

Lifting lockdown - the impact of COVID-19 for kidney patients as the pandemic eases

Findings from a third survey of people living with kidney disease March 2021

Introduction

For the third time since the COVID-19 pandemic hit the UK, Kidney Care UK has asked kidney patients to tell us how they are feeling and what the most pressing issues of concern are for them and for their families.

This survey was conducted to coincide with the introduction of the UK Governments' roadmaps to easing COVID-19 restrictions in each of the four nations of the UK and, with them, the end of shielding measures. The findings demonstrate that steps still need to be taken to ensure that clinically extremely vulnerable (CEV) people, including those with kidney disease, feel their safety is a continued priority. People living with kidney disease have legitimate questions and concerns which need to be addressed as UK Governments seek to return each nation to a more normal state of affairs.

We continue to be grateful to all of the kidney patients who have generously given their time to this and previous surveys. We also remain thankful for the dedication and commitment of our NHS and renal staff, who have tirelessly supported our community in these difficult times.

Background

Our three patient surveys across the COVID-19 pandemic have provided snapshots of the profound impact that the pandemic has had on people living with kidney disease and their families – their concerns, anxieties and unmet needs.

Across all three surveys we have heard about disrupted care, including surgery or appointments being cancelled. The first survey showed the picture of confusion, with piecemeal information, confusion over shielding advice and lack of access to centrally coordinated support for some. As we moved out of lockdowns, services began to resume 'business as usual' activities (though these were again compromised when the country returned to lockdown). Respondents expressed their fears about whether they were able to properly shield, with additional anxieties around safety and finances for those in jobs where they could not easily work from home. Patients who are parents expressed worries over how they would protect themselves once their children were expected to return to school.

As the UK moves out of restrictions in line with the published roadmaps, we wanted to find out whether and how patients' perceptions, priorities and concerns have shifted. This survey therefore sought to examine how patients felt about the announcements on how the country would return to normal, including returning to work and children going back to school, and their perception of no longer having special dispensation to avoid those areas where transmission of COVID-19 is most likely. We also asked them about whether they had been vaccinated against COVID-19, following the Government's opening of vaccination to CEV people in February 2021.

This survey found:

- **COVID-19 continues to affect many kidney patients' mental and physical health.** More than half of the respondents (56%) have had their care disrupted and nearly four in ten (38%) felt their overall health has declined over the pandemic. This raises important questions over what can be done to support people living with kidney disease to regain and maintain their health as much as possible. Emotional wellbeing ranks highly on patients' list of worries and nearly seven in ten (68%) respondents would like continued mental health support to help them cope as restrictions ease
- **Kidney patients are worried about the restart of 'normal life'.** While many in the general population may be looking forward to shops, pubs and leisure facilities being open and being able to socialise in larger groups, just 11% of respondents in this survey are looking forward to having the same freedoms as everyone else. With only 6% of respondents having had both doses of their COVID-19 vaccine at the time of asking, returning to public areas and children returning to school are still causes of much anxiety amongst survey respondents.
- **Communication needs to be clear, consistent and timely for people to feel protected when exiting lockdown restrictions.** This survey showed high rates of anxiety around returning to work, mainly because of confusion around rights and protections once shielding ends. With only a quarter (26%) of respondents who are currently in employment expected to continue to be able to work from home once restriction ease, there needs to be more information on how employees can ensure their safety at work.

Kidney Care UK is calling for:

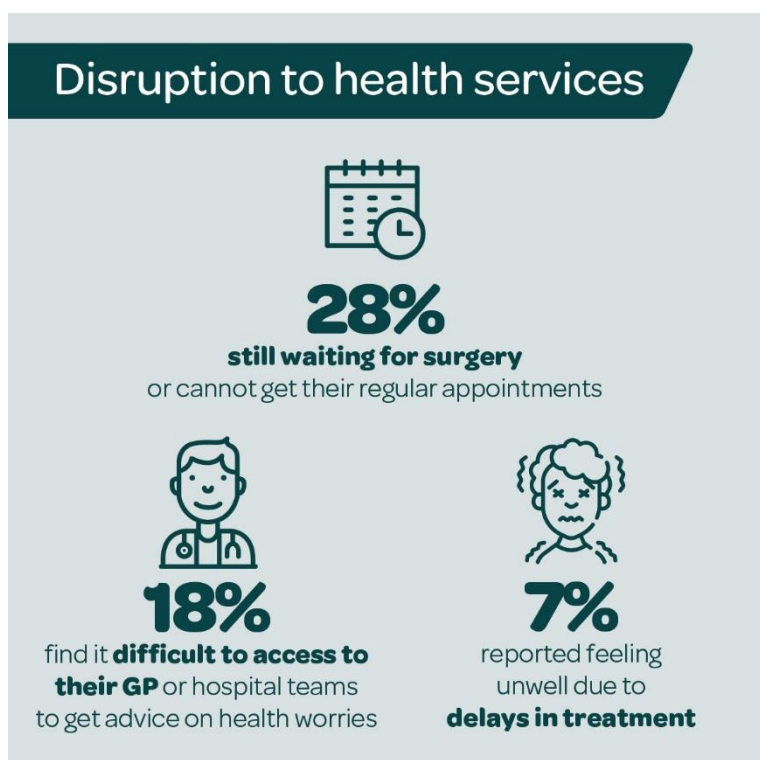
- 1. All NHS renal services to be restored to pre-pandemic levels immediately to ensure those who need urgent access to care and kidney transplants can do so safely and quickly to prevent any unnecessary illness or loss of life**
- 2. All kidney patients to be signposted to NHS mental health support services and to be adequately supported with COVID-19 related anxieties and worries to help with the mental toll of the pandemic, such as delays and reduction in access to health services, having to shield from the world and the pressure of having to return to work**
- 3. The COVID-19 vaccine programme to be accelerated so that all clinically extremely vulnerable (CEV) people have access to their second COVID-19 vaccine quicker than the current 12 week wait time to give CEV people confidence to return to work / school / other public places as pandemic restrictions are eased in-line with local government plans**
- 4. Support for all CEV people to feel safe and continue in their employment by:**
 - a. Empowering employees to know their rights and the means of raising concerns if they are expected to return to a workplace that is not COVID-19 secure;**
 - b. Ensuring employers understand the existing Government support, as well as regulations, that are in place when requiring their employees to return to the workplace**

Key findings

1. **Pressures on, and the redeployment of, the NHS is causing kidney patients' physical and mental health to deteriorate. 56% of patients reported disruption to the way they receive care from the NHS and mental health concerns are just as great as ever.**

Care is still being disrupted

Disruption to care is a key theme across all three surveys. This survey shows:



"[It is] A problem not being able to meet the support team or see my consultant in person. I feel I need that connection on my upcoming journey."

"[I have] Not been seen at any hospital appointments in a year."

"My wife and mum are waiting to find out if [they] can be living donors, all has been delayed."

"A Community Dialysis nurse used to visit at least once every eight weeks. We've had only one face-to-face appointment in the last year."

We recognise and appreciate the concerted effort by all healthcare professionals to support kidney patients throughout the pandemic. However the findings from this survey demonstrate there is much work to be done to restore renal services.

Although 5% of respondents reporting feeling better since the start of the pandemic, nearly four in ten (38%) stated they feel worse than they did a year ago. There is a need to safely restore and resume many of the services kidney patients rely on to feel well; in comments, respondents noted difficulties in contacting GPs, missing the face-to-face contact from their medical team that they had previously, and feeling frustrated that no one is there to hear their concerns. It is essential that kidney patients do not feel they are alone and are able to raise any health concerns to their healthcare professionals.

We know that COVID-19 has slowed the number of life-saving transplants as trusts have cancelled or drastically reduced the number of appointments available. This is being felt and reported by respondents in this survey. We remain very concerned by this, considering the impact on the health of kidney patients, as well as the impact on the rest of the NHS as patients continue to rely on dialysis and other forms of care to keep them well. The backlog on the transplant register continues to grow and restoration of these vital services must be a priority.

Kidney patients still have mental health worries

Many respondents told us that they are still struggling with their mental health as a result of the pandemic.

This survey shows:



"I think about my condition more than I ever have before, and feel far more anxious about it than I ever have before."

"Definitely loneliness and impact on mental health - a feeling of being 'left behind/forgotten'."

"Just generally fear people even family I don't live with."

When asked about the support the NHS provides, 42% said they would like mental health assistance, even once lockdown restrictions have ended. Increased investment in NHS mental health services is urgently needed, to support CEV people immediately to manage and resolve mental health issues and give them the confidence to take part in the same activities as everyone else, including returning to work and school. This needs to include provision for the specialist psychosocial support that is needed by people with a kidney condition, and which cannot always be fully addressed by a generalist counsellor without experience of supporting people with renal conditions.

Kidney Care UK is calling for

- 1. All NHS renal services to be restored to pre-pandemic levels immediately to ensure those who need urgent access to care and kidney transplants can do so safely and quickly to prevent any unnecessary illness or loss of life**
- 2. All kidney patients to be signposted to NHS mental health support services and to be adequately supported with COVID-19 related anxieties and worries to help with the mental toll of the pandemic, such as confusion about guidance, delays and reduction in access to health services, having to shield from the world and the pressure of having to return to work**

2. Kidney patients have significant worries and anxieties about the return to normal life, with just one in ten (11%) looking forward to having the same freedoms as everyone else and many concerned about the return to work and the opening of schools. Just 6% of kidney patients have received both of their COVID-19 vaccinations at the time of asking

As lockdown measures are ending, it is vital CEV people still feel supported, and are presented with clear, concise information about the risk to their health. This survey revealed:

Kidney patients are worried about lockdown measures easing

Kidney Care UK – and the patients we represent – appreciate the need to restart the country and to ensure that people are not required to stay at home and shield for longer than necessary. However there is scepticism and worry among people living with kidney disease about how this will impact on their likelihood of contracting COVID-19. Just 11% of people were looking forward to having the same freedoms as everyone else while, by contrast:

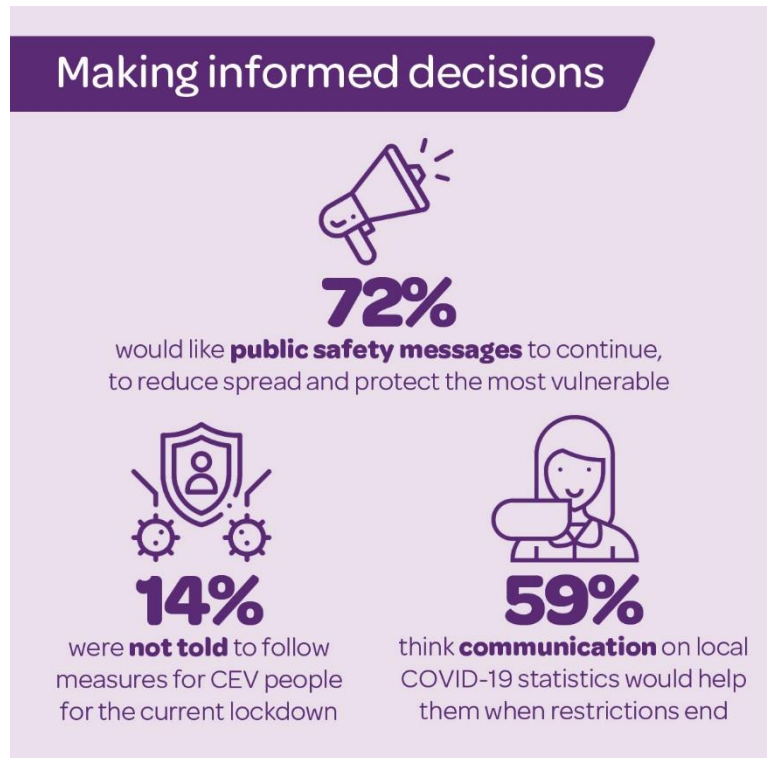


“(There should be advice on) what clinically vulnerable people should do.”

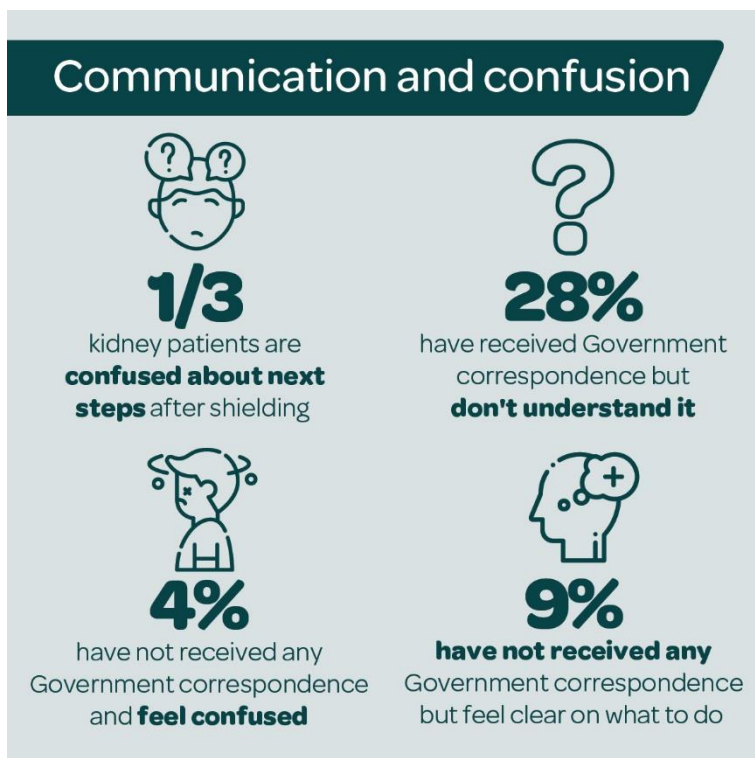
“The Government have not mentioned what the clinically vulnerable people have to do.”

Kidney patients require more help to make informed decisions

CEV people will have to make informed decisions about the risks that they will take once shielding is over, and many reported that they would like to see further communication and information being provided on this front. This encompasses both communication to the general population about how to reduce the spread, and also information to support the safety of CEV people at work. Communications from the NHS and Government need to be delivered in a way that can help to put CEV people at ease and help them to manage the risk of contracting COVID-19, even when levels are falling in the population.



Problems with the timeliness and clarity of Government communications has been an ongoing problem. The current survey found:

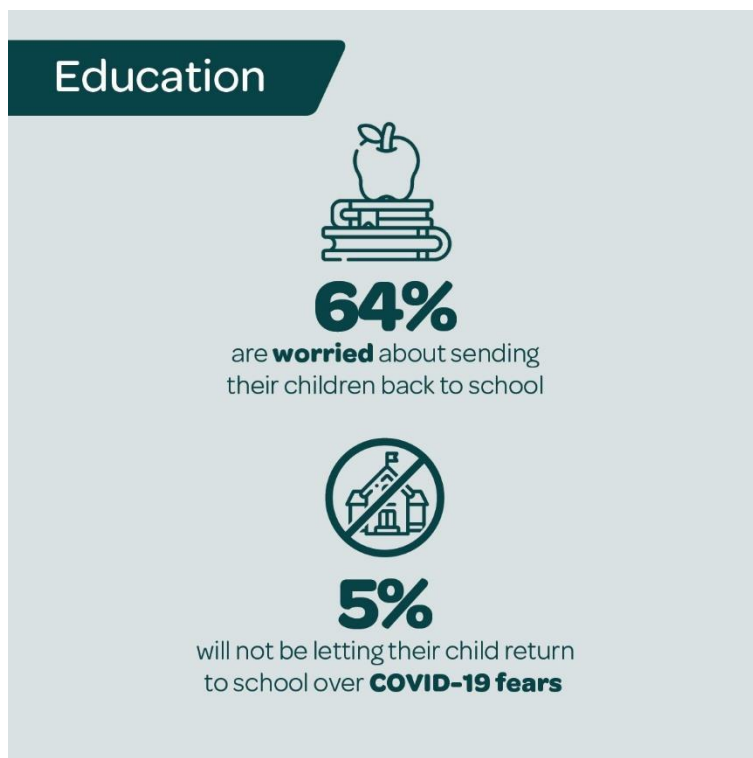


“Educating non-vulnerable people on the importance of safeguarding vulnerable people.”

“Communicate that some people are more vulnerable and maybe support for longer when using the NHS and shopping.”

These data suggest that more still needs to be done to reach all patients (given one in ten had not received any correspondence) and to simplify communications. Overall, 53% of respondents said they felt the Government had been either helpful or very helpful in supporting them, however that means 47% felt unsupported. Improved Government communication, delivered in a clear, concise way to all patients, will be essential in combatting misinformation and confusion and help people make informed choices following the pausing of shielding.

The reopening of schools is making CEV parents feel unsafe



“Not ideal but needs to happen safely.”

“I feel very anxious to be near my child while they attend school. How do I self-isolate away from them if they have been in contact with a child or teacher who has the virus?”

“I feel worried that the restrictions/safety measures in schools are inadequate.”

Returning to schools is another clear area of concern for respondents to the survey. Despite previous calls, there is still no clear-cut answer from Government as to whether it is safe for children of kidney patients to go back to school. Some respondents suggested schools could do more to have discussions with parents who are also patients about the measures they are putting in place.

Despite the public assurances that is safe and necessary for children to return to school, the possibility that children could catch COVID-19 and unknowingly bring it into the household is too much for some. Ensuring all kidney patients, including those who are parents, are vaccinated in a timely manner will increase confidence that returning to school is safe and they are less likely to become seriously ill in the event their child does bring COVID-19 into the home.

Many people living with kidney disease have unanswered questions about vaccination

The survey findings are evidence that there is still significant caution amongst kidney patients about the easing of lockdown measures and ensuring timely vaccinations is an achievable way to reassure them that their safety is still a primary consideration in roadmap and restoration plans. At the time of asking only 9% of respondents had received their second dose. Furthermore, comments indicated that people living with kidney disease have many unanswered questions about vaccination, particularly as to the efficacy of the vaccine for immunosuppressed or immunocompromised people.

While these questions remain unanswered, many people will have understandable anxieties about returning to 'normal' life. As more data are gathered on vaccine efficacy, these need to be analysed and shared to ensure kidney patients and all CEV people are receiving the second dose of the vaccine at a time that ensures maximum response and safety as shielding ends.

While the proportion of patients having had the second dose is small, encouragingly, the vast majority of respondents to our survey have had at least one dose. However, more needs to be done to encourage the remainder to be likewise vaccinated through the continuing provision of clear and reliable information in range of languages and formats.

Importantly, messaging about continuing to shield between doses was not clear; one in ten (10%) of those respondents who have had at least one dose of the vaccine were not told they needed to continue to shield after the first dose, potentially putting themselves at greater risk. While shielding is starting to pause across the UK, it is important that kidney patients receive accurate information about the level of protection offered by the vaccine and choices they can make to keep themselves safe.

Kidney Care UK is calling for the COVID-19 vaccine programme to be accelerated so that all clinically extremely vulnerable (CEV) people have access to their second COVID-19 vaccine quicker than the current 12 week wait time to give CEV people confidence to return to work / school / other public places as pandemic restrictions are eased in-line with local government plans.

“Not having any data telling us how well it [vaccination] works with people on immunosuppressants worries me.”

“I would like to know are transplant patients protected even after 2 doses? And do we continue to shield or live restricted life avoid people family friends indefinitely?”

“Not knowing how much protection I have being immunosuppressed is a worry.”

3. There is still a significant concern for many patients who completed the survey around being required to return to work, once shielding has ended. This has been a concern throughout the three surveys and remains starkly evident.

With the end of shielding imminent, the survey demonstrated that the vast majority of kidney patients do not feel ready for this eventuality. This survey found that:

Many patients are worried about returning to work

Despite increased Government instructions and funding to ensure employers can make all workplaces are COVID secure, many patients are not convinced that their workplace is, or can be made so.



“There is no social distancing in the office, but I have no choice if I want to keep my job.”

“I would like to know if the vaccine has given me immunity (immunosuppressed) or how can I possibly know it’s safe to work in a patient facing role.”

“I am considering leaving my job as my health has deteriorated since lockdown.”

“Make tough laws to stop employer intimidation and threats.”

In addition, many did not feel they would have the choice to remain working at home, despite having done so during lockdown. 60% of respondents said they have been able to work from home during the pandemic, but only a quarter (26%) expected to continue to be able to do so once restriction ease. We would like to see this choice available wherever possible for people at high risk from Covid.

We were especially concerned by comments from respondents reporting threats or intimidation from employers, and by the number of patients who felt they may have no other option than to leave their work. Indeed, we received so many comments around anxiety of returning to the workplace and pressure from employers to return to work early that these have been included verbatim in an appendix.

No one should face intimidation to return to work when it is not safe for them to do so, and especially given the current Government advice remains that people should continue to work from home where possible, and the furlough scheme remaining open until the end of September. Clear communication should also be provided to employers to reinforce their awareness of their obligations under the Equality Act 2010 and the legal duty placed upon them to take steps to ensure all employees are protected from harm – especially those in higher-risk groups.

We also received reports that kidney patients are only being offered Statutory Sickness Pay (SSP), despite the furlough scheme being extended until September and that some people with kidney disease have been disadvantaged when looking for new employment because of their shielding requirements. No one who is shielding to protect themselves or their family should face prejudice when it comes to employment.

Kidney patients require more help to make informed decisions



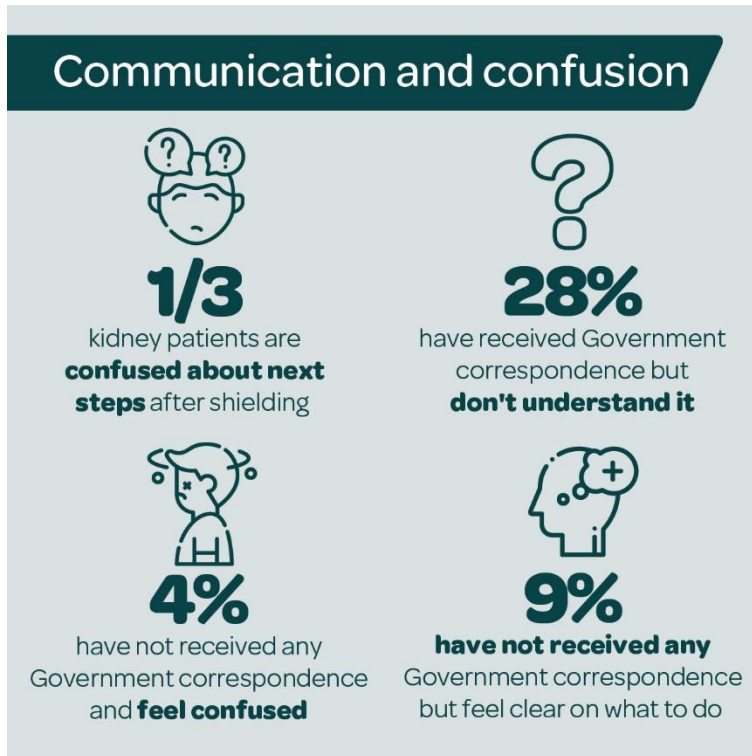
“Educating non-vulnerable people on the importance of safeguarding vulnerable people.”

“Communicate that some people are more vulnerable and maybe support for longer when using the NHS and shopping.”

CEV people will have to make informed decisions about the risks that they will take once shielding is over, and many reported that they would like to see further communication and information being provided on this front. This encompasses both communication to the general population about how to reduce the spread, and also knowledge that CEV people will be safe at work. Communication from the NHS and Government need to be delivered in a way that can help to put CEV people at ease and help them to manage the risk of contracting COVID-19, even when levels are falling in the population.

There is confusion on next steps

A third of kidney patients stated they are confused about what they should be doing, now that shielding is ending. The concerns seemed to come from communication to CEV people with:



"I'm really unsure of what to do post the second vaccine dose ... I can't stay inside for ever"

"(I need) clarification on what happens to CEV people on 31 March"

"(I need) the government to shed more light on CEV people. To address the topic of CEV people and answer CEV questions during TV announcements. It never seems to be addressed"

These data suggest that more still needs to be done to reach all patients (given one in ten had not received any correspondence) and to simplify communications. Overall, 53% of respondents said they felt the Government had been either helpful or very helpful in supporting them, however that means 47% felt unsupported. Improved Government communication, delivered in a clear, concise way to all patients, will be essential in combatting misinformation and confusion, instead kidney patients should be empowered to know their rights when it comes to protecting themselves from unsafe working environments.

Kidney Care UK is calling for support for all CEV people to feel safe and continue in their employment by:

- a. **Empowering employees to know their rights and the means of raising concerns if they are expected to return to a workplace that is not COVID-19 secure;**
- b. **Ensuring employers understand the existing Government support, as well as regulations, that are in place when requiring their employees to return to the workplace**



Methodology

The online survey was open from Wednesday 24 February – Tuesday 16 March 2021. It was advertised on Kidney Care UK social and media networks. The full list of questions is included in the appendix.

343 responses were received. The demographics of respondents were similar to the previous surveys, with a majority of respondents being female (65% vs 34% male), living in England (82%) and describing themselves as White British (93%). More detail is available in the appendix.

Appendix 1: Free text responses

Free text responses to the question: "Do you have any further comments about returning to the workplace?"

Pressure / intimidation from employers

"They are pressuring me to get the first vaccine so I can go back."

"Stop employer intimidation of family members trying to force them back into unsafe work environment when they have been working from home with no problems."

"The shielded ... have (illegally) lost their job due to disability - there should have been better protection and financial help for those of us discriminated against due to our vulnerability to the virus!"

"There is no social distancing in the office, but I have no choice if I want to keep my job."

"My productivity is less working from home, this will affect my employment and I believe will cause future inequality with employers less likely to employ potential shielders."

Worries from people working in the public sector

"I work in a primary school, in a specialist subject classroom. This means every child in school uses this classroom. I feel the risks are far too high for myself to go back, especially as children won't be vaccinated but can still spread the virus."

"Returning to work in school (teaching) so soon after schools reopening and before data is known is a big concern. Medical advice is to stay at home but unable to without formal shielding in place."

"I work in a school, I'm so worried that the general population will not be vaccinated."

"I work in the NHS [and] since the pandemic I have also been diagnosed with cancer so unsure what the future holds."

"I'm terrified as my job is visiting disabled people in their homes and I've not even been in a shop or family members home or my family member's nursing home since March 2021 but will be expected to in total stranger's homes for work."

"How safe is it returning to a hospital for work as a transplant recipient? I guess it's taking a chance, as some of the staff are refusing vaccines and I believe it's their choice."

"Continued help with furlough & with employers for CEV work in highly populated jobs. I.e. teaching staff!"

"I work in a school, I'm so worried that the general population will not be vaccinated."

"I work for different clients so the workplace for me means visiting lots of different council offices and possibly travelling by public transport which is a concern to me."

"I work on adult education. I feel it is not Covid safe."

"My workplace is currently a nightingale hospital."

"Have been off a year as I work in a primary school, I will find it difficult I think when I return."

"I work for the NHS as a frontline member of nursing team expected to return immediately."

"Working in a school I am concerned about the amount of people I will come into contact with."

"[I'm a] Secondary school teacher - some concerns."

Concerns around returning to work after the first dose of the COVID vaccine

"I would like to know if the vaccine has given me immunity (immunosuppressed) or how can I possibly know it's safe to work in a patient facing role."

"Had first injection this week not 100% about going back to work."

"I'm worried, I haven't received my 2nd dose before going back to work."

"I am concerned about returning to work due to not knowing how well the vaccine has worked on me and if my work place will assume I'm protected so will return me to full duties."

"I would prefer to return after having had the second dose of my vaccine."

"Luckily I've always worked from home part of the time not looking forward to return when I feel it still won't be safe even if many have had the vaccine."

General worries / lack of safety measures at work

"Being paid SSP instead of my wage is ridiculous."

"I don't feel totally safe."

"Public Transport may still be a concern."

"Just other people might make it difficult but that is something I'll have to deal with."

"I am considering leaving my job as my health has deteriorated since lockdown."

"When I have to go back to the office etc is all up in the air. Maybe not until June but what if it's still not safe etc."

"I returned to work (June 2020) from home post-transplant (Jan 2020). There has been occupation health contact I've been left to get on and work from home with very little support from employer. They refer you to websites for well-being. There's no assessment of my circumstances going back to work. I wasn't even asked for a fit to work note."

"My job is very close contact and work not following safety guidelines set out by Royal College of Veterinary Surgeons. And one colleague constantly breaking rules/having multiple tests. One colleague has died of covid. Plus my health has severely declined over past year and I don't feel up for the physical and mental toll of the job. I'm scared to return."

"Would like to just carry on working from home."

“The message to the general population is to work from home if you can but if you can't go into work. How is this guidance possibly safe for CEV people?”

“Worried as people think vaccine protects everyone the same but it doesn't if on immunosuppressants and worried that others won't take precautions around me.”

“I do not know whether I should go back to work or not as the government have not mentioned the what the clinically vulnerable people have to do.”

“I work in a large call centre and do not feel safe.”

“Just worried as it gets very busy.”

Appendix 2: 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
Prefer not to say
None of the above, I identify as [open text box]

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 (please specify) [open text box]

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

Chronic Kidney Disease stage 3-4
Chronic Kidney Disease stage 5 (not yet on dialysis)
Acute Kidney Injury
Kidney Cancer
Dialysis at a unit or hospital
Home Haemodialysis
Peritoneal Dialysis
Transplant

Other (please specify) [open text box]

Coronavirus support questions

6. Which of the following best describes you?

I have had two doses of a COVID-19 vaccine

I have had one dose of a COVID-19 vaccine and will have the second dose when I'm contacted

I have had one dose of a COVID-19 vaccine and don't want a second dose

I haven't had a dose of the COVID-19 vaccine but I have an appointment

I haven't had a dose of the COVID-19 vaccine because I haven't been contacted

I have chosen not to have the COVID-19 vaccine

I have chosen not to have the COVID-19 vaccine at this time, but I might consider it in the future

I'm unable to receive the COVID-19 vaccine due to allergies or other health issues

7. Have you been made aware that you should still continue to shield, even after having the first dose of the COVID-19 vaccine?

Yes

No

I'm not sure

8. Were you advised to follow guidance for clinically extremely vulnerable people during the most recent lockdown?

Yes

No

No, but I followed this guidance anyway

9. Is coronavirus affecting the treatment and support you receive from the NHS? Please tick all that apply

No, my treatments have returned to normal

Yes, I still can't have surgery or attend appointments

Yes, my dialysis programme is still altered / reduced

Yes, I am still finding it difficult to get to my dialysis appointments

Yes, I have not been able to have a planned living donation

Yes, my entry to the transplant list has been delayed

Yes, I still haven't been able to have all my blood tests

Yes, I'm still finding it difficult to get advice about any health worries from my GP or hospital team

Yes, other (please specify) [open text box]

10. How else is the coronavirus pandemic affecting you? Please circle 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern

I feel lonely / isolated

I feel anxious and/or I am concerned about my emotional wellbeing

A member of my household has returned to work to avoid losing their income although we do not think it is safe

I am paying more to get food delivered

I am struggling to get medicine delivered

I feel unwell due to cancelled / postponed / delayed treatment

I am struggling financially

Other (please specify) [open text box]

11. How has the COVID-19 pandemic impacted your health?

I feel my health has deteriorated / got worse during the pandemic

I feel better than I did before the pandemic

I feel about the same

I'm not sure

Employment questions

12. What is your employment status?

I am employed by someone else / a company

I am self employed

I am not in employment (skip to question 17)

I have lost my job due to COVID-19 (skip to question 17)

I prefer not to say

13. What is your current working situation?

I am working from home

I am furloughed

I am not able to work from home and I am receiving SSP

I continue to go out to work (**skip to question 15**)

I am not able to work as usual, but I am receiving support through the Self Employment Income Support Scheme

I prefer not to say

Other (please specify) [open text box]

14. Will you be expected to return to your usual workplace once this shielding period ends?

Yes

No (**skip to question 17**)

I'm not sure

I prefer not to say

15. Which statement best describes your feelings about returning to work once shielding has ended?

I feel OK about returning to my usual workplace

I feel concerned about going back to my usual workplace, but I have to anyway

I feel concerned about going back to my usual workplace, and will not return even if it means I lose my job

I want to go back to work but my employer won't allow me to because of my risk from COVID-19

16. Do you have any other comments about returning to the workplace?

Education

17. Do you have school-age children?

Yes

No (**skip to question 20**)

18. How do you feel about schools reopening?

I feel reassured that it's safe because of the safety measures (testing / social distancing etc)

I feel worried but my children will return to school anyway

I feel very worried and won't be sending / haven't sent my children back to school

19. Do you have any comments about children returning to school?

Government support

20. How well do you think the Government have protected clinically extremely vulnerable people? 1 – 5 star rating:

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

21. How well do you think the Government have communicated current guidance for clinically extremely vulnerable people?

I received correspondence and I understand what I am being advised to do

I received correspondence, but I'm confused around the plans for clinically extremely vulnerable people now we're easing restrictions

I didn't receive correspondence, but I understand what I am being advised to do

I didn't receive correspondence and I don't understand what I am being advised to do now

22. What ongoing support would you like from the Government / NHS in the short term as the COVID-19 outbreak continues?

Tighter / longer lockdown measures if cases rise

Delays to your country's roadmap to ease current COVID-19 restrictions

Longer / more shielding periods if cases rise

Help with shopping, e.g. access to online priority delivery / volunteer support

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) [open text box]

23. Which of the following describes your thoughts on your country's roadmap to ease current COVID-19 restrictions?

- I'm ready to have the same freedom as everyone else and begin to mix with other people again
- I'm looking forward to mixing with other people again, but I'm worried that the restrictions may be lifted too fast
- I will be limiting my contact with other people as much as possible but agree with the timetable overall
- I think shielding should remain in place for clinically extremely vulnerable people until they have all had 2 doses of the COVID-19 vaccine
- I think the current COVID-19 restrictions (i.e. national lockdowns) should have remained in place until the majority of all adults in the UK have had two doses of the COVID-19 vaccine
- I don't know
- I'm not aware of the plans

24. What ongoing support would you like from the Government / NHS to allow you to return to normal life, once it is safe to do so?

- Peer support to help with common worries / anxieties
- Professional mental health support to help reduce worry / anxiety
- Ongoing access to NHS Volunteers for help with shopping, until it's safe to go to the shops
- Continued public messages about the need for the whole population to reduce spread
- Ongoing public safety measures in indoor places, e.g. hand sanitizer, one-way systems, face masks etc
- Communication on local COVID-19 statistics, e.g. number of cases / fatalities
- Other (please specify) [open text box]

COVID-19 assistance

25. Do you think you've had coronavirus symptoms?

- Yes, and I have been tested and received a positive test
- Yes, and I have been tested but it came back negative
- Yes, but I have not been tested
- No, I haven't had symptoms
- Not sure

26. 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
- I have received support from a Kidney Care UK Advocacy Officer or Counsellor

27. Did you find Kidney Care UK information helpful?

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



28. What more COVID-19 information would you have liked from Kidney Care UK?

Mental health support

Dietary advice

Exercise support

Details of how to contact support services

Employment support

Signpost to sources of further information (e.g. money advice service or Government support)

Other (please specify) [open text box]

Appendix 3: Demographics of respondents

- 221 respondents were female (65%). 117 respondents were male (34%), with 2 non-binary, 0 other and 0 preferring not to say.

- The age brackets of respondents were as follows:

Age	Number of respondents	Percentage of respondents
0 – 15	4	1%
16 – 30	30	9%
31 – 45	81	24%
46 – 60	136	40%
61 – 75	73	21%
75+	17	5%

- Respondents' country of residence was as follows:

Country of residence	Number of respondents	Percentage of respondents
England	279	82%
Scotland	19	6%
Northern Ireland	29	9%
Wales	13	4%

- Respondents reported their ethnicity as follows:

Ethnicity	Number of respondents	Percentage of respondents
White/ White British	316	93%
Black / African / Caribbean / Black British	5	2%
Asian / Asian British	8	2%
Mixed / Multiple ethnic groups	3	1%
Prefer not to say	5	2%
Other	3	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	51	15%
Chronic Kidney Disease stage 5	26	8%
Acute kidney injury (AKI)	4	1%
Kidney Cancer	7	2%
Dialysis at a unit or hospital	25	7%
Home Haemodialysis	14	4%
Peritoneal Dialysis	17	5%
Transplant	213	63%
Other	25	7%

- The most commonly reported condition/treatment was kidney transplant (63%)
 - 16% of respondents were currently on dialysis.
- Nearly three quarters of respondents (74%) reported that they had not had symptoms of COVID-19. When asked if they thought they had had coronavirus symptoms, the respondents to this question answered:

Symptoms of coronavirus	Number of respondents	Percentage of respondents
Yes, and I received a positive test	13	4%
Yes, but I received a negative test	33	11%
Yes, but I've not been tested	16	5%
No, I haven't had symptoms	230	74%
Not sure	21	7%