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Commentary

Putting Financial Compensation for Research in a Different Risk Framework

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Abstract

In the ethics literature, concern about financial compensation has largely focused on the question of how payment could distort research participants' perception of risk. Such concern about "undue inducement" has particularly occupied institutional review boards (IRBs) and has often led to conservative judgments about how much financial compensation participants can be offered in exchange for their participation in research. Increasingly, bioethics scholars have argued that such approaches to financial compensation in research could exploit participants, on one hand, or create a barrier to their enrollment, on the other. Despite the vast literature on financial compensation for research, there has been substantially less attention to the potential risk that such payment may pose to research participants. The current system of taxing research compensation is one important example of the financial risks to research participants that warrants more analysis and legislative action.

Keywords: research participation; study compensation; taxes; risk

In the ethics literature, concern about financial compensation has largely focused on the question of how payment could distort research participants' perception of risk.[1] Such concern about "undue inducement" has particularly occupied institutional review boards (IRBs) and has often led to conservative judgments about how much financial compensation participants can be offered in exchange for their participation in research.[2] Increasingly, bioethics scholars have argued that such approaches to financial compensation in research could exploit participants, on one hand, or create a barrier to their enrollment, on the other.[3] Thus, payment for research remains a fraught issue in bioethics and for IRBs with no clear answers for how to determine how much compensation is ethically appropriate and respectful of participants' contributions to research.[4]

Despite the vast literature on financial compensation for research, there has been substantially less attention to the potential risk that such payment may pose to research participants.[5] In their excellent article in this issue, Albert-Rozenberg and colleagues have made an important contribution to this line of research.[6] Specifically, they examine the potential consequences for participants in the United States of receiving financial compensation from research on their eligibility for 12 federally funded social safety-net programs, including Medicaid, Federal Low-Income Housing, Supplemental Nutrition Assistance Program (SNAP), Supplemental Security Income (SSI), and Temporary Assistance for Needy Families (TANF). Their article is the first exploration of how clinical trial "income" could affect individuals' participation in these specific programs. Their findings reveal two potential challenges for research participants. First, clinical trial compensation conveys a real risk to participants of either being disqualified altogether from income-dependent federal programs or having their benefits reduced. Second, because of differences in state laws and the complexity of the eligibility requirements for these programs, the effects of compensation on federal programs are difficult to determine in advance and create an unreasonable burden on participants to ascertain. While the US Congress has carved out some exemptions for clinical trial compensation to count as income, such as for cancer research, Albert-Rozenberg et al. point out that most research compensation continues to be taxable income that would affect eligibility for these federal safety-net programs.

For Albert-Rozenberg et al., the focus of their critique is that the status quo of treating financial compensation for research as taxable income that affects eligibility for safety-net programs is counterproductive to other federal goals of increasing the diversity of clinical trial participants.[7] Their framing of the problem advances concerns about the inclusion of diverse participants and the barriers to recruiting more people of color into clinical trials.[8] This framing also productively shifts the focus away from individual factors, such as trust in the research enterprise, to structural factors, such as financial disincentives for low-income people of color to enroll in research.[9] This is an important and persuasive argument. For example, in the case of healthy volunteers, where research compensation is typically the most substantial of all clinical trials,[10] people of color are actually overrepresented,[11] which suggests that payment can indeed change who enrolls in research. However, under the new Trump Administration, clinical trial diversity may no longer get much traction as an argument for policy change in how compensation for research is regulated. Nonetheless, even beyond diversity goals, changes to how research compensation is categorized within the tax code are worth pursuing.

From a research ethics perspective, whether and how financial compensation for research is treated as taxable income raises

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questions of fairness. For example, Rand and Kesselheim argue that "taxing payments made to research participants is unfair when other forms of socially valuable transactions are not taxed."[12] In this vein, in my prior research, some healthy individuals who enrolled in clinical trials for the financial compensation felt that it was unfair to have this tax liability, particularly because they were taking a physical risk and were "saving lives" through their participation.[13] Simply put, treating research compensation as taxable income does not respect the contributions of participants to the broader research enterprise.

Beyond fairness, the current system of taxing research compensation also comes with financial risks that have largely been unacknowledged. Instead of focusing on undue influence, there is a need to understand that paying participants can jeopardize rather than ameliorate their financial situations. My prior research has also indicated that many healthy volunteers did not understand that the money they earned in clinical trials was taxable income.[14] Because no taxes are withheld from study payments (as participants are not employees but independent contractors), some individuals were surprised to learn they owed money when they filed their taxes. Some enrolled in another clinical trial to pay their tax bill, and others chose not to file their taxes at all to avoid the payment. These findings indicate that the consent process fails to inform prospective participants about the tax implications of enrolling in research, which puts them at even greater financial risk. Despite the insufficient information given to participants about the potential consequences of research participation, some healthy volunteers in my study anticipated the risk to their eligibility for federal programs, including student loans and social security programs, and as Albert-Rozenberg et al. suggest,[15] concerns about accessing these programs did indeed curb their clinical trial participation. Thus, in the context of healthy volunteer trials, compensation both motivated and limited participants' clinical trial enrollment depending on their financial situations. Regardless, for most healthy volunteers, the financial benefits were never as lucrative as they initially seemed,[16] and the hidden tax liability made the offer of compensation misleading because it promised more than what would actually be earned. Eliminating the tax liability for participation would go a long way to reducing the financial and legal risks to clinical trial participants — healthy or otherwise — and make the system fairer for those who are on the frontline of medical research. Albert-Rozenberg et al.'s article fits within this framework by underscoring the extent of the financial risk to which research participants may be exposed in medical research.[17]

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