

Data Standardization Work Group (DSWG)

December 13, 2024



Council of State and Territorial Epidemiologists

CSTE Data Standardization Workgroup Meeting



Please mute phone/ headset/ computer audio!

Agenda

- Welcome and Year in Review (Co-Chairs)
- Announcements and Key Updates (CSTE)
- Status Updates for Closed DESTs (JMC)
- Review of Recent DEST Consensus (JMC):
Industry and Occupation, Laboratory, Social Determinants of Health, Reporting Source
- DSWG Next Steps (JMC)
- Wrap-Up & Adjourn (Co-Chairs)

Welcome (Co-Chairs)



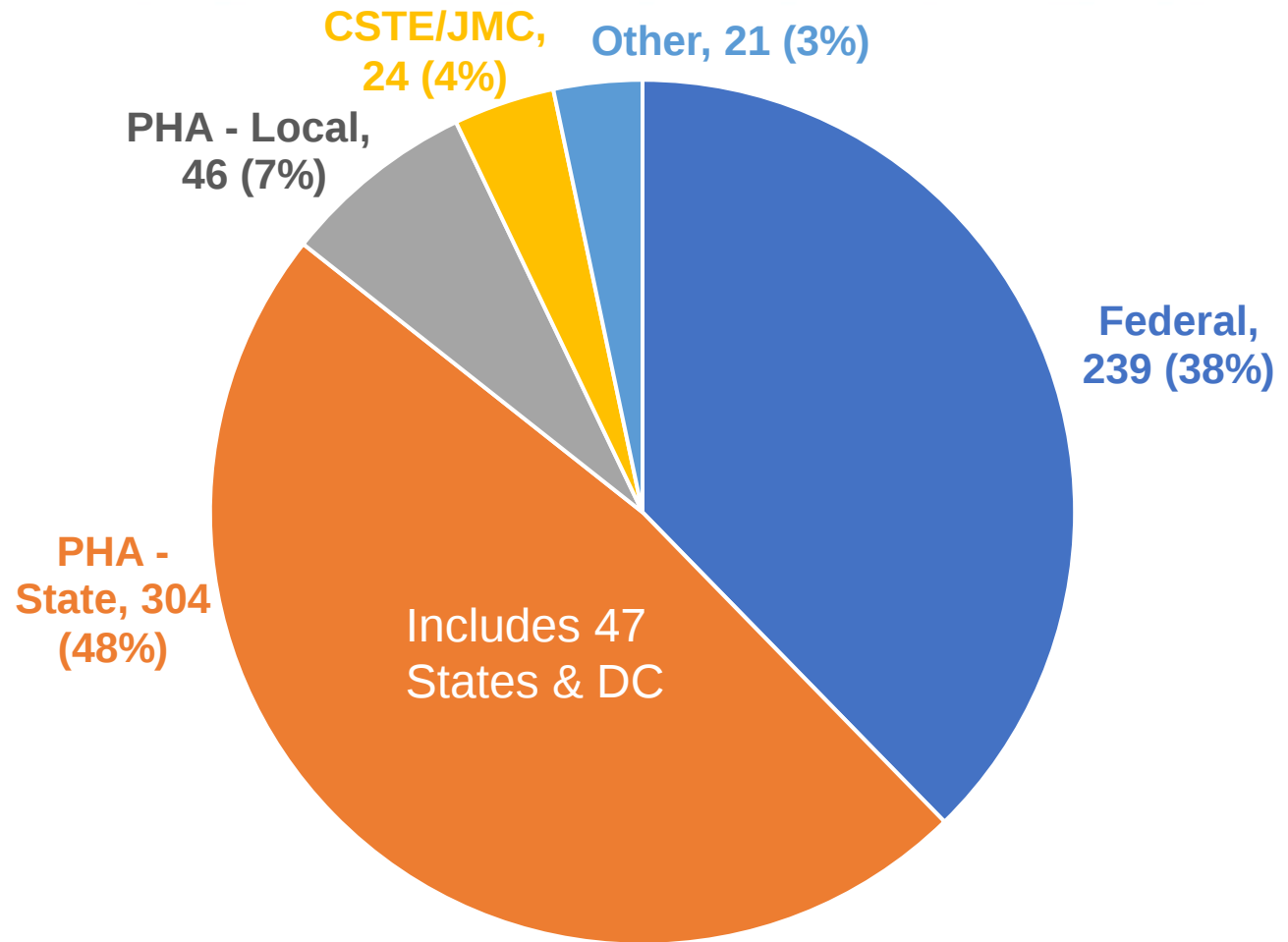
Year in Review: Participation Growth



December 2022:
120 members

December 2023:
400 members!

December 2024:
636 members!!



Year in Review: The Year of the DEST



14 data classes

83 – 326 participants/DEST



Year in Review: Effort and Results



26

DEST
Meetings

7

DSWG
Meetings

1

Conference
Roundtable

10

Recommendation Documents
Handed Off to CSTE

Announcements and Key Updates (CSTE)



Thanks to Co-Chairs

A graphic with the words 'Thank you!' written in a black, cursive script. The text is surrounded by several small, five-pointed gold stars. Below the text is a thick, gold, brush-stroke-like underline that curves to the right.

Thank you!

With gratitude, we thank
Molly Crockett for
her leadership, guidance,
tireless efforts, and
invaluable expertise
as Co-Chair.

Molly's contributions will
leave an enduring impact.

Announcements & Key Updates



- What's next:
 - Reduced/simplified meeting cadence!
 - Next meeting: January 31, 2025
- CSTE Brief - *Expected January 2025*
 - Standardizing Core Case Notification Public Health Data Elements to Improve National and Jurisdictional Surveillance and Situational Response
 - Appendix – Consensus Building Process

Status Updates for Closed DESTs (JMC)



Status update for closed DESTs



- DSWG review complete and drafts are with CSTE for next steps.
 - Hospitalization
 - Travel
 - Pregnancy
 - Immunizations
 - Death
 - Sexual Orientation and Gender Identity
 - Disability
 - Identifiers
 - Medication and Treatment
 - Exposures, Risks, and Underlying Conditions
- Draft recommendations being reviewed by DESTs
 - Reporting Source, through today (Dec 13)
 - Social Determinants of Health, through December 31
- Draft recommendations are in progress and will be shared with the DEST for review
 - Laboratory
- Working to reconcile comments on the following recommendations before handing over to CSTE for their next steps
 - Signs, Symptoms, and Clinical Manifestations
 - Industry and Occupation

Review of Recent DEST Consensus (JMC)



Industry and Occupation



Current Employment Status

Definition	Current self-reported economic relationship to work (e.g., having 1 or more jobs)
Standard Code for Transmission to CDC	LOINC: 67875-5 Employment status - current
Value set or coding system	Employed (Full-time or part-time) Unemployed (Not employed and seeking employment) Not in Labor Force (Not working and not seeking employment; e.g., retired, student) Unknown

Laboratory



Laboratory Repeating Group: Data Elements Discussed



- Test Performed
- Test Result
- Units of Measure
- Test Result Reference Range
- Performing Laboratory Type
- Specimen Type
- Specimen Source Site
- Specimen Collection Date/Time
- Date/Time of Lab Result
- Performing Laboratory Specimen ID
- Sequencing ID

Proposed Data Elements: Laboratory Repeating Group



Data Element	Definition	Value Set
Test Performed	Code for the lab test or analysis that was performed on the specimen.	LOINC (ORDER_OBS= "Observation" OR "Both")
Test Result	Qualitative or quantitative results for test performed. This can include various types of results such as numeric, coded, text, or other types relevant to the specific result.	SNOMED-CT (for coded results)
Units of Measure	Units of measure for the test result value, if applicable.	Unified Code for Units of Measure

Proposed Data Elements: Laboratory Repeating Group



Data Element	Definition	Value Set
Specimen Type	The type of specimen used in testing the resulted lab test.	2024 SNOMED Specimen hierarchy (with “Other, please specify”)
Specimen Source Site	This indicates the anatomical source of the specimen tested.	2024 SNOMED Body Structure hierarchy (with “Other, please specify”)
Specimen Collection Date/Time	Date (and time as available) a clinical specimen was collected from the patient for the laboratory testing relevant to the disease or condition being reported to a public health agency.	N/A
Date/Time of Lab Result	Date (and time as available) the latest result was released for reporting.	N/A

Social Determinants of Health



SDOH: Concepts Discussed



- Residence Type
 - Housing Status
 - Living Situation
- Primary/Preferred Language
- Educational Attainment
- Insurance Coverage Type
 - Healthcare Coverage Type?
- ~~Income~~
 - Not discussed as core, could be tackled in future for standardization by DSWG

Proposed Data Elements: SDOH



Data Element	Definition	Value Set
Housing Status	Housing status of a person at the first epidemiologically relevant date associated with the case (i.e., CCCD)	32911000 Homeless (finding) 414418009 Housed (finding) 261665006 Unknown (qualifier value)
Living Situation	Living situation of a person at the first epidemiologically relevant date associated with the case (i.e., CCCD)	Next Slide

Living Situation Value Set



- 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

Proposed Data Elements: SDOH



Data Element	Definition	Value Set
Preferred Language	The language a person is most comfortable using for communication	Minimum Value Set: NHSN Abridged Primary Language List Additional codes from ISO 639-3 as needed.
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)	• Less than 9th grade • 9th-12th grade, no diploma • High school graduate (includes equivalency - i.e., GED) • Some college/university, no degree • Technical/Vocational certification • Associate's degree • Bachelor's degree • Graduate or professional degree • Unknown

Proposed Data Elements: SDOH



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

Reporting Source



Reporting Source: Concepts Discussed



- Reporting Source in Gen v2:
 - Type of facility or provider associated with the source of information sent to public health
 - Most often (85%) reported as “Laboratory” “Other – hospital lab”, or “Unknown”
 - Primarily utilized by Division of STD Prevention where the definition is specified as “Setting or health care facility where a person first received diagnosis, treatment or testing for STD or associated syndrome reported in this case report”

Reporting Source: Concepts Discussed



- Reporting Source Type
 - Type of facility or entity reporting the initial case to public health
- Case Identification Source Type
 - Type of facility or entity where the person first received care (e.g., diagnosis, testing, or treatment) for the condition

Neither are recommended as core data elements.

Reporting Source: Concepts Discussed



- Current Reporting Source value set has 35 values
- Discussed a condensed value set with 13 values
- There was a slight preference for the condensed value set, as it is hard to identify from electronic data some of the more granular concepts (e.g. Prenatal/OB Facility and Primary Care and Family Planning Facility versus just “Outpatient”)
- If a condition specific MMG utilizes this type of data element, considerations should be made to balance the need for granular data with what’s attainable in ELR/eCR

Summary for DEST Progress



DEST Summary (as of 12/13/2024)



Data Class	WG Discussion	DEST	Draft Complete	DEST Feedback	Feedback Addressed	DSWG Feedback	Document Finalized*
Hospitalization							with CSTE
Travel							with CSTE
Pregnancy							with CSTE
Industry and Occupation							In progress
Sexual Orientation and Gender Identity							with CSTE
Immunization History							with CSTE
Death							with CSTE
Exposures/Risk Factors/ Underlying Conditions							with CSTE
Signs/Symptoms/ Clinical Manifestations							In progress
Disability							with CSTE
Identifiers							with CSTE
Medication/Treatment							with CSTE
Laboratory			In progress				
Reporting Source				In progress			
Social Determinants of Health				In progress			

* Document is with CSTE for final approval.

Legend	
	Completed
	In Progress
	Not applicable

DSWG Next Steps (JMC)



Next Steps



- These draft recommendations are in development and will be shared with DESTs for input as the next step
 - Laboratory
- Documents out for DEST Review
 - Reporting Source – deadline today (12/13)
 - Social Determinants of Health – through December 31

Other Next Steps



Upcoming meetings:

- January 31: Loose ends for Signs and Symptoms
 - Implementation of the Symptomatic Indicator (Indicator the person exhibited symptoms associated with the condition being reported)
 - Should this be tied to the list of signs and symptoms associated with the condition? If it is, is this indicator necessary? If not, should we define it better?

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?

