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## Recruiting and Retaining Mobile Young Injection Drug Users in a Longitudinal Study

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### Abstract

Longitudinal studies that research homeless persons or transient drug users face particular challenges in retaining subjects. Between 2005 and 2006, 101 mobile young injection drug users were recruited in Los Angeles into a 2-year longitudinal study. Several features of ethnographic methodology, including fieldwork and qualitative interviews, and modifications to the original design, such as toll-free calls routed directly to ethnographer cell phones and wiring incentive payments, resulted in retention of 78% of subjects for the first follow-up interview. Longitudinal studies that are flexible and based upon qualitative methodologies are more likely to retain mobile subjects while also uncovering emergent research findings.

### Keywords

Longitudinal; qualitative methodology; hidden population; high-risk youth

### Introduction

Longitudinal research designs have several distinct advantages over cross-sectional designs, such as assessing behavioral changes, determining the temporal ordering of related variables, and making stronger causal interpretations (Ribisl et al., 1996).<sup>1</sup> Retaining subjects for follow-up interviews is a crucial component of longitudinal studies, since losing significant portions of a cohort can produce biased results. For instance, missing high-risk or extreme cases during the follow-up period may overestimate the effectiveness of an intervention (and threaten a study's internal validity), or underestimate prevalence/incidence

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#### Declaration of interest

The authors report no conflict of interest. The authors alone are responsible for the content and writing of this paper.

<sup>1</sup>The reader is referred to Hills's criteria for causation, which were developed in order to assist researchers and clinicians determine if *risk factors* were **causes** of a particular disease or **outcomes** or **merely associated**. [Hill, A. B. (1965). The environment and disease: associations or causation? *Proceedings of the Royal Society of Medicine*, 58:295–300.] Editor's note.

of a phenomenon (and threaten a study's external validity) (Wright, Allen, and Devine, 1995).

Strategies for minimizing attrition and retaining participants in longitudinal studies comprise two primary types—baseline tracking procedures and follow-up procedures (Wright et al., 1995). Baseline tracking procedures, which are implemented during the first interview and occur between the interviewer and participant, include: collecting detailed locator information on the participant, such as home address, phone number, email address, and social security number (Cottler, Compton, Ben-Abdallah, Horne, and Claverie, 1996; Scott, 2004; Wright et al., 1995; Ziek et al., 1996); gathering locator information on the participant's family members or members of his/her personal networks (Cottler et al., 1996; Wright et al., 1995); motivating and educating subjects about project goals, such as reasons for follow-up interviews and how interview data will be used (Scott, 2004; Wright et al., 1995); creating a project identity, which may include providing a project ID card (Des Jarlais, Perlis, and Settembrino, 2005; Wright et al., 1995), and developing a catchy project title that subjects will remember, such as Urban Nomads (UNO) (Des Jarlais et al., 2005); and distributing debit cards that allow respondent payments to be sent electronically following remote telephone interviews (Des Jarlais et al., 2005).

Follow-up procedures, which may involve an interviewer or team approach to reconnecting with the participant after the baseline interview, involve: searching electronic databases for information on participants, including jails and prisons (Cottler et al., 1996); sending mail reminders or calling with follow-up interview dates (Cottler et al., 1996; Scott, 2004; Wright et al., 1995; Ziek et al., 1996); intensively tracking participants using locator information, agency contacts, and/or visiting field hangouts (Cottler et al., 1996; Leonard et al., 2003; Pollini et al., 2000; Wright et al., 1995; Ziek et al., 1996); offering services during follow-up, such as free drug treatment (Cottler et al., 1996), or other nonmonetary incentives, such as mugs or key chains with project logo (Leonard et al., 2003); holding frequent staff meetings and engaging in creative team work pertaining to retention and tracking (Cottler et al., 1996; Leonard et al., 2003); increasing incentive payments to build interest and motivation for follow-up interviews (Cottler et al., 1996; Des Jarlais et al., 2005); maintaining research field stations in targeted neighborhoods where participants may informally visit or be formally interviewed (Des Jarlais et al., 2005); and providing subjects with toll-free phone numbers that connect to project staff (Des Jarlais et al., 2005; Wright et al., 1995).

These strategies are a necessary component of longitudinal research designs that focus on “nontraditional populations,” (Wright et al., 1995), such as homeless persons, drug users, or persons living with HIV or AIDS, which may present particular challenges for retaining in a longitudinal study. Certain subgroups of nontraditional respondents, however, may be more difficult to track than others. For instance, Cottler et al.'s (1996) longitudinal study of 455 drug “abusers”,<sup>2 3</sup> which reported an 18 month follow-up of 97%, found that male and unemployed subjects were the most difficult to track. Ziek, Beardsley, Deren, and Tortu, (1996) longitudinal study of 409 urban crack users, which recorded a 6-month follow-up rate of 70%, concluded that persons who were younger, homeless, male, or using higher levels of crack were the most difficult to track. In contrast, Pollio, Thompson, and North's (2000) longitudinal study of 118 homeless youth, which recorded a 6-month follow-up rate of 59%, found that older youth were more likely to be lost during follow-up. Des Jarlais et

<sup>2</sup>The journal's style utilizes the category *substance abuse* as a diagnostic category. Substances are used or misused; living organisms are and can be *abused*. Editor's note.

<sup>3</sup>The reader is reminded that a built in “side effect” of language is the ease with which heterogeneous groups who are categorized are “homogenized” and if they are nontraditional populations they can easily be stigmatized, mystified and “empowered”. Editor's note.

al.'s (2005) longitudinal study of 139 geographically mobile drug users, which reported a 71% 12-month follow-up rate, found that minority, non-IDUs (IDU is injection drug user), with extensive arrest histories were most difficult to follow-up at 6 months.

This article describes the methods used to recruit and retain a sample of 101 young, highly mobile IDUs. We detail challenges, failures, and successes in retaining this sample, including specific strategies implemented during the 2-year longitudinal study. While some strategies are similar to those used by previous studies, others strategies—particularly those informed by qualitative methodologies—were devised to meet the particular needs of the target population and included the following: conducting follow-up interviews by telephone, sending incentive payments via Western Union, adding new interviewing modules to follow-ups, scheduling brief and/or intensive additional interviews soon after baseline, and developing comprehensive “super follow-up” interviews.

## Methodology

The study objectives included describing patterns of substance misuse and assessing risks for infectious disease exposure among young IDUs who inject ketamine—a dissociative anesthetic that has become increasingly popular among groups of young people participating in club/rave cultures (Jansen, 2001) and young IDUs (Lankenau and Clatts, 2002, 2004; Lankenau et al., 2007). Phase 1 of the study comprised a cross-sectional, ethnographic survey of 213 IDUs recruited in New York, New Orleans, and Los Angeles, and extended from 2004 to 2006. Phase 2 consisted of a 2-year longitudinal study of 101 young IDUs recruited in Los Angeles during phase 1 and extended from 2005 to 2007. While this manuscript focuses primarily on phase 2 longitudinal study, we describe phase 1 since the multisite methodology impacted the longitudinal design in several important ways.

New York, New Orleans, and Los Angeles were selected as phase 1 sites since prior research indicated that ketamine was being injected in each city (Lankenau and Clatts, 2002). In each site, data collection began with a community<sup>4</sup> assessment process (CAP; Clatts et al., 1995) by ethnographers to record local knowledge of the practice of ketamine injection and to determine the locations of groups of young people who injected ketamine. Towards this end, ethnographers interviewed key informants who might have direct or indirect contact with young ketamine injectors, such as directors of homeless shelters, needle exchange coordinators, and outreach workers. In most cases, key informants had limited knowledge about ketamine, or the locations of young people who injected ketamine. Although, key informants directed ethnographers to public places containing groups of young IDUs, which became the primary locations for conducting fieldwork and recruitment.

In New York, young IDUs were recruited in three contiguous areas within Manhattan's East Village: Union Square, St. Marks Place, and Tompkins Square Park. All New York interviews were conducted during a 5-month period between April 2004 and August 2004. In New Orleans, young IDUs were primarily recruited within the French Quarter during a 15-month period between March 2004 and August 2005. In Los Angeles, young IDUs were recruited from three areas: Santa Monica, Venice, and Hollywood. Santa Monica and Venice are neighboring beach communities located on the west side of Los Angeles, while Hollywood is located about a dozen miles to the east. All Los Angeles interviews were conducted during a 17-month period between January 2005 and June 2006.

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<sup>4</sup>The term 'community' has been attached to a diverse range of ideas and initiatives. One can categorize three broad types of community intervention models to consider the “demands” and “implications” of *community readiness* and *community awareness* for planned intervention. These include (1) *professional agency networks*, (2) *community partnerships* between professionals and community members and (3) *grass-roots community initiative*. Shiner et al (2004) *Exploring community responses to drugs* York, UK: Joseph Rowntree Foundation. ([www.jrf.org.uk](http://www.jrf.org.uk)) Editor's note.

Each of these neighborhoods and communities contain commercial shopping districts frequented by young people and tourists. Additionally, these areas have histories of being associated with drug use among young people (Kipke, Montgomery, Simon, and Iverson, 1997; Yablonsky, 1968). While the neighborhoods in each city are separated by thousands of miles, the types of businesses, physical spaces, and kinds of interactions within each are strikingly similar: bars, tattoo shops, retail stores, parks, panhandling, sex work, and drug selling. In short, each area contained a localized “street economy,” that is, an illicit economy featuring drug selling and other petty criminal activity (Bourgois, 1995; Kipke et al., 1997; Lankenau et al., 2004; Sanders, 2005). Additionally, each neighborhood attracted similar kinds of young people, including both local homeless youth and “traveler” or “nomadic” homeless youth (Des Jarlais et al., 2005; Hyde, 2005). Travelers move from city to city on a frequent basis in search of new adventures, work opportunities, drugs, or to avoid law enforcement—a lifestyle that increases risks for a range of negative health outcomes (Hahn et al., 2008; Lankenau et al., in press; Sanders et al., in press).

The weather differed significantly from site to site over the course of the recruitment periods, which impacted the flow of young people in and out of public spaces where ethnographers conducted fieldwork. While Los Angeles is ideal for recruiting outdoors nearly year round because of its moderate climate, the city experienced its wettest winter in over 100 years during the start of recruitment in January 2005. New York is less lively during the colder winter months, but attracted many traveler youth during the summer months. New Orleans is desolate during the hot summer, but lively during Mardi Gras and other music festivals in the spring months. Hurricane Katrina halted enrollment in New Orleans for 2 months during September and October 2006.

Young ketamine injectors were sampled by trained ethnographer in each city (New York: Sanders; New Orleans: Alarcon; Los Angeles: Hathazi and Sanders) with varying backgrounds<sup>5</sup>. Ethnographers dressed causally, e.g., jeans, sneakers, t-shirts, and carried hospital or university identification cards while conducting fieldwork. The variability across key individual characteristics, i.e., ethnicity, gender, age, education, and experience, plus the ethnographers’ informal presentation of self enabled the team to access a variety of sampling venues containing a diversity of young people. Additionally, ethnographers developed a research presence by spending 2 to 3 days per week in each neighborhood and became recognizable to a variety of area “locals,” which helped facilitate rapport with the target population.

Ethnographers recruited young ketamine injectors using a combination of chain referral sampling (Biernacki and Waldorf, 1981; Penrod, Preston, Cain, and Starks, 2003) and targeted sampling (Watters and Biernacki, 1989), which are nonrandom yet effective methods for sampling hidden populations. Guided by this sampling methodology, ethnographers entered targeted neighborhoods, observed the activities in the area, engaged young people in informal conversations, and screened individuals who might meet the enrollment criteria. Screening questions focused on health behaviors, recent drug use, and history of homelessness were asked in order to hide the enrollment criteria. Young people were eligible for study enrollment if they were between the ages of 16 and 29 years and had injected ketamine at least once within the past 2 years. These two criteria were selected to enroll a sample of young IDUs who could describe recent ketamine injection events (Lankenau and Clatts, 2004). To satisfy the criterion of injecting ketamine within the past

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<sup>5</sup>Alarcon is a Latino female, early 30s, college educated, with prior experience studying alcohol marketing in community settings in New Orleans. Hathazi is a white female, late 20s, college educated, with previous experience recruiting Vietnam veterans along skid row in downtown Los Angeles. Sanders is a white male, early 30s, Ph.D., with prior experience recruiting gang-involved youth in innercity London (Sanders 2005). Reported ages and education levels reflect each ethnographer’s characteristic at the time of study enrollment.

year, ethnographers listened carefully for convincing descriptions of practices and experiences associated with ketamine injection during the screening process. Following screening and enrollment, interviews were conducted in outdoor settings, such as along park benches, or indoor locations, such as cafes or fast food restaurants. Ethnographers repeatedly targeted select neighborhoods until 50 or more young people had been enrolled in each city, which had been determined to be the minimum sample size necessary to describe basic relationships among variables of interests. (Lankenau and Clatts, 2004; Lankenau et al., 2007). For their participation in the study, subjects received a \$20 cash payment in New York and Los Angeles, or a \$20 drug store gift certificate in New Orleans, as well as referral information for local needle exchanges, health clinics, homeless shelters, and other service organizations targeting high-risk youth populations. All procedures were approved by local Institutional Review Boards (IRB) at each site.

The phase 2 longitudinal study targeted the 101 IDUs enrolled in Los Angeles for participation in a series of five follow-up interviews occurring approximately every 3 to 4 months and two psychological testing sessions occurring at months 6 and 12. Follow-up interviews focused on changes in health status and risk behaviors, such as ketamine use, other illegal drug use, injection drug use, and housing status, while psychological testing sessions captured data on the impact of ketamine use on cognitive functioning over time. Excluding the psychological testing sessions, 290 follow-up interviews were conducted following baseline enrollment of 101 IDUs. The phase 2 design included four primary strategies to retain IDUs for follow-up interviews: collecting locator information, utilizing a toll-free number, progressively increasing cash incentives, and fieldwork.

Locator information, such as a telephone number or email address, was collected by ethnographers during the baseline interview to facilitate tracking for follow-up interviews. Since most subjects were homeless, standard types of locator information could not be provided, such as a home address. Rather, an email address was often more useful since Internet access was available at many drop-in centers and public libraries around the country. Participants were not asked to provide their real names, photographs, or other personal information, such as social security numbers or parent's home address, on the basis of a belief that participants would be more responsive and trusting if they remained relatively anonymous during the baseline interview. Rather, we accepted "street names" as the primary identifier, which also helped remind ethnographers of their identity within street settings.

A toll-free telephone number connecting directly to an ethnographer's project cell phone was provided to participants at baseline. This direct connection proved important, since it allowed a more personal relationship to develop between participant and ethnographer and constituted a reliable means of communicating. Since most participants were homeless and did not own a cell phone, the toll-free number allowed participants to call for follow-up interviews from anywhere in the USA, including payphones, which turned out to be crucial, since many regularly traveled to locations across the country. Participants were asked to call the ethnographer 3 months after enrollment to schedule the follow-up 1 interview or to call if they had any questions about the research or other related health issues, such as drug treatment or housing.

Cash incentives progressively increased for each interview by \$5, so that participants earned \$20 at baseline, \$25 for the follow-up 1, \$30 for the follow-up 2, and so on. The psychological tests required up to 4 hr to complete and were compensated at higher rates: \$50 for the first interview and \$75 for the second interview. The cash incentive schedule was described in each consent form read to participants prior to every interview.



Fieldwork often occurred on a daily basis, since ethnographers lived and/or worked in the recruitment areas of Hollywood, Santa Monica, or Venice. During fieldwork, ethnographers encountered enrolled participants, engaged them in informal conversations, reminded them of follow-up interview dates, and provided some with new cards containing the toll-free number. Ethnographers recorded their experiences with subjects, such as physical descriptions, unique identifiers, locations where encountered, relevant drug history information, and their companions, into field notes. Field notes summarized information about both subjects enrolled into the study and those screened for enrollment, but who did not qualify. This information was particularly useful, since enrollment was accomplished by two ethnographers who worked separately and who often independently encountered the same individuals in the field. Additionally, field notes were used to construct a network diagram of all enrolled subjects, which depicted how persons in the study were known or related to one another. For instance, relationships among IDUs often overlapped and were multifaceted, such as sex partner, injecting partner, and/or traveling partner. These social connections and relationships were often not revealed until visually displayed in diagram form. Also, the network diagram helped track subjects during follow-up and alert ethnographers to subjects enrolled twice under two different names. When this happened, the duplicate interview was discarded and not counted as part of the sample.

Seasonal variations impacted the likelihood of finding participants during fieldwork since many participants traveled around the country. While winter was a productive time for recruitment and finding participants for follow-up interviews, many traveled east during summer months for work or music festivals. Additionally, many youth changed their appearances during the course of the study, sometimes dramatically. For instance, one participant was recruited while confined to a wheelchair and wearing a full beard. A year later, another ethnographer screened the same individual who was both no longer using a wheelchair and beardless. Because of these changes in appearance, stature, and location, ethnographers recognized some previously enrolled participants only after initiating the screening questions or after reviewing field notes, which prevented the same participant from being enrolled in the study a second time.

While two ethnographers conducted fieldwork and enrolled subjects in Los Angeles, each maintained their original recruits throughout the study, which allowed consistent relationships to develop over time. These relationships were established at the baseline interview, enhanced during subsequent encounters in the field, and maintained during follow-up telephone calls and/or via email contacts.

## Tracking and Retention Strategies

During the first several months of recruitment, we discovered that our sampling methodology and enrollment criteria were enrolling large proportions of highly mobile homeless IDUs. After reviewing our tracking and retention procedures, we realized that the original four strategies would be insufficient to retain a highly mobile sample. Consequently, several modifications to the original design were instituted throughout phase 2 in order to retain subjects in the study, to enhance data collected, and to complete data collection by March 2007. These design changes included: telephone follow-up interviews, new interviewing modules, increasing sample size, brief ethnographic interviews, psychological testing, super follow-up interviews, and continuing the New Orleans site (see Table 1 for a summary). All design changes were approved by the IRB in Los Angeles before implementation.

Telephone follow-up interviews were introduced, since many participants left Los Angeles following the baseline interviews thereby making face-to-face follow-up interviews nearly

impossible. After the follow-up interview was conducted over the telephone, respondent payments were sent via Western Union, which worked as follows: At the end of the telephone interview, subjects provided the ethnographer with the location of a local Western Union and a code word identifier. Following the interview, the ethnographer walked to a Western Union office in Los Angeles, provided the subject's local address and code word, and paid the agreed upon incentive amount plus a \$15 processing fee. In turn, the subject reached their Western Union office, provided the code word to the teller, and received payment. Nearly half of all subjects ( $N = 45$ ) completed at least one interview by telephone (see Table 1) for a total of 183 follow-up interviews overall. All 183 payments were sent and received via Western Union without incident.

## Other Study Adaptations

New interviewing modules were introduced to collect data above and beyond the study's initial focus of tracking patterns of ketamine use and changes in homeless status, injection drug using behaviors, criminal justice involvement, and HIV/HCV serostatus. The ethnographic nature of the baseline and subsequent follow-up interviews revealed other aspects of participant lives that needed additional probing. Hence, new modules were included in each of the subsequent five follow-up interviews, such as homeless "traveler" lifestyle (follow-up 1), pregnancy and syringe sharing events (follow-up 2), family background and social class (follow-up 3), violence/victimization (follow-up 4), and accessing health care services (follow-up 5). By follow-up 3, subjects often became comfortable discussing a range of both positive and negative issues with ethnographers, such as securing a job, ending a relationship, or becoming HCV positive. More sensitive issues, such as those relating to family and violence, were saved for later follow-up interviews in order to build upon the rapport established between ethnographers and participants. The addition of new questions also kept the interviews interesting for subjects, since each follow-up interview focused on different themes and concerns.

The baseline sample was increased from 50 to 101 to ensure a sufficient number of IDUs to track longitudinally. This decision followed the realization that we would lose a significant proportion to attrition despite our modifications to retain the highly mobile sample. Additionally, our ability to enroll and interview new subjects was slowed by efforts to conduct both follow-up interviews and psychological tests. Ultimately, our period of enrollment extended for 17 months before achieving 101 baseline interviews. Hence, increasing the sample size was not a retention strategy per se, but this design change had a significant impact on the number of participants enrolled and interviewed, and necessitated the later development of a "super follow-up" interview.

A brief ethnographic follow-up interview was introduced following the discovery that 3 to 4 months was too long a time span between baseline enrollment and the follow-up 1 interview. We were concerned about losing contact with a significant portion of all subjects given the transient nature of the sample. Newly recruited subjects were scheduled for a brief ethnographic interview within 1 to 2 weeks after baseline enrollment. These follow-up interviews concerned the emergent theme of traveling, and consisted of a series of structured and unstructured questions focusing on rationales and experiences associated with a homeless traveler lifestyle. These interviews were conducted either in the field, over the telephone, or in our office suite. We began scheduling these brief interviews in June 2005, and ethnographers successfully completed them with 12 out of 18 subjects enrolled between June and August 2005. These brief interviews, however, were eventually replaced by a second design change occurring in August 2005.

Psychological testing, while originally planned for 6 months following enrollment, was performed within a week after enrollment or as soon as possible after recruitment. Following this second change, 34 out of 40 subjects enrolled after August 2005 participated in the first psychological test. Psychological testing always occurred in our office suite—a comfortable office setting centrally located in Hollywood—compared to the baseline interviews, which were typically conducted in field setting. Because of the longer, more intensive nature of the psychological testing session, participants were paid \$50 for the first 4 hr interview, plus \$75 for a second session in 6 months. Interviews were conducted by two doctoral psychology students with backgrounds in counseling. Hence, the psychological testing sessions, which included a comfortable office setting, relatively large study incentives, and well-trained staff interviewers, were likely to positively dispose subjects to follow-up interviews.

A “super follow-up” interview—a final interview containing all follow-up questions and newly devised modules—was devised for the remaining 34 subjects recruited after August. Increasing and extending enrollment (into June 2006) prevented a large number of subjects from having enough time in the study to complete five follow-up interviews and two psychological tests. Only subjects enrolled by August 2005 ( $N = 67$ ) had sufficient time in the study to participate in the scheduled seven interviews following baseline, thereby necessitating the development of the super follow-up. For these 34 subjects, one completed a super follow-up during follow-up 1, 10 completed a super follow-up during follow-up 2, nine during follow-up 3, and nine during follow-up 4. After completing a super follow-up interview, the subject was deemed to have fulfilled their commitment to the study and was no longer eligible for additional follow-ups.

Lastly, recruitment in the New Orleans site overlapped during the longitudinal study in Los Angeles in its entirety, which allowed for ethnographers from both sites to communicate about participants migrating from one city to the other. Hurricane Katrina struck New Orleans in August 2005—1 month prior to the scheduled ending date for study recruitment. Because of the unique opportunities to learn about the effects of a natural disaster on a population of young IDUs, we elected to continue data collection in New Orleans following the hurricane until May 2007. Given the mobile nature of the sample, eight subjects recruited in Los Angeles were encountered by the New Orleans ethnographer during fieldwork at least once. Upon realizing that a subject was part of the Los Angeles cohort, the New Orleans ethnographer reminded those subjects of follow-up interviews and provided toll-free numbers, which helped track and retain them. Additionally, the New Orleans ethnographer alerted the appropriate Los Angeles ethnographer that one of their subjects had been located in New Orleans, which provided notice that a toll-free call might be forthcoming.

## The Impact of Retention Strategies on a Highly Mobile Sample

Response rates during the longitudinal study were as follows: 77.2% of subjects were retained at follow-up 1, 68% at follow-up 2, 64% at follow-up 3, 58.2% at follow-up 4, and 47.9% at follow-up 5. As described earlier, two primary design changes were implemented soon after baseline enrollment to enhance the likelihood of retaining participants for follow-up interviews—a brief follow-up interview or a psychological test. Out of the final sample of 101, 43 participated in one or both design changes, whereas 58 did not. Among the 43 subjects exposed to one or both design changes, 84% ( $N = 36$ ) were retained for follow-up 1 and 74% ( $N = 32$ ) for the follow-up 2. Among the 58 subjects who were not exposed to either design changes, 74% ( $N = 43$ ) were retained for follow-up 1 and 66% ( $N = 38$ ) for follow-up 2. Overall, the design changes positively impacted retention rates between follow-ups, particularly between baseline and follow-up 1.



Despite attrition between follow-ups, the sample remained largely consistent on many demographic indicators, particularly through follow-up 4, such as age, gender, sexual identity, education, housing status, history of drug user treatment, and criminal justice involvement (see Table 2). A comparison of the demographics characteristics at different waves of follow-up indicate that the most difficult respondents to retain included persons identified as gay or lesbian, housed or having regular employment, ever been in prison, persons tested for HIV, or persons reported being HCV positive. Since the sampling methodology and follow-up tracking procedures were primarily street based, it is logical that homeless and/or street-involved youth would be more likely to be retained compared to their housed and/or employed counterparts. Over the course of the longitudinal study, ethnographers learned facts about eight youth that prevented them from remaining in the study through follow-up 5: six had either been jailed or sent to prison for an extended period of time, one checked into a mental health facility, and one traveler died while riding a freight train.

Significantly, the proportion of IDUs identified at baseline as either homeless and/or a homeless traveler increased slightly by follow-up 5 (see Table 1), suggesting that being homeless or a traveler was not an impediment to remain in the study for follow-up interviews. Among the 79 IDUs who participated in at least one follow-up interview, 56 were identified as homeless travelers. Figure 1 displays where these 56 travelers completed one or more follow-up interview via telephone. While many of these interviews took place in California, most occurred in other cities throughout the country, such as Portland, Seattle, New Orleans, Miami, Chicago, and New York. Many interviews also took place in smaller towns and rural areas. As reported earlier, 183 follow-up interviews (63%)—a majority of the total of 290 interviews—were completed outside of Los Angeles. Completing interviews remotely was possible due to the design change described earlier allowing for telephone interviews and Western Union payments. The geographic location of respondents was determined by Western Union receipts, which included a town or city address for transmitting payments.

## Discussion

We have presented a description of our longitudinal methodology based upon five waves of follow-up interviews with a mobile population of young ketamine IDUs recruited in Los Angeles. Our approach included both baseline tracking procedures, such as collecting locator information, offering toll-free numbers, and increasing incentives, as well as follow-up procedures, such as intensive fieldwork, and using telephone interviews and Western Union. The highly mobile nature of the sample required the implementation of several follow-up procedures that were not included in the original study design. Respondents exposed to these changes were more likely to be retained for follow-up interviews. A primary feature of our longitudinal approach, however, was the use of skilled ethnographers who regularly worked recruitment locations, developed solid rapport with subjects at recruitment and during follow-up, and maintained field notes to document the appearances of enrolled respondents and the relationships among respondents.

Our retention rates were not as robust as previous longitudinal studies that recruited samples of drug users (Cottler et al., 1996; Des Jarlais et al., 2005; Pollio et al., 2000; Ziek et al., 1996). It should be pointed out, however, that while other longitudinal studies have focused on young mobile IDUs (Des Jarlais et al., 2005), young ketamine injectors are a hidden population with no precedent of tracking longitudinally. Additionally, it was only after enrolling a substantial portion of the sample that we learned that a large segment of respondents were highly mobile and would require special tracking techniques

Despite attrition over successive waves of follow-up, the primary demographic characteristics of the sample changed little. The overall stability of the sample notwithstanding, the proportion of homeless youth and homeless travelers increased slightly by follow-up 5. This finding further demonstrates that mobile IDUs can be maintained in longitudinal studies (Des Jarlais et al., 2005) given the appropriate tools, e.g., toll free numbers, cell phones, Western Union, and resources, e.g., skilled ethnographers and increasing incentives. A particular advancement employed in this study was the use of toll-free numbers connecting directly to an ethnographers' cell phone. This innovation had the advantage of offering respondents the ability to directly contact the ethnographer who recruited him or her into the study from any location in the country at any time.

While longitudinal studies are likely to be judged as successes or failures on the basis of their retention rates, it is worth suggesting that the quality, breadth, and relevance of study findings should be the ultimate yardstick. In other words, it is important to consider what findings are reported in light of retention rates, and how the project utilized the opportunity to study a population longitudinally. For instance, longitudinal studies that take advantage of emergent findings during the course of data collection and adjust survey instruments accordingly may yield discoveries that are as significant as those initially charged with investigating. In particular, longitudinal studies that are based upon solid qualitative methodological foundations are most likely to uncover and benefit from emergent findings. Ultimately, longitudinal studies that are flexible and incorporate emergent findings into ongoing data collection are likely to produce results that relevant to the subject population as well as policy makers.

Lastly, the willingness of subjects to participate in research studies is often taken for granted and, consequently, frequently merits little discussion in the methodology sections of most published studies. Perhaps more than cross-sectional studies, longitudinal research relies on the conscientious behavior and goodwill of study participants. Without this ongoing cooperation, which typically takes the form of subjects choosing to complete follow-up interviews over a period of years, researchers would be left with invalid or unreliable findings. Yet, this participation occurs despite subjects being told during the informed consent process that study results will not directly benefit them. While subjects are typically offered incentives for participating in longitudinal research, subjects frequently derive a sense purpose from participation—knowing that revealing intimate details about their own, often difficult lives, might lead to findings that could prevent another person from using drugs or providing the basis for an intervention among other active drug users.

## Conclusion

Mobile populations of young IDUs can be successfully retained in longitudinal studies. Longitudinal designs that are flexible in nature and informed by qualitative methodologies are most likely to retain respondents while also uncovering emergent findings. Retaining and tracking drug users may require strategies and techniques devised for particular populations. Regardless of the study population, researchers should anticipate unexpected challenges during the course of data collection that may necessitate changing retention strategies. Quickly diagnosing difficulties and gaining approval of design changes is imperative since delays in changing course may result in losing subjects, which will ultimately decrease the quality and utility of study findings.

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## Biographies



**Stephen E. Lankenau, Ph.D.**, is an Associate Professor at Drexel University, School of Public Health, Department of Community Health and Prevention. Trained as a sociologist, he has studied street-involved and other high-risk populations for the past 10 years, including ethnographic projects researching homeless panhandlers, prisoners, sex workers, and injection drug users. He is Principal Investigator on a 4-year NIH study researching prescription drug misuse among high-risk youth in New York and Los Angeles.



**Bill Sanders, P.hD.**, is an Associate Professor in the School of Criminal Justice and Criminalistics at California State University, Los Angeles. He has approximately 20 publications on a diverse range of topics, including injection drug use, club drug use, polydrug use, drug sales, homeless youth, gang youth, youth culture, and urban ethnography.



**Dodi Hathazi, B.S.**, was as an Ethnographer at Children's Hospital Los Angeles in the Community, Health Outcomes, and Intervention Research Program where her research interests included patterns of polydrug use among homeless traveling youth and reproductive health issues experienced by high-risk youth. Currently, she is pursuing a Masters degree in Nursing at the University of Maryland.



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## Glossary

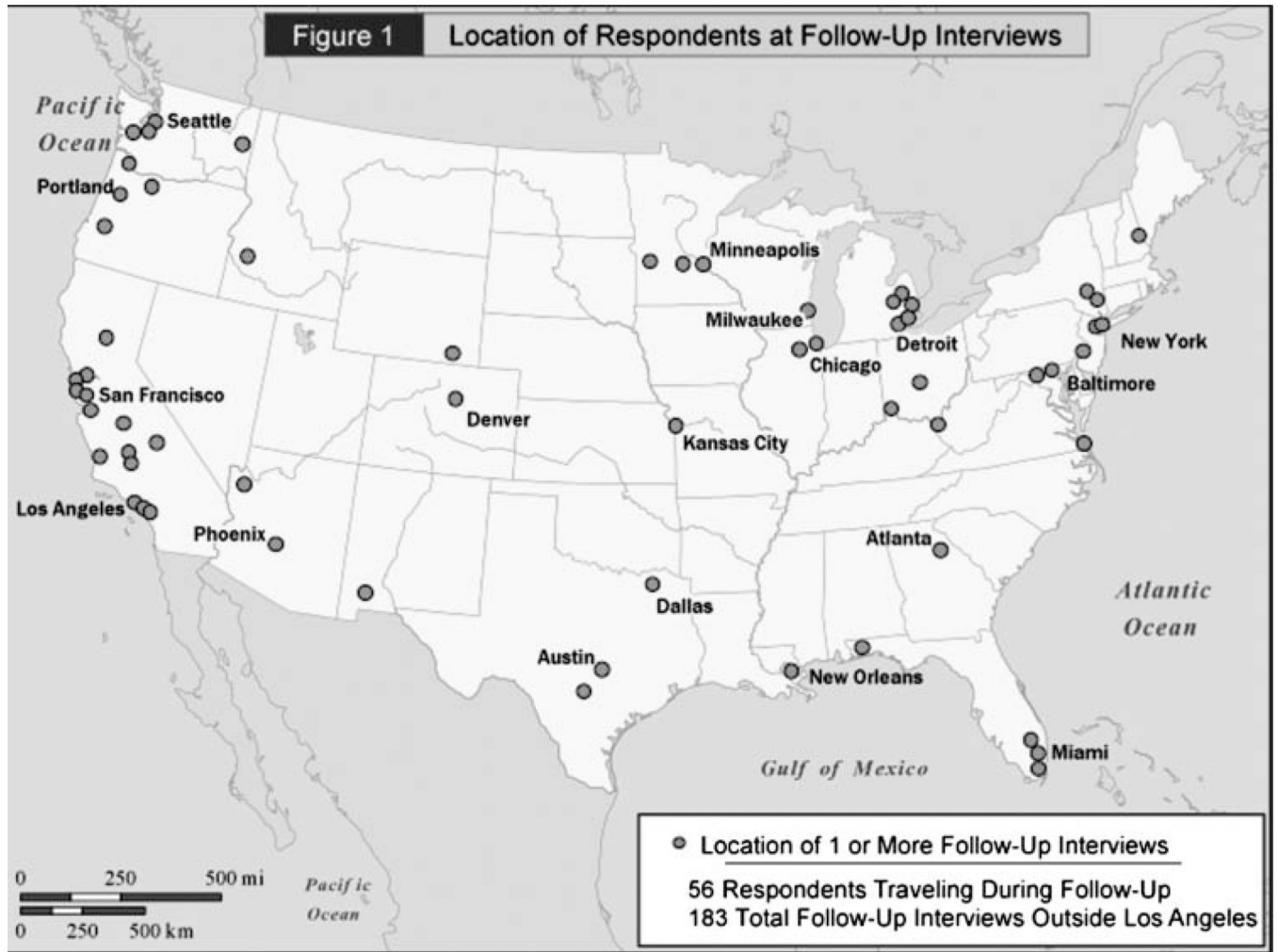
<b>Baseline tracking procedures</b>	protocol implemented during the baseline interview of a longitudinal study whereby the interviewer collects various types of locator information for the purpose of study retention, e.g., address, telephone number, email address.
<b>Chain referral sampling</b>	a nonrandom sampling approach that utilizes the personal network of a recruited participant to enroll more subjects.
<b>Community assessment process (CAP)</b>	a qualitative phase of research study involving a series of interviews with community experts and field observations to provide a current, detailed understanding of the phenomena of interest, e.g., ketamine use, from a community perspective.
<b>Follow-up procedures</b>	strategies undertaken by an interviewer or team to reconnect or retain a participant after the initial baseline interview of a longitudinal study, e.g., sending interview reminders via mail, email, or telephone.
<b>Homeless travelers</b>	homeless individuals, often teenagers and young adults, who travel from city to city every few weeks or months via hitchhiking or freight trains in pursuit of adventure, work, drugs, or to avoid law enforcement.
<b>Nontraditional populations</b>	individuals sharing a similar stigmatized status, such as homeless persons, drug users, or persons living with HIV/AIDS, who may wish to remain hidden and thereby presenting challenges for retention in longitudinal studies.
<b>Targeted sampling</b>	a nonrandom sampling technique that focuses sampling on designated neighborhoods and venues known to contain the desired population.

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**Figure 1.**  
Location of Respondents at Follow-Up Interviews.

**Table 1**

Changes implemented during phase 2 of longitudinal study

<b>Study modification</b>	<b>Month/year implemented</b>	<b>Subjects affected</b>	<b>Impact on study</b>
1. Telephone follow-up	May 2005	45	<i>a</i>
2. New interviewing modules	May 2005	79	<i>b</i>
3. Increasing sample size	June 2005	51	<i>c</i>
4. Brief follow-up	June 2005	12	<i>d</i>
5. Psychological testing	August 2005	34	<i>d</i>
6. Super follow-up	September 2005	29	<i>e</i>
7. Continuing New Orleans site	November 2005	8	<i>d</i>

<sup>a</sup> Permitted communication and completion of interviews among subjects traveling outside of Los Angeles.

<sup>b</sup> Increased subjects' interest in follow-up interview and facilitated completion of interviews.

<sup>c</sup> Enabled larger pool of subjects to be recruited and retained during longitudinal study.

<sup>d</sup> Increased retention rate.

<sup>e</sup> Enabled subjects recruited late in the study to complete all new interviewing modules.

**Table 2**  
Demographic characteristics of ketamine injectors at baseline and five waves of follow-up interviews ( $n = 101$ )

	Baseline $n = 101$	Follow-up 1 $n = 79$	Follow-up 2 $n = 70$	Follow-up 3 $n = 56$	Follow-up 4 $n = 46$	Follow-up 5 $n = 34$
Median age	22	21	21	21	21	21
Male	64.4%	60.8%	60.0%	60.7%	65.2%	64.7%
Race and ethnicity						
White/Caucasian	76.2%	81.0%	78.6%	78.6%	76.1%	76.5%
Black/African American	1.0%	1.3%	1.4%	1.8%	2.2%	2.9%
Hispanic/Latino	5.9%	6.3%	7.1%	7.1%	8.7%	11.8%
Asian or Pacific Islander	1.0%	1.3%	1.4%	1.8%	2.2%	2.9%
Native American	1.0%	1.3%	1.4%	—	—	—
Multiracial background**	14.9%	8.9%	10.0%	10.7%	10.9%	5.9%
Sexual identity						
Heterosexual	76.2%	74.7%	75.7%	73.2%	78.3%	82.4%
Gay/lesbian	2.0%	2.5%	2.9%	1.8%	—	—
Bisexual	19.8%	20.3%	20.0%	23.2%	19.6%	17.6%
Other/undecided	2.0%	3.8%	2.9%	1.8%	4.3%	2.9%
High school graduate or GED	60.4%	60.7%	60.0%	57.2%	56.5%	58.8%
Homeless	94.1%	93.7%	95.7%	96.4%	95.7%	97.1%
Homeless traveler	68.3%	67.1%	70.0%	69.6%	69.6%	70.6%
Ever homeless	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
Ever sold ketamine	34.7%	36.7%	37.1%	35.7%	32.6%	26.5%
Employed full or part time	12.9%	12.7%	12.9%	12.5%	13.0%	8.8%
History of drug treatment	58.4%	57.0%	60.0%	58.9%	58.7%	58.8%
History of mental health care	75.2%	74.7%	74.3%	75.0%	73.9%	70.6%
Ever arrested	94.1%	93.7%	98.6%	98.2%	97.8%	100.0%
Ever in jail	88.1%	86.1%	90.0%	89.3%	89.1%	88.2%
Ever in prison	14.9%	10.1%	11.4%	12.5%	10.9%	5.9%
Tested for HIV	94.1%	92.4%	91.4%	91.1%	89.1%	85.3%
HIV positive <sup>d</sup>	—	—	—	—	—	—
Tested for HCV	87.1%	86.1%	85.7%	85.7%	91.3%	88.2%

	Baseline <i>n</i> = 101	Follow-up 1 <i>n</i> = 79	Follow-up 2 <i>N</i> = 70	Follow-up 3 <i>n</i> = 56	Follow-up 4 <i>n</i> = 46	Follow-up 5 <i>n</i> = 34
HCV positive <sup>a</sup>	24.8%	25.3%	27.1%	25.0%	26.1%	20.6%

<sup>a</sup> Self reported.

\*\* Of respondents reporting multiracial ancestry (*n* = 15):

White/Caucasian = 100.0%  
 Black/African American = 13.3%  
 Hispanic/Latino = 33.3%  
 Asian or Pacific Islander = 6.7%  
 Native American = 46.7%