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Department of Health and Human Services
Board of Scientific Counselors
National Center for Health Statistics
Centers for Disease Control and Prevention
September 6–7, 2017

Meeting Minutes

Meeting Summary

The Board of Scientific Counselors (BSC) convened on September 6–7, 2017, at the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC), 3311 Toledo Road, Hyattsville, MD. The meeting was open to the public.

Board Members Present

Linette T. Scott, M.D., M.P.H., Chair, BSC
Timothy J. Beebe, Ph.D.
Virginia S. Cain, Ph.D., Executive Secretary (NCHS Staff)
Prashila Dullabh, M.D.
Darrell J. Gaskin, Ph.D.
Sherry A. Glied, Ph.D. (by phone)
Robert M. Hauser, Ph.D.
Mark D. Hayward, Ph.D.
Mary Ellen (Meg) Johantgen, Ph.D., R.N.
Virginia M. Lesser, D.Ph.
Wendy D. Manning, Ph.D.
Robert E. McKeown, Ph.D., FACE
Ninez A. Ponce, M.P.P., Ph.D.
Trivellore E. Raghunathan, Ph.D.
Robert L. Santos, M.A.
Margo Schwab, Alternate Ex Officio Member
Gretchen Van Wye, Ph.D., M.A.
Robert L. Phillips, Jr. M.D., MSPH, NCVHS Liaison (9-7-17 only)

NCHS-CDC Staff

Jennifer Madans, Ph.D.
Gwendolyn Mustaf
Chesley Richards, M.D., M.P.H., FACP

General Audience

September 6, 2017
Negasi Beyene, DRM
Jim Crower, OAE
Anne Furnia, Census

Althelia Harris, OAE
 Jill Hensley, Northrop Grumman
 Rebecca Hines, OD/OPBL (by phone)
 Debbie Jackson, OD/CPHDSS
 Meena Khare, DRM
 Suresh Srinivasan, DHIS
 Merianne Spencer, DVS
 Makram Talih, OAE
 Rashmi Tandon, OAE
 Anjel Vahratian, DHIS

September 7, 2017

Alicia Frasier, RTI International
 Rebecca Hines, OD/OPBL
 Sibeso Joyner, OAE
 Susan Schneider, OMO/NCHS
 Makram Talih, OAE
 Rashmi Tandon, OAE
 Julie Weeks, OAE

Action Steps

- Read the Evidence-Based Commission report to be released today.
- Engage in public dialogue by:
 - Listening to or participating in the hearings hosted by National Committee on Vital and Health Statistics (NCVHS) to gather stakeholder information for vital statistics, to be held September 11–12; and
 - Following the outcomes of the Healthy People 2030's advisory committees and subcommittees and providing input during the comment period.
- With the presentation materials from this meeting in mind, consider for the January meeting ways NCHS priorities can be met.
- The next BSC meeting will take place January 11–12, 2018.

Wednesday, September 6, 2017

Presenters

September 6, 2017

Stephen Blumberg, Ph.D., DHIS
 Carol DeFrances, Ph.D., DHCS
 Renee Gindi, Ph.D., DHIS
 Julia Holmes, Ph.D., OAE
 Florence Lee, M.P.H., OAE
 Jennifer Madans, Ph.D., NCHS
 Chesley Richards, M.D., M.P.H., FACP, CDC

Welcome, Introductions, and Call to Order

Linette T. Scott, M.D., M.P.H., Chair, BSC
 Virginia S. Cain, Ph.D., Designated Federal Official, NCHS, BSC

Dr. Scott welcomed the group and covered meeting logistics. Members present were asked to introduce themselves, describe the expertise they bring to the board, and state any conflicts of interest. A quorum was present, and the meeting was called to order.

NCHS Update

Jennifer Madans, Ph.D., Associate Director for Science, NCHS

Dr. Madans sent regrets and greetings from Charles Rothwell, NCHS Director. She then gave a brief budget history review illustrating the NCHS funding source transitions over the past few years between the Public Health Service (PHS) Evaluation funds and regular budget authority funding. While 2013 funding allowed for implementation of health care surveys, funding has been flat since 2014. Although the outcome of the 2018 budget request is still unknown, funding based on the President's budget request will be reduced by approximately \$5 million—from \$160 million in FY 2017 to \$155 million—in the projected 2018 budget. Because funds are also received from other agencies, cuts to those agencies affect the NCHS budget, adding another dynamic to the uncertainty. Work on the 2019 budget request is in process.

The staff update revealed a reduction in staff over the past 3 years. In addition, eight key staff retirements were confirmed. Marcie Cynamon, Division Director for the Division of Health Interview Statistics (DHIS), and Nathaniel Schenker, Division Director for the Division of Research and Methodology (DRM) retired in the spring and summer. Stephen Blumberg is the DHIS acting director, and Jennifer Parker is the DRM acting director. Upcoming retirements include Virginia Cain, the Executive Secretary of the BSC, who is retiring after 38 years of service (12 years at NCHS). New HHS appointments and nominations were reviewed. They include new CDC Director Brenda Fitzgerald, M.D., Secretary of HHS Tom Price, and Jerome Adams, Surgeon General. As of January 2017, Nancy Potok is the new Chief Statistician of the United States with the Federal Statistical System, and Bill Wiatrowski is the acting Commissioner for the Bureau of Labor Statistics.

The accomplishments of several programs were shared with the Board. The National Health and Nutritional Examination Survey (NHANES) program released three data reports highlighted in the media: sugar-sweetened beverages consumption; human papillomavirus infection (HPV); and antidepressant use. NHANES 2015–2016 Data Briefs on obesity, hypertension, and cholesterol will be released this fall. Recently released National Health Interview Survey (NHIS) reports were reviewed, including the Native Hawaiian and Pacific Islander Survey fielded in 2014 and released in March 2017. The Vital Statistics Rapid Release program's plans for quarterly estimates of national drug overdose mortality rates were reviewed, including the development of the capacity to look at the literal text on death certificates and the ability to receive mortality data within 10 days of the date of death (due to electronic information filing). A new Vital Statistics report on fentanyl deaths will be released in October 2017.

Dr. Madans then discussed health care surveys, highlighting the National Study of Long-Term Care Providers, which uses Centers for Medicare and Medicaid Services (CMS) administrative data and community survey data. Waves one and two are done; wave three is being finished. Wave four will bring a redesign where individual data will be obtained by phone for the first time. Survey data challenges were reviewed: challenges with data processing changes at the National Ambulatory Medical Care Survey (NAMCS)/National Hospital Ambulatory Medical Care Survey (NHAMCS), along with the impact on those data of the Meaningful Use Incentive Program; storage issues with the huge amounts of data being collected; and initiatives developed in response to declines in survey response rates.

Other updates included the Linkage Program in the Office of Analysis and Epidemiology (OAE); the fact sheets that are regularly updated and posted on the NCHS Web site; and three reports—Healthy People 2020, *Health, United States, 2016* (a report card on the nation's health released by the DHHS Secretary), and the new NCHS report on data presentation standards. A brief discussion followed regarding data linkages with the Census Bureau.

CDC Surveillance Strategy Update

Chesley Richards, M.D., M.P.H., FACP, CDC Deputy Director for Public Health Scientific Services

Dr. Richards presented an update on CDC's public health surveillance strategy and the role of surveillance as a foundational activity in public health. He described the need for the 120 surveillance systems that work in silos to work together and the need to leverage new technologies to respond to budget constraints and better meet the needs of local and state health departments. Progress since 2014 was reported for four strategic areas: the Vital Statistics program (mortality records received at NCHS within 10 days increased since 2014 from 7 to 58 percent); the National Notifiable Disease Surveillance System (improved data flow); Syndromic Surveillance (data coming into the system from emergency department [ED] visits increased from 45 percent in 2014 to 65 percent); and Electronic Laboratory Reporting (over 80 percent of laboratory reports now come in electronically instead of as paper reports). Dr. Richards emphasized the need for continuing timeliness in reporting while producing quality data by moving to modern systems that are more efficient and generate more timely data. He reiterated the need to facilitate a way to move from information silos to more connectivity between programs. To that end, CDC is building a digital bridge across systems to enhance reporting to CDC from local sources, along with a surveillance data platform (an IT-shared services platform for scientific data within CDC).

Discussion

Discussion followed on strategies to engage social media in the surveillance systems data (e.g., Google and Facebook) and potential barriers to using those data sources. In response to a question about the need for enhancing the validity of death certificate data, the collaborative role of the MITRE company and its federally-funded research and development centers was discussed as well as issues with local-level coroner and medical examiner data. Tools that have been developed to increase data quality are a vocabulary service and a content-based routing system. Further discussion centered on the potential role of state health information exchanges, sustaining local surveillance capabilities during severe events (e.g., hurricanes, tornados), and the usefulness and legality of gathering data from private sector organizations, such as health information vendors and multistate corporate health providers.

National Health Interview Survey Questionnaire Redesign

Stephen Blumberg, Ph.D., Associate Director for Science, DHIS
Renee Gindi, Ph.D., Redesign Co-Coordinator, DHIS

The presentation focused on an overview of the National Health Interview Survey (NHIS), an in-person survey of approximately 35,000 households conducted annually by Census interviewers to monitor the health of the U.S. population. As background, it was noted that the NHIS has been conducted annually since 1957; the redesign is the first since 1997. Dr. Blumberg explained the motivation for a survey redesign: an increase in respondent burden and a

decrease in response rates; an interest in improving the relevance of survey topics to better meet needs of the Department and users; and the need to harmonize overlapping content with other federal health surveys. The process for the redesign was described: centralized staff were designated to the redesign; criteria for prioritizing survey content were determined; stakeholders were engaged; and technical expert panels were convened. The project timeline was reviewed; the redesigned questionnaire will be launched in January 2019 after field tests in 2018.

Dr. Gindi then described the rationale behind the new structure of the redesigned survey questionnaire, explaining the core measures that will be on the survey annually, rotating core measures that will vary year-to-year, and sponsored content. She explained that more information can be gathered over several years by moving some content to a rotational system. Content and how that content will be gathered in the interview process were described. Minimal information will be collected initially: the age, sex, and race/ethnicity of each member of the household; the active duty military status, employment, and highest education obtained for each adult; and identification of parents or foster parents for each child younger than 18. Family-level variables will be collected or construed: family size and structure; family income and poverty level; does the family participate in an income transfer program (e.g., WIC or SNAP); is the housing owned or rented and is there rental assistance; financial burdens of medical care; and landline and wireless phones in the home.

A sample list of adult core topics was shared with the group: health status; health conditions (hypertension, high cholesterol, cardiovascular conditions, asthma, diabetes, cancer, arthritis, height, and weight); disability (using the Washington Group on Disability Statistics international standard to collect information about functioning); health insurance; health care access; health care utilization (usual place of care; use of urgent care, retail clinic, or ED; hospital stays); immunizations; health behaviors (smoking—other behaviors will be on the rotating core); demographics (sexual identity, marital status, veteran status, schooling, employment, and nativity—moving away from country of birth to U.S. born, state of birth, or non-U.S. born); and linkage (consent to link with vital statistics and other health-related government records). Dr. Gindi then shared sample adult rotating core topics—information that will be collected with a fixed periodicity over the course of a decade. These topics include: dental, mental, and other care access and utilization; mental health assessment (medication use, frequency of depression and anxiety, Patient Health Questionnaire, and Generalized Anxiety Disorder); chronic pain (frequency and locations); preventive services (aspirin use, screening for blood pressure, cholesterol, diabetes, colon cancer, breast cancer, and cervical cancer); health conditions (kidney problems, hepatitis, liver problems, allergies, serious psychological distress); employment (details on type and nature); injury; and health behaviors (smoking cessation, physical activity, walking, sleep, fatigue, alcohol use, and content of care).

A sample child annual core was shared. While the child core questionnaire looks like the adult core (to allow for estimates for an entire population, including adults and children), there will be some differences. For example, for the first time, questions from the Washington Group international standard for disability for children will be fielded by the NHIS, including social and emotional problem screening for very young children. Similar to the core content, the sample child rotating core is also like the adult sample, with a few differences. A full Strengths and Difficulties questionnaire will be fielded, and stakeholder comments influenced the addition of questions on social determinants, including neighborhood safety, stressful life events, and free and reduced meals.

Finally, a list of some of the topics included in the NHIS from 1997 to 2018 that will not be included in the redesigned core questionnaire was presented. These include sociodemographic

questions on country of birth, number of months worked in the last year, and personal earnings amounts; detailed family relationship questions; active military duty time periods for veterans; activities of daily living (ADLs) and instrumental activities of daily living (IADLs) questions; some details on health care access and utilization; and select immunizations. Sponsored survey supplements were discussed. In 2019 these will be limited to 5 minutes or less and will include cancer control, immunization, food security, and non-cigarette tobacco use.

Discussion

A question was posed about sponsors—how are they recruited? Dr. Blumberg responded that NHIS receives inquiries from federal agencies and nonprofits, and they also reach out to previous sponsors. Sampling style was then discussed, and Dr. Blumberg explained the sampling method (a dual frame design, using a commercial address-based sample, with supplemental use of traditional listers where address lists are deficient). A question on non-English cognitive testing and vulnerable populations brought the response that the 2019 redesign will include Spanish translations. A discussion followed on the ability to collapse data across years with the rotating questions; the ability to collapse data will not change with the new survey structure. Other questions included public access to data (all data are released publicly except data that might disclose identities); criteria for excluding certain variables from the survey due to small numbers (e.g., gender identity questions are not planned for the redesigned survey); survey respondent time (the survey time will average an hour, depending on household structure, with supplement questions limited to 5 minutes); and the results of survey length in field testing. A member expressed concern about the elimination of the question on country of birth, and suggested that it is desirable to ask not only country of birth but also country of birth of parents. Reasons for eliminating this question were discussed. It was explained that revealing country of origin can pose a risk of disclosure. With the redesign, respondents are asked if they are foreign born; the country is not given. Further discussion centered on the rapidly changing origins of some foreign-born populations. Reasons for using the Washington Group standard for disability and dropping ADLs and IADLs from the redesigned survey were reviewed. Dr. Madans explained that an ADL question remains on the survey, but detail has been eliminated. A question followed about asking for educational degrees in addition to number of years and highest years; the answer is yes. The structure of the dual frame survey design was clarified, along with the bridging of the old design and the new design. In response to a concern about testing in only one quarter of the year since there are seasonal differences between quarters, Dr. Blumberg explained that the limited budget does not allow for an expanded bridge sample. Dr. Madans further explained that originally no bridge was planned, so a one-quarter bridge is preferable to that option. Dr. Madans stated that one result of the redesign will be the need to change the regularly-released quarterly reports. In 2019, the quarterly reports will need to be revised, and the department will need to help users transition to the new reports. Input from the board regarding this will be welcomed. Final questions revolved around the survey length and how the resulting dropout rate affects data and whether data linkages to other data sets (or to electronic health records) have been considered as ways to supplement the surveys. Dr. Blumberg explained that while the system links with some data sets (National Death Index [NDI], Housing and Urban Development records, and Veterans Administration utilization and eligibility data), linkages to electronic records and other large data sets are envisioned for the future.

Update on the EHR Data Collections for the National Ambulatory Medical Care Survey and the National Hospital Care Survey

Carol DeFrances, Ph.D., Chief, Ambulatory and Hospital Care Statistics Branch, Division of Health Care Statistics (DHCS)

Dr. DeFrances provided background of the NCHS's National Health Care Surveys: describing their role in informing health care policy and serving research needs; giving a review of the four core National Health Care Surveys; and sharing examples of the data collected in the surveys. She then explained the decision to move to collecting data through electronic health records (EHRs) and the advantages: a reduced burden on the health care provider; access to more clinical detail on diagnoses, medications, and laboratory work; and it allows for the collection of more data as well as the ability to link with outside data sources (e.g., CMS data and the NDI). Dr. DeFrances explained that the decision to move to EHR data is timely with the increase in the adoption of EHR systems across the country with CMS implementing incentive programs. She then described the process for moving to EHR data collection: conducting research and pilot studies; developing data standards; incentivizing providers through the Meaningful Use program; and developing an implementation guide for data submission. A Declaration of Readiness was released in 2015, and since then more than 155,000 eligible clinicians and 900 hospitals have been registered under the Meaningful Use program. Sampled providers and hospitals are invited to testing and validation and then to survey production. The now-manual system will be automated soon.

Dr. DeFrances described the EHR data collection process in detail for two of the four surveys producing national statistics—the National Ambulatory Medical Care Survey (NAMCS) collected from office-based physicians and various types of clinicians at community health centers and the National Hospital Care Survey (NHCS).

NAMCS data were historically collected by medical record abstraction on site at physician offices by Census field representatives. As a transition, data for this survey were collected in 2016 by two modes—abstracted data were collected from a sample of 3,200 physicians by the Census, and EHR data were collected by NCHS from a sample of 500 physicians. The infrastructure was put in place to collect, test, and validate the EHR data in-house. Methods and procedures for obtaining data from providers were created; to that end, Continuity of Care Documents (CCDs) were gathered from providers' EHR systems. To date, 794 CCDs have been tested, and data has been processed for 93 physicians. Challenges encountered were reviewed:

- CCDs are a reasonable, but not perfect, match for NAMCS.
- Some physicians and physician groups could not go back and retrieve prior visits that took place earlier in the year prior to data collection (data collection started in June).
- No document tested was error free.

Dr. DeFrances then described the NHCS, which now integrates three long-standing surveys: the National Hospital Discharge Survey), which was pulled from the field in 2010; the NHAMCS, which is still in the field; and the Drug Abuse Warning Network conducted by SHAMHSA from 1992 to 2011. When the NHCS is fully implemented it will provide reliable and timely utilization data for hospital-based settings that can be linked to Medicare and NDI data. The data are collected electronically by a contractor; the sample includes 598 non-federal non-institutional hospitals with six or more staffed inpatient beds and includes all inpatient, ED, and outpatient data for a calendar year. Participation is voluntary, which hinders hospital participation

recruitment in the face of competing demands. However, in 2016, out of 98 sampled hospitals, 50 sent a test file and 41 went on to production. Challenges were:

- Custom extracts require a large time commitment by hospital staff to obtain data.
- It is difficult to obtain codebooks or reference files to look up hospital-specific codes.
- Some clinical notes were truncated by character limit defaults.
- Retrieving historical data was sometimes difficult (data collection started in May).
- No document tested was error free.

Lessons learned are:

- Meaningful Use is a powerful incentive for survey participation.
- Consolidated CDA documents are in hospital systems so they are easy to provide for both NAMCS and NHCS.
- EHR systems provide an opportunity to collect data not currently available (e.g., medication allergies, family and social history, alcohol use).
- Collecting data in-house at NCHS brought knowledge that will help with future data collections.

Plans for moving forward with the NAMCS include working with EHR vendors to build, test, and improve the HL7 CDA Implementation Guide and continuing to register hospitals and providers for public health reporting. NAMCS 2016 data collection will be closing in a few months. At that time the EHR data and the Census abstracted data will be handed off to a contractor to integrate, harmonize, and weight the data, and a public use file will be produced. 2017 data will also be collected in two modes—Census abstract data and EHR data collection at NCHS. Infrastructure development at CDC to host and warehouse EHR data will continue. Due to budgetary challenges, only abstracted data will be collected; EHR data will not be collected.

For the NHCS, work continues to link hospital claims and EHR data to the NDI; this work with the OAE is funded by the Patient Centered Outcomes Research Trust Fund. Integrated data sets for 2016 will be complete in 2018; the data will hopefully be available in the NCHS Research Data Center. No data are being collected in 2017 due to budget issues, but data collection will resume in 2018. The top priority is recruitment of sampled hospitals so national estimates can be made (national estimates have not been made). The amount of data collected will be reduced to ED data; inpatient data will be dropped but avenues for purchasing both inpatient and ED data will be explored.

Dr. DeFrances ended her presentation with a question: Does the BSC have suggestions on how to increase NHCS hospital participation?

Discussion

In response to Dr. DeFrances' question, the discussion began with comments on the difficulties of obtaining data from hospitals, even using the Meaningful Use incentive or by collecting discharge abstracts from states. The suggestion was made that vendors such as Press Ganey, who deal with a range of hospitals from small rural to large academic medical centers, may be able to provide insight on ways they collect data. In response to a question from the audience on the size of the requested data files, Dr. DeFrances clarified that the problem is not in transmitting the data, it is with the hospital creating the data with the requested variables.

A discussion followed on the long-term strategy to acquire all the notes from clinical encounters once funding is available. Clinical notes can help SAMHSA identify substances involved in drug

visits, but also present an opportunity to retrieve other important data. This led to the suggestion that a discussion take place in the future with the BSC on a strategy for mining the data being retrieved—using the latest data analytic techniques—for new data that are not currently being retrieved by other organizations.

Dr. DeFrances reiterated the NCHS charge to make national estimates and the need to continue to make that a priority. The discussion continued about how NCHS could maximize the use of data retrieved from clinical notes in the face of resource constraints, if hospital participation in providing the data can be increased.

A member posed the question: why not sample EHRs for individuals, which would show care across the health care continuum, rather than sampling at the provider level, which shows episodic care. It was noted that health plans could be a source for this EHR data. In the current fragmented system, nationally represented samples of patients' conditions and the care they receive would be useful. A member suggested talking with the Bureau of Justice Statistics, as they encounter similar data collection situations, and using qualitative research to scan hospitals to determine which ones to sample. One member asked if a validation study for the surveys is planned. Dr. DeFrances replied that there was one with the NAMCS, using data from the pilot studies; a validation study is planned for the hospital survey. In response to a member's question regarding the potential for gathering data from the 912 hospitals registered for Meaningful Use credit, Dr. DeFrances explained 98 of 912 registered Meaningful Use hospitals are in the NHCS sample. We focused on these 98 hospitals for the 2016 NHCS data collection.

The dialogue closed with a discussion of the need for interoperability to support data exchange—the ability to share EHR data between systems and providers—which would improve the ability of hospitals to share data with NCHS (as well as other hospitals or providers). The concept of information blocking—vendors charging extra money to interface with different vendors—was also mentioned as an issue with data gathering. Health information exchanges were mentioned again as a data source. Two projects looking at data interface were described: the Transformed Medicaid Statistical Information System (T-MSIS), that gathered comprehensive Medicaid information from the states; and the Patient-Centered Scalable National Network for Effectiveness Research (p-SCANNER) project, which is supported by the Patient-Centered Outcomes Research Institute (PCORI) and aims to make health data more accessible and usable.

Introducing *Health United States, 2016*

Julia Holmes, Ph.D., Chief, Analytic Studies Branch, OAE

Dr. Holmes gave a review of the background and history of *Health United States*, NCHS' flagship publication. A congressionally-mandated report, *Health United States* reports on four topic areas: health status and determinants of health; health care utilization; health care resources; and expenditures and payers. In addition to reporting on health trends for the U.S. population, it includes a Special Feature on new and emerging health issues that changes each year. Dr. Holmes gave a detailed timeline of the report from 1975 to 2017, as well as a list of topics included in the Special Features section from 2000 to 2016, a description of the length and breadth of the report, and its influence on public policy.

Instead of a Special Features section, the 2016 edition included a Chartbook on Long-Term Trends in Health to mark the 40th anniversary of the publication. Dr. Holmes described the five sections of the Chartbook along with detailed examples from each section: demographic and socioeconomic factors (population trends from 1975 to 2015); health status and determinants

(current cigarette smoking among adults from 1974 to 2015); health care utilization (prescription drug use among adults in the past 30 days); health care resources (hospital provider supply and usage data from 1975 to 2014); and health care expenditures (health insurance coverage for children younger than 18 and for adults age 18 to 64 from 1978 to September 2016).

Finally, Dr. Holmes gave an overview of the *Health United States* Web page and products and explained how to navigate the page to access specific information and topic areas.

Visualizing *Health United States*: Exploring the Use of Infographics to Enhance the Uptake of a Statistical Report

Florence Lee, M.P.H., Associate Service Fellow, Analytic Studies Branch, OAE

To continue the presentation on *Health United States*, Ms. Lee introduced four infographics produced in the past year to visually enhance the *Health United States* report. Because *Health United States* is a very large, content-heavy report, the primary objective of adding more visual content to the report was to broaden the audience by making a topic succinct and attractive without diminishing the statistical rigor of the full report. Other objectives included providing timely daily updates and generating interest in the full report by using visualization as a point-of-entry for less traditional dissemination tools, such as social media.

The four infographics developed to date were described. Each infographic is focused on one of the four mandatory reporting areas; they are published once every 3–4 months. To illustrate the construction of the infographics (“Spotlight” reports), Ms. Lee walked the board through the features of one—the Spotlight on adult cigarette smoking—illustrating the data panel, trends panel, and data highlights section. The reports are disseminated through an electronic mailing list (reaching approximately 46,000 subscribers), the NCHS Facebook page (with a following of 20,915 people), and the NCHS Twitter page (with a following of 3,329 people at the time of this presentation).

Lessons learned were shared:

- Twitter posts with more images receive more engagements than those without.
- Cross-promoting Spotlight content with other agencies (such as CDC or the American Public Health Association, which has a large social media following) enhanced reach.
- Minimizing the number of clicks from the link to the infographic increased the number of downloads.
- Releasing Spotlights between the *Health United States* full reports increased traffic to the *Health United States* Web site.

Future directions for Spotlight reports include making the reports more visually interactive, focusing reports on a specific theme within a subject area, and finding ways to make them more accessible.

Discussion

A discussion on social media followed. A member suggested that a smartphone app, similar to the FastStats app, to access and navigate the reports would be useful. A member encouraged other board members to join Twitter; another member pointed out the value of using Twitter for tweeting charts. Some members suggested building relationships with press media to find human interest stories behind the statistics and to spread the report content. Another member commented that contractors can be hired to create blogs on infographics to engage audiences.

A member suggested that people find geographical comparisons interesting, whether comparing states or regions with each other—could comparisons be included in reporting in the future? Ms. Lee confirmed that this is a topic under consideration. Another member suggested that people are interested in comparisons of normative behavior, i.e., being able to compare themselves with the norm. Dr. Holmes agreed that including comparisons is a subject worth pursuing.

A board member pointed out the educational usefulness of *Health United States* and other NCHS reports, commenting that a data repository for teachers would be extremely valuable in recruiting future scientists. A member commented that statistics is now a capstone math course in the high school Common Core curriculum, which is a large market.

Other comments included a suggestion to move from a publication framework to an interactive one, where users can manipulate the report to follow their own interests, and a question on the possibility of making international comparisons. Dr. Madans explained that staffing constraints have limited international comparisons, although data are provided to the Organization of Economic Cooperation and Development and the United Nations, and joint surveys are conducted with Canada. Dr. Madans continued that due to budget limitations creative ways need to be developed to collect and disseminate data, and choices need to be made as to which surveys to continue or discontinue. Dr. Richards explained the unique role of the NCHS as a federal statistical agency and the important role of the BSC in providing guidance needed to chart its future. Future BSC meetings will focus on NCHS strategy and priorities in the face of limited resources.

The meeting was adjourned for the day at 5:03 p.m.

Thursday, September 7, 2017

Presenters

September 7, 2017

Mark Flotow, M.A., Former BSC Member

James Hadler, M.D., M.P.H., Council of State and Territorial Epidemiologists (CSTE)

Robert L. Phillips, Jr., M.D., MSPH, NCVHS Liaison

Nancy Potok, Ph.D., Chief Statistician, Office of Management and Budget (OMB)

Welcome, Introductions, and Call to Order

Linette T. Scott, M.D., M.P.H., Chair, BSC

Virginia S. Cain, Ph.D., Designated Federal Official, NCHS, BSC

Dr. Scott welcomed the group to day two of the meeting. Dr. Cain introduced the first presentation of the morning by giving the board background on the NCVHS and the relationship between the NCVHS and the BSC. She invited the board to participate in a discussion on where and how the two committees can work together on topics of mutual interest.

Areas of Joint Interest NCVHS and the BSC

Mark Flotow, M.A., Independent Consultant, Former BSC Member

Robert L. Phillips, Jr., M.D., MSPH, NCVHS Liaison

Presentation I

Mr. Flotow presented the session objectives: provide brief reviews of current BSC and NCVHS projects or topics of joint interest; have a BSC discussion to seek level of interest or coordination (e.g., form a work together, coordinate efforts, monitor progress, or decide there is no interest); and determine an action plan for each project. Dr. Scott clarified that these discussions are setting the stage for broader conversations at upcoming BSC meetings; today's discussion will not necessarily generate action items.

Project: Next Generation Vital Statistics—originated at NCVHS, in the planning stage.

The project was developed to address structural and resource challenges of the vital statistics system by transforming (modernizing) the current data collection network to increase timeliness and security. The main feature of the project is increased federal status and funding, proposing that funding flow to the 57 U.S. vital statistics jurisdictions. Federal hearings are scheduled for September 11–12, 2017, to gather information from stakeholders. BSC members were encouraged to participate (it will be livestreamed) or listen to the proceedings afterwards. A link to log into the proceedings will be sent to members.

Discussion

In response to a question from a member, Dr. Phillips stated that there is a vision statement and a set of guiding questions and objectives for the project. The upcoming fact-finding hearings will help shape the outcome, with the goal of creating an infrastructure that will provide timely and accurate information. Another board member asked about the role of the National Association for Public Health Statistics and Information Systems (NAPHSIS), which has been looking for solutions to long-term problems with the system. Dr. Phillips explained that NAPHSIS is one of the project's key stakeholders, and NAPHSIS staff will participate in the hearing. A member shared her experience from the field, expressing that good data management is needed at the local vital records jurisdiction level to produce accurate data. Better education and training is needed; there is a lack of vital statistics education in public health programs.

Project: Commission on Evidence-Based Policymaking—originated with Congress, nearing the end of its 15-month life cycle.

The findings and recommendations for this study are intended to improve integration practices for monitoring federal program outcomes and to determine the need for a data clearinghouse, will be released today, September 7th. Both NCHS and NCVHS and the work they do are cited favorably in the report.

Discussion was deferred for later in the meeting (see Dr. Potok presentation below).

Project: 2020 Census Revised Race and Ethnicity Categories—originated with the Census Bureau's decennial planning, waiting for OMB decision.

Background on this project, intended to improve data for the Hispanic ethnicity category by modifying race categories, was shared with the board. The project proposes combining race and ethnicity into one question and adding a Middle Eastern and North African category to race and ethnicity. The OMB comment period has concluded, and OMB is now in deliberations as to whether standards will change and if so how they will change. Once a decision is reached by OMB, implementation will potentially take place across the federal data systems.

Discussion

Dr. Scott commented that if the changes are approved, the BSC, as a board representing data users, may have a role in helping NCHS in terms of implementation and messaging. A decision will probably be made prior to the next BSC meeting. The board can then discuss the best way to provide input and assistance.

Project: Health Data Framework—originated with NCVHS, 6-year process; the Framework is posted, the first stakeholder forum has been held, and IHI is organizing a public-private effort to bring the project to fruition.

This project is designed to help communities identify and manage health problems by providing: 1) a data structure for organizing small area population data; and 2) a methods taxonomy to guide data use and re-use. There are eight different products; the board was provided with slides containing live links to the products. The 6-year effort culminated this year with a health data framework white paper, a workshop summary, and a letter to the Secretary with core recommendations taken from data that communities across the country are using to assess health and wellbeing. The domains and subdomains captured include non-traditional vital statistic elements such as social determinants and community factors. The Health Data Framework committee's charter required that it turn its work over to a private entity or other agency once its charge is complete. To that end, a public-private effort has been organized by IHI's 100 Million Healthier Lives campaign to implement the Framework. The larger group has developed two subgroups, one on measure development and one on measure implementation; the subgroups are now holding meetings.

Discussion

Audience member Rebecca Hines, a designated federal official for NCVHS, stated that she will send an e-mail to the board with a link to the document containing the Framework's 10 domains and 30 sub-domains.

Project: Digital Bridge—originated with the Robert Wood Johnson Foundation, in the vision and planning and proof of content stages.

The Digital Bridge project goes beyond electronic health records; it is a digital health data exchange between health care providers and public health. The two-way data flow would create public health reports from clinical sites. The Bridge is HIPAA compliant.

Discussion

Discussion followed about the proof of concept. Dr. Richards explained that at its core the project focuses on public health care reports and notifiable diseases. It includes an understanding between the public health organizations that represent state epidemiologists and health officers and local and county officials to agree on 40–50 variables common to EHRs that could be sent by electronic message without physician involvement. While the bridge would allow health departments to receive electronic messages for notifiable diseases without interrupting clinician workflow, it would then allow public health to send messages back to the clinician pertinent to the patient's care. The project was stimulated by a Meaningful Use requirement for case reporting. Pilot demonstrations are underway, and large EHR software

vendors are participating. A public-private partnership, much of the project effort comes from local jurisdictions and their organizations, along with vendors.

Other Projects:

Mr. Flotow listed three areas for future BSC discussions: the healthdata.gov master database; BRFSS data accessibility; and ICD-11, which is on the horizon for mortality data.

Discussion

In closing, the presenters opened a discussion about ways the BSC can monitor outside projects, focusing on the roles of liaisons. Mr. Flotow suggested that the BSC may want to monitor the work of the Council of Professional Associations on Federal Statistics. Noting that with his term expiring from the board another ad hoc agency expert from the BSC to the NCVHS is needed, he asked the board to consider how and when to use joint ad hoc agency experts between the BSC and the NCVHS.

Vision for the Federal Statistical System

Nancy Potok, Ph.D., Chief Statistician, OMB

Dr. Potok began by introducing the first of her two presentation topics—the vision for modernizing the federal statistical system, and the need for strategic thinking around its future, with high quality, accurate statistics as the goal. She stated that the system as it is will not be sustainable. Dr. Potok discussed reasons for moving away from surveys: they are becoming more expensive, survey respondent cooperation is going down, and federal budgets are decreasing. Solutions include using more administrative data and in some cases commercial data.

Without a mandate for interoperability, collected data are not always available. Data often sit in agency or government silos where owners of the data are not willing to share. Reasons include data sensitivity and agency resource limitations. Other barriers to accessibility include government attorneys.

Data quality is another area of concern. Incentives are needed to ensure quality, useful data. Dr. Potok continued by explaining the need for federal agencies to partner with state and local governments to increase data quality. Foundations are playing a key role in helping state and local agencies increase their data gathering capacity and expertise. Results of these efforts will include higher quality data and increased sharing between state, local, and federal levels. In addition, statistical standards are needed, particularly a standard on quality of combined datasets. To accomplish that, Dr. Potok has directed the Federal Committee on Statistical Methodology to focus on these issues. She is also interested in determining if there is research in academia on these topics.

Dr. Potok reported on the work of the Interagency Council on Statistical Policy, which has developed six priority areas that it will focus on over the next 12–24 months. These are:

- Developing quality standards;
- Finding ways to improve access for researchers, i.e., building on the federal statistical system research data centers;
- Increasing public access;

- Investing in people already working in the system but also bringing the right mix of skills and competencies to the discussions to fill gaps in expertise (e.g., data scientists and researchers thinking about data linkages);
- Developing state and federal partnerships; and
- Determining ways to lessen the respondent burden with surveys.

Dr. Potok turned the discussion to the report from the Commission on Evidence-Based Policymaking (introduced in the previous presentation). The Commission, which was created by bipartisan legislation, focused on four areas:

- Improving access for researchers, federal evaluators, and statistical agencies to federal and state data;
- Determining the feasibility of a federal data clearinghouse;
- Protecting privacy while dealing with dissemination and reidentification issues; and
- Building federal capacity for evaluation and evidence building.

With the report coming out today, September 7, members will be able to study the report's roadmap for moving forward and recommendations for legislation.

Discussion

A member of the audience clarified that the federal system's research data centers are different than the NCHS data centers. In response, Dr. Potok gave a history of the federal research data centers, which were started in the mid-1990s by the Census Bureau and are located across the country.

A member thanked Dr. Potok for recognizing that the current system is not sustainable and her call to action in the face of that fact. Discussion followed on the reality that new methods to replace the unsustainable systems are evolving and are being developed, but will they be ready in time? Systems will change either by choice or due to budget cuts. Still, due diligence is needed. Dr. Potok emphasized that her goal is a reprioritization to focus on research that will accelerate the process.

Discussion followed on research around using administrative records and data from nonprobability panels and combining those data with survey data. The topic of using administrative records generated several comments from members. One member brought up concerns from data research users about disclosure and data security with the potential move to using administrative data. A member brought up the work of a National Academy of Science panel that released a report on combining information from multiple data sources, and Dr. Potok recommended that board members read the report, which has parallel recommendations with the Commission for Evidence-Based Policymaking report. Some members expressed caution in using commercial databases for federal statistics; Dr. Potok agreed that quality is an issue with those data for several reasons. Further discussion included: a member reiterated the tension between access and privacy; the advantages of public-private partnerships; and the importance of local level data.

The role of data research centers was discussed, and Dr. Potok explained that while these centers play an important role, the need for a clearinghouse that will improve access—a "one-stop shop" for remote access—would improve accessibility. It would provide one place in government that would be a "center for excellence" for remote access technologies as well as disclosure and reidentification technologies. Dr. Potok emphasized that discussions around

access and how to address sensitive data must continue and a national clearinghouse may be the way to bring about change in the system.

The discussion on survey data continued with a member bringing two threats to surveys to the board's attention: 1) the value of the data is being questioned by those who fund it; and 2) the ability to collect different data has changed considerably with electronic technology.

To conclude the discussion, Dr. Madans emphasized the importance of the report being released from the Commission for Evidence-Based Policymaking, asking the question: How do we look to the future and take the recommendations and vision and make them reality? How is the linkage issue resolved? The discussion on the report's findings will continue at upcoming BSC meetings.

Healthy People 2030 Methods Proposal to Address Lack of SES Data for Some HP 2030 Objectives

James Hadler, M.D., M.P.H., CSTE

Dr. Madans introduced the presentation, stating that while staff continue to work on the Healthy People 2020 objectives, they are preparing for 2030. An advisory panel is meeting to discuss structure, and recommendations have been made. She explained that the 2020 objectives use disaggregation to break out objectives by a variety of characteristics to be sure that the entire population benefits from improvements and disparity gaps are closing. She explained the lack of SES (socioeconomic status) data for some objectives. Although describing health disparities and monitoring progress in reducing them has been a national priority, many objectives lack them because of data collection for those objectives. Proposals to address the issue have been received; Dr. Hadler will present one proposal under consideration.

The presentation began with Dr. Hadler explaining that the CSTE is a co-sponsor of a resolution position statement related to the SES data concern. As background, he shared with the board a brief history of the CSTE, as well as the funding and organizational structure. The organization represents public health epidemiologists from member states and territories as well as public health epidemiologists at all levels of government. Its mission is to promote the effective use of epidemiologic data to guide public health practice and improve health.

Because of a revived interest in health disparities, the organization formed a Health Disparities Subcommittee in 2010; Dr. Hadler is a co-chair of the subcommittee. Noting that surveillance data on many public health conditions lacked SES data, the subcommittee explored and applied area-based methods recommended by the Public Health Disparities Geocoding Project to county- and state-level surveillance data. An organizational position statement has emerged from that activity, "Use of Area-Based SES to Generate National Data on Health Outcomes with Proposed HP 2030 Objectives for Which Individual SES Data are not Routinely Collected." It passed at the 2016 annual CSTE meeting.

The proposal recommends that the CDC and NCHS convene a workgroup to determine whether the use of census tract-level SES data provided by a sample of states would fill the need for national SES data for Healthy People data lacking that data, and to develop a proposal to include the data for those Healthy People 2030 objectives lacking SES data at the individual level. He explained that the purpose of the presentation was to solicit board input as to whether the CDC and NCHS should convene the workgroup proposed in the resolution. The two contexts for the discussion are the inclusion of SES measures in Healthy People 2030

objectives but also to go beyond that to examine this as a possible way to look at national surveillance data otherwise lacking SES data measures.

Dr. Hadler then provided background information on why some objectives do not have SES data measures and how the work of the CSTE subcommittee demonstrates the readiness of area-based SES (ABSES) data to be used in the national context to fill that gap. He explained the potential and feasibility of acquiring geocoded data from sentinel surveillance systems or a subset of states. This was particularly demonstrated by the Harvard-based Public Health Disparities Geocoding Project, which analyzed geocoded public health surveillance data linked to census tract poverty data in Massachusetts and Rhode Island. The United States does not have a recommended SES measure for routine collection, analysis, and display of surveillance data, but the Project laid the groundwork for a standard, national measure with its recommendation to use geocoding and census tract poverty measures for routinely monitoring U.S. socioeconomic inequality in health. Several samples from the study were shared with the board, as well as the results of subsequent studies conducted in New York City and Connecticut that demonstrated that the analyses captured meaningful data and were consistent over time. To determine if state-level data is being geocoded and linked to census tract data, the CSTE conducted the 2015 Health Disparities Assessment of States. Results from 43 respondents were:

- For malignancies, 30 routinely geocode; 22 routinely link;
- For infectious disease, 20 routinely geocode; 8 routinely link; and
- For births and deaths, 26 routinely geocode; 14 routinely link.

Sixty-nine percent of the states responded that they are willing to send geocoded data to CDC.

Finally, Dr. Hadler shared three precedents for collecting census tract SES data from multiple states and analyzing for national estimates: 1) HIV—CDC has funded 20 state and local health departments to geocode HIV case data since 2010; 2) the Emerging Infections Program—with the Active Bacterial Cores surveillance, FoodNet, a foodborne disease surveillance system, and other studies such as one done on influenza-related hospitalizations; and 3) malignancies—where the North American Association of Central Cancer Registries has collected cancer incidence data with census tract poverty from over 16 state cancer registries.

Before opening the discussion on convening a CDC-NCHS workgroup with a goal of developing a specific proposal for Healthy People 2030, Dr. Hadler shared conclusions:

- ABSES measure is needed to describe SES disparities in selected health outcomes without individual data.
- Census tract-level poverty is the ABSES measure with which there is the most experience.
- Census tract-level poverty describes substantial disparities in health outcomes by SES when those disparities exist.
- Most states have the capacity to geocode and link geocoded data to census tract SES measures.
- It is currently feasible to generate national-level data from a sample of states using census tract poverty or other census tract-level measures.

Discussion

A member commented that other activities are looking at disparity, and suggested the possibility of supplementing ABSES data with real property data as a measure of individual level SES.

Another member asked for clarification on the reference to a sample of states in the conclusions. Dr. Hadley replied that the sample would need to be determined, but it would generate to a national inference. Dr. Hadley clarified that more than 70 percent of the states are interested in or planning to geocode all of their data. Systems can be designed also to auto geocode.

Dr. Scott noted that SES data are being studied in several arenas in the public health community and by foundations. She reminded board members that the board is in an information-gathering phase, and this presentation, like others at this meeting, is helping to set the groundwork for upcoming discussions on priorities and where NCHS, with limited resources, needs to focus. While looking at SES in the context of disparity and equity is a significant activity, the BSC is not at this time adequately prepared to make a recommendation that NCHS take on the role of convening a workgroup to set standards.

A member cautioned against using a subsample of states to make a national projection because of interclass correlation. The member inquired about the fixed poverty level categories used in the Public Health Disparities Geocoding Project (<5 percent, 5-<10 percent, 10-<20 percent, and ≥ 20 percent), noting that a large number of people will fall in the ≥ 20 percent category and suggesting that there could be finer degradations of that category. Dr. Hadley explained that in some datasets the categories are modified due to the demographics of the area's population (e.g., ≥ 30 percent instead of ≥ 20 percent).

Another member commented on the groundbreaking significance of the Geocoding Project, with other projects following to develop several national and state indices, such as the National Deprivation Index, the Social Deprivation Index, the Virginia Health Opportunities Index, and the Yale Wellbeing Index. Dr. Hadley agreed, stating that his group has experience with census tract poverty, but the workgroup, if it is convened, would try to decide on the best measure. A member commented that having one measure at the census tract level hides the heterogeneity that exists within a census tract group, and individual level data could be acquired by linking records. In response, a member commented that while individual data is valuable, context matters. Members echoed the comment on heterogeneity within tracks (e.g., in rural areas). A member of the audience commented that the causal mechanism that links area level poverty to health outcomes is different than the one that links individual level poverty to outcomes; when we are suggesting that the area level estimates can be used as a proxy for the individual level one—they are a different type of analysis. Dr. Hadley acknowledged the complexities around national data collection. The audience member invited the board to follow the outcomes and recommendations of the meetings held yesterday by the Federal Advisory Committee for the Healthy People 2030's report. She suggested that BSC member input during the public comment period that ends September 29 would be valuable.

Dr. Madans closed the discussion with the observation that the structure (e.g., the number of objectives) and focus of Healthy People is still under discussion; decisions on that will influence the discussion on a socioeconomic status measure.

BSC Wrap-Up

Linette T. Scott, M.D., M.P.H., Chair, BSC

Virginia S. Cain, Ph.D., Designated Federal Official, NCHS, BSC

Dr. Scott thanked Dr. Cain for her service to the BSC. She noted again that the meeting's presentations and discussions were setting the stage for a more strategic conversation for the

BSC at future meetings. She suggested that board members prepare for the strategic conversations at the next meeting and going forward by:

- Listening to or participating in the hearings hosted by NCVHS to gather stakeholder information for vital statistics, to be held September 11–12;
- Reading the Evidence-Based Commission report to be released today;
- Following the outcomes of the Healthy People 2030's advisory committees and subcommittees and provide comment; and
- Thinking about how NCHS priorities can be met.

PUBLIC COMMENT

None.

The meeting was adjourned at 12:00 p.m.

To the best of my knowledge, the foregoing summary of minutes is accurate and complete.

/s/

November 14, 2017

Linette T. Scott, M.D., M.P.H.
Chair, BSC

DATE