healthwatch
Richmond upon
Thames

Living with Long Covid

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Executive summary

This project was undertaken over the summer 2021, to gather information about the experiences of people suffering from Long Covid. We aimed to better understand the condition itself and the impact it has on people's lives and mental health; we also sought to gather people's experiences of the support available for Long Covid, if they had received any.

The main symptoms experienced are fatigue, breathlessness, brain fog and anxiety. Non-linear recovery and significant fluctuations are characteristic of Long Covid, and were widely represented in our data. It does seem that there is a trend towards improvement over time, as people who first got ill before summer 2020 show significantly more improvement than people who got ill after September 2020.

Long Covid impacts patients' life, beyond their physiological symptoms. The overwhelming majority of our respondents reported that their mental health had deteriorated as a result of both the condition and its effects on their lives (see below). This shows mostly through anxiety and depression, as well as irritability and low mood. Some respondents told us that their mental health symptoms felt a part of the illness, rather than coming from the consequences of Long Covid on their professional and personal lives.

Beyond physical and mental health, people's lives are impacted by Long Covid on a deeper level: their employment, caring duties, social lives and domestic duties become neglected following high levels of fatigue. In many cases, it is practically impossible for people to simply carry on with lives as normal.

To meet the needs of Long Covid patients and improve their care, we recommend the following:

- The creation of a peer-led, clinician aided support group,
- Tailored and targeted communication and education on Long Covid,
- A more comprehensive screening process,
- Embedding care coordination in the assessment process.

Introduction

Long Covid, also known as Post Covid Syndrome, is defined by the National Institute for Health and Care Excellence (NICE) as *"signs and symptoms that develop during or following an infection consistent with COVID19 which continue for more than 12 weeks and are not explained by an alternative diagnosis"*. It usually presents with multiple overlapping symptoms, the most prominent ones being respiratory difficulties, generalised pain, fatigue, persistent fever, loss of taste and smell, PTSD, and cognitive and psychological problems.

Long Covid can present in many different ways, including different symptoms that do not necessarily arise at the same time. People also report fluctuating symptoms and a very much nonlinear recovery. There is also no current test for Long Covid: it can only be diagnosed by exclusion, once other possible diagnoses have been refuted. This makes the condition particularly difficult to identify and treat.

Estimates for the number of people likely to suffer from Long Covid vary greatly across different studies, from as little as 2.3% to as much as 37%[1] of all individuals infected with Covid in the first place. This can be due to the research design, the population studied or even the wording of the questions asked. This uncertain estimate makes it difficult to plan and design adequate support services for patients.

Discussions with our neighbouring Healthwatch colleagues and with the local Clinical Commissioning Group brought to light the importance of including people's voices in the design of support services for Long Covid. As a condition that is yet to be fully understood, Long Covid must be treated with the voices of patients as the very central concerns. This led Healthwatch Richmond to undertake a review of people's experiences of Long Covid.

Scope of this work

Healthwatch Richmond worked in partnership with Healthwatch Croydon, Kingston upon Thames, Merton, Sutton and Wandsworth across South West London to collect people's experiences in a similar timeframe and with a similar methodology. This allowed us to collect compatible and comparable data across South West London, to comprehensively inform support services within this area. We collected data about people's experiences of the illness itself, including symptoms and recovery, but also regarding the effects it had on their livelihoods and mental health. We asked people about the support they had received, if any, and about their unmet needs. The full questionnaire can be found in the appendix at the end of this report.

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[1] ONS and COVID-19 Longitudinal Health and Wellbeing National Core Study, (2021) "Short Report on Long Covid".

Methodology

We collected data over July and August, via an online survey. We offered respondents the possibility to contact us by email, phone or post for a more personal interview, should they be more comfortable doing so. We received a total of 93 usable responses.

An online survey was chosen as a method of data collection, as the target group of people suffering from Long Covid is heterogeneous and cannot be accessed easily through one specific organisation. Choosing an online survey allowed us to publicise our project in a widespread manner which would reach a greater number of people.

The survey was built in concordance with input from the Kingston and Richmond Post-Covid steering group, and in concordance with Healthwatch across South West London. The latter agreed to each have a different survey, which would include a common spine of unchanged questions. This allowed each Healthwatch to integrate a more specialised focus to their own survey, while still collecting compatible and comparable data across the six boroughs.

In Richmond, we communicated the survey through multiple platforms, including our own newsletter and social media, and through partner organisations in the borough. The respiratory department at Kingston Hospital, which hosts a Long Covid service, kindly shared the survey to their patients; the South West London Clinical Commissioning Group (CCG) included a link to it on their webpage on Long Covid; Richmond Council published it in their newsletter. Many other organisations and charities throughout the borough were also kind enough to share our project and survey with their service users.

Limitations

Accessing our target group was a challenge, and we would have liked to have the opportunity to reach out to digitally excluded people more than we did. We made the decision to collect data online as it allowed us to reach people during a period of uncertainty and where few in person activities were running; we however urged our partner organisations to talk to their service users that may not use the internet and encourage them to contact us by phone instead. We also mentioned our work on Long Covid and the possibility to talk to us directly every time we did outreach events, including face-to-face.

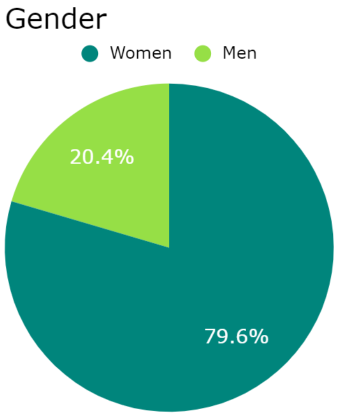
Our demographics data (page 4) shows a rather homogenous pool of respondents, especially in terms of gender, financial status and ethnicity. We discuss below the fact that some of the fields hold potential for findings relating to Long Covid (gender, for example); others are likely showing the limitations of an online survey, such as English proficiency; finally, some are, to some extent, representative of the London borough of Richmond.

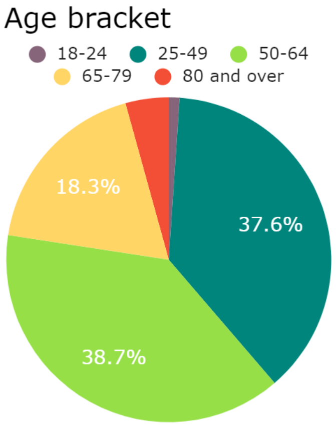
Demographics

We received 93 responses for gender and age group, 92 for English proficiency and ethnicity, 91 for pre-existing conditions and 87 for financial status. 87% of the respondents are residents of Richmond; 10% are not residing in South West London, but we expect them to engage with our health economy (e.g. Hounslow or Surrey residents).

Gender divide

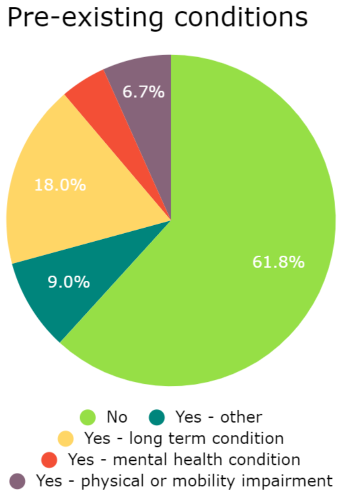
We received considerably more responses from women (74) than men (19). While women are often overrepresented in survey responses about health, the difference is greater than would normally be expected. This is consistent with the findings of studies[2] that women were more likely to report symptoms of Long Covid. This could be due to women being more likely to suffer from Long Covid, being more likely to report symptoms, or more likely to have their livelihoods impacted by the illness. We do not have sufficient data to indicate which is more likely.





Age groups

The majority of respondents are of working age. We did not receive any answer from minors, but did receive over 20% of answers from people above 65. While this can be a limitation of an online survey, it also seems consistent with the age groups of people likely to suffer more acutely from Covid-19 in the first instance (ONS data).



Pre-existing conditions

Almost 40% of the respondents reported suffering from a pre-existing long term health condition, either regarding physical or mental health. This suggests that individuals with pre-existing conditions are more likely to suffer from Long Covid. It is however important to also note that many qualitative answers detailed the lives of previously healthy individuals now suffering from severe symptoms of Long Covid.

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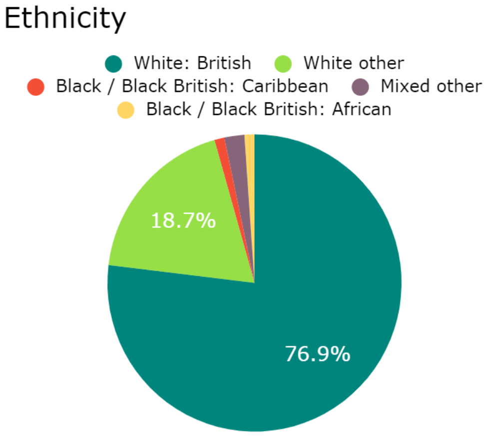
[2] H. Davis *et al* (2021). "Characterizing long COVID in an international cohort: 7 months of symptoms and their impact". Volume 38, Aug. 2021. Accessible in open access.

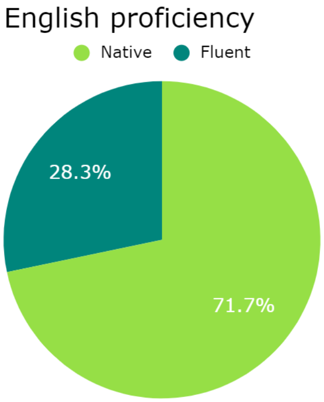


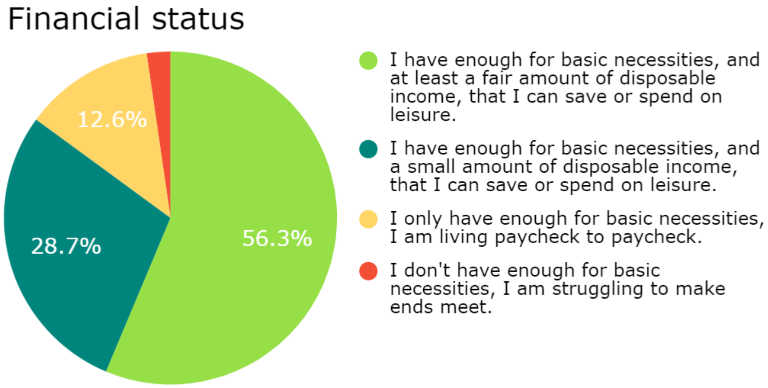
Ethnicity

The responses we received are broadly reflective of the community of Richmond for people from White British (76.9% vs 71.4% population) and White other (18.7% vs 14.5% population) ethnicities. However, the numbers of respondents from other backgrounds are very small (4.4% vs 14% population). We strive to reach our wider population, and conducted significant outreach to minority community groups parallel to this work. This however did not yield significant numbers of responses. The data we collected does not allow us to speak about the experiences of people from non-White backgrounds. Further work to understand experiences of people from Black and Asian backgrounds, perhaps over a broader geographical area is necessary.

English proficiency

The questionnaire left options for conversational, basic and no level of English, all of which were answered by none of the participants. This could be due to multiple reasons, such as people with a more limited English level would be less inclined to answer our survey, which included qualitative answers; they could also be less likely to identify as having Long Covid, or less likely to access support and therefore to answer the survey. We cannot make any assumptions based on the answers gathered here.





Key findings

Symptoms and recovery

The survey included a grid question, with 12 symptoms for which respondents could indicate the severity. The options were “Never experienced/got better within twelve weeks”, “Mild - did not stop me doing anything”, “Moderate - made it difficult to do something”, and “Severe - made it difficult or impossible to do something”. Out of 93 respondents, 7 people reported suffering from moderate to severe fever, which was significantly fewer than any other symptom. We therefore removed fever from the following analysis, for ease of reading. The other 11 symptoms were reported as follows:

	Mild	Moderate	Severe	Total	
				Percentage	Number
Breathlessness	19%	35%	15%	69%	65
Fatigue	13%	35%	39%	87%	81
Muscle pain	18%	27%	16%	61%	57
Anosmia	18%	18%	12%	48%	45
Brain Fog	24%	34%	22%	80%	74
Anxiety	24%	25%	22%	71%	65
Heart	20%	30%	13%	63%	59
Headache	23%	20%	19%	62%	58
Insomnia	19%	23%	18%	60%	56
Rashes/ Skin	28%	10%	4%	42%	39
Memory loss	26%	17%	17%	60%	56

The most reported symptoms are unsurprisingly fatigue (81 people), brain fog (74), breathlessness (65) and anxiety (65).

Respondents were also asked to provide any symptoms not listed in a free text box. The following were mentioned a number of times separately, in a follow-up qualitative answer:

- 11 dizziness, balance issues and weak legs
- 10 Gastrointestinal issues, diarrhoea and/or nausea
- 8 pins and needles (including head)
- 8 sore throat and coughing
- 7 tinnitus and hearing loss
- 6 blurred/double vision and/or watery eyes
- 3 mucus overproduction
- 2 hair loss

We focused our analysis on moderate and severe symptoms, in order to best grasp the impact that symptoms have on people's lives. Most respondents reported multiple moderate to severe symptoms lasting for at least 12 weeks. We can read in the following table that 40 people reported suffering from moderate or severe muscle pain; 29 people suffering from muscle pain also reported suffering from memory loss. Similarly, 38 of the 47 people who reported suffering from breathlessness also reported suffering from brain fog.

Moderate and severe	Breath-lessness	Fatigue	Muscle pain	Anosmia[3]	Brain fog	Anxiety	Heart[4]	Headache	Insomnia	Rashes /skin[5]	Memory loss
Breathlessness	47	42	33	15	38	27	33	25	29	10	26
Fatigue	42	69	38	23	48	40	36	36	36	12	29
Muscle pain	33	38	40	16	31	28	24	23	23	10	29
Anosmia[2]	15	23	16	28	19	17	13	11	16	8	12
Brain fog	38	48	31	19	52	34	34	31	32	12	32
Anxiety	27	40	28	17	34	43	28	25	26	9	22
Heart[3]	33	36	24	13	34	28	40	25	23	10	23
Headache	25	36	23	11	31	25	25	37	24	7	20
Insomnia	29	36	23	16	32	26	23	24	38	10	21
Rashes/skin[4]	10	12	10	8	12	9	10	7	10	13	8
Memory loss	26	29	29	12	32	22	23	20	21	8	33

The conditional formatting has been done by column, so that a darker colour shows the prevalence of a symptom or combination of two symptoms. As such, it is visible that a small proportion of people who experience fatigue or brain fog also experience rashes or symptoms related to the skin; however, since only 13 people reported suffering moderately to severely from rashes or skin symptoms, a large proportion of this group reported also suffering from fatigue or brain fog.

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[3] Was presented in the survey as "loss of smell/taste or appetite"
[4] Was presented in the survey as "Chest tightness and/or palpitations"
[5] Was presented in the survey as "Rashes and/or other symptoms related to the skin"

The same numbers can be translated into percentages for each column, as observed here:

Moderate and severe	Breath-lessness	Fatigue	Muscle pain	Anosmia	Brain fog	Anxiety	Heart	Headache	Insomnia	Rashes /skin	Memory loss	*Averages*
Breathlessness	100%	61%	83%	54%	73%	63%	83%	68%	76%	77%	79%	73%
Fatigue	89%	100%	95%	82%	92%	93%	90%	97%	95%	92%	88%	92%
Muscle pain	70%	55%	100%	57%	60%	65%	60%	62%	61%	77%	88%	69%
Anosmia	32%	33%	40%	100%	37%	40%	33%	30%	42%	62%	36%	41%
Brain fog	81%	70%	78%	68%	100%	79%	85%	84%	84%	92%	97%	82%
Anxiety	57%	58%	70%	61%	65%	100%	70%	68%	68%	69%	67%	67%
Heart	70%	52%	60%	46%	65%	65%	100%	68%	61%	77%	70%	64%
Headache	53%	52%	58%	39%	60%	58%	63%	100%	63%	54%	61%	57%
Insomnia	62%	52%	58%	57%	62%	60%	58%	65%	100%	77%	64%	62%
Rashes/skin	21%	17%	25%	29%	23%	21%	25%	19%	26%	100%	24%	25%
Memory loss	55%	42%	73%	43%	62%	51%	58%	54%	55%	62%	100%	54%
Averages	55%	46%	60%	50%	55%	55%	58%	57%	59%	69%	62%	

48 people that suffer from fatigue also reported suffering from brain fog; this translates to 92% of people suffering from brain fog also suffering from fatigue, and 70% of people suffering from fatigue also suffering from brain fog, as seen in the second table. Interestingly, on average, only 46% of people experiencing fatigue also experienced any other given symptom; conversely, on average 92% of people who experienced any other given symptom also experienced fatigue. This indicates that fatigue is a central part of Long Covid. It is unsurprising, as 74% of the total number of respondents indicated suffering from moderate to severe fatigue.

We could not identify any specific clusters of symptoms, only predominant as opposed to less common ones: it did not appear as though people were experiencing either one specific group of symptoms or another. This highlights the uniqueness of Long Covid, the many forms it can take, and exacerbates the difficulty to identify it. Further research on symptom clusters, with additional data, would be useful.

Symptom fluctuations

One reported characteristic of Long Covid is the fluctuation of symptoms and **nonlinear recovery.** With this in mind, we asked people how their symptoms were evolving over time. We included a grid question, with the same 12 symptoms as above (reported here also without fever), and the possibility for each to choose “Never experienced/got better within 12 weeks”, “Fluctuating”, “Improving”, “Worsening”, “No change” and “Unsure”. Removing “Never experienced”, “Unsure” and the blank answers, we find the following data:

	Fluctuating	Improving	No change	Worsening	*totals(n)*
Breathlessness	42%	33%	20%	5%	**60**
Fatigue	44%	32%	21%	3%	**75**
Muscle pain	24%	40%	26%	10%	**50**
Anosmia	23%	53%	23%	3%	**40**
Brain Fog	38%	38%	18%	6%	**68**
Anxiety	34%	38%	15%	13%	**61**
Heart	45%	35%	15%	5%	**55**
Headache	39%	41%	8%	12%	**51**
Insomnia	39%	25%	24%	12%	**51**
Skin	26%	41%	26%	6%	**34**
Memory loss	37%	37%	17%	9%	**54**

Reassuringly, few people reported worsening symptoms. On average, 39% of respondents indicate that their symptoms have been improving, 35% that they have been fluctuating, 19% that they have remained the same, and 7% that they have been worsening.

We asked for further details about symptoms fluctuations, so that people could give us a more qualitative description of their situation. Many people told us that their symptoms were fluctuating, sometimes **unpredictably**.

> *“It was an extremely slow journey but one I felt I was winning until about three weeks ago when I had a relapse. Heart rate has started to get higher on just walking and fatigue has been worse.”*
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> *“Symptoms have been fluctuating and I can't identify an underlying pattern.”*

Post-exertional malaise (symptoms exacerbated by exertion) is a recurring theme within the qualitative answers that we collected. 22 people told us that exercise was difficult or impossible, or that attempting it often leads to relapses in symptoms. Many explained that exercising a little beyond their comfort could lead to multiple days of being bed bound.

> *“I can't exercise and if I e.g. go for a 30 minute walk I typically can write off a whole day 2 to 3 days later.”*
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> *“I am unable to do any exercise as I end up having pain later and all my symptoms get worse if I do too much.”*
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> *“I have had 3 relapses in 10 months and it seems to be [brought] on by pushing myself too hard physically and by stress.”*

Many people told us that they had noticed the importance of **pacing**, of adapting their lifestyles to require less energy in order to avoid relapses.

> *“I don't know if my symptoms have changed that much but I am learning to manage them better. I use pacing to try to only 'spend' the limited energy that I have - to do 75% of what I think I can do - the minute I do too much I get a crashing headache and have to go to bed. I have modified my life in many ways. I have to take regular breaks throughout the day - I can't do my usual exercise schedule - nothing cardio - I walk slowly and a limited distance - social events are often a complete no-starter. I've reduced my work hours as the cognitive load is possibly greater than the physical load and screen time is really [wearing]. I can't read books - just 10 mins at a time is all I can do without a headache. I can shop for a short while but have to plan it all in advance so I can sit and rest.”*

A total of 10 people mentioned observing changes in their condition following the administration of the Covid **vaccine**, but no common trend emerged: 5 people felt their condition worsened, 5 felt it improved. We did not receive enough details to know whether there was a distinction to be made between the different vaccines.

> *“I felt I was really recovering but both Pfizer vaccinations set me back”*
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> *“tons improved a little after 2nd jab”*

The fluctuations and cycles of Long Covid are inherent to the illness, and part of what makes it difficult to live with (see later sections). Learning to pace and recognise patterns is a significant challenge for patients.

Recovery over time

Encouragingly, a number of people reported noticing some improvement in their condition, albeit slow and irregular.

“Relapses are shorter - about 2 days rather than months”

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“Fatigue is the lasting symptom, and is very slowly improving.”

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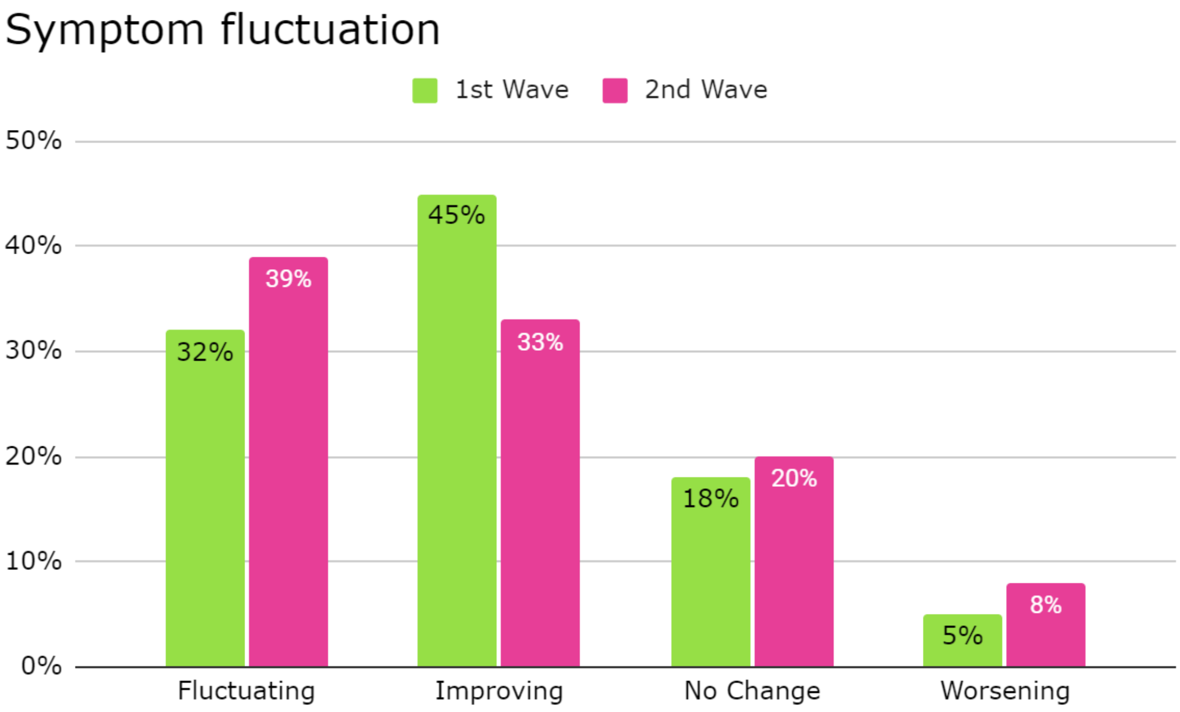
“I’ve kept a graph to chart my bad medium and good days and over a six/seven month period I’ve seen a gradual improvement with steadily increasing numbers of good days with decreasing numbers of bad days in between”

To observe if there was significant improvement over time, we divided our respondents into two groups. The first group included people who first got ill in the first half of 2020, up until July (50 people); the second group included people who first got ill afterward, from August 2020 to March 2021 (40 people). These dates emerged as clear waves of Long Covid onset from the data and is an approximation of the waves of Covid observed in the UK. 3 people had not provided an answer to this question and were therefore not included.



As shown in the above graph, we can observe that people who first got ill in the first half of 2020 show a greater tendency toward improvement than people who got ill later on. This can be due to different factors, such as a different variant of Covid or a non-representative group studied; it seems however likely, considering our qualitative answers, that people are more likely to get better after some time has passed. This is encouraging to see, especially for people who told us they were feeling anxious and fearing that they would not get better.

Living with Long Covid

Impact on life

90 people provided information about the impact of Long Covid on their lives. Of those 90, only two people answered that Long Covid had no significant impact on their life. This means that at least 93.6% of people have some significant impact on their lives. From what people have told us, we noted that the main areas of concern are people's livelihoods, their ability to fulfil caring duties, their relationships and social lives, and their ability to complete non-urgent tasks.

Strain on livelihoods

26 people told us that they had to work more flexibly or work fewer hours, which at times put a significant strain on their finances. One person told us they had to move back in with their family. 3 other people told us that their suffering from Long Covid cost them their employment.

> *"I have had to reduce my work and it makes day to day life a struggle"*
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> *"I lost my job."*
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> *"Unable to work at all for 10 mths. Lost a new job I had secured before becoming ill. [...] Unable to parent my children at all for 5 mths. [...] My partner has been my carer. Have not seen friends for 14 months as unable to socialise. Was depressed and highly anxious for 3 mths.[...] I was a hard working career woman and active involved Mum to two children. It is not only my quality of life affected but my whole family's - children and partner."*
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> --
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> *"I am unable to work at the moment and now the Universal Credit people are hounding me and treating me like some kind of criminal. I deeply resent this and it makes me horribly anxious and depressed"*
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> *" If I can't keep the pace up at work and lose my job, (work have been extremely understanding so far), how will I be able to support my family? The worry isn't helping the symptoms."*

The impact of Long Covid on people's livelihoods is clear: for so many, carrying on as usual with work and the rest of their lives is unthinkable. As can be read above, people's stories are complex, and Long Covid has an effect far beyond the physical health of one patient.

Caring and social duties

10 people told us that suffering from Long Covid impeded their ability to care for their loved ones, often their children. In many cases they had to transition from carer to being cared for.

“I have 3 young children so just keeping up with their needs takes everything out of me”

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“I now need a lot more support than I used to. Before I had a carer come in once a day and I would get by. Now I need a carer 3 times a day and a housekeeper once a week. My son comes to visit every other evening and my daughter occasionally. I can't even go to the bathroom on my own, it's that bad. I used to care for my wife and do everything for her, the cleaning, shopping cooking. Now I can't and she's in a care home that I can hardly visit. I don't think she knows me anymore. She can't do any of the things she used to like. I can just about afford private carers and I get by but it's difficult.”

These narratives show difficult stories, often with an implicit feeling of guilt for no longer being able to provide care and having to rely on loved ones to get by.

Strain on friendships and relationships

15 people told us their social life decreased or disappeared due to their condition. 8 people told us their relationships with their partner or close family suffered as a result of Long Covid.

“My husband also has long Covid. This has put a strain on our relationship and we have both been to therapists to help with the stress and anxiety.”

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“There’s isolation [...] as you can’t socialise in the way you did before. People think you look ‘normal ‘ so you must be well. My husband & I have no proper time [...] together. We miss our relationship as it was.”

People tell us that they can’t simply go out anymore, either out of anxiety or physical inability to cope with the strain. They tell us that the illness takes a toll, not just on their physical health, but also on the elements of their lives that would bring them joy.

Inability to complete small tasks

People reported having much less energy, being in pain and unable to exercise. Tasks therefore require more effort, and with a significant need for pacing, anything other than strictly necessary tasks is scrapped.

“[it] had a significant impact on my quality of life, being both unable to work, socialise or carry out most daily tasks including childcare”

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“Things like cleaning out cupboards, searching for a new sofa, fixing a broken piece of jewelry - nothing major but the sorts of things I might find time for at the weekend often go by the board.”

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“I have only just returned to work on much reduced hours, I have lost all my confidence

> *and social skills and afraid to go out, I never suffered with anxiety or depression but have now been having panic attacks too all due to this awful disease. My Husband and daughter had to help wash my hair as I couldn't lift my arms up due to the pain and [swelling] in my joints"*

Long Covid can affect lives in more ways than one, and creates situations that go beyond physical health issues for people living with it. Financial and social strain are very common themes among our responses, with terribly saddening stories at the heart of it.

Impact on mental health

73 people described a negative impact of Long Covid on their mental health, 14 reported no effect and 6 people did not answer the question. This means that at least **78% of respondents** had some impact of Long Covid on their mental health.

> *"It is very wearing spending the days feeling 50% ok. I'm managing fine and I have good friends who help but I don't know how long I can carry on in this way without some effect. Worse is the uncertainty that things may not improve or that in fact I have some other illness causing the symptoms."*
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> *"to live with a new illness with almost zero medical understanding and no route back to health or normality - I do not believe anyone can be 8 months in and not have found this mentally very challenging. I miss the person I used to be and the life I used to have. I do not know when I will get better or what treatment will ever be offered to help me. Will I ever be 'normal' or well again?"*

Anxiety, depression and general low mood were the most common symptoms reported, with 22.6% of respondents saying they were suffering from anxiety, 19.3% suffering from depression or feeling depressed, and 17% suffering from low mood. A further 8 people also told us that they were easily irritable, grumpy and frustrated, possibly due to the fatigue and lack of energy. Some people also experienced **severe mental health issues**, to the point of self-harm and suicidal thoughts.

> *"I have become more anxious and my body overreacts to situations that I would normally have been calm about. The inability to do much especially in previous months made me feel low at times. [...]I have been seeing a therapist for months to provide support."*
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> *"Regular bouts of anxiety and depression - including suicidal thoughts."*
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> *"I do not currently get enjoyment from social settings as I once did and actually feel so boring that other people will not want to be around me."*

People told us that their mental health often degraded in concordance with physical relapses, and that it sometimes **felt like a neurological or hormonal symptom** of Long Covid, on top of the generalised worry about the impact of Long Covid on their lives and an uncertain improvement.

> *"When I'm in a covid relapse I feel there is a biological cause [to] the mood impacts I experience. They completely disappear when I'm not in a relapse. Sometimes I also experience a few days of elevated mood following a relapse."*
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>
> *"Very anxious initially - felt part of the illness. Also became depressed for a while- also felt part of the illness eg low serotonin. My mental health has improved as I became physically better. I now feel low in mood sometimes but pay attention to this and work psychologically to manage it."*

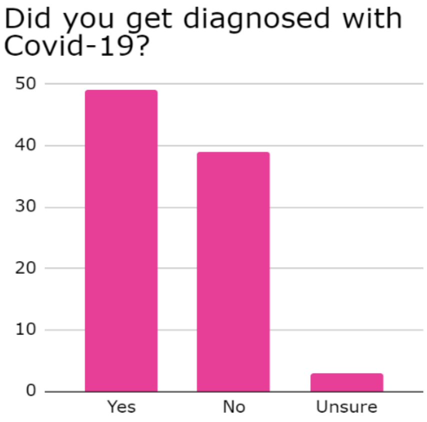
Mental health is an important aspect of Long Covid. Anxiety especially appears to be not just a consequence of lost function or quality of life but also a symptom of the illness. Damaged livelihoods make it even more difficult for people to remain mentally healthy. Many people expressed a great need for support for mental health as well as for their physical symptoms.

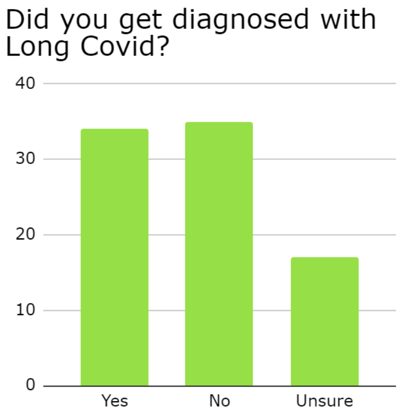
Support and access

Of our 93 respondents, only 33 told us they had accessed some level of support, 7 were not sure and 53 had not accessed any support. It is important to note that this research took place during a period of high demand on NHS Services and early in the development of Long Covid support. We hope the findings of this work will lead to improved support for people living with Long Covid.

Diagnosis and access

We asked our respondents whether they had received a formal diagnosis of Covid-19 in the first place, and of Long Covid. Most people have received a Covid-19 diagnosis but not a Long Covid one, although not by a large margin. It should be noted that 17 people did not know whether they had actually received a Long Covid diagnosis. This comes mostly from patients discussing the issue with their GP but not receiving a formal diagnosis. This makes it especially important to then know whether obtaining a diagnosis has an effect on people's ability to access support.





Getting a Covid diagnosis in the first place seems to have a limited effect on whether people accessed support:

		Did you get diagnosed with Covid-19 (When you first got ill)?				***totals***
		Yes	No	Unsure	N/A	
Did you receive any support?	Yes	19	12	1	1	**33**
	No	27	24	2	0	**53**
	Unsure	3	3	0	1	**7**
totals		**49**	**39**	**3**	**2**	**93**

Unsurprisingly, getting a Long Covid diagnosis does seem to have a much larger effect on whether people access support: of the 34 who *did* get a Long Covid diagnosis, 23 accessed support, 10 didn't and 1 was unsure whether that had received support or not for Long Covid. Of the 35 people who did *not* get a diagnosis for Long Covid, only 4 accessed support, 29 didn't and 2 were unsure whether or not the support that they received was related to their Long Covid.

		Did you get diagnosed with Long Covid?				***totals***
		Yes	No	Unsure	N/A	
Did you receive any support?	Yes	23	4	5	2	**33**
	No	10	29	10	4	**53**
	Unsure	1	2	2	1	**7**
totals		**34**	**35**	**17**	**7**	**93**

When people got sick seems to have no bearing on whether or not they received support: 56% of people who got ill in the "first wave" did not get support, as opposed to 58% for people who got ill in the "second wave". Similarly, 36% of people who got ill in the "first wave" did receive support, versus 35% for the "second wave".

If getting a diagnosis has an effect on people's ability to access support, and most people are unable to obtain a diagnosis, there is a risk that **a significant number of people will be**

excluded from support. This is consistent with multiple respondents' statements that people **did not feel believed** by healthcare professionals.

> *"Completely insufficient from the GP and NHS. Medical testing was needed from the start and more belief in my self report about my symptoms and the severity of them. I did not feel believed."*
>
> --
>
> *"Not being believed by some medics who seem to arrogantly think that if they don't understand something that means it doesn't exist, was & still can be incredibly difficult. Not having a GP that could spare the time to listen even if they didn't have the solutions. Being told it was anxiety rather than tachycardia triggered by a virus actually made me anxious & angry! Being told it was mind over matter when I couldn't walk out of my own house without ending up in bed for the next few days."*
>
> --
>
> *"You feel alone and that there is no help. Even a diagnosis would mean that you felt like there was a reason to the way you were feeling."*

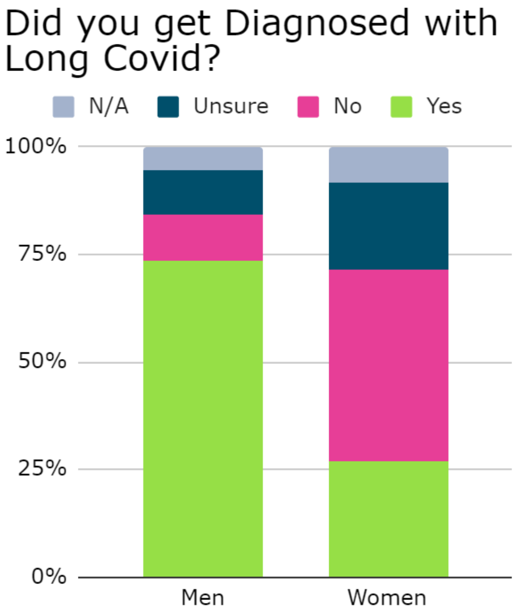
Similarly, many people **did not feel like they could reach out to their GP**, because they were aware of the pressures that the NHS was under and because they felt that either their needs were not sufficiently urgent or that practices would not see them due to the other demands on their time.

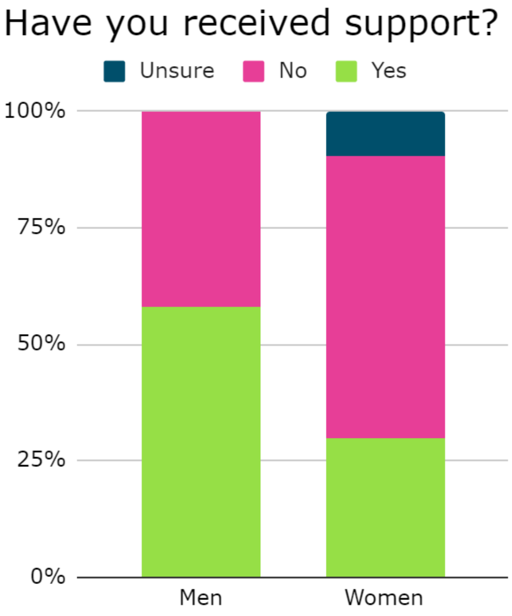
> *"I would have seen the GP months and months earlier but with the 2nd wave I thought that I should probably manage myself and leave the GP appointments for those who were more acutely unwell. I needed help but not being able to exercise didn't feel as important as people who might have been sicker."*
>
> --
>
> *"I realise that the NHS have been overwhelmed and Long Covid is a new illness but think I would have benefited from more support from the NHS earlier on. Social media has been my biggest support and I have been proactive in finding out as much as I can about it in order to support myself"*
>
> --
>
> *"I dread phoning my GP as during the whole pandemic, I found the reception staff aggressive and unhelpful. Other locals have said the same thing"*
>
> --
>
> *"Only just got in contact with doctor as they are busy and did not feel it was urgent"*

Diagnosis, Access and Gender

The below figures must be interpreted with caution, as we received only 19 answers from men, against 74 answers from women. It is possible that men are likely to identify as having Long Covid only if they received a diagnosis, and would therefore less likely to fill in the survey if they hadn't. It is also possible that different gender roles mean that more women are affected by Long Covid than men in their daily life and are therefore more motivated to report it.

Our data shows a stark **gender divide** in access to a diagnosis. 74% of the men who answered the survey received a diagnosis against 27% of women. Similarly, 58% of men accessed support for their symptoms (11), against 30% of women (22). This is despite men and women reporting the same severity of symptoms, and men showing marginally more improvement in their symptoms than women. The difference is stark enough to call for a discussion around this though, and possibly for more research.

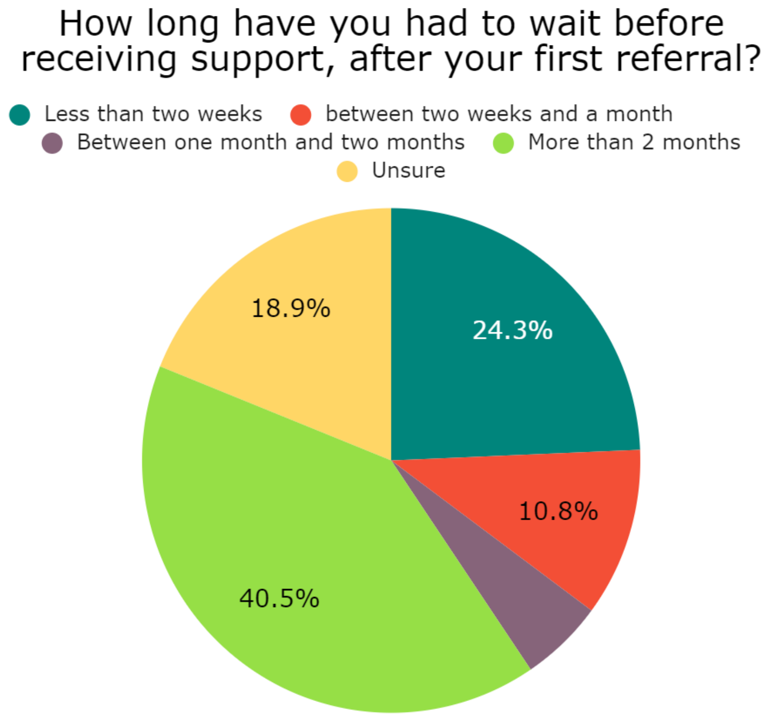




Waiting times

Of the 40 people who answered our questions on support (the people who said they hadn't accessed support were forwarded to the next section), 15 told us that they had to wait over 2 months for support after their first GP referral. This represents over 40% of the answers. Two months was the highest bracket in our scale, and qualitative answers indicate that the wait was often much longer than this.

Many of the respondents still haven't received any support and are on long waiting lists. At least one person was told by their GP that as the waiting list for the Long Covid clinic was longer than 12 months, there was no point in making a referral.



> *"We have a half hour telephone appointment with UCH next May!"*
> *(answer recorded in July)*
>
> --
>
> *"When I saw my GP, she said that the waiting list for Long Covid support was well over 12 months so there was no point in referring me."*

Of the 13 people who answered that they waited less than a month after their first instance referral, 5 later explained that they had not actually received a referral and only received support from their GP; 3 accessed support privately; 2 accessed diagnostics in the form of an ECG and an x-ray. One person got an appointment with an occupational therapist, one received support from the Long Covid clinic and one received support after being admitted to hospital (for something unrelated to Covid but testing positive) initially.

8 people told us that they had not been referred to any further service, either because the waiting lists were too long, their needs were met, or there was no knowledge of any available service. 8 other people told us they were on a waiting list.

Resorting to private support

As a consequence of long waiting times, the feeling of not being believed and the reported lack of available support, many people told us that they resorted to private healthcare, despite not always being able to afford it.

“Getting support is extremely time consuming and exhausting. Sometimes it's frighteningly expensive.”

--

“I feel incredibly fortunate that I had private medical insurance and was able to be seen quickly”

--

“I am lucky to have private medical insurance as I have been warned by my GP [that] waiting lists are large for the support I have received.”

--

“Still have not had any kind of joined-up NHS care for my long covid”

--

“The private appointments certainly helped”

--

“Only the help I have received at huge cost privately has actually helped apart from OT with pacing has been helpful”

--

“I didn't always feel believed and had to speak to multiple GPs. I needed one person to look after my case and understand it given the multitude of symptoms I had and how unwell I was. [...] I sought my own help privately after from a nutritional therapist, osteo and cardiologist. All helped. Particularly [the] cardiologist who finally believed me about my heart symptoms.”

While Long Covid is a new illness and it is fully understandable that the creation of adequate support services takes time and research, many answers show frustration, anxiety and isolation caused by the difficulty in accessing NHS support for their illness. The costs of private care, sometimes combined with a loss in revenue following the illness, create significant financial strain on patients.

What works and what doesn’t work

Long Covid manifests itself in many different ways and access to support is inconsistent. People described variation in how effective different treatments were for them and there was no consensus on what treatment options worked best for people.

In terms of **self-management**, people found that **pacing, support groups** and **nutrition monitoring** were helpful in managing relapses and anxiety. Pacing and nutrition were mentioned by 9 people as helpful in regulating energy levels and not "overspending" limited energy. Support groups were seen by 4 people as useful to reduce the feelings of isolation and worry, which were making an already difficult situation worse. Interestingly, the NHS Your Covid Recovery website was not mentioned as a helpful self-help resource. People instead seemed to find support and advice on social media or via existing groups for ME / Chronic Fatigue Syndrome.

Nutritional information and support, as well as support with understanding planning pacing, were also identified by RUILS, the social prescriber and independent living charity in Richmond, as a needs for residents with Long Covid.

"I have found help through online CFS communities and resources. Pacing, mindfulness, somatic experiencing, breathing exercises, careful diet and emotional authenticity are all important"

--

"I followed long covid support groups in sept 2020, was great to see I am not alone [...] ultimately I think from people who have left the group who have recovered it is pacing and changing lifestyle and mindset that is the most important factor"

--

"Most useful support from a Facebook group which I found early on. Mutual support and sharing of information was invaluable. This resulted in finding a yoga and PT group for Covid recovery."

--

"I am on a low histamine diet and haven't touched alcohol since early Nov. I take a range of supplements and practice meditation."

--

"I only know I'm not the only sufferer which helps me so don't feel alone"

For the people who have received or sought support, **GPs have been crucial** in determining how satisfactory the level of care was. As the first point of contact and single point of access for people who were not admitted to the hospital, GPs are central to Long Covid care. This is especially true as the varied symptoms for Long Covid are usually treated separately - by default, the GP therefore holds a care coordinating role. Some people told us that they felt their GP was not keen either to help or to believe them, and that there may still be a lack of professional understanding about Long Covid.

“Once [the GP] ruled out other serious issues I was left to my own devices”

--

“Completely insufficient from the GP and NHS. Medical testing was needed from the start and more belief in my self report about my symptoms and the severity of them. I did not feel believed.”

--

“GP no support, pass it of[f] as something else”

Others told us that the efforts made by their GP, regardless of the final outcome, were deeply appreciated. The differences in these stories only highlights the importance of GPs in patients’ care and recovery.

“My GP has been the biggest support by far. He has been actively getting me to have X-rays and blood tests, referred me to physio and CBT too. He has been prescribing me medicine to help with individual issues where he has been able to and we have [trialled] things like painkillers. I have been referred to the Long COVID Clinic in Croydon too, but in the past 3 months I have only had 2 telephone conversations and my lung tests are next week - I was told they are very busy there.”

--

“my GP [has] been helpful and ha[s] provided referral letters to access private medical”

--

“They have all done their best given little or no actual knowledge particularly in the early days.”

Some people told us about the **prescriptions** they received and whether they helped or not. The answers reinforce the point that Long Covid treatment must be done on a case by case basis, likely with some trial and error. Inhalers for example were mentioned by a few people and were sometimes considered really helpful, other times useless.

“Steroids are helping - a lot to start with but now, as the dose is reducing, they are having less effect on remaining symptoms.”

--

“Tried valproate and nortriptyline but neither were much help”

--

“The medication for my anxiety and depression is helping.”

--

“I've been prescribed an asthma pump which helps by taking the edge off of my breathlessness when I have it but doesn't completely remove the symptoms.”

--

“No help given other than inhalers which haven’t worked”

Occupational Therapists (OTs) were mentioned by 5 people, along with positive feedback. People, albeit limited numbers, who had experienced this support seemed to unanimously find OTs helpful, even when they were otherwise not satisfied with the rest of their care.

“The biggest support has been the OTs who have helped with confidence, support and encouragement and pacing advice”

--

“Only the help I have received at huge cost privately has actually helped apart from OT with pacing has been helpful”

--

“The support from the OT has been great in terms of practical things that help me manage the condition such as pacing, breathing exercises, tips for better sleep, mental health and other info. He told me about a breathing course which I have now taken part in. His support has also helped me to feel less alone with it and he has coached me to work out how to use my limited energy in a way that makes each day more possible.”

9 people told us that **the support was not person centred** and felt lacking, somewhat patchy, as it mostly treated each individual symptom instead of the condition as a whole. They felt as though a more comprehensive approach was needed, especially if different symptoms are treated within different timelines, because of separate waiting times.

“It has been patchy and piecemeal. Sometimes helpful, often useless.”

--

“It would be fantastic if I could have been offered a more holistic package of care and investigations rather than separate appointments with disjointed hospital departments. It would have been amazing if I had been asked about my broader responsibilities and my ability to cope with them.”

--

“I would really appreciate if there was support on how to pace and also on how to communicate my situation to my work etc.”

Missing from the data on what works is support for **financial needs and caring duties**. People living with Long Covid not only require help for their physical and mental health, but also for the consequences the illness has on their life, their livelihood and caring duties. This, and our above findings, are also supported by the observations of the charity RUILS in Richmond.

Outcomes

Overall, it appears that support was difficult to access which seems to have reduced the effect on people’s conditions. We therefore looked at the quantitative data collected, to estimate whether the support received made a substantial difference on whether people reported improvements.

We asked people whether each symptom was improving, fluctuating, worsening or not changing. Excluding the counts of symptoms never experienced and of questions left blank, we were able to count the number of times people reported that a symptom had evolved. This gave us a total of 217 occurrences for people who had received support and 352 occurrences for people who had not. We then differentiated this data according to whether people had reported receiving support or not - in this case, people who had answered “unsure” were not included.

	Improving	Fluctuating	Worsening	No Change	**Totals**
With Support	41%	39%	6%	15%	217
Without Support	36%	37%	9%	19%	352

People who received support reported improving more frequently (41% vs 36%) and worsening symptoms less frequently (6% vs 9%). This is consistent with the qualitative feedback detailed above, where people told us of the difficulty they had in finding treatment that worked and the high number of people reporting that they sought private support.

Key learnings and Recommendations

We acknowledge that this work was undertaken at the very beginning of Long Covid support systems being set up and with an ongoing pandemic. It is to be expected that these exceptional pressures and unprecedented challenges would result in difficulties to access care, and we are grateful to all healthcare professionals that work incredibly hard to support patients through the crisis.

Isolation and information

Many people with Long Covid feel isolated and alone. Partly this is due to social restrictions, social anxiety and fear of getting ill again. Having a new condition that is not well understood is also important in this. It is worsened by sometimes not being believed by health professionals and personal contacts, lengthy waits for support or being told that no support is available. People also said that they struggle to find relevant information to their condition, and that online support groups are helpful with this.

RECOMMENDATION 1: Create a peer-led, clinician aided support group

There is a clear demand for peer support and more widespread education on Long Covid. The Long Covid Steering Group should explore setting up support groups that are peer-led but clinician supported as they could be of great benefit to patients, offering a chance to minimise feelings of isolation and to share knowledge about the condition. Diabetes UK and similar support groups become a valued resource to patients, and a similar model would significantly help meet the needs of Long Covid patients and promote evidence based approaches to self-care.

RECOMMENDATION 2: Develop self help support

There is a lack of self-care advice and low awareness of the available resources such as they are as evidenced by its absence from responses. Communications about the national and South West London webpages of resources should be undertaken. This is an important element to let people know about what the illness is, how to self-manage it and how to access support if needed.

Online resources and community resources need to develop both to provide more options for supporting the symptoms of Long Covid and its wider impact on people’s lives, for example by linking with debt, employment and relationship advice.

As seen in our findings section, GPs are central to determining the patient’s quality of care for Long Covid. Resources should be made available to GPs to support their patients to access support.

Care coordination and person centred support

RECOMMENDATION 3: A comprehensive screening process

We saw in our findings section that people are impacted by Long Covid in many ways and often beyond their medical symptoms. People often face challenges such as loss of livelihood, impossibility to fulfil domestic and caring duties, and mental health issues.

These all represent needs that are currently not met. The first step towards meeting those needs is to develop the assessment of Long Covid beyond its medical symptoms and to include the wider implications of living with Long Covid on people's lives.

The current screening tools for Long Covid address the multitude of symptoms that are known, including mental health symptoms. We recommend that the screening tool is expanded to also assess financial, social and domestic needs.

RECOMMENDATION 4: Coordinate care

Diagnosis and treatment of Long Covid is inherently difficult as the condition comprises multiple overlapping symptoms that appear to vary widely. There are also significant pressures on waiting lists due to the pandemic which create delay in accessing care.

Most of our respondents (57%) had not accessed care. Some had resorted to private care. Most however expressed that the need for a straightforward way to access timely, comprehensive care that addresses their symptoms and wider needs is clear.

GPs are central to determining how satisfactory care is for people, particularly those who were not admitted to hospital with Long Covid. As well as providing prescriptions to treat different symptoms they play an important coordinating role in enabling people to access wider support.

Primary Care Networks (groups of GP practices) present opportunities to support care coordination and to help people to identify and access support for their medical and non-medical wider needs and to improve experience and outcomes.

Responses to our work

The Kingston and Richmond Post-Covid steering group

The Kingston and Richmond Post-Covid Steering Group brings together a number of health and care professionals and coordinates the organisation and delivery of support services for Long Covid, across the boroughs of Kingston and Richmond-upon-Thames.

We have worked in partnership with the group throughout our project, and will continue to attend meetings regularly. We asked the group to read and review our report, and provide a formal response to our findings and recommendations.

> *'We would like to congratulate Healthwatch Richmond on an informative and professional report looking at the impact of Long Covid on Richmond residents. The report provides data and insights which the Kingston and Richmond Post Covid Steering Group will be able to use to inform the ongoing development of local Long Covid Services. We look forward to continuing to work closely with Healthwatch Richmond in this area."*
>
> **Dr. Annette Pautz and Denise Madden, on behalf of the Kingston and Richmond Post Covid Steering Group**

We look forward to working in partnership with the group to see our recommendations implemented and improve the support for people suffering from Long Covid.

RUILS

RUILS is a user-led charity supporting disabled children and adults and people with long term health & mental health conditions. Part of their work relates to Social Prescribing, including befriending services and support groups; they also provide social care advice. In that capacity and considering our findings of significant isolation for Long Covid patients, we sent our report and findings to RUILS and asked them if they wished to respond.

> *"I would like to say we support your recommendations , particularly, the creation of a peer-led, clinician aided support groups, tailored and targeted communication and education on Long Covid, a more comprehensive screening process and embedding care coordination in the assessment process and as our understanding of the illness and its impact on residents improves, we will be looking to work with partners to develop bespoke activities and projects e.g. peer groups/breathlessness workshops, Long Covid walk and talk groups.*

Looking forward, it is feasible that a Long Covid recovery pathway be created where diagnosis and medical intervention work hand in hand with Social Prescribing involvement so that Long Covid clients are assured longer term support from the offset.”

Narinder Dosanjh, Social Prescribing Manager at RUILS

We look forward to working with RUILS and the Post Covid Steering Group to make sure the voices of the people who talked to us are heard, and to improve support for Long Covid.

Further information

For any questions or further information about this project, or for any queries about health and social care in Richmond, please get in touch with us. Our contact details are the following:

Healthwatch Richmond
82 Hampton Road, Twickenham, TW2 5QS
Registered Company (08382351) and Charity (1152333)

Visit: healthwatchrichmond.co.uk
Call: 0208 099 5335
Email: participation@healthwatchrichmond.co.uk
Facebook: @healthwatchrichmond
Twitter: @HW_Richmond

Appendix - full questionnaire

Thank you for considering taking part in this survey.

Long Covid is defined as signs and symptoms that develop following an infection consistent with Covid-19, which continue for more than 12 weeks. You may experience Long Covid even if you were not acutely ill in the first place. Common symptoms include breathlessness, brain fog and fatigue. Not everyone with Long Covid, particularly those who were ill early in the pandemic, will have been tested for Covid-19.

If you have been experiencing the symptoms of Long Covid (also known as Post-Covid Syndrome), whether or not you tested positive for Covid-19, then please share your experience by completing the survey.

Your feedback will help us to understand what support is needed for people living with Long Covid and will be used to produce a report to inform the relevant organisations of what you have been experiencing, and recommend how they can design services and support to better meet your needs.

We will protect your confidentiality and anonymity within our report which will include anonymous summaries of the feedback and anonymous quotes.

If you have any questions about this survey or wish to give us more information about your situation, please contact us at chloe@healthwatchrichmond.co.uk or by phone: 020 8099 5335.

Which borough are you a resident of?

1. Richmond
2. Croydon
3. Kingston
4. Merton
5. Sutton
6. Wandsworth
7. Other

Section 1 - Personal Experience of Long Covid

Did you get diagnosed with Covid 19 or Long Covid?

Not everyone who has Long Covid will have been diagnosed with either Covid-19 or Long Covid. We still want to hear from you either way. We want to know what it is like getting diagnosed and whether or not having a diagnosis makes a difference to your experience.

Multiple choice grid

	Yes	No	Unsure
Covid (when you first got ill)			
Long Covid			

Please give us more details about getting or being unable to get diagnosed? (when, where, who diagnosed you)
Long answer text

When did your symptoms start?
Select the month and year that your symptoms started below.
1. January 2020
…
20. August 2021
21. Unsure

Section 2 - Health difficulties

What are the main symptoms that you experienced, or are still experiencing, more than 12 weeks after an infection?
If you experienced symptoms only when you had an infection or they got better within 12 weeks, please tick "Have not experienced/Got better within 12 weeks" If you don't know what some symptoms are you can take a look at the NHS Long Covid page here:
https://www.nhs.uk/conditions/coronavirus-covid-19/long-term-effects-of-coronavirus-long-covid/ or the Your Recovery website:
https://www.yourcovidrecovery.nhs.uk/what-is-covid-19/long-covid/
Checkbox grid

Rows	**Columns**
Breathlessness and other respiratory difficulties	Never experienced / got better within 12 weeks
Fatigue	Mild - did not stop me doing anything
Muscle pain	Moderate - made it difficult to do something

Fever	Severe - made it difficult or impossible to do something
Loss of taste, appetite and/or smell	
Brain fog	
Anxiety	
Chest tightness and/or palpitations	
Headache	
Insomnia and trouble sleeping	
Rashes and/or symptoms related to the skin	
Memory loss	

How have your symptoms changed since you started experiencing them?
Checkbox grid

Rows	**Columns**
Breathlessness and other respiratory difficulties	Never experienced / got better within 12 weeks
Fatigue	Improving
Muscle pain	Worsening
Fever	Fluctuating
Loss of taste, appetite and/or smell	No change
Brain fog	Unsure
Anxiety	
Chest tightness and/or palpitations	
Headache	
Insomnia and trouble sleeping	
Rashes and/or symptoms related to the skin	

Memory loss	

If you have any symptoms not listed above please tell us about them
Long answer text

Can you tell us more about how your symptoms have changed over time?
How frequently and how long are the relapses, what tends to cause it, how severe does it get? How long have things been improving or worsening for? Are there things that you can or cannot do now that you could or couldn't do before?
Long answer text

Has living with Long Covid had an effect on your life?
Tell us what it has been like and how it has affected you, your quality of life, relationships, wellbeing, your ability to work, complete caring and parental roles and anything else.
Long answer text

Has living with Long Covid impacted your Mental Health? If yes, how?
If yes, can you tell us more about the effects this has had on your life?
Long answer text

Section 3 - Support accessed

Have you received any help for your Long Covid symptoms?

- Yes
- No - *if no skip part 2*
- Unsure

Support accessed - part 2

What type of support have you received? Was it satisfactory?
Long answer text

Have you been in touch with your GP or with a hospital about it? If yes, which one, and what support have they provided?
Long answer text

How long have you had to wait before receiving support, after your first referral?

1. Less than two weeks
2. Between two weeks and a month
3. Between one month and two months

4. More than two months
5. Unsure

Has the support you have accessed helped to improve your health? Tell us about what has helped and how or what didn't help and why.
Long answer text

Do you have anything more to tell us about the support you have accessed?
Long answer text

Section 4 - Current needs and possible improvements

Is there any other support that you're not currently getting that you think would help you? Tell us what support you think would help.
Long answer text

Is there anything else you would like to share with us or that we should have asked you?
Long answer text

Section 5 - About you

All answers are kept anonymous, and all questions are optional. This section is included to help us to ensure that we have reached a wide section of the community and to see if there are things that make a difference to people's experiences.

What is your gender?
1. Male
2. Female
3. Non binary

What age group are you in?
1. Under 18
2. 18-25 3. 25-49 4. 50-64
5. 65-79
6. 80 and over
7. Prefer not to say

How would you describe your ethnicity?
Dropdown choice, gov.uk standards

How well can you speak English?
1. Not at all
2. Basic

3. Conversational
4. Fluent
5. Native

Do you have a disability or long term condition?

1. Yes - physical or mobility impairment
2. Yes - sensory impairment
3. Yes - learning disability or difficulties
4. Yes - mental health condition
5. Yes - long term condition
6. Yes - other
7. No
8. Prefer not to say
9. Unsure

Which of the following best describes your current financial status?

1. I have enough for basic necessities, and at least a fair amount of disposable income, that I can save or spend on leisure.
2. I have enough for basic necessities, and a small amount of disposable income, that I can save or spend on leisure.
3. I only have enough for basic necessities, I am living paycheck to paycheck.
4. I don't have enough for basic necessities, I am struggling to make ends meet.

If you would like us to send you the results of this work please give your email address below (optional)

We will never share your email address with any other organisation. Healthwatch Richmond (your independent, local NHS and social care watchdog) will only use your email address to share the results of this survey and any information relevant to Long Covid (e.g. new NHS services or community support) with you.

Short answer text