Meeting: CSTE Data Standardization – Sexual Orientation and Gender Identity (SOGI) -Element Specific Team Meeting
Date: November 17, 2023
Attendees: 78

CSTE (3)	PHAs (37)	CDC (34)
Becky Lampkins	Co-Chairs	Allison Miller
Gillian Haney	Molly Crockett |MA	Andre
Megan Toe		Andrea Steege
JMC (4)	Members	Danielle Tack
Erin Kough	Amanda van Rest | NV	David Huang
Grace Mallard	Amy Bogucki |TN	Doris McGinness | GDIT
Natalie Raketich	Amy Lai | AZ	Gialana Dang
Sam Spoto	Amy Saupe | MN	Jenny Couse
	Brynn Stopczynski | WA	John Gerstle
	Cher Levenson | WA	Juliana Cyril
	Deepani Jinadasa | UT	Katie Tully | HHS
	EJ Klingler | NYC	Kevin Heslin
	Eman Addish | Philadelphia	Kristie Clarke
	Graham Crawbuck | WA	Lauren Lambert
	Greg Fowler | SC	Lesliann Helmus
	Greta Anschuetz |NJ DOH	Lexi Balaji
	Hanna Chakoian | MN	Lizzi Torrone
	Jacki Griffin | NYS	Luis Hernandez | GDIT
	Jordan M | NH	Meeyoung Park
	Judie Hyun | MD	Mohua Basu
	Kelsie Ostergaard | DC	Myrna del Mar Gonzalez | GDIT
	Kyra Kofodimos | IN	Nicole Lindsey
	Kyra Parks | IN	Nikolay Lipskiy | GDIT
	L Espinosa | IN	Noreen Kloc
	Maddie Sankaran | SF DPH	Pei-Jean Feng
	Margret Watkins | WV	Peter Boersma
	Maria Jaurretche | DC	Renee Boehmert
	Melanie Epstein-Corbin | CA	Robert Pratt

	Monique Birmiel | IN Nelson Lu | Chicago Nicole | ADHS Rachel Corrado | NYC Ryan Burke | MA Sam Hawkins | OR Samantha Mathieson | TN Sequoia | DE Tom Loftus | IN Trish McLendon | CA Vajeera Dorabawila | NY Vicki Stewart | WA	rvx9@cdc.gov Sandy Roush Shauna Mettee Zarecki Sonia Xingran Weng Yin

**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.
- 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?

Between Meeting polling: Response Summary

- Thanks to everyone who participated!
- There were 43 responses (15 states, three local jurisdictions, 14 CDC).
- These responses were not used to make final decisions but to help refine the initial suggestions for today's discussion.

Sexual Orientation

Note: In the previous meeting, the DEST got through the definition of sexual orientation, and today's conversation will jump back into that piece.

Core Data Element Sexual Orientation

- In the Oct 13 SOGI meeting, this was voted in as a core surveillance data element.
- The definition agreed upon was "A person's identification of their emotional, romantic, sexual, or affectional attraction to another person."

Sexual Orientation Value Set: Between Meeting Poll Results

- 23 people, more than half, felt the suggested value set was sufficient.
- 13 felt it was sufficient with adjustment.
- 6 felt it was too limited.
- Suggested comments included
    - Drop homosexual
    - Add an unknown option
    - Add pansexual
- Based on the poll, a new value set was displayed for voting. The value set included the following
    - Asexual
    - Bisexual or pansexual
    - Straight or heterosexual
    - Lesbian, gay, or same-gender loving
    - Not listed, please specify
    - Don't know
    - Prefer not to answer
- Discussion:

- Lesliann (CDC) wanted to ensure categories are chosen that will apply to standardized coding sets and noted concerns about adding pansexual to bisexual because those are different concepts. Finding a coding set that will effectively represent both will be challenging. There was also a suggestion to combine those, which is likely problematic. Adding pansexual makes sense, but I would avoid combining them. It's important to reflect on and use standardized coding sets.
- Erin (JMC) understood the concern and noted this was combined based on between-meeting polling. Erin promoted DEST discussion on identifying what is too big of a value set, how items can be put into buckets, and remembering those more established coding systems to meet in the middle.
- Molly Crockett (MA, Co-Chair) agreed that "don't know" comes from the patient, not the provider. Felt that this is an important distinction to make and noted that it's always easier to combine things after collecting the information in more detail. If we break out bisexual and pansexual and have an unknown category, that seems reasonable. This would also align with standardized coding sets cleanly.
- Erin (JMC) updated the value set to reflect the following and promoted further discussion.
    - Asexual
    - Bisexual
    - Pansexual
    - Straight or heterosexual
    - Lesbian, gay, or same-gender loving
    - Not listed, please specify
    - Don't know
    - Prefer not to answer
    - Unknown
- Emman Addish provided input for number 7 to say "unsure or questioning" instead of I don't know
- Erin (JMC): Updated the list
    - Asexual
    - Bisexual
    - Pansexual
    - Straight or heterosexual
    - Lesbian, gay, or same-gender loving
    - Not listed, please specify
    - Unsure/Questioning
    - Prefer not to answer
    - Unknown
- Molly Crockett (MA, Co-Chair) and Kevin Hesling agreed that it helps to clarify the language, and it was mentioned that "questioning" really needs to be present.

- Kevin Heslin also discussed that the “not listed, please specify” with open text can prove challenging due to mischief responses where people express absurdity/hostility toward these questions. The write-in options can be an issue.
- Lesliann Helmus (CDC) commented that we are defining a value set that will be used for jurisdictions to send to the CDC; this is not for collection for individuals in the field or a screen that an individual will answer, so this should not be an issue.
- Gillian Haney (CSTE) noted some questions about other value sets being considered. In the first calls we had, we did present all the different value sets, gender harmony, and USCDI 4, and it was felt there were limitations. The general rule we are trying to apply here is to use existing standards and value sets, but certain data variables don’t meet public health needs. Hence, we hope the work and outputs of the DSWG and recommendations for standardization will help influence how data values, such as USCDI, are collected within those standards.
- Gialana Dang (CDC, NIOSH) stated that they work to coordinate sexual and gender minority worker health program and wanted to affirm that there is justification for a write-in option given the input of this data will be public health workers and allows for greater inclusivity. Much of the gender identity data comes from write-ins due to the fluidity and inclusion as language changes.
- Erin (JMC) confirmed that this was helpful and that, per previous conversations, the group has discussed ensuring we have free text to catch signals of new things that need to be included.
- Danielle Tack (CDC) noted that we want to consider how the data flows through the system. Is there a 1:1 alignment with anything that is currently being collected? Are we changing codes so that programs must transform data through that process? They will pull that information from an EHR, assuming they cannot get an interview. If they can get an interview, and a patient provides a different option, or based on local practices, are we comfortable enough that someone can easily say what the person answered is correct with the term selected? If it’s not the correct term, then that is the purpose of having the ability to specify, and we want to be transparent about data transformation.
- Erin (JMC) appreciated the comment and noted that much information is gained from case reports and medical records, which can include patient histories. There are places where you get information that lies outside of coded values that will be in EHRs.
- Gillian Haney (CSTE) requested a discussion of the term queer as it has come up in the chat.
- Kevin Heslin commented that a reason to include Queer option is that it is used frequently by people who have a non-binary gender identity because many terms are gendered. For example, lesbian implies binary, and gay generally applies to men.
- Nikolay Lipskiy (CDC) Commented that there have been a lot of discussions in academia that suggest the acceptable wording can indicate queer folk, lesbian, gay, or some other category. Second, these nine categories would require transformation between EHR and this classification, as states and counties will not know how to transform this data.
- Sam Hawkins (OR) advocated for the inclusion of queer as people use this as their primary or sole sexual orientation, and it is similarly prevalent to pansexual/asexual. This term is also more common in minorities and younger people.
- Erin (JMC): updated the list as follows and recommended moving to a vote
    - Asexual
    - Bisexual
    - Pansexual

        - Straight or heterosexual
        - Lesbian, gay, or same-gender loving
        - Queer
        - Not Listed, please specify
        - Unsure/Questioning
        - Prefer not to answer
        - Unknown
    - Lesliann Helmus (CDC) requested a review of previously discussed standards to see how this list aligns.
    - Erin (JMC) noted that this list does not align well, and the other lists are not as up-to-date as we can make them right now.
    - Danielle Tack (CDC) commented that we must examine this in several phases. The first would be data transmission within the data pipeline. This likely looks different from what we want to state and should be improved. SNOMED codes need improvement. When we have this kind of disparate data, we want to ensure that we are transparent in our approach within the public health ecosystem. That may mean we have data flowing from old terminology. Part of the subsequent discussion will be how we develop general guidance and evolve with improved standards and language as we move forward. The most crucial part is transparency and how we display and use the data. We should strive to accommodate based on the diversity in the systems inputting the data. The goal is to be transparent to all audiences so that people recognize we're doing our best with the limitations at hand. We're balancing where things should go based on best practices and what might be at hand.
    - Molly Crockett (MA, Co-Chair) promoted the launch of a poll to establish whether the group is conceptually on the same page regarding a reasonable stratification and set of options. Then, the information can look at standards for further discussion, critical issues, and how the group wants to handle them.
    - Erin (JMC) confirmed that the process will be iterative as draft recommendations are created, and there will be a chance to bring up other items from the group as needed.

      It was determined to launch the poll to determine consensus or not from the group.

Polling – Sexual Orientation

- Q1- Is the provided value set acceptable for sexual orientation?
    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

- Results
    1. n= 52
    2. 50 (yes)
    3. 2 (no)

Gender Identity | Sex/Current Sex/Sex (assigned) at Birth

Potential Core Data Elements Sex and Gender Identity

- The table was displayed at the previous meeting based on various background work that has been done, what exists, and what we want to exist.
- Currently, we have Sex at Birth and Current Sex, which does not exist right now. Sex is the broad data received in ELR for example, and then there is Gender Identity as determined by the person.

Sex and Gender Identity Discussion Points

- Questions were presented for the group to consider for the discussion today, including
    - What is the public health importance of a Sex/Gender variable
        - Outreach?
        - Physical disease impact/risk?
    - What is the importance of sending this to the CDC, and what is the importance of any of these components?
- Lesliann Helmus (CDC) noted we almost always do epi data and break things down by sex (male/female). CDC recognizes that male/female is not an accurate representation of the population, and we must be able to go beyond that. We will continue to break down data by sex and need to represent the population better.
- Kevin Heslin agreed that sex is an essential demographic characteristic. Gender identity is something different, and people make assumptions about biology or current sex characteristics based on that gender identity question. Regarding the public health significance, this seems much broader than that. It is crucial to count transgender people for many reasons.
- Sam Hawkins (OR) discussed the term gender modality, which is one term for transgender status. The critical thing to consider for public health is the significance of sex and gender identity, the social determinants of health, and how that impacts disease risk.
- Greta Anschuetz (NJ DOH) noted that due to legislation passed in NJ where these variables became mandated, this caused many issues with incoming data, including ELRs. Information coming through an ELR is uncertain until you can talk to the provider to help ascertain if it is sex at birth or the current gender identity. NJ created a “sex for clinical use” variable that tries to get at, as discussed earlier, the body parts present because that is important to understand what tests need to be run.

- Erin (JMC) shared the information from the Gender Harmony Project, as they also included that variable. It hadn't been understood that this could be a public health variable, so that comment is helpful.
- Gialana Dang commented that at CDC, SOGI data can be used for a variety of factors, including health research and surveillance, and it depends on what purpose the data is going to be used for. First and foremost, sexual orientation and gender identity are both distinct aspects of LGBTQ Plus, and both aspects need to be represented in any health data. There is a push to consider sexual orientation and gender identity as demographic variables because they capture what the situation is as far as the starting point for health, how we look at a person moving forward in data sets, and what groups they fall into. Second, there is no standard to collect this data, and reports have come out, including OMB, that specifies there is no standard for collecting this information. There is a fine line between the data needs of the population, clinicians, and researchers to record patient information. For gender identity and sex, I think for sex assigned at birth, in sexual gender minority research, sex assigned at birth is less definitive. It's less definitive and leans towards the fact that your sex is immutable. For those who are less supportive of the community, the othering logic and erasive attitudes towards the trans community and more discriminatory attitudes towards the trans community and language used justifies this, and sex at birth hints towards that type of othering language for the trans community. There is precedent in the NASEM report for multiple steps or multiple multi-question approaches for looking at the gender identity data element, which includes asking about sex at birth and current gender identity and the Clinical uses question. Therefore, this could be on the table as well.
- Erin (JMC) appreciated the comments. This reminds everyone that this perspective focuses on surveillance when conducting a case investigation. We're talking very specifically about the information gathered when you're doing a case investigation, such as at a jurisdiction.
- Kevin Heslin commented that one of the reasons people are concerned about how we ask about sex and body parts is because survey research then determines other questions such as prostate, breast cancer, and cervical cancer screening. However, he noted that in surveillance, those are items not at stake.
- Molly Crockett (MA, Co-Chair) commented that it might not determine the survey, but it might determine which symptoms are asked about. Certain symptoms are related to body parts, and there is space where that might come into play.
- Kevin Heslin noted that there is work from the National Center for Health Statistics that suggests that some transgender people do not want to be asked about sex at birth. It is seen as an invasive question. The suggestion is a three-category gender question that includes male, female, transgender non-binary, or other gender minority. Then, when asking about body-specific questions, ask simple anatomy questions such as do you have a penis or a vagina. Additionally, it was noted that many body part inventory questions sound Latin and are not easily understood.
- Erin (JMC) provided a wrap-up for the call and appreciated the conversation from today.

Next Steps

- This team should expect communication ahead of the next meeting which will likely include some targeted discussion points.
- The next SOGI DEST meeting is scheduled for December 15 from 12-1 ET.
- The next broader DSWG meeting is scheduled for December 8 from 1-2 ET.
- 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.