

Research paper

“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

Greg Scott*

Department of Sociology, DePaul University, 990 W. Fullerton Ave., Ste. 1100, Chicago, IL 60614, United States

Received 3 July 2007; received in revised form 15 October 2007; accepted 21 November 2007

Abstract

Background: This article examines the ethical implications of using respondent-driven sampling (RDS) to conduct HIV behaviour surveillance among injection drug users (IDUs) in Chicago. Ethnographic inquiry illustrates how the design and implementation of RDS invites if not promotes manifold violations of federal guidelines governing human research subject protections.

Methods: *Post hoc* structured interviews with approximately 13% ($n=70$) of the behaviour surveillance sample ($N=529$) focused on how RDS’s “dual incentive” structure affected participants’ social, economic, and cultural milieu. Triangulated methods include interviews with owners of 20 “shooting galleries”, unofficial and illegal locales where IDUs congregate and 400 h of traditional ethnographic observation of individual IDUs and IDU networks. “Consensus analysis” allows identification of key cultural domains that define the RDS coupon market.

Results: The study reveals the power of RDS to foment a stratified market of research participation that reinforces pre-existing economic and social inequalities among IDUs. Participants co-opted RDS to develop various “underground” revenue-generating modalities that produced differential risks and benefits among participants. Deleterious outcomes include false advertising regarding the study’s risks and benefits, exploitation of relative economic deprivation, generation of sero-discordant social networks, and interpersonal and organised conflict, coercion, and violence.

Conclusion: Although RDS may involve serious ethical violations it remains the best available means for accruing a representative sample of hidden populations. It is critical, however, to supplement RDS with research into (1) the subjects’ cultural, social, economic, and political contexts, (2) the potential human subjects violations that participants experience, and (3) how these two issues might affect data integrity and interpretation.

© 2007 Elsevier B.V. All rights reserved.

Keywords: Injection drug use; Respondent-driven sampling; HIV; Behaviour surveillance; Ethnography

Introduction

Injection drug users (IDUs) constitute a *hidden population*. The parameters of their “universe” remain unknown because no master roster contains their names and whereabouts. IDUs have obvious reasons to conceal their behaviours and to avoid researchers and other officious interlopers who look for them. Sampling hidden populations poses a considerable challenge to traditional methods of survey research.

The most common approaches to sampling IDUs include venue-based sampling (VBS) (Wiebel, 1988, 1990), ethno-

graphic mapping and use of outreach workers as recruiters (Broadhead, Heckathorn, Grund, Stern, & Anthony, 1995), snowball sampling (Goodman, 1961), and targeted sampling (Watters & Biernacki, 1989). While each method has its place, none of them enjoys a design suitable for achieving a representative sample of the hidden population. The overarching reason behind this limitation is that the universe of IDUs is *a priori* indefinable (Spreen, 1992) and therefore resistant to any sampling effort that begins with a slice of the universe absent a plan for determining when the sample comes to represent the universe.

Respondent-driven sampling (RDS) ostensibly addresses these difficulties by combining the breadth of coverage of snowball-methods with greater attention to statistical validity (Heckathorn, 1997). RDS requires respondents to recruit their

* Tel.: +1 773 325 7711; fax: +1 773 325 7150.

E-mail address: gscott@depaul.edu.

peers, as in snowball sampling, and researchers keep track of who recruited whom along with each participant's number of social contacts. A mathematical model of recruitment then weights (i.e., post-stratifies) the sample to compensate for non-random recruitment patterns (Heckathorn, 2002). Under appropriate conditions RDS produces consistent estimates of terms such as HIV prevalence (Salganik & Heckathorn, 2004).

RDS revolves around a “dual incentive” payment structure: respondents get paid for completing an interview, and they receive a “finder's fee” for each peer they recruit into the study. The recruits similarly receive compensation for the interview and for the peers they recruit. After a sufficient number of waves the sample composition reaches “steady-state”, and remains unchanged during further waves, and the original seeds' characteristics do not affect sample composition (Heckathorn, 1997, 2002).

Broadhead and Heckathorn (1994) germinated the method in their article on the problems and prospects of outreach worker-driven AIDS prevention programs. The mechanics of RDS lie behind their description of the “peer-driven intervention” (PDI). HIV-prevention researchers further refined RDS to conduct research among IDUs in general (Heckathorn, 1997), and then CDC-funded researchers applied the method in studies of younger IDUs (Heckathorn, 2002). Recognising RDS's influence on the field of public health, the *Journal of Urban Health* (vol. 83, No. 7) recently published a “special issue” comprising a rich variety of RDS studies focused on the transmission of HIV and blood-borne pathogens. Recent reviews have concluded that RDS is, at present, the best method for accruing valid samples of hidden populations (Scott, 2005; Semaan, Lauby, & Liebman, 2002), although some critiques of the method's underlying assumptions have begun to circulate (e.g., Heimer, 2005).

In 2005 the National Centers for Disease Control and Prevention (CDC) used RDS to conduct a “pilot” surveillance of IDU behaviour in 25 U.S. cities simultaneously. NHBS is an ongoing behavioural surveillance system that collects cross-sectional self-report survey data among populations at relatively higher risk for acquiring HIV: men who have sex with men (MSM), IDUs, and heterosexual persons. The team responsible for carrying out Chicago's surveillance – based in the Chicago Department of Public Health (CDPH) – employed this article's author to design and carry out an independent ethnographic study of the *process* by which RDS generated the local IDU sample.

Early anecdotal reports indicated that several RDS implementation issues demanded scrutiny. First, provocative evidence (i.e., firsthand accounts and direct observation) emerged that an “underground” stratified marketplace of coupons and study-related services had cropped up. Second, prospective subjects quickly learned various methods for subverting the study's screening process, and this economy of subversive techniques engendered conflict among participants. Finally, I observed a few instances of “coercive” recruitment practices among study subjects who had

been interviewed and had received coupons to distribute to other IDUs.

Unlike other sampling methods RDS assigns the lion's share of responsibility for ethical conduct vis-à-vis recruitment to the human subjects themselves. The participant, rather than the researcher, maintains responsibility for soliciting study participation. Broadhead and Heckathorn (1994) describe this “pay for performance design” as one that “rewards the most productive recruiters. . .” (p. 488). They conclude: “As a result, subjects are paid in direct proportion to the success of their recruitment efforts and those who recruit no one receive nothing” (p. 488). RDS's “farming out” of recruitment transactions has yet to be examined closely with regard to either data integrity or potential human subjects protection violations. Articles related to RDS typically describe its application to one or another hidden population, assess its validity and/or reliability, or pose questions concerning its compatibility with theoretical enterprises. Given its widespread adoption and apparent endorsement by federal public health research funding agencies such as the CDC, however, a discussion of the method's ethical dimensions seems critical.

Methods

Study context

Since the late 1950s media attention to and empirical research on Chicago heroin users has proliferated. This inquiry's roots descend to earlier studies of opium use and abuse in the city (e.g., Dai, 1937) and to outreach-worker-driven sociological and psychiatric research on “street addicts” (e.g., Finestone, 1957; Hughes, Barker, Crawford, & Jaffe, 1971; McFarland & Hall, 1953). Between the mid-1980s and early 1990s systematic empirical research on IDUs reached its crescendo with the advent of the National AIDS Demonstration Research Project (NADR) (see Huo & Ouellet, 2007; Ouellet et al., 2000; Wiebel, 1988). In the same period Chicago experienced a surfeit of initiatives designed to engage IDUs in behavioural studies, HIV testing/counselling, and safer injection training (see Broadhead & Heckathorn, 1994). Because most of these endeavours compensated IDUs for their participation, a cadre of research savvy, “semi-professional” IDU research subjects arguably emerged.

In late 2004 I began serving as the chief ethnographer leading the formative assessment for Chicago's NHBS surveillance project. Drawing on 4 years' worth of daily ethnographic involvement with IDUs across the city, I directed a team of ethnographers through the process of collecting data to inform, shape, and contextualise the design and implementation of the upcoming surveillance. Theretofore I had logged nearly 4000 h living among IDUs—in houses, apartments, abandoned buildings, homeless encampments, alleyways, and other *in situ* venues. In addition, I had been running clinical trials of a hepatitis B vaccine schedule for

IDU patrons of 14 different Chicago syringe exchange sites. Finally, in my capacity as *pro bono* director of research and outreach educator for the Chicago Recovery Alliance, Chicago's largest syringe exchange, I had been providing on a weekly basis hepatitis B and C testing, rapid HIV testing, simple wound care, safer injection training, and other services. Hence, by the time the NHBS formative assessment began in Chicago, I had amassed a sufficient set of community contacts and a commensurately rich fund of data on which to draw.

Chicago's IDU behaviour surveillance began in summer 2005. Initially the study team distributed coupons to the first five "seeds", IDUs known to team staff with experience working in the field or IDUs whom my team had identified during the formative assessment effort. In some capacity each of the seeds maintained a connection with the syringe exchange venues through which I had already been conducting research and/or outreach projects. Ultimately, greater than 50% of this process study's participants had already operated within the "ethnographic scope" of at least one of my previous studies.

CDPH set up interview facilities in five facilities located in some of the city's most economically depressed areas. All interviewees received \$20 for the interview and \$10 for each of the three coupons that their IDU associates redeemed successfully (i.e., they qualified for the study and completed the entire interview). Hence, each participant had the opportunity to earn up to \$50 total (officially).

In a 6-month period the CDPH surveillance team surveyed 529 IDUs reporting residential addresses from 46 different Chicago zip codes, representing 87% of the city's neighbourhoods. The surveillance sample's characteristics conformed to earlier estimates of the city's IDU population (Friedman, Tempalski, & Cooper, 2004; Holmberg, 1996; Scott, 2005). I ensured that the present RDS process sub-study sample reflected the characteristics of the previously computed IDU population parameters: 45% non-Hispanic black, 40% non-Hispanic White, and 15% Hispanic. The present study's sample and the surveillance sample are nearly identical with regard to gender distribution and age characteristics.

This study drew upon a sample of 70 participants who progressed through the entire surveillance sequence. They passed screening for IDU status, completed the interview, distributed all three of their coupons, and collected what they believed would be the maximum "finder's fee" possible. In 60 of the 70 cases, participants collected their fees for all three referrals. The remaining 10 participants had two of their coupons redeemed. I intentionally focused on "successful" recruiters because the study's central question related to the social, economic, cultural, and political factors – individual, contextual, and cultural – associated with recruitment success.

Interviews and observations

The present inquiry revolved around the administration of in-depth, *post hoc* structured interviews with respondents

who had nothing further to gain or lose monetarily – in official terms – by speaking frankly with me about how their own and their peer's performance of recruitment tasks. In addition, I engaged in traditional ethnographic observational data collection, which entailed attaching myself to 25 of the most active members of the "coupon economy", a tactic that consumed more than 400 h and yielded more than 1500 pages of field notes. Finally, I spent more than 200 h in a total of 20 "shooting galleries", places where IDUs congregate to socialise, relax, consume and experience drugs, and occasionally live. Each interviewee received \$10 for allowing me to interview him or her. Those who allowed me to "shadow" them received \$20 per day.

Aside from the standard demographic variables, I collected data using mostly open-ended questions designed to elicit details of the RDS process without leading participants into speaking directly about the study's "underbelly" (e.g., "How did you end up participating in this study?" and "How did you go about getting others to participate?"). On different days of the week for an 8-week period I showed up without warning at one of the field stations and would ask study staff to refer to me people there to retrieve their final incentive payment. I then approached prospective informants, explained the project's purpose, obtained informed consent, and either conducted or arranged to conduct the interview in a private location.

Systematic computer-assisted "content analysis" of the printed interview transcripts (1000 single spaced pages) and observational field notes (1500 single spaced pages) ensued. Transcripts and field notes were subject to a multi-stage coding process beginning with "open coding" (Strauss & Corbin, 1998), a document review and analysis process that reduces large passages of text to principal concepts and their most salient properties and dimensions. "Axial coding" comprised the second stage wherein analyses focus on relating concepts to sub-categories and concepts to each other. This kind of coding allows the researcher to observe the emergence of relationships within and between cases and phenomena and to better understand the relative influence of qualitative variables.

Axial coding revolved around the deployment of "consensus analysis" (CA), an analytic paradigm that enables one to assess "the amount of agreement among a group of people about some domain of cultural knowledge" (Caulkins, 1998) and to detect "the presence and basis of cultural differences" (Handwerker, 1998). Using ANTHROPAC[®] I submitted all open-ended and discrete response data relevant to the domain for minimum residuals factor analysis to ascertain patterns of similar response among informants' descriptions of RDS coupon circulation in action and to gauge and adjust for random variation. The body of this paper is organised synchronically with the factors exhibiting the highest "score", or eigenvalue, measured as the sum of squared loadings for a given factor. The highest scoring factors – which emerged from both axial coding and from domain analysis – appear below.

The following methodological limitations affect data interpretation: (1) this sample was not selected randomly, although its demographic patterns match up with the surveillance sample and with Chicago's estimated IDU universe; (2) this study is particular to the City of Chicago—the findings may or may not be generalizable to the other 24 surveillance sites or to other RDS-driven studies, but they do suggest that greater attention be paid to the ethical dimensions of all RDS studies regardless of target population or location (in other words, one ought to exercise caution when disregarding relevance when generalizability fails to obtain); (3) because study design called for examination of “successful” recruitment, I did not constitute a control group of participants who failed to recruit more than one of their peers, so I cannot account for systematic differences between successful and unsuccessful recruiters; and (4) although my relative “outsider” status among some IDUs in the study functioned advantageously (i.e., subjects quickly adopted the role of “teacher” and I was the student) most of the time, about 40% of the sample expressed reluctance when asked about their dealings with surveillance staff because, as Fred put it, “I don't want my big mouth to get any of they asses in trouble”.

Results

Previous articles have explored a variegated array of ethical issues pertinent to studies of illicit drug use(rs) whose sample accrual hinges on paying subjects for their time and/or their help in recruiting other participants (e.g., Fisher, 2004; Fry & Dwyer, 2001; Grady, 2001; Seddon, 2005). While these studies vary in their philosophical, ethical, political, and empirical orientations, they invoke a central and seriously flawed model: estimating the subject's well being, or compromise in the subject's well being, as a result of monetary inducements to participate in research can be accomplished by extracting the subject from his/her social, economic, and cultural milieu. In other words, the prevailing view on subject well being in relation to incentive payments assumes, incorrectly, that the subject operates in a vacuum.

Human subjects, like most anyone involved in a given market, receive and spend money through transaction with others. Moreover, one's income and expenditures rarely enjoy secrecy: someone else almost always knows when/whether you receive income and when/whether/how you spend your money. RDS studies necessitate subjects' formal involvement in each other's financial affairs—one cannot even participate in the programme without someone else knowing that s/he is participating. Hence, RDS demands *prima facie* subversion of a central tenet of human subjects protection: confidentiality. See Fitzgerald and Hamilton (1997) for an analysis of confidentiality breaches as related to the devolution of ethical responsibility in research.

Nevertheless, the studies cited above enumerate hundreds of other studies where scholars mount research agendas

focused on illicit drugs. While it may be true that any study – regardless of methodology – whose subjects receive payment for participation will usher in some kind of new exploitation (or an old exploitation with a new patina), it should be noted that RDS's alleged innovations do not improve the situation from an ethical standpoint. RDS may not be any worse than other methodologies in terms of human subject protection transgressions, but the data in this study indicate that it is not likely to be immune from such criticisms.

Hustles and licks: RDS as a divisive source of revenue in impoverished neighbourhoods

A panoply of creative schemes to make additional “side money” surfaced as potential participants – injectors and non-injectors – viewed the coupon system as yet another possible “lick” or “hustle” ensconced in their neighbourhoods. The surveillance effort delivered to IDUs the same sort of subaltern money-making opportunities that past outreach/research projects had furnished to outreach workers (see Broadhead & Heckathorn, 1994). Echoing the spirit and content of such studies as those by Venkatesh (2000), Wilson (1987), and Stack (1974), Mike, a 38-year-old IDU, articulated his assessment of RDS as a potential revenue stream:

It's like a pyramid scheme, man. Somebody turns me onto the gig, and they make money off me doin' it. Then I get money for doin' it, for givin' up an hour or two of my time. Then I turn some buddies or some blood kin or maybe even some complete fuckin' strangers onto this here shit, and I get paid for each of them that do it. But there's also other ways to jump this ride and make more than the 50 dollars they say we gonna get for bein' good soldiers. 'Cause you got to understand, man, that when you put something like this here study in the middle of the ghetto, people are gonna try their damndest – and we can be pretty motherfuckin' resourceful because we used to livin' hand to mouth – to make more money than the pyramid promises. It's just the way we get down with these things, man. It's a survival thing, and most of us is gonna jump this pyramid and dig it down as far and deep as we can. And it ain't 'cause we bad people or liars or thieves or nothin' like that. But the fact is, we got habits to support, and we got families to feed.

The vast majority of participants reported residential zip codes located in areas marked by relatively severe poverty combined with an absence of commercial and social service enterprises. Preliminary data analysis indicates that 49% of participants were earning less than US\$ 10,000 per year, and 45% had been homeless at least once in the year prior to the survey. Twenty-six percent were homeless at the time of the surveillance interview.

As Venkatesh (2000) has documented, residents in neighbourhoods suffering entrenched poverty will find ways to survive. RDS's dual incentive structure welcomes such exploitation, perhaps more so than other sampling methods

used in studies of hidden populations. Chicago's RDS-based surveillance enterprise spawned a micro-economy rife with the inequalities, inequities, and conflict that characterise all capitalistic markets wherein some form of exchange value currency constitutes the primary transaction medium.

Broadhead and Heckathorn (1994) point up the "informational asymmetries" between individuals who contract for services ("principals") and those who provide services ("agents"). In their study the outreach workers were the agents and the research and/or program outfits were the principals. They find that outreach workers – former addicts – could control their principals (i.e., employers) through "evasion, dissimulation, mystification and many other deceptive practices" (p. 478). RDS, or "peer-driven intervention" as they describe it in their seminal article, fails to eradicate these problems; instead, it further devolves the exploitative dynamic to the uneven relationships between IDUs who now act as both agents and principals. Their model astutely identifies the "moral hazards" associated with employing outreach workers whose predilection for hustling ultimately causes problems for the agency. But in critiquing the indigenous outreach worker model they unwittingly promulgate a model that explains equally well how addicts will exploit each other when confronted with the opportunities and constraints of an RDS economy.

Entrepreneurial coupon transactions

Unlike other sampling methods, RDS relies heavily on participants to recruit each other. The RDS system places monetary value on recruitment activities and, more importantly, the success (or failure) of the participants' attempts to get each other into the study. As a sampling and recruitment method RDS hinges on the notion that respondents enjoy enough sufficiently trust-laden relationships to meet his or her coupon distribution "quota". The model assumes that the recruiter will feel confident that members of his or her social network will, in fact, travel to the interview site, pass the screening protocol, and successfully complete the interview thus allowing the recruiter to claim the "finder's fee". To the chagrin of most heroin addicts in the sub-sample their lives want for such trust-laden relations. This paucity explains the predominant tendency of recruiters selling rather than giving away the coupons receive. As 47-year-old IDU Steve explained:

Man, you been out here long enough to know how it is—nobody truly trusts anybody else. We burn [take advantage of] each other all the time... for money, drugs, tobacco, you name it. But it's expected—if you're a junky and you don't get over on other junkies, then they just see you as a punk and a target for all sorts of rat plays, and then you're fucked for good. See, every part of society's got a code, right? Well, we got a code of conduct, too—I call it *honourable dishonour among thieves*. You get over on me today, I get over on you tomorrow. But you never have true friendship with other junkies.

Only in a minority of cases ($n=22$) did respondents in this process study merely give away their coupons as the RDS model assumes they will do. Most sold at least one of them because they were unable to bring themselves to trust three of their social contacts to follow through with the protocol.

Recruitment overtures involve conveyance of information about the study and at least some semblance of conversation concerning informed consent. Surveillance staff vigilantly trained recruiters on how to approach their peers and what to tell them regarding the study's purpose, objectives, activities, risks, and benefits. Because RDS is predicated on a dual incentive payment system, however, the recruiter quickly finds value in assertively, inventively, and sometimes aggressively persuading potential recipients of his coupons to comply with the process. Only after the recipient has completed the interview will the recruiter receive a finder's fee. This commission structure invites new avenues for human subjects protection violation including deceptive advertising, taking advantage of addicts experiencing withdrawal, exploiting resource-deprived addicts, and fostering the creation of new social networks that put members at risk of acquiring a viral infection.

False advertising: A key issue in all human subjects protection protocols is accurate and precise explication of the study's processes, costs, benefits, and potential harms. Nevertheless, 70 informants interviewed for this sub-study said that what their recruiter told them failed to square up with what actually happened at the interview site. Moreover, all 70 reported that they, too, misrepresented the study when distributing or selling their coupons to peers. One informant, Norman, related his story about how his "associate" recruited him into the study:

Man, I'll tell you what's happenin' out there, and it happened to me too. Dude that gave me the coupon said 'Oh, you'll be in and out of there in 15 minutes tops'. So I'm thinkin' to myself that I can make \$20 for 15 minutes of my time, and then I can maybe make another \$30 if I can get my other associates here for the same thing. But then I get here today, and I find out how long it really be takin'. Man, I been here damn near two hours now. And I can't leave, seein' how the guy that gave me the coupon drove me here and plans on stayin' 'til I get finished and paid out. Then he gets his \$10 on top of the \$5 he made me promise I'd pay just 'cause he put me onto this thing.

But that's how it go on the streets. And it makes perfect sense, you know? I mean, I'm gonna do the same thing with my guys. Ain't no way I'm gonna tell 'em how long I had to wait. If I do, then they ain't gonna come. . .

Keri and John, the married couple recruited by another married couple, give their account of how the man duplicitously brought them into the study:

He said, ‘Oh man, we can hook ya’ll up at this place where you give an interview and you can make 25 bucks. He lied then. And then, once we got there and we realized that it was 20 bucks, that’s when my partner said, ‘Well, he was charging us 10 bucks for takin’ us out here. He made that up front before we pulled out from the front of the house. They were there, at the house, on time. The way they explained to us is like, after we get these three people, we get 10 dollars a piece, we get 30 dollars. When they got there and realized, oh, we get our 10 a piece right now, it was a plus. And I guess that’s what made him realize, oh, I guess I won’t charge them 10 dollars a piece, he talked to ‘em and said, ‘Oh, we didn’t get what you said. We ended up getting such and such amount. He said, No problem, just give me five a piece, but still we was charged for somethin’ that was free to him, and he was makin’ a profit out of both of us . . . on both ends . . . and at the end of it all he had more than we did . . . he was just shy 10 dollars of what we had together.

The stimulation of risky networks

The dual incentive structure of RDS compelled many heroin users – especially the more isolated ones – to reach outside of their immediate social group to distribute the coupons. More than 50 percent of respondents reported giving at least one of their three coupons to someone who was not part of their immediate social network defined by this researcher as “a friend, family member, or someone that you inject with at least once a month”. In this way they met other addicts with whom they often forged a bond, usually a partnership for engaging in criminal enterprises. Proponents of RDS argue that such “network crossover” is one of the most desirable aspects of the sampling method because it contributes to the development of a representative (though non-randomly obtained) sample. John explains how network crossover occurred in his case:

The guy I barely knew, the one that gave me the coupon and picked up my buddies and me, on time, to get our interviews done, he became my buddy, my real buddy. After the interview he took us all to cop at a spot that I ain’t never been to before. Now he done opened me up two new spots, two new clients, two new guys that I can cop for, that I can get off [consume drugs] with, two new guys to run hustles and licks with, whatever. They good guys. And what do I got to thank for that: this here study you been askin’ me about. If I never got no coupon or nothin’, I never would have met these cats.

Logistical snafus at the surveillance interview sites sometimes meant that prospective participants had to wait for long periods of time to be interviewed. During this downtime they frequently exchanged information on where to purchase high potency drugs, where to hustle for money, where to sleep for the night, and so forth. From these conversations—some of which lasted as long as four hours, new circles of friends, or

associates rather, emerged. Undoubtedly the structure of RDS implementation in Chicago led to sero-mixing of networks whose formation the design logic of RDS and the study’s implementation processes prompted.

“Coupon hawking,” another form of RDS coupon sales, also contributed to the formation of new social networks among surveillance participants. Hawking typically transpired at the busier surveillance interview sites where the facilities were under the purview of another agency, such as a city-funded clinic. In these instances the operational problem of borrowing space at a site led to large congregations of prospective respondents arriving in the window of time between the clinic opening and the study staff arriving to begin the day’s interviews. Most of the early arrivals had a coupon, but I interviewed 19 who showed up with no coupon in hand; all they knew was that a paid study was afoot. When asked how they came to be there, all 19 independently said that another drug user “sold” them information about the study.

The gatherings of non-coupon holders outside of the interview locations created a ready-made pool of referrals for the respondents leaving the facility with three coupons in hand. Although recruiters rarely succeeded in “hawking” all three coupons, having their recruits interviewed, and collecting their finder’s fees in the same day, the circumstances were such that recruits felt confident distributing coupons to the people outside of the facility for these folks had already demonstrated their initiative and commitment by showing up early without even having a coupon. This logistical problem also resulted in the formation of new social networks of IDUs.

I interviewed all members of seven new networks (total $n = 28$; mean network size = 4 members). I found that all seven networks comprised “sero-discordant” members, meaning that some of the IDUs in the new networks were HIV or HCV positive (or both), while others were not. Sero-mixing of this sort represents a considerable risk factor in the incidence and spread of viral infection (Curtis et al., 1995; Des Jarlais, Friedman, & Stroneburner, 1988; Pierce, 2001; Watters, 1989). Although this study lacks serologic data on the transmission or non-transmission of disease within these newly formed sero-discordant networks, the communal use that arose within these networks inarguably heightened each member’s risk of contracting a new infection.

Relative deprivation and risk

The participants who profited the most in the RDS cottage industry were the ones who already enjoyed greater socio-economic affluence and a less severe dependency on or addiction to heroin. The “playing field” was uneven before the surveillance began—RDS reinforced these pre-existing gradations. The relatively underprivileged often found themselves at the mercy of study participants who enjoyed more resources, such as money and transportation. Lack of automobile ownership is one indicator of poverty in the areas that the surveillance project most effectively penetrated. Participants with access to cars were well poised to make a little

money, and perhaps obtain some drugs. John, an injector, and his wife Keri, a non-injector who faked her way into the study, describe the situation they faced:

Keri: “Now when the day come to go out with these cards and get our three people picked up and took in for the interview, I got to let him [their car-owning associate] know a day ahead of time, do he got somethin’ to do. Now, despite what he say, I’m lookin’ at it realistically, it is mandatory that we put gas in the car. But honestly, now, when he see that you got three people in his car, and he got you in the car, and you all walkin’ outta there with money in the pocket, honestly now, he gonna want somethin’.”

John: “No honestly, honestly is this: He gonna let them know, when they come outta there with they \$15 – after payin’ us – they gonna wanna go cop. And he gonna get a bump outta each one of them. He did that with me. We went down to a spot I ain’t never been before. That shit scared me.”

In providing transportation services the relatively well-off coupon sellers controlled the landscape of risk facing the coupon buyers/redeemers. Oftentimes sellers and transporters put their “customers” in unfamiliar, ambiguous situations wherein buyers found it difficult to perform adequate risk calculations of their own. Their dependence on/addiction to heroin, however, overrode their trepidation as they found themselves reluctantly going along with the sellers plan for them.

Disputes in the RDS coupon market

Disputes between parties to any market’s transactions invariably occur. RDS’s dual incentive payment system turned recruiters into advertisers, sellers, and debt collectors. Physical and verbal abuse often accompanied the latter role. The 70 interviews I conducted yielded 17 accounts of threatened or actual physical violence between the recruiter and his recruits. I also observed five incidents in the field where arguments over coupon non-redemption escalated into physical attacks. In all of these cases the recruiter had given a coupon to a recruit who, according to the recruiter, was failing to follow through swiftly enough and therefore delaying the recruiter’s receipt of a finder’s fee for that person.

The following excerpt from my field notes details an instance in which a disagreement over coupon redemption escalated into violence:

Stan and Patty, boyfriend and girlfriend, are homeless. They live in a hut they built in the weeds next to freight train tracks on the city’s west side. Several weeks ago Stan – one of the study’s first seeds – gave Patty one of his three coupons. I observed that transaction, during which Patty promised to go in for the interview “in the next week”. Stan tells me that if he can trust anyone to act on their word, he trusts Patty. Since giving her the coupon, how-

ever, they have broken up. Patty has returned to sex work to support her drug habit (and drugs to deal with the anguish of sex work). Today I observe their first encounter in several weeks. We’re near the train tracks, standing among decommissioned train cars. They argue over Patty’s failure to redeem her coupon in a timely manner. Stan wants his \$10 payment now, “and I mean now”. She says that she hasn’t had time to go in for the interview. He reminds her that his finder’s fee isn’t the only thing at stake; she also stands to make \$50 for her participation in the project. Again she says that she doesn’t have time to do it, at least not today. He begins yelling, “You’ve got time to suck dicks for crack, you’ve got time to fuckin’ shoot dope and smoke rocks all day, you’ve got time to lay up in the motel room with tricks, and now you’re tellin’ me you ain’t got time to do this one little fucking thing for me? She yells back, “Fuck off! Get the fuck away from me!” Stan steps forward and shoves her into the side of an old boxcar while continuing to castigate her with insults and expletives. Finally, Patty ducks one of his shoves and flees the scene.

Unlike conventional markets the RDS coupon arena suffered an absence of a regulatory body to serve transacting parties who need help with dispute or grievance resolution. In the absence of a formal, authoritative council, aggrieved parties predictably invoked pre-existing informal modes of “street justice”. This brand of justice conventionally metes out swift and relatively severe, usually corporal, punishment to transgressors. Although RDS may not have increased street violence among IDU participants, the data indicate definitively that violence did occur as a result of disputes over RDS-related transactions.

Organised coercion: shooting gallery owners as usurious venture capitalists

On the west and south sides of the city I documented more than 20 “shooting galleries”, apartments and houses – both legally and illegally occupied – where surveillance participants (IDUs and crack smokers) customarily gathered to consume and enjoy their drugs. An average of eight people lived in these galleries with a mean of 17 IDUs trafficking through them daily. The “owner” is the person who holds the lease or mortgage – if the place is occupied legally – or the person who has come to have access and control of an abandoned house or apartment. The 20 gallery owners I interviewed conceived the surveillance project as an opportunity to mount “strong-arm” tactics to extort additional “rent” from gallery residents. The tactic is a simple one and stems organically from the structure of RDS itself: the owner recruits his three people from the residents of the gallery and then transports them to the interview location. Once the residents have completed the interview and received payment and three coupons, the owner collects their coupons and distributes them to other gallery residents until they have saturated the pool of inhabitants. Once the owner achieves gallery saturation, he distributes his tenants’ coupons to IDUs whom

he knows from the streets. John explains, as a non-gallery-resident, how this affected him:

When I took him in, my buddy that run the house [shooting gallery owner], when he finished, we go and cop. And he give his three coupons to people in the house. He created a chain reaction. He get 'em up in the mornin' and get 'em to the interview. Then . . . they get paid and he make 'em give two coupons to him and he give 'em to two more people in the house. And he don't allow nobody in the house to give they coupons to nobody else in the house. So he get paid for everybody in the house, and then he have tickets left for people he know that ain't in the house. He just lettin' 'em use one coupon for they wake-up [first injection of the day]. He already providin' a service for them. Or else he gonna hold 'em all and take care of they fixes for a little bit. You see how it is . . . a lotta people there, he already go and shop for 'em. And he so slick, he might even sell 'em. Or he gonna sell the address off the back of them.

Interviews with gallery owners confirm a pattern of capitalising on the addictions of a captive audience—the largely indigent collection of gallery residents. RDS coupons represent a fiduciary instrument, a capital-producing commodity that creates its own market of buyers and sellers. Some parties to the various transactions have more power than do others. The most vulnerable members of the market – the strung out, so-called “street junkies” – have the least amount of bargaining power and pay the highest relative price (rather, reaps the lowest relative benefit) for their participation in the project.

Tutorials with teeth: organising and disciplining IDU impostors

Many non-IDUs adroitly “faked” their way into the study either because they spend a good deal of time with injectors or because they paid an IDU to teach them how to convince the interview staff that indeed they do inject street drugs. Of the 70 formal interview participants, 28 had not injected in the year preceding the interview but had effectively convinced the study's screener and interviewer that they had injected at least once in the preceding year. Of those 28 participants, 13 had never injected drugs in their lives; all of them were, however, crack cocaine smokers who had acquired knowledge of drug injection through association with IDUs. Every participant in this sub-study reported knowing at least one other participant who “qualified” for the study without ever having injected drugs.

James, who has never injected drugs but who succeeded in “conning” study staff, shares the subversive innovation that another non-IDU surveillance participant gave him:

Well, if you got darker skin, like I got, then you already a leg up. If they don't go for the whole thing about shooting up in your private parts, and if you're not too good at tellin' 'em the specifics on using a needle, then you can show track marks. What you do is take a black Sharpie [permanent

marker] and draw a line along a couple of your veins. Then you just to smudge the marks and it look just like scarred up or burned out veins. So, really, you have a lot of angles to work in terms of getting into this study without bein' a dope fiend, ya' know?

In the first 2 months of surveillance, recruiters' attempts to train non-IDUs were intermittent and relatively unsophisticated. Typically, the recruiter would simply tell the non-IDU recruitee to tell the study staff that she or he injects in the groin, knowing that interviewers were prohibited from asking them to reveal visual proof of injection on hidden areas of the body. Then they would instruct the recruitees on the basics of injection. The study team quickly devised methods for ferreting out the non-IDUs who employed such crude tactics. As the weeks rolled on, however, training efforts became much more elaborate. On the south side of Chicago, for instance, I met five former recruiters – IDUs who had been through the study and referred their three associates – who developed their own curricula for teaching non-IDUs how to “get over” on the study.

At the end point of the chicanery evolutionary cycle were these former participants who developed curricula and marketed their services to study participants who had coupons but either limited access to IDUs or access to an abundance of non-IDUs (usually crack smokers). The enterprising “tutors” corporatised their tutorial vices, charging a fee to these participants who for one reason another wanted to refer non-IDU family members, friends, or associates to the study. Wilma, for example, is a former injector whose knowledge of injection and presence of track marks propelled her into the study and who quickly realised the value of formalising and marketing her training services. By the time I interviewed her (about 3 months into the cycle) she had trained more than 30 non-IDUs, charging each recruiter \$10 for her service. Wilma explains:

I got me a whole training program, see, because them study people is getting' smarter and smarter every day. So it's gettin' harder and harder to slip by them. You can't just say 'Oh, I shoot in my groin area' anymore, because they ain't gonna buy it. They gonna make you explain, in detail, exactly how you inject—how much dope, how much water, how you find a vein, all that little shit, shit that you know if you a dope fiend, but if you just a crackhead, you don't know it. So I got the whole program down—I go around with needles and water and filters and other supplies I got at the needle exchange, and I set 'em up and teach people exactly how its done. I don't shoot dope no more, so I just inject sterile water from the tubes. Anyway, these folks with the coupons but no dope fiends to give 'em to, I charge them \$10 to train their people. And then I sometimes get a cut of money or crack from each of their people, too.

From the standpoint of protecting human subjects, more troubling than the mere fakery was the attendant organ-

ised coercion I documented. For instance, Wilma employed strong-arm labour to coerce recruits into redeeming their coupons. I directly observed her utilise a filial tie to a drug-dealing street gang to get “kickback” money from a recruit of hers. The recruit in this case attempted to protect his funds (i.e., not pay the kickback) by trying to convince Wilma that study staff had ruled him ineligible for the study. Unfortunately for him, however, as he made his argument the telltale white envelope containing his \$20 incentive payment and three coupons jutted conspicuously from his gripped hand. When she brought this to his attention he took off running across a vacant lot. She took chase after him, all the while tethered by microphone to my audio recorder. We caught up with him in an alley where he and some friends were standing around talking jovially. Wilma reprimanded him and threatened punishment for his artifice:

Listen to me you dumb motherfucker . . . You owe me five fuckin’ dollars for settin’ you up on this lick. And it ain’t the money, you stupid ball of shit. It’s the whole principle of the thing. You tryin’ to play me like I just down on these here streets yesterday. Well, I ain’t green, I was runnin’ these streets before anybody even thought about doin’ the fucking that got you to this earth. And you know what, you go ahead and keep them five bucks. But know this, motherfucker, when I get home I’ll be talking to Terrell [her son], and I’ll let him and his crew take care of this here business.

Terrell, her 25-year-old son, lords over several drug crews affiliated with the Gangster Disciples (GDs). He has several “enforcers” (debt collectors, punishers, etc.) who work for him and who inspire fear in anyone who knows of them. As soon as Wilma makes this very real threat, the young man begrudgingly gives up \$5 plus one of the three coupons he had received. As Wilma and I walked away from the young man, she just looked at me and said, “What a fuckin’ sucker. I got him”. Very rarely (three instances) did this sort of strong-arming occur. The threat uniting the separate incidents was a close connection to a drug-dealing street gang.

Conclusion

This article documents the manifold ways that the design and implementation of RDS-driven surveillance of IDUs invites if not promotes the violation of federal guidelines governing the protection of human research subjects. In this case RDS became part of the landscape of hustles in Chicago’s most impoverished neighbourhoods and further underscored and cemented pre-existing stratification within the population of already underprivileged IDUs. By inventively co-opting RDS, the relatively privileged IDUs reinforced their superordinate position in the social and economic sphere of injectors. Their hustles and licks necessitated transactional means that

produced various harms for other IDUs participating in the surveillance effort.

Through empirically derived ethnographic insights I present here a cautionary tale of RDS implementation generally and, more specifically, of using RDS to study poverty-stricken hidden populations. The results add up to the conclusion that RDS-driven studies and/or any study involving incentive payments ought to consider installing process-oriented research to enhance the project’s capacity for determining how recruitment permutations affect data integrity and, more importantly, the well-being of the human subjects involved in the study.

Acknowledgments

I would like to thank The Chicago Center for Health Systems Development for providing funding to support this study of RDS in action.

References

- Broadhead, R. S., & Heckathorn, D. D. (1994). AIDS prevention outreach among injection drug users: Agency problems and new approaches. *Social Problems*, 41(3), 473–495.
- Broadhead, R., Heckathorn, D., Grund, J., Stern, L., & Anthony, D. (1995). Drug users versus outreach workers in combating AIDS: Preliminary results of a peer-driven intervention. *Journal of Drug Issues*, 25(3), 531–564.
- Caulkins, D. (1998). Consensus analysis: Do Scottish business advisers agree on models of success? In V. C. de Munck & E. J. Sobo (Eds.), *Using methods in the Field: A practical introduction and casebook* (pp. 179–195). Walnut Creek, CA: AltaMira Press.
- Curtis, R., Freedman, S., Neaigus, A., Jose, B., Goldstein, M., & Idefonso, G. (1995). Street-level drug markets: Network structure and HIV risk. *Social Networks*, 17, 229–249.
- Dai, B. (1937). *Opium addiction in Chicago*. Shanghai, China: Commercial Press Ltd.
- Des Jarlais, D. C., Friedman, S. R., & Stroneburner, R. L. (1988). HIV infection and intravenous drug use: Critical issues in transmission dynamics, infectious outcomes, and prevention. *Review of Infectious Diseases*, 10, 151–158.
- Finestone, H. (1957). Cats, kicks, and color. *Social Problems*, 5(1), 3–13.
- Fisher, C. B. (2004). Ethics in drug abuse and related HIV risk research. *Applied Developmental Science*, 8(2), 91–103.
- Fitzgerald, J. L., & Hamilton, M. (1997). Confidentiality, disseminated regulation and ethico-legal liabilities in research with hidden populations of illicit drug users. *Addiction*, 92(9), 1099–1107.
- Friedman, S., Tempalski, B., & Cooper, H. (2004). Estimating numbers of injection drug users in metropolitan areas for structural analysis of community vulnerability and for assessing relative degrees of service provision for injection drug users. *Journal of Urban Health*, 81(3), 377–400.
- Fry, C., & Dwyer, R. (2001). For love or money? An exploratory study of why injecting drug users participate in research. *Addiction*, 96, 1319–1325.
- Goodman, L. (1961). Snowball sampling. *Annals of Mathematical Statistics*, 32, 148–170.
- Grady, C. (2001). Money for research participation: Does it jeopardize informed consent? *American Journal of Bioethics*, 1(2), 40–44.
- Handwerker, W. P. (1998). Consensus analysis: Sampling frames for valid, generalizable research findings. In V. C. de Munck & E. J. Sobo (Eds.),

- Using methods in the Field: A practical introduction and casebook* (pp. 165–178). Walnut Creek, CA: AltaMira Press.
- Heckathorn, D. (1997). Respondent-driven sampling: A new approach to the study of hidden populations. *Social Problems*, 44(2), 174–199.
- Heckathorn, D. (2002). Respondent-driven sampling II: Deriving valid population estimates from chain-referral samples of hidden populations. *Social Problems*, 49(1), 11–34.
- Heimer, R. H. (2005). Critical issues and further questions about respondent-driven sampling: Comment on Ramirez-Valles, et al. (2005). *AIDS and Behavior*, 9(4), 403–408.
- Holmberg, S. (1996). The estimated prevalence and incidence of HIV in 96 large U.S. metropolitan areas. *American Journal of Public Health*, 86(5), 642–654.
- Huo, D., & Ouellet, L. (2007). Needle exchange and injection-related risk behaviors in Chicago: A longitudinal study. *Epidemiology and Social Science. Journal of Acquired Immune Deficiency Syndromes*, 45(1), 108–114.
- Hughes, P. H., Barker, N. W., Crawford, G. A., & Jaffe, J. H. (1972). The natural history of a heroin epidemic. *American Journal of Public Health*, 62(7), 995–1001.
- McFarland, R. L., & Hall, W. A. (1953). A survey of one hundred suspected drug addicts. *Journal of Criminal Law, Criminology and Police Science*, 44, 308–319.
- Ouellet, L. J., Thorpe, L. E., Huo, D., Bailey, S. L., Jimenez, A. D., Johnson, W. A., Rahimian, A., & Monterroso, E. (2000). Prevalence and incidence of HIV among out-of-treatment injecting drug users, Chicago 1994–1996. *Journal of Acquired Immune Deficiency Syndromes*, 25(5), 443–450.
- Pierce, T. (2001). Gen-X junkie: Ethnographic research with young white heroin users in Washington, D.C. In J. Inciardi & K. McEltrath (Eds.), *The American drug scene*. Los Angeles, CA: Roxbury Publishing Company.
- Salganik, M., & Heckathorn, D. (2004). Sampling and estimation in hidden populations using respondent-driven sampling. *Sociological Methodology*, 34, 193–239.
- Scott, G. (2005). *Ethnographic assessment of injection drug use in Chicago: A foundation for behavioral surveillance; January*. Atlanta: Centers for Disease Control and Prevention.
- Seddon, T. (2005). Paying drug users to take part in research: Justice, human rights and business perspectives on the use of incentive payments. *Addiction Research and Theory*, 13(2), 101–109.
- Semaan, S., Lauby, J., & Liebman, J. (2002). Street and network sampling in evaluation studies of HIV risk-reduction interventions. *AIDS Review*, 4, 213–223.
- Spren, M. (1992). Rare populations, hidden populations and link-tracing designs: what and why? *Bulletin Methodologie Sociologique*, 36, 34–58.
- Stack, C. B. (1974). *All our kin: Strategies for survival in a black community*. New York: Harper Torchbooks.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research. Techniques and procedures for developing grounded theory* (2nd ed.). Newbury Park: Sage.
- Venkatesh, S. A. (2000). *American project: The rise and fall of a modern ghetto*. Cambridge, MA: Harvard University Press.
- Watters, J. (1989). Observations on the importance of social context in HIV transmission among intravenous drug users. *Journal of Drug Issues*, 19, 9–26.
- Watters, J. K., & Biernacki, P. (1989). Targeted sampling: Options for the study of hidden populations. *Social Problems*, 36(4), 416–430.
- Wiebel, W. (1988). Combining ethnographic and epidemiologic methods in targeted AIDS interventions: the Chicago model. *NIDA Research Monograph*, 80, 137–150.
- Wiebel, W. (1990). Identifying and gaining access to hidden populations. *NIDA Research Monograph*, 98, 4–11.
- Wilson, W. J. (1987). *The truly disadvantaged*. Chicago: University of Chicago Press.