Meeting: CSTE Data Standardization – Sexual Orientation and Gender Identity -Data Element-Specific Team Meeting
Date: December 15, 2023
Attendees: 68

CSTE (2)	PHAs (38)	CDC (22)
Becky Lampkins Gillian Haney **JMC (6)** Erin Kough Grace Mallard Laura Lane Natalie Raketich Sam Spoto Susan Downer	<u>DSWG Co-Chairs</u> Molly Crockett | MA <u>DEST Members</u> Allison La Pointe | MN Amy Bogucki | TN Amy Saupe | MN Andria Apostolou | HIS Benjamin Schram | ND Brynn Stopczynski | WA Cher Levenson | WA Chris Dumas | SD Deepani Jindasa | UT EJ Klingler | NYC Jacki Griffin |NY Jacob Chavez | LA Jen Vargas | CT Jesse Ellis | MS Judie Hyun | MD Karene Thomas-Watts | CO Kyra Kofodimos |IN Lea Moser |NV Leah Wainman | WA Lunden Espinosa | IN Li Jiao | Harris County Madeline Sankaran | San Francisco Margret Watkins | WV Maria Jaurretche | DC Maribeth Hoyle | OR Monique Birmiel | IN Ava Nepaul | CT	Abhilasha Saxena | GDIT Allison Miller Amanda van Rest Angie | GDIT Cindy Bush Danielle Tack Doris McGinness | GDIT Gialana Dang Jennifer Fagan Jenny Couse John Gerstle Kristie Clarke Luis Hernandez | GDIT Meeyoung Park Melissa Pagaoa Mohua Basu Myrna del Mar González |GDIT Nicole Lindsey Noreen Kloc Pei-Jean Feng Peter Boersma Renee Boehmert

	Orlando Velazco | CT Rachel Corrado | NYC Ryan Burke | MA Sam Hawkins| OR Sequoia Rent | DE Stella Tsai | NJ Stephanie Moberg | NM Theron Huntamer | NV Trish McLendon | CA Yuritzy Glez Pena |OR	

**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*):

DEST Opportunities for Participation

- DEST sign-ups are ongoing
- **[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 (first meeting on 12/15)
- 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.

DSWG Product Reviews

- There are a couple of DSWG/DEST products that are currently out for review.
- The Pregnancy Core Surveillance Data Standardization Recommendation draft is open to all members of the DSWG for review. That draft can be reviewed here and input can be given via Smartsheet form by COB on Tuesday 1/2/2024.
- The Industry and Occupation Core Surveillance Data Standardization Recommendation draft is currently open for review by the members of that specific team only. The links to those items are available to those DEST members in emails.

Meeting Ground Rules and Updates

- 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.

In-Scope vs Out-of-Scope

- 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 not a discussion of how to collect this data, how to frame questions in surveys or interviews, or how to implement these data standards. This is also not meant to impose limitations in how jurisdictions collect data.

Gender Identity: Sex/Current Sex and Sex Assigned at Birth

Previously, this DEST discussed and voted on the definitions of value sets of Sexual Orientation. It this call, we will be focusing on these three sets of data elements: Gender Identity, Sex Assigned at Birth, and Sex or Current Sex.

Current State

- This slide summarizes, very briefly, the state of these data elements before this DSWG work.
- Currently, Gender Identity is only a data element in a couple of message mappings guides for transmission to CDC and these data elements are not standard across these MMGs.
- Sex at Birth is what is now more commonly referred to as Sex Assigned at Birth. This data element is also only currently marked for transmission in a couple of MMGs and the value set is limited to Female, Male, and Unknown.
- Sex and Current sex will be considered as a set. Sex is what is currently listed for transmission in Gen V2 and is captured in ELR as Administrative Sex. Current sex is not currently in any MMG and is not present as a data element in eCR or ELR. This value set is also limited to Female, Male and Unknown.

Gender Identity

Gender Identity DEST input

- This summarizes some of the most common points made during both our previous calls' discussions and in answers to between meeting polling.
- The DEST was asked to consider these points as we move through the polling process for Gender Identity.
    - There is a need to be inclusive and flexible when considering this data element. This is a topic that has changed in the past couple of years and probably isn't going to be static for a while.
    - There is a need to be able to roll data up into categories that are useful, and which might someday have an associated denominator. A distinct challenge with data elements within the SOGI space is that there is a wide variability in what states are allowed to or want to collect.
    - Another challenge is how to identify the transgender community in analyses so that messaging and outreach could be tailored to reach this vulnerable population if deemed necessary. There is a lot of variability in how states currently account for this population, including the methods listed here.
    - For SOGI variables, the DEST/DSWG must be very mindful of whether they meet OMB's expectations. OMB must approve all data elements received by CDC. For most variables, this is not a concern; however, Gender Identity is a high-profile data element and the DSWG wants to make sure that the data standard that we put forward in our recommendation is one that will be approved.
- **Discussion**

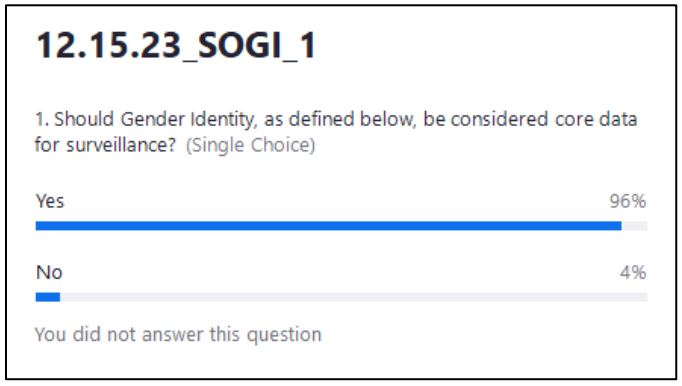
- A CDC participant (Gialana Dang) requested clarity on whether a previous OMB report that was published regarding SOGI data elements and that there was not standard recommendation for SOGI that is being encouraged or expected.
  - CDC (Danielle Tack) responded confirming that they are working closely with HHS to understand their implementation strategy and other nuances. It was also noted that recommendations will need to align with generally accepted best practices as we will need to justify through evidence or understanding of data flow on how recommendations are developed. There was confirmation that there is no standard in place but again, the recommendations will require justification. The target is also to remain flexible to align with best practices.

Gender Identity

- With all of this in mind, the following data element details were derived from various points of input and can hopefully be considered as a consensus of all discussions.
- Gender Identity is defined as "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).
- The value set allows for more than one answer to be transmitted to CDC and the combination of these multi-select values will hopefully allow for the flexibility and inclusiveness that we are striving for. In addition, there would be an associated free-text question which would allow transmission of any other gender identities which might need to be sent.
- This value set does include an option for Two Spirit to be inclusive to that cultural concept. As work on implementation goes forward, there is specific guidance on how to best collect that data in a way that maintains its cultural meaning and reduces the likelihood of appropriation. That is part of a different conversation than this one. This was discussed offline with a Tribal Epidemiology Subcomittee representative, which is the reasoning for presenting this here. It is understood that implementation will be discussed later.

Polling

Poll 1 (n = 53)

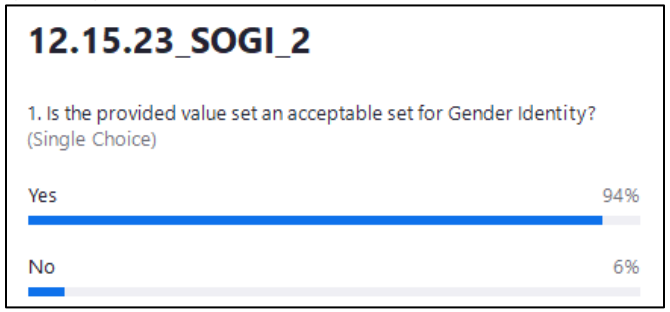


Poll 2

Pre-Poll Discussion for the value set for Gender Identity

- Chris Dumas (SD) voiced concerns over the use of this value set with a multiselect option in making it very difficult for analysis and collection of meaningful data, particularly if individuals choose woman/girl and man/boy, as an example.
- Erin Kough (JMC) mentioned that this was the result of input from several members of the DEST as well as guidance from other institutions including the White House.
- Danielle Tack (CDC) also noted that it is important to remember this is secondary data, however that discussion follows more in the path of implementation which is a future state discussion. The goal is to create a path that will allow for transparent, inclusive, and flexible data collection. It is also generally understood that surveillance data will have imperfections.
- Orlando Velazco (CT) noted support for a multiselect option and noted that data analysis is complex and variables with multi select options that are seemingly in conflict can be removed and accounted for in data analysis.
- Erin Kough (JMC) reminded the group that this is a value set for transmission to CDC and does not limit jurisdictions on how they collect or analyze the data. She also mentioned that implementation, though important to consider, is out of scope for the current project.
- EJ Klinger (NYC) commented on the concern for the burden this type of multiselect will put onto the jurisdictions to determine if their collection method is appropriate and the issue of making the executive decision on selections made. This can be complicated at the jurisdiction level.
- Erin Kough (JMC) again reminded the group that much of this will be involved in future implementation discussions.
- Giliana Dang (CDC) commented that there are instances when individuals are gender fluid, non-binary, or trans that also identify as a gender. It was noted that inclusivity should be a consideration.

(n = 51)



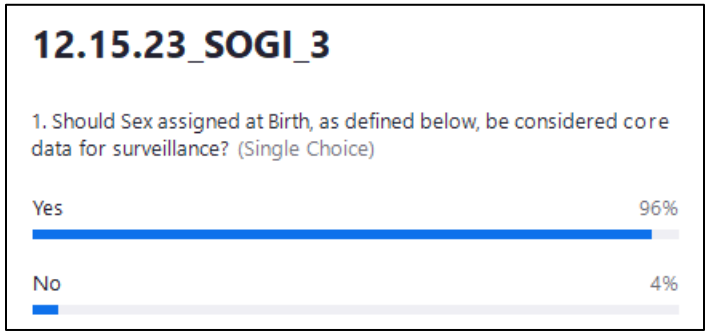
Sex assigned at Birth

Sex Assigned at Birth

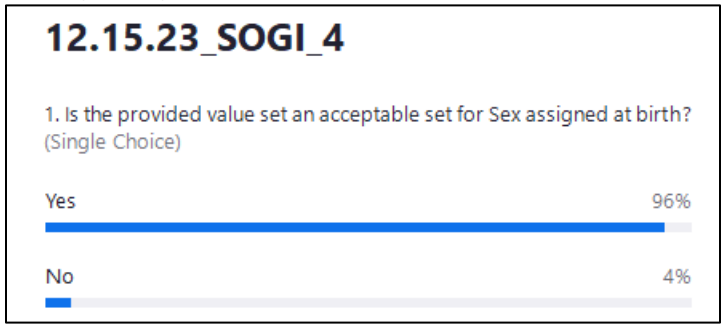
- Feedback on this data element was generally minimal and two changes were made to adapt initial suggestions to be more in line with this group's input from the discussion and between meeting polls.
- First, the data element has been renamed "Sex Assigned at Birth" to match feedback of participants.
- Second, the third value option has been clarified to include "intersex" and other non-binary markers which might exist.

Polling

Poll 3 (n = 50)



Poll 4 (n = 49)



Sex/Current Sex

Sex/Current Sex

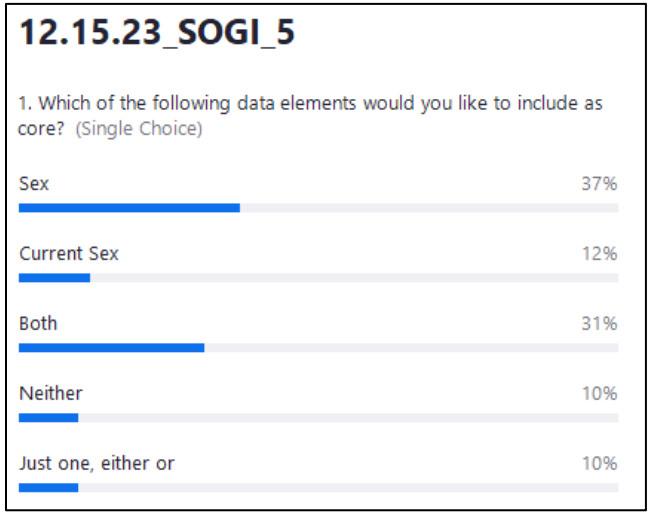
- Currently "Subject's Sex" is used in the GenV2 MMG. This is presumed to be the sex variable that is found in things such as ELR.
- It might be referred to as administrative sex by some systems.
- It has been suggested in previous conversations and polling that some places collect both sex and current sex.

Sex and/or Current Sex

- For today's discussion, this is a very basic compare and contrast of Current Sex and Sex.
- Current sex would have an implication of timing; it would be time sensitive and may suggest a more current or more specific source of information than from sex as reported in an ELR or eCR.
- Sex is more general and can reflect many data sources and may be the only information available in many cases.
- The last bullet "may be all that is available in many cases" is an important consideration for data analysis, reporting, and public health action.
- **Discussion**
    - Daniell Tack (CDC) recognized that through case notifications, in practice, the "current" piece on the CDC-side is not seen as specific. The data source is unknown. Administrative sex is more formally recognized. What we want to avoid is the assumption of what data element this information might align to. We should be able to maintain reporting, at least until systems evolve, to provide this level of information. Any process used for data visualization will require a transparent methodology. Other systems have used the term "documented" sex which indicates this came from some kind of record like a driver's license or insurance card, as an example.
    - Erin Kough (JMC) reiterated the understanding from this it seems CDC understands the limitations of the sex variable as it is reported from the jurisdictions.
    - There was a question addressed from the chat regarding administrative sex being the same as sex assigned at birth.
        - Danielle Tack (CDC) commented that from her perspective, these are the same data element. However, when it comes to implementation there are some nuances about codes and reporting.
    - Erin Kough (JMC) acknowledged there was a lot of discussion in the chat and wanted to get a pulse for what the group was thinking by launching the poll related to this discussion.

Polling

Poll 5 (n = 51)



Discussion on Sex/Current Sex (continued)

- Erin Kough (JMC) recognized additional discussion is needed given the split results.
- Danielle Tack (CDC) commented that even though this is related to implementation, is that on the CDC-side, she is unsure how "current sex" ended up in NNDSS. She raised a question to the group for this legacy data element, what does the group think. We know we don't want to lose a legacy data element but also do not want to imply specificity that doesn't exist. If the description is clear for what the data element is called, do jurisdictions have strong feelings? Again, recognizing this is likely an implementation-level discussion.
- Gialana Dang (CDC) wanted to clarify the use of the current sex variables. It was felt these might be a holdover of an internal administrative process or procedure that may be involved in emergency medical response and when there is an initial intake of a patient that this must be filled in for intake. Either the person is unresponsive, and something must be reported or there is just a built-in administrative process with electronic records that automatically pulls sex records from an electronic process. Is that correct?
- Erin Kough (JMC) Confirmed that sex, particularly sex without "current" in front of it, has a very general meaning and can be found from many sources including those administrative fields in any EHR.
- Gialana Dang (CDC), understood then that this is more of an automated field, right?
    - Danielle Tack (CDC), yes, in general that is correct. There is some level of legacy data at play here. For public health purposes, the additional variable of "sex assigned at birth" is a way to try to identify potential minority populations. This again goes back to the transparency needed within the data.

- Giliana Dang (CDC) noted that in this instance it is important that jurisdictions are able to collect this data particularly for those with legacy systems who are unable to upgrade at this time. However, also important is self-determined sex because you can capture trans populations. This would allow the ability to gather more information and a more informative and balanced approach for a provider to determine treatment.
- Erin Kough (JMC) confirmed that it in the chat there was popularity for self-determined sex.
- EJ Klinger (NYC) commented that there was still confusion about the previous definitions of sex and current sex and so it will be challenging to now bring into the discussion inclusion for self-determined sex. Understood this was more of an administrative data element and wouldn't gender identity be self-determined sex?
- Danielle Tack (CDC) Confirmed that sex for public health reporting is administrative. We need to keep in mind this is data for surveillance. It's hard to imagine how self-determined sex is going to flow through a public health surveillance system.
- Erin Kough (JMC) based on today's conversation felt a follow-up poll will be needed. Depending on those results will determine if this requires additional conversations.

Next Steps

- This is the last scheduled SOGI DEST meeting.
    - A poll and additional information will be shared with this group to refine the final discussion points that stemmed from today. Unlike previous polls the results will be used to make the final recommendations from this group.
    - Once those results are evaluated, JMC will work closely with CSTE and Co-Chairs to determine if another discussion is warranted. If we can wrap up thoughts in this final poll, JMC will work to develop the written recommendations, which will be shared with this DEST for additional review and input.
    - Please keep an eye out for that poll and information after the beginning of the year!
- The next full DSWG meeting is scheduled for February 23.
- Sign up for upcoming data element-specific teams in the interest form here
- Additional input is always welcomed between meetings from DSWG members on the form located here.