



November 6, 2020

Patricia Flatley Brennan, R.N., Ph.D.
National Library of Medicine, National Institute of Health
8600 Rockville Pike
Bethesda, MD 20894

Re: Response to RFI on Information and Data Resources Needed by the Health Services Research Community for Research and Practice.

Dear Dr. Brennan:

AcademyHealth welcomes the opportunity to provide input on the information and data resources provided by the National Library of Medicine (NLM) and the National Information Center for Health Services Research and Health Care Technology (NICHSR). We are the professional home of health services researchers, policy experts, and practitioners from public and private sectors, and we strongly support the production, dissemination, and use of evidence to inform policy, practice, and research.

The products produced and managed by the NLM are a critical foundation of our efforts to develop, disseminate, and implement health services research. Databases and services such as PubMed, Bookshelf, MedlinePlus, and ClinicalTrials.gov are regularly used by health services researchers to identify trends and patterns in research funding; investigate current research in areas of national interest, including health disparities and social determinants of health; design health system improvements based on best practices; and build resiliency and capacity of the information infrastructure as our country navigates through the greatest public health crisis in modern history. NLM operates as an honest broker of data for health services research, and in doing so adds significant value to researchers, practitioners, and funders who work to strengthen our data infrastructure and enable the elimination of health disparities in access and outcomes and the delivery of high value care and curated health information to patients and consumers.

Question One: Products that NLM currently offers in the areas of health services delivery or health services research.

The National Library of Medicine provides a suite of services and products that provide unique and significant value to health services research and healthcare delivery.

ClinicalTrials.gov and PubMed are two of the most widely used and essential tools facilitating transparency and openness within health services research. We believe that ClinicalTrials.gov would benefit from continued development to allow (if not require for Applicable Clinical Trials) uploading of full protocols and statistical analysis plans—ideally using structured fields as with its study registration and results submission functions. In our view, PubMed would benefit from including links to versions of manuscripts on pre-print servers under the “Full Text Links” section of a search result (e.g., osf.io/preprints/). NLM should also consider whether entries to pre-print servers specific to biomedical research (e.g., <https://www.medrxiv.org/>) should be listed as stand-alone entries within PubMed itself.

NLM should also explore expanding the registration functionality and discoverability of HSRProj (Health Services Research Projects in Progress) to the standard of ClinicalTrials.gov (e.g., structured fields with sufficient data to assess changes from protocols and analysis plans in final manuscripts). NLM could also



include entries from repositories of data, code, and materials used in health services research (e.g., https://www.nlm.nih.gov/NIHbmic/domain_specific_repositories.html) as results in PubMed searches.

As discussed in the August 2020 NLM Town Hall, HSRProj serves as an essential source of information for researchers to identify areas of innovation in health services research; to identify and foster collaboration with investigators whose research is in progress; and to help them stay current with COVID-19 non-clinical research investments, particularly in examining the disproportionate impact of the pandemic on Black and minoritized communities.

In addition, the “Healthy People 2020 Structured Evidence Queries” are a useful tool for health promotion specialists in health services and systems research. These structured evidence queries should be updated to reflect the recently launched Healthy People 2030 objectives.

Question Two: Information types necessary for your organization to successfully support health services research or public health.

The availability of information on quality measures and evidence-based practice are incredibly important to organizations involved at all levels of health care delivery. The information is not only key for improving patient outcomes, but also in research and testing novel approaches to care delivery. Additionally, establishing definitions and quality standards for data elements and outcomes measurements, including patient reported outcomes, would assist in standardizing and improving research impact.

NLM can also serve as a clearinghouse and organizer of health-related data to make clear the vast array of available datasets. Today, data previously not thought of as health-related are used in a range of studies, such as purchasing, social media, housing and environmental data to name just a few. It is nearly impossible for an individual investigator to be aware of, let alone easily use, these new sources of relevant information. As a component of this clearinghouse role, NLM could provide metadata on each to educate users as to the data’s scope, quality, and validity.

The NLM Value Set Authority Center (VSAC) is playing an important role in national collaborations to standardize the codes used to assess social determinants of health screening and assessment in community and clinical settings (e.g., SIREN, Gravity Project). This vital work at the intersection of healthcare delivery and public health will help to provide a foundation for standardized and structured data that improve health outcomes and community health, are useful for public health planning, and will improve the availability of standardized data for health services research in the future.

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

The COVID-19 pandemic has exposed the stark weaknesses in our public health infrastructure and our health care system – especially the deep and deadly disparities in health outcomes and undervalued health data infrastructure. Systemic racism and socioeconomic inequities directly lead to underserved communities that experience poorer health, more toxic environments, and deep disparities in care. The only way to identify and create strategies to eliminate these disparities is through robust data collection and timely health services research. NLM has an essential role to play by collecting information on health equity, health disparities, and structural racism in medicine.

At the same time, the response to the COVID-19 pandemic has varied dramatically by state and locality, with inconsistent quality and types of data available to public health leaders at the state level. NLM could support more rapid and shared learning across states by collecting and showcasing innovative approaches, cases studies, and surveillance and analytic approaches.

NLM has long focused on the training and career development of a range of professionals through its fellowships, classes, webinars, and resources for educators. Health services research has the opportunity to adapt and adopt new methods from other fields as well as increase our collective capacity to use data ethically and without bias. Health services research is the evidence base for clinical, systems, and policy decisions. Through training and capacity building, NLM can help HSR eliminates bias in research designs, data, methods, analysis, and interpretations.

NLM can also strengthen its dissemination efforts and increase public awareness and visibility of its tools, resources, and literature pertaining to public health systems research and evidence-based practice in healthcare delivery. Educational tools and outreach about health services research to non-researchers could be valuable, and NLM has the credibility to be a key leader of these efforts.

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

AcademyHealth believes that NLM has a comprehensive and deep source of quality resources for health services researchers, but more could be done to inform potential users of what is available and to improve the user experience. Increasing the visibility of the offerings by improving the appearance and navigability of tools, and highlighting and marketing examples of how the data, tools, and statistics available from NICHSR could be used to improve public policy and practice would have a significant benefit for researchers and practitioners.

For further comment, clarification, or inquiry, please email Josh Caplan at Josh.Caplan@AcademyHealth.org.