

Death

This document was developed by the Data Standardization Work Group (DSWG) of the Council of State and Territorial Epidemiologists (CSTE) Surveillance Practice and Implementation Subcommittee (SPIS) as a part of a larger data harmonization effort. It will be published and maintained in a repository on the CSTE website.

More information about the DSWG and data harmonization can be found here: [link to DSWG Core Surveillance Project Brief (pending)].

Background

Capturing mortality, or death, data is critical to nationwide public health surveillance in that it allows for analysis of the trends associated with deaths related to cases of reportable disease. Final disease outcomes, such as fatality rates, contribute directly to the development and implementation of prevention strategies and policy. On a practical level, death data is also important because it helps case investigators avoid unnecessary follow-up efforts for patients who have died.

The Generic V2.0.1 (GenV2) Message Mapping Guide (MMG) for sending data to CDC's National Notifiable Diseases Surveillance System (NNDSS) currently includes two mortality-related data elements for case notification for all conditions (Table 1). These data elements intend to capture the instance and date of a patient's death only in cases that the death was related in some way to the notifiable condition. Because these data elements are each intended to communicate two pieces of information, whether the patient is deceased and if the condition contributed to their death, there has been some confusion in the interpretation of the data. For example, if Deceased Date is populated but Subject Died is left empty or marked as "No", it is highly likely that the patient has died; however, it is unclear as to whether the condition led to that death in some way.

Condition-specific MMGs include other data elements (listed in Appendix B) which capture vital status and information related to the cause of death. Some data elements include death as one outcome in a value set which captures other outcomes. Other data elements capture cause of death information including data collected from death certificates.

Table 1. Death Data Elements Currently in the Generic V2.0.1 Message Mapping Guide

Data Element	Description	Value Set
Subject Died	Did the subject die from this illness or complications of this illness?	1. Yes 2. No 3. Unknown
Deceased Date	If the subject died from this illness or complications associated with this illness, indicate the date of death.	N/A – Date

Core Surveillance Death Data Elements for Routine Case Notifications

The data elements below are those that the DSWG agreed to define as core surveillance data for case notifications to CDC. For each of these data elements, there is no pre-defined default value for what

should be transmitted when the data element has not been populated. Refer to Tables 2-4 below for definitions and additional information for each data element. Further details on eCR, ELR, and USCDI as input data sources for death data can be found in Appendix A.

- Patient Deceased
- Date of Death
- Death Associated with Condition

Discussion among DSWG members focused largely on whether or not transmitting a patient's death information should be dependent on whether the death was associated in some way to the condition. Currently "Subject Died" and "Deceased Date" captured in the GenV2 message mapping guide are supposed to be populated only in cases when a death is associated with the condition in question. This has resulted in mixed implementation in jurisdictions and confusion in data analysis and mortality reporting at the federal level. With this in mind, it was determined that a death indicator and date of death information, separate from any implication of association with the condition, are core data elements. In addition to these, an indicator that the death was associated with the condition is also a core data element.

Table 2. Core Surveillance Data Element for Routine CDC Case Notification – Patient Deceased

Patient Deceased	
Definition	Indicator that the patient is deceased
Standard Code for Transmission to CDC	TBD
Value set or coding system	Yes/No/Unknown
Abstracted/ Derived/ Created	Abstracted or Derived
Derived from (examples)	Date of death
Recommendations for Input Data Source(s)	Case investigation ELR eCR Vital Records
Notes	N/A
Data Source Details*	
eCR CDA	CDA extension sdtc:deceasedInd is used to record that the recordTarget is deceased. CDA mapping: ClinicalDocument/recordTarget/patientRole/patient
eCR FHIR	Patient.deceasedBoolean Boolean (True/False) value indicates whether or not the individual is deceased
ELR	HL7 v2: Patient Death Indicator (PID-30)
USCDI v4	N/A
USCDI+ Public Health: Case Reporting Use Case	N/A

* Additional information on input data sources for death data can be found in Appendix A.

Interpretation Notes – Patient Deceased

This new data element decouples the indicator that a patient died from information about whether or not a patient's death can be attributed in any way to the condition. Unlike the "Subject Died" data element present in the current GenV2 MMG, this data element should be populated any time the patient is determined to be deceased and has no implications about cause of death or if it is related to the reported condition.

There was some discussion of whether the definition should include a timing element — a marker of proximity or relevance to the reportable condition — to ensure the information was pertinent to public health surveillance. The new data element is a more general variable and risks triggering new notifications for deaths when that information is no longer relevant to the specific instance of illness being captured. However, it was decided that the paired Deceased Date data element would provide an objective timing component, and concerns about irrelevant updated notifications for a specific condition should be considered during implementation. There would be no expectation that this data element would be updated and populated past the point of the jurisdiction's case investigation.

Table 3. Core Surveillance Data Element for Routine CDC Case Notification – Date of Death

Date of Death	
Definition	Patient date of death
Standard Code for Transmission to CDC	LOINC: 81954-0 – Date of death [Date]
Value set or coding system	Date
Abstracted/ Derived/ Created	Abstracted
Derived from (examples)	N/A
Recommendations for Input Data Source(s)	Case investigation eCR Vital Records
Notes	N/A
Data Source Details*	
eCR CDA	CDA extension, sdctc:deceasedTime, records time of death for the recordTarget CDA mapping: ClinicalDocument/recordTarget/patientRole/patient
eCR FHIR	Patient.deceaseddateTime Value indicates the date and time of the individual's death
ELR	HL7 v2: Patient Death Date and Time (PID-29)
USCDI v4	Patient Demographics/Information data class: • Date of Death: Known or estimated year, month, and day of the patient's death.
USCDI+ Public Health: Case Reporting Use Case	Date of Death: • Definition: Known or estimated year, month, and day of the patient's death • Part of Patient Demographics data class

* Additional information on input data sources for death data can be found in Appendix A.

Interpretation Notes – Deceased Date

This new data element decouples date of death and whether the death was related to the condition being reported to improve standardization in application and allow for direct abstraction from automated sources. Unlike the “Deceased Date” data element present in the current GenV2 MMG, this data element is to be populated any time the patient is determined to be deceased and has no implications about cause of death or relatedness to the condition.

Table 4. Core Surveillance Data Element for Routine CDC Case Notification – Death Associated with Condition

Death Associated with Condition	
Definition	Indicator that death was associated with the condition
Standard Code for Transmission to CDC	LOINC: 77978-5 – Patient died from illness of interest
Value set or coding system	Yes/No/Unknown
Abstracted/ Derived/ Created	Derived
Derived from (examples)	N/A
Recommendations for Input Data Source(s)	Case investigation Vital Records
Notes	N/A
Data Source Details	
eCR CDA	N/A
eCR FHIR	N/A
ELR	N/A
USCDI v4	N/A
USCDI+ Public Health: Case Reporting Use Case	N/A

Interpretation Notes – Death Associated with Condition

The cause of a patient’s death is often complex and multi-factorial; the phrase “associated with the condition” is used to allow for a reasonable amount of flexibility for case investigators to indicate that a condition may have contributed to a patient’s death even if it was not listed as the primary or secondary cause of death. This phrase aligns with the definition assigned to the hospitalization data element.

When determining if a death is associated with a condition, many factors might be considered, including timing of illness, clinical manifestation of illness, complications, and underlying conditions. A condition does not have to be explicitly cited in the patient’s medical or death certificate in order for the death to be considered associated with that condition. For example, if the progression of illness leads to an exacerbation of a comorbidity, then this may be enough to classify a death as associated with a condition.

This criterion may need to be applied differently depending on the condition, resource capacity, and sources of information available, as it may be unrealistic for public health staff to try to discern whether the condition is associated with the death of the case.

Appendix A. Input Data Sources for Death Data

Electronic Case Reporting (eCR)

The CDA implementation guide for eCR describes the use of extensions to the CDA standard that allow for inclusion of, among other data elements, death data. The deceasedInd extension is used to record whether or not the individual is deceased (= “true” or “false”), while the deceasedTime extension is used to capture the date and time of death. If the individual is deceased (i.e., sdct:deceasedInd is true), then a date of death must be included in the eICR.

The FHIR implementation guide for eCR includes a data element in the Patient Resource that represents death data. The Patient.deceased[x] data element can take on a Boolean (true/false) data type to indicate if the individual is deceased or not, or a dateTime data type to provide the date and time of the individual’s death.

Cause of death is not captured within the eICR in CDA format, and therefore, no determination can be made as to whether the death is associated with the condition of interest.

Electronic Laboratory Reporting (ELR)

Two death-related data elements can be transmitted via ELR messages. The Patient Death Indicator in PID-30 indicates whether or not the patient is deceased, with possible values being Yes or No (from HL7 table 0136 Yes/No Indicator). If PID-30 is valued as “Yes”, then the Patient Death Date and Time (PID-29) can be populated with the date and time at which death occurred. Otherwise, PID-29 should not be populated. No information on cause of death is included in the standard ELR message.

USCDI and USCDI+

The most recently finalized version of USCDI (version 4) only includes one data element relevant to death. “Date of Death”, first included in USCDI version 3 in the Patient Demographics/Information data class, is defined as the “known or estimated year, month, and day of the patient’s death”.

“Cause of Death” has been submitted in the Clinical Notes data class but is currently classified as Level 0, which represents the most primitive data elements in terms of data standardization and electronic exchange. “Cause of Death” includes narrative information about the underlying cause of death and/or conditions contributing to death and so is not associated with any coded value set.

The same two data elements are included in USCDI+ with the same definitions, with Date of Death being part of the Patient Demographics data class and Cause of Death Information being part of the Clinical Notes data class.

Appendix B. Additional Death-Related Data Elements

Beyond the above data elements that were discussed in the workgroup, additional data elements relevant to death may also be of interest in the context of a specific condition or group of conditions. These elements did not rise to the level of inclusion as core data elements.

- Final Disease Outcome
- Subject Outcome
- Disease Outcome Type
- Cause of Death
- Primary Cause of Death from Death Certificate
- Secondary Cause of Death from Death Certificate

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