

Metaphors matter: from biobank to a library of medical information

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The concept of the biobank is central to large-scale biomedical research enterprises such as the *All of Us* Research Program (<https://allofus.nih.gov/>). The term *biobank* has become commonplace as a signifier for the collection and storage of human biological samples for future research use but the fact that it is metaphorical is not given much attention. *Biobank* utilizes the familiar concept of a financial institution, and also has historical associations with the terms *blood bank*, *tissue bank*, and *organ bank*. We argue that, because metaphors such as *biobank* can influence public attitudes and interpretation of complex scientific concepts, yet have culturally specific meanings,¹ the choice of metaphorical terms requires careful consideration to engender trust, especially among populations underrepresented in biobank-related research.

Biobank-based research is complex and likely to be unfamiliar to many people, so the biobank metaphor can be a valuable communication tool because it links an abstract, unfamiliar concept to a concrete, familiar experience.² For example, the concept of randomization has commonly been described as a toss of a coin. However, metaphors have been widely subjected to conceptual and normative critique for their potential to mislead, to the extent that they highlight some characteristics of the target domain while downplaying others.² Because metaphors are inevitably selective, choosing any specific metaphor is a rhetorical act with normative implications, even for scientists.³

Conceptual critiques of the biobanking metaphor include arguments that the transactional nature of the commercial aspect of banking emphasizes value and exchange of tangible materials at the expense of privacy concerns by downplaying the informational nature of biobank-based research.⁴ Furthermore, the implied linkage of *biobanking* to *blood banking* and *organ banking* has been deemed problematic for drawing attention to the benefits of donation while failing to acknowledge commercial interests.^{4,5} For example, in the United Kingdom's proposals for a national biobank, the UK

government and several nongovernmental organizations may have capitalized on the sense of altruism and community benefit associated with hospitals and blood banks by using images of blood donation as a *gift to strangers*.⁵

Discourse that uses the biobank metaphor trades in particular values. However, it is an open question whether the metaphor affects public attitudes and behavior adversely, especially in culturally diverse populations whose inclusion in biobanks is critically important.⁶ Research suggests that metaphors affect how concepts are understood,² and can influence behavior of both insiders and the general public.^{7,8} For example, studies comparing descriptions of the flu literally (as a *virus*) versus metaphorically (as a *beast*, *riot*, *army*, or *weed*) found that more individuals who received the metaphorical descriptions were willing to get vaccinated.⁹ Additionally, the meanings and connotations of metaphors assumed by scientists or journalists are not always shared by the general public. For example, the assumption that the *blueprint* metaphor for DNA would be more deterministic than *recipe* was not supported by empirical study.¹⁰

In the course of developing informational trigger videos about biobank research for focus group studies of attitudes toward biobank-based research (<http://thevaluesproject.stanford.edu/>), we learned valuable lessons about how people from diverse cultural backgrounds (including native English, Spanish, and Mandarin speakers, who we engaged in these languages) perceive related metaphors. When we asked patients to tell us what the word *biobank* made them think of, they offered a number of different terms that emphasized different attributes of biobanks. These terms included *financial bank*, *gold mine*, *organ or blood bank*, *cryobank*, *database*, and *large computer*, which vary in how well they represent or emphasize important concepts of a modern biobank (conceptual accuracy); the terms also vary in whether and to what degree they carry positive or negative associations (valence). (See **Table 1**.) While *financial bank* and *organ or blood bank* both utilize the bank metaphor, they

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generated different reactions that suggested that the concept of a tissue bank has lost its figurative quality through sustained use.

The apparent drawbacks to various patient-generated terms, especially the strong negative reaction to the commercial connotations of *financial bank* or *gold mine*, suggested that a search for a more appropriate metaphor was warranted.³ *Biobank* may well be another example of how actual perceptions of a metaphor do not necessarily reflect theoretical or intended meanings.¹⁰ Although the analogies to *financial banking* and *blood banking* have been criticized for overemphasizing positive values of benefit and altruism in theory, actual patients assigned a negative valence to the biobank metaphor, spontaneously making links to the use of health information for financial gain, in the course of either drug development or health insurance provision.

We considered various alternatives, and selected *pool* or *reservoir*, and *library* as the most promising. (See **Figure 1**.) While we recognized that no metaphor would be fully representative, we chose to use the library metaphor in our

A pool or reservoir:

- Reservoirs are often fenced or walled for security
- It is a resource that is controlled and distributed for public good
- Its quality is monitored
- When new content is added, it becomes unidentifiably mixed with old contents
- When it is empty, people understand that it should be filled

A library:

- Is a resource built by and for communities
- Is partly made up of voluntary donations
- Is a storehouse of information and knowledge
- Is used for research
- Can have controlled access
- When it is empty, people understand that it should be filled

Figure 1 Alternatives to the biobank metaphor and their strengths.

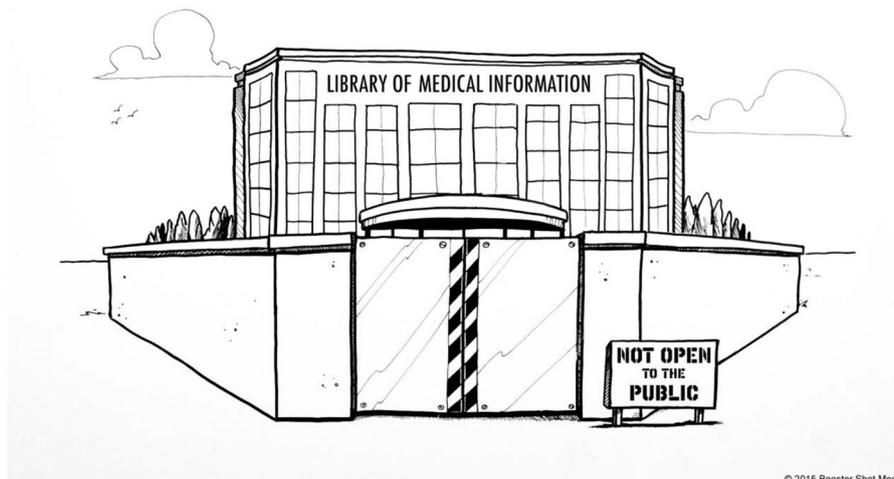
informational videos because we believed it captured more of the key characteristics than a pool or reservoir for the purposes of describing a research biobank. It was also amenable to visual representation; we used images of a building, labeled *Library of Medical Information*, to represent a biobank.

The library metaphor was advantageous for several reasons. First, it allowed us to represent the concept of electronic data or biosamples donated by human individuals in the form of file folders or test tubes that were stored on shelves. In contrast, the pool metaphor did not allow depiction of a collection of discrete items of different types, because its contents (e.g., water) become homogeneous and indistinguishable once deposited.

Second, we could address concerns about security that had been expressed by patients by highlighting differences between “your public library,” which is open to the public, and a Library of Medical Information, which has security to protect information and a gatekeeper to control access by legitimate users only. (See **Figure 2**.)

Third, the concept and images could be used to emphasize the key feature of information sharing. For example, some images showed interconnections between several similar but nonidentical libraries to illustrate how information might be networked and transferred. (See **Figure 3**.)

Fourth, *library* was familiar and also potentially minimized misunderstandings. Patients noted that libraries are widely recognized as a place for research and an important part of the community. Moreover, it allowed representation as a resource built by public support, without placing strong emphasis on the individual altruistic aspects of research participation represented by gift-based metaphors; it also allowed us to address a commonly expressed misconception, i.e., that a patient’s contributed data and samples would be used directly by physicians to inform and benefit the same patient’s health care, by disconnecting ownership and research uses from downstream findings and clinical



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Figure 2 Visual metaphor of the library: security.

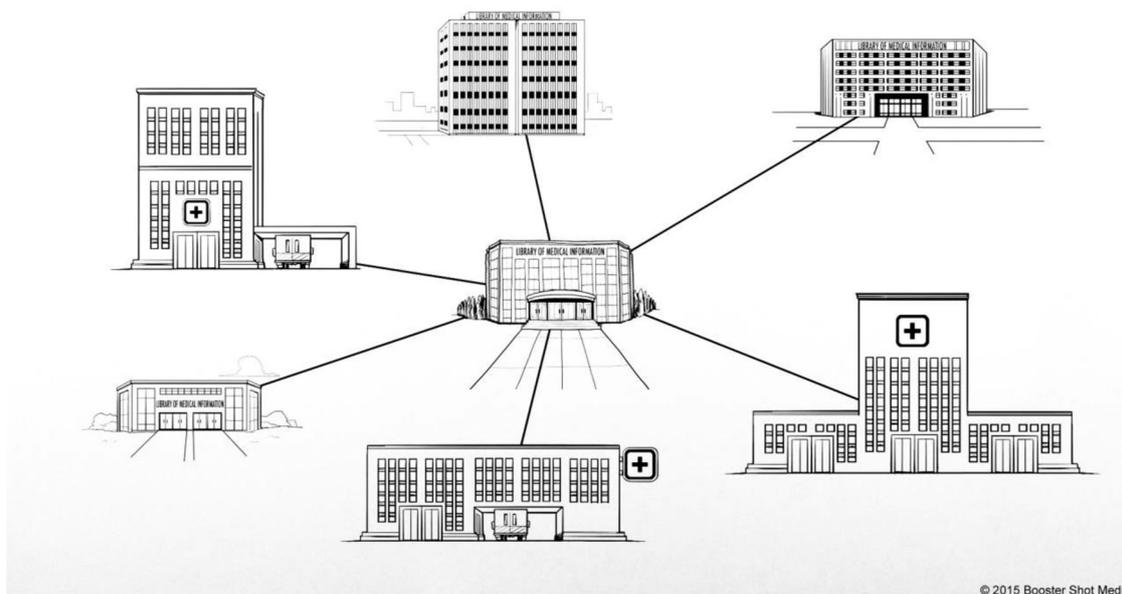


Figure 3 Visual metaphor of the library: networking and data sharing.

Table 1 Conceptual accuracy and valence of patient-generated terms

Terms	Conceptual accuracy	Valence
Organ or blood bank	Strength: conveys concept of storage of biological material	Positive: potential to minimize privacy concerns
	Weakness: might not convey privacy risks	Positive: associated with altruism
	Weakness: does not convey concept of storage of electronic data	Negative: potential to evoke suspicion of commercial motive or concerns about commercial profit
Financial bank or gold mine	Strength: conveys concept of storage of valuable material	Negative: potential to evoke suspicion of commercial motive or concerns about commercial profit
	Weakness: does not convey concepts of sharing, networking, or community resource	
	Weakness: suggests that donors are owners	
Database or large computer	Strength: conveys concept of storage of electronic information	Negative: potential to draw attention to privacy and security risks
	Strength: associated with research and knowledge generation	
	Strength: conveys concept of data sharing, access, and networking	
	Weakness: does not convey concept of storage of biological material	
	Weakness: might suggest direct access by patients for clinical use	

applications. In contrast, *banking* suggests a more direct, and potentially misleading, relationship between contribution and benefits.⁴

However, patients also noted some possible drawbacks to the library metaphor: for example, that young people might not be as familiar with libraries. Moreover, to some the idea of depicting the data as physical books rather than as electronic or computerized texts seemed outdated or overly simplistic. But others pointed out that some people do not use computers and the book analogy is universally understood.

Some patients commented that books are less likely than electronic data to raise the issue of tampering or stealing, which was, interestingly, a potential weakness also identified

about the banking metaphor to the extent that it downplays security risks. To convey this risk, we used images of a thief drilling into a vault, and to depict security we used images of the library being protected by a vault-like structure (ironically, making the library more like a bank). We illustrated control of access to the Library of Medical Information with a librarian behind a counter overseeing who could enter the library and check out the books.

We encountered specific challenges to using metaphors when translating the videos from English to other languages, especially to Mandarin Chinese, which uses a logographic writing system and in which written text may not represent typical spoken dialogue. For example, in Mandarin, the literal

translation of *library* in Chinese characters (图书馆) is a combination of the characters representing *book* (图书) and *physical place or stadium* (馆). However, when asked “What is the Library of Medical Information?” most Chinese patients would say *database* in either Mandarin or English. However, using *database* might have changed the perception of the function, risk, and benefit of the Library of Medical Information, or even caused or exacerbated misconceptions. For example, in a focus group of Chinese patients, one said that a benefit of the *database* was that a patient could directly look up information in it, obviating the need to see a doctor.

There is probably no perfect metaphoric vehicle to represent the “biobanking” aspect of large-scale biomedical research enterprises such as the *All of Us* Research Program. The ideal term would capture all important factors, be unbiased normatively, and convey equivalent meanings across culturally diverse populations. However, because *biobank* is so commonly used in public communication about biomedical research, including in recruitment and consent materials, it is particularly important to understand the actual impact of the term and to consider and evaluate alternatives.

The lessons we learned support the proposal that researchers should assess the appropriateness of metaphors for science communication, through interdisciplinary collaboration that includes expertise from biology, medicine, social sciences, and the humanities.³ Additionally, through empirical study we can better understand how potential research participants and the broader public perceive and react to commonly used metaphors and alternatives, and in turn how the use of those metaphors might affect the success of clinical and translational research.

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DISCLOSURE

G.A. and A.T. are cofounders of Booster Shot Media, the company that produced the video content described in this article, and were consultants on the National Institutes of Health grant that supported this work.

REFERENCES

1. Kimmel M. Metaphor variation in cultural context: perspectives from anthropology. *Eur J Engl Stud*. 2004;8:275–294.
2. Lakoff J & Johnson M. *Metaphors We Live By*. University of Chicago Press: Chicago, IL, 1980.
3. Kueffer C & Larson B. Responsible use of language in scientific writing and science communication. *BioScience*. 2014;64:719–724.
4. Hofmann B, Solbakk J & Holm S. Analogical reasoning in handling emerging technologies: the case of umbilical cord blood biobanking. *Am J Bioeth*. 2006;6:49–57.
5. Busby H. Biobanks, bioethics and concepts of donated blood in the UK. *Sociol Health Illn*. 2006;28:850–865.
6. Wagner J, Peltz-Rauchman C, Rahn A & Johnson C. Precision engagement: the PMI's success will depend on more than genomes and big data. *Genet Med*. 2017;19:620–624.
7. Nie J-B, Gilbertson A, de Roubaix M, et al. Healing without waging war: beyond military metaphors in medicine and HIV cure research. *Am J Bioeth*. 2016;16:3–11.
8. Nisbet M. Communicating climate change: why frames matter for public engagement. *Environment*. 2010;51:12–23.
9. Scherer A, Scherer L & Fagerlin A. Getting ahead of illness: using metaphors to influence medical decision making. *Med Decis Making* 2014;35:37–45.
10. Condit C, Bates B, Galloway R, et al. Recipes or blueprints for our genes? How contexts selectively activate the multiple meanings of metaphors. *Q J Speech* 2002;88:303–325.