

Kidney PREM written comment analysis

Patient reported experience of kidney care in the UK 2019

Introduction

The online Kidney PREM 2018 included a free-text box to allow patients to comment freely on their experience of care. The analysis of these comments concluded that it was feasible to collect written comments from patients and that these could be thematically analysed. Therefore in the online Kidney PREM 2019, a comments box was provided as a valuable method of collecting additional data on patient experience of renal care.

Of the 1218 patients completing the online Kidney PREM 2019 in English, 508 provided a written comment. Our aim in the qualitative analysis of these comments was to explore the common themes raised by patients across the different Kidney PREM themes, and investigate whether comments varied according to patient characteristics, i.e. age, ethnicity, gender, treatment modality and type of centre.

Data analysis and reporting

The comments were entered into NVivo software and were coded and thematically analysed by two researchers. A mixed inductive and deductive approach to thematic analysis was used. The 14 Kidney PREM themes were used as a starting framework for comments, as were the additional emerging themes identified in the 2018 qualitative analysis of Continuity of Care, PatientView and Pharmacy. Comments were categorised into themes and recorded as positive and negative (Table 1). Neutral comments were recorded but due to the small number (n=2), these have not been included in the analysis. The comments ranged in length and where a single comment included multiple themes, it was coded accordingly. We also included a theme of Suggestions for Service Improvements, but did not identify any other additional themes.

In order to explore the effect of patient characteristics on patient experience, we conducted a mixed methods analysis in NVivo. Potentially important patient characteristics were identified based on clinical experience and existing research, whilst considering what was feasible within the dataset. Variables were created for the relevant patient characteristics (see below), and matrix coding queries were conducted using NVivo to identify whether there were any indicative differences within the different characteristics, for example whether men and women provided more negative or positive comments for each theme. Whilst percentages are presented for ease of interpretation, these do not indicate statistically significant differences, due to the relatively small sample size and even smaller size of the different groups.

Two researchers reviewed this data independently and through discussions with a third researcher, agreed on key patterns, which have been highlighted in this report. Due to the varying number of respondents in the different patient characteristic groups, the percentages of people commenting were focused on, rather than the absolute number. If there were no meaningful differences for a given theme across any of the patient characteristics, then we have not reported this.

Table 1: Number of positive and negative comments across themes

Theme	Number of positive comments	Number of negative comments
1. Access to the renal team	17	28
2. Support	10	49
3. Communication	14	59
4. Patient information	6	33
5. Fluid intake and diet	1	14
6. Needling	0	9
7. Tests	1	21
8. Sharing decisions about your care	5	17
9. Privacy and dignity	0	10
10. Scheduling and planning	10	63
11. How the renal team treats you	88	109
12. Transport	1	55
13. The environment	5	77
14. Your overall experience	89	3
15. Continuity of care	4	52
16. PatientView	4	10
17. Pharmacy	0	6

*Suggestions for service improvement was an additional theme added, these were not coded negatively or positively and yielded 29 responses.

Patient characteristics

The gender profile of respondents was evenly spread with 47% females and 51% males (9 people did not say). 38% of respondents were aged ≤55, 28% aged between 56 and 64 and 33% aged 65+.

A large proportion of the respondents were white (89%), with 3% reporting their ethnicity as black, 3% as Asian, 1% 'other' and 3% did not say. Due to the relatively low number of patients in minority ethnic groups, for the purposes of the mixed-methods analysis, we created two groups: White and Non-White. We did not include those who did not provide their ethnicity.

The largest proportions of patients providing a free-text comment were on dialysis (39%; with 44% of those receiving haemodialysis at a satellite unit, 35% receiving haemodialysis at the hospital, 12% were peritoneal dialysis patients and 9% receiving their haemodialysis at home) or had received a transplant (35%). 26% were Chronic Kidney Disease (CKD) patients¹ For the mixed-methods analysis, we compared dialysis (all categories merged), transplant and CKD patients.

In the mixed-methods analysis we also included a variable for Centre size based on the overall number of renal replacement therapy (RRT) patients: small centres had up to 500 RRT patients, medium centres had from 500 to 1022 RRT patients, and large centres had

¹ Patients attending kidney clinic but not in receipt of dialysis or a transplant are referred to as CKD throughout this report

1053-3417+ RRT patients. For the qualitative dataset, this resulted in 22 small centres (n=68 patients), 21 medium centres (n=166 patients) and 22 large centres (n=268 patients). We also looked at whether patients were receiving care in a transplant centre or not (regardless of treatment modality).

It is important to highlight that there are differences in the characteristics of the sub-sample of patients providing a free-text comment in the online PREM and the overall sample of patients responding to the 2019 Kidney PREM. For example, the proportion of patients on haemodialysis is significantly higher in the 2019 Kidney PREM sample (58.4%) with a lower proportion of CKD and transplant patients, compared to the sample of patients who provided a free-text comment in the online PREM.

Results presented by Kidney PREM theme

Theme 1: Access to the Renal Team

Access was generally described more negatively than positively with patients reporting that they have *'huge difficulty getting to see the consultant or a trained renal doctor when it is necessary.'* Respondents also indicated how difficult it is to access the renal team outside of appointments, with limited information available on how to contact the team outside of hours.

'Sometimes when you need help in some way I don't know how to contact that person/department, I think a list of numbers for various people should be made available to patients such as renal social work or transplant Co-ordinator, ward and dialysis unit phone numbers and extension just helpful numbers in case you feel you do need support at certain times out with treatment times.'

In addition, some patients reported feeling that the renal team seldom have time to answer their questions. Several patients reported that their appointments feel rushed and therefore they do not feel comfortable asking questions, as well as indicating that often *'no one ha[s] time to talk to [them]'*.

In contrast, several patients gave positive feedback relating to renal team access, and the ease at which they can contact and communicate with their renal team via phone or email.

'They are fabulous and are on the end of the phone whenever I need them.'

'If I have any concerns I email my renal nurse and she always gets straight back to me.'

Theme 2: Support

Support was discussed widely amongst respondents, with it predominantly being described negatively. Patients described needing a variety of support, including social, emotional, psychological, specialist, personalised and treatment-specific support. Many patients reported feeling very unsupported through their patient journey, with one patient commenting *'I feel very lonely.'*

Several respondents indicated that they have lacked *'any real support from a consultant at the unit or hospital.'* Support meant different things to different people, with some referring to the support from medical professionals, *'there is a distinct lack of support to help patients to deal with the ongoing trauma of kidney dialysis'* and others felt that *'more should be done to support people who have this cruel disease.'* In addition, lack of support for non-medical

issues arising as a result of their kidney disease, was also discussed. One respondent stated that their centre *'does nothing to support non-medical issues'* even though they were aware of their *'battle with [their] workplace that is biased against [them]'* but they have received *'no guidance or direction for support.'*

Many discussed the lack of emotional or psychological support, reporting that there was a *'serious lack of emotional support at this unit'* and they *'have never been asked how [they are] coping with [their] diagnosis of chronic kidney disease.'* This was often linked to inadequate staffing or funding issues, as provision of social and emotional support services had been revoked. This was a key area of support that patients felt they needed but were not provided with.

'Lack of Renal social worker/ Psychologist'

'This unit does not employ a psychologist or social worker'

'Emotional and psychological support lacking before during and after transplant. Need someone to talk to about your journey'

'the hospital renal team really do need both a renal social worker and also a renal psychologist - something that has not been available for many years to us renal patients (and carers). sadly the current economic climate within the hospital Trust does not allow the provision of either position.'

However, there were a number of respondents who felt *'very supported'* and stated that their renal team are *'great, supportive and approachable.'*

The mixed-methods analysis highlighted some difference across patient characteristics, with a greater proportion of patients from small centres commenting negatively about the support they receive (n=9, 13.2%) than those from large centres (n=20, 7.5%).

Theme 3: Communication

Communication was generally discussed in a negative way. Most issues that were highlighted related to disjointed care and problems arising from poor or no continuity of care either within the renal team itself, or between the renal team and other medical professionals, including GPs.

'Non-existent communication between professionals'

'I also find that, within the hospital, different doctors give me contradictory information/advice and don't seem to communicate with each other.'

'Communication between specialities is poor and requires improvement.'

'I think there needs to be better communication between the unit and other hospital departments, and between the unit staff and community dialysis nurses.'

As a result of poor communication within and between teams, some patients indicated that they often had to do *'the leg work to make sure all people necessary are communicated'*

with. Several respondents also noted that communication during appointments was also sometimes challenging for example commenting that *'I'm not listened to.'* Many respondents felt that poor communication either between themselves and the renal team, or between medical teams, was detrimental to their care and impacted on their lives.

Where communication was discussed positively, patients reported feeling *'listened to'* and that good communication between medical teams enabled them to provide comprehensive care.

The mixed-methods analysis highlighted some differences across patient characteristics:

- More women commented negatively about communication than men (n=40, 16.7% vs n=19, 7.3%)
- More CKD patients commented negatively about communication (n=22, 16.3%) than dialysis patients (n=20, 10.3%) and transplant patients (n=17, 9.5%)
- More patients from medium sized centres commented negatively about communication (n=24, 14.5%) than patients from small centres (n=6, 8.8%) or large centres (n=29, 10.8%).

Theme 4: Patient Information

The majority of comments relating to patient information were negative. Patients often reported feeling that they wanted more information about their condition.

'I would like to be given more information. Information on my condition, what I can do to slow down the progression. I feel like I know nothing about my condition.'

In addition, a number of patients felt that information given to patients, particularly at the start of their diagnosis or treatment, was poor and limited.

'When first starting dialysis 2 years ago I was completely in the dark about how things worked. I feel when a new patient starts on dialysis the staff could explain things a bit better. I didn't understand anything about the treatment, my diet (and still struggle), fluid intake and why there is one. I was totally confused about weight and why I need to get weighed each session also how much they should or can take off during the session. It's such a confusing time especially if there are other health issues involved.'

Several indicated that they had never received a *'proper explanation of [their] illness,'* and others said that due to the lack of information provided to them by the healthcare professionals they have had to find out answers themselves.

'I have to find out things from google.'

Theme 5: Fluid intake and Diet

Most patients who commented on fluid intake and diet said that they had *'never been given dietary or fluid intake advice.'* A number of individuals noted that they would like to receive information around diet and fluid intake in the future and would like to see a renal dietitian where possible.

Where information had been provided, many respondents commented that the quality of information provided was poor and that they would like *'better advice.'*

Theme 6: Needling

Needling concerns were an issue for a number of patients. Often this related to the pain of needling, sometimes as a result of poor technique from staff, and staff not using different sites.

'the needling is so bad that I have severe bruising and pain'

'Some of the senior staff are terrible at needling'

Comments also alluded to the high turn-over of staff and how this causes anxiety relating to needling.

Theme 7: Tests

Issues relating to tests focused on blood tests. Patients highlighted that it would be desirable to have blood tests a few days before appointments with their consultant so that the results reviewed during the appointment were the current ones rather than the bloods taken previously. Other issues related to the length of time it took to get blood test results back, either via the doctor or on PatientView.

'I get bloods taken in the day of my appointment and don't get results to at least 4/5 weeks later from the doctor'

'Blood results are not sent through to PatientView promptly'

Theme 8: Sharing Decisions about your Care

When patients discussed sharing decisions about care it tended to be in a negative context. Several people said that there was a focus on their kidneys, rather than lifestyle, and often they are not asked about managing their own condition. A number of people said that treatment was often prescribed or was a 'one-way' conversation without time for their input.

'There is very little discussion about my condition and simply a matter of fact one way conversation. I never get asked about managing my condition'

'I think it was the focus on my kidneys but not on my lifestyle that struck me the most. I am currently fit and healthy, and lead a very active, outdoors sort of life and I still have very little idea how a transplant could and would affect my lifestyle.'

'There is no interest in improving quality of life and have never asked about goals or offered assistance meeting them.'

A few people indicated that they had actively sought to try and take a more active role in their own care and treatment, or asked for alternative treatments, but to date this had not happened.

'Enquired about someone to come and speak to me regarding home dialysis in December 2018. No one to date has spoken to me.'

Theme 9: Privacy and Dignity

Only a small number of patients referred to privacy and dignity. Those that did, spoke about lack of privacy during appointments, with several saying that *'there is no privacy.'*

'The patient care within the first assessment session lacked dignity and respect. I am spoken over rather than spoken too. Other patients taking bloods in same room. Doors are left open so patient waiting can see what going on'

Theme 10: Scheduling and Planning

A large number of people discussed scheduling and planning in their comments, and largely in a negative context. Waiting times were a clear issue, both for in-centre dialysis patients and for outpatients attending clinics. Patients waiting to dialyse reported frustration at the length of time they wait before they access the machines, with some commenting that the scheduling of arrival times for dialysis should be staggered to avoid such long waits. Others reported that waiting times in clinics often exceeded one hour, and at times some felt that this was a long wait for an appointment that they did not feel was a good use of their time.

'a lot of patients seem to arrive when they feel like it so the next person has to wait for their turn [to] get dialysis, I feel there should be a set time for being there on morning shift and the same for afternoon shift, maybe [this would] help some patients not to [be] sitting around for any longer than needed.'

Issues with travelling to clinics and different sites for blood tests and dialysis were raised by several people. Patients reported often having to travel long distances to main units rather than satellite units for certain appointments. One patient stated they felt that the arrangements for blood tests was not *'time or financially efficient.'* Another felt that travelling so far and spending so much time waiting for an appointment was a *'waste of time'* and suggested that a telephone consultation appointment could be used instead.

The arrangements for blood tests was felt to be poor, with appointments often happening after patients had seen the consultant so they could not discuss current blood test results, and instead had to discuss previous results from several weeks or months ago.

A number of patients felt that there was no flexibility with appointments and stated that they could not rearrange appointments easily, or at all, and this had a negative impact on their lives, including work and social life.

'Sticking to appointment times could be improved, 4 hours is a long time, only extended by delayed starts and somewhat sporadic times to come off. Thus a 1.30 start appointment can finish at 7.00. I realise there are unforeseen delays but could be manager [sic] better given that there are always patients there on time.'

'I can never change my appointment time, I would like to attend the satellite site more frequently, instead I only get offered these appointments when there is space otherwise I have to travel a long way to for treatment and have to take time off of work to do so. It's unacceptable that I can't attend the site closest to me.'

However, there were a small number of patients who felt that they were easily able to change appointments and that the team were often flexible with them with regards to timing or location of appointments.

Theme 11: How the renal team treats you

This was an area that patients felt very strongly about and commented on most, both positively and negatively.

Many patients praised the staff within the renal team, reporting that they felt ‘*cared about*’

and that ‘*nothing was too much trouble for them.*’ Many of the comments related to specific members of the team, including consultants and nurses, and reported both excellence and praise for staff.

‘The culture amongst the staff in the unit is excellent, regardless of how busy they are they find time to make you feel valued and genuinely cared about.’

‘Excellent senior nursing staff. Taking time to explain and very supportive. Most Renal physicians are also supportive and listen and respond to their patients.’

‘Nothing but praise from me about the renal unit... my consultant and her team are an amazing group nothing is too much trouble for them’

Patients reported that the renal team often showed a ‘*really lovely caring attitude*’ towards them, with a number saying that this made them feel welcome at the renal centre.

‘When I go to this unit, I am always made welcome they make me laugh I always feel comfortable’

However, in contrast many patients reported negative comments on how they felt they were treated by renal staff. Several commented that they were never taken seriously, whilst a large number reported that due to how busy staff were, they did not receive their full attention and found the experience negative.

‘I don't think that my renal consultant, who I have only seen once since transferring [hospitals], takes me seriously; he seemed to disregard the fact that I know my own body and having had my transplant for nearly 10 years.’

In addition, some patients felt that the staff focused solely on treatment rather than addressing them as an individual and discussing their other needs too.

Not a whole lot of interest in my needs and feelings. I came out as ignorant as I went in. Felt rather dismissed. Miserable and negative experience.

The mixed-methods analysis highlighted a number of differences across patient characteristics:

- Younger patients commented more negatively about how the renal team treats them than older patients: 27% (n=53) of the ≤55 group, compared to 16.8% (n=24) of the 56-64 year group and only 8.8% (n=15) of the group aged 65 and above.
- More women than men commented on this theme, both positively and negatively, suggesting it may be more important to them
 - Positive comments were provided by 20% (n=48) of women and 9.3% (n=24) of men
 - Negative comments were provided by 22% (n=52) of women and 15% (n=40) of men
- More non-white patients commented negatively about how the renal team treats them (27%, n=13) than white patients (17.1%, n=78)

- Dialysis patients commented more negatively about how the renal team treats them (23%, n=45) compared to transplant (15%, n=30) and CKD patients (13%, n=17).
- Patients in transplant centres commented more negatively than patients in non-transplant centres: 20.6% (n=53) of patients from transplant centres commented negatively, compared to 15.5% (n=38) of patients from non-transplant centres.
- 23.5% (n=16) of patients from small centres and 19% of patients from large centres (n=51) commented more negatively about how the renal team treats them, compared to those from medium centres, where 13.8% (n=23) commented negatively on this.

Theme 12: Transport

Transport was consistently described negatively by many people. Patients reported that transport was often 'rubbish' or 'terrible.' Dialysis patients are the largest single user group of non-emergency NHS funded transport (<https://www.thinkkidneys.nhs.uk/kquip/news/comprehensive-kidney-patient-transport-guidance-launched/>); many issues raised related to transportation to and from in-centre dialysis. Transport was a big concern for many patients and had a real impact on their lives, whether this was because of waiting times after dialysis, the availability of suitable transport or the length of time the journey took to and from the unit.

'Hospital transport is very bad standard, some days I [am] waiting after [I] finish treatment more than 2 hours when another patients [sic] finish [and] have transport already waiting.'

'Transport times after treatment are very chaotic can vary between 15 mins and 2 hours or more Saturday is especially bad'

'Transport is part of dialysis care and patients should not have to stress over pick up times. sometimes they are waiting up to two hours or even forgot about. A better system is needed, and transport designated to renal units only.'

In the mixed methods analysis, dialysis patients were more likely to comment, and to comment negatively, on transport than non-dialysis patients: 16% of dialysis patients commented negatively (n=31) with only 2.2% of transplant patients (n=4) and 0.7% of CKD patients (n=1) commenting negatively about transport.

Theme 13: The environment

Parking was a strong sub-theme within environment, with patients commenting on the lack of car parking spaces available near the hospital. It was also noted that car parking is expensive, and that this was often exacerbated by long delays in the clinic resulting in large parking expenses – a real concern for many. Several commented that designated bays for dialysis patients would be beneficial.

'Parking very expensive especially when you are expected to wait up to 2 hours when your appointment is late.'

Comfort of the treatment areas was commented on by a number of patients, largely relating to how uncomfortable the chairs, beds and pillows are. In addition, the temperature was an issue for several, with reference to it being too hot or too cold depending on the weather.

'Perpetually having to ask for the heating in the treatment area to be raised. Many patients feel the cold irrespective of using blankets. This has been raised many times at in house meetings but to no avail.'

The mixed-methods analysis showed that dialysis patients commented more negatively on environment: 18.6% of dialysis patients commented negatively (n=36), with only 12.3% of transplant patients (n=22) and 9.6% of CKD patients (n=13) also making negative comments about this.

Theme 14: Overall Experience

There were a considerable number of responses within this theme, largely with very positive comments. Patients took this opportunity to comment on how *'wonderful'* the staff are and how *'fantastic'* their treatment and care is. Many reported how caring the teams were and words such as *'lucky'* and *'indebted'* were used frequently. Comments were often written as thanks to the teams and were full of praise for the team who work with them.

'excellence comes as standard.'

'I feel very lucky to be under such a caring unit'

'Care provided by the renal team at has been absolutely fantastic at every step of the journey for me. I wish all NHS services in my area could operate in the same way.'

'The care that I received from early diagnosis many years ago to pre-dialysis, dialysis and post-transplant has been exemplary. I can't praise the team high enough.'

The mixed-methods analysis highlighted some differences across patient characteristics:

- Transplant patients commented most positively about their overall experiences (27%, n=49), then CKD patients (16.3%, n=22) and then dialysis patients (9.3%, n=18)
- Patients from small sized centres were least likely to comment positively about their overall experience: 13.2% (n=9) from small sized centres commenting positively about their experience compared to 19.3% of patients from medium sized centres (n=32) and 17.5% of patients from large centres (n=47).

The pattern across the different age groups, gender and ethnicity showed similar proportions commenting positively about their overall experience.

Theme 15: Continuity of Care

There was a lot of concern from patients around inconsistency of care, most of this focused around being seen by a different member of the renal team at each visit and there being a lack of joined up care. Many commented that they would like to *'see the same consultant each time'* they visit.

'Although we trust the standard of professionalism, we see a different person every appointment, every day in hospital. Renal patients have complicated clinical records. Health professionals cannot hope to understand from notes alone the history of every patient if they do not see them regularly. A little more continuity of care would be welcome.'

A number of patients reported feeling like they were receiving inconsistent advice from the many doctors they were seeing within the renal team as each healthcare professional had their own view and opinion on treatment. Several also commented that a high turnover of staff and no consistency of nurses within the unit made them anxious about needling because they were unsure who would be carrying it out.

'I would feel better cared for if I could be signed to just one consultant rather than seeing a different consultant at each visit. All very excellent in their own way but all have different ideas on treatment.'

'Consultant I see is variable...and dots are not joined up between consultants giving mixed information and opinions'

'I do wish I could see the same doctor on most of my visits. I changed clinics when I moved and I haven't seen the same doctor twice. Sometimes they have differing ideas about my medications. I have asked about this but I am told it is not possible.'

In addition, those individuals who were being treated across trusts, or had moved between trusts, felt that there was no continuity of care as it was difficult to get notes or information passed from one trust to the other, which often lead to repetitive appointments where the patient was having to pass the information on. This made patients feel vulnerable and anxious.

'I have recently moved...and after 18 months, my old notes...are still not available to the consultants – this is rather shocking.'

Patients felt that there was no joined up care between their GP and the renal team, typically the issue was with the GP who they felt did not pay attention to their notes.

It's disconcerting to find that when seeing a GP (different one each time) they are surprised when I point out I am a renal patient with a transplant - they clearly haven't read the notes.

Several patients also commented that the transition from child to adult services had meant changes to treatment simply because they were no longer being looked after by child services, rather than a change in their condition. They felt that this was not well communicated or explained to them, and their care was being changed unnecessarily.

'As we are transitioning over to adult services, everything is changing, I was shocked as my son (renal patient) has been on dialysis for about 8 years, now in adult services, we do not get same deliveries as on children's side, same place it comes from, I have been testing my son on his first drain and now in adult services I do not get these testing strips, this is such a dramatic change to now get used to and peace of mind, all items are cheap alternatives now in adult services as in children's I got the proper medical hand wash. I just don't understand why such a huge change when all he did was become an adult'

Theme 16: PatientView

Generally PatientView was well reviewed, with a number of patients reporting that they found it 'useful' and 'very helpful.' However, several reported that they would like it to provide more details of the blood test results. In addition, some said that it was never updated in time for hospital appointments.

'It would be nice if PatientView provided the details of every blood test done so I don't have to call my unit to get them. For example, it doesn't give all the component results of the full blood count test.'

Theme 17: Pharmacy

Pharmacy was consistently discussed negatively, with many patients reporting that changing medication or collecting a prescription or repeat prescription was challenging. This often led to feelings of frustration as many felt that this was time-consuming.

'There is a breakdown in medication from not only renal but all other areas when a consultant changes to new medication it takes too long for it to be put on repeat prescription to the GP I have waited 3 months and then had to ask for written consent to give to the GP.'

Some patients found that having to travel to the hospital pharmacy was difficult and would prefer to collect their prescriptions from a local pharmacy.

'If there was a possibility to collect transplant meds from my local chemist, rather than the hospital pharmacy, that would be very welcome. The hospital pharmacy is over half a mile from the renal unit. Total walking when visiting renal unit is over a mile. Elderly patients like me find walking that kind of distance painful.'

Theme 18: Suggestions for Service Improvement

Suggestions for improvements to care were varied and many.

- A number related to improvements in the environment where dialysis occurs, for example better quality furniture.

'Have better quality of beds and pillows as plastic sweat too much. Have tv installed at a better level so they are easier to use and again do a job of showing how to use them before anyone starts.'

'Weighing out- A whiteboard and a pen would be preferable to having to go back looking for your nurse to give your out-going weight to'

- Several commented that they would like telephone or skype appointments to negate the need to travel long distances.

'Option to Facetime / Skype long distance appn'

'To have my transplant specialist nurse ring me to do my annual review by phone as I live miles from the hospital'

'Prefer more telephone or Skype appointments.'

- Other comments related to a desire for more holistic care, including support for emotional and psychological well-being and the potential for some 'feel-good' therapies.

'Emotional and psychological support lacking before during and after transplant. Need someone to talk to about your journey especially when it's not things you'd share with family, who are worried about you.'

'No-one considers the holistic view - maybe 'feel good' therapies such as relaxation techniques, massage, the opportunity to talk about how it affects family life etc could be considered.'

- In addition, some felt that navigating the systems around their care was complex and they would like to something such as an instruction booklet, or a tour of the treatment areas and procedures, to help understand the system better.

'As kidney clinic is long term commitment and quite complicated it would be good to have something like an instruction book. This is where you get tests, this is what you need for dialysis, etc. The uncertainty of not knowing is frightening and stressful. Once you know the system it's fine.'

'Show people around before they start. Explain all the details inc (sic) what you need to bring etc.'

Summary

Of the 1218 patients completing the online Kidney PREM 2019, 508 provided a written comment. These comments were thematically analysed and coded as pre-specified themes and whether they were positive or negative. These groupings were then analysed to identify commonalities in the data. A mixed-methods analysis was also conducted to explore differences in comments by key patient characteristics, i.e. age, ethnicity, gender, treatment modality, centre size and whether a centre performed transplants or not.

The most commented-on theme was How the Renal Team Treats You, with large numbers of positive and negative comments. Overall Experience was also highly commented on, and the majority of the comments were positive, supporting the high scores on this question in the quantitative data. One of the key features within Overall Experience were positive experiences with individual clinicians and the renal team.

The quantitative analysis for the 2019 Kidney PREM showed relatively low scores for Transport and Support, and in this qualitative analysis, these areas were commented on negatively by respondents. Other themes which received a relatively high number of negative comments include Support, Scheduling and Planning, Environment and Continuity of Care.

There are some shared features across patients' comments within the different Kidney PREM themes. Patients seemed to express a need for care that is personalised and tailored to their individual needs, and they wished to play a more active role in decision-making. Patients commented on waiting times, travel times and inconvenient locations for their care, all of which had an impact on their everyday lives. There may also be a need for a more holistic approach to care, incorporating different teams and different elements of support such as psychological support.

For the majority of themes, there were no differences between the proportion of positive and negative comments from different patient groups. However, there were some differences. Most notably, dialysis patients appeared to be reporting a poorer experience across multiple themes, including their experiences of Transport, How the Renal Team Treats You, Environment and their Overall Experience. In addition, patients from small centres commented more negatively, and less positively, than those from medium-sized or large centres across a number of themes, including How the Renal Team Treats You, Support and Environment. There was a relatively small number of patients commenting from small centres, so this finding warrants further exploration.

There were some differences for gender, ethnicity, age and transplanting centre on some themes, but these differences were not as consistent across themes as for treatment modality and size of centre. The small number of comments for some themes, such as Needling and Fluid Intake and Diet, means that it would be unlikely to find meaningful differences across patient characteristics. It is also important to note that the subgroup of patients providing a free-text comment in the online PREM is self-selecting, and there were differences in the characteristics of these patients compared to the overall sample of patients who completed the 2019 Kidney PREM.

The free-text comment box on the Kidney PREM Online continues to provide valuable information and insight into patient experience. It is also feasible to explore differences across patient characteristics.