

Kidney PREM report highlights 2021

Patient reported experience of kidney care in the UK, 2021



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.

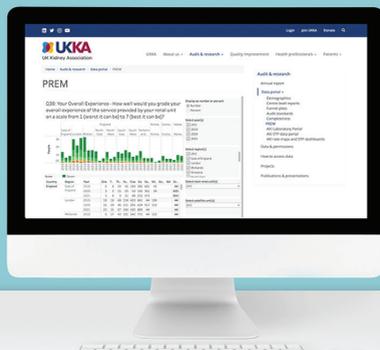
Why is Kidney PREM important?

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?

In 2021, the Kidney PREM was available both online and as a paper survey in unit, and was completed by 12,416 people with kidney disease. Four out of five of those completing Kidney PREM did so 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. You can complete it online or as a paper questionnaire. 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 are often filled with 'little gems'. These are 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. Nine in ten 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?

The Kidney PREM has been designed and tested to a standard which means it should not need to be changed very often. However, we could not ignore the pandemic, and so a question on the impact of COVID-19 was included in 2020 and again in 2021.

In 2021 three new questions were added to the Kidney PREM, in the patient characteristics' section. The survey is anonymous but it is analysed to look for any patterns relating to better or worse experiences of care that can inform improvements.

Which Kidney PREM reports are available?

The impact of COVID-19 on patient reported experience of kidney care

This is a summary report from the Kidney PREM 2020 survey. We asked people to rate if their experience of care had got better, worse or stayed the same during COVID-19, and to comment on their experience of care during COVID-19. The report was released in June 2022.

Patient reported experience of kidney care in the UK 2021

This report contains the findings of the annual, national Kidney PREM key findings from Kidney PREM 2021 survey. The report was released in June 2022.

Comments summary report: Patient reported experience of kidney care in the UK 2020/2021

This is a summary report focussing on the analysis of the thousands of free text comments collected from the Kidney PREM in 2020 and 2021. The report is due for release in Summer 2022.

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



Key findings from the 2020/21 Kidney PREM reports

How many people took part in the Kidney PREM 2021 survey?



12,416 people with kidney disease took part in the Kidney PREM 2021 survey.

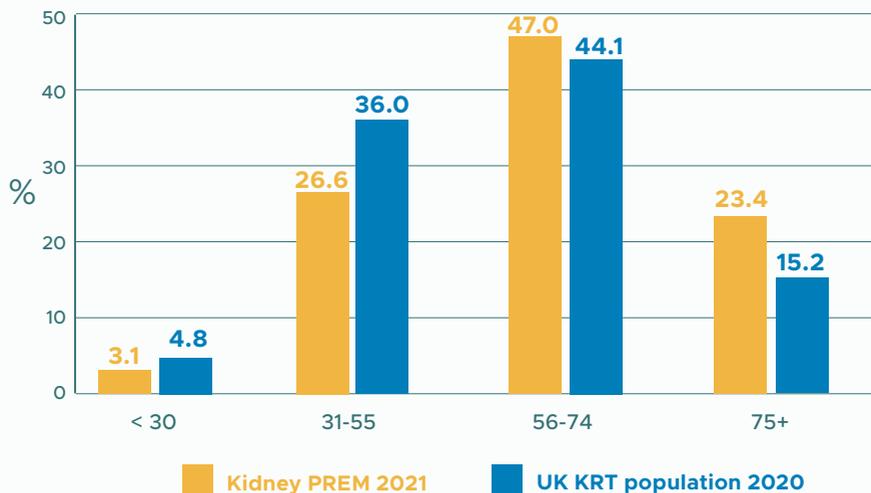


All **68** adult kidney centres across the UK took part

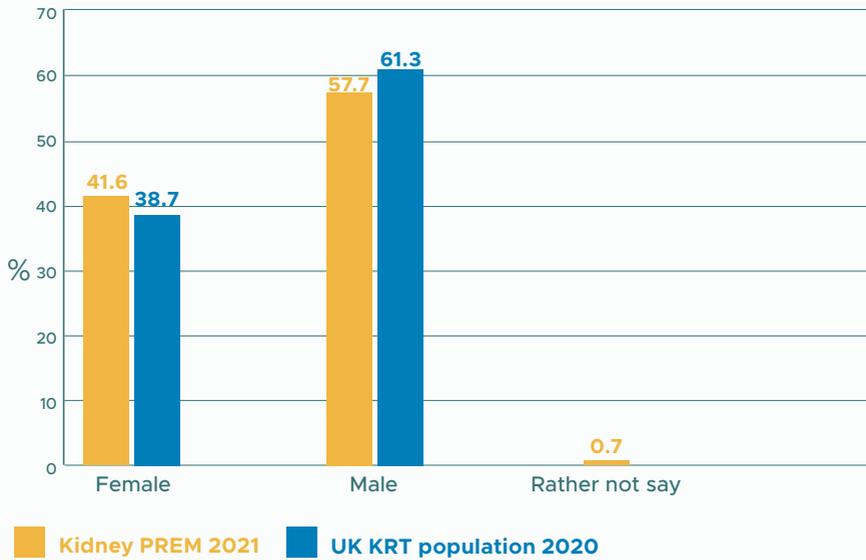
Who took part in the Kidney PREM 2021 survey?

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 2020 and were collated by the UK Renal Registry.

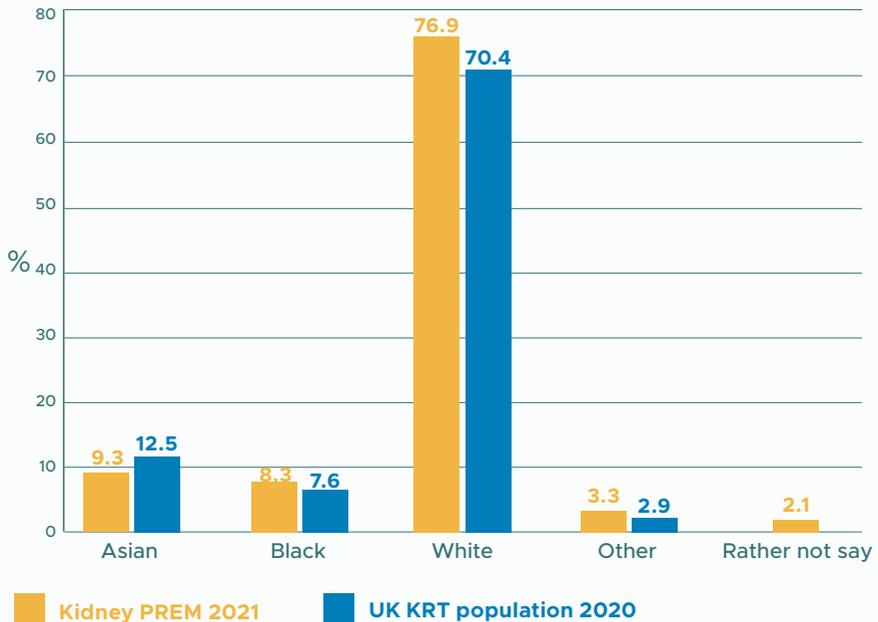
Age



Gender

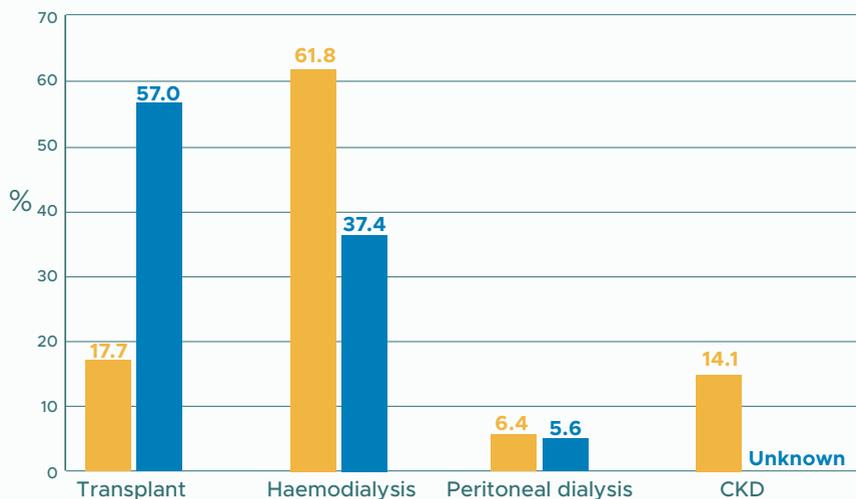


Ethnicity



*Ethnicity data from England and Wales only, with some information unavailable.

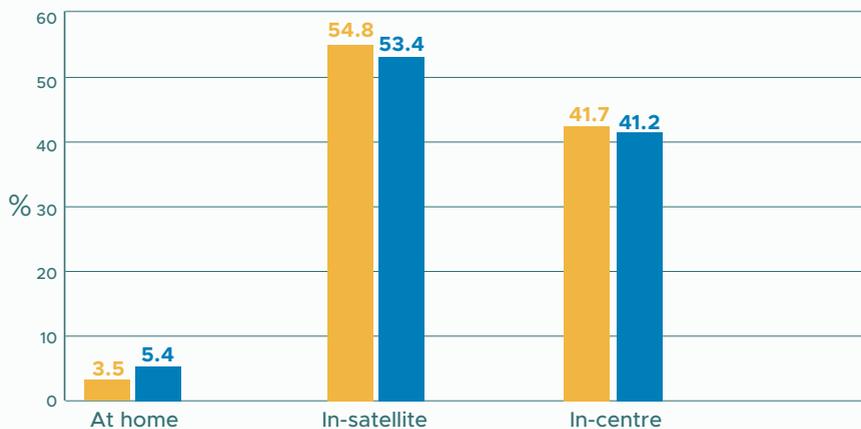
Treatment



■ Kidney PREM 2021 **■ UK KRT population 2020**

*Information is only recorded for those receiving KRT.

Haemodialysis location



■ Kidney PREM 2021 **■ UK KRT population 2020**

How is the data reported?

Patients are asked to rate their experience on a scale of 1-7 where 1 is the lowest and 7 is the highest. Average scores are reported for each question and for each centre. Some centres had only a few responses so these may not represent the views of all the people who attend these centres.

What are the key headlines from the 2021 Kidney PREM survey?



Encouragingly, people have reported a slight increase in their **overall experience of care** in 2021 with an average score of **6.24 out of 7**.



They continue to report positive experience for **Tests** with an average score of **6.20 out of 7** and **Scheduling & Planning** received an average score of **6.19 out of 7**.



Whilst improved in the last 12 months, scores for experience of **Sharing Decisions About Your Care** received an average score of **5.54 out of 7**, which is relatively low.



Patient experience of the **Support** received from their kidney team has also improved this year to an average score of **5.73 out of 7** but remains some way short of the average score in 2019.



Experience of unit-arranged **Transport** remains low, with an average score of **5.75 out of 7**, but it is still significantly higher than in 2019, and a notable area where the pandemic may have made a positive impact.



Scores for **Environment** fell noticeably in 2020 but rating of the unit environment has broadly improved in 2021.

The highest rated themes were:

Privacy & Dignity

6.40



Patient Information

6.35



Access to the
KidneyTeam

6.34



The lowest rated themes were:

Transport

5.75



Support

5.73

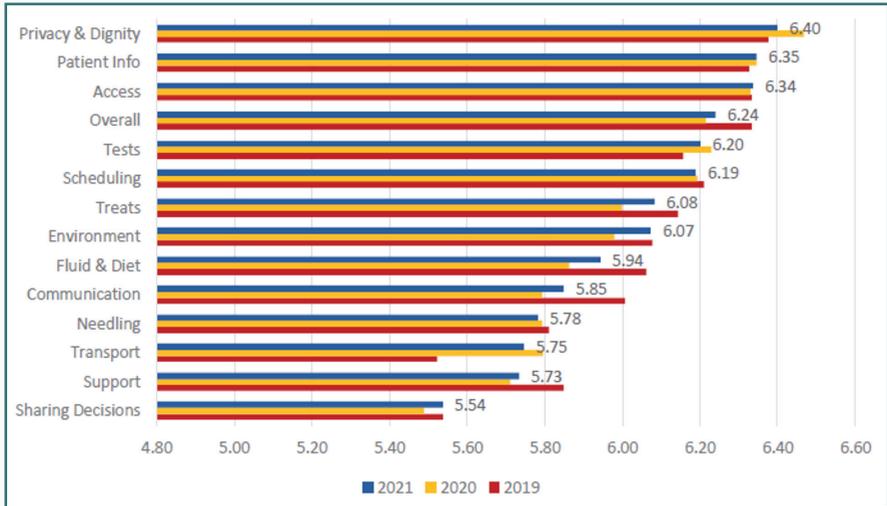


Sharing Decisions

5.54



The average scores for each theme over three years.



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

Overall experience by kidney centre scored highly at 6.24 out of 7. Most centres received an overall rating between 5-7, with five centres receiving entirely positive scores. 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 www.ukkidney.org/audit-research/data-portal/prem



What impact did COVID-19 have on patient experience of care in 2021?

Overall, people's experience of kidney care was more likely to have been better or stayed the same than be worse during the last year of the pandemic.

People receiving in-satellite and in-centre haemodialysis remain far more likely than others to feel that experience of care has stayed the same or improved. In turn, those on home therapies or with a transplant report a generally better experience than people with CKD not receiving KRT.

What impact did COVID-19 have on patient experience by kidney treatment type

	CKD not on KRT	Peritoneal dialysis	Haemodialysis	Transplant	Total
Worse	24.3%	11.6%	9.0%	24.0%	13.9%
Same	56.2%	56.7%	55.2%	48.7%	54.3%
Better	19.4%	31.7%	35.9%	27.3%	31.8%

What comments did people make in the 2021 PREM survey?

The final question of the online Kidney PREM is

“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 2021, 3,877 people completing Kidney PREM survey online provided free text comments which were read by researchers and grouped together by subject, some of which overlapped with the 13 themes in the Kidney PREM. In both 2020 and 2021, positive comments about the kidney team were by far the most common feedback given.

“**The home dialysis unit is always excellent great staff.**”
(75+, White, HHD)

“**It is easy to see what a dedicated team we are fortunate to have at UNIT NAMED Renal Unit and so caringly run by DOCTOR NAMED. I consider myself very fortunate to be under their care. The pressure they work under is immense and I don’t believe we truly. reward them all to the level we should.**”
(75+; White; CKD)

“**I am so grateful and thankful to the amount of care and work the staff at UNIT NAMED renal team put into treating me. Doctors, Nurses and Specialists would call in regularly to ensure I’m doing well and keep me informed about my treatment process. Each and every staff are so wonderful and friendly which makes the treatment journey manageable.**”
(<55, Asian, PD)

“**Nursing staff and support staff are top notch**”
(56-74, White, Sat HD)

What was learned from the free text comments?



Younger patients tended to comment on the **need for support** including general support for young people with kidney disease, and also financial support.



People who are older commented on **Environment**, including the need for more comfortable chairs, and the suitability of hospital provided Transport.



Comments relating to Environment featured highly in both 2021 and 2020 and were mostly negative; relating to **comfort, temperature control, and waiting areas**.



Support accounts for a far greater proportion of comments in 2021 compared to 2020, particularly **psychological support** and how this is lacking.



In both 2021 and 2020, people commented on **lack of Information**, particularly updates about treatment, kidney disease progression, and transplant prospects. People also want more access to advice about **diet, fluid intake and exercise**.



How can I take part in the next Kidney PREM?

The next kidney PREM survey will open in Autumn 2022. You will be able to take part, either at your kidney centre or online via the UK Kidney Association and Kidney Care UK websites.

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

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