

Patient Reported Experience of kidney care in the UK

2020 Kidney PREM explained



Working together for better patient information

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 UK kidney community.

When will the next survey take place?

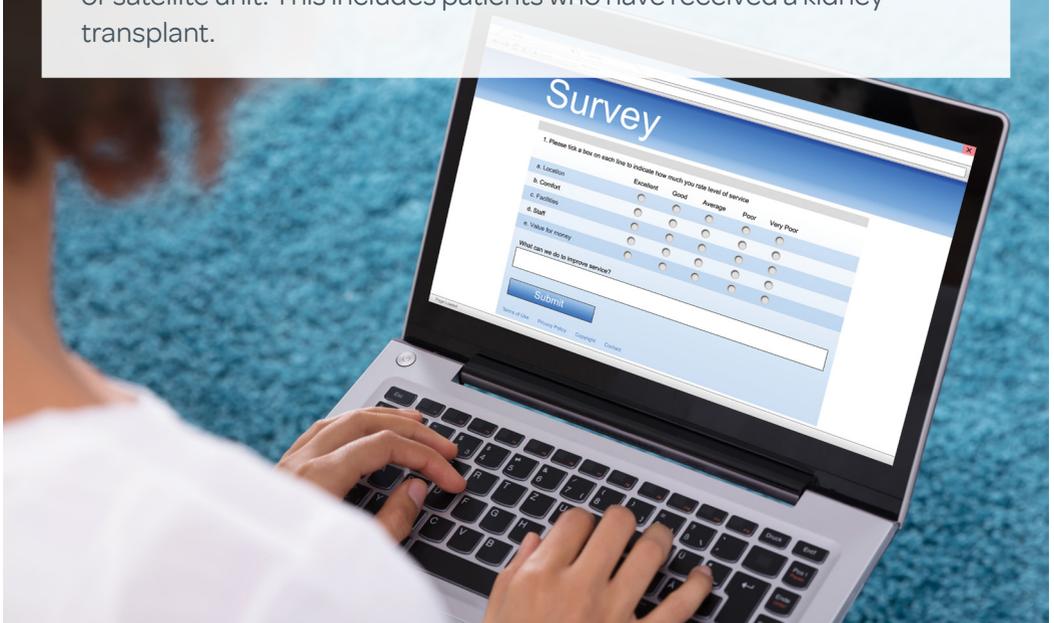
The next Kidney PREM will be collected in Autumn 2021. Responses are collected for one month every year.

How is the survey completed?

In 2020, the survey was available to complete online only. The survey allows for comments to be added and it can 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.

A free text box is provided for patients to be able to comment on any aspect of care not covered elsewhere.

This year, patients helped us to design four additional questions about specific impacts of COVID-19 on their experience of care. This data is being analysed and reported separately. It will be available from July 2021.



Who are the patients that took part?



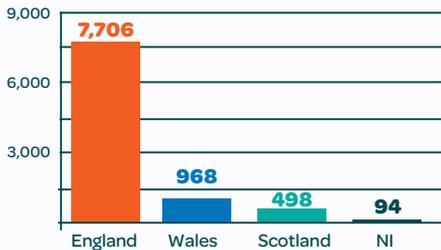
Almost **9,645** people with kidney disease took part in the 2020 survey



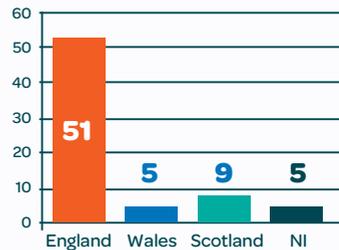
from all **70** hospitals across the UK

The number of responses for the 2020 surveys from the different parts of the UK.

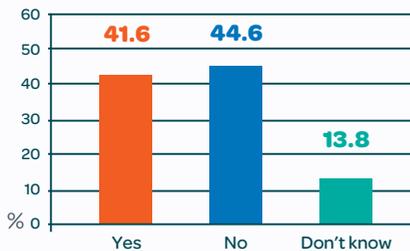
2020 returns - total 9,645



Centres - total 70



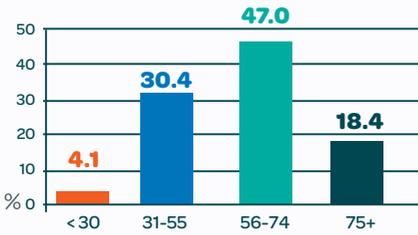
Using Patient View - 2020 PREM



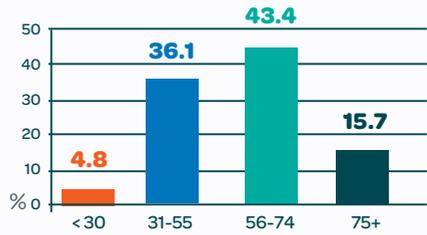
The characteristics of the Kidney PREM participants.

The characteristics of patients completing the 2020 PREM is compared to national data for all patients receiving renal replacement therapy (RRT) to see how representative of the full patient population it is. These figures are correct as at the end of 2019 and were collated by the UK Renal Registry.

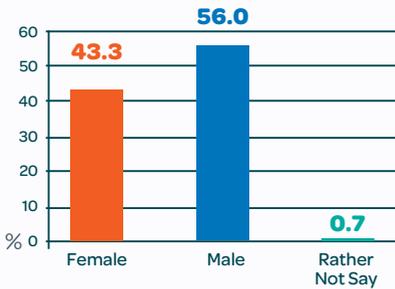
Age - 2020 PREM



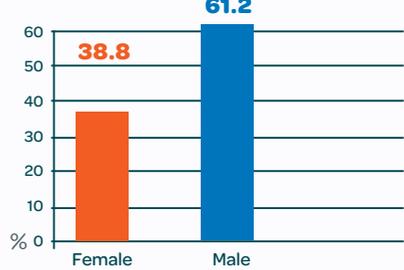
Age - UK Renal Registry data



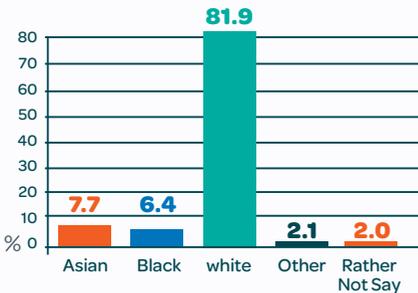
Gender - 2020 PREM



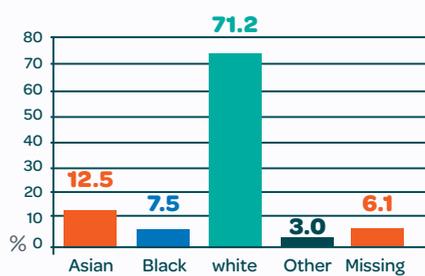
Gender - UK Renal Registry data



Ethnicity - 2020 PREM

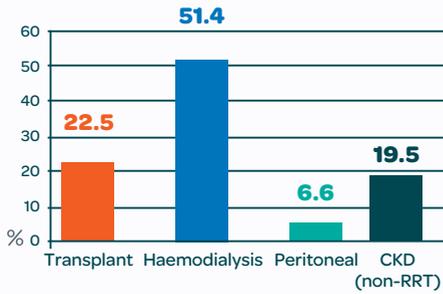


Ethnicity - UK Renal Registry data

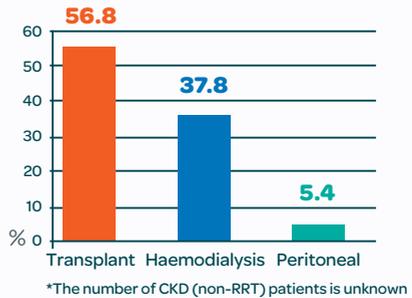


The treatment that the Kidney PREM participants are currently receiving.

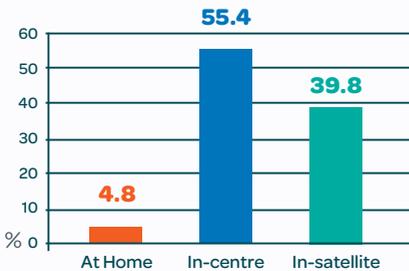
Current treatment - 2020 PREM



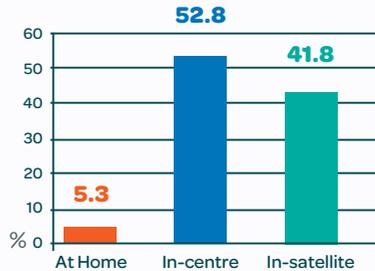
Current treatment - UK Renal Registry



Haemodialysis location - 2020 PREM



Haemodialysis location - UK Renal Registry



How is the data reported?

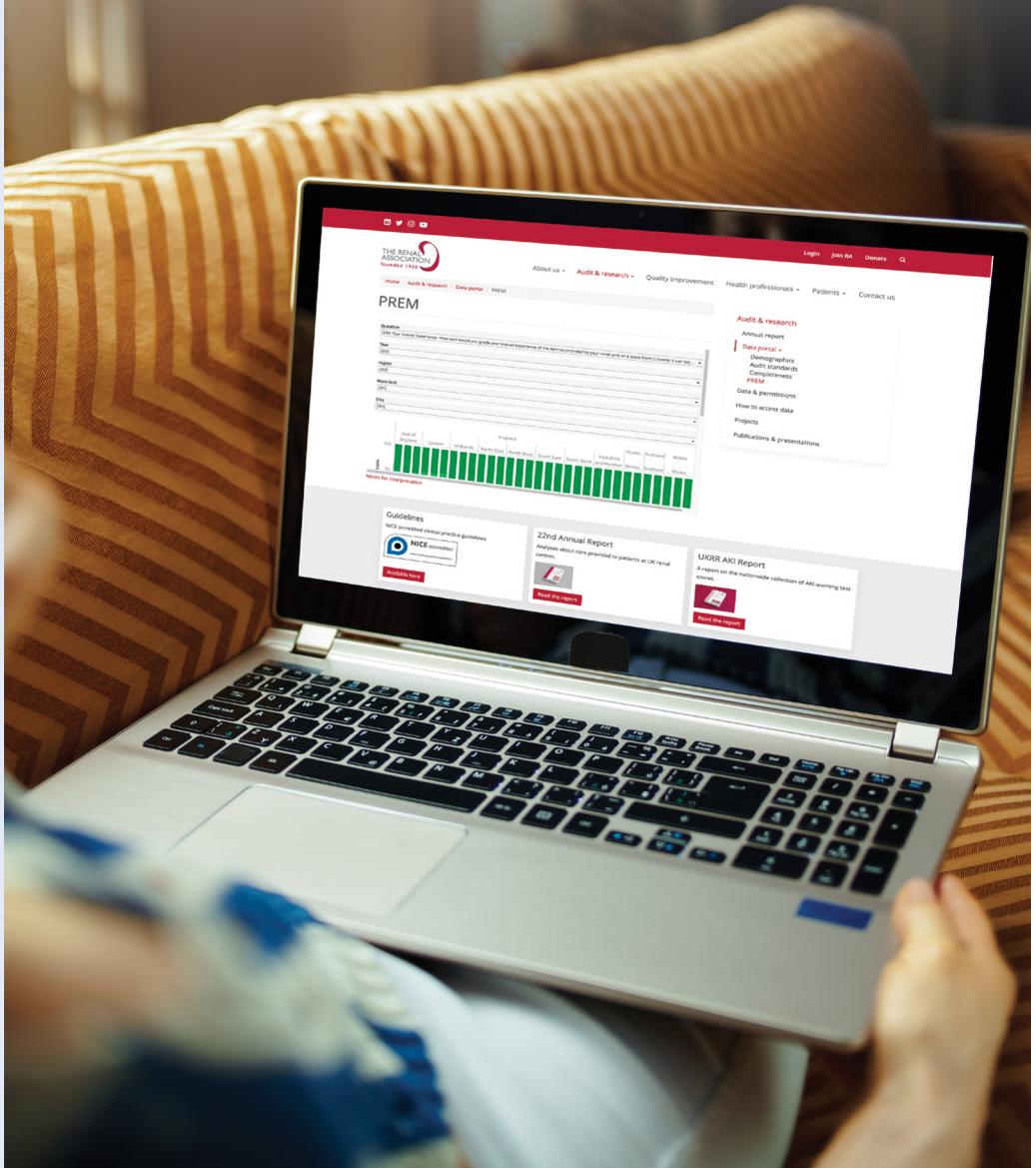
Average scores are reported for each question for each centre. Some centres had only a few responses so these may not represent the views of the full patient population.

How can I find my renal unit's results?

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

www.renal.org/audit-research/data-portal/prem

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



What did the 2020 Kidney PREM survey show?

Encouragingly, despite the pandemic, overall experience is reported as good, with an average score of **6.2 out of 7**.

The highest rated themes were:

Privacy & dignity

6.47



Access to the team

6.33



Patient information

6.35



Areas of experience needing improvement were:

Communication

5.79



Sharing decisions

5.49



Support

5.71



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.



Support and Sharing decisions fell in 2020



Experience of Sharing decisions was lowest in those receiving in-centre haemodialysis (HD)



Experience of Transport reported by in-centre haemodialysis (HD) patients **improved**



Experience of people with CKD (chronic kidney disease) but not on RRT decreased particularly for Support, How the team treats you and Overall experience

New themes emerging from patient comments include:

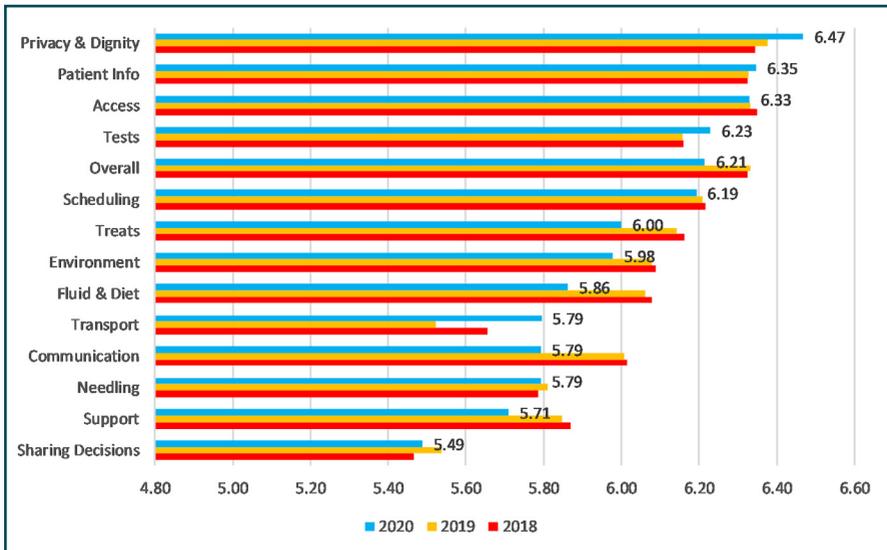


Mental health concerns



Impact of staff shortages

The average scores for each theme over 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.

What comments did participants make?

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 2020, 7,364 participants commented anonymously on their experience of kidney care; the majority of comments were thanking staff for their kindness and dedication to patients throughout what was acknowledged as a difficult year.

“I had my transplant in 2019, and my care before, pre COVID and during COVID has been first class and I consider myself very lucky”

“[Member of staff] goes above and beyond what one should expect from a consultant and represents everything that is good about the NHS. She is a credit to your organisation. You are lucky to have her in your service and I am lucky to have her as my consultant.”

“I would like to thank everyone concerned with my Renal care especially the staff at [Name of Area] Hospital. I have spent 8 or 9 weeks as an inpatient there and many months as an outpatient. The Doctors, Nurses, Cleaners, porters, diagnostic imaging, catering staff, pharmacist and others I have no doubt forgotten could not have looked after me any better. I thank you all...”

Patients commented on several issues to do with the treatment environment, including access to parking, waiting times, the temperature (cold) and general comfort of the waiting room.

As reflected in the mean transport scores, patients commented that transport had improved this year, although issues with the distance to travel to the unit, and waiting times, remain a problem for some. The new themes we see emerging from these comments include personal mental health concerns and the impact of staff shortages.

There will be a separate report interpreting all the comments received in Spring 2021.

How can I take part in the next Kidney PREM?

The next survey will open in Autumn 2021. You will be able to take part, either at your renal unit or online via The Renal Association 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/2020prem
- Kidney PREM portal:
www.renal.org/audit-research/data-portal/prem



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