Fiscal Year 2018 Committee Accomplishments

Background

The National Committee on Vital and Health Statistics (NCVHS) advises HHS on health data, statistics, privacy, national health information policy, and the Department's strategy to best address these issues. A key aspect of this work involves advising the Secretary on HHS's implementation of provisions established in health care-related legislation. For the Health Insurance Portability and Accountability Act (HIPAA), the Committee specifically advises HHS regarding adoption of standards, identifiers, and code sets for administrative transactions; privacy and security; a periodic Report to Congress; and assists and advises HHS in the implementation of the Administrative Simplification provisions of HIPAA, informing decision-making on HHS data policy, states, local governments and the private sector. As stipulated in the Patient Protection and Affordable Care Act (ACA), the Committee provides advice and guidance regarding operating rules and is designated as the official Review Committee for health care transactions – consisting of standards and operating rules – and advises HHS on opportunities to improve standardization and uniformity in a number of areas. With passage of the 21st Century Cures Act, the Committee coordinates with ONC and the Health Information Technology Advisory Committee (HITAC) on policy development for clinical (electronic health record [EHR]) and administrative data standards.

Fiscal Year 2018

The Committee focused its work in four main areas in FY18:

- Predictability Roadmap
  Developing recommendations and a timeline to make improvements to the processes for updating, adopting and using standards and operating rules for administrative healthcare transactions through development of a Predictability Roadmap.

- Health Terminologies & Vocabularies
  Examining the health terminology and vocabulary landscape to advise the HHS Secretary regarding:
  a. The changing environment and implications for timing and approach to health terminology and vocabulary standards adoption

NCVHS FY18 Recommendation Letters

- Letter to the Secretary: US Vital Registration and Vital Statistics System Recommendations– Critical Challenges and Opportunities (May 21, 2018)

- Letter to the Secretary: NCVHS Recommendations on National Council for Prescription Drugs Programs (NCPDP) Pharmacy Standards Updates (May 17, 2018)

- Letter to the Office of the National Coordinator (ONC): Proposed U.S. Core Data for Interoperability (USCDI) expansion process and emerging data classes (March 15, 2018)

b. Needs, opportunities, and problems with development, dissemination, maintenance, and adoption of health terminology and vocabulary standards
c. Actions that HHS might take to improve development, dissemination, maintenance, and adoption of standards.

- Health Information Privacy and Security Beyond HIPAA
  a. Identifying and describing the changing environment and the risks to privacy and security of confidential health information; highlight promising policies, practices and technology
  b. Laying 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
  c. Formulating recommendations for the Secretary on actions that HHS and other federal Departments might take

NCVHS FY18 Reports
• Health Terminologies and Vocabularies Environmental Scan Report
• Health Terminologies and Vocabularies July 2018 Expert Roundtable Report
• CIO Forum Summary Report
• Summary Report: Next Generation Vital Statistics—A Hearing on Current Status, Issues, and Future Possibilities
• Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue
• Health Information Privacy Beyond HIPAA: A 2018 Environmental Scan of Major Trends and Challenges

- Vision for Next Generation Vital Statistics
  Considering and identifying actions needed both to protect and improve the U.S. Vital Registration and Statistics System (VRSS) by: assessing the current status and risks to its viability and sustainability; and identifying recommendations to transform the federated system into an integrated sustainable multipurpose information system that produces timely data and information flows.

Committee Impact

Although the primary charge to the Committee is to make recommendations to the HHS Secretary as noted above, the Committee also informs decision-making about data policy by HHS, states, local governments and the private sector.

In FY18, the Committee's letter to the Secretary on vital records and statistics systems highlighted the significance of these systems to inform government officials, especially in light of events such as the opioid crisis. The Committee noted that more Federal attention needs to be paid to this critical national data infrastructure. Federal leadership is needed to work more closely with states, jurisdictions and Federal agencies to improve access to timely data as well as to ensure sustainability of the individual systems that collect these data. As one step, CDC is now considering encouraging states to use the "model law" developed to increase consistency of data and data access across jurisdictions.

In collaboration with NIH/National Library of Medicine (NLM), the Committee conducted an *Environmental Scan of Health Terminologies and Vocabularies*. This report surfaced the need to increase the understanding that redundant health terminologies present a barrier to interoperability. The NLM is using the Committee's report to inform the process of aligning health vocabularies.

The Committee's letter to the Office of the National Coordinator on the proposed U.S. Core Data for Interoperability (USCDI) expansion process and emerging data classes suggested criteria for judging the readiness of a data class for adoption. The testing and evaluation processes in the revision were consistent with this input.

The Committee convenes diverse public and private stakeholders for the purpose of gathering information to formulate recommendations to the Secretary. For example, the Committee convened a Chief Information and Innovation Officer (CIO) Forum to get feedback as part of its work to develop a Predictability Roadmap for standards as part of its role in providing feedback on HIPAA Administrative Simplification regulations. These participants, the people who must implement changes, agreed on the types of change needed to increase the benefit of adoption of standards and reductions in barriers to their implementation. Through this dialogue, these leaders came to a shared understanding of the types of changes needed within the industry. A ripple effect of this work is that, through this understanding, leaders who met as a group with the Committee will bring new thinking back within their organizations, which will increase implementation of data standards and ultimately, interoperability of data.

The healthcare community consisting of a wide range of stakeholders, also is influenced by NCVHS' work. The [NCVHS Measurement Framework for Community Health and Well-being](#) continues to be used as a national resource. For example, *US News & World Report's* Healthiest Community Survey, AETNA Community Challenge, and the Institute for Healthcare Improvement (IHI) 100 Million Healthier Lives based their population health data work on the NCVHS Measurement Framework. The Framework provides a structure for defining and identifying data needs across domains including education, economy, environment, public safety, food, health, housing, and transportation. As such, the Framework provides a flexible and comprehensive way to promote measurement in multiple sectors and makes it possible for local officials to choose locally relevant measures. The Committee's observation that a global, integrated approach to comprehensive population health measurement was missing from the field, and its work to stimulate such an approach through development of a model measurement framework, is having a tangible impact nationally.

NCVHS Meeting Highlights

The Full Committee convened three times during the year. To follow is a high-level summary of these meetings:

January 2018

The full Committee deliberated and voted to approve the report, "Health Information Privacy Beyond HIPAA: A 2018 Environmental Scan of Major Trends and Challenges," to inform work on the *Health Information Privacy and Security Beyond HIPAA* project. This effort included an exploration of challenges that extend beyond HIPAA and the range of policy options that may be available to HHS related to

privacy, security and access measures to protect individually identifiable health information in an environment of massive electronic data exchange. The Population Health Subcommittee focused on Next Generation Vital Statistics in follow up to its September 11-12, 2017 hearing and subsequent analyses conducted following the hearing. The purpose of the main project was to assess the current state of the U.S. Vital Registration and Statistics Systems (VRSS) to address concerns regarding sustainability and viability of the system infrastructure. The Committee also discussed concerns regarding decreased access to county and community-level data and potential plans to conduct work to address the issue. The Committee focused on the *Predictability Roadmap* as part of the Standards Subcommittee's project to identify possible approaches to improve the predictability and improvements in the adoption of, and processes related to, updating standards and operating rules for electronic administrative transactions e.g. claims, eligibility, electronic funds transfer; health terminology & vocabulary development, maintenance, and dissemination processes; and mapping out activities and timelines for the Committee's 2018 work.

<u>May 2018</u>

The Committee discussed and approved a letter to the HHS Secretary, together with a summary report of the hearing held September 2017 on critical issues facing the VRSS. In addition, a letter to the Secretary regarding the Committee's recommendations resulting from the March Standards Subcommittee hearing on NCPDP Updates was discussed and approved for submission. Staff from the Office of the National Coordinator (ONC) gave an update and the Committee discussed its collaboration with ONC and its advisory committee HITAC as part of fulfilling the stipulation to coordinate outlined in the 21st Century Cures Act. The Subcommittee on Standards briefed the Committee on its upcoming CIO Forum as part of the Subcommittee's project to identify approaches to improve predictability and improvements in the adoption and processes related to updating standards and operating rules for electronic administrative transactions. The Committee reviewed and refined the agenda and plans for the July Expert Roundtable examining health terminology and vocabulary development, maintenance, and dissemination processes. Members also presented the most current draft environmental scan report of the health terminologies and vocabularies landscape and discussed feedback and input from members for the next version. The Committee continued development of its *Health Information Privacy & Security Beyond HIPAA* project focusing on clinical registries as well as personal devices that produce patient-generated health data (PGHD), as use cases. An outside expert, Jon Neiditz, with Kilpatrick Townsend & Stockton LLP, was invited to provide an overview on the new European General Data Protection Regulation (GDPR). Soma Stout with the Institute for Healthcare Improvement/100 Million Healthier Lives discussed recent developments with the Committee on the NCVHS Measurement Framework implementation work. The Committee also received updates from the HHS Office of Civil Rights and CMS regarding recent developments resulting from the initial wave of the Medicare Card Project roll out.

<u>September 2018</u>

The Committee deliberated, achieved consensus and approved two reports, "Health Terminologies and Vocabularies Environmental Scan," and "Health Terminologies and Vocabularies Expert Roundtable Meeting Summary." On the afternoon of the first day, three panels of experts provided input to the

Committee in a session "Access to Small-area Population Health Data and Data Resources," regarding strategies and resources to increase access to small area data, and in general, the challenges in making relevant sub-national level health data more readily available—organized by the Subcommittee on Population Health. The co-chairs of the Subcommittee on Standards presented draft recommendations for the Predictability Roadmap as part of the Subcommittee's project to identify possible approaches to improve predictability and improvements in the adoption and processes related to updating standards and operating rules for electronic administrative transactions. The Privacy, Confidentiality & Security Subcommittee presented use cases for its *Health Information Privacy and Security Beyond HIPAA* project that highlight the intersection of the regulated and unregulated domains, and proposed a model that depicts the opportunities to address risks to individually identifiable information through improved stewardship – for consideration by the full Committee. Finally, the Committee launched into planning for its 13th Report to Congress, a congressionally-mandated report due in 2019.

Subcommittee Convenings

NCVHS Subcommittees convened the following meetings in FY18:

July 17-18, 2018: Standards Subcommittee Health Terminologies & Vocabularies Expert Roundtable
Throughout its history, the Committee has studied issues related to the adoption of uniform data standards for patient medical record information and the electronic exchange of such information. Through the Standards Subcommittee, NCVHS in conjunction with the National Library of Medicine (NLM) convened a roundtable July 17-18, 2018 in order to: 1) Assess strengths, weaknesses and gaps in the U.S. health terminology and vocabulary (T/V) environment; 2) Consider areas for near term improvement in the development, maintenance, dissemination and adoption of named code sets; 3) Discuss opportunities for improved governance, coordination and communication across terminology and vocabulary developers and their stakeholders; 4) Identify top priority gaps in the U.S. health terminology and vocabulary coverage; and 5) Envision a roadmap for introducing improvements over the next decade. The Committee identified key experts in the field to provide extensive input to the Subcommittee as it studied these questions and finalized an Environmental Scan report of the current state of the U.S. health terminology and vocabulary (T/V) environment. With this information, the Committee intends to draft recommendations to the HHS Secretary outlining actions that HHS might take to improve development, dissemination, maintenance, and adoption of standards.

May 17, 2018: Standards Subcommittee CIO Forum
The Subcommittee on Standards convened a CIO Forum as part of the information-gathering process leading up to development of draft recommendations to the HHS Secretary for improving the update, adoption and implementation process for health care administrative standards and operating rules. This meeting was part of the Standards Subcommittee 18-month process of engagement with industry and stakeholders. In August 2017, NCVHS held a dialogue with the Standards Development Organizations (SDOs) to identify an initial set of draft action steps and recommendations. The next step towards finalizing recommendations for the Secretary was to convene a group of Chief Information Officers (CIOs) who work with the standards and operating rules as end users, with health care leaders from various fields of health care technology. During the Forum, the CIOs and health care industry leaders

provided information based on their expertise and direct experience with changing business and technology needs specifically as these pertain to the standards that have been adopted under HIPAA such as claims, eligibility, referrals and authorizations. Some participants shared their experience using the standards day-to-day, and to increase efficiencies within their organizations. Other participants shared their experience implementing or seeing innovative technology being used for the exchange of electronic health care information. During the second part of the Forum, participants engaged in an open discussion about the Subcommittee's draft "Predictability Roadmap" themes and developed additional suggestions for action items and recommendations for the Secretary.

March 26, 2018: Standards Subcommittee Virtual Hearing - NCPDP Standards and Updates

The NCVHS Subcommittee on Standards convened a virtual hearing to seek input from the health care industry regarding updated versions of standards from the National Council for Prescription Drug Programs (NCPDP) – specifically, version F2 and Version 10 of the Subrogation standard for Medicaid. The Subcommittee obtained input from stakeholders for the costs and benefits of implementing the updated versions of the two pharmacy standards: NCPDP F2 and pharmacy subrogation, and to understand how they would reduce existing barriers to the use of standards, or mitigate burdens. On January 9, 2018, the DSMO submitted a letter to NCVHS recommending the adoption of two National Council of Prescription Drug Program (NCPDP) updates to the adopted retail pharmacy standards. These updates include: 1) an update to the retail pharmacy standard, the NCPDP Telecommunication and Batch standard version D.0., which was adopted in 2009. The update would be NCPDP Telecommunication and Batch standard version F2, which would enable eligibility verification, claims, services, information reporting, prior authorization (for pharmacy), and pre-determination of benefits; and 2) an update to the Medicaid subrogation standard, also adopted in 2009, to expand subrogation to all payers, including Medicare Parts C and D. The updated subrogation standard is the Batch Standard version 10, and replaces version 3.0. It will enable all payers to conduct a uniform process to support compliance with requirements for recovery of federal, state and other plan overpayments, mitigating manual processes currently in place.

November 28-29, 2017 Virtual Meetings of the Subcommittees

- Subcommittee on Population Health

  The NCVHS virtual meeting of the Population Health Subcommittee convened to discuss follow up work to the NCVHS September 11-12, 2017, Next Generation Vital Statistics Hearing. Two reports from the hearing were discussed and refined: "Next Generation Vital Statistics: A Hearing on Current Status, Issues, and Future Possibilities," and the report commissioned by NCVHS, "Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue." In addition, the Subcommittee discussed topics and projects to be considered for the 2018 workplan.

- Subcommittee on Privacy, Confidentiality & Security

  The NCVHS virtual meeting of the Privacy, Confidentiality and Security Subcommittee convened to address two overarching agenda items: discussion and refinement of a draft report commissioned by the Committee, "Health Information Privacy and Security Beyond HIPAA: A 2018 Environmental

Scan of Major Trends and Challenges"; and obtaining input from a panel of invited experts to further inform the draft environmental scan research being conducted on the Committee's behalf. The agenda also included discussion of privacy-related topics under consideration for the 2018 workplan.

- Subcommittee on Standards

  The NCVHS virtual meeting of the Standards Subcommittee convened to consider the Subcommittee's workplan and big picture milestones for three possible projects in 2018: 1) a Chief Information Officer (CIO) Forum to further inform the Subcommittee's development of recommendations for a "Predictability Roadmap" to improve the update, adoption and implementation process for health care administrative standards and operating rules; 2) the challenge of patient identification and matching for healthcare providers and patients; and 3) potential guidance pertaining to the prior authorization transaction. In addition, CMS provided a briefing to the Subcommittee on the New Medicare Card Project.

Noteworthy Presentations

- Nancy Potok, PhD, Chief Statistician at OMB, and a Commissioner of the Bipartisan Commission for Evidence-Based Policymaking gave a global overview of where federal statistical data are headed, including on health and other programmatic data needed for evidence-based policymaking. Dr. Potok pointed out that although today, federal data are a small but critical piece of the universe of data, the world is moving beyond the point where it is possible to rely solely on surveys and some censuses to collect federal data. More data sources are available, including administrative records, which are generally more complete than survey data and pertain to the entire population in question. During the discussion, members noted the challenge of assessing the value of and gaps in federal data inventories, the question of whether tests of new data science approaches can be sponsored by the federal government, and the need to incentivize agencies to test new approaches that supplant the incentives embedded in the budgetary status quo. Dr. Potok's presentation provided a useful overview of the opportunities, risks, and current challenges of ensuring the quality, availability, and accessibility of federal data and the need for more partnerships with those outside the federal government to seed innovation.

- NCVHS Member Dr. Robert Phillips attended the NCHS Board of Scientific Counselors (BSC) meetings throughout the year reporting back to the Committee on strategic plans and projects underway by the BSC with special attention on shared areas of interest and ensuring no duplication of effort.

- As part of ensuring coordination between the Office of the National Coordinator (ONC), the Health Information Technology Advisory Committee (HITAC), and NCVHS:
  - NCVHS Chair Bill Stead and Rich Landen, member of the Subcommittee on Standards, participated in the February 21, 2018 HITAC meeting, giving a high level overview of NCVHS' work relevant to HITAC to initiate and establish engagement with this new advisory committee.

- ▪ Staff from ONC presented to NCVHS on May 15, 2018 to continue discussion surrounding areas of potential collaboration under consideration.

- Following up from the Committee's previous letter to HHS regarding concerns over implementation of the New Medicare Card Project, CMS staff provided an update at the May full Committee meeting.

- Continuing the Committee's success with energizing the private sector to further its work on community health measurement, Dr. Soma Stout with the Institute for Healthcare Improvement (IHI) 100 Million Healthier Lives initiative met with NCVHS twice this year at full Committee meetings. Dr. Stout described progress by workgroups that are furthering development of essential core measures, identifying data sources as well as giving an update on the work of the stewardship workgroup tasked with guiding the implementation process.

- NCVHS Member Richard Landen presented to the National Plan Automation Group (NPAG) on August 28, 2018, to update Blue Cross Blue Shield plans that have responsibility for the electronic connectivity between the health plan and the hospitals, physicians and other providers. He provided a summary of NCVHS activities over the last year and noted the Committee's emerging understanding of the convergence of use and need for administrative and clinical/EHR data standards.

- NCVHS Member Alix Goss presented to the Work Group for Electronic Data Interchange (WEDI) at their December 2017 event. She provided an overview of the Committee's work relevant to WEDI including the Predictability Roadmap and 2018 workplan, sharing the Committee's global e perspective as it worked toward development of recommendations to increase predictability and make improvements in the adoption of, and processes related to, updating standards and operating rules for electronic administrative transactions.