

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

NCVHS

50th

Anniversary Symposium  
Reports



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention  
National Center for Health Statistics

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June 2000

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Center for Disease Control and Prevention  
National Center for Health Statistics

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## Foreword

This volume marks a significant moment in the history of the National Committee on Vital and Health Statistics. The Committee, which advises the Department of Health and Human Services, has helped shape the Nation's health statistics and information policy for more than 50 years. In June 2000, it celebrated its 50th anniversary by commissioning a history of its first 50 years and hosting a symposium that focused not on its distinguished past, but on its vision for the future. Two reports—on the National Health Information Infrastructure (NHII) and 21st century health statistics— were presented and discussed at that meeting. Those two reports, the 50-year History, and a summary of the 50th Anniversary Symposium are all contained in this book. Final reports on the NHII and 21st century health statistics are planned for 2002.

The Committee's sixth decade coincides with the beginning of a new century in which emerging technologies and means of communication are greatly enhancing the uses of information and knowledge to advance the Nation's health. While looking back at past accomplishments, we can all look forward to the Committee's continuing contributions to health information policy as NCVHS helps government, private organizations, and the public make informed health decisions.

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

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## Summary of the NCVHS 50th Anniversary Symposium

The National Committee on Vital and Health Statistics (NCVHS), established in 1949, celebrated its 50th Anniversary on June 20, 2000 with a Symposium at the National Academy of Sciences (NAS). The attendees included current and former Committee members and staff, policy makers, other government officials, members of the scientific community, and representatives of professional associations.

The participants used the occasion to reflect on the Committee's accomplishments over five decades; to review the current status of health, health care, and information in the United States and globally; and to consider future directions and priorities for the Committee. The Symposium discussions pointed firmly to the future by underscoring the need for timely action, with Federal leadership and NCVHS guidance, to harness the unrealized potential of information to improve individual, community, and national health.

Health and Human Services Secretary Donna Shalala joined the Chair of the NAS Committee on National Statistics, the three most recent NCVHS chairs, and an HHS Data Council Co-Chair in offering congratulatory remarks. Each of these speakers recognized the National Committee's past accomplishments but placed special emphasis on the important roles and contributions that lie ahead for NCVHS following this "victory lap." NCVHS Chair John Lumpkin later observed with pleasure that his forward-looking predecessors seemed most interested in "reminiscing about the future and what we need to do."

The main focus and catalyst for discussion was two NCVHS interim reports outlining facets of what former NCVHS Chair Don Detmer called an "Information for Health Strategy." The two closely related vision documents, now under development by the Committee, are "Toward a National Health Information Infrastructure" and "Shaping a Vision for 21st Century Health Statistics." (Both are published in this volume and also posted on the NCVHS Web site.)

The reports were presented by the Chairs of the NCVHS Workgroups that developed them, followed by reactions from distinguished commentators. Rather than proposing any changes to the visions, the Reactors focused on the need to implement them as soon as possible, noting the challenges that can be expected in doing so. The presentations offered complementary perspectives on using the visions to "bring knowledge to the point of service" to improve the population's health. Many speakers endorsed Dr. Detmer's suggestion that building the health dimension of the information superhighway would require "a roadmap, a budget, and a designated driver."

The following report summarizes each of the presentations and then reviews the crosscutting themes in the Symposium. What emerged was a picture of a health environment that is challenged, both positively and negatively, by the information explosion, and that faces unresolved needs among which health disparities and the lack of comprehensive privacy protections are top priorities. The Symposium created momentum for action in this environment, based on the evolving information strategy.

## **The Presentations in Brief**

### **Welcome**

#### **John E. Rolph, Ph.D., Chair, NAS Committee on National Statistics**

Dr. Rolph welcomed and congratulated the Committee on behalf of the National Academy of Sciences (NAS) and its Committee on National Statistics (CNSTAT).

CNSTAT's most recent health-related activity was convening a workshop on the future of health statistics (November 1999). The National Center for Health Statistics requested the workshop as a step in developing a vision for 21st century health statistics. The workshop's findings, scheduled for release in August 2000, are consonant with those in the NCVHS interim report on the same topic. A general theme of the workshop was that at present, "the U.S. health statistics system . . . cannot fully meet the nation's current and anticipated health information needs."

### **Opening Remarks:**

#### **Chair and Former Chairs**

##### **John R. Lumpkin, M.D., M.P.H., Chair, NCVHS**

Dr. Lumpkin noted the importance of the National's Committee's partnership with CNSTAT and his hope that it would continue to grow. He commented on the momentous changes during the Committee's 50 years of existence and the implications of those changes for the future. During that period, information and knowledge have become a transforming force in the world, facilitated by the technology of information and knowledge management. Dr. Lumpkin welcomed each of his predecessors to the podium, also encouraging participants to read the written reflections sent by former Chair Kerr White, M.D. (Chair 1975–79).

##### **Don E. Detmer, M.D., Dennis Gillis Professor of Health Management, Judge Institute of Management, Cambridge University (Chair 1996–98)**

After highlighting aspects of the Committee's history, Dr. Detmer shifted the focus to the future, observing that "it is probably better to invent part of the future than to inherit all of it." To this end, he proposed that the Committee and the Department find a way to link the two interim vision reports into a national Information for Health strategy, to bring "the right information to all the right places at the right time." Realizing this vision will require partnerships among patients, communities, and national bodies including NCVHS, the Department, and the National Academy of Sciences. He also mentioned the need for monitoring systems using solid statistical analysis, as well as progress toward global standards. Many Symposium speakers later reiterated the importance of global connections and standards.

Dr. Detmer praised the two NCVHS reports and urged steady movement toward their implementation. He identified three essential conditions for this to take place: an Information for Health roadmap, a budget, and a designated driver. Dr. Detmer observed that the U.K., Canada, and Australia, among other countries, all have maps or plans, and the U.S. needs one, too. These countries also have far more government funding than the U.S. invests in its information infrastructure. He suggested that 7 billion dollars, spread over 7 years, could move the U.S. infrastructure forward significantly. Regarding the need for a designated driver, he asserted that the U.S. needs “an agency or a center . . . that leads the agenda” and can channel the prevailing “enormous good intention and tremendous energy.”

**Judith Miller Jones, Director, National Health Policy Forum  
(Chair 1991–96)**

Ms. Jones commented on the high caliber of people in the field of health statistics, where, like the children in Garrison Keillor’s Lake Wobegon, “everyone is above average.” She noted that today’s Committee builds on 50 years of NCVHS achievements. Its work recently has been made more challenging by the Health Insurance Portability and Accountability Act, compounded by unresolved privacy concerns. Declaring that “data and health statistics are the bedrock of good policy,” she promised to redouble her efforts to improve information policy.

**Ronald G. Blankenbaker, M.D., Associate Dean,  
University of Tennessee College of Medicine, Chattanooga  
(Chair 1986–91)**

Dr. Blankenbaker praised the National Committee for approaching its work in the spirit of the broad World Health Organization definition of health. This resonated with Kerr White’s written observation that the health world is starting to recognize “the reality that the genesis of ill health and disease involves many factors other than germs and genes.”

Dr. Blankenbaker noted the challenge of managing burgeoning data and information while also providing the kind of health care implied by the WHO definition. He joined his colleagues in congratulating NCVHS for its work, affirming that “the Committee does make a difference.”

## **Opening Remarks:**

### **Department of Health and Human Services Representatives Hon. Donna Shalala, Secretary of Health and Human Services**

In introducing Secretary Shalala, Dr. Lumpkin commented on her 7 years of service as Secretary, longevity that is unusual for this position and that manifests important qualities of commitment and leadership. He reviewed her accomplishments, notably her support for upgrading the status of health information, statistics, and knowledge management within the Department.

After acknowledging the leadership of Dr. Lumpkin, the former NCVHS chairs, and NCHS Director Ed Sondik, Secretary Shalala congratulated the Committee on its golden anniversary and expressed pride in what NCVHS and the Department have accomplished together. She said of NCVHS members, “I can’t think of a group of people who have worked harder to promote a better and healthier life for the people of this country.” The Committee is meeting her goals for it, namely building a broad-based national health information infrastructure and providing bridges to industry, the research and public health communities, and the American people. She noted that there is much left to be done to “build a seamless web of information-gathering and dissemination that still protects the privacy of individual citizens.” She promised to fight for more resources to accomplish these goals.

### **John Eisenberg, M.D., M.B.A., Co-Chair, Data Council**

Dr. Lumpkin expressed appreciation for Dr. Eisenberg’s advocacy for health information and data policy within the Department.

Dr. Eisenberg congratulated the Committee on behalf of himself and his co-Chair, Dr. Peggy Hamburg, joking that NCVHS now qualifies for AARP membership. He thanked the Committee for its hard work and valuable service, “not just for the Department but for the entire nation,” and he hailed the close relationship between the Committee and the Data Council and Department. NCVHS has provided a framework for bringing the benefits of information and technology to health and health care, in a way that protects the security and confidentiality of the information.

Dr. Eisenberg reviewed the Committee’s historic contributions to advances in health information policy, noting its proposal for the first national health survey, its advice on *Health, United States*, its leadership on health data standards, and its close collaboration with HHS to develop the regulations required by HIPAA. He praised the skill with which the Committee “brings together policy and diplomacy to help people come to a consensus.” In conclusion, he urged participants to look at a new World Health Organization report, released June 20, which reflects the need to measure both the health of the public and the performance of the health care system.



## **Two Visions of Information for Health**

**Moderator: Edward J. Sondik, Ph.D., Director  
National Center for Health Statistics**

Dr. Sondik began by extending his own thanks to the Committee, its Chairs, Executive Secretary Marjorie Greenberg, and her predecessor, Dr. Gail Fisher. On the theme of rapid technological progress, he noted the short lapse in time between the horse and buggy, figuratively and literally, and the deciphering of the genome, as well as the implications of the latter breakthrough for the health community. The Committee is very important, he said, in helping to guide and catalyze responses to the technology that increasingly “drives the system.”

With this he turned to the two featured reports, first introducing John Lumpkin, who chairs the Workgroup on the National Health Information Infrastructure (NHII).

### **“Toward a National Health Information Infrastructure”**

**John Lumpkin, M.D., Chair, NHII Workgroup**

Dr. Lumpkin observed that the attainment of health is a shared responsibility. The process is driven by the use of data, which, when converted into information and knowledge, can lead to action to create better health outcomes. Information allows us to understand the links among the many factors that affect health. Although health care today is still approached much as it was 100 years ago, relying on the information in the individual physician’s head, information technology offers the opportunity to transform health care. This change can be brought about by following through on the vision for the national health information infrastructure (NHII).

The Committee envisions the NHII not as a centralized database, but as a means of connecting “distributed” health information into a secure network, with strict confidentiality provisions. Making these connections involves a data model, data standards, and connectivity standards. The purpose of the infrastructure is to “push knowledge to the point of service,” making today’s wealth of information available for clinicians, patients, and public health professionals to use in improving people’s health. These capabilities are expected to dramatically reduce medical errors and other adverse effects of care.

The NHII has three dimensions, representing the three categories of key stakeholders: personal health, health care provider, and community health. (Health statistics, the focus of the second vision report, is part of the community health dimension.) The information and knowledge within each of these dimensions is controlled by the designated stakeholder—that is, the individual, the provider, or public health workers. Dr. Lumpkin described the core data for each dimension and ways in which the dimensions and stakeholders will interact and exchange information in this dynamic system. For detail on the provider dimension, he referred the audience to the Report on Uniform Data Standards for Patient Medical Record Information (which NCVHS sent to the Secretary in September 2000).

He observed that the health care system now undergoing such transformation still must address basic issues of inequity and disparities. By providing decisional support and

improving the quality of care, objective information systems can help the nation overcome treatment and outcome disparities.

Privacy is another special challenge, and he outlined the confidentiality protections that will operate within each dimension and in the transactions between them. For example, the community health dimension will use information in its least identifiable form, with controlled access on a need-to-know basis. Despite precautions such as these, he acknowledged that protecting privacy and confidentiality remains a major challenge, along with assuring equity of access and treatment quality.

The next steps in the development and promulgation of the NHII are to validate the vision, identify the barriers, and develop recommendations. Four hearings are scheduled around the country over the next six months. "Then comes the hard part," when "we'll be done with the talking and it will be time for the doing." Dr. Lumpkin stressed the urgency of moving to the action stage, in view of the proliferation of new health information systems whose multiplicity will make change more expensive the longer it is delayed.

**Reactor: Edward Shortliffe, M.D., Ph.D., Chair, Medical Informatics,  
Columbia University; member, IOM National Research Council**

Dr. Shortliffe had earlier that day presented to NCVHS members the National Research Council report, "Networking Health: Prescriptions for the Internet." He called the NCVHS vision for a national health information infrastructure, as articulated in the NHII report, "exactly right." He focused his Symposium remarks on a complementary subject, the background and potential role of the Internet, which he suggested is "interwoven through much of what you envision for the future of the NHII" and indeed is likely to potentiate it.

Dr. Shortliffe's account of three decades of Internet development portrayed the medical world as slow to take advantage of this resource. As the infrastructure, standards, and consensus developed, parts of the medical world got involved but in general medical applications lagged far behind others. While consumers have embraced the health-related uses of the technology, "the health care community just didn't get it." Noting that the prevailing culture in the biomedical and health world creates resistance to the use of information technology, he said what is needed is nothing less than a fundamental cultural change. Part of the problem is the fragmentation of the health care industry, which exceeds that of other industries; other factors are changing modes of practice and fear related to financial pressures. At this stage, the health care community should support focused information technology research as a component of biomedical research, to further such interests as protecting privacy and achieving large-scale system integration.

Finally, he pointed out that the national infrastructure on which the Internet depends would not have come into being without a "substantial investment by the government." He stressed that government leadership remains essential to promote needed cultural change, help carry the costs of change, and bring the health world fully into the information age. Dr. Shortliffe agreed with Dr. Detmer about the three components needed to realize the NHII vision. All HHS agencies must be involved in this effort, and the National Committee is well positioned to help the government figure out its role. "Now is the time to start the Federal process," he said, even as the Committee continues to elicit comments from around the country to flesh out the vision.

## **“Shaping a Vision for 21st Century Health Statistics”**

### **Daniel J. Friedman, Ph.D., Chair, Workgroup on 21st Century Health Statistics**

Dr. Sondik acknowledged Dr. Friedman’s leadership in crafting the vision for health statistics and moving that process forward.

Dr. Friedman said that the National Committee, NCHS, and the Data Council are collaborating on developing the health statistics vision in response to a 1998 request from Dr. Sondik. The vision encompasses population health, the health care system, and the interaction of the two at local, State, and national levels, using both public and private data. An important goal of the process, beyond developing the vision, is to define what is needed to implement it—which “is going to be the really difficult part.” A related goal is to clarify the criteria for evaluating the health statistics system, today and in the future.

Developing the interim report and getting national feedback to its content represent the second of five phases planned for this process. The first phase was dedicated to learning from the past and the present through commissioned papers, consultative sessions in several communities around the United States, forums at professional meetings, and the CNSTAT workshop described above. Finding a dearth of definitions of health statistics, the Workgroup developed its own, emphasizing the use of statistics in designing, implementing, monitoring, and evaluating health policy and health programs. Phases three through five of the process—further national consultation, completion of the vision, and implementation— are described below.

U.S. health statistics have been marked by unrealized potential, Dr. Friedman said, due to this Nation’s failure to deal adequately with privacy and confidentiality issues, together with the existence of multiple unconnected data silos and the lack of a consistent conceptual and organizational structure. The result is “a surfeit of data but a dearth of information, as well as multiple unanswered questions,” at both macro and micro levels. One significant unanswered question, for instance, concerns the impact of health care on health.

From the vision development process thus far have emerged 10 “very rough-cut principles” around which a detailed 21st century vision will be constructed. Dr. Friedman commented briefly on each of the principles, which are enumerated in the report. They include the need for privacy protection, flexibility to address emergent issues and needs, usefulness at different levels of aggregation and for different purposes, maximum access and ease of use, and policy relevance. Broad collaboration among private and public stakeholders will be needed to carry out this vision.

The next steps in the process are to receive further input through regional hearings and comments from the public via the project Web site as well as at professional meetings, to map the current system against the conceptual framework, to delineate and address specific privacy and confidentiality concerns, and to produce a final vision report. The ultimate, and most important, phase follows the release of the report: using this vision for Federal, State, and local population health information planning.

**Reactor: Dorothy Rice, Sc.D., Professor Emeritus, Institute For Health and Aging, University of California, San Francisco**

Dr. Rice, who directed NCHS from 1976 to 1982, delivered the keynote address at the November 1999 CNSTAT workshop on 21st century health statistics. Dr. Sondik acknowledged her significant public health contributions, in particular her analysis of the costs of smoking.

Dr. Rice characterized the interim report on health statistics as “very, very important” and “the beginning of hopefully a very fruitful effort.” After praising Dr. Sondik for stimulating the development of the vision, she highlighted what she regards as “the most glaring gaps” and cross-cutting issues addressed in the report. The most serious gap concerns health statistics on sub-population groups, including children and racial and ethnic minorities. Compounding this gap is the difficulty of obtaining data on socioeconomic differences. More longitudinal data are also needed— “We should start with children and follow them through their life” —and she called for pilot projects to move that idea forward. Our pluralistic healthcare delivery system creates special problems in data collection, analysis, and dissemination, with proliferating data systems and little sharing. The fragmentation of the system makes it imperative to integrate statistical systems, using uniform definitions.

On the Federal side, Dr. Rice noted the many knowledge gaps that remain despite a broad array of surveys. For example, information on health insurance coverage is available only from a Labor Department report on unemployment. State and private data systems compound the fragmentation, and to these problems are added those caused by the irregular quality of data sources. She contrasted these with the more comprehensive California Health Interview Survey, one of several current models of collaborative data collection involving States, academics, and the Federal Government.

Above all, she stressed the need to invest in health statistics, as a demonstration of a “judicious political commitment to quality health statistics in the public and private sectors.” Returning to Dr. Detmer’s list of preconditions for the Information for Health strategy, she asserted that “NCHS should be the designated driver.” One of the next steps toward implementing this strategy, she said, should be an effort to “make people more conscious of the importance of health statistics,” thereby generating a constituency that would support a greater investment of resources.

**Reactor: Gary Catlin, Director, Health Statistics Division, Statistics Canada**

Introducing Mr. Catlin, Dr. Sondik noted the importance of looking to other countries to learn how they have dealt with challenges like those the United States is now facing. Mr. Catlin said Canada has confronted and is confronting the same issues as those outlined in the NCVHS health statistics report. A Canadian task force on health information in 1990 recommended creation of a health information coordinating council, citing concerns much like those identified by NCVHS. That “very influential” report led to formation of the Canadian Institute for Health Information (CIHI), an independent nonprofit organization that serves as Canada’s “designated driver” for health statistics. In 1994, Canada

started a longitudinal national population health survey and embarked on a series of cross-country consultations that resulted in the Health Information Roadmap (posted on the CIHI Web site).

The 1999 Canadian federal budget allocated \$95 million to Statistics Canada and CIHI over 3-4 years to implement the vision outlined in the Roadmap. Some 38 projects are funded to answer two basic questions: How healthy are Canadians? and How healthy is the health care system? Also under development are a health infrastructure report describing the existing health information system, and a 2-year strategic plan for moving ahead.

Canada is also dealing with privacy and confidentiality issues, with one focus being the development of harmonized privacy legislation among the provinces and territories. Like the United States, Canada envisions project-specific linkages rather than a “mega-database.” Ninety-five percent of Canadians gave their consent to linking household survey information to administrative data for the 1994 national population health survey. To combine privacy protection with controlled data access for researchers, Canada is setting up research data centers in universities around the country.

Mr. Catlin described a major initiative related to the Roadmap a new community health survey that will begin in September 2000 and generate tailored local and regional data for 130 health regions. Other Roadmap initiatives include a pilot project involving person-oriented longitudinal health histories, and the production of annual health reports. Starting in the Spring of 2000, Statistics Canada began reporting on the health of Canadians, with CIHI reporting on the health of the health care system. Dr. Catlin stressed regular reporting as an essential byproduct of health statistics. This reporting, he said, must be done “with the public in mind” and must offer the information the public wants to know. He also affirmed a priority mentioned by several previous speakers, the need to develop internationally comparable health indicators for use in health surveys and reporting. Canada, he said, would like to work with NCHS and others in moving this forward.

Mr. Catlin concluded by sharing lessons from the Canadian experience. They relate to the challenges of standardization, the importance of cooperation and consultation among “a vast number of interests,” the fact that the public “are amazed at what we don’t know,” and the need for a long-term investment to realize the vision.

## **Audience Comments**

Dr. Detmer proposed that “the market value of health has gone up”: many people are getting interested in health because of environmental concerns and other factors. Given the likelihood that this interest will stimulate a greater willingness to invest in information, those responsible for information for health must be ready to take action.

Dr. Myron Straf raised the possibility that with the proliferation of private sector data, “bad data will drive out good data” and people will lose sight of the relevance of population-based surveys. Dr. Lumpkin said the question “gets to the heart of how we use population-based data”; the latter are needed to provide the denominator that gives meaning to the numerators derivable from administrative and clinical data. Thus, the proliferation of data sources only intensifies the need for community- or population-based sources. Dr. Lumpkin and Dr. Sondik noted the worrisome trend toward the commodification of data.

Dr. Manning Feinleib suggested that basic scientists, especially those in the genome project, should be treated as an important group of stakeholders and involved at an early stage in considering confidentiality and other complex issues.

Ms. Jones observed that more and more people want to know how their individual data compare to population data, in order to know their relative risk and improve their health-related decision-making. This is an application for which health statistics could be used more effectively.

**Closing Remarks: Dr. Lumpkin**

In closing, Dr. Lumpkin noted that the Committee has recently completed three significant reports on computer-based patient records, health statistics, and the NHII. He continued, "Now that we have said what we need to do and advised the Secretary on what needs to be done, it is time to do it." Looking ahead, he said the Committee has important work to do with respect to privacy, security, population health and health statistics, and functional status measurement, among other areas.

Finally, he acknowledged the contributions of Executive Secretary Marjorie Greenberg and Executive Staff Director Jim Scanlon and their staffs, without whom the Committee's accomplishments would be impossible. He then adjourned the Symposium, inviting all participants to join the Committee and staff at a reception in the Great Hall.

## **Major Symposium Themes**

### **Information for Health**

Several speakers came armed with statistics to illustrate the rapid growth of technology, the proliferation of data sources, and the sheer quantity of data now available to health systems and health professionals. Noting the difficulty of managing the speed and volume of this “explosion” and the fragmentation that often accompanies it, they portrayed these forces as both challenges and opportunities. Proliferation, fragmentation, lack of standardization, and lack of utility were all mentioned as information challenges in the health area, both within the United States and internationally.

The point was made repeatedly that to be useful, data must be converted into information and knowledge; and beyond this, that the potential value is only realized when information and knowledge lead to action in such forms as service delivery, reporting, and policy.

A major tension in this area concerns privacy, a theme that wove through the discussions. Many speakers observed that the value of information for health is contingent on having adequate privacy protections. This point was especially salient in discussions of the two vision documents, where the Committee is designing blueprints for the “ideal” information infrastructure and applications that can only become a reality when adequate privacy protections are in place.

These challenges notwithstanding, the major emphasis of the Symposium was the demonstrated value and unrealized potential of information as a tool for improving health. Brought “to the point of service,” information can improve decision-making by policy makers, public health workers, health care providers, and consumers. Information technology greatly increases the forms and speed of communication. And given adequate laws, policies, and security measures, it can improve privacy protections. Thus, a strong message to emerge from the Symposium was that information can be a vital resource for health, provided that it is guided by a national strategy based on clear principles and goals. The elimination of disparities was highlighted as an especially pressing goal for health care and population health systems, and one for which better information can make a critical difference.

### **Time for Federal Action**

The question, then, is how to develop the national strategy and use it to take action.

Dr. Detmer moved the discussion in this direction with his call for action and Federal leadership and his characterization of the NHII and health statistics visions as a nascent

Information for Health strategy. Dr. Shortliffe added a sense of urgency by asserting that “now is the time to start the Federal action,” a point Dr. Lumpkin repeated in his final remarks.

Two questions from Dr. Detmer—“What’s holding us up?” and “What do we need to move forward?”—gave focus to the discussion. His answer, using the information superhighway metaphor, recommended three forms of facilitation: a roadmap, a budget, and a designated driver. Other speakers elaborated on these themes, including Dr. Rice’s nomination of NCHS for the role of designated driver.

In general, the Symposium discussions confirmed that the two NCVHS vision papers are a good start toward a national health information strategy and infrastructure. In the Canadian experience participants recognized an instructive model and a promising source of future collaboration. Other countries’ examples were also cited, notably those of Australia and the United Kingdom.

As these nations have shown, developing and implementing an information strategy requires an ample budget and strong leadership. The presenters agreed that in the United States, only the Federal Government can provide the leadership and funding needed for this effort.

Dr. Rice and others pointed out that the information infrastructure in general, and health statistics in particular, suffer from underinvestment. Dr. Shortliffe contrasted the 18 percent that American Airlines invests in information technology with the 2 percent invested by the health care industry. Mr. Catlin reported that Canada has budgeted \$95 million (Canadian) for its health information roadmap. Dr. Detmer noted that the U.K. has \$1.5 billion (U.S.) budgeted to modernize their information infrastructure. He suggested that the U.S. government think in terms of \$1 billion a year for 7 years.

Several presenters observed that the National Committee, through its collective expertise, commitment, relationship with the Department, and 50-year track record, is well positioned to advise the government on providing the needed leadership. The initial stages have already begun, through the actions highlighted in the Symposium: refining the visions for the information infrastructure, engaging and consulting stakeholders, and laying the groundwork for implementation.



# **The National Committee on Vital and Health Statistics 1949–99: A History**

Susan Baird Kanaan

The mission of the National Committee on Vital and Health Statistics (NCVHS) is to advise on shaping a national information strategy for improving the population's health. The Committee celebrated its 50th anniversary in June 2000 with a Symposium and reception at the National Academy of Sciences. Donna Shalala, Ph.D., Secretary of Health and Human Services, was among the dignitaries present to recognize the Committee's contributions to national health policy and population health.

The Committee is charged by Congress with advising the Federal Government on the information needs underlying health policy. Since 1949, it has carried out that charge by designing, stimulating, and coordinating improvements in national and international vital and health statistics. NCVHS provides a bridge between government, the health industry, and research and public health communities as well as connections to those working on health information policy in other countries. It is widely regarded as one of the most influential, effective, and hard-working of Federal advisory committees.

The members of NCVHS serve in a voluntary capacity and are selected for their expertise and distinction as researchers, educators, and practitioners in such fields as population-based public health, epidemiology, health services, privacy/confidentiality, health information systems, and health data standards. Since 1996, 18 individuals have served on the Committee, 16 appointed by the HHS Secretary and 2 appointed by Congress.

Over its 50 years, the Committee has reshaped and redirected itself in response to changing external needs and internal priorities and capacities. Initially, NCVHS members and affiliated subcommittees were mostly statisticians representing both public and private sectors. They worked on the technical intricacies of creating an international health statistics infrastructure, cooperating primarily with the World Health Organization. By the mid-1970s, the Committee had a broader skill base and a strong domestic policy orientation that has only strengthened since then. A new legislative mandate in 1975 empowered the Committee to actively advise the Department (then Health, Education and Welfare, later Health and Human Services) on statistical aspects of health policy.

Health policy development has increasingly required the participation of multiple Federal agencies as well as States and private organizations. NCVHS has played a strategic role in bringing these forces together around information and statistical issues. The Committee has grown ever more sophisticated at articulating the policy significance of its concerns. Members have invested considerable time and expertise since 1970 in a hallmark effort to standardize common data sets, elements, terms, and definitions. Congress elevated this NCVHS priority in 1996 when it passed the Health Insurance Portability and Accountability Act, or HIPAA, giving NCVHS a key advisory role. Privacy experts were added to the Committee roster to help the Committee advise the Department on strengthening privacy protections.

Over its five decades, the National Committee's contributions to national health information have included groundbreaking recommendations on health surveys, classification systems, minimum data sets, and cause of injury coding (E-codes). It also has supported the evolution of vital and health statistics through the discussions at its meetings, the informal efforts of members and Chairs, and the wide-ranging work of subcommittees, workgroups and panels. This evolution might be summarized as a process of broadening: from mortality to morbidity statistics; beyond hospital data to other types of care (for example, ambulatory and long term); the introduction of standardized minimum data sets to permit comparison and linkage; working to expand the data available on population subgroups and smaller geographic areas; and laying the groundwork for establishing comparability with other nations. All of these efforts have been informed by the Committee's population-based perspective, which seeks to understand and promote the health of all individuals and communities and is especially vigilant on behalf of those whose care has been neglected.

This report provides a brief overview of the Committee's development and accomplishments since 1949. The first section offers a chronological review, with special attention to the Committee's origins and early years because of the light the founders' thinking can shed on contemporary issues and choices. Following this review are brief discussions of the Committee's major areas of activity over five decades: population health, privacy, standardization, medical classification and nomenclature, and the development of broad visions and strategy for the use of information for population health. After a review of two important challenges that have variously engaged the Committee since its inception, the report ends with a look toward the future.

## A Scan of 50 Years

### Origins: An International Vision

NCVHS was the product of a post-World War II mobilization of national resources to strengthen international vital and health statistics. Two early accounts, the first from the NCVHS archive, convey the excitement of that time:

The national committee concept was born at the Paris Conference, held in the spring of 1948, for the Sixth Decennial Revision of the International Lists of Diseases and Causes of Death. The Conference achieved what seemed impossible—the international acceptance by all nations of a combined statistical classification for both causes of sickness and causes of death. . . . The conference concluded that this method of working [for example, national organizations' contribution of funds and technical skills to international agencies] could be used to great advantage in the future on the many problems facing public health statistics. It then expressed the desire that the World Health Organization. . . decentralize some of the many statistical problems in the fields of health and vital statistics for study by national technicians as a preliminary step in the international development of standards and methods. It urged that all governments establish national committees on vital and health statistics. . . , and that such national committees study broadly the problem of producing satisfactory national and international statistics in the fields of health. . . .<sup>1</sup>

The World Health Organization's account, which describes the Paris Conference as "the beginning of a new era in international vital and health statistics," shows the international body's expectations of the new national entities:

Apart from approving a comprehensive list for both mortality and morbidity and agreeing on international rules for selecting the underlying cause of death, [the conference] recommended the adoption of a comprehensive programme of international cooperation in the field of vital and health statistics. An important item in this programme was the recommendation that governments establish national committees on vital and health statistics for the purpose of coordinating the statistical activities in the country, and to serve as a link between the national statistical institutions and the World Health Organization. It was further envisaged that such national committees would either singly or in cooperation with other national committees, study statistical problems of public

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<sup>1</sup>The United States National Committee on Vital and Health Statistics, October 1949.

health importance and make the results of their investigation available to WHO.<sup>2</sup>

The WHO recommendation was evidently well received. The first document produced by the U.S. National Committee notes the assignments given to some 12 participating countries. (1, p.7-8) The United States was asked to work on adapting the International Classification of Diseases (ICD) to the needs of Armed Services, on studying methods of presentation of statistics of multiple causes of death, and on fetal death statistics. By 1969, some 50 countries had national committees, and 59 countries sent representatives to the Second International Conference of National Committees of Vital and Health Statistics, held in Copenhagen, Denmark in October, 1973.<sup>3</sup>

## **Conceiving the U.S. National Committee**

The Department of State of the United States Government acted on the WHO recommendation by asking the Federal Security Administrator to form a national committee. Early in 1949, the Surgeon General of the Public Health Service constituted the United States NCVHS with Dr. Lowell J. Reed, Vice President of Johns Hopkins University, as its chairman. Dr. Kerr White, one of Dr. Reed's successors as NCVHS Chair, describes him as "a giant in the field."

The founders gave careful thought to the composition of the Committee, and agreed on principles that still serve it well: "A principle for the selection of the membership of the committee was adopted, that members should not represent organizations or agencies but rather. . .be chosen to represent a point of view, an area of interest, or a field of knowledge essential to the carrying out of the Committee's responsibilities. . . ."<sup>4</sup>

The original group numbered 11, with its Executive Secretary serving as an additional ex officio member. The fields and areas of expertise represented in the founding Committee were epidemiology, health planning, health care, health care administration, and public health. While the fields from which Committee members are drawn have been expanded since then to include such domains as health services research, health policy, privacy, and data standards, the principle of selection has remained constant. Members bring distinctive experience and perspectives, but represent no one but themselves.

The early years of the National Committee were characterized by the long-time leadership and influence of two individuals: Dr. Reed, who served as Chair from 1949 until 1956, and Dr. I.M. Moriyama, the Committee's Executive Secretary from its founding through 1971 and then again in 1974. Both were epidemiologists, with a strong interest in international classifications. Dr. Moriyama was on the staff of the National Office of Vital Statistics, the predecessor to the National Center for Health Statistics (NCHS). These two agencies have had staffing responsibility for NCVHS for all but 4 of

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<sup>2</sup>Manual of the International Statistical Classification of Diseases, Injuries, and Causes of Death, Based on the Recommendations of the Seventh Revision Conference, 1955. Geneva. WHO, 1957. (quoted in reference 7, p.37)

<sup>3</sup>New Approaches in Health Statistics: Second International Conference of National Committees of Vital and Health Statistics (Copenhagen, Denmark in October, 1973). Geneva: World Health Organization, Tech Report Series 559, 1974.

<sup>4</sup>p. 4, The United States National Committee on Vital and Health Statistics, October 1949.

its 50 years. Terms for members were instituted in 1958; since then, most Chairs have served for 2–4 years, generally after first serving as Committee members.

The Executive Secretary has been an important source of continuity for the Committee, which has had only seven. (See [Appendix 1.](#)) This was one of the several strengths enumerated by Dr. Ruth Puffer of the World Health Organization in comments to the 20th anniversary conference of the USNCVHS:

Why is it that the present National Committee has had so much success?

I think one of the reasons is that it has called for help from many specialties.

Another reason is its choice of topics for study. And I think a third reason is the continuity of service and contributions of its Executive Secretary.<sup>5</sup>

The new body was given a broad charge that included domestic as well as international responsibilities. An early document states, “The major objectives of the National Committee are to advise the Surgeon General on matters relating to vital and health statistics and to promote and secure technical developments in the field of vital and health statistics.” This was spelled out in six areas of activity: “delineate statistical problems of public health importance. . . ; stimulate studies of such problems. . . ; review findings. . . and make recommendations for national and/or international adoption; cooperate with and advise other organizations. . . ; advise the Surgeon General on problems relating to vital and health statistics of national and international concern; and cooperate with national committees of other countries, and with the World Health Organization and other international agencies in the study of problems of mutual interest.”<sup>6</sup>

The Committee’s first Annual Report offers a picture of health statistics in 1949–50 and some of the challenges the Committee faced:

By and large, health statistics are still in the horse and buggy stage of development. Except for mortality statistics and morbidity statistics on the reportable diseases, no current index of the health of the general population exists. Mortality statistics and the reports on communicable diseases have served satisfactorily the major needs of the health programs in the past, but with the intensification and extension of health activities, they have become less and less adequate in their present form as indicators of existing health problems. However, these statistics still have very important uses and need to be developed further. . . .

The results of the National Health Survey conducted well over 10 years ago are still being used in estimating the current illness situation. More current data based upon improved sampling and survey techniques are needed. . . .

Hospital records represent the largest existing body of medical information collected currently. Only a limited amount of statistical data are now being derived from these records. . . .

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<sup>5</sup>Report of the Twentieth Anniversary Conference of the United States National Committee on Vital and Health Statistics. National Center for Health Statistics, Series 4, Number 13. Washington, D.C.: U.S. Department of Health, Education, and Welfare, Public Health Service, September 1970, p. 34.

<sup>6</sup>Functions and policies of the U.S. National Committee on Vital and Health Statistics (Washington, D.C.: PHS/HEW, date unknown)

In the field of fetal mortality, there is need for planning methods of securing useful statistics on causes of fetal death. Pregnancy wastage is a problem of considerably greater magnitude than infant mortality in the United States. . . .

The kinds of vital and health statistics needed in the United States are clear in broad outline form, but there remain the problems of filling in the outline, developing techniques and applying them in the field. Progress is hampered by confusion in terminology and lack of agreement among technicians concerning objectives and on the specific approaches to problems. Misinformation, or lack of information, regarding the feasibility of using certain source materials and the validity of results to be obtained from such source data has also added to the difficulty in arriving at satisfactory solutions. Perhaps the greatest obstacle in the development of vital and health statistics has been the lack of research to test hypotheses, methods, and procedures. The U.S. NCVHS is not in a position to conduct field studies or provide funds for research. The committee contributes to progress in the field of vital and health statistics by defining the questions on which a common perspective has been lacking, and by stimulating studies germane to their resolution.<sup>7</sup>

Because several national health statistics bodies existed at that time (notably the Public Health Conference on Records and Statistics), the Committee was careful to define its purview. “The committee recognized that its primary function was to serve as an intermediary in matters concerning vital statistics and health statistics between national and international organizations. . . . Its primary responsibility and great opportunity was to bring United States viewpoints and technical knowledge existing in . . . statistical fields before international bodies and organizations which might consider them and adapt them in whole or in part for broad international usage.”<sup>8</sup>

After surveying the areas of possible activity, the founding members created working groups in the following areas: fetal mortality, statistics of the armed forces, cancer statistics, hospital morbidity statistics, and case register and medical care statistics. Except for the last, all were concerned at least partially with creating internationally comparable statistics.

Another early document adds that “the studies that support these functions are performed by subcommittees appointed to deal with specific questions, or by other organizations cooperating voluntarily with the committee.”<sup>9</sup> Most subcommittees or working groups were composed not of Committee members but of other experts working on special projects administered by the National Committee.

The Committee thus served as the nucleus and coordinator of far-reaching work by dozens of experts. It was viewed from the outset as a technical committee—a cooperative, non-governmental effort without particular authority. (This despite the fact that several Federal employees served on the Committee in the early years.) In its first 15 years, the committee administered 24 investigations in 9 areas. Commenting on the committee’s productivity, the group’s first historian remarked,

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<sup>7</sup>1950 Annual Report

<sup>8</sup>The United States National Committee on Vital and Health Statistics, October 1949, p. 4.

<sup>9</sup>Fact sheet on the U.S. National Committee on Vital and Health Statistics, 12/1/52

The Committee has been especially successful in securing the cooperation of many workers in many fields, whether to serve on the Committee itself or its subcommittees or to act as consultants to either. The overall success of the Committee demonstrates that statisticians and experts in a variety of health areas can work and plan together to the mutual advantage of their professional interests. The institutional forms and procedures that sometimes had to be created or allowed to grow in accomplishing this should be of interest even outside the rather wide boundaries of public health.<sup>10</sup>

## **Completing an International Mission, Shifting to a Domestic Focus**

As intended, the National Committee's first 15 years were largely devoted to revisions of the International Classification of Diseases. This work consolidated the United States' earlier contribution to the shift in international statistics to encompass morbidity as well as mortality. NCVHS' recommendations between 1950 and 1964 concerned live birth and fetal death statistics, fertility statistics, illness and impairment data, the use of hospital morbidity data to study morbidity in communities, medical certification of medicolegal cases, divorce statistics, and statistics on medical economics. (See list of reports in [Appendix 3](#).)

The Committee's first impact on U.S. health statistics began in 1950 with a call for better data on illness, followed by seminal technical work that led to the development of an ongoing National Health Survey. Since the previous (and first) National Health Survey in 1937, Federal public health planners had been forced to rely on national extrapolations of local data such as the Hagerstown Survey. According to a history of the National Health Survey, "Recognizing the inadequacy of available sources and the obsolescence of existing data, the [National] Committee immediately gave its attention to the problem of obtaining adequate national morbidity statistics."<sup>11</sup> In 1953, the Subcommittee on National Morbidity Survey issued a report entitled "Proposal for Collection of Data on Illness and Impairments: United States." This became the basis for specific legislative authorization for the National Health Survey Act of 1955, signed into law in 1956. The bill authorized the Public Health Service to conduct a continuing survey of illness and disability in the Nation. This has developed into the National Health Interview Survey, conducted continuously by NCHS since 1957; the National Health and Nutrition Examination Survey; and other NCHS population surveys.

A 15th anniversary conference in December, 1964 marked a transition point for the Committee. Some 30 current and former Committee members and 7 observers and guests spent 2 days analyzing the state of health statistics and considering where the Committee could make the greatest contribution. It was a propitious time for such a gathering; NCHS Director Forest Linder (later an NCVHS Chair) noted the impending conclusion of work on the 8th ICD revision, on which the Committee had worked intensively, and predicted

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<sup>10</sup>History of the United States National Committee on Vital and Health Statistics, 1949–1964. National Center for Health Statistics Series 4, Number 5. Washington, D.C.: U.S. Department of Health, Education and Welfare, Public Health Service, June 1966. (See also Appendix, "Origins of the National Committee System," p.36)

<sup>11</sup>Origin, Program, and operation of the U.S. National Health Survey, NCHS, PHS Publication No. 1000, Series 1. No. 1. p. 4.

a new stage in which the group “has a chance to look around and see with what new and challenging ideas they might want to engage themselves.”<sup>12</sup> Dr. Robert Dyar, the Committee’s Chair, began by reminding those present of the Committee’s uniqueness:

It is multidisciplinary (an unusual concept 15 years ago); it provides a means for vital and public health statisticians to cooperate with sources and users of their data; it conducts no statistical programs of its own, has no authority except its judgment, and endeavors only to be constructively responsive to questions posed by others in the public health and medical fields; and it is part of an international movement, since some 50 countries have the same or similar framework.<sup>13</sup>

The issues on which that 1964 gathering focused still have striking currency more than 35 years later. The meeting highlighted concerns about the dominance of administrative data and the need for data on communities, socioeconomic status, internal migration, and families. Information needs around race, chronic disease, and divorce were also acknowledged. In addition, a new policy orientation with respect to health resources and services emerged out of concerns about the rising cost of health care.

Three subcommittees created in the 5 years that followed give evidence of a further broadening of the Committee’s attention, to encompass Indian health, migration, and population dynamics. The Committee also created a subcommittee on the epidemiologic use of hospital data, heralding its long involvement with the effort to standardize hospital data.

Another anniversary observance just 5 years later provides an additional window into the Committee’s work and the status of health statistics at the time. At the 20th-year conference held in June 1969, NCHS Director Theodore Woolsey, a long-time friend and supporter of the National Committee, highlighted four significant accomplishments of the National Committee:

The studies which led to the creation of a continuing National Health Survey; the long interest of the Committee in a classification of diseases that could be used to develop multiple causes of death statistics; the Committee’s report on medical economics; and its numerous reports on fertility measurement, culminating in the recommendation of a continuing fertility survey [which the Center was unable to fund].<sup>14</sup>

These anniversary observances did not continue, but the Second International Conference of National Committees on Vital and Health Statistics, held in 1973 and attended by five NCVHS members, offers a useful perspective on the period. A brief history of the National Committee in the 1979–80 Annual Report draws interesting contrasts in “the concept and practice of public health” in the 20 years between the First and Second International Conferences:

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<sup>12</sup>Report of the Fifteenth Anniversary Conference of the United States National Committee on Vital and Health Statistics. National Center for Health Statistics, Series 4, Number 4. Washington, D.C.: U.S. Department of Health, Education, and Welfare, Public Health Service, June 1966, p. 7.

<sup>13</sup>Ibid.

<sup>14</sup>Report of the Twentieth Anniversary Conference of the United States National Committee on Vital and Health Statistics. National Center for Health Statistics, Series 4, Number 13. Washington, D.C.: U.S. Department of Health, Education, and Welfare, Public Health Service, September 1970, p. 3.



At the First Conference, delegates were concerned mainly with the problems of mortality and communicable disease statistics and with ways of improving the quality of these data. At the Second Conference, health survey systems were a thing of the present for meeting the needs of health administrators and health planners. Health indexes, morbidity data from household surveys, medical care records, and data on health resources, including medical manpower and facilities and health expenditures, were an integral part of those systems.<sup>15</sup>

In 1970, NCVHS embarked on an ambitious project that is widely regarded as its signal activity: devising and promoting the standardization of health information through uniform minimum data sets and other means. Although the vital statistics system in the United States was built on the idea of uniform data (for example, uniform birth and death certificates), the principle had not yet been applied to a wide range of other health data.<sup>16</sup> Since 1970, progress in this area has been slow and not without obstacles a “two steps forward, one step backward” dance that continues to the present day. The ensuing years have seen many milestones: minimum data sets for hospital, ambulatory, and long-term care; recommendations on core health data elements; and, currently, a key role in administrative simplification activities. The Committee’s increasing consultation with private sector organizations and growing partnership with the Department have been hallmarks of these efforts. The work on standardization and the impact of the Health Insurance Portability and Accountability Act are discussed below. A few words are in order here about the dramatic changes in the Department and their effect on health statistics in the years following the establishment of Medicare (1965). The Department of Health, Education and Welfare (later Health and Human Services) acquired most of its current size, shape, and duties some 15–20 years after the Committee was formed. Thanks to a flexible structure and steady focus on its charge, the Committee was able to adapt its thinking and operations to this changing environment. A 1976 report on the Cooperative Health Statistics System describes some of those changes as background for the need for a national system to coordinate Federal, State, and local health data systems:

The great increase in the concern of the Federal Government with respect to the planning, provision, and assessment of health resources and health services has called for a corresponding need for and collection of health-related data. Federal concern, financial support, and data collection efforts related to the supply of health facilities and health manpower go back for many years. . . . Legislation supporting Medicare, Medicaid, and maternal and child health services has also given the Federal Government a major role in paying for health services and responsibility for assessing that care. The new health planning legislation has broadened and reinforced these Federal concerns.

The effects of these Federal responsibilities have resulted in a sharp growth in needs for data to plan, administer, and evaluate health service and health

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<sup>15</sup>1979–80 Annual Report, p.17.

<sup>16</sup>Origin, Program, and Operation of the U.S. National Health Survey, NCHS, PHS Publication No. 1000, Series 1. No. 1. p. 4.

resource programs and a proliferation of often duplicated reporting requirements with consequent burdens on State agencies and on health service institutions.<sup>17</sup>

## Expansion

1974 was a pivotal year for the Committee. New legislation (the Public Health Services Act, PL 93–353, sect. 306, passed in July 1974) gave it official status as advisor to the Secretary of Health, Education and Welfare, through the Assistant Secretary for Health. Speaking as the recent Chair of the Panel on Health Services Research and Development of the President’s Science Advisory Committee, Dr. Kerr White had testified in favor of this step before Senator Kennedy’s Subcommittee on Health (Senate Committee on Labor and Public Welfare):

At present there is no specific mention in the statutes of the U.S. National Committee on Vital and Health Statistics. . . . It should be formally designated as the official body for obtaining public advice, assistance and approval for the development and promulgation of terms, basic data sets, classifications, and guidelines for national and international use. All Western countries have such a body, and it is this group through which we “legitimize” common approaches to health statistics at home and cooperate with the World Health Organization and other countries so that international comparisons of health needs, services, demands, and outcomes can be made. [Such 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!<sup>18</sup>

In addition to gaining statutory authority as a result of the new Public Health Act, the Committee was expanded to 15 members and given responsibility for issuing “an annual report on the state of the Nation’s health, its health services, their costs, and distributions, and to make proposals for improvements of the Nation’s health statistics and health information systems.” Thus was launched *Health, United States*, published by NCHS in consultation with the National Committee. This annual report has been an important advance in the use and dissemination of health statistics a means of informing Congress and the public about the Nation’s health and of drawing attention to special problems. The process around the *Healthy People* objectives set for every decade since 1990 has been an important complementary activity in which the Committee also has had an advisory role.

The 1974 legislation embedded the NCVHS charter in the legislation for the National Center for Health Statistics, which has had primary responsibility for staffing it for most

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<sup>17</sup>The Cooperative Health Statistics System: Its Mission and Program. Final Report from the Task Force on Definitions to the Cooperative Health Statistics Advisory Committee, August 30, 1976. HEW Publication Series 4, No. 19, 1977, p. 8.

<sup>18</sup>White KL. Statement to the Senate Committee on Labor and Public Welfare, Subcommittee on Health, 2/19/74.

of the ensuing years and has frequently looked to it for advice. This relationship (probably compounded by the similarity of the two names) has sometimes created confusion about the separateness of the two bodies and obscured the fact that the Committee advises the entire Department. Of the various efforts to address this problem, the most effective has probably been the steady development of strong working relationships with all parts of the Department concerned with health statistics and information. Maintaining balance in these relationships is an ongoing priority for NCVHS.

The late 1970s were characterized by vigorous and productive activity by the Committee on many fronts, enabled by dozens of experts serving on Technical Consultant Panels (TCPs) under its direction. Although a preliminary version of the Uniform Hospital Discharge Data Set (UHDDS) had been devised in 1969 and recommended by NCVHS in 1972, it still was not being used. Work toward its adoption became a top priority when Dr. Kerr White became NCVHS Chair in 1975. They did not stop with hospital discharge data, however; TCPs also were established to review or develop minimum basic data sets for ambulatory care, manpower and facilities, and long-term care.<sup>19</sup> One byproduct of these discussions was a call by the Committee for a universal patient identification number—a subject still on the national agenda 25 years later. The Committee also worked closely with the Cooperative Health Statistics System, an NCHS-based, federally-coordinated program to develop and standardize public and private sector health statistics capacities at the State and local levels.

In addition to working on minimum data sets and other matters through its TCPs, the National Committee took a broad look at the Department's statistical operations. Its 1977 Annual Report called for improved coordination and standardization of Federal health statistics. The analysis was based on a study conducted by the Department's Health Data Policy Committee (HDPC), directed by Gooloo S. Wunderlich, Ph.D. (who became the NCVHS Executive Secretary in 1977, when the staffing function was moved to the Office of the Assistant Secretary for Health).

The HDPC report characterized the Public Health Service and other governmental data systems as “overlapping, redundant, data collection activities that place unnecessary burdens on respondents and produce volumes of expensive data that cannot be aggregated because they are not compatible.” It called for “a cross-cutting, coordinated effort” that it predicted would be “extremely beneficial to filling the overall information needs for monitoring changes in the health field; making resource allocation decisions; and minimizing the public burden.”<sup>20</sup> It also outlined a working relationship between the Health Data Policy Committee, the Department's internal advisory body, and NCVHS, “the primary outside advisory group of experts to the Assistant Secretary of Health. Such a relationship between these two advisory bodies,” it continued, “should result in a balanced and strong influence in the development of systematic statistical systems and mechanisms for assuring better coordination, integration, and accountability of these systems.”<sup>21</sup>

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<sup>19</sup>1975–76 Annual Report, p. 6–7.

<sup>20</sup>Health Statistics Plan, Fiscal Year 1976–77. PHS/HEW, November 1975, p. 2–3.

<sup>21</sup>Ibid, p. 35.

## Hiatus and Reorganization

These productive years were followed by a period of inactivity during which the Department reevaluated the role of the Committee and cut back the Cooperative Health Statistics System. An 11-month hiatus in 1979 was followed by a brief revival in 1980 and then—although the charter was renewed and new members were sworn in—by another hiatus beginning in July 1980 and lasting for nearly 2 years.

A significant challenge to the Committee's mode of operation had occurred in 1979, when the Office of Management and Budget ruled that its use of Technical Consultant Panels exceeded the regulatory authority of advisory bodies. Due to budget constraints and other factors, OMB was working to reduce the number of Federal advisory committees. TCPs thus ceased to operate at the end of 1979, contributing to the instability of this period for NCVHS. Nevertheless, the Committee continued its work, under the Chairmanship of Lester Breslow, M.D., with several subcommittees active in 1979–80. A milestone occurred in 1980 when the Department, with some prodding from the Committee and former members, finally endorsed the UHDDS.

The documents just preceding the long hiatus show a body eager to demonstrate its value to the Department and the health field in an atmosphere of far-reaching administrative changes and budget cuts. After quoting the Department's 1979–80 Health Statistics Plan on the need to develop coordinated and responsible health data systems, the 1979–80 Annual Report comments pointedly,

In order to ensure continuity in Federal programs and to maximize program effectiveness in the face of tightened resources, the Committee believes it necessary to further define and strengthen the Committee in its Charter-mandated role as an adviser to the Secretary and his designees. Although this advisory role has been principally carried out through the Office of the Assistant Secretary for Health, the possibility of Departmental reorganization and changes in administrative responsibilities dictate review of these relationships to ensure that the Committee's advice, consultation, and assistance will be most helpful. . . . The NCVHS believes it must continue to serve as a forum for the free and frank interchange of views on statistical matters from organizations within the Department as well as from other public agencies and the professional and lay public.<sup>22</sup>

These arguments notwithstanding, the Committee was not convened in 1981 or 1982. Theories vary as to the cause of this hiatus, reflecting the different vantage points of their proponents. Through most of them comes a picture of a large, multifaceted Department struggling for balance in the wake of the dramatic changes described above (a struggle compounded by the 1977 creation of the powerful Health Care Financing Administration) and apparently questioning the need to heed an external advisory body.

Still, NCVHS provided a unique mechanism for exchanges among multiple perspectives and interests, and recognition of its ability to link government agencies, States, and the private sector led to its revitalization by the Department in early 1983. The staffing function was returned to NCHS, with Gail Fisher, Ph.D. as Executive Secretary. The challenge then was twofold. The Committee's resources for carrying out projects had

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<sup>22</sup>1979–1980 Annual Report, p.12.

been drastically undercut by the abolition of TCPs, and the pause in its operations had weakened its institutional capacity and momentum. The Committee and staff thus needed to devote time and energy to finding the most effective structures and processes for fulfilling its mandate.<sup>23</sup>

One result of the internal analysis was the formation of an Executive Subcommittee in November 1985. Another was the development in 1986 of a list of “Characteristics for Assessing Emerging Issues” to help guide the Committee in its choice of projects.<sup>24</sup> The group also set its sights on 1–2-year projects, in order to accomplish goals during members’ tenure.

Despite the challenges and reduced resources faced by the Committee, these new approaches were strikingly successful. With tiny budgets and without the use of outside experts, subcommittees have been highly productive, both in their long-term projects and in the quality of their meetings. Between 1987 and the completion of its 50th year, the Committee released 59 reports and sets of recommendations, plus 10 annual or multi-year reports.

It is beyond the scope of this review to discuss these reports and their impact; but an impression of the Committee’s major activities in recent years can be gained from the list of reports in [Appendix 3](#). Observers have noted that since the revitalization, due partly to the changes in the Committee’s composition, NCVHS stopped doing the technical work on the issues it studied. Rather, its work became conceptual and consultative: analyzing problems, reviewing research, talking with experts and those affected by the issue at hand, and then either recommending a general approach or simply urging that a given problem be addressed. The Committee has continued to evaluate how to be most effective in its advisory role, as discussed in the final pages of this report.

The revitalized Committee regarded as critical its function as a link between the public and private sectors. It actively “strengthened its role as a voice and a representative of the private sector’s interest and concerns regarding health data collection, analysis, publication, and interpretation.”<sup>25</sup> Outreach to the private sector was motivated by growing concerns about costs, interest in health care reform, and standardization initiatives in the private sector.

Ronald Blankenbaker, M.D., the NCVHS Chair who spearheaded outreach to the Committee’s non-Federal constituencies between 1986 and 1991, observed in an interview that “the government needs input from the real world outside Washington.” This function is embodied, of course, in the expertise and perspectives of NCVHS members people who “have distinguished themselves in such fields as health statistics, health planning, epidemiology, and the provision and financing of health services.”<sup>26</sup>

Besides providing these links, Committee meetings are open forums on issues, where private sector representatives can interact with each other and with government representatives and, through the Committee, express themselves about public policy. The 1983–85 Annual Report describes meetings as “a forum for the discussion of frequently complex and sometimes conflicting opinions.” Former Executive Secretary Gail Fisher, Ph.D., believes that the meetings serve an important educational function. For example, she has

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<sup>23</sup>1983–85 Annual Report, p. 11–12.

<sup>24</sup>1986 Annual Report, p. 38.

<sup>25</sup>1986 Annual Report, p. v.

<sup>26</sup>PL 93–353, Public Health Services Act, sect. 306, July 1974 (Section (2)(A)).

cited the work on E-codes (external cause of injury coding) that took place in the late 1980s and early 1990s. The existence of a forum for the presentation and discussion of evidence of their uses in prevention convinced many people, including NCVHS members, of their value. “One of the strengths of the Committee,” she observes, “is the experience and seasoning of members, who by questioning those who testify elicit new insights, promote change, and build connections that have value for all participants.” NCVHS also has been innovative in developing mechanisms for two-way written communication with the field and holding regional hearings as ways of maximizing involvement, eliciting opinion, and building consensus.

The Committee’s substantive activities in the 1980s continued the earlier work on minimum data sets, with emphasis on long-term care. It also addressed critical and neglected areas of minority health and community health statistics. (See special sections on these topics.) In addition, concerns about the quality of cause of death statistics arose in 1989 and remained salient for several years. To address those concerns, the Committee developed a new approach: co-sponsoring with NCHS two national workshops on improving cause-of-death information (in 1989 and 1991) and an educational exhibit for physicians that was featured at several national professional meetings.

## **New Issues, New Partners**

In 1988, Congress increased the Committee’s size to 16 and member terms to 4 years, thereby increasing its ability to sustain complex projects. NCVHS stepped up its efforts to facilitate communication and cooperation among levels of government and the private sector, aided by a growing recognition in all sectors of the importance of cooperation and the policy significance of health information. This new emphasis on partnership is typified by the following statement in the 1994 NCVHS Annual Report, which assumes a web of connections between the public and private sectors:

Federal agencies and national bodies such as NCVHS are being asked to facilitate a more inclusive process whereby stakeholders can identify common data needs and find suitable ways to meet them. . . . Importantly, these calls reflect a new conception of national leadership—one that facilitates partnership and consensus rather than seeking to impose a given solution. In essence, government is being asked to assist private sector organizations and functions, not supplant them. This kind of leadership will depend on better cooperation among government agencies, both Federal and State, and private sector institutions. . . . The evolving health marketplace, characterized by a heightened need for information sharing and new thinking about the role of government, is one in which the National Committee on Vital and Health Statistics can play a strategic role.<sup>27</sup>

NCVHS published a special analysis in its 1990 Annual Report, entitled “The Status of Health Data and Statistics in the United States.” The analysis highlighted three areas of particular concern at that time: “the need to develop baseline health data for future decisions; the growing reliance on administrative data sets for setting health policy; and the use of the Social Security Number for linking health and related data.”

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<sup>27</sup>Jones JM. Foreword, The National Committee on Vital and Health Statistics, 1994, p. vi.

The third concern related to the Committee's continuing attempt to promote data linkage and its conclusion that no other mechanism existed or was forthcoming. The recommendation, which reflected the growing need for data uniformity and linkage, was made in the context of a study of personal identifiers by the Subcommittee on Health Care Statistics. That study looked at issues of linkage and the need for a consistent personal identifier across National Health Care Survey components.

The recommendation on identifiers led to an extensive review of privacy and confidentiality issues in health data. The issue had last been addressed in detail at the Committee's 20th anniversary conference<sup>28</sup> — an indication of how long this problem has been both important and unresolved. Before and since that meeting, privacy issues surfaced regularly in the Committee's deliberations, generating periodic acknowledgments of the need to balance access and confidentiality and to protect individual privacy. The decision to focus on these issues led to a 2-year study, culminating in a 1992 report. The Work Group on Confidentiality then recommended that the Committee turn the matter over to a monitor, deeming it unnecessary to commit more of the Committee's scarce resources because other public and private groups were devoting attention to it. Contrary to that prediction, privacy issues landed firmly on center stage for the Committee after 1996, when HIPAA heightened the need for privacy protections and assigned NCVHS an explicit advisory role in this area. The story of the work in the privacy area continues below.

The Committee's Chair from 1991 to 1996, Judith Miller Jones, brought a broad perspective and knowledge of the political mechanics of policy development that helped the Committee stay relevant to the rapid changes and uncertainty surrounding health care reform, which dominated its 1993 and 1994 agendas. Meetings began early on with high-level Departmental representatives appointed by the new President, to examine common concerns about data needs and gaps. From that point on, NCVHS witnessed a growing Departmental interest in a unified approach to health statistics, born of equal parts frustration at the lack of information in some areas, external pressure to consolidate, and ever more compelling reasons to cooperate with all those needing good health information.

With the defeat of system reform legislation in 1994, NCVHS refocused its attention on Departmental programs, the States, and the private sector, where despite the lack of legislation, change was gaining momentum. Among other things, the Committee called for mechanisms to ensure the monitoring of new modes of health care delivery and their outcomes. It also called for the protection of traditional methods of evaluating the Nation's health such as national surveys.

The pace of computerization and standardization in the private sector drew the Committee into concerns about protecting key data content. By 1993, communication with the health-care industry had become a priority, and NCVHS was developing new, and evidently welcome, relationships with dynamic and fast-moving private sector organizations. Members were faced with a new stew of acronyms to learn: CPRI, HOST, ANSI, ASC X12, and others. The Committee used its voice to urge that population-based

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<sup>28</sup>Report of the Twentieth Anniversary Conference of the United States National Committee on Vital and Health Statistics. National Center for Health Statistics, Series 4, Number 13. Washington, D.C.: U.S. Department of Health, Education, and Welfare, Public Health Service, September 1970, p. 5 ff.

perspectives be represented at the table, to increase the likelihood that new information vehicles would permit the monitoring of health status and care for all Americans.

A special charge and funding from PHS and HCFA propelled the Committee in 1994 into a major project to evaluate common core health data sets for enrollment and health care encounters—the latest stage of the longstanding effort to generate standardized health care information. This undertaking is described briefly in the thematic section below.

NCVHS observed its 45th anniversary in mid-1995 by revisiting the Committee's origins and affirming core principles. It published a 45-year history (which is incorporated in this document), and hosted a 45th Anniversary Symposium to explore and promote partnerships for better health information. This unusual pause at the 45-year mark reflected the Committee's desire to address the extraordinary changes underway in the mid-1990s in health care delivery and health information systems. Amid changes in the marketplace, in the Federal Government, and at State and local levels, the critical role of information was gaining recognition while the resources for infrastructure development were shrinking.

The 1995 Symposium agenda represented a broad statement of the Committee's concerns as it looked toward the next millennium. Participants examined the special data needs of community-based programs; discussed the evolving responsibilities of localities, States, and the Federal Government; and considered the impact of managed care initiatives, especially on primary care delivery programs. A central question was what types of partnerships were needed among public and private stakeholders to promote information for health.

## **The HIPAA Era Begins**

In 1996 began a new era for the Committee, bringing a strong new mandate, a heavy workload related to administrative simplification and health information privacy, and unprecedented levels of collaboration with the Department and of accountability to Congress.

A new charter in January 1996 expanded the scope of the Committee just as nine members were completing their terms and Judith Miller Jones prepared to hand the gavel to Donald Detmer, M.D. During this transition, members engaged in a vigorous dialogue with policymakers aimed at preserving the Committee's historic mission and role while reshaping it to emerging needs. The passage of HIPAA in August heightened the sense of a new era by giving the Committee new responsibilities relating to administrative simplification and privacy, and directing the Department to consult with NCVHS as it carried out the law's directives. NCVHS geared up to carry out these responsibilities while continuing its work on many other fronts. The work on HIPAA assignments—which can only be described as a sea-change in the life of the Committee—is described in the topical section below.

In 1997, NCVHS performed many information-gathering and forum functions, some but not all related to HIPAA responsibilities. In the zone of population health, the Committee also began exploring a new advisory relationship to the National Center for Health Statistics—a dialogue that lasted nearly 3 years and ultimately both changed and strengthened that relationship. Together, these bodies launched a visioning process for 21st century health statistics that is described below.



1997 also marked the retirement after 14 years of service of Executive Secretary Dr. Gail Fisher. Her successor, Marjorie S. Greenberg, is the Committee's 7th Executive Secretary in 49 years. As noted, the continuity of service and contributions of these seven individuals is regarded as an important reason for the National Committee's effectiveness. During this period, James Scanlon of the DHHS Office of the Assistant Secretary for Planning and Evaluation became the Executive Staff Director for NCVHS, facilitating the assignment of staff to the Committee from throughout the Department.

1998 brought the completion of the first phase of administrative simplification assignments and progress on large-scale visioning projects on the future of health statistics and on the national health information infrastructure. The struggle to keep privacy protections apace with administrative simplification grew intense as the Committee began to study issues associated with a unique health identifier for individuals, as part of the HIPAA mandate. Initiatives on population-based health focused on Medicaid managed care, data on the Islands and Territories, monitoring revision of OMB Directive 15 and implementation of its successor, and data on care provided in non-conventional settings such as long-term care facilities and homes (commonly called "post-acute" care, or more appropriately, continuum of care). During 1998, Don Detmer handed the gavel to the Chair who would lead the Committee into the 21st century, John Lumpkin, M.D. Dr. Lumpkin is the first State public health official to head NCVHS.

Much of the Committee's work in 1999 continued or laid the groundwork for projects planned to culminate in 2000 or 2001. These activities are described in the topical section below. The 50th Anniversary Symposium held in June 2000 marked both the Committee's passage into its second half-century of service and the unveiling of its visions for 21st century health statistics and the national health information infrastructure. The event, which is summarized in a separate report in this volume, provided a welcome vantage point from which to view the Committee's past and future as well as the needs and opportunities presented by a new century.

## **Major Areas of NCVHS Activity**

### **Population Health and Statistics on Specific Populations**

The activities described below have been spearheaded by the Subcommittee on Populations. In the 1996 reorganization, this Subcommittee was assigned the responsibilities of three NCVHS precursors: the Subcommittees on Mental Health Statistics, Disability and Long-Term Care Statistics, and Health Statistics for Minority and Other Special Populations. That broad scope has remained a challenge for the Subcommittee and the entire Committee—one discussed below in the section on Suiting Form to Function.

The Subcommittee on Populations identifies priorities, strategies and opportunities for gathering data and also works to ensure attention to these priorities by the full Committee and other bodies, including the Department. Under its leadership, NCVHS has carried out important initiatives on such wide-ranging topics as race/ethnicity data, Medicaid managed care, continuum of care, quality of care, and health statistics for the 21st century. The common denominator has been the search for better data on populations whose defining characteristic—for example, age, income, health insurance status, disability, race or ethnicity—heightens their risk of experiencing poor health outcomes (for example, excess mortality), substandard care, inadequate access to services, or other negative response from the health care system.

### **Minority Health Statistics**

NCVHS members first discussed the severe inadequacies of health information on non-white racial and ethnic groups at its 1964 15th Anniversary Conference. Until 1986, however, the only sustained and focused activity in this area was through a Subcommittee on Indian Health Statistics (1965–69). The Committee established the Subcommittee on Minority Health Data in 1986 to more systematically address the significant data gaps and inconsistencies in that area. Concerns about medical indigence resulted in 1989 in an expansion of the Subcommittee's charge and name to the Subcommittee on Health Statistics for Minority and Other Special Populations.

Illustrating the confluence of forces that precipitate change, a lawsuit filed in 1993 gave an important boost to the effort to improve race and ethnicity statistics. It charged that the Department was unable to comply with civil rights legislation because its statistics lacked sufficient detail to document the absence or presence of discrimination. Before the case was dismissed, as it ultimately was, the Department stepped up its efforts to improve its race/ethnicity data.

The Committee addressed socioeconomic factors in a special 1992 report that outlined the relationships among race, ethnicity, socioeconomic status, and health. The report was a product of a special NCVHS meeting on that topic at which experts testified

on the potential misinterpretations of race data that can occur in the absence of information on socioeconomic status. Later, in 1998, the Committee endorsed the ambitious Healthy People 2010 goal of eliminating disparities among U.S. population groups in their health status and access to prevention and care. Now its role is to help find appropriate ways to collect these data so that they can be usefully linked with healthcare and health data.

A review of Directive 15 (Racial and Ethnic Standards) by the Office of Management and Budget was a longstanding interest of the Subcommittee, working closely with the HHS Office of Minority Health. The Subcommittee submitted comments on the report of the Interagency Committee for the Review of Directive 15 in 1997, endorsing its major recommendations but expressing reservations about some aspects. It offered assistance in developing guidelines for tabulation and other technical matters, and is monitoring the implementation of the revised Directive.

## **State and Community Health Statistics**

As with minority health statistics, the problem of inadequate State and community statistics was acknowledged for many years before being institutionally addressed by the Committee. A subcommittee was created when two things coincided: the issue took on special urgency, and the right leadership was available to head up an organized effort.

The Subcommittee on State and Community Health Statistics was formed in 1991 on the recommendation of a work group on community health statistics. Unlike the aforementioned subcommittee, this one had a long lineage prior to its formal establishment. State and local statistics were first addressed in the context of the Cooperative Health Statistics System, described above. In the 1980s, the explosion of HIV/AIDS and the Department's development of Healthy People Objectives for the Year 2000 focused the Nation's attention on prevention and the need for local data. NCVHS addressed both issues from 1985 to 1988 through the Subcommittee on Data Gaps in Disease Prevention and Health Promotion and another similarly named Subcommittee (see [Appendix 2](#)).

The first report of the Subcommittee on State and Community Health Statistics, issued in 1993, explored the gaps in State and community health statistics. A major recommendation was that the Department strengthen State centers for health statistics as a way of using existing resources to enhance the national information infrastructure. NCHS staff member Mary Anne Freedman, who served on the National Committee before joining NCHS, staffed the Subcommittee and helped prepare its 1993 report. She has observed that while the recommendations were well thought-out and have merit, they require resources to implement and must compete with other Departmental priorities. They may therefore share the fate of other NCVHS recommendations that simply "sit on a Department shelf."

The Standards Subcommittee took on the portfolio of the Subcommittee on State and Community Health Statistics in the 1996 reorganization. As part of the ongoing campaign to strengthen State and local health statistics, the following year the full Committee approved recommendations concerning community health assessment and the respective roles of State health agencies and the Federal Government in facilitating the assessment process. This report was sent not only to the Secretary but also to the Association of State and Territorial Health Officials and the National Association of County and City Health Officials for their consideration.

## **Disabilities, Mental Health, and Long-Term Care**

Long-term care appeared on the NCVHS agenda in 1975 when work began on the long-term care minimum data set. The Subcommittee on Long-Term Care Statistics was established in 1987 and renamed the Subcommittee on Disability and Long-Term Care Statistics in 1994. Along with mental health, this subject area became an important mechanism for broadening the Committee's purview: beyond acute and institutional care, beyond a medical model of health, and even beyond the health care field to other service arenas. Before its domain was assigned to the Subcommittee on Populations, this Subcommittee issued a series of reports on data needs and gaps in respect to long-term care.

The Subcommittee on Mental Health Statistics, created in 1990, often worked in tandem with the one on Long-Term-Care. In its short life, this group made a mark on health statistics. Its recommendation that a mental health measure be added to the National Health Interview Survey was endorsed by NCHS in 1992, and in 1994 the National Institute of Mental Health accepted its recommendation to include a national probability sample of the U.S. child population in the 1996 Child Epidemiological Catchment Area (ECA) Study.

In 1999, the Subcommittee on Populations launched a study of the feasibility of incorporating functional status as a standard element on administrative (encounter) health records, and in particular the appropriateness of the International Classification of Functioning, Disability and Health (ICIDH-2) as a potential means of coding such data.

## **Medicaid Managed Care**

Also in 1999, the Populations Subcommittee completed a 2-year review of the data implications of the large-scale shift of Medicaid beneficiaries into managed care. The Subcommittee was motivated by two chief concerns: that the continuity of information on Medicaid beneficiaries was threatened by the limited data-collection practices of managed care organizations; and that data gaps would make it difficult to monitor the quality of care beneficiaries receive. After holding hearings in Washington, D.C., Massachusetts, and Arizona, the Subcommittee issued a report recommending ways to improve data collection to permit evaluation of the impact of managed care on the health of Medicaid enrollees and their access to and use of health care services.

## **Islands and Territories**

The same year, NCVHS approved and transmitted to the Department a report containing recommendations on health data needs and issues in the U.S.-associated insular areas (Puerto Rico and the Virgin Islands) and Pacific Islands. The Subcommittee based its report on findings from a 2-day meeting with representatives from the islands and territories.

## **Care Across the Spectrum of Settings**

A series of activities in this area began in the mid-1990s when the Subcommittee raised questions about HCFA's plan to mandate the use of the Outcome Assessment Information Set (OASIS) by home health agencies. NCVHS recommended that HCFA review all data collection initiatives concerning the continuum of care with the goal of

having consistent data collection methods. Two Subcommittees, on Populations and on Standards and Security, then met with HCFA to consider data requirements for such care. NCVHS sought to work with HCFA and the Department to develop a coherent data policy that focuses on patients' attributes rather than specific features of settings of care. However, HCFA went on to promulgate OASIS.

## **Quality**

NCVHS stays in touch with the organizations created in 1999 to carry out the recommendations of the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry. It created the Work Group on Quality in 1998 as part of the Subcommittee on Populations, to coordinate work on this subject that is of longstanding interest to the Committee. An early focus was data on the quality of care in the spectrum of settings and data on the quality of managed care for Medicaid beneficiaries.

## **Privacy and Confidentiality**

NCVHS has long recognized that the information platform for health care and health policy must have as its cornerstone strong measures to protect individual privacy. Promoting the linkage between these two has been a major NCVHS commitment in recent years, but it is not new to the Committee's work. For example, its recommendations about uniform data sets have from the beginning emphasized privacy protection as a critical precondition.

The challenges to privacy, and thus to the Committee's work, became more pronounced with the enactment of HIPAA, as outgoing Chair Judith Miller Jones observed in a prophetic statement in her Foreword to the 1995 Annual Report:

Congress has inadvertently made the work of the Committee more difficult by including administrative simplification in its recent reforms of the health insurance market without enacting confidentiality safeguards. In so doing, Congress has drawn heightened attention to these issues well before it appears ready to grapple with them. Having looked at these matters for many years now, the Committee would recommend, as always, that confidentiality safeguards already be in place as standardization efforts move forward.<sup>29</sup>

Once charged by HIPAA with moving ahead on administrative simplification, the Committee accorded privacy protection greater salience by giving it full Subcommittee status for the first time. That Subcommittee held six days of public hearings in 1997 and several roundtable discussions in 1998, providing a forum for a spectrum of views on privacy and confidentiality issues in research, law enforcement, marketing, health services, and other activities.

## **Recommendations to the Secretary**

The Subcommittee worked closely with the Department's Privacy Advocate to develop the NCVHS and HHS recommendations on privacy and to monitor the responses

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<sup>29</sup>Jones JM. Op cit, p. ix-x.

to them. The Committee issued a major report in June 1997, recommending that the Department and Administration assign a high priority to developing a strong position on health privacy. The report further recommended that the 105th Congress enact a health privacy law prior to the end of its 1998 session. Secretary Shalala echoed these recommendations in her September 1997 testimony to Congress. The Committee Chair testified before the House Ways and Means Committee on March 24, 1998, and the Committee continues to closely track proposed legislation.

When 1998 ended without passage of Federal privacy legislation, NCVHS began laying the groundwork for privacy regulations to be promulgated by the Department, as directed by HIPAA, and then submitted comments after the proposed regulations were released in late 1999.

The Committee continues to urge that strong national privacy legislation be passed without further delay, even in the presence of administrative regulations.

## **Registries**

The Privacy Subcommittee held a roundtable discussion in 1998 on health and medical registries with participants from interest and advocacy groups, government, for-profit and non-profit organizations, the health care industry, the research community and academia. On the basis of that discussion, the Committee recommended to the Secretary that health data be provided only to registries that conduct research, public health, and related activities. It also cautioned that legislation should not undermine the flow of health information into or out of such registries.

## **Identifiability**

After hosting a roundtable on identifiability, the Committee submitted 1999 recommendations to the Secretary that include the caveat that everyone who collects and uses health data should pay attention to and continually evaluate the likelihood that as technology develops, data once believed to be nonidentifiable may at some point lose that status. The recommendations state that institutional review boards, in particular, should be alerted to this issue.

## **Fraud and Abuse**

The Subcommittee sponsored a roundtable discussion with industry investigators in mid-1998, beginning a study of the issue of balancing health data confidentiality and the need to investigate and control health care fraud and abuse.

## **Review of Health Information Privacy Model Act**

In late 1998, the Subcommittee was briefed by the National Association of Insurance Commissioners about the organization's "Health Information Privacy Model Act." It sent a letter to the Association and each of the 55 Commissioners in 1999, stating its concerns about the proposed model legislation.

## Standardization

Former Chair Kerr White, M.D., has spoken of the Committee's desire to help create a seamless web of information on health and health care. The often overlooked distinction between data and information is critical to this process, as his contemporary NCVHS member James Cooney, Ph.D. makes clear in a 1980 discussion paper:

In terms of quantity, large amounts of data are available. However, as informational resources, the data have limited potential in terms of present quality and usability. 'Similar' data available from existing multiple sources generally lack uniformity of definition and universal availability. As a consequence, . . . definitional differences preclude meaningful comparisons, current redundant collection is expensive. . . , and major data gaps exist. . . .<sup>30</sup>

Promoting the standardization of health information to remedy this situation has been a consistent and defining NCVHS activity since 1970. The campaign was spearheaded originally by NCVHS Technical Consultant Panels (TCPs) and other subcommittees, after 1987 by the Subcommittee on Ambulatory Care Statistics (which in 1989 became the Subcommittee on Ambulatory and Hospital Care Statistics), and since 1996 by the Subcommittee on Standards and Security. The Committee's efforts have been, and continue to be, aimed at achieving comparability in the health data collected by Federal agencies, States and localities, the private sector, and the international community. Uniform, comparable standards are needed across geographic areas, populations, systems, institutions and sites of care, to maximize the effectiveness of health promotion and care and minimize the burden on those responsible for generating the data. To this end, the Committee has advised the Department on such matters as Federal-State relationships, and core data sets, as well as nomenclatures and classification systems and access and confidentiality issues.

The role of the Committee has, in fact, been crucial, because by its very nature standardization involves many parts of the Department and other players outside the Federal Government who need an overarching and disinterested body to facilitate the process. Descriptions of the major NCVHS standardization activities follow.

### Uniform Hospital Discharge Data Set

The first U.S. attempt at data uniformity outside vital statistics began in 1969 with an historic conference at Airlie House in Virginia that brought together an international group of public and private users and providers of information on short-stay hospital inpatients. The meeting generated a request that NCVHS develop a uniform minimum data set for hospital discharges. The idea of collecting uniform hospital data was first advanced a century earlier, by Florence Nightingale. Following the Airlie House conference, an NCVHS subcommittee was appointed for this purpose in 1970. It issued its final report in 1972, and its criteria for inclusion or exclusion of a data item from the minimum data set were adopted. (They were later broadened for generic use, picking up the Airlie House vision of linkage among multiple data sets.) The first Uniform Hospital Abstract Minimum Data Set was published in 1973 after extensive field test and study.

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<sup>30</sup>Cooney J. Discussion Paper on Uniform Minimum Health Data Sets (UMHDS), 1/2/80 (unpublished), p.1.

While not endorsed as Departmental policy until 1980, it was endorsed by several key national organizations in the private sector.<sup>31</sup>

The UHDDS concept underwent little further development until 1975, when NCVHS established a TCP to review the original recommendations in the light of current and rapidly changing needs for discharge data. The Committee endorsed the results of that review in 1979 and forwarded it to the Department. Its report on the UHDDS was published in 1980. The revision, further revised by DHHS's Health Information Policy Council, was published by the Department on July 31, 1985 and became effective on January 1, 1986.

Systematic revision activities continued for several years. The Committee recommended a revision of the 1984 UHDDS to the Department in June, 1992; an interagency task force made its recommendations for a revised UHDDS on May 1993; and NCVHS commented on those recommendations in July, 1993. The Committee incorporated these recommendations into its 1996 core health data report (see below), which as of this writing are still under review by the Department. Many of the elements are present in the standard transactions now used by the Department and industry. In 1991, the Committee made an important contribution to the use of hospital data in the area of external cause of injury codes (E-codes). After becoming convinced of the merits of E-codes for prevention efforts, the Committee's representatives attended a series of meetings of the National Uniform Billing Committee and were able to convince them to add a space for E-codes on the new Uniform Bill for Hospitals (UB-92). The Committee also recommended that E-codes become an element of the UHDDS.

The UHDDS was the flagship in what was envisioned as a fleet of minimum data sets covering ambulatory care, long-term care, health manpower, and health facilities collectively called the Uniform Minimum Health Data Set (UMHDS). (There was no effort to link the data in these data sets.) In addition to hospital care, NCVHS has concentrated on ambulatory care and long-term care.

According to Marjorie Greenberg, who has staffed the Committee since 1983 and served as Executive Secretary since 1997, "The UHDDS and the UACDS [see below] are considered de facto standards by Federal agencies, States, and much of the private sector collecting data on hospital discharges and ambulatory encounters."<sup>32</sup>

## **Ambulatory Care Minimum Data Set**

A conference on Ambulatory Care Data was held in 1972, resulting in the formation of an NCVHS Technical Consultant Panel in 1973 to identify data elements for a uniform minimum data set on ambulatory care. The Committee approved the recommended Ambulatory uniform minimum data set in 1974, and a TCP continued work on the data set during Dr. Kerr White's tenure. The data set was reviewed in 1987, and NCVHS and an Interagency Task Force jointly recommended a revision in 1989. For several years, the 1989 iteration of the UACDS served as a de facto standard in the field. The Committee reviewed the UACDS again in 1993, and transmitted its findings and recommendations to the Department in July 1994. It recommended several enhancements, but concluded that

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<sup>31</sup>Greenberg MS. History of Health Care Core Data Set Development, attachment 1 to Common Core Health Data Sets, 1/31/95 (unpublished).

<sup>32</sup>Ibid.



the 1989 UACDS is basically sound. The data set has been widely disseminated and well received in the private sector. As with the UHDDS, the elements were incorporated into the NCVHS core data recommendations in 1996.

## **Long-Term Care Minimum Data Set**

A conference on Long-Term Health Care Data was convened in 1975. That meeting fulfilled the vision of the Airlie House conference by taking a similarly broad view of the uniform minimum health data set. It recommended to the Department that

the U.S. Committee assume a developmental role in the long-term care UMHDS; all three data sets [hospital, ambulatory, and long-term care] be reviewed, revised, and promulgated by the U.S. Committee; the Department take the initiative to cooperate with WHO in joint international development of UMHDS.<sup>33</sup>

Later, however, the Long-Term Care MDS was “eclipsed by the Minimum Data Set for Nursing Facility Resident Assessment and Care Screening, mandated by the Omnibus Budget Reconciliation Act of 1987 and implemented by HCFA in 1991.”<sup>34</sup> NCVHS published reports on a long-term care minimum data set in 1980 and 1987. The Committee has followed the development of the nursing facility and resident assessment MDS and provided advice on data quality and computerization.

## **Cooperative Health Statistics System (CHSS)**

The CHSS was established in 1974 by the same landmark legislation (PL 93–353) that formalized the status of NCVHS and NCHS and that called for an annual report on the nation’s health. Until the program’s reduction in the mid-1980s, the Committee worked closely with the CHSS Advisory Committee and with NCHS, serving briefly in 1980 as the CHSS advisory body. The CHSS was designed to facilitate the development and maintenance of shared data systems to meet multiple purposes. It was essentially voluntary, moving toward agreements between Federal, State and local public and private agencies. It addressed the priority needs of health planning agencies and public health while recognizing the need to progressively use the extensive administrative health record systems that were rapidly developing. It was concerned with the proper balance between legitimate access to data and protection of privacy and confidentiality, and it worked collaboratively to develop model State legislation for these purposes.

## **Core Data Elements**

The need to standardize data definitions and transmission was one of the few things on which the national health care reform debate of the early 1990s produced agreement. This led to a new opportunity for NCVHS to promote administrative simplification and improved care management. In late 1994, HCFA and the Office of the Assistant Secretary for Health charged the Committee with helping to identify common data needs for enrollment and encounter, thus helping policy makers, payers, administrators and

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<sup>33</sup>Cooney J. Op.cit., , p.12.

<sup>34</sup>Greenberg MS. Op cit.

providers to improve delivery and quality assurance performance measures. The goals were identified as better information on the characteristics of individuals and populations through the enrollment process, and greater knowledge about health care encounters. The Department's request recognized the Committee's long experience with minimum data sets and its concern about data reliability, validity and the burden of collection.

Its charge was, in effect, to provide advice and leadership through consultation, listening and partnership—the essence of the Committee's historic role, and increasingly the role of the Federal Government. To fulfill this charge, the Committee consulted widely with those in the public and private sectors with direct experience with the issue.

The Committee concluded the 2-year project in 1996 after an extensive survey of the health field about data-collection practices, together with interaction with HCFA and other bodies also working on core data sets. The bulk of the project focused on ambulatory and hospital settings, but NCVHS subcommittees also considered additional data elements that relate to the areas of mental health, substance abuse and long-term care. The 50-page final report specifies 42 data elements that it proposes for standardization. Of these, it calls special attention to six for which “no consensus currently exists concerning appropriate or feasible definitions” namely, personal unique identifier, self-reported health status, functional status, type of encounter, current or most recent occupation and industry, and patient's stated reasons for visit or chief complaint. The Committee urged the Department to give high priority to further development of these elements. In addition to the Population Subcommittee's work on functional status, described above, the Committee is monitoring the implementation of these recommendations, particularly those requiring further research and evaluation.

## **Health Insurance Portability and Accountability Act and Its Impact**

In the 1990s, the health care industry increasingly took the initiative in bringing about forms of standardization important to its broadly defined business functions. Thus one NCVHS activity in the mid-1990s was maintaining communication with these standards development organizations, following their activities, and offering input based on its own priorities. An important emphasis was, and is, the content of data to be transmitted, in order to ensure that the transmission medium does not constrain the key messages. Finding ways for public health interests to participate in standards development has been a related concern.

The 1996 Health Insurance Portability and Accountability Act (HIPAA) mandated that the Committee advise the Department on health data standards in the following areas: 10 administrative and financial transactions, including claims attachments; identifiers for payers, providers, employers, and individuals; code sets and classification systems; security safeguards; electronic signatures; privacy; and the electronic medical record.

The progress in these complex activities is reported in detail in annual reports on HIPAA implementation that Congress has required since 1997. This reporting requirement and the two Congressional appointments since 1996 have brought NCVHS into a new, more direct relationship with Congress. The Committee has welcomed the heightened Congressional interest in its work and the opportunity to report directly to it.

The HIPAA mandate, which came on the heels of the core data elements recommendations, broadened the Committee's attention to the information needs of all health programs across the nation, both public and private. The legislation emphasized the use of standards developed by accredited standards-setting organizations, wherever possible, rather than ones exclusively developed by government or quasi-governmental bodies. The mandate of necessity shifted the Committee's focus, at least in the short run, from data content to electronic transactions. The sheer volume of responsibilities assigned to NCVHS in order to advise HHS in this area has made it difficult for the committee to sustain its work on population health information needs, a concern discussed further below.

HIPAA set in motion a strenuous process whereby the Committee, led by the Subcommittee on Standards and Security, held hearings to consult with industry, offered recommendations to the Department on the development of Notices of Proposed Rule Making (NPRMs), and commented on the published NPRMs, working closely with HHS implementation teams. The Committee also has supported outreach to the public health and health services research communities, to ensure that they understand the implications of HIPAA for them and are present at the table as decisions are being made. A November 1998 workshop on this subject, supported in part by the Committee, affirmed the potential benefits of administrative simplification for public health and research purposes and the need for these sectors to be part of the development process. The workshop led to formation of the Public Health Data Standards Consortium.

## Unique Health Identifier for Individuals

The Committee has spoken out for many years on the need for a unique health identifier, while also stressing security and confidentiality protections as a precondition. The 1996 core data elements recommendations, developed prior to the passage of HIPAA, state that "agreement on a unique personal identifier has been recognized as a key element to the successful establishment of core data elements and their use." The NCVHS recommendations advise the Department to "support the formation of a public-private working group to conduct research and provide recommendations in this area."<sup>35</sup>

This issue took on greater urgency when HIPAA imposed a timetable on the Department for deciding on a unique identifier, in consultation with the Committee. For about two years the individual health identifier commanded a great deal of attention and care by the full Committee and two of its Subcommittees (Standards and Privacy), due both to its complexity and to public concerns about real or perceived threats to confidentiality. NCVHS launched its heightened advisory role in this area by commissioning a white-paper analysis of options for the identifier. Then in 1997, with no privacy legislation in sight, the Committee took the unusual step of declining to comply with a HIPAA directive, recommending to the Secretary that it was premature to select a unique health identifier for individuals until security and confidentiality issues are resolved by Congress.

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<sup>35</sup>NCVHS core data elements recommendations, 1996. Quotation is on page 3; also see discussion on page 17.

The Committee hosted a public hearing on the individual health identifier in mid-1998, but soon thereafter suspended all work in this area pending the passage of national privacy legislation.

## **Computer-Based Patient Records**

Beginning in the early 1990s, the Committee was regularly briefed by such groups as the Computer-based Patient Record Institute and the Medical Records Institute on progress toward the computer-based patient record (CPR). NCVHS created its own CPR Workgroup in 1998 to develop HIPAA-mandated recommendations and legislative proposals on uniform data standards for patient medical record information and its electronic exchange. The Workgroup held a series of hearings that led to recommendations to the Secretary that the Committee approved on the morning of its 50th Anniversary Symposium. In its report, the Committee signaled its intent to recommend in 18 months specific standards for consideration and adoption by the Secretary through the rulemaking process.

## **Medical Nomenclature and Classification**

Classification projects have been a staple of the NCVHS agenda since its inception in 1949. As noted, the International Classification of Diseases was its major focus for the first 15 years, through the completion of the 8th revision. Complaints from medical groups about the noninclusive process used for the 9th revision led NCVHS to return to this issue in 1983, in anticipation of the 10th revision. Chairman Robert Barnes, M.D., used the Committee as a forum for input from the field, thus demonstrating the value of the newly revived National Committee. Former NCVHS member William Felts, M.D., an active participant in the process, has described the NCVHS role as strategic and successful:

NCVHS sponsored a conference to which medical organizations and specialty groups were invited, and the open forum provided invitations for their formal input into the U.S. suggestions for changes for the 10th revision. Comments were individually considered and most were subsequently included in the recommendations submitted to the World Health Organization in Geneva. Thereafter, the U.S. delegation, several of whom were NCVHS members at the time, referred to those recommendations on the floor of the Assembly of the [1989] Revision Conference in Geneva and succeeded in having most of them adopted by the Assembly after they had been questioned by WHO staff. Both the process and the representation were effective.<sup>36</sup>

Medical opinion was not unanimous about the 10th revision process for the ICD. Kerr White, M.D., appeared before the Committee at a 1983 hearing to urge on behalf of primary care physicians “that the ICD-10 revision process be delayed several years to enable restructuring of the classification to accommodate the International Classification of Primary Care (ICPC).”<sup>37</sup> Although this request was denied by the World Health

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<sup>36</sup>Felts WR. Correspondence, 6/13/95.

<sup>37</sup>1983–85 Annual Report, p.8.

Organization, the Committee has stayed abreast of the development of ICPC, which along with other primary care classifications was receiving growing attention by the mid 1990s.

Bruce Steinwald, who chaired the Subcommittee on Medical Classification Systems from 1993 to 1996, jokingly described its stance toward ICD-10 at that time as one of “eternal vigilance.” That vigilance resulted in a successful request that the Department evaluate the system’s applicability for morbidity purposes, along with expressions of concern about the serious NCHS staffing shortages and their implications for ICD-10 implementation.

Since then, NCVHS has been regularly briefed by NCHS and HCFA representatives (including the co-chairs of the ICD-9-CM Coordination and Maintenance Committee) about the transition from ICD-9 to ICD-10 for mortality coding, and about the development and testing of the clinical modification for diagnostic coding (ICD-10-CM) and a new procedure classification system (ICD-10-PCS) to replace ICD-9-CM, Vol. 3. In addition, the American Medical Association has briefed it on CPT.

The Committee co-hosted a 1993 hearing on revising the International Classification of Impairments, Disabilities and Handicaps (ICIDH), thereby giving brief attention to another international classification system and making the Committee’s forum capabilities available to the disability community. Following that meeting, the Committee decided that limited resources made it impossible to take a more active role with the ICIDH. The Committee resumed activity in this area in late 1999 with its project on functional status, described above.

The Committee has for years been planting seeds for a single procedure classification system, in hopes that they will eventually bear fruit. The subject was an area of intense activity for the Subcommittee on Medical Classification Systems. In 1983 and again in 1986, NCVHS called for “strong efforts” to develop a single procedure coding system for the United States, to replace the use of Volume 3 of ICD-9-CM in hospitals and the American Medical Association’s CPT-4 in ambulatory settings.<sup>38</sup>

Then in 1992, the same Subcommittee “undertook anew a review of procedure classification, [seeking] advice from a wide range of organizations and individuals who have a stake in procedure classification.” This involved an extensive communication process using mailed surveys and meetings, by which NCVHS elicited information and opinion from the field. The investigation resulted in a 1993 report, approved by the full Committee, recommending development of a single system. In 1994, HCFA informed the Committee that it would continue its efforts to modify Volume 3 of ICD-9-CM while continuing to use the HCFA Common Procedure Coding System (HCPCS) for physician and ambulatory reporting. (The HCPCS is based on CPT-4 and has been augmented for nonphysician services.) Subsequently, the AMA appointed an Exploratory Committee to consider the longer term future of CPT, an evaluation in which NCVHS participated.

In 1997, the Committee recommended the continued use of current code sets for diagnosis and procedure coding until replacements are ready (2001 or thereafter). It also encouraged the Department to advise industry to build and modify their information systems to accommodate a change to ICD-10-CM diagnostic coding in the year 2001. Finally, it recommended a major change by the year 2002 or 2003 to a unified approach to coding procedures, yet to be defined.

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<sup>38</sup>1983-85 Annual Report, p.7; 1993 Annual Report, p.56.

## Visioning Projects: Using Information for Population Health

In the final years of the 20th century, NCVHS embarked on two ambitious projects to clarify how emerging information capacities can be used most effectively to promote the nation's health and meet future health needs. Both projects are expected to generate detailed Vision statements in 2001: a vision for 21st century health statistics and a vision for the National Health Information Infrastructure (NHII). Each has produced an interim report, included in this volume. These reports were the centerpiece of the 50th Anniversary Symposium, hosted by the National Academy of Sciences in the Committee's honor in June 2000.

NCVHS launched the NHII initiative in 1997 and published a concept paper on it in 1999 after presenting it to the Data Council. The purpose of this sweeping project is to wrap a conceptual framework around all existing, developing, and as yet unrealized public and private sector health information networks in community, provider, and personal dimensions. By clarifying the relationships among these many facets, the NHII framework will make it possible to coordinate and integrate health information networks and activities more efficiently and to identify critical gaps.

The 21st Century Health Statistics Vision initiative began in 1999 under the joint auspices of NCVHS, NCHS, and the HHS Data Council, in response to a 1997 request by NCHS Director Ed Sondik, Ph.D. The coordinators sponsored a series of consultations around the country with health statistics users, public health professionals, and health care providers at local, State, and Federal levels. The objective was to elicit a broad range of expert opinion on the major trends and issues in population health and their implications for future information needs. This consultative process will generate a final Vision document together with suggestions for its use in program planning and criteria for evaluating future health statistics systems.

One of the anticipated benefits of these closely related endeavors is that the interconnections between population health and individual health, those between health and health care, and the implications of all these dynamics for health information policy will be clarified. This should help the Committee coordinate what Chairman John Lumpkin calls "the left and right brains" of its work<sup>39</sup> medical care and population health.

An important and stimulating dimension of both the NHII and health statistics projects is the opportunity to collaborate with and learn from other countries. These links were made manifest at the February 1999 NCVHS meeting, when the developers of the national health information infrastructures of Australia, Canada, and the United Kingdom reported on their countries' activities and plans in this area and talked with the Committee about common information needs for national health policy. The growing sense of connection to the international context in the Committee's fiftieth year neatly reconnects it with its origins "as part of an international movement."<sup>40</sup>

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<sup>39</sup>1993 Annual Report, p.56.

<sup>40</sup>See section "Completing An International Mission" in this report.

## Ongoing Challenges

### Suiting Form to Function

The National Committee has worked hard to ensure that its internal structure reflects and serves the full range of its priorities. As noted, questions of structure and process came to the fore in the 1980s; and the changes in 1996 again stimulated a study—still underway—of the conceptual and organizational structures best suited to both new assignments and ongoing commitments.

In 1996, the Committee created the Subcommittee on Health Data Needs, Standards and Security (later renamed the Subcommittee on Standards and Security) to spearhead the standards-related duties assigned by HIPAA. A Subcommittee on Privacy and Confidentiality was established to work on privacy issues within and beyond HIPAA. The new Subcommittee on Populations was given the portfolios of three former NCVHS subcommittees, representing a daunting array of population-related issues and a large and varied set of constituencies.

The challenge posed by HIPAA has been not simply the volume of work required in a very short time, but more importantly how to prevent the eclipse of longstanding NCVHS priorities related to population health. Members have labored to ensure that standards will enhance information for the public's health and not be an end in themselves or beneficial only to a few. In the Committee's estimation, however, the effort has not been fully successful. For example, in a recent stock-taking session, Populations Subcommittee Chair Lisa Iezzoni, M.D., observed that "the populations issues, the survey issues, the minority health issues, mental health, acute care . . . all of these kind of issues have not received the attention they received under the prior organization of the Committee."

NCVHS thus entered its 51st year looking for better ways to align the Committee's structure with its own priorities and those of the Department, particularly in order to more effectively address health disparities in the U.S. population, which the Department has identified as its top priority.

This effort was foreshadowed by statements by both John Lumpkin and Don Detmer (the present and former Chairs, respectively) at the time of the 50th anniversary, to the effect that NCVHS must build on and strengthen its historic commitment to promoting health for the entire population. Executive Secretary Marjorie Greenberg points out that building a public health platform under the evolving information infrastructure may call for a willingness to challenge government and industry as to how the nation as a whole will benefit from infrastructure investments.

## An Evolving Concept of Advising

The years since HIPAA's enactment have seen an unprecedented level of collaboration between NCVHS and the Department of Health and Human Services which it advises. One compensation for the extraordinary work load delivered by HIPAA is that the legislation requires HHS to consult NCVHS. This has resulted in more structured and formalized mechanisms for collaboration, facilitated by the HHS Data Council and sustained through regular consultation and participation in each other's meetings. These developments have shown that the Committee can have a real impact on health information policy.

This has not always been the case—perhaps because the Committee's advisory role sometimes calls for a more challenging stance toward Departmental policy. It is noteworthy that neither the NCVHS campaign for a unified system of procedure coding nor its effort to encourage a comprehensive approach to data on the continuum of care has produced visible action by the Department. And as this report is written, the Committee's carefully wrought recommendations on Medicaid managed care seem to have met a similar fate. Nor was the Committee invited to help develop the HHS privacy regulations, prompting Privacy Subcommittee Chair Kathleen Frawley to remark that “the Department is not utilizing the expertise of Committee members.”

Still, the relationship between NCVHS and the Department today is markedly more productive than in times past. Interviews for the 45-year history, for example, revealed a sense of frustration among some NCVHS members and close observers about the Committee's impact. Former member William Felts, M.D., shared this conclusion from his broad experience: “In general, government advisory committees are intentionally placed in postures of weakness. Government tends to hear the advice with which it agrees and to tune out that advocating another position.” Gooloo Wunderlich, Ph.D., former NCVHS Executive Secretary and a 30-year Department veteran, responded that frustration is inherent in the advisory role: “It is natural for advisory bodies to want all their recommendations implemented. It's also natural . . . for the government to take some and leave others.”

The Committee's work on standardization over 30 years typifies such variations. NCVHS has sometimes been an expert consultant whose advice is sought and followed, sometimes a stimulating forum for exploring issues and airing views, and sometimes a critic of the Department's actions or inaction. Often it has juggled a combination of these roles. In so doing, it has sometimes been the prime mover, sometimes been a partner with the Federal Government and/or private sector organizations, and sometimes looked on from the sidelines, struggling to be heard.

Of course, even when the Committee's advice is taken, the process is often slow and circuitous. Former member James Cooney, Ph.D., shepherded the UHDDS for the twelve years between its initial formulation and its ultimate approval as Department-wide policy. He lamented that nine of those years were “wasted” on battles within the Department over the minimum data set. He also put this behavior in perspective, however, noting that the Committee needs to be ten years ahead of the field. In addition to the simple influence of inertia, which is great in any institution, no significant change is implemented without pain, because it has a cost—administrative reorganization, new technology, staff training, and so on. This in itself suggests tension and almost inevitable frustration for an advisory committee.



In that vein, many observers note the Committee's role in drawing attention to issues and providing a forum for legitimizing and reinforcing new ideas. A synergism exists between NCVHS and forward-looking people in the Department who can use it as a vehicle for getting their ideas on the table. The Committee can support fledgling efforts that have merit, as well as tempering those that do not. Strengthening the international orientation, challenging the Department to develop a more integrated information strategy, and posing questions about how the entire population will benefit from infrastructure investments are contemporary examples of such leading-edge ideas.

It would seem, then, that serving effectively and deriving satisfaction as a Federal advisory committee requires a fairly broad, and evolving, definition of "advisory." The Committee's working definition has evolved considerably over its 50 years, and it will no doubt continue to do so. Advising is largely a collaborative process based on reaching out in many directions to consult and include stakeholders from many sectors. Increasingly, the Committee's advisory role resides in facilitating dialogue and multilateral partnerships among the many players in the health field—Department agencies, Congress and its staff, States, localities, researchers, professional associations, trade groups, health care providers, payers, and other interdisciplinary and advisory bodies—and then reporting what it hears in a way that is relevant to Departmental policy. This is the case for the advisory role mandated by HIPAA.

NCVHS meetings are an important part of the process, in which members chosen for their experience and perspective interact with invited guests and audience members to delineate issues and identify possible solutions. Besides inviting a range of voices to its table for special hearings, the Committee provides opportunities for public comment at every meeting. NCVHS meetings typically have an audience of 50–80, representing an array of public and private stakeholders in the health arena. The meetings are also broadcast on the Internet, and minutes are sent to some 1100 individuals and organizations. The NCVHS Web site, which stores all its documents, has greatly widened public access. Besides connecting the Department to the outside world, NCVHS fosters collaboration among Federal agencies and departments. It is significant that by 1999, some 14 agencies were providing staff to NCVHS Subcommittees and Work Groups in addition to the official HCFA and AHRQ (formerly AHCPR) liaisons to the full Committee.

Because of the respect for the consistently high quality of its analysis and recommendations, the Committee's advisory role and its influence extend beyond the Federal Government to other levels of government and to the private sector. Accordingly, former Chair Kerr White, M.D., has remarked that the NCVHS impact should be assessed outside the context of the political process: "Influence is much more important than power, in many ways. The Committee should strive to influence the situation. It will never have the legislative power to enact and enforce, but it does have the power to influence."

## Looking Ahead

NCVHS has used the two visioning projects described above to engage its varied constituencies around the country in conversations about the future of health information and health statistics and their use in improving the population's health. The Committee's 50th anniversary symposium in June 2000 provided an opportunity for public feedback on the two projects and their interim reports (published in this volume).

Both were well received. The invited commentators praised NCVHS for launching the projects, supported their conceptualization and execution, and urged prompt action and strong Federal leadership to implement the visions. Participants seized upon Don Detmer's metaphors and called for a roadmap, a designated driver, and a budget to bring the information strategies into being. The Symposium summary, also published in this volume, provides further information on the meeting.

Later that summer, the NCVHS Executive Subcommittee and senior staff held a strategic planning retreat at which they articulated the Committee's mission and purpose, clarified priorities, delineated NCVHS roles and audiences, and discussed organizational concerns such as those outlined above. This activity is really an extension of the NCVHS visioning process, aimed at clarifying a vision of the Committee itself and its role in a new century. The strategic planning exercise will continue, working toward a vision and plan that place all NCVHS responsibilities in the context of the Committee's mission—to advise on shaping a national information strategy for improving the public's health.

The Committee approaches these priorities with limited resources of time, money, and staff. Members give enormous credit for the Committee's accomplishments to the outstanding support work of its superb and dedicated staff. The relatively small size of the staff is always a factor in decisions about what can be undertaken. Similarly, the size of the Committee itself is a constraint, together with the conflicting demands on members' time. Having been selected for NCVHS membership because of their professional accomplishments and involvements, they cannot set them aside while they serve on it. Even with a ten-percent time commitment to Committee service, members must make difficult choices about what projects to take on.

In view of these mounting challenges and limited resources, the Executive Subcommittee is developing a strategic approach to advising. Members agree that an overarching goal in coming years will be to promote greater alignment between the national strategies for health and for health information. Related goals are to strengthen the Department's commitment to an information strategy and to strengthen the Committee's advisory relationship to the Department. Discussions at the 50th anniversary symposium stressed the need for strong Federal support of NHII development, which among other things should enhance the possibility of high quality health care, an issue that came to national attention in a recent Institute of Medicine report on medical errors. Both members and former members also hope the Department will increase its involvement in the international arena.

## Interviewees

The following individuals were interviewed for the 50-year history and/or the 45-year history that was published in 1996 and is now incorporated within this report:

*NCVHS Chair and former Chairs:*

Ronald Blankenbaker, M.D.  
Don E. Detmer, M.D.  
John L. Lumpkin, M.D. (current Chairman)  
Judith Miller Jones  
Kerr L. White, M.D.

*NCVHS staff and former staff:*

William Braithwaite, M.D., Ph.D. (HHS)  
Gail Fisher, Ph.D. (former Executive Secretary)  
Mary Anne Freedman (HHS)  
Marjorie S. Greenberg (current Executive Secretary)  
Gooloo S. Wunderlich, Ph.D. (former Executive Secretary)

*Former NCVHS members:*

James P. Cooney, Ph.D.  
William Felts, M.D.  
Mary Anne Freedman

## **Appendix 1**

### **Chairs and Executive Secretaries, 1949–99**

#### **Chairs**

1998–present	John L. Lumpkin, M.D.
1996–98	Don E. Detmer, M.D.
1991–96	Judith Miller Jones
1986–91	Ronald G. Blankenbaker, M.D.
1983–86	Robert H. Barnes, M.D.
1983	Cleve Killingsworth, Jr.
1979–80	Lester Breslow, M.D.
1975–79	Kerr L. White, M.D.
1973–74	Abraham Lilienfeld, M.D.
1970–72	Forrest E. Linder, Ph.D.
1967–69	Robert Berg, M.D.
1963–67	Robert Dyar, M.D.
1961–63	Brian MacMahon, M.D.
1961	Pascal K. Whelpton
1957–60	Philip M. Hauser, Ph.D.
1949–56	Lowell J. Reed, Ph.D.

#### **Executive Secretaries**

1997–present	Marjorie S. Greenberg
1983–1997	Gail F. Fisher, Ph.D.
1979	Samuel P. Korper, Ph.D., M.P.H.
1977–1979	Gooloo S. Wunderlich, Ph.D.
1975–1976	James M. Robey, Ph.D.
1973	I.M. Moriyama, Ph.D.
1972–1973	Dean E. Krueger
1949–1972	I.M. Moriyama, Ph.D.

## Appendix 2 Subcommittees, Technical Consultant Panels, and Work Groups

	<i>Appointed</i>	<i>Discharged</i>
<b>1950</b>		
<i>Ad hoc committees:</i>		
Morbidity Statistics	July 1949	Dec. 1949
Morbidity Statistics	Dec. 1949	
Medical Care Statistics	Feb. 1949	July 1949
Case Registers	Feb. 1949	July 1949
Hospital Morbidity Statistics	July 1949	
 <i>Subcommittees:</i>		
Definitions of Live Births and Fetal Deaths	July 1949	Dec. 1949
Fetal and Neonatal Mortality	July 1949	June 1950
Military Health Statistics	Sept. 1949	
Fertility and Population Statistics	Dec. 1949	Nov. 1962
 <b>1956</b>		
Classification of Physical Impairments	Feb. 1951	
Hospital Statistics	Apr. 1952	Jan. 1960
National Vital Statistics Needs	Oct. 1954	Oct. 1956
Glossary of Terms for Morbidity and Medical Care Statistics	Nov. 1954	Apr. 1956
Utilization of Marriage Statistics	Nov. 1954	Oct. 1956
Medical Certification of Medicolegal Cases	Mar. 1956	Jan. 1960
Classification of Causes of Fetal Deaths (Renamed Classification of Causes of Perinatal Morbidity and Mortality in 1959)	June 1956	Nov. 1965
 <b>1957</b>		
Development of National Statistics on Divorces (Renamed National Divorce Statistics in 1960)	Sept. 1956	June 1962
 <b>1958</b>		
Classification of Mental Diseases (Renamed Classification of Mental Disorders)	Aug. 1957	Nov. 1965
Measures of Positive Health	Dec. 1957	Aug. 1958
Classification of Cardiovascular Diseases	Jan. 1958	Nov. 1965
 <b>1959</b>		
Quantification of Wellness	Aug. 1958	Jan. 1961
International List Revision	May 1959	Nov. 1965

<b>1960</b>		
Revision of Classification of Accidents, Poisonings, and Violence	May 1960	Nov. 1965
<b>1961</b>		
Health Economics	Apr. 1961	Oct. 1963
Classification of Congenital Malformations (Renamed Classification of Congenital Defects) (1962—No new subcommittees)	Oct. 1961	Nov. 1965
<b>1963</b>		
Fertility Measurements	Nov. 1962	Nov. 1965
<b>1964</b>		
Statistics Available from Medicolegal Deaths	May 1963	Nov. 1965
<b>1965</b>		
Use of Vital and Health Statistics for Epidemiological Research	Mar. 1965	Mar. 1968
Epidemiologic Use of Hospital Data	May 1965	June 1969
Statistics of Indian Health	Jan. 1965	Nov. 1969
<b>1966</b>		
Migration and Health Statistics	1966	Nov. 1968
<b>1967</b>		
Health Resources and Services (No mention after 1968, but no indication of discharge)	Nov. 1967	
Population Dynamics (1968—No new subcommittees)	June 1967	May 1970
<b>1969</b>		
Vital Statistics System Revision	Dec. 1968	
<b>1970</b>		
(Sharp curtailment of committee activities in 1970 )		
Uniform Hospital Abstract Form	Oct. 1969	May 1973
<b>1971</b>		
Revision of the International Classification of Diseases	Apr. 1970	Apr. 1973
Working Party on Classification of Neoplasms (of the Revision of the International Classification of Diseases Subcommittee)	Apr. 1970	Apr. 1973
Financial Data Year Planning	June 1970	
Working Party of Classification of Mental Disorders (of the Revision of the International Classification of Diseases Subcommittee) (1972—No new subcommittees)	Jan. 1971	May 1973

**1973**

*(First use of technical consultant panels; no dates given.  
Existing technical consultant panels for each year are listed )*

- Ambulatory Medical Care Records
- Needed Statistics and Statistical Data Systems for  
Formulation of National Population Policies

**1974**

- Ambulatory Medical Care Records
- Analytical Potentialities of National Center for  
Health Statistics Data
- Statistics Needed for Formulation and Evaluation of  
National Policies on Fertility
- Consideration of Statistics Needed to Ascertain  
the Effects of Environment on Health

**1975, 1976**

- Uniform Ambulatory Medical Care Data Set
- Long-Term Care Minimum Data Set
- Manpower and Facilities Minimum Data Set
- Uniform Hospital Discharge Data Set

**1977**

- Statistics Needed for Formulation and Evaluation of  
National Policies on Fertility
- Consideration of Statistics Needed to Ascertain the  
Effects of the Environment on Health
- Ambulatory Medical Care Data Set
- Health Interview Survey
- Long-Term Care Data Set
- Manpower and Facilities Data Set
- Organizing Principles for Health Information
- Statistical Systems for National Health Insurance
- Uniform Hospital Discharge Data Set

**1978**

- Ambulatory Medical Care Data Set
- Health Interview Survey
- Long-Term Care Data Set
- Manpower and Facilities Data Set
- Statistical Systems for National Health Insurance
- Uniform Hospital Discharge Data Set

**1979–80**

*(Technical consultant panels were disallowed; National Committee on  
Vital Health Statistics reinstated the use of subcommittees)*

- Environmental Health Statistics 1980 \*
- Cooperative Health Statistics System 1980 \*
- Data Concepts and Methods 1980 \*
- International Statistics 1980 \*

\* Subcommittees presumably discontinued during 1981–82 hiatus.

**1983–85**

Uniform Minimum Health Data Sets	June 1983	1987
Vital Statistics Cooperative Program	June 1983	1985
Disease Classification and Automated Coding of Medical Diagnoses	June 1983	1985
Statistics Aspects of Physician Payment Systems (No dates given)		
Data Gaps in Disease Prevention and Health Promotion	Nov. 1985	1987
Work Group on NCHS Publications Review	1983	1985
Work Group on Policy and Direction	1983	1985

**1986***(Charter reassessed, committee reorganized)*

Executive Subcommittee	1985	
Minority Health Statistics (subsequently renamed several times)	1986	1996
Statistical Aspects of Physician Payment Systems	1986	1986

**1987**

Medical Classification Systems	1987	1996
Long-Term Care Statistics (Renamed Disability and Long-Term Care Statistics)	1987 1994	1996 1996
Ambulatory Care Statistics (Renamed Ambulatory and Hospital Care Statistics)	1987 1989	1996 1996
Disease Prevention and Health Promotion Statistics	1987	1988
Work Group on Data Dissemination Issues	1987	1988

**1988**

Health Care Statistics <i>(1989—No new subcommittees)</i>	1988	1990
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**1990**

Mental Health Statistics	1990	1996
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**1991**

State and Community Health Statistics	1991	1996
Work Group on Confidentiality (changed to monitor in 1993 and to Subcommittee on Privacy and Confidentiality in 1996) <i>(No new subcommittees in 1992, 1993, 1994, or 1995)</i>	1991	1993



**November 1996 to June 1998**

Subcommittee on Health Data Needs, Standards and Security

Workgroup on Data Standards

Workgroup on Population-Based Data

Subcommittee on Populations at Risk

*(renamed Subcommittee on Population-Specific Issues) (This Subcommittee, later renamed the Subcommittee on Populations, was assigned the responsibilities of the Subcommittees on Medical Classification Systems, Ambulatory and Hospital Care Statistics, and State and Community Health Statistics.)*

Subcommittee on Privacy and Confidentiality

Executive Subcommittee

Workgroup on Planning and Implementation

*(discontinued in 1998)*

**June 1998 to the present**

Subcommittee on Standards and Security

Workgroup on Computer-based Patient Records

*(absorbed into Subcommittee in 2000)*

Subcommittee on Privacy and Confidentiality

Subcommittee on Populations

Workgroup/Project on Health Statistics for the 21st Century

Workgroup on Quality

*(This Subcommittee was assigned the responsibilities of the Subcommittees on Health Statistics for Minority and Other Special Populations, Mental Health Statistics, and Disability and Long-Term Care Statistics.)*

## Appendix 3 Reports and Letters

### 1996–99 (listed in reverse chronological order)

December 1999 Medicaid Managed Care Data Collection and Reporting NCVHS Subcommittee on Populations prepared with the assistance of The George Washington University Medical Center School of Public Health and Health Services Center for Health Services Research and Policy December 1999 Health Data Needs of the Pacific Insular Areas, Puerto Rico, and the U.S. Virgin Islands, NCVHS Subcommittee on Populations

October 7, 1999, Letter to Secretary Shalala updating progress on the Health Insurance Portability and Accountability Act Report

August 24, 1999, NCVHS Report to Secretary Shalala for the period 1996–1998 (html version) July 22, 1999, Second Annual Report to Congress on Implementation of Administrative Simplification

March 2, 1999, Letter to George M. Reider, Jr., President, National Association of Insurance Commissioners, on the Health Information Privacy Model Act

December 7, 1998, Letter to the Surgeon General on “Healthy People 2010 Objectives”

October 8, 1998, Letter to the Secretary transmitting paper, “Assuring A Health Dimension for the National Information Infrastructure”

September 23, 1998, Letter to the Secretary with Recommendations on the Use of the SLAITS Survey

September 16, 1998, Comments on the August 12, 1998 NPRM on Security and Electronic Signature Standards

September 16, 1998, Comments on the Applicability of the Paperwork Reduction Act (PRA) regarding the August 12, 1998 NPRM on Security and Electronic Signature Standards

August 31, 1998, Letter to Secretaries of HHS and Labor on *Quality First: Better Health Care for All Americans*, final report of the President’s Advisory Commission on Consumer Protection and Quality in the Health Care Industry

August 27, 1998, Letter to Robert Moore, Formerly HCFA Liaison to the NCVHS

August 27, 1998, Letter to George H. Van Amburg, Former Member of the NCVHS

June 23, 1998, Responses to Congressional Questions Received During Testimony on Health Information Privacy, March 24, 1998

June 23, 1998, Letter to the Secretary with Findings of the Subcommittee on Privacy and Confidentiality Concerning Identifiability of Health Information and Confidentiality Considerations for Health Registries

June 17, 1998, Comments on the May 7, 1998 NPRM on National Standard Health Care Provider Identifier

June 17, 1998, Comments on the Applicability of the Paperwork Reduction Act (PRA) regarding the May 7, 1998 NPRM on National Standard Health Care Provider Identifier

June 17, 1998, Comments on the May 7, 1998 NPRM on National Standards for Electronic Transactions

June 17, 1998, Comments on the Applicability of the Paperwork Reduction Act (PRA) regarding the May 7, 1998 NPRM on National Standards for Electronic Transactions

March 10, 1998, Letter to Secretaries of HHS and Labor on the Consumer Bill of Rights and Responsibilities

February 3, 1998, First Annual Report to Congress on Implementation of Administrative Simplification

November 24, 1997, Analysis of Unique Patient Identifier Options—Report prepared for the NCVHS

September 9, 1997, Letter to the Secretary with Recommendations on Security Standards to Protect Health Care Information

September 9, 1997, Letter to the Secretary with Recommendations on the Standard for a Unique Identifier for Health Plans

September 9, 1997, Letter to the Secretary with Recommendations on the Standard for a Unique Identifier for Individuals for Use in the Health Care System

July 3, 1997, Letter to the HHS Data Council on the Outcome Assessment Information Set (OASIS) Data Collection Tool.

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1950	1962	1969	1977	1989
1956	1963	1970	1978	1990
1957	1964	1971	1979/1980	1991
1958	1965	1972	1983—85	1992
1959	1966	1973	1986	1993
1960	1967	1974	1987	1994
1961	1968	1975/1976	1988	1995
				1996–1998

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National Committee on Vital and Health Statistics  
2000**

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Chicago, Illinois

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Director, Division of Data Policy  
Office of the Assistant Secretary for  
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**Executive Secretary**

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Kepa Zubeldia, M.D.  
President  
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Lisa I. Iezzoni, M.D.  
Barbara Starfield, M.D., M.P.H.

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Katherine D. Jones, NCHS

### **Ex Officio**

James Scanlon, ASPE  
Marjorie Greenberg, NCHS

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Daniel Friedman, Ph.D.  
Richard K. Harding, M.D.  
Clement J. McDonald, M.D.  
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Marjorie S. Greenberg, NCHS  
Members of HHS Data Standards  
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Jackie Adler  
Suzie Burke-Beebe  
Debbie Jackson  
Katherine Jones

Traci Ramirez  
Patrice Upchurch  
Gracie White  
Brenda Wolfrey

**THE SECRETARY OF HEALTH AND HUMAN SERVICES**

WASHINGTON, D.C. 20201

**CHARTER  
NATIONAL COMMITTEE ON VITAL AND  
HEALTH STATISTICS**

**PURPOSE**

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

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

**AUTHORITY**

42 U.S.C. 242k(k), Section 306(k) of the Public Health Service Act, as amended. The Committee is governed by provisions of Public Law 92-463, as amended, (5 U.S.C. App. 2), which sets forth standards for the formation and use of advisory committees.

**FUNCTION**

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

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

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

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

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

(E) Identify strategies and opportunities for evolution from single-purpose, narrowly focused, categorical health data collection strategies to more 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 Department's data and systems, and impact of the Department's information policies and systems on the development of emerging technologies.

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

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

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

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

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

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

- The extent to which persons required to comply with Part C of the Act are cooperating in implementing the standards adopted under such part;
- The extent to which such entities are meeting the security standards adopted under such part and the types of penalties assessed for noncompliance with such standards.
- Whether the federal and State Governments are receiving information of sufficient quality to meet their responsibilities under such part.
- Any problems that exist with respect to implementation of such part.
- The extent to which timetables under such part are being met.

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

In these matters, the Committee shall consult with all components of the Department, other federal entities, and non-federal organizations, as appropriate.

#### STRUCTURE

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

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

Membership terms of more than two years are contingent upon the renewal of the Committee by appropriate action prior to its termination. Any member appointed to fill a vacancy occurring prior to the expiration of the term for which his or her predecessor was appointed shall be appointed only for the remainder of such term. Members may serve after the expiration of their terms until successors have been appointed.

Standing and ad hoc subcommittees, composed solely of members of the parent Committee, may be established to address specific issues and to provide the Committee with background study and proposals for consideration and action. The Chair shall appoint members from the parent Committee to the subcommittees and designate a Chair for each subcommittee. The subcommittees shall make their recommendations to the parent Committee. Timely notification of the subcommittees, including charges and membership, shall be made in writing to the Department Committee Management Officer by the Executive Secretary of the Committee. The HHS Data Council, through the Assistant Secretary for Planning and Evaluation, shall oversee and coordinate the overall

management and staffing of the Committee. Professional, scientific, and technical staff support shall be provided by all components of the Department. The National Center for Health Statistics shall provide executive secretariat and logistical support services to the Committee.

#### MEETINGS

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

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

#### COMPENSATION

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

#### ANNUAL COST ESTIMATE

Estimated annual cost for operating the Committee, including compensation and travel expenses for members but excluding staff support, is \$600,296. Estimated annual person-years of staff support required is 4.9, at an estimated annual cost of \$307,327.

#### REPORTS

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

#### TERMINATION DATE

Unless renewed by appropriate action prior to its expiration, the charter for the National Committee on Vital and Health Statistics will expire on January 16, 2002.

#### APPROVED:

January 31, 2000

Donna E. Shalala  
Secretary of Health and Human Services



# Interim Report: Toward a National Health Information Infrastructure

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# **Interim Report: Toward a National Health Information Infrastructure**

Prepared by  
The National Committee on Vital and Health Statistics  
Workgroup on the National Health Information Infrastructure<sup>1</sup>

## **1. Opportunities to Improve Health and Health Care**

The new century brings with it fresh hope that significant improvements in the public's health and well-being are not only possible, but close at hand. Health, we now realize, is not merely the absence of illness. Nor is health achieved solely by combating disease. Rather, as the World Health Organization puts it, health is a "state of complete physical, mental, and social well-being." Health is also clearly more than an individual matter. Personal and community health are closely connected, and depend on interwoven factors: policies, economics, the environment, housing, and heredity, to name a few. Improvements in both personal and community health are essential for a healthier nation.

The sheer breadth of the challenges facing us as a Nation calls for an equally expansive and innovative response. Fortunately, we find ourselves in the midst of a dynamic technological era where dramatic transformations in information and communication technologies offer innovative and unprecedented opportunities for health improvements on a national and global scale. The framework that can link health improvements and information technologies is the National Health Information Infrastructure (NHII).

The NHII does not exist yet in a comprehensive way. Although many pieces of an NHII are well-developed and already in use, others are only now emerging and evolving. As envisioned in this paper, the NHII is the set of technologies, standards, applications, systems, values, and laws that support all facets of individual health, health care, and public health. The broad goal of the NHII is to deliver information to individuals consumers, patients, and professionals- when and where they need it, so they can use this information to make informed decisions about health and health care.

The NHII is not an effort to collect personal health data from individuals or health care providers. Nor is it the creation of a centralized government database to store personal information about individuals. Rather, the NHII offers a way to connect distributed health data in the framework of a secure network. Comprehensive Federal and State health information privacy legislation will ensure that the network will have strict, built-in confidentiality protections for personal health information and tools that individuals can use to protect their information and privacy.

Consumers, patients, health care providers and managers, public health professionals, and policymakers share an interest in promoting equitable access to high-quality health information, available any time, any place. A recent Institute of Medicine report found that up to 98,000 people die unnecessarily each year in U.S. hospitals from preventable medical errors, which makes errors the fifth leading cause of death. A dramatic reduction

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<sup>1</sup>A list of Workgroup members and staff is given in Appendix A.

in such medical mistakes and in other adverse effects of care is one of the most significant benefits that we can expect from the NHII.

The day is not far off when a patient, pharmacy and doctor all communicate routinely through an electronic system. Consider the following story of Sam King and Dr. Jose Hernandez.

Sam: I've had this awful cough that won't go away, so I finally saw Dr. Hernandez, who checked me out and took some tests. He prescribed XX and said I should take it 2 times a day. But as Dr. Hernandez entered the name of the drug into my personal medical record, the computer beeped. My doc told me the computer was warning him that some people with health conditions like mine have developed a rash and muscle cramps when taking the drug he was going to give me. I told him, "Good catch," and was glad he wired a prescription for something else to my drugstore. Before I left, I asked Dr. Hernandez to send the prescription information to my personal health record.

Dr. Hernandez: Mr. Sam King came in last week with a persistent cough. I diagnosed ZZ, and decided to prescribe XX. But when I entered the diagnosis and prescription into Mr. King's electronic medical record, which is part of our Clinical Management System, I was told to link to the drug manufacturer's database to check out an important alert. What I found was an urgent notice about widely scattered reactions in patients with chronic conditions like Mr. King's. I quickly changed his prescription. A short time later, our CMS system got an "all points" bulletin from the manufacturer about this drug. Of course, my practice had learned already about these rare reactions, but I was relieved that providers around the country and the FDA have received the same information.

Through the use of integrated information technologies, it is hoped that different segments of the medical care system will be able to "talk" to one another better and faster, and, in the process, dramatically increase diagnostic accuracy and spot potential errors before they injure patients. For example, some physicians are already using automatic warning systems to alert them to potentially adverse drug interactions or allergic reactions. Even when health care providers administer appropriate medications or treatments, there remain other adverse effects that currently are not efficiently captured, aggregated, and analyzed in ways that could save lives. Among other uses, the NHII will help deliver such alerts in a timely and efficient manner.

The NHII can also deliver other benefits, including enhanced access to consumer health information, peer and support services; greater choice of care; tracking of health histories over a lifetime; and increased accountability for quality and costs. New tools, such as automated reminders and decision-support systems will encourage patient adherence to treatment and health maintenance plans and improve the quality of care. The NHII will also improve community health by taking seemingly isolated events, identifying patterns and trends, and suggesting public health actions to safeguard populations.

A vacation emergency in the not-too-distant future, by Joyce Peters.

When I turned 66 last month, my sister and I took a camping vacation out West. One day as we marveled at a chain of waterfalls, I got severe stomach and chest pains. Luckily, I've subscribed to the Portable Medical Alert System since my first bout of angina five years ago, so I wear patch sensors on my chest and a wrist transmitter with a built-in positioning system. My PMAS sent emergency messages to the closest paramedic team and to my own cardiologist in New York. They both got my vital signs and location. The communications system also linked my doctor to the emergency team. By the time the paramedics reached me, my doctor had sent them relevant parts of my medical history, including previous EKGs. Once at the emergency facility, Dr. Sally Smith took over. She asked my permission to access my online personal health record to get information on previous stomach problems, which didn't show up in my cardiologist's record. I agreed. After a thorough evaluation, including a new EKG for comparison, Dr. Smith told me I probably had viral gastroenteritis. We updated my personal health record at the same time Dr. Smith did hers, and then she discharged me in my sister's care.

The next day I felt much better, but I had lost the written follow-up instructions. No problem. I logged onto my mobile phone and found them where Dr. Smith had entered them the day before: on my personal health home page. My regimen was simple: lots of fluids and watch my diet. The next three days passed without incident, unless you count the elk on the trail.

The day we left, the local paper noted lots of other campers had become sick too. It turns out the local health department has an automated surveillance system that collects anonymous patient data from local health care providers. This system recognized a cluster of tourists with similar symptoms in one part of the park. After a little detective work, they found the culprit. A construction crew had punctured a sewer line, which in turn contaminated a number of wells providing water to park restaurants and other facilities. Come to think of it, my sister and I noticed that the drinking fountains in the park hadn't been working, so I guess park management got the alert.

## 2. What Stands Between the Present and the Desired Future?

Technology is not a major barrier to making this future a reality. Most of the barriers to an effective and beneficial national health information infrastructure are legal, societal, organizational, and cultural in nature.

**Privacy protections.** The most significant immediate barrier is the lack of comprehensive privacy protections for personal health information. The proliferation of web sites and systems that facilitate the collection, storage, and sharing of personal health information has outstripped protections for that same information (Goldman, Hudson & Smith, 2000). As part of the Health Insurance Portability and Accountability Act (HIPAA) of 1996, the Department of Health and Human Services proposed a set of

regulations to protect the privacy of personal health information in electronic transactions for health care. (HHS 1999; NCVHS 1997) Although these draft regulations represent progress, we still need protections that extend across all the users, technologies, and functions envisioned by the NHII. This level of protection can only be provided by comprehensive Federal privacy legislation. These protections must be buttressed by the implementation of technical solutions, such as encryption, digital signatures, useable audit trails, and authentication mechanisms, many of which are already in use.

**Information as both a private resource and public good.** As a society, we must reach consensus about how we think about health information and information sharing. There is an emerging agreement that health is determined by many factors, and that improvements in health status require information to flow in a coordinated and controlled manner among appropriate partners — consumers, patients, health care providers and community health officials — and beyond the traditional medical care delivery system. However, health care providers and organizations typically treat patient information as a private resource, rarely used for community health improvement, while patients and consumers have their own individual methods for keeping track of personal information. Rarely do any of these groups consider how individual health information might be used to help others or to understand health patterns beyond households. Nor do individual health consumers often grasp how information about community health issues may help them manage their own health. In addition, community health information systems are not integrated among themselves, much less with clinical and research systems and with those of other communities.

**Standards.** If information in multiple locations is to be searched, shared, and synthesized when needed, we will need agreed-upon information guardians that can exchange data with each other. These may include gate-keeping systems in homes, provider offices, public agencies, online commercial services, and other third parties. We will also need reliable and valid data collection methods; common vocabularies for personal, clinical and public health information; compatible systems to manage, transmit and protect the confidentiality of information; and standards for interoperability. We must capitalize on technology that allows appropriate and authorized use of data and strips personal identifiers. The concept of “minimally necessary” must be strictly applied to the use of identifiable data. We will need equitable rules of data exchange so that competitors (within or between health care provider systems, health information management companies, or health Web services) will be willing to interconnect and share data. We will need viable business models for information use and sharing that are acceptable to consumers, patients, providers, payers, and society at large. These models should address but not be limited to reimbursement, advertising, and direct consumer purchases.

**Quality standards for online information.** Because health information is much more than medical care data, the lack of quality standards for online consumer/patient information is currently a major barrier to the full realization of the NHII. Health care professionals, consumers and patients all need reliable guides to high-quality online health resources. These resources include health information and services to enable informed decision making; promote healthy behaviors, information exchange and support, and self-care; and manage demand for health services. As the amount of health activity on the Internet increases, government, professional and private sector oversight will be needed to monitor the online sale of products and services to prevent consumer fraud and reduce the risk of consumer and patient harm.

**Technology.** Security technology must be implemented to assure that health information can safely travel over the Internet. Other technology challenges include the lack of ubiquitous, interoperable wire/wireless information appliances of different sizes and functions for different users and purposes. New devices that are mobile and integrate multiple modes, including data, text, and voice, and multiple functions, such as information searching, communication, and decision support, will be needed. The Internet must develop the capacity to carry the many different types of content, such as images and sound in addition to text, that are important to health decision making, and it must become more reliable to support all the different types of critical situations, such as medical emergencies and outbreaks of highly contagious diseases, that are typical in health care and public health (National Research Council, 2000).

**Costs.** Creating the networks, systems, and applications to support the NHII will have to be accomplished as a public/private partnership. It may be misleading to estimate a single dollar figure representing specific, planned investments. Many of the individual technologies are already well under development or deployed in pilot projects. Some health care organizations may underwrite system improvements as part of capital upgrades or as a cost of doing business in a competitive environment. Other services may be supported through direct consumer payments similar to monthly utility or cable television rates.

**Attitudes and practices.** Certain shifts in societal and professional attitudes and practices must occur. Health care professionals will need to reach consensus on and accept the contribution of practice guidelines and other knowledge management tools. Public health will need to include in its toolkit integrated data systems; high-quality community-level data; tools to identify significant health trends in real-time data streams; and geographic information systems. Consumers and patients must have confidence the NHII will deliver real benefits. They will need to feel comfortable that an appropriate balance is being struck between their desire to safeguard personal health information and health professionals' need for de-personalized information to protect public health, conduct medical research, and improve health care quality.

**Equity.** Finally, and perhaps most important, the full potential of the NHII will not be achieved until its benefits can be shared equally by all. People from some racial and ethnic backgrounds and those with lower incomes often carry the heaviest health burdens. Eliminating health disparities is one of the overarching public health goals of the next decade. This means technology and online information and services must be available in all homes and communities. Online resources must be culturally and linguistically appropriate for an increasingly diverse population, and presented in clear and useful formats for all regardless of their education level.

### **3. Foundations of a National Health Information Infrastructure.**

In the last decade, many breakthrough efforts have helped lay the foundation for a national health information infrastructure. Informatics systems for processing administrative and financial information have progressed from stand-alone to networked systems. The promise of advanced computing and telecommunications technology stimulated work on an electronic patient record to facilitate the capture and analysis of health care information. Congress passed the High Performance Computing Act in 1991 to promote

work on the technical infrastructure, followed by the Next Generation Internet Act of 1998, and the Networking and Information Technology Research and Development Act of 2000, all of which address the health care sector. The President's Information Infrastructure Initiative of 1993 focused on the deployment of information technology to the home and workplace and included a Health Information and Applications Work Group. Attention to applications for public health produced a path-breaking report, "Making a Powerful Connection: The Health of the Public and the National Information Infrastructure" in 1995. The Health Information and Applications Work Group issued a final report on "Health Care and the NII" and a "Consumer Health Information White Paper" in 1996.

The work of other countries to define and implement their own national health information infrastructures also has produced useful models. Australia established a National Health Information Agreement (NHIA) in 1993, including the Commonwealth, State and Territory health authorities, the Australian Bureau of Statistics, and the Australian Institute of Health and Welfare. The NHIA seeks to improve the quality of health data and information and foster cooperation in the development of a national health information infrastructure. It ensures that the collection, compilation, and interpretation of national information are carried out appropriately and efficiently. The agreement has produced the National Health Information Management Group, National Health Data Committee, National Health Information Model, National Health Data Dictionary, national minimum data sets, and the National Health Information Knowledgebase. [<http://www.aihw.gov.au/>]

In 1997, Canada created an Advisory Council on Health Infostructure, which issued the 1999 report, "Canada Health Infoway: Paths to Better Health." The Canadian strategy has four goals: empowering the general public; strengthening and integrating health care services; creating the information resources for accountability and continuous feedback on factors affecting the health of Canadians; and improving privacy protection within the health sector. The Infoway builds on existing provincial, territorial, and health infostructure initiatives such as the Canadian Health Network, the National Health Surveillance Network, and the First National Health Information System. The Roadmap Initiative was established in 1998, with a budget of \$95 million over 4 years, to develop more integrated statistical systems and obtain consensus on the indicators and determinants of health. Canada also launched the Canada Health Infostructure Partnerships Program (CHIPP) a 2-year, \$80 million, shared-cost incentive program, aimed at supporting the implementation of innovative applications of information and communications technologies. [[http://www.hc-sc.gc.ca/ohih-bis/menu\\_e.html](http://www.hc-sc.gc.ca/ohih-bis/menu_e.html)]

In 1998, the United Kingdom National Health Service released "Information for Health 1998– 2005: An Information Strategy for the Modern NHS." The strategy commits the NHS to: lifelong electronic health records for every person in the country; round-the-clock on-line access to patient record and information about best clinical practices for all NHS clinicians; genuinely seamless care for patients through GPs, hospitals and community services sharing information across the NHS information highway; fast and convenient public access to information and care through on-line information services and telemedicine; and the effective use of NHS resources by providing health planners and managers with the information they need. Committing £1 billion to this initiative, the government established a new NHS Information Authority

that is responsible for developing national products and standards for local use and the availability of high-quality information. [<http://www.nhsia.nhs.uk/>]

#### **4. The Role of the National Committee on Vital and Health Statistics**

Recognizing the opportunities and interest in integrated health information strategies, the National Committee on Vital and Health Statistics (NCVHS), which serves as the public advisory body for the Secretary of Health and Human Services on national health information policy, created a Workgroup on the National Health Information Infrastructure (NHII) in 1998. As defined in the Workgroup's official charge:

The "NHII" is a set of technologies, standards, and applications that support communication and information to improve clinical care, monitor public health, and educate consumers and patients. It is not a unitary database. The broad goal of the NHII is health knowledge management and delivery, so that the full array of information needed to improve the public's health and health care is optimally available for professionals, policy makers, researchers, patients, care givers, and consumers. The NHII as a system should seek to improve and enhance privacy and confidentiality of personal health information. [<http://www.ncvhs.hhs.gov/nhichrg.htm>]

In October 1998, the Workgroup presented a Concept Paper to the Department of Health and Human Services. [<http://www.ncvhs.hhs.gov/hii-nii.htm>] The paper stressed that the information within an eventual health information infrastructure would be diverse, reflecting the array of purposes outlined in the Charge. Multiple stakeholders have a role to play in the NHII's development and maintenance, including public agencies, health care and research institutions, professional and standards organizations, consumer organizations, and the telecommunications and computer industries. The Workgroup subsequently examined the content and functions of an NHII in light of developments in the field and in other countries whose efforts are described above. The Workgroup's current conceptualization of the NHII is detailed in the next sections.

As a complement to the NHII, the NCVHS, the National Center for Health Statistics (NCHS), and the Department of Health and Human Services Data Council have begun to articulate a vision whereby health statistics in the United States will mobilize new capacities and fulfill the potential to promote and protect the country's health in the 21st century. The 21st century vision interim report proposes ten principles for health statistics. The vision is intended to encourage the realization of the NHII, and represent specific health statistics requirements for the community health dimension. Both the 21st Century Health Statistics project and the NHII project will include regional hearings in the fall and winter of 2000 to enable individuals, communities, and professionals to contribute to a common understanding of the country's health information needs and articulate opportunities for improvement.

#### **5. A National Health Information Infrastructure**

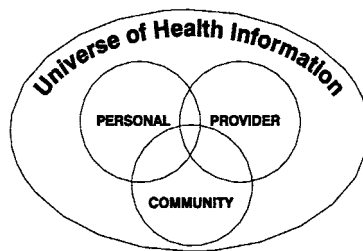
Given the Workgroup's broad understanding of health and its determinants, a national health information infrastructure must serve the public as well as professionals and



support informed-decision-making across the full spectrum of health needs and at all levels. The content of the NHII will be varied and complex. It includes clinical, population, and personal data; practice guidelines; biomedical, health services, and other research findings; and consumer health information. Currently, health information is stored in many locations. The NHII seeks to connect that information where links are appropriate, authorized by law and patient permissions, and protected by security policies and mechanisms. In effect, the content moves beyond data to information and, ultimately, to knowledge based on analysis and experience.

Because the NHII exists to serve its users, it can perhaps be best understood from their perspectives. Although there are, of course, a multitude of users, three categories represent key stakeholders: individuals, health care providers, and community health professionals. Each group has information needs that are both distinct and overlapping. They will put in, take out, and manipulate information in ways that are sometimes different, sometimes identical.

Three “dimensions” of the NHII — the personal health dimension, the health care provider dimension, and the community health dimension — illustrate the ways in which content, functions, users, and requirements overlap. The dimensions are not unitary “records” maintained in any single location, although they may include health records. Rather, the dimensions represent virtual information spaces. Each is defined by what it encompasses, who it serves, how it is used, and who has primary responsibility for content and control.



## **The Personal Health Dimension**

The Personal Health Dimension (PHD) of the NHII supports the management of individual wellness and health care decision-making. It encompasses data about health status and health care in the format of a personal health record, but also other information and resources relevant to personal health. It makes possible convenient, reliable, secure, and portable access to high quality individual health and wellness information to improve decision-making by individuals and their health care providers. The PHD will encompass information supplied both by the individual and by his or her health care providers. The information will be protected by mechanisms to ensure the confidentiality and security of personal health information.

**My birthday.** My 50th birthday seemed like a big deal. Although so far I've been pretty healthy, I wondered if big changes were in store for me. My multi-media home information center wished me "Happy Birthday" and gave me some welcoming messages, which made me feel being 50 is okay. I keep my own and my family's health histories in my secure personal health manager program, which periodically sends me health reminders that match my age and health risks. It also shows me information my doctors send after my visits. When I logged on today, I saw the results from my latest allergy tests. There was also a notice that the system would be upgrading its encryption and authentication software next week, and that my doctors and I would be alerted to reverify our log-in information and change our passwords. Anyway, today's reminders urged me to take my calcium supplement more consistently to help prevent osteoporosis and to get another Pap test and a mammogram within the year. There was also a suggestion that I discuss the symptoms of menopause at my next visit.

Just as I was about to log off, the light on my OB-GYN's link started flashing. She was notifying all her patients that she would soon move out of state, so she could practice closer to her aging parents. Now I was faced with finding a new doctor. The task was made easier because I had the name of a highly-recommended physician from my best friend. I ran the gynecologist's name through several of the "doctor-finder" services and read her high performance and personal ratings and decided to make an appointment, especially after I found out she was approved by my insurance provider. So, in one fell swoop, I made my appointment and set up the Pap smear and mammogram tests on line. I even took a "virtual tour" of the new office and forwarded relevant medical records. I decided not to mention my depression last year. It's not relevant, so I'll wait to see if I like the doctor and the practice. My wrist Internet will flash me a reminder a week before my appointment. While online, I also sent out a search for health information for women like me, which I will read tonight.

**My daughter.** My daughter has asthma, and I currently give her nebulizer treatments twice a day at a maintenance level. I check her lung functions through a peak flow meter twice a day too, and I put the results into my home information center in her personal health record. Today, she seems to have come down with a nasty cold. She is wheezing more, coughing and has a fever. I don't want to take her to the emergency room or even to the doctor if I don't have to. I e-mailed her pediatrician, who asked me to send him her daily lung function readings for the last four months. He e-mailed me later and said that, given the symptoms and her sudden decreased lung function, I should increase the frequency and intensity of her nebulizer treatments. He also asked me to send him the readings for the next few days to see if I need to take her in or increase the medication further. It sure was reassuring to sort all this out.

**My dad.** I also checked up on Dad, who lives 1000 miles away. He's given me access to his personal health page that he keeps with a secure online service—the one that's top rated by consumer watchdog groups. I logged on to look at his recent medical visit and medications. His doctor just changed his blood pressure prescription, and the automatic drug interaction program shows that there should be fewer side effects with his current combination of pills. He keeps a voice-activated medication reminder screen on his kitchen cabinet that tells him which pills he needs to take; in turn, he tells it the pills he has taken so it can keep track throughout the day. He even connected me so the system beeps me if Dad misses a pill. (I think he knows that I like this not just for the medication lapses, but as an unintrusive way to know he's okay.) Because he has respiratory problems, his home page is also set up to show the daily air quality index. Today, the icon was blinking red with a pollution alert for his neighborhood, so I called him. He had seen it and seemed insulted that I didn't give him credit for having the good sense to stay indoors.

### **What are the Personal Health Benefits of the NHII?**

Developments in the NHII can help improve individuals' health status by facilitating health and wellness management, personal health risk assessment, health decisionmaking, patient-doctor communication, and adherence to medication regimens and care plans. Problems of illegible, disorganized or misplaced information can be minimized. Potential medication errors can be identified and individuals can receive reminders about wellness actions, preventive services, medications, and medical appointments. Personal involvement in health and health care decision-making can be strengthened.

Health care quality will be enhanced when providers have convenient access to the summarized continuum of patient information in multiple types of treatment settings, including the home. The quality and quantity of preventive services will be improved when individuals and their providers receive reminders about periodic preventive care. Patient outcomes will be improved through better understanding, communication, and patient participation in the process of care. Chronic disease management will be strengthened by increased ability to tailor health education to the patient.

### **What are the Personal Health Functions of the NHII?**

The functions include the capture, storage, communication, processing, and presentation of information.

#### **Information Capture**

Personal health information in the NHII will come from many different sources. Individuals or their legal guardians will enter into personal health records that information they would want readily available to make personal health decisions or, with their approval, provided to health care workers in the case of a medical emergency. This information includes individual and family health histories, medication or food allergies, medication lists, emergency contact information, health care provider information, and health care proxies or living wills. With the approval of the patient, health care providers could send clinical information to the personal health record after office visits. Individ-

duals may also keep health and wellness information of particular personal importance, such as information about recurring or ongoing health concerns, diet plans, nutritional information, exercise regimens, or smoking cessation plans. Some individuals may routinely capture community information such as local health services or environmental hazard alerts; others may access that information only as needed. The development of widely-adopted health care data standards will allow the personal health record to be compatible with other parts of the NHII, including decision support systems and clinical records, and to interconnect as needed.

### **Information Storage**

The NHII will not create a mega database. Individuals may choose from a variety of mechanisms to store personal health information, including home health information programs, third-party information guardian services, or possibly smart cards. They are likely to keep non-personal health-related information, such as information about wellness, specific conditions, or community health issues, on their own computer or just maintain bookmarked links they can access when needed.

### **Information Communication**

The NHII will provide convenient, reliable and secure access for individuals and others authorized by them to a life-long personal history of health care, risk factors, occupational and environmental exposure, and health status information, across geography and across time. If they choose, individuals can send specific personal health information to health care providers or institutions, such as the results of an EKG or a cardiovascular stress test to a wellness program. or immunization records to schools or camps.

### **Information Processing**

The NHII will include a variety of computer-based decision-support tools that individuals can use to make better informed health-related decisions. For example, expert system software will analyze an individual's personal risk factor profile to provide personalized wellness and clinical preventive care recommendations, such as the need for cancer screenings or immunization booster shots. Medication trackers will automatically screen for drug interactions and medication allergies and will send alerts and dose reminders to individual patients and their health care providers.

### **Information Presentation**

With the patient's authorization, diverse technologies will allow convenient, reliable and secure access to personal health information in a useable, standardized format and in a variety of settings, such as work, school, the gym, or while traveling. Emergency services will be enhanced by rapid access to emergency health information "in the field." Individuals can give clinicians access to personal information at treatment sites, perhaps with the capability for multiple providers at different sites to access the same information simultaneously, such as for group consultations. Ideally, individuals will have access to their own information even in remote or rural treatment sites and other countries. Home health and social services personnel can be given access at a patient's home and possibly

at an agency office. The presentation of health information could be in text, graphics, voice, audio, video, and a choice of languages to facilitate rapid and efficient use of personal health information by individuals of any literacy level.

### **What Is the Personal Health Content of the NHII?**

Individuals will determine what is the most useful information for their needs. The contents will differ depending upon an individual's age, gender, health history, current health status, and personal choice based on health and wellness concerns. One component will be a personal health record tailored to the individual's needs. For example, a person with diabetes might have serial glyated hemoglobin measurements in their record, while a child's record would contain summaries of well-child visits and immunization history. Standards for a personal health record with a minimum data set and data dictionary will need to be developed so that records have a nationally consistent format that allows individuals to access other parts of the NHII. Content most closely related to health care delivery will overlap significantly with clinical information in medical records maintained by health care providers. Other content is created by the individual through interactive online health risk and self-care applications or "captured" from online resources maintained by diverse hosts for public or even professional audiences. In some cases, the Web site of desired content may just be listed, for access as needed.

### **Core Elements of the Personal Health Dimension**

#### **A. Personal Health Record**

- Patient identification information
- Emergency contact information
- Lifetime health history: summary of care giver records from all sources of care, including immunizations, allergies, family history, occupational history, environmental exposures, social history, medical history, treatments, procedures, medication history, and outcomes
- Lab results, e.g., EKG's; or links to results, for example, MRI results at a radiology dept data warehouse, digital images of biopsy slides, or digital video of coronary angiography
- Emergency care information, for example, allergies, current medications, and medical/surgical history summary
- Provider identification and contact information
- Treatment plans and instructions
- Health risk factor profile, recommended clinical preventive services, and results of those services
- Health insurance coverage information

#### **B. Other Elements**

- Correspondence: records of patient-provider communication, edits made to PHR, or concerns about accuracy of information in Health Care Provider Medical Records
- Instructions about access by other persons and institutions
- Audit log of individuals/institutions who access electronic records

- Self-care trackers: nutrition, physical activity, medications, and dosage schedules
- Personal library of quality health information resources
- Health care proxies, living wills, and durable power of attorney for health care

### **C. Elements from the Community Health Dimension**

- Local public health contact information
- Local health care services (for example, walk-in clinics)
- Environmental measures and alerts pertinent to an individual's home, neighborhood, school, and workplace

### **Where Will Personal Health Information be Stored?**

There is no single place in the NHII where all content will reside. Although the personal health record component could be stored in one repository — a smart card, the home computer, a third party information guardian service, or a health plan/provider server—the value of the NHII will lie in streamlining the organization of and access to content held in multiple places so that the right information is available for the right person at the right time and the right place. Ultimately, the individual will decide which information will be “captured” and kept under his or her control, which information shared with others, and which information will be located and its site URL added to a list of favorites for easy access when needed.

### **Who Uses Personal Health Information in the NHII?**

Only those persons or organizations authorized by an individual will be able to access or utilize that individual's personal health information. The individual and his or her legal guardian or authorized family members will be the primary users. The individual will authorize his or her health care provider to access specific information in the personal health record component. Individuals could pre-approve certain information in the personal health record to be made accessible through secure technology to emergency services personnel in the case of patient incapacitation, such as unconsciousness. Individuals could also decide to participate in public health surveys by approving the transfer of specific personal health information for community health analyses with protection for security and confidentiality guaranteed.

### **Privacy, Security, and Confidentiality Issues**

The strictest attention will have to be paid to protecting the physical security and confidentiality of the personal information contained in and derived from the NHII. Individuals will designate the providers and others they authorize to access specific components of their personal health record. Individuals would be able to designate varying levels of privacy for information contained within their PHD depending upon its sensitivity. Individuals would be able to establish access logs and then be automatically notified, perhaps via e-mail, of all authorized and unauthorized “visits.” Individuals could make provisions for the use of non-identifiable personal information for public health assessment. Individuals could also verify whether their personal health information maintained by health care providers, community agencies, and other entities is accurate, complete, and up to date and make corrections as needed.

## Conclusion

Advances in the Personal Health Dimension of the NHII will allow individuals to make health care and wellness choices that are better informed and more beneficial for their health. Technologies currently exist that can implement this vision of the PHD. However, to fully realize this vision, a supporting structure of national health care data standards, data security, and privacy legislation will need to be in place. Standards for personal health records need to be developed. User-friendly interfaces and cross-platform search engines are needed to permit the integration of information from multiple sources. Mechanisms to promote the quality of online health information resources, especially decision-support tools, need to be developed and implemented. The health care system and individual providers will need to adopt attitudes and practices that encourage patient participation in care decisions, and individuals will have to accept more personal responsibility for their own health.

## The Health Care Provider Dimension

The Health Care Provider Dimension (HCPD) encompasses information to enhance the quality and efficiency of health services for each individual. The HCPD includes information captured during the patient care process and concurrently integrates this information with clinical guidelines, protocols and selected information that the provider is authorized to access from the personal health record, along with information from the Community Health Dimension that is relevant to the patient's care. The HCPD centers on the individual's health care patterns. The information is typically encounter-oriented and protected by mechanisms to ensure the confidentiality of each individual's health care information. The HCPD would be relevant in physicians' offices; hospitals; ambulatory care, long term care, and mental health facilities; and home care sites to facilitate continuity of care.

Health Care Provider Perspective: My Patient with Respiratory Distress, by  
Dr. Jane White

John Smith came in for an urgent visit at 10 a.m. He described his symptoms as "difficulty breathing, dizziness, and weakness." I reviewed the vitals signs recorded at the reception desk on my palm Clinical Manager Screen. Then I called up his medical record on the screen and reviewed John's history of allergies and asthma. I wanted to see if John might have more information in his personal health record, so I asked his permission to access it. He logged into his secure health history service and we checked off the elements that I needed. I noted a long history of allergies and asthma. Recently, he had recorded several incidences of shortness of breath. I did a thorough history and examination and concluded that while his condition is worse than on previous visits, it wasn't life threatening.

I ordered pulmonary function tests as well as other lab work. The diagnostic support program, which is fully integrated with our practice's medical record system, reminded me to record my assessment of blood flow in his hands and

feet. I decided that John could be treated with relatively inexpensive modifications to medicines that he is already taking. Other possible diagnoses are more severe, but our clinical decision program confirms my belief that their probabilities are very low. John agreed that we should modify his medications, and I sent the revised medication schedule to his local pharmacy. Before he left the exam room, an alert appeared on the screen with a city-wide warning for air pollution. Because our central information server, which received the alert, identified that John Smith was already in the office, it flashed the warning in the exam room. Concerned about the impact of this on his already distressed breathing, I suggested John use his new home health monitoring system that allows him to take blood and pulmonary function tests in the privacy of his own home and have the results available to both of us immediately. John agreed to take these tests twice daily for the next three days, and to instruct the system to send me the results automatically. I updated our system's medical record and asked John which elements he would like sent to his personal health record. He said he wanted only the diagnosis and prescription, so we sent them off.

When his condition failed to improve over the next two days, I decided to modify his medications again. Immediately after I entered the change, our system alerted us to a very rare interaction reported to occur in some patients taking the same combination of drugs I was recommending. After a quick review of current literature in the University Hospital knowledge-base, I concluded that the warning did not apply to John. I discussed the risks and benefits of the new treatment with John, and we agreed to give it a try. Within three days, John improved, and continues to recover.

### **What Are the Health Care Provider Benefits of the NHII?**

The NHII will help improve the quality of patient care services by providing access to more complete and accurate patient data on-the-spot, around-the-clock. Clinical decision-making will be enhanced by the concurrent availability of medication or care path alternatives, along with warnings, alerts, reminders and information from other dimensions pertinent to diagnosis and treatment over a lifetime of patient care. Automated systems will help reduce adverse drug events by generating concurrent alerts and will facilitate recognition of these and other adverse medical events as they occur. Through the sharing of more complete and accurate information and the use of the most current clinical care plans, improvements in coordination of care among providers, across care settings, and in disease management will occur.

The existence of a HCPD will enhance both quality and efficiency in the health care system by supporting more timely and improved decisions, capturing complete and accurate information for clinical purposes, facilitating the use of derivatives of this information for reimbursement, research, and administrative purposes, and providing better data to track provider performance in terms of quality, cost, and outcomes. These benefits will help contain or reduce costs while enhancing the effectiveness of services. Clinical and population researchers, public health services and health care payors will obtain better and more accurate data from the provider dimension to improve the assessment of best practices, identify risk factors, and evaluate medical performance.



The data shared by health care providers will augment the Community Health Dimension by providing more accurate clinical data to support better patient outcomes analysis, improved services, and more detailed data for population-based and public health research. The data will augment the Personal Health Dimension by providing more consistent and complete documentation of individual encounters of care and medical events that can be summarized for inclusion or reference in the personal health record.

### **What are the Health Care Provider Functions of the NHII?**

The functions include the capture, storage, communication, processing, and presentation of information.

#### **Information Capture**

The NHII will use state of the art technologies to capture information from all patient encounters in ambulatory, in-patient, long-term care, and home/community settings. Increasingly, information will be captured closer to the point of care. The process must be easy to learn and use so that it becomes a natural part of the health care process. The information should be captured initially for clinical purposes, with derivative use of the data for reimbursement, research, and administrative purposes, and, with appropriate measures described later in the Health Care Provider section, for personal and community health management. Standards for data elements will ensure consistency, compatibility, and communication among providers and across technologies.

#### **Information Storage**

The primary record of care will be stored within the operational control of the provider who captures the original health care information. The primary record of care must be stored in a manner that will protect the completeness of the record and the integrity and confidentiality of the data. It must be part of an information system that is capable of providing authorized access seven days per week, 24 hours a day. If health care information is sent some place other than the point of care, the recipient of the information is responsible for protecting the confidentiality of the data.

#### **Information Communication**

Members of a health care team and other authorized health professionals will have access to an individual's specific and pertinent health care information. The health care information associated with a specific patient may also be communicated to payors, clinical researchers, and public health entities with appropriate permissions from the patient and appropriate legal protections for privacy, confidentiality, and security. The patient will have access to all health care information in the provider's medical records. With the patient's permission, specific information from patient visits will be placed in the patient's personal health record, which is part of the Personal Health Dimension. All communication of health care information will comply with national standards for data security including encryption and electronic signatures. These communication capabilities are essential to facilitate coordination of care.

## **Information Processing**

The NHII will encompass electronic information systems that can synthesize clinical and other information and generate alerts, warnings, reminders, or clinical guidelines to the provider during the process of patient care.

## **Information Presentation**

Standardization of data elements and formats will enhance the usefulness and exchange of information among different providers. Within these formats, providers will organize the presentation of the information in a manner that facilitates effective and efficient use of the information to provide care. Information must be presented when a provider needs it, in the most relevant medium (voice, text, or image), in the most useful and accessible manner, and at the most convenient location (usually at or near the point of care).

## **What Will the Health Care Provider Dimension Contain?**

The NHII will contain a basic core of information in individual patient records to facilitate the flow of information across the continuum of care for the individual. Although the content of the patient record will vary by site of care and nature of the patient's disease, injury, or health status, standardized terms will be used to permit consistency. The patient record will include health care information covering one or more encounters for an individual. Content of the Health Care Provider Dimension will also come from several other sources. Some patient information will come from the personal health record with authorization from the patient, or directly from the patient, family caregiver, or legal guardian. Other information will come from providers, laboratory or radiology information systems. Additionally, the health care provider dimension will also include appropriate community health information, necessary for full understanding of a patient's health concerns.

## **Core Content of the Health Care Provider Dimension**

### **A. Patient Record Elements**

- patient identification information
- sociodemographic identifiers (gender, birthday, age, race/ethnicity, marital status, living arrangements, education level, and occupation)
- health insurance information (including covered benefits)
- legal consents or permissions
- referral information
- correspondence
- patient history information (may include longitudinal history from PHD, immunizations, allergies, and current medications)
- stated reason for visit
- external causes of injury/illness
- symptoms
- physical exams

- assessment of patient signs and symptoms
- diagnoses
- laboratory, radiology, and pharmacy orders
- laboratory results
- radiological images and interpretations
- record of alerts, warnings, and reminders
- operative reports
- vital signs from ICU
- vital signs from PHD
- treatment plans and instructions
- progress notes
- functional status
- discharge summaries
- instructions about access
- audit log of individuals who accessed the patient record
- patient amendments to patient record
- provider notes such as knowledge of patient, patient-provider interactions, patient's access to services

#### **B. Other Elements That Support Clinical Practice**

- protocols, practice guidelines
- clinical decision-support programs
- referral history

#### **C. Elements from Community Health Dimension**

Depending on the patient, the Health Care Provider Dimension would include additional contextual information necessary for understanding, treating, and planning the care of the patient:

- aggregate data on the health care of community members
- community attributes affecting health (for example, economic status and population age)
- community health resources (for example, home health services)
- community health (for example, possible environmental hazards at home, work, school, or in the community at large).

#### **Who Uses the Health Care Provider Dimension?**

The HCPD is primarily for health care providers at or near the point of care. Health care providers include physicians, nurses, allied health professionals, and home health care professionals. They will be able to access health care information from whichever location is necessary to provide the highest quality of patient care and achieve the best possible patient outcome. Secondary users include clinical and public health researchers and payors. Individuals will have access to their own medical information and, if they choose, can authorize their provider to send specific information from a visit to their own personal health records.

### **Where Will Information in the Provider Dimension be Stored?**

A monolithic HCPD will not exist. The primary record of care will be stored within the operational control of the provider who captures the original health care information. It may be held onsite or on the server of a third-party health information guardian. The primary record of care must be stored in a manner that will protect the completeness of the record and the integrity and confidentiality of the data. It must be part of an information system capable of providing authorized access seven days per week, 24 hours per day. If health care information is sent some place other than the point of care, the recipient of the information is responsible for protecting the confidentiality of the data.

### **Privacy, Security, and Confidentiality Concerns**

The NHII will incorporate technologies and practices that enhance the confidentiality and security of personal health information. Access to the patient health record may be restricted by the patient, the data security policies and practices of health care institutions, and/or State or laws and regulations. Physicians, nurses, allied health professionals and home health care professionals may have access to essential data in the patient record appropriate to the patient situation.

The confidentiality of health care information will be protected by limiting access to individual health information with the use of technologies such as authorization, authentication, and restricted access by class, role, or location of the user. Confidentiality will be maintained when personal information is communicated to other health care institutions or providers with technologies such as encryption and electronic signatures.

### **Conclusion**

The vision of the Health Care Provider Dimension was outlined in the Institute of Medicine's 1997 study, "Computer-Based Patient Record: An Essential Technology for Health Care." However, many events still need to occur before the vision can be fully realized. Though technology advancements have produced much progress, the problem of incomplete and incompatible standards and terminologies, and security, privacy and confidentiality concerns need to be resolved. The full vision of the Health Care Provider Dimension is evolving with the introduction of new technological solutions, standards, and privacy and confidentiality legislation. The measure of success will be a health care system that enables continuous improvement of clinical processes in an efficient and cost-effective manner.

### **The Community Health Dimension**

The Community Health Dimension (CHD) of the NHII encompasses a broad range of information, including population-based health data and resources, necessary to improve public health. The CHD will include statutorily authorized data in public health systems and the Health Care Provider Dimension. Anonymous data could be used for research or other public health purposes. The CHD will have strict legal and technological safeguards, including appropriate security and permissions, to protect the confidentiality of data from other dimensions.

Community Perspective: Our Air Pollution Alert, by John Chang,  
Big City Health Officer

Last week, Aerometric Information Reporting System (AIRS) monitors in Big City sent an emergency alert to the Big City Health Department: ozone and carbon monoxide levels over the past 24 hours significantly exceeded National Ambient Air Quality Standards. Our Community Health Information Server immediately initiated a detailed automated air pollution emergency response protocol.

Within seconds, local health care providers and local media received the highest priority emergency electronic messages. Radio, TV, print and electronic media were asked to begin immediate and repeated air pollution alerts to advise parents with infants, elders, and others with severe respiratory problems to remain indoors whenever possible. Community kiosks in heavily-trafficked areas also began flashing alerts. At the same time, hundreds of physicians, six hospitals, five home health agencies, and ten nursing homes were alerted and told to use their electronic databases to identify and notify those most at risk. Fortunately, many members of our high-risk populations have signed up to receive automated alerts when poor air quality requires them to stay indoors. Some people like to get the alerts on their wrist systems, but most get them at home by either a visual or spoken message on their home information centers. Our community outreach workers also keep an updated list of people who prefer an automated phone call when there is an alert.

During the week of the air pollution emergency, our system analyzed information from physician and emergency room visits, and hospitalizations for infants, elders, and individuals with chronic respiratory problems. Our epidemiologists saw that older people across the city and infants and other people from the poorer, largely non-English speaking immigrant neighborhoods abutting the Big City industrial parks had especially high emergency room visit rates in the first few days of the crisis. Consequently, on the fourth day, we adjusted our strategy. Announcements were broadcast and printed in the languages spoken by Big City's two largest immigrant groups. Additionally, elder service agencies were told to conduct in-person outreach to shut-in elders, especially those with chronic respiratory problems, and advise them of proper procedures.

Due to our quick-response system, we had fewer respiratory-related health problems than the last time the pollution index hit this level. I'm glad we haven't had to activate the alert system for other environmental hazards. But just to stay ready, we've scheduled tests of those components for a month from now.

### **What are the Community Health Benefits of the NHII?**

With improved access to accurate, timely, and comprehensive information, public health professionals will be better able to identify public health threats; assess population health; focus programs and policies on well-defined health problems; inform and educate

individuals about health issues; evaluate programs and services; conduct research to address health issues; and perform other essential public health services.

The CHD will bring specific improvements to public health practice such as enhanced reporting systems to identify emerging and ongoing health problems; improved population health data to help characterize the whole population and specific sub-populations; mechanisms to identify health needs of sub-populations who are especially at risk because of social and/or environmental conditions; and expanded potential to identify factors that affect health throughout the life cycle. The CHD will also improve access to and utilization of a wide range of information essential to monitor and protect the public's health through electronic data interchange and decision-support technologies. As the mission of public health in the United States evolves to include greater emphasis on monitoring the quality of health care services, the CHD will facilitate access to and integration of all information needed to improve the population's health. An integral component of the CHD will be mechanisms to protect the confidentiality of individuals' personal data and to improve the security of public health data.

Because they can use the dimensions of the NHII to organize their health activities, Mary Jones, Dr. Jane White, and John Chang are all helping each other and, indeed, helping make their communities and the nation a bit healthier by participating in online health information networks. One cross-cutting health issue—vaccinations against preventable childhood diseases—shows how.

The vaccination records of Mary's children are part of their personal health records. Although her children have seen many different health care providers over the years, their vaccination information can be easily located. Automated reminders appear on each child's health home page when a vaccination is due. At the time each child receives a vaccine, the information is simultaneously added to their personal and clinical health records (both of which are kept secure and confidential) .

Dr. White makes sure that all vaccinations for her patients are recorded in their personal records as well as in the office's medical record. Her system is linked to the local public health reporting network and batches of vaccination records with the names, addresses, and other personal information removed are automatically sent.

The vaccine reporting system issues periodic reports back to Dr. White and to community, State and health agencies. These reports help each office make comparisons to vaccination levels recommended by CDC to protect individuals and communities against preventable diseases. Dr. White may learn that she is not achieving the recommended vaccination levels among her pediatric patients; she may receive suggestions for communicating with families not currently in the network. John Chang may learn that certain neighborhoods have especially low vaccination rates and receive suggestions for public health outreach efforts to bring vaccinations to these areas. The State and health officials can see larger patterns of vaccination rates and plan broad strategies to target resources to areas with low levels.

## **What are the Community Health Functions of the NHII?**

The functions include the capture, storage, communication, processing, and presentation of community health information.

### **Information Capture**

The CHD will capture information from conventional sources of public health data, such as vital events, communicable disease surveillance systems, and childhood lead screening and immunization programs. The CHD will also encompass information from less conventional public health sources, for example, the National Spatial Data Infrastructure. Health care providers will send patient encounter information from which all personally identifiable information has been removed for public health monitoring of population health status and health care services. Providers will send personally identifiable information only under strict protocols, for example to track highly contagious diseases or to fulfill other legally-mandated public health responsibilities.

### **Information Storage**

There will not be a single database of public health information. Diverse and separate, State, and local information systems will be maintained, with greater integration vertically and horizontally.

### **Information Communication**

The CHD will provide Federal, State and local public health professionals with information about trends in health risks, diseases, and other factors affecting community health. Clinicians and the public will be alerted to communicable disease threats and environmental hazards, and they can receive reminders about immunizations, flu shots, preventive health services and other broad-based health care opportunities. Aggregated community health profiles will be available to the public and to community groups. These community health profiles will not contain any individually identifiable data.

### **Information Processing**

CHD data standards will allow the electronic integration of conventional sources of public health data, such as those legally mandated for collection by local and State health departments, along with non-identifiable information from patient encounters. The CHD will include decision-support tools that integrate data analysis and public health practice guidelines.

### **Information Presentation**

The CHD will enable public health workers to access data, analyses, directories, and other information resources and tools from the field as well as in public health clinics and offices. The CHD will also provide useful information in usable and accessible formats to individuals, community institutions such as libraries, and community groups for identifying public health problems and planning public health interventions. The information and its presentation will be tailored to users' specific needs.

## **What Will the Community Health Dimension Contain?**

In the broadest terms, the community itself will be the focus of information within the CHD. The content will focus on the health and health care of community members, community attributes affecting health, community health resources, and broad measures of community health status. These categories of information support a focus on overall community health needs, rather than individuals and disease events.

### **Core Content in the Community Health Dimension**

#### **A. Public Health Data**

- Infant mortality, immunization levels, and communicable disease rates
- Environmental, social, and economic conditions
- Measures related to public health infrastructure, individual health care providers, and health care institutions
- Other summary measures of community health
- Registries
- Disease surveillance systems
- Survey data
- Data on Healthy People objectives and Leading Health Indicators

#### **B. Information From Health Care Provider Dimension (with personally identifiable information removed except under legally established public health protocols and strict security)**

- Health status and outcomes, health events, health risks, health behaviors, and other individual characteristics
- Health care utilization and access, health insurance status
- Health care of community members

#### **C. Other Elements**

- Directories of community organizations and services
- Planning, evaluation and policy documents
- Compendia of laws and regulations
- Materials to support public education campaigns
- Practice guidelines and training materials for public health professionals

It will be possible to aggregate data within the CHD in various ways, such as city or town, neighborhood, health service area, household, family, or other grouping. Beyond the basic core information, the specific content of the CHD will vary depending if the community of interest is defined geographically, economically, ethnically, or by some other characteristic. The specific unit of analysis of the CHD will also vary and may include individuals, communities, health episodes, or health events. Any of these community units can be analyzed both longitudinally and at a specific point in time. This ability to aggregate and analyze data from diverse sources will enhance the public health response to events such as flu epidemics or outbreaks of food poisoning, for example.



To ensure privacy and confidentiality, data within the CHD will only be linked on an “as-needed” basis for specific projects. The use of personally identifiable information will be subject to legally established public health protocols with strict protections for security and confidentiality. Different approaches will be necessary to protect the confidentiality of each type of community health information. Policies, practices, and technologies designed to address confidentiality and privacy issues are discussed at the end of the Community Health Dimension section.

### **Who Will Use the Community Health Dimension?**

The primary users of the CHD are public health professionals, community members and community groups. These individuals and organizations have principal roles in decisions and actions to improve community health. Health policy makers, including legislators and staff, population health researchers, Schools of Public Health or similar academic institutions, health care providers, and members of the general public with an interest in population health information will also be able to draw on anonymous and aggregated data in the Community Health Dimension to inform decisions and programs and to advance understanding of health issues. The CHD will be used in such locations as local, State, and public health agencies and other pertinent government offices; public and private hospitals and health care clinics; academic and research institutions; libraries and homes.

Access to the CHD will occur only along a carefully constructed and monitored continuum. Access will depend on the specific use and user of information. At one end of the continuum will be access to individually identifiable data by authorized public health workers for such legally authorized purposes as contact tracing for highly communicable diseases or identifying high-risk infants in need of intervention. At the other end of the continuum will be public access to anonymous, aggregated data to identify local public health problems and to set local public health priorities. In the middle of the continuum will be access to some identifiable data governed by protocols already in place and under the authority of groups such as the current Institutional Review Boards approved by the Federal Office for Protection of Research Risks. Access to non-personal community information and other non-sensitive resources would generally not be limited.

### **Where Will Contents of the Community Health Dimension Be Stored?**

Legal and market place developments that will occur during the evolution of the NHII will dictate its final form and architecture. A monolithic CHD utilized by all public health agencies and other users will not exist. As currently envisioned, components and data sets will reside in multiple locations, separated geographically but accessible to authorized users for approved purposes as if maintained locally. Standards for electronic data exchange will facilitate data flows within the CHD. Data sets will be linked only as needed for specific approved purposes and with appropriate anonymity.

### **Privacy, Security, and Confidentiality Concerns**

The CHD can only exist within a legal and policy framework that maximizes confidentiality, security, and appropriate use. The CHD raises legal, policy, and technical concerns that will need to be resolved before the full range of potential benefits from an

integrated public health information infrastructure can be realized. New legal protections to secure the privacy, confidentiality, and security of Community Health Dimension data will be necessary. Issues requiring resolution include development of security and confidentiality protocols covering uses, users, and access modes for personally identifiable information; statistical protocols for aggregated data to protect individual privacy; and protocols to protect individual privacy for interactive applications providing public access to aggregated CHD data.

## **Conclusion**

The Community Health Dimension of the NHII will enable public health providers and policy makers to make better use of existing information in their on-going mission to improve community health and public well-being. The CHD will help reduce the current burden on data providers by reducing duplication and overlap. It will also provide a reliable and accessible means for communities to locate de-identified data so they can more efficiently and effectively identify and solve their own health problems. In addition, it will give Federal, State and local public health agencies the tools to improve the overall health of Americans. The CHD will strengthen confidentiality of existing data and provide the strongest possible protections for new data. Access to identifiable data will be limited to those with legitimate, specifically-approved purposes.

## **6. Next Steps**

The potential components and benefits of a national health information infrastructure are already visible. Achieving the full potential of the NHII will require efforts by Congress, government agencies, health care professionals and organizations, technology and communication companies, research institutions, community organizations, and the public.

To help develop a national consensus on the best way to accomplish mutual goals, the NHII project will be joining the 21st Century Health Statistics project in a series of regional hearings in 2000–2001. Individuals, communities, and professionals will be invited to contribute to a common understanding of the country's health information needs and opportunities for improvement. This interim report will be widely distributed and publicly available on the Internet so that suggestions can be gathered. A final report with recommendations will be approved by the National Committee on Vital and Health Statistics, and presented to the Secretary of Health and Human Services, the HHS Data Council, HHS agencies, and Congress in 2001.

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# Interim Report: Shaping a Vision for 21st Century Health Statistics

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*I dream things that never were and ask, "Why not?"* (G.B. Shaw)

## Introduction: The 21st Century Vision Process

Building and maintaining a healthy population depends on information, and health statistics are a crucial dimension. Health statistics are health data that can be generalized to a known population of individuals, events, organizations, or institutions. The statistics can be used to design, implement, monitor, and evaluate specific health programs and policies. Properly organized and communicated, health statistics enable U.S.—citizens, policy makers, public health workers, and health care providers—assess local or national health, mobilize to improve it, and evaluate the success of those efforts.

An effective system of health statistics can take seemingly isolated events and reveal a broader context, identifying patterns and trends that can shape personal, professional, and public decisions. Consider these examples:

- A coalition of community groups and public and private health organizations in King County, Washington, found that the percent of Vietnamese, Lamina, Chinese, Filicinae, and Korean women receiving breast and cervical cancer screenings were much lower than the county average. In response, several health plans and hospitals that are otherwise in competition joined to fund a screening and education initiative targeted at these groups. This is typical of the activities of the coalition, called the Community Benefits Program, which analyzes local data to identify worsening trends affecting vulnerable populations and then sets priorities and funds community programs aimed at reversing the trends.<sup>1</sup>
- Any pediatrician or emergency physician knows that childhood asthma has increased alarmingly in the last decade. But without health statistics, we would be unaware that African American children are four times as likely as white children to die of this cause—and 10 times as likely if they are 1–4 years old.<sup>2,3</sup> Information such as this made childhood asthma part of a major child health initiative launched by the President in 1997.
- “Growth charts” based on national survey data are found in every pediatrician’s office. They allow parents and doctors to compare a child to a population reference standard, providing an indicator of whether the child is developing normally or is in need of nutritional or medical attention.

## Unrealized Potential

Today’s health statistics are the product of an enormous national investment over the past century. Most health statistics systems were designed decades ago to address the pressing

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<sup>1</sup>King County Health Action Plan, Community Benefits, Recommendations and Actions. [http://www.metrokc.gov/health/phnr/hap\\_commbenefits\\_rec.htm](http://www.metrokc.gov/health/phnr/hap_commbenefits_rec.htm).

<sup>2</sup>United States Centers for Disease Control and Prevention: Forecasted state-specific estimates of self-reported Asthma Prevalence-1998. Morbidity and Mortality Weekly Report. (Dec. 4, 1998) 47:1022–1025.

<sup>3</sup>Topic of the month, Pediatric Asthma. AAAAI. <http://www.aaaai.org/misc/topicofthemoth/1299.stm>



health questions of the day using the technology, resources, and structures then available. Their evolution has been shaped by a variety of institutional and public health pressures.<sup>4</sup>

Individually, these health statistics systems —such as data on AIDS and sexually transmitted diseases, registries on cancer and other diseases, birth and death records, household health surveys, and provider records—generally meet the needs they were created for, albeit with room for improvement. But collectively, as a national system of information on the health of the U.S. population, they are deficient. Because they were not planned as a unified system, they are a patchwork of data collection systems, both duplicative and full of gaps. Although rich national health data are collected, they often cannot be broken down to provide information on states or localities. Also, because they are collected using different methods and definitions, it is often not possible to combine health statistics from different States and localities to form a national picture, nor to compare States. Local, State, and national data systems cannot be combined into a coherent whole.

These limitations make it difficult, for example, to answer such basic questions as these:

- Do preventive health measures and medical care have their intended effects for individuals, communities, and the Nation?
- How are society's economic and racial inequities affecting the health of communities and individuals?
- How are environmental hazards affecting local and national health?
- Who is benefiting most from medical care, and how? Who has been left out, and why? What do we need to know and do to include the excluded?
- What mix of public health measures (for example, screening, education, attention to food and water safety) and medical care would maximize improvements in the population's health?

## **Birth of the Visioning Process**

Aware of these limitations and of the tremendous information technology capacities now available—and feeling pressure to address critical information needs —Dr. Edward Sondik, Director of the Centers for Disease Control's National Center for Health Statistics (NCHS), made a challenging request of the National Committee on Vital and Health Statistics (NCVHS) in 1998.

NCVHS is the public advisory committee on national health information policy to the HHS Secretary. Dr. Sondik, who is the Secretary's senior health statistics advisor, asked the National Committee to help articulate a vision whereby health statistics in the United States could mobilize new capacities and fulfill the potential to promote and protect the country's health in the 21st century.

The Committee rose to the challenge. In early 1999, NCVHS and NCHS joined with the HHS Data Council to launch a national consultation and visioning process that is still underway. The present interim report describes the learning that has emerged in the first

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<sup>4</sup>Friede A, Blum H, and McDonald M. Public Health Informatics: How Information Age Technology Can Strengthen Public Health. *Annual Review of Public Health* 1995. 16:239–52.

year. The report will be used to elicit further input from more stakeholders about their perceptions of future health needs and the best mechanisms for addressing them.

The overarching goal of the visioning process is to provide the information needed to enable the American public to achieve and maintain the best possible health. To this end, the visioning process is addressing a multifaceted set of questions:

- What health information will be needed in the 21st century?
- What conceptual framework meaningfully organizes the information?
- What approaches to collection, storage and communication will most efficiently get high-quality information where it can make a difference?
- What privacy, confidentiality and security protections must be in place to ensure that information can safely be used to promote the public's health?

This process calls for three kinds of vision: a good eye for detail, wide peripheral vision, and distance vision that can see far into the future without depending on outdated lenses. In other words, we need an understanding of what it is important to know, an appreciation of how best to find out, and a vision that can anticipate future needs.

The work to envision 21st century health statistics is closely related to another NCVHS project, that of envisioning and developing the National Health Information Infrastructure (NHII).<sup>5</sup> The NHII is not to be a unitary database. Rather, it is conceived of as a set of policies, practices, technologies, standards, and applications that support communication and the broad array of information needed to improve clinical care, monitor public health, and educate consumers and patients. Community, or population, health information—the essence and focus of health statistics—is one dimension of the NHII, overlapping and sharing data with the personal and provider dimensions.

## **Process, Participants, and Products**

For the health statistics vision, NCVHS, NCHS and the Data Council designed a process with many opportunities for consultation with a broad range of health statistics users, public health professionals, and health care providers from communities around the country and abroad. Special priority has been given to hearing State and local perspectives, by talking with people who use health statistics at State and local levels. The partners also commissioned five scholarly papers to contribute to a common understanding of health statistics and to help identify what needs improving. (Titles and authors are listed in the Appendix.) Key participants in the process are listed at the end of this report.

The consultative process involved these components in 1999 and early 2000:

- A total of seven workshops and meetings in Harrisburg PA, New Orleans, Albuquerque, and Washington, D.C. (Summaries of these meetings and lists of participants are posted on the NCVHS Web site.<sup>6</sup>)
- Presentations and discussions at professional association meetings, including those of the National Association for Public Health Statistics and Information Systems,

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<sup>5</sup>See the NCVHS June, 2000 paper on the NHII vision, *Better Information for Better Health: Toward a National Health Information Infrastructure*.

<sup>6</sup>[WWW.NCVHS.HHS.GOV/HSVISION](http://WWW.NCVHS.HHS.GOV/HSVISION)

the Association for Health Services Research, the National Association of Health Data Organizations, and the Council of State and Territorial Epidemiologists

- Meetings with public health and health statistics professionals within the Centers for Disease Control and Prevention (ongoing)
- A 2-day workshop on health statistics hosted in November 1999 by the Committee on National Statistics of the National Academy of Sciences, which also invited papers

This consultative process is open and ongoing, and efforts are being made to engage many more stakeholders. To continue the dialogue, NCVHS plans four regional hearings for the last half of 2000 and early 2001. Information on these events and on other ways to contribute are outlined on pages 20–21. Release of the final Vision document is slated for summer 2001.

## **Intended Impacts**

Ten principles have emerged from the consultations thus far as key elements of the health statistics vision. These principles, which are discussed below, will help focus future discussions as the consensus about the health statistics Vision continues to evolve. They are as follows:

1. The confidentiality of health information on individuals must be protected. This precondition applies to all other principles listed below.
2. An overarching conceptual framework is needed to help organize the different elements of the health statistics system.
3. The health statistics system must be flexible enough to identify and respond to new information needs.
4. Information must be available at a sufficiently detailed level (for example, geographic area, racial and ethnic subpopulation) to be relevant to real decisions.
5. Data standards are essential and should have maximum usefulness to public health, health care delivery, health statistics, and research.
6. Data should be collected once and then used for multiple purposes, using approaches that promote sharing and efficiency while protecting privacy and confidentiality.
7. Health statistics data must be provided back to communities, community groups, local governments, policy makers, health care providers, and others in ways that maximize data access and ease of use.
8. Approaches should be developed that allow system-wide planning and coordination so that resources can be better managed.
9. Health statistics must be collected, organized, and made available in ways that inform and facilitate decision-making on health.
10. Implementing a broad vision for a 21st century health statistics system will only be possible through collaboration and partnerships including both public and private organizations at the local, State, and national levels.

In addition to articulating the health statistics Vision, the 3-year national consultative process is designed to yield a practical description of the components of an integrated information system as well as ideas about how the Vision can guide local, State and Federal program planning. The process also seeks to build consensus about health

statistics priorities, to clarify roles for the levels of government and for the public and private sectors, and to identify new opportunities for partnership among these components. All of these developments will permit a more rational and cost-effective use of resources. Participants also will lay out criteria and a process for evaluating health statistics systems in the future.

## Who Will Benefit?

All Americans stand to benefit from a comprehensive and integrated health statistics system that, while protecting the privacy of individual data, “highlight[s] the distribution of health in relation to the distribution of resources directed to maintaining or improving [it].”<sup>7</sup> These benefits will be measured not only in improved health at both personal and community levels, but also in more rational and cost-effective decision-making and stronger communities. The potential beneficiaries include families, community leaders, health care professionals and institutions, businesses of all kinds and sizes, educators, local health departments, the media, social service providers, advocacy groups, foundations, and every level and branch of government.

Such enhancements will enable us to make informed decisions about health investments and then evaluate their results. Here are a few examples of potential applications:

- Billions of dollars have been allocated to provide uninsured children with health insurance through the State Children’s Health Insurance Program, or CHIP.<sup>8</sup> However, currently there is no way to know what difference this is making in their care and health. Better information would permit better outreach, better care, better comparisons of different approaches, and better monitoring of results.
- Currently, there are many concerns but insufficient knowledge about the health impact of toxins in the air, water, and food. With more complete information, we could pinpoint harmful sources, study their impact on health, design preventive measures, and track their effectiveness.
- Comprehensive, integrated local data on prenatal care, infant outcomes, and infant care would allow community health workers to design more effective approaches to prenatal and infant care, and to evaluate the performance of programs and providers.
- Currently there is no way to match the supply of primary care and specialist services to the needs of populations. Having this information would make it possible to target resources to meet the needs of people in different areas and to avoid excesses that generate unnecessary costs for the public.

## What We Have Learned So Far: Trends and Gaps Shaping the Vision

As noted, this report outlines the themes that have emerged in consultations over the last year about current and emerging health issues, health information needs associated

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<sup>7</sup>Black C, Roos N, and Roos L, “From Health Statistics to Health Information Systems: A New Path for the 21st Century,” p. 11 (commissioned paper).

<sup>8</sup>Closing the Gap, State Children’s Health Insurance Program, Providing Coverage to Nearly Two Million. <http://www.omhrc.gov/ctg/chip.pdf>

with these trends, and roles and responsibilities for providing information and statistics. The perspectives and experiences of the participants are reflected in the summaries that follow.

The primary questions to bear in mind as we look at these trends, issues, and knowledge gaps are how these forces will shape future information needs, and how a well-defined vision and unified approach might strengthen the country's ability to address the trends.

## **Socioeconomic, Demographic, and Environmental Factors**

Perhaps the strongest theme of the discussions to date has been the need for a broad definition of health, and the need to look further than the presence of disease or the pursuit of medical care in order to understand the health of the population. This means understanding the effects and interactions of the cultural, socio-economic, and environmental domains in which we all live. What trends in these domains are likely to shape future needs and opportunities? What will we want to know about them with respect to health?<sup>9</sup>

Key demographic factors include an aging population<sup>10</sup> and changes in household composition (for example, there are fewer children, more single parents, and more single-sex households).<sup>11</sup> Important socioeconomic factors in the United States include growing gaps between the resources available to the wealthy and to the nonwealthy, greater differentials in economic and social status, more self-employment and less job security, and an increase in the percentage of the population that is poor, including the working poor.<sup>12</sup>

Other significant trends are the increasing racial and ethnic complexity of American life,<sup>13</sup> with wide ethnic variations in health status within racial groups (for example, among Cambodians, Japanese, and Vietnamese) and the growing percent of multi-racial families; the resurgence of attention to social support as important to health and health statistics; and a rising awareness (and possibly growing presence) of environmental threats to health.

### **Knowledge Gaps**

To address these socioeconomic, demographic, and environmental trends, we need to close the following knowledge gaps, among others, at all geographic levels:

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<sup>9</sup>Evans RG, Barer ML, and Marmor TR, Editors. *Why Are Some People Healthy and Others Not? The Determinants of Health of Populations*. New York: Aldine De Gruyter, 1994.

<sup>10</sup> Administration on Aging, *Aging into the 21st Century, Demographic Changes*. Jacob Siegel. (<http://www.aoa.dhhs.gov/aoa/stats/aging21/demography.html#Growth>)

<sup>11</sup>Urban Institute *All under One Roof: Mixed-Status Families in an Era of Reform* By Michael Fix and Wendy Zimmermann, June 1999. [http://www.urban.org/immig/all\\_under.html](http://www.urban.org/immig/all_under.html).

<sup>12</sup>Who is Poor, 1998 Green Book. <http://www.ssc.wisc.edu/irp/faq3.htm>

<sup>13</sup>Closing the Gap, *Moving Towards Consensus on Cultural Competency*. <http://www.omhrc.gov/ctg/competence3new.pdf>

- Ongoing data on economic status, education, language, immigrant status, the availability of social supports, and the relation of each to health status
- Socioeconomic and health data on various racial and ethnic groups
- Data on specific environmental factors such as lead and ozone and their impact on health
- Mechanisms for collecting longitudinal data to help us understand emerging trends and threats to the population's health, and mechanisms for sharing and linking information, with adequate privacy protections
- Better ways to characterize the complex interactions among the factors that affect health

## **The Health of Populations**

Vision discussions to date have noted the rise of chronic illness and the growing prevalence of new and newly recognized communicable diseases as important trends in the health of the American population. Serious disparities exist among people in various groups—for example, between certain racial and ethnic groups and between economic levels—in the prevalence and severity of specific diseases and in access to and receipt of appropriate treatment. Additional data are needed at all geographic levels to track new efforts to eliminate the disparities—a major goal of the HHS Healthy People 2010 objectives.<sup>14</sup>

### **Knowledge Gaps**

To address health trends affecting populations, the following gaps must be filled, among others:

- Ongoing information—in all categories—about small geographic areas such as small towns and urban neighborhoods
- Information, especially at State and local levels, about specific population groups—for example, racial and ethnic minority groups (especially Asian and Hispanic groups), children, the aged, migrants, the working poor and nonworking poor, and people with disabilities
- Information on individuals related to comorbidity, mental and behavioral health, and health status—including their functional status with respect to physical abilities and cognitive functioning and their access to devices or other means of assisting their functioning

## **Health Care, the Health Services Delivery “System,” and Health Care Seeking**

Discussions to date have stressed that health care services at the start of the 21st century are delivered not within a system but by a disparate and rapidly changing array of institutions and relationships. In terms of information, the most important criticism is that

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<sup>14</sup>U.S. Department of Health and Human Services, 2000. Healthy People 2010. Conference Edition in Two Volumes. Washington, D.C., Government Printing Office.

too much of the data now collected is useful only nationally, or only for paying for health services. When the data are used for other purposes, they often produce misleading information.

Business trends in health care are toward capitation,<sup>15</sup> consolidation, and reliance on market mechanisms—with important implications for what information is collected, and how. In clinical care, two major trends are the growing interest in evidence-based medicine and the growing use of expensive, high-tech solutions to medical problems. Other trends are the provision of care outside traditional inpatient settings and pressures away from specialty care and toward primary care.

There is growing attention in the United States to outcomes and quality issues—at least partly in response to payer demand, public policy, and media attention. Yet little of the information that is currently collected is useful for these issues. For example, data on hospitalizations is collected completely separately from data collected in other health care settings or by surveys, and these various sources cannot be linked to provide a cogent picture of health needs and how they are being met.

In terms of health care seeking by consumers, a significant number of Americans are choosing alternative forms of treatment, some of unproven usefulness and possible harm. Consumers also are seeking information on the Web, engaging in self-care, and participating in self-help/mutual aid groups.

### **Knowledge Gaps**

In addition to those noted above, knowledge gaps related to health services delivery lie in the following areas, among others:

- The relationship between the population's health and relative investments in primary care and ambulatory specialty care
- The effectiveness for the population's health of specific medical interventions purported to improve health (Examples: What are the implications for survival of radical prostatectomy compared to brachytherapy? How much of the explosion in new and expensive drugs really improves people's health and well-being? Is the increasing cost of health insurance compromising health? What types of care produce the best results for the health of the population?)
- Information to determine whether the demonstrated benefits of surgeries, drug treatments, and putative quality of life enhancements extend to all people
- The effectiveness of investments in preventive services versus curative services
- Information about the types of services available to local populations and the balance among them
- The impact of adverse effects of medical care on the health of the population
- Data on alternative therapies (for example, procedures, providers, and consumer care-seeking)

The fragmentation of health care delivery today makes it essential to have integrated, effective information systems in order to understand the health care system and how

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<sup>15</sup>Ginsburg, Paul, Ph.D. As the System Changes, Health Policy Expert Sees Positives and Negatives, MDOptions.com, Sept. 1998. ([http://mdoptions.com/cgi-local/display\\_article\\_short.cgi?670](http://mdoptions.com/cgi-local/display_article_short.cgi?670))

people fare in it. Without this, we lack a composite picture of the preventive and treatment interventions given to individuals or to communities—making it impossible to evaluate the effectiveness of health services. Tying together information on communities, events, people, providers, and health outcomes from different sources can help create more integrated services and improve efficiency and quality.

## **Scientific Research**

Scientific research provides the evidence base, the stimulus for, and the means of evaluating both public health practice and clinical care. However, some scientific trends raise questions that merit a close look in the context of population health. The development and use of technology is proceeding at great expense to the nation and without a clear picture of its contributions to improving health.

In the 21st century, the impact of current investigations into the human genome will unfold in a host of new approaches to screening and therapy. These developments have major implications for future information needs, not only in clinical areas but also in broader ones related to family, culture, education, ethics, and social policy.

## **Knowledge Gaps**

Keeping up with the public health ramifications of scientific research will require more information in the following areas, among others:

- A population-based assessment of the outcomes of various high-tech interventions, to evaluate the outcomes of large investments in comparison with alternative uses of resources
- Information with which to evaluate whether demonstrated benefits (for example, of genetic research) extend to all segments of the population

## **Public Policy and Advocacy**

Congress affirmed the importance of standardized information and administrative simplification (and of the NCVHS advisory role) in provisions of the 1996 Health Insurance Portability and Accountability Act (HIPAA).

Elsewhere in the public policy arena, an important trend in the 1990s was the devolution of tax money and program responsibility to States. This devolution compounds the historic decentralization that has interfered with the building of national health statistics and therefore of informed public policy. This is especially the case with regard to consistent privacy protections and comparable information on the health status of all segments of the population. The shift to the States intensifies the need to clarify the respective health statistics roles of local, State, and Federal Governments so their activities can be complementary.

A striking trend in the late 20th and early 21st centuries is the upsurge of sophisticated advocacy groups intent on influencing policy. The American Association of Retired Persons, the National Alliance for the Mentally Ill, food safety and environmental organizations, and privacy advocates are notable examples. The media play a major role in this arena by directly supplying consumers with information (and sometimes misinformation) about health and health policy and the factors affecting them.



## **Information Technology**

Today's exploding information capacities make it possible to store great amounts of information and retrieve and share it quickly. By permitting rapid communication between data providers and health agencies, technology enables public health workers to promptly address local or national health problems, and to get information out to the public. In clinical care, the computer-based patient record is likely to become a mainstay.

These and other capabilities promise such boons as the extension of medical care to people living in remote places, rapid response to public health emergencies, direct communication to the public about the measures individuals and families can take, and access for health care providers to patients' medical records from any location when it is needed to deal adequately and promptly with their problems.

For some people, these capabilities raise the specter of lost privacy and the abuse of personal information a concern discussed below. Another issue related to information technology is the gulf between technological haves and have-nots, a byproduct of the country's social, economic and educational disparities. While some people are able to find information and use it to make informed decisions about their health, others lack the equipment and skills to do so. These are issues of access that must be monitored and addressed along with access to care, as information becomes ever more central to health. Certainly, realizing both the NHII and health statistics visions will depend on the continued development and equitable distribution of information technology.

## **What We Have Learned so Far: Cross-Cutting Issues Shaping the Vision**

### **Privacy and the Common Good**

As a new century begins, Americans are coming to terms with the enormous potential for abuse inherent in modern technology. Information sharing is a two-edged sword: used in the right way and for the right reasons, it can save lives; used in the wrong way or for the wrong reasons, it can ruin them.

Health statistics data are clearly important to communities, public health professionals, health care providers, researchers, the media, and policy makers. For most purposes, these data can be shared in an aggregated form that protects the privacy of individuals. For some clinical and public health purposes, it may be necessary to share individual record-level data under strict procedures for confidentiality. Although the evidence suggests that health statistics systems have done a good job of protecting confidentiality, there is still fear and even some risk that individuals can be identified and their information misused. The greatest concern is that records collected, created, or compiled for statistical purposes might be used to make substantive determinations about individuals or groups by law enforcement, insurers, employers, or others.

The concerns about privacy violations must be taken seriously. At the same time, other important considerations should be recognized: that the confidentiality of paper records is equally or even more in question than that of electronic records, and that information technology actually can be used to enhance privacy protections. Furthermore, if fears about privacy undermine people's willingness to allow even limited access to or

use of personal information for important public health purposes, the result can be incomplete information, leading to wrong policy decisions and wrong public health interventions.

A Vision for 21st century health statistics must address all these factors and strike a balance between individuals' desire for privacy and the imperative to improve everyone's health—a need that cannot be met, as we have seen, without information on such things as communicable disease, health hazards, and treatment outcomes. The issue to be resolved is how we can create adequate protections against inappropriate access and the abuse of personal information while at the same time preserving controlled access for public health agencies, health care providers, researchers, and others who need information in order to care for and improve our health.

Those with a vision for health statistics agree on the need for a two-pronged approach to this critical issue. First, and most important, the country must have strong national and State legislation that implements fair information practices and establishes strong punishments for abuses. Increased sharing of data is inappropriate without increased protections for the privacy of individuals. In order to allow for increased sharing and linkage of data, we need health statistics privacy laws that prevent individual health statistics records from being accessed and used by police, prosecutors, employers, insurance companies, marketers, and others who might use the data in a way that adversely affects the subjects of the data.

Second, Americans and their policy-makers need to become more aware of the ways in which we all depend on health statistics; and those responsible for health statistics must ensure that health statistics tell Americans what they need and want to know about their health.

## **Negotiating Boundaries: Proprietary, Governmental, and Other**

A central task in realizing the health statistics Vision is to find ways, within the context of privacy protections, to link data that now exist in separate “silos.” Consistent and controlled access to data from various sources are necessary because at present, it is difficult to do any of the following important forms of analysis:

- link or share data from different sites of care (hospitals/nursing homes/ ambulatory care)
- understand the relationships between health status, health determinants, and health services
- link data from surveys and administrative and encounter data
- link complementary data from private and public databases
- combine comparable data from local, State, and Federal systems

Because most data systems were created to address specific needs, with no common framework or consensus on an overall “system,” it has been difficult to compare or link data between data systems. There are many reasons for this difficulty: constraints on the use of specific data sets to compensate for inadequate national privacy protections,

differing practices and systems within branches and levels of government, the way data elements are defined and coded, and the technical complexity of combining data collected with different methodologies.

It should be understood that the goal is not to replace the data “silos” of today with some sort of consolidated mega-database—the mythical “Central Database in the Sky.” Rather, the goal is to provide controlled mechanisms for accessing and combining data from different sources for defined public health purposes. (This conception is much like that for the National Health Information Infrastructure.) Such linkages could enhance understanding of the causes of ill health and what to do about them. They also could make our statistical system more efficient, less burdensome to data providers, and more responsive to emerging data needs.

With a concerted effort, it should be possible to remove unnecessary barriers to an integrated, efficient system. The barriers can be overcome by greater attention to standardization and comparability, improvements in technology, and creative approaches to making data available for analytic use in ways that do not jeopardize individual privacy.<sup>16</sup>

Similar effort will be required to overcome the philosophical and practical differences preventing greater consistency, sharing, and integration across public and private entities. While many of our most historically useful data systems have been conducted by public agencies for public purposes, an increasing array of health information initiatives originate in the private sector, where data are initially justified as being useful for proprietary or institutional purposes. While these data could be of great use if placed in the public domain, it is not always clear that private organizations have the necessary incentives or protections to make data widely available. Similarly, data derived from systems established for non-statistical purposes (for example, payment systems) can be of broader use, but may not be readily converted to a useful form. A well functioning health statistics system must find ways to encourage such mutually supportive collaborations.

## **Data Quality Issues**

Data quality suffers now because of the lack of standardized terminology, definitions, concepts, transmission formats, analysis, and dissemination. The multiplicity of today’s data sources makes it necessary to pay close attention to the quality of each source and its specific limits and capabilities. Ensuring future data quality will involve improving the quality of records through technology and education of data providers. For example, technology can contribute to improved quality by permitting automatic querying while data are being collected, rather than afterwards when incompleteness and inaccuracy are more difficult to correct. In addition, surveys need to be improved by investment in survey research, cognitive research, and evaluation.

## **Resource and Burden Issues**

Looking back at the characterization of health statistics on the early pages of this report, we see that the lack of comprehensive planning has resulted in gaps, duplication,

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<sup>16</sup>“Integrating Public Health Information and Surveillance Systems,” A Report and Recommendations from the CDC/ATSDR Steering Committee on Public Health Information and Surveillance System Development, Spring 1995, US Department of Health and Human Services.

and high cost. More analysis is needed to tease apart where additional resources are needed and where they simply need to be used more efficiently in the ways outlined below.

Currently, the burden of data collection and reporting undermines both data quality and data providers' willingness to expand collection to include the many other elements on which information is needed. Burden is a concern not only for health care providers and their organizations, but also for local public health officials, especially those with inadequate technology and other resources. A related issue of concern to planners is the shortage of adequately trained personnel to analyze and interpret the data collected.

Underlying all of these concerns is the need for sustained support from knowledgeable policy-makers who understand the importance of health statistics. This, in turn, highlights the need to provide Americans and their leaders with useful information on the public's health status, health determinants, and health care.

## International Developments

International trends are favorable for the U.S. health statistics visioning process, with many countries engaged in parallel efforts to enhance their health information capacity. As in the United States, these efforts are closely and explicitly tied to the goal of improving national health. Many of the same themes being addressed in the United States, as reflected in this paper, are emerging in other countries' efforts. There is also strong momentum toward collaboration and mutual learning in health information among countries. For example, the U.S. can learn a great deal from other countries about privacy protections. All of the countries described below have national privacy laws and data protection agencies.<sup>17</sup>

The United Kingdom, Australia, and Canada all provide valuable models and opportunities for collaboration.

- England's National Health Service (NHS) has been at work on its Health Care Model since the early 1980s, supported by a government that understands investment in information technology as essential overhead for health care. The NHS published its information strategy, *Information for Health*, in 1998.<sup>18</sup>
- In Australia,<sup>19</sup> the Commonwealth, six States and two territories have signed a National Health Information Agreement that provides a cooperative framework for the collection, quality, and dissemination of national health information in that country. The agreement has produced a National Health Information Management Group and other bodies, as well as a national health information model, data dictionary, and knowledge base.
- Canadians began a systematic examination of their health information needs in the early 1990s. This led in 1998 to a broad consultative process, coordinated by the

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<sup>17</sup>International developments are explored in detail in a commissioned paper by Jennifer Zellmer et al., "Recent Developments in Health Information: An International Perspective," which was used as a source in writing this section.

<sup>18</sup>National Health Service *Information for Health: An Information Strategy for the Modern NHS*, 1998–2005. (<http://www.nhs.uk/nhsia/strategy/index.htm>)

<sup>19</sup>[www.AIHW.gov.au](http://www.AIHW.gov.au)

Canadian Institute for Health Information and aimed at crafting a “National Health Information Roadmap” to support the country’s health objectives.<sup>20</sup> These activities have led to substantial new pilot funding from the Canadian government for implementation of the Roadmap. Despite the differences in health care delivery systems, Canada’s health statistics have developed much like those in the U.S., and they have similar inadequacies in terms of their completeness, compatibility, and usefulness. The consultations and theoretical work going into Canadian Roadmap development—and the commitment to providing Canadians with accessible, useful information—offer valuable models for our country’s visioning process and its products.

- The European Union issued a Privacy Directive in 1998, intensifying the pressure on the U.S. to strengthen its own privacy protections. European nations have had a framework for addressing privacy since 1980, when the Organization for Economic Cooperation and Development (OECD) issued Guidelines on the Protection of Privacy and Transborder Flows of Personal Data. These guidelines cover such topics as limitations on data collection and use, specification of purpose, openness, and accountability.

## Principles for the 21st Century Vision

In discussions thus far, the following 10 principles have emerged as qualities that participants see as essential to developing the health statistics Vision. Future discussions will continue to hone the description of central principles.

### 1. Privacy, Confidentiality, Security, and Fair Information Practices

Protecting the privacy and confidentiality of personal health data is of highest importance. This precondition applies to all other principles discussed below.

The National Committee on Vital and Health Statistics issued recommendations to the Secretary on the privacy of medical records in mid-1997.<sup>21</sup> The NCVHS recommendations were echoed in those the Secretary made to Congress later that year, and in other Congressional testimony. Then in 1999, the Department fulfilled a HIPAA requirement and issued proposed regulations for protecting the privacy of individually identifiable health information that is electronically transmitted in connection with administrative and financial transactions. NCVHS has offered formal comments on the proposed regulations.<sup>22</sup>

The Committee’s 1997 privacy recommendations to the Secretary and the Department’s proposed 1999 regulations constitute an important step forward in protecting health information privacy. But additional national and State steps are necessary beyond

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<sup>20</sup>Canadian Institute for Health Information. Health Information Roadmap: Responding to Needs. <http://www.cihi.ca>

<sup>21</sup>The Committee’s recommendations are posted on the NCVHS Website.

<sup>22</sup>February 7, 2000, Recommendations on the notice of proposed rule-making for standards for privacy of individually identifiable health information. Posted on NCVHS Website.

this initial focus on electronically transmitted administrative and financial data, especially directed toward protecting the privacy, confidentiality, and security of all data used for health statistics.

Necessary protections for the privacy and confidentiality of health statistics data would involve a number of essential factors: adherence to strict new national and State legislation; the use of fair information practices that explicate and control data access, sharing and handling; technical security measures within every organization handling data; sanctions and punishment for misuse and abuse; sophisticated approaches to releasing data to avoid inadvertent disclosure of individually identifiable information; and new approaches to using technology to enable data sharing while protecting privacy. Linkages of anonymized or fully de-identified individual record data, or of aggregated data for small areas, must be done in ways that protect privacy and confidentiality. Linkages of individual record data must occur within a newly established legal framework, with appropriate human subject review board approval or permission from data subjects.

In general, research is needed to find technological approaches that enable data sharing while protecting confidentiality. At the same time, Americans and their leaders must tackle the difficult questions about the conditions under which the potential benefits to society justify assuming the small risk associated with using information for purposes such as research and public health monitoring.

## **2. Conceptual Framework**

Other sections of this report discuss the many facets of health and its determinants and the chronic problems of fragmentation and artificial boundaries within health statistics. Future health statistics need an overarching conceptual framework that encompasses all the relevant aspects of the population's health and reflects their interactions. An exemplary model has been developed by Evans and Stoddart and adapted by Charlyn Black and her colleagues.<sup>23,24</sup>

Combined with an integrated national implementation strategy, such a framework would guide data collection and aid in the rational and efficient deployment of information to address health concerns. The framework would make it possible to expand beyond the medical, infectious disease, and vital statistics models that can restrict the uses of information to understand and address health needs.

## **3. Flexibility to Identify and Address Emergent Issues and the Health Needs of the Population**

21st century health statistics must be able to identify and meet new information needs as they arise. Knowledge gaps are a moving target, not static. Even with good "distance vision" that sees far into the future, unanticipated population health needs are sure to arise, and health statistics systems will need mechanisms for addressing them. The same

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<sup>23</sup>RG Evans and GL Stoddart, "Producing Health, Consuming Health Care," in RG Evans, MI Barer, and TR Marmor, editors, *Why are some people healthy and others not? The determinants of health of populations*, New York: Aldine De Gruyter 1994, pp. 27-64.

<sup>24</sup>Black C, Roos N, and Roos L, "From Health Statistics to Health Information Systems: A New Path for the 21st Century," p. 11 (commissioned paper).

is true for newly emerging issues and topics with relevance to health and health care. Examples of contemporary issues are the upsurge in the use of alternative medicine and heightened concerns about adverse effects and medical errors.

In addition to being able to identify new information needs and emerging issues, health statistics must be structured so that new information and new categories of information can be easily incorporated.

#### **4. Usefulness at Different Levels of Aggregation**

Statistical systems need to provide information in sufficient detail to support decision-making. While many existing statistical systems provide rich resources for analysis and action at the national level and for the population as a whole, increasing levels of detail—both geographic and demographic—are increasingly critical.

The identification of health problems, needs, and interventions is increasingly a local function. Data from the national and State level often provide only a rough outline of real problems faced in individual communities, and cannot provide data to evaluate interventions that may be unique to a given area.

Similarly, health problems, health care access, and health outcomes can be quite different for different racial and ethnic subpopulations. Health officials need data in fine-enough detail to understand health differentials and design effective interventions.

The potential costs of meeting all data needs—for example, for each of multiple racial and ethnic subgroups in each local area—are daunting, and it is unlikely that all needs will be met. An important challenge for the health statistics system will be to develop an overall information framework that takes these and other detailed needs into account, while recognizing the expense and technical difficulty in obtaining such data.

#### **5. Compatible Standards Serving Multiple Purposes**

Standards are a necessary precondition for data sharing, linkage, and interoperability. However, only compatible, non-duplicative standards that simultaneously serve clinical, administrative, public health surveillance, and health statistics purposes will permit the kind of information systems and decision-making that are envisioned for the future.

The last decade has seen a proliferation of standards for relatively narrow purposes, and in some cases conflicting standards for a single purpose. This multiplicity is an impediment to developing an integrated and efficient information infrastructure.

Standards are still needed in many areas—for example, administrative data for monitoring care provided by health plans and public health personnel; race/ethnicity classifications; definitions of households; and geocoding. Both modification of existing standards and development of new ones should be governed by the principle of serving multiple purposes.

#### **6. Unitary Data Collection for Multiple Purposes**

The principle of collecting data once and then using the data for many purposes is the key to solving many of the current problems with statistics—burden, resource constraints, fragmentation, and so on. The multiple purposes for which unitary data collection could be used include clinical care, health services research, administration, public health

programs, public health surveillance, and population health monitoring. Strong legal protections to safeguard confidentiality and privacy, carefully structured data sharing agreements, and appropriate protocols for implementing the legal protections and data sharing agreements will all be necessary if we are to achieve unitary data collection for multiple purposes. Equally essential will be the right conceptual framework and organizational mechanisms.

## **7. Maximum Access and Ease of Use**

In order to improve the public's health and community decision-making about population health programs and priorities, health statistics data must be provided back to communities, community groups, local governments, and health care providers in ways that maximize data access and ease of use. If health statistics are to play their role in improving the population's health, the users of health statistics data cannot be confined to epidemiologists, statisticians, and other public health professionals.

To maximize access and ease of use, health statistics must be presented understandably, and for a wide range of local audiences. Useful and useable data must be provided to local communities in useful formats. Producers of health statistics must recognize that different presentations and modes of access to health statistics will be needed for different types of users. Current approaches to providing local health statistics data must be expanded upon, such as regularly updated hard copy community health profiles and user-friendly, interactive Web-based health statistics information services.<sup>25</sup>

Paradoxically, a health statistics system based on the principles described here will be simultaneously more simple and more complex than our current patchwork of data collection systems. On the one hand, the work of data providers (e.g., hospitals, physicians, HMOs, and neighborhood health centers) should be simplified by the adoption of standards and the elimination of duplicative reporting of the same data for billing and administration, multiple "silo" surveillance systems, and clinical purposes. The work of the end users of health statistics data (including community groups, public health professionals, policy makers, community groups, and researchers) also should be simplified, because of the increased understandability introduced by compatible, multi-purpose standards for what are currently called administrative, clinical, and health statistics and surveillance data.

On the other hand, the work of the data collectors (including State and Federal agencies) may become more complex, due to several factors: the need to carefully structure data distribution and sharing partnerships that conform to new legal requirements, the need to manage agreements on compatible data standards, and the need to scrupulously adhere to new security and confidentiality protocols.

## **8. Adequate, Well-Managed Resources**

As has been noted, some of what is perceived as inadequate funding is in fact a function of a lack of an overarching framework or mechanism for system-wide planning

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<sup>25</sup>Institute of Medicine, Committee on Using Performance Monitoring to Improve Community Health. Improving health in the community: a role for performance monitoring. Jane S. Durch, Linda A. Bailey, and Michael A. Stoto, editors. 1997



and coordination, and a resulting suboptimal use of existing resources. Nevertheless, it is also the case that a strong health statistics infrastructure will depend on adequate, stable, and predictable funding.

## **9. Policy Relevance**

As noted elsewhere, health statistics exist so that decision-makers of all kinds can promote and monitor the health of individuals and communities and anticipate or respond to problems. Information that is useful to policy makers will help clarify what the right questions are with respect to health and provide “actionable” answers in a timely, accessible, and usable manner. Tying information to national, State and local objectives, such as in the Healthy People 2000 and 2010 process, can be an excellent way to shine light on information gaps and to make data useful to policymakers. Finally, health statistics must be evaluated continually for their utility in informing policy.

## **10. Broad Collaboration**

Implementing the health statistics Vision will require the full participation not only of the government agencies responsible for public health but also of related government agencies, many facets of the private sector, the media, local community leaders, and individual citizens. Because implementing the Vision will depend on multi-party partnerships, mechanisms that elicit the views of stakeholders and provide ways for them to collaborate and contribute will be as important as the other mechanisms discussed above.

The potential collaborators include the following:

- Local, State, and Federal Government (with clear delineation of roles and responsibilities)
- Private sector organizations (for example, health industry, media, advocacy groups, local and national health coalitions, and information technology/informatics industries)
- Related sectors (education, housing, justice, transportation, environmental protection, health, alternative health, and nutrition)
- A public constituency: citizens and leaders who recognize the essential role of health statistics and help shape decisions about their collection and use

## **Next Steps**

As we have stressed, this is an evolving Vision that is still coming into focus. To fulfill the goal of allowing all Americans and all American communities to achieve and maintain the best possible health, the Vision must reflect true national priorities and perspectives. It also must include specific suggestions for local, State, and national action by both private and public entities.

The more the Vision represents the views of community leaders, public health workers, health professionals, data users, and policy-makers in communities across the nation, the more valid and useful it will be. Therefore, we need and welcome your input on any and all aspects. You may convey your input in any of the following ways:

- On the Web ([www.ncvhs.hhs.gov/hsvision/](http://www.ncvhs.hhs.gov/hsvision/))
- Through e-mail (HSVISION[[@0cdc](mailto:HSVISION@0cdc.GOV)].GOV) and other written comments (to this address: Health Statistics Vision, National Center for Health Statistics, 6525 Belcrest Road, Room 1120, Hyattsville, MD 20782)
- At one of the four NCVHS hearings (see below)
- At conferences and meetings where the Vision is being discussed
- Through your organization or association

The following events and milestones lie ahead:

- Hearings (summer/fall 2000. The first will be in Chicago on July 10. Subsequent hearings will be announced on the Web site.)
- Another draft of the health statistics Vision (Winter 2000)
- Final Vision report (spring/summer 2001)
- Use of the health statistics Vision to guide program plans at local, State, and Federal levels
- Ongoing consultations with key stakeholders

*This report was written by Susan Baird Kanaan*

## **Staffing and Support**

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

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Paul Newacheck, Dr.P.H.

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Dana Silverman, *Program Analyst*

Brenda Mitchell, M.D., M.P.H., *Preventive Medicine Resident*

### **HHS Data Council**

Jim Scanlon, *Executive Secretary*

## **Appendix: Papers Commissioned for the Visioning Process**

Charlyn Black, Noralou Roos, and Leslie Roos

(University of Manitoba)

“From Health Statistics to Health Information Systems: A New Path for the 21st Century”

Lorraine V. Klerman

(School of Public Health, University of Alabama at Birmingham)

“The State Children’s Health Insurance Program: A Case Study with additional material on Data Needs in the Area of Child Health”

Richard Kronick

(Department of Family and Preventive Medicine, University of California, San Diego)

“Numbers We Need: Health Statistics and Policy”

Daniel Melnick

“Building Robust Statistical Systems for Health”

Jennifer Zelmer, Shazeen Virani, and Richard Alvarez

(Canadian Institute for Health Information)

“Recent Developments in Health Information: An International Perspective”

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