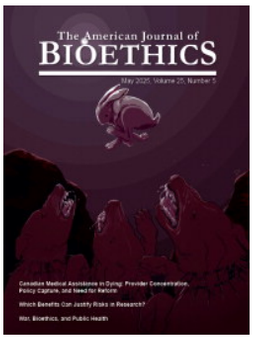

The American Journal of Bioethics

ISSN: 1526-5161 (Print) 1536-0075 (Online) Journal homepage: www.tandfonline.com/journals/uajb20

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To cite this article: Roberto Abadie, Emily Anderson, Jake Eberts, Holly Fernandez Lynch, Jill Fisher, Luke Gelinas, Emily Largent & Lindsay McNair (23 May 2025): Pursuing Fair and Just Compensation for Research Participants: An Open Letter to the Research Ethics Community, The American Journal of Bioethics, DOI: 10.1080/15265161.2025.2506328

To link to this article: https://doi.org/10.1080/15265161.2025.2506328

Published online: 23 May 2025.

THE AMERICAN JOURNAL OF BIOETHICS
https://doi.org/10.1080/15265161.2025.2506328

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GUEST EDITORIAL

Pursuing Fair and Just Compensation for Research Participants: An Open Letter to the Research Ethics Community

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A cornerstone of modern research ethics oversight is the avoidance of undue influence on potential research participants to enroll in studies. Yet little guidance is given as to what influence is "undue" (Gelinas et al. 2018). Concerns over undue influence often arise in discussions of payment to research participants, and many research ethics oversight bodies default to "payment conservatism," preferring minimal compensation to participants (or none at all) out of an abundance of caution (Largent and Fernandez Lynch 2017). This practice, however, is unfair and does not convincingly protect against harm or undue influence.

We, the 64 undersigned, from fields including philosophy, law, medicine, policy, public health, patient advocacy, and research ethics, offer this open letter to highlight the growing recognition of the pitfalls of excessive concern over payment to research participants. Experts in the field of research oversight, including institutional review boards/research ethics committees (IRB/RECs), now recognize that for adult participants capable of providing their own informed consent, instances of monetary undue influence are generally quite rare, underpayment is far more common and ethically concerning than overpayment, and that lowering payments threatens justice and fairness without providing substantive protection for participants.

There is little empirical evidence that payments at levels commonly used in clinical trials, even those in the range of several thousand dollars, result in undue influence—that is, they do not impair the ability of prospective research participants to rationally assess the risks and benefits of participation nor result in choices that conflict with their values (Emanuel 2005). This is true even among participants principally motivated by payment. Qualitative research exploring how participants conceive of payment and their own participation has failed to find convincing evidence of impaired decision-making and irrationality in the face of payment, even for highly intensive studies offering relatively large sums (Largent et al. 2022; Kraft et al. 2019; Hoogerwerf, de Vries, and Roestenberg 2020; Fisher, Monahan, and Walker 2019). Similarly, experimental attempts to find evidence of monetary undue influence of prospective research participants have failed to yield convincing evidence that the problem is at all common (Stunkel and Grady 2011; Halpern et al. 2004; Bentley and Thacker 2004; Cryder et al. 2010; Halpern et al. 2021). This also holds true for similar studies in low-income countries, even when payment is substantial relative to average incomes (Njue et al. 2014; Chi et al. 2022; Njue et al. 2018).

IRBs/RECs must be more cognizant of the negative effects of low compensation. Among healthy participants in early phase trials, low payment levels lead to targeting potential participants with greater financial need who are comparatively more willing to accept lower amounts. Rather than protecting participants, putting a ceiling on payment merely shifts the risks and burdens of research participation down the socioeconomic ladder (Lamkin and Elliott 2018). Among trials that include patients (as opposed to healthy participants), lack of adequate payment presents a financial barrier to research that may contribute to the inability for underrepresented groups to participate (Bierer et al. 2021; Winkfield et al. 2018). For non-clinical trials, greater compensation may also help promote participation by traditionally underrepresented group (Dutz et al. 2023).

Yet some IRBs/RECs remain unduly anxious about undue influence. In the United States, regulatory assurances may help assuage this fear: in 2022, then-director of the Office for Human Research

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Protections Jerry Menikoff stated that in the Office's view, payment to participants "almost never" actually constitutes undue influence, and IRBs/RECs "seem far more worried about [monetary] undue influence than OHRP as a regulator" (Menikoff 2022).

Ultimately, payment may alter one's willingness to accept risk and discomfort, but this is not unethical per se. Instead, the key question is whether one can understand potential risk and discomfort and make a reasonable, voluntary decision about participation. If there is doubt about the decision being either informed or voluntary, then efforts should focus on improving the informed consent process rather than lowering payment. If concern with payment levels for a given study persists, then the IRB/REC should examine why they worry about participation in the study—perhaps it is riskier than they initially anticipated (a distinct issue from payment) (Largent and Fernandez Lynch 2017).

Among populations that could be considered highly vulnerable, payment is still often appropriate, and even ethically mandatory at times. Far too often, in the name of protection of the vulnerable, IRBs/RECs adopt well-meaning but unnecessarily paternalistic and even condescending views of prospective participants. Unfounded assumptions about the capacity of those who use illicit drugs, engage in sex work, or live with HIV, for example, can lead to unfair mandates against any payment whatsoever, even though payment can be positive for participants (Slomka et al. 2007; Collins et al. 2017; Abadie, Brown, and Fisher 2019). The problem can also extend to the forms of payment, with some IRBs/RECs preferring gift cards, which then create additional burdens to convert to cash. Fair compensation through instruments preferred by participants is key to establishing a sense of trust and reciprocity (Abadie et al. 2018). Lowering payments out of a fear of undue influence can also slow recruitment, and by extension, the production of critical scientific knowledge needed to help the very communities and populations in question.

Absent strong evidence that monetary payment will lead to undue influence, it is likely that more harm than good is done by lowering compensation levels for a given study. Research participation generates immense social value, and generous compensation can reflect this value and serve as an important sign of respect and appreciation for participants (Fernandez Lynch et al. 2021).

Progress on compensation for research participation should also not distract from the equally important goal of realizing a comprehensive system of compensation for research-related injury in countries where such a system is not in place, including the United States (Chapman et al. 2019). While efforts on both fronts should ideally be undertaken together, better compensation for participation should not be withheld solely because of a lack of adequate compensation for research-related injury for the reasons outlined above: lowered payments do not substantively protect participants but do threaten justice and fairness.

Concern over undue influence through monetary compensation, while well intended, receives outsized attention, even at the expense of other ethical issues. Ultimately, there must be very strong rationale when suggesting such limits for an otherwise approved study, and attempts to limit payment based on the potential for undue influence should be scrutinized especially closely. IRBs/RECs should still keep in mind the amount of time required and burden on participants to ensure at least a minimum standard of compensation is met. At times, they should even require sponsors or investigators to increase compensation amounts when what they are proposing is insufficient. It is high time that the default question shift from "is this payment too much?" to "is this enough?" in clinical trials.

Individual signatories have signed in their personal capacity only. Individual signatories' institutions are listed solely for identification purposes and do not represent their endorsement of this letter.

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DISCLOSURE STATEMENT

Jake Eberts was paid by the US nonprofit 1Day Sooner for his work related to the drafting and publication of this letter. He received an honorarium and travel expenses from WCG Clinical Services to speak about compensation issues in 2023.Holly Fernandez Lynch received payment in 2020 from 1Day Sooner to lead a report on paying participants in challenge studies. She received travel expenses and an honorarium from Lilly in 2024 for a lecture on FDA approval standards. Emily Largent received payment in 2020 from 1Day Sooner to lead a report on paying participants in challenge studies. She received travel expenses and an honorarium from Lilly in 2024 for a lecture on FDA approval standards. She received an honoraria from Novartis in 2025 for consulting on an employee wellness program.

FUNDING

The author(s) reported there is no funding associated with the work featured in this article.

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