Meeting Title: CSTE Data Standardization Workgroup Meeting
Date: 6/28/2024

Attendees: 120

CSTE (3)	PHAs (60)	DSWG Members (continued)	CDC (45)
Becky Lampkins	Co-Chairs	Misty Johnson | WI	Amanda Deering
Gillian Haney	Judie Hyun | MD	Morrow Toomey | AK	Angie Agunloye
Meredith Eddy	Laura Erhart |AZ	Nora Kelly | IL	Catherine Espinosa
JMC (6)	Molly Crockett | MA	Orion McCotter| OR	Christopher Perdue
Erin Kough		Orlando Velazco | CT	Danielle Tack
Grace Mallard	DSWG Members	Pyone Yadanar Paing | WA	Doris McGinness
Laura Lane	Aileen Duldulao | OR	Rob Arciuolo | NYC	Ellen Martinson
Sam Spoto	Brianna Rossi | VA	Rob Laing | OR	Emma Baubly
Sara Sanford	Cher Levenson | WA	Ryan Burke | MA	Erin Conners
Susan Downer	Danny Power | MT	Shawna Stuck | GA	Erin Miller
	Derek Vale | HI	Sophia Cantor | WA	Fatima S.
Other/Unknown Affiliation (6)	Eden Dietle | MO	Steve Eichner | TX	Jim Jirjis
amcdonald	EJ klingler|NYC	Suzanne Gibbons-Burgener | WI	John Gerstle
Gene Shin	Elizabeth Kessler | NV	Syreen Goulmamine|VA	Katherine DeBord
Imani Carey	Elizabeth Lando-King | MN	Theron Huntamer | NV	Katie Dodd
Scott Fried	Erin Doyle | NJ	Tracy Miller | ND	Kerry Souza
Sue Soliva	Hanna Chakoian | MN	Vanessa Whattam | MT	Kristie E. N. Clarke
Todd Ashworth	Hannah Schoon | UT	Ximena Vergara | CA	Lacey Critchley
	Hollie Sheller | MO	Yi Du | NE	Lauren Korhonen
	JACOB CHAVEZ | LA		Laurie Barker
	Janet O'Conno | SC		Luis Hernandez | GDIT
	Jeff Swanson | TX		Marie Haring Sweeney
	Jennifer Floch | MT		Marion Rice
	Jennifer Kwon | LA County		Mary Alao
	Jennifer Otsubo | VT		Matt Stuckey
	Jill Krause | NB		Melissa Pagaoa
	John Satre | IA		Michelle Lin
	Juli Carlos-Henderson | LA County		Miriam Van Dyke
	Justine Maxwell | TN		Nicola Thompson
	Karen Arrowood | CDC and TX		Nikolay Lipskiy

	Karene Thomas-Watts | CO Kayleigh Nerhood | GA Kiara Vicente | AK Kyra Veatch | IN Linda Kelemen | SC Lunden | IN Madeline Sankaran | San Francisco Margaret Iiams | SC Margret Watkins | WV Maria Jaurretche | DC Health Marija Borjan | NJ Mario Beltran | MD Mary McNeill | OH Melissa Kealey | CA		Noreen Kloc Rachel Abbey Rachelle Oseni Renee Boehmert Robert Pratt Robyn Cree Sally Rodriguez Sandra Bulens Scott Grytdal Shauna Mettee Zarecki Shawn Arshad | GDIT Shelby Lyons Stacey Martin Umed A. Ajani 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)

Co-Chair Announcement

- We would like to welcome Judi Hyun, from the Maryland Department of Health, as an additional Co-Chair.
- Laura and Molly both remain in place, and this addition is expected to add additional input and support at the Co-Chair level.
- Judie is currently the Chief of the Division of Infectious Disease Surveillance and previously has worked in legionnaires disease arboviral case investigations.

Core Data: In Scope for DSWG

- For these meetings, we're most specifically identifying the core surveillance data elements 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.?

Meeting Ground Rules

- We welcome active participation and engagement from everyone on the call, including STLTs, CDC, and CSTE

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

- Upcoming DEST teams include,

  - Medication/Treatment (Call #1): July 12, 1-2 ET
  - Identifiers (Call #2): July 19, 1-2 ET
  - Upcoming: Laboratory, Reporting Source, Race/Ethnicity/Tribal Affiliation, Social Determinants of Health (SDOH)
- Tracks will occur concurrently, but meetings will not happen 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.

Announcements and Key Updates (CSTE)

Announcements & Key Updates

- Welcome to Meredith Eddy (new CSTE Senior Program Analyst)
  - She joined CSTE after some time as an Epidemiologist and Data Manager at the New York City Department of Health.
  - Meredith's primary focus and her portfolio at CSTE is supporting this workgroup, the DSWG, and other case-based surveillance activities.
- CSTE Brief for Data Harmonization – In development
  - This Brief will highlight the critical importance of this standardization effort and outline the
    - Workgroup's goals for what and how we're hoping to accomplish this work together
    - Make a case for continued widespread participation in the workgroup
    - Highlight the recommendations coming out of the DSWG to ensure that PHA's and CDC are working towards implementation in the future.
  - When it is ready, it will be emailed out, and the workgroup will be updated.
- Recap from DSWG Discussion Session at the 2024 Annual Conference
  - DSWG membership levels: 264 in October 2023 up to 559 as of June 2024 (pre-conference)
  - Laura Erhart noted that
    - The work that comes from the DSWG was mentioned in other sessions at the conference, and it is exciting to know that other groups are interested in the outcomes of these efforts.
    - During the DSWG-specific Monday session, led by Laura Erhart
      - The session was well attended, and she was surprised at how many participants were unaware of the DSWG yet were interested in attending this session. The Co-Chairs and CSTE are always exploring ways to ensure we get the right

people to the table. We appreciate member support in spreading the word and encourage members to share the sign-up form with colleagues with expertise and interest in DEST topics.

- During the session, there was also a comment on all the work done here, and we wanted to take a moment to thank each of you for your efforts in advancing this work!
- There were also discussions about which partners are at the table, and with the scope of what we need to do, we feel that relevant parties have been reached. Again, thanks to the workgroup for helping to spread the word to our various STLT and federal partners.
- Finally, it was noted that someone expressed questions about the recommendations and document versioning process. We don't have that ironed out completely, but the Co-Chairs and CSTE are considering it. It will be important to remember that this work will continue to evolve, and things will need to change to adapt to surveillance needs within the community.

Status Updates for Closed DESTS (JMC)

Data element-specific teams (also called DESTs) are considered "closed" when the call stage of the process wraps up. But the work continues past that point. Here we will share some progress made with various data classes as we've moved documents from closed DESTs through sequential rounds of reviews and edits.

Status update for closed DESTS

- DSWG review is complete, and the drafts are with CSTE for the next steps.
    - Hospitalization
    - Travel
    - Pregnancy
    - Industry and Occupation
    - Immunizations
    - Death
    - Sexual Orientation and Gender Identity
- DEST member input deadlines are June 28 for the following
    - Exposures, Risk Factors, and Underlying Conditions
    - Signs, Symptoms, and Clinical Manifestations
    - Disability
- A poll for Social Determinants of Health was shared with that DEST with a deadline of June 28 for input.
- Upcoming DESTS
    - Medication/Treatment: July 12
    - Identifiers: July 19

DEST Summary (as of 6/28/2024)

- The table shows progress with each data class that has been started.

Review of Recent DEST Consensus: (JMC)

We will review the consensus outcomes of the DESTs that have been completed since the last April DSWG meeting.

Disability: (JMC- Erin)

Disability: American Community Survey

- As a review, using a functional definition for disability is any condition of the body or mind that makes it more difficult for the person with the condition to do certain activities and interact with the world around them. Although the phrase "people with disabilities" is sometimes used to indicate a single population, in reality, it refers to a diverse group of people with a wide range of needs.
- For those who were not on the Disability team and maybe don't know a lot about this topic, this slide shows the American Community Survey disability questions. These are a set of six questions developed by a federal interagency committee for use in major surveys. These six questions capture information on functional limitations across domains of hearing, vision, cognition, ambulatory, self-care, and independent living.
- These six questions are the minimum data standard for collecting data under the Affordable Care Act and are used in Bureau of Census surveys.
- HHS includes the ACS questions as part of the published standards for data collection on race, ethnicity, sex, primary language, and disability status.

Disability: Proposed Concepts

- The DEST agreed that disability, as a demographic variable, should be considered core surveillance for submission to the CDC.
- This was discussed as a series of concepts with the American Community Survey as the base.
- The description of the overarching term is shown on the slide along with the corresponding LOINC code.
- 80% of the poll respondents agreed that it was important to be able to capture whether a screening was negative or the result was unknown as opposed to just knowing when a screening for a disability was positive.
    - 24 out of 30 indicated it was needed for all screenings.
    - 2 out of 30 said it was necessary for some screenings.

Disability: Proposed Concepts (Page 1)

- This slide displayed some American Community Survey questions as defined data values here. *The rest were listed on the next slide.*
- This contains both the label and the value description.

Disability: Proposed Concepts (Page 2)

- In addition to the base ACS questions, a couple of other concepts were added to the concept set to capture important information that may already be being collected at various jurisdictions.
  These were
  - Communication as an independent living concept, such as that which can be found in another well-researched and heavily used disability question set known as the Washington Group short set
  - A concept to capture intellectual disability or developmental delay, which is a concept collected in some jurisdictions.
- 77% (20 of 26) of the poll participants supported this list of disability concepts.

Disability: Proposed Concepts

- To allow for a potential repeating block, as we see in current message mapping guides, an associated Disability Type Indicator is also recommended.
  - This would be paired with the value set of the disability concepts in a repeating block.
- The draft document for these data elements is currently with the DEST for comment through today. After addressing comments, a new draft will go out to the larger workgroup soon.

Discussion

- *No discussion ensued following these updates on disability.*

Identifiers (JMC- Sam)

Current Standard Identifiers

- The first meeting was held in May, and today, those updates were discussed as well as a point for discussion.
- Two of the current identifier data elements in the generic v2 MMG are shown on this slide. They are the local subject ID, which is present in PID-3 in the HL7 message, and the local record ID, which is present in OBR-3 in the HL7 message. These fields intend to identify the person as a unique individual using the first local subject ID, and the case as a unique case using the local record ID.
- These identifiers are essential to the transmission of case notifications, and there was no proposal to change their intent. However, during our call, it was voiced that the current descriptions of these data elements are unclear, and it would be beneficial for the DSWG to develop improved definitions to describe what's being transmitted clearly.

Updates to Standard Identifiers

- On this slide are the proposed updates to the names and definitions of these fields. This has not come from the DEST; we're talking about it for the first time today in our larger group. The goal is to develop simple definitions that describe what is intended to be transmitted in these HL7 fields.
  - The "local subject ID" has been renamed as "Person ID” and updated the definition to "The jurisdictional identifier that uniquely identifies the person."

    - The "local record ID" has been renamed to "Case ID" and updated the definition to "The jurisdictional identifier that uniquely identifies the case."
- These definitions make the intent of these identifier fields much clearer, but we wanted to present them to the larger group today and see if anyone has any concerns about these updates to the definitions.

Discussion

- Suzanne Gibbons-Burgener noted that she the changes, but we often refer to individual people and cases. She felt we should use 'case/patients' or clarify that 'case' implies an event or disease, not the person.
    - Sam Spoto (JMC) confirmed that we previously discussed updating our language to replace 'case' with 'person,' such as using 'pregnancy status of the person' instead of 'pregnancy status" of the case to help alleviate that. Here the intention is that it is the case and not the individual.
    - Sam Spoto (JMC) noted that in the chat during the meeting, people were offering support, and someone mentioned using "instance of disease" instead of the word "case." She noted that the language could be changed to clarify that this is the instance of the disease and not the person.
- **ACTION:** JMC will be sure to update the definition to clarify that case, in this instance, means the event and not the person.

DSWG Next Steps: (JMC)

Next Steps

- If you are in the following DESTs, a reminder of the June 28 Deadlines
    - Draft recommendations review
        - Exposures, Risk Factors, and Underlying Conditions
        - Signs, Symptoms, and Clinical Manifestations
        - Disability
    - Polling for Social Determinants of Health
    - In July or August, DSWG should look out for an email with drafts or recommendation documents and feedback forms for the following
        - Exposures, Risk Factors, and Underlying Conditions
        - Signs, Symptoms, and Clinical Manifestations
        - Disability

Other Next Steps

- Upcoming meetings
    - Medication/Treatment: July 12
    - Identifiers: July 19
- Future data classes
    - Laboratory

    - Reporting Source
    - Race/Ethnicity/Tribal Affiliation
    - Social Determinants of Health
- The next broad DSWG call will be held August 30