Meeting Title: CSTE Data Standardization Workgroup Meeting
Date: 12/8/2023

Attendees: 128

CSTE (2)	PHAs (76)		CDC (40)
Becky Lampkins	Co-Chairs	DSWG Members (continued)	Allison Miller
Gillian Haney	Laura Erhart |AZ	Kayleigh Nerhood | GA	Anna Bratcher
JMC (6)	Molly Crockett | MA	Lawrence Young | CT	Antonio Neri
Erin Kough		Li Jiao | HCPH	Danielle Tack
Grace Mallard	DSWG Members	Li Kuang | NJ	Desiree Mustaquim
Laura Lane	Abi Collingwood | UT	MadelineSsankaran | SFDPH	Erin Conners
Natalie Raketich	Adrienne Erlinger | MA	Margret Watkins | WV	Erin Miller
Sam Spoto	Amy Lai (AZ)	Maribeth Hoyle | OR	Fidel Desir
Susan Downer	Amy Saupe | MN	Mary McNeill | OH	Gonza Namulanda
	Andria Apostolou | HIS	Mario Beltran |MI	Kimberly Mace
Other/Unknown Affiliation (4)	Angela Herbert | NB	Elizabeth Lando-King | MN	Karen Arrowood
Brooke Beaulieu | APHL	Annie Bergman | SD	Melanie Epstein-Corbin | CA	Katie Dodd
Johanna Bosse	Chelsea Stacy | WA	michael eberhart | PA	Katie Fullerton
John	Christopher Dumas | SD	Misty Johnson | WI	Kirsten Hagemann
Stephen Soroka	Christy Crowley | NC	Monique Birmiel | IN	Kristie Clarke
	Clifford Mitchell | MD	Morrow Toomey | AK	Kristin Delea
	Collin Morris | WI	Myron Lizak | NH	Lauren Lambert
	Danny Power | MT	Nancy Barrett | CT	Laurie Barker
	Dimple Patel | KY	Nathan Tan | HI	Lesliann Helmus
	Ed Hartwick | MI	Ava Nepaul | CT	Lexi Balaji
	Elizabeth Schiffman | MN	Nora Kelly | IL	Logan Ray
	Genie | CDPH	Orion McCotter |OR	Luis Hernandez
	Graham Crawbuck | WA	Orlando Velazco | CT	Marie Haring Sweeney
	Greg Fowler | DC DHEC	Rachel Corrado | NYC	Marion Rice
	Hanna Chakoian | MN	Rob Arciuolo | NYC	Matt Stuckey
	Hannah Giles | MN	Robbie Snyder | CDPH	Matthew Spence
	Isaiah Francis |NM	Ryan Burke | MA	Melissa Kealey | CA
	Jacob Chaves | LA	Sam Hawkins | OR	Michelle Lin
	Jeannie Woolston | ND	Sequoia Rent | DE	Myrna del Mar Gonzalez
	Jessica Mawdsley | VI	Shawna Stuck | GA	Nekole Locke

	Jill Krause |NB John Satre | IA Jordan McBride |NH Judie Hyun | MDH Justine Maxwell | TN Karen Robinson | NJ Karene Thomas-Watts |CDPHE Kate Goodin | TN Kathleen Rees | Washington County, OR	Sophia Cantor | WA Stella Tsai | NJ Stephanie Moberg | NM Steven "Ike"Eichner | TX Suzanne Gibbons-Burgener | WI Trish McLendon | CA Vajeera Dorabawila | NY Vanessa Phuong | WA Vanessa Whattam | MT Victoria Salinas | TX Yi Du | NE	Nicole Lindsey Noreen Kloc Peter Boersma Robert Pratt Robyn Cree Sara Johnston Stacey Marovich Tashina Robinson Veronica Burkel Walter Alarcon

**SOME INDIVIDUALS DIALED IN, AND THEIR NAMES ARE UNKNOWN*

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

CSTE Data Standardization Workgroup Meeting (Co-Chair, Laura Erhart)

Meeting Ground Rules

- We welcome everyone's opinions and active participation from jurisdictions, CDC programs, CSTE membership, etc.

Core Data: In Scope for DSWG

- What we're most specifically doing for these meetings is identifying those core data elements for surveillance that we will look for transmission to the CDC.
- We are looking at the core overall, focusing on case surveillance, situational awareness, or routine surveillance but going across many conditions.
- The data elements we discuss don't have to be relevant for all conditions but should also not be something that's just in one or two specific places.
- We're looking at case-based surveillance again, so it's not syndromic, not aggregate reporting.
- As we go, we'll look at specific selected data classes. Again, the scope identifies those common definitions, value sets, code sets, structure, and some interpretation notes.
- For the core data elements and where applicable, we will recommend some best practices on what we may need to collect within our surveillance systems.

FAQs

- Anything we identify for core data for CDC transmission doesn't mean it's required.

- Even if we do identify an element for transmission, it doesn't need to be filled in for every single element or every single case; it's okay to leave some of the fields blank or unknown if the information is not available, not a priority, or not useful for the condition.

Considerations

- What information is needed at the national level?
- How can we use electronic records and automation in our current electronic digital age and landscape?
- Also, how can we take the best advantage of and feed into other standardization efforts like HL7, USCDI, and USCDI+? none of what we do in public health is happening in a vacuum.
- How can we reduce the manual surveillance burden on ourselves and our partners?
- Finally, how do we position ourselves well for adding emergent conditions, exchanging information, onboarding, case notifications, etc?

DSWG Opportunities for Participation (Co-Chair, Laura Erhart)

Data Element-Specific Teams (DEST)

- Everyone here is part of the DSWG and will continue to be part of that larger work group.
- We will break up each element into teams to leverage DSWG members' expertise better.
- Each team will focus on a pre-identified topic.
- We encourage all programs and agencies to participate at the local and federal levels.

Data Element-Specific Teams (continued)

- If you join a team, you are expected to actively participate during and between meetings, including polling, providing input to draft documents, in-meeting discussion, and attending larger DSWG meetings.
- DESTs will be held monthly.
- Data element-specific teams will provide feedback on how your jurisdiction or program collects and uses the information related to that data element.
- Individuals are not expected to write documents, lead meetings, or prepare slides.
- **[ACTION REQUIRED]** Use this sign-up form to sign up for and participate in DEST teams. In the form, you can find more details on team member expectations and DEST's that are concluded, current, and upcoming.

Team Topics

- Previous and upcoming DEST teams include,
    - Concluded: Pregnancy, Industry and Occupation
    - Ongoing: Sexual Orientation and Gender Identity (SOGI); next meeting on 12/15/23
    - New Team Starting: Immunization History; first call scheduled for 12/15
    - Upcoming: Exposure/Risk/Underlying Conditions, Death, Signs/Symptoms
- Tracks will occur concurrently, but meetings will not occur simultaneously to allow people to participate in topics as desired.

- After a DEST concludes discussions, guidance documents will be developed by JMC staff, with continued input offline from the DEST, and a new DEST topic will begin.

DSWG

- The larger DSWG membership will convene bi-monthly.
- At these meetings, we'll hear updates from the DEST teams and allow the broader group to engage.
- Participation in DEST teams is encouraged as much as possible.

Approval Status for DSWG Recommendations (CSTE, Becky Lampkins)

Update on CSTE Approval Status for DSWG Products

- CSTE Brief is published!
  - This was published in October of this year, and this is the first report this Workgroup has developed.
  - You can find the link to the document here
  - Congratulations to everyone who worked on this Brief, and thanks for all your hard work!
- CSTE Best Practice Guideline – Almost published.
  - This document recommends implementing and using a standardized case counting date, known as the calculated case counting date for NNDSS case counting.
  - This document is in the final formatting stage with CSTE staff and is expected to be publicly available soon.
- CSTE Brief – In development (anticipated early 2024)
  - This is a new document that the Co-Chairs are working on to promote the importance of the work of the DSWG and DEST teams related to Data Harmonization.
  - CSTE staff have been discussing how to package the work the DEST teams are doing and the recommendations that will be forthcoming.
  - A CSTE staff member is now dedicated to moving these briefs through the CSTE approval process.
  - CSTE Briefs are a mechanism through which CSTE members can voice their opinion on any issue, topic, or policy that would not directly result in changes to state or local laws, rules, and regulations. This makes these documents distinct from CSTE position statements. Briefs are developed and authored by active CSTE members and will go through a consensus-building and approval process with CSTE's Program and Policy Committee. The draft will also be published on CSTE Connect for all members to review and comment on.
  - Laura Erhart and Molly Crockett, the DSWG Co-Chairs, will develop the Dat Harmonization Brief that will document the problem statement, outline what we are working to accomplish within the DSWG, and highlight why this data standardization and harmonization work is so critical for efficient data exchange and interoperability. The goal is also to ensure the mission of this Workgroup is known more widely across CSTE membership.
  - CSTE is hopeful this document will be ready for CSTE members' comments in early 2024 and wanted to inform everyone of this, given our next meeting is in February.
- DSWG/Data Element-Specific Team Products

- DEST teams will continue working through conversations and developing recommendation documents.
- Updates on progress across DEST teams will be shared at these DSWG meetings.
- Recommendations documents will be shared with DSWG members before being considered final.
- CSTE members will continue to use CSTE Connect as the space for building consensus and providing input on workgroup products.
- Recommendation documents will be finalized on a rolling basis and associated with the umbrella brief on data harmonization.

Status Updates: Hospitalization, Travel (JMC, Grace Mallard)

Status Update Hospitalization and Travel

- These data classes were discussed by the DSWG earlier this year and are part of the effort to identify and standardize core data elements for surveillance for notification to CDC. These discussions were completed before the launch of the DEST's.
- The recommendations documents are being finalized and have previously been sent out for comment through the DSWG. As mentioned, these documents will be associated as chapters within the new CSTE Brief for Data Harmonization that is in progress.
- Each recommendation document will be approved and finalized individually.
- Thanks to everyone who provided feedback on hospitalization in September. That feedback has been incorporated into the current draft.
- Travel is in a similar position, and the feedback poll was launched last month. We appreciate the responses received to continue informing that document's development.
- The DSWG input on these documents is critical to the work done within this and the DEST teams.
- JMC has been working closely with the CSTE Briefs team and Co-Chairs for continued input, resulting in some format changes in the final documents, but the content remains the same.
- Discussion
  - A question was posed on whether a strategy for operationalizing data collection for these recommendations has been discussed. A special focus on electronic health records and getting information from other resources like USCDI was also mentioned.
  - CSTE responded that a strategy has not been fully fleshed out, but the goal is to ensure the recommendations from this workgroup are applied broadly.

Review of DEST Consensus: Pregnancy, Industry & Occupation, SOGI (JMC, Erin Kough and Sam Spoto)

The following presentations will outline what has occurred in the DEST discussions and provide an overview of what the DSWG can expect to see coming from those teams.

Potential data elements related to pregnancy

- An overview of potential data elements related to the pregnancy data class was presented, as seen in various message mapping guides (MMGs) for transmission to the CDC's National Notifiable Diseases Surveillance System (NNDSS) or established in other standards.

- Many of these variables are only present in MMGs representing a small number of conditions, and ultimately, the variables discussed in more detail for inclusion as potential core data elements included pregnancy status, pregnancy outcome, estimated date of delivery, and gestational age.
- There was a discussion of the utility of having pregnancy-related data elements as core data elements across conditions focused on standardizing communication about whether the patient was pregnant and the timing of that pregnancy related to the reported condition.

Potential Core Data Elements

- This table, displayed, highlights the four main data elements discussed by the pregnancy data element team. The group voted with consensus that pregnancy status and estimated date of delivery should be considered core data elements, which will be discussed further on the next slide.
- The group discussion surrounding gestational age indicated that while it may be a data element that is more common to come across in a medical record than the estimated date of delivery, collection of gestational age would also require a secondary variable of “gestational age recorded date” and potentially a variable indicating the method used to determine gestational age. Estimated date of delivery is a variable that can stand alone in terms of providing details of the timing of the pregnancy about the condition and was determined by the Pregnancy Status Data Element Specific Team to be a core data element for surveillance with 85% support, versus only 18% support for gestational age when the group was polled on the preferred data element.
- Pregnancy outcome is a variable present in multiple condition-specific message mapping guides containing disparate value sets. The proposed value set discussed included the options listed on this slide. Group discussion surrounding the data element resolved with general agreement that pregnancy outcome should not be considered a core data element for three distinct reasons: It is collected for a relatively small number of conditions, the value set variations among those conditions indicate the detail needed across conditions is different, and there is particular sensitivity surrounding the collection of this information due to the potential for criminalization or other legal or social consequences in some jurisdictions as it relates to the responses.

Pregnancy Core Data Elements

- The Core Data Elements for Pregnancy, as the Data Element Specific Team decided, are displayed here. The data element "pregnancy status" has been associated with CCCD for a condition. As someone may become pregnant or not pregnant throughout a case investigation, there was a desire to tie the time of event for pregnancy status to a date associated with the case. In previous work, this group has defined the calculated case counting date as the earliest of six available dates associated with a case, ranging from the symptom onset date to the date the case is entered or recorded. There is an acknowledgment that for certain chronic conditions such as HIV or hepatitis B or C, it is relevant to public health if the case is pregnant at any point during infection. However, information on pregnancy status throughout a chronic condition is outside the scope of the definition of this core data element for case-based surveillance. It should be addressed in a condition-specific manner.
- The EDD was found to be a core data element by the team as it can stand alone to show how far along in pregnancy a case is in relation to other case dates. This data element can be estimated from the patient's gestational age, and the date the gestational age was recorded if the only variable present within the medical record is gestational age.

Potential data elements related to Industry and Occupation

- Here is a brief overview of many data elements related to industry and occupation used either in CDC NNDSS message mapping guides (MMGs) or established in other standards. Current industry and current occupation are present in a standard template utilized across CDC MMGs. Industry refers to a workplace setting, such as a restaurant, school, or hospital. Occupation refers to the kind of job someone has, such as a pilot, nurse, or teacher.
- Some MMGs ask for occupation-specific information depending on whether some locations or practices, such as healthcare, food handling, or childcare, may be common areas for transmitting a pathogen.

Potential Core Data Elements

- This table highlights the four main data elements discussed by the industry and occupation data element team. The group voted with 95% consensus that the current industry and occupation, both as free text and standardized coded fields, should be considered core data elements as a repeating group in the current MMG template. These will be discussed further on the next slide.
- An idea for a template data element was introduced that would standardize the way employment information is gathered when asking if a case worked in a particular setting during a particular time. In a between-meeting poll, the group was supportive that this type of template for standardization may be helpful. Still, it felt most applicable to address this idea further with the future data class looking at exposure and risk.
- Similarly, an idea was also discussed regarding capturing if a case's exposure to a condition is related to their occupation. There are two ways to address this type of data element, either as a part of the industry and occupation repeating group to specify separately for each occupation or as a standalone question that asks in general if the current occupation is related to exposure. A consensus was not reached on this data element becoming a core part of the repeating group, and it will be further addressed with the conversation about standardizing a structure for the Exposure and Risk data class.

Industry & Occupation Core Data Elements

- The core data elements for industry and occupation, as voted with consensus by the industry and occupation team, are shown here. These data elements may be familiar as they represent the current standard template used across MMGs for industry and occupation. Current industry and current occupation are each captured by two data elements- a free text version and a standardized code. Jurisdictions are recommended to accept and send free text and coded variables when available but can still accept and send free text if codes are unavailable. NIOSH maintains its Industry and Occupation Computerized Coding System (NIOCCS), a free web-based API that converts free text to standardized coding systems. Jurisdictions can utilize this before sending data to the CDC or by CDC after receipt of free text values.
- One update was made to the current template: to update the value sets used from the Census coding systems to the North American Industry Classification System (NAICS) for Industry and Standardized Occupational Classification (SOC) for occupation. Census codes are derived from these NAICS and SOC code systems and maintained by the Census Bureau but contain less detail than NAICS and SOC. NIOSH recommended this switch in value sets to the group as these coding schemes are more broadly utilized than census codes. The NAICS and SOC systems are hierarchical, adding information about relationships, while Census codes are not, and the NAICS and SOC coding systems are independent of one another, so coding may be clearer when only industry or occupation is available.

- A few jurisdictions spoke up on the call to indicate that NAICS and SOC are already used internally to capture their industry and occupation data, and the group voted with 93% consensus to switch from the Census code systems to the NAICS and SOC code systems.

Pregnancy and I/O

- Next week, look for an email with the draft pregnancy recommendation document and a form for feedback. Thank you to those on the pregnancy data element-specific team who already provided input. Also, this draft will be formatted differently from the version you saw as CSTE is working to standardize a format for these documents to streamline the creation and approval process and increase the ease of identifying exactly what the core data element information is.
- Next week, Industry and Occupation data element-specific team members should look for a first draft of these recommendations. This will already be in the new format. These documents will be open for comment through the end of the year.
- After the I/O DEST review, feedback will be incorporated, and after co-chair approval, an updated version will be sent to this larger DSWG for feedback in January.
- We think this written feedback process is important as hundreds of people are interested in participating in this larger DSWG. A one-hour call is certainly not enough time to hear everyone's opinions. Our data element team calls have been a great place for longer discussion and consensus-building, with around 60-80 people on those calls. Still, we also want to make sure we're making space to hear from this larger group, and these document feedback forms will be a way to provide that opportunity.
- Discussion:
    - It was mentioned that a policy brief is currently being discussed, specific to the issue of industry and occupation as a social determinants of health.
    - CSTE confirmed that this document is currently out for comment.

Sexual Orientation and Gender Identity (in progress)

- This group is in progress, and we hope to wrap up in one final call. There have been robust conversations and discussions in the previous calls.
- To date, the group has voted on sexual orientation as a core data element with the following definition and value set displayed on the slide.
- Items still working include data elements and value sets as displayed on the slide. Additional information was gathered between meeting polls to help guide the next discussion.
- DSWG members are encouraged to attend the SOGI meeting and provide more detailed input into those discussions during the DEST call.

General Discussion:

- Molly Crocket (Co-Chair) noted appreciation for the efforts of all actively participating DEST members and the work of the JMC team members to keep these data elements discussions and recommendation documents moving forward. Encouraged individuals who have not joined the DEST teams to please join and share this information with colleagues who may be interested or have the expertise needed for each group.
- Discussion for the next steps for the Brief occurred, and CSTE mentioned that implementation will not be addressed now. CSTE and CDC are working closely to continue those discussions and the next steps.

- The CDC also acknowledged JMC and the CDC Background team for their hard work, which has proven to be an effective process for facilitating discussions and moving these data classes forward. The widespread participation in the DEST teams has been critical in the process, and these meetings have been well attended, which is important.

DSWG Next Steps (JMC, Sam Spoto)

Next Steps

- DSWG members are encouraged to continue signing up for DEST teams here.
    - Immunization History – first meeting on 12/15
    - Future data classes include.
        - Exposure/Risk/Underlying Conditions
        - Death
        - Signs/Symptoms/Clinical Manifestations
- The draft of pregnancy recommendations will go out to the DSWG for comment in December.
- The Industry and Occupations draft is expected to go out to the DSWG for comment in January.
- The next large DSWG meeting will be held in February.