All official NCHS BSC documents are posted on the BSC website
(https://www.cdc.gov/nchs/about/bsc/bsc_meetings.htm)

Department of Health and Human Services

Board of Scientific Counselors
National Center for Health Statistics
Centers for Disease Control and Prevention
September 5-6, 2019

Meeting Summary

The Board of Scientific Counselors (BSC) convened on September 5-6, 2019, 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
Kennon R. Copeland, Ph.D.
Prashila Dullabh, M.D. (in-person on Day 1, by phone on Day 2)
Darrell J. Gaskin, Ph.D.
Robert M. Hauser, Ph.D. (by phone)
Mark Hayward, Ph.D.
Scott H. Holan, Ph.D.
Helen G. Levy, Ph.D.
R. John Lumpkin, M.D., M.P.H. (by phone)
Sally C. Morton, Ph.D.
Andrey Peytchev, Ph.D.
Ninez A. Ponce, M.P.P., Ph.D.
Gretchen Van Wye, Ph.D., M.A.

CDC/NCHS Participants

Jennifer Madans, Ph.D., Acting Director, NCHS
Sayeedha Uddin, M.D., M.P.H., Designated Federal Officer, NCHS
Chesley Richards, M.D., M.P.H., F.A.C.P, Deputy Director for Public Health Science and
    Surveillance, CDC

NCHS Staff

N. Ahluwalia, Division of Health and Nutrition Examination Surveys (DHANES)
Josephine Alford, Division of Health Care Statistics (DHCS)
Rihem Badwe, DHCS
Stephen Blumberg, Division of Health Interview Statistics (DHIS)
Anjani Chandra, Division of Vital Statistics (DVS)
Loraine Escobedo, DVS

Lee Anne Flagg, DVS
Sheila Franco, Division of Analysis and Epidemiology (DAE)
Cordell Golden, DAE
Ellen Kramarow, DAE
Sarah Lessen, DHIS
Don Malec, DRM
Crescent Martin, DHANES
Gwendolyn Mustaf, OD
Cynthia Ogden, DHANES
Kathy O'Connor, DHCS
Jennifer Parker, Division of Research and Methodology (DRM)
Marc Roemer, DAE
Lauren Rossen, DRM
Lisa Wagner, Office of Planning, Budget, and Legislation (OPBL)
Bryan Williams, DHCS
Margaret Warner, DVS
Lara Akinbami, NCHS
Irma Arispe, NCHS/DAE
Jim Craver, NCHS/DAE
Jim Dahlhamer, NCHS/DHIS
Michelle Oriaku, NHCS
Suresh Srinivasan, NCHS/DHIS
Angel Vahratian, NCHS/DHIS

General Audience

Alicia Frasier, RTI International
Matt Jans, ICF
Heather Morrison, Decision Information Resources

List of Abbreviations

BSC	Board of Scientific Counselors
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare & Medicaid Services
DACEB	Data Acquisition, Classification & Evaluation Branch
DAE	Division of Analysis and Epidemiology
DHANES	Division of Health and Nutrition Examination Surveys
DHCS	Division of Health Care Statistics
DHIS	Division of Health Interview Statistics
DRM	Division of Research and Methodology
DVS	Division of Vital Statistics
EDRS	Electronic death registration system
EHR	Electronic health record

FHIR	Fast Healthcare Interoperability Resources
HL7	Health Level Seven International
NAMCS	National Ambulatory Medical Care Survey
NCHS	National Center for Health Statistics
NDI	National Death Index
NEHRS	National Electronic Health Records Survey
NHAMCS	National Hospital Ambulatory Medical Care Survey
NHANES	National Health and Nutrition Examination Survey
NHCS	National Hospital Care Survey
NHDS	National Hospital Discharge Survey
NHIS	National Health Interview Survey
NIH	National Institutes of Health
NNHS	National Nursing Home Survey
NPALS	National Post-Acute and Long-Term Care Study
NSLTCP	National Study of Long-Term Care Providers
NVSS	National Vital Statistics System
OPBL	Office of Planning, Budget, and Legislation
PCOR	Patient-Centered Outcomes Research
PCORTF	Patient-Centered Outcomes Research Trust Fund
PII	Personally identifiable information
RDC	Research Data Center
SSA	Social Security Administration
UMD	University of Maryland

Action Steps

- The Board voted unanimously to form a Nonresponse Bias Workgroup; Dr. Copeland, Dr. Peytchev, and Dr. Holan volunteered to serve on the workgroup. Other BSC members who are interested in serving will notify Dr. Uddin after the meeting.
- The BSC also voted unanimously to endorse the recommendations provided by the Patient-Centered Outcomes Research Trust Fund (PCORTF) Drug Workgroup. Dr. Scott will draft a letter of support and work with Dr. Van Wye to submit the letter to NCHS.
- Board members who are willing to supply suitable pictures for the cover of future reports by the Federal Interagency Forum on Child and Family Statistics will send them to NCHS.
- NCHS welcomes input from the BSC regarding suggested topics for future NCHS publications.
- BSC members will provide recommendations to NCHS regarding priorities for data modernization and outreach.
- To facilitate outreach, BSC members will send NCHS any suggestions for new stakeholders, including contact information for individuals within those organizations.
- For future BSC meetings, Dr. Madans would welcome agenda item suggestions (at least 1 month before the meeting) from the BSC.
- Future BSC meeting dates for 2020: January 9-10; May 5-6; September 17-18.

<u>Thursday, September 5, 2019</u>

<u>Presenters</u>

Jennifer H. Madans, Ph.D., Acting Director, NCHS
Steven Schwartz, Ph.D., Director Division of Vital Statistics
Chesley Richards, M.D., M.P.H., F.A.C.P, Deputy Director for Public Health Science and
    Surveillance, CDC
Ryne Paulose, Ph.D., Acting Director, DHANES
Stephen Blumberg, Ph.D., Director, DHIS

<u>Welcome, Introductions, and Call to Order</u>

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

Dr. Scott called the meeting to order. She asked BSC members to introduce themselves and state any conflicts of interest. None of the BSC members stated a conflict of interest.

<u>NCHS Update</u>

Jennifer H. Madans, Ph.D., Acting Director, NCHS

Dr. Madans recognized the new BSC members—Drs. Copeland, Holan, Lumpkin, and Morton—and thanked Dr. Scott for agreeing to continue serving as BSC chair for 2 additional years.

Administrative & Budget Update
The NCHS annual budget has remained stable at $160.4M since FY2016, but the President's FY2020 budget is $5.4M less than the FY2019 enacted budget. NCHS will continue to receive a transfer of $14M from CDC's Public Health and Scientific Services Account.

In FY2018 and FY2019, NCHS received additional funding of approximately $12M per year from the Patient-Centered Outcomes Research (PCOR) Initiative and the Opioid Response Coordinating Unit (ORCU). It remains unknown whether NCHS will receive similar grants in the coming fiscal year.

NCHS data systems are supported at various levels by reimbursable funds, which are used to augment the surveys with content sponsored by the funder. For example, the National Survey of Family Growth receives 83% of its funding from outside sponsors whereas the Vital Statistics System receives almost no reimbursable funding. Sponsored survey items become part of the NCHS dataset and are subject to the same data release procedures/requirements used for all NCHS collections. NCHS may not know until the end of the fiscal year which sponsorship agreements will be executed for FY2020. Reimbursable funding makes planning difficult since NCHS will not know the final funding amounts until the agreements with sponsors are finalized.

Recently there has been increased interest in data and more appreciation for what an agency like NCHS does especially since our data have been used to monitor the opioid epidemic. In

May, NCHS staff were asked to meet with a congressional appropriations staffer to discuss how NCHS plans to modernize its data systems. In July, appropriations staff visited NCHS to further discuss data modernization as well as strategies to stabilize funding for current programs.

Program updates

Division of Vital Statistics (DVS)

DVS compilations of vital records remain limited by the slowest state. Jurisdictions applied to NCHS for funding to build new electronic death registration systems (EDRSs), complete building-out of EDRSs, or expand interoperability. Six jurisdictions were funded to build new EDRSs, eight were funded to complete their systems, and five jurisdictions were funded to expand interoperability with medical examiner/coroner systems. In September 2019, there will be an Implementers meeting in Atlanta, which will provide an opportunity to test and demonstrate interoperability of vital statistics collection systems. NCHS plans to release the 2018 mortality data in December or January, at which time NCHS will resume publishing the national maternal mortality estimates. NCHS will have to do a fair amount of outreach to clarify what has happened with the maternal mortality data since the last estimates were released in 2007 and how NCHS will move forward with reporting on maternal mortality.

Division of Health Interview Statistics (DHIS)

The 2018 National Health Interview Survey (NHIS) public-use files were released on June 24, 2019. Although none of the 2019 data have yet been released, the January-June data are currently being cleaned, optimized, processed, and reviewed. Additionally, comparisons of estimates based on the new versus old survey designs are ongoing. The sample adult response rate for the first six months of 2019 (60%) remains higher than it was for 2018 (53%). Since no one anticipates an increase in response rates in the future, DHIS is examining the survey data for non-response bias. DHIS recently completed non-response bias analyses for the first quarter of 2019. More will be presented on this later. The 2020 NHIS will include the same annual core, but the items in the rotating core will change and there will also be new sponsored content on diabetes and opioid use and pain management.

Division of Health and Nutrition Examination Survey (DHANES)

The DHANES director, Kathryn Porter, retired on September 1. Ryne Paulose was named Acting Director. Recruitment is underway for a new director. Normally, DHANES would have released the 2017-18 National Health and Nutrition Examination Survey (NHANES) data in September, but release has been delayed for more in-depth evaluation of non-response bias which will be presented later. DHANES needs to finalize planning for NHANES 2021-22 and is evaluating options for modifying the design for NHANES 2023+, including changes to the content as well as the sampling design (e.g., decluster the sample) and where examination components are conducted (e.g., in-home phlebotomy is being explored).

Division of Health Care Statistics (DHCS)
In January 2019, DHCS released the 2016 National Ambulatory Medical Care Survey (NAMCS) and expects to release the 2018 NAMCS in the second quarter of 2020. The 2017 NAMCS is undergoing further data processing due to the addition of electronic health records (EHR) data.

The 2016 National Hospital Ambulatory Medical Care Survey (NHAMCS) Emergency Department (ED) dataset was released in November 2018. DHCS expects to release the 2017 NHAMCS ED data at the end of 2019 or during the first quarter of 2020.

The 2017 National Electronic Health Records Survey (NEHRS) was released in December 2018. In the last quarter of 2019, DHCS plans to release the 2017 NEHRS Supplement and the 2018 NEHRS Research Data Center (RDC) file. In the second quarter of 2020, DHCS will release the first public-use version of NEHRS with data from 2018.

The 2017-18 National Study of Long-Term Care Providers (NSLTCP) completed data collection in February 2019 and plans to release a dataset in the RDC in October 2019 with public-use files available in July 2020. The 2017-2018 data collection was the first time that person-level information was collected. Starting with the 2019-20 data collection, the survey has been renamed the National Post-Acute and Long-Term Care Study (NPALS). NPALS will add two sectors—inpatient rehabilitation and long-term care hospitals—to represent post-acute care. The 2019-2020 NPALS will not include any person-level information, only summary measures at the facility level. NCHS is still in process of standing up the National Hospital Care survey that collects automated, electronic data from participating hospitals on all encounters. There is progress, and there will be more on NHCS presented at the next meeting in January.

Division of Analysis and Epidemiology (DAE)
DAE plans to release the Health, US 2018 report in October 2019. The 2018 printed report will be much shorter than in the past because detailed trend tables will be available only online. DAE has been gathering input from stakeholders as they explore redesigning this report.

Federal Interagency Forum on Child and Family Statistics
NCHS hosts this Forum, administers the Forum's work, and provides data and statistical expertise along with other forum member agencies. The new report will be published this month. Dr. Madans noted that the pictures on the cover sometimes feature the children and grandchildren of NCHS staff. If BSC members have suitable pictures they are willing to have used for this purpose, please send them to NCHS.

NCHS Publications and Media Exposure
NCHS researchers received the CDC Shepard Award in Data Methods and Study Design. Since the last BSC meeting, NCHS has released 34 new publications. In 2018, 2,002 journal articles based on NHANES data were published; the cumulative number of journal articles published during 2014-18 surpassed 5,100. Although NHANES is currently the only program that tracks related journal articles, NCHS would like to track such publications for all programs. Upcoming

NCHS reports will cover cognitive performance, asthma-related physician visits, trends in lipid markers, and maternal/infant outcomes in Appalachia and the Delta. Substantial media coverage has recently focused on prescription drug use, drug overdose rates, and the continued decline in the birth rate.

Discussion/Reaction by the Board
Discussion focused on how topics are chosen for upcoming reports, the nature of planned data modernization, and questions about the resiliency of reimbursable funds.

One Board member asked how NCHS chooses topics for upcoming reports. Dr. Madans explained that some publications are ongoing reports, while others accompany a new data release. The remainder are chosen at the discretion of the author, supervisors, and division directors. NCHS aims to address topic areas of interest to the public and the research community and would welcome suggestions from the BSC.

Another BSC member asked whether planned data modernization would focus on data collection or on analysis. Dr. Madans replied that NCHS intends to modernize in both those areas as well as other areas, which Dr. Richards will discuss later in the meeting.

A Dr. Ponce asked whether reimbursable funds had increased or decreased in recent years and how those funds could be made more resilient. Dr. Madans reported that the level of reimbursable funds has been reasonably steady over time. NCHS seeks sponsors' commitments early and through long-term contracts. Originally, sponsored content was intended to maximize use of the infrastructure, not to supplement core funding. Overreliance on reimbursable funds could leave the surveys vulnerable if sponsorship disappears.

The National Vital Statistics System: Behind the Scenes

Steven Schwartz, Ph.D., Director, Division of Vital Statistics

History: Where do the data from Vital Statistics actually come from?
Two constitutional amendments have influenced vital statistics collection in the United States. The 10th amendment stipulates that the functions of vital statistics are reserved to the people or the states. Consequently, vital statistics collection is a distributed process (i.e., among 50 states plus 7 other registration jurisdictions), which—although it allows for 57 opportunities for innovation—can make it difficult to maintain consistency across the entire country. The 14th amendment dictates that any person born in the U.S. is a citizen of the State wherein they reside. This fact helps motivate registration, because people need birth and death certificates to obtain credentials to attend school, secure employment, etc.

How does NCHS obtain high quality vital statistics in a timely manner?
NCHS collects a large volume of vital statistics data annually: 3.8M births, 2.8M deaths, and 24K fetal deaths collected across 57 vital registration jurisdictions. For the last 50 years, NCHS has collected these data through the U.S. National Vital Statistics System (NVSS), which relies on

each jurisdiction to follow similar rules. NVSS is the oldest and most successful example of inter-governmental data sharing in public health within the US. Yet, the individuals (i.e., doctors, hospitals, nurses, midwives, and funeral directors) reporting these data through the states to NCHS may not have a vested interest in ensuring data accuracy. For example, a funeral director provides the information about a decedent's race, ancestry, and occupation reported on the death certificate and may not necessarily consult the family, although it is best practice to do so.

One means by which NCHS encourages states to provide these data is through funding. Each year, NCHS pays more than $21M across 57 jurisdictions for vital statistics data. A large jurisdiction may receive about $600K annually from NCHS while also collecting about $15M per year from the sale of certificates, permits, etc. Thus, the funding a state receives from NCHS is only a small fraction of its revenue. Consequently, states are likely to prioritize the provision of certificates over providing timely public health data.

DVS faces other challenges. First, change happens very slowly at the state level. For example, the 2003 U.S. standard certificates were not adopted by all 50 states until 2016 for births and 2018 for deaths. Second, the laws and systems for registering vital events vary across jurisdictions. Finally, the implementation of and contracts for electronic systems also differ by jurisdiction. DVS works cooperatively with each state to maintain consistency.

Other ways in which vital statistics differ from other public health data systems
Vital statistics are collected more frequently (i.e., daily or several times a week) than most other public health data and must be monitored carefully for errors. Whereas most CDC data collection programs use cooperative agreements, DVS purchases the data by contract (Vital Statistics Cooperative Program contract) with 57 jurisdictions. Those contracts impose requirements regarding the timeliness of reporting, closeout deadlines for final files, and thresholds for unknown values. The contracts also stipulate that jurisdictions must respond within 30 days to any issues identified by DVS.

The Data Acquisition, Classification & Evaluation Branch (DACEB) administers the contracts with the 57 reporting jurisdictions and with the National Death Index (NDI). DACEB monitors the vital statistics database daily to identify content errors and stoppages in data transmission. Staff work closely with the states to identify problems early and troubleshoot the source of those problems.

Summary of the challenges and progress achieved
The first challenge is that information is not collected in the same way or within the same timeframe across jurisdictions. Second, not all states used the standard certificates until recently. Third, data providers may not understand the importance of data accuracy. Fourth, many cause-of-death certifiers are poorly trained or certify only a few deaths per year. Fifth, cause-of-death remains pending in many cases because of staff shortages throughout the entire system.

Despite the challenges, DVS has made major progress in finalizing files faster than ever before and making data available on an ongoing basis for surveillance, while continuing to improve data quality. DVS offers orientation, training, and E-learning to state-level staff, data providers, and registrars and also works closely with data quality workgroups. Dr. Schwartz concluded by noting the new accreditation standard for vital statistics; about a dozen states have applied for special training in vital statistics standardization through the Public Health Accreditation Board.

Discussion/Reaction by the Board

Dr. Scott emphasized Dr. Schwartz's point regarding the large difference in payment incentives that state registration systems respond to with respect to providing certificates for its citizens (the larger part of the budget) and reporting data to NCHS (the smaller part of the budget). The level of effort that states put into driving data quality is not commensurate with the amount of funding they receive for that purpose. Thus, other factors, including building strong partnerships with states and organizations such as the National Association for Public Health Statistics and Information Systems (NAPHSIS), are important.

With respect to the system for evaluating the accuracy of records, one BSC member suggested using subsampling to check measurement error (e.g., race/ethnicity and cause-of-death coding). Dr. Madans explained that DVS does not receive identifiers on certificates and would have to make special arrangements to do a follow-up survey. Although DVS extensively monitors data quality, efficiency is a challenge given the number of records being handled. For the most part, DACEB identifies errors only if the data are outside the expected range. Dr. Madans hopes that data modernization can improve the ability of the electronic system to detect and prevent errors. Other BSC members suggested conducting case studies to identify all the ways in which errors develop and using data linkage to verify data accuracy. Dr. Schwartz explained that some special projects have conducted studies that make use of data linkage, but DVS does not have the necessary funding to employ data linkage to verify all vital records.

During its long history collecting vital statistics, DVS has learned that offering the right incentives is key to encouraging jurisdictions to provide the desired data. DVS cannot pay enough to ensure accuracy, but rather must use other incentives to ensure data quality. NCHS payments may represent less than one-tenth of the total revenue received by a big state's vital records operation. It is important to align funding with NCHS priorities.

One Board member noted that DVS is faced with an informatics challenge (i.e., 57 jurisdictions looking for solutions to every problem). If all parties involved could agree on a solution, then EHR vendors would be more likely to incorporate that logic into their systems.

Summary of discussion themes from the Board
The following were identified as overarching themes from the Board's discussion:

1) Identify system opportunities to drive improvements

      i)   Some system opportunities mentioned relate to processes, people, training, IT, and technical assistance
      ii)   Consider ideas from different arenas.

2) Understanding data quality in the vital statistics
      i)   What validation studies have been done?
      ii)   Which studies can be done in the future?

3) Understanding the incentive to report vital statistics data to NCHS
      i)   Align funding with opportunities to modernize

The Board unanimously agreed on these themes for NCHS to consider.

NCHS and CDC Data Systems: Historical Context and Considerations for Modernization

Jennifer H. Madans, Ph.D., Acting Director, NCHS
Chesley Richards, M.D., M.P.H., F.A.C.P, Deputy Director for Public Health Science and
      Surveillance, CDC

NCHS History: How we got to where we are—the early years

Prior to 1956, the collection of health data was disparate in part because the laws that required reporting communicable disease varied by state. There were a few specialized and local health surveys. For example, a Nationwide Health Survey was conducted in 1935-36 that covered only urban households and the Eastern District Health Survey (1938-43) was conducted in Baltimore.

In 1956, the National Health Survey Act established sustained collection and production of current health data and called for broad cooperation across agencies. This law specifically mentioned methodology and called for the study of methods and techniques in health statistics to improve the field. The survey data were intended to provide national-level, general data rather than detailed, local data. Data collection was divided into three parts: 1) the Health Interview Survey, which comprised a national and continuing sample of households; 2) the Health Examination Survey, which included physical examination and testing of individual specimens; and 3) the Health Records Survey, which sampled health care establishments.

NHIS was launched on July 1, 1957 and has been operating continuously ever since. Its purposes are to provide data on the health status and health services utilization of the U.S. population and to address specific issues of current public health concern. NHIS was specifically designed to measure the social dimensions of morbidity (i.e., how health affects people's lives). It was designed to provide general background data on the overall health situation in the country, not detailed, local data.

NHANES (originally called the Health Examination Survey) focused on collection of objective measures of health. The first cycle (1959-62) surveyed the adult population, collecting data on the prevalence of chronic diseases. The second cycle (1963-65) focused on children, collecting

information about growth and development. The third cycle (late 1960s) covered children and youth (ages 12-17). In 1970s, during the war on poverty, an increased interest in nutrition led to the addition of a nutrition component, and the survey name was changed to NHANES.

The Health Records Survey was intended to capture statistics on the characteristics of health services and the people receiving those services. The first task was to create a master list of all health services providers. The original National Health Care Surveys included the National Hospital Discharge Survey (NHDS), which was first fielded in 1965; the NAMCS, which was first fielded in 1973; and the National Nursing Home Survey (NNHS), which was first fielded in 1973.

The NVSS was progressing separately from the health survey on its own timeline. In 1850, the federal government first published national-level birth and death statistics as part of the decennial census. In 1880, the census established a national "registration area" for deaths, which included Massachusetts, New Jersey, the District of Columbia, and several large cities. As part of the 1907 Model Vital Statistics Act, the census provided forms for birth and death registration. By 1933, the national registration area covered all 48 contiguous states (that were part of the union at that time) plus D.C. In the 1940s, as a result of World War II and a concern about epidemics, the need for up-to-date mortality data by cause-of-death became more urgent. Since the 1950s, there has been a growing focus on improvement of data quality and timeliness.

In 1960, the NVSS (which had been in the Census Bureau) and the NHIS merged to form NCHS. Since then, NCHS has made many changes (e.g., new surveys, survey redesigns, linkages with other data sources, revised data collection methods, and new ways of publishing/disseminating information), but NCHS's mission remains unchanged: to provide accurate, relevant, and timely statistical information that will guide actions and policies to improve the health of the American people.

Toward world class data and analytics
Dr. Richards outlined the CDC's vision for data modernization. The current CDC Director, Dr. Redfield, charged the organization to go from one presenting historical analysis to one that deals with real-time data and predictive analysis. To move toward a data ecosystem that allows us to do more with data more quickly, more accurately, and with more impact. One major problem is that CDC collects data in isolated ("siloed") systems that are not necessarily interoperable across programs. Furthermore, CDC's core infrastructure cannot handle the growing demand for data sharing and computing. The current CDC workforce also does not possess the data science skills needed. CDC may spend 70-80% of the time processing data and only 20-30% analyzing the data. CDC needs to obtain and share data more effectively.

The problems at CDC are compounded at the state level. Bi-directional data sharing between the states and CDC would improve interoperability and provide decision support in real-time.

Broad interoperability requires working with a multitude of partners. A CDC program known as the Digital Bridge facilitates bi-directional information flow between clinical care and public health agencies, without disrupting workflow within the health care system.

CDC has made progress improving timeliness and accuracy, in part because more data are received electronically. For example, the National Syndromic Surveillance is providing real-time data that serves as an early alert system (e.g., to identify emerging infections and disaster-related needs).

CDC has seven imperatives for 2024 toward achieving its goal of transforming from historical data analytics to predictive data science using modern IT platforms and enterprise services:

1. Most CDC data will be in a cloud;
2. Data will be reported to CDC through a common portal;
3. CDC will achieve internal and external interoperability;
4. CDC data will be shared and public, while protecting privacy and confidentiality;
5. Enterprise-level governance will promote strong decisions regarding data and IT policies;
6. CDC scientists will have efficient access to analytic tools; and
7. CDC will support state and local health departments to accomplish complementary goals.

Several funding bills currently under consideration indicate strong congressional interest in better data and improved infrastructure. Regardless of legislative changes, CDC must continue to use its funds strategically to achieve its goals.

The future of NCHS: how will we get to where we need to be
Dr. Madans continued the presentation with a review of NCHS's plans for data modernization. NCHS is already making progress by releasing data faster, focusing on topics that are relevant to current policy interests, making greater use of EHRs, and increasing data linkage across sectors. The modernizing initiatives at NCHS fall within the following four categories.

Next Generation of Survey and Data Systems
Some information can be obtained only through direct surveys. To complement and enhance its current surveys, NCHS: (1) needs to create an EHR-based platform to generate population estimates and create a single data repository for EHR data that allows for less time on data processing and more time for analysis; (2) is considering how to better combine the assets of NHIS and NHANES, while addressing response bias and growing requests for more detailed data; and (3) is improving data quality and timeliness within vital statistics by funding states to develop new electronic systems and helping states upgrade their registration systems.

Data integration, linkage, data science
NCHS plans to expand data linkage and integration. NCHS is exploring broader use of synthetic data to ensure confidentiality while expanding access to linked files. NCHS is also considering data science methods such as web-based electronic panel surveys while taking into account their known biases.

Upgrading computing technology and capacity
NCHS is exploring the use of cloud computing while considering NCHS's requirements for confidentiality and security. NCHS's concerns about using the cloud include who owns the cloud and who has control of it. NCHS also plans to increase secure storage; upgrade data processing speed and quality; and expand its use of machine learning and artificial intelligence.

Improve accessibility and usability of data
NCHS plans to redesign its website to improve data access, usability, and visualizations. Our website is organized by data system, but most of the world thinks by topic area. It is difficult to find data on the NCHS website by topic area. NCHS is also considering the use of remote access technology to expand access to the RDCs. The remote access system used by NCHS became obsolete. NCHS is working with the rest of the statistical community on remote access technology that can protect confidentiality in data that cannot be released.

Dr. Madans concluded by asking the BSC for recommendations regarding how NCHS should prioritize future data modernization activities.

Discussion/Reaction by the Board
Discussion focused on changes to NCHS surveys and their integration with other data collection and means for improving data accessibility/usability.

One Board member suggested that integrating NHIS and NHANES would increase their combined value, but another member pointed out that combining the two surveys may require prioritization (i.e., one survey may have to concede more than the other). Another BSC member proposed using model-based solutions to improve the precision of survey-based estimates while reducing cost. One approach could be for NCHS to collaborate with others working with EHR systems to standardize how data are collected and reported. Alternatively, NCHS could form partnerships with entities that are already starting to consolidate health data systems. Several BSC members endorsed the importance of making big, rather than incremental changes, which will require that NCHS have clear, concrete goals.

There was also ample discussion about improving the accessibility and usability of data. Dr. Holan asked whether NCHS had received feedback from users requesting more access to the microdata. Staff replied that there is a small subset of super users, mostly at universities, who want access to the microdata without going to an RDC. One current barrier in RDCs managed by the Census Bureau is the lengthy delays in the application approval process required to obtain microdata access. The linked files are a particular challenge because other than that for linkage

with the NDI, there is no public-use version of the dataset that enables a user to become familiar with the data before s/he enters the RDC. Thus, a public-use version would be useful, but its creation requires that all the entities involved in collecting the data included in the linked file agree on what information can be made publicly available. Synthetic datasets pose a challenging multivariate problem because it is difficult to replicate results except at the simplest level. Yet, the data lose value if they are locked away in an RDC. One Dr. Ponce asserted that people are particularly interested in their own neighborhoods and thus suggested broadening the vision of NCHS beyond the national level to include small area estimation. One challenge, however, is that it is difficult to capture change over time in small area estimates.

A Board member concluded that NCHS needs to prioritize its large number of goals and determine an appropriate sequence of steps to attain those goals. Now that the stage has been set around data modernization at NCHS, pieces of this topic will be discussed in more detail at later meetings to help NCHS decide on the appropriate steps to meet its goals.

Efforts to Improve Response Rates on NHANES and NHIS

Ryne Paulose, Ph.D., Acting Director, DHANES
Stephen Blumberg, Ph.D., Director, DHIS

Dr. Paulose noted that NHANES, like other NCHS surveys, has been plagued by declining response rates. In 2017-2018, the response rate for the initial screening stage of the survey dropped below 90% for first time, and the final exam response rate was only 47%.

To assess nonresponse bias, DHANES has adopted five approaches. First, response rates are compared across subgroups (e.g., by race) and classification trees are used to identify the relationship between response status and auxiliary variables. That information is used in developing the survey weights. Second, estimates from NHANES are compared with corresponding estimates from other sources to evaluate differences in the level and in the trend over time. The third approach examines the variations within NHANES using the R-indicator, which represents a measure of data quality before non-response adjustment weighting. A larger R-indicator is better. Despite a declining response rate, the R-indicator has remained relatively stable at about 0.7. Fourth, alternative post-survey adjustments for non-response are contrasted. Finally, the 2019 NHANES added health questions to the screening stage of the survey. This will allow NCHS to examine differences in health characteristics between the eligible respondents and the non-respondents. This information can be used to make meaningful adjustments to the non-response adjustment from the screening stage to the interview. those auxiliary variables will be useful for identifying predictors of non-response in subsequent stages of the survey.

Dr. Blumberg then reviewed the issue with respect to NHIS. The reasons for redesigning the NHIS included the need to improve the relevancy of content and address concerns about increasing respondent burden and declining response rates. NHIS reduced the average length of the survey to less than 60 minutes by eliminating the family module, rotating content, and cutting 30-40% of the content. As a result, the sample adult response rate increased by 6

percentage points. The current (pre-redesign) weighting procedure corrects for nonresponse at the level of the geographic area unit (i.e., which assumes that non-respondents are similar to respondents) and then calibrates those estimates based on independent population estimates by sex, age, and race/ethnicity. To date, DHIS has not employed nonresponse prediction or used any appended data that might identify correlates of response.

The goals of the NHIS nonresponse bias analysis are three-fold: (1) quantify the level of nonresponse bias present in the redesigned NHIS; (2) evaluate the current weighting procedure against other methods, taking advantage of improvements in auxiliary data and more modern statistical methods such as machine learning; and (3) obtain evidence to inform the decision regarding whether to implement a new weighting approach.

The contract for this work was awarded to ICF. In Stage 1, ICF used various data sources to develop separate prediction models for response at the household, adult, and child levels. The best logistic model and best machine learning model were selected based on performance metrics. In Stage 2, ICF used those models to assign propensity scores to every address and classified the scores into quintiles ranging from low to high likelihood of response. Key health indicator estimates were compared across the response quintiles to assess nonresponse bias. In Stage 3, ICF developed alternative weights (e.g., using the propensity scores to adjust for nonresponse; calibrating to population estimates for additional subgroups such as education or urban/rural). In Stage 4, ICF compared NHIS estimates for 28 health indicators using the various alternative weights versus the usual weighting strategy. The final stage evaluated the tradeoffs, recognizing that efforts to reduce nonresponse bias are likely to bear a cost (e.g., increased variance, decreased effective sample size, increased complexity of application and replication, reduced transparency of the weighting process).

ICF will provide its recommendations to NCHS, but NCHS is also requesting help from the BSC to evaluate the results from the nonresponse bias analysis and decide whether to change the weighting approach. Unfortunately, the timeline is short because the first 6-month estimates from NHIS are due to be released in early 2020. Dr. Madans asked whether BSC members are willing to serve on a workgroup, which is expected to meet once, probably in October.

Actions
The BSC voted on whether to form the proposed Nonresponse Bias Workgroup. Support was unanimous. Drs. Copeland, Holan, and Peytchev volunteered to serve on the workgroup. Dr. Hauser indicated through the WebEx messaging function that he would also serve on the workgroup. Other BSC members who are interested in serving should notify Dr. Uddin after the meeting.

NCHS Data Detectives Camp

Ryne Paulose, Ph.D., Acting Director, Division of Health and Nutrition Examination Surveys

The NCHS Data Detectives Camp is a 1-week STEM camp that aims to teach statistics to middle school students using fun, hands-on activities. There are no fees for registering or attending. The first camp was held in the summer of 2016 and was organized by collaborators at NCHS, the American Statistics Association, CDC's Disease Detectives, University of Maryland (UMD) Joint Program in Survey Methodology, and UMD School of Public Health. The partnership was expanded to include the Bureau of Justice Statistics in 2017 and the Bureau of Labor Statistics in 2018. The 2016 and 2017 camps were held at the UMD School of Public Health, but UMD could not host the camps in 2018 and 2019 because of major construction on campus. NCHS decided to host them onsite in 2018 and 2019. The statistical activities are based on common core standards and the Guidelines for Assessments and Instruction In Statistics Education (GAISE). Initially, the camp targeted grades 6-8, but after the first year the focus was narrowed to grades 6-7.

The fourth camp (August 5-9, 2019) accepted applications during January-March, receiving more than 100 applicants from across the U.S. Because the camp was limited to 30 participants, a committee conducted a blinded review to select applicants based on "fit" for the camp; 47% of the applicants were accepted during that round. Then, 30 were selected randomly with equal distribution by sex and age.

As next steps, NCHS is considering whether to move the camp back to UMD, which has great facilities, but has the drawback that parents tend to think it is a UMD camp. Hosting the camp onsite gives NCHS more visibility. There is also discussion of whether to offer both a beginner and an advanced class. Finally, NCHS is looking for a new camp director with new ideas.

Discussion/Reaction by the Board
Discussion focused on how the camp is marketed, whether NCHS might enlist other university partners to host similar camps, and on how to disseminate the developed tools to teachers.

In response to a question about how the camp is marketed, Dr. Paulose explained that NCHS posts it on their listserv and website. Organization partners also send out the announcement. One limitation is that many schools have restrictive rules about what information can be disseminated to students.

Another BSC member suggested that NCHS consider enlisting other university partners to host similar camps at other locations. For example, Dr. Gaskin noted that UCLA has a campus challenge called Data for Democracy that works with the education school to teach math and statistics at the 6th and 7th grade level, but it does not include public health statistics.

Another suggestion was for NCHS to disseminate these tools to teachers. Dr. Paulose explained that the American Statistics Association provides all the resources on their website, targeting teachers in particular.

The meeting adjourned for the day at 5:10 p.m.

Friday, September 6, 2019

Presenters

Kate Brett, Ph.D., Division of Vital Statistics
Carol DeFrances, Ph.D., Deputy Director, DHCS
Lisa Mirel, M.S. Chief Data Linkage Methodology and Analysis Branch, DAE
Gretchen Van Wye, Chair, PCORTF Drug Workgroup
Lisa Wagner, Office of Planning, Budget, and Legislation

Call to Order

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

Dr. Scott opened day two of the meeting.

Patient Centered Outcomes Research Trust Fund Projects Update

Kate Brett, Ph.D., DVS
Carol DeFrances, Ph.D., Deputy Director, DHCS
Lisa Mirel, M.S., Director, Data Linkage Program, DAE

DVS received funding from four separate grants to strengthen opioid mortality data quality and timeliness. Dr. Brett described the related projects underway within DVS. The first project aims to establish nationally approved Health Level Seven International (HL7) Fast Healthcare Interoperability Resources (FHIR) standards for vital records death reporting. DVS drafted an implementation guide for death record reporting, which was validated and approved by HL7 this spring. The first Connectathon trial of those standards will occur in 2 weeks. DVS is also planning to expand the HL7 FHIR standard to include data that DVS sends back to jurisdictions (e.g., cause-of-death and race codes) as well as the data DVS obtains from medical examiners and coroners. The second project will create applications to test the FHIR data standards. Third, DVS is modernizing the technological capabilities of the NVSS (e.g., incorporating natural language processing and machine learning techniques to code records automatically, mining literal text fields to obtain supplemental drug data). DVS hopes to transition the NVSS processing system from a batch system to one that continuously receives, codes, and returns cause-of-death codes as individual transactions from the states. Fourth, DVS is working with medical examiners and coroners to update the national guidelines on death investigation, evaluation and certification. Fifth, DVS is redesigning the Rapid Release Program to include additional demographic information and detailed drug type information. Finally, DVS is communicating with researchers and users to ensure the changes align with the end-users' needs.

The grant funding from PCORTF and ORCU also helps support many state projects to enhance EDRS use and utility. PCOR III funded two states to pilot data interoperability. ORCU FY18

funded 4 additional states to pilot data interoperability and 10 states to work on projects related to data timeliness. ORCU FY19 will establish EDRS in all 50 states, DC, New York City, and several territories; fund an additional 5 states to pilot data interoperability; and help 8 states expand the use of EDRS.

DVS's goals are for the states to transmit 80% of mortality records to NCHS within 10 days and 90% of drug overdose deaths within 90 days. The percentage of mortality records received by NCHS within 10 days increased from less than 10% in 2010 to nearly 60% in 2018. Success in receiving drug overdose deaths within 90 days varies considerably across states, but the best state has only attained 75%.

Next, Dr. DeFrances reviewed the completed FY17 PCORTF project, which aimed to link NHCS data with the NDI and Centers for Medicare & Medicaid Services (CMS) data. Ms. Mirel explained that the linkage program was designed to maximize the scientific value of the NCHS population-based surveys. Personal identifiers were used to link the data using both deterministic and probabilistic approaches. The new linked datasets are available only through the NCHS RDC, and the linkage program has published extensive documentation about these datasets and the linkage methodology.

Dr. DeFrances concluded by describing the subsequent PCOR projects that were spawned by the FY17 PCORTF project. The FY18 project added linkage with the NVSS restricted mortality data, drug specific information (NVSS-M-DO) file allowing NCHS to identify opioid-related hospitalizations and deaths and to determine the specific opioids that were involved. The FY19 grant builds on that to include a validation study of the algorithms and add linkages to CMS Part D and assessment data as well as data from the Department of Housing and Urban Development.

Discussion/Reaction by the Board
Issues raised during the discussion included questions about uncertainty with respect to the probabilistic methods and other suggestions regarding EHR data and additional linkages.

One Board member asked whether the linkage program is propagating uncertainty into the final estimates based on probabilistic methods. If not, some of the power of the probabilistic approach is lost. NCHS could use a sensitivity analysis to compare the effects of different methods.

Others suggested using natural language processing for the EHR data; linking with geographic data to obtain information regarding social determinants of health; and linking to USDA SNAP program data. The linkage program plans to link the survey data with geographic information and did an earlier pilot study with SNAP data. Unfortunately, it is very difficult to link with state-level data (e.g., SNAP) because NCHS does not have the resources to negotiate agreements with all the states.

PCORTF Drug Workgroup Report

Gretchen Van Wye, Chair, PCORTF Drug Workgroup

Dr. Van Wye, who chaired the July 18 meeting of this workgroup, reported on the results from the meeting. The goals of this workgroup meeting were to ensure that the products for improving identification of opioid-involved hospital visits and the modifications to the mortality data infrastructure are aligned with the needs of the end-users. The workgroup also was charged with reviewing effective strategies for disseminating this information to researchers and the public health community.

During the meeting, the themes that arose with respect to generating interest in the data included the need to communicate the value of the data to users; the importance of making data and methods available in an easily accessible suite of products; the value of monitoring usage of the data; the idea that users should be viewed as collaborators and stakeholders; a need for increasing the capability to investigate disparities; and the importance of including professional societies in dissemination efforts.

Regarding uses of the data, the following themes were highlighted during the meeting: documentation of the methods used to link records must be transparent; NCHS should provide contextual data that can help researchers understand state-to-state variation in mortality data quality; NCHS needs to provide guidance to users regarding appropriate use of the data; and validation studies should be published.

One theme related to data sharing was the importance of providing usable open data and code: the workgroup recommended using GitHub for sharing code and data documentation, PDFs for publishing historical information, and HTML for broader access. The workgroup also recommended publishing comprehensive orientation and summary documents, including instructions for writing a proposal using the new datasets. The workgroup also suggested creating fabricated data that allows users to test their code before entering the RDC.

With regard to enhancements of the datasets, the group suggested modifications to CDC WONDER (i.e., logical operators should include "NOT" as well as "OR" and "AND"; include place of occurrence as well as place of residence; include supplemental drug information). Meeting attendees also suggested including race and geographic data on the Vital Statistics Rapid Release interface. Finally, the group recommended providing information on provisional state mortality data thresholds.

Other ideas that emerged from the meeting included working with the National Institutes of Health (NIH) and the National Institute on Drug Abuse to highlight these datasets in future funding opportunities; waiving the dataset use fees for a small number of approved proposals in order to test the use of these datasets; requiring applicants to provide letters of support from key parties; and employing different strategies to engage different groups of data users.

Discussion/Reaction by the Board
The discussion focused on disparity analysis and issues related to dissemination.

One Board member expressed satisfaction that investigation of disparities (e.g., by race and geography) was a key theme, but inquired about the level of geographic aggregation. Dr. Van Wye explained that each death is coded at the county level. Because race on the death certificate is provided by the funeral director, there is a need to improve data quality. Hospital claims data do not include race; some information about race is included in EHRs, but it is not standardized. Dr. Madans noted that data quality regarding race/ethnicity is an issue for all administrative data. For deaths, coding is problematic particularly for Native Americans and Alaskan Natives. NCHS could link with the census for race information, but that is costly; currently, it is not feasible to link the entire NDI with data from the census. Dr. Scott noted that California provides coding worksheets for race/ethnicity to help guide funeral directors and others who may be coding those data. Perhaps a similar module could instill more decision logic into coding race/ethnicity in EHRs.

With respect to dissemination, a BSC member recommended taking advantage of the networks that already exist (e.g., groups like PCORnet and Health Care Systems Research Network). Dr. Madans mentioned that NCHS has considered holding a monthly webinar but wondered whether it would be well-attended. BSC members noted that doing a webinar at same time every month improves attendance because people can anticipate it. Attendance might be low at the beginning but grow over time. For webinars, it is important to have good presenters who engage the audience. Such webinars can help humanize the statisticians and display a different dimension of the NCHS than data tables. A Board member noted that her organization does monthly webinars (except during the summer), which are attended by 100-250 people; they are inexpensive and help engage other stakeholders. Dr. Gaskin recommended podcasts instead of webinars. Dr. Madans noted that NCHS already has several podcasts on their media page, but they get little use. She would welcome feedback from the BSC about how to make the podcasts more interesting.

Actions
Dr. Scott called for a vote regarding whether the BSC endorses the recommendations provided by the workgroup. The vote was unanimous in support. Dr. Scott will draft a letter of support and work with Dr. Van Wye to submit the letter to NCHS.

NCHS Outreach Planning

Lisa Wagner, Office of Planning, Budget, and Legislation (OPBL)

The goals for NCHS outreach are three-fold: (1) raise the visibility of NCHS and health statistics; (2) increase NCHS data use and the public's literacy with respect to health statistics; and (3) communicate information about new NCHS findings and program activities to the public.

NCHS has many partners (e.g., Friends of NCHS, congress, policymakers, U.S. DHSS, CDC, etc.), all of whom play different roles. For example, the Friends of NCHS includes more than 100 organizations, mostly professional associations as well as some university departments.

Ms. Wagner has developed a center-wide outreach plan. The first part of that plan is to compile, organize, and update the list of key contacts and expand it to new groups (e.g., health financing groups), which can help build NCHS's broader constituency and identify new sponsors. Second, to create consistent NCHS information materials for external stakeholders and partners (e.g., Ms. Wagner has developed an NCHS external monthly newsletter and is considering launching a regular blog schedule). Third, to ensure there is routine follow-up with contacts. Fourth, look for opportunities to promote NCHS externally (e.g., conference attendance; webinars or podcasts; hill briefings; seminar series). Fifth, obtain feedback regarding outreach from current stakeholders (e.g., Friends of NCHS annual meeting). Finally, emphasize the importance of consistent messaging from NCHS leadership regarding the value of outreach.

NCHS would appreciate input from the BSC regarding whether NCHS is missing valuable stakeholders or other opportunities to engage potential stakeholders; ideas for new methods of outreach; and recommendations for measuring outreach success. NCHS would also welcome feedback from the BSC regarding which data and health topics should be the focus of outreach.

Discussion/Reaction by the Board
Themes highlighted during the discussion included suggestions for additional stakeholders and methods for outreach.

The BSC offered several suggestions for new potential stakeholders: the National Academy for State Health Policy, which maintains relationships with all the states; HIMSS, which offers the perspective of health care information professionals; schools of public health (e.g., Hopkins, Maryland, George Washington); state demographers; and the philanthropic community.

Regarding outreach methods, Board members suggested: in-person meetings to bring together researchers and the public; a more consistent social media presence (e.g., Twitter, Facebook); and more engagement between NCHS and the CDC Foundation, which is very active in the Digital Bridge. NCHS could capitalize on opportunities to highlight NCHS when other organizations receive media attention for findings based on NCHS data. There was a brief discussion regarding the value of newsletters. One concern was that newsletters might consume too much time. Dr. Hayward remarked that the Pew Foundation does a great job of presenting results, often based on NCHS data, in a glossy format with attractive charts. Even if the media does not do investigative reporting, it will report findings of interest, particularly if the information is provided in copy-ready materials. NCHS tries to track where their data are being used but needs to do a better job of reaching people for whom statistics are not intrinsically interesting. One method to help people connect with the data is through storytelling. Much of the public does not know about NCHS surveys and datasets, which creates a challenge for achieving good response rates. Outreach could give NCHS more visibility and encourage respondent participation.

BSC Wrap-up
Linette T. Scott, M.D., M.P.H.

Jennifer Madans, Ph.D.

Dr. Scott closed by noting that this meeting provided a basis for future meetings as which there will be a focus on data modernization and the challenges of ensuring security. She asked the BSC to think about recommendations to NCHS regarding data modernization that members may bring to the next meeting. She also requested that the BSC provide additional feedback regarding priorities with respect to outreach if members think of other suggestions.

Dr. Madans thanked the BSC and offered a few closing thoughts. First, NCHS has always been a lean organization with respect to budget, trying to offer as much data as possible, but recognizing the need to prioritize. NCHS needs help from the BSC in establishing those priorities. Second, if BSC members have agenda suggestions for future meetings, please inform Dr. Madans at least one month in advance of the meeting. Third, Dr. Madans asked the BSC to send her suggestions for new stakeholders and if possible, provide personal contacts. Fourth, she thanked all those who agreed to participate in the temporary workgroup in October. Finally, Dr. Madans emphasized that NCHS wants to plan for the 5 and 10 years, but is also concerned about the next 2 years.

Public Comment

There was no public comment. However, Dr. Hauser suggested that NCHS might live stream these meetings if NCHS wants to engage public comment. NCHS could also have a live Twitter feed during the meeting to help generate a live audience for comment. It could be an effective form of outreach.

The meeting was adjourned at 12:02 pm.

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

_____/s/_____   _____October 29, 2019_____
Linette T. Scott, M.D., M.P.H.   DATE
Chair, BSC