

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

**Minutes
January 23-24, 2008
NCHS
3311 Toledo Rd.
Hyattsville, MD 20782**

All attendees are listed in Attachment 1.

Wednesday, January 23

Introduction: Dr. Irma Elo, Chair of the NCHS Board of Scientific Counselors (BSC), asked Dr. Edward Sondik, Director NCHS, to report on the status of the letters from the BSC to Dr. Gerberding and Secretary Leavitt expressing concern about the impact on NCHS programs as a result of budget constraints. Dr. Sondik responded that the letters were in Atlanta and no action had been taken yet. Dr. Michael O'Grady proposed and Dr. Matt Snipp seconded a motion accepted by BSC that at the end of January, if no response was provided on the letters, they would send a letter directly to Secretary Leavitt. They will also post the letter on the BSC website and distribute the letter to others to be determined by Drs. O'Grady and Snipp.

NCHS Update: Dr. Sondik provided an update on the NCHS budget and the program plans underway in accordance with the budget.

Discussion: Dr. Sondik was asked if Congress directed NCHS to spend the increase for Fiscal Year 2008 exclusively on vital statistics. He stated that both the Senate and House of Representatives identified vital statistics as their priority. Dr. Sondik was asked if NCHS could expect any CDC taps on the FY 2008 budget increase. His response was that since the money comes from evaluation funds, we do not expect a tap on those funds. Dr. Elo said the BSC letter was very important not only for Fiscal Year 2008 but also for the long-range planning process. The BSC was very concerned about NCHS's ability to fulfill its scientific mission and is worried that central CDC will take more money for Leadership and Management. Dr. Sondik was asked to reconcile his "challenges" slide about need for data for health disparities, with "budget" slide showing option to cut oversamples of minority groups. Dr. Sondik responded we can aggregate data across time to get disparity information. Dr. Elo reminded him that BSC had recommended against small cuts spread throughout NCHS programs but rather to consider major program cuts instead. She expressed concern about possibility of less data on disparities. Dr. Jennifer Madans, NCHS Associate Director for Science, pointed out that cutting sample instead of stopping oversamples may be worse as far as getting minority data. The BSC asked NCHS to provide specific numbers to show impact of oversample cuts vs. general sample size cuts, on availability of data for subgroups. Also NCHS needs to analyze how fast things (prevalence, use of health resources, etc) change over time, to help determine best choices for handling cutbacks, i.e. periodicity of surveys depends on frequency of needed data. We need to consider how changes in periodicity will affect the usefulness of our data for policy purposes.

Ms. Katherine Wallman said Dr. Sondik's options should take into account substantive costs of actions, including quality costs. She noted the need to be careful about saying it's ok to delay payment for vital statistics and catch up later when we get more money, because without money now from NCHS, states' processing and collection of data will be hampered. NCHS also needs to consider impact of vital statistics cuts on other agencies in the Federal statistical system, i.e. Census.

Dr. Elo summarized discussion: NCHS needs to describe in greater detail the costs and benefits of budget options and the impact on timeliness, data quality, etc. Also, NCHS should determine the impact of ability to drill down to local level by cutting Primary Sampling Units in surveys. The BSC needs more information so that it can provide guidance to NCHS on budget options. Dr. Elo asked Dr. Sondik to have answers before the April BSC meeting. She suggested a session at the next meeting to discuss what questions we will not be able to answer if we make various programmatic decisions in response to the budget.

Dr. Elo said CNSTAT is holding a workshop on vital statistics and that some of the topics the BSC raised, e.g. data quality, should be covered in the workshop

Dr. Stein said that the BSC needs to make clear that even with the \$6.5 M increase in Fiscal Year 2008, NCHS is not going to be able to do what it needs to do.

SLAITS Review Panel Report: See Dr. Judith Kasper's PowerPoint Presentation

CDC response: Marcie Cynamon, Chief of the Survey Planning and Special Surveys Branch, agreed with the report of the SLAITS Review Panel. She would like to see in the report that there's room in CDC for two phone surveys including SLAITS and the Behavioral Risk Factor Surveillance System (BFRSS). Ms. Cynamon stated that she would like to have the funds to conduct research to advance state-of-the-art of phone surveys. Mr. James Singleton, Chief of the Assessment Branch, Immunization Services, the organization that is responsible for the National Immunization Survey, clarified the comments in the report on less urbanized areas.

BSC Liaison response and discussion: BSC liaisons, Dr. Ruth Stein and Dr. Ray Greenberg, suggested several points that should be added to the report: 1) because of phone method, SLAITS is flexible and quick survey; 2) it is the only NCHS vehicle with state level data; 3) although not confined to children, most of the SLAITS surveys have focused on them; SLAITS needs to be strong since it's the platform for much of what we know about child health; 4) SLAITS needs to keep working on representativeness of cell phones; 5) fewer NCHS staff actually are dedicated to SLAITS than report indicated; 6) an estimate of the cost to make it free-standing should be included in the report. Dr. Greenberg said the report is what the BSC had been looking for in these program reviews. He thanked Dr. Cain for her time in getting and keeping review committee on track and acknowledged it's very labor intensive for her. Dr. Stein said report will be useful. She believes it was good to have a BSC representative at the review to keep group on target. It is a very good idea to have the Chair of the review committee present for the BSC discussion at the outset of the review. Dr. O'Grady said SLAITS is good model for the future and worth the investment. He recommended thinking of partners for SLAITS that would have interest in children—e.g. the HHS Office of the Assistant Secretary for Planning and Evaluation's welfare side, versus lurching from immunization questions for 4 year olds to asthma questions in 65 year olds. In this way, SLAITS can maintain an identity as a child survey. Dr. Snipp expressed concern about the possible misdirection in National Immunization Survey (NIS) letter that would appear to be a "bait and switch" if using the survey for other purposes than questions on small children. Ms. Wallman said that there are few fast response survey vehicles like SLAITS and it is good to have it. She recommended that NCHS present at Interagency Council on Statistical Policy to see if SLAITS may make sense for other Federal statistical agencies. She also suggested using SLAITS for non-federal organizations also such as the National Governors Association (NGA). Dr. Elo asked the Chair of the review panel to add to the report that SLAITS should market itself to NGA and others and to emphasize its fast response mechanism. Dr. Kalton said there is no reason SLAITS should be only about children. Dr. Stein suggested that the report consider costs of SLAITS being separated from NIS. Dr. Stein summarized the next steps: BSC gives review committee chair feedback on report; committee revises it and revised version is circulated to BSC members. Then BSC sends to Ed Sondik with cover letter. The BSC complimented the review panel and will send a letter to thank them.

NHANES DNA Issue: See Dr. Jennifer Madans PowerPoint.

Discussion of DNA presentation: Several questions were raised. Does BSC want to take unified position on this? Do they know enough to do so? Dr. Sondik said the issue is whether NCHS retains primary responsibility for confidentiality vs. giving the data to the National Institutes of Health (NIH) and making the investigators who use the data responsible. Dr. O'Grady asked why does there have to be agreement? Why can't NCHS and NIH have different conclusions? Dr. Madans asked the BSC to comment on whether NCHS is being too sensitive about possible risk? Dr. Snipp supported the current arrangement with NCHS retaining responsibility for the confidentiality of the data. Dr. Greenberg suggested that we ask NIH to fund a study on effect of doing it. Dr. Elo stated that NCHS has legal obligation to protect confidentiality, but also needs to make it available for dissemination. Therefore, NCHS should be flexible. Ms. Wallman recommended that NCHS should find a way to show it's being very careful about release but also work hard to find an acceptable way to disseminate the data, e.g. upgrade the Research Data Center. Dr. O'Grady encouraged NCHS to state its positions in positive way highlighting all that NCHS is doing and that the organization is seeking help in doing more within existing constraints.

The BSC discussed the upcoming meeting in March in Atlanta with CDC, NIH and investigators from the extramural research community. It was suggested that the BSC members attend the March meeting to express confidentiality concerns. The BSC understands the legal issues and confidentiality issues, but also is concerned about finding a way to make the data available. BSC members suggested that instead of spending money to re-consent participants to allow for release of the DNA, funds should be used to build a better access system.

Thursday, January 24

NCVHS Update Dr. William Scanlon and Jim Lepkowski reported on interests of the National Committee of Vital and Health Statistics (NCVHS). NCVHS continues to share interests with the BSC even though no joint meetings have been held lately. Specific areas include data access/linkage issues, balancing access and confidentiality, and vital statistics, particularly since Garland Land has joined the NCVHS. In the first week of February, the NCVHS Executive Subcommittee will meet to discuss the future agenda for the committee. Dr. Lepkowski and Dr. O'Grady will be able to attend the second day of the Executive Committee meeting. Marjorie Greenberg, the Executive Secretary of the NCVHS, suggested that a good topic for mutual discussion would be what to do with 20th century vision report recommendations. Dr. Elo concurred with that recommendation. Dr. O'Grady cautioned that NCVHS established its credentials by delivering real value to the Department and that we need to guard against the NCHS BSC being seen as just concerned about "pie in the sky" ideas, such as some in the vision report.

NHIS Review: The National Health Interview Survey (NHIS) is the next NCHS program to undergo review by the BSC. Dr. Elo introduced by phone Dr. Bob Hummer, from the University of Texas, chair of the review panel and Dr. Michael Davern, from the University of Minnesota, who is member of review panel. Dr. Elo said Drs. Rick Brown, UCLA, and Janet Currie, Columbia University, also agreed to be on the panel. The review panel still needs more people and the BSC was asked to provide suggestions to Dr. Cain.

Dr. Jane Gentleman and NHIS staff overview: See PowerPoint. Dr. Jennifer Madans introduced the NHIS and explained the need for the redesign of the NHIS in mid 90's; 1) the survey was becoming a victim of its success-- too long and 2) for scientific reasons the survey switched from a household survey to individual survey. The redesign moved the files from a condition file to a person file.

NHIS Discussion: The BSC Liaisons to the review panel, Drs. Tom Koepsell and Lynn Blewitt made preliminary comments. Dr. Koepsell stated that the NHIS is a great program and provided great value. A few topics that should merit attention by review panel are: 1) less expensive alternatives to NHIS are getting harder since phone surveys are harder--so NHIS is "safety net" for health statistics; 2) the degree to which NHIS provides method information about options to NHIS, e.g. wireless substitution work shows bias with cell phones; 3) methods reports are extremely important, e.g. two week recall for doctor visit; 4) having topics driven by who can pay is logical given money problems, but not ideal; 5) responsiveness to users--is everything being done to quantify how NCHS data are being used? Are there ways to find out

more such as tracking users of data, that' will help quantify use and also provide opportunity to get user feedback? 6) the problematic downward trend in sample size due to budget constraints; 7) the Title 13 vs. 15 issue considering the pros and cons of each to help inform decisions. Dr. Blewitt concurred with Dr. Koepsell's comments and suggested other areas for the review committee to consider: 1) the use of commercially-available lists; 2) the impact on information on health disparities of dropping sample--not only in data context but policy context; 3) how questions are decided; 4) what would happen if there's budget increase? What are key policy issues we'd want to know more about? 5) the user community which could lead to leveraging interest of users to strategically get more visibility. Policy uses of the NHIS could position NCHS as resource for monitoring health reform, Medicare, linkage, aging of baby boomers and other areas. Several BSC members emphasized the need to demonstrate value of survey across wide range of users.

Other board comments/questions: Dr. Kalton stressed the following: 1) the importance of knowing who the users are; 2) sample design and whether there is a more economical way of designing the sample; 3) whether mixed mode is a possibility, such as using phone as part of the process once the interviewer already has access to the household. Dr. Lepkowski commented: 1) phones are going to be an element of surveys so it would be good to do research on mixed modes; 2) can timelines--from concept of question to results--be thought of in a way different from annually, possibly a more continuous release of data; 3) considerable staff time is spent on getting paradata; this project needs to demonstrate value; how much does that affect timeliness; 4) can NCHS data be used to evaluate impact of various federal mandates; 5) the project needs to have a *measure* of quality, i.e. what do we mean when we say how sample reduction means less quality? Dr. O'Grady asked the review to address: 1) linkage potential; 2) usefulness of data; 3) need to match the Medical Expenditure Panel Survey (MEPS) outreach effort; 4) other possible data collection organizations; 5) user surveys to learn more about users. Dr. Elo emphasized the need to examine: 1) linkage work, which also means addressing confidentiality issues related to linkages; 2) the value/utility of NHIS for policy and how to enhance its utility; 3) the opportunities harmonization presents. She also stated that if NCHS is considering somehow combining NHIS and NHANES that needs to be factored into the discussion. Dr. Blewitt encouraged considering collaboration with the California Health Interview Survey or with a New York project.

The decision was made to postpone the NHIS preliminary review report till September, since NHIS is complex and full panel has not yet been established.

Discussion of Review Process: Future presentations by NCHS staff should be limited to presenting the "big picture" and not repeat detail found in the written reports provided by NCHS staff. A timeline of the review process or at a least sequence of activities would be helpful.

NHANES Review: The NCHS presentation will be scheduled for April and the preliminary report of the review panel for January 2009. Mr. Cliff Johnson described four major areas of the survey--general health, nutrition, environment, and infectious disease--and suggested that the review committee have representation for each major area. Dr. Lepkowski will be one of the DHANES BSC review panel liaisons. It was stated that we should be careful not to let the DNA issue overwhelm the review.

DHCS Review: The programs of the Division of Health Care Surveys (DHCS) will be the next to undergo review. Dr. Cain will explore with Dr. Jane Sisk, Director, DHCS, the best way to handle the DHCS review--whether to have one review for the entire program or multiple reviews since there are several different surveys in the program.

Data Linkage: The BSC raised the topic as to whether the data linkage activities at NCHS should have a separate review. The BSC asked to have a presentation about linkage issues at the April BSC meeting.

National Health Care Surveys: See Dr. Lauren Harris-Kojetin PowerPoint.

Discussion: Dr. Greenberg asked if funding is so tight, why isn't NCHS "pounding the pavement" for additional funds? Why isn't there more coordination among NCHS programs for seeking outside funds? Dr. Sondik offered to report on that at the next BSC meeting.

Public Comment: Deeana Jang, JD, Policy Director of the Asian & Pacific Islander American Health Forum (APIAHF) provided public comment regarding the collection of data on Asians and Pacific Islanders (API). (See attached letter.) By aggregating data on API, health problems of the subgroups are masked. APIAHF knows that NCHS has tight budget, but is still very concerned about possible reductions in sample size. They are also concerned about translation of languages. They thank NCHS for work it has done. They urge NCHS to take a leadership position in advocating for States to collect more information by API status

Response to public comment: Dr. Snipp reported that the BSC is deeply sympathetic to speaker's concerns. Dr. Elo suggested that it may be better to do a separate API survey rather than try to integrate into current NCHS surveys. Dr. Blewitt suggested that the BSC and NCHS can help identify state surveys. Dr Sondik offered at a minimum to comment on the group's efforts and provide guidance.

The meeting was adjourned at 2:00 pm.

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Irma T. Elo, Ph.D., Chair

Attachment 1

Attendance at BSC meeting: January 23, 2008	
Board Members	Other
Irma Elo, Chair Ronald Angel Lynn Blewett Raymond Greenberg Graham Kalton Thomas Koepsell James Lepkowski Michael O'Grady Matthew Snipp Ruth Stein Katherine Wallman, Ex Officio Virginia Cain, Executive Secretary	Emily Holubowich, AcademyHealth Sandy Smith Mona Bormet, APIAMF Marcie Cynamon Jennifer Pippins Eve Powell-Griner Susan Jack Debbie Jackson Katherine Jones Paul Beatty Meena Khare Gerry McQuillan Amy Bernstein Catherine Simile Rosa M. Avila Matt Bramlett Kathy O'Connor Stephen Blumberg Susan Schober Jennifer Madans Edward Sondik

Attendance at BSC meeting: January 24, 2008	
Board Members	Other
Irma Elo, Chair Ronald Angel Lynn Blewett Raymond Greenberg Graham Kalton Thomas Koepsell James Lepkowski Michael O'Grady Matthew Snipp Ruth Stein Katherine Wallman, Ex Officio Virginia Cain, Executive Secretary	Mona Bormet, APIAHF Deeana Lang, APIAHF Eve Powell-Griner Debbie Jackson Gulnur Freeman Susan Jack Ellen Kramarow Catherine Simile Jacqueline Lucas Jane Sisk Sam Notzon Lester Curtin Christine Caffrey Anita Bercovitz Fred Decker Lisa Dwyer Genevieve Strahan Brenda Wolfrey Jennifer Madans Edward Sondik