

Signs & Symptoms and Clinical Manifestations

CSTE DSWG Data Element Specific Team

2/16/2024



Council of State and Territorial Epidemiologists

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



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.

Poll 3 – Core Symptoms?



Should we work to define a list of specific signs/symptoms that are core for all conditions? (e.g., "Fever" is core.)

- Yes
- No

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Symptomatic Indicator



As a core data element, is there a need for an indicator value to identify if the case was symptomatic?

Data Element	Definition	Value Set	Abstracted/ Derived/ Created	Potential Input Data Source(s)
Symptomatic	Indicator that the case was symptomatic? Indicator that the case was symptomatic in relation to the condition being reported?	Y/N/U	Derived	Case Investigation eCR

Poll 4 – Symptomatic Indicator CSTE

Is a "Symptomatic" data element core data for surveillance?

- Yes - Indicator that the case was symptomatic
- Yes - Indicator that the case was symptomatic in relation to the condition being reported
- No

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Complications, etc.



Should we define a core data class that encompasses complications/infection type/clinical findings? (Should this concept be structured the same for all conditions, when applicable?)

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

Does this belong in the same data class previously defined?

Data Element	Definition	Coding system	Abstracted/ Derived/ Created	Potential Input Data Source(s)
Complications? Infection Type? Clinical Findings or Complications?	XXXX associated with the condition being reported	SNOMED preferred, local if necessary	Abstracted Derived	Case Investigation eCR

Poll 5 – Are Complications/Clinical Findings Core?



Are any of the concepts just discussed (clinical findings and complications and infection type) core data for surveillance?

If you think only some is core (e.g. complications are core but infection type is not), still vote "yes" here.

- Yes – Its own data class
- Yes – Only included as a part of the previous data class
- No

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Poll 6 - Definition



What belongs within this core data class?

Select all that apply.

- Clinical Findings
- Complications
- Infection Type
- Something else

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Poll 7 - Additional Data Elements



Are there any other clinical signs/symptoms related data elements that need to be discussed specifically as recommendations for core data for surveillance?

- Yes
- No

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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.