

Meeting Title: CSTE Data Standardization Workgroup Meeting
Date: 4/26/2024

Attendees: 125

CSTE (3)	PHAs (69)	<u>DSWG Members (continued)</u>	CDC (39)
Becky Lampkins	<u>Co-Chairs</u>	Karen Arrowood TX	Andrea Steege
Gillian Haney	Laura Erhart AZ	KAREN THOMAS CO	Angie Agunloye GDIT
Kirtana Ramadugu	Molly Crockett MA	Kate Goodin TN	Dors McGinness
JMC (5)	<u>DSWG Members</u>	Katie Owers Bonner NH	Desiree Mustaquim
Erin Kough	Ashley Simmons WV	Kiara Vicente AK	Erin Miller
Laura Lane	Aaron Bieringer MN	Krista Mevoli KY	Gialana Dang
Sam Spoto	Adrienne Erlinger MA	Kyra Veatch IN	Jen Fowler
Sara Sanford	Amy Lai AZ	Lakin Mauch ND	John Gerstle
Susan Downer	Andria Apostolou HIS	Li Kuang NJ	Katherine DeBord
Other/Unknown Affiliation (9)	Apaegle UT	Lunden Espinosa IN	Keaton Hughes
Katie Tully ONC	Ariel Cheatham IN	Margret Watkins WV	Lauren Korhonen
Rachel Abbey ONC	Beth Isaac NYC	Maribeth Hoyle OR	Laurie Barker
Andre	Brianna Rossi VA	Mario Beltran MD	Lesliann Helmus
Clarissa Smallridge	Brittany Martin CA	Mary McNeill OH	Marion Rice
Imani Carey	Cher Levenson WA	Megan Crutchfield ID	Mary Alao
Johanna Bosse	Claire Stump AK	Melissa Kealey CA	Meeyoung Park
Oak Slater	Damian O'Boyle MO	michael eberhart PA	Melissa Pagaoa
Robbie Lojo	David Kim OR	Misty Johnson WI	Miriam Van Dyke
Shelia Malone	Dimple Patel KY	Moji Ojo NJ	Mohua Basu
	Ed Hartwick MI	Molly Yang NJ	Myrna del Mar González GDIT
	ej Klingler NYC	Monique Birmiel IN	Nicole Gallaway
	Eman Addish Philadelphia	Morrow Toomey AK	Nicole Lindsey
	Fran Lendacki Chicago	Rob Laing OR	Nicolette Bestul
	Genie Tang CA	Shawna Stuck GA	Nnamdi Usifoh
	Graham Crawbuck WA	Sophia Cantor WA	Noreen Kloc
	Hanna Chakoian MN	Stephanie Moberg NM	Pei-Jean Feng
	Heather Elder MA	Steven "Ike" Eichner TX	Peter Boersma
	Hollie Sheller MO	Sue Soliva MA	Rachelle Oseni
	Jennifer Kwon LA County	Suzanne Gibbons-Burgener WI	Renee Boehmert
		Tiffany Smith NV	Robert Pratt

	Jennifer Loney VA Jennifer Otsubo VT Jesse Ellis MS Jessica Mawdsley VI John Satre IA Josh Nazinyan LA County Judie Hyun June Bancroft OR	Trish McLendon CA Vajeera Dorabawila NY Yi Du NE Yuritzy Glez OR	Sandra Bulens Sandra Roush Sandy Price Sara Johnston Scott Grytdal Sydney Adams Tashina Robinson Tricia Aden Walter Alarcon
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**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

- Upcoming DEST teams include,
 - Disability: May 10, 1-2 ET
 - Identifiers: May 17, 1-2 ET
 - Upcoming: Race/Ethnicity/Tribal Affiliation, Social Determinants of Health (SDOH), Laboratory, Medication/Treatment, Reporting Source
- 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

- CTSE Annual Conference
 - Pittsburgh, PA, June 9-13
 - Early bird registration is open now through May 2: <https://www.csteconference.org/index.php/registration/>
- DSWG will have a roundtable/discussion at the conference.
 - Surveillance & Informatics I- Data Standardization Workgroup (DSWG): Navigating Forward – Updates and Future Directions on Monday, June 10, 2024, from 5:30 – 6:15 PM

Key Updates

- CSTE Best Practice Guideline – Almost published (*like, next week!*)
 - Data Standardization: Workgroup Proposal for Standardized Case Counting Date, Proposed Calculated Case Counting Date for NNDSS Case Counting.
 - Reminder, this proposes a standardized calculated case counting date for NNDSS case counting.
 - CSTE has done a bit of pre-release sharing of the content with CSTE, program and policy committee and the NNDSS and leadership team at CDC.
 - Look for an email announcing the publication to all CST members, and we'll be sure that gets out to this work group as well. But we anticipate that email will go out next week.
- CSTE Brief for Data Harmonization – In development
 - CSTE briefs are a mechanism through which CSTE membership can voice their opinion on any issue, topic, policy, or best practice that would not directly result in changes to state or local law, rules, or regulation. That's what makes the Brief distinct from the CSTE position statement process. Briefs go through an approval process with CSTE's Program and Policy Committee. And then that draft is also published in CSTE Connect for all members to review and comment on.
 - The document in development is a general Brief, that documents the problem statement and express Generally what we're trying to accomplish in this work group, why the data standardization and harmonization effort is so critical for efficient data exchange and interoperability. The goal is to promote the mission of the DSWG and make that known more publicly across CSTE membership and with the State Epi community as well.
 - This document is still in development and progress is expected in Spring 2024. Drafts will be shared as able.

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 as I think we are all very aware, as we received many emails, the work continues past that point. We're excited to 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 complete, and draft is with CSTE for next steps.
 - Hospitalization
 - Travel
 - Pregnancy
 - Industry and Occupation
- DSWG input received, and the final draft is being completed with Co-Chairs and JMC. The Final draft will go to CSTE for next steps.
 - Immunizations
 - Death
 - Sexual Orientation and Gender Identity
- DEST members will soon receive a draft of the recommendations for feedback.
Recent consensus will be reviewed on the following slides.
 - Exposures, Risk Factors, and Underlying Conditions
 - Signs, Symptoms, and Clinical Manifestations
- Upcoming DESTS
 - Disability, May 10
 - Identifiers, May 17

DEST Summary (as of 4/26/2024)

- The table shows where we are with each data class started so far.
- We've made significant progress and want to thank you all for the robust discussions and draft reviews that keep this moving.

Review of Recent DEST Consensus: (JMC)

We will review the consensus outcomes of the DESTs that have recently wrapped up.

Data Class Review

- Two DESTs have wrapped up since our last general DSWG meeting. One team focused on Exposures, Risk Factors, and Underlying Conditions and the other team covered Signs, Symptoms, and Clinical Manifestations.
- As shown here, each data class which was considered represented many possible data elements. Instead of focusing discussions on the specific data elements, these DESTs considered the distinctions between and definitions for data classes.
- As part of these discussions, there were also 2 joint calls to which informaticists were invited to weigh in on the possible structures for the types of questions found in all 4 data classes and help highlight the pros and cons of each.

How will data elements be sorted into the data classes?

- Currently, message mapping guides (MMGs) might include the same data element as part of a different class. For example, Diabetes mellitus is considered an Underlying condition in the Respiratory and Invasive Bacterial Diseases (RIBD) MMG but is listed as a Risk Factor in the COVID-19 MMG.
- Because we approached these data classes differently, one question was, “How will data elements be sorted into the data classes going forward?”
- As we review the data class definitions later in the call, it is important to know that CDC programs will remain in charge of deciding which clinical manifestations, exposures, risk factors, or underlying conditions go into which data class and the sorting may not be the same across programs (and by extension messaging guides).

Data Class Structure Review

- We’ll first review the outcomes from the combined structure calls.
- The structures that we are going to be talking about are visualized on this slide which we can reference later if necessary. This example relates to exposures, but the structures can be applied to all four data classes which were discussed.
- The straightest forward are the individual questions shown on the right and boxed in green. These are separate questions and are included as such in message mapping guides. Examples here are, “While at the fair, did the person enter the cattle barn? While at the fair, did the person enter the pig barn?” These require quite a bit of approval at the federal level for additional questions to be added, a fact which severely inhibits their flexibility for new MMG development and updates to current MMGs.
- Repeating Elements are on the top left and boxed in orange. These have a general question such as “While at the fair did the person enter any of the following locations?” and then answers are a select all option from a value set. These limit a question to an indication of a positive result with no way to send No or Unknown values.
- Repeating Blocks are the bottom left and boxed in green. These can have the same general question as the repeated element, but one value set includes the locations of interest and a paired value set allows the selection of Yes, No, or Unknown.
- These are just examples of how they might look in a system and are not prescriptive.

Data Class Structure Review (continued)

- Conversations on the combined call were very enlightening and some of the high-level conclusions are summarized here.
- Individual questions were noted to require quite a bit of approval at the federal level for additional questions to be added to new or existing MMGs. This fact severely inhibits flexibility for new MMG development and updates to current MMGs. That said, they are often very easy to map and work with in a system.
- Both Repeating Groups and Repeating Elements allow for additional questions to be added as parts of Value Sets without additional OMB clearance. This flexibility is ideal for implementing new or updated MMGs in the event of things such as emerging infections or new manifestations of an existing condition.
- Several jurisdictions reported that repeating elements are easier to implement on the jurisdiction side. However, this structure prevents messaging of No and Unknown values which is less than ideal for a complete data picture.

- Repeating groups can be quite arduous for some jurisdictions to set up even if they have set up others before. However, the structure does include No and Unknown values and would accommodate an extra field being added to the Repeating to capture another data point such as a date to pair with exposures or symptoms.

Data Class Structure Review (continued)

- Here are some of the calls key takeaways.
 - It was agreed that the structure needs to be what makes sense for each data class.
 - CDC had a strong preference for the repeating group due to the flexibility it allows for updating MMGs and for developing new ones.
 - Informaticists from the jurisdictions were more evenly split about what works best for their system; but they deferred to the epis to know what works best for the data. There was concern that if any additional questions were added to the repeating blocks in a nested parent/child/grandchild structure, this would cause serious pain points for many jurisdictions.
 - Overall, there was a strong message that consistency in structure across conditions for each data class is important. Which is to say, it would be beneficial to most partners if a there is an exposure repeating group for TB, for example, then there would be exposure repeating group for all other conditions as well.

Data Class Structure Review (continued)

- Here is a visual of the Parent/Child/Grandchild for those who might be curious.

Exposures, Risk Factors, Underlying Conditions (ERU): (JMC)

ERU Proposed Definitions

- Here are the proposed definitions as voted on by the ERU DEST.
- The suggested definition for exposure is on the slide.
 - A key point to note about this definition is that it includes a timing component which is flexible enough to allow for most, if not all, condition information.
 - It also incorporates objects, locations, and people which means the exposure value set could include things such as getting a tattoo, working in a daycare, visited a water park, etc.
- The proposed definition for Risk Factors is on the slide.
 - Key points for this definition include the fact that there is no timing element, and that risk factors are related to the likelihood that someone contracts the condition whether it is a risk factor that makes a person more vulnerable to illness or increases their likelihood of coming in contact with the condition in a way that is more general than a specific exposure might imply.
- Lastly, the proposed definitions for Underlying Health Conditions is on the slide.
 - This definitions asks specifically about health conditions and there is a reference to the health condition impacting infection course or severity.
- All definitions were supported by more than 90% of the DEST participants who voted.

ERU Data Class Indicators

- The ERU DEST also considered whether each data class would benefit from a summative data element which would indicate whether a person experienced an exposure, risk factor or underlying health conditions in general. Here we call these types of data elements “data class indicators”.
- One example of this is shown at the top of the slide and reads “Did the subject have any underlying causes or prior illnesses” with a responses limited to Y/N/U.
- These data elements would exist as their own questions separate from the repeating group for the data class.
- An answer of “no” to such an indicator value may remove the need to transmit the repeating group, or in the case of a repeating element question it may add value to explain why the repeating element is absent.
- Members of the ERU DEST were polled and approximately three-quarters of the voters agreed that this might be helpful for all three data classes.
- The table at the bottom of the slide is an example of what this could look like in a draft document, however, the details of this are still to be ironed out.

Proposed Structure Recommendations

- Lastly, we polled the group on whether the ability to send No and Unknown values was important to these data classes.
- 71% of voters thought that this was Very or Moderately important for all three data classes.
- The remaining voters felt that one or two of the data classes required this ability, but not all three.
- This wraps up the summary on the ERU DEST. We will send this out to the DEST in May and then this larger group will get it after that.

Discussion

- Space was provided for participant discussion, but no questions or discussion points were raised in the meeting.

Signs, Symptoms, and Clinical Manifestations: (JMC)

Potential data elements related to Signs, Symptoms, and Clinical Manifestations

- This slide presents data elements related to signs, symptoms, or clinical manifestations that are currently used in NNDSS Message Mapping Guides. There are a variety of terms used to ask about similar concepts, and while some of these data elements remain condition specific, the goal of these calls was to standardize the way signs, symptoms, and clinical manifestations are asked about across conditions.

Signs and Symptoms- Clinical Manifestations

- Conditions have their own specific value sets for what signs and symptoms or manifestations are appropriate for that condition, and the work we did here does not change that.
- The first thing we looked at for this data class were the two main repeating groups used to ask about similar concepts, called the signs and symptoms repeating group, and the clinical manifestations repeating group.
 - No MMG uses both repeating groups, but almost all use either one or the other. These capture the terms one would generally think of when you think of "signs and symptoms", like fever, cough, or headache.

- The groups that use the term "clinical manifestations" for their repeating group rather than "signs and symptoms" gave feedback saying this was because some of the values in their value sets were not something that may be traditionally defined as a sign or symptom but are something like "abnormal chest x-ray" or lab work like "low white blood cell count".

Proposed Data Elements

- This first core data element is intended to standardize signs, symptoms, and clinical manifestations into one data class that can be used across conditions.
- Since the term clinical manifestations is broader than, and inclusive of, "signs and symptoms", the name of this data class is clinical manifestations, and the definition specifies signs and symptoms are included here.
- The value sets for each condition should be built using SNOMED, although local codes may be used if no appropriate SNOMED codes are available.

Proposed Data Elements (continued)

- Like the previous data classes, the group also talked about a summative data class indicator. This would be a separate data element that indicates if the person experienced any clinical manifestations associated with the condition being reported. This data element would convey if any of the values within "clinical manifestations" are yes, if all of them are "no" or if all are "unknown".
- As mentioned previously, this type of data class indicator is aligned with how some jurisdictional surveillance systems are already set up, and an answer of "no" or "unknown" may remove the need to transmit individual responses.

Proposed Data Elements (continued)

- Conveying if the person has any clinical manifestations is important epidemiologically, and as we said helpful for the mapping of data for some jurisdictions. However, in the minimum dataset for emergency use is a slightly different data element called the "symptomatic indicator". A large point of conversation on our last call was that a patient may have a clinical manifestation, like an abnormal chest x-ray, but still perceive themselves as asymptomatic.
- It was brought up that when conveying information to the general public, it may be more important to communicate how often people are asymptomatic rather than lack any clinical manifestations.
- Both indicator values were voted as core, although it is recognized that both may not be applicable for every condition. When working on implementation guidance for this data class we should consider when one versus the other, or potentially both, may be most applicable for a condition.

Complications – Infection Type – Clinical Findings

- The data elements on this slide are all captured separately from, and in addition to, current signs and symptoms or clinical manifestations repeating groups within MMGs.
- If you read through the examples here, you can see that the value sets include things that are a broader diagnosis or syndrome compared to what you would normally think of as a sign or symptom in the previously defined data class.
- The most common phrasing for this type of data across conditions is "Complications", but "Infection Type" and "Clinical Findings" are also data elements that contain similar concepts.

- The structure of this information varies across MMGs and includes the use of repeating groups, individual Y/N elements, or a "Select all that apply" type of approach.
- The group did not vote for these types of concepts to be their own core data class. For any condition, if there are complications or findings that do not fit with the clinical manifestations core data class, those should be handled on a condition specific basis.
- However, there is general support for the standardization of the structure of these concepts across all conditions, which should be considered in future implementation of MMGs.

Proposed Structure Recommendations

- As summarized earlier, the structure calls with the informaticists highlighted that the structure should be allowed to be whatever makes sense for the data class, but consistency in structure across conditions is most important.
- From an epi perspective, the most important distinction between the structures is that the repeating element would not allow for transmission of "no" or "unknown" values for individual clinical manifestations.
- For this data class, most of the group did find that it's either important, or at least helpful, for the structure to allow sending of these no or unknown values, which makes the repeating element structure not appropriate for the clinical manifestations data class.
- The use of individual questions vs repeating groups for clinical manifestations likely leans toward repeating groups as the most appropriate structure to allow for flexibility in value set updates without time-consuming approval and onboarding steps.
- This document will be sent out to members of the data element specific team in May for review, and once that feedback has been received a more final version will go out to the larger DSWG for comment.

Discussion

- Space was provided for participant discussion, but no questions or discussion points were raised in the meeting.

Aligning Definitions with Person-Centered Language: (JMC)

Next, we're going to talk about some work we've done to look at standardizing the language used across the data elements that we are saying are core for surveillance.

Language in Previous Definitions

- So far we've covered data elements across nine different data classes.
- Listed on this slide here, and you can see the language used to refer to a person in our data elements has ranged from subject, patient, case, and person.
- In many cases the word used was not intentional and occurred reflexively or is a relic of current language in MMGs.

Updating Language

- We'd like to take the opportunity now to talk about aligning this wording across our definitions, when appropriate.
- Patient is not the ideal term in this scenario, as in public health surveillance we are not in the role of providing medical care or treatment.

- The terms subject or case both place emphasis on the condition being reported rather than the person with the condition, and while using the term "case" may make sense for certain data elements that are very focused on case-related information, it may be less appropriate for more demographic information.
- However, we didn't want to introduce complexity where it isn't needed, and as the data we are transmitting is always about a person, using the term person across all definitions seems to be the simplest approach.

Updating Language (continued)

- Now we're going to go through exactly what it looks like to change this term across all our definitions. This also serves as a nice reminder of how much has been covered by this group already.
- First up are the data elements within hospitalization.
 - Admission Date and Discharge date will be updated to the "date on which the person was admitted or discharged", and admitted to ICU is an indicator that the person was admitted to an ICU.

Updating Language (continued)

- For travel, initially the term patient was used, but these data elements will now indicate where a person has spent time rather than a patient.

Updating Language (continued)

- Pregnancy status will be updated to the pregnancy status of the person at the time of event, and death will be defined as if a person is deceased or what a person's date of death is.
- There is only one of the immunizations related data elements that refers to an individual, and this will update to an indicator that the person has ever received a vaccine against this disease.

Updating Language (continued)

- Finally, the I/O data elements refer to a subject's current industry or occupation and will be updated to a person's current industry or occupation.

Person-Centered Language Approach

- Any data elements that we didn't review on the previous slides won't be updated, either because they are already using the term "person", or don't contain reference to an individual using this type of language.
- Another thing to note is our updates are applying solely to what we are calling our definitions for core data for surveillance. We are not talking about updating any code descriptions that may reference different terms or changing appropriate LOINC codes or other codes based on this terminology.
 - For instance, on this slide, we have the first two rows of our table for the immunizations data element "Ever Vaccinated Against this Disease".
 - The updates we are talking about today would be reflected in a change from patient to person in the first line, where the green arrow is pointing.
 - The second line contains the standard code for transmission to CDC, which uses a description that contains the word "subject". While this is a CDC local code and CDC may choose to update this description later, our documents will not reference an update to this code description, and we wouldn't recommend not using a current LOINC or other code just due to a discrepancy in this language.

Discussion: Does anyone have any concerns today about updating the language across our documents to be more consistent in our definitions, and use the term person.

- Steve Eichner was concerned about potential confusion and disconnection due to the use of different languages and terminology. They worry that using terms like "person" and "patient" interchangeably could lead to ambiguity, especially when dealing with complex examples on screen and that everything on the same line should use the same terminology. He further noted that they were having a parallel discussion about something related to vaccine scheduling and guidelines earlier today, and they had four different terms, all on the same line, describing the same thing. He commented that it was a little confounding, trying to untangle it. He noted concern that we could end up in the same place here.
 - Laura Erhart suggested that there's already a lot of variation in the terms used and proposes standardizing where possible. She acknowledges limitations in updating certain aspects but emphasized the importance of broadening and standardizing definitions. This aligns with a broader trend that has been observed in other contexts, moving from a patient-centric to a person-centric approach, despite potential ongoing disconnects. Overall, she views standardization as a positive step forward.
- Angie Agunloye asked about an instance where a data element uses the word case? Example: Case Patient a Healthcare Worker.
 - Sam Spoto noted that This is not something we have voted as core at this time, and so at this point, we're only talking about updating the data elements that we currently have listed as our core data elements.
 - Laura Erhart acknowledged that in some cases, "case" might still be the appropriate term, particularly considering examples previously discussed. However, she suggests that in most instances, "person" seems more fitting. She hypothesized that there could be situations where "case" serves to distinguish an entity from the person, although she lacks a specific example. She emphasized the importance of considering what the person is doing rather than their status as a patient.
- Steve Eichner questioned whether they are now referring to relationships in terms of "person" rather than "patient," considering scenarios like patients' parents or their children. He wondered if they'll now be collecting data about a person's relative, thus referring to "person's parent" and gathering information about that individual's connections.
 - Sam Spoto noted that this is not something that has been discussed for any of the core data elements at this time. Identifiers might be the first situation where that could arise.
- Suzanne Gibbons-Burgener commented distinguished between referring to the main person of interest and others involved. She expressed discomfort with dehumanizing terms like "cases" and emphasized the importance of finding a more generic and inclusive term and that this terminology is for data elements and not for direct communication with individuals or physicians.
 - Sam Spoto agreed that this was a good point in that recommendations are not being made on how to phrase interview questions.
- Sam Spoto emphasized the importance of context in defining data elements for case-based notifications to the CDC. She noted that in our current work, we haven't encountered any core data elements where using "person" wouldn't be suitable. She suggested that for future data elements, we can ensure appropriateness and clarity by considering the context. The goal isn't to force the use of "person" if it doesn't fit but to use the most appropriate term.

- Lesliann Helmus: reiterated the importance of using the term "person" when referring to the individual who is the subject of the report and emphasized using specific terms like "contact" or "parent" to describe others in relation to the person. She believed using "person" is appropriate and clear, if relation terms are used correctly for others mentioned. She felt this approach wouldn't pose any issues.
- Laura Erhart concluded the conversation by thanking everyone for their thoughtful input and that this would all be taken into consideration as we move forward. Based on the conversation today she recommended moving forward with the change to "person" while ensuring that this is appropriate for each of the recommendations and places where this will be updated. This will not be a "find and replace all" situation and alignment will be considered.

DSWG Next Steps: (JMC)

Next Steps

- In early May, members of the exposures, risks and underlying conditions DEST and signs, symptoms, and clinical manifestations DEST should look for an email with the draft recommendation documents and forms for feedback.
 - After these team reviews are done, updated documents will later be sent to this larger group, likely in June.
 - This written feedback process is important as we know we have hundreds of people interested in being a part of this larger DSWG, and 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 some longer discussion and consensus building to occur, with around 60-80 people on those calls, but we want to also 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.
- The next data element specific teams to convene in May will be Identifiers and Disability.
 - Anyone can sign up for those if they'd like to be added to the invitation.
 - The identifiers call in May will discuss outbreak IDs, structure of sending IDs to CDC, and methods to link maternal and infant cases. The second call will focus more on methods to link laboratory results with cases, and we will likely send that invitation to anyone signed up for both identifiers and lab, just to ensure anyone who may want to join is notified of that topic.

Other Next Steps

- These calls will be on May 10th for disability, and May 17th for identifiers.
- Our next larger DSWG call like this will be on June 28th.