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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 June 19-20, 2018**

#### **Meeting Minutes**

The Board of Scientific Counselors (BSC) convened on June 19-20, 2018, 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  
Charles J. Rothwell, M.B.A., M.S., Executive Secretary (NCHS Staff)  
Timothy J. Beebe, Ph.D.  
Prashila Dullabh, M.D.  
Darrell J. Gaskin, Ph.D.  
Sherry A. Glied, Ph.D. (by phone)  
Robert M. Hauser, Ph.D.  
Mark Hayward, Ph.D.  
Mary Ellen (Meg) Johantgen, Ph.D., R.N.  
Robert E. McKeown, Ph.D.  
Robert Phillips, M.D., M.S.P.H., National Committee on Vital and Health Statistics (NCVHS) Liaison  
Ninez A. Ponce, M.P.P., Ph.D.  
Trivellore E. Raghunathan, Ph.D.  
Robert Santos, M.A., Urban Institute  
Margo Schwab, Ph.D., Alternate Ex Officio Member, Office of Management and Budget (in person on June 19, by phone on June 20)  
Gretchen Van Wye, Ph.D., M.A. (by phone)

#### **NCHS-CDC Staff**

Charles J. Rothwell, M.B.A., M.S.  
Jennifer Madans, Ph.D.  
Gwendolyn Mustaf  
Chesley Richards, M.D., M.P.H., FACP

#### **General Audience**

##### **June 19, 2018**

Delton Atkinson, NCHS/Division of Vital Statistics (DVS)  
Shira Bettelyoun, NCHS  
Mary Ann Bush, NCHS  
Stephen Blumberg, NCHS/Division of Health Interview Statistics (DHIS)

Jim Craver, NCHS/OAE (Office of Analysis and Epidemiology)  
Carol DeFrances, Ph.D., NCHS/Division of Health Care Statistics (DHCS)  
Tala Fakhouri, National Health and Nutrition Examination Survey (NHANES)  
Alica Frasier, RTI International  
Anne Furnia, Census  
Rebecca Hines, NCHS  
Hashini Khajuria, NCHS  
Florence Lee, NCHS  
Sarah Lessem, NCHS  
Peter Meyer, NCHS/Research Data Center, Division of Research and Methodology (DRM)  
Jennifer Moore, NCHS/Office of Information Services  
Jennifer Parker, Ph.D., NCHS/DRM  
Merianne Spencer, NCHS  
Sayeedha Uddin, M.D., M.P.H., HHS Office on Women's Health  
Brent Vickers, NCHS/Division of Research and Methodology (DRM)  
Jennifer Welham, ICF  
Ashley Woodall, NCHS  
Kevin Zhang, ICF

June 20, 2018

Delton Atkinson, NCHS/DVS  
Traci Cook, NCHS/Office of Planning, Budget and Legislation  
Alica Frasier, RTI International  
Anne Furnia, Census  
Paul D. Sutton, NCHS/DVS  
Jennifer Welham, ICF

**List of Abbreviations**

API	Application Programming Interface
ASPE	Assistant Secretary for Planning and Evaluation
BSC	Board of Scientific Counselors
CDC	Centers for Disease Control and Prevention
CM	Clinical Modification
COD	Cause of Death
DHCS	Division of Health Care Statistics
DHIS	Division of Health Interview Statistics
DRM	Division of Research and Methodology
DVS	Division of Vital Statistics
ED	Emergency Department
EHR	Electronic Health Records
ER	Early Release
FACA	Federal Advisory Committee Act

FDA	Federal Drug Administration
HCUP	Healthcare Cost and Utilization Project
HHS	Health and Human Services
HL7	Health Level-7
ICD	International Disease Classification
LOINC	Logical Observation Identifiers Names and Codes
MEC	Mobile Examination Center
NCHS	National Center for Health Statistics
NCVHS	National Committee on Vital and Health Statistics
NDI	National Death Index
NHANES	National Health and Nutrition Examination Survey
NHCS	National Hospital Care Survey
NHIS	National Health Interview Survey
NLP	Natural Language Processing
OAE	Office of Analysis and Evaluation
PCOR	Patient-Centered Outcomes Research
PCORI	Patient-Centered Outcomes Research Institute
PDF	Portable Document Format
PHS	Public Health Service
PSUs	Primary sampling units
SAMHSA	Substance Abuse and Mental Health Services Administration

### **Action Steps**

- BSC members will notify Mr. Rothwell of their interest in participating in the proposed work group on patient-centered outcomes research.
- Before the next meeting, BSC members will consider whether there are other work groups they would recommend that NCHS convene (e.g., related to redesign of NHANES).
- BSC members will notify Mr. Rothwell if they have suggestions of other external experts for the proposed work group.
- Mr. Rothwell will announce new BSC members after receiving final approval.
- The next BSC meeting will take place September 6-7, 2018.
- Future meeting dates for 2019: January 15-16; May 9-10; and September 5-6.

**Tuesday, June 19, 2018**

### **Presenters**

Charles J. Rothwell, M.B.A., M.S., Director of NCHS

Irma Arispe, Ph.D., Director, Office of Analysis and Epidemiology

Renee Gindi, Ph.D., Chief, Analytic Studies Branch, Office of Analysis and Epidemiology

Kristen Miller, Ph.D., Director, Collaborating Center for Questionnaire Design and Evaluation  
Research, Division of Research and Methodology  
Denys Lau, Ph.D., Director, Division of Health Care Statistics  
Carol DeFrances, Ph.D., Division of Health Care Statistics  
Delton Atkinson, M.P.H., P.M.P., Director, Division of Vital Statistics  
Stephen J. Blumberg, Ph.D., Director, Division of Health Interview Statistics  
Tina Norris, Ph.D., Division of Health Interview Statistics

### **Welcome, Introductions, and Call to Order**

Linette T. Scott, M.D., M.P.H., Chair, BSC  
Charles J. Rothwell, Director of NCHS, Designated Federal Officer, BSC

Dr. Scott called the meeting to order. Mr. Rothwell welcomed everyone and thanked them for coming to the meeting. He then asked Board members to introduce themselves and state any conflicts of interest.

### **NCHS Update**

Charles J. Rothwell, Director NCHS

Mr. Rothwell began with a budget update: the NCHS annual budget was \$160.4M for FY2017 and FY2018. The President's FY2019 budget allocates \$155M for NCHS, which is about \$5.4M less than last year. However, this budget includes \$143M in Public Health Service (PHS) evaluation funds, which are not subject to the PHS evaluation tap or the Health and Human Services (HHS) Secretary's tap. Thus, if the budget is accepted as requested, the actual NCHS budget will be about \$4M less than last year. NCHS data collections are funded in part by funding from partners, although the percentage varies by survey. Mr. Rothwell believes that current staffing levels are at the level possible given budget constraints. Hiring is no longer frozen; they are currently hiring to fill key positions.

Mr. Rothwell highlighted several new appointments and nominations (i.e., Mr. Alex M. Azar II, confirmed as Secretary of HHS; Mr. Eric D. Hargan as deputy secretary; Dr. Robert R. Redfield, Director for CDC; Dr. James L. Woodworth, Commissioner for the National Center for Education Statistics). He also made note of few NCHS Senior Staff positions: Dr. Sayeedha Uddin (Office of the Director) will be joining NCHS next month and will take over managing the BSC; four others have been made permanent directors of their divisions (i.e., Dr. Steven Blumberg, Director of the Division of Health Interview Statistics; Dr. Jennifer Parker, Director of the Division of Research and Methodology; Dr. Dennis T. Lau, Director of the Division of Health Care Statistics; and Dr. Steven P. Schwartz, Director of the DVS). Dr. Schwartz will be joining NCHS in September and will replace Mr. Atkinson, who plans to retire at the end of the year.

### ***Program updates***

Key initiatives in Vital Statistics include efforts to: improve state performance standards through an accreditation process; enhance data quality via E-learning and greater interoperability of systems; and speed the transmission of mortality records from states to NCHS, particularly for drug deaths. NCHS has made dramatic improvements in the percentage of mortality records received by NCHS within 10 days of death as well as major improvements in the percentage of birth records received by NCHS within 10 days of birth. For deaths from drug overdose, NCHS issues monthly surveillance reports as well as quarterly mortality statistics on deaths from opioid overdose. NCHS now reports provisional ("predicted") counts for drug overdose deaths as well as the final counts after the data are complete. NCHS hopes to report total drug overdose death counts for 2017 by July of 2018. Unfortunately, a lot of

death reporting for drug related deaths occurs during that six-month lag between the end of the year and final reporting. NCHS has obtained funding from the Patient-Centered Outcomes Research Institute (PCORI) to improve the timeliness of reporting by: increasing the percentage of drug deaths that are auto-coded, working with medical examiners and coroners to report pending deaths faster, and improving dissemination via the rapid release program.

The 2019 NHIS Redesign is in final testing phases, and fieldwork will begin next year. NHIS has the same problem of declining response rates as other surveys, although the decline is not as severe as it is for NHANES.

The content for the 2019-20 NHANES has been finalized with a 20% reduction in the length of the questionnaire. Given continued declines in response rates, NCHS is considering new design options for NHANES. Several recent NCHS-authored publications using NHANES have received notable media attention (e.g., herpes simplex virus infections, depression, obesity, dental caries, and prescription medication).

The DHCS is collecting more data from Electronic Health Records (EHR). The growing wealth of data provides opportunities for more detailed analysis, but also presents a challenge for maintaining data quality standards.

### ***NCHS Publications and Media Exposure***

*Health, US* is NCHS's flagship publication; in 2017, they reduced the size of the printed report, while maintaining on-line access to the full content (<https://www.cdc.gov/nchs/hus/index.htm>). In the past, NCHS provided data and a few reports with tabulations. Currently, NCHS publishes a vast array of reports, public use files, data visualizations, and special high priority publications as well methods/evaluation reports (e.g., they have recently released guidelines for analysis of trends; two reports related to death certification and surveillance for suicide; and a reference guide for certification of deaths in event of disaster). The NCHS report on trends in suicide rates, in particular, received a lot of media attention.

The NCHS website is also using more data visualizations (<https://www.cdc.gov/nchs/data-visualization/index.htm>). This year each statistical agency provided a data visualization to the OMB, and the one selected to highlight the value of federal statistics was the NCHS monthly provisional counts of drug overdose deaths.

NCHS and all statistical agencies face significant challenges regarding declining response rates and data dissemination. As the way in which people read and access information evolves, NCHS must adapt and provide information in the form people want.

### ***Discussion***

Questions focused on the fragility of systems (with Puerto Rico as a prime example) and on budget issues.

There was a discussion of the reference guide for the certification of deaths during disasters and whether it might have helped in the case of Puerto Rico. Mr. Rothwell's view is that this guide would help in some cases (e.g., Katrina), but Puerto Rico was a particularly unusual situation. In the case of a virtual shutdown of government responsiveness, it is difficult to say whether or not these guidelines

might have helped. George Washington University is doing a special study of the Puerto Rico case. Someone pointed to a letter issued last month by NCVHS that highlights the general fragility of the vital statistics infrastructure (as exemplified during Hurricane Maria).

There was a discussion of the budget and a question about how evaluation funds can be used. One person cautioned that the President's proposed budget for 2019 is likely to change as it proceeds through congressional hearings, but noted that NCHS has a relatively small decrease (\$5M) compared with CDC as a whole (\$691M decrease). NCHS can use the evaluation dollars for whatever purpose they want within its mission, and so the NCHS director has a lot of discretion—more than in many other CDC programs—in deciding how to use the funds allocated to the agency. Thus, it is important for the BSC to communicate priorities to the NCHS director so that he can make informed budget decisions.

### **Health, United States: Past, Present, and Future**

Irma Arispe, Ph.D., Director, Office of Analysis and Epidemiology

Renee Gindi, Ph.D., Chief, Analytic Studies Branch, Office of Analysis and Epidemiology

*Health, US* is a statutorily-mandated, annual report that NCHS has been publishing for 40 years. It covers four areas (i.e., health care costs & financing; health resources; utilization of health resources; and health of the nation) and includes two printed components (i.e., the “Big Book” and the “In Brief”) as well as an array of digital content available online. *Health, US* also posts tweets.

### ***Where are we now?***

*Health, United States* is in transition because of production challenges and issues related to stakeholders and access. It is a big, visually pleasing report with high quality tables, but very labor intensive and expensive to produce. NCHS contracted out the design and production of *Health, US* 2016 and the *In Brief*. Although some issues arose, the experience demonstrated that production could be done outside of NCHS. We were able to reduce the number of printed volumes with no complaints and concluded that the decision to contract out production was a success. NCHS had planned to contract it out again in 2017, but the bid doubled in cost. Ultimately, NCHS decided to bring half of the production back in-house and contracted out the other half. This year, only selected components will be printed: it will not include the trend tables and appendices, although they will be available on-line. Changing the contract and splitting up the production resulted in a delay of about four months.

In 2016 and 2017, NCHS made improvements to the *Health, US* website to help users navigate the report to find tables and figures on specific populations and topics. Informal interviews with *Health, US* users as well as with people familiar with web access issues revealed that the audience for the large printed books could be diminishing, and that the existing PDF documents may not rank highly enough on search engines to be good sources of information for new users. Further work to incorporate this feedback is planned in the coming year.<sup>1</sup>

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<sup>1</sup>*Health, United States* 2017 with Special Feature on Mortality was released online September 20, 2018, with all components available on the website: <https://www.cdc.gov/nchs/hus/index.htm>. NCHS used several dissemination methods, including blog posts, listserv announcements, emails to Congress, and Twitter. The team is participating in a CDC innovation program to formally interview current and potential audiences to learn more about stakeholder needs. The team plans to explore several pilot projects during the next year, including making the report more search-engine friendly, engaging more directly with users with additional content throughout the year, and creating more dynamic charts.

### ***Where are we going?***

Taking over the presentation from Dr. Arispe, Dr. Gindi explained that they are considering what form *Health, US* should take in the future. To help inform that decision, they began by reviewing some examples of other annual reports to congress. There are still some very traditional reports (i.e., long, printed reports that are put on the web in PDF form). They also found many non-traditional reports: Community Preventive Services Task Force Report (i.e., 16 PDF pages with lots of links to the website <https://www.thecommunityguide.org/sites/default/files/assets/2017-congress-report-full.pdf>); Pew Research Center (figures and text are HTML-based and interactive, but there is a PDF report as well for those who want to print it; <http://www.pewsocialtrends.org/2018/05/22/what-unites-and-divides-urban-suburban-and-rural-communities/>); St. Louis Fed Reserve FRED (which includes 508,000 interactive trend graphs from 58 sources, but it does not provide the user any sense of the relevance; <https://fred.stlouisfed.org/>). They also found a transition report: the Administration on Children and Families Annual Report on Child Welfare Outcomes (which offers up-to-date access to data and graphics on their website, <https://cwoutcomes.acf.hhs.gov/cwodatasite/>, while their traditional report is still in progress).

*Health, US* has many possible options for 2018: 1) continue to publish the report in the same format as before; 2) continue “as-is” but with no special feature (which requires a significant investment of time and resources); 3) publish only the trend tables; 4) publish only the chartbook; or 5) pause production of *Health, US* for a year and spend that time on a redesign. One key question is: How can they identify and grow their target audience? They also want to learn from their competitors and better understand how users experience the report. Dr. Gindi closed by posing several questions to the Board. First, where does *Health, US* fit with other NCHS products? Second, where should they direct outreach to stakeholders? Finally, are there other model examples of annual or omnibus reports?

### ***Discussion/Reaction by the Board***

Several issues were raised during the discussion: the importance of identifying the audience; whether or not to transition to a more device-friendly format; and what role *Health, US* should play in the future.

Before deciding how to change the report, it is important to identify the audience. Several people suggested strategies to help determine what information people want and how they use it (e.g., search for how often the data are cited; take advantage of Google Analytics; make use of the cognitive lab at NCHS). Dr. Gindi noted that they have used Google Analytics, but it works better for HTML-based content than for PDFs. OAE is considering a pilot project for next year that would move some smaller sections from PDF to HTML so they can compare the analytics when the content is in HTML rather than PDF. As a means of expanding usage, someone suggested having a standing meeting every morning to identify the important news topics of the day and then send out corresponding tweets.

There was also debate regarding the format of the publication. Several people noted that a book or even PDF format may be outdated, particularly if it is to be accessible to younger people. An interactive format that can be manipulated by the user may be better. One person noted that web tables require less effort to produce than print tables and argued that the product can still be cohesive as long as it is consistent across platforms. Although the printed format is outdated, the PDF format is still useful because one can easily do text searches within the PDF without having to navigate through all the HTML links. Another suggestion was to reorganize by topic so the user can navigate based on topics of interest. Regarding the option of pausing production for a year, it is possible that someone else may fill in that

gap in the interim; it might be better to produce a very short report that still allows staff to devote more time to a redesign.

The remaining discussion centered on the role that *Health, US* might play in the future. If the private sector can do it better, perhaps NCHS should leave it to them or partner with them. Is NCHS trying to put together a compendium that is not really needed? Maybe NCHS should simply make the tables and trend information available. Then, individuals could create their own compendiums based on their particular interests. If you make the data available, other people will make use of it in ways we cannot envision.

### **Selected NCHS OPIOID Related Projects**

#### ***Investigating the Accuracy of OPIOID Use, Misuse, Impairment and Addiction Responses***

Kristen Miller, Ph.D., Director, Collaborating Center for Questionnaire Design and Evaluation  
Research, Division of Research and Methodology

The DRM does construct validity studies to identify the specific phenomena that account for a respondent's answers and comparability studies to evaluate whether a construct is consistently captured across salient respondent subgroups. For example, when parents were asked a question about whether their child had difficulty hearing, one group interpreted the question to be asking about auditory hearing, whereas the other group of parents thought the question was asking how well their child listens to them. In another example, a question about children's use of drinking water facilities at school was asked in multiple countries. U.S. parents thought the question was asking whether or not their child drinks water at school, whereas Indian parents interpreted it to be a question about the safety of the drinking water at school. Thus, context affects how people interpret a survey question.

#### ***Construct Validity Study for Sexual Identity Question***

Dr. Miller then reviewed their 2012 study of a NHIS question about sexual identity. Although the question had been widely used, it produced high levels of missing data, particularly for minorities, women, and less educated respondents. There was also suspiciously high reporting of bisexuality by those same groups. After conducting more than 100 cognitive interviews, they discovered that sexual minorities (i.e., Lesbian, Gay, Bisexual, or Transgender) perceived the question much differently than heterosexuals. For sexual minorities, sexual identity was highly salient; they chose the "something else" category because they use a different label than the one provided; they said "don't know" because their sexual identity was in transition; and misclassification as bisexual resulted because the respondent answered based on attraction/behavior rather than identity. Among heterosexuals, the concept of sexual identity was not as salient; the "something else" or "don't know" responses reflected lack of familiarity with the terminology; and some were misclassified as bisexual because they misinterpreted the term to mean heterosexual. Based on the results of this study, they revised the sexual identity question and included a follow-up question to ask why a respondent responded "something else" or "don't know." The new question eliminated the bias among racial/ethnic minorities.

#### ***Comparability Study for Opioid Questions***

Currently, they are doing a large nationwide study on opioids. Screening questions for opioid use follow two strategies: 1) the question asks about "the use prescription pain relievers called opioids," naming several example drugs; and 2) the respondent is shown pictures of pain relievers labeled with the names of those drugs and asked whether they use any of these "pain relievers," but the questions does not use the term "opioid." In the first strategy, there is a concern that use is under-reported, whereas in the

second strategy the worry is that use is over-reported. The study revealed five different interpretations of the questions: 1) some respondents were not familiar with the term opioids or the names of the drugs; 2) others linked it with medication prescribed by a doctor; 3) some viewed it as being a problem for “other” people; 4) others thought it pertained to recreational use; and 5) the remainder had experience with addiction (either self or others’).

The goal of this ongoing project is to understand what constructs are captured by the questions on opioid use. When answering the questions, what medications do respondents consider? How do they understand the concept of misuse? Are they reporting use accurately and in the way intended by CDC? Do the questions overburden the respondent to the extent that data quality is compromised? Are some of these questions too sensitive to be asked in a face-to-face, household survey?

#### *Discussion/Reaction by the Board*

Focusing on prescription opioids does not capture the much larger problem of drug use from illicit sources. Dr. Miller acknowledged that they need to start by obtaining an organized list of what substances they want to capture and determine what the current questions are actually capturing. The DRM uses semi-structured, ethnographic interviews as well as a pile sort method (i.e., respondents are asked to organize pictures of the drugs into groups and then asked why they grouped them that way and how they would label those groups). From the pile sort results, DRM hopes to be able to identify any consistent patterns across people and locations. Dr. Miller commented that questions regarding the medical system must probe very carefully because in places where there is no access to health care, respondents often lack basic medical knowledge. The interviews also probe in-depth to determine exactly what drugs the respondent is using and from what sources they are obtained.

It may be challenging to obtain meaningful estimates of trends in opioid use. With circumstances changing so quickly, the trends are likely to be useless. Dr. Miller acknowledged that they have similar problems with the sexual identity questions; so much has changed since DRM’s 2012 study that it is not clear whether the questions are still appropriate.

#### ***Identification of Substance-Involved Emergency Department Visits Using Data from the National Hospital Care Survey***

Denys Lau, Ph.D., Director, Division of Health Care Statistics (presented)

Carol DeFrances, Ph.D., Division of Health Care Statistics (chimed in during discussion)

The aim of NCHS’ National Hospital Care Survey (NHCS) is to provide reliable and timely health care utilization data for hospital settings. It is the first NCHS provider survey to be based entirely on electronic data collection (i.e., claims and electronic health records (EHR)). DHCS hopes to link episodes of care across hospital units and outpatient departments, and they also plan to link the data with external data sources (e.g., National Death Index (NDI), Medicare claims). The survey has included inpatient UB-4 claims since 2011 and hospital ambulatory claims since 2013. The target sample in 2013 was 581 hospitals. Starting in 2015, they added EHR and data from Vizient-member hospitals—which includes claims data plus some information on medications and laboratory assays.

This presentation focuses on their efforts to identify substance-involved emergency department (ED) visits using the 2013 claims data. While extraction from medical records is considered the gold standard, it has many drawbacks: it is costly, labor intensive, subject to subjectivity, and disruptive to the work flow in clinical settings. Claims data are more objective and the processing can be automated, which

allows for use in large-scale surveys. Yet, there are disadvantages as well: claims data are designed for billing rather than research; the number of clinical data elements is limited; it can be difficult to determine whether or not an ED visit is related to substance use because contextual information is lacking; it is difficult to identify specific substances because International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) classifies medications only in broad therapeutic categories; and the data may contain “carryover” diagnoses that do not pertain to the current visit.

In collaboration with the Substance Abuse and Mental Health Services Administration (SAMHSA), NHCS identified a priority list of the top 10 substance categories. Then, they developed two algorithms to identify substance-involved ED visits involving one of those substances. The first algorithm (“General”) identifies instances where: a) the ICD-9-CM external cause of injury code (E-code) includes one of the priority substances; or b) the ICD-9-CM diagnosis code indicates substance abuse, dependence, or poisoning. The second (“Enhanced”) algorithm uses those same criteria with an additional condition requiring that the ICD-9-CM diagnosis code indicates a symptom/procedure commonly associated with substance use. The Enhanced algorithm may have better specificity (i.e., lower false positive rate) than the General algorithm. When the algorithms were applied to claims data for 3.78M ED visits at 82 hospitals, the General algorithm identified 81% more substance-involved ED visits than the Enhanced algorithm (87K vs. 48K). The General algorithm may overestimate substance-involved ED visits, whereas the Enhanced algorithm may be better at identifying ED visits that relate to recent substance use. The addition of EHR (since 2015) may enhance the performance of the algorithms and will expand coverage to include all visits regardless of payment source.

They have two projects funded by the Patient-Centered Outcomes Research Trust Fund. The first explores the feasibility of linking NHCS claims and EHR data with external data. These data linkages will allow the DHCS to produce national estimates of cause-specific death rates following ED visits and hospital encounters for specific chronic conditions. The second project, which has just begun, seeks to: 1) use text mining strategies to enhance opiate identification in hospital encounters and overdose deaths; and 2) merge the data from NHCS with the NDI and the vital statistics restricted-use mortality file for drug overdose deaths, thereby creating a comprehensive data file on hospital care and mortality related to opioids and other high-priority substances. As part of this second project, they will share new data files, methods, and reports with the research community and build a web portal that will providing participating hospitals with access to the reports and findings. In partnership with the Assistant Secretary for Health and Human Services for Planning and Evaluation (ASPE), the Federal Drug Administration (FDA), the National Institute on Drug Abuse, and SAMHSA, NCHS will form a Technical Expert Panel to guide this project. To help engage external stakeholders and end-users, they are also planning to form a BSC workgroup (discussed in more detail on day two of this meeting).

As a next step, they will continue to enhance the algorithms and conduct some validation studies.

#### Discussion/Reaction by the Board

Discussion focuses on the differences between the Healthcare Cost and Utilization Project (HCUP) and these data; issues of calibration and validation of the algorithms; and ways to incentivize participation by hospitals and EHR vendors.

Unlike NHCS data, HCUP is not based on a representative sample and does not collect personally identifiable information, which limits the ability to link to external data sources. It would be almost impossible to link the two data sources for the purposes of validation.

Regarding the challenges of calibration and validation, there was discussion of the variability in E-coding within states and even within hospitals, which compromises the ability to use E-codes to accurately attribute injury to a substance and may lead to inconsistencies across regions. Because of this variation, the algorithm may behave differently in different settings. NCHS hopes that the technical expert panel can provide insights regarding coding practices. They are hoping to validate the algorithms using manual extraction of medical records. In addition, someone asked how frequently additional medical codes (e.g., Logical Observation Identifiers Names and Codes (LOINC), RxNorm) are available in the data. Dr. Lau reported that such information is often coded into SNOMED. Although NCHS provides hospitals with a guide that stipulates the recommended format for data submission, there is a lot of variability in the format of data submissions and NCHS must be able to accommodate whatever data format the hospital can provide.

The incentive system is changing, particularly as data makes the transition from paper records to EHR. It is important that NCHS emphasize where the data come from and why continued access to those data is important. If NCHS can demonstrate the value of the data to hospital stakeholders, it will serve as an important incentive. NCHS has experienced some difficulties with EHR vendors. In the future, it will be important to establish collaborative relationships with the EHR vendors rather than relying solely on incentives.

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***Modernizing the Mortality Infrastructure for Capturing Drug-related Death Information and Enhancing Research***

Delton Atkinson, M.P.H., P.M.P., Director, Division of Vital Statistics

Given the rapid rise in opioid overdose deaths, Health and Human Services (HHS) has responded with a five-point strategy, one of which focuses on "better data" (i.e., more timely, higher quality). To attain that goal, NCHS will focus on three components: DVS (i.e., how we process, collect, analyze, and disseminate the data); state Vital Records (i.e., improving the states' ability to collect, process, and transmit the data that NCHS needs); and medical examiners' and coroners' offices (i.e., how they obtain the information NCHS needs to complete death certification). Because NCHS' core funding is devoted to their basic work, they have sought competitive funds to advance these efforts. NCHS successfully obtained funding from the Office of Public Health Preparedness & Response (\$250K), PCORI (\$2.6M), Injury Opioid project #1 (\$1.9M) & Injury Opioid project #2 (\$5.9M).

Dr. Atkinson then reviewed the DVS' six key goals. First, they aim to have 80% of the mortality records (which does not necessarily include the Cause of Death (COD)) transmitted to NCHS within 10 days after death; the percentage has improved from 7% in 2010 to 63% in Jan-Apr 2018, but they will continue to work towards the 80% goal. Second, they want 90% of drug overdose deaths (including a usable COD code) transmitted to NCHS within 90 days after death; progress on that goal varies by state (e.g., examples from five unnamed states ranged from 9% to 57%). Third, they hope to code at least 90% of all mortality records with less than 1% error rate within 30 minutes of reaching NCHS and return electronically coded records back to the states within 12 hours of receipt. Currently, they can code about 79% of those records, but only about 33% of drug-related deaths can be coded automatically. Fourth, they aim to better identify and report on the specific types of drugs involved in the death. Fifth, NCHS seeks to enhance the capacity for surveillance and reporting of drug overdose deaths on a monthly basis. Sixth, NCHS wants to improve their ability to meet the needs of researchers and other end-users of our data products.

Next, Mr. Atkinson outlined eight strategies the DVS will use to attain those goals:

- 1) Modernize the technology capabilities of the National Vital Statistics System (e.g., transition from batch processing to a transactional processing system, incorporate natural language and machine learning techniques to mine the literal text fields on the death certificate, upgrade the Validations and Interactive Edits Web Service system that alerts the user to data entry problems in order to reduce the need for later data cleaning);
- 2) Fund six innovative states to create interoperable technology environments to facilitate the exchange of relevant death information (e.g., develop/implement Application Programming Interfaces (APIs) to facilitate the transfer of information between medical examiner/coroner case management systems, state electronic death registration systems, and NCHS);
- 3) Fund 9-14 states to improve quality of drug information on state death certificates (e.g., promote use of a mobile app that aids physicians in coding COD);
- 4) Establish nationally approved Health Level-7 (HL7) Fast Healthcare Interoperability Resources standards for use with Information Technology systems in health care industry;
- 5) Redesign the rapid release program;
- 6) Improve the use of National Association of Medical Exam guidelines on death investigations, evaluations, and certifications;
- 7) Study the effects of opioids/drugs on birth outcomes; and
- 8) Better align NCHS processes with the needs of researchers/end-users. The Technical Working Group being formed by NCHS will focus on improving project deliverables for patient-centered outcomes research. Although they are using the drug epidemic as a test case, they hope that what is learned can be applied to the next, as yet unforeseen, health crisis.

#### Discussion/Reaction by the Board

Topics of discussion covered issues related to incentives for adopting the standards, barriers to exchanging information, and the difficulty of accurately coding intentional versus accidental poisonings.

NCHS has two heavily used data sources (NDI & confidential mortality files) for which there is tremendous interest from federal and academic institutions as well as the private sector, all of whom want to be able to link to these data. Everyone wants better data, faster, and for lower cost. Thus, there is an incentive for broad scale adoption of the standards. Bi-directional exchange with health care industry can improve quality measures and reporting and reduce provide burden. Admittedly, the DVS does need to enforce the standards (e.g., currently only half of the records can pass NCHS edits), but first DVS must establish the standards.

State law sometimes interferes with the ability to share and exchange data. Mr. Atkinson acknowledges that the states need something that is signed off by the HHS Secretary before they can make progress.

There was also a discussion of the difficulty of distinguishing between intentional and accidental poisonings. Mr. Atkinson acknowledged that this is a very difficult problem; it is something they are discussing, but it will be very challenging to solve.

#### **Visualizing the NHIS Early Release Program: A New Online Dynamic Report**

Stephen J. Blumberg, Ph.D., Director, Division of Health Interview Statistics  
Tina Norris, Ph.D., Division of Health Interview Statistics

Dr. Blumberg noted that the last major content redesign of NHIS was in 1997, at which time the lag between data collection and release was about 18 months. In 2000, NCHS held a National Consensus

Conference to discuss using NHIS for surveillance of sentinel health events. The end result was the NHIS Early Release (ER) Program, which released its first product in April 2001. Currently, NHIS releases their first products about nine months prior to the public-use files. These early estimates are developed prior to final processing, and thus differ slightly from the final estimates. Public-use data files are released about six months after data collection for the year is complete.

NHIS does quarterly releases of estimates based on data collected approximately nine months earlier. These ER reports focus on 15 key health indicators and are about 125 pages in length, published as a PDF document; they are labor intensive to produce. In January 2017, Dr. Norris proposed using data visualization software to automate the production of this report. NCHS decided to go ahead with the proposed change, but asked Dr. Norris to adhere to the same general format as the earlier report.

Today they are releasing the new Online Dynamic ER Report, which will replace the previous static, quarterly reports. It offers interactive charts and tables along with dynamically-generated bullet points, reduces the amount of time and staff needed to produce the report, and decreases the potential for error.

### ***Where we are today?***

Dr. Norris provided a demonstration of the new Online Dynamic ER Report (<https://www.cdc.gov/nchs/nhis/releases/released201806.htm>). It offers the same level of functionality and usability as the previous PDF reports (i.e., basic charts, bullet points, and data tables), but allows users to filter the years of interest. In addition, the new report provides geographic comparisons at the Metropolitan Statistical Area (MSA) level for each of the indicators. Bullet points are dynamically generated using algorithms that evaluate estimates, differences between the estimates, and statistical significance, which is then translated into text. In a single data visualization, the user can compare estimates over the period since 2006 for any of the key indicators. Finally, the user can export figures, tables, and bullets to PDF if desired.

### ***Where are we going in the future?***

Dr. Blumberg noted that they are already thinking about the future of the Online Dynamic ER Report, particularly in light of 2019 questionnaire redesign, which will change availability of the 15 indicators. Consequently, DHIS must again consider which key indicators they will include; whether they should add more demographic subgroups; and how frequently the estimates should be released. In addition, they need to reconsider the options for online distribution. They have already transformed the PDF to make it more web-friendly, but should they further transition to an online data query system? How important is it to maintain consistency with past reports? What existing tools/solutions could be used/purchased? How do we enable efficient access for data users and app developers? There is little time to answer those questions. Field testing for the redesigned NHIS is currently underway. In October, they will begin a full-scale systems test. In January 2019, they will launch the redesigned NHIS. They will need the first ER products from the 2019 NHIS no later than December of 2019 and want to release the public-use data files by the summer of 2020. There is no time to conduct a consensus conference to answer all the questions.

Dr. Blumberg concluded by posing a number of questions for the BSC to consider. First, are these the right questions we should be asking ourselves? Second, what process does the BSC recommend for deciding how to proceed? Finally, are there data query systems or solutions that NCHS should consider?

### ***Discussion/Reaction by the Board***

Several topics were raised during the discussion: technical challenges of moving to a digital product; pros and cons of different formats; and possible changes to the financial model.

As NCHS moves to an open data platform, there is some concern about how to include all the cautionary notes regarding data quality and how NCHS can brand their data. One approach suggested was to load everything together (i.e., methodology, data dictionary, metadata, qualifications) so it is available to users. Another person cautioned that it is important to pay attention to how it renders on different platforms in order to maintain consistency.

The ideal format of the report depends on whom you are trying to target. One question is whether NCHS's goal is to create reports or to create tools that help generate reports? The latter would provide users the flexibility to create whatever reports they want, and thus may increase market share. One person expressed a desire to have all the indicators tabulated by education.

Finally, one person suggested that NCHS might reconsider its financial model. For example, the National Household Travel Survey had a small amount of money to conduct a national survey, but offered states the opportunity to contribute money for state oversamples. By charging states the average cost per unit rather than marginal cost, they generated millions of dollars that could be used for research and development and other data enhancements. Under the new NHIS, charging average cost rather than marginal cost would generate money that could be used to fund new data visualizations.

Mr. Rothwell closed the meeting by noting that NHIS was the instigator for more timely release of data. They helped foster competition within NCHS that spurred innovation. New personnel, like Dr. Norris, are a source of innovation. He credits the senior staff at NCHS who are willing to listen and take advantage of new ideas. It is important that NCHS continue to bring in more people who will foster innovation.

The meeting was adjourned for the day at 5:00 p.m.

## **Wednesday, June 20, 2018**

### **Presenters**

Charles J. Rothwell, M.B.A., M.S., Designated Federal Officer, NCHS, BSC

Paul Sutton, Ph.D., Deputy Director, NCHS

Kathryn S. Porter, M.D., M.S., Director, Division of Health and Nutrition Examination Surveys

### **Call to Order**

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

Dr. Scott welcomed the group to day two of the meeting. Mr. Rothwell asked for another round of introductions and statements regarding conflicts of interest.

Based on questions he was asked regarding yesterday's discussions, Mr. Rothwell offered a clarification of the term "reimbursables." When other organizations want to collaborate with NCHS on a survey (or sponsor some questions on the survey), they sign an agreement with NCHS that allows them to transfer money to NCHS. NCHS is very dependent on the funding of these agencies, but it is not a secure funding source (i.e., those agencies may not continue funding it).

He also provided clarification regarding “evaluation funds.” When NCHS receives evaluation funds, there are other contributions that NCHS does not need to make. Consequently, if the President’s proposed budget were to be the actual budget that emerges from Congress, it means that the \$5.4M deficit would effectively be a little less than that.

Finally, he noted that the Senate recently recommended a 1.9% salary increase for federal employees, but Congress does not provide NCHS additional funds to pay for those salary increases. Thus, if those salary increases are enacted, it would require another \$1.4M that must come from the NCHS budget, making the net deficit more like \$6.4M.

### **BSC Workgroups**

Charles J. Rothwell, Designated Federal Official, NCHS, BSC  
Paul Sutton, Ph.D., Deputy Director of Vital Statistics

Mr. Rothwell explained the purpose of subcommittees and work groups. NCHS is facing some significant challenges for which it would be useful to solicit outside input, beyond what can be provided during the three annual meetings of the BSC. One option would be to form a subcommittee to the Federal Advisory Committee Act (FACA) (e.g., BSC). Such a subcommittee would be like a mini-BSC and would be subject to the same requirements (e.g., must be public, report directly back to the BSC, members must be special government employees). In his view, it would take too long to convene a subcommittee and obtain all the necessary approvals. Also, membership of a subcommittee is not as flexible; it cannot be changed easily as issues evolve.

An alternative is to form a workgroup whose purpose is to gather information, analyze relevant issues, draft position papers, and report back to the BSC. Although the workgroup must include at least two BSC members (one of whom must act as chair), it can include outsiders such as subject matter experts and ad hoc consultants. Someone from NCHS would act as a lead to guide the work group. Under FACA requirements, the workgroup must report to the BSC and meeting summaries are required. Meetings do not have to be at NCHS and could be conducted by phone; public access is not required. Participation in such work groups is voluntary.

### ***Discussion/Reaction by the Board***

Mr. Rothwell clarified that everyone would be an unpaid volunteer, including the “consultants,” although NCHS would pay for their travel expenses.<sup>2</sup> One person noted that another workgroup used a contractor that set it up as a series of webinars, which ended up being less costly and made it easier to recruit participants because it required less time commitment. It might be a useful model. Mr. Rothwell confirmed that other, non-CDC federal employees are allowed to participate.

### ***Paul Sutton, Ph.D., Deputy Director of Vital Statistics***

Dr. Sutton explained that the purpose for a proposed BSC workgroup centers on the requirement, under recent PCOR funding, to engage with outside researchers to ensure that NCHS maximizes the utility for end users. NCHS envisions an end-user focus group to promote research and provide input on morbidity

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<sup>2</sup>Historically we have paid the people we ask to be involved in BSC activities an honorarium of \$250 per day that they are in Hyattsville. Not for the travel days or for the prep time outside of Hyattsville. This includes the BSC members who are SGEs on the days they are here and the consultants who get a check written by the AO. The situation most analogous to the workgroup is the program reviews conducted by the BSC

and mortality patient-centered outcomes throughout the PCOR III two-year life cycle. The objective of the workgroup would be to provide advice regarding DHCS/OAE- and DVS-specific issues as well as common issues (e.g., mortality coding). In addition to at least two BSC members, the workgroup would also include NCHS representatives (from DHCS/OAE and DVS) as well as permanent or ad hoc external members who have specialized expertise appropriate to support the needs of the workgroup.

He then reviewed some of the sample questions that NCHS would like the workgroup to focus on. For example, what advice can be given for the coding/classification of drugs for the end-product data file? Are there any existing natural language processing (NLP) methods for identifying conditions in EHR clinical notes that could be applied to these projects? The deliverable of the workgroup would be a presentation or report to BSC, which would become part of the public record.

### ***Discussion/Reaction by the Board***

Dr. Van Wye volunteered to chair the work group. Dr. Scott also expressed an interest in participating. Other members of the BSC were encouraged to let Mr. Rothwell know if they are interested in participating. Mr. Rothwell also noted that the BSC should feel welcome to suggest that the NCHS form other topical workgroups if they see a need.

Someone asked whether NCHS already has people with expertise in NLP. NCHS has a contract with some experts at Georgia Tech and will also have a contract with the National Library of Medicine to take advantage of their knowledge and expertise. One of the first things that ASPE asked NCHS to do was identify the research questions. At the end of the month, NCHS is doing a panel at the National Academy of Sciences to help with that, but an important task for the BSC Workgroup would be to prioritize the research questions. In New York City, they have integrated a natural language programming API (IBM's Watson) into the mortality surveillance system to evaluate deaths resulting from legal intervention. Essentially, it scans the web to identify media stories, Twitter feeds, etc. that relate to the topic in order to capture the full set of cases that fall within the domain (in this case, deaths related to legal intervention). Someone else noted that he could suggest the names of some experts on NLP. Mr. Rothwell welcomed such suggestions (i.e., names of experts who might be willing to participate in the proposed BSC work group).

NCHS will likely form other workgroups in the near future, such as for NHIS and maybe also for NHANES.

Another person asked whether it would be possible for NCHS to collaborate with the FDA to use EHR data to identify adverse events related to drugs. NCHS has already been working with the FDA for several years to create a file that uses a primitive form of NLP to extract information from the text written on the death certificate to identify specific drugs. That file is currently available in the Research Data Center.

### **NHANES 2023: The Future is Now**

Kathryn S. Porter, M.D., M.S., Director, Division of Health and Nutrition Examination Surveys

Dr. Porter began by recognizing four people in the audience who might play an important role in the discussion: Dr. Fakhouri (Office of the Director within NHANES); Dr. Wong (who led the longitudinal feasibility study); Dr. Parker (who is helping with design issues for NHANES 2023); and Dr. Blumberg (Director of NHIS).

As background, she noted that the NHANES survey design concept has not changed in two decades. It comprises an annual sample of about 5,000 respondents, samples from only 15 counties in a given year, and includes both an in-home interview and exam at Mobile Examination Center (MEC). The sampling design is based on probability sampling with oversampling of subgroups (e.g., Asians, African-Americans). They use domain sampling to ensure that all relevant subgroups (e.g., by sex, age, income, race/ethnicity, etc.) are represented, which results in a total of 85 domains. The end result is a multi-stage, stratified, clustered design that covers the whole US. Yet, the screening process to select those 5,000 respondents is very intensive. It is a traveling survey: they have three MECs (each of which comprises four trailers); at any one time, two are actively working at a site and the other is moving to the next site. Consequently, NHANES has several limitations: the small number of primary sampling units (PSUs) results in a highly clustered sample; it is expensive; they have limited time at each location; and response rates are continuing to decline (i.e., NHANES hasn't met its target of 5,000 respondents for three years).

The current data collection contract ends after the 2021-22 cycle; NCHS needs a new contract for 2023 and beyond, which provides an opportunity to consider a redesign. Yet, time is limited: if the survey is to be redesigned, they need to post a statement of work by April 2020. In August 2017, they posted a Request for Information for innovative and "outside of the box" ideas for NHANES.

Among the suggestions, the first theme related to sample design: increase the number of PSUs (to decrease clustering), which would have a favorable effect on effective sample size. Currently, NHANES covers only 30 PSUs in a two-year cycle, but increasing the number of PSUs would require changes in how NHANES collects data.

The second theme centered on data collection. For example, why limit ourselves to MECs when self-propelled vans could cover more PSUs? Another idea was to use fixed clinics, which would be open for longer periods of time. A third suggestion was to combine in-home collections (e.g., physical measures, biologic specimens) on larger sample with more specialized examinations in MECs, mobile vans, or fixed clinics on a smaller subsample.

A third theme encompassed suggestions pertaining to response burden and encouraging participation. NHANES imposes a heavy burden on respondents (i.e., asking the respondent to travel up to an hour to the MEC and spend up to six hours on the interview and examination). An alternative would be to extract data from EHRs. Another suggestion was to use multi-mode collection (e.g., web-based collection instrument). Vendors recommended market segmentation: identify respondent groups and tailor recruitment materials accordingly. Also, NCHS needs to improve their outreach campaigns and incentivize respondents in stages. Currently, NHANES exam participants are paid \$125, but that incentive is not given until the participant completes the exam. Offering incentives at screening and at the household interview as well as at the exam could encourage participation.

Dr. Porter then reviewed some of the lessons learned from the NHANES longitudinal feasibility study. NHANES re-contacted 800 previous respondents who were originally examined in 2007-14. The response rates were excellent (i.e., well over two-thirds). One key to success was the use of local health representatives, who did both the interviews and exams. Because they were local (i.e., different representatives in each community), one advantage was that they could work simultaneously in different parts of the country. They were supervised remotely with retraining via web or skype as needed. Improved advance materials were also key: instead of using dense text, the materials featured race/ethnic-specific infographics that highlighted NHANES results that may be of particular interest to

that respondent. The materials made use of color, size, etc. to encourage potential respondents to open the mail. They also used staged incentives: the first mailing had a \$2 bill showing in the envelope window; the second mailing included a blank debit card. The study demonstrated that it is possible to train health representatives to collect in-home health measures (e.g., anthropometry, blood pressure).

### ***Multiple Possible Paths Forward***

NHANES has multiple potential paths for the future. First is, they could keep the current design with no changes. When response rates were above 70%, no one complained about the design. Yet, in the current climate of declining response rates, the status quo may not be an option. No matter what NHANES does, we may not be able to increase response rates within the current design. A second option would be to increase the number of PSUs, but the question is how to accomplish that. One possible strategy is a split design: home-based collection on a larger, more geographically dispersed sample with exams (in MECs, mobile vans, or fixed clinics) on a subsample. Another strategy would be to integrate NHIS and NHANES, which has been talked about for decades, but has proven very hard to achieve. Unlike NHANES which covers only 15 PSUs in a given year, the NHIS covers 300 PSUs.

### ***Work in Progress***

In the 2019 NHIS, Dr. Blumberg has included questions asking respondents about their willingness to do an exam. In NHANES, they are currently writing a new protocol to test staged incentives. NHANES staff are also exploring home-based phlebotomy and blood processing and plan to pilot test it in 2019. Finally, NHANES personnel are writing task orders that will seek vendors to: 1) conduct a follow-up study on non-responders (i.e., qualitative interviews: why are these individuals hard to survey?); and 2) critically evaluate the NHANES protocol for obtaining cooperation and offer recommendations that NHANES can then pilot.

### ***Core content NHANES 2023+***

Dr. Porter acknowledged that one cannot redesign a survey without knowing what you are going to measure. NCHS staff believe it is best to focus on components that only NHANES can deliver rather than duplicating other data collection. NHANES is ideally suited to measure variables that cannot be determined by other means (e.g., undiagnosed conditions). NHANES data are also frequently used to obtain population-based reference ranges. As NHANES considers changing content, it is important to think about preserving the ability to identify trends. Finally, they must acknowledge that NCHS sponsors only part of the survey; collaborators also pay for a substantial share, and thus they will need to determine what the collaborators are interested in funding.

NHANES must think about the core content they will commit to maintain. They believe that includes statistics on: overweight/obesity; hypertension; dietary intake and supplement use; prescription drug use; and specimen collection (i.e., blood and urine), including banking of those specimens. If NHANES did all of that, and only that, they may still be able to complete data collection in the home, but it would be very restricted. To include other components of key interest (e.g., lung function, mental health, cognitive function), NHANES must secure outside funding. For example, some of the measures require equipment that costs \$140,000 and a time-consuming process for reading the images and maintaining quality control.

With respect to avoiding duplication, the All of Us Research program that the National Institutes of Health is getting ready to launch plans to recruit 1M volunteers, obtain EHR data, and collect specimens. The study will probably include genetic sequencing. NHANES comprises a relatively small, national

probability sample, whereas All of Us will have a huge sample, but it is not based on probability sampling. NHANES has highly standardized measurements, whereas All of Us measurements may come from EHRs and will not be standardized.

Dr. Porter closed by posing questions for the BSC to consider: How much of a limitation is the current design (small number of PSUs, high oversampling)? Since the survey design is dependent on the statistics needed, how should we go about identifying the NHANES 2023 content?

### ***Discussion/Reaction by the Board***

The discussion focused on issues of content; increasing the number of PSUs; and the possibility of a longitudinal NHANES.

In terms of content, several people recommended carefully considering the research questions and in particular, the domains that NHANES aims to address. There were also many suggestions of topics that might be added to NHANES (i.e., genetics, cognitive function, mental health, social capital, social disparities, autism, use of technology and possible links with social isolation). Yet, someone also pointed out that NHANES already requires up to six hours of time from the respondent, and those who are willing to devote that much time may not be representative. It is important to preserve the comparative advantage of NHANES and ensure that it is done well. There are always tradeoffs (e.g., the Health and Retirement Survey already collects very good data on dementia). NHANES is the only survey with an examination. Do not add so many questions to the household interview that it jeopardizes participation in the exam. Modularizing the survey may help ease response burden and make it easier to adapt to future needs by adding or dropping modules as needed.

Many agreed that increasing the number of PSUs would provide better representation, more heterogeneity, and the geographic dispersion that is needed to explore the role of place. It may also help with response rate (e.g., reduces the effect of a particular gated community that shuts out the survey, mitigates the effect of a potential disaster that shuts down survey operations in one of the few selected PSUs). Some suggested that one could accumulate PSUs over time (i.e., temporal aggregation) to help reduce clustering, but others pointed out that timeliness is crucial (i.e., they cannot wait five years to get estimates). If we want more timely data, we need to reduce clustering. NHANES' problem is a combination of sample size and clustering: estimates often show big differences that are still not statistically significant. Different uses for the survey have different needs: for reference ranges, only the distribution is needed; for analytical uses, we need to be able to detect differences of substantive meaning. There was recognition that increasing the number of PSUs depends on funding and thus, the idea of a mixed design and/or integration with NHIS seems more cost-effective and efficient.

Some people expressed desire for a longitudinal NHANES, but others pointed to the extraordinary effort required to maintain a panel and keep them engaged. There were suggestions to rotate panels, rotate PSUs, and/or plan a limited period of engagement for each longitudinal respondent.

Mr. Rothwell reminded everyone of the major problem for NCHS surveys: declining response rates. We also want longitudinal data, but that compounds to problem of response rate. NCHS wants to bring NHANES and NHIS closer together, but we do not want to contaminate NHIS with the NHANES participation problem. NCHS must keep the response issue in the forefront.

**BSC Wrap-up**

Linette T. Scott, M.D., M.P.H.  
Charles J. Rothwell, M.B.A., M.S.

Dr. Scott thanked Dr. Van Wye for taking the lead on the work group related to Patient-Centered Outcomes Research (PCOR) and asked other BSC members to consider whether they are willing to participate. For the September meeting, Dr. Scott suggested that BSC members consider whether there might be other work groups that would be useful for NCHS to convene (e.g., related to redesign of NHANES) and bring those suggestions to the next meeting. She closed by recognizing the contribution of BSC members who are rotating off the Board (i.e., Dr. Raghunathan, Dr. McKeown, Dr. Lesser, and Dr. Manning) and thanked the NCHS staff for their presentations and sharing their work and concerns with the Board.

Mr. Rothwell acknowledged that it has been taking a long time to obtain approval for the appointment of new members to the BSC, but he hopes that he will soon be able to announce new members. NCHS has good candidates. He also encouraged BSC members to contact him via e-mail if, after the meeting adjourns, they have any further thoughts or can offer other guidance. He will ensure that any such suggestions are shared with everyone else. He concluded by thanking everyone and noting how much NCHS needs their help.

**Public Comment**

There was no public comment.

The meeting was adjourned at 12:10 p.m.

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

\_\_\_\_\_/s/\_\_\_\_\_  
Linette T. Scott, M.D., M.P.H.  
Chair, BSC

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9/27/18  
DATE