Signs & Symptoms and Clinical Manifestations

CSTE DSWG Data Element Specific Team

2/16/2024

Council of State and Territorial Epidemiologists

CSTE Data Standardization Workgroup Meeting

Please mute phone/ headset/ computer audio!

Agenda

- Welcome & Announcements
- Background
- Discussion/Polling
- Next Steps
- Wrap-Up & Adjourn

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 input form is always available for additional comment
    - Be courteous and be open to new ideas

Active participation encouraged for all!

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

Core Data: In Scope for DSWG

- Identify core data elements for surveillance **for transmission to CDC**
  - For situational awareness or routine, cross-condition case surveillance
  - For case-based surveillance (not syndromic, not aggregate reporting)
  - Within *selected* data classes (e.g., hospitalization, travel history) that are used for multiple conditions

- Identify common definitions, value sets/code sets, structure, and interpretation notes for those core data elements

- Recommend best practices for how selected data elements are collected, structured or populated within PHA surveillance systems, if/when that will affect the interpretation of the data transmitted to CDC

Core Data: In Scope for DSWG

- For these larger data classes (Signs and Symptoms, Exposures, Risk Factors, etc.) we are not necessarily defining individual data elements as core. (E.g., "Fever" is a core symptom)
- Defining "Signs and Symptoms" as core means there should be a section for each condition that structures this information in the same way in a case notification message to CDC. The individual signs/symptoms contained within that section could be condition-specific.
- Jurisdictions do not need to identify on their own for each condition which parts of a CRF would go in each section. This implementation guidance would come later from CDC.

Core for CDC Transmission ≠ Required

Even if a data element or class is identified as appropriate for transmission to CDC, this does *not* mean we need to fill in or send an answer for every core element for every case!

- It is okay to leave the data field as blank or Unknown if the information is not available, not a priority, or not useful for particular conditions.

Data elements and data classes should be considered for core if they are relevant for many conditions

- There is no set number that defines "many".
- Would you rather see the element in (for example) a GenV3 MMG? or in the applicable disease-specific MMGs?

Background Information: Signs, Symptoms, Clinical Manifestations

Case Notifications to CDC
Message Mapping Guides (MMGs)

- Signs and Symptoms Repeating Group
  - Carbon Monoxide Poisoning, Rubella, Measles, RIBD, Congenital Syphilis, Foodborne and Diarrheal Disease, Listeriosis, Mumps, Pertussis, COVID-19

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Value Set Name (VADS Hyperlink)
START: Signs and Symptoms Repeating Group			
Signs and Symptoms	56831-1	Signs and symptoms associated with the illness being reported	Signs and Symptoms (COVID-19)
Signs and Symptoms Indicator	INV919	Indicator for associated sign and symptom	Yes No Unknown (YNU)
END: Signs and Symptoms Repeating Group			

- Clinical Manifestations Repeating Group
  - Babesiosis, Brucellosis, Leptospirosis, Lyme Disease, TBRD
- Clinical Section - Individual questions
  - Arboviral

Signs & Symptoms and Clinical Manifestations

Signs and Symptoms:

- 19 value sets, 111 unique codes
- 76/111 codes (68%) are only in one of the 19 value sets

Clinical Manifestations:

- 6 value sets for different conditions, 91 unique codes
- 72/91 codes (79%) are only in one of the 6 value sets

No current condition contains both of these repeating groups. There are 32 codes (~1/3) overlapping between these groups.

Signs and Symptoms Examples

Carbon Monoxide	Mumps	Arbovirus	FDD	Flu
Chest pain (finding)	Fever (finding)	Fever	Bullae	Absent (qualifier value)
Clouded consciousness (finding)	Headache (finding)	Chills or Rigors	Cellulitis	Acute onset (qualifier value)
Dizziness (finding)	Jaw pain (finding)	Fatigue or Malaise	Diarrhea	Chill (finding)
Dyspnea (finding)	Loss of appetite (finding)	Rash	Dysuria (finding)	Conjunctivitis (disorder)
Headache (finding)	Muscle pain (finding)	Myalgia	Fatigue	Cough (finding)
Nausea (finding)	other	Arthralgia	Fever	Diarrhea (finding)
other	Parotitis (disorder)	Arthritis	Headache	Dyspnea (finding)
Syncope (disorder)	Sublingual salivary gland swelling (finding)	Headache	Hematochezia	Extreme exhaustion (finding)
Vomiting (disorder)	Submandibular salivary gland swelling (finding)	Paralysis or Paresis	Loss of appetite	Feeling feverish (finding)

Clinical Manifestations Examples

TBRD	Anthrax	Babesia	Brucellosis	Leptospirosis
Anemia (disorder)	Abdominal discomfort (finding)	Anemia (disorder)	Arthritis (disorder)	Abdominal pain (finding)
Decreased blood leukocyte number (finding)	Altered mental status (finding)	Chill (finding)	Endocarditis (disorder)	Acute hepatic failure (disorder)
Eruption of skin (disorder)	Ascites (disorder)	Fever (finding)	Epididymitis (disorder)	Acute renal impairment (disorder)
Eschar (morphologic abnormality)	Chest pain (finding)	Headache (finding)	Fatigue (finding)	Altered mental status (finding)
Fever (finding)	Chill (finding)	Joint pain (finding)	Fever (finding)	Aseptic meningitis (disorder)
Headache (finding)	Coma (disorder)	Muscle pain (finding)	Headache (finding)	Bleeding from nose (finding)
other	Diarrhea (finding)	Thrombocytopenic disorder (disorder)	Loss of appetite (finding)	Cardiac arrhythmia (disorder)
Thrombocytopenic disorder (disorder)	Dysphagia (disorder)		Meningitis (disorder)	Chest pain (finding)

Case Notifications to CDC

Message Mapping Guides (MMGs)

- Complications
  - FDD: Hemolytic Uremic Syndrome, Thrombotic Thrombocytopenia
  - Malaria: Cerebral Malaria, Renal Failure, etc.
  - Babesiosis: Acute Respiratory Distress, Congestive Heart Failure, etc.
  - Mumps: Deafness, Mumps Encephalitis, Mumps Orchitis, etc.
  - Pertussis: Encephalopathy, Seizures, Other
  - Varicella: Hemorrhagic Condition, Varicella Encephalitis, etc.
- Infection Type
  - RIBD: Describes type of infection caused by the organism (Cellulitis, Encephalitis, Septic Shock, etc.)
- Clinical Findings
  - COVID-19: Acute Respiratory Distress Syndrome, Electrocardiogram Abnormal, Pneumonia, etc.

Signs, Symptoms, Clinical Manifestations Discussion

CSTE

Polling process

- Poll questions will be shown first on a slide before poll opens
  - Opportunity for clarifications & questions
- Questions will be mostly Yes/No
  - Feel free to abstain if you don't have a preference or don't feel strongly
- Opportunity for limited discussion on questions with a big split

Signs & Symptoms and Clinical Manifestations

Can we define one data class (one bucket) that encompasses these signs/symptoms/clinical manifestations or are they separate data classes?

What should it/they be called? How can it/they be defined?

Data Element	Definition	Coding System	Abstracted/ Derived/ Created	Potential Input Data Source(s)
Signs and Symptoms? Clinical Manifestations? Something else?	XXXXX associated with the condition being reported?	SNOMED preferred, local if necessary	Abstracted	Case Investigation eCR

Poll 1 - Definition

Are Signs and Symptoms and Clinical Manifestations separate data classes or one data class?

(We are NOT yet talking about complications/infection type/findings.)

- One data class: call it "signs and symptoms"
- One data class: call it "clinical manifestations"
- One data class: call it something else
- Separate data classes

Signs & Symptoms and Clinical Manifestations

Is this (or are these) data classes core?

- Should it be structured the same and included for all conditions? (Exact structure conversation coming in March.)
- Should there be a list of symptoms that are core for all conditions? (E.g. "Fever" is core.)

Data Element	Definition	Coding System	Abstracted/ Derived/ Created	Potential Input Data Source(s)
XXXX	**XXXX associated with the condition being reported**	SNOMED preferred, local if necessary	Abstracted	Case Investigation eCR

Poll 2 - Is it Core?

Are Signs and Symptoms and Clinical Manifestations core data for surveillance? (If we previously voted these are separate data classes, select all that apply.)

This means there should be a consistent place and method to transmit the data for all conditions, even though the list of signs/symptoms can vary by condition.

- Signs and Symptoms are core
- Clinical Manifestations are core
- Neither are core

Reminder:
Core data for surveillance = Data classes or elements used for situational awareness or routine, cross-condition case surveillance for transmission to CDC. These elements may remain empty for cases/conditions where not applicable or unavailable.

Next Steps

- Upcoming team meetings:
  - **3/8 1-2pm ET (and maybe 3/15 1-2pm ET if needed)**
  - Combined conversation with Exposure/Risk/Underlying Conditions DEST regarding structure of these classes
  - Please attend if you work on the back end of your surveillance system or in mapping case notifications for data transmission to CDC
  - If you don't, spread the word to those in your organization that do
  - Link to Sign Up

- The next large DSWG call will be February 23rd, 1-2pm.