

Data Standardization Work Group (DSWG)

December 8, 2023



Council of State and Territorial Epidemiologists

Please mute phone/ headset/ computer audio!

Agenda

- Welcome & Announcements (co-chairs)
- DSWG Opportunities for Participation (co-chairs)
- Approval Status for DSWG Recommendations (CSTE)
- Status Updates: Hospitalization, Travel (JMC)
- Review of DEST Progress: Pregnancy, Industry and Occupation, Sexual Orientation and Gender Identity (JMC)
- Next Steps (JMC)
- Wrap-Up & Adjourn (co-chairs)

Meeting ground rules



Discussion Guidelines

- "Raise" your hand
- Use the chat to provide feedback and ask questions
- When called, state your name and affiliation
- Stay on point, be brief, and within the context of the discussion in progress
- Co-Chairs/moderators' prerogative to move the discussion forward as needed
 - [Post-meeting survey](#) provided for additional input
- Be courteous and be open to new ideas

Active participation encouraged for all!

- Chats, voting, comments, etc.
- Includes STLT jurisdictions + CDC Programs + CSTE, etc.

- Identify core data elements for surveillance **for transmission to CDC**
 - For situational awareness or routine, cross-condition case surveillance
 - For case-based surveillance (not syndromic, not aggregate reporting)
 - Within *selected* data classes (e.g., hospitalization, travel history) that are used for multiple conditions
- Identify common definitions, value sets/code sets, structure, and interpretation notes for those core data elements
- Recommend best practices for how selected data elements are collected, structured or populated within PHA surveillance systems, if/when that will affect the interpretation of the data transmitted to CDC

Core for CDC Transmission ≠ Required

Even if a data element or class is identified as appropriate for transmission to CDC, this does *not* mean we need to fill in or send an answer for every core element for every case!

- It is okay to leave the data field as blank or Unknown if the information is not available, not a priority, or not useful for particular conditions.

- What information is needed at the national level?
- How can we best take advantage of electronic records and automation?
- How can we best take advantage of and feed into other standardization efforts (e.g., HL7, USCDI, USCDI+)?
- How can we reduce the manual surveillance burden on public health and health care entities?
- Can we position ourselves for a more efficient process for adding emergent conditions to our systems? Exchanging information? Case notification onboarding?

DSWG Opportunities for Participation (co-chair)



Data Element-Specific Teams



Purpose

These teams will focus on pre-identified topics determined by the DSWG Leadership Group (Co-Chairs, CSTE, CDC) based on multiple variables, including:

- Previous input from DSWG members
- Potential for collaboration across other groups of interest
- Common themes heard across various membership groups, including CSTE Sub-committees

Membership is encouraged from state/local/territorial jurisdictions, tribal entities, CDC and other federal agencies.

Data Element-Specific Teams



Team Member Expectations

- Attend monthly Team meeting(s) regularly to discuss data element(s)
- Participate actively during and between meetings
- Provide feedback on how your jurisdiction or program (if applicable) collects and uses information related to the data element prior to the first Team meeting
 - All DSWG members are invited to participate in this step, but expectation is higher for Team members
- Respond to surveys/polls conducted between Team meetings
- Review and provide input and comments between meetings on any draft documentation using shared Word documents

There is **NO** expectation for Team members to write documents, lead meetings, or prepare slides.

Team Topics



- Previous and up-coming Data Element-Specific Teams include:
 - Concluded: Pregnancy, Industry and Occupation
 - On-Going: Sexual Orientation and Gender Identity (SOGI)
 - **Next meeting: Friday, 12/15/23, 12:00-1:00pm Eastern**
 - New Team Starting: Immunization
 - **First meeting: Friday, 12/15/23, 1:00pm-2:00pm Eastern**
 - Upcoming: Exposure/Risk/Underlying Conditions, Death, Signs/Symptoms
- Individuals can opt into more than one team. Please keep in mind active participation is expected when participants sign up.
- Two Data Element-Specific Teams run concurrently.
- After guidance documents are developed for the data element topic, a team is sunset. A new Data Element-Specific Team convenes in the existing meeting time after previous Team sunset.

Purpose

The larger DSWG Membership will convene bi-monthly, hear updates from Data Element-Specific Teams, and continue to provide feedback on written recommendations being developed by the DSWG.

Member Responsibilities

- Attend meetings, as able, to hear updates and provide input to written recommendations
- Consider joining Data Element-Specific Teams
- Provide input on materials shared with the larger DSWG group in between meetings via polls or in shared documents
- Invite colleagues or other participants to relevant topic-specific sessions as able

Following today's meeting, the new cadence for the DSWG will be bi-monthly. The next meeting will be in early February.

Approval Status for DSWG Recommendations (CSTE)



Update on CSTE Approval Status for DSWG Products



- CSTE Brief Published!
 - *Data Standardization: Dates of Importance to Public Health Surveillance – Illness (Symptom) Onset Date, Report Dates, Laboratory-Related Dates, (Clinical) Diagnosis Date*
- CSTE Best Practice Guideline – Almost Published!
 - *Data Standardization: Workgroup Proposal for Standardized Case Counting Date, Proposed Calculated Case Counting Date for NNDSS Case Counting*
- CSTE Brief - In Development (anticipated early 2024)
 - *Data Harmonization*
- DSWG/Data Element Specific Team Products
 - DSWG data element products to be finalized on rolling basis
 - Leverage DSWG meetings and CSTE Connect to build consensus of DSWG products with CSTE membership
 - DSWG data element products to be associated with CSTE Brief on data harmonization

Status Updates: Hospitalization, Travel (JMC)



Status update: Hospitalization and Travel



- Both data classes were discussed in the full workgroup, and the resulting recommendations documents have been sent out for comment.
- Hospitalization:
 - Comment period: September 2023
 - Feedback from DSWG has been incorporated and content is complete
- Travel
 - Comment period: November 2023
 - Feedback from DSWG still being incorporated

Review of DEST Consensus: Pregnancy, Industry & Occupation, SOGI (JMC)



Potential data elements related to pregnancy



- Pregnancy Status
- Pregnancy Outcome
- Birth Weight
- Gestational Age
- Number of Weeks Gestation at Onset of Illness
- Estimated Delivery Date
- Last Menstrual Period
- Stillbirth Indicator
- Number of Total Live Births
- Pregnancy Status at the Time of First Positive Culture
- Obstetric Delivery Method
- Trimester at Onset of Illness
- Premature Infant
- Pregnancy Outcome Date
- Delivery Date
- Gestational Age Determination Method
- Gestational Age at Birth of Premature Patient in Weeks
- Infant Number
- Number of Pregnancies
- If Mother Has Given Birth in US, Number of Births Delivered in US

Potential Core Data Elements



Data Element	Definition	Value set or coding system
Pregnancy Status	Pregnancy status of the case at the time of the event.	Yes/No/Unknown
Estimated Date of Delivery	Estimated date of delivery of the pregnancy.	Date
Gestational Age	Gestational age of the pregnancy.	Date
Pregnancy Outcome	If the case was pregnant at the time of the event, the outcome of that pregnancy.	Still Pregnant Induced Abortion Intrauterine Fetal Death < 20 weeks Intrauterine Fetal Death >20 weeks Perinatal Death Live Birth – At Term Live Birth – Premature Unknown

Pregnancy Core Data Elements



Data Element	Definition	Standard Code	Value set or coding system	Recommendations for Input Data Source(s)
Pregnancy Status	Pregnancy status of the case at the time of the event (CCCD*)	LOINC: 77996-7 – Pregnancy status at time of illness or condition	Pregnant Not pregnant Unknown	• Case investigation • eCR • ELR
Estimated Date of Delivery (EDD)	Estimated date of delivery of the pregnancy	LOINC: 11778-8 – Delivery date Estimated	Date	• Case investigation • eCR

*CCCD = Calculated Case Counting Date

Potential data elements related to Industry and Occupation



- Current Industry
- Current Occupation
- Usual Industry
- Usual Occupation
- Occupation and Industry Category
- Occupational Duties
- Employment Status
- Work Site of Exposure
- Start Date
- End Date
- Food Handler
- Case Patient a Healthcare Worker
- Type of Healthcare Occupation
- Day Care Worker Within 7 Days Before Illness
- Visit Animal Environment Within 14 Days Before Symptom Onset
- Workplace Setting
- Critical Infrastructure Workplace Setting
- Employer address and name

***Bolded data elements included in standardized Industry and Occupation Repeating Group**

Potential Core Data Elements



Data Element	Definition	Value set or coding system
Current Industry	Case's current industry.	Both a free-text field and a standardized field using Industry CDC Census 2010. <i>Switch to NAICS?</i>
Current Occupation	Case's current occupation.	Both a free-text field and a standardized field using Occupation CDC Census 2010. <i>Switch to SOC?</i>
Employed in Specific Setting? [Template for specific conditions.]	During the incubation period or infectious period of the case, was the case working as a _____? (Healthcare worker, Food handler, etc.)	Yes/No/Unknown
Occupation Related to Exposure	Is the patient's exposure to the condition related to their current occupation?	Yes/No/Unknown

Industry & Occupation Core Data Elements



Data Element	Definition	Standard Code	Value set or coding system	Recommendations for Input Data Source(s)
Current Industry	Case's current industry	LOINC: 85658-3	Free Text	• Case investigation • eCR
Current Industry Standardized	Standardized code for the case's current industry	LOINC: TBD	NAICS (North American Industry Classification System)	• eCR • NIOCCS Autocoder
Current Occupation	Case's current occupation	LOINC: 85078-4	Free Text	• Case investigation • eCR
Current Occupation Standardized	Standardized code for the case's current Occupation	LOINC: TBD	SOC (Standard Occupational Classification)	• eCR • NIOCCS Autocoder

Pregnancy and I/O



- Next week look for an email with the draft pregnancy recommendation document and a form for feedback.
- Next week, members of the Industry and Occupation data element specific team should look for a first draft of these recommendations.
- After the I/O DEST review, an updated version for I/O will be sent to this larger DSWG for comment in January.

Sexual Orientation and Gender Identity (in progress)



What we've accomplished so far:

Data Element	Definition	Value set or coding system	Abstracted/ Derived/ Created	Potential Input Data Source(s)
Sexual Orientation	A person's identification of their emotional, romantic, sexual, or affectional attraction to another person.	1. Asexual 2. Bisexual 3. pansexual 4. Straight or heterosexual 5. Lesbian, gay or same-gender loving 6. Not Listed, please specify 7. Unsure/Questioning 8. Prefer not to answer 9. Unknown	Abstracted	Case investigation

Sexual Orientation and Gender Identity (in progress)



What we are still working on:

Data Element	No. of NNDSS MMGs?	NNDSS value set or coding system	Potential for Electronic Data Capture
Sex at Birth	TB, Hepatitis v2 (draft)	1. Female 2. Male 3. Unknown	• Captured in eCR as “Patient Birth Sex” • Not present as a data element in ELR
Current Sex	None Currently	?	• Not present as a data element in eCR or ELR
Sex	Gen v2	1. Female 2. Male 3. Unknown	• Not present as a data element in eCR • Captured in ELR as Administrative Sex (PID-8) with broader value set
Gender Identity	STD, Hepatitis v2 (draft)	Different Value sets for STD and Hepatitis	• Captured in eCR as “Gender Identity” value set in accordance with USCDI v2 • Not present as a data element in ELR

DSWG Next Steps (JMC)



Next Steps



- Look out for a link to sign up for data element specific teams!
 - Immunizations (meeting 1) data element team will meet on 12/15.
 - Next data classes after these will include Exposure/Risk/Underlying Conditions, Death, and Signs/Symptom/Clinical Manifestations.
- Next week, a draft of the pregnancy data class will go out to the DSWG for comment.
- In January, a draft of the industry and occupation data class will go out to the DSWG for comment.
- The next large DSWG call will be the end of February.
 - There is potential for draft documents to be emailed out for comment for data elements before the next meeting as teams wrap up elements.

Thank you!



	WG Discussion	DEST	Draft Complete	DEST Feedback	Feedback Addressed	DSWG Feedback	Document Finalized
Hospitalization	Completed	Not applicable	Completed	Not applicable	Completed	Completed	Completed
Travel	Completed	Not applicable	Completed	Not applicable	Completed	Completed	Completed
Pregnancy	Not applicable	Completed	Completed	Completed	In Progress		
Industry and Occupation	Not applicable	Completed	In Progress				
Sexual Orientation and Gender Identity	Not applicable	In Progress 3: 12/15/23					

Immunizations

12/15/23

Legend

Completed
In Progress
Not applicable