

***Session: Information-
Gathering to Inform
Effort to Define Long
COVID***

**A clinician researcher's
perspective**

**For NASEM Committee
on Examining the
Working Definition for
Long COVID**

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Use of a Long COVID definition

- Spectrum of the leading definitions and comment that definition is evolving
CDC, W.H.O., NICE, NIH, USG, etc.
- Considering context
 - Broad/inclusive for patients & clinical & access
 - Precise/granular for research

CDC definition

DEFINITION

Long COVID

*Some people who have been infected with the virus that causes COVID-19 can experience long-term effects from their infection, known as Long COVID or Post-COVID Conditions (PCC). **Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 infection.***

----- other information on CDC website -----

The term post-acute sequelae of SARS CoV-2 infection (**PASC**) is also used to refer to a subset of **Long COVID**.

Long COVID is a wide range of new, returning, or ongoing health problems that people experience after being infected with the virus that causes COVID-19. Most people with COVID-19 get better within a few days to a few weeks after infection, so **at least four weeks after infection is the start of when Long COVID could first be identified.**

WHO definition

DEFINITION

Post COVID-19 condition

*Post COVID-19 condition occurs in individuals with a **history of probable or confirmed SARS CoV-2 infection**, usually **3 months** from the onset of COVID-19 with symptoms and that last for at least 2 months and **cannot be explained by an alternative diagnosis**. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.*

US Government definition

- considerations
 - (-) Requires high health literacy to grasp
 - (+) Broad, inclusive
 - (+) Has chronicity

=== Ideas ===

- **A simple, broad top-level definition**
e.g. “Change in health status after acute COVID-19 infection”
- **Stratified subcategories** under the top-level umbrella, e.g.:
 - by chronicity (subacute 4-12wk vs chronic >3 mo), and/or
 - by known condition vs unknown, and/or
 - by acute COVID probability (W.H.O. definitions), and/or
 - systems (neuro vs cardiopulm vs gastro etc.)
- Recommendations/frameworks for different purposes (clinical, research, disability, etc.)

Signs, symptoms, diagnosis of Long COVID

- **Challenge:** at present no clear symptom, signs, or clinically available tests that easily distinguish Long COVID from other conditions that can lead to those symptoms
- **Misdiagnosis/missed diagnosis of other conditions:** not uncommon for patients who come to Long COVID clinic actually turn out to have something else:
 - thyroid disease, cardiac amyloid, brain tumor, hypercalcemia, sarcoid, ALS, etc.
 - post-vaccine reactions
 - interval events (other infections, injuries, etc.)
- **Long COVID is also misdiagnosed/missed**
 - Misdiagnosed as aging
 - Misdiagnosed as depression
 - Not diagnosed at all
- **Common new onset diagnoses post-COVID we observe**
 - Hypertension, Diabetes, Asthma, Sleep Apnea
 - ME/CFS, POTS

Distinguishing complex factors

- **Complex factors:**
 - Pandemic has greatly impacted people's lives: isolation, lost loved ones, lost jobs, worsened mental health, changed routines, etc.
 - Post-hospitalization: deconditioning, post-ICU syndrome
 - Other situational stressors
 - Stigma and facing dismissive attitudes
- **Considerations for Long COVID and complex factors:**
 - Factors are not mutually exclusive – multifactorial, layered, and interacting
 - Out of proportion to what is expected for this situation / factor? (eg deconditioning)
 - Nature of the symptom different? (eg post-exertional malaise)
- **Accommodations and disability considerations:**
 - Difficult to get disability benefits for Long COVID
 - Broader, simpler definitions likely to be more inclusive

