

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.

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Date	Article	Publication	Key Takeaways
October 2020			
29-Oct-20	Full Report Long Covid - Evidence and Action for Primary Care	<i>Stockholm Healthcare SLSO</i>	<p>Definition: “post-acute Covid-19 as extending beyond three weeks from the onset of first symptoms and chronic Covid-19 as extending beyond 12 weeks.”</p> <p>“May last 6 months to a year and more serious late effects may be permanent...can affect patients who are asymptomatic or have mild cases of COVID-19 as well.”</p> <p>Occurs equally in hospitalized and non-hospitalized patients, and high incidence also in young adults.</p> <p>Long Covid affects around 10% of 18-49 year-olds, rising to 22% of over 70s.</p> <p>70% had impairment in one or more organs four months after initial symptoms of SARS-CoV-2 infection.</p> <p>Indistinct and changing signs and symptoms: most common is fatigue, muscle and body aches, shortness of breath and difficulty breathing. Be alert to deterioration and other possible illness arising especially respiratory, heart, stroke, significant depression or anxiety. Also seeing some asymptomatic patients who have “objective radiographic findings that are consistent with COVID-19 pneumonia.”</p> <p>Many patients report not using or giving up on formal services because they either dismiss the symptoms or have nothing to offer and it is too exhausting to access services; there may be many who have not accessed services or do not bother to return but are still suffering.</p>
28-Oct-20	Severe Covid-19 Cases Leave Lasting Effects, Including on Mental State	<i>WSJ</i>	<p>Cognitive decline, depression, anxiety, sleep disorders, low hemoglobin.</p> <p>Doctors think people who have survived after being put on a ventilator will likely need at least a year for recovery.</p> <p>Haruo Nakayama, a neurologist studying recovery in Covid-19 patients at Tokyo’s Toho University Ohashi Medical Center explained “it is necessary to pay attention not only to physical symptoms such as fatigue and respiratory distress, but also to memory, depression, anxiety and sleep disorders.”</p> <p>An Italian study of 402 people who recovered from Covid-19—most of whom had been hospitalized with severe pneumonia—found more than half reported at least one mental-health issue. Thirty-one percent reported depression, 28% post-traumatic stress disorder and 42% anxiety.</p> <p>Mr. Sarkar, who contracted the disease early and is the focus of this piece, had low hemoglobin during recovery.</p>
28-Oct-20	Nurses Are at High Risk for Covid Among Health Workers, C.D.C. Says	<i>NY Times</i>	<p>According to a recent CDC study, nurses have been at significant risk of contracting Covid-19 among healthcare workers. Nurses have an increased risk “because of their frequent and close patient contact, leading to extended cumulative exposure time.”</p> <p>About 6 percent of adults hospitalized from March through May were health care workers, with more than a third either nurses or nursing assistants. Most of the hospitalized workers in the analysis were female. They also tended to be older, and more were Black employees than the overall group of health care workers who contracted the virus.</p>

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			<p>National Nurses United issued a report on worker deaths in September, which found about 2,000 workers have died from COVID-19.</p>
28-Oct-20	<p>At 12, She's a Covid 'Long Hauler'</p>	<p><i>NY Times</i> David Tuller</p>	<p>Weeks and months after exposure, these Covid “long-haulers,” as they have been called, continue experiencing a range of symptoms, including exhaustion, dizziness, shortness of breath and cognitive impairments.</p> <p>Children may also be long-haulers. Children are generally at significantly less risk than older people for serious complications and death from Covid-19, but the long-term impacts of infection on them, if any, have been especially unclear.</p> <p>Although doctors recognize that a small number of children have suffered a rare inflammatory syndrome shortly after infection, there is little reliable information about how many who get Covid-19 have prolonged complaints.</p> <p>According to the American Academy of Pediatrics, children represented 10.9 percent of reported cases nationwide as of mid-October, up from just 2.2 percent in April.</p> <p>In Baltimore, the Kennedy Krieger Institute, a treatment facility for children with neurological and other chronic disabilities, is offering multidisciplinary services for those under 21 who continue to experience challenges after Covid-19. So far the institute has seen only one patient, said Dr. Melissa Trovato, the institute’s interim medical director of rehabilitation.</p>
27-Oct-20	<p>Some Covid Survivors Have Antibodies That Attack the Body, not Virus</p>	<p><i>NY Times</i></p>	<p>New research found “autoantibodies” similar to those in lupus and rheumatoid arthritis patients. Patients may benefit from treatments for those autoimmune diseases.</p> <p>The autoantibodies that target genetic material from human cells, instead of from the virus. This may explain why so-called “long haulers” have lingering problems months after their initial illness has resolved and the virus is gone from their bodies.</p> <p>Some of the autoantibodies identified are associated with blood flow problems and it is possible coagulation issues in COVID-19 patients are related.</p> <p>If the autoantibodies turn out to be long-lasting they may result in persistent, even lifelong, problems for Covid-19 survivors.</p>
27-Oct-20	<p>‘I Don’t Even Recognize Myself’: Coloradans Share COVID-19 Survivor Stories</p>	<p><i>CBSN Denver</i></p>	<p>Damaged organs, fatigue, weight and hair loss, headaches, SOB.</p> <p>The piece tells the stories of a few Colorado survivors. One is struggling with headaches, shortness of breath, extreme fatigue, weight loss, another with scarred lungs, liver damage, weakened muscles, and significant hair loss and a third individual had to re-learn how to eat, walk, and talk following a coma.</p>
27-Oct-20	<p>COVID’s cognitive costs? Some patients’ brains may age 10 years</p>	<p><i>Reuters</i></p>	<p>Brain aging.</p> <p>A study of 84,285 people led by Adam Hampshire at Imperial College London found patients recovering from COVID-19 may suffer cognitive deficits. Worst cases of the infection linked mental decline equivalent to the brain ageing by 10 years.</p>

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			<p>Participants of the study completed the Great British Intelligence Test. Results showed “substantial” cognitive deficits. However, scientists not involved with the study noted cognitive function of the participants was not known pre-COVID, and the results also do not reflect long-term recovery—so any effects on cognition may be short term. Participants included those who self-reported having COVID-19, but no positive test.</p>
22-Oct-20	<p><u>I’m a first-responder and now, it seems, a covid-19 ‘long-hauler’</u></p>	<p><i>Washington Post</i></p>	<p>A first responder exposed at work asks: My employer has granted me short-term disability. When it runs out, I will be placed on long-term disability at 60 percent of my current salary. My employment will be terminated, and I will have to join my spouse’s health insurance plan. If I was exposed to the coronavirus at work and it is the cause of my debilitating illness, are there other routes I should explore, such as workers’ compensation? How problematic is it that I never actually tested positive? What can I do to retain my job or financial security when I finally recover?</p> <p>The coronavirus pandemic has illuminated just how “worker protection systems are inadequate,” says Elaine Weiss, lead policy analyst for income security and a specialist on workers’ compensation at the National Academy of Social Insurance.</p> <p>Workers’ compensation is designed to provide no-fault support for people injured or sickened because of their work. But aside from known occupational diseases, such as black lung in miners, it’s generally difficult to claim workers’ comp for illness. As Weiss and other NASI colleagues discuss in a recent report, covid-19 in particular is hard to pin down as job-related because it’s highly contagious, common outside the workplace, and has a long latency period.</p> <p>However, some categories of workers have a clear and disproportionate risk of exposure through their jobs. Some states have begun lowering the burden of proof for certain categories of workers diagnosed with coronavirus so they can qualify for workers’ comp. These presumptions vary widely by state; some cover only front-line health-care professionals, while others include educators, warehouse workers, retail employees, meatpackers and other vulnerable groups.</p>
22-Oct-20	<p><u>Study Highlights Need for Continued Care of COVID-19 Survivors</u></p>	<p>Director’s Blog - NIH</p>	<p>Many will leave the hospital still quite ill and in need of further care. But little has been published to offer a detailed demographic picture of those being discharged from our nation’s hospitals and the types of community-based care and monitoring that will be needed to keep them on the road to recovery.</p> <p>Data confirm numerous previous reports that COVID-19 disproportionately affects people of color.</p> <p>Many patients undergoing treatment were enrolled in Medicaid (20 percent) or both Medicaid and Medicare (12 percent).</p> <p>A substantial number also were retired (36 percent) or unemployed (8.5 percent), highlighting the role of non-occupational spread. Many others worked in the hospitality industry, healthcare, or public transportation.</p>

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21-Oct-20	Attributes and predictors of Long-COVID: analysis of COVID cases and their symptoms collected by the Covid Symptoms Study App	<i>MedRxiv</i>	Analyzed data from 4182 incident cases of COVID-19 who logged their symptoms prospectively. Long-COVID was more likely with increasing age, BMI and female sex. Experiencing >5 symptoms during the first week of illness was associated with Long-COVID, OR=3.53. Our model to predict long-COVID at 7 days, with ROC-AUC of 76%, was replicated in an independent sample.
21-Oct-20	Is COVID-19 a Perfect Storm for Parkinson's Disease?	<i>CellPress Reviews</i>	Three recent case reports (by Méndez-Guerrero et al., Cohen et al., and Faber et al.) describe the development of acute Parkinson's following coronavirus disease 2019 (COVID-19). The studies suggest COVID-19 might be associated with elevated long-term risk of Parkinson's disease and they evaluate underlying cellular and molecular mechanisms.
21-Oct-20	When the Doctor Is a Covid 'Long Hauler'	<i>NY Times</i>	<p>Provider specialization has an impact on whether they are able to continue working. Those with more sedentary specialties (contrary to surgeon, gynecologist, etc.) are able to continue work while others may become candidates for formal disability benefits.</p> <p>Coronavirus may leave patients with a condition called POTS that makes the heart rate soar after even the mildest activities.</p> <p>POTS precludes standing for more than a few minutes at a time, because autonomic damage prevents blood vessels in the lower extremities from properly returning blood to the heart and brain against gravity. Heart rate can double or triple on standing, and lack of oxygen to the brain and upper body lead to many of the symptoms seen in POTS patients: dizziness, headaches, shortness of breath, chest pain, "brain fog."</p> <p>The degree of disability that it causes is equated to that of congestive heart failure or chronic obstructive pulmonary disease. Data from the Mayo Clinic shows that about half of POTS patients have some improvement in symptoms over an average of five years. It's too soon to know how the course of Covid-induced POTS might unfold.</p> <p>Increasingly, doctors are recognizing that POTS appears to account for many of the Covid long-haul symptoms being reported around the world. It's a condition with no known cure, but the symptoms can be managed with medications, a physical rehabilitation program and dietary interventions.</p>
16-Oct-21	NCCI Says 2% of COVID-19 Work Comp Claims May Result in Permanent Disability	<i>Claims Journal</i>	The NCCI estimates that 3% of workers with severe cases of COVID-19 will receive permanent total disability benefits and 40% will receive permanent partial disability benefits. For moderate infections, NCCI assumes 20% will receive permanent partial disability benefits. There is a 2.3% chance that a reported COVID-19 claim will result in permanent partial injury and there's a 0.05% chance that a COVID claim will result in a permanent total injury.
16-Oct-20	Genomewide Association Study of Severe Covid-19 with Respiratory Failure.	<i>The New England Journal of Medicine</i>	<p>Gene cluster linked to respiratory failure.</p> <p>Conducted a genomewide association study involving 1980 patients with Covid-19 and severe disease (defined as respiratory failure) at seven hospitals in the Italian and Spanish epicenters of the SARS-CoV-2 pandemic in Europe. The study identified a 3p21.31 gene cluster as a genetic susceptibility locus in patients</p>

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			with Covid-19 with respiratory failure and confirmed a potential involvement of the ABO blood-group system.
16-Oct-20	‘Nobody has very clear answers for them’: Doctors search for treatments for covid-19 long-haulers	<i>Washington Post</i> Lenny Bernstein	<p>COVID-specific recovery centers are opening. In the article one patient is receiving comprehensive care. He sees a pulmonologist, a cardiologist, a neurologist, a respiratory therapist and a physical therapist, and soon he will see a social worker—a first step toward getting help for the toll the coronavirus has inflicted on his psyche.</p> <p>Long-haulers “are in every country, in every language,” said Igor J. Koralnik, who started a program for covid-19 neurocognitive problems at Northwestern Memorial Hospital in Chicago.</p> <p>The Center for Post-Covid Care operated by the Mount Sinai health-care system in New York City boasts on its website that it has clinical specialists from 12 disciplines. Penn Medicine’s clinic in Philadelphia bills itself as a “post-covid assessment and recovery clinic.”</p> <p>A British team recently estimated that as many as 10 percent of the people who contract the disease suffer prolonged symptoms. In July, the Centers for Disease Control and Prevention reported that 35 percent of people who had mild versions of covid-19 had not returned to their pre-disease state of health two to three weeks later.</p>
14-Oct-20	These Doctors Have Long-Term Covid. Now They’re Pushing for Better Care.	<i>WSJ</i>	<p>Doctors and other health-care professionals are heavily represented among the estimated hundreds of thousands of Covid patients who experience persistent symptoms after their acute illness. Many faced skepticism from the doctors they were seeking care from. For doctors themselves who have long-term symptoms, the experience has been eye-opening.</p> <p>Some doctors with long-term Covid symptoms are turning to each other for support and advocating for greater awareness and better treatment.</p> <p>Some are organizing in a formal way. In the United Kingdom, a group of doctors who are long Covid patients are penning letters in medical journals and lobbying the government.</p> <p>There’s no reliable count of how many medical professionals have contracted Covid, but they were among the hardest hit populations in the spring.</p> <p>A July study in the <i>Lancet</i> based on self-reported data found that health-care workers had at least a threefold increased risk of contracting Covid-19.</p>
14-Oct-20	‘We Don’t Want Other People to Suffer’: JBS Families Wait, Fight And Hope For Accountability	<i>CPR News</i>	<p>Because the meatpacking plant was part of the food supply chain, it was deemed essential.</p> <p>Despite the well-documented incidence of COVID-19 within the plant, JBS has denied that some of the worker’s infections were work-related. Via a third-party claims administrator, the company has rejected the worker’s compensation claim from Sanchez’s widow and other JBS workers. In Colorado, workers have to prove they were injured or sickened at work to claim compensation.</p> <p>Since the start of the pandemic, the state has received 2,468 non-fatal claims related to COVID-19, about 67 percent of which have been denied. Of the 20 fatal claims to reach the department, only one has been admitted.</p> <p>In September, the Occupational Safety and Health Administration fined JBS \$15,000 for failing to protect its workers from COVID-19, and new allegations of negligence surfaced last week from two temporary JBS employees.</p>

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13-Oct-20	Man, 45, is first in world to go permanently deaf suddenly from coronavirus, docs warn	<i>The U.S. Sun</i>	<p>Hearing loss.</p> <p>A 45-YEAR-OLD man has become the first in the world to go permanently deaf from the coronavirus, doctors have warned.</p> <p>The case in the UK comes after experts at the University of Manchester said people who have recovered from the virus have reported a deterioration in their hearing as well as conditions such as tinnitus. The study, supported by the NIHR Manchester Biomedical Research Centre (BRC) surveyed 121 adults admitted to Wythenshawe Hospital.</p>
11-Oct-20	‘I Feel Like I Have Dementia’: Brain Fog Plagues Covid Survivors	<i>NY Times</i>	<p>Dementia/brain fog.</p> <p>One symptom is becoming known as Covid brain fog: troubling cognitive symptoms that can include memory loss, confusion, difficulty focusing, dizziness and grasping for everyday words. Increasingly, Covid survivors say brain fog is impairing their ability to work and function normally.</p> <p>Scientists aren’t sure what causes brain fog, which varies widely and affects even people who became only mildly physically ill from Covid-19 and had no previous medical conditions.</p> <p>Leading theories are that it arises when the body’s immune response to the virus doesn’t shut down or from inflammation in blood vessels leading to the brain.</p> <p>Research on long-lasting brain fog is just beginning. A French report in August on 120 patients who had been hospitalized found that 34 percent had memory loss and 27 percent had concentration problems months later.</p> <p>In a soon-to-be-published survey of 3,930 members of Survivor Corps, a group of people who have connected to discuss life after Covid, over half reported difficulty concentrating or focusing, said Natalie Lambert, an associate research professor at Indiana University School of Medicine.</p> <p>Tiny strokes may cause some symptoms.</p>
9-Oct-20	Clinical Presentation of People with SARS-CoV-2 Infection	NIH	<p>Fatigue, joint pain, chest pain/palpitations, SOB, worsened quality of life.</p> <p>In general, adults with SARS-CoV-2 infection can be grouped into the following severity of illness categories.</p> <p>Asymptomatic or Presymptomatic Infection: Individuals who test positive for SARS-CoV-2 using a virologic test (i.e., a nucleic acid amplification test or an antigen test), but who have no symptoms that are consistent with COVID-19.</p> <p>Mild Illness: Individuals who have any of the various signs and symptoms of COVID-19 (e.g., fever, cough, sore throat, malaise, headache, muscle pain, nausea, vomiting, diarrhea, loss of taste and smell) but who do not have shortness of breath, dyspnea, or abnormal chest imaging.</p> <p>Moderate Illness: Individuals who show evidence of lower respiratory disease during clinical assessment or imaging and who have saturation of oxygen (SpO2) ≥94% on room air at sea level.</p> <p>Severe Illness: Individuals who have SpO2 <94% on room air at sea level, a ratio of arterial partial pressure of oxygen to fraction of inspired oxygen (PaO2/FiO2) <300 mmHg, respiratory frequency >30 breaths per minute, or lung infiltrates >50%.</p>

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			<p>Critical Illness: Individuals who have respiratory failure, septic shock, and/or multiple organ dysfunction.</p> <p>There have been an increasing number of reports of patients who experience persistent symptoms after recovering from acute COVID-19. At this time, there is limited information on the prevalence, duration, underlying causes, and effective management strategies for these lingering signs and symptoms. Some of the symptoms overlap with the post-intensive care syndrome that has been described in patients without COVID-19, but prolonged symptoms and disabilities after COVID-19 have also been reported in patients with milder illness, including outpatients.</p> <p>Some of the persistent symptoms that have been reported include fatigue, joint pain, chest pain, palpitations, shortness of breath, and worsened quality of life. One study from China found that pulmonary function was still impaired 1 month after hospital discharge. A study from the United Kingdom reported that among 100 hospitalized patients (32 received care in the ICU and 68 received care in hospital wards only), 72% of the ICU patients and 60% of the ward patients experienced fatigue and breathlessness at 4 to 8 weeks after hospital discharge.</p> <p>Neurologic and psychiatric symptoms have also been reported among patients who have recovered from acute COVID-19. High rates of anxiety and depression have been reported in some patients using self-report scales for psychiatric distress. Younger patients have been reported to experience more psychiatric symptoms than patients aged >60 years.</p> <p>Patients may continue to experience headaches, vision changes, hearing loss, loss of taste or smell, impaired mobility, numbness in extremities, tremors, myalgia, memory loss, cognitive impairment, and mood changes for up to 3 months after diagnosis of COVID-19. More research is needed to better understand the pathophysiology and clinical course of these post-infection sequelae and to identify management strategies for patients.</p> <p>Asymptomatic SARS-CoV-2 infection can occur, although the percentage of patients who remain truly asymptomatic throughout the course of infection is variable and incompletely.</p>
7-Oct-20	Long COVID: let patients help define long-lasting COVID symptoms	<i>Nature</i>	<p>Researchers are calling for the definition of recovery from COVID-19 to be based on extended criteria dependent on symptoms, particularly chronic fatigue syndrome. The World Health Organization is following this closely.</p>
6-Oct-20	Study finds neurological symptoms in most COVID patients	<i>AXIOS</i>	<p>Neurological symptoms.</p> <p>Most patients hospitalized with COVID-19 experienced neurological symptoms, including muscle pain, headaches and encephalopathy, according to a study published Monday in the <i>Annals of Clinical and Translational Neurology</i>.</p> <p>About 80% of the patients showed symptoms such as muscle pain, headaches, confusion, dizziness and the loss of smell or taste.</p> <p>About one-third of patients had encephalopathy or altered mental function and stayed in the hospital about three times longer than patients without. These patients were also nearly seven times as likely to die.</p> <p>The average age for those in the study with encephalopathy was 65. Patients with the condition also tended to have a history of other disorders, including high blood pressure.</p>

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6-Oct-20	Mount Sinai's Post-COVID Care Center For 'Long-Haulers' Slammed By Patient Demand	<i>Gothamist</i>	<p>The demand has increased to the point where Mount Sinai COVID-19 Care Center for long-haulers is now onboarding more staff to help ease its growing backlog of prospective patients, some of whom have been told they have to wait months for an appointment.</p> <p>The Center, which has seen some 550 patients since it opened four months ago at Mount Sinai's Union Square location, currently has five health care providers carrying out initial intake appointments and more than 25 specialists to whom patients can be referred. The Center is bringing on a nurse practitioner and physician assistant from a different unit in the health system to help increase capacity.</p> <p>The Center for Post-COVID Care was established to conduct research on the potential long-term health outcomes of COVID-19 in addition to providing care, it has so far prioritized patients who have tested positive for COVID-19 or for antibodies, which can develop as part of the immune system's response to the disease, but the Center is working to get appointments for those without a positive test.</p>
5-Oct-20	Nearly One-Third of Covid-19 Patients in Study Had Altered Mental State	<i>NY Times</i> Pam Belluck	<p>Encephalopathy; neurological.</p> <p>Nearly a third of hospitalized Covid-19 patients experienced some type of altered mental function—ranging from confusion to delirium to unresponsiveness—in the largest study to date of neurological symptoms among coronavirus patients in an American hospital system.</p> <p>Patients with altered mental function had significantly worse medical outcomes, according to the study, published on Monday in <i>Annals of Clinical and Translational Neurology</i>.</p> <p>After they were discharged, only 32 percent of the patients with altered mental function were able to handle routine daily activities like cooking and paying bills, said Dr. Igor Koralnik, the senior author of the study and chief of neuro-infectious disease and global neurology at Northwestern Medicine. In contrast, 89 percent of patients without altered mental function were able to manage such activities without assistance.</p> <p>Younger patients were more likely to develop neurological symptoms overall, except for encephalopathy, which was more common in older people. Black and Latino patients were not more likely than other groups to develop neurological symptoms.</p>