Appendix A
Commissioner Biographies

CHAIR:
Scott Wallace, J.D., M.B.A.
President & CEO
The National Alliance for Health Information Technology

Scott Wallace was appointed as the first president and CEO of The National Alliance for Health Information Technology (Alliance) in 2003. During his time at the Alliance, the organization has made great strides in ensuring, on behalf of its members, that healthcare IT issues are addressed thoughtfully and fairly, with solutions built around the consensus positions that the Alliance has helped the field to reach.

Scott previously was the principal owner of Great Lakes Capital, a financial, commercial, and business development consulting firm with a major focus in technology. Prior to starting Great Lakes Capital, Scott led several technology-based companies. He served as president and CEO of PowerClip Co, a wireless products company; president and CEO of Eichrom Industries, an advanced materials and specialty chemical company that earned a spot on *Inc.* magazine's 1996 list of the 500 fastest growing companies in America, and vice president and general counsel for GCI, a venture capital fund.

Scott earned a jurist doctorate from the University of Chicago Law School, a master's degree with honors in business administration from the University of Chicago Graduate School of Business, and has a bachelor's degree in economics from Duke University. He started his career practicing corporate and transactional law at Kirkland & Ellis in Chicago.

He was recently named to Modern Healthcare's 100 Most Powerful.

Simon P. Cohn, M.D., M.P.H., F.A.C.E.P., F.A.C.M.I.
Associate Executive Director, Health Information Policy
Kaiser Permanente

Simon P. Cohn, M.D., M.P.H. is the Associate Executive Director, Health Information Policy for Kaiser Permanente. Kaiser Permanente is the nation's largest nonprofit integrated healthcare delivery system serving 8.4 million members in nine states and the District of Columbia. Dr. Cohn is a nationally recognized expert on issues related to HIPAA Administrative Simplification, healthcare data management, clinical and administrative classifications, and the electronic transmission of healthcare data. He has been a leader in Kaiser Permanente's efforts to develop comprehensive health information systems to support both the delivery of healthcare and health research.

Dr. Cohn is Chair of the National Committee on Vital and Health Statistics (NCVHS), the main public advisory committee to U. S. Department of Health and Human Services on health information policy, HIPAA, and the national health information infrastructure. Additionally, he is a member of the AMA Common Procedural Terminology (CPT) Editorial Panel and the National Uniform Claims Committee (NUCC). He was a member of the Institute of Medicine's Committee on Data Standards for Patient Safety. In 2002, Dr. Cohn was a recipient of the President's Award from the American Medical Informatics Association for his contributions to the field and was also elected a Fellow of the American College of Medical Informatics.

He is board certified in Emergency Medicine and a Fellow of the American College of Emergency Physicians.

Don E. Detmer, M.D., M.A., F.A.C.M.I.
President and CEO
American Medical Informatics Association

Don E. Detmer, M.D., M.A., is President and Chief Executive Officer of the American Medical Informatics Association. He is also Professor Emeritus and Professor of Medical Education in the Department of Health Evaluation Sciences at the University of Virginia and Senior Associate of the Judge Institute of Management, University of Cambridge. He is a trustee of the Nuffield Trust of London, co-chair of the Blue Ridge Academic Health Group, and research director of the J&J Centre for Advancing Health Information, based in Brussels.

Dr. Detmer is a lifetime Associate of the National Academies, and a fellow of AAAS, Academy Health, and the American Colleges of Medical Informatics, Surgeons, and Sports Medicine. From 1999-2003 he was the Dennis Gillings Professor of Health Management and Director, Cambridge University Health at the Judge Institute of Management, Cambridge's business school. Prior to the years in England, he was Vice President for Health Sciences at the Universities of Virginia and Utah and on the faculty at the University of Wisconsin-Madison. He is immediate past chairman of the Board on Health Care Services of the IOM as well as the National Committee on Vital and Health Statistics. He has also chaired the Board of Regents of the National Library of Medicine.

Dr. Detmer's education includes a medical degree from the University of Kansas with subsequent training at the National Institutes of Health, the Johns Hopkins Hospital, Duke University Medical Center, the Institute of Medicine, and Harvard Business School. His M.A. is from the University of Cambridge. Dr. Detmer's research interests include contributions to national health information policy, quality improvement, administrative medicine, vascular surgery, sports medicine, and master's level educational programs for clinician-executives.

Vicky B. Gregg, R.N.
President and CEO
BlueCross BlueShield of Tennessee

Vicky B. Gregg became CEO of BlueCross BlueShield of Tennessee in February 2003. BlueCross BlueShield headquarters is in Chattanooga, Tennessee, and is the state's largest provider of healthcare services. The company was instrumental in assisting the state in the implementation of the TennCareSM program, a Medicaid expansion program that currently provides healthcare coverage to 25 percent of the State's population. BlueCross BlueShield of Tennessee also provides Medicare intermediary services in 46 states including Part A operations in Tennessee and New Jersey. The not-for-profit company has over 4,000 employees and annualized paid claims of over $14 billion.

Before becoming CEO, Mrs. Gregg served as President and Chief Operating Officer at BlueCross BlueShield of Tennessee overseeing all aspects of the company's day-to-day operations. A nurse by education, Mrs. Gregg has over 25 years of experience in diverse healthcare environments including clinical care, hospital administration, long term care, and healthcare benefits and financing. She served as President and CEO of Volunteer State Health Plan, a subsidiary of BlueCross BlueShield of Tennessee and one of the largest Medicaid Health Maintenance Organizations in the country. Prior to joining BlueCross, Mrs. Gregg served as a Vice President for Humana with responsibility for Kentucky, Ohio, and Indiana. In her role she managed all models of managed care, including preferred provider, staff, group, and academic models. She has been a noted speaker on healthcare market evolution, implications of managed care for academic medicine, Medicaid managed care, rural healthcare delivery, and healthcare reform policy implications related to the uninsured.

Mrs. Gregg serves on numerous boards including the BlueCross BlueShield Association, Council for Affordable Quality Healthcare (CAQH), University of Tennessee Chattanooga Foundation, Chattanooga State Community College Foundation, The Enterprise Center, Nashville Healthcare Council, Tennessee Healthcare Consortium for Nursing, Allied Arts of Chattanooga, United Way of Chattanooga, the Women's Leadership Institute, and the National Institute for Health Care Management. She is an adjunct faculty member of East Tennessee State University Department of Nursing and has served on numerous appointed

Gary A. Mecklenburg, M.B.A.
President and CEO
Northwestern Memorial HealthCare

Gary A. Mecklenburg is president and CEO of Northwestern Memorial HealthCare in Chicago. He joined the organization in 1985 as President and CEO of Northwestern Memorial Hospital after five years as president of St. Joseph's Hospital and Franciscan Health Care, Inc. in Milwaukee. Mr. Mecklenburg began his career in 1970 at the University of Wisconsin Hospitals, and from 1977-1980 served as administrator of Stanford University Hospital and Clinics.

Mr. Mecklenburg is a nationally recognized leader in the healthcare field. Under his leadership, Northwestern Memorial has become one of the nation's leading teaching hospitals with a reputation for both clinical and management excellence. He is a frequent speaker and guest lecturer and serves on the Advisory Board for the Kellogg Graduate School of Management of Northwestern University.

Among his many professional activities, Mr. Mecklenburg is a past chairman of the board of trustees of the American Hospital Association and of the Illinois Hospital Association. He is currently chairman of the board of the Health Forum and of the Healthcare Research and Development Institute; and he was founding chairman of the National Alliance for Health Information Technology. Mr. Mecklenburg serves on the boards of directors of the Institute for Healthcare Improvement; the National Center for Healthcare Leadership; Becton, Dickinson and Company; Regency Hospital Company; and Cogent Healthcare.

Mr. Mecklenburg received his Bachelor of Arts degree from Northwestern University and a Master of Business Administration degree from the University of Chicago.

Herbert Pardes, M.D.
President and CEO
NewYork Presbyterian Hospital

Herbert Pardes, M.D., President and CEO of NewYork-Presbyterian Hospital, has an extensive background in healthcare and academic medicine. His origins are in the field of psychiatry, and he chaired three departments of psychiatry before becoming Vice President for Health Sciences and Dean of the Faculty of Medicine at the College of Physicians & Surgeons of Columbia University. He is nationally recognized for his broad expertise in education, research, clinical care, and health policy, and as an ardent advocate of support for academic medicine. As President and CEO of NewYork-Presbyterian, Dr. Pardes has embraced a clinical mission to provide each patient with the highest quality care delivered in the most compassionate manner.

Dr. Pardes served as Director of the National Institute of Mental Health (NIMH) and U.S. Assistant Surgeon General during the Carter and Reagan Administrations (1978-84). He has also served as President of the American Psychiatric Association (1989).

Dr. Pardes left NIMH in 1984 to become Chairman of the Department of Psychiatry at Columbia University's College of Physicians & Surgeons and in 1989 was also appointed Vice President for Health Sciences for Columbia University and Dean of the Faculty of Medicine at the College of Physicians & Surgeons.

He served as Chairman of the Association of American Medical Colleges (AAMC) for 1995-96 and was Chairman of the AAMC's Council of Deans for 1994-95. In addition, he served two terms as Chairman of the New York Association of Medical Schools.

Dr. Pardes received his medical degree from the State University of New York-Downstate Medical Center (Brooklyn) in 1960. He received his Bachelor of Science degree summa cum laude from Rutgers University in 1956. He completed his internship and residency training in psychiatry at Kings County Hospital in Brooklyn and also did psychoanalytic training at the New York Psychoanalytic Institute.

Dr. Pardes chaired the Intramural Research Program Planning Committee of the NIH from 1996-1997, served on the Presidential Advisory Commission on

Consumer Protection and Quality in the Healthcare Industry, and is President of the Scientific Council of the National Alliance for Research on Schizophrenia and Depression. He serves on numerous editorial boards, has written over 130 articles and chapters on mental health and academic medicine topics, and has negotiated and conducted international collaborations with a variety of countries including India, China, and the former Soviet Union.

Dr. Pardes has earned numerous honors and awards, including election to the Institute of Medicine of the National Academy of Sciences (1997), the Sarnat International Prize in Mental Health (1997), and the U.S. Army Commendation Medal (1964) and elected to the American Academy of Arts and Sciences (2002).

Thomas M. Priselac, M.P.H.
President and CEO
Cedars-Sinai Health System

Thomas M. Priselac is President and Chief Executive Officer of the Cedars-Sinai Health System—a position he has held since January 1994.

Mr. Priselac has been associated with Cedars-Sinai since 1979. Prior to being named President and CEO, he was Executive Vice President from 1988 to 1993. Before joining Cedars-Sinai, he was on the executive staff of Montefiore Hospital in Pittsburgh.

He has served on many boards in the healthcare field over the years and currently serves as Chair-Elect of the Association of American Medical Colleges, as well as the Los Angeles Chamber of Commerce where he chairs the Health Care Committee. A past member of the American Hospital Association Board of Directors, he also formerly chaired the Hospital Association of Southern California, the California Healthcare Association, and the Association of American Medical Colleges Council of Teaching Hospitals. He also serves as an adjunct Faculty member of the UCLA School of Public Health.

A native of Pennsylvania, Mr. Priselac obtained a bachelor's degree in Biology from Washington and Jefferson College in Pennsylvania, and a master's in Public Health, Health Services Administration and Planning from the University of Pittsburgh.

Ivan Seidenberg, M.B.A.
Chairman and CEO
Verizon Communications

Ivan Seidenberg is chairman of the Board and chief executive officer for Verizon. On November 6, 2003, Verizon announced that Mr. Seidenberg would become chairman of the Board effective January 1, 2004. He has served as the sole CEO since April 1, 2002.

As chief executive of Bell Atlantic, and previously of NYNEX, Ivan Seidenberg was instrumental in reshaping the communications industry through two of the largest mergers in its history: the merger of Bell Atlantic and NYNEX in 1997 and the Bell Atlantic merger with GTE in 2000. He also led efforts in September 1999 to form Verizon Wireless, the nation's largest cellular business composed of the wireless assets of Bell Atlantic, GTE, and Vodafone Airtouch.

Mr. Seidenberg began his communications career more than 38 years ago as a cable splicer's assistant. His career has encompassed numerous operations and engineering assignments, including various leadership positions at AT&T and NYNEX.

He has a long-standing commitment to education and is a strong proponent of connecting students and teachers to technology. He championed a special rate for schools and libraries to connect to the Internet. Mr. Seidenberg's activism to provide electronic access to young people led to his involvement with The New York Hall of Science and Pace University, on whose boards he serves.

Mr. Seidenberg also champions diversity both within and outside the company. Under his leadership, the company has made great strides in increasing minority employment and initiated a partnership with the U.S. Small Business Administration to increase the company's purchasing from minority suppliers. Verizon's commitment to diversity has been widely recognized, with the company being cited by Fortune magazine in its list of "The 50 Best Companies for Minorities."

Besides his directorships at The Hall of Science and Pace University, Mr. Seidenberg serves on the board of directors of Honeywell, the Museum of Television and Radio, the Verizon Foundation, and Wyeth.

He earned a Bachelor of Arts degree in mathematics from City University of New York and a master's degree in business administration and marketing from Pace University.

Fredrick W. Slunecka, F.A.C.H.E.
Regional President
Avera McKennan

Fredrick W. Slunecka has been CEO of Avera McKennan Hospital & University Health Center, a 490-bed acute care facility affiliated with Avera Health System since 1989. He is responsible to a local board of trustees and the Avera Health Board of Directors for the operation of a $600 million organization with nearly 5,000 employees and a medical staff of 500 physicians. Major services offered include invasive cardiology, orthopedics, neurosciences, oncology including bone marrow transplant, nephrology including kidney and pancreas transplant, neonatology, obstetrics/gynecology, pediatrics, behavioral health services, inpatient rehabilitation, trauma services, helicopter and fixed wing ambulance services, home health, hospice, durable medical equipment, a 90-bed skilled nursing facility, a 100 apartment unit retirement community, and a fitness center. Residency and teaching programs in family practice, internal medicine, psychiatry, and adolescent psychiatry are offered with the University of South Dakota School of Medicine. Avera McKennan has been a national leader in telemedicine services and provides e-ICU services to several rural hospitals. Avera McKennan has received numerous accolades including Most Wired, Top 100 in Cardiology, Distinguished Hospital by Healthgrades, and Magnet Status for Nursing Care.

Mr. Slunecka is a fellow of the American College of Healthcare Executives and is involved in many civic organizations.

He received his master's degree in hospital administration from the University of Minnesota and his bachelor's degree in political science from the University of South Dakota.

William W. Stead, M.D.
Director, Informatics Center
Associate Vice-Chancellor for Health Affairs
Professor, Medicine and Biomedical Informatics
Vanderbilt University Medical Center

William W. Stead, M.D., is Professor of Medicine and Biomedical Informatics, Director of the Informatics Center and Associate Vice-Chancellor for Health Affairs at Vanderbilt University Medical Center. The Informatics Center brings together research and education in biomedical informatics with provision of the Medical Center's operation and decision support infrastructure. In addition to serving as the Medical Center's Chief Information Officer, Dr. Stead is Chief Information Architect for Vanderbilt University and Chairman of the Vanderbilt Center for Better Health. The Center for Better Health was established in June 2002 to help accelerate change in healthcare through optimal use of information technology.

Dr. Stead received his B.A. and M.D. from Duke University where he also served residencies in Internal Medicine and Nephrology. As an undergraduate in the 1960s, he was a member of the team that developed the Cardiology Databank, one of the first clinical epidemiology projects to change practice by linking outcomes to process. As a faculty member in Nephrology, he was the physician in the physician-engineer partnership that developed The Medical Record (TMR), one of the first practical computer-based patient record systems. He helped Duke build one of the first patient-centered hospital information systems. He has led (as PI) two prominent academic health centers, Duke in the 1980s, and Vanderbilt in the 1990s, through both planning and implementation phases of large-scale, Integrated Advanced Information Management System (IAIMS) projects. At Vanderbilt, his team has been successful in creating informatics techniques for linking information into clinical workflow, in overcoming the cultural barriers to changing practice to take advantage of these techniques, and in reducing the cost and time required to implement enterprise-wide information technology infrastructure.

Dr. Stead is a Founding Fellow of both the American College of Medical Informatics and the American Institute for Engineering in Biology and Medicine, and a member of the Institute of Medicine of the National Academies. He is currently Chairman of the Board of Regents of the National Library of Medicine and serves on the Computer Science and Telecommunication Board of the National Research Council. He was the founding Editor-in-Chief of the Journal of the American Medical Informatics Association, and served as President

of the American Association for Medical Systems and Informatics and the American College of Medical Informatics.

In October 2004, Dr. Stead was appointed to the Commission on Systemic Interoperability.

In addition to his academic responsibilities, Dr. Stead is a Director of HealthStream and Director of NetSilica.

DESIGNATED FEDERAL OFFICIAL:
Donald A.B. Lindberg, M.D.
Director
National Library of Medicine

Donald A.B. Lindberg, M.D., is a scientist who has pioneered applying computer technology to healthcare beginning in 1960 at the University of Missouri. In 1984, he was appointed Director of the National Library of Medicine, the world's largest biomedical library (annual budget $275 million; 690 career staff). From 1992-1995 he served in a concurrent position as founding Director of the National Coordination Office for High Performance Computing and Communications (HPCC) in the Office of Science and Technology Policy, Executive Office of the President. In 1996, he was named by the HHS Secretary to be the U.S. Coordinator for the G-7 Global Health Applications Project.

In addition to an eminent career in pathology, Dr. Lindberg has made notable contributions to information and computer activities in medical diagnosis, artificial intelligence, and educational programs. Before his appointment as NLM Director, he was Professor of Information Science and Professor of Pathology at the University of Missouri-Columbia. He has current academic appointments as Clinical Professor of Pathology at the University of Virginia and Adjunct Professor of Pathology at the University of Maryland School of Medicine.

Dr. Lindberg was elected the first President of the American Medical Informatics Association (AMIA). As the country's senior statesman for medicine and computers, he has been called upon to serve on many boards including the Computer Science and Engineering Board of the National Academy of Sciences, the National Board of Medical Examiners, and the Council of the Institute of Medicine of the National Academy of Sciences.

Appendix B
American Health Information Community Charter

Appendix C
Past Recommendations

Recommendations from Past Reports

On Healthcare, Information Technology, Patient Safety, Privacy, National Security, Computerized Medical Records, Standards, and Interoperability

Compiled May 17, 2005

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Existing laws or regulations affording individuals greater protection than the safeguard requirements should be retained, and those providing less protection should be amended to meet the basic standards set by the safeguards. In particular, we recommend:

- That the Freedom of Information Act be amended to require an agency to obtain the consent of an individual before disclosing in personally identifiable form exempted category data about him, unless the disclosure is within the purposes of the system as specifically required by statute.
- That pending such amendment of the Act, all Federal agencies provide for obtaining the consent of individuals before disclosing individually identifiable exempted-category data about them under the Freedom of Information Act.
- That the Fair Credit Reporting Act be amended to provide for actual, personal inspection by an individual of his record along with the opportunity to copy its contents, or to have copies made; and that the exceptions from disclosure to the individual now authorized by the Fair Credit Reporting Act for medical information and sources of investigative information be omitted.

In light of our inquiry into the statistical-reporting and research uses of personal data in administrative record-keeping systems, we recommend that steps be taken to assure that all such uses are carried out in accordance with five principles:

First, when personal data are collected for administrative purposes, individuals should under no circumstances be coerced into providing additional personal data that are to be used exclusively for statistical reporting and research. When application forms or other means of collecting personal data for an administrative data system are designed, the mandatory or voluntary character of an individual's responses should be made clear.

Second, personal data used for making determinations about an individual's character, qualifications, rights, benefits, or opportunities, and personal data collected and used for statistical reporting and research, should be processed and stored separately.

Third, the amount of supplementary statistical-reporting and research data collected and stored in personally identifiable form should be kept to a minimum.

Fourth, proposals to use administrative records for statistical reporting and research should be subjected to careful scrutiny by persons of strong statistical and research competence.

Fifth, any published findings or reports that result from secondary statistical-reporting and research uses of administrative personal data systems should meet the highest standards of error measurement and documentation.

In addition, we recommend that all personal data in such systems be protected by statute from compulsory disclosure in identifiable form. Federal legislation protecting against compulsory disclosure should include the following features:

- The data to be protected should be limited to those *used exclusively for statistical reporting or research*. Thus, the protection would apply to statistical-reporting and research data derived from administrative records, and kept apart from them, but not to the administrative records themselves.
- The protection should be limited to data *identifiable with, or traceable to, specific individuals*. When data are released in statistical form, reasonable precautions to protect against "statistical disclosure" should be considered to fulfill the obligation not to disclose data that can be traced to specific individuals.
- The protection should be specific enough to qualify for non-disclosure under the Freedom of Information Act exemption for matters "specifically exempted from disclosure by statute." 5 U.S.C. 552(b)(3).

- The protection should be available for data in the custody of all statistical-reporting and research systems, whether supported by Federal funds or not.
- Either the data custodian or the individual about whom data are sought by legal process should be able to invoke the protection, but only the individual should be able to waive it.
- The Federal law should be controlling; no State statute should be taken to interfere with the protection it provides.

Use of the Social Security Number

We take the position that a standard universal identifier (SUI) should not be established in the United States now or in the foreseeable future. By our definition, the Social Security Number (SSN) cannot fully qualify as an SUI; it only approximates one. However, there is an increasing tendency for the Social Security number to be used as if it were an SUI. There are pressures on the Social Security Administration to do things that make the SSN more nearly an SUI.

We believe that any action that would tend to make the SSN more nearly an SUI should be taken only if, after careful deliberation, it appears justifiable and any attendant risks can be avoided. We recommend against the adoption of any nationwide, standard, personal identification format, with or without the SSN, that would enhance the likelihood of arbitrary or uncontrolled linkage of records about people, particularly between government and government-supported automated personal data systems.

We believe that until safeguards against abuse of automated personal data systems have become effective, constraints should be imposed on use of the Social Security number. After that the question of SSN use might properly be reopened.

As a general framework for action on the Social Security number, we recommend that Federal policy with respect to use of the SSN be governed by the following principles:

First, uses of the SSN should be limited to those necessary for carrying out requirements imposed by the Federal government.

Second, Federal agencies and departments should not require or promote use of the SSN except to the extent that they have a specific legislative mandate from the Congress to do so.

Third, the Congress should be sparing in mandating use of the SSN, and should do so only after full and careful consideration preceded by well advertised hearings that elicit substantial public participation. Such consideration should weigh carefully the pros and cons of any proposed use, and should pay particular attention to whether effective safeguards have been applied to automated personal data systems that would be affected by the proposed use of the SSN. (Ideally, Congress should review all present Federal requirements for use of the SSN and determine whether these existing requirements should be continued, repealed, or modified.)

Fourth, when the SSN is used in instances that do not conform to the three foregoing principles, no individual should be coerced into providing his SSN, nor should his SSN be used without his consent.

Fifth, an individual should be fully and fairly informed of his rights and responsibilities relative to uses of the SSN, including the right to disclose his SSN whenever he deems it in his interest to do so.

RECOMMENDATION 3.2 DESCRIBING ANALYTIC METHODS

The committee recommends that a health database organization report the following for any analysis it releases publicly:

- general methods for ensuring completeness and accuracy of their data;
- a description of the contents and the completeness of all data files and of the variables in each file used in the analyses;
- information documenting any study of the accuracy of variables used in the analyses.

RECOMMENDATION 3.3 MINIMIZING POTENTIAL HARM

The committee recommends that, to enhance the fairness and minimize the risk of unintended harm from the publication of evaluative studies that identify individual providers, each HDO should adhere to two principles as a standard procedure prior to publication: (1) to make available to and upon request supply to institutions, practitioners, or providers identified in an analysis all data required to perform an independent analysis, and to do so with reasonable time for such analysis prior to public release of the HDO results; and (2) to accompany publication of its own analyses with notice of the existence and availability of responsible challenges to, alternate analyses of, or explanation of the findings.

RECOMMENDATION 3.4 ADVOCACY OF DATA RELEASE: PROMOTING WIDE APPLICATIONS OF HEALTH-RELATED DATA

To foster the presumed benefits of widespread applications of HDO data, the committee recommends that health database organizations should release non-person-identifiable data upon request to other entities once those data are in analyzable form. This policy should include release to any organization that meets the following criteria:

- it has a public mission statement indicating that promoting public health or the release of information to the public is a major goal;
- it enforces explicit policies regarding protection of the confidentiality and integrity of data;
- it agrees not to publish, redisclose, or transfer the raw data to any other individual or organization; and
- it agrees to disclose analyses in a public forum or publication.

The committee also recommends, as a related matter, that health database organizations make public their own policies governing the release of data.

RECOMMENDATION 4.1 PREEMPTIVE LEGISLATION

The committee recommends that the U.S. Congress move to enact preemptive legislation that will:

- establish a uniform requirement for the assurance of confidentiality and protection of privacy rights for person-identifiable health data and specify a Code of Fair Health Information Practices that ensures a proper balance among required disclosures, use of data, and patient privacy;
- impose penalties for violations of the act, including civil damages, equitable remedies, and attorney's fees where appropriate;
- provide for enforcement by the government and permit private aggrieved parties to sue;
- establish that compliance with the act's requirements would be a defense to legal actions based on charges of improper disclosure; and

- exempt health database organizations from public health reporting laws and compulsory process with respect to person-identifiable health data except for compulsory process initiated by record subjects.

RECOMMENDATION 4.2 DATA PROTECTION UNITS

The committee recommends that health database organizations establish a responsible administrative unit or board to promulgate and implement information policies concerning the acquisition and dissemination of information and establish whatever administrative mechanism is required to implement these policies. Such an administrative unit or board should:

- promulgate and implement policies concerning data protection and analyses based on such data;
- develop and implement policies that protect the confidentiality of all person-identifiable information, consistent with other policies of the organization and relevant state and federal law;
- develop and disseminate educational materials for the general public that will describe in understandable terms the analyses and their interpretation of the rights and responsibilities of individuals and the protections accorded their data by the organization;
- develop and implement security practices in the manual and automated data processing and storage systems of the organization; and
- develop and implement a comprehensive employee training program that includes instruction concerning the protection of person-identifiable data.

RECOMMENDATION 4.3 RELEASE OF PERSON-IDENTIFIED DATA

The committee recognizes that there must be release of patient-identified data related to the processing of health insurance claims. The committee recommends, however, that a health database organization *not* release person-identifiable information in any other circumstances *except* the following:

- to other HDOs whose missions are compatible with and whose confidentiality and security protections are at least as stringent as their own;
- to individuals for information about themselves;
- to parents for information about a minor child except when such release is prohibited by law;
- to legal representatives of incompetent patients for information about the patient;
- to researchers with approval from their institution's properly constituted Institutional Review Board;
- to licensed practitioners with a need to know when treating patients in life-threatening situations who are unable to consent at the time care is rendered; and
- to licensed practitioners when treating patients in all other (non-life-threatening) situations, *but only with the informed consent of the patient*.

Otherwise, the committee recommends that health database organizations not authorize access to, or release of, information on individuals with or without informed consent.

RECOMMENDATION 4.4 RESTRICTING EMPLOYER ACCESS

The committee recommends that employers not be permitted to require receipt of an individual's data from a health database organization as a condition of employment or for the receipt of benefits.

The committee recommends that an HDO report the following for any analysis it releases publicly:

- general methods for ensuring completeness and accuracy of data;
- a description of the contents and the completeness of all data files and of the variables in each file used in the analyses;
- information documenting any study of the accuracy of variables used in the analyses (Recommendation 3.2).

THE FOLLOWING IS THE SAME AS RECOMMENDATION 4.1

The committee recommends that the U.S. Congress move to enact preemptive legislation that will:

- establish a uniform requirement for the assurance of confidentiality and protection of privacy rights for person-identifiable health data and specify a Code of Fair Health Information Practices that ensures a proper balance among required disclosures, use of data, and patient privacy;
- impose penalties for violations of the act, including civil damages, equitable remedies, and attorney's fees where appropriate;
- provide for enforcement by the government and permit private aggrieved parties to sue;
- establish that compliance with the act's requirements would be a defense to legal actions based on charges of improper disclosure; and
- exempt health database organizations from public health reporting laws and compulsory process with respect to person-identifiable health data except for compulsory process initiated by record subjects (Recommendation 4.1).

From ***Standards for Medical Identifiers, Codes, and Messages Needed to Create an Efficient Computer-stored Medical Record*** (1994)

RECOMMENDATIONS

1. The American Medical Informatics Association (AMIA) recommends the use of the SSN as the patient identifier at the present time. In addition, we recommend the addition of a self-check digit to the SSN to reduce errors of identification whenever the number is hand-entered by an operator. Other options for patient identifiers should be explored for the long haul.
2. We suggest that the Health Care Financing Administration (HCFA) consider using alphanumeric codes (to reduce the number of key strokes needed to enter the identifier to a practical number), and that the Universal Physician Identifier Number (UPIN) be expanded to include all health care providers for the purpose of provider identification.
3. For the next five years, all private and government care agencies should use published health care informatics message standards as a starting point for all new applications involving applicable internal and external health care information transmissions. Different published standards would apply to different kinds of communications, depending upon the subject matter and kind of communication as described below.

4. AMIA recommends that HL7 be used for within-institution transmission of orders, clinical observations, and clinical data (including test results); admission, transfer, and discharge records; and charge and billing information.

5. ASTM E1238 should be used for most interchanges of clinical data between institutions. HL7, which is a practical superset of ASTM E1238, is an alternative when tighter linkages are desired.

6. ACR-NEMA should be used for the transmission of radiologic images and for message transmissions within PACS.

7. AMIA recommends the use of ASTM E1394 for communication of information from laboratory instruments to computer systems.

8. AMIA suggests that the NCPDP be used for communication of prescription billing information and eligibility information between the community pharmacies and third-party payers.

9. AMIA suggests the use of ASC X12's standards for billing and remittance transactions between a health care provider and a third-party payer.

10. AMIA recommends its (ASTM E1460, or "Arden Syntax") use for the transmission of medical logic modules.

11. AMIA recommends its (ASTM E1467) use for the transmission of such EEG and EMG signals.

12. ANSI Z39.50 is a draft standard for transmitting requests for bibliographic information to bibliographic retrieval systems. AMIA recommends that it be considered for all such communications.

13. AMIA recommends that during the initial five years of standards development, the federal government invest in efforts to integrate and extend these standards to all health care messages. Furthermore, we suggest that the federal government build public-domain translators between the current message systems to permit future integration of systems. The translators should be submitted as ANSI and/or IS0 standards, and would be based on the object modeling framework being developed by the joint working group created by the HISPP Message Standards Developers Subcommittee (MSDS) and coordinated by IEEE MEDIX for modeling.

14. With advice from AHCPR and CPRI, and in coordination with ANSI HISPP and the message standards developers, they should have the formal responsibility for developing these standards.

15. Codes are needed to address (at least, the following) subject domains:

    - Drugs (e.g., penicillin V)
    - Diagnoses (e.g., pneumonia, heart failure)
    - Symptoms and findings (e.g., fatigue, swollen ankle)
    - Anatomic sites (e.g., right lower lobe of lung)
    - Microbes and etiologic agents (e.g., E. coli)
    - Clinical observations (e.g., blood pressure, oral intake, physical examination of heart)
    - Patient outcome variables and functional status (e.g., SF-36, Hamilton depression score, Inter-Study TYPE variables)
    - Medical devices (e.g., hip implant, tongue blades)
    - Units of measure

2. All healthcare organizations, professional groups, and private and public purchasers should pursue six major aims; specifically, health care should be safe, effective, patient-centered, timely, efficient, and equitable.

3. Congress should continue to authorize and appropriate funds for, and the Department of Health and Human Services should move forward expeditiously with the establishment of monitoring and tracking processes for use in evaluating the progress of the health system in pursuit of the above-cited aims of safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity. The Secretary of the Department of Health and Human Services should report annually to Congress and the President on the quality of care provided to the American people.

4. Private and public purchasers, healthcare organizations, clinicians, and patients should work together to redesign healthcare processes in accordance with the following rules:

    - *Care based on continuous healing relationships*. Patients should receive care whenever they need it and in many forms, not just face-to-face visits. This rule implies that the health-care system should be responsive at all times (24 hours a day, every day) and that access to care should be provided over the Internet, by television, and by other means in addition to face-to-face visits.

    - *Customization based on patient needs and values*. The system of care should be designed to meet the most common types of needs, but have the capability to respond to individual patient choices and preferences.

    - *The patient as the source of control*. Patients should be given the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them. The health system should be able to accommodate differences in patient preferences and encourage shared decision-making.

    - *Shared knowledge and the free flow of information*. Patients should have unfettered access to their own medical information and to clinical knowledge. Clinicians and patients should communicate effectively and share information.

    - *Evidence-based decision making*. Patients should receive care based on the best available scientific knowledge. Care should not vary illogically from clinician to clinician or from place to place.

    - *Safety as a system property*. Patients should be safe from injury caused by the care system. Reducing risk and ensuring safety require greater attention to systems that help prevent and mitigate errors.

    - *The need for transparency*. The health care system should make information available to patients and their families that allows them to make informed decisions when selecting a health plan, hospital, or clinical practice, or choosing among alternative treatments. This should include information describing the system's performance on safety, evidence-based practice, and patient satisfaction.

    - *Anticipation of needs*. The health system should anticipate patient needs, rather than simply reacting to events.

    - *Continuous decrease in waste*. The health system should not waste resources or patient time.

    - *Cooperation among clinicians*. Clinicians and institutions should actively collaborate and communicate to ensure an appropriate exchange of information and coordination of care.

5. The Agency for Health Care Research and Quality should identify not fewer than 15 priority conditions, taking into account frequency of occurrence, health burden, and resource use.

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 on-line/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.

management programs that would provide evidence-based treatment of chronic diseases, services to detect and minimize the consequences of common geriatric syndromes, services to meet the preventive and acute care needs of the enrolled chronically ill population, and extended outreach and coordination with social and environmental services.

- Information and communications technology—A major component of these demonstrations should be the expanded use of Information and Communications Technology (ICT) to improve care for the chronically ill.
- Benefits, Co-payments, Provider Payments, and Accountability—Demonstration sites should be given the flexibility under Medicare and other insurance programs to innovate in such areas as benefits coverage, beneficiary co-payments, provider payments, and accountability.
- Learning collaboratives and community-wide educational efforts—Each demonstration site, with assistance from the National Library of Medicine and the Agency for Healthcare Research and Quality (AHRQ), should engage in efforts to assist clinicians and patients in gaining access to scientific knowledge, practice guidelines, certified protocols, identified best practices, and decision support tools.

The 21st-century healthcare system should deliver far greater value than is currently the case. Patients have a right to demand—and healthcare leaders have an obligation to act now to ensure that they receive—care that is safe, effective, patient-centered, timely, efficient, and equitable. The committee believes the proposed demonstration projects would represent a substantial step in that direction.

From ***The Future of the Public's Health in the 21st Century*** (2002)

RECOMMENDATIONS

1. The Secretary of the Department of Health and Human Services (DHHS), in consultation with states, should appoint a national commission to develop a framework and recommendations for state public health law reform. In particular, the national commission would review all existing public health law as well as the Turning Point Model State Public Health Act and the Model State Emergency Health Powers Act; provide guidance and technical assistance to help states reform their laws to meet modern scientific and legal standards; and help foster greater consistency within and among states, especially in their approach to different health threats.
2. All federal, state, and local governmental public health agencies should develop strategies to ensure that public health workers who are involved in the provision of essential public health services demonstrate mastery of the core public health competencies appropriate to their jobs. The Council on Linkages between Academia and Public Health Practice should also encourage the competency development of public health professionals working in public health system roles in for-profit and nongovernmental entities.
3. Congress should designate funds for the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) to periodically assess the preparedness of the public health workforce, to document the training necessary to meet basic competency expectations, and to advise on the funding necessary to provide such training.
4. Leadership training, support, and development should be a high priority for governmental public health agencies and other organizations in the public health system and for schools of public health that supply the public health infrastructure with its professionals and leaders.

5. A formal national dialogue should be initiated to address the issue of public health workforce credentialing. The Secretary of DHHS should appoint a national commission on public health workforce credentialing to lead this dialogue. The commission should be charged to determine if a credentialing system would further the goal of creating a competent workforce and, if applicable, the manner and time frame for implementation by governmental public health agencies at all levels. The dialogue should include representatives from federal, state, and local public health agencies, academia, and public health professional organizations who can represent and discuss the various perspectives on the workforce credentialing debate.

6. All partners within the public health system should place special emphasis on communication as a critical core competency of public health practice. Governmental public health agencies at all levels should use existing and emerging tools (including information technologies) for effective management of public health information and for internal and external communication. To be effective, such communication must be culturally appropriate and suitable to the literacy levels of the individuals in the communities they serve.

7. The Secretary of DHHS should provide leadership to facilitate the development and implementation of the National Health Information Infrastructure (NHII). Implementation of NHII should take into account, where possible, the findings and recommendations of the National Committee on Vital and Health Statistics (NCVHS) working group on NHII. Congress should consider options for funding the development and deployment of NHII (e.g., in support of clinical care, health information for the public, and public health practice and research) through payment changes, tax credits, subsidized loans, or grants.

8. DHHS should be accountable for assessing the state of the nation's governmental public health infrastructure and its capacity to provide the essential public health services to every community and for reporting that assessment annually to Congress and the nation. The assessment should include a thorough evaluation of federal, state, and local funding for the nation's governmental public health infrastructure and should be conducted in collaboration with state and local officials. The assessment should identify strengths and gaps and serve as the basis for plans to develop a funding and technical assistance plan to assure sustainability. The public availability of these reports will enable state and local public health agencies to use them for continual self-assessment and evaluation.

9. DHHS should evaluate the status of the nation's public health laboratory system, including an assessment of the impact of recent increased funding. The evaluation should identify remaining gaps, and funding should be allocated to close them. Working with the states, DHHS should agree on a base funding level that will maintain the enhanced laboratory system and allow the rapid deployment of newly developed technologies.

10. DHHS should develop a comprehensive investment plan for a strong national governmental public health infrastructure with a timetable, clear performance measures, and regular progress reports to the public. State and local governments should also provide adequate, consistent, and sustainable funding for the governmental public health infrastructure.

11. The federal government and states should renew efforts to experiment with clustering or consolidation of categorical grants for the purpose of increasing local flexibility to address priority health concerns and enhance the efficient use of limited resources.

12. The Secretary of DHHS should appoint a national commission to consider if an accreditation system would be useful for improving and building state and local public health agency capacities. If such a system is deemed useful, the commission should make recommendations on how it would be governed and develop mechanisms (e.g., incentives) to gain state and local government participation in the accreditation effort. Membership on this commission should include representatives from CDC, the Association of State and Territorial Health Officials, the National Association of County and City Health Officials, and nongovernmental organizations.

13. CDC, in collaboration with the Council on Linkages between Academia and Public Health Practice and other public health system partners, should develop a research agenda and estimate the funding needed to build the evidence base that will guide policy making for public health practice.

14. The Secretary of DHHS should review the regulatory authorities of DHHS agencies with health-related responsibilities to reduce overlap and inconsistencies, ensure that the department's management structure is best suited to coordinate among agencies within DHHS with health-related responsibilities, and, to the extent possible, simplify relationships with state and local governmental public health agencies. Similar efforts should be made to improve coordination with other federal cabinet agencies performing important public health services, such as the Department of Agriculture and the Environmental Protection Agency.

15. Congress should mandate the establishment of a National Public Health Council. This National Public Health Council would bring together the Secretary of DHHS and state health commissioners at least annually to

    1. Provide a forum for communication and collaboration on action to achieve national health goals as articulated in *Healthy People 2010*;

    2. Advise the Secretary of DHHS on public health issues;

    3. Advise the Secretary of DHHS on financing and regulations that affect governmental public health capacity at the state and local levels;

    4. Provide a forum for overseeing the development of an incentive-based federal–state-funded system to sustain a governmental public health infrastructure that can assure the availability of essential public health services to every American community and can monitor progress toward this goal (e.g., through report cards);

    5. Review and evaluate the domestic policies of other cabinet agencies for their impact on national health outcomes (e.g., through health impact reports) and on the reduction and elimination of health disparities; and

    6. Submit an annual report on their deliberations and recommendations to Congress.

The Council should be chaired by the Secretary of DHHS and co-chaired by a state health director on a rotating basis. An appropriately resourced secretariat should be established in the Office of the Secretary to ensure that the Council has access to the information and expertise of all DHHS agencies during its deliberations.

Community

16. Local governmental public health agencies should support community-led efforts to inventory resources, assess needs, formulate collaborative responses, and evaluate outcomes for community health improvement and the elimination of health disparities. Governmental public health agencies should provide community organizations and coalitions with technical assistance and support in identifying and securing resources as needed and at all phases of the process.

17. Governmental and private-sector funders of community health initiatives should plan their investments with a focus on long-lasting change. Such a focus would include realistic time lines, an emphasis on ongoing community engagement and leadership, and a final goal of institutionalizing effective project components in the local community or public health system as appropriate.

Health Care Delivery System

18. Adequate population health cannot be achieved without making comprehensive and affordable health care available to every person residing in the United States. It is the responsibility of the federal government to lead a national effort to examine the options available to achieve stable health care coverage of individuals and families and to assure the implementation of plans to achieve that result.

deepen their knowledge of public health subject matter and provide public health workers with a foundation in communication theory, messaging, and application.

24. The television networks, television stations, and cable providers should increase the amount of time they donate to public service announcements (PSAs) as partial fulfillment of the public service requirement in their Federal Communications Commission (FCC) licensing agreements.

25. The FCC should review its regulations for PSA broadcasting on television and radio to ensure a more balanced broadcasting schedule that will reach a greater proportion of the viewing and listening audiences.

26. Public health officials and local and national entertainment media should work together to facilitate the communication of accurate information about disease and about medical and health issues in the entertainment media.

27. Public health and communication researchers should develop an evidence base on media influences on health knowledge and behavior, as well as on the promotion of healthy public policy.

Academia

28. Academic institutions should increase integrated interdisciplinary learning opportunities for students in public health and other related health science professions. Such efforts should include not only multidisciplinary education but also interdisciplinary education and appropriate incentives for faculty to undertake such activities.

29. Congress should increase funding for Health Resources and Services Administration (HRSA) programs that provide financial support for students enrolled in public health degree programs through mechanisms such as training grants, loan repayments, and service obligation grants. Funding should also be provided to strengthen the Public Health Training Center program to effectively meet the educational needs of the existing public health workforce and to facilitate public health worker access to the centers. Support for leadership training of state and local health department directors and local community leaders should continue through funding of the National and Regional Public Health Leadership Institutes and distance-learning materials developed by HRSA and the Centers for Disease Control and Prevention (CDC).

30. Federal funders of research and academic institutions should recognize and reward faculty scholarship related to public health practice research.

31. The committee recommends that Congress provide funds for CDC to enhance its investigator-initiated program for prevention research while maintaining a strong Centers, Institutes, and Offices (CIO)-generated research program. CDC should take steps that include:

    - expanding the external peer review mechanism for review of investigator-initiated research;
    - allowing research to be conducted over the more generous time lines often required by prevention research; and
    - establishing a central mechanism for coordination of investigator-initiated proposal submissions.

32. CDC should authorize an analysis of the funding levels necessary for effective Prevention Research Center functioning, taking into account the levels authorized by P.L. 98–551 as well as the amount of prevention research occurring in other institutions and organizations.

33. NIH should increase the portion of its budget allocated to population- and community-based prevention research that: