NCVHS

60th

Anniversary
Symposium
and History

U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES

60th

Anniversary

Symposium

and History

1949–2009

FOREWORD

Anniversaries, besides being milestones, are like scenic overlooks with views both back over the road traveled and forward toward what lies ahead. In the last few months, the members, staff, and colleagues of the National Committee on Vital and Health Statistics (NCVHS) have relished this vantage point as they celebrated the Committee's 60th anniversary. The high point of a whole series of events was the anniversary Symposium and celebration held on June 17, 2010, at the National Academy of Sciences in Washington, D.C.

This book contains four documents related to the NCVHS 60th anniversary:

- a summary of the June, 2010 Symposium;

- an NCVHS concept paper on future health information capacities, prepared for the 60th anniversary Symposium;

- a 60-year history of the Committee, including a section describing the convocation of six NCVHS Chairs held in September, 2009, as well as historical appendices; and

- a 60-year NCVHS timeline.

We could not pause from our journey for long, though, because the world of health information policy is moving so rapidly and NCVHS has new legislative assignments as well as many other opportunities to contribute to national health information policy. We are already writing the next chapter of The NCVHS Story, focusing on the opportunities for rapid learning in our new electronic environment and the corresponding stewardship for health data and data uses.

At the anniversary celebration, I had the honor of being in the company of six distinguished former NCVHS Chairs, and being handed the gavel by my immediate predecessor, Harry Reynolds. I want to particularly acknowledge Harry's leadership, with great appreciation, along with that of all 17 leaders who have chaired the National Committee since 1949. They have helped NCVHS stay on the leading and visionary edge of health information policy for six challenging decades. The Committee is especially fortunate to have the guiding hand of its Executive Secretary, Marjorie Greenberg, and Executive Staff Director, Jim Scanlon.

It is impossible to acknowledge all the members, staff members, liaisons, and others, present and past, who together have made NCVHS what it is. However, on behalf of the Committee, I would like to single out staff member Debbie Jackson for special thanks for her pivotal roles in planning and spearheading the 60th anniversary events and commemorative film that are described in this volume.

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Justine Carr, M.D., Chair
National Committee on Vital and Health Statistics
September, 2010

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National Committee on Vital and Health Statistics
60th Anniversary Compendium
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Foreword

Summary: NCVHS 60th Anniversary Symposium

Susan Baird Kanaan

Introduction

The special Symposium hosted by the National Committee on Vital and Health Statistics (NCVHS) to celebrate its 60th anniversary was an occasion for pride in past accomplishments and excitement about the new opportunities and challenges facing the nation. Distinguished colleagues, former members, and former Chairs joined NCVHS members, staff, and liaisons for the event, held on June 17, 2010, at the National Academy of Sciences in Washington, D.C.

The Symposium occurred just three months after passage of the Patient Protection and Affordable Care Act (ACA), and focused primarily on the Committee's plans for helping lay the information foundation for carrying out and evaluating these reforms. Both the Symposium program and an NCVHS concept paper written for the occasion explored the robust health information capacities needed to support the changes the ACA and other recent policy initiatives have set in motion.[1]

These new developments promise to add momentum and scope to the striking changes already under way in the health information policy environment. The reports compiled for the 50th anniversary of the National Committee on Vital and Health Statistics are a window into the early days of the information explosion, when health information technology was starting the long transformation of health care and health information policy that continues to this day. A decade later, the discussions and documents marking the Committee's 60th anniversary attest to just how much has happened in a single decade.

To name a few of these developments, in the last decade, platforms were established for administrative simplification and privacy protection; the Office of the National Coordinator (ONC) was established; new bodies were added to the advisory landscape; progress was made toward the national goal of broad adoption of electronic health records (EHRs); early work began on meaningful use of EHRs, the Nationwide Health Information (NHIN), and health information exchanges; health surveys and vital statistics were stabilized after being threatened by underfunding; measuring and improving health care quality became a widespread endeavor; and the health care system was set on the path to new classification systems, ICD-10-CM and -PCS. As the 60-year NCVHS history describes, NCVHS was actively involved in every one of these areas and more, and in some it played a leading role.[2]

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1 NCVHS, "Toward Enhanced Information Capacities for Health," May 2010. (See pages 9–20 of this volume. In addition, all NCVHS reports, letters, and meeting minutes are posted on the NCVHS website, www.ncvhs.hhs.gov.)
2 NCVHS, "NCVHS: Sixty Years of Making a Difference," June 2010. (See pages 21–52 of this volume.)

Two colleagues of NCVHS spoke to the Symposium audience about the Committee's historic and recent contributions from their vantage points in the Department of Health and Human Services. Dr. Ed Sondik, Director of the National Center for Health Statistics, reflected on the ways NCVHS has periodically reshaped itself to "stay ahead of the challenges." He attributed the Committee's continuing impact to this foresight and adaptability. Calling particular attention to its focus on population health and disparities, he urged NCVHS to do further work on the vision for health statistics. He also highlighted these future challenges: deciding what information to collect, improving longitudinal data, strengthening data dissemination in conjunction with better privacy and confidentiality protection, getting data to community level data users, and coordinating and evaluating these and other efforts.

Jim Scanlon, NCVHS Executive Staff Director and a Deputy Assistant Secretary in the Office of the Secretary, underlined Dr. Sondik's comments on the excellence of NCVHS members, leaders, and staff. He observed that the Committee's personnel, combined with its broad and balanced approach to health information policy, are responsible for its high quality work and its realistic and useable recommendations. Several speakers added exceptional productivity and hard work to the list of NCVHS success factors.

Challenges and Opportunities Ahead

There were many references to the accelerating rate of change being spurred by new policy initiatives and the technology revolution. The Committee's recent concept paper stresses the urgency of strengthening national information capacities so that policy goals can be achieved. Harry Reynolds, carrying out his final responsibility as NCVHS Chair, summarized the concept paper for the Symposium audience. He explained that the Committee's excitement about the potential benefits of the ACA and Stimulus legislation[3] is tempered by concerns about whether the necessary information foundation will be in place for implementation and evaluation.

In the Committee's view, national information capacities should be comprehensive and accessible, protective of privacy, and standardized. They should enable not only better clinical care but also more complete population health services and assessment. Realizing the collective potential of all information sources is what will allow the U.S. to maximize the return on the national investments in system reform and health information technology (IT) for the benefit of all Americans. Thus, facilitating the multiple uses of data from a range of sources with the minimum possible burden should be a top priority for health information policy.

Public sector involvement and Federal leadership will be needed to achieve these goals, and NCVHS is ready to help the Department maximize the return on the huge national investments. Mr. Reynolds reiterated the Committee's excitement about these new opportunities to make a difference.

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3   American Recovery and Reinvestment Act of 2010 (ARRA)

Summary: NCVHS 60th Anniversary Symposium

Past as Prologue: Subcommittee Activities and Priorities

The co-chairs of the four NCVHS subcommittees reported on their groups' recent accomplishments and priorities for the future. Taken together, these plans constitute the Committee's road-map for the next few years.

Population Health

Subcommittee co-Chair Dr. Don Steinwachs defined the population health perspective as focusing on the level and distribution of health, populations at risk, and accountability. Over the past decade, the NCVHS Subcommittee on Population Health issued reports and recommendations on classifying and reporting functional status; the data needed to track and eliminate health disparities; the potential benefits of linking federal data sets, with proper protections; and a comprehensive vision for health statistics. While progress has been made in each of these areas, he said, the U.S. has a long ways to go to have granular enough data to understand the highly diverse American population and craft targeted interventions to improve its health.

Dr. Steinwachs agreed with other speakers about the particular need for community level health data for local decision makers to use. He celebrated the apparent convergence of what had once seemed to him to be "two parallel universes," now merging thanks to understanding about how health IT can be used to meet both individual and public health needs. A goal now, he said, is to build a public health information infrastructure that will enable the public and the public health sector to use and benefit from EHRs. The building blocks for such an infrastructure include relevant EHR data, localized data and data use, data linkages, and targeting of at risk populations.

Finally, citing the wide variations in environmental exposures and health services access that produce uneven health outcomes across the U.S. population, Dr. Steinwachs reiterated the importance of evaluating the effectiveness of the new reforms, especially their impact on health disparities. In view of all these priorities, the Subcommittee on Population Health has the following topics on its agenda for the near future: clarifying the policies and resources needed to build information capacities at state and community levels; examining the capacity for data linkages to provide enhanced information on health risks and population health; and examining the opportunities created by the ACA to improve population health through better use of health information.

Quality

Dr. Justine Carr, the outgoing Subcommittee co-Chair, echoed Dr. Sondik with the observation that NCVHS is always "thinking ahead to the next thing" and "focusing on the larger story." To illustrate, she reviewed a 2004 NCVHS report that identified 23 building blocks for assessing health and health care quality. She showed the Committee's continuing work in these areas, right up to the present day, and the progress made on a number of them—for example, the addition of a "present on admission" modifier and a new requirement for functional status reporting. Over the past decade, in addition to producing the 2004 report and a

July 2008 update, the Subcommittee on Quality also held hearings and issued reports and recommendations on the patient-centered medical home and meaningful measures.

Looking ahead to future challenges, Dr. Carr reviewed the recommendations of the December 2009 NCVHS letter on meaningful measurement, which remain priorities for the Subcommittee. The letter stresses the need for national coordination of quality measurement and monitoring, which have been proliferating in recent years with little synchronization of effort. It also recommends optimizing the capture of relevant individual and population health information in EHRs and strategically leveraging new types and sources of health data.

The NCVHS Subcommittee on Quality has identified several other challenges in harnessing the potential for improving health and health care in the U.S. Two major ones are developing leadership and expertise in data aggregation and analysis, and developing methods to acquire outcomes data directly from individuals. Dr. Carr observed that putting individuals at the center of measurement would mean that outcomes assessment would reflect the individual's voice, with functional status included as a measure and satisfaction with the care experience also taken into account.

Standards

Subcommittee Co-Chair Dr. Judith Warren reviewed how the NCVHS Standards Subcommittee had helped lay the health IT standards foundation for the U.S. over the previous decade. It did so primarily by recommending a long list of standards in four large areas: administrative, financial, and billing transactions and statistical use; clinical use; e-prescribing; and clinical documents. Many of the recommended standards were adopted with little or no modification. Besides advising on the standards supporting information exchange in health care and public health, the Subcommittee also studies and recommends ways to simplify implementation and modification. As part of this effort, it has held hearings to assess the health care industry's readiness to implement standards.

Looking ahead, the major challenge in the standards area is a new assignment from the ACA that charges NCVHS with making recommendations on plan identifiers and operating rules. Dr. Warren pointed out that standards must not be thought of in isolation; she outlined a context for standards that includes the NHIN model, public health policy, the data stewardship framework, and the needs of users. Thus, the new assignment has implications for the full Committee.

The Subcommittee also plans to identify and create solutions for gaps in standards and to accelerate adoption of the clinically specific standards mentioned in ARRA as well as the extension of HIPAA standards. In addition, it will work on advancing the integration of clinical and administrative standards and on meeting new health and health care requirements, such as those for medical homes, personalized medicine, health surveys, and syndromic surveillance. Finally, Dr. Warren observed that health IT standards will increasingly be international in

their development and use, requiring new models of collaboration; and tools will be needed to manage versioning and harmonization of standards.

The NCVHS Subcommittee on Standards has articulated a set of principles to guide standards development. Among other things, the principles call for openness in the development process, with input from diverse users, and for structuring standards so they do not constrain innovation.

Privacy, Confidentiality and Security

Co-Chair John Houston reported that NCVHS issued some 20 sets of recommendations on privacy and confidentiality over the past decade. Until about 2006, the Subcommittee on Privacy and Confidentiality focused on the HIPAA Privacy Rule; after that, it turned to the privacy requirements of the NHIN.[4]

Looking ahead, Mr. Houston and his co-Chair, Dr. Leslie Francis, commented on the huge impact that rapid technology change and new forms of data and data access and sharing can be expected to have on privacy and security, raising the bar for needed protections. They offered several thoughts on framing privacy and confidentiality relative to other aspects of health information policy. Mr. Houston spoke of the dynamic equilibrium between the protection of individual rights and the socially beneficial uses of health data. Dr. Francis proposed that because privacy protection can secure public trust, it is best understood as enabling beneficial information and technology uses in health care and public health, not preventing them.[5]

In the near term, the Subcommittee on Privacy, Confidentiality and Security plans to examine and offer recommendations on sensitive information and data stewardship.

In later remarks, Dr. Francis spoke to a major Symposium theme when she asserted that "one of the crucial roles of this Committee is education about how things are changing." She cited recent research showing that while "the Facebook generation really does care about privacy," both they and older Americans "are grievously misinformed about what it means to have a privacy policy."

Special Projects

In recent years, NCVHS also carried out several special projects at the request of the Office of the National Coordinator. The Committee held hearings and generated recommendations on functional requirements for the NHIN, the definition of meaningful use of EHRs, and a stewardship framework for multiple uses of health data. It then built on its work on health data stewardship by publishing an NCVHS Primer to inform a wide range of stakeholders about these critical principles and practices.

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4   Security was added to the Subcommittee's duties and name in 2009.
5   Issues such as these were explored at a March, 2010, conference on "Privacy Law and Ethics Meet Biomedical Informatics," held at the University of Utah School of Law and cosponsored by that institution and NCVHS.

Cross-Cutting Themes

Several Symposium themes stand out as especially salient for the Committee's work in the next few years.

Convergences

The principle of using the same data and data sources for multiple purposes threaded through much of the Symposium discussion. Former Chair Dr. John Lumpkin captured the intent when he reminded the audience of his predecessor Dr. Kerr White's maxim that data must be "touched by human minds" to be transformed into useful information and, ultimately, intelligence. The aforementioned NCVHS concept paper is built around the idea that information and its exchange and use can support both better health care and better population health. A similar vision underlies ONC's new "Element 3" initiative. Several subcommittee co-chairs spoke of the convergences between individual and population-oriented uses of health information and IT. This reality is creating growing overlaps among NCVHS subcommittee domains, a development to which it is paying close attention.

All of these related ideas seem to hinge on the notion of data use—by diverse appropriate users, for multiple appropriate purposes, with adequate privacy protections. While the term meaningful use has lately been framed with particular reference to EHR data, health care, and quality assessment, the principle has broader applications, as well. Given current technologies, a focus on meaningful use seems to lead naturally to thoughts of multiple data uses for multiple purposes, along with attention to the proper privacy protections. NCVHS asserts in its concept paper that a major priority of health information policy should be to facilitate interconnections and enable the multiple uses of health information to meet current and emerging needs—as always, with strong privacy protections.

Localization

Localization of data use was a related Symposium theme invoked by many speakers. NCVHS has long called attention to the need for community-level health data. What is new today is the concurrence of broad interest in getting data into the hands of local decision-makers with the technological capacity and programs that make that possible—notably, the Community Health Data Initiative, described below.

Evaluation

The theme of evaluation arose in several contexts during the Symposium. The issue of overriding concern is the need to evaluate the impact of ACA reforms. As former NCVHS Chair Dr. Don Detmer said, "We are embarking on an historic thing here," and we need to know if the significant national investment produces the desired results. NCVHS argues in its concept paper that the impact of health care reform can only be assessed by looking at the entire population, including Americans who are not receiving health care. And even with the ACA's expanded coverage and greater attention to prevention and quality improvement, health care will continue to represent only one of many influences on health and illness in the U.S. population. Therefore, promoting and assessing national health will always require a wide range of information types and sources.

The new Community Health Data Initiative (CHDI), about which NCVHS was briefed prior to the Symposium, also stimulated a discussion of evaluation. The Initiative is facilitating large scale data dissemination to local users in hopes of stimulating useful new health applications. It is taking an open, innovation driven approach to data access that represents something of a shift from the government's usual stance of rigorous control over data. Symposium participants talked about the evaluation issues this approach raises, touching on privacy and confidentiality, transparency, education, and governmental responsibility. Some suggested that in this context, the government's responsibility lies in evaluating the process of data dissemination and use in order to understand how the data and applications are used and to try and determine whether the information made a difference.

Education and Outreach

The former NCVHS Chairs in attendance had a good deal to say about the final Symposium theme, outreach and education, as described below.

The Case for Outreach and Education: Wisdom from NCVHS "Elders"

The Committee was honored by the presence of five former Chairs at the Symposium, collectively representing 24 years of NCVHS history. Executive Secretary Marjorie Greenberg began by introducing a film featuring excerpts from a roundtable discussion among the former Chairs and others, held in Charlottesville, Virginia, in September 2009. The film, which was a high point of the Symposium, is posted on the NCVHS website. Following the film, Ms. Greenberg invited the former Chairs to share their observations. Because of her own long

history of 27 years with NCVHS, she was able to weave their introductions into a first-person story of evolving Committee leadership. As the 60-year history report notes, this rare continuity of leadership plays a large part in enabling NCVHS to grow into a 60-year old learning community.

Dr. Ron Blankenbaker, who chaired the Committee from 1986 to 1991, began by commending NCVHS for living up to the goal of truly "making a difference." His successors, who echoed this praise, focused their remarks on a topic that was also prominent in their September 2009 colloquium—the importance of education and outreach for the NCVHS mission. Judith Miller Jones (1991–96) asserted that understanding the centrality of information for health would empower the public, physicians, and patients. She suggested as the key message "how good it could be if we used our data better."

Pointing out that a major purpose of information is communication, Dr. Don Detmer (1996–98) encouraged the Committee to consider developing a public education agenda on health information. He also recommended that the determinants of health, global standards, a research agenda, and evaluation be considered for the Committee's future agenda. Dr. John Lumpkin (1998–2004) urged NCVHS to use all available communication tools and technologies to get the message out about its important work. He also added his voice to others' on the importance of getting data to local decision-makers and change-agents. Finally, Dr. Simon Cohn (2005–08) commented on the exceptional quality of the Committee's work; and he, too, encouraged its members and staff to pay attention to how NCVHS "gets out and touches people."

Closing Remarks

The Symposium began and ended with comments from representatives of the Committee on National Statistics (CNSTAT), the National Academy of Sciences permanent committee most closely related to NCVHS and the Academy's host for this gathering. Early in the proceedings, Dr. William Eddy described CNSTAT's work and noted the intersections between it and NCVHS. Later, his colleague, Dr. Connie Citro, aptly characterized NCVHS in her concluding comments: "I could sense the collegiality, the hard work, the service you are all giving—not just to the Department of Health and Human Services but to the nation." She added, "I, as one citizen of that nation, thank you."

Dr. Justine Carr, the incoming NCVHS Chair, closed this 60th anniversary celebration by expressing the Committee's gratitude to Mr. Reynolds for his service as Chair and sending him off with a traditional Irish blessing.

Toward Enhanced Information Capacities for Health

An NCVHS Concept Paper (June, 2010)

Executive Summary

Health care reform and federal stimulus legislation have created an unprecedented opportunity to improve health and health care in the United States. The nation's ability to seize this opportunity will depend greatly on the existence of robust health information capacities. The National Committee on Vital and Health Statistics (NCVHS) is the statutory advisory body on health information policy to the Department of Health and Human Services. On the occasion of the Committee's 60th anniversary, this concept paper outlines its current thinking about the necessary information capacities and how NCVHS can help the Department guide their development.

We are entering a new chapter in the health and health care of Americans. The expansion of health care coverage, the infusion of new funds and adoption of standards for electronic health records (EHRs), and increased administrative simplification offer us the potential to use the enriched data generated to better address our country's health and health care challenges. Having better information with which to measure and understand the processes, episodes, and outcomes of care as well as the determinants of health can bring considerable health benefits, not only to individuals but also to the population as a whole.

To be able to achieve the promise of these new developments, we need to be attentive to the underpinnings of the resulting data, ensuring that they are easy to generate and use at the front lines as well as easy to reuse, manipulate, link, and learn from within a mantle of privacy and security. And it is important to remember that the new data sources are not necessarily a replacement for traditional sources such as administrative and survey data, which play a key role in our infrastructure. Rather, the new sources present an opportunity to augment and enrich traditional sources. While efficiency may be gained by replacing some survey and administrative data with newer, EHR-based data, we must continue to nourish and sustain the traditional data sources that offer unique and irreplaceable information for both clinical and population health purposes.

National health information capacities must enable not just better clinical care but also population health and the many synergies between the two. More specifically, health information policy should foster improved access to affordable, efficient, quality health care; enhanced clinical care delivery; greater patient safety; empowered and engaged patients and consumers; patient trust in the protection of their health information; continuous improvement in population health and the elimination of health disparities; and support of clinical and health services research. A major priority of health information policy should be to enable the multiple uses of data, drawn from the full range of sources, while minimizing burden. Most sources have primary uses for which they were designed; however, with adequate standardization, privacy protections, and technology, the data from many sources can be used for multiple purposes. Realizing the collective potential

of all information sources is what will allow the U.S. to maximize the return on its investments in system reform and health IT for the benefit of all Americans.

As information capacities expand, it is critical that the information be comprehensive, timely, efficiently retrievable, and usable, with full individual privacy protections in place. "Comprehensive" refers to the inclusion not just of traditional health-related data, but also of data on the full array of determinants of health, including community attributes and cultural context. Usability of the data—whether for initial use or reuse—requires a well-coordinated effort to assure the accessibility and availability of information as well as its standardization.

NCVHS will continue to use its consultative and deliberative processes, working collaboratively with other HHS advisory committees, to help the Department meet these opportunities and challenges. Given the rapidity of the changes now under way, we cannot over-emphasize the urgency of this endeavor and the need to move ahead with deliberate speed.

Introduction

Health care reform and federal stimulus legislation have created an unprecedented opportunity to improve health and health care in the United States. The nation's ability to seize this opportunity will depend greatly on the existence of robust health information capacities.[1] To maximize the return on these enormous investments and make it possible to evaluate their impact, health information capacities must be carefully developed with an eye to their uses for improving health care and health for all Americans. New investments in EHRs and health information exchanges are important contributors, especially for clinical care, but the benefits from these investments will be limited unless the synergies with other types of health information are recognized and used. Population-level data from vital statistics systems, surveys, and public health surveillance and health care administrative data are equally important information sources. Assuring that all these sources are adequately developed and supported and can be integrated appropriately is essential to developing the information capacities the nation needs.

The National Committee on Vital and Health Statistics, the Department's statutory advisory body on health information policy, has long assisted the Department in the development of national health information policy, providing thought leadership and expert advice in the areas of population health, privacy, standards, the NHII/NHIN, health care quality, and other areas. Nearly ten years ago, NCVHS put forward a vision for a national health information infrastructure in its 2001 report, Information for Health,[2] followed in 2002 by a vision for 21st century health statistics.[3] Today, as data and communication capacities explode and health care coverage expands, new thinking and visioning are needed to clarify the information capacities that will make it possible to meet our national goals for better health and health care for all Americans. On the occasion of the Committee's 60th anniversary, this concept paper outlines its current thinking about the required capacities and their development.

In 2009, as course-altering legislation was unfolding, NCVHS began to consider how it could assist the Department's development of the necessary information capacities.[4] All four NCVHS subcommittees have contributed to the early thinking on this subject, and all plan further work in their respective domains, as described below.[5] The Committee has crafted a highly effective process for bringing multiple points of view and areas of expertise to bear as it develops recommendations to the Secretary, and this process is well suited to the work that lies ahead. NCVHS will continue to use its consultative process to create venues for dialog, eliciting input and perspectives from stakeholders and experts regard-

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1 We use the term capacities in the sense of the ability to perform or produce. That is, information capacities are understood in relation to specific needs, purposes, and functions of information.
2 NCVHS, Information for Health: A Strategy for Building the National Health Information Infrastructure, November 2001.
3 NCVHS, Shaping a Health Statistics Vision for the 21st Century, November 2002.
4 As part of this process, NCVHS in 2009 commissioned two authors of the 2002 health statistics vision report to help the Committee consolidate and update its recommendations. Their report to the Committee is posted on the NCVHS website. < http://www.ncvhs.hhs.gov/090922p3.pdf>
5 At present, NCVHS has subcommittees on population health, standards, quality, and privacy/confidentiality/security.

ing critical challenges, potential opportunities, and next steps. It will use this external input and its own broad expertise to help the Department develop health information policies that are commensurate with new opportunities and needs. Given the rapidity of the changes now under way, we cannot over-emphasize the urgency of this endeavor and the need to move ahead with deliberate speed.

Information Capacities For Health And Health Care

Public sector involvement in health information has a long history. State, local, and federal agencies have gathered information through vital records, hospital and ambulatory data sets, public health surveillance, population surveys, and other sources to monitor health trends, identify threats, and guide interventions to protect and promote health. Congress initiated a new type of government involvement in 1996 when the Health Information Portability and Accountability Act (HIPAA) recognized the importance of protecting individuals' health care information while improving the efficiency of health care delivery through standardized electronic administrative transactions. Most recently, the American Recovery and Reinvestment Act of 2009 (ARRA) began another type of intervention, providing financial incentives for health IT adoption in the nation's hospitals and physician offices as well as funding for infrastructure support.

While much current attention is focused on the ARRA funding of health IT and critical associated tasks such as defining and implementing "meaningful use" of EHRs, a broader perspective is required to take full advantage of evolving opportunities. Widespread use of optimally configured, standardized EHRs will greatly expand the information available on health care services, users, and providers. However, promoting the health and wellness of the population also requires information about those who have not received health care services, among other things, as well as information on other determinants of health beyond traditional health care, including environmental, social, and economic factors.[6]

In short, national health information capacities must support a broad array of uses and purposes. They include improving access to affordable and efficient quality health care, supporting clinicians in delivering care, empowering and engaging patients and consumers in their care, ensuring patient safety, promoting patient trust, eliminating health disparities, monitoring and improving population health, and supporting health services and clinical research. As these capacities are developed, it is critical that the information being collected be comprehensive, timely, efficiently retrievable, and usable, and that individual privacy be protected.

In the Committee's view, this requires a well-coordinated effort that assures the following:

1. Accessibility and availability of information. The availability of sufficient, timely information from relevant sources must be assured to meet the priority needs of diverse users (including clinicians, consumers, purchasers, payors, researchers, public health officials, regulators, and policymakers) for

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6   See the NCVHS-developed graphic of the determinants of health on page 9 of its report on a vision for 21st century health statistics (see note 3).

taking action and evaluating outcomes. To minimize burden, wherever possible data should be collected once, for multiple appropriate uses by authorized users. Where appropriate, the capacity to connect data from multiple sources should be provided.

2. Standardization. Standardization is necessary to enable interoperability for the efficient collection and timely sharing of information among all types of users. Robust standards should be assured through the definition, application, and adoption of terminologies, codes, and messaging in the areas of reimbursement, public health, regulation, statistical use, clinical use, e-prescribing, and clinical documents.

3. Privacy, confidentiality, and security protections. With the increasing adoption of interoperable electronic health records technology, along with the move toward global access to health data and emerging new uses of data, methods of access and information availability raise significant new and unique privacy and security concerns. Appropriate privacy, confidentiality, and security protections; data stewardship; governance; and an understanding of shared responsibility for the proper collection, management, sharing, and use of health data are critical to addressing these concerns.

Each is briefly discussed below.

1. Accessibility and Availability of Information

In today's world, the boundaries between health care, population health, and even individual personal health management are permeable, and information exchange is increasingly multi-directional. The domains traditionally called "public health" and "health care" are increasingly intertwined, often sharing broad, common information sources and capacities. For example, promoting the health and wellness of individuals and the population requires attention to health determinants including not only the treatment and prevention of disease and the nature of community health resources but also environmental, housing, educational, nutritional, economic, and other influences. Continuously improving the quality, value, and safety of health care involves, among other things, research and knowledge management, meaningful performance measurement, education and workforce development, and support for personal and family health management. Finally, improving health and health care on a national scale requires monitoring and eliminating health disparities and assessing the health status of all Americans, including vulnerable sub-populations.

A major priority of health information policy should be to facilitate these interconnections and enable the multiple uses of information for current and emerging needs. With health IT, complemented by the necessary privacy protections and data stewardship and facilitated by well designed standards, data can be combined to create richer information and used to address a broad array of current and emerging health and health care issues. Realizing the collective potential of all information sources is what will allow the U.S. to maximize the return on its investments in system reform and health IT for the benefit of all Americans.

At present, the major sources of data on health are:

- Surveys (interview and examination) and Censuses

- Public health surveillance data (e.g., notifiable disease reporting, medical device reporting)

- Health care data (EHRs, HIEs, registries, and other such as prescription history, labs, imaging)

- Administrative data (claims, hospital discharge data, vital records)

- Research data (community-based studies, clinical trials, research data repositories)

Another essential set of sources for understanding health is the information on influences on health (including transportation, housing, air and water quality, land use, education, and economic factors) managed by various public and private sector agencies. In addition to all these well-established sources, new ones such as personal health records and computerized personal health monitoring devices are emerging with the potential to contribute to understanding health at individual and population levels. Social networking content has the potential to provide yet another new and novel resource.

Most data sources have primary uses for which they were designed. However, given adequate standardization, privacy protections, and informatics technology, these sources have great potential to be used for multiple purposes. For example, EHR data elements are collected to document and manage clinical care, but also can be used for public health reporting (such as communicable diseases and medication safety) and to evaluate population health and conduct health services research. Surveys are principally for population-level analysis, but survey information also contributes to clinical care. Vital records not only provide information about births and deaths, but also serve as the "bookends" of population health data. Administrative data (ICD-9-CM disease codes and CPT-4/HCPS procedure codes) were initially used for management and reimbursement, but today play a critical role in quality assessment and public health monitoring (e.g., quality and safety indicators and disease prevalence evaluation). As we look to the future, the goal is to leverage all these sources, when appropriate, and expand their utility for understanding personal and population health and their determinants while carefully protecting the confidentiality of the data they contain.

To bring about the needed improvements and efficiencies and draw all possible benefit from the large and growing investment in health IT, the emerging information capacities must enable both more effective and cost-effective clinical services and population health promotion, and their many synergies. This can be facilitated through multi-directional data sharing and linkages to generate information that is comprehensive and broadly representative. It will be critical to break down the silos that now make it difficult to share and connect data. This requires addressing the policy, institutional, technical, and other barriers that contribute to the existing silos. A workforce trained to take advantage of the broader data and informatics capacities is also essential. Detailed local data are needed to enable

understanding of health and health care at local neighborhood, community, sub-population, and other levels of aggregation. Key decisions about health and health care are made at the local level, and we envision the potential to meet these needs in ways not previously possible. Finally, a critical use of population health data, especially with the advent of health care reform, is to assess the effectiveness, comparative effectiveness, and equity of health care.

Because resources are limited and burden must be minimized, information policy must set priorities regarding which data are most important in order to target investments in data collection. As noted, burden can be minimized by collecting data once for multiple uses. At least in the near term, provided that data can be put in the hands of trusted stewards, enhanced administrative data may be a powerful component that reduces the burden of multiple collections. As new capacities come on line, it may be possible to curtail or redirect some current collection activities.

An important criterion is that information, whatever its source, must be meaningful to users. Experience has demonstrated that having relevant data and information available does not ensure that it is accessible in a timely manner and useful form to the full range of potential users. Delays may be created by approval processes or regulatory requirements, as well as by the lack of data handling and analysis capacities that could enable a user to pose a question, indentify relevant data sources, and request a report that is understandable and protects the privacy of data sources. Ensuring access to useful information is a critical part of the challenge. An overarching goal of all these endeavors is to assure that data can be converted into information and ultimately into knowledge that can answer the priority questions about personal and population health in the U.S. and enable effective decisions and actions to improve them.

2. Standards for Interoperability, Usability, Quality, Safety, and Efficiency

The purposes of health information standards are to ensure the efficient, secure, safe, and effective delivery of high quality health care and population health services; to support the information exchange needs of health care, public health, and research; and to empower consumers to improve their health.

The impending implementation of the next generation of HIPAA standards, the enactment of The Health Information Technology for Economic and Clinical Health (HITECH) Act in 2009, and the recent signing of health reform into law are creating an unprecedented convergence of driving forces, foundational components, technology advances and capabilities, and regulatory requirements. Together, these assets can help create a common national pathway toward achieving the vision and policy priorities of a 21st century health system that relies on a strong health information and health information technology foundation. The past five years have seen a remarkable transformation in the adoption and use of standards for electronic exchange of health information. The transformation encompasses privacy and security standards, standards for administrative and financial transactions, the establishment of unique identifiers, and more recently the adoption of standards for codifying, packaging, and transmitting clinical information between and across health care organizations. This rapidly evolving transformation is moving us closer to the ideal of a fully interoperable electronic health information collection and exchange environment that supports all functions and needs of the country's health and health care ecosystem, as discussed in the previous pages.

Data standards provide a key architectural building block that supports the collection, use, and exchange of health information. Health information standards have been developed and are being adopted and implemented in many different areas. Capturing information in codified format through standard representations such as clinical vocabularies and terminologies, code sets, classification systems, and definitions is a key strategy for achieving semantic interoperability. The inclusion of standardized metadata, which describe characteristics of the data such as provenance, increases the potential for assessing the reliability and validity of the data for aggregation, research, and other uses. Organizing and packaging data through defined electronic message and document standards to be accessed and exchanged via standardized electronic transport mechanisms and protocols achieves access and exchange of health information. The availability and integrity of health information is protected and ensured through the deployment of security standards, thus guaranteeing confidentiality and privacy of protected health information. Finally, the certification of health information technology for Meaningful Use depends on the wise deployment and use of health information standards.

3. Privacy, Confidentiality, Security

With the move toward the management of health data in electronic form, there is a significant opportunity to enhance health data access, utility in patient care, and important secondary uses. The opportunity is further enhanced through the emergence of new methods to exchange health data, both on a regional and national basis. However, the ability to realize the potential of electronic health data depends greatly on ensuring that uses are appropriate and individuals' reasonable privacy, confidentiality, and security expectations are met.

Individuals should have the right to understand how their health data may be used, and to provide consent where appropriate. Often, consent is difficult, as not all uses are known at the time the health data are collected. Further, standards do not yet exist to track an individual's consent as data are exchanged. Although many of the population health uses described in this concept paper involve aggregated or de-identified health data, legitimate concerns exist about group harms and possible re-identification. In addition, the possibility of using health data from emerging information sources, such as personal health record systems, raises unique privacy concerns.

NCVHS has discussed many of these privacy challenges in numerous reports and letters to the Secretary. Most notably, NCVHS published two reports, a *Primer* on health data stewardship[7] and *Recommendations on Privacy and Confidentiality, 2006–2008*. Both are available on the NVCHS website.[8]

Further work is necessary to develop the privacy, confidentiality, and security standards that should apply as these data uses continue to evolve. In addition, work is needed to establish governance structures to provide the proper oversight of entities that exchange and use health data. In essence, governance is the accountability for ensuring that proper data stewardship (as described in the NCVHS *Primer* cited above) is practiced. To differentiate between governance and data stewardship, data stewardship is focused on the internal practices of the entity that uses health data, whereas governance is focused on the oversight of such entities to ensure that their data stewardship practices are adequate. Such oversight includes initially approving entities that have access to data, ensuring that such entities appropriately use and protect data, and ensuring that entities that misuse data are appropriately sanctioned.

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7   An NCVHS Primer: Health Data Stewardship—What, Why, Who, How, December 2009.
8   http://www.ncvhs.hhs.gov/

The Way Forward

Taken together, today's emerging policy opportunities and the nation's long-standing health challenges create a situation of considerable urgency for the United States. The openness to bold new approaches offered by recent legislation will disappear quickly. Given that the U.S. lags behind most other industrialized countries in the health status of its citizens, we must seize the opportunities to maximize the health benefits and begin to assess whether the huge investments are indeed having the desired impact.

This paper has noted the critical federal role in devising health information policy to support national health goals. Federal leadership is more needed than ever to create the comprehensive approaches that will guide the development of information capacities and coordinate efforts by actors in the public and private sectors. Whatever progress is made in the critical transition to electronic health records, clinical data alone will not suffice; broad information capacities that draw on all the sources and serve all the purposes discussed in this paper will be necessary. This will require shoring up the data resources for public functions such as surveys, safety surveillance, and vital records, along with strategic thinking to determine what capacities will be needed in the future and how to guide their development. Many issues require research and demonstration as part of a prioritized, adequately funded research agenda. In addition, further investments in a trained workforce are needed, to ensure the availability of professionals and leaders who can properly use information resources for analysis and decision-making.

As it develops policies and strategies, the Department has always invited input from experts and stakeholders; and NCVHS has long helped to facilitate this dialogue and distill the key messages and lessons. NCVHS will continue to use its consultative and deliberative processes, working collaboratively with other HHS advisory committees, to help the Department meet the current opportunities and challenges. As noted, all NCVHS subcommittees plan to be involved in this effort; this report is an early installment on subcommittee and full Committee work plans for the coming 18 months or more. Each of the subcommittees is identifying the key issues in its domain, to be pursued through workshops, hearings, and internal deliberations as NCVHS develops recommendations for the Secretary. The subcommittees' preliminary thinking is outlined below.

Subcommittee in Quality

Over the next two years, the NCVHS Subcommittee on Quality will focus on supporting the development of meaningful measures, leveraging both existing and emerging data sources (e.g., patient-generated data, remote monitoring, personal health records), and in particular identifying significant opportunities and gaps. Critical to meaningful measurement is the availability of relevant data elements that could be easily captured using certified EHR technology and functionality, among other tools. The Subcommittee on Quality will identify emerging health data needs for a health system where the individual engages in his or her health and health care. As a near-term priority, the Subcommittee will address the data needs of person-centered health and health care, emphasizing coordination and continuity of care across a continuum of services. A longer term goal is to develop a national strategy to leverage clinically rich health data to address important national questions about determinants of health and disease.

Subcommittee on Privacy, Confidentiality and Security

The NCVHS Subcommittee on Privacy, Confidentiality and Security will focus its efforts on providing recommendations that support national priorities, in coordination with such groups as the ONC HIT Policy Committee's Privacy and Security Workgroup. In the next year, the Subcommittee plans to develop recommendations regarding governance as well as a framework for the identification and appropriate management of sensitive data. The Subcommittee will also consider transparency and the role of patient consent. In addition, it will continue to review and make recommendations regarding new privacy, confidentiality, and security regulations; compliance with these regulations; and strategies for effective enforcement.

Subcommittee on Standards

Health care reform legislation now provides a new opportunity to continue the administrative simplification that began under HIPAA—a process in which NCVHS will remain heavily involved. The NCVHS Subcommittee on Standards will continue to meet its responsibilities related to HIPAA; will implement the many administrative simplification responsibilities assigned by the Health Reform Act of 2010; and will meet new requests for recommendations on the use of standards to enhance interoperability of the transmission and semantics of health data as they arise. As we look to the future, several goals stand out with respect to standards. The Subcommittee will seek to ensure a comprehensive framework and roadmap for health information standards that support the national health IT strategic framework, vision and policy priorities; the public health policy agenda; the NCVHS proposed data stewardship framework; a national research agenda that includes comparative effectiveness; and the needs of all data users.

Subcommittee on Population Health

Understanding the population's health and its determinants relies on multiple data sources, including population surveys, clinical data, administrative data (notably, birth and death records and billing data on use of health services), and public health and environmental reporting systems. At the national level, Federal agencies such as the National Center for Health Statistics are charged with developing methods, assessing validity, and reporting national population health information. As we envision building a comparable capacity for communities and states across America, the quality of information and its timeliness will be central to success. The Subcommittee on Population Health will focus on facilitators and barriers to data linkage at state and local levels as a critical part of health information infrastructure, specifically linking EHR data with existing administrative and local survey data. Fundamental to understanding population health is describing the underlying population, which also comprises those who have not seen a doctor recently or have refused to respond to a survey. The work of the Subcommittee will focus on methods to ensure that linked data sources provide valid health information, including methods to adjust for missing data and methods to protect privacy.

The National Committee
on Vital and Health Statistics:
Sixty Years of Making a Difference

—A History—

Susan Baird Kanaan

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Introduction

At a 2009 gathering of six National Committee on Vital and Health Statistics (NCVHS) Chairs,[1] former Chairs John Lumpkin, M.D., and Don Detmer, M.D., recounted how the NCVHS vision of a National Health Information Infrastructure (NHII) created an "aha moment" that proved transformative for the nation. The setting was a special 2002 Institute of Medicine (IOM) meeting on rapid advancement in health care, called by Tommy Thompson, then the Secretary of Health and Human Services (HHS). NCVHS had published its recommendations for the NHII[2] in November 2001, just two months after the nation was consumed by the events of September 11, 2001. It was several months before NCVHS leaders were able to draw the Department's attention to the report. The moment arrived when the two Chairs told Secretary Thompson about the report at the IOM meeting, setting in motion a chain of developments that is still unfolding.

> *I think NCVHS has been most successful when it has been able to frame the issue in a way that creates an "aha moment." Don and I were present for a big one.*
>
> *— John Lumpkin*

This episode was unusual in terms of its dramatic results; Dr. Detmer said, "I've never seen anything quite like it, before or since." At the same time, it aptly illustrates what a federal advisory Committee, and specifically NCVHS, can do when the advice and the timing are right.

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1   The Convocation of NCVHS Chairs, held in Charlottesville, VA, on September 24–25, 2009, is described in detail starting on page 49.

2   NCVHS, Information for Health: A Strategy for Building the National Health Information Infrastructure, DHHS/ODPHP/NCHS-CDC, Washington D.C., November 2001. http://www.ncvhs.hhs.gov/nhiilayo.pdf>

> *We had a vision about what health IT could do for health care and for health, public health surveillance, and care delivery broadly. Information for Health came out in 2001. It was a sweeping vision. Now, most components have been accepted, but at first, it didn't get much attention. But at the IOM meeting, sitting with the Secretary, Don Detmer and I had a chance to talk about health IT. And as we began to talk about the vision of information to improve the quality of care and interface with population health and the health care system, we saw the Secretary's eyes begin to light up. This was a major transition point.* —John Lumpkin

> *When Secretary Thompson heard from us about the NHII vision at the IOM hearing, he almost exploded out of his chair! And then things started moving.* —Don Detmer

The federal government has hundreds of committees that advise it on a full range of issues. Few have as long a history as NCVHS, the statutory public advisory committee on health information policy to the Secretary of HHS. Since 1949, the Committee has maintained a close advisory relationship with the Department, its agencies and predecessors, working together on the major health data policy issues facing the nation. The simple principle underlying this relationship is that good public policy absolutely depends on good information. NCVHS has contributed to the development of the International Classification of Diseases (ICD), developed the standards foundation that now supports the emerging National Health Information Network (NHIN) and the meaningful use of health information technology (IT), made recommendations on the data aspects of many pressing national health issues, and advised on surveys and other data collection efforts.

NCVHS is known for the expertise of its members and leaders and the high caliber and impact of its recommendations. The members, who come from all regions of the U.S., serve one or more four-year terms. Sixteen are appointed by the HHS Secretary, and two by Congress. They are selected for their professional distinction as researchers, educators, and practitioners in such fields as population-based public health, epidemiology, clinical practice, health services, health economics, privacy, health statistics, health information systems, and health data standards.

NCVHS is also known for the open and effective process through which it develops recommendations on complex health information policy issues, drawing on testimony gathered primarily at NCVHS hearings. The process enables NCVHS to bring multiple perspectives to bear as it crafts its recommendations to the Secretary. Bridge is the common metaphor for this advisory function; but the term does not do justice to the Committee's creative and catalyzing role as it develops policy recommendations and connects government to non-governmental stakeholders. The external input, together with the broad-based approach NCVHS brings to all the topics it addresses, contrib-

> *The government needs input from the real world outside Washington.*
>
> —*Ron Blankenbaker*

utes to the Committee's substantive, thoughtful reports and recommendations on a wide range of policy issues. Because of widespread respect for the high quality of its analysis and recommendations, the Committee's advisory role and influence extend beyond HHS and the Federal Government to other levels of government and the private sector.

Over the past decade, NCVHS has had standing subcommittees in the domains of population health; standards; privacy, confidentiality and security; and health care quality.[3] The full Committee holds four two-day meetings a year. In addition, its subcommittees conduct workshops and hearings throughout the year. All NCVHS meetings are open to the public, and most are broadcast on the Internet. NCVHS recommendations, letters, and reports are developed by subcommittees and workgroups and ultimately brought before the full Committee for review, modification, and approval.[4] Transcripts and minutes of NCVHS meetings and all its official letters and reports are posted on the NCVHS Web site. In addition, the entire history of NCVHS is well documented. There are annual or multi-year reports from 1949 through 2006, and longer retrospectives marking the 15th, 20th, 45th, and 50th anniversaries. The serious student of NCVHS and evolving health information policy can find details and commentary in these reports, and particularly in the 50-year history. The Forewords to the reports for the years 1992–95 are especially resonant with the issues being addressed in the current health care reform initiative.

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3   Early in that decade, NCVHS also had Workgroups on the NHII and 21st Century Health Statistics.

4   The process of developing NCVHS recommendations begins with the selection of experts and thought leaders who can give multiple perspectives on a given topic or set of issues. Hearings involving these informants are generally held at the Subcommittee level, with time allowed for both testimony and questions. The Subcommittee or Workgroup then discusses the input to determine if it can develop meaningful recommendations or needs additional input or research. Draft recommendations are reviewed with NCVHS staff and members; escalated from the Subcommittee/Workgroup to the Executive Subcommittee; and finally reviewed and approved by the Full Committee before the final version is sent to the Secretary.

The present report begins with a brief review of the first fifty years. Its chief focus is the major events, accomplishments, and themes of the past decade, 2000–2009, thus completing the documentation of the Committee's first 60 years. It concludes with a summary of the 60th anniversary Convocation of Chairs and a look at the opportunities and challenges that lie ahead. These final sections bring in the voices of the six Chairs who have led NCVHS since 1986, with insights on how the Committee can best contribute to health information policy in the years to come.

> *There is a lot of synergy, mutual respect, and learning among NCVHS members and between them and staff. The members learn a lot about what's going on within government that they can take and use in their work. Conversely, the Department learns a lot about the private sector. Over the years, we've expanded this synergy by adding liaisons and more diverse staff from many HHS agencies and the VA.*
>
> *—Marjorie Greenberg*

The First Fifty Years 1949–1999

Over its six decades, NCVHS has generally moved toward increasing scope, authority, and credibility and an ever stronger advisory relationship with the Department. It has also developed stronger connections to the private sector and non-governmental organizations.[5] Throughout, the Committee has worked to carry out its mission of informing a federal strategy for improving the population's health. Fundamentally, the Committee's work can be viewed as an ongoing effort, achieved mostly in small increments, to establish the information and communication platform for improving and assessing the health of every individual, population group, and community in the U.S.

NCVHS was created in 1949 at the request of the World Health Organization (WHO) as part of an international effort to build national and international health statistics. NCVHS was charged with advising the Surgeon General of the U.S. Public Health Service on matters relating to vital and health statistics. In the early years, NCVHS members and consultants were mostly statisticians, from both the public and private sectors. They worked primarily with WHO on the technical intricacies of building an international health statistics infrastructure and contributed to the expansion of international statistics to encompass morbidity as well as mortality.[6] In this context, in 1950 NCVHS began to call for better data on illness in the U.S. Its initial work on the U.S. information infrastructure was crucial in the development of the National Health Survey.

5   The details of the Committee's evolution are described in the fifty-year history of NCVHS. See especially "A Scan of 50 Years" in "The National Committee on Vital and Health Statistics, 1949–99: A History," published in *NCVHS: 50th Anniversary Symposium Reports.* <http://www.ncvhs.hhs.gov/50history.htm>
6   Dr. Lowell Reed, Vice President of Johns Hopkins University, was the Committee's first Chair. Its first Executive Secretary, Dr. I.M. Moriyama, was on the staff of the National Office of Vital Statistics, which became the National Center for Health Statistics (NCHS) in 1960.

The Committee adopted a more domestic focus starting in 1964, following a 15th anniversary conference that highlighted such still-active concerns as the dominance of administrative data; the need for data on communities, socio-economic status, race, and chronic disease; and the rising cost of health care. International classification issues continued as an interest, especially during the periodic revisions of the ICD. The Committee is known for its work to develop uniform minimum data sets, beginning in 1969. (This is just part of the large legacy of Kerr White, M.D., who chaired NCVHS from 1975–1979.) In 1974, a new legislative mandate authorized the Committee to actively advise the Secretary of the Department of Health, Education and Welfare (renamed the Department of Health and Human Services in 1979). The 1974 mandate was the first of a series of expansions of the NCVHS size and charge over the next three decades.

Standards development has been a signal activity of the Committee since its inception, and particularly since 1970 when NCVHS began a long effort to develop and promote common data standards, terms, and definitions. The ensuing years featured many milestones: minimum or uniform data sets for hospital, ambulatory, and long-term care; recommendations on core health data elements; and a key role in administrative simplification activities. Increasing consultation with private sector organizations and growing partnership with the Department were hallmarks of these efforts.

> *[Standardization] is the best way to ensure cooperation and also provide flexibility for individual and local needs. With the advent of new technology, data can be collected in any format, aggregated by the computer and arrayed in any desired output format. This important distinction between forms for data acquisition, computer systems for data processing, standards and guidelines should be clearly stated. To do otherwise is to promote confusion and, as industry has found, increase the costs of collecting masses of data untouched by human thought!*
>
> *—Kerr White (Congressional testimony, 2/19/74)*

In the 1980s, NCVHS began work on improving the collection, analysis, publication, and interpretation of health care data. It collaborated with the Department's Health Data Policy Committee and, increasingly, with the Health Care Financing Administration, which was created in 1977 and was later renamed the Centers for Medicare and Medicaid Services. NCVHS also continued its work on minimum data sets, including one for long-term care, and addressed critical and neglected areas of minority health and community health statistics. Concerns about the quality of cause of death statistics led NCVHS to sponsor two national workshops and an educational exhibit for physicians on improving cause of death information. Under the leadership of Dr. Ron Blankenbaker, NCVHS sought out more interaction with the private sector and worked to strengthen and integrate the activities of its subcommittees, creating a new Executive Subcommittee and establishing social traditions to build connections among members. The Committee

also began to speak out about an issue that is still live today: the multiple uses of health data and the need to ensure that the data and uses are appropriately suited to each other.

The dynamic environment of the early 1990s, when Judith Miller Jones took over as Chair, took NCHVS in new directions. Ms. Jones used her knowledge of the intricacies of policy development to help NCVHS provide relevant advice during the health care reform efforts of 1993–4. The Committee called for mechanisms to ensure the monitoring of new modes of health care delivery and their outcomes, and also urged the protection of national surveys and other traditional methods of evaluating the nation's health. Besides helping to identify critical data needs and gaps, the Committee also initiated a review of privacy and confidentiality issues in health data that culminated in a 1992 report. In ways, the report foreshadowed the HIPAA assignment to NCVHS of an advisory role in this area.

> *We saw our role as relevant to both surveys and data sets, across the board. We changed the Committee's orientation away from technical issues alone to putting data concerns into a broader, Department-wide policy context. We worked hard to reach across different parts of the Department and get more engagement.*
>
> —*Judith Miller Jones*

NCVHS leaders had extensive discussions with the Department about the Committee's role in 1995–96. One result was the formation in 1995 of the Data Council, which provided a mechanism for closer collaboration with the Department and stronger support for NCVHS. In a related development, the Office of the HHS Assistant Secretary for Planning and Evaluation joined NCHS in supporting and staffing NCVHS. Around this time, the Committee conducted a large project on core health data elements, requested by HHS, and successfully recommended the addition of External Cause of Injury Codes (E-codes) to hospital records despite opposition from the tobacco industry. It also provided important advice to the Department about the implementation of coding changes on race, ethnicity and socioeconomic data in health records, particularly with regard to the revision of OMB classifications.

To mark its 45th anniversary, NCVHS held a symposium in 1995 that focused on the changes under way in health care delivery and health information systems. The Committee wanted to call the nation's attention to the critical role of information for federal and state policy and to stimulate a discussion of the kinds of public-private partnerships needed to promote information for health.

For NCVHS, as for the health care industry, HHS, and others, 1996 was a pivotal year because of the passage of the Health Insurance Portability and Accountability Act (HIPAA). Don Detmer, M.D., assumed the chair role from Judith Miller Jones that year, after a rather extensive set of conversations with the Department about the future perspective for the Committee. A new opportunity was created for the NCVHS Chair to participate in the Data Council, to relate NCVHS deliberations directly to the Council and serve as a direct conduit back to the Committee. The HIPAA legislation expanded the NCVHS charter and gave the Committee explicit responsibility for advising the Department on standards in three areas: for electronically transmitted administrative and financial transactions in health care, for patient medical record information, and to protect the privacy and security of the information. HIPAA also mandated a regular NCVHS report to Congress on implementation of the HIPAA privacy protection, administrative simplification, and standards adoption provisions. The first such report was issued in February 1998.

> *HIPAA implementation... was really a challenging time. Our job was to work with the Department. It was a close partnership with the staff of various HHS agencies and the VA, trying to develop what HIPAA implementation should look like. We served as the external voice, the hearing apparatus in developing the rules, and the external reviewer when the rules were developed.*
>
> *—John Lumpkin*

Even before the enactment of HIPAA, the Committee had called for a focus on the purposes to be served by standards and urged that privacy protections be commensurate with the growing power of information consolidation and exchange. Indeed, the period that began in the 1990s was largely dedicated to understanding, implementing, and adjusting to the dramatic impacts on the public health and health care sectors of electronic technology—the greatest innovation in communications since the invention of the printing press.

The Committee's population health initiatives during the 1990s focused on Medicaid managed care data, data on the islands & territories, monitoring revision of OMB Directive 15 on race and ethnicity data and implementation of its successor, and data on care provided in settings such as long-term care facilities and individuals' or nursing homes. 1998 brought the completion of the first phase of administrative simplification assignments, plus progress on two large-scale visioning projects on the future of health statistics and the NHII. In that year, Dr.

> *A key success factor of being Chair is understanding that there is a divide to be bridged between population health and health care, and that bridging that divide can make both systems operate better.*
>
> *—John Lumpkin*

Detmer handed the gavel to Dr. Lumpkin, who would lead the Committee into the 21st century.[7] The Committee unveiled its visions for 21st century health statistics and the NHII at its 50th Anniversary Symposium in June 2000. Dr. Lumpkin has observed that the biggest challenge for NCVHS during this period was working out "how to merge our new charge, dealing with health care IT, with our longstanding charge related to population health activities." He calls these, respectively, the left and right brains of NCVHS and says, "We worked as a Committee to use both our left and our right brain."

2000–2009–The Sixth Decade

While the year 2000 did not bring the technology crisis that many had feared, in the health information policy environment it still marked a watershed worthy of a new millennium. For much of the decade, the national health surveys and vital statistics that are the foundation for population health data were endangered by underfunding despite a series of unprecedented public health and safety disasters. The landmark IOM reports on the chasm in health care quality stimulated a multitude of quality measurement and improvement efforts.[8] Progress toward health IT adoption and the realization of the NCVHS vision for the health information infrastructure accelerated markedly, with the growing involvement and support of the administration. President Bush gave this process a significant boost in 2004 by setting a national goal for all Americans to have electronic health records (EHRs) by 2014.

New advisory bodies entered what had been "NCVHS space": the NCHS Board of Scientific Counselors, the American Health Information Community, and advisory committees on health information policy and standards.

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7 While there has been progress on many fronts since HIPAA was enacted, one need that is unmet to this day is for a uniform way to associate an individual's health data to facilitate his or her care. As recounted in the 50-year history, NCVHS made its first recommendation in this area in the 1970s.
8 Institute of Medicine Board on Health Care Services, Washington, DC: To Err is Human: Building a Safer Health System (November 1999); Crossing the Quality Chasm (March 2001), Preventing Medication Errors (July 2006).

After President Obama's January 2009 inauguration in the early stages of a deep recession, new legislation infused funding that promised to greatly accelerate health IT adoption.[9] The Committee's decade ended with strenuous efforts to expand health care coverage and bend the cost curve, championed by the new President.

Over this ten-year period, health IT became more and more integrated into every NCVHS domain. Much of the Committee's advising focused on the potential and the limits of health IT with respect to privacy, quality, standards, and population health. A growing emphasis was the pressing need for health data stewardship to permit multiple uses while affording adequate protections. The Office of the National Coordinator for Health Information Technology (ONC), which was established in response to an NCVHS recommendation, assigned four special projects to NCVHS in this period. Two of them cut across the standing subcommittees, making it necessary to organize members into ad hoc groups (see Appendix 2). NCVHS also continued its work on HIPAA, which by the end of the decade had somewhat receded in the time and attention it required from the Committee.

> *As the environment changes, NCVHS has a structure to stay in and the flexibility to build our own leadership and reconfigure our team. The Committee's structure, respect, and focus provide stability in the midst of change. Being a trusted voice is the most important thing. The NCVHS process itself adds to that trust. We're a public Committee, and everything is in the open. We hear all sides of a story and try to come out with the common good. This has been part of the history of NCVHS, regardless of the subject.*
>
> *—Harry Reynolds*

Over all, the major areas of work for NCVHS in its sixth decade were the information policy issues related to health IT and the NHII, meaningful use of EHRs, health care quality measurement and reporting, data stewardship, population health, privacy and confidentiality, security, and standards. The sections below outline NCVHS projects and recommendations in each of these areas. Of course, many issues that remain on the NCVHS agenda—including linkages, privacy, quality, diversity, standardization, and ICD codes—are longstanding concerns on which the Committee has worked for decades.

Dr. Simon Cohn began a four-year term as NCVHS Chair in 2005, bringing unusual continuity to his role after having already served as an NCVHS member since 1996. He was succeeded in 2008 by Harry Reynolds, who, like Dr. Cohn and his predecessor Dr. Lumpkin, had chaired the Subcommittee on Standards prior to becoming NCVHS Chair. Mr. Reynolds has likened the fast-moving policy environment in which NCVHS now operates to "drinking out of a barrel,

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9   ARRA Division A. Title XIII – Health Information Technology and Division B. Title IV – Medicare and Medicaid Health Information Technology. Miscellaneous Medicare Provisions are collectively cited as the Health Information Technology for Economic and Clinical Health (HITECH).]

not a glass." He credits the contributions of all of his predecessors and NCVHS staff for the fact that NCVHS is a trusted voice in this environment.

The Committee marked the end of another decade of accomplishments by gathering the current and five previous NCVHS Chairs in Charlottesville, VA, in September 2009 to celebrate the first 60 years and reflect on the significance of NCVHS and how it can make the greatest difference in the future. That event is described below (page 49).

Refining the Vision for a National Health Information Infrastructure

As noted, NCVHS released its landmark report, Information for Health: A Strategy for Building the National Health Information Infrastructure, in late 2001. Work on the vision had begun during Dr. Detmer's tenure (1996–1998), with the NHII Workgroup (which he chaired) spearheading the process. The vision continues to ramify and be shaped to this day. The policy vision for a National Health Information Infrastructure included meeting the information needs of health care providers, population health professionals, and personal health within an architecture that would facilitate seamless sharing based upon a need and right to know. This basic insight of three interdependent dimensions of information remains a robust model for policy planning and development relating to health information and communications technology to this day. By the end of the decade, the information infrastructure had changed from an NCVHS vision to a growing reality that enables or is part of nearly everything the Committee does. Yet as this report shows, ample work remains to help the nation achieve balance and synergy among the three dimensions of the envisioned infrastructure—that is, information support for clinical care, for population health, and for individual participation and responsibility.

> *When we created the NHII vision with the three overlapping circles, we argued that the country needed to organize its thinking and architecture so benefit could be drawn from the interconnectedness of information at personal, community, and national levels.*
>
> *—Don Detmer*

In the 2001 report, NCVHS stressed the need for federal leadership as the "cornerstone of implementation" of the NHII vision. Just three years later, by an Executive Order of the President, that stone was put in place with the creation of the Office of the National Coordinator for Health Information Technology (ONC), reporting directly to the Secretary of HHS. This development set in motion many of the NCVHS responsibilities and activities that have defined its most recent decade. ONC went on to frame a concept of the Nationwide Health Information Network (NHIN) as a major component of the NHII.

In 2005, the NCVHS NHII Workgroup focused on personal health records (PHRs), sending recommendations on PHRs and PHR systems to the Secretary in September.[10, 11] Over the next few years, the National Coordinator asked NCVHS to carry out four special assignments, in each case consulting with stakeholders and producing a major report and recommendations to the Secretary. These highly technical projects include studies of the functional requirements for the NHIN (October, 2006); privacy in the NHIN (June, 2006); enhanced protections for the uses of data (first of three reports December, 2007); and finally the definition of meaningful health IT use (May and June, 2009). Several of these projects are described below.

In 2009, the HITECH provisions of The American Recovery and Reinvestment Act (ARRA) greatly accelerated the pace of change by making funding available for adoption of EHRs. NCVHS has long studied the uses of this powerful technology for improving health care and population health, along with the protections and practices needed for its beneficial use. The prospect that EHRs will reach a kind of critical mass within health care in the foreseeable future has moved this technology into the mainstream of the Committee's work on quality, population health, standards, and privacy.

> *My view of NCVHS is that we help set policy, provide a longer vision of what needs to happen, and do the hard work to develop appropriate ideas and consensus around the vision. NCVHS is an expert body. It's appropriate for the Secretary and Congress to add additional structures to try and move our work forward. It's a normal transition that needs to occur.*
>
> *—Simon Cohn*

Recent changes in the advisory landscape have ushered in a new stage in the Committee's advisory role. Recognizing the potential contributions of information technology and standards to health and health care, Congress and the Department created new federal advisory committees in this sphere. In 2005, Secretary Leavitt established the American Health Information Community (now the National eHealth Collaborative, a public-private body); and in 2009, HITECH established new federal advisory committees on policy and standards. Other public-private groups—Health Information Technology Standards Panel, Health Information Security and Privacy Collaboration, Certification Commission for Health Information Technology—also were established to address standards harmonization and certification.

The presence of these new partners with responsibility for implementation in key areas of health data standards and policy has enabled NCVHS to recommit to its historic roles of thought leadership and broad, long-term visioning while it continues to carry out special assignments and the many duties in its charge. By

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10 The report was published in February, 2006.
11 By 2008, the NHII had become so integral to all NCVHS activities that the Committee retired the NHII Workgroup. Ad hoc workgroups now handle special NCVHS projects such as those named below.

> *You have to bring the country along with you as you provide thought leadership so they say, "Yes, that's the right thing." The NHII is an example; it has moved into the fabric of everyone's thinking about how we should move forward. We were clearly ahead of our time, which is very much a mark of the Committee.*
>
> *—Simon Cohn*

mid-2009, a new vision of information for the population's health that takes full advantage of emerging technology was beginning to take shape in the Committee's mind—one that weaves together all the strands of its expertise and concerns.

Clarifying "Meaningful Use" of Health IT

Meaningful use of health information has long been the entire raison d'être of NCVHS. ARRA made the phrase a narrower term of art and, by linking it to financial incentives, gave it considerable salience in health information policy. ARRA establishes incentives for Medicare and Medicaid providers that adopt and make "meaningful use" of certified EHR technology, thus making that a pivotal concept. The National Coordinator asked NCVHS to hold hearings on the definition of "meaningful use" in this context. In response, NCVHS held a public meeting on April 28–29, 2009, to which more than 100 stakeholders provided oral and written testimony aimed at giving specificity to this very broad concept and term. The hearing led to two NCVHS documents: a Report summarizing the hearing themes (May 2009) and a set of "Observations on Meaningful Use" (June 2009).

The Committee reported that it heard strong agreement among the testifiers about the need for a phased approach to achieving adoption and meaningful use of certified EHR technology. It observed that to reach these objectives, EHRs must have specific functionality that is known to improve health care and manage population health, plus a high degree of usability and the capacity to support quality measurement and reporting. Further, NCVHS said the criteria for meaningful use should focus on achieving the ultimate vision and be clear and simple, measurable through easily reportable metrics, adaptable to various provider characteristics, auditable, protective of privacy and security, and reflective of EHR functionality that enables easy use for all intended users. The Committee also stressed the need for a roadmap with clear and predictable milestones toward realistic goals. These observations offered a foundation for the subsequent work of the two new advisory committees established by ARRA.

As described below, NCVHS took the concept of meaningful use a step further in late 2009 when the Subcommittee on Quality held a hearing and then offered recommendations on meaningful measurement of quality.

Strengthening Quality Improvement and Meaningful Measurement

Over the past decade, the NCVHS Quality Workgroup/Subcommittee on Quality[12] has focused concurrently on how to improve quality measurement and the data sources and technologies that can facilitate it.

In 2004, the Workgroup reported on the findings from a multi-year series of discussions with experts about how to improve the measurement of health care quality. In the 2004 report, the Committee identified 23 candidate recommendations. It later elevated one of them and recommended to the Secretary that all inpatient claims transactions include a diagnosis indicator to flag diagnoses present on admission to the hospital. The recommendation was adopted by the National Uniform Billing Committee for inclusion in the UB-04. Congress later passed legislation requiring CMS to identify conditions that would only qualify for an increased DRG payment if present on admission, thereby limiting payment for hospital-acquired infections. NCVHS had first recommended the inclusion of a present on admission indicator in hospital data in 1992—a fact that illustrates the often slow rate of change in health information policy.

Following the lengthy project that concluded in 2004, the Quality Workgroup began to study the role of performance measurement and public reporting in improving the quality of care and how EHRs could facilitate and enhance data collection. In two 2005 hearings, it became clear that performance measurement and EHR development were happening in parallel, without integration. While most quality data were derived from administrative data, the Workgroup saw that the utility and clinical specificity of the data could be enhanced with the addition of electronically captured data elements—creating so-called "hybrid" data. The Workgroup also concluded that for the foreseeable future, EHRs alone would not be sufficient for monitoring and improving health care quality, further demonstrating the need for an interim hybrid model. A key concern of the Workgroup was that EHR systems would be built without consideration for how to capture the data elements needed for performance measurement. Five years later, the HITECH "meaningful use" provisions are an attempt to address this concern.

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12   The Workgroup became an NCVHS Subcommittee in 2008.

The Quality Workgroup organized a hearing in June 2007 to study the state of quality measurement and reporting in hospital care. The hearing resulted in a January 2008 status report for the Secretary, AHRQ, the States, health reporting agencies, and others. Then in May 2008, the Quality and Population Subcommittees jointly convened a hearing on the emerging model of care delivery in the Patient-Centered Medical Home. This hearing underscored the importance of coordination of care, which is greatly facilitated by EHRs and health information exchange.

The themes of transitioning to EHRs and simplifying the quality measurement process came together in the Quality Subcommittee's final project of 2009, on meaningful measurement. As noted, HITECH provisions are designed to incentivize EHR adoption and harness technology for better health care quality. One criterion is the use of EHRs to support clinical quality measures. The Subcommittee was concerned that in health care, ease of measurement too often takes precedence over measuring what matters. It held a hearing in October, 2009, to discuss the process for developing and updating meaningful measures and to consider how new data sources could be introduced into that process. While the testimony of 16 experts depicted a landscape intently focused on quality, the Subcommittee was particularly struck by what it did not see—coordination and strategic vision. Instead, separate measure development activities are producing what one presenter called "a cacophony of hundreds and hundreds of measures," unconnected to national goals for health care improvement.

The hearing discussions shaped a vision for quality data collection embedded in the health care process, inspiring and helping physicians to improve, and supporting health care decisions with rapid feedback mechanisms. To bring this about, NCVHS members talked with the presenters about the need for several critical elements: a national policy framework and strategy, an overarching architecture, a library of specifications for essential EHR data elements that can be the building blocks for quality and performance measures, and a new accountability and governance framework to facilitate needed breakthroughs in quality measurement and improvement. On the basis of these findings, NCVHS sent a letter to the Secretary in November with recommendations for moving the process forward.

Framing the Principles and Practices of Data Stewardship

Data stewardship emerged as a unifying theme for NCVHS in the latter part of the decade. In mid-2007, Dr. Rob Kolodner, then the National Coordinator for Health Information Technology, asked NCVHS to develop actionable recommendations on a high-level framework for the uses of clinical data for activities such as research, population health surveillance, and quality measurement and reporting. This NCVHS project refined a relatively new, integrated approach that the Committee has used with increasing frequency. It cuts across the traditional Subcommittee domains to draw upon the full spectrum of NCVHS expertise in standards, privacy, population health, and quality. The Committee sent its findings and recommendations to the Secretary in a December 2007 Report, "Enhanced Protections for Uses of Health Data: A Stewardship Framework." A summary for policy makers was released a few months later (April 2008).

The principles and practices of health data stewardship are designed to enable society to benefit from using personal health information to improve understanding of health and health care while at the same time respecting individuals' privacy and confidentiality. Because the concept of health data stewardship is so critical and yet not widely understood, NCVHS went on to develop a Primer on Health Data Stewardship (September, 2009). The Primer is intended for anyone who collects, views, stores, exchanges, aggregates, analyzes, and/or uses electronic health data and thus should practice data stewardship. This includes health care organizations, clinicians, payers, information exchanges, vendors, the quality improvement community, health statistics agencies, researchers, and caregivers as well as patients/consumers and persons training for health and information professions. The Primer explains data stewardship as the responsibility to ensure knowledgeable and appropriate use of data derived from individuals' personal health information, guided by a set of principles and practices that it outlines. A central concept is accountability, which resides in a named Data Steward who has formal responsibility for assuring appropriate use of health data and is liable for inappropriate use.

Improving the Health Statistics Enterprise and Information for Population Health

The Subcommittee on Population Health leads the NCVHS endeavor to create a strong information platform for assessing and improving the health of all Americans. The Subcommittee has studied and generated recommendations on improving data on functional status, race and ethnicity, language, and socio-economic factors in clinical records and survey data. It also has been a consistent voice, with the NCHS Board of Scientific Counselors, for the need to preserve a strong national health statistics enterprise. The nation's failure even to reduce health disparities in the past decade, despite a fairly concerted effort to do so, looms large among NCVHS priorities along with the need to actively monitor this issue. In its latest decade, the Subcommittee authored a number of major NCVHS reports or letters and recommendations, each the result of extensive investigation, consultation, and deliberation by the Subcommittee and the full Committee.

> *If we're collecting information about health, we need to define what it is we're trying to accomplish.... You can't talk about health without talking about education and poverty and all of those kinds of things as well. So when you're studying health, what is it that you're studying?*
>
> *—Ron Blankenbaker*

The 2001 NCVHS report on the collection of functional status data built on the Committee's 1996 recommendations on common core data elements for health care enrollment and encounters. The 1996 report had recommended 42 data elements for standardization and called attention to six priority elements in need of further study. Functional status was one of the six. Functional status information is important in clinical care, public health practice, policy, and administration because it enables understanding across the lifespan of the effects of people's health conditions on their ability to do basic activities and participate in life situations. The Subcommittee focused on the need for an effective way to incorporate this information into standardized records. After 18 months of study, it 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. The 2001 NCVHS report recommended a multi-year process to bring about agreement on the importance of collecting the information, followed by selection and testing of a code set for this purpose. It encouraged HHS to take the lead in these activities. NCVHS disseminated its functional status report widely nationally and internationally. In response to its recommendations, CMS devoted an issue of Health Care Financing Review in 2003 to articles on capturing functional status in administrative records for payment and quality purposes.

As noted, the need to improve data on race, ethnicity, and language has been an abiding NCVHS focus because it is impossible to understand health disparities, much less work to eliminate them, without complete and accurate data on the differences in health status, access to care, and services among specific sub-population groups in the U.S. NCVHS approved a report and recommendations on improving these data in late 2005. The report was the culmination of three years of work by the Populations Subcommittee, which hosted six hearings around the U.S. to gather information from experts and data users and studied recent landmark reports drawing attention to health disparities. The report was structured around two large recommendations, with proposed strategies and actions for carrying them out. The first recommendation, to enhance the quality, reliability, and completeness of data collection and integration, came with four strategies. The second, to increase the health statistics infrastructure' capacity to collect, integrate, analyze, report, and disseminate data, included five strategies. NCVHS distributed the report widely within the federal government and to interested organizations, researchers, and advocates. Significantly, its recommendation that primary language be collected in addition to race and ethnicity is now a requirement under meaningful use.

NCVHS entered its sixth decade already hard at work on a vision for health statistics for the 21st century. Dr. Ed Sondik, Director of the National Center for Health Statistics (NCHS), had asked the Committee to develop a vision for transforming the health statistics enterprise so it could more fully serve population health needs. The project, which paralleled the visioning for the national health information infrastructure, involved a collaboration among NCVHS (led by its Workgroup on 21st Century Health Statistics), the Data Council, and NCHS staff members. After a series of hearings and consultations, the Committee created a still-influential model of the influences on health, identified ten guiding principles for health statistics, and developed an analysis and set of recommendations for 21st century health statistics. NCVHS presented an early version of the report at its 50th anniversary celebration in mid-2000.

The final report, Shaping a Health Statistics Vision for the 21st Century, was published in 2002. In it, the National Committee prioritized the creation of an integrating and coordinating hub for the health statistics enterprise and recommended four departmental actions to accomplish this priority, along with other actions. The first of these actions, formation of a strong Board of Scientific Counselors for NCHS, took place in 2004.[13] There has been no action on the other recommendations, however—that is, creation of a national health statistics planning board, consolidation of responsibility at the state level, and new graduate-level and in-service training programs on all elements of the health statistics cycle.

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13 Because of other duties, NCVHS was unable to devote the time needed to in-depth review of NCHS data systems, which both NCHS and CDC Directors supported.

> *You know, we could reform an awful lot of health care and not change the health of the public at all—and I think there's a good chance that will happen. ... If we want to improve the health of the public of the United States, we've got to think much more broadly than is currently being thought of as health care reform. The Committee ought to play an important part in that.*
>
> *—Ron Blankenbaker*

The Subcommittee next explored the opportunities to link health-related data sets in order to maximize public value from the large investments in these data, using the framework it developed in its vision for 21st century health statistics. The ability to understand complex health and health care issues can be greatly aided by linking data from multiple sources, including health data, environmental exposures, socio-economic status, and other factors that influence health. The Subcommittee held a workshop on data linkages to improve health outcomes in September, 2006, to stimulate interest and identify best practices in using linkages to improve knowledge of health outcomes for the population and various sub-populations. NCVHS also sought to assist HHS agencies in meeting their responsibilities for performance measurement by providing more comprehensive information on the status of persons participating in government programs. The Subcommittee talked with experts from the Department and the Census Bureau about how to make linked data more available in a way that protects privacy. The resulting recommendations focused particularly on strengthening the role and efficiency of federal data centers. The Committee's June, 2007 letter to the Secretary recommended streamlining the project approval process and adding staff; HHS sponsorship of research data centers; the use of remote access technologies; and standardizing data linkage and sharing agreements to facilitate data sharing among HHS agencies and other government agencies.

As it did for its 50th, NCVHS is marking the occasion of its 60th anniversary by focusing more on its vision for the future than on its distinguished past. The Committee had again turned its attention to the health statistics vision in 2009, moved by growing concerns about population health and health disparities, worry about the stability of funding for vital statistics and surveys, awareness of the scant progress on the original recommendations, and a need to update the analysis and vision to accommodate new developments in information technology. NCVHS commissioned two of the original authors to interview stakeholders about their priorities for 21st century health statistics and to help the Committee consolidate and update its recommendations. The consultants worked with NCVHS to prioritize the original recommendations, and then focused on those priorities in interviews with key informants.

They concluded by offering three broad recommendations, drawn from the original vision, which had emerged from their review and which validated the key principles of the original report as "essential frameworks."[14]

Looking ahead to the coming decade, the Committee recognized the importance of going beyond the traditional focus on health statistics to address the broad issues involved in meeting the information needs that undergird both population health and health care.

Advising on Privacy, Confidentiality, and Security

NCVHS began raising concerns about respect for the privacy and confidentiality of personal health information long before HIPAA. When HIPAA made it responsible for advising on privacy, the Committee created the Subcommittee on Privacy and Confidentiality.[15] This Subcommittee helps maintain the necessary tension in awareness of the benefits and the risks of multiple uses of personal health information—both of which are heightened by health information technology. It also leads the Committee's work to keep privacy protections apace with information technology and standardization as they evolve, as well as to enable the appropriate use of data for population health.

The Privacy Subcommittee stayed busy for many years helping the Department develop and refine the HIPAA Privacy Rule and put enforcements in place. In February 2000, NCVHS sent the Secretary the first of 14 letters on the Privacy Rule, all developed and authored by the Subcommittee on Privacy and Confidentiality on the basis of extensive study and consultation. The final Privacy Rule was released in August 2002 and took effect for most providers in April 2003. It was generally consistent with NCVHS recommendations. Initially, the Subcommittee advised the Department on the notice of proposed rulemaking, and then on implementation of the regulations. It studied, held hearings, and developed nuanced recommendations on specific data and privacy issues including those related to marketing and fundraising, banking, law enforcement, and schools, as well as working on the role of the HHS Privacy Advocate. NCVHS urged Congress 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.

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14   In a September, 2009 internal report to NCVHS, they said this: "The mission of the U.S. health statistics enterprise is to provide statistical information that will guide policies and actions to improve the health of the American people. To realize this mission, the U.S. health statistics enterprise should 1. Improve strategies, data sources, and systems to actively monitor the population's health and potential influences on the population's health; 2. Assure that appropriate, consistent, and comparable measures of functional status and well-being are provided by the health statistics National Center for Health Statistics ; and 3. Develop and fund a research agenda to explore new data collection, linkage, analysis, and communication strategies that can rapidly and flexibly provide data on the population's health." < http://www.ncvhs.hhs.gov/090922p3.pdf>
15   It was renamed the Subcommittee on Privacy, Confidentiality and Security in 2008.

Midway through the decade, NCVHS shifted its focus to the privacy protections needed for the nascent Nationwide Health Information Network. In 2005, the Subcommittee undertook an 18-month study of privacy issues in the NHIN at the request of Dr. David Brailer, the first National Coordinator. This involved five hearings around the country and a series of public meetings and conference calls. In June 2006, NCVHS sent the Secretary and ONC 26 recommendations on privacy and confidentiality, designed to establish the high level of trust necessary for the successful functioning of the NHIN. ONC/HHS incorporated these recommendations into the RFPs for NHIN implementation projects, directing all contractors to incorporate them into their work. NCVHS wrote the Secretary again a year later to recommend updates to privacy laws and regulations to accommodate NHIN data sharing practices. In another letter that month, the Committee called attention to overlaps and conflicts between the Privacy Rule and both the Common Rule and the Family Educational Rights and Privacy Act (FERPA).

The Privacy Subcommittee also conducted a lengthy study of the complex and controversial issue of individual control of sensitive health information accessible via the NHIN for the purpose of treatment. The full Committee approved a report to the Secretary on this subject in February 2008. NCVHS concluded that NHIN policies should permit individuals limited control, in a uniform manner, over access to their sensitive information disclosed via the NHIN. In 2009, the Committee compiled all its recommendations to the Department on privacy and confidentiality between 2006 and 2008 and issued them as a single volume, to serve as a reference and resource for the field.

In 2009, the Subcommittee on Privacy, Confidentiality and Security returned to the topic of personal health records (PHRs) with an exhaustive study of the privacy issues related to PHRs. The Committee's February 2006 report to the Secretary on PHRs had conveyed 20 recommendations on terminology, privacy, security, interoperability, the federal role, and research and evaluation. That study was the first NCVHS effort to explore the direct uses of health information by consumers and patients since it developed its NHII recommendations. The 2009 study led to an NCVHS letter to the Secretary covering four themes that had emerged from hearings: (1) the need for a standard set of fair information practices to govern consumer rights across all PHRs; (2) the need to maintain regulatory flexibility to foster development and innovation in the field of PHRs; (3) the importance of protecting consumers from unanticipated or inappropriate uses or disclosures of health information in their PHRs; and (4) the need to develop a consumer education strategy that will ensure appropriate understanding of the purposes, uses, and privacy and confidentiality limitations of PHRs. The Committee also stressed the importance of true informed consumer consent, including for any disclosure of information in PHRs. It noted that such consent requires absolute transparency in a PHR supplier's privacy and security practices.

Continuing the Progress Toward Standardization

Standardization has been an NCVHS priority for most of its 60 years, and one that underlies virtually all of its health information policy work. NCVHS has recommended standards that are now the foundation for interoperability, care coordination, and the measurement of health care quality and outcomes in the U.S. The standards it has recommended during the last decade have been adopted virtually unchanged for the demonstration of meaningful use of health IT.

Starting in 1996, three major pieces of legislation—HIPAA, the Medicare Modernization and Improvement Act, and ARRA—have positioned NCVHS to make mandated recommendations on standards for transactions, terminologies to support both administrative and patient care activities, provider and plan identifiers, and overall implementation. The NCVHS Subcommittee on Standards is responsible for all of these areas. It works closely with NCHS, ONC, CMS, AHRQ, and standards development organizations and provides a communication link to stakeholders in the health care industry and public health and research arenas.[16] The Committee describes its advisory work on HIPAA in detail in its regular reports to Congress on HIPAA implementation. During its sixth decade, it authored seven such reports, numbers 2 through 8.

As described above, NCVHS has a long history of contributing to development of the International Classification of Diseases (ICD). The Committee first recommended adoption of the latest iteration, ICD-10,[17] as a HIPAA code set in 2003. This followed an NCVHS-commissioned study by RAND of the costs and benefits of a transition from ICD-9-CM to ICD-10-CM and from Volume 3 of ICD 9-CM to ICD-10-PCS. On the basis of the findings, the Committee recommended that the country shift to ICD-10 code sets for diagnosis and inpatient interventions as soon as possible. After consultation with stakeholders, the Department initiated the regulatory process in 2008 and set the adoption date for October 2013.

The HIPAA administrative simplification provisions also directed NCVHS to study and recommend standards for electronic patient medical record information (PMRI). NCVHS recognized this directive as new and strategic because all other HIPAA standards were intended to support reimbursement and statistical processes, while PMRI standards would support the patient care process in a real-time, clinically specific manner. In 2002, the Committee proposed a strategic framework as a roadmap for studying and recommending PMRI standards. Once the framework was approved by the Secretary, NCVHS used it to develop and recommend a basic set of message format standards and a core set of clinically specific terminology standards for PMRI.

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16   The Subcommittee was named the Subcommittee on Standards and Security until 2008, when the security area was assigned to the Subcommittee on Privacy and Confidentiality. The latter Subcommittee oversees the NCVHS responsibility for advising HHS on privacy, confidentiality, and (since 2008) security.
17   The U.S. adopted ICD-10 for coding causes of death in mortality data in 1999. Most developed countries adopted ICD-10 code sets for diagnosis and inpatient interventions by 2008.

The products of this NCVHS process have provided an influential standards platform for the health care delivery system. These message and terminology standards, which most people now consider to be EHR system standards, were recognized and adopted by HHS, the U.S. Department of Defense, and the U.S. Department of Veterans Affairs as the initial set of consolidated health informatics (CHI) initiative standards. The work led to the NCVHS role in the review process for the federal CHI initiative from 2004 through 2007. The CHI standards, in turn, became the foundation for the work of the Health Information Technology Standards Panel, which was created in 2005 under contract to ONC. This set of clinically specific terminologies, which was also recommended by the HIT Standards Committee in July 2009 as a requirement for demonstrating meaningful use of health IT, has now been included in the December, 2009 Interim Final Rule (IFR) among the standards requirements for meaningful use.[18] The core set of clinically specific terminologies are SNOMED, LOINC, and RxNORM.

These clinically specific terminologies will enable improved quality measures, clinical decision support, and measures of patient outcomes. The set promises to provide the foundation for the transformation of the health care delivery system by providing patient data at a clinically specific level, thus enabling true meaningful use of health IT.

The Medicare Modernization Act (MMA) of 2003 gave NCVHS additional responsibility to select and recommend electronic prescribing (e-prescribing) standards. The adoption of e-prescribing standards moved relatively quickly, thanks in part to a close and efficient working relationship between government and industry. The Committee responded to the added responsibility by sending the Secretary seven sets of recommendations on different aspects of e-prescribing between September 2004 and July 2009. Three of the first six recommended standards performed well enough in pilot testing to be recommended by the Department for full-scale adoption.

The Standards Subcommittee began addressing the next version of HIPAA transaction standards (versions 5010, D.O. and 3.0) in 2007. They are scheduled to take effect on January 1, 2012. In addition, several Subcommittee members participated in the 2006 NCVHS special project to recommend the functional requirements of the NHIN, then in 2007 in the new project on secondary uses and data stewardship and in 2009 in the meaningful use hearing.

In all, in its sixth decade NCVHS sent the Department an extraordinary 39 letters and sets of recommendations on aspects of standards in addition to the seven status reports on HIPAA implementation—all researched and written under the leadership of the Subcommittee on Standards.

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18   The IFR published electronically on December 31, 2009, is named "Health Information Technology: Initial Set of Standards, Implementation Specifications, and Certification Criteria for Electronic Health Record Technology."

Sixty Years of Making a Difference

To mark the tenth anniversary of HIPAA enactment, the Committee sent the Secretary its reflections on the HIPAA experience and lessons learned, drawing on testimony the Subcommittee had solicited over many years. A June 2006 NCVHS letter offered ten recommendations on improving HIPAA updates, adoption rates, and return on investment. The Subcommittee then turned its attention to streamlining the updating and promulgation of HIPAA and advising on standardizing health IT.

The Subcommittee on Standards sees part of its contribution as providing a public forum for enhancing standards development, modification, and implementation. To that end, it held an investigative hearing in February 2009— "Setting the Context for the Evolution of Health IT Standards" —designed to engage stakeholders in a continuing quality improvement process for the future. Occurring just days after enactment of ARRA, the hearing provided a timely opportunity to look broadly at the context for health IT standards, including the processes for standards development, selection, and implementation. The strongest message to emerge—one consistent with other NCVHS discussions—was the need to clarify the health outcomes that standards are intended to help achieve, to provide the basis for defining the goals for standards and health care. Dr. Don Detmer, who chaired NCVHS during the seminal 1996-1998 period, encouraged his former colleagues to develop an outcomes model that uses complementary health IT and health communications technology standards to help achieve population health goals. The Subcommittee also heard the National Research Committee's assessment that health care information systems "fall far short of what would be needed to achieve the IOM's vision for 21st century health care." Other presenters stressed the continued need for strong federal leadership and close collaboration along with continuous testing and evaluation of standards.

In December 2009, the Standards Subcommittee convened stakeholders for a two-day hearing on industry readiness to adopt the updated transaction standards and ICD-10 code sets. Although the first decade of the 21st century represents remarkable progress for the standards agenda, NCVHS continues to identify challenges and areas for improvement and it will monitor progress toward implementing the mandated standards.

A Broad Look at Evolving Information Capacities

Over its latest decade, NCVHS moved decisively into the role of helping government and other partners translate a broad spectrum of data and information into useful knowledge for health and health care. The Committee played a key role in the development and implementation of HIPAA, and it created a seminal vision for the national health information infrastructure that is now becoming reality.

To build on these accomplishments, NCVHS subcommittees in 2009 began to explore the increasing overlaps among their domains and how the Committee's breadth of expertise and responsibility could best help health information policy evolve in a beneficial direction. The environment for building information capacities for health and health care changed dramatically with the passage of the American Recovery and Reinvestment Act in February, 2009; and by the end of that year, all eyes were on the prospects for health care reform. These developments provided greater impetus to the Committee's search for the best ways to help the Department build the information capacities needed to meet new opportunities and challenges. A unifying concept for NCVHS is the need to mobilize multiple information sources, supported by strong privacy protections and standards, to permit the improvement and assessment of population health and health care in the U.S. The conjunction of the American Reinvestment and Recovery Act, health care reform, and accelerating technological change present an unprecedented opportunity to move ahead in these areas. None of this progress is assured, however, without careful planning and coordination. The Committee thus enters a new decade poised to help the Department take a new, more comprehensive and integrated look at the abiding questions of what data should be collected and connected, how emerging sources can contribute, what forms of data stewardship and privacy protection are needed, and how the resulting knowledge can be used to improve the health of all Americans. At its 60th Anniversary Symposium in June, 2010, the Committee will review the progress made over the past decade and present an NCVHS concept paper on the information capacities needed to enhance the nation's health and health care in the years ahead.

Making a Difference over Decades: Insights from Six NCVHS Chairs

Consistent accomplishments for decades across a broad range of national policy issues do not simply happen by virtue of the NCVHS charge and the caliber of its members, even bolstered by its superb staff; they are the result of skillful leadership. This fact was very much in evidence at the September 2009 gathering of six NCVHS Chairs, past and present.[19] The group joined long-time Executive Secretary Marjorie Greenberg and Executive Staff Director Jim Scanlon[20] for a two-day meeting at the University of Virginia School of Medicine. The site was chosen in honor of the esteemed NCVHS Chair in the 1970s, Kerr White, M.D., who lives in Charlottesville and whose library (which includes all NCVHS annual reports) is housed in the Medical School's Don Detmer Reading Room.

In its composition alone, the group illustrates one source of the Committee's effectiveness—its continuity. These leaders represent 27 continuous years of NCVHS history as members or staff, and 23 years as Chairs. With their diverse backgrounds in health care delivery, professional education, research, health policy, and public health—most spanning several of these fields—they also typify the breadth of NCVHS membership.

This celebratory event provided a unique opportunity to trace how NCVHS has carried out the purposes that motivate its work on health information policy. The discussions were a distillation of NCVHS history and highlights over nearly half its life thus far. In individual interviews and a roundtable colloquium, all of it captured on film, the participants talked about their experiences with NCVHS and, in particular, what the Committee's unique history suggests for its future directions and contributions. What emerged was a strong sense of NCVHS as a sixty-year-old learning community.

> *The fact that five previous NCVHS chairs accepted our invitation to the Charlottesville gathering shows the collegiality, sense of common purpose, mutual regard, and affection we have for each other. It also shows that others share my belief that history does matter. It's important for us to capture their wisdom and stories.*
>
> *—Marjorie Greenberg*

19 Ron Blankenbaker, M.D. (1986–1991), Judith Miller Jones (1991-1996), Don Detmer, M.D. (1996–1998), John Lumpkin, M.D. (1998–2004), Simon Cohn, M.D. (2005–2008), and Harry Reynolds (2008–present). The unreferenced quotations in this report are taken from the Charlottesville interviews and roundtable discussion.
20 Ms. Greenberg has staffed the Committee since 1982 and became the Executive Secretary in 1997. Mr. Scanlon became its Executive Staff Director in 1995 after many years of association with the Committee.

> *What I would love to see happen is a document that talks about, "Here are the kind of questions we need to address, whether we're in public health, we're in medicine, we're even administering health insurance plans. Here's what information we have, here's what we need, here are the gaps, here's what it's going to take."*
>
> *—Judith Miller Jones*

Even though Dr. Kerr White was unable to participate, his legacy was a touchstone for the discussions as it has been for the Committee since at least the 1970s. This perspective looks at health care in the broader context of health and population health and understands these in relation to the social, environmental, and other influences on them. It thus sets health information policy in a very broad context, the object of which is to gather and combine useful data from multiple sources and translate them into beneficial knowledge for appropriate and respectful use in the public interest.

The Charlottesville participants noted the range of topics the Committee integrates in its work, from the technical aspects of data standards and privacy protection to the determinants of population health. An important role of its leaders is, in the words of Don Detmer, "to pull together the mosaic to show a coherent picture." The group talked about the significant NCVHS contributions of thought leadership and consensus development and the way the Committee's open and inclusive process brings many voices into the conversation. They agreed on the need to understand that the role of a Committee like NCVHS is not to set federal policy but to advise on it, and that the NCVHS Chair must help new members recognize this sometimes-frustrating distinction.

Advising on policy in an integrative, forward-looking way means supporting innovation and breadth within government. On relatively rare occasions, this can lead to the kind of impact that the Committee achieved with its NHII recommendations. More often, progress is slow and not necessarily steady—witness the Committee's recommendations on functional status data and adoption of ICF (the International Classification of Functioning, Disability and Health). Sometimes, the Committee's advice seems not to be taken at all. John Lumpkin and Judith Miller Jones wondered what NCVHS could learn from its "failures"—and the slow adoption of ICD-10 code sets and lack of progress on unique individual identifiers were cited as examples. However, Dr. Detmer reminded his colleagues that being on the leading edge means that sometimes the Committee's recommendations will not be taken. Jim Scanlon offered perspective from his vantage point in the HHS Office of the Assistant Secretary for Planning and Evaluation: "The Committee is viewed as one of the most productive and useful HHS advisory committees. It gives the Department very practical recommendations on technical issues, and it also can look above the fray and give us a view of what the future could look like. The Committee's recommendations always get consideration and a hearing."

> *A lot of you around the table have been visionaries. What I would ask you to help us do is, when we paint a vision, to make sure we step back to bring along the masses—the education, the understanding. We've got to teach people these visions. We've got to make the vision real. We need ways to allow people to run to the vision, not wonder what the vision means.*
>
> *—Harry Reynolds*

In addition to continuity, breadth, strong leadership, and quality work, another key factor in the Committee's success is its exceptional staffing. Current Chair Harry Reynolds observed that "this is all about the team. The minute you become Chair, you have to understand the importance and quality of the staff support, which has an incredible amount to do with how well the Committee performs." The Committee's structure is challenging in that not only are its hard-working members volunteers with "day jobs," but its entire part-time staff of dozens, including the Executive Secretary and Executive Staff Director, also have other duties as federal employees. Ms. Greenberg believes this structure is beneficial, on balance, because it dynamically links NCVHS to the inner-workings of the Department and enables NCVHS members to learn from their staff colleagues about exactly how the federal government operates. In both the interviews and the roundtable discussion, the Chairs stressed how much they value this partnership between the Committee and its Executive Secretary, Executive Staff Director, and other staff members and liaisons, and their recognition that the Committee would not function effectively without it.

As much as they enjoyed sharing stories on the Committee's historical highlights and the challenges and opportunities of their respective tenures, the former Chairs were clearly most interested in talking about the current environment for health information policy—which all regarded as auspicious—and how NCVHS can make the greatest possible contribution in it. The recurring refrain was that

> *We want a value-driven health care system. And we want public health and medical care to come together. We've been talking about this for how long?*
>
> *—Judith Miller Jones*

fundamentally, the Committee's focus is information that contributes to the health of the population—whether from health care services, population health services, or other influences. Several former Chairs hailed the Committee's "return to its roots," now that advising on HIPAA and the NHIN is less all-consuming, to think about how 21st century resources can be used to strengthen the information platform for improving the nation's health. Dr. Lumpkin commented, "NCVHS did not start off as a committee for health care; it started off looking at the broader concept of health, of which health care is a component…. I think the challenge for the Committee now is to look at ways to integrate across the different areas we described in 2001 in the *Information for Health* report. Personal records, population health, clinical care —it's the interface between those different spaces that I believe no one else is really paying attention to, and the Committee can."

The participants who are still hard at work on NCVHS business—Mr. Reynolds, Ms. Greenberg, and Mr. Scanlon—welcomed this validation of the Committee's new integrative project, and they invited further contributions to it.

The Chairs—functioning in effect as a group of respected Elders—set a number of challenges before NCVHS that it is sure to keep in mind as it plans its future work:

- Think big, and think ahead. Set your sights three to five years out.

- Add research, education, and communication to the NHII vision; and work on a research agenda.

- Create communication standards to complement information standards, to greatly improve impact.

- Help establish accountability for health outcomes.

- Make the vision understandable to those working in the trenches.

- And take full advantage of 21st century tools and capabilities.

Appendix 1.

NCVHS Members, Staff, Liaisons, Retirees, Subcommittees, Workgroups

CURRENT NCVHS MEMBERS, STAFF, AND LIAISONS

(as of May 10, 2010)

Chairman

Harry L. Reynolds, Jr.
Director
Health Plan Transformation
Global Healthcare & Life Sciences Industry

HHS Executive Staff Director

James Scanlon
Deputy Assistant Secretary
Office of Science and Data Policy
Office of the Assistant Secretary for Planning and Evaluation, DHHS
Washington, D.C.

Executive Secretary

Marjorie S. Greenberg, M.A.
Chief
Classifications & Public Health Data Standards Staff
Office of the Director
National Center for Health Statistics, CDC
Hyattsville, Maryland

Membership

Justine M. Carr, M.D. (Incoming Chair, June 2010)
Chief Medical Officer
Senior VP for Quality, Safety and Medical Affairs
Caritas Christi Healthcare
Boston, MA

Leslie Pickering Francis, J.D., Ph.D.
Distinguished Professor of Law and Philosophy
Alfred C. Emery Professor of Law
SJ Quinney College of Law
University of Utah
Salt Lake City, UT

Appendix 2.

NCVHS Chairs and Executive Secretaries, 1949–2010

NCVHS Chairs, 1949–2010

1949: Lowell J. Reed, Ph.D.
1957: Philip Hauser, Ph.D.
1961: Pascal Whelpton
1961: Brian MacMahon, M.D.
1963: Robert Dyar, M.D.
1967: Robert Berg, M.D.
1970: Forrest Linder, Ph.D.
1973: Abraham Lilienfeld, M.D.
1975: Kerr White, M.D.
1979: Lester Breslow, M.D.
1983: Cleve Killingsworth, Jr.
1986: Ronald Blankenbaker, M.D.
1991: Judith Miller Jones
1996: Don Detmer, M.D.
1998: John Lumpkin, M.D.
2005: Simon Cohn, M.D.
2008: Harry Reynolds
2010 : Justine Carr, M.D.

NCVHS Executive Secretaries, 1949–present

1949: I.M. Moriyama, Ph.D.
1972: Dean Krueger
1973: I.M. Moriyama, Ph.D.
1975: James Robey, Ph.D.
1977: Gooloo Wunderlich, Ph.D.
1979: Samuel Korper, Ph.D.
1983: Gail Fisher, Ph.D.
1997: Marjorie S. Greenberg

Larry A. Green, M.D.
Professor and Epperson Zorn Chair for Innovation in Family Medicine and
Primary Care
Department of Family Medicine
University of Colorado Denver Health Science Center
Aurora, Colorado

Mark C. Hornbrook, Ph.D.
Chief Scientist
The Center for Health Research Northwest/Hawaii/Southeast
Kaiser Permanente Northwest
Portland, OR

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

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

Blackford Middleton, M.D., M.P.H.
Corporate Director, Clinical Informatics Research and Development
Chairman, Center for Information Technology
Partners Healthcare
Wellesley, MA

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

Sallie Milam, J.D., CIPP/G
Chief Privacy Officer, West Virginia Executive Branch
WV Health Care Authority
Charleston, West Virginia

William J. Scanlon, Ph.D.
Health Policy Research and Development
Washington, DC

Donald M. Steinwachs, Ph.D.
Professor and Interim Director
Johns Hopkins Institute for Policy Studies
The Johns Hopkins University
Bloomberg School of Public Health
Department of Health Policy and Management
Director, Health Services Research & Development Center
Baltimore, MD

Walter G. Suarez, M.D., M.P.H.
Director, Health IT Strategy and Policy
Kaiser Permanente
Silver Spring, MD

Paul C. Tang, M.D.
Vice President
Chief Medical Information Officer
Palo Alto Medical Foundation
Mountain View, CA

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

Liaison Representatives

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National Cancer Institute
National Institutes of Health, USDHHS
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Rockville, Maryland

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University of Michigan
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Karen Trudel
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Centers for Medicare and Medicaid Services
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NCVHS Team

Marjorie Greenberg, M.A., Executive Secretary
Debbie Jackson, M.A.
Missy Jamison, M.P.H.
Katherine Jones (Team Leader)
Hetty Khan, M.S., M.G.A., R.N.
Cynthia Sidney
Marietta Squire
Treva Thompson
Michelle Williamson, M.S., R.N.

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RETIREES, 2007 TO MAY 10, 2010

</div>

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Kaiser Permanente
Oakland, CA

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Vice President
Humana
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Anthony D. Rodgers, M.S.P.H.
Health Management Associates
Scottsdale, Arizona

Mark A. Rothstein, J.D.
Herbert F. Boehl Chair of Law and Medicine
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Louisville, Kentucky

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The Urban Institute
Washington, DC

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

Liaisons

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Justine M. Carr, M.D.
Leslie P. Francis, J.D., Ph.D.
John P. Houston, J.D.
Walter Suarez, M.D., M.P.H.
William J. Scanlon, Ph.D.
Donald M. Steinwachs, Ph.D.
Paul C. Tang, M.D.
Judith Warren, Ph.D., R.N.

Ex Officio

James Scanlon, ASPE
Marjorie Greenberg, NCHS

Liaisons

Robert T. Croyle, Ph.D., NIH
Jorge A. Ferrer, M.D., M.B.A., VA
J. Michael Fitzmaurice, Ph.D., AHRQ
Chuck P. Friedman, Ph.D., ONC
Jim Lepkowski, Ph.D., NCHS/BSC
Edward J. Sondik, Ph.D., NCHS
Karen Trudel, CMS

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Katherine D. Jones, NCHS
Lead Staff to Subcommittees

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(PREVIOUSLY SUBC. ON PRIVACY AND CONFIDENTIALITY)

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Hetty Khan, NCHS
Susan McAndrew, OS/OCR**
Sarah Wattenberg, ONC

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(PREVIOUSLY SUBCOMMITTEE ON POPULATIONS)

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Dale Hitchcock, ASPE
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Jacqueline Lucas, NCHS
Edna Paisano, IHS

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(PREVIOUSLY WORKGROUP ON QUALITY)

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Donald M. Steinwachs, Ph.D.

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National Health Information Infrastructure (2000–2006)

Members

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Health Statistics for the 21st Century (2000–2002)

Members

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.

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Edward Hunter
Robert Weinzimer

Functional Requirements (Ad Hoc, 2006)

Members

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   Michael Fitzmaurice, Ph.D.
   Helga Rippen, M.D.
   Steve Steindel, Ph.D.

Secondary Uses of Health Data (Ad Hoc, 2007)

Members

   Simon Cohn, M.D., M.P.H. Chair
   Harry Reynolds, Jr, Co Vice-Chair
   Justine Carr, M.D., Co Vice-Chair
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   Mark Rothstein, J.D.
   William J. Scanlon, Ph.D.
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   Mary Jo Deering, Ph.D.
   Erin M. Grant
   Marjorie S. Greenberg, M.A.
   Martin Landau
   John W. Loonsk, M.D.
   Steven Steindel, Ph.D.
   P. Jonathan White, MD

Appendix 3.

CHARTER

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Authority

The National Committee on Vital and Health Statistics is authorized under Section 306(k) of the Public Health Service Act, as amended, and codified at 42 U.S. Code § 242k(k). 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.

Objective and Scope of Activities

The Committee shall 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. 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.

Description of Duties

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. The Committee shall assist and advise the Secretary on health data, statistics, privacy, national health information policy, and the Department's strategy to best address those issues. Specifically the Committee shall:

(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 non-compliance 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.

Agency or Official to Whom the Council Reports

The Committee shall provide advice and recommendations regarding health data and statistics, privacy, Administrative Simplification, data standards and health information policy to the Secretary of Health and Human Services, through the HHS Data Council.

Support

The National Center for Health Statistics, CDC shall provide executive secretariat and logistical support services to the Committee. The Assistant Secretary for Planning and Evaluation shall oversee and coordinate the overall management and staffing of the Committee through the HHS Data Council.

Estimated Annual Operating Costs and Staff Years

Estimated annual cost for operating the Committee, including compensation and travel expenses for members but excluding staff support, is $395,991. Estimated annual person-years of staff support required is 4.65, at an estimated annual cost of $545,936.

Designated Federal Officer

ASPE and CDC will select a fulltime or permanent part-time Federal employee to serve as the Designated Federal Officer (DFO) to attend each Committee meeting and ensure that all procedures are within applicable statutory, regulatory, and HHS General Administration Manual directives. The DFO will approve and prepare all meeting agendas, call the Committee and subcommittee meetings, adjourn any meeting when the DFO determines adjournment to be in the public interest, and chair meetings when directed to do so by the official to whom the Committee reports. The DFO or his designee shall be present at all Committee and subcommittee meetings.

Estimated Number and Frequency of Meetings

Meetings shall be held not less than annually at the call of the Designated Federal Officer, who shall also approve the agenda. The Designated Federal Officer shall be present at all meetings.

Meetings shall be open to the public except as determined otherwise by the Secretary, HHS or designee in accordance with the Government in the Sunshine Act (5 U.S.C. 552b(c)) and Section 10(d) of the Federal Advisory Committee Act. 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. In the event a portion of a meeting is closed to the public as determined by the Secretary, HHS, in accordance with the Government in the Sunshine Act (5 U.S.C. 552b(c)) and Section 10(d) of the Federal Advisory Committee Act, 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.

Duration

Continuing

Termination Date

Unless renewed by appropriate action prior to its expiration, the charter for the National Committee on Vital and Health Statistics will terminate 2 years from the date this charter is filed.

Membership and Designation

The Committee shall consist of 18 members, including the Chair. The members of the Committee shall be appointed from among persons who have distinguished themselves in the fields of health statistics, electronic interchange of health care information, privacy and security of electronic information, population-based public health, purchasing or financing health care services, integrated computerized health information systems, health services research, consumer interests in health information, health data standards, epidemiology, and the provision of health services. Members of the Committee shall be appointed for terms of up to four years. The Secretary shall appoint one of the members to serve a two year, renewable term as the Chair.

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

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

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.

Subcommittees

Standing and ad hoc subcommittees and working groups may be established with the approval of the Secretary, HHS or designee to address specific issues and to provide the Committee with background study and proposals for consideration and action. The Chair shall appoint members to the subcommittees and designate a Chair for each subcommittee from the full Committee. The subcommittees shall make their recommendations to the parent Committee for deliberation. Timely notification of the subcommittees, including charges and membership, shall be made in writing to the Department Committee Management Officer by the Executive Secretary.

Recordkeeping

The records of the Committee, established subcommittees, or other subgroups of the Committee, shall be managed in accordance with General Records Schedule 26, Item 2 or other approved agency records disposition schedule. These records shall be available for public inspection and copying, subject to the Freedom of Information Act, 5 U.S.C. 552.

Filing Date

January 16, 2010

APPROVED:

Date:

JAN - 7 2010

Secretary of Health and Human Services

NCVHS 60-year Timeline

	1949-59	1960-69	1970-79
Chair (the first year of term is noted)	1949: Lowell J. Reed, PhD; 1957: Philip Hauser, PhD	1961: Pascal Whelpton; 1961: Brian MacMahon, MD; 1963: Robert Dyar, MD; 1967: Robert Berg, MD	1970: Forrest Linder, PhD; 1973: Abraham Lilienfeld, MD; 1975: Kerr White, MD; 1979: Lester Breslow, MD
Executive Secretary	1949: I.M. Moriyama, PhD		1972: Dean Krueger; 1973: I.M. Moriyama, PhD; 1975: James Robey, PhD; 1977: Gooloo Wunderlich, PhD; 1979; Sam.Korper,PhD
Exec.Staff Dir			
Major NCVHS foci	Major initial focus: international classifications, work with WHO Also advised on developing National Health Survey.	1964: 15th Anniversary Celebration; Shift to more domestic focus. Issues include chronic disease, administrative simplification, local data.	Work begins on standardization, core data, administrative simplification. 1979: NCVHS technical consultant panels end.
Significant developments in the health information policy environment; changes in NCVHS status, composition, charge	Initial NCVHS U.S. advisory relationship with U.S. Surgeon General.	1964: completion of the "international list," in which NCVHS heavily involved.	Work begins that leads to ICIDH (later ICF). 1974: Congr. mandate to advise HEW (later HHS) Sec'ty; growing partnership w/ HEW/ HHS; 1st of several expansions. 1977: HCFA (CMS) created.

1980-89	1990-99	2000-09	2010
1983: Cleve Killingsworth, Jr.; 1986: Ronald Blankenbaker, MD	1991: Judith Miller Jones; 1996: Don Detmer, MD 1998: John Lumpkin, MD	2005: Simon Cohn, MD 2008: Harry Reynolds	2010: Justine Carr, MD
1983: Gail Fisher, PhD	1997: Marjorie Greenberg		
	Director 1995: James Scanlon		
Expanded connections between NCVHS and private sector as well as gov't. Issues include statistical aspects of physician payment systems,	1995: 45th Anniversary Celebration. Advising on health care reform; review of privacy and confidentiality issues in health data. Several population health initiatives in this period.	June 2000: 50th Anniversary. NHII and health statistics visions published, 2001 & 2002. Focal NCVHS areas: privacy, standards, quality, population health. Special projects on NHIN for ONC.	Work in the 4 key areas and NHIN continues. Work begins on the broad information capacities needed to improve population health and health care. June 2010: NCVHS 60th Anniversary Celebration.
Growing collaboration with HCFA. 1988: NCVHS expansion to 16 members with 4-year terms.	1995: new ASPE participation, relationship to Data Council. 1996: HIPAA mandates. NCVHS charter and size expanded; Congress now appoints 2 members; annual report to Congress on HIPAA implementation.	2003: MMA mandates. 2004: Presidential goal of EHRs for all by 2014. 2004: Creation of ONC, followed by additional federal advisory bodies. Feb. 2009: ARRA/ HITECH	Health care reform passes, (Patient Protection and Affordability Care Act) March 2010