



National Committee on Vital and Health Statistics  
Advising the HHS Secretary on National Health Information Policy

## Health Terminologies and Vocabularies Project:

1. Environmental Scan,
2. Expert Roundtable Summary,
3. Preliminary themes for recommendations, and
4. Key messages for Report to Congress

**NCVHS Full Committee Meeting**

**September 13, 2018**

# Previous NCVHS Key Work Products on Terminologies and Vocabularies



- 1998 – Initial guiding principles for the selection of standards to be adopted by the Secretary
- 2000 – Report: Uniform Data Standards for Patient Medical Record Information as Required by the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act of 1996
- 2002 – Letter to the Secretary: Recommendations for the First Set of PMRI Standards
- 2003 – Letter to the Secretary: Recommendations for the Second Set of PMRI Standards
- 2003 – Letter to the Secretary: ICD-10 Recommendations

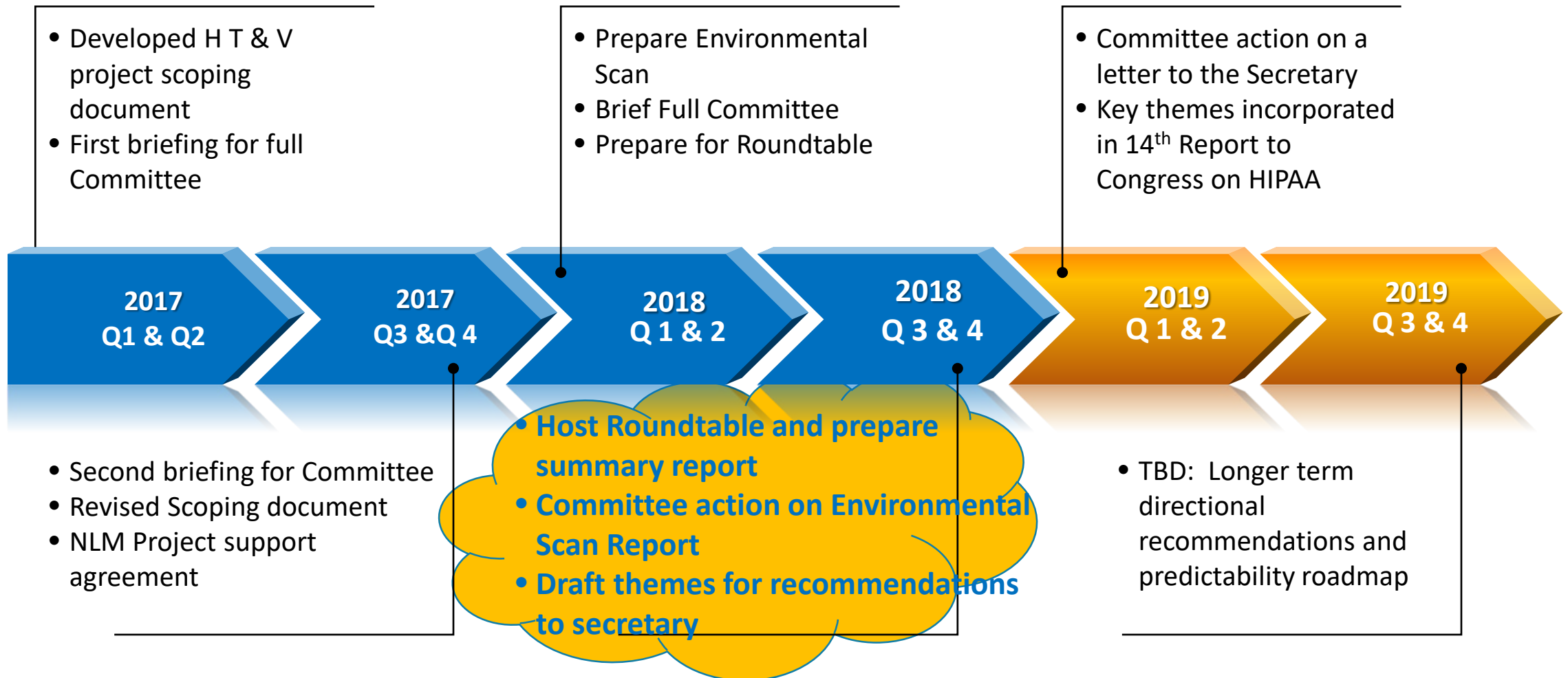
# Health Terminologies and Vocabulary Project Goals



A contemporary look at the health terminology and vocabulary landscape in order to advise the 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,
3. Actions that HHS might take to improve development, dissemination, maintenance, and adoption of standards.

# The Health T & V Project



# Health Terminologies and Vocabularies Environmental Scan



- Public recognition and thanks to NLM's Vivian Auld and Suzie Roy for leading scan development on our behalf
- Version 4.0, two rounds of input from Committee and Expert Roundtable
- Three major sections:
  - The world of health terminologies and vocabularies
  - The issues
  - Supporting detail on named standards and additional terminologies; key NCVHS reports and recommendations
- Ready for action by Full Committee

# Health Terminologies and Vocabularies Environmental Scan, V 4.0



## **Introduction**

- Purpose and Scope
- Definitions
- Background
  - HIPAA
  - 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

# Health Terminologies and Vocabularies Environmental Scan, V 4.0



## **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 and Improvement**

# Summary of Themes for Evaluation and Improvement



- 1. Build consensus on the direction forward**
- 2. Expand understanding that redundant health terminologies present a barrier to interoperability**
- 3. Mitigate the consequences of redundant terminology and vocabulary efforts**
- 4. Resource the maintenance and dissemination of named standards**
- 5. Improve governance and coordination across named terminology and vocabulary standards**



# Health Terminologies and Vocabularies Environmental Scan, V 4.0

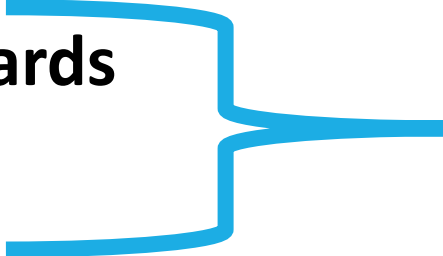


**Appendix 1: Named Health Terminology Standards**

**Appendix 2: Additional Health Terminologies**

**Appendix 3: Guiding Principles for Selecting PMRI Standards**

**Appendix 4: NCVHS Recommendation from the Report to the Secretary of HHS on Uniform Data Standards for Patient Medical Record Information**



Name
Purpose
Usage
Named Standard?
Ownership
Development Principles
Coverage
Development & Maintenance
Requesting New Content
Release & Dissemination
Overlap
Harmonizations & Collaborations

# Goals for July Expert Roundtable



1. Reach shared understanding on the current state as described in the 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.

# Expert Roundtable Agenda



## Tuesday

- Welcome
  - Our charge and challenge
  - Introductions
- Review Environmental Scan
  - V.2 Overview
  - Feedback
- Maintenance and dissemination
- Adoption and implementation
- Canada's approach
- Governance and coordination
- Recap of what we learned today
- Public comment

## Wednesday

- Gaps in named standards
  - Priorities
  - Process
- Preview of ICD-11
- Road mapping Standards
- Recap of day 1 & day 2 insights
- Next steps in NCVHS' T/V project
- Public Comment

# Roundtable Output: Areas of Opportunity



## Near term

Principles, policies and practices under control of Secretary

(to be addressed in Letter(s) to Secretary in 2019/20)

## Mid term

Deliberate and explicit pathway to convergence of clinical and administrative standards requiring public-private cooperation.

## Longer term

Technology and research to realize terminology and vocabulary-based health data ecosystem

Implication for NCVHS: Terminologies and Vocabularies must be continuing focus area

# Near Term Opportunities



1. Update\* Principles to guide adoption of health terminologies and vocabularies.
  - Explicit statements of the purpose, boundaries, and guidelines for use
  - Importance of a community of practice to define scope of a content area
  - Content development using accepted practices
  - Evaluation of how well the terminology performs for the stated purposes, its usability, currency and cost/benefit
  - Adoption process and timing suitable for terminology and vocabulary standards

\*These will update the 1998 Principles that focused on initial selection of HIPAA Code Set Standards

# Near Term Opportunities



## 2. Develop Principles for updates to health terminologies and vocabularies, including

- Curation as a continuous process
  - Backward compatibility
  - Transparency (adds, changes, deletions)
  - Updates based on accepted practices
- Published cadence reflecting explicit cost/benefit
  - Eliminate version updates from regulatory process, starting with ICD
- Dissemination
  - Electronic, including implementation and mapping tools
  - Minimize cost and licensing barriers

# Near Term Opportunities



## 3. Scope a project to evaluate ICD-11:

- Review the process NCVHS used to hold hearings and make recommendations on ICD-10, including Committee products
- Include plan to assess the fitness for US adoption of ICD-11 for mortality and morbidity
- Outline how the adoption principles in #1 will guide the path
- Evaluate the purpose and return on investment of a US clinical modification for ICD-11
- Study the design and utility of the WHO's International Classification of Health Interventions (ICHI) in comparison to ICD-PCS

# Mid Term Opportunities



1. Prepare a strategic plan for terminologies and vocabularies
  - Translate why this is important to every American
  - Expand stakeholder engagement through purposeful outreach
  - Prioritize coordination and Governance needs and study of public-private collaboration models, including international
  - Advance convergence of administrative-clinical data standards
  - Design a process for addressing gaps and changing scope and uses
  - Expand research and accelerate use of analytics and technology to inform vocabulary and terminology advances



# Mid Term Opportunities



2. Design a deliberate pathway toward convergence
  - Bridge clinical and administrative domains
  - Bridge research terminologies with clinical/administrative domains
    - Expand scope of named terminology and vocabulary standards to include:
      - vitals, public health
      - population health, social and behavioral determinants
      - mental health and substance abuse
  - Balance parsimony of named standards with flexibility and extensibility in versioning

# Mid Term Opportunities



3. Develop principles and an explicit process for addressing terminology and vocabulary gaps
  - Distinguish purposeful overlap and redundant effort
  - Integrate new concepts into existing terminologies if practical
  - Importance of a community of practice to define scope of a content area and perspectives to include
  - Curation as a continuous process, with promotion of a concept to “named status” as evaluation shows it is ready for a purpose

# Mid Term Opportunities



## 4. Improve and expand the application of the “science” of terminology and vocabulary development

- Identify research and evaluation of T/V models; biomedical, socio-behavioral, and health concepts; and application of machine learning.
- Capture the principle of computational engineered relationships between reference terminologies and incorporate as appropriate in the path to convergence and long term opportunities

# Long Term Opportunities



- Single dissemination resource center
- Use clinically useful terminologies in the EHRs (SNOMED, RxNorm, LOINC ++)
- Calculate codes from clinical content to support the range of uses:
  - payment classes
  - decision support for clinicians and patients across provider sites
  - quality and population health measures
- Decouple intervention/procedure codes from facility type
- Eliminate separate work to satisfy terminology and classification needs that should be supported by entry into EHR for provision for care – this information needs to flow seamlessly through for payment and other purposes

# Themes for the 13<sup>th</sup> Report to Congress



1. Interoperability requires terminology and vocabulary standards
  - The US has basic standards in place but their governance and management is fragmented and under-resourced.
  - The current fragmented approach adds cost to the system with no offsetting benefits
  - The tools and methods to improve the current process are available but need to be coordinated and supported.
2. Realizing the goals of the 21<sup>st</sup> Century Cures Act requires terminology and vocabulary standards
  - They are the bridge for patient care, payment, research environments
3. Modify current HIPAA regulation to remove specific reference to the version of ICD to allow for update of a version without the full regulatory update process.