

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

**Minutes of the Ninth Meeting
September 14, 2006
Hubert H. Humphrey Building**

**September 15, 2006
NCHS Headquarters
3311 Toledo Road
Hyattsville, Maryland 20782**

All attendees are listed in Attachment 1.

September 14 11:20 AM: Joint meeting with National Committee on Vital and Health Statistics (NCVHS) and National Center for Health Statistics (NCHS) Board of Scientific Counselors (BSC) convened. NCVHS Chair Simon Cohn welcomed the BSC members and said that the purpose of the joint meeting was to discuss opportunities for collaboration and synergies between the two groups. BSC Chair June O'Neill described the intramural review process being undertaken by the BSC and suggested that common issues shared by the two groups include: 1) balancing needs of data dissemination and confidentiality 2) need for more resources for NCHS. Bill Scanlon and Irma Elo, the liaisons between the two committees, agreed on the two general areas of common interest and further specified that the committees could help address issues related to data linkages and to ensuring release of vital statistics data in the context of concerns about confidentiality expressed particularly by the National Association for Public Health Statistic and Information Systems (NAPHSIS). The suggestion was made that representatives of the NCVHS population subcommittee and selected BSC members meet jointly to discuss these issues.

BSC member Steve Schwartz and NCHS Division Director Charlie Rothwell presentation on vital statistics data release: Steve Schwartz discussed challenges for states, risks associated with data release. He stated that reliance on penalties for inappropriate release is insufficient since enforcement is weak.

Charlie Rothwell described the NCHS releases; he said the public use files no longer have any geographic specificity. He said there is a two tiered approach to restricted release: Federal researchers and contractors can request geographic files; the requests are reviewed by NCHS and a state representative. Private users must go to Research Data Center (RDC).

Discussion: BSC member Janet Norwood said the issue of confidentiality vs data release is bigger than NCHS and vital statistics as it applies to Federal

statistical system overall. She gave the example of problems with release by States of economic data, because of disagreements with Federal agencies. Dr. Schwartz suggested that a possible opportunity for the BSC and NCVHS would be to develop model legislation to recommend to States on data release policy.

Charlie Rothwell presentation about Electronic Death Registration: Charlie Rothwell said that there is very little automation with mortality data. He said that the Social Security Administration (SSA) has been funding a few states each year for developing electronic data, but that NCHS hasn't benefited from SSA supported improvements. He said that NCHS recently obtained some funding to supplement SSA automation efforts, but we have a long way to go.

Discussion: Simon Cohn suggested focusing BSC/NCVHS efforts on the issues raised in the joint presentation by Charlie Rothwell and Steve Schwartz, about balancing access and confidentiality. He suggested a joint letter recommending a process for raising this issue as a higher priority in the Department of Health and Human Services (DHHS), and the possibility of developing a model state law related to data release policy. There was discussion about reviewing the 21st Century Health Statistics Vision report for references to the importance of the electronic health record and about linkage of health care records and vital statistics. The NCVHS privacy subcommittee could have a helpful role in this.

NCHS Update: NCHS Director, Edward Sondik presented an update of NCHS activities.

Liaisons update: Irma Elo and Bill Scanlon agreed that the joint meeting had been useful, and they both supported the recommendation to push for greater DHHS-level priority on resolving issues of data release. Dr. Elo suggested a joint conference call that included Steve Schwartz, to discuss next steps. Dr. Scanlon said the discussion at the meeting was useful in helping NCVHS be more sensitized to the issue of tradeoff between data release and confidentiality protection. Dr. Elo suggested using the Department's interest in intelligence reform as a "hook" to getting the attention of DHHS.

September 15, 8:30 AM

Natality Review: Dr. Barbara Luke presented the review committee report. She said there is grave concern about the natality program due to inadequate funding for the program. Her group's main recommendation was that CDC needs to provide greater support and that Vital Statistics should be a line item in the Secretary's budget.

NCHS Response: Stephanie Ventura thanked the review panel for their efforts in reviewing the Natality Program and clarified the NCHS position on some of the points raised. She will be addressing the report in greater detail in the next few months.

Discussion: Charlie Rothwell said the States need funding in order to implement the recommendations. During the discussion, several points were raised, including the benefit of bringing data users into the discussions by mechanisms such as data users groups, an external grants program, and conferences about research using the data. A suggestion was made to add information to the report on the history over the years of efforts by NCHS to fund States. The suggestion was made to develop a cooperative approach between NCHS and the states whereby funds from NCHS support NCHS objectives and rather than simply paying for pieces of data. The report needs to underscore the importance of the data and the negative impact of not having the data available. More information is needed about why some states are adopting the new certificate and others are not, and to identify barriers and how to overcome the barriers. Representatives from the States said that the states want the new data on the birth certificate and that 99% of the reason that states haven't implemented the new system is that states don't have the money. A question was raised about the feasibility of phasing in implementation of the new certificate, starting with states that are "early adopters". A possible solution was suggested to emphasize the national security importance of improved certificates, as a way to press for more funding.

Discussion on natality report will continue in the January BSC meeting.

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

June E. O'Neill, Ph.D.

Attachment 1
CENTERS FOR DISEASE CONTROL AND PREVENTION
BOARD OF SCIENTIFIC COUNSELORS
NATIONAL CENTER FOR HEALTH STATISTICS

September 14, 2006

BSC members

June E. O'Neill, Ph.D., Chair
Irma T. Elo, Ph.D.
Raymond Seth Greenberg, M.D.,Ph.D.
Michael Grossman, Ph.D.
Donald J. Hernandez, Ph.D.
William D. Kalsbeek, Ph.D.,M.P.H
Thomas D. Koepsell, M.D., M.P.H.
James M. Lepkowski, Ph.D.
Janet L. Norwood, Ph.D.
Neil R. Powe, M.D., M.P.H..
Louise M. Ryan, Ph.D.
Bill Scanlon, Ph.D. NCVHS Liaison
Steven Schwartz, Ph.D.
C. Matthew Snipp, Ph.D.
Virginia S. Cain, Ph.D.,
Executive Secretary

NCHS

Joyce Abma
Colleen Choi
Marjorie Greenberg
Althelia Harris
Julia Holmes
Debbie Jackson
Jennifer Madans
Gladys Martinez
Mary Moien
Bill Mosher
Edward Sondik
Stephanie Ventura
Robert Weinzimer

September 15, 2006

BSC members

June E. O'Neill, Ph.D., Chair
Nicholas Nash, Eberstadt, Ph.D.
Irma T. Elo, Ph.D.
Raymond Seth Greenberg, M.D., Ph.D.
Michael Grossman, Ph.D.
Donald J. Hernandez, Ph.D.
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Louise M. Ryan, Ph.D.
Steven Schwartz, Ph.D.
C. Matthew Snipp, Ph.D.
Ruth E. K. Stein, M.D.
Virginia S. Cain, Ph.D.
Executive Secretary

NCHS

Tamyra Carroll
Colleen Choi
Jane Gentleman
Eve Powell-Griner
Donna Hoyert
Jennifer Madans
Joyce Martin
Peter Meyer
Martha Munson
Sam Notzon
Charles Rothwell
Edward Sondik
Stephane Ventura
Jim Weed
Robert Weinzimer
Corrine Williams

Other attendees

Michael Cooperstock, M.D., M.P.H.
Irvin Emmanuel, M.D.
Isabelle Horan, Ph.D.
Barbara Luke, Sc.D.
Joann R. Petrini, Ph.D., M.P.H.
Nancy Reichman, Ph.D.
Robert Schoen, Ph.D.