

**Medical Library Association and Association of Academic Health Sciences Libraries
Statement on FY24 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 2,500 health information professionals. AAHSL supports academic health sciences libraries and directors to advance 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 institute of the National Institutes of Health (NIH), and recommend \$521 million for NLM in FY24, a 5% increase. Working in partnership with the NIH and other Federal agencies, NLM is a key link in the chain that translates the results of research, including data, findable and accessible to all who need it. As NLM works to achieve key objectives of its Strategic Plan – accelerating data powered discovery and health, reaching new users in new ways, and preparing a workforce for a future of data-driven research and health - it also supports NIH-wide efforts to answer the call to respond to national priorities, close the gap in health disparities, and capitalize on fundamental investments. NLM accomplishes this through effective preservation of valued scientific and data resources, judicious investments in extramural and intramural research, informed stewardship of Federal resources, and innovative partnerships to align priorities and leverage investments across HHS, the Federal government, and the biomedical research community.

As health sciences librarians who use NLM's programs and services every day, teach others how to use NLM resources, and promote NLM in our local communities, we can attest that NLM resources literally save lives. Investing in NLM is an investment in good health.

Leveraging NIH Investments in Biomedical Research

NLM's budget supports information services, research, and programs that drive the nation's biomedical research enterprise. In FY24 and beyond, NLM's budget must continue to be augmented to support the transformation and expansion of its information resources, services, research, and programs which collect, organize, and develop new ways to make readily accessible rapidly evolving biomedical knowledge resources and data. NLM maximizes the return on investment in research conducted by the NIH and other organizations. It also makes the results of biomedical information and data accessible to researchers, clinicians, business innovators, students, and the public, enabling such data and information to be used more efficiently and effectively to drive innovation and improve health. Rapid growth of data also necessitates funding that will ensure long-term sustainability of these valuable information resources. NLM is unique because it stimulates and supports innovative research in data science and information management that transcends specific disease areas and data types. This is especially crucial in an era where artificial intelligence algorithms are being rapidly developed and integrated into the systems of daily life, including healthcare.

NLM plays a critical role in NIH's data science and open science initiatives. Its intramural and extramural research programs develop and apply data science techniques to accelerate discovery and improve health through all stages of life. " **In support of open science**, NLM collaborates across NIH and the Federal Government to accelerate public access to federally funded research results through PMC and other relevant NLM data repositories. "

NLM builds, sustains, and augments a suite of almost 200 databases which provide information access to health professionals, researchers, educators, and the public. It supports the acquisition, organization, preservation, and dissemination of the world's biomedical literature. In FY 2022, NLM continued to support sharing of genetic

sequence data in support of public health response. It launched the SARS-CoV-2 Variants Overview interactive web resource. This free, open-access tool supports the identification of emerging SARS-CoV-2 variants, and provides the public health community with valuable information needed to guide COVID-19 pandemic research and response efforts. NLM continued to support NIH and interagency initiatives to make SARS-CoV-2 and COVID-19 sequence data widely available for public health response.

Growing Demand for NLM's Information Services

Each day, millions of people use NLM websites and download more than 115 terabytes of data. Thousands of researchers and businesses upload approximately 15 terabytes of data daily. Annually, NLM information systems process more than six billion human requests and eight billion computer-to-computer interactions. NLM's information services help researchers advance scientific discovery and accelerate its translation into new therapies; provide health practitioners with information that improves medical care and lowers its costs; and give 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, MedlinePlus, dbGaP, MedlinePlus, dbGaP, PubMed, and PubMed Central (PMC) are revolutionizing medicine. GenBank is the definitive source of gene sequence information. This past year, more than 430 million users accessed consumer-level information about health topics, which contains more than 22,000 links to authoritative health information on over 1,000 health topics. PubMed, with nearly 35 million references to the biomedical literature, is the world's most heavily used source of bibliographic information with almost 3.3 million users each day. PubMed Central is NLM's digital archive which provides public access to the full-text versions of more than 9 million biomedical journal articles, including those produced by NIH-funded researchers. In FY22, PubMed Central had an average of 3.2 million unique sessions per weekday.

NLM continually expands biomedical information services to accommodate a growing volume of relevant data and information and enhances these services to support research and discovery. NLM ensures the availability of this information for future generations, making books, journals, technical reports, manuscripts, microfilms, photographs and images 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.

Disseminating Clinical Trial Information

NLM's *ClinicalTrials.gov* is the world's largest publicly accessible database of privately and publicly funded clinical studies. In FY 2022, NLM received registration information for more than 38,000 new clinical research studies. NLM also added more than 4,000 new results summaries to *ClinicalTrials.gov*. Making this information visible and accessible improves transparency, accountability, and encourages public trust in science consistent with legislative requirements. With the support of NIH, NLM continued its *ClinicalTrials.gov* modernization effort and launched the first beta release of the modernized *ClinicalTrials.gov* website in FY 2022. This first release of the modernized website provides a more responsive design with an updated search experience and new study record display. The website also makes information about race and ethnicity, sex and gender, and age of participants easier to find and access.

Partnerships Ensuring Outreach and Engagement in Communities Across the Nation

NLM's outreach programs are essential to the MLA and AAHSL membership and to the profession. The NLM coordinates its Network of the National Library of Medicine (NNLM) of more than 8,800 academic health science libraries, hospital and public libraries, and community organizations to improve access to health information for all. Through the NNLM, 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.

Since May 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. Together, NLM and NIH have built the NNLM *All of Us* Community Engagement Network (CEN). The CEN focuses on NNLM's

mission to improve the public's access to health information and provide awareness of *All of Us* to communities that are Underrepresented in Biomedical Research by partnering with libraries across the United States. The CEN is designed to leverage the mission of the NNLM to help libraries in supporting the health information needs of their users.

NLM's MedlinePlus provides consumers with trusted, reliable health information on 1,000 topics in English and Spanish. It attracts more than 1 million visitors daily. NLM continues to enhance MedlinePlus and disseminate authoritative information via the website, 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.

Strengthening Data Science and Open Science Capacity

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. 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 with NIH to ensure inclusion of data science and open science core skills in all NIH training programs, and is expanding training for librarians, information science professionals, and other research facilitators. NLM is participating in NIH-wide efforts to foster 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. In FY 2022, NLM hosted 28 postdoctoral researchers, 10 post-baccalaureate trainees, 3 predoctoral researchers, 18 summer interns, 19 research fellows, 1 clinical fellow, and 2 visiting scientists. It also launched a new research summer internship program in data science and informatics that provides biomedical informatics training and research opportunities to students from diverse backgrounds, including those from underrepresented groups. The inaugural cohort of five interns worked on a variety of projects to improve methods to derive meaning from free text clinical data, explore whether different modes of gene expression occur within a tumor, characterize elements of cells that control genetic expression, use AI to predict progression of eye disease, and understand bias in machine learning.

Responding to the Coronavirus (COVID-19)

NLM has continued to support the response to the COVID-19 pandemic through the SARS-CoV-2 Sequencing for Public Health Emergency Response, Epidemiology, and Surveillance (SPHERES) consortium. NLM's involvement resulted in improved SARS-CoV-2 data submission and validation processes, enhanced graphic interfaces for data retrieval, coordinated U.S. efforts to provide publicly accessible SARS-CoV-2 data via GenBank and SRA, and support for the mpox public health emergency response with the creation of a reference genome sequence as a template for submissions. NLM continued to participate in the NIH Accelerating COVID-19 Therapeutic Interventions and Vaccines (ACTIV) Tracking Resistance and Coronavirus Evolution (TRACE) initiative to develop processes and infrastructure to monitor and evaluate emerging SARS-CoV-2 variants, and to standardize, gather, and share variant sequencing data. In FY 2022, as part of its engagement in ACTIV TRACE, NLM refined data processing and analysis methods, and provided results in a format that supports findability of data records and large-scale analysis.

Supporting Biomedical Informatics Research and Health Information Technology Innovation

NLM conducts and supports informatics research, training and the application of advanced computing and informatics to biomedical research and healthcare delivery. NLM's National Center for Biotechnology Information (NCBI) focuses on genomics and biological data banks, and the Lister Hill National Center for Biomedical Communications (LHC), is a leader in clinical information analytics and standards. 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. A leader in supporting the development, maintenance, and dissemination of standard clinical terminologies, NLM partners with the Office of the National Coordinator for Health Information Technology to support the interoperability of EHRs. 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. In FY 2022, NLM funded 208 awards across the country, including 28 co-funded with other NIH Institutes, Centers, and Offices. NLM-funded researchers develop methods to improve access, storage, retrieval, management, dissemination, and

use of biomedical data and information to support discovery and decision-making. Active NLM-supported projects develop and test health IT solutions that support clinical care and patient self-management, employ computational approaches and tools to interpret and analyze health records, and develop new AI and machine learning tools and approaches.

Closing the Gap in Health Disparities

The National Library of Medicine supports NIH's efforts to close the gap in health disparities and improve the diversity of the biomedical information science workforce. Their work supports our mission and core values to make MLA and AAHSL more diverse and inclusive organizations. NLM accomplishes this by:

- Providing open access to scientific literature through PubMed and PubMed Central make scientific literature accessible, leading to biological discoveries and providing the foundation to developing clinical guidelines that inform health care. Resources include PubMed Special Query for Health Disparities and Minority Health Information Resources.
- Utilizing the Network of the National Library of Medicine to provide equal access to biomedical information and improves the public's access to information. NNLM supports events including the recent DEI webinar series "Nine Conversations that Matter to Health Sciences Librarians" as well as NNLM Reading Clubs on Disability Health, LGBTQ Health, Racism and Health and Diversity in Medicine.
- Funding grant programs that support research to advance health equity and grants to reduce health disparities research supplements to promote diversity in health research and leveraging health information technology to address minority health and health disparities.
- Raising awareness and sparking conversations about the intersection of society and ethical considerations in biomedical research and technology through the annual NLM Science, Technology, and Society lecture series.

The NLM Information Resource Grants to Reduce Health Disparities support projects that bring useful and understandable health information to populations affected by health disparities and to their health care providers. In FY 2022, NLM awarded two grants to develop: 1) an online guide for people in rural Georgia living with and managing autism spectrum disorder, as well as resources for physicians, and 2) a combination digital resource and training program for Afghan and Syrian refugees to improve reproductive health literacy. The NLM Grants for Scholarly Works in Biomedicine and Health supports the development of monographs and books by health professionals, public health officials, biomedical researchers, and health science historians. In FY 2022, NLM awarded three grants for scholarly works about: 1) the history of health care in U.S. prisons, 2) a comparative study of medical examiner and coroner offices in the United States, and 3) the role of statistics and statisticians in modern medicine.

We look forward to continuing this dialogue and thank you for your efforts to support funding of at least \$521 million for NLM in FY24, with additional increases in future years.