



April 24, 2023

Lawrence A. Tabak, D.D.S, Ph.D.
National Institutes of Health
9000 Rockville Pike
Bethesda, Maryland 20892

Re: Request for Information on the NIH Plan to Enhance Public Access to the Results of NIH-Supported Research Notice Number: NOT-OD-23-091

Dear Dr. Tabak:

We are grateful for this opportunity to respond to the National Institutes of Health (NIH) Request for Information regarding the NIH Public Access Plan. AcademyHealth is the professional home of over 4,000 researchers, policy experts, and practitioners and we strongly support research transparency, evidence-based policy, and equity throughout all phases of research. Our membership is highly engaged in NIH and its work, with many having served on study sections and as grantees themselves. We believe in the critical importance of evidence-based healthcare and policymaking, but that only works if evidence is accessible to clinicians and policymakers. If we are not proactively supporting access and dissemination of NIH funded research at every level to policymakers, practitioners, researchers, clinicians, and patients, then “evidence-based healthcare and policymaking” is little more than a slogan.

In these comments, we provide three recommendations for NIH to support equitable access to publicly supported research and data:

1. Focus on enhancing the diversity of researchers producing the data and research findings as well as diversity of the gatekeepers of publication opportunities to enhance the depth, breadth, and relevance of NIH-supported research;
2. Expand access to publications for organizations and individuals historically excluded from access, including community-based organizations, safety net providers, patients and policymakers at every level; and
3. Actively monitor open access policies to ensure access is realized for those historically excluded.

Public Access to NIH-supported research results impacts our work frequently as well as the work of our colleagues. AcademyHealth staff will often synthesize research for policy audiences, such as this issue brief on [Understanding Pre-Hospital Diagnostic Delays](#), and we have found that we can spend significant amounts of time searching for and attempting to access scientific journal articles that are reporting findings from publicly-funded research. Unless we contact the article’s author directly, we routinely face delays in obtaining the needed information and have gaps in our final product. As we work to translate the knowledge that is built through research that NIH has supported, many of our colleagues and collaborators seek to utilize current research for their own organizational goals but are unable to access it. This is also true for individual patients seeking to gain understanding of, and agency over, their care needs and are met with journal paywalls. The lack of easy and ready access to research data and study findings impacts the research, practitioner, and patient communities alike and disproportionately affects lower resourced settings such as safety net hospitals and community health centers.

The Office of Science and Technology Policy (OSTP) [recently alerted](#) all federal agencies that agencies will be required by the end of 2025 to update their public access policies to include more forms of research and data. These changes update the guidance to include making research findings publicly



available sooner and including other publication types than journal articles as applicable to these new policies. This welcome development could remove barriers to accessing evidence for those most looking to use it if implemented with that goal in mind.

AcademyHealth believes the NIH Public Access Plan is an important step forward in ensuring all those interested and willing to learn of the research being funded by the NIH can obtain access to these results, but more can be done. For the most successful implementation of this plan, we believe meaningful diversity, funding, and support is needed. The NIH can play a significantly more active role in safeguarding equitable practices for their current and future grantees. Below, we will outline our comments addressing the issues identified in the Request for Information.

1. How to best ensure equity in publication opportunities for NIH-supported investigators.

Ensuring equity in publication begins with supporting researchers from underrepresented groups and meaningfully engaging people with diverse backgrounds and perspectives in all aspects of the publication process. AcademyHealth is driven by its efforts towards diversity, equity and inclusion in health services research (HSR). [We strive to increase workforce diversity](#) through mentoring, training, and publicly committing to diversity within our own [organization](#). These efforts to create a more inclusive space for racially and ethnically diverse researchers are still underway, but we have learned a great deal that is applicable to publication opportunities for NIH-supported investigators.

To allow for equitable publication opportunities for a diverse pool of researchers, the NIH must play a more active role in ensuring there is diversity in those behind the publication as well. This is relevant to those serving as gatekeepers to evidence, including manuscript reviewers as well as those editing the journal as a whole. Meaningful diversity in this space not only applies to race, ethnicity, geographic location, and disability status, but also but also to methodologies. Health equity researchers and those focused on social determinants of health (SDOH) often use qualitative and sociological methods that clinical and biomedical researchers may lack familiarity. Matching these manuscripts to reviewers with the appropriate knowledge base to provide meaningful feedback is integral to ensuring equity in this space. Editors from a variety of backgrounds also allow for a greater spectrum of research to be published in journals that would otherwise turn away a manuscript due to its unfamiliar methodology.

AcademyHealth conducts workshops and trainings on [eliminating bias in health services research methods](#) as well as [measuring and reporting health disparities](#), but ultimately, journals have a responsibility to do more to aid underrepresented researchers. Some journals are making strides towards this such as Health Affairs publishing a [Racism and Health issue](#) with nearly three-quarters of the articles in this issue featuring a first author who had not previously published in their journal. Other journal editors have [recognized the gap](#) in what research is publicly available through open access but acknowledge that some journals are restricted by their minimal profit margins. Yet, we believe more consistent and persistent strides can and should be made by journals to engage diverse readers, researchers, reviewers, and editors.

The NIH could impose more rigorous equity standards on the publishing industry. Below are examples of how we believe the NIH can positively affect the research publication process and industry:

- **Safeguarding diversity:** In order for federally funded research to be permissibly published in a scientific journal, the NIH could require a threshold of diversity on both editorial boards and reviewer pools.
- **Transparent internal practices:** In order to model best practices that journals may emulate, the NIH could pledge meaningful diversity in the makeup of their study sections and be transparent when doing so.

- **Training and development:** In order to develop skills among under-represented minority researchers, the NIH could offer more training programs in peer-review and study section participation.

2. Steps for improving equity in access and accessibility of publications.

Expedient access to research findings is an issue we face constantly at AcademyHealth as we seek evidence-based solutions to challenges in health services and health policy. These barriers are also faced by others within and adjacent to the research field including patients, community-based organizations, and those in policy-making positions. While those in academic settings typically have no issue accessing scientific publications, they are only a small proportion of the HSR community and the broader community of potential end-users. The issue of access is of frequent concern to both our members and collaborators.

As part of AcademyHealth's [Paradigm Project](#), we used human-centered design to better understand and find solutions to aid those unable to access research findings. Through these efforts, federal and congressional agency staff informed us of their inability to consistently access the most current research to inform the creation of policies designed to address healthcare costs, coverage, and experiences.

AcademyHealth held an [Open Science Expert Meeting](#) in May of 2021 where participants indicated that free and equitable access to scientific knowledge and quicker access to research findings were the primary concerns that make open science principles important for HSR (over concerns about selective nonreporting and replicability of findings, which may be more relevant in other, more hypothesis-driven fields). Participants also noted that the preprint process or publicly posting research findings could likely be a good avenue for better dissemination of the research, but also engaging more diverse potential reviewers.

This NIH Public Access Plan will benefit many including:

- **Community-based organizations and nonprofits:** Community-based organizations and community leaders are increasingly involved in, co-leading, or principally leading research in their communities and may not be affiliated with academic institutions that could provide access to research findings. Patients and communities may not always come into their research roles with technical training, but could more easily develop the expertise with access to timely evidence. OSTP's push for immediate access to research data will allow these groups to apply research findings more readily to the communities that have been historically excluded and marginalized and are often the most underserved. Additionally, increasing the accessibility of research results with machine readability and assistive devices allows for an equitable and patient-centered approach to sharing these findings.
- **Local and state-level policymakers:** This is especially true for those located in smaller towns, rural areas, and who otherwise lack partnerships with academic centers who can share/extend their access, as well as those with fewer or no in-house research resources and who fully rely on others' analyses to inform policy decisions. We saw this to be especially true during the COVID-19 pandemic when there was a need for immediate access to research data, but no avenue to efficiently get it into the hands of policymakers.
- **Early-career researchers:** These are individuals who are forming their careers, potentially transitioning frequently between roles, especially those on "non-traditional" pathways into and within the field. These are people who want to build careers in community-based research, knowledge translation, embedded/health system research, or contract research. This group

includes many who are less connected to academic institutions and may be well positioned to bring new and creative ideas to the field—but are working from a 12-month-old literature base.

To improve equity in the publication space, we urge the NIH to emulate global examples of fortified open access policies. Given the potential implications for equity in the Public Access Plan's implementation, we must take into consideration the ease with which a layperson will be able to find and read publications in agency-designated repositories.

Fortunately, many other countries have already made strides in operationalizing these ideals. The Scholarly Publishing and Academic Resources Coalition (SPARC) [observes](#) that the guidance brings the U.S. policy closer to that of the European Union with strong open access policies to facilitate innovation and aligns with recent [open science guidance](#) from UNESCO. The European Union created [an official portal](#) for European data through which any of the 27 countries within the EU can “maximize access” to research findings. This repository promotes greater parity in data and research access, propelling science progress globally.

Per the 2003 [Berlin Declaration](#), the international consortium cOAlition S was created to advocate for publication open access and push for “[fair and equitable publication fees](#).” cOAlition S launched Plan S, which is a set of guidelines on what an open access research world may look like. Currently, with the support of the European Commission, cOAlition S is actively pushing for journals to limit open access fees and is advocating for researchers to publicly release their peer-reviewed article as their intellectual property. AcademyHealth believes we can adapt the knowledge and experiences of our European counterparts to our American research enterprise.

3. Methods for monitoring evolving costs of publication and impacts on affected communities.

Open access fees are high, and junior researchers, those from smaller institutions, minority serving institutions, and Historically Black Colleges and Universities may be less likely to have the resources to support open access publication.

The current OSTP [policy guidance](#) includes “reasonable publication costs and costs associated with submission, curation, management of data, and special handling instruction,” but we urge for more support to be considered for open access publication fees. Without additional support, those seeking NIH funding are forced to dedicate thousands of dollars within their grant budgets to open access fees instead of their actual research needs. This could come in the form of administrative supplements available for current NIH grantees or specific grants for this purpose for those with grants that are no longer active. We encourage the NIH to take an active role in assisting researchers with affording the costs of article processing fees to guarantee the importance of open access is understood by new and veteran researchers alike.

Though there are academic institutions actively prohibiting their researchers from including funds for open access publication fees in their extramural grants, there is also the slowly growing existence of Campus Open Access Funds to assist with paying the cost of publication fees. SPARC has monitored the creation of [Campus Open Access Funds](#) across the U.S. finding there are currently only 51 universities with these mechanisms. The NIH should encourage institutions to allow for these funds or support other avenues for researchers to fund public access to their research.

Alternatively, the NIH could require all federally funded research to be open-access without restrictions. There is potential for publication fees to be included in grant funding, but for governmental entities to negotiate reasonable rates at what is necessary and fair for publishers. Though negotiating these prices does not fall under the NIH's purview, there is precedent to suggest the feasibility of this process. The [Waxman-Hatch Amendments](#) in 1984 brought about fair pricing of drugs developed using taxpayer

dollars. The Office of Management and Budget may be best equipped for these negotiations, but the result will greatly affect the accessibility of research results.

Proactively supporting more equitable practices in publication opportunities, accessibility, and access could greatly impact every field of research. NIH-funded health services research is driven by taxpayer dollars and should therefore be made available to the public. In parallel, data resulting from publicly funded research also should be publicly available once properly protected. The issues of inaccessible publicly funded research and prohibitive publication costs can be addressed with more comprehensive open access policies and additional funder support for publication efforts. The NIH Public Access Plan has the potential to advance equity in research and knowledge accessibility while changing the current pay-to-play structure. While these recommendations require a great deal of further planning and determination, NIH's Public Access Plan is one step towards a more equitable future.

Thank you for the opportunity to provide guidance and assistance on the Public Access Plan. For further comment, clarification, or inquiry, please email Josh Caplan at Josh.Caplan@AcademyHealth.org.