Department of Health and Human Services
NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS
May 15-16, 2018
Hubert H. Humphrey Building, Washington, DC

MEETING SUMMARY

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

The National Committee on Vital and Health Statistics convened May 15-16, 2018, 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
Alexandra Goss
Linda Kloss, MA
Richard Landen, MPH, MBA
Denise Love, BSN, MBA
Vickie Mays, PhD, MSPH
Jacki Monson, JD
Bob Phillips, MD, MSPH
David Ross, ScD
Debra Strickland, MS
Roland Thorpe, PhD

Lead Staff
Rashida Dorsey, PhD MPH, ASPE, Executive Staff Director
Rebecca Hines, MHS, NCHS, Executive Secretary
Kate Brett, PhD, NCHS
Lorraine Doo, MPH, CMS
Rachel Seeger, JD, OCR

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

Others (not including presenters referred to below)
Vivian Auld, MLIS, NLM
Zoe Barber, ONC/HHS
Ruth Bennett, contractor
Maya Bernstein, JD, ASPE
Michael DeCarlo, BCBSA
Michele Dillon, contractor

Others (not including presenters), continued
Helina Gebremariam, CAQH
Patrick McLaughlin, NLM
Suzanne Niemeyer, Ketchum
Lauren Richie, ONC/HHS
Susan Roy, MS, MLS, NLM
Nancy Spector, AMA
Sam Thomas, contractor
Erin Richter Weber, CAQH
Margaret Weiker, NCPDP

ACTIONS

1. The Committee passed a motion approving a summary report of the Next Generation Vitals hearing and a recommendation letter to the HHS Secretary.

2. The Committee passed a motion approving a letter to the Secretary conveying NCVHS recommendations on updated pharmacy standards, as developed by the National Council of Prescription Drugs Program (NCPDP).

—DAY ONE—

Welcome and Agenda Review—Dr. Stead

After reviewing the agenda and introductions around the room, Dr. Stead welcomed Dr. Dorsey for the first presentation of the day.

ASPE Update—Rashida Dorsey, NCVHS Executive Staff Director

Regarding personnel, Dr. Dorsey reported that Sharon Arnold became the Assistant Secretary for Science and Data Policy on April 1. She then briefed the group on the Data Council's recent activities, which include Reimagine HHS, one of whose six strategic shift areas focuses on data, and an HHS-wide data governance plan and management strategy, for which Phase I interviews have been completed. The *All of Us* research program, launched on May 6, is an historic longitudinal effort to gather data from a million or more people living in the U.S. in order to accelerate research and improve health by looking at differences in lifestyle, socioeconomics, environment, and biology. To date, about 50,000 people have consented to be part of the program, including consent for recontact. The program has 125 sites in 18 states, and some 35 community and provider partners. The research portal will be open with a public dataset in 2019. Dr. Dorsey noted that the privacy aspects involved may be of interest to NCVHS. A research data center is based at Vanderbilt, Verily, and Broad Institute. There is a tiered access approval, and no data removal, but broad access for researchers from all sectors as well as citizen-scientists. All research will be posted publicly. In other news, the Data Council is updating its data collection strategy around five priorities, including improving access to HHS data, modernizing privacy protection, and increasing data policy coordination across the Department. Finally, she said that improving the collection, access, and use of opioid data is a Data Council and administration priority, and she offered a future update on this work.

During the discussion period, NCVHS members had questions about how EHR data are being gathered and the policy on transparency of research, and asked for a cataloguing of which data have been moved from public use files into research data centers. A query about the disposition of the Medical Expenditure Panel Survey (MEPS) public use files led to another exchange later in the session, in which Dr. Mays said the fundamental question is whether there is a change in how NCHS is interpreting privacy, confidentiality and security regulations under which they operate in ways that will change researchers' access to data. Dr. Dorsey suggested raising this question with Dr. Queen during her presentation scheduled later in the meeting.

Next Generation Vital Statistics—Dr. Cohen, Dr. Ross, Delton Atkinson (slides)

Dr. Cohen began with a briefing on the status of the report on the Next Generation Vitals hearing and the recommendation letter to the Secretary. The report begins with this brief statement of its "bottom line": *"Vital records are the foundation for essential functions at local, state, territorial, and federal levels; but the system is highly vulnerable. Federal leadership is needed to secure the vital records and vital statistics data collection network as a sustainable, reliable resource."*

Delton Atkinson (NCHS, Director, Division of Vital Statistics) suggested strengthening the letter by urging the Secretary to make modernization of the vital records and vital statistics system a priority. Later in day one of this meeting, the Population Health Subcommittee brought forward a slightly revised version of the letter incorporating this point, and the Committee passed a motion approving the report and the recommendation letter.

Dr. Ross expressed the Committee's thanks to the Robert Wood Johnson Foundation (RWJF) for its support of the Digital Bridge Initiative, which helped coalesce ideas in this area. He then outlined the ideas that emerged from the hearing discussions about next steps for NCVHS regarding vital registration data and statistics. Noting that the hearing revealed the breadth and diversity of the users of vital records and statistics data, he stressed that "modernization is the meta-theme here." The task for NCVHS now is to think at a systems-level about an approach and next steps. He asked Delton Atkinson, Director of the NCHS Division of Vital Statistics, to offer his thoughts.

Mr. Atkinson outlined a seven-point vision for vital records and statistics modernization. The points include a way to credential jurisdictions to create a floor and reduce the wide range of performance among jurisdictions (a project that NCHS is working on with the Public Health Accreditation Board); more training to increase data quality and timeliness; and a nationally approved model vital records and vital statistics law. He stressed the need for a near real-time vital statistics system. Dr. Ross proposed that NCVHS focus on the goals that are not likely to happen without "a push from the Committee." Regarding the model law, Mr. Atkinson indicated that the version drafted in 2010-11 needs updating, and that many states will not consider adopting it without a recommendation from the HHS Secretary. He also called attention to his vision for an enhanced vital records electronics system, which he said needs "quite a bit of work" to shift from paper to electronic records and processes. The goals in this area include exchanging information in a near real-time basis to authorized users, maximizing the efficiency of business workflows, and improving the capacity for flexibility and accuracy during crisis events.

During the discussion period, Dr. Mays commented on the need to agree on a model for the vitals system and the need to improve mortality data, including with better race/ethnicity data and an improved National Violent Death Reporting System. Regarding next steps, Dr. Cohen wondered whether the Committee wanted a big project or a smaller-scoped one; he expressed a preference for identifying a solvable issue with potential benefit for multiple users. Ms. Love stressed that modernization involves much more than IT and includes policies that enable data sharing within the public health world. Several members called for development of a comprehensive vision for modernization.

Standards Subcommittee: NCPDP Standards Update—Ms. Goss, Mr. Coussoule, Ms. Doo (slides)

Subcommittee Lead Staff Lorraine Doo of CMS began the session with an overview of the status of prescription drug standards. The Standards Subcommittee held a hearing on March 26 on updated pharmacy standards developed by the National Council of Prescription Drugs Program (NCPDP), which recommended adoption of three new versions of the standards.

Mr. Coussoule then described the letter developed by the Subcommittee, which expresses NCVHS support for the recommended new versions, with recommendations about timing and a transition period. The letter also stresses the need for end-to-end testing across the ecosystem.

Dr. Stead noted, and Ms. Goss agreed, that NCVHS is choosing to support what the industry thinks is necessary despite the "mismatch" between these recommendations and the emerging Predictability Roadmap. However, this offers a "relatively simple use case" for consideration in developing the Roadmap. The Committee then passed a motion approving the letter.

ONC Update and Committee Discussion—Genevieve Morris, Deputy Coordinator

In preparation for this and the next session, Ms. Goss referred the Committee to a draft scoping document that describes a potential approach for collaboration between NCVHS and the ONC Health Information Technology Advisory Group (HITAC) that NCVHS staff and members developed based on discussions with ONC over recent months. The document states this is an "essential question on the road to harmonization"; "whether it is in the best interests of patients, the U.S. health care business community and health statistics and research to maintain an HL7 CDA/FHIR/XML system for clinical and an X12/NCPDP EDI system for administration and payment." The Committee briefly discussed this question.

For ONC, Ms. Morris then gave a brief overview of the Trusted Exchange Framework and Common Agreement (TEFCA) and HITAC, ONC's Federal Advisory Committee. ONC is reviewing 220 public comments it received on TEFCA and working on changes based on those and comments from HITAC, for incorporation into a funding opportunity announcement that will come out "at some point this year." ONC's goal is to work with the Recognized Coordinating Entity (RCE) and stakeholders to put terms and conditions in place in the Common Agreement and to build out implementation guides for technical standards, which will be posted for public comment. Finally, she said a HITAC workgroup had offered 16 recommendations on TEFCA, and another HITAC workgroup focused on the U.S. Core Data for Interoperability (USCDI). As their next project, they will look at use cases, as stipulated in the 21st Century Cures Act.

Ms. Morris and the Committee then engaged in a wide-ranging discussion. Dr. Stead called attention to the NCVHS recommendations and comments on USCDI, which she promised to review. Prompted by a question, she commented on the challenges of building the voice of patients into the process and how that mandate might be accomplished. After commending ONC on its educational resources for patients regarding how to obtain access to their health records, Ms. Kloss proposed a FACA-to-FACA relationship between NCVHS and HITAC around privacy, to work on special initiatives. Ms. Morris noted ONC's close collaboration with OCR and added that ONC would make structuring the proposed relationship a priority. Ms. Goss commented on the convergence of clinical and administrative data, a topic that the forthcoming CIO Forum will explore, and she engaged with Ms. Morris on the subject. Ms. Morris agreed that "we have to figure out ways to bring that data together" for the good of both patients and providers. She decried the current barriers to transmitting patient information among providers and payers, and stressed the importance of accepting that clinical data are used for administrative purposes and providing a structure to make it easier to do so. The USCDI, she noted, is part of that attempt.

Asked about fostering the use of data for research and scientific knowledge, she described ONC's programs with NIH, including Reimagine HHS and the *All of Us* research program. Asked about coordination of the work on semantics standards with the development and maintenance of related terminologies, she stressed the need to set up the right categorization of each stage of design, with attention to CCDA and FHIR specs. The idea, she said, is to signal to vocabulary groups that they need to develop the vocabulary for those data classes. She also noted the limits to ONC's purview and level of authority, which are confined to health IT systems. Asked to comment on the role of misaligned incentives, she expressed hope that the shift toward value-based payment would incentivize timeliness and quality. Regarding the impact of recommended testing on the projected timetable for the USCDI, she said ONC was evaluating the task force's recommendations. Ms. Kloss informed her that the NCVHS July expert roundtable on vocabularies and terminologies, which Dr. Jon White would attend on behalf of ONC, would provide an opportunity to raise awareness about this. Ms. Morris stressed that the industry must work together toward common goals, noting that ONC has invested staff in supporting a process for that.

Finally, asked by Ms. Goss to share her vision, she described her two chief concerns: that providers are overwhelmed because they don't have enough time with patients, and that patients are frustrated that their providers are not sharing their records. Noting that the API infrastructure is designed to improve usability and TEFCA is designed to enable data liquidity, she predicted that over time, it should be possible to make life easier for both of these groups, especially if industry starts working together. Finally, asked about the prospects for eliminating the disconnect between payment and care models, she pointed to models that incentivize data. After asserting that "the role of government is to provide consumer protection," she added that in the absence of a business case for the actions that promote care, it is government's job to step in.

Discussion on NCVHS Collaboration with ONC and HITAC—Zoey Barber, Special Assistant to Ms. Morris, and Lauren Richie, Designated Federal Officer for HITAC

This session continued the conversation with ONC, shifting the focus to opportunities for collaboration and coordination between NCVHS and HITAC. Dr. Stead noted that NCVHS had drafted and shared a scoping document on that subject. The overarching question, he said, is how to leverage the work of the two FACAs in order to "move toward convergence" in some cases and "divide and conquer where appropriate."

The discussion involved an exchange of information, plans, and commitments. Ms. Richie indicated that HITAC would begin work this summer on a set of priority standards stipulated in the Cures Act, and that she would send the list of the specified "standard priority topic areas" to NCVHS. Regarding the work on the USCDI, the HITAC task force has reviewed the NCVHS recommendations and developed another draft that the full HITAC approved for review by the National Coordinator. This is expected to lead to release of a new version. Dr. Stead asked that NCVHS be informed about when to expect that. The new draft of the TEFCA will be released sometime in the first quarter of 2019.

Ms. Goss noted that ONC and the Subcommittee on Standards will have a chance to confer at the May 17 CIO Forum, and she suggested that the two FACAs prepare to become more engaged with each other in

2019. Ms. Richie said ONC would share the scoping document drafted by NCVHS with its FACA as it begins its work on standards this summer, with an eye toward 2019 planning. The NCVHS and ONC representatives discussed the idea of scheduling time to connect after the July terminology and vocabulary meeting, which Dr. White will attend, and agreed to consider formalizing the communication, possibly with a semi-annual "co-chair sit-down." Ms. Richie promised to follow up after talking with HITAC's co-chairs.

CIO Forum and Predictability Roadmap—Ms. Goss and Mr. Coussoule

Mr. Coussoule described the plans and goals for the May 17 CIO Forum, which is part of the Predictability Roadmap initiative. The invited participants include both chief information officers (CIOs) and others with leading roles in organizations that deal with health information technology. The focus of the meeting is current and anticipated issues and challenges in this arena with respect to standards and operating rules. The Subcommittee's goal for the Forum is to learn about the participants' experiences, thoughts, and solutions to the various challenges along with their ideas for future improvements. Based on these inputs and its previous research, the Standards Subcommittee will draft recommendations for a Predictability Roadmap that informants will be asked to give feedback on.

Dr. Stead prompted a discussion by commenting on the possible steps at that point and the challenges of identifying a clear path forward. He suggested that the Committee might test different straw persons, and noted the merits of sketching a broad, long-term vision, as NCVHS has done successfully in the past. Committee members discussed alternative approaches to envisioning short-, medium- and long-term (15-20 year) changes. There was support for the idea of framing an ideal end state and also identifying early steps that would help move in that direction.

Dr. Stead set a goal for the Committee of being far enough along in its major projects, i.e., the Predictability Roadmap, Beyond HIPAA, Health Terminologies and Vocabularies, and Next Generation Vitals initiatives, to be able to report on them in the 13th Report to Congress, on which work will begin in early 2019. The implications of this goal for the first Full Committee meeting of 2019 were noted.

Health Information Privacy and Security Beyond HIPAA—Ms. Kloss (slides)

Ms. Kloss reminded colleagues of the purpose and parameters of the Beyond HIPAA initiative. The goals are to describe the changing environment, lay out integrative models, formulate recommendations to the Secretary, and prepare a report for health data stewards. The Subcommittee on Privacy, Confidentiality and Security chose two topics as exemplars, registries and personal health devices, and the present discussion will focus on the first. She noted that several guiding organizations are working in this space, and there are best practice models as well as a range of practices among the diverse registries in existence. Further, the federal government has a stake in registries, and there is a robust literature on the subject. The purpose of the exercise is to use registries as a lens through which to look at stewardship models and identify representative challenges and possible levers.

Ms. Kloss then led the Committee in a brainstorming exercise regarding the problems that can and do arise from processing personally identifiable information (PII) in registries, such as the loss of trust and actual harm. The nature of the consent involved (i.e., passive vs. active) was noted as a key factor, as well as the existence (or not) of guidelines and rules of the road regarding access, benefit, and so on. Ms. Monson introduced four models for managing PII in registries and outlined questions about how they might be assessed and evaluated.

(At this point, there was a break in the discussion for a scheduled presentation by Jon Neiditz, which is summarized following this agenda item.)

Resuming the discussion of registries, Dr. Mays asked colleagues to review the Privacy Subcommittee's plans for next steps in this initiative. They include outreach to key registry experts to further develop models and identify best practice examples; laying out a stewardship framework and integrative model(s) for how best to protect individuals' privacy and secure health data in registries while enabling beneficial uses, services and research; identifying actions that registry sponsors can take to better safeguard privacy; and identifying potential recommendations for the Secretary on actions that HHS and other federal Departments might take. Members had a few suggestions regarding other experts and resources to consult, and supported the idea of hearing the consumer voice as well.

Ms. Kloss said the other exemplar topic, personal health devices, would be discussed at the September NCVHS Full Committee meeting. She referred to a discussion draft on the topic, prepared by Rachel Seeger of OCR made available to the Committee. Dr. Stead suggested keeping the focus on situations in which data move in and out of the regulated space. Mr. Coussoule, referring to his health care organization's experience (Blue Cross/Blue Shield of Tennessee), commented that "this is happening all of the time right now," so it should be easy to find good use cases. Ms. Kloss said the Subcommittee would provide a "version .1" model for protecting PII in this context for the Committee to consider in September.

General Data Protection Regulation—Jon Neiditz, Kilpatrick Townsend & Stockton LLP (slides)

Mr. Neiditz co-leads the Cybersecurity, Privacy and Data Governance Practice at Kilpatrick Townsend & Stockton LLP, a knowledge asset protection law firm. He briefed the Committee on the European Union's (EU) General Data Protection Regulation (GDPR), stressing at the outset that "it's not just for citizens of the European Union." It also covers people traveling there and applies to EU residents in countries outside the EU. It covers entities more broadly and defines personal data more broadly than the old EU Directive did, and also defines data processors (as distinguished from "controllers") broadly. He noted areas of overlap with HIPAA, such as data minimization. The GDPR involves major changes in consent, and a detailed specification of individual rights. In some cases, Data Protection Officers are required. A new principle is the principle of accountability, and the regulation incorporates the contrast between "privacy by design" and "privacy by default." The requirements around data protection impact assessment (DPIAs) materially change the way privacy processes are evaluated to identify levels of risk to personal data. A register is required that states the intended uses of given information and how long it will be retained.

Ms. Kloss said the Committee's chief question is whether aspects of the GDPR can be layered onto PII protections in the U.S. in areas not protected by HIPAA, and Mr. Neiditz replied that many aspects are worth considering. He noted that the GDPR and the European rights-based approach is "winning globally" in comparison to APEC principles as enforced by the Federal Trade Commission. NCVHS members briefly discussed the applications of the GDPR within the U.S. with Mr. Neiditz.

OCR Update—Rachel Seeger, HHS Office for Civil Rights (OCR) (slides)

In the policy arena, OCR has been helping to support the Department's response to the national opioid crisis by issuing a series of guidances and FAQs on its website and new materials for professionals and consumers. OCR is very active in doing outreach, technical assistance, and webinars across the U.S. NPRMs are forthcoming on the perception of good faith of health care providers and on changing the requirement to obtain acknowledgment of receipt of notice of privacy practices. Future guidances are planned on texting, social media, and encryption.

Turning to HIPAA enforcement and breach highlights, Ms. Seeger reported that OCR has received more than 175,000 complaints to date, with close to 26,000 cases resolved. It expects to receive 24,000 HIPAA complaints this year. There have been 52 settlement agreements and three civil monetary penalties in all; penalties from the eight cases since April 2017 total $11.6 million. The recurring compliance issues include ones related to business associate agreements, risk analysis, failure to manage identified risk, improper disposal, and insufficient data backup and contingency planning.

OCR has revised the breach notification tool, thereby improving navigation for those seeking information and ease of use for organizations reporting incidents. Ms. Seeger shared data on the number and nature of breaches between 2009 and early 2018 that show an uptick in hacking and IT incidents. In response to a request from Dr. Stead, she promised to provide absolute numbers and trend data in the relevant categories. Finally, she described some of OCR's educational activities, including new cybersecurity guidance material and a guidance on ransomeware. OCR also operates a special portal for questions and technical assistance for health app developers. In response to a question, she indicated that HHS has been looking closely at the GDPR while waiting to see how it is received and implemented.

—DAY TWO—

Committee Updates

Dr. Stead introduced this session as an opportunity for members to provide updates on activites they have been involved with in arenas that intersect with NCVHS.

- Dr. Cohen and Dr. Stead: The NCVHS Measurement Framework on Community Health and Well-being project is on its way to being sustainable, thanks to the efforts that Dr. Soma Stout will describe later in the meeting. In addition, *US News & World Report's Healthiest Communities* is built around the Framework. Dr. Cohen and Dr. Phillips will work with that publication in June to further develop the data. At the Datapalooza conference, Aetna announced a challenge to communities related to USN&WR's *Healthiest Communities.*
- Ms. Goss: Utah Health Information Network asked NCVHS for an update, and Ms. Goss and Ms. Love provided one to their board of directors and standards subcommittee regarding the standards-related work plan of NCVHS.
- Ms. Kloss: At the invitation of Walter Suarez, Ms. Kloss presented an overview of the Beyond HIPAA environmental scan to the Confidentiality Coalition, part of the Health Care Leadership Council.

NCVHS Website Redesign—Samuel Thomas, Rose Li Associates

Ms. Hines introduced Sam Thomas, the project manager for a project to redesign the NCVHS website. Regarding website traffic, he said there were 6,000 sessions by more than 4,000 unique users in the first quarter of 2018. Asked about identifying the users and getting feedback from them, he said the first is difficult to do with precision; for the second, users can provide feedback and ask questions using a "Contact Us" function that sends messages directly to NCVHS staff at NCHS.

He then gave a guided tour of the redesigned website's features and answered questions. A major upgrade is that staff has been classifying and tagging all content so it can be searched and accessed from multiple places. Ms. Hines asked members to think about what other content or features they would like to see, and there were a few suggestions. The major ones concerned the location and treatment of meeting background materials, with emphasis on the need to distinguish between process-related materials and NCVHS reports and recommendations, which are final products. Above all, members expressed praise for the new design.

From the audience, Michael DeCarlo of Blue Cross/Blue Shield Association, who has attended NCVHS meetings since 1992, said the NCVHS website is a "very useful tool" that he visits almost every day. He endorsed the proposed clarification of the links between agendas and meeting materials.

Health Terminologies and Vocabularies Initiative
—Ms. Kloss; and Suzy Roy and Vivian Auld, National Library of Medicine (slides)

Ms. Kloss noted that NCVHS is charged with studying issues related to the adoption of uniform data standards for patient medical record information and its electronic exchange, and also with advising the Department on health data collection needs and strategies. The current NCVHS initiative takes a "deep dive" into health terminologies and vocabularies by studying the changing environment and its implications in this area; the needs, opportunities and problems with development, dissemination, maintenance and adoption; and actions HHS might take to improve them. To date in this two-year project, the Subcommittee has completed an environmental scan report that will be presented for final approval in September, and planned a July 2018 expert roundtable meeting. The goal for the present meeting is to obtain comments on the environmental scan and discuss several themes with the Committee, with particular attention to gaps.

Dr. Stead expressed hope that themes would be ready for discussion in September 2018 and a letter to the Secretary finalized in early 2019, to align with the 13th report to Congress.

Suzy Roy of the National Library of Medicine (NLM) discussed the first draft of the environmental scan report, of which she is a primary author, and requested comments. The group discussed whether social determinants of health data are covered adequately, and concluded that they are not and should be considered a gap. Dr. Stead proposed thinking of public health and social and behavioral determinants as complementary lenses. Other topics raised included issues with pharmacy data forced by Medi-Span and gender identity.

Ms. Kloss then asked members to share thoughts on near-term opportunities that are prompted by the environmental scan report. Members expressed support for using the report for educational purposes, suggested looking into known operational problems related to update cycles and the like, and proposed reviewing the next iteration of ICD as part of the project. The environmental scan is the primary input to the July expert roundtable meeting; invited experts will be provided an opportunity to review a draft prior to the roundtable meeting and provide feedback.

The Committee then discussed what measures of success would be considered for this initiative. Dr. Cohen suggested the NCVHS health data stewardship tool as a good model for a possible guide to the use of health terminologies and vocabularies. Dr. Stead envisioned identifying a few solutions to operational problems that could help the Committee begin to lay out a path toward continuous iterative terminology expansion and revision (in contrast to infrequent periodic updates). In the short term, he added, the Committee might also propose updates to the criteria for named standards.

Finally, Ms. Kloss described the agenda for the July 17-18 expert roundtable meeting on Health Terminologies and Vocabularies, with Dr. Stead expressing pleasure that most of the invited participants accepted the Committee's invitation. The meeting will be similar to other NCVHS roundtables, with a focus on eliciting the expert participants' thinking about best practices in key areas and identification of gaps.

NCVHS and NIH/NLM Collaboration—Dr. Stead (slides)

The guiding question for this session was*, How might NCVHS develop guidance for NLM on an approach to expand UMLS to include public health and social/behavioral determinants of health?* UMLS is the Unified Medical Language System. Suzy Roy, Vivian Auld, and Patrick McLaughlin of NLM were present for this discussion. Dr. Stead said a goal for the July Roundtable was to gain a better understanding of gaps in social/behavioral determinants of health and public health as well as more general gaps. Two approaches are needed in thinking systematically about how to expand the scope: identifying existing terminologies in the UMLS that represent these factors and seeing how they might be expanded; and looking at other terminologies from domains not represented in the current UMLS.

He then opened the topic for discussion. Members suggested starting by defining social determinants in this context; and there was broad support for looking at the concepts in the NCVHS Measurement Framework for Community Health and Well-being and the associated environmental scan, with a caveat to focus on those that are actionable in the short run. Ms. Goss pointed out that greater understanding of the role of social determinants is gaining much traction as a critical factor in achieving health care outcomes—for example, the National Association for Community Health Centers, with RWJF support, has set out to create a framework with process methodologies supported by EHR data acquisition to obtain data related to social determinants of health.

NCHS Update—Susan Queen, Director, NCHS Office of Planning, Budget, and Legislation (slides)

Dr. Queen briefed the Committee on NCHS budgetary, administrative, and program matters as well as major challenges and new developments. The NCHS budget has remained flat, which means having to do more with less given steadily increasing costs. The most serious impact is on innovation and the development of new methods and approaches. She noted that the redesign of the National Health Interview Survey (NHIS) was primarily undertaken because of the declining response rates and the growing burden on respondents of taking the survey. The president's budget for 2019 proposes funding NCHS out of PHS Evaluation Funds, and also proposes a cut for NCHS. Some funding comes from reimbursable dollars from partners and co-sponsors, and these agencies face budget cuts as well.

As a statistical agency, a major NCHS responsibility is producing and disseminating relevant and timely information. Dr. Queen showed data on the improvements in timeliness: to date, roughly 60 percent of information on the event of death is reported within 10 days, up from less than 10 percent in 2010. NCHS started doing monthly counts of drug overdose deaths for seven drugs in August 2017. There is a delay in reporting these data because of the investigations required. Members had several questions about the drug overdose data.

NCHS has been very productive in disseminating the information it collects, with 110 publications in the previous 12 months, including 20 on health insurance and 10 on mortality. The Rapid Release Program began in 2015, starting with mortality and selected causes of mortality on a quarterly basis and adding natality the following year. Files are also released into the NCHS Research Data Center (RDC) and other Federal Statistical RDCs (FSRDC). In 2017, almost 40 percent of the projects using data in Census RDCs used NCHS data. NCHS is represented on the Interagency Council on Statistical Policy, which has been working to provide more locations where people can access data for research purposes, and more RDCs are opening this year.

NCVHS members asked questions and commented on the need to streamline the proposal process, on the rules being used for confidentiality and the disclosure process (which Dr. Queen said has become more complicated), and on the potential for using best practices in doing risk assessment on FSRDC data holdings.

Continuing her presentation, Dr. Queen presented a slide showing "the bad news" about survey response rates, which have declined by 20 percent or more since 1997 in all modules of the NHIS. The NHIS redesign will be fielded in 2019, and NHANES is working to find alternative approaches to sample design. Finally, she said a lot of hard work is going on despite the challenges related to the budget and personnel.

Dr. Mays proposed that NCVHS start talking about data stewardship approaches that might help increase trust and survey participation in the nation.

Improving Access to Data—Dr. Phillips and Dr. Mays (slides)

This update follows on a discussion at the last NCVHS meeting. The effort began when stakeholders expressed concerns to NCVHS about loss of access to some federal data resources. The Committee is focusing on four health data systems: Community Health Status Indicators (CHSI), HHS Health Indicators Warehouse (HIW), Behavioral Risk Factor Surveillance System (BRFSS), and Health Data Interactive (HDI).

Dr. Mays said access is particularly difficult at the community level due to changes with the BRFSS. She and Dr. Phillips commented on the prospect of assessing data risk in light of the importance of the issue(s) on which data are needed as well as the potential for actual harm. Ms. Love described the difficulties states and localities are having in accessing data, especially at the sub-county level, the level at which data are actionable. She also noted that there is considerable variation among states in what can be done with their data. Dr. Queen confirmed that once data are collected with an assurance of confidentiality, restrictions on access to those data cannot be loosened.

Dr. Phillips then reported the findings from queries to stakeholders about their experiences regarding what data are no longer available, how the data had been used and what decisions and activities they supported, and whether commercial interests are affected. He summarized the responses from five sources including the American Public Health Association, University of Missouri CARES, and Trilogy Integrated Resources. All responses are compiled in a spreadsheet.

The Subcommittee is considering having a panel conversation at its fall meeting to further frame this issue, and he asked for comments and suggestions. He added that the Subcommittee has expressed interest in interacting with the Data Council on this matter and is asking the Data Council for feedback. Dr. Dorsey offered to put a discussion of this project on the Data Council's agenda. Dr. Mays and Mr. Coussoule stressed the complexity of the landscape and the importance of knowing it and the reason why certain actions are being taken well before trying to offer suggestions and solutions. There was support for the idea of a holding a roundtable or forum to obtain input from subject matter experts. Members suggested also inviting the stewards of the data so they can explain why some data are no longer available, as well as someone from a state data oversight board. Dr. Stead proposed that a panel in September might clarify the scope for an environmental scan, which in turn might set up a hearing.

Ms. Kloss said the process might lead to an NCVHS proposal for an HHS Data Access Policy, including stewardship—a topic that falls squarely within the charge to NCVHS. Members briefly talked with Dr. Dorsey about the extent to which this initiative does or does not overlap with Reimagine HHS, which is focused on facilitating data sharing across HHS. Dr. Phillips asked her to help align the two efforts.

New Medicare Card Project/SSN RI Monitoring Update
—Monica Kay and Lois Ferriol, CMS; Alix Goss and Nick Coussoule, NCVHS

CMS has begun to mail out new Medicare cards, which replace the Social Security Number with a Medicare Beneficiary Identifier (MBI). During a 21-month transition period, which ends in January 2020, people can use either the health insurance claim number or MBI for processing. Dr. Kay reviewed additional key information for providers and payers about the transition period and MBI usage. Ms. Ferriol described the card mailing process and associated outreach to beneficiaries.

As an introduction to the discussion period, Ms. Goss explained that NCVHS had planned this session primarily as an opportunity for NCVHS members to pass on to the CMS representatives the feedback they had received from their constituencies about the Medicare card initiative. In response to a question about the issues being raised by new card recipients and providers, Richard Cuchna of CMS said the MAC call center had received "very few calls" about the MBIs. Dr. Kay added that most feedback to date has been positive. Ms. Monson reported that beneficiaries were showing up at Northern Californian clinical locations asking for assistance with the new card; she suggested that CMS help providers know how to handle such requests. Mr. Coussoule pointed out that there are scams taking advantage of the change in cards as a cover to steal information from people.

Update on NCVHS Measurement Framework Implementation Work—Soma Stout, Institute for Healthcare Improvement (IHI)/100 Million Healthier Lives Initiative (slides)

Dr. Stout reviewed the steps that led to her organization's leadership role in developing measures for the NCVHS Community Health and Well-being Framework, which was published in January 2017. The overarching design principles set forth by NCVHS were 1) to be flexible enough to meet the needs of both national stakeholders and local communities and 2) to provide a parsimonious set of multi-sector measures. NCVHS handed off the process to 100 Million Healthier Lives to steward the Framework toward implementation. It convened two workgroups, on measurement development and measurement implementation, as well as a stewardship group to guide the process. It has held two in-person meetings around those tasks, and a third is scheduled for May 18. The outcome of the first two meetings, besides affirming the value of the Framework, was a decision to add domains on the wellbeing of people and on equity. Next came a detailed landscape analysis of other efforts in the field that might be knit into the NCVHS framework.

To date, two of three planned rounds of a Delphi process have been completed, with the goal of developing recommendations for measures in each subdomain for both a national set and a community set. An effort was made to include a wide range of people, bringing both national and community measurement expertise. The first round focused on missing measures; the second, on prioritization to create a shorter list; the third will take stock of where things stand today and begin to imagine what implementation might look like. The process revealed that sometimes community and national needs are the same, and sometimes they involve different priorities. There was a strong push to balance existing measures that are benchmarkable, evidence-based, and already collected with promising developmental measures; and the process showed where additional developmental work is needed.

Dr. Stead and Dr. Cohen thanked Dr. Stout for her strong and skillful leadership of this effort, and asked how NCVHS could contribute. She asked for the Committee's insights on what national adoption would mean and where there are opportunities to advance the measures within the Federal ecosystem.

In response to a question, she then described how and with whom the Framework was road-tested and evaluated, saying that the diverse group of 38 initial contributors were found using a social networking strategy. The criteria used were adapted from the National Quality Forum's criteria.

Dr. Stead described the Committee's new project for Dr. Stout to identify terminologies for the UMLS related to public health and social/behavioral determinants, for which it may draw upon the Framework and the related environmental scan. He noted the potential synergies with the effort Dr. Stout is leading. He welcomed her offer, in response, to share information about another IHI project involving a landscape analysis of how people are talking about sectors, with the aim of coming up with a common classification.

Dr. Cohen proposed that the Committee think broadly about a Measurement Framework follow-up in its upcoming workplan.

Public Comment

There being no public comment, Dr. Stead adjourned the meeting.

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

/s/	07/12/2018
Chair	Date