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Grudging Trust and the Limits of Trustworthy Biorepository Curation

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Kraft and colleagues (2018) present an analysis of focus groups assembled to provide guidance on governance practices for biorepository-based research initiatives like the NIH *All of Us* Research Program of the Precision Medicine Initiative. They emphasize respondents' interests in institutional structures and research relationships that go "beyond informed consent" and suggest that these responses support efforts to shift the focus of governance from enhancing biospecimen donor's control over the disposition of their samples to improving the trustworthiness of the repository to make dispositional decisions on their behalf. By turning to trustworthiness as a normative guide for biorepository curation, the authors align their respondents with a laudable ongoing effort to encourage more transparency and accountability in biorepository governance. But it is not clear from their own data how much control respondents would agree to entrust to such "librarians," or that the authors have thought through the limits of the model they seem to be endorsing. Their conclusions generate at least three important questions:

1) What do we seek by going "beyond consent"?

Given the limitations of "broad" or "blanket consent" as a vehicle for expressing individual agency, a focus on putting trust in governance processes has become increasingly popular in the research ethics literature. Most advocates of this goal embrace approaches that would move dispositional authority from the donors to fiduciary agents entrusted to manage donated samples on their behalf as their stewards or trustees. In the first national survey of U.S. biobanks, Henderson and colleagues (2013) demonstrated that while most biobanks do not form relationships with contributors, they do practice stewardship over storing and sharing of specimens, thus bolstering donor trust in their protections. Kraft and colleagues seem to be reading their respondents' views similarly, as endorsing a greater fiduciary role for biorepositories as a complement to individual agency, along the lines of Koenig's (2014, 33) notion of a "consent to be governed."

In this light, it is surprising that many of the results presented in their article point in just the opposite direction: rather than wishing they could turn control over to trusted institutions, their focus group respondents seem to seek systems that can more reliably support their own individual and collective control, including more participatory schemes in which individuals play a bigger role in the management of their samples and data than ever before. For example, an interest in the biorepository equivalent of an “escape mechanism” (Kraft 2018, 25 line 12) for individual donors suggests a dedication—not alternative—to meaningful personal agency. In interpreting their respondents as calling for measures “beyond consent,” the authors seem to have only blanket or broad “upfront” consent in mind, when in fact their respondents are actually calling for more opportunities to consent, not less, along the lines of the notion of “dynamic consent”.

2) What are donors entrusting to biorepositories?

In fact, the dynamic relationships that Kraft’s respondents call for are much more complex than the usual three-part conceptual account of interpersonal trust (A trusts B with X) can accommodate (Hardin 2006, 19). Kraft and colleagues’ results reflect the array of interests that respondents entrust to biorepository curators and/or researchers, including interests in privacy protections, advancing health technologies, avoiding exploitation for financial gain, or protection from group harm. It is likely that pursuing biospecimen research that prioritizes some of these interests could mean deemphasizing others.

Given the diversity of interests at stake, there is also a potential tradeoff, as local trust could come at the cost of decreasing the overall reliability of curated data. More locally sensitive research efforts might garner community trust, yet set the stage for difficult tradeoffs as larger biorepository networks face organizational needs to harmonize data sets, and secondary researchers explore research questions not originally envisioned when the specimens and data were collected. Responsive local research could present similar barriers unless care is taken to engage donors themselves on the issue of harmonization (Goldenberg and Brothers 2018). This barrier could be addressed through explicit community engagement projects explaining the need for harmonization, which could increase donor trust and also provide biorepositories with a more solid foundation for the rationale behind at least one form of community engagement. This approach would help remedy the uncertainty biorepositories confront regarding which community engagement approach to implement, and for what purposes (Haldeman et al. 2014).

3) Whose trustworthiness matters?

So far, we have been discussing trust, a concept distinct from trustworthiness. Whereas trust is a relationship of dependency, trustworthiness is often considered to be the commitments, virtues, traits, or features that ground justified or well-placed trust. The motivations deemed central to trustworthiness have been described in terms of goodwill (Baier 1986) or a responsiveness to being counted on by others (Jones 2012).

Kraft and colleagues’ focus groups reveal how challenging it is to identify whose trustworthiness matters to potential biorepository donors. While correctly identifying trust as

a major concern of their respondents, they overlook how often their respondents' trust is only grudgingly bestowed because of firm convictions that other agents and dynamics are untrustworthy. Several respondents' expressions of "resignation" (Kraft 2018, 9 line 49) suggest that some parties or driving forces at play in the biorepository context are inevitably untrustworthy—that is, paradoxically such influences are reliably unreliable. For example, one respondent mentioned *"this data can and will be used in a way that you don't want it to be used, whether it be now or whether it be in the future"* (Kraft et al. 2018, 10 lines 3–8). Another observed the inevitability of a data breach: *"It'll happen. Over years that corruption is going to happen there, here. It's gonna happen. ... That's just the way this world works"* (Kraft et al. 2018, 17 lines 10–12). Even if specific researchers or biorepository curators are trustworthy, respondents acknowledge that the good intentions of these actors or institutions are often insufficient safeguards against the risks of biorepository research participation. As one noted: *"The idea would be to take as many precautions as possible and general protocols to have in place. Nothing's 100 percent...So, I think you just trust whoever's in charge of it, and you hope that they're doing their best to protect your information"* (Kraft et al. 2018, 17 lines 28–40). And, as Kraft and colleagues note, while respondents were particularly opposed to having representatives from the pharmaceutical and insurance industries take part in oversight, they were also skeptical about the vested interests of patient representatives. These findings are morally relevant because they suggest some outer limits to the efforts of biorepository curators and researchers to establish the trust they seek, precisely because they lack the ability to ensure the trustworthiness of some agents or dynamics outside their control.

The conclusion the authors draw from the vast array of motives and interests considered by respondents is that "the implementation of strong security and enforcement processes would make the research enterprise more deserving of patients' trust; moreover, the existence of these processes can demonstrate to patients that the research enterprise is committed to building and maintaining their trust" (Kraft et al. 2018, 26 lines 26–33). We grant that this is sometimes true, but there are at least three important limitations:

First, as described above, the trustworthiness of many of the parties and institutions mentioned by respondents lies far outside the control of the more proximate biorepository "librarians," and is thus importantly also out of reach of many proposed governance schemes. Second, as social exchange theory has long demonstrated, contracts and regulations to mitigate risk and ensure proper behavior inspire *less* trust than is produced through experiences of long term, dependent relationships (Molm et al. 2000). Third, the more complex institutional arrangements become, the more difficult it can be to effectively communicate the assurances reflective of trustworthy practices and intentions. It is a discouraging but important challenge that all organizations face, that their practices can be such that they "deserve" trust, but they can nonetheless fail to inspire it; O'Neil (2002, 144) has called this the Cassandra problem. Biorepositories are no exception: establishing trustworthy practices and inspiring trust are two different aims, and might require distinct efforts.

In conclusion, libraries are trustworthy because we can count on them to use our donations wisely on our community's behalf. Other enterprises, like overnight delivery services, are

trustworthy simply because they can be counted on to follow my specific instructions on what to do with what I give them. Both forms of confidence are bolstered by transparency and accountability, but they are not the same moral concept. Planners of biorepository research initiatives should take note that the respondents in this study seem to be as concerned with the second form of trustworthiness as the first.

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