



The Impact of COVID-19 on Patient Reported Experience of kidney care

Introduction

The national Kidney Patient Reported Experience Measure (PREM) is a validated 39-question measure which measures patient experience of care. It is facilitated annually by the UK Kidney Association and Kidney Care UK. In 2020, four additional questions were introduced regarding the impact of COVID-19.

- Overall, how much better or worse was your kidney care during COVID-19?
- What was good about your experience of kidney care during COVID-19?
- What was bad about your experience of kidney care during COVID-19?
- What could have been done, if anything, to make your experience of kidney care better during COVID-19?

The first additional COVID-19 question was a question using a scale, in which patients rated their experience of care during COVID-19 from -3 (much worse) to 3 (much better) with 0 being no change. The other three additional COVID-19 questions required a free-text response.

This is a summary report focussing on the analysis of the responses to COVID-19 related questions.

The PREM 2020 was reported and can be [viewed here](#). There were 3,912 responses to the first free text question¹, the analysis of which has been reported separately.

For a more in-depth analysis of the comments, please see the full version: "[Impact of COVID-19 on patient experience of care; comments report](#)"

Comments relating to COVID-19 were left by **7,286 (75.5%)** people, there were 84 individuals who gave comments in answer to the first free text question¹, but not for any of the COVID-19 free-text items.

¹ The question: 'If there is any other aspect of your experience of kidney care that you would like to comment on, please tell us below' is asked every year online

Table 1: Characteristics of Kidney PREM 2020 Responders by Comments Provided

	COVID Questions		Comment Free Text Question		Kidney PREM 2020		UK RRT Patients as of end of 2020
Total	7,286		3,912		9,645		68,249
Age							
≤55	2394	32.9%	1159	29.6%	3329	34.5%	38.2%
56-74	3588	49.2%	1996	51.0%	4537	47.0%	46.6%
75+	1304	17.9%	757	19.4%	1779	18.4%	15.2%
Gender							
Female	3231	44.3%	1662	42.5%	4177	43.3%	38.7%
Male	4019	55.2%	2237	57.2%	5404	56.0%	61.3%
Rather not say	36	0.5%	13	0.3%	64	0.7%	-
Ethnicity							
Asian	533	7.3%	281	7.2%	743	7.7%	12.5%
Black	474	6.5%	300	7.7%	613	6.4%	7.6%
White	6005	82.4%	3189	81.5%	7896	81.9%	70.4%
Other	153	2.1%	80	2.0%	203	2.1%	1.6%
Rather Not Say	121	1.7%	62	1.6%	190	2.0%	-
Missing	-	-	-	-	-	-	7.9%
Treatment							
Transplant	1752	24.0%	907	23.2%	2172	22.5%	57.0%
Home HD	189	2.6%	97	2.5%	239	2.5%	2.0%
Satellite HD	1992	27.3%	1097	28.0%	2748	28.5%	35.4%*
Centre HD	1437	19.7%	848	21.7%	1972	20.4%	
Peritoneal	481	6.6%	253	6.5%	632	6.6%	5.6%
CKD	1435	19.7%	710	18.1%	1882	19.5%	Unknown

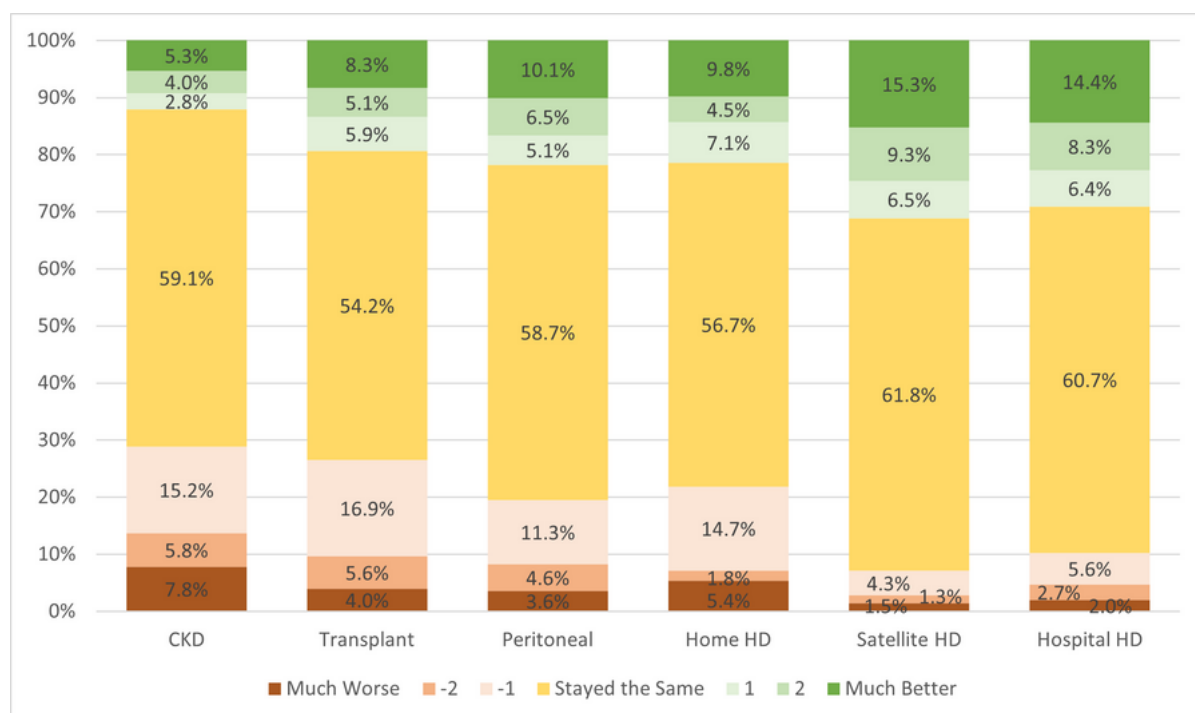
COVID-19 question using a scale

Most people reported that the care they received remained at the same level as pre-pandemic.

Those receiving satellite and hospital haemodialysis were more likely to report an improvement in their care, with **31% and 29%** respectively.

The CKD (not receiving RRT) group were more likely to report a worse experience of care with **29% scoring -1 or below**, with transplant patients similarly experiencing worse care at **26%**.

Figure 1: Responses to "Overall, how much better or worse was your kidney care during COVID-19?" by treatment modality (n=9,086)



Summary of treatment type

People with CKD

- **63.4%** of comments were about receiving treatment and appointments, with a focus on telephone calls being more convenient and blood test appointments being more accessible through the GP.
- On the other hand, **51.9%** of comments in response to "What was bad about your experience of kidney care during COVID-19?" were also to do with appointments, with patients wanting a hybrid of face-to-face and telephone appointments to suit their needs.
- CKD patients also found there to be issues with receiving their medication correctly and on time, with some patients mentioning how they wanted more information about transplant care.
- When asked what would have improved their experience of care, most comments were split across 'treatment and appointments' and 'care'. Patients wanted better methods of contacting staff in emergencies and also wanted appointments for their telephone calls to be pre-arranged.

People receiving transplants

- Comments across all three questions were evenly split across the themes that emerged, however, appointments became a prominent theme in response to each question
- Transplant patients found telephone calls and blood tests to be both positive and negative with some patients finding the changes to these appointments more convenient whereas others finding their care to be rushed.
- Staff received many positive comments and thanks from transplant patients, though better methods of contacting staff directly and quickly were asked for, as well as patients wanting better parking facilities.

People receiving peritoneal dialysis

- PD patients found contact with the renal team to be very good with **78.4%** of the comments mentioning this aspect of the experience. These mentioned examples of positive experiences with staff and staff caring for them.
- Some patients also found telephone calls and contacting the renal team to be a positive aspect of kidney care experience.
- Whilst others (**39.3% in response to Q2**) found telephone calls to be missed and rushed. To add, contacting the renal team resulted in long replies and only receiving an answer machine message.
- PD patients said that staff being more available would have improved their experience of kidney care, in particular making it easier for patients to contact staff and speak with them directly.

People receiving home haemodialysis

- HHD patients found the emerging themes 'at home' and 'Appointments' to be the most positive of their experience, finding home therapy very beneficial during the pandemic.
- Although they found the home therapy to be beneficial, contact with the renal team and being cared for by staff were some of the most common negative comments.
- HHD patients found staff not available for support with treatment, with some patients giving examples of fistulae being neglected.
- To have improved their care most comments mentioned needing more care and communication from the renal team, such as regular updates to patients and psychological support.

People receiving satellite haemodialysis

- The most positive aspect of kidney care experience to have emerged was related to support from staff. Satellite HD patients felt well supported during the pandemic particularly with regular updates from staff.
- Care received particularly negative comments (**79.1%**), the main issues being related to the number of dialysis days being reduced, lack of consultant availability and long waiting times when at the unit.
- Satellite HD found numerous areas for improvement with the majority of comments falling within 'Unit-related comments' (**43.7%**) and 'Care' (**42.5%**). A few examples are improving transport waiting times and having more direct routes home, increasing the number of staff to patient ratio, and improving communication between staff and patients.

People receiving in-centre haemodialysis

- In response to 'What was good about your experience of kidney care during COVID-19?' **69.6%** of comments were from the emerging theme 'Care'.
- There were many positive comments about staff, being well cared for by staff, and being able to interact with patients and staff during the pandemic.
- Poor experiences of kidney care mentioned were the long waiting times within the unit, as well as the lack of food and drink offered during dialysis sessions.
- To have improved their care, most comments were split across 'care' and 'Unit-related comments'. Patients wanted there to be more staff available during dialysis sessions and better communication from staff.

Examples of comments

"Staff explained what was going on. The staff worked hardest they can even though are short of staff."
 (<55, Asian, Centre HD, Female)

"The new telephone clinics made my doctor more accessible, and I found this reassuring."
 (<55, White, Sat HD, Male)

"If I needed advice the unit told me what to do, they also give me my blood results and advice following these results"
 (56-74, Asian, Sat HD, Male)

"Temperature took as soon as you walk through the door, sanitizers to hand and asked questions about your health. Very organised and friendly."
 (<55, White, PD, Female)

"Excellent safety precautions. Good communication. Easy access to get the medications safely."
 (<55, Asian, CKD, Male)

"I always felt comfortable because the centre is always clean, and the staff attitude is exceptional."
 (56-74, Black, HHD, Male)

"I really can't think of anything other than communication with GP practice does seem a little sporadic - having said that I haven't really had any urgent need to test it."
 (56-74, White, HHD, Male)

"It continued to be consistent e.g., appointments and blood tests"
 (<55, Black, Tx, Female)

"That my consultant kept an eye on me and called me in to see him when it was necessary. And he checked up on my blood tests and regularly phoned me to let me know how I was doing"
 (<55, Asian, PD, Female)

"My experience during the pandemic has not changed from the excellent support from all the team at UNIT NAME renal unit, I have been contacted by the Transplant Nurse Specialist at regular intervals."
 (75+, White, Tx, Male)

"Most of the staff are very supportive in all aspects. Social worker for renal is amazing and deserves the best praise, she has gone beyond care of duty for the patient and is always happy to help in any way she can. Renal consultant is very accessible and friendly and ready to answer any questions 24/7 by email STAFF NAME. Their attempt to ensure everyone's safety has been commendable"
 (<55, Black, Centre HD, Female)

