

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 2022

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EXECUTIVE SUMMARY

The Kidney Patient Reported Experience Measure (Kidney PREM) is facilitated annually by the UK Kidney Association and Kidney Care UK. The Kidney PREM has 39 questions covering 13 themes. Additionally, when accessed online, the Kidney PREM 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 2022, 11,063 people with kidney disease took part in Kidney PREM, with 7,030 completing the online version which included the free-text question. Of the online responses, 2,376 (33.8%) provided a further comment on their care (21.5% of all participating in 2022), 1,861 of which (78%) were coded under a theme covering an aspect of kidney care – the remainder stating that no further comments were necessary. 92.9% of responders gave consent for their comments to be passed back to their kidney centre. Generally, the profile of responders who left a free text comment matched that of the national Kidney PREM 2022; however, there was noticeably a higher representation in the comments from those who have received a functioning transplant (+5.2%). Compared to Kidney PREM 2021 the profile of responders remained consistent.

This report follows the 13 Kidney PREM themes with ***How the Renal Team Treats You*** receiving the highest number of comments (1,136), and 64% of comments under this theme were positive. This theme focused on positive comments about staff, thanking them for their care and dedication, as well as mentioning role specific staff members positively. Comments containing examples of good experiences of care featured highly.

Environment was the second most common theme to emerge from the comments and was predominantly negative (82.9%). Respondents commented on issues with parking, such as the cost of parking and availability of spaces, the temperature of the unit being too cold and the lack of variety of food which was offered to patients.

Scheduling and Planning (330 comments), ***Access to the Renal Team*** (325 comments) and ***Support*** (278 comments) received comments from individuals wanting more face-to-face contact with the kidney team, better access to the kidney team, particularly consultants and availability of consultant appointments, and more focused support for home life and the impact of treatment. Though, support throughout the COVID-19 pandemic was commented on positively.

Aspects of care such as ***Sharing Decisions***, ***Needling*** and ***Privacy and Dignity*** received fewer comments but should still be considered as important areas of care

for improvement. Individuals receiving treatment would like more opportunities to discuss what they would like from their care, needling to be performed slower, so as to be less painful and for conversations with consultants and nurses to be conducted in private.

Other Themes contain comments which do not fit the pre-existing Kidney PREM themes. 338 comments fell under the **Other Themes** and subthemes with prominent topics including mental health, psychological provision, self-care and medication. Additionally, some comments related directly to patient experience of their treatment, and some comments regarding the COVID-19 pandemic.

Respondents' characteristics were also reflected in comments: for instance, younger individuals tended to focus on **Support** and older individuals and those receiving haemodialysis in-centre or at a satellite unit, on **Environment** and **Transport**. Those yet to receive Kidney Replacement Therapy (KRT) or who have received a functioning transplant focused on **Scheduling and Planning**, **Sharing Decisions** and **Tests**. Individuals receiving home therapies were more likely to comment on **Other Themes**.

The report also shows the comparison between free text responses from Kidney PREM 2021 and Kidney PREM 2022. Only 21.5% of respondents completing the measure left a free text response in 2022, compared to 40% in 2021. In both years, the highest number of positive comments referred to *staff*, while comments on **Environment** were mostly negative. Comments in 2021 regarding **Support** included the need for more psychological support and the apparent lack of current provision. This was the same in 2022, although this year included an additional code, **support with COVID-19**, which received the greatest number of comments within this theme, most of them positive (64%). In both years issues with **Communication**, particularly individuals wanting better communication, featured as quite a negative aspect of patient care. Additionally, *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.

We hope this report will give some insight into what individuals with kidney disease think is important about their care and that their comments will help to illuminate the findings of Kidney PREM 2022 and complement efforts to improve the care of people living with kidney disease.

CHAPTER 1: INTRODUCTION

1.1: Background

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

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, Sharing Decisions, Tests, Scheduling and Planning, Privacy and Dignity, Support, Needling, Fluid Intake and Diet, Environment, and Transport.** Each theme consists of 1-5 questions, in which respondents 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 unit.

"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 participants and their kidney care teams to act on the results.

1.2: Aims and Objectives

The Kidney PREM aims to help teams understand how individuals feel about their experience of care, show where improvements can be made, and give the UK Renal Registry a national picture of people's experience of care.

The Kidney PREM is used by units, networks, and staff to implement participant suggestions, focus on areas of care which receive lower scores and praise successes in areas of care which scored highly.

1.3: Methods

Kidney PREM 2022 was available for individuals to complete online or on paper from 1st October to 12th November 2022, securing 11,063 valid responses, 7,030 of which were online. Data were downloaded from the Qualtrics platform, online survey tool, in Excel format, checked and a master file of all data¹ (from the online surveys) uploaded into QDA Miner, a computer-assisted coding software.

2,209 (92.9%) who provided a written comment gave consent for this to be passed back to their treating unit; accordingly, UKKA sent datasets and explanatory text to all Clinical Directors in February 2023. Additionally, a main centre (including satellite units) summary table of themes by sentiment was published on the UKKA data portal to accompany the comments.

Using QDA miner comments were initially screened using a text retrieval function for whether it needed further interpretation. This coded 177 comments as nothing to add. Following this, using the cluster function, in which the software groups comments based on words/ phrases, coding of the remaining comments was conducted inductively and assigned a sentiment code, either positive, negative, or neutral. Throughout the coding process, there were several quality checks in which a

¹ patient characteristics, kidney unit, responses to Q39 Kidney PREM item and free text question comments

team of researchers and a clinician, reviewed and agreed on the suitability and accuracy of the coding, ensuring interpretation of the comments was represented by the most appropriate code. Once all comments had been coded, themes were determined deductively (predefined before analysis), under the 13 pre-existing Kidney PREM themes. Codes which did not fit under these themes were placed under **Other Themes**, which contained 2 sub-themes, **Specific Areas of Treatment**, and **COVID-19**.

The coding procedure followed that of reflexive thematic analysis (Braun and Clarke, 2021²), where comments were read for familiarisation, coded, themed, and reviewed. Due to the vast number of comments received and to ensure the results of the analysis are accessible, the codes and themes have been quantified and displayed in tables for easier comparison and interpretation (Miles and Huberman, 1984³).

Analysis of the quantitative data has been reported separately and is available to view via the UK Kidney Association website⁴.

1.4: Structure of Report

Participant comments are presented by theme, the same themes as the national Kidney PREM questionnaire plus **Other Themes**, with a breakdown of sentiment (positive/ negative/ neutral) shown in a table, and variation by respondent characteristics displayed in figures or confirmed as the same as the general Kidney PREM 2022 profile. This year, respondents had the opportunity to choose non-binary and not say to the gender question; however, the number of individuals who left a comment within these categories did not meet the required minimum to ensure anonymity to be presented in the report (non-binary =1, not say = 12).

Themes with fewer comments are not assumed to be any less important for those with kidney disease, rather; fewer people had comments to make in addition to what they had already scored under the relevant theme in the Kidney PREM.

The report finishes with a comparison of comments made in Kidney PREM 2021 and Kidney PREM 2022.

DIFFERENCES IN NUMBER OF COMMENTS

Some participant 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 patients commenting.

For instance, in this example 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.

² Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, 21(1), 37-47.

³ Miles, M. B., & Huberman, A. M. (1984). Drawing valid meaning from qualitative data: Toward a shared craft. *Educational researcher*, 13(5), 20-30.

⁴ www.ukkidney.org/kidney-patient-reported-experience-measure

1.5: Overall Response

From the 2,376 respondents who left a free text response, 177 (7.4%) individuals said there was no further comment, there were 1,861 comments which related to Kidney PREM themes, and 338 comments under **Other Themes**.

The table below shows the breakdown of respondent comments by theme and sentiment. The most frequent theme that individuals commented on was **How the Renal Team Treats You**. This theme was overwhelmingly positive, as in previous years, with individuals thanking staff for providing good care. The second most commented on theme was **Environment**, followed by **Scheduling and Planning**, comments on which were largely negative. **Needling, Privacy and Dignity**, and **COVID-19** received the fewest comments.

Table 1: Total and number of comments by attitude, for Kidney PREM themes

	Total (n)	Negative	Neutral	Positive
How the Renal Team Treats You	1,136	367	31	738
Environment	334	277	5	52
Scheduling and Planning	330	239	17	74
Access to the Renal Team	325	234	17	74
Support	278	160	10	108
Other Themes	254	195	18	41
Transport	252	215	7	30
Communication	212	150	18	44
Specific Aspects of Treatment	111	62	11	38
Patient Information	87	69	2	16
Tests	57	47	2	8
Fluid Intake and Diet	53	43	1	9
Sharing Decisions	44	26	3	15
Needling	14	10	2	2
Privacy and Dignity	14	12		2
COVID-19	10	10		

1.6: Overall Patient Profile

This year (2022), 2,376 people left additional comments on their experience of kidney care. The number of comments from individuals of an Asian ethnic background remained consistent from last year, with a decrease in the representation of individuals of a Black ethnicity (-1.2%). This year a new option was offered to patients to choose Mixed ethnic heritage, and 1.4% responded with this option.

Age categories were expanded this year, with many individuals who left a free text response being aged 41 to 84 years old. From last year there has been a small increase in the number of under 30-year-olds who left a comment (+0.8%).

Table 2: Characteristics of individuals responding to Kidney PREM

	Kidney PREM 2022 Comments	Kidney PREM 2022	UK Renal Registry 2021
Total	2,376	11,063	
<u>Age (years)</u>			
16-21	26 (1.1%)	92 (0.9%)	
22-30	47 (2.0%)	271 (2.5%)	4.7% ⁵
31-40	50 (6.3%)	647 (6.1%)	35.6% ⁶
41-55	498 (21.0%)	2,084 (19.5%)	
56-64	552 (23.2%)	2,303 (21.6%)	44.2% ⁷
65-74	575 (24.2%)	2,592 (24.3%)	
75-84	440 (18.5%)	2,219 (20.8%)	15.4% ⁸
85+	89 (3.7%)	461 (4.3%)	
Missing	-	394	-
<u>Gender</u>			
Female	951 (40.1%)	4,328 (40.3%)	38.7%
Male	1,411 (59.4%)	6,346 (59.1%)	61.3%
Non-binary/ other	1 (0.01%)	11 (0.1%)	-
Rather not say	12 (0.5%)	59 (0.5%)	-
Missing	-	319	-
<u>Ethnicity</u>			
Asian	217 (9.1%)	1,008 (9.3%)	14.1%
Black	229 (9.6%)	903 (8.4%)	8.7%
White	1,805 (75.9%)	9,358 (76.9%)	73.8%
Mixed	34 (1.4%)	154 (1.4%)	1.5%
Other	51 (2.1%)	269 (2.5%)	1.9%
Rather Not Say	41 (1.7%)	127 (1.2%)	-
Missing	-	152	-
<u>Treatment</u>			
CKD	346 (14.6%)	1,605 (14.5%)	-
PD	134 (5.6%)	725 (6.5%)	5.6%
Home HD	50 (2.1%)	198 (1.8%)	5.3%
Sat HD	721 (30.3%)	3,201 (28.9%)	-
ICHD	604 (25.4%)	3,049 (27.5%)	94.7%
Tx	522 (22.0%)	1,780 (16.1%)	56.5%
Missing	-	484	-

CKD – chronic kidney disease; KRT – kidney replacement therapy; PD – Peritoneal Dialysis; HD – Haemodialysis; Sat – Satellite; ICHD – In-centre haemodialysis; Tx - Transplant

⁵ Reported as <30 years old.

⁶ Reported as 31 to 55 years old.

⁷ Reported as 56-74 years old.

⁸ Reported as 75+ years old.

CHAPTER 2: ACCESS TO THE RENAL TEAM



Availability of consultant



Contacting the renal team



Staff overworked

Access to the Renal Team



Centre attending for care



Continuity of staff

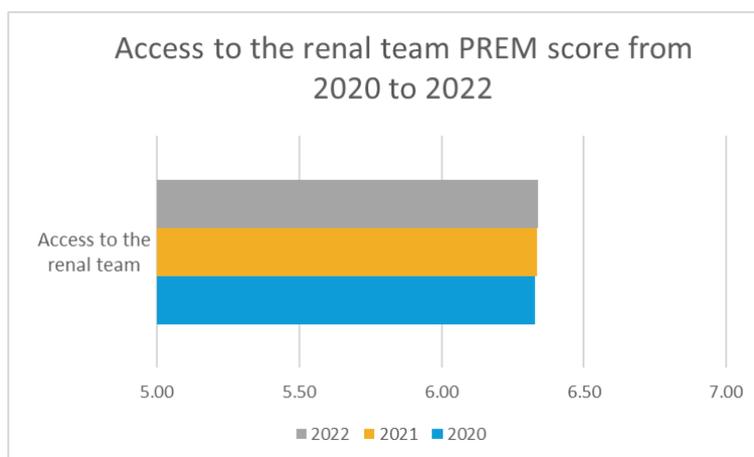


Distance to travel to the unit

The theme **Access to the Renal Team** covers areas of care such as availability of staff, ability to contact the staff when needed and ease of attending the kidney unit for treatment. This theme received 325 comments of which 72% were negative. There has been no difference in the national Kidney PREM scores for this theme over the last 3 years.

Table 3: Breakdown of Access to the Renal Team codes by sentiment

	Total (n)	Negative	Neutral	Positive
Availability of Consultants	99	80	3	16
Contacting the renal team	69	45	1	23
Staff Overworked	63	42	3	18
Continuity of staff	51	38	2	11
Unit attending for care	33	18	8	7
Distance to travel to unit	31	25	2	4

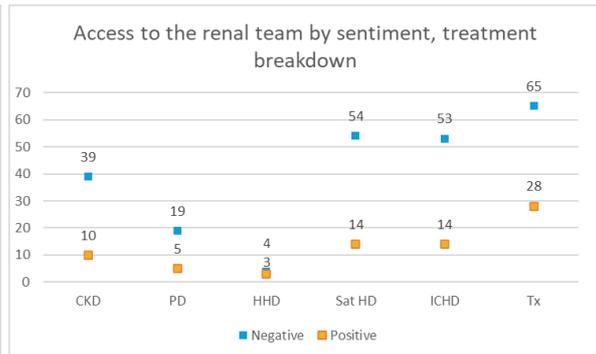
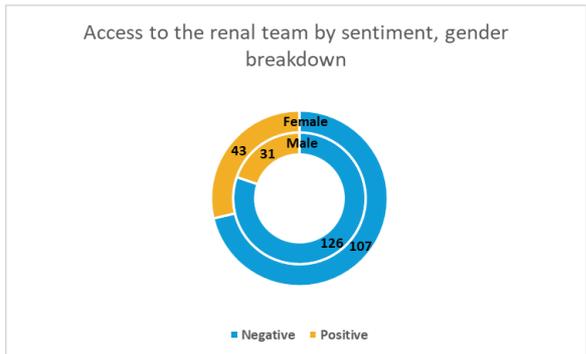
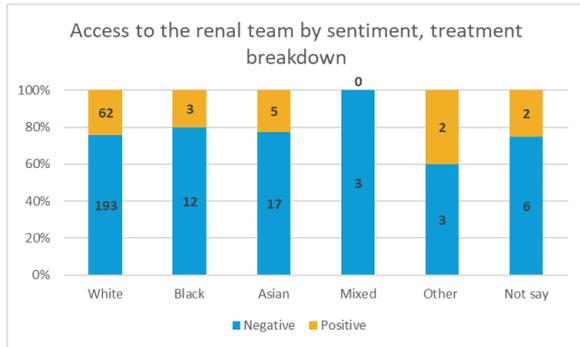
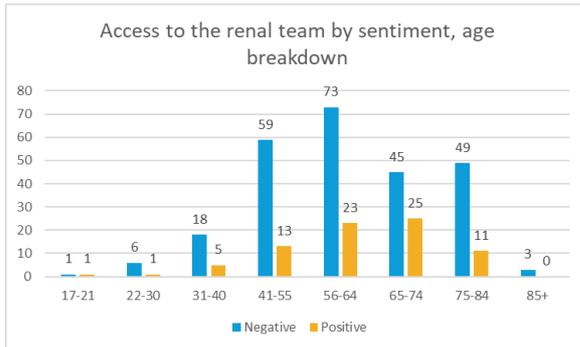


Availability of consultants received the highest number of comments (99) and appeared the most negative aspect of this theme. Individuals felt there was a lack of presence of the consultant in the unit during dialysis sessions, and that appointments with the consultants, whether telephone or face-to-face, were not regular enough. Individuals suggested that consultants could check in with their patients more frequently.

Contacting the renal team was another prominent aspect of care which was reported on. Respondents felt that it was difficult to contact the kidney team when needed, especially out of hours and suggested having a direct out of hours number. Respondents who commented positively on this subject praised staff who returned phone calls quickly or kidney units who had a contact email which was regularly monitored.

Distance to travel to unit refers to individuals who believed their care could be delivered by a kidney unit closer to their home address and spoke negatively of the unnecessary prolonged journey to the unit by drivers taking longer routes. Whereas unit attending for care discusses participants who have changed kidney units recently and their experience of the change.

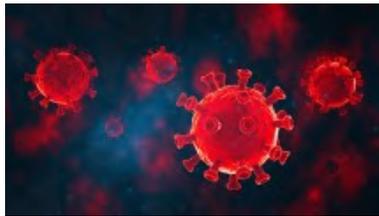
The figures below show the profile of respondents for this theme. Individuals who identified as female, those aged 65-74, and those with functioning transplants were more likely to respond positively in this theme.



 <p>Availability of Consultants</p>	<p>“Face to face contact with my renal consultant is virtually non-existent.” (ICHD, White, Male, 75-84)</p> <p>“Though I almost never get appointments on time. If consultant says 8 weeks, I will be seen in 22 weeks. If she requests 12 weeks, it could be 12 or 16 weeks. This really worries me if my BP is not stable. Thanks” (CKD, Asian, Female, 65-74)</p> <p>“Hard to get hold of Consultant to discuss issues” (PD, White, Male, 56-64)</p>
 <p>Contacting the renal team</p>	<p>“Staff are amazing and can access the doctors and nurses at any time have known them for a long time – it’s a REDACTED condition but the team make it worthwhile” (ICHD, White, Male, 31-40)</p> <p>“An on call pd nurse would be beneficial it's difficult to contact someone out of hours to discuss problems during dialysis” (PD, White, Female, 56-64)</p> <p>“I can get hold of either the Transplant team or my own consultant by telephone pretty much immediately if I need to.” (Tx, White, Male, 41-55)</p>
 <p>Staff Overworked</p>	<p>“Poor nurses rushed off their feet” (CKD, White, Female, 41-55)</p> <p>“I receive the best care! I see how busy the nursing team are, but this does not affect how I am dealt with.” (PD, White, Female, 56-64)</p> <p>“I have given the score not because the team do their in the time have I have observed how busy they are feel mindful of their time to answer my questions” (Sat HD, Black, Female, 65-74)</p>

 <p>Distance to travel to the unit</p>	<p>“The unit is a long way from my home I have to travel for 1 1/2 hours. There is a kidney unit nearer my home in LOCATION which is more local. The team are very good.” (PD, Not Say, Male, 75-84)</p> <p>“Main problem distance from home to hospital, re visits from both parties.” (PD, White, Male, 65-74)</p> <p>“The need to have maybe more units nearer to patient’s locality” (Sat HD, Black, Female, 56-64)</p>
 <p>Continuity of Staff</p>	<p>“It’s also difficult seeing a different person at every visit and having to start again” (CKD, Mixed, Female, 41-55)</p> <p>“Having continuity with doctors would help at lot.” (Tx, White, Female, 56-64)</p> <p>“It would be nice to have the same nurses needling instead of a different nurse every time you go in that way they would get to know your fistula.” (ICHD, White, Female, 41-55)</p>
 <p>Centre attending for care</p>	<p>“We were promised a new unit for dialysis but is not yet forthcoming which doesn’t seem very good to both staff and patients.” (ICHD, White, Male, 85+)</p> <p>“Used receive treatment in LOCATION moved to LOCATION not so good want to go back to LOCATION They don’t care about you in LOCATION just a number” (PD, White, Male, 75-84)</p> <p>“Like LOCATION Unit compared to other units.” (Sat HD, Asian, Male, 75-84)</p>

CHAPTER 3: SUPPORT



Support during COVID-19



Mental health support



Supportiveness of staff



Comments about mental health



Financial support

Support



Support groups



TIME OUT

Out of hours service



Home life support

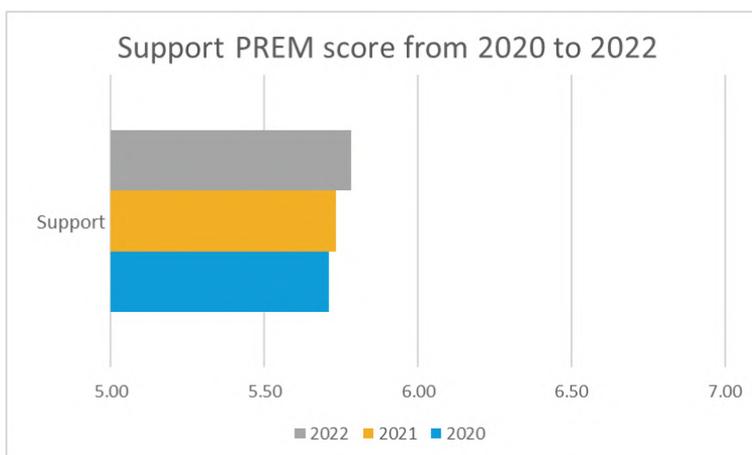


General support

The theme **Support** received 278 comments and was the fifth most commented theme to emerge from the free text comments. This theme covers respondents' experience with the provisions of support in place by the kidney unit and experiences of additional support experienced or required when receiving treatment. **Support** has seen a small increase in its national Kidney PREM score from 2020.

Table 4: Breakdown of Support codes by sentiment

	Total (n)	Negative	Neutral	Positive
Support during COVID-19	64	21	2	41
Comments related to mental health	52	37	4	11
Mental Health Support	51	41	2	8
Supportiveness of Staff	46	13	2	31
Support/ Relationships with Other Patients	15	8		7
Financial Support	14	12		2
Patients with Additional Needs	14	10	1	3
General Support	12	7		5
Out of hours service	11	7	1	3
Home Life Support	7	7		
Availability of social worker	6	6		
Support Groups	5	4		1
Support from Kidney Associations	4	3		1
Non English Speaking Patients	3	3		
Support from family	3	1		2

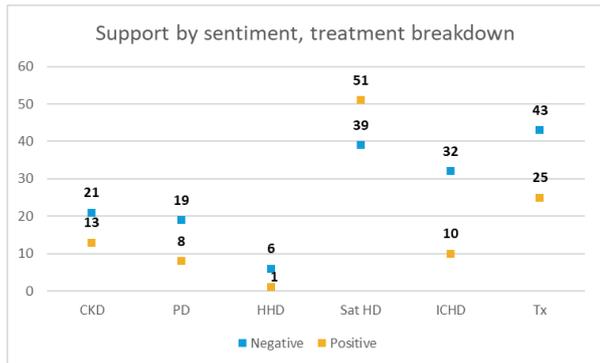
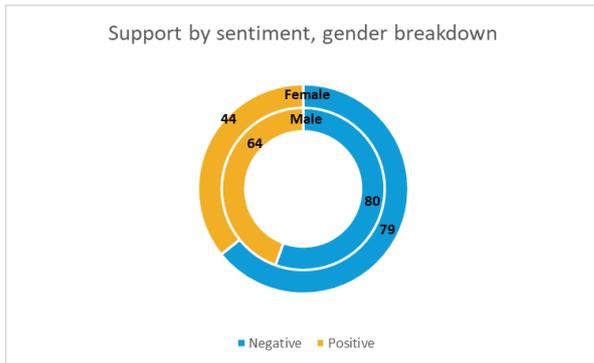
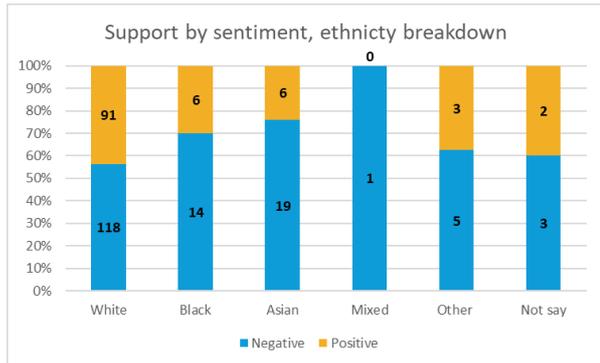
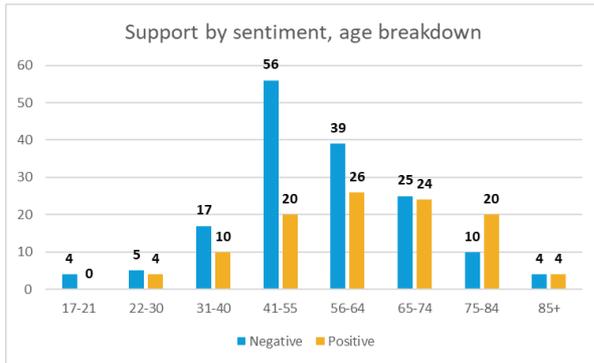


Support during COVID-19 received the most comments for this theme and received a higher number of positive comments than negative (64% vs 33%). This aspect of care discusses participants' reflections on how well the unit prepared them for the pandemic and the quality of support offered so that they could continue receiving their treatment.

Comments on how individuals' mental health had been impacted by their chronic kidney disease (CKD) diagnosis and their need for mental health support were also prominent. Respondents usually spoke about the increase in anxiety and depression they faced by having to receive constant treatment, and about how this, understandably, had increased during the pandemic. Respondents discussing mental health support asked for better availability of psychological provisions at the unit. Supportiveness of staff, though, was praised, receiving positive comments (67%) about the support offered when administering treatments.

Individuals who do not have English as a first language would like better support offered, such as the availability of a translator or staff who share their first language to help them in communicating.

The figures below show the respondent profile for responses within this theme. Individuals of all ages commented on this aspect of care, with a spike in the 41-55 years old group. Older individuals expressed a more positive experience.



Support during COVID-19

“I think all kidney patients should have been offered the spring booster Covid vaccine, but we were not” (CKD, White, Female, 56-64)

“I believe Covid treatment for CKD patients should be more accessible.” (CKD, Asian, Female, 31-40)

“Covid made health management very hard but I must say my clinics were brilliant and recovered really well they fixed things like waiting times and overcrowding at Clinic appointments. But I think they stopped hygiene and Covid measures too soon.” (Tx, Black, Female, 41-55)

Comments related to Mental Health

“Occasionally I suffer anxiety when on the machine” (ICHD, White, Male, 75-84)

“Nobody is bothered about our emotional anxieties & worries” (CKD, Asian, Female, 65-74)

“Doing HHD I feel very isolated from the renal department. With the recent cost of living increases I am questioning as to whether I can afford to carry on doing HHD.” (HHD, White, Male, 41-55)

Mental Health Support

“Where I feel the unit needs to improve is in emotional care and help with practicalities” (PD, White, Female, 56-64)

“I am not asked about my psychological problems, sometimes it might help to offload.” (Sat HD, White, Female, 41-55)

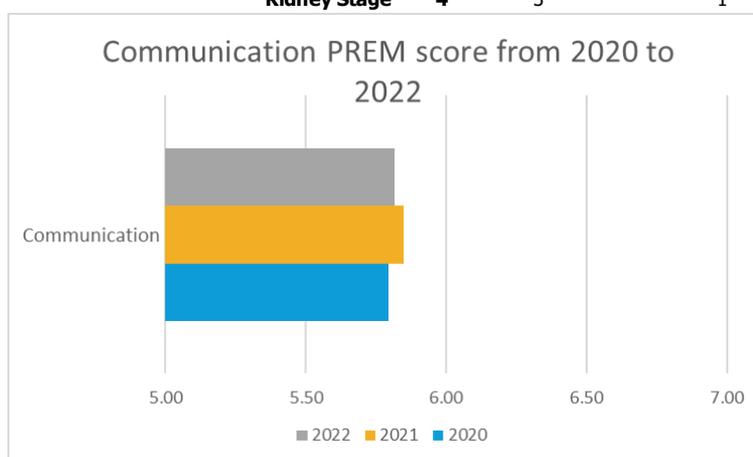
“Need to support patients emotionally, counsellors and social worker are NEVER seen or offered” (Tx, Black, Female, 41-55)

 <p>Supportiveness of Staff</p>	<p>“Thank you for all the support” (ICHD, Other, Female, 65-74)</p> <p>“The renal team have supported me excellently all the time I have been with them and increasingly during the last twelve months as my kidney care has become more developed due to worsening of my condition.” (CKD, White, Female, 85+)</p> <p>“I feel the staff is very supportive” (Sat HD, Asian, Male, 41-55)</p>
 <p>Financial Support</p>	<p>“Need to Promote what if any financial support is available especially for reimbursement to hospital appointments and for using machine at home” (PD, White, Male, 56-64)</p> <p>“Support from manager to access financial support” (Sat HD, White, Male, 75-84)</p>
 <p>General Support</p>	<p>“There should be more support given to kidney donors.” (CKD, Black, Female, 41-55)</p> <p>“No information provided regarding support etc.” (PD, Black, Female, 31-40)</p> <p>“Support always available.” (Sat HD, White, Female, 65-74)</p> <p>“I am very happy with the support I receive and the quality my treatment.” (CKD, White, Male, 65-74)</p>
 <p>TIME OUT</p> <p>Out of hours service</p>	<p>“Only problems if a renal patient become unwell no Dr on call so it could be very stressful for the patient and family.” (PD, Asian, Female, 75-84)</p> <p>“The out of hours service is non-existent & sometimes gives PD patients wrong/bad advice instead of contacting the on-call PD nurse” (PD, White, Male, 65-74)</p>
 <p>Home Life Support</p>	<p>“There is no support with things like dealing with need for suitable housing and reasonable adjustments at work.” (CKD, Mixed, Female, 41-55)</p> <p>“Factors such as home setting, interaction with supplier for home Haemodialysis, family support, personal resilience to hardship and isolation.” (HHD, White, Male, 56-64)</p> <p>“More advice for things like travel/life insurance and general life-based information that would benefit renal patients.” (Tx, White, Male, 41-55)</p>
 <p>Support Groups</p>	<p>“No information about any local support services or groups offered.” (CKD, White, Female, 56-64)</p> <p>“I’m not made aware of support groups that exist for my rare condition but have found many myself” (Tx, White, Male, 17-21)</p> <p>“Need to ensure that new patients know about Facebook groups - particularly pd one as nurse advice doesn’t come close to getting advice from people who are in the same position.” (PD, White, Female, 41-55)</p>

The theme **Communication** received 212 free text responses, of which 70% were negative and covered respondents' experiences of communicating with their kidney team and wider multi-disciplinary team, the perceived coordination between health services, and other areas of their care impacted by communication. The national Kidney PREM score for **Communication** has decreased slightly from 2021 but remains higher than in 2020.

Table 5: Breakdown of Communication codes by sentiment

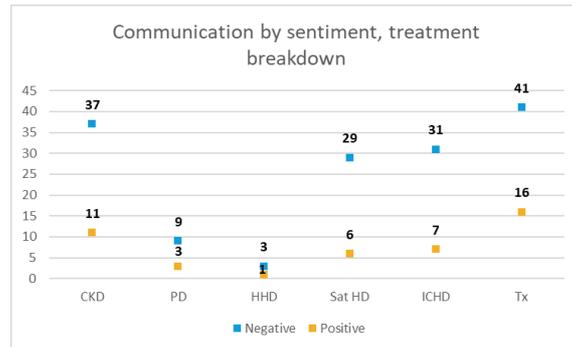
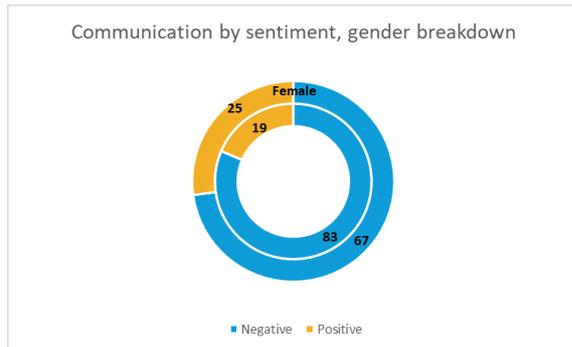
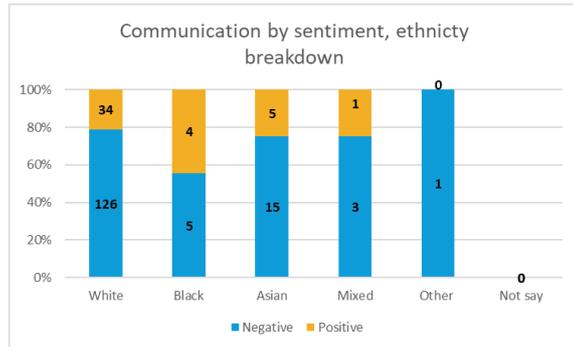
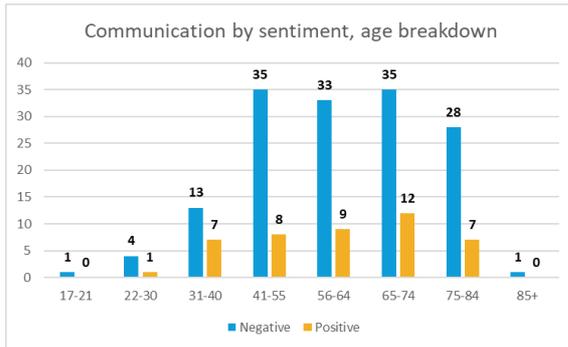
	Total (n)	Negative	Neutral	Positive
Communication from MDT	49	30	2	17
Patient Apps	37	25	2	10
Communication between the MDT	30	26		4
Communication between GP and unit	28	21	1	6
Staff Answering Patient Questions	28	16	3	9
Non English Speaking Staff	17	16		1
Coordination of results	9	9		
Patient meetings/ Review	9	8	1	
Patient New to Renal Care	9	1	8	
Communication from Transplant Team	6	4	1	1
Named Health Condition	6	4	1	1
Kidney Stage	4	3		1



Communication received from the multi-disciplinary team, (i.e., receiving communication regarding appointments, test results and the efficiency of these processes), received the most comments. This was closely followed by respondents' views on the usefulness of applications such as Patient View, Patient Knows Best and My Care. Communication between the MDT and between GP and unit discussed the perceived coordination of these teams, with respondents wanting more efficient and better communication, to ensure continuity of their care. This included coordination of results so that the same tests can be used by all departments.

The code patients new to renal care largely covers comments in which respondents explained they had only just begun KRT. Named health condition includes individuals discussing other conditions apart from CKD. Kidney stage includes comments relating to the stage of their CKD. These have been included under communication since it demonstrates that individuals had received communication on these issues from their kidney team.

The figures below show the respondent profile for this theme. Most responses come from older individuals, and those not yet receiving KRT or who have received a functioning transplant.



 <p>Communication from MDT</p>	<p>“I would also like to clarify my scores for communication - my immediate renal team communicate really well and have good systems in place.” (PD, White, Female, 31-40)</p> <p>“If they can have good communication that will help a lot of people.” (Sat HD, Asian, Female, 75-84)</p> <p>“Communication with Renal Transplant Office very poor since COVID.” (Tx, White, Female, 56-64)</p>
 <p>Patient Applications</p>	<p>“Patient view has not been working since March 2022, so viewing blood test results cannot be checked.” (ICHD, Asian, Female, 31-40)</p> <p>“Patient Knows Best is extremely difficult to use and understand. So not think I'm properly set up yet and I don't really know who to ask for help!” (CKD, White, Female, 56-64)</p> <p>“Unit stopped using Patient view to their detriment, new system poor.” (Tx, White, Female, 56-64)</p>
 <p>Communication between MDT</p>	<p>“It would be useful to link with kidney unit I am seen in outpatient’s department of the hospital” (CKD, White, Male, 56-64)</p> <p>“There appears to be a lack of communication from staff to patient in some areas of treatment. Also, between other departments within UNIT NAME itself.” (HHD, White, Female, 65-74)</p> <p>“Communication between different consultants is not typical.” (Sat HD, White, Female, 56-64)</p>

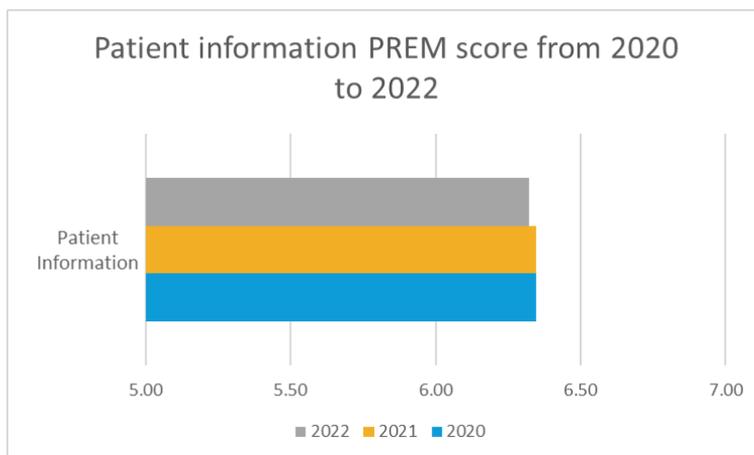
 <p>Communication between GP and MDT</p>	<p>“I chose 4 for communication between GP and Renal Team because my GP's communication is not good, not fault of Renal Team.” (ICHHD, Asian, Male, 75-84)</p> <p>“I feel that the Renal Unit and GP service are not sufficiently joined up and neither are the IT systems being used.” (CKD, White, Male, 65-74)</p> <p>“The results from my Kidney tests don't go to GP that quickly -and there is disconnect with the GP and renal about my condition.” (Tx, Asian, Male, 56-64)</p>
 <p>Staff Answering Patient Questions</p>	<p>“I don't feel I can ring them to ask questions or ask all of them during the appointment.” (CKD, White, Female, 22-30)</p> <p>“Trying to obtain advice and information from the team can be difficult from home, I have been unable to get through or nobody calls you back.” (Tx, White, Female, 31-40)</p>
 <p>Non-English-Speaking Staff</p>	<p>“Some staff are Filipino and speak to each other in front of patients in other languages which is unprofessional.” (ICHHD, White, Female, 41-55)</p> <p>“Difficulties due to language barrier.” (Sat HD, Asian, Female, 75-84)</p> <p>“Although some nurses try to explain some things, I do not always find it easy to understand their accents.” (Sat HD, White, Female, 65-74)</p>
 <p>Coordination of Results</p>	<p>“Ability to share results across hospitals and GP practice would be good.” (Tx, White, Female, 56-64)</p> <p>“Better connection between blood tests taken at GP versus during a hospital consultation. Records do not sync making it difficult to keep me informed of results.” (Tx, White, Male, 41-55)</p>
 <p>Patient Meetings/ Review</p>	<p>“Patient meetings would be beneficial, and Q&A sessions to discuss concerns etc.” (ICHHD, Black, Male, 41-55)</p> <p>“I have reviews where I am not invited to attend, and the results are not fed back to me.” (CKD, White, Female, 41-55)</p> <p>“Appear to be a lack communication or reporting between other departments. Comments made in letters not previously discussed at clinic.” (CKD, White, Male, 85+)</p>
 <p>Kidney Stage</p>	<p>“I'm at stage 4 with a rapidly declining eGFR of 22 and I have many of the symptoms, but it seems that the doctors and my GP constantly keep telling me that I shouldn't be having these symptoms at this stage. It's really frustrating.” (CKD, White, Male, 56-64)</p>

CHAPTER 5: PATIENT INFORMATION

The theme **Patient Information** received 87 comments (79% negative) and relates to respondents' experience about the quality, accuracy, and timeliness of the information they receive. The national Kidney PREM score for this theme has been quite consistent since 2020 though there has been a slight dip in 2022.

Table 6: Breakdown of Patient Information codes by sentiment

	Total (n)	Negative	Neutral	Positive
Information about treatment	49	39		10
Updates on kidney health	20	16	1	3
Transplant information	18	12	2	4
Information for Family	5	4		1



Information about treatment was the most commented on aspect of **Patient Information**, with respondents wanting more information about the treatment methods on offer, their side-effects and how it may affect their livelihood. Updates on kidney health has individuals wanting more frequent updates about their kidney decline either through reports, emails, telephone calls or appointments. Individuals waiting to receive a transplant have found a deficit in the information they have received. Some individuals would also like their families to receive information regarding their care.

Individuals of all ages and ethnicities responded under this theme; however there was a larger proportion of individuals who are not currently receiving KRT who responded.

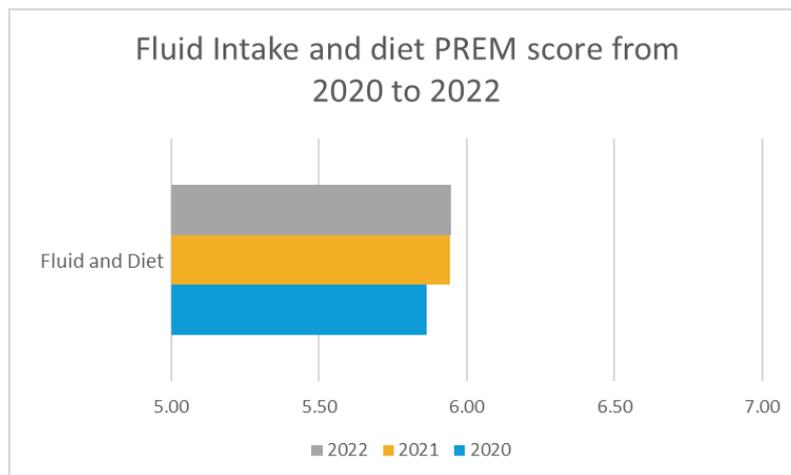
	<p>Patient Information</p>	<p>“Would like more consistent interaction with named doctor and clear concise information and not jargon.” (ICH, White, Male, 75-84)</p> <p>“Would prefer more concise information when going through options for dialysis.” (PD, White, Female, 41-55)</p> <p>“Improve the follow up and consultant instructions.” (CKD, Other, Male, 65-74)</p>
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CHAPTER 6: FLUID INTAKE AND DIET

Fluid Intake and Diet received 53 comments (81% negative), with its national Kidney PREM score remaining consistent from 2021, which is an increase from 2020.

Table 7: Breakdown of Fluid Intake and Diet codes by sentiment

	Total (n)	Negative	Neutral	Positive
Diet	23	19		4
Availability of dietician	15	14		1
Fluid	11	7	1	3
Weight management	8	7		1



Diet received the most comments and includes respondents wanting more information about the diet needed to prevent problems due to lack of function. This is followed by the availability of a dietician, with individuals wanting more regular consultations with a dietician to discuss their diet, weight management and fluid intake. Fluid, similarly, discusses respondents' needs to have more advice regarding their fluid intake and weight management, especially patients struggling to lose weight.

Individuals who commented on **Fluid Intake and Diet** were mostly aged 41-64 years old, not yet receiving KRT. Individuals who identified as female responded more positively to this theme than those who identify as male and there is an underrepresentation of individuals with a Black ethnic heritage.

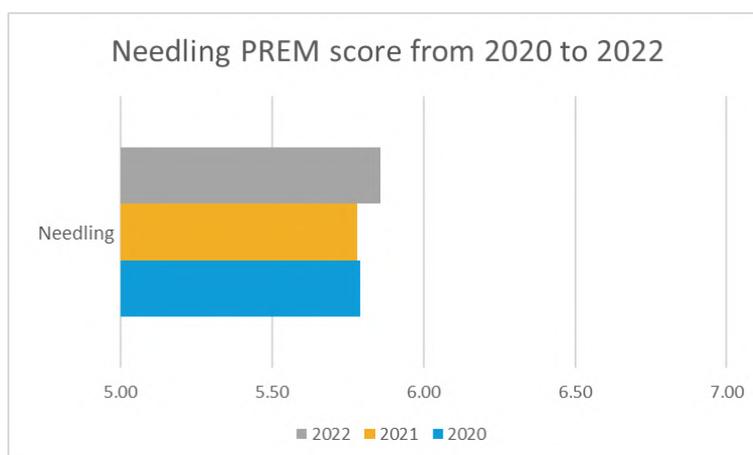
	<p>Fluid Intake and Diet</p>	<p>“Support from a dietician for suitable foods to have/avoid to help kidneys.” (CKD, Asian, Female, 65-74)</p> <p>“Had to wait 5 months before seeing the renal dietician.” (ICHD, White, Female, 41-55)</p> <p>“Too much fluid was being taken, and I kept fainting. Even after the consultant said to take less, the following appointment the nurse said to take more. This went on for a few weeks adding to my stress. I fainted in the ward a few times and in the ambulance.” (PD, White, Male, 41-55)</p>
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CHAPTER 7: NEEDLING

Needling received 14 comments (71% negative). The national Kidney PREM asks those who receive their dialysis in-centre or in a satellite unit about their experience of being needled. The Kidney PREM score for this theme has increased since 2021, suggesting that improvements have been seen in this aspect of care, perhaps accounting for the decrease in volume of comments.

Table 8: Breakdown of *Needling* codes by sentiment

	Total (n)	Negative	Neutral	Positive
Issues with fistula	8	5	2	1
Being needled	6	5		1



Issues with fistulae was the most commented on aspect, with respondents discussing negative and painful experiences with their fistula. The sentiment was predominantly negative with respondents finding it painful and, in some cases, thought staff to be inexperienced and rushed which created more pain.

Those who responded under this theme were aged 41-84 years old, receiving haemodialysis in-centre or at a satellite unit and were from a White or Asian ethnic heritage.

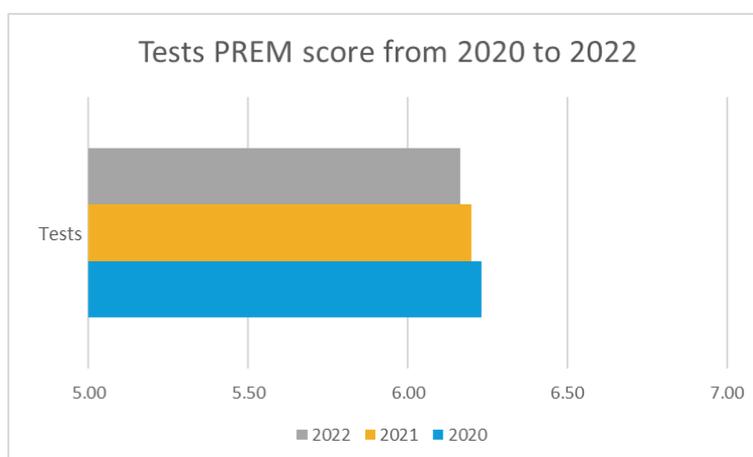
	<p>“Unnecessary fistula surgery which has caused endless problems and ultimately failed when I had a working tunnel line.” (Sat HD, White, Female, 41-55)</p> <p>“For instance same hole needle is not good for me and post dialysis bleeding so I had to insist that they kept the ladder needling with my fistula.” (ICHHD, White, Female, 56-64)</p>
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CHAPTER 8: TESTS

The theme **Tests** received 57 comments (82% negative), and over the last 3 years the national Kidney PREM score for this theme has decreased gradually. This theme concerns blood tests, with some comments relating to other tests, such as urine samples.

Table 9: Breakdown of Tests codes by sentiment

	Total (n)	Negative	Neutral	Positive
Blood Test Results	21	15	1	5
Tests - Other	17	13	1	3
Receiving test results	8	8		
Understanding Test Results	5	5		
Paper-based Test Results	4	4		
Test Results - Other	2	2		



Blood test results received the highest number of comments under this theme. Comments relate to the timeliness of receiving blood test results. Tests-other refers to respondents' experiences when having other types of tests, with many individuals wanting more tests to monitor kidney health (e.g., urine tests) to be offered. Receiving test results refers to comments about whether results are sent routinely, with respondents also mentioning the need for results to be better explained. Some individuals also requested their test results to be sent to them in paper-based format so that they have them to keep.

Most respondents who responded under this theme were aged 41 to 74 years old. Those with functioning transplants or who those who had not yet begun KRT were well represented.

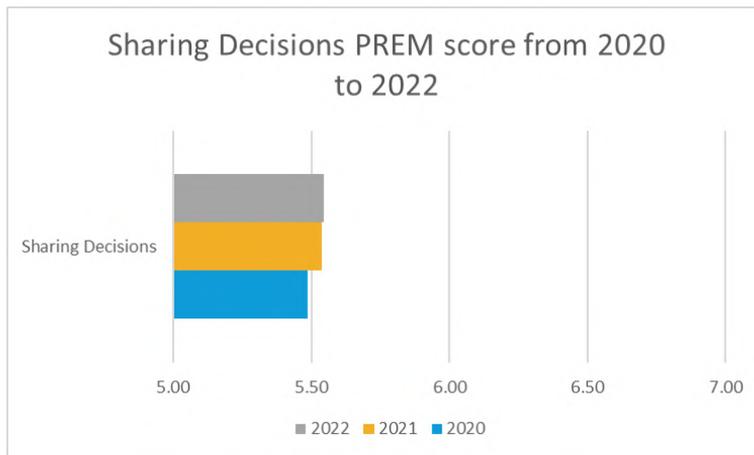
 <p>Tests</p>	<p>“Access to results of monthly blood tests not provided despite frequent requests.” (IChD, Black, Male, 65-74)</p> <p>“I never get feedback on blood results of KT/V. I keep having these things, but it feels like it's a box ticking exercise for the nurses rather than something that benefits me.” (PD, White, Male, 56-64)</p> <p>“More feedback on monthly blood results.” (Sat HD, White, Female, 85+)</p>
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CHAPTER 9: SHARING DECISIONS

Sharing Decisions received 44 comments and includes comments on respondents' experiences of being involved with decisions within their care. Though overall Kidney PREM scores were low, there has been a slight improvement since 2020, perhaps reflecting some resolution of COVID-19 related issues.

Table 10: Breakdown of Sharing Decisions codes by sentiment

	Total (n)	Negative	Neutral	Positive
Shared Decisions Comments	14	9	1	4



Those who have had a positive experience of **Sharing Decisions** gave examples of how consultants and other members of the MDT had involved them in discussions about their care, clearly explaining each process so that they could help to manage the future of their care.

Some individuals, whose responses were negative, stated a need for more control within their care and for consultants to listen to them more to allow them to contribute.

Responses to this theme were most likely to come from individuals aged 41-64 years old, of White ethnic heritage, and those with functioning transplants or not yet receiving KRT.

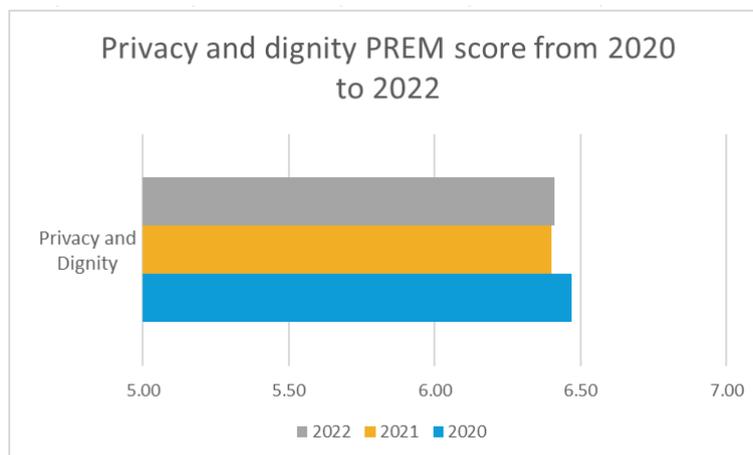
	<p>“Would love to know my personal plan but nobody around to discuss.” (ICHD, White, Female, 31-40)</p> <p>“My plans for the future are ignored even though they are time sensitive.” (CKD, Mixed, Female, 41-55)</p>
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CHAPTER 10: PRIVACY AND DIGNITY

The theme **Privacy and Dignity** received 14 comments of which 86% were negative. The national Kidney PREM score is unchanged since 2021 though lower than in 2020.

Table 11: Breakdown of *Privacy and Dignity* codes by sentiment

	Total (n)	Negative	Neutral	Positive
Privacy in the unit	14	12		2



This theme includes comments from respondents regarding whether they felt their **Privacy and Dignity** were maintained whilst attending the unit. Respondents commented on consultants discussing their care in front of other individuals, and on the lack of privacy when being weighed.

Responses were uniform across demographic and modality groups.

	<p>Privacy and Dignity</p>	<p>“I felt there was no dignity with my urine sample (same staff talking about who was having a break) as a gentleman came into the same room the sample was being held in mid-air and tested when a bit more privacy could have been used” (CKD, White, Female, 31-40)</p> <p>“No privacy when staff or doctor discusses you case while in the unit.” (Sat HD, White, Male, 75-84)</p>
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CHAPTER 11: SCHEDULING AND PLANNING



Telephone appointment



Video consultation



Waiting time at the unit



Blood test scheduling



Face-to-face appointment

Scheduling and Planning



Availability of appointment



Organisation within the unit



Appointments being moved/
cancelled

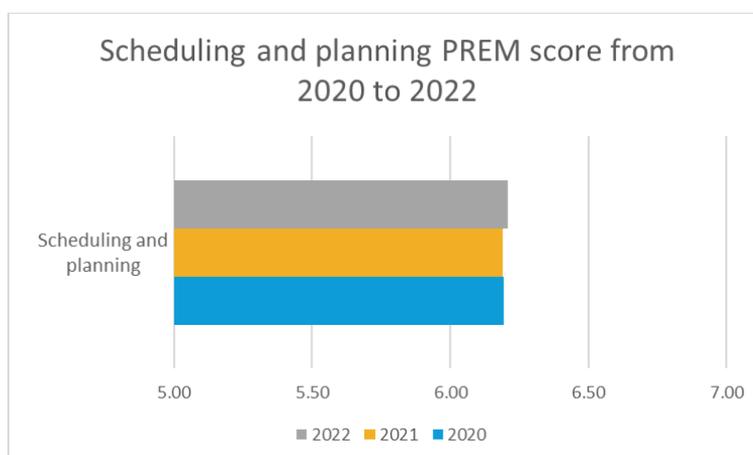


Dialysis time of day

Scheduling and Planning was the third most commented on theme with 330 comments, 72% of which were negative. The national Kidney PREM score for this theme has been consistent over the last 3 years, with a slight increase in 2022. As a theme, **Scheduling and Planning** covers participant experiences of waiting times, appointment methods, appointment planning and holiday dialysis.

Table 12: Breakdown of Scheduling and Planning codes by sentiment

	Total (n)	Negative	Neutral	Positive
Waiting time at the unit	94	77	2	15
Telephone Appointment	69	40	8	21
Blood Test Scheduling	41	31	2	8
Face-to-face appointments	31	16	2	13
Organisation within the unit	27	16	2	9
Availability of appointment	25	21	1	3
Dialysis time of day	24	19		5
Appointment Scheduling	22	17	2	3
Holiday Dialysis	20	18		2
Appointments being moved/ cancelled	14	13		1
Video consultations	13	5		8
Waiting for blood tests	11	10		1

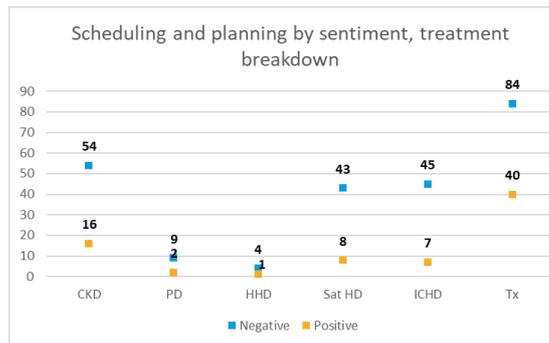
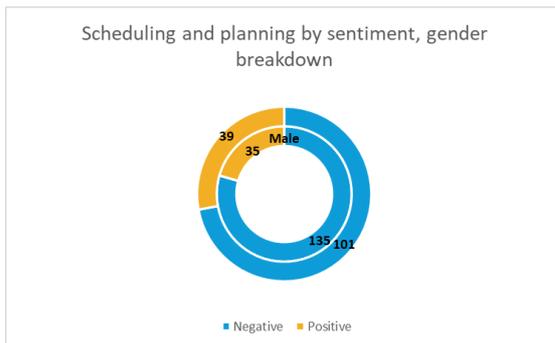
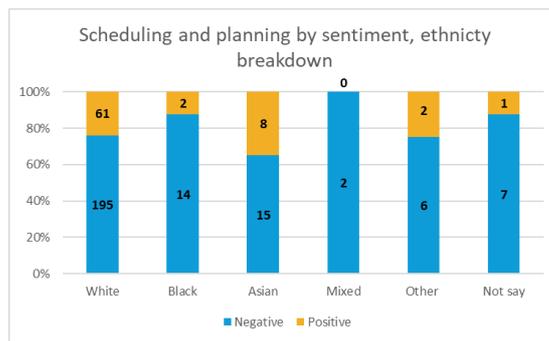
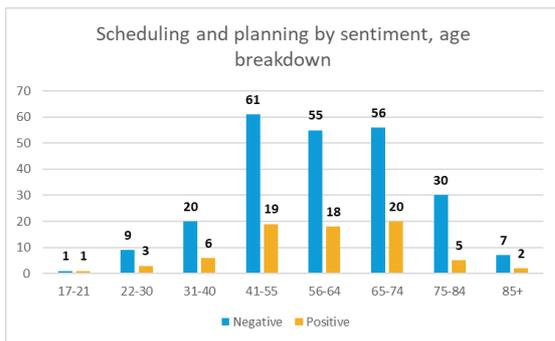


Waiting time at the unit received the most comments, which were mostly negative (82%). Respondents found the wait for appointments and receiving treatment at the unit too long. There were some positive comments from those who felt the wait times were shorter than in previous years.

Since the beginning of the pandemic in 2020, kidney appointments have been offered remotely via telephone or video consultation, as well as face-to face. Opinions are mixed on the success of remote consultations compared to in-person check-ups. Most commonly respondents found telephone/ video consultants more efficient and convenient, but now the pandemic is perceived to be no longer the threat it was, they would prefer to attend face-to-face appointments, to receive what is regarded as a fuller examination.

Other aspects of **Scheduling and Planning** related to the time-of-day participants were assigned to receive dialysis, organisation within the unit and holiday dialysis. These comments typically provided suggestions for improvement, with respondents wanting to be able to pick the time of day they receive dialysis treatment, for those who receive a longer duration of dialysis to be placed before those with shorter durations, and to have more flexibility to receive dialysis at other units for short breaks.

The figures below show the respondent profile for this theme. Responses were representative of all participant groups, with a spike in the responses from those with a functioning transplant.



Waiting time at the unit

“Takes too long to be put on, spend a lot of time waiting.” (ICHD, White, Female, 41-55)

“So useless! I waited 2 hours before going and asking why there was a waiting room full of people and no one being called.” (CKD, White, Female, 41-55)

“As a transplant patient I’ve waited 3 hours in a waiting area for a 2 min meeting.” (Tx, Asian, Male, 41-55)



Telephone Appointment

“Never see any doctors in the renal unit unless a patient has a serious condition. Appointments with consultant are only via telephone. A feeling that consultants don’t take patient concerns too seriously due to patient’s old age.” (ICHD, Not Say, Male, 75-84)

“There is no clear schedule that I know of in LOCATION and I also feel that the consultant's feel that a telephone call is sufficient and face-to-face is not really that necessary.” (Sat HD, Asian, Male, 56-64)

“Outpatient appointments are by phone which is optional and suits me best.” (Tx, White, Female, 65-74)



Blood Test Scheduling

“I would prefer blood tests to be done before my appointment and be available so that we can have a definitive discussion about all factors of my condition. I feel it is not efficient or the best use of time having doctors’ appointments on the same day.” (CKD, White, Male, 65-74)

“Sometimes have to go to UNIT NAME for just 1 thing so will be there for about 5 mins and to me is a waste of a day and money would be better doing more tests at same time.” (Tx, White, Male, 56-64)

 <p>Face-to-face Appointments</p>	<p>“I have face to face and telephone consultations, and they are both very effective.” (CKD, White, Male, 65-74)</p> <p>“I have not seen doctors face to face and my appointments always gets cancelled. Not happy.” (Sat HD, Asian, Male, 41-55)</p> <p>“It is great to be back to face-to-face appointments now that Covid-19 restrictions are being reduced.” (Tx, White, Male, 65-74)</p>
 <p>Organisation within the Unit</p>	<p>“Waiting times to get in could be better, organisation for people on longer hours should be allowed in first!!!!!!” (ICHD, White, Male, 56-64)</p> <p>“I am overwhelmed at how well my care is organised and provided.” (PD, White, Female, 75-84)</p> <p>“Booking in, is done twice I find inappropriate.” (Tx, White, Female, 65-74)</p>
 <p>Availability of Appointments</p>	<p>“No flexibility in changing time slots.” (ICHD, White, Female, 41-55)</p> <p>“Not been into clinic for 3 years.” (Tx, White, Male, 56-64)</p> <p>“It felt haphazard, fitting around the nurse’s availability.” (PD, White, Male, 41-55)</p> <p>“I seem to have lost contact with the team and have received no more appointments for a year on spite of my trying to contact them.” (CKD, White, Male)</p>
 <p>Dialysis time of day</p>	<p>“More dialysis slots to provide more choice.” (ICHD, White, Male, 41-55)</p> <p>“Appointments being made early in the morning and later afternoons. Pensioners like me should have appointments between ten and four.” (PD, White, Male, 75-84)</p> <p>“As a new patient I was given no choice in times. Although I have swapped days to fit my schedule.” (Sat HD, White, Male, 56-64)</p>
 <p>Appointments being moved/ cancelled</p>	<p>“There has been some confusion with appointments being moved last minute resulting in the need to communicate directly with the Consultant as the Admin Team weren't responsive.” (CKD, White, Male, 41-55)</p> <p>“Appointment keep getting moved, which is frustrating when working.” (Tx, White, Male, 31-40)</p> <p>“Patient unhappy with the change of appointment times.” (CKD, Other, Male, 65-74)</p> <p>“Had my appointment for next year changed twice already.” (CKD, White, Male, 41-55)</p>
 <p>Video Consultation</p>	<p>“Sending teams link to patient meeting without asking me for permission with no idea what the meeting would be about.” (CKD, Black, Female, 56-64)</p> <p>“I don't like video appointments, there is no care in them. Especially if the patient with low eGFR.” (CKD, Other, Female, 56-64)</p> <p>“Only done video appts since Covid which is far more convenient for me.” (Tx, White, Female, 41-55)</p>

CHAPTER 12: HOW THE RENAL TEAM TREATS YOU



NHS Sufficiency



Primary Care



Consultant



Renal team generic comments

How the Renal Team Treats You



Management



Quality of care received



Treatment feeling rushed



Nurses

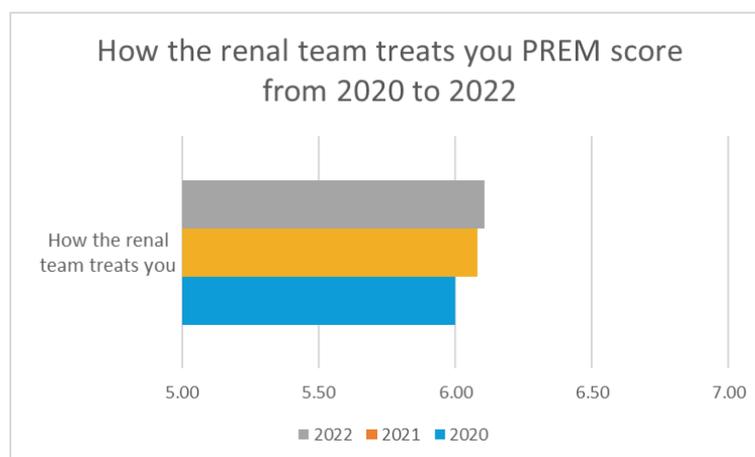


Staff training/ competency

How the Renal Team Treats You, received the most comments (1,136 comments). The majority of comments in this theme are positive (65%), with most comments thanking staff for all their care and commitment. From 2020 there has been a gradual increase in the national Kidney PREM score.

Table 13: Breakdown of How the Renal Team Treats You, codes by sentiment

	Total (n)	Negative	Neutral	Positive
Renal Team Generic Comments	458	118	10	330
Quality of Care Received	400	98	15	287
Nurses	183	73	8	102
Consultants	151	63	7	81
Primary Care	40	28	1	11
Staff training/ competency	39	32	1	6
Management	23	12	1	10
Transplant team	21	8		13
Treatment feeling rushed	19	15		4
NHS sufficiency	18	12	2	4
Negligence	5	5		

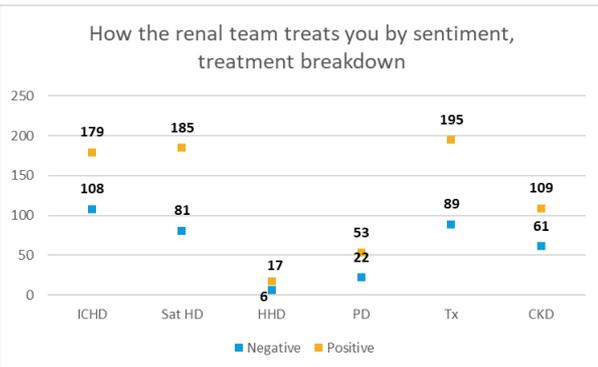
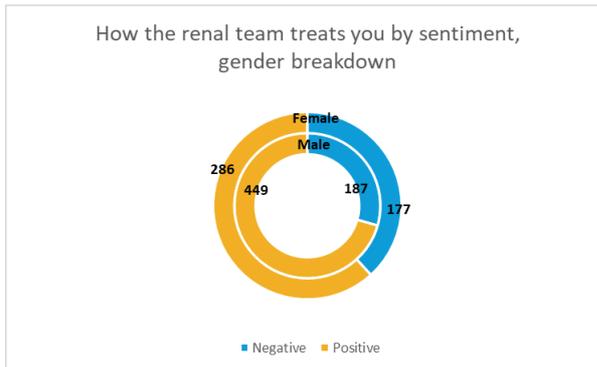
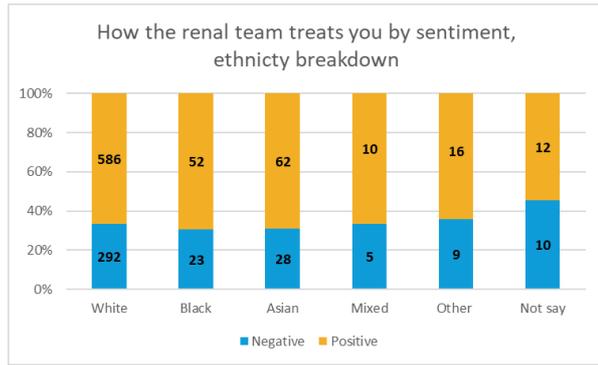
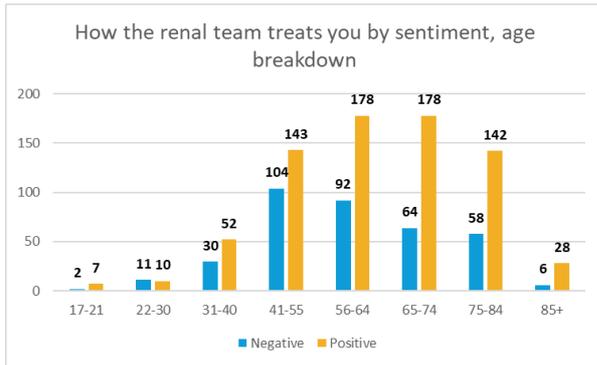


The largest group of comments related to the generic renal team, giving general thanks to the whole kidney multi-disciplinary team and for the quality of care received. Many comments gave examples of the way staff have conducted themselves when treating individuals.

Specific staff roles were also mentioned, with nurses, consultants and the transplant team being mentioned. Negative comments under these codes contain experiences where the staff in the mentioned roles had lacked empathy and understanding. Primary care received 70% negative comments, with respondents finding their GP lacked kidney knowledge and empathy, and for care to be below standard.

Staff training and competency received 39 comments, mostly negative, with respondents feeling some members of staff had not received the required training to administer the treatment, with a lack of knowledge about the dialysis machine being the most prominent. Comments on NHS sufficiency related to the lack of funding for the NHS which has led to a decrease in the standards of service offered.

The figures below show the respondent profile under this theme, which appears consistent with the UK Renal Registry data.



 <p>Renal Team Generic Comments</p>	<p>“The staff are very good at the renal unit all make you feel comfortable.” (ICHD, White, Female, 65-74)</p> <p>“Very happy with the staff at NAME unit. They are brilliant! I would recommend home dialysis as I feel my overall health both mentally and physically has improved since being at home. Previously in a huge unit in LOCATION which felt like a factory, horrible experience.” (HHD, Black, Female, 56-64)</p> <p>“Staff in renal team are amazing.” (Tx, Not Say, Male, 41-55)</p>
 <p>Quality of Care Received</p>	<p>“I am happy with the care I receive from UNIT NAME.” (PD, Black, Male, 56-64)</p> <p>“My care has been brilliant can do enough for me.” (HHD, White, Female, 56-64)</p> <p>“I am entirely happy with my kidney care so far.” (CKD, White, Male, 75-84)</p> <p>“Only to say I am satisfied with service.” (ICHD, Asian, Male, 41-55)</p> <p>“I cannot fault the renal team at UNIT NAME in any way. The treatment I receive is superb. Nothing is too much trouble for the staff, and the consultants are caring and always happy to go into any detail of my care I wish to be informed about. Big Up to them all!” (CKD, White, Male, 75-84)</p>
 <p>Nurses</p>	<p>“Dialysis nurses are excellent.” (ICHD, Black, Male, 65-74)</p> <p>“NAME renal unit, specialist nurses and consultants have looked after me for the last 21 years. The treatment has been exemplary. They have advised, listened and I feel cared about my treatment. Thank you, UNIT NAME!” (CKD, White, Female, 41-55)</p>

	<p>“The PD nurses are wonderful, do a great job and couldn’t praise them highly enough.” (PD, Mixed, Female, 41-55)</p>
 <p>Consultant</p>	<p>“I have 100% respect for my consultant & will always take his advice. He listens to me and treats me as an individual.” (Sat HD, White, Female, 41-55)</p> <p>“My consultant is great, takes me seriously and works with me.” (ICHD, White, Male, 17-21)</p> <p>“My consultant is one of the best I have ever seen, and I have seen many over the years. She is professional, informative, helpful, very knowledgeable, kind, patient and generally lovely.” (CKD, White, Female, 65-74)</p>
 <p>Primary Care</p>	<p>“I do not always get the follow up by my local doctor regarding suggested changes to my prescription by my renal consultant.” (CKD, White, Male, 85+)</p> <p>“GP service has become very poor (been at same surgery 30+ years & was good) that go directly to renal team for assistance & ignore GP.” (Tx, White, Male, 56-64)</p>
 <p>Staff training/ competency</p>	<p>“I think more people need to be trained to put on and take off people with Central Lines as not many nurses can do it.” (Sat HD, White, Male, 31-40)</p> <p>“Nurses on Ward are mostly agency and not experienced in renal or diabetes. Most of experienced nurses have left.” (Tx, White, Female, 56-64)</p> <p>“New staff are prone to not listening to their patients, they often think they know best.” (Sat HD, White, Male, 41-55)</p>
 <p>Management</p>	<p>“The service has improved over the last 3 years due to the management and staff listening to the patient’s needs.” (ICHD, White, Male, 65-74)</p> <p>“Cost cutting changes from the new company running the department are making the experience for the patients and the nurses worse.” (Sat HD, White, Male, 22-30)</p> <p>“But not management as they are very unprofessional.” (Sat HD, Asian, Male, 41-55)</p>
 <p>Treatment feeling rushed</p>	<p>“But always short staffed and under pressure to provide treatment in time, always rushing around, affecting their ability to take notes and follow up actions, often need chasing/ reminding.” (ICHD, Asian, Female, 75-84)</p> <p>“Appointments rushed, doctor no longer bothers taking blood pressure reading, always students sitting in so I cannot express the reality of how I am.” (CKD, Other, Female, 65-74)</p>
 <p>NHS Sufficiency</p>	<p>“I think there are financial issues, as we often run out of different items of stock, and a lot of the lifts don't work even though the hospital is just 13 years old.” (ICHD, Asian, Female, 56-64)</p> <p>“The time in hospital was such a waste of resources for NHS and needs addressing.” (Sat HD, White, Female, 65-74)</p> <p>“Under pressure and very much underfunded NHS.” (Tx, White, Male, 41-55)</p>

CHAPTER 13: TRANSPORT



Ambulance



Timeliness of transport Journey



General Comments on Transport

Transport



Timeliness of transport Post Treatment



Safety of drivers

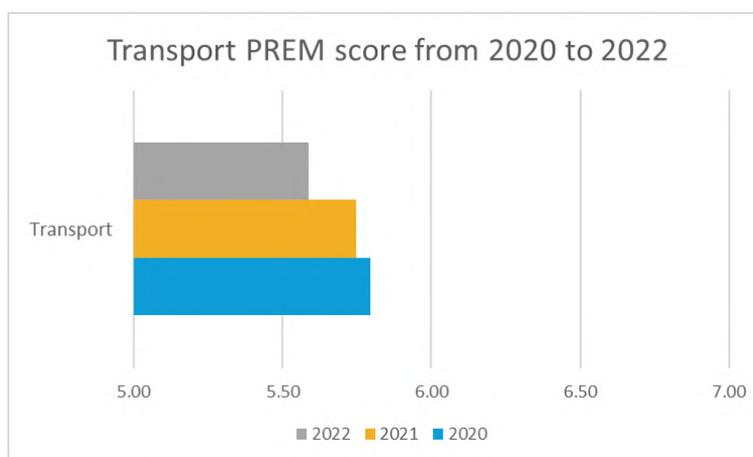


Timeliness of transport Pre Treatment

The theme **Transport** received 252 comments, of which 85% were negative. **Transport** is offered to individuals receiving haemodialysis in-centre or at a satellite unit. Comments related to the timeliness of transport pre- and post-treatment, as well as the length of time taken for the journey. The overall score for transport has decreased from 2020, in which year transport was at all all-time high, due to many individuals having organised their own transport.

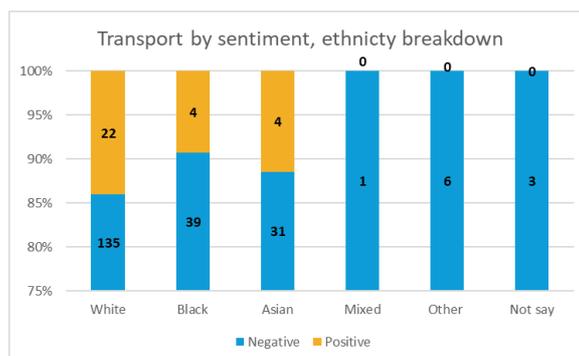
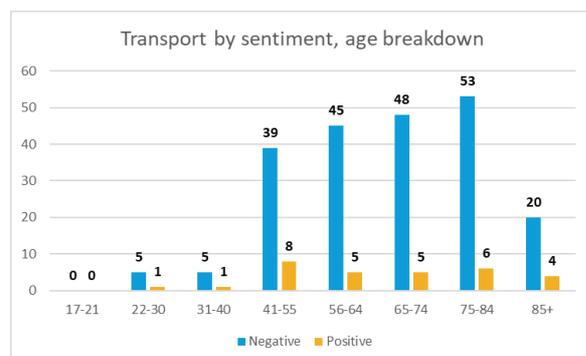
Table 14: Breakdown of Transport codes by sentiment

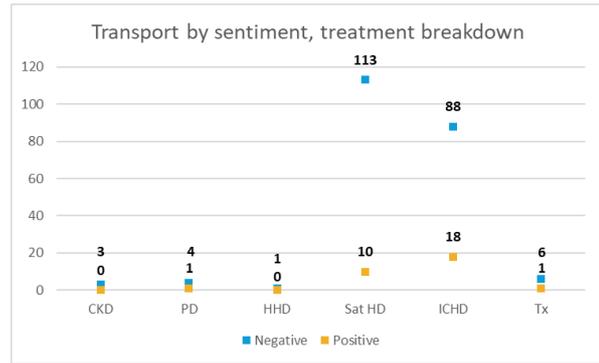
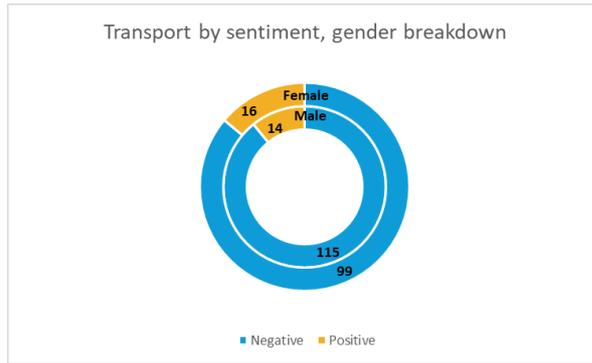
	Total (n)	Negative	Neutral	Positive
General comments on Transport	119	97	5	17
Timeliness of Transport Post Treatment	96	82	1	13
Timeliness of Transport Pre Treatment	27	25		2
Timeliness of Transport Journey	26	22	1	3
Ambulance	8	8		
Safety of Drivers	4	3		1
Communication about transport	2	2		



Most respondents who commented on the timeliness of the transport, either pre- or post-dialysis treatment, reported a negative experience and wanted shorter wait times and more direct routes home. General comments on transport relate to comments which mention suggestions to improve transport. Communication from transport team, on driver safety, and on ambulances received fewer comments but were mostly negative, with respondents wanting more efficient communication with drivers, more comfortable chairs in the ambulance and drivers to be more safety conscious.

The figures below show the profile for responses under the theme **Transport**. Majority of comments came from individuals aged 41-84 years old, receiving haemodialysis in-centre and in satellite.





 <p>General comments on transport</p>	<p>“My only complaint is with the transport system.” (ICHD, Asian, Male, 85+)</p> <p>“It is not the best location for me to get to and costs me £60 for taxi every visit.” (CKD, White, Male, 65-74)</p> <p>“Transport arrangements can be a major problem.” (Sat HD, White, Male, 75-84)</p> <p>“Parking/travel costs are quite high as I have attended quite a lot of appointments” (Tx, White, Male, 56-64)</p>
 <p>Timeliness of transport post treatment</p>	<p>“When you advise them you have been waiting too long, and they chase up transport, they don't give you an update on how long you could be waiting, you have to ask them again.” (ICHD, White, Male, 41-55)</p> <p>“I would say the waiting time for transport make me feel very tired and frustrated.” (PD, Black, Female, 85+)</p> <p>“I have to travel for over 2 hours there and back. The waiting around for hours adds to the fact it takes almost one whole day travelling.” (Tx, White, Male, 22-30)</p>
 <p>Timeliness of transport pre treatment</p>	<p>“Problems with transport picking me up in the morning for 7.30 am arrival at hospital. Majority of the time they are late.” (ICHD, Asian, Female, 31-40)</p> <p>“Patient transport often late and I have to get cab.” (ICHD, Black, Male, 41-55)</p> <p>“I happy with the care but I am picked one hour early for the treatment.” (Sat HD, Asian, Male, 56-64)</p>
 <p>Timeliness of Transport Journey</p>	<p>“Journey from home to hospital takes 1.5 to 2 hours. So overall it's a very long day for me. This is very exhausting.” (ICHD, Asian, Male, 85+)</p> <p>“Also, transport is terrible, so inconsistent, sometimes takes 30 mins sometimes 3 hours.” (Sat HD, Black, Male, 56-64)</p> <p>“I live 30 miles from LOCATION and it can take 1-2 hrs travel time if driving and longer if using public transport for a 10 min appointment, a unit in LOCATION would help.” (CKD, White, Male, 56-64)</p>
	<p>“The ambulance should be control better especially after the dialysis. The waiting time ambulance should be improved.” (ICHD, White, Female, 65-74)</p>

 <p>Ambulance</p>	<p>“Ambulance to leave centre waiting time is too long, sometimes 2 or 3 hours.” (Sat HD, Black, Female, 75-84)</p> <p>“Passenger transport control is not fit for service, and the ambulance drivers' cherry-picking culture need to be addressed.” (Sat HD, White, Male, 65-74)</p>
 <p>Safety of Drivers</p>	<p>“I am also happy with the drivers that collect me for my treatment (the NAME drivers). Even though they were sometimes late they are all kind. They often help me with my coat and sometimes my shoes and socks. They take good care of me, and they also make me feel safe.” (ICHD, Black, Female, 85+)</p> <p>“Transport driver drive [sic] very fast and made me pain...” (Sat HD, White, Female, 65-74)</p>

CHAPTER 14: ENVIRONMENT



Waiting Area - Space



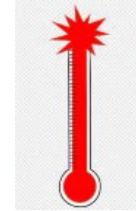
Temperature - Cold



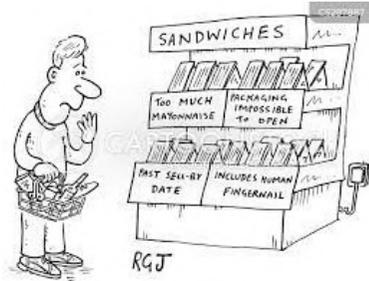
Noise



Parking



Temperature - Hot



Food Available



TV

Environment



Accessibility



Chair - Comfortable



Insufficient Toilet Facilities



Décor of the Unit

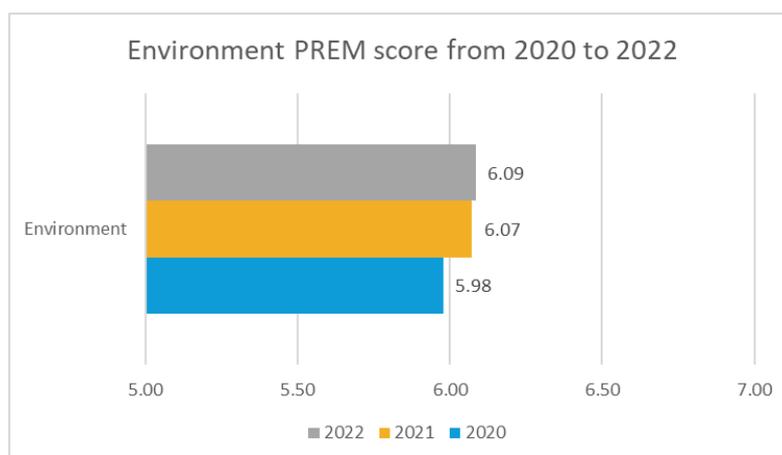


Drinks at the Unit

The theme **Environment** received the second largest number of comments. Responses discussed the facilities of the kidney unit, parking, and availability of supplies. The majority of responses were negative (81%), with comments giving suggestions for improvements such as increasing the ambient temperature of the unit. Across the last 3 years, the national Kidney PREM score for **Environment** has increased.

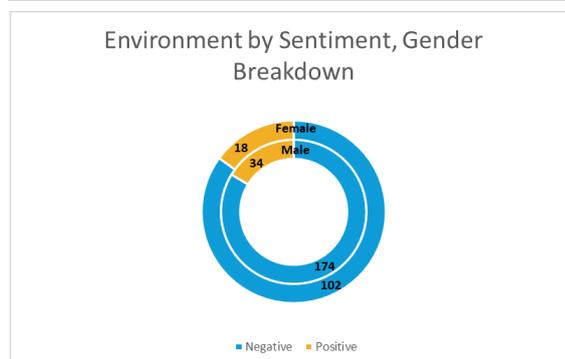
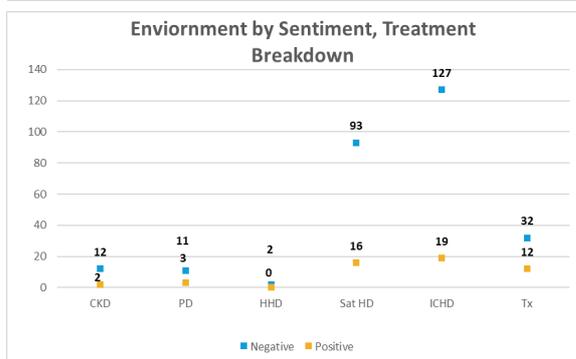
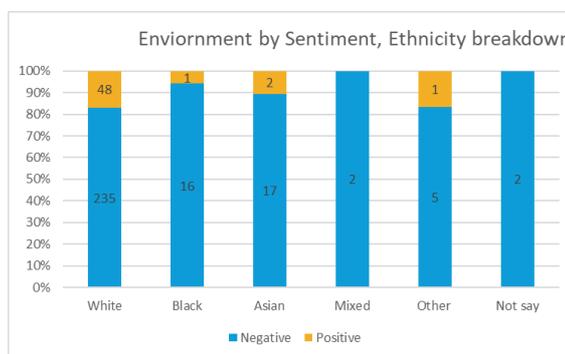
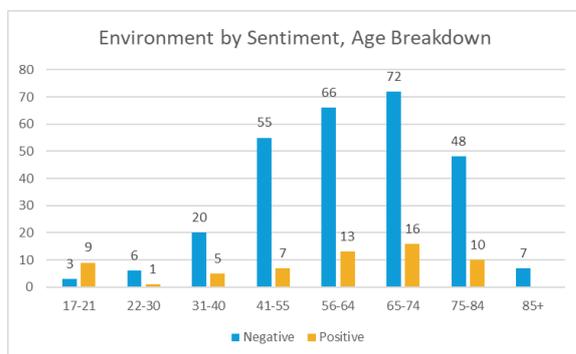
Table 15: Breakdown of Environment codes by sentiment

	Total (n)	Negative	Neutral	Positive
Parking	62	52	2	8
Temperature - cold	53	46	1	6
Food Availability	46	33	2	11
Chairs - Comfortable	43	37	1	5
Accessing the unit	31	25		6
Decor of the Unit	24	15	1	8
TV	22	19		3
Noise	21	18		3
Cleanliness	19	12	1	6
Waiting Area - Space	16	13		3
Insufficient Toilet Facilities	12	10		2
Availability of Chairs	11	11		
Drinks at the unit	11	5	1	5
Dialysis Machines	10	8		2
Beds - Comfortable	9	9		
General Comfort	9	5	1	3
Waiting Outside for Appointment	7	7		
WIFI	7	7		
Patient Activities to do	6	5		1
Disabled Parking	5	5		
Lighting	5	4		1
Pharmacy waiting times	5	4		1
Temperature - Hot	4	4		
Availability of blankets	3	3		



Parking received the highest number of comments with issues focusing on the availability of parking spaces and the cost of parking when attending the unit for treatment. The temperature of the unit also received many comments, with most respondents feeling the unit was too cold, and a small number finding it too hot. A re-occurring issue since the pandemic was the lack of food made available to those during dialysis and the variety of the food offered. Smaller issues but with potentially large impacts on experience of care were the availability of blankets within the unit, and activities for patients undergoing dialysis.

The figures below show the profile of respondents who were more likely to comment on this aspect of their care. Not surprisingly, those receiving haemodialysis in-centre or at a satellite unit were the main responders. Interestingly, those aged 17-21 years old spoke about the **environment** more positively than negatively.



 <p>Parking</p>	<p>“To have free parking for patients that drive in LOCATION satellite” (Sat HD, Black, Female, 56-64)</p> <p>“Parking is the main issue, not enough spaces for patients with parking permits.” (ICHD, White, Female, 65-74)</p> <p>“Parking fees for attending clinics etc work out to be expensive especially if going to unit twice a week.” (PD, White, Male, 56-64)</p>
 <p>Temperature - Cold</p>	<p>“Most of the time the staff insist that the air conditioning is on whatever the weather, but I get so cold and shivering that I go home feeling unwell.” (ICHD, White, Female, 75-84)</p> <p>“The air conditioning unit is far too cold and some nurses who are fully clothed want it as cold as possible, while we patients are semi-clad and shivering.” (PD, White, Male, 75-84)</p> <p>“The temperature of the unit is uncomfortable during the dialysis (cold) and we are not provided with blankets.” (Sat HD, White, Male, 75-84)</p>
 <p>Food Availability</p>	<p>“I wouldn’t mind having sandwiches rather than biscuits.” (ICHD, White, Male, 65-74)</p> <p>“Additional sandwiches would be nice.” (PD, Other, Female, 65-74)</p> <p>“Sometimes we have to wait over three hours to get a cup of tea.” (Sat HD, White, Female, 56-64)</p>

 <p>Chair – Comfortable</p>	<p>“Strong preference for a chair rather than a bed but there aren't any chairs.” (ICHD, White, Male, 56-64)</p> <p>“More back support during dialysis.” (Sat HD, Black, Female, 56-64)</p> <p>“Some of the chairs are ripped and open to infection. The chairs have no arm rest and offers no support.” (Sat HD, Black, Female, 56-64)</p> <p>“The unit’s comfort is bad as the chairs are very broken and old.” (ICHD, White, Male, 22-30)</p>
 <p>Accessing the Unit</p>	<p>“No automatic doors so have to pull doors open and time we have no energy especially after dialysis.” (ICHD, Asian, Male, 41-55)</p> <p>“Remind that I need a wheelchair on a daily basics some time the good bring it them self.” (ICHD, Asian, Male, 31-40)</p> <p>“The unit is too far away from the main entrance; it should be near the front doors so to help the people in wheelchairs to access the unit.” (Sat HD, White, Male, 56-64)</p>
 <p>Décor of the Unit</p>	<p>“The unit is not purpose built and very dated.” (ICHD, White, Female, 65-74)</p> <p>“The unit need some paints on the wall.” (Sat HD, Asian, Male, 56-64)</p> <p>“My only criticism was the facilities were very dated & not fit for purpose.” (Tx, White, Male, 31-40)</p> <p>“Brilliant colours, flowers to brighten up my day.” (Sat HD, White, Male, 56-64)</p>
 <p>TV</p>	<p>“The audio in the television doesn’t work.” (ICHD, White, Male, 65-74)</p> <p>“Please provide tv remotes.” (Sat HD, White, Male, 75-84)</p> <p>“And it could do with another tv a small complaint.” (Tx, White, Male, 41-55)</p> <p>“The TVs need to be improved. Screens turn black and it’s a long time to go without tv.” (ICHD, White, Female, 75-84)</p>
 <p>Noise</p>	<p>“I feel it is too noisy at times and have to wear ear defenders.” (ICHD, White, Male, 75-84)</p> <p>“The unit has stopped providing headphones for TV and do not allow TV sound to be audible enough.” (Sat HD, Asian, Male, 75-84)</p>
 <p>Waiting Area – Space</p>	<p>“Could do with a bigger waiting area.” (ICHD, White, Female, 56-64)</p> <p>“Waiting Room Small: Sometimes not enough seating. They try to store wheelchairs elsewhere. However, between sessions with patients in them the waiting area is very crowded. They do their best to try to get us quickly in the ward.” (ICHD, White, Female, 65-74)</p>
 <p>Insufficient Toilet Facilities</p>	<p>“Need another toilet in the unit for more than 10+ patients.” (ICHD, White, Male, 41-55)</p> <p>“Also, the toilets in the clinic are disgusting. Given that most people attending the clinic need to leave a sample there are not enough toilets and those that are there are always so dirty.” (CKD, White, Female, 31-40)</p>

CHAPTER 15: OTHER THEMES

Other Themes covers the aspects of care mentioned by individuals which do not fit into the existing Kidney PREM themes. In total there were 382 comments split across 3 subthemes, **Other Themes** (n=263), **Specific Aspects of Treatment** (n=109), and **COVID-19** (n=10).

Table 16: Breakdown of Other Themes codes by sentiment

	Total (n)	Negative	Neutral	Positive
Staff Shortage	134	110	6	18
Medication	55	42	4	9
Self-management	18	13	1	4
Pain	15	13	1	1
Suggestions for Kidney PREM	15	10	4	1
Misc	10	6	1	3
Transition to adult services	9	6		3
Pharmacy	7	3	1	3

The most commented on aspects under **Other Themes** was staff shortage, which were 82% negative. Since the pandemic the NHS has faced serious staff shortages, with kidney departments facing particular challenges.

There were many comments on medication. Respondents struggled to get their medication or to understand the reasons for taking medication. There were comments on self-management, with individuals wanting to become more independent with their care. Pain was also an issue with some suffering pain due to treatment.

This year there has also been an increase in the number of comments, with suggestions for the Kidney PREM questionnaire moving forward, such as changes to the wording regarding questions about staff.

The profile of those who commented on an aspect of their care mentioned above, mimics that of the National Kidney PREM 2022.

 <p>Other Themes</p>	<p>“Just recently the renal team have not had sufficient dressings, alcohol swabs etc although they ask they have to go to other units to try and get them.” (ICHD, Black, Male, 41-55)</p> <p>“Better guidance regarding pain issues.” (CKD, White, Male, 65-74)</p> <p>“Patients are not encouraged to do their own observation and encouraged to do home dialysis.” (HHD, White, Female, 41-55)</p> <p>“The questions are confusing as it doesn’t clearly identify if you mean my consultant care or the dialysis team. The results I provide are for the consultant care not the dialysis team.” (Sat HD, White, Male, 41-55)</p>
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Specific Aspects of Treatment

This is a subtheme of **Other Themes** which solely relates to treatment and treatment methods.

Table 17: Breakdown of *Specific Aspects of Treatment* codes by sentiment

	Total (n)	Negative	Neutral	Positive
Transplant	35	11	7	17
Treatment Side-Effects	12	8		4
Waiting for a transplant	12	10	1	1
Home Haemodialysis	11	6		5
Transitioning to home therapy	11	6	2	3
Length of Dialysis	10	8		2
Peritoneal Dialysis	9	6		3
Home visits	4	3		1
Exercise	3	2		1
Research/ New Treatment	2	1	1	

Those who have received a functioning transplant shared their experience, with 69% sharing a positive or neutral experience. Negative experiences are related to issues with recovery following transplant procedure, such as risk of infection and pain. Comments about waiting for a transplant were predominantly negative and included concerns about the length of time spent on the waiting list.

Home haemodialysis includes experiences from those who dialyse at home, with comments about the suppliers of equipment, and those receiving peritoneal dialysis commenting on complications with their digestive system and the convenience of the treatment.

Some respondents reported that they wanted to move to home therapies. There were also comments about the lack of home visits offered for those who do receive treatment at home. Others wanted exercise to be encouraged more to help with the side-effects of dialysis and weight management.

The respondent profile of this theme has a larger representation from those who have received a transplant or are receiving a home therapy (home haemodialysis or peritoneal dialysis).

 <p>Specific Aspects of Treatment</p>	<p>“It would be useful to have contingency plans for home patients needing to be admitted or respite treatment- we are sometimes treated like second class citizens.” (HHD, Black, Female, 41-55)</p> <p>“More investment, facilities in remote patient care.” (HHD, Asian, Male, 41-55)</p> <p>“Patients which attend early, have longer periods of haemodialysis and have a disability which makes unable to operate the machine should be given priority.” (Sat HD, Asian, Male, 41-55)</p>
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COVID-19

This is a subtheme of **Other Themes** which relates to **COVID-19**. In the UK, as restrictions are no longer in place, there has been a significant decrease in the number of comments relating to this theme. All comments were negative.

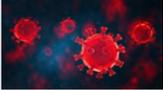
Table 18: Breakdown of COVID-19 codes by sentiment

	Total(n)	Negative	Neutral	Positive
Mask wearing	9	9		
Isolation	1	1		

The code mask wearing includes comments from individuals wanting others, both staff members and other participants, to wear a mask when visiting the unit.

The comment on isolation relates to isolation when returning from abroad.

Those who have responded to this subtheme are receiving haemodialysis at a centre or satellite unit or who have received a transplant.

	COVID-19	“I am very frustrated that I have to be in isolation when I come back from my country.” (ICHD, Asian, Female, 41-55) “COVID is still killing vulnerable people, everyone should still be wearing face masks. I haven’t had a lateral flow test since I started dialysis.” (ICHD, White, Male, 41-55)
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CHAPTER 16: 2021/2022 COMPARISON

This comparison of free text responses from 2021 and 2022 gives insight into how patient experience of care has changed following the feedback in comments from 2021. The analysis of comments has reverted to the old format (2020) which uses the existing 13 Kidney PREM themes as a way of reporting.

This year only 21.5% of respondents completing the measure left a free text response, compared to 40% last year. There were also changes to the demographic questions with individuals having more options to choose from in response to ethnicity and gender, with age being reported in 8 categories over the original 4. These changes have improved our understanding of the representation of Kidney PREM. Compared to 2021, there were fewer comments from individuals with a Black ethnic heritage (-1.2%) but this year there was a new option offered to patients to choose Mixed ethnic heritage, and 1.4% responded with this option. From last year there has been an increase in the number of under 30-year-olds who left a comment (+0.8%), with representation of gender and treatment modality remaining consistent.

As with the previous year, the most prominent theme was related to **staff** members and the quality of care patients received. These comments were predominantly positive (71%), comments mentioning specific staff roles (consultants, transplant team, nurses, primary care) had mixed views with most individuals thanking staff for providing good care and others wanting staff members to be more compassionate. Comments regarding **Environment** featured highly in both years and were mostly negative. In 2022 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 2021. Comments in 2021 regarding **Support** included wanting more psychological support and mentioning the apparent lack of provision for this. Specific support for financial issues and for participants' families were also mentioned. This was the same in 2022, though this year included an additional code, support with COVID-19, which received the most comments within this theme and were mostly positive (64%).

In both years issues with **Communication**, particularly individuals wanting better communication, featured as quite a negative aspect of care. 2021 highlighted 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. This year found issues with respondents wanting better coordination of test results and for applications, like Patient View, Patient Knows Best and My Care, to be more accessible. Additionally, *lack of information* was an issue, particularly on the adequacy of updates about treatment, progress, and transplant prospects. More access to advice about diet, fluid intake and exercise was also requested.

In both 2021 and 2022, younger individuals tended to focus on **Support** and older individuals on **Environment** and **Transport**. In 2021, those not receiving KRT and those with a functioning transplant focused on **Appointments** and **Communication**, remaining the case in 2022, with these individuals commenting on **Scheduling and Planning**, and **Access to the Renal Team**. Those receiving peritoneal dialysis or haemodialysis in-centre focussed on **Staff** and **Environment** with those receiving haemodialysis in-centre additionally commenting on **Transport** in 2021, and individuals receiving haemodialysis at home commenting on **Support** and **COVID -19**. A similar picture emerged in 2022, where those receiving haemodialysis in-centre or at a satellite unit commented on **Environment** and **Transport**, and participants with a functioning transplant or not receiving KRT, focussing on **Scheduling and Planning**, **Sharing Decisions** and **Tests**. Individuals receiving home therapies, more often commented on **Other Themes** in 2022 than in 2021.