NLM Board of Regents

Charting a Course for the 21st Century

NLM's Long Range Plan 2006-2016

September 2006

U.S. Department of Health and Human Services
National Institutes of Health

National Library of Medicine Cataloging in Publication

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

Charting a course for the 21st century : NLM's long range plan 2006-2016 / NLM Board of Regents. – [Bethesda, Md.] : U.S. Dept. of Health and Human Services, Public Health Service, National Institutes of Health, National Library of Medicine, 2006.

NLM's Long Range Plan 2006-2016

Charting a course for the twenty-first century

"September 2006."

Includes index.

1. Libraries, Medical. 2. Information Services. 3. Information Systems. 4. Research Support. 5. Training Support. 6. United States. I. National Library of Medicine (U.S.)

02NLM: Z 675.M4 N2782c 2006

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For access to all of NLM's previous planning documents, see:
http://www.nlm.nih.gov/pubs/plan/index.html

For more information about the National Library of Medicine, see:
http://www.nlm.nih.gov

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Foreword

The National Library of Medicine has a very successful history of long range planning dating back to 1985, when the NLM Board of Regents undertook to develop a 20-year 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 the National Center for Biotechnology Information, Outreach, and the Visible Human. 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 take advantage of new opportunities and changing circumstances. As with any strategic plan, it is sensible to allow for mid-course corrections as events unfold.

The Board wholeheartedly endorses this new ten year Long Range Plan and is grateful to the Planning Panels for formulating the ideas contained herein and to the Director and the staff of NLM for preparing it.

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Preface

NLM has bridged the gap from the muskets and square rigged ships of its origins to the growing understanding of the innards of human heredity today. For this transition, gratitude is due to steady and generous support by the Congress - throughout all the ups and downs of our country since 1836 when NLM began. NLM has had the help and advice of countless physicians, scientists, medical librarians, and public persons over all these years. For all this, I am grateful. Special thanks to all who contributed ideas, hopes, and criticisms to this latest NLM Long Range Plan.

A word about dates. The Long Range Plan of 1985 was a 20 year plan (supplemented by five important addenda). It helped us immensely over these years in many many ways. The current plan has a slightly more modest planning time frame: namely, ten years from 2006 to 2016. The diminution may be interpreted as the onset in the Director of age, caution, or wisdom. In any case, few will fail to see the rapidity with which our local science world and our larger geo-political world is changing. Hence the ten year planning goal.

In contrast, NLM's advisers felt strongly that our planning should begin with a longer, broader, quite unconstrained view of all these matters. A Strategic Vision, in other words. This effort was chaired by the Hon. Newt Gingrich and Dr. Bill Stead and had many distinguished collaborators. It examined the broader time range: 2005 to 2025, and thus set each planning panel into high gear immediately.

For my part, I offer my sincere admiration of our institution and my confidence it will continue in this new century to serve with distinction. I offer also my personal assessment of NLM's strengths and potential problem areas - without any blame falling on our Board or our advisers.

NLM's major strengths are in its understandable mission, its excellent staff, its historically generous funding, and its fast friends.

Mission: To acquire, organize, disseminate, and preserve the biomedical knowledge of the world for the benefit of the public health.

Staff: NLM has a highly educated multidisciplinary staff of more than 1300 employees and contractors who are innovative, productive, and dedicated to the Library's mission.

Funding: NLM's funding increases have frequently been even better than the NIH's. Like the US in 1941 we have been building a "two ocean Navy." The added efforts focused both on the rapidly growing corpus of genomic measurements and data, and at the same time, on the fast growing appetite of patients, families, and the public for access to improved understanding of information relevant to personal health and health care. Unfortunately the needs for extra budgetary growth are still present.

Friends: NLM has retained strong, stable, and long lasting connections with many relevant professional constituencies and organizations. These include the Medical Library Association, the American Association of Medical Colleges, the Association of Academic Health Sciences Libraries, the Institute of Medicine, the Computer Science and Telecommunications Board, the International Committee of Medical Journal Editors, the National Science Foundation, the American Medical Informatics Association, the Friends of the National Library of Medicine, and others.

Two dangers are impossible to miss: lack of proper space, and major external factors outside NLM's control.

Space

A great strength and advantage for NLM has been the collegial working relationships that have been maintained between its several operating divisions. There are numerous examples, but all have been facilitated and enhanced by physical facilities that provided close housing.

Similar happy working relationships have been maintained between NLM and numerous NIH research groups and a great number of outside professionals and organizations who have been hosted by NLM for conferences and collaborations. NIH has been very helpful and supportive by reassigning new space to NLM, especially to help accommodate the growing duties and services from the National Center for Biotechnology Information, and all NLM Divisions have made every effort to maintain close working relationships. Yet we currently rent 92,000 square feet of space outside the two NLM buildings. The Congress approved a new building in appropriation language on many occasions, and Congress provided funds for complete architectural plans for the new building. In fact, these full architectural plans were completed in 2003. What remains - and it is increasingly critical - is an appropriation of funds to get on with the building itself.

External Threats to Be Considered

Without descending to "the nightmare scenario" so popular with our film makers, I believe that NLM's Long Range Plan must acknowledge some external factors that are beyond our control. For example,

1. If the threat of terrorist attacks on the US increases so as to become "normal", and perhaps ultimately once again successful? The Plan urges we establish research work in Disaster Management Information. NLM has already been in the vanguard of working from home, and we keep a very capable remote computing facility. But in spite of threats, we operate an "open" shop and deliver uncensored information. Will we need to do differently in the future?
2. If the US were no longer to remain the world's superpower and richest nation? Might our range of users, sources of information, sources of innovation, and languages also change? Might free information services for the world cease to be a popular plan?

3. If the US population were to become divided in its trust of government services, including the provision of scientific information, especially the great changes in medicine that are already presaged by the Human Genome Program's successes, can NLM remain a trusted source? How?

The Board might consider at its meetings during 2006 and 2007 if supplementary planning meetings could be organized to work out an informed view of some of the major external influences upon the NLM's work. We must wonder, what will be the best course of action for NLM under adverse circumstances.

A Good Prognosis

I am confident that given well meaning, reasonable management, and given encouraging Congressional support, that NLM will continue into the distant future to perform well for medical professionals, scientists, and the public. It's a grand institution. It deserves all the help and support it has gotten over 170 years, and it deserves and will justify all our help for yet another ten years and more!

Donald A.B. Lindberg, M.D.
Director

Executive Summary

In a world that is increasingly digital, the National Library of Medicine (NLM) already plays a pivotal role in enabling biomedical research, supporting health care and public health, and promoting healthy behavior. By connecting and making the results of research — from scientific data to published literature to patient and consumer health information —readily available, the Library magnifies the positive impact of the country's investment in the creation of new knowledge. In the next ten years, NLM's programs and services will become even more central to scientific discovery, treatment, and prevention. Careful planning and visionary thinking are critical to the pursuit of that future.

This Long Range Plan contains four overall goals:

Goal 1. Seamless, Uninterrupted Access to Expanding Collections of Biomedical Data, Medical Knowledge, and Health Information

Recommendation 1.1. Ensure adequate space and storage conditions for NLM's current and future collections to guarantee long term access to information and efficient service delivery.

Recommendation 1.2. Preserve NLM's collections in highly usable forms and contribute to comprehensive strategies for preservation of biomedical information in the U.S. and worldwide.

Recommendation 1.3. Structure NLM's electronic information services to promote scientific discovery and rapid retrieval of the "right" information by people and computer systems.

Recommendation 1.4. Evaluate interactive publications as a possible means to enhance learning, comprehension, and sharing of research results.

Recommendation 1.5. Ensure continuous access to health information and effective use of libraries and librarians when disasters occur.

Recommendation 1.6. Establish a Disaster Information Management Research Center at NLM to make a strong commitment to disaster remediation and to provide a platform for demonstrating how libraries and librarians can be part of the solution to this national problem.

Goal 2. Trusted Information Services that Promote Health Literacy and the Reduction of Health Disparities Worldwide

Recommendation 2.1. Advance new outreach programs by NLM and NN/LM for underserved populations at home and abroad; work to reduce health disparities experienced by minority populations; share and actively promote lessons learned.

Recommendation 2.2. Work selectively in developing countries that represent special outreach opportunities, such as improving access to electronic information resources, enhancing local journal publications of high quality, and developing a trained librarian and IT workforce.

Recommendation 2.3. Promote knowledge of the Library's services through exhibits and other public programs.

Recommendation 2.4. Test and evaluate digital infrastructure improvements (e.g., PDAs, intelligent agents, network techniques) to enable ubiquitous health information access in homes, schools, public libraries, and work places.

Recommendation 2.5. Support research on the application of cognitive and cultural models to facilitate information transfer and trust building and develop new methodologies to evaluate impact on patient care and health outcomes.

Goal 3. Integrated Biomedical, Clinical, and Public Health Information Systems that Promote Scientific Discovery and Speed the Translation of Research into Practice

Recommendation 3.1. Develop linked databases for discovering relationships between clinical data, genetic information, and environmental factors.

Recommendation 3.2. Promote development of Next Generation electronic health records to facilitate patient-centric care, clinical research, and public health.

Recommendation 3.3. Promote development and use of advanced electronic representations of biomedical knowledge in conjunction with electronic health records.

Goal 4. A Strong and Diverse Workforce for Biomedical Informatics Research, Systems Development, and Innovative Service Delivery

Recommendation 4.1. Develop an expanded and diverse workforce through enhanced visibility of biomedical informatics and library science for K-12 and college students.

Recommendation 4.2. Support training programs that prepare librarians to meet emerging needs for specialized information services.

Recommendation 4.3. Continue support for formal, multidisciplinary education in biomedical informatics to increase the supply of informatics researchers who can work at the intersections of molecular science, clinical research, health care, public health, and disaster management.

Strategic Vision

What Might the Next Twenty Years Hold?

Special Working Group
April 11-12, 2005

Strategic Vision

This section was derived from the meeting of the Strategic Vision Working Group at the Cosmos Club in Washington, D.C., on April 11-12, 2005. See appendix 4 for names of participants. The group met to provide the broadest view of NLM's mission, current situation, and its potential future contributions to the health and well-being of America. It was asked to articulate a view of the principal features of the biomedical information landscape in the 20 year period 2005-2025. Subsequently, the four planning panels were asked for recommendations for the next 10 years (2006-2016) that will be shaped by a more distant view of the next 20.

In a world that is increasingly digital, the NLM already plays a pivotal role in enabling biomedical research, supporting health care and public health, and promoting healthy behavior. By connecting and making the results of research — from scientific data to published literature to patient andconsumer health information — readily available, the Library magnifies the positive impact of the country's investment in the creation of new knowledge.

In the years ahead, NLM's programs and services will become even more central to scientific discovery and the treatment and prevention of disease. Continuing advances in biology, clinical research, health care, computer science, and telecommunications - and changes in the way information is produced, stored, and accessed - will combine to change the nature of biological and medical knowledge.

Genomic Research

By 2025, key elements of the success of the Human Genome project – distributed, high throughput and increasingly inexpensive data acquisition, publicly available curated databases, and advanced computational methods for relating new data to multiple levels of existing information - will have led to an enormous shared pool of data about genetic variation in humans, animals, viruses, and other pathogens. The systematic study of human genetic variation and its relationship to disease and response to drugs, environmental hazards, and behavior will yield new opportunities and new ethical dilemmas for health care and prevention. Current efforts to catalog the variants in the human population including changes at the single nucleotide level (SNPs) and larger blocks of sequences up to 60,000 bases that tend to be inherited together (haplotypes) will continue. Additional work in analyzing genetic variation in cases and controls for a range of clinical conditions and tracing the development of new virus strains through whole genome analysis will be accomplished. High throughput bioassays to determine the biological activity of a large number of chemical compounds in order to identify those useful for biological research and potential drug development will challenge NLM to manage the data for a large set of chemicals and to link these appropriately to the continuously growing host of biomedical reports and further published commentary in the literature.

NLM's involvement in planning and supporting basic biomedical research will continue to grow as the cycle continues. Investment in shared data will lead to more rapid scientific discovery, which will in turn lead to more publications and more shared data, which will in turn lead to more scientific discovery.

As the amount of data and information increases, researchers – not to mention health professionals – will need assistance in identifying where new scientific opportunities lie. Sophisticated "discovery" systems will lead researchers to scientifically interesting connections and patterns in the huge quantities of available data, thus speeding new scientific insights. The public will demand their individual genetic fingerprints, and incorpora-

tion of such information into practice will present a major challenge to health care providers. Health professionals and the general public will need help to use and interpret the flood of data.

Genome research will have completed the shift from the initial sequencing of the genomes of organisms (viruses to humans) to figuring out how to apply this new knowledge to understanding biological systems and ultimately improving human health. Experimental blocking of gene translation and protein transcription with small molecules

Strategic Visions Working Group Meeting

from shared repositories will have simplified the task of filling the gaping holes in scientific understanding of the range of protein products of genes, their interactions, and the pathways through which cellular and tissue metabolism is conducted. This will greatly increase the circumstances under which genetic testing of individual patients can reliably predict clinical response or side effects of specific drugs. Better understanding of "metabolomics"[1] combined with prospective cohort studies will significantly expand understanding of the circumstances in which genetic susceptibility plus exposure to environmental toxins is likely to yield certain disease states.

Ultimately, we may see developed a classification of disease based on molecular characterization rather than traditional empirical and organ classification systems. Such a molecular taxonomy could provide the basis for earlier detection and more effective and less costly treatment.

Clinical Research

Clinical research and genomic research will overlap in studies that attempt to determine the interaction between genetic make-up, behavioral and environmental risk factors, disease resistance, drug response, and clinical outcomes. Clinical trials that would have been limited to a small number of academic centers will be carried out in partnership among organized patient communities, community-based health care providers, and academic researchers. These teams collectively will care for groups of well-characterized patients that are large enough to reliably predict whether new interventions are safe and effective. They will be able to do work that required physical collocation in the past – using robust, standards-based clinical research infrastructure which began to emerge in 2005 as a result of the NIH Roadmap.

This 21st century approach will leverage electronic records used for health care and public health reporting and employ new ways to capture clinical research data, standards for clinical research protocols, new models of cooperation between NIH and patient advocacy alliances, and new strategies to strengthen the clinical research workforce. Standard clinical research infrastructure will facilitate the production of comprehensive registries of clinical trials and more prompt and thorough reporting of their results.

[1] Metabolomics— the study of all the metabolites in a cell, tissue or organism. This science includes carbohydrates, lipids, signaling molecules, etc. See www.metabolomicssociety.org/. Metabolomics has the promise to enable detection of disease states and their progression, monitor response to therapy, stratify patients based on biochemical profiles and highlight targets for drug design.

Health Care System

A fundamental observation guiding this vision for the Library in coming decades is that publication and reading are necessary but insufficient mechanisms to turn knowledge into effective action in the 21st century. A healthcare enterprise that depends principally upon the cognitive capacity and reliability of autonomous individual practitioners and their interpretations of what they read will continue to be error-prone and have unacceptably high rates of suboptimal disease prevention, diagnosis and treatment. In the future the informed and "activated" consumer will play an increasingly important role in error prevention.

A systems approach to health care and public health, like the systems approaches to aviation safety and knowledge management in other complex industries, will depend increasingly upon "executable knowledge" in the form of computerized logic that embodies the collective best understanding and best practice for health-related practices.

Stated differently, in addition to patients, families, and the public, the Library's newest and fastest growing group of users may be intelligent devices.

By 2025, we will have left behind a world of very expensive, personally held knowledge in which people with trained intuitions based on years of education and practice could produce acceptable results in either health care or research. A worldwide Internet based cyber-infrastructure of knowledge provided in real time and mediated by expert systems exploring massive databases will be useful tools for healthcare and research. The health sciences will likely share some of the infrastructure with other scientific disciplines as part of the new world of e-science, both within the U.S. and internationally.

This infrastructure will support ubiquitous telemedicine capability allowing a trained community health aide anywhere on the globe to obtain and transmit diagnostic image and test information and obtain timely expert advice on appropriate handling and immediate treatment of patients with a wide range of conditions. Using wireless diagnostic tools produced at commercially sustainable costs, this trained aide may be able to identify and treat an increasing number of problems locally.

Patient Health Records and Personal Knowledge Bases

Patient health records will have evolved into multimedia Personal Health Knowledge Bases including individual preferences and directives, genetic make-up, best practices applicable to the individual, self tracking, and a record of care delivered and received. And the patient will always have a complete copy of his or her medical record. All of this information will be in a form permitting understanding by the individual and execution by computer programs. These Personal Health Knowledge Bases will integrate dynamically or interact with care provider systems – and selected data from them will feed public health and clinical research systems. As the knowledge of biology and health evolves in ways useful to the individual, the Personal Health Knowledge Base will link automatically to pertinent new information.

By 2025, every patient will be a potential Visible Man or Woman, with imaging data that can be viewed interactively. As the Visible Human project begins to incorporate physiology, biochemistry, and other necessary components of life, scientists

Strategic Visions Working Group Meeting

and healthcare practitioners will be able to see proteins unfolding, DNA in operation, the nanoscale activities that are at the very heart of life. The life processes that will become visible will be based on the data collected in one's own electronic health record. This record will include one's personal genome. The Visible Human could become not only a general teaching and research tool, but a personal instructional and diagnostic tool. This system will operate in both real time and be capable of speeding up and slowing down the time sequences compared to reality.

Lifelong Learning

Life-long just-in-time professional learning will replace the combination of discipline-specific just-in-case education and continuing education programs of the 20 century. Learning resources will be on line, 24-7 and pulled forward on demand by the professional who needs them. Integrated models of learning will support all health professionals and include an ascending series of complexities in language so individuals and their families can use the basic level while sophisticated advanced specialists use the most complex layer.

Simulations will greatly lessen our reliance on trial and error on patients and will be used routinely to check the limits of individual ability. Immersion facilities and personalized simulations will help in experiencing the hard to imagine. Holographic immersion, tailored based on an individual's PET scan and MRI, may allow visualizing individual patients with a breathtaking degree of accuracy. Because these resources are used to enhance entertainment and in advanced education, they will also be accessible over the network for use in K-12 education. Exposure during K-12 will prepare future consumers to be active participants in decisions about their care and prepare people coming into health education programs for more effective approaches to learning.

Community Health

Despite some residual "last mile" problems, in 2025, the "digital divide", i.e., persistent uneven access to high-speed computers and telecommunications, will have virtually disappeared in the U.S. However, disruptions in telecommunications during emergencies and disasters will continue to be problematic, due to ever increasing societal reliance on digital information. Even though technical telecommunications barriers will be greatly diminished, a sizeable fraction of the population will continue to lack the education and training necessary for the most effective use of information technology. Knowledgeable and sympathetic human beings will still be essential to helping underserved populations make effective use of information and decision support resources that are available and relevant to them. The NLM and the National Network of Medical Libraries will provide services to help minority and other underserved populations, and the health professionals who serve them, make the most effective use of

Warm and Healthy Alaskan Girl

information and decision support resources that hold the promise of promoting healthy behaviors, preventing costly and debilitating illness, and improving health outcomes when disease occurs.

Services essential to preserving the community's health, e.g., disease surveillance, environmental monitoring, food and water inspection, emergency response, will continue to be provided through many different organizations and by widely dispersed people with different types and levels of training and education. The National Network of Libraries of Medicine will continue to be essential to NLM's ability to reach both underserved populations and the varied workforce attempting to serve them.

Global Health

Whole genome analysis will be increasingly applied to new pathogens and emerging diseases. The NLM will facilitate a global system aggregating and facilitating access to information produced around the globe.

At the same time, declining costs and increasing robustness of wireless communication and portable/wearable computing devices will make reliable delivery of education and information much more feasible in even remote and very poor parts of the world. Although it cannot address the underlying problems of extreme poverty, joblessness, and lack of access to medicines, near ubiquitous access to NLM's knowledge resources will provide new opportunities for partnerships with international organizations and foreign governments to aide efforts to improve health and prevent the spread of emerging infections.

Publishing, Libraries, and Information Delivery

Beyond the development of increasingly sophisticated ways to connect scientific publications to underlying data and interactive multimedia appendices, by 2025 research will have greatly increased our understanding of visual reasoning and how different types (e.g., text, numbers, pictures, sound) and methods of interaction with information (e.g., ability to request transformations or additional details) affect identification, understanding, and retention of useful information. As a result, digital publications will have learned how to adjust on the fly to user learning styles and preferences.

As new items are added to libraries' digital collections they will be automatically connected to related information already present, expanding on techniques currently used at NLM to relate information across a wide array of Entrez databases. In this environment, books and other types of information and data will literally "talk to each other" and report any interesting findings back to human beings for further consideration and analysis. Across all types of biomedical and health-related information – and all types of users – there will be a continuing demand for ever more sophisticated computer-based systems that can understand a specific user's information need and deliver a concise and appropriate response that is readily understood by that user. There will be a thriving market for products and services tailored to the information needs of individuals - and more than enough work for skilled people who will use increasingly sophisticated software to select, organize, analyze, link, and synthesize the information in the digital libraries that feed individualized services. Thus medical libraries and medical librarians will continue to be essential, although with a host of new duties.

In a sense the role of the medical library may change from housing and archiving information to more of an essential intellectual place of collaboration and constant information analysis, and in some cases, synthesis.

As the published knowledge base continues to expand incrementally, it should be possible to create computationally-aided "ripple effects" in research, health care, and public health systems – reducing the lag time between the discovery of important new knowledge and its application in real world settings.

The majority of new scientific research results will be freely available in permanent digital archives shortly after initial production or publication, thus fueling additional scientific discovery and encouraging the development of a wide range of value-added commercial products and services.

Preservation

Preservation, version control, and continuity of access to digital information will be critical. As a result of collaborative work involving NLM, other libraries and archives, and a broad array of publishers, many formally published digital works will be released in standards-based formats that facilitate permanent access. There will be tools to assist organizations and individuals to generate records and papers that are inherently archivable. NLM will be part of an international network of trusted digital repositories in libraries and archives supported by governments, universities, and private organizations. By 2025, the network of repositories will have made some progress on establishing a rational division of labor for the expensive initial acquisition of content in a complete archivable format. They will have robust agreements and procedures to ensure that at least some important digital content is archived at multiple independent sites in geographically dispersed locations.

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Digital technology will have provided the infrastructure necessary to make progress on another great preservation challenge of the 21st century – preserving and providing permanent access to the physical papers, records, and images that document the huge explosion in biomedical discovery and health policy developments that occurred in the latter half of the previous century.

These great shifts will create a 21st Century Intelligent Health System. The NLM can play a catalytic role in this transformation by identifying and embracing new opportunities - while also paying careful attention to preserving its reputation as a credible source of reliable knowledge and a leader in biomedical informatics.

Genome Project
Changing the Face of Medicine: Exhibition
Changing the Face of Medicine | Dr. Tenley E. Albright
Unified Medical Language System (UMLS)
National Library of Medicine
Unified Medical Language System
THE VISIBLE HUMAN PROJECT™
Internet
Today and Tomorrow
NATIONAL TELEMEDICINE INITIATIVE
National Library of Medicine
Evaluation Forum
MEDLINE on CD-ROM
Bethesda, Maryland
The Visible Human Project
MedlinePlus.gov
Information Rx
Diabetes
Outreach at the National Library of Medicine
Outreach Activities & Resources
SIS Specialized Information Services
Health Information Outreach Programs
Web Sites For and About Specific Populations
MedlinePlus
Trusted Health Information for You
NIH MedlinePlus
Winning the Race
NIH MedlinePlus
Mary Tyler Moore's
Fight Against Diabetes
National Network of Libraries of Medicine (NN/LM) Home Page
NN/LM National Network of Libraries of Medicine
nnlm.gov
Resources for Members of the National Network of Libraries of Medicine (NN/LM)
Quick Links:
News & Announcements:

A Brief Report: Major Elements of NLM's Work Since its Long Range Plan of 1986

1986-2006: Two Decades of Progress

The 1986 Long Range Plan stimulated a variety of expanded responsibilities for the National Library of Medicine. Some of these required action by the U.S. Congress. Others are the result of recommendations by the Library's Board of Regents and various advisors. One gauge of this expansion is the increase in the NLM budget, from $57.4 million as reported in the 1986 annual report, to $323 million in 2006.

Some highlights from the past 20 years:

Internal Library Processes. Twenty years ago, NLM relied primarily on mainframe computers and commercial telecommunications networks. The Library Operations staff already used relatively sophisticated systems to carry out acquisitions, cataloging, indexing, preservation, and document delivery tasks, but the 1986 plan emphasized the need to rationalize, integrate, and greatly expand automated support for basic library processes. There were no electronic journals in the NLM collection. All MEDLINE citations and abstracts were keyed in from print journal issues, although NLM was talking to publishers about their ability to supply this information electronically. NLM's Reading Room patrons filled out document requests by hand, copies of articles provided in response to inter-library loan requests were delivered by surface mail, and the majority of offsite reference and customer service inquiries came by telephone to several different service points. In 2006, NLM's computers are connected to the world via the Internet. 82% of the now more than 600,000 citations and abstracts are received electronically from publishers. The rest are captured via a precisely tailored scanning and optical character recognition system developed by the Lister Hill Center. Onsite patrons generate document requests as a by product of searching NLM's online catalog or PubMed, but only if the material they are seeking is not available in electronic full-text. NLM fills 96% of roughly 274,000 annual interlibrary loan requests electronically. The Library's now consolidated customer service operation receives 67% of its requests via email and the Web.

MEDLINE.[2] In 1986, NLM enabled users to use personal computers to connect to MEDLINE via GratefulMed (now MEDLINE via PubMed). There was a modest fee for searching to cover commercial telecommunications charges and there were slightly more than 3 million online searches that year. In the 1990s NLM reinvented its legacy computer systems and was supported by Congress in making Web access to NLM services free via the Internet. The reinvention effort also supported efficient use of NLM data by external computer systems. The current rate of searching is almost one billion searches annually.

National Network of Libraries of Medicine.[3] What was formerly called the Regional Medical Library Network was renamed and enlarged. Funding for the network increased from $2.2 million to $12 million annually. The NN/LM now has some 6,000 member institutions that cooperate to equalize and improve access to information in universities, hospitals, and communities across the nation. The Network has broadened its responsibilities to serve the general public as well as health professionals, researchers, and

[2] PubMed [Internet]. Bethesda (MD): National Library of Medicine (US). 1996 Jan - [cited 2006 Oct 26]. Available from: http://pubmed.gov/.

[3] National Network of Libraries of Medicine [Internet]. Bethesda (MD): National Library of Medicine (US); [updated 2006 Sep 15; cited 2006 Oct 27]. Available from: http://nnlm.gov/.

information specialists and is a major part of NLM's strategy to reach minority groups and underserved communities.

National Center for Biotechnology Information.[4] The NCBI, created by act of Congress in 1988, has become an international leader in assembling, organizing, and making available the kinds of biological and genomic data that drive modern life sciences research. The Center works closely with researchers and institutions at NIH and around the world who contribute sequence and other data to GenBank and other molecular biology databases. In recent years, the NCBI has been tapped to develop PubChem databases that store and link data about biologically active small molecules. This is a key element in the trans-NIH Roadmap Initiative.

Outreach.[5] Prompted by a special-focus Long Range Planning report in 1989, the NLM launched a vigorous program of outreach to ensure that health professionals and the public were aware of the information resources available from NLM. Early efforts focused on letting physicians know that they could search MEDLINE from their home or office via personal computer software developed by NLM and on alerting the HIV/AIDS community to several free data resources. Today NLM and the NN/LM support hundreds of community outreach demonstrations, events, and projects every year, with special emphasis on groups with major health disparities, such as African Americans, Native Americans, and Latinos. Since 1996, the Library's major historical exhibitions and their accompanying Web sites, K-12 educational materials, and touring versions have also helped to introduce NLM's collections and health information services to wider audiences.[6]

Consumer Health Information. When MEDLINE became free on the Internet in 1997, the general public arrived at NLM's online door, and the Library began to create a series of health information resources expressly for this audience. MedlinePlus[7], the largest and most prominent of NLM's consumer health services, is used by millions each month. MedlinePlus has free health information, in both English and Spanish[8], from the NIH Institutes and other reliable sources of health information. Thanks to the efforts of health sciences librarians across the country and their state and local partners, many users can "Go Local" to find neighbor-hood health services related to topics they view on MedlinePlus. As of 2006, 15 MedlinePlus Go Local sites were operational, with more in the pipeline.

PubMed Central.[9] In February 2000, NLM launched PubMed Central, a digital archive of full-text articles from biomedical and life sciences journals, on behalf of the NIH. Starting from just two journals and a few thousand articles, PubMed Central now provides free public access to more than three quarters of a million articles cited in PubMed/MEDLINE. PubMed Central has had a major impact on policy and technical developments related to electronic biomedical journals. It is the repository specified in the NIH public access policy and by other major research funders in the U.S. and

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4 National Center for Biotechnology Information [Internet]. Bethesda (MD): National Library of Medicine (US); [rev. 2006 Oct 26; cited 2006 Oct 27]. Available from: http://www.ncbi.nlm.nih.gov/

5 Training & outreach [Internet]. Bethesda (MD): National Library of Medicine (US); 2004 May [updated 2006 Sep 6; cited 2006 Oct 27]. Available from: http://www.nlm.nih.gov/training.html

6 A recent example is: Changing the face of medicine: celebrating America's women physicians [Internet]. Bethesda (MD): National Library of Medicine (US), History of Medicine Division; 2003 Oct [cited 2006 Oct 27]. Available from: http://www.nlm.nih.gov/exhibition/changingthefaceofmedicine/. Changing the Face of Medicine is on display as a traveling exhibit in 61 libraries across the United States through November 2010.

7 MedlinePlus [Internet]. Bethesda (MD): National Library of Medicine (US). 1988 Oct - [cited 2006 Oct 26]. Available from: http://medlineplus.gov/.

8 MedlinePlus en Español [Internet]. Bethesda (MD): National Library of Medicine (US). 2002 Sep - [cited 2006 Oct 26]. Available from: http://medlineplus.gov/spanish/.

9 PubMed Central: a free archive of life sciences journals [Internet]. Bethesda (MD): National Library of Medicine (US), National Center for Biotechnology Information. 2000 Feb - [cited 2006 Oct 26]. Available from: http://pubmedcentral.gov/.

other countries. Its standard electronic format for archiving articles has been endorsed by the Library of Congress and the British Library and widely adopted by publishers. A modified version of the PubMed Central system is being used to establish similar cooperating archives in other countries.

ClinicalTrials.gov.[10] In response to a mandate in the FDA Modernization Act of 1997, NLM worked with NIH and FDA to develop ClinicalTrials.gov to allow prospective patients and their doctors to locate ongoing human research studies in which they might participate. First released in 2000 with 4,000 NIH-funded studies, the site now contains information on more than 33,000 federally and privately supported trials in more than 130 countries. The number of trials registered received a boost from a decision of the International Committee of Medical Journal Editors in September 2005 to require, as a precondition for subsequent publication of results in their journals, that clinical trials be registered before they begin.

Toxicology and Environmental Health Information.[11] In the past 20 years, NLM's toxicology and environmental health services have broadened their focus from toxicologists, chemists, and pharmacologists to provide services more usable by health professionals, emergency responders, and the public. Innovative services released within the past few years include: the Household Products Database, which provides information for consumers about potentially harmful substances in widely purchased products; ToxMap, which allows communities to determine what toxic substances have been released in their vicinity; and a hand-held hazardous substance information resource used in the field in the aftermath of Hurricane Katrina.

High Performance Computing and Communications.[12] The multi-agency HPCC program was established by Congress in 1991 to advance computing and communication and provide a platform for a national information infrastructure in the US. NLM was the initial federal representative for biomedicine and health, and the NLM Director was appointed the first Director of the HPCC National Coordination Office by the President's Science Advisor.
With substantial additional HPCC funding beginning in 1993, NLM has funded competitive research contracts for prototype advanced biomedical and health applications of computing and communications, initially focusing on telemedicine and more recently on scaleable networks and disaster information management. The Indianapolis Network for Patient Care,[13] now a national model for regional health information exchange among independent hospitals, pharmacies, laboratories, physician practices, and public health departments, was originally funded by this NLM Program. Currently funded projects are looking at self-healing networks and smart triage tags for use in coping with casualties in large-scale emergencies.

Visible Human Project.[14] Initiated by the 1990 long range plan for electronic imaging, this widely publicized Lister Hill Center program generated two large and totally novel datasets of highly detailed anatomical information, created by MRI, CT, and cryosection imaging of male and female cadavers released in 1994 and 1995 respectively.

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[10] ClinicalTrials.gov [Internet]. Bethesda (MD): National Library of Medicine (US). 2000 Feb - [cited 2006 Oct 26]. Available from: http://clinicaltrials.gov/. Developed in collaboration with the US Food and Drug Administration.

[11] SIS: Specialized Information Services [Internet]. Bethesda (MD): National Library of Medicine (US), Specialized Information Services Division; 2005 Apr [updated 2006 Oct 4; cited 2006 Oct 27]. Available from: http://www.sis.nlm.nih.gov/.

[12] Office of High Performance Computing and Communications [Internet]. Bethesda (MD): National Library of Medicine (US), The Office; [updated 2003 Oct 23; cited 2006 Oct 27]. Available from: http://lhncbc.nlm.nih.gov/ohpcc/.

[13] INPC: Indiana Network for Patient Care [Internet]. Indianapolis (IN): Regenstrief Institute, Inc.; c2000-2006 [cited 2006 Oct 27]. Available from: http://www.regenstrief.org/medinformatics/inpc/.

[14] The Visible Human Project® [Internet]. Bethesda (MD): National Library of Medicine (US); 2003 Sep [updated 2006 Jul 28; cited 2006 Oct 27]. Available from: http://www.nlm.nih.gov/research/visible/visible_human.html

Licensed at no charge by 2,000 individuals and institutions in some 50 countries, the Visible Humans have enabled a wide range of educational, diagnostic, treatment planning, virtual reality, artistic, and industrial applications. An NLM-sponsored partnership between university and industry research groups produced the open source National Library of Medicine Insight Segmentation and Registration Toolkit (ITK) for use with the Visible Humans and other image datasets. ITK is heavily used in imaging research, including work by two the NIH-funded National Centers for Biomedical Computing.

Unified Medical Language System. [15] In 1990, NLM released the initial experimental version of the UMLS Metathesaurus, including 64,000 concepts and 125,000 unique terms from less than 10 biomedical vocabularies, and the UMLS Semantic Network, a high level representation of medical common sense. The intent of the UMLS effort was to provide structured electronic knowledge sources that would aid the development of computer programs that would behave as if they "understand" medical meaning. Today, the UMLS Metathesaurus contains more than 1.3 million concepts and 6.4 million unique terms from 119 vocabularies in 17 languages. NLM is now the designated central coordinating body for clinical terminology standards within the Department of Health and Human Services (HHS). The Library funds, licenses for U.S.-wide use, and builds three core clinical vocabularies, and the UMLS Metathesaurus is the official distribution vehicle for U.S. standard administrative code sets, required to bill electronically for health services, and vocabulary standards for electronic health records. The full set of UMLS components, which also includes advanced lexical tools, is used in most serious natural language processing, data mining, and ontology research and applications in the biomedical domain. Many NLM services, such as PubMed, ClinicalTrials.gov, and Genetic Home Reference, use UMLS knowledge to enhance retrieval, and the UMLS is integral to the system that provides automated assistance to NLM's expert human indexers.

Grants for Research and Resource Development.[16] The NLM has had a program of grants since 1965. NLM's grants today are awarded primarily for projects in biomedical informatics, information management, and artificial intelligence. Resource grants now focus on a broad variety of knowledge management projects that utilize telecommunications and computers to improve information access and utilization by professionals and consumers. Approximately half of NLM' grant budget is expended in support of informatics research projects and research infrastructure such as databases and tools. Clinical informatics, the predominant theme of NLM's research grants in earlier years, continues to receive strong support, but a significant portion of NLM's informatics research budget is now allocated to bioinformatics and computational biology as the importance of computing to basic and translational science increases. NLM's grant programs are also heavily involved in such pan-NIH initiatives as Roadmap and the Biomedical Information Science and Technology Initiative (BISTI), programs designed to address the burgeoning needs of clinical and basic science for computation and for computationally sophisticated scientists. NLM has program responsibility for one of the seven National Centers for Biomedical Computing supported by Roadmap grants.

[15] Unified Medical Language System [Internet]. Bethesda (MD): National Library of Medicine (US); 1999 Jan [updated 2006 Oct 6; cited 2006 Oct 26]. Available from: http://www.nlm.nih.gov/research/umls/.

[16] Grants & funding [Internet]. Bethesda (MD): National Library of Medicine (US); 2004 May [updated 2006 Aug 21; cited 2006 Oct 27]. Available from: http://www.nlm.nih.gov/grants.html

National Information Center on Health Services Research and Health Care Technology.[17] Congress first assigned NLM special responsibility for improving information services and resources for health services research and technology assessment in 1989 and established a formal Center at the Library in 1993. In response, NLM developed databases including the full-text of clinical and public health practice guidelines and evidence summaries, information about health services and public health research in progress, and information about research datasets and tools. The Center coordinates NLM's activities related to health services research, including health data standards, and also many of its services for the public health workforce. In 1997, NLM worked with the Center for Disease Control and Prevention (CDC) to establish the Partnership in Information Access for the Public Health Workforce to bring federal agencies, the National Network of Libraries of Medicine, and public health associations together to improve information services for public health workers. Since that time, the Library has worked with the Partners to develop a range of new information services, training programs, and outreach projects directed at the public health sector and has promoted greater public health participation in existing funding and training opportunities.

Education and Training.[18] The NLM has greatly expanded the training opportunities it offers—in biomedical informatics (for example, the course given at the Marine Biology Laboratory at Woods Hole, Massachusetts), biotechnology (through the NCBI), and for medical librarians and information specialists. There has also been an emphasis on increasing, through training grants, the cadre of biomedical informaticians. In 1986, NLM supported five academic sites training a total of 29 students; two decades later, the Library supports 18 sites around the nation, with 270 students. The NLM/AAHSL (Association of Academic Health Sciences Libraries) Leadership Fellows Program has been focused since 2002 on preparing emerging leaders for director positions in academic health center libraries. Grant support is available for informationist fellowships as well.

The Library's innovations and achievements of the past 20 years have helped to inspire the visions of a positively transformed future for medical practice, public health and research. A new climate for change has been fueled by the power of electronic communications, the embrace of the World Wide Web by health professionals and consumers alike, and some deficiencies. These include inadequate health care safety and quality, the need for better disaster response capabilities, increased political support for the electronic health record, and the promise of individualized treatment building on genomic research.

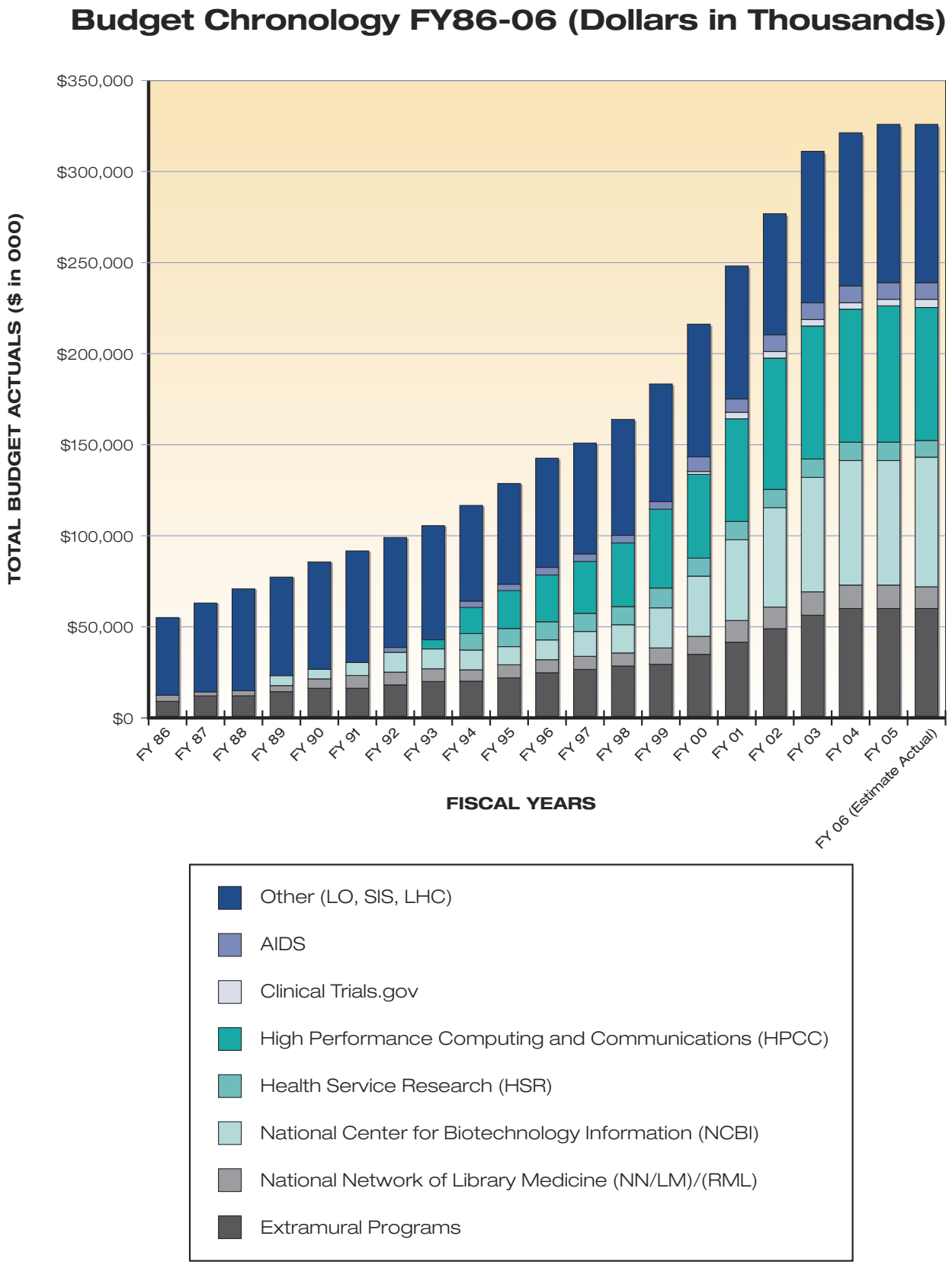
The centrality of NLM to the biomedical sciences - and to health information delivery - will not change. This plan for 2006-2016--the next decade--is organized around four key goals that will help NLM to enable the desirable future:

1. Seamless, Uninterrupted Access to Expanding Collections of Biomedical Data, Medical Knowledge, and Health Information
2. Trusted Information Services that Promote Health Literacy, Improve Health Outcomes, and Reduce Health Disparities Worldwide
3. Integrated Biomedical, Clinical, and Public Health Information Systems that Promote Scientific Discovery and Speed the Translation of Research into Practice
4. A Strong and Diverse Workforce for Biomedical Informatics Research, Systems Development, and Innovative Service Delivery

[17] Health Services Research & Public Health Information Programs [Internet]. Bethesda (MD): National Library of Medicine (US); 2004 May [updated 2006 Oct 23; cited 2006 Oct 27]. Available from: http://www.nlm.nih.gov/hsrph.html

[18] Training & outreach [Internet]. Bethesda (MD): National Library of Medicine (US); 2004 May [updated 2006 Sep 6; cited 2006 Oct 27]. Available from: http://www.nlm.nih.gov/training.html

Figure 1. NLM Budget Chronology



NLM's Long Range Plan for 2006-2016

GOAL ONE

Plan for 2006-2016

Goal 1. Seamless, Uninterrupted Access to Expanding Collections of Biomedical Data, Medical Knowledge, and Health Information

"The digital era, far from ending the physical library, will free it to facilitate learning rather than to house shelves — and will free those who work within library spaces to do less book processing and more learning facilitation."[19]

Building and maintaining the world's most comprehensive collection of biomedical literature is the one aspect of NLM's mandate that John Shaw Billings, the towering 19th century figure in the Library's history, would find most familiar. It was Dr. Billings who articulated the idea that a "national medical library" should aggressively collect and preserve the record of medicine. Today, the stream of printed books and journals being cataloged and shelved would reassure Billings, but he would no doubt be amazed by the digital publications and data that form an essential part of modern science and of NLM's collection. The Library's collection, in all its forms, is the bedrock on which today's information services rest and on which future services will be built. [20]

Recommendation 1.1. *Ensure adequate space and storage conditions for NLM's current and future collections to guarantee long term access to information and efficient service delivery.*

Inherent in the mandate of the world's preeminent medical library—to acquire, organize, preserve, and disseminate biomedical information—is the need for space to house its ever-expanding physical and electronic collections of biomedical information. These critical resources, many of which do not exist anywhere else in the world, continue to grow. Unfortunately, the shelves are filled, special collections are out of space, and computer rooms have no place to expand. Developing an expanded facility for the NLM is a small investment compared to the potential benefits of bringing the latest in biomedical science out of the laboratory and into the daily lives of millions to promote health and cure disease.

Despite great promises on the horizon, all of NLM's information-handling capabilities are being jeopardized by a lack of adequate space. Present facilities predate 1987 when Congress established the National Center for Biotechnology Information (NCBI). Built to hold fewer than 650 staff, the buildings must now accommodate more than

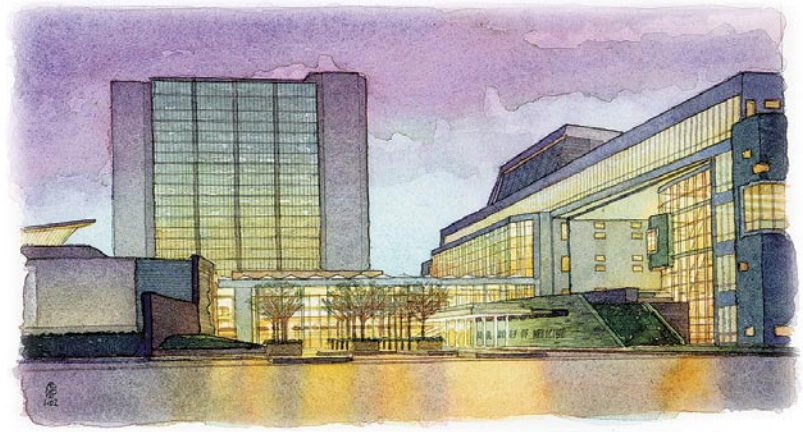
NLM Construction c. 1955

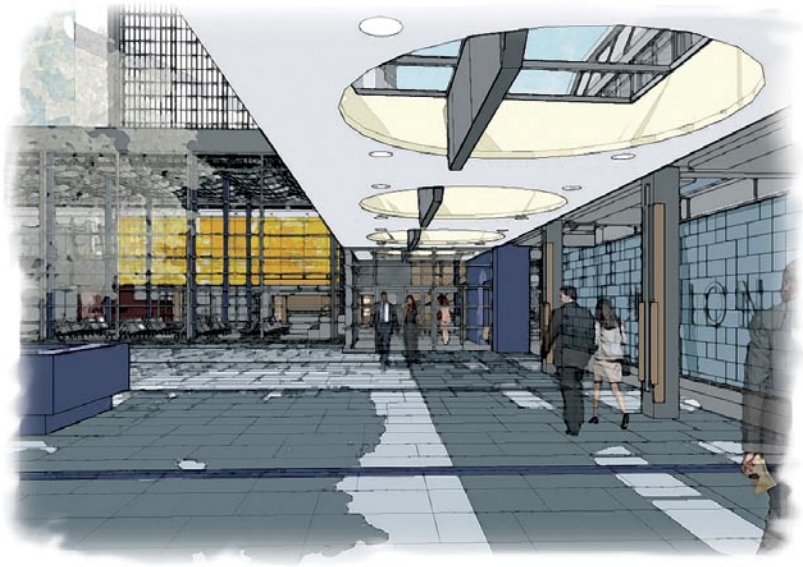
[19] Deanna Marcum, Associate Librarian for Library Services, Library of Congress in: Libraries in the digital age. NLM Newsline [Internet]. 2005 Spring [cited 2006 Oct 24];60(Spec Issue):1-20. Libraries as place; p. 4-5. Available from: http://www.nlm.nih.gov/pubs/nlmnews/spring05/60sp_newsline.pdf

[20] National Library of Medicine (US). Collection development manual of the National Library of Medicine [Internet]. 4th ed. Bethesda (MD): The Library; 2004 [cited 2006 Oct 24]. Available from: http://www.nlm.nih.gov/tsd/acquisitions/cdm

1300 with much of the increase coming from NCBI. Physical collections are overflowing the stacks, digital collections are outgrowing data center capacity and stressing electrical power and air-conditioning systems, and space for the serious multidisciplinary collaboration that underpins 21st century biomedical science is non-existent.

Architectural plans for a new NLM building were completed in 2003. The new facility would provide the Library with needed space for the biomedical archive of last resort, research on how to make information available, the work of the NCBI in molecular genetics, and a "collaboratory" that will assist in putting together teams of experts with different backgrounds to engage in large-scale multidisciplinary science.





Plans for NLM Expansion

Recommendation 1.2. *Preserve NLM's collections in highly usable forms and contribute to comprehensive strategies for preservation of biomedical information in the U.S. and worldwide.*

NLM has made significant progress in preserving its traditional physical collections through microfilming and (more recently) digitizing brittle books and journals, conservation of rare historical materials, and implementation of an onsite disaster prevention and response program. NLM should continue to use digital technology to preserve and provide permanent access to additional portions of the NLM print collection as well as its pictorial, multimedia, and archival materials.

When NLM owns both print and digital versions of the same biomedical journals, the Library should not quickly - nor unilaterally - consider abandoning its physical journal collection. NLM holds one of the world's major archival collections. It has an obligation to work in partnership with appropriate scholars and institutions worldwide to develop prudent preservation and access plans that serve science and health well in the long term future.

Because preservation of the NLM collection is necessary, but not sufficient to ensure continuing access to the complete record of biomedical and health sciences, these plans must encompass unique and important historical materials held elsewhere. Particular attention should be paid to preserving documentary evidence of the traditional healing practices of indigenous peoples.

The great preservation challenge of the 21st century is ensuring permanent access to digital information. Perhaps counter intuitively, acquiring and preserving digital data is more complex, more difficult, and more expensive (in people, space, and materials) than acquiring and preserving paper-based materials. Licensing arrangements provide current access to electronic information without transferring an actual copy that can be preserved.

Few institutions can match NLM's record of 40 years of successful preservation of the digital data it holds. Indexing citations created in the 1960s in the original batch Medical Literature Analysis and Retrieval System (MEDLARS) are searchable in PubMed/MEDLINE today, as well as available to other computer systems in fully tagged XML (Extensible Markup Language) format. The NLM experience with MEDLINE, GenBank, and many other databases shows that continual public access ensures that digital data are preserved in usable format.

NLM's PubMed Central[21], recently developed by NLM's National Center for Biotechnology Information on behalf of NIH, has led to national and international partnerships with publishers, societies, research funders, and libraries to promote and enable permanent public access to the electronic full-text of biomedical journals, including papers resulting from NIH-funded research. Thus NLM has appropriately extended its preservation plans to include information held elsewhere. The PubMed Central team led the definition of a widely adopted standard XML format for electronic articles,[22, 23] now extended to include books, and has developed an exportable version of the PubMed Central system to aid the development of similar archives in other countries. This work—and perhaps more like it—should be used by NLM as a start of efforts to assist in worldwide arrangements to guarantee the preservation of key biomedical information.

NLM must continue to work in partnership with the Library of Congress, the National Archives, other U.S. national and international government organizations, academia, publishers, and industry to develop workable long-term solutions to protect the full range of electronic materials, including scholarly publications, datasets, Web documents, interactive publications and other formats on which 21st century research, health care, and education depend. Such arrangements will almost certainly include collaboration among geographically dispersed trusted repositories. While contributing to long-term solutions, NLM should pursue immediate opportunities, including agreements with interested publishers and international peering partners for PubMed Central and other digital holdings.

Recommendation 1.3. *Structure NLM's electronic information services to promote scientific discovery and rapid retrieval of the "right" information by people and computer systems.*

Over the past decade, NLM "reinvented" its data creation, retrieval, and dissemination systems to support effective Web access, efficient interaction with external computer programs and Web applications, and output in standard formats. Improving the efficiency and effectiveness of NLM's systems is a journey - not a destination. To keep pace with the increasing flood of knowledge and data, NLM must continue to enhance the efficiency of its internal data creation and library processing systems and to provide ever more sophisticated automated assistance to the human experts who create and curate the Library's authoritative bibliographic and scientific data.

Millions of individuals and many external computer systems now retrieve terabytes of high quality health information and scientific data from NLM databases and services every day. Users of NLM services report relatively high satisfaction, and use continues to grow dramatically.[24] But most users of NLM databases fail to take advantage of the rich variety of linkages that already exist among NLM's related data sets and rely on a simple question and

[21] PubMed Central: a free archive of life sciences journals [Internet]. Bethesda (MD): National Library of Medicine (US), National Center for Biotechnology Information. 2000 Feb - [cited 2006 Oct 26]. Available from: http://pubmedcentral.gov/.

[22] Library of Congress and British Library to support common archiving standard for electronic journals. Inf Stand Q. 2006 Apr;18(2):13.

[23] The NLM standard is available at: Archiving and interchange DTD [Internet]. Version 2.2. Bethesda (MD): National Library of Medicine (US), National Center for Biotechnology Information; 2006 Jun 8 [cited 2006 Oct 27]. Available from: http://dtd.nlm.nih.gov/.

[24] For example, MedlinePlus in both the English and Spanish versions score consistently in the 86 range on the American Customer Satisfaction Index (ACSI) user survey, highest among Federal Web sites and tied with the best of the commercial offerings.

answer mode of querying, sorting through a short list of results and exiting. Many important discoveries may never be realized because of this query method. The problem will become more substantial as databases expand with new and different data types. Enhancements that improve automated assistance to facilitate discoveries are badly needed.

To address this problem, NLM should harness the combined strengths of its research and service divisions to improve its ability to lead users to the information already available in NLM resources and to provide just-in-time information delivery. Appropriate steps include development of more effective mechanisms for: retrieving across NLM's disparate resources, displaying related content from disparate resources, providing interfaces that accommodate the varying needs of individual users and external computer systems that require access to NLM data, and measuring the impact of new features on usability, user behavior, and retrieval success. NLM should also pursue ongoing work with leading commercial information technology companies to systematically probe NLM databases via sophisticated algorithms that dynamically deliver search results aimed at individual users' interests and requirements.

NLM should continue to conduct and support research and development in advanced information retrieval, synthesis, and display, including new ways to structure biomedical knowledge in electronic form; use of natural language processing techniques and software agents to integrate, access, and repackage information across multiple information resources; advanced database probing algorithms; and shareable software tools that aid customization for particular types of users (e.g., researchers, clinicians, and health care consumers).

Recommendation 1.4. *Evaluate interactive publications as a possible means to enhance learning, comprehension, and sharing of research results.*

New forms of "interactive" publications are emerging from the "multi-media" attachments[25] of some current journal articles. Despite major challenges in implementation, management, and preservation, interactive publications have the potential to enhance understanding, learning, and retention of scientific and health concepts.[26] Such publications could allow the reader (or hearer) to "point and-click" or gesture appropriately at a text passage and elicit a true multi-media response appropriate to the context. For example, the text reference to a clinical coronary angiogram might lead to a short video. Other examples might include breath and heart sounds, access to full CAT scans or MRIs in place of still illustrations, visualization of patient gait, and access to the data observations behind published summary tables and graphs. Where this supplementation is possible, one imagines a better comprehension and heightened credibility for the expert viewer, and a better learning opportunity for the less than expert viewer. These approaches might well enable more effective presentation of full results of clinical trials for both experts and the interested public.

Lister Hill Center research has developed and demonstrated a prototype system for publications with tabular data. The National Center for Biotechnology Information already is processing early examples of multimedia publications into PubMed Central, storing the multi-media and/or data attachments physically at NLM. As yet there are no generally agreed-upon standards for the format of the attached files, which complicates their management and long-term use. For those articles that are available primarily at publishers' or contractors' computer sites, the non-standard multi-media attachments may physically be stored in many different places around the world.

[25] Santos C, Blake JD, States DJ. Supplementary data need to be kept in public repositories. Nature [Internet]. 2005 Dec 8 [cited 2006 Oct 24];438(7069):738. doi:10.1038/438738a. Available from: http://www.nature.com/nature/journal/v438/n7069/full/438738a.html

[26] Lindberg DAB. Research opportunities and challenges in 2005. Methods Inf Med. 2005 Apr;44(4):483-6.

Research on enabling useful interactivity in scientific publications requires partnerships between NLM and commercial and academic journal publishers. The research agenda should address such topics as: appropriate technical formats; tool development for authoring, downloading, and viewing; thorough evaluation of the technology at various stages to ensure that the participating groups (authors, publishers, health professionals, researchers, students) benefit from this type of publication; and, after much more is learned, the development of recommended standard formats and practices.

Recommendation 1.5. *Ensure continuous access to health information and effective use of libraries and librarians when disasters occur.*

It is a distressing aspect of our era that society faces a variety of potential large-scale threats, both acts of nature and acts of humans. NLM has a significant track record in building information resources and networks that are resilient and valuable in the face of disasters from Bhopal, India, to the U.S. Gulf Coast.

The Library's first responsibility is to ensure that NLM critical information services remain available during emergencies and disasters - and it takes this responsibility seriously. NLM devotes a staff of six experts to computer security measures that prevent, detect, and minimize the effects of hostile attacks on the Library's computer systems. An offsite computer facility on a different power grid with multiple Internet access providers supports uninterrupted service from NLM's key systems. Some services are actively served by both sites, each acting as a hot standby for the other. For the warm and cold standby services, NLM cooperates with the National Network of Libraries of Medicine (NN/LM) to regularly test rerouting requests for service and assistance from one facility to another. In addition, some NLM datasets are mirrored at other sites around the world.

NLM should continue to strengthen and test its already excellent emergency response capabilities. NLM should work with the Regional Medical Libraries to establish more extensive NN/LM disaster response plans, possibly including library pairing to provide personnel and other services during emergencies. NN/LM planning should take advantage of relevant expertise and mission within HHS and military agencies, including the Uniformed Services University.

In the aftermath of Hurricanes Katrina and Rita, the NN/LM was highly effective in obtaining useful information from affected communities, rerouting requests for services, and getting equipment and personnel to locations serving evacuees and temporary health care facilities. Many public libraries served as communication and social service centers for evacuees.

Library emerges as information hub in shattered Mississippi town

"Library cards may have been washed away by Hurricane Katrina, but it doesn't really matter. Patrons in Pass Christian, Mississippi, are making do with a makeshift library that was set up in a 28-by-72-foot trailer in November. Although small, the temporary library has 17,000 volumes, wireless internet access, computers and laptops, group meeting space, and three full-time staff to help people find whatever they need...."

Oakland (Calif.) Tribune, Aug. 26, 2006

Building on this experience, NLM should work with appropriate federal, state, and local agencies to ensure that libraries and librarians are included in disaster response information plans and to identify more specifically the kinds of information they should be prepared to supply. Local 211 agencies that provide directories of essential community services, health organizations and other agencies are identifying resources in their own areas.

Veterans Administration Hospital, Gulfport, MS after Hurricane Katrina

NLM should work with relevant stakeholders to determine how this information can be organized and integrated into a national structure, analogous to the expanding MedlinePlus Go Local service that links information about locally available health services to authoritative disease, treatment, and prevention information. NLM should investigate the potential for expanding its services to encompass additional information relevant to disaster management.

Recommendation 1.6. *Establish a Disaster Information Management Research Center at NLM to make a strong commitment to disaster remediation and to provide a platform for demonstrating how libraries and librarians can be part of the solution to this national problem.*

NLM does not actually treat patients, investigate disease outbreaks, clean up toxic spills, or conduct clinical trials. Nonetheless, the Library's intramural and extramural research programs have produced innovative and robust information systems and services that assist all of these activities. In recent years, NLM has conducted and supported selected research and development projects related to disaster information management, which have been similarly useful to those involved in disaster planning and management.

Work undertaken or sponsored by NLM has produced portable devices with toxic chemical information used by emergency responders after Hurricane Katrina, software tools for robust DNA identification of victims of 9/11[27] and Katrina, prototype self-healing wireless networks to restore connectivity and smart tags to track patients during triage, transportation, and treatment, and new insights into the evolution of flu viruses derived from the analysis of genomic data which suggest more effective strategies for vaccine development.

There is ample evidence of the enormous communication and information dissemination problems that arise in large scale disasters. The area is ripe for additional research that builds on NLM's existing strengths and research portfolio. To complement and support the activities of the federal, state, and local agencies responsible for disaster planning and response, NLM should formally expand its research and development agenda in this arena and establish a Disaster Information Management Research Center within the Library. This new Center should:

- Maintain close collaboration with appropriate federal agencies and initiatives that aim at disaster prevention and remediation.
- Alert staff at NLM, NIH, and HHS to progress, experiments, and failures in this field, with special focus on information and communication systems.
- Operate across NLM Divisions so that all potential contributions to disaster remediation, including outreach and training, are coordinated and enhanced.
- Identify critical research and development opportunities, and initiate and/or collaborate in these.

[27] Biesecker LG, Bailey-Wilson JE, Ballantyne J, Baum H, Bieber FR, Brenner C, Budowle B, Butler JM, Carmody G, Conneally PM, Duceman B, Eisenberg A, Forman L, Kidd KK, Leclair B, Niezgoda S, Parsons TJ, Pugh E, Shaler R, Sherry ST, Sozer A, Walsh A. Epidemiology. DNA identifications after the 9/11 World Trade Center attack. Science. 2005 Nov 18;310(5751):1122-3. doi: 10.1126/science.1116608.

GOAL TWO

Plan for 2006-2016

Goal 2. Trusted Information Services that Promote Health Literacy, Improve Health Outcomes, and Reduce Health Disparities Worldwide

"Health literacy is the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions. But health literacy goes beyond the individual. It also depends upon the skills, preferences, and expectations of health information and care providers..."[28]

Contributing to improved health literacy is a foundational goal for the NLM. For the Nation it is both good social policy and sound fiscal policy to increase health access and improve outcomes.[29] As stated in the Board of Regents Policy on Consumer Health, NLM's primary role is "to ensure that all people in the U.S. have a known, accessible, understandable, and affordable source of current, authoritative health information." Ready access to information will not ensure understanding yet alone behavior modification, but it is often a prerequisite, and should continue to be a primary objective of NLM outreach programs. Furtherance of user understanding presents a greater challenge, and will require imaginative efforts to use user feedback, evaluation, and cognitive science principles to inform system development. Services intended for use by minority populations must also employ culturally appropriate design elements that invite and reinforce effective use.

NLM's free, high quality consumer information services are heavily used by members of the public and by clinicians as aids to patient education, but they reach only some of their intended users. At a time when the amount of doctor-patient "face time" for discussing and explaining health conditions is short and there is intensified emphasis on self-informed patients and healthy lifestyles as keys to improving health and reducing costs, the Library must continue to strengthen its efforts to promote awareness of and ability to use electronic information sources among all segments of the population. To this end, NLM must strive to provide information in forms that can help increase understanding, reduce health disparities, and promote health literacy.

NLM Director Lindberg at Smudging Ceremony opening the "Native American Concepts of Health and Disease" Consultation, December 2006, Santa Fe, New Mexico, with Mr. George Horse Capture, Curator Emeritus, National Museum of the American Indian.

[28] Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. Health literacy: a prescription to end confusion [Internet]. Washington: National Academies Press; 2004 [cited 2006 Oct 23]. Available from: http://www.nap.edu/catalog/10883.html#toc

[29] Cutler DM, Lleras-Muney A. Education and health: evaluating theories and evidence [Internet]. Cambridge (MA): National Bureau of Economic Research (US); 2006 Jul [cited 2006 Oct 26]. 37 p. (NBER working paper; no. 123520). Available from: http://papers.nber.org/papers/w12352 System requirements: Adobe Acrobat.

Recommendation 2.1. *Advance new outreach programs by NLM and NN/LM for underserved populations at home and abroad; work to reduce health disparities experienced by minority populations; share and actively promote lessons learned.*

NLM's core mission includes a vigorous outreach program to help assure that its users, including researchers, health professionals, and the lay public, are aware of and make effective use of health information available from NLM. NLM's active outreach program began when the Medical Library Assistance Act (MLAA) of 1965 mandated the formation of the Regional Medical Library (RML) Network to strengthen medical information service across the country. In 1989, encouraged by the Congress, the NLM Board of Regents issued a specific Long Range Plan Report on Outreach[30], known as the "DeBakey" report after Dr. Michael E. DeBakey who chaired the Planning Panel and had also been influential in the passage of MLAA. The 1989 Outreach Plan recommended a new name and an expanded outreach role for what is now called the National Network of Libraries of Medicine (NN/LM). In FY 1990, funding increases from the Congressional Appropriations Sub-Committee chaired by Mr. William Natcher enabled hundreds of locally-directed outreach projects to reach underserved health care professionals nationwide.

Beginning with emphases on physicians not directly affiliated with an institution having a medical library, and on the HIV/AIDS community, NLM and NN/LM outreach efforts promoted access to the newly emerging Internet and the electronic resources that increasingly became NLM's most efficient mode of dissemination.[31] The elimination of charges for MEDLINE in 1997 (due to the switch from commercial telecommunications networks to the Internet) and the development of MedlinePlus and other NLM services directed toward the general public enabled the expansion of outreach to public health professionals (via the Partners in Information Access for the Public Health Workforce), public libraries, and a growing range of community-based organizations serving minority and underserved populations.

Over the past 15 years, numerous projects have addressed infrastructure improvements in minority and rural communities and academic institutions (e.g., Historically Black Colleges and Universities and Tribal Colleges); training minority health professionals, librarians and other information professionals, and community members to use health information resources (e.g., Promotoras de Salud and Hispanic student peer tutors[32, 33]); outreach partnerships with community-based and profes-

December 2006 NLM visit to Jemez Indian Pueblo, New Mexico, Traditional Bread Making.

[30] National Library of Medicine (US), Board of Regents. Improving health professionals' access to information. Bethesda (MD): The Library; 1989.

[31] Wood FB, Sahali BA, Press N, Burroughs C, Mala TA, Siegel ER, Fuller SS, Rambo N. Tribal connections health information outreach: results, evaluation, and challenges. J Med Libr Assoc [Internet]. 2003 Jan [cited 2006 Oct 24];91(1):57-66. Available from: http://www.pubmedcentral.gov/picrender.fcgi?artid=141188&blobtype=pdf

[32] Bowden VM, Wood FB, Warner DG, Olney CA, Olivier ER, Siegel ER. Health information Hispanic outreach in the Texas Lower Rio Grande Valley. J Med Libr Assoc [Internet]. 2006 Apr [cited 2006 Oct 24];94(2):180-9. Available from: http://www.pubmedcentral.gov/picrender.fcgi?artid=1435849&blobtype=pdf

[33] Olney CA, Warner DG, Reyna G, Wood FB, Siegel ER. MedlinePlus and the challenge of low health literacy: findings from the Colonias project. J Med Libr Assoc [Internet]. Forthcoming 2006.

sional organizations (e.g., through "listening circles" and other consultations with American Indians, Alaska Natives and Native Hawaiians); and the development of culturally sensitive information (e.g., special population Web sites for Native Americans and Pacific Islanders).

"By many measures, America has an exceptional health care system. Tremendous advances have made the U.S. health system the most technologically advanced in the world. Yet that system is in trouble. Basic quality care is beyond the reach of far too many Americans. As the population has become increasingly diverse, glaring disparities in the quality of care, especially for racial and ethnic minorities, have led to thousands of premature deaths each year and incalculable hours of lost productivity, pain, and suffering."[34]

Public libraries, schools, public health departments, and a range of community based organizations are natural allies in the campaign to improve health literacy and eliminate health disparities. NLM and the NN/LM must continue to work in partnership with all of these groups to develop new models and strategies for promoting sustainable access to, and use of, health information in minority and underserved communities. Expansion of the NN/LM to include new members such as community-based organizations should be attempted.

Experience gleaned from outreach demonstration projects must be evaluated in context and disseminated widely in the interest of furthering participatory research that strengthens community-based

July 2006 NLM visit to Miloli'i Village Big Island, Hawaii, Computer Room in Village Library.

organizations, and fosters productive partnerships with libraries and health professionals.[35] NLM should consider hosting a Web site as a primary resource center and point of entry for locating health information literacy tools and materials, perhaps employing collaboration tools such as Wikis and blogs to provide dynamic reports of outreach outcomes and lessons learned. An effective practices database, modeled upon those produced for the Corporation for National Service, could reach the broader outreach community and benefit from their input.

Recommendation 2.2. *Work selectively in developing countries that represent special outreach opportunities, such as improving access to electronic information resources, enhancing local journal publications of high quality, and developing a trained librarian and IT workforce.*

At its most fundamental level, global health is America's business both on humanitarian grounds and on national security grounds. The dire health conditions in some developing nations are part of the heart-wrenching scenes of distress broadcast via TV, cable, and the

[34] Missing persons: minorities in the health professions. A report of the Sullivan Commission on Diversity in the Healthcare Workforce [Internet]. [place unknown]: The Sullivan Commission; 2004 [cited 2006 Oct 23]. Available from: http://www.aacn.nche.edu/Media/pdf/SullivanReport.pdf

[35] Siegel ER, Wood FB, Dutcher GA, Ruffin A, Logan RA, Scott JC. Assessment of the National Library of Medicine's health disparities plan: a focus on Native American outreach. J Med Libr Assoc [Internet]. 2005 Oct [cited 2006 Oct 24];93(4 Suppl):S10-20. Available from: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1255749&blobtype=pdf

Internet around the globe. Diseases in one part of the world can quickly spread. Collaboration with partners in developing regions is essential to help establish means for accessing and disseminating disease surveillance data that may be used to identify and contain new outbreaks that also become a threat to the American people. This outreach should be pursued in concert with a new NLM research agenda in disaster information management, coupled with efforts to strengthen national and local public health systems.

Installing the satellite dish for the Multilateral Initiative on Malaria communication network in Gabon.

NLM has been a significant contributor in international activities for at least half a century,[36] in part through the International MEDLARS Centers and through participation in international conferences on medical librarianship and medical informatics.

In recent years NLM has supported intensive capacity-building projects in selected developing countries. In partnership with the National Institute of Allergy and Infectious Diseases and the Fogarty International Center at NIH, the Centers for Disease Control and Prevention and numerous research agencies in the US and abroad, NLM developed and implemented a communications model for the Multilateral Initiative on Malaria that provides affordable and reliable satellite access to the Internet and electronic information resources in malaria research laboratories in 19 African countries.[37] Subsequent partnerships were established to improve the quality of African medical journals, leading ultimately to their being indexed in MEDLINE; to train IT personnel to provide local user support; and to strengthen a cadre of medical librarians to meet local needs and partner with NLM in future outreach efforts.

In Central America, an area particularly prone to natural disasters, NLM collaboration with the Pan American Health Organization (PAHO) is providing prevention and preparedness training, materials and communications infrastructure for disaster information centers in Chile, Nicaragua, Honduras, and El Salvador.

The medical library community has also actively pursued useful international partnerships. “Sister library” arrangements have been established by the Medical Library Association (MLA) in Latvia and Antigua in which more than 100 US and Canadian libraries jointly provided ad hoc training, material and communications. A more typical model pairs libraries one-on-one and fosters closer ties, but may be more difficult to sustain over time due to the intensive commitments required. An excellent example of this approach is the award-winning “two Georgias” partnership established between Emory University in Atlanta and the National Information Learning Center in Tbilisi.[38]

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[36] Corning ME. National Library of Medicine: international cooperation for biomedical communications. Bull Med Libr Assoc [Internet]. 1975 Jan [cited 2006 Oct 24];63(1):14-22. Available from: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=198850&blobtype=pdf

[37] Royall J, van Schayk I, Bennett M, Kamau N, Alilio M. Crossing the digital divide: the contribution of information technology to the professional performance of malaria researchers in Africa. Afr Health Sci [Internet]. 2005 Sep [cited 2006 Oct 24];5(3):246-54. doi: 10.5555/afhs.2005.5.3.246. Available from http://www.atypon-link.com/MMS/doi/pdf/10.5555/afhs.2005.5.3.246

[38] Burns CA, Kirtava A, Walker HK. The role of information access in sustainable healthcare in Georgia: The Atlanta-Tbilisi Health Partnership model. Inf Serv Use [Internet]. 2005 [cited 2006 Oct 24];25:125-35. Available from: http://iospress.metapress.com Free registration required to view this article.

NLM should continue its current special initiatives and identify promising new collaborative opportunities in selected countries. NLM should also investigate ways to promote effective library-peering and support models, including the Medical Library Association's emerging international visitation program "Librarians without Borders."

NLM should also explore opportunities to work with foundations that address global health needs. It may be possible to improve the capacity to access and use electronic health information in conjunction with their international endeavors. For example, the development of a Woods Hole-type informatics training program might help raise international medical informatics literacy and practical skills.[39,40]

Recommendation 2.3. *Promote knowledge of the Library's services through exhibits and other public programs.*

Exhibits and public programs can play an important role in increasing science literacy, promoting awareness of health information services, and enhancing interest in careers in science, biomedical informatics, and librarianship. Both Changing the Face of Medicine and Visible Proofs, the most recent members of NLM's acclaimed series of major historical exhibitions[41], directly address these objectives. In addition to the onsite installation, which attracts busloads of children and seniors, each exhibition has an extensive, permanent Web with K-12 curriculum materials developed in consultation with educators. NLM should also develop strategies for promoting wider use of K-12 curriculum materials in schools across the country.

An excellent collaboration with the American Library Association (ALA) has resulted in the production of highly successful traveling versions of some of the exhibitions, which have appeared in dozens of public, college, and health sciences libraries in communities across the country. All of NLM's exhibitions should travel.

Board of Regents members Dr. Thomas Detre and Dr. Tenley Albright visit the NLM exhibition Visible Proofs: Forensic Views of the Body.

NLM should continue its excellent collaboration with ALA and work with other organizations to travel appropriate exhibitions to non-library sites. NLM should also explore collaborations with science museums, including joint development of exhibitions and related programs. Museums could serve as additional important dissemination points for resources maintained and developed by the NLM and assist the Library in developing interactive resources that assist formal and informal learning across a broad range of topics relevant to biomedicine.

Primarily via the Regional Medical Libraries and other members of the National Network of Libraries of Medicine, NLM's products and services are exhibited and, in some cases featured in CE classes and program sessions, at more than 250

[39] Patel VL, Branch T, Cimino A, Norton C, Cimino JJ. Participant perceptions of the influences of the NLM-sponsored Woods Hole medical informatics course. J Am Med Inform Assoc [Internet]. 2005 May-Jun [cited 2006 Oct 26];12(3):256-62. Epub 2005 Jan. doi: 10.1197/jamia.M1662 Available from: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1090455&blobtype=pdf

[40] Marine Biological Institute; National Library of Medicine (US). BioMedical Informatics: a course for health professionals. Woods Hole (MA): MBLWHOI Library; c2006 [cited 2006 Oct 26]. Available from: http://courses.mbl.edu/mi/.

[41] Online exhibitions and digital projects [Internet]. Bethesda (MD): National Library of Medicine (US); 2004 May [updated 2006 Mar 20; cited 2006 Oct 27]. Available from: http://www.nlm.nih.gov/onlineexhibitions.html

national, regional, and local association meetings for health professionals, librarians, health educators, and consumer groups every year. NLM should continue this program, adjusting the number and the roster of meetings attended based on feedback from the exhibit staff and attendees.

NLM uses a wide range of techniques to reach the American public with the message that NLM has free, reliable Web-based information about health matters. The Library attempts to use a variety of media outlets, for example, public service announcements (PSAs) on television and radio and in magazines, public formal press releases to newspapers and journals, personal contacts with reporters and writers, announcements on the NLM Web site, and, most recently, weekly NLM Director's podcasts that highlight information sources relevant to a currently newsworthy health topic.

NLM has also developed programs to encourage doctors to refer their patients to NLM information services. In the "Information Prescription" program for physicians, patients and libraries, patients are given an Rx scrip and referred by their doctors to MedlinePlus content that is directly relevant to newly diagnosed or chronic health conditions.[42] The American College of Physicians Foundation, the Fisher Center for Alzheimer's Research, the Medical Library Association, the National Network of Libraries of Medicine, and the hospital library community have helped to promote physician participation. Similarly NLM and other NIH Institutes, in collaboration with the Friends of the NLM, have recently launched the NIH MedlinePlus magazine[43] for distribution in doctors' waiting rooms.

NLM must broaden and intensify current efforts to reach consumers and health professionals, so they know how to access this information, continue to experiment with new media and new approaches, and assess the cost-benefit of different methods.

Recommendation 2.4. *Test and evaluate digital infrastructure improvements (e.g., PDAs, intelligent agents, network techniques) to enable ubiquitous health information access in homes, schools, public libraries, and work places.*

Continuing proliferation of portable and wearable digital devices, sensors, and wireless telecommunications options will offer new opportunities for ubiquitous access to both personal health data and authoritative information about health conditions and therapies. Many organizations will hold electronic personal health data (governments, health insurance companies, disease or condition specific organizations) in addition to patients and individual and networked health care providers. Developing the effective rules of the road for this degree of complexity is a formidable task. NLM should be a significant participant in ongoing technical research and policy making, which will necessarily involve many agencies and groups. Much work remains to be done to define the privacy and technical standards and guidelines for transmitting private health information over the Internet and other electronic pathways.

Use of a wireless PDA in a disaster drill as part of the Wireless Internet Information System for Response in Medical Disasters (WIISARD) project, funded by NLM. (Photo credit: Barbara Haynor, UCSD)

[42] Siegel ER, Logan RA, Harnsberger RL, Cravedi K, Krause JA, Lyon B, Hajarian K, Uhl J, Ruffin A, Lindberg DAB. Information Rx: evaluation of a new informatics tool for physicians, patients and libraries. Inf Serv Use. 2006;26(1):1-10.

[43] NIH MedlinePlus Magazine [Internet]. Bethesda (MD): National Library of Medicine (US). Vol. 1, No. 1, 2006 – [cited 2006 Oct 26]. Available from: http://www.nlm.nih.gov/medlineplus/magazine.html

Remote Inupiat Eskimo village in the Arctic — Buckland, Alaska.

NLM should actively explore innovative technology, implementation, and policy alternatives for providing ubiquitous, appropriate access to health information. For example, an illustrative alternative approach to universal broadband would be a staged approach to access, where the availability of information could be explored through access media such as cell phones or PDAs in locations with problematic terrestrial communications, and followed up through health information access nodes at libraries, clinics or community-based organizations. Resolving the issues of direct consumer access to health information should be complemented with changes in the way health information is delivered. For example, it may be more effective to work toward the development of intelligent agents that can recommend actions, guided by the values, preferences and expectations of the patient and clinicians.

Recommendation 2.5. *Support research on the application of cognitive and cultural models to facilitate information transfer and trust building and develop new methodologies to evaluate the impact of health information on patient care and health outcomes.*

NLM has compiled an extensive record of deploying robust, multidimensional evaluation research that has been instrumental in creating and continually improving its database and Web site offerings for researchers, educators and the general public. These methodologies include usability testing, qualitative user feedback and customer satisfaction surveys, automated quantitative data collections and Web log analyses, and Internet performance and connectivity monitoring.[44] More research is needed, particularly in the area of documenting impacts on health behavior and health outcomes that are attributable to information use.

The trust patients and other health consumers place in health information, sources, and providers may be a key factor affecting consumer use of such information, and ultimately the impact of such information on their health decisions, behaviors, and outcomes. Research on health information transfer and trust building needs to draw new insights from interdisciplinary approaches. The proposed applied research emphases would benefit greatly and should draw from and utilize cognitive science principles and cultural translation strategies. The research should identify and assess the varied elements that go into effective health communication, including types of messages and channels, use of natural and understandable language, role of information intermediaries, supporting and enabling community or peer groups and organizations, diversity and characteristics of persons receiving the information. The research also should consider the elements affecting overall consumer trust, such as sources, sponsors, reviewers and review process, selectors and selection process, public access channels, interpreters and screeners.

[44] Wood, F.B., Siegel, E.R., Lacroix, E., Lyon, B.J., Benson, D.A., Cid, V., and Fariss, S.: A Practical Approach to E-Government Web Evaluation. IEEE IT Professional Magazine, May/June 2003, 22-28.

GOAL THREE

Plan for 2006-2016

Goal 3. Integrated Biomedical, Clinical, and Public Health Information Systems that Promote Scientific Discovery and Speed the Translation of Research into Practice

"The physician of the future will meet with a patient and his family members, access the patient's data in real time, including importing data from the patient's personal health record, integrate it with a host of NLM resources, access available tutorials and other educational and explanatory materials, identify relevant clinical trials, and finally export all of this just-in-time, patient-relevant information back into the personal health record – all within the space of an office visit." [45]

NLM has been working to enable the potential research, health care, and public health payoffs of integrated access to electronic scientific data, patient records, and medical knowledge at least since the 1980s, when it launched both the Integrated Advanced Information Management Systems (IAIMS) initiative[46] and the Unified Medical Language System (UMLS) project.[47] NLM's Specialized Information Services Division has worked on connecting various types of data and knowledge needed by toxicologists and the environmental health community for decades, most recently in the TOXNET system. The Lister Hill Center has conducted research and development focused on integration of image databases (the Visible Humans are the most spectacular example) with other types of information and on gateway access to disparate NLM resources.

When the rise of the World Wide Web solved many of the significant technical incompatibility and telecommunications problems of the 1980s, NLM supported new demonstration projects under its High Performance Computing and Communications initiative[48] and actively participated in federal efforts to promote health data standardization and address public policy issues (e.g., privacy, security, telecommunications, intellectual property, public access to government information) that affect the ability to integrate data and knowledge.[49]

Today the National Center for Biotechnology Information's Entrez system already enables a type of traversal from underlying biological data (at multiple levels of granularity and aggregation) to published scientific papers to synthesized

[45] National Library of Medicine (US), Board of Regents. Panel 1 report: NLM resources and infrastructure for the 21st century [Internet]. [Bethesda (MD)]: The Library; 2006 May [cited 2006 Oct 23]. Available from: http://www.nlm.nih.gov/pubs/plan/lrp06/panel1report.doc

[46] Matheson NW, Cooper JA. Academic information in the academic health sciences center: roles for the library in information management. J Med Educ.1982 Oct;57(10 Pt 2):1-93.

[47] Lindberg DA, Humphreys BL, McCray AT. The Unified Medical Language System. Methods Inf Med. 1993 Aug;32(4):281-91.

[48] Lindberg DA, Humphreys BL. The High-Performance Computing and Communications program, the National Information Infrastructure, and health care. J Am Med Inform Assoc [Internet]. 1995 May-Jun [cited 2006 Oct 24];2(3):156-9. Available from: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=116249&blobtype=pdf

[49] Humphreys BL. Electronic health record meets digital library: a new environment for achieving an old goal. J Am Med Inform Assoc [Internet]. 2000 Sep-Oct [cited 2006 Oct 24];7(5):444-52. Available from: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=79039&blobtype=pdf

information in monographs for specialists to summarized information written for the lay public.[50] A wealth of potentially useful information remains locked away in patient records. NLM should strengthen its efforts to hasten the day when electronic health records are linked to digital libraries in systems that promote scientific discovery and bring research results directly to bear on health care and public health.

"Bingo! We knew we had nailed it." This was the enthusiastic comment by a Minnesota lab director who used an NLM DNA sequence database to identify the first case of polio in the U.S. in the 21st century. The exponential growth of molecular data generated by scientists around the world will continue and present opportunities we are just beginning to imagine, for example, studying human genetic variation and its relation to disease and learning how to create personalized drugs for optimum effectiveness.

Recommendation 3.1. *Develop linked databases for discovering relationships between clinical data, genetic information, and environmental factors.*

Molecular biology and understanding derived from genomics are clearly primary drivers of medical progress in the 21st century. The quantity of genomic data has grown exponentially with the mapping of the human genome and projects that have built upon it. NLM's National Center for Biotechnology Information (NCBI) is the information hub in this biomedical revolution, developing databases and sophisticated software tools that enable researchers to make the connections that are vital to the discovery process.

Knowledge emerging from genomics has brought hope to families stricken by hereditary diseases. The Human Genome Project is transitioning from its initial emphasis on basic research on DNA sequences to activities with increasing clinical relevance. NCBI has always worked in close collaboration with the National Human Genome Research Institute. As genomics evolves from the domain of biological research into the realm of diagnosis, treatment, and prevention of disease, NCBI has increased its active partnership with other NIH components, e.g., the flu genome project with the National Institute of Allergy and Infectious Diseases, the trans-NIH PubChem development, and whole genome association studies with the National Heart Lung and Blood Institute.

NCBI should lead the development of repositories of information on human variation that will be essential tools for discovering the associations between genes and disease. These databases will need to capture in a systematic fashion a wide array of clinical and laboratory information and couple these data with genotypes and environmental factors, including pathogens and chemicals.

NCBI should continue to be the computational and database focal point in a trans-NIH program to connect clinical and genotypic data from large, long-term studies. Scores of case-control studies, such as the Framingham Heart Study, are rich sources of detailed, longitudinal phenotypic data.

Genotyping for large-scale genetic mapping studies. (Photo credit: National Institutes of Health)

[50] Wheeler DL, Barrett T, Benson DA, Bryant SH, Canese K, Chetvernin V, Church DM, DiCuccio M, Edgar R, Federhen S, Geer LY, Helmberg W, Kapustin Y, Kenton DL, Khovayko O, Lipman DJ, Madden TL, Maglott DR, Ostell J, Pruitt KD, Schuler GD, Schriml LM, Sequeira E, Sherry ST, Sirotkin K, Souvorov A, Starchenko G, Suzek TO, Tatusov R, Tatusova TA, Wagner L, Yaschenko E. Database resources of the National Center for Biotechnology Information. Nucleic Acids Res [Internet]. 2006 Jan 1 [cited 2006 Oct 24];34(Database Issue):D39-45. doi:10.1093/nar/gki062. Available from: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=540016&blobtype=pdf

For the many studies without genotype data, initiatives are underway to genotype participants and to add that information to databases housed at NLM. These resources will offer investigators an unprecedented opportunity to study the complex interactions of genes, the environment, and health in large populations. The findings will lay the foundation for the development of therapies and prevention strategies that can be targeted to a patient's genetic makeup, ushering in an era of personalized medicine.

NLM's publicly accessible tools for the analysis and integration of data across disciplines, and its funding of informatics research and training programs, place it at the center of the search for genomic discoveries that promise improved health for all. However, implementing this knowledge within the framework of the current healthcare system will require significant effort to address privacy concerns, to deliver the necessary data efficiently, to create and maintain decision support tools, and to inform the public. Families affected by hereditary diseases may wish to facilitate access to their clinical and genomic data to speed research discoveries. There should be easy mechanisms for them to do so.

NLM has an opportunity to assume a leadership role in this effort and thus contribute to the transformation of clinical, genomic, and environmental information into better evidence-based medicine and improved patient care.

To keep pace with the rapid increase in the volume of information generated in molecular biology and to respond to the new genetic, phenotypic, and environmental exposure data generated by NIH institutes, NCBI resources will need to continue to grow at a rate linked to the explosion of data, that will necessarily be greater than the rate of growth of the NIH overall. This is a direct consequence of the appearance of high throughput, high volume research technologies that produce tsunamis of data that require human intervention to covert data into information, and information into knowledge. A formula must be found for predictable and sustained resources consonant with the research support requirements of NIH initiatives.

Recommendation 3.2. *Promote development of Next Generation electronic health records to facilitate patient-centric care, clinical research, and public health.*

Current electronic health records typically resemble traditional paper-based patient charts. To a variable extent, today's electronic health records provide some or all of the record-keeping functionality of paper-based systems (e.g., recording history and physical examination notes, progress notes, consultation notes, "written" orders, laboratory and imaging study results, and so on). In addition, current electronic health records may provide digital image storage and retrieval, limited decision support tools, some cross-record analysis capabilities useful in quality assessment and research, and some patient access to health data via the Web.

Large parts of current electronic health records are still stored as free text. Even names of drugs, laboratory tests, diagnoses or therapies are often not unambiguously stored in standardized or coded form. Standardizing and structuring patient data in electronic health records are essential to enable a host of different uses, including: detection of data errors, unambiguous transfer of information between care providers and the public health system, automated connections to supporting knowledge in digital libraries, generation of alerts and reminders, automated decision support for complex cases, construction of longitudinal records for monitoring patients with chronic conditions, Web-enabled data entry by patients, and generation of databases for clinical and health services research and the assessment of health care.

Through its Unified Medical Language System (UMLS) initiative, NLM has been a leading proponent in US government efforts to promote, develop, support, and disseminate key standard clinical vocabularies, align them with electronic message standards, and map them to billing codes.

For more than a decade, NLM has commissioned or contributed to studies by such organizations as National Academy of Sciences,[51,52] the National Committee on Vital and Health Statistics, and the Presidential Commission on Systemic Interoperability[53] that have shaped the strategy for advancing the development and adoption of electronic health records in the US. Through research and development work in the Lister Hill Center and NCBI, NLM has also gained direct experience with developing databases of clinically significant data, including high resolution images and clinical research data.[54]

NLM must continue and enhance these efforts in response to specific US government priorities and feedback from those attempting to implement standards in current electronic health records and personal health records, regional health information exchanges, clinical research systems, and public health applications.

In addition to facilitating incremental improvements in retrospective data, NLM should build on its long record of conducting and supporting research, development, and policy studies related to electronic health records by promoting work to define and develop the next generation of electronic health records (EHR). Areas ripe for further investigation include: sophisticated handling of images and sounds; identification of the key patient data that actually affect care and outcomes and the best way to store and use it; application of relevant developments in computer science and telecommunications to EHR problems; advanced methods for clinical and public health data acquisition from clinicians, patients, instruments, and manufacturers, with the goal of structuring data at the source; representation of genetic information in patient records; effective strategies for linking to a variety of ancillary knowledge and decision support tools; automated transmission of notifiable disease reports to the public health system; and generation of useful research datasets that protect patient privacy.

Recommendation 3.3. *Promote development and use of advanced electronic representations of biomedical knowledge in conjunction with electronic health records.*

For more than four decades, NLM has conducted and supported groundbreaking research and development related to the representation, interpretation, and use of biomedical knowledge in electronic forms. NLM grants funded much of the important research on artificial intelligence in medicine, clinical reminder and alert systems, decision rules, medical logic modules, and biomedical ontologies. NLM's intramural research and service divisions have made leading contributions to defining useful structures for controlled vocabularies (e.g., MeSH, UMLS Metathesaurus, RxNorm) , medical publications, clinical trials descriptions,[55] electronic knowledge bases (e.g., Hepatitis Knowledge Base, Hazardous Substances DataBank, Genetic Home Reference), high resolution anatomic imaging data (the Visible Humans), semantic networks, and effective semantic links between disparate information sources (e.g., TOXNET, Entrez). The Lister Hill Center has been a major contributor to understanding of natural language and medical images.

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[51] National Research Council (US), Committee on Maintaining Privacy and Security in Health Care Applications of the National Information Infrastructure. For the record: protecting electronic health information [Internet]. Washington: National Academies Press; 1997 [cited 2006 Oct 24]. Available from: http://www.nap.edu/catalog/5595.html

[52] National Research Council (US), Committee on Enhancing the Internet for Health Applications: Technical Requirements and Implementation Strategies. Networking health: prescriptions for the Internet [Internet]. Washington: National Academies Press; 2000 [cited 2006 Oct 24]. Available from: http://www.nap.edu/books/0309068436/html

[53] Commission on Systemic Interoperability (US). Ending the document game: connecting and transferring your healthcare through information technology [Internet]. Washington: US Government Printing Office; 2005 [cited 2006 Oct 24]. Available from: US GPO, Washington, DC; ISBN 0-16-072711-1. Available from: http://endingthedocumentgame.gov/. System Requirements: Adobe Acrobat.

[54] Ostchega Y, Long LR, Goh GH, Hirsch R, Ma LD, Scott WW Jr, Johnson W, Thoma GR. Establishing the level of digitization for wrist and hand radiographs for the third National Health and Nutrition Examination Survey. J Digit Imaging. 1998 Aug;11(3):116-20.

[55] McCray AT, Ide NC. Design and implementation of a national clinical trials registry. J Am Med Inform Assoc [Internet]. 2000 May-Jun [cited 2006 Oct 24];7(3):313-23. Available from: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=61435&blobtype=pdf

In some respects, these remarkable developments have been unavailable or under-used in routine medical practice. Now recent changes in computer technology, public awareness of the need to eliminate gross clinical errors, and emerging public policies seem to mark a new time and a new opportunity for NLM and colleagues to bring together many of the past technological breakthroughs for the benefit of U.S. health care and public health.

The broad deployment and use of advanced electronic health records will provide expanded opportunities for access to biomedical knowledge and advanced decision support for the public, their care providers, and the public health workforce. To turn this potential into effective reality, NLM should continue to promote research and development on robust and scaleable approaches to synthesizing, representing, updating, and deploying electronic knowledge and decision algorithms for use in conjunction with electronic health records. Topics worthy of additional concentrated attention include: drug information structured to interact with personal health records, clinical trials results reporting, automated summarization of published evidence, representations of knowledge and rules that facilitate sharing and reuse, management and updating of digital libraries of clinical and public health support tools, and methods and timing for presenting knowledge and decision support that have the greatest probability of being used.

Research should continue to exploit the information content of biomedical images and to develop algorithms for indexing and retrieving biomedical images by picture content and semantic meaning. Most important will be the incorporation of handy new imaging systems within clinical patient care. Whenever possible, intramural research should partner with allied research groups in other NIH Institutes.

GOAL FOUR

Plan for 2006-2016

Goal 4. A Strong and Diverse Workforce for Biomedical Informatics Research, Systems Development, and Innovative Service Delivery

"In health care as much as or more than in other human endeavors, knowledge is power, and the redistribution of access to knowledge will mean an inevitable redistribution of power over the decisions that affect the delivery of health care and the makeup of the health care workforce." [56]

NLM has funded and shaped biomedical informatics education and training for 30 years. It currently supports eighteen university-based multidisciplinary informatics training centers with a total of 270 fellows in basic science, clinical medicine, public health, and information sciences. [57] Priority in selecting fellows is given to physicians and other health care professionals.

NLM's intramural research divisions also provide advanced post-graduate informatics training. The Library's extensive programs to teach biology faculty, students, and library-based bioinformatics specialists to use molecular biology and genomic databases and tools reach more than 7,000 people each year. [58] NLM supports the Woods Hole "short course" in Biomedical Informatics. [59, 60]

NLM's history of providing educational opportunities for librarians is even longer. In addition to the opportunities for librarians in its informatics training programs, NLM currently supports post-masters training of health sciences librarians through the NLM Associate Fellowship program, [61] and short courses in the use of NLM's electronic services offered through the National Network of Libraries of Medicine and via the Internet. The Library provides individual fellowships for those interested in developing the combined subject matter and information science expertise required to serve as an advanced information specialist in a particular context, e.g., as a member of a clinical team, within a biological sciences department, or within a public health context. NLM partners with the Medical Library Association, the Association of Academic Health Sciences Libraries, the American Library Association, and the Association of Research Libraries to support educational symposia on specific topics, mid-career leadership training opportunities for librarians, and scholarships for library school students, with an emphasis on minority recruitment.

Over the next ten years a greatly expanded and more diverse workforce of clinicians, informaticians and librarians will be needed to develop and deploy systems to support basic, clinical, and translational research in the genomic era, to

[56] Masys DR. Effects of current and future information technologies on the health care workforce. Health Aff (Millwood). 2002;21(5):33-41.

[57] Grants and funding: extramural programs [Internet]. Bethesda (MD): National Library of Medicine (US), Extramural Programs Division; 2003 Nov [updated 2006 Aug 31; cited 2006 Oct 27]. Available from: http://www.nlm.nih.gov/ep/Grants.html

[58] Education [Internet]. Bethesda (MD): National Library of Medicine (US), National Center for Biotechnology Information; [rev. 2006 Oct 3; cited 2006 Oct 27]. Available from: http://www.ncbi.nlm.nih.gov/Education/index.html

[59] Special topics courses: BioMedical Informatics [Internet]. Woods Hole (MA): Marine Biological Laboratory; c2005 [cited 2006 Oct 27]. Available from: http://www.mbl.edu/education/courses/special_topics/med.html

[60] Bridges J, Miller CJ, Kipnis DG, Dee CR, Markwell LG, Bandy M. Librarians in the Woods Hole Biomedical Informatics course. Med Ref Serv Q. 2006 Spring;25(1):71-81. doi: 10.1300/J115v25n01_07.

[61] Brewer J. Post-Master's residency programs: enhancing the development of new professionals and minority recruitment in academic and research libraries. Coll Res Libr. 1997 Nov;58(5):528-37.

deliver just-in-time health and emergency response information, to link electronic health records, decision-support tools, and relevant knowledge, and to ensure permanent access to digital information.[62]

NLM should help to meet this need by continuing to adapt its existing educational programs and by increasing its focus on K-12 education. Expanding the cadre of biomedical librarians and informaticians will depend on expanded science literacy in the population as a whole, a process that begins with a child's first science and mathematics lessons, and on generating enthusiasm for careers in the biomedical information sciences at a much earlier age.

Recommendation 4.1. *Develop an expanded and diverse workforce through enhanced visibility of biomedical informatics and library science for K-12 and college students.*

The 21st century health infrastructure's requirements for a diverse population of biomedical informaticians and biomedical librarians can be met only through an aggressive recruitment and retention program that targets K-12 and college students.

NLM and its outreach partners have a natural opportunity to promote interest in careers in biomedicine in general and in librarianship and informatics in particular, while increasing awareness and use of health information services among K-12 students. There is anecdotal evidence that community-based outreach efforts are already helping to recruit minority candidates into librarianship. Encouraging young people to pursue careers in the sciences is already a stated goal of NLM's exhibitions and its associated K-12 educational materials and programs. NLM should develop more systematic approaches to integrating recruitment with outreach and assess their impact.

Currently most recruits to NLM-funded postgraduate training programs discover an interest in biomedical informatics or health sciences librarianship serendipitously. Serendipity must give way to the development of programs to inform young people about the exciting career opportunities that exist in health and biomedical informatics and librarianship in the early years of college and high school, including the high quality, rigorous training programs to which they can apply. The nature of these careers and the existence of the training programs may be largely unknown to college career development offices.

Stimulating the recruitment of large numbers of underrepresented minorities into biomedical informatics remains an unanswered challenge. New initiatives are urgently needed, such as the formation of a national network for biomedical informatics recruitment, with participation sought from the NLM-funded graduate training programs. This existing training platform offers an exceptional opportunity to create an alliance of graduate training programs that could engage in special outreach activities to stimulate interest in and access to biomedical informatics careers among minority undergraduates. Existing national meetings that attract minority undergraduates in the life sciences are a fertile ground for experimenting with these efforts (e.g., Annual Biomedical Research Conference for Minority Students and the Society for Advancement of Chicanos and Native Americans in Science.)

NLM Associate Fellows, 2005-2006.

[62] Cohen JJ, Steinecke A. Building a diverse physician workforce. JAMA. 2006 Sep 6;296(9):1135-7. doi: 10.1001/jama.296.9.1135.

Training class at the University of Texas, El Paso, part of the NLM Environmental Health Information Outreach Program (EnHIOP).

Recommendation 4.2. *Support training programs that prepare librarians to meet emerging needs for specialized information services.*

As the amount and types of digital data relevant to biomedicine and health continue to grow and the sources and locations of relevant information continue to proliferate, finding, analyzing, and making efficient use of the best information for the task at hand becomes increasingly difficult. Many basic, clinical, and health services researchers are struggling to manage and keep track of their own electronic datasets, which are often inaccessible even to colleagues in the same institution. At the same time, nationally available research databases and computational tools are evolving and expanding so rapidly that research faculty and students are unable to keep up with resources that are directly relevant to their work. In health care settings, busy clinicians usually need quick access to current synthesized information that is directly relevant to specific patients - whose particular attributes (e.g., age, medications, other diseases, access to social services) may not match those in available guidelines or evidence sources. Public health workers often need to interpret health and medical information in the context of housing, economic, environmental, and other data that relate to multiple determinants of health. Their most appropriate source of information may be undocumented "lessons learned" in public health interventions in similar jurisdictions. Patients and other members of the public often need personal interaction and assistance in identifying and interpreting electronic information relevant to their questions.

In all of these cases, there are opportunities for librarians to provide valuable and cost-effective services tailored to the needs of specific groups. Existing examples of such services include library-based bioinformatics specialists who teach and participate on research teams within biological sciences departments,[63] clinical informatics specialists or 'informationists' who synthesize information for other members of health care teams,[64] patient education specialists, and hospital librarians who serve on emergency response teams. NLM should continue to support training opportunities that prepare librarians to provide specialized services to meet emerging needs. The Library should also continue to support studies that explore new roles for librarians and evaluate the impact of the specialized services they develop and provide.

Recommendation 4.3. *Continue support for formal, multidisciplinary education in biomedical informatics to increase the supply of informatics researchers who can work at the intersections of molecular science, clinical research, health care, public health, and disaster management.*

The exponential growth in data generated by patient-specific genetic sequencing, large scale clinical research studies, electronic health records, and sensing devices provides new opportunities to speed scientific discovery, improve the efficiency of clinical research, enhance patient safety, and promote rapid translation of research results into improved health care and public health practice. Systems that integrate genomic data with

[63] Geer RC. Broad issues to consider for library involvement in bioinformatics. J Med Libr Assoc [Internet]. 2006 Jul [cited 206 Oct 26];94(3):286-98, E152-5. Available from: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1525323&blobtype=pdf

[64] Giuse NB, Koonce TY, Jerome RN, Cahall M, Sathe NA, Williams A. Related Articles. Evolution of a mature clinical informationist model. J Am Med Inform Assoc [Internet]. 2005 May-Jun [cited 2006 Oct 26];12(3):249-55. Epub 2005 Jan 31. doi: 10.1197/jamia.M1726. Available from: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1090454&blobtype=pdf

electronic health records to provide patient-specific decision support and to identify populations likely to benefit from specific public health measures are now conceivable.

Turning these opportunities into usable information systems will require an expanding cadre of informatics researchers capable of crossing traditional boundaries between basic research, clinical research, health service research, health care, public health, and disaster management to conceptualize, build, and test informatics innovations that support a more integrated approach to all of these endeavors. Over the past 20 years, NLM has emphasized the importance of multidisciplinary informatics training, encompassing medicine, computer science, library and information science, linguistics, and engineering. The Library has promoted the expansion of biomedical informatics training and research programs to encompass expertise and problems in the biological sciences, health services research, public health, consumer health, and disaster management.

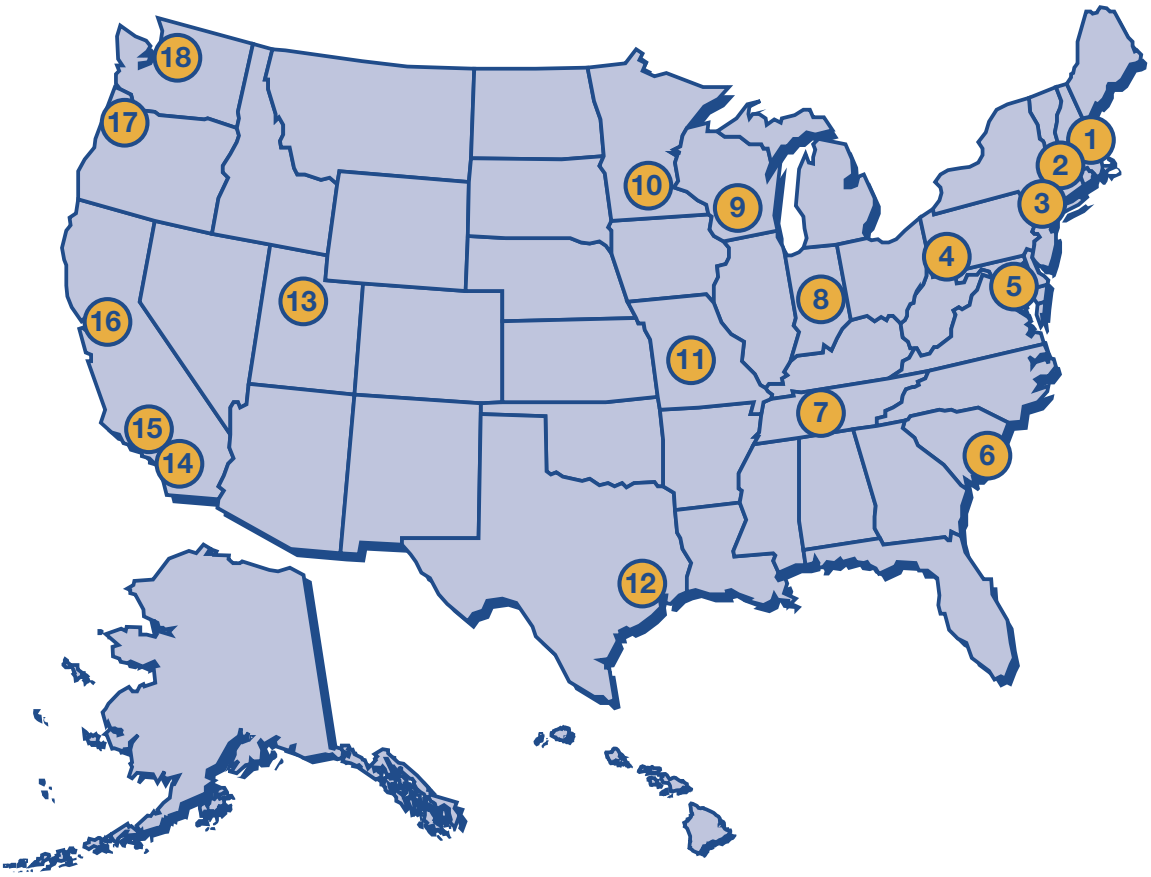
In addition to continuing to strongly encourage informatics education and research in all of these areas, the Library should promote greater attention by its funded training programs to informatics that supports more efficient clinical research and more rapid translation from basic science to clinical research studies and from clinical research to practice.

Other organizations have supported additional slots within NLM-funded informatics training programs. Several NIH institutes and the Department of Veterans Affairs have added capacity in this way from time to time.

The Robert Wood Johnson Foundation currently supports public health informatics tracks in four of the training programs. Given the huge need for advanced informatics researchers across the spectrum from basic science to health information for the public, NLM should continue to look for additional opportunities to partner with other organizations interested in building the informatics research workforce.

2006 Girls Basketball Champions of Buckland, Alaska, plus NLM visitors.

Figure 2. University Medical Informatics Research Training Programs Supported by NLM



1. Program in Biomedical Informatics, Harvard-MIT Division of Health Sciences & Technology
2. Biomedical Informatics Research Training at Yale, Yale University
3. Medical Informatics Research Training Program at Columbia, Columbia University Health Sciences
4. Pittsburgh Biomedical Informatics Training Program, University of Pittsburgh at Pittsburgh
5. Johns Hopkins Health Sciences Informatics Training Program, Johns Hopkins University
6. Training of Toolmakers for Bio-Medical Informatics, Medical University of South Caro-lina
7. Vanderbilt Biomedical Informatics Training Program, Vanderbilt University
8. Regenstrief Informatics Research Fellowships, Indiana University - Purdue University at Indianapolis
9. Computation and Informatics in Biology and Medicine, University of Wisconsin Madison
10. Health Informatics Division, University of Minnesota Twin Cities
11. Biomedical and Health Informatics Research Training, University of Missouri Columbia
12. Training Program in Computational Biology and Medicine, Rice University
13. University of Utah Medical Informatics Training. University of Utah
14. Biomedical Informatics Training Program, University of California Irvine
15. Training Program for Imaging-Based Medical Informatics, University of California Los Angeles
16. Graduate Training in Biomedical Informatics, Stanford University
17. Training Program in Health Informatics, Oregon Health & Science University
18. Biomedical and Health Informatics Training Program, University of Washington

Closing

A closing word about priorities:

In my opinion, the highest priority is construction of the third NLM building. Even without this new structure, the fastest growing component of NLM's budgets is payment for the space to house its people and enhanced infrastructure to support growth of computer systems. In addition to the square-footage, the three year delay in starting the new building since completion of the construction plans has masked substantial "delayed maintenance" on the two existing buildings needed to comply with current fire and safety regulations.

Second top priority is maintenance and expansion of the NCBI work with NIH institutes on the emerging genome/phenome studies using "whole genome analysis". NCBI databases and systems will once again provide essential infrastructure for NIH and the biomedical research community worldwide. An increasing percentage of NIH resources is devoted to generating electronic data that increases the workload at NCBI. If this work is to continue successfully, a proportionate increase in resources is needed by NLM and should be included with the base of NLM's budget allocation.

Third top priority goes to maintaining and enhancing NLM's prominent information services to the U.S. and abroad. Even without imagining brand new information services, the expected increase in the size and use of the numerous current services will undoubtedly need and deserve increased support.

Fourth. As reflected in special Presidential and Departmental initiatives, the country badly needs and wants better electronic health records. NLM has contributed to this work by funding research, by development of the Unified Medical Language System, by development of Information Technology standards, and by purchasing national usage rights to appropriate proprietary standards. We expect the need for electronic record systems to become more acute in the future. NLM should continue to contribute significantly to the solution.

Fifth. Disaster information management also looms large as a national problem. So far NLM - indeed medical libraries and librarians in general - have not been enlisted in efforts to do better. This is a serious mistake. I believe that NLM could assist in seeing that medical librarians nationally contribute to solution of this problem. We project the need for substantial increases in this area.

Sixth. NLM contributes significantly to education and training programs for biomedical informatics professionals. We project the need for some increases, partly to allow for gradually increasing recipient costs, but also to fund a stepped up effort to achieve better workforce diversity, especially by recruitment of more minority students into the pools from which informatics professionals are drawn - e.g., medicine, nursing, pharmacy, biological sciences, engineering, computer science, library and information science.

Seventh. NLM's outreach programs have been successful, and gradual increases in funding are projected. The work is carefully integrated with improvements to community and individual access to electronic information, efforts to reduce health disparities, and also to recruitment efforts.

I believe the Plan will provide genuine help and guidance to NLM over the next decade. Even great public institutions are surprisingly vulnerable - even fragile. I thank our Board and Advisers for their efforts on behalf of this great institution, the country, and for NLM's future contributions to the country.

My special thanks for good insightful work and midnight oil burning to Dr. Elliot Siegel and Ms. Susan Buyer.

Donald A.B. Lindberg, M.D.
Director

Appendices

1. Planning Process

At the September 2004 meeting, the Board of Regents decided to develop a Long Range Plan for 2006-2016. A Subcommittee on Planning was appointed, and is co-chaired by the Honorable Newt Gingrich and Dr. William Stead; members include Dr. Holly Buchanan, Dr. Wallace Conerly, Dr. Thomas Detre and Dr. Kenneth Walker.

In April 2005, a Strategic Visions Working Group comprised of outstanding leaders from all sectors of NLM's diverse constituencies[65] met to provide the broadest view of NLM's mission, current situation, and its potential future contributions to the health and well-being of America in the 21st Century. A vision statement identified new scientific, medical, technical, social and economic developments that may impact national and global needs for research, clinical and patient data and information. It formed the basis for the creation of four long range planning panels that met twice each during the months of November-December 2005, and February-March 2006, named and chaired as follows:

- Resources and Infrastructure: Dr. Edward Shortliffe and Ms. Gail Yokote
- Health Information for Underserved and Diverse Populations: Dr. Louis Sullivan and Ms. Eugenie Prime
- Support for Clinical and Public Health Systems: Dr. Reed Gardner
- Support for Genomic Science: Dr. Daphne Preuss

Nearly 100 panelists worked to identify the forward-looking strategies and infrastructure that will enable NLM to maintain its role as a premier national library and positive force for change in the US and abroad in the 21st Century. The panelists considered, among many relevant issues and trends, exciting changes in genomic and computer science, scientific publication models, and transformational changes in health care delivery, electronic health records, and quality and safety made possible by new information technology. The promise of new research correlating genotype, phenotype and environmental data figured prominently in their deliberations, as did the challenges posed by a critical lack of space needed to house NLM's programs and collections; the existence of health disparities among the underserved; a lack of trust in societal institutions, including government; and the mitigation of threats to the public health from disasters and epidemics.

For over six months the NLM planning panels members worked diligently to develop the key recommendations for the next 10 years.

[65] See appendix 4

2. Planning Panel Participants

Panel 1: NLM Resources and Infrastructure for the 21st Century

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Cosmos Club, Washington, D.C., April 11-12, 2005

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5. Four Planning Panel Reports

Available at http://www.nlm.nih.gov/pubs/plan/lrp06/reports.html

Report of NLM Planning Panel 1 to the Board of Regents: NLM Resources and Infrastructure for the 21st Century, May 2006

Report of NLM Planning Panel 2 to the Board of Regents: NLM Health Information for Underserved and Diverse Populations in the 21st Century, May 2006

Report of NLM Planning Panel 3 to the Board of Regents: NLM Support for Clinical and Public Health Systems of the 21st Century, May 2006

Report of NLM Planning Panel 4 to the Board of Regents: NLM Support for Genomic Science in the 21st Century, May 2006

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

NIH Publication No.: 07-4890