National Committee on Vital and Health Statistics in 2018

Bill Stead, MD, NCVHS Chair

February 21, 2018
Today’s Agenda

• What is NCVHS?
• Overview of NCVHS Activities and Focus
  • Standards
  • Privacy, Confidentiality and Security
  • Population Health
• Approaches to ONC/HITAC and NCVHS Collaboration
• Discussion
NCVHS is the Department of Health and Human Services’ (HHS) statutory public advisory body on health data, statistics and national health information policy.
How NCVHS Advises HHS

• 18 members appointed for four-year terms
  • Diverse backgrounds, expertise and geography

• Develops and delivers practical, timely, thorough recommendations to the HHS Secretary

• Full Committee meets three times/year and convenes public hearings, listening sessions, workshops, roundtables

• Provides periodic reports to Congress

• Develops reports and resources
NCVHS Membership

**Chair:** William W. Stead, MD, Vanderbilt University Medical Center – Nashville, TN

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

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

Bruce B. Cohen, Ph.D., Massachusetts Department of Public Health – Boston, MA
Llewellyn J. Cornelius, Ph.D., University of Georgia – Athens, GA

**Nicholas L. Coussoule,** BlueCross BlueShield of Tennessee – Chattanooga, TN

**Alexandra Goss,** Imprado / Dynavet Solutions – Harrisburg, PA

**Linda L. Kloss,** M.A., Strategic Advisors Ltd, – Sister Bay, WI

**Richard W. Landen,** M.P.H., M.B.A., (Retired) – Bonita Springs, FL

**Denise E. Love,** National Assn of Health Data Organizations – Salt Lake City, UT

Vickie M. Mays, Ph.D., MSPH., University of California Los Angeles – Los Angeles, CA
Robert L. Phillips, Jr., M.D., MSPH, American Board of Family Medicine – Washington, DC
David A. Ross, Sc.D., Public Health Informatics Institute – Decatur, GA

**Debra Strickland,** M.S., Conduent – Wallingford, Connecticut

Roland J. Thorpe, Jr., Ph.D., Johns Hopkins Bloomberg School of Public Health – Baltimore, MD
Jacki Monson, J.D., Sutter Health – Sacramento, CA

*Blue indicates Standards Subcommittee members*
NCVHS Website and Resources

- www.ncvhs.hhs.gov

- Meeting announcements, letters to the Secretary, reports, tools, other resources available

- Electronic/remote access to meetings and meeting materials
Recent Reports, Recommendations & Letters

- December 13, 2017 – Report – Health Information Privacy Beyond HIPAA: A 2018 Environmental Scan of Major Trends and Challenges
- September 14, 2017 – Letter to the Secretary – Recommendations on the CMS Transition from Social Security Numbers to a Medicare Beneficiary Identifier
- June 21, 2017 – Letter to the Secretary – Findings and Recommendations from the May 3, 2017 NCVHS Standards Subcommittee Hearing on the Health Plan Identifier
- February 23, 2017 – Letter to the Secretary – Recommendations on De-identification of Protected Health Information under HIPAA
- November 9, 2016 – Letter to the Secretary – Recommendation on the HIPAA Minimum Necessary Standard
- October 13, 2016 – Review Committee Findings and Recommendations on Adopted Standards and Operating Rules
- October 13, 2016 – ONC’s Draft 2017 Interoperability Standards Advisory
## Three Active Subcommittees

<table>
<thead>
<tr>
<th>NCVHS Domain Areas</th>
<th>Focus</th>
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<tr>
<td><strong>Standards</strong></td>
<td>Public health informatics and patient medical record standards. Standards, code sets, and operating rules for administrative transactions as required under HIPAA, MMA, and ACA.</td>
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<td><strong>Population Health</strong></td>
<td>Statistical problems bearing on health and health services from national and international perspectives. Access to population-based data to enable communities to become learning systems for health.</td>
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<td><strong>Privacy, Confidentiality and Security</strong></td>
<td>Emerging issues related to health information privacy, confidentiality and security and data stewardship.</td>
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2018 Work Plan Priority Areas

- Predictability Roadmap *(Standards)*
- Chief Information Officer Forum *(Standards)*
- Health Terminologies and Vocabularies *(Standards)*
- Health Information Privacy and Security Beyond HIPAA *(PCS)*
- Next Generation Vital Statistics *(Pop Health)*
- Health Data Ecosystem/Data Access Assessment and potential follow up on the Commission for Evidence-based Policymaking report *(Pop Health)*
2018 Work Plan (continued)

• New Medicare Card/SSN Replacement Initiative monitoring
• 21st Century Cures collaboration with ONC and HITAC
Predictability Roadmap

Background

• Industry testimony and NCVHS investigation indicate lack of predictability around development and adoption path and timing of new/updated Admin Simp regulations
• With 20 years of HIPAA and several version migrations under our belts, can we identify a more efficient path for versioning?
• Scope is on transaction and operating rules standards

Opportunity

The predictability roadmap would provide the health care industry with a degree of certainty in the timing and sequence of the development and adoption of new or revised standards and operating rules as required under the HIPAA and other legislation.
Health care organizations need access to methods of data exchange that are flexible and interoperable.

How do we create and enable greater flexibility and more rapid implementation of changes, to allow organizations to meet their business needs?

Updates to and adoption of standards and operating rules have not kept pace with the evolving business, operations and technology challenges and needs of our health care stakeholders.

How do we identify and act on the right short term challenges and barriers? Who are the right actors who can identify the solutions and break down the barriers?

PR project is on track to develop recommendations towards improvements in flexibility and responsiveness.
Recommendations for SDOs, operating rule authoring entities, HHS and industry that outline opportunities to improve the update and regulatory processes.
CIO Forum

- **Format:** One Day Forum
- **Purpose:** To solicit input from diverse group of CIOs who are end users of standards and operating rules
- **For Discussion:**
  - How their vision for predictable updates in health care technology includes the use of standards and operating rules
  - Whether the current schedule of updates is frequent enough
  - What is the ideal schedule for updates to standards
  - If the updates incorporate the types of changes that accommodate the way business is changing
  - What improvements would they propose
  - What changes do they see happening in health care that necessitate attention and might impact the roadmap.
CIO Forum
Current Workplan

• Identify and invite participants
• Create question set
• Hold Forum
• Review CIO feedback and incorporate into the roadmap
• Draft detailed recommendations for the Predictability Roadmap
• Meet with each SDO, ORAE and HHS one-on-one to review the recommendations and actionable steps
Health Terminologies and Vocabularies

A contemporary look at the health terminology and vocabulary landscape in preparation to advise the Secretary on:

• The changing environment and implications for timing and approach to terminology and vocabulary standards adoption

• Needs, opportunities, and problems with development, dissemination, maintenance, and adoption of terminology and vocabulary standards

• Actions that HHS might take to improve development, dissemination, maintenance, and adoption of terminology and vocabulary standards
Health Terminologies and Vocabularies Workplan

• Conducting environmental scan
• Full Committee to consider focus and scope
• Roundtable planned for July 2018
• Summarize findings
• Full Committee to consider next steps
• Consider Predictability Roadmap implications of code set standards
• Formulate draft recommendations
Health Information Privacy and Security “Beyond HIPAA”

A more comprehensive look at challenges beyond HIPAA and the range of policy options that may be available to the Department, to data stewards, and to the subjects of the information.

Goals

• Identify and describe the changing environment and the risks to privacy and security of confidential health information; highlight promising policies, practices and technology
• Lay out integrative models for how best to protect individuals’ privacy and secure health data uses outside of HIPAA protections while enabling useful uses, services and research
• Formulate recommendations for the Secretary on actions that HHS and other federal Departments might take
• Develop report for health data stewards
Health Information Privacy and Security “Beyond HIPAA” – Workplan

• Environmental scan complete (report on website)

• Working Question:
  How to improve the protection of data outside HIPAA’s jurisdiction?

• Develop 2 use cases
  Demonstrate challenges of data linkage between covered entities and non-covered entities
  1. Clinical data registries
  2. Consumer devices

• Hold hearing on use cases

• Draft report

• Frame larger set of ‘levers’

• Potential recommendations to Secretary
Guiding Question the Committee is Studying:

How do we transform a vulnerable, federated data collection network into a robust timely integrated sustainable multipurpose information system that produces timely data and information flows?

Broader Question:

Can efforts to improve interoperability of clinical data and administrative data be applied/transfer to vitals (birth, death), population and public health data?
Next Generation Vital Statistics/Data Access Workplan

- Held hearing September 2017
- Forthcoming Summary Hearing Report
- Conducted and published in-depth follow-up analysis (report on website)
- Drafting alternative options for future approaches
- Holding virtual hearings in 2018 to vet potential options with range of stakeholders
- Will identify short – medium – and long-term recommendations
- Draft letter to Secretary
Explore Approaches to Collaboration – ONC, HITAC, and NCVHS

• How can NCVHS best support ONC and HITAC?
• What role can NCVHS play in the short term?

Example: Provide comment on USCDI and Proposed Expansion Process
Contact

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Email: vgh4@cdc.gov
Executive Secretary/DFO: Rebecca Hines