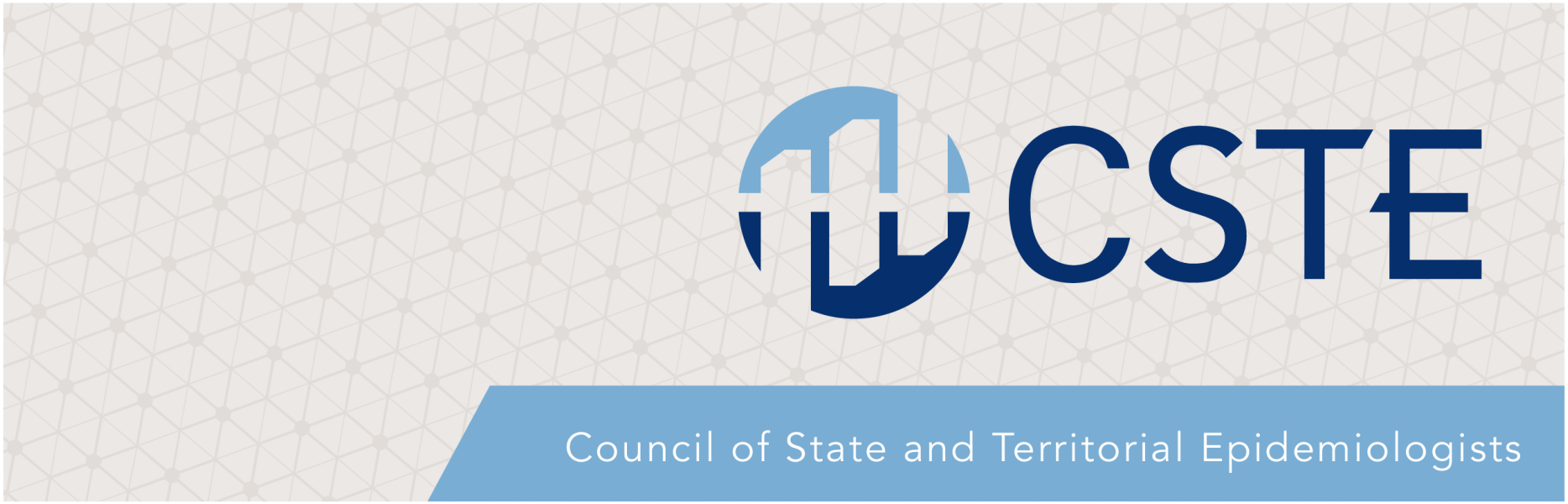
Identifiers

CSTE DSWG Data Element Specific Team

5/17/2024



CSTE Data Standardization Workgroup Meeting

Please mute phone/ headset/ computer audio!

Agenda

- Welcome & Announcements
- Identifier Structure
- Potential Core Identifiers
- Birthing Parent-Infant Linkage
- 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 FAQ

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?

Identifier Structure

Identifier Data Type

Current identifier data elements in the generic v2 message mapping guide (MMG):

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type
Local Subject ID	N/A: PID-3	The local ID of the subject/entity	Text
Local Record ID	N/A: OBR-3	Sending system-assigned local ID of the case investigation with which the subject is associated.	Text
State Case Identifier	77993-4	States use this identifier to link NEDSS investigations back to their own state investigations.	Text
Legacy Case Identifier	77997-5	CDC uses this identifier to link current case notifications to case notifications submitted by a previous system (NETSS, STD-MIS, etc.).	Text

Potential Identifier Structure

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type
Identifier Type	TBD	Description of identifier	Coded
Identifier Value	TBD	Unique identifier value	Text
Identifier Assigner	TBD	Name of organization or system that issued the ID	TBD

OBX|nn|CWE|TBD^Identifier Type^PHINQUESTION|1|TBD^NORS ID^PHINQUESTION|||||F
OBX|nn|CWE|TBD^Identifier Value^PHINQUESTION|1|EIP1234567||||||F
OBX|nn|TBD|TBD^Identifier Assigner^PHINQUESTION|1|TBD^CDC^PHINQUESTION||||||F

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 – Identifier Structure

What would your preference be for the structure of sending identifier values?

(Excluding local subject ID and local record ID.)

- Discrete Data Elements
- Repeating Group

Potential Core Identifiers

What does it mean for an identifier to be core?

A core identifier should be something that would be capable of being transmitted across conditions when needed.

- All cases require a unique ID to be identified as a unique case. (Local Record ID)
- Something like an "outbreak ID" would rarely be present, but if core then a jurisdiction should be capable of capturing/sending that field across conditions.
- Core = Will be prepared to utilize it across conditions as needed. Minimum value set/set of elements for what states are ready to send.

Current Identifiers

Current identifier data elements in the generic v2 message mapping guide (MMG):

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type
Local Subject ID	**N/A: PID-3**	**The local ID of the subject/entity**	**Text**
Local Record ID	**N/A: OBR-3**	**Sending system-assigned local ID of the case investigation with which the subject is associated.**	**Text**
State Case Identifier	77993-4	States use this identifier to link NEDSS investigations back to their own state investigations.	Text
Legacy Case Identifier	77997-5	CDC uses this identifier to link current case notifications to case notifications submitted by a previous system (NETSS, STD-MIS, etc.).	Text

CDC-assigned Case ID

- Routine Surveillance: Jurisdictions send “local record ID” to uniquely identify cases
- Emergent Outbreaks: CDC sometimes assigns each case a unique ID at the beginning of an outbreak

Mpox short case report form:

DCIPHER Data Entry Prompt Text	Field Type	Comments
State-assigned case ID:	Free text	—
State/Territory of Residence:	Drop down	Reporting Jurisdiction
Additional ID:	Free text	Additional ID field used for cross-referencing NNDSS and DCIPHER Case IDs

CDC-assigned Case ID

Should a standard field exist in some future generic MMG to place CDC-assigned case IDs in?

- Would almost always be blank, but available as soon as it's needed

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type
CDC-assigned Case ID	TBD	A CDC-assigned ID for use in situations such as an emergency response.	Text

National Outbreak ID

Current Generic v2 MMG:

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type	CDC Priority
Case Outbreak Name	77981-9	A state-assigned name for an identified outbreak.	Text	1

Proposal:

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description
Outbreak ID – Jurisdiction-assigned	TBD	A jurisdiction-assigned ID for an identified outbreak.
NORS ID	TBD	The outbreak ID from CDC's National Outbreak Reporting System (NORS) for the outbreak the case is associated with.

Minimum Set of Identifiers

Identifier Type	Code	Data Element Description
Legacy Case Identifier	77997-5	Links current case notifications to case notifications submitted by a previous system. *(Assigner could be used to further specify what system assigned the previous ID.)*
CDC-assigned Case ID	TBD	A CDC-assigned ID for use in situations such as an emergency response. *(Like DCIPHER ID for mpox.)*
Outbreak ID – Jurisdiction-assigned	TBD	A jurisdiction-assigned ID for an identified outbreak. *(Replacement of Case Outbreak Name.)*
NORS ID	TBD	The outbreak ID from CDC's National Outbreak Reporting System (NORS) for the outbreak this case report is associated with.

Poll 2 – Minimum Value Set

Should these identifiers be part of the core minimum value set/data elements for identifiers?

Yes Only some of them None are core

Identifier Type	Data Element Description
Legacy Case Identifier	Links current case notifications to case notifications submitted by a previous system.
CDC-assigned Case ID	A CDC-assigned ID for use in situations such as an emergency response.
Outbreak ID – Jurisdiction-assigned	A jurisdiction-assigned ID for an identified outbreak.
NORS ID	The outbreak ID from CDC's National Outbreak Reporting System (NORS) for the outbreak this case report is associated with.

Birthing Parent-Infant Linkage

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Birthing Parent - Infant Linkage

Congenital Rubella MMG

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type	CDC Priority
START: Maternal Clinical History				
Did the Mother Have a Rash	85733-4	Did the mother have a maculopapular rash during time she was pregnant with the infant that is being investigated as possibly having CRS?	Coded	1
What was the Mother's Rash Onset Date	85732-6	What was the mother's rash onset date?	Date	1
Mother's Rash Duration (in days)	85731-8	How many days did the mother's rash reported in this investigation last?	Numeric	2
Did the Mother Have a Fever	85730-0	Did the mother have a fever during time she was pregnant with the infant that is being investigated as possibly having CRS?	Coded	1
What was the Mother's Fever Onset Date	85729-2	What was the mother's fever onset date?	Date	1
Mother's Fever Duration (in days)	85728-4	How many days did the mother's fever reported in this investigation last?	Numeric	2
Did the Mother Have Arthralgia/Arthritis	85794-6	Did the mother have arthralgia/arthritis during time she was pregnant with the infant that is being investigated as possibly having CRS?	Coded	2
Did the Mother Have Lymphadenopathy	85727-6	Did the mother have lymphadenopathy during time she was pregnant with the infant that is being investigated as possibly having CRS?	Coded	2
END: Maternal Clinical History				

Birthing Parent - Infant Linkage

Congenital Syphilis MMG

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type	CDC Priority
Mother's Local Record ID	INV2084	Provide the local record ID used for reporting mother's case of syphilis (DE Identifier "N/A: OBR-3" in the Generic portion of the STD message). This will be used for linking the reported congenital syphilis case to the mother's reported syphilis case.	Text	1
Mother's National Reporting Jurisdiction	INV2085	Provide the national reporting jurisdiction used for reporting mother's case of syphilis (DE Identifier 77968-6 in the Generic portion of the STD message). This will be used for linking the reported congenital syphilis case to the mother's reported syphilis case.	Coded	1

Birthing Parent-Infant Linkage

Is there a preferred method to be a "default approach" to standardize linkage between a maternal case and an infant case?

- Sending birthing parent's case ID/ birthing parent's national reporting jurisdiction

or

- Re-sending data elements as needed from a birthing parent's case in the infant case notification

Poll 6 - Birthing Parent-Infant Linkage

What is your preferred "default approach" to mother/infant case linkage?

- Transmitting birthing parent's case ID/ jurisdiction in infant case

- Transmitting relevant data elements from the birthing parent's case in the infant case

Poll 7 – Birthing Parent-Infant Linkage

Should these birthing parent - infant linkage data elements be considered part of core data for surveillance?

- Yes – Add to minimum set
- No – Just support a standard approach

Data Element (DE) Name	Data Element Description	Data Type
Birthing Parent's Local Record ID	Provide the local record ID used for reporting birthing parent's case of this condition.	Text
Birthing Parent's National Reporting Jurisdiction	Provide the national reporting jurisdiction used for reporting birthing parent's case of this condition.	Coded

Next Steps

Next Steps

Upcoming team meetings:

- **7/12 1-2pm ET – Laboratory?**
- **7/19 1-2pm ET – Identifiers**
  - Identifier structure, linking labs and cases
- Link to Sign Up

ERU and Clinical Manifestations documents will go out to their respective DEST teams soon.

The next large DSWG call will be June 28th, 1-2pm.

- Medication/Treatment discussion