



Long Covid: is policy reaching patients?

People with Long Covid are desperate. Desperate to be seen, desperate to be listened to, desperate to be helped.

There has been some progress to put in place support in parts of the UK, but this is not yet reaching large numbers of people, many of whom have lived with debilitating symptoms for a year and have seen their ability to work, study or care for others significantly impaired. This is the case even for the vast majority of people who were not admitted to hospital during the early weeks of their illness.

Below we set out what people with Long Covid urgently need, encapsulated in the three word slogan we created in summer 2020 as we strove for visibility: rehab, research and recognition. We are exhausted as much from our efforts to secure support as from our illness. Patients are losing patience.

People with Long Covid urgently need rehab, research, recognition - and response

- Rehab: support for the vast and growing numbers living with Long Covid, spanning treatment as well as financial support and help returning to work¹ or school
- Research: prevention of new cases and treatment for those living with Long Covid
- Recognition: recognition of Long Covid as an occupational disease. Recognition under the Equality Act and as a critical illness. Recognition of the importance of working with patient groups to ensure resources are directed in the most efficient and effective manner

What is the problem?

Following infection with SARS-CoV-2, a significant minority of people of all ages do not regain their previous levels of health for many months - possibly longer. Initial ONS findings indicate that at least 1 in 10 people testing positive for COVID-19 still experience symptoms 12 weeks.²³

¹ Almost 70% of people with Long Covid are unable to work at all or to their previous capacity, even 7 months post infection
<https://twitter.com/athenaakrami/status/1343166511842787328?s=21>

² <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/adhocs/12788updatedestimatesoftheprevalenceoflongcovidsymptoms>

³ <https://www.ons.gov.uk/news/statementsandletters/theprevalenceoflongcovidsymptomsandcovid19complications>

People with Long Covid experience:

- **Diverse and serious symptoms.** More than 200 symptoms⁴ have been recorded, including breathing difficulties, chest pain, numbness, fatigue, tachycardia, cognitive impairment and allergies, and these often follow a relapsing and remitting pattern. Some people have been disabled by symptoms that impede their ability to function for a year or more.
- **Difficulties accessing care.** Despite concerning cardio-respiratory and neurological symptoms, most people living with Long Covid have not been able to access investigations. Some describe health practitioners who are sympathetic but unsure how to help. Others describe being dismissed as anxious, causing them distress and also discouraging them from seeking help even if they experience 'red flag' symptoms. There are high incidences of referrals to Long Covid clinics and/or hospital consultants being rejected. Patients describe being exhausted at having to research and advocate for themselves, with peer support groups their primary source of help in navigating their condition.
- **Receiving harmful advice.** Some patients are prescribed interventions such as Graded Exercise Therapy (GET), which was recently removed from the draft clinical guideline for ME/CFS. GET not only contraindicates fatigue symptoms, but can exacerbate symptoms of cardiac injury, such as myocarditis.
- **Psychological trauma.** Experiencing a serious infectious disease, followed by prolonged illness with an uncertain prognosis, invalidation from health professionals and loved ones, and in many cases loss of livelihood and relationships has led to a great deal of trauma and mental ill health. Many people, even those who were not deemed sufficiently ill to be admitted to hospital despite multiple visits to A&E, wrote their end of life wishes and spoke to loved ones about the prospect of not surviving the illness.
- **Impaired ability to work, study, and/or care for themselves or others.** Even several months after symptom onset, many with Long Covid are unable to work or carry out caring responsibilities to their previous capacity, if at all. Those who do return to work/care often push through out of necessity, for financial reasons or because their employers may not believe them nor offer adequate support. Many have considerable financial difficulties, and are being refused disability benefits.
- **Discrimination and bias.** People living with Long Covid continue to be discriminated against due to lack of testing or not having been hospitalised. Pre-existing inequities have become all the more stark, and safety and care have been compromised on account of the power imbalance between patients and health professionals.

⁴ <https://www.medrxiv.org/content/10.1101/2020.12.24.20248802v2>

What do we need?

Rehab

- **Examine us.** We welcome the opening of Long Covid clinics in England, but responses to our survey⁵ indicate that most people are struggling to secure referrals. Those of us living in the devolved nations are not able to access equivalent services, nor are children. Lack of proximity to a clinic is the greatest barrier to referral. Some patients continue to be disbelieved by their GPs as having Long Covid, and capacity and waiting lists are also an issue. Interpretation of the NICE/SIGN/RCGP guideline is leading some GPs to delay referrals until a patient has been ill for 12 weeks, on account of the rather arbitrary subdivision of the illness into three phases (0-4 weeks, 4-12 weeks and 12+ weeks) that do not align with lived experience.⁶ The clinical guideline should be updated for this reason and also to provide more actionable detail for health practitioners, including - for example - emerging learnings of what might help patients.^{7,8}

Face-to-face assessment at a multidisciplinary clinic is important, since large numbers of patients have not been seen in person by a medical professional, or - at most - received only basic observational investigations when seeking emergency medical help via A&E or 999, and alarming, potentially critical symptoms can emerge even months after infection. The Coverscan⁹ study indicates that many of us may have damage to one or more organs, and that this damage can include potentially serious issues such as myocarditis:

“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

- **Inform us.** There is an urgent need for clear, consistent information and communication of case recognition, care protocols and pathways, both for health professionals and patients. This should include pathways for people who sought referral prior to December 18th, 2020 (publication of the clinical guideline and clinics list) who are awaiting appointments with a specialist consultant rather than a dedicated Long Covid service, and whose Long Covid symptoms need to be assessed in the round.

⁵ <https://www.longcovid.org/impact/long-covid-clinics-in-england-share-your-experience>

⁶ [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)

⁷ Royal Society of Medicine COVID-19 Series Episode 62: Which treatments are effective? February 18, 2021

https://www.youtube.com/watch?v=GSB7ZaYabFw&feature=share&fbclid=IwAR11_K4WeOON1VqhrXGVglwzcrI_hjgj5qIU32ISvevl7dBu9EzjDofGNWg

⁸ <https://www.theguardian.com/commentisfree/2021/feb/28/if-oestrogen-can-save-women-from-the-worst-of-covid-they-should-be-given-it>

⁹ <https://www.medrxiv.org/content/10.1101/2020.10.14.20212555v1.full.pdf>

“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.”

The role of clinics and assessment services and what patients can expect need to be clarified and communicated, including thresholds for further investigations and treatment, continuity of care and referral pathways to further services.

There should be a central, up-to-date list of clinics and other services, which should be accessible to patients as well as health professionals, and include address and contact details. If we know there isn't yet a service in our area, we and our GPs will stop wasting time and effort to seek referrals.

Emerging learnings from research, Long Covid clinics and patient groups should be disseminated to clinics and patients, for example via a central resource.

- **Care for us.** Allocate us a single point of contact to oversee our care, and offer us assessment, appropriate investigations, treatment, safe, consistent and personalised rehabilitation advice and signposting for financial, employment, welfare and educational support.¹⁰

Those fortunate to have been able to access investigations report being sent from pillar to post for diagnostic tests that invariably do not shed light on the cause of our pronounced symptoms. The Coverscan MRI technology that scans multiple organs in a single appointment could not only improve diagnosis but also release scanning capacity for other conditions. When it comes to rehabilitation, some patients are being given advice to exercise when research indicates that a very large majority of people with Long Covid experience post-exertional malaise¹¹ and many have extreme levels of lactic acid. Indeed many patients report relapses even as a result of lung function and exercise tests. There is an urgent need for safe, effective and personalised rehabilitation advice, which should include advice for cognitive rehab.^{12 13} Your Covid Recovery has the potential to be the go-to resource for patients, but currently that is not the case. Online support and self management may have a valid role to play within a broader pathway, but must not be the default given the prevalence of red flag symptoms and potential organ damage.

- **Support us** in returning to work and school. Educate employers and schools about the debilitating effects of Long Covid, its relapsing remitting nature and the types of reasonable adjustments that may support a sustainable return to work or school, amplifying materials co-created by patients¹⁴. Those no longer able to work need advice from the DWP and access to disability benefits. Failure to address these points, alongside barriers to healthcare, will otherwise serve to widen existing inequalities.

¹⁰ <https://www.google.co.uk/amp/s/inews.co.uk/news/real-life/long-covid-clinics-coronavirus-locations-symptoms-months-795388/amp>

¹¹ <https://www.medrxiv.org/content/10.1101/2020.12.24.20248802v2>

¹² <https://longcovid.physio/exercise>

¹³ <https://twitter.com/AthenaAkrami/status/1343166471938203649?s=20>

¹⁴ https://www.som.org.uk/COVID-19_return_to_work_guide_for_recovering_workers.pdf

Research

- **Treat us.** The £18.5 million allocated to research among non-hospitalised patients is welcome, but we are concerned that there is insufficient focus among the winning applications on understanding the underlying mechanisms, including genetics and immunology, to improve our understanding and potentially lead to treatments. Given that Congress approved \$1.15 billion for the NIH to fund Long Covid research and clinical trials¹⁵, we hope that some of the strong applications that were not successful in the recent NIHR/UKRI call can also be funded. Note also that the distinction between hospitalised and non-hospitalised patients may be problematic.¹⁶ The threshold for admission was high; many of us were told not to return to A&E unless our lips turned blue or our chest pain became unbearable.
- **Prevent us** from growing in number by investing in scientific research, data on prevalence and communication:
 - Invest in research into early interventional therapeutics, to complement the vaccination programme and its associated issues relating to take-up, efficacy against new variants, timing/logistics, eligibility (e.g. children, pregnant women), etc. The aim should be to administer low cost, low/no side-effect oral medication to community cases within a maximum of 48 hours of symptom onset, with a view to stemming viral replication and preventing severe acute cases as well as Long Covid¹⁷. Consider including candidates that have previously been discounted, since previous trials may have administered these too late after symptom onset.
 - Update the NHS website and public health messaging to communicate the diversity of symptoms. Many people are unaware that they have Covid or Long Covid, leading to unwitting spread of the virus. Public health messaging should encourage people to seek tests if they experience any unusual symptoms.¹⁸
 - Make Long Covid part of the public narrative and consciousness via platforms such as the Covid briefings and news reports to encourage compliance with public health measures.
 - Adopt a phased return to fully opening schools, including measures such as a rota system to halve class sizes, vaccination of staff, mask wearing in the classroom as well as in common areas, ventilation measures and outdoor lessons where possible.

¹⁵ <https://www.healthrising.org/blog/2020/12/24/congress-billion-covid-19-long-haulers/>

¹⁶ https://www.medrxiv.org/content/10.1101/2021.01.11.20248765v1?fbclid=IwAR3FNlv7aw6FCGYv9I72xYdI56SldCvq_AZjal_o-DOHSeaFFoeEdCc3CSsE

¹⁷ <https://www.ucl.ac.uk/comprehensive-clinical-trials-unit/research-projects/2021/feb/flare>

¹⁸ https://twitter.com/long_covid/status/1291774134385545221?s=20

Recognition

- **Believe us.** Although there have been improvements thanks to media attention and publication of the NICE/SIGN/RCGP clinical guideline on December 18, 2020, too many of us continue to be dismissed by health professionals, employers and others as having anxiety or malingering. Some of us continue to be refused referrals, and others have faced disciplinary action from our employers, who accuse us of absenteeism. This underlines the need for clear and consistent information, communication and training.
- **Recognise us.** Many of us caught the virus at work. We echo the call of the All Party Parliamentary Group on Coronavirus for Long Covid to be recognised as an occupational disease¹⁹, and for frontline health and other key workers living with its debilitating effects to be compensated under a scheme similar to the Armed Forces Compensation Scheme. People disabled by Long Covid also urgently need the rights and protections afforded by the Equality Act 2010. Recognition of Long Covid as a critical illness would allow us to claim on our income protection and equivalent policies.
We call for people debilitated by Long Covid to be included on the clinically vulnerable list for vaccines. We were clearly extremely vulnerable to the disease the first time and are likely to be so again - potentially more so, given our weakened condition.
- **Count us.** Refine the ONS survey questions to seek a more accurate reflection of the scale of Long Covid by including people who have been ill for more than a few months and to gather information on the impact at different points in their illness on their ability to care for themselves and others, and to work or study. As recommended by Independent SAGE, there should be a national register of people with Long Covid to enable long-term follow-up and an improved understanding of the natural history of this condition.²⁰
- **Listen to us.** Our Long Covid Support Facebook group is the largest group of its type in the world.²¹ We are recognised by researchers, the media, employers and health professionals, who refer patients to us for support and information. WHO Director General Dr Tedros Adhanom Ghebreyesus mentioned the importance of our work at the WHO webinar on February 9th and invited us to meet and to hold a press briefing.

¹⁹ <https://inews.co.uk/news/health/long-covid-treatment-support-uk-nhs-europe-france-germany-877120>

²⁰ https://www.independentsage.org/wp-content/uploads/2021/01/Long-COVID_FINAL.pdf

²¹ We know of two larger groups (based in the US and South Africa) but they are for survivors of Covid (as opposed to focused solely on Long Covid) and are public, i.e. open to anyone. In contrast, Long Covid Support is a private group. Every prospective member is approved, and must answer joining questions confirming that they have experienced symptoms for 4 weeks or more. Direct carers of non-Facebook users are also permitted.

- **Work with us.** Our network of members, affiliates and collaborators includes broad and deep lived and professional experience in fields including medicine, research, occupational health, physiotherapy, public health, epidemiology, global health, psychology and strategy. In line with the ‘nothing about us, without us’ principle, we are keen to harness our wealth of collective expertise to work collaboratively in the design of services, research and indeed any elements impacting the lives of those with Long Covid. Please involve us to optimise support for the vast numbers affected by Long Covid. It is clear what has been developed without genuine patient involvement as it tends to miss the mark.

“Involvement of patient groups in the work at the earliest stages and cooperation in development of the work plan will help ensure the outputs are sensitive to the needs of patients and their families.”

The Royal Society, Long Covid: what is it, and what is needed? October 23, 2020²²

“Patients with Long COVID should be recognised as an extremely important resource in shaping research and policy in relation to this condition.”

Independent SAGE Report on Long Covid, January 28, 2021²³

- **Fund us.**

Members of our Long Covid Support Facebook group tell us it is a lifeline as a source of information, compassion and support, and a huge help to mental health - more than one member has told us the support from the group prevented them from taking their own life. In our tightly moderated private group, open only to those with Long Covid or their direct carers, every post is approved by our team of volunteers who work tirelessly across time zones. Our members have a safe space to confide in and support others, and often share concerns that they do not feel able to voice to family or friends. Our regular video call gatherings are a further source of comfort, particularly to those experiencing social isolation. We hope to start a choir to help with breathing as well as to provide a heartwarming communal activity in which even bedbound members can participate.

“This group saved me from feeling alone, lost and terrified. It has made a huge difference to not be alone with this. So thank you admins. What you are doing means so much ❤️❤️❤️”

Janey Colbourne, Long Covid Support Group member

Outside of the group, we have been highly active in the mainstream media as well as on social media in our efforts to raise awareness of Long Covid. In addition to advocacy and peer support, a key pillar of our work is research involvement. Alongside ISARIC and GloPid-R, we co-hosted the Long Covid Forum²⁴, the first international research conference on Long Covid, held on December 9th and 10th 2020 and opened by WHO Director General Dr Tedros Adhanom Ghebreyesus.²⁵ Our sister Facebook group Covid-19 Research Involvement provides

²² <https://royalsociety.org/-/media/policy/projects/set-c/set-c-long-covid.pdf?la=en-GB&hash=AD0672CAB24E1FCD14C2B1781A793E25>

²³ https://www.independentsage.org/wp-content/uploads/2021/01/Long-COVID_FINAL.pdf

²⁴ [https://www.thelancet.com/journals/laninf/article/PIIS1473-3099\(21\)00043-8/fulltext](https://www.thelancet.com/journals/laninf/article/PIIS1473-3099(21)00043-8/fulltext)

²⁵ <https://isaric.org/event/long-covid-joint-research-forum-virtual-events-9-10-december-2020/>

a forum for researchers and academics to interact with patients, and we have co-authored several papers published in respected journals.

Despite more resources and help becoming available, our members tell us that their doctors refer them to our group as a trusted source of information and support.

Response needed

It is clear that policy is not reaching patients. Guidance has been created but is not being used consistently. Clinics have been announced in England but large numbers of people are struggling to secure referrals. Research has been funded but there are significant and concerning gaps. Your Covid Recovery should be a complement to, not a substitute for, safe and personalised rehabilitation advice. Continued lack of awareness and knowledge of Long Covid among some healthcare workers, cross government departments, employers and the wider public is leaving people without the support they need.

As we articulated in our joint call to action²⁶ with Patient Safety Learning, we are calling for an urgent and significant increase in the scale and pace of the response, and a coordinated, multi-stakeholder approach, led by a dedicated Minister for Long Covid.

Patient engagement is proven to be a key factor in designing effective services and improving clinical outcomes; it should never be viewed as 'nice to have' or applied in a tokenistic way. Those with lived experience of Long Covid must be seen as partners at every step of the response, with a clear involvement strategy to ensure that decisions 'about them' are not made 'without them'. To undervalue this input would be incredibly short-sighted and would contravene NHS policy.

We are here. We are numerous. We are desperate. We are determined. We are ready to work together to ensure that no one is left behind.

#PatientsAsPartners

²⁶ <https://www.longcovid.org/impact/long-covid-support-patient-safety-learning-joint-call-to-action>