



As advisory committee to the Secretary of the Department of Health and Human Services, the NCVHS accomplishments in FY 2007 include:

- Working intensively to respond to the request by the DHHS Office of the National Coordinator for Health Information Policy (ONC) to help develop an overall framework for secondary uses of health data, and tie that framework to recommendations on quality measurement, improvement, and reporting. An NCVHS Ad Hoc Workgroup on Secondary Uses of Health Data has been formed to assist ONC in considering this issue and to make recommendations to the American Health Information Community (AHIC). In the hearings, testifiers helped to clarify current law, privacy and security considerations, the impact of standards and the roles of providers in capturing and using data. Committee continues to explore aspects of trust and transparency in health data uses, health data protection solutions, consent and other technical issues.
- Responded to an earlier request by the Office of the National Coordinator, by forming an Ad Hoc Workgroup on the Nationwide Health Information Network (now disbanded). NCVHS members and staff organized an intense schedule of hearings that resulted in a seminal report (October 2006) on an initial set of minimal but inclusive requirements needed for NHIN services and its possible architectural forms. The Workgroup's efforts resulted in increased cooperation and sense of alignment within the industry and eagerness to move forward. The NHIN is intended to develop widely available services that facilitate the accurate, appropriate, timely, and secure exchange of health information.
- Submitted a series of letters prepared by the Subcommittee on Standards and Security, on the implementation challenges of the National Provider Identifier, based on results from three hearings (July and October 2006, January, 2007), involving representatives from providers, vendors, clearinghouses, pharmacies, and payers. 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. The Committee recommended that the Department publish contingency guidance, similar to the one used for transactions and code sets in 2003.
- Submitted recommendations, prepared by the Subcommittee on Standards and Security based on a July 2007 hearing of stakeholders and presenters on new versions of the HIPAA transaction standards. The letter, with specific support of the 5010 HIPAA transaction standard, recommends that HHS publish proposed rules to migrate HIPAA transactions to the forthcoming versions developed by the Accredited Standards Committee X12N and the National Council for Prescription Drug Programs. The letter also includes recommendations on the type of testing, education and outreach that are needed.
- The National Coordinator on Health Information Technology or designate briefs the Committee at nearly every full Committee meeting. Also, several NCVHS members presented the Committee's NHIN Report at the December 2006 AHIC meeting, which was a teleconference.
- The National Coordinator and staff have commended the Committee's efforts at every opportunity. At a recent AHIC meeting, the Secretary specifically stated that the NCVHS is recognized for its consistency and reliability in producing quality reports. NCVHS members are represented on two AHIC workgroups (Bio-surveillance and Electronic Health Records), and the NCVHS Quality Workgroup Chair (and staff) are working very closely with the AHIC Quality Workgroup.



- In like manner, the NCVHS Chairman presented key issues from the upcoming report on Secondary Uses of Health Data to AHIC (Sept 2007).
- Concurred with the report and recommendations of the Consolidated Health Informatics (CHI) Initiative on the Functioning and Disability domains (November 2006); these recommendations include recognition of the International Classification of Functioning, Disability and Health (ICF) as a CHI-endorsed vocabulary, and join allergy and multimedia recommendations submitted last year.
- Commented on the proposed rule on Medicare Part D data and also submitted a letter on the National Drug Code (December 2006). These letters demonstrate the Committee's role in providing important input to stakeholders in the field in offering direction and issue analysis-- in this case, the Committee reinforced the public benefit of sharing (de-identified) data and health information across agencies, and supported the recommended change giving FDA control of the National Drug Code (per the NPRM).
- Received two briefings from the Executive Secretary and CDC liaison on international classifications and standards. The briefings described the World Health Organization Family of International Classifications and the Network of Collaborating Centers that maintain and promote those classifications. Developments regarding SNOMED-CT also were covered.
- Received a briefing on the International Health Terminology Standards Development Organization (IHTSDO) from Deputy Director of the National Library of Medicine. IHTSDO has acquired the intellectual property rights for SNOMED-CT.
- Committee was briefed on current quality issues involving Data Stewardship, as well as the Request for Information published by AHRQ, which seeks to address questions of responsibility for safeguarding the data beyond the original care setting.
- Through the Subcommittee on Populations, organized a workshop on Surge Capacity and Preparedness (February 2007) which covered data challenges during times of disaster, natural or otherwise. The session was organized to hear federal, state and local perspectives, on ambulance diversion data and surge capacity statistics. Subcommittee is analyzing the information to determine next steps.
- Briefed on Secondary Uses of Health Data (November 2006), with recommendations from a report by the American Medical Informatics Association (AMIA).
- Through the Subcommittee on Privacy and Confidentiality, conducted hearings (2006) that focused on the impact of the privacy rule on non-covered providers and those providing benefits and services (examples, spas, home care, personal trainers etc). During these hearings, testimony was also received from the financial industry (banking, insurers, employers), as well as on approaches for studying the impact of the Rule. Submitted letter (June 2007) 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.
- Also through the Subcommittee on Privacy and Confidentiality submitted a 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 Subcommittee on Privacy and Confidentiality conducted a hearing on "Consumer Controls for Sensitive Health Records" (April 2007) with background information about masking areas of a consumer's health record, a different methodology from deleting or expunging because the action can be reversible if needed. This area is proving to be particularly challenging to reach consensus because of the need to balance individual rights with the public good and quality of care. The Committee is extending discussion of the issues to allow further input for action at a future meeting.
- Through the efforts of the Quality Workgroup, approved a letter/report with recommendations based

on results of a hearing (June 2007) on Performance Measures and Quality Improvement and Public Reporting. Key themes were organized in the report, *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 Workgroup is exploring how to coordinate with AHIC and its Workgroup on Quality in transmitting joint recommendations to the Secretary.

- Participated in the first ever joint session between the NCVHS and the NCHS Board of Scientific Counselors (BSC) (September 2006). The Chairs of both groups along with their respective liaisons led the discussion, which included privacy and confidentiality issues, 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. The members from both groups expressed interest in continuing such joint sessions, and look forward to making joint statements about issues of mutual concern.
- NCVHS Team staff represented the Committee in attending a BSC meeting in New York City (January 2007). The board members expressed continued interest in maintaining and increasing interacting with the activities of the NCVHS Populations Subcommittee to explore topics of mutual interest.
- Through the Subcommittee on Populations, conducted a Workshop --*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 and submitted a recommendation letter in June 2006. The Subcommittee sought 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 Workshop was organized to obtain a more systematic understanding of administrative record matching activities being conducted across the Federal government and their potential for helping to understand and improve population health outcomes. According to the feedback, the session provided a rare opportunity for representatives from a range of agencies to discuss these issues, share lessons and observations and dialog about data linkages
- Based on comments at the full Committee and Executive Subcommittee retreats, the meetings have been reorganized to facilitate communication among the membership, recognize the extensive cross-cutting issues and accommodate an unusually large number of action items. The Committee's first ever Full Committee Retreat (June 2006), initiated new perspectives on Committee operations. The retreat and subsequent follow-up session 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. It has active relationships with federal and state agencies, other advisory bodies, consumer advocates, representatives of special populations, quality assurance experts, standards development organizations, data users, the health care and insurance industries, and other constituencies."