Meeting: CSTE Data Standardization – Sexual Orientation and Gender Identity (SOGI) -Element Specific Team Meeting
Date: October 13, 2023
Attendees: 77

CSTE (4)	PHAs (35)	CDC (32)
Annie Fine Becky Lampkins Gillian Haney Megan Toe **JMC (4)** Erin Kough Laura Lane Natalie Raketich Susan Downer **Unknown Affiliation (2)** Maribeth Hoyle Tracy Smith	Co-Chairs Laura Erhart |AZ Molly Crockett |MA) Other Abi Collingwood | UT Allison Schleicher | NV Amy Bogucki | TN Amy Saupe | MN Annalyse Bergman | AL Benjamin Schram | ND Brynn Stopczynski | WA DOH Cher Levenson | WA DOH Chris Dumas | SD Deepani Jinadasa | UT Ej Klingler | NYC Graham Crawbuck |WA DOH Jacki Griffin | NYS JK | NB Jordan M | NH DHHS Kayleigh Nerhood | GA Kyra Kofodimos| IN L Espinosa | IN Li Jiao | Harris County Maria Jaurretche | DC Health Melanie Epstein-Corbin (CA) Monique Birmiel | IN	Abhilasha Saxena | GDIT Allie Tuttle Allison Miller Andre Dailey Angie Agunloye | GDIT Danielle Tack Dave Jackson David Huang Doris McGinness | GDIT Hannah Bowen Jennifer Fagan John Gerstle Josh Bagley Juliana Cyril Kevin Heslin Lauren Lambert Lesliann Helmus Lexi Balaji Luis Hernandez Maddie Stewart (NBS) Melinda Thomas Melissa Pagaoa Mohua Basu Nicole Lindsey Noreen Kloc Pei-Jean Feng

	Nicole | ADHS Rebekah Cook | OR Ryan Burke | MA DPH Sam Hawkins | OR Health Authority Sequoia Rent | DE Shannon Lawrence | NB Tia Falzarano | MI Tom Loftus | IN Trish McLendon | CA Vajeera Dorabawila | NYSDOH Yuritzy Glez Pena | OR	Peter Boersma Renee Boehmert Robert Pratt Sara Johnston Sonia Singh Sundak

**SOME INDIVIDUALS DIALED IN; THE NAMES ARE UNKNOWN, AND THEY ARE LEFT OFF OF THE ATTENDANCE*

HIGH-LEVEL MEETING NOTES (*REFER TO MEETING SLIDES FOR MORE DETAIL AS NEEDED*):

Meeting Ground Rules

- We welcome everyone's opinions and active participation from jurisdictions, CDC programs, CSTE membership, etc.
- As we work through data elements/classes, we strive for 80/20 consensus. If consensus is not reached, JMC will defer to Co-Chairs for the next steps.
- We'll be monitoring the chat, and please use this for discussions.
- There is always a DSWG post-meeting input form participants can submit at any time.

DSWG Opportunities for Participation

- **[Action Requested]** Please sign up for upcoming data elements on the DEST Sign-Up here.
- The list has been updated and is more comprehensive than when initial sign-ups occurred.
- On October 20 will be Industry and Occupation
- After SOGI or Industry and Occupation wrap up, the next data elements will be
    - Exposure/Risk/Underlying Conditions
    - Immunization History

Data Element-Specific Teams (DEST)

- DEST member expectations – members are not expected to write documents, lead meetings, or prepare slides. The goal is to keep members engaged in conversations around content during and between meetings.
- There is an expectation of active participation in polling, document review, discussion, and other input during and between meetings.

Core Data: In Scope for DSWG

- Focus on core data for surveillance for transmission to CDC within selected data classes.
- We will work to identify standard definitions and value sets within that definition of core data.
- This is more clearly laid out in this CSTE DSWG- Core Surveillance Definition document

Core Data FAQ

- Identification as core does not mean it is required to fill in or send an answer for every core data for every case; it is okay to leave it blank or unknown.
- Data, elements, and data classes should be considered core if they are relevant for many conditions.
- A good way of thinking of this is if we were to create a GenV3 MMG, would it make sense to include that data element here as core?

Background Information: SOGI (CDC)

Potential Core Data Elements Related to Sexual Orientation and Gender Identity

- We have a list of data elements related to sexual orientation and gender identity in some form or fashion.
- The order is aligned with what you see in our MMGs, previous data notifications, or recent discussions for gender harmony and other health information system efforts.

HL7 v2

- First discussed HL7 as a format.
- Administrative value sets are listed here, and this concept specifies a patient's sex for administrative purposes. This doesn't necessarily mean it has any physiologic, biologic, or identity that these data elements can fully understand.
- For version 2.9, they have introduced a non-binary field to be added where gender or sex representation of the individual is not strictly male or female and is driven by jurisdictional requirements, personal needs, or legal boundaries.
- There is a sexual orientation and gender identity data exchange profile released in September of 2023, and it can be used as a message structure in any version. It includes details for sexual orientation, gender identity, and pronouns as OBX statements.

U.S. Core Data for Interoperability (USCDI)

- For USCDI, you are going to see some nuances here. First, we have sexual orientation and gender identity showing up as early as version 2 and still within version 4.
- Gender Identity captures sexual orientation as a person's emotional, romantic, sexual, or affectional attraction to another person with the values listed here.
- What I'd like to point out is we had sex assigned at birth, which was put forward in Version 2. It didn't necessarily have a definition, which was part of a challenge. It did evolve from birth, sex, and version one with a limited value set of male, female, and unknown.

HL7 Clinical Document Architecture

- This was meant to align with that birth certificate. What we have seen evolve in versions 3 and 4 is sex. This is the documentation of a specific instance of sex and or gender information.

- This historic long-term data element does not necessarily capture the complexity surrounding gender and physiologic sex variations.
- Sex is also an observation, and again, it represents the sex of the patient at birth and is written on the patient's birth certificate at the time of birth. This is always important when we talk about some of the documentation and when you start to think about birth certificates, which may be updated so that this is specific to that original assignment.

FHIR (Fast Healthcare Interoperability Resources)

- Is an HL7 base format again.
- This refers to observation being a data element, not the concept of sexual orientation.
- It has a resource profile, referred to for sexual orientation, observation, and profile.
- The code used is listed here.
- There is a core birth extension that also allows for the person assigned at birth as specified by the National Coordinator's Office for Health. It aligns with companion CDAs for sex observation, gender identity, and data elements, as well, and it uses what they call extensions, where you have the US Core Gender Identity extension listed here with individual extensions.
- As many are aware, gender is something you can change over time, like sexual orientation.

Prior work on SOGI

- These are very nuanced items with nuanced terms and identity for individuals in healthcare because terms are so important, and we need to get into healthcare. Being sensitive to this, a gender Harmony project was out of terminology in vocabulary and included a lot of terminologists.
- People within the field are thinking about how we do better care. How do we ensure the proper reference ranges are used depending on developments? We wanted to capture these and help modules with methods to create a valid document, meaning it goes out to these standards. Put out there for comments for that broader buying within information systems with appropriate value sets.
- The example here is the recorded sex or gender on the original birth certificate to help promote interoperability purposes by individual jurisdictions' recommended data. Elements include gender identity, a sex parameter for clinical use. Again, this is getting at more of the variations in physiology and laboratory, in different diagnostic testing, recorded sex and gender, which again gets at more of that administrative side where it what is being provided, or an understanding of what has been provided by the patient may not be known through pronouns and name use.
- The National Academies of Science, Engineering, and Medicine, SOGI Data Collection Report came out, and they evaluated various existing measures of sex, gender identity, and sexual orientation. To assess health and health disparities in populations and the role played by interpersonal and structural determinants of health. They focus on those measures associated with proximal and distal minority stressors, such as gender identity, the transgender experience and identity, intersex status, and sexual orientation. They provided recommendations for specific measures to help standardize the Federal collection for surveys, research, administrative and clinical or health settings. We only recognize how each of these is attempted and the need for a broad approach. They looked at this comprehensively and provided some high-level recommendations within this context.
- So, some of those high-level recommendations came out. They took the concept of sexual orientation and identity with a question that is very much asking the patient or person how they think of themselves, depending on when the data collection might be occurring. They list these

response options. The report is quite long and maybe nuanced with how we think about this and what might need to be asked, depending on the context.

- Of course, in public health. In our engagement with healthcare. We are going in the broadest approach versus a traditional one, like collecting information from a driver's license. The intent here, though, is for a personal identity. And so the person should be asked, and nothing should be assumed. Sex assigned at birth and gender identity to date. A lot of this, again, is driven by various ways of doing standardized surveys in research. This is a two-question approach because not again to get at our transgender populations that don't always necessarily identify as transgender, but rather identify as the gender they are with an ability to identify potentially missed population for care, or in our case, and public health potentially disparities in a disease or condition in the population.
- Finally, OMB recommended best practices for collecting sexual orientation and gender identity data on Federal Statistical surveys. It is important to note that this is aimed at surveys being conducted, meaning direct data collection by the Federal government done in a very standardized approach. I want to point that out because everyone should recognize that our surveillance data may be secondary or even temporary data being passed through our jurisdictions up to the CDC. There may be some primary data collection, and additional efforts have been made there. I will present considerations for including SOGI survey items to focus on that primary data collection. As I just mentioned, there are examples of approaches for those extensive general statistical surveys. There is not enough evidence to support classifying another gender identity or gender. There are a lot of items that need more research.

Case Notifications to CDC, Message Mapping Guides (MMGs)

- A traditional core, common to all our conditions, has subject sex. It's described as the subject's current sex, which has been very confusing and has the value set as male, female, and unknown.
- The vital part to note here is we traditionally align this with that administrative sex, which most of the MMGs are aligned with, and as we evolve, could be seen, as again, that recorded sex variable, which you may not know the specificity surrounding it.
- We all have gender identity and sexual orientation. Here, we do have the data element description. And we had worked to start moving in that direction for data collection efforts overall, meaning that for those at CDC or jurisdictions that may know about this. Now, we must have that permission to receive. And so we have started to move towards description, recognizing that the question is not necessarily how that data flows or that we cannot necessarily say that that is precisely how that concept was asked.

Jurisdiction Samples

- We have four to go through, and we present this here for everyone to get an idea of the variability in the data. We've reviewed the standards and what might be coming in depending on the format and the HER system. But now we're also looking at where state practices, what's been accepted by their populations and influenced by their policies and bills for various surveillance systems.

Jurisdiction Samples (Arizona)

- In Arizona, we have gender. It is at that case level under the patient demographics. And they do offer sexual orientation when they say morbidity, base meaning based on the event of disease or condition. And so it's limited to hepatitis A, C, E. Meningococcal, and HIV.
- They've listed here. The value sets for HIV only

Jurisdiction Samples (Utah)

- This shows some parts of their data dictionary. This is in practice of what is currently being done. The core question is about birth, sex, and current gender. So those top two with those values sets. This is what would be asked across any of their conditions.
- What they do see also coming through is having some of this, what I call that morbidity level, meaning there has been influence, either by how various CDC programs have asked for, or what has evolved, or what might be used for their populations by that morbidity with kind of a local groups. And so that's why you see two gender identities. But one is probably for one disease process, and one is for another, and then sexual orientation, but like Arizona. Those last 3 data elements are at that condition-level content.

Jurisdiction Samples (Tennessee)

- Tennessee. We see that we have current sex and birth sex, as well. Current sex is the only one that is on every investigation page. They do have the ability to give birth sex and gender identity as a text field. There is an additional field if someone identifies differently and provides a different term and sexual orientation. Again, those are brought in based on the condition and not necessarily offered across all conditions**.**

Jurisdiction Samples (Oregon)

- Oregon is very broad, offering these concepts across all their conditions. They ask about pronouns.
- Individuals can give descriptions that can be entered into the system, and individuals are asked different types of questions.

Case Notifications to CDC (Message Mapping Guides (MMGS)

- This is now where the data is influenced based on the data extract or what might be coming from the system. So, current sex is to help align with what is going out in notifications to the CDC. It is influenced by sex at birth, which is a similar value set that may come in or is within what they have asked or been able to get through patient interviews. Then they have an additional gender, which is those coded ones that I think help align with some of the other values in notifications that have occurred.
- So, with all of this, we have had various presentations and different items through the Federal Committee on Statistical Methodology Interest Group: Measuring SOGI Research Group, in which multiple attempts to capture this information discuss this information has been put forward with surveillance. This is very different from our primary data collection. It is other than research; it isn't easy to wrap our heads around this because it is so different. We cannot control what got built into somebody's system at a particular hospital. We cannot necessarily control how someone asks a question or does not ask a question in various situations. Additionally, their influences at the jurisdiction level with how they understand their populations when they can conduct a patient interview, and various other policies going on within their jurisdictions enable them to do various types of data collection based on this similar information as to what you have seen here.
- The red font kept the similar USCDI language around how sexual orientation is defined and the best description to put forward gender identity. The italics portion represents what is in USCDI if they say the sense of being a man, woman, both, or neither. This is trying to drive home that this is how they identify what the person reports. This is not something that someone assigns them. This is when someone was asked, which is what they told you.
- Finally, sex at birth. We've had that again as a question, and the recommendation again is because there is not necessarily a question. If this data comes through systems, we want to recognize that not everyone may know this or have this available.
- We then looked at value sets. And again, these are limited. We were looking at this both from what is coming through systems. What is that minimum? We probably should have. But again, this is going to be the discussion points and something that we would like to be able to put

forward. The most significant message is that we should not be transforming a patient's data. We want to ensure that if somebody uses a different term, we're not saying, Oh, like, well, I think that means this.

- Again, we want people to think about what we can best do within our data systems to allow the data to flow so that when we receive the data, we can be very clear in methodologies and what we might need to do to use that data. That's the most crucial piece of transparency in an evolving field such as gender identity. Again, looking at some of these concepts, what is used in there, and what is in SNOMED right now, we know that may also evolve. Still, right now, we are just trying to change some of this language to be aligned with what has been shown in some of these other survey methodologies, terminology, and finally, sex at birth.

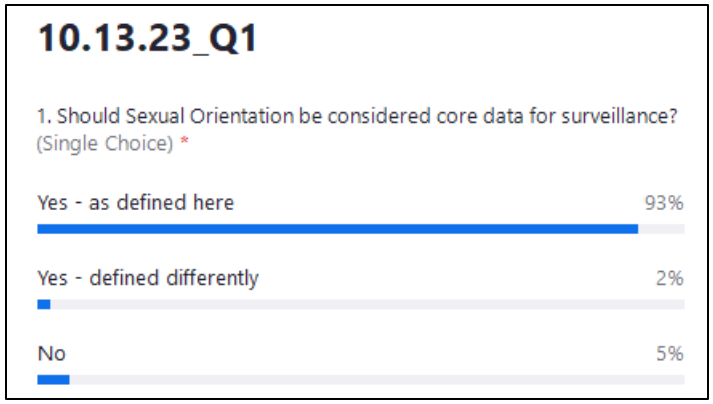
Sexual Orientation and Gender Identity (for discussion)

Potential Core Data Elements Sexual Orientation

- For discussions, we'll be separating the topics of Sexual Orientation (SO) which will be discussed today and Gender Identity (GI) (as well as new and legacy Sex variables) which will be discussed more in-depth on the next call.
- SO is currently included in two specific MMGs, HIV and hepatitis v2 (draft). Both mmgs have different value sets, which is challenging. SO is not currently present as a data element in eCR or ELR.
- The primary discussion on this call will be whether this data element should be defined for core public Health case surveillance and, if so, how should it be defined and what value set should be used to collect and send data.
- Of note, there is work being done in this space by Health and Human Services, and SO and GI are seen as key demographics. Sexual orientation is being submitted to OMB as a concept for future surveys, regardless of whether we decide its core public health. The recommendation is that we take this moment to make a recommendation regarding collection of SO and GI in a public health context. This is our opportunity to best define and determine collection with a chance to be heard. That can be a separate part of this discussion from whether this should always be sent to CDC.
- Discussion Included:
    - Interest in this data element as core with the note of being thoughtful about how the information is collected and awareness of reducing harm.
    - Multiple sources are considering sexual identity as being one of our significant indicators for health disparities. This is tied directly to various public health consequences, an essential part of the data we need to collect.
    - In general, the chat indicated a fair amount of support for this as core.
    - Concern for the age when this question would be asked was voiced and discussed.
        - It was mentioned that this question would not be forced and does not have to be asked of every patient in every case.
        - In addition, later discussions will focus on implementation, which could be addressed in a future guide.

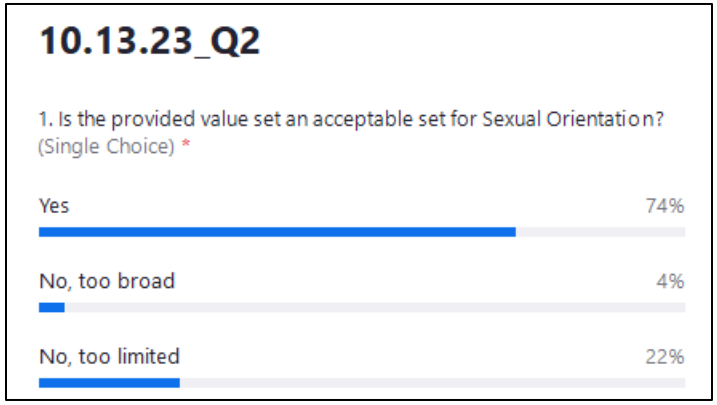
Polling- Sexual Orientation

Poll 1 (n= 55)



- Consensus was clear as yes; this should be considered core surveillance data.

Poll 2 (n = 54)



- Polling indicated a slightly more split result.

Polling Discussion

- There was a question on whether free text data would be collected as an additional response for “Other, specify”.
  - CDC mentioned that this is an expectation across the continuum of data streams.
- There was a discussion on changing options for polling questions, which will be addressed for future polls and in the next meeting.

Next Steps

- This team should expect a poll ahead of the next meeting.
- Feel free to sign up for other data element-specific teams on the interest form here
- Additional input is always welcomed from DSWG members on the form located here.