NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

NCVHS

2005–2006

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

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Foreword

This biennial report provides a broad overview of the roles, responsibilities, and accomplishments of the National Committee on Vital and Health Statistics (NCVHS). It also affords a glimpse of the inner workings of national health information policy and the complex issues affecting our nation.

Despite significant challenges, exciting progress is taking place in the health information policy arena. After a decade of strenuous work on standards and national implementations, we are beginning to turn the corner on the Health Insurance Portability and Accountability Act (HIPAA). While not all standards are identified or fully implemented, the promise of administrative simplification is beginning to be realized as the industry moves from implementation of the standards to optimization of work processes enabled by the standards. Privacy protection, HIPAA's other goal, is commanding increased attention. Just 6 years after NCVHS published its vision for a national health information infrastructure (NHII), prototypes for the Nationwide Health Information Network (NHIN) are being piloted and with attention to the NCVHS recommendations on privacy and functional requirements. There is movement toward an information technology platform for quality measurement and reporting, and while that platform evolves, quality experts are finding creative ways to combine information sources. And the list goes on.

As I write this Foreword, the National Committee is completing a significant new Department of Health and Human Services (HHS) assignment to recommend a framework for the so-called ''secondary uses'' of health information as we move into the world of the NHII and NHIN. This project has given us a rewarding opportunity to bring the diverse expertise and perspectives represented on NCVHS to bear on an urgent set of health information policy issues, and to use our capacity for combining broad visioning and rigorous detail work. This project has called on virtually every member of NCVHS, and I would like to take this opportunity to express appreciation for my dedicated, hard-working NCVHS colleagues and for the superb staff members whose support is so vital to our effectiveness in all our endeavors.

We look forward to continuing to support the Department of Health and Human Services in crafting the information tools and policies that can best enhance the health and health care of all Americans.

Simon P. Cohn, M.D., M.P.H., *Chairman*

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Introduction

This report is the latest in a series of periodic reviews of the work of the National Committee on Vital and Health Statistics (NCVHS), the statutory public advisory committee on health information policy to the Secretary of the U.S. Department of Health and Human Services (HHS).[1] During this 2-year period, the Committee produced recommendations on privacy issues in the Nationwide Health Information Network (NHIN); functional requirements for the NHIN; improvements to data on race, ethnicity, and language; personal health records and systems; multiple Health Insurance Portability and Accountability Act (HIPAA), Consolidated Health Informatics (CHI), and e-prescribing standards; quality measurement; and reflections on lessons learned from the first 10 years of HIPAA. The section on Activities and Accomplishments describes the work in each of the Committee's areas of responsibility.

The Committee's mission is to *advise on shaping a national information strategy for improving the population's health*. Its members are selected for their expertise and distinction as researchers, educators, and practitioners in such diverse fields as population-based health, health services, epidemiology, privacy, consumer health advocacy, health care, health research, health statistics, health information systems, and health data standards. Sixteen members are appointed by the HHS Secretary and two by Congress.

The National Committee not only provides expert advice to the Department, but also serves as a forum in which interested parties can consider information policy issues and bring their views and ideas before decisionmakers. 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 communi-

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[1]The Committee was created in 1949 at the request of the World Health Organization as part of an international effort to build national and international health statistics. The statute establishing NCVHS as a federal advisory committee is 42 U.S.C. 242k(k); the latest NCVHS charter is posted on its website. The full Committee meets four times a year, and each of its subcommittees and workgroups meets several times a year. All meetings are open to the public and most are broadcast on the internet. The history of NCVHS has been well documented through annual or periodic reports from 1949 on, and in special reports on the occasion of the 15th, 20th, 45th, and 50th anniversaries. Reports, minutes, transcripts, and other materials since 1996 are posted on the NCVHS website, ncvhs.hhs.gov.

ties 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. The following topical descriptions show the Committee's efforts to elicit the views and knowledge of experts and stakeholders in all these sectors.

Major themes and directions in 2005 and 2006

In the last 2 years, the health information infrastructure-which the Committee helps to create-grew ever more complex and dynamic. The HHS Office of the National Coordinator for Health Information Technology (ONC) launched prototype health information technology (HIT) projects around the United States, created the American Health Information Community (AHIC), and generated many new organizations and initiatives responsible for various dimensions of the information infrastructure. NCVHS developed major recommendations on privacy issues and functional requirements at the request of the Coordinator.

The year 2006 marked the 10th anniversary of the Health Insurance Portability and Accountability Act. The enactment of HIPAA in 1996 had a dramatic impact on NCVHS by expanding its responsibilities to provide advice for, and monitoring of, the implementation of the administrative simplification provisions of HIPAA, including the privacy and security regulations. The Committee created new structures and work plans to respond to this Congressional mandate. The reflections and recommendations that the Committee sent to the Secretary at the 10-year mark acknowledge that the process set in motion by Congress was respected for its effectiveness, but has also proven to be slow. While there are differing views as to HIPAA's contributions, it is clear that the law-the first step into the information age-has solidified the standards foundation for health information. The Committee's recommendations focus on how best to build on that foundation to realize HIPAA's potential contributions and benefits.

By 2006, the transition to the ''post-HIPAA era'' was evident in the Committee's work, with the focus shifting to streamlining the HIPAA process and to supporting the development of the NHIN. From different perspectives, and particularly in the context of its work on quality, the Committee looked at both the potential and the practical limits of electronic health records and networks for advancing national health for the benefit of all Americans. It also focused on the potential risks to individual privacy from easier transmission and exchange of personal health information. The importance of building both privacy protections and foresighted data-collection capacities into the rapidly evolving information systems and networks took on considerable urgency for NCVHS.

Part of the historic role and contribution of the National Committee is to conceptualize the future and advise the federal government and other constituencies on the long-term direction of health information policy. This interest led the Committee in recent years to produce important foundational documents on the information infrastructure and the future of health statistics.[2] It has also led to close examination of how to infuse its core principles through all the dimensions in its charge—privacy, quality, standards, security, and so on. In 2005–2006, the Committee focused its "big picture" lens on internal process and committed to an intensified effort to integrate its work, drawing out how each facet can advance population health. There was heightened recognition that a significant aspect of the Committee's contribution stems from the cross-fertilization among the areas of its expertise and responsibility, and that the growing overlaps among these areas make coordination a necessity.

Strong staffing and strong partnerships

In all the dimensions of its work, the Committee benefits from superb staffing and strong partnerships. Six federal agencies and the National Center for Health Statistics (NCHS) Board of Scientific Counselors send liaisons to the Committee (see Appendix I), and the full Committee and its subcommittees and workgroups are staffed by individuals representing 13 agencies and offices (Appendix II). All of these collaborations contribute to the Committee's effectiveness across the broad range of health information policy.

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[2]Final Report—Information for health: A strategy for building the National Health Information Infrastructure, November 15, 2001; Final Report—Shaping a health statistics vision for the 21st century, November 2002 (co-authored with NCHS and the HHS Data Council).

Major Projects and Activities

NCVHS is known for its substantive, thoughtful reports and recommendations on a wide range of policy issues, and for the integrated approach it brings to all the topics it addresses. The research and development of recommendations, letters, and reports is conducted by its subcommittees and workgroups on Standards and Security, Privacy and Confidentiality, Populations, Quality, and the National Health Information Infrastructure (NHII). The Ad Hoc Workgroup on the Nationwide Health Information Network also was created for a short-term assignment during this period.

The developmental process for these letters and reports, which can extend over a period of years, generally involves wide consultation through hearings as well as review of the significant literature, followed by careful analysis by NCVHS as it develops its recommendations. In 2005 and 2006, the full Committee or its subgroups held a total of 102 meetings or conference calls. All reports, letters, and recommendations are ultimately brought before the full Committee for review, modification, and approval. This process enables the diverse expertise and perspectives of all its members to inform the final products and recommendations, often through extensive discussion at full Committee meetings.

The following sections summarize the Committee's accomplishments in each of the areas in which it advises the Secretary.

Population health

As noted, population health principles govern all the work of the National Committee, and its members work to infuse that mission throughout all NCVHS activities. The Subcommittee on Populations is responsible for translating the population health mission into specific policy recommendations. Its charge covers health-related information on both the population as a whole and specific population segments, especially those whose health status may be negatively affected by determinants such as race, ethnicity, socioeconomic position, or disability.

Improving data on race, ethnicity, and language

In late 2005, NCVHS approved a report and recommendations on improving survey data on race, ethnicity, and language, the culmination

of 3 years of work by the Subcommittee on Populations. The Subcommittee had undertaken this project because without complete and accurate data on the differences in health status, access to care, and services among specific subpopulation groups in the United States—data that are not currently available—researchers, policy-makers, health care professionals, and community groups cannot understand health disparities, much less work to eliminate them. For example, the limited data on subpopulations in the large categories of ''Asian'' and ''Hispanic'' mask significant health differences among these subpopulation groups.

The Subcommittee hosted six hearings around the United States starting in 2002 to gather information from population health experts and data users. It also studied recent landmark reports that have drawn attention to health disparities and the need for better data. The resulting November 2005 report[3] is structured around two large recommendations, with proposed strategies and actions for carrying them out:

■ Recommendation 1. Enhance the quality, reliability, and completeness of data collection and integration. The strategies:

  ● Advance HHS leadership, coordination, and partnerships.
  ● Increase availability of data on diverse subpopulations.
  ● Improve the collection of data on geography and socioeconomic position.
  ● Enhance data collection in federal programs.

■ Recommendation 2. Increase the health statistics infrastructure's capacity to collect, integrate, analyze, report, and disseminate data. The strategies:

  ● Expand access to data on subpopulations.
  ● Improve data user training.
  ● Link data systems and dissemination methods to bridge old and new data.
  ● Improve data quality.
  ● Increase dissemination of health statistics and research findings.

NCVHS distributed the report widely within the federal government and to interested organizations, researchers, and advocates. Its thoughtful recommendations and detailed suggestions for strategies have helped advance the thinking about solutions to these critical data issues. Equally important, the Committee's public recognition of the limitations in the country's ability to answer key questions about health status has given advocacy groups a stronger foundation for raising their concerns with policymakers.

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[3]Report to the Secretary, Eliminating health disparities: Strengthening data on race, ethnicity, and primary language in the United States, November 2005.

Data linkages

The Subcommittee next explored opportunities to link health-related data sets to maximize public value from the large investment made in these data. The ability to understand complex health and health care issues can be greatly aided by linking data from multiple sources, including health data, environmental exposures, socioeconomic status, and other factors influencing health. One example is the National Cancer Institute's linkage of cancer registry data with Medicare utilization and cost data to understand use of services, costs, and other relevant outcomes of cancer treatment over time. The framework used by the committee in identifying the influences on health is discussed in the NCVHS report on a vision for 21st century health statistics and illustrated in Figure 1.[4]

The Subcommittee undertook this new project in order to talk with experts about how to make linked data more available, in a way that protects privacy, to enhance insight into population health. In a September 2006 NCVHS hearing, members talked with experts from various

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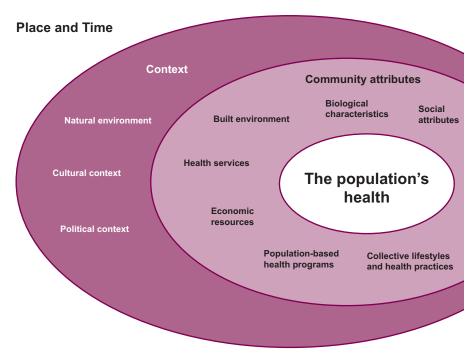[4]See footnote 2. The influences on the population's health are illustrated in Figure 1.

Figure 1. Influences on the Population's Health

branches of HHS and the Census Bureau about best practices and successes as well as barriers and ways to overcome them. A major focus was strengthening the role that federal data centers can play in facilitating access to linked data while also protecting privacy.

Surge capacity

The other major population health focus during this period concerned surge capacity. In 2006, the Subcommittee began to look at this issue, with the idea of developing recommendations to the Secretary on data needs in this area. Two recent catastrophes, 9/11 and Katrina, had dramatized the vulnerabilities of local health care systems in times of crisis and illustrated the need for large-scale emergency care and follow-up, under varied and unpredictable conditions. They also dramatized the key role of data in meeting these needs. In a national health care system that is losing inpatient hospital and emergency room capacity, this issue of preparedness is a focus of growing national concern. The Subcommittee is examining such questions as how to measure the capacity of the system at various levels, what institutions should be included, what data sources are available, how to maintain current data, and what types of disasters should be considered.

Collaboration with the National Center for Health Statistics Board of Scientific Counselors

The National Center for Health Statistics' Board of Scientific Counselors (BSC), which held its first meeting in October 2003, has become an important NCVHS partner. The BSC provides expert advice to the Center on its surveys and vital statistics and from its inception these two complementary bodies have worked to ensure that their agendas are synergistic. For example, the Committee's initiative on data linkages complements the BSC's work on multiple data sources.

2007 and beyond

The Subcommittee on Populations continued its projects on data linkages and surge capacity into 2007, developing recommendations to the Secretary regarding data linkages. It plans another hearing on surge capacity in 2008. In addition, the Subcommittee plans to revisit the vision for health statistics in the 21st century to evaluate progress toward the vision and consider how it can be updated to reflect new health information technology and other developments. It is also collaborating with the BSC to address common concerns about the threatened deterioration of health surveys and vital and health statistics as a result of budgetary constraints in recent years.

Quality

The Quality Workgroup was created in 1998 as a subgroup of the Subcommittee on Populations. The Workgroup looks at information on the clinical encounter in terms of two uses of that information: for assessing and improving the quality of health care and for assessing and improving the health of the entire population. The Workgroup advises the Department on its quality agenda, particularly through an active relationship with the Agency for Healthcare Research and Quality (AHRQ). AHRQ, like NCVHS, regards health care quality as inextricably linked to health equity, as reflected in AHRQ's annual reports on these topics.[5]

In a November 2005 letter, NCVHS moved forward one of the candidate recommendations that it had proposed in a 2004 report, recommending that all inpatient claims transactions include a diagnosis indicator to flag diagnoses present on admission. This indicator was subsequently adopted by the National Uniform Billing Committee (NUBC) for inclusion in the UB-04.[6]

The Quality Workgroup operates in a fast-moving national environment in which a host of entities are engaged in public, private, and joint initiatives to measure, report on and improve quality and patient safety. The NCVHS vantage point positions it right at the nexus of health information technology (HIT) and quality initiatives, thus highlighting the potential disconnect between the two. The Workgroup has found that while electronic health records (EHRs) and other forms of HIT may facilitate data collection and sharing for quality measurement and improvement, it is important that technology and business applications not move ahead so rapidly that systems are built before the data needed to measure and improve quality can be incorporated. Electronic clinical data will offer significant opportunity for quality assessment; however, they may not be the all-purpose source of information needed to monitor and improve quality and population health. At this stage, then, two types of bridges are needed: between HIT development and quality initiatives and between electronic clinical data and other data sources. In 2007, the Workgroup returned to a project on bridging and combining administrative data with other forms and sources of data.

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[5]AHRQ, National Healthcare Quality Report, National Healthcare Disparities Report.

[6]NCVHS also had recommended that NUBC develop coding guidelines for the indicator, which it did in conjunction with the cooperating parties for ICD–9–CM. Congress subsequently passed legislation requiring CMS to identify conditions that would only qualify for an increased DRG if they were present on admission—information that would not be available without the new indicator. The indicator—which NCVHS first recommended in 1992—also will be in next version of the 5010 HIPAA standard.

Mining the Quality-HIT Interface to improve the population's health

The Workgroup created opportunities in 2005–2006 to think through how information technology can be used to promote quality in a way that enhances the entire population's health, not just the health of some subgroups. It held special meetings in June and November 2005 to explore this question, hearing from panels of distinguished presenters.[7,8]

The Workgroup then developed a discussion paper exploring what the two hearings suggested about next steps, particularly in the light of recent quality initiatives and the principles in the Committee's two foundational vision documents. The paper concludes that the Committee's most important contribution may lie in two key areas: understanding what it would take to measure, assess, and improve quality at a population level; and understanding what it would mean to have a person-centric approach and how that links to population health.

Advising AHRQ on composite measures

In addition to the long-range work described previously, the Workgroup assisted AHRQ staff in a project to develop a set of composite patient safety indicators to be submitted to the formal consensus process of the National Quality Forum. This project continued into 2007.

2007 and beyond

Returning to the question of data sources for quality measurement, the Workgroup organized a June 2007 hearing to study the current state of health care measurement and quality reporting in hospital care. Speakers were invited to testify on three medical record models: all administrative data, all EHR data, and a hybrid of the two. The intended product is a status report for the Secretary, AHRQ, the states, health reporting agencies, and others.

Privacy and confidentiality

Since its creation in 1996 upon the enactment of HIPAA, the Subcommittee on Privacy and Confidentiality has spearheaded the National Committee's efforts to keep privacy protections apace with evolving information technology and standardization. Until 2005, the Subcommittee focused almost entirely on advising HHS on the development, enforcement, assessment, and modifications to the HIPAA Privacy Rule. While it has continued to advise on HIPAA, as mandated by law, in this

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[7]Minutes of the June 2005 meeting—http://ncvhs.hhs.gov/050602p3.htm.

[8]Minutes of the November 2005 hearing—http://ncvhs.hhs.gov/051118mn.htm.

2-year period it shifted its focus as the NHIN gained momentum and brought new urgency to the need for a comprehensive approach to privacy protection.

NHIN privacy recommendations

In 2005, at the request of the then-National Coordinator for Health Information Technology, Dr. David Brailer, the Subcommittee undertook an 18-month study of privacy issues in the NHIN. It held five hearings around the United States that year and heard from representatives of the varied constituencies concerned about the privacy and confidentiality of health information, including consumers, patients, health care professionals, associations, hospitals, insurers, and covered entities. The hearings were followed by a series of public meetings and conference calls to discuss the findings and prepare the report.

Based on this extensive consultation and public comment process, in June 2006, NCVHS sent the Secretary a report with 26 recommendations on privacy and confidentiality in the Nationwide Health Information Network.[9] The document addresses the following challenges in safeguarding health privacy in the NHIN environment:

- The role of individuals in making decisions about the use of their personal health information.
- Policies for controlling disclosures across the NHIN.
- Regulatory issues such as jurisdiction and enforcement.
- Use of information by nonhealth care entities.
- Establishing and maintaining the public trust that is necessary to ensure the success of the NHIN.

The report states, "The public concerns about EHRs and the NHIN make it essential that HHS and other public and private entities begin immediate, substantial, and sustained efforts to establish and maintain public trust in the NHIN. Maintaining a high level of public trust must be a key consideration of all associated with developing the NHIN." Among other things, the Committee recommends that the Department make public and professional education a top priority; appoint meaningful numbers of consumers to the boards governing the NHIN; and establish ongoing research to assess the effectiveness and public confidence in the privacy, confidentiality, and security of the NHIN and its components.

NCVHS intends to update and refine its recommendations as the NHIN architecture and functional requirements advance.

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[9]Letter to the Secretary—Recommendations regarding privacy and confidentiality in the Nationwide Health Information Network, June 22, 2006.

Continuing to advise on HIPAA

The Subcommittee continues to investigate the sectors that collect, store, or exchange personal health information but are not covered by the HIPAA Privacy Rule. It held a hearing on noncovered entities in September 2006. The resulting recommendations will point the way to the new protections necessitated by the expanding uses and exchange of health information. The Committee has recommended research to assess the costs and benefits of the privacy rule. In November 2006, it held a hearing on designing a research agenda for this purpose.

NCVHS also hears regular reports from the DHHS Office of Civil Rights (OCR) regarding enforcement of HIPAA's existing provisions. The Privacy Subcommittee has encouraged OCR to provide additional public data on compliance, and this information is anticipated in the near future.

2007 and beyond

Many national groups are now addressing aspects of privacy and security policy. The Committee is striving to improve coordination with these groups to ensure that work is synergistic. In 2007, ONC/HHS incorporated the Committee's June 2006 recommendations on privacy in the NHIN into RFPs, directing all contractors to incorporate the recommendations into their work. On another matter, the Subcommittee has called attention to overlaps and conflicts between the HIPAA Privacy Rule and both the Common Rule and the Family Educational Rights and Privacy Act (FERPA). NCVHS is available to advise on a new Departmental task force created to address this concern. The Subcommittee also will continue to advise the Secretary on extending privacy coverage to entities that are active in the NHIN but not covered by HIPAA. In addition, it plans to develop recommendations on patient control of personal health information.

Standards and security

Standardization has been a priority for NCVHS for most of its 58 years, beginning with its historic (and ongoing) work on the *International Classification of Diseases* (ICD). Soon after HIPAA was enacted, the Committee created the Subcommittee on Standards and Security to manage its additional responsibilities for advising the Secretary on the adoption of health data standards, monitoring their implementation, and regularly reporting to Congress on their status. The Subcommittee has developed strong working relationships with the Department and the health care industry. It has built a position as a trusted forum in which interested parties can identify the healthcare information standards and raise the issues that are critical to the establishment of interoperability within our healthcare delivery system. The NCVHS members

and the interested parties who testify to the Committee clearly understand that significant improvements in the quality of care, patient safety, and the cost effectiveness of healthcare have become increasingly dependent on the interoperability of healthcare data.

Advising on HIPAA administrative simplification

This Subcommittee's work on standards and the Privacy Subcommittee's work on privacy and confidentiality are complementary. The National Committee's advisory work on HIPAA—both administrative simplification and privacy—is described in detail in its regular, mandated status reports to Congress. The seventh such report, covering the period from January 2004 through April 2005, was sent to Congress on September 8, 2005.[10] The report on the next period (May 2005 through November 2006) was issued in September 2007.[11]

In February 2006, the Department passed a major milestone when it issued the final regulation establishing the enforcement regime for violation of HIPAA's privacy, transaction, code set, and security standards. This regulation ensures uniform rules for the imposition of civil monetary penalties for HIPAA violations. By October 2006, the Centers for Medicare and Medicaid Services (CMS) reported that 99 percent of all claims coming into Medicare were HIPAA-compliant. NCVHS sent the Secretary three letters with recommendations on specific HIPAA matters during this 2-year period, including its first letter on the National Provider Identifier.[12]

HIPAA at 10 years

The year 2006 marked a decade since the enactment of HIPAA. The Committee took the opportunity to send the Secretary its reflections on the HIPAA experience and the lessons learned, drawing on testimony it had solicited over several years. In a June 2006 letter to the Secretary, it offered 10 recommendations aimed at improving HIPAA updates, adoption rates, and return on investment.[13]

With most of the standards named in HIPAA finalized, the Committee was able to focus on streamlining the updating and promulgation of HIPAA. It engaged with industry and SDOs to evaluate how the modifi-

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[10]Seventh Annual Report to Congress on the implementation of the administrative simplification provisions of the Health Insurance Portability and Accountability Act of 1996, September 8, 2005.

[11]Eighth Annual Report to Congress on the Implementation of the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act of 1996, September 6, 2007.

[12]Letter to the Secretary—Comments on the claims attachment NPRM published Sept 23, 2005, and November 22, 2005; Letter to the Secretary—Recommendations on medical equipment, March 4, 2005; Letter to the Secretary—Preliminary observations: National Provider Identifier (NPI) implementation, November 29, 2006.

[13]Letter to the Secretary—HIPAA lessons learned, June 22, 2006.

cation process could be simplified, heard from SDOs on this matter in the summer of 2006, and plans a letter on the subject in 2007.

Standards to create the framework for electronic health records systems

The administrative simplification provisions of HIPAA also directed NCVHS to study and recommend standards for electronic patient medical record information (PMRI) standards. HIPAA provided no definition of PMRI, nor did it describe the types of standards that would make up PMRI. As a result, NCVHS developed a report providing a strategic framework for the promulgation of the PMRI standards that included the definition, scope, types of standards, and sequence for promulgation that would establish a standards framework for electronic health records (EHR) systems. This report was presented to the HHS Data Council and sent to the Secretary in February 2002[14] requesting that the Secretary approve this strategic framework as a roadmap for NCVHS to follow as it would study and recommend PMRI standards during the next 2 years. Leaders of several government agencies and Departments publicly declared this strategic framework report to be a seminal work, the Secretary of HHS approved it, and NCVHS moved forward. Based on this framework, NCVHS subsequently recommended a strategic set of message format standards for PMRI. This was followed in November 2003 by a letter and comprehensive report on PMRI terminology standards, and the recommendation of a strategic core set of clinically specific terminology standards.[15] These PMRI standards (also called EHR system data standards) were recognized by HHS, the U.S. Department of Defense, and the U.S. Department of Veteran's Affairs as the initial set of consolidated health informatics initiative standards.

NCVHS work on standardizing electronic PMRI led to its role in the ongoing acceptance process for the federal CHI initiative from 2004 through 2007. NCVHS provided an open forum for review of the CHI recommendations for standardized PMRI, as well as independent assessment of the recommendations. During 2005 and 2006, NCVHS approved letters on CHI recommendations in three domains.[16] The November 2006 letter on the Functioning and Disability domains marked the completion of the Committee's role in the CHI Council acceptance process. The letter calls the initiative "an impressive effort to bring together experts from throughout the federal government to identify standards for the electronic exchange of health information." It also

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[14]Letter to the Secretary—Recommendations for the first set of PMRI standards, February 27, 2002.

[15]Letter to the Secretary—Recommendations for PMRI Terminology Standards; Report: Patient Medical Record Information (PMRI) Terminology Analysis, November 5, 2003.

[16]Letter to the Secretary—CHI recommendations on the multimedia domain, June 22, 2006; Letter to the Secretary—CHI allergy recommendation, September 13, 2006; Letter to the Secretary—CHI recommendations on the functioning and disability domains, November 28, 2006.

states the Committee's intention to ask for periodic updates on the status of the standards recommended and adopted under the CHI process.

Continuing the standardization journey, the CHI standards provided the foundation for the work of the Health Information Technology Standards Panel (HITSP), created in 2005 under contract with the Office of the National Coordinator.[17]

E-prescribing

The Medicare Modernization Act of 2003 gave NCVHS responsibilities related to electronic prescribing. These responsibilities were taken on by the Subcommittee on Standards and Security, which took the idea from its infancy, held hearings, and recommended a maintenance mode to keep track of the new standards. Between March 2005 and December 2006, NCVHS approved five letters developed by the Subcommittee on e-prescribing, four to the Secretary, and one to CMS.[18] Three of the first six standards to be recommended by NCVHS performed well enough in pilot testing to be recommended for adoption.

As noted, the Nationwide Health Information Network (NHIN) gained increasing salience and momentum over this period. The Subcommittee held hearings on two topics that are key for the unfolding NHIN, secondary uses of clinical data and matching patients to their records. To date, it has held a total of six hearings on the latter topic.

In addition, several members were active in the Committee's project to develop recommendations on functional requirements for the NHIN, described in the following text.

2007 and beyond

In 2007, besides advising and tracking progress on National Provider Identifiers (NPIs) and following up on several of the projects described previously, the Standards Subcommittee is working on the next version of HIPAA transaction standards, the 5010. The Subcommittee held hearings on HIPAA 5010 in July 2007. In addition, some members are participating in a new project on secondary uses of clinical data, described in the following text.

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[17]The standards recommended by HITSP must be approved by AHIC and are then incorporated into the certification standards by the Certification Commission (CCHIT).

[18]Letter to the Secretary—Comment on Medicare part D data, December 15, 2006; Letter to the Secretary—Comments on the proposed changes to the National Drug Code (NDC) December 15, 2006; Letter to the Secretary—NCPDP Script 8.1 Recommendations, December 20, 2005; Letter to the Secretary—2nd set of e-prescribing recommendations, March 4, 2005; Letter to CMS—Comments on e-rx proposed rule, March 3, 2005.

Functional requirements for the Nationwide Health Information Network

The Nationwide Health Information Network (NHIN) is an evolving network of networks, still largely conceptual in nature, which is intended to facilitate the accurate, appropriate, timely, affordable and secure exchange of health information at local, regional, and national levels. Information exchange of this kind can greatly enable not only health care quality and patient safety, but also public health and biosurveillance, research, and other activities.

One of the many tasks that must be performed to bring such a network into being is the development of functional requirements for the full range of activities it encompasses. In 2006, the National Coordinator asked NCVHS to identify minimum but inclusive functional requirements needed for the initial definition of NHIN. These are considered initial requirements because the NHIN is at an early stage of evolution. They include requirements for certification, authentication, authorization, person identification, location of health information, transport and content standards, data transactions, auditing and logging, time-sensitive data access, communications, and data storage.

The Committee formed the Ad Hoc Workgroup on NHIN, which used an intensive process of consultation, analysis, and consensus development to identify the requirements. The final set was selected from a daunting initial universe of 977 potential requirements submitted by stakeholders. The process began with a hearing, held in July 2006, to obtain input from the groups involved in and potentially affected by NHIN. Those testifying included representatives from NHIN contractors including consortia, RHIOs, large provider and payer networks, consumers, and experts involved with electronic health records, biosurveillance, and other pertinent areas. All in all, throughout the refinement process, the Workgroup conducted or participated in two public forums, two public hearings, and two public conference calls. It posted interim documents on the Web for further contributions. Thus, the final recommendations represent the contributions of, and consensus among, a wide range of stakeholders.

The Committee presented a pre-final version of its report at the Second NHIN Forum in October 2006, and sent the final report to the Secretary later in the month.[19] Intended for a broad audience, the report not only offers 14 recommendations but also provides a general understanding of the concept and capabilities of a nationwide health information network and describes gaps, policy issues, and needed standards. The recommendations complement others from NCVHS that address

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[19]Letter to the Secretary–Recommendations on the initial functional requirements for a Nationwide Health Information Network (NHIN), October 30, 2006.

other requirements for a secure and effective health information network—notably privacy and confidentiality protections.

The NCVHS Chair presented the final recommendations to AHIC in December 2006, and they were well received by this advisory body as well as by ONC. The Committee's consensus development process and clearly communicated conclusions are widely regarded as a major contribution to the field, and the recommended functional requirements are considered a workable foundation for next steps. The Workgroup's efforts have enabled increased cooperation and alignment within the industry and eagerness to move forward on creating the NHIN.

2007 and beyond

Once it had completed its duties, this ad hoc Workgroup was discharged. A new group with similar composition and leadership was formed in May 2007 to tackle the request from the new ONCHIT Director, Dr. Rob Kolodner, concerning secondary uses of clinical data.
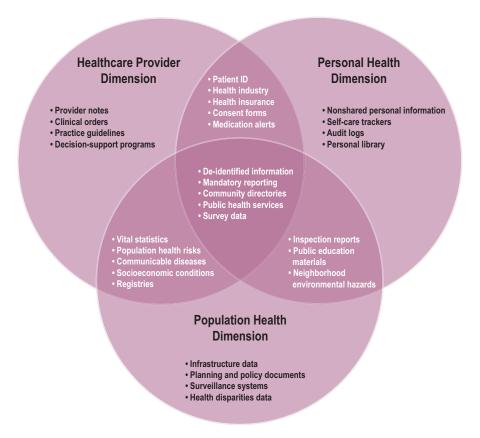
Recommendations on personal health records

Since its formation in 1996, the NCVHS Workgroup on the National Health Information Infrastructure (NHII) has taken the lead in thinking through ways to harness health information technology and connectivity for the greatest benefit for the U.S. population. The Workgroup authored the seminal NCVHS 2001 report, *Information for Health,*[20] which envisions the NHII as three co-equal and interdependent dimensions of information—personal, professional, and population health (Figure 2).

In the years since this influential report, thanks in part to strong federal leadership as recommended by NCVHS, the environment envisioned by the Committee has started to become a reality.

In 2005, the NHII Workgroup focused in on the "personal" dimension of the NHII and developed a report and recommendations on electronic personal health records (PHRs). It selected this topic partly because of the President's 2004 goal that by 2014, Americans would have "a personal health record that patients, doctors and other health care providers could securely access through the Internet, no matter where a patient is seeking medical care." Other influential bodies, notably Connecting for Health and federal agencies such as the Veterans Health Administration and the HHS Centers for Medicare and Medicaid Services, also have identified PHRs as tools with important potential for helping consumers and patients manage their health.

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[20]See footnote 2. The three dimensions are illustrated in Figure 2.

Healthcare Provider Dimension

- Provider notes
- Clinical orders
- Practice guidelines
- Decision-support programs

Personal Health Dimension

- Nonshared personal information
- Self-care trackers
- Audit logs
- Personal library

- Patient ID
- Health industry
- Health insurance
- Consent forms
- Medication alerts

- De-identified information
- Mandatory reporting
- Community directories
- Public health services
- Survey data

- Vital statistics
- Population health risks
- Communicable diseases
- Socioeconomic conditions
- Registries

- Inspection reports
- Public education materials
- Neighborhood environmental hazards

Population Health Dimension

- Infrastructure data
- Planning and policy documents
- Surveillance systems
- Health disparities data

SOURCE: National Committee on Vital and Health Statistics, *Information for Health:*
A Strategy for Building the National Health Information Infrastructure, Washington, DC. 2001.

Figure 2. Examples of content for the three dimensions and their overlap

The Committee sent its recommendations on PHRs and PHR systems[21] to the Secretary in a September 2005 letter report, followed soon thereafter by the release of an expanded but substantively unchanged version for the broad audience interested in personal health records.[22] The report offers 20 recommendations to the Secretary, based on the findings from 6 NCVHS hearings. Noting that these tools are heterogeneous and evolving, it offers a typology to begin the discussion about PHRs and recommends that HHS support the development of a consensus-based framework for characterizing these systems, building on the initial one proposed by the Committee.

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[21] The term ''PHR system'' refers to the additional computerized tools that help an individual understand and manage the information contained in a PHR.

[22] Report Recommendation—Personal health records and personal health record systems, February, 2006. (Original letter to the Secretary: September 9, 2005.)

A central set of findings and recommendations concerns privacy and security. The report stresses the importance of clarifying the respective rights of each of the stakeholders in PHR systems, and the need to respect consumers' rights to informed choice on the uses of their personal information. It also notes that an adequate security standards framework is essential. Regarding interoperability, the report points out that PHR systems will be most useful when they are capable of widespread exchange of information with EHRs and other sources of health data. It offers five recommendations in this area. Finally, it makes recommendations on the federal role with respect to PHR systems, and identifies broad areas for research, pilots, and evaluation of PHR systems.

This NCVHS report has been widely circulated and well received, and it has proven useful in the broad policy environment within and outside government. It is regarded as a well grounded overview of the key issues, and has become a resource for several organizations that are moving forward with PHR initiatives. The definitions and typology that it offers lay a foundation, and its description of the current status provides a benchmark for continuing development of this tool and understanding its place among other forms of HIT. The report also helped raise the credibility of PHRs in internal and external policy circles and contributed to the elevation of PHRs on the Department's agenda.

After completing the project on PHRs and PHR systems, several members and staff of the NHII Workgroup played key roles in the NHIN project.

2007 and beyond

NHII Workgroup members are involved in the project on secondary uses of health care data.

Future Directions and Priorities

The previous sections mention the Committee's plans for 2007 and thereafter in the program areas overseen by its subcommittees and workgroups. Here, we note three priorities that involve the full Committee.

The "secondary use" project

In May 2007, Dr. Rob Kolodner, the new National Coordinator for Health Information Technology, asked the Committee to develop actionable recommendations on a high-level framework for what are typically called "secondary uses" of clinical data. The major areas of use are research, population health, and quality measurement and reporting; the current project focuses in particular on the quality use case. Dr. Cohn is chairing the NCVHS Ad Hoc Workgroup on Secondary Uses of Health Data, with Dr. Carr and Mr. Reynolds as co-Vice Chairs.[23] Nearly all NCVHS members are participating in the project in some capacity. The project involves more than 12 days of hearings and conference calls to elicit guidance from the broad community of data sources and users and then to develop the recommendations. A report is due in November 2007. Interestingly, while members sometimes feel that the Committee's high-intensity assignments such as advising on HIPAA and on NHIN functional requirements can pose challenges for its efforts to integrate the Committee's work, this project *requires* an integrated approach and makes good use of the broad expertise in standards, privacy and security, and population health represented on the Committee.

Coordinating with other information policy bodies

In recent years, the landscape has grown rich and complex with bodies working on information policy in both the private and public sectors. In most of the areas in which NCVHS advises the Department— quality, standards, privacy, health information technology, and more—it has become necessary to study the issues and develop recommendations and to keep track of the work of other groups to coordinate efforts and avoid redundancy.

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[23]http://www.ncvhs.hhs.gov/070621p6.pdf.

In particular, NCVHS is researching alternatives to complement and coordinate with the work of AHIC workgroups and ONC contractors. Two NCVHS members sit on AHIC workgroups. The Committee is following closely the Department's plan that by December 2008, AHIC will transition into a new, public-private entity that will exercise governance over HIT activity. NCVHS is talking with Dr. Kolodner and others in HHS about how the Committee can be helpful during and after this transition.

The future of population health assessment

As noted previously, concerns have mounted about the nation's ability to continue assessing, monitoring, and improving the public's health in the face of shrinking funding for surveys and vital statistics. If not corrected, the impact of underfunding will be serious starting in fiscal year 2009, according to Dr. Edward Sondik, Director of the National Center for Health Statistics. The Center has asked NCVHS and the NCHS Board of Scientific Counselors to advise on the tradeoffs and choices it is facing; the two bodies plan to collaborate in responding to this request.

Appendix I.
Current (October 2007) NCVHS Roster and 2005–2006 Retirees

Chairman

Simon P. Cohn, M.D., M.P.H.
Associate Executive Director
The Permanente Federation
Kaiser Permanente
Oakland, CA 94612

HHS Executive Staff Director

James Scanlon
Deputy Assistant Secretary
Office of Science and Data Policy
Office of the Assistant Secretary
    for Planning and Evaluation, HHS
Washington, DC 20201

Executive Secretary

Marjorie S. Greenberg
Chief, Classifications and Public
    Health Data
Standards Staff
Office of the Director
National Center for Health Statistics,
Centers for Disease Control and
    Prevention
Hyattsville, MD 20782

Membership

Jeffrey S. Blair, M.B.A.
Director of Health Informatics
Lovelace Clinic Foundation
Albuquerque, NM 87111

Justine M. Carr, M.D.
Director, Clinical Resource
    Management
Health Care Quality
Beth Israel Deaconess Medical Center
Boston, MA 02215

Leslie Pickering Francis, J.D., Ph.D.
Chairman, Department of Philosophy
University of Utah
Salt Lake City, UT 84112

Larry A. Green, M.D.
University of Colorado
Department of Family Medicine
Health Science Center
Aurora, CO 80011

John P. Houston, J.D.
Vice President, Privacy and
    Information Security Assistant
    Counsel and Adjunct Assistant
    Professor of Biomedical Informatics
University of Pittsburgh School of
    Medicine
Pittsburgh, PA 15213

Garland Land, M.P.H.
Executive Director
National Association for Public Health
    Statistics and Information Systems
Silver Spring, MD 20910

Carol J. McCall, F.S.A., M.A.A.A.
Vice President
Humana
Center for Health Metrics
Louisville, KY 40202

J. Marc Overhage, M.D., Ph.D.
President and CEO
Indiana Health Information Exchange
Associate Professor, Indiana University
    School of Medicine
Senior Research Scientist, Regenstrief
    Institute
Regenstrief Institute, Inc.
Indianapolis, IN 46202

Harry Reynolds
Vice President
Blue Cross Blue Shield of North
    Carolina
Durham, NC 27702

Mark A. Rothstein, J.D.
Herbert F. Boehl Chair of Law and
    Medicine
Director, Institute for Bioethics,
    Health Policy and Law
University of Louisville School of
    Medicine
Louisville, KY 40292

William J. Scanlon, Ph.D.
Health Policy R&D
Washington, DC 20001

Donald M. Steinwachs, Ph.D.
Interim Provost
Senior Vice President for Academic
    Affairs
The Johns Hopkins University
Bloomberg School of Public Health
    Department of Health Policy and
    Management
Health Services Research and
    Development Center
Baltimore, MD 21205

C. Eugene Steuerle, Ph.D.
Senior Fellow
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Washington, DC 20037

Paul C. Tang, M.D.
Chief Medical Information Officer
Palo Alto Medical Foundation
Palo Alto, CA 94301

Kevin C. Vigilante, M.D., M.P.H.
Principal
Booz-Allen and Hamilton
Rockville, MD 20852

Judith Warren, Ph.D., R.N.
Christine A. Hartley Centennial
    Professor
Director of Nursing Informatics,
    KUMC Center for Healthcare
    Informatics
School of Nursing
University of Kansas
Kansas City, KS 66160

Liaison Representatives

J. Michael Fitzmaurice, Ph.D.
Senior Science Advisor for
  Information Technology
Agency for Healthcare Research and
  Quality
Rockville, MD 20850

Edward J. Sondik, Ph.D.
Director
National Center for Health Statistics
Hyattsville, MD 20782

Karen Trudel
Deputy Director
Office of E-Health Standards &
  Services
Centers for Medicare and Medicaid
  Services
Baltimore, MD 21244

Jim Lepkowski, Ph.D.
Institute for Social Research
University of Michigan
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(NCHS Board of Scientific Counselors)

Steven J. Steindel , Ph.D.
Senior Advisor
Standards and Vocabulary Resource
Information Resources Management
  Office
Centers for Disease Control and
  Prevention
Atlanta, GA 30333

Retirees, 2005–2006

Members:

Stanley M. Huff, M.D.
Professor, Medical Informatics
University of Utah
College of Medicine
Intermountain Health Care
Salt Lake City, UT 84123

Robert W. Hungate
Principal
Physician Patient Partnerships for
  Health
Wellesley, MA 02481

A. Russell Localio, Esq., M.A., M.P.H.,
  M.S.
Assistant Professor of Biostatistics
University of Pennsylvania School of
  Medicine
Center for Clinical Epidemiology and
  Biostatistics
Philadelphia, PA 19104

Liaisons:

Virginia S. Cain, Ph.D.
Acting Associate Director for
  Behavioral and
Social Sciences Research
National Institutes of Health
Bethesda, MD 20892

Irma T. Elo, Ph.D.
Associate Professor of Sociology
Department of Sociology, Population
  Studies Center
University of Pennsylvania
Philadelphia, PA 19104

June E. O'Neill, Ph.D.
Co-chair, NCHS Board of Scientific
  Counselors
Director
Department of Economics and
  Finance
Zicklin School, Baruch College
New York, NY 10010

Appendix II.
Subcommittees and Workgroups, with Lead Staff (October 2007)

Executive Subcommittee

Simon P. Cohn, M.D., Chairman
Jeffrey S. Blair, M.B.A.
Justine M. Carr, M.D.
Harry Reynolds
Mark A. Rothstein, J.D.
Donald M. Steinwachs, Ph.D.

Ex Officio
James Scanlon, ASPE
Marjorie S. Greenberg, NCHS

Liaisons
Irma T. Elo, Ph.D., NCHS/BSC
J. Michael Fitzmaurice, Ph.D., AHRQ
Edward J. Sondik, Ph.D., NCHS
Steven J. Steindel, Ph.D., CDC
Karen Trudel, CMS

Staff
Debbie M. Jackson, NCHS
Katherine D. Jones, NCHS
Lead staff to subcommittees

Workgroup on National Health Information Infrastructure

Simon P. Cohn, M.D., Chairman
Jeffrey S. Blair, M.B.A.
John P. Houston, J.D.
Paul C. Tang, M.D.
Kevin C. Vigilante, M.D., M.P.H.

Mary Jo Deering, Ph.D., NIH*
Linda Fischetti, R.N., MS. DVA
Kathleen Fyffe, ASPE
Robert Kambic, CMS
Steven J. Steindel, Ph.D., CDC
Karen Trudel, CMS
Cynthia Wark, CMS

Subcommittee on Standards and Security

Jeffrey S. Blair, M.B.A., Co-Chairman
Harry Reynolds, Co-Chairman
Justine M. Carr, M.D.
Simon P. Cohn, M.D.
J. Marc Overhage, M.D., Ph.D.
Judith Warren, Ph.D., R.N.

Denise Buenning, MSM, CMS*
Vivian Auld, NLM
Suzie Burke-Bebee, ASPE
Jorge Ferrer, M.D., VA
J. Michael Fitzmaurice, Ph.D., AHRQ
Kathleen Fyffe, ASPE
James Garvie, IHS
Marjorie S. Greenberg, NCHS
Betsy Humphreys, NLM
Randy Levin, M.D., FDA
Donna Pickett, NCHS
James Scanlon, ASPE
Steven J.Steindel, Ph.D., CDC
Karen Trudel, CMS
Members of HHS Data Standards
    Committee

Subcommittee on Privacy and Confidentiality

Mark A. Rothstein, J.D., Chairman
Simon P. Cohn, M.D.
John P. Houston, J.D.
Leslie Pickering Francis, J.D., Ph.D.
Harry Reynolds
Paul C. Tang, M.D.

Maya Bernstein, J.D.*
Amy Chapper, J.D., CMS
Kathleen Fyffe, ASPE
Gail Horlick, M.S.W., J.D., CDC
Hetty Khan, CDC
Susan McAndrew, OS/OCR**
Sarah Wattenberg, SAMHSA

Subcommittee on Populations

Donald M. Steinwachs, Ph.D.,
   Chairman
Larry A. Green, M.D.
Garland Land, M.P.H.
William J. Scanlon, Ph.D.
C. Eugene Steuerle, Ph.D.
Kevin C. Vigilante, M.D., M.P.H.

Dale Hitchcock, ASPE*
Co-lead staff, (vacant)*
Audrey Burwell, OMH
Nancy Breen, Ph.D., NCI, NIH
Leslie Cooper, Ph.D., NCI, NIH
Miryam Granthon, OPHS
Suzanne Haynes, Ph.D., OPHS
Cille Kennedy, Ph.D., ASPE
Jacqueline Lucas, NCHS
Edna Paisano, IHS
Susan Queen, Ph.D., HRSA
Harvey Schwartz, Ph.D., AHRQ

Workgroup on Quality

Justine M. Carr, M.D., Chairperson
Garland Land, M.P.H.
Carol J. McCall, F.S.A., M.A.A.A.
William J. Scanlon, Ph.D.
Donald Steinwachs, Ph.D.

Marybeth Farquhar, R.N., M.S.N.,
   AHRQ*
Gail R. Janes, Ph.D., CDC

NCVHS Team

Marjorie Greenberg
Debbie Jackson
Katherine Jones

Cynthia Sidney
Marietta Squires
Treva Thompson
Michelle Williamson

*Lead Staff
**OS/OCR Privacy Liaison

Appendix III.

CHARTER
NATIONAL COMMITTEE ON
VITAL AND HEALTH STATISTICS

PURPOSE

Collection, analysis and dissemination of health and health-related information is a crucial aspect of the responsibilities of the Department of Health and Human Services. The Department also plays a national leadership role in health data standards and health information privacy policy, and is charged with the responsibility for implementation of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996. In addition, the Department engages in cooperative efforts with other countries and the international community to foster health data standards, comparability and cross-national research.

The National Committee on Vital and Health Statistics is the Department's statutory public advisory body on health data, statistics and national health information policy. This Committee shall serve as a national forum on health data and information systems. It is intended to serve as a forum for the collaboration of interested parties to accelerate the evolution of public and private health information systems toward more uniform, shared data standards, operating within a framework protecting privacy and security. The Committee shall encourage the evolution of a shared, public/private national health information infrastructure that will promote the availability of valid, credible, timely and comparable health data. With sensitivity to policy considerations and priorities, the Committee will provide scientific-technical advice and guidance regarding the design and operation of health statistics and information systems and services and on coordination of health data requirements. The Committee also shall assist and advise the Department in the implementation of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act, and shall inform decision making about data policy by HHS, states, local governments and the private sector.

42 U.S.C. 242k(k), Section 306(k) of the Public Health Service Act, as amended; Public Law 108–173 Medicare Prescription Drug Improvement and Modernization Act of 2003, Subsection (e). The Committee is governed by provisions of Public Law 92–463, as amended, (5 U.S.C. App. 2), which sets forth standards for the formation and use of advisory committees.

FUNCTION

It shall be the function of the Committee to assist and advise the Secretary through the Department of Health and Human Services Data Council, on health data, statistics, privacy, national health information policy, and the Department's strategy to best address those issues.

Specifically, the Committee shall advise the Department in the following matters:

(A) Monitor the nation's health data needs and current approaches to meeting those needs; identify emerging health data issues, including methodologies and technologies of information systems, databases, and networking that could improve the ability to meet those needs.

(B) Identify strategies and opportunities to achieve long-term consensus on common health data standards that will promote (i) the availability of valid, credible, and timely health information, and (ii) multiple uses of data collected once; recommend actions the federal government can take to promote such a consensus.

(C) Make recommendations regarding health terminology, definitions, classifications, and guidelines.

(D) Study and identify privacy, security, and access measures to protect individually identifiable health information in an environment of electronic networking and multiple uses of data.

(E) Identify strategies and opportunities for evolution from single-purpose, narrowly focused, categorical health data collection strategies to more multi-purpose, integrated, shared data collection strategies.

(F) Identify statistical, information system and network design issues bearing on health and health services data which are of national or international interest; identify strategies and opportunities to facilitate interoperability and networking.

(G) Advise the Department on health data collection needs and strategies; review and monitor the Department's data and information systems to identify needs, opportunities, and problems; consider the likely effects of emerging health information technologies on the Departments data and systems, and impact of the Department's information policies and systems on the development of emerging technologies.

(H) Stimulate the study of health data and information systems issues by other organizations and agencies, whenever possible.

(I) Review and comment on findings and proposals developed by other organizations and agencies with respect to health data and information systems and make recommendations for their adoption or implementation.

(J) Assist and advise the Secretary in complying with the requirements imposed under Part C of Title XI of the Social Security Act;

(K) Study the issues related to the adoption of uniform data standards for patient medical record information and the electronic interchange of such information, and report to the Secretary not later than August 21 2000 recommendations and legislative proposals for such standards and electronic exchange;

(L) Advise the Secretary and the Congress on the status of the implementation of Part C of Title XI of the Social Security Act;

(M) Submit to the Congress and make public, not later than one year after the enactment of the Health Insurance Portability and Accountability Act, and annually thereafter, a report regarding the implementation of Part C of Title XI of the Social Security Act. Such report shall address the following subjects, to the extent that the Committee determines appropriate:

– The extent to which persons required to comply with Part C of the Act are cooperating in implementing the standards adopted under such part;

– The extent to which such entities are meeting the security standards adopted under such part and the types of penalties assessed for noncompliance with such standards.

– Whether the federal and State Governments are receiving information of sufficient quality to meet their responsibilities under such part.

– Any problems that exist with respect to implementation of such part.

– The extent to which timetables under such part are being met.

(N) Assist and advise the Secretary in the development of such reports as the Secretary or Congress may require.

In these matters, the Committee shall consult with all components of the Department, other federal entities, and non-federal organizations, as appropriate. To avoid unnecessary duplication of efforts, the Committee shall coordinate from time to time with the American Health Information Community, a Federally chartered advisory committee that was formed to provide advice concerning efforts to develop information technology standards, achieve interoperability of electronic health records (EHRs) and assure that the privacy and security of those records are protected.

STRUCTURE

The Committee shall consist of 18 members, including the Chair. The members of the Committee shall be appointed from among persons who have distinguished themselves in the fields of health statistics, electronic interchange of health care

information, privacy and security of electronic information, population-based public health, purchasing or financing health care services, integrated computerized health information systems, health services research, consumer interests in health information, health data standards, epidemiology, and the provision of health services. Members of the Committee shall be appointed for terms of up to four years. The Secretary shall appoint one of the members to serve a two year, renewable term as the Chair.

Of the members of the Committee, one shall be appointed by the Speaker of the House of Representatives after consultation with the minority leader of the House of Representatives; one shall be appointed by the President pro tempore of the Senate after consultation with the minority leader of the Senate, and 16 shall be appointed by the Secretary.

Membership terms of more than two years are contingent upon the renewal of the Committee by appropriate action prior to its termination. Any member appointed to fill a vacancy occurring prior to the expiration of the term for which his or her predecessor was appointed shall be appointed only for the remainder of such term. A member may serve 180 days after the expiration of that member's term if a successor has not taken office.

Standing and ad hoc subcommittees and working groups may be established to address specific issues and to provide the Committee with background study and proposals for consideration and action. The Chair shall appoint members to the subcommittees and designate a Chair for each subcommittee from the full Committee. The subcommittees shall make their recommendations to the parent Committee for deliberation. Timely notification of the subcommittees, including charges and membership, shall be made in writing to the Department Committee Management Officer by the Executive Secretary of the Committee. The HHS Data Council, through the Assistant Secretary for Planning and Evaluation, shall oversee and coordinate the overall management and staffing of the Committee. Professional, scientific, and technical staff support shall be provided by all components of the Department. The National Center for Health Statistics shall provide executive secretariat and logistical support services to the Committee.

MEETINGS

Meetings shall be held not less than annually at the call of the Chair, with the advance approval of a Government official, who shall also approve the agenda. A Government official shall be present at all meetings.

Meetings of the subcommittees shall be held at the call of the Chair, with the advance approval of a Government official, who shall also approve the agenda. A Government official shall be present at all subcommittee meetings. All subcommittees shall report their findings to the Committee. Meetings shall be open to the public, except as determined otherwise by the Secretary; notice of all meetings shall be given to the public. Meetings shall be conducted, and records of the proceedings kept, as required by the applicable laws and departmental regulations.

COMPENSATION

Members who are not full-time Federal employees shall be paid at a rate not to exceed the daily equivalent of the rate in effect for an Executive Level IV of the Executive Schedule for each day they are engaged in the performance of their duties as members of the Committee. All members, while so serving away from their homes or regular places of business, may be allowed travel expenses, including per diem in lieu of subsistence, in the same manner as such expenses are authorized by Section 5703, Title 5, U.S. Code, for employees serving intermittently.

ANNUAL COST ESTIMATE

Estimated annual cost for operating the Committee, including compensation and travel expenses for members but excluding staff support, is $677,593. Estimated annual person-years of staff support required is 4.9, at an estimated annual cost of $525,002.

REPORTS

In the event a portion of a meeting is closed to the public, a report shall be prepared which shall contain, as a minimum, a list of members and their business addresses, the Committee's functions, dates and places of meetings, and a summary of Committee activities and recommendations made during the fiscal year. A copy of the report shall be provided to the Department Committee Management Officer.

TERMINATION DATE

Unless renewed by appropriate action prior to its expiration, the charter for the National Committee on Vital and Health Statistics will expire on January 16, 2008.

APPROVED:

January 16, 2006   Michael O. Leavitt
                          Secretary of Health and Human Services

**U.S. DEPARTMENT OF
HEALTH & HUMAN SERVICES**

Centers for Disease Control and Prevention
National Center for Health Statistics
3311 Toledo Road
Hyattsville, Maryland 20782

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OFFICIAL BUSINESS
PENALTY FOR PRIVATE USE, $300