

A Penny for Your Thoughts? Moving Research Payment Transparency from Idiom to Policy

Brandon Brown, PhD, MPH, University of California Riverside and **Jerome Galea, PhD, MSW**, University of South Florida and Harvard Medical School

May 17, 2023

Payment for participation in research—especially clinical research—is a common practice, but researchers often find themselves working in a “black hole” regarding payment. There are no well-described standards for decision-making on payment amounts and forms of payment, apart from the Belmont Report’s abstract warnings against exerting “coercion and undue influence” (HHS, 1979). Without tools to support decision-making in this area, payment decision practices tend to be subjective and based on personal experience; researchers with no experience in this area may make payment decisions for research participation based on available funds, personal notions, and guesswork of “what’s best.”

Nonetheless, the authors know from personal experience that payment decisions can significantly impact studies at each step of the CONSORT process, from screening and enrollment to condition allocation and retention and, ultimately, data analysis and reporting (Altman et al., 2001). Emerging data on payment decision-making—although still limited—reveals a complex web of factors that drive payment amounts, including participant type, proximity to the study site, risks involved, procedure invasiveness, and the expectations of research participants themselves, which may be based on their experiences in other studies. Given the potential influence of these myriad factors on study participation, it is therefore surprising that to date there has been a relative absence of attention and transparency on what, how, when, and by whom participant payments are determined (Anderson and Brown, 2021).

The prevailing worry about participant payments is that they could be coercive or cause undue influence on participants’ decisions to participate in research or undertake certain study procedures. More recently, however, ethicists have moved away from this paradigm to focus on the opposite issue: *underpayment* of people who participate in research, and the ethical principle of beneficence (Largent and Lynch, 2017). Although ethics committees do not typically consider payment in the risk/benefit ratio when reviewing research, participants may view payment as another benefit of research participation.

Progress in the Science of Participant Payment

Over a decade ago, the authors proposed the creation of an incentives database to help with research decision-making (Brown and Merritt, 2013). This was easier said than done; a better understanding is still needed of what data points to collect, as well as the range of incentives to study, so as to more accurately guide decision-making according to specific research project types. In 2018, a *New England Journal of Medicine* article defined three types of payments—*incentives*, *compensation*, and *reimbursement*—which laid the groundwork for the future establishment of a practical and implementable framework (Dominguez et al., 2012). The National Institutes of Health have internal payment guidelines as part of their clinical research enterprise, indicating that scientists have indeed faced the debate of standardizing payment, at least in the primary federal agency that conducts and supports medical research (Gellinas et al., 2018).

The recently revised Common Rule offers one potential solution to the current lack of available payment data by requiring that researchers post informed consent forms on clinicaltrials.gov and regulations.gov (HHS, 2022). Since consent forms should contain payment types and amounts, the publication of these forms finally makes it possible to mine the data. But unexplained payment amounts in research suggests that a systematic collection of study features is required in order to make any useful inferences on payment data (Grady et al., 2005).

Data, Commitment, and Policy

Payment data exist but are not uniformly made public. Researchers should be required to transparently and publicly report these data (i.e., in databases and publications), just as they are required to do so for other key research elements such as study duration, specific study procedures, assurance of compliance to research ethics, potential conflicts of interest, and dissemination plans. Some studies have collected data on the perspectives of individual stakeholders

Stakeholder	Possible Activities	How They Will Benefit
Research institution	<ul style="list-style-type: none"> Track payment types/amounts provided Create payment standards for research 	Will have a reference for what type and amount of payment has been provided in research
Ethics committee	Create a method of evaluating payments, including a focus on underpayment	Will have increased opportunity to objectively review payment appropriateness on a study-by-study basis
Journals	Require authors to report payment and require reviewers to consider participant payment in their review	Will have full transparency and ensure authors know what was provided to their participants
Funders	Collect description of how payment decisions were made when researchers submit proposals	Will hold researchers accountable and optimize funders' return on investment
Researchers	Engage the participant community prior to making decisions on payment types and amounts	Will likely have more satisfied participants and better participation
Participant community	Ask how payment decisions were made	Will receive more appropriate type/amount of payment

TABLE 1 | Stakeholder Activities and Benefits of Having Transparent Payment Data

SOURCE: Created by authors.

regarding payment, with the majority of data coming from research participants themselves (Largent et al., 2022; Ripley et al., 2010). Progress in this area, however, will require the perspectives of all major research stakeholders—not only participants, but also ethics committees, lead researchers, sponsoring institutions, and funders. Without this information, it is not possible to balance all stakeholder interests. For example, participants may want higher payments, but ethics committees may be concerned that high payments have the potential of undue influence. Meanwhile, funders may want lower participant payments so as to permit the funding of more projects, while researchers may just be making their best guess at an appropriate payment amount that fits their budget. Guesswork is clearly suboptimal, and a clear payment reporting policy could make a significant difference. The policy should be data-driven, and the increasing transparency of participant payment is a promising first step. But this commitment to transparency will only work if all stakeholders are involved in collecting and framing the data.

Data which tell a more complete story are emerging—through surveys, interviews, focus groups, vignettes, and retrospective data review—but they remain very limited (Polonijo et al., 2022; Brown et al., 2021; Galea et al., 2021).

Table 1 outlines various activities that different stakeholders may undertake to increase the transparency of payment data, and how these stakeholders may benefit from their efforts (see Table 1).

Increased availability and transparency of payment data, as outlined in Table 1, will allow researchers to more robustly analyze factors linked to payments and will provide the inputs to a payment database to drive real-world decision-making. Such a payment database may collect study- and participant-related factors, then provide decision-makers with a range of payment

types and amounts offered in previous and current studies. The database may find that payment decision-making should be fluid and dynamic, similar to decision-making on what funding to pursue for specific types of research or even decision-making outside of research, such as choosing an airline flight, selecting an item from online markets, or choosing an internet service provider. But without data, decision-makers cannot and do not know. The process of deciding on the factors to include in a payment database is complex, but it is achievable.

Participant payment determination is an area with clear and achievable opportunities for research advancement. A payment database can be used to develop minimum and maximum acceptable payment amounts in research based on data distribution, measures of central tendency, and variability, or it can be used simply as a growing reference for data-driven decision-making in future research. Either way, it is time to move from idiom to policy in payment for participation in research.

References

- Altman, D. G., K. F. Schulz, D. Moher, M. Egger, F. Davidoff, D. Elbourne, P. C. Gøtzsche, and T. Lang for the CONSORT Group. 2001. The revised CONSORT statement for reporting randomized trials: Explanation and elaboration. *Annals of Internal Medicine* 134(8): 663–694. <https://doi.org/10.7326/0003-4819-134-8-200104170-00012>.
- Anderson, E. E., and B. Brown. 2021. A call for radical transparency regarding research payments. *The American Journal of Bioethics* 21(3): 45–47. <https://doi.org/10.1080/15265161.2020.1870763>.
- Brown, B., and M. W. Merritt. 2013. A global public incentive database for human subjects research. *IRB* 35(2): 14–17.

4. Brown, B., L. Marg, E. Michels, Z. Zhang, D. Kuzmanović, K. Dubé, and J. T. Galea. 2021. Comparing payments between sociobehavioral and biomedical studies in a large research university in southern California. *Journal of Empirical Research on Human Research Ethics* 16(1-2): 117–124. <https://doi.org/10.1177/1556264620987773>.
5. Dominguez, D., M. Jawara, N. Martino, N. Sinaii, and C. Grady. 2012. Commonly performed procedures in clinical research: A benchmark for payment. *Contemporary Clinical Trials* 33(5): 860–868. <https://doi.org/10.1016/j.cct.2012.05.001>.
6. Galea, J. T., K. Y. Greene, B. Nguyen, A. N. Polonijo, K. Dubé, J. Taylor, C. Christensen, Z. Zhang, and B. Brown. 2021. Evaluating the impact of incentives on clinical trial participation: Protocol for a mixed methods, community-engaged study. *JMIR Research Protocols* 10(11): e33608. <https://doi.org/10.2196/33608>.
7. Gelinis, L., E. A. Largent, I. G. Cohen, S. Kornetsky, B. E. Bierer, and H. F. Lynch. 2018. A framework for ethical payment to research participants. *New England Journal of Medicine* 378(8): 766–771. <https://doi.org/10.1056/NEJMs1710591>.
8. Grady, C., N. Dickert, T. Jawetz, G. Gensler, and E. Emanuel. 2005. An analysis of U.S. practices of paying research participants. *Contemporary Clinical Trials* 26(3): 365–375. <https://doi.org/10.1016/j.cct.2005.02.003>.
9. U.S. Department of Health and Human Services (HHS). 2022. *Informed Consent Posting Instructions*. Available at: <https://www.hhs.gov/ohrp/regulations-and-policy/informed-consent-posting/informed-consent-posting-guidance/index.html> (accessed May 4, 2023).
10. HHS. 1979. *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. Available at: <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html> (accessed May 4, 2023).
11. Largent, E. A., and H. F. Lynch. 2017. Paying research participants: The outsized influence of “undue influence.” *IRB* 39(4): 1–9. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5640154/> (accessed May 4, 2023).
12. Largent, E. A., W. Eriksen, F. K. Barg, S. R. Greysen, and S. D. Halpern. 2022. Participants’ perspectives on payment for research participation: A qualitative study. *Ethics & Human Research* 44(6): 14–22. <https://doi.org/10.1002/eahr.500147>.
13. Polonijo, A. N., K. Dube, J. T. Galea, K. Y. Greene, J. Taylor, C. Christensen, and B. Brown. 2022. Attitudes toward payment for research participation: Results from a U.S. survey of people living with HIV. *AIDS and Behavior* 26(10): 3267–3278.
14. Ripley, E., F. Macrina, M. Markowitz, and C. Gennings. 2010. Why do we pay? A national survey of investigators and IRB chairpersons. *Journal of Empirical Research on Human Research Ethics* 5(3): 43–56.

DOI

<https://doi.org/10.3147/202305a>

Suggested Citation

Brown, B., and J. Galea. 2023. A Penny for Your Thoughts? Moving Research Payment Transparency from Idiom to Policy. *NAM Perspectives*. Commentary, National Academy of Medicine, Washington, DC. <https://doi.org/10.31478/202305a>.

Author Information

Brandon Brown, PhD, MPH, is Full Professor of Medicine, Department of Social Medicine, Population, and Public Health, at University of California, Riverside. **Jerome Galea, PhD, MSW**, is Assistant Professor of Social Work and Courtesy Assistant Professor College of Public Health at the University of South Florida; Lecturer at Harvard Medical School; and a Health and Policy Advisor at Partners in Health.

Brandon Brown is an NAM Emerging Leader in Health and Medicine Scholar.

Acknowledgments

The authors would like to thank the CA\$H (Considerations Around Study Honoraria) study team and community advisory board for their contributions to emerging data on participant payment in research and working towards a future where payment data are transparent.

This paper benefited from the thoughtful input of **Sarah Greene**, National Academy of Medicine.

Conflict-of-Interest Disclosures

None to disclose.

Correspondence

Questions or comments about this paper should be sent to Brandon Brown at brandon.brown@ucr.edu.

Disclaimer

The views expressed in this paper are those of the author and not necessarily of the author’s organizations, the National Academy of Medicine (NAM), or the National Academies of Sciences, Engineering, and Medicine (the National Academies). The paper is intended to help inform and stimulate discussion. It is not a report of the NAM or the National Academies. Copyright by the National Academy of Sciences. All rights reserved.