NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

NCVHS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

NCVHS

2003–2004

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
April 2006
DHHS Publication Number (PHS) 2006-1205

Foreword

This 2-year report gives us a good opportunity to look back on the momentum of recent years and forward to the progress we anticipate in the near future. It is astonishing to realize that the national health information infrastructure (NHII) was little more than a vision as recently as November 2001, when the National Committee on Vital and Health Statistics (NCVHS) published its seminal report, *Information for Health: A Strategy for Building the National Health Information Infrastructure*. Using an architectural analogy, we might imagine the NCVHS report as the ''rough drawings'' for the NHII. The ensuing years have generated more detailed drawings, some of them provided by NCVHS itself. With the appointment of Dr. David Brailer, the first National Coordinator for Health Information Technology, we have a ''general contractor'' who has been refining the blueprints and assembling the team of builders. Now the construction process is underway and proceeding at a rapid pace.

All in all, this is an exciting time for health information policy, thanks to strong Federal leadership, engaged private sector partners, and increasingly well informed consumers. The National Committee is pleased to have contributed so substantially to the Secretary's health information technology (HIT) initiative and its growing momentum. Getting the right information to the right people at the right time is key to achieving better health for all Americans, and we look forward to new opportunities to support the Department's objectives to this end.

While a strong national health information infrastructure is a necessary precondition for addressing the health concerns facing our nation today, establishing the technical infrastructure is clearly not sufficient. Unacceptable threats to patient safety, significant health disparities among population groups, and skyrocketing costs are just some of the challenges that necessitate a broad, multipronged strategy. Among other things, we need better ways to translate knowledge into quality care, better information to facilitate health improvements for disadvantaged population groups, and privacy protections that strengthen public trust.

These priorities are all part of the broad agenda of the National Committee, and we have been hard at work on them, as the following pages show. The Committee has a 55-year tradition of diligently gathering information and expert opinion, creating a forum for the exchange of

views, identifying areas of consensus, pooling the expertise of Committee members and staff, and developing thoughtful recommendations. These approaches have worked well in the past, and we look forward to putting them to work in support of the Secretary's HIT strategy and the American Health Information Community. As we help the Department integrate its information policy activities, we expect new synergies and partnerships to develop across the five domains of NCVHS activity—standards and security, privacy and confidentiality, the NHII, population health, and quality. Our efforts will be informed and guided by the Committee's comprehensive approach to information policy and its mission to help shape policy strategies to improve the population's health.

Simon P. Cohn, M.D., *Chairman*
John R. Lumpkin, M.D., *Chairman,* 1999–2005
August 2005

Contents

Executive Summary

This report reviews the recent work and accomplishments of the National Committee on Vital and Health Statistics (NCVHS), the statutory public advisory committee on health information policy to the Secretary of the Department of Health and Human Services (HHS). During the 2-year period covered by this report, Mike Leavitt was appointed to replace Tommy Thompson as HHS Secretary. The Committee was gratified that Secretary Leavitt not only moved ahead but quickened the pace on the Department's Health Information Technology (HIT) strategy begun under Secretary Thompson. The pace of the Committee's work increased over this 2-year period as well. It produced 31 letters and reports with recommendations on a broad range of topics, based on extensive consultations with experts in industry and Government and with health care consumers. The Committee also stepped up its active partnership with the Department on the HIT agenda and the continuing priorities in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) arena, as well as on such vital issues as health care quality and race and ethnicity data. Congress added new statutory responsibilities related to e-prescribing to the Committee's charge. In addition, partnerships with health care, informatics, and standards organizations intensified.

This report describes NCVHS's activities in the domains of its five Subcommittees and workgroups (listed in the Foreword). A marked characteristic of this period, however, was the increasing convergence and overlap among these domains. The information policy issues in the arenas of standards, security, privacy, population health, quality, and the information infrastructure all interact. These interactions necessitate collaborations among NCVHS subgroups, as well as with other bodies, that are sure to increase in the future.

National Health Information Infrastructure (NHII)

As noted, the NCVHS vision for the national health information infrastructure moved vigorously onto the Nation's agenda in 2003 and 2004. The President's creation of the Office of the National Coordinator for Health Information Technology (ONCHIT) in May 2004 was consistent with the Committee's call for Federal leadership. The Strategic

Framework for HIT that launched just 2 months later opened the door for progress on many fronts. The Committee's conceptual framework for the NHII features three coequal and interactive dimensions of information and its use—personal health, health care provider, and population health. With ONCHIT focusing initially on the provider dimension, the Workgroup chose to focus in this period on the other two dimensions, personal and population health, in which progress was less robust. Among other things, the group identified significant questions relating to consumers' ability to control their personal health information and about privacy and confidentiality.

Population Health

In 2003, NCVHS began a relationship with the new Board of Scientific Counselors of the National Center for Health Statistics (NCHS), chartered to advise the U.S. Department of Health and Human Services (HHS), the Centers for Disease Control and Prevention (CDC), and NCHS "regarding the scientific and technical program goals and objectives, strategies, and priorities of NCHS." A common interest of the advisory bodies is helping to realize the vision for 21st-century health statistics, articulated in a joint NCVHS/NCHS/HHS report in 2002. The quality and completeness of the data on race and ethnicity is a major NCVHS priority for which the Subcommittee on Populations has stewardship. The Committee conveyed key findings and recommendations on race and ethnicity data to the Secretary in three letters and a broader commentary during this period. The Committee's 2003 recommendation that health plans improve and standardize the collection of these data had a rapid and measurable impact. The entire Committee worked in various ways in 2003–04 to infuse the population health perspective more deeply and concretely into its work. The release in 2003 of the first annual National Reports on Quality and on Health Disparities by the Agency for Healthcare Research and Quality heightened the national focus on these major areas of concern and illustrated the need for more complete data.

Quality

In 2004, the Quality Workgroup completed a detailed summary of its findings from the testimony of more than 40 experts over several years. The report includes proposals for improving the measurement of health care quality. These proposals, which focus mainly on the gaps in administrative data, are in four priority areas: assessing health care and health outcomes, reducing disparities, building the information infrastructure to support quality, and balancing patients' interests in quality and confidentiality. The Workgroup then conducted a series of hearings to assess the responses of diverse stakeholders to the proposals, leading to a consensus recommendation to the Department and industry. Seeing the

range of information sought by quality initiatives and the burden issues of providers, the Workgroup began to reflect on how the electronic health record (EHR) could facilitate the collection of data elements and the transmission of new knowledge about best practices. The group began work on the uses of the NHII for quality improvement in the latter part of 2004.

Standards and Security

In 2003 and 2004, the Subcommittee on Standards and Security sent 12 reports or letters to the Department, transmitting recommendations that became widely accepted. HIPAA regulations began to go into effect in this period, with NCVHS helping industry prepare for compliance and then monitoring implementation. Following a rigorous review, the Committee wrote the Secretary in late 2003 advising that it is in the country's best interest that ICD–10–CM and ICD–10–PCS be adopted as HIPAA standards. Passage of the Medicare Modernization Act around the same time added e-prescribing as an active part of the 2004 agenda, with CMS accelerating the pace of implementation. During this 2-year period, the Committee set the stage for the Department's Consolidated Health Informatics (CHI) initiative with recommendations on patient medical record information (PMRI) message format standards and PMRI terminology, developed through close work with industry and the Department. These recommendations led to the Department's 2004 CHI decisions and resulted in standards that will significantly affect the practices of the Federal government and, ultimately, the private sector.

Privacy and Confidentiality

The Subcommittee on Privacy and Confidentiality, similar to the aforementioned Subcommittee, takes the lead on aspects of the National Committee's statutory HIPAA responsibilities. NCVHS advises on the content and strategies related to the privacy rule and assesses the adequacy of outreach and education efforts. In late 2003, the Subcommittee began to study the rule's impact and ramifications in several domains, which resulted in six letters from NCVHS to the Secretary. The Committee also wrote to the Secretary in June 2004, urging the Department to conduct research on the rule's impact in specific areas and on its general impact on the privacy of personal health information. In 2004, the Subcommittee widened its focus to include the privacy issues raised by new NHII/National Health Information Network (NHIN) policies and practices, as well as those associated with e-prescribing policies.

Introduction

The National Committee on Vital and Health Statistics (NCVHS) is the statutory public advisory committee on health information policy to the Secretary of the Department of Health and Human Services (HHS). The Committee's mission is to offer advice 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 fields as population-based health, health services, epidemiology, privacy, consumer health advocacy, health research, health statistics, health information systems, and health data standards. Sixteen members are appointed by the HHS Secretary, and two are appointed by Congress. NCVHS has Subcommittees and Workgroups on standards and security, privacy and confidentiality, populations, quality, and the National Health Information Infrastructure (NHII).

In its 55 years, the Committee has built a strong reputation for thoughtful leadership, and the Department and other constituencies have come to rely on its expertise.[1] It serves as a bridge between the Department and the health care, research, and public health communities, as well as 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 topical descriptions that follow show the Committee's efforts to elicit the views and knowledge of experts in these sectors. 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 21 agencies and offices. All of these collaborations contribute to

[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 in Appendix III. The full Committee meets four times a year, and each of its five Subcommittees and workgroups meets several times a year. All meetings are open to the public and broadcast on the Internet.

the Committee's effectiveness across a broad range of health information policy areas.[2]

This report is the latest in a series of periodic reviews of the National Committee's work.[3] To mention a few highlights, the years 2003 and 2004 were a time of unprecedented activity on the health information infrastructure at the highest levels of Government and by industry. Many decisions—above all, the President's creation of the Office of the National Coordinator for Health Information Technology (ONCHIT)—moved health information policy in directions envisioned and recommended by NCVHS. In the population health and quality areas, the release in 2003 of the first annual National Reports on Quality and on Health Disparities by the Agency for Healthcare Research and Quality (AHRQ) offered new opportunities for collaboration and action on issues at the heart of the Committee's work. The 2003 recommendation by NCVHS that health plans improve and standardize the collection of race and ethnicity data had a measurable impact. In addition, the Committee welcomed the news that the President's FY2005 budget included higher-level funding for NCHS, consistent with a 2003 NCVHS recommendation to the Data Council. During this period as well, the Department's Consolidated Health Informatics (CHI) initiative added to the momentum on the health information infrastructure and demonstrated the administration's commitment to providing leadership on standardization. The Committee set the stage for the CHI initiative through its recommendations on patient medical record information (PMRI) message format standards and PMRI terminology and through close work with industry and the Department, leading to the 2004 CHI decisions. The Committee also embarked in 2004 on new responsibilities for advising on e-prescribing, assigned to NCVHS as part of the Medicare Modernization Act of 2003. These highlights and many other NCVHS activities are described further, in the domains of the Committee's subcommittees and workgroups.

---

[2]The committee used a new metric for assessing its effectiveness in its 2003 report to the General Services Administration (GSA), which tracks all Federal advisory committees. Using new GSA performance measures, the staff determined that NCVHS had made 12 sets of recommendations in FY2002, totaling 77 recommendations, and that 71 percent of these were at least partially implemented by the Department.

[3]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 from 1996 on are posted on the NCVHS Web site, http://ncvhs.hhs.gov.

Major Activities and Accomplishments

1. National Health Information Infrastructure (NHII)

NCVHS documents on the NHII, 2003–04:
- October 8, 2003, Letter to the Secretary on Federal interagency IT research and development initiatives
- September 8, 2004, Letter to the Secretary on the Health IT/NHII Summit

In 2003 and 2004, the NCVHS vision for the national health information infrastructure moved decisively onto the Nation's agenda. The Committee had enunciated its NHII vision in the November 2001 report, *Information for Health: A Strategy for Building the National Health Information Infrastructure*. The report, which was developed through extensive hearings and consultations, identified Federal leadership as "the most important missing ingredient" in accelerating and coordinating progress on the NHII. It called for "a new senior position and office at HHS (equipped with adequate funding) . . . to oversee and coordinate a broad range of health information policy, research, and program activities in different sectors, both public and private" (p. 3).

The adequacy of the evolving national information infrastructure for meeting the requirements of the health sector and public health interests were a concern about which the Committee had written the Secretary in October 2003. On the basis of findings from a hearing earlier that year, the Committee urged the Department to increase HHS agency participation in Federal interagency information technology (IT) research and development initiatives to advance an improved national health information infrastructure and represent health perspectives in the research and development process for the next generation Internet and other aspects of the information infrastructure.

These concerns were largely put to rest by the surge of activity around the NHII that began in early 2004. At the same time that he set a national goal for Americans to have electronic health records within a decade, the President created a new sub-Cabinet level post at HHS to provide national leadership and coordination on health information technology. In May, David J. Brailer, M.D., Ph.D., was appointed the first National Coordinator of Health Information Technology. Then, in July, Dr. Brailer unveiled

the Health IT Strategic Framework at the HHS Health IT Summit and National Health Information Infrastructure Conference, which the NCVHS Workgroup on the NHII helped to plan. Dr. Brailer provided an overview, and conference break-out groups reported to the NCVHS NHII Workgroup at an NCVHS meeting at the end of the conference.

In a follow-up letter to the Secretary, the Workgroup called the Strategic Framework ''a remarkable achievement in both its speed and balance.'' The group identified several areas needing additional work and offered to assist the Department in developing strategies for achieving its goals and objective. The areas included:

- Issues related to patient control of their personal health information and general policy issues related to Personal Health Records.
- Approaches, best practices, and issues related to the use of master patient indexes and other methods to ensure that health care information can be reliably associated with the right individual.
- A research agenda for NHII, particularly to support strategies in the population health and personal health dimensions of the framework.
- Issues related to the movement of data between health care, population health, and personal health dimensions and, in general, secondary uses of data from any dimension.
- A comprehensive statement of ''Rules of the Road,'' including but not limited to interoperability, legal obstacles, and, in general, the key things that potential participants need to know about how to participate in the NHII.

The NCVHS letter also suggested that the Department revisit two issues in 2005: metrics for measuring progress and conformance testing. These topics join others identified in the September 2004 letter as possible near-term priorities for the NHII Workgroup.

The Committee's conceptual framework for NHII features three co-equal, intersecting, and interactive dimensions of information and information use—personal health, health care provider, and population health. The 2001 report states that ''the greatest value derives from shared information and communication across them'' (p. 3). In this rapidly moving arena, the NHII Workgroup weighs possible next steps in terms of how and where its contribution can be most useful. With ONCHIT generating and coordinating the momentum on the provider dimension, the Workgroup has chosen to focus on the two dimensions in which progress is less robust. On the population health information infrastructure, the Workgroup held hearings in Atlanta in April 2003 on public health IT systems including registries and the National Electronic Disease Surveillance System (NEDSS), part of the Public Information Network being developed by the Centers for Disease Control and Prevention.

In 2003 and 2004, the Workgroup held several hearings on the personal health dimension, in which the goal is to enable consumers to

be equal partners in health care decision-making. Personal health records (PHRs) are a component of health IT that is moving ahead rapidly, thanks to both the visibility the President gave these records and the assiduous efforts of the public-private collaborative, Connecting for Health.[4] However, significant questions remain about consumers' ability to control their personal health information and about privacy and confidentiality issues. The Workgroup has taken time in several meetings and hearings to study this emerging technology and different PHR models and to clarify the policy issues in this area. The group plans to send a letter to the Secretary in 2005 summarizing its findings on PHRs.

2. Populations

NCVHS documents on populations, 2003–04:

- February 28, 2003, Letter to the Secretary: NCVHS supports NCHS programs
- March 27, 2003, Letter to the Secretary: Populations-based data for racial and ethnic minorities
- September 26, 2003, Letter to the Secretary: Collection of racial and ethnic data by health plans
- September 26, 2003, Letter to the Secretary: Recommendations for targeted data collection
- February 20, 2004, Letter to the National Institute of Child Health and Human Development, National Institutes of Health: Establishment of the National Children's Study
- August 23, 2004, Letter to the Secretary: Recommendations on populations-based data collection

Population health principles govern all the work of the National Committee, whose population health mission is stated previously. Helping the Committee translate its mission into practical information and policy recommendations is a responsibility of the Subcommittee on Populations. The Subcommittee's charge covers information on the population as a whole and on specific population segments, particularly those for which their health status may be adversely affected by determinants such as race, ethnicity, socioeconomic position, or disability. The Subcommittee has worked to infuse the population health perspective more deeply and concretely into all the Committee's work. In 2003 and 2004, the Subcommittee organized a series of panel presentations to the full Committee on topics including Canadian approaches to population health; population health and its implications for health statistics; and race, ethnicity, and socioeconomic position.

Contributing to the ongoing effort to improve race and ethnicity data was the Subcommittee's major focus during this 2-year period. First, the Subcommittee gathered extensive information on data issues for U.S.

[4] http://www.connectingforhealth.org/resources/generalresources.html.

population groups in far-flung hearings in 2002 and 2003. Then it worked in 2003 and 2004 to turn its findings on the immense and complex data gaps in this area into actionable recommendations to help the Government achieve the highest quality of Federal data collection and to make this information available and useful to researchers. The Committee conveyed key findings and recommendations on race and ethnicity data to the Secretary in three letters during this period. It also submitted a longer commentary prepared by the Subcommittee, ''Recommendations on the Nation's Data for Measuring and Eliminating Health Disparities Associated with Race, Ethnicity, and Socioeconomic Position.''

The Committee's September 2003 letter had a measurable impact. The letter recommended that HHS strongly encourage and support public- and private-sector health plans to collect accurate and complete racial and ethnic data using the revised Office of Management and Budget (OMB) standard categories. It observed that without the collection of standardized racial and ethnic data in health plans, progress toward achieving the national goal of eliminating racial and ethnic disparities could not be monitored. In addition, it pointed out that medical service provider administrative data are a critical source of information on the race and ethnicity of individuals, and that a uniform data collection infrastructure does not exist. Many in industry welcomed these NCVHS recommendations. A year later, a 2004 survey by America's Health Insurance Plans (AHIP) found that half of the plans were collecting race and ethnicity data in at least one of their product lines. The collection of these data will facilitate identifying, measuring, and tracking health and health care disparities within and across health plans.

The Subcommittee has led the Committee's effort to prevent or minimize slippage in budgetary support for the important population health surveys of NCHS, as addressed in a February 2003 letter to the Secretary. As noted, the following year's budget included a significant increase for NCHS, providing resources to address chronic shortfalls in the Center's programs and to ensure progress in initiatives to improve core data systems. The Subcommittee on Populations also has stewardship of the Committee's relationship with the Center's recently created Board of Scientific Counselors. This relationship opens new ways for the Committee to support the Center and its work. NCHS and its two advisory bodies share a strong interest in carrying out the vision for 21st-century health statistics that was articulated in the 2002 NCVHS publication with that title.[5] This statistical report was developed collaboratively by NCVHS, NCHS, and the HHS Data Council.

With its responsibility for an information policy for all population groups, the Subcommittee on Populations may have the broadest portfolio of any NCVHS Subcommittee or Workgroup. During this period, the Subcommittee also reviewed plans for more extensive data collection on

[5]Shaping a health statistics vision for the 21st century, November 2002.

children, the National Children's Study, resulting in a February 2004 letter and recommendations. In addition, the Subcommittee began a review of mental health data issues—a focus it plans to continue in 2005. The emphasis on mental health data grew out of concerns about 2001 changes in mental health data collection in a major general health survey that make it more difficult to understand the connections between health status and emotional well-being.

By the end of this 2-year period, the Subcommittee on Populations was conducting a significant part of its work in collaboration with other NCVHS groups. This is particularly the case with the Quality Workgroup, because improving race and ethnicity data in health care is so critical to the national effort to improve health care quality measurement. Another topic of common interest is functional status, the subject of a 2001 NCVHS report. This topic re-emerged in the context of 2004 Quality Workgroup recommendations, discussed later. The Subcommittee is also in dialogue with the Subcommittee on Privacy and Confidentiality, for example, about the fact that the cell sizes of survey data on small population groups make it difficult to release these data for research purposes.

3. Quality

NCVHS documents on quality, 2003–04:

- January 17, 2003, NCVHS Comments on Proposed Measure Set for the National Healthcare Quality Report (NHQR)
- May 2004, Report on Measuring Health Care Quality
- November 5, 2004, Letter to the Secretary: Recommendation on revisions to the Uniform Bill for Hospitals (UB04) and the ANSI ASC x 12N 8371 HIPAA Implementation Guide

The Quality Workgroup takes the lead in the Committee's work on the data and system issues involved in measuring and improving the quality of health and health care. Created in 1998, it is part of the Subcommittee on Populations. Although the Workgroup has focused much of its work on the clinical encounter, part of its mission is to help position clinical quality measurement so it has maximum utility in assessing and improving population health.

The Workgroup works in an environment in which many public, private, and joint initiatives are underway to improve quality and quality measures. In its advisory role, the Workgroup orients to and is informed by the priorities of the AHRQ, which publishes annual reports on health care quality and disparities. The Workgroup began the 2-year period under discussion by developing comments to AHRQ on its proposed measure set for the first National Healthcare Quality Report (January 2003). These comments were based primarily on testimony received from public health and health care experts at a July 2002 NCVHS hearing. The

Committee's continuing dialogue with AHRQ keeps the population health uses of quality assessment a prominent part of its perspectives.

In its early years, the Quality Workgroup organized 17 panel presentations that enabled the Committee to talk with more than 40 experts about the challenges of developing health care quality measures, implementing quality measurement and improvement projects, and using comparative performance data to drive quality improvement. On the basis of that testimony, the Workgroup developed a 2004 report summarizing its findings and translating them into proposals for improving quality measurement. It identified candidate recommendations in four priority areas: 1) assessing health care and health outcomes, 2) reducing disparities in health and health care, 3) building the data and information infrastructure to support quality, and 4) balancing patients' interests in quality and confidentiality. Some of the recommendations target existing health data systems, some target evolving systems, and a few require policy changes. All come with implementation options to be considered by and in consultation with key stakeholders.

The Workgroup faced two major challenges in developing its report. First, it needed to take into account the extensive activity underway on health care quality and standards. Second, it had to decide how to take advantage of the growing momentum in the development of NHII, particularly in electronic health records. Whereas much of the Committee's earlier research focused on gaps in administrative data, the Workgroup wanted to make its findings relevant to the transition to EHRs. In general, the Workgroup and the Committee chose to frame the 2004 recommendations on quality in the spirit of the Committee's earlier reports on the NHII and 21st-century health statistics—in other words, as a vision document to guide long-term progress through the activities and interests of myriad stakeholders.

On completion of its May 2004 report, the Quality Workgroup began an effort to increase the synergy among data standard advances, progress in the health information infrastructure, and quality improvement activities. In June and September 2004 hearings sponsored jointly with the Subcommittee on Standards and Security, Workgroup members met with representatives of purchasers, providers, health plans, insurers, quality assurance bodies, health information management professionals, and standards development organizations to discuss the feasibility and business case for each of the first 8 of the 23 candidate recommendations in the May report. While many participants stressed the importance of consensus and collaboration, the discussions also highlighted differences between purchasers and health care providers about the relative costs and benefits of collecting more data on quality. The late 2004 hearings also highlighted the importance of measuring functional outcomes, a topic that is likely to receive further attention from the Committee in the future.

In addition, the discussion clarified the feasibility of moving ahead with one candidate recommendation that was universally sought by the

purchasers of care, endorsed by the providers of care, and poised for implementation by the Designated Standards Maintenance Organizations. In a November letter to the Secretary, the Committee recommended ''that the next version of the Uniform Bill for Hospitals (UB04) and the ANSI ASC × 12N 8371 HIPAA Implementation Guide be revised to facilitate reporting of a diagnosis indicator to flag diagnoses that were present on admission in secondary diagnosis fields for all inpatient claims transactions.''

A key insight gained from the 2004 hearings was the dramatic increase in the numbers and types of information sought by various quality initiatives on both inpatient and outpatient encounters. Although claim forms can accommodate selected individual elements (e.g., lab test or vital sign or functional status), the depth and breadth of the quality indicators anticipated by the health care community have already exceeded the potential capacity of the claims transaction. This observation triggered discussion and reflection on the role of the electronic health record (EHR) as a vehicle that facilitates the collection of additional quality data elements and that also serves as a means of transferring new knowledge around best practices. The discussion of the transition to multiple EHR uses laid the groundwork for the focus of the Quality Workgroup in 2005.

4. Standards and Security

NCVHS documents on standards and security, 2003–04

- June 25, 2003, Report to the Secretary: Health care industry's readiness to comply with the October 16, 2003, implementation deadline
- June 25, 2003, Letter to the Secretary: Status of PMRI terminology
- September 24, 2003, Letter to the Secretary: CHI domain area recommendations
- October 14, 2003, Analysis of ASCA compliance plans for implementing HIPAA transactions and codes standards
- November 5, 2003, Letter to the Secretary: ICD–10 recommendations
- November 5, 2003, Letter to the Secretary: Comments on CHI domain area recommendations; patient medial record information (PMRI) terminology analysis reports
- November 5, 2003, Letter to the Secretary: Recommendations for PMRI terminology standards
- January 29, 2004, Letter to the Secretary: Final recommendations on CHI domain areas
- March 5, 2004, Letter to the Secretary: Recommendations on claims attachment
- May 10, 2004, Sixth Annual Report to Congress on the Implementation of the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act of 1996
- June 17, 2004, Letter to the Secretary: Recommendations on standards for billing of supplies
- September 2, 2004, Letter to the Secretary: First set of recommendations on e-prescribing standards

The record of 16 meetings and 12 reports or letters by the Subcommittee on Standards and Security in 2003–04 reflects the level of engagement and productivity of this Subcommittee. More important, the wide accep-

tance of these recommendations by HHS, other Federal departments and agencies, and the private sector demonstrates the leadership this Subcommittee has provided and influence it has had on the adoption of health care information standards as a key element of the foundation for the National Health Information Infrastructure (NHII). The Health Insurance Portability and Accountability Act (HIPAA) of 1996 provided the initial impetus for the work of this Subcommittee, which manages the Committee's responsibilities for advising the Secretary on the adoption of health data standards, monitoring their implementation, and reporting to Congress annually on the status of implementation. In addition, a new law, the Medicare Modernization Act of 2003, gave the Committee a new set of challenges and responsibilities related to electronic prescribing (e-prescribing). The Subcommittee carries out all its work in close partnership with the Department and the health care industry, with the Department relying heavily on the Subcommittee's advice. Through these active working relations, it is able to facilitate consensus within industry, within Government, and between the two.

In this 2-year period, the HIPAA regulations on transactions and code sets and on privacy went into effect. Final rules also were issued for the national provider identifier and for security standards, leaving only plan identifiers and claims attachment regulations to be sent through the rule-making process. Modifications to the transactions standards and code sets also were published during this period. In addition to advising on the content and pace of standardization, another role of the Committee is helping to prepare industry for compliance and assessing its readiness. The transition to compliance took effect in October 2003. At its November 2003 meeting, the Committee passed a motion commending the Department ''for taking the lead in working with its numerous partners to carry out the complex and contentious transition to HIPAA codes and transaction standards so smoothly.''

The Committee's advisory work on HIPAA is described in detail in its regular reports to Congress on HIPAA implementation. The sixth such report, covering September 2002 through December 2003, observes that significant progress occurred on several HIPAA Administrative Simplification standards during that period.[6] While the report applauds the accomplishments, it also observes that the industry's implementation activities and resource planning will be more effective—and the full economic benefits of administrative simplification realized—when the entire suite of standards is finalized. The Committee, therefore, encouraged the Secretary of HHS to expedite the publication of the remaining rules without delay, and it urged Congress to provide sufficient resources and support to ensure successful implementation of this initiative.

Recommending standards for Patient Medical Record Information (PMRI) is another facet of the Committee's responsibilities under HIPAA.

[6] http://www.ncvhs.hhs.gov/adminsip6.pdf.

The Subcommittee's findings and recommendations were conveyed through a report in 2000 and letters in 2002 and 2003. The potential benefits of the PMRI recommendations became visible during 2003 and 2004. They served as the foundation for standards in the Federal Consolidated Health Informatics (CHI) initiative, which is developing and implementing uniform standards for the interoperability of clinical information in the Federal health care enterprise. During this period, the Committee served in an advisory capacity to the CHI initiative. It held meetings that enabled industry to comment on proposed standards in a number of clinical domains, and it reviewed and commented on all the proposed CHI recommendations. The resulting standards, which were adopted by the Secretaries of HHS and Defense, as well as the Veterans Administration, will significantly affect the ways in which the Federal government—and ultimately the private sector—conduct business regarding clinical messaging and terminology.[7]

The standardization efforts of the Committee began decades ago with its historic work on the *International Classification of Diseases* (ICD)—an involvement that continues to the present day. With the 10th edition of the ICD already implemented in many countries, and in the United States for mortality data, the question of implementation for morbidity purposes in the United States has grown more pressing. In 2003, the Committee held hearings on the feasibility and desirability of replacing the existing diagnosis and inpatient procedure coding system, ICD–9–CM, volumes 1, 2, and 3, with ICD–10–CM and ICD–10–PCS, respectively. The findings of a commissioned impact study by the Rand Corporation on the costs and benefits of migrating to a new system were presented to the Committee at its September 2003 meeting, along with overviews and analyses by NCHS, the Centers for Medicare and Medicaid Services (CMS), reactor panels, and others. Based on this rigorous process, the Committee wrote to the Secretary in November 2003 to convey its recommendation that it is in the country's best interest that ICD–10–CM and ICD–10–PCS be adopted as HIPAA standards. The Department has not yet acted on this recommendation.

Passage of the Medicare Modernization Act (MMA) in late 2003 moved e-prescribing to the fore in 2004. E-prescribing represents the first broad clinical application that must address all the practical issues involved in standardization, including information linkage, privacy, patient identification, content, and interoperability. The MMA required NCVHS to conduct hearings on e-prescribing, with the input then being used to recommend to the HHS Secretary standards that could be used to implement e-prescribing in the new Medicare Part D benefit. Soon after his appointment as CMS Administrator, Dr. Mark McClellan told the Committee that the Centers wanted to accelerate the implementation of e-prescribing by proposing an initial set of well-established standards by

[7] http://www.hhs.gov/healthit/chiinitiative.html.

January 2006, when the Medicare Part D benefit was to begin. Taking up the challenge, the Subcommittee worked intensively with industry to create the requirements for e-prescribing standards. The process was extremely successful. The Subcommittee held a series of hearings in which it evaluated industry adoption of e-prescribing, the existing infrastructure, the standards being used, privacy and security policies, and research needs. On this basis, it not only recommended the foundation standards but also identified the limitations and gaps in these standards and recommended specific HHS and industry action to address these limitations and gaps (see September 2004 letter). These recommendations were later incorporated into a proposed rule, serving as a catalyst for the industry to fill standards gaps and harmonize standards to facilitate and accelerate the adoption and use of e-prescribing. The process also served as a model for obtaining industry input into the regulatory process.

5. Privacy and Confidentiality

NCVHS Documents on Privacy and Confidentiality, 2003–04:

- June 25, 2003, Letter to the Secretary: Program to measure the effects of the privacy rule
- March 5, 2004, Letter to the Secretary: Recommendation on the impact of the privacy rule (on public health and research and on health care providers, health plans, and consumers)
- June 17, 2004, Letter to the Secretary: Recommendations on the impact of the privacy rule in banking
- June 17, 2004, Letter to the Secretary: Recommendations on the effect of the privacy rule in law enforcement
- June 17, 2004, Letter to the Secretary: Recommendations on the effect of the privacy rule in schools
- September 1, 2004, Letter to the Secretary: Implementation of the privacy rule's marketing provisions
- September 1, 2004, Letter to the Secretary: Privacy advocate
- September 2, 2004, Letter to the Secretary: Findings and recommendations on the effect of the privacy rule on fundraising

The NCVHS Subcommittee on Privacy and Confidentiality shares responsibility with the Subcommittee on Standards and Security for helping the Committee advise the Department on HIPAA. As with the latter, the Subcommittee on Privacy and Confidentiality's work on HIPAA is detailed in a regular report to Congress on implementation. With respect to HIPAA, the Subcommittee concerns itself with outreach and education, implementation, and the effect of the privacy rule. It also advises on privacy and confidentiality issues associated with other laws and policies, including the privacy ramifications of the National Health Information Network (NHIN) and e-prescribing.

The Subcommittee began monitoring and advising on the Department's outreach and education efforts in support of the HIPAA privacy

rule in mid-2002. After holding hearings in three cities, the Subcommittee ended 2002 with a letter strongly urging the Department to respond to the public's lack of information about privacy rule implementation with significantly increased resources. The letter advocated an immediate and intense effort, including a massive public education program. Since that time, advising on content and strategies and assessing the adequacy of outreach and education with various constituencies have remained strong facets of the Committee's involvement with the privacy rule.

After allowing a few months for the implementation process to unfold, the Subcommittee began in late 2003 to study the impact and ramifications of the privacy rule. From the outset, the HHS Office for Civil Rights, which is responsible for enforcement and education, kept the Committee updated about the number, extent, and type of complaints submitted under HIPAA, as well as the Department's plans to address them. The Subcommittee conducted hearings in November 2003 and in February and July 2004 that enabled a wide range of constituencies and experts to present their views and experiences regarding the privacy rule. On the basis of those hearings, the Subcommittee drafted and sent six letters to the Secretary on the effects of the privacy rule in specific domains. The first letter addressed the rule's effects on research and on public health data collection. Among other things, it urged that the rule be harmonized with the Protection of Human Subjects Rule. Subsequent letters addressed the privacy rule's impact on immunization information in schools and on law enforcement, seeking in these cases to ensure that the rule does not impede appropriate Governmental functions. (Responding to one NCVHS recommendation, OCR added to its Web site a new FAQ [Frequently Asked Questions] page about disclosures to law enforcement.) The Committee's letters on the privacy rule's impact on marketing, fundraising, and banking address a somewhat different set of issues concerning the balance point between personal health information privacy and various commercial activities.

The Committee has an abiding interest in the impact of the privacy rule both on specific activities such as those highlighted earlier and, in general, on the privacy of personal health information—the object of the rule. The Committee wrote to the Secretary in June 2004 recommending that the Department conduct research on these questions. The Committee urged the Department, while implementation was at an early stage, to develop methodologies and to collect baseline data that could be used to analyze the effects of the privacy rule. Further, it recommended that the Department initiate such a program to measure the rule's effects. It proposed that the findings could be used to help refine rule-making, implementation, and enforcement strategies for the privacy rule. To date, the Department has not informed the Committee that it has undertaken the research effort recommended by the Subcommittee. The Committee also wrote to the Secretary in September 2004 to commend the outgoing

HHS Privacy Advocate John Fanning, with whom the Subcommittee worked closely, and to stress the importance of keeping that position filled.

The privacy issues raised by new NHII/NHIN policies and practices and those associated with new e-prescribing policies began to surface in the middle of 2004. The latter were the focus of the Subcommittee's final 2004 hearing. As for the NHIN, Dr. Brailer sought the Committee's advice on privacy issues in this arena when he met with the NCVHS Executive Subcommittee on the 90th day of his tenure. At the heart of NHIN policy issues is the significant challenge of protecting privacy and confidentiality while also realizing the potential personal and population health benefits of electronic health records. The Subcommittee carried a focus on these issues into its work in 2005.

Looking Ahead

The Department's Health IT Strategic Framework set in motion a number of ventures that shift from a planning to an action stage in 2005. The National Coordinator for HIT, Dr. David Brailer, calls this period a ''flexion point.'' As demonstrated previously, the National Committee helped to bring about the significant changes that are gathering momentum; it now welcomes the challenge of determining how best to marshal its expertise and resources to support the Department's HIT initiative while also pursuing the other critical priorities described previously. In all of its activities, it will continue to pursue the mission of shaping a national information strategy for improving the population's health.

Appendix I.
NCVHS Roster (September 2005) and 2003–05 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
Acting 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, DHHS
Hyattsville, MD 20782

Membership

Jeffrey S. Blair, M.B.A.
Vice President
Medical Records Institute
Albuquerque, NM 87111

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

John P. Houston, J.D.
Director, ISD; Privacy Officer; Assistant Counsel
University of Pittsburgh Medical Center
Pittsburgh, PA 15213

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, J.D., Ph.D.
Assistant Professor of Biostatistics
University of Pennsylvania School of Medicine
Center for Clinical Epidemiology and Biostatistics
Philadelphia, PA 19104

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

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.
Chairman
The Johns Hopkins University
Bloomberg School of Public Health
Department of Health Policy and Management

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

Paul 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 & Hamilton
Rockville, MD 20852

Judith Warren, Ph.D., R.N.
Associate Professor
School of Nursing
University of Kansas
Kansas City, KS 66160–7502

Liaison Representatives

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

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

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

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

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

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

NCVHS Retirees

Retirees 2003–04

John R. Lumpkin, M.D., M.P.H., Chair
Senior Vice President for Health Care
Robert Wood Johnson Foundation
Princeton, NJ

John W. Danaher, M.D.
Litchfield, CT

Peggy B. Handrich
Administrator
Division of Health Care Financing
Wisconsin Department of Health and Family Services
Madison, WS

Eugene J. Lengerich, V.M.D.
Penn State University
Hershey, PA

Vickie M. Mays, Ph.D., M.P.H.
Department of Psychology
University of California, Los Angeles
Los Angeles, CA

Clement Joseph McDonald, M.D.
Distinguished Professor of Medicine
Indiana University School of Medicine
Director, Regenstrief Institute
Indianapolis, IN

Edward H. Shortliffe, Ph.D., M.D.
Department of Medical Informatics
Columbia University
New York, NY

Kepa Zubeldia, M.D.
President
Claredi
Kaysville, UT

Retiree, 2005

Richard K. Harding, M.D.
Professor and Chair
University of South Carolina, School of Medicine
Columbia, SC

Liaison:

Judith Berek
Principal Advisor to the Administrator for National Policy Implementation
Centers for Medicare and Medicaid Services
Department of Health and Human Services

Appendix II.
Subcommittee Members and Staffs (September 2005)

Executive Subcommittee

Simon P. Cohn, M.D., Chairman
Jeff S. Blair. M.B.A.
Robert W. Hungate
Harry Reynolds
Mark A. Rothstein, J.D.
Donald M. Steinwachs, Ph.D.

Ex Officio

James Scanlon, ASPE
Marjorie Greenberg, NCHS

Liaisons

Virginia S. Cain, Ph.D., NIH
J. Michael Fitzmaurice, Ph.D., AHRQ
June E. O'Neill, Ph.D., NCHS/BSC
Edward J. Sondik, Ph.D., NCHS
Steven J. Steindel, Ph.D., CDC
Karen Trudel, CMS

Staff

Debbie M. Jackson, NCHS
Katherine D. Jones, NCHS

Workgroup on National Health Information Infrastructure

Simon Cohn, M.D., Chairman
Jeffrey S. Blair, M.B.A.
John P. Houston, J.D.
Stan M. Huff, M.D.
Robert W. Hungate
C. Eugene Steuerle, Ph.D.
Paul C. Tang, M.D.
Kevin C. Vigilante, M.D., M.P.H.

Mary Jo Deering, Ph.D., NIH*
Cynthia Baur, Ph.D., OPHS/OS
Jay Crowley, FDA
Linda Fischetti, RN, MS. DVA
Kathleen Fyffe, ASPE
Robert Kambic, CMS
Eduardo Ortiz, M.D., M.P.H., DVA
Amy Patterson, NIH
Anna Poker, AHRQ
Steven J. Steindel, Ph.D., CDC
Karen Trudel, CMS
Cynthia Wark, CMS
Michelle Williamson, NCHS

Subcommittee on Standards and Security

Jeffrey S. Blair, M.B.A., Co-Chairman
Harry Reynolds, Co-Chairman
Simon P. Cohn, M.D.
Stan M. Huff, M.D.
Judith Warren, Ph.D., R.N.

Maria A. Friedman, D.B.A.*
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 Greenberg, NCHS
Stanley Griffith, M.D., IHS
Betsy Humphreys, NLM
Wanda Govan-Jenkins, M.S, M.B.A, R.N., NCHS
Rob Kolodner, M.D., DVA
Randy Levin, M.D., FDA
Donna Pickett, NCHS
James Scanlon, ASPE
Steve 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.
Harry Reynolds
Paul C. Tang, M.D.

Maya Bernstein, J.D.*
Amy Chapper, J.D., CMS
Beverly Dozier-Peeples, J.D., CDC
Kathleen Fyffe, ASPE
Gail Horlick, M.S.W., J.D., CDC
Evelyn Kappeler, OPHS
Lora Kutkat, NIH
Catherine Lorraine, FDA
Susan McAndrew, OS/OCR**
Helga Rippen, M.D., Ph.D., ASPE/OS
Bill Tibbitts, IHS
Sarah Wattenberg, SAMHSA

Subcommittee on Populations

Donald M. Steinwachs, Ph.D., Chairman
Justine M. Carr, M.D.
Robert H. Hungate
A. Russell Localio, J.D., Ph.D.
Carol J. McCall, FSA, MAAA
William J. Scanlon, Ph.D.
C. Eugene Steuerle, Ph.D.
Kevin C. Vigilante, M.D., M.P.H.

Audrey Burwell, OMH*
Dale Hitchcock, ASPE
Lou Belmonte, OIA
Nancy Breen, Ph.D., NCI, NIH
Leslie Cooper, Ph.D., NCI, NIH
Brenda Evelyn, FDA
Miryam Granthon, OPHS
Nilsa Gutierrez, M.D., M.P.H., CMS
Suzanne Haynes, Ph.D., OPHS
Suzanne Heurtin-Roberts, Ph.D., M.S., NCI, NIH
Cille Kennedy, Ph.D., ASPE
Jacqueline Lucas, NCHS
Edna Paisano, IHS
Susan Queen, Ph.D., HRSA
Harvey Schwartz, Ph.D., AHRQ

Workgroup on Quality

Robert H. Hungate, Chairman
Justine M. Carr, M.D.
Carol J. McCall, FSA, MAAA
William J. Scanlon, Ph.D.
Donald Steinwachs, Ph.D.

Anna Poker, AHRQ*
Stan Edinger, Ph.D., AHRQ
Susan Gardner, FDA
Trent Haywood, M.D., J.D., CMS
Julia S. Holmes, Ph.D., NCHS
Gail R. Janes, Ph.D., CDC
Leroy Nyberg, Ph.D., M.D., NIDDK, NIH
Eduardo Ortiz, M.D., M.P.H., DVA

NCVHS Team

Marjorie S. Greenberg
Jackie Adler
Kevina Bracey
Debbie Jackson

Katherine Jones
Marietta Squire
Gracie White
Michelle Williamson

*Lead Staff
**OS/OCR Privacy Liaison

For complete addresses of the staff, please see our Web site at http://www.ncvhs.hhs.gov

Appendix III.

THE SECRETARY OF HEALTH AND HUMAN SERVICES

WASHINGTON, D.C. 20201

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.

AUTHORITY

42 U.S.C. 242k(k), Section 306(k) of the Public Health Service Act, as amended. 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 multipurpose, 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.

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. Members may serve after the expiration of their terms until successors have been appointed.

Standing and ad hoc subcommittees, composed solely of members of the parent Committee, 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 from the parent Committee to the subcommittees and designate a Chair for each subcommittee. The subcommittees shall make their recommendations to the parent Committee. 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 $429,000. Estimated annual person-years of staff support required is 4.9, at an estimated annual cost of $454,000.

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, 2004.

APPROVED:

January 16, 2002

Tommy G. Thompson
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

06-0068 (4/06)
CS101846
T24554
DHHS Publication No. (PHS) 2006-1205