Data Standardization Work Group (DSWG)

February 14, 2025

CSTE Data Standardization Workgroup Meeting

Please mute phone/ headset/ computer audio!

Agenda

- Welcome (Co-Chairs)
- Announcements and Key Updates (CSTE)
- Status Updates for Data Classes (JMC)
- Signs & Symptoms Loose Ends (JMC)
- SDOH – Insurance Wrap Up (JMC) *if time allows*
- SDOH – Flavors of Unknown (JMC) *if time allows*
- DSWG Next Steps (JMC)
- Wrap-Up & Adjourn (Co-Chairs)

Welcome (Co-Chairs)

Core Data: In Scope for DSWG

- 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.

Considerations

- 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.

Announcements and Key Updates (CSTE)

DSWG Update

- CSTE Brief: *Standardizing Core Case Notification Data Elements to Improve National and Jurisdictional Public Health Surveillance*
  - All-Member Review Period on CSTE Connect: begins next week
  - Appendix C: *DSWG Scope and Consensus Process* – outlines consensus process for data class review

Level of Review for Data Class Standards
Level 1: DSWG Consensus Building
Level 2: Steering Committee and Subcommittee Chair Review (S/I & SPIS)
Level 3: General CSTE Membership
Level 4: State Epidemiologist Review
Post-review formatting and posting

DSWG Consensus Development

1. DSWG Consensus Building
2. Subcommittee and Steering Committee Review
3. General Membership Review
4. State Epi Review

- Per data class, CDC conducts background research; Data Element Specific Team (DEST) is convened
- Through DEST discussions, data class research is turned into recommendations for specific data elements, usually with 80% of DEST members in agreement
- Written recommendations go to full DSWG and OPHDST for final feedback; revisions made based on feedback
- Provisional revised product shared with DSWG co-chairs, OPHDST leadership, and CSTE staff

Data Class Recommendation Progress

1. DSWG Consensus Building
2. Subcommittee and Steering Committee Review
3. General Membership Review
4. State Epi Review

- ☑ Calculated Case Counting Date for NNDSS Case Counting
- ☑ Dates of Importance to Public Health Surveillance: Illness (Symptom) Onset Date; Report Dates; Laboratory-Related Dates; (Clinical) Diagnosis Date
- ☑ Death
- ☑ Disability
- ☐ Exposures, Risk Factors, Underlying Conditions
- ☑ Hospitalization
- ☑ Identifiers (Case/Event-Related/Laboratory)
- ☐ Immunization History
- ☑ Industry and Occupation
- ☐ Laboratory Observations
- ☑ Medications/Treatment
- ☑ Pregnancy
- ☑ Reporting Source
- ☐ Signs, Symptoms, Clinical Manifestations
- ☐ Social Determinants of Health
- ☑ Travel

Next Step: Broad buy-in of these data class and data element recommendations to promote implementation within jurisdictions

Committee Chair Review

1. DSWG Consensus Building
2. Subcommittee and Steering Committee Review
3. General Membership Review
4. State Epi Review

- Reviewed by Surveillance Practice and Implementation Subcommittee Co-Chairs
- Reviewed by Surveillance and Informatics Steering Committee Chair and Vice Chair (on behalf of the P&P Committee)
- Timing:
  - Review period: 10 business days
  - Reconciliation period: 5 business days

Membership Review

1. DSWG Consensus Building
2. Subcommittee and Steering Committee Review
3. General Membership Review
4. State Epi Review

- Per data class, CSTE will host a 2-week virtual comment period on CSTE Connect
  - All members able to comment on the posted DSWG recommendation docs
  - Open for any general discussion
- Questions posed for feedback:
  - *"Do you agree with the DSWG's recommendation of including [X] (in the above-defined form) as a core data element for inclusion in case notifications to CDC?"*
  - *"Do you have any concerns with the definitions proposed for [X] data element?"*
- Timing:
  - Review period: 10 business days
  - Reconciliation period: 5 business days

Jurisdictional Leader Review

1. DSWG Consensus Building
2. Subcommittee and Steering Committee Review
3. General Membership Review
4. State Epi Review

- Smartsheet form to collect official comments from each jurisdiction
  - One Smartsheet form per data class
  - State Epis (or equivalent leaders within reporting jurisdictions) should designate at least one person (likely subject matter expert) to act on behalf of jurisdiction during comment period
- Survey open for 1-week period

Jurisdictional Leader Review

1. DSWG Consensus Building
2. Subcommittee and Steering Committee Review
3. General Membership Review
4. State Epi Review

Questions posed for feedback:	
Per data element	*"Do you agree with the DSWG's recommendation of including [X] (in the above-defined form) as a core data element for inclusion in case notifications to CDC?"*
	"Do you have any concerns with the definitions proposed for [X] data element?"
Per data class	*"Will you support and work towards implementing the ability to exchange these data elements, as defined within the [A] data class recommendation document, from your case surveillance system?"*

Simple Majority to Advance

1. DSWG Consensus Building
2. Subcommittee and Steering Committee Review
3. General Membership Review
4. State Epi Review

Jurisdictional Smartsheet Question	Consensus Levels	Path Forward
Do you agree with the DSWG recommendations that [X] is core data class to include in transmission to CDC?	Agree or Can Live with it > 50%	Core
	30% < Agree or Can Live with it <= 50%	Small working group reviews feedback and determines if (a) additional education needed to clarify common issues or (b) DEST needs to be reconvened to make small but substantive changes
	Agree or Can Live with It <= 30%	Not core; can be resubmitted in future but would require restarting of consensus process

Next Steps

Data Class	Additional WG Discussion	Feedback Addressed	DSWG Feedback	Level 2 Ready
Hospitalization	Feb/March 2025			
Travel				Yes
Pregnancy				Yes
Industry and Occupation				Yes
Immunization History				Yes
Death	Feb/March 2025			
Exposures/Risk Factors/ Underlying Conditions				In progress
Signs/Symptoms/ Clinical Manifestations	Current			
Disability				In progress
Identifiers				Yes
Medication/Treatment				Yes
Laboratory			Through Feb 21	
Reporting Source				Yes
Social Determinants of Health	Feb-25			

2. SI / SPIS Chairs → 3.) CSTE Membership → 4.) State Epis

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Status Updates for Closed DESTs (JMC)

CSTE

Status update for closed DESTs

These documents are with CSTE for Level 2 review

- Travel
- Pregnancy
- Immunizations
- Identifiers
- Industry and Occupation
- Reporting Source
- Medications

Draft recommendations being reviewed by DSWG

- Laboratory, through February 21st
- Expect SSCM by the end of Feb
- Expect SDOH in March

Signs and Symptoms Summary

CSTE

Previously in February...

Data Element	Definition	Coding System	Abstracted/ Derived/ Created	Potential Input Data Source(s)
Signs and Symptoms	Clinical manifestations, including signs and symptoms, associated with the condition being reported	SNOMED preferred, local if necessary	Abstracted	Case Investigation eCR

Voted for a core data class that is inclusive of signs, symptoms, and other clinical manifestations of a condition.

Transmitted across conditions when applicable.

Individual signs/symptoms will be condition specific and defined by CDC program areas.

Previously in March...

Data Element	LOINC & Description	Coding System
Signs and Symptoms	56831-1 – Problem associated signs and symptoms	SNOMED preferred, local if necessary
Signs and Symptoms Indicator	INV919 – Indicator for associated signs and symptoms	Y/N/U

The structure that likely makes the most sense for this data class is a repeating group structure:

- Each individual manifestation can be marked as "yes", "no", or "unknown"
- Each individual manifestation won't be a standalone data element

Previously in April…

Data Element	Definition	Value Set	Abstracted/ Derived/ Created	Potential Input Data Source(s)
Signs and Symptoms Data Class Indicator	Indicator that the person experienced any listed signs, symptoms, or other clinical manifestations associated with the condition being reported	Y/N/U	Derived	Case Investigation eCR

- Along with the ERU data classes, we found it beneficial to have a data class indicator- an overall "Y/N/U" that describes if the person had ANY of the listed signs and symptoms.
- A value for "no" or "unknown" may remove the need to send the repeating group.

Signs and Symptoms DEs

Data Element	Definition	Value Set
Signs and Symptoms Data Class Indicator Any Signs or Symptoms	Indicator that the person experienced any listed signs, symptoms, or other clinical manifestations associated with the condition being reported	Y/N/U
Repeating Group:		
Signs and Symptoms	56831-1 – Problem associated signs and symptoms	SNOMED preferred
Signs and Symptoms Indicator	INV919 – Indicator for associated signs and symptoms	Y/N/U

Previously in April…

Data Element	Definition	Value Set	Abstracted/ Derived/ Created	Potential Input Data Source(s)
Symptomatic Indicator	Indicator the person exhibited symptoms associated with the condition being reported	Y/N/U	TBD Today	Case Investigation eCR

Finally, a "Symptomatic Indicator" was weakly supported as core. Discussion was focused on the utility of this information for public health education/messaging - how many people are "asymptomatic" even though they may have other clinical manifestations (like low WBC count or thrombocytopenia)

Discussion/Polling

Polling process

- Poll questions will be shown first on a slide before the poll opens
  - Opportunity for clarifications & questions

- There will be an opportunity for limited discussion on questions with a big split, as time allows

- Participant voting
  DSWG membership has grown to include many experts and interested participants. The following guidance is requested for participating in polling:
  - Only STLTs (State, Territorial, Local, and Tribal) and Federal authorities should vote.
  - Contractors and individuals from other organizations are requested to abstain from voting unless they have specific and relevant expertise in the topic.
  - Comments and discussion are welcomed by all, but voting remains with the STLTs and federal authorities.

Current State

Data Element	Definition	Value Set
Signs and Symptoms Data Class Indicator Any Signs or Symptoms?	Indicator that the person experienced any listed signs, symptoms, or other clinical manifestations associated with the condition being reported	Y/N/U
Repeating Group:		
Signs and Symptoms	56831-1 – Problem associated signs and symptoms	SNOMED preferred
Signs and Symptoms Indicator	INV919 – Indicator for associated signs and symptoms	Y/N/U
Symptomatic Indicator	Indicator the person exhibited symptoms associated with the condition being reported	Y/N/U

Symptomatic Indicator

"Indicator the person exhibited symptoms associated with the condition being reported"

- Should this be derived based on the specific symptoms contained within the "signs and symptoms" repeating group?
  - Would require definition for each repeating group of **what's considered a symptom** versus sign/other manifestation
  - Could this just be calculated by CDC based on data received?
  - If there is a write in option for "other", up to the jurisdiction?
- Should this ignore the repeating group and be taken from directly from the individual or medical record- does the person consider themselves symptomatic?

Poll 1 – Symptomatic Indicator

How should the symptomatic indicator be implemented?

- Based on symptoms listed within the repeating group
- Does the patient consider themselves symptomatic/medical record says symptomatic

Poll 2 – Symptomatic Indicator

Should the symptomatic indicator remain a core data element?

- Yes
- No

Reminder:
Core data for surveillance = Data classes or elements used for situational awareness or routine, cross-condition case surveillance for transmission to CDC. These elements may remain empty for cases/conditions where not applicable or unavailable.

SDOH: Insurance

SDOH: Insurance

Data Element	Definition	Value Set
Insurance Coverage Type *Or* *Healthcare Coverage Type?*	Person's type of health insurance coverage *Or* *Person's type of healthcare coverage?*	Select all that apply: • Private insurance (e.g., from employer, from Marketplace) • Medicare • Medicaid • *Either "Military (e.g., Tricare, VA, on-base)" or three separate options for Tricare, VA, 'Other Military'?* • *Indian Health Service?* • *Correctional Facility Healthcare Service?* • Other public insurance (e.g. CHIP, community health care plan sponsored by local government) • Other • Uninsured • Unknown

SDOH: Insurance

Data Element	Definition
Healthcare Insurance/Access Type	Person's type of healthcare insurance or other healthcare access, select all that apply

Feedback so far:

- Generally supports the name healthcare coverage since it's inclusive of things technically not "insurance", but some concern it might be unclear if it doesn't mention insurance
- Best of both worlds approach?
- Need to be more clear that more than one option can be chosen

SDOH: Insurance

Value Set
Select all that apply: • Private insurance (e.g., from employer, from Marketplace) • Medicare • Medicaid • ***TRICARE or other military-associated health care*** • ***Veterans Health Administration (VA) health care*** • Indian Health Service funded (includes Tribe operated or Urban Indian health center) • Correctional/Detention facility healthcare service • Other public insurance (e.g. CHIP, community health care plan sponsored by local government) • Other • Uninsured/Self-pay • Unknown

Feedback so far:

- Should be inclusive of Military/ IHS/ Correctional Facilities
- Split feedback on Military granularity

Poll 3 – Insurance

Can you live with this definition and value set for Insurance?

- Yes
- No

Data Element	Definition
Healthcare Insurance/ Access Type	Person's type of healthcare insurance or other healthcare access, select all that apply

Value Set

Select all that apply:

- Private insurance (e.g., from employer, from Marketplace)
- Medicare
- Medicaid
- TRICARE or other military-associated health care
- Veterans Health Administration (VA) health care
- Indian Health Service funded (includes Tribe operated or Urban Indian health center)
- Correctional/Detention facility healthcare service
- Other public insurance (e.g. CHIP, community health care plan sponsored by local government)
- Other
- Uninsured/Self-pay
- Unknown

DSWG Next Steps (JMC)

CSTE

Next Steps

Upcoming DSWG meetings (*tentative topics)*:

- **2/28 1-2pm ET – SDOH: Flavors of Unknown?**
  Insurance Wrap Up?
  Living Situation Wrap Up

- *March and April DSWG meeting content is to be determined*

Recommendations Documents:

- DSWG Input on Laboratory Draft by 2/21/25

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.

Wrap-Up & Adjourn (Co-Chairs)

Wrap-Up

Anything else for the good of the group?