UKKA
UK Kidney Association

Kidney Care UK

The Patient Voice

An analysis of free-text responses from the 2025 national Kidney Patient Experience Survey (PREM)

Contents

Executive Summary

The national Kidney Patient-Reported Experience Measure (Kidney PREM) is a validated 39-item questionnaire facilitated annually by the UK Kidney Association and Kidney Care UK. The Kidney PREM measures patient experience of kidney care over 13 themes. The end of the questionnaire has a free-text question, asking patients to comment on aspects of their care not already covered:

"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 2025, 17,334 people with kidney disease took part in Kidney PREM, with 6,084 (35.1% of participants) adding a response to the free-text question. 94% of participants gave consent for their comments to be shared anonymously with their kidney centre, allowing the comments to be used to support quality improvement at a local level. Participant characteristics of those providing a free-text comment were consistent with the Kidney PREM 2025. Compared to Kidney PREM 2024, there was a general increase in comments from people with CKD (not receiving kidney replacement therapy; +5.5%), and a decrease in those receiving in-centre or satellite haemodialysis (-4.9% and -3.2% respectively).

This report focuses on the responses to the free-text question. As in previous years, the comments were analysed and mapped onto the 13 themes included in the Kidney PREM.

How the Kidney Team Treats You received the highest number of comments across all treatment groups. The majority of comments about the kidney team were positive (71.9%).

Overall Experience received the second highest number of comments and was also mostly positive (77.8%). Participants were generally satisfied with their experience of kidney care.

The Environment received the third highest number of comments and was mostly negative (69.1%). Over half of the comments were from people receiving in-centre or satellite haemodialysis.

Privacy and Dignity, Fluid and Diet and Needling received the fewest number of comments overall.

This report aims to help clinical teams and the wider kidney community understand how individuals feel about their experience of kidney care, to inform quality improvement in service delivery. It highlights areas for improvement whilst also acknowledging areas of strength.

Introduction

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 in Kidney PREM is voluntary and anonymous. It is open to individuals with chronic kidney disease regardless of disease stage or treatment, including those not receiving kidney replacement therapy (KRT). The Kidney PREM is promoted by kidney units, The UKKA, Kidney Care UK, and patient groups.

The Kidney PREM measures patient experience of kidney care across 13 themes:

1. Access to the Kidney Team	8. Sharing Decisions
2. Support	9. Privacy and Dignity
3. Communication	10. Scheduling and Planning
4. Patient Information	11. How the Kidney Team Treats You
5. Fluid and Diet	12. Transport
6. Needling	13. The Environment
7. Tests	

The questionnaire also includes a free-text question which aims to capture experience of care not covered elsewhere in the survey. There is no word or character limit, and participants can choose whether their comment will be shared with their kidney 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 focuses on the responses to the free-text question. It provides insight into patient experience of kidney care across the UK, maintaining the depth and richness of the free-text nature of the comments, whilst also providing sufficient analysis and interpretation to support quality improvement.

Aims and Objectives

The aims of this report are to help clinical teams and the wider kidney community understand how individuals feel about their experience of kidney care, to inform quality improvement in service delivery. The report highlights areas for improvement whilst also acknowledging areas of strength reflected by positive comments.

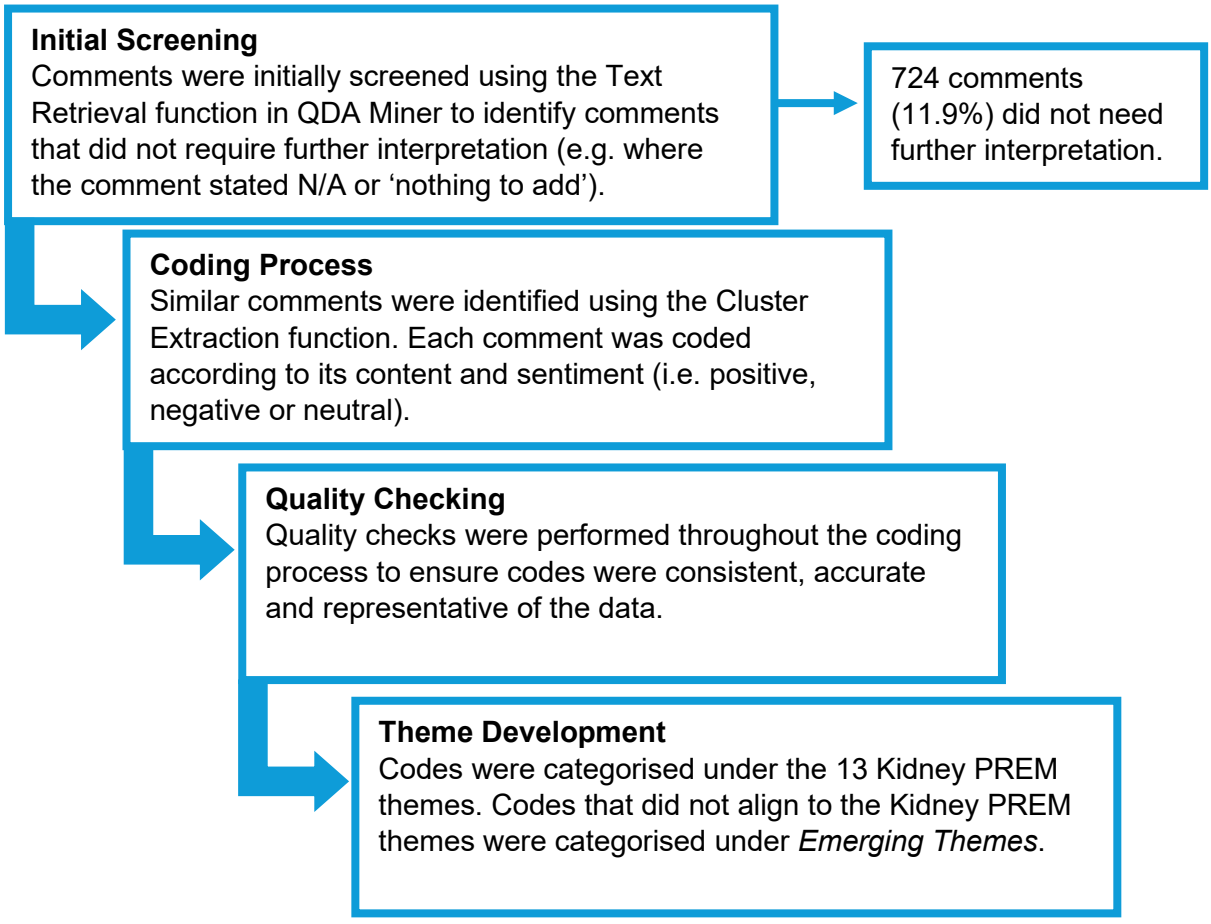
Methods

Kidney PREM 2025 was available to complete from 15th September to 10th November 2025. Data were downloaded from Qualtrics (an online survey tool) in Excel format, and quality assessed. A master file of data from the free-text comments was uploaded into QDA Miner, a computer-assisted coding software, for analysis.

The analysis (see Figure 1) followed the principals of thematic analysis as outlined by Boyatzis (1998)[1]. Due to the large number of comments received, the codes and themes were quantified for ease of comparison and interpretation (Miles and Huberman, 1984)[2].

Centre-level summary tables of themes by sentiment, including those for satellite haemodialysis units, have been published on the UKKA data portal[3]. Analysis of the quantitative data has been reported separately and is available to view via the UKKA website[4].

Figure 1. Flow chart of analytic method



[1] Boyatzis, R. (1998). Transforming qualitative information: Thematic analysis and code development. Sage.
[2] Miles, M. B., & Huberman, A. M. (1984). Drawing valid meaning from qualitative data: Toward a shared craft. Educational researcher, 13(5), 20-30.
[3] https://www.ukkidney.org/audit-research/data-portal/prem
[4] www.ukkidney.org/kidney-patient-reported-experience-measure

Report Structure

The results in this report are structured by treatment group to support more targeted quality improvement in service delivery. For this report, data related to individuals receiving in-centre haemodialysis and those receiving haemodialysis at a satellite unit are reported together. Each chapter provides an overview of the aspects of care most frequently reported within each treatment group, as well as those where the proportion of comments differed between groups. The report concludes with a reflection of Kidney PREM comments over the last five years.

Differences in the Number of Comments

Some participants mentioned multiple aspects of care within their comment. Where this is the case, the number of comments may be higher than the number of participants.

Quotes

Participant quotes are provided throughout the report to illustrate key findings. Where quotes have been amended to improve clarity or protect anonymity, this is shown.

♦ Quick Wins ♦

Quick Wins are defined as suggestions for improvements to patient experience of kidney care that could be implemented relatively easily, without significant resource or time requirements. Please note that ***Quick Wins*** do not appear for every treatment group and may not be relevant to all kidney units.

Results

Chapter 1: Profile of Participants Providing Comments

Kidney PREM 2025 received a total of 17,334 responses, with 6,084 people (35.1%) providing a free-text comment about their experience of kidney care.

The characteristics (age, gender, ethnicity and treatment type) of people providing a free-text comment were consistent with the Kidney PREM 2025[5], and similar to those reported in 2024. One exception was the increase in free-text responses from people with CKD who are not receiving kidney replacement therapy (20.1% of responses in 2025 compared to 14.6% in 2024), reflecting higher participation from this group in Kidney PREM 2025. Consequently, the proportion of people receiving haemodialysis in-centre or at a satellite unit who left a comment has decreased by 4.9% and 3.2%, respectively (see Table 1).

Table 1. Characteristics of participants providing a free-text comment

	Kidney PREM 2025	Kidney PREM 2025 Comments	Kidney PREM 2024 Comments
Total	**17,334**	**6,084**	**4,848**
Age (years)			
16-21	114 (0.7%)	25 (0.4%)	30 (0.6%)
22-30	470 (2.8%)	134 (2.2%)	100 (2.1%)
31-40	1,130 (6.6%)	378 (6.3%)	289 (6.0%)
41-55	3,187 (18.7 %)	1,113 (18.6%)	938 (19.3%)
56-64	3,582 (21.1%)	1,297 (21.6%)	1,092 (22.5%)
65-74	4,190 (24.6%)	1,508 (25.1%)	1,207 (24.9%)
75-84	3,400 (20.0%)	1,223 (20.4%)	1,001 (20.6%)
85+	662 (3.9%)	229 (3.8%)	192 (4.0%)
Rather not say	277 (1.6%)	90 (1.5%)	-
Gender			
Female	6,884 (40.4%)	2,512 (42.0%)	1,995 (41.4%)
Male	9,860 (57.9%)	3,388 (56.6%)	2,776 (57.2%)
Non-binary/ Other	36 (0.2%)	10 (0.2%)	14 (0.3%)
Rather not say	244 (1.4%)	77 (1.3%)	64 (1.3%)
Ethnicity			
Asian	2,063 (11.9%)	703 (11.6%)	561 (11.6%)
Black	1,622 (9.4%)	615 (10.1%)	429 (8.8%)
Mixed	248 (1.4%)	93 (1.5%)	50 (1.0%)
White	12,674 (73.3%)	4,397 (72.5%)	3,604 (74.3%)
Other	323 (1.9%)	124 (2.0%)	86 (1.8%)
Rather not say	368 (2.1%)	131 (2.2%)	119 (2.5%)
Treatment			
CKD (non-KRT)	3,654 (21.4%)	1,220 (20.3%)	709 (14.6%)
Peritoneal Dialysis	915 (5.4%)	305 (5.1%)	211 (4.4%)
Home HD	244 (1.4%)	103 (1.7%)	90 (1.9%)
Satellite HD	6,013 (35.2%)	2,167 (36.0%)	1,879 (38.8%)
In-Centre HD	3,657 (21.4%)	1,275 (21.2%)	1,250 (25.8%)
Transplant	2,617 (15.3%)	951 (15.8%)	710 (14.6%)

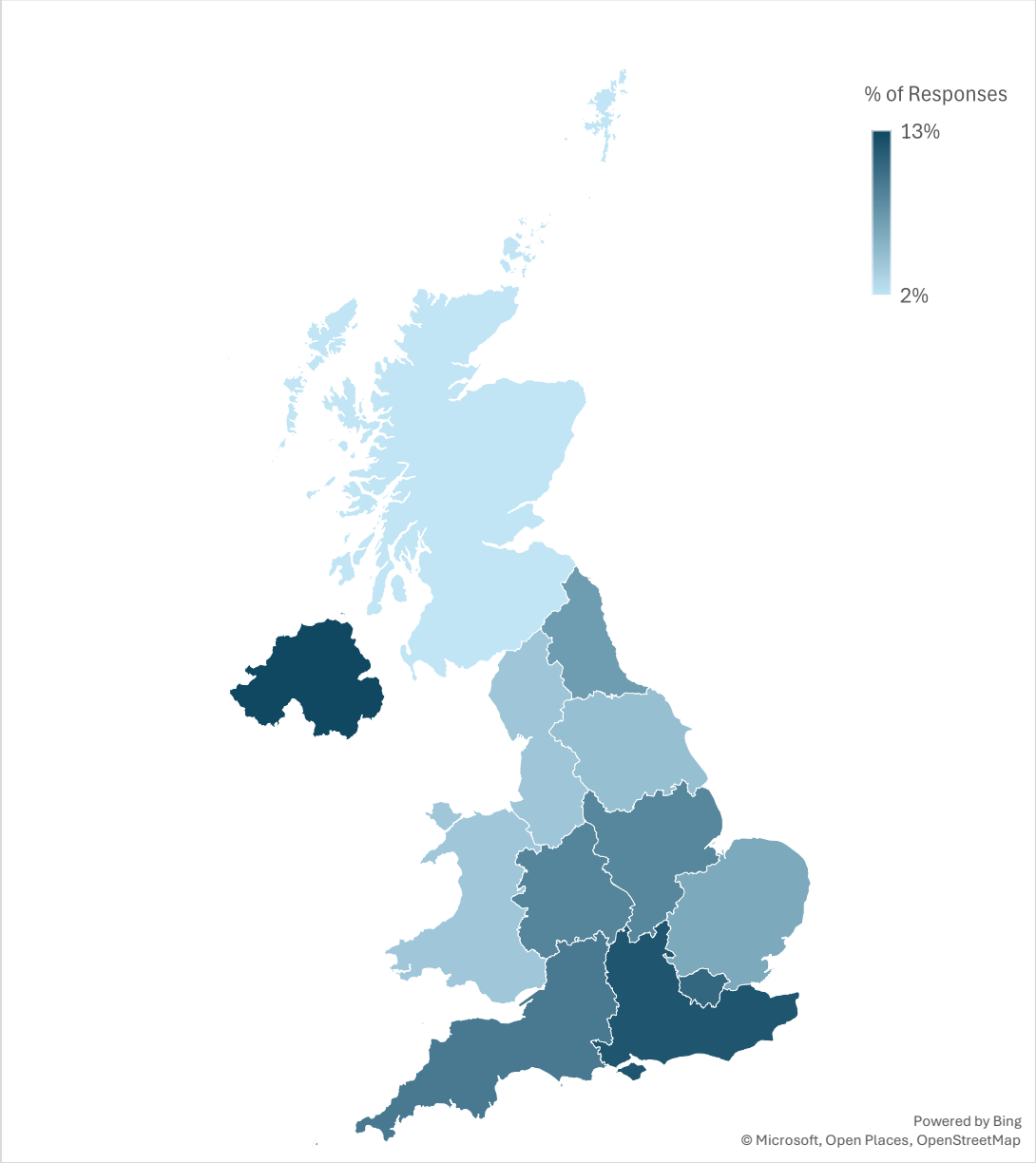
[5] www.ukkidney.org/kidney-patient-reported-experience-measure

Across all treatment groups, home haemodialysis patients represented the smallest proportion; 1.7% of all comments. However, of the 244 home haemodialysis patients who completed Kidney PREM, over 40% left a comment; the highest proportion by treatment group.

Responses by Region

There are 72 adult kidney centres across the UK, grouped into 11 geographical regions. Figure 2 shows the proportion of participants in each region who provided a free-text comment in Kidney PREM 2025, relative to the total KRT population in that region[6]. Although London had the highest number of respondents overall, Northern Ireland had the largest proportion of responses relative to its regional KRT population (13%). Scotland had both the lowest number of comments and lowest proportion (2%).

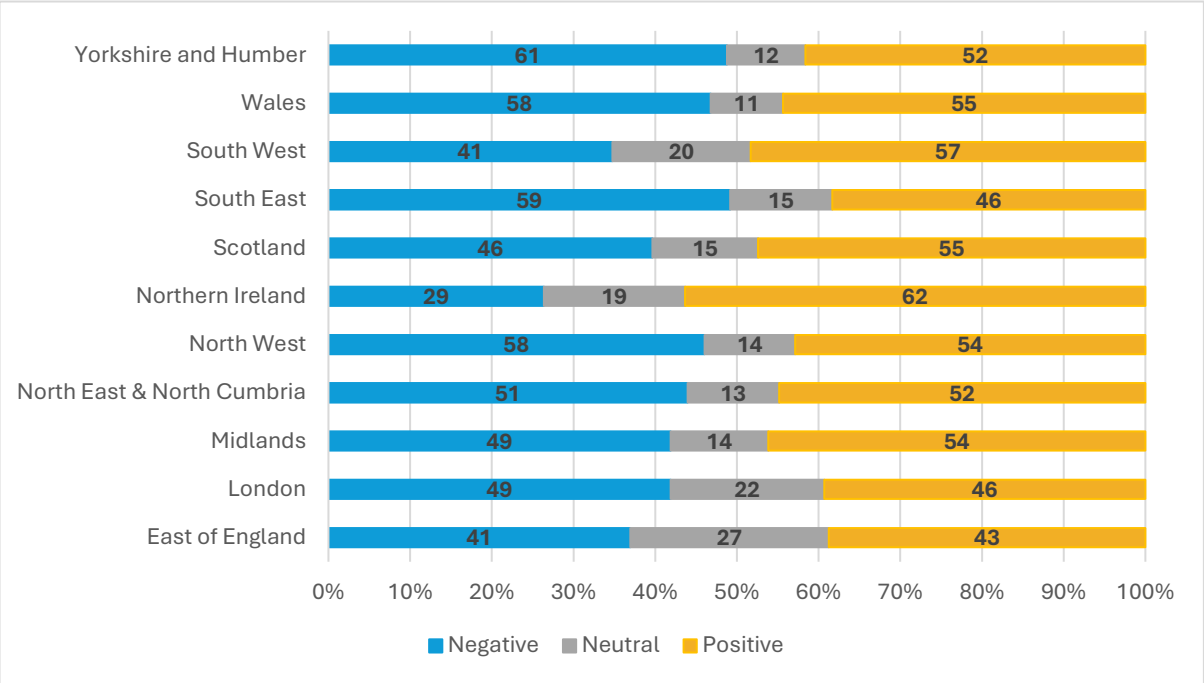
Figure 2: Map of Kidney PREM regions and response percentage for 2025



[6] Data for the total KRT population per region were obtained from the UKKA Kidney Replacement Therapy Data Portal. As the portal reports 2024 data and does not include people with CKD not yet receiving KRT, the calculated regional response proportions may be overestimated.

Figure 3 summarises the proportion of comments for each sentiment (positive, neutral and negative) by region. Northern Ireland received the highest percentage of positive comments (61.5%), while Yorkshire and Humber had highest percentage of negative comments (61.0%).

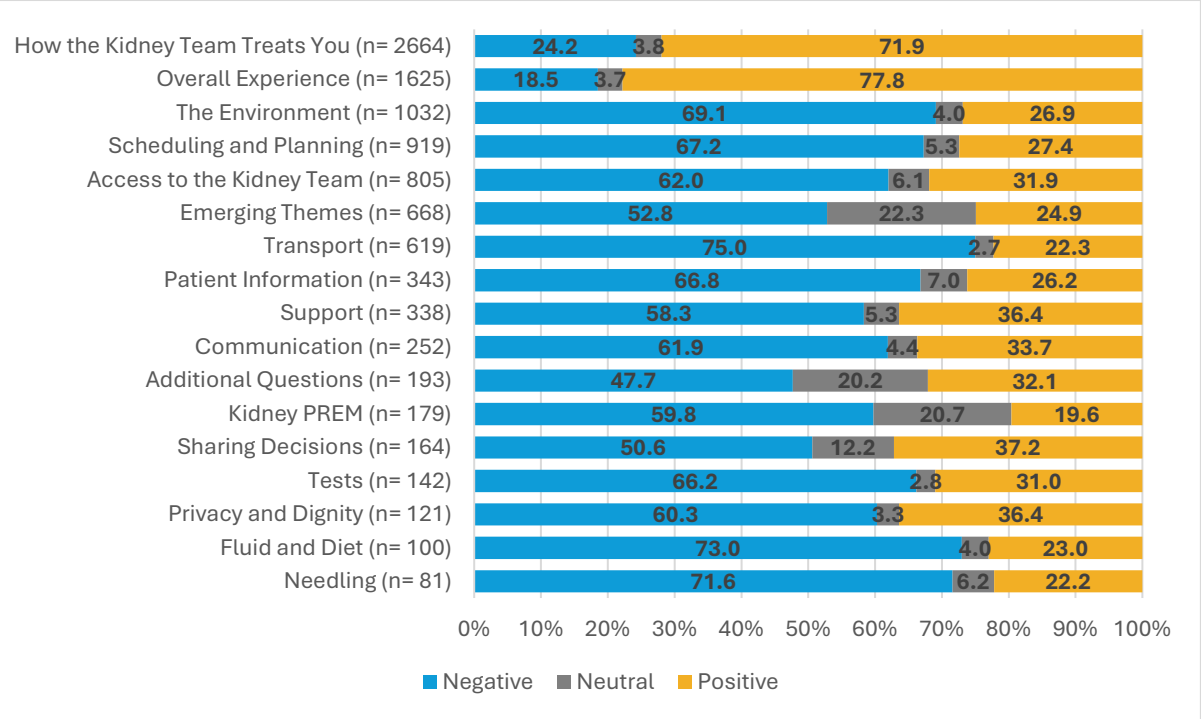
Figure 3: Percentage of comments for each sentiment by region



Chapter 2: Overview of Comments Analysis

6,084 participants provided a free-text comment[7]. Table 2 provides an overview of the number of comments and the proportion of positive, negative and neutral sentiment for each theme.

Table 2: Overview of themes by sentiment



Most Frequently Reported Themes

How the Kidney Team Treats You received the highest number of comments across all treatment groups; comments were predominately positive (71.9%). Comments referred to different members of the kidney team, including doctors, nurses, the transplant team, the home dialysis team, as well as other staff such as receptionists and housekeeping. Figure 4 illustrates the words used to describe the kidney team.

Overall Experience received the second highest number of comments, with 77.8% being positive. Participants reported being generally satisfied with their experience and expressed appreciation for the care they received.

"I'm happy with everything. The [clinic] works at the highest level. Everyone is attentive and always greets me with a smile" (Female, 56-64, White, PD)

"I'm very happy with the team and the care I'm given every visit" (Male, 41-55, Black, Centre HD)

"I am absolutely happy with the treatment I have received at the clinic and the hospital, even [when] I was hospitalised" (Female, 65-74, Asian, CKD)

[7] 734 participants wrote non-substantive comments (e.g. "Nothing to add").

Figure 4. Word cloud of common words used to describe the kidney team

Least Frequently Reported Themes

Privacy and Dignity, Fluid and Diet and Needling received the fewest number of comments overall, however the number does not reflect the importance of these topics. The proportion of participants commenting on these areas varied across treatment groups.

Most comments about ***Privacy and Dignity*** (79%) were from people receiving in-centre or satellite haemodialysis. Participants described how discussions about their health often took place on the dialysis unit, where other patients could overhear. They highlighted the lack of private or soundproof spaces for confidential conversations.

"My biggest bugbear is actually when the [doctor] is here; the conversation may as well be a group session…it is very public. Not at all confidential." (Female, 56-64, Black, Sat HD)

The majority of comments about ***Needling*** (89%) were from people receiving in-centre or satellite haemodialysis [8]. Participants reported that staff often experienced difficulties inserting the dialysis needles, resulting in pain and discomfort. Participants expressed concerns about the competency of some staff members to needle them correctly.

"When inserting the needles there is a wide variation in outcome between different nurses and I wonder how it is decided which nurses have attained the competence to do this with minimum pain and risk." (Male, 65-74, White, Centre HD)

Fluid and Diet received the highest number of comments from people with CKD not receiving kidney replacement therapy. Participants wanted more information about diet and suggested that leaflets and take-home information would be helpful.

[8] In Kidney PREM 2025, *Needling* questions were only shown to people receiving in-centre or satellite haemodialysis. Five comments related to needling were submitted by participants outside these groups. These comments referred to phlebotomy needling or experience of fistula formation.

"The only thing that is lacking is proper nutritional advice, the unit needs a renal dietician and good printed leaflets to take home" (Male, 75-84, Mixed, CKD)

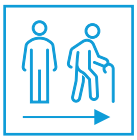
Themes by Demographic Group

People who identified as female were more likely to comment on ***Privacy and Dignity*** compared to other genders**.** They were also more likely to comment on ***Sharing Decisions,*** with some participants stating that they did not feel listened to or taken seriously by their kidney team.

"I would like my appointment with the consultant to be private, not open in the ward with everyone else." (Female, 41-55, Black, Centre HD)

"The unit does not seem to listen to my concerns and take them seriously" (Female, 41-55, White, PD)

People who identified as non-binary, or did not disclose their gender, commented more negatively on their experiences of kidney care overall.



Younger adults (under 55 years old) were more likely to comment on ***Support.*** They mentioned wanting more emotional and mental support, as well as specific support for pregnancy or young people.

Adults aged 55 years or older were more likely to comment on ***Transport***.

"Poor transition from paediatric to adult clinic… no follow-ups or interventions considered for young patients' emotional support after transitioning" (Male, 17-21, Asian, Transplant)

People from minority ethics groups were more likely to comment on **Transport,** especially in relation to transport wating times.

People who identified as White were more likely to comment on ***Scheduling and Planning****,* especially in relation to appointments and staff shortages.

People who self-reported insufficient income for their daily needs left comments which suggested a more negative experience of their kidney care compared to those with higher income.

People reporting insufficient income were more likely to comment on ***Transport*****,** and ***Support***, especially in relation to emotional, financial and social care support, compared to those with higher income.

"I don't feel my doctor is interested in the emotional effect of my kidney disease…my disease directly affects my mental health." (Male, 22-30, White, CKD)

"Not enough support for at home or everyday life. [I] have had to stop work due to this and haven't had any communication on any welfare benefits I can receive to support me financially." (Female, 22-30, White, Sat HD)

Chapter 3: Transplant

- A total of **951 people who have received a kidney transplant** left a free-text comment, accounting for 15.6% of all comments.
- Of these comments, **52.2% were positive** and **41.3% were negative.**
- The themes that received the largest number of comments were ***How the Kidney Team Treat You, Scheduling and Planning*** and ***Emerging Themes.***

Transplant recipients left a large number of comments related to ***Scheduling and Planning***, with two-thirds (66.0%) expressing negative experiences. Key issues included:

Blood test scheduling – Transplant recipients preferred having their blood tests scheduled before their consultation so that that the most up-to-date results were available to review and discuss at their appointment.

Appointment scheduling – Transplant recipients reported frequent appointment cancellations and long periods of time between follow-up appointments. They expressed a preference for more regular appointments with their kidney team.

Appointment format – Transplant recipients expressed mixed preferences regarding appointment format. Some participants found remote appointments more convenient, whilst others preferred in-person appointments, describing them as more personal and reassuring.

"On my monthly renal review, it would be better to take bloods before the appointment so the latest results can be discussed." (Male, 65-74, White, Transplant)

"My negativity regarding this year is due to the amount of cancelled appointments by the hospital which meant that, instead of being seen every 4 months, I had to wait over 9 months between appointments." (Female, 65-74, White, Transplant)

"I am able to have online appointments with my consultant…I find this very helpful and much easier and more cost effective than having to travel to the hospital each time" (Female, 56-64, White, Transplant)

I understand the need for telephone consultations but I find them impersonal and feel rushed. (Female, 56- 64, White, Transplant)

Transplant recipients commented on several ***Emerging Themes*** which reflect aspects of care not captured within the Kidney PREM. The most common ***Emerging Themes*** were:

Treatment history – Transplant recipients provided comments about their treatment history, such as their transplant date or number of years post-transplant. These comments were often used to contextualise their experience of care.

Pharmacy services – Transplant recipients reported negative experiences with pharmacy services, including long wait times and difficulties requesting or accessing repeat prescriptions.

"[I] had a kidney transplant over 10 years ago, amazing help and support in hospital and clinic." (Female, 65-74, White, Transplant).

"My experience with the pharmacy has always been poor; it takes 2 hours as minimum to get the medication" (Male, 41-55, Asian, Transplant)

Transplant recipients also expressed concerns about ***Access to the Kidney Team.*** Key issues included:

Contacting the kidney team – Participants expressed difficulties contacting their kidney team outside of routine appointments. They mentioned that telephone calls were frequently left unanswered and not followed up.

Continuity of staff – Participants reported a lack of consistency in the staff they saw at each appointment. They explained that seeing different doctors made it difficult to establish a relationship, and meant they often had to re-explain their health situation at each appointment.

"Sometimes it's very difficult to get through to the admin team, sometimes the phone just constantly rings. Other times, I have called and left a message but no-one gets back to me." (Female, 41-55, Black, Transplant)

"I feel seeing a different consultant every visit means I can't build a rapport with someone and sometimes feel like I'm repeating myself." (Male, 41-55, White, Transplant)

When commenting about ***The Environment,*** transplant recipients reported difficulties with parking, including high parking costs and a lack of available spaces.

"Parking is poor at [Hospital] spaces are taken all the time no space purely for kidney patients." (Male, 65-74, White, Transplant)

♦ Quick Wins ♦

"When I attended the renal unit for the first time after having a transplant, ***all the nursing staff and reception staff congratulated me.*** *I thought this was a lovely thing to do."* (Female, 65-74, White, Transplant)

"The ***patient forum is a real cherry on the cake*** *in terms of feeling connected and getting regular updates on improvements and issues affecting the unit."* (Female, 56-64, White, Transplant)

*"****Education days/ sessions with patients in attendance*** *also with family if possible"* (Male, 65-74, White, Transplant)

Chapter 4: In-centre and Satellite Haemodialysis

- A total of **3,442 people receiving in-centre or satellite haemodialysis** left a free-text comment, accounting for 56.5% of all comments.
- Of these comments, **43.8% were positive** and **51.5% were negative.**
- The themes that received the largest number of comments were ***How the Kidney Team Treat You, Overall Experience*** and ***The Environment.***

Approximately half of comments about ***The Environment*** were from people receiving in-centre or satellite haemodialysis. The most frequent comments related to:

Unit temperature – The dialysis unit was often described as too cold, which made people feel physically uncomfortable during their dialysis sessions.

Chairs and beds – The chairs and beds in the unit were also described as uncomfortable. Many people stated a preference for either chairs or beds and wanted better availability of their favoured option.

Food availability – People receiving in-centre or satellite haemodialysis wanted healthier and more fulfilling food options during dialysis, such as sandwiches or fruit instead of biscuits.

Unit parking – People receiving in-centre or satellite haemodialysis reported difficulties parking at the dialysis unit due to a lack of available parking spaces.

"I wish they [would] do something with the temperature system because it's freezing all the time." (Female, 41-55, White, Sat HD)

"I think the floor would be more comfortable to sit on for 4 hours rather than these beds." (Male, 41-55, Black, Sat HD)

"Could you provide sandwich[es] instead of just biscuit please!!! After 4 hours I am very hungry…" (Female, 41-55, Asian, Centre HD)

"Parking is a major problem…my last haemodialysis session took 30 minutes to access" (Male, 56-64, White, Centre HD)

The highest proportion of comments about ***Transport*** (71.6%) were from people receiving in-centre or satellite haemodialysis[9].

[9] Comment about *Transport* were also received from people in other treatment modalities, such as those eligible for NHS Non-Emergency Patient Transport Services, or from participants noting that they are no longer entitled to transport assistance after changing modality.

Comments about transport were mostly negative (74.8%), common issues included long waiting times, and poorly planned transport routes.

"Transport [is] never on time, losing time on treatment every time." (Male, 65-74, Asian, Sat HD)

"Transport provision is making [me] unwell emotionally and mentally. I have to wait for hours... Being ready two hours before treatment, having 4 hours dialysis and waiting 2+ hours to get home is awful." (Female, 75-84, White, Centre HD)

When discussing ***Access to the Kidney Team,*** people receiving in-centre or satellite haemodialysis mentioned that they would like more regular contact with their kidney doctor during dialysis sessions.

"The senior consultant at the clinic do not visit often and when they do [they] don't spend much time." (Male, 75-84, Asian, Centre HD)

"I feel that our doctors could be more visibly involved in our care and more available to us if we need them." (Female, 31-40, White, Sat HD)

Approximately 10% of comments from people receiving in-centre or satellite haemodialysis were about ***Scheduling and Planning.***

People receiving in-centre or satellite haemodialysis mentioned that they often had to wait long periods of time to be put on or taken off the dialysis machine. This often increased the overall amount of time they were required to spend at the hospital.

"[I] find myself constantly being put on later and later which has a domino effect for transport getting me home" (Female, 41-55, White, Centre HD)

"I always arrive on time for dialysis but almost always have to wait before my treatment begins. The longest wait was over 2 hours." (Male, 75-84, Other, Centre HD)

♦ Quick Wins ♦

"It would be nice if a member of ***staff were to come around during the dialysis period for a chat****."* (Female, 75-84, White, Sat HD)

"Make ***additions to the unit so people can bring a laptop*** *and be able to work. Currently, the tables do not allow for this."* (Female, 31-40, White, Sat HD)

*"****A side table for every bed*** *where patients can put their belongings"* (Male, 41-55, Asian, Centre HD)

*"****Name badges*** *for the staff"* (Male, 65-74, White, Centre HD)

Chapter 5: Home Haemodialysis

- A total of **103 people receiving home haemodialysis** left a free-text comment, accounting for 1.7% of all comments.
- Of these comments, **49.0% were positive** and **39.6% were negative.**
- The themes that received the largest number of comments were ***How the Kidney Team Treat You, Emerging Themes*** *and* ***The Environment.***

People receiving home haemodialysis mentioned several ***Emerging Themes*** not captured in the Kidney PREM. The most frequent comments related to:

Home dialysis training and support – Participants shared their experiences of home haemodialysis training and support. Comments were mixed with some people reporting that they received high-quality training and support, whilst other felt that the support they received was inadequate.

Dialysis away from base – People receiving home haemodialysis reported wanting more information about, and better availability of, dialysis away from base. Some participants experienced difficulties organising dialysis away from base, which impacted on their ability to travel for work, holidays and family events.

"The support and training we received…has been outstanding. The ongoing training and support at home has also proved to be exceptional." (Male, 75-84, White, Home HD)

"I think home patients that do dialysis out of unit hours are left to get on with it with no support…" (Male, 41-55, White, Home HD)

"It is impossible to get dialysis [away from base] in England. Units… have no spaces. I was unable to attend a family funeral because I couldn't dialyse"
(Female, 56-64, White, Home HD)

When commenting on ***The Environment***, people receiving home haemodialysis mentioned difficulties parking when attending the hospital due to the lack of disabled parking spaces.

"I have a blue badge, and the spaces have been reduced so that it is impossible to find one… There is a danger that one day I will miss my appointment due to lack of parking."
(Female, 65-74, White, Home HD)

People receiving home haemodialysis were more likely to comment about ***Support*** compared to other treatment groups.

People receiving home haemodialysis wanted more emotional and mental health support, with some highlighting the long waiting times for counselling and mental health services as a significant barrier.

"Need more emotional support as feel more anxious and depressed dealing with dialysis- most of the time it stayed at back of head." (Male, 31-40, Asian, Home HD)

Chapter 6: Peritoneal Dialysis

- A total of **305 people receiving peritoneal dialysis** left a free-text comment, accounting for 5.0% of all comments.
- Of these comments, **59.7% were positive** and **36.7% were negative.**
- The themes that received the largest number of comments were ***How the Kidney Team Treat You, Overall Experience*** and ***The Environment.***

When discussing ***The Environment***, people receiving peritoneal dialysis were more likely to comment on the proximity and condition of the kidney unit. Participants generally preferred to attend appointments closer to home and noted that some facilities were in need of repair and renovation.

"The satellite centre…has been a good addition to the [Main Centre] and means less travelling for counselling and for seeing the consultant." (Male, 65-74, White, PD)

"The unit is not in a good location. Downstairs and hidden away near the bins. It is not a good environment." (Female, 41-55, Black, PD)

The most frequently reported comments about ***Access to the Kidney Team*** related to contacting the kidney team. Some participants were able to easily contact their kidney team with any queries or concerns, whilst others experienced difficulties getting in touch by email and telephone.

"The phone is often not answered and when I email it is not clear if it has been received" (Female, 75-85, White, PD)

"The kidney team that I have access to are brilliant... If I have any queries, then you can always contact them and they always get back to you." (Female, 41-55, White, PD)

Similar to those receiving home haemodialysis, people receiving peritoneal dialysis mentioned wanting more emotional and mental health support.

"I would like to express the need for emotional and psychological support…" (Female, 41-55, White, PD)

♦ Quick Wins ♦

*"The **coffee mornings** are very good as **it is so nice to speak to likeminded people** in same situation as me."* (Male, 41-55, White, PD)

*"I think the **introduction of [patient] awareness [days]**… with **existing dialysis patients talking about their experiences** is a fantastic move forward in giving prospective patients the chance to ask questions and to fully understand how they can take control of their condition and treatment."* (Male, 65-74, White, PD)

Chapter 7: CKD (Non-Kidney Replacement Therapy)

- A total of **1,220 people with CKD who were not receiving kidney replacement therapy** left a free-text comment, accounting for 20.1% of all comments.
- Of these comments, **48.9% were positive** and **41.6% were negative.**
- The themes that received the largest number of comments were ***How the Kidney Team Treat You, Overall Experience*** and ***Scheduling and Planning.***

Over 20% of comments from people with CKD not receiving kidney replacement therapy were about ***Scheduling and Planning.*** Similar to transplant recipients, key issues were related to:

Blood test scheduling – People with CKD preferred to have their blood tests scheduled a few days prior to their appointments so that that the most up-to-date results were available to discuss with the doctor.

Appointment scheduling – Appointment cancellations and rescheduling were common among the non-kidney replacement therapy group. Participants expressed concerns about the length of time between kidney appointments due to these disruptions.

Appointment format – Preferences for in-person versus remote consultations were mixed with the CKD group. Remote appointments were often perceived as more convenient, but some participants reported feeling disconnected from their kidney team.

"Blood tests should be done a few days prior to review appointments. This would ensure that the medicine decisions are based on latest results and not [from] one- or two-months earlier" (Male, 65-74, Asian, CKD)

"There was a long period when appointments were cancelled by the hospital, and I was not seen/monitored for at least 18 months." (Male, 56- 64, Asian, CKD)

"I like to do [online] consultations because of the convenience of time. At the same time, I am becoming more and more disconnected from the team…I miss out on things like being weighed, having my blood pressure taken by a clinician…" (Non-binary/Gender Diverse, 41-55, White, CKD)

People with CKD also frequently commented on ***Access to the Kidney Team:***

Contacting the kidney team – Approximately 49% of comments about contacting the kidney team were positive, compared to 43% negative. Participants mentioned that their kidney team were easy to contact, and responsive to their questions. On the other hand, some participant experienced difficulties getting in touch with their kidney team outside of their routine appointments.

GP care – People not on kidney replacement therapy also frequently commented on the care they received from the GP. Participants expressed concerns about

GPs' knowledge and experience in managing kidney disease and described difficulties with getting a GP appointment.

"I can contact [my consultant] directly by email and they always respond promptly with positive advice and help." (Female, 56-64, White, CKD)

"It is not always easy to contact the unit by phone. Most of the time the phone rings and rings and is not answered so [I] have to hang up or I go through to an answering machine but never sure if it has been listened to." (Male, 56-64, White, CKD)

"I also struggle to engage with a GP who has any specialist knowledge of kidney issues and [I] feel that a holistic approach is lacking…I am often prescribed medication that is not suitable considering my complex needs." (Female, 41-55, White, CKD)

The highest proportion of comments about ***Fluid and Diet*** (54.3%) were from people with CKD not receiving kidney replacement therapy. Of these comments, over 90% were negative.

Participants wanted more guidance on diet, including access to a dietician, information on suitable food and drink and support with meal planning. They noted that kidney-specific diet sheets or leaflets would be helpful.

"I wish I [could] get more support for diet and menu"
(Female, 41-55, Asian, CKD)

"I have one main gripe which is that I have never received any unsolicited advice on diet and lifestyle... I have to get my dietary and lifestyle advice as it relates to my CKD from another source… nothing is proactively offered by the Kidney Team."
(Male, 65-74, White, CKD)

♦ Quick Wins ♦

*"**Open days organised by the unit** are very useful."*
(Male, 75-84, White, CKD)

*"The only thing I would suggest is a **handbook or glossary about terms and tests** as its new language I find difficult to understand."*
(Female, 31-40, White, CKD)

*"Maybe worth having **a noticeboard in each unit** with this [Of support] information."*
(Female, 31-40, White, CKD)

Chapter 8: Five-Year Reflection of Kidney PREM Comments

A total of 25,299 free-text responses were collected from 2021 to 2025. This chapter provides a five-year overview of how patient-reported experiences of kidney care may have changed over time. Findings have been based on the number of responses for each theme across the five-year period.

The number of free-text responses has steadily increased over the past five years, with 3,877 responses in 2021 compared to 6,084 responses in 2025. This reflects a general increase in engagement with the Kidney PREM, providing a rich source of insight into patients' experiences of kidney care.

How the Kidney Team Treats You has consistently received the highest number of comments since 2021. Comments related to this theme have remained mostly positive.

The Environment has appeared within the top three most-frequent themes every year since 2021. Issues related to unit temperature, food availability and parking have remained persistent during this time. Despite this, the proportion of negative comments related to ***The Environment*** has declined over time (from 84% in 2021 to 69% in 2025).

Scheduling and Planning has also remained a prominent theme, appearing within the top five most-frequent themes over the past five years. ***Scheduling and Planning*** has remained predominantly negative, with persistent issues including appointment format and appointment scheduling.

The ***Impact of COVID-19*** was referred to in the free-text comments in 2021 and 2022 only. However, comments about **infection risk and prevention** continued to appear and accounted for 0.4% of all free-text comments in 2025.

Themes such as ***Privacy and Dignity, Sharing Decisions, Needling*** and ***Fluid and Diet*** consistently receive the fewest number of comments. These themes continue to be predominately negative, but the proportion fluctuates from year to year. Notably, ***Privacy and Dignity*** has steadily improved, with the proportion of negative comments decreasing from 85% in 2022 to 60% in 2025.

Emerging Themes capture aspects of care that are not included in the Kidney PREM. Comments about medication, pharmacy services, and dialysis away from base have been mentioned consistently over the past five-years.

Conclusion

This report explores patients' experience of kidney care in the UK, using responses to the free-text question included in the Kidney PREM 2025, and some analysis of five-year trends. Over 6,000 responses were received in 2025, providing rich insight into what matters most to people receiving kidney care in the UK.

The majority of all Kidney PREM comments were positive. This was largely driven by feedback on ***How the Kidney Team Treats You*** and ***Overall Experience.*** These themes received the highest number of comments and were the only two to be rated predominately positive. ***How the Kidney Team Treats You*** has remained consistently positive over the past five years, with patients frequently highlighting the caring and professional nature of the kidney team. This highlights the important role that the kidney team have in shaping patient experience and demonstrates how much staff are valued and appreciated by people receiving kidney care.

Approximately 45% of all comments were negative, suggesting that there is significant opportunity to further enhance patients' experiences of kidney care. ***Transport*** accounted for the largest proportion of negative feedback. Some issues are not always easily modifiable or within the control of clinical teams, for example, transport and environment issues. However, it is important to acknowledge that these issues can have a substantial impact on patients' overall experience of kidney care. These issues may indicate areas of care where a national- or system-level response should be considered. Nevertheless, this report also highlights several ***Quick Wins*** that can implemented relatively easily and have the potential to make a meaningful difference to patient experience.

The five-year reflection of Kidney PREM Comments suggests that progress is being made in several areas. Themes such as ***The Environment*** and ***Privacy and Dignity*** have seen a decrease in the proportion of negative comments over time. Overall, it is hoped that this report will continue to support patient-centred quality improvement across the kidney community. Individual kidney centres have received the comments from the participants who receive care at their centre and can be used alongside the Kidney PREM results to identify specific aspects of care to improve and further enhance patient experience.