SDP-V "Preferred" Governance Process

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Introduction

This documentation describes a proposed governance process for the designation of "preferred" content in the Surveillance Data Platform Vocabulary Service (SDP-V, or the SDP Vocabulary Service). The "preferred" designation is important to promote reuse of existing content in SDP-V to create efficiency in public health surveillance. This selection of "preferred" content is generally the outcome of a data harmonization effort that sought to simplify and streamline the choices of terminology to express a concept. It is expected that a clear and understandable process will ensure that the meaning of "preferred" is recognized and trusted by stakeholders.

The Surveillance Data Standards Management and Harmonization Steering Committee (SMaHSC) is proposed to be a CDC-wide governance body that promotes collaboration and coordination across CDC's surveillance data standards and data harmonization practitioners to help CDC achieve its vision for public health surveillance in the 21st century. The purpose of SMaHSC is to increase the visibility of public health surveillance data standards management and harmonization activities across CDC, promote best practices, identify challenges, and prioritize opportunities for surveillance data harmonization and standards adoption. The SMaHSC will serve as an authoritative body for cross-program surveillance standards management, implementation, and data harmonization by providing strategic oversight and advocating for initiatives that will impact standards use, adoption, effectiveness, and data harmonization practices that are mutually valuable across program areas. SMaHSC will serve as the decision-making jurisdiction that authorizes the use of "preferred" in the SDP Vocabulary Service. In doing so, SMaHSC will observe the basic tenets of good governance, which are participatory, consensus-oriented, accountable, transparent, responsive, effective and efficient, equitable, and inclusive.

Purpose

A methodical approach to marking content in the SDP Vocabulary Service as "preferred", such as the one described here, will ensure that the SMaHSC:

- Considers prospective changes to the SDP Vocabulary Service content from a technical and a business perspective.
- Consults all key stakeholders so that they have a voice in the final decision.
- Documents and publicizes decisions.

Scope

This high-level proposed process applies to the content of the SDP Vocabulary Service.

Audience

This process is meant to be used as a starting point by SMaHSC or its equivalent, when such a governance body is established.

Assumptions

This documentation is based on the following assumptions:

- Harmonization of CDC questions and response sets is an ongoing process. Harmonization can take place at the program level as well as in larger cross-agency work groups. The output of these harmonization efforts will need to be incorporated into CDC tools and workflows to be fully useful.
- Incorporating harmonization results into the SDP Vocabulary Service will help standardize terminology at the point where data collection instruments are developed.
- A governance body to oversee harmonization activities CDC-wide will be established.

Background

SMaHSC

SMaHSC, when established, will support CDC's mission to protect the public's health and will align to the Public Health Surveillance Strategy. The goals of SMaHSC are as follows:

- 1. Increase transparency and coordination of standards management and harmonization activities.
- 2. Identify and collaborate on resources needed for standards management and harmonization activities.
- 3. Promote public health surveillance data standards adoption.

To achieve its goals and objectives, SMaHSC will:

1. Identify and support priority areas for standards management and harmonization.

- 2. Establish a communication mechanism, which is understandable and accessible by both surveillance practitioners and public health informaticists, in order to improve comprehension of surveillance data standards management and harmonization activities.
- 3. Integrate CDC's strategic priorities on managing surveillance standards and harmonizing surveillance data by facilitating collaboration and coordination for surveillance practitioners and public health informaticists.
- 4. Promote shared resources and educational opportunities on standards.
- 5. Encourage data harmonization through vocabulary repositories, such as reviewing content in the SDP Vocabulary Service to promote reuse.
- 6. Initiate cross-program work groups to increase understanding and solve challenges regarding standards management and harmonization.
- 7. Report to the Surveillance Leadership Board (or alternative authorizing body) on progress and challenges and make recommendations on standards and harmonization priorities, as well as other steering committee activities.

SMaHSC membership will represent a broad range of CDC expertise, perspectives, and familiarity with public health surveillance data needs, initiatives, and priorities of external stakeholders including surveillance partners (e.g., State, Tribal, Local, and Territorial (STLT) partners, CSTE, APHL), standards development organizations (SDOs) (e.g., SNOMED, LOINC), and other government agencies (e.g., Office of Management and Budget, Office of the National Coordinator).

Voting membership will have knowledge, skills, and experience from at least one of the groups described below:

- Program subject matter experts and surveillance practitioners (e.g., epidemiologists, public health scientists) from across surveillance programs and domains (e.g., infectious disease surveillance, chronic disease surveillance, laboratory surveillance, emergency preparedness, vital statistics, etc.) to identify barriers to standards adoption and articulate:
 - How data standards are currently used in their area of practice
 - The impact of standards adoption
 - The usefulness of standards-related shared resources and tools available
 - · The need and proposed business value of SMaHSC activities
- Public Health data standards management practitioners across CDC (e.g., informaticists, vocabularists, terminologists) who are knowledgeable of vocabularies, data exchange specifications, SDO activities and repositories, and standards development processes. Members should represent diverse standards management perspectives from different domains, including infectious disease, non-infectious disease, laboratory data exchange, vital statistics, emergency preparedness, and research.

This proposed process supports #5 in the responsibilities listed above.

SDP Vocabulary Service

The SDP Vocabulary Service provides a repository of questions, response sets, and groupings of questions (called Sections and SDP-V Surveys) that allow public health professionals to more rapidly discover, reuse or create, and deploy data collection instruments. The SDP Vocabulary Service also provides transparency across published content from multiple programs and enables use of harmonized questions and response sets. The goal of the SDP Vocabulary Service is to facilitate discovery and reuse of existing vocabulary content, thereby reducing the number of different ways the Centers for Disease Control and Prevention (CDC) asks for the same type of information across programs and surveillance systems. This will help to reduce STLT partner reporting burden, as well as drive towards harmonization in data collection instruments.

Content that can be marked as "preferred" in the SDP Vocabulary Service includes questions, response sets, sections (groupings of questions) or SDP-V surveys (grouping of sections). "Preferred" content in the SDP Vocabulary Service is selected through an established process as the way CDC wants to collect data for a particular concept. Designating content as "preferred" helps to standardize surveys and other data collection efforts, which reduces the response burden of CDC partners and simplifies data collection, analysis, and reporting.

The SDP Vocabulary Service includes an attribute that can be toggled to identify any content in the service as "preferred"; search results are sorted by the "preferred" attribute so that such content is displayed at the top of a user's search results to promote use.

Data Harmonization Terminology in the SDP Vocabulary Service

The SDP-V service has the capability to designate content to assist with reuse and harmonization. The SDP-V users identified the need to designate content as "preferred", which is content that has been selected as CDC's first choice within SDP-V to express a concept. This data harmonization term can be implemented when the curator role for the SDP-V Service is staffed. The goal of using this label is greater data harmonization.

The detailed description and the goal of "Preferred" is in the table below.

SDP-V Label	Proposed definition	Goal
Preferred	Surveys, sections, questions, data elements, or response sets that have been formally approved by SMaHSC or another CDC authority as the chosen and vetted characterization of a concept within SDP-V	User can easily find and reuse with reduced review time

The label "Preferred" is presently available in SDP-V. The governance process presented here addresses the "preferred" label and can easily be used for additional harmonization terms that may be developed in the future in the SDP Vocabulary Service.

"Preferred" Content Governance Process

We describe a process created specifically for SMaHSC. Other processes might be better suited for other authorities.

There are at least four pathways by which SMaHSC might receive proposals to consider conferring "preferred" status on content in the SDP Vocabulary Service:

- 1. A recommendation from a harmonization work group to designate specific content as "preferred."
- 2. Curation of SDP Vocabulary Service content may reveal consensus as to "preferred" content usage across programs.
- 3. Programs may nominate content they favor to be "preferred" over other content with similar meaning.
- 4. Regulation or policy from external sources such as the Department of Health and Human Services may require specific content to be "preferred."

By whatever pathway a proposal reaches SMaHSC, the approach to evaluate the proposal will be the same. An overview of the input and outputs of the process is displayed below. A proposal to designate content as "preferred" in SDP-V is required as an input, which is then reviewed and evaluated by SMaHSC. The output of the process is the decision from SMaHSC.



Roles and Responsibilities

The following roles have been provisionally identified as part of this process. Other roles may be determined as the process is implemented and improved upon.

- SMaHSC Coordinator for "preferred" review: This person will review the standard form that proposes content as "preferred" and ensures that it is complete. This person may also poll stakeholders as to their thoughts on the proposal or may delegate the task. He or she will then forward the completed proposal with stakeholder comments to the SMaHSC membership for their action.
- SMaHSC Members: The members of SMaHSC will be identified as described in the charter for the governance body. The charter also describes the voting process.
- Stakeholders: Stakeholders are specific to each proposal as users of the SDP-V content under consideration. They will likely have already participated in the harmonization activity that resulted in the recommendation of "preferred."
- SDP-V Curator: This person is envisioned as an authoritative overseer of content in the SDP Vocabulary Service, identifying informal consensus on specific content as well as synonymous content. The curator will be responsible for tagging content as "preferred".

Standard Form for Proposing "Preferred" Content

Every proposal to designate content in the SDP Vocabulary Service as "preferred" will be submitted to SMaHSC on a standard form.

The standard form will explain why the content should be flagged "preferred." Supporting artifacts such as a harmonization work group report might be included. Artifacts should include the followina:

- · The business case for the designation of "preferred"
- · The problem it solves
- · The proposed SDP-V specification

The completed standard form will list all known key stakeholders who will be affected by the change. It is likely that the key stakeholders were part of the harmonization work group that made the recommendation to begin with. It may include programs, individuals, systems, or documents. Forms lacking a mandatory field will be returned to the proposer. An sample form for a SMaHSC "preferred" proposal is pictured below.



Proposal Review

The SMaHSC "preferred" coordinator will solicit each stakeholder's approval for adding the tag "preferred" to the identified SDP Vocabulary Service content and will document it along with stakeholder comments on the form as part of the proposal review process.

SMaHSC Evaluation

The proposal with stakeholder feedback will be distributed to the members of SMaHSC, who may invite other stakeholders to provide input on the request. The proposal will be added to the next meeting agenda for discussion and voting.

SMaHSC voting members will decide to approve or deny the proposed designation, voting in accordance with the SMaHSC charter. The charter states: "Decisions shall be reached by achieving a simple majority of voting members present at a meeting. In the event of a tie vote, the Co-Chairs will have the deciding vote, or may call for a revote after further discussion by the Committee." The decision will be documented on the form, which will become part of the committee's working files.

SMaHSC may choose to send the proposal back to the submitter and the stakeholders that disagree; SMaHSC may ask them to recommend options that all can agree on. SMaHSC will consider these options and decide if they can accept one of them.

In most cases, however, the stakeholders will have been part of the harmonization effort and are being asked to approve their own recommendation.

The decision will be documented and publicized, and SMaHSC will formally advise the SDP Vocabulary Service curator to mark the content as "preferred".

"Preferred" Content Implementation

Once SMaHSC decides content in SDP-V should be marked "preferred", then the designation must be implemented in the SDP Vocabulary Service. An overview of the inputs and outputs of the process is displayed below. A decision from SMaHSC to designate content as "preferred" in SDP-V is required as an input, which is then marked and promoted by the SDP-V administrator or curator. The output of the process is the designated "Preferred" content in SDP-V.



Roles and Responsibilities

The following roles have been provisionally identified as part of this implementation process. Other roles may be determined as the process is implemented and improved upon. See the SDP-V Users Manual for more information on each of these roles.

- SMaHSC: The proposed governance body is responsible for formally advising the SDP Vocabulary Service administrator or curator to mark the content as "preferred".
- SDP-V Curator: Person responsible for curating all content across SDP-V. Within the SDP-V Service, this person will have super user access, will be able to see all data, and will be formally recognized by SMaHSC to curate content and input recommendations from SMaHSC. The Curator role will be created in future releases of SDP-V. The SDP-V Administrator role currently exists and may temporarily assist with this work.
- SDP-V Publisher: Leverages the SDP-V process to harmonize surveillance questionnaires and surveys for a single CDC program. The Publisher is the first person appointed to a collaboration group and will be a liaison with SMaHSC and harmonization working groups. The Publisher sees all content, searches for Harmonization opportunities, and works with the Administrator or Curator to identify potential "preferred" content and to clean data.
- SDP-V Author: An actor (organization, person, or program) responsible for creating and/or maintaining a data collection item, a code set, a value set, or a data collection instrument.
- SDP-V Development Team: The technical team of system architects, code developers, database administrators, etc. who maintain the SDP Vocabulary Service service.

Implementation Workflow

The figure below displays the implementation workflow for "preferred" designation of content in SDP-V. It includes the general "preferred" governance process in the first two swim lanes as discussed in more detail in previous sections. This section focuses on the the next three swim lanes, which describe the the subsequent steps to implement and publicize the "preferred" designation in SDP-V.

The implementation process involves three user roles (designated with an asterisk in the figure) within the SDP Vocabulary Service: the administrator/curator, publishers, and authors. Once SMaHSC votes on and approves the "preferred" designation, the first step is for the curator to identify the content in the SDP Vocabulary Service. If the content has not been created, it is developed and added to the service. Once the content is in the service, it is marked "preferred" by the curator. The administrator or curator submits information on the newly tagged "preferred" content for the "What's New" tab in the SDP Vocabulary Service to the SDP-V development team, who includes it in the next update of the tool. Adding this information to the SDP Vocabulary Service will highlight the designation to users.

Additional harmonization opportunities are identified by the administrator or curator, who searches the SDP Vocabulary Service for content similar to the newly designated "preferred" content. If similar content is located, the administrator or curator notifies the program publishers of the harmonization opportunity. The program publishers promote the "preferred" content during the next tool revision cycle. They encourage authors to review the content for potential applicability to the data collection instruments currently under development. Authors assess the content and incorporate it into their data collection instruments where it fits. In some cases an older or different piece of content must be used in a data collection instrument. When that happens, the author provides a business justification to the publisher to explain the continued use of non-preferred content.

