In the News

Report on Long COVID Urges Actions to Address Needs of Patients, Caregivers

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As part of a broader effort to address the long-term effects of COVID-19, or long COVID, the US Department of Health and Human Services (HHS) has released a new report drawn from the experiences of patients, their caregivers, and clinicians, with recommendations for actions to address these individuals’ concerns.

The Health+ Long COVID report, based on information gathered from workshops and more than 1000 hours of interviews, is intended to “ensure the lived experiences and perspectives of people impacted by Long COVID are integrated into the social, public health, and economic solutions being created to support the Long COVID community,” HHS notes.

The precise number of people in the US who are affected by long COVID is unknown, and estimates vary widely. According to a March 2022 federal government report, findings from US studies suggest that 10% to 30% of people with COVID-19 will develop symptoms that last longer than 4 weeks, with some resulting in significant disability. Based on these estimates, 7.7 million to 23 million people in the US may have developed long COVID as of February 2022.

More recently, according to a Centers for Disease Control and Prevention analysis of data from a US Census Bureau survey administered in June and July 2022, 18% to 19% of US adults who reported having had COVID-19 currently had symptoms of long COVID, defined as symptoms lasting 3 months or longer that were not present before these individuals became ill with COVID-19.

The new report builds on a presidential memorandum issued in April 2022, in which the Biden administration ordered the secretary of HHS to create a national action plan to coordinate research on long COVID and support for patients with the condition. In August 2022, as mandated in the memorandum, HHS released the National Research Action Plan on Long COVID, as well a guide on federal programs, supports, and services that can help individuals with long COVID and their families and caregivers.

The Health+ Long COVID report is intended to complement the findings and recommendations of these previous reports by “broadening the conversation and elevating what is often underrepresented in Long COVID statistics, scientific literature, and policy making—the narratives and expertise of people with Long COVID and what they want and need to live better, healthier lives.” To accomplish this, the 88-page report—commissioned by HHS and produced by Coforma, an independent research firm—is based on human-centered design, a collaborative approach that includes the people affected by a problem as active participants to help craft solutions that address their most urgent concerns.

The report explores how and why the effects of long COVID, which can range from mild to severely debilitating, differ from person to person. It also notes that various social determinants of health influence how profoundly long COVID affects an individual's life. These determinants include where people live (which affects factors such as housing quality, access to transportation, and availability of healthy foods), health care access and quality, economic stability, and insurance status, as well as other factors such as disparities in quality of care associated with a patient’s race, ethnicity, age, gender, or sexual orientation.

Although data on long COVID’s disproportionate effects across different communities is incomplete, the report says, "it is strongly believed that people of color are more likely to be affected by Long COVID, as a result of their increased likelihood to become infected with COVID-19 and lower access to health care." It also notes that long COVID is more common among bisexual and
transgender people because of lower access to health care, as well as stigma related to their gender or sexuality.

Based on information about common experiences shared by patients with long COVID in interviews and workshops, as well as input from caregivers, clinicians, and others, the report offers a number of recommendations. For example, to increase access to disability benefits and assistance programs, the report calls for increasing funding for community-based organizations and programs that can help patients and caregivers apply for such benefits; it also urges health care professionals and others who support and assist people with long COVID to provide referrals to these resources.

Longer-term recommendations include creating Social Security credits for people with long COVID and their caregivers, as well as consolidating—under 1 roof—treatment and professional help for navigating and understanding existing support services.

A common concern expressed by patients with long COVID is long wait times for appointments with clinicians. "A scarcity of medical specialists equipped with knowledge relevant to Long COVID means people with Long COVID often wait for months just to be seen," the report notes. "This is true across the medical field, as well as at Long COVID clinics."

To increase the capacity of health care and assistance programs to offer support to people with long COVID, a system to rate the quality of care at long COVID clinics should be developed and ratings shared with the public, the report says. It also advised improving data tracking for long COVID to better target responses and allocation of resources where they are needed, as well as establishing care managers in clinicians' offices and hospitals to help people with long COVID and their caregivers with scheduling and preparing for appointments and in managing issues with billing and insurance.

Another issue is that many clinicians, especially in the primary care community, "do not have the knowledge base that would enable them to link a constellation of potential symptoms to Long COVID," the report notes. "As a result, instead of being able to provide a diagnosis and initiate a care pathway during an initial appointment, health care providers may send people with Long COVID to a string of other specialists, delaying diagnosis, treatment, and the ability to apply for disability."

To address this issue, the report urges sending clinicians the latest information on findings, testing, and treatments in the form of "Long COVID digests," as well as enlisting academic partners to launch an "expansive outreach campaign" to train clinicians about long COVID and suggested care pathways through in-person and virtual presentations. In the longer term, it advised medical schools to increase training on long COVID and other infection-associated chronic conditions.

Other recommendations, based on experiences reported by patients, are aimed at nonclinicians. For example, the report said that educators and employers should develop and support accommodations that allow people with long COVID to continue to study and work.

The report also stresses that people with long COVID and those who care for them "feel marginalized, misunderstood, and isolated by a general public that is impatient for a return to business as usual." It urged public messaging campaigns in multiple languages and formats to increase the public's literacy and awareness regarding long COVID and said that government agency leaders should be encouraged "to amplify and share that Long COVID is real and a serious public health issue."

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ARTICLE INFORMATION

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