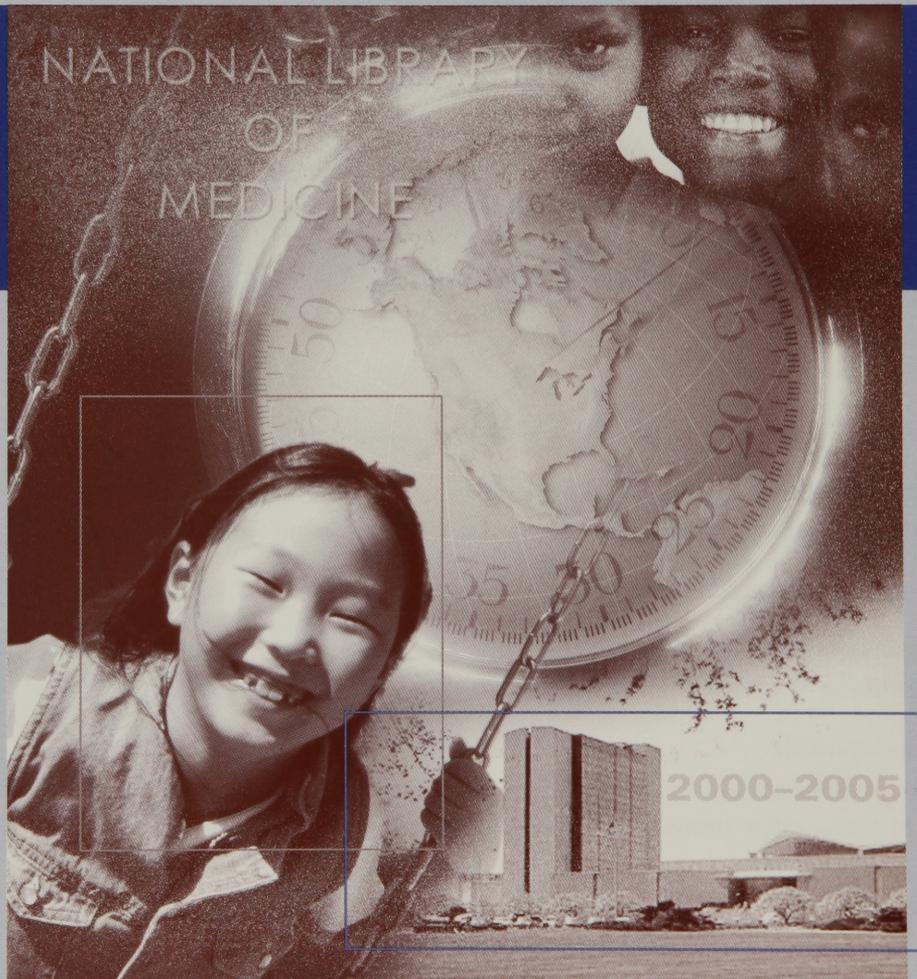


**REPORT OF THE  
BOARD OF REGENTS**

**NATIONAL LIBRARY OF MEDICINE**

# **Long Range Plan 2000-2005**



**U.S. Department of Health and Human Services  
Public Health Service  
National Institutes of Health**

National Library of Medicine (U.S.). Board of Regents

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**FOR ACCESS TO ALL OF NLM'S PREVIOUS PLANNING DOCUMENTS, SEE**  
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*<http://www.nlm.nih.gov>*

U.S. Department of Health and Human Services  
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## FOREWORD

The National Library of Medicine has a very successful 15-year history of long range planning. In 1985, the NLM Board of Regents undertook to develop a 20-year Long Range Plan to guide the Library in using its human, physical, and financial resources to fulfill its mission. Supplemental reports in the years following addressed specific topical areas, such as outreach to underserved health professionals and electronic imaging, that required a fresh look due to dramatic changes in the social and technological landscape in which the NLM operates. The Library's planning efforts have led to major new programs—such as Outreach, the Visible Human, and Biotechnology Information. They have guided the Library in resource allocation and program direction. Of course, the Board recognizes that as time passes, the Library must maintain the flexibility to be opportunistic and take advantage of changing circumstances.

In 1999, the Board of Regents asked the Director to prepare a new Long Range Plan for the Library for the next five years. The Track Record, prepared as a first step in this process, summarized these past planning efforts, and noted specifically those recommendations that have been substantially accomplished, and those that require additional attention and/or a re-direction of program efforts. The Long Range Plan for 2000-2005, reaching as it does for a time horizon of five years hence, brings closure to the 20-year cycle begun earlier. “Long range”? Perhaps not in a literal sense, but perhaps long and realistic enough in today's dramatically changing information technology environment, in which we encounter also a “new biology” that is fundamentally recasting the biomedical research process, and a health care delivery system that is often driven by seriously conflicting demand characteristics.

One can speculate 10 years out on what the future may bring. Such vision statements have value in stimulating thinking, and they have played a useful role in the discussions of our planning panel advisors, the NLM staff, and members of the Board of Regents in the course of developing the present Plan. We offer some of these “visionary scenarios” for the next 10 years in Appendix 1.

As with any strategic plan, it is sensible to allow for mid-course corrections as events unfold. The Board wholeheartedly endorses this Long Range Plan and is grateful to the Director and the staff of NLM for preparing it.

Enriqueta C. Bond, Ph.D.  
President, Burroughs Wellcome Fund  
Chair, NLM Board of Regents

## PREFACE

NLM's fundamental priority is to sustain the collections of the Library and to provide high quality library and information services. All this, of course, modulo our changing times.

For NLM, the actual core of the information we acquire, organize, preserve, and disseminate has been changed radically by scientific progress and discovery, e.g., the molecular genetics discoveries. The means by which we give access to our holdings has changed from bound volumes to telecommunication networks. And lastly, the users we serve have changed to include patients, families, and the public in addition to our historic use by health professionals, scientists, and the librarians and other information professionals who serve them. Consequently, we are especially grateful for the advice embodied in this Plan.

In addition to our traditional roles, the Plan emphasizes seven important areas for new emphasis:

- Health information for the public
- Molecular biology information systems
- Training for computational biology
- Definition of the research publication of the future
- Permanent access to electronic information
- Fundamental informatics research
- Global health partnerships

Rather than being a fixed sequence of steps by which all of NLM's goals and objectives are to be accomplished, this document is a map for the future and a set of opportunities that await NLM action and program development. Operational plans will be developed by NLM and its Board of Regents within resource limitations.

This Plan is based on the work of many advisors, colleagues, friends, Board members, and NLM staff. On behalf of the National Library of Medicine, I wish to thank all those who so graciously contributed their time, effort, and thoughts to this careful and penetrating statement.

Donald A.B. Lindberg, M.D.  
Director, National Library of Medicine

### EXECUTIVE SUMMARY

Over the past half century, the nation's investment in scientific research has resulted in unprecedented revolutionary progress in biological, medical, and material sciences. Information technology holds the promise of delivering specific knowledge in a timely manner to billions of people worldwide, in ways undreamed of even a short time ago. The National Library of Medicine (NLM), in pursuit of its longstanding mission to acquire, organize, and disseminate health-related information, now has the opportunity to provide near-instantaneous reliable access to high quality health information resources when and where decisions are made. Careful planning and visionary thinking are needed to assure that we can reach this ambitious goal.

**This Long Range Plan contains four overall goals:**

- 1. Organize Health-Related Information and Provide Access to It**
- 2. Encourage Use of High Quality Information by Health Professionals and the Public**
- 3. Strengthen the Informatics Infrastructure for Biomedicine and Health**
- 4. Conduct and Support Informatics Research**

Within these four goals are eleven objectives and over one hundred specific program plans. Ongoing emphases—such as providing basic library services—will continue.

Additionally, the NLM Board of Regents has identified its highest priority new initiatives for special emphasis in the next five years. They are introduced below and are discussed in the following chapters.

#### RECOMMENDED PRIORITIES FOR NEW EMPHASIS:

- HEALTH INFORMATION FOR THE PUBLIC
- MOLECULAR BIOLOGY INFORMATION SYSTEMS
- TRAINING FOR COMPUTATIONAL BIOLOGY
- DEFINITION OF THE RESEARCH PUBLICATION OF THE FUTURE
- PERMANENT ACCESS TO ELECTRONIC INFORMATION
- FUNDAMENTAL INFORMATICS RESEARCH
- GLOBAL HEALTH PARTNERSHIPS

#### HEALTH INFORMATION FOR THE PUBLIC

NLM has historically focused its services and products on an audience of health professionals and biomedical scientists. With widespread deployment of computers and telecommunications, the time is now right for NLM to provide access to health information that is useful both to the general public and to practitioners

who need information outside their particular field of expertise. The managed care environment is pushing members of the public to take responsibility for their health by becoming well-informed patients. Increasingly members of the public and health professionals turn to the Internet for information, where there are already thousands of health-related

Web sites, including many with inaccurate, out-of-date, or misleading information. As the world's largest medical library, NLM has a responsibility to develop technologies and information systems that meet the public's interest in accurate, current, and understandable health information. NLM should partner with federal agencies, voluntary health organizations, and others to identify gaps, arrange for development of understandable content, and help the public make effective use of electronic health information. NLM should also promote research on ways that information services can improve personal health care decisions and outcomes. (see Goal 2)



### **MOLECULAR BIOLOGY INFORMATION SYSTEMS**

NLM should continue its commitment to organize genomic data to meet the rapidly evolving genome research agenda. The explosive growth in the fields of genetics and molecular biology, spurred largely by the worldwide success of the Human Genome Project, has resulted in staggering volumes of data that have increased by many orders of magnitude over the past decade. Looking beyond the sequencing and mapping achievements of the Human Genome Project, the research focus turns to analysis of the whole genome and application of this knowledge to medical practice. NLM should continue to play a key role in developing the genomics resources needed for comprehensive analysis of the human genome. The challenge for the next decade will be to keep pace with the flood of genome data, while also designing the tools and databases for the gene discoveries of the 21st century—discoveries that will advance



understanding of molecular processes affecting human health and disease. (see Goal 4)

### **TRAINING FOR COMPUTATIONAL BIOLOGY**

The nation's biomedical research enterprise needs more trained professionals in computational biology, including mathematical modeling in the life sciences, imaging and molecular biology. NLM should contribute to National Institutes of Health (NIH) efforts to increase the number of people who are trained in computational biology, by building on its unique informatics training program that bridges the gap between basic and clinical research. (see Goal 3)

### **DEFINITION OF THE RESEARCH PUBLICATION OF THE FUTURE**

NLM should play an active role in defining the research publication of the future. Electronic methods for disseminating biomedical research results (such as PubMed Central) are being developed, keeping pace with the rapid improvements to electronic computing and communications technologies. As a major player in the management of scientific information, NLM should contribute to the development of new forms of publishing which can provide more rapid exchange of information, increased multimedia capabilities, the opportunity for lower dissemination costs, and wider global accessibility. Increasing the usefulness of and speed with which information can be disseminated and exchanged contributes toward the NLM's underlying goals of furthering science and improving public and personal health. (see Goal 1)

## **PERMANENT ACCESS TO ELECTRONIC INFORMATION**

The rapid increases in electronic publishing and technological change make the problem of ensuring long-term access to electronic information difficult. NLM must be a leader in responding to the problem of impermanence of electronic information. As a creator, organizer, and disseminator of information in electronic form, NLM has a responsibility to contribute to the development of technical methods and affordable collaborative strategies. Success will require collaboration with other libraries and a range of stakeholders to develop the necessary technical standards, and scalable national and international approaches required to ensure permanent access. (see Goal 1)

## **FUNDAMENTAL INFORMATICS RESEARCH**

Advances in computing, storage, and communications provide new opportunities for productive basic research in such medical informatics areas as data and knowledge capture, knowledge and concept representation, the marriage of expert and clinical information systems, medical natural language processing, indexing, and information retrieval, and integration of disparate information sources, including multi-media resources. Technical advances also enable research and development in Digital Libraries, including large scale image and multimedia databases. NLM should increase resources for extramural and intramural research in these areas.

A major problem for research is how to build robust systems that tailor “just in time” answers to specific questions that occur to busy clinicians in the context of direct patient care. NLM should explore the potential of research and development in information systems that move beyond information retrieval to provide specific knowledge needed for clinical decision-making. A related research issue is how to help patients and families find information specific to their immediate health concerns. (see Goal 4)

## **GLOBAL HEALTH PARTNERSHIPS**

The increasing globalization of knowledge has made it clear that domestic and international functions of the NLM are not separable. The international mission of NLM is reaffirmed. NLM should implement the recommendations contained in the recently completed planning panel report, “A Global Vision for the National Library of Medicine.” In particular, the library should focus on establishing new partnerships to leverage its resources. It should also seek to improve the effectiveness of the international initiatives of others (e.g., health science centers and libraries, research funders, donor organizations, non-governmental organizations, etc.) through improved access to and use of new computer and information technology and knowledge management tools. It is important that NLM carefully select targets of opportunity for involvement in areas of the world where NLM can make a difference. (see Goal 3)



## GOALS AND OBJECTIVES

### GOAL 1. ORGANIZE HEALTH-RELATED INFORMATION AND PROVIDE ACCESS TO IT

The advanced information products and services of the National Library of Medicine are built on the foundation stone of its unparalleled collections. They are broad (encompassing all the health sciences) and deep (from the 11th century to the present). The Library today is seen as a principal source of biomedical information and the NLM's many high-technology programs are infused with the confidence and competence resulting from a century and a half of experience in filling the information needs of health professionals. The Library continues to place primary emphasis on its role as acquirer, organizer, and disseminator of health-related information.

#### OBJECTIVE 1.

#### ACQUIRE, ORGANIZE, AND PRESERVE BIOMEDICAL INFORMATION

##### FINDINGS

The NLM continues to accord the highest priority to maintaining the integrity of its collections and serving as the library of last resort for the worldwide biomedical literature. Over the past decade, the Library assessed and enhanced its collection and bibliographic databases in molecular biology and genetics and in health services research and health technology assessment in support of major new programs in these areas. The Library has also been placing increasing emphasis on new forms of information (for example, electronic journals and computer software). The content of NLM databases has been enriched with additional types of material such as conference proceedings, clinical practice guidelines, consensus development reports, newsletters, and book sections. NLM has used advanced technology to enhance access to unique historical materials in Profiles in Science, Images from the History of Medicine,

and online historical exhibitions. Under NLM's system reinvention effort, a commercial integrated

library system has replaced an assortment of custom-built, mainframe-based processes that control acquisitions, serials, cataloging, collection management, circulation, preservation, and binding. A continually evolving online indexing system streamlines the handling of the biomedical literature for MEDLINE, from the time a journal issue arrives at the Library until it is entered into the database. More than two-thirds of MEDLINE citation and abstract data is now either received in electronic format directly from publishers or rapidly scanned into the database. NLM continues to participate actively in the evolution of cataloging, bibliographic citation, and preservation standards and practices. The Library's SGML formats required for publisher submission of MEDLINE citation and abstract data have had a standardizing effect on the structure of electronic biomedical journals.

In the area of preservation, the NLM led a successful campaign to increase dramatically the amount of medical journal publishing done on "permanent" (non-acid) paper. The Library has also made substantial progress on microfilming brittle monographs and serials; adopted a modern disaster prevention and recovery program; and established an in-house book repair laboratory. Ensuring permanent access to electronic publications, however, is a subject of increasing concern within academia, government, industry, and others interested in seeing that digital information does not disappear. NLM monitors related developments in standards, technology, collaborative strategies, and public policy, while working on practical approaches for its own electronic output.



## PROGRAM PLANS

### ORGANIZATION OF ELECTRONIC INFORMATION

- Continue to organize selected authoritative electronic information written for the general public with an emphasis on science-based, nationally applicable information.
- Develop and implement a national strategy for organization of high-quality electronic biomedical and health information aimed at any of NLM's user groups, in collaboration with the National Network of Libraries of Medicine (NN/LM) and other appropriate partners.
- Work with Federal agencies and other interested organizations to provide organized access to health data sets and other tools used in health services research.
- Continue to expand the use of publisher-supplied electronic data and to experiment with automated indexing techniques as a means for improving access to selected information (e.g., gene names, methodologies, research populations) and for reducing the level of human effort involved in indexing and cataloging.
- Modify NLM's technical processing, indexing, and document delivery systems and procedures to handle documents born digitally as efficiently as print materials are now handled.

### PERMANENT ACCESS TO ELECTRONIC INFORMATION

- Take a leadership role in ensuring permanent access to important digital materials in health and biomedicine, including electronic journals, databases, documents published on the Web, and new kinds of scholarly communication and documentation of knowledge, using NLM's own electronic output and services as initial test-beds.
- Work with national libraries and other appropriate organizations to develop, test, and implement standards and strategies for permanent access to electronic information.

### ENHANCING AND PRESERVING ACCESS TO RETROSPECTIVE AND HISTORICAL MATERIALS

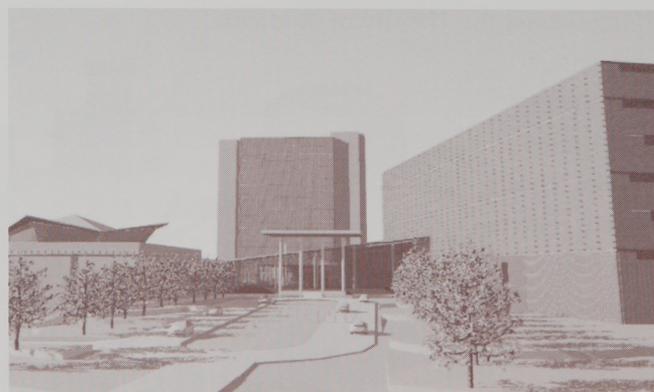
- Continue digitization of NLM's retrospective indexes and catalogs.
- Continue to organize and digitize selected portions of NLM's unique manuscript collections, with emphasis on expanding Profiles in Science.
- Identify important and unique retrospective biomedical collections held by other institutions, including historically significant records of modern biomedical and health services research, and develop a national strategy to promote enhanced access and preservation.

### SCOPE OF NLM'S COLLECTION AND DATABASES

- Expand coverage of emerging multidisciplinary areas in the health and life sciences (e.g. aquatic toxicology, plant genetics, biophysics, environmental geochemistry, chemoecology).
- Continue efforts to improve coverage and retrieval mechanisms for those working in the multidisciplinary areas of health policy and public health, including expanded access to environmental and toxicological data and to technical reports and other "grey literature," which is increasingly available on the Web.

### PHYSICAL SPACE

- Develop and implement plans for expanding and improving the physical housing of the NLM collection.



## OBJECTIVE 1.2.

### PROVIDE ACCESS TO BIOMEDICAL INFORMATION

#### FINDINGS

The Library has made good use of evolving communications technology to improve how health professionals and others gain access to biomedical information. First Grateful Med, and later Internet Grateful Med and PubMed, introduced health professionals and other end-users to easy searching of MEDLINE and other NLM databases. The introduction of free access in 1997 made NLM's databases available to anyone with an Internet connection. Internet Grateful Med and now PubMed use information from the Unified Medical Language System (UMLS) Metathesaurus to improve retrieval for MEDLINE users. Over the past decade, NLM developed a suite of health services research databases as part of a new legislatively mandated health services research information program. Special efforts were made to enhance the content and usability of NLM's environmental health and toxicology databases.

To provide access to original or full-text materials, the Library inaugurated DOCLINE in the mid eighties to electronically route interlibrary loan requests based on the journal holdings of NN/LM members. Since the early nineties "Loansome Doc" has allowed individual MEDLINE users to participate in the interlibrary loan system by entering requests for articles at their terminals. Both systems are currently being upgraded as part of NLM's System Reinvention effort, which has also led to the implementation of Relais, a system that uses scanning and electronic communications technology to allow NLM to fill interlibrary loan requests much more quickly and efficiently.

In the arena of electronic access to full-text documents, the Library has provided online access to the full-text of clinical practice guidelines since the early nineties. Links between PubMed/MEDLINE and over 1100 journal publisher Web sites now permit users to get



the text of many articles referenced in the database electronically. NLM now provides links to evaluated health information for the consumer that is published on the Web in MEDLINEplus, introduced late in 1998.

#### PROGRAM PLANS

##### DEFINING THE RESEARCH PUBLICATION OF THE FUTURE

- Manage the development of NIH's "PubMed Central" to broaden and ensure long-term access to electronic scientific reports, selected textbooks, and other materials in the life sciences, including multimedia data as an integral part of publication where appropriate.
- Address fundamental issues of electronic publication such as the structure, creation and optimal use of digital documents, navigational tools needed to search them, and necessary user interfaces.
- Work with publishers of biomedical journals to develop guidelines concerning the conversion of content currently provided in print issues to electronic formats, to provide more access to full-text journals on line, via easy links from MEDLINE citations and abstracts, and to standardize practices among science and medical publishers in licensing, URL addressing, and electronic backfile archiving.

## **DATABASE SEARCHING**

- Continue to improve NLM's retrieval interfaces to serve the needs of the general public, health professionals, biomedical, clinical, and health services researchers, and librarians and other information professionals.
- Expand scope, linking capabilities, functionality, and customization features of PubMed and Entrez (NLM's molecular biology search and retrieval system that provides users with integrated access to sequence, mapping, taxonomy, and structural data) so that different categories of users can easily retrieve appropriate information from NLM's large and comprehensive databases.
- Enhance PubMed and Entrez through links to supporting material in electronic textbooks.
- Develop an NLM Gateway that provides simple integrated access to all of NLM's databases and Web-based information for the unsophisticated searcher.
- Continue to improve the usability of NLM's toxicology and environmental health databases (including those containing information related to occupational safety and health). Explore potential implementation of gateways to external sources of toxicology information.
- Enhance features that allow network applications (as opposed to human beings at workstations) to access and retrieve information from NLM databases.

## **DOCUMENT DELIVERY**

- Enhance DOCLINE to support billing for interlibrary loan services within the NN/LM.
- Work with other NN/LM libraries and other organizations to develop better mechanisms for individual health professionals and members of the public to request and gain affordable access to single articles in biomedical journals.

## **CUSTOMER SERVICE**

- Continue to analyze use, seek out customer comments and feedback, and use this input to improve NLM products and services.

## **MANAGEMENT AND EVALUATION OF NLM COMPUTER SYSTEMS**

- Identify, develop, and utilize state-of-the-art methods, techniques, policies and procedures to safeguard NLM's systems, services, and information from threats such as unauthorized use of facilities and computer systems.
- Develop new measurement strategies and metrics to evaluate NLM's computer-based services and their accessibility to users via the Internet and the World Wide Web. This includes, for example, end-to-end performance testing of NLM applications on the current Internet and the Next Generation Internet, and valid means for assessing frequency and utility of use of MEDLINEplus.



## **GOAL 2.**

### **PROMOTE USE OF HEALTH INFORMATION BY HEALTH PROFESSIONALS AND THE PUBLIC**

To aid the dissemination of research results that can advance medical science and improve the public health, NLM not only collects and organizes the literature of the health sciences and provides information services, but also publicizes and works to make these services readily available to those involved in preventing and treating disease. For most of its history, the Library has benefited the public indirectly by making current authoritative information available to health professionals and the librarians and information specialists who serve them. Recently, widespread access to computers and the Internet has led to direct use of NLM's services by the public. To serve both health professionals and the public effectively, the Library must increase its understanding of their health information needs, use this understanding to improve NLM products and services, publicize the Library's products and services more broadly, and strengthen the ability of the National Network of Libraries of Medicine to serve the full array of health professionals and to assist in providing authoritative health information to patients, their families, and the public.

#### **OBJECTIVE 2.1.**

##### **INCREASE AWARENESS AND USE OF NLM SERVICES AMONG HEALTH PROFESSIONALS**

###### **FINDINGS**

NLM carries out a diverse set of activities directed at building awareness and use of its products and services by health professionals in general and by particular communities of interest. Considerable emphasis has been placed on reducing health disparities by targeting health professionals who serve rural and inner city areas. An extensive training program has been developed to train medical and other health professionals in Historically Black Colleges and Universities (HBCUs) to use toxicology, environmental, occupational health, and hazardous waste information resources developed at NLM. Other efforts have addressed the needs of health professionals in particular subject areas, such as AIDS, health services research, and, through the "Partners in Information Access for Public Health Professionals" initiative, the heterogeneous and multidisciplinary public health workforce. NLM has also recently focused on improving Internet connectivity and access to health information services in American Indian and Alaskan Native communities.

A five year review of NLM's outreach activities conducted in 1994 documented the specific accomplishments of nearly 300 outreach projects carried out at more than 500 institutions. Among the findings was the need for NLM and the Regional Medical Libraries (RMLs) to work together to develop further expertise in evaluation methodology and to incorporate an evaluation component in all NLM-sponsored outreach. The Library sponsored the development of an evaluation guidebook by the Pacific Northwest Regional Medical Library which is now ready for testing. The Library emphasizes training health professionals in accessing electronic information through workshops conducted by the NN/LM and through collaborations with hospital libraries, Historically Black Colleges and Universities, community-based organizations, professional associations, and public health departments.

###### **PROGRAM PLANS**

- Continue special efforts to increase awareness and use of NLM services among health professionals, with special attention to health services researchers, health policy makers, and public health professionals.
- Enhance awareness and use of NLM's toxicology and environmental health databases (including those containing information related to occupational

safety and health) building on existing programs with HBCUs and involving other institutions and communities.

- Improve awareness of NLM's historical collections among historians of science, medicine, and public health. Produce historical exhibitions and related programs that promote understanding of science, medicine, and health while highlighting NLM's collections and services.

## **OBJECTIVE 2.2.**

### **INCREASE AWARENESS AND USE OF NLM SERVICES AMONG THE PUBLIC**

#### **FINDINGS**

Starting in 1998, NLM has undertaken new initiatives specifically devoted to addressing the health information needs of the public. These projects build on long experience with addressing the needs of health professionals and on targeted efforts aimed at making consumers aware of medical resources, particularly in the HIV/AIDS area. For years, NLM has supported the use of electronic information resources by community-based organizations working directly with HIV affected individuals. A survey early in 1998 showed that about one-third of all PubMed/ MEDLINE searches are done by the public.

To serve these new users more effectively, in 1998, NLM launched the MEDLINEplus web site, which provides access to a rich array of full-text consumer health information on major diseases and conditions in addition to pre-formulated MEDLINE searches. MEDLINEplus was the centerpiece of a pilot project in which NLM worked through the NN/LM with 40 public library systems of various sizes (more than 200 libraries in all) to train public librarians to use the Internet to find reliable health information for their patrons. MEDLINEplus is being improved based on user feedback, advice from expert advisory panels, and usability testing. NLM is also working to create an easy-to-use database containing information about

clinical trials (both Federal and non-Federal) for experimental treatments for serious diseases and conditions. Drawing on lessons learned in the public library pilot test, the Library is working through the NN/LM to support outreach projects that will involve health sciences, public, and state libraries, local health professional associations, public health departments, schools, and community-based organizations, including churches, in improving the public's access to high quality health information and reducing health disparities.

### **PROGRAM PLANS**

#### **CONTENT**

- Place a major emphasis on health information for the public, including health professionals who are seeking information outside their specialties or for their patients. Serve as a primary source for reliable, authenticated, recorded, and documented information and knowledge resources, integrating content prepared by many different Federal agencies, voluntary health organizations and others.
- Collaborate with Federal agencies, voluntary health organizations, and others to identify gaps and arrange for development of understandable content for the public, including health information specially geared to the needs of children, adolescents, and seniors.
- Develop easy-to-use access and delivery mechanisms that promote the public's understanding of health information resources. These should be sensitive to cultural diversity issues, educational level, and language (e.g., Spanish). Draw upon UMLS research and development and continuing advances in multimedia and graphics technologies.
- Produce historical exhibits and related programs that promote understanding of science, medicine, and health and highlight NLM's collections and services.

## ACCESS

- Expand outreach to patients and the public as recently approved by the NLM Board of Regents:
  - Publicize relevant and reliable electronic health information services, including those available from NLM and other sources.
  - Assist those providing health information to the public to make effective use of electronic services through Internet connections, training, and other means, with an emphasis on those serving minority groups, low income populations, seniors.
  - Promote integration of NLM services with other electronic services covering regional, state, or local health information.
  - Refer members of the public to regional, state, and local libraries and continue to serve as the national backup.
  - Establish partnerships for helping and training the public to seek, evaluate, and use reliable information sources.

### OBJECTIVE 2.3.

## STRENGTHEN THE NATIONAL NETWORK OF LIBRARIES OF MEDICINE (NN/LM)

### FINDINGS

Over the last 30 years one of the most important factors in the widespread acceptance and use of NLM's information services has been the National Network of Libraries of Medicine. The NN/LM, with its 4500 members, is organized through eight regions, each with a Regional Medical Library competitively selected and supported by the NLM. Those institutions, together with 140 large academic health science libraries and the many hospital and other libraries in the network, provide interlibrary loan and other crucial information services to scientists, health professionals, and, increasingly, the public. The members of the NN/LM have conducted literally hundreds of special outreach projects, often partnering with other organizations to increase awareness and provide

training in the use of information technology and NLM services. The RMLs and other NN/LM members regularly exhibit and demonstrate NLM services at meetings of national, regional, and local professional associations and community-based organizations. The RMLs not only use the Internet to develop new and innovative services, they also help other Network member institutions, particularly small hospital libraries, to connect to the Internet. Since 1993, the percentage of hospital libraries with Internet connections has increased from 23% to 91%. In addition to their outreach efforts, NN/LM members perform an invaluable service in testing various approaches to improving access to information and in beta-testing new NLM services, such as successive versions of Grateful Med and PubMed.

## PROGRAM PLANS

- Continue to rely on the NN/LM as a critical means of outreach to health professionals and the general public. NN/LM priorities for the next five years include:
  - Expanding partnerships with state library organizations, public libraries, community-based organizations, state and local health professional associations, and public health agencies to inform health professionals, patients, and the public about NLM services and provide the training needed to use these services effectively.
  - Enhancing RML staff expertise in the full-range of NLM databases and services, including those in consumer health information, environmental health and toxicology, molecular biology and genetics, health services research, public health, and the history of medicine and science.
  - Ensuring that NN/LM members, public health agencies, and community-based organizations that provide health information to the public have effective Internet connections.
  - Increasing awareness of new NLM services, such as the Clinical Trials Database, among health professionals and the general public.
  - Evaluate and if necessary redesign NN/LM services to member libraries in light of advances in telecommunications and electronic publishing.

### **GOAL 3.**

## **STRENGTHEN THE INFORMATICS INFRASTRUCTURE FOR BIOMEDICINE AND HEALTH**

Advances in communications and networking technologies help facilitate NLM's achievement of its mission. The rapid development of Internet and World Wide Web technologies make possible the quick, cost-effective distribution and exchange of biomedical information. Progress in telemedicine offers the promise of the cost-effective practice of medicine at a distance. NLM has always been a leader in researching and applying new technologies—typically years ahead of their widespread adoption. Today, the Internet—and tomorrow its Next Generation—offer new opportunities for NLM to leverage its resources for strengthening the U.S. and global biomedical information infrastructure.

This infrastructure includes not only advanced computing and communications technologies, but also people trained to develop, use, and assist others in deploying and using advanced information systems, institutions committed and structured to make effective use of these systems, and public policy that promotes rather than inhibits important health applications of information technology.

### **OBJECTIVE 3.1.**

#### **ENCOURAGE HEALTH APPLICATIONS FOR CURRENT AND FUTURE INTERNET ENVIRONMENTS**

##### **FINDINGS**

The Internet and the World Wide Web have increased enormously the potential for health applications in research, education, and practice. NLM's role in promoting health applications of advanced information technologies was enhanced when NLM Director Lindberg was appointed by the White House as the founding director of the new multi-agency High Performance Computing and Communications (HPCC) Initiative, thus ensuring that biomedicine would be represented. Because NLM depends to a great extent on the ability of the Internet to deliver health care information, the Library is an active participant in the Next Generation Internet initiative, a cooperative effort among industry, academia, and government agencies that seeks to provide affordable, secure information delivery at rates thousands of times faster than today. In addition to enhancing the coverage of the literature of telemedicine and other health applications of information technology in its own information services, in recent years NLM has funded

many research, development, and evaluation projects in telemedicine and other health applications of the national information infrastructure and the Next Generation Internet. The Library has also actively promoted the use of advanced information technologies in the public health sector. In addition, NLM has funded influential Institute of Medicine and National Research Council Computer Science and Telecommunications Board studies on the evaluation of telemedicine and the technical capabilities that will make the Next Generation Internet suitable for routine health care and biomedical research use.

The Library has a number of assistance programs designed to help health institutions take maximum advantage of new communications modalities. The long-standing Integrated Advanced Information Management System (IAIMS) initiative helps major biomedical institutions create innovative approaches to linking and using a variety of sources of medical information, internal and external. The Association of American Medical Colleges (AAMC) is currently carrying out a major review of this program to provide advice to NLM on its future directions. Several grant programs encourage institutions and consortia of various sizes to use national electronic information resources; and a "connections" grant program helps small institutions hook up to the Internet.

The Learning Center for Interactive Technology (TLC) is a “hands-on” laboratory at NLM for educating health professionals about applications of information and educational technology in such areas as distributed learning, telemedicine, Internet/Web-based multimedia, CD-ROM, and virtual reality.

## PROGRAM PLANS

- Support research in health care applications of the Next Generation Internet, including technical capabilities for quality of service, medical data privacy and security, nomadic computing, and infrastructure technology.
- Support research in smart card technology and other enabling technologies for identification, authentication, and small-scale data storage.
- Promote research on the health uses of hand-held and wearable computers and other “Internet appliances.”
- Support research related to the development and use of computer-based patient record systems.
- Promote research and development on the electronic exchange of information between the health care and public health systems.
- Support the evaluation of the impact of telemedicine and other health applications of advanced communications networks on patient care, health professional education, public health, and the behavior of the public.
- Consider revision of NLM’s grant programs in light of recommendations from the AAMC study.
- Continue to provide support for connecting health institutions to the Internet.



## OBJECTIVE 3.2.

### FURTHER TRAINING IN MEDICAL INFORMATICS AND LIBRARIANSHIP

#### FINDINGS

NLM sponsors a variety of medical informatics training programs for health professionals and individual biologists. Over the past decade the Library has established new individual fellowships in applied medical informatics and informatics research and has increased the formal academic medical informatics programs at major universities from 10 to 12. One of the academic programs is entirely focused on training in bioinformatics and some others have bioinformatics tracks. This provides a base for NLM to assist in the NIH-wide initiative to increase the number of researchers with advanced training in computational biology.

To provide an introduction to medical informatics for health professionals, health sciences librarians, and computer scientists, NLM sponsors semiannual intensive 1-week courses in medical informatics at the Marine Biology Laboratory in Woods Hole, Mass. This extremely popular program was instituted in 1992 and expanded to two sessions per year in 1999.

There are also several informatics training programs at NLM itself. NLM’s Lister Hill Center (LHC) directs the NIH clinical elective in medical informatics for medical students and also provides training for individual visiting scientists and students. NLM’s National Center for Biotechnology Information (NCBI) accepts postdoctoral fellows and visiting scientists for work and training at the NCBI.

After the publication of the Long Range Plan report on the Education and Training of Health Science Librarians, NLM funded challenge grants which led to the development of new courses and masters’ programs at several schools of library and information science, and to an expanded internship program at an academic health sciences center. The Library has also established additional slots for librarians recruited

by any of the 12 NLM Informatics Research Training programs, and a new fellowship in applied medical informatics for those in other fields. The highly successful Library Associate Fellowship Program, which has brought recent library school graduates to NLM for a 1-year training program for more than 40 years, has recently doubled the number of trainee slots and expanded to an optional second year of mentored experience at an outside institution where librarians participate in multidisciplinary teams supporting clinical, educational, or research programs.

## PROGRAM PLANS

### ACADEMIC TRAINING PROGRAMS

- Support the NIH-wide effort to expand the number of researchers capable of working in computational biology by expanding on existing NLM-supported informatics training programs.
- Promote collaborative training efforts between NLM-funded informatics research training programs and Agency for Healthcare Research and Quality (AHRQ) (formerly the Agency for Healthcare Policy and Research—AHCPR)-funded health services research training programs.
- Broaden the spectrum of health professionals who receive medical informatics training (e.g. nurses, dentists, hospital administrators, public health professionals).
- Support and encourage minority institutions in medical informatics training.
- Encourage the development of executive master's degree programs in informatics.

### ADULT LEARNING

- Expand use of distance learning technology as one mechanism for providing continuing education in the use of information and NLM information services.
- Develop American Medical Association (AMA) Category I Continuing Medical Education (CME) Internet offerings in health informatics.

- Investigate the possibility of offering Woods Hole-type courses via distance education methods.
- Explore the development of a new mid-career training program for health sciences librarians, which would involve nomination by top administrators, onsite experience at institutions which have integrated the library into clinical, research, and/or educational activities, mentoring, and possibly support for hiring temporary replacements for people participating in the program.
- Explore the need and mechanisms for expanding the supply of specialist librarians in three areas: (a) clinical informatics—to work directly in the clinical intensive care setting, providing just-in-time, patient-specific information, (b) health policy—to provide advanced assistance to health policy makers and public health professionals with information needs that span many disciplines, (c) bio-informatics—to assist researchers in sophisticated use of molecular biology and genetic databases.

### MINORITY RECRUITMENT

- Work with the Medical Library Association (MLA), the American Medical Informatics Association (AMIA), public schools, and other appropriate organizations to recruit more people from minority groups into health sciences librarianship and informatics. Provide opportunities for practice at NLM for recipients of minority scholarships to library schools.

### EVALUATION

- Review and assess the impact on health sciences librarianship of the NLM Associate Fellowship program, the number of informatics fellowships available to librarians, and the Woods Hole Medical Informatics course.



### **OBJECTIVE 3.3.**

#### **MONITOR AND CONTRIBUTE TO PUBLIC POLICY**

##### **FINDINGS**

The spread of the Internet and the World Wide Web have increased the number of public policy issues that affect the organization, access, and use of electronic information. Public policy issues affect NLM's ability to fulfill its mission and also shape the ways in which advanced computing and communications can be used in health care, prevention, research, and education. Policy designed to correct abuses in one sector, e.g., piracy of entertainment recordings and videos, can have unintended consequences that restrict the flow of scientific and medical information. To guard against these unwanted secondary effects, NLM must monitor and contribute to policy development in such areas as electronic intellectual property rights, the application of copyright law and guidelines to electronic information, the use of contracts and licenses to provide access to information, Internet filtering, health data standards, and health data privacy. affect NLM's ability to fulfill its mission. NLM contributes to policy development in a variety of ways: highlighting the importance of policy issues to the Library's constituent groups; collaborating with library associations in defending the principle of "fair use" of copyrighted works; and commissioning or supporting studies by the National Research Council on intellectual property issues relevant to scientific databases, protecting electronic health information, and preserving confidentiality while simultaneously promoting the use of health research data sets. The Library also conducts and supports research and development related to health data standardization, including the NLM/AHRQ Large-Scale Vocabulary Test of the extent to which existing controlled vocabularies meet the needs of computer-based patient records. NLM is an active participant in the development of standards for administrative health data as mandated by the Health Insurance Portability and Accountability Act of 1996.

#### **PROGRAM PLANS**

- Continue to monitor, promote public discourse, and influence public policy related to access and use of electronic intellectual property and computer-based systems in personal health care, public health, research, and education.
- Promote and support research, development and testing of policy, national standards, institutional procedures, and technical mechanisms for ensuring the confidentiality and security of patient-identifiable health data.
- Work with other Federal agencies and outside organizations to support the establishment, ongoing maintenance, testing, and use of health data standards to enhance the quality of care and improve the data available for research. Use the UMLS Knowledge Sources and programs to facilitate the maintenance and distribution of vocabulary standards.

### **OBJECTIVE 3.4.**

#### **PROMOTE DEVELOPMENT OF THE GLOBAL HEALTH INFORMATION INFRASTRUCTURE**

##### **FINDINGS**

The increasing globalization of knowledge has made it clear that domestic and international functions of the NLM are not separable. A network of International MEDLARS Centers has grown over the years to 20 members and their work must be updated to reflect changing needs. In 1998 the Library published A Global Vision for the NLM, a supplement to the Long Range Plan that charted an international course for the institution in the coming years. NLM has added selected international libraries to DOCLINE and Loansome Doc to facilitate access to documents for international MEDLINE users. In December 1998, an invitational International Partner meeting was convened at NLM to discuss programs in areas of high priority, such as document delivery, connectivity and infrastructure, and a crosscut that focused on the

special needs of developing countries. A follow-up meeting was convened in Taiwan in May 1999 with representatives of the Asian International Centers to discuss new opportunities for collaboration with a focus on the special needs of that region. A parallel meeting was held in Germany in November 1999 with representatives of the European International Centers and others.

NLM is participating in the multi-agency Multilateral Initiative on Malaria and is leading efforts to enhance communications and Internet connectivity at malaria research sites in Africa. This project has become a model for capacity building in electronic communications in support of research collaborators in developing regions of the world. NLM is collaborating with the NIH Fogarty International Center (FIC) in a new grants program to support the training of African scientists in medical informatics, both at in-country locations and in the U.S. The program has been expanded to include trainees from Latin America.

## **PROGRAM PLANS**

### **CONNECTIVITY AND COMMUNICATIONS**

- Develop a capability to work in a few carefully selected needful areas of the world where there are severe, recent health emergencies and, with collaborative efforts with other organizations, both domestic and international, set up targeted, carefully defined efforts (such as NLM participation within the Multilateral Initiative in Malaria).
- Expand and enhance its efforts to improve Internet connectivity and communications in sub-Saharan Africa.
- Expand high bandwidth connectivity testing internationally and include protocols for vBNS (very High Speed Backbone Network Service) connections in addition to the current Internet.

## **DOCUMENT DELIVERY**

- Assist the development of effective document delivery mechanisms for international MEDLINE users:
  - Promote regional document delivery networks in areas that currently lack effective document delivery mechanisms.
  - Work with international libraries to improve access to copies of specific articles for international MEDLINE users.
  - Make low cost image transfer technology (e.g. DocView) available to international libraries and institutions in order to facilitate rapid and low cost delivery of documents from NLM and other U.S. libraries.
- Increase representation in MEDLINE of foreign journals containing useful global information including reports on local and regional health problems.

## **INSTITUTIONAL RELATIONSHIPS**

- Explore the feasibility of exploiting present day information technology to assist developing countries access the world's health care knowledge sources.
- Explore ways NLM can encourage institutional twinning arrangements, in which U.S. institutions assist foreign counterparts by means of resource sharing and staff training.
- Emphasize international partnerships in this hemisphere, including for example the provision of surveillance, disaster, emergency relief, and toxicological and environmental health information.

## **TRAINING**

- Continue to investigate new options for providing informatics training to individuals in geographic areas that lack existing training programs.

## GOAL 4.

## CONDUCT AND SUPPORT INFORMATICS RESEARCH

From research laboratories to the patient bedside, biomedical knowledge is being generated at a staggering rate. This new knowledge must be captured, analyzed, and disseminated in order for it to be useful and to make a significant difference in health care. In addition to the traditional forms of knowledge, the use of the computer has enabled researchers, practitioners, and health care consumers to more effectively gain and use knowledge. The challenge lies in finding new approaches to deal with the increasing volume and complexity of biomedical information and thereby improve our understanding of health and disease.

### OBJECTIVE 4.1.

#### FURTHER MEDICAL INFORMATICS RESEARCH

##### FINDINGS

Research is conducted at NLM both in the in Lister Hill National Center for Biomedical Communications (LHNCBC) and in the National Center for Biotechnology Information (NCBI). Lister Hill works in the more general field of medical informatics. NCBI concentrates in work relevant to molecular biology and genomics. LHNCBC work includes language and information processing, digital library research, consumer health informatics, image processing, and advanced computing and communications for health care applications. Ongoing R&D projects include the Unified Medical Language System (UMLS), Natural Language Systems, Indexing Initiative, image and document management and delivery systems, assisted searching of NLM's databases through

Internet Grateful Med, the clinical trials database, the Visible Human project, and the Profiles in Science digital library project.

The UMLS project develops and distributes knowledge sources for improved access to biomedical information. The Metathesaurus contains information about biomedical concepts and terms from more than 40 controlled vocabularies and classifications. The Semantic Network identifies the semantic types and relationships of Metathesaurus concepts, and the SPECIALIST lexicon and associated lexical programs allow for linguistic processing of biomedical text.

There are more than 1000 licensed UMLS users who use the knowledge sources in a wide range of applications, including indexing bibliographic and clinical material, retrieving information from Web-based systems, diagnostic prompting systems, electronic medical records, and formalizing the language used in medical records and messages. NLM makes use of the UMLS in its own applications, including Internet Grateful Med, PubMed, and the clinical trials database.



Natural language research is focused on the development of SPECIALIST, an experimental medical language processing system. Modules based on the major components of language, including the lexicon, morphology, syntax, and semantics, have been built and are used in research, particularly in the area of information retrieval effectiveness.

Document image analysis and recognition techniques play an important role in several research projects. One project (MARS) has partially automated the entry of citation data from scanned biomedical journals into the MEDLINE database. Another (DocView) aids the library patron in receiving library documents delivered through the Internet.

The clinical trials database project addresses issues in consumer access to health information. When fully operational, the database will be a comprehensive resource for patients, families, and members of the public, providing easy access to clinical trials funded by the Federal government and by private industry.

DXPNet, a collaborative project among the NLM, the National Center for Health Statistics (NCHS), and the National Institute of Arthritis, Musculoskeletal, and Skin Diseases (NIAMS), brings together a collection of radiographs and related text material from the National Health and Nutrition Examination Surveys.

The Visible Human male and female data sets, consisting of MRI, CT and cryosection images, were released as national resources in 1995 and 1996 respectively. Users in over 40 countries are applying them to a wide range of educational, diagnostic,

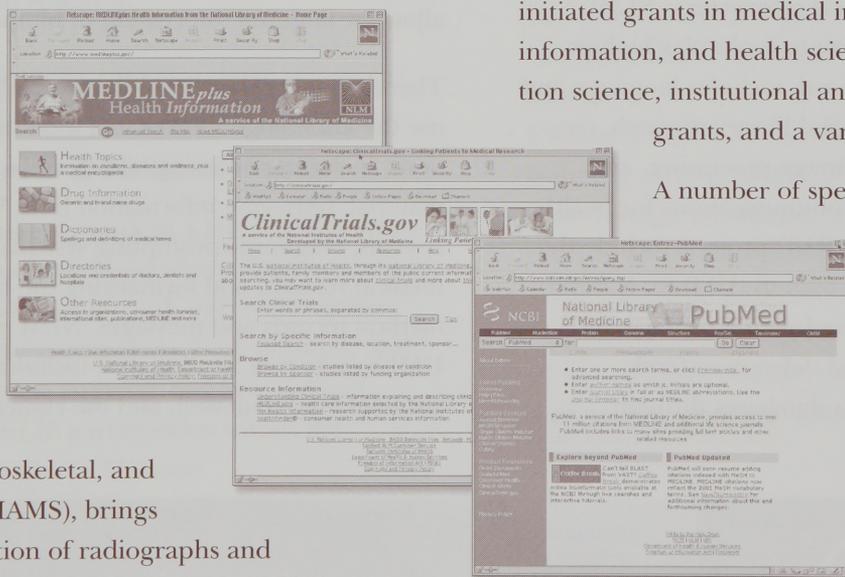
treatment planning, virtual reality, artistic, mathematical and industrial uses. Work has also begun on the next phase of development of the Visible Human, including the segmentation, classification, and three-dimensional rendering of the data sets.

The digital library research program investigates all aspects of creating and disseminating digital collections, including proposed and adopted standards, emerging technologies and formats, effects on previously established processes, and protection of original materials. The Profiles in Science digital library site focuses on major scientific achievements of the twentieth century by presenting the archival collections of prominent biomedical scientists on the World Wide Web.

Through the Extramural Programs Division, NLM has a number of programs for the support of medical informatics research in universities, hospitals, and research institutions. These include investigator-initiated grants in medical informatics, biotechnology information, and health sciences library and information science, institutional and individual training grants, and a variety of research contracts.

A number of special programs fund, for example, a collaboration with the National Heart, Lung, and Blood Institute projects to apply medical informatics techniques to speed critical life-saving information to heart attack victims. NLM

has also funded over twenty telemedicine research projects, as well as planning projects in health-care applications for the Next Generation Internet. NLM's participation in a multi-agency Digital Libraries Initiative has resulted in several large awards for health-care related digital library research projects.



NLM has carried out in-house studies and awarded research grants over the years to determine the information needs and uses of health professionals. A landmark study of this kind employed the Critical Incident Technique to identify the impact of MEDLINE-derived information on a wide range of professional activities, including medical decision-making and patient care outcomes. Other studies surveyed NLM users to determine satisfaction with specific products and services, including beta testing of new offerings such as Grateful Med. Still others queried hospital libraries, and other organizations and individuals, with respect to their readiness to adopt Internet technology. Extramurally, NLM has awarded grants that looked at information needs, usage and value, including the value of providing information at the point of care.

## PROGRAM PLANS

- Strengthen fundamental informatics research, both through intramural research at NLM and extramural research at universities, research laboratories, and other organizations.
- Increase support for investigator-initiated research grants.

## LANGUAGE AND KNOWLEDGE PROCESSING

- Continue to explore advanced indexing technologies for present and developing forms of information, including automated concept-based indexing techniques for the biomedical literature.
- Continue to identify additional concepts, organizing principles, and concepts to be added to the UMLS resources.
- Expand the UMLS Semantic Network, particularly in the areas of anatomy and the genome.
- Make the UMLS Knowledge Sources better able to reflect the different perspectives and views of medical and health concepts exhibited by the general public, health care practitioners, health policy makers, and clinical and health services researchers.
- Develop efficient methods for more frequent update and dissemination of the UMLS

Knowledge Sources to support the need for immediate access to new vocabulary in areas such as drugs and devices.

- Enhance the capabilities of the Internet-based UMLS Knowledge Source Server to make the UMLS components easier to use and to promote direct use by external software applications.

## DIGITAL LIBRARY RESEARCH

- Continue to participate with other agencies in the Digital Libraries Initiative - Phase 2 (DLI-2) to support innovative digital libraries research and applications.
- Continue digital library research, addressing issues in building, maintaining, preserving and disseminating diverse multi-media digital collections, including the use of metadata for managing, displaying, and retrieving data in digital archival systems.
  - Extend the Profiles in Science digital library site.
  - Develop collaborative projects with other institutions as test-beds for digital library research.
- Expand efforts to improve search system interfaces, search engines, and utility of intelligent agents (e.g. search assistants), both for human beings and network applications.
- Work with the database efforts of other Federal agencies and similar international efforts to enhance interoperability among databases and ease of access to data.
- Further develop document management technologies and applications, including scanning, optical character recognition, and document structure analysis.



## **VISIBLE HUMAN**

- Using the Visible Human data set, undertake and support standardization efforts for classifying, storing, retrieving, and displaying anatomic images.
- Develop 3D anatomic image sets from the Visible Human data and conduct research on effective retrieval and transmission of such images over the emerging Next Generation Internet.
- Using the Visible Human data set, conduct and support research in the development of generalizable image processing tools, such as the Visible Human Image Processing Tool Kit, a public domain, open source software toolkit which will be capable of automated segmentation and alignment of radiological and anatomical images.
- Extend basic research in automated image indexing and retrieval, using the salient features of the Visible Human images themselves.
- Conduct basic research in algorithms for automated image segmentation, recognition, indexing and decomposition.
- Work towards the further integration among the UMLS, the Visible Human, and other anatomical initiatives such as the Human Brain Project.

## **SIMULATION**

- Conduct and support research in the development of a Visible Human Project Atlas for use in educational applications, beginning with the head and neck body regions.
- Augment the Visible Human with plans and approaches for developing collections relating to various abnormalities and disease models.

## **JUST IN TIME ANSWERS**

- Encourage research, development, and innovation in “just in time” knowledge retrieval. The goal is to tailor specific answers to questions posed by clinicians at the time and place they are seeing patients, and to help patients and families to find information specific to their own immediate health concerns.

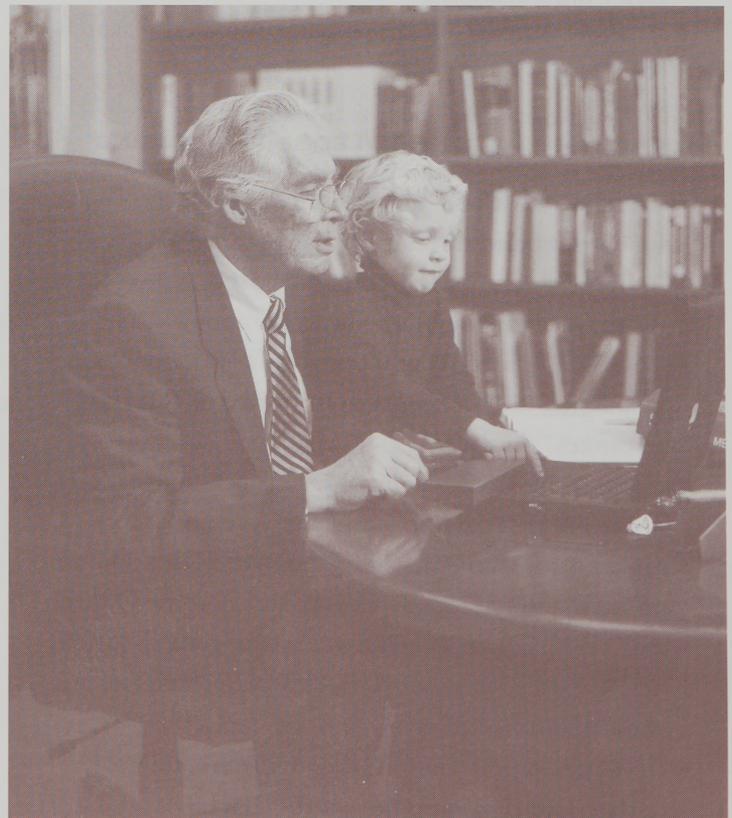
- Conduct and support research to link patient-specific data to related knowledge-based information.

## **CONSUMER HEALTH**

- Conduct and support informatics research designed to produce health information systems that the public can use easily and understand.
- Develop a consumer health terminology server to provide assistance to the increasing members of the general public who are users of NLM’s Web-based systems, including spelling correction algorithms and investigation of multi-language interfaces.
- Use NLM databases, e.g. the clinical trials database and MEDLINEplus, as test-beds for research on health information seeking behavior by the public.

## **EVALUATION**

- Conduct and support basic and applied research to identify health care professionals’, researchers’, and the general public’s need for, access to, evaluation of, and use of biomedical and health information.



Broaden end user studies beyond measures of satisfaction to include the effects of information on health outcomes.

#### **DATA MINING AND MACHINE LEARNING**

- Promote and support research on health data mining as a method for discovering new clinical, public health, and health services information, making use of UMLS tools as appropriate.
- Explore the use of data mining tools in databases, literature, and the NLM collection.
- Pursue metadata approaches to the problem of data standardization at all levels, from basic electronic transfer to higher levels of information structure.

#### **OBJECTIVE 4.2.**

#### **ADVANCE SCIENTIFIC KNOWLEDGE IN MOLECULAR BIOLOGY**

##### **FINDINGS**

The National Center for Biotechnology Information (NCBI) was established at NLM in 1988 and quickly became the focal point for bioinformatics at NIH. The Center serves as an international resource for databases and software in molecular biology, including the Human Genome project; for research in computational biology; and for the dissemination of biomedical information. NCBI has helped create new databases that combine or enhance existing molecular biology databases and develop links among them. It assumed responsibility for the GenBank DNA sequence database in 1992. GenBank (at NCBI), together with the DNA DataBank of Japan (DDBJ) and the European Molecular Biology Laboratory (EMBL) comprise the International Nucleotide Sequence Database Collaboration. These three organizations exchange data on a daily basis. NCBI also supports and distributes Online Mendelian Inheritance in Man (OMIM), Molecular Modeling DataBase (MMDB), UniGene (an experimental system for automatically partitioning GenBank sequences into a non-redundant

set of gene-oriented clusters), a Gene Map of the Human Genome, the Taxonomy Browser, and the Cancer Genome Anatomy Project (CGAP). NCBI has developed an extensive suite of software tools, including the BLAST program for sequence similarity searching.

A recent accomplishment of significant note is the production of a new “gene map,” developed in collaboration with laboratories around the world, which pinpoints the chromosomal locations of almost half of all genes. Entrez is NCBI’s search and retrieval system that provides users with integrated access to sequence, mapping, taxonomy, and structural data with the ability to retrieve related sequences, structures, and references. NCBI also developed and continues to enhance PubMed, a Web search interface providing access to MEDLINE and with links to full-text articles at participating publishers’ Web sites. NCBI’s research activities center on the areas of molecular biology databases, development of search and analysis algorithms, genome analysis, and molecular structure and function. Extramural grants for regional biology resources, biotechnology databases, genome-related informatics research, and other computational molecular biology research are supported.

##### **PROGRAM PLANS**

- Develop and publish a strategic plan for the NCBI with input from NCBI’s outside advisors and users.

##### **HUMAN GENOME**

- Assume responsibility for collecting, managing, and analyzing the growing body of human genomics data generated from the sequencing and genome mapping initiatives of the Human Genome Project to address the gap created by the dissolution of the Genome Data Bank.
- Expand GenBank, the central DNA sequence resource, to support the Human Genome Project’s goal of completing a “working draft” of 90% of the genome by Spring 2000 and the complete sequence by 2003.

- Develop a database of single nucleotide polymorphisms (SNPs) to support a major initiative of NIH and an international pharmaceutical consortium to study genetic variations in the human population.
- Establish methodologies and tools to automatically assemble and annotate the “working draft” of the human genome sequence, which will contain gaps, overlaps, and inaccuracies. This is essential to making effective use of the high-volume sequence data generated by commercial and public sequencing centers.
- Develop approaches to apply standard gene nomenclature across multiple data resources, supporting and working in conjunction with the Human Genome Organization (HUGO) Nomenclature Committee and the OMIM database.
- Develop methods of integrating and presenting composite views of multiple genome maps produced by various physical and genetic and sequence-based mapping techniques.
- Expand UniGene, a database that groups multiple DNA sequences into clusters that represent unique genes and is used extensively to guide gene hunting and genome mapping efforts, to include vertebrate models in addition to the current coverage of human, mouse, and rat.
- Develop curated and annotated reference-type sequence collections for organizing and classifying genome-scale data.
- Establish methodologies and develop tools to support analysis of genome-scale data following completion of the sequencing and mapping phases of the Human Genome Project.

### **PROTEIN SEQUENCE AND STRUCTURE ANALYSIS**

- Expand accessibility of 3D structure information to a wider range of biologists by achieving greater integration of protein structure and sequence information and developing more intuitive approaches to predicting protein structure.
- Create a system of classifying proteins into families that share common function, based on research

that compares complete genomes across different organisms.

- Develop databases of reference sequences (RefSeq) for the research community to use as standard representatives of major genes and gene families. Reference sequence standards provide a foundation for the functional annotation of genomes, as well as a stable reference point for mutation analysis, gene expression studies, and polymorphism discovery. The exponential growth of GenBank requires the production of non-redundant summary databases of representative gene sequences, each reflecting the current knowledge about a gene and its transcripts. Computational Algorithms and Methods
- Develop new algorithms, mathematical models and graphical tools for supporting computational analysis of sequences and other genome data.
- Emphasize basic research in the areas of sequence analysis, protein structure and function relationships, gene identification and functional genomics, and molecular evolution. User Education and Training
- Conduct training workshops in the use of NCBI databases and analysis tools, targeted to scientists as well as information specialists.
- Develop online tutorials and additional user documentation to improve user understanding and facilitate effective use of the resources.



## APPENDIX 1: IMAGINING THE FUTURE—2010

The following statement was requested by the Board of Regents. It reflects the underlying assumptions about the future—so far as we can tell—of many of the persons contributing to our planning process, as well as that of NLM leadership. No one will be terribly surprised, however, if events take their own turn!

### IN HEALTH CARE...

- A major reorganization of health care services will have evolved from current solo- and group practice models, with fee-for-service and insurer-indemnification financing and paper-based information systems, to nationwide managed care plans employing enhanced computer-based information systems. All this is accompanied by substantial changes in traditional health care delivery schemes.
- The public will own their health records and subscribe to “health records escrow services” that provide secure, provider-and-plan-independent online access to their fully computerized health records.
- Health care providers will prescribe information for their patients that in many cases will be delivered by a direct Internet connection.



### IN EDUCATION...

- Simulators, virtual patients, and interactive curriculum content via distance education methods over the Internet will be commonplace practices for the education and training of health professionals.
- Trained informatics professionals will be in great demand and fully integrated into all aspects of teaching, research, administrative and practice activities of health science centers.

### IN RESEARCH...

- Molecular biology discoveries will in some cases be made in extremely short periods, where novel disease-related hypotheses, gene cloning, and gene expression analysis can be done in an afternoon.
- Molecular compatibility screening will be part of drug selection for most common diseases, so that physicians will no longer just guess about which of dozens of drugs to use for conditions such as hypertension and diabetes.

### IN TECHNOLOGY...

- Electronic personal publication will be the norm and will supplement traditional commercial publishers but not replace them.
- In a world populated by trillions of network-connected microprocessors, a significant fraction of users of NLM applications will not be human beings sitting at keyboards.
- The integrity of our medical heritage will be preserved in digital form.

### IN LIBRARIES...

- Public, hospital, university, medical, and national libraries will continue to exist as physical facilities and collections, as well as places of meeting, learning, instruction, and enjoyment. Users will evermore expect libraries to be portals to electronic as well as physical knowledge sources. Users will in effect expect librarians to be expert guides in the uses of information and communication technologies.

### AT NLM...

- Learning to manage in the midst of constant change will be NLM's major challenge. Changes in NLM services and procedures will be required by increasingly “savvy” users from all of the Library's constituent communities - the public, biomedical researchers, and health care professionals.
- Carrying out the responsibility for permanent access to the digital biomedical literature will occupy

an increasingly prominent role. This task will be carried out in partnership with non-medical public institutions, and will rest upon NLM's overseas MEDLARS network as well as the National Network of Libraries of Medicine.

- There will be constant rearrangement and realignment between public and private providers of electronic information and access to this. NLM will continue to be the major public portal to careful presentation of "vetted" biomedical scientific information.
- NLM support of research, intramural and extramural, will continue to produce new forms of information and knowledge representation. Major medical discoveries will arise directly from studies of NLM files.

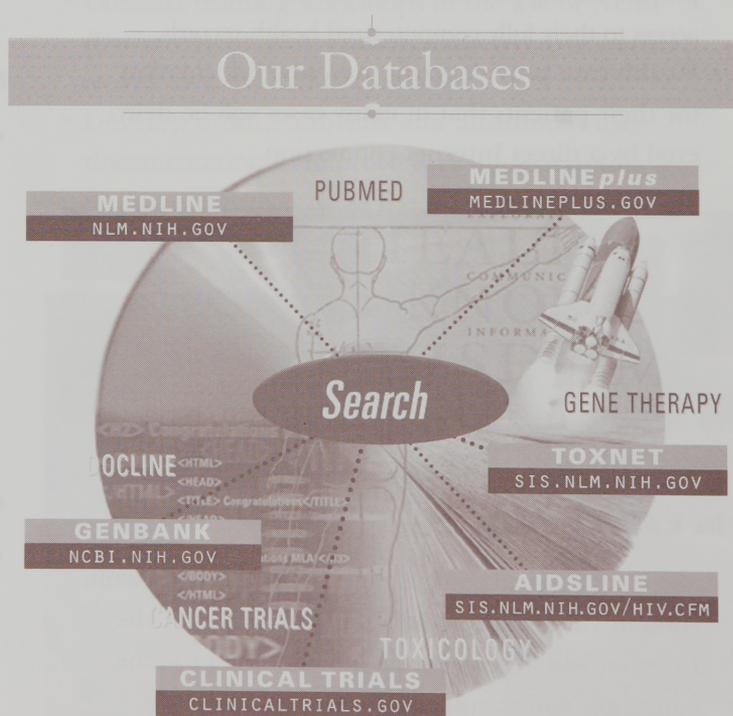
## APPENDIX 2: PLANNING PROCESS

In January 1985, NLM's Board of Regents began to develop a 20 year Long Range Plan to guide the Library in using its human, physical, and financial resources to fulfill its mission. A broadly based process, involving the participation of librarians, health professionals, biomedical scientists, medical informaticians, computer scientists, and others whose interests were intertwined with the Library's, culminated in the adoption of a report by the Board of Regents published in 1987.

Planning reports prepared since then as supplements to the original Plan (also based on the work of broadly based panels of outside experts) contain recommendations on outreach to health professionals, electronic imaging, information services for toxicology and environmental health, the education and training of health science librarians, and, most recently, NLM's international programs. As a result of this ongoing planning effort, NLM has

taken major strides forward. For example, the concept of a National Center for Biotechnology Information (NCBI) was born during a planning panel meeting.

In order to develop this Long Range Plan 2000–2005, a document called The NLM Track Record was prepared as a synthesis and summary of past planning efforts and a statement of where we are today. The Track Record was sent out to over 250 past planning panel members and other advisors for comment as well as being posted on the public NLM web site. The comments received from well over 100 individuals (see appendix 1) were reviewed by the NLM Board of Regents, who asked staff to incorporate a number of priorities into a new draft Plan for the next three to five years. A broadly representative group of NLM advisors met on December 1, 1999, to review that draft (see appendix 4). This draft reflects additional revisions prompted by comments and suggestions made at that meeting.



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