“Money Helps”: People who inject drugs and their perceptions of financial compensation and its ethical implications

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Abstract

This study documents how people who inject drugs (PWID) in rural Puerto Rico perceive payments for participating in HIV epidemiological studies. In-depth interviews were conducted among a subset (n = 40) of active PWID older than 18 years of age who had been previously enrolled in a much larger study (N = 360). Findings suggest that financial compensation was the main motivation for initially enrolling in the parent study. Then, as trust in the researchers developed, participants came to perceive compensation as part of a reciprocal exchange in which they assisted researchers by providing a trustful account of their experiences and researchers reciprocated with financial support.

Keywords

financial compensation; perception; ethics; PWID; Puerto Rico

Although some kind of compensation for participating in scholarly studies is commonly part of the research enterprise among this population (Dickert & Grady, 1999; Fisher, 2004) and is currently expected, not only by participants but also by researchers who argue that they can’t rely on altruistic participation (Abadie, 2010), this practice raises significant ethical questions. Some scholars argue that moderate payments do not negatively affect research participants (Halpern, Karlawish, Casarett, Berlin, & Asch, 2004), but many others argue that financial compensation, particularly in the case of vulnerable research populations, can unduly influence them to choose to participate (Gelinas et al., 2018; Largent, Grady, Miller, & Wertheimer, 2013; Wong & Bernstein, 2011). Some caution that financial compensation effectively restricts research participants’ ability to provide free, uncoerced, and informed consent (Grady, 2001) and prompts participants to minimize or neglect risk taking (Bentley & Thacker, 2004; Macklin, 1981) or to engage in deception (Devine et al., 2015; Dickert, 2013) Table 1 provides a summary description of the main themes that emerged during the

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In the area of substance abuse research, some have suggested that financial compensation raises ethical questions because research participants might use financial compensation to acquire drugs (Brody & Waldron, 2000; Koocher, 1991). Such concerns have led some proponents to advocate the elimination of financial compensation (Largent & Fernandez Lynch, 2017; McNeill, 1997; Reiser, 2005).

Despite having the best interests of research participants in mind, such proposals might have unintended consequences, making it harder to conduct valuable research that could benefit vulnerable research participants and their communities. Recruiting people who inject drugs (PWID) into participating in community health research is critical if we are to make a dent in the HIV epidemic in the United States and elsewhere. Monetary payments have proven effective in increasing HIV testing, antiretroviral therapy adherence, and overall HIV treatment outcomes (Bassett, Wilson, Taaffe, & Freedberg, 2015; Czaicki, Mnyipembe, Blodgett, Njau, & McCoy, 2017; de Walque et al., 2015). Payments have also proven effective in increasing hepatitis B vaccination among PWID (Topp et al., 2013). In addition, financial compensation can contribute to the recruitment of marginalized or hard-to-reach populations, enhancing thus the validity and social value of research (Abdul-Quader et al., 2006; Festinger et al., 2005; Fry, Hall, Ritter, & Jenkinson, 2006).

Injection drug use is one of the main causes of HIV transmission on the U.S. mainland and in U.S. territories, as contaminated blood is shared through syringes and injection equipment (Doerrbecker et al., 2013; Koester, Glanz, & Barón, 2005). A shift from prescription opioid use to illicit intravenous drug use has resulted in an increase of HIV and hepatitis C virus (HCV) transmission, particularly in rural areas (Van Handel et al., 2016). The most recent HIV surveillance data from the U.S. Centers for Disease Control and Prevention (CDC) indicate that Puerto Rico hosts one of the highest incidences of HIV infection in the United States. In 2010, the island reported 28.2 new HIV infections per 100,000 residents, a rate more than 1.5 times higher than that of the U.S. average and the third highest among all 50 states and six dependent areas in the nation (CDC, 2010). In addition to bearing a disproportionate burden of HIV disease in the country, Puerto Rico is the site of a very different epidemic from that operating on the continental mainland. Where only 8.3% of new HIV infections in the contiguous states were related to injection drug use in 2010, more than 20% of new diagnoses in Puerto Rico listed intravenous drug use as their cause (CDC, 2010). A study of PWID in metropolitan San Juan showed a 17% HIV prevalence and a 90% HCV prevalence (Reyes et al., 2006). In addition, a more recent study among rural PWID in Puerto Rico documented a 6% HIV prevalence and a 78.4% HCV prevalence (Abadie, Welch-Lazoritz, Khan, & Dombrowski, 2017).

Ethical debates on the issue of financial compensation among PWID enrolled in community health studies have usually relied on a normative ethics approach, without considering how participants perceive the role of financial compensation in their decision-making process (Ackerman, 1989; Barratt, Norman, & Fry, 2007). By drawing on the experiences of PWID who were previously enrolled in the Vida, Accion, Salud community study in rural Puerto Rico, the present study contributes to the literature on the ethics of financial compensation in research involving human subjects, particularly epidemiological or behavioral studies of substance abuse. Using qualitative methods involving 40 semistructured interviews with
active PWID, all 18 years old and older, we explored participants’ motivations to enroll, including the role of financial compensation, as well as participants’ views on the relationship between financial compensation and research trust. The study also asked participants about their preferred form of financial compensation.

**METHOD**

**Participants**

In-depth interviews (n = 40) were conducted from March to April 2017 among active PWID men 18 years of age or older who resided in the localities of Cidra, Cayey, Aguas Buenas, and Comerio in rural Puerto Rico. Our decision not to include women reflected the fact that women constituted a significant minority—around 10%—of PWID in rural Puerto Rico. Participants’ sociodemographic profile seems similar to other groups of PWID living on the island. More than three fourths (78.4%) tested positive for hepatitis C during the rapid test, whereas 6.0% tested positive for HIV. All 19 HIV positive participants were HCV coinfect. Approximately 90.5% (n = 285) were male, and 93.3% were born in Puerto Rico. Most PWID who declared to have been born abroad had been born in the continental United States. The sample had a mean age of 41.8 years (range = 18–70 years) and an average annual per capita income of $4,452. Participants were mostly (85.9%) unemployed, 21.9% were homeless at the time of their interview, and 52.4% were high school graduates (or higher). Only 2.9% of participants were currently married, though an additional 19.4% were living together as married, whereas 47% were single and never married (the remaining 30.8% were separated, divorced, or widowed; Abadie, Welch-Lazoritz, Gelpi-Acosta, Reyes, & Dombrowski, 2016)

Participants were selected purposefully from a larger ongoing, multiyear National Institutes of Health/ National Institute on Drug Abuse–funded parent project on social networks and HIV/ HCV risk in rural Puerto Rico conducted between April 2015 and December 2016. The parent study is divided into three phases, with the first phase being an epidemiological risk survey, HIV and HCV testing to assess sexual and injection risk behaviors of PWID residing in four rural localities (Cidra, Cayey, Aguas Buenas, and Comerio) and an evaluation of the degree of access to health-promoting services (see Abadie et al., 2017, for further description). Phase 1 included 315 active PWID, all 18 years old or older, who were recruited using respondent-driven sampling, a well-established sampling methodology for recruiting hidden and hard-to-reach populations (Abdul-Quader et al., 2006; Heckathorn, Semaan, Broadhead, & Hughes, 2002; Johnston, Chen, Silva-Santisteban, & Raymond, 2013).

**Procedure**

In the parent study, using respondent driven sampling, recruitment was initiated by starting with two “seeds,” or key participants, in each of the four municipalities. Participants received $25 in compensation and were given the chance to become recruiters. After securing consent, they were provided with three referral coupons to recruit other PWID who had not previously participated in the study. Every eligible referral earned the recruiter an additional $10; in total, this produced 307 referrals. For the second phase, we engaged in
ethnographic research with 34 key respondents to learn more about injection risk practices and the structure of their social networks; this included visiting their homes, shooting galleries, and other locations where they might inject. In this phase we recruited an addition 45 participants who were part of the key respondents’ ego networks and who had not participated in the first phase of the study. Finally, for the third phase, we selected 24 participants from the previous two phases to participate in a weeklong training in safe injection methods.

For the current study on participants’ views of financial compensation, we secured approval from the University of Nebraska–Lincoln Institutional Review Board’s (IRB’s) Committee on Human Research before we initiated data collection. All participants provided written consent at the study’s office, which was located in Cidra, prior to enrollment in the study. The informed consent form was modeled by previous research with PWID in this context and written in Spanish. A written copy of the consent form included contact numbers for the principal investigator (PI) as well as the IRB. To ensure that participants fully grasped the main information contained in the consent form, we asked follow-up questions to assess their comprehension, such as, “What is the aim of the study?” and “What are we asking you to do?” To ensure confidentiality, participants were identified through a unique ID code, which also facilitated the linking of participant data with data gathered through the parent study (such as demographics, HIV/HCV status, polysubstance and injection drug use, and injection risk behaviors). Participants in our study received $30 in cash and were handed pamphlets with information about how to prevent HIV/HCV transmission.

A community advisory board (CAB) of eight active PWID who had participated in the parent study was established prior to collecting data. Input of the CAB was sought in drafting the research design and the recruitment and consent procedures, to ensure their cultural appropriateness and sensitivity to our study population. CAB members met twice, once at the beginning of the study and once the study was completed to discuss research findings. CAB members were not recruited as research subjects, thus preserving their advisory role.

**Interview format**

In-depth interviews were conducted by the PI, who has extensive experience not only in this technique but also in working with injection drug users in Puerto Rico. With the permission of participants, all interviews were audiotaped at the research office site in Cidra, a place already familiar to study participants. We collected demographic data such as age, education, income, costs of acquiring drugs, frequency of drug use, and access to health care, complementing the broader demographic information, risk profiles, and HIV/HCV status data available through the parent study. The main focus of the interviews was to document why participants had been motivated to enroll in the parent study as well as their views on financial compensation in community-based, epidemiological studies involving PWID. A semistructured questionnaire asked participants about the role of financial compensation in their decision-making process. A probe introducing a hypothetical scenario — “Would you enroll in a study where researchers did not respect you but paid you a considerable amount?” — was used to elicit views about this topic. We also asked participants
about the role financial compensation played in their motivation to enroll, researchers’ obligations toward participants, and their own obligations toward research participation. Finally, we collected data about the participants’ disposition to participate in a study that offered an equivalent amount in the form of a gift card instead of cash.

Data analysis

The audio recordings were transcribed, and all personal identifiers were removed. The qualitative analysis software MAXQDA was used to manage coding. Data analysis was conducted by the PI. Codes were developed to convey the wide arrange of themes present in the narratives of PWID. An audit trail was maintained to keep track of how and why analytic decisions were made, and a codebook was developed to describe and define all study codes. As it is practiced in qualitative analysis, these codes were iteratively revised and regrouped until they eventually represented a set of higher level axial codes comprehensively describing participants’ perceptions regarding financial compensation. Following the grounded theory approach (Glaser & Strauss, 1967), the interpretation of the data emerged inductively from the data, instead of imposing a preexisting theoretical framework to fit the data.

RESULTS

Motivations to participate: Money helps

Receiving financial compensation was initially the main motivation and, in some cases, the only reason to enroll in the study. Some PWID inject as many as eight to 10 times a day, investing a significant amount of financial resources. In addition, frequent heroin users struggle to avoid the painful symptoms of heroin withdrawal that they experience if they can’t find a dose to relieve the nausea, vomiting, stomach pain, shivering, and general discomfort that follow. A participant provides a clue about his decision-making process:

I’ll tell you, the first time I participated [it was] because I was very sick and I needed the money. Remember that, when we first came in the morning, you helped us—if we were sick you gave us some money first[, saying]: “take this so you can take care of things and then come back ready.” Money helped us quite a bit.

(Participant A)

Participant B, a close associate of Participant A, provides a similar rationale: “I was even more determined [to participate] because I am using and needed the money.”

Almost nine of 10 participants were unemployed, and finding work in the informal economy or “hustles” was one of their main sources of income. For some participants, research studies become just another hustle, an opportunity to make money: “I am hustling, always hustling and I could really use that money” (Participant C).

Our respondent-driven sampling, which offered additional compensation for participant referrals, was also seen as an additional opportunity to increase income:
Honestly, for the money. [They told me] that they were giving away $35 for coming, answering some questions and the HIV tests. And that if you were able to bring more people to the study you would receive $10 more.

(Participant D)

One of the few middle-class participants enrolled in our study had no doubts about his motivations to participate in the study: “Knowing that I would be paid that was the main motivation—not only in my case, but for the overwhelming majority of people. And if somebody tells you otherwise, they’re a liar” (Participant E).

Although financial compensation was initially the only motivation for some participants, others were also interested in receiving results from HIV/HCV tests, which were conducted anonymously and confidentially. Because such testing was done as part of a research study, participants were not subjected to the mandatory reporting requirements established by the epidemiological surveillance programs conducted by the local Department of Health, something they appreciated as well:

Well, it was beneficial economically and besides I got HIV tested. I could know if I had the virus, [and] that it was something I was really interested in finding out.

(Participant F)

Somebody told me about the study and that you were paying for it. One afflicted by the vice is always in need [of money] so I came in and took advantage of this opportunity. I also wanted to know about the [HIV/HCV] test, get the result, and since it was for free I took advantage of it too.

(Participant G)

It [the financial compensation] helped because we are users … do you understand? But I did it not mainly for the money, I was more interested in the test.

(Participant H)

**Is financial compensation coercive?**

All participants agreed in their assessment that the need to avoid “dope sickness,” or the effects of heroin withdrawal, placed them in a relatively vulnerable position as prospective research subjects. If PWID are undergoing the effects of heroin withdrawal when they have to make a decision about enrolling in a research study, then issues that are important to them like anonymity or confidentiality might be overlooked in their quest to secure the resources required to afford their “cure,” as they call the much-needed dose. Some participants seem to reassert the validity of the principle of respect, noting that they are entitled to make a decision about whether to participate in the study. The following passage between the PI and one participant illustrate many participants’ perspective:

**Participant:** If one is sick [experiencing heroin withdrawal], desperate, it is true that the user can’t say “no” You do whatever it is that has to be done. He’s going to do whatever it takes to get the money, so if he has to participate in a study he’s gonna do it, out of necessity, I know that.
Investigator: Would you participate even if you have doubts or don’t want to do it?

Participant: Yes, even if you don’t want to do it— if they come and tell you, “I am going to give you $30 …”

Investigator: Even without the anonymity and confidentiality that you told me you value as a participant?

Participant: Without anything. [They say.] “tell me your name, give me your social security number,” and you will provide it because they’ll pay you. Do you understand? You’ll do it because you’re sick and you’re going to provide it to them coerced, because they are going to pay you. If you are sick—even without confidentiality—you are going to participate because you need money to get relief for yourself. (Participant I)

Another participant provides a vivid description of what it feels like to suffer from heroin withdrawal and what effects it might have on participants’ disposition to enroll in a community health study:

Addiction is very powerful. If I was sick [from heroin withdrawal], I wouldn’t be sitting here with you right now. But now I am cured. I have all the time in the world to be here with you because now I am feeling the way I should. … It’s not in me, this is called ‘addiction,’ I am addict, you know? Even to brush your teeth—I wake up in the morning without my cure and I put the toothbrush in the mouth to wash my teeth and I vomit. I can’t do it! I can’t function, I can’t! You can’t function until you get your cure, you don’t tie your shoelaces until you get your cure, nothing! The heroin sickness is strong, you feel it in your body.

(Participant J)

Money does not buy trust

Participants are aware that financial compensation can coerce or unduly influence their decision-making process, particularly if they are in a vulnerable situation where they are trying to avoid the effects of heroin withdrawal. But at the same time, participants recognize that money—while initially ensuring their participation—cannot, in and of itself, buy trust:

Trust has nothing to do with it [payment]. If they give you $30 to cure yourself you are going to participate. But here is where the malice comes in: if they pay you, you are going to answer their questions. But if they keep asking you things, then you tell yourself: “Oh no, I am not going to tell them that.” You know? It would take some time for me to trust them; it wouldn’t be so fast.

(Participant K)

Participant H, who is homeless and lives in an abandoned house that also serves as shooting gallery, agrees: “I wouldn’t speak with them [researchers] the same way I speak with you. I would speak with them but I would make some things up … some would be total inventions, others not.”
Others adopt a more principled approach: Not even the need to avoid the painful effects of withdrawal would be enough to induce them to participate in a study in which the researchers do not show “respect” for study participants. When asked, “Would you participate in a study with a significant financial compensation but where the researchers did not treat you with respect?” one participant responded:

No, not even being paid quite a bit of money. Why would you go to a place where you get paid but they don’t trust you, where they don’t give you respect? I am an addict but I am proud, you know? Something I don’t like is to be humiliated.

(Participant D)

Reciprocity

Although financial compensation is not enough to ensure trust, participants see it as the first step toward a trusting relationship based on reciprocity and respect. Researchers provide participants with financial support, and participants reciprocate by supporting the goals of the research enterprise. In the following quotes, participants describe how they understand compensation as an expression of respect and as part of a mutually beneficial exchange:

If you help me, you’re curing me, well, then, I give you the information you need and then we both helped each other.

(Participant L)

From the beginning you trusted me. I knew I could talk to you with the truth. Why [would I] lie if you are helping us? And then we help you, right?

(Participant D)

You have been very open. You asked us to help but you have nourished us. You have provided us with things that in other studies probably they wouldn’t care. I understand that some of the things you did were well beyond your responsibility. In turn, we are willing to be as sincere as possible and not hide anything because we want to support the study. You definitely should expect openness from us in return.

(Participant E)

Are gift cards as good as money?

Participants have a mixed view on receiving gift cards instead of cash incentives. For some, whether a gift card is acceptable depends on whether a participant is sick when he or she is approached to be part of the study. For these participants, a gift card would be a disincentive to enroll in a study: the holder would have trouble exchanging it for money and would be unlikely to get its equivalent in cash:

No, I wouldn’t do it because it is going to be very difficult to sell it. Of course, I wouldn’t use it myself. I would try to sell it on the street, but if I try to sell it nobody would give me its face value, I’d be lucky to sell it for $5 and that wouldn’t be enough to cure myself. So, no, if I am sick, I wouldn’t take it.

(Participant F)
Yet, for others, a gift card, it is not a barrier to participation: “A gift card is money. Sure, with it I can buy something good”

( Participant M ).

More entrepreneurial participants recognized that they could exchange the gift card for goods than could be sold later, in effect converting the gift card into cash: “Sure, a gift card is like money. I use it to buy something at Walmart, and whatever I buy there I sell and get the money back”

( Participant N ).

DISCUSSION

Findings show that the prospect of receiving financial compensation is a strong motivation for participants to enroll in the study. Participants who inject very frequently, and thus require significant amounts of financial resources to afford their habit, are particularly motivated by the prospect of receiving cash for their participation. Yet financial gain is not the only motivation: Participants also value the possibility of receiving HIV/HCV tests in a trusting and confidential environment. The need to avoid the painful effects of heroin withdrawal might compel prospective participants to enroll, even when confidentiality or anonymity requirements are not in place, or despite other misgivings.

Yet the relationship between financial compensation and coercion, on one hand, and vulnerability, on the other, is not as clear as some literature suggests ( Festinger et al., 2005 ). Some authors argue that IRBs tend to overemphasize participants’ vulnerability, seeing prospective research participants as prone to being abused by powerful researchers. In so doing, IRBs not only ignore participants’ autonomy but also might end up harming participants in their attempt to protect them from research risks ( Juritzen, Grimen, & Heggen, 2011 ). In a related critique, Lamkin and colleagues ( 2018 ) argued that offering low payments for relatively high-risk situations exploits research participants.

As our study illustrates, marginalized research participants might be vulnerable but they are not without power. Pressured to participate in a research study because of the need to obtain cash, participants might resort to what Scott ( 1985 ) termed “weapons of the weak,” lying or omitting important information in an attempt to protect themselves and thus disrupting a study they do not trust. In addition, participants can further disrupt a study they see as illegitimate or coercive by harming the study’s reputation, by spreading negative views about it among their peers and potentially impacting the study even further ( Devine et al., 2013 ). As participants themselves acknowledge, the prospect of financial compensation and access to desirable services ( Kamuya et al., 2014 ) might bring participants to the study’s door, but in and of itself, they cannot ensure a trusting relationship.

Participants in our study perceive trust as a process in which reciprocity pays a critical role. Financial compensation is perceived as an aspect of a relationship in which researchers support participants, not only financially but also by providing testing or other things that participants value. In turn, participants reciprocate by aligning with the goals of the study and providing a trustful account of their experiences. As Fisher ( 2011 ) and others have
argued, PWID exhibit complex moral reasoning; in this case, if they perceive that researchers are not fulfilling their obligations—proper financial compensation being one of them—then, participants, in turn, are relieved of theirs. Because money does not buy trust, perhaps we do not need to worry that excessive payments might represent an undue influence.

Furthermore, adequate financial compensation recognizes the expertise provided by research participants (Permuth-Wey & Borenstein, 2009) and provides a legitimate source of income, a welcome respite from illegal activities PWID may resort to in order to afford their habit, like sex work or drug dealing (DeBeck et al., 2007; Slomka, McCurdy, Ratliff, Timpson, & Williams, 2007). This suggests that, far from being potentially coercive, financial compensation can play a positive role for PWID who may come to feel valued members of a research enterprise.

Research on participants’ views of financial compensation suggests that participants appreciate more, not less, financial compensation (Barratt et al., 2007; Bell & Salmon, 2011; Oransky, Fisher, Mahadevan, & Singer, 2009). This finding has also been confirmed by Collins et al. (2017) in a similar study of HIV-positive PWID in Vancouver, Canada. Collins cautioned, however, that using gift cards or other modalities of compensation that do not involve cash can exacerbate existing power and social inequalities among research participants. Although some might be able to obtain the face value of a gift card, others with fewer resources or connections might receive less. Our findings, which show that participants with high-frequency drug use prefer to receive cash instead of a gift card, seem to corroborate this view while showing that providing a noncash form of compensation might not be, in itself, a barrier to participation.

The ethics of offering financial compensation to research participants has been extensively debated, including whether to impose some kind of limit on compensation to avoid creating an undue burden, or to experiment with noncash options (Davidson & Page, 2012; Ritter, Fry, & Swan, 2003). Yet these proposals should take into consideration that any measure that does not consider participants’ expectations for fair compensation risks jeopardizing the entire research enterprise (Oransky et al., 2009). Ultimately, it is the street “market,” not regulatory measures, that determines what type and level of financial compensation is considered adequate (Brown, Galea, Davidson, & Khoshnood, 2016). Dissatisfied prospective research participants might choose to “vote with their feet,” leaving researchers and the larger research enterprise vulnerable.

**Strengths and limitations**

This study has some limitations that arise from the composition of our sample. Because all of the participants had already been enrolled in a larger community health study among PWID in rural Puerto Rico, we did not gather the perspectives of those who had refused to participate in the parent study. However, because the focus of our study was not focused on barriers to participation but on how participants understand financial compensation, this limitation does not compromise the integrity of the study. Another limitation is that our sample included only men who were actively using intravenous drugs. Future studies aimed at assessing how women perceive financial payments in the context of community health...
studies among PWID should be conducted. Because participants were paid to participate in this study about compensation, it is possible that this could have led to some kind of implicit response bias. A final limitation of this study was that there was no assessment of trustworthiness of the conclusions (given the relatively small data set, data were analyzed and interpreted by only one researcher). Despite these limitations, a major strength of this study is that the data are based not on hypothetical situations formulated to elicit participants’ views but on actual research experiences. We believe that this choice enhances the validity of this study.

Conclusion

This study shows that financial compensation was the main motivation for initially enrolling in the study for a large majority of participants, but access to HIV/HCV test results was also an important consideration. As trust in research developed with participants’ continuous involvement, participants came to perceive compensation as part of a reciprocal exchange in which they assisted researchers by providing a trustful account and researchers reciprocated with financial support. In this context, far from being perceived as an undue inducement, participants understood financial compensation as a fair exchange for the expertise they brought to the study. But if trust in the study is absent, financial compensation can lead participants to reassert themselves by deceiving researchers they feel are not fulfilling their obligations, thus compromising the validity of the study. These issues might be unique to the PWID, and those conducting research with this population should consider the role that financial compensation might play in prospective participants’ motivation to participate as well as the potential for a poorly structured financial compensation system to be construed by participants as coercive.

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REFERENCES


### TABLE 1

Results: Main Themes

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<th>Theme</th>
<th>Definition</th>
<th>Relevant Quote</th>
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<td>Motivation</td>
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<td>The need to avoid the heroin withdrawal effects placed them in a relatively vulnerable position as prospective research participants.</td>
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<td>Trust</td>
<td>Participants recognize that money, while initially ensuring their participation, can’t by itself buy trust</td>
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</tr>
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<td>Reciprocity</td>
<td>Participants perceive financial compensation as an important step in the process of building trust.</td>
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