

**Trafford Healthwatch 100**

# **Awareness of Long COVID and Support in Trafford**

A report looking at people's understanding and experiences of Long COVID,  
and what resources and support are available



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## **About the Trafford Healthwatch 100**

Healthwatch Trafford is your local health and social care champion. If you use GPs and hospitals, dentists, pharmacies, care homes or other support services in your area, we want to hear about your experiences. As an independent statutory body, we have the power to make sure NHS leaders and other decision makers listen to local feedback and improve standards of care. We can also help you to find reliable and trustworthy information and advice. Last year, the Healthwatch network helped nearly a million people like you to have your say and get the support you need.

The Trafford Healthwatch 100 aims to get as many local people as possible to sign up and give their views on topics to do with health and social care via regular surveys. We want to gain as much information as possible so that we can direct our work to the issues that matter.

Full details for signing up can be found at <https://healthwatchtrafford.co.uk/the100/>.

## **About this project**

Now that COVID-19 has been present in the UK for over a year, there have been increasing reports of post infection symptoms that have come to be collectively known as Long COVID.

Healthwatch Trafford therefore conducted a specific survey to help us understand what information is being provided to local people on Long COVID. Our findings will be shared with Trafford Council and Trafford Clinical Commissioning Group (CCG) and will be made available online.

The NHS defines Long COVID as “symptoms that last weeks or months after the infection has gone”. A long list of possible symptoms has been collected by the NHS and more information on the definition can be found here:

<https://www.nhs.uk/conditions/coronavirus-covid-19/long-term-effects-of-coronavirus-long-covid/>.

More information from Trafford CCG on Long COVID can be found here:

<https://www.traffordccg.nhs.uk/Your-Health/Coronavirus/Support-for-patients-with-Post-Covid-19-syndrome-'Long-Covid'.aspx>.

We want to thank all the members of the public that took part, as well as our volunteers who assisted in the design stages of the project.

## What did we do?

We opened the survey on the 20<sup>th</sup> July 2021 and closed it on the 17<sup>th</sup> August 2021. We then sent it out to our Healthwatch 100 subscriber list, promoted it on our website and shared it across social media. Social media included Facebook, Twitter, and Instagram.

For this project we also hand delivered leaflets to local people in North Trafford as we were seeking to increase response rates here.

We used Facebook to advertise the survey using the boosting function. Boosting allows Facebook users to promote their posts to people in an area.

## Who did we speak to?

We heard from 55 people in this project, and collected anonymous demographic data as follows:

Demographic	Responses
Gender	Male 12, Female 41, Prefer not to say 1 (total 54)
Ethnicity	White British 45, White Other 2, White Irish 1, Asian or Asian British - Pakistani 1, Asian or Asian British - Indian 1, Asian or Asian British - Chinese 1, Multiple heritage - mixed race 2, Other 1 (total 54)
Age	17 or under 2, 18-34 9, 35-44 9, 45-65 23, 66-79 11 (total 54)
Sexual orientation	Heterosexual or Straight 50, Lesbian 1, Other 1, Prefer not to say 1 (total 53)
Area	North Trafford 25, Central Trafford 17, South Trafford 2, West Trafford 5, Outside Trafford 5 (total 53)

## Key findings

- Almost all the respondents had heard of the term ‘Long COVID’.
- The internet and GP surgeries were the most popular places where people might go to learn more about Long COVID. The next most likely sources were the NHS app and NHS 111.
- Only a small proportion of respondents had heard about the existing support, found online at [www.yourcovidrecovery.nhs.uk](https://www.yourcovidrecovery.nhs.uk) and available in person through the Manchester COVID-19 peer support group<sup>1</sup>.

<sup>1</sup> Manchester Foundation Trust - Manchester COVID-19 Recovery Peer Support Group <https://mft.nhs.uk/app/uploads/2021/05/CV19-Peer-Support-Group-poster.pdf> (accessed August 2021)

- Just over half the people surveyed had not had Long COVID. Of those that had, most did not seek further support from health services.

## **Recommendations**

Greater awareness is needed around the support available for those with Long COVID in Trafford.

- Though progress has been made due to Trafford CCG creating a webpage about Long COVID, local people would benefit from the basic information about possible symptoms and dedicated support being made more commonly available, both online and through peer support.
- In our report we look at possible avenues for information sharing on Long COVID and found GPs would be the best way to reach people. It may also be prudent to consider vaccination centres and other health sites such as pharmacies.

The pathway for people with suspected Long COVID needs to be clearer.

- Our understanding is that people who believe they have post-COVID symptoms should first see their GP if symptoms are serious enough to seek further investigation. Otherwise, people should consult the dedicated NHS website at [www.yourcovidrecovery.nhs.uk](http://www.yourcovidrecovery.nhs.uk).
- Beyond these two routes it would be useful for people to understand what is likely to happen if their GP is not able to resolve any issues they have. For example, we heard in one detailed account how referrals to a COVID clinic were only focused on respiratory problems. We also heard that some people were unable to find a reason for their condition, or that it took some time to find.

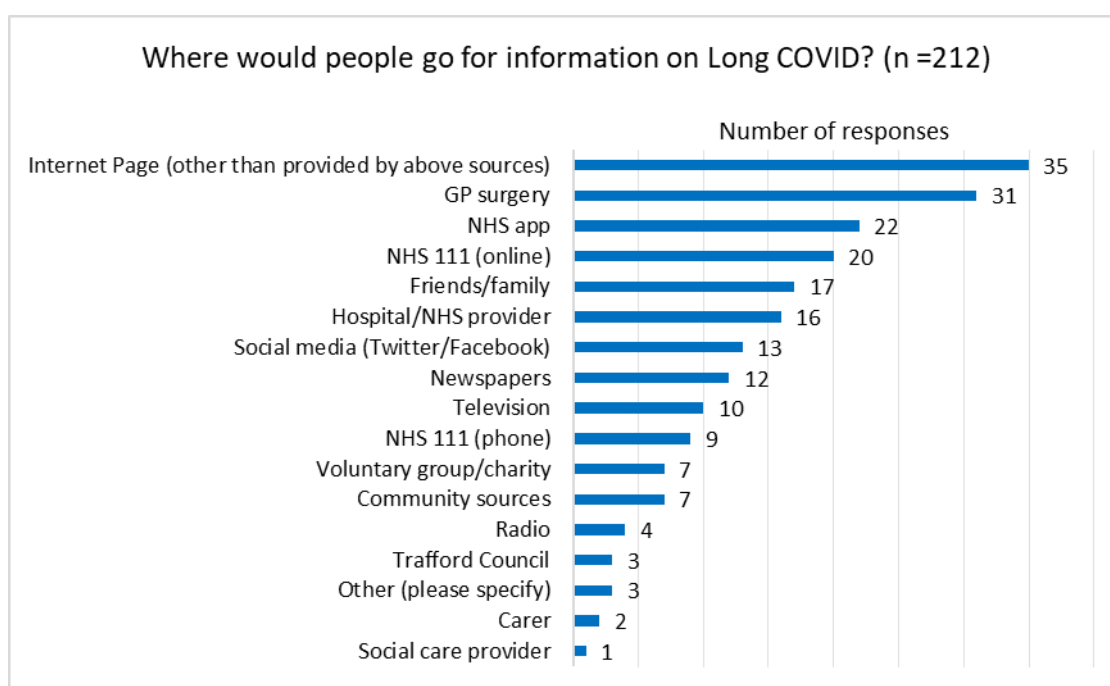
## What we heard - multiple choice answers

In the coming sections we had different numbers of respondents for respective questions. Therefore, the percentages and question totals relate to each individual question, not the overall study.

### Awareness of the term 'Long COVID'

We asked people if they had heard of Long COVID. Almost all respondents said they had, with 54 of 55 saying 'yes'. There was one person that said they were 'unsure'.

People were then asked where they might go for information on Long COVID. Respondents were able to select all they thought applied.



The most popular choice of response was 'Internet page (other than those otherwise provided by the options given)' with 35 people selecting it (17%).

Close to internet page was GP surgery, which 31 people indicated they would use (15%).

There were then two NHS information sources with popular responses: the NHS app with 22 people selecting (10%) and NHS 111 online with 20 people choosing this (9%).

We often see GP surgeries high on the selection for information-related questions because they are the first point of access for those in the community. In this case it is interesting that internet page features highly, as well as the NHS app and NHS 111.

## Awareness of support for Long COVID

NHS 'your COVID recovery' - [www.yourcovidrecovery.nhs.uk](http://www.yourcovidrecovery.nhs.uk)

We asked people if they had heard of the primary NHS web resource for those with post-COVID-19 symptoms. Of those that responded, most said 'no' (42, 78%) with a smaller proportion saying 'yes' (14, 22%).

We also requested further comments, and although only a small number of people chose to comment, the feedback was useful considering only a smaller proportion of respondents had heard of the site.

We had some simple/short comments stating the website was good:

- *"Good and still using it."*
- *"Good."*

Other experiences were somewhat in between good and bad, but it seemed from the comments that something extra was expected:

- *"It was information I was already aware of. Nothing new."*
- *"The website was informative but not comprehensive."*

Finally, we had a detailed comment based on engagement with the 'your COVID recovery' site. This feedback is interesting because it shows how there is a desire for clarity around support from health services, and possibly the need for access to support through the site:

- *"Not helpful. It is a positive step to have Long Covid recognised and have this as an acknowledgement and a general advice to those recovering at home. However, patients being expected and told to rely on this as a replacement for diagnosis and treatment is harmful. There are vaguely worded snippets of advice that is better provided by doctors, physiotherapists and peer support group elsewhere. There is an unrealistic generic approach to exercise that does not take account of underlying unresolved health issues; a limited list of symptoms and little explanation of them. There are no links to developing research and understanding of Long Covid. You can't access support through this website - although there is supposedly such a section, it is protected by a login. No clinic has provided a login and GPs seem aware that there is a need for one."*

## Manchester COVID-19 peer support group

The survey checked with respondents if they had heard of the localised peer support group available for residents in the Greater Manchester area. A phone number and email are provided by organisers for people to get in touch.

Most people had not heard of the group, with 'no' receiving the highest response (44, 83%). A smaller number of people said 'yes' (7, 13%) and two respondents 'unsure' (2, 4%).

We again asked for comments, but as only a small number had heard of the website, we did not receive many. Nevertheless, there was some awareness of the site, found online and through television. There was positive feedback as well from those that had engaged with the group:

- *“Just seen [them] on Facebook.”*
- *“I’ve seen updates on Twitter. It sounds really good.”*
- *“Not used it heard about it via a TV documentary.”*
- *“Very good. Helpful and supportive.”*
- *“Good.”*

We also received a more detailed comment that described the working of the group. The concern was that such peer support should also be able to feed into decisions about the treatment of Long COVID:

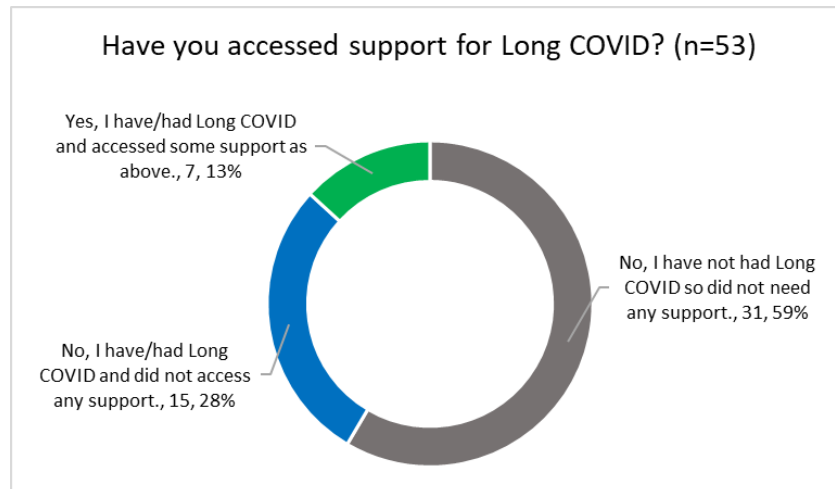
- *“This is a friendly group with a lovely, caring organiser, and it is a source of validation and mutual support. However, group talking therapy cannot replace access to medical help, which we all seem to be shouting into the vacuum to get. People are struggling with their health, with their jobs or job losses, with the benefits system. It’s good to share stories, but it makes you feel frustrated for others in the group as much as for yourself. We shouldn’t just be left to talk to each other, this group needs to be a patient voice and it needs to be listened to.”*

Though we only had one comment detailing this, the respondent raises some useful points about the need to support those living with with Long COVID through health services, not only support groups.



## Support accessed by respondents

We asked respondents if they have or have had COVID and have accessed support for Long COVID.



The majority of people have not had Long COVID (59%); however, of the other 41% (22) that have or have had COVID, only a small number decided to seek support afterwards.

Despite only a portion of respondents having Long COVID, we did receive some detailed comments about what happened when they looked for support.

### Lack of awareness of any support

In two comments people were unaware that there was anything for them, should they experience post-COVID symptoms:

- *“I didn't know there was support. I have heard of a lot of people trying to access support and saying it was fruitless and they felt patronised and told it was due to ‘anxiety’.”*
- *“Didn't know there was any.”*

Whilst our survey took place July-August 2021 and information about Long COVID has been increasing, only recently has the pathway in Trafford become clearer with the addition of details on the CCG website<sup>2</sup>.

<sup>2</sup> Trafford CCG Support for patients with Post Covid-19 syndrome 'Long Covid' <https://www.traffordccg.nhs.uk/Your-Health/Coronavirus/Support-for-patients-with-Post-Covid-19-syndrome-%27Long-Covid%27.aspx> (accessed August 2021).

## Self-managed

We also heard through a further two comments about the experience of having Long COVID and what it means. The kind of physical symptoms expressed here are in line with those mentioned by the NHS<sup>3,4</sup>, though it should be noted that there is still discussion about agreed symptoms and definitions of Long COVID itself.

- *“Although both my husband and I experienced long term effects of Covid - these have not been so bad as others we have heard of. We googled information about long term Covid and felt we were lucky compared to others and have simply dealt with it. We both suffered foggy brain, fatigue and my asthma symptoms have increased from needing my blue relief inhaler once every now and then to once a day. I have seen my GP about this and I am now on a steroid inhaler again.”*
- *“I think I had covid in Mar 20, before testing was rolled out. (I had headache, bodyaches, high temp. Husband lost taste and smell, daughter had temps) Since [then] I get random instances of breathlessness. Before I could run up and down the stairs with ease, now I need to catch my breath. My periods are all over the place and unshakeable fatigue and headaches.”*

These individuals said that having Long COVID impacts other conditions such as asthma and affects their usual energy levels day-to-day.

## Medical support

We heard that the support pathway for one patient involved their GP and hospital, plus follow-up through telephone and online. Another comment described how, for their child, Long COVID had significant consequences after infection, disrupting school.

- *“Mostly at hospital/gp with additional online and telephone support.”*
- *“My 13 year old daughter caught covid from school in November 2020 and ended up in hospital in December 2020 for 5 days. The doctors believe that covid attacked her existing chronic pain condition and made it worse. Her existing consultants have continued to collect information from us and advise us through Occupational Therapy services, however, she has still been unable to complete a full day of school since then and is unable to do certain activities such as PE etc.”*

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<sup>3</sup> NHS Post COVID syndrome <https://www.england.nhs.uk/coronavirus/post-covid-syndrome-long-covid/> (accessed August 2021).

<sup>4</sup> NHS Long COVID <https://www.yourcovidrecovery.nhs.uk/what-is-covid-19/long-covid/> (accessed August 2021).

## Mixed experiences

We had a significant number of comments relating to the experiences of seeking treatment and support for Long COVID. Most of these were rather mixed, with some parts of the support reported as good, but with others felt to be lacking or not as responsive to need.

When mentioning GP services, some commented that the difficult to define nature of Long COVID meant it was not recognised or that their symptoms were thought to be related to another issue:

- *“Had Covid. Took symptoms to the doctors. They did not recognize it as Covid. Had brain scan for possible [tumour]. Did not know some of my symptoms were Covid related.”*
- *“GP mainly, hospital said it was asthma exacerbation through COVID whereas GP [surgery] suspect long COVID so I don't [know] what it is. Support seemed to come from the Asthma Charity, they were the most useful for me.”*

Ultimately, after seeking support some were left feeling there was nothing that could be done:

- *“Saw [GP] who suggested exercise. Saw a paediatrician with my daughter (after [GP] referral) who also has it. He told me that in his opinion she didn't ever have covid although she was actually admitted to hospital and told she did have it. Bloods have been done on us both. We have been advised that there is nothing that can be done to help us.”*
- *“Saw the Dr and she wasn't helpful am having blood tests and given [ibuprofen] gel. My husband and daughter have found information on computer and my symptoms are SIRVA related.” (SIRVA - Shoulder Injury Related to Vaccine Administration)*
- *“Had covid twice in past 16 month plus had long covid symptoms on both times. Still completely tired out and having breathing problems. Total lack of support from both [Wythenshawe] hospital and Manchester royal. Doctors told to keep records and get back if any worse. No one seems to want to take responsibility.”*

We also heard in one example that referral to a physio would have been useful if no medical interventions were required:

- *“Excellent support from GP but no help no referral for physio etc.”*

There is a possibility, therefore, that it would take some time for those wondering if they had Long COVID to get support:

- *“It took too long to get to the services I need. The wait of 6-8 weeks between each consultation is too long as well. Care should be viewed holistically and offered concurrently instead of sequentially.”*

Finally, we received a detailed comment about how one patient sought help at their GP, which led to an appointment at a ‘lung centre’ in Wythenshawe. The process to get an appointment for Long COVID investigation took some time and the patient found little clear information about the pathway. For example, she had to call different departments and received mixed messages about where she would be seen and when. Ultimately, once she had been seen at referral she was immediately discharged and had to return to the GP for advice:

- *“...My GP confirmed to me that the “Long Covid clinic” was indeed just respiratory, and there was nothing else they could do. Nor could the GP. Thankfully, I am still being followed up by the lung clinic, so far. For the past 7-8 months, after a separate GP referral, I’ve been on the waiting list to see a rheumatologist for the pain and periodic dysfunction in my hands that’s developed post-Covid, since November 2020. This is not a Long Covid service, this is a waiting list for a routine appointment, with no date in sight. This symptom was not addressed by the Long Covid clinic. In practice, Long Covid services in Greater Manchester/Trafford are not truly joined up or consistent across the region, are hard to access, and there is no multidisciplinary approach - it starts and ends at respiratory, despite nationwide research into it as a multisystem syndrome. Patient experience and input does not seem to be a part of planning.”*

## What we heard - free comment answers

We gave people the opportunity to tell us more about anything else they would like to mention at the end of the survey.

In addition to further comments on the need for support for those who have post-COVID symptoms, we heard the following.

### The need for more information and awareness

We found generally high awareness of the term 'Long COVID' in this project. Nevertheless, there were three comments that called for greater awareness. Certainly, there does need to be a breakdown for local people between support that can be expected from the NHS in general and what is available to support them locally, at both a Greater Manchester and Trafford level where appropriate.

- *“Thank you for this survey. This is the first effort I have seen in Trafford/Greater Manchester to get patient or public input on Long Covid. Patient input needs to be a part of planning service provision. For me, it has taken almost a year [and] a half from falling ill to being seen by a doctor face to face - by the Long Covid clinic only to be let down at that first and last visit. In that time I've lost my job to Long Covid and have struggled to become re-employed because of [recurring] health problems. Nationwide people with Long Covid are losing jobs at a rate of 1 in 20, in frontline jobs it is 1 in 10. So [if] joined-up support isn't just a medical problem for individuals, it's a social and economic one.”*
- *“I think there needs to be more awareness about the risks of long COVID.”*
- *“I am concerned about Long Covid. I am also concerned about those with other forms of Post Viral Fatigue (ME\*) who have been suffering for years and treated as hypochondriacs. I am hoping that they too will now get better support. Everyone with a post viral conditions needs this.” \*ME - Myalgic encephalomyelitis, Chronic Fatigue Syndrome*

### COVID-19 pandemic and need for continued caution

We gathered two comments on the need for continued caution around COVID-19.

- *“I would like to see signage in public areas saying something like ‘Please be considerate to others by maintaining social distancing in public spaces and wearing a mask in indoor spaces’.”*
- *“I feel that children aged 11 and over need to have the covid vaccination urgently. 57 cases in my children school in one week. So [don't] be reckless*

*get the vaccine into children's arms to protect them and us. Or the consequent could cost us all."*

## COVID-19 pandemic and concern over response

We had one comment that was concerned about of the attention Long COVID was receiving, suggesting that the symptoms are due to previous lockdowns and the challenges that have arisen following the start of the pandemic in 2020.

- *"The symptoms of 'long COVID' are pretty general and can also be associated with the mental struggles caused by lockdowns and social isolation. 'Brain fog' and 'lethargy' are what almost everyone will feel after 18 months of lockdowns, fear-mongering and government instability. This is what happens when you live in a world that is burning around you. But no, everything must be about covid mustn't it."*

## Concluding remarks

Overall, the project highlights the complexities of Long COVID, a condition which is not yet fully clear, as per the NHS website definition. Nevertheless, almost all the people in this project were aware of the term, which shows that the issue has been widely noted.

Accounts in our comments suggest, of those that have had COVID-19, only a sample go on to need further support after recovering. Of those that do seek support there is a wide variation in what people find, and so further clarity is needed on the expected pathway and time that might be required to find a solution. Not all symptoms post-COVID-19 are Long COVID, and medical advice should be sought when difficulties continue.

On the other hand, we found little awareness of existing online support provided by the NHS for self-care and the localised support arranged at Greater Manchester level. Both options should receive further promotion as a way of increasing understanding.

## **Appendix: Full list of questions**

1. Have you heard of Long COVID as a condition?
2. If you needed to find information about Long COVID where would you be most likely to go? - select as many as apply
3. Have you heard of the post-COVID recovery resource NHS 'Your Covid Recovery' website - <https://www.yourcovidrecovery.nhs.uk/>?
4. What was your experience of using the website?
5. Have you heard of the post-COVID recovery resource 'Manchester COVID-19 peer support group'?
6. What was your experience of the group?
7. Have you accessed any support for Long COVID?
8. Please tell us more about your experiences of accessing support.
9. Anything else you would like to mention?

If you require this report in an alternative format, please contact us with your requirements.

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