Meeting Title: CSTE Data Standardization Workgroup Meeting
Date: 12/13/2024

Attendees: 110

CSTE (6)	PHAs (59)	DSWG Members (continued)	CDC (36)
Becky Lampkins	Co-Chairs	Maribeth Hoyle | OR	Andrea Steege
Gillian Haney	Judie Hyun | MD	Marija Borjan | NJ	Angie Agunloye
Kirtana Ramadugu	Laura Erhart |AZ	Mario Beltran | MI	Anne McIntyre
Megan Sullivan Toe		Mary McNeill | OH	Antonio Neri
Meredith Eddy	DSWG Members	Melissa Kealey | CA	Kristie E N Clarke
Mia Isreal	Abi Collingwood | UT	Michael From | GA	Carmen Pugh
JMC (6)	Allison La Pointe | MN	Molly Crockett	Danielle Sharpe
Erin Kough	Amy Bogucki | TN	Monique Birmiel | IN	Danielle Tack
Grace Mallard	Andria Apostolou | HIS	Morrow Toomey | AK	Doris McGinness
Laura Lane	Angela Herbert | NE	Nancy Barrett | CT	Gonza Namulanda
Natalie Raketich	Beth Isaac | NYC	Orion McCotter | OR	Hannah Perry
Nicole Kosacz	Brianna Rossi | VA	Orlando Velazco |CT	Jennita Reefhuis
Sam Spoto	Carolyn Kennison | ME	Rachel Corrado | NYC	Jessica Laury
	Cher Levenson | WA	Rob Laing | OR	Josh Bagley | BAH
Other/Unknown Affiliation (3)	Dimple Patel | KY	Ryan Burke | MA	Karen Arrowood
Andre	Ed Hartwick | MI	Sam Hawkins |OR	Katherine DeBord
Dan Tauriello | ASTHO	ej klingler | NYC	Sarah Love | Chicago	Lauren Korhonen
Vanessa	Elizabeth Lando-King | MN	Sequoia Rent | DE	Marie Haring Sweeney
	Erin Doyle | NJ	Shannon Allain | OR	Marion Rice
	Erica Rudd | NV	Stephanie Moberg | NM	Miriam Van Dyke
	Genie Tang | CA	Sue Soliva | MA	Myrna del Mar González | GDIT
	Harir Abdulla | CA	Suzanne Gibbons-Burgener | WI	Nicole Gallaway
	Hanna Chakoian | MN	Syreen Goulmamine | VA	Nicolette Bestul
	Isaiah Francis | NM	Tiffany Firestone | WA	Peter Boersma
	Jacki Griffin |NY	Trish McLendon | CA	Rachel Abbey
	Janet O'Connor | SC	Yi Du | NE	Rachelle Oseni
	Jazmin Diaz | CT		Robert Pratt
	John Satre | IA		Sandy Price
	Julie Lazaroff | NYC		Sara Johnston
	Kayleigh Nerhood | GA		Shelby Lyons

	Keely Wrolstad | WI Kiara Vicente | AK Kyra Veatch | IN Linda Kelemen | SC Madeline Kemp | WI Margaret Iiams | SC		Sundak Ganesan Sydney Adams Tashina Robinson Walter Alarcon Yasemin Kaynas (CDC) Yuritzy Glez

**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)

Year in Review: Participation Growth

- The data standardization work group, initially consisting of 120 members two years ago, has seen substantial growth, now reaching 636 members on the mailing list.
- The group includes participants from 47 states, the District of Columbia, and a mix of public health agencies (local and state), with about half from public health, 40% from federal agencies, primarily the CDC, and a smaller portion from local agencies.
- The growth and broad representation across these sectors are celebrated as significant achievements over the past couple of years.

Year in Review: The Year of the DEST

- Over the past year, the workgroup has evolved from a single monthly meeting to multiple meetings focused on 14 different data classes, covering a wide range of topics.
- These smaller groups have seen participation from 83 to 326 individuals, although not all are present in every call.
- The group has experienced significant discussion and engagement throughout these efforts.

Year in Review: Effort and Results

- Over the past year, the group has held 26 DEST meetings, seven full group meetings, and a roundtable discussion at the CSTE Conference.
- Additionally, ten recommendation documents have been successfully handed off to CSTE for further action.
- Laura Erhart (Co-Chair) expressed gratitude to everyone involved, including the CSTE and JMC staff, for their support in moving these efforts forward and thanked participants for their valuable contributions.

Announcements and Key Updates (CSTE, Meredith Eddy)

Thanks to Co-Chairs

- A heartfelt thank you was extended to Molly Crockett, who is stepping down as Co-Chair after serving since 2018.
- She played a key role in developing plans and processes that the group has followed over the years. Her contributions were instrumental in the group's achievements, and the team hopes to continue seeing her involvement with the DSWG in the future.

Announcements & Key Updates

- Looking ahead, starting in January, meetings will shift to a monthly schedule, with the DSWG meeting held on the last Friday of each month.
- Early in 2025, the group will focus on finalizing data class recommendations for broader review.
- The CSTE policy brief, outlining objectives and the process for moving recommendations through consensus building, is progressing and will be available for member comment in mid-January, followed by the consensus process for the data class recommendations.

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.

General Updates for Closed DESTS

Status update for closed DESTS

- Listed are all the data classes the group has worked on this year.
- Ten of the data classes have had their recommendation documents handed off to CSTE.
- Reporting Source and Social Determinants of Health have draft recommendations being reviewed by the DEST teams before edits are incorporated and sent out to the larger DSWG.
- The lab's first draft is in progress and will be sent out soon.
- JMC is working to reconcile comments for CSTE's next steps for
    - Industry and Occupation – which will be discussed further today.
    - Signs, symptoms, and clinical manifestations

Review of Recent DEST Consensus: (JMC)

We will review the consensus outcomes of the DESTs completed since the last DSWG meeting.

Industry and Occupation: (JMC – Sam Spoto)

Employment Status

- At the August meeting, we had a robust discussion about a data element of employment status and agreed to add this concept as a core data element to our document.
    - Both in the August meeting and in the responses received when the document was out for review, many people didn't agree with the term "or training" in the initially proposed definition of "Person's relationship to working for pay, family earnings, or training."
    - Further follow-up from NIOSH was received, and they have a second definition of Employment Status that has been previously utilized in a publication related to their Occupational Data for Health model.

    - That definition, shown on the slide, is someone's "self-reported economic relationship to work" and removes the pieces of the previous definition that were concerning to DSWG members.
- While the previous definition is what's currently present in current USCDI, ELR, and eCR standards, through support from these DSWG recommendations NIOSH would like to work to update those standards with this revised definition.
- The word "current" has been added here to align with the vocabulary we have used within our Industry and Occupation data elements, as well as with the LOINC terminology.
- Does anyone have any strong concerns about utilizing this definition within our Industry and Occupation document?
    - *There was no comment or discussion from the group.*

Laboratory (JMC – Erin Kough)

The Laboratory DEST met in August, September, and October to discuss what laboratory information would make sense in a laboratory repeating group for transmission to CDC and whether this repeating group should be recommended as core surveillance.

Laboratory Repeating Group: Data Elements Discussed

- This slide displayed all the data elements that were discussed in the lab calls.
    - Data elements in green were recommended to be included in a laboratory repeating group.
    - Those in red did not make the cut for inclusion based on discussion and polling of the DEST.
- The elements that were recommended for inclusion are discussed in the next couple of slides.

Proposed Data Elements: Laboratory Repeating Group

- Many of the data elements agreed upon are straightforward, though some may be different from what has been seen previously in message mapping guides.
- In general, changes were made in an effort either to match the laboratory data elements with the data which may be able to be pulled automatically from an electronic laboratory report or to align the data elements to definitions found in other recommendations such as the Data Standardization: Dates of Importance to Public Health Surveillance, Illness (Symptom) Onset Date, Report Dates, Laboratory-Related Dates, (Clinical) Diagnosis Date Brief.
- This slide shows the first three of seven data elements recommended as part of a laboratory repeating group. Test performed and Test result are foundational to laboratory information. Units of measure were deemed to be necessary to make sense of many quantitative lab results.
- Many of the value sets will no longer be condition-specific sets defined by CDC program areas; instead, CDC will be able to receive any value that is within the specified standard. For example, for Test Performed, any LOINC test code can be sent and successfully received by the CDC. Although this will likely simplify things in many ways, it was noted that jurisdictions would benefit from recommended lists of values generated by CDC program areas to help guide front-end surveillance system buildouts.
- Another notable change is that the Test Result data element would be one data element by which all types of lab results, qualitative, quantitative, or coded, could be sent. Instead of having separate Data Elements for each type of result, the result type would be sent in the OBX-2 of the HL7 message segment for the Test Result data element. During the call, we discussed any barriers to this consolidated Test Result

data element, but it was determined that the issues required input from technical people who were not generally on DSWG calls. We have since gathered input related to this, and while many jurisdictions reported no issues with this method, others were concerned that this would be a difficult thing to map for manually entered labs.

Proposed Data Elements: Laboratory Repeating Group (continued)

- The rest of the data elements are shown here and include Specimen Type (such as blood or urine), Specimen Source Site, such as "Entire eye," Specimen Collection Date/Time, and Date/Time of Lab Result.
- The draft recommendations document will be released to the DEST for input later today.

Social Determinants of Health (JMC – Sam Spoto)

In public health frameworks, a distinction has been made between social determinants of health (SDOH) at the community level and health-related social needs at an individual level. Acknowledging this distinction, the work of DSWG focuses on person-level data because case data are collected and sent to the CDC at the individual level. While the naming convention for this data class is the colloquially well-recognized term "SDOH," the data elements defined in this document are related to an individual's health-related social needs. These data points help public health identify which individuals may be at higher risk of adverse health outcomes due to their social conditions but also highlight factors that may increase the risk of acquiring or spreading disease.

SDOH: Concepts Discussed

- The DESTs talked about SDOH over several months, there were four topics covered by the group.
    - Residence type conveys information about where a person is living, and during discussions, was broken into two separate data elements: "housing status," which conveys if someone is homeless or housed, and "living situation," which describes the type of place a person lives.
    - Other data elements discussed as core data elements were preferred language, educational attainment, and insurance coverage type.
    - Background research was conducted on a data element for income. However, this was not discussed as a core data element as there were no CDC program areas that receive data through NNDSS that had a use case for the collection of income data. This type of data element could be tackled in the future for standardization by DSWG outside of the work toward defining core data elements.

Proposed Data Elements: SDOH

- The first two data elements discussed here are part of Residence Type.
- Both are defined using a timeframe of the CCCD, or calculated case counting date, described in more detail here as the first epidemiologically relevant date associated with the case.
- Housing Status simply has a value set of homeless, housed, or unknown.
- The Living Situation value set will be on the next slide and is more extensive. Some background to this one is our development of these data elements is based on work conducted by CDC and Fulton County, GA, to validate a question set used to assess residence type, particularly as it relates to conveying information about housing status and congregate living situations. According to this question set, the person should be asked to provide information about where they are living in their own words, and the investigator then would select the appropriate options

from an extensive list. Depending on those selections, additional follow-up questions may be required, such as whether the location is made for a human to live in or paid for by the charity.

Living Situation Value Set

- When using this validated question set, the responses can be rolled up into the options shown on this slide. CDC is working with the Gravity Project to develop standards and terminology around this work for future inclusion within USCDI and electronic health records. The DSWG data element does not require any jurisdiction to conduct interviews using the CDC-validated method, but the value set here should align with these standardization efforts by the CDC and the Gravity Project.
- Different living situations captured within this value set can convey valuable information for case surveillance on incarceration, such as the five options for correctional facilities, as well as congregate living status with options like long-term care facility or school or university dormitory.
- Participants will be able to take a closer look at this and provide feedback when the SDOH document goes out to the larger DSWG in early 2025.

Proposed Data Elements: SDOH

- Preferred Language was also voted as a core data element and is defined as the language a person is most comfortable using for communication. The minimum value set here is the NHSN Abridged Primary Language List, which is currently required by NHSN for the collection of language data. We're calling this a minimum value set because it may not include less common languages, and these languages can still be coded and sent using their appropriate ISO 639-3 code as needed for languages specifically important within your jurisdiction.
- Educational Attainment is the next recommended core data element and is defined as the highest degree or level of school completed by the person at the first epidemiologically relevant date associated with the case, or CCCD. The response options here range from less than 9th grade through graduate or professional degree. One update to this value set made by our DEST is to include an option for technical or vocational certifications. While this category is not considered a level of education by the American Community Survey or other Census Bureau data collection tools, this group found this to be an important distinction representing further education from high school graduates. Exclusion of this category enforces the stigma associated with pursuing educational opportunities outside of a traditional college track and ignores the possibility that this group could have distinct outcomes (economic or otherwise) from high school graduates.

Proposed Data Elements: SDOH (continued)

- The final data element and concept were voted as core with weak support, meaning we did not reach 80% consensus but did have support from more than half the group, which is the insurance coverage type. There's some extra wording on this one, as with the first draft of this document, we have asked the group to weigh in on some points that came up in our final call. The data element here, in general, is meant to capture a person's type of healthcare coverage, with a value set that would be a "Select all that apply" type of approach since someone may have more than one type of insurance.
- In the final call of the DEST, there was a conversation on some values within this value set, like "correctional facility healthcare service" or "Indian Health Service," as these are not technically health insurance. This data element can serve as a proxy in epidemiological analysis for understanding what someone's ability to access healthcare might be. For this reason, value sets and code systems related to the source of payment have previously included values for scenarios that don't strictly represent insurance but rather how someone is able to access care (like within a correctional facility or on a military base). This is true of the current value set utilized within the RIBD MMG. For those who are part of the SDOH DEST, you should currently have an email with this draft document and a poll asking your opinions on this topic and what

should be included. There are also some open questions on perhaps calling this “healthcare coverage” rather than “health insurance” if that helps the value set be more inclusive, as well as whether values related to the military should be one option or three.

- This document and poll were sent to the DEST the week before Thanksgiving, and we’re leaving it open through the end of 2024 just to give lots of time around the holidays. If you don’t have time to read the whole draft, it would be helpful if you could just focus on the three questions in the poll about insurance.

Reporting Source (JMC – Sam)

Reporting Source: Concepts Discussed

- Reporting Source is currently a data element in the generic v2 MMG defined as the “type of facility or provider associated with the source of information sent to public health.” In 2023 over 85% of the responses received by CDC were Laboratory, “Other” with a write-in the specification of “Hospital Lab,” and “Unknown.” This data element is primarily utilized by the division of STD prevention, where the definition is further specified as the “setting or health care facility where a person first received diagnosis, treatment or testing for the STD or associated syndrome reported in this case report.” Other program areas haven’t found as much of a use case for the data as the definition of what is being sent is vague, and information about who sent the report to public health isn’t necessarily as valuable for public health action.

Reporting Source: Concepts Discussed (continued)

- The discussion we had focused on creating a definition for this data element that is more specific so that in data analysis, we can know exactly what is being provided. The first definition is who reported the initial case to public health, and the second definition, which we called the “case identification source type” is closer to the STD program’s definition of where the person first received care for the condition.
- Discussion among DSWG members indicated that while most CDC programs do not utilize the Reporting Source variable as it is currently defined, there may be utility in a data element like “Case Identification Source Type” that explicitly captures information on where the person first received care that could be used for education and outreach planning. However, this information would likely need to come from case interviews, as the provider or facility that reports the case to public health is not necessarily the same as where the person first received care. Some jurisdictions discussed their use of the field Ordering Facility within ELR to map Reporting Source for STD cases reported. Jurisdictions also mentioned that mapping to a data element like these using facility name or address within ELR/eCR is labor intensive, requires continuous maintenance, and the same facility name/address may be comprised of multiple options within the Reporting Source value set.
- Although the discussion highlighted a potential utility of Case Identification Source Type, when polled, the group weakly supported a core data element of Reporting Source Type (60%) and not of Case Identification Source Type (35%). This may have been influenced by the fact that Reporting Source is already implemented in some systems as a part of the Generic v2 MMG. Based on these discussions and limited utility for other CDC programs, the DSWG does not recommend either of these data elements as core data elements for transmission to the CDC. Condition-specific implementation of a concept like either of these can still be considered as needed.

Reporting Source: Concepts Discussed (continued)

- Although not recommended as core, we compared and contrasted the current Reporting Source value set from genv2 with a condensed value set of only 13 values. This condensed value set tried to combine some of the more granular concepts, like “Prenatal or OB Facility,” Primary Care,” and “Family Planning Clinic,” into one value, like “Outpatient Facility.” There was a slight preference in the group for the condensed

value set, and jurisdictions noted that when mapping from electronic data, there may be many types of facilities present at the same location, making it hard to map to more granular options. Any future implementation of this type of data element should balance the need for granular information with what's attainable from electronic data sources.

- This draft document is currently with the DEST with a due date of today, and the larger DSWG can expect to see an email with the second draft for feedback to come out in January.

Summary of DEST Progress

DEST Summary (as of 12/13/24)

- The slide showed a graphic for DEST progress.

DSWG Next Steps: (JMC)

Next Steps

- These draft recommendations are in development and will be shared with DESTs for input as the next step
    - Laboratory
- Documents out for DEST Review
    - Reporting Source – deadline today, 12/13
    - Social Determinants of Health – through December 31

Other Next Steps

- Upcoming meetings
    - In the new year, we're going to have a different cadence of meetings; as we know, the two or three meetings a month have been a lot for those who have been really involved with most of the data elements. We're going back to one monthly large DSWG meeting.
    - In January, it will be on the 31st, and we're going to be revisiting Signs and Symptoms to tie up some loose ends there- specifically surrounding the implementation of the Symptomatic Indicator and what it really means. A final note we wanted to give is that all draft recommendations released for review are only drafts, and the resulting recommendations passed to CSTE for final steps have not yet been made available. Drafts can be shared and aren't secret, but nothing that you currently have in your inbox should be passed on as a final product.
- *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*.