

Coronavirus Survey - Interim Report

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

April 1 2020 - May 12 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 are now being eased.

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. This report looks at the survey responses we received between April 1st, when the survey went live on our website, and May 12th. We will be releasing another report to cover responses received after May 12th at a later date. 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 been using 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 services.

We have also been providing information to Liverpool's Clinical Commissioning Group (CCG), who plan what health services are provided locally. Our CEO has been reporting 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 are also feeding 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 436 valid responses, from a total of 501 responses overall.

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.

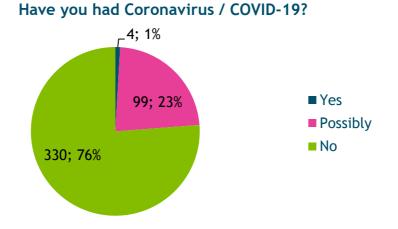


Analysis of Responses

We received 436 responses from people living in a Liverpool postcode to our survey between April 1st and May 12th.

Have you had Coronavirus / COVID-19?

Participants had the option to respond 'No'; 'Possibly - I've had symptoms, but not been tested'; or 'Yes - I've been tested'. 433 people answered this question. 330 people said that they had not had symptoms. 99 said that they had symptoms, but had not been tested, and four people said that they had been tested.



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.

102 people answered this question. 52 people said they did not seek medical treatment whilst they had COVID-19 symptoms, and 50 people said they had. A number of people who did not seek medical advice or care said they did so following the government's advice to self-isolate and manage symptoms at home.

"Did not even try get medical advice as the message was to just stay at home and isolate."



Some respondents told us that, with hindsight, they believed that they may have caught COVID-19 in the early stages of the pandemic and did not seek medical advice at the time.

"My symptoms were early March so did not happen on full alert and were excused as a chest infection by myself."

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 did so because there symptoms were very severe, or to receive clearer and more precise medical advice, and did so after seeking advice from another source first.

Some people who told us that they had sought advice from NHS 111 told us that they had to wait a long time to get through to a call-handler, and to receive follow up following their call.

"I tried to ring NHS 111 but I gave up after waiting for almost an hour."

"I did seek medical advice for my adult daughter who is disabled when she first displayed symptoms ... it took 2 hours for NHS 111 to answer my call. I was told a doctor would phone me back which they did but it took 2 days."

Some people told us that the advice they received from NHS 111 was too vague to be helpful to them. This feedback was more common from people who described experiencing more COVID-19 symptoms that were long-lasting, or when they also had additional health conditions.

"Did contact 111 online but found advice vague so ended up phoning 999, felt bad doing that. Spoke to a Triage nurse who was very helpful and reassuring. Because of health conditions they advised me to obtain antibiotics from my GP who was also very helpful."

"I didn't seek medical advice for 4 weeks ... I tried e-consult on the GP website but at the last page it said I needed to contact 111 and that my question would not be passed to GP practice. 111 site told me to go to GP ... I think 111 online script is way to narrowly focused. Covid symptoms are now known to be much broader and symptom checking in A&E reflects that."

However, this was not a universal experience, and others, including those with preexisting conditions that made them more vulnerable to COVID-19 were able to get advice and care they found appropriate and useful from NHS 111 or their GP surgery. However, some people said they were unaware they could access treatment for COVID-19 outside of hospital.



"I rang my Drs surgery after I have struggled with an illness for 2 weeks. He rang back within 5 minutes. He confirmed that it sounded like coronavirus and prescribed steroids for my asthma. I wish I'd known this was available earlier as I thought the only option was hospital."

"I had to ring 111 who advised me to start taking rescue pack straight away (I have asthma and COPD) and ring my doctor first thing in morning. Doctor advised the same thing but as she wasn't able to see me ... she couldn't be sure if it was that or the virus."

Some respondents told us that they also sought help from A&E or were hospitalised as a result of their symptoms. Feedback about care for COVID-19 in hospitals was generally positive, with respondents particularly praising the care and attention of hospital staff. Respondents also mentioned needing follow-up treatment and care following a hospital visit or stay, although we have not had much feedback yet about how appropriate follow-up care has been for COVID-19 patients.

"A&E was generally good ... I'd had a chest x ray, an ECG, some extra heart questions because I've previously spent time in the Heart Emergency Centre there. I was in for most of the day though because it took time to get results back from blood tests ... I'm endlessly appreciative of the staff. They were kind, caring, professional, as calm as could be. That isn't just the doctors and nurses but also the radiologists ... They have a basic info sheet given to people being sent home with suspected or confirmed covid. This is clear and as helpful as it can be given that it is saying that there is no treatment that can help and that advice is to rest, sleep, drink lots of water and take paracetamol and get someone to check on you by phone or text each day. I can see why some people won't like that message especially if they have no one to keep an eye on them."

"Things went downhill to the point where I got out of breath if I took one step. I knew that I was in trouble ... I called an ambulance. I had to throw the keys out of my bedroom window as I could not get down to the front door. I was taken into hospital and basically all the staff were amazing and saved my life ... Every member of staff coming into the room was putting their lives at risk to treat me and I am so grateful for all their kindness, from the nurses to the doctors to the people serving food ... I don't know how the amazing staff of the NHS are coping with having to make brutal decisions on a daily basis and constantly at risk of catching the virus. I can only admire how wonderful they have been, to the point where this week I had a call asking me how I was doing."

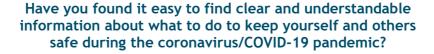
"My GP treated me for suspected Covid at home until my asthma exacerbation became unmanageable in the community. I then went into hospital for treatment ... I had multiple bilateral pulmonary embolisms, pneumonia and fluid on the lungs. I'm now at home again and my GP is once again treating me at home. I'm still experiencing problems with breathing and with the pulmonary embolisms and I'm under the care of the coagulation nurses at the hospital. I also have follow up care arranged

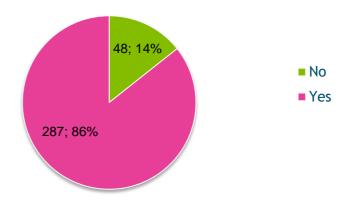


with haematology, a respiratory specialist and a liver specialist as the Covid also caused liver inflammation."

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?

435 people answered this question. 387 people said they found it easy to find clear and understandable information about how to keep themselves safe during the pandemic. 48 people said they had not found it easy to find clear and understandable information about this. There was also a free text response for respondents to provide more information about their experiences.





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); employers; shielding letters or other contact from healthcare professionals; and other websites and online content. The majority of respondents accessed information from multiple sources.

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 particularly before the start of the official lockdown.

"Initially (before the lockdown) information kept changing & it was difficult to know what was best. I have got information through the NHS website & gov.uk. I've also had texts from my GP practice."



"Most advice is vague as sometimes it is conflicting and confusing, especially at the start when the PM was even saying he was shaking hands and meeting patients with the virus."

Several respondents expressed concern about misinformation spread through news media or social media.

"I I have found it relatively easy, but ... I am a little concerned about the amount of fake news and frankly dangerous advice being circulated on social media."

Respondents who did not find it easy to find clear and understandable information said that information was inaccessible, vague, or conflicting. People who did not find it easy to find clear and understandable information were more likely to report having a pre-existing condition, disability, or were otherwise more vulnerable to COVID-19, and reported that they found it difficult to access information relevant to their particular situations and needs.

"Guidelines for who to shield with asthma has changed at least 5 times. Now the NICE guidance for severe asthma differs from NHS guidance ...This has led to difficulties as I was originally shielding and working from home but now my organisation wants me to return despite having met the criteria initially."

"The information to non-paid carers of extremely vulnerable people has left a lot to be desired, and doesn't make any sense to me. The only information about this was on the shielding letters my parents received, telling them that the people they live with should practice social distancing like everyone else, but there is no need for them to shield. It seems extremely contradictory and quite dangerous to lockdown high risk people for 12 weeks, but tell the rest of that household that they don't need to shield."

"There was a gap in info I needed. I'm pregnant and my partner is a hospital based OT. He had symptoms, tested positive and we both isolated ...We found it hard to find clear info about somebody getting over symptoms who lives with a vulnerable, but not shielding person."

We also heard from some people who had difficulty accessing clear and understandable information due to a disability.

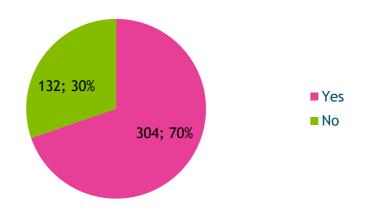
"I am registered blind. Not being able to see what is going on around me or have access to all forms of information has made it difficult."



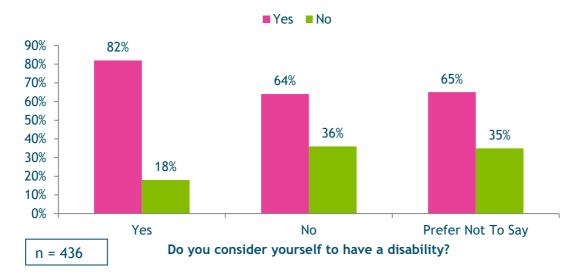
Has your mental health and wellbeing been affected by the coronavirus/COVID-19 pandemic?

436 people answered this question. 304 people said their mental health had been affected by the pandemic. 132 people said it had not. We also found that respondents who said they had a disability were more likely to say their mental health had been affected by the pandemic than those without a disability.

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



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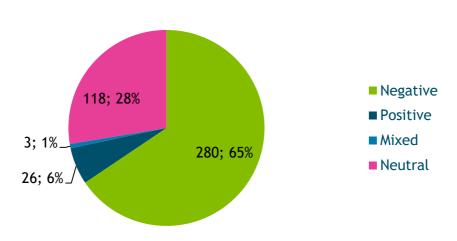


There was also a free text response for respondents to provide more information about their experiences. We used people's responses in the free text box to classify whether the impact on their mental health had been positive, mixed, or negative. People who did not write anything in the free text box, but who

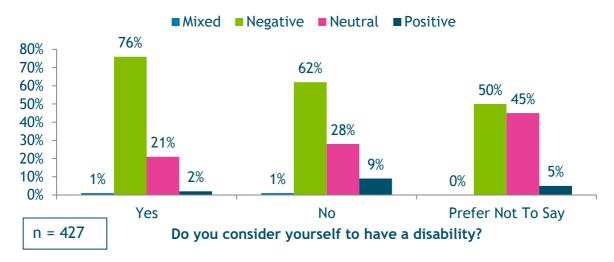


answered 'yes' to indicate their mental health had been impacted were recorded as 'neutral'.

Mental Health Experience



Mental Health Experience and Disability



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.

"I am in 12 weeks isolation but have kept busy and kept in touch with friends and family by telephone, zoom, social media etc. Good weather has helped. Obviously I've missed my usual activities and meeting friends and family but have been able to cope well."

A small number of people reported that the lockdown measures had helped improve their mental health. People who felt their mental health had been positively affected told us this was due to a decrease in stress as a result of being



off work or being able to work from home, a reduction in other stressors, the ability to spend more time socialising, and the ability to spend more time outdoors.

"It's the first time in years I haven't felt massively stressed from work and have had time to relax, read, garden and still get a lot of work done from home."

"I would say my mental health has improved because I've felt less social pressures ... I also haven't had to worry about sanctioning or housing issues such as eviction. Because of my time indoors I have found more things that I enjoy and help me cope such as exercise and I have developed a routine."

However, the majority of respondents said that the impact on their mental health had been negative. The most common negative mental health impacts on people were anxiety (mentioned by 141 respondents), isolation (mentioned by 89 respondents), and depression or low mood (mentioned by 57 respondents).

Anxiety was often linked to respondents' fears of contracting the virus themselves, or having loved ones become unwell, particularly if they were already vulnerable.

"My general anxiety levels have been through the roof - being forced to work (retail) with insufficient measures in place and customers who ignoring measures which are in place/insist on getting too close to staff/touching staff/coughing on staff etc. while having vulnerable family members at home."

A number of people told us about how the pandemic had aggravated anxiety disorders they currently had, and were worried about potential set-backs in their mental health as a result of the pandemic.

"My anxiety has been heightened because I feel overwhelmed by events and I worry about my husband and 2 of our 3 grown up children who are all key workers. It's not so much the lockdown as I am finding plenty to keep me occupied but I do worry about the future. I live with agoraphobia and it's taken me about 10 years to conquer my fear of going out and socialising. When and if "normality" returns will I be able to pick up the pieces?"

Isolation was an issue that was frequently reported, particularly by people who were shielding or living alone.

"Because I can't do the normal things like go out to museum etc when I have depression, I'm finding it hard to cope ... because I can't see my family I cry myself to sleep each night. I miss the hugs."

"I am recently widowed and living alone. The social isolation is very hard to bear."



Many people reported that the sudden change in routine and restrictions on leaving the home had a negative impact on their mental health and mood, as it meant they were unable to rely on their usual methods of self-care when experiencing depression or a low mood.

"As my Husband is in the at risk group, I am on lock down with him. Normally I walk a lot for pleasure and to help keep depression at bay. Being confined to a small house and garden depression keeps overtaking me."

We also received feedback from people or others with existing and ongoing mental illnesses and mental health issues, who told us that the pandemic had disrupted their regular mental health treatment and access to support groups and therapy. Even when remote access to counselling or other therapy has been offered to people, this has not always been appropriate for that person's life circumstances.

"I need to have monthly blood tests as I take Clozapine and have to travel to provide bloods. This journey involves two buses and because of the disrupted timetables and given the fact that I am now provided with a time slot, can prove a very difficult journey. I cannot travel alone ... I have had my May mental health review cancelled."

"My anxiety, depression and eating disorder has both been affected by the current changes to life. I have had to increase the dose of my medication ... I would volunteer 2 days a week. Not being able to go has had an impact on my mental health greatly."

"My weekly counselling has moved to every 2 weeks via Zoom, and this is more difficult as I have absolutely no privacy in my home to be able to speak openly about how I am feeling."

Some respondents have told us that they have been unable to access remote mental health care due to disability.

"Have been waiting over 2 years for counselling, my GP even chased it up with Talk Liverpool, finally had some response the beginning of March but as I have difficulty doing phone calls due to hearing loss I have to wait until lockdown is over as they are not doing face to face appointments."

A small number of respondents told us that they have experienced severe negative mental health impact, including suicidal ideation, since the start of the pandemic. In some cases, respondents told us that this was linked to financial stresses and employment worries.

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. Being unable to spend time with loved ones following a bereavement, being unable to attend funerals as usual, and being unable to access support services have been issues around bereavement that respondents have mentioned.



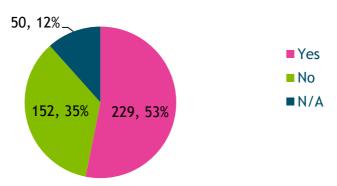
"My husband unfortunately passed away from Covid 19 and I was self isolating so couldn't see anyone and was alone, it was hard to deal with my grief and anxiety alone"

Anxiety around delayed or cancelled health care was also an issue for some. This will be discussed in more detail below.

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

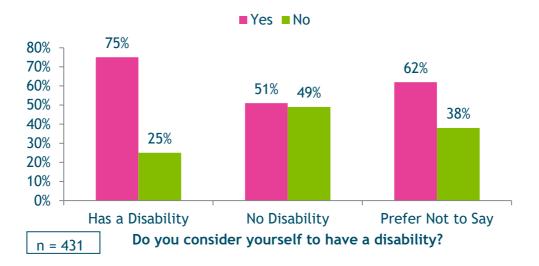
431 people responded to this question. 50 people answered 'N/A'. 229 people said that their healthcare for other conditions had been affected. 152 people said their healthcare for other conditions had not been affected. People who reported that they had a disability were more likely to report that their healthcare had been affected by the pandemic.





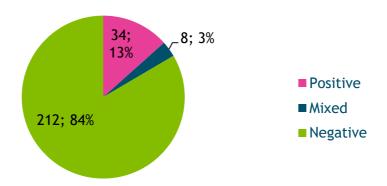


Has your healthcare for other conditions been affected by the coronavirus/COVID-19 pandemic?



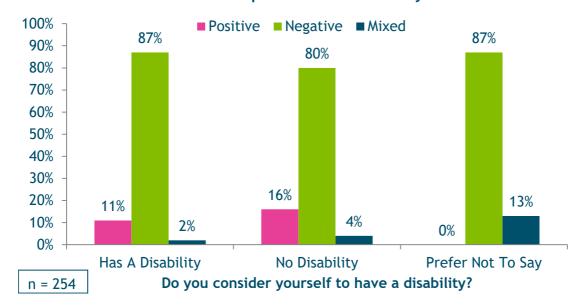
There was also a free text response for respondents to provide more information about their experiences. We used people's responses in the free text box to classify whether the impact on their mental health had been positive, mixed, or negative. The majority of respondents reported a negative impact on their healthcare for other conditions. Respondents whose healthcare had been affected, and who told us they had a disability were slightly more likely to report a negative impact.

Healthcare Experience





Healthcare Experience and Disability



Some people who said that their healthcare for other conditions had not been affected by the pandemic said that they had not needed to access healthcare during the pandemic.

Other 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 remotely, even if face-to-face appointments had been cancelled or postponed. 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 have been getting my prescriptions on line even quicker than normal. And a hospital appointment was cancelled but the doctor rang me a few days later and we did it over the phone. Was pleased and grateful." "GP surgery has been excellent as have the pharmacy. They have ensured I have the medication I need."

"Have had some hospital appointments cancelled to check on my Crohn's disease but have had a phone consultation with doctor and am stable at the moment. I also have a phone number for specialist nurses for COPD. I feel very cared for."

People who told us that their healthcare had been affected by the pandemic raised a number of ways in which their healthcare had changed. The main concerns for people were: cancelled or delayed appointments; concerns about the impact of delayed treatment on healthcare; inability to access healthcare or difficulty accessing it remotely; reluctance to access healthcare. People seeking healthcare for ongoing conditions seem to have been particularly affected.



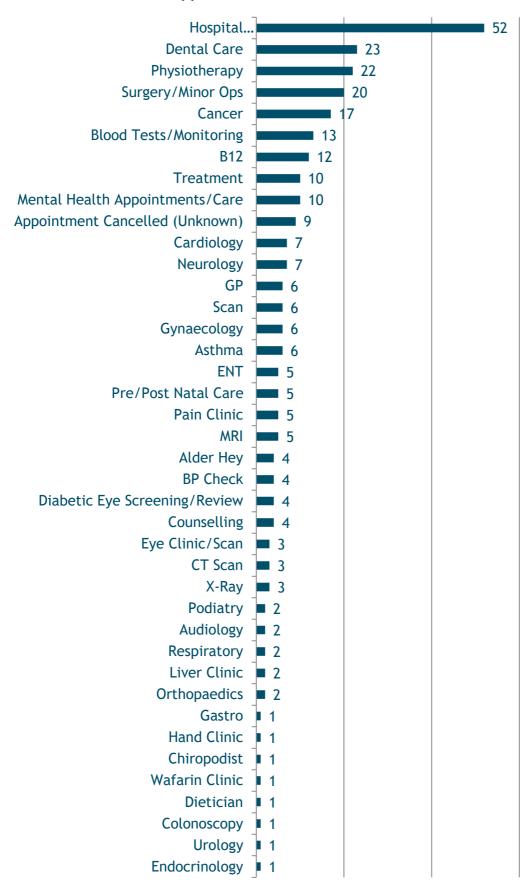
Cancelled appointments

Respondents told us about 287 cancelled appointments across various healthcare services, including surgeries, diagnostic tests, dental appointments, and injections. Some respondents told us that they had experienced multiple appointment cancellations during the pandemic.

The majority (64%) of responses mentioning cancelled appointments did not mention any alternative arrangements put in place. Some respondents told us that they had been offered a remote telephone or video consultation in place of an appointment, or that appointments had been rescheduled for a specific date. Others told us that appointments had been postponed, but they were still waiting for a confirmed date for their new appointment. Some respondents specifically mentioned being unable to make new appointments, particularly for dental care. We also received feedback from some people struggling to make GP appointments.

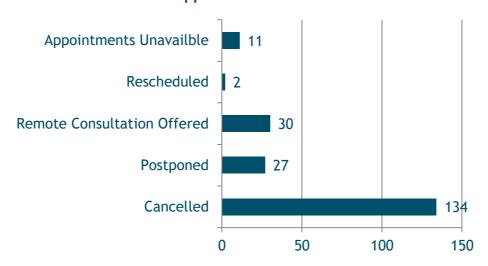


What Appointments Have Been Affected?





Appointment Status



Impact of Delays to Healthcare

Concerns around the impact of delays were often closely linked to cancelled or delayed appointments. Respondents were concerned about the cumulative impact of delayed treatment on their general health, or reported delayed care being a source of anxiety. This was particularly the case for respondents who reported that maternity care or treatment for cancer had been affected by the pandemic.

'Surgery for Ovarian Cancer cancelled. This is a recurrence and I am extremely worried about the delays and what the long term prognosis will be."

"My 84 year old father had a hospital appointment for a heart condition cancelled. This has lead anxiety on his part, my mothers and mine."

"10 weeks postnatal. No contact from health visitor for 6 weeks. GP unhelpful - no 6 week postnatal check. Phone triage only and concerns not listened to."

"I was due to have my first mammogram after having surgery and treatment for breast cancer and this was cancelled. I do understand the reasons for cancelling this appointment but feel this has set me back in moving on from Breast cancer as this is a big milestone for me."

We also heard from some people with long-term conditions about the impact of delayed and cancelled appointments, which they had already waited a long time to access.

"I had been on a six month long process to get the investigations needed to improve my health. The appointment with a gastrology specialist was cancelled and I was told I could get re-referred after the crisis. This is



going to cost me a year of my health. I should be getting investigations through an asthma consultant but that has been put on hold. This I can understand - they must be swamped and I can stay at home safely. But to be taken off the list altogether for gastrology is really thoughtless and has left me stranded."

"I normally see respiratory specialists which my appointments have now been changed to telephone, I also have urology appointment I cannot attend. I was referred to the pain management clinic which again has been cancelled as well and endocrinologist being cancelled, I waited a long time for these appointment and was hoping to get on top of my health conditions and get my life back to normal but this is all on hold now until the world is safe again."

We have also heard from a small number of respondents who have had some appointments or consultations conducted remotely but are still continuing to attend in-person appointments for other conditions.

"My six monthly blood test for my leukaemia has been cancelled but my telephone appointment for the same is going ahead. However I still am attending my warfarin clinic for my heart condition which is in the same location. Confusing. I have questioned this and have not been given a logical explanation."

A number of people who responded to the survey said they had been unable to access B12 injections, and that in some cases they been offered inappropriate alternatives, such as over the counter B12 supplements.

"I have not been able to get my vitamin B+ injection, have been told it is not important and can just buy some tablets from the chemist, which are not effective."

We also heard from a number of parents about the impact of delayed or cancelled appointments on both their children's health and their wellbeing as parents.

"I am already anxious as a parent. I am worried about my child being ill. I am also worried as he has a congenital heart disease but nobody has contacted me from cardiology to discuss if it will be risky for him. No community peadeatrician or other doctor has contacted to check on my child to ask how we are coping or if I need any further support for his medical issues."

"My son is under many teams at Alder Hey. Every appointment he had has been cancelled. Respiratory and general paeds were the most pressing. It is very odd for us to have no input or upcoming appointments. We were waiting to hear back from various departments about various issues and have not heard from any of them."



Where appointments have been moved to video or telephone consultations, respondents have left mixed feedback. The communication skills of individual staff members appears to be key in ensuring that remote consultations are a more positive experience for patients. Even when respondents have had positive experiences with remote consultations, some have still expressed a preference for face-to-face appointments.

"I had two phone consultation appointments re cancer. One ok, the other very difficult to hear and call came 3 hours late, felt rushed."

"Daughters appointment at alder hey cancelled for non urgent surgical review. Consultant called and did à very thorough assessment over the phone and devised a plan for post lockdown. I was very impressed."

"My doctor is very good by talking to me on the phone but it's not the same as face to face. Again it's not having the physical contact with people."

Inability/Difficulty accessing care

Inability or difficulty to accessing care was more frequently reported with dental services, GPs, and prescriptions. A number of people have reported being unable to access dental care during the pandemic.

"Dentist appt to check fit of mouth guard and collect it was cancelled with no rebooking ... I have him pain on and off which the mouth guard was for but I can't get it as dentist is only open for urgent treatment and I don't think this qualifies."

"I need a community dentist for treatment of broken teeth but has to wait."

While we have also had positive feedback about people's ability to access GP services remotely and obtain prescriptions online, there seems to be a greater variation in people's ability to do this. While some respondents said they had still been able to access their GP remotely, others have reported being unable to access appointments or feeling discouraged to make appointments during the pandemic.

"I feel I don't really have much option available for getting further medical care or support currently. I can't get through to my GP. I also feel bad for bothering my doctors and nurses at the moment, and don't want to take their time and add more burden on their shoulders. I feel I'm just going to have to accept the level of healthcare for now."

"I've basically felt that I shouldn't raise any health issues. My GP surgery is not allowing visits, I have 2 other conditions, but have not had either checked since start of lockdown."



Lack of internet access has been mentioned as an issue for some, particularly in ordering prescriptions online.

"Did have trouble earlier during outbreak with prescriptions as people were told to order on line, but if you don't have access it's very hard, but it's sorted now."

We have also had feedback from people who have been unable to register with a GP during this time.

"My son is registered in York as he attends uni there. As he is home he needed to register back at his surgery in Liverpool as he had undergone blood tests locally. The GP practice refused to let him reregister there as they were taking no more registrations due to the coronavirus. So he is in limbo."

Communication regarding changes to prescriptions has been an issue that some people have raised, as well as problems collecting regular prescription medication.

"Last month I had a phone appointment with my GP and we changed, added and increased some of my medications. These changes haven't been updated on my GP Access app and haven't been put on repeat, meaning I cannot order my prescription online. I now cannot get through to the practice to resolve this, and am going to soon run out of my medications."

"Difficulty getting usual prescription HRT. Got someone to collect prescription only to find 1 item of the order not the 2nd different items - I had even rung to check both were ready for collection too."

For some with disabilities, changes introduced to reduce face to face contact have had an adverse impact on their ability to access care.

"Find it hard to get my prescriptions, you have to pass info through a small window at the side of the surgery, I'm partially deaf so can't hear what's being said."

"Feel frustrated at the lack of face to face available as I struggle with what people say, on a bad day words don't register in my mind and I forget what was said to me."

Reluctance to Access Care

A number of people said that they were avoiding seeking care at the current time to avoid placing extra pressure on the NHS, because they worried about exposing themselves to risk when accessing care, or because they were unsure their care needs would be met at the current time.



"Had a severely painful wrist for weeks but didn't ask for help as no appointments available with GP and didn't want to risk the royal. Just strapped it up and bought cocodamol."

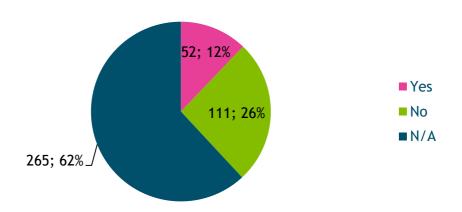
"I am due to get my bloods taken but because of my anxiety and common sense I've not been doing this. Uncertain if the hospital is still allowing this anyway but either way I would not go in current climate."

"I would not contact GP at the moment to check on relatively minor symptoms that might warrant a consultation."

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

429 people answered this question. 265 people answered 'N/A'. 111 people said their experience of social care had not been affected by the pandemic and 53 people said their social care experience had been affected. 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?



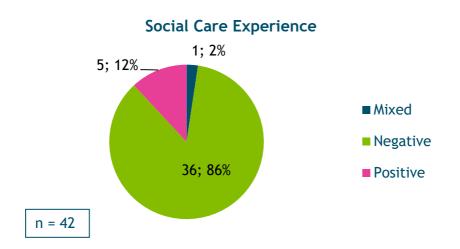
Comments from people who said their experience of social care had not been affected focused on how their care had not changed during the pandemic.

"Both social workers and mental health support worker for 2 family members continued to attend as expected."

"I have carers from a private agency and all morning and evening sessions have been covered."



Based on responses left in the free text box for this question, we categorized the experiences of those who said their social care experience had changed into 'positive', 'negative', or 'mixed'. Where people answered 'yes' or 'no' to the question but left no free text response, this was categorized as 'neutral'.



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 and were concerned for their relatives' mental health and wellbeing.

"Relative in [a care home]. Not seen or spoken to in 5 weeks. Have had to write letters. Relative has been isolated in room for 5 weeks, not allowed tv. No phone. No visitors. I wonder for his mental health."

"My father's nursing home ...are so short staffed that they cannot provide updates on him or video chats etc that would enable us to see if virtually. This is not their fault, they are doing their best. It's just heart-breaking and also means he has no social interaction with loved ones."

Additionally, we received one comment from a relative of a person living in a care home, who had been asked to sign a DNAR (Do Not Attempt Resuscitation) form for their relative during the pandemic.

"I haven't seen my husband since mid march. He is now in hospital. I was asked by telephone if I would agree to a DNAR ... There seemed to be an expectation I would say yes ... I found it inappropriate and it gave the impression that he would not be treated with the same diligence."

Some people told us that their care visits had been stopped or reduced during the pandemic.

"I'm still waiting for a care agency to be found. My social worker has been changed and he can't visit. He hasn't even phoned to check if I'm still alive to be honest."



"I no longer have carers or district nurses visit."

We also heard from people who provide care for friends and family members about the impact of service reductions or closures. Closures of day services, reductions in care visits, or fears about the risk of having multiple care workers visiting a loved one have contributed to informal carers providing more care to friends or family.

"My father suffers from Alzheimer's and vascular dementia. He attended a day care centre three days a week. This helped him and provided respite for my mum. The day care has been cancelled for weeks. Dad just sits at home now all day. Mum gets no respite from the constant care and overseeing that is required to keep dad well."

"My brother in law is severely disabled and used to go to care centre every day, he now has to stay at home, he still has a carer which is good for his dad to get a break however my partner is having to go back and forth to help 4 times a day."

Family carers also told us about the difficulties of caring for those with disabilities and conditions that impact their ability to understand the pandemic and lockdown measures.

"I am a 24/7 carer for my wife who has mobility problems and Alzheimers Disease so she can't understand why I can't take her out in the car despite repeated explanations."

"I have a severely disabled child ... He needs to be out and we spend most of our together time out doing things and activities. We have no suitable outdoor space for him ... he simply does not understand covid-19 at all. He is trying to get out of our house. Waiting at the front door from 5am. Banging his head and rocking just trying to our and get back to our usual activities."

It is clear that any changes to social care have a much wider impact, and affect friends and relatives as well as the individual person in receipt of social care.

We also received some feedback from people who work in social care services, or who work at organisations supporting people who use social care services.

"I am a support care worker ... we don't have enough PPE (mask)."

"I worked as a carer ... Watching people die daily and having poor PPE and no moral support did my head in ... Feel like I have PTSD."

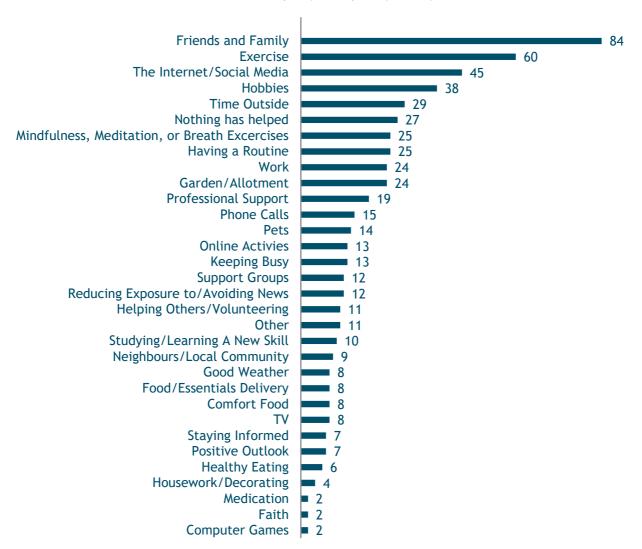
"Social workers will not visit vulnerable clients and it's hard to get them to respond to calls to Careline."



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

289 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?



"Getting out daily for exercise and greeting others doing the same whom each other would normally not engage with. The 8pm Thursday show of support for the NHS and critical workers has also been beneficial in encouraging neighbours to speak with each other."

"Support worker phones twice a week and texts and that has been helpful and pierces the loneliness."



"Being able to work from home. Walking the dog. My partner also working from home and being company for each other. Technology that allows me to video call family and friends. Knitting to raise funds for charity. Starting to learn a new language online."

"Receiving post from therapist with paperwork to support the therapy. I am visual in how I learn, and just feeling 'thought of' by receiving post rather than email helped."

"My children make me smile every day."

27 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.

"The only help I have had in over 7 weeks of isolation has been from my friend who can do shopping for me. As a Type 1 Diabetic, the right food and drink is essential and registering on the Government's "extremely vulnerable" website hasn't resulted in me being allocated delivery slots with my preferred supermarket, contrary to what they are telling people. They seemed to just want to know if you needed a food parcel, most of the contents of which, would be completely unsuitable for me. Nobody has reached out to offer help except my friend. Not anyone from the local council, government, GPs or supermarket giant."

"To be honest I can't do this much longer. I understand why lockdown is necessary but that lack of answer from the government over when certain restrictions will be lifted make it worse because I'm in my very own purgatory with no end date in sight ... I had a baby just before lockdown. I was fine but now I think I'm suffered from PND because I can't leave my home."

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. Some parents also talked about how balancing additional childcare



with work contributed to additional stress for them, which may also affect families and family health in the future.

- The impact on children with SEND (special educational needs and disability). A number of parents of children or young people with SEND commented about the difficulties they had experienced, including delays to assessments and the completion of EHCPs (Education, Health, and Care Plans); reduction of external support and care for their children; the impact of lockdown restrictions and sudden changes in routine for children with SEND; and the additional impact on family carers.
- **Employment.** Concerns about job losses, reductions in hours and therefore pay, confusion around whether people living with vulnerable and shielding individuals should go out to work, and increased work stress were a source of stress and anxiety for a number of people.
- Impact on key workers. People who identified themselves as key workers often identified their job as a source of anxiety, and sometimes even trauma, during the current time. The long term impact on key workers should be considered.



Learning Points

Following analysis of responses in the first six weeks of 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.

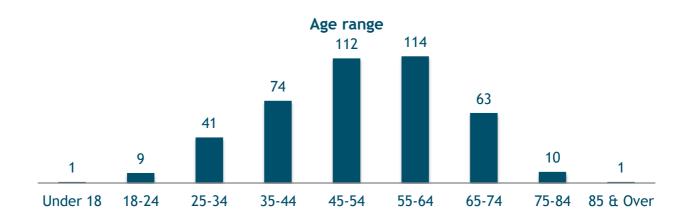
- It is clear, both through our survey response data and data that is being collected and published nationally, that the COVID-19 pandemic has had an unequal impact on communities across the UK. Nationally, BAME (Black and Minority Ethnic) groups and deprived areas have seen worse outcome, with higher rates of death and infection. Within our survey, we have identified that disabled people are more likely to experience both a negative mental health impact and 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.
- 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. 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, particularly as lockdown restrictions are eased.
- 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.
- There has been a significant impact on many people's access to health care during the pandemic, particularly for people with disabilities or those who are receiving ongoing treatment for chronic health issues.
- 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, and particularly affect people with disabilities such as hearing impairments or autism. 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

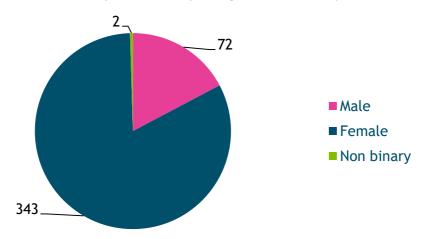
We asked respondents a number of optional demographic questions, including the first three digits of their postcode, their gender, their ethnicity, and whether or not they considered themselves to have a disability. We asked this to see who we were hearing from, and to establish if any of these factors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

Age



Gender Identity

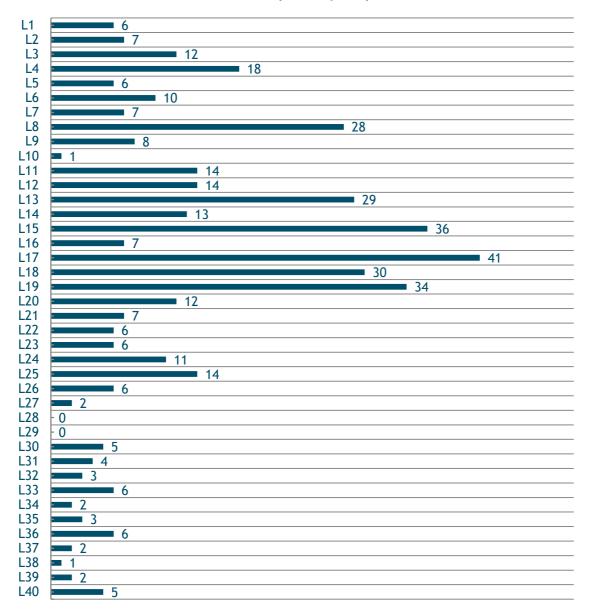
How would you define your gender identity?





Postcode

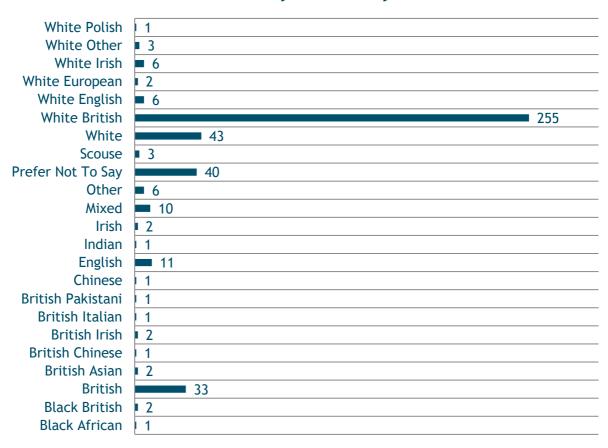
What is the first part of your postcode?



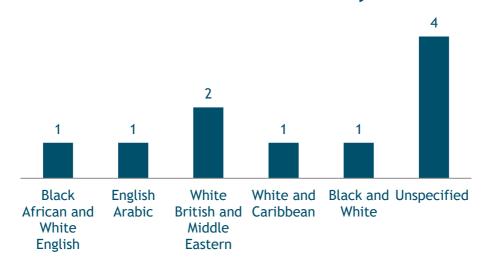


Ethnicity

What is your ethnicity?



Breakdown of 'Mixed' Ethnicity

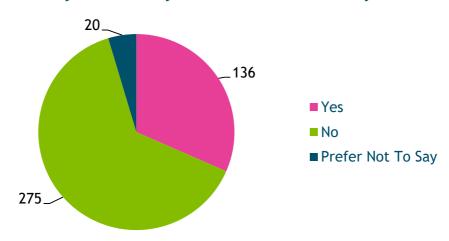


NB: Respondents included in the 'Mixed' ethnicity category described their ethnicity as 'mixed' in the free text box provided



Disability

Do you consider yourself to have a disability?



If you have a disability, which describes the kind of disability you have?



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