

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
April 2021			
27-Apr-21	<u>Gene changes might explain long-haul COVID-19 symptoms</u>	AAAS	<ul style="list-style-type: none"> • "Results from a new cell study suggest that the SARS-CoV-2 spike protein can bring about long-term gene expression changes. The findings could help explain why some COVID-19 patients -- referred to as COVID long-haulers -- experience symptoms such as shortness of breath and dizziness long after clearing the infection. • The researchers also compared their cultured human airway cells to studies from others where cells were collected from patients with COVID-19 infection. They were able to confirm that the optimized cell culture approach reflected what occurs in patients, making it useful for future translational studies."
26-Apr-21	<u>Fearing an untreated epidemic, activists fight for those with 'long COVID' symptoms</u>	MSN	<ul style="list-style-type: none"> • "Today, the Body Politic COVID-19 Support Group has registered 10,500 COVID-19 patients and their caregivers and families, who have started an independent research group and advised the National Institutes of Health. It is among dozens of grass-roots organizations around the world that have formed to make sure that a year into the pandemic — as fatigue mounts, vaccines become more available and infection rates drop — COVID-19 and its lingering symptoms" • "If projections are accurate, their concerns are well-founded. More than 32 million cases of COVID-19 have been reported in the United States, and according to one study, long COVID can affect up to a third of those who have had the disease remain in the public eye." • Mentions SurvivorCorps, Yale study, grant "The group claims nearly 160,000 members and is partially funded by a \$440,000 grant from the Gates Foundation" • The Long COVID Alliance, for instance, was co-founded by the organization Solve M.E., which for 30 years has lobbied for research and funding into chronic fatigue syndrome, which can follow a COVID-19 infection"
26-Apr-21	<u>In It For The Long Haul: What Can Be Done For Patients With Lingering COVID Symptoms?</u>	WCBU	<ul style="list-style-type: none"> • "Repeats 10% figure. • Mostly anecdotal • "Deepak Nair, an OSF HealthCare neurologist, said physicians expected to see long-term effects in patients with severe COVID-19 infections requiring an ICU stay. Some lasting damage is common with any extended hospitalizations. But he's been surprised how many people with mild or even no symptoms are reporting the same thing months after infection." • "Because COVID-19 can affect so many parts of the body in different patients...it requires a multifaceted approach. Dr. Brian Curtis, OSF HealthCare's vice president of Clinical Specialty Services, said they've developed a COVID Recovery Clinic to route long-hauler patients through their primary care provider to the specialist services they may need.""

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26-Apr-21	Survivors of severe COVID-19 may be seeing long-term symptoms ease after vaccine	WCPO	<ul style="list-style-type: none"> • "Dr. Stephen Feagins, chief clinical officer for Mercy Health and Hamilton County, said the reason some survivors feel better is just as unclear as what causes PASC in some COVID-19 survivors. ""We know that the loss of taste and smell are partially neurological and partially antibody-induced,"" said Feagins. ""And that's as far as we know.""
23-Apr-21	Why Impact of 'Long Covid' Could Outlast the Pandemic: QuickTake	WaPo	<ul style="list-style-type: none"> • "Discusses several studies, including the recent Nature study, mentions different stats, labor impact, and includes congressional funding. • "Although most long Covid symptoms don't seem to be life-threatening, sufferers had a 59% increased risk of dying within six months, a study published April 22 in the journal Nature found." • "As of November, before England experienced a severe winter surge, some 186,000 Covid survivors were living with symptoms that had persisted for 5 to 12 weeks, out of over 1 million known cases. A small study from the University of Washington reported persistent symptoms for as long as nine months after an acute bout of Covid-19. A much larger study involving almost 240,000 Covid-19 patients found one in three received a neurological or psychiatric diagnosis within six months of infection." • "Among those who'd been infected, 8% reported lingering symptoms causing moderate-to-marked disruptions of their work life, compared with 4% in the non-infected group. Uncertainties about post-Covid illness have sometimes led to what so-called long haulers describe as medical gaslighting by health professionals who don't take their complaints seriously, especially if the patient is a woman." • "The reduced work hours reported in 68.9% of long-Covid patients indicate the pandemic is crimping labor productivity. With 136 million Covid cases worldwide, even a small share with long-term debility could have enormous social and economic consequences. And these will be magnified if people end up enduring years or decades of coronavirus-related disability."
23-Apr-21	Long-haul COVID-19 symptoms common, rise with severity of illness	UPI	<ul style="list-style-type: none"> • In what may be the largest such study to date, "the findings show that beyond the first 30 days of illness, substantial burden of health loss -- spanning pulmonary and several extrapulmonary [non-respiratory] organ systems -- is experienced by survivors of the acute phase of COVID-19," according to a team led by Dr. Ziyad Al-Aly, of the VA St. Louis Health Care System, in St. Louis, Mo. • Discusses Nature article

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22-Apr-21	‘Long Hauler’ Study Shows Covid Can Kill Months After Infection, Bloomberg	Bloomberg	<ul style="list-style-type: none"> • "Repeats 10% figure. Discusses study in Nature. • “Survivors had a 59% increased risk of dying within six months after contracting the SARS-CoV-2 virus, researchers reported Thursday in the journal Nature. The excess mortality translates into about 8 extra deaths per 1,000 patients -- worsening the pandemic’s hidden toll amid growing recognition that many patients require readmission, and some die, weeks after the viral infection abates.” • “Covid-19 patients who survived hospitalization were found to have a 51% increased risk of dying compared with 13,997 influenza patients who also had been hospitalized.”
22-Apr-21	People With Severe COVID-19 Have Higher Risk Of Long-Term Effects, Study Finds	NPR	<ul style="list-style-type: none"> • Discusses Nature Article
22-Apr-21	Long-haul patients who had mild COVID cases still face worrisome health risks, study finds	The Seattle Times	<ul style="list-style-type: none"> • "Discusses Nature Article • In the study, published Thursday in the journal Nature, researchers looked at medical records of more than 73,000 people across the United States whose coronavirus infections did not require hospitalization. Between one and six months after becoming infected, those patients had a significantly greater risk of death — 60% higher — than people who had not been infected with the virus."
22-Apr-21	High-dimensional characterization of post-acute sequelae of COVID-19	Nature	<ul style="list-style-type: none"> • "Nature article described below in online articles. • “Here, we use the national healthcare databases of the US Department of Veterans Affairs to systematically and comprehensively identify 6-month incident sequelae including diagnoses, medication use, and laboratory abnormalities in 30-day survivors of COVID-19. We show that beyond the first 30 days of illness, people with COVID-19 exhibit higher risk of death and health resource utilization. Our high dimensional approach identifies incident sequelae in the respiratory system and several others including nervous system and neurocognitive disorders, mental health disorders, metabolic disorders, cardiovascular disorders, gastrointestinal disorders, malaise, fatigue, musculoskeletal pain, and anemia.” • “The results suggest that beyond the first 30 days of illness, people with COVID-19 are at higher risk of death, health care resource utilization, and exhibit a broad array of incident pulmonary and extrapulmonary clinical manifestations including nervous system and neurocognitive disorders, mental health disorders, metabolic disorders, cardiovascular disorders, gastrointestinal disorders, and signs and symptoms related to poor general wellbeing including malaise, fatigue, musculoskeletal pain, and anemia. Increased risk of incident use of several medication classes was also observed including pain medications (opioids and non-opioids), antidepressants, anxiolytics, antihypertensives, anti-hyperlipidemics, oral hypoglycemics, insulin, and other medication classes.”

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21-Apr-21	Dartmouth-Hitchcock starts program for post-COVID 'long-haulers'	WCAX3	<ul style="list-style-type: none"> • "The Dartmouth-Hitchcock Medical Center has started a post-COVID-19 program for people feeling shortness of breath, fatigue and body aches, rapid heartbeat, memory issues and other symptoms more than three months after they became infected. • Repeats 10-30% figure. • Other online articles discussing this clinic opening."
20-Apr-21	Early evidence shows COVID vaccines could help with 'long haul' symptoms	KHNL	<ul style="list-style-type: none"> • "Dr. Todd Seto, director of Research of Academic Affairs at Queen's Medical Center, is studying 2,000 Queen's employees to test for their antibody levels. He says there has been anecdotal evidence that vaccines help with COVID "long hauler" symptoms, but it's not yet conclusive."
20-Apr-21	Long COVID's long R&D agenda	Nature	<ul style="list-style-type: none"> • "As researchers work to understand the biology and epidemiology of post-acute COVID-19, a pioneering platform trial is now testing treatments to try to address the long-term complications of infection in previously hospitalized individuals. • In late April, the HEAL-COVID trial will start recruiting COVID-19 survivors from hospitals in the UK to study treatments that could reduce the long-term effects of SARS-CoV-2 infection. • Repeats 10% number. • Following the model of the RECOVERY trial — a platform trial that has now tested 13 drug candidates in nearly 40,000 hospitalized COVID-19 patients — HEAL-COVID will keep adding more patients and treatment arms as needed. As such, the investigators hope to avoid the pitfalls of the underpowered and insufficiently informative studies that have dominated the COVID-19 trial landscape. Again, following the RECOVERY model, HEAL-COVID will instead leverage linked-up electronic health-care records to collect its data."

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20-Apr-21	Long-Haul COVID Renews Push to Expand Palliative Care	PEW	<ul style="list-style-type: none"> • "Palliative and hospice organizations are in talks with the Biden administration to create such a benefit as a demonstration project in Medicare, the health plan for older Americans. If successful, they hope it would become a permanent benefit in Medicare and then be offered under Medicaid, the federal/state program that covers lower-income Americans, and commercial insurance plans as well. • Added to that list now are COVID-19 long-haulers who, months after becoming infected, continue to suffer from lingering, life-limiting symptoms such as mental confusion, nausea, dizziness, blurry vision, hearing loss, paralyzing fatigue and dizziness. Approximately 10% of people who test positive for COVID-19 remain unwell for more than three weeks and a smaller proportion for months, according to an August study in The BMJ, a medical trade journal published by the British Medical Association. • Some Medicare managed care and commercial plans offer limited home- and community-based palliative services, but Medicare fee-for-service programs do not....Providers would apply to the federal Centers for Medicare and Medicaid Services to participate in the new model advocates are seeking. Banach said he and allies have had fruitful conversations with CMS about embarking on such a model. The group's proposal calls for the expansion of a demonstration that CMS has been funding since 2016 called the Medicare Care Choices Model. Under that model, patients with terminal illnesses who did not want to abandon medical treatments intended to prolong their lives can receive hospice services through participating hospice organizations. The model resulted in a 25% savings to Medicare, largely by reducing hospitalizations, according to a CMS evaluation published in October"
20-Apr-21	Study Finds 1 in 10 Healthcare Workers with Mild COVID Have Lasting Symptoms	NIH Directors Blog	<ul style="list-style-type: none"> • "Cites previously tracked JAMA study. • Their findings show that 26 percent of those who had mild COVID-19 reported at least one moderate to severe symptom that lasted more than two months. That's compared to 9 percent of participants without COVID-19. What's more, 11 percent of the individuals with mild COVID-19 had at least one debilitating symptom that lasted for at least eight months. In the group without COVID-19, any symptoms of feeling unwell resolved relatively quickly. • The most common symptoms in the COVID-19 group were loss of taste or smell, fatigue, and breathing problems. In this group, there was no apparent increase in other symptoms that have been associated with COVID-19, including "brain fog," problems with memory or attention, heart palpitations, or muscle and joint pain. "

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19-Apr-21	<u>To defeat COVID-19, remember the children and don't let down your guard</u>	USA Today	<ul style="list-style-type: none"> • "More than 73,000 kids were diagnosed with COVID-19 in the first week of April, the highest weekly total in nearly two months. Similar to what we've seen with adults, children of color have fared the worst, with Black and Latino children representing nearly 70% of children who have been diagnosed with a related, severe pediatric inflammatory illness known as MIS-C. • In addition to the direct toll COVID-19 has taken on children, the indirect toll from parental loss, social isolation, and economic hardship has had significant psychological impacts. • Mentions Amer. Rescue Plan Act funding to reopen schools and child tax credit"
19-Apr-21	<u>Some long-haul COVID patients report vaccines are easing their lingering symptoms</u>	CBS News	<ul style="list-style-type: none"> • "Mentions Yale study: Dr. Akiko Iwasaki, professor of immunobiology at the Yale School of Medicine. Iwasaki is launching a study on people with long COVID-19, collecting blood and saliva samples to compare immune responses before and after long-haulers get the vaccine to understand if it really helps. Yale hopes to enroll 100 people with long COVID in its study to understand these phenomena and see if the relief will last. Researchers also say the findings could help in other diseases that may be triggered by a virus, such as chronic fatigue syndrome."
19-Apr-21	<u>COVID-19 long haulers are reporting an unbearable ringing in their ears that's still there months after they got sick</u>	Business Insider	<ul style="list-style-type: none"> • "Tinnitus — a persistent ringing in the ears — appears to be emerging as a COVID-19 after-effect. • One early study said that some 15% of COVID patients report the symptom. • A UK charity reported a 256% spike in calls related to tinnitus since the pandemic began. • A preliminary study published on March 21 found that 15% of people who had COVID-19 reported having tinnitus. 7.6% reported hearing loss, and 7.2% reported vertigo, which is also related to the ears."
19-Apr-21	<u>'Long-haul COVID' in Hampton Roads: How patients and doctors are coping with mysterious, lasting symptoms</u>	DailyPress	<ul style="list-style-type: none"> • "A new post-COVID clinic based at the Sentara Heart Hospital in Norfolk run by Dr. Xian Qiao, a pulmonary critical care specialist with Sentara Virginia Beach General Hospital. • They started with only patients who had been hospitalized with COVID. But they're also "seeing more and more patients who were not necessarily hospitalized but have prolonged symptoms even though they weren't bad initially," Qiao said. The estimate of about 10% of COVID patients experiencing symptoms for longer could be an undercount, he said. Even if it's not, "that's a large absolute number on the community." • Symptoms he sees include fatigue, shortness of breath despite diagnostic tests not turning up much and unexplained fast heartbeats. Then there's the brain fog. His patients often walk into rooms without remembering what they were doing and had to make adjustments to their high-functioning jobs. "That can be quite life-altering," he said."

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18-Apr-21	<u>Second Opinion: How long haul COVID could offer clues for treating other puzzling chronic illnesses</u>	Los Angeles Times	<ul style="list-style-type: none"> • "Between 40% and 75% of long-haulers describe a complex neurological constellation of symptoms and conditions. These include fatigue, intense headaches, muscle weakness, difficulty sleeping, anxiety, poor concentration, memory loss and changes to the sense of taste and smell. Most have three or more symptoms, which indicates that long-haul COVID-19 likely affects multiple parts of the brain or multiple organ systems at once. • Mentions vaccine studies on Long COVID and other studies on the immune and inflammatory response that lingers. "
16-Apr-21	<u>NC woman wrote her own obituary before dying from 'long haul' COVID</u>	Kansas City	<ul style="list-style-type: none"> • "Before Jones died on March 12, she had taken the unusual step to write her own obituary, where the Charlotte-area woman reiterated the severity of the disease not just for elderly people but young adults like herself, just "33-and-a-half years young." • Her obituary was shared Wednesday on the widely-read "Faces of COVID" Twitter account, which amplifies stories of people across the country who died of the disease."
16-Apr-21	<u>Prolonged brain dysfunction in COVID-19 survivors: A pandemic in its own right</u>	MedicalXpress	<ul style="list-style-type: none"> • "1 in 3 figure for neurological disability. • Researchers looked at 236,379 British patients diagnosed with COVID-19 over six months, analyzing neurologic and psychiatric complications during that time period. They compared those individuals to others who had experienced similar respiratory illnesses that were not COVID-19. • They found a significant increase in several medical conditions among the COVID-19 group, including memory loss, nerve disorders, anxiety, depression, substance abuse and insomnia. Additionally, the symptoms were present among all age groups and in patients who were asymptomatic, isolating in home quarantine, and those admitted to hospitals"
14-Apr-21	<u>Some long-haul patient's symptoms improve after receiving COVID-19 vaccine</u>	WishTV	<ul style="list-style-type: none"> • "SurvivorCorps mention, Indiana University • Dr. Beeler is the medical director of Infection Prevention at Indiana University Hospital. He has seen about 20%-30% of his patient's symptoms improve after getting their shots. • A study at Yale is being launched on the subject this week on vaccine and long haul covid. • People who have gotten sick with COVID-19, currently have long-haul symptoms and haven't gotten the vaccine might be good candidates for the study at Yale. Survivor Corps said they should have more information on how to sign up later this week."

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14-Apr-21	COVID-19 "long-haulers" cope with lasting virus symptoms	MSN	<ul style="list-style-type: none"> • "Repeats 5-10% figure. • Anecdotal: <ul style="list-style-type: none"> ○ Dr. Diana Kirke, an ear, nose and throat doctor at Mount Sinai Hospital, found vocal cord weakness impaired Hlavka's speech and breathing, a likely nerve injury from COVID-19. • Other symptoms include fatigue, headache, brain fog, depression and anxiety."
13-April-21	How scientists are teasing apart the biology of Long COVID	AAAS	<ul style="list-style-type: none"> • Repeats 10-30% figure. • "We have a COVID group, at least 6 weeks out from the onset of symptoms, of 18 years and older. We've enrolled about 150 survivors, and about 55% have no post-COVID symptoms. As was the case with the Ebola study, we knew it was important to have a control group. We ask participants to identify people that they had contact with who didn't get COVID, and we ask them to join the study." • "About 12% of our COVID group complains of tinnitus, and about 14% of the control group has tinnitus. It's the same thing with finding a mild abnormality in a lung test that measures how well lungs transfer oxygen to the bloodstream. About 50% or 60% of the COVID group has that, with a median age of 50." • "We've been approached by the Opera House of Montreal to develop a rehab program for patients, because a lot of these exercises work on improving lung function."
13-Apr-21	People who have recovered from COVID-19 may be at risk of developing blood clots: Singapore study	Channel News Sia	<ul style="list-style-type: none"> • "People who have recovered from COVID-19, especially those with pre-existing cardiovascular conditions, may be at risk of developing blood clots due to a lingering and overactive immune response, a Singapore study has found. • The study, led by Nanyang Technological University (NTU) scientists, investigated the possible link between COVID-19 and an increased risk of blood clot formation, shedding light on the medium- and long-term consequences of infection, or "long-haul COVID", NTU said in a news release on Tuesday (Apr 13). • Small study of 30. Cardiac, blood vessel damage and high T cell count found in patients. "

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13-Apr-21	Clinics pop up to treat long haulers' lingering COVID-19 symptoms	Yahoo	<ul style="list-style-type: none"> • ""While I'm very hopeful that the number of 'Long COVID' patients decreases dramatically over time, I do expect that there will be a smaller subset of people that continues to have some lingering issues over the next few years,"" Benjamin Abramoff, Director of Penn Medicine's Post-COVID Assessment and Recovery Clinic, told ABC News. • Mentions disability benefits. • Dr. Sritha Rajupet, a preventive and family medicine physician who helps lead the Post-COVID Clinic at Stony Brook Medicine; Humboldt Park Health, a health system based in Chicago, recently set up a post-COVID clinic specifically to address the Long COVID needs of the low-income communities it serves."
13-Apr-21	Experts discuss post-acute COVID-19	Medical Express, NIH Workshop	<ul style="list-style-type: none"> • "A paper published recently in Annals of Internal Medicine describes the workshop. Over 1,200 registered participants including researchers, clinicians, and affected community members discussed what is known about sequelae after COVID-19 and the knowledge gaps that need to be addressed in future research. • In addition to reviewing existing data the workshop presenters identified important knowledge gaps. Notably, the epidemiology is not fully characterized, and it will need to be expanded in order to identify and help vulnerable groups of people. The full clinical spectrum of post-acute COVID-19 is not yet known, nor the reasons why the symptoms manifest so differently in individuals."
13-Apr-21	They tested negative for COVID. Still, they have long COVID symptoms	Salon	<ul style="list-style-type: none"> • "Data about the frequency of false-negative diagnostic covid tests is extremely limited. A study at the Johns Hopkins School of Medicine and Bloomberg School of Public Health, which focused on the time between exposure and testing, found a median false-negative rate of 20% three days after symptoms start. A small study in China conducted early in the pandemic found a high rate of negative tests even among patients sick enough to be hospitalized. And given the dearth of long-hauler research, patients dealing with lingering covid symptoms have organized to study themselves. • Dr. Monica Verduzco-Gutierrez, a rehabilitation and physical medicine doctor who leads University Health's Post-COVID Recovery program in San Antonio, said about 12% of the patients she's seen never had a positive covid test. • Mentions disability benefits"
12-Apr-21	NIH, CDC studying kids hit with long-lasting fatigue, lethargy after COVID diagnosis		<ul style="list-style-type: none"> • "Kids are joining the rising number of people suffering from long-term COVID-19 symptoms at an alarming rate. The National Institutes of Health and Centers for Disease Control and Prevention are now studying what exactly a case of long-haul COVID-19 means for children and adults as more mysteries of the virus unfold. • Video • Children battling extreme fatigue and undergoing therapy."

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12-Apr-21	Kids can get long-haul COVID, too. Recovery can take months	MSN	<ul style="list-style-type: none"> • "Same story of girl in CBS video, recovering with physical therapy • At least five hospitals in the U.S. have started pediatric long-haul clinics to help kids with lingering COVID-19 illness as the National Institutes of Health and the Centers for Disease Control and Prevention mount a massive, nationwide study of long-haul COVID that includes children. • Nearly one in five COVID-19 cases within the last week of March were in kids under 18. • The director of the National Institutes of Health said it is likely 70% more infectious and significantly more deadly, even for young people."
11-Apr-21	Incidence of Long-term Post-acute Sequelae of SARS-CoV-2 Infection Related to Pain and Other Symptoms: A Living Systematic Review and Meta-analysis	Medrxiv	<ul style="list-style-type: none"> • "In total, 35 studies including 18,711 patients were eligible. Eight pain-related symptoms and 26 other symptoms were identified. The highest pooled incidence among pain-related symptoms was chest pain (17%, 95% CI, 12%-25%), followed by headache (16%, 95% CI, 9%-27%), arthralgia (13%, 95% CI, 7%-24%), neuralgia (12%, 95% CI, 3%-38%) and abdominal pain (11%, 95% CI, 7%-16%). The highest pooled incidence among other symptoms was fatigue (45%, 95% CI, 32%-59%), followed by insomnia (26%, 95% CI, 9%-57%), dyspnea (25%, 95% CI, 15%-38%), weakness (25%, 95% CI, 8%-56%) and anosmia (19%, 95% CI, 13%-27%)."
11-Apr-21	For many sufferers of long Covid, proving they are sick is a big part of the battle	CNN	<ul style="list-style-type: none"> • "A separate study published last month showed that seven in 10 people who had been hospitalized for Covid-19 have not fully recovered five months after being discharged. • "More than 133 million people globally have been infected with coronavirus. While it's unclear how many are suffering from long Covid, public health experts are warning of a 'second pandemic' of longhauler disease."
9-Apr-21	‘It was like the lights went out.’ Family dealing with COVID complications months after diagnoses	Dayton Daily News	<ul style="list-style-type: none"> • "A recent study done at Northwestern Memorial Hospital of 100 patients from 21 states with long-term symptoms who did not have immediate harsh reactions to the virus found that 85 percent of them experienced four or more neurological issues like brain fog, headaches, tingling, muscle pain and dizziness."
9-Apr-21	How long-haul COVID harms thousands	Daily News	<ul style="list-style-type: none"> • "Repeats 10% figure. • "This is a health, economic and social crisis on an unforeseen level, and the question facing hospitals and health-care providers now is how we address it and get long-haulers back on their feet. Our prospects for returning to normalcy and prosperity — in our health, our lives, our economy, and our institutions — hinge on it." • "In May, we started a first-of-its-kind research and treatment center dedicated to the study and treatment of people with Post-COVID syndrome. The center is designed to treat patients' symptoms through rehabilitation and medication, and we also study the kidneys, heart and nervous system, including cognitive function, to find commonalities that may shed light on the disease."

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8-Apr-21	'Long haul' COVID: Doctor describes patients' 'crushing headaches,' 'cognitive symptoms' after recovery	ABC News	<ul style="list-style-type: none"> • "Repeats 1 in 3 figure for neurological symptoms. • Mentions vaccine as potential help. • Dr. Hellmuth says her patients have several other lasting symptoms too including headache disorders, vertigo, ringing in their ears, and a condition where a persons blood pressure isn't being regulated well and they end up passing out. ""I have patients who got Covid 19 over a year ago in early march 2020 who developed cognitive symptoms when they were acutely ill who still have them, who have not gotten better,"" says Dr. Hellmuth."
8-Apr-21	Vaccine may help relieve long-haul COVID-19 symptoms	Wyoming News	<ul style="list-style-type: none"> • According to an article published by NPR last week, the evidence so far includes 40% of the 577 long-haul patients contacted by support organization Survivor Corps reporting an improvement after their vaccination; a report from Dr. Daniel Griffin of Columbia University Medical Center that up to 40% of the patients in his long-term study are seeing an improvement; and a small UK study that found about 23% of long-haul patients saw an increase in symptom resolution.
8-Apr-21	COVID-19: What will be done to help long-haulers?	The Seattle Times	<ul style="list-style-type: none"> • "This nurse had to drop out of her Masters in Nursing program because she could no longer focus or retain the information from her classes. She fought for months for the state to recognize her occupational infection. For those months she lived on her savings. To make matters worse, she must now pay for her insurance under Consolidated Omnibus Budget Reconciliation Act (COBRA) benefits. Her life has been drastically diminished, and she is paying more out of pocket to support her diminished existence."
8-Apr-21	Doctor says some patients' lasting effects are worse than COVID	Yahoo News	<ul style="list-style-type: none"> • "Repeats 1 in 3 figure for neurological symptoms • "A medical study released this week finds that one third of those who had COVID-19 are now dealing with a brain disorder, naming anxiety, mood disorders, and even strokes. Dr. Helmut says her patients have several other lasting symptoms, too. Headache disorders are very common in people, new dizziness, things we call vertigo-- processing, people who have ringing in their ears, or their blood pressure isn't being regulated well and people are passing out.""

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7-Apr-21	Symptoms and Functional Impairment Assessed 8 Months After Mild COVID-19 Among Health Care Workers	JAMA	<ul style="list-style-type: none"> • "This cohort study investigated COVID-19–related long-term symptoms in health care professionals. • Of the seropositive participants, 8% reported that their long-term symptoms moderately to markedly disrupted their work life, compared with 4% of the seronegative participants (RR, 1.8 [95% CI, 1.2-2.9]); 15% reported their long-term symptoms moderately to markedly disrupted their social life, compared with 6% of the seronegative participants (RR, 2.5 [95% CI, 1.8-3.6]); and 12% reported that their long-term symptoms moderately to markedly disrupted their home life, compared with 5% of the seronegative participants (RR, 2.3 [95% CI, 1.6-3.4]). Furthermore, 11% of the seropositive participants reported moderate to marked disruption in any Sheehan Disability Scale category as well as having at least 1 moderate to severe symptom lasting for at least 8 months, compared with 2% of the seronegative participants. • The results of this study showed that a considerable portion of low-risk individuals with mild COVID-19 reported a diversity of long-term symptoms, and that these symptoms disrupted work, social, and home life. Limitations of the study include the possibility of recall bias and the subjective rating of symptoms. "
7-Apr-21	Long Covid isn't as unique as we thought	Vox	<ul style="list-style-type: none"> • These effects, though unnerving, aren't unprecedented. Chronic symptoms, especially fatigue, have lingered after the typical recovery periods for viruses as varied as West Nile, Polio, Dengue, Zika, seasonal flu, and H1N1 as well as the new coronavirus's cousins MERS and SARS-1. Run-of-the-mill strep throat can develop into rheumatic fever, which can cause fatigue, painful joints, and fluid buildup around the heart. While reporting this story, I realized I was once a long hauler.
7-Apr-21	Long-haul COVID sufferers can get help through new city program: Mayor de Blasio	Daily News	<ul style="list-style-type: none"> • "New Yorkers experiencing long-haul COVID will now be able to seek help through a coronavirus aftercare program designed to support people with long-term symptoms. • Mayor de Blasio announced that the new initiative, dubbed NYC Aftercare, will begin Wednesday and said it would not only aim to meet people's ongoing physical needs, but also provide them with food and mental health support. • Johnson, the director of Test & Trace's Take Care initiative, will lead the city's aftercare efforts. She said such long-haul scenarios are playing out in "thousands of households across New York," and as result, the Test & Trace Corps will now begin referring long COVID sufferers to "a wide range of resources" devoted to treating it specifically. • The resources will include referrals to primary care doctors, city COVID clinics and support groups. De Blasio noted that the program's services would be provided regardless of one's ability to pay or immigration status."

COVID-19 Patient Recovery Alliance Research Tracker

Date	Article	Publication	Key Takeaways
6-Apr-21	6-month neurological and psychiatric outcomes in 236379 survivors of COVID-19: a retrospective cohort study using electronic health records	The Lancet Psychiatry	<ul style="list-style-type: none"> • Our study provides evidence for substantial neurological and psychiatric morbidity in the 6 months after COVID-19 infection. Risks were greatest in, but not limited to, patients who had severe COVID-19. • Among 236379 patients diagnosed with COVID-19, the estimated incidence of a neurological or psychiatric diagnosis in the following 6 months was 33.62% (95% CI 33.17–34.07), with 12.84% (12.36–13.33) receiving their first such diagnosis.
6-Apr-21	Specialized Boston clinics treat long-haul COVID-19 patients	MCVB Boston	<ul style="list-style-type: none"> • Tufts, Beth Israel Medical Center, and ICU Recovery Center now treating long-haulers. Mentions improvement after vaccine."
5-Apr-21	For COVID-19 Long-Haulers, Few Answers, But Meditation and Peer Support Offer Some Relief	UCSF	<ul style="list-style-type: none"> • "Two UC San Francisco clinicians from complimentary specialties have teamed up to create an integrative medicine skills program that can give such patients better tools to cope with the debilitating symptoms. The clinicians added cognitive behavioral therapy to create a low-cost, low-risk program to help patients manage stress and anxiety. They completed the first run of the three-week program in December 2020, with a group of 10 patients." • Repeats 10-30% figure.
5-Apr-21	New Long Covid Treatments Borrow From Brain Rehab Tactics	WSJ	<ul style="list-style-type: none"> • "Patients report short-term memory problems, slow processing speeds, poor word recall and difficulty multitasking. To help them, doctors at medical centers including Mayo Clinic, Yale and Johns Hopkins are starting to refer some patients to cognitive rehabilitation more typically used for patients with concussions and other traumatic brain injuries. "Even if the mechanism causing symptoms is different, the problems are often the same," says Thomas Bergquist, a clinical neuropsychologist who focuses on neurocognitive disorders at Mayo's brain rehabilitation clinic. • "Discusses successes in various clinics at Mayo Clinic, Yale, and Johns Hopkins. There are references to previously tracked studies on the neurological effects of COVID-19."
5-Apr-21	COVID: Vaccine A Shot Of Relief For Many Suffering With Mysterious 'Long-Haul Syndrome'	CBS Local SF	<ul style="list-style-type: none"> • Repeats 10-30% figure. • "In a recent poll, among 900 long-haulers who got COVID-19 vaccinations were asked what happened in the aftermath. Fourteen percent felt worse, 45 percent felt no difference, but 40 percent felt better, citing a slight relief or alleviation of symptoms, all the way to a complete resolution of problems." • o Dr. Anne Liu. Dr. Liu told KPIX 5 some long-haulers who are treated at Stanford are reporting the same benefit. Dr. John Swartzberg, an infectious disease public health expert at UC Berkeley said this phenomenon requires rigorously produced scientific evidence."

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2-Apr-21	Some COVID long-haulers reporting relief from lingering symptoms after getting vaccinated	WHTN	<ul style="list-style-type: none"> “The studies are being reported now that show about 30 – 40 percent of the long-haulers feeling better after getting the vaccination,” said Dr. Akiko Iwasaki, Professor of Immunobiology at the Yale School of Medicine. “It’s a very exciting finding.” She did point out not all long-haulers feel better after getting vaccinated. She said about 10 percent report feeling worse and the rest feel the same.”
2-Apr-21	Doctors see progress in fight against long-haul COVID	CBS58	<ul style="list-style-type: none"> Dr. Julie Biller leads the dedicated long-haul COVID clinic at Froedtert and the Medical College of Wisconsin. Shah says a combination of systemic enzyme supplements and probiotics shows promise in reducing symptoms like inflammation, swelling, and coughing. “Ninety-three-point-three percent of patients who were receiving the supplements showed clinical improvement on day ten, versus only 60-percent of patients in the control group,” she said.
1-Apr-21	A year into pandemic, long-haul COVID-19 sufferers still struggle to get care	CBS News Canada	<ul style="list-style-type: none"> “Canada has lagged behind some other countries when it comes to setting up government-funded, specialized long-haul COVID clinics. For example, in December, the U.K. announced it had invested 10 million pounds — or \$17.3 million Cdn — to open more than 60 specialized clinics across the country.” “Much of the information Clark and Mally have been able to gather has come from the COVID Long-Haulers Support Group Canada, launched on Facebook last June by Susie Goulding. The group has grown to more than 12,000 members.” 10-30% figure for PASC”
1-Apr-21	Cracking the long-haul COVID code: How a basic symptom-tracking app may predict monthslong cases	Fierce Biotech	<ul style="list-style-type: none"> Repeats 30% figure “One research team may have solved at least a small piece of the puzzle. They built on a recent analysis of self-reported symptoms in the COVID Symptom Study smartphone app—released in March 2020 by King’s College London, St. Thomas Hospitals and the startup ZOE Global Limited—to develop a simple algorithm that might identify those most likely to contract long COVID.” “Using only age, gender and the number of initial COVID-19 symptoms, the algorithm was able to accurately predict almost 70% of long COVID cases, according to a study published in Nature. It was equally effective at avoiding false positives.”
1-Apr-21	COVID 'long-hauler' symptoms affecting 10-30% get official name	Fox6	<ul style="list-style-type: none"> Common complaints include fatigue, brain fog and shortness of breath. Also seeing an increase in anxiety and depression in post-COVID patients. "It's estimated that between 10 to 30% of people who have had COVID could be in this group with PASC," said Biller.

COVID-19 Patient Recovery Alliance Research Tracker

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1-Apr-21	Mysterious Ailment, Mysterious Relief: Vaccines Help Some COVID Long-Haulers	NPR	<ul style="list-style-type: none"> • “An estimated 10% to 30% of people who get COVID-19 suffer from lingering symptoms of the disease, or what's known as "long COVID.” • "I didn't expect the vaccine to make people feel better," says Akiko Iwasaki, an immunologist at the Yale School of Medicine who's researching long COVID. • "It's all biologically plausible and importantly should be easy to test," says Dr. Steven Deeks of the University of California, San Francisco, who is also studying the long-term impacts of the coronavirus on some patients."
1-Apr-21	Long Covid: 1.1 million people in the UK report having long-term symptoms of coronavirus	MSN	<ul style="list-style-type: none"> • New figures from the Office for National Statistics (ONS) found that of these people, an estimated 697,000 first had coronavirus – or suspected they had it – at least 12 weeks beforehand, while 70,000 first had the virus or suspected they had it at least one year ago. • The 1.1 million people impacted by long Covid excludes people living in communal establishments such as halls of residence, prisons, schools, hospitals, or care homes. • Long Covid was estimated to be adversely affecting the day-to-day lives of 674,000 people, with 196,000 reporting that their ability to undertake day-to-day activities had been limited a lot. • It also found that of a sample of over 20,000 study participants who tested positive for Covid between 26 April 2020 and 6 March 2021, 13.7 per cent continued to experience symptoms for at least 12 weeks.
1-Apr-21	Long COVID: understanding the neurological effects	The Lancet Neurology	<ul style="list-style-type: none"> • Article summarizing Long COVID • “The EANcore NeuroCOVID-19 task force has also created the ENERGY registry to evaluate the prevalence of neurological manifestations in patients with confirmed COVID-19, the findings of which are expected to be published later in 2021. EAN has also established collaborations with several international organizations, including a formal collaboration with the Neurocritical Care Society in the USA.” • One of the NINDS-supported initiatives is the NeuroCOVID Project, which was launched on Jan 26, 2021, by researchers at NYU Langone Health. The project aims to build and maintain an international resource of deidentified clinical data and biospecimens. Recognising the scant understanding of the recovery process after SARS-CoV-2 infection, NINDS is also participating in the National Institutes of Health (NIH) Post-Acute Sequelae of SARS-CoV-2 Infection (PASC) Initiative.