

Data Standardization Work Group (DSWG)

February 28, 2025



Council of State and Territorial Epidemiologists

CSTE Data Standardization Workgroup Meeting



Please mute phone/ headset/ computer audio!

Agenda

- Welcome (Co-Chairs)
- Announcements and Key Updates (CSTE)
- Status Updates for Recommendations (JMC)
- SDOH – Flavors of Unknown (JMC)
- SDOH – Living Situation loose ends (JMC)
- 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.

- 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)



Announcements & Key Updates



- Reminder: CSTE Brief - *Open for comment through 3/12/25*
 - Standardizing Core Case Notification Public Health Data Elements to Improve National and Jurisdictional Surveillance and Situational Response
 - Appendix – Consensus Building Process

Level of Review for Data Class Standards
<i>Level 1: DSWG Consensus Building</i>
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

- Coming soon to CSTE Connect for Level 3 review:
 - Travel Core Surveillance Data Class – *ETA mid-March*

Status Updates for Recommendations (JMC)



Status update for recommendations



- Level 1 Review complete, drafts are with CSTE for next level.
 - Death
 - Disability
 - Hospitalization
 - Identifiers
 - Immunizations
 - Industry and Occupation
 - Medication and Treatment
 - Pregnancy
 - Reporting Source
 - SOGI
 - In Level 2 Review
 - Travel (ended Feb 24)
 - Draft recommendations in Level 1
 - Signs and Symptoms, with DSWG through March 7
 - Working to reconcile comments or other final edits for Level 2
 - Laboratory
 - Exposures, Risk Factors, and Underlying Conditions
- Level 1 Review - DSWG
 - Level 2 Review - Steering Committee and Subcommittee Chair Review
 - Level 3 Review - General CSTE Membership
 - Level 4 Review - State Epi

Recommendations Summary (as of 2/28/2025)



Data Class	Additional WG Discussion	Feedback Addressed	DSWG Feedback	Level 2 Ready
Death				Yes
Disability				Yes
Exposures/Risk Factors/ Underlying Conditions				In progress
Hospitalization				Yes
Identifiers				Yes
Immunization History				Yes
Industry and Occupation				Yes
Laboratory				In progress
Medication/Treatment				Yes
Pregnancy				Yes
Reporting Source				Yes
Sexual Orientation and Gender Identity				Yes
Signs/Symptoms/ Clinical Manifestations			In progress	
Social Determinants of Health	2/28/25			

Legend	
	Completed
	In Progress
	Not applicable

SDOH: Unknown



SDOH Data Elements



Data Element	Definition
Housing Status	Housing status of a person at the first epidemiologically relevant date associated with the case (i.e., CCCD*)
Living Situation	Living situation of a person at the first epidemiologically relevant date associated with the case (i.e., CCCD*)
Preferred Language	The language a person is most comfortable using for communication
Educational Attainment	Highest degree or level of school completed by the person at the first epidemiologically relevant date associated with the case (i.e., CCCD*)
Health Insurance or Access Type	Person's type of healthcare insurance or other healthcare access, select all that apply

CDC Methods for Conveying Unknown/Missing



CDC has previously released guidance "[Methods for Conveying Unknown or Missing Values in Case Notification Messages](#)":

"In developing these recommendations, CDC recognizes that jurisdictions could incur significant financial costs if changes to their surveillance systems were required in order to collect this information, as well as from additional time spent in data entry. Therefore, these guidelines address only the methods for data transmission in HL7 messages when the information is collected in the surveillance system, and are not a requirement for the collection of the data.

The NNDSS Program recommends that CDC Programs be judicious in requesting that submitters distinguish between "unknown" and "missing" values in HL7 messages so as to minimize the burden on the jurisdictions."

Data Element

Housing Status

Living Situation

Preferred
Language

Educational
Attainment

Health Insurance/
Coverage Type

Thinking about our core SDOH data elements- is there a public health use case for standardizing collection across PHAs *and* conveying to CDC "Not Asked", "Asked but Unknown", "Refused to Answer" instead of just "Unknown"?

Poll 1 – SDOH Unknowns



Should the data elements in the SDOH data class have one value for unknown or multiple?

- Just Unknown
- "Not Asked", "Asked but Unknown", "Refused to Answer"

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: Living Situation



- SDOH as a data class is doing something different with data collection than what's historically been done in case investigations
- These data elements add (not replace) information into case notifications
- Analysis of these data elements should be focused on if a certain population is disproportionately affected by a condition
- Not the goal of SDOH:
 - Capturing exposure for a condition
 - Capturing risk factors for a condition
 - Capturing where someone may have spread illness

SDOH: Living Situation



Living situation of a person at the first epidemiologically relevant date associated with the case (i.e., CCCD)

- Private residence in a long-term arrangement
- Hotel/motel or vacation rental in a long-term arrangement
- Private residence in a short-term arrangement of 14 days or less
- Hotel/motel or vacation rental, short-term arrangement 14 days or less
- Shelter or safe haven (incl. hotel/motel paid by charity or gov't prog)
- Structure not meant for human habitation
- Vehicle not meant for human habitation
- Open air, part of an established encampment
- Open air, not part of an established encampment
- Migrant worker housing
- Military barracks
- School/University dormitory
- Other congregate housing for workers/students
- Federal correctional facility
- State correctional facility
- Juvenile detention facility
- Jail/Local correctional facility
- Other correctional/detention facility (e.g., Border detention facility)
- Inpatient hospital/Acute care facility
- Mental/Behavioral/Substance use treatment facility
- Long term care facility
- Medical respite/Recuperative care facility
- Group home or residential facility not provided by employer or school
- Unknown
- Other

- Some circumstances it may be unclear when something should be selected as a "living situation":
 - Very short term stay in a jail? Do you pick jail or where someone actually lives?
 - Inpatient hospital/Acute care facility?
 - On a vacation in a hotel? Does that count as "hotel in short term arrangement", which is likely intended to capture sheltered homelessness?
- Does it help to ask for someone's "primary living situation"?
 - Remove the option for "inpatient hospital/acute care facility" - if this situation exists it could be classified as "Other"
- Are there other changes we could make so that people are mostly collecting this the same way?

Poll 3 – Living Situation Definition



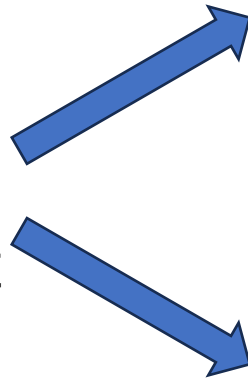
What's your preferred definition for Living Situation?

- Living situation of a person at the first epidemiologically relevant date associated with the case (i.e., CCCD)
- **Primary** living situation of a person at the first epidemiologically relevant date associated with the case (i.e., CCCD)
- Something else entirely

SDOH: Living Situation



- Private residence in a long-term arrangement
- Hotel/motel or vacation rental in a long-term arrangement
- Private residence in a short-term arrangement of 14 days or less
- Hotel/motel or vacation rental, short-term arrangement 14 days or less



"in a long-term arrangement"

"in a short-term/temporary arrangement of days/weeks"

"in a long-term arrangement of more than 14 days"

"in a short-term arrangement of 14 days or less"

Poll 5 – Short/Long Term



What's your preferred approach for the values that specify short versus long term arrangements?

- "in a long term arrangement" & "in a short term/temporary arrangement of days/weeks"
- "in a long term arrangement of more than 14 days" & "in a short term/temporary arrangement of 14 days or less"

SDOH: Living Situation



- Shelter or safe haven (incl. hotel/motel paid by charity or gov't prog)
- Structure not meant for human habitation
- Vehicle not meant for human habitation
- Open air, part of an established encampment
- Open air, not part of an established encampment



- Shelter or safe haven (congregate setting)
- Temporary, non-congregate housing provided by charity or government program (e.g., transitional housing, pallet shelter, hotel/motel)
- Structure or vehicle not meant for human habitation
- Open air
- Vehicle meant for human habitation (e.g., RV)

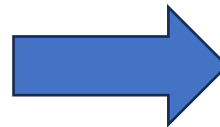
Poll 6 – Unstable Housing Options



Do you support the change in our proposed value set?

- Yes
- No

- Shelter or safe haven (incl. hotel/motel paid by charity or gov't prog)
- Structure not meant for human habitation
- Vehicle not meant for human habitation
- Open air, part of an established encampment
- Open air, not part of an established encampment



- Shelter or safe haven (congregate setting)
- Temporary, non-congregate housing provided by charity or government program (e.g., transitional housing, pallet shelter, hotel/motel)
- Structure or vehicle not meant for human habitation
- Open air
- Vehicle meant for human habitation (e.g., RV)

DSWG Next Steps (JMC)



Next Steps



Upcoming DSWG meetings:

- **3/28 1-2pm ET – Topic TBD**

Recommendations Drafts

- SSCM is with DSWG (Level 1) through March 7
- SDOH draft will be in your email inboxes soon for comments.

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)



Anything else
for the good of
the group?

