Department of Health and Human Services

Board of Scientific Counselors
National Center for Health Statistics
Centers for Disease Control and Prevention
January 11-12, 2018

Meeting Minutes

The Board of Scientific Counselors (BSC) convened on January 11-12, 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
Timothy J. Beebe, Ph.D. (by phone, Jan 11 only)
Charles J. Rothwell, M.B.A., M.S., Executive Secretary (NCHS Staff)
Prashila Dullabh, M.D. (by phone on Jan 12)
Darrell J. Gaskin, Ph.D. (Jan 12 only)
Sherry A. Glied, Ph.D.
Robert M. Hauser, Ph.D. (by phone, Jan 11 only)
Mary Ellen (Meg) Johantgen, Ph.D., R.N.
Virginia M. Lesser, D.Ph.
Wendy D. Manning, Ph.D.
Robert E. McKeown, Ph.D.
Ninez A. Ponce, M.P.P., Ph.D.
Trivellore E. Raghunathan, Ph.D.
Margo Schwab, Ph.D., Alternate Ex Officio Member, Office of Management and Budget (OMB)
Gretchen Van Wye, Ph.D., M.A.

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

January 11, 2018
Brenda Baker, NCHS
Stephen Blumberg, Division of Health Interview Statistics (DHIS)
Jim Crower, OAE (Office of Analysis and Epidemiology)
James Dahlhamer, NHIS
Tala Fakhouri, NHANES
Kathryn Forthall
Lee Anne Flagg, Division of Vital Statistics (DVS)
Alica Frasier, RTI International
Peter Meyer, Director, Research Data Center, Division of Research and Methodology

Jennifer Parker, Ph.D., Division of Research and Methodology
Kathryn S. Porter, NHANES
Tammy Stewart Prather, NCHS/OIS
Susan Queen, NCHS/Office of Planning, Budget and Legislation (OPBL)
Anjel Vahratian, DHIS
Anna Yalcovleva, NCHS/DRM (Division of Research and Methodology)

January 12, 2018
Bob Anderson, DVS
Verita Buie, NCHS/OPBL
Lorraine Escobedo, DVS
Lee Anne Flagg, DVS
Alica Frasier, RTI International
Debbie Jackson, NCHS/CPHDSS
Rose Li, Rose Li and Associates, Inc.
Don Malec, Division of Research and Methodology
Sam Notzon, NCHS International Program
Donna Pickett, NCHS/CPHDSS
Tammy Stewart Prather, NCHS/OIS
Anna Yalcovleva, NCHS/DRM

List of Abbreviations

ACS	American Community Survey
ADS	Associate Director for Science
BSC	Board of Scientific Counselors
CDC	Centers for Disease Control and Prevention
CDO	Chief Data Officer
CRVS	Civil Registration and Vital Statistics
D4HI	Data for Health Initiative
DHANES	Division of Health and Nutrition Examination Surveys
DHIS	Division of Health Interview Statistics
DRM	Division of Research and Methodology
DVS	Division of Vital Statistics
FSRDC	Federal Statistics Research Data Center
ICD	International Classification of Diseases
NCHS	National Center for Health Statistics
NCVHS	National Committee on Vital and Health Statistics
NHANES	National Health and Nutrition Examination Survey
NHIS	National Health Interview Survey
OAE	Office of Analysis and Epidemiology
OECD	Organization for Economic Cooperative and Development
OMB	Office of Management and Budget
OPBL	Office of Planning, Budget, and Legislation
RDC	Research Data Center
SNOMED	Standardized Nomenclature of Medicine
UN	United Nations

UNPD   United Nations Population Division
WHO   World Health Organization

Action Steps

- Offer recommendations for a new Director of the DVS (job announcement will be forthcoming in mid-January).
- OMB will be issuing a new Request for Information about new techniques for combining data from multiple sources and would like comments within 60 days.
- Mr. Rothwell will soon be sending out an e-mail regarding some of the issues raised during this meeting. He would like informal feedback from the BSC.
- When NCHS decides to advertise for the Director of NCHS, they will notify the BSC and ask for recommendations of potential candidates.
- Mr. Rothwell will be sending the BSC a link to the new National Academy Sciences report ("Federal Statistics, Multiple Data Sources, and Privacy Protection").
- The next BSC meeting will take place June 19-20, 2018.

Thursday, January 11, 2018

Presenters

Charles J. Rothwell, M.B.A., M.S., NCHS
Susan Queen, Ph.D., Director Office of Planning, Budget and Legislation
Tala Fakhouri, Ph.D., Non-Response Bias, NHANES
James Dahlhamer, Ph.D., Non-Response Bias, NHIS
Peter Meyer, Director, Research Data Center, Division of Research and Methodology
Kathryn S. Porter, M.D., NHANES

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 welcomed the group. Mr. Rothwell covered meeting logistics and asked Board members to introduce themselves and state any conflicts of interest.

NCHS Update

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

Mr. Rothwell provided an overview of the topics to be covered during this meeting: 1) Evidence-based policy making; 2) Non-response bias in NCHS surveys; 3) Research Data Center (RDC); and 4) Planning new content for NHANES and thinking about the future of NHANES.

First, in response to questions, he assured the BSC that the current administration has not affected decision making at NCHS compared to previous administrations.

Mr. Rothwell reviewed some of the NCHS's successes. First, he believes the redesign of the National Health Interview Survey (NHIS) was done well. NCHS felt the need to reduce the number of survey questions to make it more focused, easier to administer, and hopefully, improve response rates. In the end, Mr. Rothwell thinks they have a workable solution that will yield a substantial reduction in the length of the survey. NHIS was planning to go into the field in January of this year with the new survey, but that will not happen because their collaborators at the Census Bureau need more time to put the data collection system together. The revised NHIS will be in the field in 2019. Second, in 2017, the National Health and Nutrition Examination Survey (NHANES), publicly released data from the 2015-16 cycle as well as individual reports on hypertension, obesity, and cholesterol, which is a significant achievement for a survey of this magnitude. Third, NCHS has made improvements in vital statistics, much of it driven by the states but also owing to changes that the DVS at NCHS has made to its systems. NCHS now issues quarterly reports (they have already published reports for the first two quarters of 2017, which is faster than some states). NCHS is also preparing monthly reports on drug overdose events and tomorrow will be publishing data for June 2017 (including the preceding 12 months), which will cover the nation as well as individual states and will report on specific drugs for selected states. Thus, NCHS has made great progress from a lag of two to three years in reporting on vital events. Fourth, NCHS issued 26 data briefs last year and 17 longer health statistics reports as well as publishing *Health US* and the *2020 Healthy People Midcourse Review* (in total about 75 publications for the year in addition to data releases). He announced three new American Statistical Association fellows: Jennifer Parker, Joe Fred Gonzalez, and Don Malec.

Mr. Rothwell acknowledged that NCHS still does not have a budget yet. The federal government is under continuing resolution; there will be a government shutdown on January 19th if Congress does not settle on the budget. He expects NCHS's budget to be down about $5M but noted that NCHS has additional funding from interagency transfers. He admits they do have a significant budget problem (although it does not owe solely to the current budget climate), which became critical early last fiscal year. To maintain their data efforts, NCHS did not do any hiring last year. Consequently, NCHS staff is down almost 20% and the remaining staff has been taking on responsibilities senior to their position (for no additional pay). Soon, NCHS plans to promote some individuals internally and conduct some external hiring. In mid-January, they will be announcing a search for a new Director for the DVS. The incumbent (Delton Atkinson) will be retiring at the end of this year. NCHS would like to hire a replacement before Delton leaves so that he can provide guidance to the new person. Ideally, NCHS would prefer a candidate with state-level experience, but they do not have any specific candidate in mind.

Mr. Rothwell notified the BSC that this will be his last year as NCHS Director.

The challenges that he views ahead for NCHS are: a) no funding for innovation (i.e., must work within existing systems); b) declining response rates; c) their role as a Federal Statistical Agency sometimes inhibits their ability to act as an innovator; d) data linkage needs to be improved and expanded (which creates a host of confidentiality problems); and e) they need a National Birth Index (which could be as rich as the National Death Index).

Update on Legislation Relating to Evidence-Based Policy Making

Susan Queen, Ph.D., Director, Office of Planning, Budget and Legislation

Dr. Queen reviewed some of the history on this topic. On September 7, 2017, the Commission released its final report "The Promise of Evidence-Based Policy-making." On November 15, 2017, the U.S. House approved HR4174 (by voice vote). On the positive side, this bill took several of its major aims from the recommendations in the Commission's report, but the language in the legislation is prescriptive.

HR 4174 includes 3 titles:
- Title I: Federal Evidence Building Activities, which establishes agency Chief Evaluation Officer position and the Interagency Council on Evaluation Policy, which is modeled on the Interagency Council on Statistical Policy
- Title II: OPEN Government Data Act, which establishes agency Chief Data Officer (CDO) position and CDO Council
- Title III: Confidential Information and Statistical Efficiency

Dr. Queen noted that some of the 14 functions of the CDO appear to overlap with the realm of the statistical agencies. Indeed, the legislation states that the CDO can delegate any of these responsibilities to the Statistical Director. None of the representatives on the CDO Council will be required to have statistical expertise.

The Congressional Budget Office estimated the cost of this legislation at $75 million over 2018-22 and projected that it will require eight additional employees across 26 agencies. Yet, the legislation did not include any additional funding. Dr. Queen suggested that having a dedicated staff to deal with all these requirements may be costlier than anticipated.

On the positive side, she noted that the legislation provides some opportunities (e.g., demonstrates the value of data; encourages increased collaboration across agencies and externally; establishes standards for data sharing; provides more transparency/accountability; sets up a new framework for access to and use of data). Nonetheless, it presents several challenges as well (e.g., managing high expectations for government-wide coordination; new positions and agencies may duplicate or conflict with existing ones; legislative barriers to data sharing have not yet addressed; conflicting policy and legal interpretations; constraints on agency resources and capacity constraints to carry out these new requirements without additional support).

Discussion
A suggestion was made to point out these issues to Nick Hart (Bipartisan Policy Center) who is working with the Senate on these bills. If the purpose of these efforts is to promote better integration of agencies and data, it may serve as an opportunity for NCHS to integrate administrative data from other sources.

Discussion turned to questions regarding the degree to which the legislation is consistent with the recommendations of the commission. A board member suggested that the Ryan bill (HR4174) was not intended to do everything the Commission recommended, but rather to demonstrate that the legislature supports the work of the commission and to build on the work already underway within the 13 statistical agencies.

Under the House Bill, OMB will form a committee over the next year to discuss a Data Service and what it should entail. It is important to note that the bill has not yet dealt with the restrictive legislation that prevents agencies/entities from working with one another.

Non-Response Bias in NCHS Surveys
Jennifer Madans, Ph.D., Associate Director for Science, NCHS: Moderator
Tala Fakhouri, Ph.D., Non-Response Bias, NHANES
James Dahlhamer, Ph.D., Non-Response Bias, NHIS

Dr. Madans noted that survey non-response has been a major issue for a long time. NCHS is not alone with this challenge. If response rates cannot be improved, then NCHS needs to consider what can be done about response bias. It raises several questions: How do we document response bias? How do we make sure that response bias is documented consistently across all agencies? Are there new ways of dealing with it? If response rates are low, can we still consider a sample "nationally-representative"?

NHANES
Dr. Fakhouri reviewed the trends in response rates to nine federal US surveys (three of which are conducted by NCHS). Between 2000 and 2014, response rates generally declined. Around 2006, there was a sharper drop in response, although it is not clear why. Some have hypothesized that declining response relates to changes in the survey landscape (e.g., more gated communities and gatekeepers; increase in anti-government sentiment, which may be related to fears about immigration status as well as anti-establishment sentiment). The relationship between nonresponse and bias is generally inverse (i.e., higher response is associated with lower bias), but that is not universally true (e.g., some surveys have low bias despite low response). The downward trend in response is evident among all racial/ethnic groups, but response rates tend to be highest for African-Americans and Latinos and lowest for Asians. Between 2007 and 2016, response rates among African-Americans declined from 77%

to 63%; among Latinos, from 77% to 62%; among whites/others, from 72% to 49%; and among Asians, from 57% to 48%.

There are five approaches to addressing non-response bias: 1) compare response rates across subgroups; 2) use sampling frame data or supplemental matched data (i.e., compare sampled respondents to the frame, but this is difficult because NHANES does not have a rich data frame); 3) compare estimates to other sources (e.g., NHIS); 4) make post-survey adjustments to weights; and 5) study variations within the survey.

The remainder of Dr. Fakhouri's presentation focused on the last approach. Her analyses are based on the "Continuum of Resistance" model, where she assumes that late participants (i.e., those requiring 10 or contacts before agreeing to participate) are more like non-responders than early participants (i.e., those who responded after only a few contacts). Unfortunately, NCHS does not have any direct information about non-responders. In the 2015-16 NHANES, the range of attempts to elicit participation was 2 to 49 with a positive skew. Dr. Fakhouri divided respondents into tertiles: one third responded in 1-5 contacts ("early" responders); the second third required 6-9 contacts; and the remaining third required 10 or more contacts ("late" responders).

Early vs. Late Responders
Dr. Fakhouri found that late responders were more likely than early responders to be sent a refusal letter, live in a household that included children, need an interpreter, and speak Spanish. In terms of demographic characteristics, late responders were more likely than early respondents to be younger than age 60 and non-white or Latino, but there was little difference between the groups in income. Early responders were more likely than late responders to self-report cardiovascular disease and cancer, but there was little difference in self-reported smoking. Based on measured clinical indicators, early responders were also more likely that late responders to have diabetes, hyperlipidemia, and hypertension, but those differences disappeared with adjustment for age. Measured obesity levels did not differ significantly by number of contact attempts. In sum, compared with early responders, late responders tended to be younger, more likely to be non-Latino black or Latino, have children, and healthier. These results suggest that survey sample may be biased towards sicker individuals within the population.

Comparisons of Estimated Health based on NHANES vs. NHIS
When Dr. Fakhouri compared estimates between NHANES and NHIS, she found NHANES respondents were less likely to self-report "excellent health" and more likely to report having a medical condition. The difference between these two surveys in self-reported health has grown over time: in 2001-04 differences were much smaller, but by 2011-14, the percentage reporting "excellent" health was nearly twice as high in NHIS (29%) as it was NHANES (16%). The gap in the percentage reporting any medical condition has been more stable over time (i.e., approximately 10 percentage point difference between NHIS and NHANES). Thus, NHANES respondents appear to be sicker than NHIS respondents.

Dr. Fakhouri highlighted two models for non-response. In the first, "Common Cause Model", data on certain observable conditions (that affect both the survey variable and the propensity to participate) are missing at random and thus, the estimates can be adjusted. In the second, "Survey Variable Cause Model", the data are not missing at random (i.e., survey variables such as health affect the propensity to participate) and thus, it is much more difficult to address.

In conclusion, she notes the following:
- Response rates have declined over the past decade.
- It is not clear whether NHANES respondents are truly sicker than NHIS respondents or whether they are simply more aware of their health.
- Some estimates based on NHANES may be biased, but the extent of bias is unknown and difficult to estimate.
- NCHS does not have any direct information about non-responders; thus, it is unclear how to estimate the magnitude of the bias.

The questions the BSC should consider:
- Should we incorporate number of contacts into weight adjustments?
- Should we need to conduct a non-response follow-up study?
- How should we communicate the bias to data users? (given that different evaluation techniques yield different results regarding the level of bias)

NHIS
Dr. Dahlhamer reviewed response rates to the NHIS over the period from 1997 to 2016. Response was highest for the family module and lowest for the sample adult module, but declined over time for all modules. By 2016, response rates were down to about 68% for the family module and less than 55% for the adult module. The analysis he presented focused on bias over the last four years (2013-16).

First Approach: Study Variations Within the Survey
In his first approach to analyzing nonresponse bias, he split respondents into quintiles based on their response propensities. Again, the underlying assumption is that low response propensity cases are proxies for non-responders. He analyzed 19 health outcomes (e.g., insurance coverage, disability status, general health status, diagnosed diabetes, smoking, etc.). He examined the pattern of estimates, compared the low propensity quintile with the rest of sample, and measured relative bias. Finally, he evaluated whether the final weight (after adjusting for non-response and post-stratification) changed the estimate. Response propensities were modeled using a variety of predictors based on interviewer observations and measures from the census planning database (i.e., characteristics of the census tract, which represents a proxy for neighborhood). Ideally, he wants to include predictors that are associated with both response and with key health outcomes.

The results from this analysis indicated that the high propensity group was less likely than the low propensity group to report excellent/very good health, suggesting that the NHIS may underestimate the health of the population. The high propensity group was also more likely to smoke than the low propensity group, but there was no difference in reported asthma. Weighting had little effect on the estimates, but comparisons of the final weighted estimates with estimates based on the low propensity quintile suggest that non-responders may be healthier and less likely to smoke that the NHIS sample. Overall, across all 19 health outcomes, most (13-14 depending on the year) showed some evidence of non-response bias. For about 60% of the outcomes, the weights appeared to improve the estimates. Yet, when he compared the low propensity group with the rest of the sample, there was a significant difference for 14 out of 19 outcomes in 2013. In later years, there were fewer significant differences (9 out of 19 in 2016), suggesting that the bias may have improved over time. Estimates of the average absolute relative bias also declined steadily over time.

Second Approach: Compare to Similar Estimates from Other Sources
In the second approach, he compared the NHIS estimates for health insurance coverage and disability status with estimates based on the American Community Survey (ACS). With respect to disability status, the NHIS estimate was higher than ACS and over time the discrepancy has widened (by 2016, about 15.5% based on NHIS vs. less than 13% based on ACS). In contrast, the estimated percentage of the population with health insurance is more similar between NHIS and ACS.

Summary
Dr. Dahlhamer found evidence of non-response bias for two-thirds to three-quarters of the outcomes examined. Final weights did not always compensate for the bias. Although the bias appears to have declined in recent years, it is not clear whether the decline is real or simply an artifact of the methodology. He noted that the magnitude and direction of the bias depends on the outcome, which makes adjusting for it more complicated. His planned next steps are to make modifications to the response propensity model, seek new auxiliary variables, explore other approaches (e.g., regression trees), and examine whether bias differs by subgroup.

Discussion/Reaction by the Board
NCHS staff noted that there is no established standard for nonresponse bias analysis; all the methods are based on untestable assumptions. NCHS is under pressure to release the data, but it is also obligated to provide information about response bias (which may delay releasing the data). There is no standardized definition of "bias." There are problems not only of response bias, but also measurement differences.

A question was raised about the possibility of linking to administrative data (Medicare, Medicaid) to obtain more information about the non-respondents. Staff explained that NCHS generally does not have the necessary identifiers to make such linkages and there are issues of consent.

Discussion followed about "responsive adaptive design." It was noted that while this approach did not diminish the response rate, it was not clear anything was gained. NCHS conducted some similar experiments with NHIS: the result was a reduction in response rate with no apparent improvement in representativeness. The key problem is difficulty finding auxiliary variables that predict both non-response and health outcomes.

The issue of media coverage was raised, with NCHS staff noting, anecdotally, that interviewers say that media exposure is very helpful (e.g., response rate is better if the target respondent has just read something in the paper about NHANES). Interviewers often ask NCHS for news clippings about the survey.

Discussion turned to a question about incentives. NHIS does not offer (monetary) incentives; their earlier experiments showed that incentives may increase completion (i.e., reducing the number of respondent who failed to complete the entire survey), but have little effect on overall response rates. In the case of NHANES, the incentive for completion of the examination (>$100) may seem high but it is important to consider that it is not a lot of money given the amount of time the exam requires. NHANES does not offer incentives at the screener or interview stages. The possibility of NHANES should consider adding an incentive for the screener (given that they lose 7-8% at the screener) was raised.

Discussion concluded with comments from board members that proper adjustment for non-response bias requires direct information about the non-respondents, and subgroup analysis of non-response should examine foreign-born vs. US born (in addition to race/ethnicity).

Update on the FSRDC and the NCHS RDC

Peter Meyer, Director, Research Data Center, Division of Research and Methodology

Mr. Meyer briefly reviewed the history that led to the establishment of the Federal Statistics Research Data Center (FSRDC). NCHS developed its first Research Data Center (RDC) in 1998 to provide the research community access to data that included indirect identifiers. It was modeled on the Census RDC, formed in 1997. In 2006, the Census Bureau began developing a network model (i.e., the server could be accessed from other labs across the country) and they offered to share this model with NCHS. By 2016, the Census Bureau was operating 22 labs while NCHS had 4 labs. The expansion of the RDC system is a result of three main factors: 1) growth in the amount of external data becoming available; 2) realization that some data were more sensitive than previously thought; and 3) more merging of external contextual data (i.e., information about where the respondents live) with individual-level data, which increases the risk of identification.

The FSRDC was formed when the Census Bureau, OMB, and National Science Foundation began to consider including more agencies in the collaboration. It required two years of meetings to come to an agreement regarding governance issues. There was a lot of contention between the institutional partners; the data owners all want the same outcome, but they have different rules, priorities, and standards.

Federated vs. Confederated Model
Mr. Meyer prefers a confederated model (i.e., one which allows different partners to accomplish the same outcome but by different means) rather than a federated model (i.e., one which requires that all involved parties follow the same protocol). However, many of the other agencies want a federated model. Mr. Meyer is deferring to their preferences because he wants the FSRDC to be a success. As other agencies begin to see the difficulties inherent in the Federated Model, he suspects they may become more amenable to a Confederated Model.

Discussion/Reaction by the Board
A BSC member asked about the benefits to NCHS of this partnership, wondering if it might be beneficial to NCHS to be able link our data with other agencies' data. Staff pointed out that NCHS has long recognized the benefits of linking their data with other data sources, but there are problems of conflicting legislation that creates barriers to sharing data. There are a lot of issues to address, particularly when there are external users who want to access to the data.

Discussion followed regarding the problem of ensuring that the data remains confined to the RDC. One suggestion was the possibility of using something like block-chain capability to ensure that the data remains within the RDC. It is easy to merge data together, but much more difficult to decide how those data can be used (i.e., when linked matched files are created that are highly identifiable, the user cannot be allowed to remove those files from the RDC). The need to restrict potentially identifiable data creates an additional problem: how do you make that research replicable by other researchers?

A BSC member remarked that officials in California have worked through the governance issues over data sharing and linked data files by requiring the user to obtain approval from each organization whose data are involved before the user can obtain the linked dataset. The Vital

Records Department is key because those data are part of most of the linkages requested. It may be helpful to contact the state registrars to find out what they have done.

Planning Content in NHANES: Challenges and Next Steps

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

Dr. Porter reassured the BSC that NHANES will continue to do the standard measurements. The purpose of this presentation is to explain the process by which NHANES plans and adds new content. Proposals for new content are by open invitation. NHANES begins accepting letters of intent two years in advance. Those letters of intent are evaluated in terms of six criteria: public health significance, scientific merit, appropriateness, feasibility, ethical issues, and financial considerations. Based on that evaluation, NHANES selects the ideas for which they will request a full proposal. Such proposals are accepted 18 months prior to the NHANES cycle in question. Pilot testing begins 12 months in advance of the cycle, and NHANES staff begins writing manuals and translations 9 months prior to the data collection cycle.

Challenge #1: Doing the Same Amount of Work with Fewer Staff/Contractors
In 2011-13, NHANES had a total of 82 staff, trainees, and contractors, but that number is down to 65 in 2017-18. Currently, they have only one vacancy they can fill. Current efforts focus on: a) preparing and releasing data files from NHANES 2015-16 (the first wave of data files was published in September, but there are many additional data files yet to be released); b) overseeing data collection for NHANES 2017-18; c) planning for NHANES 2019-20; and d) examining the feasibility of a NHANES longitudinal study (i.e., they have already re-contacted 800 participants from 2007-2014 NHANES as a test of procedures).

Challenge #2: Lots of Interest in Adding New Content to the 2019-20 Cycle
NHANES has a lot of collaborating agencies (i.e., currently more than 24 funding collaborators). For FY2017, NHANES cost $38M, but less than 40% of the funding was covered by Division of Health and Nutrition Examination Surveys (DHANES); 41% came from collaborating agencies and 21% from carryover of FY2016 funds.

Dr. Porter reviewed proposed ideas involving redesign of the sample (e.g., oversample adolescents—which would have cost $6M; oversample pregnant women—which would have cost $18M; special study of infants younger than 24 months—which would have cost $64M over four years and required screening 38,000 households whereas NHANES currently screens about 13,000 households). Those ideas were not adopted because of cost and logistical constraints.

NHANES did accept several other ideas that involved additions to the physical examination (i.e., new measurements for visual acuity, balance, functional hearing—hearing words in the presence of background noise, cognitive functioning—which entails bringing back a 10-minute test based on word recall that they have done in the past). Unfortunately, the funder for the new vision measurements withdrew and thus, that addition had to be dropped. They plan to add the other new content in 2019-20. They are also piloting blood sample collection in infants younger than 12 months of age.

Various post-exam additions were considered but could not be accepted because of formidable challenges and concerns about response rates. Those rejected proposals included: In-home semen collection (because of interest in infertility); in-home stool collection (for gut microbiome); in-home saliva collection at 6, 12, 18 & 24 months post-exam (for oral HPV infection status).

Two post-exam proposals are still under consideration: 24-hour urine collection (to monitor sodium intake); and 24-hour ambulatory blood pressure monitoring.

Challenge #3: New Content in Environment of Declining Response Rates
In 2015-16, the response rate at the screening stage was 94%, household interviews were completed by 61%, and 59% were examined (the figures in 2011-12 were: $\geq$98%, 73%, 70%, respectively). In 2017, 93% completed screening, 54% completed an interview, and 52% participated in the examination. Although the participation rate for any single new measurement may seem high (e.g., participation in the oral rinse collection for HPV was 77%), the overall cumulative response rate from screening through examination is much lower (i.e., in this case, less than 40%). Dr. Porter questions whether an overall response rate of 40% can even be considered nationally representative.

Summary of Challenges and Strengths
In sum, NHANES faces several challenges (i.e., fewer staff, fragile funding, declining response rates), but also maintains many strengths (i.e., highly dedicated staff, single source of national data based on direct physical measures). She cited strong interest in new content as both a challenge and a strength. NHANES' next steps include consideration of a longitudinal NHANES study and possible redesign of the cross-sectional NHANES. Also, NCHS must continue to demonstrate need for NHANES. A new Precision Medicine Initiative (now called "All of Us") aims to create the largest data resource ever (one million people volunteering to provide health data). Dr. Porter still sees a valuable role for NHANES as a nationally-representative source of data including measured clinical markers. She concluded: we aim to do what we do well, rather than compete with other efforts.

Discussion/Reaction by the Board
Discussion of strategies for improving response rates began with a board member who reported on an experiment in which language was added to the initial letter to suggest a potential participant complete the screening survey online to "help save the government money" which improved the response rate by 6%. Staff replied that NHANES has just added multi-mode screening so that respondents can complete the initial screening online. Another person noted that the biggest drop-off in the response rate is at the interview stage, whereas NHANES is still getting a 93% response rate at screening. Survey staff acknowledged that while screening response remains high, the amount of time required to screen respondents has increased greatly over time. A board member questioned the explanation of an increase in gated communities as a major cause of declining response, citing the lack of any increase in the number of gated communities over the period in question. Staff explained that the introduction of the Asian oversample has resulted in more fieldwork being conducted in advantaged neighborhoods (which are more likely to be gated). In addition, a BSC member noted an increase in homeowner's associations acting as gatekeepers (e.g., neighbors complain and call the police). While emphasizing the value of the comprehensive health exam may be beneficial, staff noted that people may still be daunted by the time commitment (6-7 hours to complete the NHANES exam component). Public leadership that supports the effort has a big effect on response rates: NCHS needs ambassadors in the community that people trust. NCHS does a lot of work to advertise NHANES, but there are still two big problems: general distrust and people not wanting to devote the time to it. As people gain more information about their health from other means, they value the NHANES exam less.

Other discussion focused on alternative funding sources for these surveys. A BSC member noted that most collaborators appear to be government agencies but wondered if

pharmaceutical companies might be interested in the research related to infertility. Staff explained that they cannot accept funding directly from for-profit companies. Pharmaceutical companies also may be less interested in funding content because they do not get any proprietary access to the data. NHANES releases the data publicly to everyone at the same time, however funders do get a preview datafile for data quality evaluation 60 days in advance.

A question was posed about the possibility of NHANES moving to a mixed design (i.e., a more dispersed sample for household interviews, whereas the exam component is based on a clustered sample, possibly partnering with private clinics). Staff emphasized the challenge of ensuring all the protocols are done consistently across different private labs/clinics. Long ago NCHS staff had the idea of using NHIS as the interview component of NHANES, but they just could not figure out how to make it work. Another alternative is to make the interview components of NHIS and NHANES more similar. Unfortunately, efforts over the past 10 years towards that goal have not been unsuccessful.

Someone asked how individual NHANES respondents are informed about their own data. Staff explained that respondents receive a report of various exam components on the same day; laboratory assays are reported as they come in and letters are then sent to participants with values above a clinical threshold; participants are asked to call NHANES 30 days after their exam to learn the results for sexually-transmitted infections; and finally, the participants are sent a comprehensive report two to four months post-exam.

Discussion concluded with a BSC member commenting that there are two things that are important about NHANES: 1) nationally representative sample; and 2) it provides respondents with information they know as well as some information that they do not know. Many companies are now doing wellness programs: could such programs provide a substitute source of data by NCHS partnering with those companies? Staff noted that as part of the longitudinal study, NHANES is obtaining medical records for some individuals (which they could compare with the self-reported information).

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

Friday, January 12, 2018

Presenters

Donna Pickett, MPH, RHIA, Chief, Classification and Public Health Data Standards
Bob Anderson, Ph.D., Chief, Mortality Statistics Branch, DVS
Sam Notzon, Ph.D., Chief, NCHS International Program
Don Malec, Ph.D., Mathematical Statistician, Division of Research and Methodology

Call to Order

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

Dr. Scott welcomed the group to day two of the meeting and proceeded with another brief round of introductions (including statements of conflict of interest). Then, she introduced Ms. Pickett.

Update On ICD-11

Donna Pickett, MPH, RHIA, Chief, Classification and Public Health Data Standards
Bob Anderson, Ph.D., Chief, Mortality Statistics Branch, DVS

Ms. Pickett explained that the purpose of this presentation was to inform the BSC about the expected transition to ICD-11. The U.S. has been using ICD-10 for mortality since 1999, although the use of ICD-10-CM (for morbidity purposes) is much more recent.

Why Do We Need ICD-11?
- ICD-10 is now clinically outdated and fails to capture all the new knowledge and understanding of disease processes.
- Structural changes are needed to some chapters.
- The coding system must be adapted to an electronic environment.
- The coding system needs to capture more information for morbidity applications.

The goals of the ICD-11 revision are to ensure that: the coding system functions well in an electronic environment (i.e., it will be digital rather than print only; it will link with the Standardized Nomenclature of Medicine - Clinical Terms (SNOMED-CT), which forms the basis of electronic health records); it is coherent and serves multiple purposes (i.e., not just mortality but also morbidity, primary care, clinical care, etc.; it must be consistent and maintain interoperability across various uses); and will have mechanisms that simultaneously create other language versions (i.e., so other countries are not developing their own language translations).

Phases and Timeline for Development
Phase 1 (Design) began in 2007 with planned completion in 2015, but it has been delayed. The World Health Organization (WHO) now plans to release an implementation version in June 2018. Phase 2 (Consolidation) began in 2015. There is now more consensus, and WHO is working towards a full implementation package including training materials, transition guides, etc. Unlike in the past, WHO is putting more thought into international comparability rules for morbidity. Phase 3 (Implementation) will begin with the June 2018 release of the implementation version. This phase also involves forming the advisory committees: Medical and Scientific Advisory Committee and Census Scientific Advisory Committee. Phase 4 (Regular Maintenance) is planned to begin in 2021. Ms. Pickett showed an animated flowchart to demonstrate the complicated process that proposals for updating the ICD will undergo.

Field Trials
Field trials are new to this version and will test the fitness of ICD-11 to multiple purposes. The goals are to ensure comparability between ICD-10 and ICD-11; increase consistency and reduce errors; assess feasibility (ease of use) and reliability (consistency); evaluate utility (added value) for both mortality and morbidity; and test function across a variety of settings (primary care, general health care, research).

ICD-11 Tools
See also https://icd.who.int/dev11/l-m/en

The ICD-11 will include a variety of tools for coding, browsing the codes, proposal, review, translation, and mapping (including to/from ICD-10). For more information, see also the FAQs on the WHO website (www.who.int/classifications/icd/revision/).

ICD-11 Implementation Challenges (with Respect to Morbidity)
After WHO releases the implementation version in June 2018, countries will adopt the new version as they see fit. In the past, many countries have delayed adoption. One set of challenges for ICD-11 are copyright issues, which can have vendor implications for the cost and use in the US. A second challenge is the WHO intention to limit development of national modifications, the implications of which are unclear for countries like the US that have previously updated ICD twice a year based on new information about diseases. A third challenge is that many systems and standards will need to be revised to accommodate ICD-11.

ICD-11 Implementation Challenges (with Respect to Mortality)
Dr. Anderson reviewed the challenges with respect to mortality. DVS will not proceed with implementation until ICD-11 demonstrates fitness of purpose, which is the first priority. Once DVS begins implementation, the first challenge will be revising the automated coding system. DVS is pooling resources with countries who are using IRIS software (Australia and many of the European countries), but he expects revision of the decision table for selecting underlying cause of death will take about four years. A second challenge is the need to adapt to cluster coding and extension codes. Cluster and extension coding will be more extensive in ICD-11 than it is in our current automated coding system. Third, DVS must retrain coders (i.e., there will be a significant change from ICD-10 in the structure of the codes), which will require development of coder training materials and electronic tools. Finally, DVS needs to complete a comparability study (i.e., bridge coding) that will provide a cross-walk between ICD-10 and ICD-11.

Historical Timeline for ICD-10-CM
Ms. Pickett reviewed the historical timeline for the implementation of ICD-10-CM (morbidity). Evaluation for fitness of purpose spanned four years (1994-97), followed by seven years (1997-2003) of National Committee on Vital and Health Statistics (NCVHS) hearings. There was a Final Rule in 2009 and again in 2012, followed by an interim Final Rule in 2014. She expects evaluation of ICD-11 for U.S. purposes may span from 2018 to 2021 (or maybe 2022), followed by NCVHS hearings from 2021 through 2027. Beyond that, she cannot project the timing of rulemaking.

Discussion
Discussion began with a board member questioning what actual improvements we expect to gain from this new version. Staff emphasized two important justifications for ICD-11: the evolution of medical knowledge regarding the etiology of certain diseases; and the need for better integration between the ICD coding system and the coding of clinical information, which is

now based on SNOMED. ICD-10 was developed in the early 1980s and reflects medical knowledge at that time. Consequently, ICD-10 is very out of date. Responding to a question about the potential of continuing to update ICD-10. Staff explained that some of the requested revisions could not be implemented within the structure of the ICD-10 (i.e., updating was not possible given the limits to expansion within the structure of ICD-10). Notably, ICD-11 codes will comprise 7 alpha-numeric characters rather than the 4 characters allotted in ICD-10.

With respect to ICD-11 codes for socioeconomic determinants of health (e.g., ICD-10 has a code for homelessness), staff explained that a new so-called "extension" chapter may include some codes for socioeconomic determinants. Furthermore, the ICD is not a static system and thus, codes may be added later. Someone inquired how an individual could suggest changes to the ICD. Staff explained that there is a proposal platform and a mechanism for providing comments on the WHO website; it requires registration on the website, but anyone can register and make proposals/comments.

A request was made for a realistic projection of the timeline for implementation of ICD-11 for mortality purposes. Staff believes WHO will in fact release the implementation version in June 2018. At that point, DVS would begin implementation work, which could take 3-6 years, depending on resources. Full implementation of ICD-11 for mortality in the U.S. will require a minimum of five years (i.e., 2023 at the earliest).

International Activities at NCHS

Sam Notzon, Ph.D., Chief, NCHS International Program

Dr. Notzon acknowledged that although his office is small and has a limited budget, international activities are well-distributed across the different divisions of NCHS. An important benefit of these international activities is that the process of consulting with others can improve comparability. The challenges his office faces include: limited staff and budget, growing tasks and many vacancies in personnel, small and shrinking international travel budget, and the inability to implement some electronic solutions (e.g., GoToMeeting or Zoom cannot be used at NCHS because of data security concerns).

He outlined three types of international activities in which NCHS engages:
1) Activities of specific interest to NCHS;
2) Participation in activities of international organizations; and
3) Relations with health statistical organizations in other countries.

Activities of Specific Interest to NCHS
He provided some examples of NCHS's multilateral collaborations: international collaborative effort on injury statistics and automating mortality statistics (i.e., IRIS has become the new global standard for automated coding); Washington Group on Disability Statistics (i.e., which has developed question sets to promote comparability). For example, he noted that NCHS benefited from the IRIS software because it has become language independent and works well across different languages. He also reviewed some examples of NCHS's bilateral collaborations: US-Canada interchange meetings (i.e., annual meetings, which most recently led to plans for a joint study on the opioid crisis); NHANES with HANES-type surveys; US-Mexico border activities.

Participation in Activities of International Organizations
Why do we care about the activities of the international organizations? We care because these international organizations set the standards. Being involved in the process helps promote comparability. NCHS is involved with many organizations within the United Nations (UN) including the WHO, the Pan American Health Organization, the UN Population Division (UNPD, to whom NCHS has an obligation to provide data annually), UNICEF (i.e., birth registration, disability), the UN Statistical Commission (i.e., annual meetings, one of which focused on disability and resulted in the Washington Group on Disability Statistics), and the International Labor Organization. NCHS also engages with the Organization for Economic Cooperative Development (OECD), which requests from the U.S. an extensive set of health data, much of which comes from NCHS and thus requires a lot of NCHS staff time. NCHS also cooperates with the OECD on a healthcare quality study.

Relations with Health Statistical Organizations in Other Countries
NCHS maintains relationships with the health statistical organizations in other countries, which helps NCHS stay informed about activities elsewhere. Dr. Notzon mentioned the Visitors' program at NCHS, but acknowledged that new security rules have curtailed it somewhat.

Indigenous Health Measurement
He reviewed the NCHS collaboration on Indigenous Health Measurement, which involves the US, Australia, Canada, and New Zealand (who share a similar colonial history and have similar indigenous health and health data issues). The group has monthly conference calls, periodic workshops, and produces journal articles and country reports. Dr. Notzon highlighted the huge indigenous health disparities. For example, the gap in life expectancy at birth between indigenous and non-indigenous groups is more than 7 years in New Zealand and Australia; we do not have an estimate for the U.S. because we lack reliable data for indigenous population. In addition to gaps in mortality (particularly infant mortality), there are large disparities in suicide rates and prevalence of diabetes, obesity, substance use, and malnutrition. The major data issues are under-identification; unreliable data; a small, dispersed population (i.e., making it difficult to design a sample that will produce reliable estimates); and increasing indigenous self-identification. The group just had a meeting in Atlanta, and members want to raise awareness of these issues among an international audience. Thus, the group will be conducting a special session at the International Group for Indigenous Health Measurement annual meeting and will publish a special issue in the International Association for Official Statistics journal.

Bloomberg Data for Health Initiative (D4HI)
The D4HI is a four-year program aimed at improving Civil Registration and Vital Statistics (CRVS) systems and the use of health data. It involves 20 developing countries from Africa, Asia, and Latin America, and is funded by Bloomberg Philanthropies and the Department of Foreign Affairs and Trade in Australia. The responsibility of NCHS has been to help improve CRVS systems in selected African countries and assist with ICD coding in all countries. That first task is difficult because the countries do not always see the value of CRVS systems; it can be challenging to get different ministries within the country to collaborate with each other; these countries have limited resources; and any improvements made must be sustainable.

Discussion
Attempts to develop these types of partnerships at academic survey centers have proved to be expensive because the money generally flows from the U.S. to other countries. For a state university, it is very difficult to establish those sorts of relationships. A BSC member suggested

that it might be better to talk with private universities, who may have a vested interest in developing international markets.

Someone else acknowledged that it is always difficult to obtain funding for international activities from the US government. It is important to be *very specific* about what we have learned from these collaborations (e.g., we had this problem _____ for X years, then we met with Y and they had tried _____ successfully; so, we tried it and it worked; OR they had tried ___ and it failed, so we learned not to repeat their mistake). Staff commented that working with international groups may not bring in money, but it has the advantage of helping promulgate NCHS work around world.

A Discussion on Methods – The Handling of Trends in NCHS

Jennifer Madans, Ph.D., NCHS, Associate Director for Science
Don Malec, Ph.D., Mathematical Statistician, Division of Research and Methodology

Dr. Madans explained that NCHS has an informal council of Associate Directors of Science (ADS) across the center to foster consistency across the center. To date, they have had three work groups chaired by an ADS. The first was a report on presentation standards, which was led by Jennifer Parker. Today's presentation focuses on the work generated by the group on trend guidelines, which was led by Don Malec. Like the presentation standards report, these guidelines apply primarily to their large publications. Because these publications include many long tables, the process for identifying trends must be, to some degree, automated. However, these guidelines should also apply to NCHS's smaller publications, which feature more targeted analyses.

She impressed upon the BSC that these are guidelines <u>not</u> standards. Rather, the guidelines are intended to highlight the issues to which the analyst should pay attention. Ultimately, the data analyst must be able to justify the choices that s/he makes. For example, with Joinpoint regression, the choice of parameters can lead to huge variation in the results. Yet, there are no clear rules about how to set those parameters. NCHS must also keep in mind: what is the role of the statistical agency in doing these analyses? When we report on trends, how do we protect the integrity of the results as unbiased?

Dr. Malec outlined three types of trend analysis commonly used at NCHS:
1) Linear regression for population prevalence (e.g., fitting a least square or weighted least squares model using weights to represent the population or sample variance)
2) Specific comparisons (e.g., to a benchmark year)
3) Curves (e.g., polynomial regression, linear splines such as Joinpoint regression, log transforms, smoothing)

Guidance Document
The Guidance document compiled by his group has three main sections: guidance (i.e., highlights 12 issues the analysis should address); examples (i.e., worked-out examples using NCHS data systems); and technical (including 9 appendices).

Issues Highlighted in the Main Guidance Section
1) Choosing the time period and providing a rationale (or testing robustness to alternatives)
2) Using all time points versus only the beginning and ending point to identify a trend (make sure to look for non-linearity)

3) Pooling data across years/cycles (for regression modeling, it is better not to group data because ungrouped data yield more precise estimates)
4) Choosing values to represent observed time points (the guidelines recommend using mid-points of time intervals)
5) Survey Data: always use the survey analysis tools (sampling weights, corrections for correlation within primary sampling units, etc.)
6) Vital Records data: involves with population-level statistics rather than a sample, and thus, it can be beneficial to aggregate data
7) General considerations for doing trend analysis: important to check for non-linearities (e.g., explore polynomial models, restricted cubic splines)
8) Binary Outcomes (linear vs. logistic scale)
9) Trend analysis with covariates
10) Cochran-Mantel-Haenszel Test of Trend (i.e., non-parametric test; their group has found that the results are generally no different than regression on coded ordinal data)
11) Locating "joins" (i.e., changes in the lines fit with linear splines) at or between observed time points: the guidelines recommend restricting changes in the line to be <u>at</u> an observed time point rather than between observed years
12) Joinpoint Regression (which is heavily used at NCHS)

What the Guidance Section Does Not Cover
The Guidance section does not include information regarding: choice of software; time series methods; age-period-cohort models; causal analysis; superpopulation models (i.e., extrapolating beyond the observed data); nonparametric trend analysis (i.e., there is no software or guidance for that yet); and model fitting.

Illustrative Example for Choosing Model-Fitting Criteria in Joinpoint Regression
In the presented example, the dependent variable was the percentage of the population without health insurance. First, the analyst must decide how many joins to allow. Dr. Malec showed that when one uses the "permutation test criterion", the number of joins selected by the Joinpoint regression procedure is somewhat erratic (e.g., when he allowed three joins, the procedure selected only one real join/change; when he allowed four, it picked two; but when he allowed five joins, it selected only one join). Next, he showed results using Bayesian Information Criterion as the test criterion; in this case, as he allowed more joins, the procedure selected more joins up to seven joins/changes. Thus, the resulting curve matched virtually every perturbation in the data.

Alternatively, one can forgo any modeling and simply estimate 95% confidence intervals for each year. Then, one can compare those results to what was obtained using Joinpoint or a polynomial model. All these models are based on an average fit across all data points, but sometimes what the analyst wants to know is not the overall trend, but where are the biggest trends. Joinpoint is not well-suited for that purpose.

Dr. Malec reported that the publication is almost complete. The document will provide worked-out examples demonstrating what to do, including what <u>not</u> to do. It will also include a detailed discussion of Joinpoint, which is not available elsewhere.

Discussion by the Board
One person started the discussion by posing a crucial question: how does one decide which model is "best"? In uninsured example, one model says one thing (i.e., continued decline through the current year) while another model says something different (i.e., flattened out

around 2015). That is, the results differ with respect to the trends and where the change occurred. Someone else asked how Joinpoint compares with other types of non-linear models (e.g., Weibull). The guidelines should include assessing the assumptions of the model being used. Staff emphasized that a major advantage of Joinpoint is the fact that it is very flexible. The problem is it is not always clear how to assess model fit; the guidelines recommend that the analyst test sensitivity to alternatives.

There was also a discussion of using Joinpoint for trend analysis versus investigation of causal process. A board member asked about the cost of allowing more nodes in Joinpoint: one could concoct an explanation for every perturbation, but trend analysis does not try to understand the causes driving the overall trend. Staff cautioned that we do not necessarily want to match all the perturbations. NCHS data are so good that the results can be very precise and thus, very noisy. Furthermore, those minor perturbations may be more sensitive to the parameter choices. In general, NCHS simply wants to describe the overall trend. The BSC member further asked: what if we have a prior expectation (e.g., we know that some policy change was made in year t, and we want to know what effect it had)? Staff replied that if the analyst has a prior expectation, s/he can test that; however, it is important that s/he explain up front why it is being tested. Another board member argued that it is important to distinguish between two roles: 1) explaining the underlying causes of a trend (not agnostic) versus 2) describing whether there is a trend (agnostic). To maintain an agnostic approach, it is better to use a more general model (e.g., splines, smoothing using all the data) that is less sensitive to the analyst's choices. In this person's view, Joinpoint regression is designed for policy-level analysis; for description, smoothing/splines are more agnostic. Someone else commented that in New York, the statistical agency simply compares the current year with the previous year and with 10 years prior. The benefit to that approach is that it is more objective. The danger with using more sophisticated modeling is that the results may be interpreted as supporting a particular explanation. Another person wondered whether jack-knifed confidence intervals (i.e., removing one primary sampling unit at a time) could be used to put confidence intervals around the Joinpoint curve.

Someone asked where this type of trend analysis is reported. Staff explained that in NCHS's large publications (where there are lots of big tables), there are asterisks on the table indicating whether or not there is a significant trend (but there is no statement in the text about trends). In Data Briefs and other smaller reports, there are statements in the text about the long-term trend and trends within subgroups, although the publication shows the underlying data as well. NCHS could simply describe the data, but inevitably, people will ask whether the change is significant. Someone else emphasized that Joinpoint is very sensitive to all the perturbations in the data. Staff commented that NCHS cannot use Joinpoint for survey data (because the procedure cannot accommodate survey design correlations), although it is fine for vital statistics data.

A board member asked where the guidelines would be published. Staff replied that the guidelines will be published as an NCHS report, but NCHS would be willing to share it with the BSC before it is finalized if anyone is interested.

A BSC member noted that she would like to see a similar set of guidelines for confidentiality.

BSC Wrap-up

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

Dr. Scott reported that a new Request for Information will be coming out from OMB about new techniques for combining data from multiple sources. Comments are due within 60 days.

Mr. Rothwell noted that he will soon be sending out an e-mail to the BSC soliciting their informal input regarding some of the issues raised during this meeting. If NCHS decides to make a major change, they will form a formal subcommittee.

He reassured the BSC that he will remain at NCHS for the next BSC meeting in June and may continue as Director of NCHS through January 2019. He will notify the BSC when NCHS decides to advertise for the Director position (i.e., will be asking if BSC members are interested in the job or know someone who might be appropriate).

He thanked everyone for attending this productive meeting. He plans to send all of them a link to the National Academy of Sciences report entitled *Federal Statistics, Multiple Data Sources, and Privacy Protection*, https://www.nap.edu/catalog/24893/federal-statistics-multiple-data-sources-and-privacy-protection-next-steps.

He would also like to hear from the BSC about any improvements needed with respect to NCHS's communications with the Board. NCHS is planning to hire someone who will be responsible for communications, and he wants to outline the priorities for that person.

Public Comment

A board member asked whether interested BSC members can be notified about press releases. Staff explained that NCHS does not issue press releases. The media obtains updates from the NCHS website. However, staff offered to send an e-mail update every two weeks to any BSC member who signs up to receive it.

Staff emphasized that NCHS needs good people in government. BSC members may be asked if they would be willing to tell other people about the benefits of working for NCHS.

Another BSC member noted that there is a lot of work already being done using distributive models to access data (e.g., the Food and Drug Administration's Mini-Sentinel, the Patient Centered Outcomes Research Institute's PCORNet). Those working examples might be useful to the work being done at NCHS.

The meeting was adjourned at 12:20 p.m.

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

_____/s/_____   _____5/14/2018_____
Linette T. Scott, M.D., M.P.H.   DATE
Chair, BSC