

## **‘Worried sick’ – the impact of COVID-19 on people living with kidney disease: findings from a patient survey**

### **Background**

The COVID-19 pandemic has had a profound impact for people living with kidney disease. Kidney Care UK’s support services had seen a huge increase in the requests from kidney patients and their families, illustrating the challenges they face and their urgent need for information, advice and support:

- Our website saw a surge of visits to 250,000 in March, up from 40,000 in a normal month
- There was a 33% increase in calls to the charity between February and March
- Our advocacy service had the highest monthly requests for support on record - a 30% increase compared to March 2019

**3 million people in the UK have chronic kidney disease (CKD), placing them at greater risk from infection with COVID-19**, with the risk increasing as the severity of CKD increases. About 70,000 people with CKD are in the extremely vulnerable shielding group including those with transplants, those on dialysis and those with specific types of kidney disease requiring immunosuppressants. People on dialysis are at particular risk as they must go to hospital for their life-maintaining treatment three times a week.

We set up an online survey to better understand the concerns, anxieties and unmet needs of people living with kidney disease. The survey demonstrates:

- Two thirds of patients reported disruption to their care, including surgery or appointments being cancelled, or inability to have blood tests or check-ups.
- Four in ten patients reporting that their mental health has been affected.
- Confusion over shielding advice:
  - 13% of the patients who were not told to shield had conditions that meant they should have been shielding, such as transplants, dialysis or late stage CKD (stage 5)
  - 6% of patients received conflicting advice about whether or not they should shield
  - 18% of the patients told verbally to shield received no written confirmation, leaving them unable to access centrally coordinated support
- Nearly seven in ten patients are co-isolating with family members; nearly 16% of respondents reported that household members having to go to work, or lose their income, was a concern for them.

We greatly appreciate the care the NHS has given to kidney patients during the pandemic, but it is essential that the Government, NHS and other key organisations such as supermarkets learn now from the experience of the first pandemic wave, to improve resilience and communications for the future, whether or not there is a second wave of COVID-19. The publication of this report comes shortly after the government unexpectedly advised that in some UK countries those have been shielding for many weeks are now able to leave the house once a day for exercise, leaving many patients uncertain and confused.

### **Kidney Care UK is calling for:**

1. **Government to set out an evidenced plan for the future, which reassures kidney patients that they have not been forgotten, assures them that healthcare services are safe, and gives those who need to continue to shield as lockdown eases for the rest of the population hope of a way back to some kind of normality over time.**
2. Kidney patients to be prioritised and given personalised advice as the NHS works to return services to pre-COVID operation, ensuring all patients with CKD, including those who are at risk of progressing, are contacted to check and monitor their condition and offer them support, including transplantation, to help them delay further, potentially serious, deterioration in kidney function.
3. A clear plan to provide kidney patients with mental health support and an acknowledgement from Government, if not an exit strategy, for people who are facing the prospect of being housebound for many more months.
4. Government commitment to provide simple, direct, accurate and timely communications to patients and the charities that support them, now more than ever.
5. Shielding lists and systems to be improved so that all kidney patients receive accurate written guidance from Government and the NHS to enable them to protect themselves and access critical services.
6. Improvements to the Government portal, other online systems and non-digital systems to ensure that all shielded patients are able to access healthcare and essential supplies, such as food and medicines.

## Methodology

The online survey was open from 7 to 15 May 2020. It was advertised on Kidney Care UK social and media networks. The full list of questions is included in the appendix.

1,211 responses were received. The majority of respondents were female (63% and 36% male), lived in England (85%) and were White British (94%). More demographic detail is available in the appendix.

## Key findings

### **1: Two thirds of respondents have had their care disrupted. A third have had surgery or appointments cancelled.**

- 66% of respondents reported disruptions to the care they receive.
- The most common impact was surgery or appointments being cancelled (35% of respondents)
- A quarter (26%) had not been able to have blood tests or check-ups
- 18% said they had felt unwell or anxious as a result of delayed or cancelled treatment
- 17% had found it more difficult to get advice about health worries

*“Transplant lists are suspended & I am finding it difficult, mentally to be in this situation with no hope of progress.”*

*“It has not been possible to talk to my consultant directly about several concerns I have concerning current medication and other issues such as university.”*

8,000 people reach kidney failure every year and regular monitoring of people with kidney disease is essential. This can help delay progression of the disease and potentially the need for burdensome and expensive dialysis. Many kidney patients in the moderate to advanced stages of kidney disease will have had monitoring appointments cancelled during the COVID-19 outbreak. There are serious implications of failing to spot major progression in kidney disease to both the individual and NHS services.

Kidney Care UK is calling for Government to set out a plan for the future, which reassures kidney patients that they have not been forgotten, assures them that healthcare services are safe, and which gives those who need to continue to shield as lockdown eases for the rest of the population hope of a way back to some kind of normality over time.

Kidney patients to be prioritised and given personalised advice as the NHS works to return services to pre-COVID operation, ensuring all patients with CKD, including those who are at risk of progressing, are contacted to check and monitor their condition and offer them support, including transplantation, to help them delay further, potentially serious, deterioration in kidney function.

## 2: More than 4 in 10 of patients feel their mental health has been affected by COVID-19.

- 41% of respondents said they felt anxious, lonely or isolated (scoring 4 or 5 where 5 is “this is a very serious concern for me” and 1 is “this has not affected me”)
- 17% of the people who had either signed up to receive Government support or who had attempted to, wanted help with emotional or mental health support

*“The uncertainty of when we can go out again we seem to be forgotten in the future plans.”*

*“Feels like we’re out of sight out of mind.”*

A diagnosis of chronic kidney disease (CKD) can be devastating, for patients and their loved one, affecting mental as well as physical health. The COVID-19 pandemic has magnified this, and patients are understandably anxious about many different issues, from their risk of contracting COVID-19, to what they or their families need to do to shield, to their risk if they have to attend hospital for necessary treatment, to how they will access support.

As time goes on, patients have more questions about a prolonged lockdown and worries for the future, both the impact for them and for loved ones:

- 69% of respondents reported that family members were currently co-isolating with them.
- 16% of respondents reported that household members having to go to work, or lose their income, was a concern for them.

Worries about family members returning to school or work once lockdown had finished was a common theme of free text comments, with people worried about whether they could continue to successfully shield as lockdown was eased further and people are expected to return to work or education.

*“I’ve been furloughed. I’d like to know if those who shielding and furloughed will have this protection extended? My employer is unlikely to keep me on if I still have to shield.”*

*“I think there needs to be more clarity about if the support will continue until we are able to return to work / stop shielding. I’m constantly worried they could remove all support.”*

*“The longer shielding goes on the harder it is. Both my husband and I are finding it difficult.”*

*“I am having to heavily rely on the only 2 members of my family that live nearby, the prospect of having to do so for an extended time is worrying.”*

**Kidney Care UK is calling for a clear plan to provide kidney patients with mental health support they urgently need, and an acknowledgement from Government, if not an exit strategy, for people who are facing the prospect of being housebound for many more months.**

**3: Some patients with kidney conditions that meant they should have been shielding, were not told to do so, leaving them potentially unable to take protective measures. Other patients received conflicting advice. Some received only verbal advice with no written confirmation, leaving them unable to access core support services.**

- 13% of the patients who were not told to shield had conditions which meant they should have been shielding. This included 7 transplant patients, 3 patients receiving dialysis and a further 27 with CKD stage 5
- 6% of patients received conflicting advice on whether they should be shielding. This included 4 transplant patients, 4 patients receiving dialysis and a further 12 with CKD stage 5
- 18% of the patients told verbally to shield did not receive any written confirmation of this. This included 4 transplant recipients, 3 people on dialysis and 8 with CKD stage 5

Conflicting advice about the need to shield creates confusion and anxiety. Delays and confusion in communicating to very high risk kidney patients meant they did not have access to crucial information, making it more difficult for them to access healthcare while they are shielding.

*"I had to get in contact with [my local] hospital to get a shielding letter as I've had a transplant and work wanted to see the letter before I went off."*

*"I need a letter confirming/proving to my employer that I need to be shielding. My employer is not very understanding of my condition."*

*"I am unable to social distance from my young children who are co-isolating with me and there has been no advice on this situation."*

In addition, lack of written confirmation has prevented patients from providing evidence to employers or accessing crucial services such as deliveries of medicines and food (see next section).

**Kidney Care UK is calling for Government commitment to provide simple, direct, accurate and timely communications to patients and the charities that support them, now more than ever.**

**The charity is also calling for shielding lists and systems to be improved now so that, in the event of a second pandemic wave, all kidney patients receive accurate written guidance from Government and the NHS to enable them to protect themselves and access critical services.**

#### 4: Some patients told to shield were not able to sign up for Government support or did not know they were eligible, leaving them struggling to access essential supplies

- 59% of shielding patients had successfully signed up for Government support, including 68% of transplant recipients.
- 54% of people on dialysis had signed up for support, but 8% had tried and not been able to, and a further 11% did not know they were eligible

One explanation is that the confusion around whether people on dialysis should have been shielding has made it less likely that they will have signed up for support. The survey indicated problems both with accessibility and usefulness:

- 11% found it very helpful but difficult to access
- 9% not helpful but easy to access
- 9% found it unhelpful and difficult to access

The most common type of support people wanted from the Government portal was food deliveries (57%) followed by medication delivery (41%).

- 24% of all respondents reported problems with getting food delivered and 11% said that getting food delivered was a serious concern
- 11% of shielding respondents said that getting medication delivered was a serious concern

Many people used free text comments to report that they had signed up for Government support but heard nothing (even whether they had been accepted). Many people wanted to sign up just for priority delivery slots rather than the food box but found this was impossible.

Without access to essential supplies, this vulnerable population is placed at further risk by having to leave home to shop. This is a particular problem for elderly patients and those living alone. Problems with the portal and online shopping has left some kidney patients worrying about where their next meal will come from.

**Kidney Care UK welcomes the efforts by Government and supermarkets to prioritise vulnerable patients for delivery of urgent supplies and also food boxes. However, we are calling for improvements to the Government portal, other online systems and non-digital systems to ensure that all shielded patients are able to access essential supplies, such as food and medicines, easily in a further pandemic wave.**

*"I have applied twice over the last three weeks and was told would receive a letter within a week if I was eligible for support and not heard anything yet."*

*"I have been struggling to get official notification & therefore support. I live alone & have no family locally."*

*"The Government's letter to those to shield was too late with regards to support and access to food."*

*"I have been unable to receive priority delivery slots with supermarkets as they say I'm not vulnerable."*

*"I know the supermarkets were overwhelmed but it took 5 weeks after lockdown to get food delivered."*

## Appendix 1: Full list of survey questions

### Demographic questions

1. How old are you?

0 – 15 / 16 – 30 / 31 – 45 / 46 – 60 / 61 – 75 / 75+

2. What is your gender?

Male / Female / Non-binary / Other / Prefer not to say

3. Where do you live?

England / Scotland / Northern Ireland / Wales

4. Which race / ethnicity best describes you?

- White/ White British
- Black / African / Caribbean / Black British
- Asian / Asian British
- Mixed / Multiple ethnic groups
- Prefer not to say
- Other

5. What is your kidney condition/treatment? Please tick all that apply

- Chronic Kidney Disease stage 3-4
- Chronic Kidney Disease stage 5
- Acute kidney injury (AKI)
- Kidney Cancer
- Dialysis at a unit or hospital
- Home Haemodialysis
- Peritoneal Dialysis
- Transplant
- Other

### Coronavirus support questions

1. Have you been told that you should shield by any of the following \*tick all that apply\*

- An official Government letter
- A text message from the Government
- A letter from your GP
- A letter from your hospital team
- I have been told verbally by my GP or hospital doctor
- I have not been told to shield
- I have received conflicting advice

2. Have you changed your lifestyle in order to shield to the recommended level by any of the following methods: (options will be yes / no / not applicable)

- Staying at home
- Taking leave / time off from work
- Working from home
- Having food and medical supplies delivered
- Family members co-isolating
- Using personal protective equipment (PPE) when attending appointments (e.g. facemasks / gloves)

3. How confident are you that you are able to shield to the recommended level?

Very confident / Fairly confident / Not at all confident

4. Have you attempted to / signed up to receive additional support from the Government? For example with shopping and prescription delivery?

- Yes, I've signed up
- I've tried to sign up but have not been able to
- No, I haven't signed up because I don't need the support
- No, I haven't signed up because I'm not eligible for support because I'm not shielding
- I didn't know I could sign up
- I'm not sure

5. What has your experience been of the Government's additional support?

- Very helpful and easy to access
- Very helpful but difficult to access
- Not helpful but easy to access
- Not helpful and difficult to access
- I was unable to access the Government's additional support

6. What support did you/do you want help with?

- Food deliveries
- Medication delivery
- Transport to dialysis or other hospital appointments
- Access to personal protective equipment for dialysis appointments (eg facemasks / gloves)
- Financial support
- Emotional or mental health support
- Other (please specify)

7. Would you like to make any further comments on your experience of the Government's additional support?

8. Have you had difficulty getting food delivered to you?

- Yes

- No
  - No, because I do not need to shield and can go to the shops
  - No, because I have a family member to go to the shop for me
  - No, because I have a priority access delivery slot from a supermarket
  - No, because a voluntary organisation is helping me with shopping
9. Have you contacted a volunteer organisation to help with food deliveries?
- Yes, and they've been able to help
  - Yes, but they've not been able to help
  - No, I didn't know about them
  - No, I didn't think I'd be eligible
  - No, I didn't know how to contact them
  - No, I didn't know they could help with shopping
  - No, I prefer to do my own shopping
10. Which volunteer organisation did you contact?
- NHS Volunteers
  - COVID mutual aid
  - A local voluntary group
  - Other
11. Has coronavirus affected the treatment and support you receive from the NHS? \*tick all that apply\*
- I have had surgery or other appointments cancelled
  - My dialysis programme has been altered / reduced
  - I have found it difficult to get to my dialysis appointments
  - I have not been able to have blood tests or check ups
  - It has been more difficult to get advice about any health worries from my GP or hospital team
  - It has not impacted the treatment I receive
  - I have not been able to have a transplant
  - Other
12. What have been the other impacts of coronavirus? \*please circle 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern\*
- I feel anxious / lonely / isolated
  - A member of my household has had to continue going out to work, even though I am shielding, to avoid losing their income
  - I have struggled to get food
  - I have struggled to get medicine delivered
  - I feel anxious or unwell due to cancelled / postponed / delayed treatment
  - I've struggled financially
  - Other
13. Do you think you've had coronavirus symptoms?



Yes, and I've been tested / Yes, but I've not been tested / No, I haven't had symptoms / Not sure

14. Have you referred to Kidney Care UK information on COVID-19?

Yes, via website guidance/ Yes, via telephone / No, I have not needed it / No, I did not know it was available

15. Have you found Kidney Care UK information helpful?

Scale of very unhelpful – very helpful (1 to 5 stars)

16. What more information would you like from Kidney Care UK?

- Mental health support
- Dietary advice
- Exercise support
- Details of how to contact support services
- Signpost to sources of further information (eg money advice service or Government support)
- Other

## Appendix 2: Demographics of respondents

- 763 respondents were female (63%). 436 respondents were male (36%), with 2 non-binary, 2 other and 4 preferring not to say.
- The age brackets of respondents were as follows:

Age	Number of respondents	Percentage of respondents
0 – 15	53	4%
16 – 30	120	10%
31 – 45	292	24%
46 – 60	494	41%
61 – 75	214	18%
75+	34	3%

- Respondents' country of residence was as follows:

Country of residence	Number of respondents	Percentage of respondents
England	1,031	85%
Scotland	76	6%
Northern Ireland	69	6%
Wales	31	3%

- Respondents reported their ethnicity as follows:<sup>1</sup>

Ethnicity	Number of respondents	Percentage of respondents
White/ White British	1,010	94%
Black / African / Caribbean / Black British	6	1%
Asian / Asian British	28	3%
Mixed / Multiple ethnic groups	11	1%
Prefer not to say	8	1%
Other	12	1%

- Respondents reported their conditions / treatment (they could choose more than one option) as follows:

Condition / treatment	Number of respondents	Percentage of respondents
Chronic Kidney Disease stage 3-4	316	26%
Chronic Kidney Disease stage 5	178	15%
Acute kidney injury (AKI)	17	1%
Kidney Cancer	6	0.5%
Dialysis at a unit or hospital	106	9%
Home Haemodialysis	49	4%
Peritoneal Dialysis	51	4%

<sup>1</sup> Please note that this question was accidentally omitted from the first iteration of the survey so responses were only received from 1,075 patients.

Transplant	567	47%
Other	142	12%

- The most commonly reported condition/treatment was kidney transplant (47%) although 4% of these people were now again receiving dialysis.
  - 17% of respondents were currently on dialysis.
  - 23% of respondents had CKD stage 3-4 and were not on dialysis and had not received a transplant.
  - 6% had CKD stage 5 and were not on dialysis and had not received a transplant.
- Three quarters of respondents (75%) reported that they had not had symptoms of COVID-19. When asked if they thought they had had coronavirus symptoms, the 1,086 respondents to this question answered:

Symptoms of coronavirus	Number of respondents	Percentage of respondents
Yes, and I've been tested	30	3%
Yes, but I've not been tested	70	6%
No, I haven't had symptoms	815	75%
Not sure	171	16%