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Office of Health Information Programs Development
National Library of Medicine (NLM)

**Request for Information (RFI): Strategic Plan for the National Library of Medicine,
National Institutes of Health**

This Request for Information (RFI) from the National Library of Medicine (NLM) comes at an opportune moment to review the NLM's continued role supporting and promoting the use of findings from health services research (HSR). HSR builds on the foundations of basic, clinical, and population-based research to determine how best to deploy treatments and interventions to make health care safer, more effective, and more affordable as well as to promote health at the community level.

As we move into an era increasingly focused on generating new knowledge, whether on the effectiveness of a given treatment or in translating evidence into practice through 'learning health systems,' the field of HSR is integral to scientific efforts that not only create, but also draw upon a variety of open health data sources to improve health and health care.

As part of the National Institutes of Health's (NIH's) reflection upon the NLM's impact to date and its deliberation of where it should go in the future, AcademyHealth is pleased to have the opportunity to comment on the NLM's evolving efforts in:

- Bridging knowledge management and "big data";
- Supporting professional development of future leaders to manage a changing field;
- Exploring new frontiers related to open data use, open sources of data, and open source methodologies to support transparency, collaboration, and research reproducibility; and
- Setting an ambitious and inclusive agenda for translation and dissemination.

AcademyHealth commends NLM's ongoing commitment to the principles of open science, evidence-informed practice, and its leadership for promoting access to health research findings for an ever-expanding variety of audiences. As NLM continues to evolve as the "intellectual and programmatic epicenter for data science at NIH," AcademyHealth champions the NLM's efforts to continue carrying out its mission by supporting HSR and promoting the dissemination of HSR findings.



1. Role of NLM in Advancing Data Science, Open Science, and Biomedical Informatics

Identify what you consider an audacious goal in your area of interest – a challenge that may be daunting but would represent a huge leap forward were it to be achieved. Include input on the barriers to and benefits of achieving the goal.

An audacious goal for health research is reproducibility – the ability of a study to be duplicated and for its data to be shared and reused. Reproducibility in HSR is indispensable for rigorous findings that can inform improved functioning of health systems. Yet, the data, codes, and methodologies for many studies are often not accessible or transparent.

As a significant step forward for NLM in its mission to act as a “leader in efforts to support and catalyze open science, data sharing, and research reproducibility,” the NLM can address the challenge of reproducibility through:

- Engaging collaborative networks of researchers in projects that promote transparency;
- Promoting and actively encouraging free and open access to usable, high quality data within a user-friendly, technology-neutral interface;
- Encouraging code and data sharing for replicating studies and for training new researchers (e.g., by ensuring that stronger, more specific, language about data sharing is included in grants announcements and ensuring consistent application of this by NIH program officers); and
- Increasing access to metadata and data dictionaries.

The potential benefits of achieving this goal are substantial. Access to data and code can increase the rate of discovery in health care, particularly when focused on increasing patient centeredness, reducing disparities, and increasing comparative studies of the clinical effectiveness of new and existing therapies.

Furthermore, access to data and code can increase collaboration among researchers and clinicians across scientific and clinical disciplines and can increase the likelihood of dissemination of findings through multiple communications channels. In sum, NLM can serve as a bridge connecting health services researchers to usable, open data, and thus make it easier to connect decision-makers to curated, credible, and evidence-based health information.

The most important thing NLM does in this area, from your perspective.

NLM’s commitment to assuring open access to information is chief among its priorities in this space. Operationally, this involves: 1) efforts to support the principles of open

science, and 2) providing critical information resources. The NLM's efforts along these tracks will be of increasing importance as the volume of studies and variety of data sources outpace the ability of the research community to systematically review and synthesize health and health care studies using more traditional approaches.

NLM serves as the organizational leader and a major sponsor of research, development, training, and workforce development in data science, information science, biomedical informatics, and health sciences librarianship, all of which facilitate open science. Understanding trends in data management, curation, knowledge representation, analysis technologies, communications infrastructure, and the semantics and importance of new classes of health-relevant data will be essential to NLM's success in these areas in the future.

The NLM currently supports key resources that are critical for creating an open research environment. These include the Health Services Research Projects-in-Progress (HSRProj) database of the National Information Center for Health Services Research and Health Care Technology (NICHSR), which provides information on funded health services research projects before results are published in peer-reviewed journals. This database, in conjunction with other NICHSR resources like the Health Services Research Information Central (HSRIC) web portal, and the Health Services and Sciences Research Resources (HSRR) database, support open science and transparency in health services research funding through accessible information on funded research, data, and methods from the nation's major HSR supporters in both public and private sectors.

AcademyHealth encourages NLM to continue exploring new frontiers related to open data, open sources, and open methodology and to expand the number and types of communities of practice where open science is promoted and practiced. We also hope to see NLM support the development of new informatics-based approaches to synthesizing data in emerging areas of multi-sector research, including telehealth, community health, and population health systems research.

Research areas that are most critical for NLM to conduct or support data science, open science and biomedical informatics.

To advance the goal of reproducibility, NLM can support or conduct research:

- Demonstrating the value of data sharing and transparency in experimental methodology, observation, and collection and curation of data;
- Evaluating the difference in uptake of research findings in policy and practice by making scientific data publicly available and reusable;
- Communicating about research in accessible and transparent ways, including a greater emphasis and reliance on data visualization science;

- Strengthening the data infrastructure by creating and supporting web-based tools that facilitate collaboration among communities of practice; and
- Supporting fellowships and professional development opportunities that foster future leadership in data science, open science, information science, and data visualization science, ensuring that these also contribute to increasing the representation of under-represented minorities in all NLM sponsored activities.

Other comments, suggestions, or considerations for advancing data science, open science and biomedical informatics, keeping in mind that the aim is to build the NLM of the future.

The NLM has long been an intellectual leader for data science, including in both data and the peer-reviewed information resulting from data analysis in health services, health policy, and health systems research. To build the NLM for the future, the Library can play a unique and more visible leadership role in organizing and facilitating the accessibility of data and standardized coding as well as with open source algorithms and programs to help researchers do more in less time, allowing for their findings to have a greater, more timely impact on health and health care.

In the next stage of the NLM’s evolution, AcademyHealth and the field of health services research strongly support the Library’s mission “enabling biomedical research, supporting health care and public health, and promoting healthy behavior.” We encourage the NLM to maintain a broad vision to support all phases of the research continuum – basic, clinical, population-based, and health services research – and to ensure it reflects a broader range of research settings and lived experiences as well as systems thinking. As one example, we would like to see expanded consumer representation on NLM advisory boards and review committees, and to see more researchers from under-represented minority communities participating in funded research teams.

2. Role of NLM in Advancing Biomedical Discovery and Translational Science

Identify what you consider an audacious goal in your area of interest – a challenge that may be daunting but would represent a huge leap forward were it to be achieved. Include input on the barriers and benefits to achieving the goal.

Two audacious goals for NLM with respect to biomedical discovery and translational science include:

- Setting up and supporting a robust agenda for translation, dissemination, and implementation of research that builds on the NLM’s unique resources, such as PubMed; and

- Having a multi-sector, open access data commons that can accelerate the exchange and uptake of findings and the generation of new collaborative research questions.

There are two inter-related challenges to achieving these goals. They are:

- Knowledge curation and governance challenges due to the increasing amount of data and information in health and the increased number of data stakeholders; and conversely,
- Inadequate access to health data and information within specific communities and components of the health system, such as community and critical-access hospitals, and inadequate embedded research capacity to integrate, synthesize, and reuse clinical data.

For too long, we have known that it may take up to “17 years to translate 14 percent of published research to benefit patient care.” The NLM could embrace a goal to change this statistic to 5 years and 50 percent of research. The NLM stands to strengthen its position as knowledge curator by playing a greater part in ensuring that relevant, high-quality health data and information reaches those who need it through support for better resources for finding evidence and data in the public domain. In particular, we urge NLM to increase support for informatics training fellowships and to make a particular effort to include under-represented minority candidates.

The most important thing NLM does in this area, from your perspective.

The NLM is a global resource that supports and catalyzes health-related scientific discovery and the effective translation of new knowledge into practice. Integrated retrieval and analysis tools provide linkages that promote discovery across a wide variety of databases containing biomedical literature, genomic information, and many other scientific and clinical data sources. Novel translational resources, such as ClinicalTrials.gov, accelerate accrual to clinical research studies and promote scientific integrity via publication of study designs and research results. Researcher access to new classes of data, such as electronic health records, is supporting discovery science. Both curiosity-driven and translational science are expected to continue to evolve rapidly over the coming decade, and the NLM's role in promoting that infrastructure development is absolutely vital.

When it comes to advancing biomedical discovery and translational science, the NLM has the advantage of housing a wealth of resources and information from across the health system. It therefore has a distinct role to play in serving as a curator of synthesized information and as a convener in the dissemination of existing research and methods sharing to promote improved quality and applicability of research findings.

While the NLM has long served as curator of information, it should aim to strengthen its role, promoting knowledge and ensuring that relevant, high-quality health data and evidence reach those who need it by providing resources for the location and use of that data in the public domain; the NLM is well-positioned to direct people to the right places for accessing evidence and data that is of greatest use to them. For example, following its curation of new data resources, such as all-payer or partial-payer claims databases, the NLM could provide a clearinghouse that catalogs the content of these resources, the research and findings from them, and the information tools developed from this data, and direct consumers accordingly. Also wrapped into to this curation would be national and state health longitudinal surveys from the federal agencies that produce them. The availability and use of such data and evidence would promote improvements in both methods and application in the fields of health science and health systems research.

Specifically, the NLM has a unique part to play in developing more user-friendly tools targeted to health care delivery organizations as well as to policymakers. The creation of such tools would go a long way to improving ties with those audiences. The NLM may also wish to consider creating specific tools for assessing and understanding systematic reviews and meta-analysis, specifically focused on health care delivery, population health, and health care financing and policy topics.

As those working in health care delivery systems are confronted with increasing amounts of both traditional resources and emerging data sources (e.g., expanded claims data, electronic health records, and patient-generated and incidental data), there is greater opportunity for health services research. Sorting through these volumes of data and findings and assessing for research rigor can be overwhelming and time-consuming. Finding and synthesizing research relevant to a problem in practice requires a trusted curator of knowledge and information, and a bidirectional flow of data and evidence between research and action, and the NLM is well suited to fill this space.

Research areas that are most critical for NLM to conduct or support.

The NLM can build on its position in the center of a nexus of U.S. libraries and universities to synthesize and share ongoing and cutting-edge research on translation, dissemination, and implementation science, with priorities based on an assessment of various stakeholder needs.

Additionally, the NLM can identify and encourage partnerships and partnership models that have been shown to support more rapid translation and dissemination efforts. The challenge of translation, dissemination, and implementation is not unique to health science, and the NLM can partner with other science agencies (e.g., the National Science

Foundation, Environmental Protection Agency, and the Department of Education) to accelerate the development and deployment of successful innovations.

It is critical that the NLM allocate resources to both understand and support translation, dissemination, and implementation of the information housed at the NLM. Specifically, NLM can support research on questions such as:

- What factors accelerate the uptake of research findings from a repository at an institution like the NLM to policy and practice decision makers?
- How can usability problems identified by front-line staff be communicated to the NLM for the development of resources responsive to real needs?

3. Role of NLM in supporting the public's health: clinical systems, public health systems and services, and personal health

Identify what you consider an audacious goal in your area of interest – a challenge that may be daunting but would represent a huge leap forward were it to be achieved. Include input on the barriers to and benefits of achieving the goal.

An audacious goal related to the public good—and one of the preeminent challenges to achieving optimal health for all—is identifying what works for whom, and applying that information reliably to ensure high quality, effective care for all populations.

As part of the National Institutes of Health's (NIH's) reflection upon the NLM's impact to date and its deliberation of where it should go in the future, the NLM is presented with an opportune moment to fundamentally assess its approach to knowledge management and its access to scientific evidence, leveraging federal investment in health science and applying the advances that have been made in technology and information sciences in a way that benefits all Americans.

By bridging the gap between knowledge management and “big data,” the NLM would have the ability to assist decision makers in understanding bodies of knowledge and placing them in the appropriate context. In particular, the NLM can lay out an ambitious action agenda in partnership with the National Institute on Minority Health and Health Disparities (NIMHD) in support of the NIH Health Disparities Strategic Plan. Additionally, and aligned with the notion of patient-centeredness, the NLM may consider engaging lay persons from the community to influence efforts in how best to place and report findings that are of interest to the general population – e.g., specialized search (and auto updates) of research papers.

The most important thing NLM does in this area, from your perspective.

AcademyHealth recognizes the tremendous value the NLM offers for individuals who want to learn more about what affects their health and health care and for researchers who actively use evidence to inform and improve public health via programs and resources supported by the NLM. These programs and resources, such as NICHSR, HSRIC, and Public Health Partners (PHP) each have a unique role to play in lending evidence to inform critical public health efforts and for bringing stakeholders together in a forum-like setting to exchange knowledge.

At present, the public is largely unfamiliar with the vast resources available to them within the NLM; its familiarity with the NLM largely centers on its web resources, such as PubMed. Active promotion of the available resources and their use and application is an invaluable part of NLM's role.

Research areas that are most critical for NLM to conduct or support.

Advancing precision medicine requires achieving precision information and knowledge. Health services research and public health are critical elements of the NLM, and investments in this type of work are critical for the research enterprise.

The federal government supports different and equally necessary types of health research across a continuum, each of which plays an essential role in advancing evidence to improve health. Population-based research, or public health research, studies how to improve the health of the population by addressing and preventing injury, illness, and disease through non-medical means in communities where people live, work, learn, and play, while health services research studies how our health system works, how to support patients and providers in choosing the right care, and how to improve health through care delivery. In a world of multiple and competing information sources and increased access to open data, there is a need to help various users organize and contextualize sought-out information and to ensure it is of maximum relevance to their specific needs, across this continuum.

To that end, the NLM must actively work to reach communities through nuanced and creative mechanisms, such as behavioral targeting and working with private sector partners to ensure and enhance consumer engagement and get information into the hands of those who need it. It must also leverage information resources to enable researchers to reach those who do not have or have limited access to care. This includes the underserved, safety-net populations, communities of color, and low-income communities, where the burden of disparities is greatest. By housing algorithms derived to conduct analysis of behavior patterns, the NLM could improve researchers' and others' ability to understand elements of health behavior and what interventions might be most suitable for specific populations.

With new types of tools that use modern data, analytics, and search algorithms to search, filter, and organize evidence with an emphasis on usability, there are many opportunities for the NLM to achieve this end. The NLM should look to expand these tools and develop a research agenda and resources to understand which channels of information are most effective (e.g., pattern analysis) for disseminating information to certain populations. Knowledge management efforts should refine the use of data analytics to ensure that users can filter data relative to both their own characteristics and context. This will be especially relevant to minority populations in light of the dramatic changes occurring in how health care is financed, organized, and delivered.

By leveraging existing resources, considering behavioral patterns, and gaining a better understanding of what constitutes effectiveness of tools and presentation of information, the NLM will be better suited to use its resources to directly serve the American public.

Finally, it is of the utmost importance that the NLM continue its support for training, such as the National Network of Libraries of Medicine (NNLM), which is a significant source for training in informatics. This training ensures that researchers have a strong foundation in building the skill set required to make the most effective use of health informatics.

Healthcare systems and public health arenas in which NLM participation is most critical.

As a trusted public resource, several arenas would benefit from the participation of the NLM.

First and foremost, given its integrity, the NLM can promote the ideals of open science throughout the health system, as well as integrate its practice within the Library's own programs and resources. With more health data sources than ever before (e.g., EHRs, patient-generated data, etc.), it is clear that data is getting 'bigger.' However, big data can't translate to better health outcomes or more cutting-edge research unless that data is accessible and its translation into policy is encouraged and supported.

Through its role in information sharing, the NLM can help bridge the divide between public health and health care systems, which has existed for too long. This is particularly critical for less advantaged communities where the information infrastructure is particularly weak and providers and public health agencies cannot afford to invest in access to the vast amounts of biomedical information that is relevant to their populations.

The NLM's engagement is critical in facilitating evidence-based practice. While concepts such as the role of "informationists" (the growing profession comprising specialists in knowledge management and curation) have emerged, it is often unclear which clinical or

operational leaders are responsible for ensuring evidence-based practice and dialogue within a medical group or health system.

Promising models to look to could be the informationist movement, or greater involvement and partnership with other NIH institutes, such as the National Cancer Institute (NCI), which served as a host for the December 2016 9th Annual Conference on the Science of Dissemination and Implementation (D&I) in Washington D.C. Stronger partnerships and linkages with NCI and other institutes funding D&I research, for example, may be fostered through Request for Applications (RFAs) or fellowships to generate interest in, and a better understanding of, dissemination and implementation science. Such inter-institutional relationships and inter-agency agreements may facilitate resources and support a translation, dissemination and implementation research agenda using, for example, PubMed data.

Another approach might be to reach out to the NLM's previous informatics fellows, many of whom were the pioneers in their respective institutions, to identify ways they were able to promote adoption of new practices for collecting, curating, and working with clinical data. Indeed, the NLM could play a greater role in convening and supporting the cohorts of professionals that they are training and engaging through annual meetings and communities of practice. Peer to peer learning is an essential component of a strategy to accelerate the spread of new, effective approaches to knowledge curation and use in different contexts.

Finally, AcademyHealth strongly supports the use of intermediaries as a method for the NLM and National Network of Libraries of Medicine (NNLM) to help users and their networks develop skills to process information and use the NLM tools. Among these intermediaries are:

- Patient and engagement groups that could be leveraged to assist the NNLM with educational and design components of resources to ensure functionality and relevancy;
- Consumer health librarians, who can work not only to train health care staff in health literacy and consumer-friendly language, but who can also support patients by creating and disseminating relevant information, tools, and resources;
- Academic settings, hospitals, and community-based organizations, where lifelong habits of health and information-seeking behaviors are often encouraged; and
- State and local health departments, where the NNLM could act as an intermediary by increasing access and providing technical assistance to the literature with the goal of promoting evidence-based decision making.

4. Role of NLM in Building Collections to Support Discovery and Health in the 21st Century

Research areas that are most critical for NLM to conduct or support.

It is critical that the NLM support the advancement of emerging algorithms and resources that refine knowledge management and change the way that research is assessed. This involves advancing the development, curation, and dissemination and implementation of these tools and resources.

Knowledge management's role in building and aggregating information allows the scope of new resources and data to be readily comparable—both to what has been learned previously and to what information is already available. This role requires a sophisticated set of emerging resources and algorithms essential to the work of the Library in the coming decades.

Researchers need to be able to get beyond just using the data at hand in their institutions and easily identify the range of datasets available that best support analyses of their question. Such an ability to match the data to the question could dramatically enhance the scope, relevance, and impact of HSR.

To facilitate use of these and other new data types and collections over the coming decade, the NLM is in a unique position to lead the development of and help support a transparent management and curation system for the national health data infrastructure. The NLM's leadership role could involve many activities, including convening and/or participating in a federal inter-agency group that engages with private-sector standards development organizations, professional societies, and other stakeholders in a larger community of practice that already shares and standardizes data.

Additionally, as an increasing number of researchers seek to engage in data analytics projects, the NLM can support:

- Layered publication approaches: open access publications, access to data sets and methods to increase transparency in research; and
- Platforms for collaboration that foster diversity in research networks, enhancing the richness of research.

New data types or data collections anticipated over the next 10 years.

Over the past three to five years, there has been significant investment in data standards and patient-centered outcomes research (PCOR) data infrastructure. A continued focus on common data elements accompanied by guidelines on the preferred/suggested common data elements to use for certain research purposes will be critically important and – with much of the anticipated data types coming from personal health trackers and bio-

monitoring devices – should be expanded to include patient-generated data from mobile, wearable devices; video and image files; and other data sources and formats.

New data arrangements over the next 10 years will be collaborative and communicated creatively, as an increasing number of researchers seek to engage in collaborative data and analytics projects. Therefore, data and data sources must be accessible and findable for researchers, prioritizing patient-reported outcomes (PROs) and social determinants of health data. The need to advance and improve the collection of PROs data in the clinical workflow and for research purposes cannot be underestimated. Support for workflow studies involving process mapping and other “lean” tools is urgently needed, and clinical informatics researchers and other embedded health systems researchers and systems designers and engineers need to be trained in new methods to capture personal health data and to improve efficiencies in data collection.

Similarly, there should also be a national effort and action to incorporate new sources and more efficient collection of social determinants of health data into personal health records. We have seen patient/caregiver connectivity and data sharing around symptom management explode in highly capable registries. The NLM can have a role in marshalling these data and understanding needed policy changes to allow maximal use of such data. Advancing social networking methods to understand and track the data will be of value.