Published in final edited form as:
Subst Use Misuse. 2009 ; 44(11): 1642–1659. doi:10.1080/10826080802543671.

Barriers and Opportunities for Recruitment for Nonintervention Studies on HIV Risk: Perspectives of Street Drug Users

Matthew Oransky[1], **Celia B. Fisher**[1], **Meena Mahadevan**[1], and **Merrill Singer**[2]
[1]Center for Ethics Education, Fordham University, Bronx, New York, USA

[2]Center for Health, Intervention, and Prevention, University of Connecticut, Storrs, Connecticut, USA

Abstract

This study used focus-group discussions in response to a video vignette to examine attitudes toward recruitment for nonintervention research involving HIV testing. Participants were 100 ethnically diverse, economically disadvantaged urban drug users, who were recruited from New York City and Hartford, Connecticut in the spring and summer of 2006. Content analyses revealed themes including (1) fears of stigma and legal trouble balanced by trustworthiness of the recruiter; (2) fears of learning one's HIV status balanced by prospects for health benefits, and (3) the right to receive fair monetary compensation balanced by risks of coercion during periods of cravings. Limitations and implications for recruitment practices have been discussed here.

Keywords

Drug use; HIV risk; participant perspectives; monetary incentives; stigma; Trust

Introduction

Nearly three decades after the human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) epidemic was first recognized, much has been learned and much still needs to be learned about the evolving social-behavioral correlates of infection and transmission in hard-to-reach drug-using populations (National Institute on Drug Abuse/NIDA, 2007). Research involving impoverished and marginalized groups disproportionately burdened by illicit drug use and related HIV risk is essential if treatment, prevention, and harm-reduction programs are to adequately address the unique sociocultural and economic factors influencing drug users' HIV-relevant attitudes and behaviors (Adrian, 2006; Deren et al., 2003). Such research efforts continue to be stymied by the fact that these "hidden populations" are particularly difficult to recruit (Ompad et al., 2008; Scott, 2008; Singer, 1999; Vernon, 2007;Watters and Biernacki, 1989).

There is growing consensus that breaking down of recruitment barriers requires understanding of local beliefs about research practices within the context of community norms (Fisher, 2004; Fry, Madden, Brogan, and Loff, 2006; Plumridge and Chetwynd, 1998). The small but growing literature on the attitudes of marginalized groups to nonintervention research on illicit drug use and HIV risk has focused on issues of trust between drug users and research recruiters, perceived risks and benefits of research participation and the effect of monetary inducements on motives to participate (Barratt,

---

Address correspondence to Celia B. Fisher, Ph.D., Director Center for Ethics Education, Marie Ward Doty Professor of Psychology, Fordham University, Bronx, NY 10458. Fisher@Fordham.edu.

Norman, and Fry, 2007; Fisher and Ragsdale, 2006; Fisher et al., in press; Fry and Dwyer, 2001). This research suggests that recruitment of historically marginalized populations may be compromised by participants' mistrust of the scientific establishment in general (Herek and Blunt, 1988; Shaw, 2005; Singer, 1993; Stevenson, DeMoya, and Boruch, 1993; Swanson and Ward, 1995) and of researchers' motives, competence, and commitment to confidentiality and participant's welfare in particular (Fairchild and Gayer, 1999; Fisher and Wallace, 2000; Fisher et al., 2008; Fitzgerald and Hamilton, 1996).

While some studies demonstrate that community members working as frontline recruiters can increase participant trust (Broadhead and Fox, 1990), others suggest that confidentiality concerns may inhibit research participation even if recruiters and participants have pre-existing positive relationships (Fisher et al., in press; Higgs, Moore, and Aitken, 2006). Perceptions of research risks and benefits also influence recruitment. For example, Barratt et al. (2007) found that concerns about personal risk, discomfort, and inconvenience were significant barriers to recruitment for nonintervention-involving injection drug users' research in Melbourne, Australia. Fears and hopes associated with discovering one's HIV status through research participation have also been reported to influence recruitment (Sherman and Latkin, 1999; Worthington and Myers, 2002).

The use of monetary incentives to increase recruitment for drug-use and related HIV risk research has also been subjected to ethical debate (Ritter, Fry, and Swan, 2003; Seddon, 2005; Singer, Van Hoewyk, Gebler, Raghunathan, and McGonagle, 1999). The central features of ethical debate regarding the use of monetary incentives as a recruitment technique have focused on (1) whether or not it is ethical for researchers to provide cash payments when they may be used to support drug use (Buchanan et al., 2002; Fisher, 2004) and (2) whether or not monetary incentives distort the ability of members of addicted and impoverished populations to give voluntary and uncoerced consent (Dickert and Grady, 1999; Emmanuel, 2005; Festinger et al., 2005; Fry, Madden, Brogan, and Loff, 2006; Klitzman, 2005). Concerns about participants using monetary incentives to purchase drugs may be even more heightened in contemporary Western societies that place a moral imperative on health-promoting activities and condemn actions destructive to one's health (Katz, 1997). Empirical examination of these concerns have found that while drug users often cite monetary incentives as a primary reason for participation in research studies on drug use and HIV (Grady et al., 2008; Jenkins et al., 2000; Slomka, McCurdy, Ratliff, Timpson, and Willams, 2007), they also cite opportunity to gain personal and health-related knowledge, material goods for family members, or to contribute to scientific knowledge and policy (Barratt et al., 2007; Fry and Dwyer, 2001; Sherman and Latkin, 1999; Wright, Klee, and Reid, 1998). Recently, Festinger and fellow researchers (2005) found that while increasing amounts of monetary incentives were effective in preventing study attrition among drug using participants, they neither led to increased drug use nor higher rates of self-reported coercion.

Aim

The aim of this study was to explore how street drug users perceive ethical issues associated with street recruitment for nonintervention studies of drug use and related HIV risk. Specific questions analyzed were as follows:

- How do concerns regarding privacy and trust influence the ways drug users react to street-recruitment practices?
- What are the perceived personal and social risks and benefits of participating in nonintervention drug-use research that includes HIV testing?

- Are monetary incentives for participation in nonintervention research involving individuals addicted to illegal street drugs viewed as harmful, fair, or coercive?

Method

Recruitment and Population

Data for this study were collected in the spring and summer of 2006 as part of a larger NIDA-sponsored project exploring participant perspectives on ethical issues in drug use and HIV-related research. A total of 100 participants were recruited in New York City and Hartford, Connecticut. In New York City, participants were recruited from a social service organization serving homeless, drug-using, and HIV-positive individuals. An experienced agency employee, who was known to agency clients, recruited participants through posted flyers, community announcements, and word of mouth. In Hartford, an experienced recruiter conducted street outreach, targeting public venues known to be higher-density activity areas for street drug users. Recruitment interactions were initiated with a walk-up introduction and brief synopsis of the study. Interested individuals, who met study criteria, were provided with additional material and an appointment for a focus group.

According to methodological prescription (Smithson, 2008), the 11 focus groups were homogeneous with respect to gender and ethnicity—two focus groups each of African-American males and females, two Hispanic males, one Hispanic female, one Caucasian male, one Caucasian female, and two groups of MSM (men who sleep with men) of mixed ethnicity. Full demographic information is provided in Table 1. The study was approved by the institutional review boards (IRBs) at both sites and participants gave written informed consent. The consent information was explained verbally to each potential participant and individuals who evidenced intoxication or other signs of cognitive incapacity were exclude from the study.

Procedure—A focus-group approach with visual aids was utilized to stimulate an exchange of opinions (Nichter, Quintero, Nichter, Mock, and Shakib, 2004). Discussions were stimulated by three 4-min video-taped vignettes depicting drug-research scenarios portrayed by ethnically diverse professional actors in English and Spanish. Each focus group watched videos in which the “participant” was of the same gender as group members and the investigator was of the opposite gender. Discussions were tape-recorded. To protect confidentiality the investigators acquired a certificate of confidentiality and participant pseudonyms were used. Respondents were provided refreshments, reimbursed for transportation costs, and received $25 as compensation for participating in the 90–120-min session. An advisory board of drug-abuse1 advocates, social workers, and addicts assisted in deciding on a fair compensation and final content and format of the informed consent, video scripts, and focus-group questions.

The vignette of interest for this analysis depicted a recruiter approaching a “drug user”/ “potential participant” in a public park, and the ensuing conversation regarding participation in a nonintervention drug-use study that required HIV testing (The full script is available from C. B. Fisher, Fisher@Fordham.edu.)

Key chronological elements of the video vignette are included in Table 2. Using a prepared interview guide, the focus-group facilitator engaged participants in a discussion about their reactions to the video vignette. All participants were encouraged to share their comments and follow-up probes were used to prompt further discussion.

Content Analysis

The coding process used the grounded theory approach to identify common factors and relevant themes across groups (Charmaz, 2008; Glaser and Strauss, 1967). A codebook was developed integrating themes emerging from the participants' own words and themes based on the bioethics literature. The final set of codes was catalogued in a software program (Atlas.ti) that was then used to recode the transcripts and generate the final themes and subthemes (inter-rater agreement ranged from 85% to 90%).

Results

The results are reported in terms of the following emergent themes relevant to the study questions: (1) concerns about privacy and trust, (2) perceived research risks and benefits, and (3) the role of monetary incentives.

Its Out in the Open: The Public Nature of Street Recruitment

For many of the drug users in our focus groups, fears that they might "get in trouble with the law" or suffer community stigmatization for speaking with a research recruiter were significant barriers to research participation.

Are these people legit?—As individuals engaged in illegal drug use, it is not surprising that street recruitment would raise suspicions of a "set-up" or "trap" targeting drug users for arrest or "catching people that are on probation." These perceptions are captured in the following quotes:

> If somebody approached me like that, you know, there might be a camera somewhere or … I'd be scared myself, [the recruiter] might be an undercover cop or something (*African-American male*).
>
> These days with … the cops, their tactics are getting very creative. So you never know exactly what type of entrapment you're walking into. So these are his risks. He could be turned over to the authorities. He could be wanted for warrants. The fact that he's even speaking to this person, and the cops know that these workers are out there, can help him be identified as a drug user and everything else (*MSM focus-group participant*).

One word can trigger a person's ears to go up—Focus-group members expressed concern about recruiters asking eligibility questions related to drug use or HIV status in a public setting. They thought the recruiter's behavior could reveal that they were "an addict in front of the whole community" or spark rumors like "oh, that person has AIDS." For some, like this participant in an MSM focus group, recruiters approaching strangers in a public park to ask about HIV or drug use was evidence of their lack of respect for participant's privacy and dignity, "I'd have been like … why are you out here in the open asking me all this…?"

Concerns about community gossip also extended to responding to street flyers for studies conducted at hospitals or other settings associated with drug use and HIV treatment or research:

> A lot of people don't want anybody to know they got HIV … everybody don't know that people got HIV in their family. You know, somebody could by standing there taking a lunch break and here's… that's my sister right there. Oh, she's going in for an HIV study. (*1st AA female*).
>
> Right. And everybody will know you're a drug addict (*2nd AA female*).

Some participants' fears stemmed from actual experiences. As one participant described, "I have a friend who is HIV positive and people found out about her HIV status through her participation in some sort of center and it had bad consequences for her and she didn't want people to know" (*MSM focus-group participant*).

If the Information Is Confidential, Then She Can Trust Him

In the face of such fears about street recruitment, participants informed us of research practices and recruiter characteristics that would inspire confidence in the recruiter and serve to bolster recruitment efforts.

Everything is Confidential—Focus-group members emphasized that recruiter emphasis on confidentiality not only makes participation feel less risky, but it also helps establish a sense of trust in the recruiter.

> I don't see how she could face any risk if deciding to come to the study, because they are saying to her that everything is confidential, that her name is not going to appear anywhere, they are going to help her in everything they can. I wouldn't be afraid of doing this (*Hispanic female*).

Because she [the recruiter] promised she will protect what he said no matter what (*Hispanic male*).

They told her everything—Additionally, focus-group participants stressed the importance of recruiter's honesty, making sure participants know what to expect, and allowing time for participant questions.

[The recruiter] was honest. He said everything he had to say. I mean he came right out and told her everything

that she had to do. Basically, if that was me I would have done it, as long as they told me everything about it

(*Caucasian female*).

[The recruiter's] obligation is to ask her [the participant] if she understood what he said (*Hispanic female*).

She wasn't trying to downgrade him—Focus-group respondents also emphasized how important it was for researchers to be respectful, careful, and patient.

[The recruiter] had good mannerisms too, the way she approached the high person in a certain sense. She was

> smooth, she was soft, she wasn't too strong, and she wasn't trying to downgrade him (*MSM focus-group participant*).

> I appreciate the fact that [the recruiter] didn't touch her or tackle her, or anything. He gave her a chance and he just raised his voice a little and nothing got hurt (*African-American female*).

HIV Testing: A Double-Edged Sword for Research Recruitment

The inclusion of HIV testing in research was for some a barrier and to others an incentive for participation. We first describe comments illustrating fears of inflicted insight and social stigma resulting from a positive test for HIV. We then provide comments depicting the belief that having the opportunity to learn one's HIV status can be a research benefit.

Some of them really don't want to know—

Focus-group respondents frequently said HIV testing might "scare away" potential participants who fear they would be inflicted with the knowledge that they were HIV positive.

> I also think that the risk [of participating] would be to know that he is sick. He would go through the pain of finding out about his HIV condition (Hispanic male).
>
> She could be scared to find out what the results are going to be, from testing, you know, it could be a little scary for her (*Caucasian female*).

Many concerns emerged as a result of prior experiences. For example, a Caucasian female spoke about the fears that prevented her from getting an HIV test in the past: "I know for a lot of time I didn't want to take an HIV test, because I thought I might be positive. I didn't want anybody to know I was taking a test and I really didn't want to know the results." An Hispanic male spoke about the intense emotional distress experienced as a result of an HIV diagnosis, "You go crazy when you learn that you are HIV positive and sometime you even feel like you want to commit suicide."

A lot of people turn against you when they find out you're positive for HIV—

In addition, many participants spoke about the social stigma and loss of support associated with testing positive for HIV in their communities, including rejection from family, friends, and important religious centers. These fears included being treated differently, as one Hispanic male participant said, "They feel discriminated against, you know, because they are being treated differently from the ones who do not have the disease." Others made similar comments;

> If her results came out positive she's probably scared that she could lose her family or her friends because a lot of people turn against you when they find out you're positive for HIV (*Caucasian female*).
>
> I still have this issue today, going to my family's church and telling them that I have it… I feel like I'm going to be shunned once I tell them I have it (*African-American female*).

It is always important to know if there is something wrong with your health—

While words such as "stigma," "taboo," "shunned," and "turn against you" reflected perceptions that involvement in research requiring HIV testing would be emotionally or socially painful, others indicated that they would benefit from research participation that provided them information about their HIV status.

> To know about his physical condition and how he is doing… whether he may be positive or not. That is a good thing that will help him and his family tremendously. In [the] case that he finds out that he is positive (*Hispanic male*).
>
> When they do the tests on us, we get to find out if in reality we are sick or not. In that sense, if we don't take the risk of doing these tests, we won't be able to find out if we are sick or not (*Hispanic female*).

Some participants, such as this African-American female, claimed that they had learned of their own HIV status through research participation, "that's how I found out, you know, I would've never known."

It would help me get off the streets—

Furthermore, focus-group participants felt that participating in a study that involved HIV testing would also provide participants with much needed medical or mental health information and referrals.

> The benefit that if he ever finds himself in the situation of being HIV positive they can refer him to a doctor and… He can help himself with early detection so that he gives himself the chance to live (*Hispanic male*).

> If you take the test and you find out that you are positive, you can get treatment and you can find other things that are available to you (*Caucasian male*).

You can not put other people at risk—Participants explained that learning one's HIV status through research not only benefits the individual who learns his/her status, but also other members of his/her community. Asserting "knowledge is power," one Caucasian female suggested, "If you know, at least you can stop yourself from spreading it and giving it to someone else." Others agreed.

> One benefit…is that he gets the result as being positive and it was because he exchanged needles. He didn't know and he was exchanging needles with, with his friends. But because now he knows…the benefit, the benefit of not sharing needles with anyone because now, he, he knows" (*Hispanic male*).

Money Is the Best Incentive

Focus-group discussions centered on whether monetary incentives facilitated recruitment, whether cash versus coupons increased the probability of illegal drug purchases by participants, and whether monetary incentives were coercive.

The money caught his attention real quick—A salient and reoccurring theme throughout the focus-group discussions was the powerful role that money plays in motivating drug users to sign up for and follow through with studies.

> If you want the research to be done, [the] most people you are going to get, you're gonna get them with cash" (*MSM focus-group participant*).

> That's how you have to get people using drugs into a study. If you don't put no money involved, ain't nobody doing those studies without no money" (*African-American female*).

If They're Going to Get High, They're Going to Get High; It Doesn't Matter About the [Incentive] Money—While respondents acknowledged that "we know that we are going to use the money to get drugs," they derided the assumption that monetary incentives would have a significant impact on their ability or decision to buy drugs.

> [Drug users] are gonna go out and use anyway even if you give them cash even if you give them anything… anything you give them, they gonna go out and use (*MSM focus-group participant*).

> If we weren't sitting here now [in the focus group] we would find another way to get money [for drugs] (*Caucasian female*).

I'm gonna find a way to sell the coupon—Focus-group members also argued that a researcher's attempt to curb drug use by not giving cash incentives would be futile. Drug users motivated to buy drugs would sell noncash incentives, such as a food coupon, for the cash they would need to buy the drugs.

> If I'm strung out on drugs and you're telling me "I'll give you a $40 coupon," I'll just find a way… if I really want the drugs I'm gonna find a way to sell the coupons, you know, so—and it'll probably turn me off, it wouldn't be an incentive, you'd be canceling out the incentive by saying "well I'll give you coupons,"

> because that's not gonna deter a person from getting drugs in either way (*African-American male*).

It is none of your business—Furthermore, most participants felt it was not the researchers place to try and control drug users' actions through the choice of incentives.

I am choosing what I can do with my money. You don't do that (*MSM focus group participant*).

> Because once the money is in my hands, it is out of your hands. So it is none of your business what I do with it (*Hispanic female*).

She's Not Gonna Say No: Money as Coercive—While focus-group members did not believe that monetary incentives would increase drug-use behavior, some believed that such incentives might be hard to refuse.

She may have to say yes—Although they often emphasized the importance of personal agency and responsibility, many focus-group participants asserted that drug users may be unable to turn down study participation that is rewarded with monetary compensation. Indeed, when asked if "$40 is too much to say no?" participants answered "correct" and "yes, it's too much money to say no, I'm not going through with it." Other participants explained that "money would make her do something she didn't want to do," and that "she may have to say yes if she doesn't have money."

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 (*Caucasian female*).
>
> 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, you know what I'm saying? (*MSM focus-group participant*).

Cash Incentives and HIV Testing—Although monetary incentives have a strong pull on participation, fear of stigmatization in some may be stronger.

> Most situations like that, strangers get scared straight away when you say HIV. They're gonna back away from you. Money or no money, they're not gonna, they're gonna get scared, because some of them really don't want to know (*African American females*).

Paradoxically, some saw a personal benefit in the strong influence that monetary incentives exert on participation, as illustrated below:

> *P*1: That's how I found out I was sick, cause [because] they offered the money and I was using dope… and I didn't care what they asked me, my name or what, the money made me take the test.
>
> *P*2: That's how I found out…
>
> *P*1: If it wasn't for them offering the money, I wouldn't have found out I was sick at the time, and I'm glad.
>
> *P*2: Me too (*African-American females*).

Discussion

The opinions expressed by focus-group members provide an opportunity to begin to understand the subcultural and situational lens through which a diverse sample of disadvantaged illicit drug users view the efficacy and ethics of recruitment into nonintervention studies involving HIV testing. An overarching theme manifested throughout respondents' comments was a desire to be treated as persons of intrinsic worthiness who deserve respect and concern for personal welfare (Ritter et al., 2003; Seddon, 2005), a sentiment that also has been found in other street drug users' narratives (Singer, Scott, Wilson, Easton, and Weeks, 2001). Perceived risks to human dignity in the recruitment and research process included the social stigma associated with drug use and HIV infection and potentially paternalistic and coercive aspects of research incentives. Perceived valuing of human dignity included respectful recruitment approaches, confidentiality protections, and enhanced opportunities for self-care initiatives offered by HIV testing. In this section we explore how this theme permeated responses to our three areas of inquiry.

Privacy and Trust

Participants expressed fears that associating with a research recruiter could risk public awareness of drug use or HIV status that could lead to either arrest or social stigmatization by both family and community members. Many believed drug users would avoid recruiters if they suspected them to be undercover law enforcement officers. In this way, fears about being "busted" or "getting caught" were perceived as significant barriers to recruitment. These barriers to recruitment could be counteracted through recruiters' attitudes and behaviors signaling respect for privacy and confidentiality. Many respondents focused on whether the recruiter in the video approached potential participants with sensitivity, discretion, and respect, provided complete and honest information about the study, and was specific regarding the extent and limits of confidentiality.

Risks and Benefits of HIV Testing

On the one hand, across groups, respondents identified HIV testing as a deterrent to research participation. Discovering that one was HIV positive was perceived to be both emotionally distressing and potentially devastating for one's familial or romantic relationships. On the other hand, a smaller but significant number of discussants believed that knowledge of their health status would help them become more personally and socially responsible by seeking treatment and engaging in risk-reduction behaviors. Lastly, although differences in perspectives on the risks and benefits of participating in research that includes HIV testing may be expected to vary regarding knowledge of current HIV status, we were unable to assess these differences within our samples as HIV status was not disclosed during focus groups.

Monetary Incentives

Our findings add to a limited body of empirical studies of the ethics of using monetary incentives with impoverished and active drug users (Festinger et al., 2005; Slomka et al., 2007). Consistent with Slomka and fellow researchers' (2007) interview findings, focus group respondents were unanimous in their belief that monetary incentives are a highly effective, if not essential, strategy for successful recruitment. Moreover, our respondents found it patronizing, offensive, and misguided that researchers would attempt to influence drug use through providing participants with noncash coupons as opposed to monetary incentives.

At the same time, however, the use of cash incentives was also widely believed to be potentially coercive during periods of intense craving—in particular for those who were most strongly addicted. Thus, personal autonomy could also be compromised if drug users had diminished capacity to “say no” to study participation if cash payments were promised in return. These opinions contrast with previous reports that drug users do not feel compelled to participate in studies offering monetary incentives (Festinger et al., 2005; Slomka et al., 2007). One explanation could be that our sample was comprised of individuals with more severe or active drug addictions, making drug cravings a more pivotal influence over autonomous choice. As noted, none of our focus-group members were in drug-treatment programs (Festinger et al., 2005), nor did they describe their drug use as “manageable, e.g., using drugs only on the weekend” (Slomka et al., 2007; p. 1408). Of interest is the fact that some looked at the coercive nature of incentives as simultaneously presenting opportunities to improve their lives through HIV testing that they would never have considered otherwise.

Limitations

Findings from focus-group methodologies do not lead to generalization to other populations with the same degree of confidence as quantitative studies using well-defined larger samples (Nichter et al., 2004). In order to facilitate discussion, the size of each focus group must be small, and the selection of participants is nonrandom and chosen to reflect the unique community history of the particular group. Furthermore, the data are generated from dynamic interaction among participants reflecting what Fisher and Wallace (2000) have termed “opinions in progress” that cannot be isolated from either the responses of the facilitators or the comments of other group members (Krueger, 1998). Instead, themes derived from the focus groups, especially when drawn from populations under-represented in research, produce valuable heuristic concepts that can be tested in other populations and with other methods (Nichter et al., 2004).

Second, our thematic findings emerged in response to a hypothetical scenario. While many of our participants drew on their own experiences participating in research studies, their perspectives might be different if they were speaking about an actual experience with recruitment for nonintervention research. Third, while we ran focus groups that were homogeneous with respect to gender, ethnicity, and sexual orientation (although heterogeneous considering types of drugs used), this methodology is not conducive to analyses of the role these characteristics play independently or interactively in experiences with and opinions of recruitment for drug abuse and related HIV risk research.

Implications

Our findings point to several implications for recruitment for nonintervention drug abuse and HIV risk-related research. First, in light of the barriers to recruitment caused by participants’ concerns about privacy and trust, successful recruiters will avoid public practices that spotlight those they approach. It was interesting to note that some participants’ concerns about research risks were allayed when the video recruiter promised confidentiality. A possible explanation for this may be that in large cities such as New York and Hartford drug users have had a fair amount of experience with AIDS and drug-abuse outreach workers. Perhaps guarantees of confidentiality signal a degree of professionalism, respect, and trust among street drug users, as they may be associated with past experiences with outreach workers. Indeed, it may be beneficial if research recruiters seek advice or training from experienced outreach workers on how to approach the recruitment process respectfully and effectively. Second, in light of participants’ fears of discovering their HIV status through research participation, and the emotional and social fallout this may entail, recruiters may wish to emphasize the availability of post-test counseling, educational material, social-support networks, and mental health and treatment-related referrals (NIDA

Policy Statement, 2007) and begin to include in these offerings counseling on communicating one's HIV status with family members and referrals for family counseling.

The question of monetary incentives remains paradoxical. On the one hand, respondents rejected paternalistic approaches to limit monetary compensation as either efforts to limit their autonomy (Seddon, 2005) or as naïve beliefs. On the other hand, respondents also believed that some drug users suffering from drug cravings would not be able to make rational participation decisions when offered monetary incentives, suggesting that payments would compromise participant's self-determination. These findings leave no easy answer for those striving to make ethical decisions about the use of incentives in drug abuse research. Emanuel (2005) has argued that incentives should be defined as coercive only when they distort people's reasoning abilities to such an extent that they take risks that they would not take if they were not agitated, exhibiting signs of drug withdrawal, or reasoning clearly. With this in mind, decisions regarding monetary incentives will require a combination of effective strategies for determining participants' level of drug cravings during consent decisions, levels of compensation considered nonexcessive by members of the local drug community or their advocates, and consultation among investigators, prospective participants, and IRBs to determine that research risks are minimal and reasonable.

Acknowledgments

This research was supported by NIDA grant # 1 R01 DA015649-01A2 to Fordham University, Principal Investigators, Celia B. Fisher, Ph.D. and Merrill Singer, Ph.D. Both teams contributed to data collection, analysis, and the preparation of this paper. We are grateful to the staff and clients of Housing Works, NYC for their advice and participation.

Biographies

Matthew Oransky, M.A., is a doctoral candidate in the clinical psychology program at Fordham University. He has also worked at Fordham's Center for Ethics Education, where he was involved in a National Institute of Drug Abuse-funded research project investigating participant perspectives on the ethics of drug abuse and related HIV risk research. He has coauthored papers on ethics-related topics such as informed consent in psychotherapy, the therapeutic misconception in drug treatment-randomized clinical trial research, and issues of confidentiality in ethnographic research with illicit drug users. Other research interests include the development of masculine identity in adolescent boys and the correlates of adhering to traditional masculine roles.

Celia B. Fisher, Ph.D., Marie Ward Doty Professor of Psychology and Director of the Fordham University Center for Ethics Education (www.fordhamethics.org) is Chair of the Environmental Protection Agency's human research subjects board and a past member of the DHHS secretary's advisory committee on human research protections (SACHRP). She chaired the American Psychological Association's Ethics Code Task Force and the New York State Licensing Board for Psychology and served on the National Institutes of Mental Health Data Safety and Monitoring Board, and the Institute of Medicine's committee on clinical research involving children. Dr Fisher authored *Decoding the Ethics Code: A Practical Guide for Psychologists* (Sage Publications) and over 100 publications on ethics in medical and social science research and practice and life span development. She is a founding editor of the journal *Applied Developmental Science* and coeditor of seven books including *The Handbook of Ethical Research with Ethnocultural Populations and Communities* and *The Encyclopedia of Applied Developmental Science* (Sage Publications). Her federally funded research programs focus on ethical issues and the well being of vulnerable populations including ethnic minority youth and families, active drug users, college students at risk for drinking problems, and adults with impaired consent capacity.

Meena Mahadevan, Ph.D., is a Research Associate in the Center for Ethics Education at Fordham University. Dr.Mahadevan is involved in a National Institute of Drug Abuse-funded research project investigating participant perspectives on the ethics of drug abuse and related HIV risk research. She has coauthored papers on topics such as informed consent in psychotherapy, the therapeutic misconception in drug treatment-randomized clinical trial research, and issues of confidentiality in ethnographic research with illicit drug users. Dr. Mahadevan is also a nutritionist by training and her research interests include the assessment of nutritional status of African-American female drug users with HIV.

Merrill Singer, Ph.D., a cultural and medical anthropologist, holds a dual appointment as a Senior Research Scientist at the Center for Health, Intervention and Prevention and Professor of Anthropology at the University of Connecticut. Additionally, he is affiliated with the Center for Interdisciplinary Research on AIDS (CIRA) at Yale University and the Connecticut Center of Excellence for Eliminating Health Disparities among Latinos at the University of Connecticut. Dr. Singer has published 20 books and over 200 articles and book chapters on health and social issues. He is the recipient of the Rudolph Virchow Prize, the George Foster Memorial Award for Practicing Anthropology, the AIDS and Anthropology Paper Prize, and the Prize for Distinguished Achievement in the Critical Study of North America. Dr. Singer has been the Principal Investigator on a continuous series of basic and applied federally funded drinking, drug use, community and interpersonal violence, and AIDS prevention studies since 1984. His current research projects focus on health risk and relationships among inner-city young adults, effectiveness of inner-city youth interventions, ethical issues in research with vulnerable populations, oral HIV testing among drug users in Rio de Janeiro, Brazil, health and development in Cité Soleil, Haiti, and second-hand smoking among Puerto Rican families. He serves on the committee on ethics of the American Anthropological Association and the editorial boards of the International Journal of Health Policy, Medical Anthropology, and Ethnicity and Substance Abuse.

Glossary

Coercion	In the context of this article, participants are said to be “coerced” into research participation when the incentives offered are of such great appeal that participants’ reasoning about study participation becomes distorted and they participate in a study they would not have otherwise participated had they been thinking clearly (Emanuel, 2005).
Monetary inducements/ incentives	This refers to cash compensation that participants are given in return for their participation in research.
Nonintervention research	This refers to epidemiological survey and other types of research that do not include the assessment of or intervention targeting a problem behavior.

References

1. Adrian M. Addiction and sexually transmitted disease (STD), human immunodeficiency virus (HIV), and acquired immune deficiency syndrome (AIDS): their mutual interactions. Substance Use and Misuse. 2006; 41:1337–1348. [PubMed: 17002986]
2. Barratt MJ, Norman JS, Fry CL. Positive and negative aspects of participation in illicit drug research: implications for recruitment and ethical conduct. International Journal of Drug Policy. 2007; 18:235–238. [PubMed: 17689370]

3. Broadhead R, Fox K. Takin' it to the Streets: AIDS outreach as ethnography. Journal of Contemporary Ethnography. 1990; 19:322–348.
4. Buchanan D, Khoshnood K, Stopka T, Shaw S, Santelices C, Singer M. Ethical dilemmas created by the criminalization of status behaviors: case examples from ethnographic field research with injection drug users. Health Education and Behavior. 2002; 29:30–42. [PubMed: 11822551]
5. Charmaz, K. Reconstructing grounded theory. In: Alasuutari, P.; Bickman, L.; Brannen, J., editors. The Sage handbook of social research methods. Thousand Oaks, CA: Sage; 2008. p. 460-478.
6. Deren S, Oliver-Velez D, Finlinson A, Robles R, Andia J, Colon HM, et al. Integrating qualitative and quantitative methods: comparing HIV-related risk behaviors among Puerto Rican drug users in Puerto Rico and New York. Substance Use and Misuse. 2003; 38:1–24. [PubMed: 12602804]
7. Dickert N, Grady C. What's the price of a research subject: Approaches to the payment for research participation. New England Journal of Medicine. 1999; 341:198–203. [PubMed: 10403861]
8. Emanuel EJ. Undue inducement: nonsense on stilts? American Journal of Bioethics. 2005; 5:9–13. [PubMed: 16179296]
9. Fairchild AL, Bayer R. Uses and abuses of Tuskegee. Science. 1999; 284:919–921. [PubMed: 10357678]
10. Festinger DS, Marlowe DB, Croft JR, Dugosh KL, Mastro NK, Lee PA, et al. Do research payments precipitate drug use or coerce participation? Drug and Alcohol Dependence. 2005; 78:275–281. [PubMed: 15893158]
11. Fisher CB. Ethics in drug abuse and related HIV risk research. Applied Developmental Science. 2004; 8:90–102.
12. Fisher CB, Oransky M, Mahadevan M, Singer M, Mirhej G, Hodge GD. Marginalize populations and drug addiction research: realism, mistrust, and misconception. IRB: Ethics and Human Research. 2008; 30:1–9. [PubMed: 18814439]
13. Fisher, CB.; Oransky, M.; Mahadevan, M.; Singer, M.; Mirhej, G.; Hodge, GD. Do drug abuse researchers have a "duty to protect" third parties from HIV transmission? Moral perspectives of street drug users. In: Buchanan, D.; Fisher, CB.; Gable, L., editors. Ethical and legal issues in research with high risk populations. Washington DC: APA Books; (in press)
14. Fisher, CB.; Ragsdale, K. A goodness-of-fit ethics for multicultural research. In: Trimble, J.; Fisher, CB., editors. The handbook of ethical research with ethnocultural populations and communities. Thousand Oaks, CA: Sage; 2006. p. 3-26.
15. Fisher CB, Wallace SA. Through the community looking glass: re-evaluating the ethical and policy implications of research on adolescent risk and psychopathology. Ethics and Behavior. 2000; 10:99–118. [PubMed: 11841105]
16. Fitzgerald JL, Hamilton MH. The Consequences of Knowing: ethical and legal liabilities in illicit drug research. Social Science and Medicine. 1996; 43:1591–1600. [PubMed: 8961403]
17. Fry C, Dwyer R. For love or money? An exploratory study of why injecting drug users participate in research. Addiction. 2001; 96:1319–1325. [PubMed: 11672496]
18. Fry CL, Madden A, Brogan D, Loff B. Australian resources for ethical participatory processes in publish health research. Journal of Medical Ethics. 2006; 32:186. [PubMed: 16507669]
19. Fry C, Ritter A, Baldwin S, Bowen KJ, Gardiner P, Holt T, et al. Paying research participants: a study of current practices in Australia. Journal of Medical Ethics. 2005; 31:542–547. [PubMed: 16131558]
20. Glaser, BG.; Strauss, AL. The discovery of grounded theory. Chicago, IL: Aldine; 1967.
21. Grady C, Wagman J, Ssekubugu R, Wawer MJ, Serwadda D, Kiddugavu M, et al. Research benefits for hypothetical HIV vaccine trials: the views of Ugandans in the Rakai District. IRB. 2008; 30:1–7. [PubMed: 18512653]
22. Herek GM, Glunt EK. An epidemic of stigma: public reactions to AIDS. American Psychologist. 1988; 43:886–891. [PubMed: 3063145]
23. Higgs P, Moore D, Aitken C. Engagement, reciprocity and advocacy: ethical harm reduction practice in research with injecting drug users. Drug and Alcohol Review. 2006; 25:419–423. [PubMed: 16939936]

24. Jenkins RA, Tougsa K, Markowitz LE, Mason CJ, Jamroentana V, Brown AE, et al. Willingness to participate in HIV-1 vaccine trials among young Thai men. Sexually Transmitted Infections. 2000; 76:386–392. [PubMed: 11141858]

25. Katz, S. Secular morality. In: Brand, AM.; Rozin, P., editors. Morality and health. London: Routledge; 1997. p. 297-330.

26. Klitzman R. The importance of social, cultural, and economic contexts, and empirical research in examining "undue inducement". American Journal of Bioethics. 2005; 5:19–21. [PubMed: 16179300]

27. Krueger, RA. Analyzing and reporting focus group results. Thousand Oaks: Sage; 1998.

28. National Institute on Drug Abuse. Policy on HIV education, counseling, testing, and treatment for research subjects. 2007. Retrieved July 11, 2008, from http://grants.nih.gov/grants/guide/noticefiles/NOT-DA-07-013.html

29. National Institute on Drug Abuse. Drug abuse and risky behaviors: the evolving dynamics of HIV/AIDS. Proceedings of National Institutes of Health (May 8–9), Natcher Conference Center; Bethesda, MD. 2007.

30. Nichter M, Quintero G, Nichter M, Mock J, Shakib S. Qualitative research: contributions to the study of drug use, drug abuse, and drug use-related interventions. Substance Use and Abuse. 2004; 39:1907–1969.

31. Ompad D, Galea S, Marchall G, Fuller C, Weiss L, Beard J, et al. Sampling and recruitment in multilevel studies among marginalized urban populations: the IMPACT studies. Journal of Urban Health. 2008; 85:268–280. [PubMed: 18214686]

32. Plumridge EW, Chetwynd J. The moral universe of injecting drug users in the era of AIDS: sharing injecting equipment and the protection of moral standing. AIDS Care. 1998; 10:723–733. [PubMed: 9924527]

33. Ritter A, Fry C, Swan A. The ethics of reimbursing injecting drug users for public health research interviews: what price are we prepared to pay. International Journal of Drug Policy. 2003; 14:1–3.

34. Scott G. "They got their program, and I got mine": a cautionary tale concerning the ethical implications of using respondent-driven sampling to study injection drug users. International Journal of Drug Policy. 2008; 19:42–51. [PubMed: 18226516]

35. Seddon T. Paying drug users to take part in research: justice, human rights and business perspectives on the use of incentive payments. Addiction Research and Theory. 2005; 13:101–109.

36. Shaw VN. Research with participants in problem experience: challenges and strategies. Qualitative Health Research. 2005; 15:841–854. [PubMed: 15961880]

37. Sherman S, Latkin C. Aqualitative study of injection drug users' participation in a longterm epidemiological study of HIV. AIDS and Behavior. 1999; 3:289–299.

38. Singer EN, Van Hoewyk J, Gebler T, Raghunathan T, McGonagle K. The effect of incentives on response rates in interviewer-mediated research. Journal of Official Statistics. 1999; 15:217–230.

39. Singer M. Knowledge for use: anthropology and community-centered substance abuse research. Social Science and Medicine. 1993; 37:15–26. [PubMed: 8332920]

40. Singer, M. Studying hidden populations. In: Schensul, J.; LeCompte, M.; Robert, T.; Cromley, E.; Singer, M., editors. Mapping networks, spatial data and hidden populations: the ethnographer's toolkit. Walnut Creek, CA: Altamira Press; 1999. p. 125-191.

41. Singer M, Scott G, Wilson S, Easton D, Weeks M. "War stories": AIDS prevention and the street narratives of drug users. Qualitative Health Research. 2001; 11:589–611. [PubMed: 11554190]

42. Slomka J, McCurdy S, Ratliff EA, Timpson S, Williams M. Perceptions of financial payment for research participation among African-American drug users in HIV studies. Journal of General Internal Medicine. 2007; 22:1403–1409. [PubMed: 17668270]

43. Smithson, J. Focus groups. In: Alasuutari, P.; Bickman, L.; Brannen, J., editors. The Sage handbook of social research methods. Thousand Oaks, CA: Sage; 2008. p. 357-370.

44. Stevenson, HS.; DeMoya, D.; Boruch, RF. Ethical issues and approaches in AIDS research. In: Ostrow, DG.; Kessler, RC., editors. Methodological issues in AIDS behavioral research. New York: Plenum; 1993. p. 19-51.

45. Swanson GM, Ward AJ. Recruiting minorities into clinical trials: toward a participant friendly system. Journal of the National Cancer Institute. 1995; 87:1747–1759. [PubMed: 7473831]

46. Vernon IS. American Indian women, HIV/AIDS, and health disparity. Substance Use and Misuse. 2007; 42:741–752. [PubMed: 17558961]
47. Watters JK, Biernacki P. Targeted sampling: options for the study of hidden populations. Social Problems. 1989; 36:416–430.
48. Worthington C, Myers T. Desired elements of HIV testing services: test recipient perspectives. AIDS Patient Care and STDs. 2002; 16:537–548. [PubMed: 12513902]
49. Wright S, Klee H, Reid P. Interviewing illicit drug users: observations from the field. Addiction Research. 1998; 6:517–535.

Table 1

Participant characteristics

Sex		Age (years)	
Males = 68		Range = 22–70	
Females = 32		Median = 43	
Race/ethnicity	N (%)	Primary Language	N (%)
Caribbean/African-American	34 (34)	English	64
Hispanic	42 (42)	Spanish	17
Caucasian	22 (22)	Both English and Spanish	18
Other	2 (2)		
Level of Education	N (%)	Monthly Income	N (%)
8 years or less	8 (8)	None	32 (32)
High School, no diploma	42 (42)	$1–$249	27 (27)
High School diploma/GED	26 (26)	$250–$499	9 (9)
Technical/Vocational School	3 (3)	$500–$999	16 (16)
Some College, no degree	13 (13)	$1,000–$1,999	4 (4)
Associate's degree	2 (2)	$2,000–$3,999	1 (1)
B.A. or B.S.	1 (1)	$4,000–$8,000	1 (1)
		$8,000 or more	2 (2)
Employment status	N (%)	Major source of income	N (%)
Unemployed	61 (61)	Steady work	11 (11)
Working full-time	3 (3)	Pick up jobs	14 (14)
Working part-time	12 (12)	Disability	32 (32)
Full-time Homemaker	4 (4)	Welfare/other G.A.	29 (29)
Student	4 (4)	Family/spouse	9 (9)
Living Arrangements	N (%)	Marital Status	N (%)
Own house or apartment	42 (42)	Single (never married)	64 (64)
Someone else's home	15 (15)	Partnered relationship/married	10 (10)
Shelter/boarding home	32 (32)	Separated	11 (11)
Homeless	8 (8)	Divorced	9 (9)
Sexual Orientation	N (%)	Diagnosed as HIV positive	N (%)
Heterosexual	71 (71)	No	54 (54)
Bisexual	7 (7)	Yes	39 (39)
MSM/Gay/Lesbian	17 (17)		
Active drug use	N (%)		N (%)
Powder Cocaine	45 (45)	Illicit methadone	18 (18)

Heroin	44 (44)	Speedball	13 (13)
Crack	32 (32)	Xanax/Ativan/Valium	11 (11)
Marijuana	29 (29)	Polysubstance use	58 (58)

Note. Not all percentages total 100% as some participants left some questions unanswered.

Table 2

Key chronological elements of the video vignette

1 The video began with a narrator’s explanation of the aim of the study portrayed in the vignette (“to understand which sexual and drug-sharing behaviors are spreading HIV and hepatitis C infection in the community”) and instructions to focus-group members to “think about whether the research raises issues of respect, fairness, harm, or benefit” to participants.

2 The vignette begins with the “recruiter’s” initial approach and the actor/potential participant’s response of “Not interested” as he/she turned to walk away.

3 The recruiter then attempts to get the participant’s attention by saying, “We are giving people $40 to participate in a survey on HIV and drug use. We hope what we learn from the study will help improve drug use and HIV services in this community.”

4 At this point the participant stops and responds, “Forty dollars? What would I have to do,” and the recruiter explains, “You’d just need to come in to the Center for an hour to answer questions about your drug use and sexual behavior. After that we would do a blood test for HIV and hepatitis C status.”

5 This is followed by a brief dialogue involving participant questions and explanations by the recruiter about confidentiality protections, the participant’s access to his/her HIV test results, and educational counseling and referrals. The “investigator” makes clear that treatment would not be provided as part of the study.

6 The vignette ends with the drug user agreeing to an appointment to participate in the research, giving the recruiter his/her name, and responding to the recruiter’s question about whether he/she had used drugs in the past week.