

# Kidney PREM report highlights 2023

Patient reported experience measure of UK kidney care



Working together for better patient information

## What is the Kidney PREM?

PREM stands for **Patient Reported Experience Measure**. The Kidney PREM is an annual survey for people living with chronic kidney disease (CKD) in the UK, that aims to:

- Provide a national picture of people's experience of care
- Help kidney teams understand how people with kidney disease rate their experience of care
- Share feedback about where improvement can be made at a kidney centre or unit



## Who organises the Kidney PREM?

The Kidney PREM is led by **Kidney Care UK**, the UK's leading kidney patient support charity, and the **UK Kidney Association**, the professional organisation for the kidney community.

## Why is Kidney PREM important?

The Kidney PREM puts the voice of people living with kidney disease at the heart of kidney care service improvement. Using patient expertise and knowledge is key in achieving real, person-centred care. By working together and sharing best practice, kidney professionals can learn and make changes that have real benefits for those with kidney disease.

## How are the results of the Kidney PREM survey used to improve patient care?

The Kidney PREM report provides a national overview of kidney care, but we encourage Clinical Directors and individuals to look at the data in a local context, using the Kidney PREM portal hosted by UK Renal Registry. There, each kidney centre or unit can see the areas of experience by region, centre, and unit, and compare this to previous years' responses.

The data and written comments can then be shared with NHS commissioners, the multi-disciplinary team, kidney patients and patient involvement groups to provide focus for efforts to improve experience of care, from the 'little gems' to the medium, and longer-term quality improvement suggestions.

## How is the Kidney PREM completed?

11,647 people with kidney disease took part in the Kidney PREM 2023 survey, an increase of 5.3% compared to 2022. The survey was available online for eight weeks. As a pilot, one centre was provided with a printable copy of the survey in response to their concerns around digital exclusion. Data collected using these paper versions were manually inputted by volunteers at the centre into a bespoke online data capture system. Barriers to online completion were explored using an extra question within the survey.

## Who can take part?

The Kidney PREM survey is open to everyone living with chronic kidney disease who is aged 16 or over and attends a UK hospital kidney centre or satellite unit. This includes people who have a working kidney transplant.

## How can I take part in the Kidney PREM?

We are working hard to make the Kidney PREM easy to access for everyone living with kidney disease. The online survey ensures anyone can access the Kidney PREM survey in English, Welsh, Urdu or Gujarati, and also leave anonymous comments for their centre.



## How was the survey designed?

The survey was co-designed by patients, clinicians, and researchers. As well as demographic questions that cover age, gender, ethnicity and treatment, there are 39 questions covering 13 key themes that people with kidney disease say are important aspects of kidney care to them and a question about their Overall Experience of kidney care.

### The 13 themes of kidney care are:

- Access to Kidney Team
- Support
- Communication
- Patient Information
- Fluid and Diet
- Needling
- Tests
- Shared Decision Making
- Privacy and Dignity
- Scheduling and Planning
- How The Kidney Team Treats You
- Transport
- The Environment

Participants are asked to rate their experience on a scale of 1-7 where 1 is the lowest and 7 is the highest. No one can be identified by their answers and will not be contacted by their kidney unit directly about the survey.

A free text box is also provided. This offers the opportunity to provide comments on any aspect of care not covered elsewhere in the survey.

## How are the free text comments used?

The free text comments are analysed by researchers and grouped into themes to support the national analysis, but they often contain specific suggestions where care experience could be improved locally with relatively little effort, or where 'small' things impact negatively on care which might be easily changed. 94% of people gave consent for their anonymous comments to be passed back to their kidney centre so that these can be used to make local improvements that really matter to patients.

## How has the survey changed?

In 2023, the survey was primarily available online only. This resulted in an increase in completion, with 584 extra people completing the survey than in the previous year. Additionally, there were no “missing” data, which happened in previous years when people did not fully complete the paper survey.

## Which Kidney PREM reports are available?

### Patient Reported Experience of Kidney Care in the UK 2023

This report contains the findings of the annual national Kidney PREM 2023 survey.

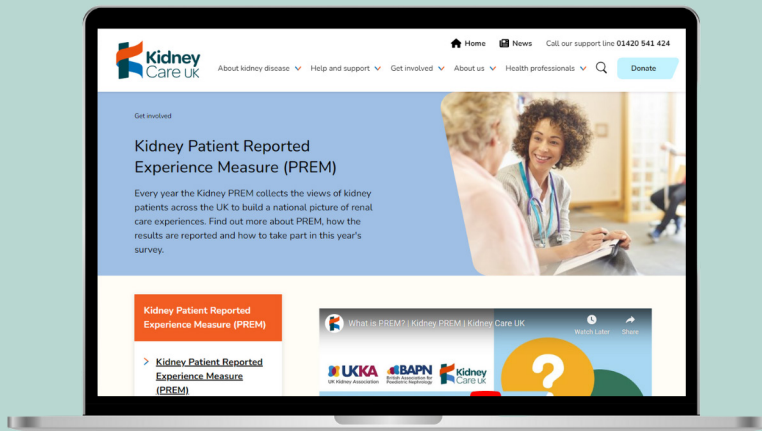
### Paediatric PREM Pilot 2023 Report

In it's second year, this pilot report asks questions for those children with kidney disease who are 12 years of age or over and for parents/ carers of children and young people of all ages.

### A qualitative analysis of patient free text comments in Kidney PREM 2023

This is a summary report focussing on the analysis of the thousands of free text comments collected from the Kidney PREM 2023.

To read the reports in full, scan the QR code or go to [www.kidneycareuk.org/PREM](http://www.kidneycareuk.org/PREM)



# Key findings from the 2023 Kidney PREM reports

HOW MANY PEOPLE TOOK PART IN THE KIDNEY PREM 2023 SURVEY?

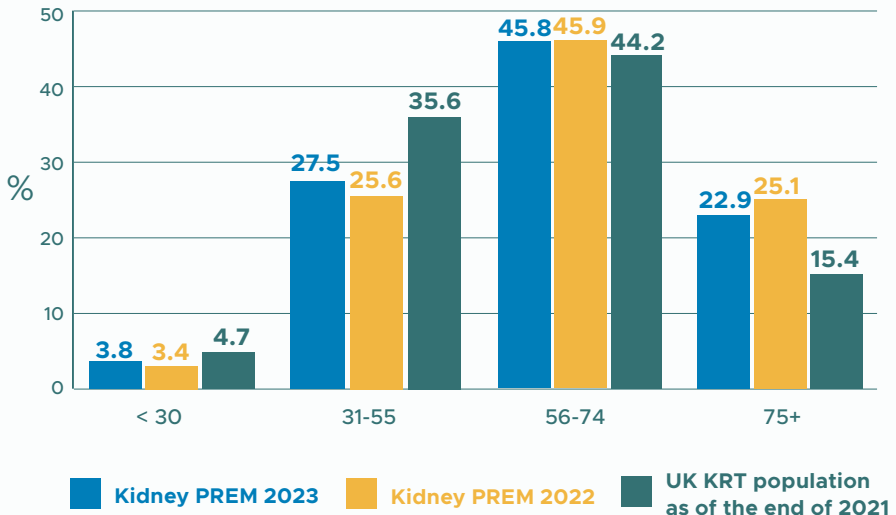


**11,647** people took part in the Kidney PREM 2023 survey

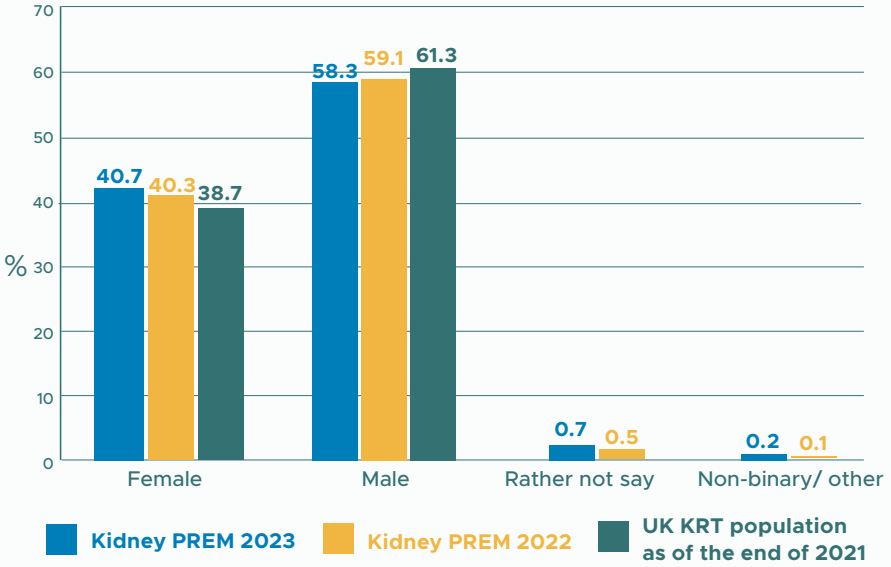
## Who took part in the Kidney PREM 2023 survey?

We compare the profile of people completing the Kidney PREM to national data for all patients receiving kidney replacement therapy (KRT) to see how representative of the full patient population our data are. These figures are correct as at the end of 2023 and were collated by the UK Renal Registry (UKRR) in 2021.

### Age

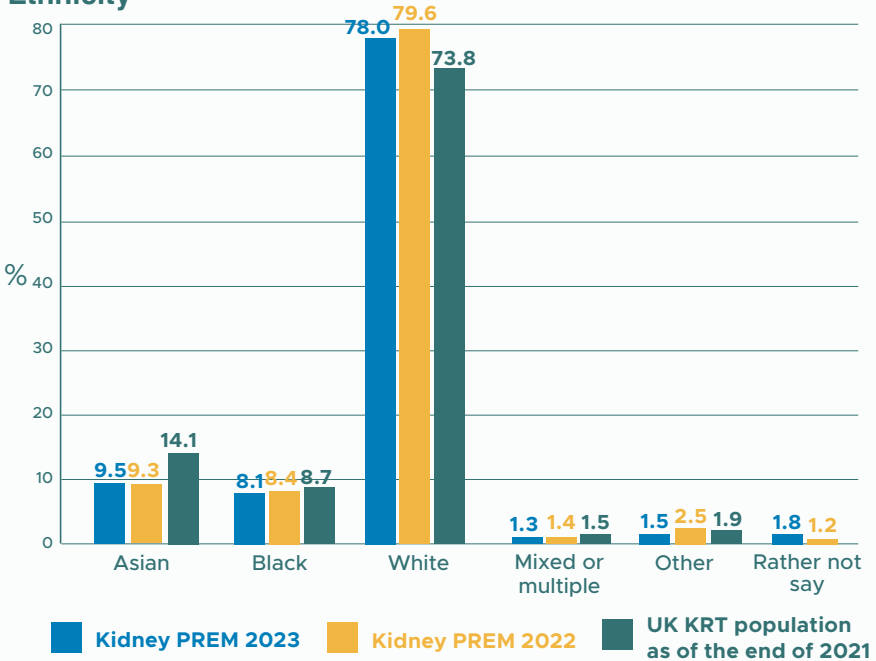


## Gender



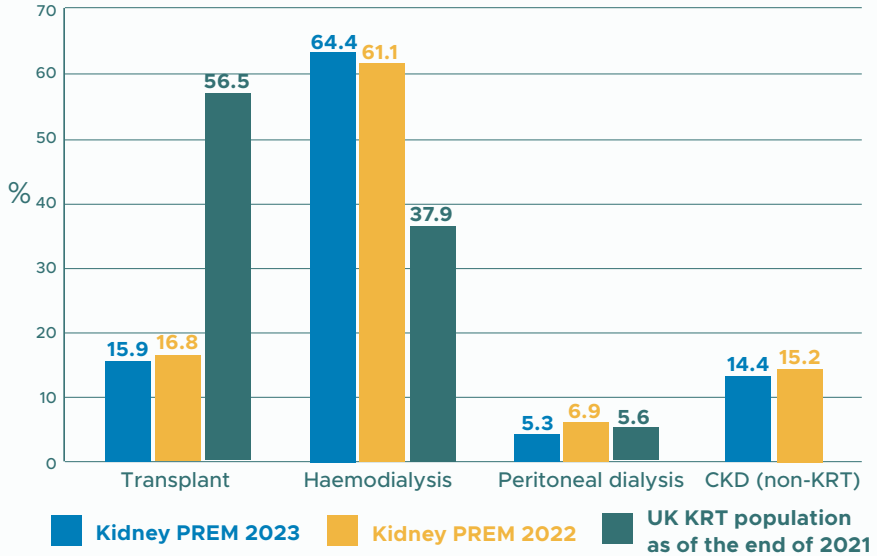
Non-binary and Other categories added to gender for 2022 and not collected by UKRR.

## Ethnicity



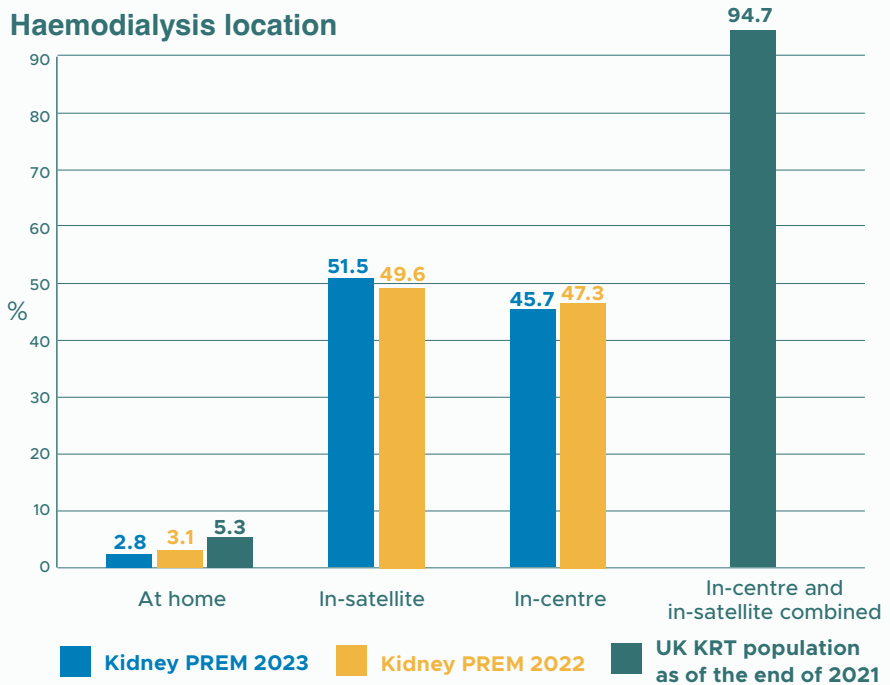


## Treatment



UKRR collects limited data for CKD patients not receiving KRT.

## Haemodialysis location



UK KRT distinction between in-centre and in-satellite haemodialysis patients unavailable.

# What are the key headlines from the 2023 Kidney PREM survey?

## 2023 results compared with 2022



**Overall experience of care** increased slightly with an average of **6.26 out of 7 in 2023**, compared with 6.25 in 2022.



**Privacy and Dignity** remained the highest scoring theme, but scored slightly lower this year, averaging **6.38 out of 7** in 2023 and 6.41 in 2022.



**Patient Information** climbed to the second highest scoring theme. In 2023 it received an average of **6.37 out of 7**, compared with 6.32 in 2022.



**Access** dropped to the third highest theme with an average score of **6.34 out of 7**. This was the same as it scored in 2022



**Communication** saw a small increase in score. It received an average of **5.84 out of 7** in 2023, compared with 5.81 in 2022.



**Needling** decreased slightly from an average score of 5.86 in 2022 to **5.83 out of 7** in 2023.



**Sharing Decisions About Your Care** increased compared to 2022. It received an average score of **5.59 out of 7 in 2023**, and 5.55 in 2022.



Experience of unit-arranged **Transport** fell further, with an average score of **5.54 out of 7 in 2023**, compared to 5.59 in 2022.

### The highest rated themes were:

Privacy & Dignity

**6.38**



Patient Information

**6.37**



Access

**6.34**



### The lowest rated themes were:

Support

**5.71**



Sharing Decisions

**5.59**

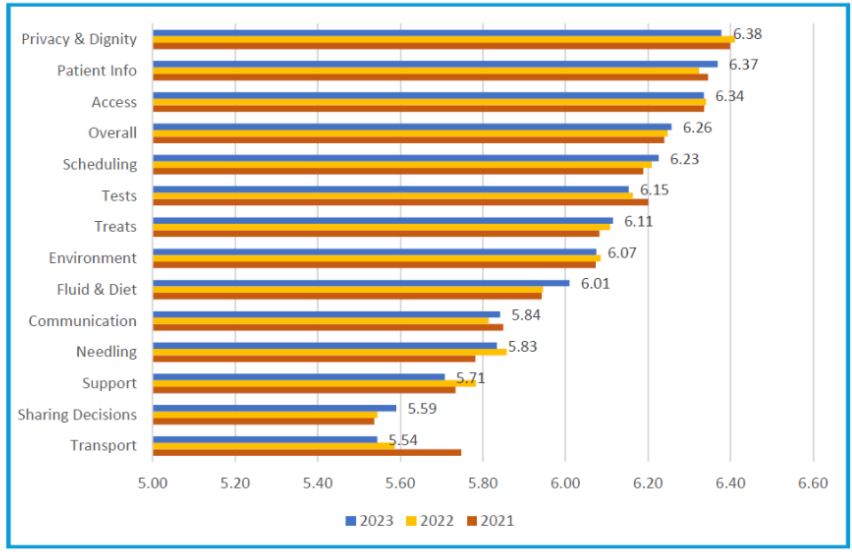


Transport

**5.54**



## The mean average scores for each theme over three years.



Mean centre scores for Kidney PREM themes, 2023, 2022 and 2021



## What were the scores for Overall Experience of care by kidney centre?

**52 out of 67** centres received positive scores over 90% of the time

**92.4%** of centres received an overall rating between **5-7**.

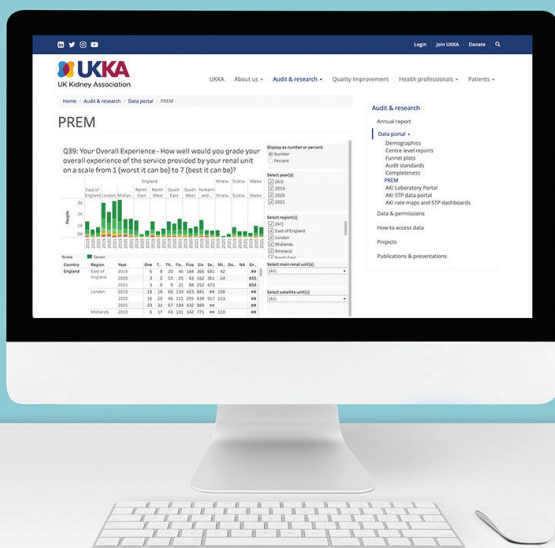
Many centres have a small proportion of participants giving poorer scores (**1 to 3 out of 7**).

## How can I find my kidney centre's results?

If you would like to look more closely at the data for your centre or unit, this can be seen online via the Kidney PREM portal where you can search the results by question, year, and hospital.



To access the PREM portal, scan the QR code or go to [www.ukkidney.org/kidney-patient-reported-experience-measure](http://www.ukkidney.org/kidney-patient-reported-experience-measure)



## What comments did people make in the 2023 PREM survey?

At the end of the Kidney PREM, when accessed online, there is a free text question:

***“If there is any other aspect of your experience of kidney care that you would like to comment on that has not already been covered, please tell us below”.***

In 2023, 4,202 people supplied written comments (compared to 2,376 in 2022). 94.1% of participants gave consent for their comments to be passed back to their kidney centre (compared to 92.9% in 2022).

The 2023 Kidney PREM Comments report follows the 13 Kidney PREM themes, with *How the Kidney Team Treats You* receiving the highest number of comments (2,283), and a total of 66% of comments under this theme were positive.

**“ I did not choose kidney care but as I require it I could not pay for better care. ”**  
(Female, White, 56-65, Transplant)

**“ The nursing staff are very knowledgeable and very caring ”**  
(Male, Asian, 41-55, Centre HD)

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

**“ All in all the CENTRE NAME is exceptional and really supports patient care to the highest quality. ”**  
(Female, Asian, 65-74, Sat HD)

**“ I am satisfied with the care I receive. ”**  
(Female, White, 65-74, HHD)

## What was learned from the free text comments?



68% of the 836 comments received about **Access to the Kidney Team** were negative. As in 2022, the most prominent theme related to **staff members** and the **quality-of-care** patients received. Individuals wanted to see the consultant more frequently, and have better access to the kidney team outside of dialysis sessions.



**Environment** continued to feature highly as a theme in both years and comments were mostly negative. Comments related to comfort, temperature, and waiting areas. There was a larger emphasis on parking and availability of food during dialysis session in 2023.



In both years issues with **Scheduling and Planning** (frequency of appointments, waiting times and appointment scheduling issues like last minute cancellations), featured as quite a negative aspect of care.



Younger people were particularly concerned about **Environment** in 2023. Whereas, they were mainly concerned with **Support** in 2022.



Older individuals were mainly concerned by **How the Kidney Team Treats You** and **Access to the Kidney Team** in 2023. They tended to focus on **Environment** and **Transport** in 2022.



**Transport** waiting times following dialysis have continued to be an issue for respondents.



Within **Emerging Themes**, comments about medication and prescriptions and information about 'holiday dialysis' has emerged both years, with individuals wanting better access to information about these aspects of care.

## How can I take part in the next Kidney PREM?

The next kidney PREM survey will open in Autumn 2024.

To keep up to date with the latest news and information, including the Kidney PREM, please sign up to our newsletter.

To sign up, scan the QR code or go to [www.kidneycareuk.org/sign-up](http://www.kidneycareuk.org/sign-up)



## Where can I find out more information?

- Kidney Care UK: [www.kidneycareuk.org/PREM](http://www.kidneycareuk.org/PREM)
- Kidney PREM portal: [www.ukkidney.org/audit-research/data-portal/prem](http://www.ukkidney.org/audit-research/data-portal/prem)

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