April 9, 2021

Michael Lauer, MD
Director
Office of Extramural Research
National Institutes of Health
9000 Rockville Pike,
Bethesda, Maryland 20892

Re: Request for Information (RFI): Inviting Comments and Suggestions to Advance and Strengthen Racial Equity, Diversity, and Inclusion in Biomedical Research and Advance Health Disparities and Health Equity Research

Director Lauer:

The American Medical Informatics Association (AMIA) and its Diversity, Equity and Inclusion (DEI) Task Force are pleased to provide input on NIH's vitally important endeavor to improve racial and ethnic diversity and inclusivity of research environments and the biomedical research workforce across the United States.

AMIA is the professional home for more than 5,500 informatics professionals, representing frontline clinicians, researchers and public health experts who bring meaning to data, manage information, and generate new knowledge across the health 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 settings and patient populations. AMIA not only counts biomedical informatics researchers among its membership, but informatics tools – many pioneered by our members – are well-suited to monitor DEI trends of interest and recommend areas for intervention.

As NIH itself confirmed a decade ago, grant applications submitted by African-American/Black principal investigators (PIs) are less likely to be funded than those submitted by white PIs.[1] Although NIH has made some improvements in this, and other DEI-adjacent areas, these have been primarily incremental.[2] We were thus pleased with Director Collins' recent acknowledgement[3] of the inadequacy or NIH's efforts to improve diversity and new commitments to make more data about the demographics of extramural grantees and NIH staff

[1] https://science.sciencemag.org/content/333/6045/1015
[2] https://diversity.nih.gov/sites/coswd/files/images/docs/ACD_2019_June_13_Valantine_Wilson_FINAL.pdf
[3] https://www.nih.gov/about-nih/who-we-are/nih-director/statements/nih-stands-against-structural-racism-biomedical-research

publicly available, appoint diversity officers at each NIH institute and center, and improve outreach about NIH's diversity training programs.

We are further pleased with the RFI's commitment to identifying, developing, and implementing strategies that will allow the biomedical enterprise to benefit from a more diverse and inclusive research workforce and a more robust portfolio of research to better understand and address inequities in NIH's existing system. We strongly urge NIH to truly seize this opportunity to operationalize these commitments. There are myriad, concrete actions that we propose NIH to adopt that can help it deliver on these commitments and fundamentally alter the structure of the biomedical research funding and workforce environment.

Create new funding opportunities for DEI research. Structural racism impacts not only physical and mental health, but the nation's economic and democratic processes and institutions. The cross-cutting nature of racism and inequity demand more support for the science of this persistent confounder of health outcomes and contributor to human suffering. NIH must thus create new funding opportunities for DEI research that seek to engage those who fall outside of the traditional biomedical researcher paradigm. Given the overlap of DEI issues and healthcare, it is more important than ever for NIH to explicitly recognize the science of DEI and its impact on health outcomes. Sociologists, economists, social workers, ethicists, philosophers, and patients, for example, also have unique perspectives that can inform DEI research. These new funding opportunities should recognize that informatics scientific expertise will also be key to conducting novel DEI research.

Prioritize DEI research proposals, researchers, training, and experience. Researchers who have demonstrated sustained commitment to DEI issues in research should be given priority in any new funding opportunities. This will help to ensure that those who have been leading the science about these issues will continue to do so and that emerging lines of research build upon previous work, rather than reinvent the wheel. As mentioned, informatics professionals are at the forefront of leveraging the ever-expanding digital data environment and data-analytics tools.

Additionally, we recommend funding new models of education and training for DEI research, as well as researchers-building a workforce, that includes humanities, behavioral science, sociology, and practical service in marginalized and minoritized communities. We envision "co-op" programs, whereby students have a version of a traditional undergraduate curriculum with strong concentrations in humanities, science, and language, combined with a supervised, paid experiential program. This will allow students to learn, apply, and build skills in the context in which they hope to focus their research.

Incentivize partnerships between institutions. We note that there is only one Historically Black College and University (HBCU) in the top 119 institutions that receive NIH funding, and all grants are concentrated among far fewer institutions.[4] We believe NIH must rethink how to fund research, and in particular DEI research, in light of the current funding imbalances. NIH should make dedicated funding available to academic and research institutions that partner with academic institutions with a historical commitment to educating students from underrepresented groups, including, but not limited to HBCUs, Hispanic-Serving Institutions (HSIs), and Tribal

[4] https://www.usnews.com/best-graduate-schools/top-medical-schools/most-research-money-rankings

Colleges and Universities (TCUs). Such partnerships should include scholars who traditionally have been excluded from such research and partnering opportunities for junior faculty researchers. Partnerships such as these have the potential to lead to further workforce development and mentoring opportunities and can complement the ongoing work of the National Institute on Minority Health and Health Disparities (NIMHD).

Prioritize DEI research that has a policy endpoint. Via the National Center for Advancing Translational Sciences (NCATS), NIH recognizes that in addition to the science of human biology, there is also the science of translational research and real-world evidence generation. NIH supports this research through partnerships with patient, provider, industry (Health Information Technology, pharma), and payer groups. Thus, the path to policy is informed by evidence relevant to the respective stakeholders.

Similarly, DEI research should ultimately lead to positive, real-world policy outcomes. Grantees of any new NIH funding should be required to delineate how their research will lead to real-world DEI policies and support DEI-based outcomes, rather than just outputs[5] with metrics to be shared publicly to ensure ongoing, sustained scientific evidence-based action at NIH-funded institutions. Further, robust oversight should be put in place to ensure that grant applicants are not simply "bolting on" DEI statements to their proposals in order to secure funding for tangential research topics that do little or nothing to advance solutions for DEI-related concerns. NIH should additionally commit to advocating for public policy in general – and DEI issues in particular – to follow the research outcomes.

Commit to ongoing evaluation of efforts and transparency of results. NIH must commit to regular, ongoing evaluation of its efforts through robust, expansive metrics. NIH must prioritize outcomes, as opposed to outputs. While we applaud NIH's efforts, for example, to increase workforce diversity,[6] this should be recognized as simply one action to achieve concrete DEI outcomes. NIH should actively promote and fund development of new metrics that meaningfully capture outcomes reflecting impact in terms of DEI-related issues, such as institutional metrics mentioned above, as well as health improvements among minority populations. As another part of the evaluation effort, NIH should include processes and ways to evaluate how NIH-funded research is used to educate lawmakers regarding the impact and value of medical science across the care continuum. In particular, DEI outcomes and results must be structurally incorporated into NIH officials' Congressional testimonies, briefs, and information for media. NIH should finally disseminate the results of these outcomes in a transparent and easily accessible way, including, but not limited to, a dedicated website, email update, and publication.

Thank you for considering our comments. This is only the beginning of an important conversation and AMIA stands ready to assist NIH in following through on its commitments, as well as developing and implementing new ones. Should you have questions about these comments or require additional information, please contact Scott Weinberg, Public Policy Specialist at scott@amia.org or (240) 479-2134. We look forward to continued partnership and dialogue.

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[5] Magowan K. Outcomes vs Outputs: What's The Difference? bmcblogs. December 9, 2019. Accessed March 27, 2021 at https://www.bmc.com/blogs/outcomes-vs-outputs/.

[6] https://diversity.nih.gov/

Sincerely,

Patricia C. Dykes, PhD, RN, FAAN, FACMI
Chair, AMIA Board of Directors
Program Director, Research
Center for Patient Safety, Research, and Practice
Brigham and Women's Hospital

Tiffani J. Bright, PhD, FACMI
Chair, AMIA DEI Task Force
IBM Watson Health Biomedical Informatician
Evaluation Research Team Lead