Report and Recommendations From the
National Committee on Vital and Health Statistics

A Strategy for Building the National Health Information Infrastructure

U.S. Department of Health and Human Services

- Office of Disease Prevention and Health Promotion
  Office of Public Health and Science
- National Center for Health Statistics
  Centers for Disease Control and Prevention

INFORMATION FOR HEALTH

A STRATEGY FOR BUILDING THE NATIONAL HEALTH INFORMATION INFRASTRUCTURE

Report and Recommendations
From the National Committee on Vital and Health Statistics

Washington, D.C.
November 15, 2001

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MEMBERS OF THE NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

CHAIR

John R. Lumpkin, M.D., M.P.H.
Director
Illinois Department of Public Health
Springfield, Illinois

MEMBERSHIP

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

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

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

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

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

Richard K. Harding, M.D.
Professor of Clinical Psychiatry and Pediatrics
Vice Chairman, Clinical Services
Neuropsychiatry & Behavioral Science
University of South Carolina
Columbia, South Carolina

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

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

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

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

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

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

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

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

NCVHS NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

December 19, 2001

The Honorable Tommy G. Thompson
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Thompson:

On behalf of the National Committee on Vital and Health Statistics (NCVHS), I am pleased to submit the report of the NCVHS Workgroup on the National Health Information Infrastructure (NHII), which was approved by the full Committee at its November 15, 2001, meeting. *Information for Health: A Strategy for Building the National Health Information Infrastructure* builds on the Workgroup's Interim Report of June 2000 and is the culmination of an 18-month review that included hearings and consultations with healthcare providers, public health professionals, consumer representatives, and healthcare information technology representatives.

Recent events make this report both timely and urgent. They have dramatically underscored the importance of an effective, comprehensive health information infrastructure that links all health decisionmakers, including the public. Based on public hearings about the NHII, the Committee has determined that Federal leadership, under the U.S. Department of Health and Human Services (HHS), is the most important missing ingredient that could accelerate and coordinate progress on the NHII. Its recommendations therefore include specific proposals for HHS oversight and coordination, supportive action by Congress, and appropriate efforts by other organizations. The latter include State and local governments, healthcare providers, health plans and purchasers, standards development organizations, the information technology industry, consumer advocacy groups, community organizations, and academic and research organizations.

NCVHS urges HHS to exercise leadership in building the National Health Information Infrastructure and to give it the priority it deserves, in collaboration with the many stakeholders whose participation will be crucial for success. The Committee would welcome annual status reports from the Department on this project, beginning in 2002.

Finally, the Committee offers its advice and enthusiastic support for all efforts aimed at developing the NHII.

Sincerely,

/s/

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

6525 Belcrest Road • Room 1100 • Hyattsville, MD 20782-2003 • (301) 458-4200 • Web site: www.ncvhs.gov

FOREWORD

Recent events have tragically underscored the need to connect healthcare and public health professionals and the public to sound information—and to each other. The National Committee on Vital and Health Statistics (NCVHS) hopes this report can prompt the vigorous strategic action that is required to make this vision a reality. *Information for Health: A Strategy for Building the National Health Information Infrastructure* offers a comprehensive assessment of the leadership required to improve the health of individuals, communities, and the Nation by better use of information and communication technology. Some of what needs to be done is already happening or is envisioned. But too many efforts are proprietary, stovepiped, or incomplete. Very little is coordinated in ways that can best serve the public interest. This report from the NCVHS Workgroup on the National Health Information Infrastructure pulls the diverse issues into a broader policy framework. Based on input from national hearings, experts, and stakeholder organizations, the Committee calls for Federal leadership, under the U.S. Department of Health and Human Services, of a collaborative public-private effort. It is a task that should engage all who have a stake in health improvement.

John R. Lumpkin, M.D., M.P.H.
Chair, National Committee on Vital and Health Statistics
December 2001

ACKNOWLEDGMENTS

The Workgroup on the National Health Information Infrastructure (NHII) wishes to thank its colleagues on the National Committee on Vital and Health Statistics (NCVHS) for their many contributions to this report. The report—and indeed, the Workgroup itself—was initiated by the former NCVHS Chair, Don Detmer, at a time when few people championed linkages between the healthcare sector, public health, and the public. Under the subsequent leadership of John Lumpkin, as Chair of both the NCVHS and the Workgroup, the NHII vision was developed and the strategic leadership requirements were defined. The Workgroup is grateful to the experts and organizations whose invaluable suggestions shaped the report's recommendations. Development of the report was coordinated by the Office of Disease Prevention and Health Promotion of the U.S. Department of Health and Human Services (HHS), which staffed the Workgroup. The HHS National Center for Health Statistics, Centers for Disease Control and Prevention, serves as Executive Secretary to the Committee and provides logistical and staff support. The Office of the Assistant Secretary for Planning and Evaluation serves as Executive Staff Director of the Committee and coordinates departmental staffing.

STAFFING AND SUPPORT

NCVHS Workgroup on the National Health Information Infrastructure

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

Office of Disease Prevention and Health Promotion (HHS)

Mary Jo Deering, Ph.D., Deputy Director for eHealth and Management, NHII Lead Staff and Project Manager and Writer for the Interim and Final Reports
Cynthia Baur, Ph.D., Senior eHealth Advisor, NHII Writer
Wayne Brandes, D.O., M.P.H., Preventive Medicine Resident and NHII Writer (Fall 1999)
Leslie D. Hsu, M.P.H., Consumer Health Informatics Advisor, NHII Web Manager and NHII Writer

National Center for Health Statistics (CDC)

Edward J. Sondik, Ph.D., Director
Marjorie Greenberg, Chief, Data Policy and Standards Staff, NCVHS Executive Secretary
Debbie Jackson, Senior Program Analyst
Michelle Williamson, Health Informatics Specialist

Public Health Practice Program Office (CDC)

Steven J. Steindel, Ph.D., Supervisory Health Scientist, NHII Staff and NHII Writer

Centers for Medicare & Medicaid Services

Theresa Krol, NHII Staff

The NHII Workgroup and its staff wish to gratefully acknowledge the many outstanding contributions of Susan Baird Kanaan, Consultant Writer.

EXECUTIVE SUMMARY

Human endeavor is caught in an eternal tension between the effectiveness of small groups acting independently and the need to mesh with the wider community.[i]

We as a Nation have a timely opportunity and an urgent need to build a 21st-century health support system—a comprehensive, knowledge-based system capable of providing information to all who need it to make sound decisions about health. Such a system can help realize the public interest related to disease prevention, health promotion, and population health.

This report from the National Committee on Vital and Health Statistics (NCVHS), a public advisory committee statutorily authorized to advise the Secretary of Health and Human Services on national health information policy, outlines a vision and a process for building such a health support system—the National Health Information Infrastructure (NHII).

The NHII includes not just technologies but, more importantly, values, practices, relationships, laws, standards, systems, and applications that support all facets of individual health, health care, and public health. It encompasses tools such as clinical practice guidelines, educational resources for the public and health professionals, geographic information systems, health statistics at all levels of government, and many forms of communication among users.

The report identifies the human, institutional, and technological factors—existing and as yet undeveloped—that must be involved in building the NHII. The Committee recommends a strategy that gives the U.S. Department of Health and Human Services a key leadership role at the center of a broadly collaborative process for the public and private sectors. In addition to offering a detailed implementation plan, the recommendations in the report are unique in that they are comprehensive; they stress the need for information flows across sectors and with the public; and they attach equal importance to the personal health, healthcare provider, and population health dimensions.

The heart of the vision for the NHII is sharing information and knowledge appropriately so it is available to people when they need it to make the best possible health decisions. To meet the Nation's health needs, the NHII must serve all individuals and communities equitably. The interconnections made possible by the NHII would allow information capacities that now exist or are developing in the health field to be put to fuller use. Ready access to relevant, reliable information and secure modes of communication would enable consumers, patients, healthcare and public health professionals, public agencies, and others to address personal and community health concerns far more effectively.

The NHII would serve important national interests. *The Committee believes that implementation of the NHII will have a dramatic impact on the effectiveness, efficiency, and overall quality of health and health care in the United States.* Serious problems such as public health emergencies, medical errors, and health disparities could be addressed in a more timely and comprehensive fashion.

THREE DIMENSIONS: PERSONAL HEALTH, HEALTHCARE PROVIDER, AND POPULATION HEALTH

The key NHII stakeholders and health information users are consumers, healthcare providers (both individuals and organizations), and public health professionals at local, State, and national levels. The applications that meet their respective needs are distinct dimensions of the infrastructure that the Committee calls, respectively, the personal health dimension, the healthcare provider dimension, and the population health dimension. These dimensions provide a means for conceptualizing the capture, storage, communication, processing, and presentation of information for each group of information users.

- The *personal health dimension* supports individuals in managing their own wellness and healthcare decisionmaking. It includes a personal health record that is created and controlled by the individual or family, plus nonclinical information such as self-care trackers and directories of healthcare and public health service providers.

Avoiding unnecessary care, cost, and anxiety: Mr. S. flies across the country to start a new job. He has already chosen a medical practice in his new town because it has the same online health support service as his previous doctor, even though it is a different medical plan. He can set up appointments, get prescription refills and lab results, e-mail the doctor or nurses, and manage his personal health history. A week after he arrives, he develops fever and muscle aches. Fearing that he may have anthrax or smallpox, he e-mails his new doctor a list of his symptoms, along with his itinerary over the previous 14 days. The doctor's automatic system immediately matches his itinerary against the public health database of anthrax and smallpox occurrences and runs his symptoms against his own personal health record, including his medications. It sends an urgent alert to the doctor, who sees no likely source of exposure for Mr. S. but spots a potential drug-drug interaction. She calls him and tells him that the new drug he just started could have caused an adverse reaction. She feels confident that he does not need to come in for tests or take unnecessary antibiotics. Instead, she changes his medication and asks him to e-mail her in 24 hours. The next day, his e-mail message confirms that his fever and aches are gone. Unnecessary lab tests, investigation by public health authorities, anxiety for Mr. S. and his family, and an unneeded antibiotic are all avoided. This "non-event" is the happiest of all endings for Mr. S., his doctor, and the health of the public.

- The *healthcare provider dimension* promotes quality patient care by providing access to more complete and accurate patient data on the spot, around the clock. It encompasses such information as provider notes, clinical orders, decision-support programs, digital prescribing programs, and practice guidelines.
- The *population health dimension* includes information on both the health of the population and the influences on it. The population health dimension makes it possible for public health officials and other data users at local, State, and national levels to identify and track health threats, assess population health, create and monitor programs and services including health education campaigns, and conduct research.

The dimensions overlap considerably. Indeed, the greatest value derives from shared information and communication across them. The interests and activities of many other important stakeholders, such as health plans and public health agencies, fall squarely in two or more dimensions.

The evolution of the NHII is already under way, but so far progress toward a fully realized NHII has been slow. Although many of the basic components for the NHII already exist and are operating in their own spheres, they lack the interconnections that could make them more useful in concert than they are as isolated pieces. Many nonhealth-specific communication technologies are already available, affordable, and widely used in multiple sectors of U.S. society. For the most part, however, their full potential is not realized because they are proprietary, incomplete, or uncoordinated. Also, many existing programs and activities in the public and private sectors provide a foundation for the NHII, but they are fragmented and dispersed throughout agencies and organizations that lack a mechanism for coordination. Their impact would be enhanced if they were part of a comprehensive NHII framework.

FEDERAL LEADERSHIP AS THE CORNERSTONE OF IMPLEMENTATION

Based on public hearings about the NHII vision, NCVHS has determined that the most important missing ingredient, which could accelerate and coordinate progress on the NHII, is leadership, specifically, Federal leadership. Public- and private-sector representatives testified that the lack of a strong Federal presence to guide the development of the NHII is a major gap. They urged immediate Federal leadership to bring about collaboration between stakeholders in the private and public sectors and among all levels of government. NCVHS has heard the message and responded with a set of recommendations that outlines the leadership needs and responsibilities to bring the NHII into being.

Consequently, the Committee recommends that a new senior position and office at the U.S. Department of Health and Human Services (equipped with adequate funding) be developed to oversee and coordinate a broad range of health information policy, research, and program activities in different sectors, both public and private.

This office should have the resources and mandate to coordinate all efforts for the NHII,

internally and externally and in both public and private sectors, and to directly fund strategic crosscutting activities. The new office should exercise both horizontal and vertical coordination: horizontally, across healthcare providers, consumers, public health programs, standards development organizations, payers, government agencies, academic and healthcare institutions, and others, and vertically, through local, State, and national entities. It must explicitly encompass the personal health, healthcare provider, and population health dimensions rather than focus on any single area. At the same time, the NHII-related activities of each HHS agency need to be strengthened and new resources added under the general coordination of the new office.

The Federal Government has a key role to play in these developments, but it cannot do so alone. A dynamic, nationwide, collaborative venture is needed for this purpose. Besides needing strong Federal leadership, the developmental process must engage a broad range of stakeholders. As things stand now, some groups have been working hard to envision and stimulate the NHII, while many other stakeholders either have not yet recognized its potential benefits or lack the resources to participate in its development. One of the chief reasons that NCVHS recommends focused Federal leadership as the NHII evolves is that without such leadership, the multitude of existing and new activities are far likelier to work at cross-purposes than to be additive and complementary.

The National Committee's 27 recommendations (which begin on page 39) spell out NHII-building activities for 9 categories of stakeholders whose roles are often parallel and always interdependent. The categories are

- The Federal Government, including the U.S. Department of Health and Human Services, Congress, and Federal health data agencies
- State and local governments, including State and local health and data agencies
- Healthcare providers, including membership and trade organizations and healthcare organizations
- Health plans and purchasers
- Standards development organizations
- The information technology industry
- Consumer and patient advocacy groups
- Community organizations
- Academic and research organizations

The Committee identifies strategic legislation and funding needed to support the NHII. It recommends that Federal, State, and local agencies and healthcare organizations strengthen their own leadership and coordination for NHII-related activities. It calls for accelerated standards development and other steps to promote information flows among the dimensions. It identifies key opportunities for specific stakeholders, including consumer groups, to advance the NHII within their own areas and in collaboration with others.

The Committee envisions three major stages in the process. NCVHS suggests that stage one be completed within 2 years, stage two within 5 years, and stage three within 10 years.

- The first stage has five major tasks: creating the recommended senior position and lead office within HHS with sufficient authority and funds and building relationships with centers of leadership in HHS and other agencies; fleshing out the vision as a national health information policy and implementation plan;

establishing incentives and requirements; launching a comprehensive standards acceleration process; and committing the resources implicit in each of these tasks.

- The second stage centers on developing and expanding collaboration at national, State, and local levels and with the private sector to complete and confirm the implementation plan. This stage will involve the most extensive and substantive forms of collaboration.
- The third stage involves carrying out the implementation plan in all relevant areas of the private sector and all levels and areas of government.

Recent events underscore that an effective NHII is not a luxury but a necessity; it is not a threat to our privacy but a vital set of resources for preventing and addressing personal and collective health threats. Better safeguards for privacy, confidentiality, and security are hallmarks of the NHII. The NHII is not intended to create a Federal database of personal health records or a centralized healthcare system. Instead, it will give users access—when it is appropriate, authorized by law or patient approval, and protected by security policies and mechanisms—to a diverse array of information, stored in locations that include providers' offices, organizational and governmental Web sites, and population health databases.

INFORMATION FOR HEALTH: A STRATEGY FOR BUILDING THE NATIONAL HEALTH INFORMATION INFRASTRUCTURE

I. INTRODUCTION

We as a Nation have a timely opportunity and an urgent need to build a 21st-century health support system—a comprehensive, knowledge-based system capable of providing information to all who need it to make sound decisions about health. Such a system can help realize the public interest related to disease prevention, health promotion, and population health.

Consumers, healthcare providers, public health professionals, employers, policymakers, and others recognize that ready access to relevant, reliable information would greatly improve everyone's ability to address personal and community health concerns.[2,3] Medical errors and adverse effects have been documented to be severe problems for which information is a crucial part of the solution.[4,5] Public health professionals know from experience that timely and complete information on abnormal patterns of disease and other public health threats would help them save lives in their communities. Health emergencies, whether personal, local, or national, all require that prompt and authoritative information about the situation, its consequences, and any victim(s) be readily available to those involved. The national goal of eliminating significant health disparities associated with income, race, and ethnicity also cannot be achieved without better information about the distribution of health inequities and effective interventions to address them.[3]

This report from the National Committee on Vital and Health Statistics (NCVHS) outlines a vision and a process for mobilizing the human, institutional, and technological factors needed to support health decisionmaking through a National Health Information Infrastructure (NHII). NCVHS, a public advisory committee, is statutorily authorized to advise the Secretary of Health and Human Services (HHS) on national health information policy. It reports annually to Congress on progress toward privacy protection and administrative simplification. The events following September 11, 2001, are irrefutable evidence of the need to be alert to health information from all sources, as soon as it emerges. These events only strengthen the Committee's belief that the United States urgently needs a comprehensive NHII that the country is clearly capable of building.

More than problem solving is at stake. Testimony in regional hearings showed a consensus that implementation of the NHII will have a dramatic impact on the effectiveness, efficiency, and overall quality of health care and public health in the United States. (See Table 1.) Making the interconnections envisioned for the NHII will allow many information capacities that now exist (or are developing in the health field) to be put to fuller use, producing widespread benefits for the health and quality of life of all Americans. In the public health arena, the disease registries that track trends in serious diseases, public health alert systems that permit rapid

Managing diabetic Medicare patients: A senior Federal health official is being briefed about plans for Medicare's pilot project, "IDEATel"—Informatics for Diabetes Education and Telemedicine. IDEATel serves Medicare patients who live in rural areas and inner cities and who tend to use costly emergency room visits because they lack regular local providers or access to specialists. The system links these underserved people to providers in distant locations; it offers home testing, Web-based input into the electronic medical record by both the provider and the patient, automated alerts to the case manager, secure clinical e-mail, and customized information on diet, medications, and exercise. The patients monitor their own conditions and send information to their case managers. The official learns that complications from diabetes cost the U. S. economy $45 billion each year, with an additional $47 billion due to the indirect costs of diabetes-related disabilities. Early intervention can reduce suffering and improve care; it also can save money. By giving patients, their case managers, and their healthcare providers tools to better manage diabetes, the Government may be able to save $247 million each year. It is estimated that the savings could reach $457 million if such a system could be widely extended.

response to emergencies, and tracking of the national objectives for Healthy People 2010 could more effectively prevent disease and promote health at national, State, and local levels if these capacities were part of an integrated nationwide system. Consumers and patients could pursue their demonstrated interest in managing their health and working in partnership with their healthcare providers if they were linked securely to online health services and information tailored to their needs. The health information contained in medical records could be much more meaningful if it were available electronically to healthcare providers and patients when needed for managing health and medical care. Clinicians also need a systematic way to increase their capacity to access and synthesize the volume of health information and knowledge that is part of contemporary medical practice and to receive expert advice and decision support on demand.

If these and other capacities could be harnessed and coordinated within an NHII, national resources could be freed up over the long term for priorities such as expanded prevention efforts and the extension of health care to underserved groups. Connections such as these are critical in today's fragmented healthcare system.

The Nation's growing information and communication capabilities already facilitate some information flow to and communication among health decisionmakers. But the health sector is lagging far behind others (banking and entertainment, for example) in adapting

Table 1. NHII Contributions to Healthcare System Improvements

Quality of care
- More consistent implementation of clinical practice guidelines
- Improved clinical data collection and analysis at the organizational and national level
- Portability of patient information across healthcare provider organizations
- Improved provider-patient communication
- More accurate and accessible patient records

Patient Safety
- Fewer drug-drug interactions and medication errors
- Automated reminders and alerts
- Continuous event monitoring to detect adverse events

Cost
- Improved triage to reduce unnecessary office and emergency department visits
- Improved home care to reduce nursing home and hospital care
- More robust disease management

Efficiency
- Reduced paper flow
- Faster processing of administrative transactions
- Automated scheduling and prescription refills

and using information technology for its own purposes.[6] Use of information technology in the health sector has been evolving, but randomly and without a plan. Much more would be possible if all the capacities could grow in a coordinated way, guided by a comprehensive vision.

Several authoritative bodies (some of whose work is cited in Section 3) have given detailed descriptions of the potential of a national health information infrastructure and offered recommendations, especially on technical matters. Their contributions provide a solid foundation for this report and its recommendations, which take the next logical step of outlining a strategy for implementing the NHII. Developing a comprehensive information infrastructure that meets both routine and emergency health information needs will require coordination and synergy among the many disparate efforts that are already under way. This will not happen without leadership.

In this report, NCVHS recommends a strategy that places the U.S. Department of Health and Human Services at the center of a collaborative process, with specific suggestions for how the Department can exercise leadership and seize the opportunity and existing momentum to help bring the NHII into being. In addition to offering a detailed implementation plan, these recommendations are unique in that they are comprehensive; they stress the need for information flow across sectors and with the public; and they attach equal importance to the personal health, healthcare provider, and population health dimensions.

Background and Overview of the Report

The National Committee on Vital and Health Statistics published its first report on the NHII in 1998.[7] The Committee concluded that the national information infrastructure that had been evolving with Federal support conspicuously lacked a health dimension. Over the ensuing 2 years, the Committee's NHII Workgroup developed a multifaceted vision for the National Health Information Infrastructure, which it described in a June 2000 Interim Report. (See the Appendix, page A-1.) In keeping with recent usage, the Workgroup on the NHII uses a very broad notion of infrastructure that emphasizes health-oriented interactions and information-sharing among individuals and institutions, rather than just the physical, technical, and data systems that make those interactions possible.

Following publication of the Interim Report, a wide range of stakeholders validated the Committee's vision for the NHII in four NCVHS hearings held around the country.[8-11] Stakeholder comments contributed to the development of the recommendations that are the centerpiece of this Final Report, building on the vision and seeking to move it toward implementation. Taken together, the NCVHS recommendations outline a collaborative public-private process with key leadership and support from the Federal Government—the one partner with the resources and the authority to take the lead. The Committee's ultimate objective is the development of a comprehensive NHII that serves the public interest and meets the needs of all those who make health decisions.

This introductory section is followed by a brief overview of the NHII as envisioned by NCVHS. Section 3 then surveys the existing technical and functional components to build on for the infrastructure. It draws on authoritative reports by the National Research Council of the National Academy of Sciences, the President's Information Technology Advisory Committee (PITAC), and the NCVHS Report on Standards for Patient Medical Record Information (PMRI). Section 4 looks at current public- and private-sector programs and activities that can contribute to the NHII. The Canadian Health Information Roadmap and Infoway/Infostructure are described as exemplary plans whose implementation is well ahead of that in the United States.

Section 5 sets the stage for the Committee's recommendations by discussing key aspects of an effective implementation strategy, highlighting the importance of leadership and resources, and noting the gaps and barriers that stand in the way of realizing the NHII vision. The recommendations, which conclude the report, are directed at nine groups of stakeholders: the Federal Government, State and local government, providers, plans and purchasers, standards organizations, the information technology industry, consumer and patient advocacy groups, community organizations, and academic and research organizations.

2. THE NHII VISION IN BRIEF

Definition and Key Elements

As envisioned, the National Health Information Infrastructure is fundamentally about bringing timely health information to, and aiding communication among, those making health decisions for themselves, their families, their patients, and their communities. Individuals, healthcare providers, and public health professionals are key NHII stakeholders and users, and the applications that meet their respective needs are distinct dimensions of the infrastructure.

Avoiding adverse events:
Concerned about his persistent cough, Mr. A. visits his doctor, Dr. Z. At the end of the visit, Dr. Z. advises Mr. A. that she will transmit an electronic prescription to the pharmacy. Dr. Z. enters the medication choice in Mr. A.'s electronic medical record, which is integrated with a prescription alert system, and receives a warning that, after taking this same medication, some patients with similar health conditions have experienced adverse effects, such as a rash and muscle cramps. Dr. Z. substitutes a different medication that is equally effective, which Mr. A. can take without incident. Dr. Z's clinical practice management system also has received a general alert from the drug manufacturer to avoid prescribing Dr. Z's first medication choice to patients with certain health conditions. The system automatically reviews all patients' records, finds no others currently taking the medications, and updates its internal drug review program.

Health information is stored in many locations, including providers' offices, organizational and governmental Web sites, and population health databases. The NHII will give users access—when it is appropriate, authorized by law and patient approval, and protected by security policies and mechanisms—to a hugely diverse array of information that includes community health data, personal health histories, consumer and clinical information, research findings, and much more.

Because information technology can be useful only when the nontechnical elements are well established, the NHII is only secondarily about technology. Taken as a whole, the NHII includes the values, practices, relationships, laws, standards, systems, applications, and technologies that support all facets of individual health, health care, and population health. It encompasses tools such as clinical practice guidelines, educational resources for the public and professionals, geographic information systems permitting regional analysis and comparisons, health statistics at all levels of government, and many forms of communication among users.

Responding rapidly to individual emergencies and local public health threats: 66-year-old Mrs. F. and her sister are camping in a national park. While hiking, she experiences severe stomach and chest pains. She activates her wireless automated medical alert system, which includes a global positioning system. It alerts the closest emergency medical team, which arrives quickly. Simultaneously, Mrs. F.'s own cardiologist, Dr. Y., in another State receives the same alert. The emergency team, which has standing permission to access relevant medical history in patients' online records, rushes Mrs. F. to the closest emergency room. All the necessary patient information is available to Dr. X., the physician on duty in the emergency room, when Mrs. F. arrives. After a thorough examination and tests and online consultation with Dr. Y., Dr. X. determines that Mrs. F. probably has gastroenteritis, advises her to drink lots of fluids, and clears her to return to her camping trip. Mrs. F.'s electronic personal health history and medical record are simultaneously updated with the information from the emergency room visit. Dr. Y., the cardiologist, is notified that Mrs. F. is cleared to continue her trip. The local public health department automatically is notified and de-identified health information from Mrs. F.'s emergency room visit is added to its database on incidents in local parks. That afternoon, health department staff identify a broken sewer line that contaminated park drinking water and caused the outbreak of bacterial gastroenteritis.

As defined by the Committee, the infrastructure includes these basic elements, each of which is necessary, but none of which is by itself sufficient:

- Values

  The guiding purpose of this NHII initiative is making possible the appropriate use of data, information, and knowledge in support of optimal health and quality of life for all Americans. This purpose emphasizes that the full potential of the NHII will not be achieved until its benefits can be shared equally by all. This means that technology and electronic information and services must be available in all homes and communities. This purpose also reflects the importance of privacy and confidentiality, consumers' control of their personal health information, cooperation, respect for the doctor/patient relationship, and prudent use of resources to minimize both overuse and underuse as the underlying values of the NHII.

- Practices and relationships

  The NHII will be established to facilitate appropriate health information and knowledge flow and communication both within sectors and between them. These sectors encompass, among others, healthcare organizations, community organizations, physicians, consumers, public health professionals, researchers, and policymakers. Knowledge sharing, information management, and communication are vital facets of the relationships between healthcare providers and patients, between public health organizations and healthcare organizations, and among peers (e.g., provider-to-provider or consumer-to-consumer). To date, structural and cultural—and, frequently, competitive—forces have worked against horizontal information flows in the health field. Realizing the full value of the NHII will involve changes in the information sharing

practices of every constituency, including consumers, that will only happen when individuals and organizations recognize the benefits they can derive once they make those changes.

- Laws and regulations

  Laws and regulations create the framework for the NHII. They set the ground rules within which private entities and Government agencies may conduct health-related business and individuals may use information. In addition to issues of privacy, security, and standards, which are covered below, Federal and State legislation establishes requirements for payment for medical services, professional licensure and liability, and intellectual property protection and equitable access. It also set rules for reporting information considered vital for public health. Legislation authorizes the use of public resources for NHII-related research, development, and training, not only for leading-edge technologies but also for innovative public health and medical practices. Laws and regulations promoting the portability of health information will be essential for the NHII.

- Privacy

  The health information infrastructure's proper functioning depends on enactment of national legislation on the privacy, confidentiality, and security of health information. The legislation must specify the conditions under which personal health information may be collected, stored, and shared, as well as penalties for abuses. The HHS privacy regulations are a step in that direction. In this context, it is important to stress what the NHII is *not.* The NHII does *not* require an integrated national database of medical records. In fact, healthcare providers will retain responsibility for maintaining their own patients' medical records. The confidentiality of personal health records and consumers' control over their own records are basic tenets of this vision, consistent with the HHS privacy regulations. The Committee expects that privacy and confidentiality protections will improve in the context of the NHII.

- Standards

  Standards are the building blocks of effective health information systems and are essential for efficient and effective public health and healthcare delivery systems. The Committee believes that standards set the foundation upon which innovation in the health information technology field can be built. Health data standards are critical to support the flow of information throughout the public health and healthcare systems. Standards are needed for core data sets; classifications and terminologies; uniform identifiers; comparable methods for data collection and reporting; data access, disclosure, and confidentiality; and data transmittal. Section 3 contains further information about electronic data standards. The Health Insurance Portability and Accountability Act (HIPAA) has put in motion activities that are moving health information toward standardization. NCVHS has set forth a comprehensive set of recommendations to enhance the effectiveness of clinical transaction standards and the development,

distribution, and maintenance of clinical medical terminologies in its Report to the Secretary on PMRI Standards.[12]

- Technology

  The tangible technical aspects of the NHII include network backbones such as the Internet in its present and future versions; the World Wide Web; wireless connections; hardware such as computers, Internet appliances, and handheld devices; and applications for information management, decision-support tools, communication, and transactional programs. Also involved are technical capabilities in areas such as bandwidth and latency.[13] A critical part of the NHII strategy will be proactive efforts to ensure that technologies and standards that enable these technologies evolve specifically to meet health needs.

- Systems and applications

  Clinical and public health information systems are the chief engines of the NHII. They capture, store, organize, and present data about medical care and population health status that are crucial for routine work, problem solving, planning, and emergency response. Applications enabling these systems to perform and communicate are already quite robust, but they tend to be vertical stovepipes of numerical content only. A fully developed NHII would improve cross-system data exchange and enhance multimedia and geospatial capacities. Essential nondata applications include interpersonal communications (text, voice, and video), remote monitoring and reporting, transactional services such as scheduling appointments and purchasing items, and interactive educational and decision-support tools for professionals and the public.

An overarching principle applies to all the elements mentioned above. It is critically important that the NHII vision and its embodiment be large enough to accommodate major changes in the future. The NHII is by its nature dynamic; every one of the elements listed above will evolve, just as the content of information and knowledge will change. All of the entities contributing to the NHII must therefore *think big*—especially the Federal Government in its leadership role. In order to coordinate stakeholders appropriately and see that everyone can benefit from the evolving information infrastructure, HHS must craft a national health information policy that is broad and flexible enough to encourage and channel—rather than inhibit—positive change.

Three Dimensions: Personal Health, Healthcare Provider, and Population Health

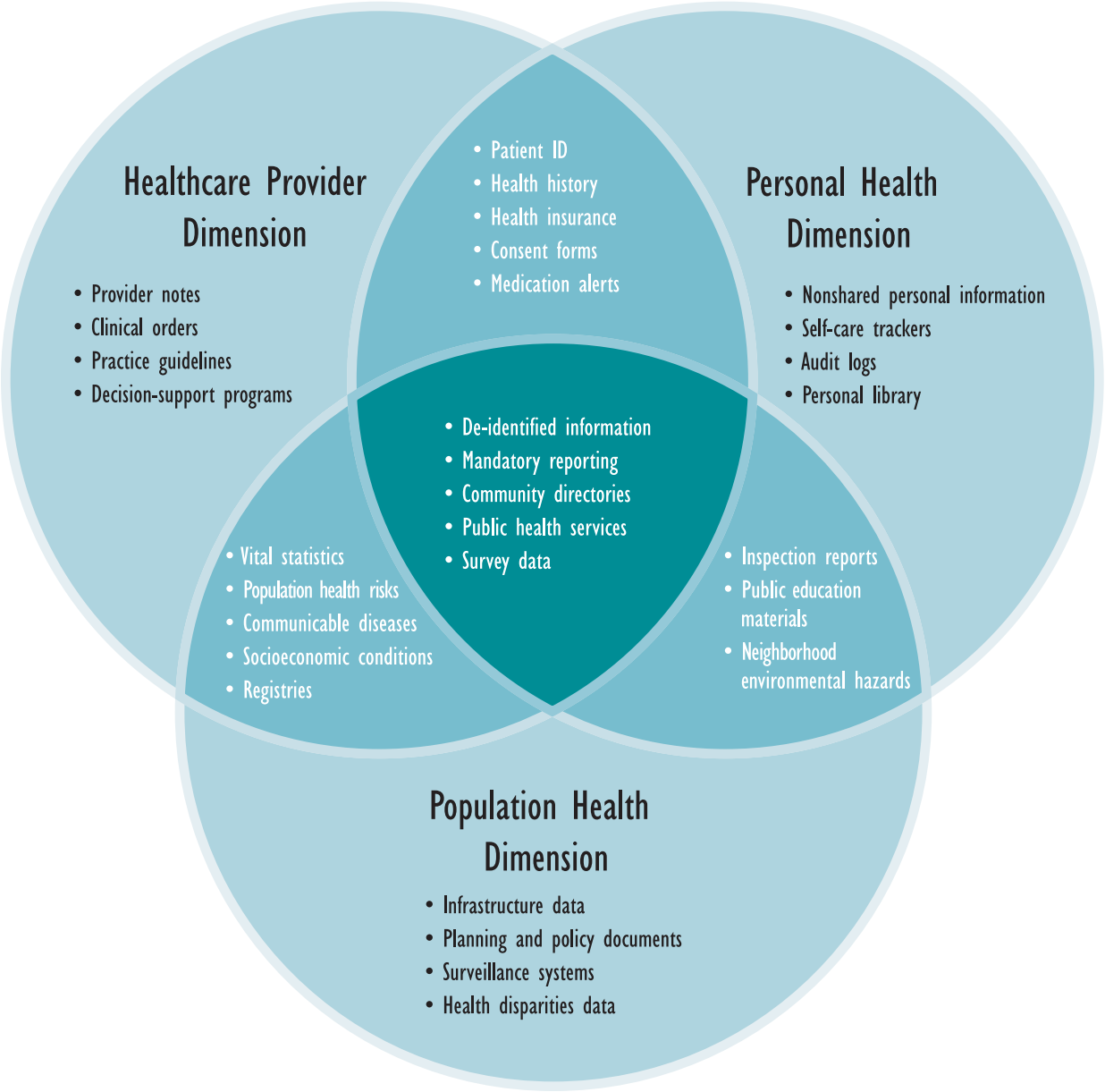
As noted, the NCVHS Interim Report on the NHII (in the Appendix on page A-1) presents the Committee's thinking in some detail, with extensive examples. Here we summarize the structure as conceptualized by the Committee and affirmed by stakeholders. The functions of the NHII can be illustrated by exploring three interactive and interdependent dimensions. (See the figure on page 16.) They are defined by what they encompass, whom they serve, how they are used, and who has primary responsibility for content and control. The dimensions provide a means for conceptualizing the capture, storage, communication, processing, and presentation

of information pertaining to the three major groups of users of information for health: consumers, healthcare providers (both individuals and organizations), and communities (local, State, and national). The Committee calls them, respectively, the personal health dimension, the healthcare provider dimension, and the population health dimension.

- The *personal health dimension* supports individuals in managing their own wellness and healthcare decisionmaking. It includes a personal health record that is maintained and controlled by the individual or family, plus nonclinical information such as self-care trackers and directories of healthcare and public health service providers.
- The *healthcare provider dimension* promotes quality patient care by providing access to more complete and accurate patient data on the spot, around the clock. It encompasses information such as provider notes, clinical orders, decision-support programs, and practice guidelines.
- The *population health dimension* (called the community health dimension in the Interim Report) includes information on both the health of the population and the influences on it. The population health dimension makes it possible for public health officials and other data users at local, State, and national levels to identify and track health threats, assess population health, create and monitor programs and services including health education campaigns, and conduct research.

Consumers, providers, and those responsible for population health at all levels use much of the same information; but they do so for different purposes—respectively, to manage personal and family health, to care for patients, and to protect and promote the health of the community and the Nation. All of these groups also have an interest in using information to track the effects of public policy and to engage in efforts to influence it. The role of some key participants in the NHII may cross multiple dimensions. Health plans' activities, for example, are reflected in both the healthcare provider and personal health dimensions. The idea behind the NHII is to push information and knowledge to the point where all these health decisions are made, so the right decisions can be made at the right time.

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



3. TECHNICAL AND FUNCTIONAL BUILDING BLOCKS OF THE NHII

A number of existing technologies, applications, and standards have the potential to be part of the NHII and, with adequate coordination, to serve the goal of providing timely health information to all who need it. The healthcare sector, for example, has been investing in specific applications, such as electronic medical records, digital imaging systems, and personal digital assistants. Consumers can use personal health records systems on Web sites to manage their information. Public health officials are using geographic information systems to enhance surveillance capabilities. For the most part, however, the three dimensions of the NHII have been evolving on separate technical and functional tracks and at an uneven pace. Moreover, according to the National Research Council (NRC) and the President's Information Technology Advisory Committee, the right technologies and functions have not been developed to support the demanding circumstances of health decisionmaking and health care.[6,13] One overarching problem is the slow development and uneven implementation of standards that allow technologies and information to be linked effectively. This has hindered private-sector innovation and public-sector responsiveness.

The Internet is the network platform for the NHII, and it will support functions and applications across the personal health, healthcare provider, and population health dimensions. The NRC has identified many of the applications and technical challenges for the three dimensions. (See Table 2.)

Many pieces of the NHII are already well-established parts of the information and communication infrastructure in the United States. These technical pieces are not necessarily health-sector specific. They are technologies that are already available to, affordable for, and widely used in multiple sectors of U.S. society. These core technical components include, among others, the Internet and the World Wide Web, e-mail,

Integrating information to make rapid improvements in patient care: Mr. B., who has a history of allergies and asthma, complains to his physician, Dr. W., of difficulty breathing, dizziness, and weakness. Dr. W. reviews Mr. B's electronic personal health history and medical record and checks the online decision-support system. A warning flashes on the monitor that a citywide air pollution alert is in effect. Dr. W. concludes that poor air quality has triggered Mr. B's problems and that relatively inexpensive modifications to Mr. B.'s existing medication regimen are all that's needed. Mr. B. agrees to use his home health monitoring system to take blood and pulmonary tests and have the results sent automatically to the doctor. Two days later, he has not improved, so Dr. W. modifies his medications. The practice's interactive medication alert system indicates a rare interaction from the drug combination for some patients. After further research using the hospital's knowledge management system, Dr. W. concludes the warning does not apply and prescribes the new regimen. Mr. B. begins to improve within 2 days.

Table 2
Selected Health Applications of the Internet

Application Domain	Real-Time Video Transmission	Static File Transfer	Remote Control
Consumer Health	Remote medical consultations to the home, office, or wherever the patient is located.	Accessing personal health records online. Downloading educational videos. Sending periodic reports on health conditions to a care provider.	Remote control of patient monitoring equipment.
Clinical Care	Remote medical consultations between clinician and patient or between two clinicians.	Transfer of medical records and images (e.g., X-rays, MRI, CT scans).	Remote and virtual surgery (a long-term possibility being examined by the defense and space communities).
Public Health	Videoconferencing among public health officials during emergency situations, such as chemical or biological attacks by terrorists.	Incident reporting. Collection of information from local public health departments and laboratories. Surveillance for emerging diseases or epidemics. Transfer of epidemiology maps or other image files for monitoring the spread of a disease.	N/A

Adapted with permission from Computer Science and Telecommunications Board, Commission on Physical Sciences, Mathematics, and Applications, National Research Council. 2000. *Networking health: Prescriptions for the Internet.* Washington, DC: National Academy Press.

databases, search engines, listservs, electronic data interchange (EDI), and encryption and authentication technologies. In many cases, the technologies have already been adapted to health-specific applications and functions and are being used extensively by consumers, clinicians, and public health officials for information, education, and data management. However, the full potential of even these fundamental technologies for decision support, coordination of care, and public health improvement is far from realized.[6,13,14]

In other cases, the health-specific applications and functions of technical components are only now taking shape or they may be utilized by only a few organizations and individuals. Examples of applications and functions that are only partially disseminated in the health sector include broadband; geographic information systems; remote video, sensing, and monitoring; customized computer interfaces and tailored Web pages; digital signatures and certificates; and wireless technologies. Pockets of users exist, but their activities and their ability to exchange information are constrained by lack of resources, organizational and professional boundaries, and traditional ways of communicating and doing business. Fuller use of these—and established—technologies can support telemedicine, electronic health records (clinical or consumer), integrated

Table 2
Selected Health Applications of the Internet (continued)

Information Search and Retrieval	Real-Time Collaboration	Primary Technical Challenges
Online searching for health information or self-assessment guides. Looking for a doctor or hospital.	Collaboration with care providers. Participation in chat groups and support groups.	Protection of sensitive patient information from breaches of confidentiality and from corruption. Ubiquity of access so that all healthcare consumers can be reached at the location at which care is needed. Tools and policies for validating the quality of online information.
Practice guidelines. Searches of professional medical literature.	Consultation among care providers, such as for surgical planning, which may involve manipulation of digital images.	Access to sustained bandwidth and low latency for remote consultations and collaboration. Security of clinical records. Network reliability. Ubiquity of access for care providers.
Access to published literature and research results as well as epidemiologic data. Delivery of alerts and other information to practitioners or other health workers.	Videoconferencing among public health officials during emergency situations, such as chemical or biological attacks by terrorists.	Security to ensure confidentiality and integrity of laboratory reports and other public health information that may contain personal identifying information. Network reliability. Security from information warfare or attacks on the network's physical infrastructure.

clinical information systems, disease management, digital prescribing, provider-patient e-mail, cross-database searching, and timely public health alerts.

There are no authoritative national reports on technology adoption in healthcare organizations. Industry surveys have found uneven diffusion of technologies and functions, although organizations report that they recognize the administrative and clinical factors that drive the need to share health information.[15] In 2001, provider organizations report that the technologies they most widely use include high-speed networks (83 percent), data security systems (78 percent), client-server systems (75 percent), and intranets (75 percent). Thirteen percent of providers have a fully operational Computerized Patient Record (CPR) system in place, virtually unchanged from 2 years ago, although another 53 percent report that they are either beginning to install the hardware and software for CPRs or have planned CPR implementation. Thirty-one percent are using handheld PDAs, and 37 percent currently employ wireless information appliances. Almost all organizations have a Web site, which is used overwhelmingly for marketing and promotion but will soon provide more functions, such as patient scheduling and electronic patient-physician communication.[16] Twenty-five percent of provider organizations already have an installed base for patient-provider e-mail.[15]

These same surveys indicate that if healthcare organizations follow through on their plans, the picture may change rapidly in the next 2 years.

A survey of 44 practice group managers found that 80 percent expect to do electronic charting by 2003, compared with 25 percent today. And 82 percent expect to automate prescription writing by 2003, compared with 16 percent today.[17] A variety of wireless appliances and applications also will support clinicians, consumers, and public health officials in the NHII. For example, Harris Interactive estimates that 50 percent of the country's physicians will be using handheld devices by 2005. But that could change markedly if insurers, employers, hospitals, and other providers mandate physician usage for prescription writing, charge capture, and results and order verification.[18] Public health workers are pilot-testing wireless systems for data transfer and communication from distant sites.[19]

This picture of current and planned use of technology does not give a definitive view of which technologies will be implemented and for what purposes. Many implementation challenges confront organizations and end-users. Some problems will require changes to the technology; others will require changes to processes and practice. Research on the ultimate cost effectiveness of the new technologies is similarly uneven.[14,20]

To support the multifunctional environment described above, the Internet, which is the backbone of NHII connections and communications, must be strengthened. It is relatively stable for some functions, such as unsecured e-mail and the exchange of small text-based files, but unstable for other functions, such as real-time telemedicine consultations and remote multimedia simulations.[13] The Internet and connected devices remain vulnerable to attack and disruption of service.[13] As mentioned throughout this report, though, the limitations of the infrastructure are not just technical. New policies and practices will be required to achieve the infrastructure's fullest use.

One of the ways the NHII could be strengthened is through more rapid adoption of and compliance with existing standards and accelerated development of other needed standards. As the Committee has noted on numerous occasions, standards are an essential component of the NHII. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides a platform for the exchange of financial, clinical, and administrative information in healthcare transactions. The HIPAA financial and

Accelerating public health responses and outreach: A major city has an Aerometric Information Reporting System that issues emergency alerts when local air quality does not meet National Ambient Air Quality Standards. The alerts trigger a detailed automated air pollution emergency response protocol. Local media, physicians, hospitals, nursing homes, home health agencies, and community information kiosks all receive the emergency notices to alert and protect vulnerable individuals. Some individuals especially at risk from poor air quality have signed up to receive notices on their personal information appliances. After a few days of poor air quality, automated tracking systems indicate that older persons, infants, and poor, non-English speaking immigrants close to industrial zones have greater than normal numbers of emergency room (ER) visits. The health department intensifies its outreach to these groups with information about how to cope with the situation, and immediately sees a drop in ER visits.

administrative transaction standards were released as regulations by HHS on August 17, 2000. These regulations will serve as a catalyst to move the healthcare industry to use more efficient and standardized electronic communications for communicating health claims, enrollment, eligibility, remittances, and related transactions. HIPAA includes not only financial and administrative transaction standards but also standards for privacy and security. Eventually, standards should make it possible to have a network architecture that is all but invisible to end users.

Along with the HIPAA financial and administrative transaction standards, a comprehensive set of Patient Medical Record Information (PMRI) standards can move the Nation closer to a healthcare environment where clinically specific data can be captured once at the point of care with derivatives of this data available for meeting the needs of payers, healthcare administrators, clinical research, and public health. This environment could significantly reduce the administrative and data capture burden on clinicians; dramatically shorten the time for clinical data to be available for public health emergencies and for traditional public health purposes; profoundly reduce the cost for communicating, duplicating, and processing healthcare information; and, last but not least, greatly improve the quality of care and safety for all patients. NCVHS issued preliminary recommendations in 2000 and will recommend HIPAA PMRI standards in 2002.

The Committee also recommended standardizing a core set of data elements for enrollment and encounter in a 1996 report on Core Health Data Elements. Uniform collection of these elements would enhance administrative as well as clinical data.[21]

A number of U.S. standard development organizations have developed clinical transaction standards for various purposes (ASTM, HL7, DICOM, OMG, IEEE, NCPDP)[a] and some of these, HL7 and DICOM, are in widespread use in the United States, Europe, and the Pacific Rim. However, substantial standardization work remains. Compliance testing is needed to ensure a uniformity in the adoption of these standards. Standards for codes that give specific meaning to the content of these messages also are needed. A number of medical terminologies with important levels of usage and utility already exist for various domains, including the Systematized Nomenclature of Medicine (SNOMED), the Logical Observation Identifiers Names and Codes (LOINC), and the Medical Collaborations Interactive Network (MEDCIN), but the adoption of these is limited.[b] Existing codes for some subject domains do not meet the needs of clinical records. For example, the National Drug Code does not include all drugs, and it is suitable only for inventory control of packages, not for prescribing where the active ingredients, dosage, and manner of administration need to be identified.

4. CONTRIBUTING ACTIVITIES AND PROTOTYPE PROGRAMS

This section begins by looking at two areas—privacy/confidentiality and standards—that cut across the three NHII dimensions. Next, programs, activities, and technologies are identified that seek to involve or benefit multiple groups. In each case, the impact of the programs, activities, and technologies would be enhanced if they were part of a comprehensive NHII framework. The section ends with a description of Canadian activities, which provides an invaluable model for the United States.

Crosscutting Activities

Privacy protections and practices. Ensuring the confidentiality and security of personal health information is paramount in the NHII. Privacy policies and practices continue to evolve, particularly for clinical and personal health information. All public health uses of information are already controlled by Federal and State laws and will remain so in the future.

In its June 1997 report to HHS, NCVHS made its privacy recommendations and stressed the need for national legislation to protect the confidentiality of medical records. The privacy regulations issued in 2001 by HHS in the absence of congressional action establish strong protections for individually identifiable health information that is held or transmitted by health plans, providers, and healthcare clearinghouses and sanctions for its misuse.[22] Although the regulations do not go into effect until 2003, and their legal status is being challenged, many healthcare providers and health Web sites are already implementing the regulations in anticipation. Their policies and specific practices vary greatly. Some major organizations have recognized that actions to improve privacy protections are a means to gain the confidence of consumers and patients. Prior to the issuance of the privacy regulations, numerous groups composed of private- and public-sector representatives (many of whom operate consumer-oriented health Web sites) developed their own guidelines for the management of personal information. These guidelines have evolved into standards and an accreditation process for health Web sites.[23]

Standardization. In the context of HIPAA, standards development is a long-term, national, public-private initiative that is closely linked to the development of privacy protections. Like privacy activities, standards development cuts across all NHII dimensions. While incomplete, the process is gradually laying a platform for the NHII that will increase in usefulness the more it addresses the information needs in each of the NHII dimensions. The greatest progress so far has been made in the healthcare provider dimension. HIPAA not only establishes standards but promotes consolidation of standards development, updating, and maintenance efforts. HHS has encouraged these efforts by recognizing a group of Designated Standard Maintenance Organizations (DSMOs) to manage the maintenance of the EDI standards adopted under HIPAA. The American National Standards Institute's Healthcare Informatics Standards Board (ANSI HISB) provides coordination and collaboration among the healthcare informatics organizations to promote and facilitate voluntary consensus for national standards. ANSI HISB is supporting the development of the United States Health Information Knowledgebase (USHIK) metadata

registry to assist in cataloging and harmonizing data elements across organizations. It also provides a forum for the HIPAA DSMOs to coordinate their efforts to define a common HIPAA electronic signature standard. International organizations are also important.[c] The International Organization for Standardization's U.S. Technical Advisory Group (ISO US TAG) coordinates the positions of U.S. standard development organizations for representation at the ISO Technical Committee 215's Committee on Healthcare Information Standards. Collaboration of government agencies and private industry within standards development organizations will be essential for creating optimum standards.

In the population health arena, various efforts are under way to improve cooperation between the public health and standards development worlds, with the Public Health Data Standards Consortium taking the lead. Since its establishment in 1999, the Public Health Data Standards Consortium has identified high-priority data needs, developed an educational strategy for public health databases to migrate to existing data standards, and established several workgroups to advance the incorporation of critical public health data into national standards.[d]

While these efforts do not directly impact the personal health dimension, they will benefit consumers to the extent that all these efforts ultimately contribute to appropriate information exchange across all the dimensions. Standards efforts unique to the personal health dimension are discussed below. The many technical and functional building blocks that standardization is contributing to NHII development were reviewed in Section 3.

The Healthcare Provider Dimension

Private-sector strategies. Although the healthcare sector as a whole lags significantly behind other sectors in integrating informatics and communication technologies, as noted above, some private-sector provider organizations have already made the strategic move toward fully integrated systems. For example, Kaiser Permanente is investing $2 billion for a Web-based system that includes a nationwide clinical information system, patient communication with doctors and nurses for advice, online guidelines and protocols for providers, and all administrative functions.[24] Partners Healthcare System is implementing a system on a virtual private network that includes electronic medical records, patient communication with providers, knowledge resources for doctors, and computerized provider order entry.[25] The "100 most wired" hospitals and health systems provide clinicians with access to patient data; offer Internet-based services to patients, clinicians, administrative staff, suppliers, and health plans; and provide online disease management.[26] They appear to be benefiting from better control of expenses, higher productivity, and more efficient use of services.[27]

These experiences are helping to clarify not only what works and what doesn't, but also how to measure return on investment. Lessons to date suggest that calculations based on a broad, long-term assessment of returns are more useful than those looking at specific projects or technologies and that while clinical, organizational, and process improvements may be important, so too are market visibility, customer satisfaction, and employee morale.

Collaborative activities. Some healthcare plans and providers are exploring collaborative efforts. Seven health plans formed MedUnite to jointly develop a common Internet-based healthcare business transaction system <www.medunite.com>. A group of national and State medical societies established Medem to provide health information for consumers and customized online patient communications for physicians <www.medem.com>. Efforts such as these that extend across multiple organizations will be vital components of the NHII, but they also underscore the need for national coordination and leadership.

Federal healthcare programs. The Federal healthcare sector, too, is laying the foundation for integrated healthcare and information systems. The Military Health System (MHS) is rolling out its E-Health Project, designed to improve healthcare services and benefits to military personnel and their dependents through the strategic use of the Internet <www.tricareonline.com>. The project is designed to provide a common Internet entry point for MHS customers, making it easier for beneficiaries to learn how to access MHS services and benefits. It will also ensure appropriate privacy policies and practices and facilitate portability of benefits. This is the first central effort to develop enterprise-wide business rules and a single, common Internet portal for all U.S. Department of Defense (DoD) patients, providers, and managers. The project is in the early stages of development and will be implemented incrementally.

The U.S. Department of Veterans Affairs' "One VA" initiative is designed to use information technology to improve service to the 26 million men and women who have been honorably discharged from the military and their families.[28] It includes e-mail with providers and other specialists, Internet-based self-service for VA transactions, and many other functions. Several VA hospital systems are among the "100 most wired" listed above, with well-established clinical information systems. Both DoD and VA also have been pioneers in clinical telemedicine. Ultimately, the lessons from these pilot projects can be integrated into the full spectrum of Federal healthcare delivery and health insurance. Their impact on the provision of health care will be felt by private-sector providers as well, through general technology transfer and the purchasing power of the Federal Government.

Enhancing continuity of care and public health outreach: Everyone benefits from automated vaccination records that are part of electronic personal health histories and medical records. Parents can track their children's immunizations over time, even if they see different physicians. Parents and doctors can receive automatic reminders when the next vaccination is due. Local vaccine reporting systems can aggregate anonymous patient data to show immunization rates by individual physician, practice group, and neighborhood. Public health officials can then compare local, State, and national rates, compare rates against CDC guidelines, and target areas for outreach and improvement.

The Population Health Dimension

Comprehensive reassessment and visioning. NCVHS began a process in 1999 to define a vision for health statistics in the 21st century, working jointly with NCHS and the HHS Data Council. Health statistics are an

important aspect of the population health dimension. They characterize the health of a population and the influences on the health of a population—factors that include the environment, genetic and biological characteristics, health care, community resources, and political and cultural contexts. Health statistics are used to design, implement, monitor, and evaluate specific health programs and policies.

The health statistics visioning process has involved discussion groups that met throughout the United States, regional public hearings, expert meetings, forums at professional association meetings, and a National Academy of Sciences workshop. The overall objective was to elicit a broad range of expert opinion from public health and medical professionals on the major trends and issues in population health and their implications for future information needs. The visioning process will result in the publication of a final report in 2002. The report will include suggestions for program planning and criteria for evaluating future health statistics systems. The NCVHS Workgroups on the NHII and on 21st Century Health Statistics have coordinated their efforts. One of the anticipated benefits of these closely related endeavors is that the work products will clarify the interconnections between population health and individual health and those between health and health care, as well as the implications for health information policy.

Local, State, and Federal systems. With current legacy public health systems, information on population health is transmitted from localities to States to the Centers for Disease Control and Prevention (CDC) via stovepipe systems that have evolved separately as a result of categorical congressional funding. CDC has several initiatives to link these self-contained, unconnected systems.

The Health Alert Network (HAN) is a nationwide integrated information and communications system that serves as a platform for distributing health alerts and disseminating prevention guidelines and other information.[29] It also serves as a platform for CDC's bioterrorism initiative and other efforts to strengthen State and local preparedness. The HAN currently encompasses 39 States. When completed, it will ensure high-speed, secure Internet connections for local health officials; capacity for rapid and secure communications with first-responder agencies and other health officials; capacity to securely transmit surveillance, laboratory, and other sensitive data; and an early warning broadcast alert system. The project includes training for public health workers in the use of information technology.

The National Electronic Disease Surveillance System (NEDSS) is a broad initiative using data and information system standards for development of efficient, integrated, and interoperable surveillance systems at State and local levels.[30] NEDSS is built so that data from healthcare providers can be sent to the health department via a secure "pipeline" to protect sensitive data. The focus initially has been on tracking systems for infectious diseases, including emerging infections, and management of possible bioterrorism events. Fifty States have received funding to plan and, in 36 health jurisdictions (35 States and 1 metropolitan health department), to implement NEDSS compatible systems. A NEDSS compatible system for State use, the NEDSS Base System, is also being developed that will incorporate standard messages, a

database model, and a platform for other modules. Twenty health jurisdictions have received funding to implement the NEDSS Base System in 2002.

Data definitions. CDC's related Public Health Conceptual Data Model provides the framework for categories of data for public health, especially surveillance. It already has been helpful in representing public health data needs to standards development organizations, specifically to promote the inclusion of the public health perspective in standards development. (This is also the objective of the Public Health Data Standards Consortium.) The model is being harmonized with the HL7 Reference Information Model. In addition to engaging in developmental work with States, standards development organizations, and other stakeholders, CDC has begun integration testing of the NEDSS Base System at the State level.[30]

The Personal Health Dimension

Consumer attitudes about health and health care are another important element in the NHII. With health premiums rising steeply and retiree health benefits expected to diminish, consumers will need to take increasing responsibility for their own health and for decisions about appropriate treatments and acceptable outcomes.

Consumers and patients have been rapid adopters of electronic communications and are using the Internet for information searching, social support, e-mail, health assessments, and other elements of personal health management. (See Table 3.) Patients are also demanding—and are willing to pay more for—online interaction with their healthcare insurers and providers. A recent survey found that 34 percent of e-health consumers would pay extra for the ability to manage their benefits online, and 25 percent would pay more for online interaction capabilities with their physicians. It was also found that 20 to 25 percent of these consumers would switch

Upgrading public health resources for the identification of bioterrorist threats: The Illinois Department of Public Health (IDPH) is notified of a credible threat that plague bacteria may be used in an act of bioterrorism. The IDPH sends out an alert through the Health Alert Network (HAN) to all local health departments. In addition, a similar alert is sent to all hospitals and emergency departments. The signs and symptoms of all forms of plague are incorporated into a software object that is then downloaded to the clinical information systems of clinicians throughout the State. Dr. T.'s system identifies two patients with a matching clinical profile in his practice. After approval by Dr. T., the system notifies the two patients by phone and their home health information system. They agree to come in later that day. That morning Dr. T. sees a patient who appears to have pneumonia and is coughing up blood. He prepares to send the patient to the hospital for x-rays and cultures when his office information systems warn him that this patient's symptoms fit the recently updated public health surveillance profile. He forwards a notice to the public health department and sends the patient into the hospital for further evaluation. The public health laboratory assists in making the diagnosis of a common pneumonia. Patterns of reports by Dr. T. and other physicians are monitored by IDPH as they continue to be alert to a potential terrorist act.

Table 3. Consumers' Use of Internet-Based Health Information Services for Decisionmaking

More than 50 percent of Americans with Internet access have turned to Web sites to find health or medical information that they use to make decisions about their health.

- 48 percent of these health seekers say the advice they found on the Web has improved the way they take care of themselves.
- 55 percent say access to the Internet has improved the way they get medical and health information.
- 92 percent of health seekers say the information they found during their last online search was useful; 81 percent said they learned something new.
- 47 percent of those who sought health information for themselves during their last online search say the material affected their decisions about treatments and care; half of these health seekers say the information influenced the way they eat and exercise.
- 36 percent of those who sought health information for someone else during their last online search say the material affected their decisions on behalf of that loved one.

Source: Fox S and Rainie L. November 2000. *The online health care revolution: How the Web helps Americans take better care of themselves.* Washington, DC: Pew Internet and American Life Project.

health plans or physicians to gain such capabilities.[31]

In addition to these uses of information for self-care and for medical care decisions, citizen advocacy groups are increasingly using health statistics for their communities to study concerns such as environmental health and health disparities, in order to influence public policy and practices in these areas. Such efforts are engaging stakeholders from all three dimensions.[e]

Health information quality. One of the most important barriers to the use of information and communications technologies to enhance health is the variable quality of the health information available through the Internet. Consumers are at risk for wasting money on useless products, avoiding needed medical care, or accepting harmful treatments. The U.S. Department of Health and Human Services has addressed this concern by developing healthfinder®, a comprehensive, user-friendly portal to reliable Internet health resources and sites <www.healthfinder.gov>. A free service, healthfinder® gives users access to more than 5,000 resources on more than 1,800 topics. The organizations that provide the resources have been reviewed and identified as reliable providers of information for the public. The Web site is coordinated by the Office of Disease Prevention and Health Promotion, which also oversees the HHS Healthy People initiative.

The development of quality criteria for health Web sites is an emerging area that may bring improvements in the reliability of online health information and services. Healthy People 2010 has set a national objective to increase the number of health Web sites that disclose critical elements of operations so that users can assess the quality of the site. Private and nonprofit organizations have developed codes

Improving individuals' ability to self-manage chronic conditions: With the help of a multimedia home information center, a 50-year-old mother, Mrs. M., manages her family's health. She receives automatic alerts and e-mails from her own doctors and her daughter's, and she also receives health information tailored to her specifications. For example, the last time her daughter had an asthma attack, Mrs. M. was able to e-mail information about her daughter's condition to the physician, receive advice within 2 hours, and avoid a trip to the emergency room. Because Mrs. M. is an authorized user for her dad's personal health information manager, she and her father, who lives far away and has emphysema, are simultaneously alerted when the air quality index in his community shows high levels of pollution. Her father also has a voice-activated medication reminder service that he accesses from the information appliance in his kitchen. The reminder service tells him which pills to take when, and he confirms that he has taken the pills as directed. His daughter also can see whether he is taking his medications correctly. The medication reminder service also tracks the need for refills and automatically sends a refill request as needed to the mail order prescription service.

of ethics and standards that will be used to accredit health Web sites. For example, URAC, an accreditation body for healthcare organizations, has developed a set of quality standards for health Web sites. [23] Organizations may apply to URAC to have their Web sites reviewed and accredited. If applied broadly and enforced consistently, quality criteria for health Web sites may provide measurable improvements that will help consumers identify the most appropriate Web resources for their needs.

The Canadian Example

As it develops the NHII, the United States is fortunate to have an excellent, comprehensive model in the Canadian Health Infostructure.[32] The purpose, process, substance, and overall level of commitment of the Canadian initiative are highly pertinent examples for the United States. The similarities begin with the basic concept. The 1999 report launching the project explains that the term "the Canada Health Infoway or health infostructure . . . refers not just to the use of information and communications in health . . . [but also] to the health information the technologies create, the policies governing the use of this information, and the people and organizations who create the information and use this infrastructure." The Infostructure is composed of elements provided by provincial, territorial, and Federal health infostructure initiatives. The vision is to "allow these diverse initiatives to complement each other in improving the health of all Canadians."[33]

Like the NHII, the Infostructure is a work in progress; however, its implementation is much further along. The initiative has been under development since 1998, with significant and growing support from the Canadian government. The initiative set out four strategic goals: empowering the general public, strengthening and integrating healthcare services, creating the information resources for accountability and continuous feedback on factors affecting the health of Canadians, and improving privacy protections within the health

sector. The early years were devoted to consultations with stakeholders around Canada. Specific projects have since taken shape. In some provinces, such as British Columbia where HL7 messages and standardized codes are used for all drug prescribing and in development for linking laboratories, effective infrastructures are developing.

Canadian Infostructure efforts focus on the three areas covered by the dimensions of the NHII. To improve population health statistics, the initiative developed a Health Information Roadmap that provides "an action plan for the 21st century."[34] Its activities have served as an example for the 21st-century health statistics visioning initiative described above. And CDC, in its documents on the Public Health Conceptual Data Model, cites the Canadian Infoway as one of the "inputs" to the CDC model. For consumers, the Canadian Health Network (CHN) was established on the Web, following the U.S. healthfinder® and National Library of Medicine models, as a national, bilingual Internet-based health information service <www.canadian-health-network.ca/customtools/homcc.html>. To improve health care, the Canadian government funded an independent corporation, the Canada Health Infoway, Inc.[35] Its objectives are to develop mechanisms to enable consumers to access health information that they can use, to facilitate the work of healthcare providers through technology, and to create a unified network of electronic health records across the continuum of care. It will identify investment opportunities with vendors and systems integrators and accelerate the development and implementation of computerized health information networks.

The Leap to the NHII

The foregoing review of functional and technical building blocks and contributing programs and activities shows that many of the basic components for the NHII already exist and are operating in their own spheres. What they lack is the interconnections that will make them more useful than they are as individual pieces. Now, new energy and resources must be introduced into the system to create a dynamic whole that is greater than, and beneficial to, all the parts. Leadership backed up by resources can bring the pieces together to craft the design of the NHII and bring it into being. We examine the new energy source and the required resources in the next section.

5. LEADERSHIP AS THE CORNERSTONE OF IMPLEMENTATION

Gaps and Barriers

Testimony at the Committee's hearings on the NHII in 2000 and early 2001 highlighted limitations in leadership, resources, standards, privacy and confidentiality protections, and consensus about appropriate information sharing as major impediments to the development of the NHII.[8-11] It is clear that the chief barriers are human and institutional, not technological. In particular, many speakers focused on the lack of a strong Federal presence to guide the development of the NHII as the most significant gap impeding its realization. The Government is already making, and has made, critical contributions to the development of the information infrastructure—some of them described above. However, these contributions have taken the form of seeding rather than leading the process. What is needed now is a shift in focus from the parts to the whole.

The Committee heard calls for Federal leadership to bring about collaboration between stakeholders in the private and public sectors and among all levels of government. The Federal Government's responsibility for strengthening national privacy protections and supporting the development and implementation of standards also was noted, along with the need for new and expanded Federal funding. This infusion of energy, resources, and direction could help organizations with existing responsibilities for health information work together for maximum benefit. The urgency of improving health communication and information flows has increased greatly since the hearings, but the nature of what is needed, as laid out in this report, remains essentially the same.

Besides strong Federal leadership, the development process needs to engage a broad range of stakeholders. Many sectors, organizations, and population groups were described in the hearings as underrepresented in NHII development to date—not only consumer advocacy and health organizations, providers in small or isolated practices, community organizations, and many public health programs, but also standards development organizations, medical device manufacturers, insurance companies, and employer groups. This situation suggests that while some groups have been working hard to envision and stimulate the NHII, many other stakeholders either have not yet recognized its potential benefits or lack the resources to participate in its development.

Many stakeholders now and in the future will share the cost of building the NHII, but guiding and creating synergy among diverse investments, promoting standards, stimulating growth, and monitoring progress are duties that rest with the Federal Government. This calls for a combination of commitment, money, and vision. The areas where Federal funding is needed are outlined in NCVHS recommendations 1, 2, and 3 below. But money alone will not make the NHII happen; spending will be cost-effective only when it is guided by a national health information policy and implementation plan, also discussed in the recommendations. Without these, uncoordinated spending on information and communication capabilities by individual stakeholders, including the Federal

Government, could exacerbate fragmentation and actually make future growth more difficult.

The examples of other countries are instructive in this regard. Over the past decade, Canada, Australia, and the United Kingdom have committed large sums to developing and implementing national information strategies; they have also officially adopted many U.S. standards. In 1998, Canada budgeted Can$95 million dollars for its 4-year Roadmap Initiative, and it now budgets more than Can$1.5 billion dollars a year for its health information infrastructure (Infoway), with an additional Can$500 million in Federal funds committed in 2001 to support a private company, Canada Health Infoway, Inc. (mentioned in Section 4).[36,37] The British government committed more than £1 billion in 1998 to a 7-year initiative to build information and communications applications for its health sector.[38] In each case, the significant spending is tied to a national vision and strategy. In the United States, Federal funding is scattered among multiple health and technology agencies with no overarching plan or coordination. Apart from a few efforts in the private and public healthcare sectors, mentioned in Section 4, there is no sustained financing for information technology investment or e-health service delivery. The series of events unleashed on September 11 particularly highlighted the lack of sufficient Federal funding to build the public health infrastructure all the way to the local level, the front line of public health services.

Disparate Responsibilities Create a Fragmented Environment

This report has shown that many NHII components already exist and that several entities have helped envision the national health information infrastructure. Moreover, numerous Federal agencies already have responsibilities for specific functions that are critical to the development and implementation of the NHII. Although the sheer number of activities offers a lot to build on, it is also a significant constraint. The current distribution of responsibilities creates a fragmented environment of separate programs governed by sector-specific mandates and policies. Transforming these diffuse elements into a comprehensive system of systems in accord with the vision requires the introduction of an entirely new set of energies, resources, and perspectives. One of the chief reasons that NCVHS recommends focused Federal leadership as the NHII evolves is that without such leadership the multitude of existing and new activities are far likelier to work at cross-purposes than to be additive and complementary.

Because of its mandate, HHS encompasses numerous agencies whose core missions or specific programs touch on the full array of NHII areas. (See Table 4.) Each of these will continue to play a vital role in their specific areas to ensure the NHII's development. HHS and the U.S. Departments of Defense and Veterans Affairs will have central involvement in the NHII because of their direct responsibilities to provide either health care or health insurance for millions of Americans.

Table 4. HHS Agencies' Responsibilities Related to the NHII

Agency for Healthcare Research and Quality <http://www.ahrq.gov>: Research on effective technologies and practices related to clinical care; development of clinical practice guidelines.

Deputy Assistant Secretary for Information Resources Management <http://www.hhs.gov/oirm>: Information technology infrastructure within HHS.

Assistant Secretary for Planning and Evaluation <http://aspe.hhs.gov>: General policy development and program evaluation.

Centers for Disease Control and Prevention <http://www.cdc.gov>: Infrastructure for population health.

Centers for Medicare & Medicaid Services <http://www.cms.gov>: Provision of care for older Americans; insurance for lower income and other disadvantaged populations.

Data Council (interagency) <http://aspe.hhs.gov/datacncl/index.htm>: Coordination of data development.

Food and Drug Administration <http://www.fda.gov>: Regulation of health-related products; monitoring and reporting on safety and adverse effects; coordination of a clinically useful drug code.

Health Resources and Services Administration <http://www.hrsa.gov>: Rural telehealth and community health clinics.

National Center for Health Statistics <http://www.cdc.gov/nchs>: Population health statistics.

National Institutes of Health <http://www.nih.gov>: Biomedical knowledge creation and diffusion.

National Library of Medicine <http://www.nlm.nih.gov>: Biomedical knowledge dissemination; research and dissemination on new technology and information networking practices.

Office of Civil Rights <http://www.os.dhhs.gov/ocr>: Privacy regulations enforcement.

Office of Public Health and Science <http://www.osophs.dhhs.gov/ophs>: Consumer information policies and programs; crosscutting e-health and prevention issues.

Multiple Federal departments currently fund numerous initiatives and programs to promote access to computers, the Internet, telemedicine, and reliable health information. HHS, DoD, and VA have longstanding programs in telemedicine. The U.S. Departments of Commerce, Education, and Housing and Urban Development all direct programs that provide computer and Internet technologies in communities, and in some cases in individual homes. Healthy People 2010 includes an objective to promote household Internet access to extend the benefits of e-health; it also includes an objective to improve the quality and privacy practices of health Web sites. The umbrella Federal gateway, FirstGov.gov, includes health information as one of its main topics, using the health portal healthfinder® and other specific HHS Web sites as content sources. The National Institutes of Health, and the National Library of Medicine (NLM) in particular, are a premier source of both scientific and consumer-oriented information across the full spectrum of biomedical issues.

Numerous national institutions and entities have responsibility for information technology research and development and advising on information policy and programs. In addition to its responsibilities as an information provider, NLM has funded research on the Next Generation Internet and medical informatics.

As noted above, NCVHS is the advisory body to HHS and Congress on health information policy. The Institute of Medicine and the National Research Council, chartered by Congress, provide authoritative guidance on health and technology issues underpinning the NHII. The National Science Foundation has a leading role in identifying and advancing the technology research agenda. The National Coordination Office for Information Technology Research and Development oversees the crosscutting $2 billion Federal information technology research and development budget. The President's Information Technology Advisory Committee provides advice and guidance on all aspects of high-performance computing, communications, and information technologies.

States and local communities are deeply engaged in health improvement and services for their populations. States and communities provide public health infrastructure and the healthcare safety net. States also are responsible for licensing physicians and pharmacists. State licensure currently results in a diverse patchwork that is at odds with the NHII requirement for seamless and portable health care for a mobile population. New forms of Federal-State cooperation will be required to achieve the full benefit of care that goes beyond geographic boundaries.

Standards development organizations and medical terminology developers are spearheading the work to recommend information transaction standards and clinically specific terminologies as described in Section 3. The HIPAA Designated Standards Maintenance Organizations are now authorized to lead the ongoing process of maintaining and revising standards. These efforts have been a locus of public/private collaboration, with strong NCVHS involvement, since HIPAA was enacted in 1996.

Several foundations are funding important research into areas touching the personal health dimension of the NHII, including the California Healthcare Foundation <www.chcf.org>, the Robert Wood Johnson Foundation <www.rwjf.org>, the Markle Foundation <www.markle.org>, and the Pew Foundation's Internet and American Life Project <www.pewinternet.org>. No national consumer advocacy group, however, has adopted consumer e-health as a major part of its agenda.

Activities and responsibilities such as those mentioned in this partial inventory have invaluable contributions to make to the evolving NHII. No existing entity, however, has the experience or authority to coordinate the activities of all the others and to create synergy among them. The question, then, is how to support all current and potential activities within a framework that maximizes coordination, collaboration, and innovation. After studying this question and consulting with many stakeholders, the NCVHS has concluded that a new senior position and office at HHS, equipped with adequate funding, are required to oversee and coordinate a broad range of policy, research, and program activities in different sectors.

Operationalizing the Recommendations

The NCVHS recommendations in the next section spell out activities and roles for each stakeholder group in building the NHII. The 27 recommendations are directed to 9 categories of stakeholders:

- The Federal Government, including the U.S. Department of Health and Human Services, Congress, and Federal health data agencies
- State and local governments, including State and local data and health agencies
- Healthcare providers, including membership and trade organizations and healthcare organizations
- Health plans and purchasers
- Standards development organizations
- The information technology industry
- Consumer and patient advocacy groups
- Community organizations
- Academic and research organizations

Of necessity, the recommendations are presented sector by sector. However, if they were laid out in a matrix, it would be apparent that the stakeholders' roles are parallel and often interdependent. For example, Federal and State governments as well as providers are advised to create strategic leadership mechanisms for the sector(s) for which they are responsible. All stakeholders are encouraged to collaborate with other organizations and agencies, in addition to carrying out actions that are particular to their domain and expertise (e.g., standards development, advocacy, or research).

The Committee believes, as has been stated, that primary responsibility for coordinating development of the NHII rests with the Federal Government and HHS specifically. This coordination must be both horizontal and vertical—horizontally, across providers, consumers, public health programs, standards development organizations, payers, Government agencies, academic and healthcare institutions, and others, and vertically, across local, State, and national entities. The coordination also must explicitly encompass the personal health, healthcare provider, and population health dimensions rather than focus on any single area.

The Committee recommends that this effort be led by a new, high-level office within HHS. It should have the resources and mandate to coordinate all efforts, internally and externally and in both public and private sectors, and to directly fund strategic crosscutting activities. At the same time, the individual HHS agencies' NHII-related portfolios need to be strengthened and new resources added, under the general coordination of the new office.

Should it accept the recommended leadership role, HHS will need to assess the associated resource needs and integrate them into its budgetary process. Former Assistant Secretary for Health Philip R. Lee, M.D., offered his thinking on funding for the NHII at a regional hearing.[39] In a written supplement to his testimony, he said, "We recommend a ten-year Federal investment in developing the NHII that will require a $14 billion investment and will generate both social and financial returns to the public."[f] Given the variety of tasks that would be encompassed, such funding would be spread across the White House, existing agencies, nongovernmental organizations, and the new office. This level of commitment is proportional to efforts in Canada and the United Kingdom.

The most important function of funding is to support the new HHS office's pivotal role in coordinating and integrating the activities of the stakeholders and convening them for this purpose. Other HHS activities on the NHII that also need support include information technology research and development; research into effective e-health technologies, applications, practices, and dissemination; investments for information technology deployment in health care and population health; dissemination networks (for the public and professionals) and integrated portals; standards development and implementation; training; data development, management, and integration to implement the vision for 21st-century health statistics; and reimbursement for pilot projects and clinically proven e-health services.

It must be understood that this emphasis on HHS leadership does not suggest a top-down, Government-controlled process. Instead, the recommendations outline a Federal role that promotes the vision and facilitates consensus on direction and process and then helps the collaborators to keep moving as intended, providing support as needed and monitoring progress. The Government is called upon to help set the stage for private innovation, to catalyze change through visioning and standard-setting, and to help build incentives, in addition to performing such traditional governmental functions as providing material support, widening participation and access, and ensuring privacy and confidentiality protections.

Comments in the hearings on the NHII and a review of successful models and best practices in the United States and abroad suggest that several attributes are critical for a collaboration that will build the NHII. In addition to inclusiveness and broad-based participation in decisions, formal mechanisms for reaching compromise on controversial issues will be needed. Stakeholders' motivations vary and sometimes may even conflict; to succeed, the collaboration must account for the full range of interests and motivations. Other important attributes are a clear leadership mandate, an appropriate distribution of responsibility and accountability, and an agreed-upon process and milestones.

While none of the following is a perfect or complete example (and other examples could be cited), three well-documented cases illustrate at least some of these attributes. The first is the Canadian Health Infoway and Information Roadmap, described in Section 4. Those in charge of that multiyear process of consultation, planning, and implementation have gone to considerable lengths to involve multiple stakeholders—providers, consumers, business people, policymakers, and more—at local, provincial, and national levels.

The second example is the National Occupational Research Agenda (NORA) public/private consensus process used to develop a research agenda for the National Institute for Occupational Safety and Health (NIOSH).[40] Some 500 organizations and individuals outside NIOSH provided input into agenda development, helped identify 21 priorities, and committed themselves to implementing the agenda. Many organizations are using NORA (which stimulated a 133-percent increase in Federal funding in this area) as a model for their own partnership and planning initiatives. Examples of organizations using NORA include the European Agency for

Safety and Health at Work, the U.S. Department of Defense, the Japanese National Institute of Industrial Health, the State of Maine, and the Chemical Industry Institute of Toxicology.

The final example of collaboration is the highly decentralized but well-coordinated process used to develop Healthy People 2010, the Nation's third decade-long prevention initiative. Leadership in 28 specific areas was delegated to agencies with primary mandates in those areas who worked closely with relevant professional and voluntary organizations. Regional hearings and online comment opportunities ensured broad input from the general public. The Assistant Secretary for Health provided overall leadership and coordination. Implementation is now equally decentralized, with virtually all States and many localities adapting Healthy People to frame their own health initiatives.

Given stakeholders' varied interests, stages of readiness, and degrees of receptivity to the NHII, the proposed new HHS office will need to use both incentives and requirements to stimulate the development process. In the Committee's view, devising these stimulants should be one of the Federal office's first tasks. Incentives and requirements may be linked as part of a national plan supporting a national health information policy. For example, grants to providers and public health agencies for investment in standardized systems might require that they incorporate standards for sharing personal health information (under strict protocols for de-identification unless mandated by law).

The standardization and administrative simplification process sparked by the 1996 Health Insurance Portability and Accountability Act is an example of this interplay of incentives and requirements. Other incentives might include differential reimbursement to providers who have implemented information systems consistent with NHII information flows, including decision-support tools for providers and patients. Other requirements might include a charge to Federal agencies to produce plans for bringing current programs into consistency with NHII information flows within 5 years.

Three Major Stages To Realize the NHII

The Committee envisions three major stages in the process. The first stage has five major tasks: creating the recommended senior position and lead office within HHS with sufficient authority and funds and building relationships with centers of leadership in HHS and other agencies; fleshing out the vision as a national health information policy and implementation plan; establishing incentives and requirements; launching a comprehensive standards acceleration process; and committing the resources implicit in each of these tasks. Taken together, these actions would demonstrate a strong governmental commitment to the development of the NHII.

The second stage centers on developing and expanding collaboration at national, State, and local levels and with the private sector to complete and confirm the implementation plan. This stage will involve the most extensive and substantive forms of collaboration.

The third stage involves carrying out the implementation plan in all relevant areas of the private sector and all levels and areas of government. This stage will include a feedback

loop in which progress is monitored and issues requiring further action are identified.

NCVHS suggests that stage one be completed within 2 years, stage two within 5 years, and stage three within 10 years. Looking to its own role in this process, the Committee expects its responsibilities as HHS's primary external advisor on health information policy to grow more focused as HHS moves into its recommended leadership role. The Committee would welcome annual reports from the Department on its progress toward implementing the recommendations, beginning in 2002. The Committee also anticipates that it will continue to hold periodic hearings to assess NHII activities in the public and private sectors.

Before turning to the recommendations of the National Committee on Vital and Health Statistics, let us review the key messages of this report. The heart of the vision for the NHII is sharing information and knowledge appropriately so it is available to people when they need it to make the best possible health decisions. To serve the Nation's health needs, the NHII must make information available to individuals, healthcare providers, public health agencies, policymakers, and all others whose decisions shape health outcomes. It must serve all individuals and communities equitably; enhanced electronic capability must not be allowed to serve preferentially the segments of the population that are already most advantaged. Better safeguards for privacy, confidentiality, and security are hallmarks of the NHII. The evolution of the NHII is already under way, but so far progress is highly fragmented. Recent events underscore that an effective NHII is not a luxury, but a necessity; it is not a threat to our privacy, but a vital set of resources for preventing and addressing personal and collective health threats. Realizing the potential of the NHII will involve changes in personal, institutional, professional, civic, and governmental practices and in the relationships among these domains. Experts and industry representatives told the NCVHS that the Federal Government has a key role to play in these developments. But the Government cannot act alone; what is needed is a dynamic, nationwide collaborative venture for this purpose. The following recommendations outline a process for bringing that about.

RECOMMENDATIONS FOR THE NATIONAL HEALTH INFORMATION INFRASTRUCTURE FROM THE NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Congress and the White House should make it a priority to develop a comprehensive National Health Information Infrastructure (NHII) for the public and private sectors. Leadership should be vested in the U.S. Department of Health and Human Services (HHS). The NHII leadership should participate in senior executive branch councils, such as the Domestic Policy Council, the National Science and Technology Council, and committees focused on bioterrorism. Legislation and appropriations to support the NHII will be needed. Congress and the White House are encouraged to examine existing and planned initiatives in population health, health care, and consumer health to ensure their consistency with the requirements of a comprehensive NHII and avoid creating future barriers.

FEDERAL GOVERNMENT

1. **The Secretary of Health and Human Services** should create a senior position to provide strategic national leadership for the development of the NHII and set the agenda for NHII investments, policymaking, and integration with ongoing health and healthcare activities inside and outside of Government. The position should report directly to the Secretary of HHS and be supported by a separate office with its own budget. At the same time, the specific NHII-related roles and responsibilities of HHS agencies should be enhanced, with appropriately increased budgets, under the strategic oversight of the central NHII office. (See #2 below.) The creation of this office responds to and would address the findings and recommendations of the President's Information Technology Advisory Committee, Panel on Transforming Health Care, and the National Research Council's Committee on Enhancing the Internet for Health Applications.[8] The recommendations from these reports should be adapted or expanded as needed to encompass the personal health and population health dimensions of the NHII as well as the healthcare provider dimension.

   The proposed office, which is envisioned as a policy and coordination office rather than an information technology office, should develop a comprehensive NHII strategic plan that encompasses public- and private-sector health information activities. The plan would be developed in collaboration with key external stakeholders, HHS agencies, and other Federal agencies and promote consistent policies nationally. Internally, it would coordinate and oversee NHII-related policy, program, and technology activities and promote timely action by HHS agencies. The office would promote and facilitate the coordination of activities within HHS related to health information privacy and security. It would support pilot projects through its own funding and encourage support for strategic projects through other funding sources inside and outside the Federal Government. This office should recognize the roles of all key stakeholders, including consumers, and conduct its work through collaborative mechanisms whenever possible. It should seek to

build upon existing programs that support the NHII and avoid duplication of activities. Specific responsibilities would include

- Coordinating the evolution of the NHII and working with all relevant stakeholders in the public and private sectors to develop a strategic plan that will, among other things, ensure the interoperability of all elements of the NHII.
- Coordinating HHS spending on NHII-related activities; ensuring that population health, personal health, and healthcare provider information needs have a high priority in crosscutting Federal information technology research and development initiatives; and sponsoring pilot projects relevant to the personal health, healthcare provider, and population health dimensions that promote effective information flows within and across the dimensions.
- Developing policies and practices to ensure the security and confidentiality of personal health information.
- Promoting the development of State and local population health information capacities.
- Promoting effective training methods in health informatics for the public and private sectors and identifying and developing health informatics skills for the Government health work force.
- Convening stakeholders from the public and private sectors to develop consensus on priorities and responsibilities for NHII development and implementation; providing an ongoing forum for discussion, consensus building, and report writing that advances the NHII.
- Reviewing all other Federal roles and responsibilities relevant to the NHII for consistency with the public interest in realizing the full benefits of the NHII, and establishing timetables for needed revisions or enhancements; reviewing with other Federal healthcare agencies all Federal healthcare programs, whether funded directly or indirectly, for consistency with the public interest in realizing the full benefits of the NHII; and establishing timetables for needed revisions or enhancements.
- Promoting standards for data and other requirements for the personal/consumer health record and the clinical health record in conjunction with other stakeholders.
- Promoting international collaboration in areas such as standards and the quality of health care and health information.
- Ensuring that all population groups share in the activities and benefits of advances in information technology and transfer and their applications.

The budget of this office should be adequate to support robust convening and coordinating functions. Other funds should be strategically targeted for grants, cost-benefit studies, research and development projects, consensus building on best practices, technical assistance, and the creation of a comprehensive program to accelerate the development of healthcare information standards in the United States.

2. **Other HHS agencies/offices** with missions and activities in NHII-related areas should designate an office or individual to participate in NHII strategic planning and ensure coordination within the agency/office and with the central NHII office. The budgets of these agencies/offices should be appropriately increased to support enhanced NHII-related activities in their specific areas,

including accelerated standards development. The agencies/offices should ensure that existing and planned activities are consistent with NHII requirements and that their impact on population health is tracked and reported to appropriate data centers.

3. **Congress** should provide new or expanded funding for programs that support the personal health, healthcare provider, and population health dimensions individually and jointly, with special attention to areas for which the Federal Government has a leading or exclusive role and areas already mandated by HIPAA. Examples of funding include support for

   - Development of State and local population health information capacities.
   - Professional training programs for the Federal, State, and local public health work force, and for the private healthcare work force, in information technology skills.
   - Technology centers that bring together interdisciplinary teams to explore issues related to the NHII, with an emphasis on activities that link the three dimensions.
   - Healthcare providers for investments in interoperable linked systems that support health-related information flows across plans and providers.
   - Federal information technology research and development activities to stimulate research in health and healthcare applications.
   - Pilot projects that integrate data from the healthcare provider and personal health dimensions into the population health dimension at the State and local levels.

   Congress should supplement HIPAA to address standards issues related to the NHII. A "Health Information Portability and Continuity Act" should provide for the portability of health information across information systems, plans, and providers to ensure continuity of care; promote the adoption of clinical data standards; and promote consumer/patient control of personal health information.

   Congress should pass national laws and identify regulatory responsibilities for overarching issues that apply to the NHII, such as the confidentiality of personal health information, the security of health information systems, reimbursement for clinically necessary and effective electronically delivered health services, and consumer protection for misuses and abuses of health information.

4. **Federal health data agencies** should collaborate with State and local government agencies and standards organizations to develop common data reporting formats and standardized methods of transmission of all pertinent health data. These activities should build upon CDC NEDSS, the Health Care Service (837) Data Reporting Guide and upon efforts to develop public health data conceptual models, extending these beyond communicable diseases. This effort also should be coordinated with the United States Health Information Knowledgebase or metadata registry operated by the ANSI Healthcare Informatics Standards Board.

OTHER STAKEHOLDERS

Although the Committee was told that the Federal Government should assume leadership, it also heard that the Federal Government can not build the NHII alone. Its ability to lead and coordinate rests on the assumption that many other stakeholders in the public and private sectors will play key roles within their own areas and will work together.

State and Local Government

1. Each State should establish a mechanism to provide strategic leadership and coordination of activities related to the NHII. This mechanism, which may be a new office, preferably located in the Office of the Governor, Office of the State Health Officer, or other combined health and human services agency, should have broad oversight of the integration of NHII components into the public health and healthcare programs in their States. The functions of the leadership would be to solicit input from all relevant stakeholders, including consumers, about the development and uses of the NHII and to oversee personal health information privacy issues and activities. Specific responsibilities would include
   - Securing funds for State and local health departments to develop their health information capacities.
   - Reviewing State healthcare programs for consistency with NHII requirements and establishing timetables for needed revisions or enhancements.
   - Reviewing State/local public health infrastructures for consistency with NHII requirements and establishing timetables for needed revisions or enhancements.
   - Reviewing medical licensing laws and taking action to maximize the extent to which the laws ensure appropriate reciprocity across State lines.
   - Reviewing other State and local laws, regulations, and programs relevant to the NHII and taking action to ensure consistency with the NHII.
   - Developing policies and practices to ensure the security and confidentiality of personal health information.
   - Coordinating NHII-related activities of healthcare providers and plans.
   - Fostering pilot projects.
   - Providing information about NHII requirements.
2. State and local data agencies should collaborate with Federal agencies and standards organizations to develop common data reporting formats and standardized methods of transmission for all pertinent health data.
3. State and local health agencies should invest in the collection and analysis of population health data to permit real-time small-area analysis of acute public health problems and to understand health issues related to new or rapidly growing populations and health disparities, and they should combine health data sources for population analysis.

Healthcare Providers

1. Membership or trade organizations. Each healthcare professional and provider membership and trade organization should establish a mechanism to provide strategic leadership on issues related to NHII development and implementation. The functions of the leadership would include representing the membership or trade organization in meetings convened by HHS and collaborative activities with other stakeholders, promoting internal review of organizational practices and systems for consistency with the NHII and developing timetables for needed revisions and enhancements, and overseeing personal health information privacy issues and activities. Membership and trade organizations should also identify the necessary incentives to promote the full participation of all healthcare providers in the NHII. Representatives of membership and trade organizations should participate actively in the work of standards development organizations and collaborate with Federal representatives in the development of standardized data reporting formats and standardized methods of transmission for population health data.

2. Healthcare provider organizations. Each individual healthcare provider organization should establish a mechanism to provide strategic leadership and coordination on issues related to NHII development and implementation. The leadership would be responsible for overseeing personal health information privacy and security issues and activities and ensuring that stakeholders from the personal health and population health dimensions can provide appropriate input into plans and decisions. The leadership should identify representatives with diverse backgrounds to participate actively in the work of standards development organizations.

Healthcare Plans and Purchasers

1. Each healthcare plan and purchaser should establish a mechanism to provide strategic leadership and coordination on issues related to NHII development and implementation. These responsibilities could be assigned to the Chief Information Officers of their organizations. A designated individual should represent the organization in meetings convened by HHS and collaborative activities with other stakeholders and oversee personal health information issues and activities.

2. Healthcare plans and purchasers should examine their practices and systems for consistency with the NHII and set timetables for needed revisions and enhancements. They should ensure that stakeholders from the personal health and population health dimensions provide appropriate input into NHII plans and decisions.

3. Healthcare plans and purchasers should identify representatives with diverse backgrounds to participate actively in the work of standards development organizations.

Standards Development Organizations

1. Standards development organizations should develop new or modified standards as requirements become known.

2. Standards development organizations should ensure participation by consumer representatives.

3. Standards development organizations should identify mechanisms to accelerate the standards development process and improve the coordination of standards development across standard-setting bodies and consistent with the direction of the NHII.

4. Standards development organizations should promote cooperation with standards being developed internationally for population health, patient care, or data-security purposes.

Information Technology Industry

1. Information technology organizations and trade groups should designate internal representatives to provide strategic leadership and coordination on issues related to NHII development and implementation. Representatives should participate in meetings convened by HHS and collaborative activities with other stakeholders.

2. The information technology industry should develop and promote cost-effective healthcare software and technologies that comply with national standards so that they can support the appropriate sharing of electronic information for healthcare providers, consumers/patients, and public health agencies and the improved delivery of clinical and public health services.

Consumer and Patient Advocacy Groups

1. Consumer and patient advocacy groups should promote policies that encourage the use of electronic technologies in healthcare organizations and by healthcare providers to improve the quality of services, to decrease rates of adverse effects, and to increase access to online/wireless health information and services for consumers, patients, and clients. They should advocate for privacy protections for consumers, patients, and clients when they exchange health information electronically and for equal access to technology and information by all population groups.

2. Consumer and patient advocacy groups should participate in NHII-related committees organized by national and State agencies, and by health plan and provider organizations, and in standards development efforts.

3. Consumer and patient advocacy groups should collaborate with healthcare provider organizations, health plans and purchasers, and public health organizations to promote and facilitate the use of information technologies by healthcare providers, health plans, and public health entities.

Community Organizations

1. Community organizations should help identify community health data needs.

2. Community organizations should identify necessary partnerships to exchange health data. They also should identify and help reduce barriers to community level collection and exchange of health data.

3. Community organizations should develop local laypersons' capacities to collect and apply health data to individual and community health improvements.

4. Community organizations should develop programs that address the "digital divide" and promote equal access to technology and information by all population groups.

Academic and Research Organizations

1. Academic and research organizations should develop research proposals that integrate health information infrastructure and applications with other types of information infrastructure development (e.g., NGI and Internet2).

2. Academic and research organizations should develop collaborations with service providers, standards development organizations, and their communities to take innovations from research to implementation.

ENDNOTES

[a] Health Level 7 (HL7) provides standards for the exchange, management, and integration of data that support clinical patient care and the management, delivery, and evaluation of healthcare services <http://www.hl7.org>. The National Council for Prescription Drug Programs (NCPDP) is a nonprofit American National Standards Institute (ANSI)-accredited standards development organization that creates and promotes data interchange standards for the pharmacy services sector of the healthcare industry <http://www.ncpdp.org>. The American Society for Testing and Materials (ASTM) is a developer and provider of voluntary consensus standards, related technical information, and services <http://www.astm.org>. Digital Imaging and Communications in Medicine (DICOM) creates and maintains international standards for communication of biomedical diagnostic and therapeutic information <http://medical.nema.org/dicom.html>. The Institute of Electrical and Electronics Engineers, Inc. (IEEE), is an international membership organization with a portfolio of standards programs <http://www.ieee.org>. The Object Management Group (OMG) produces and maintains computer industry specifications for interoperable enterprise applications <http://www.omg.org>.

[b] SNOMED (Systematized Nomenclature of Medicine) is a coded vocabulary that will allow for the full integration of electronic medical record information into a single data structure <www.snomed.org>. LOINC (Logical Observation Identifier Names and Codes) provides a standard set of universal names and codes for identifying individual laboratory results, clinical observations, and diagnostic study observations <http://www.regenstrief .org/loinc>. MEDCIN includes more than 175,000 clinical data elements encompassing symptoms, history, physical examination, tests, diagnoses, and therapy <http://www.medicomp.com>.

[c] For example, the International Organization for Standardization, which includes 140 countries <http://www.iso .ch>; the Internet Engineering Task Force, which focuses on the Internet architecture and the smooth operation of the Internet <http://www.ietf.org>; and W3C (World Wide Web Consortium), which develops common protocols for the Web to promote its evolution and to ensure interoperability <http://www.w3.org>.

[d] Information on the activities of the Public Health Data Standards Consortium is available online at http://www.cdc.gov/nchs/otheract/phdsc/phdsc.htm.

[e] Examples include the Anacostia/Ward 8 Child Health Champion Collaborative <http://www.epa.gov/reg3esd1 /childhealth/special_original.htm>, West Harlem Environmental Action <http://www.weact.org>, and the Long Island Breast Cancer Study Project <http://epi.grants.cancer.gov/LIBCSP/>.

[f] The $14 billion figure is for what Dr. Lee calls the *Health Information and Communication for America Initiative*, a broad 10-year initiative that includes statistical data management and enabling steps. See Lee PB, Abramovice BG, and Lee PR. January 2001. *Written supplement to the testimony of Dr. Philip R. Lee at the joint hearings of the workgroups on the national health information infrastructure and health statistics for the 21st century,* National Committee on Vital and Health Statistics, San Francisco, California, October 30, 2000, p. 9.

[g] The recommendations of the NCVHS are consistent with and an expansion of the recommendations contained in two publications: (1) Committee on Enhancing the Internet for Health Applications: Technical Requirements and Implementation Strategies, Computer Science and Telecommunications Board, Commission on Physical

Sciences, Mathematics, and Applications, National Research Council. 2000. *Networking health: Prescriptions for the Internet.* Washington, DC: National Academy Press. Available online at http://www.nap.edu/books /0309068436/html/ and (2) President's Information Technology Advisory Committee, Panel on Transforming Health Care. *Transforming health care through information technology.* February 2001. Available online at http://www.itrd.gov/pubs/pitac/pitac-hc-9feb01.pdf. NCVHS has called for the development of the NHII in several of its reports published since the late 1990s. The reports are available on the NCVHS Web site <http://www.ncvhs.hhs.gov/reptrecs.htm>.

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Interim Report

Toward a National Health Information Infrastructure

June 2000

National Committee on Vital and Health Statistics

Toward a National Health Information Infrastructure

INTERIM REPORT

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Toward a National Health Information Infrastructure

INTERIM REPORT

prepared by

The National Committee on Vital and Health Statistics
Workgroup on the National Health Information Infrastructure[1]

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 technologic 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 healthcare 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.

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[1] A list of Workgroup members and staff is given in the appendix.

Consumers, patients, healthcare 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 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 healthcare 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 and 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 5 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 followup 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 3 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, and 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 be provided only 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, healthcare providers, and community health officials—and beyond the traditional medical care delivery system. However, healthcare 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 gatekeeping systems in homes, provider offices, public agencies, online commercial services, and other third parties. We also will 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 healthcare 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. Healthcare professionals, consumers, and patients all need reliable guides to high-quality online health resources. These resources include health information and services to enable informed decisionmaking; 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 ensure 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 decisionmaking, 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 healthcare 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 TV rates.

Attitudes and practices. Certain shifts in societal and professional attitudes and practices must occur. Healthcare 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 that 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 healthcare 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 past 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 healthcare 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 healthcare 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 Infrastructure, 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 healthcare 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 federal health infrastructure 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 Can$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 Infrastructure Partnerships Program (CHIPP), a 2-year, Can$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-bsi/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 online access to patient records 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 online 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, caregivers, 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, healthcare 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.

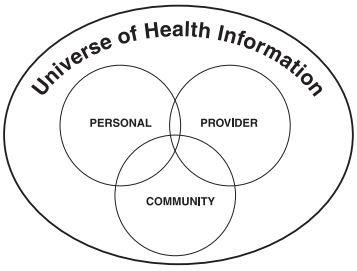
As a complement to the NHII, the NCVHS, the National Center for Health Statistics (NCHS), and the Department of Health and Human Services Data Council have begun to articulate a vision whereby health statistics in the United States will mobilize new capacities and fulfill the potential to promote and protect the country's health in the 21st century. The 21st century vision interim report proposes 10 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 decisionmaking 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, healthcare 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 healthcare 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 healthcare decisionmaking. It encompasses data about health status and health care in the format of a personal healthrecord, 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 decisionmaking by individuals and their healthcare providers. The PHD will encompass information supplied both by the individual and by his or her healthcare providers. The information will be protected by mechanisms to ensure the confidentiality and security of personal health information.

Personal Perspective: Me and My Family, by Mary Jones

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 multimedia 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, 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 online. 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 past 4 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 1,000 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 healthcare decisionmaking can be strengthened.

Healthcare 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 healthcare 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, healthcare provider information, and healthcare proxies or living wills. With the approval of the patient, healthcare providers could send clinical information to the personal health record after office visits. Individuals also may 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 healthcare 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 megadatabase. 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 nonpersonal 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 lifelong 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 healthcare 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 healthcare 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 on 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 glycated 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 healthcare delivery will overlap significantly with clinical information in medical records maintained by healthcare 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 Content of the Personal Health Dimension

A. Personal Health Record

- Patient identification information
- Emergency contact information
- Lifetime health history: summary of caregiver records from all sources of care, including immunizations, allergies, family history, occupational history, environmental exposures, social history, medical history, treatments, procedures, medication history, outcomes
- Lab results, e.g., EKGs; or links to results, e.g., MRI results at a radiology department data warehouse, digital images of biopsy slides, or digital video of coronary angiography
- Emergency care information, e.g., allergies, current medications, 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, dosage schedules
- Personal library of quality health information resources
- Healthcare proxies, living wills, and durable power of attorney for health care

C. Elements from the Community Health Dimension

- Local public health contact information
- Local healthcare services (e.g., 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 will be 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 healthcare provider to access specific information in the personal health record component. Individuals could preapprove 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 nonidentifiable personal information for public health assessment. Individuals could also verify whether their personal health information maintained by healthcare 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 healthcare 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 healthcare 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 healthcare 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 Healthcare 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

Healthcare 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 3 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 2 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 knowledgebase, 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 3 days, John improved and he continues to recover.

centers on the individual's healthcare patterns. The information is typically encounter-oriented and protected by mechanisms to ensure the confidentiality of each individual's healthcare 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.

What are the Healthcare 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 decisionmaking 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 healthcare 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 healthcare payers 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 healthcare 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 Healthcare 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 healthcare 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 Healthcare 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 7 days per week, 24 hours a day. If healthcare 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 healthcare team and other authorized health professionals will have access to an individual's specific and pertinent healthcare information. The healthcare information associated with a specific patient may also be communicated to payers, 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 healthcare 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 healthcare 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 Healthcare 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 healthcare information covering one or more encounters for an individual. Content of the Healthcare Provider Dimension also will 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, laboratories, or radiology information systems. The healthcare provider dimension will also include appropriate community health information, necessary for full understanding of a patient's health concerns.

Core Content of the Healthcare Provider Dimension

A. Patient Record Elements

- Patient identification information
- Sociodemographic identifiers (gender, birthday, age, race/ethnicity, marital status, living arrangements, education level, 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, 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 Healthcare 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 (e.g., economic status and population age)
- Community health resources (e.g., home health services)
- Community health (e.g., possible environmental hazards at home, work, school, or in the community at large)

Who uses the Healthcare Provider Dimension?

The HCPD is primarily for healthcare providers at or near the point of care. Healthcare providers include physicians, nurses, allied health professionals, and home healthcare professionals. They will be able to access healthcare 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 payers. 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 healthcare 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 7 days per week, 24 hours per day. If healthcare 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 healthcare institutions, and/or State or Federal laws and regulations. Physicians, nurses, allied health professionals, and home healthcare professionals may have access to essential data in the patient record appropriate to the patient situation.

The confidentiality of healthcare 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 healthcare 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 technologic solutions, standards, and privacy and confidentiality legislation. The measure of success will be a healthcare 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 technologic safeguards, including appropriate security and permissions, to protect the confidentiality of data from other dimensions.

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.

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 healthcare 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, 6 hospitals, 5 home health agencies, and 10 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. In addition, 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.

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 subpopulations, mechanisms to identify health needs of subpopulations 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 healthcare 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 crosscutting 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 healthcare 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 his or her 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 Federal health agencies. These reports help each office make comparisons with 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 Federal 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. Healthcare providers will send patient encounter information from which all personally identifiable information has been removed for public health monitoring of population health status and healthcare 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 Federal, 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 healthcare 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 nonidentifiable 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 of 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 healthcare providers, and healthcare 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 the Healthcare 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
- Healthcare 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 on whether 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 be linked only 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 policymakers, including legislators and staff, population health researchers, Schools of Public Health or similar academic institutions, healthcare providers, and members of the general public with an interest in population health information also will 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 locations such as local, State, and Federal public health agencies and other pertinent government offices; public and private hospitals and health care clinics; academic and research institutions; and 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 nonpersonal community information and other nonsensitive resources would generally not be limited.

Where will contents of the Community Health Dimension be stored?

Legal and marketplace 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 exist only 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 policymakers to make better use of existing information in their ongoing 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, healthcare 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 will be presented to the Secretary of Health and Human Services, the HHS Data Council, HHS agencies, and Congress in 2001.

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8. Appendix

Department of Health and Human Services
National Committee on Vital and Health Statistics
Workgroup on a National Health Information Infrastructure

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John R. Lumpkin, M.D., M.P.H., Chair
Director
Illinois Department of Public Health
Springfield, Illinois

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

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

Richard K. Harding, M.D.
Clinical Professor of Psychiatry and Pediatrics
Vice Chairman, Clinical Services
Neuropsychiatry and Behavioral Science
University of South Carolina
Columbia, South Carolina

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

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

Kepa Zubeldia, M.D.
Vice President, Technology
Envoy Corporation
Kaysville, Utah

STAFF

Mary Jo Deering, Ph.D., Lead Staff
Director of Health Communications
Office of the Secretary, DHHS
Washington, D.C.

Mike Carleton
Director
Office of Information Technology
Office of the Secretary, DHHS
Washington, D.C.

Betsy D'Jamoos
Deputy Assistant Secretary for Policy
Initiatives, DHHS
Washington, D.C.

Theresa Krol
Health Care Financing Administration
Baltimore, Maryland

Dena S. Puskin, Sc.D.
Director
Office of the Advancement of Telehealth
Health Resources and Services Administration
Rockville, Maryland

Steven J. Steindel, Ph.D.
Centers for Disease Control and Prevention
Chamblee, Georgia

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