

**TESTIMONY**

**OF**

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**DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**BEFORE THE**

**ENERGY AND COMMERCE HEALTH SUBCOMMITTEE**

**U.S. HOUSE OF REPRESENTATIVES**

**The Long Haul: Forging a Path through the Lingering Effects of COVID-19.**

**April 28, 2021**

Chairwoman Eshoo, Ranking Member Guthrie, and distinguished members of the Subcommittee, it is an honor to appear before you today. My name is Dr. John Brooks, and I am CDC's Chief Medical Officer for our COVID-19 Response. I am grateful for this opportunity to discuss post-COVID conditions, including what is called long COVID, and to review the Centers for Disease Control and Prevention's (CDC) efforts to define these conditions, characterize their incidence, identify persons at increased risk, and develop and inform recommendations on their treatment and prevention. As we work to bring this pandemic under control over the months to come, we cannot ignore those who may continue to suffer from post-COVID conditions.

### **CDC's Response to the Coronavirus Pandemic**

CDC is America's health protection agency. We work 24/7 to prevent illness, save lives, and protect America from threats to health, safety, and security. Addressing infectious diseases and pandemics, like COVID-19, is central to our mission. CDC's expertise lies in our ability to study emerging pathogens like SARS-CoV-2, to understand how they are transmitted, and to translate that knowledge into timely public health action. By deploying experts on the ground to support our state, Tribal, local, and territorial partners, we translate science into guidance that protects individuals, communities, and populations. In our work with other federal agencies we ensure the safe and appropriate use of medical countermeasures, including vaccines, and collaborate with the academic sector to further our understanding of new diseases.

The scale of this unprecedented public health emergency requires unprecedented action — at CDC, more than 8,500 CDC personnel have been part of our COVID-19 response, both at CDC headquarters and in the field. More than 1,500 staff have taken part in over 3,000 deployments to nearly 300 cities across the U.S. and around the world.

CDC is working to ensure that public health decisions are based on the highest-quality scientific information. Since the start of the pandemic, nearly 250 COVID-19 studies have been published in the *Morbidity and Mortality Weekly Report* (MMWR) and other publications on a broad range of topics, including on post-COVID conditions and health disparities exacerbated during the pandemic.

COVID-19 has highlighted long-standing systemic health and social inequities. Data repeatedly show the disproportionate impact of COVID-19 on racial and ethnic minority populations, as well as other population groups such as people living in rural or frontier areas, people experiencing homelessness, essential and frontline workers, people with disabilities, people with substance use disorders, people who are incarcerated, and non-U.S.-born persons. While we do not yet have clear data on the impact of post-COVID conditions on racial and ethnic minority populations and other disadvantaged communities, we do believe that they are likely to be disproportionately impacted by these conditions as they are more likely to acquire SARS-CoV-2 and less likely to be able to access health care services. As with all our work, CDC is committed to addressing post-COVID conditions through a lens of health equity.

### **Defining Post-COVID Conditions**

CDC uses the term post-COVID conditions to describe health issues that persist more than four weeks after a person is first infected with SARS-CoV-2, the virus that causes COVID-19. While the exact cause of and risk factors for developing post-COVID conditions are not yet fully understood, these health issues are real and concerning for both the people who have them and their loved ones.

Although most people with COVID-19 get better within weeks of illness, some do not. Even people who are not hospitalized and who have mild illness can experience persistent symptoms or long-term effects. Older patients and those with underlying health conditions are at increased risk for severe disease at the time of infection and later long-term effects from critical illness. However, even people who are young and without underlying health conditions have reported long-lasting symptoms and conditions after initial illness, including those with asymptomatic infection. It's also important to note that there is a wide range of post-COVID conditions, with varying health effects. Additionally, some patients with post-COVID conditions may not have a documented SARS-CoV-2 test result, particularly those who developed COVID-19 early in the pandemic when testing was limited.

Post-COVID conditions are currently being referred to by a wide range of names, including post-acute COVID-19, long-term effects of COVID, long COVID, post-acute COVID syndrome, chronic COVID, long-haul COVID, late sequelae, and others; as well as the research term being used by the National Institutes of Health (NIH): post-acute sequelae of SARS-CoV-2

infection (PASC). Although standardized case definitions are still being developed, in the broadest sense, post-COVID conditions are generally characterized by the development and persistence of new or recurrent symptoms that occur after the acute illness has resolved. On our website, CDC has classified three general types of post-COVID conditions, although the names and classifications may change as we learn more. It's also important to note that these categories are not mutually exclusive. People can have multiple types of long-term health effects following infection with SARS-CoV-2.

The first, called long COVID, involves a range of symptoms that can last for months after first being infected with SARS-CoV-2 or can even first appear weeks after the acute phase of infection has resolved. Long COVID can happen to anyone infected with SARS-CoV-2, even if the illness was mild or entirely asymptomatic. People with long COVID report experiencing varied symptoms, including tiredness or fatigue, abnormal sleep patterns difficulty thinking or concentrating (sometimes referred to as “brain fog”), headache, loss of smell or taste, fast-beating or pounding heart (also known as heart palpitations), chest pain, shortness of breath, cough, joint or muscle pain, depression, anxiety, and fever. The causes of long COVID are still unclear, although there are several hypotheses, including damage to blood vessels, autoimmune effects, and ongoing infection.

Multiorgan effects of COVID-19 are the second type of post-COVID condition as described on CDC's website. COVID-19 can affect and cause long-term damage in multiple body systems including those involving the heart, lung, kidney, and brain. These effects can include conditions that occur shortly after the acute phase of SARS-CoV-2 infection, like multisystem inflammatory syndrome (MIS) and autoimmune conditions. MIS is a condition where different body parts can become inflamed. CDC is studying inflammatory symptoms in both children (called MIS-C) and adults (called MIS-A). COVID-19 illness can also precede the development of autoimmune responses which cause the immune system to attack healthy cells by mistake and damage different parts of the body. Multiorgan effects include reports of neurological conditions, kidney damage or failure, diabetes, cardiovascular damage, and skin conditions.

Finally, post-COVID conditions also include the longer-term effects of COVID-19 treatment or hospitalization. Some of these longer-term effects for those who were hospitalized

are similar to those seen in people hospitalized for other reasons, such as severe respiratory infections caused by other viruses or bacteria. Effects of COVID-19 treatment and hospitalization can also include post-intensive care syndrome, which refers to health effects that remain after a critical illness. Post-intensive care syndrome includes severe weakness, brain dysfunction, and mental health problems like stress disorders. Some of these symptoms can overlap with those observed with long COVID.

Early estimates of the prevalence of post-COVID conditions vary. According to one survey from UK's Office for National Statistics, among people who tested positive for SARS-CoV-2, 21 percent - or about one in five people - reported one or more symptoms at least five weeks after their estimated date of infection, and 14 percent - or about one in seven people - for up to 12 weeks.<sup>1</sup> Existing estimates may change as we continue to define post-COVID conditions, and refine our understanding of the long-term burden. CDC, other federal partners, and researchers are currently gathering evidence on the longevity and severity of these symptoms. Post-acute COVID care clinics are being established at medical centers across the United States, bringing together multidisciplinary teams to provide a comprehensive and coordinated treatment approach to COVID-19 aftercare. While these clinics are a critical resource for those suffering from post-COVID conditions, many people do not have access to them due to geographic location or insurance status. In addition, survivor support groups have developed and are connecting people, providing support, and sharing resources with survivors and others affected by COVID-19.

CDC, NIH, and experts around the world are working to learn more about short- and long-term health effects associated with COVID-19, identify those people who may be at greater risk for post-COVID conditions, understand why these conditions occur, and determine which interventions may help lessen severity or shorten the period of time people suffer from these symptoms. Infection with SARS-CoV-2 is not unique in terms of causing both an acute illness followed by longer-term conditions; some post-COVID conditions are likely to be similar to those seen after other infectious diseases, but others may be more specific to COVID-19. Post-

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<sup>1</sup> UK Office for National Statistics. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 1 April 2021. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1april2021>

COVID conditions may also overlap with complications not related specifically to SARS-CoV-2 infection, making them hard to differentiate and define. Health complications may persist for several months or lead to new diagnoses of clinical conditions. At this time when we are still early in our understanding of COVID-19 and post-COVID conditions, there is no official U.S. guidance on post-COVID conditions, and the management of these conditions can be difficult and complex.

It is important to note that the best way to prevent all the long-term complications of COVID-19 from occurring in more people is by preventing SARS-CoV-2 infection. We must continue to use every tool we have to fight the spread of this virus, including public health prevention measures such as wearing masks, social distancing, and handwashing. Vaccination is a critical, effective, and safe tool to bring this unprecedented pandemic to an end. As of April 25, over 228 million doses of COVID-19 vaccine have been administered in the United States, and over half of American adults had received at least one dose of vaccine. Although media articles have reported that some people with post-COVID conditions say their symptoms improved after being vaccinated, additional studies are needed to determine the effects of vaccination on these conditions.

### **Addressing Post-COVID Conditions**

CDC is actively studying the epidemiology of post-COVID conditions, including the prevalence, duration, and severity of symptoms following acute SARS-CoV-2 infection, as well as risk factors for developing post-COVID conditions. This work will help to establish a more complete understanding of the natural history of SARS-CoV-2 infection and post-COVID conditions, which can inform healthcare strategies, clinical decision-making, and the public health response to this virus. In alignment with CDC's broader mission to improve data collection, CDC is leveraging surveillance systems to monitor for disparities as we continue to learn more about post-COVID conditions.

Starting in July 2020, CDC established long-term prospective studies with external partners that will be critical in learning more about post-COVID conditions. These ongoing studies will follow patients for up to two years and provide information on the percent of persons who develop post-COVID conditions. This will help researchers better characterize post-COVID conditions and symptoms and assess long-term immunological responses to the infection. These

studies include measures to verify COVID-19 illness either through SARS-CoV-2 PCR testing or other evidence of natural infection from serology tests. Symptoms may be reported by study participants directly or captured through review of electronic medical records. These studies will also gather information on new diagnoses across a range of symptoms including neurological, respiratory, cardiovascular, metabolic, kidney, and liver diseases that may result from infection with the virus that causes COVID-19.

To collect data while the prospective studies are underway, CDC is also using multiple de-identified electronic health record (EHR) databases to better understand post-COVID conditions. These databases include PCORnet®, a national research network with EHR data, and Premier®, a national database of inpatient and hospital-based outpatient discharge data. CDC is also partnering with Kaiser Permanente of Georgia to examine healthcare utilization of their patient population after initial infection with SARS-CoV-2. Using these databases, CDC is examining the persistence of symptoms and incidence of post-COVID conditions. CDC is also partnering with health systems to perform in-depth medical record reviews, which can provide more granular detail than is present in large databases. These reviews provide insight into the patterns of health effects that patients are experiencing and will improve our ability to characterize post-COVID conditions.

CDC is also working with multiple partners to conduct online surveys that ask people directly about symptoms that occur more than a month after they were initially diagnosed with COVID-19. These surveys will help to estimate the prevalence of post-COVID conditions among those who have reported SARS-CoV-2 infection. To allow for comparison, some surveys also ask people without reported SARS-CoV-2 infection about the same types of symptoms, since some symptoms of post-COVID conditions also occur in the general population. Given anecdotal reports that in some people symptoms may have improved after vaccination, some surveys will include questions about changes in symptoms following vaccination.

CDC is also working to raise the awareness of post-COVID conditions among patients, clinicians, and health systems through its website, partnerships and other means. To this end, CDC is working on interim guidance for health care providers on long COVID, with a focus on equipping primary care providers with available information on diagnosis and management. Although evidence is still limited, having guidance for front-line providers is critical, since it's

likely that millions of people have been affected, and many will not be able to seek care in dedicated post-COVID clinics. CDC is working actively with national clinical organizations like the American College of Physicians, the American Academy of Family Physicians, the American Academy of Pediatrics, and the American Academy of Physical Medicine and Rehabilitation to solicit feedback that will help ensure this guidance is as informative and helpful as possible.

CDC frequently communicates and collaborates with partners and key organizations on post-COVID conditions, including NIH, the Centers for Medicare & Medicaid Services, the World Health Organization, providers at post-COVID care clinics, clinical organizations, and patient groups such as Body Politic and Survivor Corps. Finally, CDC is disseminating information about post-COVID conditions through multiple other channels, including Clinical Outreach and Communication Activity (COCA) calls targeting healthcare providers, as well as publications on the topic in CDC's *Morbidity and Mortality Weekly Report* (MMWR) and other scientific journals.

## **Challenges**

There are many challenges and unknowns regarding post-COVID conditions. However, CDC understands that patients and the public need information and guidance now. CDC is committed to providing up-to-date and relevant information to address the major long-term health effects from COVID-19 – as the available information and data changes, we will update our guidance to reflect the latest science.

While CDC has established methods of surveillance for MIS-C, surveillance for other post-COVID conditions is not as straightforward given the wide range of non-specific symptoms that can also result from other causes. A key step in establishing surveillance for post-COVID conditions is to better characterize their clinical presentation and develop a standardized case definition. CDC is working to identify potential long-term surveillance possibilities, including leveraging existing systems and research. More data would allow researchers to better determine how common post-COVID conditions are, monitor for disparities, better characterize conditions typical of a case of post-COVID conditions, identify risk factors for developing post-COVID conditions, provide key information to better prevent and treat the condition, and to monitor its impact at a population level.

Other areas where additional targeted studies and further investigation may be beneficial include, but are not necessarily limited to:

- The long-term impact of post-COVID conditions on individuals stratified by age, sex, race or ethnicity, severity of illness, social determinants of health, access to health care and other factors that might indicate who is at greater risk.
- Determining if SARS-CoV-2 variants may cause changes in the epidemiology and severity of post-COVID conditions.
- Determining if vaccination improves or changes severity of post-COVID conditions.
- Determining what proportion of people with post-COVID conditions had similar physical or mental symptoms prior to acquiring SARS-CoV-2.

While CDC and NIH have significant roles to play in this effort, addressing post-COVID conditions is a nationwide effort to be done in partnership with other research organizations, health care providers, patient groups, and across all levels of government.

## **Conclusion**

Given the magnitude of the pandemic, many Americans will continue to suffer from post-COVID conditions, presenting a tremendous burden on the individuals themselves and the health care system. Even after the average number of new cases declines, CDC will continue monitoring and addressing the impact of post-COVID conditions.

CDC is committed to advancing the science around post-COVID conditions and providing corresponding guidance rooted in that science. Additionally, we are committed to improving health equity, including as it relates to post-COVID conditions. CDC efforts to address post-COVID conditions will maintain health equity as a key goal, and CDC is working to collect data on these conditions by race and ethnicity and other demographic features to inform decision-making.

We look forward to working together to address both the immediate challenges of this pandemic and the long-term challenges associated with post-COVID conditions. Thank you again for the invitation to testify today and I look forward to answering your questions.