



# Identifying Long COVID Deaths using Death Certificate Literal Text from the National Vital Statistics System

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# Post-Acute Sequelae of COVID-19 (PASC)

- Commonly referred to as “long COVID”
- Definition: Long-term symptoms experienced after an individual has recovered from acute infection with SARS CoV-2, the virus that causes COVID-19


# Long COVID Deaths in the U.S.

- No estimates on the number of long COVID deaths are currently available
- Challenges:
  - Evolving diagnosis guidelines
  - Changing terminology
  - No standardized guidance for listing long COVID as a “cause of death” on death certificate
  - Currently, no cause-of-death code for long COVID in the U.S.

# Cause-of-Death Coding

- National Vital Statistics System (NVSS) codes death certificate data according to *International Classification of Diseases, Tenth Revision (ICD-10)*
- ICD-10 code **U09.9**
  - For coding and reporting of post-COVID conditions linked with preceding acute COVID-19
  - Approved by World Health Organization in September 2020
  - Not yet adopted by NVSS for mortality coding in the U.S.

# Why doesn't NVSS use the ICD-10 code U09.9?

- Steps for implementing a new ICD-10 code
    - Develop coding guidelines and training for manual (human) coders
    - Develop coding logic for automated coding systems
    - Update downstream data systems to recognize new ICD-10 code
  - Need exploratory analysis to understand
    - What literal text terms are most commonly used
    - How often are the terms found in text
-  **This knowledge will inform how coding systems are updated once the new code is implemented.**

# Exploratory analysis

- Goal: Quantify long COVID in death certificates using literal text
- Methods:
  1. Identify a list of key terms
  2. Use key terms to identify death certificates with long COVID
  3. Quantify and summarize deaths

# Literal text key terms

- Conducted literary search, including CDC's clinical guidance for PASC
- Consulted with subject matter experts from CDC's COVID-19 Response

## Terms included in analysis:

- |                       |  |
|-----------------------|--|
| ▪ Long COVID          | ▪ PASC                                     |
| ▪ Long haul COVID     | ▪ Post-acute sequelae of COVID-19          |
| ▪ Long hauler COVID   | ▪ Post-acute sequelae SARS-cov-2 infection |
| ▪ Post COVID          |  |
| ▪ Post COVID syndrome |  |

# Data considerations

- Limit to deaths with COVID-19 (coded as U07.1) as a contributing or underlying cause
- Data completeness
  - Limit general study period: January 1, 2020 through June 30, 2022
- Compute crude and age-adjusted rates
  - 12-month period: July 1, 2021 through June 30, 2022
  - For rates by age, sex, and race/ethnicity



# Next steps to consider

- Summarize and publish results in Vital Statistics Rapid Release Report
- Potential future steps
  - Update analysis with more recent data
  - Refine key terms if necessary
- For consideration
  - Certification guidance to promote consistent and accurate reporting of long COVID on death certificates.
  - Implementation of the ICD-10 code U09.9 for cause of death coding.

# Questions to the BSC

- Is there additional information we should examine when considering:
  - Issuing death certificate guidance for long COVID deaths?
  - Implement the ICD-10 code U09.9 in NVSS cause of death coding?

For more information, contact CDC  
1-800-CDC-INFO (232-4636)  
TTY: 1-888-232-6348 [www.cdc.gov](http://www.cdc.gov)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

