

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS



2000-2002



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention  
National Center for Health Statistics

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NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

**NCVHS**



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Centers for Disease Control and Prevention  
National Center for Health Statistics

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## Foreword

The year 2003 will be seen as a watershed year in the drive to automate health information. This year, Secretary Thompson announced the adoption by the Department of Health and Human Services (HHS) of clinical data standards as part of the Consolidated Health Informatics Initiative of DHSS, Department of Defense, and the Department of Veterans Affairs. This year will also see the implementation of the Health Insurance Portability and Accountability Act (HIPAA) privacy regulations and the transaction electronic data interchange standards. All of these changes set the stage for the adoption of an automated health and health care system that is able to deliver high-quality service safely, efficiently, and effectively.

The events of September 11, 2001, and its aftermath pointed out the vital role that health statistics and health informatics play in our national security. As this Nation struggled to manage the loss of life and the health, environmental, and economic consequences of the attacks in New York City and our Nation's Capital, we were faced with a new and more sinister threat, bioterrorism. These and other national and international events have underscored the importance of information—immediate, accurate, and reliable information—for decisionmaking, for analysis, and for action. At the same time, ongoing regional situations continue to demand immediate and fully functioning data systems to address increasingly complex public health needs. Throughout its 50-year history, the National Committee on Vital and Health Statistics (NCVHS) has been steadfast in fulfilling its mission while mindful of the pressing issues on the national scene, and this period is no different.

The 3 years represented in this report (2000–2002) cover an unprecedented period during which the foundation for the dramatic changes in health informatics has been laid. Restructured to facilitate an emerging role with HIPAA, NCVHS is effectively making the transition from rule development to implementation, with special attention to health information privacy and the adoption and implementation of health data standards. The letters and reports launched during this period, instantly available to the public through Web capability, reflect the Committee's groundbreaking emergence in consensus building, reflecting, and initiating. During this period, the Committee held numerous hearings on HIPAA implementation and standards and a whirlwind of hearings organized to provide timely input about the privacy regulations. As such,

NCVHS continues to play a pivotal role in accelerating the evolution of public and private health information systems within the framework of protecting privacy and security. Its recent reports on the National Health Information Infrastructure and Health Statistics for the 21st Century recognize the need for strategic Federal leadership. At the same time, the Committee remains vigilant about understanding the data issues underlying the health care needs of special populations and will be directing even more attention to population health issues in future agendas.

It was also during this period that we lost a true champion for health information, Dr. John Eisenberg. His wisdom, insight, and wit as former Chair of the Data Council paved the way in the deliberation and execution of many policy decisions. He will be sorely missed as a treasured colleague and friend.

In these challenging and changing times, the country's evolving data systems will be called upon to meet immediate and sometimes seemingly contradictory needs. Over the years, NCVHS has built a hard-earned reputation for thoughtful deliberation about a wide range of issues pertaining to health information policy and data standards. The 3 years reflected in this report represent enormous changes in our country's operations and security. I am pleased to submit this report as a reflection of the Committee's accomplishments and capacities as we strive to meet the evolving needs.

John Lumpkin, M.D., M.P.H.  
*Chair*  
National Committee on Vital and Health Statistics

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## Executive Summary

The National Committee on Vital and Health Statistics (NCVHS) is the statutory public advisory body to the Secretary of Health and Human Services and Congress on the information needs underlying health policy. Its mission is to advise on shaping a national information strategy for improving the population's health. NCVHS serves as a bridge between government and the health care industry and research and public health communities. These constituencies increasingly rely on the expertise embodied in the Committee, which in its 50-plus years as a Federal advisory committee has built a reputation for thoughtful leadership.<sup>1</sup>

The Committee was highly productive in the years 2000–2002, producing 7 major reports and sending 18 letters with recommendations to the Secretary or other members of the Administration. It continued to advise the Department on the development and implementation of HIPAA standards on data, communications, patient medical record information, and privacy. The Committee issued recommendations on population health topics, including race/ethnicity and functional status data, and it advised on such government activities as the National Healthcare Quality Report, the National Electronic Disease Surveillance System (NEDSS), the OMB Guidance on race/ethnicity data, and the Consolidated Health Informatics (CHI) initiative. Brief summaries of the Committee's major activities during this period follow.

### Two Visions for Using Information Capacities to Promote Health

The NCVHS report, *Information for Health: A Strategy for Building the National Health Information Infrastructure*, outlines a vision and a developmental process for a comprehensive, knowledge-based system that can connect health decision makers to sound information and to each other. It reflects expert testimony at four regional hearings. As envisioned, the NHII has three overlapping and interactive dimensions—personal health, healthcare provider, and population health. Much of its value lies in the connections and multidirectional information sharing it makes possible among these dimensions. Acting on a strong message from the field

<sup>1</sup>The Committee marked its 50th anniversary in June 2000 with a symposium hosted by the National Academy of Sciences. The proceedings of that symposium are published, together with a 50-year history of NCVHS and preliminary reports on the NHII and health statistics visions described below, in *NCVHS 50th Anniversary Symposium Reports* (September 2001).

about the need for Federal leadership, the NCVHS report recommends an NHII development strategy that places HHS in a leadership position at the center of a collaborative process involving private and public sectors. After releasing this report in late 2001, the NHII Workgroup turned its attention to the personal and population health dimensions and to health data needs related to national preparedness. It will pursue these initiatives in 2003, and will continue to advise on and monitor the implementation of the Committee's NHII recommendations. HHS is identifying opportunities for coordinating activities on the NHII within the Department and with external groups.

A second report on a component of the NHII, *Shaping a Health Statistics Vision for the 21st Century*, aims to transform health statistics activities so they more fully serve population health needs. The report was developed through a 2-year national consultation with more than 200 stakeholders across the United States, coordinated jointly by NCVHS, the National Center for Health Statistics (NCHS), and the HHS Data Council. These bodies also coauthored the report, which was approved in September 2002. NCVHS recommendations for translating the vision into practice (attached to the report) give top priority to building an integrating and coordinating hub for the health statistics enterprise. Among other things, the Committee urges HHS to assign responsibility and authority for health statistics leadership within the Department to a reconstituted NCHS, supported by a strong Board of Scientific Counselors. The Committee has been in dialogue with the NCHS Director for several years about his need for ongoing external advice, and it supported the Center's decision to charter a Board of Scientific Counselors that would have a strong liaison with NCVHS.

## **Standards for Patient Medical Record Information**

Electronic medical records are an essential building block for every dimension of the NHII, and the subject of another series of NCVHS reports.<sup>2</sup> Following 6 hearings over a 2-year period and testimony from more than 90 experts, the Committee submitted its first report on the subject, *Uniform Data Standards for Patient Medical Record Information*, to the Secretary in July 2000. Following further hearings, it sent a letter in February 2002 recommending HIPAA Patient Medical Record Information (PMRI) message format standards. It plans to forward recommendations on HIPAA PMRI terminology standards in late 2003. NCVHS has agreed to serve in an advisory capacity to the Consolidated Health Informatics Initiative, a vehicle for Federal adoption of standards recommended by NCVHS.

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<sup>2</sup>This and other aspects of the Committee's advisory work on HIPAA are described in annual NCVHS reports to Congress on the implementation of the administrative simplification provisions of HIPAA (see Appendix: NCVHS Reports and Recommendations). All NCVHS reports are available on the NCVHS Web site, [www.NCVHS.hhs.gov](http://www.NCVHS.hhs.gov).

## **Improving Privacy Protections**

The Committee views health information privacy protection as a precondition for progress on all information technology applications to improve population health and the health system's efficiency and effectiveness. Privacy protection is also the foundation for health care administrative simplification standards. In February 2000 NCVHS sent the Secretary detailed comments on the Notice of Proposed Rule Making (NPRM) on Standards for Privacy on Individually Identifiable Health Information. In 2001, based on a series of hearings on implementation, NCVHS sent letters and recommendations to the Secretary on five aspects of the proposed rule. These recommendations contributed to an NPRM issued by the Department in March 2002, proposing modifications to the original rule, and to a final revised rule in August 2002. Based on the findings in three public hearings during the autumn of 2002, the Committee wrote the Secretary in September 2002 urging the Department to step up its public outreach for implementation of the final rule, following with detailed suggestions in November. These recommendations informed a December 2002 Guidance issued by the HHS Office for Civil Rights, which is responsible for implementation and enforcement.

## **Advising the Department on HIPAA**

Carrying out its congressionally mandated roles related to HIPAA, NCVHS advises the Department on process and content in the development and implementation of health data standards. It has formed close partnerships with HHS and standards development organizations. The six groups named as Designated Standards Maintenance Organizations (DSMOs) signed a Memorandum of Understanding at a March 2000 Subcommittee on Standards and Security meeting. NCVHS was instrumental in coordinating efforts for extending implementation of the transaction and code sets rule to October 16, 2003, with a focus on submission of implementation plans by covered entities.

## **Better Data on Race and Ethnicity for Eliminating Health Disparities**

The evaluation of efforts to eliminate health disparities, which is an explicit departmental priority, requires race- and ethnicity-specific data that are not currently available. The NCVHS Subcommittee on Populations is a lead advisor to the Department in this area. In recent years it has concentrated on gathering information from the field about their experiences implementing the new OMB Standards for Federal Data on Race and Ethnicity, and more generally about the collection of race/ethnicity data. The Subcommittee is preparing a report elucidating the Commit-

tee's historical and current activities on racial and ethnic data and disparities and consolidating and updating NCVHS recommendations. The report will be released in 2003.

## **Recommending Collection of Functional Status Data**

Functional status information is important in clinical care, public health practice, policy, and administration, enabling understanding across the life span of the effects of people's health conditions on their ability to do basic activities and participate in life situations. The Committee concluded after 18 months of study that the International Classification of Functioning, Disability, and Health (ICF) is the only viable candidate for a code set for classifying functional status in clinical and administrative records. The July 2001 NCVHS report, "Classifying and Reporting Functional Status," recommends a multiyear process, led by HHS, to bring about agreement on the need for this information followed by the selection and testing of a code set for this purpose. The report has been disseminated widely. An issue of *Health Care Financing Review* in 2003 will focus on capturing functional status in administrative records for payment and quality.

## **Plans for 2003 and Beyond**

In addition to the plans noted above and ongoing attention to the implementation of all NCVHS recommendations, the Committee anticipates the following activities in 2003 (see detailed report below for further information):

- The Workgroup on Quality is summarizing testimony before the Committee on improving quality measurement for publication in 2003. The Workgroup will continue to advise the Agency on Healthcare Research and Quality on development of the National Healthcare Quality Report, also scheduled for publication in 2003.
- The Subcommittee on Standards and Security commissioned an assessment of the potential costs and benefits of a proposed transition from ICD-9-CM to ICD-10-CM (diagnoses) and from Volume 3 of ICD-9-CM to ICD-10-PCS (inpatient procedure codes). This assessment will inform the Committee's continued study of the subject in 2003.
- The Committee will continue an effort to strengthen the linkages among its activities and to undertake projects that cut across the purviews of its subcommittees and workgroups. It plans to engage its population health mission by studying the nature and determinants of population health through a series of panel discussions. It also intends to assess NCVHS projects in terms of how they improve population health.

## Introduction

The National Committee on Vital and Health Statistics (NCVHS) is the statutory public advisory body to the Secretary of Health and Human Services and Congress on the information needs underlying health policy. Its mission is to advise on shaping a national information strategy for improving the population's health.<sup>3</sup>

Established in 1949, NCVHS serves as a bridge between government and the health care industry and research and public health communities. These constituencies increasingly rely on the expertise embodied in the Committee, which has built a reputation for thoughtful leadership. NCVHS provides this leadership by carrying out legislatively mandated roles,<sup>4</sup> advising on HHS initiatives, producing influential reports and recommendations, and providing a forum for stakeholders through its meetings and hearings. The subjects in its purview include health care quality, race/ethnicity, standards, privacy, population health, health statistics, and the information infrastructure.

The 3 years since the Committee began its second half-century have seen the onset of a "new millennium" and the tragedies and aftermath of September 11, 2001. Each of these defining events has major implications for health information policy—the first with the opportunities and expectations surrounding a new century, plus the press of "Y2K" computer issues; the second because of the direct assaults on public health and the governmental responses they set in motion. Adding to the changes, the 2000 election brought a new administration with a new HHS Secretary. During this period, as well, the HIPAA process began the transition from rule development to implementation, ending the most intense phase of the Committee's work on standards adoption and freeing some of the Committee's resources to pursue other priorities in the years ahead, along with its continued work on standards implementation.

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<sup>3</sup>NCVHS is composed of 18 individuals from the private sector, selected for their expertise and distinction as researchers, educators, and practitioners in fields including population-based public health, health services, health statistics, privacy and security of electronic health information, health data standards, epidemiology, computerized health information systems, and purchasing or financing of health care services. The Secretary of HHS appoints 16 members and Congress appoints 2, all for 4-year terms. The Committee's Charter, last revised on 1/31/02, is posted on its Web site at [www.ncvhs.hhs.gov](http://www.ncvhs.hhs.gov).

<sup>4</sup>The statute establishing NCVHS as a Federal advisory committee is 42 U.S.C. 242k(k). Also, both the 1996 Health Insurance Portability and Accountability Act (HIPAA) and the Administrative Simplification and Compliance Act of 2002 define roles for the Committee.

The Committee's long practice of working with other organizations and agencies intensified during this period. In 2002 the National Center for Health Statistics (NCHS), the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH) joined the Agency for Healthcare Research and Quality (AHRQ) and Centers for Medicare and Medicaid Services (CMS) in naming liaisons to the NCVHS full Committee and Executive Subcommittee (see [Appendix I](#)). Moreover, all of the Committee's reports and recommendations reflect interactions with stakeholders including private sector organizations, researchers, public health officials at all levels, standards development organizations, and government agencies. Its seven subcommittees and workgroups<sup>5</sup> convened dozens of hearings and panels in these 3 years, with the dual purpose of learning from these constituencies and encouraging more interaction and cooperation among them.

The years 2000–2002 were a highly productive period for NCVHS, which produced 7 major reports and sent 18 letters with recommendations to the Secretary or other members of the Administration. The Committee continued to advise the Department on the development and implementation of HIPAA standards on data, communications, patient medical record information, and privacy. In addition, NCVHS issued recommendations on population health topics, including race/ethnicity and functional status data, and it advised on such government activities as the National Healthcare Quality Report, the National Electronic Disease Surveillance System (NEDSS), the OMB Guidance on race/ethnicity data, and the Consolidated Health Informatics (CHI) initiative. Brief summaries of these activities follow.

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<sup>5</sup>In addition to the Executive Subcommittee, in this period NCVHS had Subcommittees on Standards and Security, Privacy and Confidentiality, and Populations, as well as Workgroups on the National Health Information Infrastructure, 21st Century Health Statistics, and Quality. The Workgroup on 21st Century Health Statistics was discontinued upon completion of its report.

## **Major Accomplishments: 2000, 2001, and 2002**

### **Two Visions**

During this period, two NCVHS Workgroups completed multiyear projects to clarify how emerging information capacities can best be used to promote the Nation's health. Each involved the clarification of a vision—one for a National Health Information Infrastructure (NHII), the other for 21st Century Health Statistics (part of the NHII). Both reports were developed through extensive consultations that delivered the same strong message: HHS should take the lead in collaborative national processes to develop the needed infrastructure. The preliminary reports were presented and discussed at the Committee's 50th Anniversary Symposium<sup>6</sup> and finalized in subsequent years.

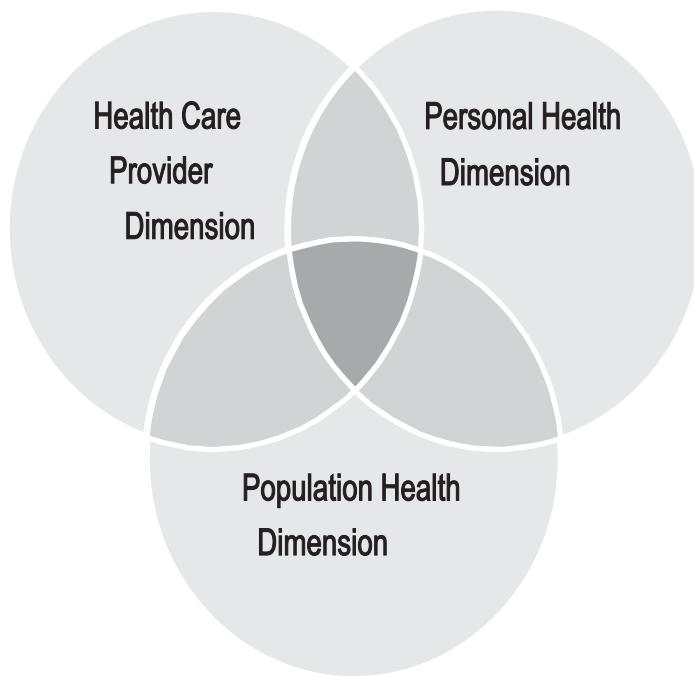
#### **1. A Strategy for Building the National Health Information Infrastructure**

*Information for Health: A Strategy for Building the National Health Information Infrastructure* outlines a vision and a developmental process for a comprehensive, knowledge-based system that can connect health decision makers to sound information and to each other. It reflects expert testimony at four regional hearings. As envisioned, the NHII includes not just technologies but values, practices, relationships, laws, standards, systems, and applications that support all facets of individual health, health care, and public health. It has three equally important dimensions—personal health, healthcare provider, and population health. The dimensions overlap considerably, and some key stakeholders such as public health agencies and health plans have activities in two dimensions. The greatest value of the NHII derives from information sharing and communication among the dimensions, moving in all directions.

The Committee believes that implementation of the NHII will have a dramatic impact on the effectiveness, efficiency, and overall quality of health and health care in the United States. When the infrastructure is realized, it will make it possible to achieve health objectives such as those for national preparedness and health care quality. The interconnections in the NHII will allow much fuller use of the health field's information capacities than is now possible.

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<sup>6</sup>The preliminary vision reports are published, together with a 50-year history of NCVHS, in *NCVHS 50th Anniversary Symposium Reports* (September 2001).



**Figure. Schematic representing functions of the National Health Information Infrastructure (NHII) through 3 interactive and interdependent dimensions**

In the NHII report, NCVHS identifies the human, institutional, and technological factors needed to build the NHII. Responding to the strong message it heard from the field, it recommends a strategy that places HHS, with adequate funding, in a leadership position at the center of a collaborative process involving private and public sectors. What is now slow, fairly random evolution of the health information infrastructure could in this way be transformed into accelerated, coordinated progress in that direction. The Committee envisions the NHII becoming operational by the end of the current decade.

The NHII report and recommendations were released in late 2001 and presented to the HHS Data Council by the NCVHS Chair. He urged HHS to exercise leadership in building the NHII, both by setting priorities and by developing specific proposals for HHS oversight and coordination. The Department has taken the Committee's recommendations under consideration, and HHS staff are identifying opportunities to coordinate activities on the NHII within the Department and with external groups. HHS will host a national conference in summer 2003 to develop an action agenda on the NHII.

The NHII vision already provides a context for developing national health information policy. Several private sector initiatives have embraced the NHII as a framework for their activities. A 2002 report from the

Institute of Medicine, "Fostering Rapid Advances in Health Care,"<sup>7</sup> includes several references to the NCVHS report on the NHII, as well as to its closely related reports on patient medical record information (PMRI) standards (described below). The NHII Workgroup held a hearing in Chicago in July 2002 that further explored implementation of the population health and personal health dimensions.

In response to new concerns about bioterror, in early 2002 the Committee looked at health data needs related to national preparedness. After the full Committee met with an expert panel to discuss these issues, it wrote the Secretary in February 2002 to encourage immediate attention to consistent data standards to enhance national preparedness. The NCVHS letter stresses the importance of continued development of NEDSS for this purpose and notes that the implementation of NEDSS-based systems in each State must be both standards-based and interoperable. A lack of clear leadership and guidance by CDC and the Office of Public Health Preparedness could result in incompatible implementations that would undermine preparedness. In response, the Secretary wrote the Committee in October, stressing the Department's intention to adhere to national data standards and saying that CDC would carefully review the NCVHS recommendations.

### Plans for 2003

- The NHII Workgroup will study issues related to disease registries, surveillance, and NEDSS in the population health dimension, with special attention to national preparedness.
- The Workgroup will gather information on data needs of a personal health record and the implications of a PHR for standards development, privacy, and healthcare practice.
- The Workgroup will continue to monitor NHII-related activities within the public and private sectors and will support strengthened collaboration.
- NCVHS was asked in late 2002 to advise on the Consolidated Health Informatics Initiative. Because of the broad implications of the CHI initiative, the full Committee chose to take on this advisory role rather than delegating it to the NHII Workgroup.

## 2. A Vision for 21st Century Health Statistics

*Shaping a Health Statistics Vision for the 21st Century* aims to transform health statistics activities so they more fully serve population health needs contributing to the development of the Population Health Dimen-

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<sup>7</sup>IOM Committee on Rapid Advance Demonstration Projects, Health Care Finance and Delivery Systems, *Fostering Rapid Advances in Health Care: Learning from System Demonstrations*. J Corrigan, A Greiner, and S Erickson, Editors. National Academies Press, Washington DC. 2002.

sion of the NHII. This report, approved in September 2002, was developed through a 2-year national consultation with more than 200 stakeholders across the United States. National hearings were held during 2001 in four cities to receive input on both the NHII and 21st century interim reports. NCVHS, the National Center for Health Statistics, and the HHS Data Council coordinated the consultations and produced the final report. A basic premise is that to be useful for health and health policy decisions, health statistics must represent all the factors influencing population health—not just all dimensions of population health outcomes (including measures of functional status and well-being as well as disease), but also community characteristics, the natural environment, and cultural and political contexts. Ten principles emerged as essential to developing the health statistics vision, including enterprise-wide planning and collaboration, privacy protections, and continuous evaluation.

NCVHS developed recommendations for translating this vision into practice and attached them to the report. The recommendations target the adoption of an overarching conceptual framework and further articulation of the guiding principles. The top priority, in the Committee's view, is building an integrating and coordinating hub for the health statistics enterprise. This hub would coordinate the activities of the health statistics enterprise, stimulate collaborative efforts, set standards, review and revise the vision, generate new methods and approaches, and protect privacy, confidentiality, and security.

NCVHS recommends four departmental actions to accomplish this priority:

- Assign responsibility and authority for health statistics leadership within HHS to a reconstituted National Center for Health Statistics, supported by a strong Board of Scientific Counselors.
- Establish a national Health Statistics Planning Board with overall responsibility for planning and agenda setting for health statistics in the United States.
- Designate overall responsibility for health statistics planning and coordination activities within each State's government to a single State agency, supported by autonomous State Health Statistics Planning Boards.
- Develop appropriate graduate and in-service training and continuous education addressing all elements of the health statistics cycle.

The report, recommendations, and a summary for policy makers are posted on the NCVHS Web site and were presented to the HHS Data Council in March 2003. Followup on the report was referred to the NCVHS Subcommittee on Populations.

In a related sphere, the Committee began a dialogue with the NCHS Director in 2000 about his need for ongoing external advice. This resulted in a decision by the Center, supported by the Committee, to charter a

Board of Scientific Counselors, with the intent to ensure strong liaison between that body and NCVHS. This represents a major new direction in the Committee's longstanding relationship with NCHS.

### Plans for 2003

- In early 2003 NCVHS will widely distribute print versions of the report and recommendations on 21st century health statistics and the summary for policy makers.
- The Committee will strategize on how to promote implementation of its recommendations.

## Standards for Patient Medical Record Information

*NOTE: This and other aspects of the Committee's advisory work on HIPAA are described in greater detail in annual NCVHS reports to Congress on the implementation of the administrative simplification provisions of HIPAA (see Appendix: NCVHS Reports and Recommendations). All NCVHS reports are available on the NCVHS Web site, [www.NCVHS.hhs.gov](http://www.NCVHS.hhs.gov)*

Electronic medical records are an essential building block for every dimension of the NHII, and the subject of another series of NCVHS reports. HIPAA directs the Committee to "study the issues related to the adoption of uniform data standards for patient medical records (PMRI) and the electronic exchange of such information." In response, the Computer-Based Patient Record Workgroup of the Subcommittee on Standards and Security held 6 hearings over a 2-year period and received testimony from more than 90 experts representing data collectors, users, and standards organizations. The Committee submitted its first report on the subject, *Uniform Data Standards for Patient Medical Record Information*, to the Secretary in July 2000, and presented it to the Data Council in August of that year. The report discusses the need for PMRI standards, explores impediments to their development and implementation, and proposes recommendations to address these impediments.

The Committee followed the July 2000 report with a February 2002 letter to the Secretary with recommendations for message format standards, the first set of HIPAA PMRI standards. Before selecting these standards, the Subcommittee on Standards and Security held further hearings to get input from standards development organizations, health care information system vendors, health care organizations, professional societies, and other potential standards users. After completing its work on message format standards, the Subcommittee on Standards and Security turned its attention to the selection of HIPAA PMRI terminology standards.

During 2002 the Department assumed the lead in chairing an electronic government initiative to support electronic interoperability of clinical data in Federal programs. The Consolidated Health Informatics (CHI) initiative is a vehicle for Federal adoption of standards recommended by NCVHS, which has agreed to serve in an advisory capacity. The Department's CHI Workgroup has a prominent role in orchestrating the adoption by HHS of previous and forthcoming clinical data interoperability standards.

### **Plans for 2003**

- The Subcommittee is gathering information from terminology developers and others, and expects to make recommendations on HIPAA PMRI terminology standards to the full Committee by late 2003.
- The Subcommittee will continue to advise the Consolidated Health Informatics initiative.

### **Improving Privacy Protections**

The Committee views health information privacy protection as a precondition for progress on all information technology applications to improve population health and the efficiency and effectiveness of the health system. Privacy protection is also a foundation for all health care administrative simplification standards.

In February 2000 NCVHS sent the Secretary detailed comments on the Notice of Proposed Rule Making (NPRM) on Standards for Privacy on Individually Identifiable Health Information. In addition to commenting on the NPRM, NCVHS urged Congress in its annual report on HIPAA implementation to build on the framework of the HHS privacy regulation by enacting a comprehensive and balanced health information privacy law that extends privacy protection to all entities that hold individually identifiable health information. It also urged the enactment of antidiscrimination legislation.

During 2000 the Committee held hearings on State privacy laws and on privacy issues related to the Internet and Institutional Review Boards. In 2001, based on a series of hearings on implementation of the final rule, the Committee sent letters and recommendations to the Secretary on the following aspects of the proposed rule: consent requirements, minimum information necessary, research, fundraising, and marketing provisions. These issues had been identified as high priorities by the HHS Office for Civil Rights, which is responsible for enforcing the privacy rule. The Committee's recommendations contributed to an NPRM issued by the Department in March 2002, proposing modifications to the original rule.

After the Department issued a revised final rule in August 2002 (which was generally consistent with NCVHS recommendations), the Subcom-

mittee on Privacy and Confidentiality held three public hearings in Boston, Baltimore, and Salt Lake City on its implementation. The hearings revealed considerable confusion and distress among covered entities about the impending rule, and the need for easier access to better information about implementation. Based on this input, the Committee wrote the Secretary in September 2002 following the first hearing, strongly urging the Department to step up its outreach to the public and covered entities to build readiness for the rule's implementation in April 2003. In a November 2002 followup letter, NCVHS offered detailed suggestions based on all three hearings, calling for better coordination and collaboration; extensive education, outreach, and technical assistance efforts; communication of enforcement plans; and guidance tailored to a variety of groups. The Committee also urged the Department to fund research on the effects of all facets of the Privacy Rule. These recommendations informed the Guidance issued by the Office for Civil Rights in December 2002.

### **Plans for 2003**

- The Subcommittee on Privacy and Confidentiality will continue to advise on and monitor the implementation of the HHS Privacy Rule.
- A priority area for the Subcommittee is privacy issues raised by the migration of personal health records out of traditional health care domains and into others.

### **Advising the Department on HIPAA**

As is evident in the report documenting the Committee's first 50 years, standardization is a long-standing NCVHS priority and is regarded as a prerequisite for the optimal use of information for health. Since 1996 HIPAA has provided the dominant framework for such efforts. Carrying out this congressional mandate, NCVHS advises the Department on process and content in the development and implementation of health data standards. NCVHS works with HHS and the health care industry to communicate the requirements of HIPAA, identify and evaluate existing industry standards for adoption, develop workable rules, and encourage the participation of all segments of the health industry and the adoption of HIPAA standards. Acting primarily through its Subcommittee on Standards and Security, the Committee has developed close partnerships with HHS and standards development organizations (SDOs). The Committee provides a communication link between the Department and stakeholders in industry and the public health and health services research arenas. The Committee also follows the activities of the Public Health Data Standards Consortium, which serves as a mechanism for ongoing representation of public health and health services research interests in HIPAA implementation and other data standards-setting processes.

As part of the transition to standards maintenance, the six groups named as Designated Standards Maintenance Organizations, or DSMOs, signed a Memorandum of Understanding at a March 2000 Subcommittee on Standards and Security meeting, agreeing to a national process to manage the maintenance of HIPAA transaction standards. The DSMO process represents an industry effort to keep the standards current, permitting full public input and a way for disparate constituencies to work together. The Chair of the DSMO process reports to the Subcommittee on an annual basis, and the full Committee comments on and transmits the DSMO recommendations to the Department.

NCVHS was instrumental in coordinating efforts for extending implementation of the transaction and code sets rule to October 16, 2003, with a focus on submission of implementation plans by covered entities. The Administrative Simplification and Compliance Act gave NCVHS responsibility for reviewing a sample of the extension plans submitted and distributing best-practice solutions to compliance problems.

In 2002 the Subcommittee on Standards and Security studied the proposed transition from ICD-9-CM to ICD-10-CM (diagnoses) as well as from Volume 3 of ICD-9-CM to ICD-10-PCS (inpatient procedure codes). The Subcommittee agreed to commission an assessment of the impact of this transition on the health care industry, articulating both costs and benefits.

As noted, the Committee submits an annual progress report to Congress on implementation of the administrative simplification provisions of HIPAA. All reports are posted on the NCVHS Web site.

### **Plans for 2003**

- The Subcommittee will continue its deliberations on code sets during 2003.
- The Subcommittee will continue to consider the need for new and modified standards and review such standards as they are developed.
- The Committee plans to develop the linkages between its standards work and other priorities, notably population health, in the coming years. One example is an expected review of issues related to race/ethnicity data in administrative transactions.

### **Better Data on Race/Ethnicity for Eliminating Health Disparities**

The evaluation of efforts to eliminate health disparities, which is an explicit departmental priority, requires race- and ethnicity-specific data that are not currently available. Improving data relevant to disparities has long been an NCVHS focus, carried out by its Subcommittee on Populations and predecessor groups. The Subcommittee is a lead advisor

to the Department in this area, commenting on HHS initiatives and organizing panels of experts and advisors.

The Committee followed up on a 1999 report on Medicaid managed care<sup>8</sup> by sending letters to the Centers for Medicaid and Medicare Services and the HHS Secretary in 2001, once again encouraging the uniform collection of Medicaid enrollment data (notably, race and ethnicity and other demographic data). It has continued to disseminate the report on Medicaid managed care data to interested organizations. NCVHS commended the Administration for supporting race/ethnicity data collection in the State Children's Health Insurance Program (SCHIP).

The Subcommittee on Populations organized a panel in 2002 to hear panelists' experiences in implementing the new OMB Standards for Federal Data on Race and Ethnicity, especially with regard to Federal surveys. Also in 2002, it held two hearings on collecting race/ethnicity data in health statistics. A hearing in Denver in September, following the Office of Minority Health meeting on Native American Health, focused on issues in collecting data on American Indian/Alaska Native populations and their utility in reducing health disparities. In November the Subcommittee convened a hearing in Philadelphia to learn State perspectives on collection and use of racial and ethnic data.

### Plans for 2003

- The Subcommittee is reviewing past NCVHS recommendations on race/ethnicity data and expects to produce a report in 2003. That report will elucidate the Committee's historical and current activities in this area and consolidate and update its recommendations.

### Recommending Collection of Functional Status Data

A Populations Subcommittee project that culminated in 2001 picked up an important thread of the Committee's 1996 core data elements recommendations.<sup>9</sup> That report was the result of a 2-year evaluation of common core health data sets for enrollment and health care encounters, involving a survey of the health field. The report recommends 42 data elements for standardization and calls attention to 6 priority elements needing further study. Functional status was one of the six.

Functional status information is important in clinical care, public health practice, policy, and administration. The information enables understanding across the lifespan of the effects of people's health condi-

<sup>8</sup>"Medicaid Managed Care Data Collection and Reporting," NCVHS also issued "Health Data Needs of the Pacific Insular Areas, Puerto Rico, and the U.S. Virgin Islands" in 1999. Both were transmitted and presented to the Data Council in 2000.

<sup>9</sup>August 1996, *Core Health Data Elements Report*.

tions on their ability to do basic activities and participate in life situations. What is needed is an effective way to incorporate this information into standardized records.

After 18 months of study, the Committee concluded that the *International Classification of Functioning, Disability and Health* (ICF) is the only viable candidate for a code set for classifying functional status in clinical and administrative records. Its July 2001 report, "Classifying and Reporting Functional Status," recommends a multiyear process to bring about, first, agreement on the importance of collecting the information and, subsequently, selection and testing of a code set for this purpose. It encourages HHS to take the lead in the recommended activities.

The report has been disseminated to target audiences in the United States and internationally, and has been presented at several meetings. One instance was a December 2002 meeting on "The ICF: Potential Influence on Disability and Rehabilitation in Federal Agencies," sponsored by The Interagency Committee on Disability Research and the National Center for Health Statistics.

In response to the NCVHS findings and recommendations on functional status, the Centers for Medicare and Medicaid Services is devoting an issue of *Health Care Financing Review* in 2003 to articles on capturing functional status in administrative records for payment and quality purposes.

## **Data Issues in Quality Measurement**

Quality of care and the information needed to measure and improve quality became a formal part of the NCVHS work plan in 1998 with the establishment of the Workgroup on Quality. The Workgroup has organized some 17 panel discussions, most with the full Committee, on a range of data issues related to quality measurement. The Workgroup is developing a report on the major themes and issues that emerged in these presentations to be released in 2003.

In a related activity, the Workgroup is advising the Agency on Healthcare Research and Quality (AHRQ) on development of the National Healthcare Quality Report, the first edition of which is also due for publication in 2003. The Workgroup held a hearing in Chicago in 2002 to facilitate public comments on the measures used in the AHRQ report.

## **Celebrating 50 Years of Service**

The Committee marked its 50th anniversary in June 2000 with a symposium hosted by the National Academy of Sciences. Attendees included current and former Committee members and staff, policy-makers, government officials, members of the scientific community, and professional association representatives. Then-HHS Secretary Donna Shalala, the Chair of the NAS Committee on National Statistics, the three

most recent NCVHS chairs, and an HHS Data Council Co-Chair all spoke of the Committee's past accomplishments and stressed the growing importance of its contributions. As the centerpiece of the symposium, the preliminary vision reports on the NHII and 21st century health statistics—together called an "information for health strategy" by former NCVHS Chair Don Detmer—were presented, discussed, and validated by participants.<sup>10</sup>

## **Learning From International Experience**

Although the Committee's principal focus has been on the domestic front, the members have sought to stay abreast of relevant health information activities in other countries and international organizations. The NHII and 21st century visions, as well as the Committee's work on PMRI standards, have all been informed by similar efforts in Canada, the United Kingdom, and Australia. The Committee also has followed the World Health Organization's work on international classifications and health systems performance assessment, as well as related departmental exploration of summary health measures.

## **New Agency Liaisons: New and Retiring Members**

Three new agency liaisons became part of the NCVHS process in the latter part of 2002. The Committee welcomed representatives from NCHS, NIH, and CDC, joining the AHRQ and CMS liaisons. At its November 2002 meeting, the Committee also welcomed five new members and said a grateful farewell to four members retiring after many years of distinguished service. New and retiring members as well as agency liaisons are identified in the Committee roster ([Appendix I](#)).

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<sup>10</sup>*NCVHS 50th Anniversary Symposium Reports* (September 2001).

## The Years to Come

Whether the focus is the NHII, health information privacy, standards, health statistics, quality measurement, or population health, the Committee is aware that each of these domains is present in all NCVHS projects. Stimulated by a strategic planning process that began in 2000, the Committee has launched an effort to strengthen these linkages and to undertake more cross-cutting projects. This is compatible with the "One Department" initiative underway at HHS.

The Committee plans to engage its population health mission by studying the nature and determinants of population health through a series of panel discussions in 2003. It also plans to develop a practice of assessing NCVHS projects in terms of how they improve population health. The principle behind these changes is making population health the explicit framework and yardstick for all the Committee's work.

## **Appendix I.**

### **National Committee on Vital and Health Statistics Membership, Staff, Liaison Representatives, and Retirees (April 2003)**

#### **Chair**

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

#### **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, DHHS

#### **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

#### **Membership**

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

Simon P. Cohn, M.D., M.P.H.  
National Director for Health  
Information Policy  
Kaiser Permanente Medical Care  
Program  
Oakland, California

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

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

Richard K. Harding, M.D.  
Interim Chair  
Neuropsychiatry and Behavioral  
Science  
University of South Carolina  
Columbia, SC

John P. Houston, J.D.  
UPMC Health Systems  
Pittsburgh, PA

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

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

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

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

Vickie M. Mays, Ph.D., M.S.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

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

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

Donald M. Steinwachs, Ph.D.  
Chairman  
The Johns Hopkins University  
Bloomberg School of Public Health  
Department of Health Policy and  
Management  
Baltimore, MD

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

#### **Liaison Representatives**

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

Virginia S. Cain, Ph.D.  
Deputy Director  
Office of Behavioral and Social  
Sciences Research  
National Institutes of Health

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

Steven J. Steindel , Ph.D.  
Supervisory Health Scientist  
Public Health Practice Program Office  
Centers for Disease Control and  
Prevention

Edward J. Sondik, Ph.D.  
Director  
National Center for Health Statistics  
Centers for Disease Control and  
Prevention

### **NCVHS Retirees, 2000–2002**

Kathryn L. Coltin, M.P.H.  
Director, External Quality and Data  
Initiatives  
Harvard Pilgrim Health Care  
Wellesley, MA

Kathleen Frawley, J.D., M.S., RHIA  
Director  
Health Information Services  
St. Mary's Hospital  
Passaic, NJ

Daniel J. Friedman, Ph.D.  
Assistant Commissioner  
Bureau of Health Statistics, Research  
and Evaluation  
Massachusetts Department of Public  
Health  
Boston, MA

Kathleen Fyffe, M.H.A.  
Federal Regulatory Director  
Health Insurance Association of  
America  
Washington, DC

Robert M. Gellman, J.D.  
Privacy and Information Policy  
Consultant  
Washington, DC

Paul Newacheck, Dr. P.H.  
Professor of Health Policy and  
Pediatrics  
Institute of Health Policy Studies  
School of Medicine  
University of California, San Francisco  
San Francisco, CA

Barbara Starfield, M.D., M.P.H.  
Distinguished University Professor  
and Professor of Health Policy and  
Pediatrics  
School of Hygiene/Public Health  
The Johns Hopkins University  
Baltimore, MD

M. Elizabeth Ward, M.D.  
CEO, Foundation for Health Care  
Quality  
Seattle, WA

## **Appendix II.**

### **National Committee on Vital and Health Statistics Subcommittees, Memberships, and Staff (February 2002)**

#### **Executive Subcommittee**

John R. Lumpkin, M.D.,M.P.H., Chair  
Simon P. Cohn, M.D.  
Kathryn L. Coltin, M.P.H.  
Daniel Friedman, Ph.D.  
Vickie M. Mays, Ph.D.  
Mark A. Rothstein, J.D.  
Barbara Starfield, M.D., M.P.H.

#### **Ex Officio**

James Scanlon, ASPE  
Marjorie Greenberg, NCHS

#### **Liaisons**

Gary G. Christoph, Ph.D., CMS  
J. Michael Fitzmaurice, Ph.D., AHRQ

#### **Staff**

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

#### **Lead Staff to Subcommittees\***

#### **Workgroup on National Health Information Infrastructure**

John R. Lumpkin, M.D.,M.P.H., Chair  
Jeffrey S. Blair, M.B.A.  
John W. Danaher, M.D.  
Daniel Friedman, Ph.D.  
Richard K. Harding, M.D.  
Clement J. McDonald, M.D.  
Edward H. Shortliffe, M.D.  
Barbara Starfield, M.D., M.P.H.  
Kepa Zubeldia, M.D.

Mary Jo Deering, Ph.D., OPHS\*  
Theresa Krol, CMS  
Steve Steindel, Ph.D., CDC  
Michelle Williamson, NCHS

#### **Workgroup on Health Statistics for the 21st Century**

Daniel Friedman, Ph.D., Chair  
Vickie M. Mays, Ph.D., M.P.H.  
Paul Newacheck, Dr.P.H.  
Barbara Starfield, M.D., M.P.H.

Debbie M. Jackson , NCHS\* (Acting)

### **Subcommittee on Standards and Security**

Simon P. Cohn, M.D., Chair	Karen Trudel, CMS*
Jeffrey S. Blair, M.B.A., Vice Chair	Judy Ball, Ph.D., SAMHSA
Clement J. McDonald, M.D.	Suzie Burke-Bebbe, NCHS
Kepa Zubeldia, M.D.	J. Michael Fitzmaurice, Ph.D., AHRQ
	James Garvie, IHS
	Marjorie Greenberg, NCHS
	Mel Greberman, M.D., M.P.H., FDA
	Stanley Griffith, M.D., IHS
	Betsy Humphreys, NLM
	Rob Kolodner, M.D., DVA
	James Scanlon, ASPE
	William Yasnoff, M.D., Ph.D., CDC
	Members of HHS Data Standards Committee

### **Subcommittee on Privacy and Confidentiality**

Mark A. Rothstein, J.D., Chair	Stephanie Kaminsky, OCR*
Jeffrey S. Blair, M.B.A.	John Fanning, LL.B., ASPE
Simon P. Cohn, M.D.	Gail Horlick, M.S.W., J.D., CDC
John W. Danaher, M.D.	Walter Stone, CMS
Richard K. Harding, M.D.	
Kepa Zubeldia, M.D.	

### **Subcommittee on Populations**

Vickie M. Mays, Ph.D., M.S.P.H., Chair	Susan Queen, Ph.D., HRSA*
Kathryn L. Coltin, M.P.H.	Dale Hitchcock, ASPE*
Eugene J. Lengerich, V.M.D.	Olivia Carter-Pokras, Ph.D., OMH
Paul Newacheck, Dr.P.H.	Aaron Handler, IHS
Barbara Starfield, M.D., M.P.H.	Suzanne Heurtin-Roberts, NCI, NIH
	Cille Kennedy, Ph.D., ASPE
	Jacqueline Lucas, NCHS

### **Workgroup on Quality**

Kathryn L. Coltin, M.P.H., Chair	Stan Edinger, Ph.D., AHRQ*
John R. Lumpkin, M.D., M.P.H.	Gail R. Janes, Ph.D., CDC
Barbara Starfield, M.D., M.P.H.	Leroy Nyberg, Ph.D., M.D., NIDDK, NIH

### **NCVHS Team**

Marjorie S. Greenberg	Marietta Squire
Jackie Adler	Traci Ramirez
Suzie Burke-Bebbe	Gracie White
Debbie Jackson	Michelle Williamson
Katherine Jones	

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

## **Appendix III.**

### **National Committee on Vital and Health Statistics Reports and Recommendations**

2000–2002 (listed in reverse chronological order)

January 17, 2003 NCVHS Comments on Proposed Measure Set for the National Healthcare Quality Report (NHQR) (approved in 2002)

November 2002 Final Report, Shaping a Health Statistics Vision for the 21st Century, with Separate Summary for Policy Makers

November 25, 2002 Letter to the Secretary—Comments on the Implementation of Privacy & Confidentiality Regulations

September 27, 2002 Letter to the Secretary—Comments on Preparations for Implementation of Privacy and Confidentiality Regulations

June 27, 2002 Letter to the Secretary—Comments to the Secretary Regarding the NPRM (CMS-0003-P and CMS-0005-P) Proposing Modifications to the Original HIPAA Transaction and Code Set Standards

April 25, 2002 Letter to the Secretary—Privacy and Confidentiality Additional Recommendations and Response to NPRM

March 1, 2002 Letter to the Secretary—Privacy and Confidentiality Recommendations on Marketing and Fundraising

February 27, 2002 Letter to the Secretary—Recommendations on Implementation of NEDSS

February 27, 2002 Letter to the Secretary—Recommendations for the First Set of PMRI Standards

November 21, 2001 Letter to the Secretary on Research Recommendations as It Relates to the New Privacy Rule

November 15, 2001 Final Report, NHII—Information for Health: A Strategy for Building the National Health Information Infrastructure

October 19, 2001 Letter to CMS on Racial and Ethnic Data Collection

October 1, 2001 Letter to the Secretary on Consent Requirements and Minimum Necessary Provisions as It Relates to the New Privacy Rule

September 2001 NCVHS 50th Anniversary Symposium Reports (Symposium Summary, 1949–99 NCVHS History, and Interim Reports on NHII and a Vision for 21st Century Health Statistics)

July 17, 2001 Report to the Secretary on Classifying and Reporting Functional Status

July 6, 2001 Recommendations to HCFA on SCHIP Data Collection

June 29, 2001 Recommendations to the Secretary on Industry Readiness for HIPAA

June 29, 2001 Letter to the Secretary on DSMO Recommendations for HIPAA

March 22, 2001 Fourth Annual Report to Congress on the Implementation of the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act

March 14, 2001 Letter to Katherine Wallman, Chief Statistician, Office of Management and Budget regarding Provisional Guidance on the Implementation of the 1997 Standards for Federal Data on Race and Ethnicity (December 15, 2000)

February 22, 2001 Letter to the Secretary on Implementation of National Drug Codes (NDCs)

October 16, 2000 Letter to the Secretary on Implementation of Administrative Simplification Final Rules

October 3, 2000 Letter to the Secretary on the Status of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH)

July 6, 2000 NCVHS Report to the Secretary on Uniform Standards for Patient Medical Record Information

March 27, 2000 Third Annual Report to Congress on the Implementation of the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act

February 7, 2000 Recommendations on the Notice of Proposed Rule Making for Standards for Privacy of Individually Identifiable Health Information

## **Appendix IV.**

### **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**

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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**

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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.

#### 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, MD 20782

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**OFFICIAL BUSINESS  
PENALTY FOR PRIVATE USE, \$300**

