White Paper: Summary of Discussions at a Planning Meeting on The Roles of Information Infrastructure in Health and Health Care

National Research Council

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Meeting of October 5-6, 1993 on The Roles of Information Infrastructure in Health and Health Care

ABSTRACT

Intending to conduct a study on roles for national information infrastructure in support of health and health care, the Computer Science and Telecommunications Board and the Institute of Medicine (IOM) of the National Research Council (NRC, described in Appendix A) hosted a meeting on October 5-6, 1993, to advise the NRC on the issues that such a study should address.

This meeting was chaired by C. Everett Koop, former surgeon general, and Edward H. Shortliffe, professor of medicine and of computer Science at Stanford University. Meeting participants (Appendix B) were drawn from both the health care community and the information technology community so that each could learn from the other. The meeting agenda is given in Appendix C.

Meeting participants endorsed the concept that the NRC should undertake a project that would articulate a vision of how national information infrastructure could help to reduce the cost of health care, increase its quality, and improve access to it. In addition, the project would identify critical barriers to the realization of that vision and develop strategies for how those barriers might be overcome.

1 - The Clinical Context

Dr. Koop reviewed the clinical context that frames the issue of using information infrastructure for health and health care in the United States. He focused on four main themes:

Health care reform is inevitable. There is so much dissatisfaction across the nation with the current health care system that the only real questions on health care reform are when we will have it and how much of it we will have. Regardless of the details of the reform package that is ultimately adopted, an information infrastructure will have to be in place to support health care reform.

Health education is central to health care reform. Health education involves two components:

Education of health professionals. Medical education is much more than medical school. It involves premedical education and college; science education for junior high and high school students; teaching teachers at all grade levels how to seek out and nurture the aptitude for science, medicine, and the health professions; internships and residencies after medical school; and continued learning throughout a provider's lifetime. Each of these phases of education provide opportunities for health care professionals to learn how to use information technology to improve the quality of the care they deliver. For example, many residents and interns are learning to use a hand-held computer to retrieve information when needed rather than relying on memory or journal articles. For lifetime learning, information technology should be used to bring the expertise of the medical center to the setting where providers are caring for patients.

Education of the public. A major opportunity to reduce the costs of health care lies in preventing disease and promoting health. Prevention of disease is key to the future of American health and U.S. health care. Health care providers must learn to instruct the public in the techniques of behavioral change necessary to promote healthful practices and appropriate lifestyle changes. These efforts must be directed not only at individual patients but also at whole communities. National information infrastructure can be used to deliver this information to the public using the same channels that will be used for other educational purposes.

Primary care is the backbone of U.S. medicine. The primary care physicians and other health professionals who serve the forty percent of the U.S. population outside of major urban areas are perhaps the most important target of the communications system that a national information infrastructure can support. Such communication will provide continuing education, contact with specialists, and access to the most current medical information, all of which will reduce some of the disincentives for providers to practice in smaller communities.

Outcomes research is needed to support intelligent choices about health care. National information infrastructure offers the opportunity to assemble data needed for outcomes research of various types. The effectiveness of treatments and diagnostic techniques must be established. The success rates of individual doctors and hospitals in treating specific diagnoses and performing certain surgical procedures should be assessed. Utilization patterns can be compared across different regions. Perhaps the most important research needed is examining patient values as they are reflected in measures of patient preferences for and satisfaction with various medical procedures. Indeed, when patient values are taken into account, patients may be more satisfied by low-cost, low-technology medicine and surgery than by more expensive services.

2 - The National Information Infrastructure

Dr. Shortliffe reviewed the origins of the national information infrastructure and its suitability for health-related applications. The concept of information infrastructure refers to the hardware needed to connect information systems (e.g., cables, switches, computers, and other components needed to route and manage traffic), the architecture for arranging these components, and the software, services, support, and operating procedures, policies, and regulations that makes the hardware useful for acquiring, transporting, managing, and processing information. A national information infrastructure (NII) refers to such resources and services that are accessible on a national basis.

NII is an evolving concept. Certain elements of an NII exist today (e.g., the Internet,[1] the telephone system, broadcast media such as radio and television, cable television), but for the most part they operate independently. NII in the future is expected to include not only the hardware used to transmit, store, process, and display voice, data, and images, but also a multitude of technologies for handling or processing information (computers, telephones, video, fiber optics, satellites, and so on) that will be integrated in what appears to users as one seamless web.

The notion of connecting a wide range of health-related computer applications has been evolving for about 20 years. In 1973, the first non-defense-related computer connected to the Arpanet (an early component of the Internet) was a system in the area of health care and health care research. A variety of health-related applications of information infrastructure have been demonstrated; however, with few exceptions, these applications have been site-specific solutions that cannot be generalized to other settings.

More recently (in 1986), the National Library of Medicine (NLM) sponsored a Long Range Planning Panel on Medical Informatics, which noted that "widely disseminated medical information systems will require high-

bandwidth communications to allow access to the computational, data, and information resources needed for health care and research."

Furthermore, it articulated the goal that by the end of the next decade, there will be a national computer network for use by the entire biomedical community, both clinical and research professionals. The network will have advanced electronic mail features, as well as capabilities for large file transfer, remote computer log-in, and transmitted graphics protocols. It will either be part of a larger national network . . . or will have gateways to other federally sponsored networks.

In 1986, these statements were mostly of academic interest. They generated some enthusiasm within the NLM, but in the absence of a congressional mandate, the NLM had no way to act on the Panel's ideas. More recently, the confluence of two major trends has dramatically increased the level of national attention to health-related information infrastructure. First, the pressure for health care reform-specifically, the desire to restrain health care costs, to improve quality, and to increase access-puts a great premium on making more effective use of health-related information. Second, the number of parties using the Internet has grown remarkably and the technologies that support the Internet and other electronic networking enterprises have developed rapidly. Both trends have attracted attention in the Congress[2] and the Administration,[3] as well as other important work undertaken in the private sector.[4]

3 - Roles of National Information Infrastructure in Health and Health Care

Meeting participants discussed a number of health-related uses for an NII that build on capabilities for communication, data collection, and access to data and other forms of information. They emphasized that applications must respond to the information needs of health professionals, consumers, and policy makers. Identifying those needs and articulating how to meet them through an NII may require assistance from technologists, but technological solutions crafted in ignorance of these needs may not be readily accepted by their intended users.[5] Health-related uses of an NII discussed or referenced at the meeting include:

Distribution of and access to health-related information: Health professionals are finding it difficult to keep us with the rapid growth of knowledge in their fields. Computer-mediated interactions with databases of health-related research and literature could help health care professionals find relevant information as needed. More sophisticated applications would enable health professionals to use intelligent "agents" to monitor the expanding literature and call out articles on specified topics of interest. Other applications could support electronic distribution of practice guidelines and outcomes management to care givers and their automatic integration into providers' information systems devoted to patient care.

Public access to health-related information through personal health information systems: Consumers have a key role to play in reducing the cost and increasing the efficacy of the health care system by taking responsibility for maintaining personal health through preventive measures and making informed decisions about when and how to seek direct medical attention. To do their part, however, consumers need appropriate information. An NII has a major role to play in delivering to consumers easy-to-obtain and easy-to-understand health information that can help them live in a healthy manner and interact with the health care system as well-informed customers.

Support for public health surveillance and assessment: At the local, state, and national levels, public health agencies have a responsibility to collect, analyze, and disseminate information on the health status of the population and the health needs of the community. The resources offered by an NII can assist with all of these tasks and may be particularly valuable for transferring data between the local level and state or national agencies.

Access to computer-based patient records: A recent IOM study (The Computer-Based Patient Record: An Essential Technology for Health Care, National Academy Press, Washington, DC, 1991) noted that computer-based patient records could help to ensure the completeness of information available to providers at the time of interaction with patients because they could be made sharable with the appropriate parties under the appropriate circumstances. An NII would be the means through which such records could be shared among provider institutions and clinicians-a clear need for our highly mobile society.

Telemedicine: Health professionals (e.g., physicians, nurse practitioners, social workers) in remote or underserved areas (e.g., rural and inner city areas) are often isolated from the support that providers in better-served communities and in academic health centers take for granted. An NII could facilitate access to information resources and consultative services for isolated health care providers, thereby enhancing patient access to state-of-the-art health care in the communities they serve. Network-based multimedia conferencing and consultation may also be valuable for any practitioner, regardless of practice setting, when specialized services are needed.

Financial and administrative transactions: Billing and insurance claims for health care services account for the vast bulk of the administrative information associated with health care. A 1991 study asserted that some 25 percent of the U.S. health care budget is spent on administration and that a large fraction of this amount was attributable to the multitude of health care payers, each making different demands on health care providers.[6] To the extent that the same administrative procedures, information, and data formats could be required, costs could be much reduced. Administrative burdens could be dramatically reduced, and patient information could be transmitted, processed, and reviewed in a matter of minutes rather than weeks.

Support for health policy analysis: At present, the health care system and policy makers lack adequate data to make good judgments about the quality and cost of health care or the health of the public. Comprehensive information is not available on providers, patients, or the population as a whole. In many cases, the available policy-relevant data are administrative (e.g., data derived from Medicare or Medicaid reimbursement claims) rather than clinical data on a patient's condition, treatment, and functional outcome. Other datasets that rely on voluntary submission of data by providers are often incomplete and generate information of questionable value. These limitations make it difficult or impossible for analysts to determine if individual providers are giving safe, appropriate, and effective care or to document the most efficacious and cost-effective treatments for various clinical conditions (the focus of outcomes research). An NII could greatly facilitate compilation of population-based data or patient-level clinical data from patient records (with information identifying individuals removed as appropriate) into policy-relevant databases, thus minimizing inconsistencies, errors, and delay in assembling data to make such assessments.

Support for clinical trials and submission of clinical reports to federal agencies and manufacturers: New medical procedures should be tested for clinical efficacy and cost-effectiveness (outcomes research). For drugs and medical devices, manufacturers must undertake extensive pre-market clinical trials of their products as well as post-marketing surveillance to monitor the emergence of adverse reactions associated with their products. Certain diseases and adverse drug reactions are also reported to federal agencies (e.g., the Centers for Disease Control and the Food and Drug Administration, respectively). An NII could greatly facilitate the communication of clinical results and the identification of adverse reactions and side effects from patient records, thus eliminating the additional manual reporting required of clinicians today, increasing the speed with which such information is passed on to the appropriate parties, and ensuring greater completeness of that information.

Support for information needs under health care reform: The Administration plan for health care reform calls for timely access to reliable data that can be used to assess the health status of the population and the state of the health care system through "report cards" for health plans. Such data will provide feedback to health care providers on their performance. The information transfer and analytic capabilities enabled by an NII may be an essential resource.

4 - Activities To Facilitate Use of NII for Health

Meeting participants generally agreed that the obstacles to widespread use of an NII for health are more logistical, political, and financial than technological (though new technologies could well reduce the cost and increase the usability of health-related applications). A variety of health-related applications that could build on an NII have been demonstrated, thus suggesting the potential benefits of such applications. But the lack of a common information infrastructure has meant that these applications have been custom-designed and individually constructed to solve only the problems at the particular installations where these applications operate; these applications have, for the most part, been unable to take advantage of other work, and their mutual incompatibility and lack of interoperability has meant that no synergistic effects have been possible.

To promote the development and use of a common information infrastructure on which health-related (and other) applications can build, a number of activities must be undertaken by appropriate parties, notably government and vendors. Meeting participants discussed a number of activities that would help to overcome the logistical, political, and financial impediments to using NII for health purposes:

Establishing a policy framework for health-related applications of an NII: A coherent policy framework is a pre-condition for widespread use of an NII for health purposes. A key point noted by meeting participants is that there is no governing focal point of responsibility for coordinating policy for health-related NII issues across federal agencies. Meeting participants believed that as a result, federal policy and leadership in this area has been lacking. They particularly underscored the need for federal policy regarding health-related applications of an NII to go beyond collecting and managing the data necessary for assessing health care reform. A consistent, coherent, and comprehensive policy framework would address issues such as:

The need for and possible roles of a national chief health information architect. Such an official would have resources and institutional influence to coordinate federal policies relating to health-related information across agencies. Such a person would need to consider government data needs as well moving information out to provider institutions and practitioners.

Potential incentives for the health-related use of an NII. "Non-market" incentives may be necessary to create a degree of connectivity sufficient to make it worthwhile for users to use NII routinely and for developers to work on new applications. For example, at a time when few users transmit claims or payment data via electronic data networks, financial incentives to do so could increase connectivity to such networks. Once large numbers of users have such connections, applications developers would find it worthwhile to provide other services and any individual user could have reasonable confidence that another potential user was also connected.

Possible options for information policy. Matters related to data collection, use, comparability, accuracy, completeness, security, and privacy will need attention before an NII will be used extensively for health-related purposes.[7]

Possibilities for pre-emptive federal legislation. At present, health care is governed by a patchwork of different state laws and regulations. However, the concept of national information infrastructure for health presupposes some uniformity from state to state. Matters related to compensation, accountability, and liability (among others) will need attention.[8]

Possible roles of government in promoting NII for health. Some meeting participants noted that a government role may be appropriate when the private sector does not find it financially viable to be involved in research and development. Government may have an important role to play in the continuing support of a testbed that is several years ahead of the commercial infrastructure. Other participants, citing early federal support for the Arpanet that has led to an Internet now used increasingly for commercial purposes,[9] argued that government support for an initial infrastructure can result in a critical mass upon which the private sector can then build.

Developing standards: Many existing health-related applications of information technology are unable to exchange information with each other. The promulgation and acceptance of appropriate standards are a pre-requisite for "plug-and-play" applications that will operate in many environments and communicate with one another. These standards cover a variety of domains: codes, knowledge/logic, terminology, descriptors, and connectivity. (As one concrete example, there are no technological barriers in principle to transporting entire computer-based patient records over a network, but ensuring that a sent record is actually usable when it is received is a matter of in-place standards that specify the format of such a record.) In some cases (e.g., medical or nursing terminology), consensus on standards remains remote, while in others (e.g., connectivity or the transport of medical laboratory data), standards are relatively well developed. Even in the case of relatively well developed standards, however, the relevant stakeholders (e.g., vendors, users) have not accepted a set of standards governing the products they sell and use, and the pace of applications development has slowed as a result.

Adopting an open-systems philosophy: Related to standards is a philosophy of open systems. Historical experience with computing suggests that when applications developers can count on the availability of a set of useful "operating system" services whose characteristics are widely known, a very large number of different applications will become available to the user community. Accordingly, a similar philosophy must guide the underlying design of an NII. Most meeting participants were encouraged that those involved in the design of NII appear to understand this point, although much remains to be done to translate this philosophy into practice.

Developing a system of universal patient and provider identifiers: Without a system of public and provider identifiers, many potential advantages of an NII are not achievable; these include simplification of administrative information requirements, better matching of patients and their records, and construction of databases with longitudinal records for individuals. Any system of universal identifiers must, however, address the legitimate privacy and security concerns that such identifiers raise for the public.

Providing education and training: Adoption of new technologies is often difficult to achieve. In some instances, implementations of new technology are not well suited to the needs of the user, but in other instances, potential users do not perceive how a new technology could help improve their routine practices. (This premise is at the heart of the "business practice re-engineering" that is receiving considerable attention in industry today.) Health care providers and the public may need to be shown how their health-related needs could be better met through the use of information infrastructure and must be trained in how to use this technology. Training in professional schools may be needed to introduce health care providers to new information technologies and prepare providers to use those technologies effectively.

Undertaking demonstration projects: Such projects would illustrate the impact of health-related NII applications on cost-effectiveness and quality. They could help educate policy makers, administrators, public health officials, health care providers, and the public about the value that an NII could have for health matters. Successful development of high-payoff applications that can be implemented in a relatively short time would help build public support for further development and deployment of other health-related applications of information infrastructure. As importantly, high-payoff applications that can be implemented in the short term can help to promote wide acceptance of a particular choice of architecture. Two of many potential demonstration projects offered by meeting participants (as examples only) were the use of the health security card in selected large managed-care organizations and the development of a national immunization registry connected to an NII to stimulate the development of health-related infrastructure components.

Establishing a clearinghouse on NII and health: Meeting participants were aware of a large number of activities, both past and present, that are relevant to health applications for an NII, and they expressed concern that future efforts not "reinvent the wheel." A clearinghouse could provide information on past activities (so that the lessons of previous experience could be accommodated in present efforts), present activities (so that duplication of effort today could be reduced), and funding opportunities (so that researchers and developers could seek support for their efforts).

5 - Issues Affecting the Implementation of an NII for Health-related Purposes

Meeting participants discussed many issues that must be resolved for health-related NII activities to gain acceptance and grow. These include:

Sharing information: The concept of sharing is the underpinning of an NII. Data must be shared as applications communicate with each other; a shared notion of system and network architecture will facilitate the development of "plug-and-play" applications; shared analytical methodologies will facilitate analysis of data contained in national databases; and shared metrics for evaluation will help establish consensus regarding the efficacy and utility of an NII.

Assuring data quality and appropriateness: The people who generate and collect data should have incentives to ensure that those data are accurate and timely, and making data useful to those who collect them can be an incentive for ensuring data quality. Meeting participants were sympathetic to a premise of data collection stating that when clinical data are collected and

recorded for a purpose other than patient care, those data are likely to be less reliable, accurate, timely, and complete than the patient care data themselves. At the same time, individuals reporting data may-for entirely legitimate reasons-be inclined to provide different data under different circumstances of data collection.

Defining the appropriate role of computer-based patient records: While the IOM report on the computer-based patient record articulated many advantages of using computer-based patient records over paper records, the relationship of the computer-based patient record to an NII remains to be defined. The potential to distribute information to large numbers of recipients quickly raises important policy concerns. For example, this distribution ability may raise patient concerns about storing sensitive medical information (e.g., HIV status) in computer-based patient records. Reconciling patient sensitivities in this area with medical needs for complete information remains an outstanding issue.

Developing local, regional, and state information infrastructure: Although a national information infrastructure will be critical for some health-related activities, much of the data collection, analysis, and use will take place on local, regional, and state levels. Information infrastructure at each of those levels linked through an NII may enable more effective use of the data collected.

Resolving questions of access to patient data: To the extent that easy collection of data is facilitated by the existence and the availability of an NII for health-related purposes, demands for access to data may well increase. Those demands may, however, create disincentives for the comprehensive collection of data and could thus make records less useful. For example, a care provider may wish to collect certain data that he or she would not want to be shared with outside parties (e.g., an insurance carrier trying to make the provider more efficient, a lawyer investigating possible malpractice claims, a government regulator examining the provider's style of practice). Meeting participants generally agreed that not all parties have an equal right to obtain data about patients and provider practices. A framework must be established for deciding who will have access to what data and under what circumstances.

Clarifying intellectual property rights to information: To the extent that NII is a means by which information (e.g., published research) is disseminated electronically to clinicians and consumers, many intellectual property issues arise for those who would otherwise publish these materials in print. Furthermore, the "information" in question is not limited to articles that appear in journals; it also includes clinical guidelines and health-related software that may be useful to many clinicians or consumers across the nation. Such issues involve the appropriate degree and balancing of compensation and protection rights vs. fair use and broad access.

Integrating health-related services supported by an NII with other social or educational services: A longer-term vision of health-related applications of an NII sees these applications integrated into the complete web of social and educational service applications that would also be supported through an NII. For example, the Department of Defense is supporting development of a workstation that is designed for community-based social workers who need access to information ranging from bus schedules to clinic schedules to local doctors' appointments. Pre-hospital emergency medical services offer another example of the need to integrate into the health information system data generated and collected by individuals and organizations in other sectors. Specifically, pre-hospital care may be provided by a fire department, a police department, a private company, or a volunteer service, but such entities are not a standard part of the health care environment where clinical information would be easily collected or where they would normally connect to health information systems. A third example might be health information systems that serve private homes directly.

Developing good user interfaces: Regardless of the underlying technology, the interface to an NII needs to offer health care providers and consumers a critical mass of utility with a net benefit (taking into account the need to change routines) and reduce or eliminate the need to perform boring, repetitive, time-consuming tasks. These interfaces must initially require little or no change in the usual practices of users but also facilitate re-engineering of traditional practices as desired or necessary.

Defining metrics of success for the health-related use of an NII: Metrics must be defined that enable decision makers to gauge the extent to which an NII is being used for health-related purposes and the success of these efforts. As importantly, these metrics should provide guidance and feedback on how to enhance applications and increase their use.

6 - An NRC Study on Information Infrastructure and Health

Given these strengths, what special role could the NRC play in studying the above issues and providing recommendations to the government, the health care industry, the health professions, and the public?

Meeting participants endorsed the notion that the NRC -- specifically the Computer Science and Telecommunications Board and the Division of Health Services of the Institute of Medicine -- should undertake a project that would articulate a vision of how the use of information could benefit clinicians, health care organizations, patients and consumers, and society at large (Box 1). In addition, the project would identify critical barriers to the realization of that vision and develop strategies for how those barriers might be overcome. Meeting participants placed special emphasis on developing a strategy to accelerate creation of standards critical to collecting and analyzing data in support of health care reform and on the need to coordinate government activities (internal and extramural) for efficient and appropriate sharing of data and information.

Finally, meeting participants stressed the need for an NRC project to produce results that would contribute in a timely manner to the national debate and deliberations on health care reform, focusing especially on the identification of key problem areas early in the project. An essential aspect of this project would be intensive dissemination efforts employing a multitude of channels for bringing the study's message to the appropriate parties. A variety of dissemination channels were discussed, including public service announcements, distribution through the Internet, video, and articles in professional and lay publications.

A formal NRC proposal that takes into account the insights developed at this planning meeting will be formulated in the near future. But for the project to become reality, funds will have to be raised. Suggestions for potential funders (and offers of assistance!) will be gratefully accepted.

BOX 1: The Charge to the NRC:

To articulate a vision of how information infrastructure can help to reduce the cost of health care, increase its quality, and improve access to it.

Key Questions

- What high-payoff public health and health care applications of information infrastructure can be implemented in a relatively short time?
- What are the social and behavioral impediments to implementing the vision?
- What are the policy and other roles of the federal government in facilitating the widespread use of information infrastructure for health-related applications?
- What are the fiscal implications of health-related information infrastructure?
- What technology issues are central to health-related applications of information infrastructure?

The initial task of the NRC project would be identify the most important issues within each of these questions that can be addressed within the resources available to the project. The committee would then develop recommendations for how these issues might be resolved.

Box 1: An NRC Study of Information Infrastructure, Health, and Health Care

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NOTES:

1. The Internet is a highly decentralized but world wide "network of networks" connecting some 2 million computers and tens of millions of users. It is used for academic, research, government, and commercial purposes.

2. For example, Senate Bill S-4 (The National Competitiveness Act of 1993) and House Bill HR-1757 (High Performance Computing and High-Speed Networking Applications Act of 1993) both single out health care as an important application area for national information infrastructure.

3. For example, in April 1993, the Working Group on Computerization of Patient Records submitted to the Secretary of the U.S. Department of Health and Human Services a report entitled Toward a National Health Information Infrastructure.

4. Examples of work undertaken in the private sector on health-related applications of information infrastructure include a white paper by the Computer Systems Policy Project on health care (Information Technology's Contribution to Healthcare Reform), which identified five generic barriers to the widespread use of information technology in health care, including commercial viability of health-related applications, professional adaptation to the use of information technology, the need to re-engineer business and clinical practices established in a paper-based environment, the lack of standards, and the lack of certain enabling technologies; the Institute of Medicine report on The Computer-Based Patient Record: An Essential Technology for Health Care (1991), which articulated the many advantages of a computer-based patient record and successfully advocated the creation of an institute to encourage the adoption of such records; the Arthur D. Little consulting firm report Can Telecommunications Help Solve America's Health Care Problems?, which estimated a possible annual savings of $36 billion through the use of four health-related telecommunications applications; and the forthcoming IOM report on Health Data in the Information Age: Use, Disclosure, and Privacy, expected in January 1994, which will address many data policy issues.

5. The cultural differences between technologists and health care professionals are quite profound. For example, terms such as "network" and "standards" have entirely different connotations to these two groups. For technologists, "health care network" might refer to the physical, wired connections between different sites for health care delivery, whereas to health care providers, "health care network" may well refer to a formal or informal association between providers.

6. Steffie Woolhandler and David Himmelstein, "Administrative Costs of U.S. Health Care", New England Journal of Medicine, Volume 324(18), 1991, pages 1253-1258.

7. The IOM report, Health Data in the Information Age: Use, Disclosure, and Privacy will address matters related to the accuracy, completeness, security, and privacy of data contained in large-scale health databases.

8. Three problem areas stand out as particularly important. State laws vary greatly with respect to the legal acceptability of electronic signatures, the acceptability of electronic vs. paper records, and the penalties for failure to respect patient confidentiality. These matters are discussed (though not resolved) in Appendix B of the IOM report on the computer-based patient record.

9. While definitive data are not available, one participant estimated that the current federal investment in the Internet accounts for less than 3% of total expenses.

Appendix A

On the National Research Council

The National Research Council (NRC) is the operating arm of the Academy complex, which includes the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine (IOM). The NRC is generally regarded as a source of impartial advice to the federal government and other policy makers that is able to bring to bear the best scientific and technical talent in the nation to answer questions

of national significance. In addition, it is able to act as a neutral party in convening meetings among multiple stakeholders on any given issue, thereby facilitating the generation of consensus on controversial issues. The NRC generally does not undertake original scientific research on its own, relying instead on the expert judgment of its committees and the existing literature and research. Projects are funded by the federal government, foundations, and industry, though NRC policy states that no funding in excess of 49% will be obtained from sources that may have a financial interest in the outcome of a project.

The Computer Science and Telecommunications Board (CSTB) of the NRC considers technical and policy issues pertaining to computer science, telecommunications, and associated technologies. The CSTB monitors the health of the computer science, computing technology, and telecommunications fields, pays attention as appropriate to the issues of human resources and information infrastructure, and initiates studies involving computer science, computing technology, and telecommunications as critical resources and sources of national economic strength.

The Division of Health Care Services of the IOM identifies important policy issues in the planning, organization, financing, and delivery of health care services--including issues of cost, quality, and access and related issues of health resources and health services research, and it oversees studies and other activities in these areas by the IOM that lead to greater understanding of these issues and contribute to productive policy decisions.

Appendix B

Planning Meeting On Information Infrastructure, Health, And Health Care
October 5-6, 1993 LIST OF PARTICIPANTS

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Appendix C

MEETING AGENDA
INFORMATION INFRASTRUCTURE AND HEALTH CARE

October 5-6, 1993
National Academy of Sciences
1055 Thomas Jefferson Street, N.W.
Washington, D.C.

Room 2004, Foundry Building

This agenda is subject to mid-course correction!

Tuesday, October 5, 1993

8:30 - 9:30 Continental breakfast in meeting room, Foundry 2004
9:30 - 9:40 Welcome and logistics (include brief review of NRC and how it works)
9:40 - 10:00 Focus and context setting: C.E. Koop on clinical issues
10:00 - 10:20 Focus and context setting: Ted Shortliffe on information infrastructure issues
10:20 - 12:00 Round-robin of meeting participants (5 minutes per person)
12:00 - 12:30 gather food for working lunch
12:30 - 1:15 Round-robin continued
1:15 - 1:30 CSPP work on health care

1:30 - 1:45 Regional database organization presentation (strongly related IOM study)
1:45 - 2:00 Pediatric EMS study; National Forum on Health Statistics (other related IOM work)
2:00 - 2:15 Break
2:15 - 3:15 Federal/State gov't issues and needs
3:15 - 4:00 Needs of parties to health care: clinicians, consumers, carriers, researchers
4:00 - 4:15 Break
4:15 - 5:30 Needs continued
5:30 - 6:45 Reception
6:45 Dinner (Working groups to address what needs to be done in short, medium, and long term?)

Wednesday, October 6, 1993

7:30 - 8:30 Continental breakfast in meeting room, Foundry 2004
8:30 - 9:45 Recap of previous day (including report of working groups)
9:45 - 10:45 Impediments to adoption of information infrastructure for health care
10:45 - 11:00 Break
11:00 - 12:15 Impediments continued
12:15 - 1:15 Lunch
1:15 - 3:30 Elaboration of NRC proposal -- what issues should be addressed, and how
3:30 Adjourn