National Committee on Vital and Health Statistics

Virtual Meeting of the Population Health Subcommittee

November 28, 2017

9:00 am–1:00 pm EST

Note: For details on this meeting, please refer to the transcript and slides posted at www.ncvhs.hhs.gov

NCVHS Members and Staff in Attendance

Bruce Cohen, PhD* **Subcommittee Co-chair**

Robert Phillips, Jr., MD, MSPH,* **Subcommittee Co-chair**

Llewellyn J. Cornelius, PhD, LCSW*

Nicholas L. Coussoule

Alix Goss

William W. Stead, MD, **NCVHS Chair**

Richard W. Landen, MPH, MBA

Denise E. Love, BSN, MBA*

Vickie M. Mays, PhD, MSPH*

Jacki Monson, JD

Helga Rippen, MD, PhD, MPH, FACPM*

Debra Strickland, MS*

*Member of the Subcommittee on Population Health

Kate Brett, PhD, Lead Staff to the Subcommittee on Population Health

Division of Vital Statistics

National Center for Health Statistics, CDC, HHS

Rebecca Hines, MHS, NCVHS Executive Secretary/DFO

Health Scientist

National Center for Health Statistics, CDC, HHS

Rashida Dorsey, PhD, NCVHS Executive Staff Director

Director, Division of Data Policy

Office of the Assistant Secretary for Planning and Evaluation, HHS

Maya Bernstein, JD, ASPE, HHS

Geneva Cashaw, NCHS

Debbie Jackson, MA, NCHS

Katherine Jones, MS, NCHS

Marietta Squire, NCHS

Others in Attendance

Melissa Carlier, ASPE, HHS

Kelly Baker, Health OK

Kristin Dawsen, BCBS

Robert Demichelis

Mike Denison, Changehealthcare

Devine George, Louisiana Government

Gail Kocher, BCBSA

Seth Miller, Nccsite

Gib Parrish, Consultant to NCVHS

Dan Rode, Dan Rode Associates

Shawna Webster, NAPHSIS

To begin, the co-chairs reviewed the meeting agenda.

Agenda Item: Review of September 2017 Vital Statistic Hearing Summary Report

Bruce Cohen led off with a summary of the September hearing. The objectives of the hearing were to identify the essential elements of the vital registration data system, to assess its current status, and consider what actions are needed to protect and improve the system, using a multi-stakeholder presentation and discussion approach. The high-level findings from the hearing fall into four areas:

Current status of the U.S. Vital Registration and Statistics System (VRSS)

Challenges identified during the hearing

Approaches to address challenges

Vision for vitals in the U.S.

Participants at the hearing came from a wide range of organizations involved in the collection and use of vital registration and statistical data (from medical examiners, state/local registrars, funeral directors, researchers, Federal agencies, as well as the business sector). Bruce Cohen asked – was there any particular perspective missing from the hearing discussion? Helga Rippen noted that the Committee needs to be proactive about considering privacy/security concerns in consultation with privacy/security experts. Bob Phillips brought up the fact that researching international perspectives could provide useful background as part of the Committee's information gathering process.

Bruce Cohen noted that as a result of the hearing, the Committee now has a greater understanding of the breadth of the use and need for vitals data: many different uses of vitals data for many different functions by many different groups and the various ways the federal agencies are paying for these data. The interactive discussions during the hearing helped elucidate all of these different uses of the data. If there was a lesson learned, it was that as a Committee, it is helpful not only to have the opportunity to have experts provide input to us, but also to listen to experts discuss amongst themselves the issues they understand well.

Also emerged was an appreciation of the complexity not only of data collection, but the multi-faceted aspects of the vitals system—to keep the data secure, to keep them accurate, to keep them timely, to keep them maintained, and to keep them functioning for all the functions that are needed.

Helga Rippen suggested combining the discussion of data users with the data uses in the meeting summary to avoid redundancy. During discussion of the main data users and challenges, Bob Phillips noted that the value of data for data collectors is going to be one of the more difficult issues to contemplate without additional conversation and input from this segment of the data community. Data collectors have an enormous responsibility to ensure availability of high quality data, yet there is little return value to them.

Focusing on approaches, the business model of the federated system needs to be better elucidated and explored. Helga Rippen indicated that the Committee needs to be careful about this, since the core function of health issues lies with the States; thus, identification and understanding of the implications of a more federal approach should be discussed in a thoughtful way.

Bill Stead noted that one thing that came out in the hearing— and probably will come out in the follow up report under development—is the redundancy, overlap and incompleteness of the various approaches used to make the data accessible. This is a different issue from quality of the original data.

Longer-term vision, possibilities, and suggested directions for NCVHS discussed included: development/revisiting of a model law that States could adopt; increase the public’s and policy makers’ awareness of the value of vital statistics data; and align this work with complementary streams of other NCVHS work.

Denise Love pointed out, as the Committee assesses the value proposition of Vitals, she wants to make sure that the Committee’s report emphasizes that vitals are just one part of a State’s information system, and the Committee should avoid proposing that one system compete for money to the detriment of others.

Bruce Cohen focused the discussion on the hearing report (refer to slides).

Helga Rippen indicated that the report should reflect the balance of what was said at the hearing, not letting who said what influence the importance of the information. Then we can use this report combined with the analysis the Committee commissioned to figure out new directions for the Committee.

Rich Landen indicated that there is a wealth of information generated from the hearing. We should incorporate all of that information as best possible into the report, e.g., the integration of EHRs.

Agenda Item: Review and Comment on the Draft "Data Uses, Users and Costs Report" Authored by Dr. Gib Parrish

Dr. Gib Parrish led off this portion of the agenda. As a result of the September hearing, the Committee realized it needed more detailed analysis on the underlying users and uses of vital registration and statistics data. The Committee asked Dr. Parrish to prepare a follow-up report that would examine in greater detail the uses, users, and sources of revenues of the National Vitals data system. He was also asked to look at the operational costs of collecting vitals data; however early into the project he discovered that cost information is challenging to ascertain and thus will not be a major focus. Dr. Parrish started off his analysis with a thorough review of the September hearing transcript to identify sources. He reviewed a number of websites for greater detail on different systems, state level vital records offices, the NAPHSIS website and other sites, to gather information on organizations and people who use vital records and vital statistics data. In addition he conducted interviews to obtain more depth on issues related to uses, users and sources of revenue.

Dr. Parrish described the birth registration system overview slide starting off with the generation and collection of data for the birth certificate itself. The key challenge for the birth certificate are that data needs to come from several different sources, from the mother, typically from hospital records of various sorts, both the obstetric and pediatric data in addition to information from the perinatal visits that may have occurred. Some of this information may be accessible from electronic health records which the birth clerk may use; however that process is in its infancy. Once the information is collected and entered into the Electronic Birth Registration System, it is further processed there by the state health department and made available to various users. The state health department, and this varies state to state, may provide information from neonatal screening programs to immunization registries within the state because there are immunizations that take place essentially at the time of birth, the hepatitis B vaccinations, in particular. Because some births may occur in a given jurisdiction but that is not necessarily the jurisdiction in which the mother and baby are residents, there is often a need for exchange of records between jurisdictions.

Members followed up with questions that stemmed from Dr. Parrish's description of the birth registration and data system. Subsequently, he moved to describe an overview of the death registration system referring to the illustration on the slide. Multiple parties are involved in the generation of a given death record and this depends, in part, on where the death occurs and the circumstances and cause of the death. Unlike births, only about half of deaths in the US occur in hospitals, others occur out of hospitals, some are injury-related deaths that may occur anywhere. Thus it's a system in which there are multiple players that include physicians, funeral directors, funeral homes, medical examiners and coroners for medical legal death, and then the family or other informants who provide information. Typically, the funeral home has, in the past at least, been the focus of the data collection for this and ensuring that data comes from appropriate people, for example, physicians who would be certifying the cause of death, but in some situations, the death may be investigated by medical examiners and coroners and the person who originates the death certificate in different states may vary. It may originate with the physician or medical examiner in some states or it may originate with the funeral director in other states.

Many funeral directors and to some extent other certifiers may interact with the Electronic Death Registration System which is present in many states though not all states at this time, unlike birth where the Electronic Birth Registration System is essentially present in all states. Dr. Parrish went into significant detail regarding the different data suppliers and variation across jurisdictions.

Members followed up with questions, such as: how data are supplied to the National Violent Death Reporting System (NVDRS); the cause of variation in the cost of death certificates across jurisdictions; on uniformity/quality of data; and variation in ability to access death data. Each state and jurisdiction has its own laws and regulations governing access to individual and aggregate records. Bruce Cohen reviewed the goals of the Model Law and some of other systems. The aim is to move states in the direction to unify and standardize approaches to accessing data to minimize variations in restrictiveness.

Dr. Parrish explained that standard certificates were designed in collaboration between NCHS and states to collect a core set of information. States can add additional items for their own use, but there is no structure set up to influence other states to do the same between versions of the standard certificate. Also, edit checking systems built into the electronic birth and death registration systems are designed to improve data quality by potentially identifying inaccurate information and providing instructions on how to enter correct information.

Bob Phillips raised the question whether information entered into the systems flows back to the data generators and suppliers. Dr. Parrish was unaware of feedback sent directly, for example, back to funeral directors or the birth clerks at a given hospital concerning the data. Dr. Parrish noted that inside some of the electronic registration systems there are feedback loops that provide information as to whether data is being entered correctly and possibly some information to help put the correct information in.

Agenda Item: Scoping Out Future Vitals Statistics System Work

Bruce Cohen led a discussion on developing next steps for the Subcommittee. Members discussed and agreed that additional information on access, funding, redundancy, content will likely be needed. The Subcommittee will need to define a reasonable scope of work, both long- and short-term. To consider – is there “low-hanging fruit” that the Committee could address? And the question as to whether it would be possible to develop shorter-term recommendations that could be included in a letter sometime early in 2018 – or whether additional work is needed before the Committee can reach consensus on next steps.

Bruce Cohen suggested that developing some use cases to test some of the ideas about how the system could work more effectively and efficiently would be one possible approach.

Vickie Mays suggested it would be important to have a conceptual model of how vitals fit into the information flow for all national health data – through development of a visual that shows all the ways the information fits in and how it fits into data flow. That would support the Committee in being able to point to particular groups and their respective data needs and where the Committee needs to focus.

Helga Rippen reflected that birth and death data is used for more than just health. The Committee will need to decide whether its focus is going to be narrower, which is the public health component, which then defines the challenges specific to this sector. Or alternatively, take a more global view of the entire process, which becomes more complex. The Committee will need to decide how much to take on – the scope. Bill Stead inquired whether there is a federal public health authority that meets the condition of being a public health authority for HIPAA that could receive the fact of birth information. Even if it was the state but somewhere outside of the registrar, it would be easier to suggest new options. This is a legal question that could be answered. Helga Rippen suggested it is enough to say that there hasn't been enough effort spent to understand the complexities. The Committee needs to avoid recommendations that may potentially harm the system that is currently in place.

Bob Phillips noted that aspects of the vitals data question could easily fall into the conversation about the Commission of Evidence-Based Policymaking – it's important to keep this in mind. Rich Landen pointed out, in light of the significant jurisdictional differences, it's not clear that the Committee could develop recommendations that would effectively deal with these complexities. To conclude, Helga Rippen put forth an approach that would highlight that there is a challenge and there isn't sufficient enough investment in the structure and infrastructure – and that it's at risk. And then highlighting the value and benefit of the system and the data.

Commission on Evidenced-based Policymaking (CEP)

Bob Phillips reviewed the background on the CEP as well as the Commission's report and recommendations in detail using slides. Recently, the House passed legislation (Foundations for Evidence-Based Policymaking Act of 2017), which includes 4 areas for improvement: modernizing privacy protections, improving access to federal data, strengthening federal capacity to build evidence, and implementing a national secure data service. The legislation has not been taken up by the Senate and so we are holding to wait until Congress passes a final law and then HHS takes up the legislation. CEP recommendations 3 and 5 are most relevant to NCVHS work: Enhancing privacy protections (recommendations 3.1-3.4) and strengthening the evidence-building capacity within the federal government (recommendations 5.1-5.5). Bob reminded the Subcommittee that Commission members met with NCVHS at two full Committee meetings in 2017 and the Committee provided input into CEP's deliberation process.

Bruce Cohen noted that once HHS has developed some direction, following up on the CEP's recommendations will align with the Committee's charge. Bill Stead noted that the legislation passed by the House would provide significant progress to move forward on the Commission's recommendations. The NCVHS Measurement Framework would be a good use case for the

Commission's recommendations. Another use case is the Committee's work on Healthdata.gov. Rashida Dorsey noted that HHS sees a role for NCVHS should the legislation pass the Senate. There are targeted areas in early 2018 that would be very helpful for the Committee to help the Department move forward on, especially with the implementation of whatever becomes the final law. She suggested that recommendations from the Committee would be useful at that stage. It was noted that the House version of the bill has no budgetary implications. Bill indicated that this is likely the first of several laws that would build on one another. There is no known timeline as to when the Senate will take this up, thus no additional work can be planned at this time.

HHS Data Access Issues: Framing the Scope

Bob started off by framing the issue. Members of the Committee have experienced increased difficulty with data access. And also have heard from external stakeholders who have provided similar feedback about particular HHS datasets that were public and now are no longer available, or at least in the way that they had been available. The Community Health Status Indicators (CHSI) project was launched in 2000, disrupted in 2003 (removed from HRSA's website), and was subsequently operational off and on under HRSA and then CDC. There is some overlap with County Health Rankings, but with significant differences (only 29 measures and no standard error measures). With CHSI, there were peer county data comparisons, many more data elements and every estimate came with confidence intervals. CHSI had over 300 measures at the Census tract level with 78 core measures including features such as mortality data broken down by age, race, gender, and inclusive of some of the social determinants measures with standard errors around those. So it was a pretty robust project. This project was discontinued in August of 2017. The HHS Health Indicators Warehouse (HIW) was discontinued in 2016. Access to BRFSS 7-year rolling averages at the county level is now no longer available. There are vendors that relied on those 7-year averages and now are having to use modeled data that do not appear to be as robust. The 500 Cities Project is an asset but most cities and Census tracts are not included in the project and the modelled data in the project may also be problematic. Finally, Health Data Interactive (HDI) which made pre-tabulated data available to the public, was discontinued in 2016.

Bob Phillips then asked Vickie Mays to continue the discussion. She indicated that, in some cases, the loss of available data has been determined to be due to cost. Federal agencies are indicating they are not sufficiently funded, that the cost of collecting, storing and curating this data has gone up and without additional resources, they can't do it. In addition, there are some losses happening due to removal of data linkages (e.g., NIHS/MEPS), which may be the result of changes in interpretation of laws/rules around confidentiality, privacy, security, even cybersecurity issues. In addition, some of the access has been moved from the public to Research Data Centers (RDCs), which removes such data from anyone except researchers. Then there is the issue of what the definition of health is, and what non-health domains should be included in health data systems.

Some of the change in access has removed the ability for entrepreneurs to gain access to data that they then repackaged for public access and use, for example: what is the best hospital for a given procedure in a given location? Different, perhaps less reliable data are available. Bruce Cohen raised the question as to how the Committee would go about gathering more information to describe the breadth of the issues being described.

Bruce Cohen asked how this information could be used to form the basis of the Committee's work during the year ahead. Bob Phillips referred to the draft workplan. Possible approaches include finding out how to collect data on problems of data access as well as talking with the HHS Data Council. Rashida Dorsey indicated it would make sense to start with the Data Council. There are efforts being followed within the purview of the Imagine HHS project. Vickie Mays noted there are additional groups that should be included beyond HHS: Census, DOD, VA, SSA. Helga Rippen noted that impacts on business should be identified and included.

The discussion moved to considering the possibility of creating some recommendations/guidance for how one decides what data are needed and can be created publicly. During the discussion, Bill Stead suggested that the Subcommittee try to define discrete activities for each quarter. May want to have electronic fact-finding of some sort (not related to the Data Council), to guide understanding of how close the Committee is to understanding the problem. From there, the Subcommittee would then decide what the Committee's next step would be, possibly even a go/no go decision by the second quarter of 2018. Members discussed the possibility of creating an initial fact base that could be shared with the Committee during the January 2018 meeting.

Workplan Review

Subcommittee members reviewed and discussed the workplan for the year ahead.

<u>Next Generation Vital Statistics</u>

Bill Stead inquired, given what the Committee has learned from the hearing and vitals data analysis report, do we think we can get to recommendations without needing to convene another meeting, and if not, can we convene something in Q3 of 2018 so that we can create recommendations in Q4? Helga Rippen pointed out that the Subcommittee will need to meet soon so they can sketch out what is doable. She noted that Bill Stead wants the Subcommittee to take what we have and create some process milestones leading up to development of recommendations. She also noted that several people have suggested that the Committee probably will need another hearing before being comfortable with issuing recommendations.

Bob Phillips inquired whether resources would be sufficient to support a hearing in this fiscal year. Rebecca Hines responded that each Subcommittee will need to put forth a list for the Executive Subcommittee to review together as a whole and then make a decision based on overall Committee priorities and availability of resources. At this time, it was not clear whether the Committee could support a follow-up hearing or meeting.

Commission on Evidence-based Policymaking

The Committee's workplan for this project is wholly dependent on whether the Senate takes up the bill passed by the House and passes it. Should that be the case, the Committee's focus also would be dependent on whether HHS requests input or a specific project or question to be explored.

Measurement Framework

Bruce Cohen provided an update on the NCVHS Measurement Framework for Community Health and Wellbeing completed early in 2017, which has catalyzed two relevant projects: 1) The Institute for Healthcare Improvement's (IHI) 100 Million Healthier Lives lead, Soma Stout, is convening workgroups to continue the Committee's work and they are, right now, in the process of getting folks to review other existing measurement frameworks to identify measures suitable to populate the NCVHS framework along with other related activities. They continue to meet on an ongoing process; 2) The second is the US News and World Report Project—they have already collected preliminary data at the county level for the approximately 16 measures that they have identified using the NCVHS Framework; experts are reviewing their work with the intention of publishing the data by early next year.

Public Comment

No comments were submitted. The meeting was adjourned at 12:50 pm.

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

/s/ November 8, 2018

Chair Date