

Summary report of patient comments

Patient reported experience of kidney care in the UK, 2021



Working together for better patient information

Introduction

The national Kidney Patient Reported Experience Measure (PREM) is a validated 39-item questionnaire facilitated annually by the UK Kidney Association (UKKA) and Kidney Care UK (KCUK). The Kidney PREM measures patient experience of kidney care over 13 themes and is relevant to patients receiving all types of treatment for kidney disease across the UK. The Kidney PREM has been available in paper format since 2016, and online since 2018. The online version includes a free text question, to capture experience of care not covered elsewhere.

“ 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. ”

This report summarises the full comments analysis, which is available on the UK Kidney Association website¹.

Methods

Comments were coded and themed using computer software, with some of the themes identified matching with the existing Kidney PREM themes. Coding and theming were quality checked with differences resolved by discussion and consensus. Patient characteristic data collected in the Kidney PREM provided for a mixed methods analysis.

Participant profile

In 2021, 12,416 people with kidney disease took part in Kidney PREM; 9,850 online, 39.5% of whom provided a further comment on their care (3,877; 31.2% of all participating in 2021). 3,498 (90.2%) who provided a written comment gave consent for this to be passed back to their treating centre.

¹ www.ukkidney.org/kidney-patient-reported-experience-measure

Table 1: Characteristics of people taking part in Kidney PREM 2021, and providing a free-text comment

	Kidney PREM 2021 COMMENTS RECEIVED	Kidney PREM 2021 TOTAL
TOTAL	3,877	12,416
Age (years)		
≤30	89 (2.3%)	376 (3.1%)
31-55	1,051 (27.1%)	3,261 (26.6%)
56-74	1,934 (49.8%)	5,763 (47.0%)
≥75	803 (20.7%)	2,868 (23.4%)
Gender		
Female	1,645 (42.4%)	5,038 (41.6%)
Male	2,209 (56.9%)	6,986 (57.7%)
Rather not say	26 (0.7%)	86 (0.7%)
Ethnicity		
Asian	374 (9.6%)	1,137 (9.3%)
Black	419 (10.8%)	1,005 (8.3%)
White	2,857 (73.6%)	9,358 (76.9%)
Other	149 (3.8%)	402 (3.3%)
Rather Not Say	81 (2.1%)	260 (2.1%)
Treatment		
Transplant	886 (22.8%)	2,172 (22.5%)
CKD*	589 (15.2%)	1,882 (19.5%)
In-centre HD	837 (21.6%)	1,972 (20.4%)
Sat HD	1,298 (33.5%)	2,748 (28.5%)
Home HD	80 (2.1%)	239 (2.5%)
PD	187 (4.8%)	632 (6.6%)

*Chronic Kidney Disease (not receiving kidney replacement therapy)

Aspects of care people chose to comment on

Figure 1 shows a word-cloud depicting the scale and breadth of the comments. Comments covered 14 emerging themes of kidney patient experience including the renal unit team, care, environment, and communication. Comments on the renal unit team and care were largely positive, whilst comments on environment, communication, and appointments were largely negative (Table 2). Of the 3,877 patients who left a comment, 545 (14%) said there were no further comments.

Figure 1: Aspects of care mentioned



Table 2: Aspects of care commented on, by sentiment

	Total (N)	Negative	Neutral	Positive
The renal unit team	1,323	509	38	776
Care	753	280	18	455
Environment	501	404	12	85
Communication	474	339	15	120
Appointments	470	292	29	149
Waiting times	324	278	6	40
Treatment	319	193	20	106
Impact of COVID-19	304	211	16	77
Patient information	259	201	13	45
Scheduling	233	167	11	55
Transport	226	181	7	38
Support*	199	124	10	65
Other aspects of care	163	80	35	48
Non-renal illness	51	38	1	12

*Comments on **support**, were often related to psychological provision with patients feeling there is a lack of psychological support. Others commented on the lack of general peer support.

Key findings

Comments about **the renal unit team** and the **care** they provide were overwhelmingly positive, with references made to the level of compassion shown across the multi-disciplinary team. For many people this led to feelings of gratitude for 'excellent care'. Where people felt negatively about the renal team and care, this included wanting better access to see a consultant and other specialist staff.

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

All staff have shown a considerate and caring approach to my situation. They are a fantastic group of people.
(56-74, I would rather not say, Male, HHD)

I would like easier and more frequent access to the renal doctor and other specialist doctors
(75+, Asian, Male, Sat HD)

I wish patients are referred to the dieticians as soon as they are diagnosed with kidney problems
(31-55, Black, Female, CKD)

Many thanks to all the kidney staff.
(65-74, Asian, Female, CKD)

Difficult to see kidney doctor. This need to be looked at seriously
(31-55, Black, Male, Sat HD)

Where people commented on the **environment** this was often negative, notably on comfort and temperature control, with patients finding the chairs uncomfortable and the unit too cold. Accessibility, such as gaining access into the unit, and parking arrangements, particularly the availability of spaces, were also criticised.

However, access to the hospital is disastrous and impossible for anyone with a physical disability. It is being rebuilt but in the interim, it is tired, dirty and feels deeply unsafe.
(75+, White, Male, CKD)

Coming into the hospital entrance, the security guards do not allow easy access to the unit. I have to walk 10 minutes to get to the unit.
(31-55, Black, Female, Sat HD)

Key findings

Comments on **support**, were often related to psychological provision with patients feeling there is a lack of psychological support. Others commented on the lack of general peer support.

As patient I can see staff working at the hospital are busy. However, they need to make an effort to spend more time with patients on home visits. They also need to enquire about our wellbeing and chase the patient rather than the patient chasing them.
(31-55, Asian, Male, HHD)

Wife/family does not get enough support or enough information about kidney disease
(75+, White, Male, Sat HD)

Access to patient support group in every area would improve awareness to how deal with ups and downs of the condition and levels of fatigue as this can be considerable.
(75+, White, Female, CKD)

5% of comments related to **other aspects of care** included pharmacy, the negative effects kidney disease has on mental health, and how hard it can be to organise blood tests.

As a renal-patient I feel very isolated.
(75+, White, Female, CKD)

Also, the renal team, are trying to reduce the frequency of our blood tests. We have always had them every month and consider that to be essential in order to keep good control of the kidney failure.
(56-74, White, Male, HHD)

Pharmacist being near waiting room is extremely helpful
(56-74, Asian, Male, Tx)

There were 116 patients who made a comment suggesting an improvement or made an observation on how care could be improved or on how information could be provided to make things easier to understand. Sub-themes to these suggestions were (suggestions that could be implemented with apparently little effort); **Suggestions for the longer term; Post-COVID suggestions** and **Frequently Asked Questions**.

Could do with somewhere to put coat etc. before being weighed.
(56-74, White, Female, Satellite HD)

Gated/secure car Park lighting is inadequate and needs updating.
(56-74, White, Male, Sat HD)

Key findings

I still think when admitted to hospital you should have at least one visitor this is something the patient looks forward to and helps the recovery of the patient

(56-74, White, Male, HHD)

I have no knowledge of PatientView so do not know whether I should/need to join?

(56-74, White, Female, CKD)

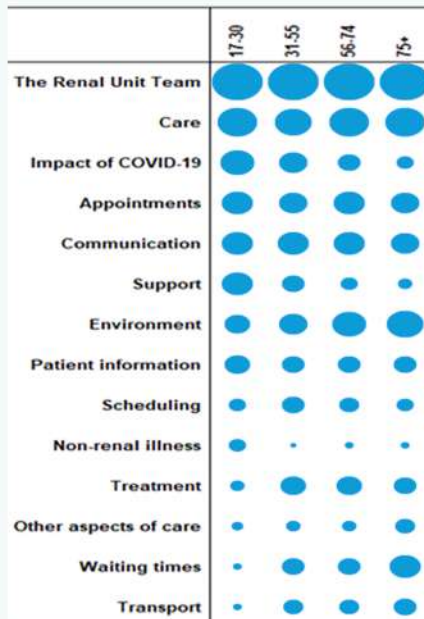
Patient experience of kidney care is unique and individual, with factors such as age, ethnicity and treatment type affecting the perception of the care received.

Age

Support and **impact of COVID-19** were of particular importance to people aged under 30 years old, who were also more likely to comment on their **non-renal illness**.

Comments on **environment**, **waiting times** and **transport** were greater from older people, who are also more likely to be receiving haemodialysis in-centre.

Figure 2: Themes by age group



Ethnicity

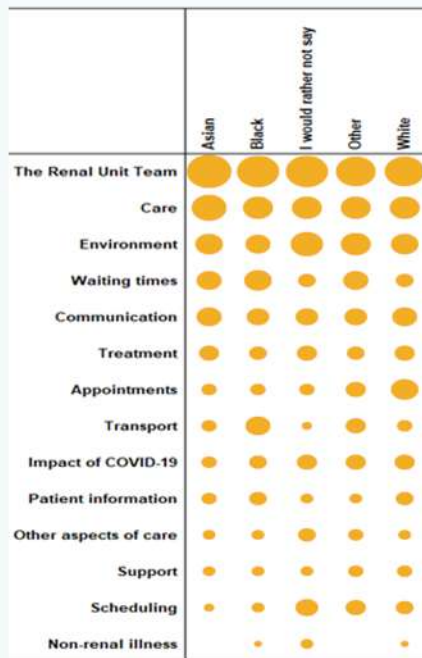
People of an Asian ethnic background were more likely than others to comment on **the renal unit team** and **care**.

People of a Black ethnic background commented particularly negatively on **transport**, and also on **patient information** to a greater extent than others.

There were no comments on **non-renal illness** from patients from an Asian or 'other' ethnic background.

Patients from other ethnic backgrounds and patients who did not state their ethnicity tended to comment more negatively on **scheduling**, mentioning difficulties faced while trying to book blood test appointments and issues with not receiving blood test results in time for consultations.

Figure 3: Themes by Ethnicity



Treatment

Patients with CKD commented negatively about **appointments** and **communication**, including concerns about lack of appointments, and wanting better communication between the renal team.

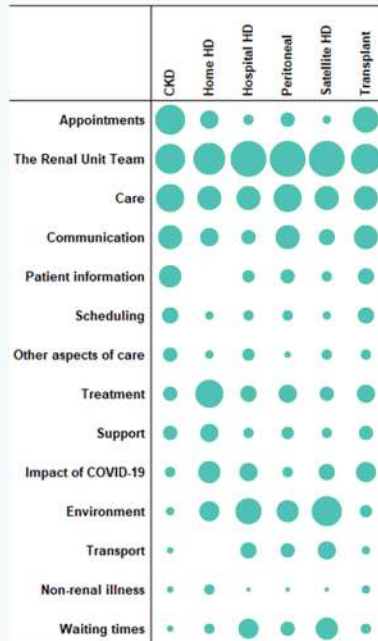
Those receiving haemodialysis at home highlighted their **treatment** and the **impact of COVID-19** as area of concern. These responses were linked, with the impact of COVID-19 (feeling unsafe, wanting to have visitors attend appointments) affecting their experience of treatment (feeling isolated and forgotten).

The negative responses of patients receiving haemodialysis in satellite units or in-centre are extremely similar, though with some differences – notably with those patients receiving haemodialysis in satellite units commenting more on **environment**, **waiting times** and **transport**.

Individuals with functioning transplants commented negatively on **appointments** and **communication**. They have also been more negatively affected by COVID-19, causing restrictions in access to care.

Patients receiving peritoneal dialysis appeared to have the fewest issues with their kidney care. Areas of concern for patients receiving peritoneal dialysis fell within **the renal unit team** and **environment** (reflecting the age profile), with comments including issues with lack of parking.

Figure 4: Themes by treatment group



2021 / 2020 comparison

This comparison of free text responses from 2020 and 2021 gives insight into how patient experience of care has changed following the feedback in comments from 2020, along with the areas of care which seem to be a persistent issue for patients.

- In both years, around 40% of patients responding to Kidney PREM provided additional comments on their experience of kidney care. The number of comments from patients of a Black ethnic background or Asian ethnic background has increased from 2020 (24% vs 17%).
- The analysis of comments changed format between 2020 and 2021, with 2020 using the existing 13 PREM themes and 2021 introducing emerging themes.
- Importantly, positive comments about **staff** remained the most prominent response in patient comments about their kidney care. Patients were generally more positive about their experience of care than in 2020.
- Comments regarding **environment** featured highly in both years and were mostly negative. In 2021 the largest proportion of these were related to comfort, temperature control, and waiting areas. This was also the case in 2020, though then there was more emphasis on waiting times in the unit.
- In contrast to 2020, **support**, particularly psychological support, featured in a large number of comments.
- Issues with **communication** featured in both years. Comments in 2020 focused on patients wanting communications with them to be more frequent, whilst in 2021 comments focused on communication within the kidney team.
- In both years lack of **patient information** was an issue, particularly in relation to adequate updates about treatment, progress, and transplant prospects, and to advise about diet, fluid intake and exercise.
- Both years saw patients offering **suggestions to improve their experience** of kidney care. In particular, these comments featured 'little gems' with similar suggestions between both years.

2021 / 2020 comparison

- In 2021 younger patients tended to focus on **support** and older patients on **environment** and **transport**, this was the same for 2020.
 - People with CKD (not receiving KRT), in 2021, focused on **appointments** and **communication**, as did those with a functioning transplant for whom COVID-19 was also major concern. This compares to 2020, in which patients with a working transplant and patients not receiving KRT highlighted issues about psychological care.
 - In 2021 patients receiving peritoneal dialysis and In-centre haemodialysis focussed on **staff** and **environment** with the latter also commenting on **transport**. In 2020, patients receiving haemodialysis in-centre and in satellite units raised issues about involvement in **decision making**, **scheduling** and **needling**, whilst those receiving peritoneal dialysis focussed on **communication** and discussion of **test results**.
 - Patients receiving haemodialysis at home commented on **support** and **COVID-19** in 2021. **Support** was also a concern in 2020 for these patients.
-

Contact us



 3 The Windmills, St Mary's Close,
Turk Street, Alton GU34 1EF

 www.kidneycareuk.org

 01420 541424

 [kidneycareuk.org](https://www.facebook.com/kidneycareuk)

 [@kidneycareuk](https://twitter.com/kidneycareuk)

 [@kidneycareuk](https://www.instagram.com/kidneycareuk)

In partnership with:



UK Kidney Association

 Brandon House Building 201a,
Southmead Road, Bristol, BS34 7RR

 www.ukkidney.org

 [@UKKidney](https://twitter.com/UKKidney)