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Beyond Embargos: Accessibility Considerations for Building New Public Access Policies



Disclosures

- I DO have conflictual interests related to this material
- I DO have federal, state, municipal, and private grants
- I DO advise several medical technology companies:
 - Tactile Navigation Tools, LLC* [devices will be presented] – patent, minority equity, advisor
 - Tactonic Technologies, LLC* – minority equity, advisor
 - Physiclo, INC* – minority equity, advisor
 - Helius Medical Technologies/ NeuroHabilitation Corp. – SAP, travel award, honoraria
 - ARx Vision* – minority equity, advisor
- I DO serve on Scientific Advisory Boards (SAB) / Board of Directors:
 - MTA of NY
 - Choroideremia Research Foundation
 - CityAccess NY
 - Envision Research Institute
 - VETHack (Wounded Warrior NPO)

**NYULMC and Dr. Rizzo have equity interests in the technology companies described above*

THANK YOU

To Our Federal Partners



NIH, Administration for Children and Families (ACF), Administration for Community Living (ACL), Food and Drug Administration (FDA), and other HHS agencies, and do not create new or reinforce existing inequities in publishing opportunities.

Grants:

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Agenda

- **Overcoming Access Barriers**

- ★ • Explore obstacles to public access to diverse *HHS-funded research results*.
- Address exclusion issues faced by *underrepresented communities in research discussions*.

- **Community Engagement**

- ★ • Discuss strategies for building and sustaining *bridges to diverse communities*.
- Emphasize inclusion of varied perspectives to *enhance public access through publishing*.

- **Equity Enhancement**

- Consider steps to improve *equity in publication access* for a diverse user community.
- Advocate for removing the 12-month *embargo period for federally supported publications*

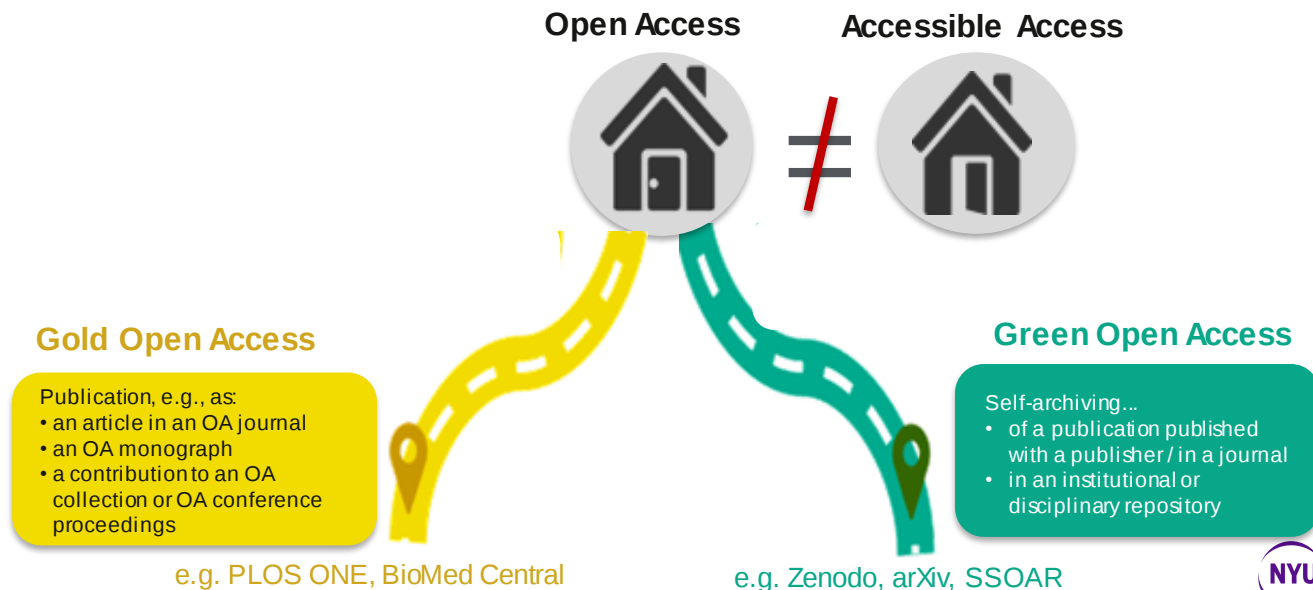
Discussion

- What **challenges** do specific stakeholder groups face in accessing scientific *publications*, and what potential solutions can address these issues?
- How can we **ensure** that the unique needs and perspectives of diverse communities are considered in the *development and evolution of initiatives to make research more accessible*?
- What **strategies** can be implemented to actively involve and amplify the voices of underrepresented groups in shaping *new public access policies*, fostering a more inclusive approach from the outset?

#1 – Access

Does Open Access mean Equitable Access?

- If we assume “open access” to the manuscript, does this grant access to the **content**?
 - Open access does **not** mean content/information access
 - **Digital accessibility** features crucial for ensuring an inclusive and equitable experience

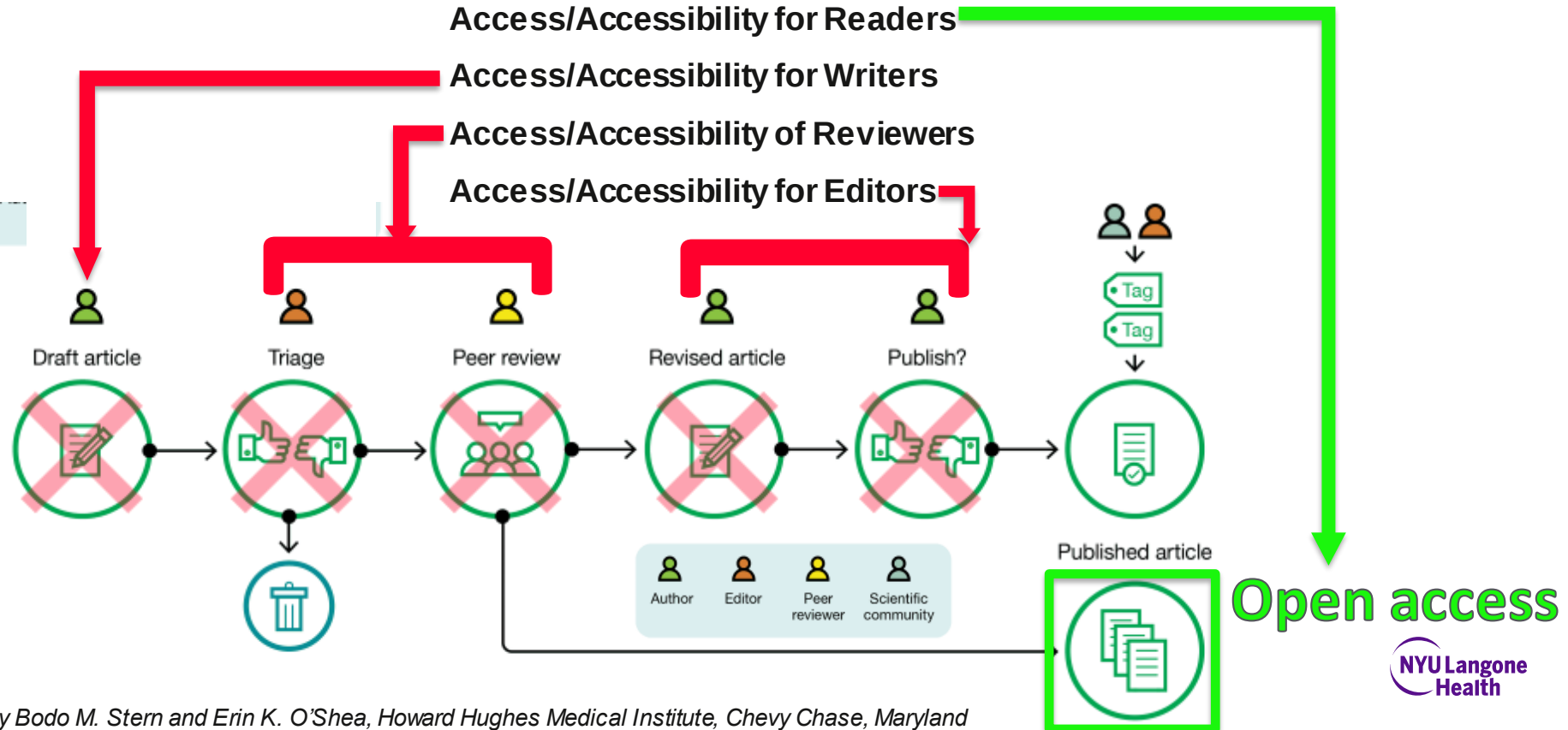


Strategies for Content/Information Access

- New accessibility policies and best practices in accessible *scientific publishing*:
 - Key considerations
 - writer/drafter,
 - reviewer,
 - editor,
 - publisher
- **Action plan:**
 - Devise a general-purpose “roadmap to accessibility”
 - Create an accountability structure
 - Launch an “accessibility checker”
 - Minimum Standard based on Scoring?

#2 – Evaluation

Are we Inclusive throughout the Peer-Review Process (PRP)?



Strategies for Full-spectrum Access/Accessibility in PRP

- New policies and best practices with inclusive review processes that are best served to judge and subsequently uphold the **validity** of the scientific process
- Inclusion is critical at **all** stages of the Peer-Review Process from *creation-to-submission, submission-to-revision and revision-to-publication*
- **Action plan:**
 - Create standards that promote inclusion:
 - Website(s) accessibility (review journal submissions procedures)
 - Frontend - journal submission portal accessibility
 - Backend - journal reviewer/editor portal accessibility
 - Disseminate inclusion practices for journals at all stages of the PRP
 - Devise an accountability matrix with public reporting
 - Increase community engagement

#3 – Community Cooperation

How Participatory is the Research Process?

- Is the voice of end user **central**?
- Bodies of high-quality **qualitative** research with the voice of the end user highlighted
- What happens throughout the **rest** of the scientific process?
- Millions of Americans have **PhDs in Lived Experience** (PhD LE)
 - Are we taking advantage of the expertise that we have available to us?

Strategies for Panoramic Participatory Research

- New policies and best practices with inclusive designs, methods and evaluation that optimize the integrity *of the scientific process*
- **Action Plan**
 - **Inclusive Co-design & Collaboration**
 - If your topic is about disability, then Include someone with lived experience as a co-author.
 - **Inclusive (Participatory) Methods**
 - If your topic is about disability, engage end users with lived experience in methods or testing.
 - *Simulators or simulations* may only be considered a piece of a more sophisticated design
 - **Inclusive Evaluation**
 - If your topic is about disability, should peer-review with population-concordant lived experience be compulsory?
 - Is this any different than esoteric data analytics that require statistical reviewers?

Conclusion

- Open Access does **NOT** ensure Information/Content Access
- Accessibility and Access are required at **ALL** Stages of the Peer-Review Process
- Participatory Design is required across the **ENTIRE** Scientific Process

thank you