CSTE Revised COVID-19-associated Death Classification Guidance for Public Health Surveillance Programs

Version 2 (updated 11.22.22)

Executive Summary

In the current phase of the COVID-19 pandemic, it is essential for state, territorial, local, and tribal health departments (STLT) to continue to accurately count mortality associated with COVID-19, including tracking which populations are bearing the highest burden. The revised COVID-19-associated death classification is intended to provide useful and comparable data for public health classification of COVID-19-associated deaths through a more sustainable and consistent approach, using readily available data without depending on collecting additional information from case investigations. As such, death certificates should serve as the primary source for identifying and classifying mortality associated with COVID-19. This approach should be augmented by case investigation data, when available, and enhanced surveillance and special studies for COVID-19-associated mortality in sentinel sites with requisite resources.

Background

This guidance was developed by the Council of State and Territorial Epidemiologists (CSTE) with input from members and in collaboration with the Centers for Disease Control and Prevention (CDC). The guidance provides a revised consensus-based COVID-19-associated death classification, updating the prior document titled "Interim Guidance for Public Health Surveillance Programs for Classification of COVID-19-associated Deaths among COVID-19 Cases" (posted December 22, 2021). The prior classification included COVID-19-associated deaths identified through case investigation of confirmed and probable COVID-19 cases, deaths that occurred within 30 days of specimen collection of a laboratory test used to define the case (and the death was due to natural causes), and deaths identified only on vital records that lists COVID-19 or an equivalent term as an underlying or contributing cause of death without laboratory evidence.

Throughout the pandemic, to provide timely information on COVID-19-associated deaths, STLTs developed surveillance systems to rapidly generate mortality data including case investigation data, mortality reporting systems, and through matching SARS-CoV-2 infection electronic laboratory reporting case surveillance with temporally associated death data from vital statistics. These data have often been generated, posted publicly, and reported to CDC prior to the availability and posting of CDC National Center for Health Statistics' (NCHS) National Vital Statistics System (NVSS) official data.

Since the prior classification document was produced, several changes in the evolution of the SARS-CoV-2 virus and the COVID-19 pandemic response have occurred. These changes include:

• Circulation of the Omicron variant and its subvariants with growth advantage, increased transmissibility, and resultant high levels of community spread. These high levels of community spread, in conjunction with high population rates of immunity from prior infection and

vaccination, and ability of the virus to cause asymptomatic infection, led to increased numbers of incidental findings of SARS-CoV-2 positivity in those who may have died from another cause.

- A marked increase in the use of at-home rapid over-the-counter SARS-CoV-2 tests generally not reported to public health.
- STLTs have transitioned away from universal case investigation and contact tracing¹, which has limited the availability of case investigation data for mortality surveillance.
- STLTs have transitioned to a less frequent reporting cadence (e.g., daily to weekly) and the <u>CSTE</u> <u>Update to the Standardized Surveillance Case Definition and National Notification for SARS-CoV-</u> <u>2 Infection</u> recommends case surveillance transition to a routinely notifiable approach. These changes are reflective of a shift to a more sustainable and efficient approach to surveillance.
- Many jurisdictions have made improvements and advancements over the course of the pandemic in access to vital records and data sharing including access to provisional² death certificate data and implementation and advancement of electronic death registries, allowing for more timely availability of vital records data.
- The Interim CSTE and Association of Public Health Laboratories (APHL) Strategic Framework for SARS-CoV-2 Infection and COVID-19 Surveillance: Priorities and Approaches for State, Territorial, Local, and Tribal Public Health Agencies emphasizes the importance of the sustainability and flexibility of surveillance approaches for the current phase of the COVID-19 pandemic response which should be achieved by building on existing capabilities and shifting away from metrics dependent primarily on universal individual case investigations. The framework highlights five surveillance priority goals, including evaluating the severity of COVID-19 through tracking COVID-19-associated deaths.

This revised guidance is intended for STLTs preparing reports for situational awareness and public health response. It is not intended for use by physicians or other healthcare providers assigning causes of death on death certificates. Standard guidance on how to report COVID-19 on death certificates has been made available throughout the pandemic and is available at the <u>CDC NCHS Reporting and Coding Deaths</u> <u>Due to COVID-19</u>.

Data Sources Available to Health Departments for Identification and Classification of COVID-19-associated Deaths

Throughout the pandemic response, public health agencies have used information from laboratory and healthcare provider reports, healthcare facility and long-term care facility (LTCF) reports, public health case investigations, and death certificates to perform surveillance for COVID-19-associated deaths. Vital

¹ Joint Statement on Public Health Agencies Transitioning Away from Universal Case Investigation and Contact Tracing for Individual Cases of COVID-19 (January 24, 2022).

² Provisional data, which are based on death certificate data received but not fully reviewed by NCHS, provide an early estimate of deaths before the release of final data. While sometimes referred to colloquially as preliminary data, the term provisional data is preferred as these data are constantly undergoing revisions and updates to improve accuracy based on review by NCHS, receipt of additional information, and other correction efforts. Provisional death data provide actionable information sooner than do the final mortality data. <u>Ahmad FB, et al.</u> <u>Provisional Mortality Data - United States, 2021. CDC MMWR. April 29, 2022; 71(17);597-600.</u>

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registries and the NCHS compile official data regarding causes of death for all deaths, based on information entered on death certificates. This information comes from healthcare providers, medical examiners, and coroners. Provisional and final death certificate data, including for deaths where COVID-19 or an equivalent term is listed as a cause of or contributor to death, are available at <u>CDC NCHS</u> <u>COVID-19 Death Data and Resources</u>.

These NCHS statistics will not include or count deaths as COVID-19-associated if COVID-19 is not indicated as a cause of or contributor to death on the death certificate. There may also be deaths included in the official NCHS or vital registry statistics that are not due to COVID-19 but where COVID-19 is entered on the death certificate.

Death certificate cause of death data can take several weeks to become available after the death; however, this varies by jurisdiction. Electronic death registries can provide more timely access to these data; however, there is variability by jurisdiction in how the systems are implemented (e.g., participation is voluntary in some jurisdictions) and timeliness of death certificate data submission to NCHS. Provisional death certificate data may provide more timely information, where available within jurisdictions and COVID-19 surveillance programs, although access and timeliness vary by jurisdiction. A best practice includes granting communicable disease surveillance staff access to daily provisional death certificate data. This provides mortality data in approximately one week's time (dependent on the frequency of provisional data access, timeliness of death certificate submission, staff availability, and other jurisdictional factors). Frequency of death certificate data transmission to NCHS, where data are then automatically coded and reviewed, is variable among jurisdictions, affecting timeliness of access to ICD-10 coding data. Therefore, ideally, jurisdictions require access to provisional (not yet completely NCHS coded) data to identify and classify COVID-19-associated deaths through both keyword searches and searches of automatically coded data in order to provide weekly COVID-19-associated mortality data.

Revised COVID-19-associated death classification³

The death certificate indicates COVID-19 or an equivalent term as an immediate, underlying, or contributing cause of death.

OR

A case investigation for a <u>confirmed, probable, or suspect SARS-CoV-2 infection case</u>⁴ determined that COVID-19 was the cause of death or contributed to the death⁵

The <u>CSTE 2022 Update to the Standardized Surveillance Case Definition and National Notification for</u> <u>SARS-CoV-2 Infection</u> classifies a case as suspect if vital records criteria are met without confirmatory or

³See appendix for operational considerations for STLT implementation of this classification.

⁴ See <u>CSTE's Update to the Standardized Surveillance Case Definition and National Notification for SARS-CoV-2</u> Infection.

⁵ For jurisdictions where case investigation information is available based on local priorities and resources.

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presumptive laboratory evidence for SARS-CoV-2. Typically, STLTs do not report suspect cases publicly or to CDC. However, this revised COVID-19-associated death classification would count deaths where a death certificate indicates COVID-19, or an equivalent term, as a cause of or contributor to death, even if there were no presumptive or confirmatory laboratory evidence for SARS-CoV-2. This means that an individual who may not be reported publicly as a SARS-CoV-2 infection case will be counted as a COVID-19-associated death if identified and classified through the death certificate only (without confirmatory or presumptive laboratory evidence). The reason for this difference is the recognition of the importance of counting all COVID-19-associated deaths, including deaths that may occur after an at-home over the counter antigen SARS-CoV-2 result, if COVID-19 is felt to be a cause of or contributor to death by the healthcare provider certifying the death. Current applied public health data suggest that these numbers of deaths identified through death certificates only, without accompanying confirmatory or presumptive laboratory evidence, are a low percentage of the total. However, as at-home testing has become more available, it is possible this will be a larger proportion moving forward and, nonetheless, these deaths are important to count. Given these different approaches and definitions, it is important that these two different sets of data are not used to determine case fatality rates. Some STLTs may choose to publicly display total deaths and also specify the number of non-laboratory-confirmed COVID-19-associated deaths (those that are identified and classified by death certificate only).

To provide a clearer epidemiologic picture of COVID-19-associated mortality, COVID-19-associated deaths should be counted by date of death on the death certificate, rather than date of report. Additionally, COVID-19-associated deaths should be counted by jurisdiction of the decedent's residence, rather than the location of the death. COVID-19-associated mortality data should be updated over time, as data become available for residents who have died in other jurisdictions.

To implement this approach to COVID-19-associated death classification, STLTs must have timely access to vital records with an appropriate data sharing agreement, including provisional death certificate data. Jurisdictions which have implemented widely adopted electronic death registries will have more timely access to vital records data. In jurisdictions where this is not currently available, or with inadequate staff to implement it, this classification may provide less timely COVID-19-associated death data and alternative methods of classifying COVID-19-associated deaths may be needed.

This COVID-19-associated death classification is intended to provide useful and comparable data across jurisdictions with sustainable public health approaches given current resources. The classification attempts to balance the need for the highest level of accuracy with the realities of limited public health resources and is meant primarily for surveillance purposes and for providing data for tracking trends and performing epidemiologic analyses. While the definition aims to be as accurate as possible, it will not classify deaths correctly 100% of the time. These approaches will not count deaths as COVID-19-associated if COVID-19 is not documented on the death certificate nor reported to the public health authority, where resources are available for mortality-related case investigations.

While this classification includes COVID-19 (or an equivalent term) as either a cause of or contributor to death on the death certificate, at times, STLTs or NCHS may evaluate the data by either the cause of or the contributor to death.

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The numbers of COVID-19-associated deaths identified through this standardized classification may be different than the number of COVID-19-associated deaths compiled previously by STLTs or as reported by vital registries or NCHS. Reasons for the differences in counts may include differing definitions as well as the sources of information for the data, classification of deaths by residence of the decedent versus location of the death, and/or timeliness of accrual of data. Multiple sources provide useful information on COVID-19-associated mortality, and valid conclusions can be drawn based on trends or analyses of data offered by each system. It should be recognized that provisional death data will change over time with receipt of additional information, NCHS review, and other corrections to improve accuracy. Additional, data, including excess deaths can be useful as they are not sensitive to testing practices or classification processes, and should be considered as complementary measures which can help to assess mortality associated with SARS-CoV-2.

Special Populations

This classification should be evaluated over time to assess the accuracy for specific sub-populations of public health concern with regard to health equity (race, ethnicity, location of residence), those who died at home, mortality in LTCFs, and pediatric-aged patients. Additional efforts may be required over time to augment COVID-19-associated death data for these special populations. Additional data, including excess deaths, should be considered as complementary measures which can help to assess mortality associated with SARS-CoV-2.

People with post-COVID-19 conditions (PCC) (also known as 'Long COVID') may have a wide range of symptoms that can last more than four weeks or even months after SARS-CoV-2 infection. The precise contribution of PCC to COVID-19-associated mortality is not yet fully elucidated. The sensitivity and specificity of this classification to identify individuals who had PCC and a COVID-19-associated mortality is unknown, although individuals who met criteria for PCC would likely be included within this classification of COVID-19-associated mortality. The complexity of identifying the condition through public health data and its contribution to COVID-19-associated mortality are important areas which require further study through clinical research, patient registries, sentinel site enhanced surveillance networks, and EHR evaluations, among other approaches, which will require ongoing funding and support.

Enhanced and Sentinel Surveillance

Enhanced surveillance and special studies are needed to augment core mortality data to collect detailed data on risk factors, vaccine effectiveness, disparities, variant severity, PCC, and other factors associated with COVID-19-associated mortality. These evaluations can be performed in enhanced surveillance networks such as the <u>COVID-19-Associated Hospitalization Surveillance Network (COVID-NET</u>). Future funding is critical to support additional enhanced surveillance activities nationally and to expand the breadth and depth of COVID-NET, including supporting additional sites to enhance representativeness of findings, improve response to emerging variants, and provide resources for additional evaluations. Such sentinel findings can provide more robust and accurate data and, if representative, may be extrapolated to form national estimates.

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Conclusion

This classification may need to be reevaluated as new variants emerge with different epidemiologic and clinical characteristics and given the evolution of surveillance methodologies, testing strategies over time, and changes in jurisdictional vital records practices. Additionally, as COVID-19 continues to affect the U.S., a more holistic approach to surveillance for mortality of respiratory viral pathogens, including but not limited to COVID-19-associated and influenza-associated mortality, will be needed.

Beyond a standardized classification, a long-term goal of well-resourced, timely, consistent, and standardized methods for data collection and processing of COVID-19-associated mortality surveillance and vital records data across jurisdictions would further improve accuracy and comparability of data. To implement these surveillance goals and methods nationally, sustained and increased investments are needed for data modernization of public health surveillance systems. These include improvements to electronic death certificate systems; increased access to provisional death certificate data; automated death certificate data transmission to NCHS for rapid coding and review, and interoperability between jurisdictions, between coroner/medical examiners and STLTs, between STLTs and CDC, between surveillance systems, and importantly, with case surveillance systems. In addition, investment in the public health workforce that collect and generate data is needed at the federal and STLT levels and is essential for streamlined, accurate, and effective surveillance of COVID-19-associated deaths, as well as future emerging infectious disease threats.

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Appendix: Operational Considerations

The following factors may be considered in STLT public health surveillance program implementation of the CSTE COVID-19-associated death classification guidance. Each jurisdiction will consider these factors in their approach to COVID-19 mortality surveillance depending on their jurisdictional needs, vital records practices in their jurisdictions, and available data and resources. Not all considerations below may be needed or possible in every jurisdiction and some jurisdictions may incorporate multiple considerations below to enhance their jurisdictional COVID-19-associated mortality surveillance. Where public health agencies have information in addition to the criteria presented below, they should exercise professional judgment about whether to include a death in COVID-19 surveillance counts.

Implementation considerations:

- For jurisdictions that are able and where data are available, a case should be counted as a COVID-19-associated death if a case investigation for a confirmed, probable, or suspect SARS-CoV-2 infection case⁶ determined that COVID-19 was the cause of or contributor to death. The case may be counted as a COVID-19-associated death, even if not identified and counted via death certificate data.
- Alternatively, where data are available and jurisdictions are able, if a case investigation for a confirmed, probable, or suspect SARS-CoV-2 infection case⁴ clearly determined that COVID-19 was not a cause of contributor to death, or an alternate cause of death is identified, jurisdictions may opt to not count the case as a COVID-19-associated death, even if death certificate data initially identified the case as a COVID-19-associated death.
- STLTs may consider not classifying deaths as COVID-19-associated when attributed to non-natural causes on death registries (e.g., gunshot injury, motor vehicle accident).
- STLTs may consider mechanisms to improve ascertainment of at-home and LTCF COVID-19associated deaths which may be more likely to be missed by death certificate data alone. Efforts to address this concern may include increased enforcement of existing reporting requirements for LTCFs and improved education and enhanced relationships and with medical examiners and coroners.
- When there is a notation of 'history of COVID-19' on the death certificate or other wording
 indicating that COVID-19 was not a recent event, jurisdictions may consider whether to include
 these as a COVID-19-associated death depending on vital records practices in their jurisdictions,
 STLT data, where available, and depending on whether this categorization is believed to be an
 underlying or contributing cause of death. Case investigations or auditing of these scenarios may
 assist STLTs in establishing their preferred approach. Benefits of inclusion include the reliance on
 medical providers and their determination of cause of or contributor to death, inclusion of potential
 mortality-associated with post-COVID-19-conditions (PCC) (also known as 'Long COVID'), simplicity,
 and relatively low volume of these scenarios. Alternatively, in some STLTs these scenarios, upon
 review, may have indicated distant past infection and be unrelated to the cause of or contributor to
 death and may be excluded.

⁶ <u>CSTE's Update to the Standardized Surveillance Case Definition and National Notification for SARS-CoV-2</u> Infection.

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- If and where laboratory data are available and reported to public health, jurisdictions may consider including a 1 year or 6-month timeframe between symptom onset date or the specimen collection date of the positive result on a SARS-CoV-2 laboratory test used to define the case and the date of death on the death certificate listing COVID-19 as a cause of or contributor to death.
 - Each additional limitation may improve specificity of the definition; however, this may occur at the cost of sensitivity, particularly for any mortality associated with PCC.
 - It is important to note that the implementation of these timeframes will be challenging as at-home OTC COVID-19 testing is common and is generally not reported to public health. Of note, applied public health data suggests that at the time of this writing the vast majority of persons who had COVID-19 listed as a cause of or contributor to death on the death certificate, and were cared for during the illness in a hospital or died in the hospital, had an associated positive laboratory result reported to public health.
 - Considerations for time frame limitations, if applied, for the timing between the date of death, when COVID-19 is indicated as a contributor or cause of death on the death certificate, and the date of symptom onset or specimen collection.
 - Cases with "date of death" within 6 months or 1 year of positive specimen collection date
 - "date of symptom onset" or "Investigation start date" used for cases missing specimen collection date
- ICD-10 code searches of death certificate data provide a useful mechanism to ascertain COVID-19associated deaths; however, timeliness in availability of ICD-10 codes will be dependent upon jurisdictional operations and frequency of transmission of death certificate data to NCHS where the data are coded and reviewed. While most records are automatically coded and available to jurisdictions within minutes (currently about 85% of all deaths are automatically coded), records that cannot be coded automatically are queued for manual coding, which can take a week or more. Therefore, to ensure completeness and, in jurisdictions where there are less frequent transmissions to NCHS, key word searches for COVID-19 and equivalent terms are likely necessary.
- Samples of Key Word and ICD-10 Code search terms to use during data extraction from vital records death certificate data include:
 - o ICD-10 Code search
 - ICD-10: U07.1
 - Key Word Search
 - See Table 1 below
 - MIS-C or MIS-A relevant codes may also be considered
 - Other text for consideration
 - "Suspected COVID"
 - "History of" text strings
 - "Hx of COVID" or "History of COVID"
 - Text for consideration of exclusion during key word search
 - " "COVID Exposure", "COVID vaccine", or "Vaccinated for COVID"

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Table 1. COVID-19-associated Death Key Word Search Terms for Provisional Death Certificate Data

Data
2019 COVID
2019 NOVEL CORONA
2019-NOVEL-CORONA
CORONA VIRUS 19
CORONA VIRUS 2
CORONA VIRUS 2019 DISEASE
CORONA VIRUS COVID 19 INFECTION
CORONA VIRUS2
CORONA VIRUS-SARS-2
CORONAVIRUS 19
CORONAVIRUS 2019
CORONA-VIRUS-2
CORONA-VIRUS-DISEASE-2019
CORONA-VIRUS-SARS2
CORONA-VIRUS-SARS-2
COV2
COVID
COVID - 19 VIR
COVID 19
DELTA VARIANT
NCOV
NOVEL CORONA
NOVEL CORONA VIRUS
NOVEL CORONAVIRUS
NOVEL-CORONAVIRUS
SAR 2 COVID 19 INFECTION
SAR 2 COVID INFECTION
SAR COV 2 COVID
SAR COVID 19 INFECTION
SAR COVID INFECTION
SAR COVID VIRUS
SARS 2 CORONAVIRUS
SARS 2 COV
SARS COV 2
SARS COV2 INFECTION
SARS COVID
SARS COVID 19
SARS COVID 2
SARS COVID INFECTION



SARS COVID19 INFECTION
SARS-2-CORONAVIRUS
SARS-2-COV
SARS-CORONAVIRUS-2019
SARSCOV2
SARS-COV-2
SARSCOV2 INFECTION
SARS-COV2 VIRUS
SARS-COV-2019
SARS-COVID
SARS-COVID 19
SARSCOVID INFECTION
SARS-COVID-19
SARSCOVID19 INFECTION
SEVERE ACUTE RESPIRATORY SYNDROME CORONAVIRUS 2019
WUHAN-CORONA