Selling Ethics

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Selling Ethics

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Barnes et al. (2025) emphasize the need for current biobanking consent models to more deeply engage participants who want to determine how their data are used. We appreciate their desire to provide participants with real-time updates on the status of their data and make the process more accessible. We additionally agree with the goal of making biobanking data more private and secure. However, despite agreeing with the authors on these broader aims, we identify deep moral difficulties with their article on two levels. On one level, we worry that the authors have not engaged deeply enough with some of the constituent parts of their proposal. On a different level, rather than critically examining the use of novel technological methods for managing biobanking data, the article instead reads as an effort by the authors to "sell" the underlying technology under the guise of an ethics paper.

THE PROPOSED CONSENT FRAMEWORK AND AI ETHICS

The core novel concept presented by the authors is that of "demonstrated consent," a consent framework

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comprising (1) an initial, personalized consent strategy, (2) access to constantly-updated information regarding the use of donated materials, and (3) the ability to alter consent preferences at any point, including withdrawing consent. The goal of this framework is commendable. Giving users near-constant control and feedback regarding how their donated samples will be used in future studies would be an effective means of ensuring the fulfillment of three criteria originally laid out by Mikkelsen et al. (2019). However, the authors have not done enough to defend their claim that demonstrated consent is indeed a novel framework. Rather, demonstrated consent appears to be a copy of the "dynamic consent" model, simply rearticulated through a different platform (i.e. generative AI and distributed ledger technology). The model is not new; the means of enacting it is.

Yet, the authors fail to engage deeply with core issues in the ethics of AI that are directly relevant to their proposal. The rapid advancement of generative AI research and development in recent years is already giving rise to potential use cases—and corresponding ethical concerns—across a broad range of disciplines, encompassing more general concerns (e.g., privacy, misinformation, responsibility, bias, trust) as well as more discipline-specific concerns (e.g., environmental impact and sustainability, changes in education and industry; Al-Kfairy et al. 2024). While the authors address some ethical concerns regarding these technologies, their discussion is primarily limited to the topic of the blockchain (e.g., regarding security and privacy, energy consumption, and diminished oversight). Even then their analysis runs shallow to the point of resembling what Evgeny Morozov calls "technological solutionism," an approach to new technology that "presumes rather than investigates the problems that it is trying to solve" (Morozov 2013, 6). It seems that, to Barnes et al., the answer to any potential problem with the proposed framework is given by "promising technical solutions on the horizon"; the authors do not dig into the wealth of critical literature on generative AI ethics (Al-Kfairy et al. 2024)—especially as it relates to biobanking (Brault and Aucouturier 2022; Kargl, Plass, and Müller 2022)—to interrogate whether their proposed AI would truly fulfill the criteria they list. The outcome is the impression that these technologies are unequivocally net social goods—a specious conclusion at best.

This undercurrent of technological solutionism extends to the authors' analysis regarding the conflict between the core characteristics of blockchains and the sensitive and personal information captured in biobank data (e.g., blood and tissue samples, genomic data). As highlighted by the authors, blockchain technology's appeal lies in its decentralized, distributed architecture, which ensures transparency of changes across the network as well as resistance to tampering attempts. However, this ingrained transparency presents a fundamental challenge: how to effectively enforce privacy measures to protect participant data stored on the blockchain (Zhang, Xue, and Liu 2020). While the authors touch on and recognize the validity of these privacy-related concerns as a limitation of their proposal, the discussion is only cursory. This is in contrast to Racine's (2021) recent assertion that blockchain technology alone cannot adequately ensure participant privacy because its decentralized nature inherently conflicts with the ability to ensure individual autonomy. Oddly, Barnes et al. do not cite Racine at all; given the significant overlap in subject matter, engaging with it may have helped them avoid some of the pitfalls of their argument that we raise here.

A second concern arises when considering another novel concept proposed by the author a fourth consent model criterion ("Balance Criterion") aimed at weighing protections of individual autonomy with "wider societal interests in the progress of science and medicine." However, this term remains under-defined. Specifically, the article that the authors cite to explain the term does not itself utilize this term, and while they state this criterion is "implicit in the argumentation," to leave this criterion implicit is to leave an explanatory gap that obscures the possible injustices made possible through it. We are willing to believe that there may very well be tradeoffs between individual autonomy and overall security, but we can easily imagine these wider societal interests overriding the interests of vulnerable communities, or conversely the interests of the wealthy taking precedence over those same societal interests. Injustice is fluid, and it finds its way through the cracks in our concepts. It remains unclear how the authors envision that we safeguard against these potential injustices.

"SELLING" ETHICS

Taking all of these critiques together leads to a central question: what is the overall goal of this paper? The goal does not appear to be to advance a truly novel consent framework, nor is it to interrogate the relationship of AI and blockchain technology with biobanking. Rather, the paper reads as an effort by the authors to "sell" the underlying technology under the guise of an ethics paper. We call attention to this as a review-level concern because this issue is enabled by the fact that, during the review process, the American

Journal of Bioethics does not include author conflicts of interest (COI) on the "peer review only" copy of the paper, and on the finalized paper, the COIs are listed at the bottom of each article. Given that one might not expect an ethics journal to field an article that is first-authored by the CEO and founder of a blockchain company that may materially benefit from the publication of said article, one might not know to look for this COI. The question of how to format COI disclosures to best mitigate the effects of bias has been a continuing discussion in biomedical research (Dunn et al. 2016). What is surprising in this case, however, is the framing: while companies have historically promoted technological developments via publications in *scientific* journals (Dunn et al. 2016), it is far less common to see this occur in an *ethics* journal. In the future, authors should be mindful to include information about their positionality and potential COIs in the body of the paper. Furthermore, editors-in-chief should ensure that pertinent COI information is available at the top of a journal article to allow for evaluative triangulation of the presented analysis.

This practice of "selling" ethics threatens to undermine the integrity of academic writing and publishing. Instead of cultivating a space for genuine ethical debate, which is critical for the effective evaluation of this technology, this trend threatens to turn credible journals into platforms for corporate marketing disguised as scholarly discourse. We believe that this is an especially pernicious form of what one may call *ethicswashing*, a process wherein a company portrays its work as the result of ethical conduct to increase audience buy-in (Schultz, Conti, and Seele 2024).

CONCLUSIONS

Despite its presentation, this article does not represent an effective examination of the ethics of utilizing blockchain and generative AI technology for biobanking data. Rather, it represents an attempt on behalf of the authors to "sell" the underlying technology (and, thereby, the affiliated company) to a general audience. When viewed in this light, the foundation giving rise to the critiques we laid out in the first section (the dubious novelty of demonstrated consent as a framework, the undercurrent of technological solutionism) becomes clearer; in the world of business, you want to sell the sizzle, not the undercooked steak.

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