



**As advisory committee to the Secretary of the Department of Health and Human Services, the NCVHS accomplishments in FY 2008 include:**

- Finalized and approved the seminal report : *Enhancing Protections for the Uses of Health Data, A Stewardship Framework for “Secondary Uses” of Electronically Collected and Transmitted Health Data (November 2007)* . After significant discussion, deliberation and review, the Committee unanimously approved the report. The members worked through complex and contentious issues determined to produce a document that represented the Committee’s best effort to address and respond to the request by the Office of the National Coordinator for an overall framework for secondary uses of health data, tying that framework to recommendations on quality measurement, improvement, and reporting.
- In developing the Report on Secondary Uses of Health Data, clarified aspects of “data stewardship” from the Committee’s perspective and finalized the Guiding Principles. The Ad Hoc Workgroup that developed the report also worked through how to represent the concerns of the 400+ responses from the public who expressed concern about the potential “unauthorized” use of their medical information. The Ad Hoc Workgroup effectively made every effort to obtain input from the public and stakeholders on the issues as part of the deliberations by posting the report on the web for comment; holding a public conference call, announced in the federal register; and presenting an early draft at the Fall AMIA meeting for deliberation.
- Finalized and approved another significant letter pertaining to “Sensitive Information in the Electronic Health Record” (May 2008) a particularly challenging document for the Committee because it tackled the potentially polarizing basic issues of control and access to one’s personal health records-- who has access, when and how etc. The Committee tried to come to consensus on these issues over the course of a year’s deliberation in plenary session, subcommittee meetings and countless conference calls. That a letter was approved (with only one opposition) is a testament to the leadership and commitment of the membership. Received response from the Secretary (April 3, 2008) to the letter, expressing appreciation for the Committee’s “continuing diligence and thorough analysis of the policy challenges” of the NHIN noting that the Committee’s “recommendations ...have been very informative” for the Department, as well as “indirectly for those ...now actively engaged in setting up and operating these networks.”

- Approved a letter developed by the Subcommittee on Standards and Security (September 2007) on the X12 5010 transactions and NCPDP transactions as revised HIPAA standards. Based on testimony heard over the course of several hearings, the letter alerts the industry of imminent changes, strengthens the business case for the standards and clarifies aspects of testing and overall coordination. The Committee received a response from the Secretary, expressing appreciation for the Committee's diligence in researching and advising on these matters supporting the usability of electronic transactions and a logical tested approach to implementation.
- Approved a letter on e-prescribing (May 2008) with recommendations on voluntary use of the most recent version of the SCRIPT standard in long-term care and ambulatory care settings and on lifting the exemption from the requirement to use the NCPDP SCRIPT standard for non-prescribing providers in long-term care settings. Both recommendations will promote greater use of e-prescribing standards.
- Approved a letter/report (September 2007) submitted by the Quality Workgroup based on a June 19, 2007 hearing; key themes from the hearing were organized in the report, *Hospital Quality Measurement and Public Reporting in the Current Health Care Environment*, which describes the current hybrid model that spans paper and electronic records, integrating information from medical records with administrative and claims data. Recommendations focus on improving the quality and integrity of data, developing a standardized set of patient-centric measures, accelerating the development of EHRs and supporting necessary research. The American Health Information Community (AHIC) is incorporating aspects of the report into its own considerations of payment reform and clinical decision support for HIT. The NCVHS Quality Workgroup (now a Subcommittee) continues to coordinate with the AHIC Quality Workgroup with both agreeing on the importance of cross-communication between the two groups with periodic conference calls to assure that everybody is aware of current and ongoing projects in quality.
- Approved background document, *23 Building Blocks for Quality: The View from 2008*, which provides an update on the 23 candidate recommendations in areas covered in hearings four years prior-- assessing health care, reducing disparities, building data infrastructure to support quality, and balancing patients' interest in health care quality and privacy.
- Developed a letter for approval (Sept 2008) on e-prescribing issues that pertain to the Drug Enforcement Administration (DEA). Issues include sensitive and even controversial aspects of e-prescribing for controlled substances.
- NCVHS conducted a hearing on the Patient-Centered Medical Home (PCMH) organized by the Population Subcommittee (May 2008) to gather information from key actors and stakeholders of the PCMH and to answer questions about the potential of the PCMH to improve the quality and lower the cost of health care in the U.S. The meeting was structured to receive testimony on: 1) a definition and overview of the PCMH; 2) the PCMH in practice; 3) the economic viability of the PCMH; 4) data

to measure the presence of a PCMH; and 5) health information technology support of the PCMH. The Committee's attention to this highly charged topic has already resulted in special appreciation from professional groups and societies eager to see a galvanizing approach in addressing the issues. The committee was energized and motivated by the testimony on the PCMH, and activities are planned to capitalize on the hearing.

- Was briefed by representatives of the Robert Graham Center Policy Studies (November 2007) who reported on a recent conference on Harmonizing Primary Care Clinical Classifications and Data Standards and related activities. A key finding of the conference was that it is important to act now to establish the data model for personal doctoring in the medical home to enable progress on important transformations of health care that are already underway, and "to a stunning extent" dependent on communication and use of data. The Subcommittee on Populations followed up on issues raised by the presenters and conference regarding the data necessary for establishing and evaluating a "medical home."
- The National Coordinator on Health Information Technology or designate briefs the Committee at nearly every full Committee meeting. He also attended portions of the Executive Subcommittee strategy session relaying particularly relevant information about the AHIC transition plans. The National Coordinator and staff have commended the Committee's efforts at every opportunity noting specifically that the Secretary appreciates NCVHS for its consistency and reliability in producing quality reports, and that the hearings encourage helpful dialog, gather evidence and analyze and develop positions.
- Considering the Committee's long-standing support for replacing ICD-9-CM with ICD-10-CM and ICD-10-PCS, a key strategist in the area, Dr. Christopher Chute provided information on plans for ICD-10-CM to evolve with the development of ICD-11 as well as on the revision process, itself (February 2008). NCVHS has a long historical involvement with past ICD revisions, and its responsibilities related to the ICD are in accordance with its charter and mission.
- Received a briefing on Healthcare Terminology from Deputy Director of the National Library of Medicine (May 2008). on key issues raised at the briefing by Dr. Chute, highlighting some of the collaborations and priorities to map code sets and classification systems. The briefing also included information on the International Health Terminology Standards Development Organization (IHTSDO), which has acquired the intellectual property rights for SNOMED-CT.
- Received a briefing from the American Health Information Management Association (AHIMA) and the American Medical Informatics Association (AMIA) on an Action Agenda they have developed for Healthcare Terminologies and Classifications. The joint report proposes formation of a Centralized Terminology Authority in the United States to rationalize and coordinate disparate activities and oversee U.S. classification and terminology development and maintenance.

- The Subcommittee on Populations is continuing to prioritize its topics and projects, to include harmonizing vital statistics across the States and improving health information through data linkages.. The Subcommittee will also be following up on the NCHS challenges of sharing data, specifically NHANES specimens-- with DNA and genomic implications-- and how to deal with the impending levels of confidentiality risk involved. Basic questions entail how to assure confidentiality, eliminate any possibility of a breach, and make sure that all parties carry the same weight of responsibility and accountability as NCHS. The Subcommittee welcomed the participation of NCHS Board of Scientific Counselors (BSC) representatives in its sessions and is relying on their ongoing involvement in implementing the Populations Subcommittee agenda. Both groups recognize the impact of tightening privacy regulations and policies on collection and analysis of health data, strengths and weaknesses of aggregated data, the current status of electronic birth and death records, and the confusion of operating under different and sometimes conflicting state laws.
- Continues to make use of the information gathered from the Workshop organized by the Subcommittee on Populations--Using Administrative Data to Improve Statistics on Health Outcomes, (September 2006) to identify data linkages within and among federal government agencies with a view to promoting best practices. Department staff frequently refer to the gathering and the report which helped to identify baseline issues in using administrative data. The Committee continues to seek ways to promote data linkages that can improve health information for Americans and identify factors that influence disparities in health care and health status. The session continues to be recognized for providing a rare opportunity for representatives from a range of agencies to discuss these issues, share lessons and observations and dialog about data linkages and probably will be repeated in 2009 or 2010.
- Subcommittee on Standards continues to monitor the status of implementation of the National Provider Identifier; an NPI is a unique identification number for health care providers that will be used by all health plans and is intended to simplify the current system where different identification numbers are assigned to health care providers.
- Developing a Monograph reflecting the substantive work and recommendations of the Subcommittee on Privacy and Confidentiality during 2006 - 2008 ,covering the impact of the Privacy rule on non-HIPAA covered entities and providers and privacy and confidentiality issues in the Nationwide Health Information Network Compendium includes the letters recommending that laws and regulations be established to assure that all entities that create, compile, store, transmit, use personally identifiable health information be covered by a federal privacy law.
- Received response from the Secretary (March 12, 2008) to the Committee's earlier letter on the relationship between FERPA (Family Educational Rights and Privacy Act) and HIPAA privacy rule with regard to school health records and the need for

further clarification. The Secretary noted that the NCVHS recommendations “are important in helping the Department achieve” balance between protections and access to quality health data and included a report on issues raised by the Virginia Tech Tragedy, reinforcing the urgency of considering these important issues.

- Continues to evolve in recognizing the extensive cross-cutting issues being covered in the Committee, shifting from technical to more conceptual work over the years in a more collaborative, integrated model. Members developed a background PowerPoint presentation and graphic that reflects the Committee’s ongoing transition to operating across the fields rather than in highly concentrated “silos” of previous operations. As such, the Committee organization has shifted to reflect and accommodate this reality.
- In several organizational adjustments, the Quality Workgroup was elevated to a Subcommittee, and several subcommittees were re-named to reflect a shift of focus. (Details provided in the Performance Measures portion of this report). With these changes, the Committee and executive leadership are committed to help “prepare the landscape for data-driven reform,” and develop an – Information Framework for Health Care Improvement. The retreats and a recently created Committee Operations document, overseen by the Executive Secretary, were instrumental in spearheading much of the improved communication and coordination that have been implemented within the Committee operations. These developments have been helpful and effective in dealing with the increasing amount of overlap and interconnectedness in the Committee’s deliberations.
- Prepared and submitted a 2005-2006 report which reflects the Committee’s extensive activities related to population health data, data standards, quality assessment and privacy and confidentiality. The report notes that “In its 58 years, NCVHS has built a strong reputation for thoughtful leadership, and the Department and many other constituencies have come to rely on its expertise. It serves as a bridge between the Department and the health care, research and public health communities as well as to the public.” The report captures and reflects the Committee’s particularly productive period and continuing transition in developing pivotal projects in record time and involving extensive coordination with AHIC and the Office of the National Coordinator, its role in providing input on development of HIPAA regulations, its first ever full Committee retreat, and strategies to increase its effectiveness with the increasing overlap and interconnectedness in its deliberations.
- NCVHS Executive Secretary organized a trip (May 2008) with the Director of the Robert Graham Center, to meet with Dr. Kerr White to honor Dr. White’s contributions to population health, health statistics and primary care research and to gather information for the 60<sup>th</sup> anniversary of the National Committee on Vital and Health Statistics, which Dr. White chaired from 1975-79. Dr. White continues to demonstrate significant insight and shared some of the historical moments in NCHS and NCVHS history, while stressing the continuing importance of population health.

- The NCVHS Executive Secretary and Senior Program Analyst have already started strategizing plans for the NCVHS 60<sup>th</sup> Anniversary Celebration. The Executive Secretary has been in contact with former member Dan Friedman to discuss possibilities of updating the Health Statistics for the 21<sup>st</sup> Century report highlighting the relationship of the vision to the HIT agenda which has blossomed since the original report. Potential questions include: What progress has been made on the goals; how do we update initiatives; what is the link between electronic health records and health statistics? Other ideas include celebrating with a series of events over 2009-2010, culminating in a significant gathering in June 2010.

