# The Changing Nature of Telecommunications and the Information Infrastructure for Health Care

Edward H. Shortliffe, MD, PhD

Professor of Medicine and of Computer Science

Section on Medical Informatics

Stanford University School of Medicine

300 Pasteur Drive

Stanford, CA 94305-5479

ehs@camis.stanford.edu

## Introduction

Discussions at this workshop and in other forums are confirming the notion, often voiced in medical computing circles, that the use of computers and communications for health care is roughly a decade behind routine applications of the technologies for much of the rest of society. The details provided today about Citicorp, however, suggest that the gap is closer to two decades! Much *is* happening in the medical computing world, but the story is different from that for many other segments of society, and today I will try to explain some of the reasons for those differences.

It would be inaccurate to give the impression that the medical community has been oblivious to the potential role of computers and networking in biomedicine. In fact, in the early 1970s, the first node on the Arpanet that was not a defense-funded resource (either through DOD grants to academic institutions or direct military support) was the NIH-funded SUMEX-AIM resource at Stanford University School of Medicine, a machine dedicated to biomedical applications of artificial intelligence research. With the subsequent addition of many more medically-oriented nodes to the national network, a small but active segment of the biomedical community grew up with the Arpanet during its transition to the Internet of today.

Furthermore, it is revealing to look back to a prophetic 10-year-old document that was produced by a long-range planning panel for the National Library of Medicine (NLM) in 1986 [2]. Shortly after the new Director of the NLM took office in 1985, he brought together people who could help devise a grand plan for what the institution should be doing to prepare for the decades ahead. One report dealt with the future of medical informatics and 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" (p. 60). An explicit goal mentioned in the report was that "by the end of the next decade [presumably 1996], 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 the larger national network ... or will have gateways to other federally sponsored networks" (p. 65). The report includes much discussion of the Arpanet, as it was still called in 1986, as a model for the national network that would facilitate a variety of applications in biomedicine and health care delivery.

Despite this explicit call for the biomedical community to embrace the potential role of a national communications infrastructure, little happened in the intervening years. The NLM expressed an

interest in pursuing the topic, but it needed incremental funding to do much and the rationale for new efforts was extremely hard to sell to the mainstream medical community and hence to the Congress. Yet in the last year, since the passage of the High Performance Computing and Communications Act and the election of an administration with particular interests in both the national information infrastructure *and* in health reform, we have seen the awakening of interest among leaders for whom computers and telecommunications for health care had previously been viewed as an esoteric topic.

## Stimuli to Change

Some key forces are driving such changes in awareness and interest. First, the shift to managed care and capitation is changing dramatically the requirement for communication among the parties involved in health care. Insurers are demanding a basis for making comparisons among providers (both institutional and individual) and suddenly new kinds of clinical data need to be collected, communicated, and collated. Pressures to develop and manage such comparative clinical data did not exist in the past to the same extent.

Second, proposed health care reform legislation, and the resulting high profile discussions of health care financing and organization, are reinforcing and broadening the pressures on health care institutions and providers. When President Clinton introduced his health reform proposals to the Congress on September 22, 1993, he referred explicitly to the opportunities for increased efficiency, technology assessment, and cost savings offered by information technology. Computing and communications technologies have emerged as key elements in the strategic plan for eliminating waste in the health care system. Clearly such an impact will be easier claimed than achieved, but the expectations do help explain the sudden shift in interest among health planners.

There are other prominent examples of a growing societal awareness of the potential role for the national information infrastructure (NII) in supporting health reform. In April of this year, the Computer Systems Policy Project (CSPP), composed of senior executives from the major vendors of computer systems, released a report on the relevance of the NII to health care [3]. During that same month, a report commissioned by the Department of Health and Human Services, and developed by a panel formed by the American Hospital Association, was released [4]. Although the committee that drafted the report had been convened to look at issues in the creation of computer-based patient records, they soon chose to address more broadly the issues of information infrastructure required to support the notion of individual patient records. This broader view is

especially valid when one begins to envision longitudinal medical records that are tied to a mobile patient rather than to a single provider's office or to a hospital.

For those who have been interested in medical informatics and biomedical communications for some time, now is an exciting period. Key decision makers are listening and becoming very enthusiastic about seeing profound changes, both in the health care system itself *and* in the creation and use of an underlying information infrastructure. Until recently, the role of regional and national communications in support of health care has been a largely grass-roots activity, with limited shared national vision and leadership. Some of the most successful experiments have been in the area of "telemedicine", in which, for example, electronic communications have been used to provide consultation by specialists to physicians in rural, inner city, or other isolated locations. As the Internet increases in its capacity, it will be able to accommodate the kinds of voice and video transmissions that are crucial for this kind of telemedicine activity. Constraining progress, however, have been frequently voiced concerns regarding risks to the privacy and security of clinical information. Such concerns have led many health-care institutions to resist exploring modern networking technologies, both within their own walls and when considering linkage to outside networks in their communities or beyond [5].

## Recognizing the Need for Improved Clinical Data Systems

Until 1993, there was essentially no federal involvement in defining the role of the information infrastructure as it relates to the *delivery* of health care. Beginning in the late 1980s, largely through the activities of the NLM, we did see the involvement of the health sector in discussions of how the NII might support research and education in biomedicine. Unfortunately, there has been little or no knowledge of the existing NII, nor an understanding of its implications, among the leaders in the health care industry. Those few hospitals that are connected to the Internet are mostly academic institutions that have sought such connections through their main university campuses. Recently the NLM initiated a grants program to encourage more hospitals to institute Internet connections and to begin to explore the ways in which national networking could support their clinical mission.

Obstacles to the more effective use of the existing NII in healthcare, and to an informed anticipation of how emerging communications and computing technologies will affect health care, are largely logistical, political, and financial, rather than technological. About two years ago I was asked to give a talk at a conference here in Washington on gigabit networking. My message was that, for

the present, we can largely ignore biomedical gigabit networking issues and simply work to make better use of the technologies that we have today. That is not to say biomedicine could not do more with gigabit speeds in the future, but that is not the major need at present.

One way to make progress in dealing with the logistical, political, and financial barriers to acceptance of computing and communications technology has been to demonstrate the relevance of such methods to cost savings and to health reform. We are beginning to see data in the literature that demonstrate how computing holds the promise of impressive economies. One recent report, from the Regenstreif Institute at the University of Indiana Medical Center, describes a well-designed prospective trial demonstrating more than $800 in savings per patient stay in a controlled trial during which some physicians used computers to order tests and to receive reminders, whereas other providers did not use the technology [6]. As the article notes, such figures "would amount to savings of more than $3 million in charges annually for this hospital's medicine service and potentially tens of billions of dollars nationwide." The problem is that large, complex systems such as the one that has been built at Regenstreif Institute over the past 20 years could not be duplicated simply for implementation at another hospital. In the absence of standards for system integration and data sharing among instititutions, transporting a highly tuned technology from one hospital to another can be next to impossible.

Data such as those from the Indiana study are clearly needed to demonstrate the value of interinstitutional network connections and the role that the NII could play. Such fiscal data make hospital CEOs pay attention, and they are having much to do with a reassessment of how hospital data systems need to be designed and especially how they might become more clinical in their emphasis, departing from a traditional administrative and financial orientation.

Also driving the need for more clinically-oriented data systems is our current lack of data to gauge the quality or the cost of health care. Employers and insurers are increasingly choosing to contract with the hospital that can show the highest quality at the lowest cost; if an institution charges more, it must be able to show that the higher cost is associated with higher quality. If provider institutions lack the data systems that allow them to demonstrate improved outcomes over competing hospitals, they may increasingly find that they are unable to win the managed care contracts required to keep their beds full. Subjective impressions that one hospital is "better" than another hold little sway with an employer or insurer that is fighting frantically to control health care costs.

There are generally no community-wide data bases that store information on providers and patients, although there are a few experiments to develop regional health databases [5]. When there are pooled data for regions, they tend not to record patient-centered information on topics such as consumer satisfaction or functional outcomes after treatment. Similarly, there is generally no reasonable way to determine whether doctors are performing safe, appropriate and effective care, despite demands that we begin to develop the kind of data sets that allow such information to be released.

We clearly need better data collection methods than we have today. For example, clinical data sets derived from insurance claims and depending on voluntary submission of diagnostic and outcomes information by providers are often rendered useless by inconsistent compliance and information of questionable accuracy. Several recent studies regarding the health of our nation are based upon data submitted to Medicare on claims forms. Clinical information on such claims provides a limited proxy for medical reality. This helps explain the Medicare system's recent pressure for the creation of a Uniform Clinical Data Set [7]. We clearly need better ways of collecting comprehensive clinical data than to depend on insurance claims submissions. This is one of the many justifications for the recent push to see the creation of computer-based patient records [8].

## Attracting Physicians to Information Management Tools

A colleague and I recently argued that clinicians are inherently "horizontal" users of information technology [9]. By this we mean that they require a critical mass of functionality from the system they are using before routine use of the computer will be viewed as worthwhile to them. If the computer is useful only occasionally, say for one or two patients per day, then the inertia involved with going to the machine will typically prevent the effective use of that technology. But if the computer provides functionality useful for essentially every patient seen, and if that use is as good as or better than the manual methods previously available, then it is reasonable to assume that physicians will begin to turn to the computer for support. It is also important to recognize that physicians seek help with the noxious tasks associated with data management but are not interested in having computers infringe on valued tasks. Furthermore, they require intuitive interfaces that require little or no training (similar, for example, to the training required to use the telephone or, more topically, an automated teller machine).

Part of this critical mass of functionality will be made available not within the physician's local environment but via the NII. Imagine the model shown in Figure 1, in which providers are linked,

either directly or through the hospitals at which they practice, to research and public health data bases or to national repositories of patient data. When people become sick away from home, there would be tremendous utility to a system that permitted authorized health workers, say in an emergency room, both to identify you and to access key clinical data about your medical problems, allergies, medications, and the like from a centralized data resource provided via the network. Physicians could also be provided with access to third-party payers, to Medicaid/Medicare, to the Food and Drug Administration, to the Centers for Disease Control, to medical schools and their continuing education activities, to a variety of vendors such as pharmaceutical companies or software companies, to information resources such as Medline, and to patients themselves. If the network provides health workers, patients, and the public with access to all these kinds of information sources, plus with two-way communication that allows both retrieval of data plus submission of information (e.g., claims), then one can begin to imagine the appeal and the acceptability of the NII and its health-care role. There has been remarkably little planning initiated regarding the implementation of these kinds of connectivity, but I believe that Figure 1 demonstrates that the NII has the potential for a major impact on health care.
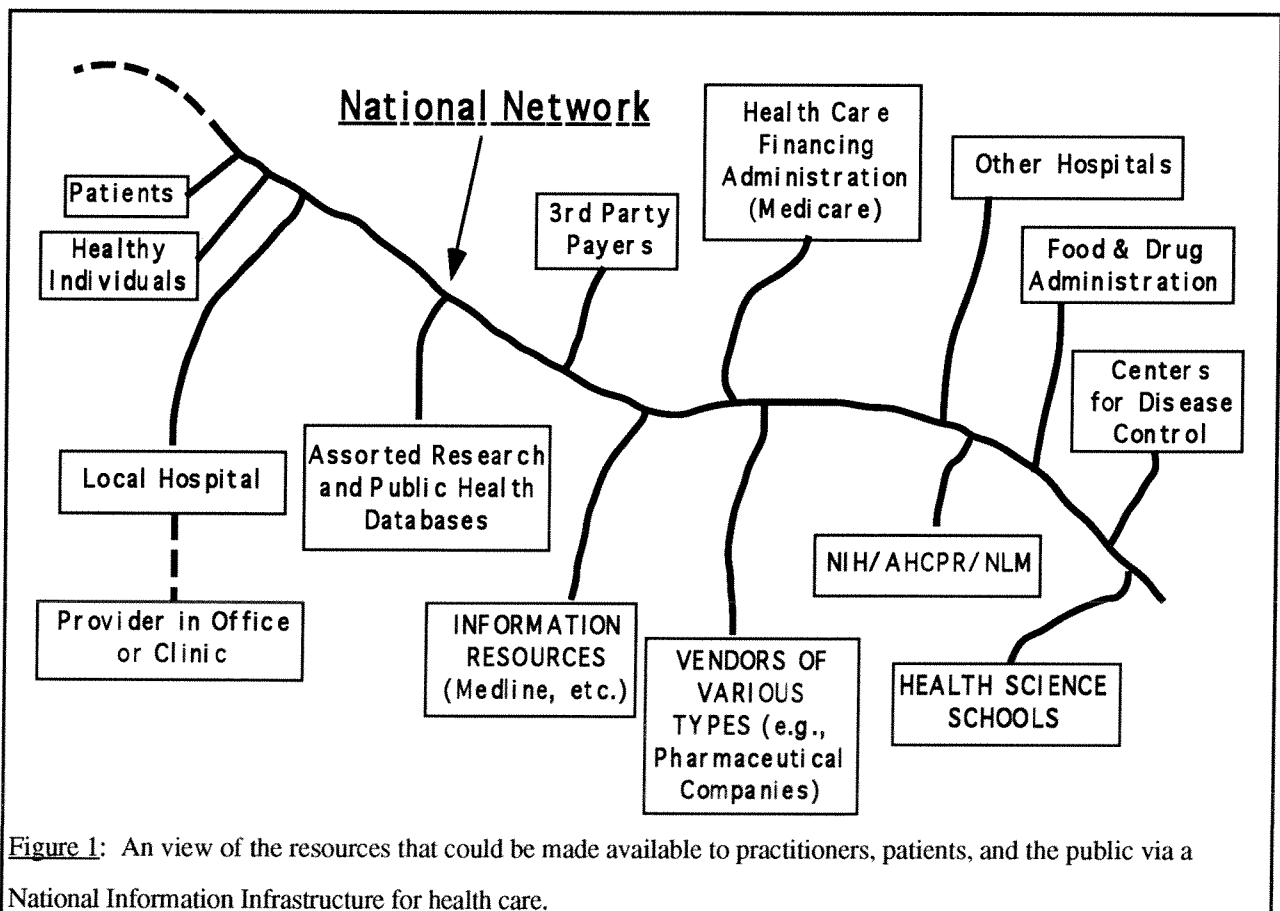


Figure 1: An view of the resources that could be made available to practitioners, patients, and the public via a National Information Infrastructure for health care.

## Example Uses of the NII for Health and Health Care

A recent workshop jointly sponsored by the Computer Science and Telecommunications Board of the National Research Council and by the Institute of Medicine offered a variety of possible uses of a national information infrastructure for health and health care. I close by summarizing those here since they follow naturally from the discussion above:

- information distribution and access, including bibliographic-retrieval software for searching the medical literature;

- population databases (regional, state, and national) with specialized interfaces that allow retrieval of subsets of patients meeting particular search criteria;

- access to longitudinal, sharable, standardized health records for individual patients—particularly important for providing continuity of care for our highly mobile society;

- telemedicine, especially to provide enhanced care and information access in underserved areas such as in rural regions or the inner city;

- personal health information systems, which would provide individuals, whether sick or healthy, with educational materials plus a personally maintained health database;

- databases for research and outcomes assessment, as previously described;

- systems to handle billing, finance, reimbursement, and eligibility determination;

- multimedia communication and video conferencing;

- implementation of practice guidelines and outcomes management advice with specialized software at the point of care that allows access to the individual guidelines that may be available locally or over the network;

- submission of clinical reports to federal agencies, such as reportable disease information to the Centers for Disease Control or adverse drug reaction reporting to the Food and Drug Administration.

## Conclusion

The future world that I have described here (assuming appropriate safeguards to protect patient privacy and confidentiality of data) offers a set of features that many observers believe would not only be acceptable to practitioners but would enhance their practices in positive ways while helping to reduce some of the waste in our current health-care system. Unlike technologies that have played a role in escalating the cost of health care in this country, there is reason to believe that computing technology, coupled with a standardized communications infrastructure, could actually eliminate waste and reduce the total health bill. In order to achieve these goals, however, a variety of enabling activities is required. Among these are the need for improved national leadership and a greater understanding of the federal role in guiding the development of standards, the education of practitioners and others regarding the role of the NII for health care, the creation of incentives, and attention to how the health-care system should reimburse those who use the information infrastructure in support of health-care delivery. Several observers have noted the need for preemptive federal legislation in the areas of privacy and confidentiality in particular, but also to deal with authentication of electronic signatures to assure their acceptability for legal documentation. The goal of developing centralized longitudinal lifelong medical records that could be accessed by providers (when authorized to do so by individual patients [5]) requires that we address the need for national patient and provider identifiers while balancing that need against the civil liberties issues involved in linking health-care identifiers with other identifiers used in our society. There is clearly a major need for training and education, not only of health professionals, but also of the public and for the development of a new cadre of medical-computing professionals who are sensitive not only to the technological issues involved but also to the realities of health-care practice, ethics, and financing. Finally, there is a major need for demonstration projects to help prove the technology's cost effectiveness and its impact on the quality of care. One complicating factor in the evolution of this field has been the difficulty in developing demonstration projects with sufficient scope, penetration, and generalizability to assure that they can provide meaningful data regarding the technology's potential impact on cost and quality.

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**Question/Answer Session Following Dr. Shortliffe's Presentation:**

MR. ROBERTS:  There is a lot of clamor these days for improving the security of the network, especially the Internet so I think Colin has got it right and that is, especially in a network that has to have universal access, you assume the network is at some level insecure and you secure the applications.  I will be curious.  The question is, for public sector areas that are critical such as health care and libraries, and intellectual property, what sort of process should we be thinking about from a policy standpoint in securing those applications?  Is it possible, for instance, to have the sort of certification of applications that the financial people can do very privately and behind closed doors applied to private sector applications?

Is it possible to apply product liability sorts of considerations to that area even in the public sector?

DR. AHO:  Colin, do you want to take that or does anyone have a perspective on that?

DR. SHORTLIFFE:  I have some thoughts about it.  I am not sure who you were asking but I will say a couple of things.  One of the intriguing problems about privacy and confidentiality of health care data is that the issue is not necessarily the security of an application per se but what somebody who has access to the data does with them.  In other words, there is potential for abuse by people who are authorized to access patient data.  That is why legal remedies with criminal penalties are required when someone misuses privileged medical information to which they have access.  There are no national standards in this area at present.  As a result, one of the big emphases I have heard in the medical area is that we need to begin to introduce some uniform penalties, probably with preemptive federal legislation about the misuse of data to which people do have valid rights of access.

As for the more generic issue of trying to prevent people from breaking into data sets, instituting appropriate certification of software has a valid role.  What you are talking about is simply having data bases out on the network with lots of different applications that could access them.  Of course, you run into the question of what should be the nature of the varied access methods that you could use to get to those data sets, independent of specific applications that may  have been written to access them.

MS. DEERING:  Mary Jo Deering in the Office of the Assistant Secretary for Health who directs the U.S. Public Health Service.  As health care is to the financial community, certainly public health is to health care and we are happy to be here.

I have a question or request to Ted Shortliffe, whose clear vision I have always appreciated, but also to people in the audience who are both in the engineering and content side. It picks up on something that Charlie Firestone said this morning about the process of dis-intermediation that is going on in society with regard to information. Actually, he then went on to say something that sounded more to me like re-intermediation or neo-intermediation. The same thing is going on in health actually, and it is a process which is parallel to the de-institutionalization of health care. Health care reform is really going to continue pressure in those directions, with an emphasis away from hospitals and high end acute care providers, toward primary care and preventive medicine and home care for that matter.

I guess my request or question, and it is specifically to Ted right now, is that wonderful sketch, I think it was about your next to the last or third to the last slide where you actually began to paint what the health information infrastructure would look like, it did not really include any of the linkages that provide, that would reflect that type of new reality in health, the linkages that would be necessary among these non-hospital institutions, non-specialty providers and perhaps the consumer so I am wondering whether, when you finally turn it in, whether you could dress it up a bit and show me because I think we would all like to see what that would look like.

DR. SHORTLIFFE: You are absolutely right. If you look at some of the later slides in the packet that I did not get to in the talk, you will see public health data bases mentioned prominently. As you know, we had a meeting on the subject of the NII and health care last week that the NRC sponsored at which I think that message was driven home loud and clear. I personally am in primary care and therefore I am sensitive to it as well. Good point.

DR. KAHN: Okay, the comment I had, question really for Ted, was we have heard form one Bob that the Internet, to certain kinds of businesses, essentially looks almost free and from another Bob we have heard that to the educational community it is virtually uneconomic at the moment. In the case of the medical community, I am sort of wondering where it fits. I think we heard from you that there is a strong motivation on the part of physicians in the hospitals to gain access to this technology. The medical profession itself, and I believe you, could provide a good, strong justification for that. In fact, I see it coming.

The question I have is whether there is any economic justification for the end patient, namely the user of the health care system having tied coupling to the Internet and if so, at what level of capability.

DR. SHORTLIFFE:  This sort of relates to Mary Jo's question.  First, when you look at what the health care field is spending on computing right now, the amount of money that it would take for any given institution to hook up to the Internet is minuscule compared to what they are spending overall in information technology, so I don't see cost as a barrier per se.  It is more the perceived benefit and how you actually would make use of the national network given the lack of standards for actual connectivity and data sharing.

The same kind of argument could be made as we begin to see the evolution of new health delivery plans.  It may well become economically beneficial for the health care providers to pay for linkages into the homes in order to provide patients with access to information that would prevent them from becoming more expensive users of the health care system.  A lot of visits to doctors are unnecessary.  If people only had more easy access to the kind of information they might need, you can imagine how this might have an impact on overuse of certain kinds of facilities.

The problem with that theory is you are hypothesizing not only an availability but an education of the end user patients and health care user which right now is unlikely.  The biggest users of health care are the people least likely to have the facilities in their homes at present, and the ones least likely to have the education that would allow them to make optimal use of such technology.  So we are talking about a major social issue that would facilitate allowing patients in their homes, and people who are non-patients who simply need access to health information, to make good use of the kind of information that might be made available.

DR. KAHN:  Is that a practical suggestion you just put out, that the doctors literally pick up that mantle somehow or hospitals?

DR. SHORTLIFFE:  It is not going to be the doctors.  If you think the doctors are in charge of the health care system, you are a few years behind.  It is going to be these health plans that begin to look for how they can compete for patients in large areas, especially in the big metropolitan areas.  How this will play out in more rural areas is another matter which I think is of great worry to people because the emphasis tends to be on the competitive marketplaces around the big cities.  However, the health plans will pay for these technologies if they find it is to their competitive advantage to do so.