

How does it feel for me during Covid 19? - Weekly real-time report Week Commencing 31st August

Public Voices: the Summer Check In

In mid-August, we launched our “Summer Check In” to find out how people in Leeds were feeling about some of the key topics we have looked at over the past five months. Over the two weeks that followed, 120 people got in touch to share their thoughts and experiences.

Mental wellbeing: over half say the pandemic is still impacting on their wellbeing

We asked people how the pandemic and its restrictions are impacting on their mental health right now.

32% of our respondents (38 out of 119) told us they were doing OK. 13% (15) said that the pandemic had impacted their wellbeing for a while, but they are feeling better now.

Nearly half (47% or 56 people) told us their well-being was being affected “a bit” by coronavirus. Most commonly, this was due to feelings of **anxiety**.

Sometimes, people linked this anxiety to fears about **catching the virus** or seeing a second surge of cases:

- “I’ve been anxious, particularly about increasing numbers of cases at a time when it feels like the world is opening up.”
- “Anxiety, palpitations and beginning to see signs of OCD re hygiene”

Some people linked their anxiety to worries over **managing their health** or not being able to **access services**:

- “Myself and my husband contracted covid and still feeling after effects although back to work full time”
- “difficulties accessing treatment for my wife”

Second most commonly, people told us about feelings of being **isolated, lonely or “trapped”** by ongoing restrictions:

- “feeling restricted on what I can do, loss of freedom and choice”
- “Shielding makes me feel like a prisoner”

About 15% of the people who say their mental health has been affected “a bit” put this down to **work-related stresses** over lockdown:

- “increased stress and workload attributed to managing the pandemic. Always have a sense of concern which is difficult to switch off from and impacts on home life also, working more which isn’t generally an issue but relaxing and winding down is more difficult”
- “I have lost confidence in my ability to make decisions. I have lost contact with people and feel more alone. My health has suffered as my posture at home was not as good and I have gained weight and prefer not to be seen in online meetings. My work has been more difficult and stressful and I fear redundancy.”

- “I get very down some days due to working from home and not seeing people”

13% of this group of people also told us about feelings of **demotivation and lethargy**:

- “Low mood, low motivation and poor concentration”

8 people told us about their worries for loved ones or about how being a carer for a vulnerable person had affected them:

- “The person I care for has had all her appointments and social events cancelled, her mood is bad so I get the worst of it every day.”
- “i am a full time unpaid carer for my son who has a learning disability and autism. The vast majority of activities he accessed before covid are still not operating so I have to deal with his frustration and anxiety which impacts on my mental health.”
- “I am finding it stressful as the restrictions have been lifted [...] my daughter been expected to go back to work in a restaurant, my children receiving their A level and GCSE results”
- “I've a specific worry about my mum who is stuck in her care home without visits or outings.”
- “Primary carer for a shielding person. My options for going outdoors has been severely restricted by this virus, so feel like I have cabin syndrome.”

10 people (8% of our respondents) told us their mental health was still being affected “a lot” by the pandemic. Often, these respondents cite several different ways in which they have been impacted. Anxiety and loneliness are mentioned more often than any other feeling, for example:

- “Very low, anxious, scared to go out, crying much of the time, unable to see friends or do activities, eating disorder worse etc.”
- “I have not been able to manage my mental health as well by not being able to go out, see others, socialise, do sporadic things or things I enjoy doing, I am home a lot, working a lot, feeling under pressure and anxious about everything and everyone. Began anti-depressants in lockdown due to increasing low mood”
- “Anxiety stress hyper vigilance comfort eating and increased alcohol intake difficulty sleeping”

Staying informed about primary care: most people have been given the info they need

We asked people if they knew that their GP practice had stayed open during lockdown. 75% (89 out of 119) said that they had **always known their practice was open**. 14% (17 people) said they had thought their practice was shut for a while; 9% (11 people) weren't sure; and a very small number (2% or 2 people) believe their practice is shut to this day.

58% (67 people) say their GP practice told them about any **changes** in the way they would attend appointments; 26% (30 people) had not been informed; and 16% (19 people) had been partially informed.

Most of those who had been kept fully or partially informed were contacted by **text** (71% or 57 people). 14% (11 people) were contacted by phone; very few people were contacted by email (3) or letter (1).

Accessing services digitally or by phone

64 people told us about their experiences of accessing services digitally or by phone over lockdown.

58% (37 people) had had a **positive experience**. Most often, this was because it saved them the hassle of having to come into the surgery or it meant they got to speak to a doctor sooner than they ordinarily would have done:

- “With phone the GP called back the same day. Usually with face-to-face appointments I can wait more than 2 weeks to be seen.”
- “If things can be sorted easily it saves the practice time and money which can be spent on other things and saves the patient the time and possible expense of attending the surgery.”
- “good for when I needed antibiotics quickly and felt too ill to come in so telephone appointment was useful”

We heard some examples of **great practice** from this group of people:

- “Diagnosed with severe hypothyroidism early on in lockdown. Regularly telephoned, appointments and results for blood test very quick, drugs ordered quickly and NHS prescription exemption card sorted very quickly. I love my GP practise”
- “My aftercare from Chapel Allerton hospital has been good. They have emailed me exercises and been their to answer my questions.”
- “It was an appointment for my son. It went well and the dr followed it up with a further weekly check in”
- “I was reassured that if I needed to be examined they would get me into the surgery.”
- “effort was made to communicate with me by text without asking / needing help so I had the awareness of what was available to me should a problem occur - this makes it easier to access the help when you need it as you are not just assuming it'll be shut / too busy / too difficult to find out”

30% (19 people) told us they had had a **mix of positive and negative** experiences of phone or digital appointments. When people told us about the latter, they most often said that the **lack of face-to-face contact** had prevented them from conversing openly:

- “I didn't feel able to open up as easily as if it was face to face.”
- “felt lack of empathy during phone consultations”
- “I think there are lots of issues (particularly mental health) whereby you need a personal touch and you don't have that connection over the phone. I also think it's harder to feel as comforted on a phone call.”
- “Had a good telephone appointment doctor listened carefully. However picking up forms for a blood test was not good. They were shoved through the surgery post box with no explanation”

Sometimes the lack of **physical contact** was an issue:

- “Okay for GP appointments but not for Midwifery appointments when normally they would have been checking my BP and doing a urine dip”
- “I feel that I have not been examined only described the pain.”

Sometimes people's less positive experiences were due to technical or organisational issues at the GP surgery:

- “There had been difficulties with a nurse getting through to me because she works at a health centre where phone reception is very poor”
- “Overall it was more positive than negative but it did take two days for me to get through to the phone lines but I did receive the treatment I needed.”
- “hard to get through by phone, once they ring you back it's good, but if you miss the call you are in trouble”

8 people (13%) told us they had had **negative experiences** of phone or digital services.

2 of the 8 told us they felt they or their child had been **misdiagnosed** because a physical examination hadn't taken place.

4 told us about how their experience had impacted on their relationship with their surgery or their GP, for instance:

- "Telephone appts only lasting maximum of 5 mins. Feel GPs lack any empathy"
- "Told my GP wasn't available for call back and they hung up!"
- "lack of care no interest in finding solutions without sending to A&E"

Feeling safe in public places: 8 out of every 10 people feel unsafe at least some of the time

107 people told us how they felt from coronavirus while they were out and about in public places such as the shops, park or library.

21% (22 people) said they felt **safe**. 18% (19 people) said they felt **unsafe**. The majority (62% or 66 people) told us **it depends**.

When people felt unsafe at least some of the time, in the vast majority of cases this was due to "other people's behaviour" when they "do not respect social distancing/mask wearing or get shouty when places try to enforce these measures".

For instance:

- "A well-organised setting which isn't too crowded feels safe. There are settings where your safety depends entirely on the choices and actions of other people."
- "My son cannot wear a mask due to his disability so I am always very stressed when we go out together both because I don't know if anyone will say anything to us about him not wearing a mask and the worry that he will contract something from someone as people just do not keep their distance"

A number of people noted that "some shops are managed better than others", for example:

- "Some places are [better] at distancing and mask wearing than others. I've noticed shops hand sanitizer is usually empty in a lot of shops now, cleaning areas have gone or not stocked. Trolleys and baskets no longer cleaned. The few shops that have maintained this make me feel safe, unfortunately lots of shops I avoid or will only go in when absolutely necessary"

It is clear that the majority of our respondents feel that the danger is far from over:

- "if there is still a need to wear face coverings & stand any distance apart then there is still a risk & it is not worth going out & risking getting ill"
- "I hate it when the government says its 'safe' to do this and that, when it's not."

However, they are also often reassured when they observe strong and clear sanitary measures in place:

- "Some shops are set up well with sanitiser and you know the trolleys etc are wiped. with others it is not so clear."
- "I also feel safer when I witness staff cleaning items (petrol pumps/tables/menus etc.) after they have been used"
- "the rules around policing the restriction is unclear and unenforceable which makes it feel like a lottery. A lot of ambiguity which I think makes it hard for all"

Two people told us how **autism** made adjusting to reduced measures particularly hard:

- "I am autistic, and have other health conditions. Only saw the so called real World on t.v now it's hard to adjust to it. Scared I will get unwell."
- "couple of times been out I had to take my son with me who has learning difficulties/Autism and other medical conditions, he's even more concerned"

about even going out at all than I found it very difficult and stressful mainly due to fact he was having difficulty wearing mask”

The 85 people who told us they felt unsafe at least some of the time in public places explained whether this was affecting how **fit and healthy** they felt.

The largest number said it was impacting their fitness “a bit” (44% or 37 people), while 20% (17 people) said it was impacting their fitness “a lot”.

36% (31 people) said it hadn’t had any effect on their health and fitness.

Leeds Autism Services

This week, we caught up with the team at [Leeds Autism Services](#) to find out how the pandemic had been affecting their service users. Members of staff from several of LAS’ services shared their observations with us. LAS provides specialist support for autistic adults and works to create a more autism-friendly society.

1. How is your service users’ mental health and well-being at the moment?

“Overall, service users have coped remarkably well during the pandemic; however, we have seen issues with anxiety, boredom & frustration due to changes to routine and community activities they have been unable to access. Staff have been extremely creative by adapting the way we support people to help transition and create new routines” (Residential Manager)

“We have seen one of our service users struggle significantly during the pandemic and has not been able to access our services due it being too different for them and they have struggled massively to adjust to the changes we have seen. We have worked hard with this SU to provide daily outreach support and with the measures becoming less restrictive over time we have seen this SU progress and their mental health and well-being improved as a result.” (Vocational and Community Support (VACS) Manager)

“We are experiencing more difficulties with mental health as the situation goes on. Some people have recently restarted or increased their support due to difficulties with staying at home for such a prolonged period, which seems to have helped those who we have been able to put something in place for.” (CEO)

2. Have your service users had any trouble accessing their GP?

“Accessing GP has not been an issue; however we’ve had issues with accessing NHS dental treatment for 2 service users throughout the whole covid pandemic. One person we support had a filling come out at the start of lock down which he still hasn’t been able to see a dentist about due to only doing emergency extractions. The advice was to increase oral hygiene by using mouth wash and brushing teeth after eating and drinking. Ordinarily this would be fine but due to his autism and routines he struggles to do this.

“Another person has been complaining of mouth pain for a few months and refusing to wear his false teeth and is now starting to refuse meals. We’ve been through GP to rule out all medical possibilities but have really had to battle to even get a telephone appointment with a dentist.”

(Residential manager)

3. How have your service users adapted (or not adapted) to phone and online services?

“We have a high level of non-verbal service users, so phone and online services are not their preferred forms of communication. Instead we convert key messages about

healthcare, government advice, rule changes etc into our own easy-read visual guides to help people to understand the information better” (Residential Manager)

“We have been offering a lot of service users support sessions over Zoom. We have also been conducting regular wellbeing calls, as and when service users and their families have requested them. This has allowed us to keep in contact with people even though they have not been coming into the bases. This helps to keep relationships with staff and communication with the service maintained during this time and has worked really well in easing pressure for families/parents/carers at home” (VACS Manager)

“The people who have accessed online support or activity have responded really well to it. However, a very large proportion of the people we support don’t have online access; the reasons for this can be complex and difficult to overcome, so we have created new roles and a part of their job will be to work with individuals / families / carers to overcome barriers and get more people online” (CEO)

4. How are you and your service users finding the messages around coronavirus at the moment? Do they need to be clearer and is there a way to get them to your service users more effectively?

“At LAS we have provided our own literature materials regarding COVID 19 in the form of the easy read guides and social stories. This has meant we have been able to give our service users the key information they have needed in a way that is easy for them to understand and digest.

We find the #TogetherLeeds newsletter¹ a valuable source of up-to-date information that we share with our supports on social media and on our website. The short, snappy, relevant articles are easy to convert into easy read guides for our service users.” (Partnership & Development officer)

“A lot of our service users are finding this very difficult to navigate. Thankfully there are lots of great resources around to deliver information which people find very helpful. People are reporting difficulties in how the guidance is applied differently in different settings and knowing what is expected of them (and what they can expect) when they visit different places. Some people are also finding the guidance around meeting and interacting with other people to be a tricky area, especially when terms such as ‘social bubbles’ are used; these messages can be difficult to get across in an easy-read format, so it would be great if there were some easy to understand video resources around to help explain the post-lockdown rules” (CEO)

5. How safe do your service users feel when they are out and about in public?

“Most of service users have felt very safe when accessing the community with staff support. We have followed the guidelines and provided face masks etc. to our service users who have wanted to use them. Some of our service users have been more apprehensive when accessing the community but we have encouraged and reassured them of how to access the community safely and confidently.” (Partnership & Development officer)

“Some people are more worried about negative responses from members of the public, particularly if they are unable to tolerate wearing a face covering. Fortunately, we’ve

¹ The Together Leeds bulletin is created jointly by local NHS and Council partners. It aims to provide an overview of the key messages that need to go out to local people. It has been developed in response to the Covid-19 pandemic, and in light of an increase in misinformation being shared across traditional and digital channels. If you’d like to join the mailing list, please email dex@healthwatchleeds.co.uk

not had reports of any serious issues arising with members of the public, other than a few ‘dirty looks’” (CEO)

6. How are you finding the “return to normal” as an organisation? What would help you at this stage?

“In the early stages, we saw a large reduction in the delivery of face-to-face support, and started to deliver more remote support through Zoom, Teams and wellbeing checks. Initially, it was a challenge to ensure these were recorded properly and that outcomes were being measured effectively; it was probably challenging because things moved so quickly in the early part of the lockdown. We are seeing more people return now that lockdown measures are easing, which is great. However, managing social distancing remains a priority. It has also been a challenge from a technological point of view. We have an analogue phone system, so calls cannot be diverted through mobile networks. We have also found that home working / remote delivery of support is heavily reliant on technology, so it has proved (and is still proving to be) very expensive to make the changes which are required to facilitate new ways of working.

“In terms of our bases, it’s more the challenge of trying to offer our services and support to as many of our service users as we can; this can be tricky due to lack of space within bases to be able to implement social distancing. We are trying to offer more online services and outreach support as and when we can facilitate this. Service users are slowly been able to start accessing more of their preferred activities in the community and carry out more of their usual sessions, as we see restrictions ease further. As a company, we have had to be able to adapt and come up with new ways of working. This has provided development opportunities for staff too, so we have introduced 3 new job roles (Activity Coordinator roles) in order for us to develop the great work and creative ideas highlighted during lockdown. This should help us to create a new branch of online services for our organisation and hopefully be able to support more autistic people on an outreach/remote basis in the future” VACS Manager

“As an organisation, we seem to be doing comparatively well with managing the return to normal. We’re gradually being able to provide more hours of support and people are able to enjoy doing the things they want to again. Our biggest concerns are really more long term, specifically in how we can deliver people’s funded hours of support whilst maintaining social distancing. This is a huge challenge; we do have plans in place but there’s no straightforward solution at this time. Thankfully, there’s a lot of peer support work from partner organisations going on throughout the city, which is a massive help!” (CEO)

Huge thanks to the team at LAS for sharing their experiences with us.

Sisterhood

Sisterhood is a group for Black and Minority Ethnic women aged 16+, who live in Leeds run by Leeds Survivor Led Crisis Service and Leeds Mind. Thank you to the organisation’s leader for sharing her observations with us.

Although many Sisterhood members are experiencing loneliness and anxiety, the organisation hasn’t noted any severe causes for concern. There have also been a few elements of positivity, in that some service users “feel lucky to be alive” or doing things they wouldn’t normally do (or doing them differently).

There is a portion of Sisterhood members who are missing out on services as they only want face-to-face contact.

Sisterhood's service users sometimes find it difficult to understand messages about staying safe because these aren't always clear and straightforward. For example, people are being encouraged to go out to eat - but not to each other's houses. Most messages are shared from person to person through phone calls. Many don't have family or friends so have no-one to discuss these matters with.

Service users have been careful to follow the rules nonetheless, but they have observed others flouting them, making them feel unsafe.

Sisterhood's managers have been very supportive, and the organisation is doing phased return, re-opening services with reduced contact.

These reports are designed to support decision makers during this time. If you find them useful, we would love to hear from you! Please do drop us a line at info@healthwatchleeds.co.uk to tell us what you have found most useful.