

# Data Standardization Work Group (DSWG)

September 15, 2023



Council of State and Territorial Epidemiologists

***Please mute phone/ headset/ computer audio!***

## Agenda

- Welcome & Announcements
- Pregnancy Status 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.

# Administrative Updates



- Hospitalization - Currently seeking feedback on the draft of recommendations
  - **Deadline for input is close of business today!**
  - Includes background for current overall effort, to use as a framework for subsequent data classes
- Travel – Draft recommendations currently in process. Will soon be available for feedback from DSWG members.

# Data Element-Specific Teams



## Team Member Expectations

- Attend monthly Team meeting(s) regularly to discuss data element(s)
- Participate actively during and between meetings
- Provide feedback on how your jurisdiction or program (if applicable) collects and uses information related to the data element prior to the first Team meeting
  - All DSWG members are invited to participate in this step, but expectation is higher for Team members
- Respond to polls conducted between Team meetings
- Review and provide input and comments between meetings on any draft documentation using shared Word documents

There is **NO** expectation for Team members to write documents, lead meetings, or prepare slides.

# 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 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?

# Pregnancy



# Potential Core Data Elements



| Data Element               | Number of NNDSS Conditions? | NNDSS value set or coding system                 | Potential for Electronic Data Capture                                                                                                                                                                                                                                                                  |
|----------------------------|-----------------------------|--------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Pregnancy Status           | Gen v2 (widely applicable)  | Yes/No/Unknown                                   | <ul style="list-style-type: none"><li>• PSWG recommends capture through ELR for <u>certain conditions</u></li><li>• Present as data element in eCR, but not consistently populated</li><li>• Recommended value set for ELR/eCR includes "pregnant, not pregnant, possibly pregnant, unknown"</li></ul> |
| Estimated Date of Delivery | 1 condition                 | Date                                             | <ul style="list-style-type: none"><li>• Present as data element in eCR, but not consistently populated</li><li>• Recommended by the PSWG as a minimum data element to include in regulatory language</li></ul>                                                                                         |
| Pregnancy Outcome          | 12 conditions               | Four Different Value Sets Used Across Conditions | <ul style="list-style-type: none"><li>• Not present in current eCR IG (v1.1) but present as a data element in v3.1</li></ul>                                                                                                                                                                           |

# Potential Core Data Elements



| Data Element               | Definition                                                                        | Value set or coding system | Abstracted / Derived / Created | Recommendations for Input Data Source(s)                                                                                  |
|----------------------------|-----------------------------------------------------------------------------------|----------------------------|--------------------------------|---------------------------------------------------------------------------------------------------------------------------|
| <b>Pregnancy Status</b>    | <b>Pregnancy status of the case at the time of the event.</b>                     | <b>Yes/No/Unknown</b>      | <b>Derived</b>                 | <ul style="list-style-type: none"> <li>• <b>Case investigation</b></li> <li>• <b>eCR</b></li> <li>• <b>ELR</b></li> </ul> |
| Estimated Date of Delivery | Estimated date of delivery of the pregnancy.                                      | Date                       | Abstracted/ Derived            | <ul style="list-style-type: none"> <li>• Case investigation</li> <li>• eCR</li> </ul>                                     |
| Pregnancy Outcome          | If the case was pregnant at the time of the event, the outcome of that pregnancy. | ?                          | Dependent on Value Set         | <ul style="list-style-type: none"> <li>• Case investigation</li> <li>• eCR (Potential Future)</li> </ul>                  |

Pregnancy Status: Core Data Element, as defined here, with 81% consensus.

EDD & Outcome: About 2/3 Core Data Element, with 1/3 not a Core Data Element.

# Timing of Pregnancy



- Estimated Date of Delivery was proposed as a Core Data Element to capture the timing within the pregnancy associated with the event
  - ~2/3 of the DSWG support it as a core data element.
  - Enough to include it as “weak support”.
- Chat discussion suggested Gestational Age is more reliably available.
  - May also require a date associated with it.

## **For Discussion:**

Is one of these better than another? Should both be included?

# 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

# Polling - Timing of Pregnancy CSTE

Should either Estimated Date of Delivery or Gestational Age/Gestational Age Recorded Date be a core data element?

- Yes, only one.
- Yes, both.
- No, neither.

*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.

# Polling - Timing of Pregnancy



Should Estimated Delivery Date be a core data element?

- Yes
- No

Should Gestational Age/G.A. Recorded Date be a core data element?

- Yes
- No

*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.

# Pregnancy Outcome Value Sets – Bug or Feature?



| Data Element      | Definition                                                                        | Value set or coding system | Abstracted / Derived / Created | Recommendations for Input Data Source(s)                                                             |
|-------------------|-----------------------------------------------------------------------------------|----------------------------|--------------------------------|------------------------------------------------------------------------------------------------------|
| Pregnancy Outcome | If the case was pregnant at the time of the event, the outcome of that pregnancy. | ?                          | Dependent on Value Set         | <ul style="list-style-type: none"> <li>Case investigation</li> <li>eCR (Potential Future)</li> </ul> |

| Pregnancy Outcome (CDC) - Arboviral   | Pregnancy Outcome (Listeria) | Birth Outcome (Rubella) | Fetal Outcome (RIBD)          |
|---------------------------------------|------------------------------|-------------------------|-------------------------------|
| Fetal death (Fetal loss)              | Fetal death                  |                         |                               |
| Delivery (Live birth)                 | Delivery (live birth)        |                         |                               |
| Still pregnant                        | Still pregnant               |                         | Still pregnant                |
| Therapeutic termination of pregnancy  | Induced Abortion             |                         | Induced Abortion              |
|                                       | Other (specify)              | Other                   |                               |
|                                       | unknown                      | Unknown                 | Unknown                       |
| Perinatal death                       |                              |                         | Live birth/neonatal death     |
| Premature birth of newborn            |                              | Live Birth with CRS     | Survived, clinical infection  |
| Stillbirth (Intrauterine Fetal Death) |                              |                         | Abortion/still birth          |
|                                       |                              |                         | Survived, no apparent illness |

# Pregnancy Outcome Suggested Value Set



- Still Pregnant (77386006 Patient currently pregnant)
- Induced Abortion (57797005 Induced termination of pregnancy)
- Intrauterine Fetal Death < 20 weeks (17369002 Miscarriage)
- Intrauterine Fetal Death >20 weeks (237364002 Stillbirth)
- Perinatal Death (10588007 Perinatal death)
- Live Birth – At Term (21243004 Term birth of newborn)
- Live Birth – Premature (282020008 Premature delivery)
- Unknown

# Polling - Pregnancy Outcome



Should Pregnancy Outcome be considered a core data element for surveillance?

- Yes
- No

## *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.

## Other potential data elements related to pregnancy



- Premature Infant
- Gestational Age Determination Method
- Infant Number
- Number of Pregnancies
- If Mother Has Given Birth in US, Number of Births Delivered in US
- Birth Weight
- Last Menstrual Period
- Number of Total Live Births

# Polling - Additional Pregnancy Variables



Are there any other pregnancy related variables that need to be added as recommendations for core data for surveillance?

- Yes
- No

*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



- Look out for next steps via email. Poll? Draft document?
- Upcoming team meetings:
  - 10/13 1-2pm ET– SOGI
  - 10/20 1-2pm ET– Pregnancy or I/O?
  - [Link to Sign Up](#)
- The next large DSWG call will be the beginning of December.