

Sexual Orientation and Gender Identity (SOGI)

CSTE DSWG Data Element Specific Team

11/17/2023



Council of State and Territorial Epidemiologists

Please mute phone/ headset/ computer audio!

Agenda

- Welcome & Announcements
- DSWG Opportunities for Participation
- SOGI Discussion/Polling
 - Feedback from between meeting 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 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.

DSWG Opportunities for Participation



- The Data-element Specific Team Interest Sign-Up sheet has been updated to include known future data classes:
 - Immunization History
 - Exposure/Risk/Underlying Conditions
 - Identifiers (Case/Event Related/Laboratory)
 - Death
 - Signs/Symptoms/Clinical Manifestations
 - 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>

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 class 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
- **Review any pre-recorded background presentations sent via email**

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

- 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?

Between meeting polling: Response Summary



- Questions covered most of the remaining SOGI definitions and questions.
- These polls were not used to make final decisions about definitions or value sets.
- Answers were used to refine the initial suggestions into the ones that will be presented here.
- 43 Responses
 - 15 states
 - 3 local jurisdictions
 - 14 individuals from CDC



Sexual Orientation



Core Data Element Sexual Orientation



Reminder:

Sexual Orientation was voted in as a core surveillance data element at the Oct 13 SOGI DEST meeting.

Data Element	Definition	Value set or coding system	Abstracted/ Derived/ Created	Potential Input Data Source(s)
Sexual Orientation	A person's identification of their emotional, romantic, sexual, or affectional attraction to another person.	1. Asexual 2. Bisexual 3. pansexual 4. Straight or heterosexual 5. Lesbian, gay or same-gender loving 6. Not Listed, please specify 7. Unsure/Questioning 8. Prefer not to answer 9. Unknown	Abstracted	•Case investigation

Sexual Orientation Value Set: Between meeting poll results



Suggested

1. Asexual
2. Bisexual
3. Straight or heterosexual
4. Lesbian, gay, or homosexual
5. Not Listed, please specify
6. Don't know
7. Choose not to disclose

Votes

- No, too limited (6)
- Yes (23)
- Yes, with adjustment (13)

Suggestion from comments

- drop homosexual
- add an unknown option
- Add pansexual

Polling – Sexual Orientation



Is the provided value set an acceptable set for Sexual Orientation?

- Yes
- No

Value set or coding system

1. Asexual
2. Bisexual
3. pansexual
4. Straight or heterosexual
5. Lesbian, gay or same-gender loving
6. Queer
7. Not Listed, please specify
8. Unsure/Questioning
9. Prefer not to answer
10. 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.

Gender
Identity

Sex/Current Sex/Sex
(assigned) at Birth



Potential Core Data Elements

Sex and Gender Identity



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

Sex and Gender Identity Discussion Points



What is the public health importance of a Sex/Gender variable?

- a. Outreach?
- b. Physical disease impact/risk?