

# Summary report of patient comments

Patient reported experience of kidney care in the UK, 2023



Working together for better patient information

## Introduction

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. The Kidney PREM measures patient experience of kidney care over 13 themes and is relevant to patients receiving all types of treatment for kidney disease across the UK. In 2023, Kidney PREM 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.* ”

This report summarises the full free-text comments analysis, which is available on the UK Kidney Association website<sup>1</sup>.

## Methods

Kidney PREM 2023 was available for individuals to complete online from 11th September to 6th November 2023. Data were downloaded from the Qualtrics platform (online survey tool) in Excel format, checked and a master file of all data<sup>2</sup> uploaded into QDA Miner, a computer-assisted coding software.

Using QDA Miner, comments were initially screened and 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 Patients Know 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, 2021<sup>3</sup>), and due to the vast number of comments received, the codes and themes were quantified for easier comparison and interpretation (Miles and Huberman, 1984<sup>4</sup>).

## Participant profile

In 2023, 11,647 people with kidney disease participated, with 4,202 (36% of responses) providing a further comment on their care. The number of respondents leaving a comment increased by 14.5%, in part due to the Kidney PREM being online only. This increase in comments improves understanding of patient experience of kidney care and helps to explain the reasons for any 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 at a local level.

1 [www.ukkidney.org/kidney-patient-reported-experience-measure](http://www.ukkidney.org/kidney-patient-reported-experience-measure)

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

3 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.

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

The representation (age, gender, ethnicity and treatment type) of those who provided a free text comment was similar to 2022, Table 1. 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 observable effect of hosting Kidney PREM online only.

**Table 1: Characteristics of individuals leaving a comment in Kidney PREM**

	Kidney PREM 2023 Comments	Kidney PREM 2023	Kidney PREM 2022 Comments
<b>Total</b>	<b>4,202</b>	<b>11,647</b>	<b>2,376</b>
<b>Age (Years)</b>			
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	1041 (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 (3.75)
<b>Gender</b>			
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%)
<b>Ethnicity</b>			
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%)
<b>Treatment</b>			
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**

## Overall Response

**Access to the kidney team** Overall Experience **Tests**  
 Additional Questions **Support** **Communication**  
**How the Kidney Team Treats You**  
**Emerging Themes** **Environment**  
**Scheduling and planning** **Privacy and dignity**  
**Transport** **Patient information**  
 Sharing Decisions **Needling** **Fluid and Diet**

Table 2 shows the breakdown of the number of comments for each theme, by sentiment (positive, negative, neutral). From the 4,202 respondents who left a comment, 417 individuals (9.8%) stated that there was nothing further to add.

**Table 2: Total and number of comments by sentiment, for Kidney PREM themes**

	Total (n)	Negative	Neutral	Positive
How the Kidney Team Treats You	2,283	678	91	1,514
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



## Key Findings

*How the Kidney Team Treats You* received the most comments (2,283 comments). The majority of comments in this theme are positive (66%), with most comments thanking staff for their care and commitment.

“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)

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

(Female, White, 56-65, Transplant)

“Staff is supporting, respond quickly.”

(Male, Black, 56-64, PD)

The theme *Access to the Kidney Team* received the second largest number of comments. 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. The majority of the comments were negative (69%).

“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)

“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)

“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)

*Environment* included comments on wanting better parking facilities and food to be offered during dialysis sessions. These comments were mostly negative (76%).

“We need sandwich rather than biscuits-small.”

(Male, Black, 41-55, 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)

“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)

## Key Findings

The theme *Scheduling and Planning* covers areas of care such as appointment availability. Individuals reported that they wanted 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.

“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)

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

“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)

*Transport* covers respondents' experiences with hospital arranged transport for 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.

“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)

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.

**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)

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

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

**Privacy and Dignity:** “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)

## Key Findings

This year, comments which reflected the overall quality of care were coded *Overall Experience* to align with the Kidney PREM. 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)

The theme *Additional Questions* included any comments made about questions asked in addition to the Kidney PREM measure itself, 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 learn about people’s experience of certain topics deemed important by the national Kidney PREM working group in collaboration with experts by experience.

“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)

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’.

“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)

## Key Findings

**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 that Little Gems do not appear for every theme and may not be relevant to all kidney units.

“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)

“Handheld book for renal foods to be taken out and about with patients.”

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

“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)

## 2023 / 2022 Comparison

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. The analysis of comments was 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 relate 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 36.1% 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.

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 comments 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 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 session was also a problem.



In both years issues with *Scheduling and Planning* (frequency of appointments, waiting times and appointment scheduling issues such as last minute cancellations), featured as a negative aspect of care. Similarly, *Transport* waiting times following dialysis have continued to be an issue for respondents. Within *Emerging Themes*, comments about medication and prescriptions and information about 'holiday dialysis' have featured in 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 focussed on *Scheduling and Planning*, and *Access to the Kidney Team*. In contrast, those receiving haemodialysis in-centre or at a satellite unit commented more often about the *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 remains consistent with that of 2022.

## 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.

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