Organizing Electronic Information to Serve the Needs of Health Practitioners and Consumers

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Abstract

From its beginnings as the Library of the Army Surgeon General to today's Internet-driven information environment, the U.S. National Library of Medicine (NLM) has served a variety of audiences. As NLM strives to provide the best possible service to health scientists and consumers, the form of that service has changed depending on resources available and the state of technology. Throughout its history, NLM has adopted innovative programs and technology at the earliest sensible moment that would serve its patron needs. Today, NLM is a leader in providing electronic biomedical information to health professionals, researchers, the public, and anyone else with access to the Internet. These services have evolved in response to available technology and the demands of the various audiences, from clinicians to consumers. To serve the needs of this variety of patrons, NLM connects health information resources in ways that enable each audience to find the information appropriate to its need. NLM continues to improve this organization as the demand and technology and resources allow.

Serving Librarians and Physicians Before the Electronic Age

The National Library of Medicine (NLM) began in 1836 as the Library of the Army Surgeon General, serving military physicians through the U.S. Civil War period. In the 1870s, under the stewardship of John Shaw Billings, the library, located in Washington, D.C., was opened to the entire medical profession Monday through Saturday (Miles, 1982, p. 91). Shortly after the Civil War, Billings began to loan books and journals to local medi-

cal officers, and by 1874 he had put in place a written policy for lending materials, through the postal service, to those who could not come to the library. He would lend books for two weeks to a medical society or librarian who assumed responsibility for the materials, allowing their use within the organization's library or reading room only. This requesting organization was to mail them back in good condition and to deposit enough money to pay for any lost materials (Miles, 1982, p. 100). This early service was not electronic, of course, but it still served the need of delivering medical information to remote clinicians and researchers who needed it, without them traveling to the library.

By 1911, NLM's interlibrary loans and personal loans totaled 7,500 per year, filling an important gap, as no other medical library in the United States sent out books on loan (Miles, 1982, p. 202). For the next forty years, the library continued to lend materials locally and to clinicians throughout the country, responding to a growing demand. Though there were many medical libraries in the United States, and cooperative arrangements existed, collections in these libraries were judged inadequate to meet the demand. The Medical Library Assistance Act of 1965 (MLAA) authorized NLM to provide grant funding to medical libraries to improve their collections, facilities, and services. Establishment of the Regional Medical Library (RML) Network in 1967 marked a major change in NLM's role from being a central source for medical information to serving as a comprehensive backup resource to a hierarchical RML Network made up of 11 geographically dispersed regional libraries, 100 academic medical libraries, and some 500–600 hospital and other local health libraries (Bunting, 1987, p. 9). NLM itself served the Mid-Atlantic Regional Library. The major services to be provided by the RML libraries were "free loans of library materials to qualified users" as well as literature search services of NLM's MEDLARS batch retrieval system and backup reference support to other libraries in the region (Bunting, 1987, p. 7). Libraries provided document delivery services for free until 1978, when the high demand for interlibrary loan forced the RML Network to institute a standard charge of $5.00 per loan. By establishing this network, NLM was able to effectively serve the health professional audiences through their libraries.

NLM Serves Librarians and Their Clients Online

Billings believed it was important to provide printed catalogs and indexes of biomedical literature to serve physicians and librarians (Miles, 1982, p. 112). The library printed *Index Medicus* and others for over a century. NLM realized early in the evolution of computers that these new machines had great potential to make publishing these extensive volumes efficient and then to enable distribution of the information to searchers, whether at the library, in another state, or in another country. In 1971 NLM made an electronic index, MEDLINE (for MEDLARS Online) accessible, eventu-

ally through nationwide telecommunications networks. Because MEDLINE required leased telecommunications lines and extensive training of three weeks, at first this online system served health professionals and researchers through librarian intermediaries (Kassebaum & Leiter, 1978, p. 166). In these early online days, clinicians, researchers, and students continued to use printed *Index Medicus* volumes in their local medical library. They turned to their librarian for more extensive or complicated searches where the online MEDLINE provided superior results.

To complement MEDLINE's strength in identifying biomedical literature, NLM, with the Regional Medical Library Network, launched the DOCLINE system in 1985. DOCLINE provided automated interlibrary loan (ILL) requesting and routing for librarians, a quantum leap in the efficiency and effectiveness of ILL in health sciences libraries. For twenty years NLM has provided the DOCLINE system at no cost, but libraries bill each other for supplying the articles. In 2004, 3,260 libraries worldwide made 2.7 million requests through DOCLINE (National Library of Medicine, 2005c, p. 16). About 13 percent of these requests, 360,000, were handled by NLM. Once again, this system serves health practitioners and other professionals through their institutional librarians. It was not until the personal computer became available that NLM was able to allow these health professionals and researchers to request articles from their libraries more directly.

From Librarians and Information Professionals to Health Practitioners and Consumers

After he began his tenure in 1984, one of the first projects NLM director Dr. Donald A. B. Lindberg inspired was for NLM to provide software for the personal computer that enabled individuals who had no training to search MEDLINE. "Grateful Med" debuted in 1986. Using Grateful Med, anyone with an NLM user ID, personal computer, and telephone modem connection could, for 2–3 dollars per search, retrieve references to the latest biomedical literature. Grateful Med cost just $30, and NLM sent annual updates, which included the latest Medical Subject Headings (MeSH) vocabulary, for free. Physicians were among the early adopters of this technology, and NLM distributed over 96,000 copies of the Grateful Med software to physicians, researchers, and librarians all over the United States and Canada. Librarians, who had served as intermediaries for MEDLINE for many years, had concerns about NLM marketing Grateful Med to physicians; these concerns ranged from a loss of status and intellectual work for the librarian to the lack of physician expertise to perform well-formed searches (Humphreys, 2002, p. 12). Despite the concerns of some, many librarians promoted end-user searching, which is now the overwhelming norm.

Now armed with a citation, which included only an abstract of the article from a Grateful Med search, what users really sought was easy access to the

full text. In 1992 Grateful Med incorporated a software component called Loansome Doc. Loansome Doc software made the link between Grateful Med and DOCLINE and enabled health professionals to request articles directly from their local library (Glitz & Lovas, 1996, pp. 206–207). From that library, staff filled the request from their own collection or through interlibrary loan and delivered it to the health professional. With Grateful Med, NLM directly delivered biomedical literature references to health professionals. With its companion, Loansome Doc, NLM brought the two user groups together, linking librarians electronically to health professionals. There are currently 75,000 individuals registered to order articles using Loansome Doc. In 2004 they requested over 800,000 articles from libraries who serve them (National Library of Medicine 2005c, p. 16).

Impact of the Internet

Few would argue that "the Internet represents the most important technological development of our generation," as stated by the University of Southern California Annenberg School Center for the Digital Future (2004). One of the ten trends noted in its comprehensive 2004 *Digital Future Report* is that the Internet has become the number one source of information for Internet users and that eventually almost every American will be an experienced user (Lebo, 2004, p. 9). The United States, with a total population of 296 million, has an estimated Internet user population of 201 million, or 68 percent. This has grown 105 percent since 2000 (Internet World Stats, 2005). Recent estimates of the number of Americans who search the Internet for health-related information are fairly consistent at 75–80 percent of adult users, or close to 100 million users (Manhattan Research, 2004; Fox, 2005, p. 1).

In 2005 nearly 100 percent of U.S. practicing physicians reported having accessed the Internet in the past twelve months, and 99 percent of online physicians reported that they use the Internet for professional purposes. In fact, professional use accounted for 55 percent of the overall use (Manhattan Research, 2005). Though the increase in the number of Internet users has slowed in recent years, the rapid growth of broadband use both in the workplace and at home has meant that people spend much more time online (Pew Research Center, 2005, p. 67).

From Low Cost to No Cost

This rapid adoption of the Internet by all sectors in the United States has enabled NLM to serve librarians and health professionals, and virtually anyone who chooses to "logon," as never before. In 1993 NLM was one of the first U.S. agencies with a presence on the World Wide Web. The first NLM Web site offered programmatic information about the library and its services, but it did not provide health information. During the first few years, the site grew from providing information about services to a portal

to the services themselves. The most important service was MEDLINE in its expanded form, PubMed, searched through the National Center for Biotechnology's (NCBI) Entrez search system, first released on the Internet in 1997 (National Library of Medicine, 1997).

With the release of MEDLINE/PubMed, NLM provided MEDLINE for free for the first time, and, like Grateful Med, it required no special training. Anyone with Internet access, from researchers to clinicians to librarians, could now search MEDLINE/PubMed. Novice users searched the literature using simple keywords. Experienced librarians, with previous training in MEDLINE searching and MeSH, learned Entrez's advanced features for more precise or comprehensive results, depending on the needs of their clinician clients. The impact of free Medline through the Internet has been astounding. Use of the system has grown from 7 million user searches in the year 1997 to 2.7 million searches each day in 2004 (National Library of Medicine, 2005c, p. 51).

A 1997 NLM survey of MEDLINE/PubMed users showed that a surprising number, over 30 percent, identified themselves not as scientists or health professionals or librarians but rather as members of the general public. MEDLINE has always indexed the professional literature of health and medicine, but it was not until it became free on the Internet that the layperson, whether patient, family member, or friend, had easy access to this rich resource. The survey made it clear that free PubMed on the Internet attracted all kinds of users. At the same time, an analysis of the search logs of NLM's main Web site showed that over 90 percent of the search terms entered were for medical information, even though the site contained programmatic library information and almost nothing for consumers (Miller, 1997). Clearly, people who searched the main NLM Web site expected health information, and many consumers attempted to use PubMed to find answers to their health questions. NLM responded to this need by releasing MedlinePlus.gov, a consumer health portal to the Internet in October 1998 (National Library of Medicine, 1998).

NLM Reaches Patients and the General Public

MedlinePlus began modestly to serve consumers, with just over twenty key health topics. As the site grew, feedback from NLM's outreach project with libraries and other sources made it clear that not all consumers needed or wanted the same level of information. Usability and customer feedback indicated that some consumers want just basic background information on the causes, symptoms, and treatments for a disease or condition. Some consumers are looking for information on wellness and fitness. In contrast, patients and families dealing with a very acute or long-term medical problem may want the latest research and clinical information from the biomedical literature found in MEDLINE or current research studies from ClinicalTrials.gov.

The core of MedlinePlus is links to information from the National Institutes of Health (NIH) and other government and authoritative organizations, but even this large number of documents does not cover the breadth of information consumers want. To meet user needs for broader coverage, MedlinePlus licensed a medical encyclopedia. The encyclopedia provides information on symptoms, such as swollen glands, rashes, or chest pain, and tests such as hematocrit, sigmoidoscopy, or lipid profile. It describes these topics briefly and with colorful, clear, illustrations. In another example of meeting consumer needs, a MedlinePlus search log analysis showed that the second most frequent type of term users entered, after diseases and conditions, were generic and brand names for drugs (McCray, Loane, Browne, & Bangalore, 1999). In response NLM licensed consumer-level drug information to inform patients about this important health care component. Health news and weekly alerts for current awareness followed. To address the need for simple, low-literacy materials, MedlinePlus provides talking tutorials on many basic health topics and procedures (National Library of Medicine, 2005b). Each of these licensed information sources responds to a particular consumer need.

MedlinePlus Also Serves Healthcare Professionals

While continuing to develop and improve MedlinePlus for consumers, NLM had evidence that health professionals were using the site as well. A 2001 survey showed that 11 percent of the repeat users were healthcare providers, as were 11 percent of the first-time users (National Library of Medicine, 2001). The follow-up 2003 survey showed that 11 percent of the respondents were healthcare providers (National Library of Medicine, 2004). With over 60 million visits per month, MedlinePlus is clearly serving many professional care providers as well as the consumer audience.

NLM's March 2005 Web-based survey results show how the audiences of MedlinePlus and MEDLINE/PubMed differ by role, reason for visiting the site, and results of their visit.

Table 1 shows the roles of visitors to the two sites. For PubMed, more users self-report being Researcher/Scientists (46 percent), than any other role, while only 3 percent of MedlinePlus users come from this category. The largest proportion of MedlinePlus respondents describe themselves as Patient/Health Consumers, while respondents in this role make up only 3 percent of PubMed users. Those using the sites in the role of Physician make up 20 percent of PubMed users and 16 percent of MedlinePlus users. As the survey responses illustrate, these sites serve users in many professional and personal roles, from scientists to consumers to physicians, but clearly the nature of the content appropriately affects the proportions of each role. Thus, both sites have physician visitors in similar proportions, while MedlinePlus draws a much larger proportion of consumers.

Table 1. Responses to NLM 2005 Survey: "In what role are you visiting this site today?"

Identified Role	PubMed (%)	MedlinePlus (%)
Physician	20	16
Researcher or Scientist	46	3
Patient/Health Consumer	3	42
College or Graduate Student	22	9
Secondary Student	n/a	3
Educator	2	7
Librarian	2	4
Other	4	10
News/Media	n/a	2
Healthcare Administrator	n/a	4

Note: n/a indicates that the category was not an option on the PubMed survey.

As in the reported roles, the responses that PubMed and MedlinePlus users give for the "result of their visit" reveal similarities and differences in the audiences. Table 2 shows the "result" responses for each resource; users were allowed to select as many results as they wished. PubMed users most frequently responded that their PubMed use resulted in "keeping up to date about research" and "obtaining full text of articles." Next most often, PubMed users "learned about methods relevant to research," "improved understanding of a disease, diagnosis, or treatment," and "conducted further research." In comparison, MedlinePlus users most often reported "improved understanding of a disease, diagnosis, or treatment," which is the fourth most often result reported by PubMed respondents. MedlinePlus users also reported the results of "delivering search results to a requester," "conducting further research," and "discussing a disease . . . with a family member or friend." MedlinePlus users reported the result "made decision about patient care" much more often than PubMed users. Thus, these two resources share some user results, but they serve two audiences with different focuses and results.

Table 3 shows the reasons PubMed and MedlinePlus users visit each of the sites. Once again, respondents selected as many reasons as appropriate. Because the responses offered from each survey differ, these categories show no overlap, but they do provide insight into why users visit each site. The common reasons users visit PubMed are to "Perform basic biological research," "Find articles by specific authors," "Perform clinical research," "Education," and "Find articles in a specific journal." In contrast to the basic research and biomedical article purposes reported by PubMed users, MedlinePlus users most often report that they wish to "Find information on a specific disease, condition, diagnosis, or treatment," "Find information on medicines or prescription drugs," "Find general health and wellness information," "Keep up with breaking health news," and "A project

Table 2. Responses to 2005 NLM Survey: "What best describes the result of your visit?"

Answer	PubMed (%)	MedlinePlus (%)
Conducted further research on disease, diagnosis, or treatment	23	27
Discussed search results with my healthcare professional	4	12
Delivered search results to the requester	6	29
Improved understanding of a disease, diagnosis, or treatment	26	57
Made decision about patient care	9	16
Other	4	6
Sought further information from library	14	7
Kept up to date about research in field of interest	55	n/a
Obtained full text of selected articles of interest	50	n/a
Learned about methods relevant to research	27	n/a
Obtained help in reporting research results	17	n/a
Determined viability of research area	13	n/a
Completed administrative responsibilities	3	n/a
Did not find what I wanted	4	n/a
Altered exercise or eating habits	n/a	7
Discussed a disease, condition, diagnosis, or treatment with family member or friend	n/a	23
Made a doctor's appointment for self or another	n/a	7
Nothing specific happened	n/a	6
Switched from one medicine or prescription drug to another	n/a	4
Used information for a project or presentation	n/a	21

Note: n/a indicates that the category was not an option.

or presentation." The predominantly consumer MedlinePlus users seek health information, while the researchers and scientists using PubMed seek scientific and research information and find and/or verify articles.

These survey results illustrate that, after years of growth and improvements based on customer feedback, PubMed and MedlinePlus serve a variety of audiences, providing a continuum of health and biomedical information. For example, PubMed is just one of the many services NCBI offers to the scientific, clinical, and research communities. NCBI creates public databases and offers important databanks and software tools for scientists and researchers throughout the world (Wheeler et al., 2005). MedlinePlus and PubMed are interlinked so that consumers and health professionals can move easily between the two major resources.

MedlinePlus health topic pages from abdominal pain to x-rays have at least one, and often several, stored PubMed searches. National Library of Medicine reference librarians maintain these nearly 1,000 searches so that they retrieve fewer than 100 current review and clinical articles on a given topic. As soon as PubMed adds an article that meets the MedlinePlus stored search criteria, the stored search will retrieve it. For PubMed users, NCBI

Table 3.   Results of 2005 NLM Survey: "What is your primary reason for visiting the PubMed/Medline Plus site today?"

Reason	PubMed (%)
Perform basic biological research	49
Find articles by specific authors	37
Perform clinical research	37
Education	26
Find articles in a specific journal	26
Check journal reference	22
Patient care	13
Other	6
Own health care or that of family or friend	5

Reason	MedLine Plus (%)
Find info on a specific disease, condition, diagnosis, or treatment	63
Find info on medicines or prescription drugs	39
Find general health and wellness info	33
Keep up with breaking health news	21
For a project or presentation	21
Find info on alternative treatments, herbals, or vitamins	16
Search for health care products or services	11
Other	9
Find info on clinical trials	8
Obtain the opinion of a healthcare provider	7
Search for healthcare provider	4
Find health self-help groups	3

provides LinkOuts to appropriate MedlinePlus topic pages. These contextual links allow users to navigate between the sites within their health topic of interest, without starting at the beginning of their subject search as they move from one resource to the other. This context-based navigation is very important in serving the different users from these electronic resources. These subject-based links allow PubMed health professional users to easily link to consumer-level information for their own background material or for a patient or family member. From the consumer resource, MedlinePlus enables consumers, students, clinicians, and anyone else to quickly retrieve the most recent biomedical journal citations on the topic.

NLM uses this same approach to guide users of MedlinePlus and PubMed to ClinicalTrials.gov, a registry of over 13,000 clinical studies sponsored by NIH, other government agencies, and private industry, and to the Genetics Home Reference (http://ghr.nlm.nih.gov), NLM's consumer health guide to understanding genetic conditions and the genes and chromosomes responsible for them (See Figure 1). By creating topical links on each of the tools and others, NLM facilitates users of all categories moving to and from basic health information, clinical trials, or in-depth research reports on a topic as their information needs evolve. NLM creates these interconnec-
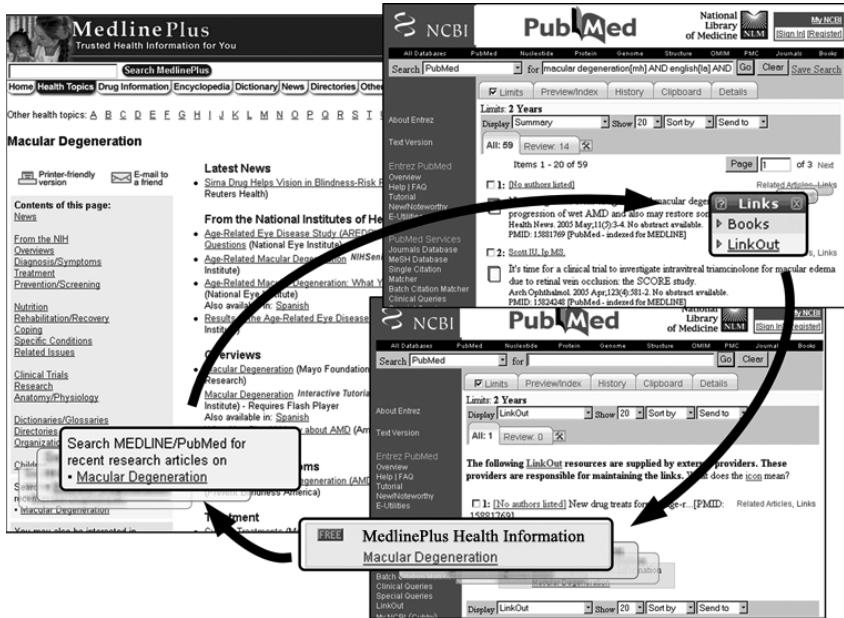
Figure 1. Topical links connect PubMed's biomedical research articles with the consumer health information in MedlinePlus so clinicians, consumers, and all users can easily navigate to other information. Other NLM services, such as ClinicalTrials. gov and Genetics Home Reference, provide comparable links.

tions based on vocabulary mappings from the Medical Subject Headings, the Unified Medical Language System (UMLS), and related vocabulary tools and keeps the links current so clinicians, consumers, and others always have access to the most recent information.

While NLM continues to improve its extensive services for clinicians and the public, it is also expanding services to other audiences. For example, NLM released a Spanish version of MedlinePlus in September 2002 to provide Spanish-language consumer health information for patients and their intermediaries, whether professional or family (National Library of Medicine, 2002). This site now delivers over 9 million pages of authoritative health information each month. More recently, NLM released WISER, a Wireless Information System for Emergency Responders (National Library of Medicine, 2005a). WISER provides critical information on 400 hazardous substances, including substance identification, physical characteristics, human health information, and containment and suppression guidance to first responders and other emergency personnel. NLM extensively tested each of these services with the target audience and made improvements to the service before public release; NLM continues to improve them based

Table 4.   Selected NLM Resources and Target Audience

Resource	Health Practitioners	Consumers
Clinical Trials.gov–Patient studies for drugs and treatment	X	X
GENBANK® –Genetic Sequence Databank	X	
Genetics Home Reference–Genetic conditions and the genes responsible	X	X
Health Services Technology Assessment Texts (HSTAT)– Full-text documents providing health information and support for healthcare decision making	X	X
Household Products Database–Health and safety information		X
MedlinePlus®–Health information for patients, families, and healthcare providers (also in Spanish)	X	X
NIHSeniorHealth–Easily-accessible age-related health information		X
Profiles in Science™–Archival collections of leaders in biomedical research and public health	X	X
PubMed Central™–Digital archive of life sciences journal literature	X	X
PubMed®/MEDLINE®–References including abstracts from thousands of biomedical journals	X	X
TOXNET®–Network of databases on toxicology, hazardous chemicals, and environmental health	X	X
ToxTown–Interactive guide to toxic chemicals and environmental health risks (also in Spanish)		X
Unified Medical Language System® (UMLS®)– Electronic "Knowledge Sources" and associated lexical programs including SNOMED CT®	X	
Visible Human Project®–Three-dimensional representations of the human body	X	X
WISER–Designed to assist first responders in hazardous material incidents	X	

Note: For the Web site addresses of each resource, see *http://www.nlm.nih.gov/databases/.*

on user suggestions and experience. These are just two examples of how NLM continues to reach out to a variety of audiences, using their feedback to create the most useful product possible. Table 4 presents a selected list of NLM databases and resources and their target audience.

To serve new users and also more traditional audiences, NLM uses its strengths in organizing and disseminating authoritative biomedical and health information and in responding to user needs. Achieving this service goal requires dedication to maintaining vocabularies and system-relationships that ensure sensible links for users to navigate among the information resources. Long before computers and the Internet, NLM made these links between biomedical information, physicians, and librarians and continues to maintain those key connections while expanding services to directly serve clinicians and consumers. NLM will continue to serve both clinicians and consumers and others as it moves further into the twenty-first century.

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