



Long Covid Patient Experience

Assessment Services Survey

March 2021

As of March 21st, 74% of respondents to our survey had struggled to secure referrals to assessment services since publication of the clinical guideline and list of clinics

Of **268** people who sought referrals on or since December 18th

- **70** were referred successfully
 - **32** have been seen to date (face to face or video call)
 - **7** have completed a questionnaire/had online help only
- **11** were referred but clinic refused to give appointment
 - **6** no positive test or not hospitalised
 - **2** told I live too far away
 - **3** refused as under community care/other
- **181** were refused referral
 - **129** My doctor is unaware that there is a Long Covid clinic in the area (including in areas where clinics are listed)
 - **31** I don't think my GP believes I have Long Covid
 - **12** GP won't refer as not hospitalised/no positive test
 - **6** clinic not open yet/clinic since closed/not yet 12 wks+/other
 - **3** GP won't refer as service doesn't cover patient's symptoms
- **6** are currently awaiting a response from their GP

Background

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

Of respondents seeking referral after December 18th, 82% failed to secure referrals in the first data cohort compared with 67% in the second

	Responses until 2 nd Feb 2021	Responses between 2 nd Feb and 21 st March 2021
Total number seeking referral	128	140
Successfully referred	23	47
- seen to date (face to face/video call)	6	26
- questionnaire/online resources		7
Referred but clinic refused	4	7
- due to no test/not hospitalised	3	3
- too far away	1	1
- already community care/not ill recently enough/other		3
Refused referral	95	86
- GP disbelieves	15	16
- due to no test/not hospitalised	8	4
- GP won't refer as doesn't cover symptoms		3
- GP unaware of clinic in area	72	57
- clinic not yet open/been closed/not 12wks+		6
Awaiting response from GP	6	

Of **268** respondents seeking referral after December 18th, **39** (15%) have been seen, of whom **4** (2%) have been satisfied with the experience

Key Concerns Reported by Patients

- GPs are not aware of a clinic/service available locally, either because there is not one or there is but the GP lacks information
- GPs are unaware what service the clinic/service offers, what the referral criteria are or how referral pathways work
- GPs state that the service is limited and not relevant to the patient's symptoms
- Patients who have previously been offered other community care services are being refused referrals once a clinic has been set up
- First wave patients are being refused access because they have not had Covid-19 recently enough
- Patients are being refused referrals until 12 weeks or more of being ill
- Patients cite the following reasons for not being satisfied:
 - telephone consultation or online/app based service only
 - questionnaire based/no follow up treatment
 - limited service offer/not multidisciplinary
 - long gaps between appointments

Patients feel that their symptoms are not being investigated appropriately, and are frustrated by the lack of a multidisciplinary approach

“It appears this long covid clinic is a physio exercise program only and no other specialists there which I find disappointing as I was hoping I would be able to get help in all areas of symptoms not just an exercise program. After waiting for an appointment, hoping for answers, I'm left frustrated and still without answers from neurology or pulmonary.” Surrey

“I was sick in March 2020 and was only able to gain a referral to a long covid service in Feb 2021. My local long covid service is offering no physical assessments or tests at all and I am concerned that there may be underlying causes for my breathing issues and other issues which is being missed. Respiratory physio isn't going to fix my breathing issues if my issues are e.g. due to heart issues.” Bolton

“I feel that the clinic concentrates too heavily on mental health and not the physical implications and symptoms. Leading terminology is used in the app and heavily focused on mental and emotional aspect. When tracking symptoms suggestive wording used is anxiety, frustration and fear. I am sure that exists for many patients.” Winchester

“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

“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 I 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

Some patients feel their symptoms are not being taken seriously

“The initial triage by a nurse was within three weeks of my referral. About a week later, I had an online assessment with a doctor, a psychologist and a physiotherapist. The out come was that I need further tests and the doctor would write to my GP to get these done. The doctor also said my breathing problems were due to being overweight (I am now but I wasn't before covid!) and due to being out of condition (I was very fit prior to covid but have had to cut activity right back as it was making me worse). I was told that the headaches are tension headaches - I am absolutely certain that they are triggered by doing too much and they are by far the worst headaches I have ever had. The psychologist wants to book me a further appointment over my anxiety about return to work - my 'anxiety' stems from the fact that I think I may lose my job if I don't return and I think this is a normal reaction to threat of job loss rather than a mental health issue. I was told that both the letter and the follow up appointment will take at least 6 weeks. It has been 4 and half weeks now and so far I have had no contact. I understand that the NHS must treat those whose lives are at risk first but I was hoping for investigations into heart rate and breathing when exercising. I was hoping for investigation into the headaches other than don't do anything during the day because activity triggers them. I was hoping to be referred for scans of my heart, lungs and brain if the initial investigations warranted it. I was not hoping for more blood tests and a urine test!”

Buckinghamshire

Patients are still not being taken seriously by medical professionals

“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

Even those who manage to secure a referral face lengthy waits to be seen

“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

“Next appointment is in around 6 months time. I think too long.” North East Essex

“I still have not received contact from the clinic nor has my GP been in touch since I contacted them middle of Jan.” Leeds

“Yes asked to be referred but because I havn't had covid in the last month they said I couldn't be referred.” Dudley

“Spent over a year fighting this, but still not seen.” Norfolk and Waveney

This patient cites barriers of waiting times, complex, unclear referral pathways and lack of multidisciplinary care, and has had to give up her job of a decade

“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: Patient response by CCG for referrals on or after Dec 18th 2020

CCG	Unable to get referral as GP unaware of clinic	Unable to get referral (GP disbelieves/ no positive test/not hospitalised /other)	Waiting to hear back from clinic	Referral refused by clinic	Awaiting appoint	Had first appoint	Total
NHS Barking and Dagenham CCG	1						1
NHS Barnet CCG	1						1
NHS Barnsley CCG						1	1
NHS Basildon and Brentwood CCG			1		1		2
NHS Bath and North East Somerset, Swindon and Wiltshire CCG				1			1
NHS Bedfordshire CCG	1	1				1	3
NHS Berkshire West CCG	1	1				1	3
NHS Birmingham and Solihull CCG	2		1		1	1	5
NHS Blackpool CCG	1	1					2
NHS Bolton CCG	2	1				2	5
NHS Bradford District and Craven CCG	2	1				2	5
NHS Brent CCG	1						1
NHS Brighton and Hove CCG	1					1	2
NHS Bristol, North Somerset and South Gloucestershire CCG				1	1	1	3
NHS Bromley CCG	1						1
NHS Buckinghamshire CCG	2		1			2	5
NHS Calderdale CCG	2	1		1			4
NHS Cambridgeshire and Peterborough CCG		4		1			5
NHS Cannock Chase CCG	1	1					2
NHS Central London (Westminster) CCG				1	1		2
NHS Cheshire CCG	1			1		2	4

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NHS Chorley and South Ribble CCG	2		1				3
NHS City and Hackney CCG	1						1
NHS County Durham CCG	2					1	3
NHS Coventry and Rugby CCG	1						1
NHS Croydon CCG		1					1
NHS Derby CCG		3				1	4
NHS Devon CCG	2	1		1			4
NHS Doncaster CCG	1						1
NHS Dorset CCG	1						1
NHS Dudley CCG		1			1		2
NHS Ealing CCG						1	1
NHS East & North Herts CCG			1				1
NHS East Berkshire CCG					2	1	3
NHS East Riding of Yorkshire CCG	1	2					3
NHS Enfield CCG					1		1
NHS Gloucestershire CCG	3	3					6
NHS Greater Huddersfield CCG	1						1
NHS Halton CCG		1					1
NHS Harrow CCG					1		1
NHS Havering CCG	1						1
NHS Herefordshire and Worcestershire CCG	4	2					6

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NHS Herts Valleys CCG	4			2		1	7
NHS Heywood, Middleton and Rochdale CCG	1						1
NHS Hounslow CCG	1						1
NHS Hull CCG	1						1
NHS Ipswich and East Suffolk CCG	4	2				1	7
NHS Kent and Medway CCG	9		1				10
NHS Kernow CCG	1	1					2
NHS Knowsley CCG	1						1
NHS Leeds CCG	4		1		1	2	8
NHS Lincolnshire CCG		1				1	2
NHS Liverpool CCG			1				1
NHS Manchester CCG	1	1					2
NHS Milton Keynes CCG	2					1	3
NHS Morecambe Bay CCG	2	1					3
NHS Norfolk and Wavering CCG						3	3
NHS Northamptonshire CCG		2			1		3
NHS North Central London CCG		1	1				2
NHS North Cumbria CCG	1						1
North East Essex CCG						1	1
NHS North East Sussex CCG						1	1
NHS North Hampshire CCG						1	1

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NHS North Kirklees CCG	1		1				2
NHS North Yorkshire CCG	1					1	2
NHS Northumberland CCG	1	1					2
NHS Oxfordshire CCG	1				2		3
NHS Rotherham CCG					1	1	2
NHS Sheffield CCG	1						1
NHS Shropshire CCG					1		1
NHS Somerset CCG	4				1		5
NHS South East London CCG	1	3	2		1	1	8
NHS Southampton	1					1	2
NHS South Sefton CCG	2						2
NHS South Warwickshire	1					1	2
NHS South West London	3	3			1	1	8
NHS Southend CCG	1						1
NHS Stafford			1				1
NHS Stockport CCG	3						3
NHS Stoke on Trent CCG			1				1
NHS Sunderland CCG	1						1
NHS Surrey Heartlands CCG	1	1				1	3
NHS Surrey Heath CCG	2					1	3
NHS Tees Valley CCG	1	1			1		3

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NHS Telford and Wrekin CCG	1	1					2
NHS Tower Hamlets CCG		1				1	2
NHS Trafford CCG	1	3					4
NHS Wakefield CCG	1	1					2
NHS Walsall CCG	1						1
NHS Waltham Forest CCG				1		1	2
NHS Warrington CCG	1		1				2
NHS Warwickshire North CCG	1						1
NHS West Hampshire CCG	1					1	2
NHS West London CCG		1					1
NHS West Essex CCG		1					1
NHS West Sussex CCG	2	2	1		1	2	8
NHS Wigan Borough CCG	2						2
NHS Wirral CCG			1				1
NHS Wolverhampton CCG	1	1					2
Dumfries and Galloway Community Health Partnership	1						1
Swansea Bay University Health Board	2						2
Location unknown	5	2					7
TOTAL	118	56	17	10	20	43	264

About us

Long Covid Support is a peer support and advocacy group for people living with Long Covid. Our 37,000 members span 100 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

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Long Covid Support Group

<https://www.facebook.com/groups/longcovid>



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