

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.

Date	Article	Publication	Key Takeaways
October 2021			
3-Oct-21	As students with long-haul covid return to school, many districts don't fully know how to help	The Washington Post	As students are returning to in-person instruction, families and school districts are navigating how to best support children with long-COVID. Since long-COVID is a relatively new diagnosis and little is known about how symptoms change over time, it has been difficult for administrators to create a plan for children with long-COVID. In addition, administrators are simultaneously managing contract tracing, quarantine, and mask policies to reduce day-to-day COVID-19 transmission. Possible accommodations could include increased test-taking time and additional time to switch classrooms.
3-Oct-21	COVID-19 long-haulers plead for government action	The Hill	COVID-19 long-haulers and advocates are calling state and federal officials to take action and launch initiatives to support COVID-19 survivors. The grassroots group COVID Survivors for Change launched an advocacy campaign with delegations from all 50 states to draw attention to the burden long-COVID and request more research and funding.

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6-Oct-21	Another Face of Long COVID: Kidney Disease	Medpage today	<ul style="list-style-type: none"> In the post-acute phase of the disease, people with COVID-19 are at increased risk of acute kidney injury, chronic kidney disease, and end-stage kidney disease. The risk was higher for patients who were hospitalized for COVID-19 and needed intensive care. About 13.44 per 1,000 people with COVID-19 will develop kidney injury or disease, which translates to over half a million people in the U.S.
6-Oct-21	VA launching outreach and care networks for Long COVID	VA Blog	<ul style="list-style-type: none"> The VHA Innovation Ecosystem and the Office of the Chief Technology Officer are launching an effort to understand and treat long COVID. Their work will include conducting an environmental scan to understand the current state of long-COVID care; creating clinical decision and support tools; and conducting interviews with veterans, caregivers, and staff to better understand the long-COVID experience.
6-Oct-21	WHO publishes clinical case definition for long COVID	Healio News	<ul style="list-style-type: none"> The WHO released a new standardized definition of long-COVID: a condition that “occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis.” The WHO identified 12 domains to be included in the clinical case definition: <ul style="list-style-type: none"> History of SARS-CoV-2 infection Laboratory-confirmed SARS-CoV-2 infection Minimum time period from the onset of symptoms (or from date of positive test for asymptomatic) of 3 months Minimum duration of symptoms of at least 2 months Symptoms such as cognitive dysfunction, fatigue, shortness of breath, among others Minimum number of symptoms Clustering of symptoms Time course of symptoms Sequelae of well-described complications of COVID-19 Symptoms cannot be explained by alternative diagnosis Application of definition to different populations Impact on everyday functions
7-Oct-21	Long-Covid Concerns Help Fuel Biden Administration’s Broad Vaccine Booster Push	The Wall Street Journal	<ul style="list-style-type: none"> Some officials within the Biden administration are pushing to offer COVID-19 vaccine booster shots more widely to decrease COVID-19 infection and reduce the risk of developing long-COVID. Other officials and health experts support boosters for a narrower population of seniors, people with weakened immune systems, and others, arguing that there isn’t sufficient evidence to support broader use.
11-Oct-21	New Clues Emerge About Whether Vaccines Can Help Fight Long-COVID	The Wall Street Journal	<ul style="list-style-type: none"> Research suggests that vaccines may help reduce symptoms in some people and reduce the likelihood of individuals developing long-COVID symptoms in the first place. A Lancet study found that fully vaccinated people who got a breakthrough infection were 50% less likely to develop long-COVID compared to unvaccinated people with COVID-19. Preliminary findings from another study found that after vaccination long-COVID individuals reported fewer symptoms compared to the control group. One hypothesis is that the vaccine may clear out some of the remaining virus that is causing symptoms; another hypothesis is that the placebo effect is at play.

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12-Oct-21	Why Impact of 'Long Covid' Could Outlast the Pandemic	The Washington Post	<ul style="list-style-type: none"> Long-COVID is part of the pandemic's hidden toll. An estimated 10-20% of individuals experience long-COVID symptoms that linger for weeks to months after the initial COVID-19 infection. The demand for specialized, post-acute COVID clinics has increased recently. Broader implications of the COVID-19 pandemic include increases in chronic fatigue syndrome, dementia, Parkinson's disease, diabetes, kidney impairment, and other long-term issues, as well as concerns about increases in suicide and opioid overdoses.
13-Oct-21	Short-term and Long-term Rates of Postacute Sequelae of SARS-CoV-2 Infection: A Systematic Review	JAMA Network Open	<ul style="list-style-type: none"> A systematic review of 57 studies with 250,351 survivors of long-COVID found that over half (54%) of COVID-19 survivors experienced long-COVID symptoms 6 months after recovery. The most prevalent symptoms and disorders were chest imaging abnormality, difficulty concentrating, generalized anxiety disorder, general functional impairments, and fatigue or muscle weakness. The findings demonstrate the overwhelming burden of poor health in COVID-19 survivors.
14-Oct-21	Long Covid Doubles Burden of Mystery Illness Few Doctors Treat	Bloomberg Law	<ul style="list-style-type: none"> Before the pandemic, there were 1-2 million people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Now, there are roughly twice as many people with ME/CFS due to long-COVID. Many physicians do not know how to diagnose or treat ME/CFS, which can be frustrating for patients. More research is needed on the root cause of ME/CFS and effective treatments
14-Oct-21	Diabetes Not Associated with Increased Risk of Long-Term COVID-19 Symptoms	Endocrinology Network	<ul style="list-style-type: none"> A multicenter case-control study in Spain (n=1800) suggests that the presence of diabetes does not increase the risk of developing long-COVID symptoms. Diabetes seems to play a more relevant role in the acute phase of COVID-19 rather than in the long term
15-Oct-21	Women more likely to suffer from long COVID-19, study shows	The Japan Times	<ul style="list-style-type: none"> A survey conducted by the National Center for Global Health and Medicine in Japan (n=457), 26% of individuals had long-COVID symptoms 6 months after and 9% had long-COVID one year after their initial infection. Women were twice as likely to experience fatigue and three times more likely to have hair loss after COVID-19 infectio
17-Oct-21	The WHO is letting down long Covid patients	The Guardian	<ul style="list-style-type: none"> The WHO recently released a clinical definition for "post-COVID-19 condition". The definition focuses on symptomology and does not reflect many long-lasting manifestations caused by COVID-19, such as new onset diabetes, heart disease, and kidney disease. The WHO also makes long-COVID a diagnosis of exclusion, which insurers may use to deny insurance coverage down the line and fuel skepticism around long-COVID symptoms.
19-Oct-21	Long COVID: Comparing the WHO Definition with CDC's	American Physical Therapy Association	<ul style="list-style-type: none"> Both CDC and WHO have a clinical definition for "post-acute COVID-19 conditions". Both definitions emphasize the lengthy duration of long-COVID symptoms, as well as the wide range of symptoms. The WHO definition provides more detail and attempts to capture the long-term effects of COVID on everyday functioning. The WHO definition also acknowledges that symptoms may fluctuate over time. Both definitions are likely to change over time as we learn more about long-COVID.
19-Oct-21	Factors impacting mental health and wellbeing of long covid patients	News Medical	<ul style="list-style-type: none"> British researchers conducted interviews with 21 individuals with long-COVID symptoms. The most common symptoms were fatigue, muscle pain and weakness, shortness of breath, concentration problems, and memory lapses. Common themes related to their mental wellbeing included availability of care and understanding from others, lack of treatment options, disruptions caused by long-COVID symptoms to ordinary living, lack of clarity about the outcome of their illness, and change it caused to their identity.

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22-Oct-21	Don't give Covid-19 long-haulers the silent treatment	Stat News	<ul style="list-style-type: none"> • “As Covid-19 survivors and families careen into the months and years ahead, those with long Covid — long-haulers, as they’ve come to be known — face uncertainty and confusion given the array of unexplained and fluctuating symptoms that are remote from their original illness”. • “I regularly ask people with PICS, long Covid, and the combination what they want from their doctors. They all say the same thing: “I don’t want to have an invisible disability.” • “First, I want someone just to listen,” Rogers says. “Second, I want my doctors to say that I’m not making this up. That I have a very real set of problems even though testing doesn’t confirm or define them. Third, I want them to admit that they don’t understand my chronic disease, and that they won’t abandon me even though they feel uncomfortable not having solutions for me. And lastly, to be assured that researchers won’t stop until we have treatments.”
22-Oct-21	What doctors wish patients knew about long COVID	American Medical Association	<ul style="list-style-type: none"> • Long-COVID symptoms can result from direct cell damage due to the virus, related to chronic hospitalization, or the interplay between inflammatory markers and the immune system. Long-COVID affects all organ systems and children too. Women are affected more than men and vaccination can help prevent the development of long-COVID symptoms.
22-Oct-21	UMass Chan study finds association between long-COVID symptoms and altered oral microbiome	Umass Chan Medical School	<ul style="list-style-type: none"> • A study conducted at UMass found that patients with persistent long-COVID symptoms have oral microbiomes with a significantly higher abundance of bacteria that induce inflammation, suggesting that dysfunction in the oral microbiome may contribute to long-COVID symptoms. Using whole genome sequencing and other algorithms, researchers found that 19 bacteria species were found in abundance in patients with long-COVID symptoms that did not appear in other patients.
22-Oct-21	Assessment of Cognitive Function in Patients After COVID-19 Infection	JAMA Network Open	<ul style="list-style-type: none"> • Researchers followed 740 patients with a history of COVID-19 through a Mount Sinai Health System registry. The mean follow-up time was 7 months past their initial COVID-19 diagnosis. The most prominent cognitive deficits were in memory encoding (24%), memory recall (23%), category fluency (20%), processing speed (18%), executive functioning (16%). Hospitalized patients and patients treated in the ED were more likely to have cognitive long-COVID symptoms compared to those treated in the outpatient setting.
25-Oct-21	In-Depth: Researchers find similarities between long COVID and chronic fatigue syndrome	Jarod Aarons	<ul style="list-style-type: none"> • Given the similarities between symptoms of long-COVID and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), advocates are calling on the NIH to fund joint investigations of these diseases. One study found that nearly half of long-COVID patients met the criteria for an ME/CFS diagnosis. Another study found the same biological markers present in long-COVID patients and individuals with ME/CFS. At the moment, there are no FDA-approved treatments for either disease.
26-Oct-21	Major study to gather long Covid patient data in Scotland	BBC News	<ul style="list-style-type: none"> • All adults who tested positive for COVID-19 will receive a text message asking them to take part in a large-scale study. Patients will be asked to log their symptoms using an app. The study will help researchers better understand how many people have long-COVID and the impact of long-COVID on day-to-day activities.

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29-Oct-21	How to help kids with 'long COVID' thrive in school	The Conversation	<ul style="list-style-type: none">Given the similarities between long-COVID symptoms and symptoms experienced after a concussion (fatigue, brain fog, and memory impairment), strategies that schools use to support students with concussions may also help kids with long-COVID. Parents, teachers, and doctors need to work together to support kids with long-COVID and establish temporary accommodations, which can include reducing physical activity, modifying the academic workload, providing additional time to complete assignments and tests, and creating an emotional support plan to prevent anxiety and depression. The accommodations can be scaled back as students recover from long-COVID.