

National Institutes of Health

Advisory Committee to the Director

National Library of Medicine (NLM) Working Group

FINAL REPORT – JUNE 11, 2015

MEMBERS: Eric Green (co-chair), Harlan Krumholz (co-chair), Russ Altman, Howard Bauchner, Deborah Brooks, Doug Fridsma, Steven Goodman, Eric Horvitz, Trudy MacKay, Alexa McCray, Chris Shaffer, David Van Essen, Joanne Waldstreicher, James Williams, II, Kathy Hudson (ex officio), Lyric Jorgenson (executive secretary) (*titles and affiliations listed in Appendix A*)

EXECUTIVE SUMMARY

The NIH Director charged the National Library of Medicine (NLM) Working Group, hereafter referred to as the Working Group, with articulating a strategic vision for NLM to ensure that NLM remains an international leader in biomedical and health information. Over the course of five months of deliberations, the Working Group reviewed numerous documents and reports pertaining to NLM's mission and activities, consulted with NLM leadership and staff, and solicited public comments and suggestions. The Working Group recognizes that NLM has an important opportunity to play a key leadership role in one of the most exciting periods of biomedical history: data science is increasing rapidly, computational power is expanding at a breathtaking pace, the breadth and depth of digital health data are undergoing unprecedented and accelerating growth, a movement towards more interdisciplinary work and team science continues to gain momentum, a broad commitment to open science is becoming increasingly adopted, and the demand for services to support an ever more engaged and informed public is expanding. To leverage these historic changes, the Working Group, with respect for the outstanding history of NLM and its potential for the future, formulated a series of recommendations to guide the future of NLM:

RECOMMENDATION #1. NLM must continually evolve to remain a leader in assimilating and disseminating accessible and authoritative biomedical research findings and trusted health information to the public, healthcare professionals, and researchers worldwide.

RECOMMENDATION #2. NLM should lead efforts to support and catalyze open science, data sharing, and research reproducibility, striving to promote the concept that biomedical information and its transparent analysis are public goods.

RECOMMENDATION #3. NLM should be the intellectual and programmatic epicenter for data science at NIH and stimulate its advancement throughout biomedical research and application.

PRE-ACD VOTE

RECOMMENDATION #4. NLM should strengthen its role in fostering the future generation of professionals in biomedical informatics, data science, library sciences, and related disciplines through sustained and focused training efforts.

RECOMMENDATION #5. NLM should maintain, preserve, and make accessible the nation's historical efforts in advancing biomedical research and medicine, thereby ensuring that this legacy is both safe and accessible for long-term use.

RECOMMENDATION #6. New NLM leadership should evaluate what talent, resources, and organizational structures are required to ensure NLM can fully achieve its mission and best allocate its resources.

The collective vision represented by these recommendations aims to position NLM to capitalize fully on current and future opportunities and to emerge as a unifying force in biomedicine that promotes and accelerates knowledge generation, dissemination, and understanding in the United States and internationally.

INTRODUCTION

NLM has an outstanding record of being at the forefront of how biomedical data and health information are collected, shared, and analyzed. It has, particularly over the past two decades, responded to changing opportunities and emerging technological capabilities. For many people around the world, NLM is a trustworthy and comprehensive source of health and biomedical information, with PubMed as its most visible asset (but with many other essential and valued programs representing critical NLM contributions). In addition, NLM is a source of support for training the next generation of data scientists and librarians, the place to learn about the past and explore the history of medicine and biomedical research, a source of new knowledge and standards as a result of its intramural research programs, and a repository of data for use in myriad research studies. The remarkable work of NLM has generated international goodwill and reflected positively on NIH and the United States. In fact, for many, NLM is the most visible face of NIH.

Though NLM's accomplishments are numerous, there is a need to assess how NLM can leverage new opportunities and address the many challenges that lie ahead. Biomedical and healthcare science is at a critical juncture, with the growth of data science, leaps in computational power to store and analyze the data, and the ubiquitous reach of large-scale networked systems in science and society. At the same time, biomedical research has evolved to become more interdisciplinary and team-oriented, with an increasing commitment to the use of 'big data' and open science. Finally, with the growth and ubiquity of the Internet, the general public needs easy access to online, high-quality services and information, especially related to their health. Framed by this context, the recommendations in this report aim to provide guidance on efforts and investments that will position NLM to become a trusted and valuable 21st-century nexus for health and biomedical information – a visionary library of the future.

Recognizing the opportunities and challenges on the horizon, the NIH Director convened this Working Group of the Advisory Committee to the NIH Director (ACD) to articulate a strategic vision for NLM to ensure that it remains an international leader in biomedical and health information. In addressing its charge, the Working Group was asked to specifically assess how NLM should:

- Continue to meet the biomedical community's rapidly evolving scientific and technological needs;
- Lead the development and adoption of information technologies;
- Facilitate the collection, storage, and use of biomedical data by the biomedical and health research communities;
- Continue to lead in promoting open access models for biomedical data and scientific literature;

PRE-ACD VOTE

- Balance computational methods and human-based approaches for indexing;
- Maximize the utilization and cost-efficiency of NLM's National Network of Libraries of Medicine;
- Maximize the usefulness of NLM's other outreach and exhibits programs in the context of future opportunities;
- Interface effectively with the broader and expanding NIH efforts in data science; and
- Directly contribute to addressing the major data science challenges facing the biomedical research enterprise.

This report summarizes the deliberations, observations, and recommendations of the Working Group.

PROCESS FOR DELIBERATIONS

To address its charge, the Working Group met on four conference calls and at two in-person meetings over five months to review the current mission, organization, and programmatic priorities of NLM; consult with NIH and NLM leadership (see Appendix B); evaluate NLM's strengths and weaknesses; identify emerging opportunities and challenges; and craft final recommendations. Frequent and considerable communications between and among Working Group members took place between meetings. The Working Group studied numerous materials, including NLM's Long Range Plan issued for 2006-2016¹, allocation and utilization of resources, programmatic activities, priority setting processes, oversight structures, and relationships with other entities.

Given the diversity and scope of NLM's mission and its stakeholders, the Working Group felt that it was critical to solicit broad public input. Thus, NIH issued a Request For Information (RFI) on the Working Group's behalf to gain further insights into what is needed from a future NLM (see Appendix C). In addition, the Working Group collected public comments throughout the process and considered them throughout its deliberations. It should be noted that the Working Group recognized that its task was to define the strategic vision and direction for NLM, but not define the operational path needed for achieving that vision. The Working Group recognizes that, ultimately, it will be the new NLM director who must create a strategic plan to build upon and implement the vision described by the Working Group. Therefore, the report does not specify changes, and the assumption is that an operational plan will follow based on subsequent analyses and deliberations.

¹ <http://www.nlm.nih.gov/pubs/plan/lrpdocs.html>

SUMMARY OF OBSERVATIONS

NLM has been a center of information innovation since its founding in 1836. Its stated purpose is “to assist the advancement of medical and related sciences and to aid the dissemination and exchange of scientific and other information important to the progress of medicine and to the public health”². This mission is achieved through the conduct of many crucial functions, among them, NLM:

- Serves as a national information resource for medical education, research, and service activities of Federal and private agencies, organizations, and institutions;
- Serves as a national information resource for the public, patients, and families by providing electronic access to reliable health information issued by NIH and other trusted sources;
- Publishes in print and electronically guides to health sciences information in the form of catalogs, bibliographies, indexes, and online databases;
- Provides support for medical library development and for training of biomedical librarians and other health information specialists;
- Conducts and supports research in methods for recording, storing, retrieving, preserving, and communicating health information;
- Creates information resources and access tools for molecular biology, biotechnology, toxicology, environmental health, and health services research; and
- Provides technical consultation services and research assistance.

Given the breadth of its functions and activities, it is not surprising that NLM has many stakeholders – many of whom express resounding support for its mission. This enthusiasm was evident in Working Group’s analysis of the responses to the RFI issued by NIH; in total, 650 responses were received from both domestic and international individuals and organizations. Working Group members undertook an in-depth review of these submissions, finding broad support for many of NLM’s programs and tools (e.g., PubMed, MedlinePlus, ClinicalTrials.gov), along with its functions in organizing, indexing, and providing access to data. NLM’s training programs were also prominently commended for their essential role in cultivating the next generation of biomedical informaticians, health science librarians, health services researchers, and related professionals. The responses highlighted the diversity of users and breadth of programs that NLM has managed over its illustrious history. NLM is a trusted authority for the sharing of quality health information to the public and is relied upon for many programs and resources, including health information, data services, and training programs.

Over its history, NLM has become a leader in making high-quality health and science information easily, publicly, and freely available to everyone. The provision of access to scientific literature through PubMed and PubMed Central is invaluable to researchers, clinicians, and the public all over the world. The creation and maintenance of public health

² <http://www.gpo.gov/fdsys/pkg/USCODE-2011-title42/html/USCODE-2011-title42-chap6A-subchapIII-partD.htm>

PRE-ACD VOTE

information portals like MedlinePlus and ToxNet, and improved transparency of the research process for patients and the public through ClinicalTrials.gov are further examples of NLM seeking to improve the availability of health knowledge. Additionally, NLM's unparalleled collection of primary historical sources and growing digital collections of medical artifacts are depended upon by historical researchers and educators.

NLM has been a critical partner in the advancement of library science innovation and established its reputation as an institution of expertise and leadership in the collection, organization, curation, and dissemination of biomedical data. NLM recognized the burgeoning need for genomic data infrastructure and informatics research, leading to the creation of the National Center for Biotechnology Information (NCBI) and a public reputation for assimilating biomedical and genomic data, maintained and made accessible in numerous high-quality databases and data resources.

NLM's information and data services are relied upon every day by millions of scientists, health professionals, and the public everywhere, in the United States and around the world. The incredibly positive relationship that NLM has built with its broad range of users is a tribute to its long and illustrious legacy. It also enables NLM to serve as the most well-known ambassador of the NIH to the world, and this role will continue to be a tremendous opportunity for NLM and NIH going forward.

However, NLM is not without its challenges. Reflecting its broad mission, NLM has been adept at absorbing additional functions and responsibilities related to information collection and dissemination when called upon by public need. However, in being responsive to varied mandates over its ~180 year history, the organization has faced challenges in the integration of its programs into a prospective framework. NLM's broad range of users creates diverse needs for NLM programs and tools. A major challenge for NLM is maintaining interaction with users across programs in a consistent fashion; this interaction is critical for optimizing the development and use of NLM products. Moving into the future of biomedical research, in which data science will continue to play an increasing role, NLM will encounter greater demands on its expertise and resources. The rapid expansion of data science and biomedical informatics, in the face of ongoing budget constraints, will force NLM to maximize efficiency of its existing functions and future priorities into a cohesive structure. NLM's involvement in data science applications in biomedical research has been essential, but careful consideration and strategic planning will be essential for NLM to maintain (and likely expand) that role.

In summary, NLM's path going forward must build upon its prior successes, leverage existing strengths, and capitalize on emerging opportunities. Choices will need to be made with respect to what new programs should be developed, as well as what current programs should be expanded or stopped. The recommendations set forth in this report aim to encompass these principles to craft a bold yet attainable vision for NLM.

RECOMMENDATIONS

RECOMMENDATION #1. NLM must continually evolve to remain a leader in assimilating and disseminating accessible and authoritative biomedical research findings and trusted health information to the public, healthcare professionals, and researchers worldwide.

While NLM has been a leader in identifying, storing, promoting, and disseminating a wealth of biomedical information to individuals and organizations around the world, it needs to adapt to a rapidly changing science and technology landscape. To succeed in these efforts, NLM must leverage emerging technologies, promote data standards, and engage directly with biomedical researchers, healthcare professionals, industry, government organizations, and the public in carrying out its mandate. In short, NLM must remain committed to consistent and sustained interactions with its broad base of stakeholders in carrying out its activities. From identification of user requirements to development of services to evaluation of impact, the success of NLM's programs will be enhanced by user engagement.

Recommendation #1a. NLM should coordinate with other U.S. and international agencies on the collection, interpretation, and access of biomedical and healthcare-related information.

Recommendation #1b. NLM should directly engage its constituents in an iterative process of resource creation, maintenance, and evaluation. This process should be uniformly applied across NLM programs to achieve meaningful interactions with users.

Recommendation #1c. NLM should promote the connection of disparate data sources and streams to enable improved knowledge integration and generation. Techniques or integration resources should be identified and developed that can assure better links between and among NLM informational resources, including PubMed, MedlinePlus, biobanks, model organism databases, and registries. NLM should also play a leadership role in harmonizing and connecting with international databases. For example, one could envision a future in which ClinicalTrials.gov drives global harmonization of requirements and standards, while also expanding in scope to accommodate the hosting of metadata and even participant level data.

Recommendation #1d. NLM should seek to understand, integrate, and leverage the complementarity of its resources and services with the access and availability of biomedical and health information via search engines and browsing of other sources of health information on the web, whether commercial, non-profit, or open-source. It should augment these other resources to provide high-quality resources and services unique to the mission of NLM.

RECOMMENDATION #2. NLM should lead efforts to support and catalyze open science, data sharing, and research reproducibility, striving to promote the concept that biomedical information and its transparent analysis are public goods.

PRE-ACD VOTE

NLM should be a leader and innovator in open science efforts worldwide, leveraging the power of data and devising new strategies for integrating and sharing diverse data types, along with building upon its prior successes. NLM should make data accessible (i.e., curating and exposing data, promoting the development and availability of application program interfaces (APIs), and identifying standards when necessary). Its efforts should support the creation of markets for data and encourage the development of reusable tools and resources that provide health information and knowledge at the point of need. Tools and resources must be designed for efficient and effective integration into workflows in support of users with different roles and with varying levels of expertise. Methods and services should be made transparent, and efforts should be directed towards a future where valuable health-related data can be logged, accessed, searched, and shared to enhance the reproducibility of results and to maximize the value of investments in biomedical research. The overarching goal is to empower people, including scientists, with data to improve knowledge generation and promote an understanding of biomedical information. Overall, this represents a strong commitment to transparency.

Recommendation #2a. NLM should serve as a locus of expertise for the management and evaluation of NIH databases and knowledge bases, maintaining a broad perspective of trans-NIH database management efforts, playing a role in establishing common policies and coordination strategies, and promoting sharing in the most responsible ways.

Recommendation #2b. NLM should lead NIH efforts to engage the research community and public in examining the ethical, legal, and social implications of sharing biomedical data, and should participate in the broader efforts to develop policies in these areas.

Recommendation #2c. NLM should lead efforts to promulgate and implement best practices in open source, open science, standards, and data harmonization, forming partnerships across communities, stakeholder organizations, agencies, and countries. NLM should be an active participant in the design and oversight of programs that incentivize and celebrate the open sharing of data and resources.

Recommendation #2d. NLM should actively collaborate with developer communities. Tools and resources should be disseminated using industry standards for data sharing and programmatic access (e.g. well documented APIs or SPARQL endpoints) to enable reuse by researchers and other stakeholders.

RECOMMENDATION #3. NLM should be the intellectual and programmatic epicenter for data science at NIH and stimulate its advancement throughout biomedical research and application.

The last decade has brought breathtaking advances in both our ability to collect biomedical data and our ability to analyze large datasets. As a result, NIH (and indeed, the entire biomedical research enterprise) faces extraordinary ‘big data’ opportunities as well as

challenges. In 2012, the NIH ACD Data and Informatics Working Group³ made recommendations about these circumstances, focusing on the need for systematic efforts in data sharing, methods, and workforce development, and refining NIH's internal structure and operations in this area. The acceptance and implementation of these recommendations was ultimately framed around the recently coined term "data science", construed broadly to reflect multiple contributing technical disciplines (e.g., computer science, statistics, bioinformatics, biostatistics, computational biology, medical informatics, information science, quantitative biology).

Among the initial steps to nurture and accelerate data science programs at NIH were the establishment of a new NIH leadership position (the NIH Associate Director for Data Science) and the launching of a major new trans-NIH program—the Big Data to Knowledge (BD2K) Initiative, which includes training, creation of research hubs, support for investigator research, and other key activities. However, these steps represent just the beginning of a series of needed long-term institutional efforts to adequately position the NIH for a future in which data science is central to virtually all aspects of biomedical research. The Data and Informatics Working Group left unresolved the issue of where the center of intellectual and programmatic activities in biomedical data science should reside at NIH.

NLM is now poised to build on its activities in computational-based research, data dissemination, and training to assume the NIH leadership role in data science. Indeed, while essentially all the other NIH Institutes/Centers are involved with and depend upon data science, none is best situated to serve as its epicenter within NIH. Partly for this reason, the new BD2K Initiative was launched as a trans-NIH effort. It is clear, however, that BD2K must have a stable, long-term home to provide support sustainable oversight and an appropriate programmatic infrastructure. NLM's history of innovation together with its strengthened focus on supporting and catalyzing open science make it the obvious choice to oversee these activities under the leadership of its incoming director.

Recommendation 3a. NLM should become the programmatic and administrative home for the BD2K Initiative, taking the lead in advancing BD2K and defining subsequent data science efforts. In addition, NLM should lead the coordination of data science programs (and programs with large data science components) conducted at other NIH Institutes/Centers, in order to maximize synergies and minimize redundancies.

Recommendation 3b. NLM should promulgate intramural and/or extramural expertise, knowledge generation and dissemination, and leadership in areas of data science that are critical to the NIH mission. For example, NLM should help nurture a national talent pool in the science and engineering of Electronic Health Records (EHRs), the analysis of biomedical text, the integration of diverse and multimodal datasets, the application of novel computational and statistical methods to extract knowledge, and future domains that involve extracting data and producing knowledge from digital health sources. These areas are just a sample of those

³ <http://acd.od.nih.gov/diwig.htm>

PRE-ACD VOTE

required to advance important health initiatives, such as the recently announced Precision Medicine Initiative. Other data science areas that need robust research and/or training programs at NIH should be identified as part of NLM's strategic planning efforts.

RECOMMENDATION #4. NLM should strengthen its role in fostering the future generation of professionals in biomedical informatics, data science, library sciences, and related disciplines through sustained and focused training efforts.

NLM should expand its role in training the next generation workforce in its mission-critical areas, either as a primary sponsor or a facilitator working with other NIH Institutes/Centers, agencies, and organizations. The efforts should range from high school programs and/or curricula through post-doctoral programs. NLM should also be a leader in developing programs or materials for practitioners who could use NLM resources in the provision of medical care and public health services. This workforce includes medical students and physicians, public health professionals, nurses, first responders in many domains, and information specialists who support such activities. The dearth of human capital in this area must be addressed by a national strategy that is led by NLM.

Given the above recommendation about data science (Recommendation #3), it is imperative that NLM develop a national strategy for training data scientists in a manner that recognizes the breadth of fields that need this expertise (beyond bioinformatics) and the intrinsic interdisciplinary nature of successful science. In addition to directly supporting training, NLM needs a comprehensive understanding of the nature, number, and coordination of training programs in the various disciplines of data science across NIH, government partners, and the general biomedical research community.

Recommendation #4a. NLM should develop and support new, comprehensive, and coordinated strategic training initiatives related to professional development across multiple spheres – from training for librarians on NLM's various databases to designated point-of-need training for clinicians, data managers, first responders, historians, and nurses. Health sciences curricula on the use of NLM resources for patient care and research should also be developed.

Recommendation #4b. NLM should be the center for nurturing the core science and methodologies of biomedical informatics, data science, and library science through research and training programs; it should also nurture partnerships with other NIH programs, other Federal agencies, and outside organizations in which informatics and biostatistics are a core component.

RECOMMENDATION # 5. NLM should maintain, preserve, and make accessible the nation’s historical efforts in advancing biomedical research and medicine, thereby ensuring that this legacy is both safe and accessible for long-term use.

NLM should continue to be the national custodian of historically important biomedical data and health information in print and digital formats (e.g., film, audio, video, paper, data, and databases). NLM should enable access to these materials and those housed by other institutions, so that they can be used to conduct basic and applied research, practice evidence-based medicine, and make informed healthcare decisions. Preservation and access are basic tenets for libraries, and NLM is no different. NLM should thus be a leader in the preservation and access domain. Digital preservation in this case assumes continuous processes for bit validation and bit-checking. It assumes robust dark and light storage, redundancy in digital preservation sites, and preservation of all formats of information. It also assumes persistent and intuitive search and retrieval protocols that provide recall over time, regardless of the audience or inquiry.

Recommendation #5a. NLM should lead and form partnerships to advance the core professional domains of data and knowledge capture, such as archiving, search, and analysis.

Recommendation #5b. NLM should develop and implement a strategic preservation and access plan for medical knowledge in all formats, including the ephemeral forms that are increasingly dominating medical communication (e.g., online journals, blogs, and databases).

RECOMMENDATION #6. New NLM leadership should evaluate what talent, resources, and organizational structures are required to ensure NLM can fully achieve its mission and best allocate its resources.

In making this recommendation, the Working Group focused on the vision for NLM’s future, not on evaluating how it might have to modify its existing priorities, functions, and organizational structure to achieve that vision. There is a recognition that resources for NLM are unlikely to increase markedly, and there will thus be a need to seek efficiencies, eliminate redundancies, leverage technologies, and make difficult choices in order to implement these recommendations. The new NLM Director will need to conduct a rigorous and thorough review of all components of the organization to determine which ones are optimally positioned to accomplish these recommendations. A particular challenge will be to determine clear programmatic and oversight distinctions between activities, scientific services, and resources that are administered through NLM’s intramural program versus those served through NLM’s extramural program – and how critical knowledge generation that resonates with NLM’s mission can be best accomplished. This will require a careful assessment of how to best position the overall research program to be most highly impactful.

The Working Group concluded that such a ‘functional audit’ of all NLM programs and

PRE-ACD VOTE

subcomponents is needed, but recognized that it could not adequately complete such a task on the short timeline assigned.

Recommendation #6a. NLM leadership should critically evaluate the current NLM portfolio of databases, resources, and services. The objective should be to ensure the continued success and enhancement of services that are vital to the community, and to identify and address efforts that are not serving the community optimally. This evaluation should also be undertaken in the context of the broader NIH, aiming to make strategic recommendations on consolidating and/or better coordinating overlapping programs across the agency.

Recommendation #6b. NLM leadership should review and potentially reorganize the structure and functions of NLM to ensure that they align with the contemporary vision and mission. The existing advisory and oversight structures should be reviewed, with consideration of how they can best assist the NLM Director.

CONCLUDING REMARKS

NLM has an exemplary history of excellence, both in terms of accomplishments and world-wide reputation in the research and health sciences communities. This report provides an overarching vision for NLM to continue that legacy into the future as part of NIH's mission "to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability." In doing so, NLM has the opportunity to modernize the conceptualization of a 'library'—leading the way in demonstrating how information and knowledge can best be developed, assimilated, organized, applied, and disseminated in the 21st century.

To realize the vision embodied by the above recommendations, the Working Group believes that NLM must evolve to seize this critical moment in biomedical history and be a trustworthy source of biomedical data and information, an advocate for open science, a promoter of the next generation of data scientists, a protector of the legacy of the past, and a vital partner for those who are generating biomedical knowledge for the future. NLM is a precious national resource with international reach. It succeeds best when its work produces better health, better science, and better information for all. Achieving these recommendations will ensure the continued success of this critical resource in a period of immense opportunity in biomedical research, healthcare delivery, and public health.

APPENDIX A – ROSTER

Eric Green, MD, PhD (co-chair)

National Institutes of Health

Harlan Krumholz, MD (co-chair)

Yale University

Russ Altman, MD, PhD

Stanford University

Howard Bauchner, MD

Journal of the American Medical Association

Deborah Brooks

Michael J Fox Foundation

Doug Fridsma, MD, PhD

American Medical Informatics Association

Steven Goodman, MD, MHS, PhD

Stanford University

Eric Horvitz, MD, PhD

Microsoft Research

Trudy MacKay, PhD, FRS

North Carolina State University

Alexa McCray, PhD

Harvard University

Chris Shaffer, MS

Oregon Health and Science University

David Van Essen, PhD

Washington University

Joanne Waldstreicher, MD

Johnson & Johnson

James Williams, II, MS

University of Colorado, Boulder

EX OFFICIO MEMBERS

Kathy Hudson, PhD

National Institutes of Health

EXECUTIVE SECRETARY

Lyric Jorgenson, PhD

National Institutes of Health

APPENDIX B – NLM CONSULTATIONS

Donald Lindberg, MD – Director, National Library of Medicine, National Institutes of Health

Betsy Humphreys, MLS – Deputy Director, National Library of Medicine, National Institutes of Health

Philip Bourne, PhD - Associate Director for Data Science, National Institutes of Health

Joyce Backus, MSLS – Associate Director for Library Operations, National Library of Medicine, National Institutes of Health

Ivor D’Souza – Director of Information Systems, National Library of Medicine, National Institutes of Health

Valerie Florance, PhD – Associate Director for Extramural Programs, National Library of Medicine, National Institutes of Health

David Lipman, MD – Director, National Center for Biotechnology Information, National Library of Medicine, National Institutes of Health

Clement McDonald, MD – Director, Lister Hill National Center for Biomedical Communications, National Library of Medicine, National Institutes of Health

Steven Phillips, MD – Associate Director for Specialized Information Services, National Library of Medicine, National Institutes of Health

Request for Information (RFI) Soliciting Input into the Deliberations of the Advisory Committee to the NIH Director (ACD) Working Group on the National Library of Medicine (NLM)

Notice Number: NOT-OD-15-067

Key Dates

Release Date: February 13, 2015

Related Announcements

None

Issued by

National Institutes of Health ([NIH](#))

Purpose

This Notice is a time-sensitive Request for Information (RFI) soliciting input into the deliberations of the Advisory Committee to the NIH Director (ACD) Working Group on the National Library of Medicine (NLM).

Background

As defined in statute, the NLM was established to “assist the advancement of medical and related sciences and to aid the dissemination and exchange of scientific and other information important to the progress of medicine and to the public health.” The world’s largest biomedical library, the NLM maintains and makes available a vast multimedia collection of published literature, organizational archives and manuscripts, and still and moving images; builds and provides electronic information resources used billions of times each year by millions of scientists, health professionals, and members of the public; supports and conducts research, development, and training in biomedical informatics, data and information science, and health information technology; and coordinates a ~6,100-member National Network of Libraries of Medicine that promotes and provides access to health information in communities across the United States. In pursuit of its mission, the NLM has achieved many successes, such as pioneering free Internet access to PubMed, access to genetic and genomic data through GenBank, clinical trial registration and results through [clinicaltrials.gov](#), NIH-funded biomedical research as part of the NIH Public Access Policy, and supporting the research and training programs of institutions throughout the country. The full scope of activities of the NLM can be found at <http://www.nlm.nih.gov/>. Ultimately, the creation and maintenance of these resources help to support and enable access to the results of research funded by NIH and many other organizations.

NIH is committed to ensuring that the NLM continues to leverage technological advances in information and data science to facilitate scientific breakthroughs and understanding of health and disease by scientists, health professionals, and the public. In order to help chart the course for the future of the NLM, the NIH Director established a working group charged with (1) reviewing the current mission, organization, and programmatic

priorities of the NLM; and (2) articulating a strategic vision for the NLM to ensure that it remains an international leader in biomedical and health information. In addressing its charge, the working group is to assess specifically how the NLM should:

- Continue to meet the biomedical community's rapidly evolving scientific and technological needs;
- Lead the development and adoption of information technologies;
- Facilitate the collection, storage, and use of biomedical data by the biomedical and health research communities;
- Continue to lead in promoting open access models for biomedical data and scientific literature;
- Balance computational methods and human-based approaches for indexing;
- Maximize the utilization and cost-efficiency of the NLM's National Network of Libraries of Medicine;
- Maximize the usefulness of the NLM's other outreach and exhibits programs in the context of future opportunities;
- Interface effectively with the broader and expanding NIH efforts in data science; and
- Directly contribute to addressing the major data science challenges facing the biomedical research enterprise.

As part of the working group's deliberations, NIH is seeking input from stakeholders and the general public through this RFI.

Information Requested

This Request for Information (RFI) seeks input regarding the strategic vision for the NLM to ensure that it remains an international leader in biomedical data and health information. In particular, comments are being sought regarding the current value of and future need for NLM programs, resources, research and training efforts, and services (e.g., databases, software, collections) – collectively referred to in this RFI hereafter as “NLM elements”. Your comments can include but are not limited to the following topics:

- Current NLM elements that are of the most, or least, value to the research community (including biomedical, clinical, behavioral, health services, public health, and historical researchers) and future capabilities that will be needed to support evolving scientific and technological activities and needs.
- Current NLM elements that are of the most, or least, value to health professionals (e.g., those working in health care, emergency response, toxicology, environmental health, and public health) and future capabilities that will be needed to enable health professionals to integrate data and knowledge from biomedical research into effective practice.
- Current NLM elements that are of most, or least, value to patients and the public (including students, teachers, and the media) and future capabilities that will be needed to ensure a trusted source for rapid dissemination of health knowledge into the public domain.
- Current NLM elements that are of most, or least, value to other libraries, publishers, organizations, companies, and individuals who use NLM data, software tools, and systems in developing and providing value-added or complementary services and products and future capabilities that would facilitate the development of products and services that make use of NLM resources.
- How NLM could be better positioned to help address the broader and growing challenges associated with:
 - Biomedical informatics, “big data”, and data science;
 - Electronic health records;
 - Digital publications; or
 - Other emerging challenges/elements warranting special consideration.

How to Submit a Response

Responses to this RFI must be submitted electronically via: <http://grants.nih.gov/grants/rfi/rfi.cfm?ID=41>. Responses will be accepted through March 13, 2015. Responses to this RFI are voluntary. Please do not include any proprietary, classified, confidential, or sensitive information in your response. The NIH will use the information submitted in response to this RFI at its discretion and will not provide comments to any responder's submission. The collected information will be reviewed by NIH staff, may appear in reports, and may be shared publicly on an NIH website. The Government reserves the right to use any non-proprietary technical information in summaries of the state of the science, and any resultant solicitation(s). The NIH may use the information gathered by this RFI to inform the development of future funding opportunity announcements. This RFI is for information and planning purposes only and should not be construed as a solicitation or as an obligation on the part of the Federal Government, the National Institutes of Health (NIH), or individual NIH Institutes and Centers. No basis for claims against the U.S. Government shall arise as a result of a response to this request for information or from the Government's use of such information.

Inquiries

Please direct all inquiries to
Lyric Jorgenson, Ph.D.
Office of the Deputy Director for Science, Outreach, and Policy
Telephone: 301-496-1455
Email: jorgensonla@od.nih.gov