



# Health Terminologies and Vocabularies Expert Roundtable

## Meeting Summary

Held July 17-18, 2018

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**Subcommittee on Standards**

**National Committee on Vital and Health Statistics**



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

This report was written by NCVHS consultant writer Jill W. Roberts, M.S., and colleagues at Rose Li and Associates, Inc., in collaboration with NCVHS members and staff.

### **NCVHS Members and Staff in Attendance**

William W. Stead, MD, **NCVHS Chair**

Alexandra Goss,\* Subcommittee Co-chair

Nicholas L. Coussoule,\* Subcommittee Co-chair

David A. Ross, ScD

Debra Strickland, MS\* (by phone)

Linda L. Kloss, MA, RHIA,\* **Meeting Chair and Terminology and Vocabulary Lead**

Llewellyn J. Cornelius, PhD, LCSW

Richard W. Landen, MPH, MBA\*

Robert L. Phillips, Jr., MD, MSPH

Vickie M. Mays, PhD, MSPH

\*Member of the Subcommittee on Standards

Vivian Auld, MLIS, **Co-lead Staff for Terminology and Vocabulary**

Senior Specialist for Health Data Standards

National Library of Medicine, NIH, HHS

Susan Roy, MS, MLS, **Co-lead Staff for Terminology and Vocabulary**

SNOMED CT Coordinator

National Library of Medicine, NIH, HHS

Rebecca Hines, MHS, **NCVHS Executive Secretary/DFO**

Health Scientist

National Center for Health Statistics, U.S. Centers for Disease Control & Prevention (CDC), HHS

Rashida Dorsey, PhD, MPH, **NCVHS Executive Staff Director**

Director, Division of Data Policy Senior Advisor on Minority Health and Health Disparities Office of Science and Data Policy Office of the Assistant Secretary for Planning and Evaluation, HHS

Suzie Burke-Bebbee, DNP, MSIS, MS, RN, ASPE, OS, HHS

Lorraine Tunis Doo, MPH, CMS, HHS

Debbie Jackson, MA, NCHS, HHS

Marietta Squire, NCHS, HHS

**See Appendix B and C for a complete list of meeting attendees.**

**The National Committee on Vital and Health Statistics** (NCVHS) serves as the advisory committee to the Secretary of Health and Human Services (HHS) on health data, statistics, privacy, national health information policy, and the Health Insurance Portability and Accountability Act (HIPAA) (42 U.S.C. 242k[k]). The Committee also serves as a forum for interaction with interested private-sector and industry groups on important health data issues. Its membership includes experts in health policy, health statistics, electronic data interchange (EDI) of health care information, electronic health records (EHRs), privacy, confidentiality, and security of electronic information, population-based public health, purchasing or financing health care services, health care delivery systems, integrated computerized health information systems, health services research, quality measurement, patient safety, consumer interests in health information, health data standards, epidemiology, and the provision of health services. Sixteen of the 18 members are appointed by the HHS Secretary to terms of 4 years each. Two additional members are selected by Congress. The NCVHS website provides additional information: [www.ncvhs.hhs.gov](http://www.ncvhs.hhs.gov)

Issued September 2018

## Introduction and Overview of the Meeting

The National Committee on Vital and Health Statistics (NCVHS) has two charges related to data standards, which are to (1) *study* the issues related to the adoption of uniform data standards for patient medical record information and the electronic exchange of such information and report to the Secretary of the Department of Health and Human Services (HHS) recommendations and legislative proposals for such standards and electronic exchange, and (2) *advise* HHS on health data collection needs and strategies, and *review and monitor* HHS's data and information systems to identify needs, opportunities, and problems. In partial fulfillment of these charges, the Subcommittee on Standards developed the Health Terminologies and Vocabularies initiative.

On July 17-18, 2018, the NCVHS Subcommittee on Standards hosted an expert roundtable on health terminologies and vocabularies in Washington, DC. The invited experts represented government, academia, health industry associations, health care providers, health insurance companies, health information management companies, health care quality organizations, and standards development organizations. See Appendix A for agenda, Appendix B for roster of attending experts, Appendix C for audience attendees, and Appendix D for a list of acronyms. The meeting slides are available on the NCVHS website at <https://ncvhs.hhs.gov/wp-content/uploads/2018/07/Presentation-Health-T-V-Expert-Roundtable-Kloss-and-Stead.pdf>.

During this two-day meeting, the experts reviewed progress, identified gaps, brainstormed solutions, and developed a roadmap to meet the goals of the Health Terminologies and Vocabularies initiative. NCVHS intends to integrate this work with that of its Predictability Roadmap initiative.<sup>1</sup> This report summarizes the discussions and identifies outputs from the 2-day meeting.

### Introductions and Opening Background

To begin the day, NCVHS Chair Bill Stead described the meeting objectives within the context of the overall charge of the Committee to advise the HHS Secretary on data standards and national health information policy. These objectives were to:

1. Reach shared understanding on the current state as described in the NCVHS Environmental Scan report.
2. Consider areas for near term improvement in maintenance, dissemination, and adoption of named code sets.
3. Discuss opportunities for improved governance and coordination across terminology and vocabulary developers and their stakeholders.
4. Identify top priority gaps in the US health terminology and vocabulary coverage.
5. Envision a roadmap for introducing improvements and updates to standards.

He reviewed the main areas where expert input to the Committee would be most useful including maintenance and dissemination, adoption and implementation, governance and coordination, and identification of key gaps in standards.

Dr. Stead then invited participants to introduce themselves, the role they play within their respective organizations, and a response to the question "What do you hope will be discussed by the close of the meeting?" Highlights of participants' responses are provided in Table 1.

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<sup>1</sup> NCVHS Predictability Roadmap project scope: <https://ncvhs.hhs.gov/wp-content/uploads/2018/09/NCVHS-Standards-Predictability-Roadmap-Scope.pdf>

To provide context, Ms. Kloss reviewed the previous work of NCVHS and the Subcommittee on Standards leading to the development of the Health Terminologies and Vocabularies initiative. In 2017, the Committee organized briefings on health terminologies and vocabularies to establish a baseline for the Committee's examination of the topic. With this background, the Subcommittee on Standards developed a scoping document<sup>2</sup> and partnered with the National Library of Medicine (NLM) for project support. The initiative involves conducting a contemporary survey of the health terminologies and vocabularies landscape, including development of an environment scan, with the overarching goal of advising the HHS Secretary regarding:

1. The changing environment and implications for timing and approach to health terminology and vocabulary standards adoption;
2. Needs, opportunities, and problems with development, dissemination, maintenance, and adoption of health terminology and vocabulary standards; and
3. Actions that HHS might take to improve development, dissemination, maintenance, and adoption of standards.

During the first half of 2018, in close collaboration with the National Library of Medicine, the Subcommittee conducted research and wrote the health terminologies and vocabularies Environmental Scan report,<sup>3</sup> which was shared with invited roundtable meeting participants for review and comment prior to the meeting. Based on the input received during this expert roundtable meeting and the final version of the Environmental Scan report, NCVHS will draft short term recommendations for the Secretary of HHS, frame intermediate and long-term opportunities, and incorporate relevant findings from the health terminologies and vocabularies initiative into its 13th Report to Congress.

### Roundtable Meeting Design

Ms. Kloss described the format of the meeting, which was centered on small-group breakout sessions for each health terminologies and vocabularies main topic: maintenance and dissemination, adoption and implementation, and governance and coordination. On the second day as a large group, the agenda included time for invited experts to discuss the topic of gaps in named standards.

She laid out the ground rules for discussion, encouraging participants both to feel at liberty to share ideas and to listen carefully given the wide range of perspectives of participants. The agenda was designed to include blocks of time for small group roundtable sessions to promote intensive dialogue and debate and ensure that all participants had the opportunity to fully participate. Invited experts were encouraged to reach consensus on key issues that may be actionable in the short term. In addition, they were also

**Table 1. Topics Identified by Invited Experts for Discussion at the Roundtable**

- Common understanding of where we want to arrive
- More streamlined update process
- Identify solid opportunity for improved interoperability
- Develop framework for integration and systematic update methods
- Opportunities to streamline standards and greater simplicity
- Don't lose sight of value of standard terminology → why they are worth the investment
- Steps to identify gaps
- Promote increased use and value of terminologies
- Modernization of ICD maintenance process
- Include voice of clinician
- Steer process to improve patient care
- Tighter integration of models
- Come away with tangible action items

<sup>2</sup> NCVHS Health Terminologies and Vocabularies project scope: [https://ncvhs.hhs.gov/wp-content/uploads/2018/09/NCVHS-Project-scoping-Terminologies-and-Vocabularies-6\\_5\\_2017.pdf](https://ncvhs.hhs.gov/wp-content/uploads/2018/09/NCVHS-Project-scoping-Terminologies-and-Vocabularies-6_5_2017.pdf)

<sup>3</sup> NCVHS Health Terminologies and Vocabularies Environmental Scan: <https://ncvhs.hhs.gov/report-health-terminologies-scan-2018>

encouraged to capture ideas for longer-term directions and to share any “ah ha” moments with the larger group during the report-out portion of each round of small group breakout work.

### **Role of Environmental Scan for Pre-meeting Input and Framing Discussion Issues**

To provide background and frame the discussion, NCVHS circulated a draft of the Environmental Scan report to invited experts more than a month prior to the meeting. Their collective feedback was incorporated, and the revised report was redistributed a week prior to the meeting. The lead authors of the report, Vivian Auld and Susan Roy, with the National Library of Medicine, presented slides to describe and summarize the content of the 100-page document and thanked the experts in the room for their input.

The aim of the report is to capture the current state of the field in the United States and to illuminate areas that would benefit from further discussion, consideration, and action. This comprehensive report captures the complexities of the health terminologies and vocabularies field from all viewpoints and summarizes the overarching themes that the Committee identified as opportunities for evaluation and building consensus on the direction forward.

The report authors invited and encouraged participants to review the updated and revised draft of the Environmental Scan and provide a final round of feedback after the meeting.

**Table 2. NCVHS Environmental Scan Report Outline**

#### **Introduction**

- Purpose and Scope
- Definitions
- Background
  - Health Insurance Portability and Accountability Act (HIPAA)
  - Unified Medical Language System (UMLS)
  - Terminology and Vocabulary Milestones
  - Key organizations

#### **Selection of Standards for Adoption**

- Evolving Levers for Standards Adoption

#### **Health Terminology Standards**

- Named Standards
- Additional Standards
- Gaps in Content
- Potential Solutions to Gaps in Coordination Efforts
  - Expanding a Current Standard
  - Naming an Additional Standard
  - Developing New Terminologies

#### **Governance and Coordination of Standards**

- Governance and coordination of individual vocabularies and terminologies
- Cross-standard governance and coordination
- Current governance and coordination strengths and weaknesses

#### **Maintenance and Dissemination of Standards**

- Overview of approaches and services
- Support for users
- Current maintenance and dissemination strengths and weaknesses

#### **Adoption of Standards**

- ICD-10-CM & ICD-10-PCS as an illustrative case study
- Lifecycle terminology and vocabulary standards management
- Current adoption strengths and weaknesses

#### **Summary of Themes for Evaluation & Improvement**

<https://ncvhs.hhs.gov/report-health-terminologies-scan-2018>

Ms. Kloss then moved to set up participants to begin working in small discussion groups and report back to the full group. A summary of the discussions follows below.

## **Maintenance and Dissemination of Standards**

Health terminologies and vocabularies standards require ongoing maintenance and updating as health care evolves. Dissemination of updated standards is best executed in a timely, efficient, and cost-effective manner. Invited experts identified issues, strengths, and weaknesses in the current processes to maintain, update, and disseminate standards. They suggested short-term opportunities to improve the state of the field and shared guiding principles for the process.

### **What Are the Issues?**

Invited experts identified the following issues related to maintenance and dissemination of health terminologies and vocabularies standards:

- A more predictable transparent process and schedule is needed for dissemination.
- Updates, changes, additions, and deletions often lack transparency.
- Health terminologies and vocabularies standards can be siloed and have proprietary user groups.
- Identification of a steady funding source would improve the stability of the process.
- Maintenance and dissemination would be improved through public/private collaboration. The federal government's role in maintaining and disseminating health terminologies and vocabularies standards is not well defined—in addition, federal activities lack an international scope.
- There is no free, end-user resource center, or one-stop clearinghouse for hosting resources, providing the rationale for using code systems in daily business, and describing successful business cases.
- The current processes for maintaining and disseminating health terminologies and vocabularies standards do not keep up with advances in clinical knowledge.
- One participant recommended that "curation" replace "maintenance" to more accurately describe the process.

### **Strengths and Weaknesses in Current Processes**

Invited experts listed the following strengths and weaknesses in current health terminologies and vocabularies standards maintenance and dissemination processes:

- The Unified Medical Language System (UMLS) is an example of a method for coordinated dissemination of a set of related standards.
- The American Medical Association's Current Procedural Terminology (CPT) code includes redlined changes in its updates.
- The Healthcare Common Procedure Coding System (HCPCS), which is based on CPT, has an effective public rulemaking and comment process.
- The International Classification of Diseases (ICD) does not redline its updates.
- ICD, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), and Systemized Nomenclature of Medicine – Clinical Terms (SNOMED CT) are not harmonized.
- Several health terminologies and vocabularies standards do not have backward compatibility with new versions.

### **Short-term Opportunities**

#### *Maintaining Standards*

Invited experts offered the following suggestions for improving the health terminologies and vocabularies standards maintenance process:

- Because predictability is a key component of maintenance, create a predictability roadmap with a defined cycle for updates.

- Identify a process for public health emergencies that cuts across all terminologies.
- Obtain frequency/utilization data from large vendors to determine which codes are most used. Build utilization data into the maintenance process.
- Develop a broad catalog with information about every code set, not only those included in the Environmental Scan report (e.g., include genetics and social determinants of health).
- Define the boundaries of each code set and provide clear information to the community about how to request changes to each code set. Prioritize the methods that need to be revised.
- Establish industry-wide principles for adoption by all organizations that:
  - Promote strong electronic quality control processes that add transparency, extend public comment periods for changes with significant potential impact, allow adequate input from stakeholders, and ensure interoperability over time.
  - Promote versioning practices that add backward compatibility for specific terms and include proper resourcing.
  - Promote cross-version capabilities for future versions and make changes in the native format (i.e., the same format that is being developed).
  - Promote the application of systematic evaluation criteria to determine the clinical value and return on investment. Update the concepts with the end-user in mind.
  - Promote computable, concept-based class systems with explicit computable definitions.

### *Disseminating Standards*

Invited experts offered the following suggestions for improving the health terminologies and vocabularies standards dissemination process:

- Engage health terminologies and vocabularies vendors in efforts to improve the dissemination process.
- Identify useful and consistent models to exemplify excellence to others (e.g., UMLS). Include examples from other countries (e.g., United Kingdom, Australia, or Canada).
- Promote or coordinate a seamless, consistent, and predictable process for disseminating updates (e.g., iPhone or iPad updates) that requires little effort or thought by the end-users and does not disrupt their workflows.
- Establish across-the-board technical means for updating terminologies, which might entail multiple approaches for different users.
- Help end-users understand the production cycle (e.g., a published schedule helps users anticipate resource allocation).
- Create cadenced, predictable, understandable, and accessible dissemination schedules that are based on input from stakeholders and align with the needs of the health care community. Prevent multiple releases from occurring in a single time frame, and do not force everyone to follow the same schedule.
- Coordinate the release of health terminologies and vocabularies standards by domain or across domains to show understanding of each area of health care. Allow the process to be directly informed by the needs of the community for each domain.
- Name a chief coordinator to coordinate code sets with release dates and formats. Name a chief educator for each system.
- Promote organizational software licensing rather than personal or individual software licensing.
- Change the name of the process from "maintenance" to "curation."

### **Guiding Principles for Maintaining and Disseminating Health Terminologies and Vocabularies Standards**

Invited experts identified several guiding principles for improving the maintenance and dissemination of health terminologies and vocabularies standards:



- Patient care must remain central to the process. Data collection should improve, and not interrupt, providers' ability to provide patient care. Health terminologies and vocabularies standards should balance clinicians' responsibility to care for patients with their needs to be paid.
- Health terminologies and vocabularies standards and code sets must stay current with changes in health care.
- Improving existing health terminologies and vocabularies standards is preferable to creating new standards.
- The most effective health terminologies and vocabularies systems are structured, have content development deadlines, minimize duplication, and are easy to integrate and use.
- Transparency, openness, and clarity are essential for updating health terminologies and vocabularies standards, especially for public domain code sets.
- The best approaches to maintenance and dissemination are pragmatic, high-quality, easy to use, and responsive to end-user needs.
- National governments should offer guidance and support for health terminologies and vocabularies vendors but should not be primarily responsible for health terminologies and vocabularies standards maintenance and dissemination.
- Public/private collaboration can be beneficial for maintaining and disseminating health terminologies and vocabularies standards. Private partners could assist with financing, (e.g., Google and Apple have shown interest in investing in the health care industry).

### **Adoption and Implementation of Standards**

In this process, regulators adopt named terminology and vocabulary standards and the industry implements them by incorporating them in operational systems and processes. Invited experts identified (1) issues, strengths, and weaknesses in these two processes; (2) short-term opportunities to improve the state of the field; and (3) guiding principles.

#### **What Are the Issues?**

Invited experts identified the following issues related to adopting and implementing health terminologies and vocabularies standards:

- The implementation of health terminologies and vocabularies standards is not mandatory, which results in concurrent use of overlapping standards and many versions of a given standard.
- It is unclear how many, and to what extent, organizations and individual end-users have implemented a standard.
- In general, larger organizations (e.g., commercial laboratories) are more successful than smaller ones (e.g., small hospitals) with implementing health terminologies and vocabularies standards because they have more resources to deploy.
- Organizations and end-users implement health terminologies and vocabularies standards using many different lenses.
- Not all organizations offer incentives (e.g., reimbursement) for implementing health terminologies and vocabularies standards.

#### **Strengths and Weaknesses in the Current Process**

Invited experts listed the following strengths and weaknesses in the current health terminologies and vocabularies standards adoption and implementation processes:

- The U.S. Core Data for Interoperability (USCDI) and the Interoperability Standards Advisory (ISA) are models for end-user participation in their rulemaking procedures.
- The Argonaut Project offers an example of a non-regulatory, private-sector approach to advancing adoption of interoperability standards.
- Apple has developed a private-sector approach to obtaining mobile health records on its devices.
- ICD's naming convention for its various versions of ICD-10 is confusing.

## Short-term Opportunities

### *Adopting Health Terminologies and Vocabularies Standards*

Invited experts offered the following suggestions for improving the health terminologies and vocabularies standards adoption process:

- Identify best practices for non-regulatory adoption. For example, a version update with a manageable scope should not require a regulatory change.
- Articulate the benefits of adopting new standards by using business cases and by clearly communicating the value proposition of adoption (e.g., using compliance, quality indicators, and benchmarking).
- Incentivize implementation of health terminologies and vocabularies standards.
- Make realistic assessments for the cost of adopting health terminologies and vocabularies standards.
- Pursue formal clinical leadership support for adoption.
- Use vendor-demonstrated systems of implementation.
- Make version changes incrementally using streamlined processes and automated distribution tools.
- Promote usability standards certification that is attractive to customers.
- Promote administrative simplification and better mapping of terminology.
- Lower the energy of activation. For example, integrate adoption of newly named standards into existing and relied-upon terminologies.

### *Implementing Health Terminologies and Vocabularies Standards*

Invited experts offered the following suggestions for improving the health terminologies and vocabularies standards implementation process:

- Emphasize the benefits of adopting and implementing health terminologies and vocabularies standards (e.g., simplified processes, improved patient care, and competitive advantage). Draw on outcomes-based examples from other countries.
- Engage health terminologies and vocabularies vendors in efforts to improve standards implementation.
- Provide examples of how standards are used effectively and make data accessible.
- Create nationally developed and vetted implementation standards.
- Simplify implementation into a seamless process that requires little end-user attention.
- Improve systems that provide decision support for implementing health terminologies and vocabularies standards.
- Create implementation and mapping tools.
- Develop a warranty-type approach in which end-users know they are using the most current version of a coding system.
- Obtain leadership commitment and support for implementation. Identify and engage clinical champions who recognize the value of data for making decisions.
- Be cognizant of the burden on clinicians, especially regarding documentation.
- Identify mechanisms for maintaining funding and staffing levels to preserve newly implemented health terminologies and vocabularies standards.
- Learn from other industries that implement standards (e.g., software engineering, patient safety).

## **Guiding Principles for Adopting and Implementing Health Terminologies and Vocabularies Standards**

Invited experts identified several guiding principles for improving the adoption and implementation of health terminologies and vocabularies standards:

- Adoption must keep pace with advances in health care.

- Adoption and implementation require engaging all stakeholders, clearly stating all expected outcomes, and achieving collective understanding and appreciation of the processes.
- Organizations and end-users must be ready to implement new health terminologies and vocabularies standards.
- To improve implementation, health terminologies and vocabularies standards must have explicit boundaries around a stated purpose and detailed explanations of their uses and usability.
- The value of the health terminologies and vocabularies standard and any incentive for its implementation should align with the implementing organization's values.
- Terminology must be of high quality and reduce redundancy.
- Adoption and implementation require transparency and clarity around the costs of implementing new versions and changing a few codes. They also require determination of the cost/benefit ratio.
- Adoption and implementation require shared accountability between regulators, vendors and end user organizations.
- Standards should evolve without overregulation, and regulations should be fit for purpose and as simple as possible to fulfil their purpose.
- Implementing new health terminologies and vocabularies standards in thirds (1/3, 1/3, 1/3) makes large projects manageable.

### **Learning from Other National Models**

In her presentation to the group, Kathleen Morris, Vice President of Research and Analysis at the Canadian Institute for Health Information (CIHI) described the Canadian government's roles in health care and CIHI's model for providing financial support to provinces in exchange for public reporting. CIHI is an independent, nonprofit organization that provides information about Canada's health systems and public health. To support its work, CIHI maintains standards for information, data exchange, privacy, and security. CIHI is funded by all levels of government (i.e., federal, provincial, local). In return, funding agencies receive CIHI data. Although provinces are not required to submit data to CIHI, they voluntarily participate in return for information on benchmarking, standards, capacity building, and value-added projects.

Canada implemented ICD-10 for morbidity over a 5-year period from 2001 to 2006. Implementation was completed on a staggered schedule one hospital at a time in each province with extensive in-person training, including for basic computer skills. A federally funded nonprofit program called Canada Health Infoway was established in 2001 to accelerate progress on the interoperability of electronic health records. It is now developing products like Prescribe-II—an electronic prescription service—and an online patient portal.

CIHI has experience working with many health terminologies and vocabularies standards and interoperability mapping groups, including SNOMED CT, WHO, and the North American Collaborating Center, which has begun work on the adoption of ICD-11. CIHI is continuing to modernize data supply, access, utility, and harmonization; improve public reporting and accountability; and collaborate with non-healthcare industries that are also interested in data (e.g., economic, genomic).

### **Governance and Coordination**

The public or private governance and coordination of each named terminology standard or vocabulary can originate at an international, national, regional, local, or organizational level. Invited experts identified issues within and key characteristics of effective governance and coordination of health terminologies and vocabularies standards. They then suggested short-term opportunities for improving the state of the field in these areas.

#### **What Are the Issues?**

Invited experts identified the following issues related to the governance and coordination of health terminologies and vocabularies standards:

- There is no current ecosystem or strategic plan for governance and coordination.
- Governance and coordination are expensive processes that require significant resources, expertise, and training.
- Previous unsuccessful efforts for governance and coordination warrant careful review before moving forward with new efforts.
- Some stakeholders advocate for less governance.
- Several health terminologies and vocabularies standards do not work well together. Terminologies with purposeful overlap in scope should be coordinated and synergistic.
- Organizations that support overlapping terminologies and do not collaborate are not required to explain the differences and the rationale for remaining distinct (e.g., SNOMED CT and Logical Observation Identifiers Names and Codes [LOINC], or CPT and ICD-10).

### **Key Characteristics for Effective Governance and Coordination**

Invited experts identified numerous examples of characteristics of effective health terminologies and vocabularies standards governance and coordination processes.

Ideal governance and coordination:

- Are transparent, open, and based on evidence not advocacy.
- Include both national and international considerations.
- Incorporate open standards with participation and contribution from all stakeholders, including end-users. Participation provides value and meaning to stakeholders.
- Are centered on transparency, traceability of past decisions, interoperability, and inclusivity for all major stakeholders, including industry partners, innovators, and consumers. Interoperability matches the use case.
- Use established concepts from existing standards (e.g., UMLS). New standards should not be developed based on institution-specific terminology.
- Require interoperability on a global standard that matches use cases with input from vendors, consumers, and innovators.
- Include the commitment of resources for a maintenance process.
- Requires a balanced, open, and clear process for curation.
- Depends on the willingness of end-users to be governed. Usage governance is more challenging than standards governance, and building goodwill can assist in determining the value of developing a governance model.
- Includes models based on health care delivery needs rather than regulatory or lobbying needs. Useful models include logic for electronic deployment. The best models align businesses within the private sector and public interests within the public sector and then find a balance between the two perspectives.
- Play a key role as catalysts in the field and use expertise to train the next generation of health terminologies and vocabularies standards professionals.

### **Short-term Opportunities in Governance and Coordination**

Invited experts offered the following suggestions for improving the health terminologies and vocabularies standards governance and coordination process.

- Focus on the areas with the highest need for coordination.
- Create a willingness to be governed, with different levels of agreement and standards for decision-making (e.g., majority and super majority).
- Acknowledge barriers that have prevented progress. Learn from, rather than replicate, past efforts.
- Incentivize broader participation with money and an open process.

- Study efforts by other countries that use application programming interfaces to coordinate standards (e.g., Canada and Australia).
- Promote and incentivize international stakeholder collaboration and communication centered on flexibility and openness, e.g., SNOMED CT's mental disorders work could follow the American Dental Association's process for the Systematized Nomenclature of Dentistry (SNODENT).
- Promote consistent funding via nonpolitical or public/private processes. For example, the U.S. Food and Drug Administration (FDA) recently formed a partnership with the National Quality Forum; and the Health Standards Collaborative (HSC) is an executive forum for collaboration and idea sharing.
- Learn from the experiences of terminology organizations with successful collaborations.
- Tackle the issue of duplication in coding sets. Establish boundaries and domains and agree on a standard frequency of updates to create predictability. Promote the idea of allowing domain expertise to control content over time. The coordination between the Radiological Society of North America (RSNA) and radiology lexicon (RadLex)<sup>4</sup> is a model of a joint effort to unify terminology products in an overlapping space with shared maintenance.
- Promote interoperable systems with agile host organizations that can respond to the needs of the public and private sectors.
- Assist in improving the process for adding new terms to health terminologies and vocabularies standards. Terminologies that use public input (e.g., ICD) should provide access to the comments and explanations for the decisions that are made.
- Expand and electronically publish the health terminologies and vocabularies standards inventory that was started in the Environmental Scan report. Identify gaps and prioritize areas of coordination.
- Develop models or case studies with authority, transparency, resources, maintenance, and accountability to the vision. Define who pays for what and who benefits. Use CPT as a model.
- Require domains that overlap to explain their differences or provide valid crosswalks where appropriate.

### **Gaps in Health Terminology and Vocabulary Standards**

Susan Roy introduced this topic by presenting the perceived content gaps in current named health terminologies and vocabularies standards. She clarified that the draft Environmental Scan report does not provide an exhaustive compendium of gaps, rather the aim was to bring to light some of the current known gaps and the key emerging areas in health care that need better representation in terminology standards.

Ms. Roy presented the eight significant content gaps outlined in the draft Environmental Scan and invited the group to provide feedback on the current process for addressing gaps as well as critique and identify omissions, use cases, or relevant ongoing work. The perceived gaps outlined in the draft Environmental Scan report included vital statistics/demographics, gender/sexuality, genetics/genomics, medical devices, mental health, public health, rare diseases, and social and behavioral determinants of health. As a full group, participants identified the following significant concerns:

- It was noted that standards related to disability and substance abuse were not included in the draft Environmental Scan—after the meeting the report was updated to include these in the gaps section as well as more detail regarding functional status and mental health.
- It was noted that Canada uses InterRAI to address functional and cognitive gaps in health terminologies and vocabularies standards.<sup>5</sup>
- Because standards in some areas of health care (e.g., laboratory data) do not include numeric results that can be used for comparative analyses, even standards that are not considered gap areas still

<sup>4</sup> See <http://www.rsna.org/RadLex.aspx>.

<sup>5</sup> See <http://www.interrai.org/>.

require improvement and expansion. For example, the National Library of Medicine's RxNorm does not include non-prescription or illicit drugs. A terminology of illicit substances is needed especially given the opioid crisis.

- SNOMED International has formed a workgroup focused on medical devices and will be meeting this fall to create an approach to develop a new concept model.
- Nontraditional and key emerging areas of health care currently lack representation within health terminologies and vocabularies standards.
- Fast Healthcare Interoperability Resources (FHIR) is a system for connecting and integrating data from older health care systems to a wide variety of modern computers and devices.
- An FDA-sponsored Unique Device Identification (UDI) learning community is tackling issues related to describing a device, including those that relate to health terminologies and vocabularies standards.<sup>6</sup>
- A communication gap between clinical medicine and basic scientific research affects the development of health terminologies and vocabularies standards (e.g., genetics and genomics research).

### Short-term Opportunities

Ms. Roy described the process that occurs when a gap is identified. Three potential solutions are: expansion of a standard, the naming of an additional standard, or creation of a new terminology. Invited experts offered the following suggestions for improving the gaps in health terminologies and vocabularies standards:

- Activate and align communities of practice to create better connections between existing standards.
- Promote the incorporation of interoperability standards into the health terminologies and vocabularies field using the USCDI standards as an example.<sup>7</sup>
- Document structural changes in how health care practices capture information as they mature. This type of change requires expansion of the standards to add the new content.
- Recommend health terminologies and vocabularies expansion for behavioral health areas (e.g., well-being and aging) and for data that are used in mobile health applications (apps).
- Create an inventory of health terminologies and vocabularies standards that are used in the rapidly growing field of mobile apps that collect and communicate health information.

### Guiding Principles

Invited experts identified two guiding principles for addressing gaps in health terminologies and vocabularies standards:

- Achieve consensus for integrating current standards rather than creating new health terminologies and vocabularies standards.
- Ensure that data exchange is an important component of any future development in health terminologies and vocabularies standards.

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<sup>6</sup> See Unique Device Identification – UDI at <https://www.fda.gov/medicaldevices/deviceregulationandguidance/uniquedeviceidentification/>.

<sup>7</sup> Healthcare Informatics. HIT Advisory Committee Advances Recommendations on Core Data for Interoperability. See <https://www.healthcare-informatics.com/news-item/interoperability/hit-advisory-committee-advances-recommendations-core-data-sets>

### **ICD-11 Adoption and Implementation Issues**

Donna Pickett and Bob Anderson gave a 45-minute update on plans for the adoption and implementation of ICD-11 over the next several years. They identified several issues that the World Health Organization (WHO) is addressing as a part of this process, including the following:

- The five-step adoption process for ICD-11 began in 2007 and has involved 95 countries whose international working groups provided input, comments, and technical consultation. The June 2018 release of ICD-11 will continue through the implementation process until it officially goes into effect on January 1, 2022.
- The WHO Family of International Classification (FIC) network governs ICD-11 and will provide maintenance and updates, development of new tools (e.g., mobile coding), ongoing crosswalks with other standards (i.e., SNOMED CT), country support, workshops, and tooling integration during implementation.
- The ICD-11 implementation package includes advocacy materials, training materials, a quick guide, maps from and to ICD-10 (i.e., transition tables), and a training/testing platform.
- There is still a need for both electronic and print versions of ICD-11 due to worldwide differences in technology use and availability.
- Implementation of the mortality component in the United States will take a minimum of 5 years (i.e., 2023) and involves:
  - Revision of automated coding systems and decision tables
  - Retraining of nosologists and medical coders
  - Revision of computer edits and database specifications to accommodate new format
  - Revision of tabulation lists and table programming
  - Comparability study (bridge coding)
  - Development of educational and promotional materials
- For the morbidity component of ICD-11 in the United States, WHO's implementation considerations and challenges are centered on licensing, limiting national modifications, and revising existing HIPAA standards.

NCVHS committee members identified the following short-term opportunities for the adoption of ICD-11:

- Review the process that NCVHS used to hold hearings (i.e., previous lessons learned/guiding principles), review those outputs, and make recommendations on ICD-10. Include antagonists and protagonists in this process.
- Scope a project to evaluate the fitness of ICD-11 Mortality and Morbidity Statistics for U.S. adoption for mortality and morbidity, evaluate the purpose and return on investment of the potential U.S. modifications, and evaluate the International Classification of Health Interventions (ICHI) for interventions.
- Capture the principle of computational engineered relationships between reference terminologies and incorporate them, as appropriate, into the path to convergence and into the long-term opportunities.

### **The Path Forward**

While NCVHS continues to develop recommendations around health terminologies and vocabularies standards, it will be considering the opportunities identified by the experts and will use the key principles to guide future actions. The Standards Subcommittee plans to focus on the following four areas:

- A predictability roadmap for health terminologies and vocabularies standards
- Issues surrounding the adoption of ICD-11
- The short-term priorities identified by the experts; and
- The longer-term opportunities that emerged during the meeting.

The meeting concluded with a discussion of each of these areas, which is summarized below.

### **Summary of Key Principles Guiding Future Actions**

NCVHS has identified a need to bridge the current divide between the HIPAA named standards and the health terminologies and vocabularies standards that fall under USCDI. This divide affects how standards are operationalized, how they are used clinically, and how they affect patient care. The Subcommittee outlined the following steps to establish a deliberate pathway toward convergence:

- Bridge the clinical domain with administrative and research domains to align standards.
- Distinguish between purposeful overlap and redundant effort.
- Balance the limited optionality of named standards with flexibility in versioning (parsimony of named standards). Establish a common floor (the oldest version allowed) that is regularly used and that meets business needs. Remove choices between two standards that achieve the same thing. Promote extension instead of versioning.
- Research and evaluate HV/T models for biomedical and health concepts and machine learning.
- Add behavioral or social determinants of health under the broad definition of health. Add substance abuse to mental health.
- Clarify “community of practice” as the correct subject matter experts. SNOMED CT also uses this term for its users.
- Consider including the intellectual disability community when describing terminology that affects their lives (as a part of community engagement).

### **Implication of the Predictability Roadmap for Health Terminologies and Vocabularies Standards**

Alix Goss and Nick Coussoule, co-chairs of NCVHS’ Subcommittee on Standards, presented slides to describe the committee’s history and accomplishments in developing a “Predictability Roadmap” for standards and operating rules for administrative health care transactions. The presentation, which was specific to health care transactions, provided the pre-2012 through 2018 timeline and noted that one version upgrade every 20 years is not keeping pace with the health care industry.

To begin the Predictability Roadmap project, the Subcommittee on Standards engaged several partners (e.g., standards development organizations (SDOs), industry stakeholders, federal regulators, and an operating rules authoring entity (ORAE)) to begin to formally outline how standards and operating rules for transactions are developed, adopted, and implemented. The Subcommittee then held a visioning workshop with SDOs, federal partners, and interested stakeholders to identify specific opportunities for action, which led to the identification of five preliminary themes for the roadmap. After that, the Subcommittee interviewed HHS regulatory authorities to understand the opportunities and limits of the regulatory process. It then held a Chief Information Officer (CIO) Forum to understand end-user perspectives.

Moving forward, the Subcommittee on Standards plans to study the convergence of terminology and vocabulary standards with transaction standards. It will consider the topics of data classes, data exchange, data harmonization, and how to keep pace with both business and health care needs (e.g., how providers document transactions for value-based care). Further topics include the rapid expansion and incorporation of mobile health apps into electronic health records, which is creating concerns for cybersecurity and patient privacy.

### **Short-term Priorities**

From those identified in each area discussed during the expert roundtable, the Subcommittee listed the following items as the priority opportunities for improving the field of health terminologies and vocabularies standards:

- Principles to guide adoption include:



- Explicit boundaries, defined purpose, and use specifications
- Uses, usability, currency, and cost/benefit
- An adoption process that is suitable for health terminologies and vocabularies
- Principles to guide updates include:
  - Curation with backward compatibility and transparency for additions, changes, and deletions
  - A published cadence, (i.e., a regular and reliable cycle schedule), that reflects explicit cost/benefit and eliminates version updates from the regulatory process, starting with ICD
  - Dissemination that is electronic and includes implementation and mapping tools while minimizing cost and licensing barriers

### **Longer-term Opportunities**

During the discussion, Subcommittee members identified the following items as possible longer-term opportunities for improving the field of health terminologies and vocabularies standards:

- Create a single dissemination resource center
- Use clinically useful terminologies in electronic health records (e.g., SNOMED CT, RxNorm, LOINC++)
  - Decouple intervention/procedure codes from facility type
  - Calculate payment classes from clinical content
  - Calculate quality measures from clinical content
- Expand scope of named health terminologies and vocabularies standards to include:
  - Vital statistics and public health
  - Population health and social and behavioral determinants of health
  - Mental health and addiction disorders

### **Conclusion**

The NCVHS Expert Roundtable on Health Terminologies and Vocabularies achieved its stated goals and gained traction on others. Participants began to reach a shared understanding of the current state of the health terminologies and vocabularies field by carefully reviewing and suggesting edits to the newly released Environmental Scan report, and then having the opportunity to discuss the complexities of the current state and what is needed to make improvements going forward. Participants identified important priority areas for short-term improvement in the maintenance, dissemination, and adoption of named code sets. It discussed ideas and opportunities for improving governance and coordination across and between health terminologies and vocabularies developers and their stakeholders. Meeting attendees considered how redundancy and overlap in content might be handled and how content gaps identified in the Environmental Scan report might be best addressed. After listening to ideas on standards implementation in Canada, learning about plans for the ICD-11 release, discussing its implementation in the United States, and hearing an update on the Predictability Roadmap project, experts began to outline elements of a roadmap for introducing improvements and updates to standards.

### **Appendices**

- A. Expert Roundtable Meeting on Health Terminologies and Vocabularies Agenda
- B. Invited Experts
- C. Audience Attendees
- D. List of Acronyms



## Appendix A

### Agenda

National Committee on Vital and Health Statistics (NCVHS)

In conjunction with the National Library of Medicine

### Expert Roundtable Meeting on Health Terminologies and Vocabularies

July 17-18, 2018

HHS Headquarters, Hubert Humphrey Building  
200 Independence Avenue, SW, Room 705-A  
Washington, DC 20201

#### Meeting Objectives:

- Reach shared understanding on the current state as described in the Environmental Scan report, including the assessment of strengths, weaknesses, and gaps in the US health terminology and vocabulary (T/V) environment.
- Consider areas for near term improvement in the development, maintenance, dissemination, and adoption of named code sets.
- Discuss opportunities for improved governance, coordination, and communication across terminology and vocabulary developers and their stakeholders.
- Identify top priority gaps in the US health terminology and vocabulary coverage.
- Envision a roadmap for introducing improvements over the next decade.

#### Tuesday July 17

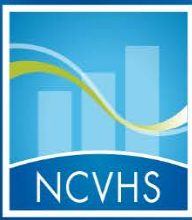
9:00—9:30 am	Welcome and Meeting Goals Introductions	William Stead, MD NCVHS Chair
9:30—9:45 am	NCVHS Health Terminologies and Vocabularies Project and Roundtable Design	Linda Kloss, MA NCVHS Committee
9:45—10:10 am	Highlights of Environmental Scan report	Susan Roy, MS, MLS SNOMED CT Coordinator and Vivian Auld, MLIS Senior Specialist for Health Data Standards
10:10—11:00 am	<b>Discussion Topic 1:</b> Maintenance and dissemination of Health T/V: Opportunities and principles	National Library of Medicine (NLM) National Institutes of Health (NIH) Roundtable Discussions
11:00—11:15 am	Break	

11:15—11:45 am	Discussion 1 Report Out	
11:45—12:30 pm	<b>Discussion Topic 2:</b> Adoption new or updated health T/V versions: Opportunities and principles	Roundtable Discussions
12:30—1:30 pm	Lunch Break	
1:30—2:00 pm	Discussion 2 Report Out	
2:00—2:45 pm	Learning from other National Health T/V Models	Kathleen Morris Vice President, Research and Analysis Canadian Institute for Health Information (CIHI)
2:45—3:00 pm	Break	
3:00—4:00 pm	<b>Discussion Topic 3:</b> Governance and coordination across named code set developers	Roundtable Discussions
4:00—4:30 pm	Discussion 3 Report Out	
4:30—4:45 pm	Recap of insights from the day & discussion	Bill Stead, Linda Kloss
4:45—5:00 pm	Public Comment	Rebecca Hines, MHS NCVHS Executive Secretary
5:00 pm	Adjourn	William Stead, MD NCVHS Chair

### Wednesday July 18

8:30—8:45 am	Review Morning Work Plan	William Stead, MD NCVHS Chair
8:45—9:30 am	Discuss gaps in named standards	Susan Roy and Vivian Auld, NIH/NLM
9:30—10:30 am	Review Status of ICD-11	Donna Pickett, RHIA, MPH Chief, Classifications & Public Health Data Standards
		Bob Anderson, PhD Chief, Mortality Statistics Branch National Center for Health Statistics/CDC
10:30—10:45 am	Break	
10:45—11:30 am	Road-mapping Standards including Health T/V	Alix Goss and Nick Coussoule Co-chairs Standards Subcommittee
11:30—11:45 am	Next Steps in NCVHS Health T/V Project	Linda Kloss

11:45—11:55 am	Public Comment	Rebecca Hines NCVHS Executive Secretary
11:55—12:00 pm	Adjourn Roundtable	William Stead, MD
1:00—2:50 pm	NCVHS Standards Subcommittee Working Session <ul style="list-style-type: none"><li>• Review Roundtable findings</li><li>• Refine Health T/V Scoping Document and work plan based on findings</li><li>• Determine how best to brief and engage the full Committee at its September meeting</li></ul>	NCVHS Standards Subcommittee
2:50—3:00 pm	Public Comment	Rebecca Hines NCVHS Executive Secretary
3:00 pm	Adjourn	William Stead, MD



## Appendix B

### NCVHS Subcommittee on Standards Health Terminologies & Vocabularies Expert Roundtable Invited Participant List

*July 17-18, 2018*

**Robert N. Anderson, PhD**

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## Appendix C

### Expert Roundtable on Health Terminologies and Vocabularies Audience and WebEx Attendees

Joyce Backus, NLM

Kate Brett, CDC, NCHS

Laurie Burckhardt, WPS Health Insurance

Susan Dardine, Genesis HealthCare

Michael DeCarlo, Blue Cross Blue Shield

Jorge Ferrer, U.S. Department of Veteran's Affairs (VA)

Helina Gebremariam, Council for Affordable Quality Healthcare, Inc.

Freida Hall, Quest Diagnostics

Holly Hedegaard, CDC, NCHS

Sarita Keni, VA

Susan Langford, Blue Cross Blue Shield

Peter Olsen-Phillips, U.S. News & World Report

Teresa Rivera, UHIN Standards Development Organization

Dan Rode, Dan Rode & Associates

Stephanie G. Smith, American Psychiatric Association

Nancy W. Spector, AMA

Margaret Weiker, National Council for Prescription Drug Programs



## Appendix D

### Expert Roundtable on Health Terminologies and Vocabularies List of Acronyms

Acronym	Acronym Definition
AHA	American Hospital Association
AHIMA	American Health Information Management Association
AMA	American Medical Association
CDC	U.S. Centers for Disease Control & Prevention
CIHI	Canadian Institute for Health Information
CPT	Current Procedural Terminology
DSM	Diagnostic and Statistical Manual of Mental Disorders
FDA	U.S. Food and Drug Administration
FHIR	Fast Healthcare Interoperability Resources
FIC	Family of International Classification
HCPCS	Healthcare Common Procedure Coding System
HHS	U.S. Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HSC	Health Standards Collaborative
ICD	International Classification of Diseases
ICHI	International Classification of Health Interventions
ISA	Interoperability Standards Advisory

LOINC	Logical Observation Identifiers Names and Codes
NCQA	National Committee for Quality Assurance
NCVHS	National Committee on Vital and Health Statistics
NIH	National Institutes of Health
NLM	National Library of Medicine
RadLex	Radiology Lexicon
RSNA	Radiological Society of North America
SNODENT	Systematized Nomenclature of Dentistry
SNOMED CT	Systemized Nomenclature of Medicine – Clinical Terms (name no longer used, acronym considered a brand name)
UDI	Unique Device Identification
UMLS	Unified Medical Language System
USCDI	U.S. Core Data for Interoperability
VA	U.S. Department of Veteran’s Affairs
VHA	Veteran Health Administration
WHO	World Health Organization