

Paying for Participating in Social-Behavioral Studies: Practical and Ethical Considerations

Celia B. Fisher, Ph.D.

Director, HIV/Drug Abuse Prevention Research Ethics Training Institute

Marie Ward Doty University Chair in Ethics

Professor of Psychology

Director Center for Ethics Education

fisher@fordham.edu

**Beyond Altruism – Exploring Payment for
Research Participation
2022 OHRP Exploratory Workshop**



ETHICS BEYOND THE DOLLAR

- In social-behavioral non-intervention studies involving economically marginalized populations, researchers, IRBs, and CABs can determine a fair and equitable payment.
- However, ethical dilemmas *still arise* from the interface between such payments and participants' lived experience.

OVERVIEW

ARE FAIR PAYMENTS
JUST OR UNJUST IF
THE RESEARCHER
KNOWS...

- Participants would prefer not to participate, but do so because they need money or are pressured by outside sources?
- Populations recruited *because* they engage in health comprising behaviors, tell the investigator they will use the payment to engage in these behaviors?
- Community researchers will bear the burden of payment-related threats to scientific validity and moral harms?

PAYMENT FOR SBR NON-INTERVENTION
RESEARCH WITH
WOMEN INVOLVED IN SEX WORK (FSW)

- FSWs in under-resourced countries are at high risk for HIV/STI
- FSWs are a “hard to reach” and socially stigmatized population
- Research on individual and systemic factors is critical to promote health equity through informing FSW sensitive public health policies.

*RESEARCH PAYMENTS THROUGH
A PARTICIPANT LENS:*

**FSWS IN ANDHRA PRADESH INDIA WHO
HAD PARTICIPATED IN SBR STUDIES**

37 post-study interviews on their experiences

- Epidemiological studies of HIV risk behaviors
- Studies involved surveys, interviews and HIV/STI testing
- All studies had IRB approval

Reed, E., Fisher, C. B. Blankenship, K. & Brook, S.W. Khoshnood, K. (2016).

IS UNDERSTANDING
THE RIGHT TO
WITHDRAW
ENOUGH?

**FSWs living under dire
economic conditions**

“They [investigators] read ‘If you do not like you can quit’”

“What if we do not have money? That is why I signed the form.”

“I signed with fear...I was getting [money] If I eat one meal...it is difficult to get the other meal the same day.”

“But if I quit in the middle...no one would call us [to participate in future studies]”

THE RIGHT TO
WITHDRAW

INFORMED CONSENT
AUTHORITY &
COMMITMENT

“We usually control ourselves because we feel that it does not look respectful to discontinue”

“How can anyone quit the study just because the questions are not comfortable even after going through the consent form”

**Gate Keepers and
Respondent Driven Sampling**

**FAIR PAYMENT AND
COMMUNITY
COERCION**

“I was forced [to participate in the study] and they [brothel managers] took [a portion of the research] money from me”

“I had to give commission [pay another women involved in sex work] for my participation.”

SACHRP (2019)

“THE MERE FACT THAT PAYMENT INFLUENCES A DECISION TO PARTICIPATE IN RESEARCH DOES NOT MAKE THAT DECISION INVOLUNTARY OR THAT INFLUENCE UNDUE,

EVEN IF AN INDIVIDUAL WOULD NOT HAVE CHOSEN TO PARTICIPATE WITHOUT PAYMENT”

Is “fair payment” ethically sufficient as long as FSWs in dire economic conditions...

- Understand the research risks and benefits and their right to withdraw, but
- “Sign with fear” because they need the money, or
- Fear refusing participation will jeopardize future opportunities for research payment?

SACHRP (2019) DISTINGUISHES

COERCION: INVESTIGATORS' THREAT TO SOMEONE'S RIGHTS, OR WITHHOLDING OF MONEY TO OBTAIN COMPLIANCE

INDUCEMENT: A GENUINE OFFER OF PAYMENT FOR RESEARCH PARTICIPATION

Should fairly priced inducements or compensation be offered when...

- The amount itself is not coercive, but leads to coercion by community gatekeepers?
- When not offering payments will jeopardize enrollment rendering FSWs research orphans?
- When individual participants may be subject to community coercion, but a CAB of FSWs has approved the study as in the best interest of their community?

*PAYMENT IN SBR NON-INTERVENTION
RESEARCH INVOLVING PEOPLE WHO INJECT
DRUGS (PWID)*

- PWID are at high risk for HIV and other co-morbidities
- PWID are a “hard to reach” and socially stigmatized population
- Ethnographic interviewing on social (drug) networks and systemic and individual risk factors contributes to development of effective public health policies

STANDARD RESEARCH PAYMENT PROTECTIONS FOR PWID PARTICIPANTS

SBR investigators studying addiction in economically marginalized communities:

- Consult with CABs to determine fair payment
- Assess for inebriation and cravings that compromise informed consent
- Often pay or reimburse individuals for travel and invite them to return when they are in a better position to understand the consent and participate in the study

*RESEARCH PAYMENTS THROUGH
A PARTICIPANT LENS:*

PEOPLE WHO INJECT DRUGS (PWID)

- Focus groups 100 urban PWID (homeless, living in shelters) who obtain illicit drugs through street dealers
- Participants were shown a video of PWID “street recruitment” mentioning payment for participation, and
- A video of a PWID participant asking a researcher who had interviewed them several times, for a payment advance

Participants were asked...

SHOULD RESEARCHERS GIVE
MONEY TO PWIDS WHO MAY
USE THE MONEY TO
PURCHASE DRUGS?

“If they’re going to get high, they’re going to get high; it doesn’t matter about the money.”

“If we weren’t sitting here now [in the focus group] we would find another way to get money [for drugs]”

Participants were asked...

WOULD PEOPLE ADDICTED
TO DRUGS PAY ATTENTION
TO THE DETAILS OF THE
STUDY IN DECIDING
WHETHER TO PARTICIPATE?

“If I was using crack right now and somebody said I know how you can make \$30 answering questions, I don’t care what the questions are about. I’ll do anything to get that money.”

“When a drug addict is feeling for drugs, he don’t care about all the other reasons, he care about that next hit or that next blow or that next whatever.”

Beyond “What if” Payment Decisions

WHAT ARE ETHNOGRAPHERS’
OBLIGATIONS IF A
PARTICIPANT TELLS THEM
THEY WILL IGNORE
INFORMED CONSENT TO
OBTAIN MONEY FOR DRUGS?

- Does the interview relationship between an ethnographer and participant require greater relational obligations?
- Does the investigator’s silent acceptance undermine the obligation of informed consent in ways that jeopardize participant protections or knowledge gained?
- Can ethnographers justify payment if they are told it will be used to purchase drugs-- *when research is a minimal risk activity compared to other ways PWID may obtain money to buy drugs?*

RESEARCH PAYMENTS THROUGH A PARTICIPANT LENS:
MORAL DISTRESS AMONG FRONTLINE COMMUNITY
ADDICTION RESEARCH WORKERS (CRWS)

- 275 addiction and HIV research CRWs responded to a survey developed from initial focus groups
- Many CRW respondents:
 - Lived in the communities in which they worked
 - Had themselves suffered from drug addiction or were living with HIV

CRW PERSPECTIVES:

THE IMPACT OF
RESEARCH PAYMENTS
ON PARTICIPANTS

Approximately 50% endorsed the following:

I believed that offering money made some participants ignore the risks of research

I know some participants had given false answers to get into the study

I do not believe that some participants really understood the research they agreed to participate in

Research exploits drug users who are desperate for help

CRWS' PERSPECTIVES:

WORKING WITHIN THE
LIMITATIONS OF RESEARCH
PAYMENTS

Approximately 30% endorsed the following:

*I use my own money to buy coffee or other
small goods to keep drug users interested in
participating*

*I could not provide the participants with the
service referrals they needed*

*Even when it is not my job, I counsel
participants about their drug problems*

CRW PERSPECTIVES:
BURNOUT AND MORAL
DISTRESS

Over 30% endorsed the following:

*[My research organization] Overworked CRWs
because of lack of money*

*[My research organization] Put too much pressure
on CRWs to get high numbers of participants*

I was over-burdened by the demands of my job

I was emotionally drained at the end of the day

CRW PERSPECTIVES & BURDENS

“We’re the people that have stuff! Everyone’s asking us for things. I’m never really off [duty]”

- Are “fair” research payments sufficient in communities with participants in desperate need of health and social services?
- How do we address issues of pay justice when participant economic and health needs place the burden of economic equity on CRWs?
- How do we address the joint effects of participant and CRW economic needs that negatively impact CRW mental health and scientific validity?

PAYMENT JUSTICE & EQUITY:
ETHICS BEYOND THE
DOLLARS

SACHRP (2019)

- Failure to provide adequate incentives [reimbursement and compensation] can have a detrimental effect on research and research participants
- It may lead to difficulty reaching enrollment targets necessary to answer the scientific questions of interest.
- Under-enrollment risks wasting resources and exposing participants to risks and burdens without adequate social value

**PAYMENT JUSTICE &
EQUITY:
ETHICS BEYOND
THE DOLLARS**

How can SBR research achieve payment justice and equity beyond \$\$\$ amounts when:

- Informed consent is inadequate to insure voluntary participation?
- Fair payment leads to community coercion?
- Money is used for health compromising behaviors?
- Research staff (CRWs) bear the burden of participant economic desperation and health inequities?

FAIR PAYMENT

PARTICIPANT PROTECTIONS

SCIENTIFIC AND SOCIAL
VALUE

If fair payment is essential to respecting participant time and effort and securing population representative enrollments, how do we balance:

- Harms that arise from the interface between fair payments and participants' lived experience...
- With the obligation to ensure fair access to studies that can inform health policies tailored to the unique needs of economically marginalized communities?

ACKNOWLEDGMENTS



National Center for Research Resources
1R21RR026302-01

National Institute on Drug Abuse
R25 DA031608-01
R01 DA015649-01A2

My Co-Authors

The participants who generously shared their ethical values
and concerns



REFERENCES

- Fisher, C. B., & Goodman, S. J. (2009). Goodness-of-fit ethics for non-intervention research involving dangerous and illegal behaviors. In D. Buchanan, C. B. Fisher, & L. Gable (Eds.), *Research with high-risk populations: Balancing science, ethics, and law* (pp. 25–46). Washington, DC: APA Books.
- Fisher, C. B., True, G., Alexander, L. & Fried, A. L. (2013). Moral stress, moral practice and ethical climate in community-based drug use research: views from the frontline. *American Journal of Bioethics: Primary Research*. 4(3), 27–38. PMID: 27795869. PMCID: PMC5082423. <https://doi.org/10.1080/21507716.2013.806969>
- Oransky, M., Fisher, C. B., Mahadevan, M., & Singer, M. (2009). Barriers and opportunities for recruitment for nonintervention studies on HIV risk: Perspectives of street drug users. *Substance Use & Misuse*, 44, 1642–1659. PMID: 19938935; PMCID: PMC3638737. NIHMSID: NIHMS458113. <https://doi.org/10.1080/10826080802543671>
- Reed, E., Fisher, C. B., Blankenship, K. & Brook, S.W. Khoshnood, K. (2016). Why Female Sex Workers Participate in HIV Research: The Illusion of Voluntariness. *AIDS Care*, 29, 914-918. PMID: 28030960 PMCID: PMC5453832. <https://doi.org/10.1080/09540121.2016.1271935>
- True, G., Alexander, L., & Fisher, C. B. (2017) Supporting the role of community members employed as research staff: Perspectives of community researchers working in addiction research. *Social Science & Medicine*, 187, 67-75. PMID: 2865482, PMCID: PMC5554448, NIHMSID: NIHMS888020. <https://doi.org/10.1016/j.socscimed.2017.06.023>
- SACHRP (2019). Addressing Ethical Concerns Regarding Offers of Payment to Research Participants. <https://www.hhs.gov/ohrp/sachrp-committee/recommendations/attachment-a-september-30-2019/index.html>