

Department of Health and Human Services  
NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS  
February 6-7, 2019  
Hubert H. Humphrey Building, Washington, DC  
MEETING MINUTES

**Note:** For details on this meeting, please refer to the transcript and slides posted at [www.ncvhs.hhs.gov](http://www.ncvhs.hhs.gov). See "Related Items" associated with the meeting agenda.

The National Committee on Vital and Health Statistics (NCVHS) convened on February 6-7, 2019, at the Department of Health and Human Services' Hubert H. Humphrey Building in Washington, DC. The meeting was open to the public. Present:

**Committee Members**

William W. Stead, MD, Chair  
Bruce Cohen, PhD  
Nicholas Coussoule  
Llewellyn Cornelius, PhD, LCSW  
Alexandra Goss (by phone)  
Linda Kloss, MA, RHIA, CAE, FAHIMA  
Richard Landen, MPH, MBA  
Denise Love, BSN, MBA  
Vickie Mays, PhD, MSPH  
Jacki Monson, JD (by phone)  
Bob Phillips, MD, MSPH  
Debra Strickland, MS

*Absent:*

Roland Thorpe, Jr., PhD

**Lead Staff**

Sharon Arnold, PhD, ASPE, Executive Staff Director  
Rebecca Hines, MHS, NCHS, Executive Secretary/DFO  
Lorraine Doo, MPH, CMS, Lead Staff  
Rachel Seeger, JD, OCR, Lead Staff

**NCVHS Staff**

Debbie Jackson, MA, NCHS  
Marietta Squire, NCHS  
Geneva Cashaw, NCHS

**Others (not including presenters)**

Geanelle Herring, CMS  
Suzy Roy, NLM  
Maya Bernstein, ASPE  
Mike Lincoln, VA  
Suzanne Niemeyer, Ketchum  
Gail Kocher, BC/BS  
Susan Baird Kanaan, contractor/writer

## ACTIONS

The following documents were approved at this meeting and are posted on the NCVHS website, [www.ncvhs.hhs.gov](http://www.ncvhs.hhs.gov).

1. The Committee unanimously approved a letter to the Secretary with recommendations on a Predictability Roadmap, pending inclusion of minor edits discussed and approved.
2. The Committee unanimously approved a letter to the Secretary with recommendations on selection criteria for adoption of health terminology and vocabulary standards and guidelines for curation and dissemination of these standards.
3. The Committee unanimously approved a letter to the Secretary with recommendations on regulatory simplification for the International Classification of Diseases (ICD).
4. The Committee unanimously approved the content of the 13<sup>th</sup> Report to Congress on the Implementation of HIPAA, along with the following process for finalizing the Report: The Report will be revised to incorporate the edits agreed to during this meeting. A redlined version of the revised report will be circulated to the Full Committee; members are to review edits and forward any concerns about the revised version. The Executive Subcommittee is authorized to approve the final version ensuring approved edits are incorporated.

## —DAY ONE—

### **Welcome and Agenda Review—Dr. Stead**

Dr. Stead welcomed those present and reviewed the agenda. It featured three action items as well as reports from ASPE, NCHS and ONC; a farewell to three long-time members; presentation of the 100 Million Healthier Lives Well-being in the Nation (WIN) Measurement Framework, which is based on the NCVHS Measurement Framework on Community Health and Well-being; and planning for ongoing NCVHS projects.

### **Predictability Roadmap: Draft Recommendations—Mr. Coussoule, Ms. Strickland (SLIDES)**

Mr. Coussoule began with providing background on the Predictability Roadmap initiative. The Subcommittee on Standards has spent two years focused on this project in consultation with industry, standards development organizations (SDOs), and operating rule authoring entities (ORAEs). Besides making a number of presentations to organizations, it held a visioning workshop, a CIO Forum, and a two-day hearing in December 2018, all to obtain input on the standards process from stakeholders. The December 2018 hearing elicited input on draft NCVHS recommendations, which provided significant information to the Subcommittee as it developed its initial recommendations to HHS. Mr. Coussoule thanked all those who contributed to this process.

What the Subcommittee heard from stakeholders through this consultative process was that there is an urgent need to accommodate business and technology changes in health care by improving standards development processes from conception to implementation to adoption, to ensure that the regulatory process enables use of updated or new standard transactions and operating rules and to reduce

administrative burden. The Subcommittee identified opportunities for improvement in federal processes, the processes of SDOs and ORAEs, and governance and oversight. This includes opportunities to foster innovation, facilitate diverse participation, create greater transparency, and ensure value.

During the December hearing, 36 panelists from diverse stakeholder groups responded to the following questions about the Subcommittee's 23 original draft recommendations, calls to action, and measurements:

1. Would these recommendations improve the predictability of the adoption of administrative standards and operating rules?
2. What additional recommendations are critical to achieve predictability?
3. How can we achieve the desired outcomes?
  - What is the value proposition of each recommendation and what improvements to the current state could arise from these recommendations?
4. What are the unintended consequences of the recommendations?

The themes that arose at the hearing related to timing, voluntary use of standards, transparency, education, evaluation, and return on investment. The Subcommittee also received significant written comments from more than 30 sources. The process yielded the following recommendations, which are contained in the letter to the Secretary being presented today to the Full Committee for approval:

1. Remove regulatory mandate for modifications to adopted standards and move towards industry driven upgrades.
2. Promote and facilitate industry's voluntary testing and use of new standards or emerging versions of transactions or operating rules.
3. Improve the visibility and impact of the administrative simplification enforcement program.
4. Provide policy related guidance from HHS for administrative standards adoption and enforcement.
5. Re-evaluate the function and purpose of the Designated Standards Maintenance Organizations (DSMOs).

As next steps, the Standards Subcommittee plans to collaborate with HHS, DSMOs, WEDI, and industry on the next version of DSMOs ("2.0"); to collaborate with the Office of the National Coordinator (ONC) and its advisory committee, HITAC, on convergence of administrative and clinical standards; and to develop and update the Subcommittee's work plan.

Ms. Strickland then reviewed the draft letter with the Committee and invited their questions, comments, and suggested modifications. Mr. Coussoule and Ms. Goss provided occasional commentary on the Subcommittee's thinking about various passages. A few minor modifications were suggested and accepted. A topic of particular interest to the Committee concerned DSMOs and the recommended evolution toward "DSMO 2.0." Dr. Stead explained that there was clear and strong consensus on the first four, very targeted recommendations, while the fifth one surfaced as an area on which further work is needed. Ms. Kloss added that the first four are in the purview of the Secretary while the fifth is at the juncture of private and public; and Ms. Goss noted that the fifth area is a prime candidate for collaboration. Mr. Landen explained that the idea behind recommendation 5 is to "start the thinking process about what the DSMO should morph into" in order to bring greater collaboration. He also noted

the relevance of the convergence of administrative and clinical data (another theme of this NCVHS meeting). Several members expressed agreement with Dr. Mays on the importance of creating a broad umbrella and engaging bodies that thus far have been underrepresented in the standards process, such as Federally Qualified Health Centers and the Indian Health Service.

The Committee then unanimously passed a motion approving this letter to the Secretary, pending minor changes.

Mr. Coussoule stated the Subcommittee would next write a scoping document to frame its forthcoming work related to "DSMO 2.0." It also will update the narrative report on the December hearing. Dr. Stead extended his thanks to the Subcommittee and its staff for their work on this project.

### **ASPE Update—Sharon Arnold, ASPE**

Dr. Arnold, HHS Executive Staff Director for NCVHS, noted that two of the Secretary's four priorities—moving toward value-based purchasing and reducing the risk of opioid overdose—are particularly reliant on improving data and interoperability, and thus closely linked to NCVHS work. She cited the importance of protecting privacy as part of the growing effort to link data and the Department's interest in the Committee's guidance around standards. She then reviewed the chief components of the recently enacted Foundations of Evidence-Based Policymaking Act. The HHS Data Council is looking into establishing a data catalog as called for in the new law.

Dr. Arnold announced that the Secretary had approved Dr. Bill Stead to continue as NCVHS chair to the end of his tenure, approved a second term for Ms. Denise Love, and appointed a new member. He is Frank Pasquale, professor of law at the University of Maryland and an expert in health law and the law on artificial intelligence, algorithms and machine learning, among other topics. Finally, she expressed warm thanks to Dr. David Ross, Dr. Bruce Cohen, and Ms. Kloss, the members whose terms have ended. She also noted that this is the 70<sup>th</sup> year of NCVHS and acknowledged its "continued legacy and really helpful products."

In the discussion period, members called the following issues and NCVHS products to Dr. Arnold's attention for discussion:

- Report to the Secretary on [healthdata.gov](http://healthdata.gov);
- White paper on a Health Data Framework (March 21, 2017);
- Issues emerging in the state orbit; and
- Opportunities to link the new WIN Measurement Framework to the work on the Federal Data Strategy.

Dr. Arnold expressed interest in collaborating with NCVHS in the future, though noting that the Department continually struggles with having to "do more with less" due to flat, and in some cases declining budgets.

### **Health Terminologies and Vocabularies: Draft Letters—Ms. Linda Kloss (SLIDES)**

On behalf of the Subcommittee on Standards, Ms. Kloss brought forward two letters to the Secretary, one on selection criteria and guidelines for health terminologies and vocabularies and the other on an evaluation pathway to ICD-11.

- **Recommendations to the HHS Secretary on selection criteria for adoption of health terminology and vocabulary standards, and guidelines for curation and dissemination of these standards**

The goals of the health terminologies and vocabularies project, which began in early 2017, are to 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) the needs, opportunities, and problems with development, dissemination, maintenance, and adoption of health terminology and vocabulary standards, and 3) actions that HHS might take to improve development, dissemination, maintenance, and adoption of standards. The Committee's analysis and consultations have included two hearings, development of an environmental scan, and an expert roundtable meeting. Having begun with a broad scope and process, it is now setting a narrower scope for the next step.

Ms. Kloss described the first letter, which reflects the consensus at the roundtable that it was time to update the principles to guide adoption of health terminologies and vocabularies that NCVHS had approved in 1998, and also to develop a first set of guidelines for updating terminologies and vocabularies. In addition, the Committee recognized a near-term opportunity to apply the selection criteria and guidelines in a project to evaluate ICD-11 (see the second letter, below). The first letter recommends that the Secretary adopt the criteria and guidelines, which are attached to the letter. The criteria are designed for use in the official capacity of secretarial adoption, while the guidelines, which are aspirational, are intended as a resource for organizations that curate and disseminate health terminologies and vocabularies. Ms. Kloss invited members' comments and suggestions, and a few were offered. In response to a question, she said the Committee expects to address questions of governance and/or coordination as a mid-term step in the future as part of a strategic planning process.

Regarding the guidelines, she noted that this is a new set, intended to be fundamental. The Committee's discussion of the guidelines at this meeting focused particularly on the intended usage. Dr. Stead explained that the letter anchors NCVHS' role in recommending the criteria and guidelines in its role with respect to HIPAA, but was also careful to avoid limiting the applicability of the two attachments to things that relate to HIPAA. He acknowledged the contributions of Mike Lincoln and Steve Brown from VA in this work, as well as those of colleagues from the National Library of Medicine.

The Committee then passed a motion approving the letter to the Secretary, subject to the few editorial changes suggested.

- **Recommendations to the HHS Secretary on Regulatory Simplification for the International Classification of Diseases (ICD)**

They then moved on to the draft letter recommending regulatory simplification for ICD. Ms. Kloss explained that this issue arose in the environmental scan and the roundtable from the recognition that the ICD was the only classification system for which an update required regulation; all others are managed according to a schedule from the sponsoring organization. NCVHS members reviewed and discussed each of the recommendations and suggested a few modifications. Action on this letter was deferred to later in the meeting, after revision of one section based on this discussion was completed.

### **13th NCVHS Report to Congress on Implementation of the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act of 1996—Dr. Bill Stead (SLIDES)**

The Committee's two-fold purpose with this Report to Congress, which covers 2017-2018, is: 1) to meet its statutory requirement to report regularly on HIPAA implementation status and 2) to outline ways in which HIPAA needs modernizing so it can support needed improvements in innovation and health care while reducing costs and administrative burden. Dr. Stead reminded members of the Committee's multi-step process to develop the report, starting in August 2018 and involving numerous stages of iteration to obtain input and review from NCVHS subcommittees and members. He explained the thinking about the structure and key messages of the report and shared documentation of the huge potential savings to be realized from "complete" administrative simplification. The Report delivers these key messages:

1. HIPAA was a visionary Law that put the country on a path toward standardizing electronic health care transactions and protecting patients' health care information.
2. It has achieved considerable success. However, the regulatory processes it put in place have not kept up with changes in technology and health care.
3. Revisions to the current HIPAA Rules would facilitate the agility industry needs to keep pace with the opportunities and challenges of today's ever-changing health care landscape.

In developing the Report, the subcommittees identified actions within their respective domains that the legislative and executive branches along with private sector and community-level entities might take, separately or preferably jointly, to introduce into HIPAA the flexibility and pace that today's rapidly-evolving environment demands. Part 1 of the report presents these suggested actions in the areas of: 1) transactions, operating rules & associated terminologies & vocabularies and 2) privacy, confidentiality, and security. All the suggested actions are predicated on distinct roles for Congress, the Executive branch, and multiple private sector actors. NCVHS believes that these distinctions will facilitate efficiency and coordination, while concerted action across them will produce compounding effects. This foundational insight about distinct *and* complementary roles emerged from the work on the Predictability Roadmap, along with awareness of the strong consensus in the health care industry about the key messages outlined above.

Part 2 of the Report presents a status report on administrative simplification implementation, with a set of themes and takeaways based on NCVHS work in 2017-2018 on transactions standards and operating rules; terminologies and vocabularies; and privacy, confidentiality, and security. At this meeting, the co-chairs of the relevant subcommittees outlined the themes and takeaways they had contributed to the report.

Part 3 of the Report focuses on the data essential for management of population and community health. Dr. Bruce Cohen presented the themes, takeaways, and suggested actions in this realm, which has become critically linked to health care management and delivery now that the relationship between individual and community/population health is well established in public policy and health care.

Finally, Part 4 reiterates the Report's key messages and outlines the Committee's next steps on three NCVHS initiatives—the Predictability Roadmap, Health Terminology and Vocabulary Standards/Systems, and A Health Privacy and Security Framework for the 21st Century.

Dr. Stead opened the floor for discussion and invited final revisions to the Report, and the Committee reviewed it line by line. Members engaged in a rich discussion, indicating support for the substance while suggesting various ways to clarify and/or strengthen specific passages. The Committee then unanimously voted to approve the Report, subject to editing and final approval by the Executive Subcommittee. In the

interim, all members will be sent a redlined version of the revised Report, with the opportunity to provide feedback with any remaining concerns. Dr. Stead welcomed the Committee's action on the Report, noting that "this is an environment in which this Report will be useful."

### **Recommendations on Regulatory Simplification for ICD, continued**

As their final act on this full day, members returned to the revised letter with recommendations on regulatory simplification of ICD-11 and unanimously approved the letter, as revised. Dr. Stead remarked that NCVHS had never before approved three action letters and a Report to Congress on the same day, and he thanked everyone for their "unbelievable preparation." The Committee then recessed until the following day.

## **—DAY TWO—**

### **Committee Updates**

- Dr. Bob Phillips reported on the National Center for Health Statistics (NCHS) Board of Scientific Counselors (BSC), on which he represents NCVHS. The Federal Data Strategy, which has moved rapidly, was the biggest news. It involves an effort to increase security and access, with a vision for 30 research data centers across the U.S. The budget for the Center is flat. The National Hospital Ambulatory Medical Care Survey and the National Hospital Care Survey are being rolled together to create a combined data stream for obtaining hospital-focused data. Dr. Phillips briefed the BSC on the NCVHS work on the next generation of vital statistics.
- Ms. Alix Goss reported that as part of the Predictability Roadmap effort, she gave presentations to the Workgroup for Electronic Data Interchange (WEDI), the National Uniform Claims Committee, the National Uniform Billing Committee, and CAQH CORE. Ms. Debra Strickland also presented for a WEDI webinar.
- Dr. Vickie Mays said the Statistics Committee of the National Academy of Medicine might want to be briefed by NCVHS in June about the changes happening to the Census.

### **Well-being in the Nation (WIN) Measurement Framework —Soma Stout, MD, IHI/100 Million Healthier Lives (SLIDES)**

Dr. Cohen welcomed Dr. Soma Stout, Vice President of the Institute for Healthcare Improvement (IHI) and Executive Lead for 100 Million Healthier Lives. NCVHS conferred stewardship for the NCVHS Measurement Framework on Community Health and Well-being to 100 Million Healthier Lives, and they have built a collaborative process over the past year to select measures for the Framework and move toward implementing it. He observed that this group has been notably dedicated and has shown outstanding accomplishments.

100 Million Healthier Lives (100mHL) is a partnership among thousands of organizations working to improve health, well-being, and equity throughout the globe. Dr. Stout asked the Committee to think about whether the WIN Framework aligns with the approach and principles NCVHS set out in the initial Framework and report and to offer guidance on implementation.

In her presentation, Dr. Stout described the process taken thus far in developing the Framework and how it has evolved; named some key decision points; and outlined next steps. Starting in the summer of 2017, 100mHL convened groups on metrics development and measurement implementation, together

representing nearly 100 organizations, along with a Stewardship Group to oversee the process. The process began with a landscape analysis, compilation and rating of hundreds of measures based on a set of criteria, followed by four rounds of a Delphi process involving more than 100 organizations. Over all, people found significant value in the concept of a framework with multisector measures that matter at both national and community levels. However, there was a communication challenge in that people found the name of the NCVHS framework difficult to remember and the large number of domains and sub-domains a challenge to apply. The 100mHL process also revealed strong interest in including the well-being of people and equity as separate domains, with equity at the core.

Dr. Stout showed a slide summarizing how the initial NCVHS Framework evolved into the WIN framework. The WIN core measures have three overarching “themes”: well-being of people, well-being of places, and equity. This super-structure helped make the Framework more comprehensible and enabled “a mobilization to action across the board.” She stressed that all the original NCVHS domains and sub-domains are still included but the simpler structure facilitates communication about core measures. The organizers also found that an overwhelming number of groups see child poverty as the single most significant measure of a community’s health. Another structural change made to the NCVHS Framework was to divide the WIN Framework into prioritized “leading indicators” and an expanded set with “developmental indicators” that can be the focus of research and testing.

Dr. Stout named a dozen categories of committed implementation partners for the WIN Framework, to date, including multiple health systems, states, federal agencies, foundations, public health agencies, and technology groups including Community Commons. *U.S. News and World Report* has adopted the initial framework for its ranking of healthy communities, and the American Heart Association is using WIN measures for its national initiatives.

She concluded her presentation by asking the Committee four questions:

- Does this framework evolution feel consistent with the intent of the NCVHS framework’s original intention and principles?
- Are you comfortable with the structure and the new name?
- Should we include measures for all domains and subdomains in both the leading indicators and the full set?
- What recommendations do you have to guide us as we advance into implementation?

In the discussion period, members were interested in how this dynamic Framework would evolve. Dr. Stout said the plan is to keep core measures and leading indicators stable for at least a year, and to annually review and elevate or demote measures. Developmental measures can be updated and adopted at any time. As for dissemination, a Web platform is being developed that will feature the Framework, implementation guides, and a “change library” with use case stories. 100mHL also has monthly calls with communities and regular webinars. Broadly speaking, the initiative is creating “a measurement and improvement ecosystem for well-being.”

Dr. Phillips noted that many of the items in the Framework depend on federal data sources and wondered about a receptor site in the federal government, in view of the Federal Data Strategy and the Evidence-Based Policymaking Law. It was suggested that NCVHS build this question into its future work plan. Dr. Mays later suggested focusing at the state level.

Dr. Stead praised the direction the Framework is moving, and suggested as a clarification that well-being of people, well-being of places, and equity be framed as outcomes. He and Dr. Cohen expressed



satisfaction that the NCVHS domain structure remains “recognizable” by the different executive secretariats/departments across the federal government, e.g., Transportation, Housing, Education, etc.

Finally, Mr. Landen, Ms. Hines, and Dr. Stead responded to the four questions Dr. Stout had asked of NCVHS as follows:

- The Framework evolution does feel consistent and is right on target, and NCVHS is eager to see the process keep moving.
- The structure and new name are at the discretion of 100 Million Healthier Lives, the steward to which NCVHS turned over its Framework.
- Dr. Stead suggested that the measures for the domains and subdomains be assigned based on the priorities that arose through the Delphi process; those that are not deemed valid should be included as developmental measures. He noted that this process will be much like what the Predictability Roadmap is recommending for standards: promotion “up from use cases” rather than “down from regulation.”
- Dr. Cohen asked the Subcommittee on Population Health to review the final draft report and provide any further feedback to Dr. Stout.

In conclusion, Dr. Stout announced a Well-being Trust meeting in Oakland, CA on April 10, which can be attended virtually or in person. The meeting will focus on the strategy for assuring data availability and access, including commitments to fund data collection where needed; how to make adoption easier; and creating a set of stewards for the learning process.

### **Healthy People 2030: Federal Role in Supporting State, Local, and Community Measurement —Carter Blakey, Office of Disease Prevention and Health Promotion (ODPHP) (SLIDES)**

Ms. Hines introduced Ms. Blakey, who is the Deputy Director of ODPHP. Ms. Blakey began by expressing excitement about the work described by Dr. Stout and the hope that their programs can work together at some point. She then gave a brief history of Healthy People (HP), which began in the 1970s with about 200 objectives and grew to more than 1,200 objectives in its fourth decade. She described the ongoing effort to reduce the objectives to a manageable number that still allows stakeholders to “see themselves.” At present, HP2030 has 355 objectives, and another 25 or so may be added as its ongoing development process continues.

The process for developing the 2030 objectives, as in the past, involves an advisory committee of outside experts; two groups within federal government, the Federal interagency workgroup and topic area co-leads across the 42 topic areas; and public comment. The first phase, the framework, was completed in June 2018. The goals for HP2030 are to:

1. Attain healthy, thriving lives and well-being, free of preventable disease, disability, injury and premature death.
2. Eliminate health disparities, achieve health equity, and attain health literacy to improve the health and well-being of all.
3. Create social, physical, and economic environments that promote attaining full potential for health and well-being for all.
4. Promote healthy development, healthy behaviors and well-being across all life stages.

5. Engage leadership, key constituents, and the public across multiple sectors to take action and design policies that improve the health and well-being of all.

In addition to core and developmental objectives, there is a new category of research objectives, to explicitly encourage research and data collection.

Ms. Blakey described the thinking, efforts, and plans around data infrastructure and accessibility for HP2030. For example, the Secretary's Advisory Committee on Healthy People recommended the following: "To support programs and inform policies to meet the objectives, data specific to the community are needed.

- "HHS should work with communities to frequently (e.g., every quarter) update community-level information (e.g., numerical data, observations that community members are making about progress or barriers).
- "Community-level information should be used together with national, state, and tribal data to enable accountability, surveillance, and decision-making."

After outlining the steps between now and implementation in 2020, she invited questions and comments from NCVHS.

In the discussion period, Dr. Mays expressed excitement about the research category and wondered about collaboration with other federal agencies to fund that kind of research. Ms. Blakey responded that ODPHP "has no money" but is good at partnering. Asked about a strategy to connect with community data collectors, she said ODPHP plans to do this.

### **Essential Role of Vital Registration Data and Statistics in Community Measurement —Steve Schwartz, Director, Division of Vital Statistics (DVS), NCHS (SLIDES)**

Dr. Cohen introduced Dr. Schwartz as his "experienced friend and colleague" from the days when they both worked at the state level. Dr. Schwartz, who recently became the Director of DVS, described his long-time work as Registrar for "the great state of New York City" (as one of the 57 vital registration jurisdictions). He noted that vital statistics work has both a retail side, serving customers, and a wholesale side, compiling public health data. As a federated system, the quality of the national Vital Statistics System depends on how well everyone works together. This System has grown in timeliness and vibrancy to become "more of a surveillance system" today. Dr. Schwartz showed slides illustrating the improvements in timeliness, especially for natality. Mortality data are less timely, partly because deaths often require more investigation. However, DVS is working for faster reporting with medical examiners and coroners, with funding from AHRQ and PCOR. Other enhancements under way include improving systems to automate more of the report production and providing greater detail. Interoperability is a challenge because states have unique systems, and that is another issue receiving attention.

In the discussion period, several members offered assistance from NCVHS and asked what role Dr. Schwartz would suggest for the Committee, and around what priorities. He identified his priorities as getting 90 percent of medical examiner/coroner cases to NCHS within 90 days, getting death data out more quickly, and working with Research Data Centers to improve access to data. Asked about persuading stakeholders and vital registration jurisdictions of the value proposition for accurate and timely data, he expressed excitement about the recent awarding by the Public Health Accreditation Board of a unique public health accreditation category for vital records and vital statistics. NCHS hopes to fund states to move toward this form of accreditation. Ms. Kloss described the forthcoming NCVHS work on a

pathway toward ICD-11 and said the Committee would likely call on his division as part of this work. Asked about the possibility of further PCOR funding to improve vital statistics, Dr. Schwartz noted that the tragedy of the opioid epidemic paradoxically presented an opportunity to push for faster data. He also described the challenge of getting funeral directors and hospitals to do a better job with race and ancestry reporting on death certificates. Dr. Stead called attention to NCVHS's 2017 hearing and report on vitals, supported by an analysis by Dr. Parrish, noting its conclusion that the system is fragile and federal leadership is essential.

### **ONC and HITAC Update and Discussion—Jon White, MD, ONC**

Dr. White is Deputy National Coordinator for Health Information Technology. He began by thanking the Committee for "the amazing work that you do." Noting that ONC would release its proposed rulemaking to outline policies as required by the 21<sup>st</sup> Century Cures Act "very soon," he urged members to "get on their boards and start paddling." The provisions are intended to advance interoperability, a major focus of the Cures Act. A concurrent CMS rule on interoperability is also under review.

Dr. White also briefed the Committee on the following ONC activities:

- The next iteration of the draft Trusted Exchange Framework, with policy guidance on health information exchange, on which ONC would like NCVHS input.
- The eighth annual ONC meeting last November, with documents available on HealthIT.gov;
- November 2018 release for public comment of a draft Strategy on Reducing Regulatory and Administrative Burden Relating to the Use of Health IT and EHRs. ONC got several hundred comments, and will release a final version this Spring.
- Request for information on the EHR reporting program, which netted 77 comments; ONC will soon hold nationwide stakeholder engagement sessions to further develop the program.
- HITAC met last December and discussed draft recommendations related to standards for referral and care coordination. Dr. White expressed gratitude that NCVHS is committed to coordinating with HITAC, stressing his belief that the two advisory bodies play complementary roles.
- On the 13<sup>th</sup> Report to Congress, which he called "spot on," he thanked the Committee for clearly laying out the coordination with ONC. He added that other recent NCVHS work would be very useful to ONC.

In the discussion period, Dr. Stead expressed the Committee's interest in adding to the traction toward a convergence of administrative and clinical standards. Dr. White endorsed this goal (while noting the issues around who has control over what types of data), and predicted that ONC could "find some specific things we could use to move that forward." He, Ms. Goss, and Mr. Coussoule agreed to continue this discussion after the meeting. Ms. Kloss told him that NCVHS planned to start advancing the thinking on ICD-11 as an outgrowth of its work on terminologies and vocabularies; and Dr. Stead alerted him to the forthcoming NCVHS letters on terminologies and vocabularies criteria and guidelines.

### **ICD Scoping—Ms. Kloss**

Ms. Kloss presented the work plan for the NCVHS project on ICD-11, which is influenced by the World Health Organization's timetable for adoption. The project goals are to develop a series of recommendations for the HHS Secretary regarding the pathway to ICD-11 that address the following:

1. Evaluate ICD-11 against updated principles for adoption and implementation of named health terminology and vocabulary standards.
2. Evaluate the benefit of moving to ICD-11 for mortality reporting and the costs associated with implementation.
3. Evaluate the benefits of moving to ICD-11 for morbidity classification, including the cost-benefit of developing a US clinical modification to ICD-11, against the costs of moving to a new version.
4. Stakeholder engagement and industry communications.
5. A simplified regulatory process for version updates.

The project plan currently includes four phases, the first of which, the letter to the Secretary, was completed at this meeting. Donna Pickett of NCHS is assembling information on the history of ICD evaluation and adoption, and NCVHS has scheduled an expert hearing for early August to design research questions. The working group for this project includes Ms. Kloss, Dr. Stead, and Mr. Landen from NCVHS; Mike Lincoln and Steve Brown from the VA; Donna Pickett from NCHS; and Vivian Auld and Suzy Roy from NLM.

Dr. Cohen called attention to the historic deficit in looking at comparability ratios, post-implementation, and the impact that has on mortality trend analysis, especially for population subgroups. He urged that there be attention to the impact of changes on mortality trend analysis. Ms. Love added that there also were no morbidity comparability ratios. She suggested the researcher Pat Romano, and Ms. Kloss said he had attended the expert roundtable last summer.

#### **NCVHS Work Plan—Ms. Hines**

Ms. Hines led the group through a quick review of the work plan for the next few months, noting that a decision on special meetings or hearings is needed in early March.

#### **Health Information Privacy and Security Beyond HIPAA—Ms. Kloss**

Ms. Kloss joined Ms. Hines and Ms. Bernstein in welcoming Frank Pasquale to the Committee. She noted that he would be joining the Subcommittee on Privacy, Confidentiality and Security.

After briefly addressing the language for one passage in the Report to Congress (generating further discussion among members), she turned to the Beyond HIPAA project. The goals of that project are to:

1. Describe the changing environment and identify the risks to privacy and security of confidential health information, highlighting promising policies, practices and technology;
2. Propose integrative models for how best to protect individuals' privacy and secure health data uses outside of HIPAA protections while enabling important uses, services and research;
3. Formulate recommendations for the Secretary on actions that HHS might take; and
4. Prepare a report for data stewardship.

The Subcommittee on Privacy, Confidentiality and Security initially looked at three use cases before refocusing on laying out an integrative model. It also reviewed relevant past NCVHS work, notably a 2008

report, and concluded that it would be useful to “contemporize past work and roll it forward” into the present time, when the threats and risks are very different. Thus it wants to create a 2019 version of the 2008 document, based on principles relevant to both the regulated and unregulated worlds. A group of experts, including Melissa Goldstein and former NCVHS members Barbara Evans, Leslie Francis, Sallie Milam, and Mark Rothstein, have agreed to serve as experts and “brain trust” by participating in the first day of a 2-day meeting on March 21-22. The report that they help develop is intended for stakeholders, policymakers, and agencies.

Ms. Kloss asked fellow NCVHS members for their thoughts on the March meeting plan and agenda. Dr. Phillips pointed to the Committee’s statutory authority to advise Congress and urged that Congress be considered one of the audiences for NCVHS advice on data protections and security. Dr. Stead suggested taking a staged approach in which NCVHS finalizes its recommendations to the Secretary and then builds on them in thinking about how (or whether) to reach out to Congress. Mr. Landen suggested looking at what is going on internationally in this area. Mr. Pasquale offered input, noting the utility of a typology of threat scenarios, and suggested providing concrete examples of invasions of privacy that led to troubling outcomes. Ms. Goss pointed to the intersection of personal and public health, including the social and behavioral determinants of health, in terms of what is and is not regulated. Dr. Cohen commented on the enormous “gray area” of exploding health data in which policies could be strengthened and made consistent across organizations, for public benefit. Mr. Landen noted that both the sources of data and the destinations to which data go have expanded, along with patient access to data. Dr. Mays pointed to the topic of data-sharing during disasters; and Mr. Pasquale pointed to trade secrecy as an important issue.

There being no public comment, Ms. Hines concluded the meeting by thanking Dr. Cohen and Ms. Kloss for the “fundamental roles” they had played in their respective areas of expertise. The two departing members responded that they enjoyed their tenure and learned a lot from serving on NCVHS, which Ms. Kloss called “a great capstone to my career.”

Dr. Stead then adjourned the meeting.

I hereby certify that, to the best of my knowledge, the foregoing summary of minutes is accurate and complete.

/s/

Chair

04/16/2019

Date