Medical Library Association and Association of Academic Health Sciences Libraries
Statement on FY18 Appropriations for the National Library of Medicine
Submitted to the Senate Subcommittee on L-HHS, Education & Related Agencies

The Medical Library Association (MLA) and Association of Academic Health Sciences Libraries (AAHSL) thank the Subcommittee for supporting appropriations for the National Library of Medicine (NLM), an agency of the National Institutes of Health (NIH), and recommend at least $412,097,000 for NLM in FY18. Working in partnership with the NIH and other Federal agencies, NLM is the key link in the chain that translates biomedical research into practice, making the data and results of research readily available to all who need it. NLM plays an increasingly important role in NIH-wide efforts in big data and data science. As health sciences librarians who use NLM's programs and services every day, we can attest that NLM resources literally save lives making NLM an investment in good health.

NLM Leverages NIH Investments in Biomedical Research

In today's challenging budget environment, we recognize the difficult decisions Congress faces as it works to improve our nation's fiscal stability. We thank the Subcommittee for its long-standing commitment to strengthening NLM's budget. NLM's budget supports intramural services and programs that sustain the nation's biomedical research enterprise and more—it builds, sustains, and augments NLM's suite of almost 300 databases which provide information access to health professionals, researchers, educators, and the public. It also supports all aspects of the Library's operations and programs, including the acquisition, organization, preservation, and dissemination of the world's biomedical literature, no matter the medium, and critical funding for research and training in biomedical informatics and data science.

In FY18 and beyond, it is critical to continue augmenting NLM's baseline budget to support expansion of its information resources, services, and programs which collect, organize, and make readily accessible rapidly expanding biomedical knowledge resources and data. NLM maximizes the return on investment in research conducted by the NIH and other organizations. The Library makes the results of biomedical information more accessible to researchers, clinicians, business innovators, educators, and the public, enabling such data and information to be used more efficiently and effectively to drive innovation and improve health. Recognizing NLM's leadership in big data, the Advisory Committee to the NIH Director recommended that NLM become the intellectual and programmatic hub for data science at NIH and stimulate its advancement throughout biomedical research. NLM also plays a critical role in accelerating nationwide deployment of health information technology, including electronic health records (EHRs), by leading the development, maintenance and dissemination of key standards for health data interchange that are now required of certified EHRs. NLM also contributes to Congressional priorities related to drug safety, through expansion of its clinical trial registry and results database (ClinicalTrials.gov), and to the nation's ability to prepare for and respond to disasters.

Growing Demand for NLM's Basic Services

NLM delivers more than 50 trillion bytes of data to millions of users daily that helps researchers advance scientific discovery and accelerate its translation into new therapies; provides health practitioners with information that improves medical care and lowers its costs; and gives the public access to resources and tools that promote wellness and disease prevention. Every day, medical librarians across the nation use NLM services to assist clinicians, students, researchers, and the public in accessing information they need to save lives and improve health. Without NLM, our nation's medical libraries would be unable to provide the quality information services that our nation's health professionals, educators, researchers and patients increasingly need.

NLM's data repositories and online integrated services such as GenBank, the database of Genotypes and Phenotypes (dbGaP), Genetics Home Reference (GHR), PubMed, and PubMed Central are revolutionizing medicine and ushering in an era of personalized medicine in which care is based on an individual's unique genetic profile. GenBank is the definitive source of gene sequence information. GHR contains more than 2,500 consumer-level summaries of genetic conditions, genes, gene families, and chromosomes and is accessed by some 2 million users. PubMed, with more than 27 million references to the biomedical literature, is the world's most heavily used source of bibliographic information. Almost 1.2 million new citations were added in FY16, and the database provided high quality medical information to more than 2.4 million users per day. PubMed Central, NLM's digital archive, provides public access to the full-text versions of more than 4.2 million biomedical journal articles, including those

produced by NIH-funded researchers. On a typical weekday approximately 1.4 million users download more than 2.8 million full-text articles, including those submitted in compliance with the NIH Public Access Policy.

As the world's largest and most comprehensive medical library, NLM's traditional print and electronic collections continue to steadily increase each year, standing at more than 21 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health sciences information in all formats, NLM ensures the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and guaranteeing that citizens can make the best, most informed decisions about their healthcare.

Encourage NLM Partnerships

NLM's outreach programs are essential to MLA and AAHSL membership and to the profession. Through the National Network of Libraries of Medicine (NNLM), with over 6,500 members in communities nationwide, the NLM educates medical librarians, health professionals and the general public about NLM's services and trains them in the most effective use of these services. Beginning with the 2016-2021 funding cycle, the NNLM includes Coordinating Offices that independently support Network activities by providing technical expertise, planning, and coordination, and serve as the Network's central point of contact to reduce redundancy of effort throughout the Network.

The NNLM serves the public by promoting educational outreach for public libraries, secondary schools, senior centers and other consumer-based settings, and its emphasis on outreach to underserved populations helps reduce health disparities among large sections of the American public. NLM's "Partners in Information Access" program improves access by local public health officials to information which prevents, identifies and responds to public health threats and ensures every public worker has electronic health information services that protect the public's health.

NLM's MedlinePlus provides consumers with trusted, authoritative health information on more than 1,000 topics in English and Spanish. It has become a top destination for those seeking health information on the Internet, attracting more than 1 million visitors daily. NLM continues to make enhancements to MedlinePlus and disseminates information via the website, a web service, XML files, and social media. MedlinePlus and MedlinePlus en Español have been optimized for easier use on mobile phones and tablets. Other products and services that benefit public health and wellness include the *NIH MedlinePlus Magazine* and is Spanish-language equivalent, *NIH MedlinePlus Salud*, available in doctors' offices nationwide, and NLM's MedlinePlus Connect—a utility that enables clinical care organizations to link their electronic health records systems to relevant patient education materials in MedlinePlus.

MLA and AAHSL applaud the success of NLM's outreach initiatives, and we look forward to continuing to work with NLM on these programs.

Emergency Preparedness and Response

Through its Disaster Information Management Research Center, NLM collects and organizes disaster-related health information, ensures effective use of libraries and librarians in disaster planning and response, and develops information services to assist responders. NLM responds to specific disasters worldwide with specialized information resources appropriate to the need, including information on bioterrorism, chemical emergencies, fires and wildfires, earthquakes, tornadoes, and pandemic disease outbreaks. MLA and NLM continue to develop the Disaster Information Specialization program to build the capacity of librarians and other interested professionals to provide disaster-related health information outreach. Working with libraries and publishers, NLM's Emergency Access Initiative makes available free full-text articles from hundreds of biomedical journals and reference books for use by medical teams responding to disasters. MLA and AAHSL ask the Subcommittee to support NLM's role in this crucial area which ensures continuous access to health information and use of libraries and librarians when disasters occur. NLM has created a comprehensive web page to gather resources on emerging health issues arising from the Zika Virus. Many medical libraries include links to it on their Web sites. This is another example of the fine work that NLM does on behalf of the public.

In 2015, NLM and the Health and Human Services Office of the Assistant Secretary for Preparedness and Response released a new version of the Radiation Emergency Medical Management website which gives health care personnel

key information about the diagnosis and treatment of radiation injuries and access to interactive clinical tools and data. The site provides just-in-time, evidence-based, usable information with sufficient background and context to make complex issues understandable to health providers without formal training or expertise in radiation medicine.

Health Information Technology and Bioinformatics
For more than 40 years, NLM has supported informatics research, training and the application of advanced computing and informatics to biomedical research and healthcare delivery including telemedicine projects. Many of today's biomedical informatics leaders are graduates of NLM-funded informatics research programs at universities nationwide. A number of the country's exemplary electronic and personal health record systems benefit from findings developed with NLM grant support.

The importance of NLM's work in health information technology continues to grow as the nation moves toward more interoperable health information technology systems. A leader in supporting the development, maintenance, and dissemination of standard clinical terminologies and standards for free nationwide use (e.g., SNOMED, RxNORM, LOINC), NLM works closely with the Office of the National Coordinator for Health Information Technology to promote the adoption of interoperable electronic records. NLM has developed tools to make it easier for EHR developers and users to implement accepted health data standards in their systems and link to relevant patient education materials, which can improve patient understanding and safety.

Dissemination of Clinical Trial Information
ClinicalTrials.gov, the world's largest clinical trials registry, was expanded in FY16, and now includes more than 238,000 registered studies and summary results for more than 24,500 trials, many of which are not published elsewhere. As health sciences librarians who fulfill requests for information from clinicians, scientists, and patients, we applaud the NIH and NLM for implementing the requirements for clinical trials registration and results submission consistent with the Food and Drug Administration Amendments Act of 2007 and for applying them all NIH-supported clinical trials. These efforts enhance the transparency of clinical trial results and provide patients with more information to make necessary health care decisions, including critical information about the safety of products and treatment options and potential enrollment in clinical trials. Clinicians have access to results information about efficacy, adverse effects, and safety; and biomedical researchers have information on research design, safety, and scientific results that can inform future protocols and discoveries. ClincalTrials.gov is an incredible and vastly important database of clinical data and knowledge for clinicians, scientists, and patients who need access to cutting-edge information.

Improving Public Access to Funded Research Results
In 2015, the Department of Health and Human Services (DHHS) announced it plans and common policy approach to expanding public access to the results of scientific research funded by HHS agencies. Its operating divisions (Agency for Healthcare Research and Quality, Centers for Disease Control, Food and Drug Administration, and NIH), as well as the Assistant Secretary for Preparedness and Response and Administration for Community Living, will utilize NLM's PubMed Central as the common repository for providing public access to peer-reviewed publications and PubMed for sharing citation metadata. Several other Federal departments and agencies have also announced plans to use PubMed Central and PubMed to increase public access to articles resulting from research that they fund. NLM's experience in developing these systems and related tools and engaging the health sciences library community in outreach will be essential to successful and cost-effective implementation of Federal-wide policies and improving compliance.

Thank you again for the opportunity to present our views. As health sciences librarians who use NLM's products and services, and as intermediaries who serve the information needs of researchers, clinicians, and the public, we value and rely upon the high quality resources, services, and leadership that NLM provides in support of our nation's health professionals, educators, researchers, and the public. As the needs of these audiences continue to evolve, we are confident that NLM's vision and understanding of the role of information, data science, and technology will continue to fuel the development of just-in-time resources and tools that will keep our nation's health, biomedical, and scientific professionals at the forefront of health care, discovery, and innovation.

We look forward to continuing this dialogue and supporting the Subcommittee's efforts to secure the highest possible funding level for NLM in FY18 and the years beyond to support the Library's mission and growing responsibilities.

SUMMARY OF FISCAL YEAR 2018 RECOMMENDATIONS

- Continue the commitment to the National Library of Medicine (NLM) by supporting a funding level of at least $412,097,000.
- Continue to support the medical library community's role in NLM's outreach, telemedicine, disaster preparedness, health information technology and data science initiatives, and health care reform implementation.

Organizational Bios

The Medical Library Association (MLA) is a nonprofit, educational organization with 3,500 health sciences information professional members worldwide. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledgebase of health information research, and works with a global network of partners to promote the importance of quality information for improved health to the health care community and the public.

The Association of Academic Health Sciences Libraries (AAHSL) supports academic health sciences libraries and directors in advancing the patient care, research, education and community service missions of academic health centers through visionary executive leadership and expertise in health information, scholarly communication, and knowledge management.