# New CDC Data Identify More Than 5,000 Long COVID Deaths

However, experts say this tally is likely a substantial undercount.

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Last week, the Centers for Disease Control and Prevention (CDC) released new data on deaths caused by long COVID, reporting that more than 5,000 Americans have died from this disease since 2020. The new data release coincided with the death of former U.K. Labour Party lobbyist Derek Draper from long COVID-related complications [on January 5].

The CDC's numbers most likely represent significant undercounts of long COVID-related deaths, experts say, highlighting a need for better reporting standards and education for the people who fill out death certificates.

To identify long COVID deaths, researchers at the CDC's National Center for Health Statistics (NCHS) searched through death certificates that mention "long COVID," the medical term "postacute sequelae of SARS-CoV-2 infection" (PASC), or related terms such as "post COVID" and "chronic COVID." NCHS published its first tally of these deaths in December 2022, then shared an updated count via an article at Medscape.

While NCHS has not yet published comprehensive data from its January 2024 update yet, the numbers shared with Medscape suggest that more long COVID deaths were identified in 2023 compared with prior years. The CDC researchers counted 1,491 deaths in 2023, compared to 3,544 deaths between January and June 2022; the agency's prior report similarly identified more deaths in 2022 than in 2020 and 2021. This increase could be attributed to worsening symptoms over time for some people with Long Covid, combined with increasing recognition of the disease among healthcare workers.

Recognition of long COVID is key for accurate death data, my colleagues and I at MuckRock found when reporting on NCHS's initial tally in 2022. When a person with long COVID dies, their death certificate may be filled out by an expert physician who's familiar with the disease and its potentially debilitating symptoms — or by a locally-elected coroner who has never heard of long COVID. Medical education is incredibly varied among people who fill out death certificates, and this variability has contributed to undercounting of COVID-19 deaths, according to MuckRock's reporting.

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For long COVID, still poorly understood by many in the medical community, the potential for undercounting is magnified. The NCHS's 2022 death tally included primarily older adults, who may be more likely to have comprehensive medical records detailing long-term symptoms compared to younger adults who had mild initial cases of COVID-19, experts told MuckRock.
People of color, those with lower incomes, and others with marginalized identities may be similarly less likely to have medical documentation of long COVID symptoms, leading to inaccurate death certificates if they pass away. Counts based on death certificates also tend to leave out deaths from suicide, despite evidence that people with long COVID are at higher risk for suicide and deaths of prominent community members.

To improve data on deaths from long COVID, the CDC issued guidance in February 2023 explaining how to report the disease on death certificates. People filling out these certificates should "consider that the death was due to long-term complications of COVID-19, even if the original infection occurred months or years before death," the guidance states. It's unclear how the CDC and other public agencies have actually publicized this guidance or improved medical education on long COVID; we hope to report on this topic further at The Sick Times.

Despite the significant flaws in the CDC's data, last week's updated count is still significant as an acknowledgment that long COVID can lead to death. Sharing the Medscape article on Twitter, former Biden COVID-19 advisor Dr. Zeke Emanuel wrote, "We need more data like these to raise

awareness and find ways to help those suffering now and in the future.”

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