Comments of the Medical Library Association/Association of Academic Health Sciences Libraries Submitted October 19, 2020

In Response to: Request for Information (RFI): Strategic Opportunities and Challenges for the National Library of Medicine, National Institutes of Health https://rfi.grants.nih.gov/?s=5f15a5e3104800009c001082

Introduction

The purpose of this Request for Information (RFI) is to solicit public comment to assist and guide the National Library of Medicine (NLM) in identifying new, and updating ongoing, efforts to implement the NLM Strategic Plan 2017-2027: A Platform for Biomedical Discovery and Data-Powered Health.

Information Requested

NLM is requesting public comment on major opportunities or challenges relevant to the NLM mission that have arisen or become more important in the last five years and that have implications for the future of NLM in its capacity both as an institution conducting and supporting research and as a national library providing biomedical information products, services, training, capacity-building, and other resources to the world. This information will be used to guide NLM's continuing implementation of its strategic plan. Response to this RFI is voluntary. Respondents are free to address any or all topics listed below and are encouraged for each topic addressed to describe the opportunity or challenge and how NLM might address it.

Name:

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Name of Organization:

Medical Library Association (MLA) & Association of Academic Health Sciences Libraries (AAHSL)

Role in Organization:

MLA Director of Information Issues and Policy; submitting on behalf of the health sciences librarian community

Last 5 Years Categorized Feedback: Major opportunities or challenges that have emerged over the last five years and that have implications for the future of NLM in the area of:

Science (including clinical health sciences, biomedical science, information science, informatics, data analytics, data science, etc.)

The Medical Library Association and Association of Academic Health Sciences Libraries (MLA & AAHSL) recommend increasing funding opportunities for NLM extramural research supporting the development of health equity in clinical sciences, biomedical science, information science, informatics, and data science. In collaboration with directly affected communities, NLM should develop openly licensed, accessible training for researchers and community advisory boards on community-involved research practices, and recruitment and participation of multiple populations in studies to ensure strong samples from sub-groups, as well as tracking and reporting data and analyses at subgroup levels along

with overall results. Librarians must be key contributors on collaborative research teams and need training to develop the required skills to effectively participate in the latest research methodologies beyond their core strengths in literature synthesis and data science.

NLM, AAHSL and MLA should partner to develop expanded research methodology learning opportunities. MLA's work developing the Research Training Institute is a good example of the potential of such programs. NLM, AAHSL and MLA must commit to supporting librarians in accelerating the implementation of scientific discovery. This should include data-science related disciplines but should not overlook the importance and value of literature navigation and other information mediation work.

<u>Technology</u> (including biotechnology, platforms, hardware, software, algorithms, processes, systems, etc.)

MLA/AAHSL recommend that NLM promote librarian and information professional involvement in the creation, development, and implementation of systems for healthcare delivery, education and research. NLM should address the following key areas:

Education and Programming

NLM should be involved in improving education and support for a ubiquitous, interoperable EHR that addresses infrastructure, privacy and security, regulatory, and cultural challenges. NLM should develop programs that educate and promote the use of virtual and augmented reality to enhance and improve both patient education and medical education. NLM must train information professionals to engage in artificial intelligence (AI) and machine learning (ML) initiatives for improved clinical diagnosis and decision making and administrative/operational improvements in healthcare.

Community

NLM should work with clinical information stakeholders to create a community of practice that includes health sciences librarians in conversations about electronic health records. MedlinePlus Connect is an example of a way in which NLM supports the integration of librarian-mediated health information into the electronic health record, but this work can be furthered beyond the area of patient education.

Infrastructure

More support is needed for a national health information technological infrastructure that enhances interoperability, reduces risk, and maintains privacy and security of information. NLM should have a role in setting standards that prevent hospitals from creating systems that actively obstruct the free flow of health information, and support hospital librarians in their role in ensuring that their institutions meet these standards.

NLM must acknowledge and collaborate with technology companies so hospitals and health care professionals can better utilize the 21st century technologies that NLM and other technology companies are developing, and to ensure they are compliant with current and future federal and state regulations such as HIPAA. Many of the products, services, and initiatives from NLM and technology companies (e.g. data sharing and document sharing/storage) are blocked by institutions because they are considered a risk to healthcare security and HIPAA.

Equity and Access

NLM must support research on the development and on-going assessment and review of algorithms, processes, and systems that shape our information environments. Such research must focus on the conduct of and participation in health research, and how these algorithms, processes, and systems support health information equity and reduce health disparities (see Noble, Safiya Umoja. Algorithms of Oppression: How Search Engines Reinforce Racism, New York University Press, 2018; Algorithmic Bias In Health Care: A Path Forward | Health Affairs). Unbiased tools are essential to the mission of health sciences librarians to provide health information services to marginalized and underserved populations.

<u>Public health, consumer health, and outreach</u> (including epidemic disease surveillance, culturally competent engagement, optimizing the experience of resource users, etc.)

MLA/AAHSL recommend that NLM address inequities in access to information and services that include consideration of social stigmas and social determinants of physical and mental health. NLM should more effectively utilize the existing workforce of health information professionals and community educators (public librarians, school teachers, etc...) to help improve community physical and mental health and patient care outcomes.

Education & Programming

NLM must develop programming that improves understanding of mental health issues, increases access to mental health literature, and better educates and assists people in crisis. In our current environment NLM should collaborate with partners such as the National Institute of Mental Health to further the physical and emotional health of the nation.

Another initiative could include developing lesson plans for middle and high school teachers and librarians that showcase NLM resources targeted to health consumers.

NLM should strengthen information access across the nation by serving as a coordinating body across federal agencies, developing standards for collecting, disseminating, and making accessible public health information in times of emergency. This would reduce the redundancies and inconsistencies that we have seen proliferate in the current pandemic, and provide a strong foundation of evidence upon which the national emergency response is based.

Outreach

The Network of the National Library of Medicine (NNLM) must strengthen its outreach role by redeveloping and expanding promotional materials that are reproducible, attractive, and relevant to the health information needs of the communities they serve. NNLM can accomplish this by providing programming materials or templates that can be used by all types of libraries and adjusted to specific audiences.

NLM must also utilize linked data/API technologies to make NLM & NIH information resources more publicly available and accessible; it is a missed opportunity that MedlinePlus and other NIH-funded resources are not often used as sources for promoted information in search engine results, one that can be amended with more expansive website metadata.

Equity & Access

NLM must develop programming and tools to improve the public's knowledge of and access to teleheath and telemedicine services, particularly for underserved community members.

NLM should also expand their consumer health resources to make them available in more languages and to those with varying physical abilities. Specific opportunities include: additional site-wide translation of consumer health resources beyond the availability of MedlinePlus in Spanish (the consolidation of HealthReach into MedlinePlus is the beginning of this work); developing graphic publications to catch the attention of young adult readers and those with limited literacy; moving towards a climate of cultural humility by integrating this principle into all aspects of NLM's work; requiring that all NLM information meets accessibility standards beyond the minimum of ADA requirements.

<u>Library functions</u> (including collection development, access, preservation, indexing, library metadata, service agreements with other libraries, etc.)

MLA Caucuses (special interest groups) are currently collecting terms for literature search hedges for sex, gender, and racial minorities; NLM is an ideal partner in making these and similar search tools available to a broader audience.

NLM should partner with MLA, librarians, and schools of library and information science to develop a health information curriculum for library school students, in particular, one that supports the development of modules teaching advanced use of NLM resources.

NLM can connect health sciences libraries whose collections have been destroyed or made inaccessible by disasters with sources of essential health information, such as other health sciences libraries.

NLM should take a leadership role in the development of metadata requirements and standardize them across the STEM environment. As more articles, datasets, videos, ebooks, etc. are made available online and released early (preprint), it is imperative that the items have basic standardized metadata associated with them. This would make them more discoverable to current and future databases, search engines, discovery systems, natural language searching, etc., and future search retrieval systems could be designed to look for that metadata. It is also important for NLM to lead the way in considering language and categories used in metadata that may replicate discriminatory language or concepts. This includes implementing inclusive practices, international standards for multilingual metadata.

NLM should refocus and enhance its research, development, training, and information services to make more biomedical data findable, accessible, interoperable, and reusable (FAIR), to invent the tools and services that turn data and information into knowledge and insight, and that develop the workforce capable of doing so. Medical libraries are the bridge to NLM's expansive collection of resources but can only promote what they are able to find and access.

NLM must advocate for a culture shift for information professionals as integral participants and partners in, not just supporters of, the healthcare education, research, and patient care ecosystem.

One of the goals in NLM's Strategic Plan is to "Create a sustainable institutional, physical, and computational infrastructure." For NLM to do so requires the support of both hospital and academic

medical libraries located at universities and tertiary research centers. This covers everything from strengthening and improving the new DOCLINE, to making an inventory of what resources are no longer available due to hospital library closings. Archival print cannot not be discounted, as so much of it is not deemed profitable enough to be converted to digital, and yet the print is still valuable on its own merits, not "just" as a historical artifact. The approach to tracking this sprawling "collection" is daunting, although DOCLINE does this to a certain extent, but how else to determine what remains versus what has been lost/will be lost? NLM cannot become a repository for all medical literature, but a finger on the pulse of available professional medical literature is needed, a Medical Wayback Machine.

Modes of scholarly communication (including researchers' use of social media, preprints, living papers, changes in the roles and practices of publishers, data-driven approaches to studying historical medical texts, images, and datasets, etc.)

NLM must work with publishers to provide standard publication metadata; crucial information is lost because it is not discoverable due to lack of or inconsistent metadata (especially in the case of preprints, living papers, images, and datasets).

NLM must support research on the development and on-going assessment and review of algorithms, processes, and systems that shape our information environments. Such research must focus on the conduct of and participation in health research, and how these algorithms, processes, and systems support health information equity and reduce health disparities (see Noble, Safiya Umoja. Algorithms of Oppression: How Search Engines Reinforce Racism, New York University Press, 2018; Algorithmic Bias In Health Care: A Path Forward | Health Affairs). Unbiased tools are essential to the mission of health sciences librarians to provide health information services to marginalized and underserved populations.

NLM can support research and actions to diversify inclusion of global and multilingual research in databases and other information sources: in NLM's own tools, as well as by advocating in the publishing and research professions. (Related citation:

https://crln.acrl.org/index.php/crlnews/article/view/24321/32136)

As NLM implements its strategic plan, MLA/AAHSL recommend that NLM publish regular reports highlighting the progress of specific initiatives outlined in the 2017-2022 plan, holding NLM accountable to its stakeholders. NLM should develop a regular communication platform to share new scientific and technological developments in information science. This would promote the role of libraries to the research community and allow health information professionals to monitor and share them with their service communities. This should include NLM's progress in reaching the goals of its strategic plan such as the development of the new, proposed PubMed-NextGen.

NLM must consider ways that current scholarly communication practices disadvantage historically underrepresented groups and set up a plan to address these issues. Two potential methods of redress include: engaging and providing assistance to under-represented researchers in the health information sciences and supporting libraries that are working on reducing bias and racism in current publishing practices. <u>Perspectives, practices, and policies</u> (including those related to open science, the need for diversity, equity, and inclusion in research, algorithmic bias, expectations of reproducibility of research, etc.)

MLA/AAHSL recommend improving support of global health through collaboration with international health information organizations, such as through the establishment of an international health information liaison position, or through the establishment of a Network of the National Library of Medicine (NNLM) Office of Global Health, hosted by a Regional Medical Library. NLM should also seek to overcome current geographic and language limitations and barriers in scholarly communication and research sources. The freely accessible nature of NLM's resources contributes to PubMed and other NCBI tools' status as tools for global health. Global health requires global research information access and discoverability.

NLM must intentionally examine its own practices in research and information resource creation. Are the communities that are directly affected by this research and these resources included in the process at NLM? In her 2020 MLANET lecture and follow-up Q&A, "How Health Care Inequities Have Been Exacerbated by COVID-19" Esther Choo stressed the importance of 'community-involved research,' and the importance to recruit and involve underrepresented, underserved communities and populations to be part of *designing* research studies, as well as to increase the participation of such groups in research studies to allow for statistical power and the capability of meaningful sub-group data analysis and results. Community-involved research that designs studies addressing health disparities and collects meaningful subgroup data is essential to achieve health equity.

Workforce needs (including data science competencies, effective strategies for recruitment and retention of underrepresented minorities, opportunities for training and continuing education for middle- and late-career researchers and librarians, etc.)

Broadening Our View on Roles and Retention: In Objective 3.3, NLM affirms its commitment to a diverse workforce. These efforts are essential steps in moving the needle on recruitment and retention. Underrepresented minorities with STEM and data skills are highly sought-after employees. They are recruited by the world's top-level tech companies, are paid high salaries, and receive competitive benefit packages. Libraries are not able to compete in these areas and therefore must get creative. The educational and background requirements to work in libraries must be reconsidered as roles expand into new and emerging service offerings. The focus cannot be about retaining one diverse librarian at one specific library or in one specific program; this issue needs to be approached as a profession with NLM's support and in collaboration with other organizations and institutions.

Building the Career Pipeline: In Objective 3.3, NLM commits to helping high school and college students consider careers in health information technology, medical librarianship, and data science. Outreach to underprivileged youth in secondary schools can introduce new career options and increase the diversity of the library profession. Students learning coding, web design, and app creation, are often unaware that they can use these skills in a library setting. The impact of underfunded schools closing their libraries has resulted in unstaffed multipurpose rooms with computers and no books. Outreach could take the form of librarians going into the classroom, providing after school enrichment programs, or incorporating library perspectives into STEM summer camps. One model of outreach is the National Society of Black Engineers (NSBE) which has chapters in high schools, colleges, and professional

chapters in cities across America and has resulted in the recruitment and retention of African American engineers.

Training and Continuing Education: NLM must take the lead in identifying and exploring new roles and services and providing professional development opportunities for them. This includes roles in data science, hospital librarianship, educational and clinical support, as well promoting and supporting the librarian as researcher. Providing a variety of fellowships, internships, boot camps, etc. to support these expanding roles will create opportunities to help new and current librarians expand their skills and also serve to attract new and diverse librarians from underrepresented groups. New partnerships with Library Science programs and training organizations can expand the reach of these types of training opportunities.

MLA's efforts to explore and develop guidelines for the evolving skills needed by health information professionals have been extensively explored and developed, and can guide NLM's training efforts to meet the workforce needs of the health research, education, and clinical communities. NLM's Data Sciences in Libraries Project and NLM's workshop on Developing the Librarian Data Science and Open Science Workforce projects showed that this work will not be simple but is crucial. Projects like these are examples and models for the profession, and should be continued and expanded upon. One opportunity is Network of National Library of Medicine (NNLM) financial support for fellows selected to participate in MLA's Research Institute.

Last 5 Years General Feedback: Major opportunities or challenges that have emerged in the last five years and that have implications for the future of NLM in other areas or areas not well captured above.

Health Science Librarians as Key Stakeholders in the Future of the National Library of Medicine
Health sciences librarians across the United States and globally continue to maintain a strong sense of
connection to NLM through freely available, high quality resources such as PubMed and other NCBI
databases. As "power users", educators, and promoters of these resources to students, clinicians, and
researchers, health sciences librarians have a vested interest in the design and content of these resources.
As NLM grows in exciting new directions, health sciences librarians need to know that their voices and
feedback are being heard and that we are being engaged in discussions regarding the redesign of current
resources (such as PubMed) and the sunsetting of others (such as Genetics Home Reference). Current
communication mechanisms, such as the NLM Director's Musings from the Mezzanine blog, have
assisted some, but these mechanisms appear to serve as marketing tools, rather than inviting honest
feedback and true transparency. We call for a richer form of dialogue between our associations.

Another important relationship between medical libraries and NLM is NLM's role as a support utility providing systems and resources such as DOCLINE, which are crucial supports to medical libraries. The Network of the National Library of Medicine is an essential coordinator of these services as well as professional development and outreach resources for medical librarians.

Calling for an Inclusive and Supportive National Library of Medicine

Common themes in this document include:

- An increased need for technological, administrative, and professional infrastructure
- A more intentional pursuit of health equity, global health and effective clinical care.

Many of the tools and resources created by NLM and other groups cannot be utilized by hospital librarians and healthcare professionals because of technological limitations and lack of institutional support. Community clinical settings cannot be left behind as technology and tools advance. Regulations, local culture, resource limitations make it difficult for both clinicians, clinical organizations, patients and others to take advantage of the things NLM is developing. NLM must develop and promulgate the infrastructure that will make these resources accessible and usable in these settings, and be mindful of the limitations of the organizations and industry with which they are working.

Medical libraries and Health Information Professionals need to prepare to play a key role in supporting the effective access to and use of the new tools and resources by the healthcare institutions and communities they support.

Next 5 Years: Opportunities or challenges on the horizon over the next five years that fall within the purview of the NLM's mission.

Access and the dissemination of information may be impacted due to factors associated with future pandemics, global warming. NLM needs to incorporate responses to extraordinary situations such as these into future strategic planning efforts. NLM must be responsive and flexible to the variety of environments that its stakeholders work in, both now and in the future.

Community-involved health research, health assessment, and health information outreach have become essential aspects of health equity, as can be seen in <u>APHA's statement</u>. Future strategic planning must include these principles. NLM must also consider ways that current scholarly communication practices disadvantage historically underrepresented groups (such as non-English speakers and patient communities) and set up a plan to address these issues.

As librarians are the bridge between NLM and the world, there is an opportunity to work together with them to more effectively connect communities with NLM resources. NLM should also use this connection to address health information inequities, combat misinformation, and restore the public's trust in science, both within the United States and globally.

The key underlying theme of the strategic plan is that "the National Library of Medicine (NLM) envisions a future in which data and information transform and accelerate biomedical discovery and improve health and health care." Advances in technology provide an opportunity for medical libraries and Health Information Professionals to work with NLM to continue to play a key role in supporting the effective access to and use of the new tools and resources evisions in the Strategic Plan by the healthcare institutions and communities they support. The already strong relationships and cooperation between NLM and MLA and AAHSL need to continued to be developed and strengthened to enable medical libraries to be able to support the ambitious goals and services presented in the 2017-2017 Strategic Plan and this needs to be a major emphasis in the newly reconfigured Network of the National Library of Medicine.

One potential next step is for NLM to convene a cross-organizational libraries group including representatives from NLM, MLA, and AAHSL, to discuss how to coordinate efforts and work together, as

well to provide a forum for feedback that represents the diversity of our health information environments, such as hospitals, communities, higher education, and research settings.

The MLA and AAHSL Boards thank the following members for contributing comments to this RFI. Their comments reflect the breadth of knowledge, expertise and diversity of MLA and AAHSL's communities of practice and include: 25 members, two standing committees, 13 MLA caucuses, and the 2019 Michael E. DeBakey Fellow:

- Cristina Pope, AAHSL
- Chris Shaffer, Joint MLA/AAHSL Legislation Committee, AAHSL
- Don Jason, AAMLA, Clinical, Informationist Caucuses
- Sarah L. Carnes, Consumer and Patient Health Information Caucus
- Mary Katherine Haver, Consumer and Patient Health Information Caucus
- Susan Swogger, Collection Development Caucus
- Suzanne Duncan, Clinical Caucus
- Janet Hobbs, Curriculum Caucus
- Peg Burnett, Data Caucus
- Amy Lyons, Data Caucus
- Margaret Ansell, Governmental Relations Committee and Joint MLA/AAHSL Legislation Committee
- Michelle Kraft, Hospital Libraries Caucus
- Angela Spencer Hospital Libraries Caucus
- Helen-Ann Brown-Epstein, Hospital Libraries Caucus
- Virginia Pannabecker, International Cooperation Caucus
- Lilian Hoffecker, International Cooperation Caucus
- Mary Piorun, NNLM, Leadership and Management Caucus
- Sarah Wade, Nursing and Allied Health Resources Caucus
- Rachel Keiko Stark, Nursing and Allied Health Resources Caucus
- Lisa K. Traditi, MLA President
- Eleanor Truex, Nursing and Allied Health Resources and Hospital Libraries Caucuses
- Sylvia McAphee, Public Health/Health Administration Caucus
- Diane Schwartz, Research Caucus
- Catherine Pepper, Research Caucus
- Deborah West, Research Caucus
- Michael Kronenfeld, 2019 NLM Michael E. DeBakey Fellow