



**Association of
American Medical Colleges**
2450 N Street, N.W., Washington, D.C. 20037-1127
T 202 828 0400 F 202 828 1125
www.aamc.org

March 13, 2015

Lyric Jorgenson, Ph.D.
Office of the Deputy Director for Science, Outreach, and Policy
9000 Rockville Pike
Bethesda, Maryland 20892

**RE: NOT-OD-15-067, 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)**

Dear Dr. Jorgenson:

The Association of American Medical Colleges (AAMC) appreciates the opportunity to comment on the National Institutes of Health (NIH) request for information regarding the strategic vision for the National Library of Medicine (NLM). The AAMC is a not-for-profit organization representing all 141 U.S. allopathic medical schools, nearly 400 teaching hospitals and health systems, and 90 academic societies. Through these institutions, the AAMC represents 128,000 faculty members, 75,000 medical students, 110,000 resident physicians, and thousands of graduate students and post-doctoral trainees in the biomedical sciences.

The AAMC has long been mindful that, given the respective public health missions of the NIH and our member institutions, we should ensure that research models, data, and repositories upon which medical advances depend should be shared to maximize the potential of these resources. In 2011, the AAMC partnered with the NLM to hold a summit on “Sustaining the Digital Research Enterprise,” which envisioned an environment in which investigators both contribute to and draw from big data to explore the molecular basis of human health and innovate health care. Strategies for the development and maintenance of the digital infrastructure supporting such a system, as well as the training of a research workforce able to effectively utilize these new resources, are essential to move forward the process of scientific discovery.

As the primary provider of access to the results of federally-funded research through numerous online repositories and data banks, the NLM is uniquely positioned to support this ongoing transition to a digital research enterprise. The NLM’s role in information collection and dissemination is essential to facilitate evidence-based research and practice in academic medicine across the health continuum.

In response to the NIH request, the AAMC is pleased to provide comment on areas of current and future focus for the NLM which are of particular value to the researchers, health professionals, and patients at our member institutions, as well as the broader public.

Basic Biomedical Research and Training

The AAMC strongly supports the NLM's current engagement with the NIH Office of the Associate Director for Data Science on ongoing data science initiatives, including Big Data to Knowledge (BD2K) grant and training programs. We encourage NLM to continue to work with journals and publishers and to support open access models of publishing for programs like these, and additionally address issues surrounding digital publication, such as storage, access, and attribution.

Additionally, the NLM should continue to provide career development offerings in data science/informatics, and training in the use of specific NLM products and services to ensure a workforce that will sustain these research ventures. These trainings are particularly of value when they bring together professionals from inter-disciplinary backgrounds to collaborate to solve health challenges.

Clinical Research and Decision-making

The NLM-managed ClinicalTrials.gov serves a critical function in registration and results reporting of clinical trials. Investigators, institutional sponsors, and patients alike have indicated that the interface of this important resource can be difficult to navigate. The AAMC encourages NLM to increase the usability of the site for both investigators and sponsors as well as patients and the public, by responding to user suggestions regarding improvements to the interface and by providing clear and accessible information about purpose and use of the site.

The NLM should also continue to facilitate the integration of medical and health informatics into clinical care, including ongoing generation of the widely-used open application programming interfaces (APIs) which link information and databases to Electronic Health Records (EHRs) at the point of care, or providing information directly to patients through MedLine Plus. The NLM may also in the future consider providing support for the integration of EHRs for research purposes.

Community Health and Health Disparities

The free access to results of research through PubMed Central (PMC) and MedlinePlus provides all organizations, from large universities to community health centers with equal access to essential research and health information. Maintaining these resources is a fundamental role for the NLM in carrying out its mission.

The AAMC also urges the NLM to continue its current strategic goal in support of health literacy and the reduction of health disparities, through programs and funding opportunities such as the NLM Information Resource Grants to Reduce Health Disparities. A recent report by the AAMC and AcademyHealth on the state of health equity research,¹ containing a systematic review of health disparities-focused health services research, was conducted under the auspices of a NLM-funded Health Services Research Projects-in-Progress (HSRProj) contract. NLM should also continue to evaluate outreach mechanisms and solicit feedback from the public to determine effective strategies to for information dissemination.

As the research enterprise moves into an era where data are generated in increasing volume and complexity, the NLM has a critical role to play in the development of new methods to facilitate sharing, access, and dissemination of data and publications. The AAMC supports the continued evolution of the NLM as a leader in the emerging digital research enterprise through providing infrastructure, training, and guidance for the rest of the research community. As multiple federal agencies implement their plans for public access through PMC and PubMed, resulting in a much larger and more inclusive body of research becoming publicly available, increased access to research on public health and health services is poised to directly affect and promote innovations in health care and delivery. The NLM should continue to grow its capability for rapid dissemination of this health knowledge into the public domain.

Throughout these strategic planning efforts, the AAMC urges NIH to ensure that the intended audiences and beneficiaries of the NLM's impressive catalog of work are engaged with the NIH in identifying NLM's priorities and implementation and dissemination strategies. The success and effectiveness of NLM's initiatives will be significantly impacted by including meaningful representation from patients and members of underserved populations and communities.

The AAMC is again grateful for this opportunity to comment, and would be happy to provide any further information which would be of use to the NIH as it prepares a strategic plan for the future of the NLM. Please contact me, or my colleagues Heather Pierce, J.D., M.P.H. (hpierce@aamc.org) or Stephen Heinig (sheinig@aamc.org) with any questions about these comments.

Sincerely,



Ann C. Bonham, Ph.D
Chief Scientific Officer

¹ Available at: <http://www.aamc.org/initiatives/research/healthequity/348640/aboutthehealthequity.html>