

AN OVERVIEW OF DIGITAL INFORMATION IN MEDICINE: NEW RESOURCES FOR PRACTITIONERS AND PATIENTS

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Abstract

This paper presents a discussion of trends in the use of digital libraries in medicine and health care, using examples chosen primarily from North American experience, with a few examples from Japanese practice. The trends fall into five categories: clinical digital libraries; digital research libraries; digital libraries for education; digital libraries of patient and consumer health information; and digital libraries that enhance traditional medical libraries. In addition, five areas of social concern with respect to digital medical libraries are briefly discussed: cost, design, access, quality control, and indexing issues. A list of URLs and selected readings accompany the paper.

1 Introduction

As Professor Shigeo Sugimoto wrote in his remarks as Program Chair for the 1995 International Symposium on Digital Libraries, "a digital library is a library without walls," and nowhere is that image of that expanded library better seen than in medicine. Because medicine is a field of scholarship that deals with the so-called "life and death" issues, it is often (at least in North America) a field where innovation is rapidly funded and research moves quickly from the theoretical to the practical level. This tradition of innovation and application is true for projects involving digital libraries, particularly where major funding for such research has come from the National Library of Medicine, and the National Institutes of Health.

There are numerous good examples of digital library projects in medicine and health care, and they cover a wide range of applications for both practitioners and patients. These examples can be broken down into five main areas of emphasis:

- *clinical digital libraries that support practitioners and health care providers who are taking care of patients*
- *digital libraries that support large scale research projects in the health sciences*
- *digital libraries designed to facilitate education and continuing education of health professionals*
- *digital libraries that are designed to provide information to patients and health care consumers*
- *digital information that comes from medical libraries themselves.*

These digital libraries are provided by both the not-for-profit sector and by the commercial sector. The most common methods for accessing these digital libraries are through direct searching or surfing on the World Wide Web, or by connecting directly to a server supplied by a large health care institution or health sciences library.

One must make a distinction between digital libraries designed for the use of *practitioners*—health care providers who may be physicians, research scientists, nurses, and others concerned with direct patient care or basic biomedical research—and digital libraries designed for the use of *patients*—sick people themselves, their relatives and friends, and the general public which is perceived to be very interested in health information in the 1990s. In North America, practitioners are also known now as *providers*, and patients as *consumers* of health care, reflecting an economic view of the health care continuum. There are examples, however, of digital libraries designed to meet the information needs of both groups.

2 Social and Behavioral Issues

Professor Sugimoto also wrote in his remarks as Program Chair for the 1995 International Symposium on Digital Libraries that these workshops should also pay attention to "social and cultural issues." This is an important concept for the study of digital libraries in medicine, as a number of specific issues arise in any discussion of these resources.

For example, one of the unresolved issues in digital library applications in this field is *who will pay for these expensive resources*. At the moment, most digital libraries for providers and practitioners are

funded by an institution—either a health care system, an educational institution or a government agency—while many of the sites for patients and consumers are funded by advertising revenues, and some are maintained by fees charged for use of the information.

A second issue is that of *who will design and care for these digital libraries*, particularly in a field where knowledge and technology change daily, and where inaccurate information or the inaccessibility of information due to technical difficulties can literally prove fatal to an individual. Some digital libraries are developed by large staffs of trained professionals working for financially-sound institutions, while others are developed and mounted by volunteers or struggling entrepreneurs whose time and technical knowledge may be limited. There are, however, also excellent examples of digital libraries and Web pages maintained by single individuals.

An obvious issue is the question of *who will index these digital libraries* so that others may find and use the information effectively. Some resources are in fact restricted to individuals who have a formal relationship to the developer (as in digital libraries for which you must enter a university ID number in order to access the resources), while others may be accessed by anyone with the equipment to do so.

An issue of paramount importance, however, is *who will maintain quality control for these digital libraries*. There are countless examples of wrong information, questionable information, and biased information being made available, and there is no agency or body currently charged with the review of digital libraries for their accuracy or appropriateness or even legality. Ethical issues are regularly arise, as do major privacy concerns.

Finally, there is the age-old issue of *who will provide access for those who cannot access digital libraries on their own*. People who are computer illiterate, those who lack the financial resources to acquire access, those who are geographically isolated, children, the disabled, those who are too sick to use the digital resources—these people will need intermediaries to assist them in their quest for information that may only be available in a digital resource. And, it must be noted, that both practitioners and patients, providers and consumers, may be computer illiterate or geographically isolated or lacking funds for computing. Rural health care providers and the urban inner-city poor may be equally unable to access digital resources.

3 Clinical Uses

Much of the most innovative work in digital libraries in medicine is being done in support of clinical care. The digital information is presented in ways which enhance a physician's or nurse's ability to do the job of providing safe, effective, efficient health care to patients. Two important aspects of these digital endeavors are the digitizing, storage and retrieval of patient records, and the amassing of libraries of clinical practice guidelines and critical pathways for caregiving. Because this kind of information is often confidential (because it concerns a specific individual or because it is part of a hospital's in-house procedures), it is difficult to demonstrate publicly-accessible examples of these digital libraries. The electronic medical record, the "smart card" for personal health data, the possibility of the paperless patient chart, however, have all been the subject of many talks and demonstrations at meetings such as SCAMC [the Symposium on Computer Applications in Medical Care], or as it is now known, the AMIA Annual Symposium.

There are digitized libraries of practice guidelines that can be used publicly, and the work of the US Agency for Health Care Policy and Research is an excellent example. This Federal agency has funded

the development of guidelines for specific health conditions, based on reviews of the medical literature and clinical trials by major hospitals; these guidelines are now available on the World Wide Web, and cover such common medical problems as pain management, otitis media, smoking cessation, urinary incontinence, and low back problems. Other non-Federal sources of these guidelines include various professional societies such as the American Association of Clinical Endocrinologists.

A third area of clinical interest is the development and use of decision support systems for medicine, whether for diagnosis or therapy. Much of the development and use of these systems depends upon access to large digitized banks of information to support artificially intelligent expert systems or neural networks. Some of them, such as the Physician's Online/QMR, or the Harvard/Massachusetts General Hospital's dxplain system are now accessible on the World Wide Web, if the user is a registered participant. They are not, however, available free to anyone who wishes to use them.

Another promising area of research on digital libraries in clinical care is the development of telemedicine projects. This marriage of medicine and telecommunications has largely been shaped by two forces: research and demonstration projects which link rural, geographically isolated health care practitioners (mostly physicians and physician assistants) to tertiary care facilities for the referral of seriously ill patients and for their own continuing medical education, and research on methods that allow physicians (often surgeons) to practice on patients located at a distance. This latter work has been tested by the US military as a way of caring for battlefield casualties without sending surgeons to the site of the conflict; the physician is miles from the battlefield, and the care is delivered by a medic or even a robot, working under the direction of the physician. Small scale investigations of computer-assisted remote surgeries are underway. Public health experts, such as those at the University of Pittsburgh's Global Health Net project are planning "cyberdoc" projects that are predicated on placing trained specialists in remote areas with backpack computers, solar panels, and satellite transmissions for downloading data and information to use in fighting epidemics. The electronic communication of images, patient data, and directions for care is essential to this kind of medical care.

4 Research Uses

Large scale digital libraries have also been developed to support basic biomedical research, and their use has been facilitated by Internet distribution of data, and electronic communications between and among researchers.

A primary example of this is the enormous project to map the human genome; the digital work for this project is centered at the US National Center for Biotechnology Information at the NIH campus. This effort is paying off in the development of genetic therapies for human cancers, in the development of vaccines against dread diseases, and in the understanding of the genetic bases of disease. The large libraries of genetic information that result from this mapping effort are impossible to use without computational tools. The huge number of researchers working on this effort around the world could not accomplish their research as quickly as they are doing it without a heavy reliance on telecommunications as their primary means of professional communication. Many of the digitized files of genetic information are accessible by scientists through specialized web-based search engines.

Other digital resources for research are less massive but nonetheless useful. Libraries of data describing grants and funding opportunities, laboratory facilities, staff members and leaders of research teams, even maps of major research centers, are now widely available to scientists and students. Other sites are

helpful for locating specific information about research endeavors at a particular site; the files describing the "virtual hospital" at the University of Iowa medical center and the research projects at the University of Pittsburgh Medical Center are good examples.

Historical research is also facilitated by digital libraries of images and manuscripts in the history of medicine. The digitized file of 60,000 images from the History of Medicine Division at the US National Library of Medicine is an outstanding example of electronic access to unique pictorial material drawn from photographs, art works, and printed texts.

5 Education/Continuing Medical Education Uses

Much emphasis has been placed of late on changing the ways in which health care practitioners are educated, and on the continuing education of health care providers in new techniques. Digital libraries have revolutionized some aspects of these two kinds of medical education.

In medical schools, both the use of patient simulations (such as the Interactive Patient project at Marshall University in West Virginia, and large anatomical databases (the Visible Human project supported by the National Library of Medicine) have made the study of anatomy much more flexible and diverse. There are projects which are investigating virtual bodies through visualization techniques based on digitized anatomical information. The innovative three dimensional Virtual Colonoscopy project allows users to view the human colon in great detail and provides fly-through animation along the inside of the colon. Researchers in Texas have created a simulated emergency medicine scenario of a gunshot wound to the right chest which includes x-ray images and photographs of the shooting victim. Students may practice their emergency room skills on this make believe patient.

Some medical schools are even administering examinations over the Internet as they do at Vanderbilt University in Nashville, TN, while other schools test computer and information competence among their students with digital assessment tools. Medical students share digital libraries of notes and use interactive group learning software to enable small group learning in a problem-based learning curriculum. Those providers who want to work with deaf patients can learn to use a common English sign language via a digital library of American Sign Language, while those who would serve blind clients can network through the resources of the Blind Children's Center.

Distance learning involving remote transmission of medical images and interactive discussions of patients, diagnoses, and therapies has made it possible for geographically isolated health care providers to learn cutting-edge techniques and new methods of treatment. Internet delivery of workshops and classes, as well as two-way video hook-ups have allowed major medical centers to offer their experts to affiliated sites around the world at much lower cost. Medical students who are doing a clerkship or rotation in rural medicine also benefit from these computer-supported distance learning techniques.

6 Patient and Consumer Uses

It is in the area of consumer informatics that the largest number of digitized resources have been developed, but many of them are not well-built, and they may contain biased and factually inaccurate material. The sources for this information range widely, with some emanating from world-class health care institutions, expert professional societies, and government agencies. These digital libraries may be disease-specific, such as the web-based resources of American National Stroke Association or they may be

wellness-oriented, as the Food Guide Pyramid published electronically by the Food and Nutrition Information Service of the US Department of Agriculture's National Agricultural Library. Others may offer specific advice for parents, as in the MultiMedia Tutorials for Children and Parents from the University of Virginia or the pediatric advice from Dr. Greene, a popular pediatrician in California.

A number of sites have also been developed as entrepreneurial for-profit efforts, whose developers may expect to make their fortunes from these "libraries." The resources often carry advertising messages, or large sponsorship announcements about the organizations whose dollars are funding the digital library. The Medical Multimedia Group in Libby, Montana, has produced a series of "patient's guides" that are contain a link to a further "product information". The Eyes on the Web site opens with a large box inviting users to visit its sponsor, a vision care company called Opticare.

At the same time there are sites which promise quick or quack cures, promote products that have never been shown to have clinical effectiveness, or deliver healthcare information that is one-sided. The Gypsy Folk Medicine page, the Sumeria site with information on the questionable substance laetrile, and the somewhat dubious bibliography on their "Recommended Reading List on Cancer" are examples of some of these digital libraries of unproven medical information.

It is true, however, that some resources do deliver helpful medical information in a humorous way that informs and amuses the user. Sites specifically for non-traditional segments of society also exist; two good examples are the resources of the Haight Ashbury Free Clinics Inc (which has been around since the hippie days of the 1960s) and the information in the digitized library for Rock Medicine (yes, rock as in rock'n roll).

Other patient and consumer-focussed projects are designed to showcase or market the institution which sponsors the electronic presence. These sites can be very good sources of information for consumers and their family caregivers who are seeking basic information on which to make a choice about a particular hospital or practitioner. The previously-cited University of Iowa's "virtual hospital" is a particularly good example of this kind of site.

There are also mega-sites which attempt to be gateways to all kinds of consumer health information, and which have been built to serve the general public of patients and consumers—sites such as NOAH in New York City, which offers health information in both English and Spanish, the COHIS (Community Outreach Health Information System) developed by Boston University Medical Center, or the Health Education Program of the American Academy of Family Physicians Foundation, and the NABCO site developed by the National Alliance of Breast Cancer Organizations.

Other digital libraries are commercial in their origin, such as the huge Achoo site (named for the American word that represents a sneeze!) or the Health Hippo site with many resources on US health policy and law. Additional well-known commercial sites with a major Web presence include the Tripod library directed to students and the HealthWorld Online which markets health foods and holistic health supplies.

These consumer and patient libraries are often the most artfully designed resources, with color graphics and user-friendly navigation. The intent is clearly to provide health information in a form which is not technical, which is written in simple English, and which provides links to specific services and personnel offered by the affiliated institutions. Much use is made of linking and navigational aids and the user may actually be travelling to many different servers in search of the requisite information. This international navigation is obvious in the digital site DeathNET with its information on suicide, death planning, etc.

Among the multi-purpose digital libraries with resources for both practitioners and patients are sites such as the PharmInfonet, which has won several "cool site" awards. Similarly, the Health*touch*-tm site combines drug and pharmaceutical information with many other kinds of digitized medical information. Both are commercially-supported digital libraries.

7 Library Uses

In many North American institutions, health sciences and hospital libraries have taken the lead in organizing large digital libraries to support the clinical practice and teaching needs of their clients. The previously-cited Active Digital Library of the Eskind Medical Library of Vanderbilt University, with a resident staff of medical informaticists, is one of the most sophisticated of these library-related projects, while the digital library information presented by the Health Sciences Library System of the University of Pittsburgh is a good example of work done by talented reference librarians. In Canada, the personal home page of a very experienced reference specialist, Tom Flemming, has become a highly respected stand-alone Health Information resource.

Many of these digital library projects allow a traditional library to offer its clients much more than the traditional book and journal collections, a particularly attractive prospect in times of stagnating budgets for collection development. A digital library and the purchase of site licenses for certain resources can allow a library to serve more people in more sites, as technology then enables the library to do more work and provide more services with the same number of staff members. Electronic versions of distinguished medical journals are popular, as in the digitized versions of the New England Journal of Medicine, the British Medical Journal, the journal called Science, and even the medical new reporting from the New York Times, available daily. Calendars of medical center events, upcoming conferences, faculty bibliographies, new books lists, and access to databases which index the biomedical literature are often found in the digital collections.

Most of these libraries with digital libraries are housed at large academic medical centers. The famed Mayo Clinic site is typical. It is rare to find a digital library coming from a hospital that is not an affiliate of a large medical school. Many of those who work in the smaller hospital libraries, however, are users of the digital library resources in larger institutions, as the digital library projects become a networked resource for smaller less-privileged institutions.

8 Japanese digital medical libraries

Although I am limited in my web-surfing by the fact that I cannot read Japanese, in either kanji or romaji, I have located examples of some of these digital library trends in sites in Japan.

The home pages for the Department of Pediatrics at the University of Tokyo, and the websites for the National Institute of Animal Health located here in Tsukuba, the National Institute of Genetics, and the National Cancer Center are good examples of sites with information about research and educational facilities, their staffs, projects, and facilities. Similarly the site for the International Medical Center of Japan is a good example of a digital resource supporting a clinical care facility. There is a smaller hospital website in Chiba.

The page for Neurosurgery developed at the Yamagata City Hospital is very detailed and contains links to world sites for neurological disease; its guide to digital resources for Mad Cow disease is particularly

interesting. Two Japanese medical research organizations also have complex and well-designed pages with English versions: the Japan Society of Magnetic Resonance in Medicine here in Tsukuba, and the Japanese Anatomy Page developed for the Japanese Association of Anatomists, mounted on the American Association of Anatomists homepage. The Anesthesiology and Critical Care division of the Hiroshima University School of Medicine has a page on malignant hyperthermia, and there is a very detailed radiology teaching file on oral (head and neck) diseases put up by the Nagasaki University School of Dentistry.

9 Conclusions

There can be no doubt that the digital library movement in medicine is here to stay. An ever-increasing number of institutions will turn to the collection and management of digital resources as a means of enabling excellence in clinical care, as a way to enhance research effectiveness, as a technique to allow greater access to more information, and as a state-of-the-art tool for communication among diverse groups of clients, be they practitioners or patients.

If there are problems, they are clearly in the social and behavioral areas of cost, accessibility to those without technological literacy, quality control of the information contained in the resources, and instruction in the use of the digital library. These are expensive libraries to build and maintain; they are difficult to locate and index without new and sophisticated computer-based tools for navigation. They are full of information that may be questionable for its accuracy and currency, and end users will require much help in learning to use these resources effectively and efficiently. Sadly, perhaps, there will be a generation of healthcare providers and a generation of patients who will never be able to take advantage of these resources, because they are phobic about technology, because they cannot afford the means of access, or because they are ignorant and poor.

However, there is a bright future for professional information workers who can serve as managers, indexers, evaluators, and intermediaries for digital libraries in medicine. These individuals may be called "digital librarians," or "digital health information specialists", and they must be prepared in institutions of higher learning such as the University of Pittsburgh's School of Information Sciences or the national University of Library and Information Science in Tsukuba Science City. It is therefore necessary that these programs of graduate and undergraduate education must also change so that they are ready to prepare the new generation of digital health information workers.

10 Tables of URLs

TABLES OF URLs

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GENERAL SOURCES OF FUNDING FOR DIGITAL MEDICAL
LIBRARY PROJECTS [examples]

National Library of Medicine
<http://www.nlm.nih.gov>
National Institutes of Health

<http://www.nih.gov>

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GENERAL CONFERENCE FOR DIGITAL MEDICAL LIBRARY
PROJECTS [examples]

AMIA Annual Symposium
<http://www.amia.org>.

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CLINICAL DIGITAL LIBRARIES THAT SUPPORT
PRACTITIONERS [examples]

Agency for Health Care Policy and Research, Practice Guidelines

<http://www.text.nlm.nih.gov/>

American Association of Clinical Endocrinologists

<http://www.aace.com/guidelines/nodule.html>

Physician's Online/QMR

<http://www.po.com/qmr.html>

Harvard/Massachusetts General Hospital dxPlain

<http://www.lcs.mgh.harvard.edu/>

Telemedicine in the US Department of Defense

<http://www.matmo.army.mil/>

University of Pittsburgh Global Health Net project

<http://www.pitt.edu/HOME/GHNet/GHNet.html>

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DIGITAL LIBRARIES THAT SUPPORT RESEARCH
[examples]

US National Center for Biotechnology Information, NIH

<http://www.ncbi.nlm.nih.gov>

The Virtual Hospital, University of Iowa

<http://indy.radiology.uiowa.edu/>

University of Pittsburgh Medical Center

<http://www.upmc.pitt.edu>

History of Medicine Division, National Library of Medicine

<http://www.woli.nlm.nih.gov>

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DIGITAL LIBRARIES FOR EDUCATION/CONTINUING
MEDICAL EDUCATION [examples]

Interactive Patient

<http://musom.marshall.edu>

Visible Human, National Library of Medicine

http://www.nlm.nih.gov/research/visible/visible_human.html/

3DVirtual Colonoscopy

<http://www.cs/sunysb.edu/colonoscopy>
Gunshot wound
<http://rmstewart.uthscsa.edu.subclaviancase.html>
Vanderbilt University Active Digital Library
<http://www.mc.vanderbilt.edu/adl>
American Sign Language
<http://home.earthlink.net/~mastertek/ASLDict.html>
Blind Children's Center
<http://www.blindcntr.org.bcc/>

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DIGITAL LIBRARIES FOR PATIENTS/HEALTH CARE
CONSUMERS [examples]

National Stroke Association
<http://www.stroke.org>
Food Guide Pyramid, US Department of Agriculture
<http://nal.usda.gov:8001/py/pmap.htm>
MultiMedia Tutorials for Children and Parents, University of Virginia
<http://galen.med.virginia.edu/~smb4v/tutorial.html>
Dr. Greene
<http://www.drgreene.com>
Medical Multimedia Group "patient's guides"
<http://www.sechrest.com/mmg/>
Eyes on the Web
<http://www.io-ltd.com/eyeweb/16.htm>
Gypsy Folk Medicine
<http://www.cam.org/~jennyb/gypsy.html>
Sumeria/laetrile
<http://www.livelinks.com/sumeria/health/laetrile.html>
"Recommended Reading List on Cancer"
<http://www.cco.net/~trifax/books/cancer.html>
Dr Bil
<http://www.hooked.net/usus/wed/bilspix.html>
Haight Ashbury Free Clinics Inc
<http://www.hafci.org/hafci/>
Rock Medicine
<http://www.hafci.org/hafci/rockmed/>
NOAH
<http://www.noah.cuny.edu/>
COHIS, Boston University Medical Center
<http://web.bu.edu/COHIS>
Health Education Program, American Academy of Family Physicians
http://research.med.umkc.edu/aafp/pt_ed.html
National Alliance of Breast Cancer Organizations

<http://www.nabco.org/>
Achoo
<http://www.achoo.com/>
Health Hippo
<http://www.winternet.com/~hippo>
Tripod
<http://www.tripod.com>
HealthWorld Online
<http://www.healthy.net>
DeathNET
<http://www.rights.org/~deathnet/>
PharmInfonet
<http://www.pharminfo.com>
Healthtouch-tm
<http://www.healthtouch.com>

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DIGITAL INFORMATION FROM MEDICAL LIBRARIES

[examples]

Health Sciences Library System, University of Pittsburgh
<http://www.falk.med.pitt.edu>
Tom Flemming
<http://www-hsl.mcmaster.ca/tomflem/top.html> .
New England Journal of Medicine
<http://www.nejm.org>
British Medical Journal
<http://www.bmj.com/bmj>
Science
<http://www.aaas.org>
New York Times
<http://nytsyn.com/medic/>
Mayo Clinic
<http://www.mayo.edu>

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JAPANESE DIGITAL MEDICAL LIBRARIES [examples]

Department of Pediatrics, University of Tokyo
<http://www.ped.h.u-tokyo.ac.jp/index.html>
National Institute of Animal Health
<http://ss.niah.affrc.go.jp/NIAH/hoge4.html>
National Institute of Genetics
<http://www.nig.ac.jp/home.html>
National Cancer Center
<http://wwwinfo.ncc.go.jp/index.html>

International Medical Center of Japan

<http://www.imcj.go.jp/imcj2.htm>

Hospital in Chiba

<http://www.bekkoame.or.jp/~satsou>

Neurosurgery, Yamagata City Hospital

<http://www.sm.rim.or.jp/~amagusa>

Japan Society of Magnetic Resonance in Medicine

<http://www-jmrm.bk.tsukuba.ac.jp/jmrm/>

Japanese Anatomy Page

<http://www.anatomy.org/anatomy/japan.html>

Anesthesiology/Critical Care, Hiroshima University School of Medicine

<http://mh.med.hiroshima-u.ac.jp/documentation/Ewelcome.html>

oral (head and neck) diseases, Nagasaki University School of Dentistry

<http://w3.dh.nagasaki-u.ac.jp/tf/content.html>

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12 References

These are general articles which discuss the trends described in the paper; they can be consulted for further and more detailed discussions of these issues.

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