

Signs & Symptoms and Clinical Manifestations

CSTE DSWG Data Element Specific Team

4/19/2024



Council of State and Territorial Epidemiologists

Please mute phone/ headset/ computer audio!

Agenda

- Welcome & Announcements
- Summary of Previous Calls
- 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" as a core symptom)
- Defining "Signs and Symptoms" as core means there should be a section for each relevant 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 case report form 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?

Summary of Previous Calls



Previously in February...



Data Element	Definition	Coding System	Abstracted/ Derived/ Created	Potential Input Data Source(s)
Clinical Manifestations	Clinical manifestations, including signs and symptoms, associated with the condition being reported	SNOMED preferred, local if necessary	Abstracted	Case Investigation eCR

Voted for a core data class that is inclusive of signs, symptoms, and other clinical manifestations of a condition.
Transmitted across conditions when applicable.

Previously in March...



- Structure should be what makes sense for the data class.
- CDC: strong preference for repeating block
- STLTs: preferred structure was split between the three, likely reflecting differences in surveillance systems used across the US
- Adding additional elements into a repeating group can be complex to implement in some jurisdictional systems.
 - Parent/child/child is simpler than parent/child/grandchild.
- Strong message that consistency in structure across conditions for a data class is important.

Complications, etc.



How will data elements be sorted into the data classes?

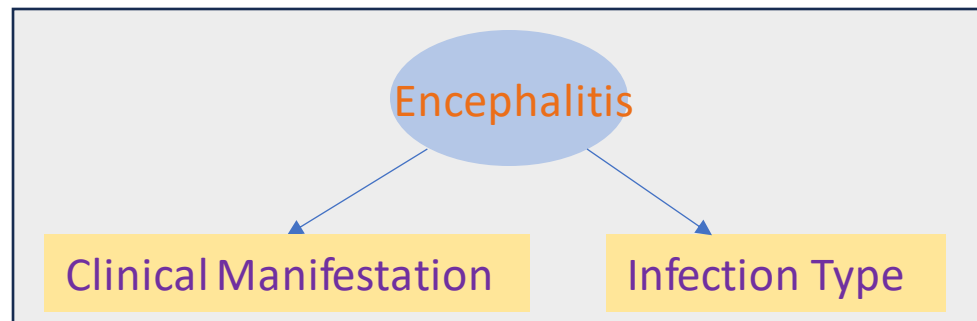


Data elements will be assigned to the **data classes** at the discretion of CDC programs.

→ Similar **Data elements** might be assigned to different **data classes** in different MMG's

Example:

Encephalitis may remain as a **Clinical Manifestation** in the Lyme MMG and may still be referred to as an **Infection Type** in the Respiratory and Invasive Bacterial Diseases MMG.



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.

Complications, etc.



Should we define a core data class that encompasses complications/ infection type/ clinical findings? (Should there be a bucket defined for all cases that contains this information, filled out when applicable to the condition?)

Alternatively, should this information be part of the clinical manifestations data class?

Data Element	Definition	Coding system	Abstracted/ Derived/ Created	Potential Input Data Source(s)
Clinical Complications or Findings	Complications, diagnoses, syndromes, and other findings associated with the condition being reported	SNOMED preferred, local if necessary	Abstracted Derived	Case Investigation eCR

Polling process



- Poll questions will be shown first on a slide before poll opens
 - Opportunity for clarifications & questions
- 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

Poll 1 – Are Clinical Complications and Findings Core?



Is this concept (clinical complications and findings) core data for surveillance?

- Yes – It's own data class
- No - When possible, include as a part of the clinical manifestations data class.
- No – Prefer this type of information is standardized in structure, but it is not 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.

Data Class Indicator



Data Class Indicator



- "Symptoms Present" is part of the Minimum Dataset for Case Notification during an Emergency
- "Was the patient symptomatic" used in some condition specific MMGs
- Implementation of a summative data element is easy to neutral according to structure discussion with informaticists

Data Element	Definition	Value Set
Clinical Manifestations Indicator	Indicator that the person experienced any clinical manifestations	Y/N/U
Clinical Manifestations	Clinical manifestations, including signs and symptoms, associated with the condition being reported	SNOMED/ local

Data Class Indicator



Should a clinical manifestations (or complications) indicator value be a core data element?

Data Element	Definition	Value Set	Abstracted/ Derived/ Created	Potential Input Data Source(s)
Clinical Manifestations Indicator	Indicator that the person experienced any clinical manifestations	Y/N/U	Derived	Case Investigation eCR
Clinical Complications or Findings Indicator	Indicator that the person experienced any clinical complications or findings	Y/N/U	Derived	Case Investigation eCR

Poll 3 – Data Class Indicator



Select if any data class should use a summative indicator as part of core data for surveillance. (*Select all that apply.*)

- Clinical Manifestations
- Clinical Complications and Findings
- Neither

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Structure



March Structure Calls - Review



1. Did the person have any of the following clinical manifestations?

- ☐ Fever
- ☐ Cough
- ☐ Sore Throat

Repeating
Element

Individual
Questions

Did the person have any of the following clinical manifestations?

1. Fever

- ☐ Yes
- ☐ No
- ☐ Unknown

2. Cough

- ☐ Yes
- ☐ No
- ☐ Unknown

Repeating
Group

1. Did the person have a fever?

- ☐ Yes
- ☐ No
- ☐ Unknown

2. Did the person have a cough?

- ☐ Yes
- ☐ No
- ☐ Unknown

3. Did the person have a headache?

- ☐ Yes
- ☐ No
- ☐ Unknown

Structure Recommendations



- Summarize March discussions and include pros/cons of each structure type.
- Leave exact structure decisions for future implementation.
- Key epi consideration for this (these) data class(es):
 - Repeating block or individual questions allow for transmission of “Y/N/U” response for each individual symptom
 - Repeating element structure would be “select all that apply” type of structure- no distinction for individual symptoms if they are not present or unknown
- **Is transmitting No/Unknown for each individual symptom or complication important? Is it acceptable to only transmit “Yes” responses?**

Poll 4a – Yes/No/Unknown



For Clinical Manifestations- Does the structure need to allow for sending of No/Unknown responses for all values?

- No
- Probably Not – Likely not adding much.
- Maybe – Might be helpful sometimes.
- Yes
- I don't know.

Poll 4b – Yes/No/Unknown



For Complications- Does the structure need to allow for sending of No/Unknown responses for all values?

- No
- Probably Not – Likely not adding much.
- Maybe – Might be helpful sometimes.
- Yes
- I don't know.

Final Loose Ends



Poll 5 -Defining Core Symptoms



Does this group need to define a list of clinical manifestations that are core for all conditions? (e.g. "Fever" should be included as a core symptom for all conditions)

- Yes
- No – Every condition has it's own list of relevant clinical manifestations.

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Poll 6 - 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:

- **5/10 1-2pm ET – Disability**
- **5/17 1-2pm ET – Identifiers**
 - Outbreak identifiers, Identifiers to link labs and cases, Linkage of maternal/infant cases
- [Link to Sign Up](#)

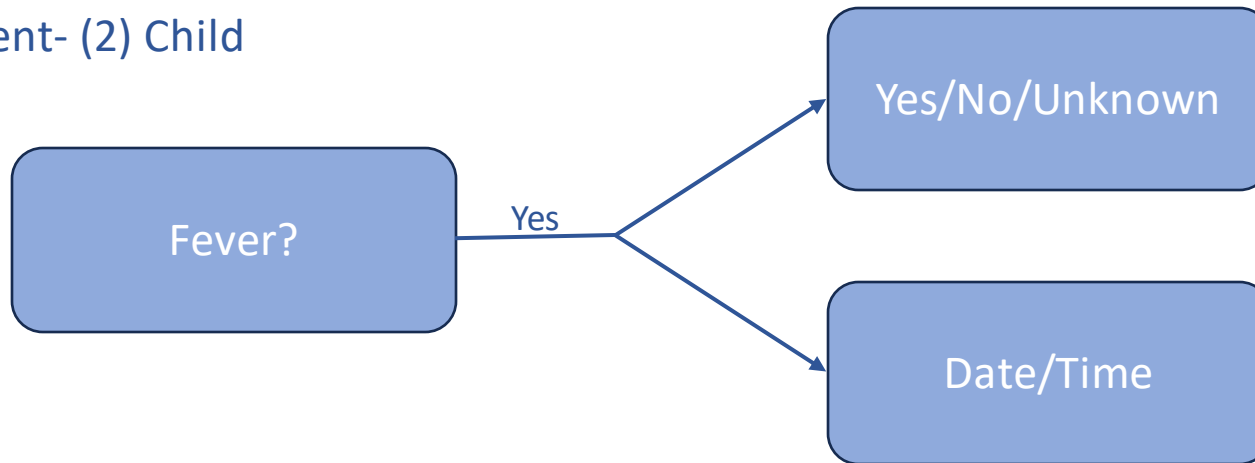
SOGI Draft comments due April 22nd.

The next large DSWG call will be April 26th, 1-2pm.

March Structure Calls - Review



Parent- (2) Child



Parent-Child-Grandchild

