

How does it feel for me during Covid 19? - Weekly real-time report

Week Commencing 20th July

Below is a summary of what we are hearing from stakeholder organisations and the public.

<p>Stakeholder organisations Week commencing 20th July</p>	
<p>Maggie's Leeds A support service for people with cancer and their loved ones</p> <p>The hospital team have had to make very difficult decisions about pausing or cancelling treatments, which was worrying for Maggie's service users. Maggie's has observed that the hospital team were very aware of the need for clear information, so they worked together to create a COVID-19 hotline run by Maggie's staff.</p> <p>As services resume, Maggie's has noted that patients are relieved but also apprehensive about returning to hospital as many are shielding. They are particularly worried about other people's behaviours, as they see some not following guidance. Maggie's is also starting to see the consequences of delayed treatment, such as progression of cancers.</p> <p>Families have experienced difficulties, as only a limited number of visitors could visit inpatients (including during end-of-life care) or attend treatment appointments.</p> <p>Maggie's is now welcoming people back to its centre for one-to-one support. Maggie's has learnt that some services work well virtually as an option for people not able to travel and will keep these in parallel to face-to-face services. Likewise, service users have found the 'check in' telephone calls useful, so Maggie's will continue to provide them.</p> <p>Maggie's is reliant on fundraising, which has been extremely challenging in current circumstances.</p>	
<p>The Stroke Association</p> <p>The Stroke Association in Leeds has had conversations with people who experienced a stroke during lockdown who felt they were discharged without much information. Unfortunately, because COVID-19 made it impossible to provide therapy at home except to patients at high risk of falls, some stroke survivors' recovery has been delayed and their rehabilitation potential has not been as high as it otherwise would have been.</p> <p>For survivors who don't use technology or find communication difficult due to their</p>	<p>Leeds Parkinson's Group</p> <p>Many service users have expressed concern about when their annual secondary care (hospital outpatient) treatment reviews will resume, as many have found them enormously beneficial in the past. Clients and carers are uncertain as to whether these would take place and how. A letter about this would be greatly appreciated. Those clients who have had reviews by telephone say these have gone well.</p> <p>Parkinson's UK has a local adviser who has proved invaluable in making links with secondary care specialist services.</p>

stroke, accessing services remotely is tricky. However, the Stroke Association has observed that those who can use technology find Zoom calls to be the second-best option after face-to-face contact. The organisation is also running a telephone service to help combat social isolation.

Some service users have expressed discomfort that the “return to normal” is happening too quickly. The Association in Leeds still has some reservations about organising face-to-face meetings because of the risk to service users and staff.

Easing lockdown hasn't made a great difference to service users, as they are still taking care and adhering to guidance.

Many service users and carers would like group meetings to resume (particularly the exercise groups). However, they understand difficulties associated with this. There are some concerns that, even if restrictions are lifted, it will be hard for groups to resume as buildings have to be risk assessed.

Case Study: A Stroke Survivor's Observations

As well as contacting the Stroke Association, this week we spoke to a former long-standing stroke support group leader in Leeds who shared his observations of how stroke survivors have experienced lockdown.

Like other long-standing stroke patients that he knows, he has been able to access his medical treatments as usual during lockdown. He has noticed a lack of consistent information from central government, especially given that care homes can set their own rules. He has heard about fears that lockdown is being eased too quickly, risking a potential second wave of COVID-19 cases.

Some stroke survivors have limited mobility and cannot use a computer or phone, but a lack of technical knowledge is the biggest stumbling block for support group members he is aware of.

Positives he has noted as someone involved in supporting his community include:

- An increase in community mindedness
- Increased numbers of clinical communities
- Zoom
- For some organisations, it is more economical to work from home

Public Voices: Staying Informed About Care & Treatment Under Lockdown

We launched our latest survey on 8th July. This time, we wanted to find out how people in Leeds were keeping informed about care and treatment that had been paused under lockdown.

212 people responded to us over the following two weeks. Detailed findings will be shared in the next Weekly Check-In summary but, in the meantime, here are some of the key headlines from our respondents.

- 53% (113 people) said they had been kept informed about their healthcare appointments or treatment during lockdown.
- 96 of the 113 people who had been kept informed explained what this was like. 66% (63 people) said that communications had told them everything they needed to know, with a further 13% (12 people) saying the information had been partially useful.

- 21% (20 people) of those who had received communications said they had not been told what they needed to know. Most often, this was because they had been informed that appointments had been cancelled without any indication as to when they would resume.
- Access to pain relief was one of the most common answers when people were asked what could be done to help them as they waited for treatment.

What citywide communications work is happening in Leeds?

We recently spoke with communications leads at Leeds Teaching Hospitals NHS Trust (LTHT) and Leeds CCG. Here is what they have been doing to keep people in Leeds informed about accessing services:

“LTHT has been providing leaflets with information about services and safety arrangements at the hospitals, including social distancing, separation of clinical areas where possible, wearing masks, keeping to appointment times etc. Patients and carers/families who have not seen these can find the leaflets and lots of additional information via the following web page: <https://www.leedsth.nhs.uk/coronavirus/>

The Trust is working out the best way to provide information directly to patients on waiting lists and where this is appropriate and possible, mailings are expected to start before the end of July.”

“As part of the citywide approach to reassuring people in Leeds, a number of resources have been developed locally. These highlight how services are still open should anyone have any concerning health symptoms or need to be seen urgently or in an emergency. They form part of the NHS here for you campaign that includes information available in a number of different formats including easy read leaflets and an animation. The information has been shared both electronically and in paper format such as information leaflets being included in the emergency food parcels. We continue to share resources and ask our community partners to share these messages. The resources are available from www.leedsccg.nhs.uk/HereForYou

The citywide approach also includes a consistent approach to asking people to wear a face covering when accessing health services unless they are exempt from doing so. This message has been shared on social media and with local news agencies [through this press release](#). If anyone would like the social media assets please email Leedsccg.comms@nhs.net. We’d like to remind people that if they need an exemption certificate that means they are unable to wear a face covering due to an existing medical reason, they can access these [through Metro](#), the transport network, or by visiting transport hubs. GP surgeries and other health services cannot provide exemption cards for travel or shopping.

Recommendation: Citywide partners, including third sector organisations, should continue to share the NHS here for you messages including easy read documents that can be downloaded and printed as required. There’s also an animation that can be used on social media or websites, all available from www.leedsccg.nhs.uk/HereForYou”

Healthwatch Leeds Enquiry Line: Reset Plans

We have heard some feedback from the public that there is uncertainty about when services are due to re-start, with some indications that communications haven’t been

sufficient. For example, people have shared with us that they've been told GPs can't currently refer and there is no information about when this will change. One organisation told us that some of their staff are off work while awaiting physiotherapy - but because hospital staff have apparently been re-deployed, they don't know how long they'll have to wait.

This week, we also received an enquiry from a former cancer patient in Leeds who has been experiencing worrying new symptoms (including pain) since the start of the year. She contacted her GP before the lockdown, who referred her to a gynaecologist. She was also due to have a CT scan.

The lockdown came into force before she was able to have either of these appointments. Since then, she hasn't received any information about when her tests will resume. This has, of course, been very worrying for her, and her GP has prescribed anti-depressants to help her cope with the toll it is taking on her mental health.

Our caller explained that she understands that the coronavirus has had a hugely disruptive effect on hospital services, but that it would be reassuring to know when she can expect to have her symptoms assessed. She is concerned at some suggestions that all referrals prior to lockdown have been "cancelled", meaning she would be compelled to go back to the start and get another referral from her GP.

Having explored her options for contacting the hospital department without success, the patient contacted Healthwatch Leeds. Contact has been made with the PALS team and Patient Experience at LTHT, who are working to ensure the patient has the information she needs.

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

We have recently seen a spike in calls and emails to our information and advice service from people wanting to find out how to register with a NHS dentist in Leeds. Accessing NHS dental treatment was an issue pre-COVID but, with reduced capacity and not all practices open, the current situation appears to be having a particularly detrimental effect on people who have been waiting for treatment for a long time. This week, the British Dental Association (BDA) said that from 20th July, it expects all NHS practices to be providing face-to-face interventions and delivering as comprehensive a service as possible.

The BDA also said they know that many practices are still struggling with capacity, and this presents a problem for patients being able to access care. Feedback from practice owners indicates that most are still operating at less than a quarter of pre-COVID activity levels. While some practices are able to offer a full range of care, others are still building up their range of activity after the lockdown period.

The biggest barrier to increasing the level of care remains the fallow period required after an aerosol generating procedure (currently set in the UK at one hour between patients). Nearly all practices have said that the fallow period is having a significant impact. Until this can be reduced, patient access will continue to be affected.

Healthwatch Leeds Enquiry Line: Communicating the right information about face coverings

We have heard some confusion and concern around protective face coverings over the last few weeks. There appears to have been a lack of clarity about what constitutes an acceptable “mask”. Some of the Public Health imagery has had a focus on medical-type masks instead of the “make at home” type.

We also received an enquiry from a caller who had a hospital appointment and who, as a Universal Credit recipient, cannot afford transport to the hospital or a face mask to wear on the bus. As a result, he was going to cancel his appointment, which could have had serious implications relating to his medical needs. We were able to advise that any type of face covering was acceptable (including, for example, a scarf), but this enquiry highlighted a lack of clarity around what kind of protection is adequate and the financial implications this has on some people.

Similar concerns about the financial burden of buying facemasks were expressed at a recent Communities of Interest meeting. At this meeting we also heard that some community members still believe GP surgeries are shut or not fully operational.

We have also been told that there is a lack of clarity about which medical conditions make a person exempt from covering their face. The prospect of a £100 fine for those people is worrying.

In addition to this, it is clear that there is still work to do around ensuring people in Leeds are fully informed about the need to maintain social distancing even when masks are in use.

Healthwatch Leeds Enquiry Line: Infection control in care homes

Healthwatch Leeds is currently gathering the views and experiences of care home workers via the following link: <https://www.surveymonkey.co.uk/r/XFRBL6Q>
Since the project started earlier this month, we have heard positive feedback about good team-working and managerial support in care homes, as well as comments from a variety of homes that governmental guidance for keeping residents and staff safe has not always been clear.

In addition to this work, we were contacted this week by a care worker from a home in Leeds who wished to voice concerns about the ongoing risk of catching COVID-19 to themselves and the residents they look after.

They explained that fellow workers do not routinely wear masks and it is impossible for them to maintain social distance from one another or residents. Noting that deaths have already occurred in the home, they expressed concern that a second wave may be imminent if safety measures are not enforced. As a person from a Black, Asian or Minority Ethnic background, they feel particularly vulnerable to the virus.

In their message to us, the worker emphasised the importance of reiterating the dangers of virus transmission to care home staff who may feel invulnerable due to their young age or ethnicity.

It is also worth noting that, as well as contacting us anonymously, the worker felt too afraid of “victimisation” to contact infection control teams.

It is important to note that government guidance on wearing masks has been updated as of 20th July. It is now clear that masks must be worn by all staff at all times in [care home](#) and [domiciliary](#) settings, regardless of whether those staff are direct care givers.

Leeds City Council, Public Health and Infection Control are currently working together to develop some “short sharp reminder” training about the importance of PPE to go on

staff phones and handheld devices. Videos will be designed for both managers and care workers.

Clear and regular information for people with learning disabilities/autism

The citywide Inclusion for All Hub held in mid-July has highlighted that information is not always reaching people with autism or a learning disability in a way that suits them (even among those who are very connected to several social and support groups).

While there has been a lot of great work in the city around accessible information and easy-read formats (see below), examples were shared with us about people with learning disabilities being unsure about whether to contact their GP, whether surgeries were open and whether the hospital was seeing patients. It was emphasised to us that tailored messages need to be sent out continually so that they remain impactful over the long term, and that health and care services should be pro-active in providing regular, accessible information to people with learning disabilities. (It was also pointed out that communications that are accessible to people with learning disabilities might not be for people with autism).

However, we also heard about good work that is also going on to support people with learning disabilities in hospital settings. One attendee told us about his hospital admission during lockdown. He said that the hospital staff explained everything clearly, and he was very pleased that they spoke directly to him and not his carer. He said the staff on the ward were “fabulous” and that they listened to him and answered his questions. He thinks the information he was given on discharge was easy-read, although he hasn’t read it yet. His overall experience was very positive and his access requirements were met.

Digitising Leeds: Risks and Opportunities for Reducing Health Inequalities

The coronavirus crisis has accelerated Leeds’ plans to introduce a wider variety of ways for people to access services, from telephone calls with consultants to video chats with GPs, text messaging and more. This key moment of transition presents a great opportunity for reducing health inequalities in the city, so the [People’s Voices Group](#) decided to form a subgroup dedicated to this very issue.

The subgroup’s digital inclusion briefing has now been shared with partners across the West Yorkshire and Harrogate region and includes sections on:

- When people in Leeds say digitisation works for them
- When people in Leeds say they would like a flexible approach to digitisation
- Key challenges and next steps for the city and its organisations

The report can be read in full here: <https://healthwatchleeds.co.uk/covid-19/2020/digitising-leeds/>

The PVG would welcome any partners who would like to join the subgroup, which will continue to monitor and feed into progress being made in Leeds.

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.