

Department of Health and Human Services

Board of Scientific Counselors

September 13-14, 2012

NCHS Auditorium
3311 Toledo Road
Hyattsville, MD 20782

Meeting Minutes

The Board of Scientific Counselors was convened on September 13-14, 2012 at the National Center for Health Statistics in Hyattsville, MD. The meeting was open to the public.

ACTIONS

- A conference call of the BSC's NHANES DNA subgroup will soon be arranged to establish clear subgroup goals and to determine follow-up to the cognitive interview discussion of September 13, 2012. This will occur prior to the NAS Workshop. The outcome of the call will be emailed to BSC members for feedback.
- A BSC member will serve on a larger workshop planning group.
- Dr. Himes volunteered to participate in the Health Indicators Warehouse working group.
- Reconsideration of the review process (an agenda topic for the next BSC meeting) will require one or more conference calls in order to frame the discussion. Dr. Schwab agreed to participate in the conference calls and others who have been previously involved will be contacted.

The next BSC meeting will take place on February 7-8, 2013.

Thursday, September 13, 2012

Welcome and Call to Order

Lee Cornelius, Ph.D., Chair, BSC and Edward Sondik, Ph.D., Director, NCHS

NCHS Update

Edward Sondik, Ph.D.

Dr. Sondik provided NCHS budget and legislation overviews and updates (FY 2012 and 2013), noting a tight budget climate and level funding in 2013. A history of NCHS appropriations was outlined. Legislation affecting surveys was highlighted (examples given). Departing BSC board members were recognized and NCHS staff updates announced. Highlights of the 2012 conference were presented. The NHANES Mobile Exam Centers in Washington D.C. and Maryland were described. In NHIS, testing of sexual identity questions is progressing. Future

plans include testing home biomarkers in collaboration with NHANES. A web-based component to NHIS is planned. Healthcare survey changes were outlined. A positive collaboration with the Office of the National Coordinator for Health Information Technology was mentioned; and challenges of using electronic health records data were acknowledged.

A Vital Statistics update indicated preliminary data output within nine months; a new five year contract with the states; and consideration of a new model law and birth certificate regulations by HHS. The ICD-10 implementation date, delayed by one year, has been moved to October 2014. More than 111 NCHS publications are planned for 2012 (examples given), noting an extraordinary focus on IT and data. ASPE and CDC updates included staff changes at ASPE; a small area data project with ORM; and a change in CDC's accounting system.

Discussion Conference abstracts are on the website. It was noted that multiple years of fetal deaths will be published although not in the preliminary data release. When fetal deaths are up-to-date, the intention is to put them on the same schedule as births and deaths. It is hoped that NCHS will establish a workgroup that addresses the challenges of coordinating data in electronic health systems with other systems. The HHS Data Council should be involved. At present, there are no plans to do data collection with prisoners although information about healthcare provided in prisons is ongoing.

National Survey of Family Growth Post Review Update

William D. Mosher, Ph.D., Statistician, Reproductive Statistics Branch, DVS

Dr. Mosher presented a status report since the last BSC review (April 2010). The three most urgently recommended tasks have been accomplished, to include awarding a new contract for the 2010-2020 survey to the University of Michigan Research Center; getting the survey into the field again; and releasing the 2006-2010 data files. How the NSFG works was reviewed, noting a 2006 change in interviewing that has resulted in larger samples, more frequent data releases and a large increase in interviewees. A brief history of NSFG was provided as were sample sizes and response rates. Field work challenges and accomplishments were delineated. The Review Panel's seven additional recommendations and NSFG's responses were outlined.

Discussion There was no discernible trend over 2006-2010, noting a one percent decrease in response rate during the first year. Percentage points are likely to move up with interviewer experience. Although blood spots are not an option in the current contract, two other options were mentioned. Extending the age range would improve marriage, cohabitation, infertility, infertility services and adoption data. A suggestion was made to include new reviewers with built-in opposition (such as someone who had rejected use of the survey). Reviews change based upon different organizations. Increased survey costs and decreased survey response rates are of concern and should be addressed. What kind of self-evaluation and data collection should be built into programs prior to review panel intervention is another consideration. In addition, the Panel might examine response rates across programs – a good topic for a larger discussion about future direction of reviews. Individual program quality is very important, noting that certain questions are larger NCHS concerns (e.g., engaging communities that can use the review and supporting its use).

The status and content of Spanish interviews were outlined. The use of separate and independent samples of men and women were questioned in that the same questions asked of partners would increase ways to examine reliability and validity of responses. However, the most compelling reasons to include men are public health-related, which require independent

samples. To include couples would require a longitudinal design, which would become a different study.

Office of Research Methodology Review and Discussion

Nathaniel Schenker, Ph.D., Assoc. Director, ORM

Roderick Little, Ph.D., U.S. Census Bureau and University of Michigan

Hermann Habermann, Ph.D., BSC Liaison

Alan M. Zaslavsky, Ph.D., BSC Liaison

Dr. Schenker presented a brief overview of what the Office of Research and Methodology (ORM) does; its organizational structure; four basic components; vision; initial goals of the new director; a non-random sampling of recent ORM activities that include research and technical assistance and work in the scientific community (examples given); accolades in 2012; and challenges and opportunities.

ORM's four core areas were delineated as were primary activities and internal and external collaborations. Communication within ORM has increased with regular staff meetings and streamlined administration. It was noted that increased strategic planning at the senior staff level would be beneficial. Staff is encouraged to publish research and peer-reviewed articles. The greatest challenges rest with staffing and personnel, to include budget concerns, succession planning, recruitment of necessary talent and statistics and survey methodology to address NCHS's methodological needs. When working with NCHS, it is important to "market" ORM; balance research and technical considerations; and engage other NCHS units in research. Broad areas for research expansion must be determined.

Dr. Habermann also raised concerns about staffing in addition to operational challenges. Dr. Zaslavsky addressed issues of continuity and the balance between internal and external NCHS work. In addition, he wondered how well the crosscutting structure functions and whether the budget supports this structure. NCHS involvement in substantial research could help users understand how useful the data are, their shortcomings; and how they can be made more valuable.

Discussion Consideration of other metrics that could impact ORM (e.g., Citation and Google Scholar) was raised as was the question of whether the review process would consider accessibility to the RDC by researchers. How should NCHS collaboration with other agencies (a potential revenue generator) be balanced with the draw on resources for NCHS-related work? More thought must be given to whether staff members should apply their expertise across different data collection programs or within single programs. The broader question of how ORM relates to statistical methods that support health research as well as individual programs was posed with regard to strategic and operational issues. Program quality is of utmost importance.

Changing technology provokes questions about the future of survey research. The BSC's mission will shift depending upon the nature of the questions and on what happens in the field. What more can be done to utilize new technologies strategically? The Census Bureau has a new Center for Applied Technology that examines outside products to determine their use for data collection.

NHANES DNA Update

Rosemarie Hirsch, M.D., M.P.H., Dep. Director, NHANES; and Lee Cornelius, Ph.D.

Dr. Hirsch recommended a New York Times article by Gina Kolata (August 2012) that summarizes current NHANES DNA issues. Her presentation reviewed the February 2012 BSC input to the NHANES Genetics Program and provided an update of activities since that time. Major items from a BSC letter to NCHS were outlined and the May 2011 NHANES Genetics Program Workshop highlights were reported. Outreach efforts were also described.

Dr. Cain noted the interest of Connie Citro, Director of the Committee on National Statistics (CNSTAT), in the development of a spring 2013 workshop that would involve the National Academy of Sciences and the IOM. The Steering Committee would include a BSC member. A public dialogue would be part of the design and population-based studies would be emphasized. Attention would be paid to writing the 2015 consent and what to do with collected data with consents that are not optimal. A statement about the degree to which contributors are responsible for maintaining contact with biobanks should be written into consents and procedures. Inclusion of lab and survey staff in the workshop was recommended, particularly because DNA and SNP data are imprecise.

Dr. Hirsch noted that DNA is not currently being collected due to the cost of processing specimens (2013-14 agreement has not yet been confirmed); and because of ethical concerns about data collection under a no re-contact consent form. If the consent form that won't test for anything in Bin 1 or 2 is not changed, the information gathered will never be used. Ethical concerns about re-consent and change were reiterated. Minimal guidelines are needed on the level of quality for reporting as a first step.

Discussion A long-range vision is needed for how to incorporate technological changes. An additional bifurcation would be necessary for a longitudinal study. At present, there is no new consent to test because what will emerge from the workshop is unknown. The complexities of cognitive testing of focus groups on old specimens have been recognized as was the value of conducting cognitive or focus groups before the spring workshop. Other pre-workshop considerations are how to re-consent and what re-consents would look like. Many subjects believe that researchers have a responsibility to give back to them. So, what are the underlying principles? Economics is an additional consideration. What can be done now to inform the workshop?

There must be a consent that says that subjects will be notified under certain circumstances. There are questions about how to word the consent; whether people will understand its intent; and whether it should be worked on before or after the workshop. A suggestion was made to break off the re-consent piece and focus on developing the next sample. While it might be useful to identify details of the key issues at the workshop and take on re-consent afterwards, Dr. Madans did not think that viable when taking thousands of unused specimens into account. A consent form will be written and tested after the workshop, once governing principles are established. Discussion ensued about the ethics of re-contacting subjects who never agreed to re-contact except under circumstance of ethical necessity.

What is most important for NCHS is to have a workshop that focuses on the issues of old participants and on moving forward. But what if the workshop does not provide NCHS with what it needs in a timely fashion? NCHS should pay attention to who oversees the workshop.

NHANES: Current and Future

Vicki L. Burt, Sc.M., RN, Chief, Planning Branch, NHANES

Ms. Burt provided a brief overview of NHANES content, staff and how data are currently collected. The 2011-2012 data and data collection process were enumerated, with references made to anticipated 2013-2014 adjustments. Logistical challenges were described.

Discussion TB testing, which is extremely expensive, was only planned for two years. A “token of appreciation,” the amount of which varies by age, is paid to participants as an exam incentive. Follow-up activities are also remunerated.

Departing BSC members Dr. Cornelius and Dr. Himes were recognized for their service.

The discussion was followed by tours of NHANES Trailers and dinner. The meeting was adjourned at 4:04 p.m.

Friday, September 14, 2012

Mortality Surveillance: Real-Time Monitoring for Improved Data Quality and Public Health

Paul D. Sutton, Ph.D., Health Scientist, Mortality Statistics Branch, DVS

Mortality surveillance was defined. The objectives/goals, methods and characteristics of the Mortality Surveillance Program (new to NCHS) were described as were potential surveillance topics and partners. The program’s first project about rare causes of death (specifically, vaccine-preventable diseases) was outlined, noting objectives of the new protocol for confirming rare causes of death. This protocol has eliminated waiting for the annual file to close, especially for vaccine-preventable deaths. A new part of the process has NCHS sending an abstract of key information to NCIRD for investigation and verification. Early success stories and challenges were described.

Discussion The importance of certifiers in this process was illustrated. Coordination with the Nationwide Emergency Departments Sample (NEDS) group and with the Infectious Disease Surveillance group was recommended. Death data are now being coded by NCHS, noting the value of nosologists in identification and coding. Emergency preparedness staff is likely to support these activities. Certain NCHS coding challenges were further discussed as was the role of nosologists and automated systems in cause of death coding. Public health emphasis is to report back as close to real time as possible when examining acute issues.

Much was learned from the Vitals Review (2006). Since then, the process has taken advantage of new technologies as well as a new focus and vision. A huge improvement in timelines was noted. The current focus on data quality represents a return to program roots. This is a basic change in how the death data system is viewed relative to what it can do. Is it a good use of resources? Dr. Madans believes that the commitment to maintain 57 partners on vital statistics, 57 partners on the health department side as well as CDC partners is worthwhile because it improves public health and the data.

The number of vaccine-preventable deaths is under 100 per year. Often, information about mortality surveillance is not received quickly enough, noting that such information can be useful in drug-induced or adverse-event situations. Because some reporting already occurs within

CDC (i.e., infectious disease), finding partners for other kinds of deaths (e.g., heat-related) would be a better way to tabulate.

Feedback from BSC members was requested about whether the current direction makes sense (i.e., tracking a small number of cases that use the data system to its fullest). It was suggested that it would be more valuable to implement the program in areas with no redundancy in reporting. A recommendation was made to develop agreements about individual file use before requests arrive. A question was raised about whether resources and systems should be used for statistical and processing speed or for the development of algorithms that determine what is worthy of investigation (in contrast to investigating and coding individual cases). HRSA, a potential partner that hasn't been mentioned, is working to increase the number of states with maternal mortality review committees.

National Committee on Vital and Health Statistics Update and Recommendations on Measuring Socioeconomic Status (SES) in Surveys
Marjorie S. Greenberg, Executive Secretary, NCVHS

Ms. Greenberg's overview of the history, function, structure and organization of NCVHS was followed by a report of activities since BSC's last meeting (February 2012). Subcommittee hearings and letters were described as was the development of a new working group on HHS Data Access and Use. Major themes and guiding principles were identified at an Executive Subcommittee strategic planning "retreat" (August 2012). The focus of NCVHS's September 2012 meeting was outlined. Common interests of NCVHS and the BSC were identified, to include population health data and standards for population health data; privacy and confidentiality; and data access and use. The liaison positions on each Committee are yet to be filled, noting that Dr. Len Nichols has been asked to serve as the NCVHS liaison to the BSC. A half-day meeting of NCVHS and the BSC was suggested for cross-fertilization purposes, perhaps on the topic of socioeconomic status or data access.

Discussion NCVHS was asked by the Data Council to examine minimum standards for population-based surveys relative to SES measurement. While some categories might be more important than others in certain areas, the biggest population-based surveys have generally collected fairly comparable data. A central question (for OMB as well) is what can be recommended that is fairly uniform across surveys. While NCVHS participants do not think they have enough information to determine specific questions, they are very willing to work with the Data Council. The Data Council is examining administrative data alongside other priorities. It was suggested that future work on these issues be joint endeavors between the BSC and NCVHS.

People measure SES in different ways. The intent of providing a certain level of detail was to allow researchers to choose relevant categories. However, standards provide a common denominator that allows for comparison across surveys as well as a way to identify priorities. NCVHS cannot recommend a standard on SES at this time. Mark Hayward and colleagues are writing a review and additional analyses of the education-health relationship, which is not as stable as previously perceived. Minimum standards differ in varying populations (e.g., immigrants). Standardized information is worthwhile because the methodology is changing in significant ways (e.g., methods for getting income are far more sophisticated). It was argued that this is an OMB rather than an NCVHS or Data Council issue. The issue of what is and is not "minimal" becomes important although this notion was challenged. Instead of focusing on a "minimum," the focus might be on what specific information is needed. Especially in the big surveys, it is helpful to have consistency in the denominators.

NCVHS is passionate about standards and about determining areas of exploration. As a vehicle that contributes to the development of a minimum standard, the Data Council needs leadership at the top. The Population Health Subcommittee, in particular, would like further discussion with the BSC. A suggestion was made to summarize the discussion on minimum standards to bring to NCVHS and the Data Council for further consideration. It was reiterated that OMB should define minimum standards. The usefulness of a minimum is a science or research question.

Health United States, 2011, In Brief Interactive

Sheila J. Franco, Health Statistician, Analytic Studies Branch, OAE

Ms. Franco focused her presentation on NCHS's collaboration with the National Library of Medicine in making the *Health, United States in Brief* interactive. Project collaborators were recognized. The goal was to make the document more engaging and flexible, to reach a wider audience and to make large stores of research data available to the scientific publishing community. A demonstration of the site was given (go to: <http://www.cdc.gov/nchs/hdi.htm>). Tutorials explain the system. Feedback thus far indicates that the most appreciated feature is the ability to easily create charts and change chart designs.

Discussion Physician data comes from the AMA while personal expenditures are from CMS. The site's welcome page has a statement that absolves NML and NCHS of responsibility for what is done with the data. A suggestion was made to add text about data use or a watermark to the slides. With regard to statistical accuracy, there are generally standard errors on the website. Standard error features will be added to the interactive edition. Coupling the interactive report with the Health Indicators Warehouse is under consideration.

BSC Wrap-Up

Lee Cornelius, Ph.D., Chair, BSC

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

BSC is in transition with some slots waiting to be filled. The NHANES DNA Subgroup should be maintained with a more precise charge. A conference call with current members will be set up to sharpen the focus on what needs to be done. Once clear goals are established, the group can determine the context of the work and respond to such questions as, "Will the group provide basic principles? If not, what is the output? What constitutes next steps and how do we get there?" A recommendation was made to focus on gathering prospective rather than retrospective data for the NAS workshop. This would involve synchronization between the Subcommittee and future meetings of the BSC.

A BSC member will serve on a larger workshop planning group. Dr. Himes volunteered to participate in the Health Indicators Warehouse working group. Reconsideration of the review process will be on the agenda for the next meeting. A liaison for the NCVHS Committee is needed.

Public Comment: NONE

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

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

Chair

DATE

ATTENDANCE**Committee Members****Present**

Llewellyn Cornelius, Ph.D., Chair BSC
 Hermann Habermann, Ph.D.
 Kathleen Mullan Harris, Ph.D.
 Christine L. Himes, Ph.D.
 Carol J. Hogue, Ph.D., M.P.H.
 Raynard Kington, M.D., Ph.D.
 Stanley Presser, Ph.D.
 Elizabeth (Lou) Saadi, Ph.D.
 David Takeuchi, Ph.D.
 Katherine K. Wallman (phone 9-14-12)
 Alan M. Zaslavsky, Ph.D.

Absent

José Escarce, M.D., Ph.D.
 Stanley Presser, Ph.D. (9-14-12 only)
 Duncan Thomas, Ph.D.

Staff and Liaisons

Virginia S. Cain, Ph.D., Executive Secretary
 Clarice Brown, Director, DHCS
 Jane Gentleman, Ph.D., Director, DHIS
 Marjorie S. Greenberg, Executive Secretary, NCVHS
 Jennifer Madans, Ph.D., NCHS
 Nathaniel Schenker, NCHS
 Edward Sondik, Ph.D., Director, NCHS (phone 9-14-12)

Presenters**September 13, 2012**

Vicki L. Burt, Sc.M., RN, NHANES
 Hermann Habermann, Ph.D., BSC Liaison
 Rosemarie Hirsch, M.D., M.P.H., NHANES
 Roderick Little, Ph.D., ORM, U.S. Census Bureau
 William D. Mosher, Ph.D., DVS
 Nathaniel Schenker, Ph.D., ORM
 Edward Sondik, Ph.D., Director, NCHS
 Alan Zaslavsky, Ph.D., BSC Liaison

September 14, 2012

Sheila J. Franco, OAE
 Marjorie S. Greenberg, NCVHS
 Paul D. Sutton, Ph.D., DVS

Others**September 13, 2012**

Joy Abma, DVS/RSB
 Victoria Albright, RTI
 Brenda Baker, NHANES
 Lisa Breitman, DHANES
 Suzie Burke Bebee, ASPE
 Stephen Blumberg, DHIS
 Lori Borrud, DHANES
 Verita Buie, OPBL
 Anjani Chandra, DVS/RSB
 Valerie Chepp, ORM
 Casey Copen, DVS/RSB
 Jim Craver, OAE
 Kim Daniels, DVS/RSB
 Sandra Decker, OAE
 Ann Driscoll, OAE
 Isaedmarie Febo, NCHS
 Leonard Horning, Budget
 Meena Khare, NCHS
 Peter Meyer, ORM
 Jodi McLean, DHANES
 Gerry McQuillan, DHANES
 Mary Moren, OPBL
 Ryne Paulose, NHANES
 River Nolan, ORM
 Paulina Rumchera, ORM
 Iris Shimizu, ORM
 Anna Sandoval, ORM
 Margo Schwab, Ph.D., OIRA
 Kassi Webster, NCHS
 Rong Wei, ORM
 Abers Wouhib, ORM

September 14, 2012

Michael Albert, NCHS/DHCS
 Kelly Brown, NCHS/DVS
 Liz Fomegne, NCHS/OPBL
 Glen Ford, NLM
 Dina Demner-Fushman, NLM
 Julia Holmes, NCHS/OAE
 John Hough, NCHS/CPHDSS
 Christine Jamieson, APA
 Katherine Jones, NCHS/CPHDSS
 Charles Rothwell, M.S., DVS
 Naga Shanmugam, NCHS/OAE
 Sandy Smith, NCHS/OCD
 Suresh Srinivasan, NCHS/DHIS