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Department of Health and Human Services

Board of Scientific Counselors National Center for Health Statistics Centers for Disease Control and Prevention

September 24-25, 2015

National Center for Health Statistics 3311 Toledo Road Hyattsville, MD 20782

Meeting Minutes

The Board of Scientific Counselors was convened o September 24-25, 2015 at the National Center for Health Statistics I Hyattsville, MD. The meeting was open to the public.

Committee Members

Present

Raymond S. Kington, M.D., Ph.D., Chairman

Wendy Baldwin, Ph.D.

Virginia S. Cain, Ph.D., Executive Secretary

Michael Davern, Ph.D.

Ana Diez Roux, M.D., Ph.D., M.P.H.

Mark Flotow, M.A.

Christine L. Himes, Ph.D.

Genevieve M. Kenney, Ph.D.

Virginia M. Lesser, Ph.D.

Robert E. McKeown, Ph.D., FACE

Javier Nieto, M.D., M.P.H., Ph.D.

Trivellore Rahunathan, Ph.D.

Margo Schwab, Ph.D. (via phone a.m.)

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

Katherine K. Wallman, Ex-Officio, OMB (via phone p.m.)

Not Present

Hermann Habermann, Ph.D. Thomas LaVeist, Ph.D.

Wendy D. Manning, Ph.D.

Senior NCHS Staff Members

Irma Arispe, Ph.D., OAE

Delton Atkinson, Director, DVS

Clarice Brown, M.S., Director, DHCS

Sherry Brown-Scoggins, Acting Director, OIT and OIS

Virginia Caine, Ph.D., Dir. Extramural Research and Exec. Secretary for the BSC

Marcie Cynamon, Director, DHIS

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

Donna Pickett, Chief, Classification and Public Health Data

Kathryn Porter, M.D., Director, DHNES

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

Charles Rothwell, Director, NCHS

Michael Sadagursky, Management Officer

Nathaniel Schenker, Director, ORM, and Deputy Director, NCHS

Presenters

September 24, 2015

Raynard Kington, M.D., Ph.D.

Charlie Rothwell

Robin A. Cohen, Ph.D.

Kate Brett, Ph.D.

Naman Ahluwalia, Ph.D., D.Sc.

Walter Suarez, M.D., M.P.H.

Michael Davern, Ph.D.

Nathaniel Schenker, Ph.D.

Presenters

September 25, 2015

Paul Sutton, Ph.D.

Bob Anderson, Ph.D.

Margaret Warner, Ph.D.

Robert McKeown, Ph.D.

Nathaniel Schenker, Ph.D.

Donald Malec, Ph.D.

Raynard Kington, M.D., Ph.D.

Virginia Cain, Ph.D.

Others

Bob Anderson, DVS/MSB

MaryAnn Busch, OAE/ASB

Yinong Chong, NCHS Robin Cohen, DHIS Traci Cook, OPBL Marcie Cynamon, NCHS Kim Daniels, DVS/RSB Renee Gindi DHIS John Hough, CPHDSS Debbie Jackson, NCHS Katherine Jones, CPHDSS Olga Joos, DVS Hashini Kayuna, OAE/ASB Deanna Korzan-Moran, DHANES Don Malec, ORM Hanyu Ni, NCHS Jim Nowicki, NGC-Atlanta Susan Queen, NCHS/OPBL Chesley Richards, CDC/OPHSS Lauran Rossen, OAE Carl Scheffey, DVS Alan Simon, OAE Jessica Simpson, DHIS Angel Vahratian, DHIS Kassi Webster, OPBL

MEETING SUMMARY September 24-25, 2015

ACTION STEPS

 A document describing the new TCPA ruling and its impact on the organization will be prepared to make recommendations to the Secretary of Health and Human Services.

Thursday, September 24, 2015

Welcome, Introductions and Call to Order

Raynard Kington, MD, PhD, Chair, BSC and Charles Rothwell, Director, NCHS

NCHS Update

Charles Rothwell

BSC members were welcomed and staff updates were announced. Budget highlights included: The 2016 budget was reported including the additional \$6.5M received from Patient Centered Outcomes Research Institute (PCORI) which will be distributed throughout 25 states to improve timeliness and data quality. Additionally, in an effort to

foster partnerships with universities and others, a competitive process has been established to develop a small grants program in research and health statistics. Administrative updates were announced relative to building space and location. Selected NCHS accomplishments described included: The National Conference on Health Statistics; data collection and presentation innovation such as the data visualization gallery currently available to provide trend information based on indicator of choice; and access to statistical information via FastStats, a downloadable app. Furthermore, NHANES will release 2013 and 2014 data in October; the DNA repository for the bio-specimen program will open in 2016; and 2016 quarterly reporting will include a variety of high risk indicators as well as high risk births.

<u>Discussion</u> NCHS is continuing its effort to develop partnerships at the high school and university level. Discussion ensued about plans to engage high school students in a competition designed to encourage their participation in STEM programs. Suggestions to make use of available resources to offer the activities virtually thereby increasing participation in STEM education and hosting summer camp competitions were well received. A dialogue concerning survey alignment to improve data collection focused on the departmental process. Also, the history of NCHS was discussed in relation to seeking a mechanism to plan for the future as in an "innovation center," to explore new ideas.

<u>Update on NHIS Insurance Estimates</u> Robin A. Cohen, Ph.D., DHIS

The health insurance estimates release occurred six weeks earlier than in the past due to priority given to new processing measures. Timeliness was achieved without compromising quality. A new reporting format was designed, which is more figure driven to explain the data. Also produced in the quarterly data report is an additional set of tables: age groups, race, ethnicity, sex, and poverty, which also include estimates of exchange plan enrollment. Preliminary microdata files will now be produced four times a year as a result of the expedited process.

In the first three months of 2015, the number of persons found to be uninsured at the time of interview was at 9.2% (or 29 million). Using more recent data for three different measures: uninsured at the time of interview, uninsured for at least part of the past year, and uninsured for more than a year, there is a steady decrease to 6.5%. Additionally, 66.5% of persons under 65 had private coverage including 3.6% who obtained coverage through health insurance market place or state-based exchanges at the time of interview.

<u>Discussion</u> Analysis by race and ethnicity show the highest amount of uptake was among Hispanic individuals, while by the largest group that take up the exchange plans are those who are between 100-200% of the federal poverty level.

Timeliness combined with technology has improved data quality having field edits available. Discussion continues addressing comparisons to other government surveys as well as other non-governmental services. The strength of NHIS is that it provides a tremendous amount of health insurance detail. Mr. Rothwell proposed a series of questions regarding alignment of surveys, health insurance and capturing the data to measure the value of health coverage and its impact on health status. Various entities have relevant information to utilize for this purpose. Dr. Kington suggested that NCHS can take the leadership role in gathering both governmental and non-governmental entities who are considering downstream consequences of insurance changes. There is an ongoing evaluation of the survey to reduce the content. Additionally, a review of Healthy People objectives is necessary to ensure that they align with the changes in health insurance.

NCHS Data Access Tools

Kate Brett, Ph.D., Detail, Office of the Center Director

Dr. Brett provided an overview of the project conducted by Dr. Brett and Mr. Rothwell in which data access tools were reviewed in the context of various system attributes including purpose, audience, incorporated data, cost, and usage. Additional analysis focused on assessing other statistical agency tools to create a more user friendly experience. A summary of access tools available on the website was presented depicting query system functionality ranging from systems that target non-statistical users to those with knowledge of statistics.

Conclusions: all NCHS data systems are represented in the interactive table systems, but not all have query systems and whether or not that is valuable needs to be determined; queries are difficult to create and maintain; each tool is unique which requires separate learning curves; and tools created outside of the data systems tend to be topic oriented and not data oriented. Following the analysis, a recommendation was made to have clear and complete meta-tags on all of the data systems. Next steps consist of writing descriptions of each tool to provide users information that will help direct them navigate the process.

<u>Discussion</u> Discussion ensued regarding overlap of the tools. Each tool is unique and different. The only overlap is in Healthy People 2020 and the Health Indicators Warehouse. Ideas were exchanged as to how to engage the research community for feedback on usability and increase website marketing. Conversation continued concerning complications in using NCHS' data sets, current systems ease of access, and external systems development. Currently, there is exploration around analytics as a service to provide tools that run the data rather than making the data publicly releasable.

There is a need to take a strategic approach in reviewing what the purpose of NCHS is in providing information. The center cannot support all of the different systems and an

alternative means must be considered. Although the discussion provided input, a discussant suggested perhaps having data visualization tools as a place to import data on a quarterly or annual basis.

<u>Dietary Guidelines for Americans (DGA), 2015: Role of NHANES</u> Naman Ahluwalia, Ph.D., D.Sc., Nutrition Monitoring Advisor, DHNANES

Dietary guidelines – Dietary guidelines are the science-based federal recommendations on healthy eating that can be adopted by the public. Information was presented on the production of the dietary guidelines. The Dietary Guidelines Advisory Committee (DGAC) independently produced a report that received an overwhelming response during the public comment phase. The report is currently in review by the federal committee. An example was given as to how the press highlighted an element from the committee report, which does not reflect the guidelines, as they have not been completed.

For the first time as a special section, the committee covered caffeine consumption for children and adults. Also new is the Birth to 24 Months (B-24) and Birth to Pregnancy Project (B-24/P), which supports the development of dietary guidance for this age group. This new process focusing on B-24/P will address topics such as; what is human milk and infant formula feeding; what should go in the formula; is this consistent with growth, development outcomes and intake. They will examine linking practices to outcomes from existing data. Because this is the first time, the federal group is compiling a working document to provide to the DGAC in approximately two years. It is likely that NHANES will be contacted to provide important data that the DGAC can use for further analysis helping to build guidelines for babies.

Since 1960, NHANES has been monitoring the nation's nutrition and health by collecting data on: dietary intake; dietary supplements; consumer behavior; and physical activity. In order to preface the discussion about the controversy involving NHANES data, a thorough description explaining the NHANES dietary data collection process was given. In assessing what people eat over a two day period, the Automated Multiple-Pass Method (AAMP) is used to validate what energy is consumed and what is expended. AMPM has been standardized and validated against reference methods called doubly labeled water method. Additionally, databases to analyze what people report consumed such as the Food and Nutrient Database for Dietary Studies (FNDDS), keep current with food change as they relate to nutrient quality.

A group of researchers from the University of South Carolina used one day of NHANES dietary intake data to estimate what people are eating. Using energy intake from one day intakes they related to energy output. As a result of their calculations, they reported a gap between what NHANES reports as energy intakes versus their reported energy expenditure, which turned into a media frenzy as NHANES results were questioned.

Reactions to the study weighed in from epidemiologists, vital statisticians, and media as well. Of those who joined in on the discussion, they reported that the findings are not novel, particularly when you don't use multiple days of data. While the researcher's findings were not new, there was concern with regard policy implications to the NHANES dietary data quantity. Dr. Ahluwalia and team collaborated to write an article that has been accepted, clarifying what NHANES collects, and how it collects in the context of a broad multi-purpose survey. Finally, the value of NHANES dietary data was reiterated as a useful tool as in eliminating iron deficiency.

<u>Discussion</u> Discussion ensued with regard to the funding from Coca Cola for this study and the level of restrictions on publications. Other comments were raised concerning various ways in which the data can be leveraged in a manner to make it useful for policy evaluation and natural experiments to learn what policies might work. Also, NHANES can do more to understand the data by using it to link to nutritional environment data on the community level.

New Directions for National Committee on Vital and Health Statistics (NCVHS) Walter Suarez, M.D., M.P.H., Chair, NCVHS

With health information policies as an overall theme, the history of HIPAA was presented depicting a timeline examining the committee configuration as well as the role of the National Committee on Vital and Health Statistics. The responsibilities include: advising the Secretary on improving interoperability as it relates to the recent 21st Century Cures legislation approved by Congress; hosting committee and sub-committee meetings as public forums for gathering feedback from the industry; and generating a periodic HIPAA report to Congress at least every other year accumulating information in terms of changes, updates, modifications and adoptions of standards. The presentation provided a detailed account of the work of the committee which is segmented into four domains: standards; population health; privacy, security and confidentiality; and data access and use.

Accomplishments included: participation in drafting the 21st Vision for Health Statistics; participation in the National Health Information Infrastructure; and publishing tools related to community health data.

In addition to hosting several functions for cross collaborations, new works by domain include:

Standards - operate in current responsibilities as a review committee to the provisions in the Affordable Care Act; monitoring ICD-10; issuing a new HIPAA report next year;

Privacy and Security - monitoring the implementation of privacy and security in terms of HIPAA law; and focusing on topics such as data segmentation and data provenance.

Population health - developing an identifier set of health data indicators at the community level.

Vital and Health Statistics – review the standardization and the interaction of public health agencies with EHRs to capture and exchange information.

<u>Discussion</u> Current activities include identifying and organizing the domains. The data standards group has developed a number of crosswalks to address the challenges transitioning ICD-9 to ICD-10. A question that was raised about the future of precision medicine. Dr Suarez responded by explaining that this is an area of possible cross collaboration between the Board and the National Committee in moving precision medicine beyond the molecular level into population health and other levels.

<u>Telephone Consumer Protection Act (TCPA)</u> Michael Davern, Ph.D., BSC Member

A quick summary was given describing the changes in the interpretation of the Telephone Consumer Protection Act (TCPA) and how that has impacted the survey organizations. The FCC issued a Declaratory Ruling that provided the definition of an auto dialer and added the ability to revoke consent to dial cell phones. Emphasis was made clarifying the potential implications for survey research. Two distinct impact issues are as follows: phone surveys – complying with TCPA may increase cost by approximately 30-60% depending on what type of survey and how it would be conducted; field surveys – it may decrease the response rate for all surveys as this method is used for follow up and to verify data.

<u>Discussion</u> The legal aspect is directly related to the impending retroactive lawsuits that can be filed. Additionally, the Census is in legal discussions with the FCC to get an exemption to the ruling. Other Federal agencies are coordinating their efforts with the Census. To date, there has been no formal petition filed.

Federal TCPA Update

Nathaniel Schenker, Ph.D., Deputy Director, NCHS

Dr. Schenker reiterated his suggestion that the interested Federal agencies, should address this issue collectively. With regard to data, sample bias can be introduced as the demographics of cell phone only customers differ from the general population.

<u>Discussion</u> Although the intent is to address the massive use of non-human intervention dialing, the unintended consequences regarding health surveys increase. An extended conversation ensued deliberating the role of the committee that included: writing a letter to the Secretary for advisement purposes; addressing cell phone number recycling; distinguishing hard refusals; maintaining an 80% response rate; and categorizing qualitative differentiation in cases of follow back.

Friday, September 25, 2015

Welcome, Introductions and Call to Order

Raynard Kington, MD, PhD, Chair, SC and Charles Rothwell, Director, NCHS

<u>Mortality Timeliness Initiative and Surveillance Activities</u> Paul Sutton, Ph.D., Deputy Director, Division of Vital Statistics (DVS)

An overview was presented to include: the results from the 2014-2015 flu season pilot that has since been designated as the primary system for surveillance in the upcoming flu season; the initial phase of the disaster-related mortality surveillance project; timeliness improvements (e.g., electronic death registration system improvements); update on projects funded by PCORI; and existing challenges with outstanding data from a small number of states and the impact of pending data (example given of drug overdose). Goals over the next 12 months are to evaluate additional causes of death, adding estimates based on birth data and to establish a routine release schedule.

<u>Discussion</u> The annual statistical files were described, noting that files close without receiving updates. However, new surveillance tools have the ability to continue to receive updates and process for states that provide the information. Timeliness improvements were acknowledged. The frequency of releasing reports is based on a cost-benefit analysis. Although funding is available to states to improve timeliness, some states are already doing well. Additionally, this funding has been used to address unique issues encountered at the state level, as all states are encouraged to submit a proposal.

Mortality Data Quality – Improving Cause of Death Data Bob Anderson, Ph.D., Chief, Mortality Statistics Branch, DVS

A summary of how the National Vital Statistics System collects data was given. The distinction between diagnostic errors and certification errors were introduced. An example to illustrate poor cause of death certificate reporting was given. Errors of this nature affect death statistics, which is further complicated by declining autopsy rates. Is there a federal role in funding a certain percentage of autopsies to improve cause of death reporting? While promoting federal funding to increase the number of autopsies is important, another aspect involves timing that would be impacted by obtaining family permission. Ill-defined conditions, illogical sequences, and the exclusion of external causes of death were detailed as three main problems with cause of death certifications.

Current initiatives include: developing E-learning training attached to E-credits, as previous modules were not 508 compliant nor did they provide continuing education credits; developing a cause of death app; improving VIEWS to provide real-time guidance to physicians as they are completing death certificates; disseminating training

materials through organizations that directly interact with physicians; using funding for hiring, and conducting studies in an effort to progress the initiatives.

<u>Discussion</u> It was agreed that an exception is needed for the 508 training tool compliance. However, to include the E-learning training on the education and training website, 508 compliance is required.

Medical Examiner/Coroner Projects and Initiatives Margaret Warner, Ph.D., Injury Epidemiologist

A focus of DVS is to promote the quality and consistency in death investigations. An overview of the medical examiner's approach to death investigations, and responsibilities of medical examiners/coroners was followed by an explanation regarding variation in state laws relative to the medical/legal death investigation system. Dr. Warner collaborated with a lawyer from the Public Health Law Program who used a series of questions to guide research into the enabling statutes by state. Enhancing the efficiency of data collection involves reviewing the EHR death registration state wide systems, which lack interoperability among jurisdictions. DVS is currently reviewing different death investigation tools; coordinating efforts with federal partners and other stakeholders, reviewing death in custody and homicide statistics with DOJ, and car crash statistics with DOT. Drug overdoses, as a leading cause of death, is the focus of concern regarding: diagnostic issues, certification process, forensic science (medical/legal death investigation), and the qualifications and training o the medical death investigators.

<u>Discussion</u> An idea to sponsor a conference focusing on improving the data quality on vital records was raised. Additionally, a request was made to revive the Medical Examiner and Coroner Sharing Program. Small sample sizes were problematic with the efforts to have hospital data link up to death certificate data at the national level. However, further consideration can be given to exploring how linking the data, from a program administration perspective, can be more informative. Mr. Rothwell will follow up with requests to states to determine their capability to link hospital data, vital records, and claims data. While there was much debate surrounding how to delineate natural causes versus external causes of death, the discussion shifted concentration to the value and challenges of systematically collected information. The main problem is the need for proxy reporting of personal characteristics about the deceased as opposed to self-reporting.

<u>Using NCHS Data for Teaching</u> Robert McKeown, Ph.D., BSC Member Nathaniel Schenker, Ph.D.

An overview was presented on the many uses of NCHS' data, tools, and downloadable resources for teaching in secondary school or university level. Examples of class

activities and research projects were also provided. In an effort to foster a more savvy population with a better understanding of health statistics, Dr. McKeown suggested the following: to facilitate sessions on teaching and using the resources at the data conference; to host synchronous and asynchronous workshops on how to use the data and resources to improve health.

<u>Discussion</u> Discussion ensued about existing resources that may be available. Although the role of NCHS does not include creating recommended tools, an invitation was extended to Dr. McKeown to develop an outline that would help with understanding what is needed in the creation of an instructor's manual.

<u>Development of Trend Analysis Guidelines at NCHS</u> Donald Malec, Ph.D., Associate Director of Science Office of Research and Methodology

These guidelines were developed out of a need to systematize and coordinate the variety of trend analysis that comes through the Center. Using descriptive statistics, the aim is to document issues in trend analysis that may cause controversy. Several examples were given highlighting the specific patterns that would raise interest. Trend analysis incorporates analysts experience and knowledge with statistics and outsider statistics. NCHS analyzes trends to evaluate changes overtime or changes in policies or programs. Methodological issues include how to choose a timeframe, the choice of transformation, and the choice of model.

<u>Discussion</u> Analysts have access to all available data. As a result, discussion included the use of micro-level data to estimate properly. Other comments referenced the use of modeling correlations for the analysis of long-term and short-term trend analysis.

BSC Wrap-up Raynard Kington, M.D., Ph.D. Virginia Cain, Ph.D.

Dr. Kington briefly reviewed the three outcomes from the meeting:

- There will be a letter developed by the board to the Secretary
- Teaching possibilities
- NCHS Website and Resources enhancement

Public Comment None.

The meeting was adjourned at 11:55 a.m.

To the best of my knowledge, the foregoing summary of minutes is accurate and complete.	
<u>/s/</u>	<u>January 27, 2016</u>
Raynard S. Kington, M.D., Ph.D. BSC Chair	Date