

Defining Core Data for Case Surveillance

Data Standardization Work Group (DSWG)



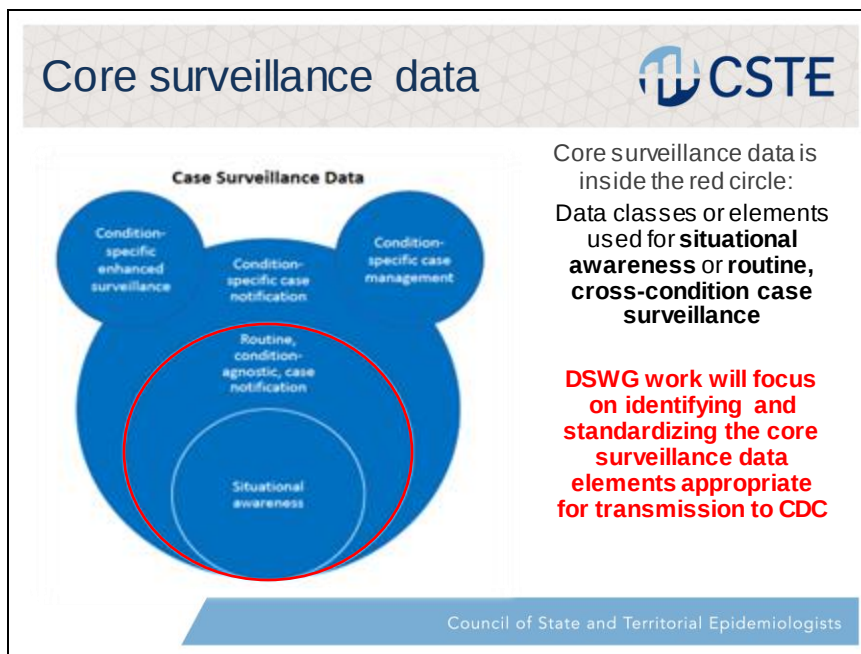
What are "core" data elements?



- **Data elements/data classes that are "core" to case surveillance are those that public health wants to collect and define similarly across many conditions and across jurisdictions.**
- Standardization of the structure, value set or definition of these elements should provide value
 - Facilitate receiving elements as part of interjurisdictional exchange
 - Improve efficiency of ingesting elements, regardless of sender
 - Utility across multiple conditions -- elements available for many conditions
 - Facilitate national case notification

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The CSTE Data Standardization Work Group is aiming to define data elements that are to be considered "core" to case surveillance. The group will decide what is "core" to case surveillance by discussing data elements that should be collected and defined by public health in a similar way across conditions. This will facilitate cross-jurisdiction data transfer and will help define future guidance for data elements included in case notification to CDC. The group discussion will work towards a goal of majority consensus on the definition of each core data element, the applicable value set(s) for the data element, and standardization of the structure.



The focus of the DSWG will be to identify and standardize data elements that are appropriate for transmission to CDC during case notification for case-based surveillance. These core data elements will apply during routine, condition-agnostic case surveillance, or for notification as a part of situational awareness during emergent or novel public health situations. It will not include data elements that are only relevant to a few conditions, or that have condition specific definitions or value sets.

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

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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 for cases or conditions if the information is not available, not a priority, or not useful for particular conditions.

Data elements and data classes should be considered for core if they are relevant for many conditions

- There is no set number that defines "many".
- Would you rather see the element in (for example) a GenV3 MMG? or in the applicable disease-specific MMGs?

It is important to note that defining a data element as a core data element for case surveillance does NOT mean this data element will be required in transmission of all cases. If the data element is present, the definition and interpretation will be consistent across cases and conditions. For cases or conditions where the data element is not relevant, is not collected, or is unknown then the data element may be sent as blank or unknown.

There is no set number that defines how many conditions a data element must be relevant for in order to be considered a core data element. A way to think about this is to think as future surveillance data exchange standards are developed, would this data element be appropriate in some potential future generic message mapping guide, or should it be present in condition-specific message mapping guides?

Core Data: Out of Scope for DSWG CSTE

- Standardization of data elements that the DSWG does *not* identify as part of routine, case-based data transmission to CDC.
- These may include:
 - Data elements that are critical to case-based surveillance across conditions and/or interjurisdictional data exchange, but that are not appropriate for transmission to CDC (e.g., personally identifying info)
 - Data elements relevant for only a small number of conditions
 - Data elements mainly for research purposes or special studies

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Core Data: Out of Scope for DSWG

- Condition-specific details and value sets (even for data elements identified as core data for transmission to CDC)
 - For example:
 - Condition-specific timeframes for core risk/exposure elements
 - Condition-specific value set for a common risk/exposure element, if relevant values vary by condition
- Data exchange mechanism or format for sending data to CDC
- Specific implementation plans/guidelines
- Related (but separate) efforts are out of scope for DSWG:
 - When to send case notifications
 - List of data elements to be sent to CDC in emergencies

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Some core data elements may need specific definitions or value sets that are condition-specific. These pieces of information will not be decided in these discussions by the DSWG. For instance, certain risk or exposure related data elements may need to reference a specific timeframe based on incubation, or be defined by a condition specific value set. These are out of scope of this DSWG work. However, the DSWG may define a template format for how a data element should be collected across conditions, even if the value set differs.

This work will also NOT define a data exchange mechanism or format for case notification to CDC, and will not define implementation plans/guidelines. Future work occurring in those realms will utilize this work done by the DSWG.

While the DSWG is defining core data elements that may be used to help determine data elements sent to CDC as a part of emergency response, this work is related to but separate from the creation of a comprehensive list. That work is being completed separate from the DSWG.

Similarly, this work does not define when to send case notifications to CDC.

Resources for standardization



- Background research presented to the DSWG for each data class will include existing formats, standards and potential data sources
 - USCDI
 - eCR (CDA & FHIR)
 - ELR
 - MMGs
- Experience and expertise of DSWG participants, including surveillance and informatics staff from STLTs and CDC, and representatives from STLT and CDC programs!

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At the start of work on each data class, background research will be presented that summarizes existing data elements, standards, and potential data sources. This can include what data elements are present in current generic or condition-specific MMGs, if and how the data elements are defined within USCDI, and if and how the data elements may be present in public health data sources (eCR and ELR). This background research is consolidated into potential core data elements with possible definitions, to facilitate discussion within the DSWG. The background and expertise of the DSWG participants will inform the final recommendations.

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 align with 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?

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Some considerations that can help guide the group toward a common definition of a core data element are included here.