

Meeting: CSTE Data Standardization – Death -Data Element-Specific Team Meeting

Date: January 12, 2024

Attendees:

CSTE (2)	PHAs (33)	CDC (22)
Becky Lampkins Gillian Haney	<u>DSWG Co-Chairs</u> Molly Crockett MA	Abhilasha Saxena GDIT Andrea Steege
JMC (6)	<u>DEST Members</u>	Andria Apostolou GDIT Angie Agunloye GDIT
Erin Kough Grace Mallard Laura Lane Natalie Raketich Sam Spoto Susan Downer	Aaron Bieringer MN Amanda van Rest NV Amy Lai AZ Beth Isaac NYC Cher Levenson WA Elizabeth Lindsay LA Elizabeth Schiffman MD Gail Gustavson MD Greg Fowler SC Hanna Chakoian MN Isaiah Francis NM Jessica Kumar NY State Jim Sainsbury IN Karen Arrowood TX Karene Thomas-Watts CO Kayleigh Nerhood GA Kyra Kofodimos IN Lakin Mauch ND Laura Erhart AZ Lunden Espinosa IN Lydia Fess MN Maria Jaurretche DC Mario Beltran MD Monique Birmiel IN Morrow Toomey AK Nwanne Onumah MS Rob Laing OR	Cindy Bush Erin Miller Jennita Reefhuis Jenny Couse Jessica Fridge John Gerstle Kevin Lan Kristie Clarke Lesliann Helmus CDC Lauren Korhonen Luis Hernandez GDIT Marie Haring Sweeney Meeyoung Park Myrna del Mar Gonzalez GDIT Peter Boersma Robert Pratt Sara Johnston Yan Yuan

	Sam Groppell Dallas County Shaquania Dorsett FL Shawna Stuck GA Stephanie Moberg NM Suzanne Gibbons-Burgener WI	
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**SOME INDIVIDUALS DIALED IN; THE NAMES ARE UNKNOWN, AND THEY ARE LEFT OFF OF THE ATTENDANCE*

HIGH-LEVEL MEETING NOTES (REFER TO MEETING SLIDES FOR MORE DETAIL AS NEEDED):

Death data elements

DEST Opportunities for Participation

- DEST sign-ups are ongoing.
- **[Action Requested]** Please sign up for upcoming data elements on the [DEST Sign-Up here](#).
- Upcoming data elements
 - 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?)
 - Laboratory
 - Race/Ethnicity/Tribal Affiliation
 - Medication/Treatment
 - Reporting Source
 - Disability
 - Social Determinants of Health
- DEST member expectations – members are not expected to write documents, lead meetings, or prepare slides. The goal is to keep members engaged in conversations around content during and between meetings.
- There is an expectation of active participation in polling, document review, discussion, and other input during and between meetings.

DSWG Meeting Reminders

- SOGI post meeting poll closes on Friday, 1/19/24.

Meeting Ground Rules

- We welcome everyone's opinions and active participation from jurisdictions, CDC programs, CSTE membership, etc.
- As we work through data elements/classes, we strive for 80/20 consensus.

In-Scope vs Out-of-Scope

- Focus on core data for surveillance for transmission to CDC within selected data classes.
- We will work to identify standard definitions and value sets within that definition of core data.

- This is not a discussion of how to collect this data, how to frame questions in surveys or interviews, or how to implement these data standards. This is also not meant to impose limitations in how jurisdictions collect data.

Background Information: Death

Potential data elements related to Death

- This slide presents data elements related to death that are used either in NNDSS Message Mapping Guides and in other standards.
- Data elements related to death are largely limited to three categories, including whether a patient died (such as subject died, subject outcome, and final disease outcome), the date of death (or deceased date), and the cause of death (either as a general data element or asking for specific causes listed on the death certificate).

U.S. Core Data for Interoperability USCDI

- Within USCDI, “Date of Death” was included in the demographics data class starting in version 3. The description for date of death is “Known or estimated year, month, and day of the patient's death”.
- Cause of death is included in USCDI at level 0, the lowest level within USCDI, indicating it is captured, stored, or accessed in limited settings and it is not represented by a terminology standard or SDO-balloted technical specification or implementation guide.
- Both are included in USCDI+ within the case reporting use case as well.

Electronic Lab Reporting (ELR)

- Data on a patient’s vital status can come through electronic lab reporting.
- The PID-30 field contains a Yes/No indicator to denote whether the patient is deceased. If PID-30 is yes, indicating the patient is deceased, then patient’s death date and time can be populated in PID-29.
- Information on cause of death is not in the standard ELR.

Electronic Case Reporting (eCR)

- Like ELR, eICR can capture that the patient is deceased and the time of death.
- The DeceasedInd extension contains information on whether the patient is deceased and the deceasedTime extension captures the date and time of death.
- Cause of death is not captured within eICR.

HL7 Fast Healthcare Interoperability Resources (FHIR)

- Within FHIR, the patient resource captures whether a patient is alive or deceased, though it does not capture cause of death. With the patient resource, the information that a patient is deceased can be sent in two ways. It can be sent as a Boolean (True/False) data element, indicating whether the patient is deceased. Alternatively, this information can be sent as the datetime that the patient passed away. In US Core and US Public Health profiles, deceased information is structured the same way.
- Cause of death is captured separately. It is included in a cause of death condition profile which can be initially specified with text and then sent to NCHS for coding.

Case Notifications to CDC: Message Mapping Guides (MMGs)

- Within the generic v2 MMG are two death-related data elements. The first, “subject died”, has a description of “did the subject die from this illness or complications of this illness” and a value set of ‘Yes’, ‘No’, and ‘Unknown’. The second data element, “deceased date” is used to capture date of death when the subject died from the illness. Currently MVPS has a business rule that provides a warning if “Subject Died” is ‘No’ or ‘Unknown’ but “Deceased Date” is populated. This is intended to prevent the inclusion of a death date if the case did not die from the illness. It is helpful to note that this approach differs from the standards discussed in previous slides in that this asks whether patient died of the illness, rather than died of any condition.
- During COVID, there were concerns over how a few jurisdictions sent date of death and over how “subject died” was being populated. For subject died, some jurisdictions populated the DOD regardless of the cause then included ‘No’ in the death indicator field if death was not associated with COVID. This combination of approaches made it difficult to interpret the data.
- It is useful to consider how often these fields are populated. Over the past two years, 30% of case notification messages had completed the “Subject died” DE but deceased date had around 0.5% completion.
- Other MMGs ask specifically about death due to the condition. First, the Foodborne and Diarrheal Diseases MMG contain a “Subject Outcome” data element with values of ‘alive,’ ‘patient died’ and ‘unknown’. The Tuberculosis MMG has a “Final Disease Outcome” data element with a description of “Did the patient die either before diagnosis or at any time while being following by TB program?” and values of ‘Yes’, ‘No’, and ‘Unknown’. Finally, the leptospirosis MMG which has been under development has a data element of ‘Disease Outcome Type’ with a description of ‘Patient’s status or outcome for this condition’ and a value set of ‘Dead’, ‘Feeling ill’, ‘patient recovered’, ‘patient still hospitalized’, and ‘Unknown’.

Death Data Elements

Discussion Points

- The discussion started with conversations around death versus death from/due to a condition.
- What does CDC need to know?
 - Is value of this information confined to whether the condition was considered a factor in the death?
 - Is it realistic to expect that all deaths can be investigated and determined as either associated with a condition or not?
- A second more logistical point how are jurisdictions collecting/storing this information?
 - Is it two points or three? If the third point relates to the condition, are they the same across conditions or do they vary?
- Open Discussion
 - Erin Kough (JMC) prompted a question to start the discussion. Does the group think there is value in the CDC knowing if someone is dead or not, regardless of the condition?
 - Suzanne Gibbons-Burgener (WI) noted that in Wisconsin they can collect all three of these elements. She would assume that regarding notification to CDC, that this would be tied to a reportable condition, so she expressed uncertainty if they would find it valuable knowing the person died without more information like a date or if it was related to a specific condition. Her jurisdiction does take this

into account, whether it is attributed to a condition, but it takes a lot of work sometimes to match that information and it is not possible for all diseases. There was interest in knowing the CDC's thoughts on this.

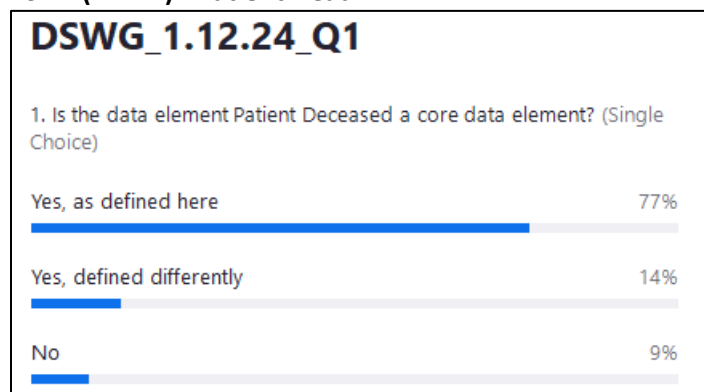
- Beth Isaac (NYC) noted that it has been helpful for their jurisdiction to have two separate fields about whether the person has died and whether it's related to the condition. Sometimes that second question is just an unknown.
- Elizabeth Schiffman (MN) agreed with previous comments and how states can collect the data but uncertainty with what CDC's needs are.
- Lydia Fess (MN) mentioned that they work primarily with COVID mortalities and through that lens it would really depend on how capable a jurisdiction is able to get this type of information to associated death and disease. Getting that information for all cases would be difficult and onerous creating a potential for bias.
- Erin Miller (CDC/TB) noted that from a condition point of view and a general CDC point of view, would be condition dependent. There is an argument for having this information at a broader level, but it would have limited utility.
- Marie Haring Sweeney (CDC/NIOSH) commented that there are many situations where it is important to know if a death was related to say work like pesticides, silicosis, carbon monoxide poisoning and more, which are in NNDSS.
- Erin Kough (JMC) pulled out a few highlights of note from the chat occurring within the meeting. It appeared that many people felt that identifying if death is related to the condition, there is a case that this can be particularly important for chronic disease for transmission to CDC. If we are trying to make this uniform across even those chronic conditions, it is difficult. There is also mention in the chat regarding infant death being special as well. She requested thoughts from the group on these points.
- Jessica Kumar (NY) commented that for infections, the time they hear about a death there is nothing from the surveillance side that would make this helpful to do anything proactively. For the most recent years, when it is immediately attributable to conditions like RSV or COVID, it is helpful to know because it helps understanding all-cause mortality, capacity of hospitals, and shape pandemic and resource planning.
- Suzanne Gibbons-Burgener (WI) noted that this element could be related to non-infectious diseases and that there are some infectious diseases with long durations of illness and potential death. Many programs are dependent upon the date of death and being able to compare that with date of onset, date of diagnosis for a particular illness to help them make determinations if there is not a death certificate and analyze if the disease contributed to the premature death of the person. Have the date of death is critical even with chronic diseases and therefore she advocated for that.

Proposed Data Elements

- You can see that two of the three data elements have variations that can be discussed further.
- In this configuration, we are going with a three data element approach to start the core discussions and polling.
- Things are broken up as Patient Deceased as a general data element with no conditional requirements.
- The second data element could have a condition or not.
- The third is related directly to death related to a condition but there needs to be discussion about phrasing.

Polling

Poll 1 (n = 44) - Patient Dead



- **Discussion**

- Erin Kough (JMC) for those who said yes, but to define this differently, what is your concern for this definition?
- Suzanne Gibbons-Burgener (WI) It could be when it says the patient is deceased at the time of the report and because there is variability when the report is sent to the CDC based on the disease. For clarity, the question being asked is “is the patient deceased” and is this decision being made at the state level? She mentioned she answered no to this question but can understand there might be a different way of defining it. When working with TB or fungal diseases cases aren’t always finalized in a timely manner. There is a concern about updating records for the outcome of a disease. It just depends on if CDC wants to know if somebody died of a specific cause. If so, there is a more specific variable they should be relying on.
- Elizabeth Schiffman (MN) was curious as to how else you can say at the time of onset the person was deceased; it seems that is what we would use. She noted that she struggled to think about how this could be asked more specifically and doesn’t necessarily disagree with it.
- Sara Johnston (CDC) noted that jurisdictions that have systems where the person record is where this information would be held if this person is deceased and they also have or are developing the linkage with their vital records systems, so the information will be more populated, where do we have jurisdictions where this data would be populated outside of the case investigation? Then later on, after the case investigation has closed and the death is unrelated as the case, and it goes to CDC as the person has died, but not related to the case. Is that a scenario that is likely in some systems? Is this more likely as we have more linkages with vital records and other systems? Will this muddy the waters of this data element as it is sent to CDC?
 - Erin Kough (JMC) noted that in the chat there were comments that yes this would be an issue.
 - Lydia Fess (MN) commented that she had a related question regarding a timeframe for updating cases. For example, there are COVID cases going back through 2020 and they might get E. Coli in 2024 and die and their record is marked as dead. The question is, will then update their COVID case and get sent to CDC.

- Erin Kough (JMC) noted that from her experience in MN that if the case was closed this information will not be updated in the record. She could not speak to other state systems. She also commented that this is driving more into implementation which is out of scope for our discussions and current project scope.

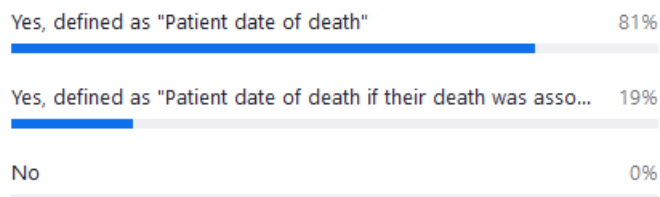
Poll 2 (n = 43) – Deceased Date

• Pre Poll Discussion

- Erin Kough (JMC) this question is asking do we want deceased date as it currently is, which is if their date of death was associated with the condition, or do we just want a patient date of death - a date of death that is sent when the person dies, and it does not say anything more than this person died on this day.
- Erin Miller (CDC) noted that if a core data element is submitted to the CDC the date of death is mostly likely what you are looking for. Jurisdictions would have other dates in their system for use as needed. The date of death alone would be sufficient and is a more generalizable core element.
- Robert Pratt (CDC) commented that this is a TB heavy discussion, but he doesn't see the date of death as important unless we know that the patient died, so the first core element is needed. We could ask for date of death and separately a yes/no/unknown if it is associated with the condition.
- Erin Kough (JMC) commented that she understood that sending the date of death is sufficient for core.
 - Erin Miller (CDC) agreed and noted that yes as a core data element its core and the other details would be program specific.
- Kristie Clarke (CDC) noted that it's tempting to consolidate in this way but then there are unforeseen circumstances where it creates confusion. It's trying to answer two questions, both the date of death and the association. It seems best to stick to a question that gives a singular clear answer.
- Erin Kough (JMC) noted appreciation for that clarity and leveraged the opportunity to launch the second poll.

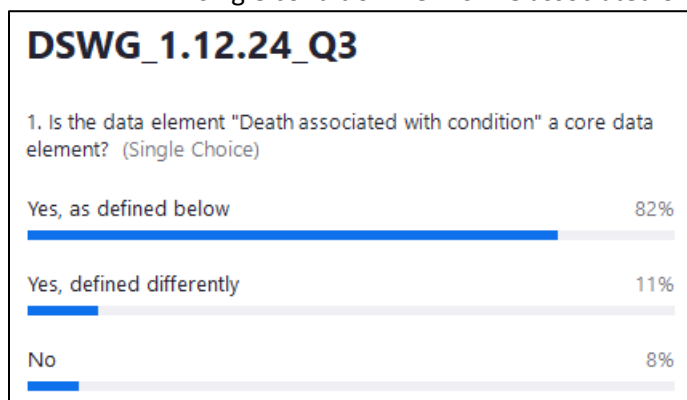
DSWG_1.12.24_Q2

1. Is "Deceased date" a core data element? If so, which definition is best for the data element? (Single Choice)



Poll 3 (n =38) – Death associated with condition

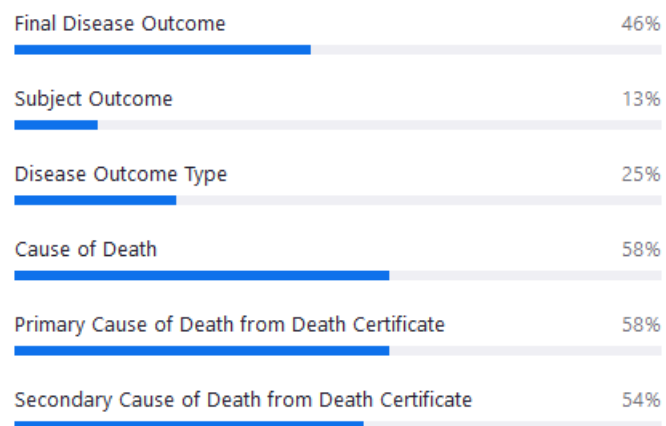
- Erin Kough (JMC) noted that during the hospitalization DEST there was discussion about how to word this and it was decided to use the indicator that hospitalization was associated with the condition. She posed a question to the group to determine if they wanted to align with that language.
- Discussion
 - Jennita Reefhuis (CDC) commented that alignment is best when possible and agreed with “associated with.”
 - Marie Harring Sweeney (CDC) had a question about the meaning associated with the condition, does that mean that hospitalization caused the problem, like the hospitalization caused an infection or that the condition was associated with the patient being hospitalized?
 - Erin Kough (JMC) clarified that this meant the person hospitalized as associated with the condition.
 - Marie Harring Sweeney (CDC) then felt that the wording “due to the condition” would be more appropriate.
 - Erin Miller (CDC) commented that when people have multiple conditions saying that “due to” can be very limiting and “associated with” allows for more flexibility.
 - Lesliann Helmus (CDC) agreed with Erin’s statement and that it’s difficult to definitively say death or hospitalization is “due to” one single condition. Terms like associated or related to give us the flexibility needed to make this workable and practical.

**Poll 4 (n = 24) – Other data elements**

- Erin Kough (JMC) commented that the last question is to determine if it is strongly felt that other elements should be considered for core and if so, what that should include. Without a “None of the Above” option in the poll, it was determined that 20 votes would be the cutoff for further discussion of an element.

DSWG_1.12.24_Q4

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



- The elements with the most votes were Cause of Death and Primary Cause of Death with 14 votes each. Since neither of these elements hit the required 20 votes, it was determined that the group would move on without further discussion.

Next Steps

- JMC will now work closely with CSTE and Co-Chairs on the draft document which will be sent to this team for review in the near future.
- A reminder that Call number 2 for the Immunization data class will be next week, same time, same place.
- The first call for Risk, Exposure, and Underlying conditions will be on February 9th at 1 pm. And it's likely that the Signs, Symptoms and clinical manifestations data-element specific team will kick-off the following week on February 16th at 1 PM.
- The next non DEST DSWG call will be on February 23. That call will have a review of several of the data classes which have recently finished and we hope to see you there.