Patient reported experience of kidney care in the UK 2019



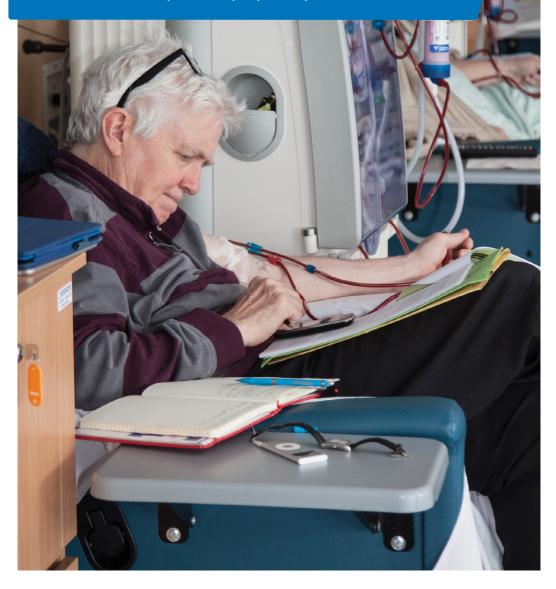




What is the Kidney PREM?

PREM stands for **Patient Reported Experience Measures.** The Kidney PREM is an annual survey of UK kidney patients that aims to:

- Help renal 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



Who runs the Kidney PREM?

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

When will the next survey take place?

The next Kidney PREM will be collected in Spring 2020. Responses are collected for one month every year.

How is the survey completed?

The survey can be completed on paper forms available from UK renal units, or online. The online survey allows for additional comments to be added and can also be taken in English, Gujarati, Urdu or Welsh.

Who can take part?

The survey is open to everyone over the age of 16 who receives treatment for chronic kidney disease (CKD) in a UK hospital renal unit or satellite unit. This includes patients who have received a kidney transplant.



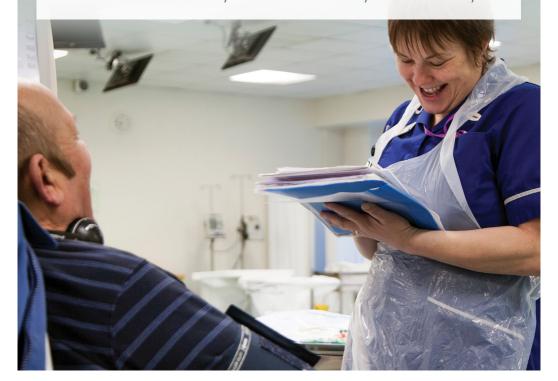
How was the survey designed?

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 patients say are important to them:

- · Access to renal team
- Support
- Communication
- Patient information
- Fluid and diet
- Needling
- Tests

- Shared decision making
- Privacy and dignity
- Scheduling and planning
- How the renal team treats you
- Transport
- The environment

Patients are asked to rate their experience on a scale of 1-7 where 1 is the lowest and 7 is the highest. Patients cannot be identified by their answers and will not be contacted by their renal unit directly about the survey.



How many patients took part?



Almost **16,500** people with kidney disease took part in the 2019 survey



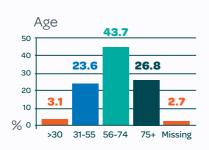
across the UK

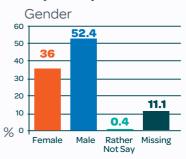
The number of responses for the 2019 surveys from the different parts of the UK.

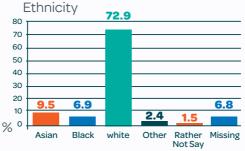




The characteristics of the Kidney PREM participants.

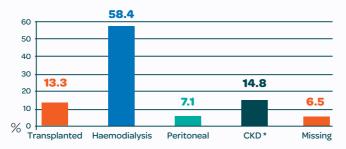






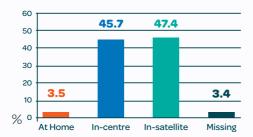
The treatment that the Kidney PREM participants are currently receiving.

Current treatment



^{*} Attending kidney clinic but not on dialysis or transplantation

Haemodialysis location



How is the data reported?

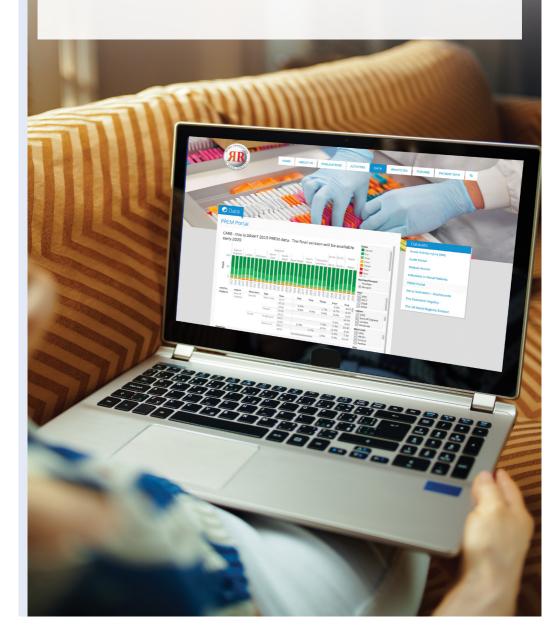
Average scores are reported for each question for each centre. Some centres had only a few responses so these may not represent the views of the full patient population.

How can I find my renal unit's results?

The data can be seen online via the Kidney PREM portal at

www.renalreg.org/datasets/prem-portal

You can search the results by question, year and hospital.



What did the 2019 Kidney PREM survey show?

Overall patient experience is reported as good, with an average score of **6.3 out of 7.**

The highest rated themes were:

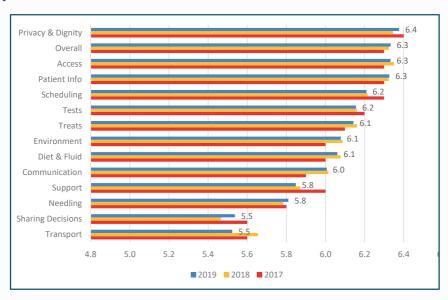


The lowest rated themes were:



There was a lot of variation in the care that patients receive between centres. In publishing the results of the Kidney PREM it is hoped that this variation will reduce so that patients have a consistently positive experience of care, regardless of where they are treated.

The average scores for each theme over the previous three years.



Why is Kidney PREM important?

PREM puts the patient voice at the heart of service improvement. Using patients' own expertise and knowledge of their health 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 patients.

How are the results of the Kidney PREM survey used to improve life for kidney patients?

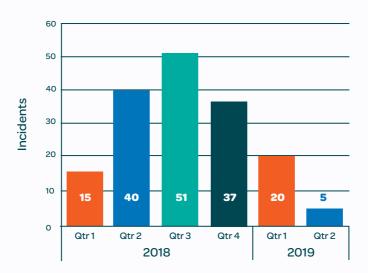
The data from the Kidney PREM survey is being used by local renal teams, managers and patient groups to improve patient care across the country. The data is available from the UK Renal Registry (part of The Renal Association) for anyone to use within their projects. It is seen as an official tool to reduce the variation in how kidney services are delivered across the NHS and promote the sharing of best practice to improve patient care.

Case study

One of the main issues for kidney patients is transport – getting to and from dialysis sessions and clinic appointments. Kings College Hospital used the results of the 2018 Kidney PREM survey to review transport contracts, set up meetings with patient groups and transport providers to discuss potential improvements and to swap patients with another local hospital, significantly reducing patient journeys.

This resulted in a reduction of negative transport incidents, more favourable scores in the 2019 survey in relation to transport and greater awareness of the difficulty that patients face with transport, amongst both hospital staff and transport providers.

Renal transport adverse incidents at Kings College Hospital, Jan 2018 - May 2019.



How can I take part in the next Kidney PREM?

The next survey will open in Spring 2020. You will be able to take part at your renal unit (look out for yellow surveys) or online via the UK Renal Registry and Kidney Care UK websites. It will also be advertised on Patient View and The Renal Association and Kidney Care UK social media pages.

To keep up to date with the latest news and information, including the Kidney PREM please register here:

www.kidneycareuk.org/sign-up



Where can I find out more information?

- Kidney Care UK: www.kidneycareuk.org/2019prem
- Renal Registry: www.renalreg.org/projects/prem







www.kidneycareuk.org



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