



Coronavirus Survey - Interim Report

Liverpool residents' experiences of health, social care, and wellbeing during the Coronavirus pandemic

May 13 2020 - August 30 2020

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Background

Throughout the early months of 2020, COVID-19 (commonly known as Coronavirus) spread across a significant number of countries globally, and has emerged as a major new disease and health issue. The spread of COVID-19 in the UK became increasingly prevalent in March 2020. Throughout March 2020 the UK government and the NHS announced a number of measures to reduce the spread of the virus and create more capacity in the NHS to treat people with COVID-19. These measures included postponing pre-planned, non-emergency surgeries to increase bed space in hospitals; asking retired NHS staff and final-year medical students to join the NHS workforce; advising elderly people, and those with long-term health conditions to self-isolate for 12 weeks to reduce their risk of contracting the virus; and imposing a 'lockdown' across the country, under which people would be encouraged to stay home and only leave their home to go to work, obtain food or medication, seek healthcare, or provide care to a vulnerable person. Some of these restrictions were eased in Summer 2020, although a second-wave of infections has seen some restrictions re-imposed both locally and then on a national scale, with Liverpool moving into 'Tier 3' local restrictions on October 14th and England re-entering a national lockdown on November 2nd.

At Healthwatch Liverpool, we were aware that COVID-19 could have a potentially significant impact on local people's health, wellbeing, and access to health and care services, particularly after the UK government announced its 'lockdown' on March 23rd. We launched an online survey, hosted on our website, to obtain people's feedback. We received a significant number of responses, which confirmed the significant impact of COVID-19 on people's mental health, health care, and social care. This report looks at the survey responses we received between May 12th and August 30th, when this survey closed. An earlier report, [available on our website](#), looks at responses between April 1st and May 12th. Following the closure of our initial survey we launched a second survey on September 1st with more detailed/focused questions, largely informed by the public's responses to the first survey, and we will continue to publish reports summarizing the feedback we receive.

We would like to thank everyone who has responded so far for their openness in sharing their experiences with us during these difficult and unprecedented times.

Where we've used your feedback

We've used your responses to our COVID-19 survey to feed into how the health and social care sector is responding to the pandemic both locally and nationally.

Nationally, we've contributed to evidence provided by Healthwatch England on cancer, mental health, and maternity service provision during the pandemic to an enquiry organized by the UK Parliament Health and Social Care Select Committee. You can read that evidence online, on the [UK Parliament website](#).

Locally, we've provided information to individual NHS trusts to give them both a general overview of the information we're receiving from patients locally, and also to let them know anonymised feedback about their own services.

We have also provided information to Liverpool's Clinical Commissioning Group (CCG), who plan the type of health services provided locally. Our CEO has reported on our survey to the CCG Governing Body. Additionally, when we saw the number of respondents discussing the negative impact the pandemic was having on their mental health, we sent a summary of this feedback to the mental health service commissioners at Liverpool CCG to make sure they were aware of it. We have also shared this feedback with Liverpool's Mental Health Strategy Steering Group.

We have also fed in to the city's Health and Social Care recovery group. This is a senior group with representatives from Liverpool City Council, Liverpool CCG, Public Health, and the University of Liverpool who meet regularly and can ensure that public feedback shapes the response of health and social care services locally, as they deal with the ongoing effects of the pandemic and begin to return to normal.

Methodology

The survey asked eight questions, in addition to demographic information.

- Have you had coronavirus / COVID-19?
- If you think you may have had coronavirus / COVID-19, did you seek medical advice or care whilst you had symptoms?
- Have you found it easy to find clear and understandable information about what to do to keep yourself and others safe during the coronavirus/COVID-19 pandemic?
- Has your mental health and wellbeing been affected by the coronavirus/COVID-19 pandemic?
- Has your healthcare for other conditions been affected by the coronavirus/COVID-19 pandemic?
- Has your experience of social care been affected by the coronavirus/COVID-19 pandemic?
- Has anything helped you cope day-to-day during the pandemic? Would you like to tell us more about this?

- Is there any other way that you feel your health, care, or wellbeing has been affected by the coronavirus/COVID-19 pandemic that you would like to tell us about?

Participants could answer 'yes', 'no', or 'not applicable' to most questions, and the majority of questions were accompanied by a free text response in which participants were asked to provide further details of their experiences.

We chose to use free text responses to collect information as we launched our survey in the early days of lockdown and were unsure how events would unfold, and how they would affect people in Liverpool. We therefore wanted to give people the space and opportunity to let us know about whatever impacts to their health and care they were experiencing. Collecting data mostly through free-text responses has provided us with a very broad range of information, and has demonstrated how deeply this pandemic has affected the lives of local residents and their families.

The survey was hosted on the Healthwatch Liverpool website. It was promoted through the Healthwatch Liverpool membership newsletter; via social media websites including Facebook, Twitter, and Next Door; through Liverpool City Council, and through contacts we have established with local voluntary sector organisations and community groups.

For the analysis of results, we removed responses from people who provided a non-Liverpool postcode, and we have passed these responses on to the relevant local Healthwatch for their area. Some responses were duplicates, and we also removed these prior to our analysis. This left 194 valid responses for the period from 13th May to August 31st, when we closed this survey. We have published a separate summary for responses we received between April 1st, when this survey opened, and May 12th (see details above).

A team of Healthwatch Liverpool staff worked together to add tags to all of the responses received. Questions on mental health, healthcare, and social care were tagged 'positive', 'negative', or 'mixed' based on comments left in free text boxes, or 'neutral' where a free text box was left empty.. Responses were also tagged with 'themes' that were mentioned within the free text responses, for example, 'cancelled appointments', 'depression', 'dental care', 'shielding'. Once responses had been tagged, they were collated and merged into a single data set. We then used these tags to analyse the response data, going back to the full free text responses to find illustrative quotes to include in the report.

Analysis of Responses

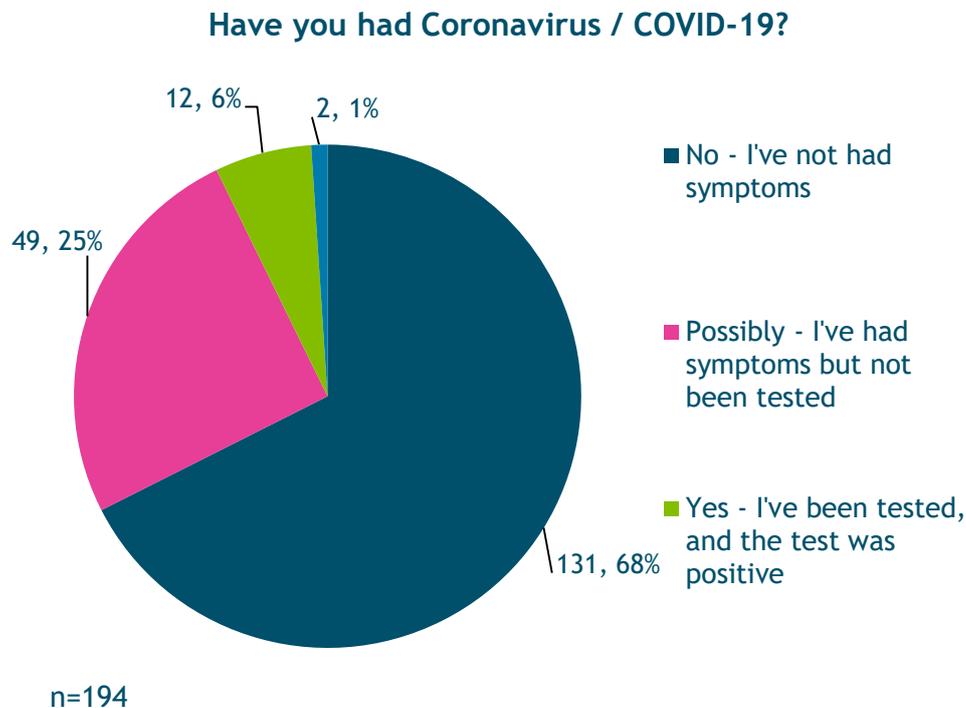
We received 194 responses to our survey from people living in a Liverpool postcode between May 12th and August 31st, when the survey closed.

Have you had Coronavirus / COVID-19?

Participants had the option to respond 'No'; 'Possibly - I've had symptoms, but not been tested'; 'Possibly - I've had symptoms, but my test was inconclusive'; or 'Yes - I've been tested'. 194 people answered this question.

131 people (68%) said that they had not had symptoms. 49 (25%) said that they had symptoms, but had not been tested, and 14 people (7%) said that they had been tested. Of these, 12 had tested positive, and two had an inconclusive or negative test. Compared to responses we received between April 1st and May 12th, slightly fewer people told us they had not have Coronavirus/COVID-19.

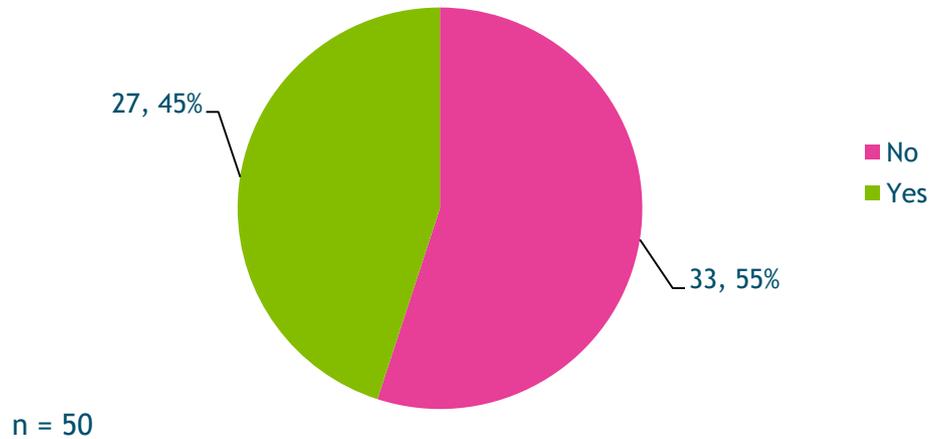
Compared to the first batch of results, between April 1st - May 12th, more people said they had been tested for Coronavirus/COVID-19. As testing for COVID-19 became more accessible over the summer, we added an additional option for people to say they been tested, but the test had come back with an inconclusive result.



If you think you may have had coronavirus / COVID-19, did you seek medical advice or care whilst you had symptoms?

If people said that they 'possibly' had coronavirus, or had been tested, they were asked an additional question about whether or not they sought medical advice or care whilst they had symptoms. They could select 'yes' or 'no' to this question, and there was a free text response for them to provide more information about their experiences.

If you think you may have had coronavirus / COVID-19, did you seek medical advice or care whilst you had symptoms?



50 people answered this question. 33 people (55%) said they did not seek medical treatment whilst they had COVID-19 symptoms, and 27 people (45%) said they had.

Some people who said they did not seek medical advice or care said they did not think their symptoms were serious enough to require medical attention, or were not severe enough to be treated in hospital.

“I understood that unless my symptoms became serious (i.e. affecting my breathing), there was no need to seek medical advice.”

“As temperature was never over 40 degrees ... I felt it was not worth contacting anyone or going to A&E as from what I heard from others plus news it appeared unless you had temp over 40c even if you had difficulty breathing you would be sent home - a friends daughter had this happen.”

Other people said they were concerned about catching COVID-19 in hospital, and would rather manage their symptoms at home.

“I stayed active and hydrated and ... kept track of my temperature regularly. I'm fearful of attending hospital as it would be a strong place to develop covid if I had something other than covid, so I treated at home.”

Others thought they may have had COVID-19 in the early weeks of the outbreak, but did not realise it at the time, as they experienced symptoms that were identified further into the pandemic, such as loss of smell or taste.

We also began to receive more feedback about COVID-19 testing in this period. Most of the feedback we had about testing was from people who had experienced difficulty accessing a test.

“Partner had symptoms, rang 111 was told to isolate etc. I then got it. I tried to order an online test but the website didn't work. I tried to order a drive through test (from Liverpool) and was told the nearest test was in Haydock or Manchester. Absolutely useless.”

“I followed instructions to order an at-home test - put my details into a form on gov.uk, including my NI and NHS numbers, and was told that I'm unable to get an at-home test because my identity cannot be "verified" by their external identity check service ... I'm not sure how or why I failed this identity check, and I'm concerned that this would place additional barriers to testing for people who are more vulnerable.”

People who did seek medical advice or care for possible COVID-19 symptoms told us they sought help from a number of places, including their GP, NHS 111, and 999. People who contacted NHS 111 or a GP told us that they were generally advised to rest, self-isolate, and to call back if their symptoms deteriorated. Those who called 999 told us they did so because their symptoms were very severe.

People generally reported having a more positive experience seeking help from their GP than NHS 111. This echoed feedback we received in our survey prior to May 12th.

“I rang NHS 111 but because I didn't have a cough or temperature they said there was nothing they could do for me. I rang my doctors surgery and was advised to ring 111 again which I did. Again I was told if I wasn't gasping for breath then there was nothing they could do. I finally got a GP from my surgery to give me a telephone consultation. He prescribed antibiotics for me.”

“Phone consultations with GP. Was really helpful and put my mind at ease.”

“I was advised to shield and tell 111 if I had symptoms, which I did. It was on day 7 that I needed advice again as breathing became effected ... had to wait for call back but after 3hrs still no call back and when we rang back they had no details of me previously calling. Felt I wasn't assessed daily either as steroids were prescribed with antibiotics but I still deteriorated. I ended up being rushed to hospital two days later where I remained for 8 days.”

Some people, who did not need to be hospitalized but were still badly affected by COVID, reported some confusion in being referred for treatment.

“Had several telephone calls with GP over five weeks to assess my symptoms. All were very supportive but initially there was a real confusion as to procedure (GP wanted me to have ECG due to chest pain but after discussion with colleagues, instructed me to drive to Royal with friends in separate car. Friends would then go into A&E and inform staff I was outside in car with potential coronavirus symptoms and in need of ECG. My

father, who is also a GP, telephoned the Royal and they instructed us to call an ambulance instead).”

We heard from some people with young families who told us that seeking care and support whilst suffering from COVID-19 had been an additional struggle.

“We tried to follow NHS guidelines and always followed official sites. However, we found it difficult to access help - a consultation with our GP or some other health advisor would have been better. We all developed symptoms, including our children: 5 and 6 months old ... Upon phoning 111 we were left to deal with it on our own: only phone when you feel you cannot cope. We did and we were told not to go to hospital and not to phone an ambulance ... We would have liked some form of support from GP or NHS/hospitals.”

We also heard from a number of people who were suffering with long-term symptoms of COVID-19. Some of these people were not hospitalised when they first contracted COVID-19. Others were initially hospitalized, and as well as managing their physical recovery were still dealing with the impact of having been seriously ill in hospital. As well as the physical impact of COVID-19, it is clear that there can be a strong mental health impact felt by people who have suffered from the virus.

“Ten weeks on, I am now chronically fatigued and still suffering an array of bizarre symptoms. I have had no advice on how to deal with this 'Long Tail' of Coronavirus from GPs, 111 or the hospital. I am relying on Facebook support groups ... and the internet for advice on how to cope.”

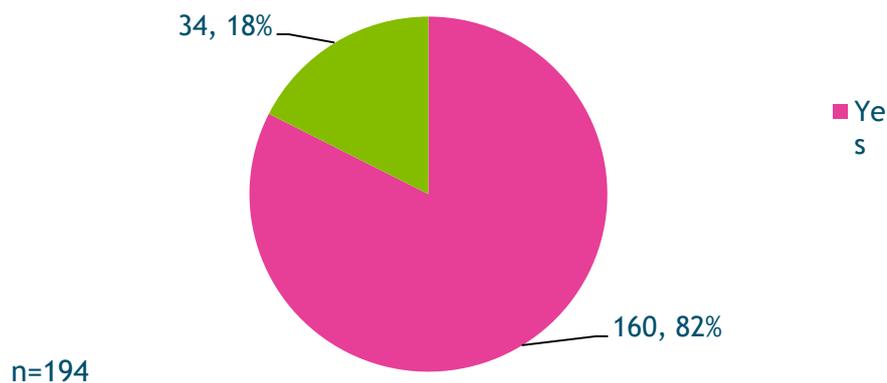
“Had a follow up x-ray which showed lung damage which wasn't there 4 weeks earlier at the time of my A&E visit. Have since been referred for a respiratory consultant at Heart and Chest Hospital and a neurologist at Walton Centre for ongoing symptoms/consequences. At first the message was that covid was mild for most people and should be over in a couple of weeks at home. For many people that isn't the case and that message is really unhelpful ... I hope that as understanding of the illness increases, people affected in any future waves will have better information and care rather than figuring out what helps and what doesn't by trial and error.”

“I was so seriously ill in hospital ... the reality that the severity of critical care intervening in my care is something I just cannot deal with mentally. I am knowingly putting it to the back of my head and not dealing with it ... the thought of lockdown ending is giving me such anxiety.”

Have you found it easy to find clear and understandable information about what to do to keep yourself and others safe during the coronavirus/COVID-19 pandemic?

194 people answered this question. 160 people (82%) said they found it easy to find clear and understandable information about how to keep themselves safe during the pandemic. 34 people (18%) said they had not found it easy to find clear and understandable information about this. Slightly more people said they found it harder to find clear and understandable information compared to responses we received between April 1st and May 12th, when 14% of people told us they had not been able to find clear and understandable information. There was also a free text response for respondents to provide more information about their experiences.

Have you found it easy to find clear and understandable information about what to do to keep yourself and others safe during the coronavirus/COVID-19 pandemic?



Most respondents were able to easily access information and advice. The most common sources for information and advice have been: TV, Radio, and Newspapers; Social Media; Official websites (NHS Online, gov.uk, Liverpool City Council website, and GP Practice Websites); shielding letters or other contact from healthcare professionals; and other websites and online content. The majority of respondents accessed information from multiple sources.

“News & internet. Although some information is confusing and some circumstances are more complicated than others. I found applying common sense & caution about advice was the best thing to do.”

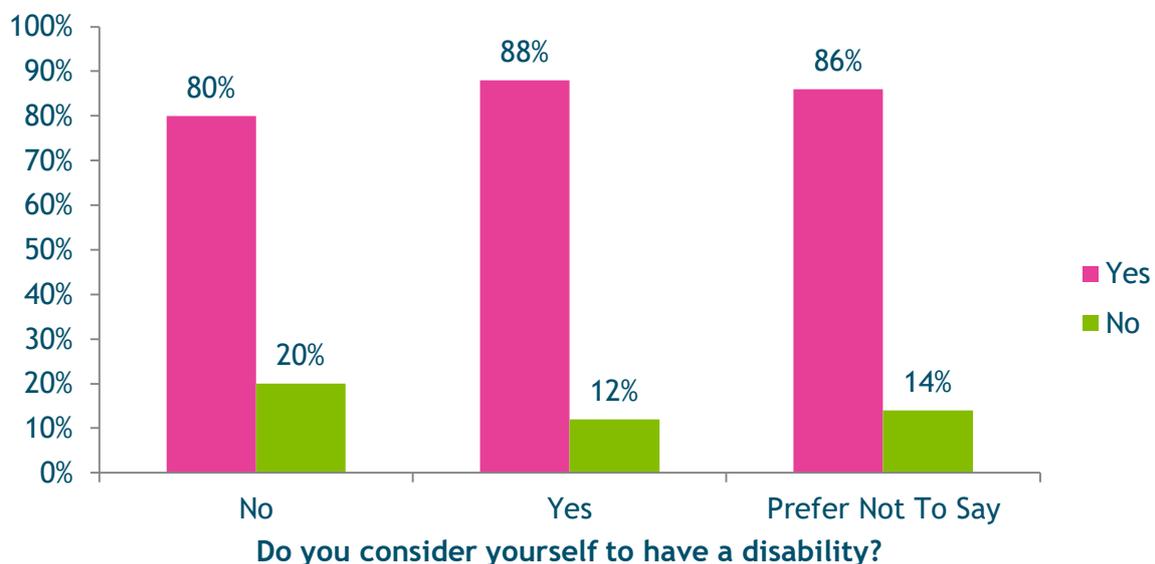
“We have had information from the GP, Government and NHS as I am classed as a vulnerable patient.”

Whilst the majority of people said that it had been easy for them to find clear information, frequent changes to advice were a cause of confusion for some.

“The information has become less clear as time has gone on through. At the time of completing this (early June), I'm feeling pretty confused about what is and isn't safe.”

Respondents who did not find it easy to find clear and understandable information were more likely to have a disability. People with existing chronic health conditions told us that they had difficulty finding information that was relevant to their circumstances.

Have you found it easy to find clear and understandable information about what to do to keep yourself and others safe during the coronavirus/COVID-19 pandemic?



“I have found it hard to find clear advice on how much I should avoid social contact as a person with asthma ... The only information for people with health conditions is on a vague government advice page on their official website which state asthmatics are high risk and should take 'extra care', but I haven't had any communication from my GP or the government.”

“I am isolating and not understanding whether I can go out for safe exercise. My consultant said she would get back to me but hasn't.”

We also heard from people who were caring for vulnerable and shielding family members who had difficulty finding clear information on what they should do to help keep their family members safe.

“Advice about shielding is not clear. I care for my elderly father with the support of a care package, I have to go to work but I'm unsure as to whether I should be working.”

We also heard from others about how some confusion around information has been linked to different interpretations of advice by employers.

“The information which the government advises and how my employer interprets it are both conflicting.”

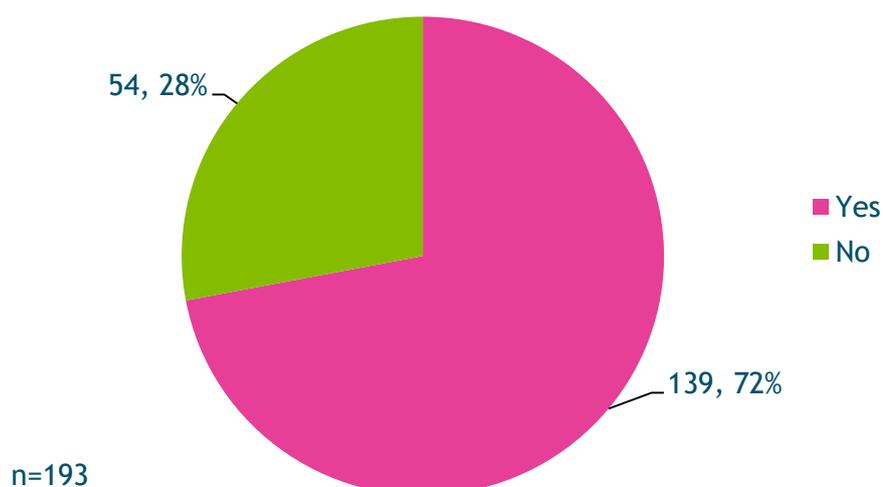
Others told us that they felt information was also unclear and difficult to understand for those with English as a second language, or without strong English-language skills.

“Although I found the information provided clear and understandable I don't think my parents who speak broken English would if I wasn't about to translate in better detail. I just worry for those that don't have that support.”

Has your mental health and wellbeing been affected by the coronavirus/COVID-19 pandemic?

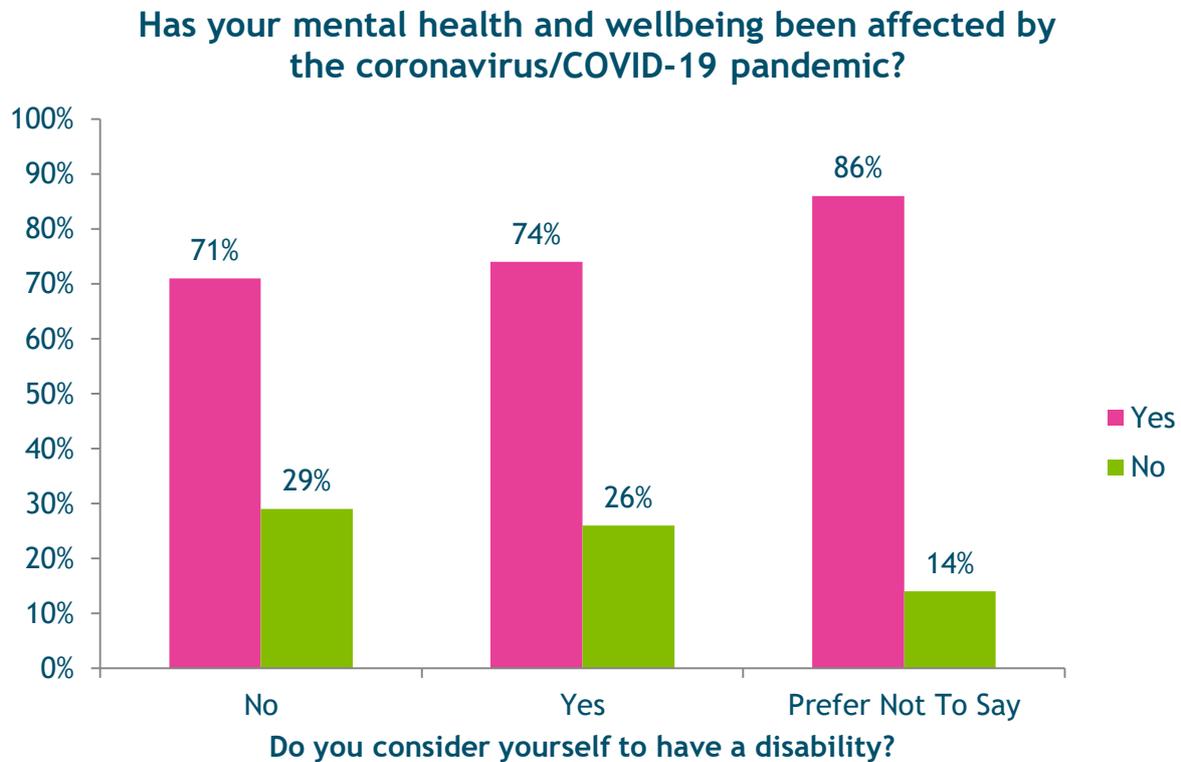
193 people answered this question. 139 people (72%) said their mental health had been affected by the pandemic. 54 people (28%) said it had not. This was similar to the responses we received between April 1st and May 12th, where 70% of respondents said their mental health had been affected, and 30% said it had not.

Has your mental health and wellbeing been affected by the coronavirus/COVID-19 pandemic



We also found that respondents who said they had a disability were slightly more likely to say their mental health had been affected by the pandemic than those

without a disability. The proportion of people who said they had a disability and that their mental health had been affected by the pandemic was lower than for initial responses we received between April 1st and May 12th, when 82% of people with a disability said their mental health had been affected compared to 74% for responses after May 12th.



Some people who said their mental health had not been affected used the adjoining free text box to talk about the coping mechanisms they used to manage their mental health during the pandemic.

“A friend and myself have phoned daily ... Set myself tasks daily including painting fencing. Learned to shop online. Spent lots of time in the garden. Attended church online.”

“I have kept myself busy with hobbies & exercise. I have access to a small but private outdoor space.”

Others told us that, while they found some aspects of the pandemic difficult, they did not consider the impact on their mental health to be significant.

“Already on sertraline, been fine, a couple of wobbles but so has everyone I guess.”

A small number of people told us that the pandemic had a positive impact on their mental health. People who felt their mental health had been positively affected said they had been able to find a better work-life balance during the pandemic.

“Working from home has given me back some work life balance that I was missing before. I have been able to spend more time taking care of my physical, emotional and mental health.”

However, the majority of respondents said that the impact on their mental health had been negative. The most common negative mental health impact on people was increased anxiety, which was mentioned by 62 respondents.

“In the early stages and at the beginning of lock down I was very anxious. I’ve been working from home and the thought of going back to work makes me very nervous.”

“I am scared of getting the virus as a simple cold can cause me having to go into hospital for treatment ... My anxiety etc is increased horrendously.”

Isolation was an issue that was a number of people reported, particularly those who lived alone. A number of people also told us they found it difficult or distressing to be unable to see family members and loved ones for a long period of time.

“I have found it difficult because I am unable to see my parents as they are both in the vulnerable category, my mum is struggling and I find it hard to see her so upset.”

“As a nurse, I was very worried about face to face contact with known covid positive patients, well any patient really. At the beginning we did not have adequate PPE. I live alone and felt very sad and isolated from my family and friends. I cried at least once every day and still feel very emotional. The loss of peoples lives is overwhelming. I miss my family and my social life and I miss going to church on Sundays.”

We received feedback from a number of carers, who told us about the mental health impacts of providing care for loved ones during the pandemic. A number of carers told us that, as well as worrying about the health of their loved ones, other support they received has decreased and that an inability to take respite breaks had a strong impact on their mental health.

“I am a carer for my partner who has a progressive terminal illness. This virus has put more pressure on an already vulnerable situation. I had to fight to get my partner a shielding status, which has taken 8 weeks ... Just feel like I have been left to get on with it.”

“Stress caring for a 90 year old vulnerable person with heart failure and depression who wakes during the night ... Had some phone support asking how we were coping. What can you say as there are many other people in a worse situation.”

“I usually have school, support workers and therapy for my two boys who have ASD, LD and ADHD. They struggle to regulate their emotions and therefore are taking pretty much every bit of my time to support them. I'm not getting any rest time.”

A number of people with existing mental health conditions told us they had been exacerbated or become harder to cope with during the pandemic. While some respondents told us they had received support for dealing with their mental health condition during the pandemic, others told us they were unable to access support.

“I already have a mental health condition and the situation has exacerbated it. I've felt heightened anxiety, low mood and paranoia. I have received lots of support from my CMHT and work.”

“I have a panic disorder that I've been managing myself at home, but I have definitely had a lot more panic attacks during the pandemic, and that has also been really draining.”

“About 4 weeks ago I called the crisis team who said they would email my shrink and that's the last I heard!!”

“I have existing anxiety, eating disorder and PTSD. Anxiety and eating disorder symptoms have worsened during the pandemic. I am on waiting list to receive trauma based CBT for PTSD and am very worried about any delay to treatment as a result of pandemic.”

While some respondents told us that remote access to therapy or counselling had helped them, others also told us that moving to remote support for mental health issues had not been suitable for them.

“Was under a short talking therapy. Had two sessions left. Was told over a month after my appointments where postponed that I had to have a phone consultation or had to get referred again when everything's all over. I have autism so can't do phone consultations.”

“I had also just begun a course of counselling for severe depression and anxiety, this went from face to face, to phone and it was not a good experience for me, putting my progress back quite significantly.”

“I also take a counselling course with Talk Liverpool to learn more about managing my anxiety and mental health which is especially applicable during this time.”

We have also heard from a number of people who have been affected by bereavement during the pandemic, both as a result of COVID-19 and from other causes. People told us that being unable to attend funerals or grieve with loved ones had an impact on their mental health.

'My Uncle died of Covid-19, we could not comfort our mother or attend his funeral, this has been very difficult to deal with...'

"My father died and I was on a COVID -19 ward with him when he died so I needed to isolate for 2 weeks, living alone meant I needed to rely on neighbours to bring me shopping. It was also difficult for friends and family to support me with this loss. It was surreal attending his funeral."

"My mother died of Covid19 and my best friend died of a non covid related death so experiencing grief as well as being a key worker working with people dying all around me"

We also heard from people who had been unwell with COVID-19, including some people who were suffering from long-term symptoms of the virus, about this impact this has had on their mental health. Coping with sudden changes to their lifestyles and general health, inability to use previous coping-mechanisms, and a lack of medical or social support were cited as having a detrimental impact on the mental health of people who had been unwell with COVID-19.

"I'm now largely housebound due to ongoing post Covid consequences. Most of my usual wellbeing enhancing activities I've had to stop. I used to be very active but now can only walk in about a 5 minute radius around my home. This has had a major impact on my feeling of wellbeing. I generally only see other people online. The longer my health problems go on the less optimistic I feel about making a full recovery. I'm in contact with lots of other people affected by long term Covid consequences. Many of those have been even more severely affected. And I'm often talking to people who feel suicidal. This can be very draining and also takes a toll on my own wellbeing."

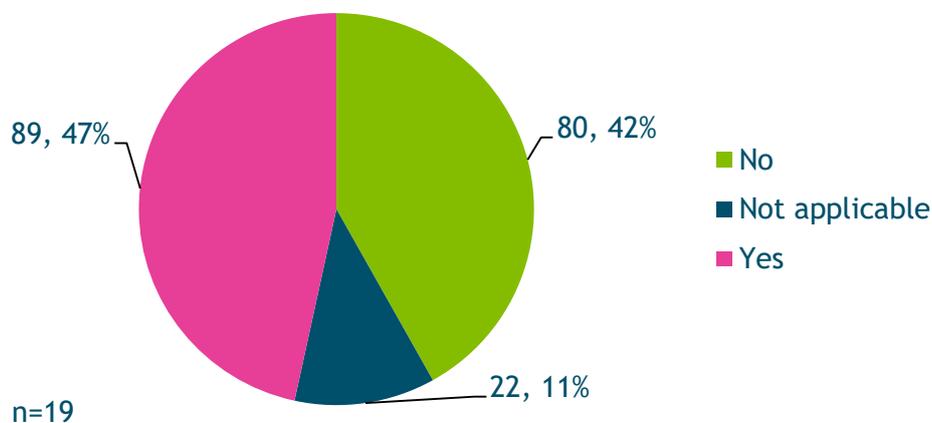
"I am now suffering a great deal from the fear that I'm suffering from a mystery disease with no end in sight. I was suffering anxiety to such a degree that I have had to go onto SSRI medication. I now suffer from suicidal thoughts. I'm living an extremely reduced life due to STILL suffering from the Covid-19 long tail, over ten weeks in. I'm unable to do any exercise at all because if I exercise it sets me back and grounds me with fatigue - so I can't manage anxiety or depression the way I usually would. I'm feeling hopeless about the future - worried that I might have ME / CFS for the rest of my life. I've lost my livelihood and my home and I've had to move back in with my parents at the age of 38 as I can't care for myself anymore."

"I was discharged from hospital with no aftercare, no call from anyone to check up, no advice given for recovery. Nothing. Being a relatively active person the struggle between my mind and body remains today 9 weeks after discharge."

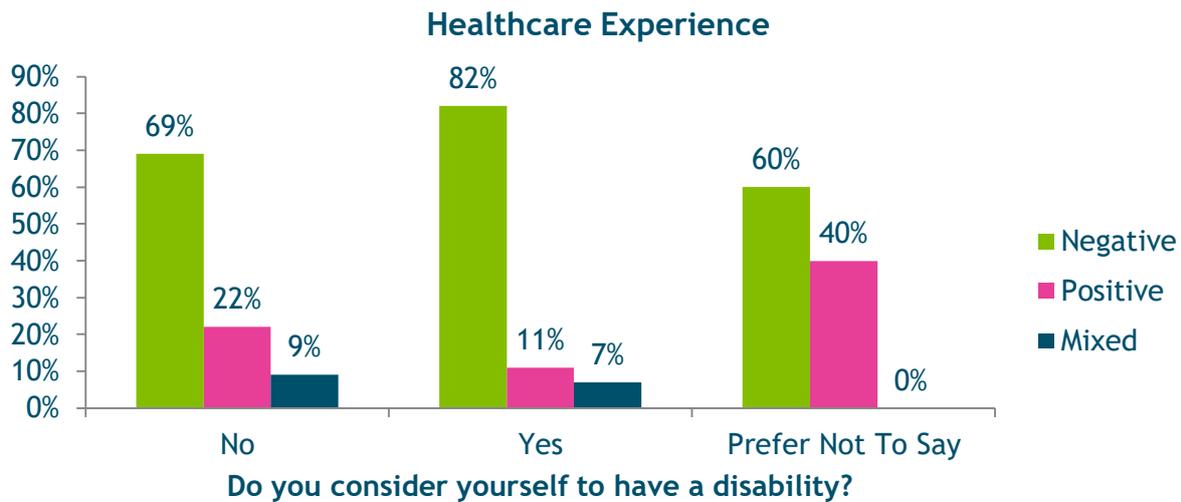
Has your healthcare for other conditions been affected by the coronavirus/COVID-19 pandemic?

191 people responded to this question. 22 people (11%) answered 'N/A'. 89 people (47%) said that their healthcare for other conditions had been affected. 80 people (42%) said their healthcare for other conditions had not been affected. This was different to the responses we received between April 1st and May 12th, where 53% of respondents told us their healthcare for other conditions had been affected, and 35% of people said their healthcare for other conditions had not been affected.

Has your healthcare for other conditions been affected by the coronavirus/COVID-19 pandemic?



There was also a free text response for respondents to provide more information about their experiences. We used people's responses in the free text box to classify whether the impact on their mental health had been positive, mixed, or negative. The majority of respondents reported a negative impact on their healthcare for other conditions. People who did not write anything in the free text box, but who answered 'yes' to indicate their healthcare had been impacted were recorded as 'neutral'. People who reported that they had a disability were more likely to report that their healthcare had been negatively affected by the pandemic.



A number of people who said their healthcare had not been affected said that they had still been able to obtain prescription medication online, or that were still able to access appointments with both GPs and hospital clinics either remotely, or face-to-face where appropriate and necessary. People who said their healthcare had not been affected by the pandemic, but who still wrote about obtaining prescriptions online or accessing appointments remotely were more likely to talk about their healthcare during the pandemic in positive terms.

“I was diagnosed with cancer in April, managed to have operation in May, then second operation in June and I am still receiving regular treatment at present the NHS consultants, nurses and all staff have been exceptional.”

“My GP has been doing my repeat prescription every month as normal, I've arranged to have them delivered. Dr rang me at home to give me a prescription for a nasty chest infection I have and was lovely to me over the phone, I was able to get prescription same day.”

Some people who told us that the way they accessed their healthcare had changed were positive about how these changes had been made and how they were still able to access care.

“I needed a prescription from a family planning clinic and was worried about not being able to go to the clinic or to collect it. I called the clinic and a lovely nurse did a triage over the phone then assured me she'd send my prescription by post - it arrived a few days later with a nice handwritten note. She also asked me if it was ok to send it to my address and if I was safe at home or experiencing any form of domestic violence. I really appreciated her going the extra mile, such a great service and a lovely person.”

“I have ongoing medical conditions. I've been able to access my GP and a hospital consultant remotely, which has enabled me to effectively manage my conditions throughout the pandemic.”

However, not every respondent had a positive experience of accessing appointments remotely. Some told us they felt that a remote appointment was inappropriate for the type of care they were receiving, or that promised telephone appointments has not taken place.

“I have had a telephone appointment and will have another in December but this is not as satisfactory as a face to face consultation. The telephone consultation was with a physiotherapist not with a doctor. I had been referred to a specialist ... so would have preferred a consultation with a doctor ... I appreciate the tremendous pressure the NHS is under because of the backlog of delayed outpatient appointments but I felt the advice given by the physio was not correct in my circumstances.”

“I went through a course of physiotherapy entirely over the phone. I'd been referred at the start of the year to the Royal, and started phone physio sessions at the start of April. I was pleased to be able to get help over the phone, and that all my calls happened with the same person ... but I was also discharged from the service without ever being seen in person, which felt a bit strange and disheartening. I have no idea if I am doing my exercises "correctly" or the extent to which they've strengthened the muscles they're meant to.”

“My little boy's appointments at Alder Hey have been cancelled. On two occasions they have told us we would have a phone consultation. They did not ring on either occasion.”

Some respondents had difficulty in accessing care from their GP.

“I need injections in both knees but cannot access GPs to have them done. Also, we moved GP in January so haven't been assessed by new GP as to the knee injections. Currently having gone 8/9 months without injections which normally happen quarterly. Currently having quite a difficult time getting up our stairs due to state of knees.”

“It was extremely difficult to get through on the phone to speak to GP to request restarting inhaler.”

“My father in law needed advice from the GP. He was very unwell with vomiting and diarrhoea. The GP would not assess him face to face ... my father in law ended up in hospital as an emergency admission. I feel it could have been avoided with better community support.”

We also heard from people who told us the pandemic had a significant impact on their ability to recover well from surgeries and procedures they had undergone prior to the pandemic and lockdown. Others told us about interruptions to care and treatments they had either started, or were due to start, prior to the lockdown. People who told us about such issues said they were worried about the impact on their health of these interruptions to their care.

“I had surgery for lumbar discectomy in May 2019 and have had flare ups of issues with my back since then. As part of my rehabilitation walking is an essential part. As I have been shielding this has not been possible and I feel my overall health including my back pain has suffered as a consequence. I have not had difficulty accessing GP appointments or medication, but ... I can no longer use certain drugs and have to try to tolerate the pain to minimise my reliance and avoid addiction to certain drugs such as tramadol and diazepam. My condition will not improve until I feel safe to be able to go out walking, and I do not feel safety while there is still infection in this city.”

“My wife had an operation at end of February involving amputation. Post-operative care has been non-existent. Telephone calls cannot make up for lack of care. No physio recommended which can't be right.”

“Two injections for my extremely painful cervical dystonia have been cancelled. My diabetic eye review was cancelled. No new dates for either of these appointments for the foreseeable future. I'm now into the second month of waiting for an Urgent referral for trigger finger treatment on both thumbs and my right index finger, the pain from which makes it impossible for me to do my insulin injections at times and I have to rely on others for help.”

We received feedback from a number of people who were unable to access dentistry. Where this was for routine check ups, people were understanding of delays and cancellations, but we also heard from people in pain unable to access emergency treatment. One person told us they were unable to access a dental prescription.

“Dentist cancelled my appointment for dental work. Luckily nothing urgently serious !”

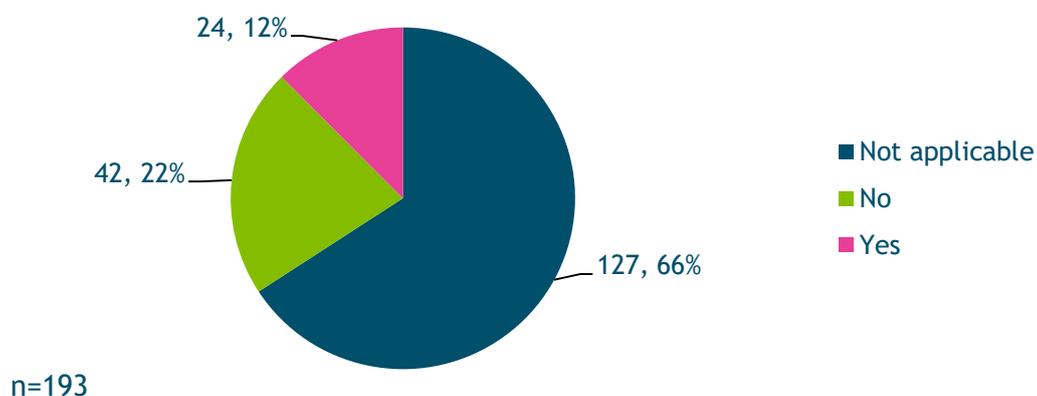
“Oh my god, I've been in such horrendous pain due to a tooth ache and haven't been able to be seen and get treatment. It's the worst torture ever and a disgrace. Why wouldn't dentist see emergency patients if they are provided with adequate PPE.”

“I've ran out of prescription only medicine toothpaste and my dentist cannot prescribe it. I understand difficulties for dental examinations but I don't want an examination - just a repeat prescription.”

Has your experience of social care been affected by the coronavirus/COVID-19 pandemic?

193 people answered this question. 127 people answered 'N/A'. 42 people (22%) said their experience of social care had not been affected by the pandemic and 22 people (12%) said their social care experience had been affected. This was similar to the responses we received between April 1st and May 12th, where 12% of people told us their experience of social care had been affected by the pandemic and 26% said it had not. There was also a free text response for respondents to provide more information about their experiences.

Has your experience of social care been affected by the coronavirus/COVID-19 pandemic?



Lots of respondents provided comments that reflected the experiences of people they provide care for.

Comments from people who said their experience of social care had not been affected focused on how their care had continued during the pandemic.

“My son uses short breaks which has continued through this which has helped immensely as he’s off school so long and has autism.”

“We have had phone consultations with the services that support my daughter they have stayed in touch.”

Some people told us that their care visits had been stopped or reduced during the pandemic. For carers, providing feedback on social care service for those they care for, this reduction in care visits has had a significant mental health impact.

“My sister is disabled and normally has carers in twice a day; however for over two months now the care agency has only been able to cover the morning shifts and my father and I have had to cover the evening ones ... I am definitely concerned that there has been no contact from social

services, her GP or any other agency (even the care provider) to check how she is coping during this crisis, given that she is housebound. As she does not have the specific conditions which would make her at high risk of getting COVID-19, she is not included on the government's vulnerable people list (we did ask but were informed she could not be added)."

"My wife is bedbound ... Care worker visits now do not happen for her care leaving it all to me."

A number of people who said their experience of social care had been affected told us about relatives living in care homes. A number of people told us that they had not been able to visit, or even speak to, relatives living in care homes during the pandemic. This included cases where their relative is on end of life care, or passed away during the pandemic.

"Unable to visit our grandma in a care home. She is on end of life care for cancer and also has dementia."

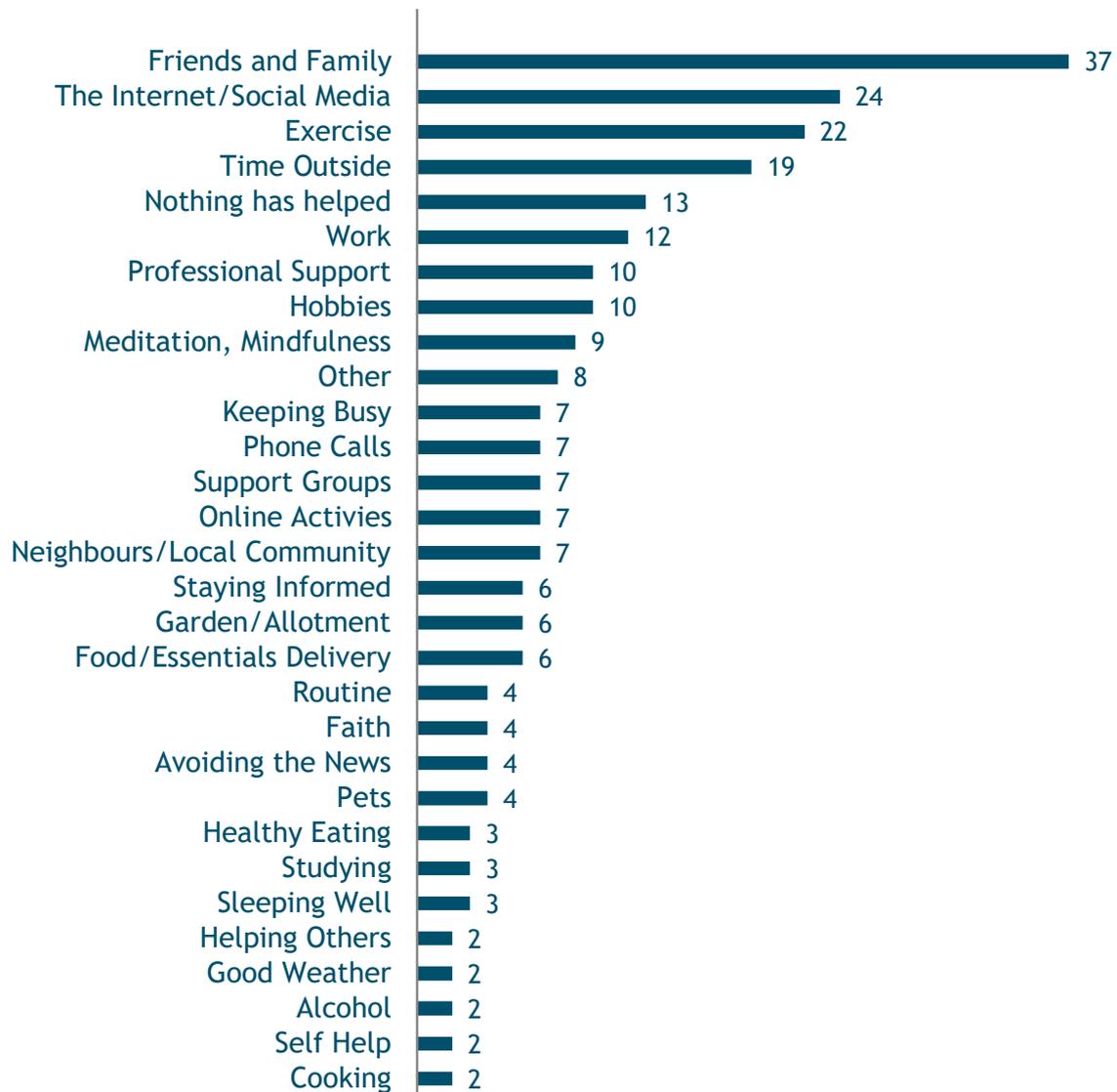
"My mum has dementia and lives in a care home. I have not seen her since 13 March. At one point she was isolated as she had Covid 19 symptoms and another time she was hospitalised. I still have no idea if my mum had Covid 19 as she has never been tested ... I know my mum is well cared for, but I still have no idea when I'll see her again and I miss her terribly."

"My father has dementia he got shingles in March. Sadly he died in his care home. So we couldn't visit or arrange a proper funeral."

Has anything helped you cope day-to-day during the pandemic?

117 people responded to this question, which was answerable via a free text box. People who responded commented with a wide variety of things that had helped them cope. The three most common responses were family and friends, exercise, and internet access/social media. A number of people commented with multiple things that helped them to cope day-to-day.

What has helped you cope day-to-day?



“Thanks to Zoom meetings I have been able to participate in things outside my home which has helped.”

“Keeping in touch with friends and colleagues, just an occasional message. On-line communities and entertainment have also helped. I did also help an elderly neighbour with some errands. Catching up on tasks at home

always a feel good factor. There is a local park, and canal, so day or evening walks really help, and no problem with social distancing.”

“I’ve had support from the community through food parcels as I was registered with the government for priority deliveries with supermarkets. Accessing food has been a struggle especially with my partner being back at work.”

“My psychological therapy over the phone has been invaluable as this has helped me to rationalise my thoughts and feelings as normal and understandable responses to a national emergency.”

13 people commented to say that they had received no support, or had not found anything to help them cope day to day. A number of the people who gave this response had reported having problems with their health, mental health, or social care during the pandemic, or were categorized as vulnerable and had been shielding, but had not been offered significant formal support during this time.

“No. There is no support for mental health. Only support is general advice like exercise or read a book.”

“Not been given any help.”

People who told us they had been seriously ill with COVID-19, both those who had been hospitalised during their initial illness and those suffering with long-term symptoms, were more likely to say they had not received help or support. It is clear there is a gap in support around recovery.

“What support from the community ??? I got help from my family whom dropped of food when in isolation and some of my work colleagues whom contacted me to see if I was okay, but other help non-existent and none offered.”

“I struggle with being able to achieve what I used to physically and in the future would like to speak to a support group and would like to have information on how we can go forward with understanding post covid symptoms.”

Other Feedback

We received a wide variety of comments and responses through our survey. Other key areas that arose frequently in survey responses include the following:

- **The impact of the pandemic on children and young people.** Most of the responses quoted above are adults talking about their own experiences, but we have also received a number of comments from parents about the impact of the pandemic on their children, including the impact of home schooling

and the lockdown restrictions on children and young people's mental and physical health, and the impact of homeschooling and being away from school. Parents with very young children told us they were concerned about the impact of the pandemic on their social development. We also heard from parents of children with SEND (special educational needs or disability), who expressed concern about the impact of the pandemic on their children, particularly with regards to reduction in support available and the impact of this on family carers.

- **Impact on key workers.** People who identified themselves as key workers often identified their job as a source of anxiety and trauma during the current time. The long term impact on key workers should be considered.

Learning Points

Following analysis of responses to our survey, we have identified the following areas that we believe local decision-makers should take into consideration when planning their ongoing responses to the pandemic, and their plans for how health and social care services can return to a more 'normal' mode of operation.

- It is clear, both through our survey response data and data that is being collected and published nationally, that the COVID-19 pandemic has had an unequal impact on communities across the UK. Nationally, BAME (Black and Minority Ethnic) groups and deprived areas have seen worse outcome, with higher rates of death and infection. Within our survey, we have identified that disabled people are more likely to experience a negative healthcare impact as a result of the pandemic. Decision makers should recognise this unequal impact, and take it into active consideration in future planning.
- A number of people who reported having COVID-19 said they continued to suffer from long-lasting symptoms for many weeks after their initial illness, having a detrimental impact on their physical and mental health, and their quality of life. Not all of these people were hospitalised during their initial illness, although some were. Decision makers should bear in mind the need to offer adequate support for all persons recovering from COVID-19, and be aware that it is not just those who have been hospitalised that will require additional support as they recover.
- People with existing health conditions were less likely to be able to find clear and understandable information about how to keep themselves and others safe during the pandemic. They were also more likely to report negative impacts on their ongoing healthcare. When issuing advice and guidance, decision makers should not assume that generic advice is suitable for everyone, and should plan for how more specific and personalized advice may be given to people, also including people whose first language is not

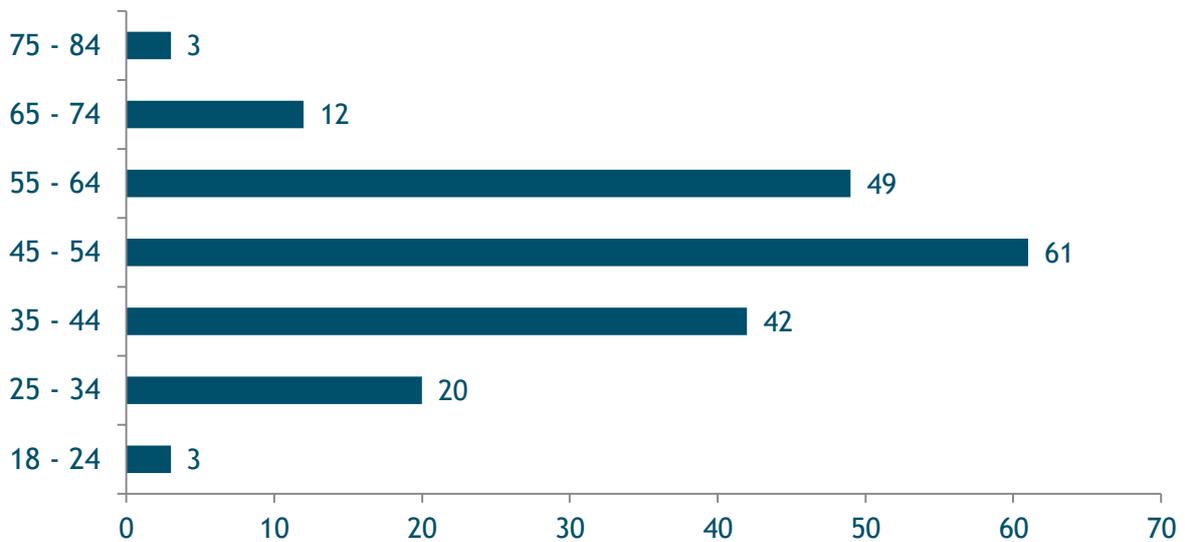
English, particularly as lockdown restrictions are eased. Care providers should also consider the impact of delays to care on those with long-term conditions as they return to more 'normal' service-delivery, or in making plans for further waves of widespread COVID-19 transmission.

- The COVID-19 pandemic has had a clear and wide-ranging mental health impact on Liverpool residents. As the mental health impacts of COVID-19 are diverse and stem from a range of factors, a one-size-fits-all approach to dealing with these mental health impacts would be inappropriate.
- Whilst telephone and video appointments have allowed NHS services to stay in contact with some patients during the pandemic, these forms of remote appointments are not suitable for all patients or for all forms of treatment, and particularly affect people with disabilities such as hearing impairments or autism, alongside those who are digitally excluded. Decision makers must take this in to consideration when planning how NHS services can be offered in the future, and should not rely exclusively on telephone or video access to services.

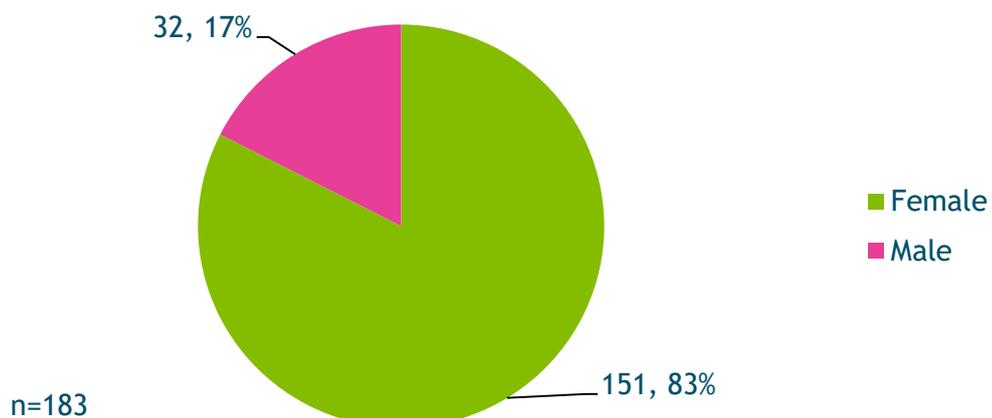
Demographic Data

We asked respondents a number of optional demographic questions, including the first three digits of their postcode, their gender, their ethnicity, and whether or not they considered themselves to have a disability. We asked this to see who we were hearing from, and to establish if any of these factors had an impact on people's experiences during the pandemic.

Age Range

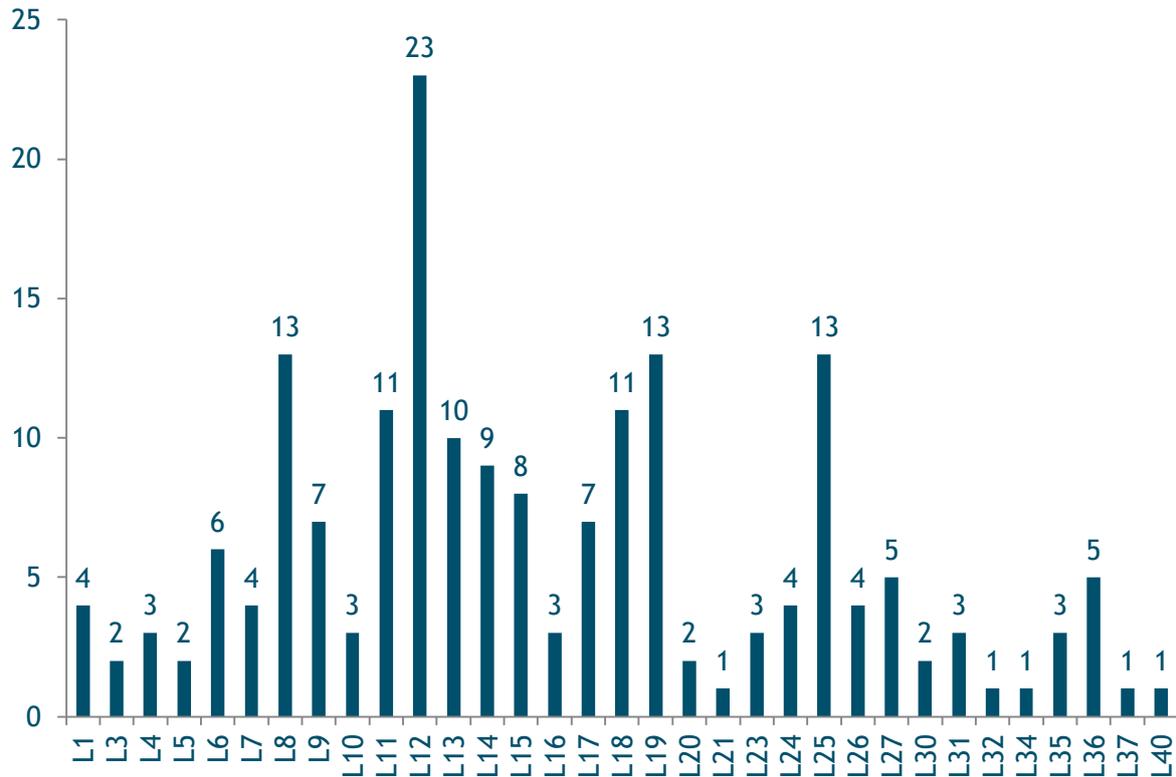


Gender

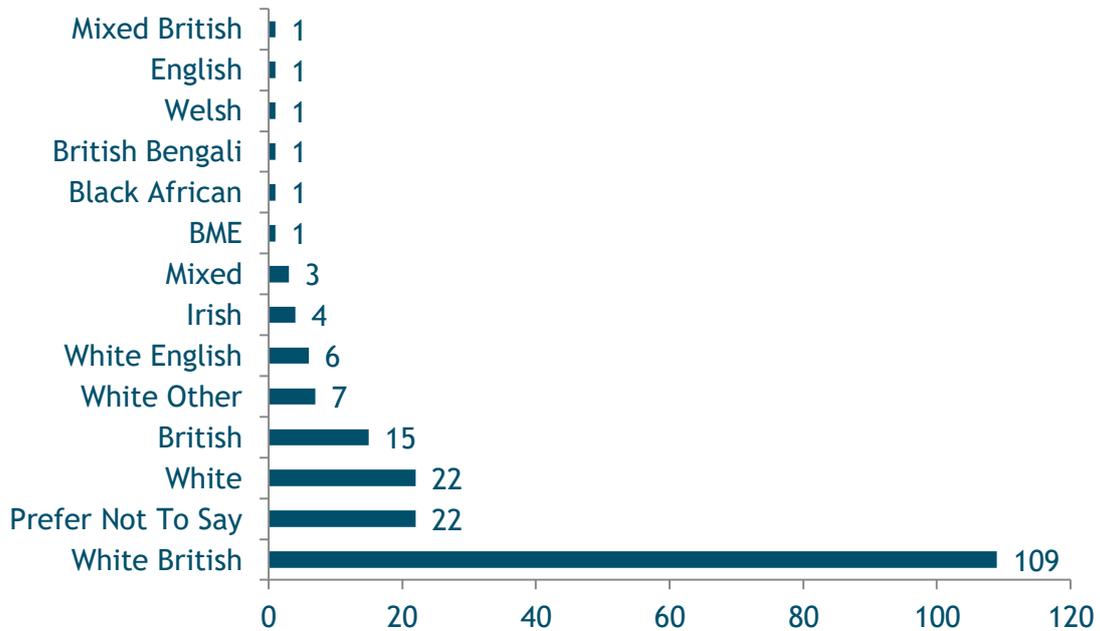


Postcode

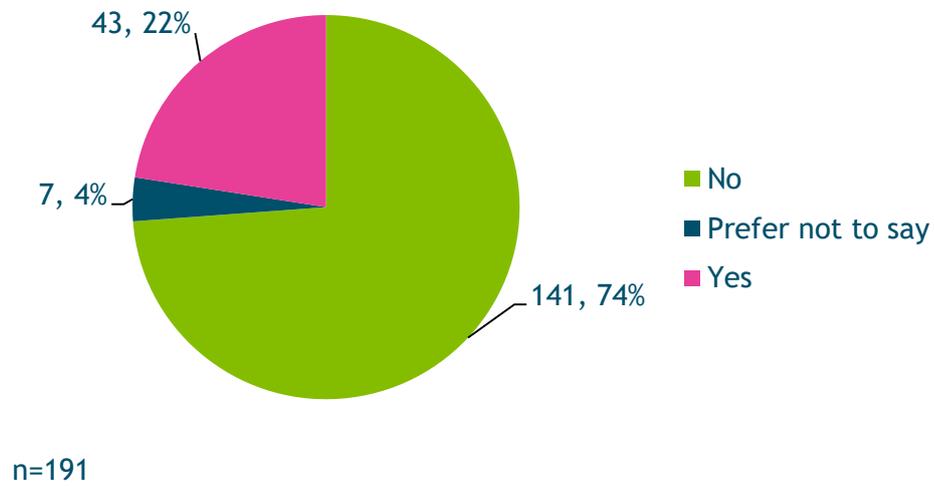
n=188



What is your ethnicity?



Do you consider yourself to have a disability?



NB: Respondents who said they had a disability were able to select multiple forms of disability.