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

May 7, 2009 NCHS 3311 Toledo Rd. Hyattsville, MD 20782

Attendees are listed in Attachment 1.

Dr. Irma Elo opened the meeting at 2:00 PM and welcomed Dr. Steve Solomon, Director of the Coordinating Center for Health Information and Service, CDC, to the meeting.

NCHS Update: Dr. Edward Sondik, Director NCHS, update the BSC on NCHS activities. *Discussion:*--Dr. Elo asked how the Division of Health Care Statistics' (DHCS) stakeholder meeting meshed with BSC program reviews of the Division's programs? Dr. Jane Sisk, Director of DHCS, reported that some of the BSC members including liaisons to the review panels and the chair of one of the review panels had been invited to the stakeholders meetings. Unfortunately, the BSC members were unable to attend. Additionally, NCHS will provide the BSC review panel with a copy of the stakeholder report. The BSC recommended that in the future the BSC liaisons to the panels be invited to relevant stakeholder meetings. Additional discussion took place on the role of the BSC reviews in context of how they differ from and inform other activities including stakeholder meetings.

Dr. Jim Lepkowski commended NCHS for the CDC Director's Award for Innovation, which was received by the Division of Health and Nutrition Surveys (DHANES) tutorial team, and for the American Association of Public Opinion Research's (AAPOR) 2009 Warren J. Mitofsky Innovator's Award given to Stephen J. Blumberg, Julian V. Luke and Marcie L. Cynamon of the Division of Health Interview Statistics.

Chair's Update: Dr. Elo reported that she was part of Population Association of America (PAA) delegation to House and Senate appropriations and authorizing committees and the National Institutes of Health (NIA and NICHD). Based on these meetings, she reported that Congressional staff was aware of budget shortfalls for vital statistics and NCHS surveys. She referred BSC members to materials distributed in the packets, including a response from Dr. Richard Besser, Acting Director, CDC to the BSC letter sent to then Acting DHHS Secretary Charlie Johnson, and a letter from the Annie E. Casey Foundation urging NCHS not to cut data items from the vital statistics data sets.

Discussion:

BSC member Dr. Lynn Blewett asked about the process following the program reviews, i.e. is there program feedback on how staff implements recommendations? Dr. Elo responded that the programs report back to the BSC in approximately one year post review on how the program has responded to the recommendations. In fact, the State and Local Area Telephone Survey (SLAITS) was providing a one year update later in the day. It was suggested that SLAITS would be a good platform for NCHS to do quick turnaround surveys to track health reform.

Dr. Michael O'Grady, BSC member, asked what rules govern BSC members' participation in briefings and meeting on Capitol Hill. Dr. Elo responded that she went as a representative of the PAA as someone who is knowledgeable about NCHS's activities,, and she was not representing

the BSC. Dr. Virginia Cain, BSC Designated Federal Official, said members cannot lobby on days that they are paid as special government employees but that on other days they have the same rights as private individuals to lobby Congress. Dr. O'Grady asked Dr. Cain to provide the BSC with rules regarding lobbying and suggested that BSC members consider a strategy whereby they might go as individuals to discuss statistical agency needs with Congressional staff, including staff at the Congressional Budget Office. The BSC requested that letters sent to Congress by the Friends of NCHS be distributed to the members of the BSC.

NCHS Core Mission and Budget Issues Working Group Report: Dr. O'Grady, chair of the working group, reported on the issues deliberated by the Working Group. A major consideration that affects many other issues is the organizational location of NCHS. NCHS has been located within the CDC for the past 20 years, but prior to that time it was an independent agency within the Department of Health and Human Services. NCHS has some characteristics that make it unique among the CDC centers. It is one of the Federal statistical agencies and as such has some responsibilities and requirements that other CDC centers do not have. The Working Group raised questions about whether NCHS should remain in CDC, be part of a combined HHS statistical organization, be a stand alone agency or function under some other arrangement. Other discussion items that were raised included: how can NCHS meet/lead HIT? Should NCHS have a mainly analytic or descriptive role? How can NCHS and others demonstrate that work by NCHS is vital to the policy/scientific community? Should NCHS continue to depend on finding clients to fund surveys or should NCHS have core funding without the need to rely on money from other agencies? How should health be defined? It was suggested that an ideal NCHS would have several characteristics, including: 1) flexibility to respond to policy questions; 2) ability to inform policy and at the same time conduct high quality science with an appropriate balance between the two; and 3) provision of leadership in cutting edge data collection and development of new methods. A primary question that needs to be addressed is how to ensure proper sustained budget funding over time.

Discussion:

BSC member Dr. Lynn Blewett reported that Dr. Anne Haddix, CDC's Chief Policy Officer, had recently visited the University of Minnesota and talked about the need to monitor health reform. Dr. Blewett suggested that NCHS position itself so that it can contribute to that effort. BSC member Dr. Lee Cornelius added that NCHS needs to be ready to show how it can be valuable.

The Board discussed the roles that NCHS can play with regard to being a purely statistical agency or having more direct contribution to policy issues. Dr. Ken Prewitt, BSC member, stressed the need to emphasize that statistical agencies are a part of the scientific infrastructure and need secure funding to do their jobs. Dr. O'Grady asked the BSC to discuss two models for the agency: 1) a "pure" statistical agency only or 2) one similar to the Agency for Healthcare Research and Quality that combines healthcare data collection and policy. Dr. Margo Schwab, representing OMB, suggested that a model like the US Department of Agriculture's Economic Research Service which has a purely statistical role but also provides information for policy needs.

Dr. Jennifer Madans, NCHS Associate Director for Science, suggested that the BSC develop criteria for what an organizational structure would have to look like in order for NCHS to meet needs that the BSC believes NCHS has or should have. BSC members concurred with this approach. Therefore, the next step for the Working Group is to develop and propose to the BSC criteria that would then drive a recommendation on organizational location.

Survey Redesign: Integrated Interview and Examination Survey: Dr. Virginia Cain, chair of the NCHS Survey Redesign Working Group, presented the results of the Working Group's deliberations up to this point. The working group was charged with designing a survey to meet the information needs that have evolved over the years, currently met by National Health

Interview Survey and National Health and Nutrition Examination Survey; in other words, a survey that would combine these two efforts.

Discussion: The BSC discussed several aspects of a combined interview and examination survey. Dr. O'Grady stressed the need to consider how modeling might be used to obtain small area estimates and what data would be needed to put into the models. BSC member Dr. Jim Lepkowski also suggested that the redesign group think about the end product and users. The resulting product should not be too complicated for NCHS audiences. Dr. Kathie Harris suggested that NCHS think about how users currently use the data to help inform decisions about the new survey. The Board also cautioned that NCHS should make sure that data are usable from the standpoint of confidentiality concerns. Linkage with other data is desirable but the Center should think about how the Research Data Centers can facilitate usage of data in an environment that will assure confidentiality and wide access.

Dr. Lepkowski suggested that NCHS think of this as not simply integrating two existing surveys but rather think of it as one survey with mixed modes, which can get complicated as it is not always possible to transfer information from one mode to another. The new survey might be called something like the National Health Survey indicating that it is one survey. While the BSC recommended continued consideration of Electronic Medical Records (EMR) as a source of data, members did not think that they will replace surveys.

On the issue of content of the proposed surveys, BSC member Dr. Holly Hedegaard applauded the proposed increase in data on the social determinants of health. Dr. Lepkowski said that NCHS needs to also think of opportunities to remove content when it is no longer applicable for meeting current data needs.

Committee members were somewhat divided on whether the proposed project should try to focus on expanding the data available on smaller racial and ethnic groups or smaller geographic units. Each approach had strong supporters but there was recognition that limited resources may not permit NCHS to accomplish all desirable goals.

Dr. Margo Schwab from the Office of Management and Budget recommended that NCHS decide upfront what the goal is. Is it to simply to meld the goals of the two current surveys? Does NCHS really want a new study or just to reduce costs by combining existing surveys?

Budget Update: Dr. Sondik announced that the just released Fiscal Year 2010 President's Budget included \$138,683,000 for NCHS which a \$14M, 11% increase over Fiscal Year 2009. The budget must still go through Congressional appropriations before becoming final and may change during that process.

BSC Working Groups

<u>Vital Statistics Working Group</u>: Dr. Steve Schwartz, Working Group Chair, reported that while the group had not had an opportunity to meet recently its goal was to create a vision for vital statistics in the future and not just fight over how money should be spent. It is considering how quality and responsiveness can be improved and how technology can contribute. He emphasized the importance of the stability of resources for maintaining and improving the system.

Discussion: BSC discussed the importance of trying to move forward in this area and agreed to continue the working group.

The BSC discussed the need for resources for vital statistics. The Committee considered sending a letter to Dr. David Blumenthal, the new National Coordinator for Health Information Technology, about the lack of resources for what some consider the first electronic health record, the birth certificate. The BSC agreed to wait on developing a letter until it is clear whether it would be productive and what approach would be most effective.

<u>Proposed Working Group to Provide Advice to the NHIS:</u> Dr. Cain presented an idea that had been raised by the Director of the Division of Health Interview Surveys to form a BSC working group to provide ongoing advice to the NHIS. The formation of some sort of ongoing advisory group had been strongly recommended in the review of the NHIS. Government regulations restrict the ability of organizations to establish new ongoing advisory groups. Therefore, at this time, the only way to form such a group would be through the charted BSC. The BSC briefly discussed how such a group might work and the role that the BSC members would play. It was suggested that Dr. Elo and Dr. Cain further discuss how this recommendation might be implemented and present a proposal for further BSC discussion at a later meeting.

BSC member Dr. Graham Kalton suggested that it would be helpful to clarify the role of a BSC liaison to various committees, working groups and review panels. As the BSC has evolved since its inception, the number of groups to which members serve as liaisons and the extent of involvement has also evolved. Dr. Cornelius suggested that the orientation of new BSC members should spell out what is expected of them with regard to serving as liaisons to various committees and review panels. Dr. Cain and Dr. Elo will work on a document that clarifies liaison roles.

US-Mexico Collaboration: Dr. Sam Notzon, Director, NCHS International Program, presented work that is ongoing with the Mexican collaborators along the US-Mexico border. (See PowerPoint.)

Discussion: The BSC commended Dr. Notzon for the US-Mexico Border Health Project. Questions were raised concerning whether a similar project could be conducted along the US-Canada border. The BSC also asked whether Mexican collaborators could be included in the annual US-Canada interchanges. Dr. Notzon responded that efforts have been made in the past to conduct a three country interchange but a number of factors prevented a fully successful meeting. He is continuing efforts to bring in representatives from Mexico.

Q-BANK: A Question Evaluation Database: Dr. Kristen Miller, Office of Research Methodology, NCHS, presented an overview of the Q-Bank project, a database consisting of scientific reports that evaluate survey questions. Many of the Federal statistical agencies contribute to Q-Bank which is made available to survey designers. (See PowerPoint.)

Discussion: The BSC was enthusiastic about the project. They raised several questions about whether administrative data was included, how batteries of questions fit in and whether there were multiple reports for any one question.

National Committee on Vital and Health Statistics (NCVHS) Update: Dr. Donald Steinwachs, chair of the NCVHS Population Health Subcommittee, joined by phone to update the BSC on those committee's activities. The Subcommittee had held a hearing on the Meaningful Use for Health Information Technology to help define and clarify the term "meaningful use" with respect to the American Recovery and Reinvestment Act (ARRA) of 2009 directives for "Medicare incentives for adoption and meaningful use of certified EHR technology." (For summary of the meeting http://www.ncvhs.hhs.gov/090518rpt.pdf .)

There will be an upcoming NCHVS meeting in Hyattsville on June 10-11, 2009 where the committee will get an update on the *Health Statistics for the 21st Century*, a report being developed by the Population Health Subcommittee.

State and Local Area Integrated Telephone Survey (SLAITS) Update: Ms. Marcie Cynamon, Chief, Survey Planning and Special Surveys Branch, NCHS update the BSC on SLAITS activities since the program review in 2008. SLAITS staff has been very productive in terms of presentations and publications. The second National Survey of Children's Health has just been completed. Marketing of the survey has gone well and the staff is operating at maximum capacity. The Maternal and Child Health Bureau plans to continue funding the National Children's

Health survey and other organizations are interested in future projects on such topics as adoption and influenza. SLAITS continues to advance with respect to the recommendations that were made in the review.

Discussion: The BSC praised the project team for its many accomplishments. The fast turnaround on surveys is particularly impressive. SLAITS should continue to make a contribution to the field of children's health and may expand into other areas.

The meeting adjourned at 5:00 PM.

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Irma T. Elo, Ph.D.

Date