Request for Information (RFI): Information and Data Resources Needed by the Health Services Research Community for Research and Practice

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Purpose

This <u>Request for Information</u> is to solicit public input on future resource and program directions for the National Library of Medicine (NLM) support of information related to health services research, practice guidelines and health technology, including technology assessment.

Background

NLM is the world's largest biomedical library, established to "assist with the advancement of medical and related sciences and to aid in the dissemination and exchange of scientific and other information important to the progress of medicine and the public health."

Since the early 1990s and the establishment of the National Information Center for Health Services Research and Health Care Technology (NICHSR), NLM has taken steps to ensure that its general activities and its core collections of journals, journal articles, books and manuscripts reflect the current state of health services research (HSR), including practice guidelines and health technology and technology assessments. Additionally, NLM has developed specialized products targeted toward the HSR community. These resources were designed to address challenges in accessing certain information understood to be needed by the health services research community: the academicians, clinicians and other health professionals engaged in conducting, disseminating, or implementing health services research, including the public health workforce.

Information Requested

NLM seeks input from all participants and disciplines of the health services research community, regardless of previous engagement with our products.

We invite your comments in the following areas:

1. Products that NLM currently offers in the areas of health services delivery or health services research.

- 2. Information types necessary for your organization to successfully support health services research or public health.
- 3. Tools, resources, or health services literature that are the most critical for NLM to collect or support.
- 4. Any other comments that would enable NLM to support future work related to the delivery of health services, or health services research.

Medical Library Association and Association of Academic Health Sciences Libraries Comments

Submitted November 20, 2020

Your organizational affiliation

Medical Library Association and Association of Academic Health Sciences Libraries

Your role (public health officer, researcher, etc.)

MLA Director of Information Issues and Policy

NLM seeks input from all participants and disciplines of the health services research community, regardless of previous engagement with our products.

For recommendations you make, please consider indicating appropriate objective success criteria, including quantitative and qualitative benchmarks and milestones for gauging progress in the corresponding area.

Products that NLM currently offers in the areas of health services delivery or health services research

Health search research products are hard to find, especially as more products are created and they are not easily accessible/discoverable. NLM must increase its efforts to market their HRS products and services; one way to do this is by partnering with relevant professional associations. Marketing also needs to incorporate feedback from users, responsively making changes to products to meet evolving user needs.

There currently is no good discovery tool for the end user that assists them in finding what they need quickly and easily. A topical listing of resources is not helpful; there needs to be a high-level summary of NLM's health service research resources and services. A FAQ page also would be a valuable tool for some users. NLM also needs to consistently communicate about changes to the availability of its resources; for example, as temporarily available information is withdrawn by publishers as the pandemic begins to resolve, NLM should make efforts to communicate this with users.

In Healthy People 2020, NLM contributed search hedges to facilitate finding literature relevant to the objectives. Healthy People 2030 has not been updated with search hedges, which were an important tool used by both researchers and librarians to keep up to date with the progress made on these objectives.

Information types necessary for your organization to successfully support health services research or public health

Specific types of information valuable to health services research include health service usage data, more detailed patient demographics and the ability to interconnect and cross-compare demographics with usage data, as well as sociodemographic data. These types of data are useless unless connections can be made between them. For example, providing connections between pockets of data from Healthy People 2030 to All of Us data.

To do this, we need built-in relational databases that users can query easily through a web interface. Especially helpful would be GIS-specific data where you can search based on geographic location. Ideally, researchers need a clearinghouse for health service research information that runs across agencies. NLM should partner with DHHS and other agencies to make resources like health.gov more usable/searchable, and to incorporate information from MedlinePlus, PubMed, Public Health Partners, and AHRQ across various resources and platforms. The lack of collaboration between these agencies creates redundancy in health research information tools and wastes taxpayer funds. Interoperability between information resources is a key aspect of making these efforts successful.

Some previously-existing useful products were developed, but later eliminated, not out of obsolescence but due to lack of marketing within user groups and general awareness of their existence. Health sciences librarians should not bear the burden of being NLM's sole marketing arm, while we are happy to share and teach about NLM products, we can more easily do so if NLM has marketing resources readily available for us to disseminate.

To make this resource more useful for the public, MLA and AAHSL recommend increasing the number of public health Information resources in many languages and making graphic health information materials available for populations with low literacy and/or visual learner.

Information has gone beyond the realm of journal literature. NLM can harness journal table of contents sections, association or foundation webpages for gray literature, perhaps from some of the health service-oriented organizations formerly followed by New York Academy of Medicine's quarterly Grey Lit Report http://www.greylit.org/publishers/list.

MedlinePlus is a good model for how to pull together curated literature; why can't they move faster into new areas of publishing ("accelerating discovery")? Preparing searches is frustrating and slow.

Tools, resources, or health services literature that are the most critical for NLM to collect or support

MLA and AAHSL recommend that NLM include or expand resources in the areas of women's health; health service disparities and diversity; race and disability; rural and urban areas; osteopathic medicine; and physician assistant and nursing.

We also recommend the inclusion of white papers and reports on health economics, including data on health service costs, insurance and various payer types, health care personnel incentives, and supply/demand economies of scale. This should also include conference products (such as posters, papers, proceedings) discussing experiments and models of cost reduction methods that minimally impact quality of care. Other resources should include news and drafts or revisions to state and federal policies, regulations, executive orders that affect the delivery of health services, medical device information and litigation, drug approvals, fact sheets on continuity of care.

Additional research included should be studies on implementation science as applied to health service issues, as well as additional or expanded statistical data, and more clinical trials data related to people of color and other diverse populations. While there is a lot of information out there, it is hard to find and work through.

We recommend that NLM create a single portal that searches for information in NICHSR OneSearch (Health Services Research Projects in Progress), <u>HSRR</u> (Health Services and Sciences Research Resources), and <u>HSRIC</u> (Health Services Research Information Central). This would serve as a one stop collection of open access/publicly- and freely-available health services research information, since much of this type of information is behind the paywalls of professional organizations or hospitals and the rest is so scattered that it is time-consuming and frustrating to locate.

MLA and AAHSL recommend that NLM expand the availability of training products such as those at https://www.nccmt.ca/knowledge-repositories/public-health-plus.

The COVID-19 pandemic revealed new information needs related to health services, in particular as a result of the rampant misinformation that spread in public and news sources. It would be helpful to have one central repository for all information related to COVID-19. Perhaps this portal could lead to pages or sections on different aspects of health services, such as personnel management, supply & demand, and quality improvement regardless of specific health condition

Addition of information and resources about what to stock up on during rationing of supplies due to COVID-19 and how many months to prepare for (e.g., prescribed medicines).

One Health

MLA and AAHLS recommend that the NNLM should consider addressing the relationship between humans and animals or One Health (https://www.cdc.gov/onehealth/basics/index.html), and within that context, veterinarians who often have no information resources. While the Centers for Disease Control and Prevention has some materials and education on this topic, the CDC does not have the reach of the NNLM to provide education and provide a concentrated training in these vital issues.

Current areas where NLM could help support services, resources and training include providing more educational material on <u>zoonoses</u> which is the Infectious diseases spread from animals to humans. "6 out of every 10 infectious diseases in humans are spread from animals." https://www.cdc.gov/onehealth/index.html;

NLM could also provide resources about mental health and the human-animal bond (e.g., health advantages to having pets or companion animals, reluctance of people to take advantage of social services such as shelters because of bond to animals that cannot also be accommodated e.g., homeless shelters, evacuation shelters) http://dx.doi.org/10.1186/s12888-018-1613-2; http://dx.doi.org/10.1371/journal.pone.0179494; and

MLA and AAHSL also recommend working to provide information services on One Health to veterinarians, public health providers and epidemiologists (especially in rural populations). With these services tied to libraries they can provide resources and training to help educate populations on food supply contamination, antimicrobial resistance, zoonoses, and medical physicians and other healthcare practitioners who may not be as well trained in zoonoses or parasitology.

Any other comments that would enable NLM to support future work related to the delivery of health services, or health services research

NICHSR contains a wealth of information, data, and policy related information but it is not easily accessible.

NLM's 2017-27 Strategic Plan states "Achieving this vision will require NLM to refocus and enhance its research, development, training, and information services to make more biomedical data findable, accessible, interoperable, and reusable, to invent the tools and services to turn data and information into knowledge and insight". This is another way of saying we are seeking support in the realm of Data Science and the diverse components that the domain captures.

NLM needs solid, long-term financial commitment to the technology and personnel so that it can build, maintain, curate and update the final product, particularly if the US moves toward greater use of health technology assessments and in light of healthcare reforms possibly stemming from the US experience of the pandemic.

Integration of Products through a single discovery interface

The resources and data provided by NICHSR are a prime example of the importance of expanding NLM's integration of different types of information into an accessible and convenient discovery interface. There are several different ways in which this integration can take place:

- Developing data driven KBI/information/data systems and tools to organize and integrate traditional and new data sets and formats to accelerate discovery in the digital era.
- Integrating health services research curated literature queries (such as those based on the Healthy People 2030 objectives) into PubMed's search filters. Health services research could be a subject filter similar to the AIDS or cancer subsets. This addition would result in enhanced support for health services research.
- Increasing discoverability of health services research tools through search engine optimization, to increase the relevancy ranking of these products in general search engine results.
- Health Services Research project connection to published articles in PubMed

Communicating the Value of HSR Products to a Variety of Users

MLA and AAHSL believe that expanded, targeting marketing could have a significant valueadded effect on the overall status and recognition of NLM's contribution to the field of health services research.

The MLA and AAHSL Board of Directors thank the following members who provided comments for this RFI:

MLA/AAHSL Volunteer Workgroup:

- Maggie Ansell, Cochair, Governmental Relations Committee; Joint MLA/AAHSL Legislation Committee member
- Michelle Kraft, Hospital Libraries Caucus
- Michael Kronenfeld, 2019 Michael DeBakey Fellow
- Sylvia McAphee, African American Medical Librarians Alliance Caucus
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- Deborah West, Research Caucus