

Enhancing Public Access to the Results of Research Supported by the Department of Health and Human Services

Day 1 Breakout Summary:

Supporting New Public Access Policies that Promote Equity and Accessibility

Best Practices

Approach: Establish a gold standard checklist/framework for accessibility of research results.

Proposed Actions

Government agencies, publishers, researchers, institutions and other stakeholders:

- Engage patients/researchers/disability communities early on and throughout the process of developing checklists/frameworks/best practices to meet the needs of end users for accessibility to research results.
- Leverage existing standards for accessibility (e.g. Web Content Accessibility Guidelines) and re-interpret for the specific needs of different stakeholder groups.
- Shorter-term: address staffing issues when it comes to roles/responsibilities (e.g., chief accessibility officer).
- Long-term: integrate principles of universal design across the educational system to build sense of shared responsibility.

Approach: Develop plain language summaries to increase communication of scientific findings to the public across different communities.

Proposed Actions

Funders, tech companies, publishers, researchers, and other stakeholders:

- Collaborate with patients/researchers/disability communities as equal partners throughout the process to provide access to published research in different formats.
- Define what “plain language” means for different communities.
- Develop a framework for training generative AI tools for generating plain language summaries.
- Develop toolkits to assist authors in developing plain-language summaries.

Inclusivity

Approach: Involve patients and patients advocates as partners throughout the research process.

Proposed Actions

Government agencies, publishers, researchers, institutions and other stakeholders:

- Find avenues to compensate patients and patient advocates for their input as a way of valuing their expertise, time, and increase willingness to participate in the process.
- Integrate patient advocates in research and publication as co-authors.

Approach: Make publications and the platforms hosting publications publicly accessible.

- Agencies, publishers, researchers, and other stakeholders engage specific communities to learn their accessibility needs to engage fully with research results.
- Agencies work with stakeholders to ensure publications are accessible to screen readers or other assistive technology.

Data Sharing

Approach: Ensure greater organizational participation from all stakeholders in metadata and PID infrastructure.

Proposed Actions

- Persistent identifier (PID) organizations reduce cost and technical barriers for participation of, including for stakeholders with the limited technical or cost resources.
- Funders require/enforce PID registration for grants and support training that emphasizes the responsibility of all participants in the completeness and readiness of their data.
- Funders and publishers openly share the metadata in their systems, repositories, and records.
- Repositories and journals embed editorial processes in metadata (e.g., peer review taxonomies).

Experimentation & Flexibility

Approach: Explore new business models and leverage existing infrastructure to support public access.

Proposed Actions

- Federal agencies support multi-year pilots that can support engagement with interim products (i.e., lay summaries, creating platforms for research or open review).
- Libraries, institutions, funders, and other stakeholders leverage existing infrastructure for sharing information across institutions.

- Agencies and publishers develop mechanisms to track who is accessing publications, how they're being used, and where there are barriers to sharing.
- Publishers, funders, researchers, and other stakeholders work together to ensure sustainable financial resources are available to support the editorial process.
- Publishers, funders, researchers, and other stakeholders work together to develop guidance for financial stability for solutions developed.
- Federal agencies, institutions, and other funders work towards a central university system that supports public access to federally funded research.
- Agencies, publishers, and researchers co-create systems to share negative research results.

Culture Shift

Approach: Promote a culture shift among authors and generators of research findings to share work they have done.

Proposed Actions

- Institutions, funders, and researchers work together to reform tenure and promotion to encourage open access.
- Institutions and funders include interim products as a measure of productivity on the part of researchers to support integration of shared interim findings throughout the research workflow.
- Institutions, funders, researchers, and other stakeholders separate dissemination from curation to prioritize other goals for the system.