

Summary report of patient comments

Patient reported experience of kidney care in the UK, 2022



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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 (KCUK). 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. Additionally, when accessed online, the Kidney PREM has a free text question,

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

This report summarises the full free-text comments analysis, which is available on the UK Kidney Association website¹.

Methods

Kidney PREM 2022 was available for individuals to complete online or on paper from 1st October to 12th November 2022. Data were downloaded from the Qualtrics platform (online survey tool) in Excel format, checked and a master file of all data² (from online surveys) 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 **Other Themes**, which contained 2 sub-themes; **Specific Areas of Treatment**, and **COVID-19**.

The coding procedure followed that of reflexive thematic analysis (Braun and Clarke, 2021³), and due to the vast number of comments received, the codes and themes were quantified for easier comparison and interpretation (Miles and Huberman, 1984⁴).

Participant profile

In 2022, 11,063 people with kidney disease took part in Kidney PREM, with 7,030 completing the online version which included the free-text question. Of the online responses, 2,376 (33.8%) provided a further comment on their care (21.5% of all participating in 2022). 2,209 (92.9%) of those providing a written comment gave consent for this to be passed back to their treating centre.

¹ 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.

Table 1: Characteristics of People Taking Part in Kidney PREM 2022, and providing a free-text comment

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

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

Aspects of care people chose to comment on

Waiting times Support COVID-19 Tests
 Scheduling **Care** Communication
The renal unit team
 Specific aspects of treatment Environment
Appointments Privacy and dignity
Transport Patient information
 Shared decisions Needling **Diet**

From the 2,376 respondents who left a free text response, 177 (7.4%) individuals said there was no further comment. There were 1,861 comments which related to Kidney PREM themes, and 338 comments under **Other Themes**. Table 2 shows the breakdown of the number of comments for each theme, by sentiment (positive, negative, neutral).

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

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

Key Findings

How the Renal Team Treats You received the most comments (1,136 comments). The majority of comments in this theme are positive (65%), with most comments thanking staff for all their care and commitment.

“I am happy with the care I receive from UNIT NAME.” (PD, Black Male, 56-64)

“My care has been brilliant can do enough for me.” (HHD, White Female, 56-64)

“I am entirely happy with my kidney care so far.” (CKD, White Male, 75-84)

“Only to say I am satisfied with service.” (ICHD, Asian Male, 41-55)

“I cannot fault the renal team at UNIT NAME in any way. The treatment I receive is superb. Nothing is too much trouble for the staff, and the consultants are caring and always happy to go into any detail of my care I wish to be informed about. Big Up to them all!” (CKD, White Male, 75-84)

“The staff are very good at the renal unit all make you feel comfortable.” (ICHD, White Female, 65-74)

The theme **Environment** received the second largest number of comments. Responses discussed the facilities of the kidney unit, parking, and availability of supplies. The majority of the comments were negative (81%), with comments providing suggestions for improvements e.g., to increase the ambient temperature of the unit.

“To have free parking for patients that drive in UNIT NAME satellite” (Sat HD, Black Female, 56-64)

“The temperature of the unit is uncomfortable during the dialysis (cold) and we are not provided with blankets.” (Sat HD, White Male, 75-84)

“I wouldn’t mind having sandwiches rather than biscuits.” (ICHD, White Male, 65-74)

“Additional sandwiches would be nice.” (PD, Other Ethnicity Female, 65-74)

“Strong preference for a chair rather than a bed but there aren’t any chairs.” (ICHD, White Male, 56-64)

“More back support during dialysis.” (Sat HD, Black Female, 56-64)

“No automatic doors so have to pull doors open and time we have no energy especially after dialysis.” (ICHD, Asian Male, 41-55)

Key Findings

Scheduling and Planning included comments on waiting times at the unit, which were mostly negative (82%). Respondents found the wait for appointments and to receive treatment at the unit too long, though some felt the wait times were shorter than previous years.

Additionally, since the beginning of the pandemic in 2020, kidney appointments have been offered remotely via telephone or video consultation, as well as face-to-face. There have been mixed opinions but generally respondents found telephone/video consultants more efficient and convenient, but face-to-face appointments were preferable as they are perceived to be a fuller examination.

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

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

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

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

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

The theme **Access to the Renal Team** covers areas of care such as availability of staff, ability to contact the staff when needed and ease of attending the kidney unit for treatment. Availability of consultants received the highest number of comments (n=99) and appeared the most negative aspect of this theme. Individuals felt there was a lack of presence of the consultant in the unit and suggested that consultants could check in with their patients more frequently.

“Face to face contact with my renal consultant is virtually non-existent.” (ICHD, White Male, 75-84)

“An on call pd nurse would be beneficial it’s difficult to contact someone out of hours to discuss problems during dialysis” (PD, White, Female, 56-64)

“Hard to get hold of Consultant to discuss issues” (PD, White Male, 56-64)

Key Findings

Support covers respondents’ experience with the provision of support put in place by the kidney unit and experiences of additional support experienced or required when receiving treatment. Support during COVID-19 received the most comments for this theme and received a higher number of positive comments than negative (64% vs 33%). Comments on how individuals’ mental health had been impacted by their chronic kidney disease (CKD) diagnosis and their need for mental health support, were also prominent.

“No information about any local support services or groups offered.” (CKD, White Female, 56-64)

“I would like to meet other patients in the same situation as I am. I feel isolated using dialysis at home.” (PD, White Female, 65-74)

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

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

Patient Information, Fluid Intake and Diet, Needling, Tests, Sharing Decisions, and Privacy and Dignity received fewer comments, but should not be assumed less important.

Patient Information: “Would like more consistent interaction with named doctor and clear concise information and not jargon.” (ICHD, White Male, 75-84)

Fluid Intake and Diet: “Support from a dietician for suitable foods to have/avoid to help kidneys.” (CKD, Asian, Female, 65-74)

Needling: “Unnecessary fistula surgery which has caused endless problems and ultimately failed when I had a working tunnel line.” (Sat HD, White Female, 41-55)

Tests: “Access to results of monthly blood tests not provided despite frequent requests.” (ICHD, Black Male, 65-74)

Sharing Decisions: “Would love to know my personal plan but nobody around to discuss.” (ICHD, White Female, 31-40)

Privacy and Dignity: “No privacy when staff or doctor discusses your case while in the unit.” (Sat HD, White Male, 75-84)

Key Findings

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

Other Themes: “Just recently the renal team have not had sufficient dressings, alcohol swabs etc although they ask they have to go to other units to try and get them.” (ICHHD, Black Male, 41-55)

Other Themes: “Better guidance regarding pain issues.” (CKD, White Male, 65-74)

Specific Aspects of Treatment: “It would be useful to have contingency plans for home patients needing to be admitted or respite treatment- we are sometimes treated like second class citizens.” (HHD, Black Female, 41-55)

Specific Aspects of Treatment: “More investment, facilities in remote patient care.” (HHD, Asian Male, 41-55)

COVID-19: “I am very frustrated that I have to be in isolation when I come back from my country.” (ICHHD, Asian Female, 41-55)

2022 / 2021 Comparison

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


- In 2022, only 21.5% of respondents completing Kidney PREM left a free text response, compared to 40% last year.
- As with the previous year, the most prominent theme was related to **staff** members and the quality of care patients received. These comments were predominantly positive (71%), comments mentioning specific staff roles (consultants, transplant team, nurses, primary care) had mixed views with most individuals thanking staff for providing good care and others wanting staff members to be more compassionate.
- Compared to 2021, there were fewer comments from individuals with a Black ethnic heritage (-1.2%) but this year there was a new option offered to patients to choose Mixed ethnic heritage, and 1.4% responded with this option.
- From last year there has been an increase in the number of under 30-year-olds who left a comment (+0.8%), with representation of gender and treatment modality remaining consistent.
- Comments regarding **Environment** featured highly in both years and were mostly negative. In 2022 the largest proportion of these were related to comfort, temperature control, and waiting areas. Accessibility and parking arrangements were also criticised. This was also the case in 2021.
- Comments in 2021 regarding **Support** included wanting more psychological support and mentioning the apparent lack of provision for this. Specific support for financial issues and for participants' families were also mentioned. This was the same in 2022, though this year included an additional code, support with COVID-19, which received the most comments within this theme and were mostly positive (64%).
- In both years issues with **Communication**, particularly individuals wanting communication to be improved, featured as quite a negative aspect of care. 2021 highlighted issues predominantly within the kidney team, whereas this year the main issues were with respondents wanting better coordination of test results and for applications, such as PatientView, My Care and Patients Know Best to be more accessible.

2022 / 2021 Comparison

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

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