

Data Standardization Work Group (DSWG)

June 28, 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)
- Review of Recent DEST Consensus (JMC):
Disability, Identifiers
- DSWG Next Steps (JMC)
- Wrap-Up & Adjourn (Co-Chairs)

Welcome (Co-Chairs)



Co-Chair Announcement



Welcome to the new third DSWG Co-Chair:

Judie Hyun!



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.

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



- Upcoming Data Element-Specific Teams include:
 - **Medication/Treatment (Call #1): July 12th 1-2PM ET**
 - **Identifiers (Call #2): July 19th 1-2PM ET**
 - Upcoming: Laboratory, Reporting Source, Race/Ethnicity/Tribal Affiliation, Social Determinants of Health (SDOH)
- Individuals can opt-in to 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.

DSWG meetings may also serve as a forum for discussion of broader topics or questions.

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 & Key Updates



- Welcome to Meredith Eddy (new CSTE Senior Program Analyst)!
- CSTE Brief - In Development
 - *Data Harmonization*
- DSWG membership levels:
 - 264 in Oct. 2023, up to 559 June 2024 (pre-conference)
 - ~200 CDC, >300 PHAs, ~30 others
 - DESTs: 102 – 259 participants for each DEST
- Recap from the DSWG Discussion Session at the 2024 CSTE Annual Conference

Status Updates for Closed DESTs (JMC)



Status update for closed DESTs



- DSWG review complete and draft is with CSTE for next steps.
 - Hospitalization
 - Travel
 - Pregnancy
 - Industry and Occupation
 - Immunizations
 - Death
 - Sexual Orientation and Gender Identity
- DEST members are reviewing the following recommendations drafts through June 28 (**TODAY**).
 - Exposures, Risk Factors, and Underlying Conditions
 - Signs, Symptoms, and Clinical Manifestations
 - Disability
- A poll for Social Determinants of Health has been shared with participants in that DEST with a deadline of June 28 (**TODAY**).

DEST Summary (as of 6/28/2024)



Data Class	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	Completed	Completed	Completed
Industry and Occupation	Not applicable	Completed	Completed	Completed	Completed	Completed	Completed
Sexual Orientation and Gender Identity	Not applicable	Completed	Completed	Completed	Completed	Completed	Completed
Immunization History	Not applicable	Completed	Completed	Completed	Completed	Completed	Completed
Death	Not applicable	Completed	Completed	Completed	Completed	Completed	Completed
Exposures/Risk Factors/ Underlying Conditions	Not applicable	Completed	Completed	In Progress	Completed	Completed	Completed
Signs/Symptoms/ Clinical Manifestations	Not applicable	Completed	Completed	In Progress	Completed	Completed	Completed
Disability	Not applicable	Completed	Completed	In Progress	Completed	Completed	Completed
Identifiers	Not applicable	Call #2: 7/19/24	Completed	Completed	Completed	Completed	Completed
Medication/Treatment	Not applicable	Call #1: 7/12/24	Completed	Completed	Completed	Completed	Completed

* Document is with CSTE for final approval.

Legend	
Completed	In Progress
Not applicable	

Review of Recent DEST Consensus (JMC)



Disability



Disability: American Community Survey



Disability Type	Question	Reponses
Hearing	Are you deaf, or do you have serious difficulty hearing?	1. Yes 2. No
Vision	Are you blind, or do you have serious difficulty seeing, even when wearing glasses?	
Cognition	Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?	
Ambulatory	Do you have serious difficulty walking or climbing stairs?	
Self-care	Do you have difficulty dressing or bathing?	
Independent Living	Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a physician's office or shopping?	

Disability: Proposed Concepts

Disability Type: LOINC 95377-8

Description: Type of disability (vision, hearing, mobility, cognition, self-care, independent living, communication, or or intellectual or developmental).

Note: Must be able to capture No and Unknown values for all disability screenings.

Disability: Proposed Concepts (Page 1)



Disability Type: LOINC 95377-8

Description: Type of disability (vision, hearing, mobility, cognition, self-care, independent living, communication, or intellectual or developmental). Indicate all that apply.

Value Label	Value Description	Code
Impaired cognition (finding)	Cognitive (serious difficulties such as concentrating, remembering, or making decisions due to a physical, mental, or emotional condition)	386806002
Decreased hearing (finding)	Hearing (serious difficulty hearing or deafness)	103276001
Impaired mobility (finding)	Mobility (serious difficulty walking or climbing stairs)	82971005
Abnormal vision (finding)	Vision (serious difficulty seeing or blindness, even when wearing glasses)	7973008

Disability: Proposed Concepts (Page 2)



Disability Type: LOINC 95377-8

Description: Type of disability (vision, hearing, mobility, cognition, self-care, independent living, communication, or intellectual or developmental). Indicate all that apply.

Value Label	Value Description	Code
Difficulty performing personal care activity (finding)	Self-care (difficulty dressing or bathing)	284778005
Functionally dependent (finding)	Independent Living (difficulty doing errands alone)	718705001
Difficulty communicating (finding)	Communication (difficulty communicating, understanding others, or being understood, using your usual language)	288579009
Intellectual disability (disorder) synonym: Intellectual developmental disorder	Intellectual or developmental disability (any intellectual disability or developmental delay)	110359009

Disability: Proposed Concepts CSTE

Disability Type Indicator: Code TBD

Description: Indicator representing whether or not the person had the disability in the corresponding instance of the repeating group.

Value Set: Yes
No
Unknown

Identifiers



Current Standard Identifiers



Two of the current identifier data elements in the generic v2 message mapping guide (MMG):

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description	Data Type
Local Subject ID	N/A: PID-3	The local ID of the subject/entity	Text
Local Record ID	N/A: OBR-3	Sending system-assigned local ID of the case investigation with which the subject is associated.	Text

PID-3 identifies the person as a unique individual, and OBR-3 identifies the case as a unique case.

Updates to Standard Identifiers



The previous definitions were found to be unclear in the DEST- below are proposed updates to these definitions. (These clarify, not change, the intent of these fields.)

The HL7 message locations will not change.

Data Element (DE) Name	DE Identifier Sent in HL7 Message	Data Element Description
Local Subject ID	N/A: PID-3	The local ID of the subject/entity
Person ID	N/A: PID-3	The jurisdictional identifier that uniquely identifies the person.
Local Record ID	N/A: OBR-3	Sending system-assigned local ID of the case investigation with which the subject is associated.
Case ID	N/A: OBR-3	The jurisdictional identifier that uniquely identifies the case.

DSWG Next Steps (JMC)



Next Steps



- If you are in any of the following DESTs, a reminder for today's June 28 deadline (**TODAY**) for
 - Draft recommendations review
 - Exposures, Risk Factors, and Underlying Conditions
 - Signs, Symptoms, and Clinical Manifestations
 - Disability
 - Polling for Social Determinants of Health
- In July or August, DSWG members should look for an email with the drafts for recommendation documents and feedback forms for the following.
 - Exposures, Risk Factors, and Underlying Conditions
 - Signs, Symptoms, and Clinical Manifestations
 - Disability

Other Next Steps



Upcoming meetings

- Medication/Treatment: **July 12th 1-2PM ET**
- Identifiers: **July 19th 1-2PM ET**
 - Identifier Structure, Identifiers to link labs and cases
- Future data classes:
 - Laboratory
 - Reporting Source
 - Race/Ethnicity/Tribal Affiliation
 - Social Determinants of Health (SDOH)

The next broad DSWG call will be **August 30, 1-2 ET.**

Wrap-Up & Adjourn (Co-Chairs)



Wrap-Up



Anything else for the good of the group?

