

2024 NASEM* Long COVID Definition

**A Chronic, Systemic Disease State
with Profound Consequences**

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2024 NASEM Long COVID Definition: Overview

1. NASEM Committee rationale, goals, process
2. Long COVID definition: core & features
3. How this definition can help with diagnosis
4. Current state and future plans

NASEM Long COVID Definition: Key Links

FULL PDF: June 2024

A Long COVID Definition: A Chronic, Systemic Disease State with Profound Consequences

<https://nap.nationalacademies.org/catalog/27768/a-long-covid-definition-a-chronic-systemic-disease-state-with>

Report highlights

https://nap.nationalacademies.org/resource/27768/Long_COVID_Definition_Highlights.pdf

Definition infographic

https://nap.nationalacademies.org/resource/27768/Long_COVID_Definition_infographic.pdf

Definition 1-pager

https://nap.nationalacademies.org/resource/27768/One_pager_Long_COVID_Definition.pdf



2023: Need for a Clear Definition

- Millions of individuals across the globe experienced ongoing, profound symptoms following infection with SARS-CoV-2
- Numerous definitions/ descriptions of Long COVID existed but there were significant differences among them.
- No agreement on a common definition across the US
- Situation challenging for clinical care, research, surveillance, and support services
- **Office of the Assistant Secretary for Health (OASH) & Administration for Strategic Preparedness and Response (ASPR)** asked NASEM for help

Committee Charge: Recommend New LC Definition

- **Phase 1: March – June 2023**

“conduct a series of public workshops to examine the current U.S. government (USG) working definition for LC and related technical terms”

- Learn about challenges and barriers of current definitions
- Seek public input re: refinement, dissemination, and implementation

- **Process:**

- EnSpark Consulting
 - Created online survey for comments (N = 1,181)
 - Conducted focus group with 134 participants
- Held 4 public meetings online to gather info, hear testimony, present/ discuss findings



Committee Charge: Recommend new LC definition

- **Phase 2: October 2023 – June 2024**

“integrate and synthesize information from...engagement and information

gathering [to] produce a letter report”

- Review additional evidence
 - Consider already-completed efforts
 - Recommend new definition and technical terms, with circumstances for adoption
-
- **Process:**
 - Outlined definition elements/ issues
 - Conducted scoping review – 116 papers
 - Examined primary literature where needed
 - Heard expert testimony
 - Met multiple times for deliberations

What Constitutes a Definition for a Disease?

- No published, standardized guidelines for the development of disease definitions.
- The committee articulated several possible key elements of a disease definition.

Element	Description
Attribution	Source responsible for causing the disease
Time	Onset of disease
Clinical Features	Symptoms, symptom course and duration, and symptom severity of the disease to be defined
Equity	Identify persons affected and consider equity implications
Functional Impairment	Effect of the disease on daily activities
Exclusions/Alternative Diagnoses	Consideration of alternative diagnoses
Biomarkers and Laboratory Criteria	Objective tests (e.g., blood tests, neuroimaging, cognitive batteries) that help identify the disease
Risk Factors	Characteristics associated with a higher probability of disease or adverse outcome

Foundational Criteria

- **Seven factors:** precision, feasibility, acceptability, accessibility, balancing benefits and harms, potential impact on health equity, and avoiding unintended consequences.
- Intentionally inclusive
 - Incorporate varying presentations
 - Accommodate evolving scientific discoveries & different uses
 - Address impact of social determinants of health on diagnosis

Ultimately, clinical judgement prevails:

“the patient’s treating clinician is best poised to strike the right balance between avoiding a false positive and a false negative classification”

Consistent terminology important

- **Long COVID** – Simple, familiar, descriptive (WHO guidelines), patient-proposed
- **Infection-associated chronic condition (IACC)** –
 - Triggered by viruses, bacteria, fungi, or parasites.
 - Share symptoms, features with already known conditions like ME/CFS, Post-treatment Lyme Disease, Multiple Sclerosis, Q-Fever Syndrome, etc.
 - Makes no assumptions about pathobiological mechanisms.
- **Disease state** – To stress the systemic reality of Long COVID.

2024 NASEM LC Definition: Core

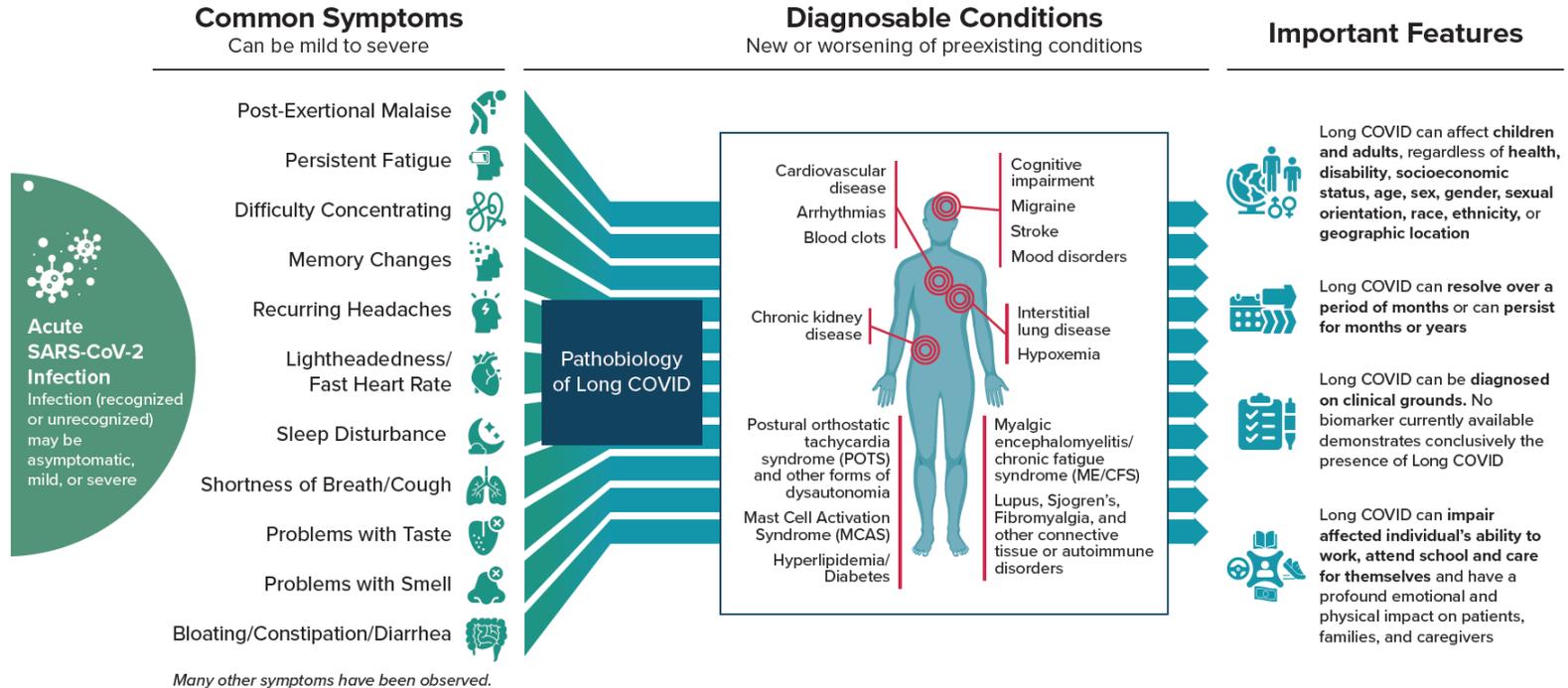
Long COVID (LC) is an infection-associated chronic condition (IACC) that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems.

(Published June 2024)

2024 NASEM LC Definition: Figure & Features

The Disease State of Long COVID

An Infection-Associated Chronic Condition (IACC)



Can be continuous from acute infection or delayed in onset

Diagnosable when symptoms/conditions are intermittently or continuously present for at least 3 months

NASEM publications and in [L Chu et al.; JGIM, March 2025](#)

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LC manifests in multiple ways. A complete enumeration of possible signs, symptoms, and diagnosable conditions of LC would have hundreds of entries.

LC patients can present with...

- **single or multiple symptoms:** shortness of breath, cough, persistent fatigue, post-exertional malaise, difficulty concentrating, memory changes, recurring headache, lightheadedness, fast heart rate, sleep disturbance, problems with taste or smell, bloating, constipation, and diarrhea.
- **single or multiple diagnosable conditions:** interstitial lung disease and hypoxemia, cardiovascular disease and arrhythmias, cognitive impairment, mood disorders, anxiety, migraine, stroke, blood clots, chronic kidney disease, postural orthostatic tachycardia syndrome (POTS) and other forms of dysautonomia, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), mast cell activation syndrome (MCAS), fibromyalgia, connective tissue diseases, hyperlipidemia, diabetes, and autoimmune disorders such as lupus, rheumatoid arthritis, and Sjogren's syndrome.

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Important Features of LC:

- LC can follow asymptomatic, mild, or severe SARS-CoV-2 infection. Previous infections may have been recognized or unrecognized.
- LC can be continuous from the time of acute SARS-CoV-2 infection or can be delayed in onset for weeks or months following what had appeared to be full recovery from acute infection.
- LC can affect children and adults, regardless of health, disability, or socioeconomic status, age, sex, gender, sexual orientation, race, ethnicity, or geographic location.
- LC can exacerbate pre-existing health conditions or present as new conditions.
- LC can range from mild to severe. It can resolve over a period of months or can persist for months or years.
- LC can be diagnosed on clinical grounds. No biomarker currently available demonstrates conclusively the presence of LC.
- LC can impair individuals' ability to work, attend school, take care of family, and care for themselves. It can have a profound emotional and physical impact on patients and their families and caregivers.

How is this Definition Different/ Useful?

- (1) Uses intentional terminology (Long COVID, IACC, disease state)
- (2) Provides explicit but non-exhaustive list of common symptoms
- (3) Duration of at least 3 months required but no restrictions on time of onset, including delayed onset*
- (4) Recognizes different course patterns, including intermittent and worsening
- (5) Establishes that LC is NOT a diagnosis of exclusion by listing common co-existing conditions and diseases
 - If LC+, check for co-morbidities
 - Future LC treatments might help with co-morbidities

[*Thaweethai et al. \(2025\)](#) showed 6% developed LC symptoms 12+ months after acute infection.

Current State and Future Plans

- Definition has been adopted across federal agencies, e.g., [CDC](#), [NIH RECOVER](#))
- Implementation of definition and monitoring of use may be hampered by changes like dissolution of the Secretary's Advisory Committee on Long COVID
- Professional medical organizations adopting and disseminating

- New discoveries might alter definition: definitive test for LC, better understanding of pathophysiology, medium-long-term consequences observed
- Committee suggested revision within 3 years or when significant research progress occurs, whichever time is earlier

Getting diagnosed: Ideas – 1

1. Don't assume healthcare providers hold negative views; maintain neutral attitude
2. Ask: "I'm experiencing....." "My symptoms seem to fit a diagnosis....." "What do you think?" "Have you had patients with.....?"
3. Share brief documents from sources they may trust (NEJM, JGIM, NASEM, etc.)
4. Be open to suggested testing, referrals, treatments = may take time for diagnosis
5. More than one visit might be necessary (marketing rule of sevens)
6. Keep diary of symptoms, activities & share what makes you worse/ better
7. Provide objective data: [NASA Lean Test](#), step count, sleep data, [cerebral blood flow](#)
8. Bring up something positive during the visit

Getting diagnosed: Ideas – 2

1. Bring up ME/CFS with your other current healthcare providers
2. If all providers resistant, seeks professionals who have experience with similar conditions, are open-minded, generally excellent
3. If possible, see a specialist, even for one visit
4. Try treatments that don't need a prescription (pacing, electrolytes/ water, meditation, etc.)

Read others' experiences <https://howtogeton.wordpress.com/diagnose-me-cfs-myalgic-encephalomyelitis-chronic-fatigue-syndrome/>

Robert Cialdini's "Science of Persuasion": <https://www.youtube.com/watch?v=kv0sOX6Alrk>

How the Definition is Different/ Helpful - 1

Table 1. Components of Long Covid Definitions.*

Elements of Disease Definition	U.S. CDC, 2020 ¹¹	U.K. NICE, 2020 ¹²	U.S. OASH, 2022 ¹³	WHO Adults, 2022 ¹⁴	WHO Children, 2022 ¹⁵	U.S. RECOVER, 2023 ¹⁶	NASEM, 2024 ⁵
Classification							
Uses the term "long Covid"	Yes	No	Yes	No	No	No	Yes
Describes long Covid as a disease state	No	No	No	No	No	No	Yes
Places long Covid among infection-associated chronic conditions	No	No	No	No	No	No	Yes
Attribution to infection							
Allows inclusion of asymptomatic, mild, or severe acute SARS-CoV-2	Yes	No	No	No	No	Yes	Yes
Requires proof of confirmed or probable infection or requirement of SARS-CoV-2 test	No	No	No	Yes	Yes	No	No
Timing							
States symptoms or conditions present for at least 3 mo	No	Yes	No	No	No	Yes	Yes
Indicates continuous or delayed onset of symptoms or conditions	Yes	Yes	Yes	Yes	Yes	Yes	Yes

[Ely et al., NEJM, 2024.](#)

How the Definition is Different/ Helpful - 2

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Clinical features							
Indicates long Covid is a single or multiple organ disease state	No	Yes	Yes	No	No	Yes	Yes
Includes new clinical features or exacerbation of preexisting features	No	No	No	Yes	Yes	No	Yes
Mentions severity of symptoms	No	No	Yes	No	No	Yes	Yes
Describes continuous, relapsing–remitting, or progressive nature of symptoms	No	Yes	Yes	Yes	Yes	Yes	Yes
Includes language on recovery timeline (can resolve or persist for months to years)	No	No	No	No	No	Yes	Yes
Patient-oriented features							
Includes equity language	No	Yes	No	No	No	No	Yes
Highlights effect on daily functioning	No	No	No	Yes	Yes	Yes	Yes
Incorporates alternative diagnoses	No	No	No	No	Yes	No	Yes
Indicates that diagnosis is a clinical judgment due to absence of proven biomarkers	No	No	Yes	No	No	No	Yes
Includes risk factors	No	No	Yes	No	No	No	No†