

October 3, 2022

### National Science and Technology Council Subcommittee on Equitable Data

Office of Science and Technology Policy Eisenhower Executive Office Building 1650 Pennsylvania Ave. NW Washington, D.C. 20504

# **RE:** Office of Science and Technology Policy's Request for Information on Equitable Data Engagement and Accountability

The American Society for Biochemistry and Molecular Biology is an international nonprofit scientific and educational organization that represents more than 10,000 students, researchers, educators and industry professionals. The ASBMB strongly advocates for strengthening the science, technology, engineering and mathematics workforce, supporting sustainable funding for the American research enterprise, and ensuring diversity, equity and inclusion in STEM.

The White House Office of Science and Technology Policy (OSTP) published a request for information titled "<u>Equitable Data Engagement and Accountability</u>" on Sept. 2 seeking feedback on how federal agencies can better support collaboration with other levels of government, civil society, and the research community regarding the production and use of <u>equitable data</u>.

The ASBMB previously has recommended equitable data practices to the National Institutes of Health and the Department of Education and has compiled the following recommendations in response to the prompts provided in the RFI.

1. What are *examples of successful collaborations* involving equitable data between the Federal government and (a) Tribal, territorial, local, and State governments, or (b) local communities?

No response.

2. Among examples of existing Federal collaborations with (a) Tribal, territorial, local, and State governments or (b) local communities involving equitable data, *what lessons or best practices have been learned from such collaborations*?

No response.

3. What resources, programs, training, or other tools can facilitate increased data sharing between different levels of government (Tribal, territorial, local, State, or Federal) related to equitable data?

# Include Tribal leaders when looking to provide resources, programs, training, or other tools for Tribal governments.

Unintended consequences are a frequent outcome when conducting research with Native American tribes due to academic researchers' lack of familiarity with their culture. It is therefore critical that <u>informed consent beyond conventional institutional review board (IRB) review</u> be upheld when collaborating with Tribal Nations by involving not only the community but also permissions from Tribal leaders. Tribal nations must be given the opportunity to identify any potential adverse



outcomes, and the efficacy of avoiding harmful outcomes is dependent on the Tribal leader's understanding of the assumptions and methods of the proposed research. And if a given research project is approved, it is critical that tribes be truly equal partners in study design, data collection, interpretation and publication. The National Science Foundation has strived to be a leading example in engaging and including Tribal nation voices within its community. It hosts an <u>Indigenous STEM</u> <u>Affinity Group within the Inclusion Across the Nation of Communities of Learners of</u> <u>Underrepresented Discoverers in Engineering and Science</u> national network and also has engaged in <u>direct communication</u> with Tribal leaders. As OSTP and other federal agencies outline new strategies for resources, programs, training, or other tools to facilitate increased data sharing with Tribal communities, the voices and opinions of Tribal leaders must be kept at the forefront.

4. What resources, programs, training, or other tools can expand opportunities for historically underrepresented scholars and research institutions to access and use equitable data across levels of government?

# Include minority-serving institutions and emerging research institutions as an institution type in federal agency databases, such as the NIH RePORTER and the National Center for Science and Engineering Statistics surveys.

There is a significant disparity in graduate training diversity grants awarded to minority-serving institutions (MSIs) compared with other types of institutions, such as more established R1 universities. To ensure that funding decisions are equitable, public databases, such as the NIH <u>RePORTER</u> and the NSF <u>Award Search</u>, should include more descriptive categories within institution type, including MSIs and institutional classification (using the <u>Carnegie Classification of Institutions of Higher Education</u>). Even more helpful would be the further categorization of the <u>seven federally recognized types of MSIs</u> that serve distinct populations. Additionally, emerging research institutions (ERIs) should be included as an available institution type according to the definition used in the <u>National Science Foundation for the Future Act</u>.

Research has thoroughly established that <u>MSIs strengthen the U.S. STEM workforce</u> and increase the retention of students from historically marginalized backgrounds. Collecting and making public more detailed data on the institutions receiving federal grants will help hold funding agencies accountable. Agencies must ensure a significant percentage is being given to MSIs that have proved to be effective at retaining researchers from historically marginalized backgrounds.

### Modernizing the technology infrastructure at MSIs, ERIs and rural areas.

Without better technology infrastructure, MSIs, emerging research institutions (ERIs) and rural communities will be ill-equipped to access and use equitable data (as defined by the OSTP Equitable Data Working Group in its 2022 report, <u>A Vision for Equitable Data</u>). To conduct research with large datasets, MSIs and ERIs need expanded broadband access and modernized technology to meet hardware, security and infrastructure requirements. In 2020, a <u>nationwide survey</u> demonstrated a strong need for better broadband infrastructure at MSIs. Connectivity, equipment, security and access to technology were cited as most important in supporting the goals and objectives of research programs at MSIs. Data storage, data management and data analytics were also reported as significant. Broadband must also be strengthened and expanded for the <u>20 to 30</u> percent of Americans in rural areas and Tribal lands that lack broadband internet to ensure equitable access to data.



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### Create standards for de-identifying data to support availability of disaggregated datasets.

The needs of historically marginalized populations from intersectional identities are lost when researchers and institutions lack clear standards and procedures for disaggregating data in a manner that is safe and adherent to data privacy. Furthermore, the equitable data must be sufficiently detailed to allow for increased depth of analysis to dissect trends in these smaller subsets or intersectional identities of larger populations. Individuals, organizations and communities then need access to these de-identified datasets to perform and report their own independent analyses. Each of these steps is essential for researchers to access and use data that will further identify and address inequities experienced by historically marginalized populations.

### Better practices when collecting data on gender identity and sexual orientation.

The ASBMB has previously <u>recommended</u> that the NIH expand its data collection to include both intersectional identities and institutional classifications to produce more useful data tools. Federal agencies might publish demographic data, such as in the NIH Data Book, but it isn't always consistent in how it describes certain categories and should, in fact, contain additional categories. For example, these resources should not conflate sex and gender. The ASBMB recommends including gender identity and sexual orientation and using standardized language when collecting these data so that the agency will be better positioned to respond to issues facing lesbian, gay, bisexual, transgender or queer (LGBTQIA+) individuals.

### 5. What resources, programs, training, or tools *can increase opportunities for community-based organizations to use equitable data to hold government accountable to the American public?*

No response.

6. What resources, programs, training, or tools *can make equitable data more accessible and useable* for members of the public?

#### Require Federal agencies to publish a public report presenting relevant trends in their data.

Members of the public often do not have much experience with data analytics. If the public had access to summary reports from federal science agencies every few years that explained relevant trends in their data on a reoccurring basis, it would increase access, comprehension and allow the public to utilize the equitable data that is collected and provided by federal agencies. Importantly, these reports should be written in lay terms given that <u>over half of the U.S. population reads at below a sixth grade level</u>. The ASBMB recommends that OSTP require federal science agencies to generate, publish and distribute such reports to make equitable data more accessible and usable for members of the public.

### Provide web-based embedded data analysis tools and methods within the database that are intuitive, thorough and robust.

Embedded data-visualization tools make it easier for the public to investigate and understand trends when using available databases. Without these tools, only those with knowledge of third-party data analytic software and programs can make the most of the public data. The NSF's National Center for Science and Engineering Statistics provides many tools, although the breadth of data that can be



examined in the tools is sometimes limited. Federal agencies should ensure table and figures can be exported for use in studies and reports.

7. In which agencies, programs, regions, or communities *are there unmet needs, broken processes, or problems related to participation and accountability* that could be remedied through stronger collaborations and transparency around equitable data?

### Enhance and standardize data collection on individuals with disabilities.

There are many limitations to collecting and reporting data on individuals with disabilities. Many of the limitations are highlighted in the National Center for Science and Engineering Statistics <u>technical notes</u>, including variable definitions of a disability, self-reporting nature of surveys, and inconsistent institutional records. Inequitable data and a lack of consistency in the way this information is provided and reported significantly hinders equity for disabled persons. The ASBMB recommends the OSTP take steps to further standardize data collection and reporting practices regarding the disability status of individuals in science and higher education.

# Streamline and harmonize institutional review board (IRB) policies and permissions when collecting and reporting human research data.

IRBs are responsible for protecting the welfare, rights and privacy of human subjects during research activities, but their decisions are becoming <u>increasingly inconsistent</u> both within and across IRBs. These inconsistencies as well as the <u>time-consuming and potentially costly</u> process of getting IRB approval are barriers to equitable data. The ASBMB recommends the OSTP implement a toolkit for IRBs to regulate and better operationalize the ethical decision-making process. With a more structured toolkit, IRB decision-making will become more standardized to facilitate more timely, consistent and equitable scientific data collection from human subjects.

# Include and empower members from underrepresented groups to be the leaders and researchers of the projects involving their communities.

As explained in our response to Question 3, it is critical to involve the communities that are part of a given research study. This recommendation extends beyond the Tribal community and should be applied to all historically marginalized populations. The scientific community must address the cultural barriers in academia that lead to strained relationships between universities and their local community leaders include more transformative discussions on race, power and privilege as well as encouraging universities to undergo intra-organizational changes.

The ASBMB has previously recommended the Department of Education and the National Institutes of Health support transparency and equity of federal data in several capacities. Below is a list of our prior recommendations regarding data equity and transparency that have yet to be implemented to the best of our knowledge.

# The ASBMB <u>encouraged</u> the Department of Education to report the diversity of their reviewers.

The ASBMB recommended that the department research the diversity of its peer reviewers and conduct outreach to underserved institutions to facilitate grant-writing workshops. Currently, there is



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no public data on the diversity of peer reviewers. As the department collects data from grantees to fulfill the <u>Executive Order</u> to "assess whether underserved communities and their members face systemic barriers in accessing benefits and opportunities available pursuant to those policies and programs", we recommended the department also conduct research on the type of institutions and demographics of peer reviewers to determine which groups are underrepresented in peer review. Moreover, to support transparency, we asked that the department publish a report on its findings to the equity dashboard.

# The ASBMB <u>recommended</u> the NIH consolidate and publish their data on DEAI-related activities.

Given that the agency has eight diversity offices, we recommended that the NIH house all data produced by culture and climate surveys and by all of its other DEAI initiatives in a public, centralized database. Publishing all information in one location (such as <u>COSWD</u>) will make it easier for the STEM community and the public to keep track of and evaluate the outcomes of the agency's DEAI-related activities. The NIH must be transparent if it is to be perceived as a leader in DEAI in STEM.

# The ASBMB <u>urged</u> the NIH to add sexual orientation to the demographics of the NIH Scientific Workforce Recruitment Tool.

The ASBMB urged the NIH to include collecting data to better understand the barriers to inclusion for LGBTQIA+ scientists in the scientific workforce diversity plan by adding sexual orientation to the demographics of the NIH Scientific Workforce Recruitment Tool. LGBTQIA+ scientists are more likely to experience harassment and career obstacles than their non-LGBTQIA+ colleagues. As it currently stands, there is only <u>one large-scale study</u> about the experiences of LGBTQIA+ scientists, indicating that the research community needs to conduct more research to better understand the barriers LGBTQIA+ scientists face. The NIH, as the research agency leader, should initiate these research projects to better understand how they can support this community.

# The ASBMB <u>endorsed</u> the LGBTQ Data Inclusion Act that, if passed, would require federal agencies to improve their survey demographics by including sexual orientation and gender identity as a voluntary option.

Federal agencies must be more vigilant and inclusive of the identities and unique struggles that face the LGBTQIA+ community. The ASBMB has endorsed the LGBTQ Data Inclusion Act that, if passed, would require federal agencies to improve their survey demographics by including sexual orientation and gender identity as a voluntary option. With better and more equitable data on gender identities and sexual orientation in combination with other metrics, advocates and agencies can identify and better tackle issues within the LGBTQIA+ community such as job security, sexual harassment and less adequate resources in the workplace.

### The ASBMB supported establishing an NIH administrative data enclave.

There has been an increasing demand for access to sensitive information collected via the grants process. Such data includes information on peer review outcomes, progress reports, as well as, demographic information such as age range, sex/gender, race and ethnicity of individuals listed in NIH grant applications, etc. To address this demand, the NIH is considering making sensitive data available by establishing a data enclave. The research that will be made possible by the proposed



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data enclave will provide the opportunity for independent analyses of the NIH funding process, holding NIH accountable to taxpayers and the public. Analyses could be paired with the history of publicly-stated NIH funding policies and programs to provide a view of the consequences, intended or unintended, of how changes in NIH policies and funding levels have affected the landscape of NIH-funded research and the biomedical research enterprise. Armed with these new analyses, the NIH would be in an improved position to make further course corrections and adjustments that increase the efficiency of funding policies and programs to ensure the long-term viability of a robust biomedical research enterprise.

The ASBMB recommends that NIH and other federal science agencies establish a data enclave that provides equitable, transparent and accessible data on how taxpayer's dollars fund scientific research.

For further questions or discussion, please contact Sarina Neote, Director of Public Affairs, at publicaffairs@asbmb.org.