Communicating About Biorepository Research with Communities

Approaches to communicating with communities and the public

It is important for scientists to share their work clearly and openly with the public. This is true for all research, but it is especially important for research that uses data from repositories.

Why Communication Matters in Biorepository Research

Community involvement in primary research results in more rigorous, relevant, and understandable science.[1] In repository research, community involvement is very challenging. The data in repositories are collected from tens or hundreds of primary research studies. Also, repositories usually contain only anonymized data.

For these reasons, repository researchers do not have pathways to engage participants in their research processes. This distance between researchers and those being researched can impact the quality of repository research in at least three ways:

- **Misalignment with community needs -** When people can't see or comment on how their data are used, researchers might study questions that do not reflect what those communities care about.
- **Less accuracy and relevance -** Without input from communities, researchers can miss key information. This can make their work less accurate or useful.
- **Erosion of trust -** When data are reused without transparency, it can reduce trust in science. This wariness is understandable. Unfortunately, communities have been hurt

in the past and some experience ongoing hurt from research today. Open and honest communication helps rebuild trust and makes future research stronger.

To read more about this, see our other reading "Cases of Group Harm in Biorepository Research."

How to Communicate Openly in Biorepository Research

Direct vs. Public Communication

In repository research, it is usually not possible to communicate with individuals who donated their data. But repository researchers *can* communicate with the groups represented in their data. Depending on the project, researchers may be able to do this in a direct way. For example, by meeting with a relevant patient or community group.

Methods for Communicating Directly with Communities

- Biorepository newsletter
- Presentation to a patient or community group (in-person or virtual)
- Social media post in a community forum (e.g. a subreddit)

But direct communication methods are not feasible for all projects. **Often, researchers will need to communicate indirectly via the broader public.**

Methods for Communicating with Communities *via the Public*

- Blog post (personal, institutional, or biorepository-hosted)
- Post on a project or lab website
- Social media post (e.g. LinkedIn, X/Twitter, Reddit)
- Social media video (e.g. TikTok, Instagram, YouTube)
- Public-facing presentation (e.g. podcast, radio segment, news article)

Communicating with other researchers may be another way of reaching communities. Academics may be dual space holders, belonging to one or more of communities in addition to their academic identities. These academic colleagues may be able to provide insights and guidance based on their lived experiences as well as from an academic perspective.

Communicating within Academia

- Journal article
- Other academic publications (white paper, thesis, preprint, etc.)
- Poster or talk at a scientific meeting

More Than Just Findings

Another unique aspect of communication in repository research is that it can be done at any point in a project's lifecycle. Since the data has already been collected, there is no risk of influencing data collection as there would be in primary research.This opens the door to more opportunities for when and what to share.

Scholars like Contera note that it is important to share more than just research outcomes. People respond better when science communication includes elements like:[2]

- The researcher's own motivations
- The researcher's relationship to the research topic
- The possible benefits and unintended outcomes of their work

➔ *CHIRON Exercise 4 - Communicating Transparently* helps researchers create a brief, easily shareable project summary.

More Resources

Public communication can be daunting at first. Here are some resources we recommend for guidance and inspiration. (Hyperlinks are available in the web version of this reading).

- **American Association for the Advancement of Science's Communication Toolkit**[3] – A practical guide on how to communicate science clearly. It includes:
    - Tips for identifying audiences, tailoring messaging, and avoiding jargon.
    - A social media guide with advice on matching the goals of your communication to suitable online platforms.
    - A guide to using multimedia like graphics and video.
- **TikTok: An Emergent Opportunity for Teaching and Learning Science Communication Online**[4] – This paper describes how TikTok can be used to share research with the public.
- **Reddit** allows researchers to post to condition-specific subreddits or the broader Ask Me Anything (r/ama) subreddit.
    - **Example:** a group of researchers led an "ask us anything" about endometriosis research in the r/endometriosis subreddit.[5]
- **Instagram** may be a useful platform for sustained project communication depending on the target audience.
    - **Example:** the trans-ilience research team uses instagram for community communication and outreach.[6]

A Tip for Digital Communication

Online platforms change quickly, so guidance can become outdated fast. If you have communication or social media experts at your institution, reach out to them. They can help you choose the right tools and approach.

Final Thoughts

Talking openly with the communities whose data you use is **essential**. It is both a **responsibility** and a **pathway to improving the quality of science**.

Because biorepository researchers often don't know the people whose data they use, it's even more important to share information with the public. There are many ways to do this, and it doesn't have to take much time.

You don't need to be a "science influencer." Sharing your work in a clear and respectful way helps build trust and makes the research better.

Sources and Further Reading

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