SUCCESSFUL RECRUITMENT AND RETENTION OF PARTICIPANTS IN LONGITUDINAL BEHAVIORAL RESEARCH

Noelle R. Leonard, Patricia Lester, Mary Jane Rotheram-Borus, Kathy Mattes, Marya Gwadz, and Bill Ferns

Longitudinal behavioral research with underserved and HIV-affected populations presents enormous challenges to community researchers. Recruitment and retention of participants into intervention trials is vital for the development of empirically validated treatments and prevention programs. Successful recruitment and retention of participants is highly dependent on an effective structural and motivational system designed to engage and reward individuals at every level of the investigation, including community organizations, project managers, field staff, and participants. This article outlines some of the key elements in developing and maintaining high quality research efforts.

Recruitment and retention of underserved and HIV-affected populations into behavioral research studies, particularly those involving interventions, is difficult. For populations that have been historically understudied, such as runaway youth, other homeless persons, or ethnic minorities, monitoring the impact of mental health care interventions over time is especially challenging. Longitudinal studies for prevention trials depend largely on the ability of the research team to manage the inherent obstacles of participant recruitment and subsequent retention (Glasgow, Bull, Gillette, Klesges, & Dzewaltowski, 2002). Recruitment of a representative study population influences the external validity of prevention trials, while participant retention is a critical factor in the maintenance of internal validity. Over the last 12 years, the UCLA Center for Community Health has done eight successful intervention trials with...

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underserved populations, maintaining high follow-up rates ranging from 84 to 97% at 2 years and 71% at 7 years (NIMH, 1997; Rotheram-Borus, Gwadz, Fernandez, & Srinivasan, 1998; Rotheram-Borus & Koopman, 1991; Rotheram-Borus, Lee, Gwadz & Draim, 2001a; Rotheram-Borus, Murphy, Fernandez, & Srinivasan, 1998; Rotheram-Borus, Murphy, & Parra, 1995; Rotheram-Borus, Piacentini, Cantwell, Belin, & Song, 2000; Rotheram-Borus, Rosario, Reid, & Koopman, 1995; Rotheram-Borus et al., 2001b). We have refined our own organizational strategies around the same behavioral principles that inform our intervention strategies. We present our center-wide motivational system designed to reward each level of the investigation—from community organizations to project managers and staff to participants—for genuine engagement with intervention research goals.

Response rates for participation in intervention studies are commonly quite low (20 to 25%; Fontana, Fleischman, McCarton, Meltzer, & Ruff, 1989; Mirken, 1995; Myers et al., 1990; Sikkema, Winett, & Lombard, 1995), and retention rates range from 25 to 85% with most between 45 to 65% (Firestone & Witt, 1982; Fraser, Hawkins & Howard, 1988; Kazdin, 1985; Resnik, 1985). In addition, there are disparities within these rates. For example, there are typically too few African-American (Neal & Turner, 1991) and Latino (Marin & Marin, 1991; Rogler, Cortes, & Malgady, 1991) participants enrolled in intervention studies for valid conclusions to be made across ethnic groups. Common difficulties in recruitment and retention have been previously described in the context of early interventions (Fontana et al., 1989; Patteson & Barnard, 1990), parenting programs (Herzog, Cherniss, & Menzel, 1986; Titterington, 1990) and services for high-risk populations (DeMarsh & Kumpfer, 1986; Kazdin, 1985). Despite these reports, there has been little information on the structural, motivational, and behavioral factors related to participation in intervention research. Most evaluations typically identify the barriers related to recruitment and retention of participants (BootsMiller et al., 1998; Gwadz & Rotheram-Borus, 1992). This article aims to take a comprehensive look at the organizational structures and challenges that can facilitate high retention and recruitment.

DEVELOPMENT AND MAINTENANCE OF SUCCESSFUL LONGITUDINAL RESEARCH

We focus on four central components of our successful approach: 1) collaborating with community based agencies, 2) organizational structure and project management, 3) selecting and training motivated field staff, and 4) participant-focused interventions.

DEVELOPING EFFECTIVE COMMUNITY PARTNERSHIPS

Successful longitudinal research starts in the planning phase. Cooperating community based organizations (CBOs) are vital in the development and implementation of longitudinal research projects. We have found that the maintenance of a meaningful, reciprocal relationship between researchers and the key players of community organizations is often the sustaining source of success as the research project unfolds. The researcher should choose agencies and organizations that have good administrative structures and well-established community relations because integrating a research project into a well-run agency is cost-effective and pragmatic. Administrators of CBOs are often motivated to participate in research projects that may offer insight into clients’ needs and lead to new or more effective services. Many organizations find
that participation in a research treatment protocol is an ideal way to develop expertise in empirically validated treatments and play a role in treatment dissemination.

The relationship between the principal investigator or project director and a key member of the management team of the community-based organization is extremely important and needs to be cultivated throughout the life of an individual project and beyond. The responsibility for maintaining this relationship usually falls on the researcher whose main focus is the research project, unlike the CBO administrator who has many competing priorities.

Community-based agencies may underestimate the time and resources involved in participating in a research project. It is the researcher’s responsibility to work with the community agency to help define the impact of the research protocol on staffing and resources. In addition, the researcher must establish benefits to cooperation with the study protocol and provide the necessary resources to enable the project to be successfully implemented in a community organization.

The experience of empowerment and involvement in the initial stages of research can be a key motivation for agency staff. Staff can be involved in focus groups, and staff surveys can shape research design, particularly the design of the recruitment process. Incentives should vary by individual roles: Administrative staff may be motivated by a higher profile image in the community as well as by publication credit, while counseling staff may find extra income more salient. For most agency staff, motivation stems from four main areas: a) there is a benefit for their clients, b) respected colleagues within their agency believe the research project is useful, c) the research will add something useful to their agency, and d) they do not believe that involvement will add to their already over-burdened workload.

We find that identifying potential benefits is also central to developing relationships with community agencies, health care facilities, and other participant recruitment sites. These relationships foster communication between the agency and project staff, developing a deeper understanding of community and provider needs and goals, and guiding research goals. Many of the projects we have undertaken have been collaborations among community-based agencies, hospitals, clinics, and local departments of health. Often, these collaborations involve the recruitment of participants by both agency and research staff. We start by eliciting ideas from the staff about challenges they face in providing quality care to their clients and suggest ways that the research protocol may assist in those efforts. For example, case managers who are concerned about their clients’ substance use may feel supported by a research intervention that directly targets that issue. These relationships must be nurtured throughout the life of the project. In the early phases, project managers work closely with key agency personnel to develop an ongoing communication mechanism, recruitment protocols which meet the needs of both the research project and the agency, and plans for anticipated problems.

ORGANIZATIONAL STRUCTURE: WHAT DETERMINES SUCCESS OF THE PROJECT?

Effective management of the research team starts with the principal investigator, who must determine an organization structure and design a management team. While the underlying organization structure is essential to the success of study outcomes, little information exists about developing these structures for those conducting research (Evans & Berryman, 1998; Fowler & Mangione, 1990; Torralba-Romero, 1998). Development of an effective management team, as well as the necessary infrastructure
and technical support, builds the foundation for accomplishing the project goals. We
focus on recruiting a managerial team whose individual members are inherently moti-
vated by both the academic goals of the projects, as well as its potential social benefit.
These guiding principles are enhanced through an organizational system that offers
motivational opportunities to further both individual and organizational goals simultaneou-
ly.

We believe that the success of project managers is linked to their own research
and professional goals. The qualities we have found that make for successful manag-
ers include: high levels of organizational skills, attentiveness and vigilance to the co-
hort, and good employee management skills. Effective managers are often motivated
by a desire to improve the lives of others through scientific research. They also seek to
build their own research careers and obtain valuable experience managing the
day-to-day operations of the project. The opportunities to work closely with principal
investigators, to contribute to empirical papers, and to develop their own research in-
teres are highly motivating and contribute to managers’ job satisfaction. Over time,
managers within a larger research organization may develop specialized areas of ex-
pertise as part of their career development. When more than one study is conducted
out of a central site, a centralized staffing pool can be developed to support the chang-
ing needs of different projects, increasing organizational flexibility, and maximizing
staffing contributions to project goals.

The first aspect of effective management is accountability. All levels of the man-
gagement team for longitudinal behavioral research must be highly organized and com-
mitted to the project goals. We have found that appointing specific project managers,
whose sole responsibility is a single study cohort, is essential for maintaining organi-
zational reporting and to clarify responsibilities for recruitment, intervention, and
follow-up.

Project managers and coordinators must model appropriate behavior for their
staff. Since many of our studies deal with sensitive health issues such as HIV/AIDS or
substance abuse, organizational structures to maintain participant confidentiality are
essential. In our experience, management sets the tone for scrupulous attention to this
issue. For participants in high-risk populations, maintaining the security of identify-
ing information is particularly important. Careful attention must be paid to any possi-
ble breaches of confidentiality. For example, we do not mention study identifiers such
as HIV or AIDS in any materials sent to participants, in verbal or written project de-
scriptions, or on our answering machine. Moreover, nothing that would associate the
project with a particular group or illness should be displayed on office walls or indi-
vidual staff bulletin boards. This issue is emphasized repeatedly in the training and
re-training of interviewers and recruiters.

A second aspect of managerial responsibility involves monitoring the progress of
the project. Project managers must be vigilant in their oversight of the field staff with
respect to the quantity and quality of their work. Each project manager is accountable
for ensuring that recruitment goals are established and maintained, baseline and fol-
low-up interviews are completed, and participants attend intervention sessions. Pro-
ject managers must be aware of each participant’s progress during both the
recruitment and retention phases. Computerized database systems facilitate execu-
tion of these tasks and can be custom-tailored to meet the needs of each individual
project. For example, project managers should track which participants are expecting
a second phone call from a recruiter and which participants are scheduled for baseline
interviews. Database systems can assist managers in this effort by development of a
“tickler” file command that can quickly provide this information on a regular basis. Moreover, project managers can use these systems to provide weekly or monthly status reports to principal investigators about specific numbers of participants recruited and interviewed, as well as the rate of attendance to intervention sessions. This up-to-the-minute information can be vital in ascertaining the effectiveness of specific recruitment strategies and identifying problem areas.

Management strategies that increase productivity include giving field staff a monthly quota, carefully balancing their workload, and developing and maintaining systems for task completion. In addition, managers monitor adherence to study protocol through random review of taped participant interviews. We conduct participant satisfaction surveys by randomly calling subsets of participants and asking them about their satisfaction with the project, including interviewer behaviors such as punctuality. Attentiveness to the quality of the work is not only good research practice, but it also helps uncover issues that may result in participant attrition.

The third aspect of management involves supporting the team. Recognition that recruitment and retention efforts are extremely labor intensive must come from all levels of management (principal investigators, project directors, project coordinators). Thus, organizational structures should be developed to foster teamwork, providing a supportive network for project managers and enhancing their work environment. While this seems obvious, support takes the form of not only providing positive reinforcement for a job well done, but also ensuring that the flow of cash interviewers use to pay participant stipends is timely.

Other examples of successful management strategies are found in Table 1.

### TABLE 1. Management Strategies

- Use project–specific computerized tracking systems to calculate the dates of follow–up interviews, maintain multiple address and phone information for each participant, and calculate follow–up rates.
- Require interviewers to audio–tape all interviews and conduct quality assurance checks.
- Conduct regular supervision meetings to provide field staff with general comments from quality assurance checks.
- Use hiring committees comprised of project managers and experienced field staff when interviewing and selecting new field staff.
- Maintain productivity reports of recruitment and follow–up rates for each field staff member in addition to rates for the project as a whole.

Locating and maintaining effective recruitment and interviewer staff represents the next key step in launching a longitudinal intervention trial. Representing the critical link between study design and participants, the quality of field staff is a central component of data collection success (Stouthamer-Loeber, van Kammen, & Loeber, 1992). Prior reports from research with ethnic minority populations have shown building rapport is a key factor in successful participant recruitment (Demi & Warren, 1995). Further, reports on obstacles to ethnic minority participation in research trials have cited lack of culturally compatible research staff, underscoring the importance of hiring and training research staff who understand cultural differences (Area & Gallagher-Thompson, 1996). Thus, selecting and training field staff to enhance their ability to develop relationships with participants is of fundamental importance.

Our staffing model was developed to select interviewers and recruiters who would find both study goals and participant contact personally and professionally re-
warding and reinforcing. Interviewers and recruiters are motivated by a variety of individual factors, many of which may be enhanced by matching these to the study goals and motivating staff successes throughout the life of the project. For example, most members of the field staff are selected in part for their commitment to the overall goals of the research project. For these individuals, interviewing contributes to identifying the health needs of particular communities. Some interviewers are members of the participant community and are motivated by the fact that they are helping their community; others have a strong interest in working with participants vastly different from themselves. Many interviewers begin interviewing as a way of gaining experience for pursuing a research or human services career. These interviewers often find academic and career mentors within the managerial staff (project coordinators, project directors, principal investigators). We have also found that many interviewers and recruiters are motivated by their own success in tracking down difficult-to-reach participants. Participant tracking becomes a challenge, and the sharing of these successes, as well as debriefing of failures, promotes both professional development and an esprit de corps among the field staff team. Thus, an important role of the project manager is to understand the individual goals of the field staff in order to provide opportunities for professional growth and development.

Personal attitudes and skills held by the highest performing interviewers and recruiters include: 1) a capacity to communicate enthusiasm about the project to others; 2) interpersonal persistence in a manner that is highly respectful to participants; 3) flexibility about scheduling appointments; 4) resilience in the face of rejection (for example, having the younger children of participants hang up on them, or participants not scheduling a follow-up interview or not showing up for a scheduled appointment); and 5) non-judgmental attitudes towards participants who may be engaging in behaviors that put themselves or others at risk. We have also found that the most productive interviewers have a basic understanding of behavioral research, including the need for careful attention to detail.

Other attributes that distinguish effective field staff include possessing the basic clinical skills needed to ask difficult questions related to sexuality and bereavement, to manage intense affects that surface during the interview, and to attend to participant confidentiality. Clinical skills are also an asset in setting appropriate boundaries with participants. Achieving the delicate balance between building personal relationships with participants and maintaining appropriate boundaries is an issue that requires a great deal of initial and ongoing training and support.

Building a successful team of field staff requires extensive ongoing training. During hiring and training, recruiters and interviewers are asked to role-play challenging situations, such as reluctance on the part of an adolescent to begin the interview once the interviewer arrives in the home, loud music or multiple phone interruptions during the interview, and requests participants may make that are outside the scope of the interview protocol, such as an additional stipend or loan from the interviewer. Because some interviews are conducted in participants’ homes, training stresses the need to ensure that the interview is conducted out of earshot of other family members. This is often difficult to do because many participants live in small, overcrowded apartments. During regularly scheduled meetings, veteran interviewers share successful tips and techniques—for example, ensuring privacy by conducting the interview in a stairwell or a quiet corner of a local fast-food restaurant or helping a participant “save face” for not showing up at a scheduled appointment by accepting whatever excuse is offered or even suggesting a plausible excuse like “something must have come up at the last min-
ute.” In general, much of the training focuses on teaching interviewers how to handle difficult situations in a way that maintains appropriate boundaries. This must be balanced with not antagonizing or alienating participants so they continue with participation in the study. The staff training manual includes a list of helpful hints for recruiting, interviewing, and retaining participants.

We have found that a project coordinator whose main responsibilities involve managing the cohort and the field staff helps to maintain a productive pool of field staff over time. As this individual is the field staff’s main supervisor, his or her knowledge of both the participants and the interviewers allows the coordinator to give field staff a balanced caseload (e.g., a combination of hard-to-reach and easy-to-reach participants) and to provide incentives for the most productive interviewers (e.g., a salary bonus for interviewing 85% of their caseload). We have found that graduate students represent a pool of effective interviewers, as they often possess a combination of altruism, professional motivation, clinical or research experience, and flexible schedules, as well as a need for supplemental income. While part-time staff is typically less committed, full-time staff may have periods of down time. Given this, a combination of full- and part-time staff is probably the most effective staffing configuration. We have also found that payment on a per interview basis provides superior results to full-time staff members with quotas. We pay between $50 and $85 per interview, depending on length and format of the interview.

PARTICIPANT-FOCUSED INTERVENTIONS: WILL THIS HELP ME OR MY FAMILY?

Participation in a behavioral intervention trial offers family members a number of rewards: 1) a set of relationships with skilled study staff that may provide ongoing beneficial interpersonal contact as well as referrals to community agencies; 2) the possibility of benefiting from the intervention under investigation; and 3) the opportunity to participate in a study that may contribute to others. In our research we have found that initial recruitment and subsequent retention of participants depends on establishing a credible interpersonal relationship through the demonstration of respect, interest, and reliability.

The first and most important principle in establishing that relationship is demonstrating respect for potential participants and their situations. As has been reported for other intervention studies, we found this particularly true for ethnic minority participants (Miranda, Azocar, Organista, Munoz, & Lieberman, 1996). Many participants reported a recruiter’s respectfulness as the main motivator for initial participation. We found that in most cases of initial refusal, participants are willing to hear back from a recruiter who is respectful of their schedule and priorities. In other cases, when participants understand that the interview can be scheduled at their convenience, the recruiter can inform them that the interview can take place within a few hours or days for face-to-face assessments or right then for interviews conducted over the phone. While the recruiter must be extremely flexible in terms of scheduling the interview, we have also found that giving a slightly reluctant participant a choice of times often results in a scheduled interview.

Showing warmth and interest in a participant’s life and expressing appropriate empathy are key ways to spark interest in the project. The use of open-ended questions rather than questions which lend themselves to yes or no answers is often a way of initiating conversation. Clinically oriented skills such as empathizing and reflective listening are useful tools in establishing rapport. Different strategies may be required for
different populations. For example, adults often enjoy telling their stories, while adolescents may be more reluctant to share details of their lives, especially at first. Establishing a relationship with the participant is also central to identifying and resolving practical barriers to participation. For initial recruitment as well as ongoing follow up, we framed barriers to participation as problems to be solved in collaboration with the participant. By reframing obstacles as challenges, we are able to create a collaborative relationship with the participant and to address most concerns, such as lack of transportation or child care. Another technique for maintaining trust and collaboration with participants is providing appropriate referrals to agencies, such as community food banks, housing, or mental health services, when needed.

By conceptualizing recruitment as a process rather than a single contact, the field staff is able to demonstrate reliability through multiple contacts. To develop a relationship with a potential participant, the same recruiter must often make multiple calls over time and remember specific details of the participant’s life. Central to this work is providing a feeling of personal rapport and continuity between phone calls. The first few moments of the initial call are crucial to spark interest and establish the credibility of the recruiter. This initial pitch provides essential information about the study (including incentives to participation), links this call to the prior study letter, and reminds the participant of who gave us their name, while stressing confidentiality. When potential participants demonstrate initial reluctance to participation, the recruiter respectfully leaves the door open, asking, “Would it be okay if I called you back in a few weeks?” Trust is also established by doing what we say will do, for example, offering to call back at a more convenient time and actually calling back at that agreed-upon time.

We also found that many participants are motivated by altruism, as well as by the opportunity to obtain services designed to address their needs. While the monetary stipends we provide often act as the “hook” for their initial agreement to participate, many adolescents and adults are motivated by other reasons. Many of our studies are designed to address the impact of illness on underserved communities. When study goals are explained, many people are happy to participate in something that might help others in their same situation. Normalizing and emphasizing the behavior of their peers (for example, “over 300 families like yours are participating in the project”) is a helpful recruiting technique. Often adults and adolescents feel they have something to contribute and want to share their challenges, successes, and insights with others. In addition, many participants view the opportunity to participate in a behavioral intervention study as a needed way to obtain psychosocial services that address their current life circumstances. For parents, family participation in a study is often seen as potentially beneficial to their children.

Finally, once participants have agreed to participate, we have found that having Institutional Review Board-approved informed consent forms that include broad but specific guidelines about how the interviews will be conducted and what the participants can expect in return establishes a contract between the research team and the participant and formalizes the parameters of the relationship. Attention to anticipated tracking needs during development of informed consent is important to maintaining a relationship with the participant. For example, establishing an agreement with participants about key contacts to be accessed by the project if the researcher is unable to reach the participant is particularly helpful with difficult-to-track populations.

Recruitment Vignette. The following vignette illustrates several of these key relationship-building strategies:
What does the participant need?: Maria was a 38-year-old HIV-positive mother of three children ages 7, 13, and 15, who was approached by her caseworker and agreed to be contacted by project staff. Maria had worked as a nurse’s aide for many years before learning of her diagnosis and, despite two recent hospitalizations, continued to work 12-hour shifts at a local nursing home. Project staff made several attempts to contact Maria who did not return phone messages taken by her children nor did she respond to the flyer sent to her home. Because the recruiter did not know if Maria had disclosed her HIV status to her children or if her children were aware that she had health problems, any messages left for her had to be vague. Realizing that Maria was never home during the day or in the early evening, the recruiter attempted to call later in the evening and finally reached her. Once the recruiter got Maria on the phone, she quickly established her identity and referenced her agreement to her caseworker allowing her to be contacted. During this initial explanation, the recruiter also asked Maria if she was in a place where she could talk for a few moments. The recruiter could hear through the phone that a popular television program was about to begin. After Maria moved into her bedroom, she listened politely to the recruiter’s description of the project but told the recruiter that she had “many things going on right now and could not commit to something new at this time.” The recruiter responded in a relaxed tone that she understood, it was late after all, and that Maria must be tired since she just came home from work and might want to watch television to wind down. The recruiter asked Maria if she could call her on another evening at this or a better time. Maria agreed that the recruiter could call her back in a few weeks. During this second call, the recruiter stated that she understood how busy Maria was and that many of the other mothers the recruiter had spoken to had similar issues. The recruiter also indicated that other mothers were nervous about participating since their children did not know they were HIV positive. This approach helped to normalize Maria’s initial reluctance, and she talked to the recruiter at some length about her conflicting feelings about disclosing to her children. The recruiter assured Maria that her children did not have to even know that she was being interviewed. Maria indicated that she did not talk to anyone about her health, that she rarely kept her medical appointments, and that her old case worker had been transferred and she had yet to meet the new one. Feeling more understood after this conversation, Maria said she would like to participate and agreed to complete the baseline interview. After several months in the study, she agreed that her children could also be interviewed.

MAINTAINING THE RELATIONSHIP: TRACKING PARTICIPANTS

Maintaining participant motivation for continued involvement in a longitudinal study is a continual challenge but is built on the same principles described for recruitment. By effectively developing initial contact with the family, the field staff is able to develop a network of “anchoring contacts” for the participating family members. At the time of their enrollment in the study and at every follow-up assessment, participants are asked for a large number of anchor points—names and contact information of people who might know where they may be found or places where they might socialize. This includes family members and friends, case managers, health care providers, multi-service organizations, neighborhood storeowners, bartenders, neighbors, etc. While eliciting this information, interviewers stress that the names of these contacts will be kept confidential and most importantly, if they are called, no information
is shared with them about the participant or the nature of the project. When contacting these anchor points, project staff use benign phrases like, “she’s participating in a survey and gave us your name as someone who might know her new number.” We also ask participants for their Social Security number and for permission to contact them through the Social Security Administration. In addition to standard venues of tracking including phone, mail, and agency contacts, we have also provided incentives to individual “anchors” for their assistance in locating a hard-to-find participant. See Table 2 for additional strategies (see also Gwadz & Rotheram-Borus, 1992, for strategies specific to tracking hard-to-find participants).

Just as a participant’s initial agreement to enroll in the study was based on his or her recruitment relationship, securing a good fit between the interviewer and the participant is essential for long-term follow-up. Ensuring a good fit rests with a project manager who knows something about each family and their history with the project and who can assign an appropriate interviewer. For example, certain interviewers have an excellent rapport with adolescents who may be reluctant to complete a follow-up interview. Respect and appreciation for participants’ continued participation can be conveyed in a variety of ways. This includes birthday and holiday cards to every participant, as well as active listening and appropriate social service, medical, and mental health referrals. See Table 2 for more strategies.

Maintaining the families’ trust is central to ongoing enrollment. In our studies, participants are informed about staffing or protocol changes that may affect them, such as a new interviewer or an additional interview. Another, less obvious way of conveying respect, is by making the interview an experience participants would not mind repeating and providing a level of compensation that matches their time and effort. For example, in longitudinal studies of adolescents, we modified the interview to reflect developmental changes and raised the stipend provided for each interview.

An important tool in tracking participation of large populations is the use of carefully maintained computerized tracking databases. At each contact with the participant, the study team updates and records key contact information. Provided with a toll-free project number, participants are encouraged to call or contact project staff with any major life changes, such as relocation, new jobs, incarceration, or school graduations. In addition, on-line, public domain databases are used by project staff to provide tracking resource information, including phone directories, address listings, on-line maps, and other databases. Every state has a Web site with information for accessing the state prison system either by phone or through an on-line search engine. In

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<th>TABLE 2. Strategies for Maintaining Participant Relationships</th>
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<tr>
<td>• Mail birthday and holiday cards.</td>
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<td>• Send flyers to remind participants about an upcoming interview using brightly colored paper.</td>
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<td>• Use certified, overnight, or “return receipt requested” mailings which require signatures.</td>
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<td>• Maintain a project identity with a bright, simple project logo that is not associated with HIV/AIDS (e.g., red ribbon). Include the project’s toll-free number on the logo.</td>
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<td>• Pay stipends to participants in a timely manner.</td>
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<td>• Provide certificates of participation at project milestones (e.g., one year anniversary with project).</td>
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<td>• Provide participants with useful products (mugs, key chains) with the project logo and toll-free number.</td>
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<td>• Send out newsletters with project updates, including brief notes about alumni interviewers (e.g., “Sharon is in graduate school in Virginia and says hi to all her old participants”); introduce new interviewers and provide progress reports (e.g., “over 350 participants completed their 5th-year interview”).</td>
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addition, some state departments of motor vehicles offer a letter-forwarding service for a nominal fee, and the Social Security Administration will forward correspondence to a participant who has signed a consent form allowing them to be tracked via their Social Security number.

Tracking Vignettes. The following vignettes illustrate some of these strategies.

“Listening to what the participant really wants”: Joe, an adolescent in one study, continuously canceled and rescheduled his follow-up interviews. Eventually, his interviewer found him, but a few minutes into the interview, he decided that he did not want to continue with the questions and ended the interview. When the project coordinator contacted him, Joe expressed appreciation for her concerns but said he was feeling very upset over the death of his mother and did not want to be interviewed. She expressed to Joe that she respected his feelings about not completing the interview; she also acknowledged the stress he was feeling about his mother, and offered to provide a counseling referral. At the end of their conversation, she asked if she could contact him soon to check in. Joe agreed and also accepted a referral from the project. When she contacted Joe two weeks later, he thanked her for the referral and said he was ready to finish his interview.

“Understanding the community network”: Recruited in San Diego, Perry was an HIV-positive homeless youth from the East Coast, who volunteered at needle exchanges and did survival sex work. He was a “fixture” in the street youth social scene in San Diego. Since he was well known by other HIV-positive youth we were recruiting, we them if Perry could be added to their locator forms as a contact in the event we could not find them for future interviews. If the youth agreed, Perry became our source of timely, vital, and exceptionally accurate information as to the whereabouts of other participants that would typically lead to a successful follow-up interview—even when the “lost” participant was incarcerated or out of state. Of course, if the participant did not give us permission to contact Perry, we could not utilize what became known as the “Perry factor.”

“Phone Home”: Recruited in San Francisco, but originally from New Jersey, Elaine, a 24-year-old HIV-positive young woman, was very connected to her childhood home and gave us multiple names, addresses, and phone numbers of family and friends for her locator form. Unfortunately she was estranged from her family, so when we lost contact with her, calls to family members did not provide us with any clues as to where she was currently living. One reference Elaine had given us, however, was for a rabbi with whom she regularly kept in touch. We called the rabbi, and, after telling him that Elaine had given us his name so we would be able to find her, he gave us her latest phone number. Calling that number, we found it had been disconnected. About once a month after that, we called the rabbi to get a new phone number for Elaine. Finally, after approximately five months of regular follow-up with the rabbi, we were given a cell phone number. Upon calling it, Elaine answered. She was sitting in a restaurant in Alabama and was so impressed that we had actually found her that she agreed to do the interview right then over the phone!
SUMMARY

Successful community-based, longitudinal research rests on the researchers’ ability to recruit and maintain a population of participants. While most researchers tend to focus primarily on the study population, our experience has taught us that the most effective way to conduct longitudinal research is by developing a comprehensive organizational approach based on the principle of developing and maintaining positive, consistent relationships at each level of the study. From initial protocol development with community organizations, to developing an effective management and field team, and engaging with participants in their communities, the key component of success is developing reciprocal, positive relationships for all individuals and organizations involved in the process. As in all meaningful relationships, the needs, motivations, and contributions of each individual are fundamental to creating enduring bonds between the researcher and the larger project. These bonds must be cultivated, not only during the initial development of the study, but over time.

REFERENCES


