

# Underutilization of specimens in biobanks: an ethical as well as a practical concern?

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“It’s totally false . . . that “if you build it they will come.” I thought if we build this [biobank] we’ll have people knocking on our door to use it” (Interview with a biobank director, 2011).

Biobanks, organizations that acquire and store human specimens and associated data for future research use, may be essential to realizing the promise of translational research—but not if researchers fail to come knocking on their doors. Indeed, lack of use of specimens and data by researchers may lead to biobank closure. Recent interviews and a national survey with US biobankers,<sup>1–4</sup> indicate that worries about underutilization may be widespread.<sup>3</sup> We conducted interviews with 24 biobank workers from six biobanks who were selected based on their job title or function: principal investigator/director, study coordinator or manager, information technician, public relations representative, and institutional review board/ethics board member.<sup>3</sup> For the survey, we recruited the biobank director or manager or, when necessary, some other individual with sufficient knowledge of the biobank’s operations to complete our survey. Underutilization was a concern for fully 67% of survey takers; when asked about the “greatest challenge” facing their biobank, the second most common response (after funding) was getting researchers to use their specimens.<sup>3</sup>

What do these responses mean? Are biobankers worried that their collections contain an insufficient number of useful specimens or that their outreach efforts are not attracting enough researcher requests? Even if acquisition and requests are adequate, are they concerned that their specimens are not being used to contribute to important translational discoveries? In fact, we know little about what “underutilization” means to biobankers, whether and how it relates to the mission or funding of their biobanks, or the relationships with the individuals who donated specimens to the biobank. Considering the great diversity of biobanks,<sup>2</sup> it becomes even more challenging to define “adequate” or “optimal” utilization for biobanking policy purposes.

What we do know is that for some biobankers, “underutilization” carries an ethical as well as a practical significance. Consider this statement made by an interview respondent:

“I think we’ll be judged long-term by discoveries that are made using the samples that we’ve collected . . . This community [of specimen contributors] really, really wants to participate in something that has the chance to revolutionize medicine, and I’d really like to deliver on that.” If such implicit promises and judgments of blame or praise are taken seriously, they will shape how “adequate” and “optimal” utilization are understood. Although there is considerable literature on ethical issues in biobanking, the biobankers’ ethical imperative to encourage utilization has rarely been discussed.

On the basis of the literature and our previous work, we can identify three sets of commitments that may underlie biobankers’ ethical concerns: (i) a scientific imperative to share research resources, (ii) an obligation to uphold the public trust, and (iii) an implied promise to use specimen contributions wisely and productively. It is still unclear which of these rationales dominates the community’s thinking or how biobankers understand their connections. However, further research fleshing out these commitments and testing them against the realities of biobanking experience may help move the field toward an ethical foundation that addresses the complicated issue of underutilization.

## SCIENTIFIC IMPERATIVE TO SHARE

The narrowest interpretation of a professional obligation to optimize utilization arises from the scientific imperative to share research resources widely.<sup>5</sup> Collecting but not utilizing specimens challenges professional norms of scientific conduct such as those behind the data and publication sharing policies of the National Institutes of Health (NIH). Optimizing utilization is a professional ethical imperative in the same way that appropriate citation and fair peer review are ethical matters: it reflects the communal nature of the scientific process and its common goal to advance reliable knowledge for its own sake.<sup>6</sup>

This interpretation offers strong motivation for biobankers to publicize and provide easy access to their collections, but it cannot fully explain their concerns. As long as they are not inhibiting access, a lack of users does not impugn biobankers’ scientific integrity—only, perhaps, their skills as communicators. But biobankers usually understand their obligation to be an active one, aimed at doing more than simply opening their doors to

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encourage use. For example, as one interview respondent commented, “Our mission basically is to put ourselves out of business ... to solve [this disease].” Sentiments such as this suggest that some other moral considerations are at stake beyond the scientific imperative to share.

### PUBLIC TRUST

A broader source of concern might be the moral obligation to use public funds to maximally benefit public welfare. Most biobanks are established with concrete aspirations to find cures, develop therapies, and increase scientific knowledge. For many biobankers then, less-than-optimal utilization of specimens is a failure to deliver on the promise of advancing translational research. Even when no voluntary donation is involved, biobankers may feel obligated not to “waste the gift” when public resources are expended in the acquisition and storage of specimens.<sup>7</sup> One interview respondent noted, “I want to make sure they get used because the biggest criticism we got ... was “Yeah, we love this concept, but gosh, every time NIH has invested in a specimen repository, the specimens are collected and they aren’t used.””

### COVENANT WITH CONTRIBUTORS

Biobankers do worry about promises to their specimen contributors. It is difficult to imagine that contributors are ever explicitly guaranteed that their samples will be used in research, yet the perception that an implicit promise has been made to contributors to make the best use of their donation is a recurrent theme. This perception has been echoed in the research ethics literature from the perspective of contributor expectations<sup>8</sup> and fits within a “stewardship model” that informs the governance of biobanks generally.<sup>4,9</sup> Jeffers notes, “Stewardship recognizes the importance of not only preserving the human dignity of individual research participants, but also changing what is stewarded to benefit the community of the participant.”<sup>9</sup> In mission-oriented biobanks that are created and managed cooperatively by patient advocacy organizations, this perception is strengthened by the stakeholders’ sense of solidarity and mutual investment. As one biobanker noted, “We are the stewards of those samples trying to use them in a way that’s productive toward some kind of mitigation of the disease .... We’re the trusted entity that is the guardian of the sample.” Whether grounded in stewardship or solidarity, or implicitly or explicitly promised, many biobankers seem to understand themselves as bound by a covenant of trust that would be violated if contributors’ samples were to go unused. Of course, given the long-term nature of biobanks, upholding this trust is particularly challenging because contributor preferences for the uses of their specimens may change over time and biobanks often have no mechanisms by which they are held accountable for the uses of specimens.

### CONCLUSION

Together, these commitments provide a framework for thinking about underutilization as a professional ethical issue in

biobanking. None alone captures the full range of moral intuitions that biobankers bring to the issue, and it is unclear how they actually fit together as a professional ethical framework. For example, is biobankers’ commitment to share samples simply an application of the duty to maximize their collection’s potential for public benefit? Are both of those commitments independent of the importance of being trustworthy stewards for the contributors, or is that ideal perceived as instrumental toward furthering better science or public welfare? As promising as these findings seem as the basis for an ethic of utilization, a more detailed empirical understanding of biobankers’ perceptions of underutilization and its relationships with other aspects of biobanking is needed in order to clarify the ethical foundations of biobankers’ utilization convictions. Once clarified, they may also help frame approaches to other ethical challenges. For example, is “underutilization” less a problem when it reflects efforts to sustain trustworthy and transparent governance? What if explicit covenants with contributors actually restrict utilization in ways that could possibly trump scientific obligations to share specimens? When biobank contributors want to know the uses to which their sample will be put, it may be because they might not find all uses equally respectful of their donation. For traditional charities, donor concerns over the beneficent impact of their donations have placed a premium on open disclosure of organizational overhead costs and “pass-through” efficiency. Tax-supported public programs face similar requirements for transparency. Do commercial biobanks face the same levels of public trust duties as biobanks that rest ultimately on tax dollars?

It is not surprising that the ethical dimensions of underutilization have not been fully explored: social scientific research on the organizational dynamics of biobanks, including how specimens are used and by whom, is only now getting under way. Moreover, the literature on ethical issues in biobanking has been dominated by a focus on specimen contributors’ views on sample collection and management and, to a lesser extent, the obligations of researchers in accessing specimens for use. Our data suggest that another critical research focus lies with the moral convictions of the biobankers themselves and the ways that their concerns may mediate the acquisition of specimens from contributors and their subsequent use by researchers.

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## DISCLOSURE

The authors declare no conflict of interest.

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