
MedlinePlus®: The National Library of Medicine® Brings Quality Information to Health Consumers

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ABSTRACT

The National Library of Medicine's (NLM®) MedlinePlus® is a high-quality gateway to consumer health information from NLM, the National Institutes of Health (NIH), and other authoritative organizations. For decades, NLM has been a leader in indexing, organizing, and distributing health information to health professionals. In creating MedlinePlus, NLM uses years of accumulated expertise and technical knowledge to produce an authoritative, reliable consumer health Web site. This article describes the development of MedlinePlus—its quality control processes, the integration of NLM and NIH information, NLM's relationship to other institutions, the technical and staffing infrastructures, the use of feedback for quality improvement, and future plans.

THE NATIONAL LIBRARY OF MEDICINE BEGINS DIRECT SERVICE TO CONSUMERS

The legislation establishing the National Library of Medicine (NLM) (42 U.S.C. § 286) as a component of the National Institutes of Health (NIH) in 1956 describes the mission of the library as collecting, preserving, and disseminating medical literature as well as making "available its bibliographic, reference, or other services, to public and private entities and individuals." NLM fulfilled this mission for many years by primarily serving health professionals, especially through the MEDLINE® database of references to millions of biomedical research publications. In recent

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years, NLM's governing Board of Regents encouraged NLM to expand its services to the general public of health consumers (NLM, 2000).

When the MEDLINE database became free to the Internet public in 1997, NLM embarked upon this expanded mission of serving the general public. Early studies showed that many MEDLINE users were not professionals and researchers but rather were members of the general public seeking health information for themselves, family members, and friends (*Free MEDLINE*, 1997). MEDLINE began indexing a few consumer-level publications in early 1998 (*MEDLINE to index*, 1998), but it was clear that NLM could do more to provide quality health information for the public. In 1998 NLM began a project with the National Network of Libraries of Medicine (NN/LM) to work with public libraries to better serve health consumers (Wood et al., 2000). This project found that public librarians needed training to become more comfortable providing health information and a trusted place to turn for health content.

With the advice of public libraries and customer feedback from users of other NLM products, NLM released MedlinePlus on October 22, 1998. In creating MedlinePlus, NLM drew upon the skills of medical librarians and information technology professionals to make consumer-level authoritative medical information available to anyone with access to the World Wide Web. Combining this expertise with the strength and authority of NIH and other government and nongovernment organizations, MedlinePlus has become a source of health information to millions of health consumers as well as their health care providers.

HEALTH TOPICS: QUALITY AT THE CORE OF MEDLINEPLUS

Initially, MedlinePlus provided consumers with authoritative health information from the federal government and other organizations. These lists of links, or Health Topic pages, remain the core of MedlinePlus. Health Topic pages are highly selective collections of links to Web documents, not comprehensive lists of everything on the Web. They point consumers to the best Web resources and minimize redundant listings. The experienced biomedical librarians who create and maintain the Health Topic pages organize them into categories such as overviews, diagnosis, treatment, and prevention. They also identify the publishing organization, easy to read materials, and other special features such as pictures, diagrams, and flowcharts. The Health Topic pages function like a table of contents to a virtual Internet book broken down into chapters. This organization helps consumers easily scan the page and provides them with a refuge from the overwhelming amounts or varying quality of Internet health information.

Addressing the Need for Quality

The number and popularity of sites providing health information to consumers constantly increases. This growth heightens concern in the medi-

cal profession about the importance of reliable, quality information (Fox & Fallows, 2003; Licciardone, Smith-Barbaro, & Coleridge, 2001). One study shows that only a quarter of health information seekers check the quality of the Web resources they use (Lewis & Behana, 2001). Many consumers consider a professional-looking Web design with scientific-looking touches to be sufficient assurance of the high quality of the information on the Web site (Eysenbach & Köhler, 2002). Rather than appearance, health information experts know that consumers should look for key characteristics when evaluating a health information Web site. These criteria include author and author affiliation; attribution of sources and references used; information about funding, ownership, and sponsorship of the Web site (Gagliardi & Jadad, 2002); and clear labeling of advertising (Karp & Monroe, 2002).

For MedlinePlus, NLM uses written guidelines to identify and select high-quality information produced by other NIH Institutes, government organizations, and nongovernmental health information providers. The librarians building MedlinePlus Health Topic pages follow the same model that collection development librarians have used for years to create print reference collections, but the Web format creates additional challenges to collection evaluation and selection. MedlinePlus publishes these guidelines so that organizations can evaluate themselves against the selection standards. These guidelines assure users that the information they find on Health Topic pages is reliable and up to date. They cover four main areas:

1. **Quality, authority, and accuracy of content:** Sites must provide the names of their advisory board members or be published by a government agency. MedlinePlus staff check board members' names in MEDLINE and other databases to ascertain whether they have published on the subjects covered by the Web site. If the medical authority of the site is not evident, the MedlinePlus team contacts the site's Webmaster requesting information or clarification.
2. **Purpose of site:** The site's primary purpose must be to provide health information, not to sell a product or service. Intrusive or content-linked advertisements disqualify pages from inclusion. Most of the content must be free and not require registration.
3. **Maintenance:** The site must be consistently available, without broken links, and provide a Webmaster address. Pages must display dates.
4. **Quality, nonredundant content:** Because MedlinePlus is selective, not comprehensive, links on Health Topic should have minimal redundancy. Each linked document provides unique information to the consumer using that Health Topic page. Some links bring users a clear summary of an entire disease or condition, while others bring unique features, such as different reading levels, clear diagrams, illustrations, or interactive programs.

As a government Web site, MedlinePlus offers consumers an Internet experience free from advertisements. The site also uses no cookies and does not request any personal information.

The Language of Health Consumers

Studies of NLM Web site search logs from the mid-1990s revealed that over 70 percent of the searches were for medical information (Miller, 1997). The logs of user terms provided a valuable window into consumers' interests and the vocabulary they used to express their information needs. The Lister Hill National Center for Biomedical Communications used Unified Medical Language System (UMLS) tools to further analyze search logs and created a ranked list of search terms organized by NLM's Medical Subject Heading (MeSH) vocabulary (McCray, Loane, Browne, & Bangalore, 1999). These studies of the language of users' searches gave direction for developing the vocabulary terms MedlinePlus uses to direct users to Health Topic pages.

To best serve consumers, MedlinePlus terminology reflects users' expectations as expressed in their own search words. Once again, NLM staff experience in medical terminology is a key factor in making the MedlinePlus vocabulary work well for consumers. MedlinePlus developers examine a number of vocabularies to create Health Topic names and "see references." NLM's own MeSH vocabulary, developed for health professional literature, provides background for the structure of medical knowledge, but it is often too scientific for consumers. Other medical thesauri that provide inspiration include the Planetree Classification (Planetree Health Resource Center, 1991), the CINAHL Thesaurus (CINAHL Information Systems, 2004), and the terms used on other consumer health Web sites. The final Health Topic page names are based on considering all these sources.

For Health Topic pages, MeSH terms are preferred when they coincide with consumer use in search logs, consumer-focused documents, and other sources. For example, MedlinePlus has Health Topic pages that use MeSH terms for cataract, fibromyalgia, and multiple sclerosis. In contrast, there are Health Topic pages for heart attack rather than myocardial infarction, breast cancer rather than breast neoplasms, and high blood pressure rather than hypertension. In other cases, MeSH does not have certain consumer concepts, such as club drugs or men's health. In these cases, MedlinePlus uses the consumer term. MedlinePlus includes liberal "See references," so more technical versions or synonyms become links in alphabetic topic lists. This process of using customer suggestions and search behavior to improve MedlinePlus keeps the quality, usability, and customer satisfaction at the highest level possible.

Integrating Medical Subject Headings into MedlinePlus.

Although MedlinePlus displays a unique consumer vocabulary, the links from MedlinePlus to other NLM resources depend on MeSH. Behind the scenes, software allows MedlinePlus staff to link MeSH vocabulary with

Health Topic pages. The MedlinePlus management system generates the files that allow MedlinePlus to link to MeSH-based NLM resources. For example, one file creates the links between ClinicalTrials.gov and MedlinePlus. These links allow users of ClinicalTrials.gov to learn more about medical conditions in research trials and MedlinePlus users to find clinical trials on a particular condition. Another file enables PubMed/MEDLINE to link from biomedical article references to MedlinePlus Health Topics. These PubMed/MedlinePlus mappings allow users to select the "Consumer Health" LinkOut text from PubMed/MEDLINE and immediately explore that Health Topic page on MedlinePlus. Librarians maintaining MeSH in MedlinePlus keep it up to date with annual changes and improvements to MeSH and the systems themselves.

RELATIONSHIPS WITH NIH INSTITUTES AND OTHER ORGANIZATIONS

As a part of the NIH, NLM is an important partner in bringing the knowledge of the United States' premier biomedical research organization to the public. NLM staff work with the staff of other NIH Institutes who write and publish unbiased, well-reviewed information for consumers. NLM provides feedback from MedlinePlus users to the institutes that they consider as they determine priorities and policy direction.

Leveraging NLM's Strengths as an NIH Institute

NIH Content and Collaboration NIH consumer health documents are an integral part of MedlinePlus. Each MedlinePlus Health Topic page features a link to the institute with primary research responsibility for that disease, condition, or health issue. These institute links connect users to a premier research organization for additional resources as they seek information.

The NIH MedlinePlus Advisory Group is key to ensuring the quality and direction of MedlinePlus (*MedlinePlus Counts on Input*, 2003). This group consists of public information office managers who are responsible for information dissemination to the public from the NIH Institutes, such as the National Cancer Institute and the National Institute of Diabetes and Digestive and Kidney Diseases. The advisory group meets three times a year to learn about new MedlinePlus developments, advise on future directions, and inform each other about new projects and resources. This group ensures good coordination and communication between NIH organizations providing health information to consumers and contributes to the quality of all the NIH consumer Web information. Staff from these offices interact with NLM staff throughout the year to improve NIH content linked from MedlinePlus.

Non-NIH Organizations The MedlinePlus Health Topic Pages link to documents from hundreds of organizations. These organizations include well-known professional organizations (American Academy of Family Phy-

sicians, American Academy of Orthopaedic Surgeons), large voluntary associations (American Heart Association, American Diabetes Association), groups dealing with a specific problem (Lupus Foundation of America, Macular Degeneration Partnership), and well-known health care organizations (Mayo Clinic, National Jewish Research and Medical Center.) While selecting and maintaining these links, MedlinePlus staff often contact these organizations and encourage them to follow the MedlinePlus selection guidelines on their health Web sites. Requests range from dating pages, to updating older documents, to removing registration requirements from sites. By working directly with these health information producers, MedlinePlus serves the public by encouraging as many as possible to adhere to the selection guidelines. Many of these contacts have evolved into ongoing cooperative relationships and link exchanges.

Enhancing MedlinePlus with Licensed Content

One goal of a collection development librarian is to cover a subject as completely as needed by the patron. Biomedical librarians construct MedlinePlus Health Topic pages to provide as complete a consumer resource as possible on a disease or condition. However, topic coverage depends on organizations to publish documents that meet the selection criteria. Examinations of "zero hit" terms from MedlinePlus search logs show that Health Topic page links do not cover all medical issues of interest to consumers. Licensed content supplements the Health Topic pages in areas where authoritative Web content is not available. MedlinePlus licenses drug information, a medical encyclopedia, health news, a medical dictionary, and low-literacy interactive health tutorials and makes them freely available to the public for personal use. These materials supplement the information provided on the Health Topic pages. They are kept up to date by the licensed content providers and make up an important component of the Web site. All MedlinePlus licensed content is available at no charge. Users may read and print all these materials; in addition, they may email single copies of many materials to share with family and friends for personal use.

LEVERAGING NLM'S STRENGTHS

The MeSH vocabulary is the key to linking MedlinePlus users to other NLM products. Staff make these links behind the scenes in the systems that manage the vocabulary. These systems create the links that provide options for consumers to navigate between MedlinePlus, PubMed/MEDLINE, ClinicalTrials.gov, and Genetics Home Reference.

Integrating NLM Products and Services into MedlinePlus

PubMed/MEDLINE Customer feedback and other research have taught NLM that patients and families need information at a variety of levels. For users who want to read research literature, MedlinePlus integrates

PubMed/MEDLINE searches of peer-reviewed biomedical journal citations into the Health Topic pages. Expert searchers from the Library's Reference and Customer Service Section create "prepackaged" searches tailored for consumers and review them twice a year to maintain quality. These searches retrieve citations to English-language review articles, evidence-based medicine, and consensus practice guidelines, and run on demand when the user selects one. Patients and families coping with a serious or chronic illness use this feature to learn more advanced information or to keep up with the latest developments on a disease or condition. Health practitioners report using the searches as a quick start in areas outside their expertise.

ClinicalTrials.gov In February 2000 NIH launched the ClinicalTrials.gov database (*National Institutes of Health Launches*, 2000), providing consumers with access to medical research studies that seek to evaluate the safety and effectiveness of new drugs, medical procedures, or other means of treating, diagnosing, or preventing diseases. The database is built by the NLM's Lister Hill National Center for Biomedical Communications. To deliver the most recent information to consumers, the MedlinePlus ClinicalTrials.gov link performs a new search each time a consumer uses it. These searches retrieve clinical trials currently recruiting patients on the subject of the MedlinePlus Health Topic pages. Once again, biomedical librarians use their well-honed search and retrieval skills to review links every six months and after the annual MeSH vocabulary changes.

Genetics Home Reference The Genetics Home Reference (GHR) is a recent addition to NLM's consumer health information Web sites (*Genetics Home Reference*, 2003). Produced by the Lister Hill National Center for Biomedical Communications at NLM, the site provides in-depth information on dozens of genetic conditions, such as Marfan's syndrome, as well as other conditions with a genetic component, such as breast cancer. Again, the GHR records link to MedlinePlus pages and vice versa using MeSH and a mapping file maintained by MedlinePlus librarians.

Libraries Assisting Consumers

NLM is the world's largest medical library, but it depends on collaboration with other libraries to provide consumer health information wherever consumers need it. Sometimes that "location" is the Internet. Other times, it is a local library. The public library pilot project showed that consumers prefer that health sites provide full-text information they can print on demand. They also expect local access to libraries where staff can help them find information when they need it. These consumer expectations are why MedlinePlus Health Topic pages link, wherever possible, to pages of full-text information, not to other portals or lists of links. Today, public libraries throughout the United States use MedlinePlus as a primary health resource for their patrons and continue to provide valuable feedback.

Linking Consumers to Libraries

From its inception, MedlinePlus provided consumers with a single page of links to biomedical libraries willing to serve consumers. This list was incomplete because it depended on libraries contacting MedlinePlus staff to request a listing. In the spring of 2003 MedlinePlus began to build the library directory pages from a database of "Institutions" in NLM's interlibrary loan system, DOCLINE. NLM added the ability for DOCLINE libraries to choose to be listed in the MedlinePlus directory of biomedical libraries willing to serve consumers. Each library listing includes its address, phone number, and Web site URL. MedlinePlus library pages include over 600 libraries from the United States, Canada, U.S. territories, and foreign countries. Forty-nine states list at least one library (the smallest states, Rhode Island and Delaware, each list three), and many states list dozens (Colorado lists forty-one, and Michigan lists thirty-two). Through DOCLINE and MedlinePlus, every biomedical library can offer their expert services to health consumers.

MedlinePlus en español

Public librarians in the pilot project as well as many others requested that MedlinePlus expand and provide Health Topic pages entirely in Spanish to assist them in providing information to Spanish-speaking patrons. In response to these requests and to better serve the Spanish-speaking populations, MedlinePlus en español (<http://medlineplus.gov/esp>) made its debut in September of 2002 (*Medlineplus goes Spanish*, 2002).

MedlinePlus en español contains over 600 Health Topic pages with thousands of links to information that meet the same selection guidelines as those on the main site. The Spanish-language site also includes drug information, an encyclopedia, news, and Spanish-language interactive tutorials. For non-Spanish speakers, a single click on the español link leads from the English content to its corresponding Spanish content.

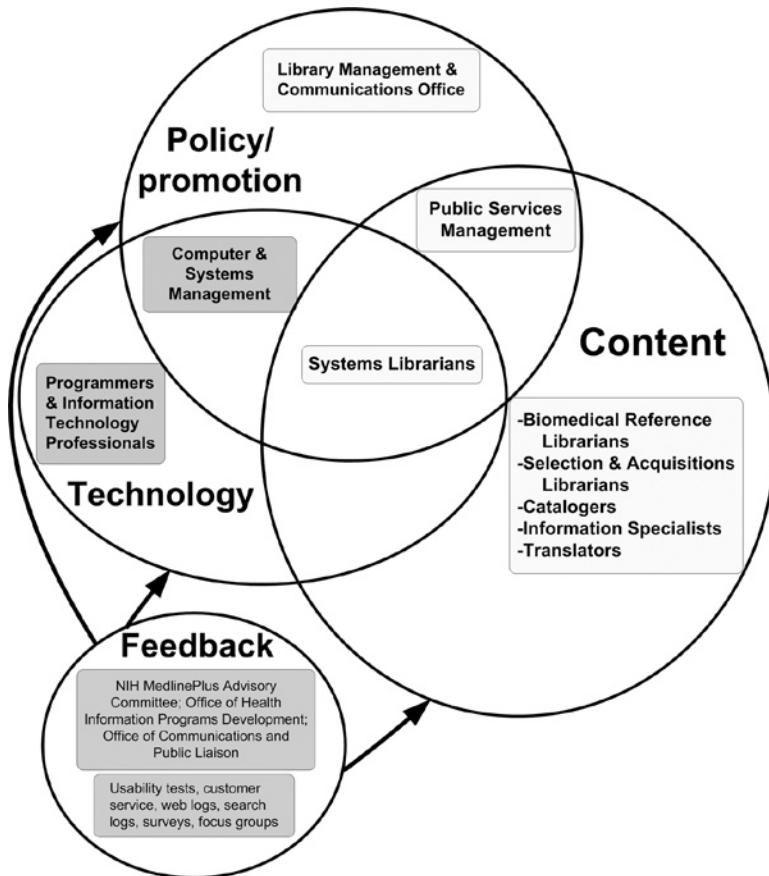
The processes for developing Spanish Health Topic pages are designed to maintain the same high-quality standards that govern the MedlinePlus Health Topic pages in English. These parallel procedures manage Spanish-language Health Topics and associated vocabulary. Bilingual medical librarians select and review Web site records, build new topics, and update existing topics every six months. MedlinePlus en español uses the same selection guidelines as the MedlinePlus site. However, the Spanish-language site links to more information from local governments, university departments, and international sources than the English version because there are not as many Web documents available in Spanish from national U.S. organizations. By using the same procedures and guidelines that have proven vital to the success of MedlinePlus, MedlinePlus en español provides authoritative, quality information.

MEDLINEPLUS STAFFING, ROLES, AND WORKFLOW

Staffing

Staff positions for MedlinePlus include librarians, computer specialists, managers, and others. MedlinePlus is a collaborative effort among several NLM departments. Medical librarians at medical schools and hospitals contribute their expertise to MedlinePlus through several contracts. Figure 1 provides an overview of staff functions for policy, content, technical demands, and feedback, all important aspects of maintaining a quality site. MedlinePlus draws upon staff strengths throughout NLM. MedlinePlus benefits from name authority and selection expertise from the Technical Services Division, promotion and evaluation expertise from its Office of

Figure 1. MedlinePlus staffing.



the Director, health information expertise from the Reference and Customer Services Section, and programming and technical skills from the information technology department. The strength and quality of MedlinePlus comes from each NLM organization contributing its best expertise to benefit the health consumer.

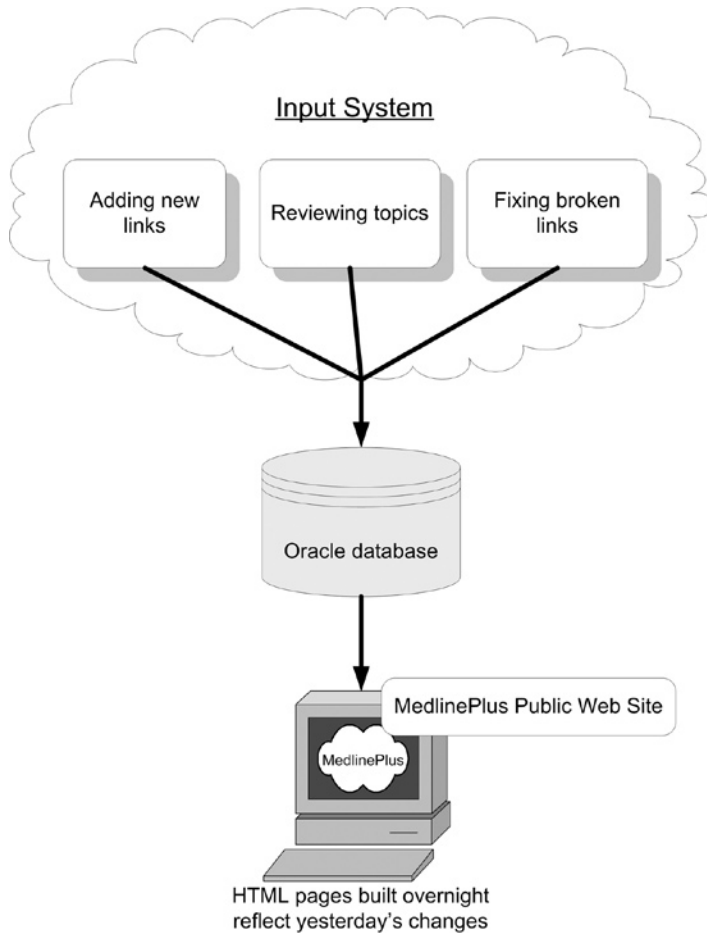
Keeping the content of the MedlinePlus Health Topics pages maintained at a high standard requires two primary categories of librarians: selectors and reviewers. Selectors search the Web for appropriate materials, apply the selection guidelines, enter records into the database, and review Health Topic pages every six months. Records include information such as the name of the page, URL, type of site (NIH, other government agency, or nongovernmental organization), MedlinePlus Health Topic, and the organization responsible for the page. These selectors can work anywhere they have a computer with a browser and an Internet connection.

Selectors enter information for pages they choose to add to a Health Topic page and also for Web pages that do not meet the MedlinePlus selection guidelines. The MedlinePlus staff records these decisions for several reasons: to record the decision for other selectors who find that Web page later, to hold the information while staff contact the organization and ask them to correct a problem, and to review the Web site later during Health Topic Page review. Selectors and reviewers make notes that become a record of the decisions made regarding a Web page so that the corporate memory retains this information even as the people change.

Reviewers, the second category of users, release selectors' work to the public site or return it to selectors for revision. Their eyes provide the last check before information appears to the public. These senior librarians also perform overall management tasks that include creating new Health Topics, subcategories, and "see references"; releasing records and Health Topics to the public; and performing system management functions like adding new users and removing obsolete records. These persistent review processes and daily link fixes keep MedlinePlus as up-to-date and accurate as possible in the world of constantly changing medical information and Web sites (Figure 2).

A small team of NLM staff oversees the overall process of content quality assurance. A content manager from the Public Services Division Web team approves requests for new topics and resolves conflicts of opinion as they arise. MedlinePlus en español has a corresponding content manager who serves this role for that site. An acquisitions librarian from the Selection and Acquisitions Section evaluates organization information at least annually. A Topic Manager from the Reference and Customer Services Section maintains the schedule of topic reviews and identifies high-profile topics for quick review on an as-needed basis. The MedlinePlus content team meets with all selectors and reviewers monthly via teleconference and posts meeting summaries on an internal listserv. Once again, each of these staff

Figure 2. MedlinePlus input system diagram.



members contributing their specific information skills adds to the quality and accuracy of MedlinePlus.

Building a Maintenance System for MedlinePlus

NLM staff created a few basic HTML pages for the MedlinePlus prototype in the summer of 1998. While creating this prototype, staff quickly realized there were many problems of consistency, reliability, and scalability if this simple approach were used for an entire health information Web site. With manually developed HTML pages, two staff members might find the same Web page and describe it in two different ways. Staff indexing a page called "Stroke Risks: High Blood Pressure Can Lead to Stroke" might use both a title and subtitle on the high blood pressure page but use only

its title on the stroke page. For consistency and maintenance, Web document links need the same description every place they appear on the site. A database was the answer for developing a large Web site and maintaining it in good working order.

The MedlinePlus development team turned to NLM's Office of Computer and Communications Systems (OCCS) to develop a system to create, review, and maintain MedlinePlus. OCCS recommended using a database to ensure consistency of vocabulary and descriptions. The database also allows staff to create and maintain records centrally for display on multiple MedlinePlus pages. They also recommended that the public Web site not use the database directly but rather an HTML version of the site. This structure allows NLM to deliver pages quickly and securely to the public and to use existing Web management tools including a search engine, link checker, and Web statistics software. The MedlinePlus system combines an Oracle database, which stores all data, with a Cold Fusion Web forms-based system to control the data and workflow (Figure 2). Today, this Web-based system design ably serves the MedlinePlus public and allows medical librarians at geographically dispersed sites to perform any MedlinePlus update or maintenance task.

FEEDBACK DRIVES FUTURE PLANS

Customer feedback of many types drives improvements to MedlinePlus. NLM staff gather this feedback through both passive and active collection. Passive collections of user behavior such as examining search engine and Web activity logs guide MedlinePlus toward better serving user needs. The medical terms users type into the search box are a valuable source of consumer feedback. These search terms suggest new MedlinePlus topics and "see references," requests to NIH Institutes to develop new materials, and new variations for the list of misspelled words for the search engine to map to correct spellings. Web traffic logs provide information about the most used pages and those that consumers use less frequently. Use statistics guide the list of frequently requested topics on the Health Topics home page and suggest topics for MedlinePlus home page features.

NLM also solicits active user feedback for advice on MedlinePlus improvements. Customers send thousands of unsolicited comments each year using the "Contact Us" link on every page. Other active methods include online surveys, focus groups, and usability tests. Before each released improvement to the site, focus groups and usability testing provide staff with insight into how consumers use MedlinePlus and how it does or does not meet their expectations. As the Internet and Web change, so do users' skills and expectations, and MedlinePlus endeavors to change with consumers. Gathering feedback via multiple methods and making improvements suggested by consumers is an important key to maintaining user confidence in the quality and reliability of MedlinePlus.

INTO THE FUTURE

NLM is undertaking several new initiatives to enhance MedlinePlus. Linking consumers from authoritative health information to information about health services in local geographic areas is the focus of the "Go Local" project. The goal is that a MedlinePlus user on the breast cancer page using the "Go Local" link is presented with a page listing cancer clinics, oncologists, support groups, and other providers, programs, and services. The University of North Carolina at Chapel Hill (UNC) developed the first Go Local site, NC Health Info (<http://www.nchealthinfo.org>). The NC Health Info team built a database of local Web sites, an input and maintenance system, local and MedlinePlus vocabulary mappings, and a Web interface. Since then the University of Missouri has linked its Community Connection Web site (<http://www.communityconnection.org>) to MedlinePlus. Both Missouri and North Carolina support all of the technical hardware and software involved in providing a large-scale Web site to the public.

NLM is releasing a Go Local hosting system, which it will maintain centrally, to help states and regions make services available to residents and their families and friends. Using this system, Go Local teams will create and update content on a system where NLM maintains the hardware, software, vocabulary mappings, user interface, and statistics for the site. The NLM-supported model will be available in 2004 for Go Local sites to begin creating new Go Local resources to benefit residents of their state or region. NLM will work with the local sponsors to release these Go Local sites as they are ready.

MedlinePlus will also focus more on content for specific audiences. The Easy-to-Read pages were the first of these specialized pages. Released in November 2003, they gather together materials that sponsoring organizations identify as suitable for low-literacy consumers and display them by health topic. MedlinePlus also displays pages that list links for low-vision users. Using technologies developed for another NLM consumer health Web site, NIHSeniorHealth, the low-vision page brings together health information with enhanced accessibility features such as the ability to change the contrast and enlarge the font. In the future, other special pages will be developed.

SUMMARY

Since its inception in 1998, MedlinePlus has evolved from a handful of Health Topics linking to NIH, other government, and nongovernment consumer health information to over 650 Health Topics linking to information from nearly 1,000 organizations. To meet consumer needs and expectations for health information, MedlinePlus licenses drug information, interactive health tutorials, a medical dictionary, and an illustrated encyclopedia. NLM has instituted computer system and human processes that build on the strengths of staff at NLM and elsewhere to create the highest-quality

consumer health information portal possible, and consumers continue to respond by visiting the site by the millions. The National Library of Medicine is committed to continuing to improve MedlinePlus so that it will remain an authoritative, quality Web site for consumer health information.

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