

Bioethicists call for end to 'pay-to-play' clinical research

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Charging people to participate in research studies is likely to undermine the fundamental ethical basis of clinical research, according to a new paper written by bioethicists, including lead author Ezekiel Emanuel, MD, PhD, chair of the department of Medical Ethics and Health Policy at the Perelman School of Medicine at the University of Pennsylvania, and published in *Science Translational Medicine*. The paper outlines the arguments for and against the concept of "pay-to-play" research, ultimately concluding that this type of approach compromises the overall integrity of clinical research.

The paper was prompted by a call asking Emanuel about the legality and ethics of such "pay-to-play" research by researchers who are frustrated over shrinking budgets. The researchers wanted to charge research participants as a way to fund research that otherwise wouldn't move forward. In the paper, the authors suggest that with current resource constraints in medicine leading to patients bearing more of their medical costs—through high-deductible plans, for example—it may seem natural to ask participants to contribute to the price of research that could potentially benefit them.

The two strongest arguments for charging research participants are that "pay-to-play" research would fund studies that otherwise would not be conducted, and the freedom argument that patients should be free to do whatever they want with their money as long as it does not harm others, so buying into research is just one way they should be able to spend their money. But the authors say that "pay-to-play" research might actually be

harmful. First, it could exploit desperate patients who will do anything to save their own life or a loved one, and who don't have the ability to properly evaluate the likelihood of receiving benefit from the research. Furthermore, once people pay to be part of research studies, this is likely to skew both the types of studies that are conducted and how they are conducted. Paying research participants are unlikely to accept being randomized, especially if it might get them a placebo or a control intervention, and they might be reluctant to abide by the need to report side effects and other problems with a study.

"Because pay-to-play research has a high likelihood of undermining the research enterprise by skewing the types of studies pursued and the researchers and facilities devoted to particular projects, exploiting people, and compromising the methodological rigor of clinical studies, it is not accurate that no one is harmed by people's exercise of their freedom," write the authors. "We are all harmed with the integrity of [clinical research](#) is compromised."

More information: Clinical research: Should patients pay to play?, [stm.sciencemag.org/lookup/doi/ ... scitranslmed.aac5204](http://stm.sciencemag.org/lookup/doi/.../scitranslmed.aac5204)

Provided by University of Pennsylvania School of Medicine

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