Meeting Title: CSTE Data Standardization Workgroup Meeting
Date: October 25, 2024

Attendees: 143

CSTE (2)	PHAs (82)	DSWG Members (continued)	CDC (45)
Becky Lampkins	Co-Chairs	Justine Maxwell Mwose | TN	Amanda Deering
Meredith Eddy	Laura Erhart |AZ	Karen Arrowood | CDC and TX	Angie Agunloye
JMC (4)	Molly Crockett | MA	Kayleigh Nerhood | GA	Kristie E N Clarke
Erin Kough		Keely Wrolstad | WI	Carmen Pugh
Laura Lane	DSWG Members	Kristin Goldesberry | IL	Chirine Chehab
Natalie Raketich	Aaron Bieringer | MN	Kyra Veatch | IN	Chrissy Miner
Susan Downer	Abi Collingwood | UT	Lakin Mauch | ND	Cindy Bush
	Adrienne Erlinger | MA	Li Jiao | Harris County	Danielle Sharpe
Other/Unknown Affiliation (10)	Alan May | AR	Linda Kelemen | SC	Doris McGinness | GDIT
Graeme Chiasson	Alina Paegle | UT	Luke Dalton | MI	Gonza Namulanda
Janine Young	Allison La Pointe | MN	Marija Borjan | NJ	Hannah Perry
Johanna Bosse	Amy Bogucki |TN	Mario Beltran | MI	Henrietta Smith
Julian Grass	Andria Apostolou | IHS	Mary McNeill | OH	Jenny Couse
Lisa Nelson | MyDirectives	Angela Herbert | NE	Melissa Kealey | CA	Jessica Laury
Manjula Dharmawardhana	Anna Kocharian | WI	Michael Eberhart | PA	John Gerstle
Mya Pierson	Ben Meana | WA	Misty Johnson | WI	Josh Bagley | GDIT
Roger	Benjamin Schram | ND	Moji Ojo | NJ	Julie Vanderkolk
Scott Fried	Beth Isaac | NYC	Monique Birmiel | IN	Kayode Olupinyo
Sophia	Brittany Grogan | Madison and Dane	Morrow Toomey | AK	Kristin Delea
	County	Nancy Barrett | CT	Lacey Critchley
	Christy Crowley | NC	Nathan Tan | HI	Lauren Korhonen
	Cher Levenson | WA	Nora Kelly | IL	Lesliann Helmus
	Clifford Mitchell | MD	Orlando Velazco | CT	Luis Hernandez | GDIT
	Deb Loniewski | MI	Pyone Yadanar Paing | WA	Marie Haring Sweeney
	Debra Rivera | NM	Rachel Corrado | NYC	Mariel Marlow
	Deepani Jinadasa | UT	Rob Laing | OR	Mary Alao
	Dimple Patel | KY	Ryan Burke | MA	Miriam Van Dyke
	Ed Hartwick | MI	Sam Hawkins | OR	Myrna del Mar González | GDIT
	EJ Klingler | NUC	Sarah Love | Chicago	Nekole Locke
	Elizabeth Lando-King | MN	Shannon Allain | OR	Nicole Gallaway

	Eman Addish | Philadelphia	Sudeep Neupane | TX	Nicolette Bestul
	Emily Walsh | Maricopa County	Sue Soliva | MA	Otto Ike
	Erin Doyle | NJ	Suzanne Gibbons-Burgener | WI	Rachelle Oseni
	Genie Tang | CA	Tashauna Lane | SC	Renee Calanan
	Genny Grilli | MN	Taylor Bednarz | Maricopa County	Robert Pratt
	Graham Crawbuck | WA	Theron Huntamer | NV	Sally Rodriguez
	Heather Elder | MA	Tiffany Firestone | WA	Sandy Price
	Inaya Wahid | DE	Trish McLendon | CA	Sara Johnston
	Isaiah Francis | NM	Tyler Riedesel | UT	Shelby Lyons
	Janet O'Connor | SC	Vajeera Dorabawila | NY	Sonia Singh
	Jennifer Floch | MT	Yuritzy Gonzalez | OR	Stacey Martin
	Jill Krause | NB		Sydney Adams
	John Satre | IA		Tashina Robinson
	Josh Nazinyan | LA County		Val Reagon
	June Bancroft | OR		Veronica Burkel

**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

Welcome (Co-Chairs)

Core Data: In Scope for DSWG

- For these meetings, we're most specifically identifying the core surveillance data elements 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 examine specific selected data classes. Again, the scope identifies 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 best take advantage of and feed into other standardization efforts like HL7, USCDI, and USCDI+? None of what we do in public health happens 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-Chairs)

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 merge each element into teams to better leverage DSWG members' expertise.
- 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,
    - Social Determinants Health
        - November 8 (Call 3)
        - November 15 (Call 4)
        - These calls will focus on Language, Education, Insurance, Income

- Tracks will occur concurrently, but meetings will not happen simultaneously to allow people to participate in topics as desired.
- After a DEST concludes discussions, JMC staff will develop guidance documents with continued offline input 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

- CSTE Brief– Pending Steering Committee approval
    - The CSTE Policy Brief we've been discussing has been submitted from the DSWG co-chairs to CSTE and is pending steering committee chair approval.
    - The Brief outlines the objectives and scope of the work coming out of the DSWG, as well as a plan for moving our recommendation documents through the CSTE consensus-building process.
    - It's currently pending a few more approval steps and will hopefully be available for broader membership review in December via CSTE Connect.
- CSTE Cooperative agreement update
    - CSTE has received a notice of award for several projects funded through our cooperative agreement with CDC, one of which is a project called Data Standards Harmonization, which supports the continued work of the DSWG. We're excited that CDC is prioritizing this work with the goal of supporting the project further into implementation.
    - We're currently putting together a detailed work plan for the next year and hope to have more details to share with you all in December about the next steps and what future calls will look like.
- DSWG on CSTE Connect
    - This is a carryover from the last meeting and a reminder that this space on CSTE Connect is being developed for the DSWG.
    - The DSWG Community on CSTE Connect will replace Basecamp.
    - Look for more emails coming soon with more details.

Race/Ethnicity (CDC)

Race and Ethnicity Updates

- *Please see the slide deck for information that was shared during the meeting*

CDC Race and Ethnicity Code System Overview

- *Please see the slide deck for information that was shared during the meeting.*

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

- The following DESTs are closed, and recommendations documents are with CSTE for the next steps
    - Hospitalization, Travel, Pregnancy, Immunizations, Death, Sexual Orientation and Gender Identity, Disability, Identifiers
- Draft recommendations are in progress and, when complete, will be shared with DESTs for review
    - Laboratory
- This is with the DSWG for review
    - Medications – out for review through November 4
- JMC is working closely with Co-Chairs to reconcile comments on the following recommendations before handing over to CSTE for their next steps
    - Signs, Symptoms, and Clinical Manifestations
    - Exposures, Risk Factors, and Underlying Conditions
    - Industry and Occupation (updates for "employment status")

Clinical Manifestations

Clinical Manifestations

- Earlier this year the DEST for Signs, Symptoms, and Clinical Manifestations created a document that was provided to DSWG for feedback that includes the first two data elements shown on this slide. As CDC is working to implement the Minimal Data Necessary (MDN) data elements, which were developed separately from DSWG, the goal is to reconcile differences between our two groups during implementation with the consensus-based product we're developing.
- The clinical manifestations data class has caused some complexity here. Our DEST worked hard to come up with terminology that was very inclusive and technically correct of the information that we wish to be transferred in this data class, which is information about any clinical manifestations inclusive of signs and symptoms in one data class. This data class can be transmitted using a repeating group, and there was also a desire to transmit a summative indicator value that expresses if any of the values within the repeating group are "yes" or if all of them are "no." Separately, our document also has a symptomatic indicator that is meant to capture if the person experiences themselves as symptomatic or asymptomatic, which is not shown on this slide. It is recognized that the data element also requires additional discussion surrounding implementation; however, we're not going to discuss that today.
- In the dates of public health importance brief the DSWG defined a "symptom onset date", meant to be the earliest date of onset of signs or symptoms, and it's important to note that this data element was defined prior to the work of the DEST that defined Clinical Manifestations.

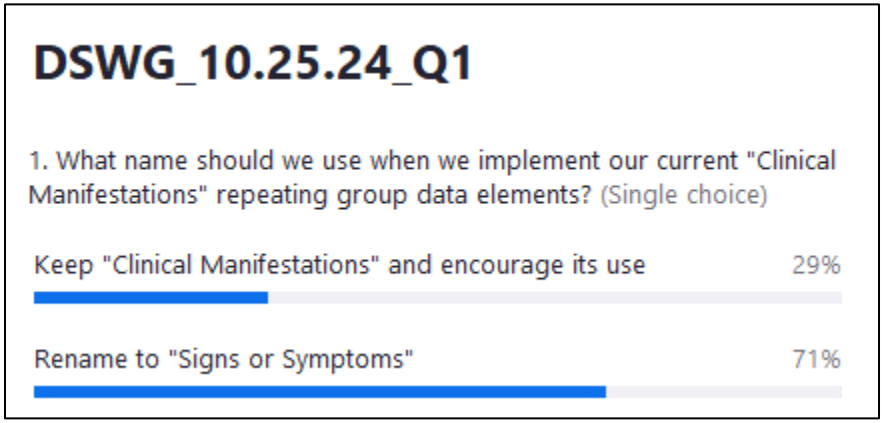
- When we think about the implementation of all three of the data elements shown on this slide as related to the MDN, it's pretty clear from the definitions that we would like all of them to transmit information about the same concept, which is any clinical manifestation or sign or symptom associated with the condition. At this point, the consistent terminology we've come up with to utilize for this concept is Clinical Manifestation.
- While the data element name of what is transmitted between a jurisdiction and CDC does not need to represent what something is called in a jurisdictional surveillance system, as these data elements are implemented into things like the MDN, they are going to be widely presented and discussed with groups that are not just informaticists and with people who were not part of DSWG discussions. While our workgroup has come up with a technically correct term, it has felt awkward to commit to using terms like "clinical manifestations indicator" and "clinical manifestation onset date" as these terms are uncommon and might cause confusion upon distribution throughout public health.
- We'd like to propose today that we potentially update what we have named some of these data elements to be more colloquially recognizable in the wider epi community. The definitions that describe what is captured in these data elements from the DEST will not change. As the symptom onset date from the brief was defined prior to our work, we would like to standardize that definition to match the others, adding the description of "clinical manifestations, including" in front of signs and symptoms.
- Does anyone feel strongly that we should keep our data element names as "clinical manifestations"? Keeping Clinical Manifestations as the name would mean our group would firmly adopt that term and encourage the CDC to implement data elements and socialize the use of it when talking about these data.

  Discussion
  - Suzanne Gibbons-Burgener noted that in the past, 'symptoms' have generally been used inclusively, though there is a distinction between signs and symptoms that most laypeople—and even some outside the medical field—may not know. However, it's helpful to clarify that clinical signs, such as an abnormal radiograph, can be included, as they are typically observed and identified by a physician, not by the individual themselves. This distinction is essential as 'symptom onset' is commonly referenced in terms of what led the patient to seek medical care. While 'clinical manifestations' might sound technical, they are no more complex than 'signs and symptoms' in capturing both observed and experienced health indicators.
  - Erin Kough recognized that there was a question in the chat about whether the problem onset date or condition onset date differs from signs or symptoms. She noted that the draft recommendations in the appendices clarify different HL7 concepts, which may be helpful.

Poll – CM or SS?

- What name should we use when we implement our current "Clinical Manifestations" repeating group data elements?
  - Keep "Clinical Manifestations" and encourage its use
  - Rename to "Signs or Symptoms"

- Poll results (n=38)



General Updates for Closed DESTS

DEST Summary (as of 10/25/2024)

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

DSWG Next Steps: (JMC)

Next Steps

- These draft recommendations are in working and will be shared with DESTs for input as the next step
  - Laboratory
- Documents out for DSWG Review
  - Medications – through November 4, 2024

Other Next Steps

- Upcoming meetings
  - Social Determinants of Health, 1-2 pm EST
    - Call #3: Friday, November 8
    - Call #4: Friday, November 15
    - Calls 2 and 3: Language, education, insurance, income
- The next broad DSWG call will be held on Friday, December 13
- *Note: All drafts released for DEST/DSWG review are drafts, and the resulting recommendations passed to CSTE for final steps have not been made available. Please do not pass on draft documents as final products*.