



# Experiences of Long Covid

November 2022

**healthwatch**  
Sutton



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# About Healthwatch Sutton

Healthwatch Sutton is your local health and social care champion. From Worcester Park to Wallington and everywhere in between, we make sure NHS leaders and other decision makers hear your voice and use your feedback to improve care.

If you've recently visited your GP or local hospital, or used any health and social care services in the London Borough of Sutton, we want to hear from you. Whether you've had a good or bad experience, we can use your feedback to improve services for everyone and we have the power to make NHS leaders and other care providers listen to what you have to say.

We're completely independent and impartial and anything you say is confidential. We also offer information and advice to help you get the support you need. Our service is free, simple to use and can make a real difference to people in Sutton and beyond.

Find out more about us on our website: [www.healthwatchsutton.org.uk](http://www.healthwatchsutton.org.uk)

# Background

Many people recovering from Covid-19 have been experiencing long-term effects and symptoms that have affected many aspects of their life. This is called 'Long Covid' or 'Post Covid Syndrome.'

## What is Long Covid?

The Office for National Statistics (ONS) defines 'self-reported Long Covid' as 'symptoms persisting for more than four weeks after the first suspected Covid-19 infection that were not explained by something else.'<sup>1</sup> NICE defines 'on-going symptomatic Covid-19' as 'signs and symptoms of Covid-19 from 4 weeks up to 12 weeks' and 'post Covid-19 syndrome' as 'signs and symptoms that develop during or after an infection consistent with Covid-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.' NICE states that the term 'Long Covid' usually includes signs and symptoms following Covid-19 that continue or develop 4 weeks after acute Covid-19.<sup>2</sup>

Symptoms that people may have include fatigue, breathlessness, cough, fatigue, sleep disturbance, anxiety or depression, hair loss, cognitive impairment, difficulty concentrating and many others. The ONS survey estimated that 72% of those with Long Covid had symptoms interfering with their day-to-day activities and 21% said their day-to-day activities were 'limited a lot'. It is unclear whether some of these symptoms may be due to the effects of social isolation as opposed to infection with the Covid-19 virus.

## How many people are affected by Long Covid?

A survey released by ONS in August 2022 estimated that Long Covid is currently affecting 2.8% of the UK population. This suggests that there are likely to be approximately 6,000 people living in Sutton with Long Covid, with 2,500 of them having had symptoms for over a year, and 1,200 for over two years.

## Aim of this survey

We wanted to understand what people are experiencing and recommend how decision makers can design services and support to better meet their needs.

## Integrated Post-Covid Assessment Service

Epsom & St Helier University Hospitals Trust, Sutton Health & Care and Surrey Downs Health & Care have developed an Integrated Post Covid Model of Care to support patients experiencing ongoing symptoms of Covid-19. The team consists

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/latest#measuring-the-data>

<sup>2</sup> <https://www.nice.org.uk/guidance/ng188/resources/covid19-rapid-guideline-managing-the-longterm-effects-of-covid19-pdf-51035515742>

of doctors, nurses, psychologists and physiotherapists and aims to provide a holistic approach to assessment and treatment based on the needs and goals of the patient.

Patients are seen face to face in clinic where they will have an opportunity to explain their symptoms in detail with one of the team. The service offers medical, physical and psychological assessment, MDT discussion and onward referral to the most appropriate specialist treatment pathway or rehabilitation services.

Rehabilitation can include a fatigue management course, an exercise and education course and a breathlessness management course as well as regular support by the team, as we recognise that symptoms may fluctuate and change over time. Support with returning to work can also be provided. These courses are designed to help patients develop techniques to manage their Long covid symptoms.

Patients who think they are experiencing Long Covid should see their GP, who can refer them to the service.

# What we did

We launched a survey to find out from people about their experiences with signs and symptoms lasting more than 12 weeks after an infection consistent with Covid-19.

Questions included in the survey covered topics such as symptoms, receiving treatment (including hospital treatment) and the impact of Long Covid on work, relationships and mental health.

The survey was open from 23<sup>rd</sup> September 2021 to 31<sup>st</sup> March 2022. It was promoted online via social media, e-bulletins and on our website. We also asked Sutton Council, the local NHS and our partners in the voluntary sector to share our survey in their newsletters and social media channels.

In addition to this, we contacted the Post Covid Assessment Service who distributed a copy of our survey to the people who have accessed their service.

We also spoke to the Carshalton & Wallington Long Covid Support Group, which has been set-up on Facebook to help people experiencing Long Covid who helped to promote our survey to their members.

**We received 79 responses.**

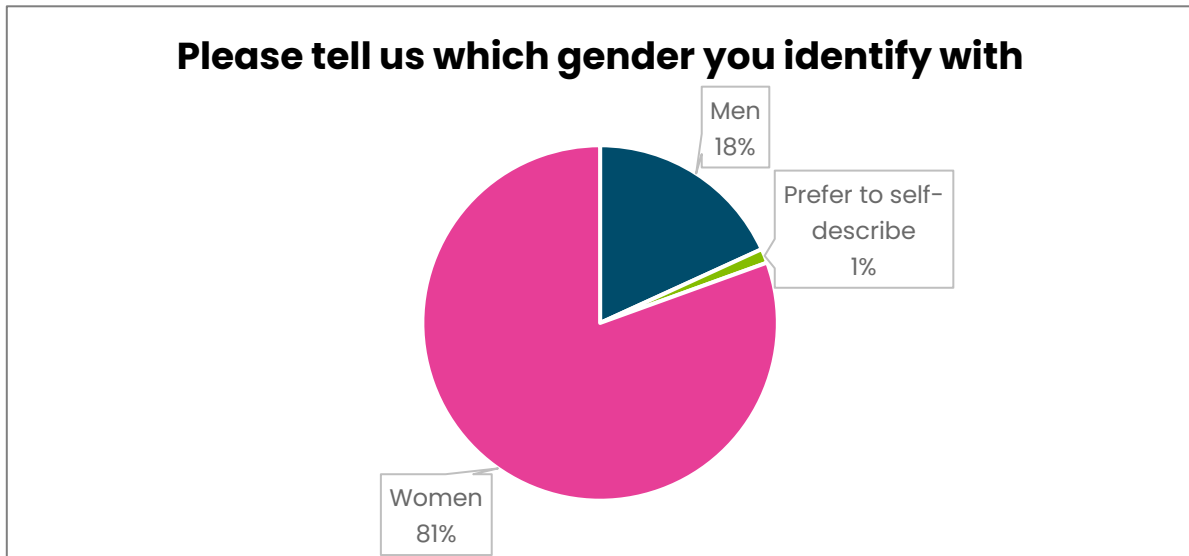


# Who we heard from

At the end of the survey, we ask respondents to tell us information about themselves. This information helps us better understand how people's experiences may differ depending on their personal characteristics. These questions are optional.

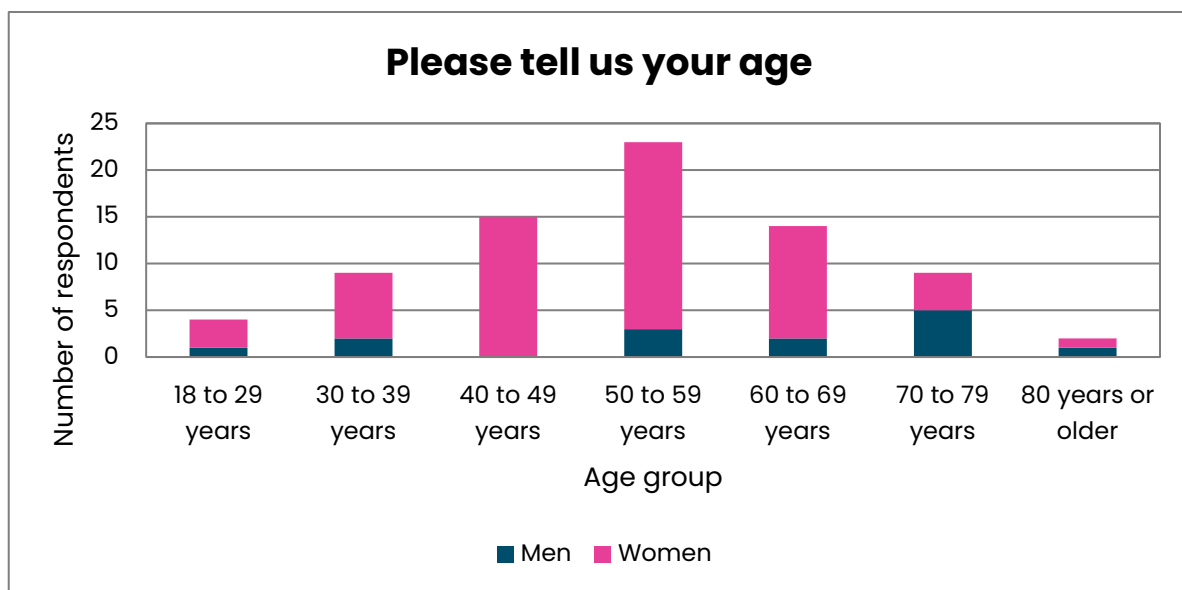
## Gender

The majority of the respondents (81%, N = 62) identified as women.



## Age

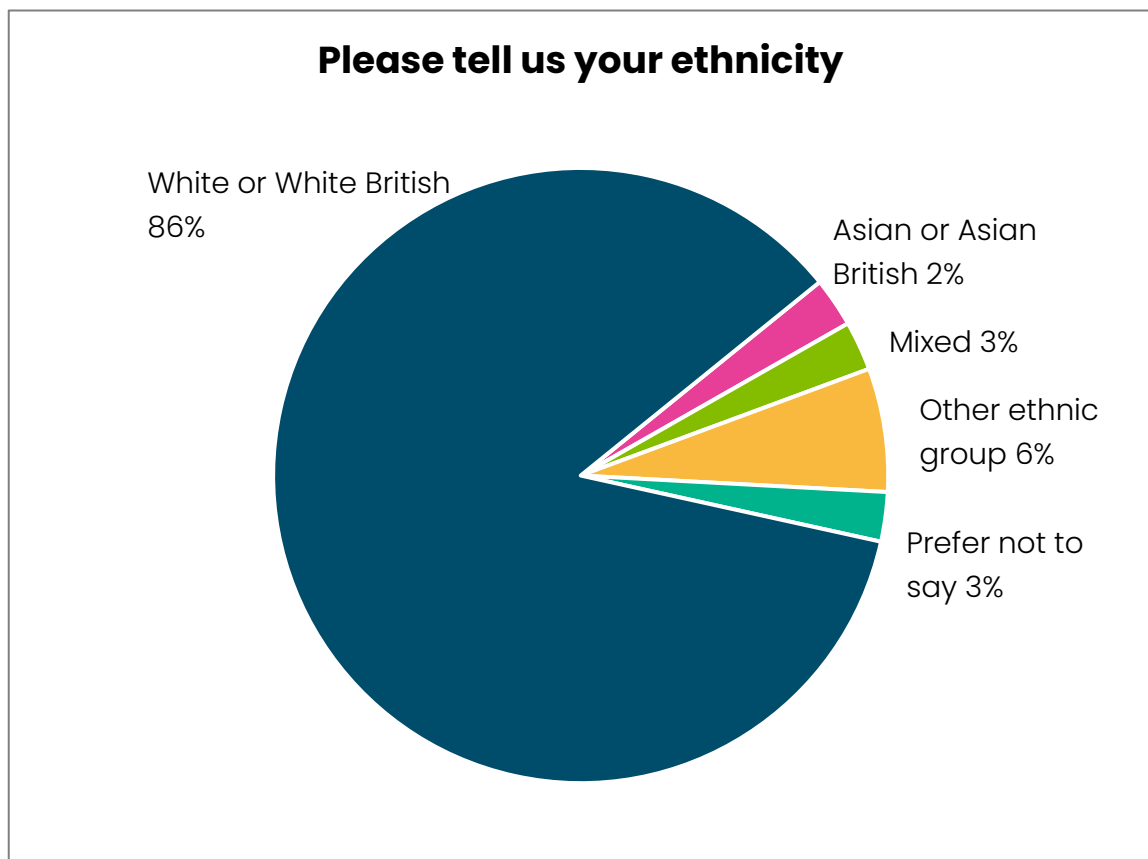
The most common age group was 50-59 (30%, N = 23). Men formed a larger proportion of the over-70s than in the younger age groups.





## Ethnicity

The majority of respondents (86%, N = 66) identified as White British.



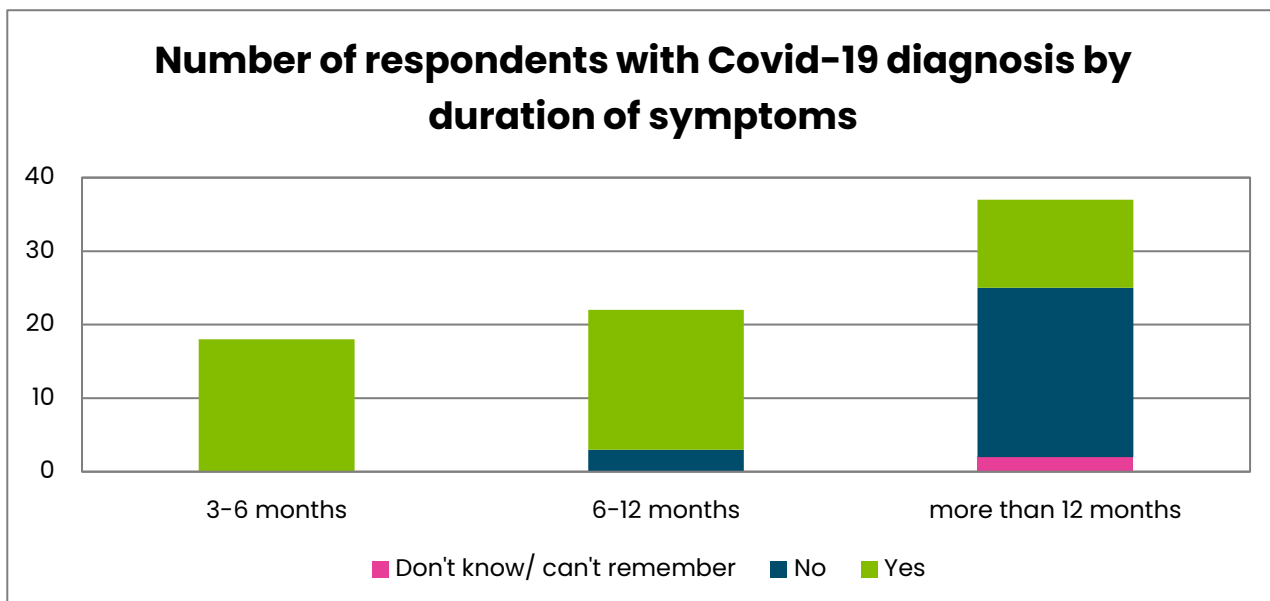
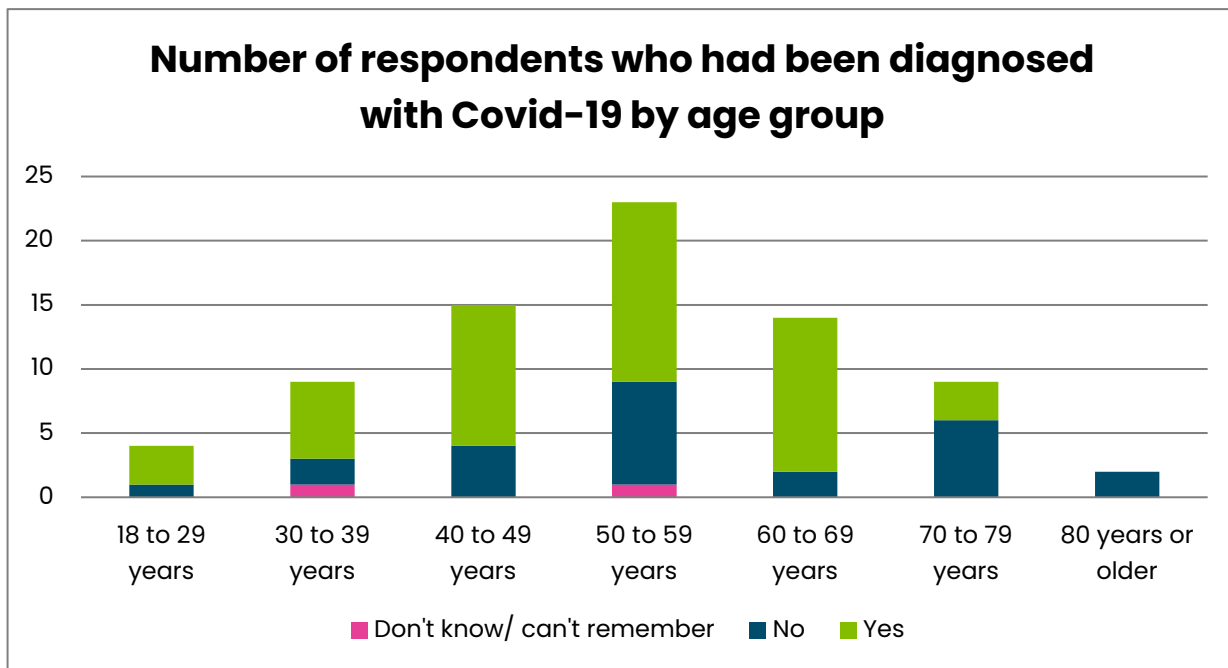
# What we found

## Covid-19 diagnoses

### Did you receive a positive Covid-19 test result before you experienced Long Covid symptoms?

64% (N = 49) of respondents told us that they had received a diagnosis of Covid-19.

34% (N = 26) had not received a diagnosis and 3% (N = 2) were unsure.



Respondents in the older age groups and those who had had symptoms the longest were the least likely to have had a Covid-19 diagnosis. This is likely to be because it was not as easy to get tested early on in the pandemic, a time when many older people were affected by covid.

## Hospital treatment for Covid-19

### Have you been admitted to hospital due to Covid-19?

42 people answered this question of whom ten said they had been admitted to hospital with Covid-19 and 32 said they hadn't.

### Please tell us about your experience in hospital



'I was in hospital for 10 days with Covid and Covid Pneumonia. I felt extremely unwell.'



'Excellent treatment 24 hours and hats off to NHS for making me feel better and caring for me.'

'I was intubated and put into an induced coma to help my lungs and the rest of my body fight the infection/Covid. I am aware of some things that happened, being put into machines/going in lifts and hearing voices. [...] after some bed exercises I was taken off of oxygen and was given breathing exercises. 4 wonderful physios got me to the edge of my bed and after 3 tries I got onto my feet, I cried quite a bit and did it again. [...] I will be forever grateful to the NHS and their help in getting me home'

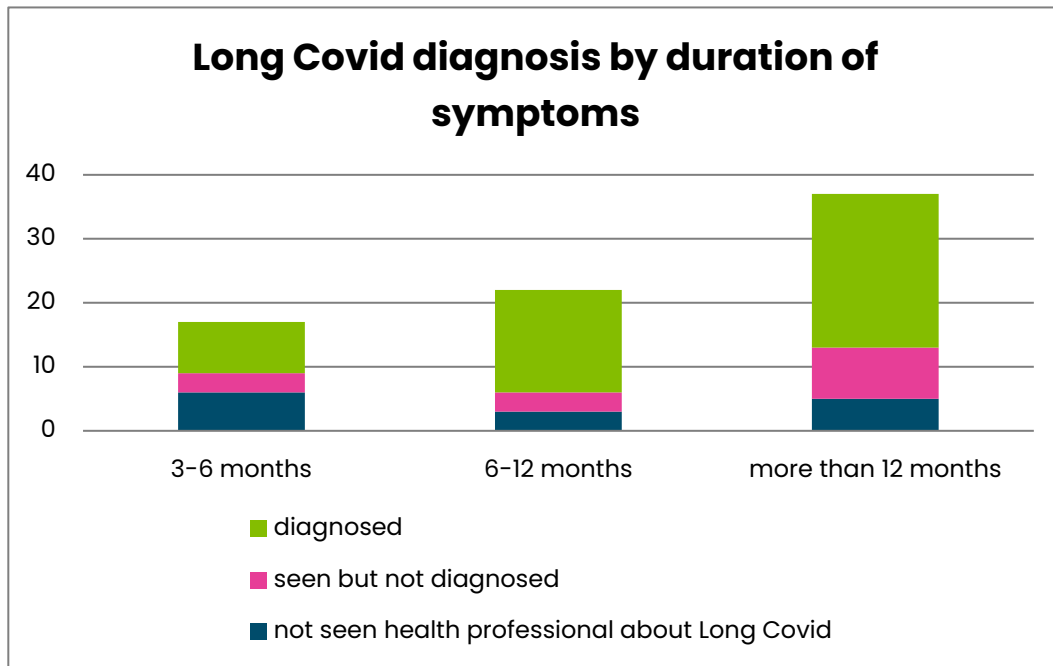
'Epsom & St Helier very very good'

## Long Covid diagnoses

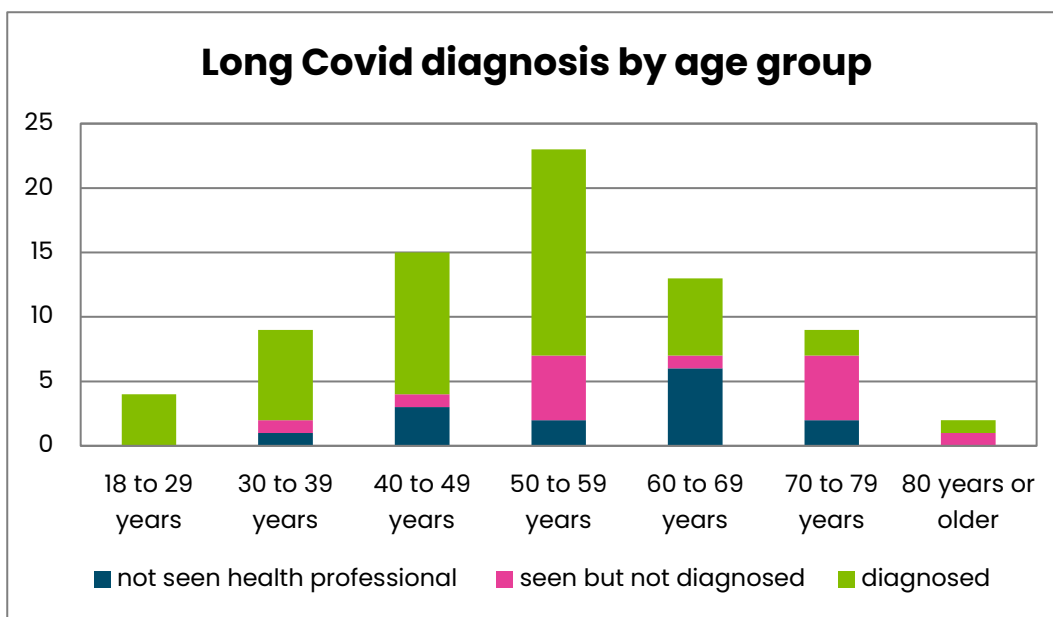
### Which of the following best explains your position with regards to Long Covid?

63% (N = 48) of respondents told us that they have had a diagnosis of Long Covid confirmed by a health professional. 18% (N = 14) had seen a health professional about their symptoms but without being given a diagnosis and 18% (N = 14) had not seen a health professional.

Over a third of those who had been experiencing symptoms for more than a year had not received a diagnosis.



There seems to be a trend for those in the older age groups to be less likely to have been given a Long Covid diagnosis.



## Symptoms

How have you experienced symptoms?

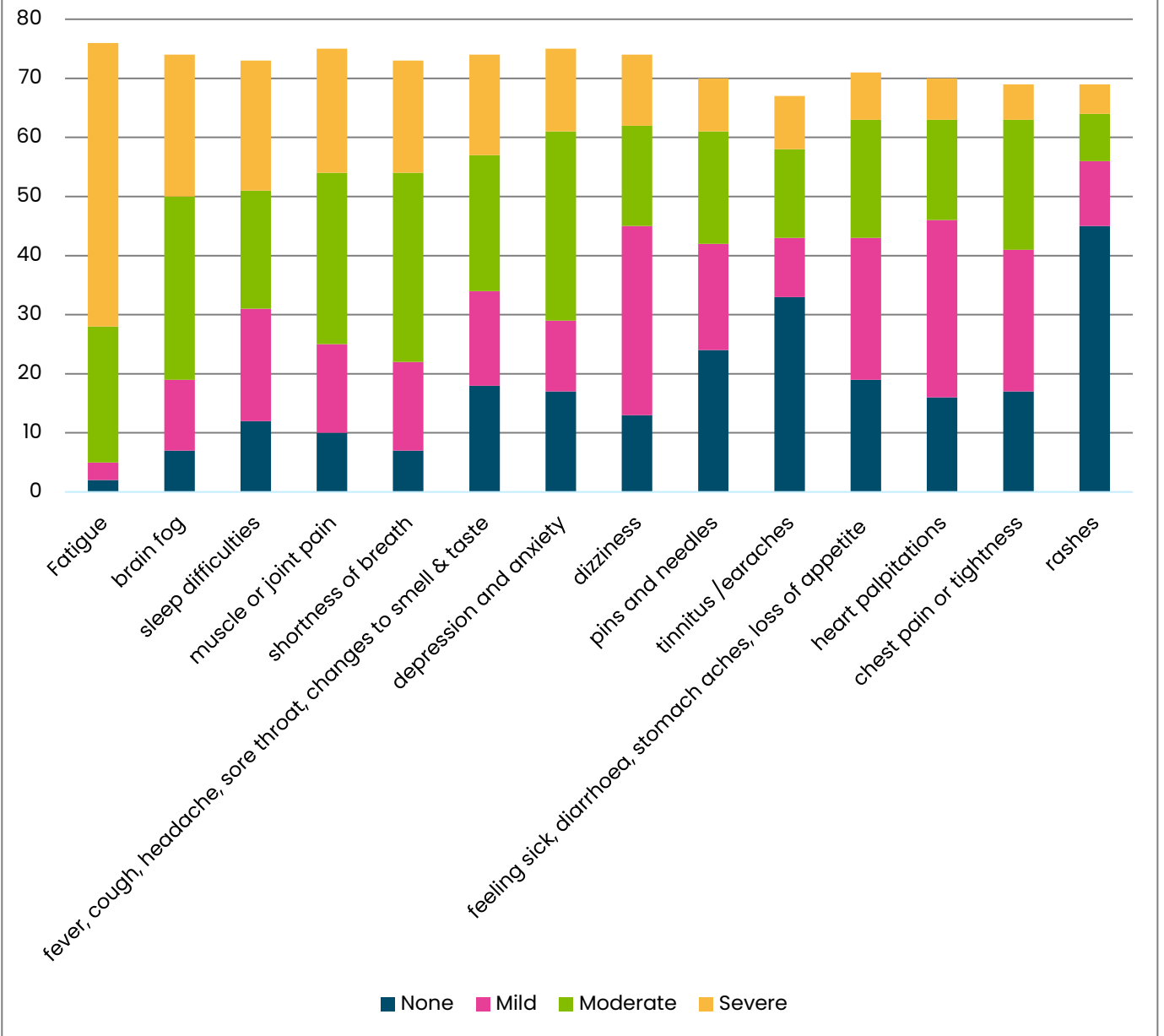
How long have you been experiencing (did you experience) symptoms of Long Covid?

Which of the following symptoms have you experienced (please rate all)?

Symptom	Percentage of respondents reporting moderate or severe
Fatigue	92%
Brain fog	71%
Shortness of breath	66%
Muscle or joint pain	65%
Depression and anxiety	60%
Sleep difficulties	55%
Fever, cough, headache, sore throat, changes to smell & taste	52%
Dizziness	38%
Pins and needles	36%
Feeling sick, diarrhoea, stomach aches, loss of appetite	36%
Chest pain or tightness	36%
Tinnitus/earaches	31%
Heart palpitations	31%
Rashes	17%

The most common symptoms were fatigue, reported by 92% of respondents, and brain fog, reported by 71%,

## Symptoms experienced and their severity

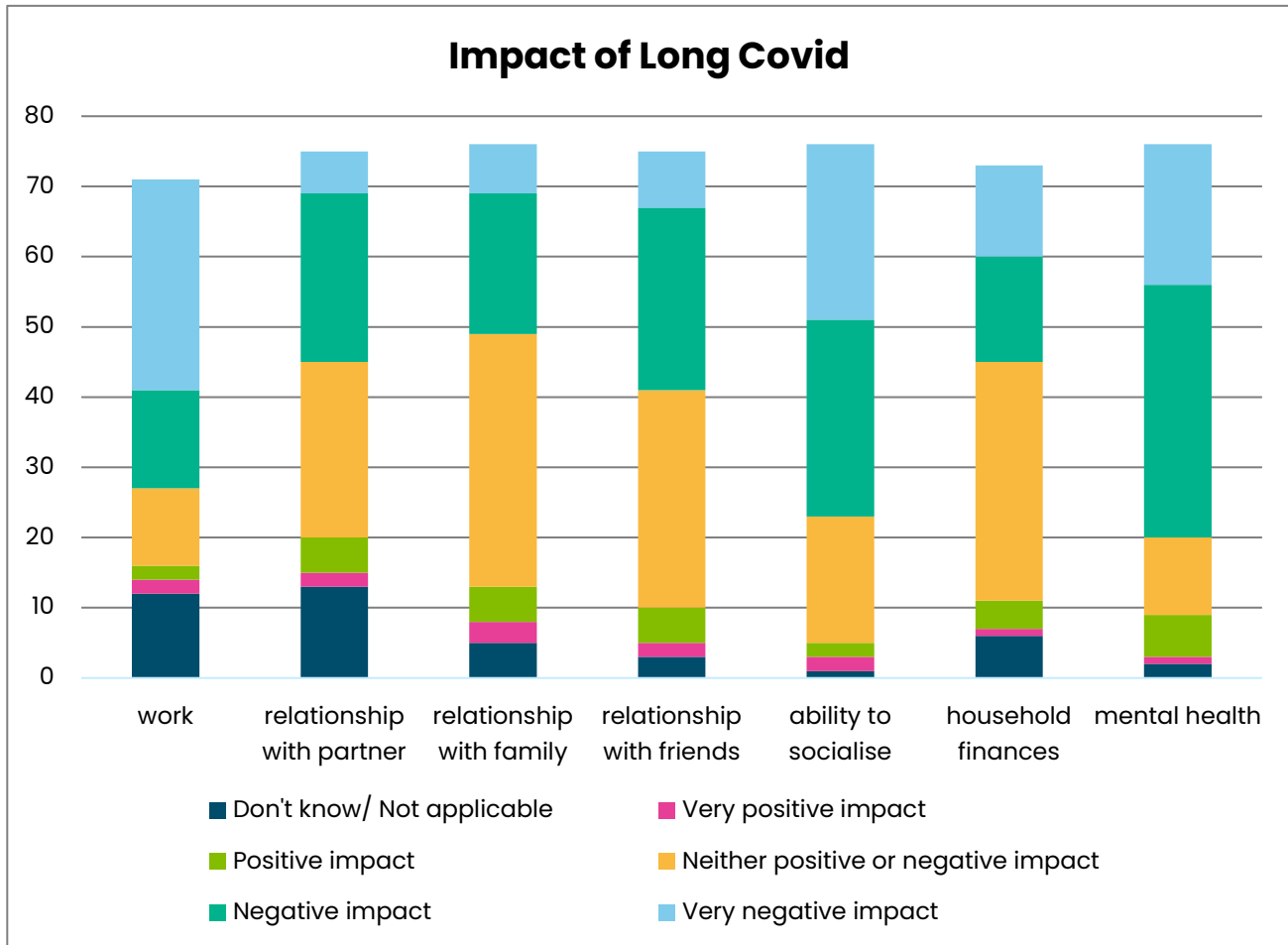




# Impact of Long Covid

## What impact has Long Covid had on the following parts of your life?

Nearly three quarters of the respondents said that Long Covid symptoms had a negative or very negative impact on their mental health. Ability to socialise and work were the other two areas most affected, but for many there was also an impact on finances and on relationships with partner, family and friends.



Aspect of life	Percentage reporting negative or very negative impact
Mental health	74%
Ability to socialise	70%
Work	62%
Relationships with friends	45%
Relationship with partner	40%
Household finances	38%
Relationship with family	36%

## Treatment

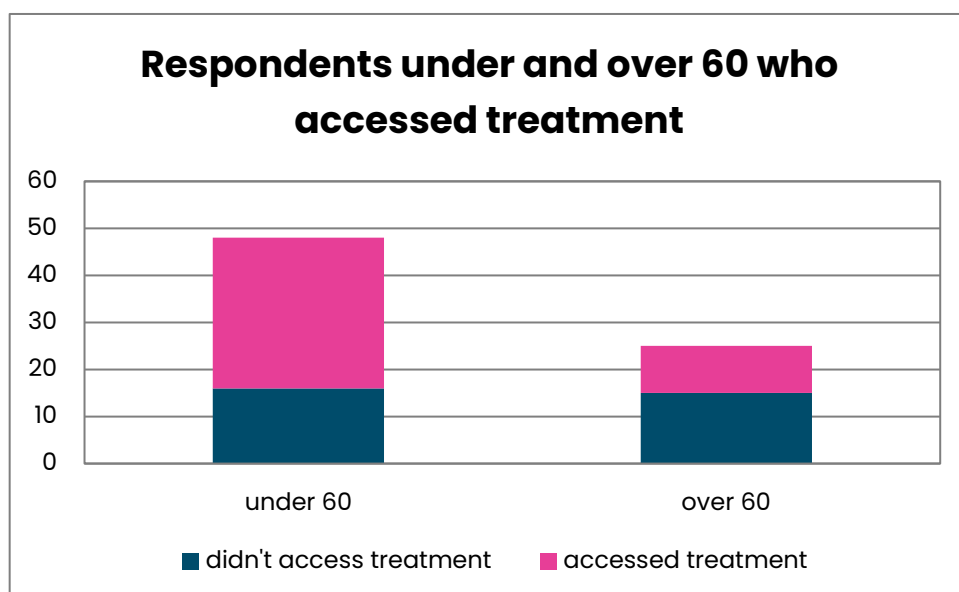
### Access to treatment

#### Are you now/or have you received treatment for your symptoms?

58% (N = 43) of respondents told us that they had accessed treatment for Long Covid.

Older people were significantly less likely to have accessed treatment.

Similar proportions of men and women had accessed treatment.



82% of the respondents who had been given a diagnosis of Long Covid had accessed treatment.

### **How long did you have to wait to receive treatment?**

Although a few people were seen quickly (within a few weeks), 61% of respondents told us they waited over 2 months. The Sutton Post Covid Service aim to see all patients within 3 weeks, and commented in autumn 2022 that this had been consistently achieved.

### **Which treatments have you received?**

Many of the people responding to this question mentioned the Post Covid Assessment Service:

'Zoom meeting fortnightly for 6 weeks Long Covid Clinic'

'Long Covid clinic for fatigue and breathlessness'

6 Weeks of physio sessions with the Long Covid Rehab Clinic'

'NHS Long Covid group exercise classes to help with breathing'

Inhalers were mentioned several times. Other respondents referred to a variety of investigations and medications, perhaps reflecting the diverse ways in which Long Covid affects different people:

'Levothyroxine and an inhaler'

'Ongoing investigation, CT, physio, medication'

'Medication for anxiety, medication for vertigo, vocal therapy'

'Anti-inflammatories and pain killers'

'Tests, bloods, heart monitor, blood pressure monitor'

'MRI scan, fitting for hearing aid due to profound deafness'

'Fucidin cream twice for skin rashes, asthma pumps twice (stronger one recently prescribed) Amitriptyline for nerve & joint pains'

## Have the treatments you have received been effective?

People received a variety of treatments with varying degrees of success. The majority of respondents reported some partial benefit from the treatment saying that it had helped somewhat, or helped some symptoms but not others.

30 people reported getting at least some benefit from the treatment they received, 8 said the treatment hadn't helped and 3 said it was too soon to say.

Those reporting benefits also often said that these were limited or short-lived

'The issue remains as does brain fog and numerous other symptoms coming and going'

'Still have a cough after 5 weeks, still exhausted weeks on, still have skin rash 5 weeks on, achy joints, severe asthma'

'Rehab helped for a while, but I relapsed a few months later'

Some people mentioned specific things that had been helpful with physical symptoms. Inhalers were mentioned by 3 people, and help with fatigue and breathlessness were also found valuable by some.

'Good for management of fatigue and breathlessness'

'Exercise and fatigue class helped me get back on track'

'Inhalers I would be so much worse without'

Some also expressed appreciation of the support to cope psychologically:

'They helped me deal with the symptoms mentally, but not necessarily physically'

'Rehabilitation improved my confidence to get moving again'

'CBT was great as it gave me the tools to cope with my anxiety and depression towards my illness'

'The counselling was very helpful'

But it was clear that people's needs varied and some found it less helpful:

'Not a lot as breathing wasn't my main problem'

## Concerns

We also asked respondents if they have any concerns regarding their experience of Long Covid that they would like to share with us. Their responses are below.

Many respondents mentioned the impact of their symptoms on their day-to-day life, along with concerns about the future, and lack of understanding, support and treatment.

## Current impact



'My breathlessness is not improving. I'm still finding difficulty doing simple things i.e. walking, stairs, housework.'



'There is no 'cure' and I will be losing my job in the next few weeks as I am no longer able to do it and have used up all my sickness.'

'I am concerned about my breathlessness'

'I have had to leave work permanently because of what covid did to me'

'Ongoing breathlessness'

'Exhaustion, fatigue, falling asleep unexpectedly'

## Fear of the future



'I worry that I won't recover completely.'



'How much longer I can keep going just accepting my current health situation'

'I worry that I won't recover completely.'

'Is it ever going to go away or will I be on brown and blue inhalers daily for the rest of my life? Is there anymore that can be done?'

'Fear of not getting better, no cure available'

'I often feel will I ever be me again'

'That my brain fog won't clear and that I won't be able to do my job'

'When will it end?'



## Lack of support and understanding



'Still no diagnosis or help with symptoms. Have to self-fund private consultation.'



'No financial or employee support.'

'I've asked my doctors 3 times and been put off'

'I felt very isolated and as if it was treated as not genuine by some people'

'I would like some support please'

'I'm concerned that the health professionals were unwilling to help'

'Lack of understanding from employer'

'More support needed financial and home care'

'There is no support or proper guidance from the government for employers. Employers just fire/terminate contracts. They don't know enough about LC'

## What can the NHS and other organisations do?

We asked respondents if there is anything that the NHS or other organisations could do to improve their experience of Long Covid.

## **More awareness**

Many mentioned the importance of increasing awareness

### **Among the general public**

'Get the message out to the general public that the condition exists and is genuine'

'Make public more aware of it'

'The public need to be made more aware also'

'Ensure that the wider population are aware of its possible impact'

### **and among health professionals**

'Believe us and not dismiss symptoms as anxiety'

'Take it seriously and recognise it as a debilitating condition'

'Believe that this is a real problem. My oxygen is still unstable overnight going as low as 71% but no one seems bothered now'

'More awareness of this condition amongst GPs and healthcare professionals'

'Health professionals need to be more aware of this life changing illness with no light at the end of the tunnel and no support'

**Respondents mentioned the need for more support, including from primary care:**

'Make it easier to have a face to face consultation with my GP'

'Still not able to get to see my GP'

'Follow-up checks and assessments'

'I'd like to see a doctor and get a diagnosis'

'Give support instead of ignoring my symptoms and concerns'

'Offer ongoing support as now I feel I have just been left to get on with it'

**Some people commented on waiting lists:**

'Shorter waiting lists'

'Shorter waiting times to be seen and referred'

'To see people sooner'

'Still waiting'

## **and mentioned the need for more help for specific symptoms**

'Help with my memory, help with my tiredness just some kind of help I am really struggling'

'Offer an apt with specialists in the area impacted eg lungs and memory'

'Help with my loss of smell – it has been over two years since I could smell'

'Mental wellbeing [...] seems to be ignored'

### **Specific suggestions:**

'An easy way to report symptoms on my record without bothering the GP for an appointment each time might give them a more accurate picture of what I am going through'

'Broaden the remit for the Long Covid Clinic. Physio I saw could only help with shortness of breath, fatigue and brain fog. [...] When I told her of [pins and needles] she said she couldn't help'

'Long Covid clinics offer at more times and locations'

### **Some people expressed an acceptance of the limitations of the limits of what can be offered and appreciation for the help received**

'Don't suppose there is anything that can help'

'Be honest about they can do'

'NHS has done what they could and I thank them from the bottom of my heart'



'A support group with other Covid long haulers.'



# Key findings

- Over a third of those who had symptoms for over a year still hadn't been given a diagnosis
- The older respondents were less likely to have been diagnosed with Covid-19 when they were originally ill, less likely to have been given a diagnosis of Long Covid and less likely to have accessed treatment
- Long Covid is having a very significant impact on people's ability to work, on their finances, relationships, social lives, and mental health
- Many had found it difficult to access support
- The majority of people who accessed treatment found it beneficial. Although problems often persisted, they found treatment helped to manage their symptoms better.
- Different people found different treatment components helpful
- Respondents expressed considerable understandable concern for the future because of the lack of a cure or clear treatment plan
- There was a strong message about the need for better understanding by the general public, by employers and by health professionals

## Limitations and discussion

As with all surveys, it is important to remember that the people we didn't hear from may have had different experiences and would have expressed different views about the treatment and support they have received.

### Who are we hearing from and not hearing from?

Most of the people who took part in our survey were women who identified as White British and were aged between 40 and 69. We heard from relatively few men, people from other ethnic groups, and other age groups. This is likely to be due to a combination of factors including who in the community is most likely to experience Long Covid, who is most likely to respond to surveys, the demographic make-up of the London Borough of Sutton, and our approach to recruitment.

### Are people who haven't accessed treatment under-represented in our survey?

One of the ways we distributed the survey was via the Long Covid clinic which meant that a substantial proportion of the people we heard from were clinic patients. This gives us more confidence in the finding that many people attending the clinic found it helpful in managing at least some of their

symptoms. However, we may not have done so well in capturing the views of those who haven't accessed treatment.

On the other hand, the findings across Healthwatch surveys appear to be similar, in terms of symptoms, impact on everyday life, and recommendations for better support, despite differences in the ways people were invited to participate.

### Are men under-represented in our survey?

Only 19% of the people responding to our survey were men. Surveys carried out by other Healthwatch teams in other boroughs also had relatively few responses from men. National surveys carried about by the Office for National Statistics report that Long Covid affects more women than men, but not by such a large margin: their report published in July 2022 estimates that 58% of those experiencing Long Covid are women.<sup>3</sup> Furthermore, women make up 65% of the people attending the Post Covid Assessment Service.

	People responding to Healthwatch surveys	People attending the Post Covid Assessment Service	People with Long Covid based on ONS data
% women	Richmond 80% Wandsworth 74% Merton 83% Kingston 80% Sutton 81%	65%	58%

Overall it seems that we heard from more women partly because Long Covid affects more women, but also because the recruitment methods used in the Healthwatch surveys tend to get more responses from women.

There is also a suggestion in our data that some men are more likely to respond than others. For example, in our survey, men made up a larger proportion of the older age groups, and Healthwatch Richmond found that the men in their survey were more likely to have been given a diagnosis of Long Covid and more likely to have accessed treatment.

### Are different age-groups represented as expected?

In terms of age, our survey respondents seem to be representative of the people attending the Post Covid Assessment Service, with 50-59 years being the commonest age bracket.. This is slightly older than would be expected based on the ONS survey data: 48% of our respondents were aged 50-59 as compared with only 39% of the ONS sample. However, this could reflect the age profile of

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/alldatarelatingtopercentageofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk>



Sutton which has slightly fewer people between 20 and 40 and slightly more between 40 and 60 than the national average.

### **Are different ethnicities represented as expected?**

This is difficult to assess. Although the proportion of respondents from ethnic minorities was lower than would be expected on the basis of demographic data for the Sutton population as a whole, we know that the younger age groups, who are less likely to have been affected by Long Covid, are more diverse than older groups. Therefore the difference may be at least partly explained by the different age profiles of different ethnic groups. This is something that needs to be explored in more detail in any follow up work and future surveys.

### **Age group differences**

The older respondents were less likely to have been diagnosed with Covid-19 when they were originally ill, less likely to have been given a diagnosis of Long Covid and less likely to have accessed treatment. This may have been due to a number of factors. Older members of the population were affected most in the early waves when testing was limited. If they accessed services less frequently, they would be less likely to get a diagnosis. The reasons for not accessing services was not always clear in this survey. It could have been difficulty in physically accessing them or it could have been a feeling that a diagnosis would make little difference to treatment, the efficacy of which was not clear anyway. It may have been a shortage of services in the early stages when Long Covid was not recognised as an entity.

# Recommendations

We make three main recommendations about future work with Long Covid:

1. **To raise awareness among the general public, employers and people working in health and social care**

Increased awareness is important in helping people experiencing Long Covid to recognise the symptoms and access treatment, and for reducing the stress associated with having to explain this little-understood condition to family, friends, colleagues and managers. One immediate action is to share the information leaflet created by the charity Long Covid Support and available at

<https://www.longcovid.org/resources/information-leaflet>.

2. **To facilitate access to peer support**

One theme from the survey was the desire for more peer support. Therefore an important action is to identify sources of peer support, both local and online, and thus enable the Integrated Post Covid Assessment Service to give all their patients information about the different sources of peer support that are available to them.

3. **For the Integrated Post Covid Assessment Service to continue offering a range of different types of support, including support for emotional and psychological as well as physical symptoms as this is clearly valued by their patients**

Anyone who is experiencing any of the symptoms associated with Long Covid should contact their GP.

# Acknowledgements

Thank you to everyone who took part in our survey.

Thank you to Tom Williamson and the team at the Post Covid Assessment Service for helping to distribute the survey.

Thank you to Lara who distributed our survey to members of the Carshalton & Wallington Long Covid Support Group to distribute the survey.

Thank you to Janet Wingrove for your help in the analysis and creation of this report.





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