

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

Minutes of the Fourth Meeting
September 9-10, 2004
National Center for Health Statistics Headquarters
3311 Toledo Road
Hyattsville, Maryland 20782

June O'Neill, Ph.D., Chair of the Board of Scientific Counselors (BSC), National Center for Health Statistics (NCHS), convened the fourth meeting of the BSC at 2:15 p.m. on Thursday, September 9, 2004. The names of those attending the meeting are listed in Attachment 1#.

State of the Center:

Dr. Edward Sondik, NCHS Director, provided an update on the status of the CDC Futures Initiative. He described the new organizational chart that placed the "customers" of CDC at the highest level. He explained how CDC was being reorganized into four "coordinating centers," and that NCHS was being placed in the Coordinating Center for Health Information and Service (CoCHIS). The new CoCHIS would also include a National Center for Health Marketing and a National Center for Public Health Informatics. Dr. Sondik said that CDC Director Julie Gerberding views the central role of CDC to be that of an information agency. He said that Dr. Gerberding wants CDC to have a strong research component, including a research component related to health marketing. Dr. Sondik said that he had been assured by Dr. Gerberding and Dr. Jim Marks, acting Director of CoCHIS, that he would continue to have the same access to Dr. Gerberding as he did before the CoCHIS Center was established. He said that under the new organizational structure, NCHS would maintain its broad national mandate as a Federal Statistical agency.

Dr. Sondik introduced Dr. Jane Sisk, the new Director of NCHS's Division of Health Care Statistics. He gave an update on the status of the FY 2005 budget, in which the President requested a \$22 million increase for NCHS. He said the increase was not yet definite, but that the increase, if received, would prevent further erosion of NCHS statistical capacity.

Dr. Sondik provided an update on NCHS programs, identifying new data releases and special activities such as a workshop on measuring the severity of injury. He pointed out that virtually all NCHS data collection is done in collaboration with other Federal partners.

Dr. Sondik told the Board that NCHS had followed its advice to collaborate more closely with health economists, and said that NCHS would be conducting a workshop at the July,

2005 meeting of the International Health Economics Association. He identified some key issues for NCHS for the Board to consider, including the balance between confidentiality and data dissemination; summary measures of health; and data for population subgroups. He asked the Board to begin to think about reviewing NCHS programs, as part of compliance with the CDC directive for periodic review of intramural activities.

Discussion

Concern was expressed about the placement of NCHS in the CDC reorganization, and NCHS's ability to maintain its independence as a Federal Statistical agency under the new structure. Specific concerns were expressed about additional levels of review of the timing and content of NCHS data releases, and possible controls over personnel decisions.

A suggestion was made that the Board consider whether or not the placement of NCHS within CDC is the right model for a Federal statistical agency, or if a more appropriate model might be the Census Bureau in the Department of Commerce.

Dr. Sondik was asked how the CDC reorganization would affect the demands placed on NCHS by other parts of CDC. Dr. Sondik replied that CDC doesn't place big demands on NCHS. He said that NCHS has good relationships with other parts of CDC, and he said that NCHS collects data in collaboration with many CDC components. Dr. Sondik said that while the new "goals" structure of CDC will lead NCHS to release more data by goals, NCHS already releases data based on *Healthy People* goals. Dr. Sondik said that requests had been made by CDC colleagues to have first access to NCHS data before it is released to the public; however, according to Federal statistical policy, NCHS is required to release data as rapidly as possible to all users.

It was noted that in a talk given by Dr. Claire Broome of CDC, she referred to the importance of "actionable" data, and concern was expressed that an emphasis on producing "actionable" data could conceivably lead to pressure that would compromise the NCHS mission of neutrality.

A request was made for clarification about the top level of the CDC organizational chart, listing CDC partners and stakeholders. There was concern that the research community was not identified as a key partner. There was also concern about the placement of NCHS as a conduit to customers, since this creates the appearance that NCHS is simply a conduit for data and leaves out the importance of the role NCHS has in research. Dr. Sondik replied that Dr. Gerberding is "very strong on" research. A question was asked about where, based on the new organizational chart, would one engage CDC in research. There was a suggestion of adding a separate "research" box in the new organizational diagram.

There was more general discussion about the ability of NCHS to maintain its independence as a statistical agency in the new organization. There was concern about

how resources would be allocated within CDC, given the centralization described in the reorganization plans. Would NCHS still have control over the budget for its programs and activities? There was a comment that it is important for CDC to recognize the reputation of NCHS as a national statistical agency as well as a part of CDC.

A recommendation was made that the Board express its concerns about the CDC reorganization to Dr. Gerberding and that the Board invite Dr. Gerberding to explain to the Board how she would address the issues raised about the role of NCHS in research and its role as a Federal statistical agency. The tone of the invitation was suggested to be that the Board was not opposing reorganization, but that it wanted to reinforce NCHS's statistical responsibility outside CDC and ask that CDC take care to protect that as it moved forward with the reorganization. The Chair asked 2 members to take the lead in drafting a letter to Dr. Gerberding expressing the Board's concern.

There was a question about the different measures of health insurance coverage by various government agencies. Dr. Madans said that the ASPE was now meeting to determine how to best coordinate data collection from the various sources. A comment was made that the NHIS data are the best source of health insurance coverage, but that the CPS is used more because it includes additional economic variables of interest.

A request was made for an update on NCHS international activities, and Dr. Sam Notzon of NCHS took a place at the table. Dr. Notzon outlined several initiatives including International Collaborative Efforts on injury and on automated mortality data processing; work with the United Nations' "City Group" on disability statistics; the US/Canada Joint Survey of Health; the US/Mexico Border Health activities; NCHS's role in OECD, and the World Health Organization, including that related to classification activities; and NCHS collaborations with Hungary and with Russia.

Discussion by Board of Approach to Assisting NCHS: Rob Weinzimer, acting Executive Secretary, summarized the results of an informal query of Board members prior to this meeting, to help guide deliberations. (Attachment #2.) Mr. Weinzimer said that Board members liked the concept of using informal working groups to facilitate their discussions, and that these should be organized by cross-cutting issues as well as by individual NCHS surveys.

Mr. Weinzimer summarized the list of topics Board members expressed interest in tackling in working groups. A suggestion was made that methodological issues be added as a topic. A preference was noted for NCHS staff to bring to the Board the issues on which NCHS wanted guidance. A suggestion was also made that the Board devote a block of time at each meeting for discussion and vote on formal recommendations to NCHS.

Dr. Sondik was asked to elaborate on NCHS priority topics (Attachment #3). Dr. O'Neill led a discussion about how the BSC could best assist NCHS address these topics.

Confidentiality: Dr. Sondik said the confidentiality issue was complicated because of issues of laws and regulations, including the new CIPSEA. He said that NCHS could prepare background information for the Board on rules affecting confidentiality and data access, and could invite representatives of other agencies to an upcoming Board meeting, to discuss how they address the issue. A suggestion was made for the Board to consider the issue of data linkage in combination with the confidentiality topic. Another suggestion was made to look at the work of NISS in addressing technology issues connected with confidentiality.

Review of NCHS Programs: Dr. Sondik asked the Board to consider the major dimensions of what would constitute a generic program review, to help NCHS meet CDC's requirement of peer review of intramural programs. He asked the Board to identify critical health issues and how NCHS might modify its current processes to best address those issues. Dr. Madans said that for the purpose of intramural program review, the Board should consider the NCHS research agenda as an NCHS program, in addition to the four major NCHS data divisions and two NCHS offices (ORM and OAE). A comment was made that in doing program reviews, the Board needs to take into account the fact that NCHS has many outside data collectors. There was agreement that data collection decisions aren't always within the control of NCHS; much is driven by state laws and state issues, especially in the area of vital statistics data. There was a suggestion that the Board begin the program review process right away; this could be done while concurrently discussing cross-cutting topical issues. A request was made for NCHS to choose the order of program areas for review.

Health Economics: The Board was referred to a newspaper article highlighting costs of health care, and there was a suggestion that the BSC review what NCHS is currently doing and needs to do to make cost data available. In addition, the Board should look at where there is overlap of survey data on health costs, ie. between AHRQ and NCHS. A statement was made that perhaps the MEPS survey should be done by NCHS instead of AHRQ. A problem was noted with data collection about health costs in that different data collectors use different definitions. A recommendation was made that NCHS convene a meeting of agencies to review they type of data collected by each. Kathy Wallman could help support this activity. It would be useful to look at data available from health companies as well, and the BSC was advised not to look only at information about prices, but also on "drivers" of costs, such as technology and the aging of the population.

Update from NCVHS: Dr. Mays and Dr. Robbins updated the Board about NCVHS activities. They said that most of the focus of the Committee had been on information technology solutions for the new Office of Health Information. Other issues of interest to the NCVHS include privacy, confidentiality, population health, and quality of care. At the NCVHS August Executive subcommittee meeting, the group proposed 3 joint activities with NCVHS and the BSC: 1) a joint hearing on quality of life measurement, in 2004-5; 2) a joint meeting of the executive subcommittees of the two groups in 2005, with the purpose of planning the 3rd activity; 3) a joint meeting in 2006 of the NCVHS and the BSC. (*note: the BSC has no executive subcommittee*). Dr. Mays invited BSC

members to observe, over the internet, the upcoming NCVHS hearing in September. She directed to Board to the NCVHS website, at www.ncvhs.hhs.gov, for meeting minutes and additional information about the Committee. Dr. Mays asked the Board to consider the role of the traditional health statistics community in relation to the world of health information technology and related issues of coding, privacy and confidentiality. She asked the Board to advice her on how she could best fulfill her role as liaison.

Discussion: It was stated that NCHS has done more than any statistical agency in helping to address issues of multiple race reporting, and a question was asked about how difficult it has been for states to adapt to new OMB categories for coding race and ethnicity. Dr. Madans said that only a very small number of people choose multiple races, but that in Hawaii there were 22% who classified themselves as of multiple races. Thanks was given to NCHS for its leadership on addressing these classification issues. Dr. Mays was asked if the 9-11 report created an opportunity to modernize certificates and if there were findings from the report that the National Committee might see as opportunities for using the report to promote improvements on the certificates. Dr. Mays responded that this hasn't been looked at closely by the NCVHS thus far. It was suggested that the BSC consider this question, perhaps as part of a joint discussion with the NCVHS. Dr. Sondik stated that he welcomed the idea of collaboration between the BSC and NCVHS.

Vote on letter from the BSC to Dr. Gerberding about the CDC reorganization: It was moved that Board send a letter ([Attachment #4](#)) to Dr. Gerberding, through Dr. Sondik, that invited Dr. Gerberding to address BSC concerns about the CDC reorganization. The motion was seconded and approved by a vote of 14-0.

Presentation on the National Survey of Family Growth (NSFG): Dr. William Mosher, of the NCHS Reproductive Statistics Branch, made a presentation about the design for Cycle 7 of the NSFG. Dr. Mosher presented a brief history of NSFG, including how Cycle 6 was conducted, with the addition of male respondents for the first time. Dr. Mosher said that findings from Cycle 6 would be released in the fall. He outlined limitations of the current NSFG design and spelled out the advantages of moving toward continuous survey data collection. He identified some of the design, content and management issues associated with a continuous approach.

Agenda-setting for next Board meeting: The Board agreed that before the next meeting, 1) Mr. Weinzimer should arrange a conference call between NCHS staff and Board members interested in discussing a process for review of NCHS programs, that could be presented at the next Board meeting; and 2) NCHS should select one topic area for discussion at the next meeting, and refine this through a conference call among interested BSC members.

Announcements: The next meeting of the BSC will take place on January 27-28, 2005, in Hyattsville, Maryland.

The Chair adjourned the meeting of the BSC at 1:30 pm.

I hereby confirm that these minutes are accurate to the best of my knowledge.

/S/_____

June E. O'Neill, Ph.D.

September 20, 2004

**Attachment #1: Attendance: Fourth Meeting of the Board of Scientific Counselors,
NCHS, September 9-10, 2004**

Members present were:

Chair: June E. O'Neill, Ph.D.

Designated Federal Official: Robert J. Weinzimer

Nicholas Eberstadt, Ph.D.

Raymond Greenberg, M.D., Ph.D.

Michael Grossman, Ph.D.

Vivian Ho, Ph.D.

William Kalsbeek, Ph.D.

Janet Norwood, Ph.D.

Alvin Onaka, Ph.D.

Alonzo Plough, Ph.D.

Neil Powe, M.D.

Aldona Robbins, Ph.D.

Louise Ryan, Ph.D.

Matthew Snipp, Ph.D.

Robert Wallace, M.D..

Members not present were:

Fernando Trevino, Ph.D.

Liaison to the BSC present was:

Vickie Mays, Ph.D., University of California at Los Angeles and National Committee on
Vital and Health Statistics

DHHS staff present was:

Dale Hitchcock, Office of Assistant Secretary for Planning and Evaluation

NCHS staff present were:

Mary Moien

Debbie Jackson

Marjorie Greenberg

Jane Sisk

Katherine Jones

Sam Notzon

Diane Makuc

Jane Gentleman
Al Zarate
Larry Cox
Cliff Johnson
Nathaniel Schenker
Jill Marsteller
Bill Mosher
Charlie Rothwell

Attachment #2: Poll of Board Members

Attachment #3: Listing of NCHS Priority Topics:

1. Confidentiality and dissemination: meeting confidentiality constraints while achieving the wide possible dissemination of data.
2. Subpopulations: adding more focused data to a national profile
3. Summary measures: research and practice on summarizing health
4. Quality of life: adding such measures to morbidity, mortality and health system usage.
5. Methodological issues in health statistics: recommendations on a methodological research agenda and priorities
6. Staff generated issues: issues raised by the NCHS staff
7. Input into survey/vital statistics content and reporting: recommendations on assessing data needs and priorities.
8. Program reviews: guidelines for the key questions and preparation of materials for program reviews
9. 9/11 report: discussion of implications for NCHS and other CDC data collection and reporting.
10. Health information technology/computer-based medical records: implications for NCHS.
11. Research agenda—current quality of science; research that might improve quality; implications for NCHS; NCHS interaction with research community. Potential for greater use of clinical data (ie. NHANES); how to greater engage the research community
12. Health economics.

Attachment #4: Letter from the BSC to Dr. Gerberding