June O’Neill, Ph.D., Chair of the Board of Scientific Counselors (BSC), National Center for Health Statistics (NCHS), convened the seventh meeting of the BSC at 2:00 p.m. on Thursday, September 15, 2005. Dr. O’Neill announced that Kathleen Fyffe, the last speaker on the agenda, would be unable to attend due to her commitments in the wake of Hurricane Katrina. Dr. O’Neill welcomed to the table, Dr. William Scanlon, liaison from the National Committee on Vital and Health Statistics. The names of others attending the meeting are listed in Attachment #1.

**State of the Center:**

Dr. Edward Sondik, NCHS Director, referred Board members to the “NCHS Update” (attached) that he distributed to Board members in advance of the meeting. The update highlighted CDC and NCHS program activities and major NCHS data releases. Dr. Sondik announced the appointment of Dr. Steven Solomon as Director of the CDC Coordinating Center for Health Information and Service. He distributed copies of the new NCHS publication, “Sexual Behavior and Selected Health Measures,” which was released on September 15. He also distributed the announcement by DHHS Secretary Leavitt of the American Health Information Community (AHIC), formed to advance efforts toward electronic health records.

**Discussion:**

Dr. Sondik was asked about the impact of Hurricane Katrina on NCHS survey work. He reported that the impact was expected to be small. Contact was lost temporarily with some Census Bureau interviewers, and NCHS telephone surveys in the region were on hold. Board members recounted their response to information needs related to Katrina. Drs. Ho and Kalsbeek were asked to provide input into quick-turnaround surveys being conducted in the region. Dr. Schwartz explained that the need of State registrars was not in the area of death registration, as might have been expected; rather, it was in birth registration. Displaced families required birth certificates to place children in schools. Dr. Schwartz reported that the National Association for Public Health Statistics and Information Systems (NAPHSIS) facilitated an agreement whereby any state can...
be an agent of the state of Louisiana for the purpose of obtaining a birth certificate.

Several Board members stated that NCHS possesses many of the skills required to respond to emergency needs for health information and Dr. Sondik was asked whether these skills were utilized. Drs. Sondik and Madans reported that two NCHS staff members were deployed to the region and that others were prepared to go if called upon, but that the emergency information needs were being handled more along CDC’s “outbreak” model, with EIS officers being called upon rather than NCHS survey experts. After further discussion, the Board voted unanimously to request that Dr. Sondik raise the issue at the next meeting of the Interagency Council on Statistical Policy, of how NCHS and other Federal Statistical agencies can be more fully prepared and utilized to respond to quick-turnaround survey needs in the future.

**Update from NCVHS:**

Dr. William Scanlon was introduced as the new NCVHS liaison to the BSC. He said that since the last BSC meeting in April, NCVHS produced three reports: (1) “Eliminating Health Disparities” reports that the need is great for improved data collection on the health of population subgroups, and for greater use of data; (2) the report on Personal Health Records shows that there is a great deal of variability regarding personal health records, and it would be useful to develop a framework to help facilitate more comparability; (3) the 7th annual HIPAA report indicates that there is progress in this area but it is slow. Dr. Scanlon reported that the NCVHS also is considering what can be done to improve the capability of DHHS to respond rapidly to future “Katrinas.” How can information technology improve health and health care? Dr. Scanlon reported that the August meeting of the NCVHS Executive Subcommittee focused largely on the matter of health information technology, which demonstrates the importance of this topic.

**Discussion:**

Board members reiterated the importance of strengthening the role of Federal statistical system in responding to future emergency data collection needs. It was suggested that this might be an appropriate subject for a CNSTAT panel to address.

**Status of Vital Statistics Review Process:**

Dr. Kalsbeek summarized the review process and reported that the panel to review the NCHS Mortality program has been formed. Dr. Schwartz expressed concern over the absence of a State representative with responsibility for mortality data collection. The Board agreed to add such a representative. Dr. Schwartz will provide suggested candidates.
New Designated Agent Authority:

Mr. Hunter described the new Designated Agent Authority included in the Confidential Information Protection and Statistical Efficiency Act of 2002 (CIPSEA). CIPSEA provides NCHS (and others in the Federal government performing statistical activities) the authority to designate non-NCHS employees as agents who can then access non-public data. In effect, these individuals would act as if they were NCHS employees or contractors for this purpose, allowing NCHS to extend the reach of its confidentiality policies and practices to these individuals. Agents must be under the supervision of NCHS and be conducting work consistent with NCHS’s mission. Mr. Hunter said that NCHS has sought this authority for many years, and he is pleased that it was finally enacted. Mr. Hunter said the new authority would be implemented gradually, with implementation assessed after 6 months before being extended further.

Discussion:

Several Board members expressed concern about what they described as the difficulty of researchers accessing data from the NCHS Research Data Center. Chief among the problems, they said, is the length of time for review of applications. Mr. Hunter stated that this is a separate issue, and that the Designated Agent authority will actually facilitate access to NCHS data. Nevertheless, the discussion that followed focused on the need for NCHS to improve access to its data files.

Board members said that NCHS needed to think of creative ways to ease access to its data. They emphasized that doing so would result in greater support for the Center. There was the suggestion that additional Research Data Centers would be useful. Board members said that it was important to publicize the availability of the Research Data Center, to promote its use. Board members questioned why some other agencies seemed to be able to more easily disseminate their files. It was explained that differences in legislative requirements allow some agencies, such as the National Center for Education Statistics, to use mechanisms not available to NCHS. Board members commended Mr. Hunter for moving in a direction that can expand access to NCHS data, and suggested that the new policy be promoted through newsletters of AAPOR, PAA, and other groups.

New Statistical Policy on Data Release:

Ms. Smith described a draft Statistical Policy designed to give Federal Statistical agencies the sole authority to determine content and timing of news releases, and to allow release without agency policy statements. Dr. Norwood expressed her hope that such a policy would strengthen the independence of the statistical agencies.
Research Agenda Update: Health Insurance:

Dr. Bilheimer discussed efforts to improve estimates of the uninsured from national surveys. She described ASPE’s concerns about differing estimates of the uninsured, discussed major surveys that estimate the uninsured, explained factors contributing to the different estimates, and highlighted NCHS efforts to improve measures of coverage.

Discussion:

Board members commended Dr. Bilheimer on her talk and suggested that it be submitted for publication in a health research journal. Board members noted that Census Bureau health insurance releases are limited in some respects (for example, response rates in city centers are low) and do not mention that there are other sources of such data. It was suggested that Census reports indicate that there are other sources of health insurance data. There was discussion as to whether the public is best served by determining the single-best data collection program on health insurance, or whether it is beneficial continue to have multiple data sources. Board members raised issues about specific population sub-groups, including the institutionalized population; veterans who do not have health insurance coverage per se, but who have access to care; and Medicaid-eligible people who do not know that they are eligible for coverage.

Research Agenda Update: Methodological Issues:

Dr. Madans highlighted NCHS activities to support DHHS efforts to address methodological issues in four subject areas: 1) health insurance coverage; 2) income, 3) prescription drugs, and 4) race/ethnicity. The concern is that the Federal statistical system produces different estimates on these measures from different data collection programs. Dr. Madans reported that NCHS is also working on a number of sampling issues. The Center is currently evaluating the utility of using the U.S. Postal Service list in place of the NCHS listed sample; studying methods for quick-turn around surveys; making efforts to produce state-level estimates; looking at differences in estimates of disability; and studying issues in surveying cell phone-only households.

Discussion:

Board members encouraged NCHS to be “at the table” for discussions within the Department on all topics where there are discrepancies in survey results. The suggestion was made that a possible topic for discussion at an upcoming meeting would be issues reporting income data and health.
New Statistical Policy on Survey Standards:

Dr. Madans announced that OMB is requesting comments on a revised Statistical Policy Directive on Standards for Statistical Surveys. This is part of an ongoing effort to improve the quality, objectivity, utility, and integrity of information collection and disseminated by the Federal Government. (Draft policy attached.)

Vital Statistics Data Release Issues:

Mr. Rothwell discussed the NCHS response to the call for a modification of NCHS Data Release policy for vital statistics data. Mr. Rothwell described the current NCHS policy and explained that jurisdictions have asked NCHS to review this policy because of concerns that it is in variance with State laws, regulations and/or practices. Other concerns presented by jurisdictions centered around the costs of implementing new standard certificates. Mr. Rothwell stated that NCHS is currently in negotiations with NAPHSIS on a proposed new approach.

Discussion:

Dr. Schwartz stated that the cost of implementing new standard certificates is very expensive, and only 12% of States' budgets for vital statistics comes from the Federal government. Dr. Schwartz said that only two states have implemented new items on the birth certificates; so the problem is not a case of States in general having a great deal of new information to which they are restricting access. Several Board members emphasized the need to show the importance of vital statistics data to for policy-making. Demonstrating how the data would be used, would support efforts to provide better access.

Status of Intelligence Reform and Impact on Vital Statistics Program:

Mr. Rothwell provided an update to the Board on the Intelligence Reform and Terrorism Act and its impact on NCHS. Mr. Rothwell described the role of NCHS in coordinating efforts to develop standards for creating the most secure possible vital registration system.

Agenda-setting for next Board meeting:

Dr. Koepsell suggested that the subject of imputation be considered as a topic for a future BSC meeting. Dr. Madans offered to send Board members the NCHS technical document outlining imputation issues and approaches.

Dr. Elo proposed—and the Board unanimously agreed—that the Board establish a working group related to limited-access data from NCHS. The working group would keep abreast of issues, and consider how to make the Research Data
Center most accessible and most useful. Mr. Weinzimer was asked to canvass Board members to solicit their interest in participating.

Dr. O’Neill invited Board members to think about candidates for the Natality review panel (to be formed following completion and evaluation of the Mortality review).

Announcements:

The next meeting of the BSC will take place on January 26-27, 2006 in Hyattsville, Maryland.

The Chair adjourned the meeting of the BSC at 12:00 p.m. on September 16.

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

/S/ __________________________
June E. O’Neill, Ph.D.

Attachment #1: Attendance: Sixth Meeting of the Board of Scientific Counselors, NCHS, September 15-16, 2005.

Members present were:
Chair: June E. O’Neill, Ph.D.
Designated Federal Official: Robert J. Weinzimer

Irma Elo, Ph.D.
Raymond Greenberg, M.D., Ph.D.
Michael Grossman, Ph.D.
Vivian Ho, Ph.D.
William Kalsbeek, Ph.D.
Thomas Koepsell, M.D.
Janet Norwood, Ph.D
Neil Powe, M.D.
Louise Ryan, Ph.D.
Steven Schwartz, Ph.D.

Members not present were:
Nicholas Eberstadt, Ph.D.
Alonzo Plough, Ph.D.
Matthew Snipp, Ph.D.
Fernando Trevino, Ph.D.
NCHS staff present were:
Linda Washington
Charlie Rothwell
Debbie Jackson
Sandy Smith
Robin Cohen
Eve Powell-Griner
Cliff Johnson
Jane Sisk
Diane Makuc
Mike Sadagursky
Colleen Choi
Lester Curtain
Stephanie Ventura
Marcie Cynamon
Bob Anderson
Ken Kochanek
Julie Kowaleski
Linda Bilheimer
Ed Hunter
Anjani Chandra
Jo Jones
Meena Khare
Nathaniel Schenker
Mary Moien
Rebecca Middendorf

Other Attendees
William Scanlon