“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.”

“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.”
Health Terminologies and Vocabulary Project Goals

Take 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.
Goals for 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.
Introductions & Participant Goals:

Name and current role

“At the end of this meeting, I hope we will have discussed…..”
The Health T & V Project

- Developed H T & V project scoping document
  - First briefing for full Committee

- Second briefing for Committee
  - Revised Scoping document
  - NLM Project support agreement

- Prepare Environmental Scan
  - Brief Full Committee
  - Prepare for Roundtable

- Committee action on a letter to the Secretary
  - Key themes incorporated in 14th Report to Congress on HIPAA

- Host Roundtable and prepare summary report
  - Committee action on Environmental Scan Report
  - Draft project report and letter to secretary

- TBD: Longer term directional recommendations and predictability roadmap
## Our 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

### Wednesday
- Gaps in named standards
  - Priorities
  - Process
- Preview of ICD-11
- Road mapping Standards
- Next steps in NCVHS’ T/V project
- Public Comment
A few ground rules to help everyone contribute and be heard…

• Use your tent cards to indicate you wish to speak.
• Speak into a microphone for recording purposes.
• Breakout discussions designed to be less formal so everyone can contribute.
• Our Chair reserves the right to move us along to stay on topic and schedule.
• You have a wide range of perspectives, so please listen carefully and respect each others’ views.
Health Terminologies and Vocabularies
Environmental Scan, V 3.0

- Feedback and clarification
- Additional suggestions
- Next steps
Health Terminologies and Vocabularies
Environmental Scan, V 3.0

Introduction
• Purpose and Scope
• Definitions
• Background
  • Terminology and Vocabulary Milestones
  • Key organizations

Selection of Standards for Adoption
• Evolving Levers for Standards Adoption

Health Terminology Standards
• HIPAA Named Standards and Other Standards
• Additional Standards

Content Gaps in the Current Named Standards
• Potential solutions to named standards gaps
  • Expanding a Current Standard
  • Naming an Additional Standard
  • Developing New Terminologies
### 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

### 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

### Summary of Themes for Evaluation and Improvement
Health Terminologies and Vocabularies
Environmental Scan, V 3.0

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

<table>
<thead>
<tr>
<th>Name</th>
<th>Purpose</th>
</tr>
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<tbody>
<tr>
<td>Usage</td>
<td></td>
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<tr>
<td>Named Standard?</td>
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<tr>
<td>Ownership</td>
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<tr>
<td>Development Principles</td>
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<tr>
<td>Coverage</td>
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<tr>
<td>Development &amp; Maintenance</td>
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<td>Requesting New Content</td>
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<td>Release &amp; Dissemination</td>
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<td>Overlap</td>
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<tr>
<td>Harmonizations &amp; Collaborations</td>
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</table>
Breakout exercises

A. Generate dialogue and debate, but reach consensus at least about the key issues that may be actionable in the short term, but...
B. Capture your ideas for longer term direction
C. Share “ah ha’s”
Discussion Topic 1: Maintenance and Dissemination Opportunities and Principles

• Begin with 3-5 minutes of individual reflection

• Reach consensus on 2-3 near term opportunities to improve the maintenance of health terminology and vocabulary standards:
  • To redress known operational problems or to improve value (cost and quality) of health T/V standards

• Reach consensus on the near term opportunities to improve dissemination of terminology and vocabulary standard version updates, including correction, guidance and support?
  • To redress known operational problems or improve value

• Identify principles that should guide maintenance and dissemination decision-making.
Table ___: Discussion of Maintenance and Dissemination Opportunities and Principles

<table>
<thead>
<tr>
<th>Near term opportunities to improve maintenance of T/V are:</th>
<th>Near term opportunities to improve dissemination of T/V are:</th>
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<tbody>
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<td>1.</td>
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<td>3.</td>
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</table>

What guiding principles should guide Maintenance and Dissemination:

1.  
2.  

Other insights you wish to share:

1.  
2.  
Discussion Topic 1: Maintenance and Dissemination Opportunities and Principles

This 45 minute session of Concurrent Roundtable Discussions will not be broadcast. Once the full group resumes meeting, broadcasting will resume.
Discussion Topic 2: Adoption and Implementation
### Federal Regulatory Process

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><strong>Initiating Events</strong>&lt;br&gt;Request for rulemaking</td>
</tr>
<tr>
<td>2</td>
<td><strong>Determination whether rule is needed</strong>&lt;br&gt;Administrative Procedures Act provisions include information about forms, agency organizations and methods of operation</td>
</tr>
<tr>
<td>3</td>
<td><strong>Preparation of Proposed Rule</strong>&lt;br&gt;Administrative Procedures Act provisions require steps 3 through 6 to be completed before rules may be established</td>
</tr>
<tr>
<td>4</td>
<td><strong>OMB Review of Proposed Rule</strong>&lt;br&gt;90 days allowed</td>
</tr>
<tr>
<td>5</td>
<td><strong>Publication of Proposed Rule</strong></td>
</tr>
<tr>
<td>6</td>
<td><strong>Public Comments</strong>&lt;br&gt;OMB requires 60 days</td>
</tr>
<tr>
<td>7</td>
<td><strong>Preparation of Interim or Final Rule</strong></td>
</tr>
<tr>
<td>8</td>
<td><strong>OMB Review of Interim or Final Rule</strong></td>
</tr>
<tr>
<td>9</td>
<td><strong>Publication of Interim or Final Rule</strong></td>
</tr>
</tbody>
</table>
Discussion Topic 2: Adoption and Implementation Opportunities and Principles

- Begin with 3-5 minutes of individual reflection

- Reach consensus on 2-3 near term opportunities to improve the regulatory process for terminology and vocabulary standards adoption.

- Reach consensus on 2-3 characteristics of organizations that successfully implement and use vocabulary and terminology standards?

- Identify principles that should guide adoption and implementation decision-making
Table ___: Adoption and Implementation
Opportunities and Principles

<table>
<thead>
<tr>
<th>Near term opportunities to improve regulatory adoption of T/V are:</th>
<th>Key characteristics of successful implementation and use of T/V by stakeholders</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>What guiding principles should guide adoption and implementation decision-making and execution:</th>
<th>Other insights you wish to share:</th>
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Discussion Topic 2: Adoption and Implementation

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Canadian Institute for Health Information (CIHI)

Kathleen Morris
Vice President, Research & Analysis
Discussion Topic 3: Governance and Coordination
Discussion Topic 3: Governance and Coordination Opportunities and Principles

- Begin with 3-5 minutes of individual reflection
- Reach consensus on 2-3 near term opportunities to improve coordination across T/V stakeholders.
- Would more formalized governance of health vocabulary and terminology standards advance best practices? Reach consensus on most useful governance model(s) for this domain.
- Identify key governance and coordination principles
<table>
<thead>
<tr>
<th>Table ___: Discussion of Governance and Coordination Opportunities and Principles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Near term opportunities to improve coordination across T/V stakeholders are:</td>
</tr>
<tr>
<td>1.</td>
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<td>2.</td>
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<td>3.</td>
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<tr>
<td>Identify key governance and coordination principles:</td>
</tr>
<tr>
<td>1.</td>
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<tr>
<td>2.</td>
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<tr>
<td>Characteristics of most useful governance model(s) for health T/Vs:</td>
</tr>
<tr>
<td>1.</td>
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<td>2.</td>
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<tr>
<td>Other insights you wish to share:</td>
</tr>
<tr>
<td>1.</td>
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<td>2.</td>
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</table>
Discussion Topic 3: Governance and Coordination

This 60 minute session of Concurrent Roundtable Discussions will not be broadcast. Once the full group resumes meeting, broadcasting will resume.
To Submit Public Comment

- By email to NCVHSmal@cdc.gov
- Use the live WebEx broadcast dashboard

Please include your name, title, and organization
Health Terminologies and Vocabularies Expert Roundtable

NCVHS Standards Subcommittee
Day 2
Gaps in Named Terminology & Vocabulary Standards
Preview of ICD-11
Predictability Roadmap for Standards
History of the Predictability Roadmap

• HIPAA Legislation was enacted more than 21 years ago to promote administrative simplification efficiencies and effectiveness of the health care system through the use of standards for electronic transactions between health plans, clearinghouses and certain health care providers.

• The Patient Protection and Affordable Care Act included provisions to support HIPAA, both reinforcing certain requirements (adopt attachment standard), and adding new ones (adopt operating rules), increase enforcement.

• Industry feedback to NCVHS indicated the need for predictability in how standards are developed, adopted and implemented.

• We undertook a project engaging the industry in developing a predictability roadmap. We met with the following: Standard Development Organizations, Operating Rules Authoring Entity, Federal regulators, and industry stakeholders.
History of the Predictability Roadmap

Pre-2012
NCVHS submitted letters to the Secretary identifying concerns for the development, maintenance, and update process for standards and operating rules relating to administrative transactions.

2016
In its annual Report to Congress, NCVHS identified the development of a predictability roadmap as one of its priorities based on on-going industry feedback about the update and adoption process for standards.

2017-2018
NCVHS has been working to identify and understand the strengths and weaknesses in the current SDO/ORAE processes. The recommendations for actionable improvements will be compiled into the predictability roadmap.
What We’ve Accomplished

1. Met with standards organizations to understand current practices
   • Outcome: Published a comprehensive overview of development procedures, organizational compositions and workgroup structures.

2. Conducted a daylong visioning workshop with standards organizations, federal partners and interested stakeholders to identify specific opportunities for action
   • Outcome: Summary report of the workshop, and consolidation of ideas into 5 agreed upon themes

3. Interviewed HHS to understand the opportunities and limits of the regulatory process

4. Held a CIO Forum to understand end-user perspectives
   • Outcome: published summary of Forum
Where should we go from here?
The Health T & V Project

• Developed H T & V project scoping document
  • First briefing for full Committee

2017 Q1 & Q2

• Second briefing for Committee
  • Revised Scoping document
  • NLM Project support agreement

2017 Q3 & Q4

• Prepare Environmental Scan
  • Brief Full Committee
  • Prepare for Roundtable

2018 Q1 & 2

• Host Roundtable and prepare summary report
  • Committee action on Environmental Scan Report
  • Draft project report and letter to secretary

2018 Q3 & 4

• Committee action on a letter to the Secretary
  • Key themes incorporated in 14th Report to Congress on HIPAA

2019 Q1 & 2

• TBD: Longer term directional recommendations and predictability roadmap

2019 Q3 & 4
What other advice do you have for the Committee as it continues with the T/V Project?
To Submit Public Comment

- By email to NCVHSmall@cdc.gov
- Use the live WebEx broadcast dashboard

Please include your name, title, and organization