

Computerized tracking and follow-up techniques in longitudinal research with drug users

Karen F. Corsi · Benjamin Van Hunnik ·
Carol F. Kwiatkowski · Robert E. Booth

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Abstract Thorough follow-up and tracking procedures are critical when working with hard-to-reach populations such as drug users. Attrition in research can affect internal and external validity; therefore it is particularly important to use unique and creative tracking strategies in conducting longitudinal studies. Computerized follow-up procedures that were used to re-locate injection drug users (IDUs) and crack cocaine users after a 4–13 year period are described. Data are from a follow-up study conducted from 1999 to 2003, which re-located subjects who were initially recruited for NIDA's Cooperative Agreement, which took place from 1990 to 1995 in Denver, Colorado. Trackers used traditional approaches as well as computerized means to locate subjects despite scant locator information. Important lessons can be learned about the use of electronic means for locating hidden populations for health sciences research.

Keywords Tracking techniques · Follow-up methods · Injection drug users

1 Introduction

Tracking hard to reach study subjects such as drug users has challenged researchers for many years (Bootsmiller et al. 1998; Goldstein et al. 1977; Hansten et al. 2000; Nurco 1990). Since drug users are typically more hidden and transient than other populations, they are more difficult to locate over time (Bale et al. 1984; Cottler et al. 1996; Goldstein et al. 1977; Nurco 1990). High follow-up rates are important in research in that they increase internal and external validity of study findings (Biglan et al. 1991; Hansen et al. 1985; Scott 2004). Minimal attrition is particularly important for valid comparisons across study conditions (Biglan et al. 1991). Otherwise, it is difficult to determine whether differences in outcomes were due to the intervention or to the specific characteristics or behavior of those

K. F. Corsi (✉) · B. Van Hunnik · C. F. Kwiatkowski · R. E. Booth
University of Colorado at Denver and Health Sciences Center, Denver, USA
e-mail: karen.corsi@uchsc.edu

who were followed (Biglan et al. 1991; Ribisl et al. 1996). High attrition also affects the generalizability of findings (Biglan et al. 1991; Cottler et al. 1996; Hansten et al. 2000; Twitchell et al. 1992). For example, studies have shown that increased attrition is associated with more severe psychiatric and substance abuse problems (Biglan et al. 1991; Hansen et al. 1985; Walton et al. 1998). In such cases, findings may only generalize to individuals with less severe psychiatric and substance abuse problems, i.e., those who were successfully followed. In the context of drug use research, it is vital that new and systematic follow-up methods are developed in order to provide continued HIV prevention and other needed services to this hard-to-reach population (Ziek et al. 1996).

A number of studies have outlined ways in which to find hidden and hard-to-reach populations, and it is known that drug users can be found after extended periods of time, even up to 7 years (Cottler et al. 1996; Ribisl et al. 1996; Scott 2004; Woody et al. 1994). Researchers have provided rich information on how to locate these subjects, including specific steps to take during recruitment and follow-up (Cottler et al. 1996; Desmond et al. 1995; Hall et al. 2003). These studies outline the importance of systematic and thorough collection of locator information, qualified staff for tracking, remuneration for subjects and adequate resources allocated for locating subjects (Bootsmiller et al. 1998; Cottler et al. 1996; Desmond et al. 1995; Scott 2004; Wright et al. 1995). Additionally, studies have described traditional locating strategies such as sending out letters and calling phone numbers, as well as the importance of rapport-building, gaining trust during the initial interview, and contacting community and social service agencies to locate subjects (Bootsmiller et al. 1998; Cottler et al. 1996; Twitchell et al. 1992; Walton et al. 1998; Woody et al. 1994). In one of the earliest articles describing tracking procedures with this population, Goldstein and colleagues (Goldstein et al. 1977) discuss the importance of using both formal and informal resources to track study subjects. These resources include peer and family networks as well as formal institutions with which the subject may be affiliated. Those same methods are used today, almost 30 years later, in combination with other, more current methods. It is evident that many diverse and complementary strategies for tracking drug users are called for, including traditional as well as innovative approaches (Wright et al. 1995).

Most studies to date have not detailed a comprehensive use of computerized methods to capture a large portion of the population who may be otherwise unreachable. Some studies have recommended the use of various agencies and institutions, without providing detail for using Internet resources to access their information, as those websites may not have been available at the time (Cottler et al. 1996; Ribisl et al. 1996). Computerized methods have been recommended in other research, albeit in less detail than described here (Cottler et al. 1996; Gwadz and Rotheram-Borus 1992; Hall et al. 2003). The research presented here describes electronic methods and resources for finding information such as telephone numbers, updated addresses, vital statistics and jail or prison status. Although researchers at the University of California-Los Angeles developed a tracking manual in 2003 that includes some electronic methods for tracking study subjects (Hall et al. 2003), the use of computerized databases for tracking is a relatively new concept, since many local and national databases, as well as Internet search engines and websites, are being developed and improved upon almost daily. Therefore, the importance of staying current and up-to-date on websites and data sources is critical to utilizing them to their full potential.

This article describes methods used to re-locate drug users who participated in the National Institute on Drug Abuse (NIDA)'s Cooperative Agreement between 1990 and 1995 in Denver, CO (one of 23 participating cities), which was a study of drug users' risk behaviors in the context of HIV prevention. In this original study (1990–1995), 987 subjects were recruited in Denver, interviewed and received an intervention. The tracking methods presented here come from a study conducted between 1999 and 2003 in which outreach workers attempted to re-locate the original participants from the Cooperative Agreement study. Therefore, in this follow-up study, termed the Cooperative Agreement Follow-Up study, methods for locating individuals after 13 years are presented. This paper differs from other work in this area (Desmond et al. 1995; Hansten et al. 2000; Ribisl et al. 1996) in that it describes a study that followed people after up to 13 years without contact and it provides more current information on electronic methods and resources for tracking study subjects.

2 Methods

In the original Cooperative Agreement study (1990–1995), outreach workers (primarily former drug users) recruited study participants and were instructed to collect locating information (for the short-term follow-up of the original study) including: name, gender, ethnicity, age/date of birth (DOB), social security number (SSN), address, phone number, date of interview, social network characteristics, drug of choice, geographic area of contact, relative's address/phone, and descriptive physical characteristics (tattoos/scars). Unfortunately, the only information that was typically recorded was the subject's name or alias, a false birth date and information about places that the subject frequented to find drugs ("copping areas"). For the Cooperative Agreement Follow-up (1999–2003), newly hired outreach workers (trackers) were charged with the task of locating the 987 original study subjects, who had participated in the earlier research study. We were able to achieve an 83% follow-up rate over 4 years of searching for all prior clients. Table 1 below shows the breakdown of what proportion of subjects were found over the life of the project. Outreach workers reported an average of 5.4 attempts to locate (including phone contact, sending letters and postcards, visiting addresses and checking jails) before successfully locating a client. What follows is a detailed description of the methods used to locate these subjects, with a particular focus on electronic methods used to locate those subjects not found through traditional approaches.

Both the Cooperative Agreement and the Cooperative Agreement Follow-Up studies were approved by the University of Colorado Multiple Institutional Review Board. Long-term follow-up was not foreseen or built into the specified requirements

Table 1 Proportion of 819 total subjects found at various time points of the project

Time period	Percent found (%)	Cumulative percent (%)
In first 6 months (Aug 99–Jan 00): 6 months	11.0	11.0
In next 6 months (Feb 00–July 00): 1 year	17.0	28.0
In next 6 months (Aug 00–Jan 01): 18 months	18.0	46.0
In next 6 months (Feb 01–July 01): 24 months	16.0	62.0
In next 6 months (Aug 01–Jan 02): 30 months	12.0	74.0
In next 6 months (Feb 02–Jun 02): 36 months	26.0	100.00

of the earlier Cooperative Agreement Study, and therefore it was not possible to get prior consent for this new late-term follow-up study. However, informed consent was obtained for the conduct of follow-ups at the time of entry into the new study. When study participants were contacted for the follow-up described here, their prior involvement with the earlier study was recalled to them and they were asked if they would agree to continue their participation. At that time, they also signed a new informed consent indicating their further participation in this follow-up study. Protecting the confidentiality of the research subjects was paramount to the successful conduct of this study. Locator information provided by subjects was used in tracking them for follow-up, however, information provided in the research interview (e.g., drug use and HIV risk behaviors) was never linked to locating information and was never used for tracking. Locator information and subject interview data were kept in separate, password-protected locations only accessible to staff who required them. In addition, when a tracker set out to find a subject, details about the nature of the research were never given to anyone but the subject. If in doubt, trackers assumed that it would break confidentiality and did not provide details. This included times when the tracker was talking to a significant other, family member, or neighbor of the person that was being located, and in dealing with on-line resources.

2.1 Tracking strategies

There were 6 staff members involved in follow-up and tracking of subjects from the earlier study. Five of those staff were involved in more traditional methods, including phone calls, sending postcards, and visiting addresses. The sixth tracker was mainly involved in using electronic methods to find addresses, phone numbers and other systems information and acted as support for the other trackers. There were two main strategies for locating a subject based on information that was available in the locator database. First, it was essential that the tracker obtain a valid name and/or current address and phone number. Second, once the address/phone numbers were generated and somehow verified, then the trackers attempted to make contact by phone, mail or in person. The specific steps that a tracker might take for each strategy are described below. While some information must be adapted to the local setting, these are general guidelines for conducting follow up.

Strategy One: Depending on what information is likely to be more complete and accurate from the original locator data, a subject's name can be used to find an address or phone number (straight search). Alternatively, the subject's address/phone can be used to find their correct name (reverse search). The following databases are the most useful for this approach.

- Merlin's "Link to America" (www.merlindata.com) is the least expensive and most powerful search engine for finding people. There is an application process to use this, and only institutions with good intentions are eligible to gain access. The applicant's driver's license and other identification are needed to qualify. Searches are available for a small fee. If no results are generated then there is no charge for the search. Addresses on this database go back 30 years, and it is often useful to search on all addresses that a subject gives, since sometimes it is a family member's address and that person might still be able to contact them. "Link to America" is connected to the Social Security Death Index (SSDI), so anytime a SSN comes up that is in the SSDI, then it will display that the person is deceased.

- Quickinfo website (www.quickinfo.net). This website provides voters and vehicles databases.
- FlatrateInfo database (www.flatrateinfo.com). This database provides names, addresses, SSNs, and sometimes DOB and phone numbers. This database may also be used to search Social Security Numbers with a wild card (e.g. 999-48*: this generates all of the people with these first 5 numbers in their Social Security Number).

Once an address is obtained, it can be validated using the National Address Server (www.cedar.buffalo.edu/adserv.html). If a valid address is entered, this service will rewrite the complete mailing address including street type (Ave., St., Rd.) and full zip code. If the address doesn't exist, the server will return an invalid notification. Subjects for whom no address can be generated, but for whom there is a DOB or SSN, may be in jail/prison or deceased. In order to search most of the jail and Department of Corrections (DOC) databases, a tracker needs the person's full name and DOB. Jails sometimes have aliases used by inmates. Thirty-four states have some type of database to link to their jail records. In nine states, only County records are offered, and in 6 states, only State records are offered. There are 19 states, however, that offer online services with both State and County records. It should be noted that since prisoner access for research studies is often limited by Institutional Review Board restrictions, subjects found in the corrections system may not be able to participate in the follow-up research. If Review Board approval is obtained, the following databases may be useful.

- County Jail (www.vinelink.com). This is a free database on the Internet that allows for checking county jails and state prisons for people in the states in which this service is offered. It is provided primarily as a resource for victims of domestic violence.
- Department of Corrections (www.inmatesplus.com). This website offers links to online state prison searches. Not all states offer this service, but for those that do not, the website provides phone numbers to call for inmate information. Inmate number, court dates, next parole opportunity, mandatory release date and the charges are available as public record in some states.
- Federal Prison (www.bop.gov). This is the online search for federal inmates.

Information on subjects who are deceased can be found through the Social Security Death Index (SSDI) and the State Vital Records.

- Social Security Death Index (<http://www.ssdi.genealogy.rootsweb.com/>). A DOB can be run in the SSDI within the parameters of the state signified by the first three numbers of the SSN. This site requires a fee and is available to anyone who has Internet access, however only deaths reported to the Social Security are available. Also, it may take from 2 months to 1 year from the time that the death is reported for the information to show up on the database.
- State Vital Records (www.vitalrec.com). This website has links to every state's vital records web page. This is sensitive information, so there is an application process in order to gain access to the records. These records generally cost \$10–\$20 per certificate, with an additional search fee. The fastest results come when a valid SSN is used to search. Information on address, birth, relatives, and death, among other vital statistics are available on this site.

Strategy Two: The next steps entail making contact through phone numbers and addresses.

- First, phone numbers are called. Because most people have routines, it is often necessary to try different times of day to reach a subject over the phone. Trackers record times of the day that are attempted and whether or not it is successful. If the phone is disconnected, the tracker checks the number periodically, as it may have been temporarily disconnected. Trackers keep detailed logs of all contact attempts and never erase phone numbers, because the old numbers may prove useful with public records.
- Next, postcards or letters are sent to addresses. “Address Service Requested” is written on all mail that is sent. The letter/postcard stresses the importance of the study but does not give any further details. Often, personal handwriting is used on the envelope so that it was not tossed out as “junk mail.”
- Finally, addresses are visited, starting with the most recently reported address. It is often more fruitful to do residence searches on cold days, as people are more likely to be home. Trackers dress casually in order not to appear as a person of authority. Additionally, they try not to be intrusive and forceful and always thank anyone with whom they speak. The tracker always has an ID or business card available to show someone who asks. This simple document is important in reducing suspicion, but should not contain any specific information about the nature of the research study.

Once a subject is identified as the person that the tracker was looking for, then the match is confirmed. In this study, there were several pieces of information that had to match in order to confirm. First, gender and ethnicity had to match from the original study. Next, the tracker had to match at least two out of three of the following criteria: date of birth, social security number, and part of the first and/or last name. If the tracker matched the person on at least two of these items, then it was considered a match. The tracker often further confirmed the match by comparing other information such as handwriting from the original study or identification of descriptive characteristics (e.g., tattoos or birthmarks).

2.2 Encouraging subjects to participate in the follow-up study

Subjects sometimes displayed initial resistance to participating in the follow-up study. Trackers were sensitive to subject’s wishes and handled each situation with caring and flexibility. If the subject did not have time (e.g., had a job or other commitment), the tracker stressed flexibility with interviews, and arranged weekend or evening interviews as needed. If the subject stated that they did not need the money, the tracker acknowledged the positive aspect of this and stressed the importance of sharing the information to help other people in worse situations. If the subject was concerned about people finding out that he/she currently or had previously used drugs, the tracker emphasized the confidentiality aspects of the study, and sometimes suggested a mutual public place to do the interview, instead of at the research office. If possible, a phone interview was offered since that is perceived as less threatening and more anonymous. In situations where subjects had quit using drugs or did not want to be reminded of their past, the tracker celebrated the situation with the subject, and also stressed the importance of the information that such a subject could contribute to the

follow-up research, in particular, the circumstances surrounding how the subject was able to quit using drugs. In these cases, trackers also mentioned that it would help people that are in the same situation they used to be in. Trackers always stressed that there was flexibility around doing the follow-up interview and did everything possible to accommodate the subject's schedule. In the end, however, it was more important that the tracker respected the subject's position. With these cases, the tracker recorded the reason for refusal and moved on to the next subject. If the subject simply was not interested in participating in the study, the tracker tried to encourage them by describing the advantages, such as the honorarium, free condoms and bleach kits, helping people through research findings, and free HIV and HCV testing.

2.3 Combining electronic and traditional tracking methods: the importance of flexibility, ingenuity and persistence

During the course of the study, trackers learned valuable lessons about what they could find with insufficient locating information from subjects. For example, at least one part of the full name originally provided was usually accurate, and more often it was the first name. Furthermore, if someone did give an accurate last name, the first name used was sometimes the middle name. If a date of birth was false, the trackers often found that it was very similar to the actual date of birth. Like dates of birth, false social security numbers (SSNs) were often similar to the subject's real one. If a given address did not exist, sometimes the real address was on the same block. Trial and error was a common approach to deciphering accurate information from falsified or insufficient information. The case studies below demonstrate how false information that subjects give can still lead a tracker to find the person, with persistence and innovative techniques. All social security numbers, birthdates, addresses and names used in the following case studies are false in order to protect the confidentiality of the subject.

Case Study 1: Old Man Tony and Bob Anybody.

Two hanging partners from the early study had only provided the names "Old Man Tony" and "Bob Anybody," respectively. The tracker first ran DOB searches on both of them with no results. Over the next 2 years, he repeated these searches to no avail. The tracker then noticed that Old Man Tony had reported hanging out with a subject who had already come into the follow-up study. The tracker contacted her, and she said Old Man Tony lived somewhere on the west side of town. The tracker asked if she knew Tony's last name and she told him it was Lopez. The full name was then run through the Links to America database with a good list of results. Tony had given a date of birth exactly 10 years different than his real one. The tracker sent postcards to the addresses and Tony called in. He confirmed that he remembered the study from 10 years ago. Before setting up the appointment, the tracker asked Tony if he knew where Bob Anybody was. Tony said that Bob lived near downtown and that he would bring Bob with him when he came in for the interview. When the tracker picked them up, he asked Bob if he remembered the name he gave when he came in 10 years ago. The subject responded Bob Anybody, which helped confirm the subject match. Both interviews were conducted that day.

Case Study 2: Janice Smith.

In the original study, "Janice" gave a false last name of "Smith." So the tracker ran a DOB search for Denver and acquired the accurate full name of client ("Janice

Smithson”). Through public records, he acquired two addresses given by Janice. The tracker sent postcards to the two addresses, one of which was returned. The tracker stopped by the address that did not return the postcard. A man was doing yard work in the front yard. When asked about the client, the man angrily told the tracker that nobody by that name lives at this address. The tracker thanked the man and as he walked away, complimented the man on his flowers. The man was receptive to this and engaged in a conversation with the tracker. After a couple of minutes, the man said that the client did not live there, but that her mother lived upstairs. The tracker knocked on the door for the upstairs and spoke with Janice’s mother. He left a message with her for Janice to call him. A few days passed with no response. The tracker went to the address again but no one was home, so the tracker left a letter in the mail slot. Janice called in the next day, and the interview took place the following day. Note, all names and identifying information have been changed.

Case study 3: Unique name search.

A subject had very distinct name, so searching public records was quick and fruitful. The subject had numerous addresses in Colorado and out of state. The tracker sent postcards to every address, with almost every one being returned by the post office. Two addresses in another Colorado city were not returned. Two trackers traveled to that town to visit the addresses. One woman knew of the subject, but said she had not seen him in a couple of years. The tracker went by two other addresses in Denver, both of which turned out to be false. For the next 2 years, some new addresses were generated but nothing came of them. Near the end of the study, the tracker took a chance and put the subject’s distinct name in a general Yahoo search (www.yahoo.com). One result given was an article from a newspaper in a neighboring town. The subject had stabbed somebody and was being held in the county jail. The tracker called the jail and confirmed that this was the subject. Although the subject was located, the tracker was not able to do the interview due to Institutional Review Board policies.

3 Discussion

Previous research has outlined specific methods for re-locating study subjects (Bootsmiller et al. 1998; Cottler et al. 1996; Ribisl et al. 1996; Scott 2004; Wright et al. 1995). We have added to this body of knowledge by including more recent electronic means and by providing information on how to conduct a follow-up study using scant locator information. The current study operated under many constraints. The original Cooperative Agreement study, conducted between 1990 and 1995, was one of the first national consortia to look at drug users and HIV risks. At the time, less was known about locating hidden and hard-to-reach populations such as drug users and methods for obtaining locating information were not as systematic as more current studies. Trackers in the study presented here often had very little to go on. Despite these constraints, the trackers achieved an 83% success rate. It is important that researchers share their knowledge of successful tracking procedures so that others may benefit, particularly at this time when computerized methods are changing rapidly.

There are limitations to the study that affected follow-up rates. Due to the ever-changing nature of electronic resources, the trackers only had access to some of the

more fruitful databases for the final 8 months of the study. These powerful search engines provided many addresses and would have generated many more leads had the trackers had more time to use them and follow-up on the multitude of addresses generated. In longitudinal research with drug users, attrition problems are maximized by social and lifestyle behaviors typical of this population that make it difficult to re-locate them (Scott 2004). For example, chaotic and unstable daily operations and living arrangements are often a part of a drug user's life. Criminal justice involvement and mental health issues also complicate the stability of drug user's lives, making following them difficult if not impossible in some cases. The information available through computerized tracking techniques can be invaluable in re-locating subjects who may be more transient and have less stable housing than other study populations.

Navigating computerized channels can be overwhelming and time-consuming without a comprehensive guide to methods that work and do not work. The data presented here provide information on successful resources and strategies for other researchers studying similar populations. With the epidemics of HIV and Hepatitis C rampant among injection drug users, it is more important than ever to collect valid longitudinal data in this population (Woody et al. 1994). These techniques facilitate locating a transient population in the interest of collecting useful and valid behavioral research data.

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