



Designing & Conducting Payment & Incentives for Research

Guidelines for CHIBE and PAIR

Research Payment Types



Reimbursement

for expenses



Compensation

for time, effort, and burden



Incentives

to encourage participation or
promote certain behaviors

The guidelines described in this PowerPoint should apply to all categories of payment, except when noted.

Table of Contents

[Ethical Considerations](#)

[Equity Considerations](#)

[Research Risks & Benefits](#)

[Payment Methods & Timing](#)

[Size of Payment](#)

[Regulations & Governance](#)

[Planning & Administration](#)

[References](#)

Ethical Considerations

Principles of Ethical Considerations

Payment (e.g., incentives) constitutes an offer instead of threat and generally places no restriction on choice, so ethical concerns of **coercion are often unjustified**

Improving decision-making processes through incentives is often a legitimate feature in behavioral research design

Participatory autonomy and **intrinsic motivation** can be negatively affected

Principles of Ethical Considerations

It's important to differentiate concerns of **undue inducements** by diminishing peoples' sensitivity to research risks, or **unjust inducements** by preferentially increasing burden among underserved individuals, compared to intended, **socially responsible, and beneficial influences**

Prior literature suggests that offering payment might induce potential participants to deceive investigators about their eligibility for study participation

Practical advice: Ethical Considerations

- Payment should not be bundled with access to clinical care to avoid chance of coercion or exploitation
- Expected payout should not be unreasonably large due to concerns that excessive payment may lead to undue or unjust inducement of participants of lower socioeconomic status

Practical advice: Ethical Considerations

- A study should allow payments to be declined, substituted to support causes such as charity, or simply re-purposed by participants who are driven by altruistic motivations
- Investigators should consider the risks of deception due to payment, and rely more on using objective criteria or measurements rather than self-reported data

Equity Considerations

Principles of Equity Considerations

Socioeconomically vulnerable groups may have higher disease burden, inadequate social support, and poor access to care, leading to distrust

Higher hurdle to participate in research

Payment or incentives are considered **disproportionately influential** on the most vulnerable

It is important to consider these challenges to promote **justice and fairness** to these participants

Practical advice: Equity Considerations

- It is recommended to offer sufficient payment to help participants overcome barriers in research participation
- **Pay equally regardless of individual's socioeconomic status or income**, or risk undermining the principal of equal pay for equal work
- Unequal pay may be acceptable (but needs careful review) only if higher compensation is used to nudge members of lower income and/or underrepresented groups

Practical advice: Equity Considerations

Careful review by the researchers or the research governance bodies, such as IRBs, is recommended under the following circumstances:

- If payment or incentives are designed to only target certain participants such as socioeconomically vulnerable populations
- If a study attracts more socioeconomically vulnerable participants (e.g., concern of research commercialization)
- If a study is unable to recruit enough socioeconomically vulnerable participants from the population at risk (e.g., payment or incentives are not set high enough to help them overcome barriers for participation)

Research Risks & Benefits

Principles of Research Risks & Benefits

Payment may be **perceived as risk** by participants; this is particularly true given the level of **distrust** among certain sociodemographic groups historically impacted by exploitive research practices.

Payment can potentially influence participant's willingness to **accept higher risks**

Additionally, **risk tolerance and required compensation may vary** based on one's socioeconomic status – leading to complex ethical and equity challenges

Principles of Research Risks & Benefits

Research **payment or incentives should not be used as a benefit** to participants and should **not** be used to offset research risk

Payment should only be used to fairly compensate participants for their time, effort, and opportunity cost; or in the case of incentives, as part of study design to motivate desired behaviors

Principles of Research Risks & Benefits

Risks and benefit should be balanced. Individuals who bear the risks and burdens of research should be in a position to enjoy its benefits, and those who benefit should share some risks and burdens.

In studies involving more than minimum risk, researchers need to consider non-monetary benefits derived from research.

Practical Advice: Research Risks & Benefits

Potential risk should be clearly communicated with prospective participants through informed consent process.

- Use of an information or decision aid can help with this process.
- Participants' risk assessment or risk perception should be evaluated and considered

Practical Advice: Research Risks & Benefits

We caution against tying payment to potential research risk

- Discourage use of payment to compensate for risk
- Instead, focus on addressing adverse events

We recommend decoupling payment from potential health benefit to research participants

- Studies that hold the prospect of direct health benefit should pay no less compared to studies with no prospect of such benefit

Practical Advice:
Research Risks & Benefits

It's justifiable to **target underrepresented or underserved socio-demographic groups** for research enrollment, **if** they also derive greater benefit from such research

Our recommendations may not apply when research risk is considered moderate or high

Payment Methods & Timing

Principles of Payment Methods & Timing

Common payment methods may include cash, checks, debit cards, prepaid cards (such as gift cards), and account-to-account money transfers

However, **innovations in payment technologies** do not always apply to all segments of the population equally

Study participants of lower socioeconomic status are often unbanked or underbanked, and **constrained with the type and variety of payment methods** available to them

Principles of Payment Methods & Timing

With the COVID-19 pandemic, many research studies shifted to virtual/digital payment methods, mostly eliminating the option to provide **cash payments** to research participants.

Unfortunately, the **non-cash options create barriers** especially for those who do not have a secure location to receive mail, bank access, or are experiencing homelessness or housing instability

Principles of Payment Methods & Timing

The likelihood that an individual will **prefer a card payment** over cash is largely dependent on one's household income

Unbanked and underbanked individuals often **prefer cash payment** or a general purpose reloadable prepaid card, compared to limited use payment, such as a gift card

There are **large differences in payment preference** by race, ethnicity, gender, income, and education

Principles of Payment Methods & Timing

There is a lack of information on how individuals like to receive payment, but there are studies on consumer preferences, in usage of different payment instruments (**not intended as recommendation**)

Asian individuals are much less likely to prefer debit cards, *but* more likely to prefer credit cards than cash

Black individuals are less likely to prefer debit cards *and* much less likely to prefer credit cards compared to cash

Hispanic individuals are about equally likely to prefer debit cards when compared to cash

Women are more likely to prefer cards over cash *and* are twice as likely to prefer debit cards

Practical Advice: Payment Methods & Timing

Participants often have different preference of receiving payment

- Efforts should be made to make multiple payment options available

Although researchers are often constrained in their ability to pay participants in cash, efforts should be made to offer participants options to receive cash payment when possible

Practical Advice: Payment Methods & Timing

- Study teams should investigate **potential costs or fees** related to payment methods and **communicate such information** to research participants
- Payments and incentives should be **made as soon as the required action by participants is completed** throughout the research processes
- Expected or unexpected **delays in payments**, including mailing payment cards, should be **clearly communicated** with research participants

Practical Advice: Payment Methods & Timing

- The last research visit may be “valued” at a higher rate, as the individual’s participation is more useful to the research if the participant completes all visits; however, it would be **inappropriate to withhold all payments** until the end of a study
- Researchers can also **proactively develop strategies to reduce participant costs** other than, or in addition to, direct payment:
 - Identifying study locations near where participants work or live can reduce both travel time and associated costs
 - Researchers can provide food, transit or transportation, and on-site childcare for participants

Size of Payment

Principles of Size of Payment

Based on our literature review and feedback from our focus group, the overarching concern is not overpaying our study participants, but **heightened risk of underpaying** them

Research shows that **desired payment differs significantly** by racial or ethnic groups, with minority groups, such as Black and Hispanic participants, often **requesting higher payment**

Similar findings suggest that **requested payment is often higher among lower income groups**

Principles of Size of Payment

Compared to other participants, those from lower socioeconomic and racial or ethnic minority groups **may consider payment inadequate** even when some still participate in your research

Payment should not vary based on individual wages or earning capacity, or other sociodemographic characteristics

Amount of reimbursement can vary based on actual expenses incurred by individual participants.

We recommend offering everyone an **average estimated fair rate** to cover expected costs

Practical Advice: Size of Payment

- In order to achieve representativeness of racial or ethnic groups, a **higher payment may need to be established** to attract potential participants who are traditionally underrepresented in research
- Though some participants can still be recruited **without higher payments, it may lead to feelings of exploitation** and therefore is not recommended
- Payment should **not be reduced commensurate with participants' lower socioeconomic status** or earning capability

Practical Advice: Size of Payment

- Payment is needed to address **opportunity cost** – not addressing it leads to under-representation, under-enrollment, and/or exploitation.
- **Almost all studies aimed at representative recruitment should consider using payment or incentives**
- When setting payment amounts for specific research procedures, these amounts should be anchored in **standard operating procedures (SOP)** to account for variation while promoting consistency (e.g. avoid making different payments for similar blood draw procedures across studies)

Examples of Payment Models

Wage-payment model suggests that payment be determined against a benchmark on prevailing wages. Paying at minimum wage is generally considered insufficient, Therefore, it is recommended to pay the minimum wage with upside adjustment (e.g., 2x or 3x), this is considered to be a better option when determining payment level. If wage is designed to be commensurate with participant's primary income, it has the potential to attract participants with higher income and is difficult to implement.

Market model, or supply-demand model, suggests that payment will be determined solely based on the supply and demand of research participants. It has high potential for undue influence if high incentives are offered for risky research, and shifts the burden of research to individuals of lower socioeconomic status.

Reimbursement model is payment offered to research participants to reimburse them for actual expenses, such as travel, meals, and parking. One version of a reimbursement model would also offer reimbursement for lost wages.

Appreciation model conceives of money as a reward or token of appreciation for a participant's contribution to research. Appreciation can be shown by awarding a wide range of amounts of money as well as nonmonetary gifts. Exclusively employing the appreciation model may not cover costs accrued by participants.

Regulations & Governance

Principles of Regulation and Governance

There is a **lack of guidance or policy** around research payment

For example, there is **no consensus about what counts as undue inducement** or an unjust distribution of research burdens among bioethicists

Without such consensus and guidance, researchers need to be aware that members of research governance bodies, such as IRBs, tend to take abstract positions which can be **inconsistent or incongruent**

Principles of Regulation and Governance

Based on several survey studies, IRB members may be concerned about undue influence due to any **study-related payment**; many are concerned about offering money as an **incentive** to participate in research, and even more are concerned about using payment as **compensation for risk**

IRB members may not have already developed a structured view to **balance ethical and equity considerations**

Practical Advice: Regulation & Governance

- Review **Penn IRB guidance** document on Human Subject payment: <https://irb.upenn.edu/wp-content/uploads/2023/02/Payments-to-Human-Research-Subjects.pdf>
- Working with governance bodies, such as IRBs, researchers are encouraged to **advocate for policy guidance and educational efforts** that are needed to promote a balanced view towards participant payment

Practical Advice: Regulation & Governance

- Clearly communicate the **rationale for payment** amounts to the IRB by itemizing payments according to the following categories:
 - Reimbursement for out-of-pocket expenses
 - Compensation for time and burdens
 - Recruitment or other incentives
- Include **justification** for the specific amounts proposed

Practical Advice: Regulation & Governance

Consider the following when using incentives in research:



Use of payment **lowers barriers** and makes it more likely for those of lower socioeconomic status to benefit from research



The study may otherwise fail to recruit enough people from unrepresented groups that will **hurt scientific validity and the principle of fairness and justice**



Alternative approaches to payment that leave participants **financially worse off** for taking part in research are inherently unjust; this is often the case when studies plan for no or low payment and/or do not consider opportunity cost



Whether the study is considered minimum or low risk and therefore is **favorable risk-benefit proposition** for prospective participants

The background features a large, abstract teal graphic on the right side, consisting of overlapping, rounded shapes in various shades of teal, creating a modern, organic feel.

General Recommendations: Planning & Administration

- Payment strategies should be informed by **input from participants**, participant groups, and where relevant, their families or communities
- However, there is little research to date that directly examines participant views and preferences regarding research payment
- JRP is working on better understanding these factors through **designing a participant survey** that can be used across studies

- Costs associated with participation, including opportunity costs, should be **anticipated and explained during the consent process**; any limitations on payment such as reimbursement should be determined in advance and communicated explicitly
- Other elements involving payment should be **clearly communicated with participants upfront**, including form, size, timing, and frequency of payments, as well as conditions for determining payment eligibility

- Be mindful that a participants' eligibility to benefit from **Entitlement Programs**, such as Medicaid or SNAP, may be impacted by the research payment; this should be **clearly communicated** to prospective participants
- **Tax considerations** of payment need to be explored and **clearly communicated** with potential participants

References

- Addressing equity in research participation incentives. Website: <https://irwg.umich.edu/news/addressing-equity-research-participation-incentives>. *University of Michigan Institute for Research on Women and Gender*. Michigan, USA. Accessed 3/3/23.
- Beyond altruism – exploring payment for research participation. Website: <https://www.hhs.gov/sites/default/files/oew-program-book-2022.pdf>. *OHRP Exploratory Workshop, HHS*. Washington, DC, USA. Accessed 3/20/23.
- Bierer, B. E., White, S. A., Gelinas, L., & Strauss, D. H. (2021). Fair payment and just benefits to enhance diversity in clinical research. *Journal of Clinical and Translational Science*, 5(1), e159.
- Cheff, R., & Roche, B. (2018). Considerations for compensating research participants fairly & equitably: A think piece.
- Shy, O. (2020). Low-income consumers and payment choice. *Research in Economics*, 74(4), 292-300.
- Eshun-Wilson, I., Akama, E., Adhiambo, F., Kwena, Z., Oketch, B., Obatsa, S., ... & Abuogi, L. (2022). Adolescent and young adult preferences for financial incentives to support adherence to antiretroviral therapy in Kenya: a mixed methods study. *Journal of the International AIDS Society*, 25(9), e25979.
- Foster, K., Greene, C., & Stavins, J. The 2021 Survey and Diary of Consumer Payment Choice: Summary Results.
- Gelinas, L., Largent, E. A., Cohen, I. G., Kornetsky, S., Bierer, B. E., & Fernandez Lynch, H. (2018). A framework for ethical payment to research participants. *New England Journal of Medicine*, 378(8), 766-771.
- Grady C. (2005). Payment of clinical research subjects. *The Journal of clinical investigation*, 115(7), 1681–1687.
- Grady, C., Dickert, N., Jawetz, T., Gensler, G., & Emanuel, E. (2005). An analysis of US practices of paying research participants. *Contemporary clinical trials*, 26(3), 365-375.
- Halpern, S. D., Madison, K. M., & Volpp, K. G. (2009). Patients as mercenaries? The ethics of using financial incentives in the war on unhealthy behaviors. *Circulation: Cardiovascular Quality and Outcomes*, 2(5), 514-516
- Halpern, S. D., Karlawish, J. H., Casarett, D., Berlin, J. A., & Asch, D. A. (2004). Empirical assessment of whether moderate payments are undue or unjust inducements for participation in clinical trials. *Archives of Internal Medicine*, 164(7), 801-803.
- Halpern, S. D., Chowdhury, M., Bayes, B., Cooney, E., Hitsman, B. L., Schnoll, R. A., ... & Stephens-Shields, A. J. (2021). Effectiveness and ethics of incentives for research participation: 2 randomized clinical trials. *JAMA internal medicine*, 181(11), 1479-1488.

References

- Jennings, C. G., MacDonald, T. M., Wei, L., Brown, M. J., McConnachie, L., & Mackenzie, I. S. (2015). Does offering an incentive payment improve recruitment to clinical trials and increase the proportion of socially deprived and elderly participants?. *Trials*, *16*(1), 1-9.
- Largent, E., Grady, C., Miller, F. G., & Wertheimer, A. (2013). Misconceptions about coercion and undue influence: reflections on the views of IRB members. *Bioethics*, *27*(9), 500-507.
- Largent, E. A., & Lynch, H. F. (2017). Paying research participants: regulatory uncertainty, conceptual confusion, and a path forward. *Yale journal of health policy, law, and ethics*, *17*(1), 61.
- Largent, E. A., Grady, C., Miller, F. G., & Wertheimer, A. (2012). Money, coercion, and undue inducement: a survey of attitudes about payments to research participants. *Irb*, *34*(1), 1.
- Lynch, H. F., Joffe, S., Thirumurthy, H., Xie, D., & Largent, E. A. (2019). Association between financial incentives and participant deception about study eligibility. *JAMA network open*, *2*(1), e187355-e187355.
- Ngo, S., Kim, A. S., & Chiong, W. (2021). Evidence for the Ethics of Incentivizing Clinical Trial Enrollment?. *JAMA internal medicine*, *181*(11), 1488-1489.
- Noordraven, E. L., Schermer, M. H., Blanken, P., Mulder, C. L., & Wierdsma, A. I. (2017). Ethical acceptability of offering financial incentives for taking antipsychotic depot medication: patients' and clinicians' perspectives after a 12-month randomized controlled trial. *BMC psychiatry*, *17*(1), 1-8.
- O'Brien, S. (2014). Consumer preferences and the use of cash: Evidence from the diary of consumer payments choice. *Federal Reserve Bank of San Francisco, Tech. Rep.*
- Resnik, D. B. (2015). Bioethical issues in providing financial incentives to research participants. *Medicolegal and bioethics*, *5*, 35.
- Slomka, J., McCurdy, S., Ratliff, E. A., Timpson, S., & Williams, M. L. (2007). Perceptions of financial payment for research participation among African-American drug users in HIV studies. *Journal of general internal medicine*, *22*, 1403-1409.
- Walter, J. K., Burke, J. F., & Davis, M. M. (2013). Research participation by low-income and Racial/Ethnic minority groups: how payment may change the balance. *Clinical and translational science*, *6*(5), 363-371.
- Williams, E. P., & Walter, J. K. (2015). When does the amount we pay research participants become "undue influence"?. *AMA Journal of Ethics*, *17*(12), 1116-1121.
- Zutlevics, T. L. (2016). Could providing financial incentives to research participants be ultimately self-defeating?. *Research Ethics*, *12*(3), 137-148.