Department of Health and Human Services

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

September 13-14, 2018

—Virtual Meeting—

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).

Due to weather, the National Committee on Vital and Health Statistics convened on September 13-14, 2018, in a virtual meeting format via telephone and WebEx. The meeting was open to the public.

Present by telephone and WebEx:

Committee Members

William W. Stead, MD, Chair
Bruce Cohen, PhD
Nicholas Coussoule
Llewellyn Cornelius, PhD, LCSW
Alexandra Goss
Linda Kloss, RHIA, MA, FAHIMA
Richard Landen, MPH, MBA
Denise Love, BSN, MBA
Vickie Mays, PhD, MSPH
Jacki Monson, JD
Bob Phillips, MD, MSPH
David Ross, ScD
Roland Thorpe, PhD
Absent: Debra Strickland, MS

Lead Staff and Liaisons

Rebecca Hines, MHS, NCHS, Executive Secretary
Rashida Dorsey, PhD MPH, ASPE, outgoing Executive Staff Director
Sharon Arnold, PhD, ASPE, incoming Executive Staff Director
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)

Maya Bernstein, ASPE
Suzy Roy, NLM
Vivian Auld, NLM
Margaret Weiker, NCPDP

ACTION

The Committee passed motions to approve two documents produced as part of the health terminologies and vocabularies work:

NCVHS Health Terminologies and Vocabularies Environmental Scan, and

Health Terminologies and Vocabularies July 2018 Expert Roundtable Meeting Summary.

—DAY ONE—

Welcome and Agenda Review—Dr. Stead

After thanking NCVHS staff and support staff for their work in preparing for this virtual meeting, Dr. Stead reviewed the agenda. He encouraged members throughout the meeting to keep an eye on and note opportunities to increase value and reduce burden, the central topic of the forthcoming 13th NCVHS Report to Congress on the implementation of HIPAA.

Updates

- ASPE Update—Rashida Dorsey, outgoing Executive Staff Director, and Sharon Arnold, incoming Executive Staff Director

Dr. Stead thanked Dr. Dorsey for her nearly two years of service to NCVHS and congratulated her on her new position at the US Equal Employment Opportunity Commission. Dr. Dorsey, in turn, thanked NCVHS members for their service to HHS and the nation. She said that at EEOC, she would work on data on the social determinants of health (SDOH) and continue to follow the Committee's work.

Dr. Stead then introduced and welcomed Dr. Sharon Arnold, the new NCVHS Executive Staff Director. She has been with ASPE since April 2018, and was Deputy Director at AHRQ immediately prior to that. Dr. Arnold highlighted recent HHS activities, including hurricane relief from last year's three hurricanes and preparation for Florence. The Department continues to prioritize the opioid crisis and explore how to further leverage the power of data at HHS for analytics and business operations.

Committee Updates

This session provided an opportunity for members to give updates on activities in areas that intersect with NCVHS.

Dr. Bob Phillips, the NCVHS liaison to the NCHS Board of Scientific Counselors, reported on their June meeting, where the $700m reduction in the CDC's proposed budget was a focus of concern. There are interesting new developments in vital statistics reporting, and progress toward a redesign of the National Health Interview Survey and NHANES. He reported to the BSC on NCVHS's recent work on vital statistics. He called attention to the fact that the BSC has secured PCOR funding. He then described a project on value-based payment and reimbursement to improve Medicare post-acute care, as directed by the IMPACT Act, and its need for data on socioeconomic status. The National Academies of Sciences, Engineering and Medicine (NASEM) has published a series of reports in this area, and one highlights data needs.

Mr. Rich Landen gave a presentation on recent NCVHS activities to the National Plan Automation Group (NPAG) and had a productive discussion with them. Among other things, the group affirmed the need for the Predictability Roadmap that NCVHS is developing, and endorsed the findings of the CIO Forum held in May of this year. Because they lack a trade association, they were unsure how to stay abreast of this work and offer comments on it.

Dr. Bill Stead reported that conversations continue between NCVHS and ONC about coordinating NCVHS and HITAC activities. Ms. Hines added that NCVHS will meet with HITAC in October or November, and ONC has committed to sitting down with NCVHS in January 2019 to map out points of intersection over the coming year. She acknowledged ONC's participation in the CIO Forum, and thanked Mr. Landen for his help with this.

Health Terminologies and Vocabularies Initiative—Dr. Stead and Ms. Kloss (SLIDES)

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. This two-year NCVHS initiative is studying the rapidly 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, NCVHS has completed an environmental scan, drafted a report on the scan, and conducted a roundtable in July 2018. Dr. Stead said the goals for this session are to approve the environmental scan, take action on the expert roundtable summary, discuss preliminary themes for recommendations, and identify key messages in this area for the report to Congress. He added that this work, which aims for completion of a letter to the HHS Secretary in February 2019, will be a significant update to the work NCVHS conducted in the late 1990s and early 2000s.

After noting that this project aligns closely with the Predictability Roadmap effort, Ms. Kloss described the structure and content of the latest version of the environmental scan report and described the changes from the previous version. As she did so, she invited questions and comments from the Committee, leading to a few minor revisions to the final version of the report. The Committee then passed a motion to finalize the environmental scan report.

The next action item concerned the report summary from the expert Roundtable meeting held on July 17-18, 2018, the goals for which were to convene public and private sector experts and academics to reach a shared understanding on the current state of the field as described in the environmental scan report. The Roundtable meeting revealed wide support for the environmental scan and generated useful input. Ms. Kloss reviewed the Roundtable meeting summary with the Committee. The Committee then approved the final summary report.

Next, Dr. Stead and Ms. Kloss led a discussion of near-term recommendations for actions under the Secretary's control that will be included in a letter to the Secretary. The letter will also telegraph mid-term and longer-term opportunities that will require further work by NCVHS and the industry.

After inviting comments and questions, Ms. Kloss and Dr. Stead commented on the current thinking about somewhat longer-term opportunities that require more study and the convening of expert groups. They relate, generally, to the development of a strategic plan for health terminologies and vocabularies, including a pathway toward the convergence of administrative and clinical domains. Dr. Stead said the ultimate objective is to capture information with clinical terminologies that make sense in a clinical context and to derive administrative information from them without the burden of separate administrative capture or of putting the burden of administrative capture on the clinical interaction. Related to this is the goal of eliminating the separate work to satisfy terminology and classification needs for entry into the EHR for payment and other purposes. Committee members added a few comments and questions, and expressed support for the direction in which the project is heading.

Approach to NCVHS 13th Report to Congress (SLIDES)—Dr. Stead

Dr. Stead reminded members that the 12th Report to Congress, issued in 2017, identified four cross-cutting themes that had emerged from the Committee's work in the preceding two years. It also gave a status report on key topics and closed with next steps. He believes "we are at a very different place now": while progress has been made toward Administrative Simplification, there is a growing gap between that progress and what is needed to gain additional efficiency and support the transition to pay for value and population health. He proposed that the 13th Report to Congress:

- Portray the "burning platform"—the gap between what is needed and the advances in administrative simplification standards and privacy and security;
- Present stories that describe the desirable outcome, the current trajectory, and the gap between the two; and
- Propose a set of possible complementary actions in legislative, executive, and public/private partnership arenas that would help close the gap.

Dr. Stead then invited discussion of this topic, as preparation for further discussion scheduled for day two of this meeting. Ms. Bernstein reminded the Committee of the statutory requirement to report on the status and progress of HIPAA. Dr. Stead responded that NCVHS can achieve that purpose in the proposed context, and other members agreed. Ms. Goss noted that HIPAA was passed in a paper-based era (1996); this report provides an opportunity to urge Congress to modernize HIPAA, as NCVHS has heard in testimony from the industry for the Predictability Roadmap. She cited 21st Century Cures and IMPACT as examples of recent "great work" by Congress. Mr. Coussoule pointed out the need to provide the rationale for saying that now is the time to make adjustments.

Exploring Access to Small-Area Population Health Data and Data Resources
—Dr. Phillips and Dr. Mays (SLIDES)

Dr. Phillips described the goal of the afternoon, which consisted of a series of panel discussions from invited guest presenters, hosted by the Subcommittee on Population Health, on access to small-area population health data and data resources. He thanked those who helped prepare this session. Past NCVHS reports on measuring health at the community level have identified issues with small-area data, which is also a federal stakeholder issue. NCVHS turned its attention to data access issues recently in response to concerns about the loss of four federal health data systems—Community Health Status Indicators, the Health Indicators Warehouse, the multi-year roll-ups of the BRFSS, and Health Data Interactive. The purpose of this day's discussions is to understand the gaps including those created by these losses and consider new options for filling them. As next steps in its work plan, the Subcommittee plans to consider the option of conducting an environmental scan and developing recommendations in this area.

Dr. Mays added her thanks to the panelists and introduced the members of the first panel.

Panel I: Challenges in Accessing Health-Relevant Data

- Mark Hayward, UT Austin and Member, NASEM Committee (SLIDES)

Dr. Hayward is a member of the NASEM Committee on Accounting for Socio-Economic Status in Medicare payment Programs. His presentation focused on its fourth report, "Accounting for Social Risk Factors in Medicare Payment: Data" (October 2016). He discussed a graphic showing a conceptual framework of social risk factors and performance indicators of value-based payments. The NASEM Committee's task was to recommend existing or new sources of data on these factors and strategies for data collection. He commented on three data sources—CMS data, providers and plans, and other government data sources (notably, the American Community Survey)—and noted that patients are the best source of information on social risk factors. Issues of concern include burden, accuracy, and clinical utility. The Committee came up with a set of five guiding principles.

Dr. Hayward then discussed a table summarizing the availability of social risk factors data (#4 in Dr. Phillips' slides). The Committee ranked the desired data in four categories of availability, on a continuum from "available for use now" to "research needed to understand the relationship with health care outcomes and how best to collect the data." It recommended that CMS collect information about relevant, relatively stable social risk factors such as race, ethnicity, language, and education at the time of enrollment. In closing, Dr. Hayward recommended all the NASEM reports, which he said are very well done.

- Angela Johnson, Senior Research Project Analyst, Missouri CARES (SLIDES)

CARES, the Center for Applied Research and Engagement Systems, specializes in data visualization and reporting with a focus on GIS and spatial data analysis. It emphasizes population health and social determinants in the community context, and reaches a wide audience through partnerships with Community Commons and many other organizations. CARES takes data, usually national secondary data, and adds value through data visualization tools, customized reports, and improved access. The metrics are contextualized through mapping, benchmarking, and charting. CARES also does its own analyses.

CARES gets its data from over 360 sources across nearly 100 agencies, facing a variety of access challenges in doing so. The data are in information silos by agency; and they are "one-offs" more often than in standard formats, making it impossible to automate data acquisition. Small-area (neighborhood-level) estimates, which are important for serving diverse communities, are a major challenge, as is the lack of data uniformity. As a result of these and other challenges, data users lose the ability to make well-informed decisions for population health.

Turning to possible solutions, Ms. Johnson noted that the Health Indicators Warehouse provided a unified governance framework for health data, and she stressed the importance of such a governance framework. Second, she stressed the need to continue to fund work around small-area estimates.

- Linette Hudson and Valerie Hayes, Community Hospital Corporation (CHC) (SLIDES)

CHC owns and/or provides management, consulting, and other services for not-for-profit community hospitals across the U.S., primarily in rural areas. It supports community health needs assessments and implementation planning for its hospitals, some related to physician recruitment, based on data on the communities these hospitals serve, drawn from a wide range of data sources. Rural areas face particular data challenges as a result of the lack of availability, comparability, and timeliness of data and the high margin of error in small area estimates. The use of averaging has generated data on rural areas; but this methodology introduces problems, such as by smoothing highs and lows and thus minimizing specific health concerns. There are also challenges in comparing data related to trending, differences in data definitions across data tools, and other factors. Ms. Hayes discussed several of the comparison challenges. She said the Community Health Status Indicator data were the most “relatable” and powerful data available to CHC and provided easy access to benchmarks such as Healthy People 2020. Now, CHC is unable to make the same level of comparisons among peer counties because of the elimination of the CHSI.

In sum, the lack of actionable data leads to barriers in addressing persistent community health needs. The size, dispersion, and inaccessibility of rural populations can impact the adequacy of sample sizing. Data clarity, currency and availability leave rural hospitals to make decisions based on assumptions. Lagging data causes hospitals to question the impact of initiatives. Ms. Hudson stressed that access to detailed, valid small-area information would enable rural hospitals to make decisions based less on assumptions and more on meaningful data, and would facilitate strategic planning, community benefit planning, and physician recruitment.

- Kaye Bender, President and CEO, Public Health Advisory Board (PHAB) (SLIDES)

The lens for Dr. Bender’s presentation is the accreditation of state, local, and tribal public health departments, which PHAB administers. She focused on three areas of challenge with respect to data availability: community health assessments and improvement planning and the issue of small area data; population health benchmarking; and workforce education related to data use. For PHAB, community health assessment and monitoring of outcomes of improvement efforts require at a minimum stable indicators, a description of the area’s health issues, and analysis of contributing causes including environmental factors. Population groups are often divided into subgroups for analysis, requiring more precise data. In that context, she affirmed the comments made by the preceding panelists.

Health departments often try to collect their own data, she said, but primary data collection is difficult for them and often leads to confusing data that impede the development of priorities. Communities sometimes do not trust the work of their health departments because of the confusing data issues, and monitoring becomes difficult because of the lack of meaningful comparison groups or targets. PHAB intends to establish a national database of health outcomes and associated objectives chosen by accredited health departments, in order to document how their work contributes to better outcomes. The challenge, however, is the shortage of benchmark data sources providing reliable peers cohorts and baseline data for measuring population health.

Finally, while she acknowledged that this topic may be beyond the purview of this NCVHS project, Dr. Bender stressed that the education of the public health workforce about setting measurable goals and targets and tracking and monitoring those goals in the context of the local population of interest is a huge challenge. She urged that attention be paid to how to help the public health workforce use data to make good decisions.

- Afshin Khosravi, CEO, Trilogy Integrated Resources (SLIDES)

Trilogy, which provides access to information on community-based programs in the health and human services area, is the developer of Network of Care for Public Health Assessment and Wellness. It is active in about 30 states, and is “a backbone” for local health departments for integrating and aggregating information. Before the Health Indicator Warehouse was launched, Trilogy collected data from some 50 sources at an average cost of $60,000 for a county of 250,000. The introduction of the Warehouse greatly reduced the time required to access and aggregate data, thus reducing the cost of the service by half, as well as increasing the quality and level of detail of the information. Now, with the elimination of the Health Indicator Warehouse, Trilogy must again go to the individual data sources, resulting in higher costs and significantly longer deployment cycles.

Questions and Comments from the Committee

Dr. Mays noted that a theme had emerged across the foregoing presentations about the costs and difficulties rising from the different formats of data. She asked whether the panelists were calling for standardization of data collection, and if so, whether they thought the federal government should lead this process. Mr. Hayward said it made sense for a federal program such as Medicare operated by CMS, to provide the standardization needed for its own policy rules, but it might not be possible to extrapolate from this context to understanding the needs of communities and states. Dr. Khosravi echoed Ms. Johnson's earlier recommendation that federal-level data governance would be very helpful, and added her own call for national-level governance to create uniformity, manage, and provide an access point for data, replacing a process that is now "entirely manual" and must draw from 50 ever-changing data sources.

Asked to describe the magnitude of the disruption caused by the closure of these important federal data sources, the panelists described the impact as resulting in far more labor-intensive processes, lost technological capacity, increased costs, and inferior resulting data and information. Dr. Cornelius wondered if NCVHS and the NCHS Board of Scientific Counselors should try to figure out some kind of continuity in view of these losses.

Dr. Phillips thanked the panelists and noted the common themes related to the types of data needed, the need for standardization and the ability to understand and compare small areas, and the need for data resources that can be updated on a routine basis.

Panel II: Federal Sector Strategies to Increase Access to Small Area Data and Resources

Panel II focused on federal sector strategies to increase access to small area data and resources. The panelists were asked to address these questions:

1. What are current activities underway to improve access to county and sub-county level data? Please also describe whether/how these activities will produce public use files or access via some other means.
2. What additional strategies are being developed/proposed in the near and long term?
3. Are federal health agencies pursuing new data technologies, such as synthetic data, to provide health information without threatening privacy?

- Kurt Greenlund, CDC/National Center for Chronic Disease Prevention and Health Promotion (SLIDES)

CDC's Division of Population Health, part of NCCDPHP, operates two programs that are relevant to the panel's topic: the Behavioral Risk Factor Surveillance System (BRFSS) and the 500 Cities Project (funded by the Robert Wood Johnson Foundation). In addition, several programs do some small area estimation related to specific diseases, often using BRFSS data. Dr. Greenlund stressed that BRFSS, a cooperative program with state health departments, is continuing. While it was originally designed to provide state-based estimates, there are increasing requests for data at the county level, and other sub-state areas, and CDC has been looking at small area estimation techniques to meet this demand. As a result of the fact that Federal agencies also rely heavily on BRFSS data, it was mandated in 2015 that CDC seek OMB approval for the BRFSS work and follow OMB guidelines. Some have hampered what the program is able to do. County-level data are available through the NCHS Research Data Center; and state health departments get their own data. CDC continues to look at how it can provide county-level estimates directly from the BRFSS.

The 500 Cities project provides local estimates for the 500 largest cities in the U.S. using several statistical methods. CDC has conducted external validation studies of these methods, which are also used by other CDC projects. CDC argues that small area synthetic estimates should supplement rather than replace direct estimates. It is still assessing whether they can be used for assessing changes over time. It is continuing to validate 500 Cities and also hopes to expand it beyond the original 500; and it is looking into whether it can provide county estimates for all U.S. counties, using the methods used in this project, and then integrating population health data from the BRFSS.

- Carla Medalia, Bureau of the Census/Economic Reimbursable Surveys Division (SLIDES)

Ms. Medalia described six Census Bureau projects that use Census data to build and evaluate the Census Data Linkage Infrastructure, produce statistics, and engage in evidence-building research, all in order to study small area health outcomes. They are:

  - The Census Data Linkage Infrastructure, which links data from multiple agencies and sources at the person level using anonymized keys;
  - The Mortality Disparities in American Communities project, which studies the relationship between demographic and socioeconomic factors and disparities in U.S. mortality rates;
  - The Small Area Health Insurance Estimates program, which draws on multiple sources to produce model-based estimates for all U.S. counties;
  - A project on improving fertility measurement that aims to understand fertility for demographic subgroups in smaller geographic areas and the undercount of young children;
  - A pilot on enhancing health data that aims to link health data in EHRs and medical claims data to existing data linkage infrastructure sources, to facilitate research on the social determinants of health (now in the pilot phase); and
  - A project to automate disclosure avoidance, aimed at streamlining the process in order to optimize Census data availability while protecting the confidentiality of individuals and businesses. One of the potential prototypes includes privacy-preserving small area estimation.

Ms. Medalia called attention to the significance of the match ratio, which varies by county. She described how to access information on each of these projects. (See the transcript and slides for further details.) In conclusion, she stressed that the Bureau is always interested in building new partnerships with other data providers and researchers and in engaging in joint evidence-building research.

- Benmei Liu, NIH/National Cancer Institute (NCI) (SLIDES)

Dr. Liu is a statistician with a special research interest in small area estimation (SAE). Because accurate local statistics on a host of cancer-related measures have been difficult to obtain, model-based estimation methods are needed to increase the precision. The key idea is to borrow strength from relevant sources such as the Census or other administrative records and from other areas with similar characteristics. The chief model used is the Fay-Herriot Model, on which a lot of theoretical work has been done. Final estimates are developing using combinations of direct and synthetic estimates, varying with the availability of data for direct estimates. Dr. Liu described several SAE projects that NCI has been working on for nearly a decade:

- Small area estimates using the NCI-sponsored Tobacco Use Supplement to the Current Population Survey;
- Small area estimates using the NCI-sponsored Health Information national Trends Survey;
- Combining BRFSS/NHIS for Cancer Risk Factors and Screening Behaviors at the State and County Level; and
- Spatial-temporal models for cancer burden mapping.

To disseminate its SAE results, NCI developed the website SAE.cancer.gov and has released all the results obtained so far. It also communicates with data users through focus groups and email. These estimates are an important data resource for cancer research.

The challenges in conducting representative and informative health research include dispersion and accessibility issues that can increase logistical costs; the difficulty of obtaining adequate sample size; and the "meaningfully different" issue. Dr. Liu commended to the Committee the report from a NASEM Workshop convened to discuss alternative study designs, innovative methodologies for data collection, and innovative statistical techniques for analysis ("Improving Health Research on Small Populations"). Finally, she gave a brief overview of applications of synthetic data at NCI and noted the particular challenges of rural cancer control research, a focus of her division's work.

Questions and Comments from the Committee

Asked about the timeline for the BRFSS projects on synthetic and small area estimation, Mr. Greenlund said he hoped there would be a decision within the next year. To a follow-up question, he said CDC is looking into the capacity to create specific estimates for specific purposes.

Ms. Love commented that the promise of linking State and Census data is tempered by political barriers and limited staff resources. Ms. Medalia agreed, and offered to brainstorm solutions with Ms. Love after the meeting.

Dr. Mays suggested that the Census Bureau empower and form partnerships with its Community Centers, such as the one at UCLA (CSAC, per Ms. Medalia), which produce population-specific data for communities. Ms. Medalia said the Bureau does reach out to and have partnerships with them.

To another question, she said nothing has been decided yet about increasing or decreasing the availability of products coming out of the 2020 Census. A Federal Register Notice that closes on September 17 includes a request for input from users on important uses for the data, to inform the decision.

Panel III: Reactor Panel

- Brian Quinn, Robert Wood Johnson Foundation (RWJF)

Dr. Quinn is an Associate Vice President for Research, Evaluation, and Learning at RWJF. He noted that the 500 Cities and County Health Rankings are signature RWJF projects. The Foundation is also supporting the USA LEEP project in partnership with NCHS and NAPHSIS, to provide life expectancy data at the Census tract level. The foregoing session on small-area population health data, he said, underscores the fact that the field is flourishing with projects that have the potential to be transformative. He offered five reflections around the themes in the presentations.

- It is important to think about the theories of change underlying this work. It appears that a common, implicit theory of change is that more data at an increasingly local level will lead key local actors to become aware of local health issues and "stand up and take action." That in turn is based on assumptions about the correct audiences, how to provide the information, and how people can turn the information and knowledge into action. Thus there is important work to be done to understand how these assumptions and dynamics actually play out, rather than taking it for granted that the hard work under way will turn into the hoped-for action.
- Regarding transparency, it is important to think about how to communicate with lay audiences so they understand the data nuances and assumptions that researchers may take for granted.
- There is "a ton going on," but it can be "a little bit scatter-shot." It is important to be thoughtful and "planful" about priorities going forward with respect to the most important measures, the right geographic levels and population groups to focus on, and so on. Dr. Quinn proposed a "less is more" philosophy.
- While the various new sampling and estimation techniques are important, creativity about collecting new data, such as from wearable devices and apps, is also advisable.
- It is important not to lose sight of the ultimate goal of providing enough longitudinal data to make it possible to assess the impact of various interventions and strategies.

- Soma Stout, 100 Million Healthier Lives (SLIDES)

Dr. Stout is a Vice President at the Institute for Health Care Improvement and Executive Lead for Health Improvement. She noted that while most people are aware of the existence of data on community and population health, they have no idea that certain tools are available for using the data; thus she stressed the need not just to produce good data but to think about the end users and how to make the data accessible to them. Recent work on the NCVHS Framework for Community Health and Well-being revealed that different groups value different things. Despite recent data losses, there is still "an ocean of data," housed in different sources, that is not designed for the average end user and not integrated across sectors. She stressed the need to prioritize a few core things and provide interfaces that make the data accessible to people across sectors at a small-area level, for use to improve health and well-being. In addition, people need to be able to participate in data collection and analysis at the local level. She added that she was impressed by the day's presentations for the many potential opportunities for partnerships.

She then reviewed a few major takeaways from the panels. She praised the idea of a unified data governance framework, citing the example of the internet with its standard operating agreements and standards that allow things to be interoperable. The goal, she said, is to reduce complexity and do a few things really well and seamlessly, with a focus on getting useful data into the hands of users and enabling them to easily collect useful data. Citing the example of weather information, which is clear and easily accessible, she wondered how information on equity, a major driver of health outcomes, could become as standard and easily available. One opportunity for testing, she noted, is the NCVHS Measurement Framework, and she described the Delphi process that 100 Million Healthier Lives has been using to vet measures to advance its further development. Finally, she articulated a vision for an ecosystem of tools, platforms, and partnerships to assure that good data get into the hands of the people who need it, calling this "a norm in a democracy."

Final Discussion

Dr. Phillips began the discussion by articulating a vision for a set of commonly used data elements from multiple HHS sources, using a common methodology, shared via an API or other standard process without having to go through an RDC. Dr. Stout said that is exactly the vision of the more than 100 groups that came together for the Delphi process and in-person convenings around the NCVHS Measurement Framework. Asked about ideas for an "equity index," she said her organization's idea is simply to identify and measure equity outcomes and the key drivers of inequitable outcomes.

Dr. Cohen asked the reactors to comment on "the sweet spot for NCVHS" as the journey continues. Mr. Quinn stressed the need for technical assistance to local areas, to help them collect and use data. Dr. Stout agreed, and added that she saw two major roles for NCVHS: as an integrator across Federal agencies, and as the holder of a vision of what is possible that guides, supports, brings people together, and helps support relationships.

Finally, Dr. Mays noted that communities struggle with issues related to data from institutionalized populations. Ms. Medalia said there is "definitely interagency collaboration" about that, and she offered to work further with others on these issues.

Public Comment

Ms. Hines read a public comment, submitted via the WebEx, from Adam Romero of the Williams Institute and Academic Research Center at the UCLA School of Law. It urges the Committee to "take appropriate steps to protect and advance data collection at HHS about the health of sexual and gender minorities including lesbian, gay, bisexual, transgender, and LGBT people." It also urges NCVHS to support research that would address the computational challenges with small area estimation for LGBT people, given the low base rate, to make SAE feasible. The written comment and appendices describe recent developments with respect to four HHS surveys in which sexual orientation and gender identity data collection have been recently endangered or could be better secured or improved.

Dr. Stead then adjourned the meeting for the day, to reconvene the following day.

—DAY TWO—

Opening Remarks and Farewell to Dr. Ross—Dr. Stead

On the occasion of Dr. Ross's final meeting as an NCVHS member, Dr. Stead expressed his gratitude for his contributions and described him as "a wonderful partner in always helping us connect to the value and purpose that connects to people."

Predictability Roadmap—Mr. Coussoule, Ms. Goss (SLIDES)

Note: The session slides provide a detailed presentation of the process and thinking behind the draft recommendations, their overarching structure and content, and the Subcommittee's planned next steps and project timeline. Please see the slides for the details of the presentation and the transcript for their comments.

Mr. Coussoule thanked his co-chair, Ms. Goss, and the Subcommittee's staff, Lorraine Doo and Geanelle Herring, and Subcommittee members for their work on this project. The major goal of this session is to review the draft recommendations on the Predictability Roadmap and obtain members' input. He briefly described the 18-month process through which the Subcommittee arrived at the draft recommendations.

While administrative standards have significantly improved the efficiency of the health care system, improving the process would further improve the system's efficiency. Changes in the industry and technology have outpaced the ability to keep up. A more predictable and flexible approach would likely address these challenges. The vision the Roadmap is intended to help bring about is: "For covered entities and business associates to be able to use up-to-date HIPAA standards consistently, garnering increased value from the standards by avoiding 'one-off' work-arounds, and to reliably know when updated versions will be updated and adopted in time to prepare systems, resources and business processes."

After a brief overview of the standards process, Ms. Goss described the extensive and rigorous process of consultation and investigation that the Subcommittee engaged in to develop the draft recommendations. The themes that emerged from the initial consultations were affirmed by participants in a CIO Forum held in May 2018.

Before inviting members' questions and comments, the co-chairs then gave a thorough overview of the context and logic for all the draft recommendations, calls to action, and proposed measurements in light of their interrelationships and interdependencies. They are grouped into three large categories, with sequential timeframes:

Improved education, outreach and enforcement (2019-2020)

Policy levers (2020-2021)

Regulatory levers (2021-2024)

The co-chairs stressed that the critical next step, following this discussion with the Committee and any requested revisions of the draft recommendations as advised, is to obtain and incorporate input from the industry. In addition to participating in a December 12-13 hearing, stakeholders can submit comments in writing, the process for which will be announced in an upcoming Federal Register Notice. Based on that input, the Subcommittee will prepare final recommendations for the Full Committee to review, leading to a letter to the Secretary in early 2019.

Committee Suggestions and Discussion

Many members commended the co-chairs, the Subcommittee, and Ms. Doo for the quality, clarity, and vision of the draft recommendations and the extent to which they reflect the input received by the Subcommittee. This discussion is the first public discussion and deliberation of the draft recommendations.

Mr. Landen commented that the Subcommittee's approach of thinking large and acting small is "exactly what information technology needs." The co-chairs said they made an effort to present the recommendations as "a go-forward change opportunity" rather than a criticism of any past developments.

Dr. Mays and others said the clarity of the recommendations helped them understand how to think about the issues and participate in this process. She suggested that NCVHS members who are not on the Standards Subcommittee may be able to help think through how to expand outreach, and several members had suggestions for outreach. Ms. Goss said "the holy grail" is to find ways to get providers engaged earlier in the process. In that regard, Mr. Coussoule noted the opportunities inherent in the growing convergence of two historically divergent paths: administrative standards and clinical standards. On this point, Dr. Phillips commented that provider organizations are now engaged, and see the policy arena as the solution, while standards development and vetting may be a more productive place for them to be involved. He suggested meeting with the larger provider organizations. Ms. Love expanded the perspective by noting that in the early days of HIPAA, public health and states were engaged and at the table, but shrinking resources have lessened their participation. Noting that public health and states are a missing piece, she stressed the importance of getting them "back in the tent." Continuing the theme of outreach, Dr. Cohen recommended creating a brief "standards for dummies" paper that explains the history, the importance, and the dynamic process of standards.

Dr. Stead recommended that the Committee make sure it understands the degree of difficulty for HHS and the industry to take the actions proposed for 2019-20 (improving education, outreach and enforcement). Ms. Goss responded that this is a matter of choice and aligning resources, and the Subcommittee regards these initial actions as low-hanging fruit. The HHS CMS/Division of National Standards will be represented at the December hearing being held to obtain input on the draft recommendations. Mr. Coussoule expressed his view that sequentially, the recommendations go down the right path. He summarized the Subcommittee's intent as to enable the kind of creativity and flexibility to keep all the players in the ecosystem advancing in at least a minimum way while enabling willing participants to move faster.

NCVHS members suggested a few ways to strengthen or clarify specific recommendations and arguments in the draft document, such as on the potential benefits of transparency and matters related to non-covered entities. There were also questions on how certain recommendations were intended to work in practice. There was brief discussion, too, of how to handle cross-cutting recommendations (e.g., involving industry).

The draft recommendations, revised based on the foregoing discussion, will be sent to stakeholders prior to the December hearing along with another document providing further background and detail. Both will be posted on the NCVHS website. The co-chairs emphasized that they want and need feedback from stakeholders who will be directly affected by the proposed recommendations.

Ms. Hines read a WebEx comment submitted by an ONC staff member, suggesting that it's important to consider the opportunity, as technologies advance, to move away from the currently dominant model of 'billing-system-with-clinical-bolted-on' and towards integrated systems that use one set of underlying standards (or, better yet, a single harmonized standard) that reflect the reality that this is all supposed to be about one goal: patient care. He further commented that standards would do a lot to advance the technology field toward integrated, seamless systems.

In response, Mr. Landen asserted that the Roadmap vision does not necessarily translate into a call to migrate to a single system, and that data can be harmonized without dismantling systems in which entities have made huge investments.

In conclusion, Ms. Goss acknowledged the "phenomenal staff support" provided by Lorraine Doo in producing the narrative report and guiding the Subcommittee's refinement of the language in the draft recommendations. She reiterated the importance of stakeholder support and engagement through the process to date, and looked forward to further constructive feedback in the future.

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

Note: See the session slides and transcript for the details of this substantive presentation and the Committee discussion.

The Beyond HIPAA initiative builds on NCVHS's past work and that of other government and private initiatives to consider a health data privacy and security framework for 21st century health information challenges. In May, the Committee suggested that the Subcommittee on Privacy, Confidentiality and Security (PCS) start work to develop a model to assist in understanding and addressing the subject.

After reviewing the project work to date, Ms. Kloss introduced the draft model, provisionally titled "Stewardship by Design, as Applied to Data Device and App Exemplars." An earlier version was reviewed by a small expert group composed of previous NCVHS PCS Subcommittee members. The goal for this day's discussion is to get feedback from the Full Committee about the model's content and usefulness and to consider next steps for the PCS Subcommittee.

She began by describing the thinking used to develop the underlying concepts. The concepts of harm and risk draw on work by the National Institute of Standards and Technology (NIST). As discussed in a book by Michael Chertoff, privacy is too narrow a value; the focus should instead be on how to preserve autonomy, the core of freedom. This concept underlies the General Data Protection Act and a new California law that Ms. Monson will report on later in this session. A key premise of the draft NCVHS model is that HIPAA-covered entities and business associates and entities not covered by HIPAA are on a continuum, rather than part of a binary construct that focuses only on compliance. Covered entities can do more than what HIPAA requires to protect privacy, as some entities are already doing. Further, entities not covered by HIPAA can adopt strong data stewardship practices, and society can enact new data protections. Such mechanisms exist in both public and private sectors and involve both public actions and private mechanisms. The draft model cites examples of the types of mechanisms private entities could take and possible steps under governmental jurisdiction, in both cases across a spectrum that includes protections beyond regulatory compliance, improvements to data stewardship, and enactment of new data protections (see slide 9).

Members generally praised the model and offered a few comments and suggestions about specific aspects. They also commented on certain practical realities and challenges that have an impact on attempts to protect privacy and preserve autonomy; Ms. Kloss welcomed these as topics for continued discussion. The model was described as a way of framing the landscape and a picture of possible levers.

Ms. Kloss noted that as development of this project moves forward, the Committee will have to decide whether to be bold or modest and incremental in its recommendations. She then asked PCS Subcommittee member Jacki Monson, an attorney with Sutter Health in California, to brief the Committee on the California Consumer Protection Act (CCPA).

The California Consumer Protection Act—Ms. Monson (SLIDES)

This California law, passed in June 2018 after a fast-track process, is designed to increase transparency and give consumers more privacy rights with respect to data ownership, control, and security. It applies to for-profit business entities with a gross revenue of $25 million or more that receive or share information from more than 50,000 consumers, households, or devices, and earn more than half of their revenue from the sale of personal health information. Exceptions are made for HIPAA, the California Medical Information Act, and the Gramm Leach Bliley Act. (Whichever one is more stringent would apply.) The law does not apply to non-profits. The law defines personal health information broadly and includes devices. Consumers are given a number of rights, which Ms. Monson described, along with other highlights. (See slides.) Failure to comply will cost a business $7500 per violation, money that goes to the state. Consumers have a right of private action, ranging from $100-$750 per violation. The law is slated to go into effect in January 2020.

Ms. Monson invited questions and comments. In response to a comment about potential negative consequences for socially beneficial uses of health data, she noted that the bill was drafted and pushed through in three months, spurred by concerns about social media companies that are exchanging and selling data, and legislators did not necessarily contemplate the impact on broader data sharing. Amendments have already been proposed. She expects multiple addenda and possibly an extension of the compliance date. One challenge, she said, is defining the difference between protected health information in the scope of HIPAA and the law's very broad definition of personal information. She agreed with Ms. Goss that many non-residents of California will be covered by the Act—for example, Facebook users—thus adding to the complexity of what consumers have to try and understand. Asked about other states, she said California tends to lead in the regulatory space, particularly in privacy and security, and many states are watching. Dr. Mays noted the complexities related to the many public-private partnerships, and described the challenges the law poses for the University of California.

Dr. Phillips suggested a role for NCVHS in helping states develop better laws and convening to help clarify what the laws and rules mean and how to respond to them. Other members supported these suggestions. Mr. Coussoule raised the specter of 50 different sets of rules to comply with. Ms. Love suggested that NCVHS produce educational pieces for consumers on the importance of their PHI for population health and price transparency.

Next Steps for this Project

Transitioning back to the "Stewardship by Design" model, Ms. Kloss noted that the CCPA underscores that the NCVHS environmental scan is a living document in a changing environment, and that NCVHS can play a role in putting a stake in the ground saying that proactively introducing protective mechanisms in both public and private sectors is overdue. She then showed a slide that uses the model, as a test (or use case), to look at registries, personal health devices, and an app. Members briefly discussed whether the model would be helpful in evaluating emerging laws such as the CCPA.

Given the Committee's general endorsement of the draft model, the Subcommittee plans to take version 1.1 to its panel of outside experts (former members) for their reactions. It also plans to turn the slide deck into a short written narrative report, and to hold a hearing or roundtable in early 2019. Finally, it will continue to develop themes for incorporation into the 13th Report to Congress. Ms. Kloss said that in addition to providing further evidence of the ways the environment is changing, these themes show that there is an opportunity to increase protections and choice for consumers while reducing burden.

NCVHS 13th Report to Congress Brainstorm—Dr. Stead

Dr. Stead presented a revised draft outline for the 13th NCVHS Report to Congress that incorporates ideas from the previous day's discussion. There was broad support for the framing. Members agreed that the progress and status section should be subdivided into transactions and operating rules; terminologies and vocabularies; privacy, confidentiality and security; and access to data.

Dr. Stead then led the members in a brainstorming session on what compelling stories might be used to show the contrast between what is possible and what we have today, as a basis for a call to action. Several members proposed topics, and the group discussed what further information, ideas, and culling are needed to come up with a few compelling stories. Ms. Love will abstract and share an example from an NPRM comment by 20 states and the National Academy of State Health Policy. Next, members proposed a number of specific potential levers as examples of actions that could help achieve the desired trajectory and "change the game" in the areas within the NCVHS purview. Dr. Ross will write up and share an example from his international work.

Dr. Stead explained that the report would identify actions NCVHS thinks Congress should consider taking to progress from the current state to a much improved, less burdensome state. The report will also suggest recommendations for additional possible actions in the executive branch and public/private partnership sectors. He added that while in its letters to the Secretary, the Committee is very careful not to recommend things that require legislative action, the report to Congress does not need to be constrained in this way. The Committee's projects on predictability of standards adoption, health terminology and vocabularies, privacy "Beyond HIPAA", and vital statistics data will supply most of the major themes.

As to timeline, the fall season will be dedicated to Subcommittee work on the content in their respective areas, advanced and integrated through monthly Executive Subcommittee calls. The report will be drafted using these raw materials starting in mid-December and into January, and is slated for review by the Full Committee during its next meeting on February 6.

The Committee then briefly discussed its work plan for 2019.

Public Comment—Ms. Hines

Ms. Hines read a comment submitted by Margaret Weiker about recommendations 3, 4, 5 and 6 of the Predictability Roadmap. It was forwarded to the Subcommittee on Standards.

Closing Remarks—Dr. Stead

Dr. Stead closed the meeting by thanking the staff of all subcommittees, the NCHS team, ASPE staff and leadership, the logistics contractor, and Ms. Hines. He noted the effort involved to shift to a virtual meeting because of the weather, which was accomplished in just 24 hours. He then adjourned the meeting.

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

/s/ 11/14/2018

Chair Date