

Is there any other aspect of your experience of kidney care that you would like to comment on?

A qualitative analysis of patient free text comments in Kidney PREM 2021

**31<sup>st</sup> May 2022**

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Thank you to all who collaborated in the production of this report, and those who participated in the Kidney PREM 2021 and commented on their experience of kidney care.

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## Executive Summary

The Kidney Patient Reported Experience Measure (PREM) is facilitated annually by the UK Kidney Association and Kidney Care UK. The PREM has 39 questions covering 13 themes. Additionally, the PREM, when accessed online, has a free text question

*“If there is any other aspect of your experience of kidney care that you would like to comment on that has not already been covered, during COVID-19 or another time, please tell us below”.*

In 2021 there were 12,416 PREM responses, 9,850 of which were completed online. 3,877 of responders (39.5%) supplied written comments, 3,179 of which (82%) were coded under a theme covering an aspect of kidney care – the remainder stating that no further comments were necessary. 90% of responders gave consent for their comments to be passed back to their kidney centre. The profile of responders matched that of PREM 2021. There were noticeably more comments from ethnic minorities than in 2020 (24% vs 17%).

In this report there has been less emphasis on the well-defined PREM themes and more on emergent themes. Indeed, the largest single emergent theme was the renal unit team, and 68% of comments under this theme were positive. General comments about staff were overwhelmingly positive (80%), thanking them for their care and dedication. This also reflected in role-specific comments though negative comments about staff availability and difficulty accessing appointments were more common. There were also negative comments about staff shortages and inadequate training, and about access to primary care. Overall, 20% of all free text responses to PREM 2021 were positive comments about staff. Patients were generally positive too about their experience of care, though with some negative comments about lack of patient-centredness and staff being rushed and too busy.

In contrast to the predominantly positive comments relating to staff and care, there were a number of other themes in which comments had a more negative emphasis. The largest of these related to environment and particularly to comfort, temperature control, and waiting areas and times in the haemodialysis unit. Accessibility and parking arrangements were also criticised. In keeping with this transport arrangements continue to draw many negative comments.

Many patients commented on lack of support – particularly with respect to psychological support and the apparent lack of provision for this. There were also issues with communication – predominantly within the kidney team – with the main difficulties being accessing members of the team between appointments, receiving the results of tests in a timely fashion, and messages not being passed between team members. Communication between the kidney team and other teams within and without the institution – notably primary care – also raised concerns. Related to this many patients commented on lack of information, particularly that they had not received adequate updates about their treatment, progress, and transplant prospects, and that they would like more access to advice about diet, fluid intake and exercise. Perhaps not surprisingly the impact of Covid-19 drew largely negative comments concerning changes to arrangements, though reactions to changes to appointments processes was mixed. During the course of comments many patients made potentially helpful suggestions some of which might be taken up quickly and inexpensively – such as coat hooks next to weighing scales!

Patient characteristics were reflected in comments, for instance younger patients tended to focus on support and older patients on environment and transport. Those on CKD focused on appointments and communication, as did patients with a working transplant who also focussed on COVID-19. Patients receiving peritoneal haemodialysis and patients receiving in-centre haemodialysis (ICHHD) focussed on staff and environment with the patients receiving haemodialysis also commenting on transport. Patients receiving haemodialysis at home commented on support and COVID-19. The report also shows the comparison between free text responses from PREM 2020 and PREM 2021. In both years, positive comments about staff received the highest amount of comments.

We hope this report will give some insight into what patients think is important about their care and that the depth of these comments will enhance the findings of PREM 2020 and complement efforts to improve the care of people living with kidney disease.

## Chapter 1: Introduction

### Background

The national Kidney Patient Reported Experience Measure (PREM) is a validated 39-item questionnaire facilitated annually by the UK Kidney Association (UKKA) and Kidney Care UK (KCUK). Participation is voluntary and anonymous, open to patients regardless of stage of disease or treatment, and is facilitated by renal units, kidney organisations, patient groups and various social media.

Kidney PREM measures patient experience of kidney care over 13 themes: Access to the renal team, Communication, How the renal team treats you, Patient Information, Shared decisions, Tests, Scheduling and planning, Privacy and dignity, Support, Needling, Fluid and diet, Environment, and Transport. Each theme consists of 1-5 questions, in which patients rate their experience of care on a Likert scale from 1 (generally equating to 'Never' and being the worst score) to 7 ('Always', being the best score). Participants are also asked to rate their overall experience of care, where 1 is worst it can be, 7 is best it can be.

Kidney PREM has been available online since 2018, and includes a free text question, to capture experience of care not covered elsewhere. There is no word or character limit, and respondents choose whether their comment is seen by their treating centre.

*“If there is any other aspect of your experience of kidney care that you would like to comment on that has not already been covered, during COVID-19 or another time, please tell us below”*

This report provides insight into patient experience of kidney care across the UK, maintaining the depth and richness of the free text nature of the comments, yet providing sufficient analysis and interpretation to allow patients and their kidney care teams to act on the results.

## Methods

Kidney PREM 2021 was available for patients to complete online or on paper from 1st November to 12<sup>th</sup> December, securing 12,416 valid responses, 9,850 of which were online. Data was downloaded from the Qualtrics platform in Excel format, checked and a master file of all data<sup>1</sup> uploaded into QDA Miner software.

3,498 (90.2%) who provided a written comment gave consent for this to be passed back to their treating centre; accordingly, UK Kidney Association sent datasets and explanatory text to all Clinical Directors in February 2022.

Using QDA Miner, responses were coded and then themed using a mixed inductive/deductive approach, aligning with existing PREM themes and topics emerging in previous years, but allowing new themes to come to the fore. Comments were dual coded; for content and for attitude (positive/negative/ neutral). Where one person provided a comment describing many experiences, or provided many comments, each one was coded separately. One researcher coded, with another quality checking at predefined intervals. Differences in opinion were discussed and resolved by agreement. Two researchers were responsible for initial theming and sub-theming, with a team of four, including a clinician, reviewing, and agreeing the final structure, grouping, and labelling.

Kidney PREM 2021 data were imported into QDA Miner, allowing a mixed methods analysis of comments, patient characteristics and responses to the scalar items. Analysis of the quantitative data has been reported separately and is available to view via the UK Kidney Association website<sup>2</sup>.

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<sup>1</sup> patient characteristics, renal centre, responses to Q39 PREM item and free text question comments

<sup>2</sup> [www.ukkidney.org/kidney-patient-reported-experience-measure](http://www.ukkidney.org/kidney-patient-reported-experience-measure)



## Response Profile - patients

As was the case in 2020, approaching 4,000 people left additional comments on their experience of kidney care. The number of comments from patients of an Asian ethnic background, Black ethnic background or Other ethnic backgrounds has increased, and there is a marked difference by treatment type this year, with less from patients ages under 30 years old (2.3%).

The profile of patients leaving a comment to the free text question matches that of patients responding to PREM 2021.

*Table 1: Characteristics of Patients responding to PREM*

	Kidney PREM 2021 Comments	Kidney PREM 2021	Kidney PREM 2020 Comments	Kidney PREM 2020
<b>Total</b>	<b>3877</b>	<b>12416</b>	<b>3912</b>	<b>9645</b>
Age				
≤30	89 (2.3%)	376 (3.1%)	- <sup>3</sup>	400 (4.1%)
31-55	1051 (27.1%)	3261 (26.6%)	- <sup>4</sup>	2929 (30.4%)
56-74	1934 (49.8%)	5763 (47.0%)	1996 (51.0%)	4537 (47.0%)
≥75	803 (20.7%)	2868 (23.4%)	757 (19.4%)	1779 (18.4%)
Gender				
Female	1645 (42.4%)	5038 (41.6%)	1662 (42.5%)	4177 (43.3%)
Male	2209 (56.9%)	6986 (57.7%)	2237 (57.2%)	5404 (56.0%)
Rather not say	26 (0.7%)	86 (0.7%)	13 (0.3%)	64 (0.7%)
Ethnicity				
Asian	374 (9.6%)	1137 (9.3%)	281 (7.2%)	743 (7.7%)
Black	419 (10.8%)	1005 (8.3%)	300 (7.7%)	613 (6.4%)
White	2857 (73.6%)	9358 (76.9%)	3189 (81.5%)	7896 (81.9%)
Other	149 (3.8%)	402 (3.3%)	80 (2.0%)	203 (2.1%)
Rather Not Say	81 (2.1%)	260 (2.1%)	62 (1.6%)	190 (2.0%)
Treatment				
Transplant	886 (22.8%)	2148 (17.7%)	907 (23.2%)	2172 (22.5%)
CKD	589 (15.2%)	1710 (14.1%)	710 (18.1%)	1882 (19.5%)

<sup>3,4</sup> In 2020 those aged under 55 were analysed as one age group, totalling 1159; 29.6%

In-centre HD	837 (21.6%)	3090 (25.7%)	848 (21.7%)	1972 (20.4%)
Sat HD	1298 (33.5%)	4054 (33.7%)	1097 (28.0%)	2748 (28.5%)
Home HD	80 (2.1%)	259 (2.2%)	97 (2.5%)	239 (2.5%)
PD	187 (4.8%)	772 (6.4%)	253 (6.5%)	632 (6.6%)

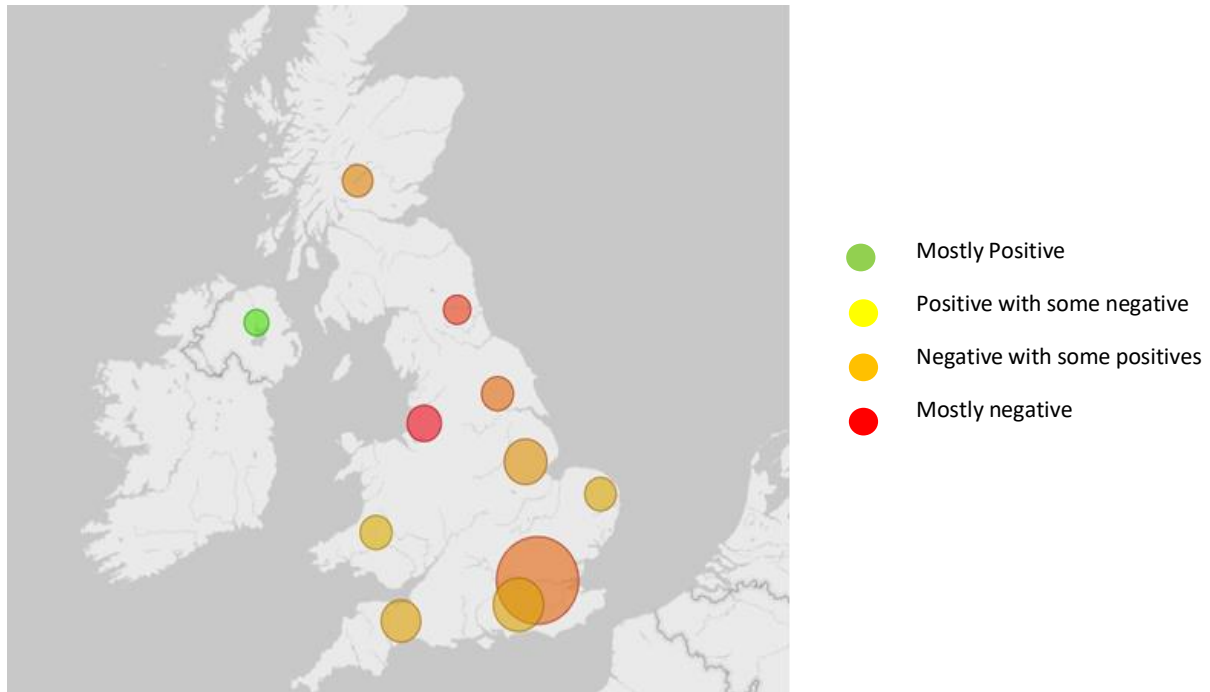
## Response profile - centres

As shown in Table x, and consistent with responses to the 2021 Kidney PREM, most responses were provided by people receiving kidney care in England (88.8%), primarily London and the South East. Comments from patients in England, Scotland and Wales lean towards the negative (Figure x).

*Table 2: Response profile by region*

	<b>PREM 2021 Comments</b>	<b>PREM 2021</b>
<b>England</b>		
East of England	262 (6.8%)	880 (8.5%)
London	1127 (29.0%)	3281 (31.7%)
Midlands	359 (9.3%)	1660 (16.1%)
North East	93 (2.4%)	580 (5.6%)
North West	234 (6.0%)	770 (7.5%)
South East	553 (14.3%)	1651 (16.0%)
South West	300 (7.7%)	926 (9.0%)
Yorks & Humber	176 (4.5%)	587 (5.7%)
	<b>3,104 (88.8%)</b>	<b>10606 (86.2%)</b>
<b>Northern</b>		
<b>Ireland</b>	<b>47 (1.3%)</b>	<b>264 (2.6%)</b>
<b>Scotland</b>		
	<b>146 (4.2%)</b>	<b>520 (5.0%)</b>
<b>Wales</b>		
	<b>198 (5.7%)</b>	<b>886 (8.6%)</b>
<b>UK Total</b>	<b>3,495</b>	<b>12416</b>
Missing	385	

Figure 1: Rag colour coded response rate by region



## Report structure

Patient comments are presented by theme, generally in order according to number of comments, but also variety of positive/ negative/ neutral, range of sub-themes, and variation by patient characteristics. Themes appearing towards the end of the report are not assumed to be any less important for patients, rather, fewer people had comments to make in addition to what they had already scored under the relevant theme in the Kidney PREM.

In each section, the profile of people making comments is either described, or confirmed as the same as the general Kidney PREM 2021 profile.

Chapters 16 to 18 present further analysis of the comments by patient characteristic and PREM scores, as well as comments containing patient suggestions.

The report finishes with a comparison of comments made in PREM 2020 and PREM 2021.

### **BUBBLE CHARTS**

Bubble charts provide an at-a-glance summary of how patients commented on their experience of care according to their age, treatment, or ethnicity.

Bubble charts are based on column percentages. The size of the bubble relates directly to the proportion of comments made by that patient group; big bubbles represent the most popular comments for a group and small bubbles the least common comments from a group.

### **DIFFERENCES IN NUMBER OF COMMENTS**

Some patient comments covered multiple topics and attitudes, such as one positive aspect of care and another negative aspect of care. These positive and negatives each contribute to the total number and so the total of positive and negative comments may be larger than the total number of patient comments.

For instance, in the example above the total comment is one but the number of positive and negative comments is two.

### **QUOTES**

Verbatim comments are provided throughout the report; where these have been amended to protect anonymity, this is shown.

## Chapter 2: The Renal Unit Team

Most of the feedback about experience of care was about the renal unit team; this was the biggest theme to emerge, with 1,475 comments (38%). 20% of all free text responses to PREM 2021 were positive comments about staff in particular roles, some fed back on the general adequacy of staffing, including across GP surgeries.

*Table 3: List of themes relating to the Renal Unit Team shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Role Specific Comments</b>	<b>632</b>	294	24	314
<b>Kidney Care Team</b>	<b>621</b>	109	14	498
<b>Adequacy of Staff</b>	<b>168</b>	138	5	25
<b>Primary Care</b>	<b>54</b>	40	3	11

The profile of patients who commented about their experience of the renal team is the same as the profile of those completing the Kidney PREM.

### Role Specific

This subtheme covers comments about the different members of the multidisciplinary team such as consultants, social workers, nurses, healthcare assistants, receptionists, and dieticians.

*Table 4: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Consultants</b>	<b>366</b>	195	17	154
<b>Nurses</b>	<b>200</b>	60	7	133
<b>Dietician</b>	<b>27</b>	17		10
<b>Receptionists</b>	<b>15</b>	7		8
<b>Social Worker</b>	<b>15</b>	13		2
<b>Health Care Assistants</b>	<b>9</b>	2		7

Table 4 shows that positive comments about receptionists, health care assistants and nurses outweighed the negative, with patients generally sharing their experience of care with these members of staff. Dieticians and social workers received more negative comments mainly related to lack of accessibility with patients having difficulty obtaining appointments. Comments included wanting to have access to a dietician or social worker to discuss particular issues or wanting to have their appointments sooner after diagnosis. Positive comments about consultants named members of staff, thanking them for their care. Negative comments included issues patients faced obtaining appointments with consultants, consultant availability and whether they felt the consultant had listened to their concerns.

## Kidney Care Team

Overwhelmingly, 80% of comments regarding the kidney care team were positive. These responses consisted of comments thanking staff for their dedication and help throughout their treatment and giving examples of members of staff who have offered great care. Other topics included mentioning staff who made treatment fun by using humour and showing interests in patients' personal lives, making them feel important. Comments stated staff as a general term, implying they meant the whole of the renal team. Some of the negative comments surrounding the kidney care team, mentioned examples of how some members of staff had shown no empathy, ignored patients in need or were seen to show favouritism.

## Adequacy of Staffing

*Table 5: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Staff shortage</b>	<b>139</b>	114	4	21
<b>Training</b>	<b>29</b>	24	1	4

Staff shortages was an issue within renal care across all regions, London being the most affected with 20% of the comments. Another issue was staff training. Comments included how new staff appeared to have a lack of training e.g., not being able to use the dialysis machines.

## Primary Care

Primary care comments related to issues patients faced when being treated in general practice. Comments were mostly negative and mentioned how there were a lack of GP appointments available, and that the GP appeared to lack concern for the patient's welfare. These issues seemed mostly to affect transplanted patients and patients not currently receiving renal replacement therapy (RRT).

***Patient comments about the Renal Unit Team***

*I wish patients are referred to the dieticians as soon as they are diagnosed with kidney problems  
(31-55, Black, CKD)*

*Difficult to see kidney doctor. This need to be looked at seriously  
(31-55, Black, Sat HD)*

*Appointment with consultant impossible  
(56-74, Asian, CKD)*

*Getting general practice doctor appointments face-to-face is virtually impossible so with that you  
have to bother the hospital which is not acceptable in my view  
(56-74, White, HHD)*

*The knowledge, understanding, professionalism and care shown by my consultant, STAFF NAME, is  
outstanding. They are just brilliant! The best in 53 years of renal failure  
(56-74, White, Tx)*

*We need a permanent consultant at UNIT NAME, our blood result and medication takes time to be  
sorted out  
(56-74, Black, Sat HD)*

*No access to speak to a consultant. The best option is to contact the community team, they contact  
the registrar. You wait for the registrar and talk to them. They then talk to the consultant and then  
the registrar reports back. Only time you get to speak to your doctor is in clinic.  
(17-30, White PD)*

*Nursing staff and support staff are top notch  
(56-74, White, Sat HD)*

*The home dialysis unit is always excellent great staff.  
(75+, White, HHD)*

*No everything is covered by the excellent staff.  
(31-55, Other, Transplant)*

*All staff have shown a considerate and caring approach to my situation. They are a fantastic group  
of people.  
(56-74, I would rather not say, HHD)*

*Very caring and professional.  
(75+, Other, ICHD)*

*I am grateful to everyone in my renal unit.  
(75+, White, ICHD)*

*Many thanks to all the kidney staff.  
(65-74, Asian, CKD)*



## Chapter 3: Care

The next most reoccurring theme in response to the free text question was care. The comments within this theme fell into two subthemes, experience of care and patient-centred care.

*Table 6: List of themes relating to Care shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Experience of care</b>	<b>623</b>	182	13	428
<b>Patient-centred</b>	<b>131</b>	88	5	38
<b>Staff too busy</b>	<b>41</b>	32	3	6

### Experience of Care

Experience of care refers to patient comments which describe specific examples of how patients perceived their experience of care from the renal team. The majority of comments (69%) were positive.

### Patient-centre care

*Table 7: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Patient-centred</b>	<b>48</b>	31	2	15
<b>Rushed Care</b>	<b>39</b>	28	1	10
<b>Active in care</b>	<b>35</b>	21	2	12
<b>Discrimination</b>	<b>9</b>	8	0	1

This theme included how patients perceived the way that staff had treated them, for example whether they felt their care was rushed, whether they felt involved in their care and whether staff used a patient-centred approach. The comments represented the response profile of PREM 2021, with rushed care affecting patients receiving satellite haemodialysis (Sat HD) the most and patients not yet receiving RRT wanting to be more active in their care, such as being involved with discussions about their treatment options.

### Staff too Busy

This theme includes comments from patients who perceived staff to be too busy to fulfil their duties of care. These comments are predominantly negative (table X) with staff appearing overworked.

**Patient comments about Experience of Care**

*With our renal team your care depends on who you see, 1 of the consultants just seems rushed and does not listen to anything you have to say  
(31-55, White, CKD)*

*Everyone is trying and doing their best although listening to patients need and concerns should be prioritised.  
(56-74, Asian, Sat HD)*

*Feel pressurised at the end of treatment to close off and get out to allow the Quanta machine switch out and setup of 5008 units ready for haemodialysis patient arrival  
(31-55, White, ICHD)*

*My consultant Dr Popoola is the loveliest most kind Dr She never rushes the appointment and listens to all my concerns  
(56-74, Black, CKD)*

*Staff need to attend patient quick when required for help. Patients with no understanding of the English language need to be catered with good interpreters. Patients should be given a chance to express their needs, feelings, requirements of the unit and staff  
(31-55, Asian, Sat HD)*

*Staff are too busy, at times, to give the time we would like.  
(57-74, White, Sat HD)*

*Although it is a little reduced because of an increase in patients. This is because units have come together, some closing and some enlarging. If not done properly, this can be bad experiences for patients.  
(56-74, Asian, Tx)*

*Overall, the care of the home team at other times has been exemplary  
(56-74, White, PD)*

*It is not holistic. It does not focus on how I feel or the difficulties I experience, it is just about results and numbers.  
(31-55, White, CKD)*

*As a home dialysis patient, I sadly feel left out and overlooked.  
(31-55, White, HHD)*

*I am well looked after, and the staff are very friendly.  
(75+, Asian, ICHD)*

*I think they should be a close contact within the nurses and the patient, they should always see to it whether I come early, or I come late because some of the nurses they never see to that  
(75+, Asian, ICHD)*

## Chapter 4: Transport

Kidney PREM questions regarding transport refers to the transport provided by the centre, so comments included in this theme are typically from patients receiving haemodialysis in-centre or at a satellite unit, however, comments on 'distance to the unit' were predominantly from transplanted patients.

*Table 8: List of themes relating to Transport shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>General Transport</b>	<b>110</b>	87	5	18
<b>Centre Provided</b>	<b>78</b>	64	4	10
<b>Route</b>	<b>66</b>	50	1	15

### General Transport

*Table 9: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>General Transport</b>	<b>86</b>	69	4	13
<b>Taxi</b>	<b>20</b>	14	1	5
<b>Transport Clean</b>	<b>4</b>	4	0	0

Comments in this theme cover other aspects of transport such as cleanliness of the vehicle, travelling by taxi and other general issues like organisation of transport. 22% of comments on general transport issues came from patients from a Black ethnic background.

### Centre Provided

*Table 10: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Ambulance</b>	<b>25</b>	19	2	4
<b>Drivers</b>	<b>24</b>	17	1	6
<b>Unreliable</b>	<b>17</b>	16	0	1
<b>Suitability</b>	<b>14</b>	12	1	1

Comments under this theme discuss aspects of centre provided transport including travelling by ambulance, suitability of the transport provided, whether the transport is reliable and the drivers. Mostly, these comments are negative with some pockets of positivity, for example describing how some drivers had gone out of their way to be helpful and friendly.

## Route

*Table 11: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Distance to Unit</b>	<b>48</b>	34	1	13
<b>Journey Route</b>	<b>18</b>	16	0	2

This theme consists of comments about distance to the unit and the journey route the transport followed. Patients felt that their journey to the unit for treatment is unreasonably long either due to the distance the unit is from their home or due to the route the transport took to get there.

### **Patient comments about Transport**

*Transport can improve with cleanliness. Due to covid  
(56-74, Black, Sat HD)*

*I have no real issues other than travelling by ambulance is very tiring and a long wait to get home. I would prefer being able to get my bloods done local instead of having to go to a main hospital where it's impossible to park. Bearing in mind most of us have problems walking  
(56-74, White, Tx)*

*Cars and taxis are good to travel in, but the ambulances are uncomfortable  
(56-74, Black, Sat HD)*

*The distance of the patient to the hospital are not put into consideration in terms of transferring the patients to far distance unit that will involve transport, whereas the patient could be sent to close unit whereby the patient may not require transport from NHS. The management have to fill the gap in the transport system.  
(31-55, Black, ICHD)*

*Transport should be available to bring patients in earlier especially those doing longer hours...without being told that they are not regular so will be picked up later. This resulting in patient not getting full treatment.  
(31-55, Asian, ICHD)*

*I would like to be able to attend my appointments closer to home rather than having to do a 30 mile round trip for my appointments when there are closer hospitals to me.  
(56-74, White, PD)*

*I travel 14 miles across LOCATION for my kidney care so I leave home at 6.00am and get home at around 2.00pm, an 8 hour day. I think that this is unacceptable as there are 3 kidney units close to my home. I can travel to and from a local hospital and have my dialysis in about 5.00 hours saving my 9.00 hours a week. I also find that the journey makes me feel unwell. My doctors have asked for me to be transferred to a local unit but do not seem to get a reply.  
(75+, White, Sat HD)*

*Patient Transport is desperately overworked.  
(56-74, White, Tx)*

*Taxi transport when used instead, results in delays at being picked up after dialysis. The new vans for community transport have very deep steps causing me difficulty to climb up them.  
(56-74, White, Tx)*

*Sometimes the vehicles are too high to get in.  
(56-74, Black, Tx)*

*Transport is very hit or miss, they picked me up over an hour late despite ringing more than once. I understand this happens but when it affects treatment it is not good enough  
(31-55, White, Sat HD)*

## Chapter 5: Appointments

There were 534 comments about appointments split across appointment format, with telephone appointments and face-to-face appointments being the most common, 32.8% and 23.4% respectively, issues with appointments and reliability.

The majority of comments about appointments were from transplanted patients and patients not receiving RRT.

*Table 12: List of themes relating to Appointments shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Appointment format</b>	<b>350</b>	188	28	134
<b>Issues with Appointments</b>	<b>90</b>	66	3	21
<b>Reliability</b>	<b>55</b>	51		4

### Appointment Format

*Table 13: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Telephone appointments</b>	<b>175</b>	78	17	80
<b>Face-to-face appointments</b>	<b>125</b>	91	8	26
<b>Video calls</b>	<b>23</b>	7	2	14
<b>Online appointments</b>	<b>17</b>	7	1	9
<b>Home visits</b>	<b>10</b>	5	0	5

As seen in table X, telephone appointments received slightly more positive comments with these patients finding them more favourable over attending the unit, though most would like to attend the unit for face-to-face appointments at regular intervals to ensure their kidney health is stable.

Video appointments were thought to be better than telephone appointments though could not fully replace face-to-face appointment, Online appointments also receiving similar comments.

Home visits was split evenly between positive and negative comments with negative comments stating how patients would like home visits to take place and positive comments mentioning the convenience of home visits.

## Issues with Appointments

*Table 14: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Seeing same staff member</b>	<b>82</b>	59	3	20
<b>Review of care</b>	<b>8</b>	7	0	1

Other aspects of appointments patients commented on related to how there was an inconsistency in the member of staff who treats them, with patients wanting to see the same member of staff at each appointment to build good working relationships and discuss progress in their care.

Additionally, patients mentioned (8 comments) that they were not receiving a review of their care during appointments, to discuss kidney decline, treatment options and the future.

## Reliability

*Table 15: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Lack of appointment</b>	<b>34</b>	32	0	2
<b>Cancelled Appointments</b>	<b>21</b>	19	0	2

Reliability relates to how appointments had been cancelled or how some patients had received less or no appointments for some time. The positive comments indicate that a few such patients had been satisfied with the way these issues have been dealt with e.g., reasons for these being cancelled were well communicated.

### **Patient comments about Appointments**

*Not been seen by consultants for 18months due to the cancelling!  
(31-55, White, CKD)*

*My consultant did get me in once since the pandemic so that he could check my fistula, so I applaud him for that. The community renal nurse even arranged for me to have my epo injections at the surgery when I was not able to do it myself anymore. They have been very helpful and supportive. In fact, one of them came to take my blood at home. They are really lovely.  
(56-74, Black, CKD)*

*The cancellation of a check-up in April 20 resulted in a drastic change in circumstances moving from well managed ckd3 condition to kidney failure in May 2020  
(17-30, White, PD)*

*Would like to see a specialist sooner. Appointment cancelled 3 times.  
(75+, White, Sat HD)*

*If possible, face to face appointment would be good to patients, who are now facing challenges by themselves despite with family members, who are not professional to take care of their health concerns or anxiety, which the patient's do not wish to worry their beloveds.  
(56-74, Asian, Tx)*

*Not been able to see my consultant face to face despite asking various times to discuss changes to my care and medication.  
(17-30, Other, Sat HD)*

*Excellent remote support and home delivery of immunosuppressive drugs and blood forms. Ability to use other local facilities for blood taking.  
(56-74, White, Tx)*

*The introduction of video appointments has been fantastic. The stress and anxiety of travelling to the hospital (via tube) has been taken away which is a real benefit for me, but I still get the same quality of time with my consultant. I hope it continues  
(31-55, Other, Tx)*

*Missing the monthly home visits by the Home Care Nurse.  
(56-74, White, HHD)*



## Chapter 6: Support

Support has been divided into 5 subthemes, young persons, financial, peer, family and psychological. The most commented on aspect of support was psychological provision which received mostly negative comments.

Patients with a working transplant were more likely to comment on support, closely followed by patients receiving haemodialysis at a satellite unit. Females were also more likely to comment on support than males.

*Table 16: List of themes relating to Support shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Psychological</b>	<b>152</b>	95	6	51
<b>Family</b>	<b>16</b>	12		4
<b>Peer</b>	<b>16</b>	9	3	4
<b>Financial</b>	<b>13</b>	8	1	4
<b>Young Persons</b>	<b>9</b>	6		3

### Psychological

*Table 17: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Psychological provision</b>	<b>92</b>	69	3	20
<b>General Support from staff</b>	<b>55</b>	23	3	29
<b>Kidney Organisations</b>	<b>5</b>	3		2

Comments regarding psychological support focussed on the lack of psychological health provisions in place, such as a lack of availability of psychologists and perceived lack of concern for patient's mental health during appointments. As mentioned, this aspect of support received the majority of comments which were mostly negative (75%) and from transplanted patients (33.7%). Other comments under this theme include support from kidney organisations and general support from staff during appointments/ treatment.

## Peer

*Table 18: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Support Groups</b>	<b>9</b>	7		2
<b>Peer Support</b>	<b>7</b>	2	3	2

The subtheme 'peer' includes the codes, support groups and peer support. Peer support refers to the comments by a number of patients who would like to either volunteer to offer support to other patients as a 'buddy' or are from patients who would like to share and talk about their experiences with others. Patients receiving peritoneal dialysis, those who have been transplanted and those not receiving RRT also commented on the lack of support groups to aid them living with kidney disease and its treatment.

## Family

Support for family members of patients was commented on frequently. Patient comments recognised the impact their diagnosis and treatment has on their family and mentioned a lack of dedicated support tailored for family members

## Young persons

Comments on young person's support were mostly negative and stated how these patients felt there was a lack of support for young people particularly in transitioning from paediatric care to adult. These comments, as expected, came from patients aged 17-30 years old, with one comment from the 31-55 years old age group. 66.7% of comments in this subtheme came from males.

## Financial

There were 13 patients who asked for financial support to be offered. There were no comments asking for financial support from patients aged over 75 years old.

**Patient comments about Support**

*Very happy about the support I get in the Unit. Thank you.  
(75+, Black, Female, ICHD)*

*As patient I can see staff working at the hospital are busy. However, they need to make an effort to spend more time with patients on home visits. They also need to enquire about are wellbeing and chase the patient rather than the patient chasing them.  
(31-55, Asian, Male, HHD)*

*Wife/family does not get enough support or enough information about kidney disease  
(75+, White, Male, Sat HD)*

*Access to patient support group in every area would improve awareness to how deal with ups and downs of the condition and levels of fatigue as this can be considerable.  
(75+, White, Female, CKD)*

*The support I have received from everyone in this department has and still is, absolutely amazing. Dialysis and Transplant both covered. Luckily neither is needed at the moment.  
(56-74, White, CKD)*

*My unit have always supported me and my family. Very pleased.  
(56-74, White, Tx)*

*I feel I get more information on my condition from the Facebook group for kidney care UK and feel more supported by this group.  
(56-74, White, ICHD)*

*Everyone has been very kind and supportive. They answer my questions and make me feel important, like I am participating not just that things are happening to me.  
(31-55, White, CKD)*

*The youth team are brilliant.  
(17-30, White, Tx)*

## Chapter 7: Communication

Table 19 shows the breakdown of comments in regard to communication, comments fell into 3 themes internal communication, external communication and answering questions.

*Table 19: List of themes relating to Communication shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Internal Communication</b>	<b>353</b>	262	9	82
<b>External Communication</b>	<b>66</b>	51	1	14
<b>Answering Questions</b>	<b>72</b>	34	5	33

### Internal Communication

*Table 20: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Contacting the renal team</b>	<b>129</b>	81	4	44
<b>Test Results</b>	<b>100</b>	82	3	15
<b>Communication with patient</b>	<b>83</b>	67	2	14
<b>Communication between MDT</b>	<b>48</b>	37	1	10
<b>Understanding test results</b>	<b>18</b>	12		6
<b>Staff languages</b>	<b>17</b>	14		3
<b>Communication with consultant</b>	<b>6</b>	6		

Typically, patients found contacting the renal team to present the biggest issue, with patients being unable to contact the renal team outside of appointments. Patients receiving peritoneal dialysis found contacting the renal team to be a more positive experience.

Communication between members of the multidisciplinary team seemed to lack coordination with messages not being passed on and confusion within the team. Furthermore, receiving test results in a timely manner and in a format accessible to the patient was a concern. 82% of comments regarding test results were negative. Understanding test results was also an issue with patients feeling that their results had never been explained to them.

Staff languages refers to staff members difficulty expressing themselves in English or not appearing to understand English. A few comments (n=4) referred to patients who do not have English as a first language and struggled to communicate.

## External Communication

*Table 21: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Communication between RRT and GP</b>	<b>51</b>	39	1	11
<b>Communication between centres</b>	<b>11</b>	8		3
<b>Communication for Tx</b>	<b>4</b>	4		

External communication includes the communication between centres, the GP and renal team and patients receiving communication from the transplanting team. Comments reported that their GPs were not being updated about patient care and GPs not informing consultants of such changes either.

## Answering Questions

Answering questions refers to patient comments which explain whether they feel their questions have been adequately answered during appointments or at other times. These comments were split between positive and negative, with some patients feeling all their questions had been answered to the best of the staff member's ability and that there were ample opportunities to ask questions.

Other patients felt that they were not given direct answers to questions and that they were not given opportunities to ask questions. Typically, transplanted patients and patients receiving haemodialysis in-centre and at a satellite unit found answering questions a positive experience compared to patients not receiving RRT and patients receiving haemodialysis at home.

**Patient comments about Communication**

*When we have blood tests it would be nice for a nurse to come round to each patient and explain the results so that the patient understands every they need to do to improve their treatment  
(31-55, Black, ICHD)*

*I reported a lower score for communication between my GP and the Renal Unit. This is in no way a fault of the Renal Unit. My GP surgery is very hard to contact, and I have to chase them up with everything.  
(75+, Asian, ICHD)*

*Poor communication with inaccurate appointment letters. Very difficult to contact the renal team the onus is on the patient to find out information.  
(56-74, White, Tx)*

*Communication is simply abysmal. Phones do not get answered, call back don't happen, generally unable to get to talk to anyone. The stress and general level of frustration this causes is off the charts.  
(56-74, White, CKD)*

*At UNIT NAME is local to go to for tests and they are efficient with transferring information to UNIT NAME good system  
(56-74, White, CKD)*

*Accessing a kidney doctor, even by phone, has been difficult, even before COVID-19, but since the pandemic, it has now become practically non-existent.  
(31-55, White, HHD)*

*Cannot get through on the phone - ward clerk needed for evenings  
(56-74, Asian, ICHD)*

*My only complaint is the transplant team do not keep you updated when you give the details of a live donor, I gave one and she got a questionnaire, filled it out and returned it but is wondering what is going on as she hasn't had a further contact  
(31-55, Black, PD)*

*I do find getting answers to sometimes simple questions about my treatment or possible transplant very difficult. I tear my hair out in frustration sometimes that communication with specialists in particular is so poor. The system is not efficient!  
(56-74, White, PD)*

## Chapter 8: Treatment

There were 344 comments about treatment across 7 subthemes: transplant, haemodialysis (general), medication, home haemodialysis (HHD), in-centre haemodialysis (ICHD), peritoneal dialysis (PD), and CKD. Characteristically, the negative comments outweighed the positive, with the exception of comments relating to transplant and PD (table X).

*Table 22: List of themes relating to Treatment shown by frequency and attitude*

	Total (n)	Negative	Neutral	Positive
<b>Transplant</b>	<b>103</b>	42	7	54
<b>Haemodialysis (General)</b>	<b>80</b>	69	1	10
<b>Medication</b>	<b>65</b>	48	3	14
<b>HHD</b>	<b>49</b>	25	3	21
<b>ICHD</b>	<b>28</b>	17	3	8
<b>CKD</b>	<b>12</b>	5	4	3
<b>PD</b>	<b>11</b>	5	1	5

### Transplant

Comments on “transplant” were the most common and predominantly positive (51.5%). As expected, the majority of these comments came from transplanted patients sharing their experiences of this treatment. Some comments (30.6%) came from those not receiving RRT or those receiving haemodialysis in-centre/ at a satellite unit, who were wanting to be transplanted.

### Haemodialysis (General)

*Table 23: List of codes shown by frequency and attitude*

	Total (n)	Negative	Neutral	Positive
<b>Holiday dialysis</b>	<b>21</b>	17	1	3
<b>Fistula</b>	<b>19</b>	16		3
<b>Pain</b>	<b>12</b>	11		1
<b>General Treatment</b>	<b>9</b>	8		1
<b>Dialysis Machines</b>	<b>6</b>	6		
<b>Being Needled</b>	<b>5</b>	4		1
<b>HD</b>	<b>5</b>	4		1
<b>Weight gain</b>	<b>3</b>	3		

This subtheme focusses on aspects of needling such as being needled, pain when being needled and fistulas, with negative patient experiences being shared. Additionally, there were comments on holiday dialysis, outdated dialysis machines, weight gain and general treatment issues. Holiday

dialysis is yet to be resumed following COVID-19 with patients expressing their desire for this to return. There were also negative comments from patients worrying about weight gains.

## Medication

Comments on medication were mainly from transplanted patients from a white ethnic background discussing issues with immunosuppressant medication, prescriptions and worries about side effects.

## Home Haemodialysis

*Table 24: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>HHD</b>	<b>37</b>	18	2	17
<b>Suppliers</b>	<b>12</b>	7	1	4

Responses on HHD were primarily from patients receiving this treatment, with some comments from patients receiving ICHD wanting to move to HHD. Training to move to HHD as a treatment has seen delays due to staff issues and COVID-19 thus receiving mostly negative comments. Unlike the other treatment types which were largely positive or neutral, comments about home haemodialysis had more negative comments than positive. This subtheme consisted of comments on home haemodialysis as a treatment including training for HHD, as well as comments about suppliers for dialysis equipment.

## In-centre Haemodialysis

*Table 25: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Shared Care</b>	<b>18</b>	9	3	6
<b>Amount of time on dialysis</b>	<b>10</b>	8		2

PREM 2021 introduced a question asking patients about shared care, this sparked responses on this topic with patients sharing positive experiences of shared care and negative comments from patients wanting to begin shared care. Comments were received from patients dialysing in-centre and at satellite units. This subtheme also comprised of negative comments (80%) about the amount of time spent on dialysis, with patients not being informed of the reasons for having their dialysis times changed.



## Peritoneal Dialysis

Comments about peritoneal dialysis gave examples of patient experiences on this treatment - both positive and negative.

## CKD

All comments regarding the subtheme CKD, were from patients being monitored, and yet to start RRT. Patient comments focused on wanting to have more frequent appointments, especially with the consultant.

### **Patient comments about Treatment**

*Despite a note from the surgeon on my records saying I needed a second operation for a fistula and having seen 3 Drs (2 renal and one rheumatology specialists) on 6/7 appointments no one had read the letter and was aware.*

*(56-74, Black, CKD)*

*The satellite unit I attend does not have the knowledge of the various complications I have. They misdiagnosed a reaction to blood pressure medication as rejection. I have asked to transfer back to UNIT NAME.*

*(31-55, White, Tx)*

*Nurses are rushing to put the needles in. They do not talk to patients. I am not happy here as I live far from the unit. I want to move to UNIT NAME.*

*(56-74, Black, Sat HD)*

*Very happy with dialysis experience in unit not happy with the experience with her fistula formation and the surgeon.*

*(56-74, White, Sat HD)*

*If I had been treated properly by my GP (the practice closed its doors for a year) when my kidney function went below 30% I should, apparently, stopped taking metformin. This did not come to light until my kidney function was at 8%; then they told me to stop taking them*

*(56-74, Black, ICHD)*

*Disgusting experience. My nurse is booking my pd training and few days before she cancels it on stupid reasons like not being able to reach me on the phone over a 15-minute window. As I work full time, I am not reachable by phone at any moment and she aware of this. Very vindictive attitude. Twice I had my pd training cancelled after waiting for 2 months for it. At this point I have given up and bought a pd machine off eBay and using it without any specialist care as I think they are a waste of public money. Disgusting experience*

*(31-55, White, Tx)*

*Home haemodialysis should be more advertised in unit, definite lack of staff to achieve this getting bigger*

*(56-74, White, HHD)*

*I am 100% happier at home and would highly recommend to other patients as*

*(31-55, Black, HHD)*

*As far as PD itself is concerned I think I am generally well looked after. I should also note that the staff are generally caring and hardworking and act quickly when necessary.*

*(56-74, White, PD)*

*Everyone should be entered for transplant register irrespective of age and sex*

*(75+, Asian, Sat HD)*

*Home haemo needs much more attention - it is rarely offered.*

*(56-74, White, Tx)*

## Chapter 9: Impact of COVID-19

PREM 2021 asked patients to rate the extent to which their experience of care had been impacted by COVID-19. Some patients in response to the free text question commented on the impact of COVID-19 on their care. Within this theme there are three subthemes: patient information, communication, and impact of COVID-19. Patients who have been transplanted were most affected by COVID-19 and vaccination, whereas female patients were most impacted by delayed treatment.

*Table 26: List of themes relating to Impact of COVID-19 shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Impact of COVID-19</b>	<b>280</b>	190	14	76
<b>Information</b>	<b>44</b>	35	2	7
<b>Communication</b>	<b>28</b>	23	1	4

### Impact of COVID-19

*Table 27: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Impact of COVID-19</b>	<b>90</b>	57	9	24
<b>Safe</b>	<b>43</b>	18	1	24
<b>Face Masks</b>	<b>34</b>	28	1	5
<b>Delayed treatment</b>	<b>30</b>	25		5
<b>Visitors in the unit</b>	<b>23</b>	17	1	5
<b>Social distance</b>	<b>17</b>	15		2
<b>COVID-19 Positive</b>	<b>16</b>	9	2	5
<b>Waiting Outside</b>	<b>13</b>	11		2
<b>COVID-19 Testing</b>	<b>7</b>	3		4
<b>Sanitisation</b>	<b>7</b>	7		

The impact of COVID-19 covers changes to patient care such as wearing face masks, patients feeling safe when visiting the unit, social distancing, having to wait outside for treatment and not being allowed visitors in the unit. Responses reflected that patients felt safe when visiting the unit though they missed not being able to have visitors and disliked having to wait outside during the winter months. Other aspects of care impacted by COVID-19 were delayed treatment such as delayed starts for HHD training and transplant procedures being suspended during the first wave of the pandemic, as well as the need to test frequently for COVID-19. Delayed treatment affected most patients but especially female patients, with mixed reviews on COVID-19 testing.

## Patient Information

Comments include patients wanting to know more about the availability of vaccinations and the protection offered by vaccinations. These comments were mainly from transplanted patients, who shared concerns about being immunosuppressed and needing protection against COVID-19.

## Communication

This subtheme includes comments about being updated about changes to treatment and care as a result of COVID-19. Most of the comments were negative with patients wanting updates from the renal team more frequently and personalised to their care needs. This was another aspect which impacted transplanted patients more than any other treatment groups.

### **Patient comments about Impact of COVID-19**

*Pandemic problems when I did not see the specialists, but our kidney nurses were only a phone call away, I caught the virus in hospital and the renal nurses checked me every week until the tests proved clear.*

*(75+, White, CKD)*

*Before covid clinic was always full, lucky to find a seat and waiting time was much longer, the restructure now I can find seating while social distances in the nice airy clinic, waiting time to see Consultants is down and I actually remember more what I want to say once to them.*

*(31-55, Black, Tx)*

*Finding anyone in the NHS who knows about the 3rd primary vaccine has been impossible. Literally! No-one knows about it!*

*(31-55, White, CKD)*

*Local blood testing clinics have not reopened since March 2020, travel by public transport doesn't always feel safe, due to lack of Masks, particularly since removal of mandatory masks.*

*(56-74, White, CKD)*

*COVID has had a big effect on inpatient care lack of visiting and resultant isolation has been extremely detrimental to patients and relatives alike with adverse effects to health outcomes.*

*(56-74, White, HHD)*

*Overall as I commenced home dialysis once Covid-19 occurred, I have felt much safer and manage my care.*

*(56-74, Rather Not Say, HHD)*

*Sometimes I feel that the pandemic lockdown the rules were not strictly enforced as they could have been. One time most patients were affected in the unit and the team has not changed anything to improve social distancing*

*(17-30, Black, PD)*

*Too crowded in the morning and too many people in the waiting area. Let patients wait beside dialysis chair is ready. No social distancing in waiting area.*

*(56-74, Asian, Sat HD)*

*The transplant was hard without family support in hospital but that's no fault of anyone.*

*(31-55, White, Tx)*

*COVID has caused delays to transplants. We have not been allowed to make that time up, which has caused other knock-on effects. Which will have a severe detrimental impact on my survivability.*

*(31-55, White, Sat HD)*

## Chapter 10: Environment

Environment was the third largest theme to emerge from the comments analysis, with four subthemes. As seen in table X, all codes received more negative comments (84.1%) than positive comments. Responses to this theme follow the response profile of patients responding to PREM 2021.

*Table 28: List of themes relating to Environment shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Furniture and Equipment</b>	<b>340</b>	275	8	57
<b>ICHD</b>	<b>144</b>	124	3	17
<b>Accessibility</b>	<b>41</b>	33	2	6
<b>Parking</b>	<b>74</b>	72	2	

### Furniture and Equipment

*Table 29: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Temperature</b>	<b>79</b>	71		8
<b>Comfortable</b>	<b>50</b>	41	2	7
<b>The unit</b>	<b>40</b>	23		17
<b>Waiting area</b>	<b>40</b>	34	1	5
<b>TV</b>	<b>26</b>	22		4
<b>Equipment</b>	<b>22</b>	19	1	2
<b>Cleanliness</b>	<b>21</b>	13	2	6
<b>Toilets</b>	<b>15</b>	12		3
<b>Blankets</b>	<b>10</b>	9		1
<b>Weighing scales</b>	<b>10</b>	8	2	
<b>WIFI</b>	<b>10</b>	8		2
<b>Pillows</b>	<b>7</b>	7		
<b>Lack of windows</b>	<b>6</b>	5		1
<b>Lighting</b>	<b>4</b>	3		1

Patient comments under the subtheme furniture and equipment include the unit being too cold, the waiting area being inappropriate for the number of patients, lack of working TVs and poor WIFI. Moreover, patients would like chairs more suited to dialysis so that they are more comfortable. They would also like more pillows and better lighting.

## In-centre Haemodialysis

*Table 30: List of codes shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Food and drink offered</b>	<b>63</b>	56		7
<b>Issues with other patients</b>	<b>16</b>	14		2
<b>Lack of sheets</b>	<b>15</b>	13		2
<b>Being put on dialysis machine</b>	<b>14</b>	14		
<b>Crowded</b>	<b>11</b>	9		2
<b>Noisy</b>	<b>10</b>	9	1	
<b>Activities at the unit</b>	<b>8</b>	5	2	1
<b>Interactions within the unit</b>	<b>7</b>	4		3

This subtheme considers issues within the unit for patients receiving haemodialysis (both in-centre and satellite). Comments included wanting food and drink to be offered during dialysis sessions, lack of interactions with other patients and activities during dialysis, issues with other patients, overcrowding, and wanting better organisation when being put on the dialysis machine i.e., rotation around which patients are seen to first.

### Accessibility

Patients commenting on accessibility, particularly mentioned navigating from the car park to the unit and patients with mobility issues wanting to have automatic doors at the entrance to the unit.

### Parking

Parking appeared to be a big issue for transplanted patients (32%), with “extortionate” parking costs and little availability of spaces especially for those requiring disability parking spaces.

**Patient comments about Environment**

*However, access to the hospital is disastrous and impossible for anyone with a physical disability. It is being rebuilt but in the interim, it is tired, dirty and feels deeply unsafe.*

*(75+, White, CKD)*

*Being allowed to talk to other patients would be great as we help each other through our experience of dialysis and it helps with the depression that we go through*

*(56-74, White, ICHD)*

*Would like a cushion as feels uncomfortable*

*(31-55, Other, Sat HD)*

*Sandwiches instead of biscuits and coffee please.*

*(56-74, Black, ICHD)*

*Coming into the hospital entrance, the security guards do not allow easy access to the unit. I have to walk 10 minutes to get to the unit.*

*(31-55, Black, Sat HD)*

*Floors are not cleaned properly on regular basis. Have seen spillage marks on floor left for a week before being cleaned up.*

*(56-74, White, HHD)*

*My not so good experiences come when having to have dialysis at the unit. The surroundings are cold, dark, and uncomfortable and the atmosphere is miserable.*

*(75+, Other, HHD)*

*To receive sandwiches would be great, because many of morning shift dialysis patients don't have breakfast and are diabetic, or at least put in a sandwich machine don't mind paying for it*

*(31-55, Asian, ICHD)*

*Building is old / draughty and tricky if you have mobility issues the team make the best of 150yr+ building but a more friendly environment and nicer for staff too they do a great job with what they have*

*(31-55, White, PD)*

*Tiny waiting area especially with wheelchairs*

*(75+, White, Sat HD)*



## Chapter 11: Patient Information

CKD patients had most comments on patient information. This theme has 4 subthemes: Patient View, transplant information, family, and patient care information.

*Table 31: List of themes relating to Patient information shown by frequency and attitude*

	Total (n)	Negative	Neutral	Positive
<b>Patient View/ My Care</b>	<b>71</b>	45	5	21
<b>Patient Care Information</b>	<b>165</b>	141	7	17
<b>Transplant information</b>	<b>38</b>	30	2	6
<b>Family</b>	<b>8</b>	5		3

### Patient Care Information

*Table 32: List of codes shown by frequency and attitude*

	Total (n)	Negative	Neutral	Positive
<b>Patient Care Information</b>	<b>70</b>	61	2	7
<b>Kidney information</b>	<b>46</b>	38	2	6
<b>Dietry advice</b>	<b>40</b>	34	3	3
<b>Exercise</b>	<b>5</b>	5		
<b>Fluid intake</b>	<b>4</b>	3		1

87.1% of patients who commented on patient care information, stated that they had not received adequate updates about their treatment and progress. This subtheme also includes patients wanting to receive dietary advice, advice on fluid intake and guidance on exercise to benefit kidney health. Patients recently diagnosed with kidney disease (CKD) also wanted to receive information about kidney disease and treatments.

### Patient View

PatientView is the online application used for patients to access their renal record and view their test results. PatientView, has been received positively, specifically for the way patients are able to view their information, with the negative comments being as a result of the transition to My Care<sup>5</sup>, a like-for-like replacement of PatientView in some centres. Patients have found My Care to process results slower and be less responsive than PatientView. The majority of these issues were reported by transplanted patients.

<sup>5</sup> 'My Care' was mentioned by name in patient comments. Other similar applications were not mentioned.

## Transplant Information

Patients receiving haemodialysis in-centre or at a satellite unit commented on wanting more transplant information. Comments including wanting to know about the waiting list, eligibility criteria and to receive updates about transplant care. Other treatment groups such as CKD, patients receiving peritoneal dialysis and those with a working transplant, also commented about transplant information, with both negative and positive comments about the information they have received.

## Family

The subtheme family includes comments from family members of patients who would like more information about kidney disease and their family member's treatment.

**Patient comments about Patient Information**

*Always been left in the dark, its up to me constantly to follow up on what the next plans are rather than them letting me know.*

*(17-30, White, ICHD)*

*It has been 7years plus and I still do not know what is happening, with treatment or anything that would give me more information regarding my kidneys. No one seems to be interested with my condition. I was 57 first diagnosed I'm 65 years old now.*

*(56-74, White, CKD)*

*The absolute lack of communication from my renal team to myself. Especially during the pandemic which I received no guidance from them whatsoever. Didn't even receive any letters. See a different consultant on every visit so near impossible to build up trust and a working relationship.*

*(31-55, White, Tx)*

*Could you please pass on any information or concerns to my wife who waits for me as I do not always understand*

*(56-74, Asian, ICHD)*

*Wife has to read leaflets an information summary from unit would be great*

*(56-74, White, Sat HD)*

*When first starting dialysis, I would have liked more information, maybe a visit and a bit more understanding what happens. I found it a scary experience at first*

*(31-55, White, Sat HD)*

*I experienced a rare complication of Peritoneal Dialysis which I hadn't been warned about in advance. Also, I don't think enough information was provided on other side effects like drain pain. The information provided only lists Peritonitis as the possible complication.*

*(56-74, White, PD)*

*Pre dialysis information not so good*

*(56-74, White, Tx)*

*I feel diet, lifestyle and exercise have all helped me once I started to look into my own health 2 years ago but have never spoken about it during any visit and when I've asked what I can do I've been told nothing!*

*(56-74, Other, CKD)*

*My son had questions about my care and the consultant took considerable time to discuss and answer despite an extremely busy clinic he was very clear and patient and honest*

*(56-74, White, Tx)*

*More nutritional advice would be helpful but not essential.*

*(75+, White, Tx)*

*I have always been satisfied with the treatment I have experienced with the team. They explain everything to me and put me at ease.*

*(75+, White, CKD)*

## Chapter 12: Non renal illness

As shown in table X, this theme includes comments about ailments not directly linked to kidney disease. Most of the comments are negative, impacting CKD patients and transplanted patients the most.

*Table 33: List of codes relating to Non-renal illness shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Non renal illness</b>	<b>27</b>	22	0	5
<b>Patients with additional needs</b>	<b>15</b>	10	0	5
<b>Diabetes Department</b>	<b>7</b>	4	1	2
<b>Dermatologist</b>	<b>3</b>	3	0	0

Non renal illness comments describe personal experiences of having other illnesses which are not dealt with by the renal team.

Comments about the diabetes department and dermatologist, are from patients wanting to receive treatment from these specialist departments. With patients with additional needs discussing how the renal team are not equipped to care for them inclusively.

### *Patient comments about Non-renal illness*

*I am blind and gave a hearing impairment and physical disability and I often feel my disabilities are not considered  
(56-74, White, ICHD)*

*If you have a problem unrelated to a renal issue but non the less important to your health you are referred elsewhere which is time consuming and frustrating in trying to get prompt treatment initially.  
(56-74, White, HHD)*

*The team you have at Tunbridge Wells are absolutely fantastic! So friendly, so patient, so kind and understanding. My mother has dementia, but they always talk to her despite the fact they know she doesn't really understand. But they consult me too (her daughter) on her care, results and what her choices would be. They are excellent.  
(75+, White, CKD)*

## Chapter 13: Scheduling

Scheduling covers aspects of care related to organisation of appointments, blood tests and other tests (see table X).

*Table 34: List of codes relating to Scheduling shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Blood test scheduling</b>	<b>103</b>	68	4	31
<b>Scheduling appointments</b>	<b>61</b>	42	3	16
<b>Dialysis scheduled time</b>	<b>28</b>	26	1	1
<b>Lack of tests</b>	<b>24</b>	21	1	2
<b>Organisation</b>	<b>24</b>	17	2	5

CKD patients and transplanted patients were most concerned with scheduling, with comments stating that there was a lack of organisation and frequent confusion over appointment date, times, and method of attendance e.g., telephone or face-to-face. Blood test scheduling received negative comments about the availability of blood tests, especially within reasonable travel distance. However, some patients have had a positive experience, praising that they are now being scheduled to have their blood test appointments prior to seeing the consultant and at their GP surgeries.

### *Patient comments about Scheduling*

*Coordinate other departments for same day attendance  
(56-74, White, ICHD)*

*More frequent consultations. Used to be 3 monthly now moved to 6 monthly due to increased pressure on NHS [I guess] I have elected to have remote appointments for convenience due to Covid.  
(75+, White, CKD)*

*They always schedule my appointments too early! I have a free bus pass but appointments before 9.00 AM means I cannot use it and have to pay bus fare.  
(56-74, White, CKD)*

*The new appointment system is a great improvement and is now top class.  
(56-74, White, Tx)*

## Chapter 14: Waiting times

Waiting times consist of two subthemes, patients waiting at the centre for appointments/ treatment and patients waiting for transport to arrive following treatment.

*Table 35: List of codes relating to Waiting times shown by frequency and attitude*

Code	Total (n)	Negative	Neutral	Positive
<b>Transport Waiting times</b>	<b>212</b>	190	5	17
<b>Waiting times within the unit</b>	<b>117</b>	93	1	23

Waiting times are a big issue for patients attending a centre or satellite unit for haemodialysis. Moreover, in comparison to the response profile of the PREM, patients from a Black ethnic background and Asian ethnic background had more issues, contributing to 19.3% and 16.7% of the comments, respectively. Patient comments included having to wait in excess of an hour for their transport home following treatment and being at the centre/unit for an extended period of time due to waiting times to attend their appointment.

### *Patient comments about waiting times*

*Transport is always late, I am the last patient in and the last patient out, I am ready at 6 often not picked up until 7-8 affect my treatment time. Ready to leave at 11.30 not collected until at least 1 o'clock.  
(75+, Black, Sat HD)*

*Transport home can take up to 2 ½ hours  
(56-74, Black, Sat HD)*

*Waiting so long till they put me on the machine (around one hour)  
(31-55, Asian, ICHD)*

*Appointments never run to time, usually have to wait at least an hour before being seen  
(31-55, White, CKD)*

*The waiting time for blood tests at the clinic could be reduced (this usually accounts for the longest period spent in the clinic).  
(75+, Rather Not Say, CKD)*

## Chapter 15: Other areas of care

These themes contain comments based on the other aspects of kidney care. The majority of these themes received mostly negative comments, with the exception of ‘patients are happy’ and ‘management of the unit’.

The response profile of patients leaving a comment for each of these codes, matches that of the patients responding to PREM 2021.

*Table 36: List of codes relating to Other areas of care shown by frequency and attitude*

	<b>Total (n)</b>	<b>Negative</b>	<b>Neutral</b>	<b>Positive</b>
<b>Blood test appointments</b>	<b>139</b>	91	7	41
<b>Mental Health</b>	<b>67</b>	55	1	11
<b>Patients are happy</b>	<b>48</b>			48
<b>Change of unit</b>	<b>43</b>	24	6	13
<b>Privacy</b>	<b>42</b>	33	1	8
<b>Pharmacy</b>	<b>39</b>	5	1	33
<b>General Comment</b>	<b>35</b>	8	24	3
<b>NHS</b>	<b>32</b>	20	1	11
<b>PREM</b>	<b>31</b>	17	5	9
<b>Management of the unit</b>	<b>29</b>	14		15
<b>Kidney Health</b>	<b>24</b>	14	3	7
<b>Research</b>	<b>11</b>	6	1	4
<b>Room for Improvement</b>	<b>9</b>	8		1

Blood test appointments, generally referred to outpatient blood tests covering issues whilst attending a blood test. The comments are generally negative and refer to patient experiences of difficulties faced when attending for a blood test e.g., long waiting times.

Mental health received 67 comments, in which 82% were negative. Patients describe how having kidney disease and receiving treatment has had a negative toll on their mental health, leading to depression, anxiety and in some cases Post-traumatic stress disorder.

Change of unit refers to patients who have been moved to a new unit due to a restructure of centres across the UK. Patients affected have found the change difficult due to not knowing the staff and the staff not knowing them and their needs.

Additionally, there has been many responses concerning the lack of privacy within the unit, the lack of research into kidney disease, issues with the pharmacy and general ways patient experience could

improve. Comments relating to PREM discuss issues with accessing and completing the PREM measure.

Patient responses referencing unit management were mixed with some patients finding their unit well managed and others not. 48 patients commented that they were happy with their care and treatment.



**Patient comments about Other aspects of care**

*As a renal-patient I feel very isolated.  
(75+, White, Female, CKD)*

*Better staff salary award staff overtime undertaken  
(56-74, Black, Female, PD)*

*The majority of care focuses on the physicality of your condition.  
(31-55, White, Male, Tx)*

*I am pleased the Renal team continue studies after being an Outpatient. To help future patients.  
(31-55, White, Female, CKD)*

*I have only had dialysis during covid  
(31-55, White, ICHD)*

*Big improvement in health since treatment started.  
(75+, White, ICHD)*

*I have appreciated taking part in the NAME study and the efforts put in by the renal researchers and others into effectiveness of vaccines renal patients. This was valuable work.  
(31-55, White, Tx)*

*Confidentiality in reception is not always good when booking transport for other appts.  
(56-74, White, Sat HD)*

*Would like to see more proactive interest taken in recent research into the impact of diet on reversing PKD and Subsequent advice being given to patients.  
(31-55, White, CKD)*

*I am pleased with the survey, only can they review the seriousness of my kidney disease  
(31-55, Black, ICHD)*

*Wants to be transferred to unit near his home but it is not possible at the minute.  
(75+, Asian, ICHD)*

*Pharmacist being near waiting room is extremely helpful  
(56-74, Asian, Tx)*

*Very lucky to have the NHS.  
(31-55, White, CKD)*

*General lack of energy and motivation and very low mood  
(56-74, White, Sat HD)*

*Blood test results are not routinely provided unless asked for  
(75+, White, Sat HD)*

## Chapter 16: Patient Suggestions

In response to the free text question, there were 116 patients who responded with suggestions to improve their experience of kidney care. These suggestions were coded under 4 subthemes based on the resources needed to enforce them: Quick wins, Long-term suggestions, FAQs, and Post COVID-19 suggestions.

Responses containing suggestions were mostly from older patients from a white ethnic background receiving haemodialysis at a satellite unit. There was a higher representation of patients from an Asian ethnic background (11.1%).

Table 37 shows a breakdown of these codes and some of the suggestions from patients. Important to note is the code ‘Quick wins’, which are the suggestions that could be implemented with apparently little effort.

*Table 37: Patient Suggestion codes with examples and quotes*

Quick Wins	Long-term Suggestions	Post COVID-19 Suggestions	FAQs
<ul style="list-style-type: none"> <li>• Hooks at the weighing scales</li> <li>• Staff interactions</li> <li>• Diet information</li> </ul>	<ul style="list-style-type: none"> <li>• Automatic doors at the unit entrance</li> <li>• Change of dialysis chairs</li> <li>• Improvements at the unit e.g., WIFI, TVs, Water machines</li> <li>• Parking facilities</li> <li>• Holiday dialysis</li> </ul>	<ul style="list-style-type: none"> <li>• Having food and drink in the unit</li> <li>• Being able to have visitors at the unit</li> <li>• Regular PCR testing</li> </ul>	<ul style="list-style-type: none"> <li>• COVID-19 vaccinations</li> <li>• Test results</li> <li>• Patient View</li> <li>• Transplant eligibility and waiting list</li> </ul>

<p><i>"I would like to dialyse near my friends so that we can chat." (56-74, White, ICHD)</i></p>	<p><i>"It would be good to be given a card to carry with up-to-date numbers or even receive an email with the same information as it changes over time." (31-55, White, Tx)</i></p>	<p><i>"I still think when admitted to hospital you should have at least one visitor this is some think the patient looks forward to and helps the recovery of the patient" (56-74, White, HHD)</i></p>	<p><i>"I have no knowledge of Patient View so do not know whether I should/need to join?" (56-74, White, CKD)</i></p>
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### *Patient Suggestions Examples*

*Still need improvement with policing the biscuits tin.  
(56-74, Black, ICHD)*

*STAFF NAME makes sure the transport is ready to pick you at the right time  
(31-55, Black, ICHD)*

*The team at PDU go out of their way to give us patients the best care possible they explain what is going on and answer questions, if they do not know the answer, they will find someone who can. The manager regularly goes round the unit talking to all the patients and listens to concerns and ideas on how to improve the patients time whilst on dialysis. The team are fabulous and make our time on dialysis entertaining  
(31-55, White, ICHD)*

*Could do with somewhere to put coat etc. before being weighed.  
(56-74, White, Satellite HD)*

*We should be allowed to have tea and something to eat during 4hours dialysis  
(75+, White, Tx)*

*Would like to have access to blood tests online, so I can check them when I want. Not totally sure how to do this but told it can probably be done  
(75+, Other, PD)*

*The team may benefit from more online tools to share notes, make appointments etc. they are still heavily reliant on paper diary, post stick notes and just talking to each other. More organisational tools would save them time and improve patient comm  
(31-55, White, PD)*

## Chapter 17: Spotlight on negative comments made by patients reporting poorer experience of care in the Kidney PREM 2021

The aim of this analysis was to find specific aspects of kidney care that can be improved, focussing on comments provided by patients who report particularly poor experience of kidney care.

The final question in the Kidney PREM asks patients to grade their overall experience of the service provided by their renal unit (1-7, worst to best it can be). For this analysis, we grouped respondents according to their scores: low (1-2), medium (3-5) and high (6-7), with a focus on the low scoring group to allow us to focus on the most extreme definitions of poor experience.

As shown in Table X, these patients were more likely to comment negatively on their care. Whilst we cannot be certain that the negative comment relates directly to the low score, it is reasonable to assume these comments contain insights into ways patient experience of care can be improved.

*Table 38: Number of patients per Q39 score group*

Score	Number of patients	% providing negative comments
1-2	112	95%
3-5	822	84%
6-7	2946	40%

For this analysis, comments were filtered to extract only negative comments from patients scoring their renal units low for 'overall experience.' We produced a thematic network of negative aspects of care, which was then developed into a word cloud (Figure X). This allowed us to identify areas of care most commented on by patients who report poor experience in their renal units.

Just 112 (2.9%) of the 3,877 individuals who responded to the free text question fell into the lowest-scoring overall experience category, rating this 1 or 2 out of 7, with 95% of these comments describing a negative experience of kidney care. As shown in Table X, patients commenting on poor experience tended to be younger CKD (non-RRT) patients in contrast to the response profile of the Kidney PREM.

	Low Scoring Patients	Kidney PREM 2021 Comments
<b>Total</b>	<b>112</b>	<b>3877</b>
Age		
≤30	4 (3.6%)	89 (2.3%)
31-55	45 (40.2%)	1051 (27.1%)
56-74	53 (47.3%)	1934 (49.8%)
≥75	10 (8.9%)	803 (20.7%)
Gender		
Female	53 (47.3%)	1645 (42.4%)
Male	55 (49.1%)	2209 (56.9%)
Rather not say	4 (3.5%)	26 (0.7%)
Ethnicity		
Asian	4 (3.6%)	374 (9.6%)
Black	10 (8.9%)	419 (10.8%)
White	83 (74.1%)	2857 (73.6%)
Other	6 (5.4%)	149 (3.8%)
Rather Not Say	9 (8.0%)	81 (2.1%)
Treatment		
Transplant	31 (27.7%)	886 (22.8%)
CKD	41 (36.6%)	589 (15.2%)
In-centre HD	17 (15.2%)	837 (21.6%)
Sat HD	17 (15.2%)	1298 (33.5%)
Home HD	1 (0.9%)	80 (2.1%)
PD	5 (4.5%)	187 (4.8%)
England		
East of England	6 (5.4%)	262 (6.8%)
London	28 (25.0%)	1127 (29.0%)
Midlands	9 (8.0%)	359 (9.3%)
North East	2 (1.8%)	93 (2.4%)
North West	10 (8.9%)	234 (6.0%)
South East	12 (10.7%)	553 (14.3%)
South West	10 (8.9%)	300 (7.7%)

Yorkshire & Humber	10 (8.9%)	176 (4.5%)
Northern Ireland	2 (1.8%)	47 (1.3%)
Scotland	4 (3.6%)	146 (4.2%)
Wales	0 (0.0%)	198 (5.7%)



This word cloud (figure X) shows the aspects of care which low scoring patients commented on, with the larger the word indicating a higher frequency of comments on this theme. Figure 2 shows that ‘the renal unit team’ is the most notably aspect of care for these patients and included issue such as availability of consultants. This was followed by care, patients sharing negative experiences about their care, communication, issues with contacting the renal team outside of appointments and appointments, patients having appointments cancelled and not rescheduled. Scheduling, patient information, and other aspects of care has also been an issue for low scoring patients but received fewer comments. Using this word cloud, we gain a visual representation of areas of care that are negatively affecting patient experience of kidney care.



## Chapter 18: Analysis by patient characteristics

Patient experience of kidney care is unique to each patient with factors such as age, ethnicity and treatment type affecting the perceived accessibility of care. An analysis looking at patient characteristics provides a better understanding of the aspects of care patients have found to be positive and areas with room for improvement. Importantly, the analysis shows the similarities and differences in experience of care between patients of different ages, ethnicities, and treatment types.

### Age

*Table 40: Number of responses per theme by age*

Themes	Total number of negative responses per theme	Number of negative responses by Age			
		≤30	31-55	56-74	≥75
Staff	595	17	186	299	93
Environment	504	8	120	269	107
Communication	387	8	125	199	55
Appointments	333	12	80	189	52
Care	312	9	106	156	41
Waiting times	284		67	140	77
Impact of COVID-19	250	9	93	125	23
Patient Information	223	7	65	115	36
Treatment	211	2	74	106	29
Transport	201	1	53	97	50
Scheduling	174	4	65	85	20
Support	132	7	59	54	12
Non-renal illness	39	1	9	25	4
Other aspect of care	80	1	24	39	16

*Figure 3: Bubble chart of themes by Age*

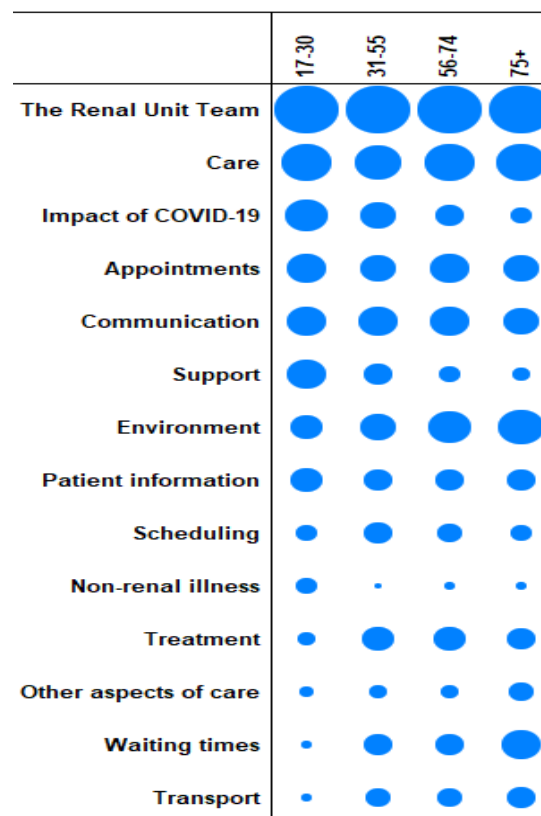
Figure 3 shows the number of negative responses to each theme by age group, showing that there were many similarities in the way patients responded such as most patients, irrespective of age, commented on the renal unit team and non-renal illness received the fewest comments across the board.

Support presented the biggest issue for patients aged 17-30 years old, with waiting

times receiving no negative comments from this age group.

Patients aged 31-55 years old and 56-74 years old followed a similar trend in their free text responses, with 31–55-year-olds having more negative comments on support, impact of COVID-19 and scheduling.

For patients aged over 75 years old the most pressing issues were related to the renal unit team, environment, and waiting times.



## Ethnicity

Table 41: Number of responses per theme by Ethnicity

Themes	Total number of negative responses per theme	Number of negative responses by Ethnicity				
		Asian	Black	White	Other	Rather Not Say
Staff	595	53	55	443	19	25
Environment	505	41	39	380	25	20
Communication	387	31	31	301	13	11
Appointments	333	15	12	295	6	5
Care	292	31	27	225	5	4
Waiting times	284	39	45	177	17	6
Impact of COVID-19	250	13	17	203	9	8
Patient Information	223	12	18	184	5	4
Treatment	211	18	20	157	9	7
Transport	201	15	43	131	10	2
Scheduling	174	6	10	138	10	10
Support	133	8	8	108	5	4
Non-renal Illness	39		3	32		4
Other aspect of care	80	8	7	52	6	7

Figure 4: Bubble chart of themes by Ethnicity

Figure 4 shows the number of negative responses per patient ethnic group. The number of negative responses within the themes renal unit team, environment, and treatment are similar across all ethnic groups. Patients from a black ethnic background provided more negative comments on transport. Non-renal illness received no negative comments from patients from an Asian ethnic background or other minority ethnic background.

73.6% of all responses to the free text question came from patients from a White ethnic background and this group provided large numbers of negative comments on many themes, including appointments, impact of COVID-19, and patient information. Patients from other ethnic backgrounds or patients who did not state their ethnicity provided more negative comments on scheduling, mentioning the difficulties faced while trying to book blood test appointments and issues with not receiving blood test results in time for consultations.

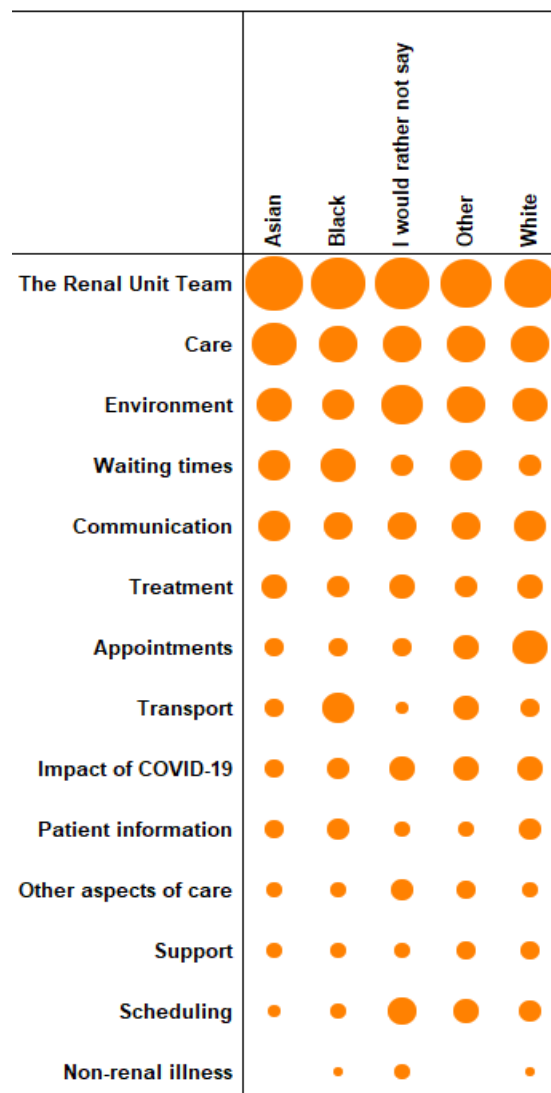


Table 42: Number of responses per theme by Treatment

Themes	Total number of negative responses per theme	Number of negative responses by Treatment					
		CKD	Home HD	Peritoneal	Hospital HD	Satellite HD	Transplant
Staff	595	73	18	31	162	194	117
Environment	504	15	11	144	26	256	52
Communication	387	97	11	23	48	64	144
Appointments	333	136	7	10	21	21	138
Care	312	60	13	22	61	72	84
Waiting times	284	9	3	10	84	150	28
Impact of COVID-19	250	19	14	4	58	64	91
Patient Information	223	78	0	13	32	39	61
Treatment	211	20	14	12	50	57	58
Scheduling	174	46	1	6	24	25	72
Transport	156	9	0	11	5	108	23
Support	132	23	9	8	23	23	46
Non-renal illness	39	7	3	2	7	5	15
Other aspect of care	80	20	1	2	16	22	19

Figure 5: Bubble chart of themes by treatment

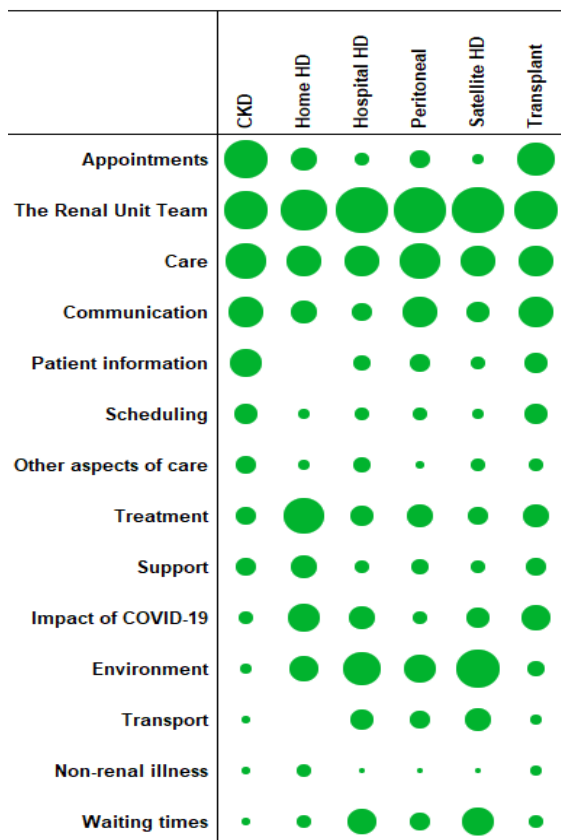


Figure 5 shows the negative responses to each theme by treatment modality. As shown, the number of negative responses varies greatly by treatment type.

CKD patients provided mostly negative comments on appointments and communication, with comments including concerns about lack of appointments and wanting better communication between the renal team.

Patients receiving haemodialysis at home were most concerned about treatment and the impact of COVID-19. These responses were linked, with the impact of COVID-19 (feeling unsafe, wanting to have visitors attend appointments) affecting their experience of treatment (feeling isolated and forgotten).

The negative responses of patients receiving haemodialysis in-centre or at a satellite unit were similar, with the limited differences in that the latter patients commented more on the environment, waiting times and transport. Issues with transport included negative experiences with drivers, travelling by taxi and

the journey route making travel times longer.

Comments regarding environment include poor WIFI, lack of sheets and feeling uncomfortable.

Similar to patients not receiving RRT, transplanted patients commented negatively on appointments and communication. They were also most negatively affected by COVID-19 causing restrictions in access to care. This

included lack of appointments, lack of communication from consultants and lack of care from Primary Care.

Patients receiving peritoneal dialysis appeared to have the fewest issues with their kidney care. Areas of concern fell within the theme staff and environment, with comments including issues with lack of parking.

## Chapter 19: 2021 / 2020 Comparison

This comparison of free text responses from 2020 and 2021 gives insight into how patient experience of care has changed following the feedback in comments from 2020, along with the areas of care which seem to be a persistent issue for patients. The analysis of comments changed format between 2020 and 2021, with 2020 using the existing 13 PREM themes as a way of theming and 2021 introducing emerging themes. In both years, around 40% of patients responding to Kidney PREM left additional comments on their experience of kidney care. The number of comments from patients of a Black ethnic background or Asian ethnic background increased from 2020 (24% vs 17%), and there was a difference in age profile, with less from patients aged under 30 years old (2.3%).

Importantly, positive comments about staff remained the most prominent response in patient comments about their kidney care. Any negative comments within this theme related to the lack of availability of specific renal team members, consultants, dieticians, social workers. This was the same for both years. 2021 comments also found patients were generally positive about their experience of care whereas in 2020, in the theme 'How the renal team treats you' which received similar comments, only 39% were positive.

Comments regarding environment featured highly in both years and were mostly negative. In 2021 the largest proportion of these were related to comfort, temperature control, and waiting areas. Accessibility and parking arrangements were also criticised. This was also the case in 2020, when waiting times in the unit were a larger issue.

In contrast to 2020, support featured in a high number of comments. Comments in 2021, included wanting more psychological support and mentioned the apparent lack of provision for this,

additionally specific support for financial issues and family of patients with kidney disease were mentioned.

Issues with communication featured in both years, with comments in 2020 focussing on patients wanting communication to be more frequent. 2021 found issues predominantly within the kidney team – with the main difficulties being accessing members of the team between appointments, receiving the results of tests in a timely fashion, and messages not being passed between team members. In both years lack of information was an issue, particularly in relation to adequate updates about treatment, progress, and transplant prospects. More access to advice about diet, fluid intake and exercise was also requested.

Both years saw patients offering suggestions to improve their experience of kidney care. In particular, these comments featured ‘quick wins’ with 2020 comments stating the need for a chair by the weighing scales and a need for diet sheets. In 2021, the quick wins focussed more on what staff had done and could do to make their experience of care special, the need for diet sheets, and suggesting coat hooks by the weighing scales.

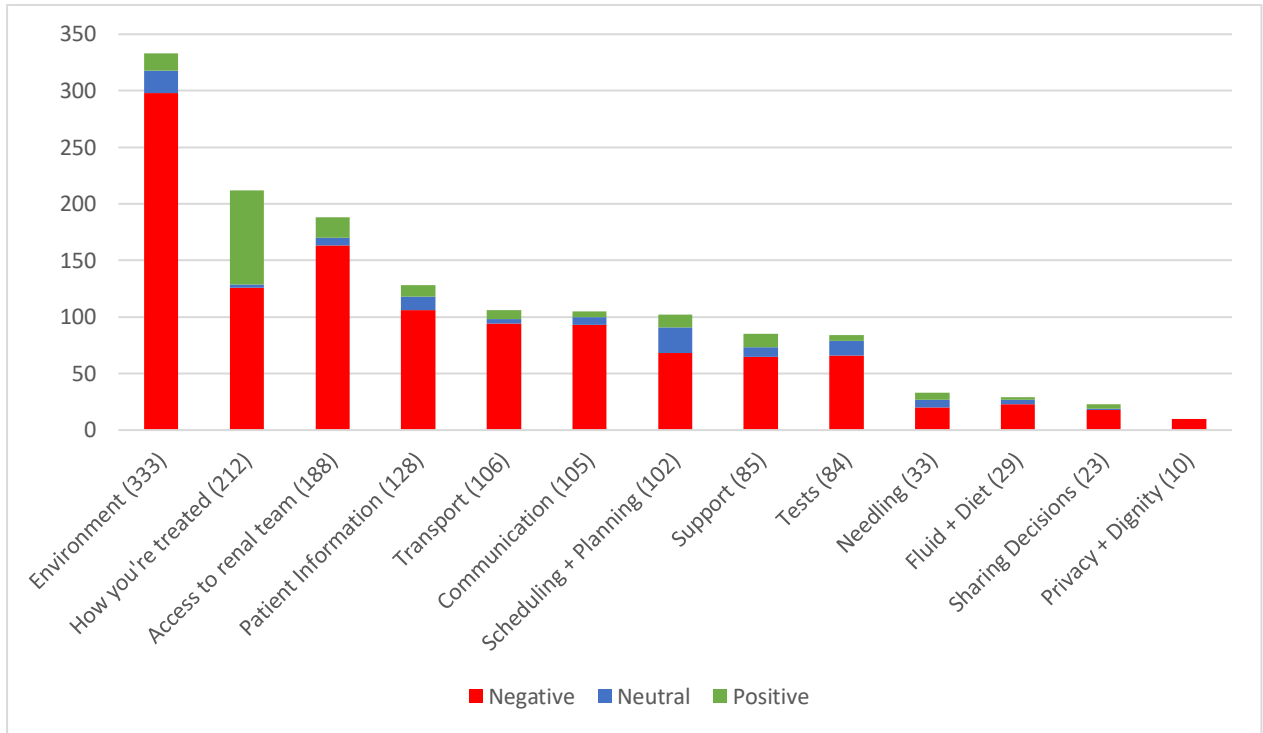
In 2021 younger patients tended to focus on support and older patients on environment and transport, this was the same for 2020. In 2021 patients not receiving RRT focused on appointments and communication, as did patients with a functioning transplant who also focussed on COVID-19. In 2020 transplanted patients and those with CKD highlighted issues about psychological care. In 2021 patients receiving PD and ICHD focussed on staff and environment with patients receiving ICHD also commenting on transport. In 2020 patients on in-centre and satellite haemodialysis raised issues about involvement in decision making, scheduling, and needling, whilst those receiving peritoneal dialysis focussed on communication and discussion of test results. In 2021 patients receiving haemodialysis at home commented on support and Covid -19.

## **Annex – Summary of 2020 comments**

In 2020 over 40% of patients who completed the Kidney PREM provided a response to this question.

63% of comments covered experiences relating to established Kidney PREM themes, with 729 comments relating to emergent themes. Most were categorised as negative in viewpoint, though often providing potentially helpful suggestions.

Figure 6: Breakdown of each theme by number of comments and whether the comments were positive, negative or neutral



Perhaps surprisingly there was no relationship between the ranking of themes in Kidney PREM 2020 and the numbers of comments received in relation to these themes, nor between the proportions of these comments which were negative or positive.

Figure 7: Overall domain scores from the previous 3 Kidney PREMs



## Key Points

- Comments about **staff** and the team were overwhelmingly positive, with references made to the level of care and compassion shown across the whole MDT, and often how this leads to a feeling of gratitude for excellent care.

*"I am so grateful and thankful to the amount of care and work the staff at UNIT NAMED renal team put into treating me. Doctors, Nurses and Specialists would call in regularly to ensure I'm doing well and keep me informed about my treatment process. Each and every staff are so wonderful and friendly which makes the treatment journey manageable." (<55; Asian; Peritoneal Dialysis)*

*"This unit has been an eye opener for kindness, caring, dedication, teamwork, respect of one another both in team and towards patients, all contributing to a sense of comfort, knowing that they are doing their utmost to provide excellent care and understanding. thank you once again UNIT NAMED. I cannot thank them enough" (56-74; White, In-centre HD)*

*"It is easy to see what a dedicated team we are fortunate to have at UNIT NAMED Renal Unit and so caringly run by DOCTOR NAMED. I consider myself very fortunate to be under their care. The pressure they work under is immense and I don't believe we truly reward them all to the level we should." (75+; White; CKD)*

*"The renal technicians have been fantastic and gone above and beyond in their efforts to me dialysing at home." (56-74; White, Home HD)*

*"The team look after us fantastically well. They really care about us as both patients and human beings. They always do their best for us and I'm confident that they always will. We have had several team members leave over the past year or so but thankfully we have gained some excellent replacements. As a patient I feel extremely lucky and fortunate to have such highly skilled professionals caring for me." (<55; White, Satellite HD)*

- **"Access to the renal team"** was another high profile issue with many comments about not being able to see a doctor. Poor accessibility and renal awareness of GPs also drew many comments.

*"There is no regular consultant. I see different doctors which is hard as I am there so often. Sometimes you meet a new doctor, and they have a different view and then you are sent off for new tests or scans. It's very frustrating." (<55, Other, Tx)*

*"THE DIETICIAN IS ALSO EXCELLENT, ALWAYS KEEPING AN EYE ON BLOOD TESTS RESULTS AND COMING TO DISCUSS YOUR DIET IF THE RESULTS ARE NOT GOOD WITH IDEAS ON HOW TO IMPROVE YOUR DIET IN WAYS THAT ARE SUITABLE FOR YOU" (56-74, White, Sat HD)*

*"We are however short of a social worker and could do with more mental health support." (56-74, White, Tx)*



- **“How the renal team treats you”** figured highly but with a relatively high proportion of comments (39%) being positive. Poor communication between staff and patients, between different departments within the unit, and between the unit and GPs also featured frequently.

*“I am stage 3 sometimes it feels like its a minor illness but its a big deal for me. Questions are answered for me by the consultant because they assume at my stage I don't have any symptoms so I stopped mentioning them” (<55, White, CKD)*

*“In this unit staff should pay more attention to their patient than their mobile phone's once the patient's on the machine. Also give medication in a timely manner.” (<55, Asian, Sat HD)*

*“A bit more empathy would help. I have a sunny disposition but can see that depression could easily set in with this complaint. e.g.I had an operation to resite my catheter recently and the after effects were pretty painful. At no time did anyone ring up to find out how I was getting on which I thought was bad.” (75+, White, PD)*

- There was a wide range of issues commented on as **emerging themes** including staff shortages, transplant care and Mental Health.

*“Staff numbers could be increased so it does not feel like an imposition to ask for help and when help is needed it comes quickly whilst dialysing on the ward.” (<55, White, Home HD)*

*“I was very anxious to come in although I know everything will be okay.” (<55, Black, Centre HD)*

*“Just my mental health hasnt been good and I have been waiting since July 2019 to be seen by mental health, It would be good to be able to talk to someone at the unit instead of having to wait so long” (<55, White, Tx)*

*“The pre-transplant and post-transplant precautions taken by the transplant teams were excellent” (56-74, White, Tx)*

- There were also **COVID-19 related comments**, mainly negative, pertaining to quality of advice given, availability of PPE, and difficulties with the use of facemasks, particularly among older patients. Comments on the safety of the unit were predominantly positive.

*“Need more information about the pandemic” (<55, Black, Sat HD)*

*“I am not completely clear whether getting Covid could prove very serious (even fatal) for someone in my situation. For that reason I am still self-isolating.” (56-74, White, TX)*

*“Staff are very caring but not valued sufficiently by government. Kidney patients were not recognised as vulnerable in early stages of covid19 so difficult to get support with many aspects of life ie shopping delivery slots. Not enough recognition as a medical condition requiring support.” (56-74, White, TX)*

- The most commented on Kidney PREM theme was **‘Environment’** with 333 comments. Comments covered many issues with waiting times being a particular problem, particularly for patients receiving haemodialysis in-centre/satellite.

*“No water dispenser.” (56-74, White, Sat HD)*

*“The UNIT NAME unit is very old and out-dated; we have been waiting modernisation for some time and I started dialysis there 8 years ago and have listen to expectations ever since.” (56-74, White, Sat HD)*

*“Free parking for kidney patients!!!” (<55, White, PD)*

*“The machines are never ready from one session to the next. I could be sitting and waiting for machine to be ready for at least one hour. The same people get top priority all the time.” (75+, White, Centre HD)*

*“It would be helpful if machines were ready when you have a set time to be there instead of waiting 30 minutes for machine to clean itself” (<55, White, Centre HD)*

- **‘Patient Suggestions’** emerged as a new theme with 92 comments across 5 codes; Quick wins, Suggestions for long term, COVID-19 related suggestions, Potentially resolved and FAQs. Important to note is the code ‘Quick wins’, which are the suggestions that could be implemented with apparently little effort.

*“Would like chair next to weighing scales so don't have to bend for bags off floor losing balance.” (56-74, White, Sat HD)*

*“It is much helpful for patient if staff could smile to their patients and not frowning because it gives negative vibes to us as patient” (<55, Asian, PD)*

*“Probably diet sheets would be a good idea.” (56-74, White, CKD)*