Board of Scientific Counselors
National Center for Health Statistics
Centers for Disease Control and Prevention
Minutes of the First Meeting
October 9-10, 2003
Room 1403A and 1405B
3311 Toledo Road
Hyattsville, MD 20782

MINUTES OF THE MEETING October 9, 2003

The first meeting of the Board of Scientific Counselors (BSC), National Center for Health Statistics (NCHS), took place at the NCHS office in Hyattsville, Maryland, on October 9 and 10, 2003. The Chair, June O'Neill, Ph.D., called the meeting to order at 2:05 pm on October 9. The names of those attending the meeting are listed in Attachment #1.

Opening Comments. Edward J. Sondik, Ph.D., Director, NCHS, welcomed members to the BSC and noted that efforts to establish the Board began four years ago. He acknowledged the importance of having a structured means for NCHS to receive input into its programs and that the Center has not had an opportunity for continuous focused advice on its scientific and technical programs and activities. In the past NCHS has had the advice and guidance of the National Committee on Vital and Health Statistics (NCVHS), however, more recently, NCHVH has taken on a very broad agenda that encompasses the full range of data initiatives throughout the Department. Since he views NCHS as a research entity, Dr. Sondik noted that the BSC is absolutely essential for giving research guidance to the Center. He extended his gratitude and appreciation for the BSC's efforts.

Following introductions of members and staff, Dr. O'Neill called on Renee Ross, Committee Management Specialist, Management Analysis and Services Office, Centers for Disease Control and Prevention, who provided a brief introduction to the Federal Advisory Committee Act (FACA). In her remarks Ms. Ross noted that for the BSCNCHS a quorum would consist of nine members. Members discussed briefly occasions when a BSC meeting would close, how and when working groups and subcommittees can meet and operate.

John Condray, from the DHHS Office of General Counsel, led a discussion of ethics considerations for special government employees. Following a video on conflict of interest situations members queried Mr. Condray about particular situations and whether they could incur a conflict of interest. Mr. Condray encouraged members to contact the Executive Secretary for guidance regarding circumstances in which they are concerned about a conflict of interest.

Administrative Matters. The Executive Secretary, Mrs. Linda Blankenbaker, discussed matters pertaining to the BSC Charter, particularly the structure of membership of the Board. She explained how lunch would be handled on the following day and noted the forms in the Meeting Book for arranging for taxi/shuttle service following adjournment of the meeting. Ms.

Patrice Upchurch, Office of Management Operations, NCHS, explained how members should complete and file travel reimbursement claim forms.

Mission and Research of NCHS. Jennifer H. Madans, Ph.D., Associate Director for Science, NCHS, gave a background presentation on the Mission and Research Priorities of NCHS, linking these to issues of maintaining quality, the CDC Futures Initiative, Public Health Research, and the NCHS Research Agenda. She provided a brief glimpse of NCHS intramural projects and described the current extramural research activities, Centers of Excellence in Health Statistics—three cooperative agreements now concluding their last year of funding. Dr. Madans called attention to an ongoing CDC initiative to establish a very active extramural research program; NCHS' plan calls for a central role of the BSC in concept development and second-level review.

Dr. O'Neill encouraged members to consider carefully what was not presented during the day's presentations and to discuss these issues during the next day's meeting. She adjourned the meeting at 6:00 pm.

October 10, 2003

Dr. O'Neill called the meeting to order at 8:40 am. Following mention of a few procedural matters and administrative logistics, she turned to Dr. Sondik for his presentation on the State of the Center.

State of the Center: In his remarks Dr. Sondik questioned whether NCHS is doing what it should be doing, whether there are gaps in its foci and what it should be doing to build for the future. He acknowledged the need for a base of research to move NCHS programs forward. In describing the State of the Center he characterized it as in better shape than it ever has been, but a number of new initiatives, such as re-engineering data systems, present challenges. The BSC can play a significant role in assessing and assuring the quality of NCHS programs and activities and offer advice on how the Center can be more efficient, especially as the Center attempts to fulfill its obligation to disseminate data in a timely manner without impact on privacy and confidentiality. He reemphasized the complementary roles of the BSCNCHS and the NCVHS. NCHS engages also in a number of international activities; examples include the upcoming annual Interchange with Statistics Canada, a productive forum in which staff from both groups deliberate on matters of mutual interest, and the joint US/Canada Survey.

Dr. Sondik's presentation also commented on the NCHS budget history and obligations, staffing in the Center, facilities in both Hyattsville and Research Triangle Park, NC, and various collaborations within and external to DHHS. He pointed to long-term initiatives and the importance of responding to recommendations contained in <u>Shaping a Health Statistics</u> Vision for the 21st Century.

Discussion following his talk focused on several key topics.

NCHS budget: the difference between the Congressional allocation and CDC's centralized mandatory fund, and the extent to which NCHS is funded via budget authority or evaluation funds (in FY2003, the funding is entirely from evaluation funds; in FY2004, a mixture of budget authority and evaluation funds is proposed); justifying the budget in light of national expenditures on health care; the role of the BSC in addressing budget issues; the extent to which NCHS plays an active role in the development of budget proposals and has an opportunity to explain the importance of data in the budget setting process.

In reply to members' comments Dr. Sondik noted that NCHS discusses budget issues with partners within and external to the Department and receives plenty of guidance from the CDC and the Department regarding budget development. He explained that Dr. Julie Gerberding, Director of CDC, is a great supporter of the Center, and awareness of the NCHS financial situation is wider now. He acknowledged the various trade-offs that must occur throughout the budget process—within CDC, at the Secretary's level, the Office of Management and Budget, and Congress—and the need to put NCHS's budget in the context of the various components in the process.

<u>Programmatic gaps</u>: examining National needs and whether NCHS is addressing them (e.g., following people through the trajectory of the middle-aged and elderly populations, tracking children longitudinally; assessing how the health care system operates, social and mental health, domestic violence, public health emergencies and outbreaks); Community Health and Nutrition Examination Survey (CHANES) and the importance of local level analysis for understanding population health; a larger role for NCHS in rapid identification of urgent public health situations and in preparedness; conducting surveys in languages other than English and Spanish.

Dr. Sondik explained that the division of labor within CDC places some activities in the purview of other CDC entitities (e.g., surveillance programs). Regarding emergent, urgent public health circumstances, Dr. Sondik agreed that making sense of signals or recognizing anomalies relates to surveillance activities, but carrying out research that examines a "signal to noise" relationship fits well within the mission of NCHS. The Center was able to respond quickly to include bio-terrorism questions on the health care survey. The current NCHS budget does not permit the Center to mount CHANES broadly, but a strategy might be to adjust the operating budget to allow a look at different populations. The BSC can be helpful in this regard.

Overview of the National Health Interview Survey: Jane Gentleman, Ph.D., Director of the Division of Health Interview Surveys, gave an overview of the National Health Interview Survey (NHIS), its contents, sample design, redesign, field procedures, response rates, and integration with other surveys. She explained the main aspects of the re-engineering project and expected benefits, how the staff are coping with a flat budget, and topics of current analytic projects. The agenda called for a brief presentation of a topic of special interest, the State and Local Area Integrated Telephone Survey (SLAITS) and a discussion among BSC members of a particular

methodologic issue that arose in analysis of the results of the National Survey of Children with Special Health Care Needs. Unfortunately, discussion of this latter survey did not take place due to time constraints. In response to a question about sample cuts, Dr. Gentleman explained that higher field costs and the flat budget account for the need to consider reduction in sample; she noted that costs for the Census Bureau to carry out the survey amount to approximately \$18million per year. She also commented that the SLAITS on Children with Special Health Care Needs was conducted in 10 different languages and that the Joint Survey with Statistics Canada is being conducted in English, Spanish, and French.

Overview of the National Health and Nutrition Examination Survey: Kathryn Porter, M.D., gave a presentation on the National Health and Nutrition Examination Survey (NHANES), with a focus on the survey's goals, planning processes, collaborators, content areas, sampling and oversampling, and information flow. A brief video, designed for use with local health commissioners to garner their support for locating the mobile examination centers (MECs) provided a concise view of the MECs, how they are configured, and the kinds of laboratory and other testing that take place within the MEC. Dr. Porter posed some challenges for the future, including disclosure risk, survey content, focus on special populations, and sample design. In response to a question regarding what NHANES could do with new funds, she replied that a candidate activity would be longitudinal follow-up. Touching on the role of collaborators and partners in proposing and developing questions for the NHANES, she explained that most proposals for topics are really quite good. A question that arises is whether the survey should retain certain components and for how long.

Members suggested some topic areas worthy of consideration: racial and ethnic differences, measurement of stress hormones, mental health/stress (impact of discrimination and other markers), cognitive function in older persons, insurance coverage and use of health services (currently not comprehensive as it would lengthen the interview portion of the survey), oral health (there is a 15-minute oral health component to the survey), identification of environmental toxins (in lactating women). A concern raised by one member pertains to the issue of a "revolving door" of components, that is, the shuffling in and out of foci on particular parts of the anatomy.

Dr. Porter explained that NHANES does have a limited longitudinal component: six months post examination, staff follow subjects in whom hepatitis C and high prostate specific antigen have been identified to see what they have done; there are also matches of NHANES survey data to the National Death Index (NDI).

General discussion: Following the lunch break Dr. O'Neill took the Chair's prerogative to alter the agenda and opened the floor for general discussion among the BSC members. She asked members to give close consideration to the role of the Board and future agenda topics, encouraging use of email to facilitate communication. Members should suggest ideas for enhancing communication between face-to-face meetings. Dr. O'Neill suggested that a conference call before the January 22-23, 2004, meeting would be useful. Turning to Dr.Sondik, she inquired how he thought the BSC

could be helpful to NCHS. He responded that it could examine the relationship between surveys, looking at them simultaneously to identify inter-relationships (are there same or different items on surveys?). Members offered suggestions of future topics: more details on how NCHS makes decisions on technological aspects (for example, selection of BLAISE and editing systems); random digit dialing (RDD) surveys and the impact of cell phones on response rates, levels of response rates (how low can they be before NCHS determines to cease a survey?), more discussion of budget and how NCHS has accommodated, advantages and limitations of scientific and cost consolidation or integration of survey components (pruning or eliminating redundancy, tracking utility of components and the usefulness of results). Members wondered whether location of BSC meetings would confer more prominence to the proceedings and have an impact on attendance by persons who could influence budget development.

Mrs. Blankenbaker called members' attention to the need to recruit replacements for Drs. Bailar, Crimmins, Rodriguez, and Scheuren who will complete their terms at the end of April 2004. Nominations of principal and alternate candidates for nomination should be provided to her by no later than October 31, 2003.

Overview of the National Vital Statistics Program: Stephanie Ventura presented the National Vital Statistics Program and explained its history, particularly the Federal and State roles in the collection of data pertaining to births, deaths, marriages, and divorce. She highlighted the uses of vital statistics and future activities. NCHS has been working with partners to revise birth and death certificates, an activity that occurs every 10 years. Ms. Ventura pointed to progress to date and NCHS's role in the transition to a re-engineered vital registration system. Current budget resources limit the extent to which NCHS can move the effort forward.

Turning to the National Survey of Family Growth, Ms. Ventura explained its purpose, the content of the survey, its history, and new components in Cycle 6 of the survey. At present, interviews have been completed, with a 79% response rate, and data release is expected in summer 2004. Planning for Cycle 7 of the survey is now underway.

Ms. Ventura noted that during periods of flat funding, staff have had to eliminate collection of marriage and divorce data. Members inquired about the impact of parent surname differences in terms of determining out-of-wedlock births and whether the birth certificate captures race of the child as opposed to just the mother. Ms. Ventura responded that the birth certificate does not ask for the race of the child and that comparisons of surnames is no longer used to determine if a birth is out of wedlock.

Overview of the National Health Care Survey: Tommy McLemore described the "family" of surveys that comprise the National Health Care Survey. This set of surveys includes six components, not all of which are in the field every year. His presentation explained that all the health care surveys employ a common methodology, and data are used extensively to understand health care practice, identify and track specific conditions and problems, establish national priorities, and measure Healthy People

objectives. He provided examples of some key data from the various surveys and their application. Key goals for staff are to increase the relevance and timeliness of survey data, be more responsive to data needs for public health, health services research, and DHHS initiatives, and expand the surveys to include the full spectrum of health care providers. The National Health Care Surveys face some challenges, including establishing priorities among many competing data needs, balancing data needs and respondent burden, developing new initiatives while maintaining necessary trend data, and resource management.

During discussion of Mr. McLemore's talk members raised questions about response rates and costs necessary to maintain them. Mr. McLemore acknowledged that budget is a continuing issue for his division. The surveys experienced tremendous growth from 1989-1995, but, more recently, in order to field the nursing home survey, staff had to pull the home and hospice survey out of the field. Due to resource constraints, NCHS cannot conduct all six of the health care surveys in a year. He admitted that pulling and refielding tends to be costly in the long-run and that knowing over the long-term what to anticipate in budget resources would be helpful. To maintain response rates requires great effort in development of materials to "sell" the surveys. The hospital discharge survey is the only one of the six surveys for which NCHS provides an incentive (for pulling and refiling medical records). Because of these efforts the surveys have very high response rates. Staff exerted great effort to ward off any significant impacts on response rates of the implementation of HIPAA.

Mr. McLemore explained that an area presenting some difficulty pertains to identifying assisted living settings and other long term care facilities. DHHS has interest in surveying long term care facilities, and an inventory of inventories would be very useful. At present most of the available resources are devoted to getting the nursing home survey in the field in 2004; staff need to tackle the home and hospice survey next. A significant data gap in the program is the absence of the National Survey of Ambulatory Surgery.

In concluding this discussion, Dr. Sondik noted that the decline in the number of active individual health care surveys is important to consider. An issue is that the "family" of surveys suffers from being a "family" of surveys. In periods of limited resources NCHS has found it easier to operate by shifting surveys in and out of the field.

Health, United States: History and Future Directions: Diane Makuc, Dr.P.H., opened her presentation with a brief review of the legislation that mandates publication of *Health, United States*, its goals and audiences, and general content. This report to the Secretary and Congress receives widespread distribution through multiple media (hard copy, CD-ROM, web) and serves varied purposed. With recent publication of the 27th annual report, Dr. Makuc noted that it's time to take a look at future directions. Keeping in mind several constraints (legislative, resource, clearance), she asked how NCHS should decide on future directions for the report; whether there should be a review outside of the annual departmental clearance process; what aspects of the report

should receive this review (target audience, content, format); what process should be employed; who should provide the input.

Members posed a number of questions and suggestions:

How often does NCHS update the tabulations?

Dr. Makuc explained that staff update the data tables to the extent possible prior to publication, and vital statistics tables are usually updated on the web in between published versions. The report is on the NCHS web site.

Could NCHS put the data on the web as they become available?

Yes, that is possible.

Does NCHS have a good sense of how people use *Health, United States*? Are there activities that might be done to enhance how it's used? Could NCHS add additional search capacity for on-line use?

Dr. Makuc answered that NCHS has some limited information on how it's used—for research, faculty use in courses, and preparation of grant applications.

One member wondered whether NCHS could distribute the report totally electronically since that would assure a more up-to-date presentation of the data. Another member described the report as a "great source book" for quick reference and argued for keeping a bound version as it would reach a broader audience. Given its value to consumers, another recommendation was to place the report for sale in commercial book shops (it can be purchased via Amazon.com as well as through the Government Printing Office). In terms of increasing public relations and awareness, Dr. Makuc agreed that staff could prepare a magazine article that reports data from *Health*, *United States*; she noted that in the past Secretaries of Health and Human Services have had great interest in the report and held press briefings to announce its availability. A question about number of "hits" on the web drew a response that there had been 4,330 in the week since its appearance.

Members of the BSC offered some suggestions pertaining to the report:

- Extend the potential audience beyond that currently receiving the report
- Develop supplementary reports in formats for different audiences
- Distribute solely on the internet because of its greater flexibility and ability to reach more audiences, particularly lay audiences

Several members requested more information about web access to the report: number of "hits" and what parts of the report are searched. A concluding comment from a member extolled the value of the report, noting that it provides a history of health statistics and that its historical value is enormous.

Dr. Sondik encouraged members to peruse the hard copy and web versions of the report and send suggestions and potential future options prior to the next meeting.

Dr. O'Neill inquired if there were any remarks from members of the public. There being none, she asked members of the BSC to consider agenda topics for the next meeting (January 22-23, 2004) and to develop a list of long-term issues the Board should take under advisement. BSC discussions likely should examine essential trade-offs that NCHS confronts and how best to use limited resources. Dr. O'Neill stated that there are some topics that may need more in-depth discussion and reiterated her sense that funding for health statistics must be related to the aggregate of health expenditures in this country. She recommended a review of budgets of other data collection agencies to compare expenditures against those for NCHS.

Dr. O'Neill adjourned the meeting at 3:48 pm.

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

June E. O'Neill, Ph.D.

December 1, 2003
Date

Attachment #1: Attendance First Meeting of the Board of Scientific Counselors, NCHS October 9-10, 2003

Members present were:

Chair: June O'Neill, Ph.D.

Designated Federal Official: Linda W. Blankenbaker

Barbara Bailar, Ph.D.

Eileen Crimmins, Ph.D.

Vivian Ho, Ph.D.

William Kalsbeek, Ph.D.

Janet Norwood, Ph.D.

Aldona Robbins, Ph.D.

Rene Rodriguez, M.D.

Louise Ryan, Ph.D.

Fritz Scheuren, Ph.D.

Robert Wallace, M.D.

Alvin Onaka, Ph.D. Alonzo Plough, Ph.D.

Members Nicholas Eberstadt, Ph.D., and Fernando Tevino, Ph.D., were absent.

Liaison to the BSC present was:

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

DHHS staff members present over the course of the meeting were:

John Condray, Office of the General Counsel

Dale Hitchcock, Office of the Assistant Secretary for Planning and Evaluation

Audrey Burwell, Office of Minority Health

Miryam Grantham, Office of Disease Prevention and Health Promotion

Steve Cohen, Agency for Healthcare Quality and Research

CDC staff members present were:

Cathy Ramadei and Renee Ross, Management Analysis and Services Office (MASO), Committee Management and Program Panels Activity

NCHS staff members present were:

Jack Anderson Marjorie Greenberg

Irma Arispe Marni Hall

Lew Berman Rosemarie Hirsch

Amy Bernstein Ed Hunter
Stephen Blumberg Susan Jack
Vickie Burt Debbie Jackson
Larry Cox Julia Holmes
Randy Curtin Jean Kozak

Julius FosterDewey LaRochelleJane GentlemanJennifer Madans

Nathaniel Schenker Diane Makuc Cynthia Sidney Jill Marstellar Sandy Smith Thomas McLemore Edward Sondik Peter Meyer Mary Moien Genevieve Strahan Gwen Mustaf Anne Stratton Sam Notzon Patrice Upchurch Kathryn Porter Stephanie Ventura Rob Weinzimer Eve Powell-Griner Howard Riddick Al Zarate

Members of the public attending the meeting were:

William Tatum, COSSA

Updated: 10/22/03