



# Long Covid Patient Experience

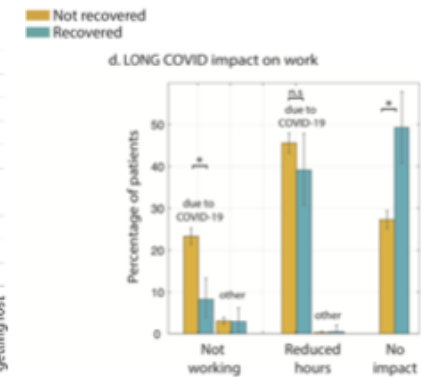
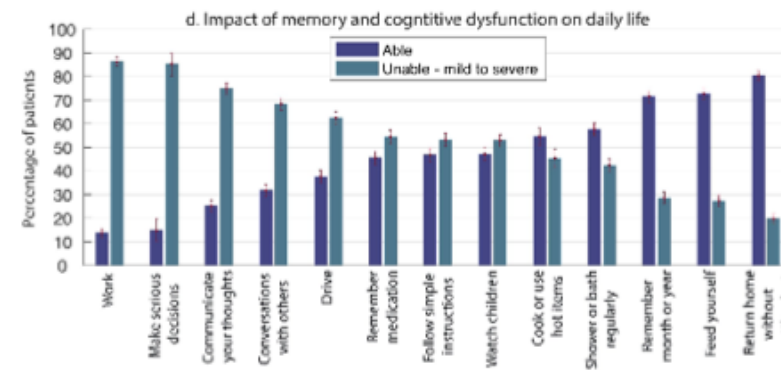
NHS England Taskforce on Long Covid

February 4<sup>th</sup>, 2021

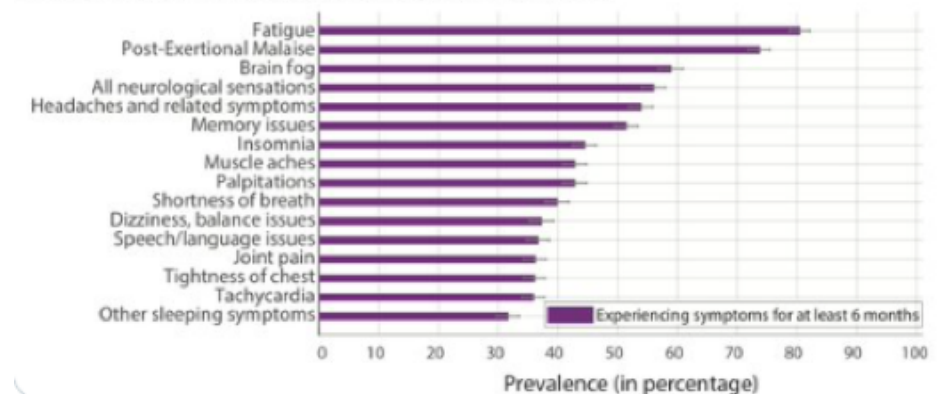
# An estimated 90+% of Long Covid patients were not hospitalised. 7 months post infection, c.70% reported being too unwell to work at all or to their previous capacity

- Patient Led Research of 3,762 cases with illness lasting >28 days and onset prior to June 2020, allowing the characterisation of symptom profile and time course over 7 months, along with the impact on daily life, work and return to baseline health
- 4.4% were hospitalised; 37.5% visited A&E/ER/urgent care but were not admitted
- >200 symptoms were reported
- The mean number of organ systems affected in each respondent was 9.08/10
- 88.0% of the total respondents (3,310) experienced either cognitive dysfunction or memory loss, with substantial impact on daily life, particularly work
- Almost 70% reported being unable to work at all or to previous capacity:
  - 45.2% of respondents reported requiring a reduced work schedule
  - 22.3% were not working due to their health
- A total of 2,454 (65.2%) respondents were experiencing symptoms for at least 6 months. The top remaining symptoms after 6 months were primarily a combination of systemic and neurological symptoms

## PATIENT LED RESEARCH For COVID-19



## a. Remaining symptoms after month 6 (prevalence > 30%)



1. <https://patientresearchcovid19.com/publication/>

## 82% of respondents to our survey have struggled to secure referrals since publication of the NICE/SIGN/RCGP guideline and list of clinics

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Of **128** people who sought referrals on or since December 18<sup>th</sup>

- **23** were referred successfully
  - **6** have actually been seen to date
- **4** were referred but clinic refused to give appointment
  - **3** no positive test or not hospitalised
  - **1** told I live too far away
- **95** were refused referral
  - **15** I don't think my GP believes I have Long Covid
  - **8** GP won't refer as not hospitalised
  - **72** My doctor is unaware that there is a Long Covid clinic in the area (including in areas where clinics are listed)
- **6** are currently awaiting a response from their GP

### Background

- On-going survey, launched January 5<sup>th</sup>, 2021
- Disseminated via Long Covid Support Facebook group, Twitter, LongCovid.org, Patient Safety Learning Hub
- Responses for referrals and appointments in England only
- 128 responses analysed for referrals sought on or since December 18<sup>th</sup>, 2020 (date of publication of NICE/SIGN/RCGP guideline and list of clinics in England)

## There is an urgent need for information and clarity of referral pathways, to remove barriers to access as well as inefficiencies

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*“GP denied local clinic (Suffolk) existed. I googled and sent link to him. Replied to say specialist assessment has to be done before referral but he was unable to access the document on SystemOne.” Ipswich and East Suffolk*

*“It has taken me six months to get a referral to a respiratory consultant even though I know there is a long Covid clinic at my local hospital, my GP says he does not know the referral pathway.” Sheffield*

*“It would be good to publicise the proper pathway so we can all know how referrals should work (for e.g. is there a prerequisite to have the tests before being referred?). Also why can't I be referred for support whilst waiting for imaging results (which will take a month according to my GP)?” West London*

*“My GP said she could refer me to the nearest LC clinic, BUT they would not have access to the tests already done.”  
West Sussex*

*“She said that the clinics are merely data collecting and that after the Yorkshire screening tool, they have no clinical knowledge or referral powers - they refer you back to the practice!” Suffolk*

*” I feel that NHS has misinformed us about Long covid clinics being open. The Lancashire one is still not up and running and my GP practice had to make a lot of calls to even try and find out who will be running it etc. I emailed the Trust 2 weeks ago myself and they still haven't replied to me about the clinic. It's a mess!” Chorley and South Ribble*

## This example of a positive experience reflects proper service implementation. Nevertheless, without known treatment options, practical help may be limited

*“It was a thorough assessment and I was there for nearly 4 hours. Multi disciplinary team were involved - when I was seen in November they had only just started seeing patients with long covid - it was a post Covid clinic. Most of the patients to date had been hospitalised. Although I had never tested positive (no tests available at initial infection) I felt listened to and the consultant said it sounded likely that it was covid I had. Referred for CT scan, MRI & follow up with further potential for consultation with neurology for my neuro issues with memory and word finding and rheumatology to do with ongoing joint pain and muscle pain. Referral for further tests, scans or investigations, Rehab / physio advice, Referral for additional support, e.g. mental health.”*

*[Newcastle upon Tyne NHS Trust at the RVI (Clinicians seen - Physio, Mental health professional, Nurse, Infectious Diseases consultant)  
Also referred to Nuffield Health post covid rehab programme]*

### **Beyond referring people for multiple scans, it is not clear that clinicians know how to help**

*“So far, I have had multiple CT and MRI scans, been admitted to A&E following routine blood tests, yet the only thing the clinicians and doctors can agree on is that I am suffering from chronic fatigue. To date, I am yet to be referred to a long covid centre. I feel helpless and am conscious of being a burden to the health service due to being passed from pillar to post.”*

## There is an urgent need for information and comms to reach GPs and other health professionals to help patients access investigations and treatment, safely and consistently

- Long Covid symptoms; many patients won't know they've had Covid or Long Covid (NHS website lists only 3-4 symptoms vs >200 by Patient Led Research; NICE guideline lists <30 at the end of a long document)
- Referral pathways
- Location and contact details of clinics and other services: need for a central, up-to-date list accessible to patients as well as health professionals
- Role of assessment services, what patients can expect, including threshold for further treatment, continuity of care and referral pathways to further services
- Pathway for those who sought referral prior to December 18th who are awaiting appointment with specialist consultant rather than dedicated Long Covid assessment service; how will they be assessed for all Long Covid symptoms?
- SNOMED codes: ability to locate (post acute Covid vs Long Covid), retrospective application, difficulties of diagnosing



## Patients and health professionals need access to a central list of clinics and other services that is kept up to date and includes contact details

**The Dec 18th announcement ‘[Long COVID patients to get help at more than 60 clinics](#)’ was a source of relief for many people who had been struggling alone for months. The expectation being that these would meet the criteria set out in the 5 point plan announced on Oct 7th [NHS to offer ‘long covid’ sufferers help at specialist centres](#)**

‘Designated Long Covid clinics, as announced today. This will involve each part of the country designating expert one-stop services in line with an agreed national specification. Post-Covid services will provide joined up care for physical and mental health, with patients having access to:

- A physical assessment, which will include diagnostic testing, to identify any potential chronic health issues.
- A cognitive assessment, to assess any potential memory, attention, and concentration problems.
- A psychological assessment, to see if someone is suffering potentially from depression, anxiety, PTSD, or another mental health condition

Patients could also then be referred from designated clinics into specialist lung disease services, sleep clinics, cardiac services, rehabilitation services, or signposted into IAPT and other mental health services.’

**For many patients the reality is falling short of expectations. It is essential that better information is provided so that patients can navigate services.**

*“[Despite being listed among the 69 clinics in the December 18th press release] apparently Hull University Teaching Trust has decided not to run Long Covid Clinics and now we are being passed to people who want to help but can't. The doctor knows I/we need more help than she could offer she apologised and clearly wanted to help more than she could but said the trust wasn't setting up long covid clinics, she had seen a few other long covid sufferers but all she could do was apologise again and examined my chest which was her speciality but as I have so many other symptoms and my breathing is actually fine now the appointment was a waste of her time and mine.”*



# We are concerned that patient safety is being compromised with the current approach to identifying and managing Long Covid

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## **Patients (as well as crucial information) are being lost in a system that is difficult to navigate**

*"I managed to explain to her, following my meeting with the Long Covid clinic, where all of my letters had been filed on the system - under the questionnaires and surveys section?!?! My Dr had no idea, didn't even know that there was a questionnaires and surveys section and said she had never been told that's where LC patient info would be kept and was not happy when she opened it to see that there were 'urgent notes to GP' on there!" Suffolk*

## **Patients are being given unsafe advice**

*"I asked to be referred twice. 04/12/20 and 04/01/21. Denied both times, sent for blood test instead and told to push myself with exercise and stop "negative thoughts"." Hounslow*

## **GPs don't know how to help, and are directing patients to peer support groups (who are not able to offer medical advice)**

*"My GP does not know how to treat my symptoms. He has asked me what medication I would like and suggested I research this via long covid support groups." Bedfordshire*

## **Patients are still being disbelieved**

*"The Consultant I was seeing told me he couldn't see any connection between having COVID in March 2020 and my feeling terrible now and since." Tees Valley*

*"My doctor clearly thinks I'm malingering and told me to self-refer to a physio which I have out of desperation. I presented to A&E because I was having chest and shoulder pain and thought I was having a heart attack and my pulse went up to 150 and stayed very high for around 5 hours. I was told I was having a panic attack and was not believed when I explained that I'd had panic attacks in my youth and they did not feel like this. Ironically, not being believed that my symptoms are physical is causing me more anxiety than I ever felt before." North Central London*



# It is vital that safe and effective rehabilitation advice is disseminated to health professionals and patients as a matter of urgency

## Influential people spoke in the media recently about their personal experience of Long Covid, advocating exercise and positive thinking as the route to recovery

*"One afternoon, I felt as though I had been drugged, and felt so heavy I thought I could not raise my arms from the bed. I knew the symptoms were real, but I needed to distract my brain from them. So I thought, let's do it: I will either die or recover, I got out of bed and went to Sefton Park to join a military fitness session."*

**Prof Paul Garner, BMJ Opinion, January 24, 2021<sup>1</sup>**

*"There is nothing that isn't made better through exercise. Nothing. No matter what age, what condition, exercise will always improve it."*

**Dr Clare Gerada, BBC Breakfast, January 28, 2021**

## Research indicates that a high proportion of people with Long Covid experience post-exertional malaise and have detectable organ damage

*"In a young, low-risk population with ongoing symptoms, almost 70% of individuals have impairment in one or more organs four months after initial symptoms of SARS-CoV-2 infection."*

**Multi-organ impairment in low-risk individuals with long COVID, October 16, 2020<sup>2</sup>**

*"89.1% of participants reported experiencing either physical or mental Post-Exertional Malaise: 'worsening or relapse of symptoms after physical or mental activity'."*

**Athena Akrami, Patient Led Research, December 27, 2020<sup>3</sup>**

*"Pacing and heart rate monitoring are likely to be effective rehabilitation interventions for people living with Long Covid. Caution and risk stratification is required before exercise can be considered as a rehabilitation intervention. There is currently an absence of scientific knowledge on the safety or effectiveness of exercise for people living with Long Covid."*

**<https://longcovid.physio/rehabilitation>**

1. <https://twitter.com/PaulGarnerWoof/status/1353792263424503809?s=20>
2. <https://www.medrxiv.org/content/10.1101/2020.10.14.20212555v1.full.pdf>
3. <https://twitter.com/AthenaAkrami/status/1343166471938203649?s=20>

## We outline below the patient perspective on the NHS England Five point plan

	Assessment
NIHR-funded Research	Our calls for research fall into two main categories, both equally urgent: how to prevent new cases, and how to treat the vast numbers who have Long Covid; we eagerly await the announcement of the recipients of funding.
NICE/SIGN/RCGP Guideline	<p>We welcome its holistic approach but are disappointed that several concerns raised during the consultation process<sup>1</sup> were not addressed, including:</p> <ul style="list-style-type: none"> <li>- insufficient guidance on the range of physical symptoms leading to problems of diagnosis, coding, referral and treatment</li> <li>- the rather arbitrary three phases, risking barriers to investigations and care, as evidenced in the NHS guidance for clinics <i>“Patients who were not admitted to hospital should be offered referral if they have been experiencing post-COVID syndrome symptoms for 12 weeks or longer.”</i><sup>2</sup></li> <li>- the name, leading to problems with applying codes (post acute Covid rather than Long Covid in EMIS)</li> </ul> <p>We recognise that this is a living guideline and trust that these issues will be addressed as a matter of urgency.</p>
Long Covid Clinics	These are currently only in England, there are large geographical gaps even in England, significant barriers to access (being believed, identifying operational clinics, waiting times, proximity, etc.), and clinicians don’t know how to help.
Rehabilitation / Your Covid Recovery	<p>There is an urgent need for safe, effective and personalised rehabilitation advice.</p> <p>Your Covid Recovery has the potential to be the go-to resource for patients, but currently that is not the case.</p>
NHSE Taskforce	Our vision would be to have patients at the heart of decision making, as co-developers of solutions. We eagerly await the terms of reference, the remit and the registration process for patient members.

1. [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)32705-7/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)32705-7/fulltext)

2. <https://www.england.nhs.uk/coronavirus/publication/national-guidance-for-post-covid-syndrome-assessment-clinics/>

# Our calls for research fall into two main categories, both equally urgent: how to prevent new cases, and how to help the vast numbers who have Long Covid

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## What can we do to prevent Long Covid, as well as severe acute cases and transmission?

- Can we identify an early intervention to be taken soon after symptom onset to stop viral replication? (community, orally administered, low side effects, low cost, linked to Test & Trace)?

## How can we help those living with Long Covid?

1. What **causes** Long Covid (persistent virus, aberrant immune response/inflammation, autoimmunity, other) and the individual symptoms within Long Covid?
  - Are people with Long Covid at risk of developing an associated health problem, e.g. chronic medical conditions, mental health issues, fertility problems, menstrual issues?
  - What causes the relapses and fluctuating symptoms (and how/why do various factors have an impact, e.g. the menstrual cycle, hormones, mental effort, physical activity, diet etc.)?
2. What are the **treatments** for Long Covid and its individual symptoms (e.g. medications, diet adjustments, supplements, exercise, physio)?
  - What treatments at the acute stage of Covid-19 infection can prevent Long Covid?
  - What is the process and length of time of Long Covid recovery?
3. What are the **risk factors** for Long Covid and how does this vary by factors such as age (including children), sex, ethnicity, socioeconomic group?

We can see what needs to be done, and are very keen to work with you to help make this happen

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We have written a separate paper in which we have outlined strategic priorities to ensure resources are allocated effectively to maximise help for people with Long Covid and prevent others from joining our ranks

Dedicated Long Covid Minister with responsibility, accountability and a cross-departmental remit<sup>1</sup>

Patient panels to review and approve any initiative: 'nothing about us, without us'

- Diverse
- Comprising 'lay people' and representatives from patient groups
- Transparent decision making

Focus on two key strands

- Prevention of Long Covid (and severe acute Covid)
- Treatment and support for those living with Long Covid

1. <https://www.pslhub.org/learn/coronavirus-covid19/patient-recovery/long-covid-minister-needed-to-respond-to-growing-crisis-3-february-2021-r3983/>

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# Annexes

## Annexe A: A snapshot of feedback received on patient experience

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*“I requested referral to UCLH long covid clinic in October. I sent my then-GP’s practice the referral criteria. I had at that point, already had a chest X-ray taken 6 weeks after positive test result. It showed significant fibrosis and read of ground glass opacity. GP said this would “clear up”. My then-GP said I was not ill, despite fatigue, difficulty breathing, loss of feeling in fingers and toes etc. Rather, he said, I had anxiety and depression. I pressed for a referral to UCLH and asked for an appointment for a stand-sit test. My then-GP claimed no such examination existed and refused to help. I switched practices and am now going through referral process, 6 months after contracting covid. As a result of my initial experiences with old GP practice I am worried that I will not be believed, and do not deserve help because I am a “depressed and anxious” middle aged woman.” South East London*

*“I get the impression my GP doesn’t think my referral is important in the grand scheme of everything else going on. I am made to feel like a time waster for asking to see multiple specialists for my multi system issues, even though as a previously healthy 40 yr old I now faint every day, have chronic fatigue, breathing difficulties, and rashes all over my body. I am on the verge of giving up my career as a scientist because my symptoms seem to be getting worse not better 10 months on.” Cambridge and Pembrokeshire*

## Annexe A: A snapshot of feedback received on patient experience

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*“Rehab and occupational health and fatigue people are fantastic but only offer strategies to help manage symptoms rather than have any answers or treatments. Consultants only interested in 1 organ at a time and seem flummoxed if symptoms cannot be explained by a pre existing test. I think these clinics should be led by a consultant who is genuinely interested in Long Covid and committed to finding out why certain people suffer so. I'm grateful to be on their books but am I any better? Not really.” Oxfordshire*

*“Next appt with Respiratory Team. After being taken by the paramedics to A&E in August 2020 the GP was advised by the hospital to organise a 24 hour heart monitor. Despite chasing this, it still hasn't happened and we are in January 2021. Symptoms worsened during this time and it was only after requesting this yet again, that there was an admission that they had dropped the ball. I requested to be sent to Imperial and I finally got to have a 9 minute telephone appointment with a cardiologist. Still awaiting next tests!” South West*

*“The long covid clinic was the first chance in nearly 9 months to tell my covid story and be taken seriously. But it wasn't like that. I wanted to list all my experienced symptoms and have them recorded. A few were outright dismissed as "not part of covid" and there wasn't time to say the others. Knowing clinicians are super busy I'd made a word doc list and offered to send that but that wasn't permitted. I've been having some symptoms in my chest and breast which I really would have liked to discuss as well as the facial pain which has been quite debilitating. I got referred on to respiratory clinic when ongoing respiratory symptoms don't seem to be my issue. This seems a waste of nhs resources and my time. I'm left wondering if I should keep that appointment or not.” South West London*



## Annexe A: A snapshot of feedback received on patient experience

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*“I very much appreciate my GP's efforts to help and the assessment and follow up I had from the respiratory clinic. However this is not a Long Covid clinic. My GP made an urgent referral to them the summer, four months after the acute illness and three after secondary pneumonia, but when I was still in acute pain and suffered a combination of new symptoms that made me unable to work. The referral raised my hopes of getting help, but they were dashed by the end of that month when I heard nothing. When I chased up the hospital weeks later I was told that my appointment was reclassified from urgent to routine, without any explanation. Eventually I received a letter to say it would be a remote assessment by phone. I had believed I would get help and would be able to return to work - but in reality it took three months for repeatedly delayed assessment call to materialise. In that time I had been forced to give up my job of more than a decade, and I've been unable to work since. I appreciate that assessment by the chest clinic, the follow on referral for tests and their efforts to help now - I can't fault them, although all assessments have been remote, and will still be remote this month and the next. I will not be seen by anyone face to face. The respiratory specialists are very knowledgeable in their area, but they are not specialised in other areas of post-viral care, and they are not able to address the range of Long Covid symptoms I have, including ongoing pain, neurological symptoms and limited use of limbs ten months after the initial illness. They hope to help me address breathlessness through physio at some point this year, hopefully, but they can't do anything about anything else. The announcement of Covid clinics supposed to be in our large, highly populated metropolitan area has made it no clearer where they are and how to be referred to them. It remains unclear to the GP who would like to refer me to a clinic but cannot. Was an already busy respiratory department just rebranded as a "Long Covid clinic" without any additional resources and expertise - or does this clinic exist? If it does, how can a GP access it?” Trafford*

## Annexe B: Patient response by CCG for referrals on or after December 18<sup>th</sup> 2020<sup>1</sup>

CCG	Unable to get referral as GP unaware of clinic	Unable to get referral (GP disbelieves/ don't have a positive test/ not been hospitalised/ other)	Waiting to hear	Referral refused by clinic	Awaiting appointment	Had first appointment
NHS Barking and Dagenham CCG	1					
NHS Barnet CCG	1					
NHS Basildon and Brentwood CCG			1		1	
NHS Bath and North East Somerset, Swindon and Wiltshire CCG				1		
NHS Bedfordshire CCG	1					
NHS Berkshire West CCG	1					1
NHS Birmingham and Solihull CCG			1			
NHS Blackpool CCG	1	1				
NHS Bolton CCG	2					
NHS Bradford District and Craven CCG	1					
NHS Brighton and Hove CCG	1					
NHS Bristol, North Somerset and South Gloucestershire CCG				1	1	
NHS Bromley CCG	1					
NHS Buckinghamshire CCG	2		1			
NHS Calderdale CCG	1			1		
NHS Cambridgeshire and Peterborough CCG		2				
NHS Cannock Chase CCG	1	1				
NHS Central London (Westminster) CCG				1	1	
NHS Chorley and South Ribble CCG	2		1			
NHS City and Hackney CCG	1					
NHS County Durham CCG	2					
NHS Coventry and Rugby CCG	1					
NHS Croydon CCG		1				

1. Patients were asked to select their CCG from the NHS published list.

## Annexe B: Patient response by CCG for referrals on or after December 18<sup>th</sup> 2020<sup>1</sup>

CCG	Unable to get referral as GP unaware of clinic	Unable to get referral (GP disbelieves/ don't have a positive test/ not been hospitalised/ other)	Waiting to hear	Referral refused by clinic	Awaiting appointment	Had first appointment
NHS Doncaster CCG	1					
NHS Dudley CCG					1	
NHS East Berkshire CCG					2	1
NHS East Riding of Yorkshire CCG		2				
NHS Enfield CCG					1	
NHS Gloucestershire CCG	3					
NHS Harrow CCG					1	
NHS Herefordshire and Worcestershire CCG	3	1				
NHS Herts Valleys CCG	3					
NHS Heywood, Middleton and Rochdale CCG	1					
NHS Hounslow CCG	1					
NHS Ipswich and East Suffolk CCG	3	1				1
NHS Kent and Medway CCG	6					
NHS Kernow CCG	1	1				
NHS Knowsley CCG	1					
NHS Leeds CCG	3				1	1
NHS Manchester CCG	1	1				
NHS Milton Keynes CCG	2					
NHS North Central London CCG		1	1			
NHS Northamptonshire CCG		1			1	
NHS Oxfordshire CCG	1				2	
NHS Rotherham CCG					1	

1. Patients were asked to select their CCG from the NHS published list.

## Annexe B: Patient response by CCG for referrals on or after December 18<sup>th</sup> 2020<sup>1</sup>

CCG	Unable to get referral as GP unaware of clinic	Unable to get referral (GP disbelieves/ don't have a positive test/ not been hospitalised/ other)	Waiting to hear	Referral refused by clinic	Awaiting appointment	Had first appointment
NHS Somerset CCG	2				1	
NHS South East London CCG	1	1	1		1	
NHS South Sefton CCG	2					
NHS South West London		1			1	
NHS Southend CCG	1					
NHS Stockport CCG	3					
NHS Sunderland CCG	1					
NHS Surrey Heartlands CCG	1	1				
NHS Surrey Heath CCG	1					1
NHS Tees Valley CCG		1			1	
NHS Telford and Wrekin CCG		1				
NHS Tower Hamlets CCG		1				
NHS Trafford CCG	1					
NHS Wakefield CCG	1	1				
NHS Walsall CCG	1					
NHS Warwickshire North CCG	1					
NHS West Hampshire CCG	1					
NHS West London CCG		1				
NHS West Sussex CCG	1	1				1
NHS Wigan Borough CCG	2					
NHS Wolverhampton CCG	1	1				
Location unknown	1					

1. Patients were asked to select their CCG from the NHS published list.

# About us

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**Long Covid Support is a peer support and advocacy group for people living with Long Covid. Our 35,000 members span 98 countries.**

Long Covid Support was formed by a group of people struggling to recover from Covid-19, who found each other online and have been facilitating international peer support and campaigning in the UK for recognition, rehabilitation and research into treatments since May 2020.

Our international [Long Covid Support Group](#) is a warm and inclusive space for people experiencing the diverse, debilitating and alarming symptoms of Long Covid to share information, help each other through the bad days and rejoice in the good. We have several sister and affiliate groups that focus on particular areas:

[Long Covid Kids](#), a parent-led campaign and support group.

[Long Covid Scotland](#), an action group focused on the specific issues facing people living in Scotland.

[Long Covid Wales](#), a patient-led support group focused on the specific issues facing people living in Wales.

[Covid-19 Research Involvement Group](#), where investigators can make connections with patients for involvement, participation and engagement in research into Covid-19.

[Long Covid Physio](#), a global peer-support and advocacy group for Physiotherapists (Physical Therapists) and support workers living with Long Covid.

# Find us

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LongCovid.org



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@longcovid



[info@longcovid.org](mailto:info@longcovid.org)