National Committee on Vital and Health Statistics (NCVHS)

Health Terminologies and Vocabularies Project Scope

Subcommittee on Standards

Background

The NCVHS Charter calls for the Committee to "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 Health and Human Services (HHS) recommendations and legislative proposals for such standards and electronic exchange." Further, the Committee is to "Advise the Department on health data collection needs and strategies; review and monitor the Department's data and information systems to identify needs, opportunities, and problems." NCVHS has offered recommendations supporting the adoption of ICD-10-CM and ICD-10-PCS but last examined health terminology and vocabulary "needs, opportunities, and problems" more broadly in 2003 when it offered recommendations to the Secretary on PRMI (Patient Medical Record Information) Terminology Standards.

Use of the terminologies and vocabularies are included in Administrative Simplification provisions of the Health Insurance Portability and Accountability Act (HIPAA), related regulations and adopted transaction standards. Generally, the term "code sets" is used to reference terminology and vocabulary.

The National Center for Health Statistics (NCHS) (within HHS' Centers for Disease Control) serves as the World Health Organization (WHO) Collaborating Center for the Family of International Classifications for North America and is responsible for coordination of all official disease classification activities in the United States relating to the ICD and its use, interpretation, and periodic revision. ICD-10, effective October 1, 2015, is the current version used for cause of death and morbidity classification. U.S. developed the Clinical Modification (ICD-10-CM) for morbidity classification based on WHO's ICD-10. The Collaborating Center is also responsible for the WHO Family of International Classifications, which includes the International Classification of Functioning, Disability and Health (ICF).

HHS' Center for Medicare and Medicaid Services (CMS) is responsible for development and maintenance of Procedure Coding System (PCS) used for acute care procedures in the United States (US). Outpatient and physician office procedures are coded using the Current Procedural Terminology (CPT) developed and maintained by the American Medical Association (AMA). The ICD-10 Procedure Coding System (ICD-10-PCS) is a newly designed system and is not based on an international coding system. Representatives from NCHS and CMS co-chair the ICD-10 Coordination and Maintenance Committee meetings. Responsibility for maintenance of the ICD-10 is shared between these two agencies, with NCHS having lead responsibility for ICD-10-CM for diagnoses and CMS having lead responsibility for ICD-10-PCS for inpatient acute care procedures.

The National Library of Medicine (NLM) is the central coordinating body for clinical terminology standards within the Department of Health and Human Services (HHS), so designated by the Secretary of HHS in 2004 in response to a recommendation from the NCVHS.   NLM has long supported the maintenance, dissemination, and free US-wide use of SNOMED CT (2003-), Logical Observation

Identifiers Names and Codes (LOINC) (1999-), and RxNorm (2001-), the primary clinical terminology standards required for electronic exchange of clinical health information under Stage 2 Meaningful Use. NLM also develops and provides tools to facilitate their adoption and use, including subsets, mappings, APIs, and the Value Set Authority Center.

SNOMED CT, required for problem lists, procedures and some clinical findings, is now owned and maintained by SNOMED International (the International Health Terminology Standards Development Organization (IHTSDO)), a not-for-profit organization. NLM is the US IHTSDO member and the National Release Center for SNOMED CT, paying the US membership fee and providing SNOMED CT data and resources under the SNOMED CT Affiliate License (incorporated as part of the Unified Medical Language System (UMLS) Metathesaurus license). RxNorm, a standardized nomenclature for clinical drugs required for medication data, is produced by NLM in cooperation with the FDA and is linked to NDCs and many of the drug vocabularies commonly used in pharmacy management and drug interaction software. LOINC, a nomenclature and coding system for tests and measurements, is produced and disseminated free of charge by the Regenstrief Institute, with financial support from NLM. LOINC is required for reporting laboratory tests and clinical documents; it also covers clinical measurements, including questionnaires and assessment instruments. NLM also actively promotes the use of UCUM (Uniform Code for Units of Measure). In addition to being available separately, SNOMED CT, RxNorm, and LOINC are all included in the UMLS Metathesaurus, where they are linked to many other classifications and vocabularies, including the HIPAA code sets, MeSH, the Gene Ontology, etc.

In addition to the systems developed, maintained, and supported by HHS agencies, US healthcare uses proprietary terminologies and classifications such as CPT, DSM and others.

Project Description and Goals

This project is designed to take a contemporary look at the health terminology and vocabulary landscape in order that NCVHS is able to advise the Secretary regarding

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

Plan

This project will be carried out in two phases:

Phase I – Briefings on adopted terminology and vocabulary standards. Rather than starting at a subcommittee, these briefings will be before the full Committee.   This will be done in two parts:

- June 2017 – Briefings from NCHS, CMS and NLM
- September 2017 – Briefings from non-governmental developers and other stakeholders in a position to contribute to the committee's understanding about development, dissemination, maintenance, and adoption opportunities and barriers.
- January 2018 – Report summarizing the current state

Phase II - Analyze what was learned from briefings and formulate areas of opportunity for improvement in at least the following areas:

- Standards adoption
- Maintenance and dissemination
- Governance and coordination

Approach: The Executive Committee will need to consider how to transition from Phase I to Phase II. Depending on what we learn in Phase I, we may want to consider drafting a coordinated framework to allow development, maintenance and dissemination to shift toward continuous enhancement.   In that case, phase 2 would include drafting the framework; holding a hearing to get input on the draft; issuing a report; and preparing letter with recommendation for the Secretary to optimize the value of terminologies and vocabularies for health reform going forward.   Potential recommendations might include:

- Criteria for adoption of named code sets
- Governance and coordination of code set standards
- Strategies for adoption that align with the NCVHS' Standards Predictability Road Map and ONC's health IT Strategic Plan

It may be appropriate to appoint an ad hoc committee (home-based in one of the subcommittees) to ensure the framework takes into account standards, public health, administrative simplification and other perspectives.

Timetable

Phase I: June 2017 – January 2018 Committee meetings
Phase II: Ad hoc committee frames issues and opportunities for discussion by Committee in May 2018; hearing summer 2018; Report and Letter to Secretary in Fall 2018 or January 2019

References

1. Report on Uniform Data Standards for Patient Medical Record Information (2000), https://www.ncvhs.hhs.gov/wp-content/uploads/2014/08/hipaa000706.pdf .
2. Information for Health: A Strategy for Building the National Health Information Infrastructure. Report and Recommendations from NCVHS (2001), https://aspe.hhs.gov/report/information-health-strategy-building-national-health-information-infrastructure.

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