

**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)**

**Comments of the Medical Library Association**

**March 13, 2015**

The following comments were developed by a broad cross section of MLA members currently serving on the Board of Directors, Governmental Relations Committee, Joint MLA/AAHSL Legislative Task Force, Scholarly Communications Committee, and representatives from the Consumer and Patient Health Information Section, Hospital Libraries Section, Medical Informatics Section, Nursing and Allied Health Resources Section, and Public Health/Health Administration Section, including

Maggie Ansell, Sandra Bandy, Linda Hasman, Cynthia Henderson, Emily Hurst, Barbara Jones, Claire Joseph, Andrea Ketchum, Michelle Kraft, Kay Hogan Smith, Jean Song, M.J. Tooley, Emily Vardell, and Linda Walton, Drew Wright. Kevin Baliozian and Mary Langman provided staff support.

**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.*

The provision of free access to health-related information for the research community is critically important for future health care outcomes. Committing resources to sustain and further enhance access to medical data and literature ensures that scientific research will continue to advance health care and health outcomes through innovation and discovery.

The most fundamental and valuable research tools and resources are the National Library of Medicine's (NLM's) more than 200 databases that are freely available to libraries, research institutions and organizations. Examples include PubMed, PubMed Central, PubMed Health, that specialize in systematic review and clinical effectiveness research, GenBank, and Genetics Home Reference. In addition the Lister Hill Center for Biomedical Communications (LHNCBC), an Intramural Research Division of NLM, continues to make strides to provide access to research data and innovative tools. An important focus of the LHNCBC is the development of Next Generation electronic health records (EHRs) to facilitate patient-centric care, clinical research, and public health. Lister Hill Center also does research on natural language processing, image processing, and vocabularies/terminologies that support many of NLM's products and services and EHR use.

The National Center for Biotechnology Information (NCBI) also is part of NLM, and advances science and health by providing access to biomedical and genomic information through its

databases, which include GenBank, PubMed, NCBI Epigenomics, and most recently ClinicalTrials.gov. NCBI's latest efforts to link data through their databases allows researchers to more quickly and easily to find connections and make cross-disciplinary connections. The growth rate of medical literature and data is unprecedented. Without NCBI's tools and databases, efficiently searching these data would be impossible for the research community. Online, in-person, on-demand, and just-in-time learning options allow NLM to ensure the research community has the necessary training to use the myriad of available resources.

Clinical research data are a key component of precision medicine. Through collection and analysis of data from resources such as the Database of Genomes and Phenomes, ClinVar, and the Genetics Testing Registry, as well as ClinicalTrials.gov, NLM is poised to provide clinical research specialists with the data needed to target treatment to patients' individual needs. Using NLM's Unified Medical Language System, clinical data can be captured from within the EHR. Enhancing clinical EHR use of NLM resources puts high-quality information into the hands of researchers. Further linking behavioral data with health outcomes may help researchers better understand the impact of health disparities and provide solutions that will benefit the population at large.

The mission of NLM's National Information Center on Health Services Research (HSR) and Health Care Technology is to improve the collection, storage, analysis, retrieval, and dissemination of HSR results. Researchers depend upon HSR data, tools and statistics, and guidelines that support access to comprehensive, science-based information on common, costly medical conditions and new health care technologies, and contribute to the information infrastructure needed to foster patient record systems that can produce useful health services research data as a by-product of providing health care.

Public health researchers have NLM to thank for more than thirty-five databases including but not limited to: American Indian Health, Arctic Health, Asian American Health, and HealthReach (quality multilingual health information for those providing care to speakers of languages other than English). NLM's databases that provide just-in-time information to support public health and first responders during times of disaster, environmental, and toxicology emergencies include Chemical Hazards Emergency Medical Management, Integrated Risk Information System, International Toxicity Estimates for Risk, Radiation Emergency Medical Management, and the Wireless Information System for Emergency Responders. Key databases that positively affect public health are: Household Products Database (safety and health information for products used in and around the home), Tox Town (an interactive guide to toxic substances and environmental health issues in everyday places), and TOXMAP (geographic representation of toxic release inventory data). These databases are essential for the continued research, education, and support functions of those involved in public health, including state and local health departments. In addition, the Outreach and Special Populations Branch works to improve access to accurate, quality health information by underserved and special populations. NLM's Disaster Information Management Research Center (DIMRC) provides online and downloadable resources that support emergency preparedness initiatives, and just-in-time, targeted resources to support response and recovery efforts during times of natural, accidental, or deliberate disasters. Public health researchers benefit from the Partners in Information Access for the Public Health Workforce portal. A collaborative effort that could not have been achieved without NLM's

support, the Partners website provides convenient access to select resources and is updated frequently by NLM. The public health research community benefits daily from using the myriad of resources provided in the portal.

Clinical research scientists also benefit from NLM's strong array of resources such as ClinicalTrials.gov. As more emphasis is placed on the development and use of clinical trials it is important that NLM have the necessary fiscal and human resources to maintain a robust database of results information that provides clinical scientists with access to complete and transparent results of all clinical trials. MLA strongly supports approaches that will enhance the transparency of clinical trial results reporting and provide clinicians and biomedical researchers with access to results information about efficacy, adverse effects, and safety, as well as information on research design, safety, and scientific results that can inform future protocols and discoveries. MLA also supports timely, easily understood, and accurate reporting of all clinical trials, especially those supported by federal funding, regardless of agency and phase of the clinical trial. The new NIH Proposed Rulemaking for Clinical Trials Registration and Results under the Food and Drug Administration Amendments Act and the draft NIH Policy on Dissemination of NIH-funded Clinical Trials Information will strongly further the accomplishment of these goals.

A recent study published in the *New England Journal of Medicine* addressing the lack of compliance in results reporting in ClinicalTrials.gov has drawn national attention to the importance of results reporting as well as the unfortunate lack of compliance that is being seen in this area [1]. Additional training and stronger enforcement of rules related to clinical trial results reporting will ensure that more results data are captured and made freely available to clinical research scientists and patients. The growing importance of data in clinical research deserves further exploration by NLM.

For historical researchers, NLM's History of Medicine Division collects, preserves, provides access to and interprets a vast collection of historical resources on disease and human health. There are over 100,000 images dating from the 15th century to the 21st century. The more than 600,000 printed works include pre-1914 books and serials, thousands of pamphlets and dissertations, and pre-1871 journals, about 200 pre-1601 Western and Islamic manuscripts, and more than 7,000 catalogued films and video recordings, 900 of those titles date from before 1950. Increasing access to and preserving historical materials is an important role for NLM. Today's technology allows digitization of both print and 3-dimensional materials. Ensuring free and open access to historical materials related to health sciences facilitates scientific research and inquiry.

As the historical record can greatly impact medical practice, it is important for NLM to continue to digitize and provide access to these historically significant collections. For example, NLM's digitized collection of public health resources related to the AIDS epidemic has positively impacted current research and assisted researchers in better understanding the history of this disease. In addition, NLM's collection of historical research related to tropical diseases provides both historians and researchers with a broad historic overview of the impact of these diseases and a better understanding of techniques modern medicine could employ in their eradication. As we have observed today with ongoing outbreaks of measles, the diseases of the past can still wreak havoc on modern society. NLM's digital collections help both the public and research

community to better understand the severity of diseases and help forge new methods of treatment and prevention that will ensure the health and safety of the whole population.

As interdisciplinary research becomes more and more the norm, and as the National Institutes of Health (NIH) moves to support translational research, NLM will continue to be a linchpin in the provision of vital research information that is freely available to anyone with Internet access. Future capabilities that will be needed to support evolving scientific and technological activities and needs include, but are not limited to: accelerating the ability of NLM to combine research results, scientific data, and health information with EHRs; increasing digitization of rare books, manuscripts, pictures, and historical films; enhancing the linking of behavioral data with health outcomes to help researchers better understand the impact of health disparities and provide solutions that will benefit the population at large; and continuing to be a leader in making information accessible through mobile devices.

[1] Anderson ML, Chiswell K, Peterson ED, Tasneem A, Topping J, Califf RM. Compliance with results reporting at ClinicalTrials.gov. *N Engl J Med.* 2015 Mar 12;372(11):1031-9. Internet. <http://www.ncbi.nlm.nih.gov/pubmed/25760355>.

## **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.*

NLM's educational programs and training for librarians and other information professionals literally save lives.

There can be no more dramatic example of this than the 2001 Johns Hopkins' tragedy where an otherwise healthy twenty-four-year old volunteer in an asthma study died needlessly as a result of inhaling hexamethonium because the lead researcher had failed to adequately research the chemical's potentially fatal effects. A reporter asked "Could librarians have prevented a death?" [1]; the answer is a resounding "YES." The US Office for Human Research Protections (OHRP) found that the needed information was "readily available via routine MEDLINE and Internet database searches," [2], sources that librarians would automatically utilize.

NLM has developed and continues to develop databases that span the health sciences and related fields. The databases are of exceptional quality and apply to a variety of disciplines. NLM should continue to envision the continuing need for health information while incorporating technological change to provide researchers, clinicians, educators, librarians, and the public with the health information each needs.

Through the National Network of Libraries of Medicine (NN/LM), NLM provides a variety of services that assist many populations in the use of the databases they produce. NN/LM provides

education to health professionals, educators, public health workers, students, and librarians that enable them to use the databases in an efficient and effective way. These training programs are formal and informal, synchronous and asynchronous; they are all valued and valuable. The 8 regions of NN/LM evaluate their programs individually; in the MidContinental Region – states of Missouri, Kansas, Nebraska, Colorado, Wyoming and Utah – the significant focus is on service to librarians, and in the past 3 years, 2,201 librarians, 270 health professionals, and 194 patients and members of the public have taken classes. In the MCR, at least 90% of the class attendees have ranked the class as meeting or exceeding class objectives. The NN/LM also provides education through exhibits at national and local conferences, in an atmosphere where questions can be addressed individually and many professionals can be impacted in one visit. Often at both national and local exhibits, NN/LM personnel will present a paper or class at the attached conference. They are available for consultation and one-on-one brief education moments with conference attendees at the exhibit booth. With outreach programs and funding, the NN/LM extends its reach into the community, working with a large variety of community groups to incorporate high-quality health information into local programming. These educational programs are still desperately needed as an alarming 2009 study of 1,900 physicians found that 50% used Wikipedia to answer health questions [3]. Research studies have shown that a majority of health care professionals do not have time to seek information, and that searchers find what they need less than 50% of the time [4], and that Google and other Internet search engines access only 7% of available health-related information [5].

NLM provides other educational programs through the National Training Center (NTC), which trains librarians across the country, both in person and online, on the use of PubMed and the toxicology databases. These training programs are widely attended, are high quality and provided free of charge. NLM also collaborates with the Medical Library Association (MLA) to provide continuing education for health sciences librarians.

Another example of the great impact that NN/LM funding and resources make on medical libraries, health information professionals, and patient care outcomes is demonstrated by the research study, “The Value of Library and Information Services in Patient Care: Results of a Multisite Study.” [6] The NN/LM, Middle Atlantic Region formed a planning group in 2007 to explore the possibility of replicating a landmark study on the value and impact of hospital libraries on clinical care, popularly referred to as “the Rochester study” [7]. The Rochester Study was among the first to relate information services provided by librarians to patient care outcomes, and it has continued to be cited as evidence of the value and impact of library services. Since that time, several more studies have been published that address the value of library resources to health care providers in two mid-continental states; the return on investment in Department of Veterans Affairs (VA) libraries; clinical librarians at the point of care, and the impact of librarian-provided information in primary care. [6] Without support from NLM and the NN/LM, these studies may not have occurred and provided data that supports the value of information and information services that librarians provide.

For the future, we recommend that NLM:

- Focus on resources for health care providers
- Focus on resources for patients and families
- Incorporate health literacy practices into consumer-related products so that even the lowest reading levels can benefit from the product
- Continue to add foreign language translations into databases
- Continue to provide information on clinical failures as well as successes
- Continue vigorous support of open access policies
- Continue to produce supporting materials for database users, trainings, documentation, etc.
- Continue to work toward resource inclusion in to the electronic health record
- Support efforts to determine the effect of evidence and information on patient safety, diagnosis, and quality improvement
- Improve funding to promote resources and their appropriate use for health care

In the future, NLM also should support the role of the health sciences librarian in the process of disseminating and obtaining needed evidence and information. The volume of literature published and the complexity of the evidence/information landscape makes a navigator/librarian a valuable asset to a health care environment. Librarians' skills can find needed information in a timely manner that does indeed save lives [1, 3].

1. Perkins, E. Johns Hopkins' tragedy: could librarians have prevented a death? [Internet] [cited 5 Mar 2015] <http://newsbreaks.infotoday.com/NewsBreaks/Johns-Hopkins-Tragedy-Could-Librarians-Have-Prevented-a-Death-17534.asp>.
2. Office for Human Subject Protection (OHRP) suspension letter to Johns Hopkins University 2001 Jul 19:2. [http://ohrp.osophs.dhhs.gov/detrm\\_lettrs/july01a.pdf](http://ohrp.osophs.dhhs.gov/detrm_lettrs/july01a.pdf). [cited in Savalescu J, Spriggs M. Current controversy: the hexamethonium asthma study and the death of a normal volunteer in research *J Med Ethics*. 2002;28:3-4.
3. Comer B. Docs look to Wikipedia for condition info: Manhattan Research [Internet] New York, NY: MM&M Medical Marketing and Media; 21 Apr 2009 [cited 4 Nov 2010]. <<http://www.mmm.online.com/docs-look-to-wikipedia-for-condition-info-manhattan-research/article/131038>> Cited in Kupferberg N, Protus BM. Accuracy and completeness of drug information in Wikipedia: an assessment *J Med Lib Asso*. 2011 Oct;99(4):310-13.
4. Feldman S. Enterprise search technology: information disasters and the high cost of not finding information. *Portals Mag* 2004:27-28.
5. Henderson J. Google scholar: A source for clinicians? *CMAJ*. 2005;172(12):1549-50.
6. Marshall JG, Sollenberger J, Easterby-Gannett S, Morgan LK, Klem ML, Cavanaugh SK, Oliver KB, Thompson CA, Romanosky N, Hunter S. The value of library and information services in patient care: results of a multisite study. *J Med Lib Asso*. 2013 Jan;101(1):38-46. <<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3543128/>>.
7. Marshall, JG. The impact of the hospital library on clinical decision making: the Rochester study. *Bull Med Lib Asso*. 1992 Apr;80(2):169-78. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC225641/>.
- 8.

- 9.
- 10.
- 11.

### **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.*

In a health care system that demands a great deal from patients and family caregivers in terms of navigating that system as well, as asserting oneself in working with health care providers to obtain optimal care, programs and services for consumers of all levels are vital. NLM serves patients and the public by providing a wide array of health information meeting the need for improved patient-provider health communication, health literacy, and patient engagement to achieve improved health outcomes and greater efficiency. Other benefits include student exposure to health careers, and educator and entrepreneur access to ongoing health sciences research and data.

Current NLM programs/resources that support these demands and are of the most value to the public include:

- MedlinePlus – Free consumer health information gateway site receiving over 1 million visits per day with links to reliable health information on over 900 topics from diseases and wellness to drugs to procedures and tests, in English, Spanish, and 40 other languages, including easy-to-read materials. It includes a mobile version for smartphones and other devices. *MedlinePlus* magazine, in print and online, is free through doctors’ offices, community centers, and libraries, and reaches over 5 million readers nationwide. MedlinePlus is a primary resource for librarians serving the public with health information requests around the country.
  - MedlinePlus patient-centered information contributes to improved patient-provider health communication, health literacy, and patient engagement.
  - MedlinePlus is the most efficient solution for the HITECH Act Stage 2 Meaningful Use Core Objective, “Engage Patients & Families/Patient-Specific Education Resources.” It also offers MedlinePlus Connect, technology linking patient portals and electronic health records (EHRs) to consumer health information.
- NLM funds outreach projects to connect health practitioners and the general public with the health literature it collects, organizes, and provides. NLM works through community organizations, libraries, and its National Network of Libraries of Medicine (NN/LM) to reach underserved populations with reliable health information and give their health care providers the resources and skills they need to practice evidence-based medicine. NLM’s outreach projects place special emphasis on the needs of minority and other underserved populations and their health care providers, empowering patients and caregivers to make

informed medical decisions about their health. Unaffiliated health professionals, and health professionals in urban and rural areas rely on NLM to provide resources and training to promote evidence-based practice. A few examples of recently funded NLM outreach projects include:

- *A Day in the Life, Mapping Project* is a collaborative project with the University of Chicago, Rush University Medical Center, University of Illinois at Chicago, Loyola University, Midwestern University, and Southern Illinois University. The study investigators will gain an understanding of ethnographic methods used at the University of Rochester Libraries and their applicability to health sciences libraries. The findings will provide insight for future review on how and how well the library is meeting the current needs of fledgling practitioners and what additional resources and services are needed to support a clinician's health practice.
- Librarians at the Ebling Library, University of Wisconsin-Madison participated in a major collaborative effort with UW Health Integrative Medicine and the Veterans Health Administration to identify, review, and provide access to the core research (evidence) for 25 common conditions, as well as the inclusion of integrative approaches that could be utilized by VHA physicians and others to treat their patients.
- The University of Colorado Health Sciences Library has worked with Health and Human Services Region VIII and the Office of Civil Rights to develop health information literacy training, programming, and outreach to Colorado health care providers working with underserved communities. Health Sciences Library staff has also served numerous years on the planning committee for the Culture of Data Conference, which convenes hundreds of community providers and advocates, state and federal health officials, students, and community members to discuss the role data play in addressing health disparities and improving health and well-being across communities.

Other valuable programs and resources include:

- Personal Health Record (PHR) Project: Aims to set standards, identify best practices, and provide an open source platform for this patient tool. Linked to an EHR, a PHR improves health literacy and engages patients and their families with their health care.
- PubMed: One of the largest, most frequently consulted online scientific medical bibliographic databases in the world, it is accessed by patients, the media, students, and commercial entities as well as researchers for a variety of purposes. Open access publishing has made more full text available immediately, as well as linkage to PubMed Central, making PubMed increasingly effective for rapid dissemination of health knowledge.
- PubMed Health: Reviews of clinical effectiveness with summaries targeting consumers, PubMed Health educates the public on the science of medicine, promoting understanding and critical thinking in evaluating medical advances and media coverage of the same.

- PubMed Central: NLM's web-based repository of full-text biomedical literature provides free access to more than 43 million journal articles. PubMed Central supports the NIH Public Access Policy, which results in an additional 80,000 NIH-funded articles per year. It serves over 1 million different users each day who download over 1.65 million articles. The materials available through PubMed Central at no cost support patient searches as well as student, media, commercial, or other research.
- Rotating NLM exhibits: Focusing on the history of medicine, health care and the arts, social issues such as HIV, and technology, the excellent travelling exhibits that NLM allows local libraries to schedule promote interest among the public and increase visitors to the libraries that sponsor the exhibits. NLM online exhibits may continue the interest in issues, or online multidisciplinary K-12 exhibits may excite and encourage a new generation to study the sciences.
- ClinicalTrials.gov: The world's largest clinical trial registry and results database, is currently used by over 55,000 different users every day and provides patients with information on more than 185,000 clinical studies of drugs, biological products, medical devices, and other interventions. The consumer-friendly website was initially created in 2000 to give patients easier access to clinical trials and remains the most advanced, accurate resource for clinical trial information for the public and professionals everywhere.
- The Biomedical Informatics Course: A week-long, residential course in biomedical informatics hosted by the Georgia Regents University Robert B. Greenblatt, M.D. Library, partnering with NLM in a multi-year contract. The purpose of the course is to familiarize individuals with the application of, and policies related to computer technologies and information science in biomedicine and health care. They will learn skills to apply informatics solutions to current challenges in research, practice, and education. The program is directed at biomedical educators, medical librarians, medical administrators, faculty, and others who are not currently knowledgeable but can become agents of change in their institutions. It is held twice a year and is open to all US citizens and US permanent residents.
- The University of Iowa Hardin Library for the Health Sciences: In collaboration with the University of Iowa Obstetrics and Gynecology Department (OB/GYN) and the Pediatrics Department located at the University of Iowa Hospitals and Clinics, the university is conducting a two-year study to increase the understanding and appreciation of women's health and wellness research, and to help build a well-trained, diverse, and vigorous women's health research workforce at the university. The Hardin Library staff has partnered with faculty members of the OB/GYN and Pediatrics Departments to develop a three-pronged approach to increase awareness of and access to quality information on sex and gender differences research. The components of the approach include online and didactic instruction for residents in women's health research, journal clubs for discussion of evidence-based medicine for women's health, and outreach to Iowa health

professionals and consumers regarding quality women's health information through exhibits at conferences.

We recommend support for the following needs to further future capabilities:

- Increased promotion of MedlinePlus: Engage local media via news releases detailing new features, programs and success stories.
- Budget support for unfunded mandates such as ClinicalTrials.gov: Increasing interest among patients for participation in clinical trials as well as the needs of researchers for qualified participants makes this resource a natural target for much-needed investment.
- Financial support for regular updates and further development of specialized filters for PubMed such as filters for clinical specialties, updates to current filters, creation of additional subsets of interest to public sectors.
- Support for collaboration with the public to produce digital methods of information dissemination, such as the Show Off Your Apps competition in 2011, which invited innovative use of NLM open data. This produced 5 winning mobile apps and 5 honorable mentions.
- Increased promotion of MedlinePlus Connect: A key component of the EHR, strengthening patient access to appropriate health information.

#### **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.*

NLM has a vested interest in training the next generation of health sciences library leadership. The Associate Fellowship program trains recent library graduates to become leaders in the field and boasts an extensive list of alumni who now serve as leaders from their local libraries to the national level. The one-year Associate Fellowship hosted at NLM provides an in-depth look at the myriad of services provided by the NLM, preparing associates to go out into the health sciences field as advocates of quality health information. In addition, the biomedical informatics short course program educates librarians, researchers, statisticians, and bioinformaticians at many career stages with a focus on diversity in recruitment. These programs play a strong role in the development of biomedical scientists and health informatics leaders. They offer intense, high-quality education and training on cutting edge resources and research, as well as provide networking opportunities to ensure that participants remain up-to-date and competitive in the changing health care landscape.

Thanks to collaboration between the National Network of Libraries of Medicine (NN/LM) and the Medical Library Association (MLA), librarians now are able to equip themselves to serve

populations whose needs have previously been unrecognized or underserved. Through the MLA/NLM Spectrum Scholarship, NLM supports minority students seeking a career in health sciences librarianship so that every perspective is given a voice, and every population has an advocate in the health information field. The continuing rise and development of consumer health requires that librarians used to serving clinicians understand the unique resources and information needs of the general public. Certifications programs like the MLA's Consumer Health Information Specialization encourage librarians to pursue advanced training in this much-needed area. By offering credits toward certification through the NN/LM's freely available online classes, the CHIS program makes it possible for librarians throughout the country to obtain the training they need to serve their users regardless of their location or funding availability. In addition, recent natural disasters have revealed a need for reliable information and communication in times of public health crisis or disaster, and once again collaboration between NN/LM and MLA have created an opportunity for librarians and health information professionals to step in and serve in this capacity through the Disaster Information Specialization program.

In addition to creating and managing dozens of databases on a broad range of health and bioscience topics that are essential to the work of researchers, clinicians, and the general public, NLM has developed tools that make integrating these databases into other products simple. Over two dozen application program interfaces <<http://www.nlm.nih.gov/api/>> are available free to organizations and individuals so that the most recent disease, drug, treatment, and trial data can be incorporated into any health sciences technology. In addition, NLM maintains a searchable database of resources <[https://wwwcf2.nlm.nih.gov/nlm\\_eresources/eresources/search\\_database.cfm](https://wwwcf2.nlm.nih.gov/nlm_eresources/eresources/search_database.cfm)> designed to be used by web developers and programmers, with filters such as encoded data, datasets, and utilities. Tools like this are essential to disseminating the latest research and validated health tools to the public through whichever product they choose. These tools are particularly crucial because of the NLM's status as the clearinghouse for all publications that must be available to the public as a result of the NIH public access policy.

### **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.*

As the technologies required to perform the most basic health services advance by leaps and bounds, NLM must continue to be poised to stand as a publicly-minded advocate for underserved

populations as well as an impartial adviser to the organizations who will be creating tomorrow's health service tools. Two areas in particular deserve the NLM's attention and resources: the expansion of biomedical informatics and data science through the Big Data to Knowledge (BD2K) initiative and the standardization and development of EHRs.

In describing the role of the BD2K initiative

([http://bd2k.nih.gov/about\\_bd2k.html#sthash.d0DBgte9.dpbs](http://bd2k.nih.gov/about_bd2k.html#sthash.d0DBgte9.dpbs)), the National Institutes of Health says:

“It is believed that the ability to harvest the wealth of information contained in biomedical Big Data will advance our understanding of human health and disease; however, lack of appropriate tools, poor data accessibility, and insufficient training, are major impediments to rapid translational impact. The NIH BD2K initiative addresses four major aims that, in combination, are meant to enhance the utility of biomedical Big Data:

- To facilitate broad use of biomedical digital assets by making them discoverable, accessible, and citable.
- To conduct research and develop the methods, software, and tools needed to analyze biomedical Big Data.
- To enhance training in the development and use of methods and tools necessary for biomedical Big Data science.
- To support a data ecosystem that accelerates discovery as part of a digital enterprise.” [1]

As a critical component of NIH, NLM has the expertise and skill needed to put BD2K into reality. With the proper resources, NLM can build tools including metadata structures and citation analysis protocols, develop a training program, and embed BD2K tools and resources within the already established NLM directory of resources so that Big Data can be discovered and used to enhance research.

Thanks to financial incentives and strong government support, the widespread implementation of EHRs in hospitals is rapidly becoming a reality: as of 2013, 59% of hospitals have established a basic EHR program, compared to 9% in 2008 [1]. However, as EHR use has risen, so certain challenges to using them have become apparent. A lack of standardization beyond the widespread use of certain commercial products such as EPIC has created barriers to clinical data exchange, an essential part of today's health care system. As the central coordinating body for clinical terminology standards within the Department of Health and Human Services (DHHS), NLM has the expertise required to support the development and updating of data-entry standards that can be implemented across all EHR systems. Standardized EHRs facilitate HIPAA-compliant, up-to-date clinical data exchange between health care providers, ensuring that clinicians have access to all the information they need to provide safe and effective clinical decision making and care. NLM works closely with the Office of the National Coordinator for Health Information Technology (ONCHIT) to support ongoing development and updating of standards to reflect new drugs, tests, and changes in biomedical knowledge and health practice—

and allows them to be used free-of-charge in US systems that support health care, public health, and biomedical research. NLM's Value Set Authority Center, developed in collaboration with ONCHIT, the Centers for Medicare and Medicaid Services, the HHS Office of the Secretary, and others provides authoritative access to the standard vocabulary components of clinical quality measures. With the support of NIH, the barrier to patient safety that lack of standardization presents can be overcome with the enforcement of basic quality and safety standards.

In addition, NLM can support the increased practice of evidence-based medicine through the development of a standardized clinical decision support tool connected to patient EHRs. MedlinePlus Connect is an example of the kind of quality product that NLM can create. In the future, NLM should support the creation of a free evidence-based medicine (EBM) gateway to facilitate clinician searching using pre-defined strategies similar to the PubMed's Clinical Queries. While there are EHR-integrated commercial clinical decision support (CDS) tools available to healthcare providers, the lack of standardization and cost prevent widespread adoption beyond medication safety tools. As the expert body in both data standardization and evidence-based medicine, NLM is an integral part of the ongoing effort to create a free, trustworthy, integrated CDS tool. Future efforts will require NIH's advocacy of basic CDS quality standards as NLM makes advances in this area.

1. DesRoches CM, Charles D, Furukawa MF, Joshi MS, Kralovec P, Mostashari F, Worzala C, Jha AK. Adoption of electronic health records grows rapidly, but fewer than half of U.S. hospitals had at least a basic system in 2012. *Health Affairs*. 2013;32(8):1478-85.