Re: 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)

(* = Required fields)

* Name of Organization

AcademyHealth

* City and State

Washington, D.C.

Comment 1

Current NLM elements that are of the most, or least, value to the research community (including biomedical, clinical, behavioral, health services, public health, and historical researchers) and future capabilities that will be needed to support evolving scientific and technological activities and needs.

AcademyHealth commends the National Library of Medicine’s (NLM’s) commitment to the principles of open science. In particular the NLM is a recognized international leader in promoting open access to health research. These efforts will be of increasing importance as the research community continues its efforts to expand the knowledge base surrounding health and health care. Despite challenges to ensuring open access to the findings of federally-funded research, AcademyHealth strongly supports this role and encourages NLM to continue exploring new frontiers related to open data, open source, and open methodology.

Advancing precision medicine requires achieving precision information and knowledge. Health services research and public health are key 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 the 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 the sought-out information and to ensure it is of maximum relevance to their specific needs, across this continuum.

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, NLM is presented with an opportune moment to fundamentally assess its approach to knowledge management and the 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.
Comment 2

Current NLM elements that are of the most, or least, value to health professionals (e.g., those working in health care, emergency response, toxicology, environmental health, and public health) and future capabilities that will be needed to enable health professionals to integrate data and knowledge from biomedical research into effective practice.

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

Health services researchers, public health researchers, and health care practitioners each value the availability and organization of information from NLM to ensure we can answer the right questions related to the service and delivery of this care; it is through this evidence and information that we can use and improve evidence-based decision making. 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. 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 resources and algorithms that is emerging. The NLM could play a key role in advancing the development, curation, dissemination and implementation of these tools and resources. In a similar vein, the National Network of Libraries of Medicine (NNLM) is a significant source for training in informatics. NLM’s support for its ongoing training mission is important; this training ensures that researchers have a strong foundation in building the skill set required to make the most effective use of health informatics.

Comment 3

Current NLM elements that are of most, or least, value to patients and the public (including students, teachers, and the media) and future capabilities that will be needed to ensure a trusted source for rapid dissemination of health knowledge into the public domain.

The academic enterprise, though a critical for research and the dissemination of this work, has a dominant, singular approach to assessing scholarly contributions by traditional bibliometric methods, such as the Citation Impact Factor, which represents the average number of citations received per paper published in the past two years in the Journal Citation Reports. Reliance on such measures has ossified academic incentives for promotion, tenure, and advancement to these high ‘Impact Factor journals,’ which are often not the best venue for reaching those audiences best-suited to take action. A broader set of metrics are needed to recognize and value scholarly contributions, publications, and other modalities of translation and dissemination that advance the performance of the health care system and improve health.
Comment 4

Current NLM elements that are of most, or least, value to other libraries, publishers, organizations, companies, and individuals who use NLM data, software tools, and systems in developing and providing value-added or complementary services and products and future capabilities that would facilitate the development of products and services that make use of NLM resources.

AcademyHealth recognizes the tremendous value NLM contains for individuals who want to learn more about what affects their health and health care. However, at present, the public's familiarity with NLM largely centers on its web resources, such as PubMed.

In order to extend beyond its current audience, NLM must leverage information resources to reach those who do not have or have limited access to care: the under-served, safety-net populations, communities of color, and low-income communities—those where the burden of disparities is greatest. NLM should continue to explore nuanced and creative ways of reaching communities, such as behavioral targeting and working with private sector partners such as Google ensure and enhance consumer engagement and get information into the hands of those who need it.

Similarly, by housing algorithms derived to conduct analysis of behavior patterns, NLM could improve researchers’ and others’ ability to understand elements of health behavior and what interventions might be most suitable for specific populations. We encourage the NLM to support the introduction of new types of tools using modern data analytics and search algorithms to search, filter, and organize literature, with an emphasis on their usability. 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. In other words, 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 health reform.

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 NLM tools. Among these intermediaries are: (1) Patient and engagement groups that could be leveraged to assist NNLM with educational and design components of resources to ensure functionality and relevancy; (2) Academic settings, hospitals, and local health departments, where lifelong habits of health and information-seeking behaviors are often encouraged; and (3) State and local health departments, where 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. By leveraging existing resources, considering behavioral patterns, and gaining a better understanding of what constitutes effectiveness of tools and presentation of information, NLM will be better suited to use its resources to directly serve the American public.
Comment 5

How NLM could be better positioned to help address the broader and growing challenges associated with:

- Biomedical informatics, “big data”, and data science;
- Electronic health records;
- Digital publications; or
- Other emerging challenges/elements warranting special consideration.

“Big data” is an important scientific frontier and presents an important opportunity for NLM not only to support the development of emerging methods, but also to facilitate the sharing and archiving of data for studies that use complex longitudinal data. Achieving the goals of precision medicine will entail broader access to big data researchers can use to understand interactions across biological, social, and environmental systems, including: genomics, epigenomics, environmental impacts (e.g., stress and the built environment), and clinical care.

There is support for research to maximize the use of health information technology (e.g., mHealth and electronic health record data for precision medicine) to fill current gaps in support for research ranging from clinical to health services research. The NLM should focus on increasing open access to data and methods for health care delivery research to promote transparency and reproducibility, as well as encourage multidisciplinary collaboration across the research continuum. A particular focus on the use of electronic health record (EHR) and mobile health data is warranted, especially as these data and methods relate to federal data sources and trial data.

The NLM should also consider providing assistance for research to better understand clinical decision support. In these efforts, AcademyHealth encourages NLM to play an ongoing role in developing and maintaining systems to ensure the credibility as well as appropriate academic credit for data sets or products of research in addition to just the research findings.

If you have any questions about these comments, please don’t hesitate to contact Dr. Lisa Simpson, President & CEO, AcademyHealth at lisa.simpson@academyhealth.org.