

Kidney PREM report highlights 2022

Patient reported experience of kidney care in the UK

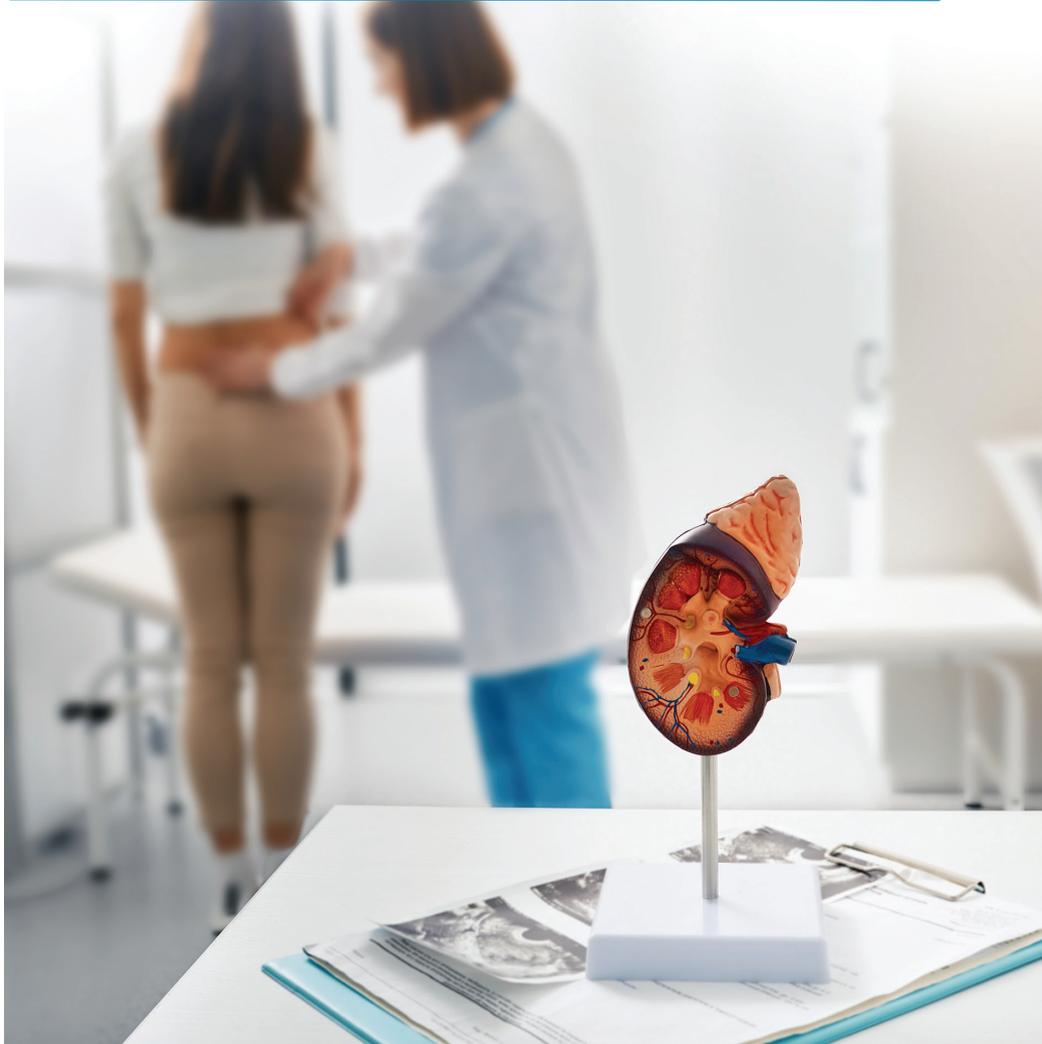


Working together for better patient information

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 UK 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.

This data and written comments are shared with NHS commissioners, the multi-disciplinary team, people with kidney disease 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?

11,063 people with kidney disease took part in the Kidney PREM 2022 survey. The survey was available both online and on paper in-unit. 63.5% of people chose to complete the survey online.

Who can take part?

The Kidney PREM survey is open to everyone living with chronic kidney disease who is aged 17 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. If you complete it online you can do so in English, Welsh, Urdu or Gujarati, and also leave written comments for your 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 38 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 on the online survey where comments on any aspect of care not covered elsewhere in the measure can be made.

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. 93% 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 2022, the first Paediatric PREM was launched to include children and young people with chronic kidney disease (CKD) aged 12 years or older, and parent/carers of children and young people of all ages. Additionally, for the first time ever, participants were also asked whether English was their primary spoken language.



Which Kidney PREM reports are available?

Patient Reported Experience of Kidney Care in the UK 2022

This report contains the findings of the annual national Kidney PREM 2022 survey.

Paediatric PREM Pilot 2022 Report

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. This is the first year that the Paediatric PREM (PPREM) has been piloted, with every centre in the UK contributing.

A qualitative analysis of patient free text comments in Kidney PREM 2022

This is a summary report focussing on the analysis of the thousands of free text comments collected from the Kidney PREM 2022.

To read the reports in full,
scan the QR code or go to
www.kidneycareuk.org/PREM



Key findings from the 2022 Kidney PREM reports

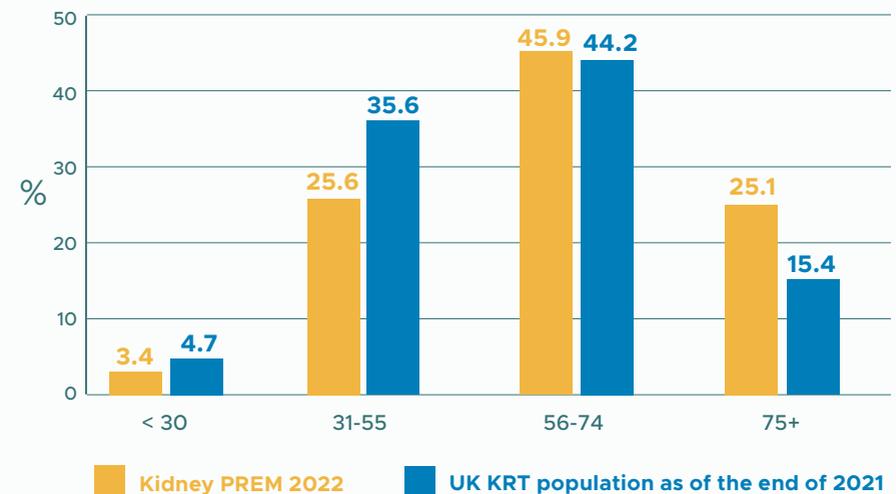


11,063 people with kidney disease took part in the Kidney PREM 2022 survey.

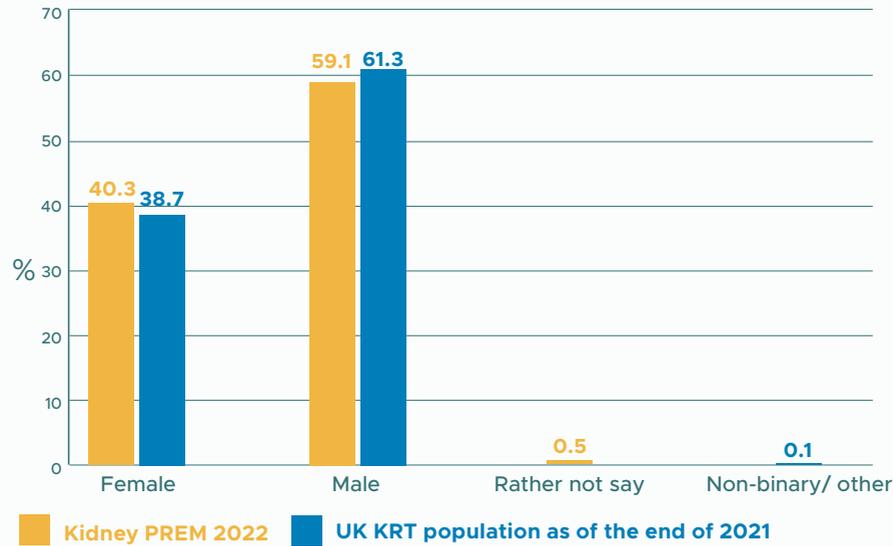
Who took part in the Kidney PREM 2022 survey?

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 it is. These figures are correct as at the end of 2022 and were collated by the UK Renal Registry (UKRR).

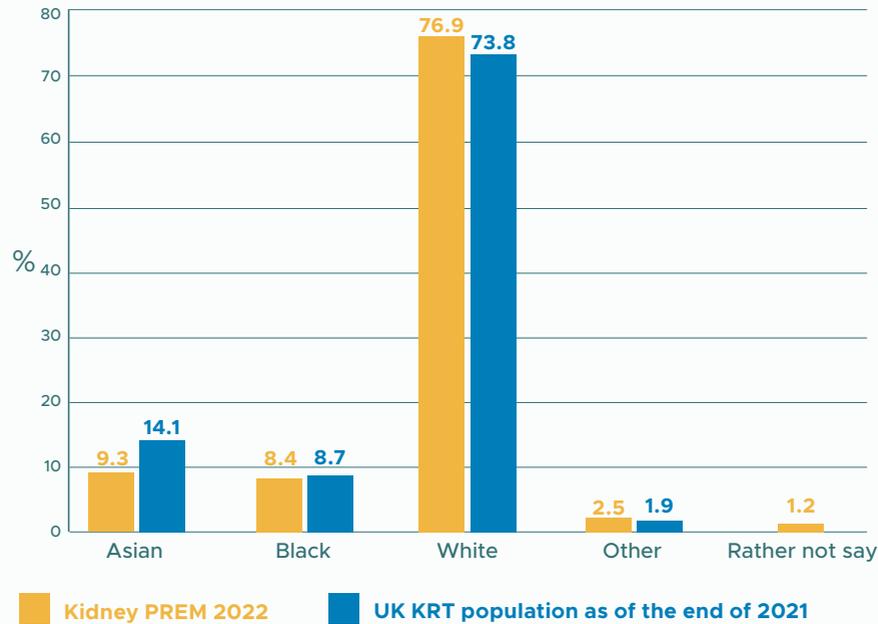
Age



Gender

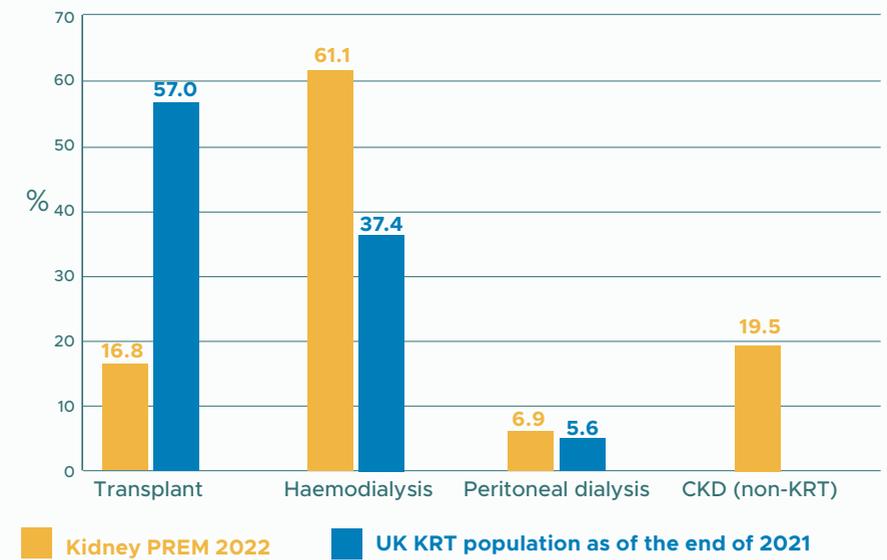


Ethnicity

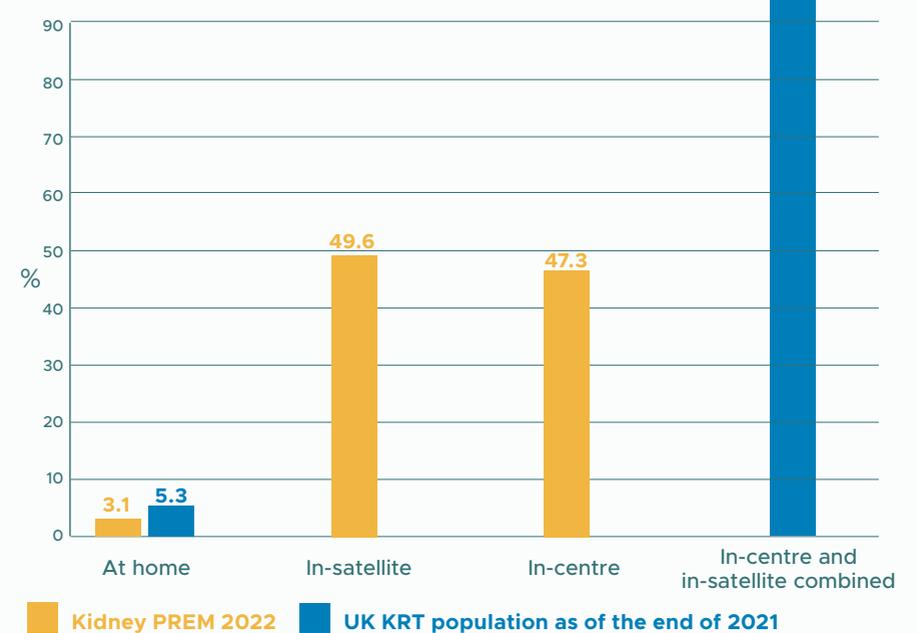


More detailed Ethnicity options available in 2022. UKRR Ethnicity data does not include Scottish centres and has additional missing data for 1,777 individuals (2.8% of total).

Treatment



Haemodialysis location



Distinction between in-centre and in-satellite haemodialysis patients unavailable. UKRR collects limited data for CKD patients not receiving KRT.

What are the key headlines from the 2022 Kidney PREM survey?



Encouragingly, people have reported a slight increase in their **overall experience of care** in 2022, with an average of **6.25 out of 7**.



They continue to report positive experience for **Privacy and Dignity** with an average score of **6.41 out of 7**, and **Access** with an average score of **6.34 out of 7**.



Patient experience of the **Support** received from their kidney team has also improved this year to an average score of **5.78 out of 7**.



Patient Information was among the highest scoring themes, with an average of **6.32 out of 7**.



Experience of unit-arranged **Transport** remains low, with an average score of **5.59 out of 7**.



Whilst improved in the last 12 months, scores for experience of **Sharing Decisions About Your Care** received an average score of **5.55 out of 7**, which is relatively low.

The highest rated themes were:

Privacy & Dignity
6.41



Access
6.34



Patient Information
6.32



The lowest rated themes were:

Sharing Decisions
5.55



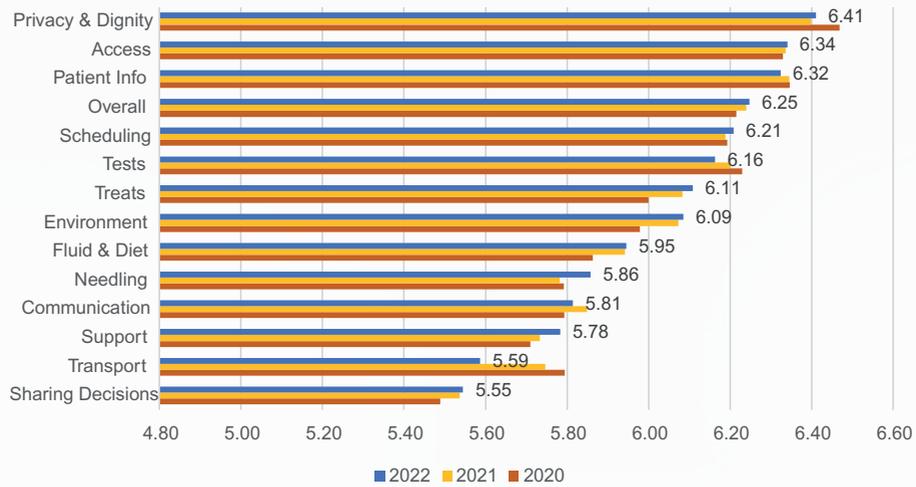
Transport
5.59



Support
5.78



The average scores for each theme over three years.



Mean centre scores for Kidney PREM themes, 2022, 2021 and 2020



What were the scores for overall experience of care by kidney centre?

Overall experience by kidney centre scored highly at **6.25 out of 7.**

92.3% of centres received an overall rating between **5-7**, but only one centre received entirely positive scores (compared with five centres in 2021).

Many centres have a small but significant proportion of patients scoring overall experience poorly, between **1-3**.

How can I find my kidney centre's results?

If you would like to look closer 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 <https://ukkidney.org/kidney-patient-reported-experience-measure>



What comments did people make in the 2022 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, during COVID-19 or another time, please tell us below”.

In 2022, 2,376 people supplied written comments. 92.9% of participants gave consent for their comments to be passed back to their kidney centre.

The 2022 Kidney PREM Comments report follows the 13 Kidney PREM themes, with **How the Renal Team Treats You** receiving the highest number of comments (1,136). A total of 64% of comments under this theme were positive, focusing on comments about staff and thanking them for their care and dedication, as well as mentioning role-specific staff members positively.

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

(CKD, White, Male, 75-84)

“**Dialysis nurses are excellent.**”

(ICHD, Black, Male, 65-74)

“**The PD nurses are wonderful, do a great job and couldn't praise them highly enough.**”

(PD, Mixed, Female, 41-55)

“**I have 100% respect for my consultant & will always take his advice. He listens to me and treats me as an individual.**”

(Sat HD, White, Female, 41-55)

What was learned from the free text comments?



Comments by younger individuals tended to focus on **Support** and older individuals on **Environment** and **Transport**.



Like last year, the most prominent theme related to **staff members** and the **quality-of-care** patients received.



Comments relating to **Environment** featured highly in both 2022 and 2021 and were mostly negative; relating to **comfort, temperature control, and waiting areas**.



As in previous years, issues with **Communication**, particularly individuals wanting better communication, featured as quite a negative aspect of care. This year, issues included wanting better coordination of test results and for applications, like Patient View, to be more accessible. Additionally, lack of information was an issue, particularly in relation to adequate updates about treatment, progress, and transplant prospects. More access to advice about diet, fluid intake and exercise was also requested.



As in 2021, comments in 2022 regarding **Support** included wanting more psychological support. Unlike last year, the 2022 PREM included **support with COVID-19**, which received the most comments within this theme and was mostly positive.



How can I take part in the next Kidney PREM?

The next kidney PREM survey will open in Autumn 2023.

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



Where can I find out more information?

- Kidney Care UK: www.kidneycareuk.org/PREM
- Kidney PREM portal:
www.ukkidney.org/audit-research/data-portal/prem

Contact us



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