Meeting Title:	**CSTE Data Standardization Workgroup Meeting**
Date:	2/14/2025
Attendees:	84

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

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

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.

Announcements and Key Updates (CSTE, Meredith Eddy)

DSWG Update

- In our last meeting, it was mentioned that the DSWG Brief was moving along through rounds of review, and since our last meeting, things have been moving fast! We're nearing the completion of the review process for the Brief, and it's now about to open for an all-member comment period on CSTE Connect. This could happen as soon as next week. Once the comment period opens, CSTE will also aim to send out the latest draft to this workgroup since many DSWG participants may not be CSTE members.
- The Brief outlines the objectives and scope of the work coming out of the DSWG and includes a plan for moving our recommendation documents through the CSTE consensus-building process. One of the appendices outlines a consensus process for our data class documents and is designed to gather member and jurisdiction opinions and facilitate buy-in on the data element recommendation products that all of you helped to develop.
- The process was reviewed and approved by CSTE's Program and Policy Committee last month, and CSTE is soft launching the plan now so that the first of the data class documents would open for member comment in early March. This review process is subject to change, depending on how things go, but now that it's approved, we wanted to go over that plan with all of you so you know what's happening next with all the products you've worked so hard on over the last few years.
- This table shows a high-level overview, so let's review it.

DSWG Consensus Development

- These slides are partly from a few presentations we've given to other committees and subcommittees to get CSTE members ready to comment on the Brief and subsequent data class documents and facilitate buy-in of data standards from STLT PHAs.
- The first "level" in the data class consensus development and approval process is the work that we do here in the DSWG. The content here you already know, so we won't go through it today. Still, the central message outlined in the Brief is the robust process our workgroup has deployed to develop the best set of recommendations that we can by going into detail on background research, the process of deliberation within the DESTs, our high standards for defining support, and the multi-level revisions process we use for developing data class recommendation documents**.**

Data Class Recommendation Progress

- We've also been communicating that this work is largely complete at this point, that we're tying up loose ends on a few data classes but that at this point we're ready to launch into subsequent levels of review for most of the data classes reviewed to date.

Committee Chair Review

- So, what comes next for each data class document? For level 2, we would send each document to the chair of the Surveillance Practice and Implementation Subcommittee, our surveillance and informatics steering committee chair, and vice chair to review and sign off on the products.
- These would be in the chairs' hands for about 2 weeks and then another week to allow for the reconciliation of any feedback

Membership Review

- Past this point, the data class document would open for broader CSTE member comments via CSTE Connect.

- In this phase, members will be presented with a data class recommendation document and will be asked to respond to a CSTE Connect discussion thread with answers to the following questions:
    - Do you agree that the data elements within the data class are core?
    - Do you have any concerns with the proposed definition?
- Key here: the general membership will comment, but they will not agree on behalf of their jurisdiction to implement these recommendations.
- As with the previous phase, the comment period would be open for about 2 weeks, followed by another week for feedback reconciliation

Jurisdictional Leader Review

- In the last phase, the plan is to release one Smartsheet input form per data class for jurisdictions to respond to with official comments. The goal is to get one response per jurisdiction, and that response can come from a state epi or someone who that state epi delegates to respond to the input form on behalf of the jurisdiction.
- This form would be open for 1 week, which is not a lot of time. Still, we'd encourage state epis to work within their health departments during the general membership review period to formulate official responses.

Jurisdictional Leader Review (continued)

- State Epis will be asked to answer the same questions as the general membership. Additionally, we're asking (per data class) whether a jurisdiction agrees to work towards implementing whatever measures they need to take to be able to exchange these "core" surveillance data elements from within their surveillance systems.

Simple Majority to Advance

- From the Smartsheet input form, CSTE is looking for a simple majority of jurisdictions to define an element as core.
- If only 30-50% of jurisdictions agree that an element is core, we'll convene a small working group to determine the next steps—revising the data element definition, providing additional context to the state epis, or reconvening the full DSWG for further discussion.
- If less than 30% of jurisdictions agree that an element is core, the data element will not be considered core. However, the DSWG may reopen conversations on that particular data element if we think it's necessary.

Next Steps

- So, where do things stand now? This plan was approved by the P&P committee toward the end of last month, and we've since "soft launched" the process by sending along our latest version of the Travel data class document for Level 2 review with SI and SPIS chairs. The goal is to obtain and reconcile any feedback so that the Travel document is ready to post to Connect for CSTE membership to review and comment on in early March.
- Since we have many data class documents for review, the goal is to send subsequent data classes in manageable batches and with different levels of review happening concurrently. For example, once the Travel document moves to the all-member comment period, SI chairs can begin reviewing the next batch of documents. (This chart is borrowed and not in any particular order)
- Of note, depending on how the early rounds of this process go, the timing of these different levels of review may need updating. But generally, the hope is that review for all of the drafts that we've started to date will have begun by this summer, with hopefully several being concluded in time for discussion of the process at the CSTE Annual Conference.

Discussion

- A question was asked about whether the process for building consensus and setting data standards includes flexibility to continue collecting and adhering to those standards, even if the CDC cannot accept certain data elements due to federal-level constraints. The speaker expresses concern about adjusting classifications or requirements for public health needs, only for the effort to be rejected, potentially undermining the work done.
  - It was noted that these concerns were acknowledged and as more information is available updates will be shared with the group.

Status Updates for Closed DESTS (JMC)

Status update for closed DESTS

- Laboratory is currently out for comment with this large DSWG group, and the feedback for that data class is due the 21st.
- Today, we are going to hopefully finish up our discussion of Signs and Symptoms
- There are a few more loose ends to tie up with SDOH that will happen on the 28th before that draft goes out to DSWG members.

Signs and Symptoms Summary: (JMC – Sam Spoto)

Previously, in February…

- In February of last year, when this group met, we talked about the current use of two different repeating groups by MMGs called clinical manifestations and signs and symptoms. The content of what's in the value sets as "clinical manifestations" or "signs or symptoms" across conditions has a lot of overlap between the two, and it was decided by the group that there should be a core data class to encompass these values. The terminology we were using for the name on that call ended up as "clinical manifestations, including signs and symptoms" since the term clinical manifestations includes everything that would be defined as a sign or a symptom but can be more comprehensive terminology for things such as laboratory findings.
- As we discussed in November, we have simplified our official data element name and definition a bit. Calling the data element "signs and symptoms" aligns with the vernacular used commonly in public health, and the definition maintains that it should include any clinical manifestations, including signs or symptoms. These should be identified using SNOMED codes when possible, and assigning which signs and symptoms are associated with a particular condition would be done by the CDC program areas.

Previously, in March…

- In March, we talked about the structure of this data class and landed on the structure that likely makes the most sense, which is a repeating group. This means that each individual sign or symptom can be marked as yes, no, or unknown, and each sign or symptom won't be a standalone data element in an MMG. The first data element seen here of "signs and symptoms" would have a value set of SNOMED codes for the signs and symptoms that apply to the condition. The signs and symptoms indicator would be linked to this data element and indicate if that sign or symptom is yes, no, or unknown.

Previously, in April…

- Finally, in April, we talked a little more about structure, and for both this data class and the exposure risks and underlying conditions data classes, the group thought it was beneficial to have a data class indicator. This would be an overall indicator value that indicates whether the person experienced ANY of the listed signs or symptoms associated with the condition in the repeating group. If the answer to this overall indicator is no or unknown, it may not be necessary to transmit a repeating group at all.

Signs and Symptoms Des

- To show these three data elements on one slide, the bottom two orange rows in the box are the repeating group data elements, and the top green row is the overall data class indicator. We've thought about renaming this as "Any signs or symptoms" to try and make things more clear if someone not from this workgroup were to be reading this in an MMG.

Previously, in April…

- Also, in April, the subject came up with a "symptomatic indicator." This arose from the discussion about the data class indicator, as at that time, the MDN had a data element called a symptomatic indicator, and there was a conversation about how it might be useful to public health for messaging purposes to understand whether or not someone perceives themselves as symptomatic, even if they may have other signs or clinical findings associated with a condition, like an abnormal chest x-ray or high white blood cell count. Ultimately, this symptomatic indicator was weakly supported by the group as core.

Discussion Polling

Polling Process

- Each poll question we do today will have its own slide. The goal is to reach 80% or more agreement and ideally have additional discussion when not quite there.
- Data elements that receive at least 80% agreement are considered resolved with “strong support”. If for any questions we can't reach the target agreement of 80%, but still more than half the group is in agreement, these points have been included in previous recommendations documents as having "weak support".

Current State

- This slide shows the current state of things. As mentioned previously, the top line for the data class indicator would be transmitted to share if the case had any of the associated signs or symptoms. This is a summary data element that stands on its own. The two rows in orange inside the box are the two data elements that make up the repeating group. This is how we share if each individual sign, symptom, or clinical manifestation is yes, no, or unknown. Finally, the blue row on the bottom is the symptomatic indicator. This is another stand-alone indicator that intends to transmit if the person exhibits symptoms associated with the condition. Our conversation today is going to focus on this data element in particular. Does anyone have any questions about the symptomatic indicator before we move on?
- As we were going through the feedback we received, it was clear that having so many indicators can be confusing. We want to make sure we think through this data class as a whole and name and define everything in a way that is understandable for people who haven't been part of this working group.

Symptomatic Indicator

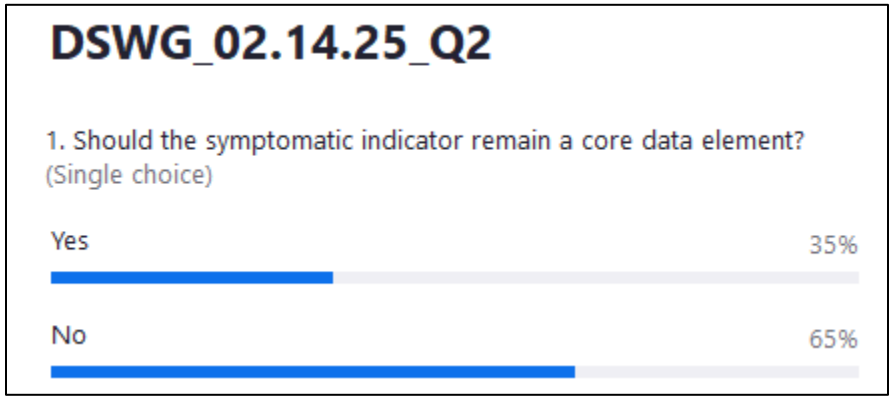
- Focusing on the symptomatic indicator- when we were reconciling feedback, a point we got stuck on and wanted to bring to the workgroup was about how the definition affects implementation. Our current definition is an "indicator the person exhibited symptoms associated with the condition being reported."
- A question we'd like to answer today is if this data element should be derived based on the specific symptoms contained within the signs and symptoms repeating group. This would require that each jurisdiction interprets the same way what's a symptom versus not a symptom, which is generally not a distinction we have made in MMGs previously. It was also brought up in comments that if this is tied to only the listed symptoms to determine what's "associated with a condition," the receiver of the data could use the information in the repeating group to determine if any of the symptoms are yes.
- An alternative way to implement the symptomatic indicator is to define it as something that is just taken from an interview or medical record review- do they consider themselves symptomatic? Is there documentation that just says "patient is symptomatic"? This would un-link its implementation from the repeating group and make it more of a standalone concept that could be populated when information about specific symptoms may be unknown.
- As we consider this, this data element was only weakly supported the first time around, so there is also the option that today, once we think about this data class holistically, we might decide it's not necessary. We'd like to have a discussion first on how people think this data element should be defined, and we're going to poll on that first. Once we have agreement on what definition we generally prefer, we're then going to talk about whether it should be core at all.
- Who has thoughts on whether this should be linked to the values listed in the repeating group versus simply a standalone concept of being symptomatic?

  Discussion:
  - The discussion focused on defining and implementing the symptomatic indicator in data collection. The group debated whether the indicator should be derived from listed symptoms in the repeating group or stand alone as a general symptomatic status from medical records or interviews. Concerns about consistency across jurisdictions and whether the indicator should align with surveillance case definitions were raised. The discussion aimed to determine the best definition and whether the element is necessary at all.

Poll 1 – Symptomatic Indicator

- *Given the flow of the discussion, the first poll was not used*

Poll 2 Symptomatic Indicator (n= 40)



SDOH: Insurance

SDOH: Insurance

- This is where we landed on an insurance data element after our SDOH calls and the first round of review. There was some question in the calls about options for "correctional facility" or "military" or "IHS" being part of an insurance data element since technically these are not forms of insurance. However, when we asked for feedback all respondents were supportive of including these options in this data element as what's really being captured here is information about someone's ability to access healthcare.
- Another topic we had a discussion on was the granularity present in this value set, specifically surrounding military-associated settings. We're going to talk about these things today.

SDOH: Insurance (continued)

- First, the name. The feedback we got generally supported naming this data element healthcare coverage since it's inclusive of things not technically insurance, but there is concern that it might not be clear for those not in this workgroup if it doesn't mention insurance. We thought maybe we could go with a best-of-both-worlds approach where we call this "Healthcare Insurance or Coverage Type" with a definition of "Person's type of healthcare insurance or other healthcare coverage, select all that apply." Does anyone have any strong objections to this approach?

SDOH: Insurance (continued)

- Again, everyone generally agreed to include the options here that are not technically insurance, but we did receive a lot of split feedback on the granularity needed for collecting military-associated settings. An approach suggested a few times, used here separates military into two options- one for TRICARE or other military-associated health care, and VA health care, as this is a distinct population. We've also added some additional detail to the IHS option here, specifying it includes Tribe operated or Urban Indian health centers.
- We are working with CSTE's tribal subcommittee to see if they have any other feedback on this data element.
- Does anyone have any strong thoughts on the edits to the value set we've made here?

Poll 3 – Insurance (n= 33)

- Question: Can you live with this definition and value set for insurance?
    - Responses: Yes = 32; No= 1

DSWG Next Steps: (JMC)

Next Steps

- Thanks to everyone for joining today!
- We will meet again in two weeks on the 28th, which is our normally scheduled meeting for February, and continue our SDOH wrap-up.
- This group will receive the edited version of Signs and Symptoms via email to review.
- The Laboratory draft is out for DSWG review until February 21st.