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August 7, 2024

The Honorable Chair Cathy McMorris Rodgers
House Energy and Commerce Committee
215 Rayburn House Office Building
Washington, DC 20515

The Honorable Chair Robert Aderholt
House Appropriations Subcommittee on Labor, Health and Human Services, and Education
H-307 The Capitol
Washington, DC 20515

Re: Reforming the National Institutes of Health: Framework for Discussion

Submitted electronically via NIHReform@mail.house.gov.

Dear Chairs Rodgers and Aderholt,

The American Medical Informatics Association (AMIA) appreciates your interest in improving NIH and especially appreciates your call to scientists, researchers, and patient advocates in your June 14 opinion piece, *NIH needs reform and restructuring, key Republican committee chairs say*, to partner with you as you work to better the NIH.¹ **AMIA is responding to that call now by asserting the need to consider and protect informatics research funding in any potential NIH reform.** More specifically, AMIA encourages the preservation of the National Library of Medicine (NLM) and informatics training and research.

AMIA is the professional home for more than 5,500 informatics professionals, representing frontline clinicians, researchers, public health experts, and educators who bring meaning to data, manage information, and generate new knowledge across the research and healthcare enterprise. As the voice of the nation's biomedical and health informatics professionals, AMIA plays a leading role in advancing health and wellness by moving basic research findings from bench to bedside, and evaluating interventions, innovations and public policy across care settings and patient populations.

As your proposed Framework, *Reforming the National Institutes of Health* ("Framework"), recognizes, the National Institutes of Health (NIH) is the primary federal agency responsible for conducting and supporting medical, health, and behavioral research and NIH plays a vital role in training and funding biomedical researchers, collection and dissemination of health information, and collaboration with the private sector to drive scientific advances. NIH is the largest public funder of biomedical research, supporting hospitals, medical schools, universities, and other

¹ Rodgers, CM and Aderholt, RB. (June 14, 2024). *NIH needs reform and restructuring, key Republican committee chairs say*. Stat+. <https://www.statnews.com/2024/06/14/nih-restructuring-proposed-by-top-congressional-republicans/>.

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research institutes conducting vital work to care for Americans. With a rapidly aging population, nationwide clinician shortage, and the mainstream implementation of Artificial Intelligence (AI) tools in provision of care and medical innovation, NIH needs resources and support now more than ever. Informatics is a key component of the healthcare industry and many of our members work closely with the NIH as research grantees; experts on the collection, analysis, dissemination, and bedside application of health information; and members of the private sector that collaborate with NIH. As such, AMIA has a vested interest in the Framework's recommendations and aims to help your offices effectively improve the NIH by providing feedback.

AMIA Feedback to the Framework

Overall, AMIA encourages Congress to move forward with some of the recommendations outlined in the framework that focus on improving and modernizing the NIH, as these are two goals we should be prioritizing in all branches of government. AMIA encourages you to maintain the NLM, rather than consolidating it with two other institutes under the "National Institute of General Medical Sciences", as its work cuts across all other ICs with its mission of enabling biomedical research, supporting healthcare and public health, and promoting healthy behavior by acquiring, organizing, preserving, and providing free online access to scholarly biomedical literature from around the world. NLM does not serve a particular disease or disability, but medical information, as does informatics.

AMIA's specific feedback to the Framework follows.

- (1) The final paragraph of the "Background" section states:

The NIH must be committed to strategically supporting our nation's role as a leader in Scientific research and discover and medical innovation while remaining fully accountable to taxpayers. *Stonewalling, deceit, and refusals to cooperate with congressional investigations and abide by important laws, such as the Freedom on Information Act (FOIA), is inconsistent with accountable government.*

This portion cites two reports on investigations into one institute with NIH – the National Institute of Allergy and Infectious Diseases. Given the concern is with one institute, this should not be stated as an NIH-wide issue or cited as a reason to cut 12 institutes within NIH.

- (2) The Framework recommends a complete and comprehensive review of the NIH. AMIA strongly encourages that this recommendation be updated to require an unbiased review of NIH's performance, mission, objectives, and programs by including scientific professionals and patient advocates who regularly work with the NIH be included as part of the review board. This will ensure that the review board will have the scientific and medical education, background, and experience required to understand NIH's national biomedical goals and what the NIH is (or is not) doing to accomplish them. Including such people will also ensure that the review board has real, day-to-day experiential knowledge of working with NIH.
- (3) The Framework recommends introducing term limits for Institute and Center (IC) leadership. AMIA encourages you to consider that, in addition to possibly accomplishing

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your goal of reducing a stagnant culture, this may also force someone out who is doing a great job in their position and adapting to changing workplace cultures.

- (4) AMIA applauds the recommendation to eliminate silos between ICs. AMIA encourages Congress to allocate additional resources specifically dedicated to the production of the reports and the related work required to increase transparency and IC coordination.
- (5) The Framework recommends a restoration of Congress's role in directing funding. AMIA discourages Congress from moving forward with this recommendation, as Congressional leaders will not have the expertise required given their focus on so many other national issues and issues that are close to their home constituents. Rather the review board that includes scientific professionals and patient advocates may review any funding concerns that are noted in the biennial reports.
- (6) Regarding the Framework recommendations concerned with foreign entities, AMIA encourages you to consult the AMIA [comments](#) in response to the DOJ's ANPRM on Americans' bulk sensitive personal data and government-related data by countries of concern.

Preserve the National Library of Medicine

NLM already cuts across all the ICs and does not need to be consolidated further. The NLM has been in position in some of form since 1836, giving it an invaluable historical understanding of the development of the American medical system, peer-reviewed medical research, and the status we hold as one of the world's leading medical innovators. NLM is currently the world's largest biomedical library² and their databases are highly regarded.³ NLM created and maintains three of the best medical databases. NLM introduced MEDLINE, clinicaltrials.gov, PubMed, and PubMed Central (PMC), all of which provide access to nearly 40 million biomedical literature citations that are regularly used by clinicians, researchers, and the public to better understand cutting edge research and care options for American patients. These databases house information from the mid-1900s and clinicaltrials.gov, PubMed, and PMC are free resources. This vast collection biomedical knowledge is unparalleled and consolidating NLM into a more generic institute will deplete the resources needed to maintain these databases, including the free access to them. American healthcare and healthcare information needs to be more accessible to the people, not less.

In addition to the maintenance of these massive medical resources, NLM has always been on the forefront of finding new ways to deliver medical knowledge to those who need it – researchers, clinicians, and patients – whether it was by indexing journals on a book shelf, publishing Index Medicus, providing librarians a way to search for citations electronically, delivering journal articles to resource poor areas through Grateful Med, collecting toxicology

² *National Library of Medicine*. USA.gov. <https://www.usa.gov/agencies/national-library-of-medicine#:~:text=The%20National%20Library%20of%20Medicine,preserving%2C%20and%20communicating%20health%20information>.

³ *A guide to the NLM Databases*. Wolters Kluwer. <https://www.wolterskluwer.com/en/expert-insights/a-guide-to-the-nlm-databases#:~:text=The%20databases%20of%20the%20National,regarded%20indexes%20of%20biomedical%20literature>.

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information for disaster workers, imaging every cubic millimeter of two human bodies, and more. NLM continues to push forward by archiving algorithms for the research record, in addition to data, articles, images, audio, and videos that chronical the progression and treatment of various diseases. It is not just the resources that may be lost – it is the ability to innovate to deliver new ones.

NLM directly supports the careers of our members, which ultimately advances healthcare and access by the American patient population, in countless ways. A few examples are:

- 1) Current grants investigate large scale changes in our healthcare system and how the changes affect the provision and access to care in our nation. One such grant is the This NLM R01 grant [Assessing the Effect of Telemedicine on Physician EHR Work Cognition, and Process Outcomes \(ASPIRE\)](#) grant. This grant allows the grantees to generate rapid evidence on how the fast, large-scale shift to telemedicine caused by the pandemic impacted physician Electronic Health Record (EHR) work. Gathering this evidence will result in EHR design recommendations to accommodate today's reality of physician work schedules that feature a mix of face-to-face and telemedicine visits. This single grant tackles several major themes in healthcare today, including health data privacy, patient access to healthcare, and clinical burnout.
- 2) Direct patient care. In the pre-internet days, the literature resources in patient care settings were largely unavailable, out of date, or difficult to access in a timely way during patient visits. With NLM's massive online databases, our members can access the latest medical literature to support clinical decision making. For example, when an AMIA member leader built one of the first Web-based patient record systems at Columbia Presbyterian Hospital, he used NLM resources to link patient data to information resources that brought knowledge to point of care. The NLM's Unified Medical Language System enabled him to translate patient data into search strategies and PubMed provided the ability to automatically execute those strategies to bring medical literature to the exam room.

Thank you for your consideration of these comments. If you have questions, please contact Reva Singh, AMIA's Vice President of Public Policy, at rsingh@amia.org. AMIA would be thrilled to serve as a resource as you continue to consider your plans.

Sincerely,

Genevieve Melton-Meaux, MD, PhD, FACMI
AMIA Chair/President

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