



Fiscal Year 2019 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 advises HHS regarding the implementation of the Administrative Simplification provisions of the law, specifically adoption and implementation of standards, identifiers, and code sets and the privacy and security rules. The Committee also makes a periodic Report to Congress on the status of 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 the Office of the National Coordinator of Health Information Technology (ONC) and the Health Information Technology Advisory Committee (HITAC) on policy development for clinical (electronic health record [EHR]) and administrative data standards.

NCVHS FY19 Recommendation Letters to the HHS Secretary

- Letter to the Secretary: Recommendations for HHS Actions to Improve Privacy Protection for Health Information not Subject to HIPAA Regulations (June 17, 2019)
- Letter to the Secretary: Recommendations on Regulatory Simplification of the International Classification of Diseases (ICD) (February 21, 2019)
- Letter to the Secretary: NCVHS Recommendations on New Approaches to Improve the Adoption of National Standards for the Health Care Industry (February 13, 2019)
- Letter to the Secretary: Recommendations on Criteria for Adoption and Implementation of Health Terminology and Vocabulary Standards, and Guidelines for Curation and Dissemination of these Standards (February 13, 2019)

Fiscal Year 2019 Overview

In FY19, the Committee completed its Thirteenth Report to Congress while focusing its work in five overarching areas.

- Thirteenth Report to Congress

In March 2019, the Committee released its “Thirteenth Report to Congress on the Implementation of the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act (HIPAA).” Through the report, the Committee advised that revisions to current HIPAA rule-making processes are needed to facilitate the agility industry needs – and currently lacks – to keep pace with the opportunities and challenges of today’s health care landscape. While the processes HIPAA set in motion were essential at the time enacted, they have not kept pace with the rate of change in policy, health care, and technology – greatly constraining administrative simplification and clinical interoperability.

- Privacy for Health Information not Covered by HIPAA

Informed by hearings and the development of an extensive environmental scan, this year the Committee produced a letter with six recommendations and a report for policymakers, “Health Information Privacy Beyond HIPAA: A Framework for Use and Protection,” focused on the dynamic and largely unregulated world of health and health-related information not covered by the HIPAA Privacy and Security Rules.

- Health Terminologies & Vocabularies

In the first half of FY19, the Committee recommended two significant updates to previous recommendations for HHS consideration:

- a. Criteria for Adoption and Implementation of Health Terminology and Vocabulary Standards
- b. Guidelines for Curation and Dissemination of Health Terminology and Vocabulary Standards

Health terminology and vocabulary systems, such as the International Classification of Diseases (ICD), are the backbone of interoperable health information, health statistics, and research. These recommended criteria and guidelines will serve HHS when it considers the adoption of standards.

- Recommendations on the Upcoming Transition to ICD-11

In the first half of FY19, the Committee submitted three recommendations to the HHS Secretary with advice for simplification of the adoption of future versions of the International Classification of Diseases (ICD) and related health terminology and vocabulary standards.

In the second half of FY19, the Committee convened an ICD-11 expert roundtable meeting of experts representing government, academia, health industry associations, health care providers, and other stakeholders. After evaluating input from invited experts, the Committee:

- identified main lessons learned from the ICD-10 planning process/transition and the differences between ICD-10 and ICD-11;
- recommended that HHS conduct or contract for research to inform evaluation of cost and benefit of transition from ICD-10 to ICD-11 for mortality and morbidity; and
- framed key messages and topics to communicate to the industry to foster early stakeholder engagement and preparation for the transition to ICD-11.

- Predictability Roadmap

The Subcommittee on Standards began the fiscal year by convening a hearing of experts to provide input to the Committee’s work in developing recommendations to address current challenges regarding the update, adoption, and implementation of health care administrative standards and operating rules. This culminated in five recommendations submitted to the HHS Secretary that outlined approaches to improve the adoption of national transaction standards. The Subcommittee held a follow-up “visioning” meeting in July 2019 focused on the function, purpose and evaluation of the Designated Standards Maintenance Organizations (DSMOs) – with the goal to define a timeline and approach to standards updates and adoption by the government to promote predictability in the health care industry.

- Collaboration with ONC on the Intersection of Clinical and Administrative Data Standards

As stipulated in the 21st Century Cures Act, NCVHS and ONC continued to collaborate their respective data standards work. In March 2019, NCVHS Chair Bill Stead together with the co-chairs of the Subcommittee on

Standards participated in a joint hearing with ONC’s HITAC focused on understanding the major obstacles with the prior authorization transaction. Meeting participants expressed consensus that improved coordination of clinical information exchange with administrative transaction standards is essential to reduce burden. Don Rucker, National Coordinator for Health Information Technology (HIT) participated in the June NCVHS meeting. As a result, NCVHS and ONC came together to define the broader issues at the intersection of clinical and administrative data standards, with defined projects anticipated for fiscal year 2020 that will coordinate the respective work of NCVHS and HITAC.

NCVHS FY19 Reports	
▪	NCVHS Thirteenth Report to Congress on the Implementation of the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act (HIPAA) (March 14, 2019)
▪	Health Information Privacy Beyond HIPAA: A Framework for Use and Protection. A Report for Policy Makers (June 18, 2019)

Committee Impact

Four sets of recommendations were developed for the Secretary this fiscal year through letters submitted to the Secretary from February 2019–July 2019. The Committee issued a fifth letter in response to a request for comment on the Federal Data Strategy 2019-2020 Action Plan. In addition, the Committee issued two reports of national interest, both of which informed its recommendations:

- “13th Report to Congress: On the Implementation of the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act (HIPAA) of 1996,”
- “Health Information Privacy Beyond HIPAA: A Framework for Use and Protection—A Report for Policy Makers.”

The Committee has been a steady influence in providing guidance and support for the administrative simplification process, including the standards development process and interoperability. Many of the recommendations pertain to aspects of health information policy that have evolved over decades.

Implementation of these recommendations usually requires consensus and collective activity from multiple agencies and components of the Department. As stipulated in its Charter, the Committee regularly interfaces with stakeholders in the field and takes their input into account in development of reports and recommendations.

- NCVHS was highlighted in *Health Data Management*, April 1, 2019, "Regulators get industry guidance for the future of ICD-10 updates," that featured the Committee's recent letters. The article indicated that NCVHS is offering ideas for changes that would affect adoption of future versions of the code sets and related health terminology and vocabulary standards. In noting that HIPAA requires HHS to review adopted standards and make modifications when appropriate, the article noted that NCVHS identified three recommendations for HHS regarding ICD-10 version updates.
- In October 2019, HHS published a Final Rule that amended 45 CFR 162.103 and repealed 45 CFR 162.502-514 to rescind the adoption of the Health Plan Identifier (HPID) and Other Entity Identifier (OEID) under the Administrative Simplification provisions of HIPAA. The final rule eliminated the regulatory requirement for health plans to obtain and use an HPID and eliminates the voluntary acquisition and use of the OEID. NCVHS [issued a letter to HHS in 2017](#) with a recommendation that the Health Plan Identifier be rescinded.
- The sixth most read story of 2019 in APHA's *Nation's Health* magazine was a [story highlighting the findings](#) of the US News and World Report's Healthiest Communities Rankings. USNWR credits NCVHS as the originator of the work: <https://www.usnews.com/news/healthiest-communities/articles/methodology>.
- In response to the Committee's report "Health Information Privacy Beyond HIPAA: A Framework for Use and Protection. A Report for Policy Makers":
 - Don Rucker, National Coordinator for Health IT invited NCVHS to present the report findings to the Health IT Advisory Committee (HITAC).
 - NIST and OCR invited NCVHS to present the report and findings at the fall 2019 Conference on Safeguarding Health Information.
 - American Medical Informatics Association (AMIA) leadership drew upon the report to inform its research and analysis prior to briefing Senate HELP Committee staff.
 - [Hogan Lovells Chronicle of Data Protection](#) cited the NCVHS report in a blog post including a link to the report further disseminating the report to a broader audience.
- At the request of ONC, NCVHS provided input into the Draft National Health IT Research Priorities Policy and Development Agenda that increased specificity in key areas.

Other Noteworthy Activity

Several Standards Subcommittee members presented on the Predictability Roadmap topic to stakeholders throughout the year. The goal of the Roadmap is to identify possible approaches to improve the predictability and improvements in adopting and updating standards and operating rules for electronic administrative transactions, e.g. claims, eligibility, electronic funds transfer. Alix Goss, Subcommittee co-chair, was a featured speaker at the spring Workgroup on Electronic Data Interchange (WEDI) conference, May 20, 2019, where she provided an NCVHS update on recommended reform for improved interoperability. The conference convened health care leaders across payers, providers, government regulators and industry vendors to discuss critical challenges facing the industry including public and private entities. Alix Goss also delivered a webinar to the CAQH CORE community

in November 2018. In August 2019, Rich Landen presented an update on all NCVHS work, with a focus on Standards, to the National Plan Automation Group (NPAG, now newly renamed as eSolutions Xchange).

NCVHS Meeting Highlights

The full Committee convened twice during the 2019 fiscal year, as well as November 2019 (FY2020). To follow is a high-level summary:

February 2019

The Committee met to deliberate its draft 13th Report to Congress and three letters to the HHS Secretary—all of which were unanimously approved and finalized during the meeting. The letters put forth to HHS:

- Five recommendations on new approaches to improve the adoption of national standards for the health care industry to support greater predictability industry-wide;
- Two recommendations for revisions to criteria for adoption of health terminology and vocabulary standards/systems and new guidelines for curation and update of already adopted standards; and
- Three recommendations to advance regulatory simplification for the International Classification of Diseases (ICD).

The Subcommittee on Privacy, Confidentiality and Security reviewed its progress and plans for a Subcommittee meeting in March to complete work to develop recommendations pertaining to health information privacy not covered by HIPAA and propose a new privacy framework. The Subcommittee on Population Health organized a briefing from the Institute for Healthcare Improvement-100 Million Healthier Lives leadership on the Well-being in the Nation (WIN) measurement framework, a project originally spearheaded by the Committee. The Committee turned over its work to the private sector for refinement and implementation to improve measurement capability and data accessibility in support of population health improvement.

June 2019

The Committee met to deliberate on a draft report on health data privacy and letter to the Secretary developed by the Subcommittee on Privacy, Confidentiality and Security, both of which were finalized and approved by the full Committee. The letter transmitted recommendations on actions HHS could take to improve privacy protections for health information not subject to HIPAA regulation, e.g., health data registries, mobile devices and apps, genetic information and commercial organizations in possession of both individually identifiable and de-identified personal health information outside the scope of HIPAA. The Committee heard from invited experts on the upcoming transition from ICD-10 to ICD-11. This input informed plans to develop Committee recommendations for a pathway to ICD-11 that supports the Department's priorities and is aligned with other health terminology and vocabulary priorities and industry standards. The Standards Subcommittee reviewed the status and strategic plans for its July meeting focused on Designated Standards Maintenance Organizations (DSMO). The National Coordinator for Health Information Technology provided an update on the collaboration between ONC, HITAC and NCVHS. Finally, the Population Health Subcommittee led a discussion to prepare a comment

letter from the Committee in response to an Office of Management and Budget (OMB) request for public comment on the Draft 2019-2020 Federal Data Strategy Action Plan.

Subcommittee Convenings

NCVHS Subcommittees convened the following four meetings in FY19:

December 12-13, 2018: Predictability Roadmap Hearing

NCVHS's Subcommittee on Standards held a hearing in continuation of the Committee's work to identify the challenges regarding the update, adoption, and implementation of health care administrative standards and operating rules. The Committee's overarching objective was to create a Predictability Roadmap to enhance the transparency and pace of change of the standards promulgation process under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The purpose of the hearing was to obtain stakeholder perspectives on the Committee's draft recommendations developed with industry's input and released to the public on September 30, 2018. The feedback received informed development of recommendations submitted to the HHS Secretary by the full Committee in early 2019.

March 21-22, 2019: Subcommittee on Privacy, Confidentiality and Security Meeting

The Subcommittee on Privacy, Confidentiality and Security held a working session focused on health information privacy and security beyond HIPAA. The purpose of the meeting was to develop recommendations to define a contemporary framework of data stewardship for the HHS Secretary, including a pathway for improving private and public sector governance of health information over the next decade building on the Committee's past work in this area. The working session successfully:

- Outlined key principles for stewardship of health data described in the environmental scan that was developed last year and noted the essential public and private actions needed for progress;
- Developed recommendations to define a contemporary framework of data stewardship for the HHS Secretary, including a pathway for improving private and public sector governance of health information over the next decade;
- Developed a strategy to build on NCVHS's past work including the Environmental Scan, recent hearing, and letters to the Secretary, reach consensus on actions to update NCVHS' 2008 report, "Enhancing Protections for Uses of Health Data: A Stewardship Framework - Summary for Policy Makers;" and
- Identified key themes to communicate these messages to individuals, policymakers, and stakeholders in the private sector.

The result of the meeting was a recommendation letter to the Secretary together with the report "Health Information Privacy Beyond HIPAA: A Framework for Use and Protection—A Report for Policy Makers."

July 10-11, 2019: Subcommittee on Standards Visioning Meeting

The Subcommittee on Standards held a meeting to gain input from industry experts to support formulation of recommendations for improving the processes for both updating and adopting standards and operating rules. In its February 2019 recommendation to the Secretary, NCVHS urged HHS “to re-evaluate the function and purpose of the Designated Standards Maintenance Organizations (DSMOs).” In this meeting, invited participants provided input focused on the re-evaluation of the DSMOs, and the impact that might have on improving standards updates and their ultimate adoption by the government.

Improving these processes would enhance the predictability of implementation, enable innovation and support changes in technology. In light of advances in the industry over 20 years, action is needed to improve the process for updates, adoption and implementation of transaction standards and operating rules to keep pace with innovative business needs, and technology changes including the electronic and digital environment. In this facilitated visioning session, industry stakeholders envisioned a set of viable options for a next generation DSMO and made a clear call to “do something and do it now”. Subsequent to the meeting, the Subcommittee drafted additional recommendations to improve the process, based on the input received during this meeting. The Committee approved the recommendations at its November meeting and sent the letter to the Secretary on December 10, 2019.

August 6-7, 2019: Subcommittee on Standards Meeting

The NCVHS Subcommittee on Standards held an ICD-11 Expert Roundtable meeting to:

- Develop a shared understanding of lessons from the ICD-10 planning process/transition and the differences between ICD-10 and ICD-11;
- Reach consensus on the research questions to be answered to inform evaluation of cost and benefit of transition from ICD-10 to ICD-11 for mortality and morbidity; and
- Identify key topics/messages to communicate to the industry to foster early stakeholder engagement and preparation for the transition to ICD-11.

The extent to which implementation and use of ICD-11 can be automated in real-world settings in the U.S. will require research and evaluation. In the Committee’s assessment, the need for research is compelling given ICD-11 may, or may not, provide significant opportunity to reduce provider burden and increase interoperability of electronic health information – high priority goals for the U.S.

Informed by input received from experts, the meeting outcome was a recommendation letter to the HHS Secretary that included a set of research questions and communications plan approved at the November meeting. The Committee’s main message to HHS is that taking a proactive approach to research, communications, and copyright for the transition to ICD-11 in the U.S. will enable key stakeholders, led by HHS, to identify the optimal path forward, maximizing benefit and minimizing cost.