

Death data elements

CSTE DSWG Data Element Specific Team

01/12/2023



Council of State and Territorial Epidemiologists

Please mute phone/ headset/ computer audio!

Agenda

- Welcome & Announcements
- Death data element background
- Death data element discussion and polling
- Next Steps
- Wrap-Up & Adjourn

DEST Opportunities for Participation



- The Data-element Specific Team (DEST) Interest Sign-Up sheet has been updated to include known future data classes:
 - Immunization History (Call #2 on Jan 19)
 - Exposure/Risk/Underlying Conditions (Call #1 on Feb 9)
 - Signs/Symptoms/Clinical Manifestations (Call #1 on Feb 16?)
 - Identifiers (Case/Event Related/Laboratory)
 - Laboratory
 - Race/Ethnicity/Tribal Affiliation
 - Medication/Treatment
 - Reporting Source
 - Disability
 - Social Determinants of Health

Link to Sign-Up sheet:

<https://app.smartsheet.com/b/form/3da89d48bda94fc7a33c4a8a505fe54a>

If you have signed up previously but feel you are not getting the emails/meeting invites that you expected to get, please reach out directly to llane@jmmichael-consulting.com.

- SOGI post-meeting poll
 - Open for input from SOGI DEST members only
 - **Please provide input by the close of business, Friday 1/19/24**

Meeting ground rules



- Discussion Guidelines
 - "Raise" your hand
 - Use the chat to provide feedback and ask questions
 - When called, state your name and affiliation
 - Stay on point, be brief, and within the context of the discussion in progress
 - 80/20 consensus
 - Co-Chairs/moderators' prerogative to move the discussion forward as needed
 - [Post-meeting survey](#) provided for additional input
 - Be courteous and be open to new ideas

Active participation encouraged for all!

- Chats, voting, comments, etc.
- Includes STLT jurisdictions + CDC Programs + CSTE, etc.

In-scope vs Out-of-scope



What this is:

- Discussion about data elements which are:
 - collected at the jurisdiction and sent to CDC for surveillance purposes
 - Abstracted, calculated, or derived from a combination of electronic sources, patient interviews and chart abstractions
- Collaborative consensus building about the best ways to approach the transmission of public health data in the very fluid landscape of sex and gender identity

What this is not:

- Discussion of data elements for research studies
- Recommendations for public facing surveys
- Limitations on what can be collected for a data element within a jurisdiction
- Recommendations for how to ask about gender identity or sex in a case interview
- Implementation guidance

Background Information: Death



Potential data elements related to Death



- Subject Died
- HiNSES Fetal Death
- 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
- Patient Death Date and Time
- Deceased date

Date of Death (V3)

Known or estimated year, month, and day of the patient's death.

Cause of Death (L0)

Cause of death information includes the sequence of events leading to death as well as other conditions significantly contributing to death. The underlying cause of death may be different than the terminal condition. This may include summary of death note, and/or death information that may be captured within the discharge summary note or other cause of death documentation within the clinical notes section.

Patient Death Indicator (PID-30)

- Indicates whether or not the patient is deceased.
- Yes/No indicator for valid values.

Patient Death Date and Time (PID-29)

- Contains date and time at which death occurred.
- Should only be valued if PID-30 is valued 'yes.'

Electronic Case Reporting (eCR)



- Deceased
 - deceasedInd extension
 - records that the patient is deceased as True/false
- Death Date:
 - deceasedTime extension
 - Records the date and time of death

HL7[®] Fast Healthcare Interoperability Resources (FHIR)



Resource: Patient

Element: deceased[x]

.... deceasedBoolean

.... deceasedDateTime

Description: Indicates if the individual is deceased or not

Case Notifications to CDC

Message Mapping Guides (MMGs)



Generic v2 MMG

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type	CDC Priority	Value Set Code
Subject Died	77978-5	Did the subject die from this illness or complications of this illness?	Coded	1	PHVS_YesNoUnknown_CDC
Deceased Date	N/A: PID-29	If the subject died from this illness or complications associated with this illness, indicate the date of death.	Date	1	N/A

NOTE:

The current emergency response draft data elements align with these generic v2 MMG data elements.

Case Notifications to CDC

Message Mapping Guides (MMGs)



Example 1: Foodborne and Diarrheal Diseases MMG

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type	CDC Priority	Value Set Code
Subject Outcome	FDD_Q_1038	Subject's outcome	Coded	P	PHVS_ConditionStatus_FDD

Example 2: Tuberculosis MMG

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type	CDC Priority	Value Set Code
Final Disease Outcome	INV1167	Did the patient die (either before diagnosis or at any time while being followed by TB program)?	Coded	1	PHVS_YesNoUnknown_CDC

Example 3: Leptospirosis MMG (draft)

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type	CDC Priority	Value Set Code
Disease Outcome Type	91541-3	Patient's status or outcome for this condition	Coded	1	PHVS_DiseaseOutcomeType_Leptospirosis

Death Data Elements



Discussion Points



- "Death" vs "death from/due to a condition"
 - What is the value of knowing that a person has died at the CDC level?
 - Is the value of this information limited to whether or not the condition was a factor in their death?
 - Is it realistic to expect that all deaths can be determined as from a condition or not?
- Are jurisdictions currently collecting/storing this information as three distinct data elements (1. Person has died, 2. Death as an outcome of this condition, 3. Date of Death)
 - If so, are they different questions depending on condition?

Proposed Data Elements



Data Element	Definition	Value Set	Potential for Electronic Data Capture
Patient Deceased	Is patient deceased?	Yes No Unknown	• PID-30 in ELR • deceasedInd extension in eCR
Deceased Date	Patient date of death <i>OR</i> Patient date of death if their death was associated with this condition	Date	• PID-29 in ELR • deceasedTime extension in eCR
Death associated with condition (discussion on wording to follow)	Indicator that death was associated with the condition	Yes No Unknown	N/A

Poll 1 – Patient Dead



- Is the data element Patient Deceased a core data element?
 - Yes, as defined here
 - Yes, defined differently
 - No

Data Element	Definition	Value Set	Potential for Electronic Data Capture
Patient Deceased	Is patient deceased?	Yes No Unknown	• PID-30 in ELR • deceasedInd extension in eCR

Poll 2 – Deceased Date



- Is “Deceased date” a core data element? If so, which definition is best for the data element?
 - Yes, defined as “Patient date of death”
 - Yes, defined as “Patient date of death if their death was associated with this condition”
 - No

Data Element	Definition	Value Set	Potential for Electronic Data Capture
Deceased Date	TBD	Date	• PID-29 in ELR • deceasedTime extension in eCR

Discussion Points



- Previous discussion for Hospitalization data elements resulted in the following definition:
 - “Indicator that hospitalization was associated with the condition”
- Is it best to align these data elements or should death be different?
 - “death due to”
 - “death from”
 - “death related to”

Poll 3 – Death associated with Condition



- Is the data element “Death associated with condition” a core data element?
 - Yes, as defined below
 - Yes, defined differently
 - No

Data Element	Definition	Value Set	Potential for Electronic Data Capture
Death associated with condition	Indicator that death was associated with the condition	Yes No Unknown	N/A

Poll 4 – Other data elements CSTE

Should any of the below data elements be considered for core surveillance? (Select all that apply.)

- 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

Next Steps



- Look out for next steps via email. Draft document?
- Upcoming team meetings:
 - 1/19 1-2pm ET– Immunization Call #2
 - 2/9 1-2 pm ET – Risk, Exposure, Underlying Conditions
 - 2/16 1-2 pm ET – Signs, Symptoms, Clinical Manifestations
 - [Link to Sign Up](#)
- The next large DSWG call will be on 23 February 2024.