

Data Standardization Work Group (DSWG)

February 23, 2024



Council of State and Territorial Epidemiologists

Please mute phone/ headset/ computer audio!

Agenda

- Welcome (Co-Chairs)
- DSWG Opportunities for Participation (Co-Chairs)
- Announcements and Key Updates (CSTE)
- Status Updates for closed DESTs (JMC):
Hospitalization, Travel, Pregnancy, Industry & Occupation
- Review of Recent DEST Consensus (JMC):
Sexual Orientation and Gender Identity, Death, Immunization History
- DSWG Next Steps (JMC)
- Wrap-Up & Adjourn (Co-Chairs)

Welcome (Co-Chairs)



- 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?

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.

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.

- To sign up fill in this interest form: <https://app.smartsheet.com/b/form/3da89d48bda94fc7a33c4a8a505fe54a>

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:
 - In Progress
 - Exposures/Risk Factors/Underlying Conditions & Signs/Symptoms/Clinical Manifestations
 - Joint meeting scheduled for Friday, 3/8/24, 12:00-1:00pm Eastern
 - Will also utilize Friday, 3/15/24, 12:00-1:00 Eastern if needed
 - Upcoming: Reporting Source, Identifiers, Lab, Medication treatment, Race/Ethnicity/Tribal Affiliation, SDOH, Disability, Reporting Source
- 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. When discussions for one data element are concluded, a new data element convenes in the existing meeting time.
- After guidance documents are developed for the data element topic, a team is 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

Announcements and Key Updates (CSTE)



Announcements



CSTE 2024 Annual Conference

- Pittsburgh, Pennsylvania, June 9-13
- Early Bird Registration is now open through May 2: <https://www.csteconference.org/index.php/registration/>
- Invitations sent to presenting authors – March 7

CSTE DSWG is collecting interest for Co-Chair position

- The deadline is February 29
- The link to the interest form is here <https://app.smartsheet.com/b/form/90446153afed478c8bf3b3e345916e35>

Key Updates



- 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
- DSWG Membership Information
 - 325 from PHAs
 - 195 from CDC
 - 21 from CSTE + JMC

Status Updates for Closed DESTs (JMC)



Status update for closed DESTs



- DSWG review complete and draft is with CSTE for next steps.
 - Hospitalization
- DSWG input received, and final draft is being completed with Co-Chairs and JMC. The finalized draft will go to CSTE for next steps.
 - Travel
 - Pregnancy
 - Industry and Occupation
- DEST input received, and updated draft recommendations will next go to DSWG for review and input.

(Recent consensus will be reviewed on the following slides.)

 - Death
 - Immunization History
 - Sexual Orientation and Gender Identity

DEST Summary (as of 2/23/2024)



	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	In Progress
Pregnancy	Not applicable	Completed	Completed	Completed	Completed	Completed	In Progress
Industry and Occupation	Not applicable	Completed	Completed	Completed	Completed	Completed	In Progress
Sexual Orientation and Gender Identity	Not applicable	Completed	Completed	Completed	In Progress	Not applicable	Not applicable
Immunization History	Not applicable	Completed	Completed	Completed	In Progress	Not applicable	Not applicable
Death	Not applicable	Completed	Completed	Completed	In Progress	Not applicable	Not applicable
Exposures/Risk Factors/ Underlying Conditions	Not applicable	Call #2: 3/8/24	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable
Signs/Symptoms/ Clinical Manifestations	Not applicable	Call #2: 3/8/24	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable

* Document is with CSTE for final approval.

Legend
Completed
In Progress
Not applicable

Review of Recent DEST Consensus (JMC)



Sexual Orientation and Gender Identity



Potential data elements related to Sexual Orientation and Gender Identity



- Sexual Orientation
- Gender Identity
- Sex at Birth
- Current Sex
- Pronouns
- Sex for Clinical Use
- Recorded Sex or Gender

Proposed SOGI Data Elements



Data Element	Definition (93% consensus)	Value Set (96% consensus)
Sexual Orientation	A person's identification of their emotional, romantic, sexual, or affectional attraction to another person.	Asexual Bisexual Pansexual Straight or heterosexual Lesbian, gay, or same-gender loving Queer Not listed, please specify Unsure/questioning Prefer not to answer Unknown

Proposed SOGI Data Elements



Data Element	Definition (96% consensus)	Value Set (94% consensus)
Gender Identity (<i>multi-select</i>)	Person identified gender identity (i.e., an individual's personal sense of being a man, woman, or another gender, regardless of the sex that person was assigned at birth).	Woman/Girl Man/Boy Transgender Non-binary or genderqueer Two Spirit Another gender, please specify Choose not to disclose Unknown

Proposed SOGI Data Elements



Data Element	Definition (SAB 96% consensus) (Sex 83% consensus)	Value Set (SAB 96% consensus) (Sex 83% consensus)
Sex Assigned at Birth	Sex a person was assigned at birth, for example on their original birth certificate.	Female Male Intersex/Non-binary marker/X Unknown
Sex	Sex, from any data source.	Female Male Intersex/Non-binary marker/X Unknown

Death



Potential data elements related to Death



- Subject Died
- HiNSES Fetal Death
- Final Disease Outcome
- Subject Outcome
- Disease Outcome Type
- Cause of Death
- Primary Cause of Death From Death Certificate
- Secondary Cause of Death From Death Certificate
- Patient Death Date and Time
- Deceased date

Proposed Death Data Elements



Data Element	Definition	Value Set
Patient Deceased	Is patient deceased?	Yes No Unknown
Deceased Date	Patient date of death <i>OR</i> Patient date of death if their death was associated with this condition	Date
Death associated with condition	Indicator that death was associated with the condition	Yes No Unknown

Immunizations



Potential data elements related to immunizations



- Vaccine Type
- Vaccine Administered Date
- Vaccine Dose Number
- Vaccine Manufacturer
- Vaccine Lot Number
- Vaccine Expiration Date
- National Drug Code (NDC)
- Vaccination Record Identifier
- Vaccine Event Information Source

- Did the subject ever receive a vaccine against this disease
- Vaccinated Per ACIP Recommendations
- Reasons Not Vaccinated Per ACIP Recommendations
- Vaccination Doses Prior to Onset
- Date of Last Dose Prior to Illness Onset
- Vaccine History Comments
- Number of Doses received Before 1st Birthday
- Source of Mother's Vaccine Information
- Were Any of the Children Living in the Household Immunized With Rubella-Containing Vaccine

Potential Core Data Elements



Vaccine History Repeating Group	Core Data Element?
Vaccine Type (CVX)	97% - Yes
Vaccine Administered Date	97% - Yes
Vaccine Manufacturer (MVX)	87% - Yes
Vaccine Event Information Source	58% - Yes, Weak Support
Vaccine Dose Number	44% - No
Vaccine Lot Number	40% - No
Vaccine Expiration Date	39% - No
Vaccination Record Identifier	29% - No
National Drug Code (NDC)	23% - No

Potential Core Data Elements



Interpretive Vaccine History (no repeat)	
Did the subject ever receive a vaccine against this disease?	89% - Yes
Vaccination Doses Prior to Illness Onset	75% - Yes, Weak Support
Date of Last Dose Prior to Illness Onset	68% - Yes, Weak Support
Vaccinated per ACIP Recommendations?	48% - No
Reason Not Vaccinated Per ACIP Recommendations	28% - No
Vaccine History Comments	7% - No

Immunizations Core Data Elements



Data Element	Definition	Value set or coding system	Recommendations for Input Data Source(s)
Vaccine Type	The type of vaccine administered for the condition being reported	CVX codes – Vaccines Administered (HL7 Standard Code Set)	• IIS • Case investigation • eCR
Vaccine Administered Date	The date that the vaccine was administered	Date	• IIS • Case investigation • eCR
Vaccine Manufacturer	The company which manufactured the vaccine	MVX – Manufacturers of Vaccines (HL7 Standard Code Set)	• IIS • Case investigation • eCR
Vaccine Event Information Source*	The information source for this vaccination record	Vaccine Event Information Source (NND)	• IIS • Case investigation • eCR

*Weak Support

Immunizations Core Data Elements



Data Element	Definition	Value set or coding system	Recommendations for Input Data Source(s)
Ever Vaccinated Against this Disease	Indicator that the patient has ever received a vaccine against this disease	Yes/No/Unknown	• IIS • Case investigation • eCR
Vaccination Doses Prior to Illness Onset*	Number of vaccine doses against this disease prior to illness onset	Numeric	• IIS • Case investigation • eCR
Date of Last Dose Prior to Illness Onset*	Date of last vaccine dose against this disease prior to illness onset	Date	• IIS • Case investigation • eCR

*Weak Support

Next Steps



- In early March look for an email with the draft Death and Immunization recommendation documents and feedback forms.
- In early April look for an email with the draft SOGI recommendation document and feedback form.
- This process will complete before our next DSWG meeting on April 26th.

DSWG Next Steps (JMC)



Next Steps – Combined Message Structure Call



Upcoming Message Structure Calls



Previous calls have considered each question that might fall within a data class as individual questions in which DSWG members:

1. Try to determine if a data element meets the criteria of core surveillance for reporting for CDC
2. Try to come to consensus about a distinct data element's definition and its associated value set
 - Definition – What is question we are asking?
 - Value Set – What is the recommended answer set or format?

Upcoming Message Structure Calls



Current calls about Exposures, Risk Factors, Underlying Conditions, Signs/Symptoms, Clinical Manifestations are trying to:

1. Come to consensus about any potential individual data elements which core maybe considered core, complete with definitions and value sets.
2. Come to consensus about larger data concepts which might require a more flexible approach to its definitions, value sets, and structure within a message to CDC.
 - DEST calls on 8 March and 15 March will discuss the structure question.
 - Initial meeting invites will go out Monday, Feb 26. New sign-ups will be added on Fridays on a rolling basis.

Upcoming Message Structure Calls: What is the structure question?



- Current state of message mapping guides
 - Many message mapping guides include these **data concepts** as either:
 - Individual questions, each representing one **data element**
 - Repeating blocks allowing for many **data elements** in the same data concept with Yes/No/Unknown
 - What are the pros and cons of messaging in these two different formats?
 - If one format could be chosen as **THE** format, which is better?

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type	Value Set Name (VADS Hyperlink)
START: Epidemiological Exposures Repeating Group				
Exposure	INV1085	In the 14 days prior to illness onset, did the patient have any of the following exposures	Coded	Exposure Setting (COVID-19)
Exposure Indicator	INV1086	Exposure Indicator	Coded	Yes No Unknown (YNU)
END: Epidemiological Exposures Repeating Group				
Name of Ship	TRAVEL53	Name of ship patient sailed on	Text	N/A
Workplace Critical Infrastructure	95373-7	If workplace exposure, is the workplace critical infrastructure? Workplaces classified as Critical infrastructure are defined at the state or local level.	Coded	Yes No Unknown (YNU)
Critical Infrastructure Workplace Setting	95374-5	If critical infrastructure, specify workplace setting	Coded	Critical Infrastructure Sector (NND)

Pulled from the COVID-19 MMG

Other Next Steps



- SOGI/Death/Immunizations for DSWG Review
- [Poll:](#) Reporting Source data elements- due March 8th
- Sign up for current and future data element specific teams
- Upcoming meetings
 - DEST: Exposure, Risk Factors, and Underlying Conditions & Signs, Symptoms, and Clinical Manifestations **Joint Call on Structure** March 8
 - Will also use March 15 if needed
 - Please attend if you work on formatting messages for sending data to NNDSS
 - The next broader DSWG call will be April 26, 1-2 EST.

Wrap-Up & Adjourn (Co-Chairs)

