

# Research Payment and Its Social Justice Concerns

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The field of bioethics has had a long preoccupation with payment for research participation. The end result of these debates has largely been consensus that there is nothing ethically wrong with paying people to participate in research and yet it does not feel quite right either. This discomfort is particularly striking when it comes to paying healthy individuals to enroll in Phase I clinical trials that test the safety and tolerability of investigational drugs because these studies can pay substantial sums of money (at least compared to other research) and because there are so-called professional guinea pigs who treat these clinical trials as a job. The two articles published in this issue of *AJOB* shed light on these topics, with Millum and Garnett (2019) focusing on the problem of how compensation can raise important ethical concerns that are separate from the consent process itself and Malmqvist (2019) interrogating the nature of work to query whether healthy volunteers should be considered workers. These articles offer much to debates about payment for research participation, but they also both miss an important ethical concern that emerges when financial compensation is offered in contexts of profound social and economic inequality.

Revisiting the relationship between coercion and research payments, Millum and Garnett advance a new conceptualization of coercion. They argue that bioethicists have principally conceived of coercion in terms of its consent-undermining nature, meaning cases in which a person would risk losing something or be harmed by declining enrollment. In these instances, participation is not voluntary and consent is essentially meaningless if participants have no other choice but to submit. Millum and Garnett do not dispute that payment to research participants typically cannot be coercive in this way, given that financial offers contain no threat. However, Millum and Garnett depart from the field's conventional approach to the topic by claiming that a second form of coercion—"coercion as subjection"—emerges from research payments. Taking this form of coercion into account recognizes that payment can lead to a "forced action" in which the will of research participants is subordinated to the will of investigators. Participants' consent is still voluntary, but they experience a loss of freedom because it is difficult to refuse the offer of

compensation. In this way, high levels of compensation do not necessarily lead to irrational decision making; participants are able to evaluate the risks of research, but they might be more inclined to focus on the monetary benefit of enrolling when their financial need is great. Extending the logic of this ethical concern to how much participants should be paid, Millum and Garnett advance an argument for larger payments to participants based on the need to provide ample benefits to those who enroll or, conversely, to recruit only those individuals who have acceptable alternatives to research or who share similar motives and interests to the researchers.

The concept of coercion as subjection incisively advances bioethical discussions about payment for research participation by productively accounting for individuals' social contexts. However, the concept maintains a focus on the individual, placing the will of the participant and that of the researcher at potential odds. It conjures a fiction that participants and researchers should share interests, as if this would neutralize highly asymmetrical power relations. It also implies that individuals make decisions within a vacuum, determining on their own that research participation is "their only way of avoiding unacceptable alternatives," such as continued extreme poverty (to take Millum and Garnett's example). The reality is that individuals are influenced by their social networks and their prior experience, so that paid research participation becomes the best or most obvious way of dealing with a bad situation—and even less-than-ideal ones—as opposed to the only way. That is why people engage in serial research participation and are often encouraged to enroll for the first time by a friend or family member who has also participated and recommends it as a source of income. Participation is a socially embedded activity. By focusing on discrete individuals, the concept of coercion as subjection also ignores larger demographic patterns of who participates in the highest paid research opportunities. Specifically, the majority of healthy volunteers participating in U.S. Phase I clinical trials are racial and ethnic minorities despite their underrepresentation in later phases of research (which, notably, do not compensate as handsomely) (Fisher and Kalbaugh 2011).

Elsewhere, I have argued that *structural coercion* provides a better lens to understand why individuals from

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certain groups are more likely to be overrepresented in paid research (Fisher 2013). This conception of coercion builds on the anthropological literature on structural violence to argue that the threat of harm is external to the research context itself but nonetheless compels people to enroll in studies because the risk of not enrolling exceeds (at least in the minds of participants) the risks of any research protocol (see also Cottingham and Fisher 2016). The commercial clinical trials industry has referred to such prospective participants as “ready to recruit,” which really means that they are ready to consent to research (Fisher 2007). Within the context of profound social and economic inequalities in the United States, racial and ethnic minorities face the most difficulty securing and maintaining stable employment at living wages. Increasing the amount paid for research participation might certainly make the activity less exploitative, but it does not change the broader pattern of burden being placed on certain members of society—that is, members who are the least likely to benefit (at least in the short term) from advances in medical research. Researchers cannot themselves solve the problem of structural coercion, as broad societal reforms are necessary to eliminate, or at least mitigate, the many forms of structural violence to which people are subjected. Payment to participate in research is nonetheless central to this problematic and cannot be rectified by accounting only for coercion as subjection.

In his article, Malmqvist is somewhat dismissive of the concept of structural coercion because of the lack of a regulatory fix to the problem within the domain of human subjects research and because, to his mind, the situation is equivalent to “being ‘structurally coerced’ to make a living flipping burgers.” Yet this is where the question of whether research participation should be considered work intersects with the ethics of paying people to enroll in clinical trials, particularly in a context of profound social inequality. Because research participation is not employment as regulated by federal labor law, it is not at all like flipping burgers. Regardless of whether fast-food work is desirable, employees are entitled to a minimum wage, safe working conditions, and nondiscrimination, as well as the right to form labor unions. Although federal labor laws might not be sufficiently robust in the United States (compared to other countries and particularly in regard to paid leave), research participants have no recourse to any employment rights. At the same time, this is not to say that people paid to participate in research should be considered employees. Given what research typically entails, it would be difficult to argue that participants should be considered employees based on the short-term nature of the activity as well as other myriad factors that make it qualitatively different from more traditional forms of employment. Yet this is a different issue from whether research participation is “work” or should be considered a “job.”

Healthy volunteers in Phase I clinical trials are technically independent contractors who receive taxable income from their trial involvement, making them

effectively self-employed in this economic activity. This is true regardless of how healthy volunteers perceive themselves or how frequently they enroll in clinical trials. Malmqvist focuses on professional guinea pigs because they do pursue clinical trials as their job, squarely situating research participation as work. Although it is a newer form of labor than paid research participation, the gig economy today (e.g., Uber and TaskRabbit) encapsulates many of the promises and perils of working as an independent contractor for businesses that offer flexible ways to make money with none of the security of traditional employment (Friedman 2014). The rise of this labor market indicates that U.S. employment laws are no longer equipped to adequately protect individuals who are not employees but routinely engage in insecure work.

I agree with much of what Malmqvist has to say about healthy volunteers’ involvement in clinical trials. Still, by focusing on “professional” participants alone, the view of payment for research participation problematically conflates an economic activity pursued by a relatively small—though fascinating—number of research participants with a larger and more ethically fraught trend wherein clinical trials serve as a type of safety net for individuals in precarious financial situations. This brings us full circle back to Millum and Garnett’s article. Debating whether paid research participation is work or the extent to which participants must subordinate their will to that of the researchers has the potential to distract bioethics scholars from focusing on the broader justice issues that emerge when economically vulnerable populations disproportionately enroll in paid research. ■

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