



Long COVID-19 Data Collection at NCHS

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What is long COVID?

- A term with many names - long COVID, long-haul COVID, post-acute COVID-19, post-acute sequelae of SARS CoV-2 infection (PASC), long-term effects of COVID, and chronic COVID
- Wide range of new, returning, or ongoing health problems that are experienced after being infected with the virus that causes COVID-19
- Conditions can last weeks, months, or longer
 - Has been defined at both 3 months after infection and 4 weeks post-infection
- Anyone infected with the virus that causes COVID-19 can experience long COVID

But what is long COVID, really?

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The Atlantic

IDEAS

What Doctors Still Don't Understand About Long COVID

Even mild COVID-19 is at least correlated with a startlingly wide spectrum of seemingly every illness. We need a much better taxonomy to address people's suffering.

By Adam Gaffney

“Doctors and scientists still have much to learn about symptoms that continue—or first turn up—months or weeks after an initial COVID infection. What’s clear today is that long COVID can be many different things.”

“Our next national health disaster”

Perspective

AUGUST 12, 2021

Confronting Our Next National Health Disaster — Long-Haul Covid

Steven Phillips, M.D., M.P.H., and Michelle A. Williams, Sc.D.

Now that more than half of U.S. adults have been vaccinated against SARS-CoV-2, masking and distancing mandates have been relaxed, and Covid-19 cases and deaths are on the de-

cline, there is a palpable sense that life can return to normal. Though most Americans may be able to do so, restoration of normality does not apply to the 10% to 30% of those who are still experiencing debilitating symptoms months after being infected with Covid-19.¹ Unfortunately, current numbers and trends indicate that “long-haul Covid” (or “long Covid”)

control and Prevention (CDC) estimates that more than 114 million Americans had been infected with Covid-19 through March 2021. Factoring in new infections in unvaccinated people, we can conservatively expect more than 15 million cases of long Covid resulting from this pandemic. And though data are still emerging, the average age of patients

care system, in light of the complex and ambiguous clinical presentation and “natural history” of long Covid. There is currently no clearly delineated consensus definition for the condition; indeed, it is easier to describe what it is not than what it is.

Long Covid is not a condition for which there are currently accepted objective diagnostic tests or biomarkers. It is not blood clots, myocarditis, multisystem inflammatory disease, pneumonia, or any number of well-characterized conditions caused by Covid-19. Rather, according to the CDC,

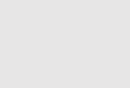
“Long Covid is not a condition for which there are currently accepted objective diagnostic tests or biomarkers”

Measurement challenges... and opportunities

- Given the lack of clinical and diagnostic criteria, how do we measure long COVID?
- NCHS data collection systems may help fill some gaps:
 - National Health Interview Survey and National Health and Nutrition Examination Survey
 - National Vital Statistics Mortality data
 - Collaborating Center for Questionnaire Design, Evaluation, and Research



Panel Presentations



Input for further consideration

- Is there additional information we should examine when considering:
 - Issuing death certificate guidance for long COVID deaths?
 - Implementing the ICD-10 code U09.9 in NVSS cause of death coding?
- What should CCQDER focus on in the upcoming rounds of testing?
- What should be considered as the potential analytic priorities? With the long COVID questions and other related data in our survey, what are the research questions we should address first?
- Given that the characterization of the post-COVID conditions is still evolving, are there areas of Long COVID that you think we are missing and could be added?