

COVID PATIENT RECOVERY ALLIANCE

The COVID Patient Recovery Alliance is a multi-sector collaboration with the mission to support the energy and innovation of government and private-sector leaders as they care for individuals with long-COVID. The Alliance is developing national solutions that link diverse data sources, improve clinical care pathways, and ensure sustainable federal financial support for the care of these patients. The Alliance is particularly interested in those patients who served their communities and nation when called to duty; whose COVID-19-related costs are extraordinary and burdensome; or who are underserved by existing programs, including racial and ethnic minorities and communities experiencing health disparities.

For more information, please visit our website at COVID19PatientRecovery.org.

PURPOSE OF RESEARCH TRACKER

The research, news, and knowledge of long-COVID is quickly evolving. To stay up-to-date and informed on long-COVID, the Patient Recovery Alliance is performing routine intel scans from a variety of sources – from peer-reviewed publications to various news websites – and on variety of long-COVID-related topics, including health care coverage, workers' compensation, impacted populations, symptoms, and prevalence. The outputs of these intel scans are compiled in this document, which will be periodically updated.

COVID-19 Patient Recovery Alliance Research Tracker

Date	Article	Publication	Key Takeaways
January 2021			
31-Jan-21	Dangerous new coronavirus strains may incubate in COVID-19's sickest	<i>Yahoo</i>	<p>Genetic transformation in patients who have been reinfected and show long-term symptoms may be leading to the creation of variants.</p> <p>"Among the sickest of COVID-19 patients, this population of 'long haulers' appears to play a key role in incubating new variants of the coronavirus, some of which could change the trajectory of the pandemic."</p>
28-Jan-21	How the Coronavirus Turns the Body Against Itself	<i>NYT</i>	<p>"A growing body of evidence suggests that autoimmunity contributes to the severity of Covid-19 in some people. A study published online in October found that among 52 patients with severe Covid-19, more than 70 percent carried antibodies against their own DNA and against proteins that help with blood clotting."</p> <p>"A study in the journal Science Translational Medicine in November (measured eight types of aPL antibodies in serum samples from 172 patients hospitalized with COVID-19) found that half of patients hospitalized for Covid-19 had at least transient autoantibodies that cause clots and blockages in blood vessels."</p>
28-Jan-21	Denied treatment, some Covid long-haulers could become lifelong-haulers	<i>Stat</i>	<p>"In a recent survey by an international team of researchers, among the 3,762 respondents from 56 countries, 33.7% were 40 to 49 years old and 26.1% were 30 to 39 years old."</p>
27-Jan-21	WHO Issues New Clinical Advice on Treating COVID-19 Patients	<i>MedScape</i>	<p>"The World Health Organization (WHO) issued fresh clinical advice on Tuesday for treating COVID-19 patients, including those displaying persistent symptoms after recovery, and also said it advised using low-dose anti-coagulants to prevent blood clots."</p> <p>"WHO also said patients with suspected or confirmed COVID-19 of any disease severity who have persistent, new or changing symptoms should have access to follow-up care."</p>
27-Jan-21	Can't Cut This: Reimbursements Crucial for Long-Term COVID-19 Treatments	<i>US News</i>	<p>About 50% of COVID-19 ICU survivors who required mechanical ventilation will require physical therapy or psychological services. However, CMS may not be able to expand coverage through Medicare for those who cannot meet a formal criteria for their diagnosis.</p>
27-Jan-21	Immune determinants of COVID-19 disease presentation and severity	<i>Nature and PubMed</i>	<p>"It is now clear that mild to severe acute infection is not the only outcome of COVID-19, and long-lasting symptoms are also possible. In contrast to severe acute COVID-19, such 'long COVID' is seemingly more likely in women than in men. Also, postinfectious hyperinflammatory disease has been described as an additional outcome after SARS-CoV-2 infection."</p> <p>"An exact definition is lacking, but typically symptoms with a duration >2 months are considered long COVID. The condition involves a range of symptoms such as persistent fatigue, myalgia, autonomic dysregulation manifested as postural orthostatic tachycardia syndrome, abnormal thermoregulation, intestinal disturbances and skin manifestations."</p> <p>"This post-COVID syndrome bears resemblance to postinfectious syndromes that followed outbreaks of chikungunya and Ebola, for example, and selected symptoms overlap with myalgic encephalomyelitis, a disease that is also often triggered by infection and immune activation."</p>

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26-Jan-21	Africa: WHO Recommends Follow-Up Care, Low-Dose Anticoagulants for Covid-19 Patients	<i>AllAfrica</i>	<p>“Evidence was gathered on the post COVID condition, so-called ‘long COVID’, where people who have recovered from COVID-19 continue to have longer-term issues like extreme fatigue, persistent cough and exercise intolerance.</p> <p>“Understanding this condition is one of WHO’s priority areas of work. In February 2021, WHO will organize a series of consultations to reach consensus on a description of this condition and its subtypes, and case definitions. This scientific understanding will inform the name of the condition.”</p>
26-Jan-21	NIH launches database to track neurological symptoms associated with COVID-19	<i>NIH Press Release</i>	<p>On January 26, the NIH launched database to track neurological symptoms associated with COVID-19. A new database will be collecting neurological symptoms, complications, and outcomes associated with COVID-19. The database will be maintained by NYU Lagone Health and supported by the National Institutes of Health’s National Institute of Neurological Disorders and Stroke (NINDS). This database will include symptoms from people of all ages, including the effect on pre-existing conditions. Barbara Karp, M.D., program director at NINDS, stated, “There is an urgent need to understand COVID-19-related neurological problems, which not uncommonly include headaches, fatigue, cognitive difficulties, stroke, pain, and sleep disorders as well as some very rare complications of serious infections.”</p>
25-Jan-21	Recovered COVID-19 patients experience array of neurological issues: report	<i>New York Post</i>	<p>“Recovered COVID-19 patients are experiencing perplexing neurological issues—including stuttering, according to a report. An early survey of 153 COVID-19 patients in the U.K. and a more recent preprint study of people hospitalized with the disease in Italy both found that about a third had neurological symptoms of some kind.”</p> <p>“[O]ne theory is that it triggers an inflammatory response that affects speech.”</p>
24-Jan-21	Long-haul COVID-19 similar to post-polio syndrome	<i>Daily Herald</i>	<p>Both long-haul COVID-19 and post-polio syndrome occur only in a subset of survivors. There are believed to be about 300,000 polio survivors in the U.S., and from one-fourth to one-half of them may experience some degree of post-polio syndrome. Long-haul COVID-19 is so new that we don’t yet know how often it occurs, but it may be as many as 20% of patients with COVID-19. People with either syndrome may experience only mild symptoms, or they can find themselves dealing with what is essentially a new and ongoing illness.</p>
23-Jan-21	Coronavirus Disease 2019 (COVID-19) Clinical Presentation	<i>Medscape</i>	<p>The US National Institutes of Health includes discussion of persistent symptoms or organ dysfunction after acute COVID-19 within guidelines that discuss the clinical spectrum of the disease.</p> <p>The UK National Institute for Health and Care Excellence (NICE) issued guidelines on care of long-COVID that define the syndrome as: signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks, and are not explained by an alternative diagnosis.</p> <p>An international web-based survey of respondents (n = 3,762) with suspected and confirmed COVID-19 from 56 countries tallied prevalence of 205 symptoms in 10 organ systems, with 66 symptoms traced over 7 months. The most frequent symptoms reported after 6 months were fatigue (77.7%), postexertional malaise (72.2%), and cognitive dysfunction (55.4%).</p>

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21-Jan-21	What If You Never Get Better From COVID-19?	NYT	<p>About 10 percent of Covid-19 patients end up developing symptoms that persist for months and months—roughly 100,000 chronically sick people in New York State alone.</p> <p>A third, much larger study, from China, reported that three-quarters of those patients who were hospitalized with Covid-19 and then discharged still experienced at least one symptom six months later. (1733 of 2469 discharged patients with COVID-19)</p> <p>The strange symptomology of long Covid calls to mind another mysterious, poorly understood condition: myalgic encephalomyelitis, more familiarly known as chronic fatigue syndrome.</p>
21-Jan-21	Fast-spreading COVID variant can elude immune responses	Nature	<p>There is now proof of several reinfections with the South African variant.</p> <p>It has become increasingly likely that the variant’s ability to spread in places hit hard by earlier waves of COVID-19 is driven, in part, by the variant’s capacity to evade immune responses that developed in response to earlier versions of the virus.</p>
14-Jan-21	The Early Impact of COVID-19 on Workers Compensation Claim Composition	WCRI - Workers Compensation Research Institute	<p>An overwhelming amount of worker’s compensation claims are in the service industry, followed by living facilities and hospitals.</p>
19-Jan-21	Trying to Make Sense of Long COVID Syndrome	NIH Director’s Blog	<p>“Posted on January 19th, 2021 by Dr. Francis Collins, NIH Director’s Blog lists several studies where long haul symptoms are described: medRxiv, is based on survey results from more than 3,700 self-described COVID ‘Long Haulers’ in 56 countries, online Body Politic COVID-19 Support Group and its Patient-Led Research for COVID-19, the new survey-based study led by Athena Akrami, with Patient-Led Research for COVID-19 and University College London, England, and recent study from China further documents the tendency of COVID-19-related symptoms to linger past the usual recovery time for a respiratory virus published in Lancet.</p> <p>“The NIH held a workshop last month to summarize what is known and fill in key gaps in our knowledge about Long COVID syndrome, which is clinically known as post-acute sequelae of COVID-19 (PASC). In December, Congress authorized funding for continued research on PASC, including an appropriation of funds for NIH to support continued study of these prolonged health consequences. As these efforts and others proceed in the coming months, the hope is that we’ll gain much more insight and get some answers soon.”</p>
19-Jan-21	We know this is real’: New clinics aid virus ‘long-haulers’	Yahoo News	<p>Current indications suggest up to 30% of patients continue to have significant problems that intrude on daily life two to three weeks after testing positive. As many as 10% are still afflicted three to six months later, according to Dr. Wesley Self, a Vanderbilt University emergency physician and researcher who co-wrote a July report from the Centers for Disease Control and Prevention.</p> <p>COVID-19-specific clinics now include Jamaica Hospital Medical Center, University of Texas Medical Branch, New York’s Mount Sinai, which has over 1,600 patients, St. John’s Well Child and Family Center, a network of community clinics in south Los Angeles.</p>

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18-Jan-20	One in eight recovered COVID patients die from illness complications within 5 months: UK study	<i>New York Post</i>	<p>“Researchers at the UK’s Leicester University and the Office for National Statistics found that out of 47,780 people discharged from the hospital, 29.4 percent were readmitted within 140 days, the Telegraph reported. Of the total, 12.3 percent ended up dying.” Almost a third of recovered COVID-19 patients in a UK study ended up back in the hospital within five months—and up to one in eight died of complications from the illness, according to a report.</p> <p>“Respiratory disease was diagnosed in 14,140 of the COVID cases after discharge, with 6,085 of the diagnoses in patients who had no history of respiratory conditions. The mean age of study participants was 65 years.”</p> <p>Researchers were surprised that many people were readmitted with a new diagnosis, adding that it was important to make sure people were placed on protective therapies, including statins and aspirin.</p> <p>“We don’t know if it’s because COVID destroyed the beta cells which make insulin and you get Type 1 diabetes, or whether it causes insulin resistance, and you develop Type 2, but we are seeing these surprising new diagnoses of diabetes,” Kamlesh Khunti, a professor of primary care diabetes and vascular medicine at Leicester University, said.</p> <p>“We’ve seen studies where survivors have had MRS scans and they’ve cardiac problems and liver problems,” Khunti added. “These people urgently require follow-up and the need to be on things like aspirin and statins.”</p>
13-Jan-21	Can COVID Long-Haulers Access Disability Benefits? Experts Are Uncertain	<i>WGBH</i>	<p>The articles suggest the SSA should issue guidance on COVID-19 long haulers and disability coverage, as even a million people affected will have severe consequences for society.</p>
12-Jan-21	Intestinal bacteria may affect severity of COVID-19, researchers find	<i>New York Post</i>	<p>There is increasing evidence that intestinal bacteria may play a role in the severity of how sick someone gets from COVID-19 and could be a potential explanation for why some symptoms persist as long-COVID.</p> <p>A team at the University of Hong Kong studies samples from 100 patients and reported that “[g]ut microbiome composition was significantly altered in patients with COVID-19 compared with non-COVID-19 individuals irrespective of whether patients had received medication.”</p> <p>“Based on several patients surveyed in this study for up to 30 days after clearing SARS-CoV-2, the gut microbiota is likely to remain significantly altered after recovery from COVID-19,” the researchers said.</p> <p>“The researchers said patients with severe illness exhibit high blood plasma levels of inflammatory cytokines and inflammatory markers—and that there is ‘substantial involvement’ of the GI tract during infection, given ‘altered gut microbiota composition in SARS-CoV-2 infected subjects.’”</p>
10-Jan-21	Does vitamin D combat Covid?	<i>The Guardian</i>	<p>Strong links between COVID and vitamin D.</p> <p>“‘All the observational studies show strong vitamin D effects on infectiousness, morbidity and mortality,’ Davis says. ‘This disease exists seriously above 40 degrees latitude, because that’s where the UV light disappears in the winter.’ All of this evidence together, he says, makes it ‘very, very plain that vitamin D has a material effect.’”</p>

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8-Jan-21	Long-term follow-up of recovered patients with COVID-19	<i>The Lancet</i>	<p>One study published in The Lancet described the clinical follow-up of a cohort of 1733 adult patients (48% women, 52% men; median age 57.0 years, with COVID-19 who were discharged from Jin Yin-tan Hospital (Wuhan, China). “6 months after illness onset, 76% (1265 of 1655) of the patients reported at least one symptom that persisted, with fatigue or muscle weakness being the most frequently reported symptom (63%, 1038 of 1655). More than 50% of patients presented with residual chest imaging abnormalities. Disease severity during the acute phase was independently associated with the extent of lung diffusion impairment at follow-up (odds ratio 4.60, 95% CI 1.85–11.48), with 56% (48 of 86) of patients requiring high-flow nasal cannula, non-invasive ventilation, and invasive mechanical ventilation during their hospital stay having impaired pulmonary diffusion capacity.”</p> <p>“Even though the study offers a comprehensive clinical picture of the aftermath of COVID-19 in patients who have been admitted to hospital, only 4% (76 of 1733) were admitted to an intensive care unit (ICU), rendering the information about the long-term consequences in this particular cohort inconclusive. However, previous research on patient outcomes after ICU stays suggests that several patients with COVID-19 who were critically ill during their hospital stay will subsequently face impairments regarding their cognitive and mental health or physical function far beyond their hospital discharge.”</p> <p>“Outpatient clinics that are dedicated to following up on lasting disabilities in the large number of patients who previously had COVID-19 are opening in many hospitals, especially in areas where large SARS-CoV-2 outbreaks have occurred. However, this initiative implies a further burden on the health-care system in terms of human and economic resources, in addition to conventional health-care services. Unfortunately, these clinics are largely unaffordable in most low-income or middle-income countries that have also been severely affected by the COVID-19 pandemic.”</p>
7-Jan-21	Fatigue, Brain Fog Most Common in ‘Long COVID’	<i>Medscape</i>	<p>Fatigue, post-exercise malaise and cognitive dysfunction (or brain fog) are the most common symptoms reported by COVID long haulers 6 months after contracting the coronavirus, according to a new preprint study published on MedRxiv. (3,762 respondents from 56 countries.)</p> <p>On average, the survey respondents experienced symptoms from nine different organ symptoms. About 65% of respondents experienced symptoms for at least 6 months. About 45% of people said they still required a reduced work schedule, and 22% weren’t working at all due to their ongoing health issues.</p>
6-Jan-20	Modern Healthcare Webinar with Dr. Davis, President and CEO of Mt. Sinai	<i>Webinar</i>	<p>Mt. Sinai has about 8,000 employees in hospitals and about 20,000 in outpatient clinics and they are all seeing patients with chronic COVID conditions.</p>
4-Jan-21	“No One Else is Listening:” Readers Share Experiences with Long-Haul Covid	<i>WSJ</i>	<p>Symptoms include brain fog, severe fatigue, and racing heart rate, numbness and tingling, tight and heavy feeling in chest, aching in various body parts, headache, ringing in ears, low oxygen levels, lost or altered smell.</p> <p>Some have been diagnosed with POTS.</p>
1-Jan-21	“Long-Hauler:” When Symptoms Last and Last	<i>WSJ</i>	<p>“The stories of ‘long-haulers’ have become a central component of how scientists, doctors and policymakers view long-term effects of the coronavirus.”</p>

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			<p>Both “long-haulers” and “long-COVID” are fast becoming standard terminology in the medical field.</p> <p>Amy Watson started a Facebook group called Long Haul Covid Fighters in April, and the term caught on.</p>