



**Patient Reported Experience
of Kidney Care in the UK
2020**

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Foreword

We are delighted to present the 2020 Kidney Patient Reported Experience Measure Report. One of the great strengths of the Kidney PREM is that it truly represents a fusion of ideas from both patients and clinicians. As a kidney patient and a kidney clinician we know that 2020 has been a year like no other. Both patients and professionals were hugely affected by COVID-19 so it is a testament to the value of these reports and the hard work of the whole community that the 2020 Kidney PREM was completed (entirely digitally for the first time) and that almost 10,000 responses were received representing every one of the 70 UK Renal centres. 39 questions across 13 areas of care continued to reflect a broad range of themes with much valued free text comments available to capture more personal experiences. This year four additional questions attempted to capture new and unique challenges during COVID-19.

It therefore seems especially fitting in a year that has seen patients and clinicians work together more closely than ever that this foreword has been written by a patient who helped develop the original survey and has seen it grow and by a clinician who was working in one of the centres which was hardest hit by COVID-19.

Having been involved with the Kidney PREM since its inception with Transforming Participation in Chronic Kidney Disease (TPCKD), I am delighted that not only am I still involved with it, but that it has now become established as an annual event.

As a patient, and Co-Chair of the Measurement Work Stream, it was important to me, right from the beginning that the Kidney PREM should reflect the views of the patients themselves, as what is important to a patient may be totally different to what is important to a member of staff. As a scientist and member of hospital staff, I was aware that the results had to be relevant to the individual renal centres as well, so a fully rounded all-inclusive Kidney PREM had to be produced. Thankfully TPCKD was co-produced, equal numbers of patients and professionals, so working together we managed to develop a questionnaire which both sets of people were interested in.

This year has been very difficult for everyone and changes have been made to every aspect of renal care which was mirrored in the Kidney PREM, where for the first time, it could only be completed on line with no paper versions available. This presented both opportunities and challenges to patients and staff alike.

Having heard and read comments from renal patients on social media struggling with the restrictions and changes which have had to be made both in their treatment and their private lives, it is encouraging that the Kidney PREM has shown that patients still appreciate the work done by all the renal staff for their benefit.

As a clinician working through 2020, it was perhaps surprising to see that overall Kidney PREM scores fell only slightly from 6.3 out of 7 in 2019 to 6.2 out of 7 in 2020 indicating that services remain greatly appreciated by patients who place huge trust in their renal care despite the pressures of the last year. Familiar themes remain challenging such as Transport, Shared Decision Making and Needling with Patient Information, Privacy and Dignity and Access to the Team continuing to perform well.

Patients receiving treatments managed largely out of hospital such as Chronic Kidney Disease (CKD), transplant, peritoneal dialysis and home haemodialysis returned lower scores than areas such as in-centre haemodialysis perhaps reflecting a diversion of resource at a time of huge pressures on the NHS.

It was noticeable that CKD patients gave the lowest scores possibly reflecting how easy it is for patients who are off-site to suffer in a pandemic. A need to move our focus to include those further back in the CKD journey and before the start of renal replacement therapy is a theme being picked up by the wider community. Earlier CKD care will be more extensively reported in the UK Renal Registry data and will be the focus of a new UK Kidney Association CKD Special Interest Group – there is a real opportunity to improve care moving forwards.

As we re-build so many NHS pathways after COVID-19, renal has a unique opportunity. The availability of the Getting It Right First Time report, the delivery structures of the Kidney Quality Improvement Partnership and the Kidney Specialist Interest Groups all working with the Renal Services Transformation Programme offer an opportunity for the whole community to work together across clinicians, commissioners, patients and charities to redesign and offer the best possible experience for renal patients.

We hope that centres will be able to read the report and be very proud of the care that they provided to patients during these extraordinary times. We also hope that units can use the learning to make even better services for the future.

This is just the beginning of the journey - please read, reflect, discuss and continue to innovate and improve!



Claire Corps
Kidney patient
Doctor of Research Science



Katie Vinen
Kidney Doctor
Clinical Vice President of The Renal Association

Acknowledgements

The Renal Association and Kidney Care UK would like to thank the following people, without whom the Kidney PREM 2020 would not have been possible:

- People living with kidney disease who completed the Kidney PREM online;
- The kidney care workforce and volunteers in all UK renal centres;
- The Kidney PREM working group;
- Transforming Participation in Chronic Kidney Disease Measurement Workstream members who developed the Kidney PREM and worked with the University of Hertfordshire on its validation;
- Kidney Patient Association members;
- UK Renal Registry Patient Council; and,
- The University of Hertfordshire who analysed the Kidney PREM 2020 data and led the production of this report.

Statistical Glossary

Range: When a group of scores are calculated, such as theme scores for each centre, the *range* is the difference between the largest (maximum) and smallest (minimum) score. The range provides useful information about the spread, or *variability*, of scores across a centre.

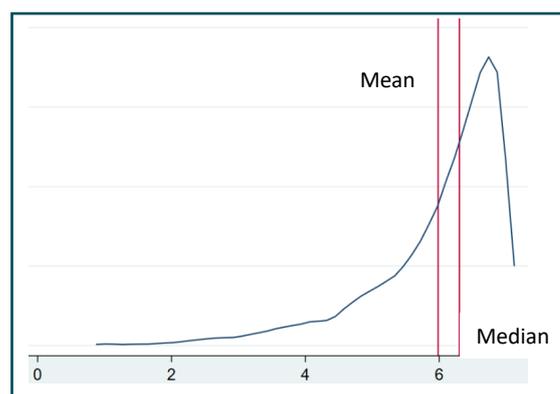
Mean: The *mean* centre score is calculated across patient scores by adding them together and dividing by the number of scores used, giving the mathematical average value.

95% Confidence Interval: When patient scores are combined to calculate the mean centre score, there is a 95% chance that the *95% confidence interval* would contain the true centre score that would be obtained if all patients were included. Higher *variability* and/or a small number of patient scores can result in wider 95% confidence intervals.

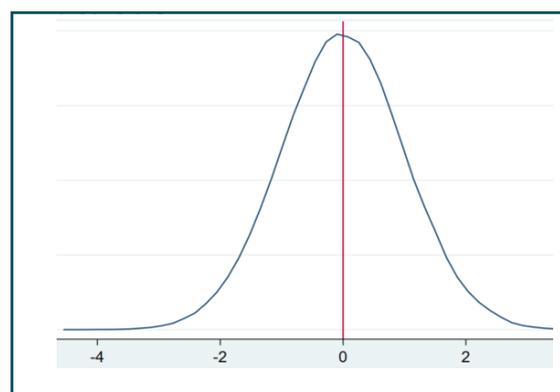
Median: If patient scores for a particular centre were listed in order, the *median* is the middle value separating the high scoring (top half) from the low scoring (bottom half).

Lower/Upper Quartiles and Interquartile Range: If patient scores were again listed in order and divided into four groups of equal size, the lower quartile (or 25th centile) would be the value below which the bottom quarter of scores lies. Conversely, the *upper quartile* (or 75th centile) is the value above which lie the top quarter of scores. The difference between the upper and lower quartiles is the *interquartile range*, which contains the middle 50% of scores and is a measure of *variability* of scores.

Left-Skewed: Scores are *left-skewed* (or negatively-skewed) if there are lots of high value scores (e.g., 6s and 7s) and few low value scores (1s, 2s and 3s). For left-skewed data, the median score is always larger than the mean.



Normal Distribution: Scores are *normally distributed* if the mean and median are equal, with the scores distributed symmetrically around them.



Executive Summary

Since 2016, The Renal Association and Kidney Care UK have worked with patients and renal centres to make the Kidney PREM an annual chance for kidney patients to have their say, and 2020 was no exception. Whilst the pandemic changed how the Kidney PREM was accessed by patients, it was an important way for the kidney community to understand how care was experienced, so we can all continue to learn lessons, and make patient-informed improvements to kidney care.

Headline findings in 2020

- Encouragingly, despite the global pandemic, patients continue to rate their **Overall Experience** of the service provided by their renal centre highly.
- Patient reported experience of **Support** and **Sharing Decisions About Your Care** fell in 2020.
- Patient scores for **Support** fell amongst Chronic Kidney Disease (CKD), peritoneal dialysis, home haemodialysis and transplant patients compared to 2019.
- Patient experience of **Sharing Decisions About Your Care** was lowest in those receiving in-centre or in-satellite haemodialysis.
- Patient reported experience of **Transport** improved for in-centre and in-satellite haemodialysis patients in 2020.
- The experience of **patients living with CKD but not receiving renal replacement therapy** notably decreased in 2020 compared to 2019, particularly for **Overall Experience, Support** and **How the Team Treats You**.

The Kidney PREM was available online for six weeks from 1st October 2020, in English, Gujarati, Urdu and Welsh. The current version of the Kidney PREM was validated in 2018, comprising 39 questions about 13 aspects of kidney care, and an overall experience question. A free text box is provided for patients to be able to comment on any aspect of care not covered elsewhere. This year, patients helped design four questions about specific impacts of COVID-19 on their experience of care. These data are being analysed and reported separately.

Response Profile

A total of 9,645 valid surveys were submitted by patients from all 70 renal centres, including 297 satellite units. The majority of responses were from patients treated in English centres (83%) with 11%, 5% and 1% respectively from patients treated in Wales, Northern Ireland and Scotland.

The profile of patients completing the Kidney PREM in 2020 was closer to the profile reflected in the UK Renal Registry (UKRR) data than in previous years: 56% male, 36% <55 years of age, 47% aged 56-74, 18% aged >75. The largest single group were on haemodialysis (51.4%) (5.3% of these were receiving haemodialysis at home), followed by patients who have received transplants (22.5%), those with CKD but not on renal replacement therapy (RRT; 19.5%) and those on peritoneal dialysis (6.6%). Only 22.5% of responses were from transplant patients, though they comprise 56.8% of RRT patients according to UKRR data. Patients of Asian ethnicity were particularly underrepresented at just 7.7% of responses compared to the UKRR figure of 12.5%, based on those receiving RRT. 81.9% of patients were White, 6.4% Black and 2.1% of Other minority ethnicity.

Key Findings

Experience by Centre

- Patients continue to rate their Overall Experience of the service provided by their renal centre highly; 6.2 out of 7.0, compared to 6.3 in 2019;
- The range of scores across centres is wider in 2020 than in previous years, reflecting a greater level of variation in patient experience of kidney care in 2020;
- The highest rated aspects of care continue to be Privacy & Dignity, Patient Information and Access to the renal team; each scoring between 6.33 and 6.47 out of 7.0;
- Sharing Decisions was rated particularly poorly in 2020, scoring 5.49 out of 7.0;
- Support (5.71), Needling, Communication, Transport (all 5.79) and Fluid & Diet (5.86) are the other areas of care where patient reported experience was less positive;
- Themes where experience is most positive (notably Privacy and Dignity, Tests, Scheduling and Planning) reported the narrowest ranges in scores, and thus the least variation in experience according to treating centre;
- There is increased variability in patient experience of many aspects of care in 2020. Of note, themes generating poorer scores, notably Transport, Sharing Decisions and Communication, tended to generate wider variation in experience according to which centre patients attend for their care.

Experience by Treatment Type

- Experience of people with CKD (attending kidney clinic but not on dialysis or transplantation) was notably poorer in 2020 compared to 2019 across eight of 13 themes of care, notably for Overall Experience, Support and How the team Treats You. CKD patients reported the worst score within Overall Experience and Fluid & Diet themes compared to other treatment groups.
- Patients on peritoneal dialysis and those who have received a transplant reported poorer experience across seven themes than in 2019, notably Support and Fluid & Diet;
- Home haemodialysis patient reported experience of care was poorer with regards Support, Communication and Tests than previously.
- In-centre haemodialysis patients had poorer experience of Sharing Decisions than home haemodialysis patients in 2020, but better experience of Communication;
- Transport was one of several areas of care witnessing improved scores from in-centre haemodialysis patients, others included Access to the team, Support, Tests and Sharing Decisions (all seeing an increase of 0.33 in 2019 to 2020 median scores).

Recommendations

These data are just one part of the improvement journey. The report is designed to open up conversations with patients and staff – locally and between centres – about what is good or bad about kidney patient experience and how experience can be improved and best practice shared.

The widening variation in scores between centres this year means there are opportunities for kidney services to hear from each other regarding how they have tackled the challenges of providing kidney care during a pandemic.

We recommend centres use this report and the Kidney PREM portal to look at the themes of experience in which their centre falls above or below the interquartile range, discuss key findings with patients and staff locally, and create an action plan in response to any areas in need of improvement. This could include contacting centres with high scores in an area they want to improve in.

We recommend patients ask their kidney team about their centre's Kidney PREM results, find out if they are creating an action plan for improvement and how to get involved if they would like to. We also encourage patients to share with their kidney team how their experience of care relates to the Kidney PREM results presented in this report if they feel comfortable to, and/or to discuss the Kidney PREM within an appropriate forum such as their local Kidney Patient Association or with a Kidney Care UK Advocacy Officer.

Comments Analysis

The final question of the online Kidney PREM was “If there is any other aspect of your experience of kidney care that you would like to comment on that has not already been covered, during COVID-19 or another time, please tell us below”. There are no character or word limits in the free text box.

Responses have been coded and themed using a mixed inductive/deductive approach, being aware of where responses fit within the existing Kidney PREM themes, but allowing new themes to emerge. The full report is available via the Renal Association website from June 2021.

In 2020, 7,364 participants commented on their experience of kidney care; the majority of comments were thanking staff for their kindness and dedication to patients throughout what was acknowledged as a difficult year.

“I had my transplant in 2019, and my care before, pre COVID and during COVID has been first class and I consider myself very lucky”

“[Member of staff] goes above and beyond what one should expect from a consultant and represents everything that is good about the NHS. She is a credit to your organisation. You are lucky to have her in your service and I am lucky to have her as my consultant.”

“I would like to thank everyone concerned with my Renal care especially the staff at [Name of Area] Hospital. I have spent 8 or 9 weeks as an inpatient there and many months as an outpatient. The Doctors, Nurses, Cleaners, porters, diagnostic imaging, catering staff, pharmacist and others I have no doubt forgotten could not have looked after me any better. I thank you all...”

Patients commented on several issues to do with the treatment environment, including access to parking, waiting times, the temperature (cold) and general comfort of the waiting room. As above and seen in the high overall Kidney PREM scores, patients tended to be happy with the care received from staff, though there were some who felt that treatment recently had been rushed.

As reflected in the mean transport scores, patients commented that transport had improved this year, although issues with the distance to travel to the unit, and waiting times, remain a problem for some.

Emerging themes include personal mental health concerns and the impact of staff shortages. Several such COVID-19 specific issues are to be reported in the spring, in the mixed methods analysis of in the region of 20,000 comments received from patients on aspects of their care which were particularly good, bad, and could have been improved during the pandemic.

Kidney PREM 2020

Introduction

The COVID-19 pandemic made 2020 an exceptional year, with many additional constraints placed on the kidney community. Patients were subject to transplant cancellations, shielding, changes to delivery of care and the uncertainty all this brings. Centres have reported difficulties such as staff shortages caused by sickness or self-isolation, suitable spaces to ensure adequate social distancing and high numbers of positive COVID-19 cases and related severe illness amongst their patients.

We deliberated over whether to proceed with the Kidney PREM in 2020, since it was clearly unreasonable to expect centres to have had any opportunity to act upon results from 2019, which were published in January. However, we decided to proceed to give patients the opportunity to have their say, and to give the kidney community a better understanding of patient experience of kidney care at this time, in a year where that had the potential to be more important than ever.

To reduce the burden upon centres and in accordance with infection control measures, we hosted the survey online rather than providing paper questionnaires as in previous years. This gave us an opportunity to co-design some additional questions with patients and ask those responding to Kidney PREM to rate their care during the COVID-19 pandemic. Patients were able to tell us, in their own words, what was good and bad about their care during the pandemic and to suggest ways in which their experience could have been improved. It is testament to the willingness of kidney patients to be involved in the ongoing improvement of care that nine in ten of the 7,370 who provided comments were willing for their comments to be shared with their treating centre. Comments will be returned to centres and an analysis of these comments will be published separately.

The majority of patients responding to the Kidney PREM felt that, overall, their care during COVID-19 had stayed the same (59%), with slightly more stating that it had improved to some extent (24%) as opposed to worsening (17%), Table 1. Patients living with CKD but not receiving renal replacement therapy (RRT) felt that the quality of their kidney care got worse during the pandemic (29%), true of just one in ten haemodialysis patients, a significant proportion of whom felt that their experience of care was overall much better (30%).

Table 1: Summary of patient experience of care during COVID-19

	CKD		Haemodialysis		Peritoneal		Transplant		Total	
	N	%	N	%	N	%	N	%	N	%
Worse	494	28.9%	430	9.0%	114	19.5%	540	26.5%	1578	17.3%
Same	1011	59.1%	2912	61.1%	343	58.7%	1104	54.2%	5370	59.0%
Better	206	12.0%	1423	29.9%	127	21.7%	394	19.3%	2150	23.6%

In this report, the results have been presented objectively. We do not hypothesise reasons for changes for two reasons; firstly, centres are best placed to know the reasons for local changes or differences in patient experiences and we encourage them to use this data to support further investigation and local action. Secondly, when comparing centre scores across the years, some have a vastly different number of responses in 2020 compared to 2019, as shown in **appendix A**. It is difficult to determine whether changes in results were caused by response number variations or by other factors, including the impact of the pandemic. Further local discussion between staff and patients as well as review of local comments is required to fully understand the reasons behind experience scores and to create action plans for improvement.

This report summarises information about the patients, scores for each treatment groups and variation in scores across centres. Additional results and information, including results at satellite unit-level and individual question-level data is available online, allowing centres to look at their results in more detail. This includes the following information:

- Analysis of free text responses to the question ***“If there is any other aspect of your experience of kidney care that you would like to comment on that has not already been covered, during COVID-19 or another time, please tell us below”***
- Analysis of free text responses to the questions on experience of care during COVID-19
- Graphs showing the centre scores for each theme comparing 2020 to 2019
- Centre scores for each theme by treatment groups
- Centre and satellite level results by question via the Kidney PREM portal
- Technical Report
- The full Kidney PREM 2020 survey

Full 2020 Kidney PREM reporting is available at:

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

Methodology

The validated Kidney PREM contains 13 themes, each consisting of between 1 and 5 questions, and an Overall Experience question. Patients select answers from 1 (generally equating to 'Never' and being the worst experience score) to 7 (generally 'Always', being the best experience score). Responses to questions were used to calculate overall scores for each theme, as well as the 'scale score' (the total Kidney PREM score) across all themes. For details of how scores were calculated and the data processed, please refer to the [Kidney PREM Technical Report](#). There was one free text question, where patients could comment on any other aspect of their experience of kidney care that has not already been covered. In 2020 there were four additional questions related to care during the pandemic:

- Overall, how much better or worse was your kidney care during COVID-19? (from -3, Much Worse to +3, Much Better)
- What was good about your experience of kidney care during COVID-19?
- What was bad about your experience of kidney care during COVID-19?
- What could have been done, if anything, to make your experience of kidney care better during COVID-19?

The Kidney PREM was hosted online for six weeks, from 1st October to 12th November 2020, with links available on both The Renal Association and Kidney Care UK websites. Supporting promotional material (such as business cards, posters) was distributed to centres in September. Some centres also utilised technology available to them by sending the survey link to patients via text message or email. Response numbers were monitored throughout the collection period. The survey was promoted via adverts on Facebook, targeting kidney patients in geographical areas where response numbers and awareness appeared low.

As well as English, the Kidney PREM was available in three additional languages; Welsh, Urdu and Gujarati. Respondents selected their renal centre from a drop-down list or entered it manually if they were unable to find it. Patients whose treating centre could not be identified were excluded from centre scores but are shown as centre "Missing" in graphs later in this report.

Hosting the survey online has improved the quality of data, as no questions could be missed unless a patient stopped completing the survey. Treatment-specific questions were directed appropriately; the Needling question was displayed only for in-centre and in-satellite haemodialysis patients and the blood test question (in the Scheduling and Planning theme) for all other patients. Although in previous years we have analysed Transport themed responses for all patients, this question was only directed at hospital-based haemodialysis patients in 2020. For the first time, the quality of data has allowed us to explore differences in haemodialysis treatment location, which can now be reported separately.

The current Kidney PREM has been used since 2018. There are some differences compared to the 2017 version and more substantial changes in 2016. Some amendments to the calculation of Needling and Scheduling & Planning scores were made in 2019, so caution should be taken when comparing results of these themes across years.

Throughout this report, the total used to estimate individual statistics may vary since not all questions were answered by all patients. In cases where estimation of a group mean is based on fewer than seven responses, the data is withheld to preserve patient anonymity.

Kidney patients who are not receiving any RRT are referred to as CKD patients for the purpose of this report.

Response Profile

A total of 9,645 valid surveys were submitted, down from 16,469 in 2019. Responses were received from each of the 70 adult UK renal centres, across 297 satellite units.

For the first time, enough surveys were completed such that mean scores could be estimated for every centre. Most surveys were completed in English, with just 6 in Welsh, 3 in Gujarati and 1 in Urdu.

Centres based in England, Northern Ireland and Scotland saw a reduction in patient numbers compared to 2019. However, Wales saw an increase in returns from 365 in 2019 to 968 in 2020, making up over 10% of the total Kidney PREM. The treating centre could not be determined for 379 patients. Overall, out of the 2020 Kidney PREM responses 83% were from patients in England, 11% in Wales, 5% Northern Ireland and 1% Scotland.

Appendix B shows responses received from patients receiving RRT, i.e. dialysis or transplant, as a proportion of the total number reported by UKRR as at the end of 2019 for each nation. Particularly notable were the Welsh responses, where over a quarter of the nation's RRT patients participated in the Kidney PREM. Of the total UK RRT population, 11% participated in this year's Kidney PREM.

9,645

kidney patients
completed the
survey online



Case Study

Collaborating to promote the Kidney PREM and ensure digital inclusion Welsh Renal Clinical Network (WRCN)

Our ambition was set this year that every RRT patient in Wales was to be offered the opportunity to participate in the 2020 Kidney PREM. The Lead Nurse approached the process as a national audit and sought interest from each dialysis unit, home dialysis team and transplant coordination team to act as a Kidney PREM link person.

The role of the Kidney PREM link person was to:

- Attend Kidney PREM link training delivered virtually by the WRCN
- Cascade learning to provide education regarding the importance of the Kidney PREM to staff and patients
- Identify difficulties in accessing the Kidney PREM
- Support patients with digital access
- Completion and submission of the audit tool
- Liaise with kidney charities who had already offered direct patient support.

Overcoming digital exclusion

As our ambition was set at 100% of RRT patients being offered the Kidney PREM to complete, lack of access to a digital device was not an acceptable barrier. Working with the kidney charities, 54 hand held devices were sourced and distributed to dialysis units and teams. The devices were pre-loaded with internet access and key communication platforms such as Zoom and TEAMS and had a suitable pre-paid sim card installed. For patients who were not confident in using the device, nurses reached out to the kidney charities for a volunteer support.



Communications

As well as raising awareness about the Kidney PREM through link nurse education, posters and regular social media messages, we also featured the Kidney PREM in our patient newsletter.

Issue 9 led with the Kidney PREM survey and a reminder to patients that “their voice mattered” and support was available to participate in the survey digitally.

Outcome

Patient participation in Wales rose significantly in 2020 to 902 responses which represents a 40% increase on the 2019 submissions and accounts for 27.2% of the RRT population.

The findings will be used to drive forward quality improvement programmes on a regional and national level.

“[The Kidney PREM] really puts patients as the drivers of innovation and improvement... We are looking forward to seeing all the service improvement programmes in Wales when the analysis is published.”

Welsh Renal Clinical Network Manager

70

adult centres took part,
covering **297** units
across UK



Patient Characteristics

The UKRR collates data for patients receiving renal replacement therapy (RRT), with figures correct as at the end of 2019. Table 2 shows how patients compare to this group. Overall, the age profile and haemodialysis location were closer to UKRR RRT patient figures than in previous years.

A higher proportion of females completed the survey (43.3%) than expected (38.8%). Asian patients were underrepresented comprising 7.7% compared to an expected 12.5%. More White patients participated (81.9%) than anticipated (71.2%). Although the UKRR does not record information about CKD patients, it is likely that this group is underrepresented since they are known to vastly outweigh RRT patients in clinic. Transplant patients remain underrepresented although to a lesser degree than in previous years.

As shown in Table 2, some changes in patient characteristics were seen in 2020 compared to 2019, notably:

Age: Most respondents were aged 56-74 years (47.0%), with 4.1% aged 30 years or under. More detailed age analysis is in [appendix C](#); there has been a relative increase in participation for those aged 22-64 years and a corresponding drop in the over 75s .

Gender: As in previous years, more males (56.0%) than females (43.3%) participated. The proportion of females has increased since 2019, when it was 40.6%.

Ethnicity: A larger proportion of White respondents in 2020 (81.9%) than in previous years (78.2% in 2019).

Treatment: Whilst responses were predominantly from haemodialysis patients (51.4%), 2020 saw increased participation from patients undertaking other treatments. In particular, the percentage of transplant and CKD patients have each increased compared to previous years (transplant from 14.2% to 22.5% and CKD from 15.8% to 19.5%).

Haemodialysis Location: The proportion of home haemodialysis patients has increased to 4.8% from 3.6% in 2019. More responses were received from in-satellite patients (55.4%) than in-centre patients (39.8%).

PatientView: There was an increase in the proportion of patients who use PatientView from 30.2% in 2019 to 41.6% in 2020.

Differences in ages across treatment types are shown in [appendix C](#). Little difference in age profile was seen in those patients not receiving RRT in 2020 compared to 2019. Age profiles across treatment types were as expected; older patients (over 75) were more likely to receive in-satellite, in-centre or peritoneal dialysis. Over a half of patients receiving haemodialysis at home were aged 31-55 years.

Table 2: Characteristics of the people who completed the Kidney PREM in 2020, 2019 and 2018

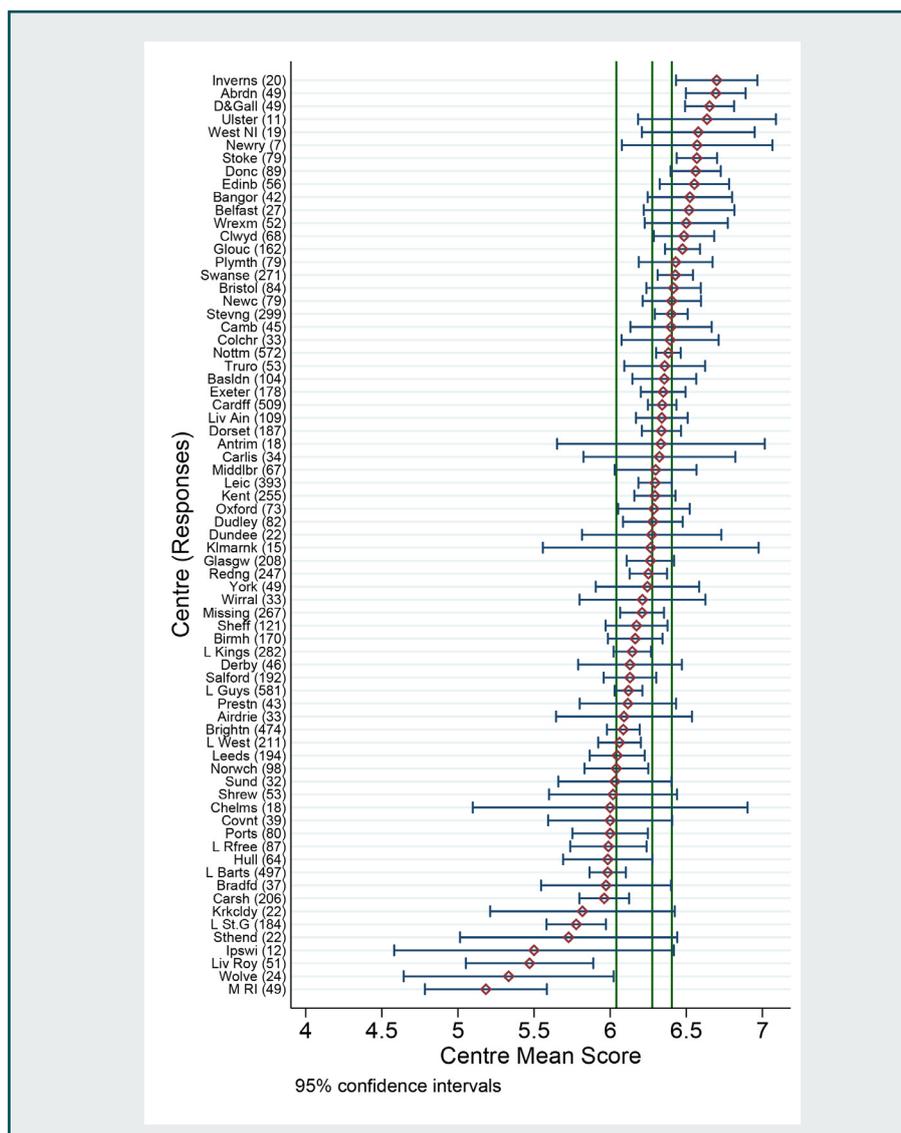
Characteristic	PREM 2020	PREM 2019	PREM 2018	UK RRT Patients as of end of 2019 ¹
Total	9645	16469	13770	68111
Age				
≤30	400 (4.1%)	514 (3.2%)	391 (2.9%)	4.8%
31-55	2929 (30.4%)	3892 (24.3%)	3095 (22.9%)	36.1%
56-74	4537 (47.0%)	7198 (44.9%)	6042 (44.8%)	43.4%
≥75	1779 (18.4%)	4416 (27.6%)	3970 (29.4%)	15.7%
Missing	-	449	272	-
Gender				
Female	4177 (43.3%)	5937 (40.6%)	4891 (39.9%)	38.8%
Male	5404 (56.0%)	8629 (58.9%)	7295 (59.6%)	61.2% ²
Rather not say	64 (0.7%)	74 (0.5%)	57 (0.5%)	-
Missing	-	1829	1527	-
Ethnicity				
Asian	743 (7.7%)	1558 (10.1%)	1275 (9.9%)	12.5%
Black	613 (6.4%)	1137 (7.4%)	829 (6.4%)	7.5%
White	7896 (81.9%)	12010 (78.2%)	10267 (79.4%)	71.2%
Other	203 (2.1%)	401 (2.6%)	355 (2.7%)	3.0%
Rather Not Say	190 (2.0%)	401 (2.6%)	202 (1.6%)	-
Missing	-	1117	842	6.1%
Treatment				
Transplant	2172 (22.5%)	2183 (14.2%)	1399 (10.9%)	56.8%
Haemodialysis	4959 (51.4%)	9618 (62.4%)	8834 (68.6%)	37.8%
Peritoneal	632 (6.6%)	1166 (7.6%)	982 (7.6%)	5.4%
CKD (non-RRT)	1882 (19.5%)	2437 (15.8%)	1659 (12.9%)	Unknown
Missing	-	1065	896	-
Haemodialysis Location				
At Home	239 (4.8%)	337 (3.6%)	299 (3.5%)	5.3%
In-satellite	2748 (55.4%)	4557 (49.0%)	4412 (51.6%)	52.8%
In-centre	1972 (39.8%)	4400 (47.3%)	3843 (44.9%)	41.8%
Missing	-	324	280	-
Patient View				
Yes	4012 (41.6%)	3866 (30.2%)	2928 (26.9%)	Unknown
No	4300 (44.6%)	6523 (51.0%)	5583 (51.3%)	Unknown
Don't Know	1333 (13.8%)	2411 (18.8%)	2364 (21.7%)	-
Missing	-	3669	2895	-

¹ Ethnicity data based on England, Wales and Northern Ireland only.² Currently, patients only able to select Male or Female

Overall Patient Experience

Patients are asked “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)?”. Average (mean) scores were calculated for each of the 70 renal centres, shown in figure 1.

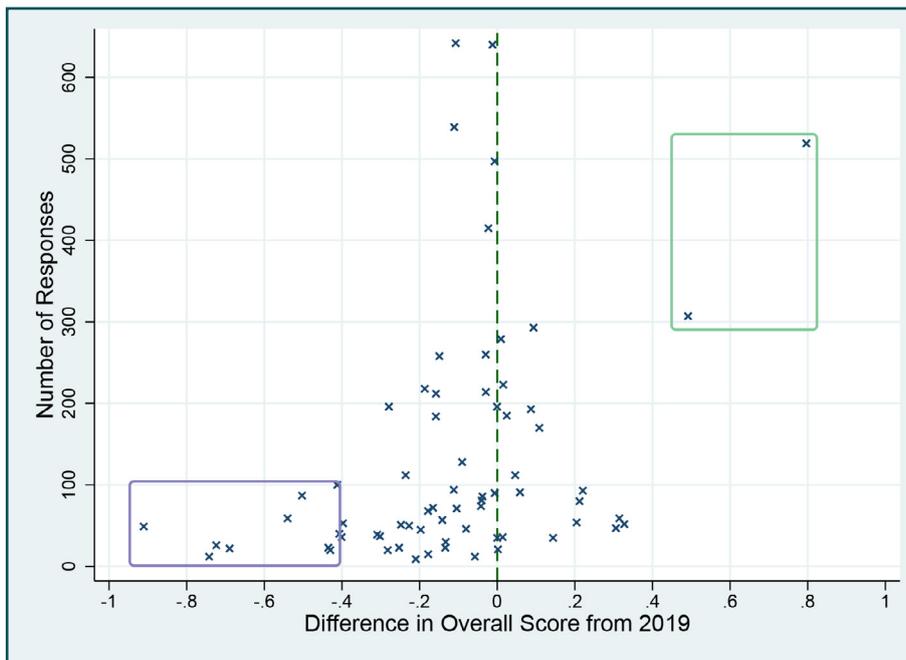
Figure 1: Centre scores for overall experience of the service provided by renal centres (Question 39 in the 2020 Kidney PREM)³



³ Blue horizontal lines represent 95% confidence intervals, illustrating the level of certainty around the estimate. In general, the more responses a centre receives, the more narrow the confidence interval. The lower quartile, median and upper quartile of the centre means are shown as vertical green lines.

As shown in figure 2, where centres had notable decreases in their Overall Experience scores in 2020 compared to 2019, they also had fewer responses. There were 11 centres with year on year decreases of at least .4 along with fewer than 100 responses. In contrast, the two centres with increased scores of .4 or more each received over 300 responses to this year’s Kidney PREM.

Figure 2: Difference in Overall Score and Number of Responses by Centre



Variation in Patient Experience between Centres

Centre scores were calculated for each theme of the Kidney PREM and are shown in figure 3.

High Scoring Themes: As in previous years, Privacy & Dignity (6.47), Patient Information (6.35) and Access (6.33) remain high scoring themes. Previously stable, Overall Experience has seen a slight drop in score in 2020 but remains high at 6.21. Patients continue to report positive experience for Tests (6.23) and Scheduling & Planning (6.19).

Low Scoring Themes: Patient experience of Sharing Decisions (5.49) and Needling (5.79) remains low, with scores remaining stable over the past three years. In 2019, Transport was the worst performing theme, but 2020 saw an increase in score to 5.79 and so is now equal to experience of care within Communication and Needling. Communication (5.79), Support (5.71) and Fluid & Diet (5.86) scores have decreased in comparison to 2019.

Figure 3: Mean scores for the 13 Kidney PREM themes and the Overall experience question, showing values from 2020, 2019 and 2018

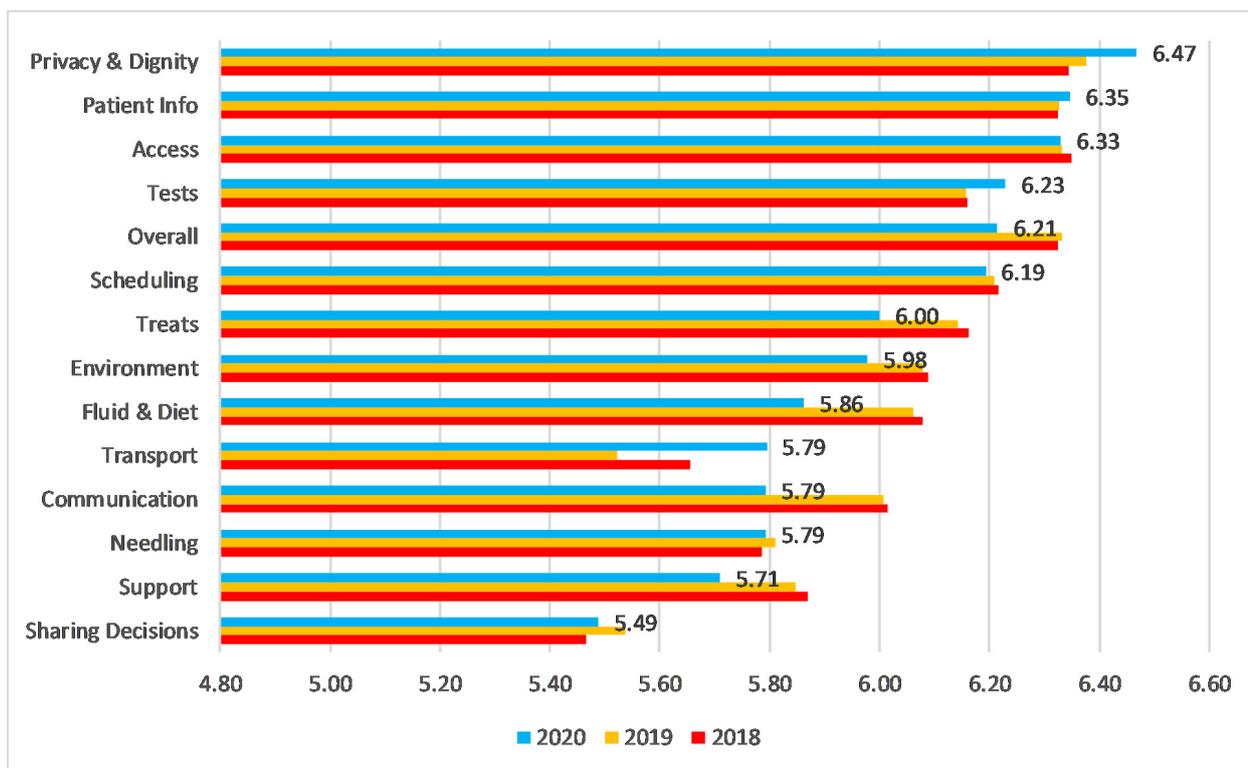
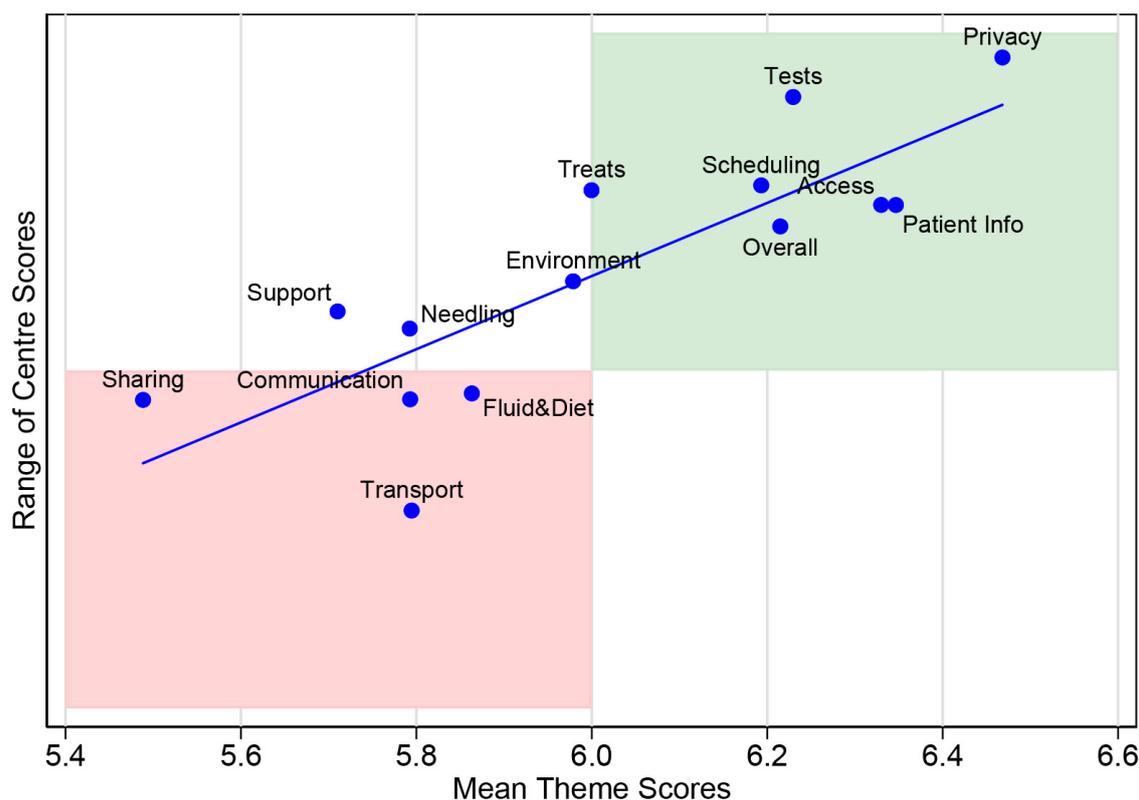


Figure 4 shows how mean centre scores are related to the range of scores for each patient experience theme in 2020. Scores for 2020, 2019 and 2018, along with the range of scores for each theme are available in [appendix D](#).

Figure 4: Mean Theme Scores by Centre against Range of Scores⁴

The relationship between the mean score for each theme (e.g., patients rated Transport 5.8 / 7.0) to the range of scores for each theme (e.g., the difference between the scores generated by the highest and lowest performing centres for transport was 2.3) is shown graphically in figure 5, highlighting:

Increased variability between centres, particularly where experience is poorer:

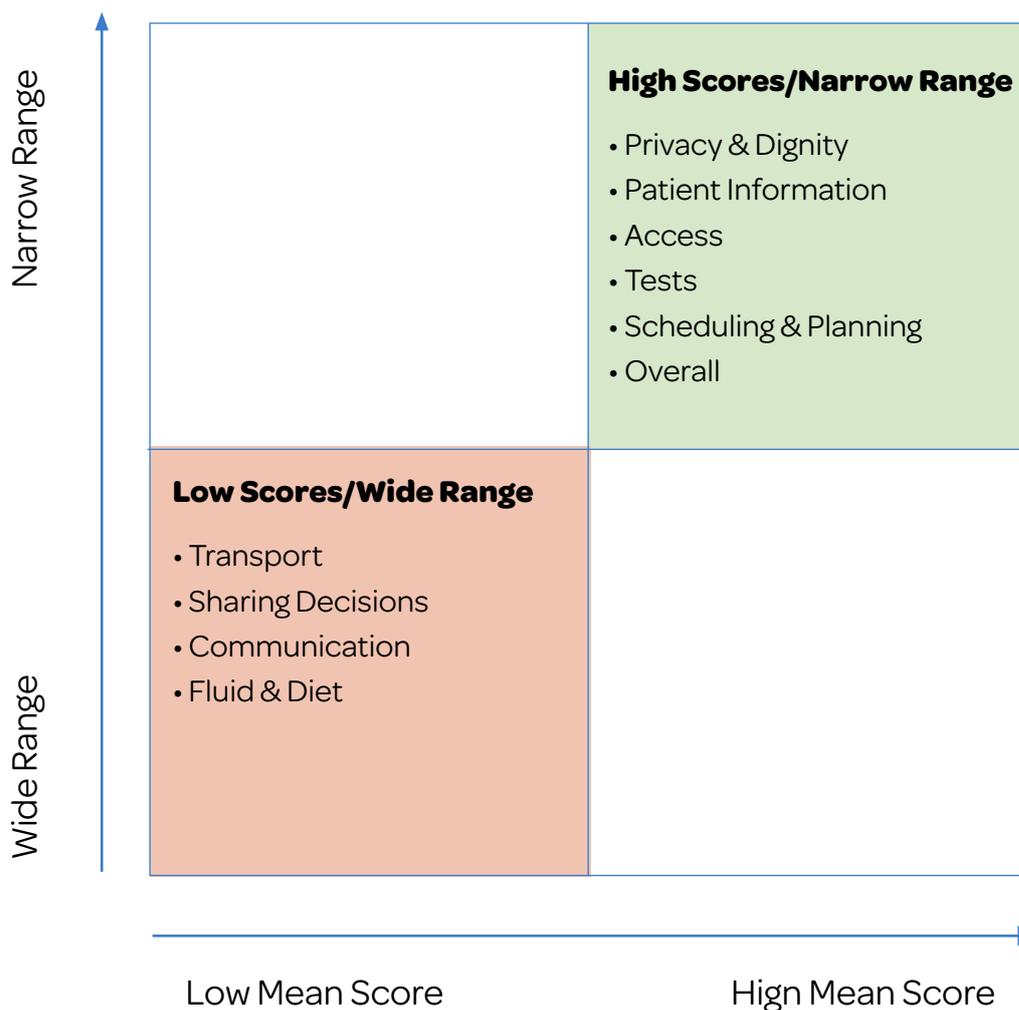
In general, the ranges of scores generated by different centres have increased a little compared to 2019, suggesting more variability in patient experience. Themes generating poorer mean scores from centres tended to have a wider range of scores, again, suggesting variability between treating centres. This suggests there may be areas where investigating and sharing best practice from centres with high scores would be beneficial for themes where experience was reported poorer nationally (e.g., Transport, Sharing Decisions, Communication, Fluid & Diet, highlighted in red in bottom left quadrant).

Decreased variability between centres in aspects of care where patient experience is most positive:

As in previous years, in 2020 the themes with narrow ranges tended to be those with higher mean scores (Privacy & Dignity, Tests, Scheduling & Planning, Patient Information, Access, Overall, highlighted in green in the top right quadrant).

⁴ Red shading: Low mean centre scores/high range of scores
Green shading: High mean centre scores/low range of scores

Figure 5: Relationship between Theme Scores and Theme Ranges



Patient Experience across Kidney PREM themes by Treatment

Data Analysis and Interpretation

In this section, *medians and interquartile ranges (IQR)* have been used because they are a good way to measure changes in scores across most patients within each group. This is particularly the case for Kidney PREM, as theme scores are heavily *left-skewed* (most patients have selected high values (5/6/7) with very few low scores chosen (1/2/3)).

An alternative way to summarise theme scores is to calculate *means and 95% confidence intervals (95% CI)* for each treatment type. Means are a useful, familiar way to make comparisons between groups, but are influenced by small numbers of low scores. **Means of left-skewed data will always have lower values than the medians.** Mean scores and 95% confidence intervals are also shown in **appendix E**. Other sections and charts within this report use means to describe centre scores. This was appropriate because these values are approximately *normally distributed*.

Kidney PREM scores by treatment group have been summarised in Table 3. Median scores which declined from 2019 to 2020 are shown in red. Total scale scores showed little difference across treatment groups, with median scores ranging from 6.23 to 6.37. However, some differences were seen in individual themes.

Changes in experience across years by treatment type:

CKD (Non-RRT): Median scores were lower than or equal to 2019 across all themes. The most notable change was in Overall, the median now 6 compared to 7 in 2019. Support and How the Team Treats You each decreased by 0.67 in 2020.

Peritoneal dialysis: Median scores have either dropped or remained the same compared to 2019, but with less change than seen in CKD scores. The largest decreases were in Support (from 7 in 2019 to 6 in 2020) and Fluid & Diet (from 7 to 6.5) themes.

Home haemodialysis: Experience scores remained stable compared to 2019, with only Support and Communication seeing small decreases.

Satellite and centre haemodialysis: These were the only treatment groups achieving little to no change in experience scores in 2020 compared to 2019, with small increases in experience scores across Transport, Access to the team, Support, Tests and Sharing Decisions

Transplant: Similar amount of change from 2019 across theme scores as seen with peritoneal dialysis patients. Fluid & Diet theme achieved the greatest decrease in score, from 7 to 6.5 in 2020.

Variation in experience by treatment group:

Support: Decreased from 2019 to 2020, across all treatment groups with the exception of in-centre and in-satellite dialysis. CKD had a theme score of 6.00, whereas all other treatment groups scored 6.33.

Communication: Experience amongst home haemodialysis patients was slightly less positive than for all other treatment types.

Fluid and Diet: Median score decreased in 2020 for transplant, peritoneal dialysis and CKD patients, with a wide interquartile range for CKD patients. All HD types had median score 7, transplant and peritoneal dialysis each scored 6.5 with CKD scoring 6.

Sharing Decisions: In-satellite and in-centre haemodialysis had the lowest median scores (6) and home haemodialysis the highest (6.67).

How the Team Treats You: Scores remained the same or increased for all haemodialysis types, each scoring 6.67, whereas they decreased for all other treatment groups compared to 2019, although peritoneal dialysis patients had a high score of 6.67 (down from 7 in 2019).

Transport: An increase for in-centre patient experience means that in-centre and in-satellite scores are now equal (6.00)

Overall: All treatment types scored 7 in both 2019 and 2020, with the exception of CKD which was the only treatment group whose score decreased to median of 6 in 2020.

Overall experience remained high despite the global pandemic

6.2 out of 7



Experience of people with chronic kidney disease but not on RRT **decreased** particularly for **Support, How the team treats you** and **Overall experience**

Experience of **transport** reported by in-centre haemodialysis patients **improved**



Table 3: Comparison of Median Kidney PREM scores by treatment group for 2020 and 2019

	Peritoneal Dialysis					CKD (non-RRT)				
	2020 (n=595)		2019 (n=1092)		2020 v 2019	2020 (n=1739)		2019 (n=2189)		2020 v 2019
	Median	IQR	Median	IQR		Median	IQR	Median	IQR	
Access to team	7.00	6.33-7	7.00	6.33-7	0.00	7.00	6-7	7.00	6.33-7	0.00
Support	6.33	5-7	7.00	5.5-7	-0.67	6.00	4-7	6.67	5-7	-0.67
Communication	6.25	5-7	6.60	5.75-7	-0.35	6.20	5-7	6.67	5.67-7	-0.47
Patient Information	7.00	6-7	7.00	6.5-7	0.00	7.00	6-7	7.00	6-7	0.00
Fluid and Diet	6.50	5.5-7	7.00	6-7	-0.50	6.00	3.5-7	6.50	5-7	-0.50
Needling	-	-	-	-	-	-	-	-	-	-
Tests	6.33	5.5-7	6.67	6-7	-0.33	6.67	5.67-7	6.67	6-7	0.00
Sharing Decisions	6.33	5-7	6.67	5.5-7	-0.33	6.33	4.5-7	6.67	5.33-7	-0.33
Privacy & Dignity	7.00	6.5-7	7.00	7-7	0.00	7.00	7-7	7.00	7-7	0.00
Scheduling & Planning	7.00	6-7	7.00	6-7	0.00	6.67	6-7	7.00	6-7	-0.33
How team treats you	6.67	5.33-7	7.00	6-7	-0.33	6.33	5-7	7.00	6-7	-0.67
Transport	-	-	6.00	4.67-7	-	-	-	6.00	4-7	-
Environment	6.00	5.2-6.8	6.20	5.5-7	-0.20	6.00	5.2-6.6	6.20	5.5-7	-0.20
Overall experience	7.00	6-7	7.00	6-7	0.00	6.00	6-7	7.00	6-7	-1.00
Scale Scores	6.33	5.62-6.75	6.47	5.97-6.82	-0.14	6.23	5.38-6.69	6.46	5.82-6.8	-0.24
	Home Haemodialysis					Satellite Haemodialysis				
	2020 (n=227)		2019 (n=325)		2020 v 2019	2020 (n=2706)		2019 (n=4267)		2020 v 2019
	Median	IQR	Median	IQR		Median	IQR	Median	IQR	
Access to team	7.00	6.33-7	7.00	6.33-7	0.00	7.00	6-7	6.67	5.67-7	0.33
Support	6.33	5-7	6.67	5.33-7	-0.33	6.33	5-7	6.00	5-7	0.33
Communication	6.00	5-7	6.40	5.2-7	-0.40	6.33	5.25-7	6.25	5.25-7	0.08
Patient Information	7.00	6-7	7.00	6-7	0.00	7.00	6-7	7.00	6-7	0.00
Fluid and Diet	7.00	6-7	7.00	6-7	0.00	7.00	5.5-7	6.50	5.5-7	0.50
Needling	-	-	-	-	-	6.00	5-7	6.00	5-7	0.00
Tests	6.67	6-7	6.83	6-7	-0.17	6.67	5.67-7	6.33	5.67-7	0.33
Sharing Decisions	6.67	5.33-7	6.67	5.67-7	0.00	6.00	4.33-7	5.67	4-7	0.33
Privacy & Dignity	7.00	7-7	7.00	7-7	0.00	7.00	6-7	7.00	6-7	0.00
Scheduling & Planning	7.00	6-7	7.00	6-7	0.00	7.00	6-7	6.50	5.5-7	0.50
How team treats you	6.67	5.33-7	6.67	5.67-7	0.00	6.67	5.33-7	6.50	5.33-7	0.17
Transport	-	-	5.00	3.33-6.67	-	6.00	5.33-7	6.00	4.67-7	0.00
Environment	6.00	4.8-6.6	6.00	5.2-6.75	0.00	6.50	5.8-7	6.40	5.75-7	0.10
Overall experience	7.00	6-7	7.00	6-7	0.00	7.00	6-7	7.00	6-7	0.00
Scale Scores	6.34	5.79-6.72	6.45	5.83-6.8	-0.11	6.29	5.58-6.71	6.17	5.41-6.68	0.13
	Centre Haemodialysis					Transplant				
	2020 (n=1887)		2019 (n=4074)		2020 v 2019	2020 (n=2065)		2019 (n=2025)		2020 v 2019
	Median	IQR	Median	IQR		Median	IQR	Median	IQR	
Access to team	7.00	6-7	6.67	5.67-7	0.33	7.00	6.33-7	7.00	6.33-7	0.00
Support	6.33	4.67-7	6.00	5-7	0.33	6.33	5-7	6.67	5.33-7	-0.33
Communication	6.25	5.2-7	6.33	5.2-7	-0.08	6.25	5.25-7	6.40	5.5-7	-0.15
Patient Information	7.00	6-7	7.00	6-7	0.00	7.00	6.5-7	7.00	6.5-7	0.00
Fluid and Diet	7.00	5.5-7	7.00	5.5-7	0.00	6.50	5.5-7	7.00	5.5-7	-0.50
Needling	6.00	5-7	6.00	5-7	0.00	-	-	-	-	-
Tests	6.67	5.67-7	6.33	5.33-7	0.33	7.00	6.33-7	7.00	6-7	0.00
Sharing Decisions	6.00	4-7	5.67	4-7	0.33	6.33	5.33-7	6.67	5.33-7	-0.33
Privacy & Dignity	7.00	6-7	7.00	6-7	0.00	7.00	7-7	7.00	7-7	0.00
Scheduling & Planning	6.50	5.5-7	6.50	5.5-7	0.00	6.67	6-7	7.00	6-7	-0.33
How team treats you	6.67	5.33-7	6.50	5.33-7	0.17	6.33	5.5-7	6.67	5.67-7	-0.33
Transport	6.00	5-6.67	5.67	4.33-6.67	0.33	-	-	5.67	4.33-7	-
Environment	6.40	5.5-7	6.25	5.5-7	0.15	5.80	5.2-6.6	6.00	5.4-6.8	-0.20
Overall experience	7.00	6-7	7.00	6-7	0.00	7.00	6-7	7.00	6-7	0.00
Scale Scores	6.27	5.44-6.69	6.14	5.34-6.64	0.13	6.38	5.81-6.71	6.44	5.85-6.77	-0.06

Patient Experience Scores According to Treatment Type and by Centre

This section of the report presents graphs showing centre scores and 95% confidence intervals for each theme of the 2020 Kidney PREM. Vertical lines show the median, lower quartile and upper quartile. As before, the size of the confidence interval usually relates to the number of responses for each centre, with an increasing level of uncertainty if few surveys were received.

Centre scores could be estimated if at least 7 responses were received. This year we have included a variable 'missing', comprising patients for whom a centre could not be attributed (from what they typed in the 'Renal Unit' free text box). This usually scored in the middle of the centre averages, suggesting no difference between these patients and those who provided a legible treating centre.

The number of responses used to calculate the scores are in brackets after each centre name. Each chart shows how many patients from each centre completed the questions being reported, as opposed to the number of patients from each centre who completed the Kidney PREM. This is particularly important where questions are filtered and bases for analysis become smaller (e.g., only 200/300 of a centre's respondents might complete the question on Needling, as this is only relevant to the 66% of patients on haemodialysis).

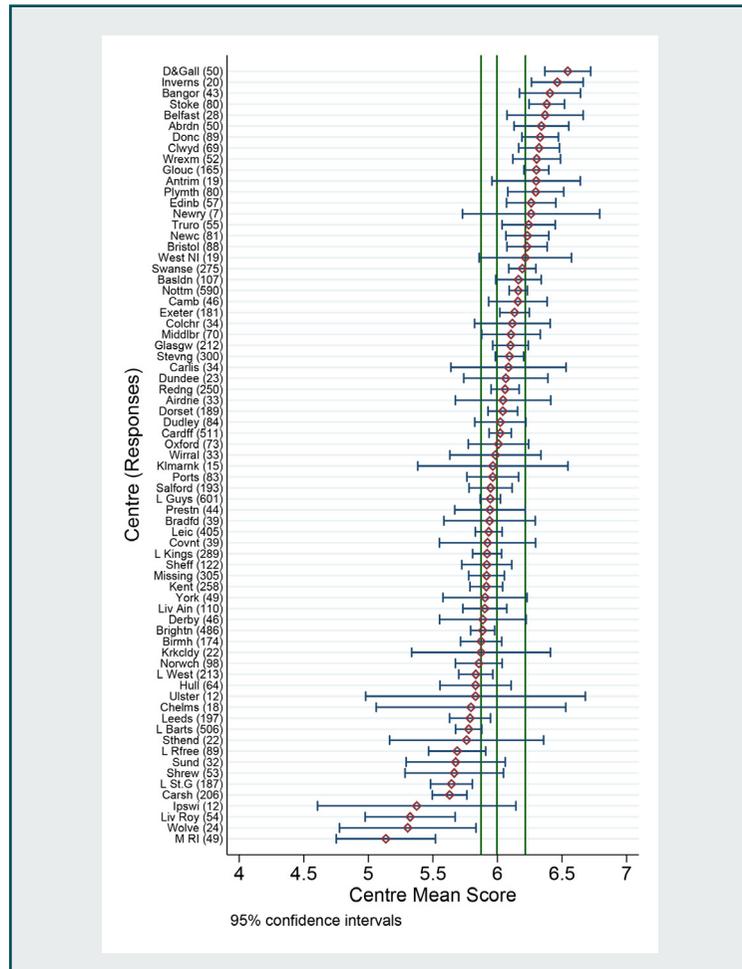
For most themes, centre scores are mostly within a small range. However, each theme's graph shows a tail of outliers at the bottom, where centre scores were lower than others.

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

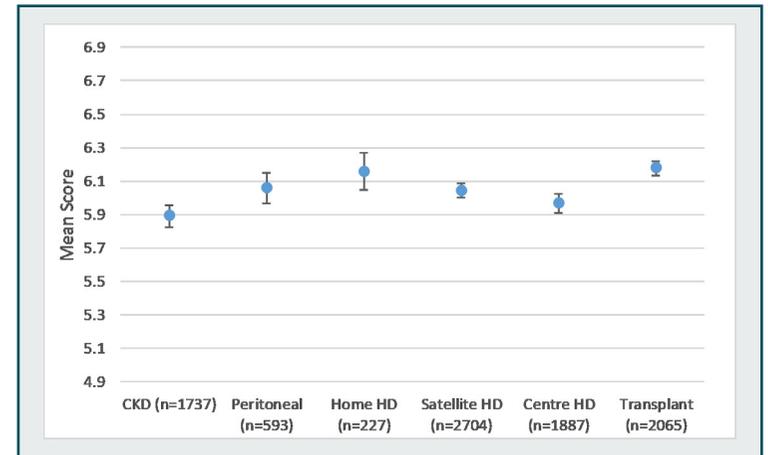
The figure on the right of each page shows the mean score and 95% confidence interval (CI) for that theme by treatment type. The number of patients used to calculate the scores for each treatment group is shown in brackets after the treatment name.

Scale Total: Responses across all themes

A)



B)



Scale total calculated across all theme scores.

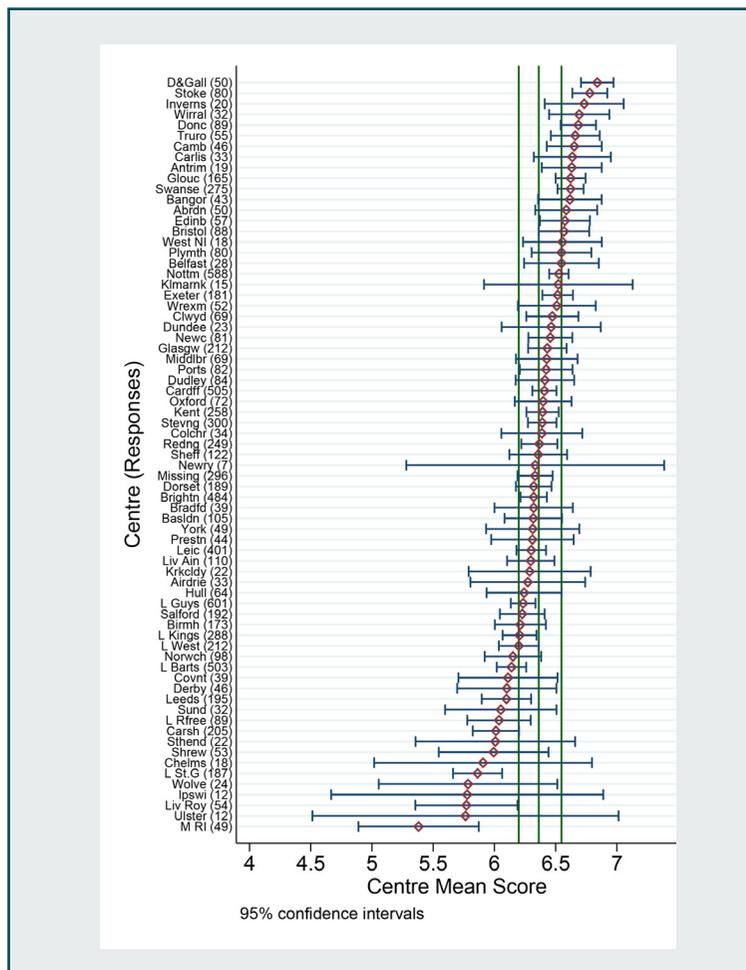
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

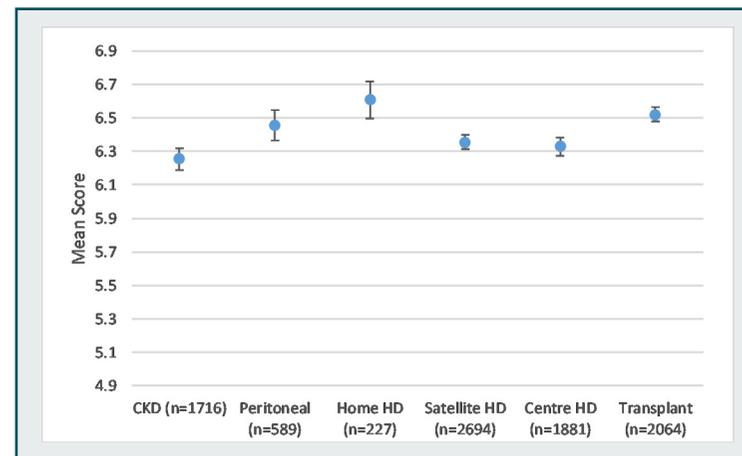
Number of responses used to calculate each score are shown in brackets.

Section 1: Access to the Renal Team

A)



B)



Theme questions

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

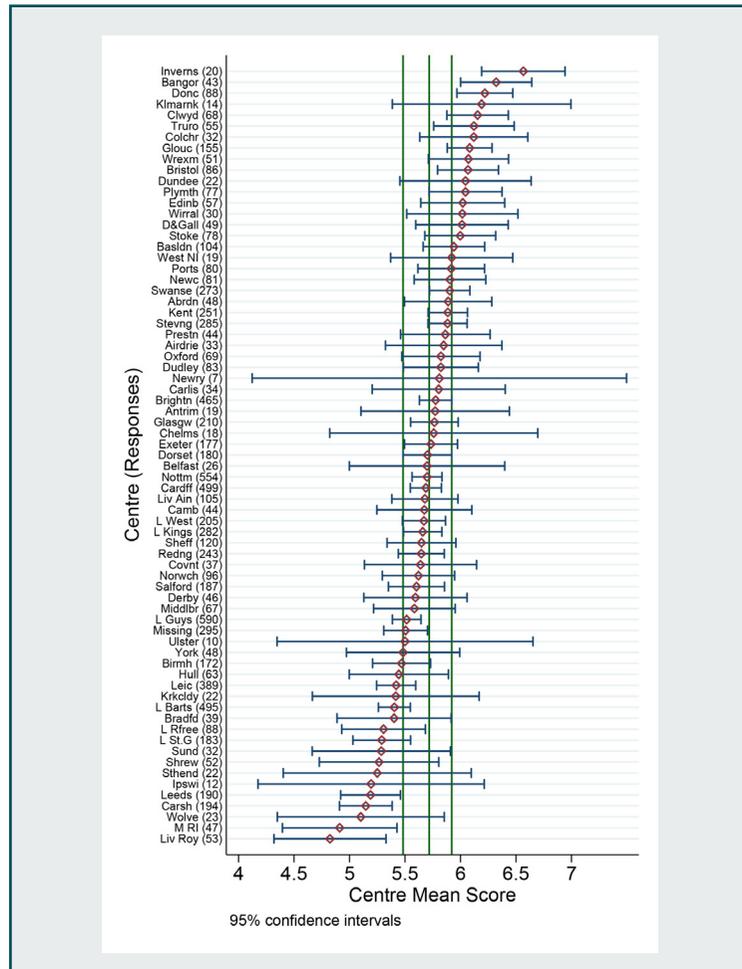
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

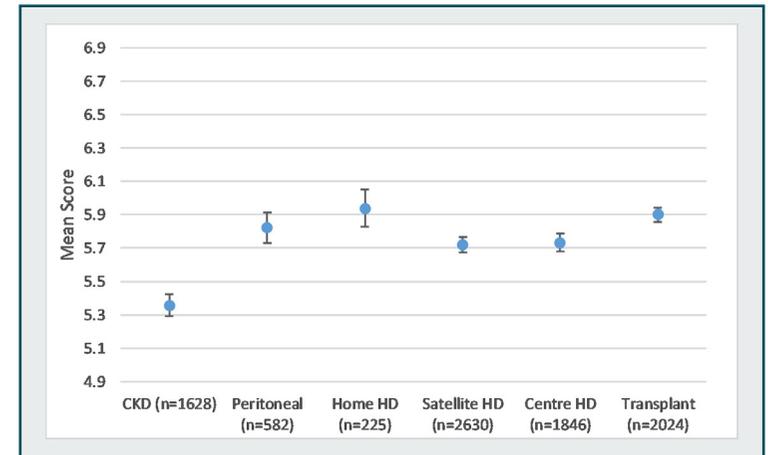
Number of responses used to calculate each score are shown in brackets.

Section 2: Support

A)



B)



Theme questions

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

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

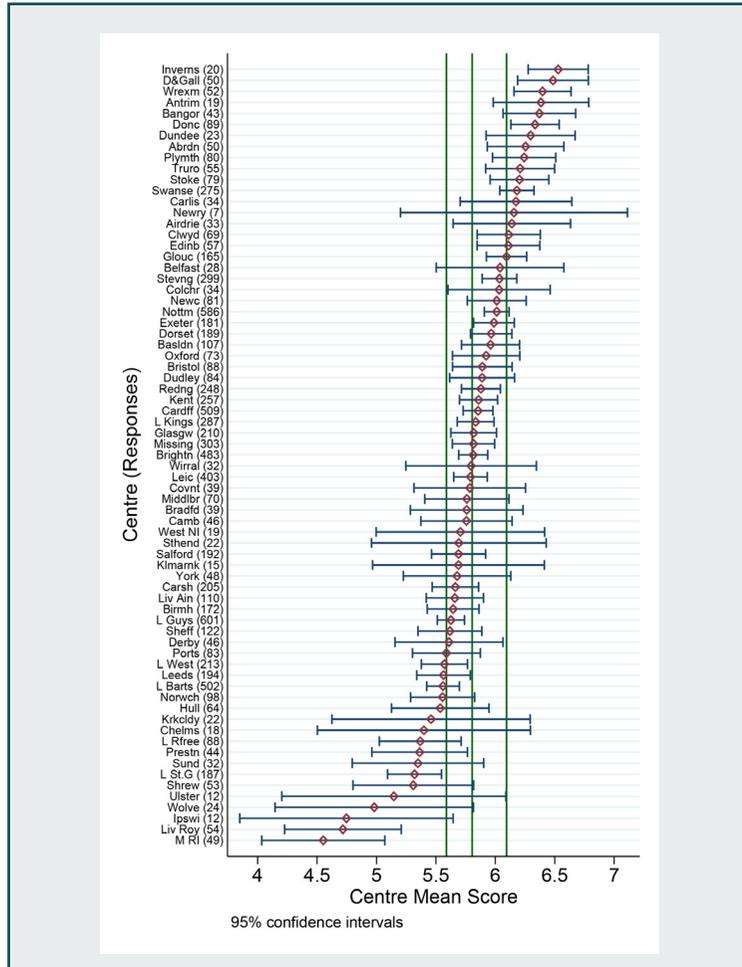
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

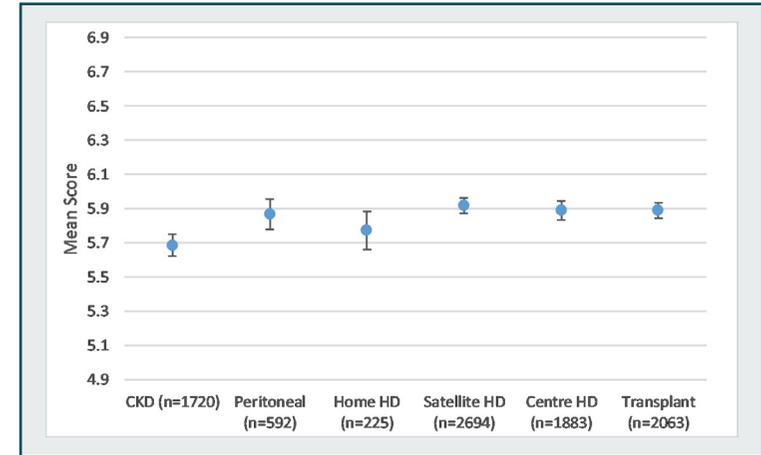
Number of responses used to calculate each score are shown in brackets.

Section 3: Communication

A)



B)



Theme questions

Do you think there is good communication between:

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

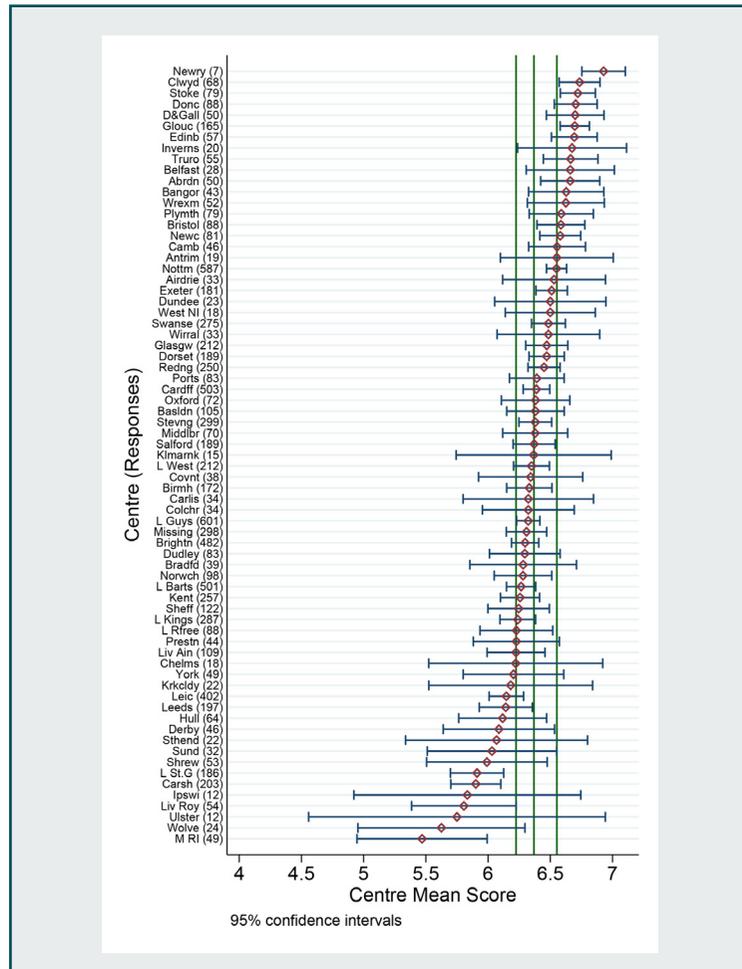
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

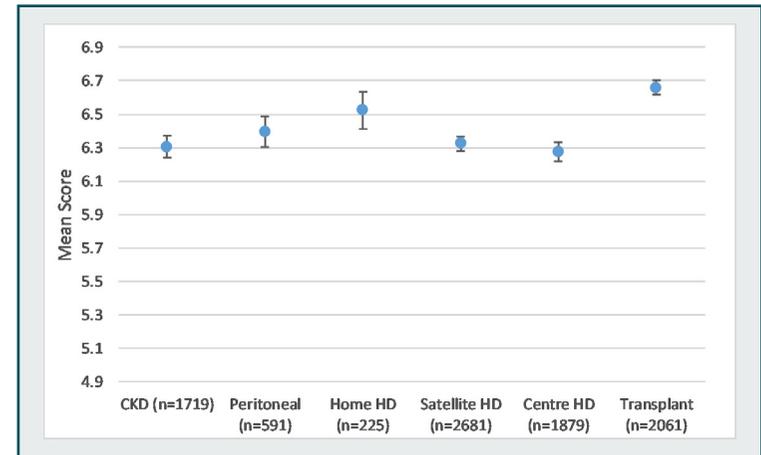
Number of responses used to calculate each score are shown in brackets.

Section 4: Patient Information

A)



B)



Theme questions

Does the renal team:

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

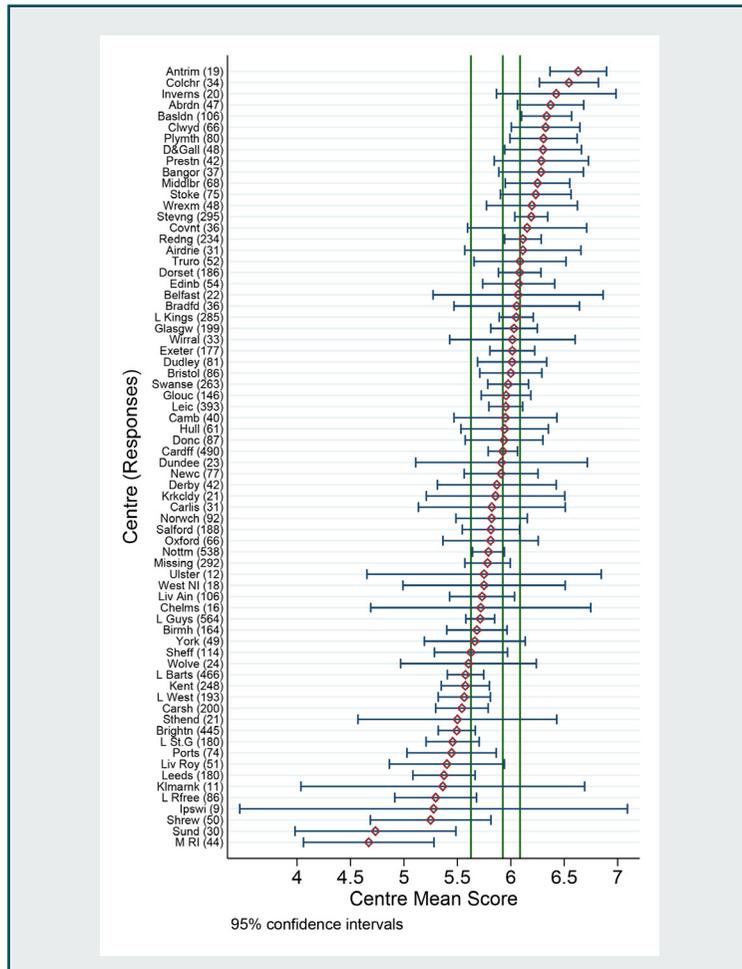
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

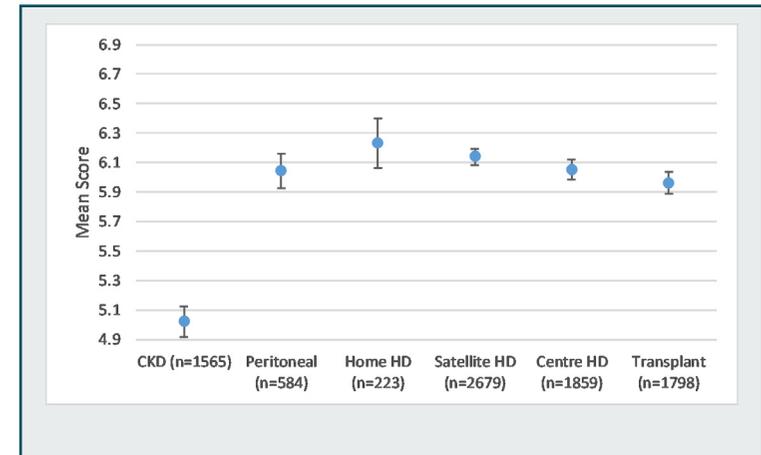
Number of responses used to calculate each score are shown in brackets.

Section 5: Fluid Intake and Diet

A)



B)



Theme questions

Thinking about the advice you are given about fluid intake:

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

Thinking about the advice you are given about diet:

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

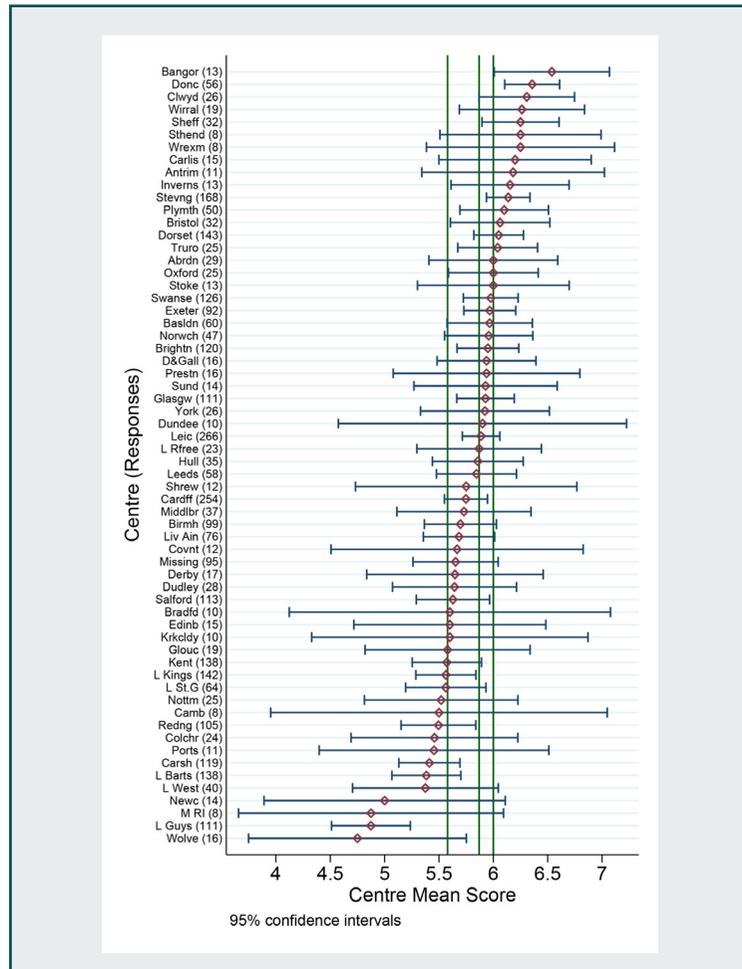
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

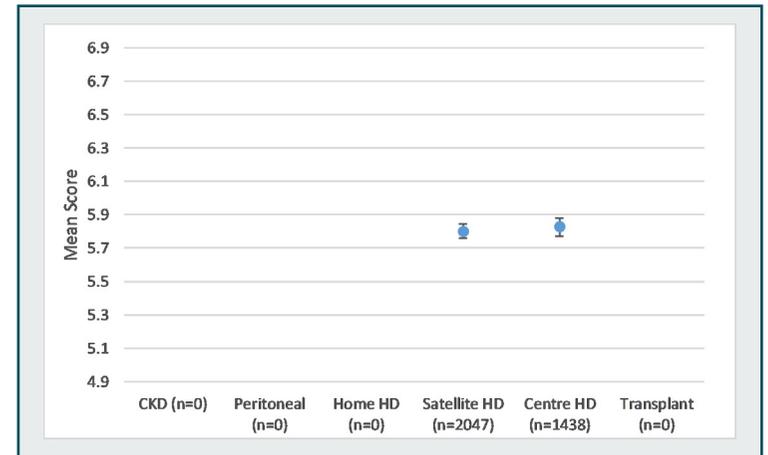
Number of responses used to calculate each score are shown in brackets.

Section 6: Needling

A)



B)



Theme questions

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

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

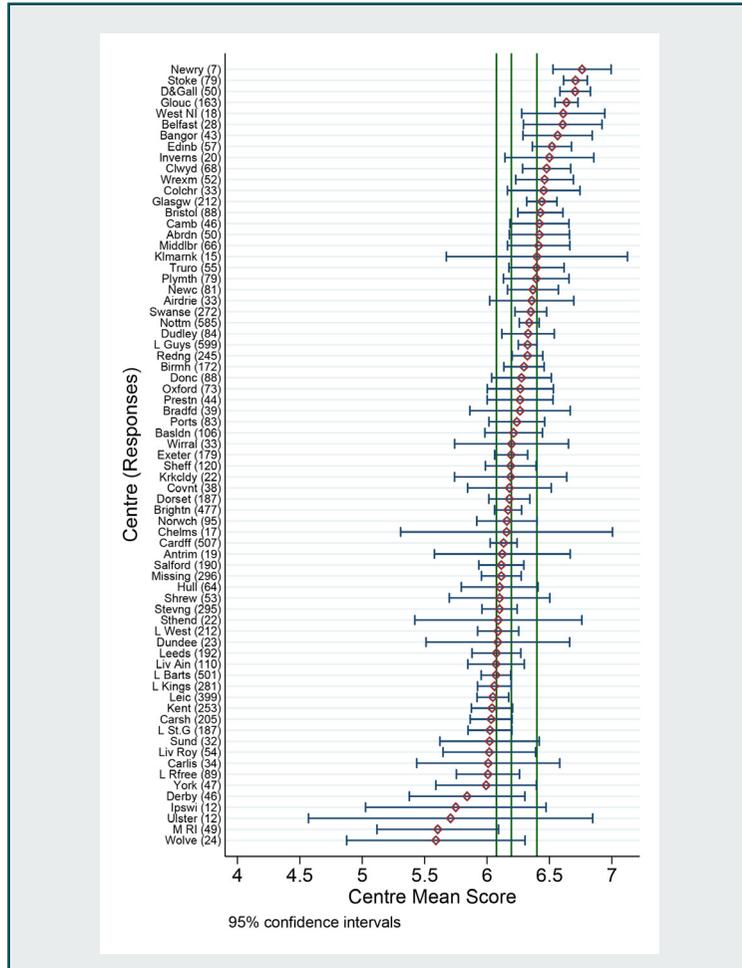
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

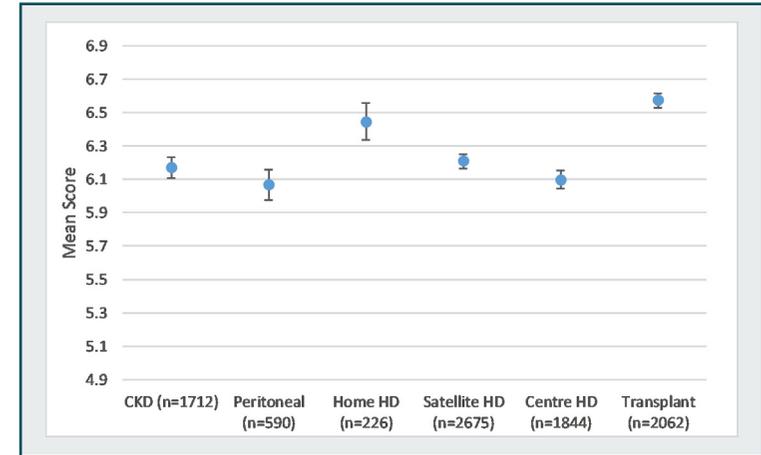
Number of responses used to calculate each score are shown in brackets.

Section 7: Tests

A)



B)



Theme questions

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

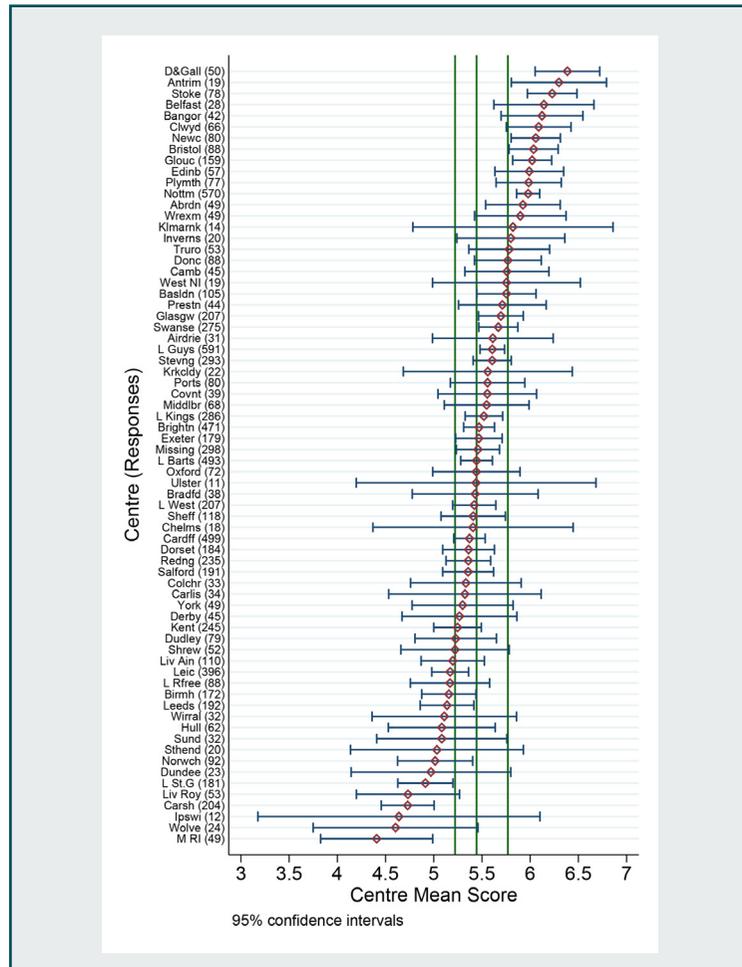
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

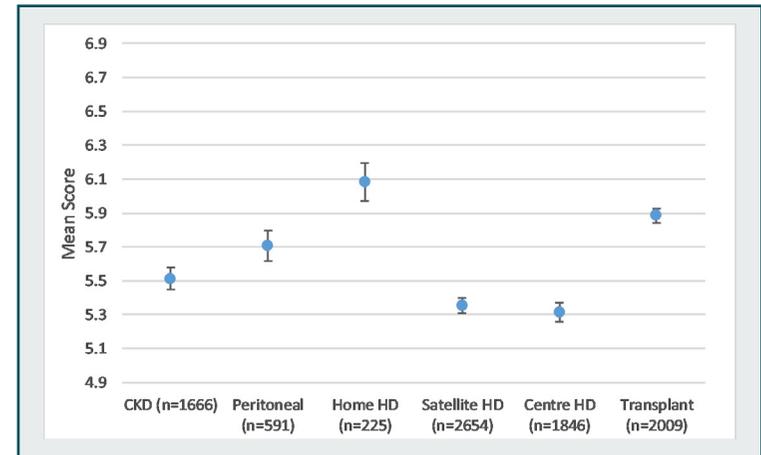
Number of responses used to calculate each score are shown in brackets.

Section 8: Sharing Decisions about your Care

A)



B)



Theme questions

Does the renal team:

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

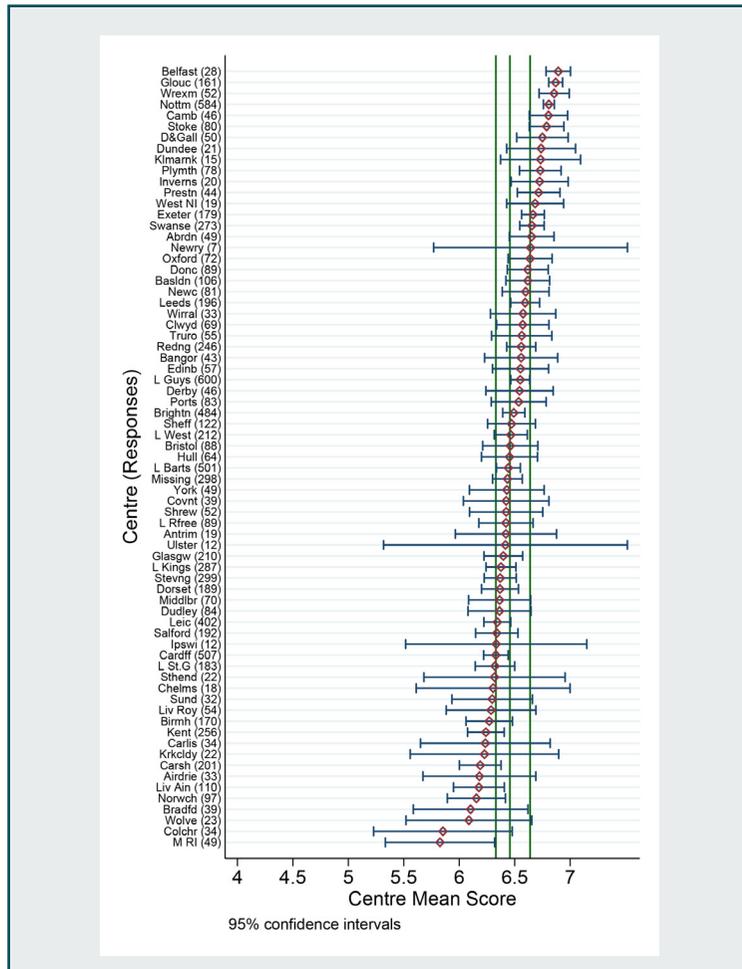
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

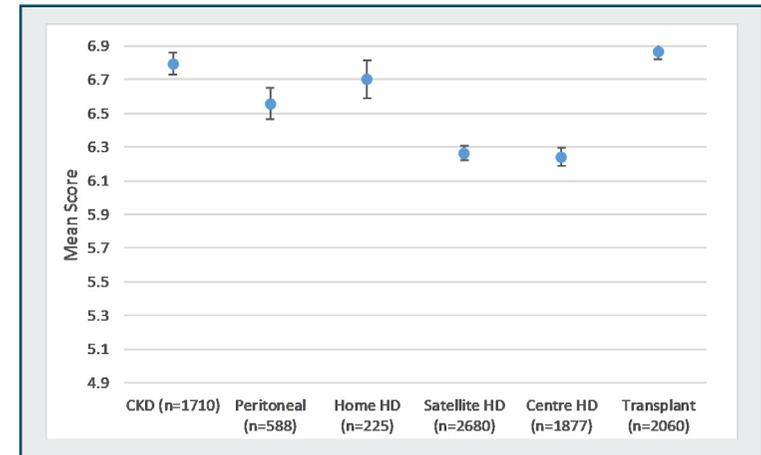
Number of responses used to calculate each score are shown in brackets.

Section 9: Privacy and Dignity

A)



B)



Theme questions

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

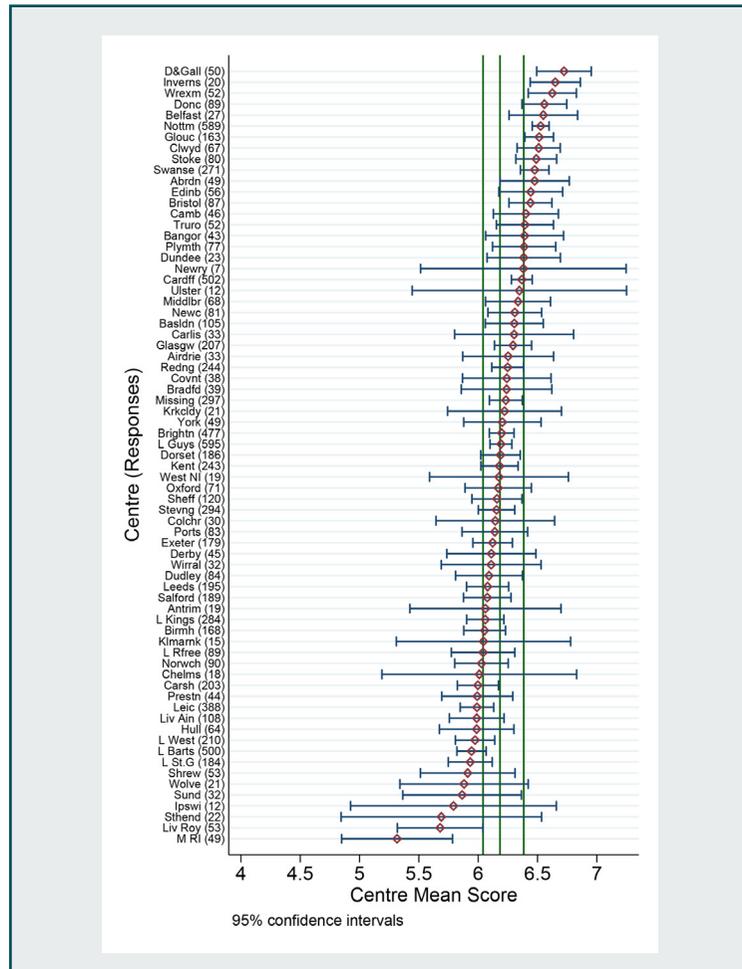
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

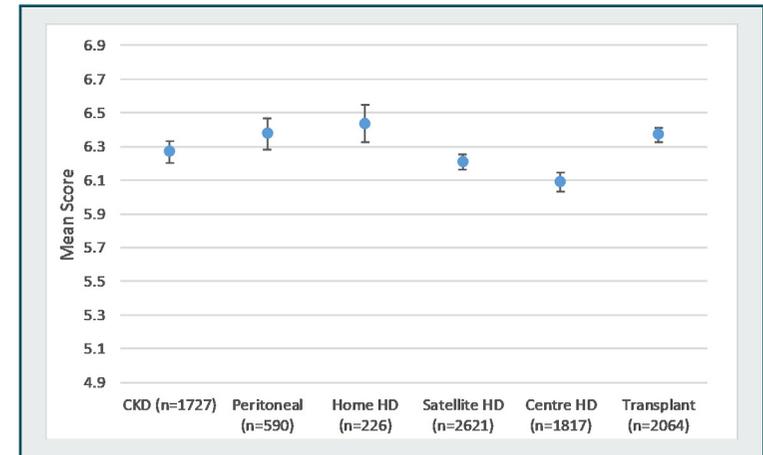
Number of responses used to calculate each score are shown in brackets.

Section 10: Scheduling and Planning

A)



B)



Theme questions

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

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

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

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

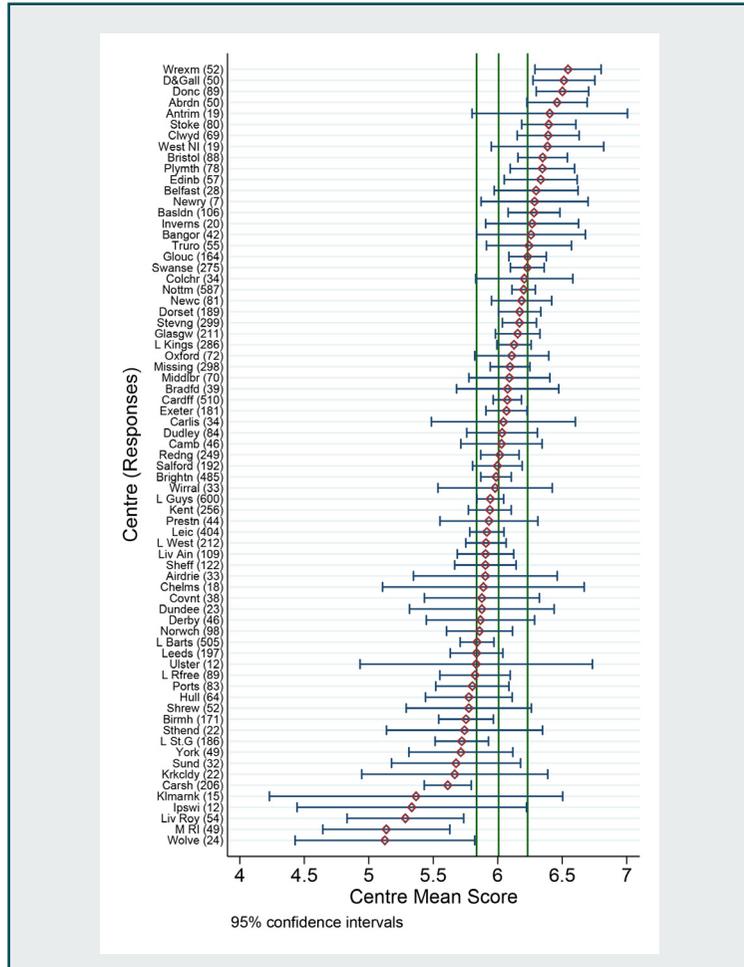
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

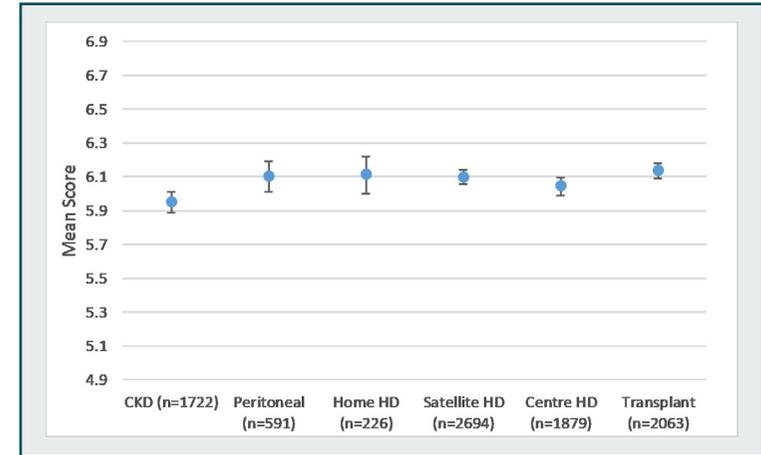
Number of responses used to calculate each score are shown in brackets.

Section 11: How the Renal Team Treats You

A)



B)



Theme questions

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

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

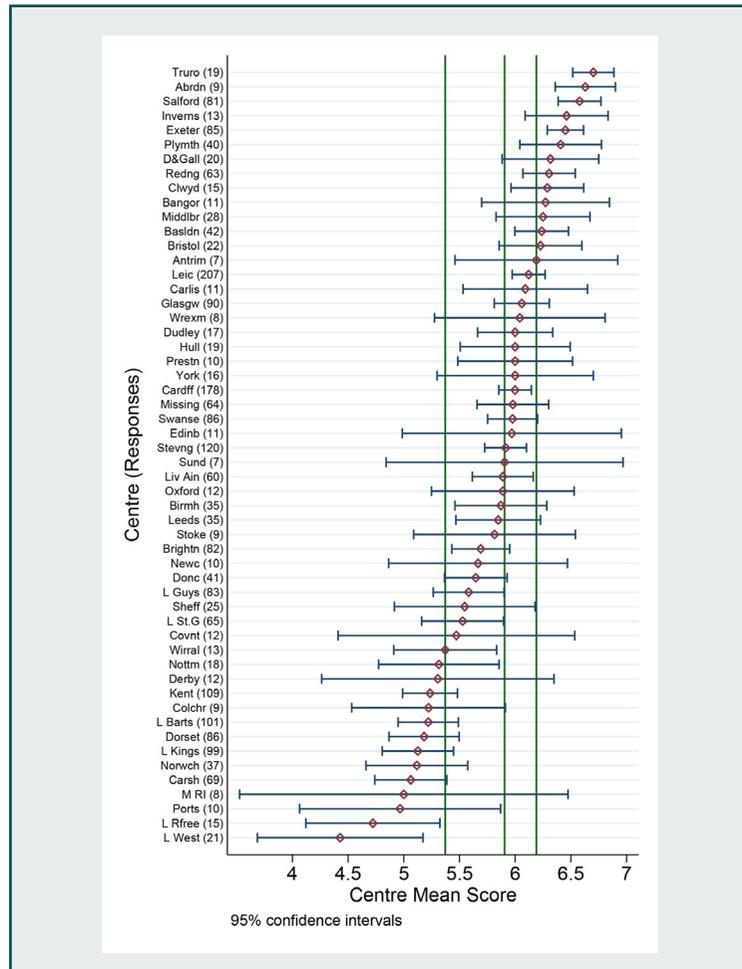
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

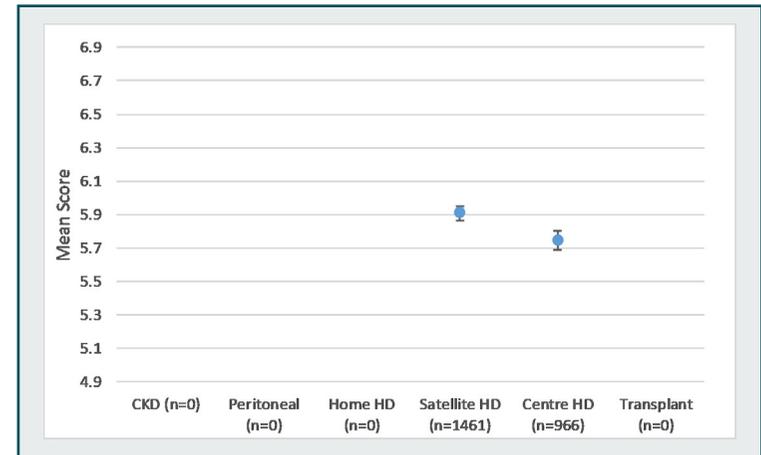
Number of responses used to calculate each score are shown in brackets.

Section 12: Transport

A)



B)



Theme questions

If the renal unit arranges your transport:

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

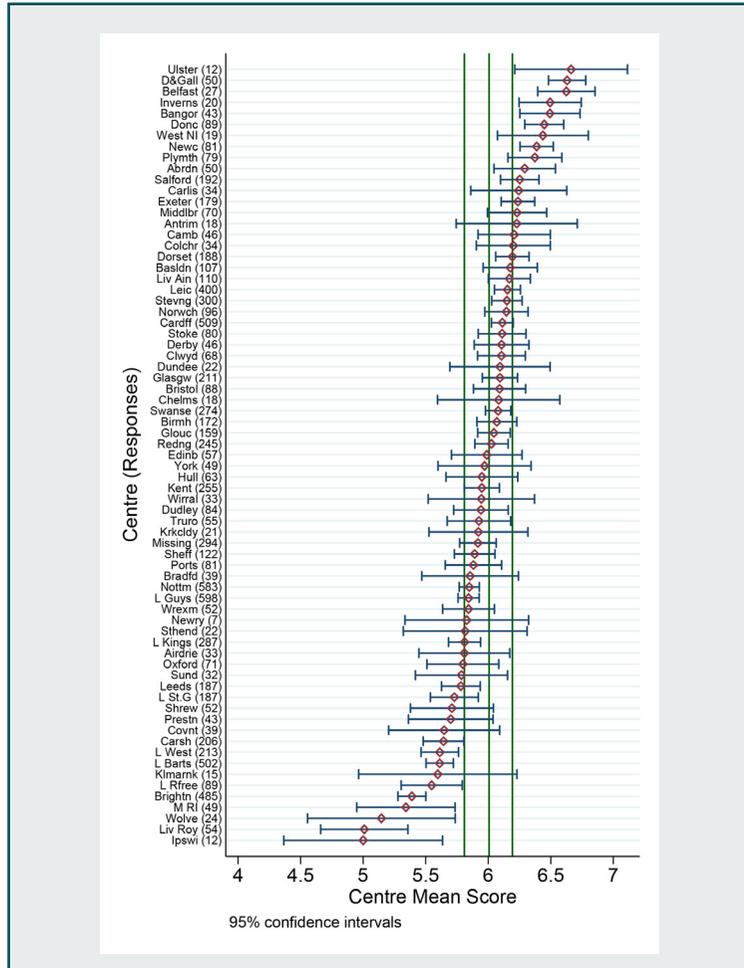
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

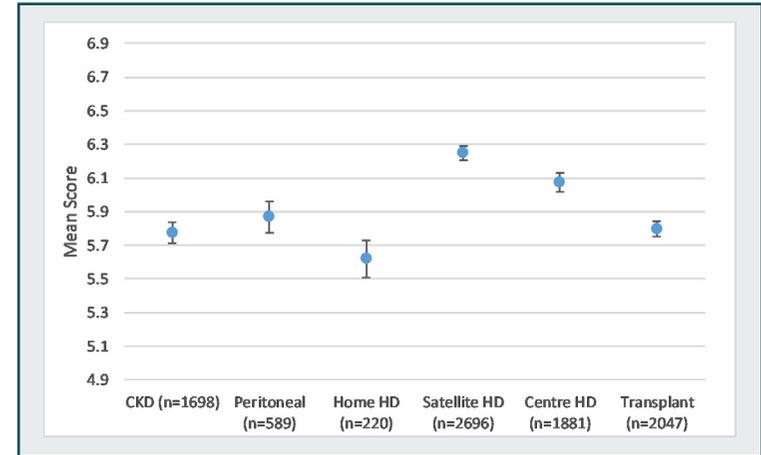
Number of responses used to calculate each score are shown in brackets.

Section 13: The Environment

A)



B)



Theme questions

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

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

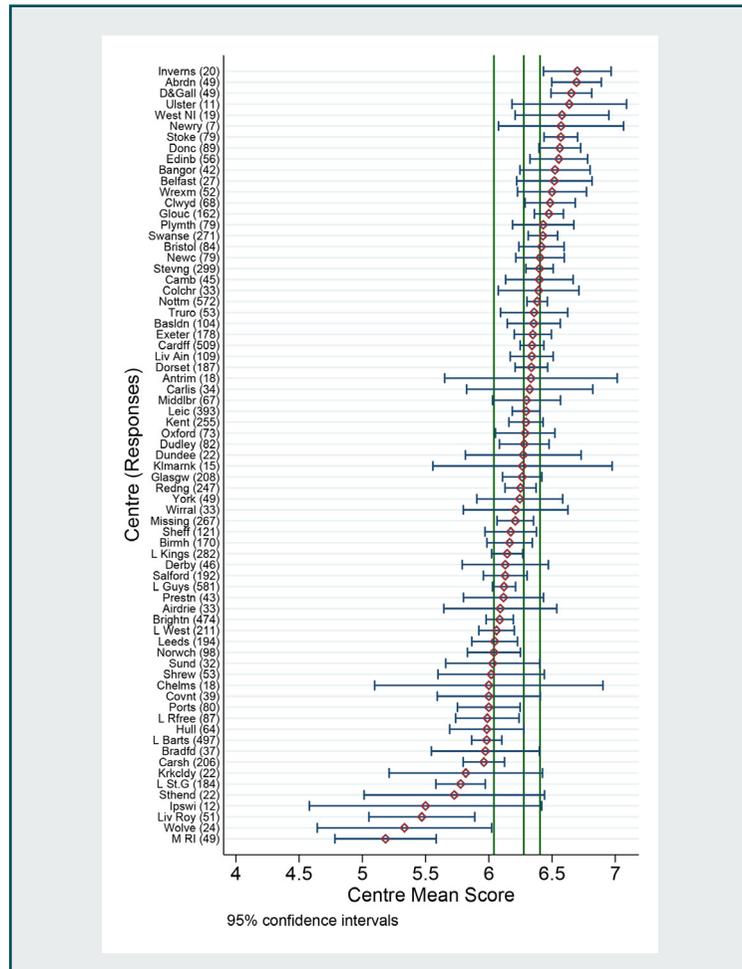
A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

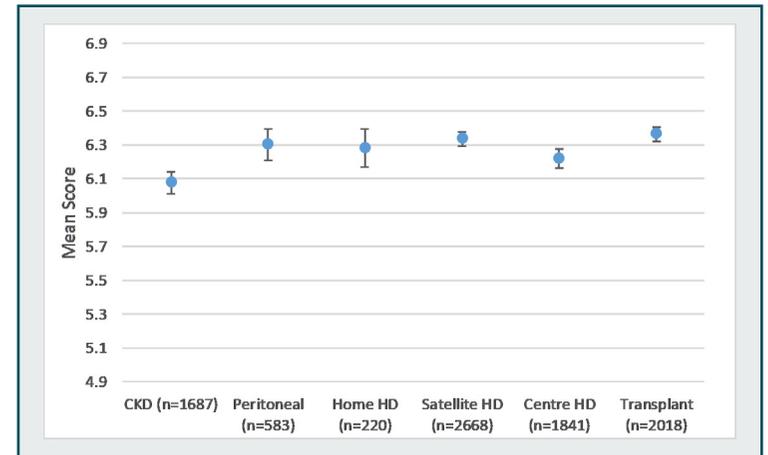
Number of responses used to calculate each score are shown in brackets.

Section 14: Your Overall Experience

A)



B)



Theme questions

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

A) Scores by centre (left figure): Horizontal lines represent 95% confidence intervals. Lower quartile, median and upper quartile of the centre means are vertical green lines

B) Scores by treatment (right figure): Means, 95% Confidence Intervals and number of patients for each treatment group.

Number of responses used to calculate each score are shown in brackets.

What's next? Activating the Kidney PREM data

A person's experience of care cannot be captured solely by a number. There are many complex factors contributing to a person's choice in experience score and it is those things that need to be understood in order to turn data into knowledge and create meaningful improvements.

This data is one part of the improvement journey. The report is designed to open up conversations with patients and staff – locally and between centres – about what is good or bad about kidney patient experience and how experience can be improved and best practice shared. The report is complemented by patient free text comments which have been sent directly to centres, and it should be read in conjunction with these. The Kidney PREM portal also allows centres and patients to look at these themes in more detail and understand any variation in experience across the kidney service, or between the questions making up that theme.

www.renal.org/audit-research/data-portal/prem

The widening variation in scores between centres this year means there are opportunities for kidney services to hear and learn from each other how they have tackled the challenges of providing kidney care during a pandemic.

We suggest four things that each centre could do to take the next step towards activating the Kidney PREM data:

1. Use this report and the Kidney PREM portal to look at the themes of experience in which your centre falls either above or below the interquartile range.
2. Read any patient comments that have been returned directly to your centre alongside these data to add further insight to your results.
3. Set up a focus group (or use existing forums) including patients and the multi-professional team to discuss your centre's key findings and create an action plan in response to any areas in need of improvement. This could include contacting centres with high scores in an area you want to improve in.
4. Share your centre's key findings and action plan with your wider patient population and workforce, as well as your hospital's patient experience lead.

"Our renal leadership team reviewed and presented our PREM results to the wider team at one of our monthly, multi-disciplinary "Renal Grand Rounds", facilitating analysis and formulation of an action plan."

Lead nurse, Imperial College Healthcare Trust

“When the Kidney PREM results came out, we shared the results locally at 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...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...We managed to significantly reduce adverse incidents related to transport, 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.”

Matron for satellite services, Kings College Hospital



We suggest three things that each patient could do to take the next step towards activating the Kidney PREM data:

1. Ask your kidney team about your centre's Kidney PREM results, find out if they are creating an action plan for improvement and how you can get involved if you would like to.
2. Think about how your experience of care relates to the Kidney PREM results and the reasons behind any good or bad experiences – share your thoughts with your team if you feel comfortable to or raise them within an appropriate forum such as your local Kidney Patient Association or Kidney Care UK Advocacy Officer.
3. Take a look through this report and/or the Kidney PREM patient information leaflet, to find out how other patients at your centre and across the UK scored their experience of kidney care.

The Kidney PREM team will be supporting kidney teams and patients to learn from and act on the survey findings. Resources such as template posters to fill out with action plans and display locally, slide-decks to support sharing the messages of the Kidney PREM during local, regional or national meetings, infographics and patient information leaflets will be produced to aid improvement planning. These resources will all be available at:

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



Case Study Evidence

"[The Kidney PREM] really puts patients as the drivers of innovation and improvement... We are looking forward to seeing all the service improvement programmes in Wales when the analysis is published."

Welsh Renal Clinical Network Manager

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

You can read more about what other centres are doing here:

www.renal.org/kquip/qi-stories/case-studies

The results of the Kidney PREM provides data to accompany the biochemical data gathered routinely by renal centres 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 latest Annual Report - Plain English summary, slides and full report:

www.renal.org/audit-research/annual-report

Ongoing improvements to the Kidney PREM

The robustness of the measure has enabled the Kidney PREM dataset to be widely 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, the Kidney Quality Improvement Programme, as well as presented in local trust audit meetings, service reviews and governance settings.

2020 was the first time the survey went fully digital. We are delighted with the engagement from nearly 10,000 patients in this online survey during such a difficult year.

Collecting online not only improves the quality of data, as no questions can be missed unless a patient stops completing the survey, but also creates the potential for more timely reporting of raw data in future as there is no time needed for couriering, scanning and validating paper surveys.

The age and haemodialysis location profiles were closer to UKRR RRT patient figures than in previous years, however we know that patients of Asian ethnicity and patients who have received a transplant are particularly underrepresented in the Kidney PREM. The UKRR does not record information about CKD patients, but it is likely that this group is also underrepresented. Gaps in knowledge include understanding the experience of people who do not speak English, and the impact of deprivation and health literacy on experience (as this is not collected in the Kidney PREM).

We are setting up an inclusivity working group to develop plans to better reach underrepresented groups and measure their experience, as well as understand the impact of deprivation and health literacy on kidney patient experience.

Finally, The Renal Association and Kidney Care UK have successfully partnered with University of Hertfordshire on a British Renal Society / Kidney Care UK research study looking at centre characteristics, practice patterns and the experience of kidney patients during the COVID-19 pandemic. This study will identify characteristics of kidney centres which best relate to patient experience of kidney care during the pandemic (using the Kidney PREM 2020 dataset) in order to optimise learning and inform provision of treatment services.

We hope this data is used by many more researchers, kidney teams, patient groups and policy makers to improve the experience of care of people living with kidney disease in the future.



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