COMMENTARY Tax the Rich! Tax the Research Participants?

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altz, David, and Fisher claim that the bioethics literature has been "silent about any tax liability associated with [research] payments."1 But there has, at the very least, been a whisper that taxation is one amongst a host of ethical and legal issues that ought to be considered when payment is offered to research participants.² Offers of payment can serve various functions - to reimburse reasonable research-related expenses, to compensate participants for their time and other contributions to research, and to incentivize research participation.³ As Waltz et al. note, participant payments, excluding reimbursements, are taxable income, and as such must be reported to the Internal Revenue Service (IRS). Though this may seem like a dull bureaucratic detail, it is a detail worthy of ethical reflection.

What are the ethical implications of taxing researchrelated income? If participants pay their taxes, their take-home pay from research participation is lower than their gross pay. Although there are often worries that participants are paid too much, this concern generally affixes to what is paid *prior to deductions*. When we think instead about net pay, it may change our sense of what counts as fair payment and, perhaps,

Emily A. Largent, J.D., Ph.D., R.N., is the Emanuel and Robert Hart Assistant Professor of Medical Ethics & Health Policy at the University of Pennsylvania Perelman School of Medicine, and she holds a secondary appointment at the University of Pennsylvania Carey Law School. lend support to the argument that we should worry less about over-paying and more about under-paying participants.⁴

If participants do not pay their taxes, they are exposed to financial and legal risks. It has long been recognized that the risks of research participation are not limited to the physical and psychological but can also encompass the economic and social. Risks must be minimized and accurately communicated to participants through an informed consent process.⁵ Yet, as Waltz et al note, and as I too have found in prior empirical research, the tax implications of participant payments are often not sufficiently addressed in consent documents.⁶

There is another financial risk associated with payment for research participation that must be made clear. Participants may find that earning researchrelated income affects their eligibility for Supplemental Security Income (SSI) — monthly payments to low-income older adults and persons with disabilities — and other public benefits programs. Waltz et al. make the irony apparent. People often express concerns that there is an unjust reliance on — even exploitation of — worse-off individuals to fill Phase I trials. Yet, participation in these same trials may make it more difficult to access or prevent individuals from accessing public assistance programs intended for the worse-off.⁷

Some may wish to argue that this is good: if income is a primary driver of program eligibility, becoming ineligible is a sign of less need. Others (including myself) will cast aside such optimism in favor of skepticism. Payments from Phase I trials are more likely to yield short-term changes in income or circumstances, rendering individuals temporarily ineligible,

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than to create sustainable changes. Income volatility is not problem-free. Consider that people on Medicaid who experience "churn" — a temporary loss of coverage, often due to income fluctuations, characterized by individuals disenrolling and reenrolling in a brief window — leads to coverage gaps, erects barriers to accessing care, and is associated with greater administrative costs.⁸ Appreciating these complications, we can see why "perverse" efforts to keep one's researchrelated income low, a finding reported by Waltz et al, are also rational. Act of 2015, signed into law by President Obama, allows individuals participating in clinical trials for rare diseases to receive up to \$2,000 in research compensation without having this counted as income for SSI and Medicaid eligibility calculations. This could serve as a model for broader legislation — broader in terms of the total allowable compensation or the research encompassed by it.

Yet, this is not a straightforward solution. We must still grapple with what amount of research-related income it is appropriate to exempt from tax calcula-

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In their article, Waltz et al. focus on participants in Phase I studies, in which average payments to participants are larger, because that was the sampling frame for their qualitative research. Yet, the issues they identify arise in later-phase studies too, and when payments are relatively more modest. For example, I led a qualitative study to understand the effects of payment on individuals' decisions to participate in a randomized controlled trial evaluating an ambulation intervention; the trial was deemed minimal risk and offered a prospect of direct benefit to patientparticipants. One participant asserted that the \$300 payment offered to participants "helped me with my financial problems" but also described feeling "uneasy about the tax [consequences]...[b]ecause I am on SSI."9 Thus, the authors' call for greater attention to the tax and benefit implications of payment applies to research broadly, though the stakes may be heightened in Phase I studies.

I was somewhat surprised that neither the authors nor the individuals they interviewed offered a robust argument for paying research participants more. Perhaps they viewed this as a non-starter given ethical debates swirling around payment. Rather, Waltz et al. conclude that "research compensation should be categorized as non-taxable income." In fact, there is a precedent for this. The Ensuring Access to Clinical Trials tions and for what kinds of studies. Tax exemption would function as a research subsidy. Participants would surely enjoy the additional personal consumption that came from untaxed income, potentially making research participation relatively more attractive than alternative uses of their time. Tax exemption would likely also benefit sponsors (often pharmaceutical companies) and funders, who would not themselves be paying participants more, and perhaps eventually taxpayers. But to what extent is research participation simply a job to be done and to what extent is it special, deserving of special tax status?

Perhaps a friendly amendment to Benjamin Franklin's famous adage is that nothing is certain but death and taxes ... and the persistence of ethical questions regarding payments to research participants.

Note

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