



# Enter and View Visit Royal Sussex County Hospital Sussex Kidney Unit August 2025

Project Coordinator – Katy Francis



**healthwatch**  
Brighton and Hove

## Thank you

Healthwatch would like to express its thanks to University Hospitals Sussex NHS Trust for facilitating our visit. Particular thanks go to Emma Gillingham, Victoria Ingham and Nicole Chavaudra.

Our sincerest thanks go, as always, to our volunteers who supported our visit: Bharti and Vanessa.

# Summary

**Our visit to the Sussex Kidney Unit of the Royal Sussex County Hospital reveals an overall positive picture from the patient perspective but has identified some areas that need improvement.**

We attended the unit in response to findings from a 2024 survey (PREM), led by The UK Kidney Association in partnership with Kidney Care UK, to listen to patients' concerns in more depth.

In consultation with the renal department's clinical leads, we focused on asking patients about their experience of communication with their care team. We replicated lower-scoring PREM questions and gave patients the opportunity to comment openly on each. We also asked about the environment and conducted an environmental audit.

We used the survey as a prompt to have in-depth discussions with fourteen haemodialysis patients, with most interviews lasting around 30-45 minutes.

## Our overall conclusions on communication

Overall, our survey findings reveal that dialysis patients are generally happy with the Sussex Kidney Unit at the Royal Sussex County Hospital. Patients scored communication highly overall (average score of 5.37/7.00) and there were many positive comments about the care they receive as well as an awareness of the constraints of the system. One patient was so pleased with their care, they said they were hesitant to move as they were concerned that they wouldn't find as good of a renal team elsewhere.

However, upon further discussion and when asked about more specific areas of care, patients did indicate some improvements that could be made.

There were some quite mixed and polarised opinions about communications in some areas such as test results, dietary advice, and life goals discussion. Some explanations for this could be personal preference in how much detail they like to hear and how they like to be communicated with, different treatment rooms and/or different staff providing a different patient experience, and length of time the patient has been in renal care and the severity of their condition.

## Communications between the renal team and patients

Two areas were raised as particularly upsetting for some patients. Firstly, regarding some instances of poor communications around changes to

treatment at dialysis appointments. Secondly, some patients felt there were poor letter communications about significant changes to care.

One patient spoke of differences in care between floors, with their experience of floor 9 (which takes care of renal inpatients) being far more positive.

Opinion was mixed regarding test results, with some not understanding them online and finding this frustrating, but others trusting in the clinicians to make decisions for them and not wanting detail. However, there was an instance of a very dismissive consultant which was especially unhelpful.

Whether the renal team asked patients about their emotional feelings was the second poorest scoring question, with 43% of patients stating that they were never asked about this. However, there were also some positive comments. We note that the trust has plans to recruit a social worker to work alongside their welfare officer, which would increase the counselling service's capacity.

Only 21% of patients scored that they 'always' know who is caring for them on the day indicating the need for better introductions, staff information on display in the unit, and more visible ID badges.

Access to patient support groups scored very poorly at 2.64/7.00 with a mix of opinion indicating that more awareness needs to be spread, and more support given, however, there are some patients who are not interested.

The mixed results around dietary advice indicated that more dietician capacity may be needed. There were similarly mixed results for patients' ability to talk about other concerns or anxieties resulting from kidney disease or treatment. These results suggest some patients may like to be asked more proactively rather than volunteering information on a needs-basis. Moreover, qualitative findings indicated that generally patients do not feel that they are regularly asked about their life goals.

### **Communications between the renal team and other services**

Opinions were mixed on communications between renal staff, with some saying it was good and others saying sometimes things get missed on handover, there needs to be more staff, and there are poor follow-ups. Unlike the PREM 2024 survey, we did not record any concerns about staff speaking to each other in other languages in the clinical area.

GP communications with the renal team was one of the poorest scoring questions (3.90/7.00). Many of the issues raised were around general practice rather than the renal team, but some patients did complain of poor communications both ways.

Between other medical specialists and the renal team, responses were generally quite positive, however some patients cited issues such as different messages from different professionals and difficulties getting appointments.

There were a mix of responses regarding the renal team's support with accessing other services. Some patients did not know these could be available through the renal team, others had been helped, and some referred to waiting lists.

## Recommendations based on patient feedback included:

- Improve communications about changes in care. The department have informed us that they plan to send a 'monthly patient information summary' sheet which should help to improve communications about individual care.
- Ensure sensitivity in letter communications when related to significant changes in care. Consider offering consultation to discuss bigger changes. The department are struggling to keep up with demands of increasing haemodialysis numbers which means patients currently may need to be moved from Brighton for their treatment. Some patients have been upset by this and how it has been communicated via letter. The department are looking to increase letter sensitivity.
- Ensure staff introduce themselves and wear clear ID badges.
- Increase discussions around life goals, concerns related to care and emotional feelings with patients.
- Increase patient information awareness and availability (including about patient groups).
- Increase support service capacity (e.g. dietitians and counsellors).
- Improve communications between GPs and the renal team.

(Detailed recommendations are at the end of the report).

## Our conclusions on the environment

Our audit involved visiting the outpatients waiting room, the Stirling day case unit, the four main haemodialysis rooms, and the dialysis waiting room. We scored all areas aside from the dialysis waiting room highly for the environments being welcoming, safe, caring, well-organised and calm. Scores were six out of ten for the dialysis waiting room, due to storage, information, and safety issues, but ranged between eight and ten for the other areas. The smallest haemodialysis room (room 1) lowered the results for its section as it felt cramped and cluttered.

85% of patients said they were either satisfied or very satisfied with the environment. However, they raised some concerns around the dialysis waiting room, parking, dialysis room 1 being cramped, ceiling tiles and the broken lift.

We note that the trust already has plans to improve the environment and enact some of the following changes.

## Recommendations by Healthwatch representatives included:


- Improvements to storage
- Improvements to the dialysis waiting area (e.g. seating, placing a manned desk and WC repair)
- Improvements to patient information on display (e.g. information about staff)
- Replacement of some ceiling tiles

- Fixing the second lift which is out-of-order.

(Detailed recommendations are at the end of the report).

## Response from University Hospitals Sussex NHS Foundation Trust

Healthwatch Brighton and Hove invited a response from University Hospitals Sussex NHS Trust to our findings. This is their response:



*"We would like to thank Healthwatch Brighton and Hove for accepting our invitation and visiting our Brighton unit to speak with some of our haemodialysis patients. The detailed report provided offers valuable insights that will guide us in improving our service, particularly in enhancing communication with our patients. We are also deeply grateful to our patients for their candour and honesty, which is essential in helping us deliver better care."*

**Emma Gillingham, Head of Nursing for Renal and Vascular**





# Introduction

## Background

The Sussex Kidney Unit (SKU) is part of [University Hospitals Sussex NHS Trust](#) (UHSx). The SKU is a specialist service providing renal care for the patients of Sussex. The hub is at the Royal Sussex County Hospital (RSCH), but bespoke services spread beyond the standard geography of UHSx. SKU is made up of:

- Haemodialysis departments – Providing care for over 500 patients across Sussex who attend for treatment 3x week for approximately 4-5 hours per session. There is the Main haemodialysis unit (at Brighton) and four satellite haemodialysis units across Sussex (in Bexhill, Crawley, Eastbourne, and Worthing). The Brighton unit has doctors on site and cares for patients with more complex conditions in comparison to the nurse-led satellite clinics.
- Renal Outpatient services, including clinics in general nephrology, advanced kidney care, renal vasculitis, and transplant and dialysis clinics.
- Renal Transplant department
- Home Therapies department (providing training and support for patients receiving Home Haemodialysis and Peritoneal Dialysis)
- The Trafford Renal ward at Brighton has 28 inpatient beds and an Acute Dialysis area (for inpatients with an Acute Kidney Injury or for haemodialysis patients that are not well enough to attend their outpatient treatments)

The [Kidney PREM](#) (Patient Reported Experience Measure), led by [The UK Kidney Association](#) in partnership with [Kidney Care UK](#) is an annual, national survey of UK kidney patients that aims to:

- Help kidney unit teams understand how patients feel about their experience of care
- Show where improvement can be made from a patient perspective
- Provide a national picture of people's experience of care

It contains 39 questions encompassing 13 themes of patient care and overall experience. Respondents score their experience of kidney care from worst (1) to best (7), generally on a scale of 'Never' to 'Always'.

The results of the 2024 PREM ranked Sussex Kidney Unit as 63 out of 66 centres, making it one of the lowest ranking renal services in the country. The scores were generally not poor, with an overall mean centre score of 5.63/7.00. High scoring areas were 'privacy & dignity', 'patient information' and 'access'. However, there were some areas that were highlighted as needing some improvement.

The lowest scoring areas were concerned with:

1. Sharing decisions

2. Support (e.g. counsellors, social workers, and pharmacists)
3. Fluid & diet
4. Environment
5. Communication
6. Transport

UHSx invited Healthwatch Brighton & Hove (HWBH) to conduct an [Enter and View](#). Healthwatch has a legal responsibility to carry out an Enter and View programme, but we are not inspectors, instead, we focus on gathering the views and experiences of the people receiving care.

Healthwatch engaged in discussions with the SKU clinical leads to explore which areas they would like to receive more in-depth feedback on, as the PREM offers only one general opportunity to provide open-ended answers.

Healthwatch in Sussex (including HWBH) is conducting a survey on Non-Emergency Patient Transport services (used by renal patients) in Autumn 2025. Therefore, this visit focused on speaking to patients primarily about communication and the lowest-scoring PREM questions that focused on sharing decisions, support, and fluid & diet. We also spoke to patients about the environment and conducted an environmental audit of four areas.

This project's scope was focused on haemodialysis patients at the RSCH Brighton site. It is important to note that the experience of patients who are not having haemodialysis and/or who are at satellite sites may have significantly different experiences of their care.

## What we did

On 19<sup>th</sup> August 2025, between 11-4pm, two trained and DBS-checked<sup>1</sup> Healthwatch volunteers and two members of Healthwatch Brighton and Hove staff visited the Sussex Kidney Unit at the Royal Sussex Hospital. Staff members conducted an environmental audit and volunteers joined from 1:30pm to conduct interviews.

## Interviews with patients and their carers

We spoke to fourteen patients about communication using a survey designed with some of the lower-scoring PREM questions in mind. This was informed by a discussion with the kidney clinical leads on priority areas to explore.

We used the survey as a prompt and spoke to patients in-depth, gathering qualitative data to complement quantitative data.

Notes from these conversations were recorded anonymously to maintain patient confidentiality.

Over two hours, the team spoke to patients and their carers and asked them for their views on their experience of communications about their care as well as their views on the environment. Discussion length varied by patient and ranged from 15 to 45 minutes, with most being around 30-45 minutes.

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<sup>1</sup> Disclosure and Barring Service - <https://www.gov.uk/government/organisations/disclosure-and-barring-service>

Patients were asked to save their feedback on transport for an upcoming Healthwatch in Sussex survey on Non-Emergency Patient Transport services (NEPTs).

## Environmental audit

Two members of staff visited the following areas on level 8 of Sussex Kidney Unit (SKU):

- Outpatient waiting area
- Dialysis waiting area
- Main haemodialysis rooms x4
- Stirling day case unit

Our representatives recorded their views of the physical environment, and they also completed a checklist to capture positive findings, challenges, and concerns, as well as anything staff told us. Representatives recorded their recommendations for improvement. Our findings are summarised in the next section, with more detail provided in a separate [report](#).

# Results

The results of our visit will be presented as follows:

### A. Survey methodology

### B. Background of participants

### C. Communication findings

#### 1. Communication between the renal team and patients:

- a. Overall satisfaction and general feedback
- b. Changes to treatment
- c. Letters
- d. Do patients know who is caring for them?
- e. Understanding test results
- f. Clear dietary advice
- g. Ability to talk about other concerns or anxieties resulting from kidney disease or treatment
- h. Treatment and life goals
- i. Managing own care
- j. Emotional feelings



- k. Support accessing patient groups such as Kidney Patient Associations (KPAs)

## **2. Communication between the renal team and other services**

- a. Between members of the renal team
- b. GPs and the renal team
- c. Other medical specialists and the renal team
- d. Other services such as counselling, social work, and welfare/housing

## **3. Patient suggestions to improve communications**

### **D. Environmental findings**

The findings regarding the environment consist of the patient survey feedback and the audit carried out by the Healthwatch representatives.

#### **1. Patient environmental satisfaction**

#### **2. Environmental audit**

Detailed recommendation will then follow on from the results.

## **A. Survey methodology**

Over two hours (1:30–3:30pm) on Tuesday 19<sup>th</sup> August 2025, the Healthwatch team of two volunteers and two staff members spoke to a total of fourteen patients across the four main haemodialysis rooms.

A questionnaire was devised in advance of the visit. Discussions between Healthwatch and the renal clinical leads at University Hospitals Sussex took place so we could hear what staff were particularly keen to receive feedback about based on the PREM 2024 survey results. We replicated poorer-scoring PREM questions (under 5.40/7.00) in areas such as sharing decisions, support, and diet and fluid, and those related to communication as a prompt for discussion. We also replicated all the 'communication' questions from the PREM and asked one question about the environment. We gave patients the opportunity to comment for each question so lower scores could be better understood.

All respondents were asked if they would like to take part and were told that the research was confidential and that they would not be made identifiable. Some quotes have been edited to ensure patients are not identifiable. Respondents were free to withdraw from the research at any time.

The interviews were mostly in-depth discussions, lasting around 30–45 minutes. Not every patient scored every question as the survey was used as a prompt for discussion and some people preferred not to answer some questions (e.g. demographic questions such as age and gender). The number of responses are stated with the percentage in the findings.

It is important to note the following limitations of the survey:

- Some of the survey data results (quantitative data) were not entirely consistent with what people told us (qualitative data). This was due to the exploratory, discussion-style format, which we found generated more authentic and detailed answers which were often raised further into the conversation and after initial scoring had taken place.
- Nevertheless, survey data has been themed together in the findings. With this in mind, we consider that the qualitative data will likely be more reflective of patients' experiences
- Some patients interpreted and answered some replicated PREM questions in a way that was not exactly what the question intended to ask. Therefore, scores should be taken with caution and we consider that the qualitative data should be paid more attention to. This is explored further in the findings. In some cases, patients may have heard a keyword like 'GP' or 'patient group' and scored poorly due to purely negative experiences with the GP or the patient group. This was evident in the qualitative data collected for the following questions:
  - Understanding test results
  - Clear dietary advice
  - Treatment and life goals
  - Support with accessing patient groups
  - GP and renal team communication

## B. Background of participants

Of the fourteen respondents, nine were men, two were women, and three preferred not to say. Ages ranged between 18 and 82, with the average age being 58 years old:

| Age Range | Count |
|-----------|-------|
| 18-24     | 1     |
| 25-34     | 0     |
| 35-44     | 2     |
| 45-54     | 1     |
| 55-64     | 3     |
| 65-74     | 0     |
| 75-84     | 4     |

|       |   |
|-------|---|
| 84-95 | 0 |
|-------|---|

In terms of ethnicity, nine people were from 'White-British' backgrounds, one person was from 'Mixed/multiple ethnic groups: Black African and White' background, one was from an 'Arab' background and three preferred not to say. Six people did not want to share their financial situation.

Which of the following best describes your current financial situation?  
(n=14)



## C. Communication findings

### 1. Communication between the renal team and patients

Whilst the question 'Do you think there is good communication between you and your renal team?' didn't score particularly poorly in the 2024 PREM (5.89/7.00), communication came up as a negative theme in the comments.

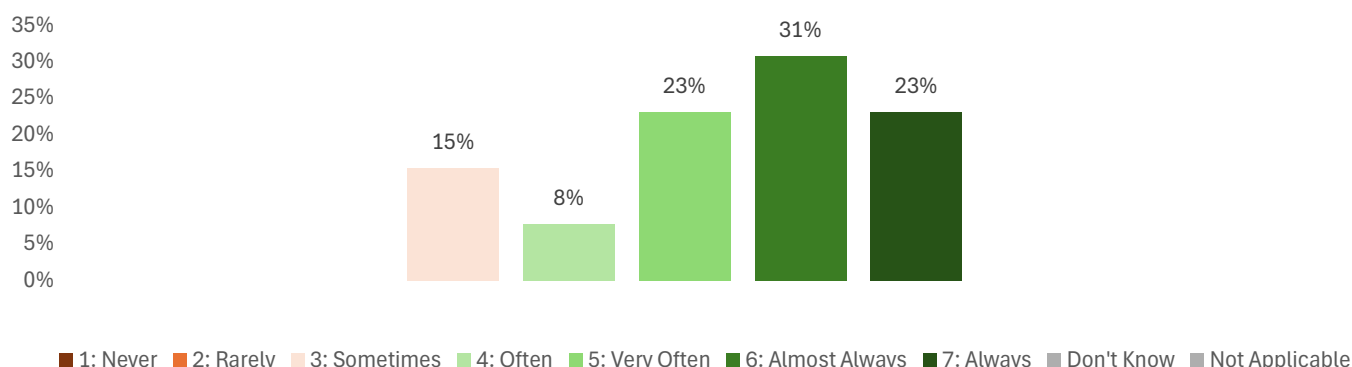
We consider that the term 'good communication' may be a little vague for patients to respond to, so to contextualise this overarching question, we replicated the poorest-scoring PREM questions (i.e. those below 5.40) related to communication (sections e-k).

We encouraged patients to consider specific aspects of their experience, such as understanding test results or dietary advice. These questions were framed to give patients the opportunity to provide more detailed feedback through open comments.

#### a. Overall satisfaction and general feedback

We replicated the PREM question, "Do you think there is good communication between you and your renal team?" The average score was 5.38/7.00. This is broadly similar to 2024's PREM average score of 5.89/7.00.

### Do you think there is good communication between you and your renal team? (n=13)



However, there was a variety of feedback on this question. Some patients scored positively when asked about communication, however, when given the opportunity to speak more openly, raised some more significant issues. Two patients raised issues with communication around changes to treatment which is covered in the next section (b).

**Positive comments** included helpfulness, positivity, speed, and being left to their own devices.

*"Recently, we considered moving to be closer to family. What stopped us was the thought of finding a renal team as good elsewhere."*

*"There is very fast sharing of information. For example, there were issues with a fistula, but this was addressed quickly. There are the usual NHS constraints which affect the department, but overall, I think it's brilliant."*

*"I'm happy with things the way they are. I think I have a good relationship with the staff."*

*"I'm happy to pass the time with music and games whilst on dialysis. I appreciate being left alone except when required to talk with staff."*

*"They are very helpful."*

*"The nursing is superb! They're always so positive so you don't know if they're having a bad day privately. They listen and work as a team."*

**Mixed comments** arose around busyness (good care but the need for more staff) and differences in care on floors 8 and 9.

*"The staff have a warm approach. I don't feel anything could be improved here but I do think more staff are needed as staff are usually very busy."*

*"Floor 9 communication was always phenomenal. Floor 8 is more faceless with less fostering of relationships and the wheels grind slower."*

*"Though the care is good here, sometimes it can feel mechanical."*

**Negative comments** included chasing to find out what's going on, not checking in when there's patient lateness or absence, wanting to see consultants more, and transport communications.

*"I think it is alright. You can feel a bit lost; they do not tell you what is going on and you have to chase to find out what is going on. For example, I had low bloods and I saw the results but had to chase to find out what was happening".*

*"I wish I could see the consultant more. I don't feel I can ask the nurses certain things; I need the consultant."*

*"Transport pickups could be better; you get dumped at the end waiting very frustrating. Shift patterns can change or if you want to change for a personal event don't know of confirmation changes to last minute."*

*"If I am late or don't attend, no one calls to check on me. This worries me in case something was seriously wrong with me. It would be reassuring if someone called to check."*

[The department assured us they have a set protocol that staff follow when patients are absent from dialysis.]

## **b. Changes to treatment**

When given the opportunity to feedback about communication overall, two patients raised issues regarding poor communication around changes to their treatment.

One patient was very hesitant to speak negatively about their care, and this only came out much further into the conversation. The duration of their dialysis session changed, and they had not been informed.

*"No one explained to me why it was happening or what caused it. That was really upsetting. It helps me if I can prepare mentally for the change rather than it just happening and no one telling me why."*

Another patient had raised issues with the team about side effects from medication related to their renal care. This was dealt with and a change to medication was made, but no one informed the patient of the outcome during a dialysis session when it was already in motion. The patient had to ask repeatedly to be told what was going on.

### c. Letters

Two patients raised issues with letter communications in further discussion when asked about communication overall.

One referred to a negative incident involving a lack of sensitivity that other patients were also upset about. The patient described an incident where a letter was sent out to patients stating that there were too many patients attending the unit and that some would have to be moved to satellite locations. The patient felt that the nature of this letter was not sensitive or nuanced, and it affected the patient negatively.

*"This letter was a blunt object"*

They stated that it didn't demonstrate the usual levels of sensitivity they expect from the department. They stated that patients were not consulted prior to it being sent, so wondered where has this issue been raised. Other patients were also upset by it with one saying that they would stop attending appointments altogether if they had to move. Their consultant did ask if they wanted to make a formal complaint when they raised the issue. They said no but did stress that the choice of communication overall could have been more considered.

*"The experience created a feeling of resentment."*

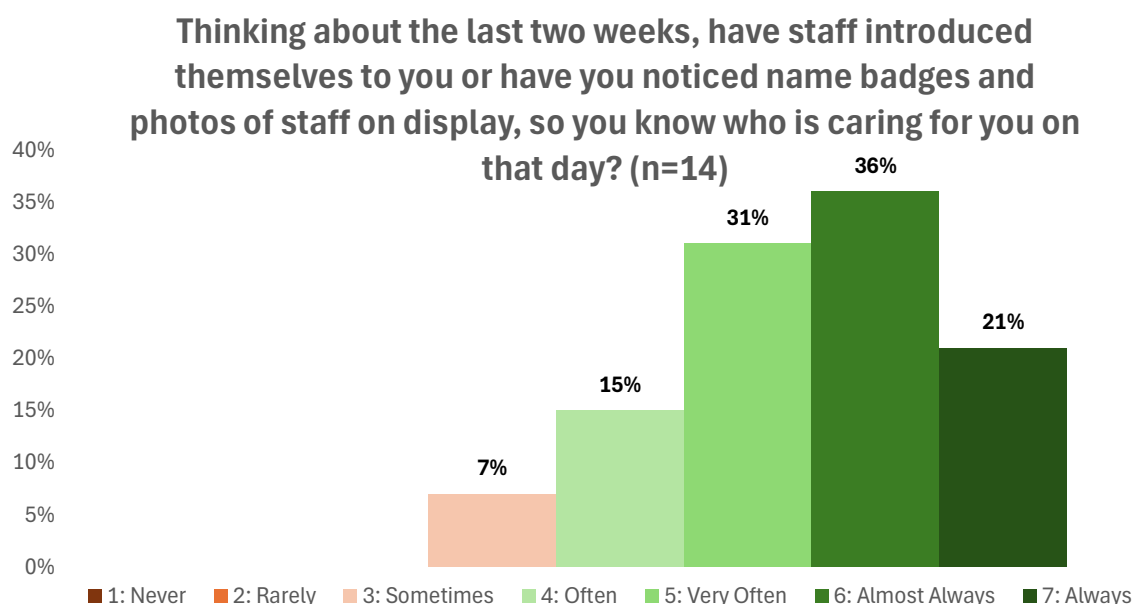
Another patient did not like receiving letters as it makes them feel anxious. They stated that when appointment information is sent, it's sent via post (on paper) and via the Patients Know Best App.

*"I don't need both and I feel sick with anxiety whenever a letter comes through the letterbox."*

They thought all information should be shared via the App so they can choose when to engage with the information. They also think that sending via the post is a waste of money.

### d. Do patients know who is caring for them

We asked this question as it was raised as a concern in the comments from 2024's PREM.





Comments were mostly positive however only 21% scored that they **always** know who is caring for them on the day. The average score was 5.50/7.00.

Two patients commented that it was hard to see staff badges and sometimes it was covered by their uniform.

Another mentioned that he had been coming for around 2 years but when there's a new person, he must ask for their name rather than being told.

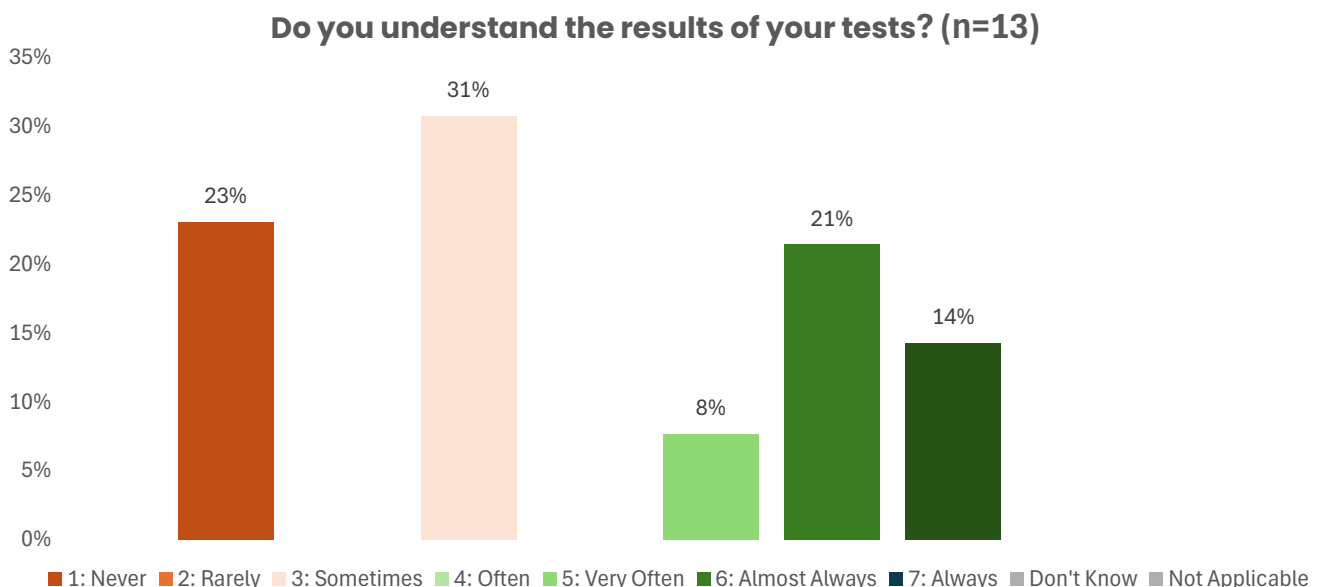
*"I already know most of the staff but when I don't, I have to ask, they don't introduce themselves and I find it hard to see the name badge."*

In contrast, a patient who had only been attending for 7 weeks said they already felt like they knew who was caring for them.

### e. Understanding test results

We asked this as it was a lower-scoring PREM question (5.33 in 2024 PREM).

The scores were varied with an average of 4.00/7.00.



There were mixed views for this question. However, the lower scores don't necessarily represent dissatisfaction. Upon further discussion, some patients appeared to be answering this question by referring to their understanding of test results on the NHS app rather than in general or when results are explained to them in person by clinicians.

Some patients said they trusted the clinicians to act appropriately for them and did not feel they needed to fully understand test results themselves when looking online. They also said they know they can ask if they want to.

*"I'll ask if I want to. I don't want all the detail."*

In contrast, there were some patients that did want the information explained to them more proactively.

*"I had low bloods, and I saw the results but had to chase to find out what was happening."*

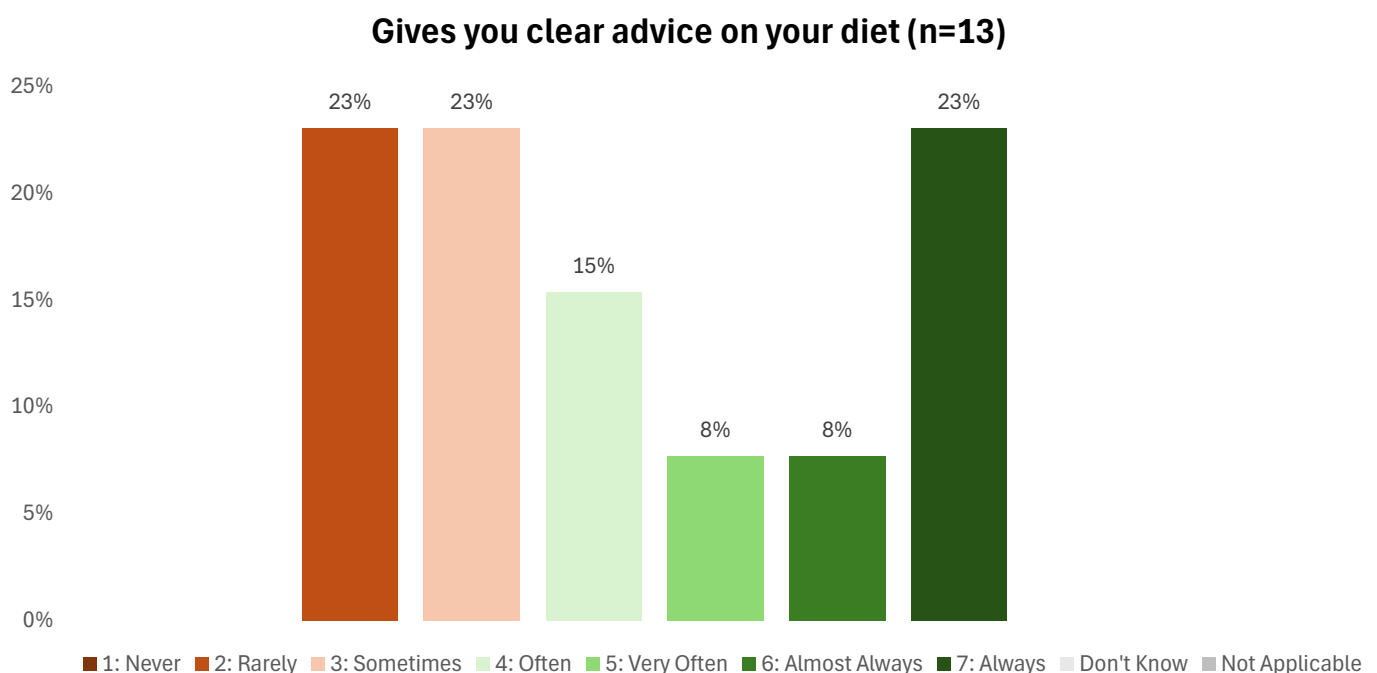
One patient pointed out an example of a consultant being very dismissive when they did ask for further explanation.

*"I have to ask to understand. I was concerned because my blood test was out of range. I was told by the consultant, 'don't look at them then', which isn't very reassuring at all."*

## f. Clear dietary advice

We asked this as it was a lower-scoring PREM 2024 question (5.12/7.00).

Patients scored 4.23/7.00 on average with polarised results.



Several patients commented positively mentioning that they regularly see a dietician.

One patient was particularly positive.

*"Dietician gave a four-month plan which is consistently renewed. A good system of communication where the dietitian has always 'done their homework'. For example, when I went onto the transplant list, they already knew this and planned with it in mind."*

However, two commented more negatively.

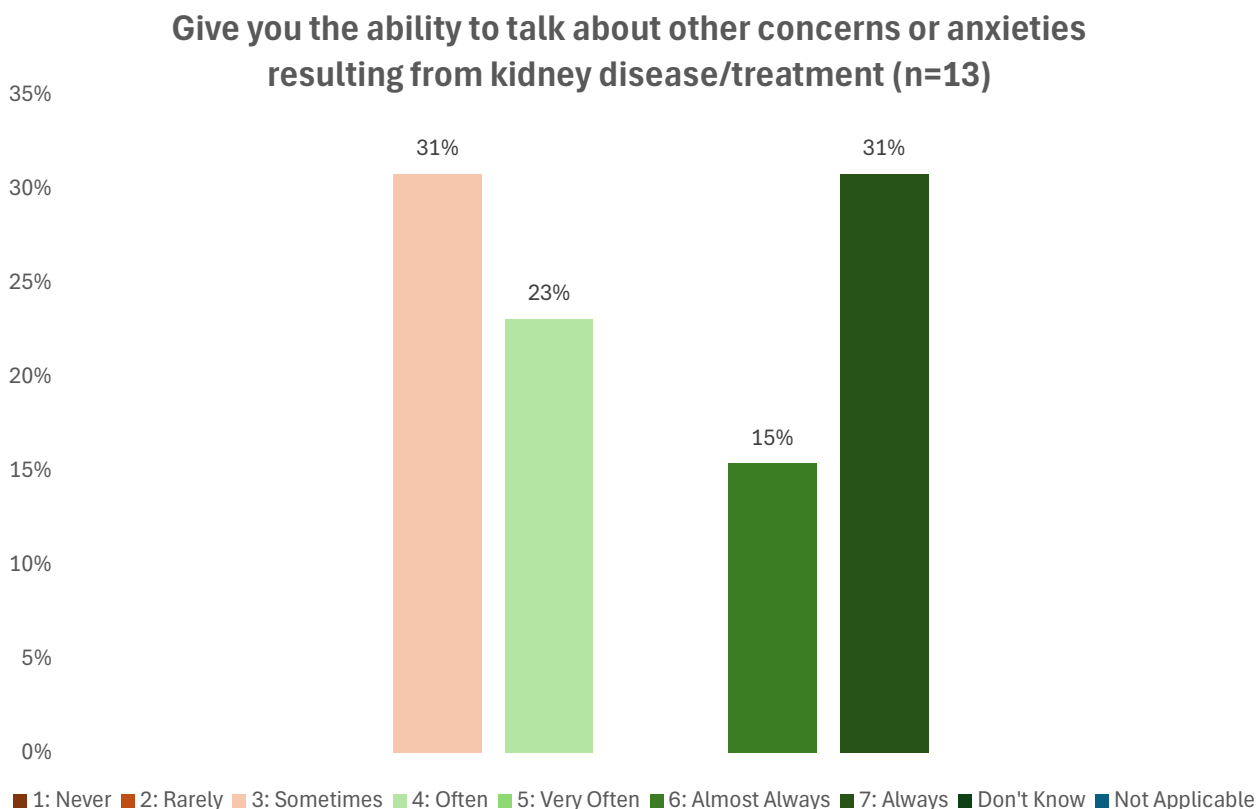
*"I've had to ask questions about my diet rather than being told."*



### g. Ability to talk about other concerns or anxieties resulting from kidney disease or treatment

We asked this as it was a lower-scoring PREM 2024 question (5.35/7.00).

Patients scored 4.92/7.00 on average with a range of responses.



From discussions, patients generally said felt they could speak to staff about concerns on a need's basis. One patient mentioned that they appreciate it when the team actively ask.



*"I feel able to talk about concerns or anxieties when it comes up in conversation with the renal team. I'm still coming to terms with need for dialysis and appreciate it when it crops up as I'm not much of a talker."*

*"We talk about that on a needs basis."*

*"I had [an injury] and didn't know whether I could have dialysis. On arrival, the registrar helped and wrote a prescription. It was very helpful, and I was able to have dialysis."*



One patient said they would like to see their consultant more and another felt like they had to create opportunities to speak to clinicians.

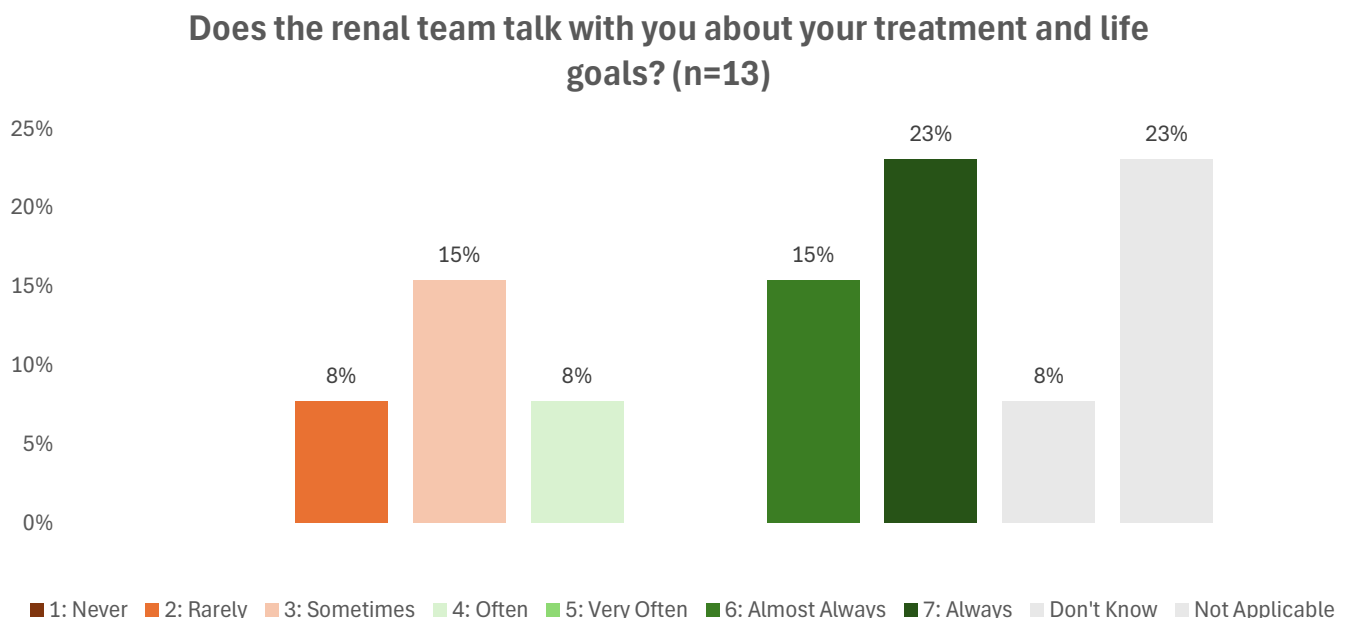
*"I intentionally use a toilet farther away so I can bump into clinicians, so I have the chance to ask them questions."*

The lower scores e.g. 'sometimes' could indicate that patients would like to be actively asked if they currently have any concerns rather than them having to volunteer it on a need's basis.

### h. Treatment and life goals

We asked this as it was a lower-scoring PREM 2024 question (5.07).

Patients scored 5.00/7.00 on average with a mix of responses (n=9. A further 4 patients selected 'don't know' or 'not applicable').



Four commenters said they were spoken to about treatment but not life goals.

This suggested that some patients interpreted the question as asking about treatment and life goals separately, rather than their treatment in relation to their life goals.

There were contrasting opinions, and this question may have scored more highly because patients heard 'treatment' and responded based on the fact that their treatment is spoken about a lot, rather than it being spoken about in relation to their life goals. The qualitative data suggests that treatment in relation to life goals is not spoken about regularly.

*"The team always talk about treatment but not about life goals."*

*"Staff have occasionally talked about treatment goals."*

*"I sometimes have to dig a bit to talk about treatments and life goals."*

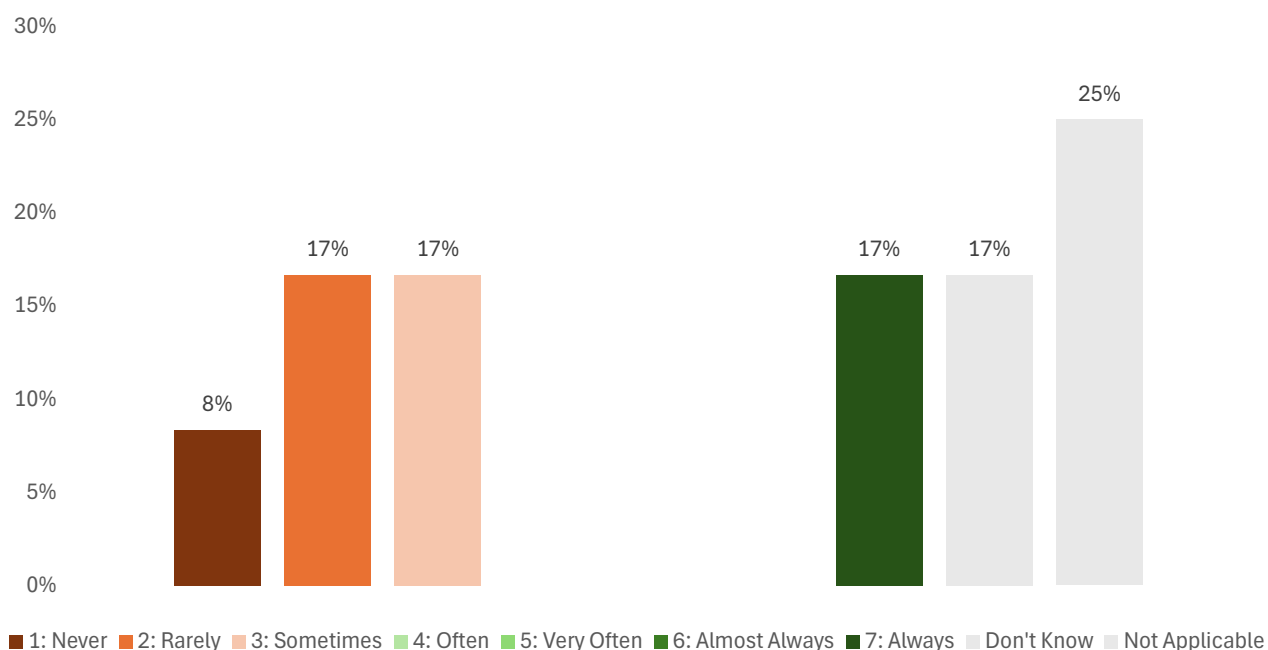


### i. Managing own care

We asked this as it was a lower-scoring PREM 2024 question (4.96/7.00).

Patients scored 3.57/7.00 on average with mostly less frequent responses, although two patients scored that it was 'always' spoken about (n=7. A further 5 patients selected 'don't know' or 'not applicable').

#### Does your renal team talk with you about taking a more active role managing your own kidney care?



Through further discussions, some patients explained that self-management is not possible for them, or they prefer to be treated at the unit. This may explain some patients scoring 'never' and 'rarely'.



*"We don't have managing own care conversations because I can't be treated at home."*

*"Staff talked to me about it when I first started at the unit. But I like to come to the unit and be looked after."*

One patient did mention that discussions had changed since they moved floor.

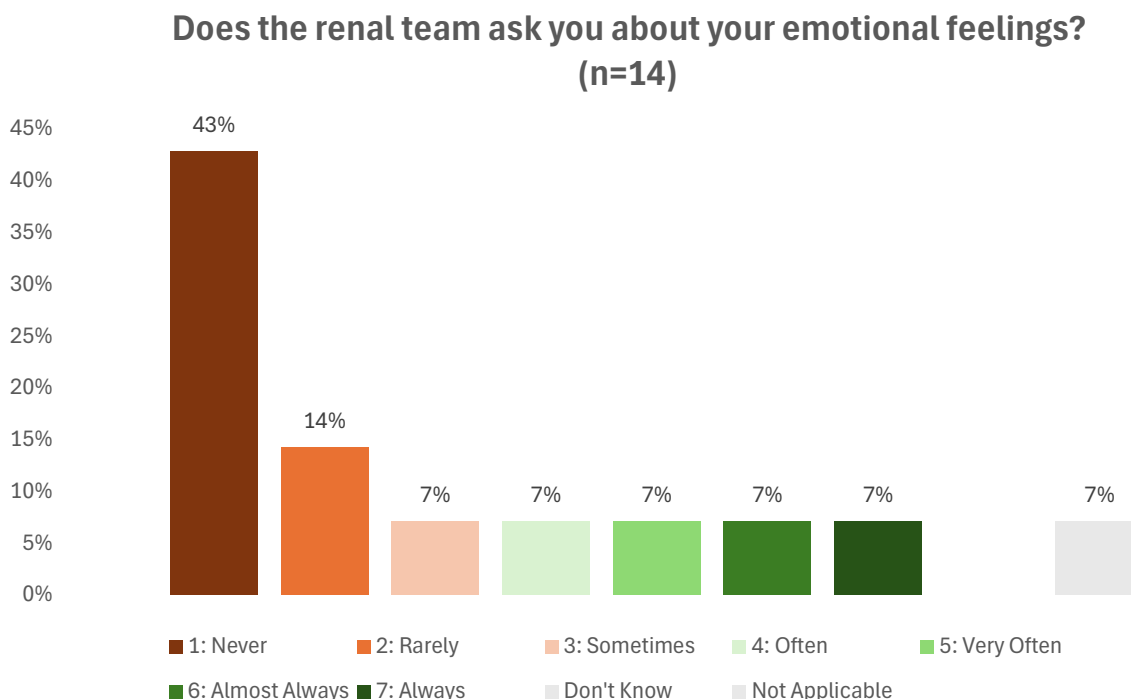
*"This was part of the discussion all the time on floor 9, but that there has been no discussion of this on floor 8."*



## j. Emotional feelings

We asked this as it was a lower-scoring PREM 2024 question (4.58/7.00).

Patients scored 2.69/7.00 on average. Six of the fourteen respondents (43%) said they are **never** asked about their emotional feelings.



There were mixed responses in the comments. Some felt they had never been asked. One patient said it is on occasion:

*"I discuss my emotional needs, but it is as and when, more of a judgement call as to when appropriate."*

There were some positive comments:

*"I feel that staff are aware of how I'm feeling and cheer me up occasionally. I feel their actions are aligned with how I'm feeling."*

*"Staff do ask about emotional feelings often and I feel that's helped me connect more with them."*

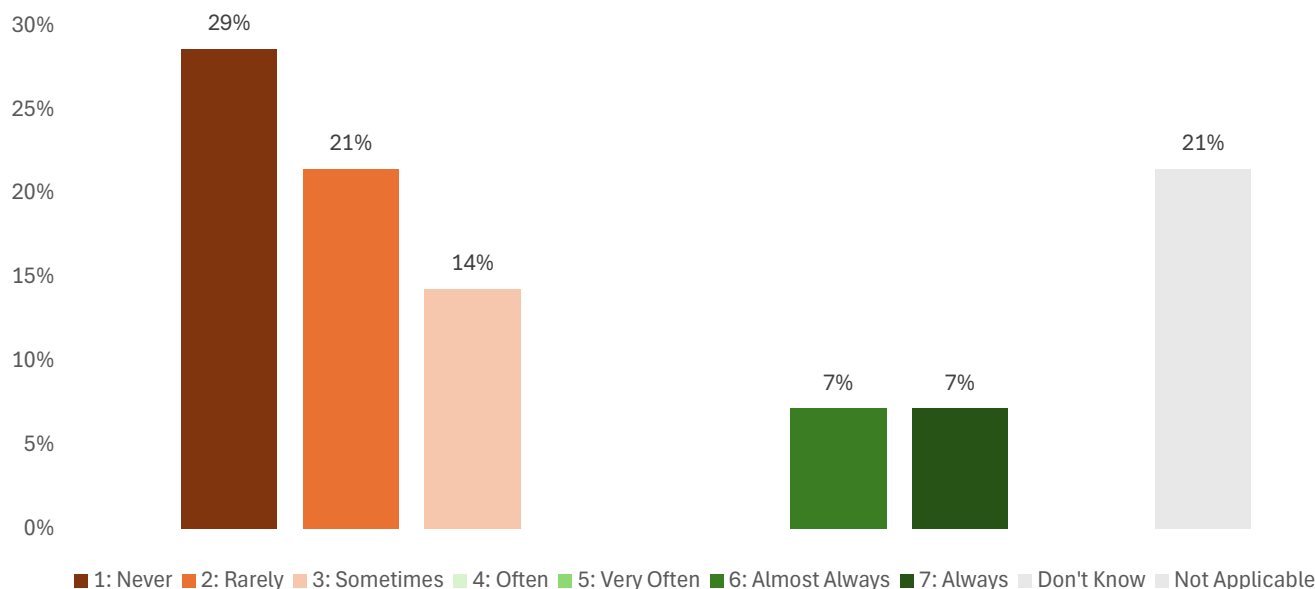
## k. Support accessing patient groups such as Kidney Patient Associations (KPAs)

We asked this as it was a lower-scoring PREM 2024 question (4.44/7.00).



Patients scored 2.64/7.00 on average (n=11, with an additional three patients selecting 'Not Applicable').

**Do your renal team help you to get the support you want to access patient access groups such as Kidney Patient Associations (KPAs)?  
(n=14)**



Two patients didn't want to access KPAs citing reasons such as preferring to speak to a counsellor and being a private person.

*"The team have let me know about access to support services sometimes but I am a private person."*

*"I've opted to not take part and prefer to connect with my counsellor."*

Two patients spoke of negative experiences they have had with KPAs.

*"I'd been offered access to a support group but I'd have to travel to Brighton from home in Eastbourne, so said no. This is too far, especially when already travelling in for dialysis. I would have tried a group in my local area, if offered, and instead have taken to Facebook independently and sought out support groups there."*

*"I contacted a KPA on one occasion, but they never returned my call, so very disappointed."*

Three patients stated that they didn't feel they have been given information:

*"I have not been supported with this and need signposting."*

*"I hadn't thought about support type groups so I haven't brought it up yet with staff. May ask in near future."*

*"I found KPAs by myself online, but the renal team did not help."*

In contrast, two patients pointed out the posters present in the unit. However, not all patients sit in the waiting room and are brought straight into the dialysis room from their transport so do not get the opportunity to see displayed information.

*"I've been signposted to leaflets about support groups and I know I can access them if needed."*

*"There are adverts everywhere [in the unit]."*

## **2. Communication between the renal team and other services**

We asked patients four questions replicated from the PREM about communication between the renal team and other services.

- a. Between members of the renal team
- b. Between the patient's GP and the renal team
- c. Other medical specialists and the renal team
- d. Other services if you need them such as counselling, social work, and welfare/housing

### **a. Between members of the renal team**

**"Do you think there is good communication between members of the renal team?"** (PREM 2024 score: 5.87/7.00)

Patients scored an average of 5.90/7.00. Scores were not polarised for this question, with the lowest score being '4: Often'.

Comments from the PREM 2024 survey consisted of some concerns around renal team members not speaking to each other in English in the clinical areas. Two patients raised this point unprompted by the interviewers as they had seen mention of it on the 'You said, We did' posters from the PREM 2024 survey results in the waiting area.

These patients wanted to state that it was not an issue for them and no other patients raised this point.

6

*"I noticed the posters regarding staff not speaking English. I don't have an issue with it at all if they can communicate quickly and efficiently in another language so long as they talk to us in English, which they do."*

*"The motivation in the renal team is great, and I don't think the staff talk in different languages in the common space. They might use a different language when having a private chat but never in front of others who don't speak the language or in public areas."*

9

**Positive comments** consisted of staff keeping each other up to date and collaborating well.

6

*"People come back from holiday and are immediately updated and up-to-speed. I'm never let down in this regard."*

*"I feel like they involve others in the team when needed like the doctor. They seem like they collaborate to provide my care in respect to my bloods and the renal machine."*

9

**Negative comments** consisted of slow progress and lack of communications between staff, as well as the need for more staff and more training.

6

*"There hasn't been any progress on my living donor offer. Throughout this process, there hasn't been any clarity or communication. My consultant asks for updates [but] there is then also no follow-up."*

*"Only one nurse knew how to deal with the change of flowrate alarm."*

*"Sometimes, on handover, things get missed."*

*"There needs to be more staff."*

9

## **b. GP and the renal team**

**"Do you think there is good communication between your GP and the renal team?"** (PREM 2024 score: 4.65/7.00)

Patients scored 3.90/7.00 on average (n=10, an additional 2 answered 'don't know' and 1 'not applicable')

Several concerns around general practice were raised in discussion. Many of the patients' negative ratings of this question seemed to be mostly related to their issues with their GP service rather than the renal service. Some patients pointed out that renal to GP communication seemed fine, but the other way around was poor. There were, however, some comments around it being poor both ways.

### Negative about GP:

*"It's a waste of time speaking to the GP. They used to ring me to check in but don't anymore. I see district nurses who take care of my foot, but I don't trust them because of previous bad experiences. It's an issue with the GP rather than renal team."*

*"I am also diabetic. With my previous GP I felt I was taken off certain medications. I feel I slipped through the net for continuity in care and some of my kidney challenges may be a result of this. I am now with a new GP practice. I have been waiting for heart failure medications for a while and the communication has been poor. "*

*"Non-existent GP to consultant communication. No GP call reviews for my conditions. Renal to GP ok."*

### Positive about GP:

*"My GP connects with the renal team on blood pressure issues. It's high and has been trying to reduce for some time. GP texts me when needed and I connect with the GP via phone."*

**Negative both ways** included slow transfer of information and poor communication regarding barriers to other investigations due to renal condition.

*"There was an issue when I was referred for a colonoscopy. I was required to take 200ml of water which I am unable to do due to my kidney condition, but my GP and consultant could never get to speak to each other."*

*"100% no! It's shocking. It takes a month for any information from the renal team to get onto my GP record, and I have to call up my GP to confirm that this has been done. With everything now being online, that transferral of information should be close to instant. Also, Brighton and Eastbourne's health authorities don't communicate well at all."*

*"The GP gets the letters, but the updates are patient-led. Dietary information has not been shared though."*

Positive about renal team:

*"I want to stress how good of a department the renal team is, for example, working with and supporting me through my treatment for [another condition]."*

### c. Other medical specialists and the renal team

**"Do you think there is good communication between the renal team and other medical specialists?"** (PREM 2024 score: 5.16/7.00)

The average score was 5.17/7.00 (n=12, with an additional patient selecting 'don't know').

There were mixed and negative comments related to continuity of care, delays and differing messages.

*"I felt this is good with the pharmacist. There was a confusion with some medications, and this has now been resolved. But different messages from different professionals can add to the confusion and this could be more consistent."*

*"I feel there is room for improvement. Cardiology and Urology needs are an example. I had to insist on consultation appointments and have encountered many delays. These could be organised better with respect to continuity in care."*

*"There needs to be better communication between renal team and cardiologist."*

*"The only issue is getting appointments, but this is down to the inevitable delays due to the current pressure on the NHS."*

There were two positive comments.

*"During my experience of x-rays and support from radiologists, I found that everything was usually ready to go, so no waiting around. I had to wait one time but it's almost always an efficient process."*

*"The Eye Hospital lets me schedule appointments ahead of dialysis which is helpful."*

#### **d. Other services if you need them such as counselling, social work, and welfare/housing**

"Do you think there is good communication between the renal team and other non-healthcare services if you need them, such as such as counselling, social work, and welfare/housing?" (PREM 2024 score: 3.98/7.00)

The average score was 5.50/7.00 (n=4, with 5 selecting 'don't know' and 4 'not applicable').

Some patients were hesitant to speak about their financial situation and/or welfare support (as seen in demographic: with 6 'prefer not to say' responses) or felt it was not related to them.

Those who used the welfare/housing services said it was useful, but some were accessing support elsewhere like through their GP.

Some had no idea about access to support services through the renal team, were still waiting for appointments, or the location of counselling was inconvenient.

*"Didn't know about it and wife sorts everything for me. I don't feel I need the support from the team now I've been through it. Maybe would have been helpful at the beginning."*

*"I've had nothing like that. Rang the GP Occupational Therapist to get brackets outside my house and had no response. I have a healthcare visitor every day which is self-funded but I've had to cut out Sunday because cost is too high. The counselling service is too busy."*

*"I have been referred to counselling but still waiting for an appointment."*

*"I attended four counselling sessions, however, I felt sad each time and felt that the counsellor wasn't for me. These sessions were offered in Polegate. I was offered more sessions but this time in Brighton, so I didn't want to travel back for this kind of support. Instead, I speak to friends."*

Some patients pursue social care support independently from the renal team.

*"My daughter is supporting a conversation for a stair lift – pursuing this independently of the renal team."*

*"I go to my GP for social and welfare needs."*



Four patients spoke positively and have been helped:

*"They are helpful with housing."*

*"The counselling and welfare team are a very good team and have helped me."*

*"Welfare officer was available initially at start. There was a problem with the council that was resolved. No need for counselling or welfare at moment."*

*"[name removed] helped with welfare and housing. Happy to ask for help if I need it."*

*"I was initially connected to welfare and counselling via the renal team. I've sought advice and guidance since and feel it's available when needed. Did not know if these services connected with the renal team or vice versa about my needs or care."*

### 3. Patient suggestions for improving communications

Patients were asked if either of the following would improve their experience of communications:

- A **newsletter** from the renal team that gives updates on the service and improvements that have been made: **6/14** patients would be interested.
- **Informational videos** to watch on a tablet during dialysis to explain things related to your care: **3/14** patients would be interested.

They were then given the opportunity to make comments and offer other ideas.

There were positive comments regarding a newsletter and informational videos:

*"I would like a newsletter. If not paper, my daughter can help me access. A tablet with 5-minute type additional information whilst on dialysis would be a good idea."*

*"A newsletter would help. I'm digital savvy, so informational videos would be welcome. No other suggestions."*

*"A newsletter would be a good idea."*

*"A newsletter would be interesting to see."*

Two patients stated they are already satisfied with the level of communication.

*"I feel like I'm told what I need to know. Occasionally, I get a letter."*

*"I find the team email useful. Additional information that is not specific to my care would not help further. I'm happy with listening to music during the dialysis."*

Two patients stated that the suggested options above would not solve their issues with communication e.g. around personalised care and wanting to speak to a person.

*"Newsletters etc were not needed as I want information that relates to my immediate need."*

*"No to both options. I want to speak to a person! Phone is definitely the preferred mode of communication. Floor 9 was great as you could easily phone and speak to someone, and you knew their names. I'm not so confident that this would be the case on floor 8."*

Two patients suggested introductory information that would be helpful about parking, transport, contact numbers, legal rights, social care access, grants, dietary information, and how to understand test results.

*"The parking permits and what you're entitled to aren't clear, and it's a 'random' start to your experience of coming in for treatment. They should 'frontload' information like this on arrival, including common problems like transport. This introductory communication could also include contact numbers and general housekeeping. I have no preferred mode of communication but a poster in the waiting area would be helpful, or a member of staff who takes patients through an induction on arrival."*

*"There could be a welcome pack for patients who were new to the ward. The contents could Legal Rights, How to get Social Care, Charitable Grant, Information on Diet. Also, something about interpreting or understanding test results."*

There was a further suggestion for a check-in screen in the waiting room.

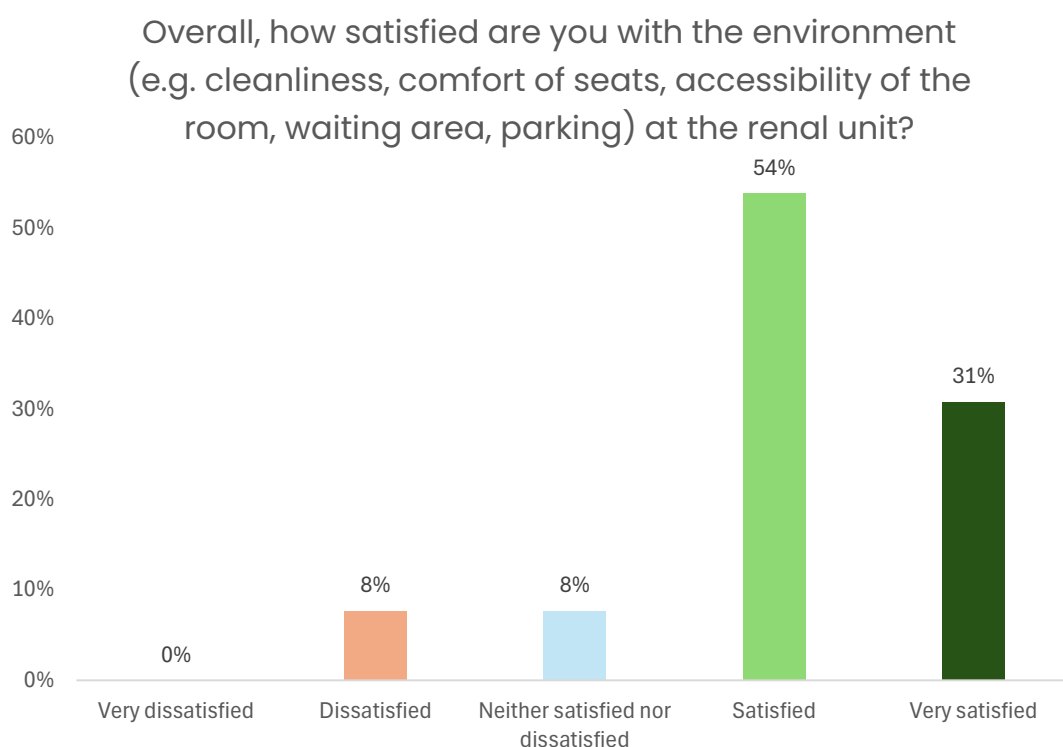
# Environmental findings

We asked patients to rate their satisfaction with the environment and gave them the opportunity to share comments.

In addition, two Healthwatch staff conducted an environmental audit of the four main haemodialysis rooms, the outpatient waiting room, the dialysis waiting room, and the day case unit.

## 1. Patient environmental satisfaction

We asked patients overall how satisfied they were with the environment. Responses were mostly positive, with 85% saying they were either satisfied or very satisfied.



Positive comments included satisfaction with the (larger) treatment rooms and welcoming receptionist.

*"I'm ok with the dialysis room as this is where I'm looked after and I feel comfortable. Corridors don't matter."*

*"The treatment room matters most as that's where I spend most of my time and it is reasonably comfortable."*

*"The reception staff are lovely with one particularly nice and smiley lady."*

Negative comments included issues with the accessibility, the waiting room, overcrowding in the (smaller – room 1) dialysis room, the carpark, lift access, the temperature being too cold and the condition of ceiling tiles.

*"I am familiar with specialised SEN(D) policies which are not evidently in place in the renal unit. People are respected and treated fairly but there isn't specialised support. One should consider people with SEN who can't ask, for example, about transport. The waiting room isn't accessible for people with these needs. I understand that the environment can't be bespoke to these needs, but a relevant policy might be positive."*

*"The dialysis room is overcrowded with clutter, and the staff area is tiny! The staff are facing challenges with space in a similar way to patients."*

*"The carpark (the old one) is horrendous! The guys on the gates to the carpark are miserable, it's dark, and the spots are small. I once had to crawl in through my boot to get into the car. It's a very stressful experience every time which isn't welcome given the nature of the appointment at the hospital. This is in stark contrast to the new carpark by the Louisa Martindale building which is lovely."*

*"One of the lifts not working is a real issue."*

*"It can be a bit chilly."*

*"There's a really grungy ceiling tile that isn't very nice to look at it and could be replaced." (Room 4)*

Three people commented negatively about the waiting room.

*"The waiting area is a bit depressing and needs a refresh. It can be quite crowded."*

*"The waiting room could be better."*

*"TV in the waiting room is never on and it'd be good if it could be. All they play is music out the radio. Waiting for transport, I can spend 45 minutes in the waiting room and nurses don't check on us. I'm diabetic and I feel rough after dialysis. This makes me nervous."*

## 2. Environmental audit

Two trained, DBS-checked Enter and View staff members visited level 8 of the Sussex Kidney Unit as part of Healthwatch Brighton and Hove's visit. The Head Nurse for Renal and Vascular care kindly showed us around the department before allowing us to conduct the visit.

Full details of our audit are contained in a separate [report](#).

Healthwatch asks its representatives to give a score out of 10 for each area as a simple way to assess various aspects. The scores represent the subjective views of our representatives and are not part of a national scoring system. Healthwatch considers that:

- 9 or 10 indicates that the ward or unit is performing strongly with little or no room for improvement and areas of excellence have been observed.
- 7 or 8 suggests there are a number of areas which require attention in order to improve the environment, but overall, things are good.
- a score of 6 or less indicates that significant changes may be needed to improve the environment.

Each department was awarded an overall score; the results follow below.

We scored all areas aside from the dialysis waiting room highly for the environments being welcoming, safe, caring, well-organised and calm. Scores were six for the dialysis waiting room but ranged between eight and ten for the other areas.

As you enter level 8 of the unit, you are greeted by the outpatients waiting room, which feels very welcoming and open with lots of useful information on display and friendly staff. The Stirling day case unit, which carries out day case procedures such as infusions and biopsies, was also a particularly strong area with little room for improvement necessary.

The main haemodialysis rooms were mixed, most were satisfactory (room 4 was particularly welcoming) but room 1, the smallest room, felt cramped and cluttered. The dialysis waiting room and the corridors surrounding were cluttered with beds and needed some maintenance as well as better patient information displayed. The trust already has plans to rejuvenate the space including using other areas in the department for storage and treatment.

Our recommended areas for improvement are at the end of this report.

| <b>Checklist area:</b> | <b>Main haemodialysis rooms x4</b> | <b>Dialysis waiting room</b> | <b>Outpatient waiting room</b> | <b>Stirling Day Case Unit</b> |
|------------------------|------------------------------------|------------------------------|--------------------------------|-------------------------------|
| <i>Welcoming</i>       | 8                                  | 6                            | 9                              | 9                             |
| <i>Safe</i>            | 8                                  | 6                            | 9                              | 10                            |
| <i>Caring</i>          | 10                                 | 6                            | 10                             | 10                            |
| <i>Well-organised</i>  | 7                                  | 6                            | 10                             | 10                            |
| <b>Overall score</b>   | <b>8.3</b>                         | <b>6</b>                     | <b>9.5</b>                     | <b>9.8</b>                    |

# Recommendations

## 1. Communication

- When there are changes to a patient's care e.g. length of dialysis or medication changes, the patient should be clearly informed in a timely way by the team including on the day when it is changing. Low staffing (as raised by patients) may be a factor in this as staff may be more time-limited to explain care to patients. However, this could be particularly upsetting for patients and should be prioritised. **UHSx have informed us that they plan to send a 'monthly patient information summary' sheet which should help improve communications.**
- Ensure sensitivity in letter communications when related to significant changes in care. Consider offering consultation to discuss bigger changes. **The department are struggling to keep up with demands of increasing haemodialysis numbers which means patients currently may need to be moved from Brighton for their treatment. Some patients have been upset by this and how it has been communicated via letter. The department are looking to increase letter sensitivity.**
- Inform patients that they can update their communication preferences and opt-out of certain routes (e.g. through posters in waiting rooms, at appointments or via e-comms). For example, if a patient prefers not to receive physical letters, they can do this via the patient hub. They can ask staff to change their preferences for them, or they can do this.
- Ensure staff badges are as visible as possible (not covered by uniform, and at eye-line, if possible), and staff are introducing themselves when they are new to the patient or when the patient is new. Posters in the treatment and waiting rooms with photos and names of staff would also be helpful.
- Ensure patients are proactively asked if they have concerns or anxieties resulting from their kidney disease or treatment.
- Ensure patients are asked about their life goals in relation to their treatment.
- Ensure patients are asked about their emotional feelings and have access to support services if they need them. Not all patients will feel comfortable talking about this with the team, but the opportunity should be made clear.
- Reminders from the team about accessing patient support groups would be helpful. Some patients do not see the posters in the unit. Reminders could be verbal or through e-communications.
- Explore with general practice how to improve two-way communication about patients, escalating to NHS Sussex primary care as required.
- Increase support service capacity including dietitians, counsellors, and social workers and ensure patients are aware of offer. (The trust already plans to recruit a social worker which will increase some counselling capacity).



- Consider creating a welcome pack for patients (two patients suggested this). This could also be given to all patients (not just new) electronically as a reminder of the support they can access and helpful general information about their care (including social care, legal rights, welfare, diet, patient support groups, contact numbers etc).
- Consider a patient e-newsletter from the renal team that gives updates on the service and improvements that have been made. One section of the welcome pack could be spotlighted each newsletter to keep up reminders of available support. Patients could be given a QR code to scan during dialysis and they could view the newsletter on their phone/tablet, as well as, being sent out to all kidney patients.

## 2. Environment

The trust already has plans to enact some of these changes such as utilising new space they have acquired to increase treatment rooms and storage space as well as placing a manned desk in the dialysis waiting area.

- Improve storage particularly in the dialysis waiting area and dialysis room 1.
- Improve seating in dialysis waiting area.
- The trust informed us that they plan to place a manned desk in the dialysis waiting area for patient safety and information. This would improve the environment significantly. This point also raised by a patient who was concerned for their safety post-dialysis with no staff supervising in the area except in passing.
- Improve information (including about staff, staff uniforms, and in accessible formats) particularly in the dialysis waiting room. Ideally, with a screen with a slideshow of useful information.
- Consider adding signs about the planned changes to the environment.
- Consider posters next to the water cooler and on the WC door to make information more visible.
- Consider having the TV in the dialysis waiting room on silent with subtitles for patients waiting for transport (as suggested by patient). This is done in some other departments like Digestive Diseases.
- Replacement of any grungy ceiling tiles.
- WC in the dialysis waiting area needs to be repaired.
- Fixing the second lift which is out-of-order.

### UHSx told us they have the following plans to improve the environment:

- New furniture for the Level 8 Haemodialysis waiting area, including a manned/staff desk (*"We are grateful for the support from the SEKPA charity who are funding the new furniture"*).

- New Haemodialysis room (room 5) on Level 8 to provide treatment for the growing number of patients.
- Increased Haemodialysis storage on Level 8 and Level 10
- Therapy room on Level 8 for therapeutic interactions in a room that feels less clinical.



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**Click here** to share your experiences and feedback with us, or if you need help or advice. **Thank you!**

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