D.A.B. Lindberg,
B.L. Humphreys

National Library of Medicine,
Bethesda MD, USA

The Promise

A Time of Change for Medical Informatics in the USA

1. Telecommunications, Including World Wide Web

Over a relatively short time, the telecommunications capability of American health care professionals in academic positions has increased remarkably. As an indicator, in 1993 the percentage of academic medical libraries with Internet connections was only 72%, and the percentage of community hospital libraries with Internet connections was 24%. Four years later, the figures were 96% and 72% [1]. The National Library of Medicine assisted this growth in Internet access by awarding 128 connection grants resulting in new connections for approximately 400 institutions between 1994 and 1998.

The corresponding percentage of the general population with routine access to the Internet at home or at work is hard to quantify. Data collected for the U.S. National Telecommunications and Information Administration by the U.S. Census Bureau in 1997 indicated that 37% of U.S. households owned computers, 26% had modems, and 17% used e-mail. Since 1994, the number of households with computers had increased 60%, with modems 139%, and with e-mail 397%. Affluent whites are much more likely to have computers and Internet access in the home than other population groups, but the numbers are going up in all segments of the population [2]. Undoubtedly, many more U.S. residents in all population groups have access to the Internet at work or in school than have it at home.

Some insight into the potential medical impact of the current level of connectivity can be gained by the recent experience of two NLM-sponsored telemedicine projects. In a university medical center in California, patients were sought for an experiment involving Internet access to their own medical records. The investigators had no problem recruiting participants (including university participants) who could provide their own Internet access either at home or at work. In contrast, investigators in Massachusetts found only half of the parents of high-risk newborns had routine Internet access either at home or office. Experiments involving a cross-section of population groups in other parts of the country might have found much lower percentages of connectivity.

Beyond the bare bones numbers of health care professionals, institutions, and patients connected to the Internet, there is, of course, a need to assess the quality of the connection and the extent to which this matches the medical uses to which the telecommunications are put. In the U.S. virtually all residents have telephone service. Generally, individuals at home access Internet via ordinary voice grade telephone lines, sometimes dedicated to computer use, and analog modems (typically 28-56 Kb). To obtain a faster connection, individual households may use ISDN lines or digital modems attached to the television cable services. The problems with these arrangements are variable prices for ISDN depending upon the part of the country (and the presence or absence of pricing legislation in that state), and the same variability in cable connections and willingness of the cable operators to connect digital modems. Both systems do work quite well under the right circumstances.

Recently, NLM carried out studies of the nature of end-to-end Internet service, both within the USA and also between NLM and selected overseas collaborators among the G7/8/8 countries [3]. There are, of course, many physical and circuit elements in the global Internet, and a decline in performance could be due to any of these elements. Careful monitoring of services dispelled some old misconceptions and provided a baseline for future evaluation of global telecommunications systems. For instance, before these studies we had heard many times that the speed of Internet service in Britain and on the European Continent declined precipitously "when America woke up." Our tests repeatedly showed the reverse: the decline in Internet capacity occurred when local users "woke up" to their normal business day. This was true between NLM and collaborators in Britain, Sweden and

France. It was also true between NLM and its medical collaborators in American cities in different time zones, including Los Angeles, California and Seattle, Washington.

While it is easy (perhaps even gratifying) to blame remote users or communication elements, our experiments indicated that Internet usage problems are local. Examples included major network elements simply swamped by awakening local business users, local routers (i.e., message switches) that failed to keep up with traffic demands even though the carrier lines themselves were free, problems due to the user's personal computer (e.g., an older unit too slow to keep up with input from the Internet), and software problems within the user's institution. For example, some institutions that were paying for T1 service (i.e., 1.54 Mb/sec) had firewall software so close to impenetrable that users inside the fire wall had effective Internet access comparable to that provided by a 28 Kb analog modem on a voice-grade telephone circuit. One of the goals of the G7/8 Internet performance evaluation project led by NLM is to produce a kit of test software that will allow individual users and institutions to diagnose and report the specific problems and barriers that are affecting their local performance and then monitor the effect of corrective actions taken inside the institution or by local telecommunications providers.

A number of American federal agencies are joined in a five-year effort (1997-2002) to imagine and build the Next Generation Internet (NGI). This initiative follows a presidential commitment to add 100 million US$ to the existing 1 billion US$ High Performance Computer and Communications program [4] and subsequent funding by the Congress directed toward research into the new system. While the current Internet is amazingly capable, as well as subject to additional improvement by the kind of careful incremental analysis and adjustments just described, a wholly new structure will be needed eventually. The current Internet was designed to offer highly reliable service, via adaptive routing. The spectacularly successful World Wide Web, developed at CERN [5], added high efficiency to the Internet, via the connectionless protocol. Adaptive routing and high efficiency do not ensure the data security required for routine health care uses of the Internet. In addition to security and privacy, existing and potential health applications of high-speed networks demand – or would benefit from – other features that are not part of the existing Internet. Prime among these is "Quality of Service". An analogous earlier concept was known as "video dialtone", implying that one could obtain immediate (or even scheduled) access to very-high speed telecommunication services without having to subscribe to such costly service for 24 hours per day. This may or may not be a universal need, but it is required by a number of biomedical applications.

Detailed requirements have been calculated for some individual applications. For example, a digital mammography network involving six remote sites and a central reference and interpretation service can easily benefit from (or even require) line speeds above OC3 (155 Mb/sec) for acquisition of the clinical studies and companion previous patient images and for "management" of the case even short of a definitive diagnosis. Yet this service cannot possibly occupy an entire OC3 line continuously for 24 hours per day. Beyond simply (and grossly) overspecifying line speeds required for the application, there is no way to guarantee that the requisite quality of service will be available at the times it is needed. Guaranteed quality of service is a prime topic for network research under the NGI program. The NGI effort will also examine the problems and possibilities for providing negotiated, guaranteed levels of medical data privacy within the NGI whether these are accomplished via certified application programs or as network services, or both. NGI, research will also address technical considerations such as minimizing "jitter" (e.g., imperfect alignment of moving images) and latency (time to effect a new system command). These problems are reasonably well understood by telecommunications engineers, but their implications in health care settings have not yet been well explored. To assist all this work, NLM has commissioned a study by the National Research Council's Computer Science and Telecommunications Board, "Enhancing the Internet for Medical Applications: Technical Requirements and Implementation Strategies", chaired by Edward H. Shortliffe, M.D., Ph.D. of Stanford University [6].

2. Consumer Health Information

Increasingly, health care professionals and biomedical scientists are recognizing the value and importance of providing to patients, families, and the general population access to scientific facts related to health and disease. Naturally, the availability of personal computers, the growth of Internet access, especially via the World Wide Web protocol, and the presence of a large, educated and interested public have all contributed to this development. Enthusiasm for the role that the Internet can play in providing the public with rapid access to health information has been accompanied by serious concerns about the huge quantity and variable quality of the information available [7]. This had led to the development of many sets of criteria for reviewing and rating health informatio on the Internet [8]. There is interest in coordinated national and even international projects to organize and validate electronic health information, but no overarching approach has yet developed. In the meantime a number of individual biomedical institutions or groups of institutions, including medical libraries, have stepped forward to offer their own selections of relevant and reliable information sites. Examples of such offerings include New York Online Access to Health (NOAH) [9] and HealthWeb [10].

The NLM also recognizes that the spread of the Internet and the World Wide Web provides an opportunity for the Library to participate in the important (and difficult) work of enhancing access to consumer health information. Beyond implementing free Web access to MEDLINE and other NLM online services in mid-1997, NLM has taken two additional steps: first, to establish our own Web pages designed for the consumer (http://www.nlm.nih.gov) and second to conduct an experiment in partnership with a group of U.S. public libraries (http://www.nlm.nih.gov/news/) and members of the National Network of Libraries of Medicine. On October 22, 1998, the Library introduced MEDLINEplus, which provides Web users with relatively specific subject access to selected sources of health information – from the NLM, from other components of the U.S. National Institutes of Health, other U.S. government agencies, and selected non-governmental agencies. This service covers a steadily increasing number of high-interest topics, e.g., breast cancer, diabetes and also has links to self-help groups, clearinghouses, dictionaries, lists of hospital and physicians organizations and libraries which provide health information to the public, and clinical trial information.

MEDLINEplus is a key part of a pilot project involving 37 local public library systems (more than 200 individual libraries) in 9 states and the District of Columbia, members of the National Network of Libraries of Medicine (NN/LM), the American Library Association, and Medical Library Association, and the W.K. Kellogg Foundation. The pilot public libraries were selected to represent a range of community sizes and diverse populations. The plan is to provide training to local librarians in the use of NLM's Web information services; assign each public library system to an NN/LM member library which can provide additional training, medical document delivery, and other assistance. This partnership is aimed at determining first-hand the range of persons and questions encountered, the information that might be provided that could assist the client, and to understand the kinds of demands and problems encountered by public libraries and by other health sciences libraries, many of which have long experience in serving patients, their families, and the general public. Naturally, we hope to see ways in which NLM can help public libraries and other health sciences libraries to serve members of the public who seek biomedical information.

It is an old assumption that patients, their families, and the general public need a wholly separate representation of medical information than that written for scientists and clinicians and published in the scientific literature (preferably in peer-reviewed journals with suitable references to the scholarly record). Indeed, NLM has several times in the past examined the feasibility of employing medical writers to recast key medical reports in lay language. However, since MEDLINE became freely available on the Web, the Library has learned that many members of the public are willing to make the effort to read (if necessary to re-read and study) the actual scientific articles for guidance on treatment or management of themselves, family members, or friends. In fact, many are specifically interested in seeing "the same information the doctors see". Numerous anecdotal reports document the circumstances in which lay persons have found their way through the often badly written technical literature to find medical guidance (sometimes to find a physician with special experience relevant to their concerns).

There is a general move in the U.S. to make every effort to facilitate the public's access to scientific literature – despite a paucity of evidence that such access improve health outcomes. This is compatible with the ancient traditions of libraries, including NLM, to allow access by anyone to any holding, and with democratic traditions. It is also facilitated by modern technology. We at NLM fully subscribe to the need to enhance public access to scientific information, irrespective of the current level of proof that it has direct medical and health benefits.

3. New Opportunities for International Collaboration

There are no doubt hundreds of international collaborations involving biomedical investigators in the U.S. The G7/8/8 Global Health Care Applications Project offers a new avenue for international collaboration on advanced applications of information technology to medicine and health. Although it is not a source of additional funding for U.S. scientists, the G7/8/8 umbrella can potentially add legitimacy and visibility to international medical informatics efforts.

The G7/8/8 health projects currently underway are quite diverse. In addition to the Internet end-to-end performance evaluation previously described, the U.S. is participating with Japan and Italy in an effort to assemble proper Japanese and Italian natural language equivalents for the English and Latin anatomical terms associated with the Visible Human data set. This work is being carried forward through use of international high-speed lines (e.g., T1s to Hokkaido). A Visible Human mirror site is also planned for Japan.

Within the G7/8/8 subproject on Smart Cards, the U.S. is participating via experiments being conducted by the Western Governors Association. This experiment will involve about 22,000 mothers in three Western cities. The data contained on the card include identification and a number of social services entitlements, including women's, infants', and children's Medicare/Medicaid. In addition, immunization records for the mother and her children will be recorded on the card itself. Readers for these cards are already available within the three states involved in the study. This relatively small study contrasts sharply with the experiments in Europe that involve tens of millions of cards for general identification purposes in France, Italy, and Germany. Even so, we believe there will be a distinct advantage to the United States in playing a semi-active observer role in the important studies going on in Europe. There is some possibility that France, Italy, and Germany might benefit in the long run by the more narrow experiments underway in the U.S. The U.S. smart cards can be viewed as initial studies with sharply focused specialized smart cards that are deployed in "testbed" mode. The experiences of European countries, and the more limited experiences within the U.S. will, we hope, advance the cause of electronic medical records and allow us to study a number of technical and public policy problems in the limited context of the smart card testbeds.

4. Changing Goals and Assumptions

Smart cards are just one of many technological developments that prompt the rethinking of some long-held goals and assumptions, including the computer-based patient record. The actual conceptual model that has underlain the host of experimental and commercial patient record systems over the past 30 years has always been that of numbers and characters printed on paper or displayed on radiant devices. Basically, this is the teletype version of the written patient record. One might call this the ASCII character model, except that the systems that formed the model actually rested upon even earlier encoding schemes such as Baudot, Hollerith, and Gray [11-13].

The evolution of systems away from teletype-style records is gradual now, but sure. The newer experimental systems are really image-based [14,15]. They emphasize use of the World Wide Web interface via Internet, with ready availability via thumbnail sketches to records of radiographs, CT scans, magnetic resonance images, PET scans, full motion angiograms, ECGs, and even histological material from the surgical pathology laboratories. Strangely, pictures of the patient seem so far to be missing, but critical digital telemedicine studies are appearing [16].

Another subtle change in the nature of the patient record is the growing use of e-mail exchanges between patients and physicians. One can easily imagine in the future this most authentic source of symptoms, principal complaints, follow-up data, and advice to supplant the old fashioned transcription of written records. Indeed a formal standard for patient-physician e-mail to be included in the patient record has already been proposed [17]. As with all changes in medical practice, some welcome the new opportunity [18]; some warn of new legal liabilities [19]. In contrast to our impression (based on several public discussions) that patient-physician e-mail is reasonably frequent and geographically widespread, one information study recently suggested that only 1-2 percent of U.S. physicians actually provide the opportunity for e-mail with patients [20]. A very basic and well-worn assumption is that best information practice is to completely separate data files from the retrieval engines (in artificial intelligence terms, the equivalent is separating the knowledge sources from the reasoning system). This practice has indeed served the field well for many years, but it is being challenged from an unexpected side; namely, molecular biology. The work at NLM by the National Center for Biotechnology Information (NCBI) has advanced rapidly to constitute an important resource for investigators worldwide. The size of these records and of the collection means that, for practical purposes, there is no "retrieval of the answer" or even "retrieval of the most likely relevant records." The records retrieved relevant to an NCBI query typically are multiple linear DNA sequences (variously overlapping, derived from up to 6,000 different species and man, and including inherently about 1% data errors). Thus, the "answer" absolutely must be accompanied by programs (or computer services) that manipulate the complex data that are retrieved and/or computed.

Examples of the manipulations include tools that identify potentially overlapping sequences (e.g., ESTs with genomic sequence), computation of translation homologies with respect to protein products, and linkage of the "results" to other computer information sources. An example of the latter is the increasingly useful full 3-dimensional structures (derived from X-ray and visualization) of biologically important protein molecules. It is obvious that these structures must be accompanied by appropriate programs in order to be viewed. Again, a specific example is the program "Cn3d" that NCBI sends on-line to users who retrieve and wish to display and rotate protein structures stored at NCBI [21]. The kind of molecular biology results referred to above seem to us fundamentally different from traditional library services. Not only do they have a totally different form, but they differ from the traditional display of an abstract of an article or a results table in other ways too. The abstract or the table can be read and pondered by the library user; the vastly long series of sequence symbols and the heavily coded protein molecular structures (while these are represented internally in the computer as data as well) simply are unusable separate from the display programs. Furthermore, the availability of display programs very quickly determines the kind of data stored in the computer and the kind of biological results that are sought. The program technique "JAVA" developed by Sun Microsystems represents the general case for linking executable code with retrieved information [22].

Thus, now is a time of change and examination for medical informatics in the U.S. Yet, we are re-focusing on the eternal dynamics of central versus network services, the ever shifting relationship between data and programs, and the democratization versus the intermediation of knowledge. Taking a leaf from the book of international wisdom, it looks very much as if "plus ça change, plus ça la même chose."

References

1. Lyon BJ, Stavri PZ, Hochstein DC, Nardini HG. Internet access in the libraries of the National Network of Libraries of Medicine. Bull Med Libr Assoc 1998 Oct;86:486-90.
2. *National Telecommunications and Information Association.* Falling through the Net II: New Data on the Digital Divide. *Washington DC, July 28, 1998.*
3. Wood FB, Cid VH, Siegel ER. Evaluating Internet end-to-end performance: overview of test methodology and results. J Am Med Inform Assoc 1998;5:528-45.
4. Lindberg DAB, Humphreys BL. The High Performance Computing and Communications Program, the National Information Infrastructure and Health Care. J Am Med Inform Assoc 1995;2:156-9.
5. Schatz B, Hardin J. NCSA Mosaic and the World-Wide Web: Global Hypermedia Protocols for the Internet. Science 1994 Aug 12;265:895-901.
6. Information about this study is available on the National Academy of Sciences Website, www.nas.edu.
7. Silberg WM, Lundberg GD, Musacchio RA. Assessing, controlling, and assuring the quality of medical information on the Internet: caveant lector et viewor – let the reader and viewer beware. JAMA 1997;277:1244-5.
8. Jadad AR, Gagliardi A. Rating health information on the Internet: navigating to knowledge or to Babel? JAMA 1998;279:611-4.
9. Voge S. NOAH – New York online access to health: library collaboration for bilingual consumer health information on the Internet. Bull Med Libr Assoc 1998;86:326-34. (http://www.noah.cuny.edu/)
10. Redman PM, Kelly JR, Albright ED, Anderson PF, Mulder C, Schnell EH. Common ground: the HealthWeb project as a model for Internet collaboration. Bull Med Libr Assoc 1997;85:325-30. (http://healthweb.org/)
11. Lindberg DAB. The computer and medical care. In: Laboratory Data Systems without Computers, Chapter VII. Springfield: (Ill): Charles C. Thomas, 1968.
12. Lindberg DAB. Collection, evaluation, and transmission of hospital laboratory data. Meth Inf Med 1967;6:97-107.
13. Barnett GO, Baruch JJ. Hospital computer project. Memorandum VIII. Status report 1965. Boston, Massachusetts General Hospital, 1965.
14. McDonald CJ, Overhage JM, Dexter PR, et al. Canopy computing: using the Web in clinical practice. JAMA. 1998;280:1325-9.
15. Lowe HJ, Antipov I, Walker WK, Polonkey SE, Naus GJ. WebReport: a World Wide Web based clinical multimedia reporting system. Proc AMIA Annu Fall Symp 1996;314-8.
16. Perednia AA. Telemedicine technology and clinical applications. JAMA 1995; 273:483-8.
17. Kane B, Sands DZ. Guidelines for the clinical use of electronic mail with patients. The AMIA Internet Working Group, Task Force on Guidelines for the Use of Clinician-Patient Electronic Mail. J Am Med Inform Assoc 1998;5:104-11.
18. Fridsma DB, Ford P, Altman R. A survey of patient access to electronic mail: attitudes, barriers, and opportunities. Proc Annu Symp Comput Appl Med Care. 1994;15-9.
19. Spielberg AR. On call and online: sociohistorical, legal, and ethical implications of e-mail for the patient-physician relationship. JAMA 1998;280:1333-5.
20. Hoffman A. Take 2, and e-mail me in the morning: doctors consult patients electronically. New York Times-CyberTimes. June 3, 1997. Available at: http://search.nytimes.com/search/daily/bin/fastweb. (Accessed December 4, 1998.)
21. Hogue CW. Cn3D: a new generation of three-dimensional molecular structure viewer. Trends Biochem Sci. 1997; 22:314-6.
22. Rodgers RPC. JAVA and its future in biomedical computing. J Am Med Inform Assoc 1996;3:303-7.

Address of the authors:
Donald A.B. Lindberg, M.D., Director,
National Library of Medicine,
Betsy L. Humphreys, Assistant Director for Health Services Research Information,
National Library of Medicine,
Bethesda MD 20894,
USA
E-mail:lindberg@nlm.nih.gov