

**Medical Library Association and Association of Academic Health Sciences Libraries
Statement on FY20 Appropriations for the National Library of Medicine**

**Submitted to the Senate Subcommittee on Labor, Health and Human Services, and
Education, and Related Agencies**

I, Mary M. Langman, Director, Information Issues and Policy, **Medical Library Association** (MLA), submit this statement on behalf of MLA and the **Association of Academic Health Sciences Libraries** (AAHSL). MLA is a global, nonprofit, educational organization with a membership of more than 400 institutions and 3,000 professionals in the health information field. 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.

We thank the Subcommittee for the opportunity to submit testimony supporting appropriations for the National Library of Medicine (NLM), an agency of the National Institutes of Health (NIH), and recommend \$463,599,000 for NLM in FY20, the funding level provided by the Committee on Appropriations in House Report 116-62.

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 is also a leader in data science and open science and is facilitating implementation of NIH-wide efforts data science activities. 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 Amplifies NIH Investments in Biomedical Research

NLM maximizes the return on investment in research conducted by the NIH and other organizations. It makes the results of biomedical information accessible to researchers, clinicians, business innovators, and the public, enabling such data and information to be used more efficiently and effectively to drive innovation and improve health. NLM's budget supports intramural services, research, and programs that sustain the nation's biomedical research enterprise and more—it builds, sustains, and augments a suite of almost 300 databases which provide information access to health professionals, researchers, educators, and the public. It also supports the acquisition, organization, preservation, and dissemination of the world's biomedical literature and information. To support exponential growth of data and information, in FY20 and beyond, NLM's budget must continue to be augmented to support expansion of its information resources, services, research, and programs which collect, organize, and develop new ways to make the rapidly expanding biomedical knowledge resources and data readily accessible.

NLM plays a critical role in NIH's open science and data science initiatives and in enhancing interoperability of health information technology, including electronic health records (EHRs). NLM leads the development, maintenance and dissemination of key standards for health data interchange that are now required of certified EHRs. NLM also addresses Congressional

priorities through ClinicalTrials.gov, response to the opioid crisis, and disaster preparedness and response efforts.

Growing Demand for NLM's Information Services

NLM delivers more than 50 trillion bytes of data to millions of users daily, which 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's services to assist clinicians, students, researchers, and the public in accessing information to save lives and improve health. Without NLM, our nation's medical libraries would be unable to provide 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, dbGaP, Genetics Home Reference (GHR), PubMed, and PubMed Central (PMC) are revolutionizing medicine and ushering in an era of personalized medicine. GenBank is the definitive source of gene sequence information. Some 2 million users accessed consumer-level information about genetics from GHR which contains more than 2,500 summaries of genetic conditions, genes, gene families, and chromosomes. PubMed, with 29 million references to the biomedical literature, is the world's most heavily used source of bibliographic information with more than 1.3 million new citations added in FY18 and more than 2.9 million users each day. PubMed Central (PMC) is NLM's digital archive, which provides free public access to the full-text versions of more than 5.1 million biomedical journal articles, including those produced by NIH-funded researchers and also public access to research funded by ten other federal agencies. On a typical weekday approximately 2.5 million users download more than 5 million articles from PMC.

NLM's traditional print and electronic collections increase steadily each year, standing at more than 21 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. NLM ensures the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and enabling citizens to make the best, most informed decisions about their healthcare.

NLM's MedlinePlus provides consumers with trusted, reliable health information on 1,000 topics in English and Spanish. It attracts more than 277 million visitors annually. NLM continues to enhance MedlinePlus and disseminate authoritative information via the website, a web service, and social media. MedlinePlus and MedlinePlus en Español have been optimized for easier use on mobile phones and tablets. *NIH MedlinePlus Magazine* and *NIH MedlinePlus Salud* are available in doctors' offices nationwide, and NLM's MedlinePlus Connect enables clinical care organizations to link from their EHR systems to relevant patient education materials.

Encourage NLM Partnerships

NLM's outreach programs are essential to the MLA and AAHSL membership and to the profession. Through the National Network of Libraries of Medicine (NNLM), with over 7,100 members nationwide, NLM educates medical librarians, health professionals, and the general

public about its services and provides training in their effective use. The NNLM serves the public by promoting educational outreach for public libraries, secondary schools, senior centers and other consumer settings, and its outreach to underserved populations helps reduce health disparities. NLM's "Partners in Information Access" provides local public health officials with online information that protects public health.

Since 2018, the NNLM has partnered with the NIH *All of Us* Research Program to support community engagement efforts by United States public libraries and to raise awareness about the program. To date, more than 247 libraries across the United States have joined the NNLM *All of Us* Community Engagement Network to support health literacy by offering free health and wellness resources and programs in local communities.

Data Science and Open Science

NLM is a leader in data science and open science, including the acquisition and analysis of data for discovery and the training of biomedical data scientists. The library aims to strengthen its position as a center of excellence for health data analytics and discovery, and to spearhead the application of advanced data science tools to biological, clinical, and health data. The library aims to fund research that proposes state of the art methods and approaches to address problems and ethical issues with large health data sets, tools used to analyze them (e.g. artificial intelligence (AI)), or inferences drawn based on them. For example, exploring approaches to characterize the data, correct biases or compensate for missing data, and analyze health data while preserving confidentiality, accuracy, and security. NLM is building a workforce for data-driven research and health by funding PhD-level research training in biomedical informatics and data science. The library also partners across the NIH to promote and facilitate inclusion of data science and open science core skills in NIH training programs, and is expanding training for librarians, information science professionals, and other research facilitators. NLM is fostering a culture that advances science and ensures the development and retention of a diverse, safe, and respectful workforce for data-driven research and health well into the future.

Emergency Preparedness and Response

NLM's Disaster Information Management Research Center 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 opioid response, bioterrorism, chemical emergencies, fires and wildfires, earthquakes, tornadoes, and pandemic or epidemic disease outbreaks (e.g., Zika, HIV/AIDS). NLM's Disaster Information Specialization builds the capacity of librarians to provide disaster-related health information outreach. Working with libraries and publishers, NLM provides free full-text articles from hundreds of biomedical journals and reference books to medical teams responding to disasters.

NLM Conducts and Invests in Biomedical Informatics Research and Health Information Technology

NLM conducts and invests in informatics research, training, and the application of advanced computing and informatics to biomedical research and healthcare delivery. Through its Intramural Research Program, NLM's National Center for Biotechnology Information (NCBI) focuses on computational biology, genomics, and biological data banks, and the Lister Hill National Center for Biomedical Communications (LHC) is a leader in clinical information analytics and standards.. A leader in supporting the development, maintenance, and free, nationwide dissemination of standard clinical terminologies, NLM partners with the Office of the National Coordinator for Health Information Technology to support adoption of interoperable EHRs that enable health information exchange. NLM also develops tools to make it easier for EHR developers and users to implement accepted health data standards and link to relevant patient education materials. NLM grant support contributes to research and development of electronic health records (EHR) systems and personal health libraries. NLM is expanding its extramural grant programs to support growing demand for innovation in data science, including methods for extracting meaning from data, such as genomic sequences or clinical data from EHRs. Many of today's biomedical informatics leaders are graduates of NLM-funded informatics research training programs at universities nationwide. NLM also funded five new Small Business Innovation Research and Technology Transfer awards to facilitate innovations, such as block-chain enabled decision support to safeguard privacy and security of patients and research participants.

Dissemination of Clinical Trial Information

ClinicalTrials.gov, the world's largest clinical trials registry, now includes more than 287,000 registered studies and summary results for more than 33,000 trials. As health sciences librarians who fulfill requests for information from clinicians, scientists, and patients, we applaud NIH and NLM for implementing requirements for clinical trials registration and results submission consistent with the FDA Amendments Act of 2007, and for applying them to all NIH-supported clinical trials. These efforts increase transparency of clinical trial results and provide patients and clinicians with information to guide health care decisions. They also ensure biomedical researchers have access to results that can inform future protocols and discoveries.

Improving Public Access to Funded Research Results

The Department of Health and Human Services (DHHS) announced a common policy approach to expand public access to the results of HHS-funded scientific research. Its operating divisions, and other Federal agencies, will use NLM's PubMed Central (PMC) as a common repository to provide free public access to peer-reviewed publications resulting from research funded by NIH and ten other federal agencies.

We look forward to continuing this dialogue and thank you for your efforts to support funding of at least \$463,599,000 for NLM in FY20, with additional increases in future years.