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8600 Rockville Pike
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Re: Request for Information (RFI): Strategic Opportunities and Challenges for the National Library of Medicine, National Institutes of Health

Dr. Flatley Brennan,

The University of Minnesota Health Sciences Libraries writes in response to the request for public comments on "The Strategic Opportunities and Challenges for the National Library of Medicine, National Institutes of Health," published on August 6, 2020. We are offering responses and recommendations aligning with the three broad areas of interest outlined in the RFI.

1. **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:**

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

   Corporate/health care partnerships, such as the recently-announced collaboration between the Mayo Clinic and Google,[1] aim to mine health data and surface information to solve complex health problems. These partnerships promise to shift the landscape of evidence-based health information and impact the way health providers and others access information to inform patient care and health decision-making, setting a potentially limiting precedent for private ownership of public/patient data. NLM has an opportunity to participate in, influence, and inform how these new models take shape, serving as an advocate for public access and other policies that will have lasting impacts on access to health information.

   NNLM has promoted citizen science through CE courses and resources offered in different NNLM regions, such as the NLM Resources for Citizen Scientists course.[2] Additionally, while NLM's All of Us program and their partnership with SciStarter are laudable, a centralized strategy around citizen science could both improve the success of individual initiatives and encourage broader, public participation in and understanding of science. Given their commitment to health literacy and consumer

[1] https://www.healthcareitnews.com/news/mayo-clinic-google-launch-major-new-10-year-partnership
[2] https://nnlm.gov/classes/national-library-medicine-resources-citizen-scientists

health information, and existing relationships with public libraries, NLM is well-positioned to provide leadership in this area.

B. Technology (including biotechnology, platforms, hardware, software, algorithms, processes, systems, etc.)

Researchers, clinicians, students, and information professionals engage with more systems today than ever before. Multiple systems are used for the collection, analysis, sharing and discovery of data and information sources, and these systems are often siloed and their outputs cannot be easily combined. NLM has made important contributions in this area through their role coordinating clinical terminology standards for HHS, facilitating the effective implementation of interoperable health information technologies and infrastructure. NIH's recent notice in support of the United States Core Data for Interoperability (USCDI) is a positive step towards interoperable data structures. NLM should consider how this work could be expanded upon, both in the case of clinical data, but also considering research more broadly. The rapid and continued increase in the number of data and information products, and the diversity of resources through which they can be found, poses challenges for consistent metadata standards. NLM may wish to consider how applications of blockchain technology and artificial intelligence could build upon standards to provide a consistent discovery experience at scale.

The range of resources and systems available poses challenges for discovery. NIH currently supports approximately 100 data repositories, while researchers may also make data available through generalist or institutional repositories, or through repositories supported by other agencies. A similar diversity of information sources is seen with research publications. While consolidation into a single repository would not be feasible given the diversity of objects and disciplines, shared standards, when broadly applied, could also facilitate the creation of discovery layers, which would streamline discovery and access for researchers and members of the public.

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

Health literacy has long been a focus of NLM, especially through NNLM programming. Recent shifts in data science / data communication indicate an ongoing need for health literacy training, highlighting a focus on data literacy and building public trust in science. Research shows that visual abstracts are more frequently requested by publishers for communicating research findings,[3] that physicians commonly use abstracts to answer clinical questions,[4] and that there is increased use of social media

[3] Ramos E, Concepcion BP. Visual abstracts: Redesigning the landscape of research dissemination. Semin Nephrol. 2020;40(3):291-297. 10.1016/j.semnephrol.2020.04.008

[4] Marcelo A, et al. A comparison of the accuracy of clinical decisions based on full-text articles and on journal abstracts alone: a study among residents in a tertiary care hospital. Evid Based Med. 2013;18(2):48-53. 10.1136/eb-2012-100537.

for research dissemination, continuing education, and public knowledge.[5] These findings, combined with evidence of "spin" in research titles and abstracts,[6] indicate the need for 1) increased data literacy skills and 2) increased skills related to the ethical representation of data and accessibility/design best practices as applied to data communication. NLM has the opportunity to focus on these two health literacy skills to ensure researchers will be able to share information in a way that is accurately presented for understanding and trust building for both health providers and the general public.

D. Library functions (including collection development, access, preservation, indexing, library metadata, service agreements with other libraries, etc.) (301 words)

Through DOCLINE and similar programs, NLM holds significant, valuable data that could provide insight into health information needs. While we fully recognize the importance of ensuring the privacy of individual patrons and institutions, we would encourage NLM to consider a formalized mechanism to facilitate data sharing at a more aggregated level. Such sharing would align with NLM's principles of open science while allowing libraries and researchers to gain insight into overall borrowing and lending patterns and information needs of the broad health sciences community. NLM may wish to consider establishing an advisory board and formalized policies and procedures surrounding these topics.

As libraries redesign and convert spaces from journal and book storage to spaces for users, the need for collaborative print programs at the regional and national level is increasing. The MedPrint program is the only national shared print program specific to health sciences libraries. The NLM and NNLM should expand this program to include titles and subject areas beyond the original 250 Abridged Index Medicus (AIM) list. While MedPrint's distributed model ensures that there are copies in the different regions, we encourage NLM to seek out partnerships with print depository programs, to remove the need for libraries to house and store these items on-site and allow them to deposit items in a shared print repository such as the Shared Print Repository of the Big Ten Academic Alliance.

The changing landscape, closure, and consolidation of health sciences libraries means that NLM's role as the world's largest and most comprehensive medical library is of continuing importance. The continued growth of health science and medical literature limit the capacity of libraries to collect and retain the array of resources their users need. More libraries will be turning to the collections at the NLM to provide access to resources their users need.

E. Modes of scholarly communication (including researchers' use of social media, preprints, living papers, changes in the roles and practices of publishers,

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[5] Ibrahim AM, Lillemoe KD, Klingensmith ME, Dimick JB. Visual abstracts to disseminate research on social media: A prospective, case-control crossover study. Ann Surg. 2017;266(6):e46-e48. 10.1097/SLA.0000000000002277

[6] Kinder NC, Weaver MD, Wayant C, Vassar M. Presence of 'spin' in the abstracts and titles of anaesthesiology randomised controlled trials. Br J Anaesth. 2019;122(1):e13-e14. 10.1016/j.bja.2018.10.023

data-driven approaches to studying historical medical texts, images, and datasets, etc.)

We commend NLM's commitment to open science and open access, and the work being done to promote open access to a broad range of scholarly outputs. The integration of datasets associated with PMC articles, the NIH figshare pilot, and the preprint pilot are all notable accomplishments that promote synchronous discovery of high quality research. While we fully recognize the challenges associated with facilitating the colocation and discovery of these works, we strongly support these efforts and encourage NLM to continue their commitment. NLM may wish to consider potential partnership opportunities and interoperability with existing repositories or other discovery platforms. This could include activities such as expanding upon the range of preprint servers whose content is eligible for inclusion in PMC.

NLM may wish to consider issues of health and science communication as a component of scholarly communication. Lay summaries, otherwise known as plain language summaries, are an increasingly common component of knowledge dissemination practices. While these have been common in systematic reviews produced by the Cochrane Collaboration and Campbell Collaboration, these lay summaries are now a requirement of all clinical trials sponsored in the European Union. The NLM, through its alignment with NIH, could contribute to and advance policy-related initiatives, such as the Making Research Accessible initiative (MRAi), which provides open access to research alongside plain language summaries and community-generated grey literature.

F. Perspectives, practices, and policies (including those related to open science, the need for diversity, equity, and inclusion in research, algorithmic bias, expectations of reproducibility of research, etc.)

Diversity, equity, and inclusion should intersect with and be at the heart of NLM projects and plans for the future. Historical medical collections housed at NLM should be expanded beyond a Western perspective to include historical health information from a diversity of cultures.

Data mining of health information will only help shift the balance of evidence-based medicine if enough marginalized communities are included in the data. Citizen science programs present a remarkable opportunity to reach out to marginalized and diverse communities and involve individuals in health and science research. Workforce efforts should focus on recruiting, training, and employing diverse candidates--which means that there need to be jobs available to new librarians when they graduate. NLM should seek out diverse groups to advise on strategic priorities to ensure all voices are heard.

As a public health resource, NLM and MedlinePlus should ensure that people from a diversity of backgrounds see themselves and their concerns represented. For example, a Google search for Kawasaki disease, which primarily affects boys of Asian descent, returns many stock images of white children; MedlinePlus has no stock images of this disease. Ehlers-Danlos syndrome is often underdiagnosed in BIPOC because pictures

readily available on the internet are overwhelmingly of white bodies; Genetics Home Reference and MedlinePlus both feature images of white bodies in their EDS articles.

Historically marginalized communities have a deserved distrust of health science research, public health, and the role of "the government" in health research. The promotion of All of Us and similar programs needs to take this distrust into consideration and actively work toward dismantling the systems that have created and upheld this distrust by taking concrete steps to reach out to and work with marginalized communities. Incidents such as the Tuskegee Syphilis Experiment do not exist only in the past; the recent allegations against ICE for performing sterilization procedures on immigrants in their care will stoke the deserved flames of distrust of healthcare providers.

The erosion of public trust in science and expertise is an ongoing challenge. We would encourage NLM to consider its role in being an organization that seeks to promote health literacy, trust in information, and trust in expertise. This aligns with NLM's mission of "enabling biomedical research, supporting health care and public health, and promoting healthy behavior." As an advocate for health information and consumer health, NLM should make diversity, equity, and inclusion issues an overarching theme in all aspects of NLM's purview.

G. 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.)

The NLM, via its NLM Associate Fellowship Program and NNLM funding, has the opportunity to build a more diverse workforce that is better equipped to address the NLM strategic goals related to data-driven research. Health information professionals are well-positioned to bring data communication skills to biomedical research and can enhance information dissemination strategies through that work. Library centered expertise in information organization, and data management, along with deep knowledge of the grants and scholarly publishing process, align with new and emerging data communication needs within the health sciences. Recruitment for the NLM Fellowship Program could be expanded to accept graduate students outside of an ALA-accredited program to bring a broader disciplinary perspective to the fellowship, which would allow representation from diverse backgrounds and underrepresented groups that are not heavily represented within library science. The NNLM could provide an infrastructure (via the Training Center, subcontracts, or a new center or approach) to support a cohort of data science fellows with diverse recruitment goals who would collaborate across the country to further the data services and training work of the NNLM, such as the the NNLM RD3: Resources for Data-Driven Discovery program.

2. 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.

The last decade has seen an erosion of trust in expertise and science in the minds of the American people. In 2019, a poll found that 17% of Americans agreed that the "idea

of a manmade global warming is a hoax intended to deceive people."[7] Fueled by groups on social media platforms like Facebook, these communities create, consume and share massive amounts of disinformation. Facebook communities have been shown to advance anti-vaccination messages at a higher rate than pro-vaccination groups,[8] thus potentially swaying undecided individuals with messaging placing individual rights over the need for a common good. Public health recommendations during the current COVID-19 pandemic to wear masks in public and maintain physical distancing have been met by scorn and derision by some Americans and some political leaders. Public health expertise and recommendations are being interpreted by some Americans as a path to totalitarianism such as in Idaho where a state senator claimed that "listening to experts to set policy is an elitist approach and I'm very fearful of an elitist approach."[9] Clearly, there is a need to counteract the levels of disinformation Americans believe about health topics and the degradation of 'expertise'. We see future roles for NLM as an advocate for expertise and trust in the science and research behind public health initiatives and actions. NLM could initiate activities via the NNLM to have librarians create communities in social media platforms that present evidence-based information on health science topics.

3. **Opportunities or challenges on the horizon over the next five years that fall within the purview of the NLM's mission**

The COVID-19 pandemic has caused massive disruptions for global economies. The US Congress supplied financial assistance in the spring of 2020 via the CARES Act and the Payroll Protection Program but since then Congress has not come to any resolution on expanding aid to either individuals or states. This lack of financial support will be extremely stressful to budgets at the state level and for municipalities and public institutions which rely on funding from the state. Public libraries, academic libraries at public colleges and universities, as well as hospital libraries that are supported by the state and/or cities, will have to face devastating budget choices that will result in closures, reduction of hours and/or services and staff contraction via layoffs. Health science libraries across the country may lose the ability to expand their scope of activities and engage in new endeavors.

NLM's role as the world's largest medical library will become increasingly important during this time, as limited budgets will likely lead to even greater interdependence between libraries. Specialized information resources, such as NLM Drug Information Portal, PillBox, and Genetics Home Reference, are important consumer health resources used by academic libraries, as well as in public libraries, medical libraries, schools, and by members of the public. Consideration of reduction of the number of these resources should carefully assess how such decisions may create additional financial burden for these groups, and whether such actions will disproportionately impact certain communities, such as rural communities or underserved populations.

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[7] https://www.theguardian.com/environment/2019/may/07/us-hotbed-climate-change-denial-international-poll
[8] https://www.sciencedaily.com/releases/2020/05/200513111440.htm
[9] https://www.boisestatepublicradio.org/post/idaho-lawmaker-listening-experts-elitist-approach-coronavirus-restrictions#stream/0