

Meeting Title: CSTE Data Standardization Workgroup Meeting
Date: 8/30/2024

Attendees: 127

CSTE (7)	PHAs (63)	DSWG Members (continued)	CDC (47)
Annie Fine	<u>Co-Chairs</u>	Kyra Veatch IN	Akaki Lekiachvili
Becky Lampkins	Judie Hyun MD	Li Kuang NJ	Andrea Steege
Gillian Haney	Laura Erhart AZ	Margaret Iiams SC	Angie Agunloye
Melissa Powell		Mary McNeill OH	Brenna VanFrank
Meredith Eddy	<u>DSWG Members</u>	Melissa Kealey CA	Carissa Rocheleau
Shaily Krishan	Aaron Bieringer MN	Monique Birmiel IN	Carmen Pugh
Taylor Pinsent	Allison La Pointe MN	Nora Kelly IL	Doris McGinness GDIT
	Andria Apostolou IHS	Orion McCotter OR	Gonza Namulanda
JMC (5)	Beth Isaac NYC	Rob Laing OR	Hailey Vest
Erin Kough	Brittany Martin CA	Ryan Burke MA	Henrietta Smith
Grace Mallard	Cher Levenson WA	Sam Hawkins OR	Jeanne Ocampo
Laura Lane	Claire Stump AK	Sarah Kemble HI	Jenny Couse
Natalie Raketich	Cory Cline NM	Stella Tsai NJ	Jessica Purser
Sam Spoto	Deb Loniewski MI	Steve "Ike" Eichner TX	Joe Holbrook
	Dimple Patel KY DPH	Sue Soliva MA	Josh Bagley
Other/Unknown Affiliation (5)	EJ Klingler NYC	Suzanne Gibbons-Burgener WI	Julie Vanderkolk
Alibek Mereke	Elizabeth Jump San Mateo County	Taylor Bednarz Maricopa County	Katie Dodd
Imani Carey	Elizabeth Kessler NV	Tiffany Smith NV	Kayode(Kay) Olupinyo
Jim Jirjis	Elizabeth Lando-King MN	Tracy Miller ND	Kerry Souza
Scott Fried	Elizabeth Schiffman MN	Vajeera Dorabawila NY	Kristie Clarke
Todd Ashworth	Eman Addish Philadelphia	Yi Du NE	Lauren Korhonen
	Emily Walsh Maricopa County		Luis Hernandez GDIT
	Erin Doyle NJ		Manjula Gama Ralalage
	Genie Tang CA		Marie Haring Sweeney
	Hanna Chakoian MN		Mary Alao
	Heather Elder MA		Michelle Lin
	Isaiah Francis NM		Miriam Van Dyke
	Jacki Griffin NY		Myrna del Mar González GDIT
	Jacob Chavez LA		Nicola Thompson
	Janet O'Connor SC		Nicolette Bestul

	Jeff Swanson TX Jennifer Floch MT Jennifer Loney VA Jesse Ellis MS Jessica Romano TX John Satre IA Josh Nazinyan LA County Karen Arrowood TX Kate McCoy WI Kayleigh Nerhood GA Keegan McCaffrey CO Keely Wrolstad WI Kiara Vicente AK Kristen Merrell MT Kristin Goldesberry IL		Nikolay Lipskiy Noreen Kloc Peter Boersma Rachel Abbey Rachelle Oseni Renee Calanan Robin Kelley Roger Mir Sandra Roush Sandy Price Sara Johnston Shawn Arshad GDIT Shelby Lyons Sundak Susan Carlson, CDC Walter Alarcon Yan Yuan
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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)

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-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 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,
 - Laboratory (Call #2), September 13, 1-2 PM ET
 - Social Determinants of Health (Call #1), September 20, 1-2 pm ET
 - Call 1: Residence type (related to homelessness/incarceration)
 - Calls 2 & 3: 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– In development (coming this Fall)
 - Standardizing Core Case Notification Public Health Data Elements to Improve National and Jurisdictional Surveillance and Situational Response
 - Previously referred to as the Brief for Data Harmonization
 - This Brief will highlight the importance of the DSWG's work, outline the problem statement, and justify moving toward standardization and case notification. It will also highlight the importance of this group's work during the commenting and reviewing processes, highlighting the efforts in developing these recommendation documents.
 - Will include an Appendix – Consensus Building Process
 - This will outline CSTE's expectations and timelines for broader CSTE membership review after the DSWG's recommendations documents are released.
 - The goal for these documents is to look forward to implementation and ensure a broad review across CSTE members, including the state epidemiologist community.
 - The plan is to share the data class recommendations documents after publishing the Brief. We'll be looking to obtain information on agreement or disagreement with the overall document and feasibility for implementation at the jurisdictional level.
 - The goal is to release these on CSTE Connect in October or November.
- Next steps
 - Be on the lookout for the Brief, with the appendix, and DSWG Data Class recommendations documents posted to CSTE Connect in October or November 2024.
 - CSTE Cooperative agreement update
 - CSTE took a moment to thank all the members who participated in this work. The DSWG's work is dependent on the volunteers in this group.

- Additionally, funding is made possible through CDC and CSTE's Cooperative agreement, which allows CSTE to bring in the consulting team, J. Micheal Consulting, who expertly prepares materials and facilitates many of the meetings over the past year.
- CSTE is applying for the next round of funding, and the results will impact the pace, support, and direction of the DSWG.
- CSTE is aware of the need to look towards implementation discussions.
- Thanks to everyone on the call for the incredible work completed this past year!
- DSWG on CSTE Connect
 - CSTE is working on migrating information from Basecamp to CSTE Connect.
 - The DSWG Community in CSTE Connect will host meeting notes, announcements, a calendar of events, and more.
 - We'll share announcements and updates as we work to complete this transition.

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.

Industry and Occupation (I&O) Recommendation Update

- Providing an update to Industry and Occupation (I&O) data elements, which have been expanded to include employment status. The inclusion of Employment Status in our I&O data elements aims to enhance our understanding of how employment, or the lack thereof, impacts public health outcomes. We'll first discuss what our I&O data elements previously included and then explain why Employment Status is a critical addition.

Previous Recommendations for I&O

- In October, the DSWG voted with more than 80% consensus that these data elements should be considered core data elements. These elements provided valuable insights but had limitations, particularly when the data was incomplete or when individuals were not employed. The lack of context around employment status sometimes led to data interpretation challenges, bringing us to our next point.

Introduction of Employment Status

- To summarize the rationale behind including Employment Status as part of the I&O data class, this update aligns with the CDC's recommended standards for I&O data collection. It shows our commitment to evolving standards based on the latest research and public health needs. It is also the leading data element that informs the other I&O elements. This data element already exists in eCR and FHIR standards, which helps ensure consistency and interoperability across different health data systems.
- Additionally, employment status is a key social determinant of health, influencing critical aspects like economic stability and access to healthcare. While this update emphasizes the inclusion of employment status as a key SDOH, more detailed discussions on other key aspects of SDOH will be covered in future DEST calls. Addressing employment status now will allow us to concentrate on other relevant SDOH topics during those discussions fully.

Definition of Employment Status

- Broad definition: Person's current working condition during data collection.
- Valid values:
 - Employed: A person is considered employed if they worked for at least one hour during the past week, with or without pay. They could have worked for a business, the government, or themselves in their own business, farm, or professional arrangement. A person who did not work in the past week is still considered employed if they were temporarily absent from their job but will return.
 - Not in Labor Force: A person who has no job and is not looking for one.
 - Unemployed: A person who does not work right now but has been trying to find work.

Discussion and Poll

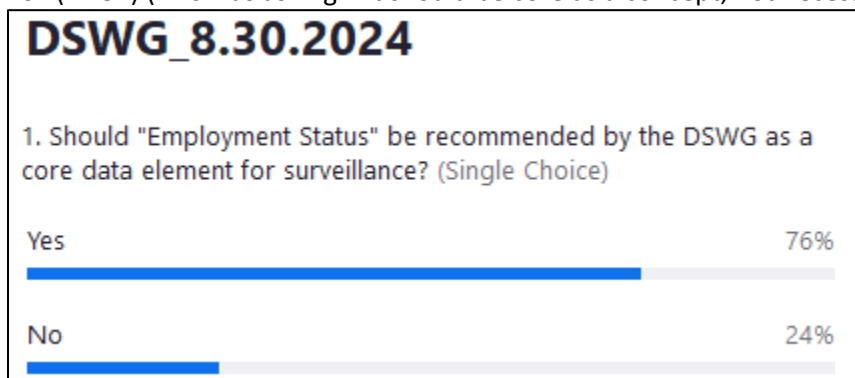
- We wanted to take time today to see where the group stands about this data element through discussion and polling. If we find through our discussion today that there's more to discuss, we might continue to engage on this topic in a future industry and occupation call. For now, I'd like to open it up to hear from anyone who has thoughts they'd like to share on employment status as a potential core data element or the definition or value set shared here.

Discussion

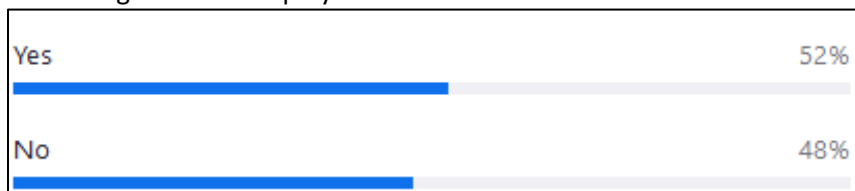
- A question was posed in the chat: "Are you proposing to add employment status without removing or altering the industry and occupation fields?"
 - Sam Spoto responded that this was correct. Employment status would be a separate data element. It could serve as an initial data point, with the industry and occupation fields treated as a distinct repeating group.
- Gillian Haney wanted to get the group's thoughts on the value set, particularly the absence of a "did not ask" or "did not respond" option.
- EJ Klingler asked if "employed full-time" and "employed part-time" are separate categories, or is it simply "employed" with no distinction between full-time and part-time? Or is the value set not that specific yet?
 - Sam Spoto responded that the value set currently only includes "employed," covering all options shown on this slide. However, it's open to discussion if more details should be added.
- Suzanne Gibbons-Burgener asked if we need to specify that the employment status refers to the time of the health or disease event. In Wisconsin, we have options to select "current" or "past" status, and we can also provide dates. So, there are different ways to indicate this.
 - Sam Spoto noted that this is a good point. The industry and occupation data elements only refer to "current industry" and "current occupation" without specifying any time related to diagnosis or reporting. The definition doesn't include a timeframe, but it's worth considering. She shared a reminder that the current definitions only state "current" with no further details.
 - Kerry Souza shared that this variable is typically associated with the visit date or a similar event. Some surveillance efforts, like during COVID-19, were used to ask about a recent time, such as, "Have you been employed within the last X number of weeks?" The approach may vary based on specific needs, but no specific date range is generally tied to the variable.

- Steve Eichner commented that a question to consider is whether there is a need to collect employment location, such as working from home or in an office, given the current environment. Would that be relevant?
- Marie Haring Sweeney noted that the goal is to include employment status as one of the core variables. If jurisdictions need more information, they could ask those questions, but this would stand alone. There was also a question about age in the chat. It's important to note that even young teenagers can be employed. While you might not ask a 5-year-old, a 10-year-old could work on a family farm or engage in unpaid labor, so we wouldn't want to exclude very young workers.
 - Steve Eichner noted that we haven't included anything about volunteer activity or training at the facility. While it's mentioned in the definition, it's not reflected in any value set elements. He considered the alignment of the definitions and the value set. He also noted that they generally considered volunteers as part of the workforce.
 - Marie Haring Sweeney commented that first, the concern about including "student" or "retired" in employment status categories. These are not employment statuses but indicate whether someone is in the labor force. If someone is retired but takes a part-time job elsewhere, they should be considered employed. Second, the focus should be on whether a person is in the labor force and earning a wage. Volunteer work could be considered an ancillary question, but it should not complicate the core definition of employment status.
 - Suzanne Gibbons-Burgener noted that she agrees that the exposure could be the same, whether or not compensation is involved. However, "employment" implies a contractual arrangement and an exchange of compensation.
 - Annie Fine shared that the way this information is collected depends on the questions being addressed. For example, volunteers in a hospital setting might have exposures relevant to public health. It's important to consider asking about these exposures separately, especially for case notifications related to environmental risks or activities.
 - Gillian Haney noted that it's important to consider the purpose behind collecting this information for surveillance—specifically, its relevance to assessing risk. This point, mentioned earlier, highlights why this data is being gathered. Other comments on this topic are welcome.
 - Sam Spoto agreed that these are all good points. It's important to consider this as an introductory question to the industry and occupation repeating group, where current industry and occupation are collected. The original definition and value set come from the Occupational Data for Health format, which includes categories like employed, unemployed, and not in the labor force. Whether volunteers are included may depend on how the question is answered at a healthcare facility, but the current definition likely excludes volunteers.
 - Katie Dodd noted that regarding our other data elements in occupational data for health, volunteer status would be captured under work classification, which can include categories like self-employed, armed forces, and volunteer status. Employment status serves as an introductory section, and for more detailed information, work classification could be explored further.
 - Erin Kough had a clarifying question: Earning a wage was mentioned as a qualifier for "employment" but also, kids working on family farms may not earn a wage. Where is the distinction between volunteer and employed? If one of the work classifications is "volunteer," does that mean volunteers would be included under "employed"?

- Kaie Dodd responded that we could consider structuring it to include employment and volunteer work, especially for roles like emergency responders. This would be relevant for job classification purposes.
 - Laura Erhart noted an observation from the discussion: We seem to be addressing two different uses of this data: one related to social determinants of health and the other to risk. The value set and usage may differ slightly between these two contexts. We need to consider how to collect and distinguish this information effectively.
 - Sam Spoto reflected that the discussion had been very productive. She made some edits to the slide in real-time to capture key points. She also monitored the chat, and many of these issues naturally emerged in our conversation. She opened the poll to gauge everyone's views and see if we're aligned or need further discussion.
- Poll (n= 54) (This was asking if it should be core as a concept, not necessarily with this definition/value set.)



- Poll asking whether Employment Status needs more discussion before writeup



- Laura Erhart wondered which aspects might need further discussion. Is it the definition versus the value set? Could those who feel that further discussion is needed write their primary concerns in the chat?
 - Sam Spoto agreed it would be helpful to use the chat to share concerns. She was also interested in whether there are issues with the current definition and value set or if more context is needed to respond in specific situations, such as choosing an option for someone who is retired or a student.

- Gillian Haney asked if the value set did not include options for "unknown" or "not asked/provided." If the Data Standardization Work Group recommends collecting employment status for core surveillance, how would the absence of these options affect implementation? Would the CDC be able to update the value set based on the work group's recommendations?
 - Marie Haring Sweeny replied that there are concerns about including options like "not asked," "not provided," and "unknown" in the value set. One concern is that collectors might be disincentivized from asking the question if these options are available. This could lead to an overuse of these options, with many responses marked as "unknown" or "not asked." Updating the value set to include these options might complicate rulemaking processes and create additional challenges.
 - Annie Fine noted that in real-world scenarios, interviewees may decline to answer questions or fail to answer for various reasons, such as hanging up or other interruptions. It is important to include options for "declined to answer" and "not asked" to reflect these situations accurately. These options help account for instances where the question might not have been asked or was left unanswered. In public health case investigations, there may be instances where questions cannot be asked or answered due to the nature of the investigation or the source of the data. For example, data might come from electronic health records rather than direct interviews, affecting what information can be collected. Acknowledging these limitations as part of the data collection process is important.
 - Eman Addish commented that it's worth noting that investigators often report individuals asking why the information is being collected
- Sam Spoto acknowledged that this was a valuable discussion today. There's more to discuss, which could be addressed in a future call or through document revisions and feedback. We'll coordinate with the Co-Chairs to determine the next steps.
- **Special Discussion:** Items in the chat noted following Laura Earhart's request for more information from the group
 - Elizabeth Jump: It seems unclear what the data element is meant to measure. Is it risk, economic opportunity, or something else?
 - John Satre: One of the most common uses for collecting employment status is to exclude infected people from daycare or work. Which seems different from the purpose of this question.
 - Kerry Souza: Unless not asked/provided, is an option for other data elements; I am not sure why it would be added specifically for this data element.
 - Renee Calanan: You could ask about current work status and have "employed for wages" be one of the response options (like BRFSS) and also volunteer, not working, unable to work, not asked, unknown, etc. response options.
 - Meredith Eddy: My understanding is that this element could serve as a parent data element so that Unknown, not asked, is informative if subsequent I/O fields are missing.
 - Emily Walsh: I think it depends on why you are asking it. If it is for surveillance, then a broad approach is good. From a health equity standpoint, you would want to be more specific.
 - Suzanne Gibbons-Burgener: I generally think of "employment" as an activity for which one receives taxable income as compensation. To receive income/compensation below a threshold is often considered incidental and not "employed."

General Updates for Closed DESTS

Status update for closed DESTS

- DSWG review is complete, and the drafts are with CSTE for the next steps.
 - Hospitalization
 - Travel
 - Pregnancy
 - Immunizations
 - Death
 - Sexual Orientation and Gender Identity
- DSWG member input deadlines are August 30 for the following
 - Exposures, Risk Factors, and Underlying Conditions
 - Disability
- Draft recommendations are in progress and will be shared with DESTs for review
 - Medications
 - Reporting Source
- Coming soon for DSWG-level review
 - Identifiers
- JMC is working with Co-Chairs to reconcile comments on the following documents before handing over to CSTE for their next steps
 - Signs, Symptoms, and Clinical Manifestations

DEST Summary (as of 8/30/2024)

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

Review of Recent DEST Consensus: (JMC)

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

Medications: (JMC- Erin)**Proposed Data Elements: Medication Repeating Group**

- Currently, there is a large variation in the data elements used to collect medication information in message mapping guides across conditions. The same concept code is sometimes defined differently across guides, and each condition has its own specific value set of medications. The goal for this data class was to standardize the medications repeating group to make things easier for jurisdictions to implement and maintain.
- This slide shows the proposed standardized repeating group for medications. One of the most significant proposed changes is eliminating condition-specific medication value sets. Instead of maintaining lists of medications pertinent to a condition, any RXNorm code would be accepted by the CDC. RxNorm is a standardized coding and terminology system developed and maintained by the National Library of Medicine

(NLM) that contains all generic and brand-name drugs available on the US market. All levels of this hierarchy would be acceptable, meaning that a general term such as Naproxen would be accepted and a more specific term such as NAPROXEN 250 mg ORAL TABLET.

Medications: Polling Results

- The group was polled to see if medication information should be considered for inclusion as core surveillance. Only 59% of poll participants voted for inclusion in core surveillance, with the rest of the group against the idea or unsure. This outcome meant that the call focused more on the advantages and disadvantages of the proposed data elements and their value sets instead of whether each data element was to be included in any recommendations document.

Medications: Polling Results (continued)

- Although the group was mixed on whether a medications repeating group should be present for all conditions, there was strong support in general for a standardized medications repeating group that would be the same across conditions.
- Participants were asked which of the questions they would support in such a repeating group, and their response is shown here. All data elements had over 60% support for inclusion in a repeating group. Medication name and date medication had the strongest support and was noted to be the most important.
- The condition agnostic value set was noted to have pros and cons. It was agreed that not having to maintain condition-specific lists relieves a burden for many jurisdictions; however, the broad RxNorm standard might be tricky for some jurisdictions to manage. It was also recommended that any guides include a specific version of RxNorm to prevent ambiguity.
- The recommendations document will be out to the DEST for review this week.

Identifiers (JMC- Sam)

Updates to Standard Identifiers

- Participants may remember last time in this large DSWG meeting, we discussed the standard identifiers used to identify a person as an individual and a case as a unique event in case notification messages. Through that discussion, we have renamed the "local subject ID" "Person ID" and updated the definition to "The jurisdictional identifier that uniquely identifies the person." We have renamed the "local record ID" to "Case ID" and updated the definition to "The jurisdictional identifier that uniquely identifies the case (event ID)."
- These updates to the definitions don't change the intent of the previous definitions, and the HL7 message locations used to transmit these identifiers are not being changed.

Identifiers Repeating Group

- In addition to updating those two identifiers, a new identifiers repeating group has been voted as core that will encompass other identifiers previously captured as individual data elements. This structure allows for the transmission of multiple identifiers per case, and the structure can be used to send condition-specific identifiers as needed.
- This repeating group has two data elements: the Identifier Type, which indicates what kind of identifier is transmitted in the second field, Identifier value. The Identifier value transmits the unique identifier for the case that corresponds to the type.
- The example on this slide shows the transmission of an identifier type of NORS ID, with an identifier value for that case of EIP123456.

Identifiers Value Set

- The group also voted on a minimum value set for Identifier Type in this repeating group. This minimum value set represents individual identifier types that should be able to be transmitted for all conditions when applicable. However, additional identifiers may be added to this value set for more condition-specific needs.
- The three identifier types voted as core are:
 - The CDC-assigned case ID that can be used in situations such as emergency response. You can think of this field as something that would have been useful at the beginning of the mpox response.
 - The next ID is a jurisdiction-assigned outbreak ID if the case is part of a jurisdictional outbreak.
 - The final ID is the outbreak ID from NORS, or CDC's National Outbreak Reporting System, if the case is associated with an outbreak in NORS.

Identifiers Value Set (continued)

- Other identifier values that were discussed are shown on this slide. These identifiers were not broadly applicable across most conditions, but the identifiers repeating group can be used to transmit these identifiers as needed for certain conditions. These include identifiers like a CDC or Public Health Specimen ID for laboratory specimens, a legacy case identifier for use by jurisdictions undergoing a surveillance system transition, and a birthing parent's case ID and national reporting jurisdiction for use in linking infant cases with the birthing parent's case. Additional identifier type values that could be used in this repeating group are not limited to those on this slide.
- A draft of this document for this group's review should be ready in the next few weeks so you can review the content in more detail and provide any feedback you have.

DSWG Next Steps: (JMC)

Next Steps

- DSWG deadlines are today (August 30) for the following draft recommendations
 - Exposures, Risk Factors, and Underlying Conditions
 - Disability
- These draft recommendations are in working and will be shared with DESTs for input as the next step
 - Medications
 - Reporting Source
- In September, DSWG members should look for the following draft recommendations for feedback
 - Identifiers

Other Next Steps

- Upcoming meetings
 - Laboratory (Call #2), September 13, 1-2 pm EST
 - SDOH (Call #1), September 20, 1-2 pm EST
 - Call #1: Residence type related to homelessness/incarceration)

- Calls 2 and 3: Language, education, insurance, income
- The next broad DSWG call will be held on October 25
- *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.*