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

Minutes of the Second Meeting
January 22-23, 2004
Room 1403A and 1405 B
3311 Toledo Road
Hyattsville, MD 20782

June E. O'Neill, Ph.D., Chair of the Board of Scientific Counselors (BSC), National Center for Health Statistics (NCHS), convened the second meeting of the BSC at 2:05 pm, on Thursday, January 22, 2004. The names of those attending the meeting are listed in Attachment #1.

Following introductions of Board members and staff, Dr. O'Neill turned to the Director of NCHS, Edward J. Sondik, Ph.D., for remarks.

State of the Center. Dr. Sondik mentioned that he would cover a number of topics very quickly. He noted that CDC is awaiting details on the fiscal year 2004 budget and that resources will be very tight for NCHS. The Center is looking to the Office of the Secretary, DHHS, for relief. The President's budget for fiscal year 2005 will be announced on February 2, 2004.

Since the last meeting of the BSC, NCHS has made several key staff appointments: Michael Sadagursky as Associate Director for Management and Operations and Charles Rothwell as Director of the Division of Vital Statistics. Recruitment for the Director of the Division of Health Care Statistics is nearing completion.

Dr. Sondik called the Board's attention to the presence of a number of fellows, interns, and Epidemiologic Intelligence Service (EIS) officers, all of whom are conducting studies at NCHS. Some 16 persons are participating in this capacity. A slide photo depicted a portion of the total group. Those in attendance at the meeting rose and announced their specific research interests. Dr. Sondik noted NCHS' interest in IPAs—Intergovernmental Personnel Act--persons participating at NCHS and staff taking on activities external to NCHS.

To set the context in which NCHS (and other governmental agencies) operates, Dr. Sondik described the key elements of the President's Management Agenda (PMA) which deals with significant aspects of program management and implementation. NCHS has responded to the PMA by consolidating certain administrative functions, abolishing organizational components, and centralizing administrative services. There has been no real elimination of programs, however, a challenge is to monitor closely the ratio of staff to supervisors. Maintaining this balance may have some impact on promotion opportunities for staff. As part of the PMA, NCHS is also paying attention to workforce planning and development. The Office of Management and Budget (OMB) also requires that Federal entities complete a Program Assessment Rating Tool (PART) which deals with product quality and program performance. Dr. Sondik noted that the BSC could play an important role in helping the Center prepare for PART by evaluating whether NCHS is meeting its mission.

With respect to activities in CDC, Dr. Sondik described the CDC Futures Initiative which is examining where CDC should be in 15-20 years, particularly focusing on developing quantitative goals for the next 5-10 years. An outcome of this activity is the realization of the need for a stronger CDC research endeavor. Further, identifying CDC's customers was something of a revelation inasmuch as previously CDC put its focus on state and

local governments. The Futures Initiative revealed that the people of the U.S. are, indeed, CDC's customers. The Advisory Committee to the Director of CDC will be looking in depth at the Futures Initiatives at its February 5, 2004, meeting. Chairs of all of the CDC advisory committees and boards of scientific counselors were invited to attend this meeting.

Another activity that ultimately will have an impact on NCHS programs is an overhaul of the OMB statistical standards, some of which date from quite a long time ago when agencies were using punch cards and were told to assure that staff "lined up" the cards appropriately. Specifically, the Federal Committee on Statistical Methodology (FCSM) was asked to examine directives 1 & 2 and to rewrite them as one document. The target completion date is six months. The resulting standards will apply to large Federal statistical agencies and will align the standards with the quality guidelines. The standards will achieve more consistent reporting of survey operations and results so that quality can be evaluated.

A number of legislative activities are of potential interest to NCHS, particularly bills from Congresswoman Nancy Johnson and Senator Hillary Clinton that promote standards for a national health information infrastructure. A listing of legislative initiatives is included in the agenda book.

BSC members received copies of revised birth and death certificates at the October 2003 meeting. Since that meeting the Secretary, DHHS, has approved these certificates. The revision process took place over many years and involved a broad spectrum of groups and individuals with expertise and interest in the birth and death registration process. Improvements include guidance for completing the forms and the collection of more information regarding automobile accidents. Once the registration system is fully revised (or re-engineered), through the use of the internet, revisions to the certificates can be made more rapidly. NCHS anticipates that the enhanced registration system will be more flexible and will permit the conduct of a larger number of studies.

A hallmark of NCHS data collection programs is the extent to which staff undergo retraining. There is no substitute for this annual revitalization, and the activities are aimed at maintaining the quality of what NCHS does. Recently, NCHS staff and contractors for the NHANES, NHIS, and health care surveys underwent various training activities.

The NCHS Data Users Conference, taking place July 12-14, 2004, at the Omni Shoreham Hotel in Washington, DC, provides an opportunity for NCHS staff to offer hands-on training to a wide variety of data users. The conference announcement will be distributed in March 2004, and Dr. Sondik encouraged BSC members to attend this very popular meeting. Registration for the conference will be on-line (or via mail).

NCHS has issued a number of data releases since the BSC's last meeting, and examples of these releases are included in the agenda book. Two notable reports that demonstrate heavy reliance on NCHS data are the recent National Healthcare Quality Report and the

National Healthcare Disparities Report, both of which were issued by the Agency for Healthcare Research and Quality. Dr. Sondik also noted that a 2002 article on obesity (authored by NCHS staff) was one of the 10 most cited papers in the Journal of the American Medical Association.

In follow-up to discussion about *Health United States 2003* at the October BSC meeting, Dr. Sondik called attention to a brief article that was widely distributed to lay publications (such as Self) and to some general statistics about use of the NCHS web site. In October 2003 there were a total of 1.4 million visits to the web, and the most often visited or downloaded site was that for *Health United States 2003.* Interestingly, *Health United States 2002* was among the top 20 sites visited in October.

Dr. Sondik concluded his remarks by noting that NCHS continues to make excellent progress even in the face of constant challenges.

BSC members raised a number of questions and comments:

How much coordination is there among NCHS programs, particularly regarding the complementarity of questions?

> Because of the extensive reviews that surveys undergo, both within NCHS and at OMB, staff are relatively successful in this regard. Survey designs are sensitive to duplicative questions and respondent burden.
>
> NHANES staff are working closely with USDA and National Cancer Institute staff on questions pertaining to food and nutrition (24-hour recall for USDA and food frequency approach for NCI). This is an example of complementary approaches to data collection.

The data on web downloads and visits point to an incredible trend; clearly resources need to be put into the web.

> NCHS makes continual efforts to improve the web; obviously, it serves the public well.

What is the status of the authorization for NCHS? How can the BSC be helpful in moving this along?

> Although the legislation has expired, the authority continues as long as NCHS receives appropriations. There are ongoing discussions within CDC, but there is no proposal for any real changes to the authorization NCHS has had opportunity to contribute to the dialogue. Not many health bills have gone through the Congress.

Could NCHS be reauthorized in a different structure or a different way?

NCHS has not been involved in any discussions that would suggest any real change.

Is there any way to tally the kinds of inquiries and the nature of inquiries on the web?

Currently, there is no real way to ascertain the nature of web downloads.

Do death certificates provide any indication of the kind of vehicle involved in a vehicular death?

NCHS staff work closely with the National Highway Traffic Safety Administration which collects this type of information. Re-engineering of the NCHS vital statistics system will help in acquiring these statistics from NHTSA.

Training people to complete vital records, especially cause of death, is very important. Many studies show there are problems. This would be a perfect area for a grant program.

NCHS will do everything to make this a priority.

Persons collecting these types of data are not highly trained or sophisticated; we need operations research not high level research to study the spectrum of skills needed for collecting the data.

Technical appendices that accompany data releases and reports provide a good documentation of programs. We know how to fix the programs but less about how to do the training. Re-engineering, new certificates, and clearer instructions will go far to improving data collection. If we had sufficient resources, we could do a pre-post survey to assess skills.

Staff could make a presentation to the BSC on the vital statistics re-engineering effort from the quality perspective. We have an opportunity to change public health reporting—many individuals are involved with vital statistics data before the data arrive at NCHS.

This topic might be suitable for a BSC/NCVHS workshop.

Report from the National Committee on Vital and Health Statistics. Vickie M. Mays, Ph.D., liaison to the BSC from the National Committee on Vital and Health Statistics (NCVHS), gave a brief overview of the NCVHS and noted that as of 1996 the committee was restructured to meet expanded responsibilities of the Health Insurance Portability and Accountability Act (HIPAA) of 1996. NCVHS works closely with the DHHS Data Council; evidence of the committee's productivity and activity is on the NCVHS web site which also includes copies of letters that the committee sends. Three subcommittees and a workgroup conduct the business of the NCVHS. The committee receives guidance from hearings, commissioned papers, and users; it reviews and

comments on national reports and proposals; and carries out various projects. The Executive Committee of the NCVHS has proposed a joint meeting with the BSCNCHS in 2005.

Process and Results from NHANES Forum. Clifford L. Johnson, Director of the Division of Health and Nutrition Examination Statistics (DHANES), discussed the process and results from the NHANES Forum, noting that the activity was the second such forum. The novel aspect of the recent forum was the use of Open Space Technology which allows participants to design their own agenda for the meeting and provides the recommendations, conclusions, and plans for immediate action within days of the event. The September 2003 NHANES Forum involved almost 100 persons and featured 28 different sessions. Participant feedback was very positive: increased knowledge about NHANES and availability of technical support; enhanced communication and collaboration; examination of innovative methods and survey design. The Open Space Technology allowed for good brainstorming, leveled the playing field for all participants, and facilitated connections among persons with similar interests and ideas. Action items emerging from the Forum include examination of the National Children's Survey and the overlap with NHANES, implementation of Community HANES, development of international collaboration and cooperation (taking place through discussions with Mexico and Canada), and linking NHANES data with other sources.

Questions and comments from the BSC:

Were there any real results or measures? Did the Forum identify new things to include in the survey or things to eliminate?

> Staff tackled the most obvious recommendations quickly. Some suggestions will be difficult to incorporate. A result of the Forum was the need to do a better job of demystifying NHANES. Some individuals noted difficulty in finding information or how to use data. As a result, staff have modified the NHANES web site to make it easier to find particular items. In terms of deletions, staff have worked closely with Federal partners. The bottom line is that NHANES staff do listen and do make changes as necessary.

What's the level of subject participation in the survey?

> NHANES staff commit a significant amount of resources (dollars and time/effort) to outreach designed to maintain high response rates. It is a constant effort and requires a vast array of tools to encourage participation.
>
> The current NHANES includes the full age range and almost all "body parts."

The survey has included mental health modules on and off over the years. The National Institute of Mental Health will drop out of the survey in 2005-6 due to a number of decision factors.

The first BSC meeting featured overview presentations on the main NCHS data collection and survey programs. Overviews from the remaining scientific and technical programs were on the agenda for the second meeting.

Overview of the Office of Research and Methodology. Lawrence H. Cox, Ph.D., Associate Director for Research and Methodology, briefly described the organizational structure of the Office of Research and Methodology (ORM) and noted the major activities in the purview of ORM. The staff carry out a number of activities pertaining to survey design, modeling research, analysis, confidentiality and disclosure limitation. In addition ORM houses interdisciplinary research centers and laboratories, including the Research Data Center and the Questionnaire Development Research Laboratory. An active research program takes place, and staff produce a number of peer-reviewed publications annually. ORM also takes advantage of opportunities to engage extramural researchers in its activities. Dr. Cox posed a major issue for the BSC's consideration: how can NCHS position survey methodology programs for the next generation of national data needs? Are there new paradigms for survey design and analysis? How can NCHS better position its Research Data Center? How can NCHS increase the capacity of a research program in a small statistical agency?

Dr. Cox noted that it is the responsibility of a statistical agency to provide guidance to the analysis process and that ORM staff have applied modeling techniques to the issue of cutting sample. Research data centers allow for performing confidentiality and methodological research.

In response to a question concerning the basic cognitive work that addresses issues surrounding bioterrorism, Dr. Cox explained that a CDC statistical advisory group has focused a report on the mathematical aspects of anticipating instances of bioterrorism and concludes that there is a need to involve more data scientists in this issue.

Dr. Sondik remarked that the Futures Initiative surveys revealed a sense on the part of public health professionals that CDC is organized into a set of silos. There is a need to bridge the silos; ORM's cognitive laboratory is certainly of value to DHHS in this regard.

A BSC member called for greater collaboration and for NCHS to provide more statistical advice to CDC. It is important that the BSC make it clear that there is a two-way street between the medical/clinical and statistical communities. NCHS could really be helpful in forging a more collegial relationship. There's a sense that the cognitive laboratory does a lot of work for external partners.

Dr. Sondik acknowledged the need for cross-walks and bridges to the various silos at CDC and that the work of NCHS does cut across CDC. Nevertheless, there's still a proprietary sense that characterizes other programs at CDC.

CDC is trying to gather expertise and use it more aggressively to forge collaborations.

Whom does the cognitive laboratory serve?

The primary beneficiary of the lab's work is NCHS, although other entities such as the CDC PRAMS program, EPA, and FDA avail themselves of the lab's expertise.

A question of balance arises—meshing a small staff, carrying out service work, and conducting research.

In an effort to acquire more data on race and ethnicity, it would seem important to permit the sharing of data and to develop more data centers. National Science Foundation funding might be applicable in this regard.

NCHS has approached a number of universities regarding establishing research data centers. Resources, outreach, and training are integral to sustaining this type of activity.

A member made several suggestions for NCHS to consider:

Disaggregate activities into problem-solving areas-for example, there is a need for sero-surveillance. Perhaps NCHS could designate a separate cohort from whom it acquires only sero-data.

In addition to representative samples, spend some time on non-representative small cohorts (for example, discharges from prisons, disease inception cohorts, the homeless, troops returning from overseas, day laborers). It would seem important to gain information about what's going on in the country.

Dr. Sondik stated that NCHS is in a perfect position to discuss these issues/ideas at the DHHS level and that this might be suitable for consideration at the NCVHS. In some respects the longitudinal children's study (led by the National Institute of Child Health and Human Development) responds to the suggestion for a disease inception cohort. The study could possibly look at the role of environment as an influence on children's growth and health.

Another member commented that there are cheap and expensive ways to do things. What are the most cost-effective ways to get needed answers? NCHS should keep these questions in mind.

Hearings conducted through the auspices of the NCVHS might be a way to identify partnerships that would facilitate understanding of what data needs are not being met at the DHHS. Tapping into various foundations could be useful as well.

A final recommendation from a BSC member was for NCHS to take advantage of its mission and expertise and promote its value and potential for service throughout the DHHS.

This portion of the meeting concluded at 5:45 pm.

January 23, 2004

BSC members reconvened on Friday, January 23, 2004, at 8:50 am. Following introductions of three additional members, Dr. O'Neill called on Diane Makuc, Dr.P.H., to continue with the final NCHS program overview.

Overview of the Office of Analysis and Epidemiology. Dr. Makuc, Acting Director of the Office of Analysis and Epidemiology (OAE) touched briefly on a number of the diverse activities taking place in her program. The office carries out a cross-cutting analytic program and collaborates with NCHS, CDC, and HHS staff in various activities. Dr. Makuc reminded members that OAE produces *Health United States* but also focuses on Healthy People 2010, aging and chronic disease, infant/child/women's health, injury and disability, and developing file linkages.

OAE staff provide support for monthly Healthy People 2010 progress reviews which Dr. Sondik presents to the Assistant Secretary of Health. The NCHS web site includes materials from these periodic reviews. Staff also design and carry out statistical workshops on tracking health indicators. To facilitate data linkages, OAE developed an automated tracking system that includes current addresses of all NCHS survey participants. An example of a file linkage activity is work that matches NHIS, mortality, Medicare, and Social Security data. Evaluation research includes analysis of probabilistic matching techniques used by the National Death Index to identify deaths.

OAE staff are actively involved in the longitudinal children's study mentioned previously. One staff member is on a part-time detail to NIH to assist in planning activities. The study will focus on subjects pre-birth through age 21.

A significant OAE activity is the International Collaboration Effort (ICE) on Injury Statistics, a 10-year program that addresses issues in collecting, coding and grouping injury data to improve comparability and quality of data. An annual injury report will be able to show the nature of injury, thereby leading to better injury prevention practices.

Staff also examine trends in summary measures of health, mental health of the elderly, and prescription drug use among the elderly. Dr. Makuc noted that trends show some increase in healthy life expectancy (HLE) and that preparation of trends in asthma is underway.

As part of its dissemination activities, OAE has developed a data warehouse on trends in health and aging. The warehouse includes tables (charts, maps, explanatory notes) and is

available on the NCHS web site. A Spanish version of the warehouse is under development.

Dr. Makuc's presentation generated much discussion and many questions.

Does the data warehouse contain pre-prepared tables?

> Yes. The warehouse includes very large tables; users can select from variables to pare down the size of the tables. These are not microdata.

Can one perform on-line tabulations?

> NCHS is hoping to have capability this spring to allow for real-time tabulations; this will involve use of SETS (Statistical Export and Tabulation System). The Census Bureau's Ferret system can be used to access NCHS data, but NCHS really does need to develop its own system like Ferret.

Does the data warehouse include variance functions?

> Yes, the warehouse does include variance estimates.

What will have data on prescription drug use?

> *Health United States* will provide these data from the National Ambulatory Medical Care Survey and the National Hospital Ambulatory Medical Care Survey. Over the counter drugs will be included as well. Some NHANES data will provide information.

There's a question of the quality of data on prescription drugs and costs and a gap between what's written/prescribed and what's purchased. There may be a need to link with a consumer expenditures survey. The Health and Retirement Survey (HRS) contains an estimate of out-of-pocket drug expenses.

Has NHCS considered developing its own sampling frames? Commercial entities can't compete with government in this area. This is a real private-public sector issue. With the emphasis on government contracting out, it would seem that there would be more encouragement to develop public/private collaborations. This is an issue that should be discussed.

With a more efficient system, dollars would go further. NCHS needs a good sampling frame in order to have a good survey. There is great inefficiency and cost to the government for private groups to develop frames.

> NCHS still develops its own frame and is not using Census listings. There has been some discussion of using a supplemental frame, such as the American

Community Survey (ACS) to identify rare groups. There are downsides to using Title 13 data. A subcommittee of the BSC could look at this issue.

A good time to bring this issue to the fore would be during reauthorization of the Census Bureau whose Title 13 legislation looms as a safeguard as well as a barrier. This title protects Census data and affects privacy.

How does OAE determine what topics to address and findings to report?

For preparation of the report from the Forum on Child and Family Statistics, the interagency process develops the indicators that are included. There are not a huge number of health statistics in this report. Reports on Healthy People 2010 rely on other DHHS individuals to suggest topics—this is a collaborative process throughout the department. Some topics of OAE activities are staff-generated (individual interests and initiative) and constitute intramural research; others are generated by external parties through a variety of advisory bodies and the department. Most projects require concurrence from senior NCHS leadership.

The National Indicators Project (through the General Accounting Office/GAO) involves a large number of groups, including NCHS, and is examining what components should be included in health.

It's not clear what the principal measure of health actually is. One doesn't want to focus entirely on mortality. Disability would also be important.

To what extent does NCHS involve itself in collaborations surrounding development of a measure of healthy life expectancy (HLE)? We need some measure of fitness as well.

NCHS has participated in REVES and has been interacting with WHO, the United Nations, and other parties to determine how health should be measured. PAHO has described something like a dashboard approach—a set of critical elements needed to characterize health. A final set of indicators has not yet been determined. Many indicators of health are used in *Health United States* and Healthy People 2010, but in other reports health gets only a limited number of indicators. There's a lack of agreement on what indicators should be considered, but mortality always makes its way into the equation. A joint meeting in Geneva in several months will tackle some of these issues.

The DHHS InterAgency Working Group on Summary Measures of Health has been examining different views of summary measures within the department. We do need a summary measure that captures broad information and is transparent.

Members should refer to one of the first methodological products of a recent workshop, a publication entitled Summary Measures of Health, Report of Findings on Methodologic and Data Issues.

Examples of NCHS Data Collection and Dissemination Activities. The next three sessions are linked loosely to focus on collection and dissemination of particular data, the full array of data that NCHS surveys capture, and new means for disseminating NCHS information and carrying on outreach activities.

NHIS Early Release (ER) Program. Jane Gentleman, Ph.D., and Hanyu Ni, Ph.D., from the Division of Health Interview Statistics, presented information about the Early Release (ER) Program that provides timely access to the most recent NHIS key estimates, based on partial-year data. These estimates appear only on the NCHS web site (in the NHIS portion) and currently address 15 measures. The key estimates are taken from microdata every quarter. An expert meeting guided the selection of the set of descriptive statistics, and data on health insurance was high on many individuals' lists. Dr. Ni showed examples of the ways in which estimates are presented (trend tables, graphs, and charts) and gave particular attention to the lack of insurance measure. She pointed out that three national surveys capture estimates of uninsurance (NHIS, the Current Population Survey, and the Medical Expenditure Panel Survey). The NHIS is able to provide the most recent estimates, but it should be noted that each survey asks different questions. Members received copies of the most recent ER on lack of health insurance and a paper that attempts to explain the differences in estimates.

Questions from the BSC included:

Does a one-year estimate permit disaggregating Hispanic origin?

> While NCHS oversamples Hispanics, there aren't enough in the sample for making estimates for subgroups.

Are there many items missing?

> The amount of missing data is very small.

What kind of information does NCHS include and not include in an early release?

> NCHS simplifies what is included in an early release. Other documents, such as Advance Data, provide much more detail.

Of the three health uninsurance numbers, which one should be used?

> The NCHS number. The Current Population Survey asks a different question.

The new report looks very helpful, and the ER is a great addition. What can be said about cohort effects and response rates?

> NCHS can look at cohort effects in other reports; it is hard to do this in an Early Release. The overall response rate to the NHIS is about 87%; it depends on what part of the sample is involved and differs according to which regional office

collects the data. The survey is about 57 minutes long with about 20 minutes for supplements.

Summary Review of NCHS Survey Questions. Jennifer Madans, Ph.D., NCHS Associate Director for Science, discussed a draft table of selected topics covered in NCHS surveys and data collections activities. She noted that NCHS data systems were initially designed to complement one another. The National Health Interview Survey is the oldest survey (1957), but the first physical examinations started soon after in the early 1960s. NCHS leadership realized the need for objective data early on. Duplication across the surveys is not such a worry—in fact, there probably could be more duplication. A worry is gaps. To make identification of gaps a bit easier, staff rearranged the survey matrix (included in agenda books at the front) to focus on content. The draft content chart includes generic topics on the stub with the ongoing periodic surveys listed across the top. This chart includes the core activities from the matrix. Dr. Madans asked whether there might be other ways to organize the matrix to illustrate content. She noted that the list of diseases/conditions/injuries grows very long, so this information is not provided. The chart does attempt to include measures of functioning; staff can provide a list of the functional status items from the NHIS.

Dr. Madans asked members to advise whether the chart is useful and if it would be helpful to users and collaborators. In studying the chart, the overlap of NHANES and NHIS is obvious, but data are collected in ways to maximize what each of these surveys does best. If there is overlap in questions, they should be the same in all surveys. NCHS sees this as integration rather than duplication.

Staff have long thought about incorporating blood draws on the NHIS; this would allow targeting certain areas and could be less expensive than through NHANES. There's a huge interest in environmental factors, and NHIS could capture this kind of information and provide state data.

Discussion of the draft chart focused on whether it is wise to have data on one large topic from multiple perspectives and the feasibility of doing a blood draw on an interview survey. A concern would be response rates. Dr. Madans asserted that it is worth testing, although there would be some IRB issues, and NCHS would likely have to address the use of incentives.

In response to the question about whether NCHS had considered a dual frame, Dr. Madans indicated that there was an attempt to use Social Security files to sample the elderly population, but there wasn't sufficient funding. Some consideration was given to conducting NHANES as a subsample of the NHIS, but it wasn't practical. MEPS is a subset of the NHIS. NCHS could do an area sample and list frame, but current resources won't permit this. NHIS includes data only on non-institutionalized individuals.

To the question of whether NCHS surveys capture information about health on the job—preventive services and treatment in the workplace—Dr. Madans answered in the negative. NCHS does, however, capture information about injury on the job. She

reminded members that all NCHS surveys are available in microdata on the web; vital statistics information is on CD.

Other questions pertained to how NCHS acquires information about substance abuse (its surveys do get tobacco and alcohol data); NHANES laboratory tests can identify illicit drug use. Acquiring very sensitive information from respondents requires use of ACASI (Automated Computer-Assisted Interviewing Technology) which is used in NHANES and NSFG. It would be very nice to use ACASI on NHIS as it would allow collection of information from adolescents and afford them the privacy they need to answer sensitive questions. Lack of resources prevents NCHS from employing this approach. Doubling the budget for NHIS would allow staff to accomplish some significant results.

NCHS has proposed doubling the NHIS although not as a single major initiative. Another single initiative worthy of support would be longitudinal studies that could offer opportunity to do some very interesting analyses. If resources were available, NCHS could pursue some follow-up studies that would allow, for example, the estimation of transition probabilities and to follow persons into nursing homes.

NCHS Dissemination Activity—Fact Sheets. Rob Weinzimer, Special Assistant for Outreach, presented the final component of this session and explained the purposes for the NCHS Outreach Program: to support acceptance of NCHS data collection and survey activities and to promote data access and use. His talk described methods of outreach, the partners in the endeavor, and fact sheets, particularly those that deal with cross-cutting issues such as race/ethnicity, asthma, health insurance and access to care. Outreach activities are geared to boost response rates and to gain more information about the public's data needs. Among the several means of communicating with constituents and collaborators is an electronic newsletter from the Director, NCHS. The fourth edition is forthcoming.

A suggestion was that NCHS could be more aggressive in placing guest articles in periodicals. Partnering more with relevant individuals and institutions might facilitate this effort. Key users of NCHS data are in the economics community; NCHS could become more pro-active in encouraging economists to use its datasets. A suggestion was to work with research funding organizations to stimulate them to link their research solicitations to NCHS datasets. Mr. Weinzimer commented that the first meeting of the Friends of NCHS took place in October and that this group's second meeting would occur in mid-February.

Another idea was to target specific user groups for the Data User Conference where persons could receive hands-on training in the use of the data. To further training in use of the data, NCHS could bundle sample datasets and analysis software for distribution to students. Dr. Gentleman cautioned about the ease of analysis, particularly of NHIS. Her staff try to offer courses to instruct folks to analyze data properly. Careful methods are necessary.

In terms of marketing itself to the department, NCHS uses the Data Council to inform others of its activities and services. BSC members suggested a short, concise, and systematic approach to make DHHS more aware of NCHS. Some target groups who should be apprised of NCHS data collection and survey activities are the Congressional Research Service and the Congressional Budget Office as well as local public health officials (National Association of City and County Health Officers). Noting that NCHS constituencies come from a broad spectrum, one member stated that NCHS should be commended for what it has done to reach its audience.

Another important audience is the general public. What is NCHS doing to reach this community? How much do we know about what the public wants in the way of information? The CDC Futures Initiative has attempted to delve into what people think they need. NCHS learns what the public wants through secondary disseminators. Marketing surveys would be useful for determining what the American public would want. Survey findings for this segment might need to be different than those for a researcher. NCHS should think differently about how to present findings for the general public. This would entail learning what kinds of questions they have about their health and their needs are.

The current efforts to redesign the CDC web site, along topic lines rather than organizationally, may further the public's understanding of health information.

NCHS does partner with webMD and provides a variety of public information to DHHS. It is difficult to prepare materials for the public; staff are not used to addressing this particular audience. A BSC member suggested that this is a way to build grass roots constituency for NCHS. A suggestion was to expand the current internship program and consider one for journalism students.

Future Agenda Topics and NCHS Intramural Program Review. The afternoon session focused on a discussion paper, Potential Approaches/Opportunities/Perspectives for Evaluating NCHS Scientific and Technical Programs. Members suggested several tacks to take:

Improve the visibility of the Center
Get an adequate set of resources to carry out programs
Build an argument to garner the support to double the NHIS
Examine the really large activities
Look at opportunities to undertake new initiatives
Document the value of NCHS more fully to CDC
Explain the importance of NCHS data
Determine how to make recommendations through different ways of looking at NCHS (BSC viewpoint)
Place the health insurance paper in a policy-setting journal
Send a BSC-prepared memo to the Secretary promoting the use of the NCHS insurance estimate

Conduct a longitudinal study; ask ORM to share its thinking on doing a longitudinal study, with input from BSC
Operate at a strategic level; align BSC's plans with the CDC Futures Initiative and the Secretary's initiatives and work collectively
Address some of the substantive issues to bolster recommendations for the organizational structure/placement of NCHS
Work with NCVHS to take on large visionary recommendations
Invite users to attend BSC meeting to get their impressions
Learn about NCHS data users and what more NCHS could do
Hold BSC meetings in a location that would encourage attendance by Congressional staff
Promote NCHS data to research community
Hold a BSC meeting on users
Determine how NCHS will deal with outcomes of the NHANES Forum
Describe how NCHS finances are dispersed across data collection and survey activities

Following the offering of these various suggestions, the BSC recommended that its next meeting be held in a downtown Washington location and that it focus on users:

Who are they?
What do they want to learn from NCHS data?
How well are their needs met?
What is the impact of the absence of NCHS data?

A further recommendation was to invite a large set of people to attend this meeting, including DHHS and CDC individuals.

Dr. Sondik noted that NCHS has some information about some of its users (for example, the Division of Health Care Statistics routinely surveys the published literature to identify research and policy articles that use NCHS data). He took as a recommendation that he should present the results of the NHANES Forum to NCHS Senior Staff for inclusion in the Center's planning process. The BSC may want to keep as an ongoing agenda item the recommendations from the Report on Health Statistics Vision for the 21st Century. A panel discussion on this topic at the March 4 meeting of the National Committee on Vital and Health Statistics might also be useful for BSC members to address some conceptual models that would be of importance to NCHS. The agenda for that meeting will be located at the NCVHS web site.

Key concepts of importance to NCHS are policy and research needs and how to maintain quality. Dr. Sondik urged that the BSC look at some of NCHS' activities in some depth, including dissemination and use, to make sure that the public is getting the most for its investment. Dr. O'Neill encouraged members to suggest ideas for future agendas and to recommend key persons who should receive invitations to attend the April 2004 BSC meeting.

There were no members of the public who requested time to speak to the BSC.

The Executive Secretary, Linda Blankenbaker, reminded members that the next meeting will take place April 22-23, 2004, starting at 2:00 pm on April 22; completed travel vouchers should be sent to Ms. Cynthia Sidney as soon as possible; Drs. Bailar, Crimmins, Rodriguez, and Scheuren will complete their tour of duty on the BSC and will "graduate" at the next meeting (with suitable pomp and circumstance); Dr. Robbins will provide feedback from the NCVHS meeting via email.

There being no further business, Dr. O'Neill adjourned the meeting at 2:50 pm.

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

_____/s/_____
June E. O'Neill, Ph.D.

February 17, 2004
Date

Attachment #1: Attendance
Second Meeting of the Board of Scientific Counselors, NCHS
January 22-23, 2004

Members present were:

Chair: June O'Neill, Ph.D.
Designated Federal Official: Linda W. Blankenbaker

Barbara Bailer, Ph.D.
Eileen Crimmins, Ph.D.
Nicholas Eberstadt, Ph.D.
Vivan Ho, Ph.D.
William Kalsbeek, Ph.D.
Janet Norwood, Ph.D.
Alvin Onaka, Ph.D.
Alonzo Plough, Ph.D.
Aldona Robbins, Ph.D.
Rene Rodriguez, M.D.
Louise Ryan, Ph.D.
Fritz Scheuren, Ph.D.
Fernando Trevino, Ph.D.
Robert Wallace, M.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 (NCVHS)

DHHS staff members present over the course of the meeting were:
Dale Hitchcock, Office of the Assistant Secretary for Planning and Evaluation

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

Olufunkle Ajayi
Irma Arispe
Amy Bernstein
Stephen Blumberg
Edward Buckley
Liming Cai
Robin Cohen
Chris Cox
Randy Curtin
Krystal Davis
Lois Fingerhut
Jane Gentleman
Marjorie Greenberg
Ken Harris
Don Hayes
Allison Hedley
Ed Hunter
Mary Huynh
Susan Jack
Debbie Jackson
Cliff Johnson
Meena Khare
John Kiely
Richard Klein
Jennifer Madans
Diane Makuc
Jill Marsteller
Heather McAdoo
Tom McLemore
Kristen Miller
Lisa Moses
Kathy Moss
Zakia Nelson
Hanyu Ni
Jennifer Parker
Charles Rothwell
Melanie Pickett
Eve Powell-Griner
Alexander Prikhodko
Howard Riddle

Asel Ryskulova
Michael Sadagursky
Sharon Saydah
Nathaniel Schenker
Susan Schober
Ken Schoendorf
Judy Shinogle
Sandy Smith
Edward Sondik
Kathleen Turczyn
Stephanie Ventura
Rob Weinzimer
Gracie White
Doug Williams
Barbara Wilson
Libei Zhen