

The Patient Voice

An analysis of free-text responses from
the 2023 National Kidney Patient
Experience Survey (Kidney PREM)

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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, and in 2023 was available online only. The end of the survey has a free-text question asking participants to comment on any aspect of their care.

“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, please tell us below”.

In 2023, 11,647 people with kidney disease took part, with 4,202 (36% of responses) providing a further comment on their care. The number of individuals responding to Kidney PREM increased slightly from 2022, with the number of respondents leaving a comment increasing by 14.5% in part undoubtedly due to the nature of Kidney PREM being online only. This increase in the number of comments improves understanding of patient experience of kidney care and helps to explain the reasons for changes in theme scores in the national report from the previous year. Additionally, 94.1% of responders gave consent for their comments to be passed back to their kidney centre meaning they can be used to help inform quality improvement. Generally, the profile of responders who left a free-text comment matched that of the national Kidney PREM 2023; however, there was a higher representation in the comments from individuals of a Black ethnic heritage (+1.3%). Compared to Kidney PREM 2022, the profile of responders remained consistent.

Comments were mapped to the 13 themes of experience that make up the Kidney PREM survey, as the free-text responses align with them well.

How the Kidney Team Treats You received the highest number of related comments (2,283), with 66% of comments under this theme being positive. Comments under this theme focused on positive views 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.

Access to the Kidney Team was the second most common theme (721 comments) to emerge from the comments and was predominantly negative (69%). Respondents commented on wanting to see a consultant more frequently, as well as having appointments scheduled with the dietician, social worker and psychologist. Additionally, respondents mentioned the need for better access to the kidney team outside of dialysis sessions.

Environment (649 comments), ***Scheduling and Planning*** (546 comments), and ***Transport*** (525 comments) received comments from individuals wanting better parking facilities, food to be offered during dialysis sessions and for appointments to be more frequent and better organised with no last-minute cancellations. Appointments via the telephone had mixed reviews with some finding them more convenient and a better use of time, whilst others feel they are less person-centred. Waiting times for transport following dialysis sessions continues to be an issue with individuals having to wait longer than an hour on most occasions.

Aspects of care such as ***Needling, Privacy and Dignity***, and ***Sharing Decisions*** 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 by competent members of staff, so as to be less painful and for conversations with consultants and

nurses to be conducted in private, with those who identify as female having a separate space to dialyse to maintain dignity.

Emerging Themes (494 comments) contain comments which do not align with the Kidney PREM themes, including medication and prescriptions, information about diagnosis or specific treatment issues, and 'dialysis while on holiday'. This year, in alignment with the Kidney PREM survey, two new themes arose from the free-text responses, **Overall Experience** and **Additional Questions**. There were 255 comments (98% positive) about overall experience of care, and 353 comments about additional questions that were asked within the Kidney PREM survey such as whether individuals use Patient Knows Best, language barriers and feedback from last year's Kidney PREM report.

Respondents' characteristics were also reflected in comments: for instance, younger individuals tended to focus on the **Environment** and older individuals on **How the Kidney Team Treats You** and **Access to the Kidney Team**. Those receiving haemodialysis in-centre or at a satellite unit were more likely to comment about the **Environment** and **Transport**, with those not receiving Kidney Replacement Therapy (KRT) or who have received a functioning transplant focused on **Scheduling and Planning**, and **Access to the Kidney Team**.

We hope this report will give some insight into what individuals with kidney disease think is important about their care experience and that their comments will help to illuminate the findings of Kidney PREM 2023, complementing 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 promoted 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 Kidney Team, Communication, How the Kidney Team Treats You, Patient Information, Sharing 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 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'.

In 2023, Kidney PREM was exclusively digital giving all respondents access to the free-text question which aims to capture experience of care not covered elsewhere¹. 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, 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 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 kidney community a national picture of people's experience of care.

The Kidney PREM is used by units, networks, and staff to implement improvements in areas of care which receive lower scores and to celebrate successes in areas of care which scored highly.

1.3: Methods

Kidney PREM 2023 was available for individuals to complete online from 11th September to 6th November 2023, securing 11,647 valid responses. Data were downloaded from the Qualtrics platform, an online survey tool, in Excel format, checked and a master file of all data² (from responses containing data in the free-text box) uploaded into QDA Miner, a computer-assisted coding software.

There were 4,202 written comments - 36% of responses, 3,958 (94.1%) of those who provided comments gave consent for this to be passed back to their treating unit; accordingly, UKKA sent datasets and explanatory text to all Clinical Directors in March 2024. Additionally, a main centre (including connected satellite units) summary

¹ one centre was provided with a printable copy of the survey in response to their concerns around digital exclusion and did not include the free-text question in the paper versions.

² patient characteristics, kidney unit, responses to Q39 Kidney PREM item and free text question comments

table of themes by sentiment³ was published on the UKKA data portal to accompany the comments.

Using QDA Miner, comments were initially screened using a text retrieval function to ascertain if further interpretation is needed. This coded 417 (9.8%) comments as having 'nothing to add', e.g., none, N/A. 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, several quality checks were conducted in which a 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 **Emerging Themes**. Additionally, this year, comments relating to other questions about patients asked within Kidney PREM (e.g., whether they needed help to complete the survey, or used the Patient Knows Best platform) were grouped under the theme **Additional Questions**, with a theme, **Overall Experience** being introduced for comments which discussed the respondent's overall experience.

The coding procedure followed that of reflexive thematic analysis (Braun and Clarke, 2021⁴), 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, 1984⁵).

Analysis of the quantitative data has been reported separately and is available to view via the UK Kidney Association website⁶.

1.4: Structure of Report

Participant comments are presented by theme, displayed in the order presented in the Kidney PREM, with a breakdown of sentiment (positive/ negative/ neutral) shown in a table, and variation in the characteristics of those leaving a comment displayed in figures or confirmed as the same as the general Kidney PREM 2023 profile. Like last year, respondents could select non-binary and other to the gender question, alongside male and female; however, the number of individuals who identified as non-binary or other and left a comment did not meet the required minimum to ensure anonymity to be presented in the report (non-binary n=6, other n=3).

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 2022 and Kidney PREM 2023.

³ The number of comments within each theme there were negative, neutral or positive.

⁴ 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.

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

⁶ www.ukkidney.org/kidney-patient-reported-experience-measure

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.

QUOTES

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

◆ Little Gems ◆

Little Gems are defined as the suggestions, within the free-text comments, for improvements to patient experience of kidney care that could be implemented relatively easily, without significant resource or time requirements. Please note not that Little Gems do not appear for every theme and may not be relevant to all kidney units.

1.5: Overall Response

The table below shows the breakdown of respondent comments by theme and sentiment. The most frequent theme that individuals commented on was ***How the Kidney 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 ***Access to the kidney team***, followed by the ***Environment***, comments on which were largely negative. ***Needling, Privacy and Dignity***, and ***Sharing Decisions*** received the fewest comments. From the 4,202 respondents who left a comment, 417 individuals (9.8%) said there was nothing further to add.

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

	Total	Negative	Neutral	Positive
How the Kidney Team Treats You	2,283	678	91	1514
Access to the Kidney Team	721	496	36	189
Environment	649	494	25	130
Scheduling and Planning	546	380	46	120
Transport	525	413	28	84
Emerging Themes	494	278	94	122
Additional Questions	353	256	27	70
Overall Experience	255	6		249
Communication	239	173	13	53
Patient Information	215	151	15	49
Support	206	144	12	50
Tests	87	67	5	15
Fluid and Diet	72	50	6	16
Needling	64	48	3	13
Privacy and Dignity	57	46	3	8
Sharing Decisions	46	24	3	19

1.6: Overall Patient Profile

In (2023), 4,202 people left additional comments on their experience of kidney care. There was little difference in proportion of comments from individuals according to age, gender or ethnicity. However, because of the increase in comments received compared to 2022, the number of comments from individuals of an Asian heritage almost doubled from 217 to 410. From last year there was an option to select 'other' under gender, this had little representation in the data. The proportion of comments from people receiving centre-based haemodialysis (ICHHD plus Sat HD) increased from 45.7% to 49.1%, whilst the proportion from transplanted individuals decreased from 22% to 18.2%.

Table 2: Characteristics of individuals leaving a comment in Kidney PREM

	Kidney PREM 2023 Comments	Kidney PREM 2023	Kidney PREM 2022 Comments
Total	4,202	11,647	2,376
Age (years)			
16-21	20 (0.5%)	89 (0.8%)	26 (1.1%)
22-30	92 (2.2%)	358 (3.1%)	47 (2.0%)
31-40	285 (6.8%)	798 (6.9%)	50 (6.3%)
41-55	884 (21.0%)	2,402 (20.6%)	498 (21.0%)
56-64	928 (22.1%)	2,501 (21.5%)	552 (23.2%)
65-74	1,041 (24.8%)	2,828 (24.3%)	575 (24.2%)
75-84	788 (18.7%)	2,228 (19.1%)	440 (18.5%)
85+	166 (3.9%)	443 (3.8%)	89 (3.7%)
Gender			
Female	1,751 (41.7%)	4,743 (40.7%)	951 (40.1%)
Male	2,416 (57.5%)	6,793 (58.3%)	1,411 (59.4%)
Non-binary/ Other	9 (0.2%)	27 (0.2%)	1 (0.01%)
Rather not Say	28 (0.7%)	84 (0.7%)	12 (0.5%)
Ethnicity			
Asian	410 (9.8%)	1,110 (9.5%)	217 (9.1%)
Black	395 (9.4%)	939 (8.1%)	229 (9.6%)
Mixed	52 (1.2%)	146 (1.3%)	34 (1.4%)
White	3,204 (76.2)	9,079 (78.0%)	1,805 (75.9%)
Other	65 (1.5%)	169 (1.5%)	51 (2.1%)
Rather Not Say	78 (1.9%)	204 (1.8%)	41 (1.7%)
Treatment			
CKD (non-KRT)	632 (15.0%)	1,678 (14.4%)	346 (14.6%)
Peritoneal Dialysis	231 (5.5%)	620 (5.3%)	134 (5.6%)
Home HD	89 (2.1%)	208 (1.8%)	50 (2.1%)
Satellite HD	1,319 (31.4%)	3,864 (33.2%)	721 (30.3%)
In-Centre HD	1,166 (27.7%)	3,428 (29.4%)	604 (25.4%)
Transplant	767 (18.2%)	1,849 (15.9%)	522 (22.0%)

CKD – chronic kidney disease; KRT – kidney replacement therapy; HD – Haemodialysis

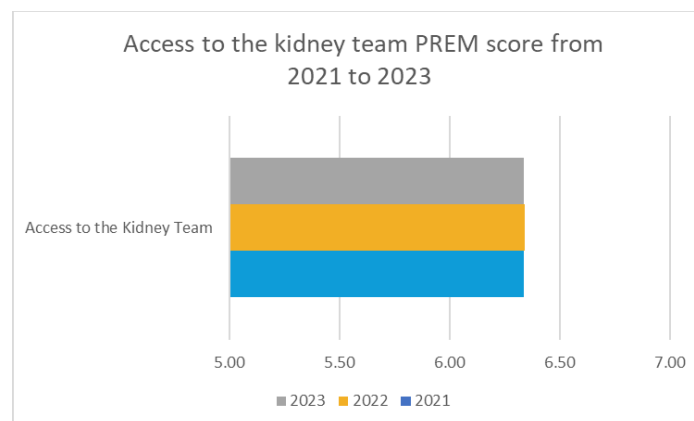
CHAPTER 2: ACCESS TO THE KIDNEY TEAM

The theme **Access to the Kidney Team** covers areas of care such as availability of staff, ability to contact staff when needed and staff shortages. There were 836 comments which aligned with this theme, making it the second largest theme, of which 68% were negative. Kidney PREM scores for this theme are generally high and have remained stable over the last 3 years at around 6.3 out of 7 (figure 1).

Table 3: Breakdown of subthemes for Access to the Kidney Team by sentiment

Subthemes	Total	Negative	Neutral	Positive
Access to the kidney team	236	166	11	59
Need for more staff	164	119	7	38
Access to the team outside of appointments	153	98	8	47
Access to the MDT	120	81	9	30
Continuity of Care	92	60	7	25
Primary Care	71	45	5	21

Figure 1: Scores for Access to the Kidney Team from 2021 to 2023.



Access to the Kidney Team

There were 236 comments which related to respondents' ability to access members of the kidney team such as consultants or specialist consultants, as well as comments regarding having student doctors at their appointments. 70% of comments were negative with individuals wanting to see a consultant more frequently, for example having a consultant present during dialysis sessions. Specialist consultant refers to comments in which individuals mention being referred to a specialist or specialist consultant as part of their care but being placed on long waiting lists.

Table 4: Breakdown of codes for Access to the Kidney Team by sentiment

	Total	Negative	Neutral	Positive
Consultant	205	145	11	49
Specialist Consultant	21	13		8
Seeing a student Dr	10	8		2

"I am very unhappy to be only able to see my consultant every 6 months, it is not enough."
(Female, Black, 31-40, Centre HD)

"Doctors limits you to 5 minutes only."
(Female, Asian, 56-64, Transplant)

"At outpatients appointments I would like to only consult with a kidney consultant not junior doctors."
(Female, White, 56-64, Transplant)

Need for more staff

There were 164 comments about the lack of staff available at the unit. These were mostly negative with positive comments stating how well staff were handling the staff shortages.

“Very short staffed in unit. They have had to cut downsize of twilight shift due to lack of staff. Staff are slow answering call bells probably due to lack of staff.”
(Male, White, 56-64, Sat HD)

“Sometimes the unit has an atmosphere, due to being understaffed quite often.”
(Not Say, White, 31-40, Centre HD)

Access to the team outside of appointments

There were 153 comments related to participants ability to contact the kidney team or about the lack of facilities for care outside of kidney unit opening hours. Specifically, comments mention not having a direct contact number for the kidney unit.

Table 5: Breakdown of codes for Access to the team outside of appointments by sentiment

	Total	Negative	Neutral	Positive
Contacting the kidney team	131	82	7	42
No emergency care	22	16	1	5

“If I have a question/emergency and the weekend when the clinic is closed, I’m never very sure who I should call - usually the renal ward and I feel like I’m inconveniencing them.”
(Female, White, 41-55, Transplant)

“I had made attempts to get any of my renal team to fill out 2-page form but all efforts got no response. I sent emails, contacted customer unit and I missed the deadline eventually.”
(Male, Black, 41-55, CKD)

“Would be good to know which telephone number to ring with a problem. Seems to be quite a few different ones.”
(Female, White, 65-74, Transplant)

Access to the multi-professional team (MPT)

Access to psychologists, social workers or dieticians was mentioned in 120 comments, with individuals stating that they would like to seek advice from members of the MPT more regularly.

Table 6: Breakdown of codes for Access to the multi-professional team by sentiment

	Total	Negative	Neutral	Positive
Dietician	45	32	3	10
Renal Psychologist	38	22	3	13
Social Worker	37	27	3	7

"I wish we have access to the social worker more like before."
(Female, Black, 56-64, Sat HD)

"It would be helpful if the kidney care team would arrange an appointment with a dietician to assist with meal prep that entails less potassium."
(Female, Asian, 56-64, CKD)

"Provision of psychiatric advice to assist mental health."
(Female, Black, 41-55, Sat HD)

Continuity of Care

There were 92 comments (65% negative) about the lack of continuity in care, with individuals suggesting having one designated consultant they see at each appointment.

"As far as Kidney Team is concerned, it would be better if you could see the same clinician each time to build a relationship and feel more confident/comfortable."
(Female, White, 56-64, Transplant)

"I see the same people which is hugely important and totally trust them and feel I can contact them at any time if required."
(Female, White, 56-64, PD)

Primary Care

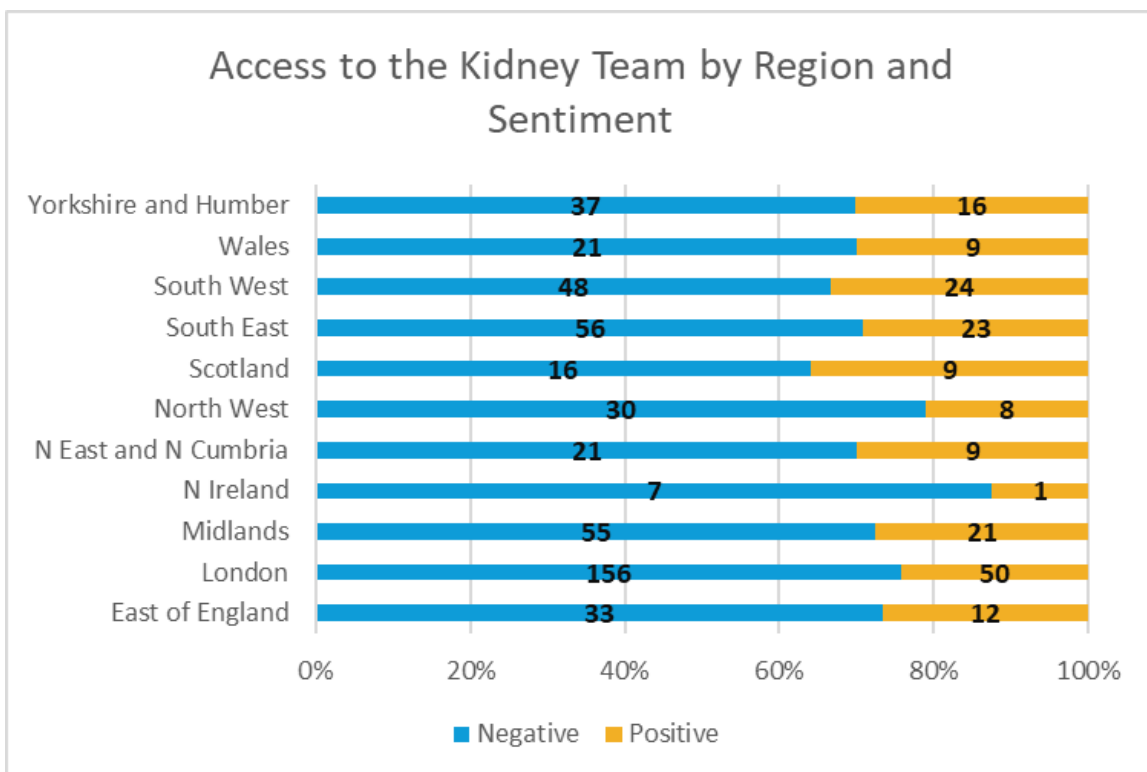
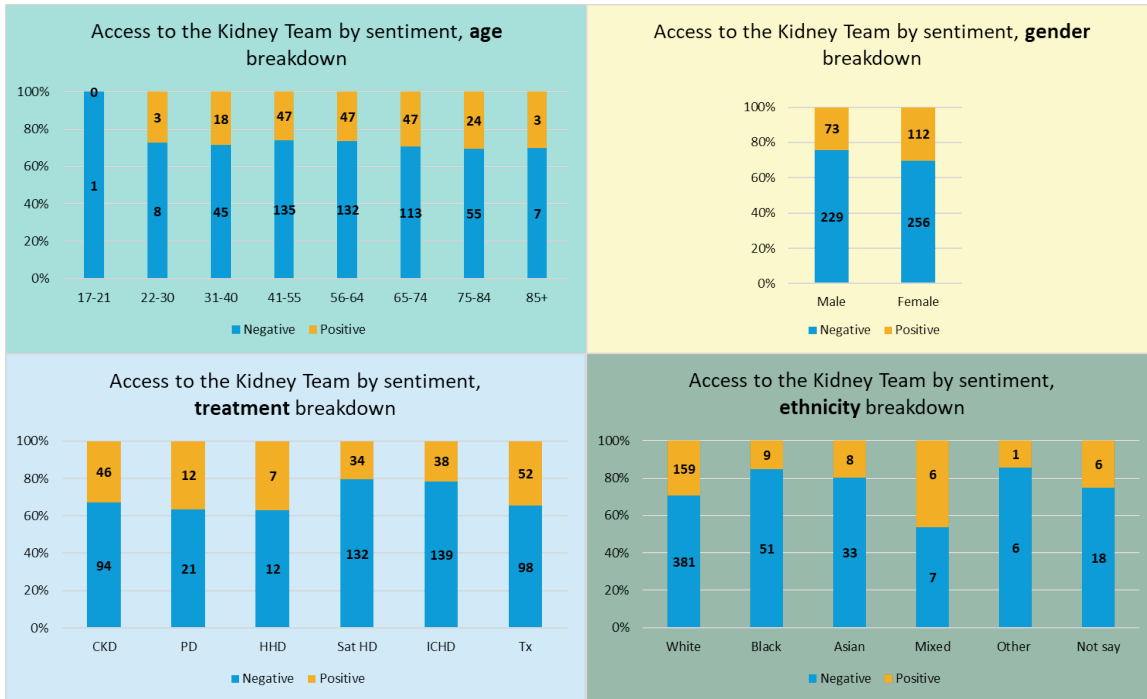
Comments about access to GPs and GP knowledge of kidney disease were found in 71 responses, predominantly negative (63%) with respondents wanting better access to primary care to discuss issues related to their kidney disease.

"The usual response being told to speak to your GP which is impossible and usually the problem is beyond a GPs remit."
(Male, White, 56-64, Centre HD)

"My GP is useless and I may hear from him every six months or so."
(Male, White, 75-84, PD)

Characteristics of respondents commenting on Access to the Kidney Team

Individuals who identified as female were more likely to comment on an aspect of their care relating to **Access to the Kidney Team**, additionally those aged between 45 years old and 84 years old were more likely to comment. There were similar response rates for negative and positive sentiment across all geographical regions in the UK.



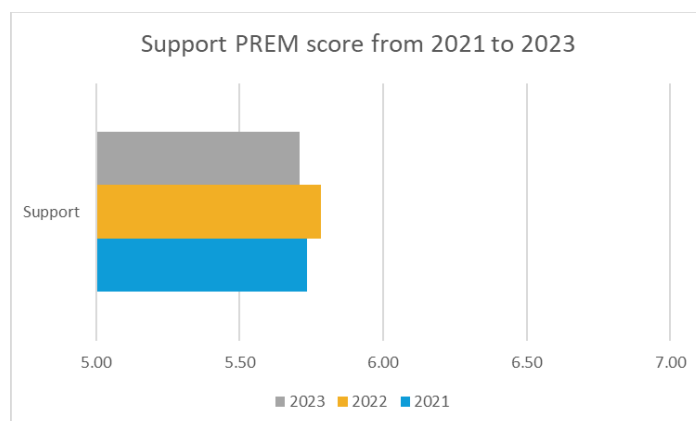
CHAPTER 3: SUPPORT

There were 216 comments which aligned with the theme **Support**, with 69% of comments being negative. Individuals commenting on **Support** would like more information about availability, including support for treatment, emotional support, financial support and at home support such as housing and home care. **Support** is one of the most poorly scoring themes of Kidney PREM each year, at around 5.7 out of 7 (figure 2).

Table 7: Breakdown of subthemes for Support by sentiment

	Total	Negative	Neutral	Positive
Support with treatment	70	47	1	22
Emotional support	58	36	6	16
Financial support	35	31		4
Patients with additional needs	34	22	5	7
At home support	19	14	2	3

Figure 2: Scores for Support from 2021 to 2023.



Support with treatment

A total of 70 comments discussed support with treatment, such as how to deal with the side effects of dialysis and for those receiving dialysis at home to feel supported with aspects of care such as delivery of supplies and training.

“Better information and support from unit now that I am having home haemodialysis.”
(Female, White, 65-74, Home HD)

“Level of support and care post-transplant has been excellent thank you.”
(Male, White, 56-64, Transplant)

Emotional support

There were 58 comments affiliated with emotional support. These related to information about support groups, support provided to family, specialised support for young adults and support offered by kidney charities. Positive comments included individuals giving examples of the support they had been given, with negative comments showing a need for better information about the types of support available.

Table 8: Breakdown of codes for Emotional support by sentiment

	Total	Negative	Neutral	Positive
Support groups	19	13		6
Family support	16	9	3	4
Young adult support	13	9		4
Kidney charities	10	5	3	2

“Also, information on support groups or forums would be useful.”
(Female, Asian, 56-64, CKD)

“The only information and support I have received is from the Kidney Care charity.”
(Female, White, 56-64, CKD)

“More attention and focus on the younger patients. Seems like older (males) are give preferential treatments at time.”
(Male, Mixed, 31-40, Sat HD)

Financial Support

There were 35 responses which discussed financial support, with 88% of comments mentioning there was a lack of financial support offered to individuals, for example reimbursement for private travel to the unit or support for applying for Personal Independence Payment (PIP).

“Some of the costs associated with home dialysis seems to be alarmingly shifting to the patient, placing home patients at a disadvantage.”
(Not Say, Not Say, 56-64, Home HD)

“Utility Bill reimbursement waiting well over a year and still no payment contribution from the trust.”
(Male, White, 65-74, PD)

Patients with additional needs

There were 34 responses from individuals giving examples of needing additional support for their needs, such as having communication aids for individuals who are hard of hearing.

“Staff need to listen to the carers and take them seriously. When a patient is non-verbal the carer is that person's voice. The carer will know by body language and behaviours what the patient is probably experiencing. Do not assume all carers are ignorant.”
(Female, White, 41-55, Centre HD)

“As a patient who is deaf find it hard to communicate with staff and other people.”
(Female, White, 56-64, Centre HD)

At home support

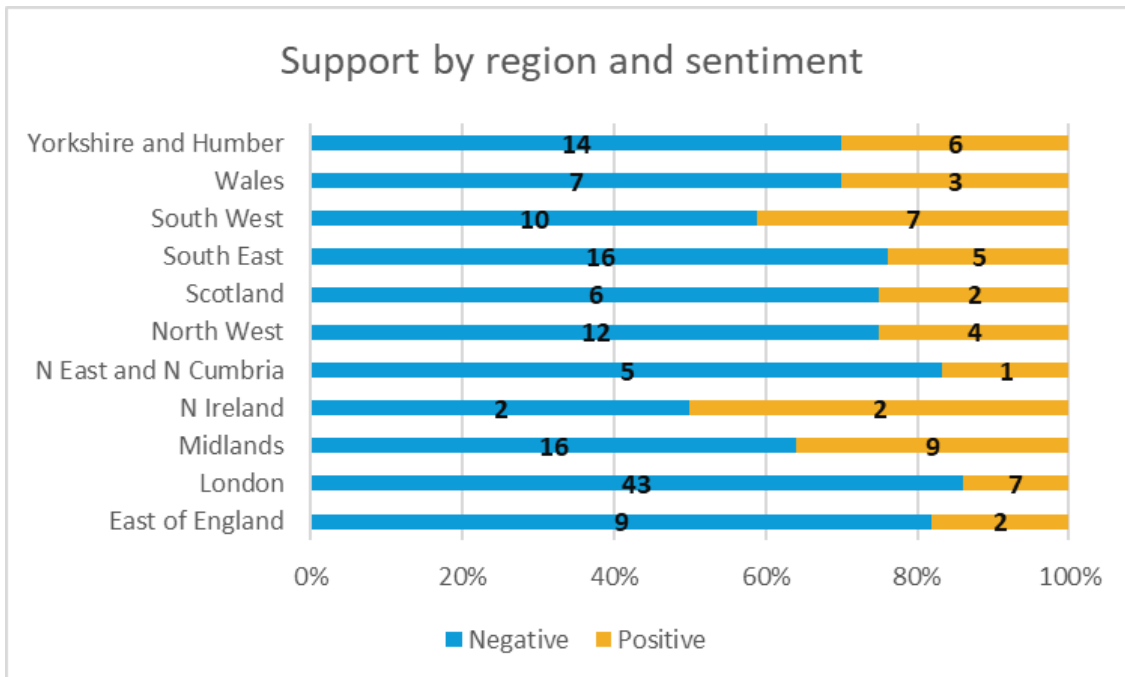
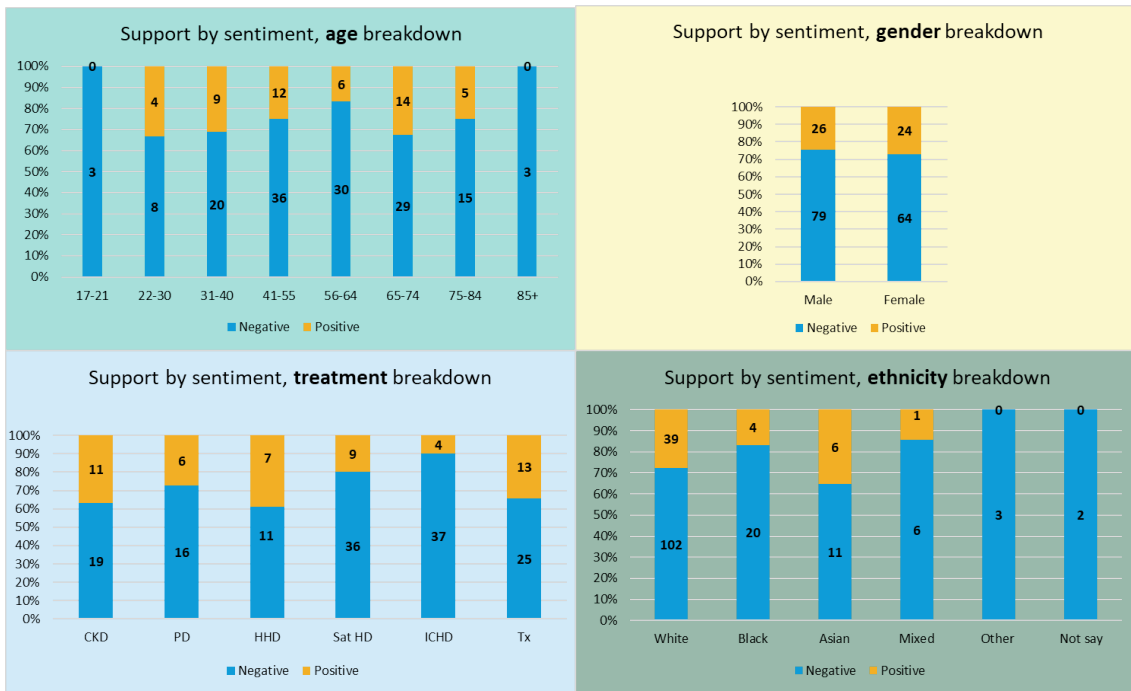
Nineteen comments relate to at home support, which discussed wanting help with social housing, routines and childcare.

“Ways of helping me access housing and benefits will, before great help.”
 (Male, Asian, 56-64, Centre HD)

“There is absolutely no support for people who work in general, zero understanding.”
 (Female, White, 41-55, Sat HD)

Characteristics of respondents commenting on Support

Individuals of all ages and ethnicities responded under this theme. However, there was a larger proportion of individuals aged 41 years old to 74 years old receiving haemodialysis in centre or at a satellite unit who commented more negatively.



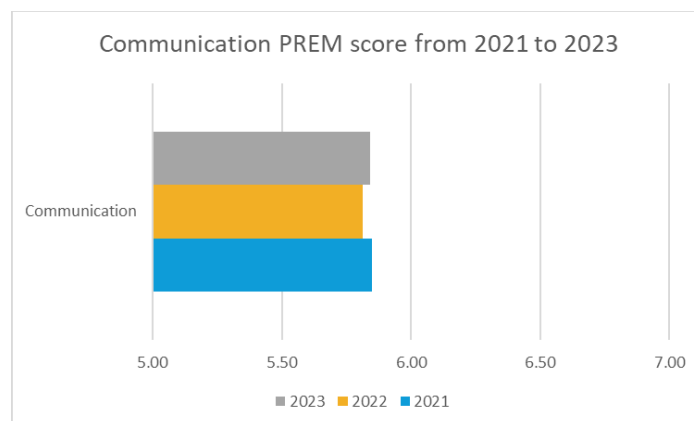
CHAPTER 4: COMMUNICATION

Communication was associated with 253 comments, of which 72% were negative. There has been little change to the communication Kidney PREM score in the last 3 years, remaining around 5.8 out of 7 (figure 3). This theme covers communication between the individual and the kidney team, between members of the kidney team, between the kidney team and other specialists and between the kidney team and primary care. Additionally, there were 27 comments on the timeliness of response from the kidney team.

Table 9: Breakdown of codes for *Communication* by sentiment

	Total	Negative	Neutral	Positive
Communication with kidney team	95	67	5	23
Communication between kidney team and other medical specialists	57	37	4	16
Communication between kidney and GP	51	40	3	8
Timeliness of response	27	21	2	4
Communication between members of the kidney team	23	16	1	6

Figure 3: Scores for *Communication* from 2021 to 2023.



Communication with the kidney team was mostly negative (70%) with individuals wanting more frequent communication from their kidney team, such as regular check-ins to see how they are doing. Issues with communication between teams include a lack of communication resulting in poor care coordination for example having to have repeat blood tests for each department or delays in prescribing medication. Additionally, respondents felt that communication from their GP regarding their kidney disease was poor and wanted the GP to converse more frequently with their kidney consultant.

"I find that there is poor communication between my Kidney Team and GP. Been asked to replicate some blood tests by GP and although the GP gets a letter on each visit have a feeling it is just "filed away" and the contents not noted."
(Male, White, 65-74, Transplant)

"Clear lack of communication between the nurses and the consultant."
(Female, Black, 31-40, Centre HD)

"Letters can take three to four weeks to arrive to me, so these further delays are of considerable concern."
(Male, White, 65-74, CKD)

Characteristics of respondents commenting on *Communication*

There was good representation of all participant profiles, reflecting the profile of responses to Kidney PREM 2023, with spikes in negative responses from those aged 65-74 years old with a functioning transplant.

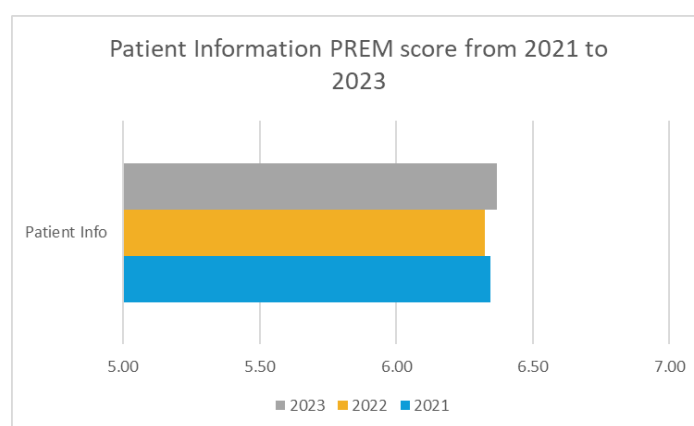
CHAPTER 5: PATIENT INFORMATION

There were 220 comments which were included under the theme **Patient Information**, with 70% of these being negative. Kidney PREM scores for **Patient Information** are consistently high, at around 6.4 out of 7 over the past three years (figure 4).

Table 10: Breakdown of codes for Patient Information by sentiment

	Total	Negative	Neutral	Positive
Explanation of treatment	134	91	6	37
More information about transplants	81	61	7	13
Information about other patients	5	3	2	

Figure 4: Scores for Patient Information from 2021 to 2023.



Individuals wanting the reasons for their treatment, medication and tests being better explained accounted for 91 comments, with 43 individuals finding the information provided was sufficient. Particularly, respondents felt they were not given information about the different treatment options so were not fully informed to make decisions about their care. Moreover, there were 81 comments asking for information about transplants and five comments asking for updates about patients who no longer attend the same dialysis session.

Characteristics of respondents commenting on Patient Information

Younger patients were less likely to leave a comment about the information available, with those receiving haemodialysis in centre or those with a functioning transplant most likely to comment.

◆ *“For new patients it would be good to have a pre visit to a dialysis unit to see machines and what to expect, also a book about the dialogue of renal information in layman’s terms.”* ◆
(Female, White, 65-74, Sat HD)

“Recommendation: I should know more about what caused my kidney problem from the beginning.”
(Female, Black, 75-84, Centre HD)

“Like to know when someone passes away or received a new kidney as relationships form with patients within the unit.”
(Male, White, 56-64, Centre HD)

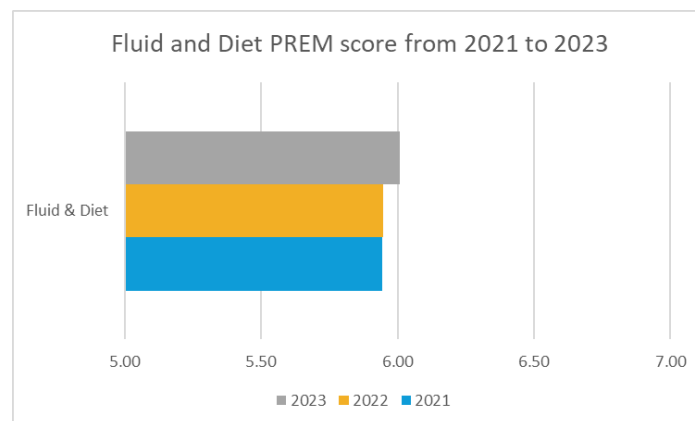
CHAPTER 6: FLUID AND DIET

Fluid and Diet accounted for 75 comments, with most respondents (69%) wanting better access to dietary information and personalised fluid intake advice. This theme saw a fractional increase in its Kidney PREM score this year, from 5.9 in 2021 and 2022 to 6.0 out of 7 in 2023 (figure 5).

Table 11: Breakdown of codes for *Fluid and Diet* by sentiment

	Total	Negative	Neutral	Positive
Dietary advice	65	43	6	16
Issues with fluid intake	10	9	1	

Figure 5: Scores for *Fluid and Diet* from 2021 to 2023.



Examples of comments from this theme include wanting units to provide tailored diet plans which are kidney-friendly and in line with individual needs such as allergies or being diabetic. Issues with fluid intake include individuals discussing their experiences of fluid retention and wanting advice for preventing this.

“Better information on food and fluids in book form would be good when you first try dialysis also how it affects your life.”
(Female, White, 56-64, Sat HD)

“When you start dialysis, I think you should be educated as to fluid control.”
(Male, White, 41-55, Sat HD)

◆ *“Handheld book for renal foods to be taken out and about with patients.”* ◆
(Female, White, 65-74, Sat HD)

Characteristics of respondents commenting on *Fluid and Diet*

The profile of responses for *Fluid and Diet* matched that of Kidney PREM, with those who identified as female, aged 41-55 and not receiving kidney replacement therapy being most likely to comment.

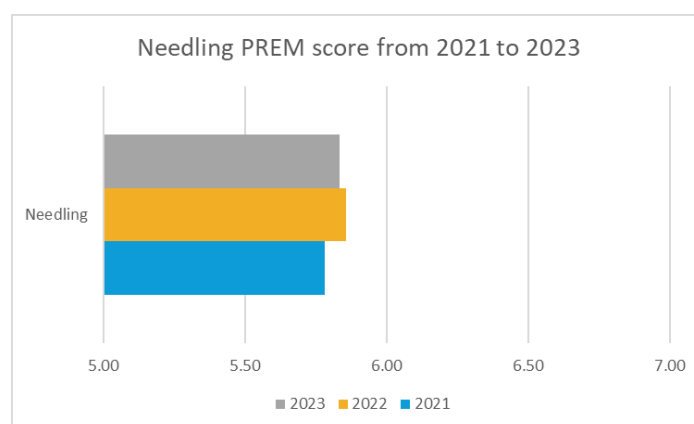
CHAPTER 7: NEEDLING

In Kidney PREM, participants receiving haemodialysis in centre or at a satellite unit are asked to rate their experience of being needled. The Kidney PREM score for **Needling** has seen a slight decrease this year but remains around 5.8 out of 7, one of the lower-scoring themes (figure 6).

Table 12: Breakdown of codes for *Needling* by sentiment

	Total	Negative	Neutral	Positive
Issues with fistula	23	16	2	5
Pain when needling	22	17		5
Issues with needling	19	15	1	3

Figure 6: Scores for *Needling* from 2021 to 2023.



Responses regarding needling were coded under three areas, examples of problems with fistulas such as having fistulas blowing, extreme pain when being needled and issues with needling itself like wrong-sized needles being used. This theme was mostly negative, with positive comments thanking staff for the care and attention given whilst needling.

“Never gently while doing the needle Never gentle while removing the needle Always rushing to do the needle.”
(Female, Asian, 41-55, Centre HD)

“Needling is an issue. Too many people inserting the needles leads to false tracks and the requirement for new sites to be made. A more consistent approach is required.”
(Male, White, 56-64, Centre HD)

“Concerns about the status of my fistula that has been created since February but still hasn’t used. They know that my veins are short yet still insisted to create a fistula.”
(Female, Asian, 65-74, Centre HD)

Characteristics of respondents commenting on *Needling*

The majority of responses came from individuals receiving haemodialysis in centre or at a satellite unit, this is expected because within Kidney PREM needling is addressed to those receiving this treatment modality. Individuals aged 56-64 years were more likely to comment than any other age group.

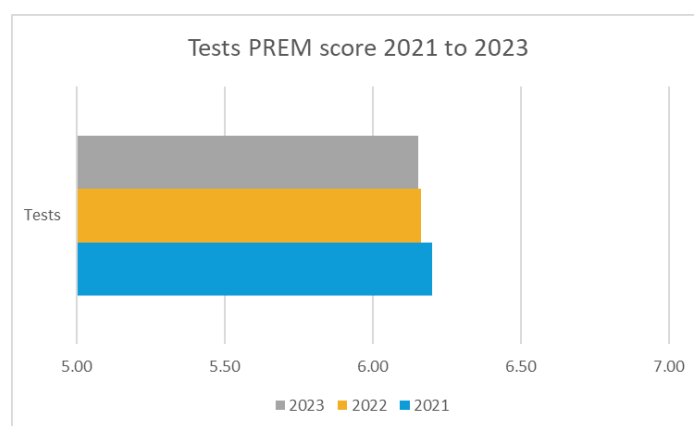
CHAPTER 8: TESTS

There were 91 comments regarding **Tests**, 67% of which were negative. Comments included timeliness of test results, having test results explained and experience of receiving blood tests. Kidney PREM scores have remained consistent over the last 3 years, at 6.2 out of 7 (figure 7).

Table 13: Breakdown of codes for Tests by sentiment

	Total	Negative	Neutral	Positive
Having test results explained	46	35	3	8
Timeliness of results	39	31	2	6
Experience of blood tests	6	3	1	2

Figure 7: Scores for Tests from 2021 to 2023.



Having blood test results explained occurred most often within this theme, with most comments asking that results be discussed with individuals so they can better understand the effectiveness of treatment. Comments relating to the timeliness of receiving blood test results, also occurred frequently, with respondents wanting results to be received more quickly and in time for their appointments. There were few comments about the experience of blood tests, evenly split by positive and negative sentiment. Some felt the pain experienced during the blood test was due to a lack of competency of staff whereas others described good experiences.

“I would like a follow up on blood test and how I could improve my test results. Get a paper print out on my monthly blood results.”
(Male, Asian, 65-74, Sat HD)

“When I have bloods taken, they aren’t reviewed for weeks.”
(Female, White, 31-40, Centre HD)

“Very painful blood tests compared to previous hospital.”
(Female, White, 56-64, Transplant)

◆ *“The stickers on the urine sample bottles are impossible to write on. Could we have better stickers or better pens, please.”* ◆
(Female, Black, 56-64, Transplant)

Characteristics of respondents commenting on *Tests*

Individuals not receiving kidney replacement therapy, who identified as female and those aged 65-74 years old, were more likely to leave a free-text comment about tests. Those receiving home therapies were least likely to comment about tests.

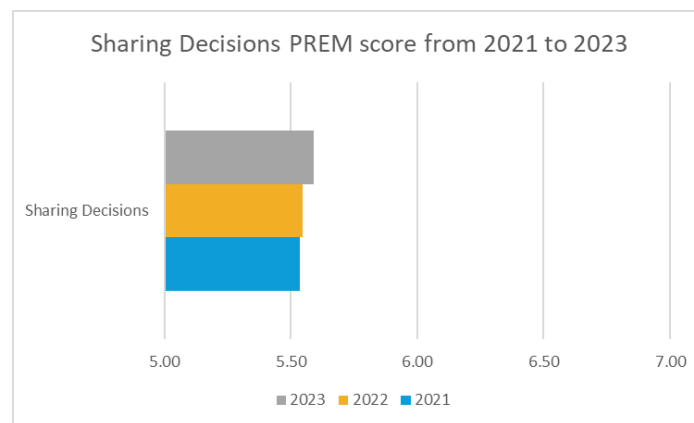
CHAPTER 9: SHARING DECISIONS

Sharing Decisions describes patients' ability to be involved in their care, make decisions about their care, and make choices for treatment and goals. There were 46 comments which fell under this theme, with individuals commenting on their ability to have an active role in their care. In recent years, **Sharing Decisions** has been the poorest performing theme of Kidney PREM, but a small increase in 2023 to 5.6 means that this is no longer the case (figure 8).

Table 14: Breakdown of codes for *Sharing Decisions* by sentiment

	Total	Negative	Neutral	Positive
Taking a more active role in kidney care	46	24	3	19

Figure 8: Scores for *Sharing Decisions* from 2021 to 2023.



Those who have had a positive experience of **Sharing Decisions** (41%) gave examples of how they are involved in discussions about their care, with those whose responses were negative, stating that decisions were made without their awareness or that there were no discussions about future goals for treatment.

“Nurses also take decisions about your care without consulting you.”
(Female, Black, 31-40, Centre HD)

“We work on my treatment together so there is shared understanding, and he always ensures I am in agreement.”
(Female, White, 41-55, CKD)

“Our 6 weekly blood and doctors chats happen without us present, so we never get to really be involved in our care.”
(Female, White, 31-40, Sat HD)

“More input in treatment, prefer alternative treatments e.g. cell treatment.”
(Female, Asian, 41-55, CKD)

“Shared decision making discussed regarding any treatment option.”
(Male, White, 56-64, Transplant)

“They also trust me to take decisions for myself.”
(Female, White, 65-74, Transplant)

Characteristics of respondents commenting on *Sharing Decisions*

There was representation of all patient groups which matched the profile of Kidney PREM 2023 respondents. Individuals aged 56 years and above had more positive things to say about their ability to be involved in their care, whereas those receiving haemodialysis in centre or at a satellite unit felt less involved in making decisions about their care, reflecting the Kidney PREM scores nationally.

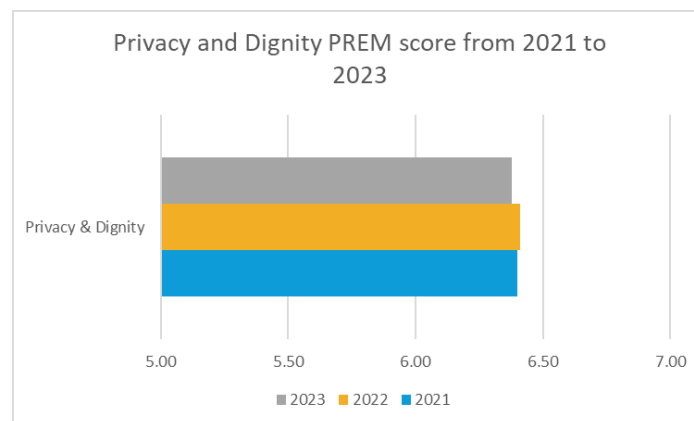
CHAPTER 10: PRIVACY AND DIGNITY

There were 57 comments coded under the theme **Privacy and Dignity**, 46 (80%) of which were negative. **Privacy and Dignity** has been the highest-performing Kidney PREM theme over the past three years, scoring around 6.4 out of 7 each year (figure 9).

Table 15: Breakdown of codes for *Privacy and Dignity* by sentiment

	Total	Negative	Neutral	Positive
More privacy needed	53	42	3	8
Females wanting own space/ staff	4	4		

Figure 9: Scores for *Privacy and Dignity* from 2021 to 2023.



This theme includes comments from individuals regarding whether they felt their **Privacy and Dignity** were maintained whilst attending the unit. Respondents commented on the lack of privacy when having discussions with consultants. Additionally, four comments mentioned how females would like their own section when dialysing and to have female members of staff deliver their care.

◆ *“I would like to suggest that a notice be put on the side room doors to inform that personal care is taking place and to ‘please knock, before entering’.”* ◆
(Female, Black, 56-64, Sat HD)

“I would prefer different areas for female and male dialysis to ensure privacy and comfort.”
(Female, Asian, 41-55, Centre HD)

“I would like more privacy for being weighed.”
(Female, White, 31-40, Transplant)

Characteristics of respondents commenting on *Privacy and Dignity*

Unsurprisingly, there were no responses from individuals receiving home therapies likely due to fewer interactions at the unit. There were more responses from females than males, with participants being treated in all regions providing comments under this theme with the exception of those based in Northern Ireland.

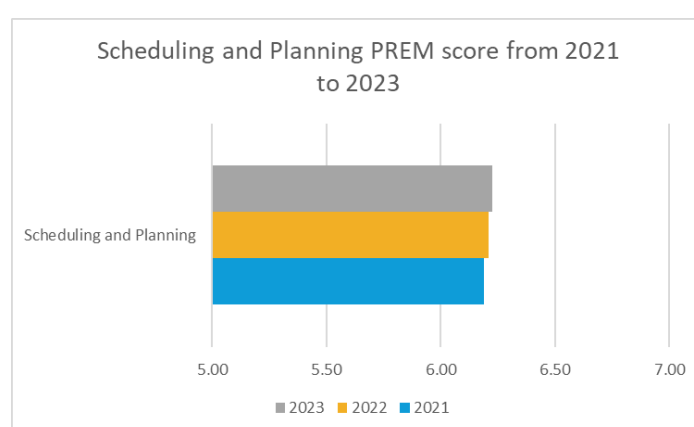
CHAPTER 11: SCHEDULING AND PLANNING

There were 546 responses which aligned with **Scheduling and Planning**, discussing appointments, waiting times, blood tests and staff workload. The Kidney PREM score for **Scheduling and Planning** theme has remained consistent since 2021, at 6.2 out of 7 (figure 10).

Table 16: Breakdown of subthemes for Scheduling and Planning by sentiment

	Total	Negative	Neutral	Positive
Appointments	306	200	33	73
Waiting at the unit	151	118	5	28
Blood tests	136	91	15	30
Staff are overworked	42	28	2	12

Figure 10: Scores for Scheduling and Planning from 2021 to 2023.



Appointments

A total of 306 comments relating to appointments were analysed, with 65% of these being negative. These comments covered aspects of scheduling such as appointments not being face to face, cancelled or rescheduled appointments, wanting appointments to be more frequent, and wanting more flexibility with appointments. Appointments being over the phone had mixed reviews, with some finding them more convenient and others feeling they are less person-centred.

Table 17: Breakdown of codes for Appointments by sentiment

	Total	Negative	Neutral	Positive
Appointments not F2F	94	49	15	30
Appointment scheduling issues	89	69	2	18
Frequency of appointments	62	40	9	13
Flexibility of appointments	61	42	7	12

*“Saw consultant for the first time in Feb and only saw him again in August and that was only due to pt complaining.”
(Female, White, 56-64, Centre HD)*

*“Also appointments start at around 10.30 and there are no earlier appointments which is a shame as I would prefer earlier appointments.”
(Female, Asian, 41-55, Transplant)*

*“The blood tests are normally done within the GP unit with the nursing staff, these monthly tests are very efficient and a great help.”
(Male, White, 65-74, CKD)*

Waiting at the Unit

There were 144 comments regarding waiting times at the unit and another 7 comments about having to wait outside for early morning dialysis sessions. The majority of comments were negative with individuals wanting to be put onto the dialysis machine quicker and to have earlier access to the unit.

Table 18: Breakdown of codes for Waiting at the Unit by sentiment

	Total	Negative	Neutral	Positive
Waiting time at the unit	144	111	5	28
Having to wait outside the unit	7	7		

*“Access in the morning the unit is locked have to wait for staff.”
(Male, White, 56-64, Centre HD)*

*“The machines are not ready, and sometimes you have to wait long time before they put you on, but they should put on people who come first sometimes they don’t. It depends who’s on.”
(Male, Asian, 56-64, PD)*

*“Long waiting periods and appointments often running 2 hours late.”
(Female, Asian, 31-40, CKD)*

Blood Tests

Additionally, there were 136 comments about the scheduling and planning of blood tests, with 67% negative comments suggesting that blood tests should be scheduled to coincide with appointments so that the results can be discussed at the appointment. Individuals found the wait times for blood tests to be excessive.

Table 19: Breakdown of codes for Blood Tests by sentiment

	Total	Negative	Neutral	Positive
Scheduling blood tests	111	72	13	26
Waiting time for blood test	25	19	2	4

*“Blood tests should be carried out local to patients rather than expecting patients to travel into hospital. In my case this is a 3 hour round trip.”
(Male, Asian, 41-55, PD)*

*“I would like to comment only about the blood test waiting time which is too long to wait.”
(Female, Not Say, 31-40, CKD)*

Staff are overworked

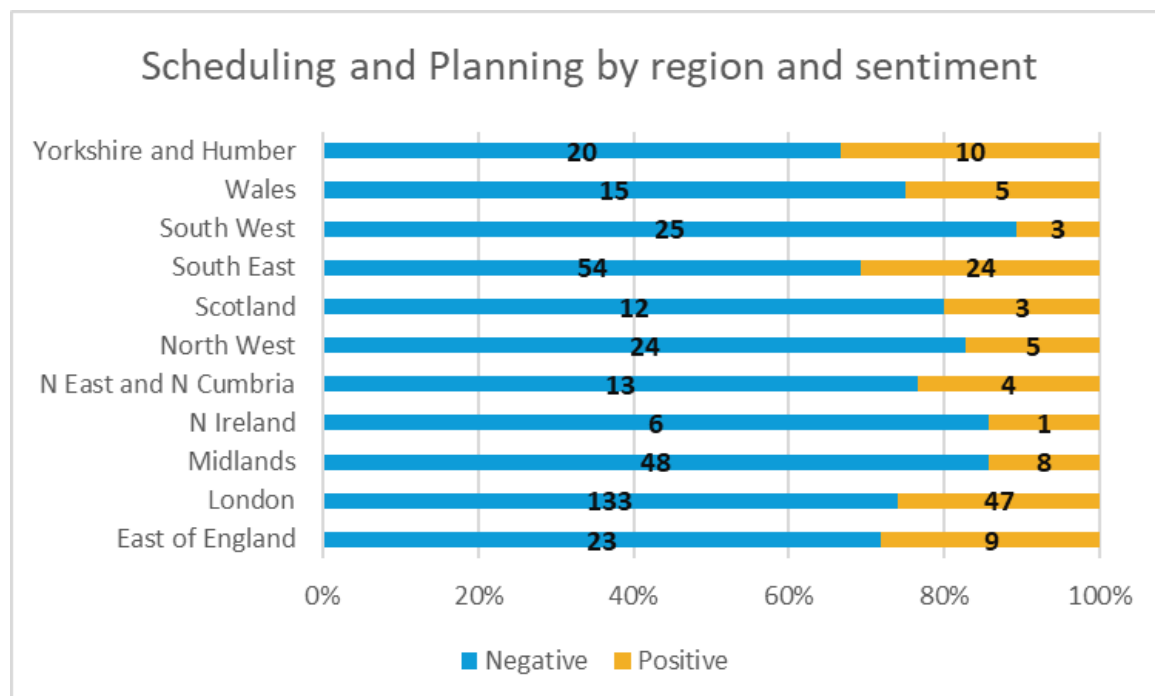
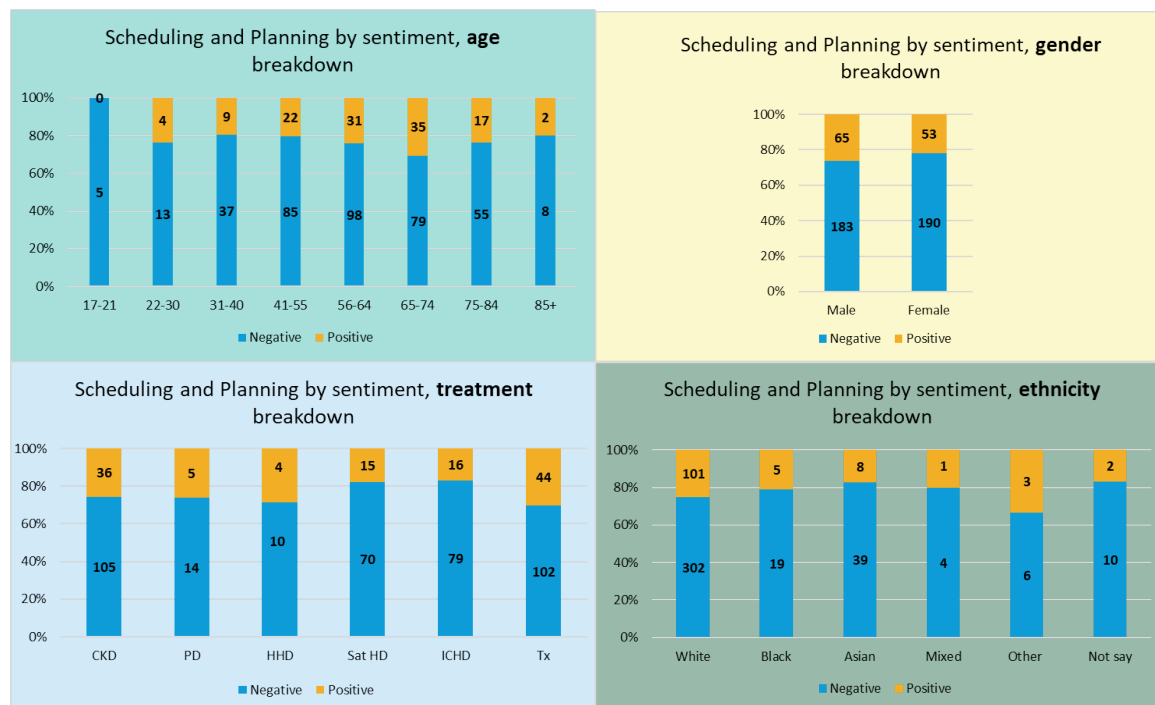
There were 42 comments regarding staff workload, with 28 comments (67%) stating staff are overworked and have little time to deliver good care to patients. The remaining comments (14 comments, 33%) note that although staff are overworked and busy, the standard of care has not dropped.

*“The nurses work I’m redibly [incredibly] HARD, running around all day. BUT NO TIME FOR PATIENTS.”
(Female, White, 75-84, Centre HD)*

*“I also think it is insane how much work is piles onto the nurses like <NURSE NAME> and <NURSE NAME> - they need more support, they do amazing work and are always supportive but they are under far too much pressure due to excessive workload.”
(Female, Asian, 41-55, Transplant)*

Characteristics of respondents commenting on *Scheduling and Planning*

There was representation of all patient groups in the comments related to scheduling and planning. Individuals from an Asian ethnic heritage or who preferred not to state their ethnicity had a higher representation in this theme compared to other themes.



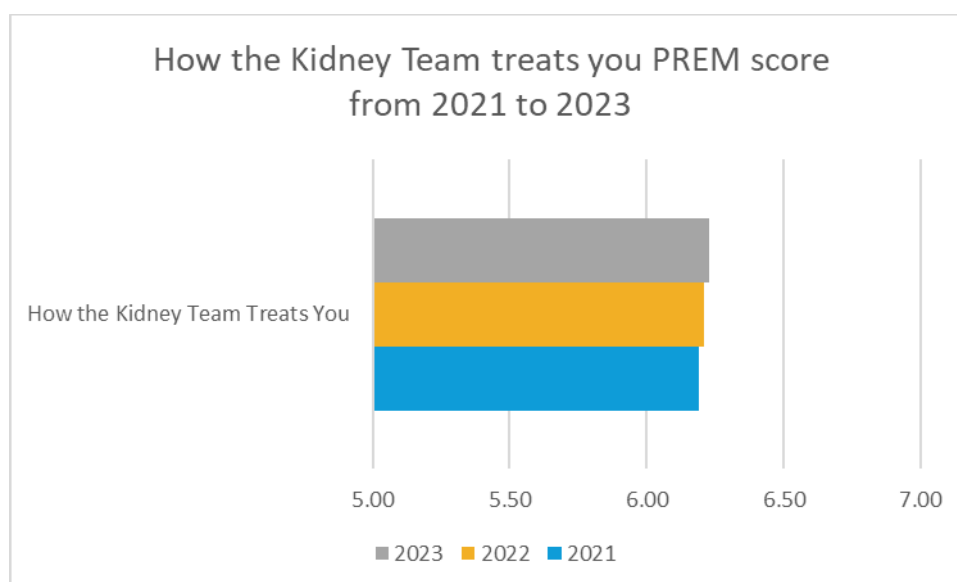
CHAPTER 12: HOW THE KIDNEY TEAM TREATS YOU

Like previous years, comments relating to the kidney team and the quality of care received the highest number of comments and were overwhelmingly positive (65%) compared to other themes. The score for *How the Kidney Team Treats You* has been consistently 6.2 out of 7 for the past three years (figure 11).

Table 20: Breakdown of subthemes for *How the Kidney Team Treats You* by sentiment

	Total	Negative	Neutral	Positive
Members of the team	1,835	551	81	1,203
Quality of care received	737	221	36	488
Elements of care	242	139	4	99
Staff speaking in first language	11	7		4
Better pay for staff	3	3		

Figure 11: Scores for *How the Kidney Team Treats You* from 2021 to 2023.



Members of the team

Covering 80% of *How the Kidney Team Treats You* theme, comments regarding staff members in general, specific staff members such as consultants and nurses, and wider team members were predominantly positive. Many individuals mentioned how members of staff had been kind and caring. Negative comments discussed how some staff lacked desired empathy.

Table 21: Breakdown of codes for Members of the team by sentiment

	Total	Negative	Neutral	Positive
Staff	1,099	254	38	807
Consultants	308	122	23	163
Nurses	290	111	12	167
Management of the unit	71	42	6	23
Transplant care	55	17	2	36
Multidisciplinary team (MDT)	12	5		7

“I would like to say that the kidney team at <UNIT NAME> has been brilliant. They look after their patients & staff well thankyou to the kidney team.”

(Male, Black, 56-64, Transplant)

“The nursing staff are very knowledgeable and very caring.”

(Male, Asian, 41-55, Centre HD)

“My Consultant is great and we have a great relationship. I can contact her at anytime if I require an answer to a question or query.”

(Male, White, 65-74, CKD)

Quality of care received

This code covers comments about the perceived standard of care the individual received. Most (66%) are positive with individuals giving examples of times their care surpassed expectations, with negative comments giving examples of times when their care has been below par, such as staff members having a bad attitude towards patients.

“I am satisfied with the care I receive.”

(Female, White, 65-74, HHD)

“All in all the <UNIT NAME> centre is exceptional and really supports patient care to the highest quality.”

(Female, Asian, 65-74, Sat HD)

“I did not choose kidney Care but as I require it I could not pay for better care.”

(Female, White, 56-65, Transplant)

Elements of Care

Several individuals (242) discussed elements of their care that affected how well they felt cared for. Because of the large number of comments within this group, the category was broken down further for ease of reporting. Comments relating to patient-centred care discussed how respondents want care to be individualised and for staff members to address them by their name, whilst others mentioned competency of staff, being mostly negative (65%), and giving examples of how some staff do not seem well-trained for their role. There were 46 comments which mentioned whether the respondent felt supported by the team: 63% felt they were. However, there were 33 comments which mentioned patients feeling dismissed with 61% of these comments stating that the individual often felt dismissed, for example feeling that the team did not acknowledge what they were saying. Positive comments under this code included individuals feeling they rarely felt dismissed.

Table 22: Breakdown of codes for Elements of Care by sentiment

	Total	Negative	Neutral	Positive
Patient-centred care	74	49		25
Competent staff	52	34	2	16
Patient feels supported	46	17	0	29
Patients feel dismissed	33	20		13
Care feels rushed	29	19	2	8
Helpfulness of staff	8			8

“Always find staff willing to help.”
(Male, White, 75-84, CKD)

“Staff are always rushing to put people on and take people off. They never seem to have time to be with a patient. Think staff morale is very low.”
(Male, White, 56-64, Sat HD)

“Staff is supporting, respond quickly.”
(Male, Black, 56-64, PD)

Staff speaking in first language

There were 11 comments about staff speaking in languages other than English around patients, with 63% stating that it was inappropriate. Positive comments were from individuals who do not have English as a first language who found it helpful that staff could translate to them in their mutual language.

“Groups of staff members of the same nationality converse in their language at my bedside which I find uncomfortable.”
(Female, White, 56-86, Centre HD)

“I am happy with everything and everyone. I always get help from admin as she speaks same language she is always here to help if I have any problems.”
(Female, Asian, 31-40, Sat HD)

Better pay for staff

Three respondents stated that staff should be paid more money for the work they do.

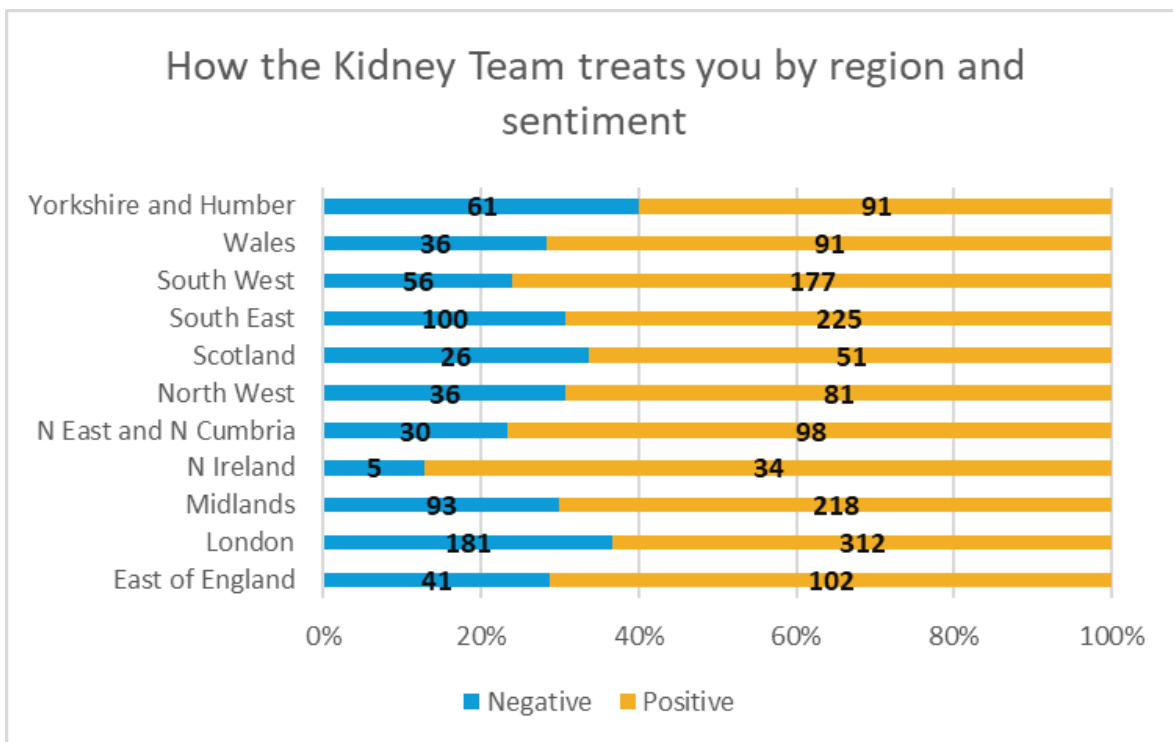
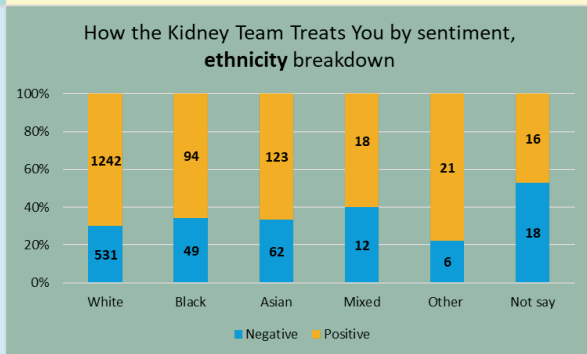
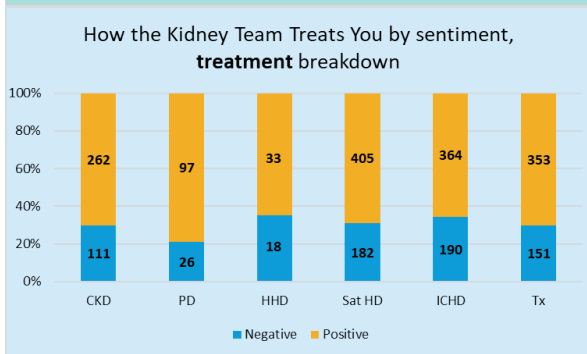
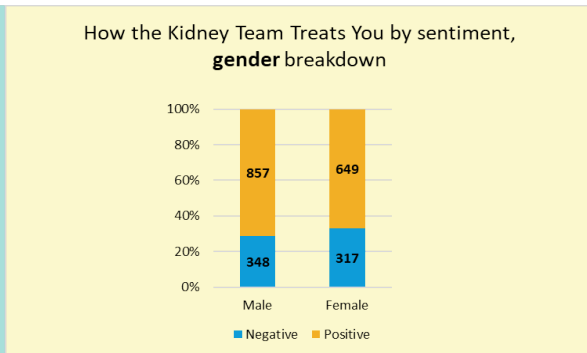
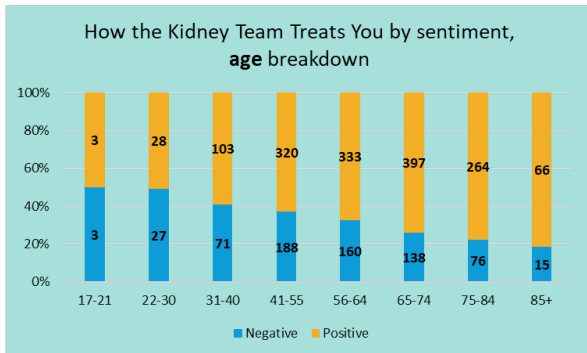
“Nurses are not paid enough.”
(Male, White, 75-84, Sat HD)

“Nurses need better pay.”
(Female, White, 65-74, Sat HD)

“Cutting wages does not improve services.”
(Male, White, 65-74, Sat HD)

Characteristics of respondents commenting on *How the Kidney Team Treats You*

There is representation from all patient groups within this theme. Younger patients tended to have a more negative opinion about the quality of care they received, as did those who would rather not disclose their ethnicity.



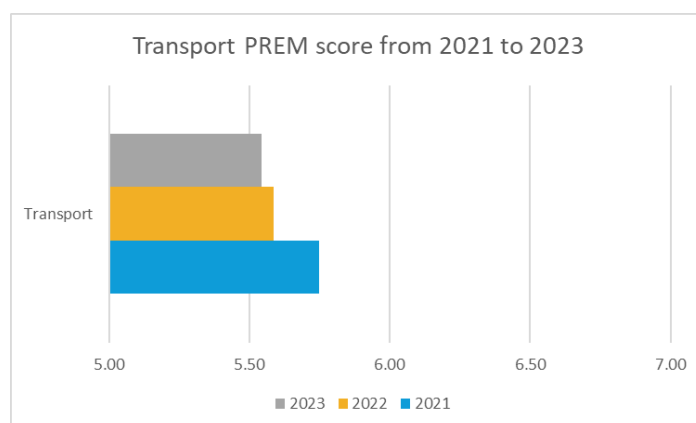
CHAPTER 13: TRANSPORT

There were 582 comments related to the theme **Transport**, of which 78% were negative. Hospital-arranged transport is offered to individuals receiving haemodialysis in-centre or at a satellite unit. Comments related to the timeliness of transport post-treatment, as well as the suitability of the vehicle. The overall score for **Transport** has decreased slightly in recent years, now 5.5 compared to 5.7 in 2021, and in 2023 is now the most poorly scoring theme of Kidney PREM (figure 12).

Table 23: Breakdown of subthemes for Transport by sentiment

	Total	Negative	Neutral	Positive
Waiting times for transport	290	243	10	37
Transport in general	153	111	12	30
Distance to travel to kidney unit	39	27	5	7
Transport staff	37	21	1	15
Ambulance transport	30	23	3	4
Transport to unit	21	15	1	5
Accessibility of transport	13	12		1

Figure 12: Scores for Transport from 2021 to 2023.



Most respondents who commented on the timeliness of the transport reported a negative experience, wanting shorter wait times. General comments on transport mention suggestions to improve transport, for example having patients who travel together finishing dialysis at the same time. Ambulances, accessibility of transport and transport to the unit received fewer comments but were mostly negative, with respondents finding ambulance transport inaccessible and uncomfortable, or wanting more suitable transport for accessibility such as larger cars that are easier to transfer into, and for transport to the unit to be more reliable.

“Before dialysis the transport comes at around 5:45 and the dialysis unit opens at 7am. It is extremely early considering I live quite close.”
(Male, Asian, 56-64, Centre HD)

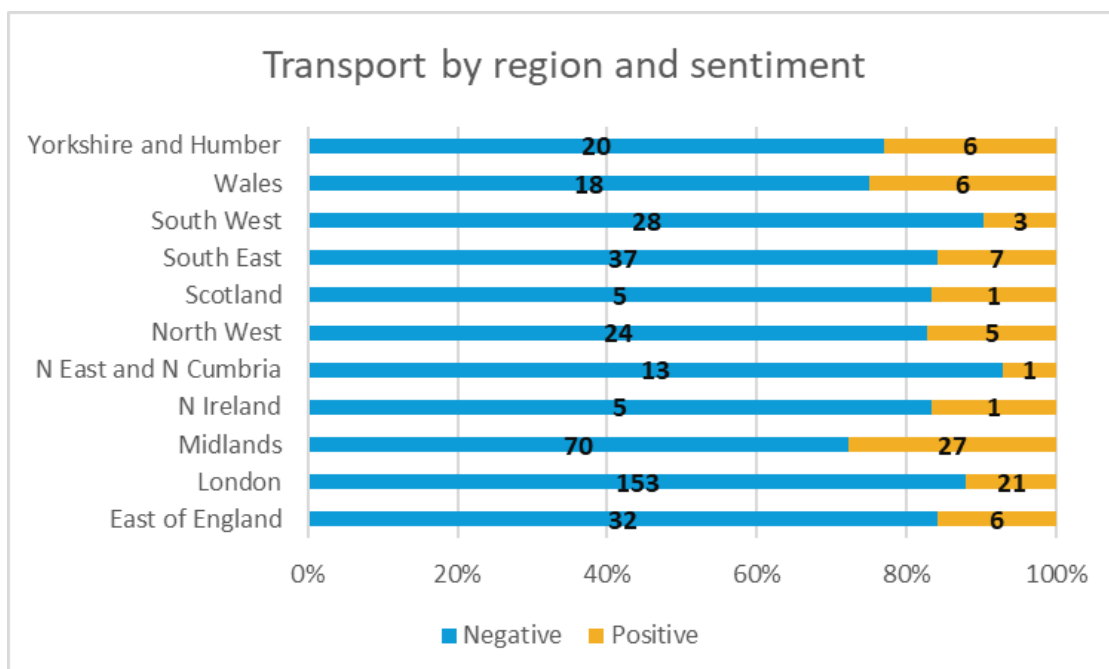
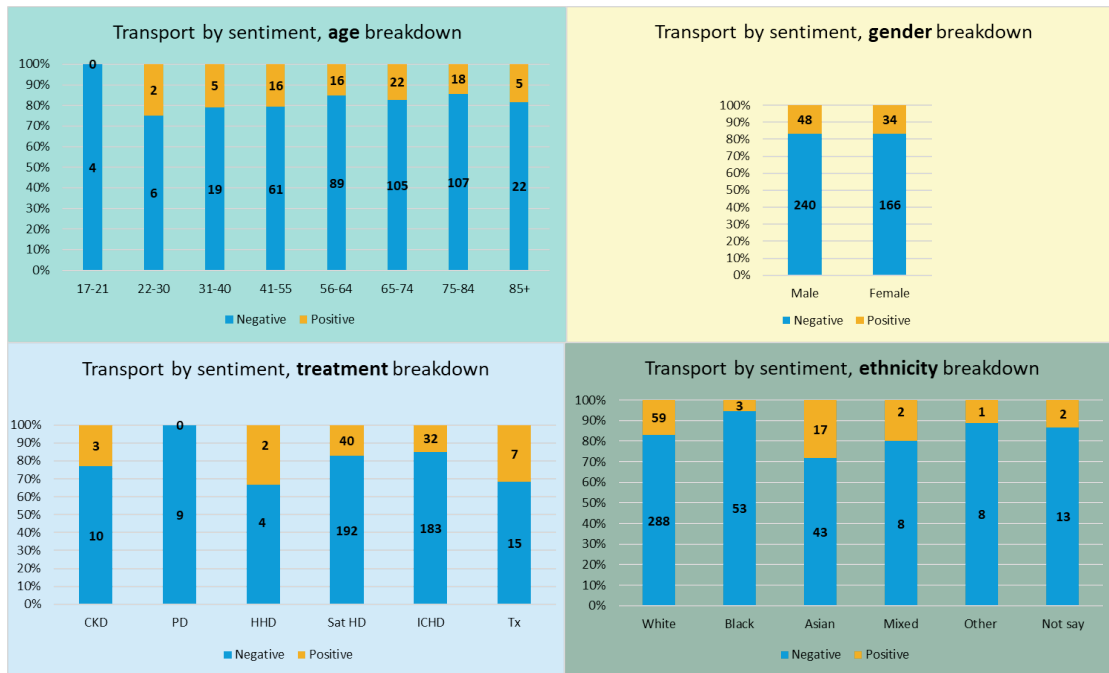
“The transport should be better organised in a way that doesn't keep the patient waiting for long before and after dialysis.”
(Male, Black, 56-64, Centre HD)

“Ambulances with poor suspension.”
(Male, White, 75-84, Sat HD)

“Ambulances <NAME> - new ones not comfortable and passenger door difficult to access. Back 2 seats have no hand rests. Aisle too narrow for walkers. Insufficient handrails.”
(Female, White, 65-74, Sat HD)

Characteristics of respondents commenting on *Transport*

In Kidney PREM, questions about transport are directed at individuals for whom the kidney unit arranges transport to and from in-centre or in-satellite haemodialysis, hence it is not surprising that individuals receiving in-centre or in-satellite dialysis are more likely to comment on transport in their free-text response compared to other treatments. Individuals aged 41 years to 84 years old are more likely to comment on this theme, with individuals from a Black ethnic heritage commenting on *Transport* more than any other theme.



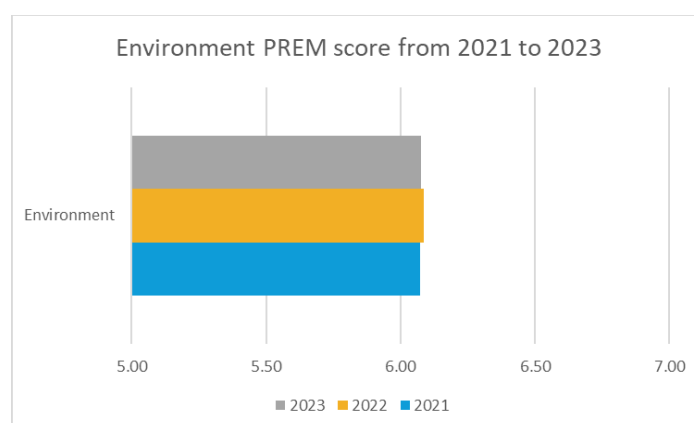
CHAPTER 14: ENVIRONMENT

The theme the **Environment** was the second largest theme to have been discussed in participant comments. Respondents discussed the availability of refreshments offered during dialysis, parking, and comfort of the unit. Most were negative (75%), with comments giving suggestions for improvements such as increasing the ambient temperature of the unit. The overall score for the **Environment** has been consistent over the last 3 years, at 6.1 out of 7 (figure 13).

Table 24: Breakdown of subthemes for Environment by sentiment

Subtheme	Total	Negative	Neutral	Positive
Food and Drink	171	134	9	28
Parking	154	113	8	33
Comfort during dialysis	153	126	6	21
Being occupied during dialysis	100	71	7	22
Suitability of the unit	92	62	5	25
Accessibility	66	50		16
Equipment	60	46	2	12
Cleanliness	42	27		15

Figure 13: Scores for Environment from 2021 to 2023.



Food and Drink

This subtheme was discussed in 171 comments, of which 78% were negative. Comments included individuals wanting more food or drink offered during dialysis, wanting sandwiches to be offered in place of biscuits and comments regarding the quality of food available.

Table 25: Breakdown of codes for Food and Drink by sentiment

Codes	Total	Negative	Neutral	Positive
Need refreshments	84	63	5	16
Bring back sandwiches	54	49	1	4
Quality of food offered	33	22	3	8

“We need sandwich rather than biscuits-small.”
(Male, Black, 41-55, Centre HD)

“Why were the sandwiches stopped?”
(Female, Asian, 56-64, Sat HD)

“Other than the availability (or lack thereof) of hot drinks during treatment I cannot think of any additional comments or remarks at this time.”
(Male, White, 31-40, PD)

“Better catering, sandwiches not nice for breakfast. Toast would be nice as we can smell it when staff are having theirs.”
(White, Not Say, 41-55, Centre HD)

Parking

There were 154 comments, 73% which were negative, that discussed parking. Comments regarding parking were about the lack of parking available in general, lack of disabled parking available and the cost of parking when visiting the kidney unit. From the 7,894 respondents who answered question 38 of Kidney PREM (*When you attend the renal unit, how would you grade parking?*), excluding those who answered ‘not applicable’ or ‘don’t know, 15% rated it as the worst it could be (scoring it a one out of seven).

Table 26: Breakdown of codes for Parking by sentiment

Codes	Total	Negative	Neutral	Positive
Parking	131	94	7	30
Availability of disabled parking	23	19	1	3

“Need more disabled parking spaces.”
(Female, Mixed, 31-40, Centre HD)

“However, I do feel it is wrong to pay for parking at the hospital 3 times a week it is very expensive especially if you are on dialysis for years.”
(Female, Asian, 41-55, Sat HD)

“Parking is poor often late for appointments.”
(Male, White, 65-74, Transplant)

Comfort during dialysis

There were 153 comments related to comfort during dialysis, with comments split evenly between the beds and chairs provided for dialysis being uncomfortable, and the temperature of the unit being too cold. Most (82%) comments were negative.

Table 27: Breakdown of codes for Comfort during dialysis by sentiment

Codes	Total	Negative	Neutral	Positive
Beds/ Chairs	78	60	4	14
Temperature	75	66	2	7

“The unit is always cold due to the fact it only has air conditioning. Some days total lack of blankets.”

(Female, White, 75-84, Centre HD)

“Room temperature should be warmer.”

(Male, Asian, 65-74, Centre HD)

“Patient beds are solid and uncomfortable (back breaking and sore bum) and not good when sitting for four or five hours.”

(Male, White, 41-55, Centre HD)

“Comfort can be a real issue. There are only a number of cushions available and sitting there for 4 hours straight is quite a difficult thing to do, especially if you are uncomfortable. There are also a number of comfy beds on the unit but these are not always used and I cannot understand why as they are a lot more comfortable especially for the elderly patients.”

(Not Say, Not Say, 31-40, Transplant)

Being occupied during dialysis

There were 100 comments discussing the televisions, noise of the unit, wanting something to do during dialysis and the WiFi. Most comments were negative (71%). Examples of suggestions from individuals included having more remotes available for the televisions, staff encouraging the use of headphones so that the unit is quiet for those who want to sleep and staff providing activities during dialysis, for instance facilitating exercise.

Table 28: Breakdown of codes for Being occupied during dialysis by sentiment

Codes	Total	Negative	Neutral	Positive
Televisions	33	24	3	6
Unit too noisy	25	18		7
Entertainment during dialysis needed	21	12	4	5
WiFi	21	17		4

“It would be great if there could be a TV to watch as it is very boring just lying in bed for 3 and half hours or perhaps some music to listen to.”

(Male, White, 65-74, Centre HD)

“And if your providing TVs for entertainment, make them work. Past 3 years most TVs don't work at beds.”

(Male, Black, 56-64, Sat HD)

“It can be loud in the treatment room at times.”

(Female, Not Say, 56-64, Centre HD)

“On unit - could do with radio playing in background.”

(Female, White, 31-40, Centre HD)

Suitability of the unit

There were 92 comments about the suitability of the unit, which covered the waiting area, décor of the unit, availability of toilets and unit building works. Most were negative (67%), with the waiting room described as small and the chairs as uncomfortable. Décor of the unit was seen as outdated by many individuals (62% of comments). Comments regarding the building works found the works to be disruptive to care, with positive comments thanking staff for their perseverance during this time.

Table 29: Breakdown of codes for Suitability of the unit by sentiment

Codes	Total	Negative	Neutral	Positive
Waiting area - comfortable	52	36	2	14
Décor of the unit	24	15	2	7
Buiding works in the unit	11	8		3
Availability of toilets	5	3	1	1

*“Access to reception is very difficult b[e]cause of building works & wheelchair from vehicle drop off point was impossible to get.”
(Female, White, 75-84, CKD)*

*“The waiting area could be improved, it feels too claustrophobic. Maybe some clear panels would help.”
(Male, White, 56-64, Centre HD)*

*“Decorations would be nice because the rooms are so depressing.”
(Female, White, 17-21, Centre HD)*

Accessibility

In total, accessing the unit was mentioned in 66 comments, with 75% of these being negative and suggesting small improvements for accessibility such as fixing the lifts provided, using lighter doors to make access easier or using automatic doors to enter the unit.

Table 30: Breakdown of codes for Accessibility by sentiment

Codes	Total	Negative	Neutral	Positive
Ability to access the unit	66	50		16

*“The entrance is not fully level with the ground so patient needs help to get to the unit.”
(Female, White, 56-64, Centre HD)*

*“The lifts take forever, not that clean and are always out of order.”
(Female, Asian, 22-30, Transplant)*

◆ *“Main entrance door to reception slams every time someone enters it exits. This should be repaired as it is a simple and low cost task.”* ◆
(Male, White, 41-55, CKD)

◆ *“it would be useful to have a hand rail outside as there is [a bit] of a slope when walking to and from my car. (near the portacabins).”* ◆
(Male, White, 65-74, Centre HD)

Equipment

There were 60 comments regarding equipment, 76% were negative. Comments included wanting better equipment such as newer dialysis machines and more supplies, with individuals giving examples of certain types of needles not being available.

Table 31: Breakdown of codes for Equipment by sentiment

Codes	Total	Negative	Neutral	Positive
Better equipment needed	38	31	1	6
Lack of supplies	22	15	1	6

"I needed some patches since I was getting treatment here. I couldn't get any at hospital or GP. They kept me going round in a circle. I end up buying some with help from family. It is not the correct 1. But can't be helped."
 (Female, Asian, 75-84, Centre HD)

"Often there are machine breakdowns. They could do with being replaced and updated now."
 (Male, White, 75-84, Centre HD)

Cleanliness

There were 42 comments regarding cleanliness, 33 comments covered cleanliness of the unit and nine comments specifically about the cleanliness of the toilets. Most were negative (64%) with patients wanting the unit to be cleaned more frequently and to a higher standard.

Table 32: Breakdown of codes for Cleanliness by sentiment

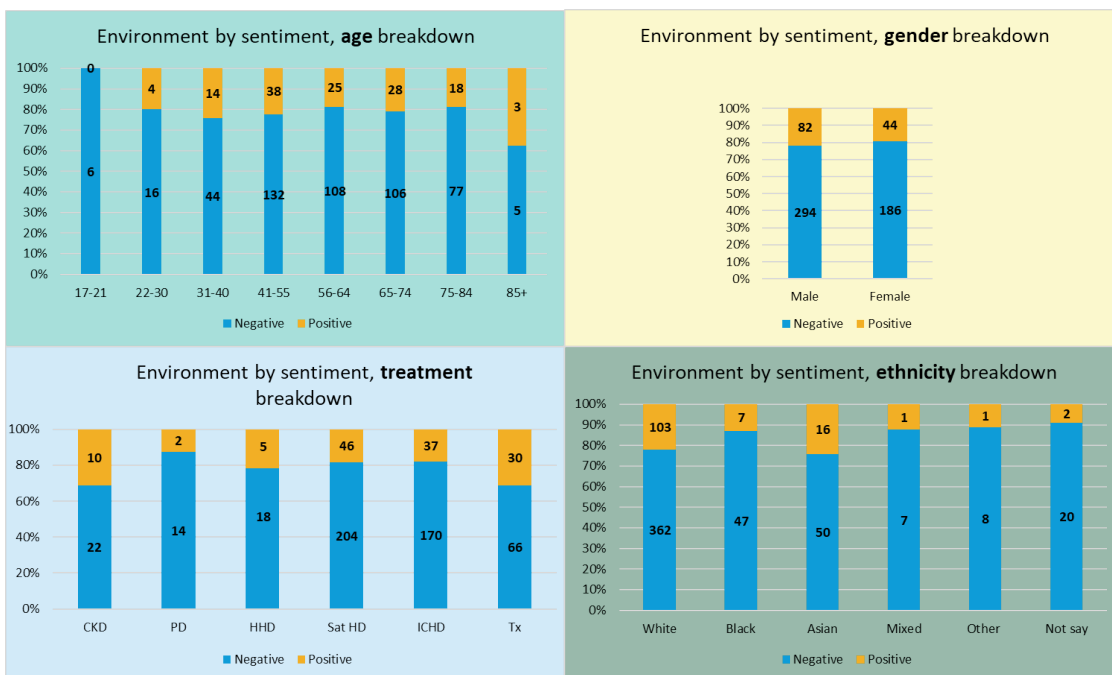
Codes	Total	Negative	Neutral	Positive
Unit is clean	33	19		14
Toilet - cleanliness	9	8		1

"The dialysis place in this unit is not clean and every time I come in it smells like a dirty toilet which is never been clean."
 (Male, Black, 31-40, Sat HD)

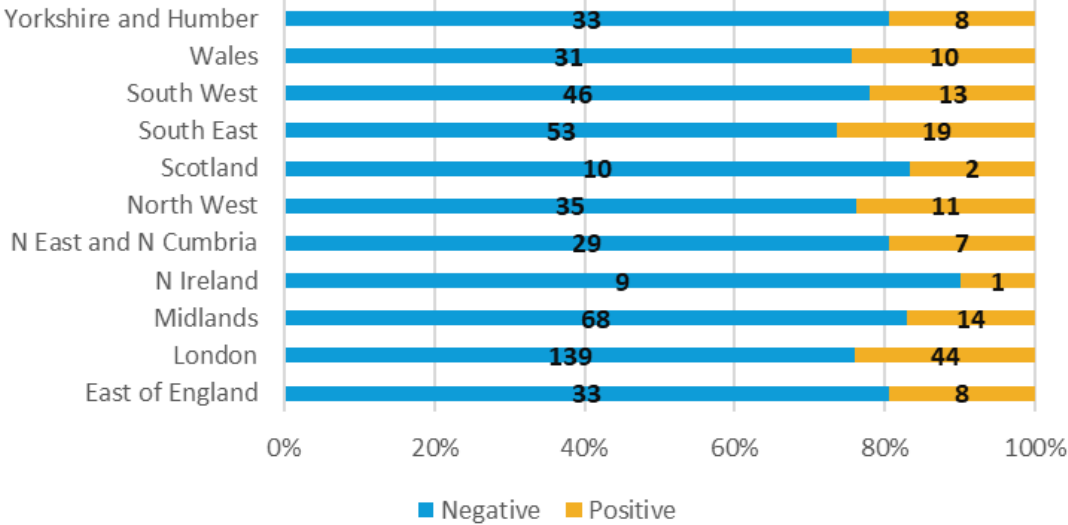
"Toilets on the unit are filthy and not cleaned regularly enough. Especially when there is a blockage."
 (Female, Black, 41-55, Centre HD)

Characteristics of respondents commenting on Environment

The figures below show the profile of respondents who commented on this aspect of their care. Not surprisingly, given the location of treatment, those receiving haemodialysis in-centre or at a satellite unit were those who commented most.



Environment by region and sentiment



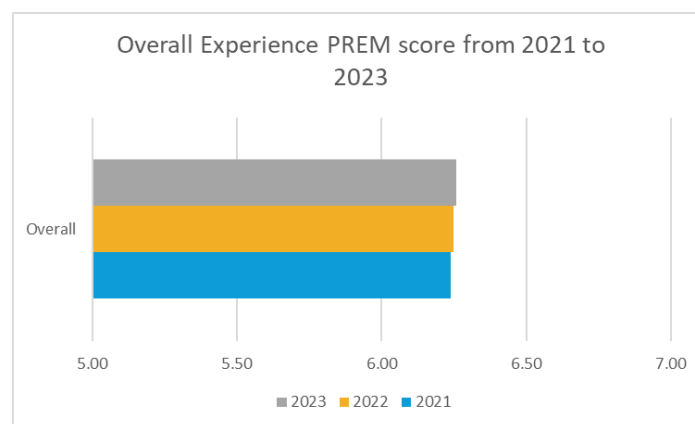
CHAPTER 15: OVERALL EXPERIENCE

This year comments which reflected the quality of care overall were coded **Overall Experience** to align with the Kidney PREM. Over the last 3 years, the Kidney PREM score for **Overall Experience** has been consistently one of the highest themes at around 6.2 out of 7 (figure 14).

Table 33: Breakdown of codes for Overall Experience by sentiment

	Total	Negative	Neutral	Positive
Overall Experience	255	6		249

Figure 14: Scores for Overall Experience from 2021 to 2023.



There were 249 positive comments (97% of all comments related to this theme) which stated that overall, their care was good. Only six comments suggested there was room for improvement but did not specify how it could be improved.

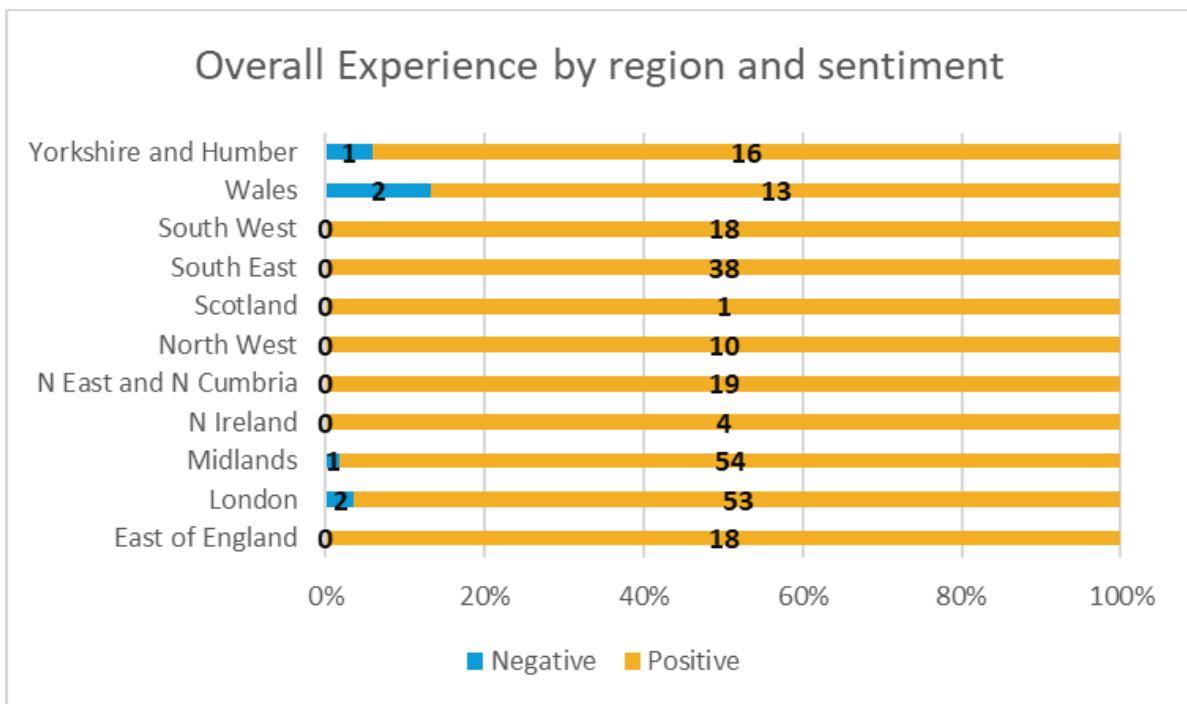
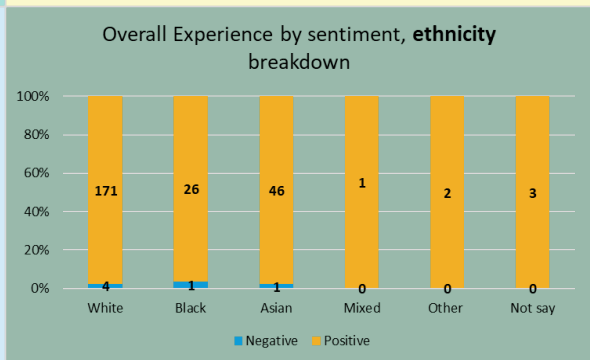
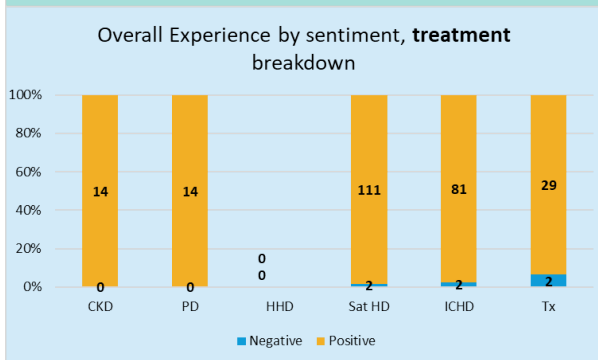
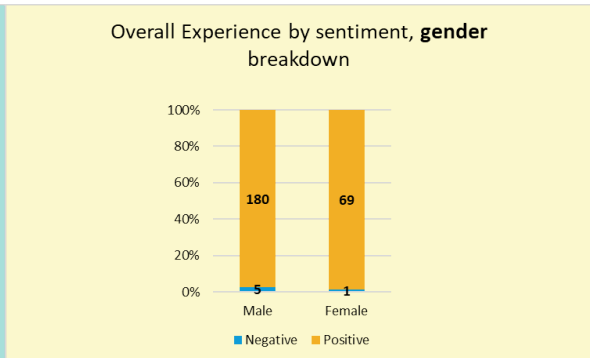
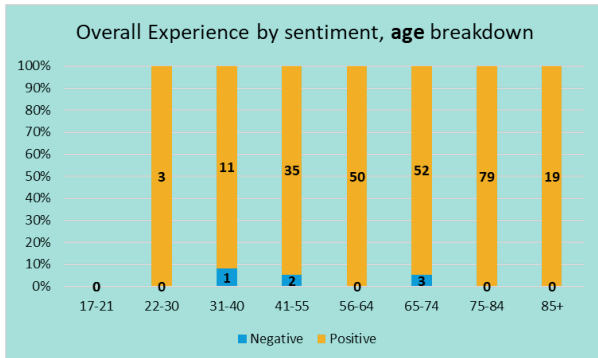
“Exceptional Quality Service.”
(Male, Black, 56-64, CKD)

“Don't change anything.”
(Female, White, 75-84, HHD)

“Overall everything is going on great.”
(Male, Black, 41-55, Transplant)

Characteristics of respondents commenting on Overall Experience

Those who left a free-text comment which summarised their overall experience, and for most in a positive way, were more likely to identify as male and be aged over 41 years old. There was representation from all ethnicity groups.



CHAPTER 16: ADDITIONAL QUESTIONS

In addition to the 39 questions of Kidney PREM on care experience, there are questions asked to better understand the characteristics of the person responding, such as whether the individual uses an online patient platform to access details about their kidney care, or whether the person speaks English as a first language. This year, there were also three additional questions asked at the end of the Kidney PREM to find out more about people’s experience of certain topics deemed important by the national Kidney PREM working group.

These were:

1. Have your kidney team talked to you about your wellbeing in the last year?
For example: benefits/housing/mental health
2. Who are your kidney clinic letters addressed to? Me only, Me and copied to GP, GP only, GP and copied to me, Either, Don't know
3. Has anyone from your unit talked to you about last year’s PREM report?

Comments relating to patient characteristics, and these additional questions have been aligned under this **Additional Questions** theme.

Table 34: Breakdown of codes for *Additional Questions* by sentiment

	Total	Negative	Neutral	Positive
Change to PKB	153	114	11	28
Lack of mental health support	147	103	8	36
Feedback from PREM	25	15	6	4
Who letters are addressed to	18	15	2	1
Language barriers	15	12		3
Data Protection	7	5		2

There were 158 comments about the change from PatientView to Patients Knows Best (PKB), both web-based applications used by patients to access results and appointment information. A total of 75% of the comments discussed teething issues with the new application such as results being presented in a table that was hard to read on a small device. However, respondents often stated that they were glad to have such an application available. Individuals from Northern Ireland who do not yet have access to PKB would like it.

Individuals discussing mental health support (147 comments) found that the kidney team, especially consultants, rarely asked how they were doing. Participants reported that they were not offered support for their mental health (70% of these comments), whilst others gave examples of how the kidney team had showed concern for their wellbeing. Feedback from Kidney PREM was mentioned in 25 comments with most respondents (60%) noting that they had not been informed about their centres PREM results from previous years. The remaining 40% of comments include examples of kidney units which have displayed Kidney PREM results and discussed actions for quality improvement. Some individuals mentioned not receiving any clinic letters regarding their kidney care (15 comments), with 3 responses stating they were happy that they had received their clinic letter and their GP had been copied in. Comments regarding language barriers discussed respondents who do not speak English and therefore struggle to understand their

Kidney team, needing assistance from translators. Data protection was raised by a small number of individuals (n=7), mainly asking how their data is used by the kidney unit.

“Mental health is not asked about or helped with.”
(Female, White, 22-30, Sat HD)

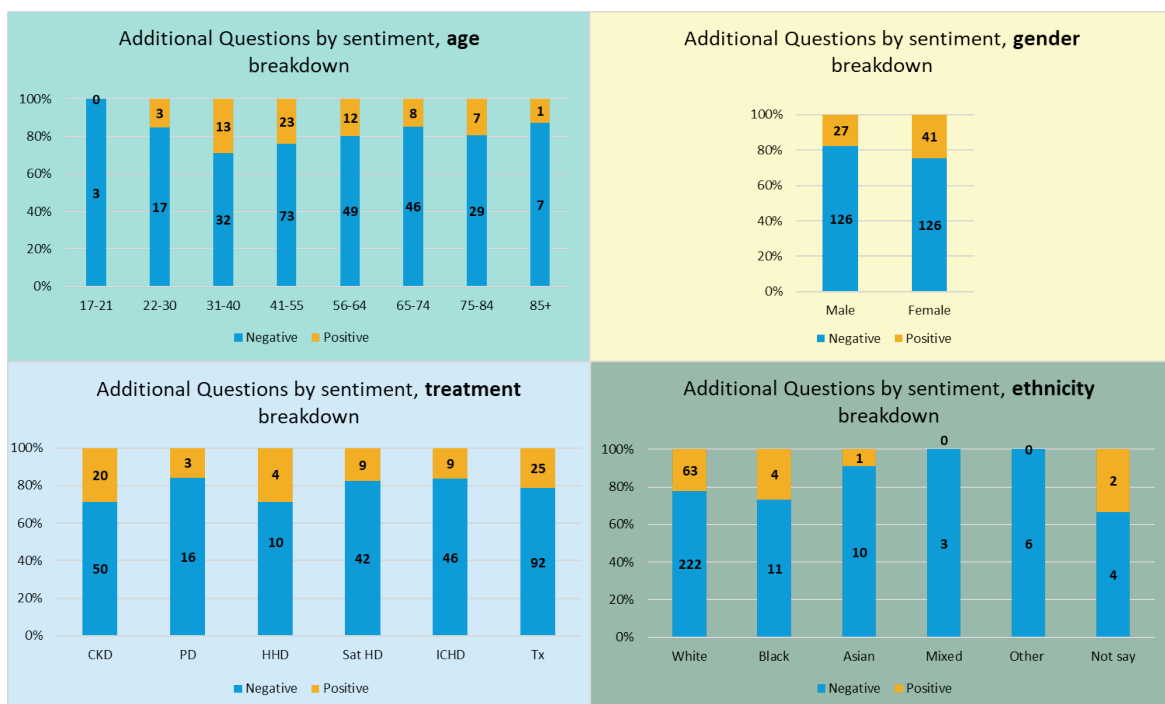
“There is a lack of information regarding protocols used, especially regarding data capture via tests and alternative modelling.”
(Male, Other, 65-74, CKD)

“I would like access to Patient Knows best . Despite trying I have been unable to access it, and I would like to be able to.”
(Female, White, 65-74, Centre HD)

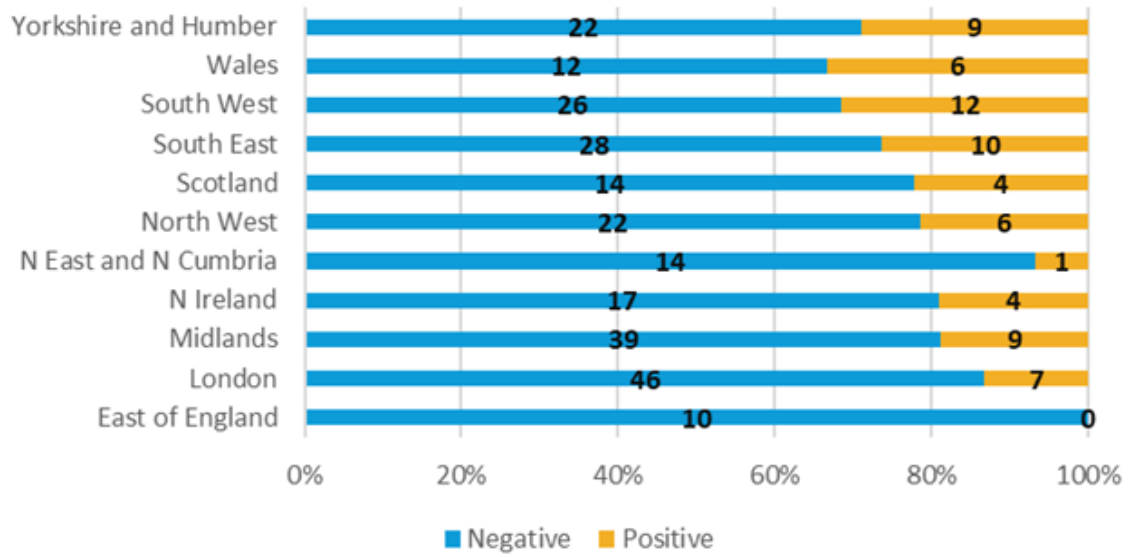
“I used PKB since Patientview was ceased to read my blood test results, I’m a transplant patient of 2yrs. I find it difficult to see what bloods results range they should be on PKB....”
(Female, White, 56-64, Transplant)

Characteristics of respondents commenting on *Additional Questions*

The profile of individuals who responded to this theme matched that of those who responded to Kidney PREM, though there was a spike in responses from individuals who have received a functioning transplant.



Additional Questions by region and sentiment



CHAPTER 17: EMERGING THEMES

Comments which did not relate directly to the 13 Kidney PREM themes or other questions asked were coded under **Emerging Themes**. In total, there were 520 comments, ranging from examples about their treatment or diagnosis, medication or prescription queries and questions about booking ‘holiday dialysis’.

Table 35: Breakdown of codes for *Emerging Themes* by sentiment

	Total	Negative	Neutral	Positive
Information about treatment/ diagnosis	184	88	52	44
Medications/ prescriptions	111	77	5	29
Transferring units	64	29	19	16
Comments about PREM survey	59	27	19	13
Hygiene	36	28	1	7
Ability to sort 'holiday dialysis'	27	18	1	8
More research needed regarding kidneys	15	10	1	4
Issues with other patients	14	11		3
NHS	10	8	2	

There were 184 comments with specific statements about an individual’s treatment or diagnosis, for example CKD stage or treatment method. These were mixed in sentiment (positive/ negative) depending on the experience of diagnosis and treatment, with 28% neutral. Medication and prescriptions received 111 responses with individuals discussing the wait to collect medication, shortage of medication or medication side effects. Of these, 69% were negative with individuals finding the wait too long or their necessary medication not being available. Individuals who have changed units often described the reason for the transfer, for example, capacity issues, distance to the unit or wanting to receive treatment at a closer location.

There were 59 comments about the Kidney PREM survey itself with individuals verifying the reason for certain scores. Hygiene comments included hand washing by both staff and other patients, as well as the use or lack of use of PPE, specifically face masks. Some individuals feel that face masks should still be worn to stop the spread of viruses, with COVID-19 given as an example. 27 respondents mentioned the concept of ‘holiday dialysis’, with 18 individuals wanting more information about organising ‘holiday dialysis’. 30% of these responses discussed how they had successfully experienced ‘holiday dialysis’ in which they were able to temporarily receive treatment at another centre in the UK.

“I am a new patient within this unit I have been transferred from a dialysis unit in Galway and have only been receiving dialysis for 1 month within this unit.”
(Female, White, 65-74, Centre HD)

“I have been unable to receive my receive my prescriptions on time.”
(Female, White, 85+, CKD)

“Will I be able to go on holiday and what advice can I get?”
(Female, Black, 56-64, Centre HD)

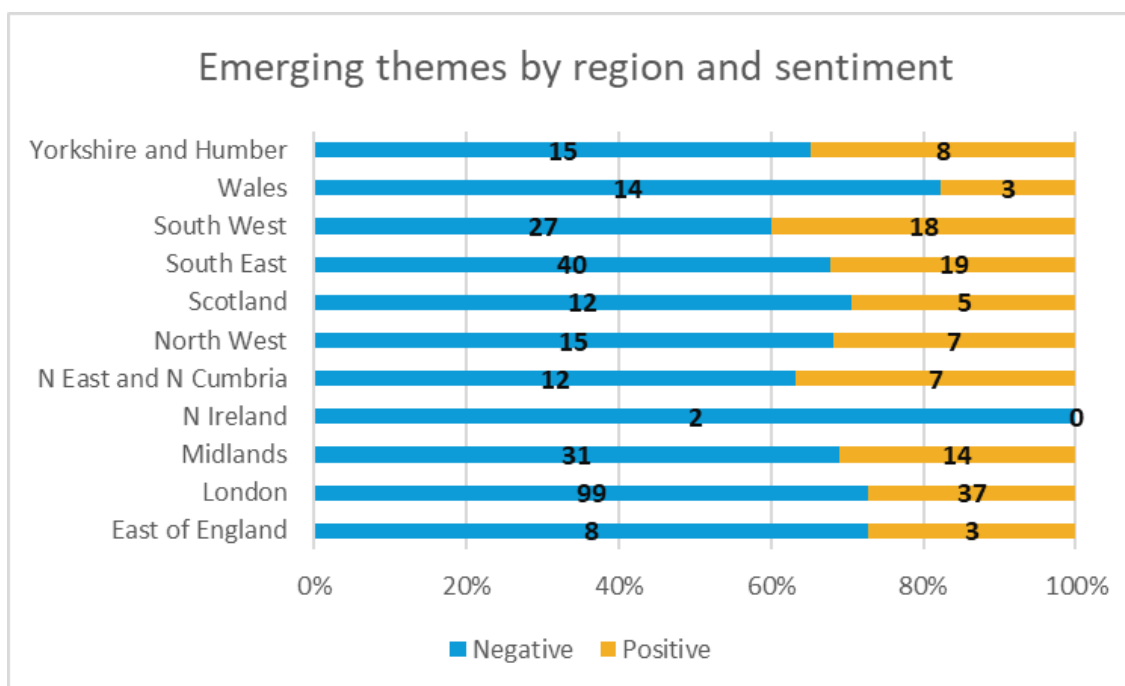
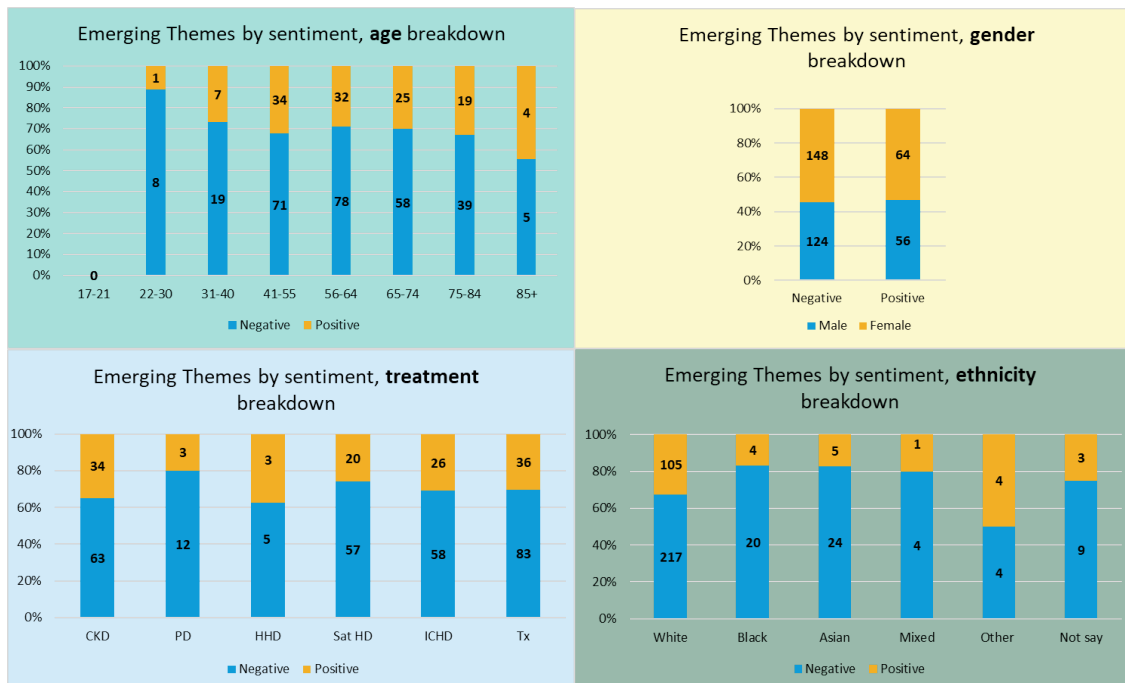
“Sometimes there is no sanitizer in the waiting areas.”
(Female, Black, 56-64, Centre HD)

“Example of the NHS at its very best.”
(Male, White, 41-55, Sat HD)

◆ *“Suggestion slip box.”* ◆
(Male, White, 56-64, Sat HD)

Characteristics of respondents commenting on *Emerging Themes*

Like the theme *Additional Questions*, the profile of individuals who responded to this theme matched that of those who responded to Kidney PREM, though there was a slightly higher number of responses from transplant recipients.



CHAPTER 18: COMPARISON OF FINDINGS FROM 2022

A comparison of free-text responses from 2022 and 2023 gives some insight into how patient experience of care has changed following the feedback in comments from 2022. The analysis of comments has been performed similarly with comments being coded under the Kidney PREM themes, where appropriate. Additionally, for 2023, themes (**Overall Experience** and **Additional Questions**) have been presented to better correlate to the Kidney PREM.

In 2023, the Kidney PREM was only available online, which increased the percentage of the total respondents who left a free-text response when completing Kidney PREM from 21.5% in 2022 to 36% in 2023, and nearly doubling the number of comments from 2,376 to 4,202. The representation of those who left a free text comment was similar to 2022, however, the number of comments from individuals of an Asian heritage almost doubled from 217 to 410. Overall, there remains good representation from all patient groups with no seen effects from having moved Kidney PREM to online only.

As with 2022, the most prominent theme was related to **How the Kidney Team Treats You**. These comments were predominantly positive (66%). 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 **Access to the Kidney Team** received the second highest number of comments in 2023, with accessing the clinical team such as nurses and consultants receiving a high proportion of negative comments (70%). In 2022, **Accessing the Kidney Team** received fewer comments, however the frequency of seeing the consultant received the most comments for this theme in both years.

Environment featured highly as a theme in both years and was 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 remained the case in 2023, with a larger emphasis on lack of parking and the price of parking causing an issue for individuals. Additionally, availability of food during dialysis sessions was also a problem.

In both years issues with **Scheduling and Planning** (frequency of appointments, waiting times and appointment scheduling issues like last-minute cancellations), featured as quite a negative aspect of care. Similarly, **Transport** waiting times following dialysis has continued to be an issue for respondents. Within **Emerging Themes**, comments about medication and prescriptions and information about 'holiday dialysis' have emerged both years, with individuals wanting better access to information about these aspects of care.

In 2022, younger individuals tended to focus on **Support** and older individuals on the **Environment** and **Transport**. Those not receiving KRT and those with a functioning transplant focused on **Scheduling and Planning**, and **Access to the Kidney Team**. Whereas those receiving haemodialysis in-centre or at a satellite unit commented on **Environment** and **Transport**. A similar picture emerged in 2023, with younger individuals focussing more on the **Environment**, and older individuals commenting on **How the Kidney Team Treats You** and **Access to the Kidney Team**. The responses from different treatment groups remain consistent with that of 2022.

CHAPTER 19: CONCLUSION

Over 4,000 comments from people living with kidney disease have provided a rich commentary that sits alongside the national Kidney PREM report and provides insight about what is important to people receiving kidney care in the UK. The authors hope this information is reviewed and used by the kidney community to make patient-centred improvements to care. Where patients have given consent, kidney centres have received the comments written by people being treated at their centre, to enable local-level changes to be made in response to their local reported patient experience.