

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 2022			
4/3/2022	How long covid is accelerating a revolution in medical research	The Washington Post	<p>“What is relevant to policymakers and clinicians is not always what is most important for patients,” said Nabil Natafqi, an assistant professor in the department of health services policy at the University of South Carolina’s Arnold School of Public Health. Natafqi said the pandemic has forced researchers to rethink how best to engage patients in research and make it more relevant for them. “[the RECOVER initiative] will be a national treasure once it’s assembled,” said Bruce Levy, principal investigator of one part of the initiative, the Greater Boston COVID Recovery Cohort. “But it’s not really structured for quick answers, that’s for sure.” Berrent believes that long covid will change how research is done going forward. “Once you’ve seen science move at warp speed, you’ll never go back,” she said.</p>
4/5/2022	Fact Sheet: The Biden Administration Accelerates Whole-of-Government Effort to Prevent, Detect, and Treat long-COVID	The White House	<p>The announcement builds on the Administration’s ongoing work to implement the recommendations of the Presidential COVID-19 Health Equity Task Force. It also builds on a number of additional actions the Administration is taking to support the millions of Americans experiencing long-COVID and their families by delivering high-quality care and expanding access to services and supports, as well as actions to advance efforts to detect, prevent, and treat long-COVID, including: Delivering high-quality care for individuals experiencing long-COVID, Making services and supports available for individuals experiencing long-COVID, and advancing the nation’s understanding of long-COVID.</p>
4/7/2022	Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK	U.K. Office for National Statistics	<p>An estimated 1.7 million people living in private households in the UK (2.7% of the population) were experiencing self-reported long-COVID as of March 5, 2022. Of people with self-reported long-COVID, 24% first had (or suspected they had) COVID-19 less than 12 weeks previously, 69% at least 12 weeks previously, 45% at least one year previously, and 4% at least two years previously. Long-COVID symptoms adversely affected the day-to-day activities of 1.1 million people (67% of those with self-reported long-COVID), with 19% reporting that their ability to undertake their day-to-day activities had been "limited a lot". Fatigue continued to be the most common symptom reported as part of individuals' experience of long-COVID (51% of those with self-reported long-COVID), followed by shortness of breath (34%), loss of smell (28%), and muscle ache (24%). As a proportion of the UK population, prevalence of self-reported long-COVID was greatest in people aged 35 to 49 years, females, people living in more deprived areas, those working in social care, teaching and education or health care, and those with another activity-limiting health condition or disability.</p>

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4/7/2022	How to prepare for the financial hit of long COVID	Reuters	“People are now realizing that this doesn’t just devastate you physically, it can ruin you financially,” says Diana Berrent, founder of Survivor Corps, the world’s largest COVID grassroots movement with around 200,000 members. According to the 2020 benefits report of the Society for Human Resource Management, 71% of organizations surveyed offer long-term disability coverage, and 62% provide short-term coverage. But since long-COVID is a recent phenomenon with more than 200 potential symptoms and little understanding of its underlying causes, sufferers often run up against roadblocks dealing with health insurance companies and government agencies. And many employers do not offer disability coverage. In addition, growing numbers in the workforce operate on a freelance or short-term contract basis, without access to company benefits. In such cases, it might be worthwhile to secure disability coverage on your own. The wisdom of that goes beyond COVID, since a quarter of Americans will experience disability at some point in their working lives, according to the Social Security Administration.
4/5/2022	Gastrointestinal post-acute COVID-19 syndrome - PMC (nih.gov)	Nature reviews: Gastroenterology & hepatology	Owing to the robust constitutive expression of angiotensin-converting enzyme 2 on the brush border of the small intestinal mucosa, acute COVID-19 is associated with gastrointestinal symptoms such as nausea, vomiting, diarrhea and abdominal pain. In patients with PACS, gastrointestinal-related symptomatology includes loss of appetite, nausea, weight loss, abdominal pain, heartburn, dysphagia, altered bowel motility and irritable bowel syndrome. Emerging evidence demonstrates persistent and aberrant inflammation as well as induction of autoimmunity in a subset of patients with PACS. Viral persistence beyond acute COVID-19 has also been documented within multiple organs, including the gastrointestinal tract and central nervous system. However, conclusive evidence linking viral persistence to PACS has not been demonstrated thus far.
4/10/2022	Long Covid: the invisible public health crisis fuelling labour shortages	Financial Times	“While long-COVID is taking a heavy toll on the individuals affected, it also represents a disaster in the making for businesses and economies – potentially pushing significant numbers of people out of labor markets where employers are already struggling to hire.” 1 in 5 hospitalized COVID patients were still not working 5 months later, according to a UK study. A similar population had changed their job because of health issues. “So far, the scale of the problem is globally unknown...but, in some countries, labor market data give an idea of how long-term health issues grew during the pandemic. In the US, labor force market data show the number of civilians with a disability who are working or seeking work grew by 1.36 million, a 23% increase, from January 2021 to January 2022. 200,000 workers have dropped out of the UK workforce due to long-term illness since the start of the pandemic. “There’s a crunch point coming very, very soon,” says Rayner. She believes the numbers affected will become more visible as businesses ask staff to return to the offices.
4/11/2022	Living With Long Covid 'Is Frustrating,' Says Sen. Kaine	Bloomberg	“I started to talk about it in committee hearings because I wanted folks watching to know there is at least somebody on the dais who believed them – many long-COVID sufferers are not being believed.”

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4/13/2022	When Symptoms Linger for Weeks, Is It Long Covid?	Kaiser Health News	<p>“There could be more to help people understand that it’s not always a quick bounce back right away after the initial infection,” said Dr. Ben Abramoff, director of the Post-COVID Assessment and Recovery Clinic at Penn Medicine in Philadelphia. “This is still a very significant viral infection, and sometimes it’s just a more gradual recovery process than people’s previous viral illnesses.”</p> <p>Failing to treat covid as a serious condition could prolong recovery. Patients should monitor and care for themselves attentively, no matter how mild the infection may seem, Abramoff said. “It’s something that could kill somebody who’s in their 70s,” he said. “It’s not nothing.”</p>
4/16/2022	Global Prevalence of Post COVID-19 Condition or Long COVID: A Meta-Analysis and Systematic Review The Journal of Infectious Diseases	Journal of Infectious Diseases	<p>This study aims to examine the worldwide prevalence of post COVID-19 condition, through a systematic review and meta-analysis. 50 studies were included, and 41 were meta-analyzed. Global estimated pooled prevalence of post COVID-19 condition was 0.43 (43%). Hospitalized and non-hospitalized patients have estimates of 0.54 and 0.34, respectively. Regional prevalence estimates: Asia: 0.51, Europe: 0.44, North America: 0.31. Global prevalence at various intervals: 30 days = 0.37, 60 days = 0.25, 90 days = 0.32, 120 days = 0.49. Fatigue was the most common symptom reported with a prevalence of 0.23, followed by memory problems (0.14)</p>
4/18/2022	Six-month sequelae of post-vaccination SARS-CoV-2 infection: a retrospective cohort study of 10,024 breakthrough infections	Brain, Behavior, and Immunity	<p>N= 10,024 vaccinated individuals with SARS-CoV-2 infection; 9479 were matched to unvaccinated controls. Receiving at least one COVID-19 vaccine dose was associated with a significantly lower risk of respiratory failure, ICU admission, intubation/ventilation, hypoxaemia, oxygen requirement, hypercoagulopathy/venous thromboembolism, seizures, psychotic disorder, and hair loss, but not other outcomes, including long-COVID features, renal disease, mood, anxiety, and sleep disorders. Receiving 2 vaccine doses was associated with lower risks for most outcomes (not long-COVID features). “The absence of a protective effect against long-COVID features is concerning given the high incidence and burden of these sequelae of COVID-19. However, the risk of several individual long-COVID features were significantly associated with prior vaccination (but did not survive correction for multiple comparisons): myalgia (HR 0.78), fatigue (HR 0.89), and pain (HR 0.90), with potentially additional protection after a second dose of the vaccine against abnormal breathing (HR 0.89) and cognitive symptoms (HR 0.87).” “The findings that vaccination against SARS-CoV-2 does not protect against some of the post-acute outcomes of COVID-19 should not obscure the fact that vaccination remains an important protective factor against these outcomes at the population level, since the best way to prevent those outcomes is to prevent SARS-CoV-2 infection in the first place.” “However, these findings highlight that some post-acute outcomes of SARS-CoV-2 (and notably long-COVID presentations) are likely to persist even after successful vaccination of the population, so long as breakthrough infections occur. These findings thus help in determining the necessary service provision. They also underline the urgency to identify other preventive or curative interventions to mitigate the impact of such COVID-19 sequelae.”</p>

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4/18/2022	The case for testing Pfizer's Paxlovid for treating long COVID	Reuters	<p>Reports of two patients who found relief from long COVID after taking Pfizer Inc's antiviral Paxlovid, including a researcher who tested it on herself, provide intriguing evidence for clinical trials to help those suffering from the debilitating condition, experts and advocates say. "This provides really strong evidence that we need to be studying antiviral therapy in this context as soon as possible," said Dr. Steven Deeks, a professor of medicine at the University of California, San Francisco (USSF), and an expert in HIV cure research, adding that he has heard of yet another anecdotal case at UCSF in which a long COVID patient's symptoms cleared after taking Paxlovid. Pfizer spokesman Kit Longley said the company does not have any long COVID studies underway and did not comment on whether it would consider them. There are currently fewer than 20 clinical trials led by individual researchers or small drugmakers testing treatments for long COVID, only a handful of which have moved beyond early stages, a Reuters review found</p>
4/7/2022	Factors Associated with Post-Acute Sequelae of SARS-CoV-2 (PASC) After Diagnosis of Symptomatic COVID-19 in the Inpatient and Outpatient Setting in a Diverse Cohort	Journal of General Internal Medicine	<p>N= 1,038 adults with laboratory-confirmed symptomatic COVID-19 infection. 29.8% developed PASC. The most common persistent symptom was fatigue (31.4%) followed by shortness of breath (15.4%) in hospitalized patients and anosmia (15.9%) in outpatients. Hospitalization for COVID-19 (odds ratio, 1.49), having diabetes (OR, 1.39), and higher BMI (OR, 1.02) were independently associated with PASC. Medicaid compared to commercial insurance (OR, 0.49) and having had an organ transplant (OR 0.44) were inversely associated with PASC. Age, race/ethnicity, Social Vulnerability Index, and baseline functional status were not associated with developing PASC.</p>