



## National Committee on Vital and Health Statistics (NCVHS)

### Health Terminologies and Vocabularies: Evaluating Pathways to ICD-11

#### Background on the Health Terminologies and Vocabularies Initiative

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.” Terminologies and vocabularies are also a dimension of the Committee’s charge as part of advising the Secretary and reporting to Congress on adoption of standards under the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act (HIPAA).

To advance these goals, the Committee undertook a comprehensive environmental scan of the state of health terminologies and vocabularies in the US. The environmental scan findings are detailed in the Report, “Health Terminologies and Vocabularies Environmental Scan” completed in September 2018.<sup>1</sup> The Committee also hosted an Expert Roundtable meeting in July 2018 to review and comment on the Scan report and to discuss current challenges and future adoption needs and pathways.<sup>2</sup>

The Environmental Scan Report concludes that “While the U.S. has made progress in electronic health data exchange, this review brings to light several opportunities to improve regulatory and sub-regulatory adoption, governance and coordination, maintenance, and end user support. It also identifies gaps in terminology standards coverage and, at the same time, areas of redundant and overlapping content.”<sup>3</sup> The Committee considered the areas of opportunity to be addressed categorizing them into near term, mid-term and longer term. Near term areas are those that in the Committee’s judgement require study leading to recommendations to the Secretary over the next 12 to 24 months.

#### Background on the ICD-11 Focus for 2019

Evaluating pathways and making recommendation to the Secretary regarding adoption and use of the new version of the International Classification of Diseases (ICD-11) in the US is one of the near-term areas of obligation identified by the Committee for focus in 2019. The World Health Organization (WHO) released ICD-11 in June 2018 so countries could preview and begin their planning. In May 2019, the World Health Assembly will consider and vote on adoption of ICD-11 with an effective date of January 1, 2022. ICD-11 is intended by the WHO for use for both mortality (i.e., cause of death) reporting and morbidity (i.e., diseases) reporting.

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<sup>1</sup> NCVHS Health Terminologies and Vocabularies Environmental Scan. <https://ncvhs.hhs.gov/wp-content/uploads/2018/10/Report-Health-Terminologies-and-Vocabularies-Environmental-Scan.pdf>.

<sup>2</sup> NCVHS The Health Terminologies and Vocabularies Expert Roundtable Meeting Summary, July 17-18, 2018. <https://ncvhs.hhs.gov/wp-content/uploads/2018/09/Report-Health-Terminologies-and-Vocabularies-Expert-Roundtable-Report.pdf>.

<sup>3</sup> NCVHS, Health Terminologies and Vocabularies Environmental Scan, p. 50. <https://ncvhs.hhs.gov/wp-content/uploads/2018/10/Report-Health-Terminologies-and-Vocabularies-Environmental-Scan.pdf>.

The National Center for Health Statistics (NCHS) (within HHS' Centers for Disease Control and Prevention) serves as the 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. As with ICD-10 and previous versions of ICD, the NCVHS has a role in supporting the work of the Department by considering fitness for use of new versions for mortality and morbidity review and the timing for adoption in the US. The release of ICD-11 triggers a new cycle of evaluation and prompts our focus on developing recommendations for a pathway to ICD-11 that supports HHS's priorities and is aligned with other health terminology and vocabulary priorities, and the adoption of other industry standards.

ICD-10 went into effect for mortality reporting in the US in 1999 and ICD-10-CM, the US clinical modification for morbidity reporting became effective in the US on October 1, 2015 as a medical code set adopted under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). A new procedure coding system developed by HHS' Center for Medicare and Medicaid Services (CMS), ICD-10 Procedure Coding System (ICD-10-PCS) and not based on the international coding system, also went into effect for acute care procedures on October 1, 2015. Thus, the US recently experienced a major and protracted transition in HIPAA mandated code sets that constitute master data, touching virtually every clinical and administrative health system. Adoption in the US for morbidity reporting came 25 years after the system was adopted by the WHO. In advising the Secretary, the planning for ICD-11 should apply principles for adoption of health terminologies and vocabularies identified in the September 2018 NCVHS Environmental Scan and expert roundtable:

- 1) Conduct the research needed to understand the benefit and cost of moving to a new version.
- 2) Evaluate whether a clinical modification to ICD-11 is necessary or whether the new design of ICD-11, which includes additional morbidity detail, is adequate for US purposes or can be supplemented through other Standards named in HIPAA regulation or Promoting Interoperability (formerly Meaningful Use).
- 3) Simplify the rule making process.
- 4) Describe the pathway that balances priorities and communicate the pathway clearly to all industry stakeholders.

Importantly, this initiative also serves as a test bed to put into place many of the recommendations put forth by the Expert Roundtable participants with regard to adoption, implementation, maintenance, dissemination, governance and coordination of standards. It also permits a focus on engagement and communication across the industry to develop a broader consensus on the recommended path forward.

## Project Goals

The goals for the ICD-11 Pathways Evaluation project are to:

- a) Foster early stakeholder engagement and industry communications; and
- b) Develop a series of recommendations for the HHS Secretary regarding a pathway to ICD-11 that address the following:
  - 1) **[Completed]** Recommend a simplified regulatory process for version updates: See [Feb 2019 Letter to HHS Secretary](#).
  - 2) **[First half is completed – document review will be second half]:** Document the ICD-10 process and evaluate the benefits, costs and problems that have resulted from the ICD-10 transition.
  - 3) Evaluate ICD-11 against updated Criteria for Adoption and Implementation of Health Terminology and Vocabulary Standards.
  - 4) Evaluate the benefits of moving to ICD-11 for mortality reporting and the costs associated with implementation; evaluate the impact of moving to ICD-11 for mortality rapidly (for example within 3-4 years of adoption by the World Health Assembly) or slowly (for example within 9-10 years of adoption by the World Health Assembly).
  - 5) Evaluate the benefits and costs of moving to ICD-11 for morbidity classification, including the benefit and cost of developing a US clinical modification to ICD-11, against the costs of moving to a new version and barriers to implementation, e.g., readiness of transaction standards. Evaluate the impact of not moving to ICD-11 for morbidity.

## Project Description

This project will be carried out in multiple phases:

### Phase I –

**[Completed February 2019]** Lay out rationale for simplified regulatory adoption of code set version updates. Prepare a letter for the Secretary on regulatory simplification to remove the requirement of formal rulemaking for ICD version updates.

### Phase II –

**[Completed July 2019]** Compile relevant historical timeline and impact data on ICD-10, ICD-10-CM and ICD-10-PCS. In essence, creating a mini environmental scan of the transition and its impact. Complete by end of July 2019 in advance of August expert round table meeting.

- 1) Develop an understanding of the steps and timetable for the pathway to adoption of ICD-10. NCHS staff are currently compiling information that will be helpful in identifying all the steps necessary in adoption of ICD-11 for mortality and morbidity.
- 2) A similar timeline is needed from CMS.
- 3) Compile what the industry has learned about the value of ICD-10 and any identified limitations.

### Approach:

- 1) Briefing to NCVHS by NCHS and CMS on preparation for adoption of ICD-10- and ICD-10-CM and ICD-10-PCS;
- 2) Compile existing research on impact of ICD-10, ICD-10-CM, and ICD-10-PCS:
  - a) Identify relevant literature and summarize main findings (by mid-May)
  - b) **[Task Revised and Completed]** Review reports and data from VA:

- **Findings:** VA conducted two small operational studies that found some impact on providers that resulted from the ICD-9 to 10 change.
- c) What have been the costs and benefits of the ICD-10 transition? How do they compare to the projections in the 2004 Rand analysis? – will be informed by the literature review
- d) **[Completed]** Solicit feedback on how well ICD-10 is working for cause of death reporting (does WHO capture this?)
- **Findings:** WHO does not capture this. No data are available.
- 3) WHO approved ICD-11 in May. NLM will produce the following technical analysis of ICD-11 – the outline of the analysis is as follows:

### 1) Fundamental Analysis

- a) General characterizations of ICD-11 – what has changed?
- i) New design principles – foundation component (ontology) with linearizations, post-coordination etc.
  - ii) Expanded scope - e.g. traditional medicine, primary health
  - iii) Organization – re-arrangement of chapters, new chapters
- b) Quantitative analysis
- i) Number of codes and their distribution (without post-coordination)
  - ii) Comparison with ICD-10 and ICD-10-CM
    1. direct comparison – at chapter/block/category levels
    2. evaluate maps provided by WHO between ICD-10 and ICD-11 (in both directions) – coverage, nature (exact/non-exact), cardinality
    3. additional analysis
      - (a) mapping of ICD-11 to ICD-10 and ICD-10-CM using the lexical resources in the UMLS (this will inform future process of incorporating ICD-11 into the UMLS)
      - (b) indirect assessment through SNOMED CT maps – triangulation by way of existing maps from SNOMED CT to ICD-10, ICD-10-CM and ICD-11 (a small subset of about 6,000 concepts has been mapped by SNOMED International)
  - c) Qualitative analysis – in-depth review of some selected disease areas e.g. cardiovascular diseases, infectious diseases, cancer, diabetes
  - d) Implications for stakeholders (e.g. coders, IT vendors, researchers, data analysts)

### 2) Post-coordination Analysis

- a) Mechanics of post-coordination in ICD-11: scope and formalism, machine-readability of rules, implementation guidelines and implications on tooling
- b) Benefits: expanded coverage, increased granularity – comparison with ICD-10-CM and other terminologies
- c) Potential problems: multiple ways of expressing same meaning (means for equivalence checking), user training, coding consistency, heterogeneity of tooling support

### 3) Interoperability Analysis – focus on the ontological foundation component

- a) Mechanics of the foundation component - formalism, definition and implementation of linearizations
- b) Impact on interoperability with other logically defined terminology

**Deliverables and Timeline:**

1. Report to NCVHS in early August – this will cover findings from the fundamental analysis.
2. Publication of full research as a journal paper in 6 months – this will cover all findings, including the methodological aspects of the post-coordination and interoperability analysis

**Phase III –**

Identify research questions to inform evaluation of benefit and cost of transition from ICD-10 to ICD-11 for mortality and morbidity and identify impacts of not moving to ICD-11. (Q-3/4 of CY2019)

**Approach:**

- 1) Convene a roundtable of terminology experts, economists, and health researchers to reach consensus on the research questions on cost and benefit of the transition from ICD-10 to 11 on mortality, and ICD-10-CM to ICD-11 or ICD-11-CM for morbidity. Currently scheduled for 8/6-7/2019.
- 2) In August/September, develop a letter to the Secretary outlining the key research questions on the cost and benefit of the transition to ICD-11 identified during the August expert roundtable. Target completion time for the letter to the Secretary is the October NCVHS meeting.
- 3) At the October full Committee meeting, take action on the letter to the Secretary.

**Note:** Once research questions are identified, HHS would be well-positioned to evaluate the fitness of ICD-11 for coding mortality and morbidity.