Joint Informational Hearing
Senate Health Committee and Special Committee on Pandemic Emergency Response

The Long Haul: Preparing for the Impacts of Long COVID

March 9, 2022—1:00 p.m.—Senate Chamber

Background

The purpose of this hearing is to examine Post COVID Syndrome, its causes and symptoms, how it affects those living with it, California's planning and response activities, and its potential long term impacts.

Overview
On March 11, 2020, The World Health Organization declared SARS-CoV-2, the pathogen which causes the infection known as COVID-19, a global pandemic. On March 13, 2020, COVID-19 was declared a national emergency in the United States, just nine days after Governor Gavin Newsom declared a state of emergency in California in preparation for widespread COVID-19 infections.

COVID-19 is a viral infection that primarily targets the respiratory system, causing symptoms including, but not limited to, coughing, difficulty breathing, body aches, fever, runny nose, exhaustion and fatigue, sore throat, and loss of taste and/or smell. As of March 4, 2022, COVID19.CA.GOV reports 8,399,677 positive cases of COVID-19 and 85,353 deaths in California.

Typically, patients who have contracted COVID-19 begin to experience symptoms four to five days after exposure. For mild cases, which account for 75% to 80% of infections, patients recover within seven to ten days. In more severe cases requiring hospitalization, it can take several weeks for patients to recover. For some patients, symptoms can persist for weeks or even months after recovery from acute illness. These persistent symptoms are known as "Post COVID Syndrome" by the Centers for Disease Control and Prevention (CDC), and also commonly referred to as Long COVID, long-haul COVID or post-COVID conditions.

The CDC defines Long COVID as COVID-19 symptoms which last four or more weeks after the initial COVID-19 infection. The symptoms can include the persistence of previously experienced COVID symptoms (such as fatigue, headaches, trouble breathing, exhaustion), or a range of new, ongoing health problems, including chronic fatigue, brain fog, or cardiovascular and multi-organ effects. Even people who did not have COVID-19 symptoms in the days or weeks after they were infected can have post-COVID conditions.

The exact number of people who develop Long COVID after infection is still unknown, though current estimates suggest 10% to 50% of COVID patients overall may experience persistent symptoms. As the long term effects of COVID-19 infection continue to emerge from ongoing Long COVID research, it will take significantly more time for definitive symptoms and conditions of the disease to be fully understood.

Long COVID Infection Conditions and Symptoms

Ongoing symptoms of Long COVID can include the persistence of previously experienced symptoms (such as fatigue, headaches, trouble breathing, exhaustion), or a range of new, ongoing health problems, including chronic fatigue, brain fog, or cardiovascular and multi-organ effects.

Multi-System Inflammatory Syndrome in Children (MIS-C). Although post-COVID conditions more commonly affect adults, children have also been diagnosed with differing post-COVID conditions, including MIS-C. MIS-C is a rare, but serious, conditions involving the inflammation of one or more organs (including the heart, lungs, kidneys, brain, skin, eyes, or gastrointestinal organs). MIS-C does not affect all children recovering from COVID-19 infection. While children as young as three years old have been diagnosed with the disease, the average age of diagnosis occurs at eight years old.

According to information from the California Department of Public Health (CDPH), there have been 867 cases of MIS-C reported statewide from March 23, 2020 (when tracking began) to February 28, 2022. As with COVID-19 infection and death rates overall, MIS-C affects minority communities disproportionately. Latino children make up 56.3% of the cases of MIS-C in California, despite comprising just 47.7% of the population under 21 years of age in the state. African American children make up 9.6% of MIS-C cases despite making up just 5.6% of the population under 21 in the state, while white children make up 16.3% of cases, but are 29.2% of the population under 21 in the state. *See graph below.*

Race/Ethnicity	Percent of MIS-C Cases in California (%)*	Percent of California Population <21 Years (%)	Percent of MIS-C Cases in U.S. (%)**
Latino	56.3%	47.7%	27.1%
White	16.3%	29.2%	33.0%
African American	9.6%	5.6%	31.8%
Other	8.4%	--	3.5%
Asian	4.2%	12.9%	2.5%
Unknown	4.0%	--	--
Multi-Race	<1.0%	3.8%	<1.0%
Native Hawaiian and Other Pacific Islander	<1.0%	<1.0%	<1.0%
American Indian	<1.0%	<1.0%	<1.0%

[1]

Although most children with COVID-19 recover without any lasting conditions, CDPH reports that MISC-C case numbers tend to rise around three to eight weeks following a surge in COVID-19 cases. As children recover from the Omicron variant responsible for the most recent spike in cases and the surge declines, doctors around the country expect case numbers of MIS-C to rise again in the coming weeks.

Brain fog: Brain fog appears to be one of the most prevalent symptoms for those suffering from Long COVID. One study from the University of California (UC) San Francisco[2] found that 30% to 40% of all COVID patients develop some kind of cognitive symptom. The phrase 'brain fog' can encompass a number of cognitive symptoms that patients can experience, including but not limited to:

- Trouble with memory and finding words;
- Loss of execution function, such as inability to complete targeted tasks;
- Reduced attention span and speed of information processing;

[1] Source: California Department of Public Health, *Multisystem Inflammatory Syndrome in Children (MIS-C) Data.* February 22, 2022. Multisystem Inflammatory Syndrome in Children (MIS-C) Data (ca.gov) .

[2] University of California, San Francisco. *Cerebrospinal Fluid Offers Clues to Post-COVID 'Brain Fog'.* January 22, 2022. Cerebrospinal Fluid Offers Clues to Post-COVID 'Brain Fog' | UC San Francisco (ucsf.edu) .

- Dizziness; and,
- Continual headaches

Patients may experience one or more of these symptoms at the same time. The causes of this specific Long COVID condition are still unclear, though many hypotheses have been proposed, including potential loss of blood flow to the brain during infection, and the over stimulation of immune cells in the brain, which triggers auto-immune disorders. Some patients with brain fog have shown improvement over time, but length of recovery remains unpredictable, as further research is still needed. It appears that a person who has more health risk factors, such as obesity or a compromised immune system, prior to contracting COVID-19 is more likely to experience Long COVID symptoms, such as brain fog.

Strokes and heart/circulatory issues. Another lasting Long COVID condition is dysfunction with the circulatory system, including breathing issues while exercising, irregular heart beating, heart palpitations, or higher risk of stroke and heart attack. According to the American Heart Association, states should expect "a tidal wave of cardiovascular events in the coming years from direct/indirect cases of COVID." Cardiovascular doctors expect a rise in heart problems not only for those who have recovered from COVID or who are dealing with long COVID, but also in those who have suffered tertiary effects of the pandemic, such as loss of work, a decrease in quality of life, inability to exercise, and lack of access to caregivers or assistance.

There are many theories surrounding the causes of cardiac conditions associated with long COVID, but, like many of the possible roots of other long COVID symptoms, none have been directly proven. The National Heart, Lung, and Blood Institute has suggested that the virus could inflict direct harm to heart muscle cells, which die and then weaken the heart, or that infection damages blood vessels through clots/inflammation and subsequent scarring from the healing process stiffens vessels throughout the body. Further research is continuing.

Trouble Breathing and Pulmonary Issues. Another extremely common Long COVID condition is difficulty breathing or shortness of breath. For many people with long COVID, physical tasks that were once easy prior to infection, such as climbing stairs, walking to work, or carrying groceries, now are sources of exhaustion and difficult breathing; sometimes for hours afterward, or even in perpetuity. Breathing exercises and respiratory therapy have been shown to help, but similar to other Long COVID conditions, rate of recovery remains unknown, as more time is needed to study these problems.

Federal and California Efforts

Federal and state partners are working together to learn more about Long COVID and determine the best ways to study Long COVID patients over time. Some of these efforts are highlighted below:

Studies. In December 2020, Congress allocated $1.15 billion to the National Institutes of Health (NIH) to study the long-term health effects of COVID-19 infection. In response, NIH launched the RECOVER (Researching COVID to Enhance Recovery) Initiative to learn why some patients have prolonged symptoms or develop new or returning symptoms after the acute phase of

COVID infection. Studies funded through the Initiative will include adult, pregnant and pediatric populations; enroll patients during different phases of COVID-19 infection; evaluate tissue pathology; and use smartphone apps and wearable devices to gather data in real time. Taken together, the studies are expected to provide insights over the coming months into the incidence and prevalence of Long COVID, the range of symptoms, underlying causes, risk factors, outcomes and potential strategies for treatment and prevention.

As part of the National COVID-19 Preparedness Plan released this month, the federal Agency for Healthcare Research and Quality will propose and seek resources from Congress to launch Centers of Excellence in communities across the country to provide high-quality, high-value care for individuals experiencing Long COVID. These centers will bring together leading researchers and care providers across health systems, health centers, and Long Term Care Facilities to study and promote evidence-based care for children, older adults and high-risk populations.

The Long-term Impact of Infection with Novel Coronavirus (LIINC) Study taking place at UC San Francisco is an observational, prospective study of individuals previously infected with COVID-19 who have recovered from acute illness. The study aims to investigate the clinical consequences of COVID-19 infection, including the pre-existence and development of medical conditions, measures of immune activation and inflammation, changes in immunologic function, and variability in host responses.

Funded by the CDC and headquartered at UC Los Angeles, the INSPIRE (Innovative Support for Patients with SARS-CoV-2 Infections Registry) Study is intended to examine the long term physical and mental effects of COVID-19. Study participants share their personal health information with the study team via online surveys and secured electronic health record data to identify specific themes and patterns in order to improve long-term clinical care for those facing long COVID challenges.

Long COVID Programs. UC operates a Long COVID clinic task force and was among the first partners in the nation to begin addressing the complications of Long COVID, opening some clinics in late 2020. Among them, UC Irvine's outpatient treatment centers provide comprehensive evaluation, referral to specialists, follow-up care, and monitoring throughout patients' recovery. UC Davis operates a Long COVID Clinic comprised of pulmonary care specialists, hospital medicine and emergency medicine teams to provide a centralized comprehensive approach to addressing the needs of patients with ongoing COVID-related symptoms. UC Los Angeles operates a Long COVID Program comprised of teams of multidisciplinary physicians who coordinate care for long COVID patients as well as a Post COVID Psychiatry Clinic, which treats patients with neurological post-COVID symptoms. UC San Francisco's Post COVID-19/Post-Intensive Care Multidisciplinary Clinic provides specialized streamlined care to patients who were hospitalized with COVID-19 or have persistent lingering symptoms.

CDPH is studying post-COVID conditions in Californians through research and partnerships with these academic institutions and is also in the process of creating educational and communication materials for the public on post-COVID conditions.

Additionally Children's Hospital Los Angeles operates a Long COVID Recovery Care Program to provide pediatric infectious disease expertise, a team approach, and access to clinical trials for children experiencing long haul COVID.

Conclusion

The American Academy of Physical Medicine and Rehabilitation estimates that 30% of COVID patients overall suffer lingering symptoms. This means that potentially more than two million Californians are struggling with Long COVID, including higher medical expenses and lost income from reducing their work hours or not being able to work at all due to their illness. While Long COVID qualifies as a disability under the Americans with Disabilities Act, it remains an invisible illness as many patients report that they are often not taken seriously or are told they are making up their symptoms.

According to the Patient Led Research Collaborative, a patient advocacy organization, there are currently fewer than two dozen Long COVID treatment centers throughout the state with patients reporting long waiting lists. Consequently, many patients with Long COVID go untreated or have difficulty accessing treatment. These disparities are even more pronounced in communities of color which have been disproportionately affected by all aspects of the pandemic, including Long COVID.

As California adapts to the next phase of managing the pandemic, the impacts of Long COVID will be felt across multiple systems, including physical and behavioral healthcare, education, employment, and workers compensation, for years to come. It will be critical for stakeholders to collaborate across systems and lean in to chronic disease approaches that emphasize coordinated care, not only for Long COVID patients but for all patients living with chronic illness. Obtaining proper treatment can mean the difference between recovery and ongoing or worsening disease.