

How does it feel for me during Covid 19? - Weekly real-time report Week Commencing 3rd August

Public Voices: Staying Informed About Care & Treatment Under Lockdown

We launched our latest survey on 8th July to find out how people in Leeds were keeping informed about care and treatment that had been paused under lockdown. 233 people responded to us over the following weeks. The findings below are based on their experiences.

Have you been kept informed during lockdown about what is happening with your healthcare appointments or treatment?

Just over half of our respondents (52% or 122 people) had been kept informed over lockdown.

Please tell us how you've been kept informed.

100 people told us how services had kept them informed about the plan for their healthcare over lockdown. The most common answers were:

1. Phone call (63%)
2. Letter (41%)
3. Text message (19%)

10 people had received an email. Only 1 person told us they had accessed information online.

Did the communication you got about your treatment tell you everything you needed to know?

100 people answered this question.

The majority (66%) said that communications had told them everything they needed to know.

A further 12% told us that they had “mostly” had the information they needed or had enough information in some areas but not others. Most often, the information they were lacking was a timescale for when they could expect treatment or appointments to resume. For example:

“Yes and No. Yes, in the sense that it was clear nothing would happen any time soon in respect of treatment and no because I would have liked some kind of timescale to be given.”

“Yes and no [...] Don't know if I will be recontacted when they restart services or if I need to contact them or re-referral?”

“Not really, but it was good to know I'd not been forgotten”

21% of people said the information hadn't told them what they needed to know. This was most often because:

- they didn't know when their care or treatment would restart;
- they hadn't been told how services would resume (for example, whether they would need to seek out another referral); or

- they had been informed their treatment had been cancelled and they would have to go back to the start of the process to seek support

“No info about when I will be treated and had already been on waiting list for a long time”

“not clear on how to re-access the service when appropriate”

“stated cancelled but did not indicate what next steps would be taken for the “new normal”

“It just said that my scan had been cancelled and if I wanted it to go ahead at some point in the future I should discuss it with my GP who would then make the arrangements.”

2 people also told us how their child had not been able to access the communications they had received because these weren’t suited to their autism and/or learning disability:

“the only contact I have had was a phone call from the consultant to advise he would ring again in six weeks to see how he is. Not really sufficient support for some who is autistic and severely learning disabled and in pain which he doesn’t understand.”

“Difficult with phone calls as my autistic daughter doesn't always feel able to communicate that way”

What would have been the best way to keep you updated?

104 people answered this question, with some offering more than one way they would like to be contacted.

The two most popular answers were a phone call (44% or 46 people) and a letter (43% or 45 people).

The third most popular answer was email, which was suggested by 28% (29 people). It is worth bearing in mind that our online survey’s respondents were more likely than not to feel comfortable using technology, which isn’t the case for everyone in Leeds. However, when we compare the percentage of people who say they would like to be contacted by email against the percentage who said they had been contacted by email (28% vs 10%), the disparity suggests email is perhaps an underused resource, at least among people with digital skills.

15% (16 people) would have liked to have received a text message and 10% (10 people) said that any means of contact would have been better than nothing.

41 people who responded to this question were aged 65+. Their top three preferences were as follows:

1. Phone: 56% (23 people)
2. Letter: 24% (10 people)
3. Email: 24% (10 people)

50 respondents were aged 35-64. Their top three preferences were:

1. Letter: 56% (28 people)
2. Phone: 36% (18 people)
3. Email: 34% (17 people)

The sample size for people aged 34 and under was too small to provide reliable information.

We only received a limited number of responses (17) from people from BAME backgrounds. 53% (9 people) said that letter would have been their preferred means of

communication while 24% (4 people) said phone. By way of comparison, 48% of our 81 respondents from White British backgrounds said they preferred phone calls and 41% said they preferred letters.

5. If you are currently waiting for treatment, how are you managing your health? Is there anything you need help with?

153 people answered this question.

34% (52 people) told us there was nothing they needed help with. Sometimes, this was because they already had the medication they needed to manage their condition.

18% (27 people) told us in general terms about how they were struggling mentally with the stresses of managing their illness on their own. Some were unaware of anything they could do to manage their health. For example:

“My son is waiting for an operation and is very stressed verging on depression”

“Struggling to manage symptoms and living good quality life due to them. Weight loss due symptoms causing additional health concerns”

“There is nothing I can do. I cannot change the drugs and dosage without seeing a clinician and being reassessed”

“I have quite a few health problems at the moment that need attention but with being bed bounds again I cannot make or attend appointments.”

14% (22 people) told us they need help with the pain they are experiencing. For example:

“I need steroid injection in my knee once a month. I'm 79yrs old and usually cope quite well but going 7 months without my treatment I cannot do anything. Toilet in the night I'm falling or crashing into things. Can't put the washing out, can't stand for long (3 mins) that's all, so I can't cook. The pain is too much. My GP keeps sending pain killers which are knocking me out. I'm giving up a little more each day and most mornings I don't want to wake up. My daughter helps me a lot but she needs to return to work soon or she could lose her job. I don't know what to do?”

8% (11 people) told us either how services had successfully supported them to manage their health during lockdown or that their care had now restarted. For example:

“Just got told a plan is been worked out for my needs”

“No [I don't need help], my consultant said if my health deteriorated I should let my GP know and they would prioritise me on the Waiting List”

“no problems local doctor has been very supportive”

5% (7 people) again wrote that they need more information about how their treatment will be handled over the coming months. For example:

“The tests are all on hold due to Covid-19 which I totally understand but it is hard waiting & not knowing when I will be seen. It would be helpful to know when the service is likely to re-open & an approximate time scale”

Positive experiences of accessing health and care during the pandemic

We've heard lots of stories about how services have been continuing to support Leeds residents despite the hugely challenging circumstances the COVID-19 pandemic has created.

Here are a few of their experiences of Leeds Teaching Hospital Trust:

- “I was signposted to a waiting area in a well-planned area [...] The experience was the best I can remember - This team made me feel valued and did a great job”
- “Was extremely anxious coming to LGI during Coronavirus pandemic but I was amazed at how well organized it was. Fantastic hospital and such kind, caring staff. I was here during the night so expected maybe staff would be a little tired, or looking/seeming over worked due to Coronavirus, but couldn't have wished for better care.”

We've also heard examples of great practice in GP surgeries:

- “Every time I have been to Burley Park, the staff in reception as well as the doctors and nurses have been nothing short of wonderful, especially during a pandemic they have been so supportive with advice and always keep to help out and make sure their patients have the best care.”
- “I attended the surgery this morning for the first time during the covid crisis. The receptionist (at 8.45am) was really friendly and helpful. The HCA was kind and professional. She really put me at ease and is obviously very competent at her job.”

Healthwatch Leeds Enquiry Line: A new mother's experiences during and after lockdown

This week, we heard from a first-time mother “Katie” in Leeds who gave birth during lockdown. She told us about some of her experiences:

- Katie needed stitches after her baby's birth but, since these were done, she has not been examined by any medical professionals to check she is healing properly.
- No breastfeeding experts have been available to support her. As a result, Katie had to turn to formula milk after six weeks of attempting to breastfeed.
- Katie's GP wasn't able to assess her baby daughter in person when she was suffering a health complaint, which Katie feels made it harder to get the right diagnosis.
- Katie's health visitor was not able to touch her baby to assess her health.
- Katie did not get a six-week postnatal check; instead, both she and her baby were assessed at eight weeks. During this appointment, a doctor carried out checks on the baby then left the room. Before the doctor returned or Katie was given any idea of how her child was doing, she was told the appointment was over.

Katie also points out that, given that they are less able to get face-to-face support from friends and family, new mothers are now more reliant on health services than ever.

Healthwatch Leeds Enquiry Line: Difficulties finding an NHS dentist in Leeds

We have continued to hear about people's difficulties in getting both routine and urgent dental care in Leeds. Waiting lists for those practices which are accepting new patients remain consistently lengthy, with some anticipating not being able to see recent registrations for two years.

While Leeds residents are managing to access urgent dental care through NHS 111, a couple of people have got in touch with us to explain that the treatment offered is only a “temporary fix” rather than a resolution to their dental problems. Like others in

Leeds, they are now searching for a dentist to treat them before their symptoms deteriorate further.

**Healthwatch Leeds Enquiry Line:
Supporting care home residents to interact with loved ones**

Care homes and visiting family members are still having to manage the risks COVID-19 presents, especially when it comes to giving residents the chance to interact with loved ones in a safe environment.

This week, we heard from a Leeds resident (“Joanne”) whose mother lives in a care home in the city. Joanne has been banned from the home for two weeks after a staff member witnessed her touch her mother’s hand.

Joanne had been doing a “window visit” when, crying and shaking with pain because of a medical condition, her mother reached her hand out to her daughter through the gap in the window; Joanne instinctively responded to her mother’s gesture by taking her hand. Both Joanne and her mother had been seen disinfecting their hands before the visit.

Joanne is now not permitted any further visits for two weeks (including window visits), and her mother has to isolate in her room for the same period. Joanne is concerned about the effects this will have on her mother’s mental and physical health.

Gathering staff’s experiences & views

Healthwatch Leeds is continuing to canvas care home workers’ observations to get a picture of what has gone well since March 2020 and what could be improved on.

We have also heard from a worker at Leeds Autism Services, who writes that LAS “has dealt with the covid situation extremely well”, citing “good provision of PPE to staff, manageable amount of service users attending the service in regards to space and staff available, good working from home alternatives available when needed, proportionate amount of work provided to staff working from home”.

We’d love to hear from as many care home workers as we can, so to send in your response, please click [here](#).

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.