

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

Minutes of the Eighth Meeting
January 26-27, 2006
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 eighth meeting of the BSC at 2:00 p.m. on Thursday, January 26, 2006. Dr. O'Neill welcomed Dr. William Scanlon, liaison from the National Committee on Vital and Health Statistics (NCVHS), and five members of the Vital Statistics Mortality Review Panel. All attendees are listed in Attachment #1.

State of the Center:

Dr. Edward Sondik, NCHS Director, provided an update on the NCHS budget, program activities and accomplishments, and data releases. (See attached powerpoint presentation.) Dr. Sondik offered to provide a demonstration of the new NCHS website, "Health Data for All Ages," at the next BSC meeting.

Presentation on *Health, United States, 2005*:

Dr. Amy Bernstein of NCHS presented highlights from the publication, *Health, United States, 2005*. (See attached PowerPoint presentation.) Dr. Bernstein was asked about the process for obtaining input into the report and about feedback received from users. She said that NCHS encourages suggestions for special topics for each year's edition. She pointed to actions taken in response to user feedback, such as providing *Health, United States* tables in PowerPoint format on the NCHS website. Dr. Koepsell stated the *Health, United States* publications are used more than any other data source in his epidemiology course at the University of Washington, and that he especially appreciates Appendix I's information about national health data sources.

Introduction to the Mortality Statistics Program Review:

Dr. O'Neill summarized the process agreed upon by the Board for NCHS program reviews. She thanked Dr. Kalsbeek for his leadership in developing the review procedures and she introduced the five of seven mortality program reviewers who were present. Dr. O'Neill emphasized that the Board was interested not only in their review of the mortality program, but also, in their advice about how to improve the review process.

Presentation of Report of the Review of the Mortality Statistics Program:

Dr. Randy Hanzlick presented the review panel's report. (See attached PowerPoint presentation and Word document.) He described the approach taken by the panel and summarized their recommendations. Dr. Hanzlick explained that the panel customized the generic matrix developed by the Board to evaluate each NCHS program. He also said that the panel asked a vital statistics registrar to review the report, because there were no registrars on the panel.

The report of the panel began by commending the NCHS Mortality Statistics Program for its many accomplishments. The two "overarching recommendations" of the panel were to improve data input quality and process and to improve data access and dissemination. The panel called for NCHS to appoint an ongoing workgroup to develop a strategic analytic plan and to monitor progress, and to fully implement the recommendations over the next 5-10 years.

Board Discussion of the Mortality Review

All of the Board members commended the panelists for their work. Dr. Kalsbeek led the discussion. He agreed that the panel's revised evaluation matrix was appropriate for the mortality review.

Much discussion focused on the practicality of implementing the recommendations. Dr. Hanzlick said that the panel did not attempt to attach dollar amounts to their decisions, and there was general agreement that this was a necessary next step in the process. Board members noted that some of the recommendations—such as those related to state law—were beyond the control of NCHS. There was general agreement that many of the issues—especially those that cut across Federal agencies—should be raised at the national level, through such entities as the Department of Health and Human Services (DHHS), the National Committee on Vital and Health Statistics (NCVHS), the Committee on National Statistics (CNSTAT), and the Institute of Medicine.

Board members and panelists agreed that many of the recommendations overlapped and that—given more time—there were opportunities for consolidation. Several said that the evaluation should be seen as the beginning of a process and not a conclusion. Suggestions were made for additional activities including canvassing information from states and from statistical offices of other nations.

Several Board members and reviewers suggested that the role of NCHS should be to provide leadership at the national level to improve data collection and to support data analysis. NCHS should work with state and local officials, organizations of funeral directors, and others to improve the data quality. Educational activities and the use of incentives were suggested among other means to do this. NCHS should encourage analyses by supporting multiple-cause-of-death research and by facilitating data linkages.

NCHS Response:

Dr. Sondik, Mr. Charles Rothwell, and Mr. Robert Anderson all commended the panelists on their report. Dr. Sondik supported the idea of raising the various issues with NCVHS, DHHS, and the other entities suggested during the discussion. Mr. Rothwell and Mr. Anderson stated that many of the recommendations in the report were already being implemented to the extent possible, given budgetary and legal restraints. They asked the Board for the opportunity to respond in writing to the report.

Other Comments:

Mr. Dale Hitchcock, representing DHHS's office of the Assistant Secretary for Planning and Evaluation, noted that the panel's recommendations may be received very differently by different audiences. He suggested, for example, that some in DHHS will respond that the recommendations about race and ethnicity data should receive higher priority. Dr. Madans recommended that the panel's report be presented to the DHHS Data Council.

Dr. Scanlon, representing NCVHS, agreed that implementation of many of the panel's recommendations were beyond the scope of NCHS and he supported the suggestion that the report be presented at higher levels.

Debriefing/ Lessons Learned about the Review Process for BSC Program Reviews:

Dr. Hanzlick summarized the pPanel's recommendations for improving the NCHS Program Review process. He said that future panels need more time, as well as a defined budget and sense of NCHS staff time available to assist them. For example, could NCHS staff have been called upon to survey state registrars if the panel wanted this done? He said there needs to be a clear understanding of whether the panel reports to the BSC or to NCHS, and about how much in advance of the meeting the report is to be provided to the BSC and to NCHS. Future panels need to know how to factor issues of costs and practicality into their consideration of recommendations. Dr. Hanzlick said it was important to consider broad representation of experience on future panels. He noted that for his panel, only one member represented the data provider side.

Board's Next Step with Mortality Report:

Dr. O'Neill stated that the Board intends to transmit the panel's report to NCHS within the next few weeks, but that the report would be considered an initial document. The Board asked that the panel continue its work and produce a supplemental report based on further examination (including, perhaps, a visit to the NCHS facility at Research Triangle Park). Through email or conference call, the BSC will develop a letter of transmittal of the initial report to NCHS with Dr. Kalsbeek taking the lead on this.

Plans for the Next BSC Program Reviews:

The BSC and NCHS agreed that the NCHS Natality Statistics Program would be the subject of the next program review. Drs. Eberstadt and Ryan agreed to represent the BSC for this review. It was suggested that the National Health Interview Survey (NHIS) be the following program reviewed, and that preparation for the natality and NHIS reviews could be done concurrently.

Update from NCVHS:

Dr. Scanlon said that NCVHS continues to be engaged in activities related to information technology (including the new American Health Information Community), Health Insurance Portability and Accountability Act (HIPAA) implementation, and population health (especially efforts to improve race and ethnicity data). He identified two newer areas of NCVHS interest: 1) “Katrina fallout”—the health system’s capacity for dealing with catastrophes, and 2) how to get more out of data through linkage of datasets. Dr. Scanlon proposed that the BSC and NCVHS consider holding a joint session of some kind in September 2006 when the meeting dates of the two groups overlap. Possible topics of mutual interest include data access, issues raised in the review of the NCHS mortality program, and data collection issues. Dr. Sondik supported the suggestion and Drs. Koepsell and Elo agreed to pursue this on behalf of the BSC.

National Home and Hospice Care Survey:

Dr. Robin Remsburg of NCHS made a presentation about the redesign of the National Home and Hospice Care Survey. She said that changes have been made in methods for sampling discharges and in the types of patients and discharges. The reason for the changes was to improve the ability to examine subgroups and to analyze the relationship between agency characteristics and patient outcomes. (See attached PowerPoint presentation.)

Research Data Center report:

Ms. Margot Palmer of NCHS briefly discussed a recent evaluation of the NCHS Research Data Center (RDC). Ms. Palmer led an NCHS Steering Committee established in December of 2004 in response to user concerns about the RDC process for approving research proposals and about RDC customer support. In September 2005, the Steering Committee presented recommendations for improvement, that addressed issues of staffing, internal coordination, timeframes and procedures, user charges, RDC promotion, “best practices”, and creation of remote Research Data Centers.

Dr. Larry Cox of NCHS summarized developments since the RDC was established in 1998. He emphasized the importance of the RDC for NCHS and the U.S. statistical and health communities and that the recommendations should prove useful in clarifying and addressing important issues for the RDC. Dr. Cox said that developments in data access have moved very rapidly since 1998 in the US and abroad and that users expect more and

faster. The user profile is changing significantly, and there is a need now to look at longer term issues, including: establishing additional RDC sites; second generation remote data access; analytical support to users; development of a research program; confidentiality; record linkage/file merging; analytical methods; international contacts and activities; partnering, e.g. with Census; and the evolving mission, client base, and visibility of the RDC.

Dr. Grossman, representing the new BSC working group formed to help NCHS address issues of access to restricted data, identified 4 areas of particular interest: 1) potential use of Census RDC's to access NCHS data; 2) ability for RDC users to use STATA and SUDAAN remotely (currently this can only be done on-site); 3) waiver of RDC fees for Ph.D. candidates; and 4) ability to do linkages with detailed mortality files.

Announcements:

The next meeting of the BSC will take place on May 4 and 5, 2006 in Hyattsville, Maryland.

The Chair adjourned the meeting of the BSC at 2:00 p.m. on January 27, 2006.

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

/S/
June E. O'Neill, Ph.D.

**Attachment #1: Attendance: Eighth Meeting of the Board of Scientific Counselors,
NCHS, January 26-27, 2006.**

Members present were:

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

Designated Federal Official: Virginia S. Cain, Ph.D.

Nicholas Eberstadt, Ph.D.

Irma Elo, Ph.D.

Michael Grossman, Ph.D.

Vivian Ho, Ph.D. (via telephone)

William Kalsbeek, Ph.D.

Thomas Koepsell, M.D.

Louise Ryan, Ph.D.

Steven Schwartz, Ph.D.

Matthew Snipp, Ph.D.

Members not present were:

Raymond Greenberg, M.D.

Janet Norwood, Ph.D.

Alonzo Plough, Ph.D.

Fernando Trevino, Ph.D.

NCHS staff present were:

Amy Bernstein

Anjani Chandra

Traci Cook

Chris Cox

Larry Cox

Brady Hamilton

Kenneth Harris

Rosemarie Hirsch

Julia Holmes

Susan Jack

Debbie Jackson

Jo Jones

Sharon Kirmeyer

Marian MacDorman

Jennifer Madans

Michael Martinez

Heather McAdoo

Brittany McGill

Fay Menacker

Martha Munson

Margot Palmer

Yasha Patel

Eve Powell-Griner
Robin Remsburg
Alvin Sirrocco
Edward Sondik
Paul Sutton
Stephanie Ventura
James Weed
Robert Weinzimer

Other Attendees

William Scanlon
Bruce Cohen
Randy Hanzlick
Joann Petrini
Richard Rogers
Robert Schoen