Hospital	Chelmsford - Main Unit (115)	Chelms (115)
Colchester General Hospital		Colch (0)
*University Hospital Coventry & Warwickshire	UHCW - Main Renal Unit (89) Walsgrave Hospital - Rugby (52) Walsgrave Hospital - Nuneaton (12) Walsgrave Hospital - Whitnash (12)	Covnt (166)
Ysbyty Glan Clwyd (Rhyl)	Rhyl - Main Unit (28)	Clwyd (28)
Royal Derby Hospital	Royal Derby Hospital (230)	Derby (230)
Doncaster Royal Infirmary	Doncaster - Main Unit (117) Bassetlaw (33) Dearne Valley (20)	Don (170)

Main Centre	Unit / Satellite Location	Centre abbreviation
*Dorset County Hospital	Dorchester - Main Unit (12)	Dorset (19)
Russell's Hall Hospital	Dudley - Main Unit (62) Kidderminster (25) Tipton (24)	Dudley (111)
*Royal Devon and Exeter Hospital ⁵	Exeter - Main Unit (12)	Exeter (16)
*Gloucestershire Royal Hospital	Gloucester - Main Unit (93) Severn (18)	Glouc (119)
Hull Royal Infirmary	Hull - Main Unit (76) Grimsby (43) Scunthorpe (46)	Hull (166)
Ipswich Hospital		Ipswi (2)
Kent and Canterbury Hospital	Canterbury - Main Unit (127) Maidstone (62) Margate (29) Medway (53) William Harvey (39) Dover (19)	Kent (329)
*St James's University Hospital & Leeds General Infirmary	Leeds - Main Unit (164) Dewsbury (29) Seacroft - Ward B (28) Seacroft - R & S (50) Calderdale (31) Pontefract (30)	Leeds (334)
Leicester General Hospital	Leicester - Main Unit (93) Boston (28) Kettering (67) Lincoln (69) Loughborough (27) Peterborough (61) Skegness (17) Hamilton (45) Grantham (13) Chandra Mistry (24) Northampton (36)	Leic (480)

⁵ Results from Royal Devon and Exeter should be treated with caution as this centre informed the UK Renal Registry that they were not taking part.

Main Centre	Unit / Satellite Location	Centre abbreviation
Aintree University Hospital	Liverpool - Main Unit (34) Waterloo (23) Aintree (24) Southport (43)	Liv Ain (124)
*Royal Liverpool University Hospital	Liverpool - Main Unit (54) Warrington (20) St Helens (30)	Liv RoyUH (116)
Barts & The London Hospital	London - Main Unit (30) Whipps Cross (38) King George (40) Queen's Hospital (69)	L Bart (177)
Royal Free Hospital	London - Main Unit (23) Barnet (11) Edgware (28) Mary Rankin / St Pancras (35) Tottenham Hale (17)	L RoyF (114)
*West London Renal & Transplant Centre	Hammersmith (155) St Mary's - West Middlesex (53) St Mary's - Northwick Park (177) St Mary's - St Charles (99) St Mary's - Watford (65)	L West (550)
St George's Hospital and Queen Mary's Hospital	London - Main Unit (73) North Wandsworth (21) Colliers Wood (11)	L St.G (105)
Guy's Hospital and St Thomas' Hospital	London - Main Unit (195) Forest Hill (17) Camberwell (65) New Cross Gate (42) Sidcup (16) Borough (63) Tunbridge Wells (73)	L Guys (471)

Main Centre	Unit / Satellite Location	Centre abbreviation
King's College Hospital	London - Main Unit (209) Dulwich (73) Woolwich (41) Bromley (83) Dartford (39) Sydenham (83)	L Kings (528)
*Manchester Royal Infirmary	Manchester - Main Unit (64) Macclesfield (22) Tameside (35)	M RI (125)
The James Cook University Hospital	Middlesborough - Main Unit (102) Darlington (45) Stockton (52) North Ormesby (29)	Middlbr (228)
Freeman Hospital and Royal Victoria Infirmary	Newcastle-upon-Tyne - Main Unit (939) North Tyneside (22) Alnwick (17)	Newc (978)
Norfolk and Norwich University Hospital	Norwich - Main Unit (16)	Norwch (16)
Nottingham City Hospital	Nottingham - Main Unit (249) Kings Mill (35) Ilkeston (21) Lings Bar (19)	Nottm (324)
*John Radcliffe Hospital and Churchill Hospital	Oxford - Main Unit (25)	Oxford (37)
*Derriford	Plymouth - Main Unit (139)	Plym (143)
*Queen Alexandra Hospital	Portsmouth - Main Unit (143) Basingstoke (13) Isle of Wight (12) Totton (19) Bognor Regis (21)	Ports (232)
*Royal Preston Hospital	Preston - Main Unit (19)	Prest (27)

Main Centre	Unit / Satellite Location	Centre abbreviation
Royal Berkshire Hospital	Reading - Main Unit (61) Windsor (16) Bracknell (17)	Redng (94)
Salford Royal Hospital	Salford - Main Unit (54) Rochdale (17) Oldham (54) Wigan (26) Bolton (30)	Salfd (181)
Northern General Hospital	Sheffield - Renal Unit G (140) Sheffield - Peter Moorhead (74) Barnsley (48) Chesterfield (21) Rotherham (43) Heeley (55)	Sheff (381)
*Royal Shrewsbury Hospital	Shrewsbury - Main Unit (100)	Shrew (101)
Southend Hospital		Sthend (4)
Lister Hospital	Stevenage - Main Unit (116) Luton & Dunstable (68) St Albans City (45) Harlow (50) Bedford (32)	Stevng (311)
Royal Stoke University Hospital (University Hospital of North Midlands)	Stoke-on-Trent - Main Unit (150) Leighton (48) Stafford (25)	Stoke (223)
Sunderland Royal Hospital	Sunderland - Main Unit (160) Durham Dryburn (27) Washington (47)	Sund (234)
Morrison Hospital - Swansea	Swansea - Main Unit (128) Aberystwyth (12) West Wales (56) Withybush (27)	Swan (223)
Royal Cornwall Hospital	Truro - Main Unit (85) Aubrey Williams (19) Bodmin (21)	Truro (125)

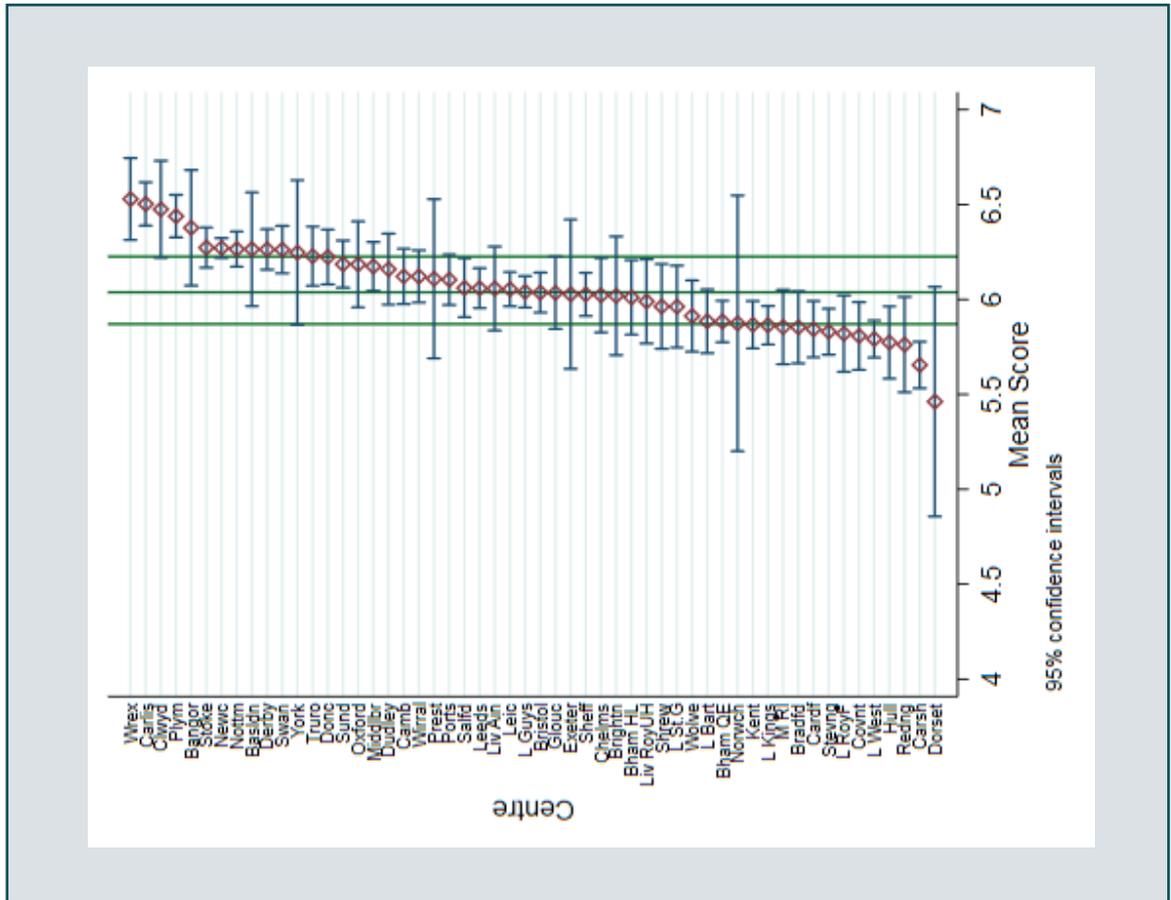
Main Centre	Unit / Satellite Location	Centre abbreviation
Arrowe Park Hospital	Wirral - Main Unit (54) Chester (65) Clatterbridge (95)	Wirral (214)
New Cross Hospital	Wolverhampton - Main Unit (41) Cannock (33) Walsall (34) Pond Lane (24)	Wolve (132)
Wrexham Maelor Hospital	Wrexham - Main Unit (22) Welshpool (16)	Wrex (38)
(The) York Hospital		York (13)

Appendix 4: Mean 2017 theme score by centre

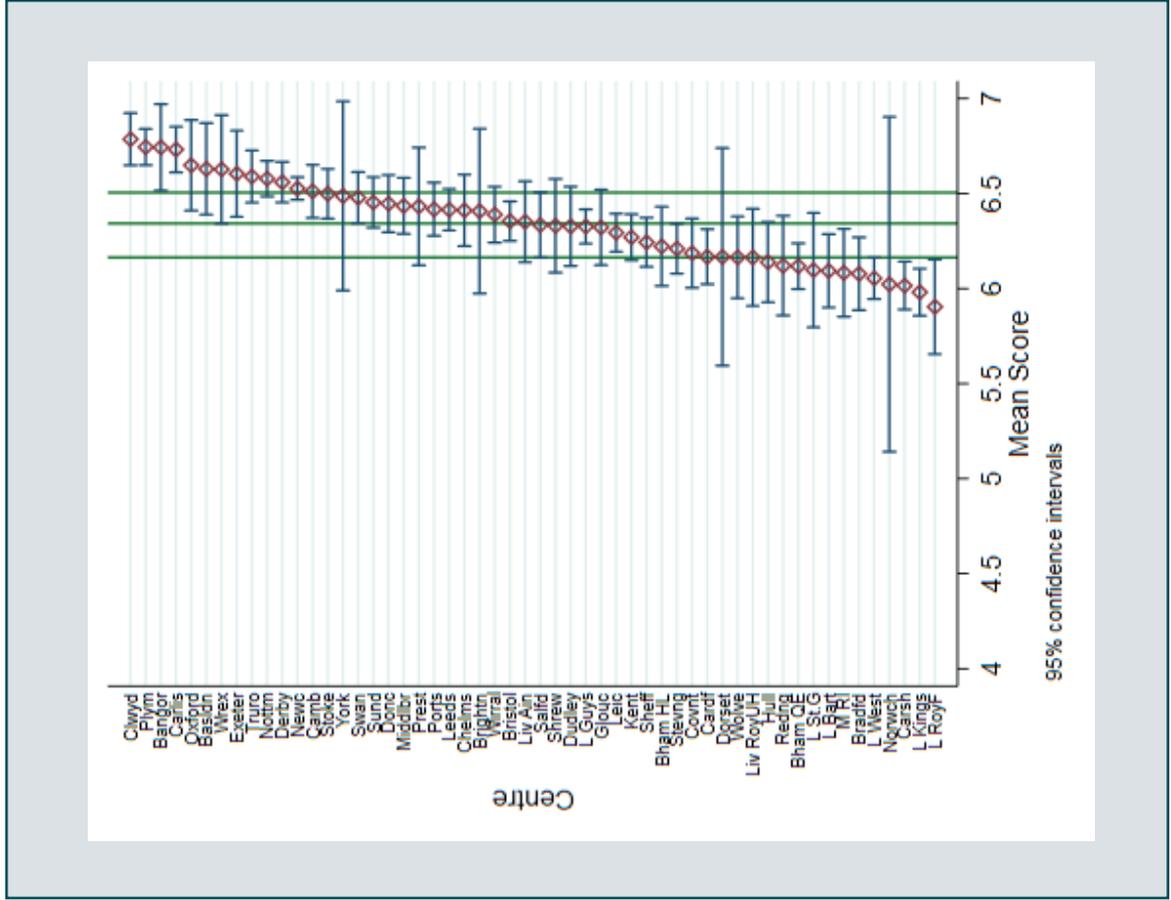
These charts give the centre mean score for each theme, with the 95% confidence interval (where there were more than 7 responses in a theme). Each chart also shows the overall median and quartile scores of the centre means. This gives an indication of how the centres compare to the overall mean scores. 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 range.
	Left line = lower quartile Middle line = median Right line = upper quartile

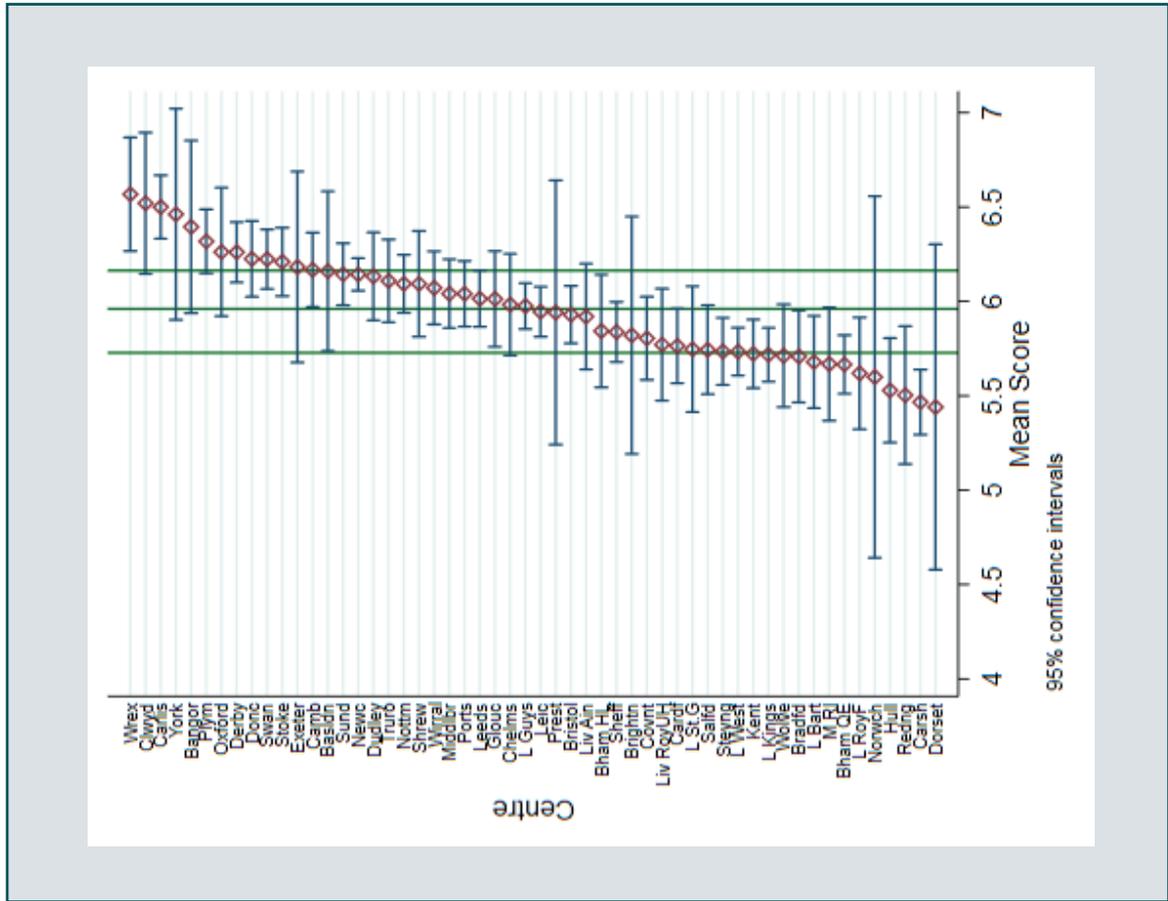
Scale Total. Responses Across All Themes



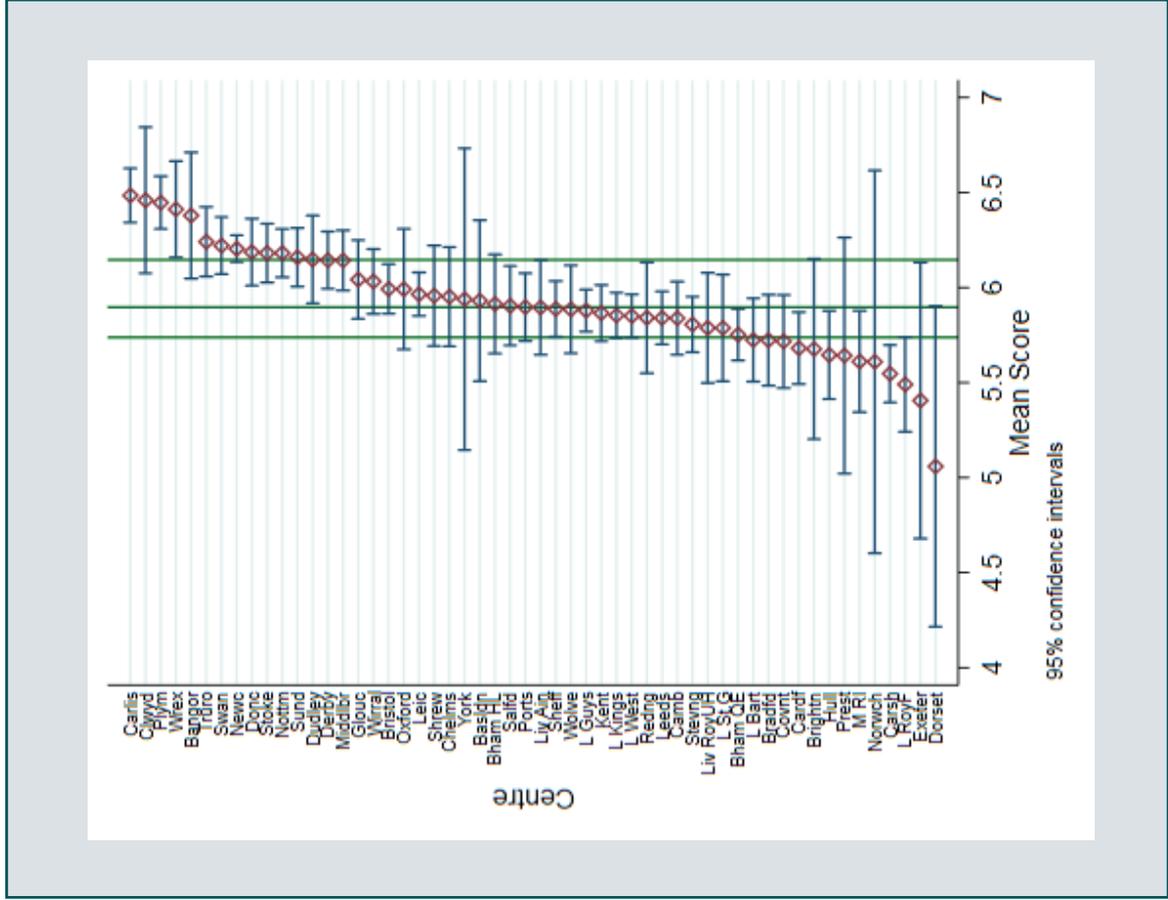
Section 1. Access to the Renal Team



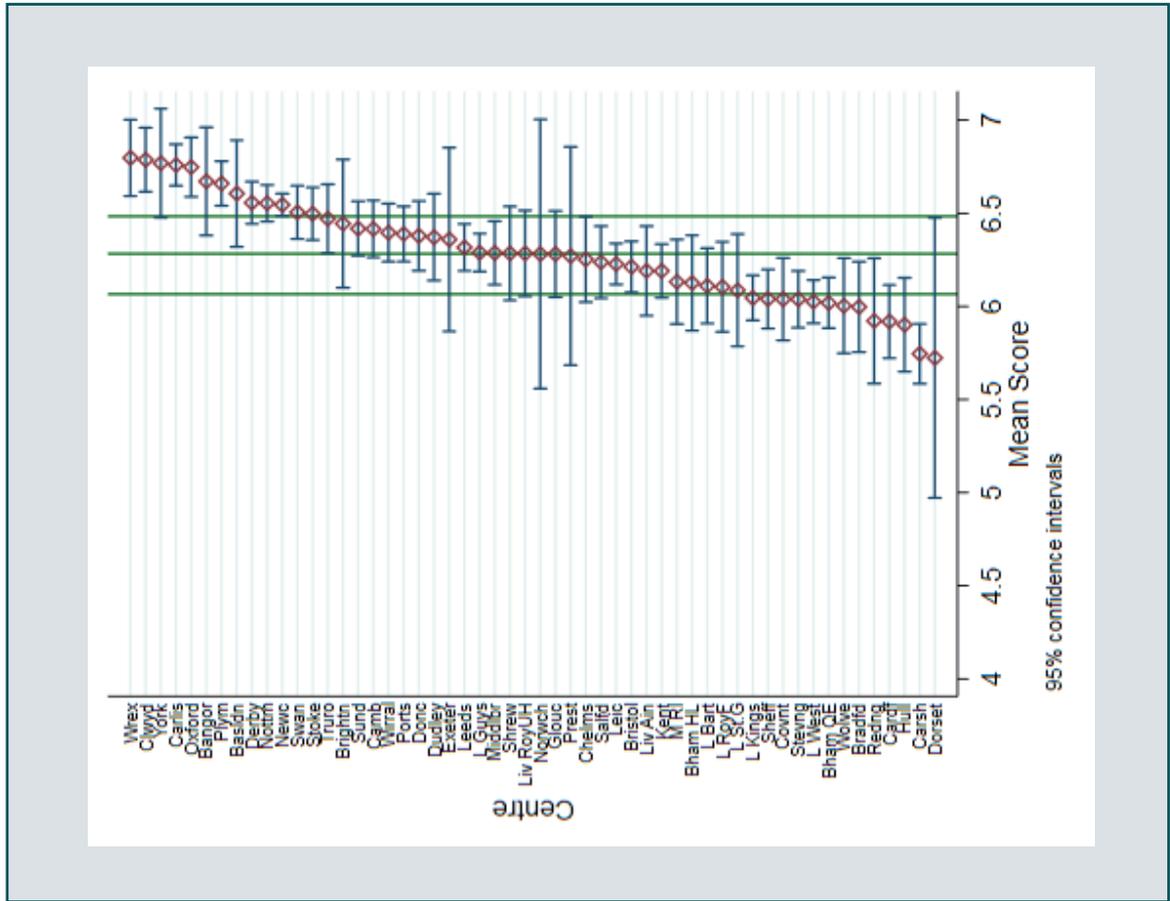
Section 2. Support



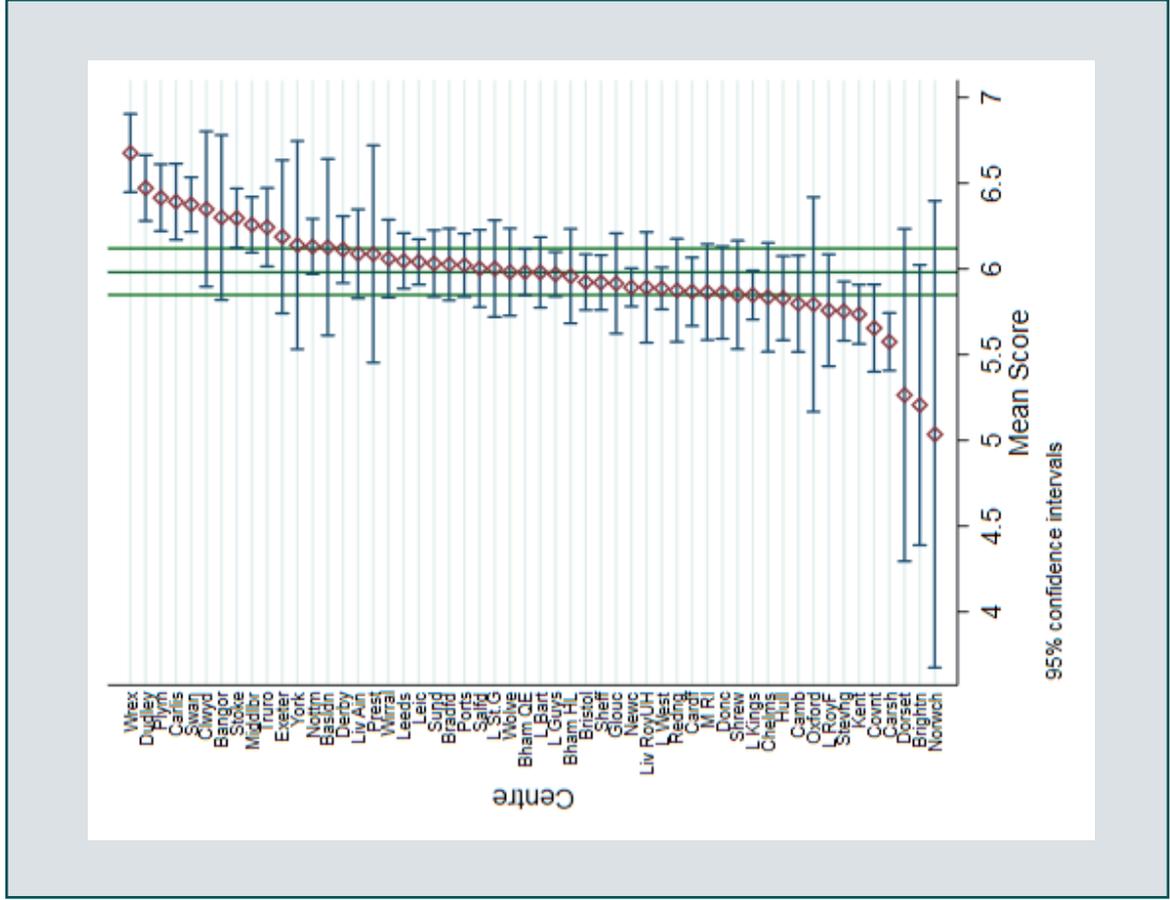
Section 3. Communication



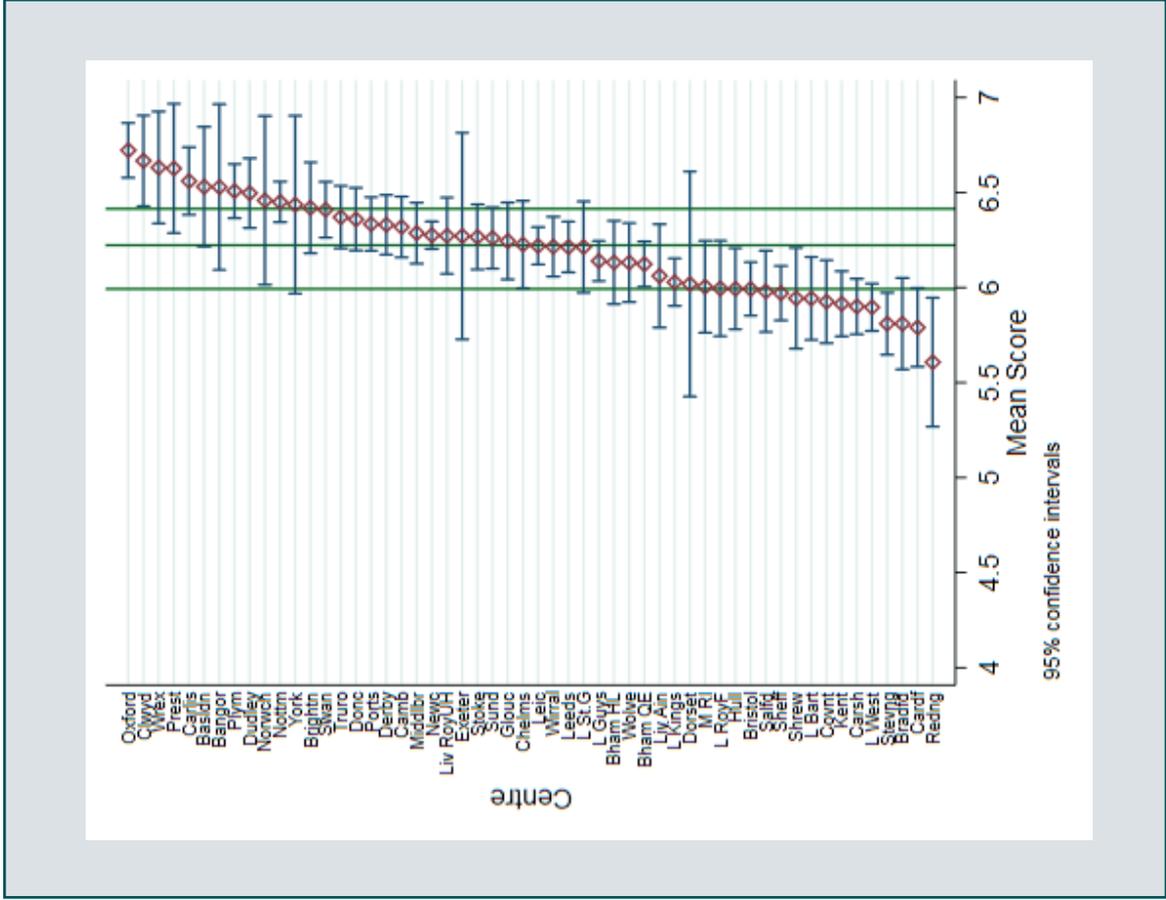
Section 4. Patient Information



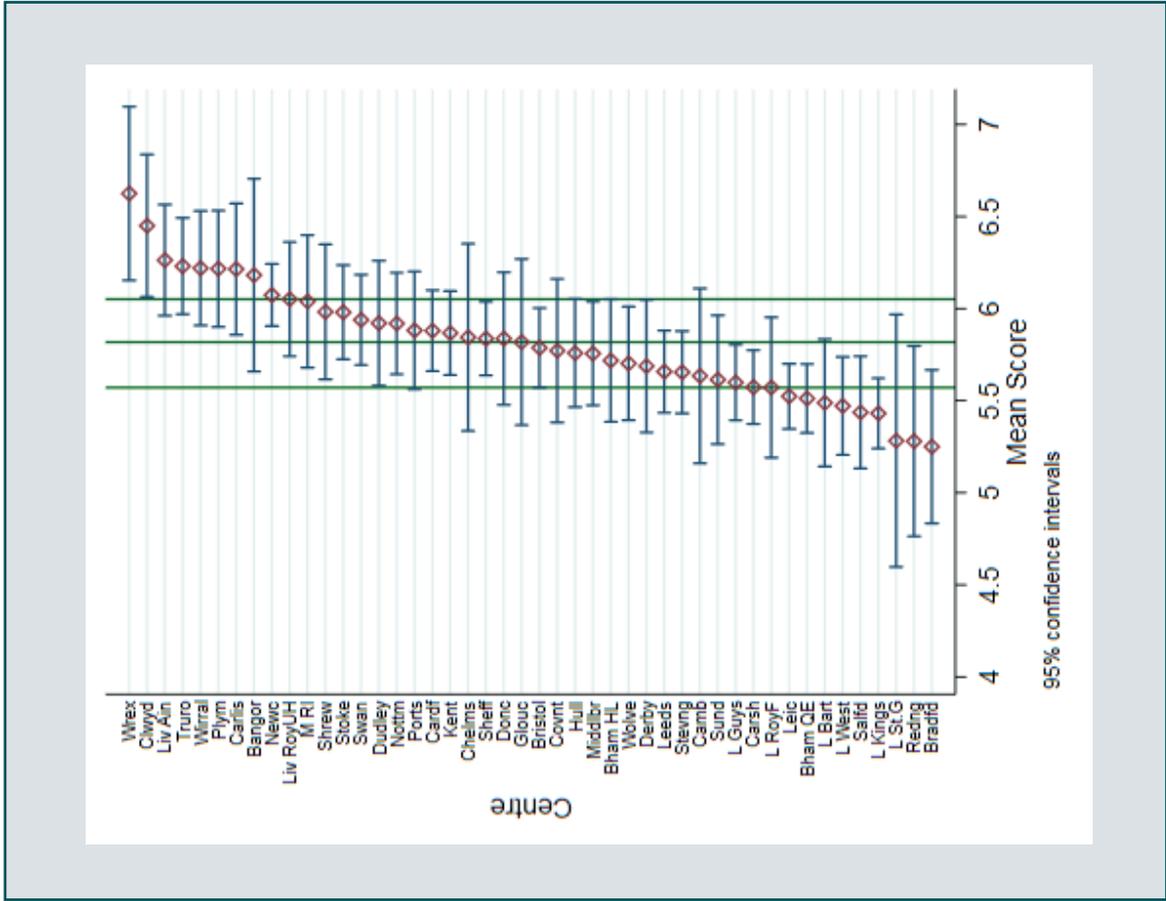
Section 5. Fluid Intake and Diet



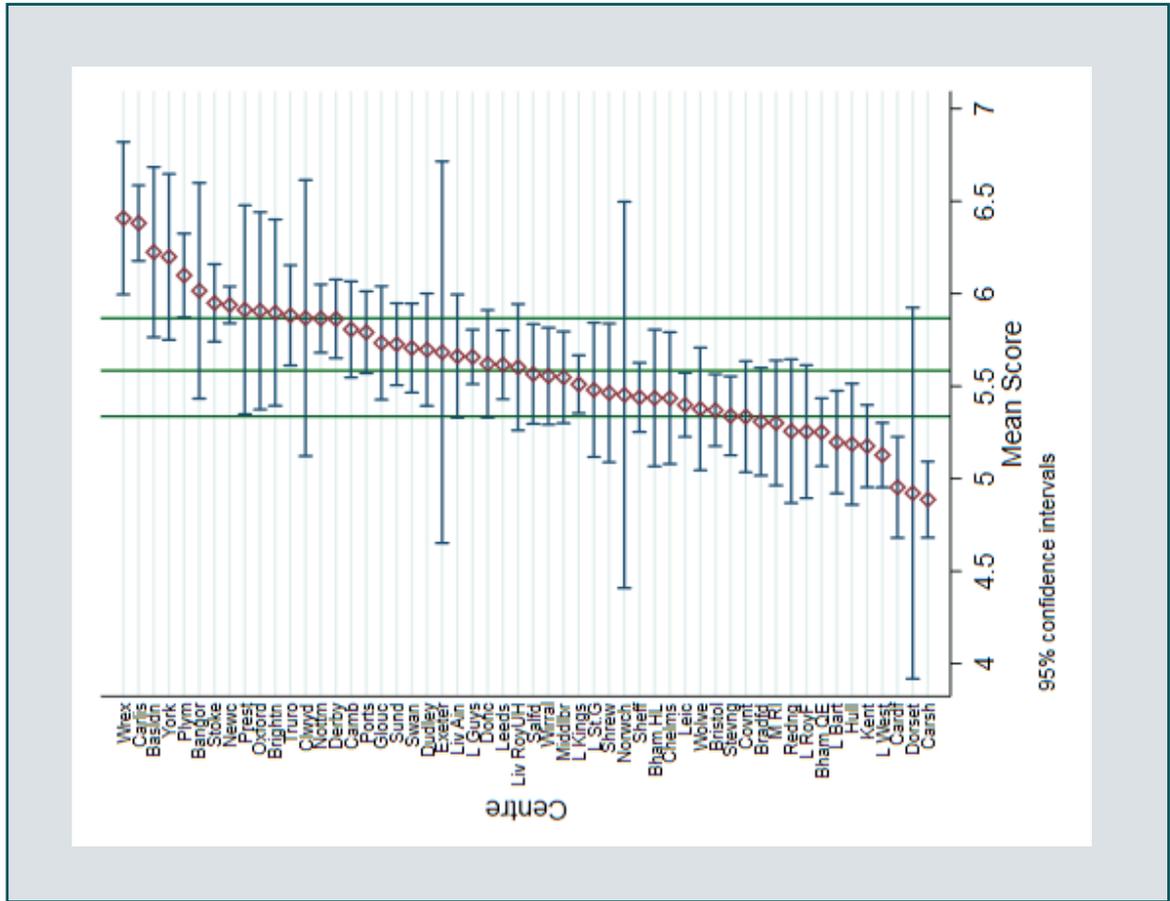
Section 7. Tests



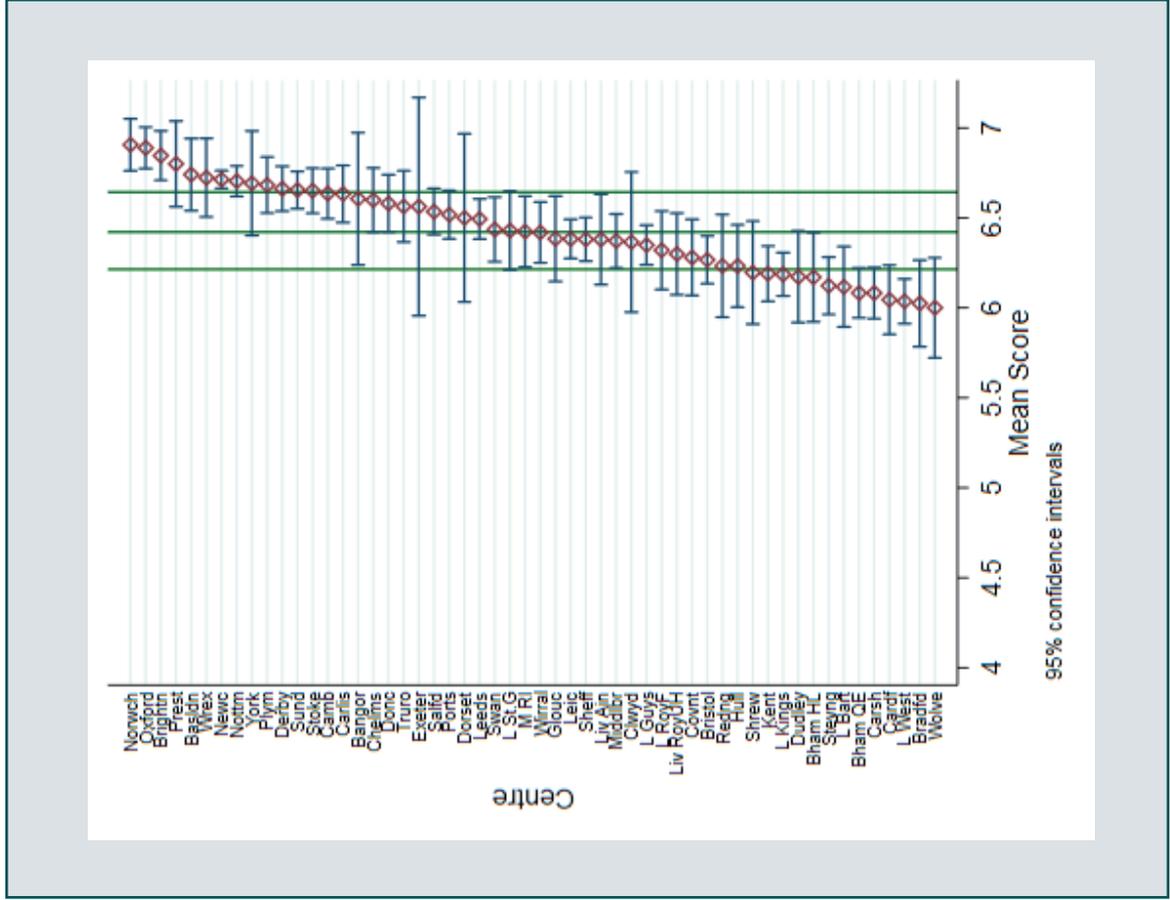
Section 6. Needling



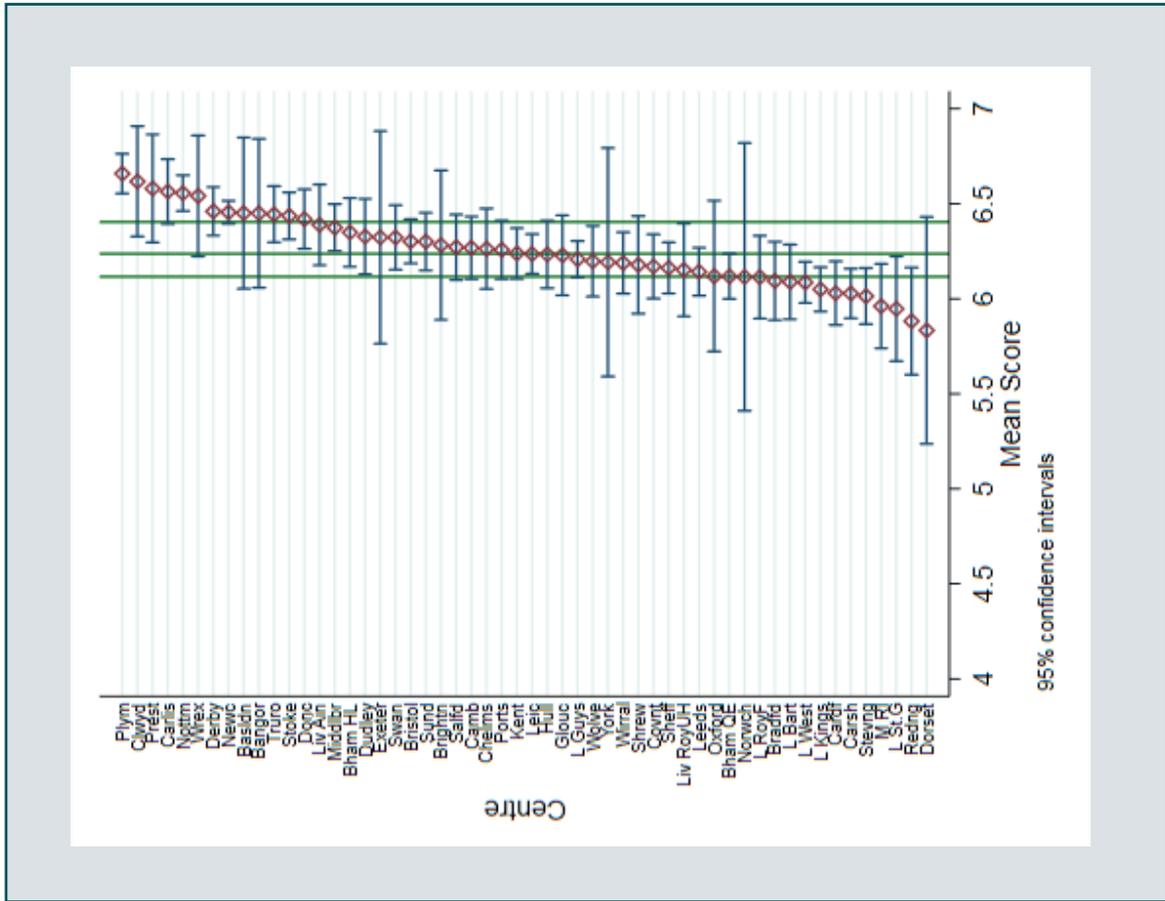
Section 8. Sharing Decisions About Your Care



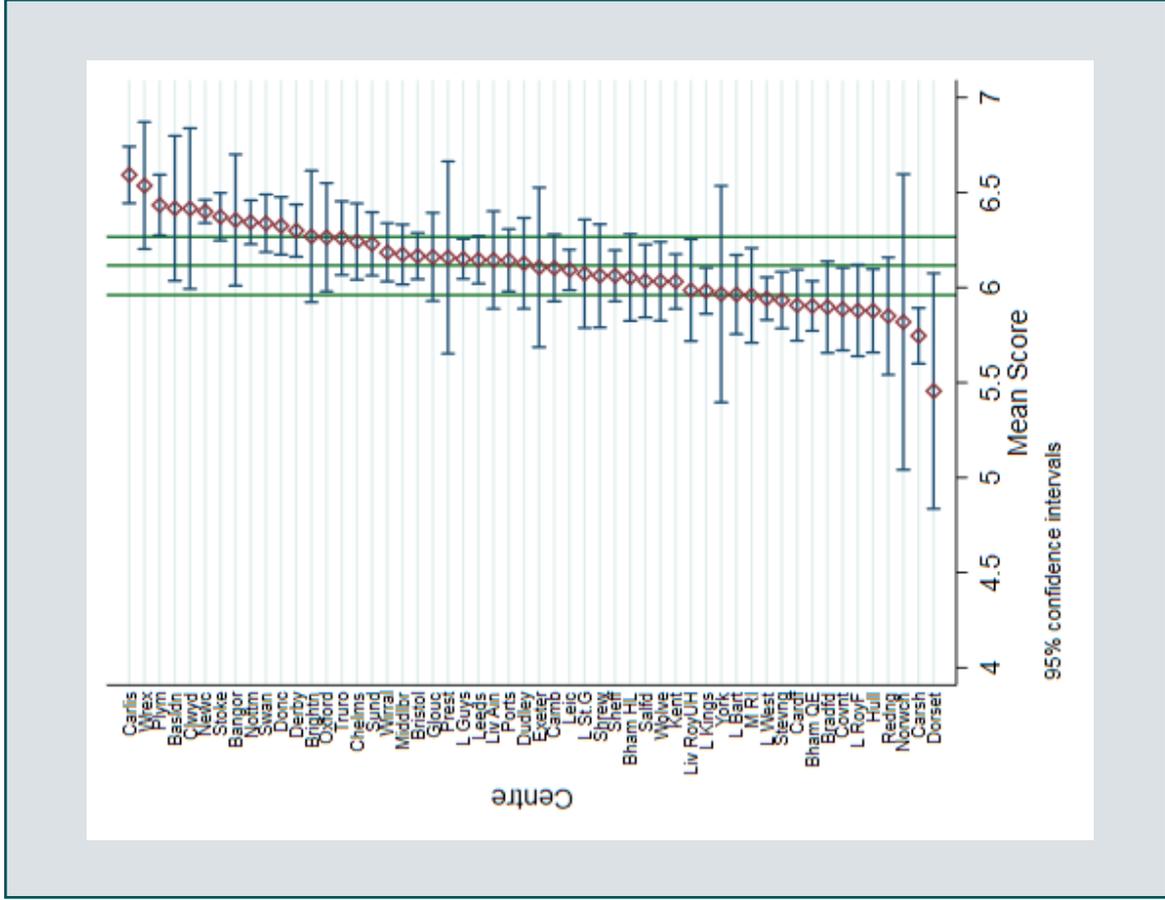
Section 9. Privacy and Dignity



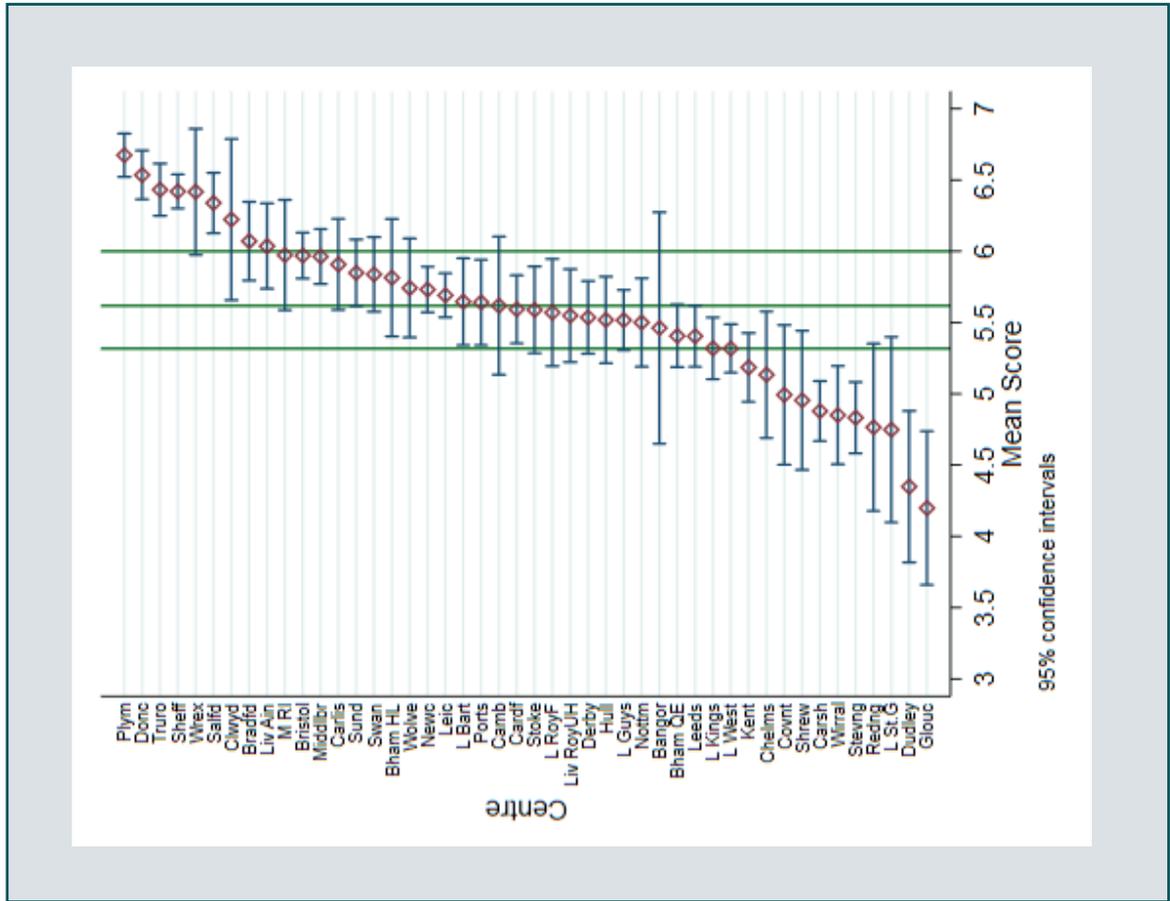
Section 10. Scheduling and Planning



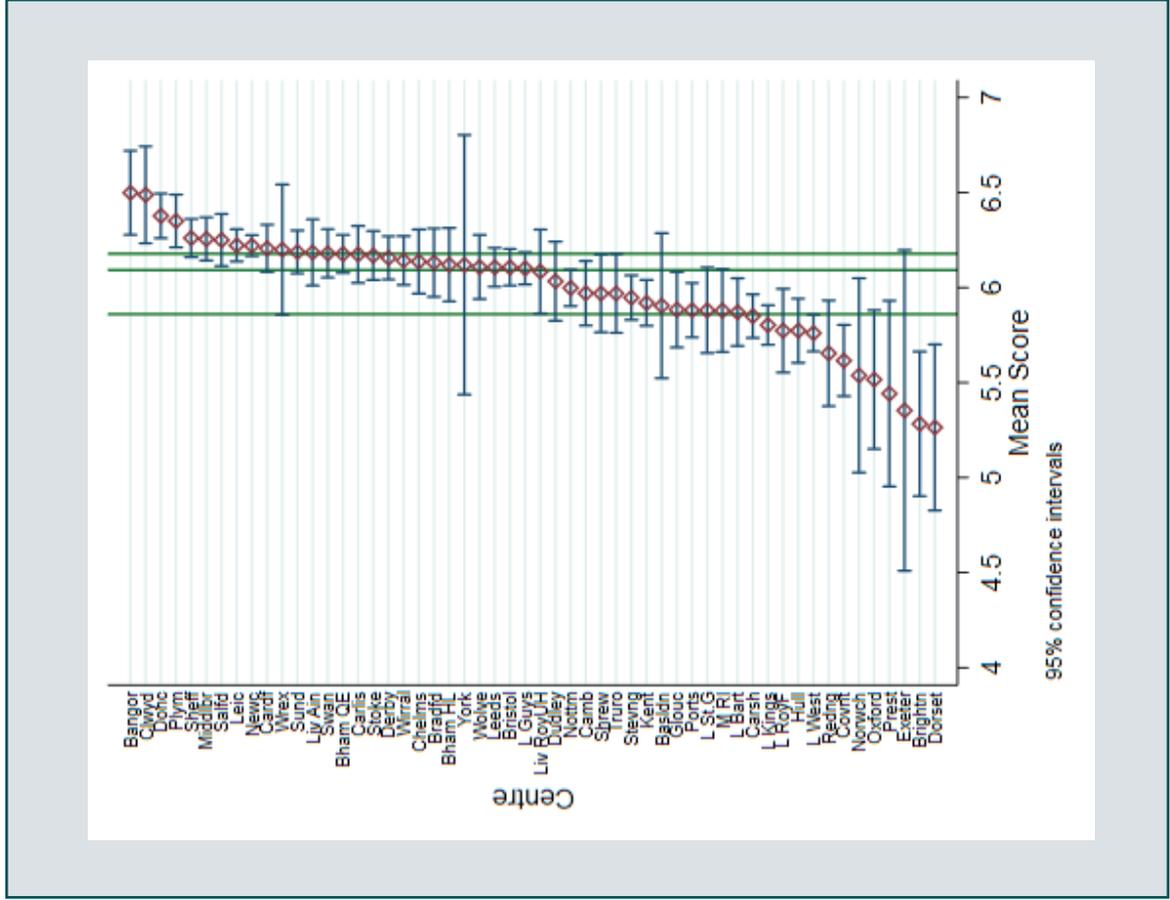
Section 11. How the Renal Team Treats You



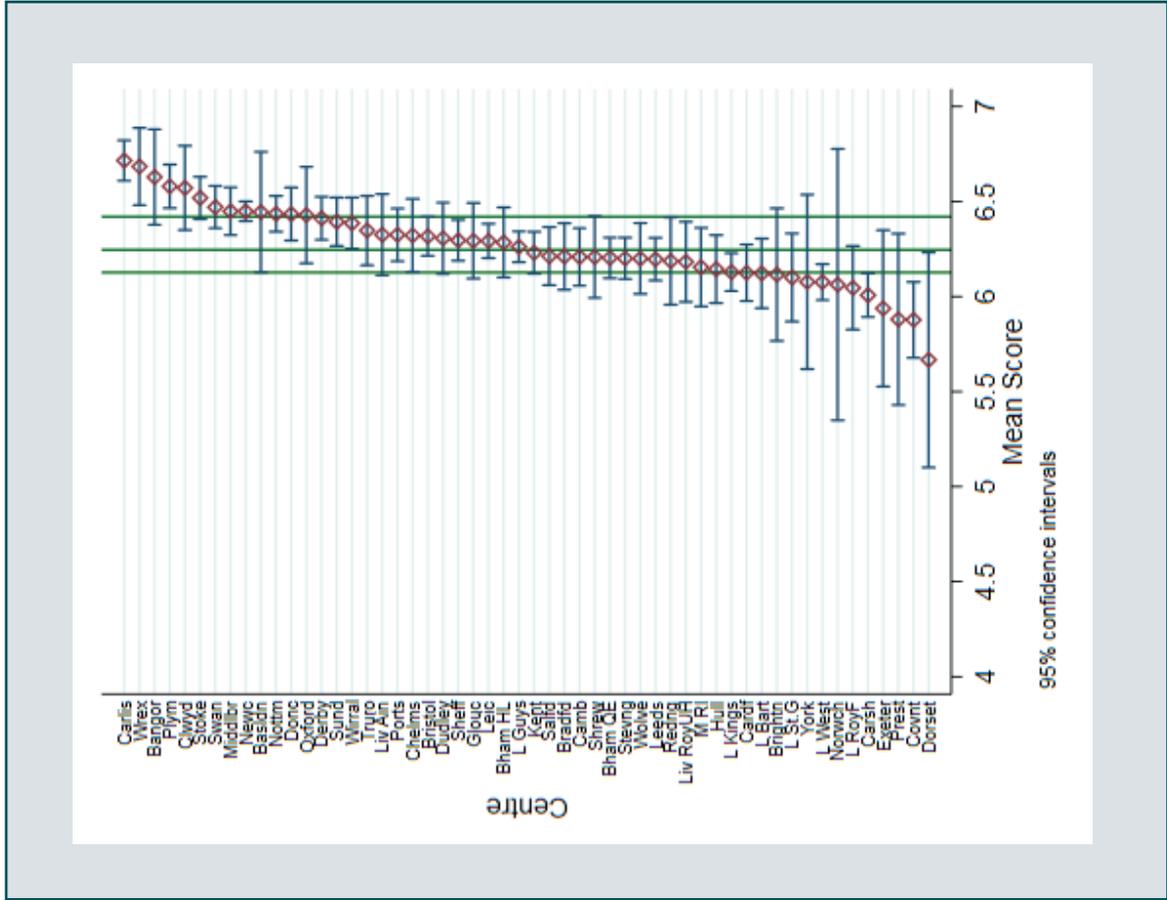
Section 12. Transport



Section 13. The Environment



Section 14. Overall Experience



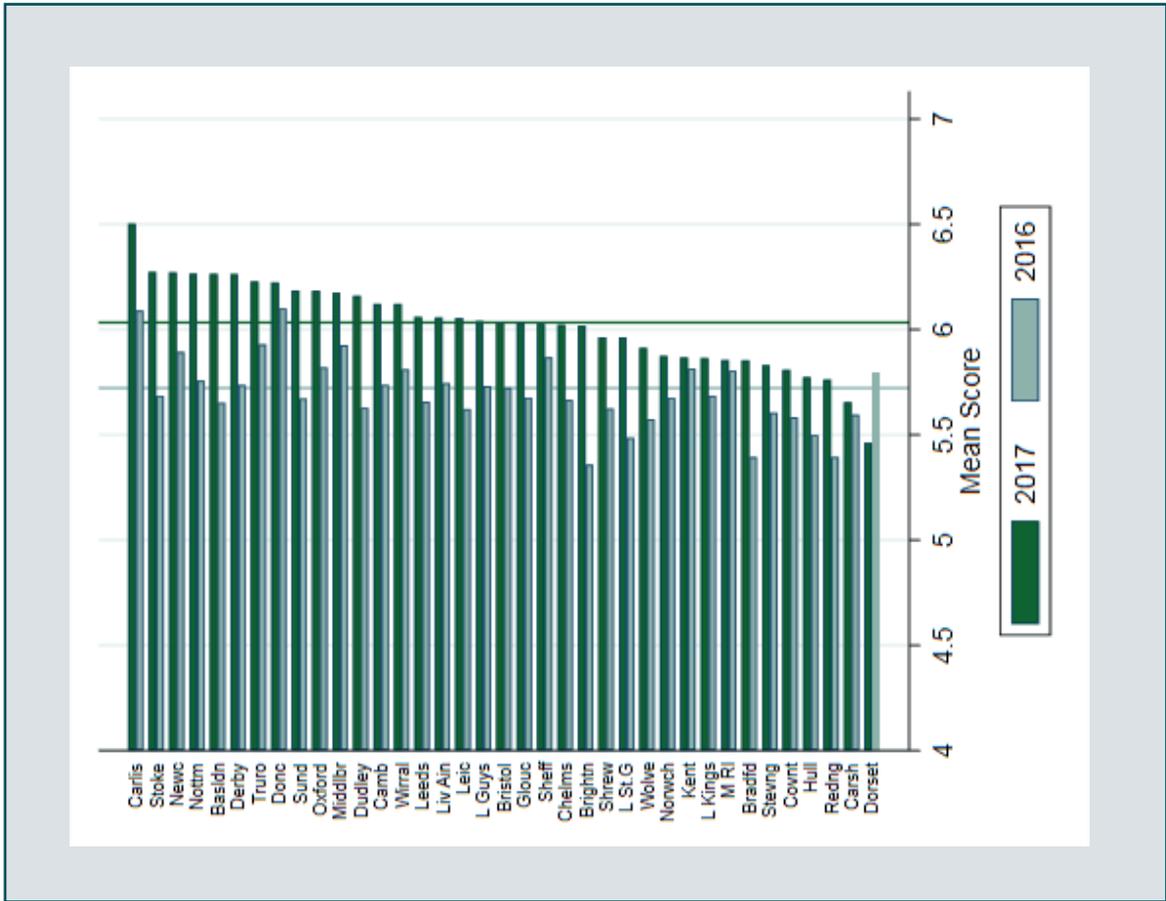
Appendix 5: 2016 / 2017 theme comparisons

These charts show mean centre scores in 2016 and 2017, with the mean of mean scores in each year. This is the same 2017 data as in the preceding charts, but with an adjusted score for 2016⁶. Differences between 2016 and 2017 need to be interpreted with reference to the commentary above, and to Appendix 6 which identifies changes made to the PREM in 2016 to form the 2017 PREM, and also noting that in 2017 the response scale was changed from a categorical format to a linear one. Some changes may be attributable to these changes, and not to changes in the experience of respondents.

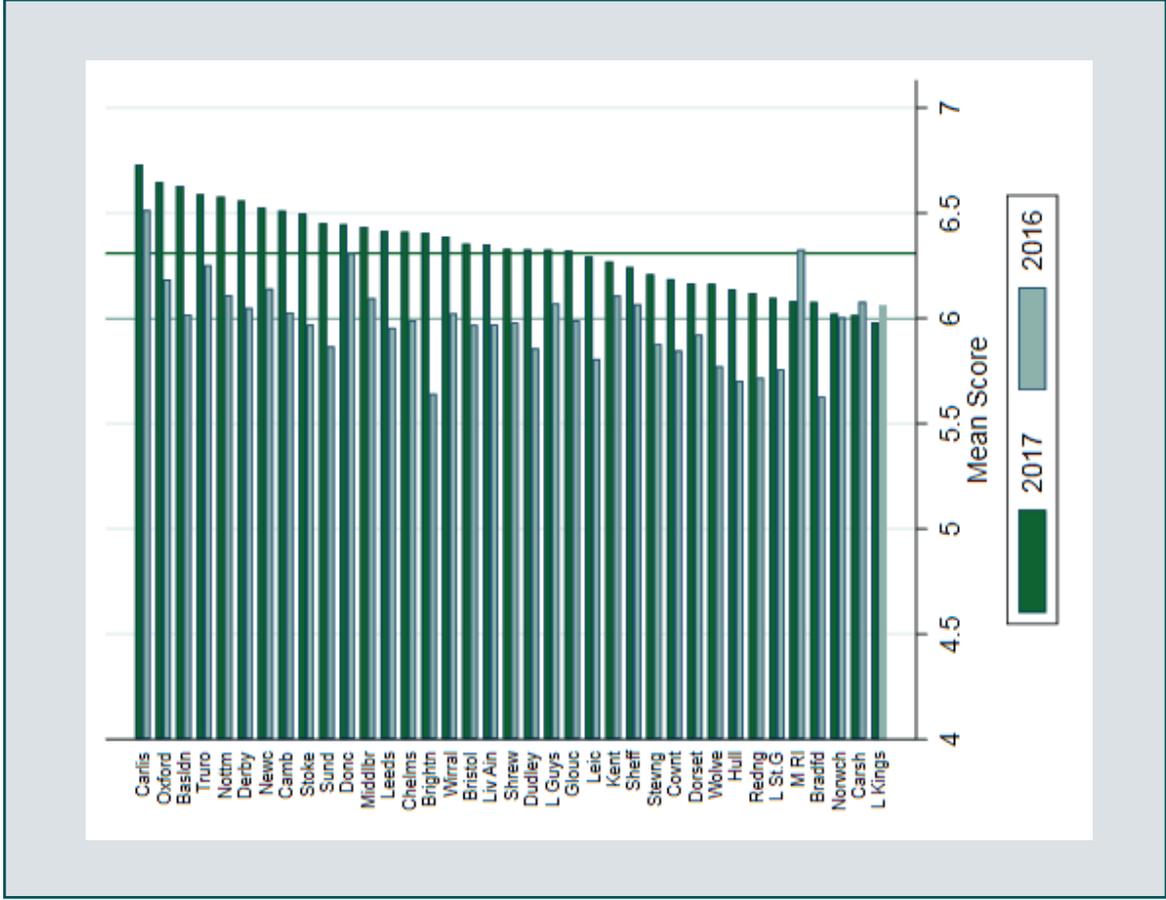
Other changes may be due to difference in the type of people responding, and to the number of people responding in each year (see Table 2).

⁶ The scale in 2016 ran from 1 to 4. The 2016 mean scores have therefore been transformed to be equivalent to the 1-7 scale used in 2017.

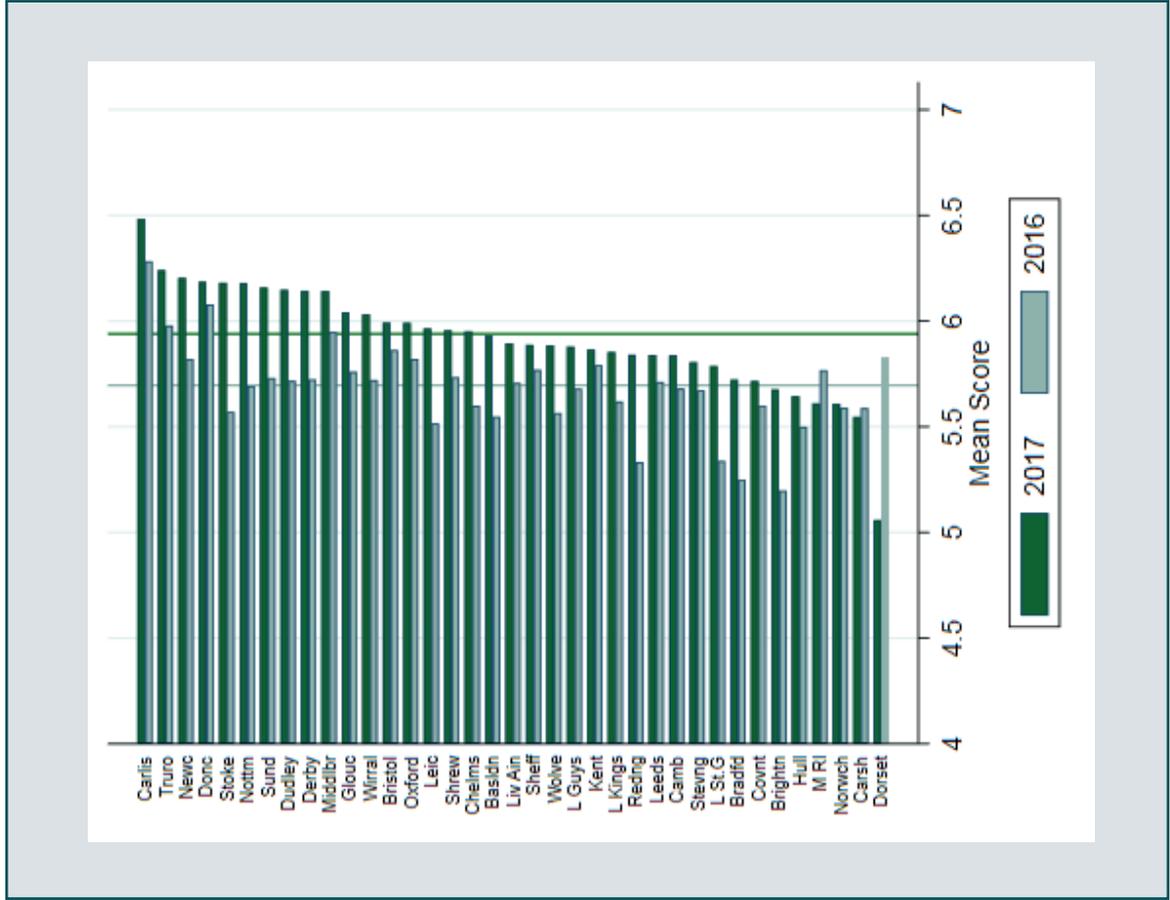
Access to the Renal Team



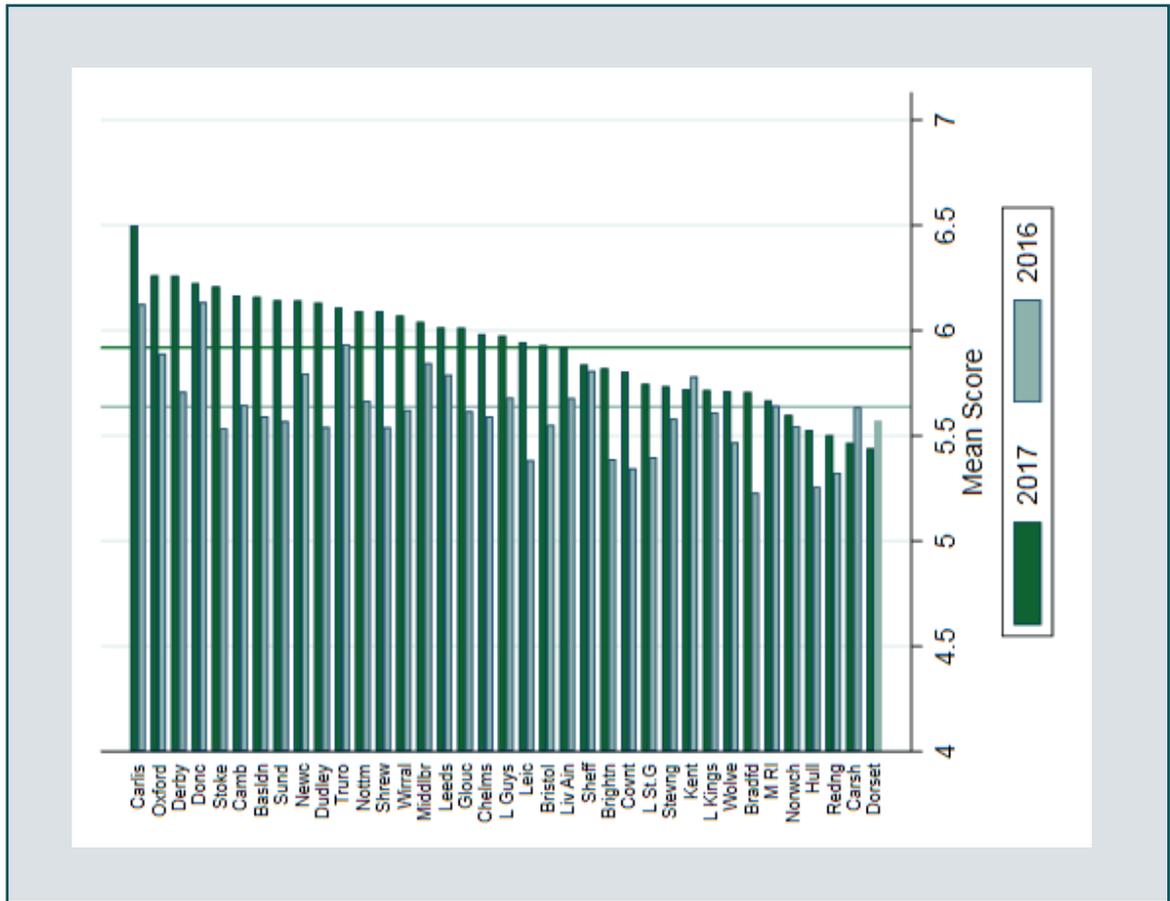
Scale Total. Responses Across All Themes



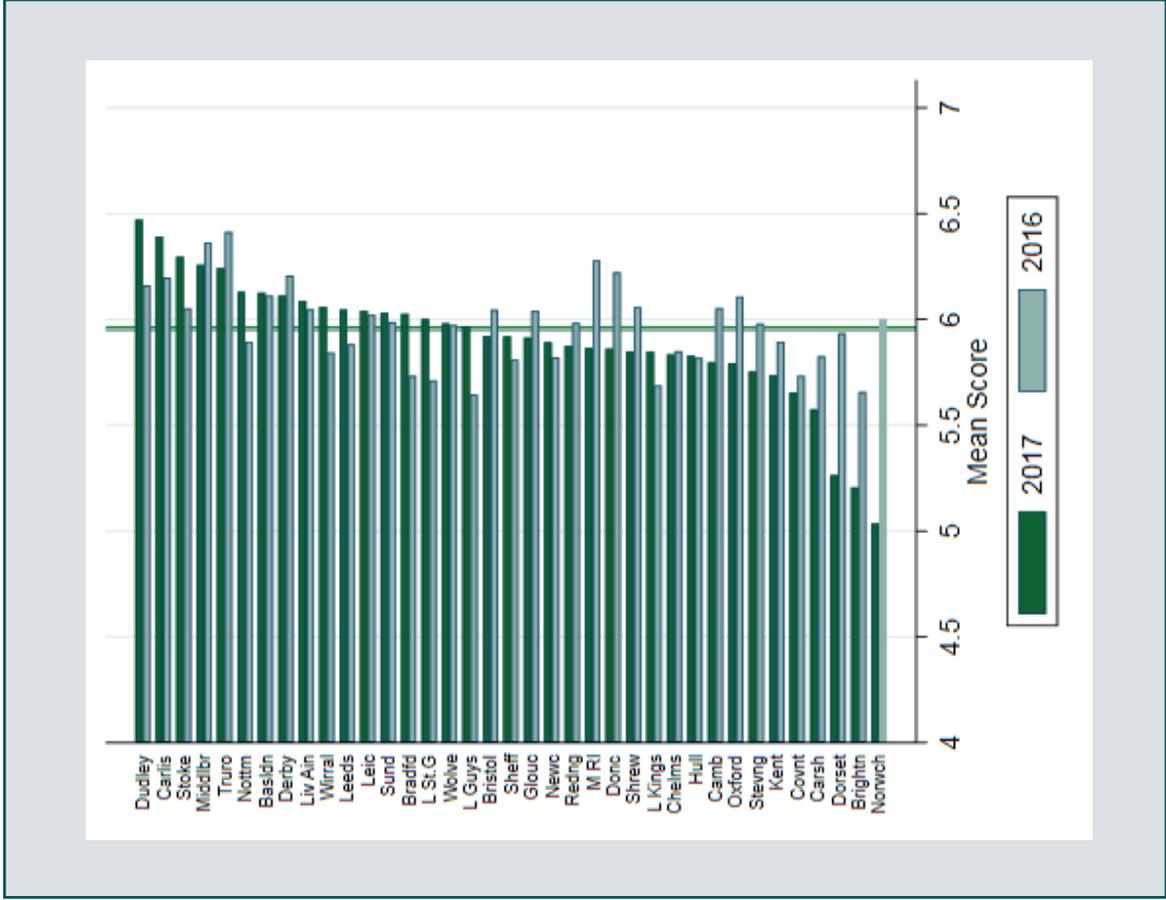
Communication



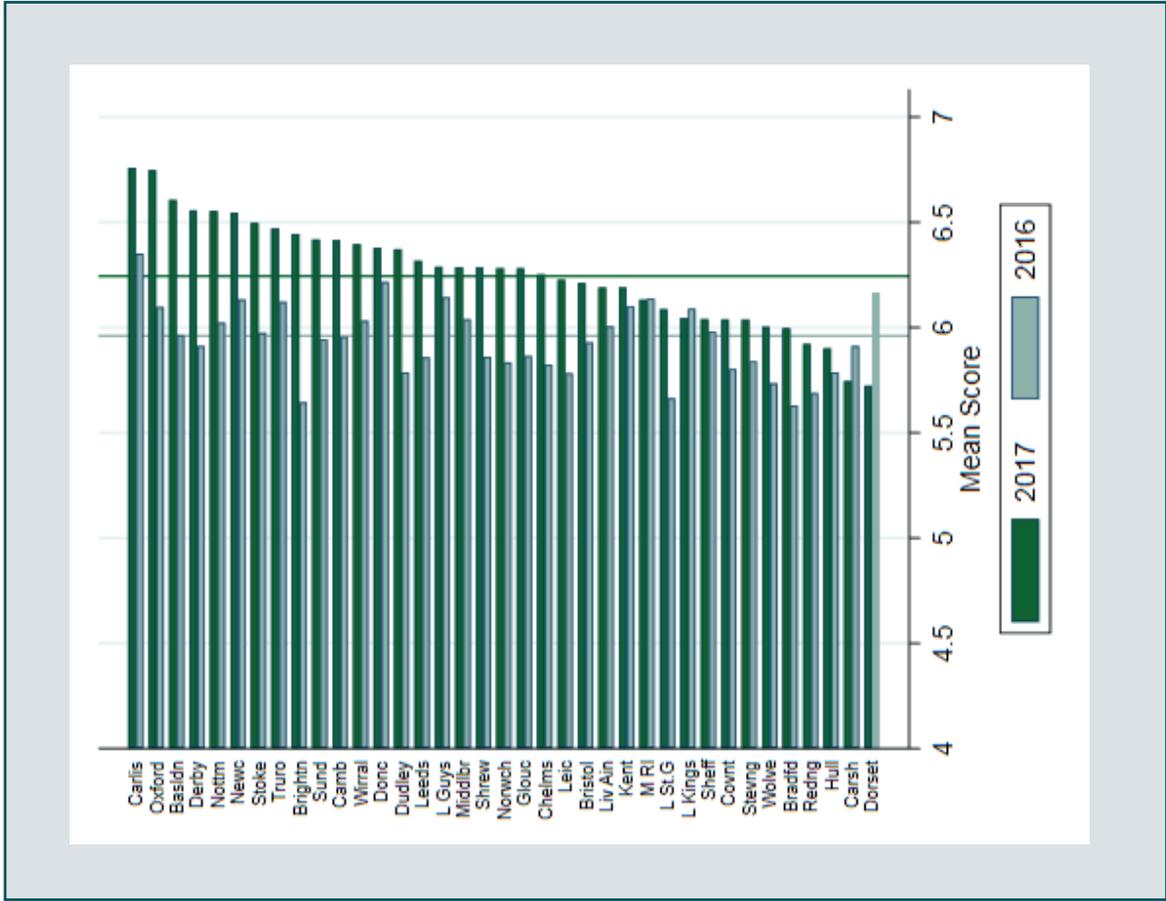
Support



Fluid Intake and Diet

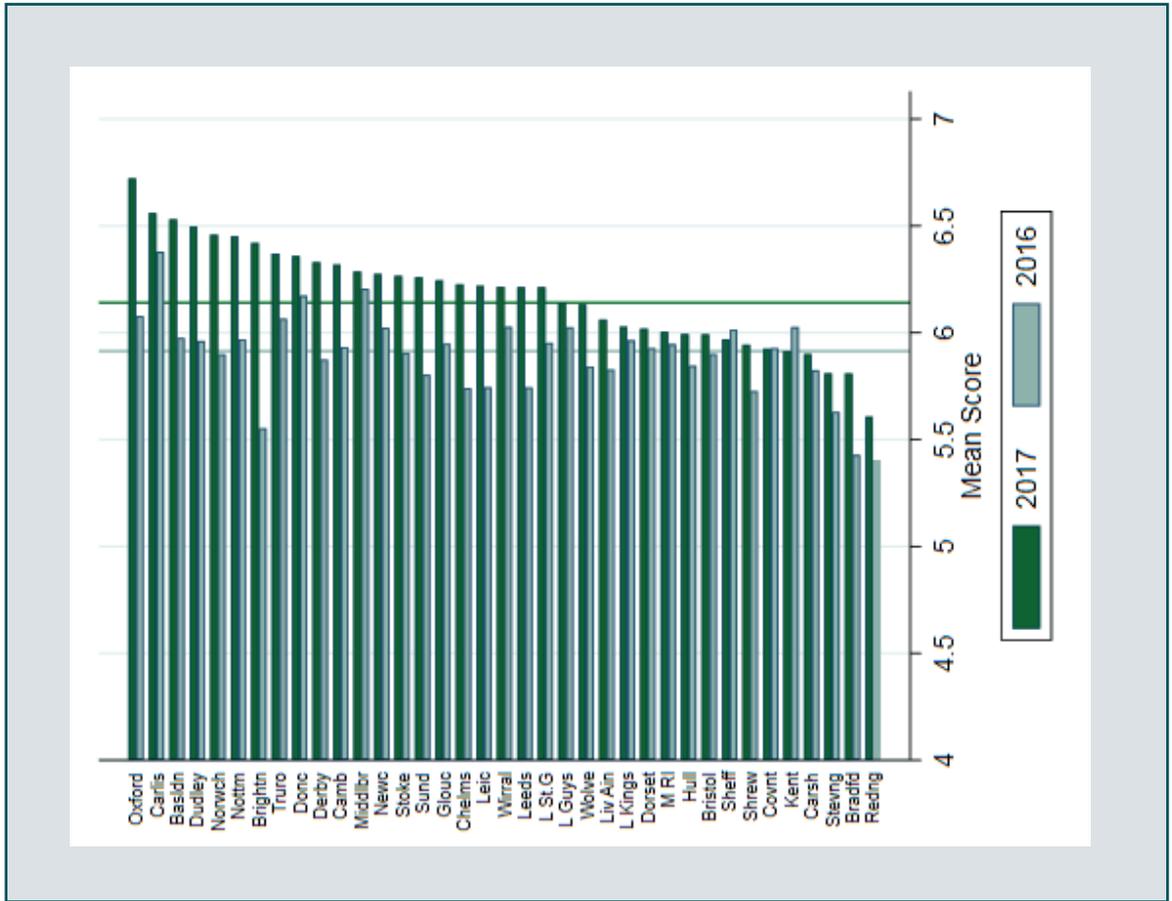


Patient Information

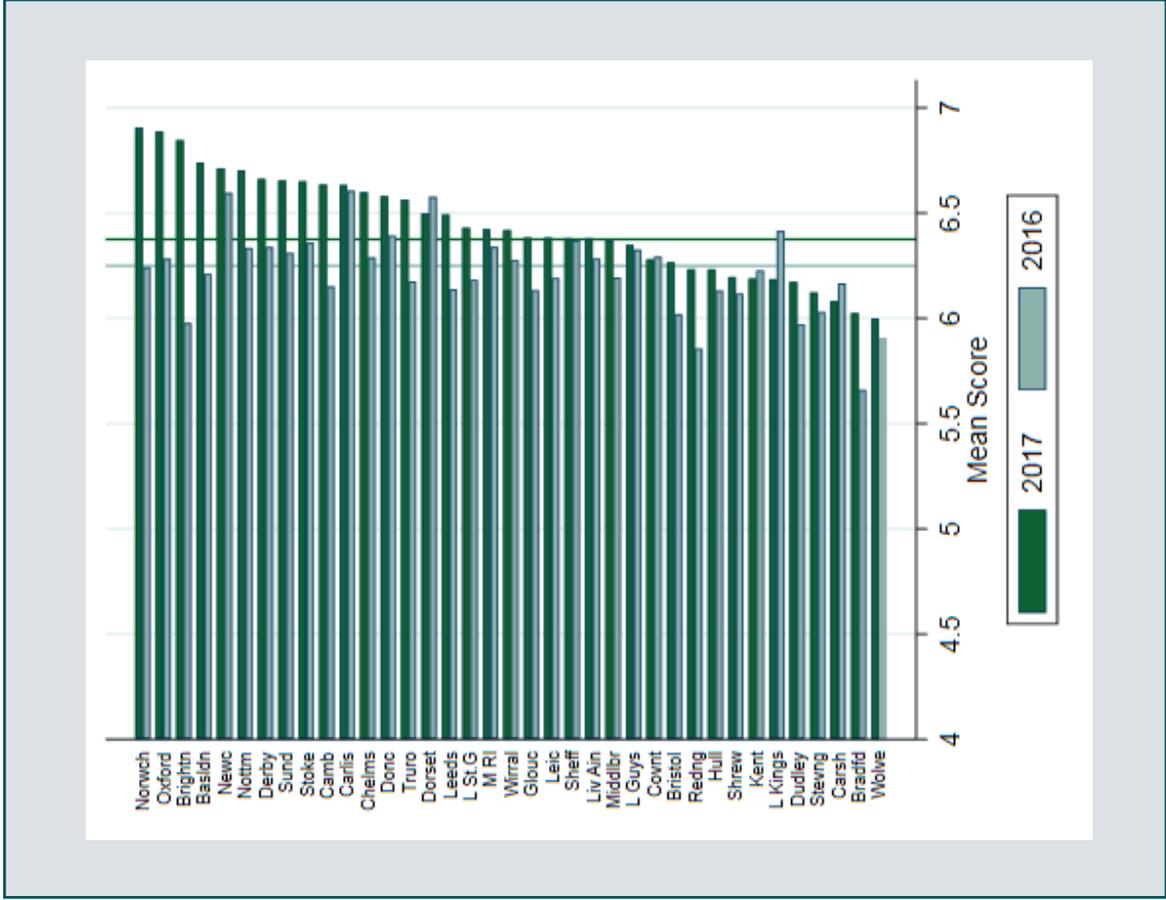


Tests

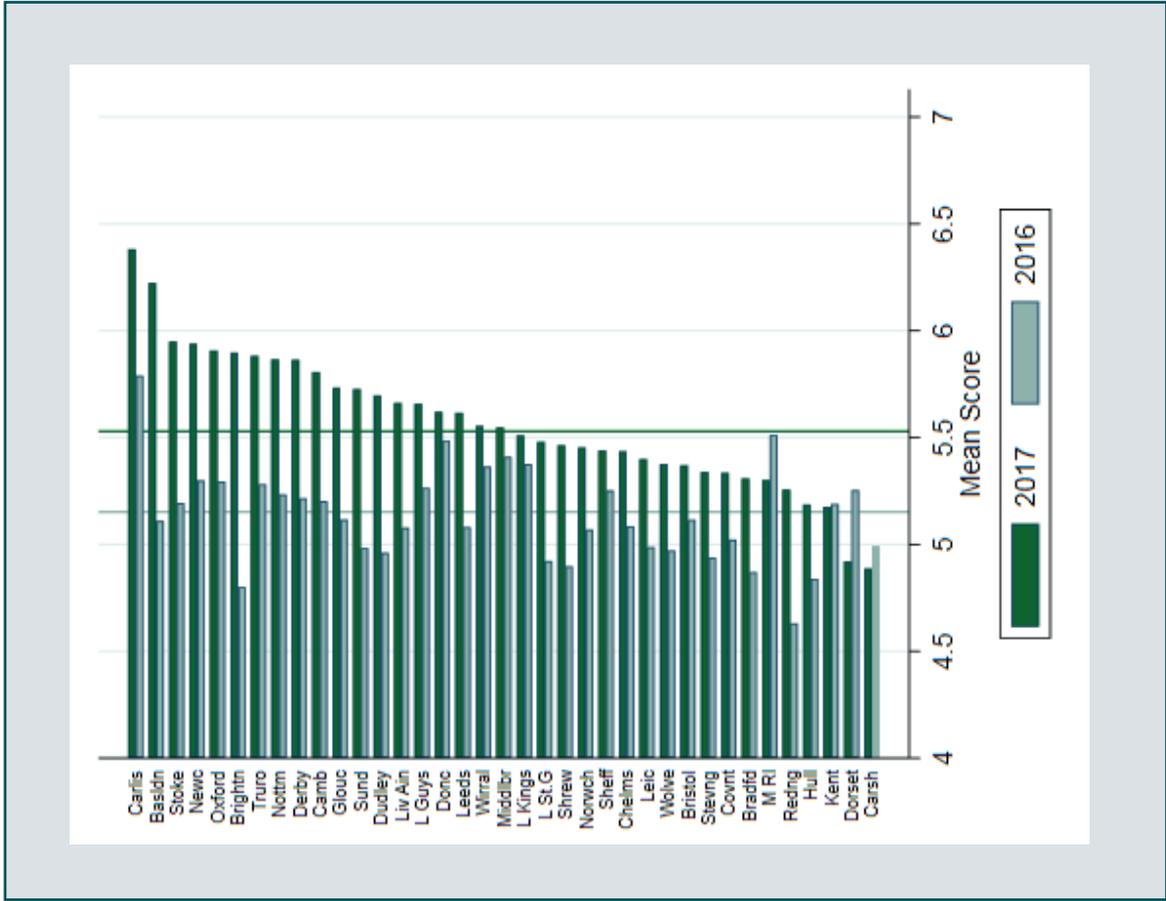
Needling was new to the 2017 PREM, so there is no comparative data.



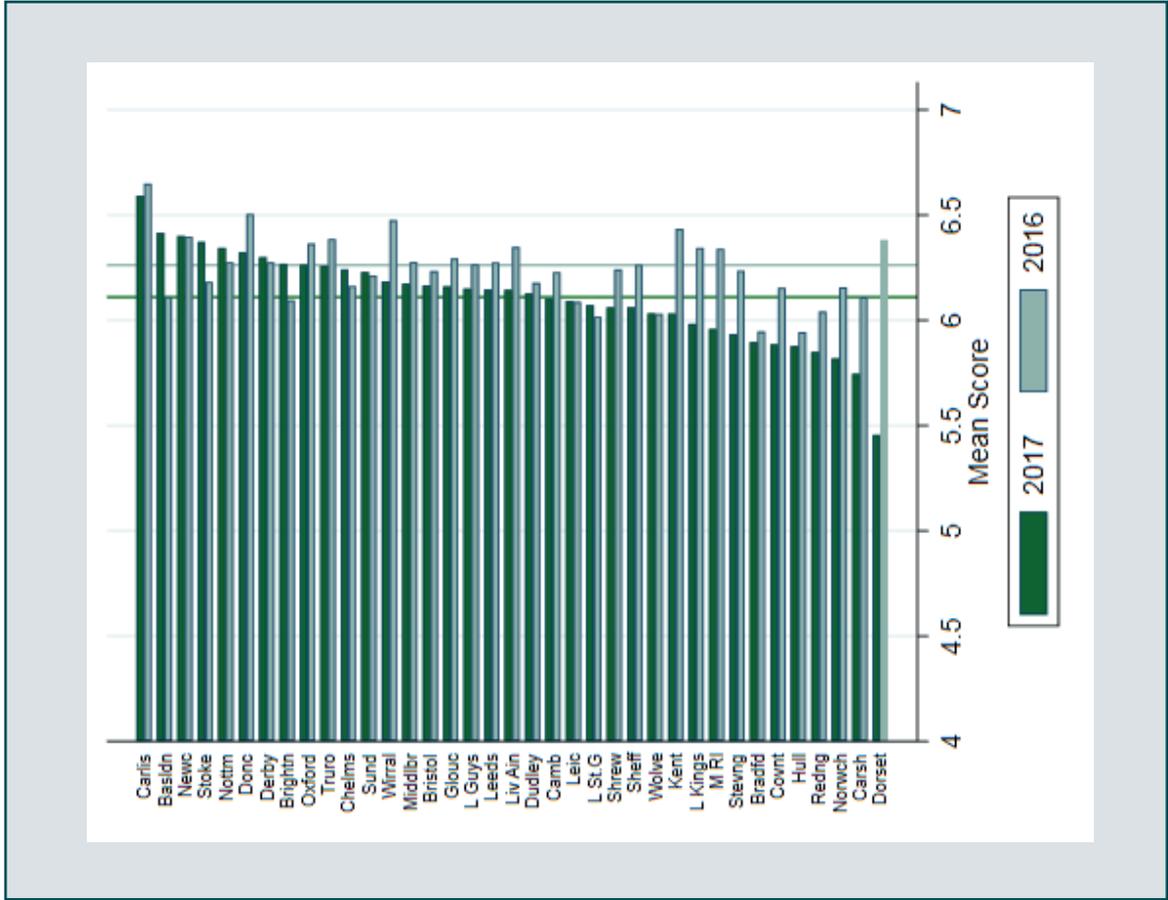
Privacy and Dignity



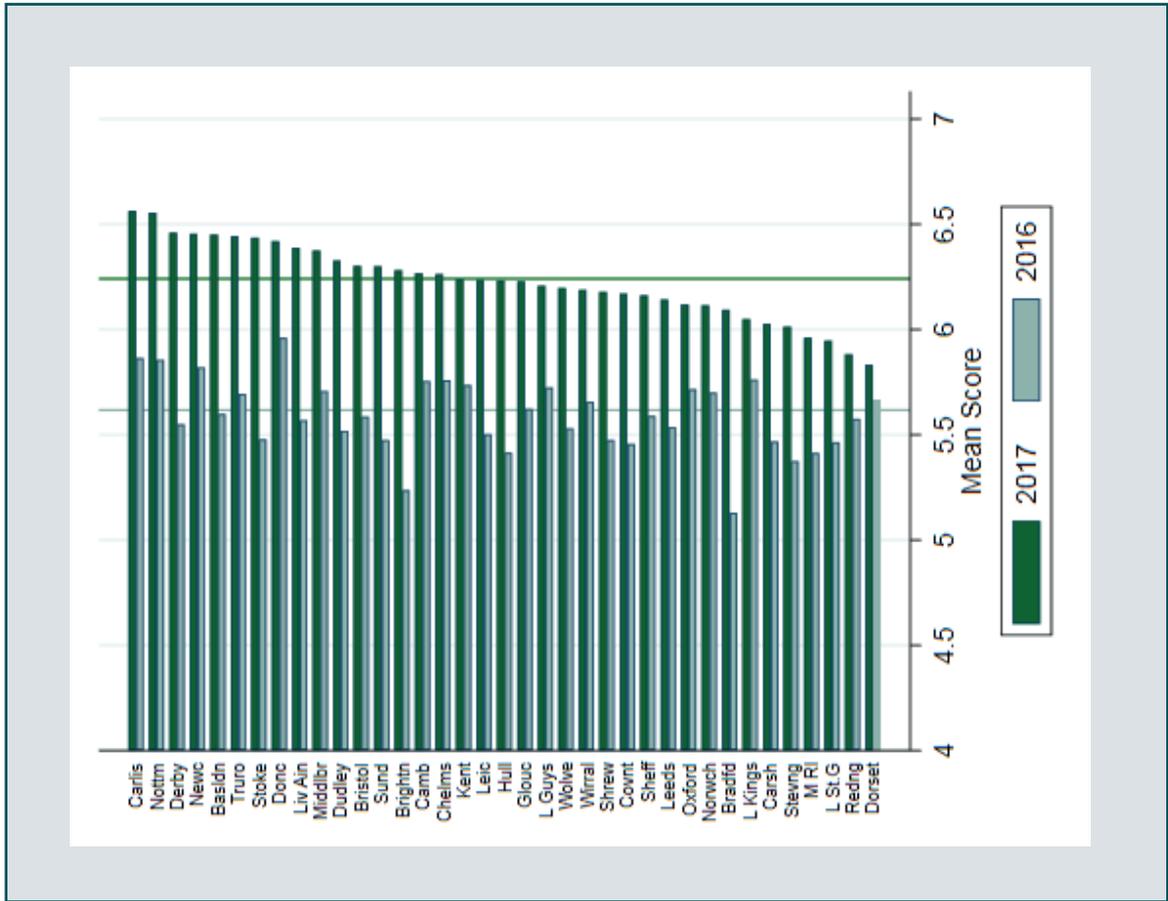
Sharing Decisions



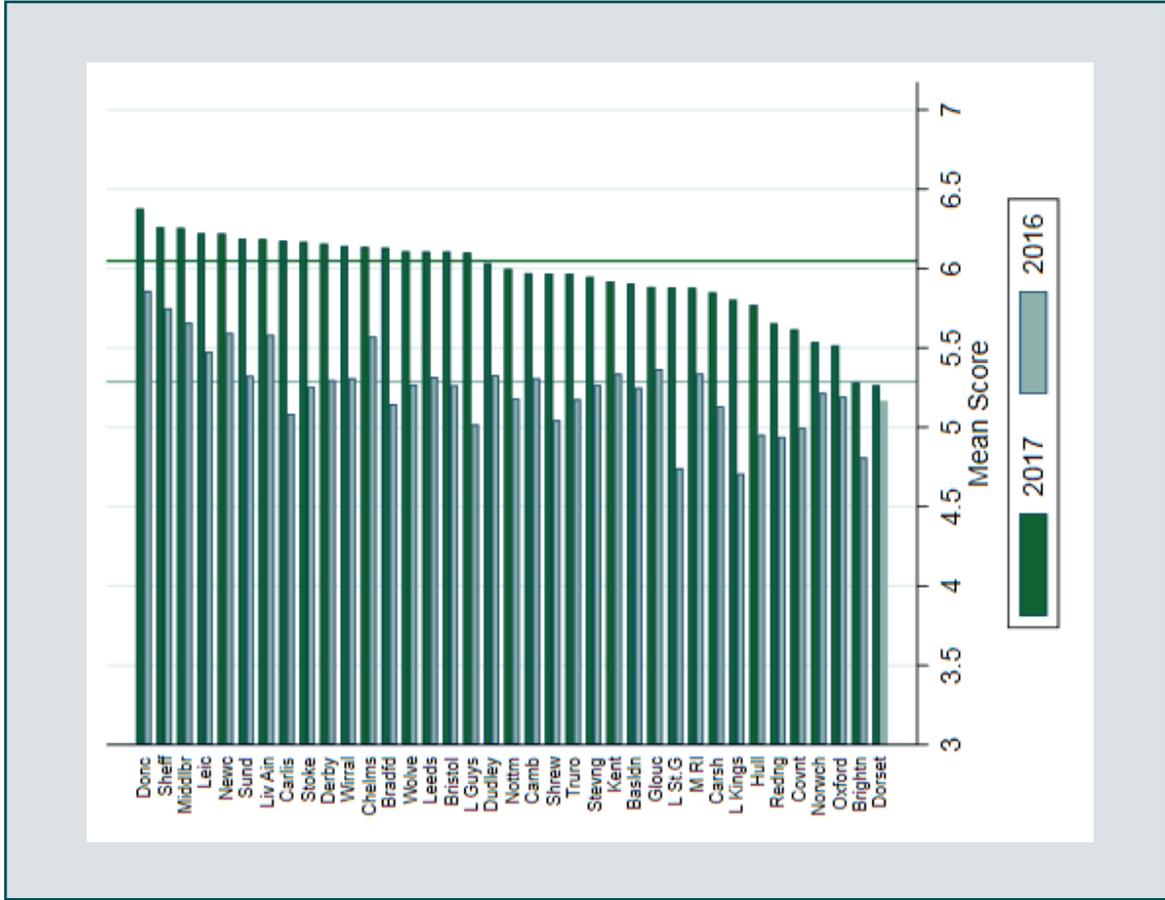
How the Renal Team Treats You



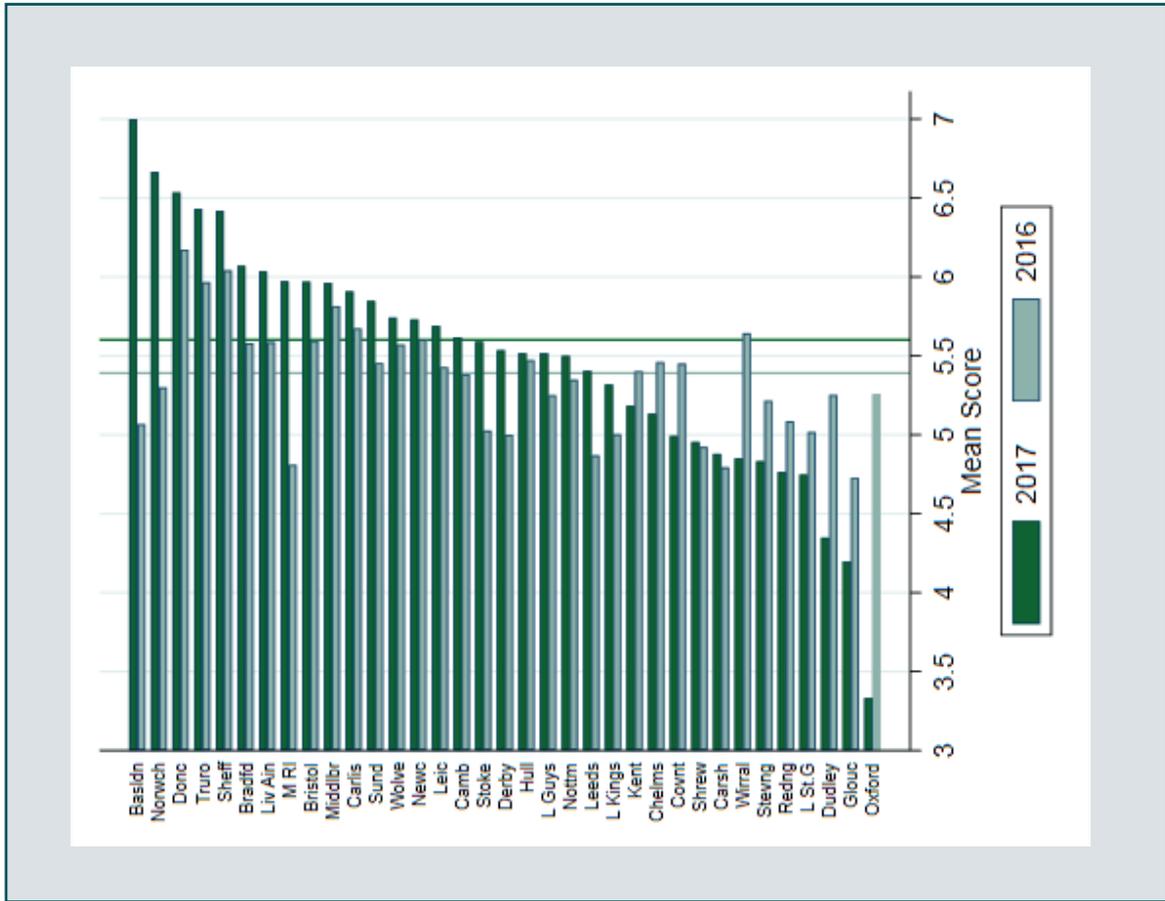
Scheduling and Planning



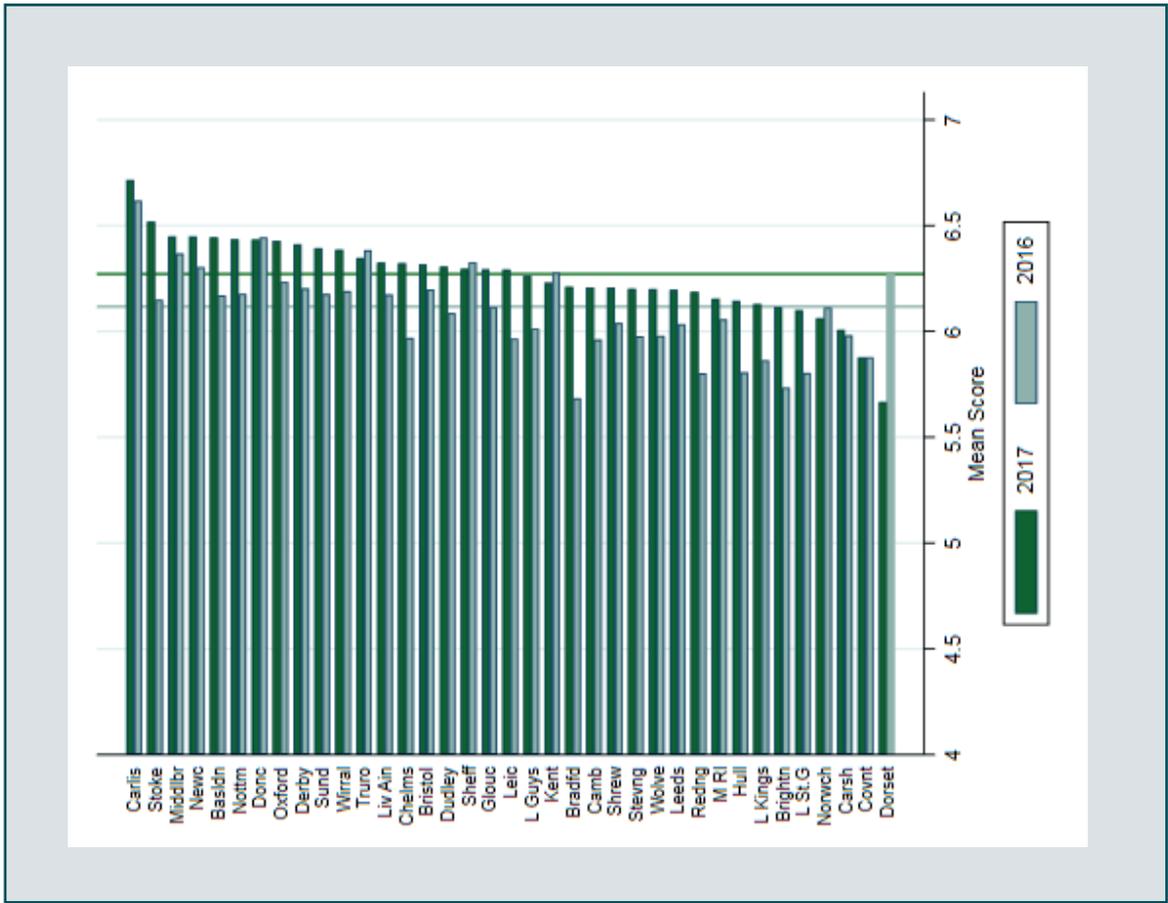
The Environment



Transport



Overall Experience



Appendix 6: Changes to PREM between 2016-17

Missing data was a significant issue in 2016, with 10 of 43 questions attracting more than 15% missing responses. This was a major driver of changes to the PREM for 2017 (Appendix 1), which was modified following patient review and analysis of the 2016 data. The number of questions was extended to 50 to clarify some patient experience themes. We also expanded and changed the response scale to be consistent across the PREM. The response scale now runs from 1 to 7, representing:

- Never to Always for questions 1-44;
- Poor to Excellent for questions 45-49 (the environment) and,
- Worst to Best it can be for question 50 (overall experience of care).

The options 'Don't Know' and 'Not Applicable' are available for all but the question on overall experience. For three sections the 'filtering' has been improved, making it clear that some questions were only applicable to some patients (Needling [in-unit haemodialysis only], Arrangements for blood tests [all but in-unit haemodialysis], Transport [only patients using hospital transport]). Other sections and questions were changed to clarify meaning, and three questions were modified to be positive in tone instead of negative.

Theme	2017		2016		Changes
	Section	No. of questions	Section	No. of questions	
Access to the Renal Team	1	3	2	3	Changes to clarify meaning
Support	2	4	3	5	Changes to wording, removed a question
Communication	3	6	4	4	Substantial changes to clarify meaning
Patient Information	4	4	5	4	Changes to clarify meaning
Fluid Intake and Diet	5	6	6	2	Substantial changes to content, separating fluid from diet
Needling	6	1			New section
Tests	7	3	7	3	Changes to clarify meaning
Sharing Decisions About Your Care	8	4	8	4	Substantial changes to clarify meaning
Privacy and Dignity	9	2	9	2	Minimal changes
Scheduling and Planning	10	3	10	3	Substantial changes to wording, introduction of a filter around the blood test question. Change in tone of 1 question from negative to positive
How the Renal Team Treats You	11	5	1	4	Moved from first section to 11. Some changes to clarify meaning. Added new question about emotional support
Transport	12	3	11	3	Changed to emphasise focus on hospital transport only. Minor changes to wording
Environment	13	5	12	5	Minor changes
Your Overall Experience	14	1	13	1	Minor changes to the questions, considerable changes to the response scale
Total number of questions		50		43	

Appendix 7: 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



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