

Sexual Orientation and Gender Identity (SOGI)

CSTE DSWG Data Element Specific Team

10/13/2023



Council of State and Territorial Epidemiologists

Please mute phone/ headset/ computer audio!

Agenda

- Welcome & Announcements
- DSWG Opportunities for Participation
- Sexual Orientation and Gender Identity (SOGI) Background
- SOGI 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 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:
 - Exposure/Risk/Underlying Conditions
 - Immunization History
 - 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>

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
- **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?

Background Information: SOGI (CDC)



Potential data elements related to Sexual Orientation and Gender Identity



- Sexual Orientation
- Gender Identity
- Sex at Birth
- Current Sex
- Pronouns
- Sex for Clinical Use
- Recorded Sex or Gender

- Administrative Sex (PID-8)
 - Value set: Female, Male, Ambiguous, Not applicable, Other, Unknown
 - Concepts specifying a patient's sex for administrative purposes.
 - Non-Binary was introduced as a concept in v2.9 to allow for *situations where the gender or sex representation of the individual is not strictly male, or strictly female, and is driven by jurisdictional requirements, personal needs, or legal boundaries.*
- Sexual Orientation and Gender Identity Data Exchange Profile
 - Released September 2023
 - Can be used in any message structure in any version
 - Includes details for including sexual orientation, gender identity, and pronouns as OBX segments.

Sexual Orientation (Version 2-4)

A person's emotional, romantic, sexual, or affectional attraction to another person.

- Value sets: *Lesbian, gay or homosexual; Straight or heterosexual; Bisexual; Something else, please describe; Don't know; Choose not to disclose*

Gender Identity (Version 2-4)

A person's internal sense of being a man, woman, both, or neither.

- Value sets: *Male; Female; Female-to-Male; Male-to-Female; Identifies as non-confirming gender; additional gender category or other, please specify; choose not to disclose*

Sex (Assigned at Birth) (Version 2)

No definition available.

- This evolved from Birth Sex(v1)
- Value sets: *Female; Male; Unknown*

Sex (Version 3-4)

Documentation of a specific instance of sex and/or gender information.

CDA Mappings

- Gender Identity Observation
 - This observation represents the gender identity of the patient, defined as: "One's basic sense of being male, female, or other gender (for example, transgender or gender queer).
 - Code: 76691-5
 - Value set: Gender Identity USCDI core
- Birth Sex Observation
 - This observation represents the sex of the patient at birth. It is the sex that is entered on the person's birth certificate at time of birth.
 - Code: 76689-9
 - Value set: ONC Administrative Sex
- Sexual orientation
 - Not included in eCR CDA Implementation Guide (IG)
 - Included in C-CDA companion guide

FHIR (Fast Healthcare Interoperability Resources)



- Sexual Orientation Observation
 - Resource Profile: US Core Sexual Orientation Observation Profile
 - Code: 76690-7
- US Core Birth Extension: A code classifying the person's sex assigned at birth as specified by the Office of the National Coordinator for Health IT (ONC). This extension aligns with the C-CDA Birth Sex Observation.
- Gender Identity Data Element
 - US Core Gender Identity Extension
 - genderIdentity Extension
 - Individual Gender Identity Extension

Prior work on SOGI



Gender Harmony Project (GHP)

- Aims to capture "sex" and "gender" in health models using proven methods with the goal of creating a balloted document defining use-context collections and appropriate value sets
- Recommendations guide the implementation of sex- and gender-related EHR elements, including suggestions for clinical use
- HL7 GHP concepts offer flexibility and durability in sex/gender data collection and can be templated as HL7-RSGOBC for interoperability purposes by individual jurisdictions
- Recommended Data Elements (DEs)
 - Gender Identity (GI)
 - Sex Parameter for Clinical Use (SPCU)
 - Recorded Sex and Gender (RSG)
 - Pronouns
 - Name to Use

National Academies of Science, Engineering, and Medicine (NASEM) SOGI Data Collection Report

- Evaluated existing measures of sex, gender identity, and sexual orientation to
 - Assess health and health disparities in the population,
 - The role played by interpersonal and structural determinants of health
- Focused on those measures associated with proximal and distal minority stressors
 - Gender identity
 - Transgender experience and identity
 - Intersex status
 - Sexual orientation
- Provides recommendations for specific measures to help standardize federal collection for
 - Surveys
 - Research
 - Administrative
 - Clinical and other health settings

Prior work on SOGI



NASEM SOGI Data Collection Report Recommendations

Concepts	Question	Response options
sexual orientation identity	Which of the following best represents how you think of yourself? (SELECT ONE):	- Lesbian or gay - Straight, that is, not gay or lesbian - Bisexual - [If respondent is American Native] Two-Spirit - I use a different term: [free-text] - (Don't know) - (Prefer not to answer)
sex assigned at birth and gender identity	Q1: What sex were you assigned at birth, on your original birth certificate?	- Female - Male - (Don't know) - (Prefer not to answer)
	Q2: What is your current gender? [Mark only one]	- Female - Male - Transgender - [If respondent is American Native] Two-Spirit - I use a different term: [free text] - (Don't know) - (Prefer not to answer)

Prior work on SOGI



- Recommendations on the Best Practices for the Collection of Sexual Orientation and Gender Identity Data on Federal Statistical Surveys (OMB)
 - Importance of research to identify best questions, order, and value sets
 - Considerations for including SOGI items on surveys
 - Focus on PRIMARY data collection where the order of the questions are controlled and administered the same way every time
 - Example approaches for collection and reporting for the large, general purpose statistical surveys that currently collect SOGI data
 - Not enough evidence to support classifying those who report “another gender identity” into the “gender minority” category

Case Notifications to CDC

Message Mapping Guides (MMGs)



- Generic v2 MMG

Data Element Name	Data Element (DE) Description	Value set
Subject's Sex	Subject's current sex	1. Female 2. Male 3. Unknown

- Hepatitis, STD and Tuberculosis MMGs

Data Element Name	Data Element (DE) Description	Value set
Sex at Birth	Hepatitis MMG: What sex were you assigned at birth, on your original birth certificate? TB MMG: What was the patient's sex at birth?	1. Female 2. Male 3. Unknown

Case Notifications to CDC

Message Mapping Guides (MMGs)



Data Element Name	Data Element (DE) Description	Hepatitis Value set	STD Value set
Gender Identity	Patient identified gender identity (i.e., an individual's personal sense of being a man, woman, or other gender, regardless of the sex that person was assigned at birth)	1. Female 2. Male 3. Female-to-male/Transgender Male/Trans Man 4. Male-to-Female/Transgender Female/Trans Woman 5. Genderqueer, neither exclusively male nor female 6. Additional gender category or other, please specify 7. Choose not to disclose	1. Cisgender/Not transgender 2. Female-to-make transsexual 3. Male-to-female transsexual 4. Transgender unspecified 5. Unknown
Sexual Orientation	Patient identified sexual orientation (i.e., an individual's physical and/or emotional attraction to another individual of the same gender, opposite gender, or both genders)	1. Bisexual 2. Straight or heterosexual 3. Lesbian, gay, or homosexual 4. Something else, please describe 5. Don't know 6. Choose not to disclose	1. Bisexual 2. Straight (not gay or lesbian) 3. Gay or lesbian 4. Other 5. Unknown

Jurisdiction samples



Arizona

- Gender is case level, under patient demographics
- Sexual orientation is morbidity based and currently captured for Hep A, Hep C, Hep E, Meningococcal, and HIV
 - HIV only
 - Straight or Heterosexual
 - Gay or Lesbian
 - Bisexual
 - Queer, Pansexual, and/or questioning
 - Declined to answer
 - Unknown

A screenshot of a web-based form titled "Demographics". It features a dropdown menu for "Gender" with the following options: Man, Woman, Transgender Man, Transgender Woman, Transgender Unspecified, Nonbinary/Genderqueer/Gender non conforming, Two-spirit or other native, Agender, Polygender/Pangender, Unknown, and Declined to answer. Below the gender dropdown is a field for "Tribal Affiliation" with a question mark icon and a "Country" field with a dropdown arrow.

MORBIDCD	Qcode	Label	Type	Dropdown/Notes
				Bisexual Heterosexual Homosexual Unknown
HAV/HEV	NSEXPREF	What is the patient's sexual preference?	DROPDOWN	Straight or Heterosexual Gay or Lesbian Bisexual Queer, Pansexual, and or/ questioning Declined to answer
HCV	NSEXPREF	What is/was the patient's sexual orientation?	DROPDOWN	Unknown
				Yes No Not applicable Unknown
MNG	QMSM	Is the case a man who has sex with men (MSM)?	DD	

Jurisdiction samples



Utah

Data Element	Field Type	Values	Definition
Birth sex	Coded	4 options including [blank], "Unknown", "Female", and "Male"	The biological sex that a person is assigned at birth.
Current gender	Coded	4 options including [blank], "Unknown", "Female", and "Male"	How an individual perceives themselves or identifies based on behavior, lifestyle, and life experience. This may not align with their sex assigned at birth.
Gender identity	Coded	"Male", "Female", Transgender -MTF, Transgender-FTM, Transgender unspecified, Declined to answer, Additional (specify), Not Asked	
Gender identity	Coded	CIS Male, CIS Female, MTF Transgender, FTM Transgender, Unspecified transgender, queer/gender non-binary, unknown, Other, Refused	
Sexual Orientation	Coded	"bisexual", "refused", "Heterosexual/Straing (not gay or lesbian)", "Lesbian/gay/homosexual", "other/don't now"	

Jurisdiction samples



Tennessee

Data Element	Field Type	Values	Definition
Current sex	Coded	"Ambiguous", "Female", "Hermaphrodite", "Male", "Not applicable", "other", "transsexual", "unknown"	
Birth sex	Coded	"Ambiguous", "Female", "Hermaphrodite", "Male", "Not applicable", "other", "transsexual", "unknown"	
Gender identity	Coded	"choose not to disclose", "Female", "Female-to-Male/Transgender Male/Trans Man", "Genderqueer", "Male", "Male-to-Female/Transgender Female/Trans Woman", "unknown"	
Additional gender	Text	N/A	free text to go with gender identity if a value is not offered
Sexual Orientation	Coded	"bisexual", "choose not to disclose", "don't know", "Heterosexual", "Lesbian or gay", "other"	

Jurisdiction samples



Oregon

Data Element	Field Type	Values
Pronouns	Coded	She/her; He/him; They/them; Ell; El; Elles; none use my name; not listed, specify; don't know; don't know what this is asking; don't want to answer
Gender describe	Text	describe your gender in any way you prefer
Gender	Coded	"man/boy", "Woman/girl", "non-binary", genderqueer", "agender/no gender"; "questioning"; "don't know", "don't know what asking"; "don't want to answer"; "not listed (specify)"
Transgender	Coded	"Yes", "No", "Don't Know", "Questioning", "don't know what asking", "don't want to answer"
Orientation describe	Text	describe your sexual orientation or sexual identity in any way you want
Orientation	Coded	"same-gender loving", 'same-sex loving", "Lesbian", "Gay", "Bisexual", "Pansexual", "Straight (attracted only or mainly to other genders)", "asexual", "queer", "Questioning", "Don't Know", Not listed, specify", "don't know what asking", "don't want to answer"

Jurisdiction samples



Oregon (cont.)

Data Element	Field Type	Values
Current sex (case)	Coded	Female; Male; Non-binary; Other; Unknown; Refused
Sex at Birth (person)	Text	Female; Male; Non-binary; Other; Unknown; Refused
Gender_2	Coded	Female; Male; Transgender Man; Transgender Woman; Transgender, unspecified; Gender non-binary or gender queer; Unknown; Refused

Case Notifications to CDC

Message Mapping Guides (MMGs)



- Modifications suggested by case surveillance workgroup within the Federal Committee on Statistical Methodology (FCSM) Interest Group: Measuring SOGI Research Group

DE Name	Current DE Descriptions	Suggested DE Descriptions
Subject's Sex	Subject's current sex	Documentation of a specific instance of sex and/or gender information.
Sexual Orientation	Patient identified sexual orientation (i.e., an individual's physical and/or emotional attraction to another individual of the same gender, opposite gender, or both genders)	<i>A person's identification of their emotional, romantic, sexual, or affectional attraction to another person</i>
Gender Identity	Patient identified gender identity (i.e., an individual's personal sense of being a man, woman, or other gender, regardless of the sex that person was assigned at birth)	Patient identified gender identity (i.e., an individual's personal sense of being a man, woman, or other another gender, regardless of the sex that person was assigned at birth)
Sex at Birth	What sex were you assigned at birth, on your original birth certificate?	Assigned sex at birth, for example what is on the original birth certificate

Case Notifications to CDC

Message Mapping Guides (MMGs)



- Modifications suggested by FCSM

Name	Current Value sets	FCSM Suggested Value sets
Sexual Orientation	1. Bisexual 2. Straight or heterosexual 3. Lesbian, gay, or homosexual 4. Something else, please describe 5. Don't know 6. Choose not to disclose	1. Bisexual 2. Straight or heterosexual 3. Lesbian, gay, or homosexual 4. Something else, please describe Please specify 5. Don't know 6. Choose not to disclose 7. Asexual
Gender Identity	1. Female 2. Male 3. Female-to-male/Transgender Male/Trans Man 4. Male-to-Female/Transgender Female/Trans Woman 5. Genderqueer, neither exclusively male nor female 6. Additional gender category or other, please specify 7. Choose not to disclose	1. Female 2. Male 3. Female-to-male/Transgender Male/Trans Man 4. Male-to-Female/Transgender Female/Trans Woman 5. Genderqueer Non-binary, neither exclusively male nor female* 6. Additional Another gender -category or other, please specify 7. Choose not to disclose
Sex at Birth	1. Female 2. Male 3. Unknown	1. Female 2. Male 3. Unknown 4. Non-binary marker

*expand value options to not lump +/- guidance on what would fall under this value

Sexual Orientation and Gender Identity (SOGI)



Potential Core Data Elements Sexual Orientation



Data Element	No. of NNDSS MMGs?	NNDSS value set or coding system	Potential for Electronic Data Capture
Sexual Orientation	HIV, Hepatitis v2 (draft)	Both MMGs have different value sets	• Not present as a data element in eCR or ELR

Potential Core Data Elements Sexual Orientation



For discussion:

Sexual Orientation is currently a condition-specific data element. Should this data element be defined for core public health case surveillance?

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. Bisexual 2. Straight or heterosexual 3. Lesbian, gay, or homosexual 4. Other, please specify 5. Don't know 6. Choose not to disclose 7. Asexual	Abstracted	•Case investigation

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

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?

Polling – Sexual Orientation



Should Sexual Orientation be considered core data for surveillance?

- Yes – as defined here
- Yes – defined differently
- No

Definition

A person's identification of their emotional, romantic, sexual, or affectional attraction to another person.

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 – Sexual Orientation



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

- Yes
- No, too broad
- No, too limited

Value set or coding system

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

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.