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## Injustice in Bioethics Research Funding: Going Further Upstream

Himani Bhakuni, Rieke van der Graaf & Seye Abimbola

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## Injustice in Bioethics Research Funding: Going Further Upstream

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Fabi and Goldberg (2022) have helpfully shed some light on the wrongs perpetuated by the current funding architecture on research, sponsorship, and career development in the field of bioethics. They cite Edwards (2020), who suggests that carving out space for unfunded research can be considered a form of resistance in the current academic climate. They also argue that “entrepreneurial” cultures in higher education value academic careers based on the capacity to attract funding, and as such negatively impact the careers of researchers with non-or-less-fundable topics. Their central point is that the priority placed by bioethics funding bodies on emerging technologies, genomics, neuroethics, etc., comes at the cost of bioethics research dealing with population-level drivers of health, including the prime determinants of health and its distribution. Fabi and Goldberg claim that the current skew in funding allocation perpetuates two specific kinds of injustices: epistemic (specifically hermeneutical) and racial injustice.

While we agree that funding priorities can, and often do, exacerbate existing inequalities that can lead to unjust outcomes, we believe that the causal link drawn by the authors between skewed funding priorities and epistemic and racial injustice needs further examination. Skew in funding priorities that divert the means to pursue knowledge in specific fields is a topic that merits moral critique. However, classifying the relevant injustices as epistemic might end up obscuring the relevant kind of wrongs and injustices that are perpetuated by the existing funding architecture, and the social structures that sustain it.

The concept of epistemic injustice, as pioneered by Fricker, is intertwined with levels of credibility

afforded to knowers, which is rooted in prejudices and biases based on the identity of knowers (Fricker 2007). Epistemic injustice can be of two kinds: testimonial and hermeneutical. The authors emphasize hermeneutical injustice which, according to Fricker, occurs when owing to identity prejudices, “a subject who is already hermeneutically marginalized (that is, they belong to a group which does not have access to equal participation in the generation of social meanings) is thereby put at an unfair disadvantage when it comes to making sense of a significant area of their social experience” (Fricker 2013). The claim that funding priorities in bioethics research perpetuates hermeneutical injustice would therefore be justified only if one could show that scholars of systematically unfunded structural issues belong to a hermeneutically marginalized group and that funding decisions are based on identity prejudices.

The framework of epistemic injustice conceptualizes instances of injustice in knowledge production, use, and dissemination, but one must not forget that knowledge exists beyond the boundaries of academic research (Bhakuni and Abimbola 2021). Knowledge on structural determinants of health (e.g., colonialism, sexism, poverty, exploitative trade deals, or racial discrimination) is consistently being produced by academic and non-academic researchers alike (Abimbola 2021), many of whom do not pursue knowledge based on funding priorities. The claim that systematic exclusion of topics from bioethics funding that focus on structural determinants of health would lead to a lack of shared resources needed to *interpret* and *comprehend* the significance of population-level or public health issues also goes unsupported throughout the

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paper. It is a claim that, at least at face value, strikes us as mistaken. Academic bioethics is not the only source of knowledge on structural determinants of health.

One thing is to divert people's attention from certain topics. Another is to rob peoples' ability to comprehend and interpret the significance of a certain social issue. Many people in society fully comprehend and can interpret the significance of the structural determinants of their own health—especially people with the experience of being disadvantaged by those structural determinants (Bhakuni and Abimbola 2021). That the interpretive resources at their disposal are not broadly shared by others speaks to deeper structural issues in society, such as the systematic exclusion of marginalized groups in society (and not only among researchers). Merely altering funding priorities is unlikely to address those structural issues, and it is unlikely that lack of funding on certain topics will have an effect of the magnitude described by the authors. Again, to classify the issue as one of hermeneutical or testimonial injustice the authors would have to provide some evidence that funded research is somehow afforded more credibility owing to structural biases against the identities of the researchers who do not get funded.

As Fabi and Goldberg also acknowledge, the field of bioethics is vast and there are many ways of doing bioethics. While some academic bioethicists work within projects that require dedicated external funding for support, others have academic freedom (e.g., through tenure or permanent positions). While more funding is often desirable, the domain of ethical inquiry can, and often does proceed without external funding. It might be true, as the authors claim, that many bioethics researchers who study structural issues are people of color, and that lack of funding for such research negatively impacts their careers and might lead to a lesser academic understanding of unfair distributions of the social determinants of health. But it may be injudicious to claim that, by itself, bioethics research funding leads directly to racial or epistemic injustice without rigorous empirical and theoretical analysis, and without considering alternative explanations for skewed funding allocations. One such potential explanation is the lack of representation of specific groups in positions of power whether as funders or researchers.

We believe that the explanation for skew in fundable topics is likely to be further upstream from the funding decisions themselves. If funders and academics are drawn from the same skewed socio-

demographic pool, they would both tend to prioritize the same topics to fund or study. One way to address such skew in the pool has been to include diversity and inclusion initiatives across sectors that influence academic research. The past few years have witnessed a change in the mission statements of both academic institutes and major funding bodies. They now proclaim to be committed to diversity and inclusion. Such diversity and inclusion should reflect in the funded topics as well, but as critical scholars have noted, diversity and inclusion are usually managerial buzzwords with no anchoring (Tyler 2019). Inclusion has become the prevailing method through which differences between people are not simply cataloged and governed, but also “made up,” where people are often brought into the folds to be appropriated (Dahl 2014). Funding bodies and academic institutes, who we believe often have good intentions, should strive to avoid being deceptive. A real commitment to diversity and inclusion ought to include the understanding of the human condition in its entirety—which should trickle down to the composition of funding committees and funding decisions themselves.

That said, if a topic is less likely to receive scholarly attention *because* it is less likely to receive funding, then the problem does not lie exclusively with the decisions of funding bodies, but also with the choices made by bioethicists themselves and (academic) bioethics institutions alike. Perhaps the bigger problem of the funding model is not that it can exacerbate epistemic or racial inequalities (of course it *can*), but that it *does* create perverse incentives (including incentives to exacerbate epistemic and racial inequalities, such as incentives to focus on issues and ideas that matter to dominant groups in society). It is our claim that the current funding ecosystem steers bioethics researchers to do research for the wrong reasons. It gives researchers strong strategic reasons to do research for prestige and career interests rather than for the value of discovery and social benefit. The funding ecosystem creates reasons for researchers to look at research and research activities as a game where scoring points based on arbitrary metrics replaces or instrumentalizes the search for truth, innovation, and social change. Therefore, the wrongs and injustices perpetrated by our funding ecosystem are best seen as wrongs and injustices toward the very value and point of research.

Though it may be tempting (because it is easy) to send funders to the wall, we should resist this temptation. Funders are only *partly* to blame for propagating these injustices. Our current funding model in bioethics with its skew away from upstream social

determinants of health largely depends on researchers and research institutes playing along. And some choose to do so even when they could have reasonably chosen otherwise. As bioethics scholars, we should take our fair share of the responsibility for those wrongs and their elimination. Some of us are powerholders in a position to change the direction of research funding—we should ask why this power is scarcely used. As critics of the current funding model, we must also train our eyes to recognize that, further upstream, funders and researchers have much in common with each other. After all, funding priorities are not set in isolation from the interests of dominant bioethics researchers. If anything, they mutually influence each other, as bioethics scholars are often invited to determine the research agenda of funders.

Edwards and Roy (2017) have written about the disastrous consequences of perverse incentives in STEM (Science, Technology, Engineering, and Mathematics) disciplines and have warned that “a tipping point is possible in which the scientific enterprise itself becomes inherently corrupt and public trust is lost, risking a new dark age with devastating consequences to humanity.” While this might sound hyperbolic to some, their empirically informed analysis is anything but. We fear that much of the effects of perverse incentivization in STEM fields will also hold for disciplines like bioethics if researchers fall into this rat race for funding. Fabi and Goldberg have done well to bring this issue to light because it supports our conviction that bioethics, of all fields, cannot afford such corruption.

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