# **Department of Health and Human Services**

#### **Board of Scientific Counselors**

January 28, 2011

NCHS Auditorium 3311 Toledo Road Hyattsville, MD 20782

# **Meeting Minutes**

The Board of Scientific Counselors convened on January 28, 2011 at the National Center for Health Statistics in Hyattsville, MD. The meeting was open to the public.

# Friday, January 28, 2011

#### **ACTIONS**

- The BSC has been appointed as the oversight committee for the Health Indicators
  Warehouse. Dr. Duncan Thomas, Dr. Lynn Blewett, and Dr. Holly Hedegaard volunteered
  to become the BSC-HIW Liaison Committee.
- Dr. Cain requests comments on revised recommended office procedures and selfassessment guidelines (as opposed to guidelines for the Data Collection Program) by February 15, 2011.

#### **Welcome and Call to Order**

Lynn Blewett, Ph.D., BSC Chair

#### NCHS Update

**Edward Sondik, Ph.D.** 

Data and measurement provisions of the Patient Protection and Affordable Care Act were described as were NCHS program changes. The proposed 2011 budget was delineated in such areas as Vital Statistics (\$11 M); Health Interview Survey (\$8M); National Ambulatory Medical Care Survey (\$3.5 M); and maintenance (\$0.7 M). A budget history from 2007 to 2011 was presented (2012 budget is still uncertain). Survey sample sizes were discussed.

The new *Health, United States, 2010* (out Feb. 9, 2011) focuses on death and dying. Highlights of NCHS programs (and more specifically DHANES programs) were presented. New NHANES exam content (2011-2012) was mentioned as were sampling domain changes. National Health Interview Survey data releases were identified. It was noted that National Vital Statistics reports include birth data as well as recent trends in births and fertility rates. Health care surveys focus on electronic medical records, with NCHS tracking and monitoring progress of EHR implementation. Research has been done on advanced directives and long-term care populations. Also mentioned were specific Health Care Survey changes and a Look-Back Module on Prevention of Heart Disease and Stroke. The new Hospital Care Survey is moving forward a more direct use of EHRs in survey activities. Useful information is being gathered from the National Survey of Long-Term Care Providers.

The purpose of the Open Government Initiative was discussed as was its connection to the Health Indicators Warehouse (HIW). The HIW is making community health data far more

accessible. Dr. Monroe Sirken, due to retire at the end of January 2011, was recognized for sixty years of service and significant contributions to the Federal Statistical System. (See PowerPoint presentation for specifics)

<u>Discussion</u> The need to integrate and develop working relationships across survey and administrative data and across federal agencies was emphasized. To accomplish this, cooperation between the Departments of Labor and Health and Human Services is needed. Some are opposed to data exchanges. Questions were raised about funding for state-level data and about who should link new data. NCHS is "at the table weekly" with regard to data needs and health reform tracking. As yet, there are no discussions about detailed data needed for exchanges. It was noted that those who determine how to do exchanges are anxious about what they can accomplish when they don't know how to do linkages. Technical guidance is needed.

# Addressing Provisions of the Affordable Care Act on the 2011 National Health Interview Survey Robin Cohen, Ph.D., DHIS

The presentation hand-out (a summary of areas addressed by the 2011 National Health Interview Survey [NHIS]) was reviewed. Certain provisions of the Affordable Care Act were discussed. Provisions of the law are being enacted in stages. Accomplishments of Year One were followed by a description of what will occur in 2011 and beyond. The 2011 NHIS questions about extended health insurance, access and utilization have been grouped into four themes.

Examples of 2011 NHIS expansions addressed some provisions of the Affordable Care Act more comprehensively. Data from California, Massachusetts and Ohio were presented about the percent of uninsured persons in the U.S. between 18-64 years and about the percent of persons without medical coverage due to cost. The positive impact of Massachusetts' 2006 health care reform bill was noted as was the importance of having a national baseline. (See PowerPoint presentation and Summary Hand-Out of areas addressed in the 2011 National Health Interview Survey).

<u>Discussion</u> Claims data are a good way to gather information about areas such as preexisting conditions but are surveys the right tool to gather such information? The need to include the expansion age of 26 in the Survey was questioned. A discussion ensued about the decision-making process for what to include in the Survey [examples given]. Further history of survey question development was given, noting that survey questions uncover certain issues that medical records do not (e.g., increased access to health insurance from the purchaser's perspective). A question was asked about the impact of health policy on premiums.

Budget concerns were discussed and funding to increase sample size was emphasized. Survey decisions are not made unilaterally by NCHS. Developing a support base for NCHS's budget appropriation was recommended. Data gathering about relationships within households was commended. The Survey covers specialist availability in most instances. Data to be collected in the 2012 National Ambulatory Medical Care Survey (NAMCS) was described. An ongoing need for larger sample sizes and the need to have a tolerable survey length were highlighted. It was pointed out that denial of specialist care is more likely to come from over- or undersupply. A suggestion was made to drop survey questions that become less relevant over time and to examine ways to better distinguish between specialists and PCPs in the Surveys.

#### **Launch of Health Indicators Warehouse and Governance**

# Linda Bilheimer, Ph.D., OAE and Amy Bernstein, Sc.D., OAE

A "soft launch" of a preliminary Health Indicators Warehouse (HIW), Version 1.0, occurred in late January 2011 in order to update, edit and prepare for a larger future launch (to occur in conjunction with the launch of HealthData.gov). The content of HIW and identification of user types were presented. Amy Bernstein and Jim Craver were recognized for significant contributions to the HIW. This is one of the first CDC projects to complete the Information Resources Governance (IRG) process. There will be multiple links within HealthData.gov to the Warehouse as well as media events and training sessions to teach the press how to use the Warehouse and Code-a-thons (organized by Health 2.0 to promote web applications development with health data). The Warehouse is intended to help others pull data for their applications. Issues to address have mostly to do with statistical standards and priority setting. Resources are limited although funding may be forthcoming from the HHS Enterprise Investment Trust Fund. Dr. Bernstein demonstrated ways to access Warehouse information on the website and responded to participant questions. (See PowerPoint presentation for specifics)

<u>Discussion</u> A question was raised about the accuracy of RTI code categories (race and ethnicity). A decision to be made about the governance process should address what happens when the HIW receives information that doesn't meet standards (e.g., Medicare). Health-related data come from many different types of sources, some of which cannot be evaluated. Although not included with CMS data, evidence-based interventions are included with other initiatives such as Healthy People. Care must be taken when suppressing data. It is important to identify where HIW data have come from while not identifying them as HIW applications. How to handle competing estimates (or the same indicator from several sources) was discussed.

Generally, all information cites sources, which allows for evaluation of data source strengths and limitations. Indicators from the same source that are differently defined pose challenges (also identified as the "thorny issue of harmonization"). In these cases, an executive decision is made about what to use, a process approved by HRSA. The process of coming to agreement about National Health Indicators was further discussed. The intention is for initiatives to eventually use Warehouse data that is harmonized based on statistical methodology and standards. Although the process of integrating new initiatives has not yet been determined, such integration will be a part of the governance process. The BSC has been appointed as the HIW's oversight committee. A brief discussion about imprecise data (e.g., county-level data) and suppression criteria ensued.

# Survey Cost Savings Task Forces: U.S. Census Bureau Data Collection Cost Savings Operations and Federal Agency-Sponsored Demographic Surveys Barbara O'Hare, Census Bureau

Background about the Census Bureau Cost Savings Task Forces was presented. Two Task Forces involve NCHS surveys. The complexities and rising costs of gathering health data were recognized, especially relative to gathering data in the field. The HIS (household demographic) was differentiated from NAMCS/NHAMCS, where the unit of analysis is the patient record. Data collection challenges were mentioned as was the goal of identifying promising opportunities to improve cost efficiency of survey data collection procedures in Census reimbursable surveys. General characteristics of the Task Forces were described. Task Force surveys were identified as were key opportunities. Recommendations were presented to improve survey management; data collection; and adaptive survey design. Survey-specific and interagency collaboration on cost were identified as opportunities for sponsors. Progress to date was outlined.

(See PowerPoint presentation for specifics)

<u>Discussion</u> A suggestion was made to use Medicare or the State Board of Medical Examiners (responsible for licensing) rather than AMA records to gather physician information. Sample sources and alternatives were noted as good discussion topics. Efficiency was stressed. Also mentioned was a possible reduction in Census survey costs to NCHS.

An investment in more efficient methodologies was seen as cost-effective and other cost-effective maneuvers were identified. The length of data collection should be further discussed for potential savings. The concept of cost efficiency derived from a longer period at a particular doctor's office was challenged relative to what might be lost vis-à-vis variability across doctors. A question was also raised about the standard sampling challenge of what response rates are tolerated. A suggestion was made to increase the scope of within doctor practice sample size in order to characterize practice styles. It was noted that the original goal (since 1973) was to obtain a representation of doctor visits across the United States with a secondary goal of characterizing how doctors practice.

#### Health U.S.: Death and Dying

Amy Bernstein, Sc.D., OAE

Made public on February 9, 2011, *Health U.S. 2010* is a congressionally-mandated report to Congress that features death and dying. Increasingly, *Health U.S.* is the "encyclopedia" of NCHS and other data, a comprehensive (primarily) web-based resource, components of which were described (e.g., trend tables; prevalence rates). A demonstration was given on how data is presented on-line along with a description of features and substance within the current issue. The hope for the future is to place all *Health U.S.* data into the HIW. (SeePowerPoint presentation for specifics)

<u>Discussion</u> A suggestion was made to examine the setting or site of death to better understand patterns of injury versus medical conditions.

#### **Vital Statistics Update**

#### ICD-11: Why, What, When, How?

Robert N. Anderson, Ph.D., DVS

A history of ICD revisions was reviewed . The ICD-11 schedule was presented with the goal of a May 2014 submission to and approval by the World Health Assembly. Major differences between ICD-10 and ICD-11 were described relative to production style; category information ontologies; and deliverables. The content model was put forth as was the organizational structure for the revision. The latest update notes that: the beta draft should be ready (although not complete enough for field testing) by May 2011; some TAGS are behind schedule; and to date, the code structure has not been determined. ICD-11 will look very different from ICD-10. Implementation (which could occur by 2016 at the earliest), will involve retraining coders; reprogramming an automated coding system (MMDS); revising tabulation lists; and performing a comparability study.

(SeePowerPoint presentation for specifics)

<u>Discussion</u> What goes into ensuring proper death certificate information and coding was described. An on-line tool is being developed to train physicians on proper completion of death certificates. The goal is to get states to make this training part of their electronic death registration systems. A question was asked about significant improvements of ICD-11. Also discussed was the difference between an automated mortality system (adopted and

internalized) with a morbidity system that will not be implemented until 2013. Implementation date for ICD-11 is seen as 2020 (earliest) rather than 2016. Decisions must be made about code structure and morbidity rules, to be decided by a WHO Revision Steering Group. If changes to ICD-11 are too drastic, adoption may take many years. Advantages of ICD-11 were outlined. Differences between mortality and morbidity were further discussed. One goal is to make ICD-10 much more useful for morbidity, noting the need for clinical modification. The complexities of changing international classifications were noted and a question was asked about what all this means for CMS in the future.

#### A New Model Law for Vital Statistics

Julie L. Kowaleski, DVS

The model law revision, a joint project of NAPHSIS and NCHS, was delineated along with reasons for the update. The Model Law Revision Workgroup members were identified as were functional focus areas (with input from the states). Workgroup objectives were identified and accomplishments to date were outlined. The 2011 timeline was presented as was an overview of changes from the 1992 version of the law. (SeePowerPoint presentation for specifics)

<u>Discussion</u> DVS has a cooperative agreement with NAPHSIS that includes implementation of the model. States can choose to adopt the law and what areas to pursue. The resolution must pass in 2011 in order to get significant buy-in on NAPHSIS from states. Then, the law exists as a model. It was noted that the release date has tightened because some states have more restrictive research and disclosure policies than others; and that different guidelines exist for different groups. The Model Law includes interjurisdictional exchange of death certificate information between states.

### **Program Review Plans**

Lynn A. Blewett, Ph.D., BSC Chair and Virginia S. Cain, Ph.D., Executive Secretary

The NCHS program review process will resume in spring 2011, when a review of the Office of Analysis and Epidemiology will also begin. Although the Warehouse was developed to improve the agency, it has opened doors to a wide range of potential new clients. NCHS/OAE does a lot of cross-cutting work with data systems. Dr. Bilheimer described OAE's process of linking surveys longitudinally to administrative data for Medicare, Medicaid, Social Security and environmental data. OAE is promoting their use within the research community (a hard sell) and also conducting research with them to demonstrate the power of the link. Funding has come from clients or "collaborators." A question was raised about influence on research decisions by clients/collaborators who donate funds.

(Seehand-outs entitled, *Procedures for Reviewing NCHS Programs: National Health Interview Survey (NHIS)* (March 2008 and January 2011); *Guidelines for Self-Assessment and Preparation of Program Materials by NCHS Program Staff for Program Reviews* (November 2007 and modified January 2011); *Review of NCHS Research Programs* (not dated).

#### **ATTENDENCE**

# **Committee Members**

Lynn A. Blewett, Ph.D., BSC Chair Ronald J. Angel, Ph.D. Patricia Buffler, Ph.D., M.P.H. (by phone) Llewellyn Cornelius, Ph.D. José Escarce, M.D., Ph.D. Holly Hedegaard, M.D. Graham Kalton, Ph.D. Michael J. O'Grady, Ph.D. Duncan Thomas, Ph.D. (by phone) Katherine K. Wallman, Ex Officio Member

#### **Absent**

Kathleen Mullan Harris, Ph.D. Elizabeth (Lou) Saadi, Ph.D.

# **Staff and Liaisons**

Virginia S. Cain. Ph.D., Executive Secretary Jennifer Madans, Ph.D., NCHS Edward Sondik, Ph.D., Director, NCHS

#### **Absent**

William J. Scanlon, Ph.D. – NCVHS Liaison

#### **Others**

Linda Bilheimer, NCHS/OAE Stephen Blumberg, NCHS/DHIS Pei-Lu Chiu, NCHS/DHIS Traci Cook, NCHS/OPBL Jim Craver, NCHS/OAE Anne Driscoll, NCHS/OAE Alyson Essex, NCHS/DHCS Elena Fazio, NCHS/OAE Virginia Freid, NCHS/OAE Jane Gentleman, NCHS/DHIS Renee Gindi, NCHS/DHIS Marjorie Greenberg, NCHS/CPHDSS Brady Hamilton, NCHS/DVS Julia Holmes, NCHS/DVS John Hough, NCHS/CPHDSS Susan Jack, NCHS/DHIS Debbie Jackson, NCHS, CPHDSS Clifford Johnson, NCHS/DHANES Katherine Jones, NCHS/CPHDSS Sharon Kirmeyer, NCHS/DVS Ken Kochanek, NCHS/DVS Ellen Kramarow, NCHS/OAE Mary Moien, NCHS/OPBL

Brenda La Rochelle, NCHS/DHIS Diane Makuc, NCHS/OAE Michael Martinez, NCHS/DHIS Heather McAdoo, NCHS/OPBL Pauline Mendola, NCHS/OAE Michelle Ostermon, NCHS/DVS Jennifer Parker, NCHS/OAE Laurie Pratt, NCHS/OAE Cheri Rice, CDC Howard Riddick, NCHS/DHIS Nathaniel Schenker, NCHS/ORM Margo Schwab, OMB Angela Sharpe, Consortium of Social Service Assns. Iris Shimizu, NCHS/ORM Monroe Sirken, NCHS/OCD Sandy Smith, NCHS/OCD Paul Sutton, NCHS/DVS Stephanie Ventura, NCHS/DVS

#### **Presenters**

September 28, 2011
Robert N. Anderson, DVS
Amy Bernstein, NCHS/OAE
Linda Bilheimer, Ph.D., Director, NCHS/OAE
Lynn Blewett, Ph.D., BSC Chair
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Robin Cohen, DHIS
Julie Kowaleski, DVS
Barbara O'Hare, Census Bureau
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