

‘THINK
KIDNEYS’

Patient Experience of Kidney Care

A Report on the Pilot to Test Patient Reported
Experience Measures (PREM) in Renal Units in
England 2016



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1. Foreword

It is said that an individual's experience of the health care they receive is as important as the outcome of their care, and this is especially so for patients living with long term conditions, such as chronic kidney disease, who use NHS services extensively.

We were pleased when, at a meeting of renal unit clinical directors in February 2016, there was overwhelming support to implement an initiative to deliver a Patient Reported Experience Measure (PREM), which would provide them with information about their services from their users' perspectives. Our vision was to create a kind of 'trip advisor' for renal services; providing information that would show what concerns people have about aspects of their care; demonstrating where improvement had an impact, where it was needed, and where comparisons could be made year on year. The aim would be to embed the patient voice at the heart of renal service improvement.

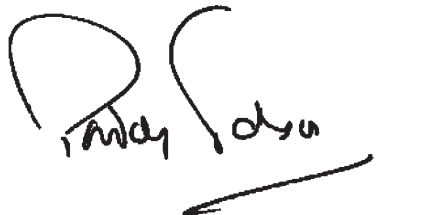
Given we had no mandate for this work, the response to the PREM from renal units was unexpected and positive. In fact we struggled initially to cope with the volume of responses we received. The response recognises the renal community's ongoing commitment to improving services for their patients, and reflects their willingness to open themselves to potential criticism at a time when resources are stretched and finances challenged.

The PREM will become an annual survey as a result of this pilot. We believe that it will ensure support for continuous improvement and that the PREM should, in time, become part of 'how we do things here'. Following the pilot, a wider ambition is that the national picture of experiences of long term renal care, demonstrated through the PREM, will drive and influence how those providing services for people living with other long term conditions might learn from the renal community.

Our thanks go to staff, patients and carers and volunteers in the 39 renal units who managed, took part and got involved with the first PREM. We hope to build on the success of the first year and continue to develop understanding of what's important to people and what their priorities are, and ultimately, to have an impact on individuals' quality of life.



Ron Cullen, CEO
UK Renal Registry



Paddy Tabor, CEO
British Kidney Patient Association

2. Aims and purpose

The UK Renal Registry (UKRR) and the British Kidney Patient Association (BKPA) are organisations committed to improving the quality of life for patients living with renal disease. As such they are keen to encourage people to speak out about their experience of care so that a loud and strong patient voice is heard, shared and acted on. The patient voice will help the renal community understand and take account of people's views of their experience, and use it as the starting point for quality improvement and change in renal care and how it is delivered. The aim is that the PREM helps develop dynamic partnerships for patients and renal staff so that their views and involvement drive change and continuous improvement.

The complexity of renal disease, the frequency and longevity of care for people with renal disease, and the cost of delivering high quality renal services has long been acknowledged. However, it is increasingly recognised that renal disease has a massive impact on the emotional well-being and quality of life for the individual, which in turn has an impact on physical health. The information provided by the PREM results can provide deep and meaningful insight into people's experiences.

The results from the PREM surveys will provide data which complements the biochemical data gathered routinely by renal units and collated by the UKRR, and which forms the statistical data detailed in the UK Renal Registry's annual report.

The main aim of the PREM pilot was to develop a feasible mechanism and process for collecting information from patients which would then provide national, regional and local perspectives on services; the variation in how users perceive care and services, and then to use the data to improve services – at a unit level. In time, and using comparative year on year data, renal units will be able to demonstrate what they have done to make changes and improve care in response to what their patients told them. This source of data is much more reliable and useful, when people are free to have their say anonymously (with no fear of repercussions), than attempting to learn from anecdote, ad hoc or less formal feedback, or complaints.

The plan is for the PREM to be run annually so that comparison can be made, a rationale for change provided and explained, and improvement initiated and measured.

3. Background and how PREM for renal patients came about

A central tenet of the “NHS Five Year Forward View”, published in October 2014 was better care and better patient experience, stating that

“There is broad consensus on what the future needs to be. It is a future that empowers patients to take much more control over their own care and treatment.

The recent update “Next Steps on the NHS Five Year Forward View” (March 2017) states that

*‘The public are highly satisfied with the NHS, but concerned for its future. Perhaps surprisingly, newly published independent data spanning three decades shows that **public satisfaction with the NHS is higher than in all but three of the past 30 years**. And it reveals public satisfaction with hospital inpatients is at its highest for more than two decades.’*

Data on overall satisfaction levels with NHS services can be viewed here or at www.england.nhs.uk/statistics/statistical-work-areas/pat-exp Given this is the case it is important that patient experience is continually monitored, giving the patient a voice and enabling closer co-operation and understanding between the individual and the team caring for them.

Examples of other large scale experience measures for renal patients include the following:

- a) The CHOICE survey - Choices for Healthy Outcomes in Caring for ESRD
 - o Developed as research in the USA in 1997 [Rubin 1997 AJKD], suitable for kidney patients on HD and PD, 23 items on satisfaction with nephrologist, other staff, information, treatment, support in case of problems, etc. Applied in studies, and used in Diaverum centres worldwide in 2008 [Rubin 2004 JAMA; Palmer 2014 BMJ Open]
- b) CAHPS - Consumer Assessment of Healthcare Providers and Systems
 - o Developed by AHRQ in the USA in 2000, for kidney patients on in-centre HD, 42 items in 4 scales (kidney doctors, dialysis centre staff, dialysis centre, treatment). Routinely used as annual survey by Centers for Medicare and Medicaid Services [Paddison 2013 AJKD]
- c) Renal Treatment Satisfaction Questionnaire
 - o Developed in the UK in 2005 [Barendse 2005 AJKD] and suitable for kidney patients on HD, PD, Tx. 11 items in 1 scale on satisfaction with treatment. No information on (routine) use

In the above surveys patients were involved in the development of the survey, through focus groups to rate the importance of questions, and cognitive testing to ensure questions were understandable. This was of paramount importance to the new PREM in its development stage.

NHS England's 'House of Care' was developed as the framework for person centred and co-ordinated care, and the drive to listen to patients has only intensified during the intervening years.

The Transforming Participation in Chronic Kidney Disease (TP-CKD) Programme was established in 2015 by the UK Renal Registry, supported by NHS England, and was the second programme to be developed under the umbrella brand of Think Kidneys.

The overall aim of the programme is to answer the following questions

1. Is it possible to routinely gather information about a patient's level of skills, knowledge and confidence which might help patients to manage their own kidney health?
2. Does a patient with a high level of knowledge, skill and confidence have a better personal reported health and experience outcome (patient reported outcome measures (PROMs) and patient reported experience measures (PREM) than someone who does not understand how to self-manage their care?
3. Can the use of intervention programmes such as peer support, education days, one to one support and coaching, help to improve a patient's level of knowledge, skill and confidence to manage their own kidney health needs?

The vision for the programme:

People with chronic kidney disease and their families will be supported and empowered to achieve the personal and clinical goals that are important to them, wherever they are in the pathway of care. Patients, carers and clinicians will be valued and supported to develop the knowledge, skills and confidence to work together toward the best possible clinical and person centred outcomes.

The work of the TP-CKD programme focusses on -

- Working with renal units and their patients to support, facilitate and measure the difference and improvement in care and outcomes for patients with kidney disease
- Developing a pathway of care for local health communities starting with people's skills, knowledge and confidence and offering a full range of information, support for self-management, self-care, shared care and peer support. This will help people manage their condition, plan their care and improve their physical and mental wellbeing
- Sharing and learning from what currently exists so that we are not re-inventing the wheel but building on the success of pioneers in this important work.

Testing the feasibility of routinely collecting patient-reported outcomes and experience measures in CKD patients who are treated in renal units, was the focus of the programme's Measurement Workstream. The team developed or selected the surveys (from a number already in existence, such as the PAM) which would be introduced in the first year through the 10 renal units which formed the first cohort of Trusts involved.

The four surveys were

- Patient Activation Measure (Insignia Health) - PAM
- Clinical Support for Patient Activation Measure (Insignia Health) - CSPAM
- Patient Reported Outcome Measure (POS-S renal) - PROM
- Patient Reported Experience Measure (newly developed) - PREM

So, while the PREM was initially one of a series of patient measures for the TP-CKD programme, to be implemented in the 10 renal units in Cohort 1, it became something bigger when the renal unit clinical directors agreed at their annual forum in 2016, that a national PREM survey would be of value, and that many would be keen to participate.

As the Measurement Workstream had already commenced work on a series of questions for inclusion in the PREM survey, the team were further involved in developing and agreeing the final set of 43 questions. The Measurement team comprised patients and experts in research and statistics, and included representatives from the BKPA and the National Kidney Federation (NKF). The patient members provided a very clear steer on the topics for inclusion in the survey, and what and how the questions should be asked. The statisticians and researcher members contributed their understanding and knowledge of past patient experience measures and their impact.

The agreement and enthusiasm of renal clinical directors, as demonstrated at their forum was a major driver to run the PREM as a pilot in 2016, and so it was important to maintain the momentum and enthusiasm by acting quickly to deliver the pilot survey in a relatively short timescale.

4. Methodology

Following the support of the renal unit clinical directors for the PREM pilot, the UKRR and the BKPA joined forces with the Measurement Workstream of the TP-CKD programme, to plan how the PREM would work.

The Measurement Workstream's earlier work on the development of the questions for the TP-CKD PREM was expanded. It was important to ensure that the questions would provide results covering aspects of care, or themes, that could be acted on. The first rule of engagement is to make sure that you can respond to the results you get from the questions, and make improvements – if you can't, then you shouldn't ask. The questions were tailored for renal patients.

Planned Timeline for the PREM

| Date | Action |
|--------------------|--|
| February 2016 | Clinical Directors' Forum meet and, when asked about a pilot PREM, are supportive |
| March 2016 | UKRR and BKPA meet to discuss the logistics of moving quickly on this initiative |
| April 2016 | <ul style="list-style-type: none">• Letter to renal clinical directors, explaining the timings for the pilot• Letter to Kidney Patient Association Chairs asking them to encourage people to take part in the PREM• Development of the Renal Unit Guidance for implementing the PREM – thinking about all the information units would need to run the PREM successfully with a good level of response and aiming to make the process as easy as possible |
| May 2016 | Resources and guidance developed and sent out to units <ul style="list-style-type: none">• Guidance on how to run your PREM survey – the Renal Unit Guidance (RUG)• Hard copies of the survey• Envelopes and post box for completed surveys• Poster explaining the survey and why it's important• Information leaflet for patients and staff about PREM |
| June 2016 | Renal units undertook the survey for a two-week period in June or July. More copies of the survey requested and sent out to many units |
| July & August 2016 | Completed surveys returned by courier to the UKRR in Bristol Surveys checked and electronically scanned Dedicated UKRR personnel dealing with queries, collating completed surveys |

| | |
|----------------------|--|
| November 2016 | <p>Access to results on the UKRR website given to clinical directors</p> <p>Data anonymised so that all units' data can be seen for comparative purposes. This was planned to be made available in November, but due to the number of responses, was delayed and published a month later in December</p> |
| March 2017 | De-anonymised data made available to clinical directors on the UKRR website enabling them to compare their unit's results locally and nationally. |

Renal units chose which of their patients they surveyed by treatment or care type, and the two-week period during which they would distribute the survey. For the pilot the surveys were printed as hard copies. Some renal units chose to ask every patient who attended their clinic to complete the survey; others focused solely on their haemodialysis patients. While this resulted in many completed surveys, over 8,000 in total, it meant that like for like comparisons of results were not wholly reliable. It should be remembered that the first year was a pilot and the survey was not validated. This has been addressed for the 2017 PREM.

Completed surveys were returned in the sealed postboxes by courier to the UKRR in Bristol where they were checked and electronically scanned. Dedicated UKRR staff dealt with queries from units, gathered the surveys and responded to requests from units for more hard copies of the survey.

Scanning software was configured to read the surveys with a third-party supplier who provided support throughout the process. Errors were identified and worked through. Despite best efforts, and due entirely to the enormous response to the PREM surveys, original timescales for publishing the results to clinical directors were delayed by two months. This can be considered both negatively and positively.

The structure of the PREM survey

- 43 themed questions, with advice about how to complete the survey and how to get help if required (see Appendix C for the full PREM survey)
- Subject areas for questions were divided into 13 themes -
 - How the renal team treat you
 - Access to the renal team
 - Support
 - Communication
 - Patient Information
 - Diet and fluid intake
 - Tests
 - Sharing decisions about your care
 - Privacy and dignity
 - Scheduling and planning
 - Transport
 - The environment
 - Your overall experience

5. PREM survey results and interpretation

Of the 52 adult renal units in England, 39 units (75%) took part in the pilot PREM. Over 8,000 people responded, completing the survey. This is a remarkable result for a pilot project of this scale and complexity, and represents around 16% of people being cared for in renal units.

The intention was to have results available in October. However, due to the number of surveys returned, the process took longer than planned. It was December 2016 when results of the survey by unit were made available to renal clinical directors, accessed through the UK Renal Registry's website. The results were presented as raw data scores with no detailed analysis or narrative about what the results were showing. Results were initially anonymised, but clinical directors were made aware of which renal unit number was theirs.

From March 2017, the PREM results were attributed to the units, so that some comparison could be made, though, as previously stated, as the PREM survey was not validated, direct comparisons could not be made as units had surveyed different groups of patients.

Caveat about the results - *It should be noted that some renal units chose to target the survey in 2016 to a specific group or groups of patients where they felt they needed to improve engagement or focus their improvement efforts. It therefore follows that direct comparison of results between units may be difficult at this stage of the PREM's development. The PREM for 2017 is for all participating units to engage with all patients within the agreed timeframe.*

Overall Results from the PREM Pilot

The CKD PREM consists of 43 questions which cover 13 themes, including communication, support, diet and fluid and transport (Table 1). Each question refers to a specific part of the renal patient's experience of care, and asks patients to rate their experience on a scale of 1-4, where 1 means they 'never' have that experience' and 4 means that it is 'always' the case. Theme 13 is about the patient's overall experience question, asking the to evaluate their experience on a scale of 1-10.

The questions contained in the themes from 'Support' through to 'Scheduling and Planning' were evaluated as the questions most representative of patient experience in the validation analysis. Other questions, especially those in the last 3 sections of the PREM will be changed in later versions of the PREM.

For 10 of the 43 questions, more than 15% of respondents or more did not assign a score: they either indicated that they had no experience with that issue, they did not know, or they did not respond to that issue at all. Future versions of the PREM will be redesigned to reduce these responses where appropriate.

Last it was noted in the validation report that in general when patients are asked if they are treated well, or about their experience overall, no matter what the context, responses do tend to be very positive. This observation was supported in the PREM pilot where responses on the first and last themes ('How your renal unit treats you' and 'Overall experience') were overwhelmingly positive. For this reason less emphasis should be given to a high score in these themes; conversely falling scores in these themes are an indication of a systemic change in patients' experience of their care within a service.

Table 1: The 13 themes around which the PREM questions were developed, and the 'Overall experience' question (Theme 13). The number in brackets gives the number of questions in each theme

| Theme | Topic | Score range | Theme | Topic | Score range |
|-------|------------------------------------|-------------|-------|---------------------------------------|-------------|
| 1 | How your renal unit treats you (4) | 1 – 4 | 8 | Sharing decisions about your care (4) | 1 – 4 |
| 2 | Access to the Renal Team (3) | 1 – 4 | 9 | Privacy and dignity (2) | 1 – 4 |
| 3 | Support (5) | 1 – 4 | 10 | Scheduling and planning (3) | 1 – 4 |
| 4 | Communication (4) | 1 – 4 | 11 | Transport (3) | 1 – 4 |
| 5 | Patient information (4) | 1 – 4 | 12 | The environment (5) | 1 – 4 |
| 6 | Diet and fluid intake (2) | 1 – 4 | 13 | Overall experience (1) | 1 – 10 |
| 7 | Tests (3) | 1 – 4 | | | |

Table 2 Characteristics of the 8,162 people who completed the PREM survey

| Characteristic | N | % |
|------------------------------|-------|-------|
| Age | | |
| ≤30 | 325 | 4.0 |
| 31-55 | 1,910 | 23.4 |
| 56-74 | 3,134 | 38.4 |
| ≥75 | 2,110 | 25.9 |
| Missing | 683 | 8.4 |
| Total | 8,162 | 100.0 |
| Gender | | |
| Male | 4,250 | 52.1 |
| Female | 3,652 | 44.7 |
| Missing | 260 | 3.2 |
| Total | 8,162 | 100.0 |
| Type of treatment | | |
| Peritoneal dialysis | 738 | 9.0 |
| Haemodialysis | 4,433 | 54.3 |
| Transplant | 1,070 | 13.1 |
| Pre-dialysis | 493 | 6.0 |
| Missing | 1,428 | 17.6 |
| Total | 8,162 | 100.0 |
| Type of haemodialysis | | |
| Home | 226 | 5.1 |
| In-centre | 3,353 | 75.6 |
| Missing | 854 | 19.3 |
| Total | 4,433 | 100.0 |

Participants

In total 8,460 people from 40 renal units across England participated in the PREM. A total of 8,185 of these people completed sufficient questions for their responses to be included in the analyses of the survey. From these patients 17 were excluded since they were incorrectly assigned to a centre which did not participate, 5 patients were excluded because their centre was unknown, and 1 patient was excluded as the patient was the only one to complete the questionnaire at one renal centre. The total number of patients included in the analysis in this report was 8,162 and the average number of respondents per renal unit was 209, but this varied widely, ranging from 34 to 815.

The characteristics of people completing the survey can be seen at Table 2. The majority of participants were between 56 and 74 years old; on in-centre haemodialysis. A similar number of men and women participated in the survey.

It should be noted that people completing the PREM were older compared to all people who are on RRT in the UK. This may be explained by the fact that relatively few transplant patients – who tend to be younger – completed the survey. Compared to all people on renal replacement therapies in the UK, dialysis patients were over-represented in the PREM. However, the age and gender of people on dialysis who completed the PREM survey were similar compared to all dialysis patients in the UK.

Overall experience

Average patient experience of renal unit services is high across all 13 themes; ranging from 3.08 (for 'Sharing Decisions About Your Care') to 3.63 ('How the Renal Team Treat You' and 'Privacy and Dignity'). On the response scale this means that on average patients are reporting that they "usually"¹ have a positive experience.

Patient rating of their 'Overall experience' (question 43) highly, with a mean rating of 8.8 out of 10. The majority of responses for this question were 8, 9 or 10 (83.2% of responses), showing as expected that the vast majority of patients responded very positively to this question.

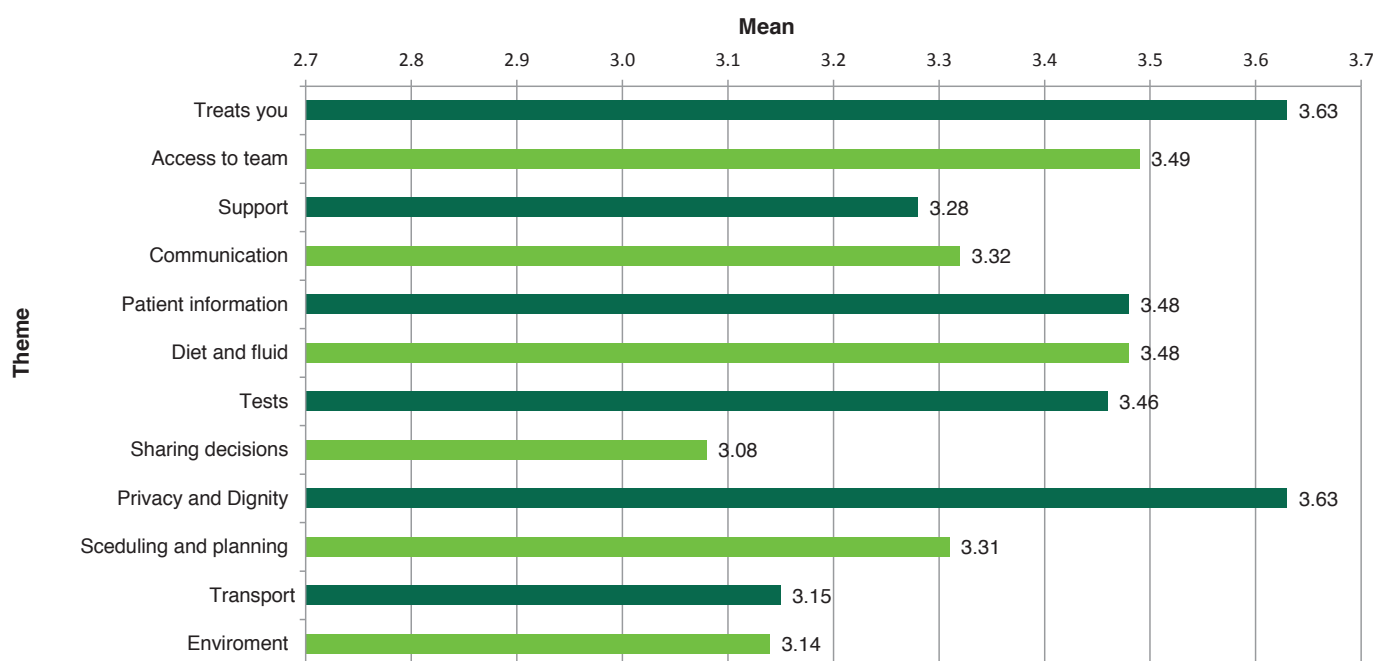
Figure 1 (Mean scores for all centres) shows that the highest reported mean scores are for the themes 'How the renal unit treats you', and 'Privacy and Dignity' with a mean 3.63. There is then a cluster of themes with means ranging from 3.46 to 3.49 ('Access to the team', 'Patient Information', 'Diet and fluid', and 'Tests'). Apart from the Theme 1 and question 43 ('Overall experience') this gives a good indication that the other 5 themes represent the strongest elements of patient experience in the renal services that participated.

The three lowest mean scores were 'Sharing decisions about your care' (3.08), 'Environment' (3.14) and 'Transport' (3.15). Anecdotally patients' experience of transport

Anecdotally patients' experience of transport is difficult. Similarly, environments tend to be fixed, and is commonly seen as an issue for patients. The appearance of shared care as the lowest scoring theme is particularly.

¹ The scale responses are "Never" "Seldom" "Usually" and "Always". On some questions patients could response "Don't Know" or "Not applicable"

Figure 1: Mean scores for the 12 Themes



Note: The mean score for overall experience was 8.8 with a maximum score of 10.

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

| Theme | Topic | Range** | Mean Scores** |
|-------|-------------------------------------|---------|---------------|
| 1 | How your renal unit treats you * | .36 | 3.47 – 3.83 |
| 2 | Access to the Renal Team | .46 | 3.30 – 3.76 |
| 3 | Support | .49 | 3.06 – 3.55 |
| 4 | Communication | .56 | 3.07 – 3.63 |
| 5 | Patient information | .38 | 3.30 – 3.68 |
| 6 | Diet and fluid intake | .36 | 3.35 – 3.71 |
| 7 | Tests | .48 | 3.21 – 3.69 |
| 8 | Sharing decisions about your care # | .58 | 2.81 – 3.39 |
| 9 | Privacy and dignity * | .53 | 3.28 – 3.81 |
| 10 | Scheduling and planning | .32 | 3.07 – 3.49 |
| 11 | Transport # | .77 | 2.81 – 3.58 |
| 12 | The environment # | .58 | 2.84 – 3.42 |
| 13 | Overall experience | 1.03 | 8.28 – 9.31 |

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

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

Variation in patient experience between services

Table 3 highlights variation in patient experience between responding units. Given the large variation in the number of patients surveyed between units (34 to >800), and considerable variation in the type of patients surveyed between units (some units only surveyed HDD patients, others included CKD and Transplant patients), caution must be taken in interpreting the meaning of the observed differences in means scores between units.

The range of scores in each theme are of particular interest, as this gives an indication of the extent of variation between units. Note that a range of 1 would indicate a 25% variation in the mean response. The lowest range of .32 represents 8%, and the highest range of .77 represents 19% of the response range, thus indicating that even for the smallest range there remains nearly 10% variation between services.

Ignoring theme 1, the lowest variation observed in mean scores between services were for 'Patient information', 'Diet and fluid intake' and 'Scheduling and planning'. 'Patient information', and 'Diet and Fluid', also have relatively high mean scores indicating that there is consistently good patient experience in these areas. 'Scheduling' and 'planning' has a relatively low mean, indicating a consistently poorer patient experience in this area.

Ignoring theme 13, the highest variation in patient experiences are in 'Transport' [.77], 'Sharing decisions' [.58] and 'Environment' [.58]. Transport is commonly raised as a problem for patients in a wide range of contexts, and the variation between services is not particularly surprising given the wide range of locations in which the services operate. However, the indication of poor experience in this area is one that can be raised as a consistent problem in some locations. It is notable that the environment also has relative high variation between units, most likely for similar reasons. Notably 'Sharing decisions' has both a very high variation between services, and has the lowest overall mean. Similarly, 'Environment' has a relatively low mean, and one of the highest range of differences between centres (.58). This indicates that patient experience in these areas is not as good as in the other areas of the PREM, and also that some services do relatively well (up to 3.39 'Sharing decisions' and 3.42 Environment) indicating the potential for learning.

It is notable that although 'Privacy and Dignity' has one of the highest mean scores overall, there is also a relatively large variation between units (range .53), indicating that in some units patient experience in this area is relatively poor.

Validating the 2016 Pilot PREM

The UKRR and BKPA appointed the University of Hertfordshire to undertake a full validation of the PREM. This validation was considered an important development for the survey because it gives it credibility and increases the robustness of the responses. Their work, during the winter of 2016/17, sought to establish two aspects of robustness of the survey: validity - to check that the PREM is measuring what we think it is, and reliability - to see if responses are consistent over the themes of the scale, and over time. The validation exercise was undertaken with renal units in Wales, and involved almost 800 patients.

The aim of the validation work was to

1. Understand the relationships between the items on the PREM, to confirm that it measures appropriate aspects of patient experience, extending analysis of scale validity
2. Check the reliability of the PREM, including its stability over time and internal consistency, and
3. Establish whether patients understood and could respond to the PREM in the way intended, using Cognitive Interviewing (Sudman et al, 1996).

There were three stages to the validation. The first was to ask patients to complete the PREM, the second step was to subject the responses to a variety of analyses. Step three involved interviews with 12 patients as they completed the PREM in three renal units. The interviews checked the individual's understanding of the questions, and that their response to the questions provided the information intended. A test and retest exercise was also undertaken, with patients completing the survey twice (one month apart) to see if there were differences and thereby checking the stability of the survey.

Results of the evaluation have informed the PREM survey for 2017 and beyond. The survey for 2017 has been reworked and approved by patients involved in its development. Now validated, the PREM has a stable format, so regional comparisons will be possible as well as year on year comparisons. It will also be possible to highlight improvement in patient experience nationally and locally.

Newcastle upon Tyne Hospitals NHS Foundation Trust was one of the Renal Units that took part in the PREM Survey and they did so with much commitment. Dr Katy Jones and Rachel Fraser, a pharmacist, shared their experience of implementing the PREM in their Trust on the TP-CKD website. [Click here to read the full story.](#)

Newcastle started the PREM by bringing together a group of staff members from different areas of the department and a lead patient. The PREM timeframe was tight, so the team agreed a provisional plan and allocated a lead person in each area during a planning meeting to get momentum and enthusiasm going. They wanted as many patients as possible to complete the survey to get an accurate picture of strengths and weaknesses and, thanks to commitment from staff and volunteers, managed to get a great response from in and out-patients, peritoneal dialysis, transplant, young adults (over 18 years only), as well as supportive care and home haemodialysis (HD) patients. Volunteers attended out-patient clinics to help with completion of surveys.

Katy said "We agreed that it's really important to share the results and give feedback to everyone who took part, patients, volunteers and colleagues alike. We will meet to review the results and feedback, then to encourage engagement in the next PREM survey for 2017 and share our findings and the actions we are going to take as a result, probably in a 'You said; we did' format.

To share learning the Newcastle team have provided a list of actions they took that they think led to them achieving a high response rate. These include

- Arrange an inclusive meeting to plan your approach to PREM with as much lead time as possible – and identify a lead in each area of the unit to organise the distribution of surveys and decide which patient groups to include
- We found the help we got from the Trust volunteer team and the Tyneside Kidney Patients Association to be invaluable and strongly recommend using volunteer groups to help deliver the PREM survey to patients
- Patient volunteers were essential and provided independent support to patients to complete the survey
- Manually completing the 'Renal Unit Name' and 'UKRR Code' on each survey, and completing the return address on the SAE was time-consuming. We hope that pre-populated documents will be available next time.

The Newcastle Team valued the support of the TP-CKD team, who were responsive to ideas and questions about how to deliver the PREM this year and getting the survey to so many patients. The team is really excited about their results and the information they will provide on their services.

6. What is next?

The overall results of the PREM pilot are positive, indicating the tremendous commitment and care provided by renal staff across the country.

The response from the 39 renal units who took part was excellent, particularly given the short timescale within which the survey was implemented. This demonstrates the appetite for improvement in renal teams.

Renal units taking action

Results from the PREM have been reported back to the 39 renal units and at the time of writing they are analysing their scores and considering what actions to take. The results should be used by the units as drivers for change where improvement in scores could be seen following service changes or improvement projects focussing on particular themes of the survey. In the future, it would be useful to share the learning and improvement that leads to change so that others can learn. Shared online case studies would be a useful medium for this. The results provided to the renal units were in raw data format, with no analysis or narrative about the results or recommendations for improvement. This will be discussed with clinical directors and agreed for the PREM results for 2017.

Overall it is expected that the PREM survey will help renal teams to work with their patients to focus on simple changes that will improve their patients' experiences. While the overall results are positive and people feel they are well served by their renal units the results highlight areas for improvement, many of which could be quick wins. The UKRR and BKPA will work with the renal unit teams to encourage feedback of results to patients. This, in turn, will encourage patients' involvement in the survey in future years, and support a cycle of continuous improvement.

Administering the PREM in 2017

Clearly there were lessons to be learnt about the process of administration and management of the PREM for both from the UKRR and the renal units. The UKRR distributed the survey and managed the collation, scanning and analysis of the completed forms. The renal units managed distribution within their clinics and in many instances included volunteers and staff to encourage and support patients in completing the survey. Lessons learned have been logged and will influence the Renal Unit Guidance for the PREM survey in 2017.

Renal Unit Guidance on running the PREM in 2017 is being refreshed and updated and will include advice and learning from the units which participated in the pilot PREM. One major change is that the survey will be available electronically for people happy to access it online. This was requested by both patients taking part in the survey and staff in the units who were supporting them.

Spreading the word

The impact and influence created by asking patients about their experience of care is not just of relevance to those people living with renal disease. There is significant potential for application of patient reported experience measures for others living with long term complex conditions. The UKRR and the BKPA will create publicity about this ground-breaking work so that its success is recognised and becomes the foundation on which the renal community and others can build.

7. Acknowledgements

The UK Renal Registry and the British Kidney Patient Association would like to thank the following people for their contribution to making the pilot PREM a success

- The patients who completed the PREM survey
- The clinical directors, their staff and volunteers in the 39 renal units in England who participated
- Think Kidneys Transforming Participation in Chronic Kidney Disease Measurement Workstream members
- British Kidney Patient Association members
- National Kidney Federation members
- UK Renal Registry programme team and The Patient Council
- The University of Hertfordshire team for their work on validation of the survey

8. Appendices

A. Results

- i. renal unit abbreviations used in data tables and graphs
- ii. the scores for each question by unit in graphical form
- iii. the average scores overall for all aspects surveyed

B. Timescale for the PREM 2017

C. The PREM Pilot Survey 2016

D. Renal Unit Guidance 2016

F. Patient and staff information leaflet and poster

Appendix A – Survey Results

Renal Unit abbreviations used in data tables and graphs

| Town or city | Name of the unit or hospital | Abbreviation used in graphs |
|-------------------|--|-----------------------------|
| 1. Basildon | Basildon Hospital | Basldn |
| 2. Bradford | St Luke's Hospital | Bradfd |
| 3. Brighton | Royal Sussex County Hospital | Brightn |
| 4. Bristol | Southmead Hospital | Bristol |
| 5. Cambridge | Addenbrooke's Hospital | Camb |
| 6. Carlisle | Cumberland Infirmary | Carlis |
| 7. Carshalton | St Helier Hospital | Carsh |
| 8. Chelmsford | Broomfield Hospital | Chelms |
| 9. Coventry | University Hospital Coventry | Covnt |
| 10. Derby | Royal Derby Hospital | Derby |
| 11. Doncaster | Doncaster Royal Infirmary | Donc |
| 12. Dorset | Dorset County Hospital | Dorset |
| 13. Dudley | Russells Hall Hospital | Dudley |
| 14. Gloucester | Gloucestershire Royal Hospital | Glouc |
| 15. Hull | Hull Royal Infirmary | Hull |
| 16. Ipswich | Ipswich Hospital | Ipswi |
| 17. Kent | Kent and Canterbury Hospital | Kent |
| 18. Leeds | St James's University Hospital & Leeds General Infirmary | Leeds |
| 19. Leicester | Leicester General Hospital | Leic |
| 20. Liverpool | Aintree University Hospital | Liv Ain |
| 21. London | St George's Hospital and Queen Mary's Hospital | L St.G |
| 22. London | Guy's Hospital and St Thomas' Hospital | L Guys |
| 23. London | King's College Hospital | L Kings |
| 24. Manchester | Manchester Royal Infirmary | M RI |
| 25. Middlesbrough | The James Cook University Hospital | Middlbr |

| Town or city | Name of the unit or hospital | Abbreviation used in graphs |
|-------------------|--|-----------------------------|
| 26. Newcastle | Freeman Hospital and Royal Victoria Infirmary | Newc |
| 27. Norwich | Norfolk and Norwich University Hospital | Norwch |
| 28. Nottingham | Nottingham City Hospital | Nottm |
| 29. Oxford | John Radcliffe Hospital and Churchill Hospital | Oxford |
| 30. Reading | Royal Berkshire Hospital | Redng |
| 31. Sheffield | Northern General Hospital | Sheff |
| 32. Shrewsbury | Royal Shrewsbury Hospital | Shrew |
| 33. Southend | Southend Hospital | Sthend |
| 34. Stevenage | Lister Hospital | Stevng |
| 35. Stoke | Royal Stoke University Hospital | Stoke |
| 36. Sunderland | Sunderland Royal Hospital | Sund |
| 37. Truro | Royal Cornwall Hospital | Truro |
| 38. Wirral | Arrowe Park Hospital | Wirral |
| 39. Wolverhampton | New Cross Hospital | Wolve |

The average scores for all aspects of the survey

The CKD PREM comprises 43 items (or questions) which cover 13 themes. Each question refers to a specific part of the renal patient's service experience, and asks them to rate that experience on a scale of 1-4, where 1 means they 'never' have that experience' and 4 means that it is 'always' the case.

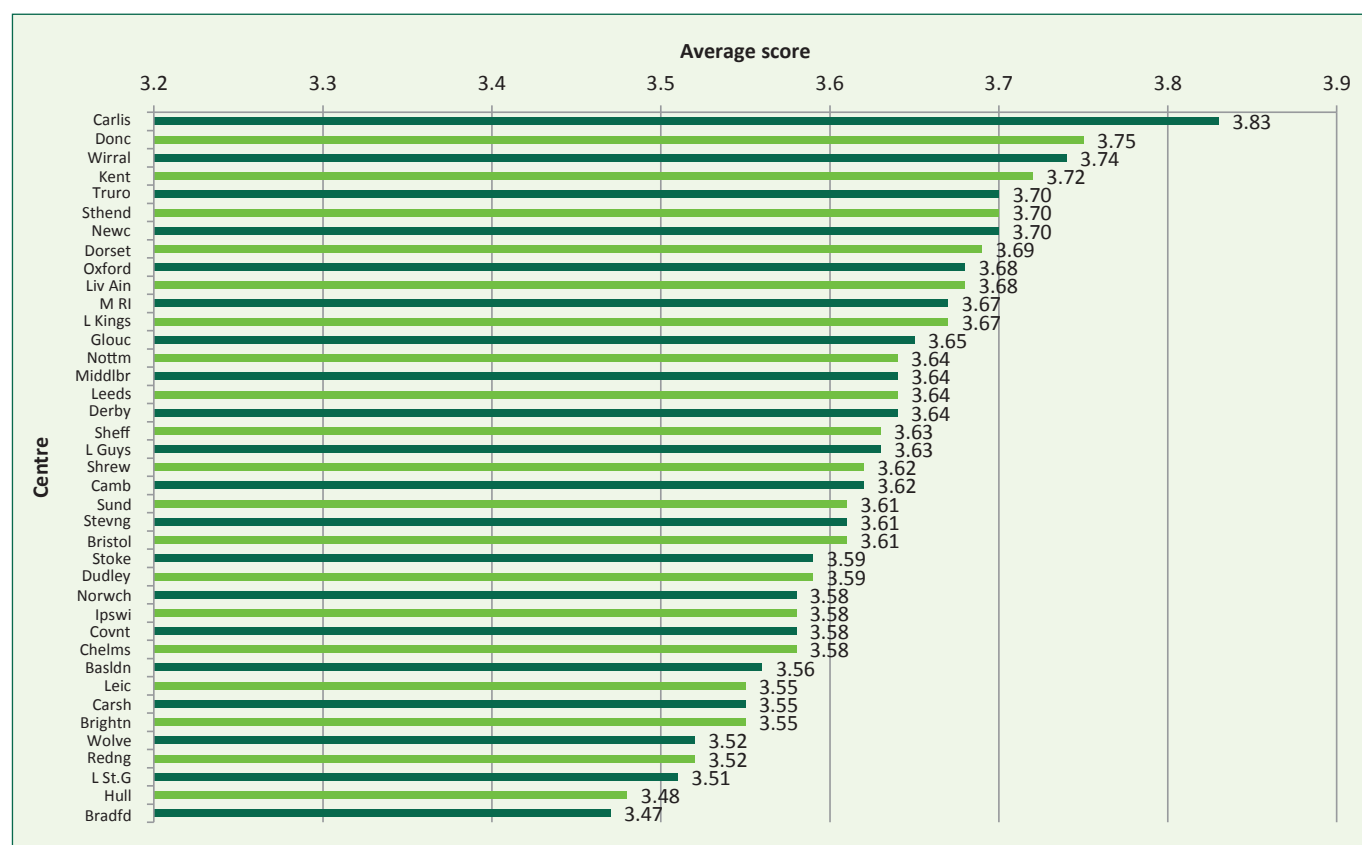
The overall experience question asks participants to grade their response on a scale of 1-10. The full survey of questions can be seen below at Appendix C.

The themes are questions related to the following:

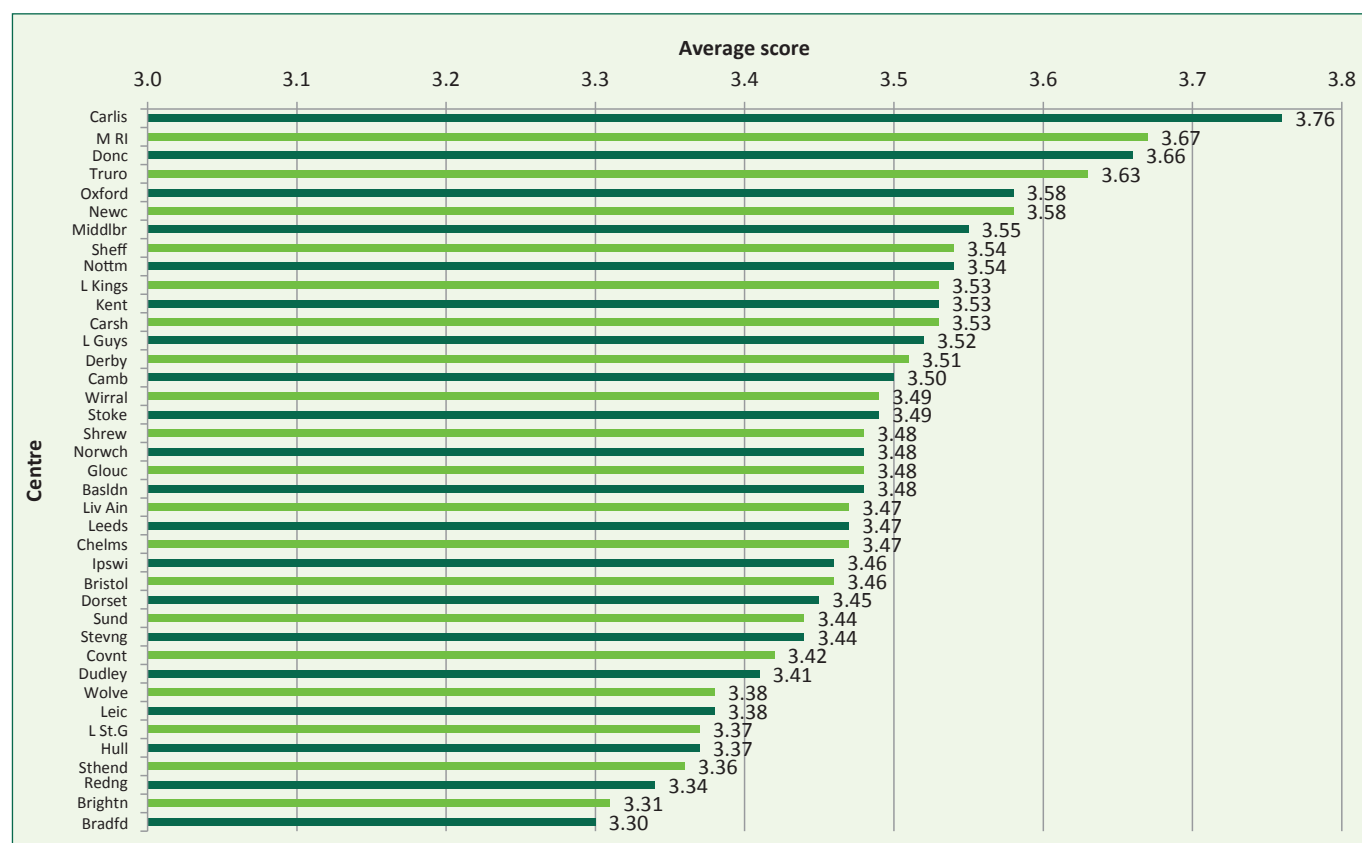
1. How the renal team treat you
2. Access to the renal team
3. Support
4. Communication
5. Patient information
6. Diet and fluid intake
7. Tests
8. Sharing decisions about your care
9. Privacy and dignity
10. Scheduling and planning
11. Transport
12. The environment
13. Overall experience

The graphs show results by renal unit for each theme. The graphs show the number of responses for each unit and their score.

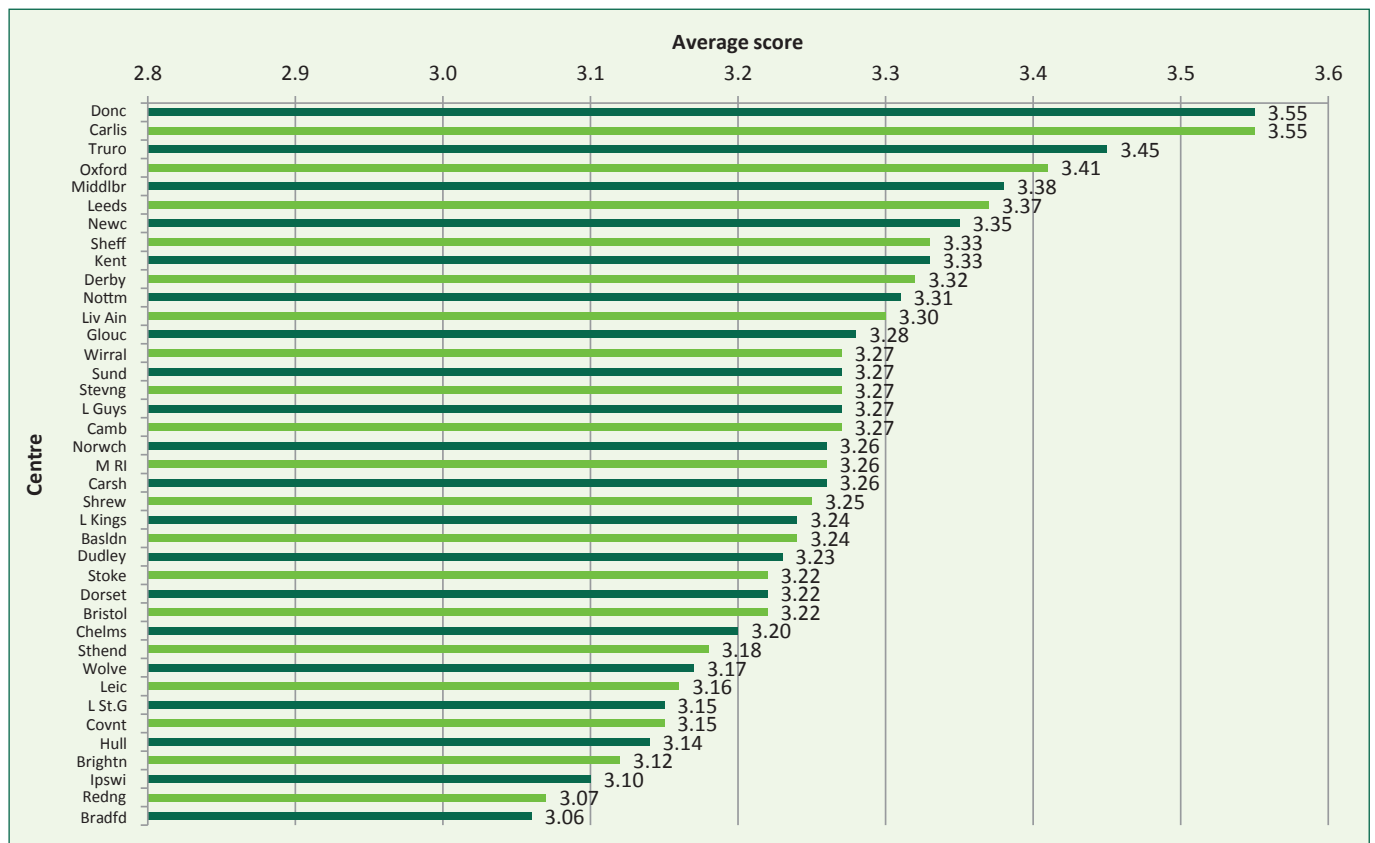
1. How the renal team treat you



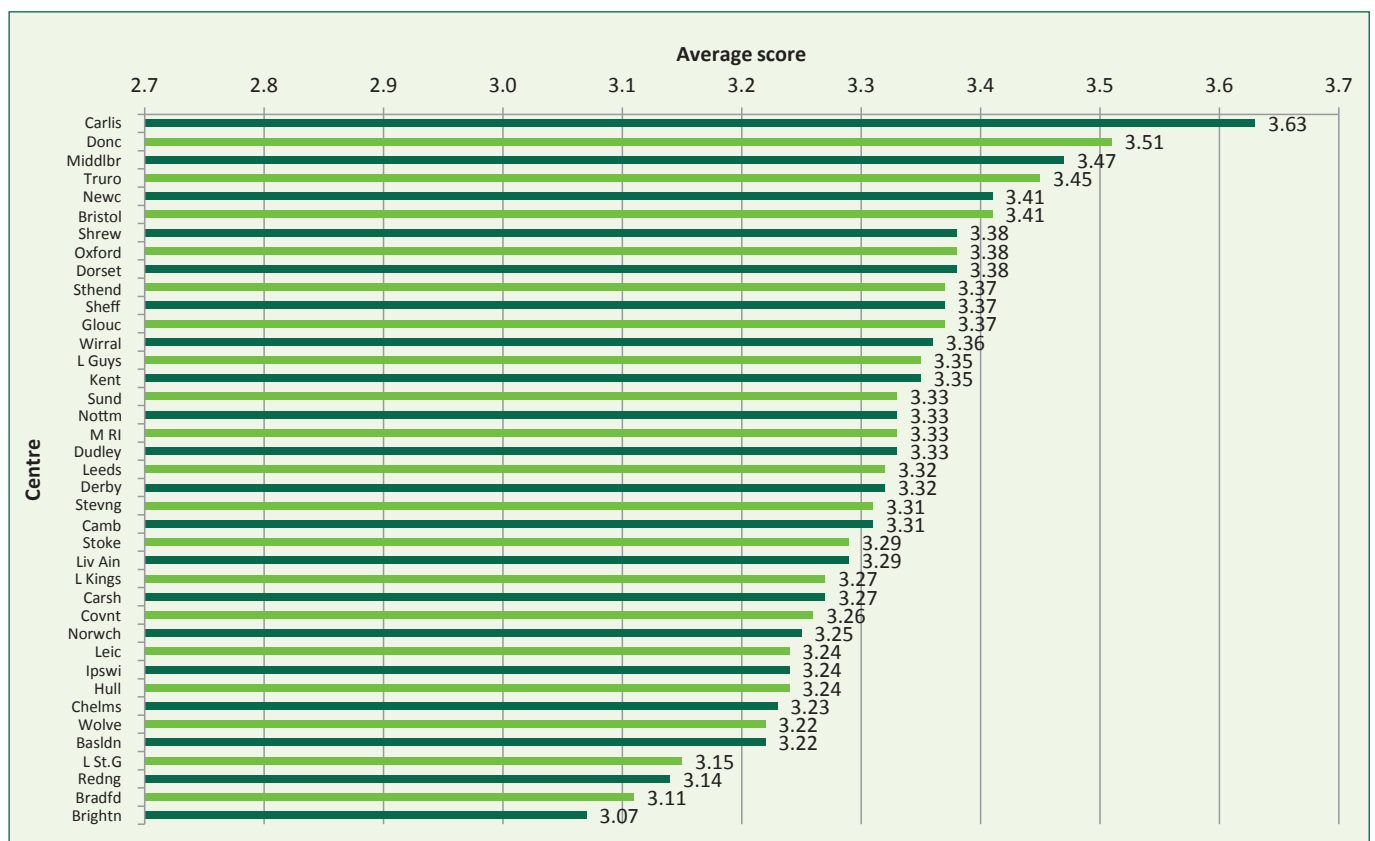
2. Access to the renal team



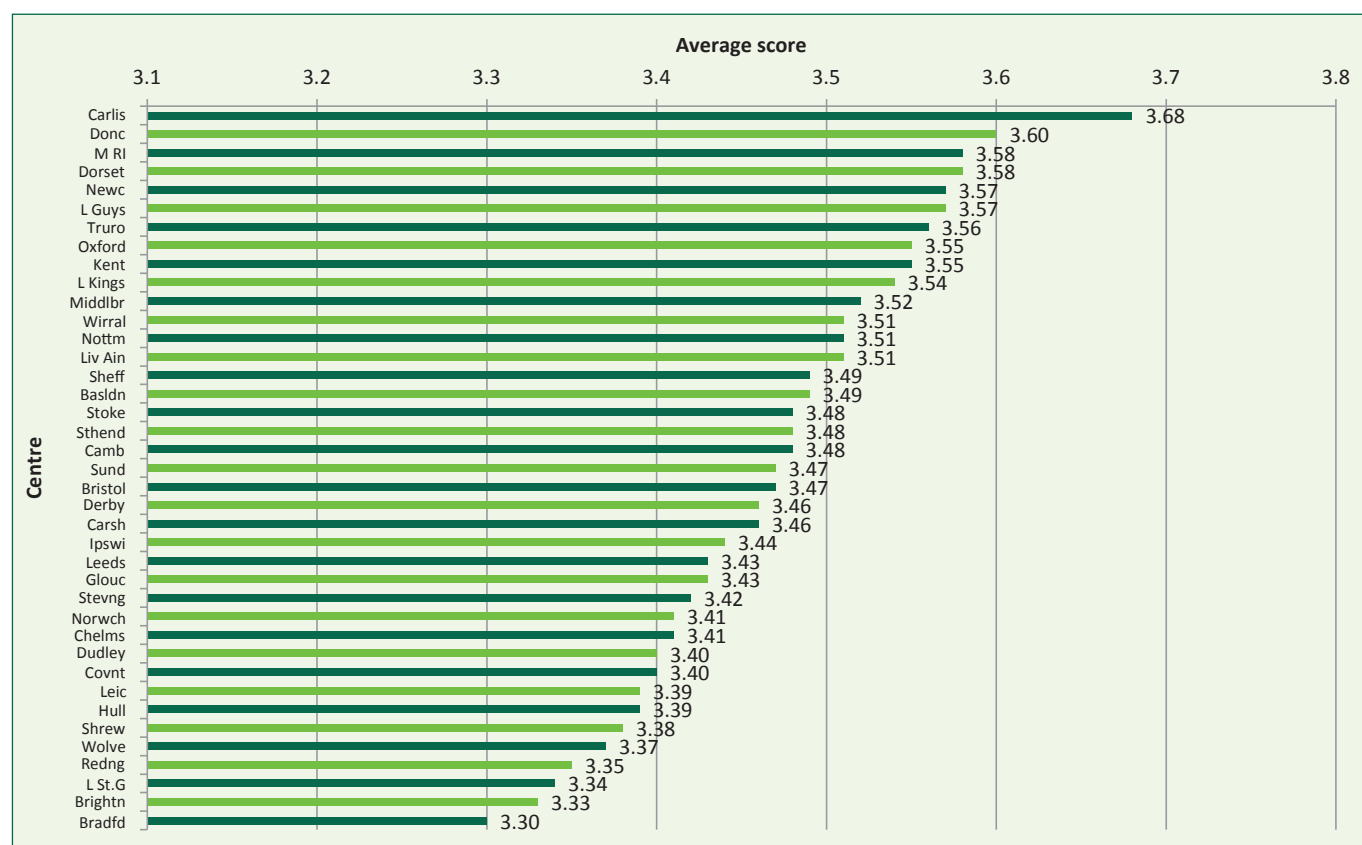
3. Support



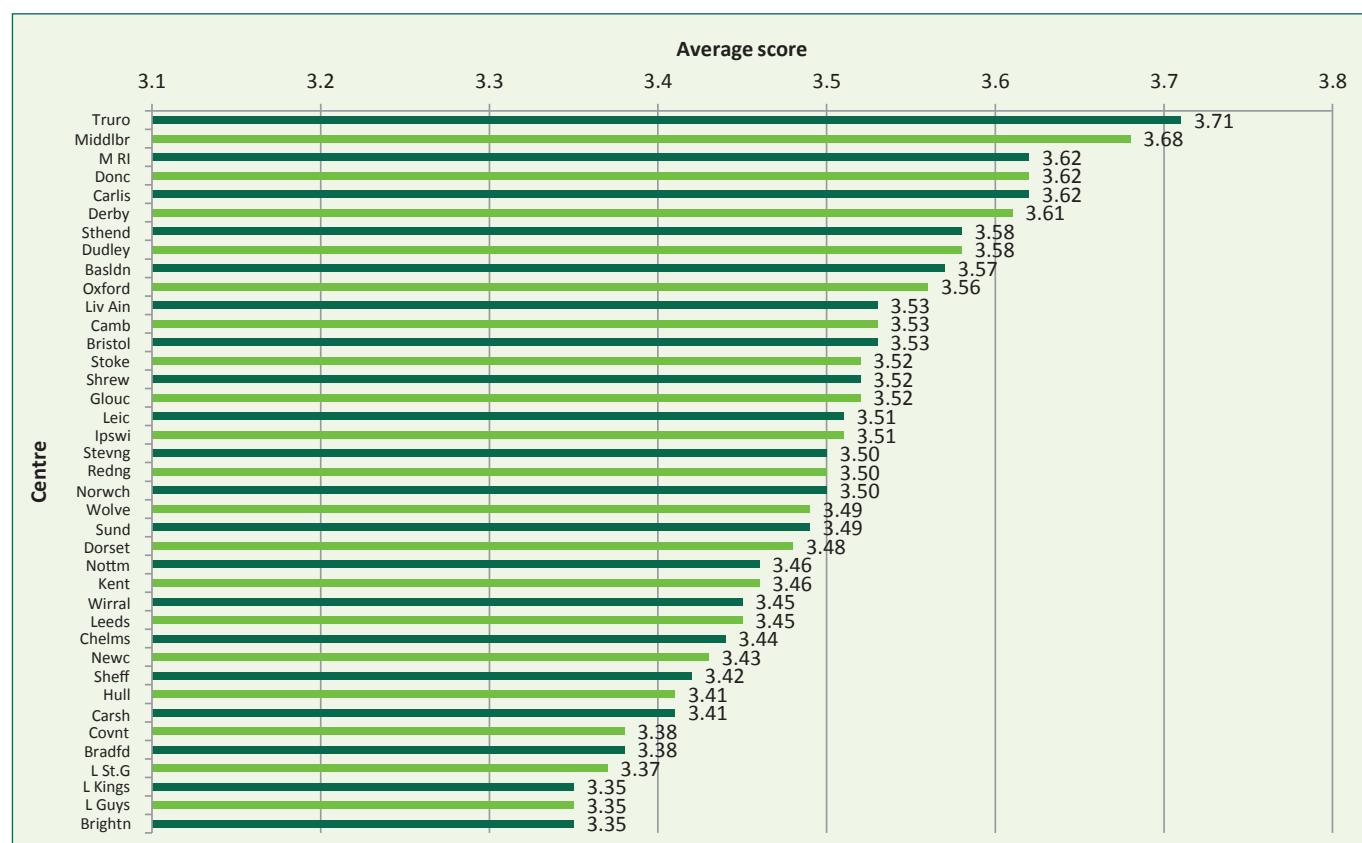
4. Communication



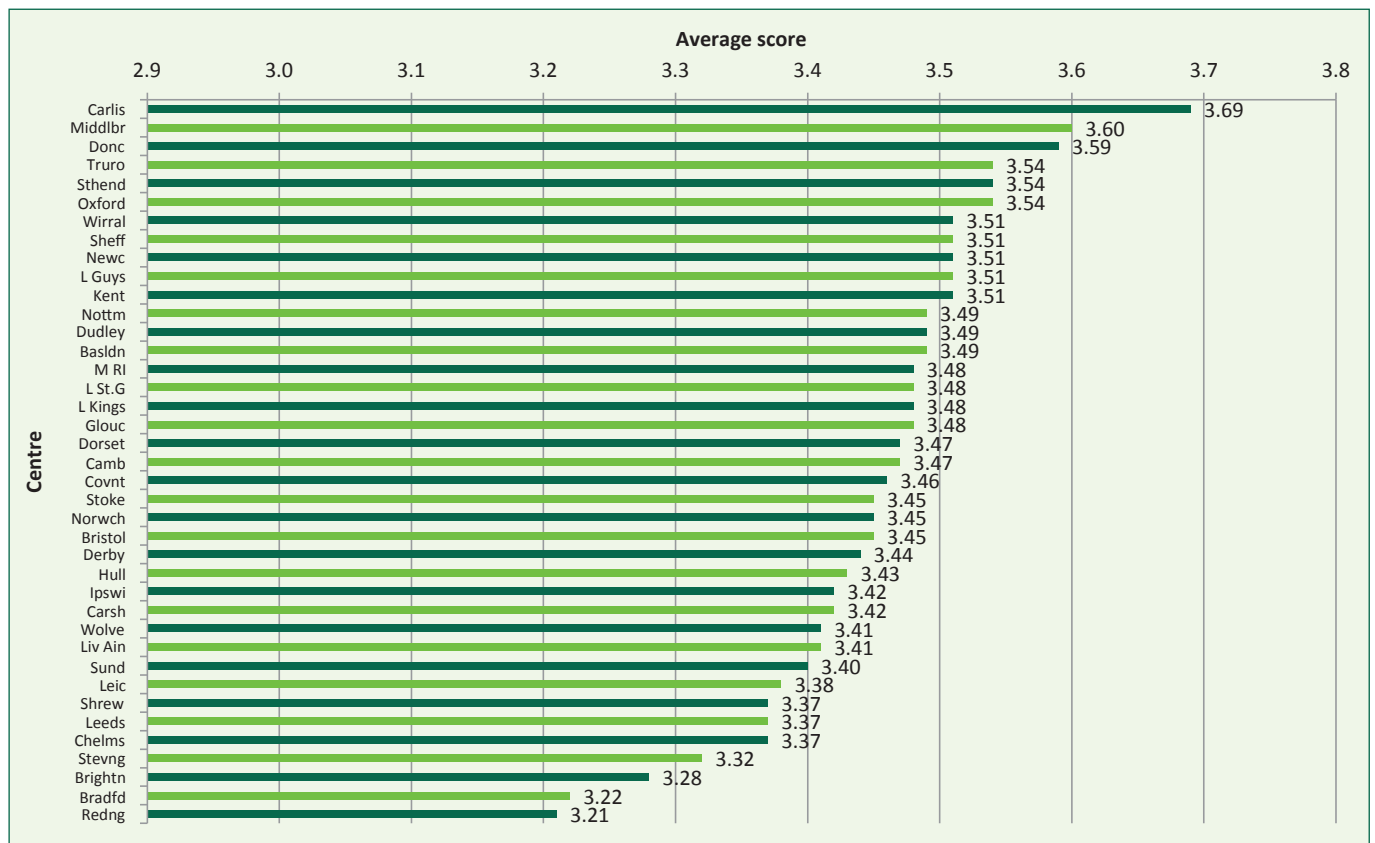
5. Patient information



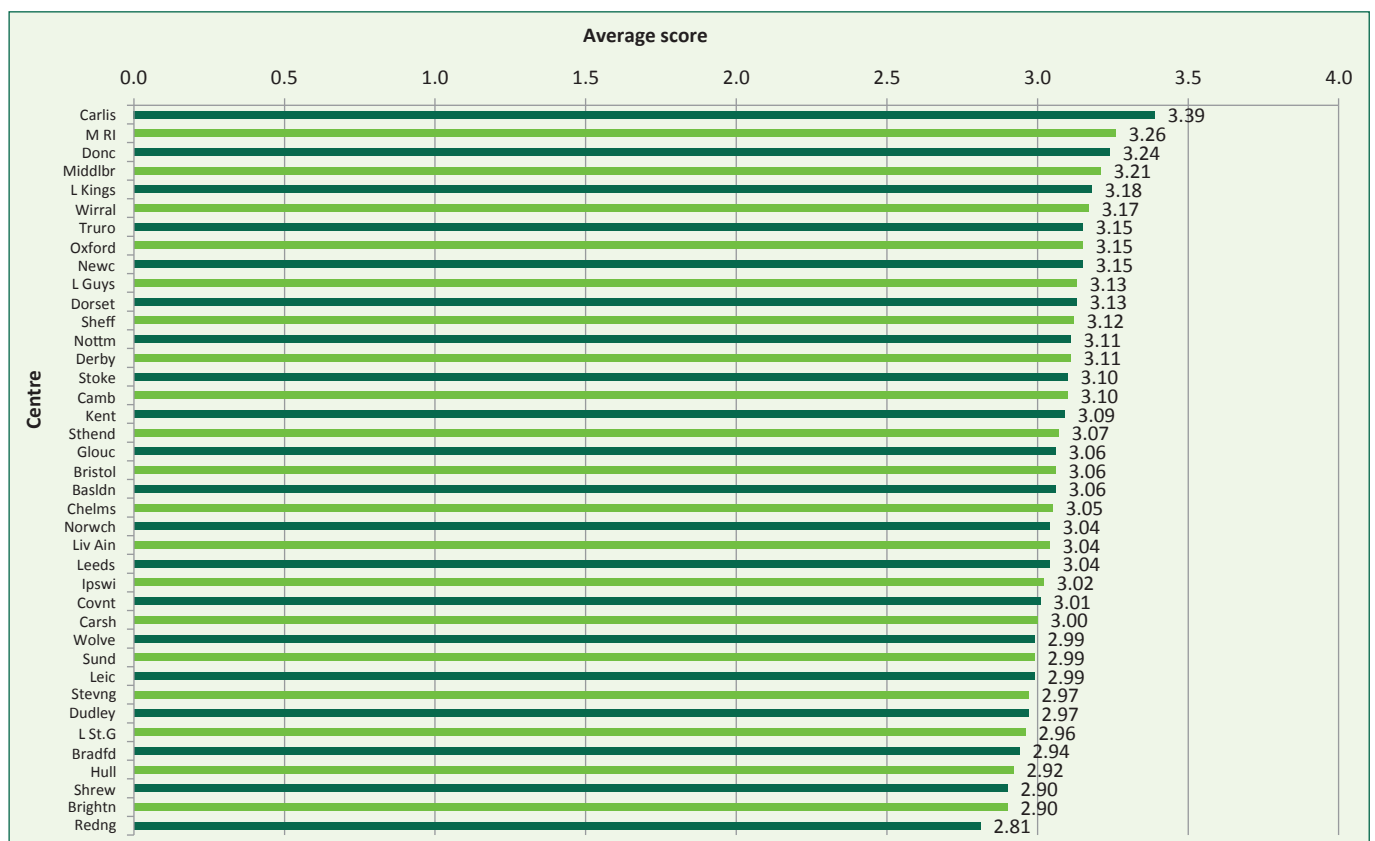
6. Diet and fluid intake



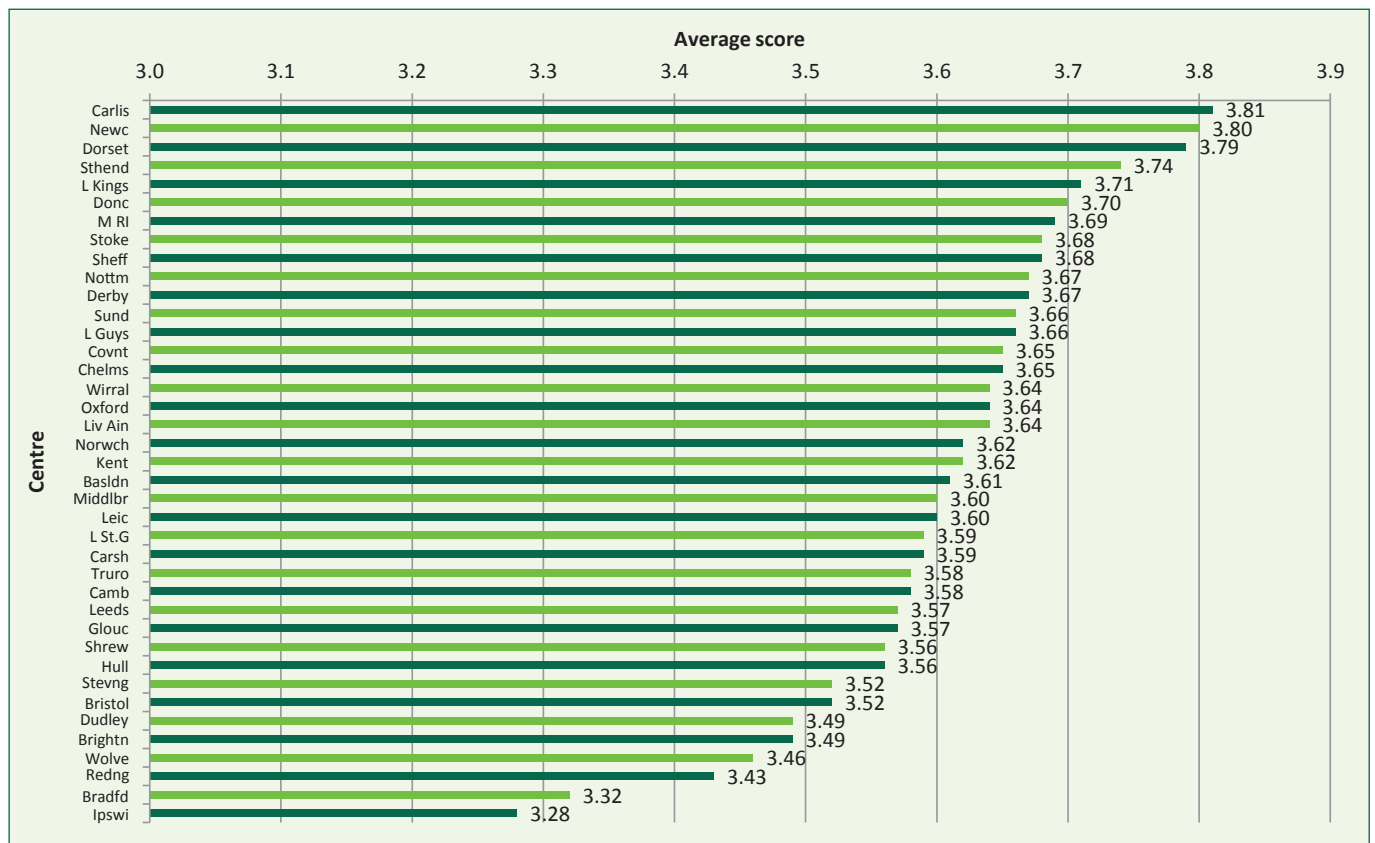
7. Tests



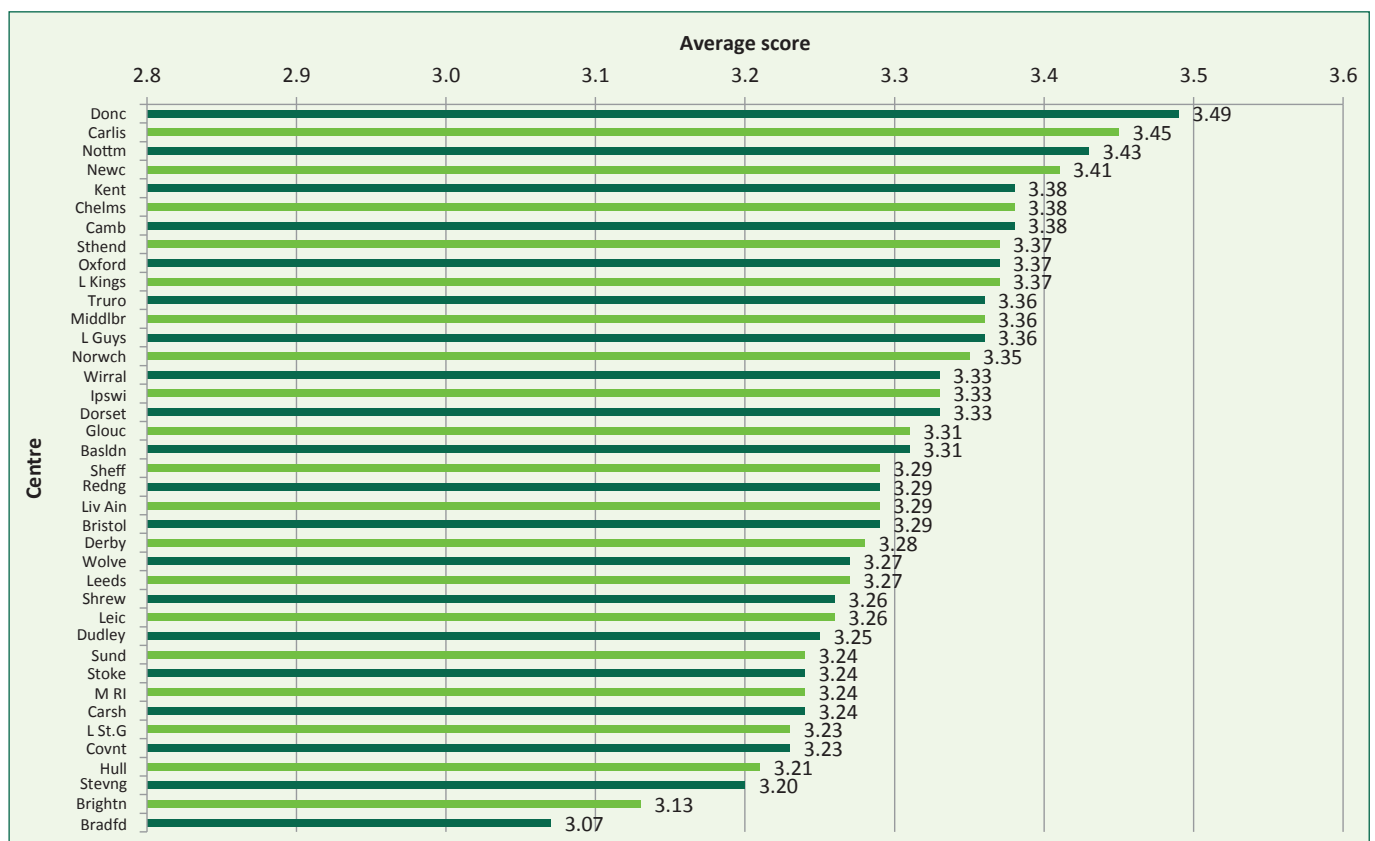
8. Sharing decisions about your care



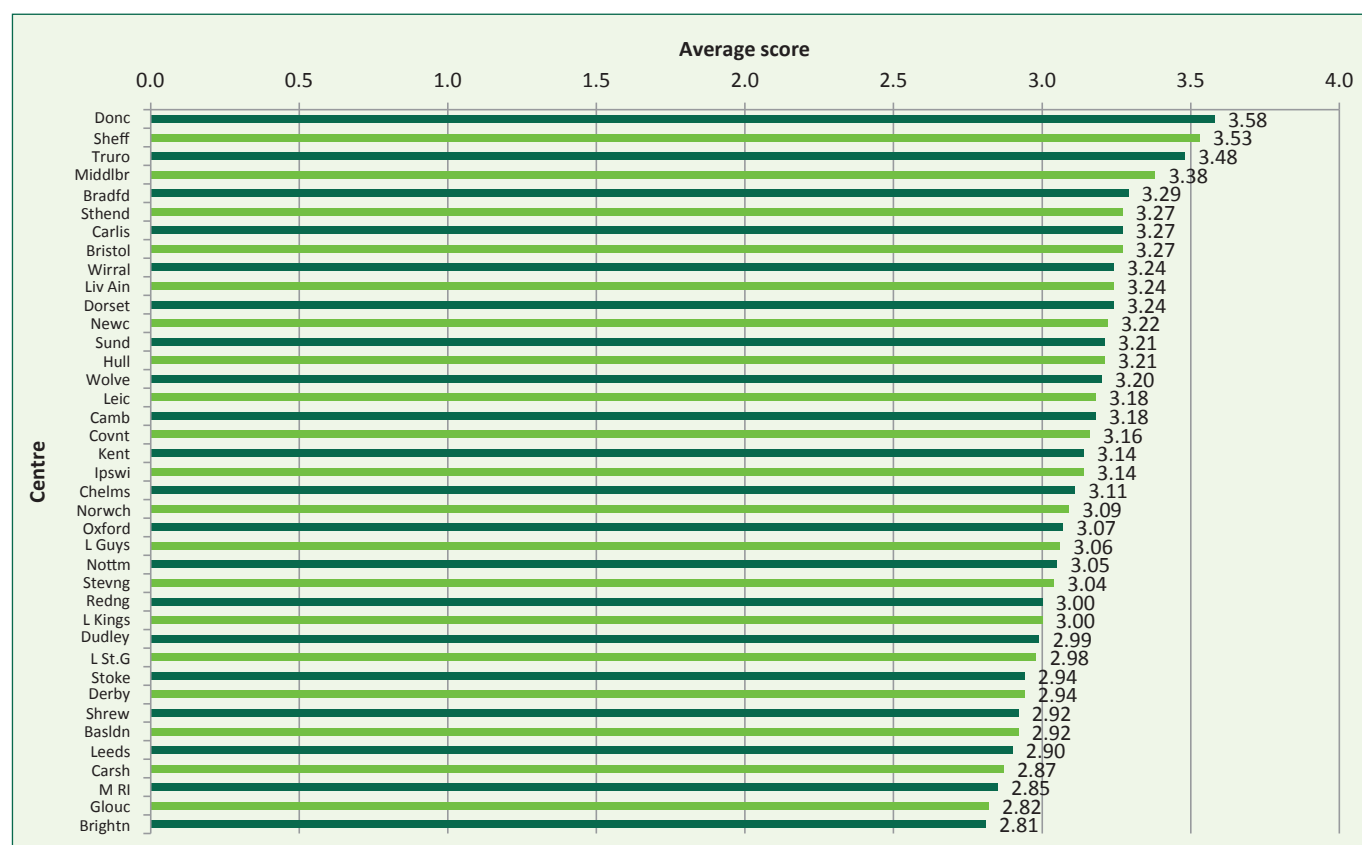
9. Privacy and dignity



10. Scheduling and planning



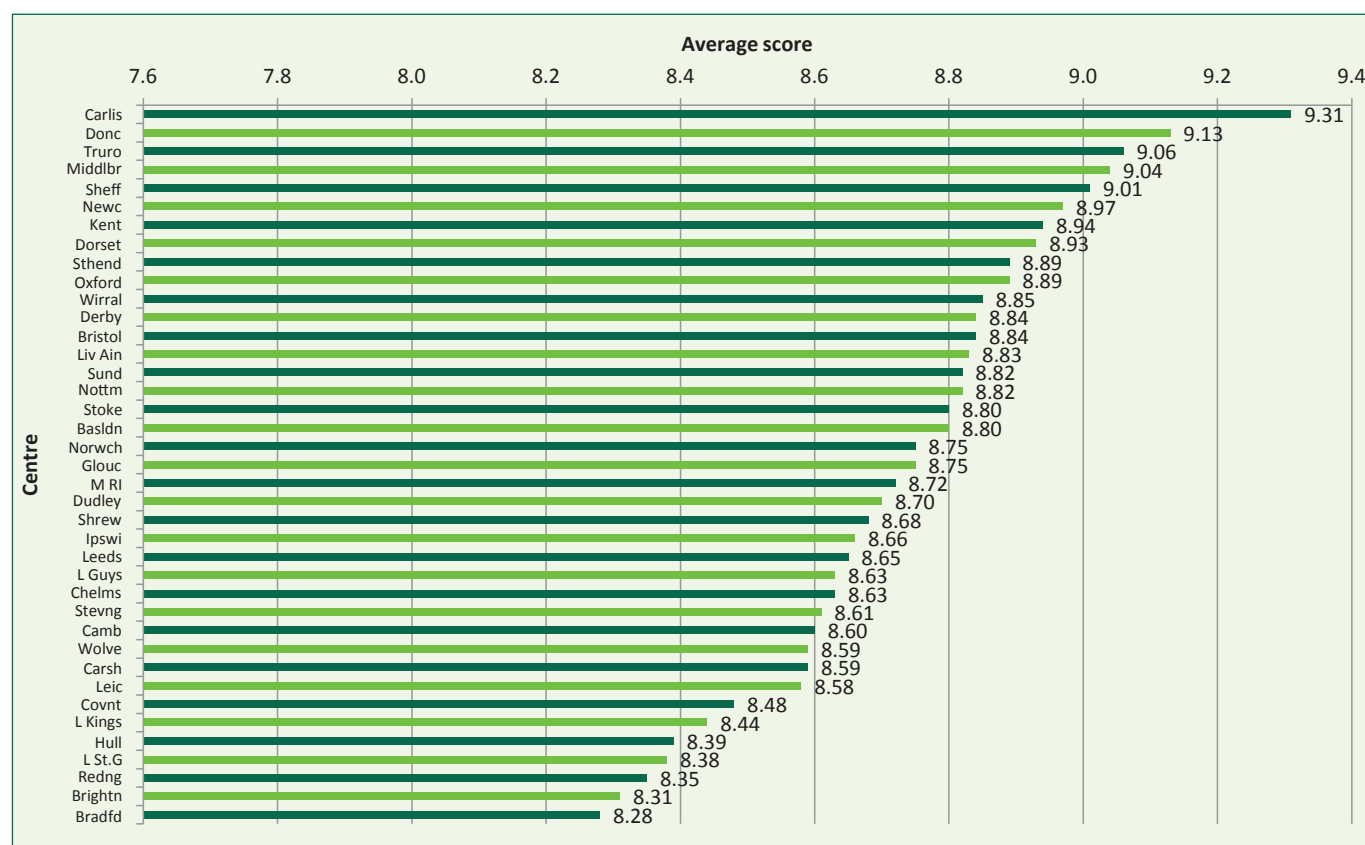
11. Transport



12. The environment



13. Overall experience



Appendix B - Timescale for PREM 2017

The PREM will again take place during the summer months as follows:

- Mid May – early notice and call to action to clinical directors informing them of key PREM dates and actions to take
- End May – distribution of the PREM results report for 2016
- Mid-June – distribution of resources and materials for PREM couriered to renal units in England and Wales
- July – PREM survey is completed by patients
- August – completed surveys are returned to UKRR for scanning
- September & October – work is undertaken to analyse the results. Online survey to leads in units to ascertain what worked well and what might be improved in respect of the process and timings
- November – results sent to clinical directors
- December – PREM 2017 results report completed
- January 2018 – planning commences for PREM 2018

Appendix C - The Annual Survey of Patient Reported Experience

About this survey and why it's important

Kidney units often introduce health questionnaires as a way of getting feedback about your care and their services. This is a new national annual survey being led by the British Kidney Patient Association (BKPA) and the UK Renal Registry (UKRR) who are also managing the survey and results.

Patient representatives from the UKRR Patient Council, the National Kidney Federation and the BKPA have been involved in the work to develop the survey. The survey is supported by the Think Kidneys programme Transforming Participation on Chronic Kidney Disease. The responses to the survey will provide valuable information about your experience of the care that you receive. Your views matter. We want to find out what you think works well with your care and what doesn't work so well.

By completing the survey you can help shape the services your kidney unit provides and that you are part of, as well as helping us build an overall picture of kidney services in the UK. This will help improve services. We hope your renal team will give you feedback on their results so that you know that by taking part you are making a difference.

The UK Renal Registry and the BKPA will use the information to create an annual report, which will be published on both organisations' websites.

The surveys are anonymous. Your name will not appear anywhere on the survey.

Completing the questions

The following questions are about your experience and how you feel about the care you receive from your renal team and the environment where your care takes place.

The survey should take about 15 minutes to complete. You can ask your partner, a friend or family member to help you.

Choosing not to take part will not affect your care in any way.

You may be asked to complete this survey again in a year's time so think about your experiences of care during the last few times that you have attended so that your responses relate to your recent care. Please fill in the survey as truthfully as possible.

On completion

Please place the completed questionnaire in the envelope provided and post it in the box or hand it to a staff member.

By completing the questionnaire anonymously you are consenting to your answers being sent to and held by the UK Renal Registry and your renal unit.

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

Renal Unit

Gender *Male* *Female* *I would rather not say*
If HD, are you *Home HD* *In Centre* *Satellite*
Type of treatment *Peritoneal dialysis* *Haemodialysis* *Transplant* *Pre-dialysis*
UKRR Code

*Please complete the name of the renal/satellite unit where you are completing this survey from.
For each question please use a black or blue pen.*

Age 0-11 12-16 17-21 22-30 31-40 41-55 56-64 65-74 75-84 85+

HOW THE RENAL TEAM TREAT YOU

Does the renal team:

1. Listen carefully to you?
2. Spend enough time with you?
3. Take you seriously?
4. Show a caring attitude towards you?

ACCESS TO THE RENAL TEAM

Does the renal team:

5. Take time to answer your questions about your kidney disease or treatment?
6. Encourage you to contact the unit from home if you are anxious or worried about your kidney disease or treatment?
7. Let you make an additional appointment with your kidney doctor if you want to?

SUPPORT

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

8. Anxieties or worries about your kidney disease or treatment?
9. Medical problems resulting from your kidney disease?
10. Practical problems resulting from your kidney disease?

Does the renal team help you to get access to support from:

11. Other patients if you need it?
12. Social networks (such as family and friends) or within your community if you need it?

COMMUNICATION

Do you think there is good communication between the:

13. Members of the renal team?
14. Renal team and your GP?
15. Renal team and other medical specialists?
16. Renal team and other non-healthcare services if you need them, such as social work or housing?

PATIENT INFORMATION

17. Does the renal team explain things to you in a way that is easy to understand?
18. Does the renal team give you as much information about your kidney disease or treatment as you want?

Is this information given to you:

19. In a format that is suitable for you?
20. At a time that is right for you?

DIET AND FLUID INTAKE

21. Does the renal team give you the advice you want on your diet and fluid intake?
22. Is that advice clear and consistent?

TESTS

Does the renal team:

- 23. Explain the reasons for your tests in a way that is easy for you to understand?
- 24. Get your test results back within an acceptable time period?
- 25. Explain the results of your tests in a way that is easy for you to understand?

SHARING DECISIONS ABOUT YOUR CARE

Does the renal team:

- 26. Enable you to participate in decisions about your kidney care as much as you want?
- 27. Give you enough information so that you can understand what these decisions involve?
- 28. Support you with setting and reviewing the goals that are important to you?
- 29. Encourage you to take a more active role in managing your own kidney care?

PRIVACY AND DIGNITY

- 30. Are you given sufficient privacy when discussing your condition or treatment?
- 31. Are your privacy and dignity respected during visits and clinical examinations?

SCHEDULING AND PLANNING

- 32. Are the arrangements for your blood tests convenient for you?
- 33. Are you consulted about appointment times as much as you would like to be?
- 34. Do you feel time is wasted on appointments relating to your kidneys? (e.g. waiting to be seen, repeating tests)

TRANSPORT

If the renal unit arranges your transport:

- 35. Is the vehicle provided suitable for you?
- 36. Is the time it takes to travel between your home and the renal unit acceptable to you?
- 37. Once your visit to the renal unit is finished and you are ready to leave, do you have to wait more than 30 minutes before actually leaving?

THE ENVIRONMENT

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

- 38. Accessibility (e.g., lifts, ramps, automatic doors)?
- 39. Comfort?
- 40. Cleanliness?
- 41. Parking facilities?
- 42. Waiting area?

YOUR OVERALL EXPERIENCE

- 43. How would you grade your overall experience of the service provided by your renal unit on a scale from 1 (very poor) to 10 (excellent)?

Thank you for completing this questionnaire

For further information please visit the Transforming Participation in CKD Website
www.thinkkidneys.nhs.uk/ckd

Appendix D - The Renal Unit Guidance

Contents

- Introduction
- About the Patient Reported Experience Measure
- Getting the most from the survey for your renal unit and satellites
- The resource pack
- What the PREM survey looks like
- What to do with the PREM – rally the troops and make it available
- Completing the survey
- After the survey – what happens next?
- PREM Survey results
- PREM in 2017 and beyond
- Questions and ideas

Introduction

This document contains everything you need to help you manage the Patient Reported Experience Measure successfully in your renal unit. From here on the survey is referred to as the PREM.

About the Patient Reported Experience Measure

The UK Renal Registry (UKRR) and British Kidney Patient Association (BKPA) have developed a national strategy for an annual PREM survey. The PREM is a survey for all renal units and their satellites to take part in. It comprises 43 questions and is currently a hard copy survey for all renal patients, regardless of the type of treatment they are receiving, or where they receive therapy - at home or in your unit or satellite clinic.

The survey has been developed by members of the Measurement Workstream of the Think Kidneys Programme – Transforming Participation in Chronic Kidney Disease. The survey has had input from kidney patient charities such as the National Kidney Federation, BKPA and the UKRR Patients' Council.

We all recognise that the patient voice should be at the heart of quality improvement. This pilot is the first stage in making sure renal patients' views and experiences have an impact on how services can change to bring about better experiences and outcomes, improve patients' quality of life, improve value and reduce unwarranted variation in service.

The national PREM strategy and data collection aims to:

1. Facilitate benchmarking of kidney patient experience
2. Inform service improvement for individual renal teams

Getting the most from the survey for your renal and satellite units

The best way to ensure your unit benefits from implementing the survey is to get as many people in the team as possible engaged and involved in the initiative. Helping people to understand why the survey is being undertaken will encourage staff to make sure as many patients as possible complete the survey. This will then give you results that demonstrate where your unit's strengths and opportunities lie, as well as challenges and areas requiring change. Gaining the support from as many people in your unit as possible will have a direct impact on the information you get from the survey.

Remember to provide carers and volunteers or other supporters in your unit with information about the survey so that they can encourage patients to complete the forms. The patient leaflet will help you with this.

The resource pack

Each renal unit will receive the following:

- This guidance document on how to get organised and run the PREM
- Copies of an information leaflet for patients, carers, family and friends as well as staff about PREM
- Posters for your renal unit noticeboards about PREM
- Printed copies of the survey and envelopes to be handed out to patients coming into your unit or satellite clinic
- Copies of the survey for home therapy patients, as well as pre-paid envelopes for completed surveys to be posted directly back to the UKRR. Also included will be stamped, but not addressed envelopes, which you will address and send to your home therapy patients along with the survey and return UKRR envelope. You can also give home therapy patients visiting clinic the survey by hand if they are attending.
- Cardboard post boxes for completed surveys to be posted in – one each for your unit and satellites – and to be returned to the UKRR after the survey has completed.

What the PREM survey looks like

The PREM survey comprises 3 A4 sheets with print on 5 sides. The survey is printed on yellow paper to help visually impaired patients.

At the moment the survey is only available in English but we will look to expand languages next year. Similarly we are looking to making the survey available online – possibly through Patient View - for next year.

What to do with the PREM – rally the troops and make it available

A copy of the survey and an envelope should be handed out to each patient visiting the unit – both central renal unit and satellite / peripheral units - over a five day period (to be determined by you) during the third or fourth week in June. Within the two week period you should select one week during which you will run the survey – either 20 June or 27 June and survey all patients for 5 days.

- All patients being treated in your renal unit and satellites are eligible to participate, regardless of their CKD stage or treatment modality, with the exception of children. For transplanted, pre-dialysis and in-centre haemodialysis patients, the survey can be handed out when they visit.
- Your patients can choose to complete the survey in the waiting room, or during dialysis. Encourage them to ask their carer, a family member, friend or another patient to help them complete the form, if they need it.
- Patients can also take the survey home to complete as long as it brought back to the renal unit and posted in the post box.
- The survey should also be posted to patients undertaking home therapies for them to complete and return back directly to the UKRR. As listed above, the resources to do this will be supplied.

You will need to determine who, in your unit, is responsible for distributing the survey out to patients as they arrive on the unit. Some units may ask the receptionist to do this, others are arranging a rota for volunteers, some of whom are patients, to be on hand to give the surveys out and to offer help with

completion. Whoever does this needs to be 'on message' so that patients are encouraged to take part and are told why it's important if they question the need to complete the PREM.

All the information needed to brief your staff is in the leaflet which has been produced to help you explain the PREM to patients. The leaflet is included your pack.

The patients should be asked to complete the survey, fold in half, place in the envelope provided, and then post in the cardboard post box.

It is important that the information leaflets, surveys and envelopes, and post box are in a prominent position in your unit and are clearly visible. This will not only make it easier for patients to respond but it will also send a strong message about the importance of the PREM to your unit.

Completing the survey

There is information on the front sheet of the survey which explains the PREM to patients and why it's important that their experiences of their care are captured. There are also instructions on how to complete the survey.

The fact that the survey is completely anonymous is stated twice on the survey. This is important because patients need to know they can be completely honest in their responses and that there is nothing that can identify them in the survey. Honest responses are the most useful for your unit.

The surveys can be completed by the patient in the renal unit, or they can be taken home by the patient, completed and then returned on their next visit to the unit.

It's because of this that staff are not expected to help patients complete the survey. If this were to happen, patients might feel they needed to be less than honest, or that their care might suffer as a consequence. Patients needing help to complete the survey should ask a carer, relative or friend. You might also ask for volunteers among your patients to help out.

The survey should take around 10 minutes to complete and, as it will be electronically scanned, it's important that it's completed using a black or blue pen.

Completed surveys are then placed in the post box provided.

After the survey – what happens next?

Once you have collected all completed surveys (remember to collect them from your satellite clinics) these need to be returned to the UKRR within two weeks for scanning and analysis.

Contact Sarah Evans at the UKRR by email – sarah.evans@renalregistry.nhs.uk when you have collected the completed surveys and Sarah will arrange for a courier to collect them from your unit. A return address label will be provided in your resource pack to stick on the post box.

PREM Survey results

Around eight to 10 weeks after the UKRR has received the surveys from your unit (both your central renal unit and satellites) you will receive analysis on the data collected from your patients. This will be mid-September.

This analysis should be used as the basis for each unit/satellite team to discuss the findings and start to develop an action plan. The information will be presented graphically.

When you have received this analysis it is important that you give feedback on the results to your patients. You can do this in a number of ways. These might include the following

- A “you said...we did....” board describing the findings and the actions you are taking
- A leaflet, handout or poster. Your communications team may be able to help you with this.

At the end of October we will publish, on a closed part of the UKRR website, a full report on the national data collected from the PREM survey. Renal units will be able to access this, check the data and comment on the results and the process.

Following this, at the end of November we will publish the full report on the public part of the website. This report will be promoted on the BKPA’s and Think Kidneys’ websites as well. The data in the national report will not be anonymised (by unit) to enable renal units to assess their performance and compare results regionally and nationally.

The UKRR will also provide renal units with posters and leaflets about the national results, signposting to the BKPA and Think Kidneys websites so that you can share national information with your staff and patients.

PREM in 2017 and beyond

2016 is the first year for the national PREM survey and is a pilot. We will learn from the survey this year so that we can refine it for subsequent years. We are already reviewing how to validate the survey to strengthen its impact for year two. For 2017 and following years, we anticipate the PREM will be run for two weeks in April, with results available for comment between June and September and publication of the national report in October. We will also review whether it would be best to move to electronic data collection using Patient View as well as paper based.

Questions and ideas

If you have any questions about PREM and how you are going to manage it in your renal unit, please email Sarah at sarah.evans@renalregistry.nhs.uk who will be able to help you.

We will provide a forum on the Think Kidneys website for discussion about PREM and you may find support from others there, as well as contacts and information on how people are managing the process.

**‘THINK
KIDNEYS’**

The National Patient Reported Experience Survey

Your Voice Matters!

- This unit is taking part in an important survey about your care
- Our aim is to improve services for people with kidney disease
- We'd like you to complete the survey to help us
- The survey is completely anonymous
- We'll give you feedback on the results and let you know what actions we're going to take as a result
- What you think really does count. Be honest and help us to help you. Thanks.

BRITISH KIDNEY
Patient ASSOCIATION
improving life for kidney patients



The National Patient Reported Experience Survey

Your Voice Matters!

June 2016

The teams who deliver NHS kidney services across the country work hard to make sure they care for you in the best possible way.

To make sure this happens and that kidney care is always improving it's important that you have your say about your experiences of care. It's by listening to you that we can make change happen and improve services for people. Your views really matter to us.

This year for the first time, all kidney units have the opportunity to take part in a national survey and this unit is doing just that.

It's called Patient Reported Experience Measure – or PREM, for short – and it's hoped that as many people as possible will take part. What we learn from the survey will help us see where we can do better, the parts of the service that are working well and how we can change services to improve care for people with kidney disease.

The survey will run annually to make sure that your views about your care are always at the heart of improving services.



BRITISH KIDNEY
Patient ASSOCIATION
improving life for kidney patients

About the survey

The survey does not include your name and has nothing on it that could identify you, so please feel free to answer as honestly as possible.

The survey has 43 questions and will take about 10 minutes to complete. You can ask your spouse, partner, friend or relative who is with you in clinic to help you if you need it. Or you can take it home and complete it and bring it back when you next visit.

The questions are about things like how the team treat you, talk with you and the support they give you. There are also questions about the information you have about your condition and how decisions are made about your care. A few questions are about the clinic or dialysis unit itself – arrangements, transport, cleanliness etc. The questions have been developed with the help of patients from the UKRR Patient Council, the National Kidney Federation and the British Kidney Patient Association.

Please help us to improve care services by taking part, completing the survey and posting it in the box provided. You can help us make a real difference.

The local and national results of the survey will be completed in a few months' time and you will be able to see them. Your kidney unit will let you know when they are ready, this is likely to be in the autumn.

Thank you for taking part and contributing to this valuable work which will help kidney services improve for everyone.



BRITISH KIDNEY
Patient ASSOCIATION
improving life for kidney patients

