

Department of Health and Human Services

Board of Scientific Counselors

April 14-15, 2011

NCHS Auditorium
3311 Toledo Road
Hyattsville, MD 20782

Meeting Minutes

The Board of Scientific Counselors convened on April 14-15, 2011 at the National Center for Health Statistics in Hyattsville, MD. The meeting was open to the public.

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.
Carol J. Hogue, Ph.D., M.P.H.
Kathleen Mullan Harris, Ph.D.
Holly Hedegaard, M.D.
Michael J. O'Grady, Ph.D.
Elizabeth (Lou) Saadi, Ph.D.
David Takeuchi, Ph.D.
Duncan Thomas, Ph.D.
Katherine K. Wallman, Ex Officio Member
Alan M. Zaslavsky, Ph.D.

Absent

José Escarce, M.D., Ph.D.
Graham Kalton, Ph.D.

EXECUTIVE SUMMARY **APRIL 14-15, 2011**

ACTIONS

Because this meeting was not published in the Federal Register, it cannot be considered an official board meeting.

- Dr. Gold asked that the Board of Scientific Counselors (BSC) react to the IOM Report presentation. The BSC agreed to send a written response.
- A suggestion was made to develop a BSC position paper that challenges current thinking about the health indicators. A draft paper (developed by Dr. Blewett, Dr. Cain and Dr. Madans) will be circulated among BSC members, whose recommendations

could move the health indicators discussion forward. Specific input from BSC members was requested for the upcoming draft.

Welcome and Call to Order

Lynn Blewett, Ph.D., BSC Chair

NCHS Update

Edward Sondik, Ph.D.

The NCHS budget and its implications were reviewed as were current NCHS activities. Participants were encouraged to attend a June 9, 2011 NIH meeting about application and data use and challenges. Jane Sisk and Linda Bilheimer, both of who will be leaving their current positions, were recognized for their valuable contributions to NCHS.

Discussion The importance of understanding the impact of health care reform longitudinally was raised. NCHS's job is to track, monitor and provide data that address key issues. Concerns about NCHS's role; and the importance of noting the scientific component within the healthcare reform were noted.

Update on the NCHS Health Indicator Warehouse

Amy Bernstein, Sc.D.

The presentation focused on what is involved in defining governance of the Health Indicator Warehouse (HIW). The Warehouse's current status was outlined as was the proposed governance structure. Membership and roles of its three groups, Statistical Standards Group (SSG), Indicators Advisory Group (IAG), and BSC, were delineated. Progress to date, next steps and recommendations were reviewed.
(see *PowerPoint for specifics and examples*)

Discussion Questions were raised about applying the same standards to initial Warehouse users that will be expected of future users. It is important to be clear from the start that the standards will evolve. The SSG could screen and make recommendations to the IAG about indicator issues. The report template has strength and limitation sections, noting that a five or ten point rating scale could be considered. States and smaller geographic regions have a great interest in Warehouse information. An appeal process was suggested for rejected datasets. The validity of future indicators will be evaluated by IAG members. The question of "what is valid" was discussed, using BRFSS as an example. Concerns about determining validity without clear cut rules were raised.

Clear labels should specify whether indicators meet statistical standards (or have been given a temporary exemption as in the case of BRFSS). Differences between "data" and "indicators" were discussed, with examples given. Everything in the Warehouse is an indicator (there are no microdata). Modeled estimates were discussed (e.g. BRFSS county-level) relative to the harmonization process. A suggestion was made to develop a consumer ranking indicator structure. Concerns about restricting frameworks warrant further discussion. It might be easier to identify the Warehouse's development phase as a pilot, which would allow for more experimentation. Balancing the need to get timely information to the public verses the need to develop standards was discussed. Recommendations include being explicit about waivers and temporary inclusions; and developing a consumer report about indicator reliability and validity. The *Healthy People* review process was described and the need for quality reviews was emphasized. A draft of explicit standards would be useful as would examples of indicators that do not meet those standards.

Leading Health Indicators for Healthy People 2020: IOM Report and NCHS Response

Rebecca Hines, MHS

An overview of the history and context of the *Healthy People (HP)* initiative (which houses the Leading Health Indicators [LHI] program) was presented. It was noted that what the IOM Committee identified as leading indicators were not actually indicators nor were their objectives actually metrics. The IOM Committee has integrated a useful life-course/health determinants model.

The purpose of leading health indicators was described as were a framework and nine criteria for selecting objectives. Health determinants, outcomes and life course stages were delineated. Proposed topics and objectives were identified along with 2020 topics without objectives. A Hardship Index containing six key determinants was outlined. Suggestions were made for 2020 topic areas. The NCHS response provided with big picture and specific objective feedback (further feedback is welcomed). Seventy-five percent of the objectives were found to have sufficient data. The process of finalizing LHIs was further described, with a full copy of the report available at: www.iom.edu/Reports/2011/Leading-Health-Indicators-for-Healthy-People-2020.aspx (see PowerPoint for specifics)

Discussion Fourteen indicators for social determinants were identified in contrast to four chronic disease indicators. Early attention to broader determinants can reduce the incidence of chronic disease. Elements of sexual behavior indicators were challenged. Questions were posed about: “must-have” indicators; an ability to change indicators over time; and rankings to get onto the “short” list. A methodology weakness was identified with regard to health indicator goals. Are certain indicators social determinants or social predictors? No single framework evaluates contribution to health-adjusted life years or medical costs that take different levels of causal factors into account.

Hard scientific evidence and a structure are needed for indicators to be taken seriously (e.g., a methodology identifying how many die or become disabled from a specific indicator; or what drives up costs). One suggested criteria had to do with where local and state health departments could or should make measurable changes (e.g., infant mortality). The decision-making process about indicator selection must be transparent. A question was asked about input from the general public. Challenges were posed with regard to unemployment and dependency ratios as social determinants; and about using social determinants with no linkable outcomes. An alternate model for determining indicators was presented. Given the many concerns raised, further discussion is warranted. A suggestion was made to develop a BSC position paper that challenges current thinking about health indicators. A draft paper (developed by Dr. Blewett, Dr. Cain and Dr. Madans) will be circulated among BSC members, whose specific recommendations could move the health indicators discussion forward. Specific input from BSC members is requested for the draft.

For the Public’s Health: The Role of Measurement

Martha R. Gold, M.D.

The Robert Wood Johnson Foundation has funded a two-year IOM exploration of measurement, law and regulations and financing that relate to strategies to improve public health and strengthen governmental public health infrastructure in the United States (2009-2011). The intention is to better understand why the U.S. ranks first in the world in medical care expenditures but 49th in life expectancy (“high investment, poor return”). Three integrated reports with actionable recommendations for public health agencies and other players will be

written. Population health strategies will be reviewed within the context of healthcare reform (report released in December 2010). IOM's view of the health system (2003) has evolved to become IOM's current understanding of that system, which at its center, is the governmental public health infrastructure rather than population health conditions. Committee members believe that individual behaviors are deeply influenced by a person's environment, society, messages received and opportunities.

Health determinants were identified. Changing health conditions begins with measurement (data and indicators); and what is accomplished with such measurement was described. A range of specific recommendations were made. It was noted that the second IOM report, out in July 2011, will review legal statutes and regulations with a goal of preventing injury and disease, saving lives and optimizing health outcomes. The third report is about funding. (see PowerPoint for specifics)

Discussion Recommendation 3 required clarification in that monitoring determinants differs from monitoring the breakdown of outcome variations. The audience for these reports was delineated. Challenges to senior civil servants versus political appointees were discussed with regard to Recommendation 1 (with its focus on coordination and integration). How can social determinant messages be communicated effectively? A key question asks what must be transformed in order to create a complete and comprehensive a picture of health outcomes and determinants; and how best to disseminate that information at the national, state and local levels. Recommendations can be considered through particular entities or groups such as the DHHS Data Council. A widespread discussion of standards would be beneficial.

Resources are needed to better coordinate and integrate health determinants more than an alternative model or an independent agency. A question was raised about where NCHS should exist in the larger organizational chart of CDC and other entities. The notion that socioeconomic status drives health was discussed. The need for resources and accountability to ensure data quality, especially from hospitals, was stressed, although it was noted that no data collection system yet exists to determine what is collected and where or how the data connects. The IOM report recommends that NCHS develop such a system. Examples of uncoordinated data were given. The BSC was asked to comment on the IOM report, noting that a formal letter to IOM would be enthusiastically received.

Recommendation 6 (about modeling) was clarified. Discussion revolved around the need for adequate resources to provide good local data for policymakers and local decision makers. Federal funding will not pay to answer questions of non-federal policymakers. The IOM report encourages discussion about a more united framework for our health system. NCHS should support the development of tools for states and local government that gather and analyze information; and should develop resource allocation strategies. A suggestion was made to add a member of the Association of State and Territorial Health Officers (ASTHO) to the BSC.

Question Evaluation of NCHS Sexual Identity Measures Heather Ridolfo, Ph.D.

(Note: Prior to the presentation, Dr. Cain noted that LGBT health issues are increasingly viewed as a major health disparities issue. Recently, relevant survey questions (such as those in NSFG) have been improved; and an exploration about how to add relevant sexual health questions to the National Health Interview Survey (NHIS) is underway. This work will introduce a new mode of data collection, Audio Computer Assisted Self Interviewing (ACASI) into the NHIS.

Background was provided about the need to understand health disparities among sexual minority groups and about the development of a sexual identity question for the NHIS. Based on studies to evaluate different measures, conclusions indicate a range of challenges to validity. Such challenges are likely to occur among respondents who are less educated, transgender or belonging to certain racial and ethnic minority groups (e.g., Hispanic). Findings from the National Survey of Family Growth (NSFG) and the National Health and Nutrition Examination Survey (NHANES) noted systematic missing data and missing data rates for the sexual identity question from 2002-2008. Implications of the findings were delineated. It is very challenging to develop a single measure of sexual identity that is meaningful and comparable across American socio-cultural groups, but strides are being made. It might be useful to examine survey interview characteristics relative to influence on missing data. To date, 75 English interviews have been conducted and 60 Spanish interviews are in process with 200 more scheduled using ACASI. Current definitions will be revised.
(see PowerPoint for specifics)

Discussion The best way to consistently administer the sexual identity question, which focuses on identity rather than behavior, is on an ACASI system. The term “identity” (rather than orientation) is used because its concept is more specific. A wide variation in gay population estimates exists in different surveys. The goal of gathering these data is tied into disparities and healthcare access issues although some acknowledged a discrimination or civil rights issue.

Sexual Behavior, Sexual Attraction and Sexual Identity in the United States: Data from 2006-2008 National Survey of Family Growth (NSFG) Anjani Chandra, Ph.D.

Co-authors Casey Copen and Bill Mosher were acknowledged. Background was provided about the evolution of the NSFG. The presentation focused on measures of overall sexual behaviors (particularly same sex) and the correspondence of specific social behaviors with NSFG measures of sexual attraction and sexual identity. NSFG findings were compared to other national data (e.g., NHANES and the General Social Survey). Sexual attraction, sexual behavior and sexual identity were distinguished as separate concepts and measured separately. Recent data were compared to past data in these areas. Findings were reported in light of question redesign leading to a reduction in amount missing data. Next steps were identified. (see PowerPoint for specifics)

Discussion Comparison surveys with comparable age ranges and mode of (in-person) interviewing were included. *Add Health* and other surveys should be considered.

CNSTAT Workshop on the Future of Federal Household Surveys Tom Plewes

Several BSC board members and staff belong to Steering Committee for the Workshop on the Future of Federal Household Surveys. In November 2010, CNSTAT held a public workshop on the future of federal household surveys and the role of the American Community Survey (ACS) in relation to other federal household surveys (workshop summary is forthcoming). A wide range of concerns about survey quality and the future of household surveys were presented. Without a systematic, timely and comprehensive way to examine these surveys, the ability of the statistical system to provide policy-relevant information and solutions will be compromised. Solutions to address concerns were suggested.
(see PowerPoint for specifics)

Discussion The forthcoming report has much relevance for the federal statistical agencies and, in general, takes into account such topics as: defining federal relationships with commercial sources of health information; understanding the burden of doing household surveys; and thinking more broadly about data collection and integration, noting that the norm is a representative cross section. Because the industry is changing rapidly, new and innovative data collection methods must be considered. Longitudinal data is especially useful; as might be data from individual networks.

FRIDAY, APRIL 15, 2011

Welcome and Call to Order

Lynn Blewett, Ph.D., BSC Chair

The BSC process and role were presented for the benefit of new members and liaisons. Reviews of intramural programs occur under BSC auspices, noting that program reports are reviewed. The focus of today's meeting is to identify what the BSC would like the Review Panels to address. As such, programs are presented to familiarize BSC members with the program prior to the commencement of the review and to help members develop review questions. Drafts of review results are presented to the BSC to accept, reject or request revision. If accepted, a final report is sent to NCHS for action.

A flexible approach ensures a review process that fits the programs. Reviews will proceed with the OAE and the Ambulatory and Hospital Care Statistics Branch despite the upcoming leadership transitions within those organizations.

Program Report: Office of Analysis and Epidemiology **Linda Bilheimer, Ph.D.**

An overview of OAE was presented to include role, staff, organization, functions, activities (i.e., products; tools; and interagency and international collaborations) and the 2011 budget. Challenges and opportunities were identified.
(see *PowerPoint for specifics*)

Discussion Questions were raised about OAE's priorities, core clients and mission; and about OAE's role in health reform state tracking and monitoring. Should a more web-based (as opposed to print-based) dissemination strategy be instituted? While OAE's work is very broad, it is primarily focused within the Department (to include CDC, ASPE, the Children's Forum and the Aging Forum). Other topics included: ways to facilitate use of the Resource Data Centers; how best to teach users to use linked files; disciplines within personnel; program values and investigator and incentives; OAE outreach and targeted collaborations; post-doctoral training programs and fellowships. Further, should standardization of analyses be operationalized across branches? OAE managers and the Associate Director for Science meet weekly to tackle administrative and research issues and to maintain standards. A recommendation was made to maintain IT capacity; and funding was further discussed.

Could expertise and evaluation measures within NCHS be used by those who collect, prepare and analyze their data with NHANES? Noting that such information resides more within DHANES, a discussion followed about “fuzzy” areas of measurement and analysis and the importance of OAE’s role in thinking through what is being measured and why. Further discussion ensued about the use of link files, to wit, the gap between the development of such files and the policymakers using them, noting RDCs as stumbling blocks. Competition, growth areas, logistical and cost challenges were raised. The need for multi-variate modeling in disparities reports was suggested, noting that cross-tabulation and multi-variate modeling have been done for the last few years within OAE. A question was asked about using new technologies within linked files with sensitive data to increase access and fortify the importance of these data. OAE does not control the Research Data Center or data access but they continue to discuss ways to improve access, noting that confidentiality requirements must be met. Requirements of the Confidential Information Protection and Statistical Efficiency Act of 2002 (CIPSEA), Federal Information Security Management Act of 2002 (FISMA) and the definition of designated agent might be topics for a future agenda.

Ways in which the Health Indicators Warehouse (HIW) has dominated OAE’s attention were mentioned. What began as a project intended to improve efficiency grew significantly, as did its support from NCHS. A long-term funding guarantee is crucial to such a project. The OAE review should examine current operations, vision and plans for the future. External funding for the Research Data Centers should be considered; as should partnering with or obtaining resources from NIH (example given). OAE might better advertise its openness to IPAs and collaborations from NIH, other government departments and academia. The complexities of establishing such personnel exchanges and other concerns involving favoritism and resources were noted.

Program Report: Ambulatory and Hospital Care Statistics Branch (AHCSB)
Paul Beatty, Ph.D.

An overview of the AHCSB report was presented, to include mission and role within the Division of Health Care Statistics; NCHS; data products, uses of data and dissemination; and key challenges and opportunities. The status of the ambulatory and hospital care surveys (NAMCS; NHAMCS; and NHDS) were reviewed, noting distinctive aspects (specifics given). Specific surveys and the *Look Back* Module initiative were delineated and ways to improve data collection were outlined. Benefits of a paper to electronic shift are considerable for clinical and administrative data (pilot is currently underway). A timeframe for recruiting new samples and gathering electronic data was presented with associated milestones. New and expanded surveys were described (i.e., Electronic Health Records Supplement; the Physician Workflow Supplement; the National Survey of Prison Health). The Branch’s objective is to make data files quickly and readily available. The website has a data products page; publications (e.g., E-Stats; data briefs; reports); list serves; and sources of technical support. The data are used in many journal articles and to facilitate decision-making within public and private organizations (examples given). Flexibility and continual updating are a must.

Given the many changes in health care in recent years, it is important to keep surveys relevant and timely. Challenges and opportunities were presented, also in relation to EHRs; hiring and retaining staff; fostering a culture of innovation; data quality; training; response rate; and sustainable funding. Many partnerships and collaborations were acknowledged.
(see *PowerPoint for specifics*)

Discussion Discussion ensued about why it is easier to collect protected health information at the federal rather than state level. Some of the biggest changes in the last 25 years in health care financing and access are occurring currently. The hope is to trigger changes in the health care delivery system and address such challenges as poor quality; lack of coordination; lack of emphasis on prevention; and high costs. The review will emphasize the Branch's focus; investment of resources; and general direction. Branch efforts to link hospital to ambulatory surveys will be useful for collecting data about hospital and post-hospital care within a changing environment. Gathering granular state data for local level use should be encouraged. Digitizing data collection aids timeliness. Documenting best practices was encouraged.

Gathering additional mental health services and suicide prevention information from the prison survey was suggested. Determining ways to avoid staff burn-out (a major concern) was recommended, noting that many onerous tasks associated with the automation process are short-term. The importance of maintaining response rates was reiterated. Specific questions about surveys were addressed while the need to protect the Branch's core investments was acknowledged. Discussion ensued about who participates in the hospital care survey; obtaining data from exchanges; and changing data collection and processing (as in all-payer claims data collection and implications of its use for the future). More granularity is needed for survey questions about Medicaid changes. Questions about accepting new patients with Medicare and Medicaid have been added to the survey to track such data by state, starting in 2012. Further concerns were raised about sensitive data relative to HIPAA provisions and federal preemption even with state laws.

It was suggested that some BSC members write a response to the *Leading Health Indicators for Healthy People 2020: IOM Report* for publication in a journal, although not as a BSC activity.

The meeting was adjourned at 12:30 p.m.

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

-S-

Lynn Blewett, Ph.D., Chair

8/7/11

DATE

Appendix

Attendance

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

Lesley Agress, OAE
Paul Beatty, DHCS
Amy Bernstein, OAE
Farida Bhuiya, DHCS
Clarice Brown, DHCS
Jim Craver, NCHS/OAE
Sandra Decker, DHCS
Cordell Golden, OAE
Deborah Ingram, OAE
Debbie Jackson, NCHS, CPHDSS
Clifford Johnson, NCHS/DHANES
Ellen Kramarow, NCHS/OAE
Diane Makuc, OAE
Peter Meyer, ORM
Donna Miller, OAE
Brenda La Rochelle, NCHS/DHIS
Don Malec, ORM
Diane Makuc, NCHS/OAE
Pauline Mendola, NCHS/OAE
Jennifer Porter, OAE
Nathaniel Schenker, NCHS/ORM
Margo Schwab, OMB
Jane Sisk, DHCS
Jackie Smith, OMO
Sandy Smith, NCHS/OCD
Brenda Wolfrey, FMO
David Woodwell, DHCS

Presenters

April 14, 2011

Amy Bernstein, NCHS/OAE
Lynn Blewett, Ph.D., BSC Chair
Anjani Chandra, Ph.D., DVS
Marthe R. Gold, M.D., IOM
Rebecca Hines, MHS, OAE
Tom Plewes, CNSTAT
Heather Ridolfo, Ph.D., ORM
Edward Sondik, Ph.D., Director, NCHS
Steven Wolff, M.D., M.P.H., IOM

April 15, 2011

Paul Beatty, Ph.D., DHCS
Linda Bilheimer, Ph.D., OAE
Holly Hedegaard, M.D., BSC Liaison
Sharon Long, Ph.D., University of MN
Neil Powe, M.D., UCSF (by phone)
Lou Saadi, Ph.D., BSC Liaison
Duncan Thomas, Ph.D., BSC Liaison