

Board of Scientific Counselors
National Center for Health Statistics
September 24 – 25, 2009
Minutes

Thursday, September 24, 2009

Welcome and Introductions

Dr. Irma Elo, Chair of the Board of Scientific Counselors (BSC), called the meeting to order and introduced Dr. Ed Sondik, Director of the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC). Dr. Sondik welcomed the group and acknowledged returning BSC members, Dr. Elo, Dr. Tom Koepsell and Dr. Steve Schwartz. He provided an overview of CDC's recent organizational changes and gave updates on NCHS programs and activities.

Dr. Sondik announced the recent appointment of Dr. Thomas Frieden as CDC Director and Administrator of the Agency for Toxic Substances and Disease Registry (ATSDR). Dr. Frieden, formerly the Commissioner of the New York City Department of Health and Mental Hygiene, brings to CDC/ATSDR his commitment to epidemiologic surveillance and statistics, with particular interests in NCHS' statistical data collection and dissemination efforts. Dr. Sondik outlined Director Frieden's five priority areas: strengthening surveillance and epidemiology; strengthening the ability to support state and local public health; providing public health leadership in global health; providing public health leadership in health policies, especially health reform; and, better addressing of the leading causes of death and disability. Among the list of Dr. Frieden's recent actionable interventions at CDC, Dr. Sondik noted the following: reinstating the Public Health Grand Rounds, eliminating the Coordinating Center organizational structure, creating new positions within the Office of the Director, including Associate Director positions for Communications (Acting Associate Director, Donna Garland); Policy (Acting Associate Director, Mr. Donald Shriber); Programs (Acting Associate Director, Dr. Janet Collins); and Science (Acting Associate Director, Dr. Peter Briss); and, establishing new Offices and Centers -- the Global Health Center, formerly the Office of Global Health; the State and Local Support Office; and the Office of Surveillance, Epidemiology, and Laboratory Services (the Acting Associate Director is Dr. Stephen Thacker). Dr. Sondik also announced that Dr. Thacker might attend the next BSC meeting.

With a FY10 budget increase of \$14 million over the President's FY09 budget request, Dr. Sondik reported that NCHS was able to avoid severe cuts to surveys, particularly to the National Health Interview Survey (NHIS). He also reported the House endorsement of a \$1 million increase to NCHS (from \$138.7 to \$139.7 million) to enhance birth certificates and infant mortality data.

Dr. Sondik announced new NCHS data releases, including the release of the 2009 America's Children Key National Indicators of Well-being, the first release of 2007- 08 National Health and Nutrition Examination Survey (NHANES) findings, the report on

health insurance coverage since 1959, and the new data brief on “Delayed Childbirth”. Dr. Sondik mentioned Director Frieden’s interest in the Data Brief format and particularly in translating infant mortality data into a data brief. He explained that NCHS continues to assess message and information dissemination effectiveness, formatting options and data content for these data publications. Other NCHS programmatic updates and conference meeting dates were reported, including the new Health Care Survey activity (support from ONC for state-level data on EMR adoption; support from the Department of Justice (DOJ) for survey of hospital prisons), the Research Data Center openings in Atlanta (May 2009), the APHA (November 9 - 11, 2009), and the Question Evaluation Methods Workshop (October 21 – 23, 2009).

Dr. Elo referenced Dr. Michael O’Grady’s workgroup report on the “Future of NCHS” and raised questions about how CDC’s reorganization might affect NCHS or possibly require a location change for the agency. Dr. Sondik commented that there had been no mention of fractionating or relocating various parts of NCHS and he had provided written response as part of the transition briefing for new CDC leadership. In his response, he explained NCHS’ congressional mandate to work with agencies across the Department of Health and Human Services as a federal statistical agency.

Dr. James Lepkowski raised concerns about how budget will affect survey redesign and asked if the integration of the NHIS and NHANES are at a lower priority level given budget constraints. Dr. Sondik responded that the priority level of the survey redesign has not dropped; workgroups are still engaged, exploring a range of 3 – 4 options and alternatives, and continuing in the same directions as reported by Dr. Virginia Cain, BSC Executive Secretary, at the last Board meeting. Recognizing the implications of the survey redesign efforts for the next 10 years, Dr. Elo offered recommendation from the Board that as the redesign workgroups move forward they should tap into the expertise of the BSC review panels for NHIS and NHANES. She recommended that the BSC devote time to discuss survey redesign updates at the January BSC meeting.

Dr. Lynn Blewett suggested tabling the discussions around location of NCHS, now that new administration is in place. Dr. O’Grady recommended that rather than tabling the issue, discussions should be reframed relative to implications for policy direction or relative to some consistent set of issues that would affect NCHS despite political leadership.

Dr. O’Grady commented on CDC’s ability to step into the policy arena, particularly given the new positions of experienced staff such as Mr. Donald Shriber who previously served as Counsel to the House Commerce Committee. He described NCHS as being a department-wide resource, unless CDC, in its newly organized structure, will play a much broader role. Dr. Sondik mentioned his interest in having the Board assess the effects of the new organizational structure on NCHS’ ability to implement its current mission to serve broadly, as well as to address efforts related to newer initiatives, like health reform.

Dr. O'Grady encouraged NCHS' interest in putting these concerns on the table for discussion; he emphasized that this is the time for rethinking outreach and building relationships (i.e., ASPE seed money for Assisted Living Survey); in order to ensure better return on investments and to enhance NCHS' position the next time serious budget constraints occurs. Dr. Sondik agreed and added that during this time NCHS can make clearer its role and capabilities across the agencies; perhaps establishing a Memorandum of Understanding (MOU) between NCHS and other agencies to provide a viable framework.

Dr. William Scanlon asked for an update on vital statistics, relative to how states are progressing (given budgetary constraints) in birth and death registrations. Dr. Sondik discussed earlier proposals to use a portion of DVS funds to create high and low priority data sets – the top priority data set being used to help build electronic medical records or electronic health records (EMR/EHR) systems, particularly for death registration. He explained the decision to have DVS continue asking states to collect full data sets for the next couple of years; and then over time to look at ways to provide training and resources to states for alternative processes. There had also been past discussions, he explained, about renegotiating state contracts, but this was decided against due to the widely varied range of performance capabilities across the states. NCHS continues to explore options for enhancing the performance of poorly performing states without sacrificing the performance of other states. Dr. Sondik advised that at this time, there is no way to channel stimulus funding to enhance state and local efforts for developing EMR systems; distribution of stimulus funding has been monitored by “meaningful use” of dollars. NCHS continues discussion with the Office of the National Coordinator (ONC) for Health Information Technology (HIT) which seems to be responsive to the idea that birth and death information constitutes “meaningful use” of funds for development of Electronic Health Records (EHR).

Dr. Elo suggested that NCHS solicit input from the Board either directly or perhaps through a DVS workgroup, to guide discussions with CDC Director Frieden about providing support to states for EHR adoption. Dr. Blewett mentioned that states are applying for HIT dollars and wondered if they can integrate birth and death EHR into their requests. Dr. O'Grady added that HIT has assumed that the current status of vital statistics is the baseline and that we need to convey to HIT that this is not true; EHRs are not in place. If we don't have a baseline for EHR systems, then we can't implement intervention. Dr. Schwartz agreed and added that data users and stakeholders generally take for granted the quality, timeliness, and completeness of birth/death certificate data and assume these data are already in place. Dr. Elo noted the importance of having complete birth/death (e.g., tracking cause of death info) for monitoring health reform issues. Dr. O'Grady raised concern for finding ways to communicate the importance of having complete data sets for DVS and to show consequences of insufficient funding; he noted that DVS concerns should be a top priority for the Friends-of-NCHS.

Members suggested that states can also take the initiative to communicate DVS concerns to HHS, proposing performance based measures for integrating birth/death data into a broad medical record system. Dr. Ruth Stein and Dr. O'Grady cautioned against

foregoing one effort for the other – interim data collection on births and death should continue as efforts to integrate these data into medical health record systems are underway. Dr. Schwartz commented that DVS is still challenged even when budgetary funding is available. He suggested a collective approach whereby NAPHSIS and states work together with NCHS to craft a marketable vision for a new DVS system. Dr. Jennifer Madans, Dr. Llewellyn Cornelius and others discussed strategies for funding a small scale pilot test with input from states; Dr. Elo added that states could participate in the DVS system-redesign, creating buy-in overtime and establishing a baseline that would be more compelling legislatively. Dr. Sondik described NCHS’ role as maintaining accurate and complete data and supporting efforts to show the value of vital statistics to EHR adoptions. Dr. Elo offered the Board’s continued interest in following these concerns.

Report of Long-term Care Statistics Program Review

Dr. Elo commended panel review members for their Long-Term Care Statistics Branch (LTCSB) program report and recommendations and introduced Dr. Penny Feldman, Chair of the LTCSB Review Panel.

Dr. Feldman acknowledged Dr. Sondik and BSC members and thanked LTCSB panelists -- Dr. Peter Kemper, Dr. Andrew Kramer, Ms. Nancy Mathiowetz, Dr. Vincent Mor, and Dr. William (Bill) Scanlon); BSC Liaisons -- Drs. Graham Kalton and Mike O’Grady; Scientific Writer, Ms. Sandra (Sandy) Smith; LTCSB Chief, Dr. Lauren Harris-Kojetin, and the LTCSB staff for their participation during the program review process. Among the findings and recommendations presented by Drs. Feldman and Scanlon were the following key themes: the long-term care sector is diverse and ever evolving – there are multiple payers and varied services, settings and providers(paid and unpaid); there is growing demand and rapid change (approximately 70% of persons will need some long-term care arrangements in their lifetime); and interaction with medical care systems requires urgent attention (there are direct and indirect contributions to total health care expenditures).

The panel highlighted a few major challenges facing the LTCSB:

- chronic staffing shortages and budget shortfalls
- survey scope and coverage of long-term care data
- the role of state policy (the intersection of state and federal long-term care policies)
- response rates and data quality
- managing data user outreach and input
- exploiting other information sources

There were two overarching panel recommendations presented: development of a strategic plan to define NCHS’ role in the collection of long-term care data to meet future policy needs (i.e., consideration for new provider-based surveys, person-based surveys or some combination of survey types); integration of all existing and future long-term care provider surveys into a unified set of surveys – the National Long-Term Care Provider

Surveys (NLTCPS). Panelists expressed concern that the current status of long-term care (data collection and dissemination) is driven more by resources (budgetary funding) than by results and by vision of strategic plan.

In her program response, LTCSB Chief Dr. Harris-Kojetin thanked panelists for their careful review and recommendations and reflected on some of the viewpoints and recommendations that she shared with panelists:

- creating a unifying conceptual framework for the NLTCPS – with a common set of core data elements (perhaps, core questions like the HIS model) that can be rotated in- and out- of the survey or core modules that can be alternated (to avoid periodicity challenges, like the last redesign effort when the surveys were out of the field for 5 – 7 years)
- creating the capacity to add topical modules for policy response
- developing a strategy for linking administrative records data to the NLTCPS

She also recognized such benefits of the provider surveys such as the technical aspects of quality surveys (delivery, receipt of care, and quality of care); being more cost effective than population survey; and providing opportunities for data linkages with use and outcome of care.

Discussion

The group discussed variations for deploying long-term care (LTC) surveys, including such options as integrating the surveys; alternating the field years for the surveys; piloting and assessing feasibility of fielding only the population survey; assessing comparability of the landline versus cell phone survey; and rotating and linking provider survey with population surveys.

Board liaisons, Drs. Kalton and O’Grady, were appreciative of the excellent work and insightful recommendations offered by the review panel. Dr. Kalton described the recommendations and suggestions as forward thinking and creative, despite the overarching fiscal restraints and the varied challenges associated with different types of long-term care: licensed and non-licensed facilities; paid and non-paid care providers; population-based, provider-based or person-level surveys; and different survey modes (landline/cell phone/web based). Dr. O’Grady described the long-term care issue as “the sleeping giant of the baby boomers”, affecting society in more far reaching ways than the challenges of the uninsured. He encouraged focus on policy content and emphasized the need for having a strategic vision (exploring options with integrated survey approaches, provider and person level surveys, utilizing comprehensive administrative records to create opportunities for linkages) before fiscal resources will come. Dr. O’Grady pointed to the CMS’ Medicare Current Beneficiary Survey as one useful reference. Dr. Stein noted that 40% of people receiving long-term care are under age 65; this long-term care is not restricted to nursing home care, but is often community-based intervention or relies on family members as providers. She emphasized the need for survey scope that is not narrowly focused on long-term care facilities, but is rather broad-reaching enough to address various long-term care situations. Dr. Blewett pointed to the need for state level input to ensure usefulness of data. Dr. Scanlon also addressed this concern for

understanding state level policy and realizing implications of survey outcomes without state estimates.

Dr. Elo added that this is an opportune time to pull a committee/panel together to look at the LTC survey needs, looking at uniformity of questions across surveys. Dr. Kemper advised against bringing work to a halt while planning; rather, he encouraged continuing with ongoing surveys (including the Residential Facilities 2010 survey) while planning strategically. Strategic planning is always an added task; having data available for policy use is important. Dr. Scanlon reminded the group that the panel's first recommendation for LTCSB is to assess and fill data gaps, and that strategic planning isn't completely an agency responsibility; NCHS is a preeminent data agency with broad reaching goals. Dr. O'Grady asked the Board if the HHS Data Council might be a more viable group to assess these LTC issues. Dr. Madans explained that the Data Council doesn't really provide institutional backdrop for such issues. She suggested that these LTCSB strategic planning challenges are NCHS' responsibility and encouraged the Board to assist in identifying shorter-term vision and immediate changes to survey schedule or survey components (e.g., identifying what 4 questions can be asked now). Members discussed the need for maintaining all 5 LTCSB surveys and the enormity of managing the contracts, data collection and dissemination for these existing surveys. Dr. Blewett and other Board members suggested getting dedicated resources, through a contractual consultant(s) or advisory group(s) (in accordance with FACA regulations), to explore short- and long-term strategic planning related to varied types of long-term health care options, opportunities for administrative and other data linkages (e.g., CMS data on morbidity of elderly populations) and partnering with other agencies or organizations to explore long-term care related to various populations and issues (e.g., TBI - traumatic brain injury). Dr. Kalton expressed concern that strategic planning is an NCHS agency responsibility, rather than the responsibility of the LTCSB; he agreed that some mechanism is needed for developing an LTC strategic plan, but was not as comfortable as others with suggestions to put a contractor in this capacity. Dr. Cain reminded the group that the panel's report isn't final and any input solicited from the Board would be to provide clarification to the report, rather than to formally make changes.

Dr. Sondik added that a long-term strategic plan should include a set of policy related research questions showing NCHS' forward focus in this area, and defining the important dimensions of long-term health care, including mechanisms for capturing various data. Irma concluded discussion, adding that the panel would send the Board its final report; appropriate suggestions and supplemental ideas will be added in a transmittal letter to Dr. Sondik.

National Survey of Family Growth (NSFG)

Dr. Cain announced that the NSFG is the next program to undergo peer review by the BSC. Dr. Wendy Manning has agreed to serve as chair of the peer review panel which will be scheduled early in 2010. Dr. William Mosher, leader of the NSFG, made a presentation to the BSC on the NSFG.

Drs. Cornelius and Harris, BSC liaisons to the review, suggested a number of questions that should be answered by the review panel and then led a BSC discussion on the NSFG. A set of questions regarding the capacity and resources of the program, efforts to improve the survey, products, and outreach to the user community came out of the discussion.

NCVHS Update

Dr. William Scanlon, NCVHS Liaison to the BSC reported on activities of the NCVHS relevant to the BSC. The NCVHS is updating a previous report developed by the committee on statistics for the 21st century. This report is being developed with input for NCHS staff as well as many stakeholders. The report will be released at the June 2010 meeting of the NCVHS which will be a celebration of the committee's 60th anniversary.

Friday, September 25, 2009

Dr. Elo announced the 50th anniversary celebration of the National Health and Nutrition Survey (NHANES), highlighting Congressional activity on the Hill on Wednesday, November 4, 2009.

NCHS and Health Reform

Dr. Bilheimer, Director, Office of Analysis and Epidemiology (OAE) provided an update on NCHS' Role in Health Reform. As background, Dr. Bilheimer explained that NCHS began filling health insurance coverage data requests last year, based on published reports and relevant data runs. Since then, NCHS has been called upon to address health reform and health policy issues in a much broader context – reviewing legislation from the Hill, working with technical advisors from other agencies (ASPE) to assist with data dissemination and data interpretation, and to address a variety of health reform related data requests, from CDC/Washington to the White House Office on Health Reform (OHR). She explained that staff members in OAE and in the Division of Health Interview Statistics (DHIS) have teamed to provide rapid response (within 28- 48 hours) to these types of data requests. The July 2009 release of NCHS' comprehensive report on the "Health Insurance Coverage Trends, 1959 – 2007, Estimates from the National Health Interview Survey" has been an excellent reference document, as has the OHR's website, www.healthreform.gov. Dr. Bilheimer also credited the work of staff in the Office of Information Services (OIS) and the Office of Information Technology (OIT) for creating an NCHS web page to post agency responses to recent health policy requests.

Discussion

Dr. Bilheimer pointed to several examples of how NCHS data has been recently used in policy discussions, including those related to health disparities and to the health needs of middle class Americans. There was some discussion around challenges related to the data transparency and data interpretation in policy, research and reporting. Dr. O'Grady asked if NCHS had any concerns about "showing their hand" by making specific data publicly available on the website. Dr. Bilheimer responded that while there is ultimately no control of how data are used, NCHS has created a good rapport with the OHR through the many recent data calls and responses. She explained that only the final data sets are posted, limiting some possibilities of data misreporting or misinterpretation. Drs. Blewett,

O'Grady and other Board members were pleased overall that NCHS is moving more toward policy issues in data publications and that whether or not data is shared in the public domain, it is important that NCHS data become essential to policy discourse.

Health Insurance

Dr. Robin Cohen, DHIS, presented slides that she and Dr. Diane Makuc (OAE) prepared on "Monitoring Health Insurance and Access to Care Using the National Health Interview Survey" (NHIS). During her presentation, Dr. Cohen shared NHIS data on state level estimates, long term health insurance coverage trends for various age groups and sub-populations (poor children and poor adults), and private health care coverage with and without high deductible health care plans. She discussed comparisons among percentages of persons, by age group, having private health care plans with 1) a low deductible; 2) a high deductible and a health savings account; or, 3) a consumer-directed health plan without a health care savings plans. She discussed the percentages of persons, by age group and type of private health insurance, who had unmet medical needs due to cost, and the percentages of persons, by age group and type of private health insurance, who had a visit to the dentist in the past year. Dr. Cohen discussed data interpretation challenges that arise when comparing health insurance coverage data that are collected differently (i.e., point-in-time health coverage vs. full year health coverage). She described such differences as those noted in the 2008 health insurance data for the NHIS and American Community Survey (ACS), reflecting point-in-time data, and the Current Population Survey (CPS), reflecting full year data.

Discussion

Board members discussed many concerns associated with health insurance data interpretations, and expressed importance in creating consistency and accuracy across surveys. Members raised concerns related to several factors that affect health insurance data: varied sample sizes, misreporting (under- and over-estimations), recall period, respondents' understanding of health insurance concepts and their knowledge about the benefits structure within their own health policies (high- vs. low-deductible coverage; health care savings plan). The group discussed how differences in sample size affect estimates and create differences in standard error. Dr. Madans commented that when the HIS sample size had been cut in half, the standard error was greater. Dr. Stein asked whether estimates on small sample sizes should include a bar in the charts to show that 'standard error' (SE) is a factor. Dr. Cohen commented that quarterly estimates of health insurance have been released over many years; NHIS will produce results based on full-sample size in December 2009 and they will examine estimates to see if they vary significantly from estimates on half-sample sizes.

Dr. O'Grady and Dr. José Escarce raised concerns about the significance of issues such as state subsidies and small population estimates (i.e., Indian Health Service data) in determining estimates of health insurance coverage and unmet need. Dr. Blewett and others discussed the importance of state level information and commended Dr. Cohen and the NHIS for the efforts to produce the Early Release report on health insurance coverage for the 20 states with the largest populations.

There was lengthy discussion about the importance of data accuracy and the challenges of “uncertainty” in health insurance estimates across surveys. Members discussed various factors related to discrepancies in health insurance survey responses and reasons for possible error in these estimates, such as: recall period; who is surveyed in the family; the number of health insurance policies per family; reweight and imputation issues.

Dr. O’Grady raised questions about identifying the differences between “unmet need” and “utilization” in survey outcomes (looking at the misreporting and the under- and over-counting of those state level data for Medicaid enrollees).

Members shared thoughts on national estimate surveys like Census/CPS and local estimate surveys like ACS, as well as pros and cons of full year estimate surveys and point-in-time survey estimates. Dr. O’Grady mentioned that point-in-time data is not as helpful as data gaps are more prevalent (e.g., gaps for college students) and raised questions around which survey is the ‘gold standard’ for having the most reliable (best) health insurance data (HIS or MEPS), particularly relative to the blurred lines created with data linkages.

Dr. Makuc suggested that although there is variation across surveys, the answer is not to pick one survey over the other as a one-size-fits-all solution. Of the four surveys being discussed, NHIS, ACS, CPS and MEPS, Dr. Makuc pointed out advantages and disadvantages of each: ACS has a large sample size every year the ACS can support the release of single-year estimates for geographic areas with populations of 65,000 or more; the NHIS can provide early release data on state level health insurance coverage (the 2008 NHIS report provided estimates for the 20 largest states); MEPS has smaller sample size, yields approximate point-in-time estimates, and links with the NHIS. CPS provides long-term trend data for issues; although there are issues related to recall period and to full year estimates that appear to look more like point-in-time estimates. CPS estimates are probably used the most, although challenges with data inaccuracy probably occur more often.

Dr. Stein added concern about data accuracy, based on respondents’ knowledge of their health insurance packages and respondents’ recall; she pointed out that respondents don’t typically develop knowledge of their health packages until they need to use their benefits and that respondents in surveys with longer reference periods tend to have greater recall error (like CPS, which has a point-in-time measure of health coverage and requires respondents to reference health coverage they’ve had up to 15 months prior to the interview).

Members agreed overall that methodology and survey coordination focus should be a budget and policy priority. They discussed the need for establishing methodology for cross-validation to address challenges around data consistency and accuracy, particularly relative to health insurance coverage estimates across various surveys (NHIS, CPS, ACS, the Survey of Income and Program Participation (SIPP), and the Medical Expenditure Panel Survey (MEPS)). There were several suggestions for enhancing data quality by

improving survey questions (survey questions in CPS and MEPS income questions) to ensure user confidence in the survey outcomes.

The Board also outlined a few general goals and objectives for consideration to move this survey discussion forward: methodological development, coordination across surveys, robust funding. Dr. Elo asked how the Board can help address these survey challenges, and suggested that perhaps a small group be established to explore next steps. Dr. Sondik agreed with Dr. Elo's suggestion and recommended that the topic be placed back on the BSC agenda, to further review strategy on data rigor for policy relevance.

NHIS Update – Jane Gentleman

Dr. Jane Gentleman, Director, Division of Health Interview Statistics (DHIS), presented an update on activities related to the National Health Interview Survey (NHIS) Review Panel recommendations. The review panel's one overarching recommendation was to continue the NHIS; they also offered a set of specific high-priority recommendations and other suggestions. Despite budgetary and staffing constraints, Dr. Gentleman discussed several cost-cutting measures that have been implemented by DHIS (from FY08 – FY2010), to ensure the continuation of the NHIS -- reducing address listings and cutting ½ of sample size, cancelling classroom refresher training classes, temporarily diverting salary costs for the Census Branch Chief, and delaying release of FY2010 funding to Census (\$1.2M) for redesign activities. She also mentioned the anticipated costs of adding two panels to NHIS (from Oct – Dec 2009) which will allow the survey to achieve maximum sample size (~87,500 persons) in 2009; adding one panel (from Jan – Mar 2010); and adding enhanced refresher training session(s) (Jan 2010). In addition to careful management and monitoring of NHIS budget, DHIS received some extra funding from NCHS/OCD and from NIH/OBSSR (end-of-FY09 monies); pending funds are anticipated from NIH/OD to help cover survey costs.

Dr. Gentleman provided follow-up comments to a few panel recommendations. She noted that NIH does not want biomarkers, which is in contrast to the (methodological studies) suggestion, to "...add biomarkers...at the minimum...consider...blood spots, cell swab kits, height, weight..." She also mentioned a few "wish list" items from the first report of the Task Force on the next NHIS Redesign, including flexibility of using multiple survey modes as needed; more flexibility within the questionnaire; and more state-level, small area population data .

Discussion

Dr. Elo thanked Dr. Gentleman for her presentation and for the DHIS' efforts to address budgetary and staffing constraints to support the continuation of the NHIS. Some of the group discussion focused on comparability of measured data and self-reported data; Dr. Madans described the Canadian Community Health Survey (CCHS) survey methods, particularly related to measures of height and weight. Other discussion was focused around strategies for getting more state-level and small area population data. Dr. O'Grady emphasized that states should have some funding responsibility and noted that the size of the state doesn't always correlate with available funding.

Data Users Conference - Jennifer Madans

Dr. Madans circulated copies of the 2008 Data Users Conference (DUC) Program; she provided background information on the initial concept and structure of the DUC and gave a brief overview of changes over time, including the decreased attendance in recent years (Dr. Madans would provide Board members with actual numbers of participants at the 2008 DUC), increased involvement from senior staff, and increased numbers of concurrent workshops and hands-on work sessions. Dr. Madans invited Board members to share ideas for plenary speakers and thoughts on how to enhance the scope of the conference for a broader appeal to DUC attendees.

Dr. Madans explained that as the name Data “Users” Conference implies, the DUC was initially designed to introduce “new” data users to the NCHS data systems. The content focus of the conference has expanded to include work sessions that are both data system specific and topic/subject specific, and intended to appeal to mid- and senior-level federal and academic employees and researchers.

Discussion

Board members raised several suggestions:

Enhance advertisement of DUC at the academy level – Dr. Escarce asked about greater outreach to the academy; Dr. Madans explained that current DUC outreach is distributed to university faculty listed as Department Chairs. Dr. Elo suggested that an email of invitation be sent to Department Chairs with instructions to forward broadly for wider outreach across the academic community.

Develop a social marketing strategy – Dr. Sondik suggested a social marketing strategy; highlighting the DUC as a good place for data users to exchange ideas.

Push an impact statement – Members asked, “What creates the expectation people have about this conference?” Dr. O’Grady suggested developing an “impact statement” as part of a DUC marketing plan, with emphasis on “why” data users should attend the DUC.

Broaden the content focus and change the name – In addition to covering technical aspects of data surveys at NCHS, Dr. O’Grady pointed out the need for a more research based conference, with discussions around policy implementation, as a strategy for broader appeal to an audience of academic researchers and mid- to senior-level scientists. Dr. O’Grady suggested a conference name change to, “NCHS Data and Research Conference”.

Canvass and Network – Members suggested canvassing and networking with former DUC presenters and attendees for feedback, input on program layout and ideas for potential speakers and speaker topics. Dr. Holly Hedegaard commented that regular DUC attendees have described the conference as being the “same, year after year”. She suggested that the pool for potential speakers should extend beyond NCHS/CDC/HHS, and that conference sessions could possibly include abstract presentations, as well as

plenary sessions and topics related to NCHS data surveys. Dr. Kalton suggested outreach to other agencies, like the National Center for Education Statistics (NCES), who hold a similar conference to exchange planning ideas and lessons learned.

Create opportunities for cross-pollination – Dr. O’Grady commented that many conferences are silos of information, having a singular theme and showcasing similar types of speakers (e.g., statistical survey topics and presented by statisticians). He suggested creating opportunities for cross-pollination in conferences through an interdisciplinary approach, with opportunities for researchers, economists, and epidemiologists to show the integration of certain topics, concepts and ideas. Dr. Elo added that this approach provides data users the chance to hear about the same data in different ways, and allows for potential discussion of data’s policy relevance (perhaps in plenary sessions) with experts from the Hill, the Congressional Research Service (CRS), or other policy venues.

Dr. Cornelius generally summarized the purpose of these proposed enhancements to the DUC, as an effort to create a technical “hands-on conference”; to show impact of the NCHS data systems and publications; to provide a “forum” where data users (scientists and academics) can collaborate and exchange ideas from their publications which use NCHS data for cutting edge research; to showcase hot topic issues and NCHS data during a “plenary” or featured speaker session. He pointed to the National Health Policy Forum, as an example of a gathering of policy makers and researchers who come together to exchange ideas in a forum setting. (Bill Scanlon is currently a Key Advisor to the National Health Policy Forum.)

Health U.S. Publication and Distribution

Drs. Bilheimer and Makuc, OAE Director and Deputy Director, led the HUS discussion. They circulated copies of the 2008 HUS and presented underlying issues related to the ongoing challenges of currently producing and distributing the HUS report.

- The HUS report, an annual print publication (with tables available on CD-ROM) is voluminous, covering more than 500 pages -- including an executive summary, data highlights and a special feature, a chartbook with data tables, and more than 300 pages of trend tables and appendices.
- Cost feasibility is becoming increasingly challenging, given the volume of the HUS print publication, and the growing mailing list of data users who receive copies of the report.
- To address budgetary issues and other challenges related to the publication and distribution of HUS, printing numbers have greatly decreased over the past few years. (NCHS printed about 12,000 copies of HUS in 2004; about 3,000 copies in 2008; and this year, total copies are expected to be 500 or fewer.)

Dr. Sondik explained that NCHS is legislatively mandated to submit the Health, U.S. (HUS) report to the HHS Secretary (in compliance with Section 308 of the Public Health Service Act). He mentioned Dr. Frieden’s recent interest in having a shorter, more user-friendly version of the HUS, addressing certain key health indicators, major data updates

and issues that might be particularly relevant for policy makers.

Dr. Sondik invited BSC members to share their opinions and comments.

Discussion

The discussion focused on underlying issues related to two primary points: the data content of the HUS and the increased volume and size of the HUS print publication over time. BSC members discussed several options in response to these challenges and to address Dr. Frieden's interest in creating a shorter, more user-friendly version of the HUS.

BSC members reported that they like the HUS print publication and find the data content relevant to their data needs. Overall, members agreed that print publications should continue, but on a smaller scale (the process for determining publication numbers was not discussed in detail); they agreed that a combination approach of providing a full-version print publication of the HUS, along with a shorter companion version of select data excerpts and tables (available also on CD-ROM) would be an efficient option.

Currently, the comprehensive version (or full-version) of the HUS print publication includes an executive summary, data highlights, a special feature, a chartbook with data tables, and more than 300 pages of trend tables and appendices. Members discussed a variety of publication scenarios:

- Print publication (full-version) with tables also on CD-ROM (inserts in back of HUS or separate)
- Print publication (full-version) with tables also on web
- Companion print publication featuring excerpts, key indicators and data tables (shorter-version; to accompany smaller distribution of full-version prints)
- Web only (full-version) to be updated regularly and routinely
- "Dashboard" View (web-version) with a possible print version companion, featuring key indicators and relevant data tables

There were advantages and disadvantages discussed relative to each of the scenarios outlined above.

- Data users like reading and referencing the hard-copy HUS print publication for their analytic research, but the size and volume of the report make it cumbersome and costly to produce and distribute.
- Web based data and data tables (and data tables on CD-ROM) are easy to access and convenient; however, data are not routinely and regularly updated and not all users will have web access.
- A shorter print version of data excerpts and data tables from HUS provide a nice companion report to supplement the full-version of the report; this option gives users more flexibility. If data needs are more policy relevant, then the companion report may be more appropriate for a quick reference.
- A "Dashboard" web view would possibly address Dr. Frieden's concern that important data points may be lost in the volume of the current HUS; the

“Dashboard” web view could provide quick and easy reference for a variety of data users.

BSC members discussed the importance of continuing the distribution of HUS print publications (to libraries, universities, etc.) for users in rural areas and for others who have limited web access.

Members also addressed media interests in HUS. They pointed out the possible benefit of lessening the risk of inappropriate or inaccurate data report by the media, by providing media contacts with a condensed (companion) report, reflecting content and format preferences of the data analysts.

Dr. Schwartz and other members suggested other alternatives for publication, like the Books on Demand option. This option would allow users to access a full-version of the HUS online for a fee. (There was discussion about NCHS covering part of the user’s fees for the publication order.)

Dr. Bilheimer also asked members to also consider how the Special Feature would be integrated into these publication scenarios. Members suggested review of other Public Health Department web sites, particularly the N.Y. State Public Health Department web site, to see how online features of such Special Feature topics are handled.

BSC Documents

Dr. Elo and Dr. Cain circulated draft documents for Board members’ review and input.

- 1) A “CDC Standard Operating Procedures” document which explains the CDC policy requiring that all research and scientific programs conducted or funded by CDC are subject to periodic BSC review, at least once every five years. (SOP) document for BSC Research and Scientific Program Reviews: This document
- 2) The “Program Advisory Groups under the Auspices of the BSC” document which clarifies the structural and operational differences between BSC subcommittees and workgroup models relative to CDC and Federal Advisory Committee Act (FACA) regulations.
- 3) The “Responsibilities of the BSC” document which outlines the roles and responsibilities of the BSC as a primary scientific advisory body to the agency (NCHS).

Overall, members recommended that BSC groups should be allowed to establish their own timelines for program reviews, rather than having arbitrary timelines in place. The NCHS BSC has already established procedures and program review timelines that are successful in meeting the agency’s (NCHS’) programmatic needs and the BSC members who are volunteering their time, resources and subject matter expertise.

Regarding the establishment of BSC Program Advisory Groups, members expressed various concerns about possible conflicts of interest with other ongoing workgroups or advisory groups. Dr. Elo asked if the Board needed to establish formal standards or if the agency (NCHS) should manage the role and practices of an advisory or working group?

Dr. Cain described as a major difference between subcommittees and workgroups, the formality of the subcommittee appointments by the Secretary. Members discussed the National Survey of Family Growth's (NSFG) advisory model which operates separately from the Board; they also described a scenario where BSC liaisons might serve on a workgroup or in an advisory capacity along with funders or technical experts, but voting privileges would be reserved for BSC members. Dr. Stein advised against creating a situation where advisory groups might offer different recommendations from the Board. Dr. O' Grady commented that the role of an advisory group should be to offer expertise to the agency -- technical or otherwise -- rather than making recommendations. Dr. Elo asked that the agency (NCHS) develop an advisory or working group implementation plan for BSC review and discussion at the January meeting.

The meeting was adjourned by Dr. Elo.

The next meeting is scheduled for January, 14 – 15, 2010.

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Irma T. Elo, Ph.D., Chair

Date

Attachment 1

Board of Scientific Counselors Meeting
September 24th – 25th, 2009

Attendees:

BSC

Irma, Elo, Ph.D.: Chair
Virginia Cain, Ph.D: Executive Secretariat
Ron Angel, Ph.D.
Lynn Blewett, Ph.D.
Llewellyn Cornelius, Ph.D.
Jose Escarcé, MD., Ph.D.
Kathleen Harris, Ph.D.
Holly Hedegaard, MD, MSPH
Donald Hernandez, Ph.D.
Graham Kalton, Ph.D.
Thomas Koepsell, MD, MPH
James Lepkowski, Ph.D.
Michael O'Grady, Ph.D.
Kenneth Prewitt, Ph.D.
Steven Schwartz, Ph.D.
Ruth Stein, MD
Katherine Wallman
William Scanlon, Ph.D.

LTCSB Panel Review Members

Penny Feldman: Chair
Peter Kemper, Ph.D

NCHS staff

Linda Bilheimer, Ph.D.
Robin Cohen, Ph.D
Traci Cook
Jane Gentleman, Ph.D.
Jennifer Madans, Ph.D
Diane Makuc, Dr.Ph
William Mosher, Ph.D.
Sandra Smith
Ed Sondik, Ph.D.