

Hearing Before the United States Congress
The Long Haul: Forging a Path Through the Lingering Effects of COVID-19
House Committee on Energy and Commerce, Subcommittee on Health
April 28, 2021

The Long COVID Experience

Evidence from Patient-Led Research and the Patient Community

Lisa McCorkell, MPP
Team Lead and Researcher
Patient-Led Research Collaborative



Introduction

At least 21 percent of people who contract COVID-19 experience prolonged symptoms, spanning all organ systems and causing significant impacts to people's lives.¹ With over 31.8 million cases of COVID-19 reported in the United States, this translates to **over 6.7 million people experiencing prolonged symptoms, referred to as Long COVID.**² While initial reports of COVID-19 warned of severe disease that could result in hospitalization or death, the outcome of Long COVID has proven that the pandemic is also a mass disabling event, the effects of which will be seen for decades.

The patient-preferred term for this illness is Long COVID.³ We define Long COVID as continuing to experience symptoms after a confirmed or suspected SARS-CoV-2 infection for at least 28 days. Long COVID encompasses a group of conditions that patients face following acute infection, and may include organ damage, post-viral illnesses, reinfections of previously dormant viruses like Epstein-Barr virus, and more. Some patients may have one of these subsets of Long COVID, some may have all. It affects people of all ages, genders, races, and ethnicities across the country.

Patient-Led Research Collaborative (PLRC) is a group of Long COVID patients who were the first to conduct research on Long COVID. Our mission is to facilitate patient-led and patient-involved research, and to advocate on behalf of Long COVID patients. After our symptoms from a mild/moderate COVID-19 illness did not subside after several weeks, each of PLRC's co-founders joined the Body Politic COVID-19 Support Group.⁴ PLRC was founded in April 2020 when the group of us recognized the need to aggregate all of the information people were sharing within the support group to understand what was happening to our bodies. PLRC has grown to now have over 30 contributors, with backgrounds in data analysis, neuroscience, public policy, participatory design, machine learning, and more.⁵

PLRC's primary form of research is conducting surveys of the Long COVID patient community. Our survey questions are developed from what the Long COVID patient community is asking and reporting. This ensures that the surveys capture the various Long COVID experiences. Patients have a more intimate understanding of an illness than any doctor or researcher who has not experienced it. This is reflective in the types of research questions patients ask and what patients want to be asked by doctors and researchers.

Over the last year, we have presented to the World Health Organization (WHO) and been part of their Long COVID working group, and have held ongoing meetings with the Centers for Disease Control and Prevention (CDC) Post-COVID Conditions Unit in partnership with Body Politic. Our research has been cited in and contributed to over 70 scientific publications, guidance for clinicians, and policy documents,⁶ and been written about by the National Institutes of Health (NIH) Director Dr. Francis Collins.⁷ We are also part of the Long COVID Alliance, a network of

patient-advocates, scientists, and disease experts whose aim is to educate policymakers and accelerate research into all infection-triggered illnesses.⁸

PLRC Research

Our first report, released on May 11, 2020, analyzed 640 responses of people who experienced prolonged symptoms from COVID-19.⁹ The report documented the prevalence of non-respiratory symptoms, particularly neurological, many of which were not yet acknowledged by the medical community and major media outlets. Since the respondents who completed this survey became sick at a time when diagnostic testing for COVID-19 [such as polymerase chain reaction (PCR) and antigen] was widely inaccessible, nearly half of respondents (47.8 percent) were not tested (either denied or had no access to a test). Of those who were tested for COVID-19, the only differences between those who tested positive and those who tested negative was: (1) *when they were tested* (day 10 from original onset of symptoms on average for those who tested positive, day 16 for those who tested negative) and (2) those who tested positive were more likely to experience loss of smell and taste than those who tested negative. Only 28.5 percent of respondents felt very supported by medical staff, while 21.5 percent did not feel supported and 50 percent felt somewhat supported. This report was cited in some of the first media articles on Long COVID,¹⁰ has been cited in academic journals,⁶ and led to conversations with the WHO and CDC.

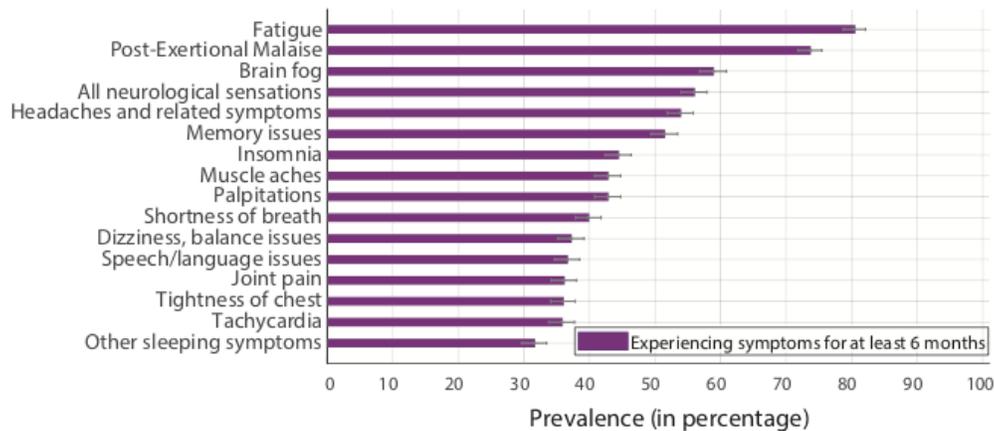
Our second report is awaiting journal acceptance, and was posted as preprint (not peer reviewed) on December 26, 2020. “Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact” analyzes responses from 3,762 participants ages 18 years or older with confirmed or suspected COVID-19, with illness duration of at least 28 days. 41.2 percent of respondents are residents of the United States.

Here are the key findings from our second report:

- Long COVID symptoms span all organ systems, with 205 symptoms documented.
- **45.2 percent of respondents who had been working before getting COVID reported requiring a reduced work schedule compared to pre-illness, and 22.3 percent were not working at the time of survey due to their health conditions.**
- 91.6 percent of respondents were not hospitalized. (Some of these patients may have needed hospitalization but were not admitted due to overwhelmed hospitals. Most, however, had an initially mild or moderate COVID-19 illness.)
- **The primary difference between respondents who tested positive and those who tested negative via a diagnostic COVID-19 test was when they were tested:** those who tested positive were tested on day 6 of symptoms while those who tested negative were tested on day 43 of symptoms on average. Symptom prevalence and trajectory between the two groups were remarkably similar, with only loss of/changes to smell and taste showing a significant difference.

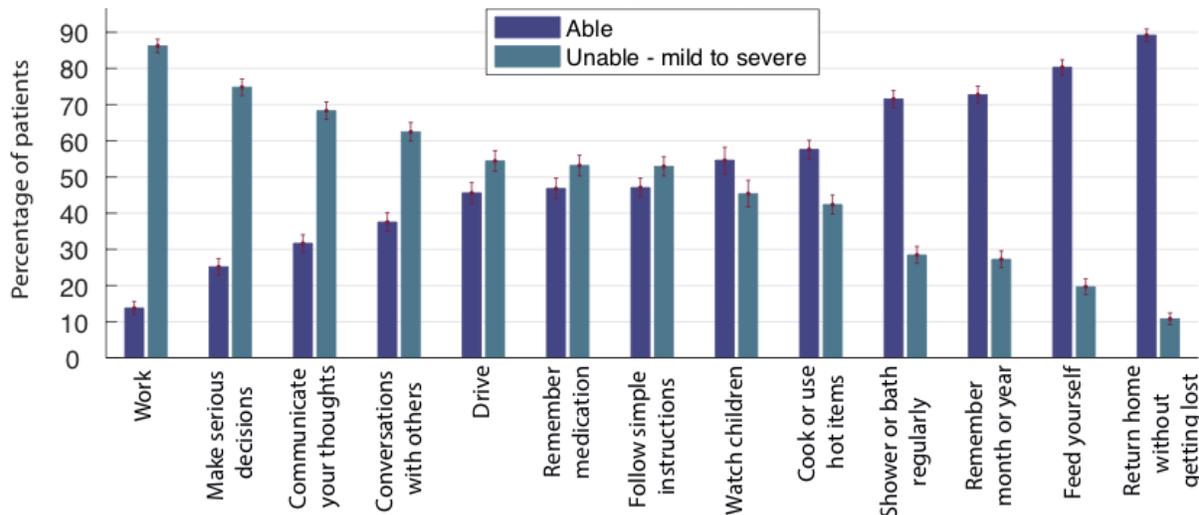
- The most common symptoms reported by patients were fatigue (reported by 98.3 percent of respondents), post-exertional malaise (89.1 percent), and cognitive dysfunction/brain fog (85.1 percent). Fatigue and cognitive dysfunction were also in the top three of the most debilitating symptoms reported by respondents, in addition to breathing issues. See Figure 1 for the most prevalent symptoms reported in respondents after month 6.

Figure 1: Most prevalent symptoms in respondents after month 6 of illness



- Of those who experienced memory issues and/or cognitive dysfunction, 86.2 percent felt mildly to severely unable to work, 85.3 percent were unable to make serious decisions, and 74.8 percent felt unable to communicate thoughts and needs (Figure 2).

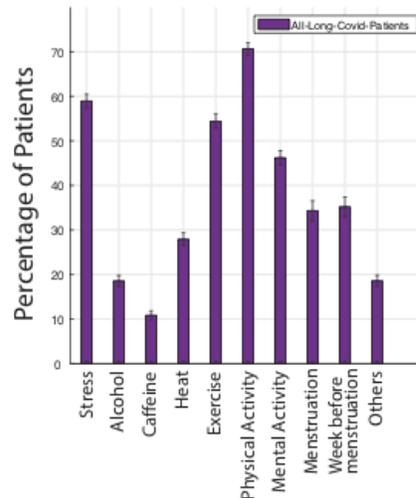
Figure 2: Impact of memory and cognitive dysfunction on daily life



- There was *no significant difference in memory issues, cognitive dysfunction, or impact on life by age*, meaning that the prevalence and impact of these symptoms for respondents ages 18-29 was similar to respondents ages 70+ .
- Respondents with symptoms over 6 months experienced an average of 13.8 symptoms in month 7.

- 85.9 percent of respondents experienced relapses, with exercise, physical or mental activity, and stress as the main triggers (see Figure 3).

Figure 3: Triggers of relapses



- 4.4 percent of respondents experienced a temporary break in symptoms, only to have symptoms return later on.
- 40.7 percent of unrecovered respondents experienced extreme levels of fatigue at time of survey.
- The following organ systems were most impacted: 100 percent of respondents experienced HEENT (head, ears, eyes, nose, throat) symptoms, 99.7 percent of respondents experienced systemic symptoms (such as fatigue, weakness, and fever), 93.9 percent experienced musculoskeletal symptoms, 93.0 percent experienced pulmonary/respiratory symptoms, and 91.4 percent experienced sensorimotor neuropsychiatric symptoms.
- 36.1 percent of respondents who reported having a menstrual cycle reported experiencing period/menstrual issues.
- Other serious symptoms reported by respondents include hearing loss (reported by 9 percent of respondents), vision loss (1 percent), facial paralysis (3 percent), and suicidality (12 percent).
- Many of the symptoms documented, as well as what diagnoses patients had already received at time of survey, suggest that a subset of patients develop postural orthostatic tachycardia syndrome (POTS; a type of dysautonomia), myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and mast cell activation syndrome.

This paper has been viewed over 118,000 times, downloaded over 56,000 times, and is in the top 0.1 percent of outputs on medRxiv, the preprint website it is posted to.

Barriers for Long COVID Patients

From our research, others' research on Long COVID, and what we hear from the Long COVID patient community, we are intimately aware of the barriers Long COVID patients face to adequate care, treatment, and recovery, and how that will translate to impacting healthcare and the economy.

Testing

Long COVID patients who do not have a positive COVID-19 diagnostic (PCR/antigen) or antibody test are often denied access to services that are afforded to those who do have a positive test such as healthcare services for diagnostic and symptom management, health insurance coverage of those services, school and workplace accommodations, research participation, and worker's compensation or disability benefits. There is no evidence to support the justification of this, and in fact, several studies have shown what ours has in that symptoms do not differ between Long COVID patients who have a positive test and those who do not, with the exception of loss of smell and taste.¹¹

At the beginning of the pandemic, and for some communities throughout, access to COVID-19 diagnostic testing was extremely limited. Once tests were developed, for several months they were reserved for hospitalized patients, patients with history of international travel, or patients who exhibited specific symptoms. As testing became more accessible, communities who are outside of the traditional healthcare system still may not have received a test. Further, a recent study has documented that 32% of people reporting symptoms after two months were initially asymptomatic at time of SARS-CoV-2 testing, indicating that testing could be missing a group who were initially asymptomatic but did not have a known exposure or access to a test.¹² Therefore, some patients who may have otherwise tested positive were either not tested at all or tested at a time when the test would not capture the virus, leading to some patients not receiving the care and benefits they deserve.

Additionally, PCR and antibody tests are not guaranteed indications of SARS-CoV-2 infection. The likelihood of false negatives from a PCR test increases after day 3 of symptom onset, when the false negative rate is 20 percent, reaching 66 percent by day 21.¹³ In fact, up to 54 percent of patients could have an initial PCR false negative result.¹⁴ Additionally, antibody tests are not completely accurate in detecting the presence of SARS-CoV-2 antibodies. Antibody tests have been shown to be less accurate in women than men, and less accurate for people under 40 years old and over 70 years old.¹⁵ Even if the test is accurate, low antibody levels in the earlier stages of patients' illnesses were associated with persistent symptoms 7 months later, indicating that Long COVID patients may not be developing antibodies in the same way that COVID patients who do not develop Long COVID do.¹⁶

Therefore, the lack of a positive COVID-19 test must not preclude patients from being covered by insurance, having access to post-COVID clinics, being eligible for government benefits, accessing accommodations, and participating in clinical research and trials.

Clinical diagnoses, and retrospective clinical diagnoses, must be accepted as a valid indication of COVID-19. Limiting any access to care and benefits to patients with a positive test will further exacerbate inequities in care amongst racially and ethnically marginalized and low-income populations, who experience more barriers to testing and therefore are more likely to not have a positive test.

Currently, PLRC has heard from patients who are denied the following because they do not have a history of COVID-19 test result:

- Access to Post-COVID treatment centers;
- Referrals or specialty appointments to evaluate for organ damage following suspected COVID-19 infection;
- Health insurance coverage of testing and treatment related to Long COVID;
- COVID-related paid leave from work;
- Worker's compensation and disability benefits;
- Workplace accommodations related to Long COVID; and
- Participation in Long COVID research.

Medical Care

There are several barriers Long COVID patients face in receiving proper medical care.

First, Long COVID patients are often not believed by doctors. They can be told that the symptoms are “in their head” and attributed solely to anxiety, especially when blood tests and imaging do not show abnormalities. However, post-viral illnesses are documented in medical and historical literature, though historically have been very underfunded and poorly understood. People of color, women, and LGBTQ(IA+) face additional prejudice and discrimination throughout the medical field, increasing the prevalence of gaslighting and disbelief by medical professionals.

Every patient has the right to be believed. Only they know what they feel. When doctors come to the conclusion that symptoms are imaginary and not worth investigating further, this assumes that modern medicine has discovered everything about the human body. Medical research says otherwise.

A recent CDC study found that of nonhospitalized adult patients with a positive COVID-19 test, two-thirds had at least one outpatient medical visit between one and six months post-diagnosis, and 38 percent went to a specialist.¹⁷ Because of the multi-organ impacts of Long COVID, many patients see multiple specialists. When patients go to different specialists who do not

collaborate with each other, valuable information is lost and patients suffer.¹⁸ Additionally, for patients with limited energy, seeing multiple specialists is draining and not conducive to recovery. Medical care must include meeting patient needs by helping patients navigate the healthcare system, whether by making it easier to see multiple specialists in one visit or performing home visits to run lab tests.

At the beginning of the pandemic, several academic and large medical centers opened post-COVID clinics to aid in rehabilitation of COVID-19 patients who had lengthy ICU stays and required intensive rehabilitation. They quickly saw demand for their services by many COVID-19 patients who continued experiencing symptoms weeks or months after their infection, and had never been hospitalized. Many post-COVID clinics have adapted to serve this need by providing interdisciplinary specialty care in partnership with rehabilitation professionals. Many of these clinics offer interdisciplinary coordinated care for Long COVID patients, resulting in better care for patients.¹⁹ However, patients have reported that a majority of these clinics require a positive COVID-19 test, patients often have to wait months for an appointment, and clinics are not covered by all insurance policies.

Related to reimbursement, the CDC National Center for Health Statistics proposed adopting a diagnosis code for Long COVID, ICD-10-CM code of U09.9 - Post COVID-19 Condition. Adopting this code will assist in proper reimbursement of associated healthcare costs and will assist in the tracking of prevalence, mortality, and morbidity of Long COVID patients who have access to healthcare. As it stands now, though, if adopted it will be implemented in November 2021, leaving several months without a proper Long COVID code.²⁰

The mental health impacts of the global pandemic are well-documented but rarely fully explored in COVID and Long COVID patients. Becoming ill with a novel virus that is often framed within a death-recovery binary means that those who experience prolonged symptoms, protracted recovery, or an evolving and unstable health status can experience a tremendous amount of cognitive dissonance, confusion, and shame along with the acute trauma and post-traumatic stress disorder-like symptoms from having become ill with COVID-19. Especially for those from marginalized communities or identities, such as women, people of color, or LGBTQ people, there is also an open door to medical mistreatment and gaslighting. Patients are perceived as being “recovered” or labeled a “survivor” but who are far from their previous baseline of health, and are often subsequently psychopathologized and under-treated for their symptoms. Further, given the extensive neurological symptoms documented for COVID-19 and Long COVID, it remains an open question for clinicians to investigate whether symptoms of depression, anxiety, and other mental illnesses or chronic conditions like insomnia are actually neurological in nature and will resolve with adequate treatment for Long COVID neuropathies. Mental health treatment for Long COVID patients should be readily accessible but should also be viewed as secondary for symptom-management and processing the grief and loss caused by debilitating symptoms and new chronic illness, and not as a primary treatment strategy for Long COVID.

Lastly, patients are having difficulty paying their medical bills and navigating insurance companies' policies. When many patients are unable to work or have decreased their working hours, paying for multiple specialist visits, diagnostic tests, and potential treatments is often not possible. Ensuring reimbursement is done correctly can also take hours of phone calls between doctor's offices and insurance companies, though many patients do not have the cognitive function nor energy to make these calls.

Research

Prior and current research on Long COVID is often not representative of Long COVID patients. Much of the research is on hospitalized patients; while this research is important, it cannot claim to be representative of a group who was largely non-hospitalized. Additionally, the vast majority of research is limited to people with positive PCR or antibody tests, excluding the large subset of patients who were untested or received a negative test but present as a Long COVID patient. Communities who are Black, Indigenous, and people of color have been historically excluded from medical research, and must be prioritized in research into Long COVID especially due to COVID-19's disproportionate impact on these communities. Due to the lack of funding in research for illnesses like ME/CFS, there is a lack of awareness among the research community of the research that *has* been done that could help in solving Long COVID. Because of this, there is a risk of funding going towards research that has already been completed and/or is uninformed.

To ensure that many of these concerns are addressed, it is critical that Long COVID research engage patients through all stages of research development. Patient engagement in research leads to more relevant research that address patients' real-world needs and concerns.²¹

Lack of Education

Despite being over one year since Long COVID patients began sounding the alarm for what they were experiencing, many clinicians and researchers are unaware that a large subset of COVID-19 patients are experiencing these prolonged symptoms. This has led to poor medical care and dismissal of symptoms. While the CDC and NIH have publicly recognized Long COVID, many patients are not seeing the results of this education in the doctor's office.

Further, many common Long COVID symptoms that patients report are not being acknowledged by medical and public health professionals who are aware of Long COVID, particularly menstrual and genitourinary symptoms. People who make decisions about and for Long COVID patients must have a deep understanding of the evidence of Long COVID to date, as well as related illnesses like ME/CFS, dysautonomia, and mast cell activation syndrome. This includes clinicians, CDC leadership and staff working on Long COVID, as well as NIH leadership and staff who are currently reviewing research proposals for the first round of Long COVID research opportunities.²²

The public also needs to be educated on Long COVID. The narrative that young people (including children) without pre-existing conditions are not at risk from a COVID-19 infection doesn't address the risk of Long COVID, which is happening in up to a third of people with COVID-19 infections. It is imperative for the public to understand the risks of Long COVID when making decisions about their risk tolerances, vaccination, and reopening.

Workforce Impact

67.5 percent of our respondents were unable to work or had to reduce their hours as a direct result of their illness. Inadequacy in paid medical leave, disability benefits, and accommodations exacerbate the impact Long COVID has on patients' financial stability.

Lack of access to comprehensive paid medical leave from work has led to worse outcomes in Long COVID. Pacing, an activity management strategy which prioritizes avoiding overexertion, is key to recovery and symptom management.²³ Our survey found that pacing was the treatment that patients found most "significantly helpful"; another paper found that those who were able to get adequate rest in the acute stages were less likely to have a more debilitating course of Long COVID later on.²⁴ Further, overexertion in the early stages of ME/CFS, another post-viral illness, was found to be associated with deterioration and severity.²⁵ ***However, many patients have to choose between providing for themselves and their family, or giving their bodies the ability to recover during the crucial early recovery period.***

For patients who require lengthier medical leave while recovering from COVID-19 infections *and* have a short term disability insurance policy, there are significant barriers in receiving approval for short term disability benefits. PLRC has heard from patients who have been denied these short term disability benefits due to insufficient evidence of disability caused by Long COVID, which is likely due in part to the lack of adequate tests to measure symptoms of Long COVID.

For patients who require lengthier medical leave who do *not* have a short term disability insurance policy, **there is no federal short term disability benefit.** The Social Security Administration (SSA) website says they "assume that working families have access to other resources to provide support during periods of short-term disabilities, including workers' compensation, insurance, savings, and investments."²⁶ This assumption is not reflective of Americans' financial situations: prior to the pandemic, 45 percent of Americans had no savings, and 24 percent had less than \$1,000 in savings.²⁷ For many Long COVID patients' families, any savings that existed was likely wiped out by the financial impacts of the pandemic alone. In order to receive unemployment insurance, individuals must certify they are "willing and able" to work, but these patients are not able to work. Additionally, worker's compensation benefits are not an adequate safety net --- PLRC has heard from several Long COVID patients who were undoubtedly exposed to COVID-19 on the job and have been denied worker's compensation benefits for the long-term effects of the infection.

Additionally, there are patients who even with pacing will be unable to work substantially and therefore will require long-term disability benefits. Many of these patients face barriers applying for and receiving long-term disability benefits, including Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) as well as private long-term disability benefits. Social Security disability benefits are difficult to obtain due to SSA's requirement of proof that a condition significantly limits one's ability to do work-related activities like sitting, walking, and remembering for at least 12 months, in addition to work requirements for approval. With a relapsing-remitting illness that some Long COVID patients experience, in combination with the newness of the condition, proving this length of disability is difficult to do.²⁸ Further, patients have just started to mark their year anniversary of symptoms so can only now indicate that their condition affects their work. Additionally, the average processing time of these applications is over 100 days, and many Social Security offices were not open to the public during the pandemic unless for emergency situations. Compounding on barriers to application and approval, there is a five month waiting period before SSDI benefits are paid and a two year waiting period for Medicare coverage, starting from date of disability.²⁹ All of these barriers combine such that at this point, these patients have been without financial assistance for months.

Patients have also reported being denied accommodations at work. Accommodations like working remotely, having a flexible schedule, and restructuring the job or reassignment as appropriate can make the difference between a patient being able to work and not work.³⁰ Further, patients do not have enough workplace protections, with patients reporting being fired as a direct result of their illness or being denied accommodations because their employer does not believe they have Long COVID or that it can be considered a disability.

Prevalence

Estimates for the prevalence of Long COVID are wide ranging. Depending on how studies define Long COVID and when they capture prevalence in relation to the patient's illness, estimates range from 2.3 percent³¹ to 35 percent.³² Many of these studies that claim to represent prevalence often limit the symptoms they ask about and require a positive COVID-19 test which will miss a subset of patients. These estimates can be helpful, however, in seeing the extent of Long COVID and who it is impacting. For example, Table 1 contains the United Kingdom's Office of National Statistics estimates, which shows that **children as young as 2 years old** have been documented having prolonged symptoms after a COVID-19 infection.¹ Performing a prevalence study in the United States, and attempting to include people who did not have a positive COVID-19 test or are outside of the healthcare system, will be important to understanding the the extent of impact Long COVID will have on healthcare systems, the economy, and marginalized communities.

Table 1: Estimated five- and twelve-week prevalence of select symptoms among Coronavirus Infection Survey participants testing positive for COVID-19¹

Group	Estimate at 5 weeks	Estimate at 12 weeks
All people	21.0	13.7
Male	18.7	12.7
Female	23.0	14.7
Age 2-11 years	9.8	7.4
Age 12-16 years	13.0	8.2
Age 17-24 years	16.9	11.5
Age 25-34 years	22.6	18.2
Age 35-49 years	25.6	16.1
Age 50-69 years	25.1	16.4
Age ≥70 years	15.9	11.2

Tracking Long COVID death rates is also critical. Long COVID patient deaths are often not included in COVID-19 death numbers because the deaths occur after the length of time local health departments track COVID-19 deaths, doctors do not attribute the deaths to COVID-19, or the patient never had a positive COVID-19 test.

Recommendations

Support the COVID-19 Long Haulers Act

Representatives Don Beyer (D-VA) and Jack Bergman (R-MI) announced on April 21, 2021 that they will be introducing the COVID-19 Long Haulers Act.³³ The Act will do the following:

- Accelerate Long COVID research through data harmonization;
- Research Long COVID treatment efficacy and disparities, including access to treatment for veterans, the elderly, disabled, and low-income communities; and
- Educate Long COVID patients and medical providers. The Act will authorize funding for the CDC to develop and disseminate information for medical providers and the general public about common symptoms, treatment, related illnesses, and proper billing.

We urge the Committee Members to support the Act. If passed, we urge the responsible agencies to include Long COVID patients in the research authorized and the development of educational materials.

Create a Federal Advisory Committee

We urge Congress to establish a Federal Advisory Committee on Long COVID within the Department of Health and Human Services, composed of Long COVID patients as stakeholders, external experts in researching and treating post-infectious chronic illness and their comorbidities, and disability advocates. This committee would be similar in structure to the Tick-Borne Disease Working Group, established in 2016 as part of the 21st Century Cures Act.³⁴ A Federal Advisory Committee is needed to facilitate timely and necessary coordination between relevant federal agencies and stakeholders. It would assist in providing coordinated recommendations related to Long COVID in response to the urgent crisis of a subsequent pandemic of disability in the wake of COVID-19 infections. Further, this Federal Advisory Committee should ensure that all staff at the CDC, NIH, and other federal agencies working on Long COVID, particularly reviewers of research proposals, be educated on the biomedical evidence of ME/CFS and related illnesses. Additionally, we urge that these meetings be live streamed with closed captioning for accessibility. We also recommend that this committee meet on a frequent basis, due to the urgency and scale of the issue.

Increase Access to Post-COVID Clinics and Integrated Medical Care

We urge Congress to appropriate funds for states to open additional, and fund existing, post-COVID clinics. The COVID-19 Long Haulers Act will help determine equitable and effective treatment, but additional dedicated funding is necessary to carry out said treatment in clinics nationwide with adequate reimbursement rates for the lengthy interdisciplinary visits necessary to support Long COVID patients. To improve access, more clinics must be opened to cut down on waiting times, and these clinics must be open to patients with and without a positive COVID-19 test, be geographically accessible, and be inclusive of Medicaid-served patients and communities who are disproportionately Black, Indigenous, and people of color. We must ensure that those who have been disproportionately impacted by the virus, infections, and deaths have access to knowledgeable, comprehensive care, including specialist care, diagnostics, and effective treatments equal to what is afforded to more privileged patients with private insurance. Where clinics are unable to be established, Congress should urge the CDC to provide guidance for clinicians to work together to address a patient's physical and mental health holistically.

Count Long COVID

We urge Congress to task the CDC with estimating Long COVID's prevalence. Efforts must be made to include people who do not have access to healthcare and those without a positive COVID-19 test in prevalence estimates.

Ensure Long COVID Research is Inclusive and Historically Informed

Congress must urge NIH to prioritize research into Long COVID that is inclusive of patients who were not hospitalized, those who do not have a positive COVID test, and of marginalized communities. In any future appropriations for Long COVID research, Congress should mandate inclusion of these populations. Further, research that builds on prior ME/CFS and related chronic illness research and that considers links between Long COVID and ME/CFS, dysautonomia, and mast cell activation syndrome should be prioritized. Additionally, projects should be funded that include patients in the development and execution of the research study.

Ensure Medical Care and Treatment is Affordable

Short term solutions:

- Congress should urge the CDC to implement the proposed ICD-10-CM code immediately to ensure proper reimbursement. Congress should also urge the CDC to ensure that medical providers know to code U09.9 regardless of a positive COVID-19 test.
 - If this is not possible, interim guidance is needed for providers, health insurance companies, disability insurance and worker's compensation benefit companies. We recommend in the interim to use Z86.16--personal history of COVID-19 as well as B94.8--Sequelae of infectious and parasitic disease, and pair it with applicable codes such as G93.3 postviral fatigue syndrome based on patient's symptoms
- Congress should urge the Centers for Medicare & Medicaid Services to establish a payment strategy for post-COVID clinics that offers adequate reimbursement for longer length appointments and interdisciplinary care.

Long term solutions:

- ***Congress must pass universal healthcare.*** Health is a fundamental human right; it must no longer be tied to one's ability to pay.

Increase Workplace Protections and Accommodations

We urge Congress to ensure that Long COVID patients' jobs are protected by enforcing existing laws such as the Americans with Disabilities Act and Family and Medical Leave Act, and consider whether additional employment protections are needed. As part of provider education (which may be provided through the COVID-19 Long Haulers Act), Congress should urge the CDC to encourage clinicians to refer their patients to vocational rehabilitation services as well as occupational therapy, and be willing to work with their patients to support paperwork for school or employment accommodations that are right for them, including flexible work schedules and telework.³⁰ Patients should be able to take extended paid leave from work and have the opportunity to return to their same position, or to have metered returns to allow for pacing at the beginning stages of their illness.

Expand Access to Disability Benefits

We urge Congress to ensure that Long COVID patients who are unable to work have access to sufficient financial assistance. This includes:

- Introducing federal short term disability benefits for Long COVID in the next federal relief bill, or amend unemployment insurance to include this population.
- Overhauling Social Security disability (both SSI and SSDI) to provide shorter application processing times, update SSI benefits to 100 percent federal poverty level, remove waiting periods between approval and benefit payment as well as Medicare coverage, review and update work requirements necessary to qualify to apply for SSDI which may disproportionately impact marginalized communities and women with employment gaps due to child rearing, update outdated asset limits and income exclusions and require they increase with cost of living, remove the marriage penalty and in-kind maintenance and support component of SSI, and expand criteria for approval of both SSDI and SSI. A dedicated Social Security disability program for post-COVID conditions should be explored by a Long COVID Federal Advisory Committee which includes Long COVID patients as stakeholders.
- Initiating a federal investigation of private disability benefit and worker's compensation insurance practices to investigate why Long COVID patients, many of whom were exposed to COVID-19 infections in the workplace, are being denied benefits they qualify for and they/their employers paid into.

Expand Access to and Amount of Paid Sick Leave and Family Leave

We urge Congress to expand access to paid sick and family leave for people who are not a covered employer under the Families First Coronavirus Response Act. Further, Congress must increase the amount of paid sick and family leave available to account for Long COVID - the previous authorization did not consider the possibility of an employee or loved one getting Long COVID, the need to pace particularly in the beginning of recovery, and vaccination reactions.

References

1. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK - Office for National Statistics. Accessed April 24, 2021. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1april2021>
2. CDC. COVID Data Tracker. Centers for Disease Control and Prevention. Published March 28, 2020. Accessed April 25, 2021. <https://covid.cdc.gov/covid-data-tracker>
3. Callard F, Perego E. How and why patients made Long Covid. *Soc Sci Med* 1982. 2021;268:113426. doi:10.1016/j.socscimed.2020.113426
4. Support Group. Body Politic. Accessed April 25, 2021. <https://www.wearebodypolitic.com/covid19>
5. McCorkell L, S. Assaf G, E. Davis H, Wei H, Akrami A. Patient-Led Research Collaborative: embedding patients in the Long COVID narrative. *PAIN Rep*. 2021;6(1):e913. doi:10.1097/PR9.0000000000000913
6. Select Citations. Patient-Led Research Collaborative. Accessed April 24, 2021. <https://patientresearchcovid19.com/select-citations/>
7. Trying to Make Sense of Long COVID Syndrome. NIH Director's Blog. Published January 19, 2021. Accessed April 24, 2021. <https://directorsblog.nih.gov/2021/01/19/trying-to-make-sense-of-long-covid-syndrome/>
8. Home. Long-COVID Alliance. Accessed April 24, 2021. <https://longcovidalliance.org/>
9. Assaf G, Davis H, McCorkell L, et al. What Does COVID-19 Recovery Actually Look Like? An Analysis of the Prolonged COVID-19 Symptoms Survey by Patient-Led Research Team. Published online May 2020. <https://patientresearchcovid19.com/research/report-1/>
10. Impact/Press Patient Led Research for Long Covid. Patient-Led Research Collaborative. Accessed April 25, 2021. <https://patientresearchcovid19.com/our-impact/>
11. Tabacof L, Tosto-Mancuso J, Wood J, et al. Post-acute COVID-19 syndrome negatively impacts health and wellbeing despite less severe acute infection. *medRxiv*. Published online November 6, 2020:2020.11.04.20226126. doi:10.1101/2020.11.04.20226126
12. Huang Y, Pinto MD, Borelli JL, et al. COVID Symptoms, Symptom Clusters, and Predictors for Becoming a Long-Hauler: Looking for Clarity in the Haze of the Pandemic. *medRxiv*. Published online March 5, 2021:2021.03.03.21252086. doi:10.1101/2021.03.03.21252086
13. Kucirka LM, Lauer SA, Laeyendecker O, Boon D, Lessler J. Variation in False-Negative Rate of Reverse Transcriptase Polymerase Chain Reaction–Based SARS-CoV-2 Tests by Time Since Exposure. *Ann Intern Med*. Published online May 13, 2020. doi:10.7326/M20-1495
14. Arevalo-Rodriguez I, Buitrago-Garcia D, Simancas-Racines D, et al. FALSE-NEGATIVE RESULTS OF INITIAL RT-PCR ASSAYS FOR COVID-19: A SYSTEMATIC REVIEW. *medRxiv*. Published online August 13, 2020:2020.04.16.20066787. doi:10.1101/2020.04.16.20066787
15. Vashisht R, Patel A, Crews BO, et al. Age- and Sex-Associated Variations in the Sensitivity of Serological Tests Among Individuals Infected With SARS-CoV-2. *JAMA Netw Open*. 2021;4(2):e210337. doi:10.1001/jamanetworkopen.2021.0337
16. Augustin M, Schommers P, Stecher M, et al. Recovered not restored: Long-term health consequences after mild COVID-19 in non-hospitalized patients. *medRxiv*. Published online March 12, 2021:2021.03.11.21253207. doi:10.1101/2021.03.11.21253207
17. Hernandez-Romieu AC. Health Care Utilization and Clinical Characteristics of Nonhospitalized Adults in an Integrated Health Care System 28–180 Days After COVID-19 Diagnosis – Georgia, May 2020–March 2021. *MMWR Morb Mortal Wkly Rep*. 2021;70.

doi:10.15585/mmwr.mm7017e3

18. Belluck P. Patients With Long Covid Face Lingering Worrisome Health Risks, Study Finds. *The New York Times*.
<https://www.nytimes.com/2021/04/22/health/covid-patients-health-risks-long-term.html>.
Published April 22, 2021. Accessed April 24, 2021.
19. Autonomic conditioning therapy reduces fatigue and improves global impression of change in individuals with post-acute COVID-19 syndrome. doi:10.21203/rs.3.rs-440909/v1
20. ICD - ICD-10-CM - Coordination and Maintenance Committee. Published March 18, 2021. Accessed April 24, 2021. https://www.cdc.gov/nchs/icd/icd10cm_maintenance.htm
21. Forsythe LP, Carman KL, Szydlowski V, et al. Patient Engagement In Research: Early Findings From The Patient-Centered Outcomes Research Institute. *Health Aff (Millwood)*. 2019;38(3):359-367. doi:10.1377/hlthaff.2018.05067
22. NIH launches new initiative to study “Long COVID.” National Institutes of Health (NIH). Published February 23, 2021. Accessed April 25, 2021.
<https://www.nih.gov/about-nih/who-we-are/nih-director/statements/nih-launches-new-initiative-study-long-covid>
23. Goudsmit E, Howes S. Pacing: a strategy to improve energy management in chronic fatigue syndrome. *Health Psychol Update*. 2008;17:46-52.
24. Ziauddeen N, Gurdasani D, O’Hara ME, et al. *Characteristics of Long Covid: Findings from a Social Media Survey*. *Epidemiology*; 2021. doi:10.1101/2021.03.21.21253968
25. Friedberg F, Bateman L, Jason LA, et al. ME/CFS: A Primer for Clinical Practitioners. :51.
26. Social Security’s Definition of Disability. *Social Security Matters*. Published August 1, 2019. Accessed April 25, 2021. <https://blog.ssa.gov/social-securitys-definition-of-disability/>
27. Survey: 69% of Americans Have Less Than \$1,000 in Savings. *GOBankingRates*. Published December 16, 2019. Accessed April 26, 2021.
<https://www.gobankingrates.com/saving-money/savings-advice/americans-have-less-than-1000-in-savings/>
28. When Does COVID-19 Become A Disability? “Long-Haulers” Push For Answers And Benefits. *NPR.org*. Accessed April 24, 2021.
<https://www.npr.org/sections/health-shots/2021/02/22/966291447/when-does-covid-19-become-a-disability-long-haulers-push-for-answers-and-benefit>
29. SSA Open Data | Average Processing Time for SSI & SSDI Disability Reconsiderations. Accessed April 25, 2021.
https://www.ssa.gov/open/data/disability_reconsideration_average_processing_time.html
30. Accommodating Employees with COVID-19-Related Symptoms. Accessed April 25, 2021.
<https://askjan.org/blogs/jan/2021/03/accommodating-employees-with-covid-19-related-symptoms.cfm>
31. Sudre CH, Murray B, Varsavsky T, et al. Attributes and predictors of Long-COVID: analysis of COVID cases and their symptoms collected by the Covid Symptoms Study App. *medRxiv*. Published online October 21, 2020:2020.10.19.20214494.
doi:10.1101/2020.10.19.20214494
32. Tenforde MW. Symptom Duration and Risk Factors for Delayed Return to Usual Health Among Outpatients with COVID-19 in a Multistate Health Care Systems Network – United States, March–June 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69.
doi:10.15585/mmwr.mm6930e1
33. Beyer RD, Bergman J. #StopTheLonghaul The COVID-19 Longhaulers Act. :1.
34. Health (ASH) AS for. Tick-Borne Disease Working Group. *HHS.gov*. Published July 14, 2017. Accessed April 24, 2021.
<https://www.hhs.gov/ash/advisory-committees/tickbornedisease/index.html>