

# Sexual Orientation and Gender Identity (SOGI)

CSTE DSWG Data Element Specific Team

12/15/2023



Council of State and Territorial Epidemiologists

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

## Agenda

- Welcome & Announcements
- SOGI Discussion/Polling
  - Gender Identity
  - Sex Assigned at Birth
  - Sex/Current Sex
- Next Steps
- Wrap-Up & Adjourn

# DEST Opportunities for Participation



- The Data-element Specific Team (DEST) Interest Sign-Up sheet has been updated to include known future data classes:
  - Immunization History (first meeting today at 1PM ET!)
  - Exposure/Risk/Underlying Conditions
  - Death
  - Signs/Symptoms/Clinical Manifestations
  - Identifiers (Case/Event Related/Laboratory)
  - Laboratory
  - Race/Ethnicity/Tribal Affiliation
  - Medication/Treatment
  - Reporting Source
  - Disability
  - Social Determinants of Health

Link to Sign-Up sheet:

<https://app.smartsheet.com/b/form/3da89d48bda94fc7a33c4a8a505fe54a>

If you have signed up previously but feel you are not getting the emails/meeting invites that you expected to get, please reach out directly to [llane@jmmichael-consulting.com](mailto:llane@jmmichael-consulting.com).

- Pregnancy Core Surveillance Data Standardization Recommendation draft
  - Open for input from entire DSWG
  - [located here for review](#)
  - **Please provide input [in this form](#) by the close of business, Tuesday 1/2/24**
- Industry and Occupation Core Surveillance Data Standardization Recommendation draft
  - Open for input from Industry/Occupation DEST members only
  - **Please provide input by the close of business, Tuesday 1/2/24**

# 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 survey](#) provided for additional input
  - Be courteous and be open to new ideas

## **Active participation encouraged for all!**

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

# In-scope vs Out-of-scope



## What this is:

- Discussion about data elements which are:
  - collected at the jurisdiction and sent to CDC for surveillance purposes
  - Abstracted, calculated, or derived from a combination of electronic sources, patient interviews and chart abstractions
- Collaborative consensus building about the best ways to approach the transmission of public health data in the very fluid landscape of sex and gender identity

## What this is not:

- Discussion of data elements for research studies
- Recommendations for public facing surveys
- Limitations on what can be collected for a data element within a jurisdiction
- Recommendations for how to ask about gender identity or sex in a case interview
- Implementation guidance

Gender  
Identity

Sex/Current Sex  
Sex Assigned at Birth



# Current State



| Data Element    | No. of NNDSS MMGs?        | NNDSS value set or coding system                                                             | Potential for Electronic Data Capture                                                                                                                                       |
|-----------------|---------------------------|----------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Gender Identity | STD, Hepatitis v2 (draft) | Different Value sets for STD and Hepatitis                                                   | <ul style="list-style-type: none"><li>• Captured in eCR as “Gender Identity” value set in accordance with USCDI v2</li><li>• Not present as a data element in ELR</li></ul> |
| Sex at Birth    | TB, Hepatitis v2 (draft)  | <ol style="list-style-type: none"><li>1. Female</li><li>2. Male</li><li>3. Unknown</li></ol> | <ul style="list-style-type: none"><li>• Captured in eCR as “Patient Birth Sex”</li><li>• Not present as a data element in ELR</li></ul>                                     |
| Current Sex     | None Currently            | ?                                                                                            | <ul style="list-style-type: none"><li>• Not present as a data element in eCR or ELR</li></ul>                                                                               |
| Sex             | Gen v2                    | <ol style="list-style-type: none"><li>1. Female</li><li>2. Male</li><li>3. Unknown</li></ol> | <ul style="list-style-type: none"><li>• Not present as a data element in eCR</li><li>• Captured in ELR as Administrative Sex (PID-8) with broader value set</li></ul>       |

# Gender Identity



# Gender Identity DEST input



- A general desire for flexibility and inclusiveness
- Need to be able to roll data up into categories which are useful and which might potentially (someday) have an associated denominator
- Current high variability as to how states account for the transgender population
  - o Sex Assigned at Birth (SAAB) vs Gender Identity (GI) discordance (with mixed reviews)
  - o Transgender options within GI
  - o Separate transgender question
- SOGI variables require extra consideration to OMB review and approval of these standards

# Gender Identity



| Data Element    | Definition                                                                                                                                                                  | Value set or coding system                                                                                                                                                                                                                                        | Abstracted/ Derived/ Created | Potential Input Data Source(s)                                                   |
|-----------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------|----------------------------------------------------------------------------------|
| Gender Identity | Person identified gender identity (i.e., an individual's personal sense of being a man, woman, or another gender, regardless of the sex that person was assigned at birth). | <ol style="list-style-type: none"><li>1. Woman/Girl</li><li>2. Man/Boy</li><li>3. Transgender</li><li>4. Non-binary or genderqueer</li><li>5. Two Spirit</li><li>6. Another gender, please specify</li><li>7. Choose not to disclose</li><li>8. Unknown</li></ol> | Abstracted<br>Derived        | <ul style="list-style-type: none"><li>•Case investigation</li><li>•eCR</li></ul> |

## Notes:

- Question would be multi-select.
- There would be an associated free-text question to capture "Another gender, please specify".

# Polling – Gender Identity



Should Gender Identity, as defined below, be considered core data for surveillance?

- Yes
- No

## Definition

*Person identified gender identity (i.e., an individual's personal sense of being a man, woman, or another gender, regardless of the sex that person was assigned at birth).*

*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 – Gender Identity



Is the provided value set an acceptable set for Gender Identity?

- Yes
- No

## Value set or coding system

1. Woman/Girl
2. Man/Boy
3. Transgender
4. Non-binary  
or genderqueer
5. Two Spirit
6. Another  
gender, please specify
7. Choose not to disclose
8. Unknown

### *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.

# Sex assigned at Birth



# Sex Assigned at Birth



Sex at Birth is currently used in 2 condition-specific MMGs. Should this data element, renamed as "Sex Assigned at Birth," be defined for core public health case surveillance?

| Data Element          | Definition                                                                           | Value set or coding system                                                                                                           | Abstracted/ Derived/ Created | Potential Input Data Source(s)                                                   |
|-----------------------|--------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------|------------------------------|----------------------------------------------------------------------------------|
| Sex Assigned at Birth | Sex a person was assigned at birth, for example on their original birth certificate. | <ol style="list-style-type: none"><li>1. Female</li><li>2. Male</li><li>3. Intersex/Non-binary marker/X</li><li>4. Unknown</li></ol> | Abstracted<br>Derived        | <ul style="list-style-type: none"><li>•Case investigation</li><li>•eCR</li></ul> |

# Polling – Sex Assigned at Birth



Should Sex assigned at Birth, as defined below, be considered core data for surveillance?

- Yes
- No

## Definition

Sex a person was assigned at birth, for example on their original birth certificate.

### *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 – Sex Assigned at Birth



Is the provided value set an acceptable set for Sex assigned at birth?

- Yes
- No

| Value set or coding system      |
|---------------------------------|
| 1. Female                       |
| 2. Male                         |
| 3. Intersex/Non-binary marker/X |
| 4. Unknown                      |



*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.

Sex/Current Sex



Subject's Sex is currently used in the Gen V2 MMG. How should this data element be defined for core public health case surveillance?

| Data Element | Definition                  | Value set or coding system                                                                                                | Abstracted/<br>Derived/<br>Created | Potential Input<br>Data Source(s)                                                              |
|--------------|-----------------------------|---------------------------------------------------------------------------------------------------------------------------|------------------------------------|------------------------------------------------------------------------------------------------|
| Sex          | <b>Person's Sex</b>         | <ol style="list-style-type: none"><li>1. Female</li><li>2. Male</li><li>3. Unknown</li><li>4. Non-binary marker</li></ol> | Abstracted<br>Derived              | <ul style="list-style-type: none"><li>• Captured in ELR as PID-8, Administrative Sex</li></ul> |
| Current Sex  | <b>Person's Current Sex</b> | <ol style="list-style-type: none"><li>1. Female</li><li>2. Male</li><li>3. Unknown</li><li>4. Non-binary marker</li></ol> | Abstracted<br>Derived              | <ul style="list-style-type: none"><li>• Not present as a data element in eCR or ELR</li></ul>  |

# Sex and/or Current Sex



For Discussion:

*Sex **OR** Current Sex **OR** Both **OR** Neither?*

## Current Sex

- Timing sensitive
- May suggest a more specific source of information than Sex from ELR or eCR

## Sex

- More general
- Can reflect many data sources
- May be all that is available in many cases

# Polling – Sex Data Elements



Which of the following data elements would you like to include as core?

- Sex
- Current Sex
- Both
- Neither
- Just one, either or

*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.
- Upcoming team meetings:
  - 12/15 1-2pm ET– Immunization (Up next – Same zoom link!)
  - 01/12 1-2pm ET – Risk, Exposure and Underlying Conditions
  - **1/19 1-2pm ET– Immunization** (or Death?)
  - [Link to Sign Up](#)
- The next large DSWG call will be at the end of February.