

Appendix to the Kidney PREM 2018 report: Comments from patients completing Kidney PREM online, on their experience of renal services in the UK

Background

Following the 2017 Kidney PREM, patients suggested that it would be useful to have a comments box allowing them to comment freely on their experience of care. This was piloted in the 2018 online survey to see whether we can collect free text and process and analyse it in a meaningful way.

Patients who completed Kidney PREM 2018 online in English were informed of this pilot and presented with a comment box which asked 'if there is an aspect of your experience of kidney care that is not covered in the PREM questions, please tell us below'.

Of the 687 patients completing Kidney PREM online in English, 317 (46%) provided a written comment. The gender profile of respondents was even (52% male, 47% female) with the majority being aged 41-75; 12% were under 40, 9% were over 75. Patients providing a comment tended to be White (91%), with 3% stating their ethnicity as Black and 3% Asian.

The modality profile of those providing a written comment reflects the profile of patients completing Kidney PREM online, and provide the context for the comments. The largest proportions of patients had received a transplant (36%) or were on haemodialysis (31%; broadly half of whom were home dialysis patients). 27% were attending kidney clinic but not in receipt of dialysis or a transplant, and 7% were peritoneal dialysis patients.

The comments were entered into NVivo software and coded and thematically analysed by two researchers. After an initial read of the comments, we decided to use a mixed inductive and deductive approach to coding as whilst the comments were intended to cover aspects of renal care not already covered in Kidney PREM, many of them fell into the 14 Kidney PREM domains.

Conclusion

It is feasible to collect written comments from patients in an open text box appended to the online Kidney PREM; comments are of sufficient number and quality to thematically analyse. The free text box will continue to be provided at the end of the online Kidney PREM.

Access to the Renal Team

Access was generally described negatively, with examples of how it is difficult to access medical professionals on twilight dialysis shifts, evening and weekends, or to find staff who are receptive to queries.

Issues are now being emailed to the registrar which now means a long wait for an answer - this can be physically painful and also emotionally draining. I feel like I'm distrusting them and quite honestly think twice before phoning.

All staff are keyed to answer "see your GP" no matter what the question is.

Access to renal Doctors in the evening and weekend is poor, with referral to out of hours and A&E common place.

Support

This was a significant issue for patients, with several sub-themes.

Types of support needed

Patients described needing financial, social, emotional, specialist, personalised and treatment-specific support. The impact on a patient of not receiving this could be quite significant.

Also practical help with benefits forms from a professional would be good

As I worked when my kidneys failed all medical help was given. But emotional support or support to get help for financial reasons you don't get if I had cancer I would of got support of MacMillan but no support from renal team or guidance to support groups.

I started home dialysis in March, I had a weeks training at home and then I was just left to it. Nobody ever called me to see how I was getting in. No contact from the team until mid June and they just asked me to go for a blood test....It is very scary when you start doing it and I felt totally alone and totally unsupported and they have not improved even after telling them how I felt.

Lack of emotional support

Some patients were quite clear in their need to speak with someone about their emotions. For others, the lack of emotional engagement, with them or their family, makes their experience of the renal team negative.

I would prefer some discussion with renal staff on my emotional and more general issues, such as my life expectancy. With someone who is very familiar with my circumstances, medical and otherwise.

In my experience there is very little if any easy access psychological support at all to be found from this unit when it is needed by the patients and in particular, their families who often suffer just as much as the patients.

This sub-theme is strongly related to the theme of consistency of staffing.

Lack of support at certain times in the care pathway;

Many patients were specific about the time in their kidney disease and treatment pathway where they felt they hadn't had enough support: in the early days, after operations, on discharge, and for some, on an ongoing basis thereafter.

This was partly due to 'crash landing' but did not feel there was enough support in the early months.

After my kidney transplant operation I was discharged and sent home. Apart from regular transplant clinic there is no other support particular after the discharge from hospital.

The expectation is your life is transformed after transplantation, but in reality this may not be the case, yes no dialysis, but not necessarily feeling any better and the feeling of guilt you carry that someone has died, for you not to feel 100% after transplantation does not go away. More support should be available if required.

Not knowing where to get support

Some patients either stated that they don't know where to get support or how to access networks, or described the type of support they would find useful. On occasion this was the type of support that might be available through a Kidney Patient Association.

I do not know who to call for support. I usually use the Kidney care UK Facebook page!

There is a need for a support network for patients, carers and family members, to meet with other kidney patients for support, sharing ideas, experiences etc

Good support

Good support includes support for non-renal issues, generally supportive staff, staff who make themselves available to patients and examples of strong support networks. Some patients commented on how their positive experience of support is the exception, or how they have had particularly poor experiences in other units or at other stages of their disease.

The renal team at [centre] are excellent and very professional and are always available to help with any concerns we might have.

All good; they helped me even with non kidney problems eg. arranged to have my hips replaced after they found out I had AVN [avascular necrosis].

I am lucky to have a good and in the main, understanding consultant, but I do know that this is not always the case within the dialysis unit itself as many of the staff have a lack of empathy

Communication

Where patients commented that communication was good, they were generally quite emphatic, citing how teams work well together and the positive impact this can have on (their perception of) their care. In contrast, it was common for communications to be described as lacking in some way, disjointed either within or between clinics, hospitals and

GP practices. This has led to duplication of tests for some patients and the need for patients to close the information gaps in others, both situations which patients describe negatively.

The collaborative approach of the consultants in the renal unit at [centre], is worthy of commendation. [staff member] etc are exemplary but so are the vast majority. I have nothing but high praise for them.

I have often reported to the unit, having been told that certain procedures/tests would be carried out, only to find that the member of staff dealing with it has not been properly briefed by the staff member who arranged for the procedure

I also felt that the coordination between Renal and Urology on responsibility for blood tests and general approach was poor. Patients are one human being, not a set of plumbing. This put a massive amount of stress and distress on me as a patient as I felt it was my responsibility to close the gap of information and awareness between the two departments. I am fairly on the ball and any more passive patient would not have had a chance.

A number of patients commented on having or wanting remote consultations; either by phone, or using email or Skype.

Patient Information

Comments relating to information tended to be negative, relating to a lack of information, often at a particular stage of disease or treatment. Patients were often able to say what sort of format or content would have been needed, be that some discussion with an experienced or otherwise knowledgeable patient or professional, better education or improved leaflets, books or packs. This theme is closely related to support.

On discharge from the ward could a brochure be added to the discharge documents, this could provide the contact links for this much needed support.

Re education about how to live with a new transplant after multiple transplants. What to do and what not to do after a new one rather than presuming we know.

The side effects of dialysis are hardly discussed, if at all, particularly in regards to men & that they aren't permanent.

Provision of information inconsistent and sporadic, would like to see patients handbook developed.

Fluid Intake & Diet

Some patients described not seeing a dietician, or not seeing one as often as they would like, notably transplanted patients who were aware of the lack of ongoing advice and support. A general lack of information had a number of causes: poor fact sheets, the need for better fact sheets, poor advice from dieticians or information that would have been more beneficial at an earlier stage of disease or treatment.

I feel diet could have been talked about more at an earlier time in my treatment and how that might have helped in understanding more about my kidney function.

Not enough support regarding diet. It seems that guidance is provided in the form of leaflets etc in the main, but what I want is to talk to someone and plan a diet with a professional who knows what they are talking about.

Needling

Reflecting the profile of patients providing a written comment, needling concerns were a focus for a small number of patients: how to give feedback after a poor experience, staff turnover impacting on the availability of staff with good cannulation skills, and the inappropriateness of not having anaesthetic spray due to financial constraints.

Cannulations should be overseen on a regular basis (at least monthly) by different more senior skilled staff and the patient's feelings elicited.

Tests

Issues relating to blood tests were wide ranging, including how it would be desirable to have blood tests between appointments in order to monitor health and that access to blood test results would be desirable, something that could be achieved by the centre subscribing to PatientView. Timing of tests was also an issue for some patients, either the amount of time they have to wait in clinic to have their blood tests done, or the inappropriate length of time between their blood tests and renal clinic appointments.

There have been times between monthly appointments when I have felt unwell / under the weather with my condition and feel a 4 to 5 weeks till my next out patient appointment and blood tests, should be supplemented with a mid-way set of blood tests at my local GP surgery which my renal team have access to

Shared Decision Making

Comments on shared decision making tended to describe it as a good thing, although rarely as one that happens as standard. Whilst there are examples of good practice and the impact this has, there are a greater breadth and depth of comments relating to the lack of discussion and consultation. Some patients describe actively seeking the opportunity to understand and contribute to decisions through greater access to test results, or differently structured clinical sessions.

I receive Consultant care only, we work together in treatment planning and we are able to come to a joint consensus on how we progress. I think that my Consultant is very approachable and listens well to what I have to say which instils my utmost confidence in her.

Plus one of the Renal team changed my dosage level without considering the impact on my quality of life...my blood pressure dropped, I had no energy and was lethargic.

I feel I would be more empowered to take control over my health if I had access to my blood results so I can monitor and see for myself how my bloods are

I have to keep reminding them to keep me fully informed of my treatment and condition.

Privacy & Dignity

Privacy and dignity were an issue for very few patients and related to confidentiality.

One of the dialysis nurses in my unit often speaks too freely about other renal patients and their care. Whilst no names are mentioned I often wonder if my case / treatment is also discussed with other patients.

Due to the lack of privacy and space between the patients. I am unable to maintain my dignity if it is necessary to speak of person issues .

Scheduling & Planning

Waiting times were a clear issue, both for in-centre haemodialysis patients and for outpatients attending clinics. Patients waiting to dialyse can feel frustrated at the length of time it takes to get onto machines, with some querying whether the ordering of patients according to the length of their dialysis prescriptions is appropriate.

Clinic waiting times were a common comment; frustration exacerbated when patients do not believe the appointment was necessary and / or fruitful. Systems issues include duplicate appointments and having to wait for appointments in the post as opposed to making them in person. Some patients found it hard to travel long distances for short appointments which they felt could be done over the phone. On a positive, patients described how clinics could be co-ordinated, or were flexible in their scheduling.

The often disorganised beginning of the morning session can be quite disturbing. I see no reason that patients cannot be given a designated bed and a designated time to be connected.

Too long appointment waiting times and no communication between nurses and patients giving an update on this. My last appointment took 2.5 hours and I was in pain sitting in the reception area.

I also have other appointments in the same location and where possible, they are arranged on the same day which is much appreciated.

How the Team Treats You

How The Team Treats you was another significant area for patients, with several sub-themes emerging.

Praise for renal team

The most common comments were full of praise for renal teams and wider staff, who are seen as caring, friendly, approachable, kind and patient focussed. For some patients this comes as a positive in the negative situation of having kidney disease.

I find the renal team very patient focused from admin / nurse level through to the consultants, they are one hard working team who aims to deliver the best for their patients

The team show interest and support regarding other family members. They are consistently kind and caring and treat me with respect and consideration, both as an out patient and as an inpatient, as a PD patient, as a haemo patient and also as a transplant patient.

On the plus side, most of the medical professionals are pleasant.

Variable experience of renal team

Some patients describe a combination of good and bad experiences of their renal team, often a generally good and caring team over-shadowed by one individual who is seen in a very negative light. This can be extreme and is described by some as changing their whole view of their treatment.

I guess all my answers could be positive if it were not for one Dr and one staff nurse in whom I have no trust and have between them have caused life changing negative results

Not treated as an individual

Some patients commented on not feeling understood, treated or considered as an individual, which could be due to lack of time or awareness by renal staff. Others described how a more individual approach would help their situation and make them feel better about their care. Some patients described how they are made to feel like a burden to staff; sometimes this is softened by an acknowledgement that staff can be under great pressure.

As someone who is registered blind, I find that not all of the nurses keep me informed of their actions, e.g when they are connecting me, or giving heparin or flushing the line etc. It would be helpful and considerate to be kept informed of the procedures and stage of dialysis.

One of the nurses when I recently was just going for bloods and I wanted to get a letter and my blood pressure checked was extremely rude and I was treated like a burden. I was very disappointed. The sister/head of nursing and the consultants have never treated me as an inconvenience and have been brilliant. Perhaps just a bad day.....not what I would expect from a nurse on a transplant clinic. But we all have them.

Linked to emotional support, some patients described how medical staff not appearing to care, or not offering emotional support could affect their experience of their renal team. Being Treated as an Individual is also strongly related to the theme of Consistency, below.

Sometimes more often than not the Kidney specialist makes me feel rushed and I feel he doesn't actually hear what I have to say, they know the science of Kidney disease but they have no idea what it is like to live with it and the effect it has ...they seem to lack empathy, the nurses are lovely and do what they can but the specialists are totally different and I think need to be more considerate.

My doctor seems does not care my well-being, worries, future anymore. Stuff got better since 2015 .I feel like if he does not care. I should not bother explain myself any more. I am suffering alone, handling my emotions alone.

A very small number of patients described a very poor situation where staff appear to them to be explicitly unprofessional or rude.

The staff at the renal centre are more interested in picking on and making fun of certain patients than actually paying attention to the job they're supposed to be doing.

Transport

Patients tended to provide common sense solutions to known problems, such as planning transport for patients who live close to each other, or letting patients know when they will be picked up, to save them waiting at home for long periods.

Patient transport could be better. eg. keeping down the cost for the NHS. Two or more could travel in the transport to and from hospital. Transport coordinators should be given a list of patients living in same areas to be able to lessen the transport runs. I live in [village] and others on the same day living in close proximity but 30 minutes different in Dialysis times. Give these patients the same time and transport to cut down on transport costs.

I have to be ready to leave at least two hours before my appointment for a forty-minute journey. It would be of great assistance if someone connected with hospital transport could telephone me the day before, advising roughly what time I shall be picked up for my appointment and if my return journey could be better organised.

Environment

Parking was a strong sub-theme within environment, patients commenting on the cost and lack of parking at renal centres, notably that free parking should be made more widely available. The expense of parking is a real concern for some patients, as is the related stress of paying in advance for a period of time which is then exceeded because of delays in clinic.

Unit cleanliness was commented on by a number of patients largely related to toilets and general communal areas. Several patients described how beds, mattresses, chairs and pillows are uncomfortable, others focussed on the temperature being too hot or cold depending on time of year and functioning of air conditioning.

Free parking for transplant patients too as chronic renal issues cause other health problems, last year I spent so, so, so much money in hospital car parks

I have been surprised at the poor level of hygiene in the public areas of the renal and transplant unit and the transplant wards. The air conditioning system where I attend is either too hot or too cold, which can make dialysis sessions unpleasant.

Some beds are uncomfortable. Old mattresses. Too short.,

Overall Experience

This was a considerable theme, largely very positive comments praising committed staff and excellent service, words like fantastic, lucky, first class, came up often. There was often a sense of gratitude and comments that patients would recommend their centre to others in the same position.

The experience I have had at the [centre] has been second to none, I cannot rate the hospital and staff high enough. I understand that I am not the only patient at the hospital and sometimes the waiting period is longer than normal owing to doctors getting called to the wards now and again. Me personally I could not want a better lot of staff from reception to the consultants.

Nurses are fabulous at treating us week to week and the consultants, doctors have guided my treatment excellently. Thank you.

The treatment and care provided in [centre] I received during my stay there for kidney transplant was outstanding. As was the co ordination between them and [centre]. The Nurse Transplant Co Ordinators in both hospitals do an amazing job, they provide excellent care provision.

My experience of the [centre] is; that the nursing and medical staff are very kind and attentive, there is excellent social worker support and the transport service using the cars is friendly and efficient. Overall I would highly recommend the service provided.

In contrast, there were very few negative comments. Those made were general, stating that the centre is poor or that there are many improvements to be made.

It can be incredibly frustrating being a patient at the [centre] currently. Since it has taken over other hospitals the service has declined massively.

Overall I feel like a mushroom, kept in the dark and manure thrown over me every now and then.

PatientView

PatientView was generally described positively, with some patients giving very powerful accounts of the difference PatientView has made to their management of their condition.

The new drug failed. Because I was able to view blood results myself through Patientview I had evidence fairly early on, although I did feel grim. I called the Unit and within 10 minutes my Consultant returned my call and advised me.

Whilst some were critical of the functioning of PatientView (how long it takes to upload results; whether they upload at all), there were a number of positive suggestions for how it could be improved by extending the information available on the system.

I don't know why it does not include the measure of TSAT [transferrin saturation]. I'm told there is no interface so I have to phone my GP to get this result.

I would like to see more of the letters relating to my treatment on patient view, particularly non renal issues.

Would be nice to get bmi and height on there also?

Continuity of care

Reflecting the profile of patients providing a written comment (a high proportion of whom will receive care primarily at outpatient clinics), patients who commented on the tendency to be seen by a different member of the renal care team at each visit often viewed this negatively, feeling that they received less consistent care, were unsure of who 'owned' them and their treatment, or were concerned that it might be 'damaging' their health prospects. Others described the anxiety and frustration caused by not knowing who were going to be seen by in advance.

I would like to see a regular doctor when attending appointments but instead I often meet somebody new at every appointment. This can be frustrating as they will only have a short time to read my notes before meeting me and don't actually know me.

I believe that, even though there are post clinic meetings of the team, my overall care is less consistent than it could be and is affected by the experience of the person I am seeing.

Pharmacy

There were several comments on the arrangements for collecting prescriptions, although whether this is better or worse organised centrally is individually perceived.

It would make for an easier life if all my medication was dispensed by the hospital.

Overall experience 6. I'd give a 7 but the need now to collect immunosuppression tablets from the hospital pharmacy. Prior to the change was able to order and collect them from my GP.

Suggestions for Kidney PREM

Some patients commented explicitly on questions they felt were missing. These tended to relate to specific treatment pathways and stages of kidney disease, questions relevant to transplanted / home haemodialysis / long term transplanted patients.

I think some more questions covering the home therapy team.

You could ask some questions about patients' experiences as an inpatient when admitted for renal related issues.