

## **Paying Project Participants: Dilemmas in Research with Poor, Marginalized Populations**

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**Abstract:** *This paper presents a case study about issues that can arise in research with marginalized populations. We use our experiences during a focus group conducted with low-income men to discuss how using monetary incentives can lead to ethical and methodological dilemmas, including participants' misrepresentation of their demographic backgrounds to match study criteria. We address difficulties caused by the Institutional Review Board process' inability to account for unanticipated circumstances during fieldwork. We note that any resolution of such dilemmas must prioritize responsible research practice and protecting participants. We also note the need for more research on the impact and ethics of monetary and other incentives in recruiting participants for studies such as ours that include populations from diverse socioeconomic backgrounds. The issues raised in this paper have implications for those considering research design, especially concerning incentives and screening questions.*

**Keywords:** *Marginalized populations, recruitment, research design, research incentives, research participation*

### **INTRODUCTION**

One of the principles of the Code of Ethics of the National Association of Social Workers [NASW] (NASW, 2008) is social justice. Social justice requires that all people receive equitable access to information and services. However, a great deal of the research that forms the basis for providing such information and services, especially those that are health-related, is conducted with White, middle-class, heterosexual respondents (Fredriksen-Goldsen & Hooyman, 2007). Many of the resultant articles end with recommendations to include more diverse populations in future samples, but few investigators actually do this. Our project was one attempt to rectify this situation. Our original intent was to investigate gay men's perceptions of prostate health and prostate cancer and their perceptions of the effects of prostate cancer on sexuality and relationships. Most prior work had been done with presumptively heterosexual men. We also wanted a sample that was racially and socioeconomically inclusive, as, with the exception of Heslin, Gore, King, & Fox (2008), there are few studies on this topic conducted with non-White or low-income gay men.

When we recruited low-income marginalized men using protocols established with middle-class men, however, complications arose. Primarily, our participation incentive of \$40, modest by middle-class standards, proved problematic when advertised among low-

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income populations. Some of our volunteers seemed to misrepresent themselves, presumably motivated by the financial incentive and their own economic needs. The NASW code calls on social workers to “educate themselves, their students, and their colleagues about responsible research practices” (NASW, 2008, 5.02p). Our experience raises several issues related to responsible research practices that are pertinent to social work and health-related fields, as well as other disciplines. The topics we address in this paper include: incentives and the possibility of participants misrepresenting their demographic background to match study criteria; the limits posed by protocols approved by Institutional Review Boards (IRBs), which cannot be immediately altered as issues arise in the field; and research ethics. We conclude with recommendations for fieldwork arising out of our experiences.

## RESEARCH METHODOLOGY

### Research Subjects and Method

The design and protocols of our study (Asencio, Blank, Descartes, & Crawford, 2009; Blank, Asencio, Descartes, & Griggs, 2009; Descartes, Asencio, Blank, & Crawford, forthcoming) replicated standard procedures used in typical prostate-related research (Eton & Lepore, 2002; Sanda et al., 2008). The major difference was that, as stated, we intended our sample to be gay men and we hoped for racial, ethnic, and socioeconomic diversity. Participation eligibility was limited to those who were gay, male, and 40 years old or older (the age demographic most likely to face prostate health-related issues). These criteria were stated clearly in all our advertisements and reiterated to those who contacted us.

Our research was exploratory, and a qualitative approach thus was deemed most suitable. We decided to use focus groups to bring diverse groups of gay men together to talk about their knowledge of and share their experiences with prostate health issues. We set the participation incentive at \$40, well within the range of incentives commonly given in health-related research (Grady, 2005; Klitzman, Albala, Siragusa, Nelson, & Appelbaum, 2007).

### Site, Recruitment, and Participants

We conducted the study in Hartford, Connecticut, a small city that has a significant Latino and Black population. We distributed flyers announcing the focus groups to community organizations that had programming for gay men and at the local Pride celebration. Postings also were placed on relevant electronic mailing lists. In the first four (out of five) focus groups these methods recruited gay men who fit our criteria.

The participants in the first four groups included a significant number of low-income men. These men revealed particular needs and issues that we wanted to explore more fully. We thus decided to specifically recruit low-income men for a fifth group. We contacted an outreach worker from a local organization serving poor Latino and Black men and women, many of them homeless and with a history of drug use. Some, he

believed, were gay men. With our flyers in hand and our criteria in mind, the outreach worker set about recruiting for our next group.

### **DILEMMAS IN THE FIELD: THE FIFTH FOCUS GROUP**

Each of our first four focus groups had six to eight participants. In this fifth group, however, a total of 22 people were waiting for us when we arrived a half hour before the scheduled start. Many of them had been waiting an hour for us to arrive. As we looked around the room, we noted with concern that some people looked much younger than 40, a few were instantly recognizable as having attended earlier groups, and one appeared to be a biological female. Based on (admittedly unreliable) cues, we did not even get the sense that all those in the room actually were gay. Some seemed unusually uncomfortable, some seemed to avoid eye and physical contact with those around them, and so forth.

Because IRB procedures are established well before the study begins and any changes need to be approved ahead of time (sometimes with a lag of several weeks), unanticipated challenges in the field such as these cannot be addressed easily or in a timely manner. Requesting a driver's license or identification card would have helped us to establish sex and age. Our IRB-approved protocol, however, did not include this step. When developing the research protocol, we thought that asking for identification might be threatening for some of the men, such as those engaged in illegal activities or those who might be undocumented immigrants. Some, being poor and homeless, might not even have had access to identification documents. A driver's license or identity card would not have answered the question of sexual orientation anyway. There thus was no way to determine who met our criteria.

Cancelling the focus group and starting fresh did not make sense as we likely would have lost the participation of the waiting men who did fit the criteria. Such a move also might have initiated confrontations with this large, increasingly impatient, group. We decided to continue and provide the study information and consent forms. As we did so, we reinforced how important it was that participants fit the criteria. We gently queried those who appeared not to fit the study's requirements, as well as those we recognized as prior participants. We were concerned that anything beyond requests for confirmation might violate the men's rights to ethical treatment. If we had gone further in questioning those we were concerned about, we would have been attacking their self-representations in front of the large group gathered. This clearly would have violated the NASW Code of Ethics statement concerning "due regard for participants' wellbeing, privacy, and dignity" (NASW, 2008, 5.02e).

We recognized one man in particular from a prior focus group, but he gave a different first name this time. He vehemently denied being the same man, even though he was not easily forgotten because of unusual tics and mannerisms. When he was told that one of the investigators distinctly remembered him, he said the "other" man had been his twin brother. He was adamant that he was going to stay. We wished to avoid further confrontation, and as always, we wished to treat all participants with sensitivity, so we moved on.

We then approached a potential participant who appeared to be a (non-transgender) woman dressed in baggy, figure-obscuring clothing, sitting with a man who appeared to be the person's partner. This incident highlights the challenge in trying to confirm someone's sex. This person could have been transgender, given that visual cues are unreliable. The person identified as male when we asked. Given the awkwardness of the question and having no way to determine otherwise, we accepted the response. While we understand that issues of sex and gender are complicated, for the purpose of this study, participants needed to have a prostate.

There were also several men who looked younger than 40, including one particularly youthful looking man. When he was reminded of the age criterion, he told us that he had just turned 40. At this point, all those about whom we were concerned seemed completely comfortable in maintaining that they fit the study's criteria. Reminders of how important the criteria were for the research goals did not result in any voluntary withdrawals. We had a group at least half of which we suspected to be not 40, not gay, and/or not male. To complicate matters more, we also had the repeat attendee.

Given our concerns, the importance of protecting our participants' privacy and dignity, and our inability to change IRB-approved procedures in the field, we decided that there was only one way to proceed. We did not question anyone further. We gave the participation incentive of \$40 before the focus group commenced, which was a regular step of our protocol. We then announced that anybody could leave if they wanted to, without being asked to return the money. Although we made similar statements in previous focus groups, no one had ever taken the money and walked out. This time, however, the room quickly started to clear. All those we were concerned about, whether we'd spoken to them directly about it or not, left immediately, as did several others. At the end, seven remained. We presume (and visual cues indicated) that those who stayed did so because they actually fit the gay, male, age 40-and-over category. We were distressed, as we lost funds that might have enabled an additional focus group, but we felt we had maintained integrity with our participants, the validity of our data, and our ethical stance.

### **ISSUES IN RESEARCH WITH MARGINALIZED POPULATIONS**

Despite this challenging experience, we continue to believe that it is crucial that hard-to-reach and marginalized people are included in all research. Although human services research does this as a matter of course, health-related research often does not. As we found, (Descartes, Asencio, Blank, & Crawford, forthcoming; also see Augustus et al., 2009; Diebert et al., 2007), the perspectives, knowledge, and attitudes of poorer and/or less educated people can differ from those of the middle-class, highly educated populations more often included in such work (Augustus et al., 2009; Eton & Lepore, 2002; Sanda et al., 2008). Studies that have been conducted with middle-class populations should be extended to incorporate more diverse people, rather than simply accepted as being non-representative. Yet, inclusion of poor and marginalized populations presents very real issues around recruitment and financial incentives. These issues include the potential for participants to misrepresent themselves. At least one death is attributable to this—in an NIH sleep study, one woman died as a result of her

participation, after giving false medical information in order to be included (Kolata, 1980, as cited in Ripley, 2006).

The related issue of “professional” research participants, those who make part or all of their living by participating in any study they can, is a problem in academic investigation. Indeed, two of our participants subsequently contacted one of us with rather aggressive requests for other paid research opportunities. Market researchers, however, seem to be among the few publicizing concerns about professional focus group attendees (FocusGroupTips.com, n.d.). Their suggestions on how to address this issue (take names, request identification, keep databases that record identifying information) are not always practicable for academic researchers, however. This is especially the case for social workers, health researchers, and others who research sensitive topics with marginalized populations.

Much of what has been published about ethics and financial incentives to vulnerable populations comes from addiction, homelessness, and adolescent studies. Concerns expressed in this literature include what the participants will do with their money—for example, the potential for drug users to use their money to purchase drugs (noted by Ensign & Ammerman, 2008). Although we feel participants’ spending is their own business, the literature observes that the prospect of buying drugs might influence decisions to participate and violate voluntary and informed consent, because of the nature of addiction (Fry, Hall, Ritter, & Jenkinson, 2006). The NASW Code of Ethics indeed requires that there not be “undue inducement to participate” in research (NASW, 2008, 5.02e). Both Fry et al. (2006) and Ripley (2006) provide guidelines for considering whether researchers should provide payments as incentives, and both note the possibility that some people might misrepresent themselves to participate in research. Fry et al. (2006) raise the possibility of screening procedures to address such issues.

Some factors, however, as noted, are difficult to screen for. Participants motivated by monetary considerations can easily lie, as for example, when a heterosexual man says he is homosexual or a biological woman dresses in obscuring clothing and insists that she is a gay man. Age can be verified, but a person’s sexual history (or, as other examples, addiction history or mental health symptomatology) are not necessarily easily confirmed. Ways out of such dilemmas are difficult if not completely impossible to implement fully. Incentives are difficult to consider giving up. Studies have shown that they raise the participation of low-income people in research (Mack, Huggins, Keathley, & Sundukchi, 1998; Martin, Abreu, & Winters, 2001, both as cited in Singer & Kulka, 2002). Reaching populations who are low-education and low-income is critical. It is precisely in those populations, however, that incentives can be transformed from a simple “thank you” to reasons to do whatever it takes to obtain the money.

## RECOMMENDATIONS

It is imperative that marginalized populations be included in research. By attempting to recruit non-White and low-income gay men we obtained important data about the diverse experiences of a range of men who are confronted with prostate health issues. Our experiences, however, highlight the difficulties that such efforts can bring. Even with

knowledge of potential challenges, investigators can be taken unaware when they are actually in the field.

Some of our issues arose due to the inflexibility of the IRB process, which is unlikely to change much in the near future. We had a serious predicament in the field and could not change our protocols in a timely manner. The only solution is to try to foresee awkward and ambiguous situations and incorporate those into the IRB submission. The impetus behind this article was to add to the resources available for anticipating such circumstances. In our own case, we could have tried using identification to establish eligibility but foregone any recording of names and addresses. Private time with each focus group participant also might have made a difference. We did not reserve separate rooms in which to give the participants their initial consent forms. The men came together in one large room, and consent was gone over with them individually or in small groups, in front of the others waiting. Privacy for this stage of the research process would better have enabled potentially sensitive topics to be addressed more freely. Along those lines, screening questions need to be thought through thoroughly regarding criteria that are not easily verifiable, such as sexual identity. "Describe how you came to realize you were gay" for example, might have been a better way of encouraging only gay men to stay for the focus group, as a narrative requires more from a respondent than simply showing up for a group advertised as being for gay men. Those truly committed to getting the money no matter what, however, might still have fabricated something in order to get the incentive.

Financial incentives with marginalized populations do need to be considered in terms of their coercive potential. Forty dollars is minimal to a middle-class person and hardly worth lying for. For a homeless person, however, it may be a very attractive sum. We do want to note that concerns about monetary incentives are not something only involving the poor. One of the few articles in the social work literature addressing monetary incentives and unethical behavior involved doctors who received \$1000 from pharmaceutical companies to recruit patients (Fast, 2003). What our research experiences show is that what is considered a small amount of money by middle-class participants may be seen as a lot by less well-off participants. Unfortunately, determining the appropriate and ethical level of monetary incentive, particularly in a study recruiting participants with a mix of socioeconomic backgrounds, has not been researched.

To avoid the issue of the coercive potential of money altogether, some researchers have used prepaid phone cards as incentives for those who are homeless (e.g., Ensign, 2003). Such incentives, however, may not be particularly appealing to those who are middle-class, who are likely to own cell phones. For a study recruiting people of different socioeconomic statuses, as ours did, this would be a problem. Incentives that appeal primarily to members of a specific identity might have been a better solution for our work. Gift cards to a gay bookstore or gift shop or for entry to a gay-themed event might have worked well to reduce the likelihood of misrepresentation and the potential coercion of a monetary inducement.

## CONCLUSION

Our focus group taught us a number of lessons about the challenges that can arise in a project where both middle- and low-income participants are included. In our case, we confronted issues not indicated by our initial literature reviews that were difficult to deal with given the timeframe of IRB approvals. Although some of the situations we encountered can be avoided by us in the future and by other researchers who take our experiences into account, some of the issues likely have no solution. There is no way to verify sexual orientation, for example. It is a completely self-reported, non-measurable categorization and thus entirely falsifiable. Therefore, the participant's truthfulness on the subject of identity is crucial. Making sure that truthfulness is not subverted by the incentive of payment will likely remain a challenge.

The sharing of these types of research experiences, however, highlights: 1) issues and problems that need to be anticipated before commencing fieldwork; 2) measures that may help reduce some of the challenges encountered; and 3) the need for more research addressing the use of incentives when dealing with both privileged and marginalized populations in the same study. It also adds to a continuing conversation on how to support the commitment, as called for in the NASW code of ethics, to advance social justice and responsible research practice.

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