FROM: Zweben A, Barrett D, Carty K, McRee B, Morse P, Rice C. Strategies for Facilitating Protocol Compliance in Alcoholism Treatment Research. Project MATCH Monograph v. 7 (NIH Pub. No. 98-4144). Bethesda, MD: National Institute on Alcohol Abuse and Alcoholism (NIAAA), 1998.

Handling Noncompliance

David Barrett, M.S., and Priscilla Morse, M.A.*

Center for Addiction and Behavioral Health Research, University of Wisconsin-Milwaukee and Covenant Health Center; and *Department of Psychiatry, University of Connecticut Health Center

This section focuses on procedures developed to maintain study participation for individuals who become lost or resist followup interviews. These methods were employed in Project MATCH when information could not be obtained by other means. Because many of them represent a deviation from standard interviewing techniques and may result in incomplete data, it is important that they be closely monitored.

Although all of these methods were used for Project MATCH to some degree, it seemed that the more organized and skilled the staff became, the less we had to rely on customized followup strategies. Nevertheless, no matter how well a staff organizes and anticipates, there will be some situations where they will need to adapt the followup in order to achieve high compliance rates. Some of the strategies described in this chapter may not be appropriate or feasible for every research study. We suggest that each research project prioritize its efforts and employ the strategies that are likely to offer the largest return in terms of complete and accurate data and high rates of continuation. Remember, *the goal is to minimize lost or contaminated data and maintain the active involvement of the participant.*

Addressing Compliance: A Balancing Act

As in other areas of health care, the practitioner is often the most important factor in preventing compliance problems (Meichenbaum and Turk 1987; Blackwell 1997). Many factors impinge on the participant's decision to cooperate with followup, and these factors must be considered in attempting to resolve noncompliance. Our approach reflects the belief that the research staff can take proactive steps to reduce noncompliance among clients who are having difficulties or expressing dissatisfaction with some elements of research participation.

Understanding Noncompliance

Adopting a proactive stance requires an understanding of the multidimensional causes of noncompliance and skill in negotiating the conditions of participation. The treatment outcome literature tells us that noncompliance does not necessarily mean that an individual has relapsed or is doing poorly. Missed appointments, or even a refusal to schedule a followup, do not necessarily indicate that someone is dissatisfied with the study.

Researchers have concluded that there is a role for persuasion in clinical research. While "persuasion" is not explicitly defined, it seems to incorporate elements of listening, encouraging, and using contingent rewards (Capaldi and Patterson 1987; Mackenzie et al. 1987; Robles et al. 1994; Strohmetz et al. 1990). These studies suggest that resistance can be overcome by procedures that establish and maintain rapport. The process of obtaining informed consent is critically important as well, as it not only educates the individual on the roles and responsibilities of participation, but also sets the stage for addressing later concerns.

Research teamwork has been found to be the best way to identify and resolve issues affecting participation (Young and Dombrowski 1989). Project MATCH achieved impressive compliance rates in part by establishing guidelines for the research staff to follow, setting up boilerplate letters for staff to use to fashion a personalized letter to someone refusing to schedule, and providing ongoing supervision and support. For instance, clients who were unable (or unwilling) to come to the research site for a followup interview were offered a home visit or an interview by telephone. Accordingly, two telephone versions of the primary assessment instruments on alcohol consumption were developed for special situations. Form 90-Q was used to obtain essential followup data from the participant. If participants were successfully engaged, they were invited to complete the more detailed Form 90-T.

Adapting the Protocol

Sometimes it becomes necessary to adapt the followup protocol in order to prevent attrition. This means that either some data elements or the standardization of collection procedures must be sacrificed in order to preserve the research agreement so that future interviews can be conducted. Deciding when and how to adapt the protocol requires an understanding of how missing data affect data analysis and good judgment regarding when to scale back the demands of participation in order to overcome resistance. "Some data are better than no data" is a reasonable rule of thumb for a clinical researcher.

Provisions should be made to allow research staff to adapt the followup protocol in order to prioritize the data elements and focus on obtaining the most important information when complete data are not possible. Regular meetings of the entire research

team can maximize opportunities for creative problemsolving about difficult situations and cases and provide mutual support, encouragement, and advice on how best to address noncompliance. They also allow the research investigator an opportunity to monitor the drift that can occur as staff adapt the protocol in order to engage resistant participants.

Flexibility and Timing

As George Vaillant (1983) so aptly said, "The alcoholic, like the unconscious, has little sense of time" (p. 308). Individuals whose lives are disorganized and chaotic are often not used to making and keeping appointments (Capaldi and Patterson 1987). Followup is given a low priority by these individuals, who are likely to be experiencing significant life events. During times of stress, they often need additional time and concrete support in order to follow through on their commitment (Robles et al. 1994). Flexibility with respect to the demands that the study places on clients increases the likelihood that they will complete the followup.

Research staff also need flexibility in the amount of time they are given to locate, schedule, and complete followup interviews with participants. Desmond (1995) points out that high followup rates are impossible to achieve when the staff faces strict time constraints. High rates of compliance with his group of highly unstable "lost" participants required more staff time to complete the interview (mean of 36 days from due date versus 3 days for controls), more travel to sites other than the treatment center (66 percent offsite versus 5 percent offsite for controls), and more flexible interviewing procedures because of the likelihood of meeting clients in a site not conducive to the exact protocol. Desmond states, "Doubling the size of the followup staff will not necessarily cut the time required [to obtain the data] in half." In other words, a research assistant may simply have to wait it out until the problem is resolved (or the participant sobers up) before the followup interview can be completed.

It is also important to remember that, at any moment, the participant's status may change. This can work for or against compliance. Sometimes postponing data collection results in lost data. Other times, postponing an interview is wise because it reduces the demands on an overloaded life and allows participants the time they need in order to resolve life problems. The client who is unable to comply given his present situation will often be able to meet his commitment later. It is important to communicate that the issue is not "if" but "how and when you are going to do the interview."

Develop a Plan

Often, compliance issues can be resolved by talking through participants' complaints or concerns about their role in the study.

This could be considered a “reinduction,” because the initial experience of noncompliance provides an opportunity to review the informed consent and to reestablish an understanding about the costs and benefits of research participation as well as the importance of continuing in the study despite personal problems. In many cases, noncompliance can be easily resolved, and the participant will be no more likely than others to have further compliance problems. In other cases, however, compliance problems are ongoing, and high rates of data collection are achieved only with a considerable expenditure of staff time and energy directed at maintaining contact and persuading reluctant participants to continue.

This section describes three steps or stages for developing a plan to address serious or persistent noncompliance. Step 3 represents the most serious threat to the methodological integrity of the study, because in this stage the staff engage participants in a discussion of their problems and adjust the demands of the study in order to overcome their resistance. Staff are instructed to employ such specialized or customized strategies to resolve compliance problems only when routine procedures have failed.

A Plan to Address Compliance Problems

STEP 1	STEP 2	STEP 3
Categorize the noncompliance by *type*:	Construct a working hypothesis about the probable *source(s)* of noncompliance:	Construct a *plan* to resolve the noncompliance:
■ Lost ■ Resistant • Difficult to schedule • Difficult to interview ■ Refusing	■ Situational factors ■ Interactional factors ■ Individual factors • Relapse	■ Locating strategies ■ Interactive strategies ■ Adaptive strategies

Step 1: Categorize

Moos and Bliss (1978) found a clear correlation between difficulty of followup and treatment outcome. They distinguished between *lost* and *resistant* participants and developed indexes of “locatability” and “cooperation,” defined by both the number and the type of followup activities required to complete an interview. The two groups represented different potential sources of bias in the findings, and different approaches were required to retain them in the study. These results are consistent with other researchers (Armor et al. 1978; Sobell et al. 1984; Mackenzie et al. 1987), who state that the two groups of noncompliers are different on important dimen-

sions and require different followup strategies. Using Moos' typology, we have categorized participants into three types: lost, resistant, and refusing.

- *Lost* participants cannot be located. They have moved, disconnected or changed their telephone numbers, or taken other steps to make it difficult to locate them. Issues associated with lost participants have received considerable attention because they represent a major reason for missing followup data. Moos and Bliss (1978) define "locatability" by the number and type of information sources needed to find the current location of a lost participant. Thirty-six percent of their lost sample were found using institutional information sources in addition to, or instead of, known (baseline) information sources. More than half of this group required multiple other-agency contacts in order to be located. Lost participants tended to be more deteriorated than resistant subjects, but once found, they could usually be interviewed.

- *Resistant* participants are difficult to schedule and interview. They seem to want to be lost, but their location is known. They often cannot be reached, do not return telephone calls, or are very busy and resist efforts to engage them in scheduling or completing the interview. Some do not schedule or keep appointments because they are doing well and perhaps do not want to be reminded of a painful past (Sobell and Sobell 1981). For others, their condition has deteriorated. They are preoccupied with serious life problems, or they are reluctant to admit their "failure" to the research team with whom they have developed a relationship.

- *Refusing* clients have made a decision not to participate. This may be an impulsive decision, or it may have been carefully thought out, such as when they are doing well and want to distance themselves from anything to do with treatment or their alcoholic past. One approach to this refusal would be to accept it at face value as a decision to drop out and make no further attempts to reinvolve that person in the study. This may, in some instances, be appropriate. However, the circumstances behind these decisions are so varied that we recommend first trying to address these participants' problems with the study so that they may reconsider and continue participation.

The type of noncompliance determines the initial thrust of the customized approach. Obviously, a lost participant needs to be found before staff can determine whether there is a problem with cooperation. Clients who have not responded to repeated attempts to engage them are either experiencing significant life problems

or are ambivalent about continued participation in the study (Howard et al. 1986). In either case, the participant will need to be persuaded to become reinvolved with the study, and this may require some adapting of the followup.

Step 2: Construct A Working Hypothesis

The next step is making an informed guess (i.e., a working hypothesis) about the factors associated with the noncompliance based on a careful review of the history and circumstances of the case and developing a realistic plan for addressing the problem. By considering the wider context of the individual's social, cultural, and environmental surroundings, staff may be able to identify the factors that are blocking compliance. This often suggests ways to persuade the individual to continue in the study.

Factors That May Hinder Compliance

- *Interactional*: The participant is having a communication problem with a member of the research team.
- *Situational*: There are barriers to participation, such as the client not having money for transportation or childcare, or being in jail, hospitalized, or homeless.
- *Individual*: The participant's personal circumstances (e.g., depression, medical illness, wanting to forget the past) interferes with participation.
- *Relapse*: The participant has started drinking or using drugs and so is unwilling or unable to complete a followup interview at this time.

Noncompliance usually results from a confluence of factors that affect the participant's decisionmaking about continued involvement in the study (Strohmetz et al. 1990). It is helpful to be mindful of the instability of most participants' lives. They may be doing well or doing poorly. Do not rule out a possible source of trouble because it has not characterized the participant up to that point, and explore all potential sources of noncompliance. Remember what has been learned from other participants. Be creative. Ask questions such as—

- Are there small children and perhaps no one to babysit while she comes for her appointment? (*situational*)
- Has there been a domestic fight and he's no longer living at home? (*individual*)
- Is she drinking and afraid that she has let us down? (*interactional*).

Step 3: Construct A Plan

An adapted followup can include any combination of the strategies directed at relocating or gaining cooperation. While it may be possible to identify characteristics at intake that might lead to problems at followup, it is difficult to say which strategies will ultimately be successful in resolving a given situation (Moos and Bliss 1978). Therefore, the research team's approach needs to be flexible and persistent in the use of a range of available strategies. Documenting the incidents of noncompliance, and how they were resolved, will provide important clues for planning the approach.

Assuming the participant has been located, adapting the followup is usually a two-stage process that begins with trying to uncover the sources of the noncompliance and then offering to adapt (as necessary) the protocol to meet the individual circumstances. For someone who is about to drop out of the study, this may be the one and only chance to reconnect, so plan the approach carefully.

Plan for Resolving Noncompliance

- *Locate*

  Find the participant.
- *Interact*

  Engage the participant in a discussion about the problem with participation looking for possible solutions.
- *Adapt*

  Change the rewards or demands of the research to increase its attractiveness, paying attention to flexibility and timing.

Interactive strategies allow staff to learn how participants' circumstances and attitudes may have changed and provide an opportunity to remind them about the importance of their contribution to the study. If interactive strategies are not sufficient, then adaptive strategies should be employed. Listening to participants' concerns about the study and offering a choice from a range of mutually acceptable alternatives often results in their choosing to give the personal interview with no lost data.

Locating Lost Participants

At some point, this will surely happen to any followup researcher—an attempt to telephone a participant results in a recording that the number has been disconnected or changed to an unlisted number, or a letter is returned stamped "Return to sender. No forward order on file." The research assistant calls the locator, who is (or was) the participant's girlfriend, and she says they broke up and she has no knowledge of his whereabouts. The

research assistant feels particularly frustrated because she is fairly certain she could complete the interview if she could just find the participant. But for the moment, he is *lost*.

This is not an uncommon experience in longitudinal research. The longer the time in followup since treatment, the more difficult it is to locate the participants (Moos and Bliss 1978; Twitchell 1992). Yet every lost client represents a potential bias in the study and limits the generalizability of the data because the treatment outcome is unknown (Sobell et al. 1984; Strohmetz et al. 1990; Twitchell et al. 1992). Thus, we stress the importance of procedures to track and locate participants over time and in spite of their negative life events. Efforts put into locating lost participants generally pay off; once they are relocated, they can almost always be persuaded to continue in the study.

Useful information can be gathered from anyone who may be able to shed light on the participant's whereabouts or attitudes about involvement in the study. Consideration must be given to privacy and confidentiality, but there are many sources of information that can be tapped without revealing sensitive data about the participant.

Getting Started

The best way to proceed is to start by thinking about the possible sources of noncompliance. The reason why clients cannot be located may relate to a number of factors that have come to affect their status. This can include social and economic circumstances as well as beliefs, perceptions, and expectations. Review this participant's file to see if there has been a pattern of noncompliance or any new information that may shed light on his frame of reference. Is he trying to hide from someone or avoid the research team? Has he improved or has his situation deteriorated? Might he be institutionalized, homeless, or deceased?

Individual Factors

A research team may be unable to locate participants because they are trying to hide from someone, such as friends, family, business acquaintances, the police, social service agencies, or collection agencies. Keep in mind the natural history of alcoholism, with its ups and downs and many life events. Avoidance as a coping mechanism is common with this population and can be associated with either improved or deteriorated status. Given this fact, it should not be surprising to encounter avoidance behavior in the course of followup. The following case is an example of hiding from someone.

> At intake, Ed had asked to be contacted at his office for scheduling followup interviews. He gave his secretary as his collateral, saying he had no family or friends in the area. All went well for the five followups scheduled over the period of a year after treatment.

> However, when the 3-year followup was due, Ed could not be located. The office telephone was disconnected; mail was returned with no forwarding address. His apartment address and telephone number were obtained through a locator service, but upon calling the number, we discovered that the telephone was no longer in service, and our letter sent to the new address was returned. We called Directory Assistance and were given another telephone number, which turned out to be the telephone number for Ed's ex-wife, who informed us that Ed had left the country to avoid making child support payments. We enlisted her help and were eventually able to call Ed at his European location and complete the interview by telephone.

Interactional Factors

It should be no surprise when clients have trouble communicating with others in their life, including the research team. Participants may be trying to hide from people, and these same people may be reluctant to help you find them.

Participants often drop out of sight because of a problem related to the study. Reasons for avoiding the research staff can be complex. Two of the most common causes are dissatisfaction with some aspect of the study (e.g., treatment assignment) and concern about confidentiality. Interactional factors are a challenge to overcome, but once the participant is located, skilled negotiation can almost always work out the issues so that data are not lost.

Situational Factors

If participants are not avoiding someone and cannot be reached through a collateral or locator, then it is likely that they are homeless, in a hospital or prison, or deceased. Given the unstable life of substance abusers, any of these situations is possible. Or the participant may be doing well and does not want to be reminded of bad times in the past. If clients can be found, there is a high probability that they will agree to be interviewed, although the followup protocol may need to be modified for their situation. Following are three common scenarios when a person cannot be located.

Doing well. Participants may be doing well and very busy with their new lives and may have put the project out of their minds. Silverman and Beech (1979) examined data on dropouts from treatment at a community mental health center and found that 80 percent who dropped out said that their problem had been resolved. While the percentage for substance abuse treatment dropouts doing well is likely to be far smaller, it still represents an important source of contamination of the data.

Finding someone who is doing well presents its own problems, because clients are less likely to show up at an institution such as an alcohol detoxification center where they could be located. They may have moved, changed their friends, changed jobs, and

changed the telephone number to an unlisted one. The following case is an example of doing well.

> Robert was lost for 11 months. Scheduling had always been an issue with him. He had moved several times but had always been willing to come in for the interview. His collateral was Sue, a long-time girlfriend who had been very cooperative in the past. He had no other family in the area but had assured us that Sue would always have his current location. This time was different. Sue had not spoken to or heard from him in almost a year. There was no forwarding address or telephone number. Robert was finally found through a Locator Service that provided a current address and telephone number. When contacted, Robert reported that he had married, started his own business, and was doing well. He stated that with all of the positive events in his life, he had "forgotten about the study." He had left no forwarding address because he was trying to avoid Sue. When assured that his current location would remain confidential, he was happy to provide an interview.

Not doing well. Participants in this category may be drinking heavily, seriously ill and hospitalized, or in jail, homeless, or in a detoxification or treatment facility. Locators may know the participants' location but may not be willing to say how to find them. They may be upset and disappointed with the participant or may even blame the research team for the relapse. Certain populations (e.g., veterans) with access to medical and social services often live in close proximity to the institution on which they depend. The good news is that this may help in locating the individual and complete the followup. The bad news is that research staff must weave their way through the red tape of an institution and act quickly to interview the clients before they leave. Since many of these places do not give out any information about residents and clients, and staff are not likely to have a valid consent for release of information, they may need to overcome some hurdles in order to contact the participant.

Deceased. Individuals with a history of alcohol problems have a high mortality rate due to accidents or alcohol-related medical problems. If the staff knows that participants' status has deteriorated or they had a history of severe medical problems, consider that they may be deceased and check with the coroner's office.

Relocation Strategies

Relocation efforts comprise a major part of the specialized activities within the compliance model. Twitchell et al. (1992) provide guidelines for followup structure and strategies to relocate lost participants. These guidelines emphasize obvious sources of information, such as family and friends, as well as official records and directories (motor vehicle and Social Security records, reverse telephone directories, marriage and death certificates).

In a longitudinal study with an unstable group of patients on methadone maintenance, Desmond et al. (1995) reported impressive compliance rates by incorporating strategies that emphasized institutional information sources and field work. A significant proportion (49 percent) of the sample was prematurely discharged from treatment and at risk for attrition from the study. These individuals required considerably more staff time and effort to locate and complete the interview because they were likely to have left the area, severed contact with the sponsoring agency, and encountered new problems secondary to their substance abuse. Forty percent of this group was found and interviewed in jail or prison, necessitating knowledge of and coordination with other institutional policies.

Sources of Information for Relocation

Known Sources	Institutional Sources
■ Last telephone number	■ Public data bases
■ Directory assistance and telephone directories	■ Locator service
■ Last address	■ Institutions
■ Mail service and directories	■ Field work
■ Collateral/locators and known informants	
■ Known associations	

Finding a lost participant requires that staff pull together all the information that has been gathered, especially that provided at intake. Membership in a fraternal organization (e.g., Moose Lodge) or another group in the community (e.g., a church) or inclusion in a special population (e.g., ethnic group, Vietnam Vets) may help to narrow the search. The more information that has been documented, the more leads staff will have to build on. Begin with the information provided by the participant at the last contact and, if this does not work, proceed to the more time-consuming strategies, such as institutional data bases and field work.

Known Sources of Information

Relocation starts with information that is already known, such as the last telephone number and address, the telephone number at work, the collateral or locator provided at the last contact, and other associations that are known about through their contact with the participant. In our experience, collateral informants have been the most productive sources of information about the status and location of a lost client. These individuals have often partici-

pated in collateral interviews and have a basis of trust and cooperation with the research staff.

Phone Directories

If the individual has moved and established telephone service at the new location, it will generally be given when you call the old number. If the new number is not given, try Directory Assistance under the full name and the last name with first initial (e.g., John Doe and J. Doe). The amount of help obtained from the operator depends on how the request is phrased. For instance, we called and said, "I'd like the telephone number for Lonnie Smith." The operator said, "There is no listing for that person." We called again and said, "I called the telephone number listed for Lonnie Smith at 159 Main Street and received a message that the number was no longer in service. Do you have a new listing for that address?" "The operator said "No, but I have an L. Smith at 13 Elm Street," and gave us the telephone number we were seeking. Perhaps giving more information sounded more credible, so the operator was more willing to try to help.

Another option is using an automated telephone directory. With the explosion of telemarketing, there are now CD-ROM telephone directories for sale that can be updated several times a year for an additional fee. Such directories are also available on the Internet. These automated directories can be very helpful *except* when the participant has an unlisted telephone number. Otherwise, staff can enter the telephone number and get the address, or enter the address and get the telephone number as well as addresses and telephone numbers of persons nearby. Reverse telephone directories, which are available at the library, are a hard-copy resource that lists the telephone subscriber (including unlisted numbers) by consecutive addresses within a given community. This can be a help if the staff knows clients' approximate address and suspect that they may be avoiding contact.

Mail Service and Directories

If the participant has moved, send a letter to the last known address and write on the envelope ACRDNF (address correction requested, do not forward). The letter will usually be returned with a new address or with "No forwarding address." We say "usually," because the postal service is now cutting back on the information it gives out. If a new address is received, note this in the file and send a new letter to the new address. Once the current address has been obtained, try to get the new telephone number from Directory Assistance or the CD-ROM telephone directory program.

Collaterals and Locators

When asked to name collateral informants, participants usually identify individuals who know them intimately and are invested in the outcome of their treatment. Usually, collaterals are involved in the study as an additional source of information about how the

participant is doing, so they will understand why staff is calling when a participant cannot be located. Thus, these individuals are the best source of information at any time in the study *unless* they are angry at the participant or the study itself or are no longer involved in the participant's life.

Locators are individuals who are likely to know the participant's whereabouts. Depending on the protocol for the study, there may or may not be a release of information for these persons on file. Without signed consent from the participant, staff will not be able to say why they are trying to locate the participant, and this often creates problems. Do not lie, and do not say things like, "Well, I can't say why I'm calling," which would create an air of suspicion, but give out only the most basic of information.

> Hello, this is Jan Smith from the West Haven VA Medical Center. I'm trying to get in touch with Joe Jones about completing a survey that he had agreed to do. He is no longer at the same address, but gave your name and number as a trusted friend who would know how to reach him. Is it possible that you could give me his new number or get a message to him that I am trying to reach him?

Locators may not trust you and may incorrectly suspect your reasons for trying to locate the participant. For instance, they may think that you are from a collection agency. The *most* important thing is to protect the anonymity of the participant. If the locator is suspicious and uncooperative at this moment, it is likely that a carefully crafted letter will dispel the questions. Better to be patient and have a later opportunity to contact the lost individual than to violate confidentiality. Staff should always try to end a telephone call asking for permission to contact the locator again. For instance, you might say, "If I don't hear from [participant] in a few days [or weeks, if appropriate], would you mind if I call again to see if you have heard from him?" This maintains a communication link with the locators and, while they might not bother to call you with information, they are usually more receptive to talking with you on another occasion.

Institutional Sources of Information

Institutional sources of information are more important with less socially stable population groups and with individuals who have few close relationships. This may influence how unique identifiers are collected and information is tracked at intake. It is important to obtain identifiers such as Social Security Numbers in order to use public data bases to seek lost participants. It is also important to obtain consent to use these sources of information. This section describes how to obtain information from sources other than what the client provides at intake.

Public Data Bases

Historically, researchers have used the most readily available sources of information, such as telephone directories, and public records, such as those at the Veterans' Administration, the Social Security Administration, and the Department of Motor Vehicles (DMV). However, recent rulings on the confidentiality of public domain information as well as concerns about individual privacy and safety jeopardize these relocation tools. For instance, when Project MATCH began, we expected to rely on DMV records to track lost participants. However, during the course of the study, a change in public policy made these records off limits in some states without specific consent from the individual to access this information. Obtaining consent at the beginning of the study to access public data bases will simplify your job if someone becomes lost.

Locator Services

Locator services provide another way to access comprehensive, updated information. These services are routinely used by business, marketing, and credit firms to verify information or track the location of individuals in the United States. They can be helpful when other sources have failed to produce a current address or telephone number.

Locator services create a data bank using a number of public domain directories, such as Social Security Administration files, U.S. Post Office National Change of Address files, telephone directory files, and credit information from banks, credit unions, and other sources of commercial credit. Access to the more sensitive information in the data bank (such as credit history) is restricted to qualified credit agencies.

Gaining access to the locator data base requires a contract with the host agency, which then links up computer access via personal computer and modem located at the research site. This process does not compromise confidentiality, because the research staff conduct the search. The identity of the participant is not revealed to any outside entity.

A limitation of this service is its reliance on credit history, telephone directories, and so forth. It is unlikely that participants will be applying for credit, and they may not even have a telephone. Try repeating the query every 6 months for a persistently lost participant. For more information on locator services, contact any credit agency.

Jails or Prisons

If staff know or suspect that the participant is in jail, they can call a correctional facility telephone number for that State (in the blue pages) and ask them to check their computer to see if the participant is an inmate and, if so, at what location. For instance, by

calling the central correctional facility in New Haven, Connecticut, we located a participant in the Bridgeport facility.

Given the security concerns in prison institutions, staff will need to follow certain procedures to gain access to an incarcerated individual. These adaptations are time consuming and, therefore, expensive. However, a participant who is incarcerated is usually happy to have a visitor. In addition, staff has relative assurance that the individual will be sober at the time of the interview. Do not delay in arranging an interview, since the incarcerated person may be moved to another facility or released without notice.

The first contact at the institution will probably be a switchboard operator who will refer the caller to a supervisor or the counselor in charge of the inmate. It is unlikely that the project will have a release of information for this institution, so the research assistant will need to ask the counselor to inform the participant that the project is attempting contact and needs verbal consent so the

Locating and Scheduling Individuals in Correctional Facilities

- Call the correctional facility (phone number in blue pages of telephone directory).
- Introduce yourself as a professional associated with a university or hospital study.
- Ask the person who answers to check their computer to confirm that your participant is incarcerated and at what facility.
- Call the appropriate facility and explain that you would like to arrange a professional interview. (You will be referred to a supervisor or counselor.)
- Ask the supervisor or counselor for the appropriate procedure for arranging a professional interview and follow that exactly. You will probably need to call again at a prearranged time or send an individualized letter to the participant to request permission to conduct the interview. Get exact instructions on how to set or confirm the interview date and time.
- Ask participants how they want the payment handled. Cash may need to be checked with the cashier. Obtain a receipt and send a copy to the participant.
- For an interview conducted on site, leave your purse or brief case in your car, dress professionally, and carefully follow the institution's regulations for visitors.
- Bring photo identification and a letter of introduction with the participant's full name and date of birth.

research assistant can explain the reason for a visit. The research assistant then calls back at a designated time and finalizes arrangements for the interview. An alternative method is to write to the participant or to leave a message for the participant to call the project. Inmates are generally allowed to place collect telephone calls for a limited period of time.

Prison interviewing environments vary considerably, from the inmate's cell to the prison cafeteria to private interviewing rooms. The person doing the followup should be someone who will feel comfortable in a prison environment. For example, an interviewer may have to walk by inmates who will call out rude or sexual comments or ask for favors. It is also advisable to do these interviews in teams. Certain institutions, such as federal prisons, do not allow inmates to have personal contact with anyone outside of immediate family. In such cases, the protocol must be adapted so that followup data can be collected entirely by mail.

Institutions Hospitals, recovery centers, halfway houses, and so forth usually have rules to protect the confidentiality of the residents. If the project does not know the name of the client's health care provider, contact the agency's administrative or social service department. Since it is unlikely that either the research project or the institution has consent to release information, research assistants can only say that they have spoken to the person in the past and that the person would probably be interested in knowing that they were calling. One method that works is to assume that the participant is a resident there and request that a message or a letter be forwarded.

Field Work

Drive-bys, canvassing a neighborhood, and networking with people who may know the whereabouts of an individual are last-resort measures to take when other, simpler strategies do not work. These strategies are time consuming and have some inherent risk, but they can pay off when other methods have failed. When doing field work, keep in mind that the personal safety of the researcher is a primary concern. Use a buddy system by working in pairs. Staff should also let their supervisor know where they are going and when they plan to return. If possible, have staff carry a cellular telephone so they can call in if a problem arises. Have current, detailed street maps of the area, and find out the kind of neighborhood the research assistant will be going into by asking a social worker, visiting nurse, or police officer. If necessary, schedule the trip in the morning when the streets are quieter and carry "pepper spray" (if legal in that State) as a deterrent for dogs or other unwanted confrontations.

Driving by the last known address can sometimes provide clues for finding the participant. If the residence is a house, the research

assistant can see if it is occupied or for sale. If people are out and about, she can say she is trying to get in touch with the participant and is wondering if perhaps he has moved. In our experience, people are more willing to provide information to someone in person, especially if that person looks and acts friendly. If the project is affiliated with an institution such as a university or hospital, an identification badge may help credibility. Leave pocketbook or wallet locked in the trunk and dress in clothing appropriate for the setting.

If the participant lived in a rental home or apartment, the research assistant can try contacting the landlord to see if he knows the location of the participant. Usually a telephone call to the city or town tax collector will generate the name of the owner of the property. If there has been a problem with the participant, the landlord will often be more than willing to share the story. If he refuses to share information but indicates some knowledge of the participant, the research assistant can ask to leave a message. If he agrees, then he is probably in contact with the participant. If the landlord questions the reason for the call, explain that it is a personal business call from the organization represented, for instance Brown University or Rhode Island Hospital. Very often, the mention of a well-known facility is enough for a landlord to offer information about the participant. The research assistant can also go to the apartment building and look at the listing of names on the mailboxes to see if the participant is listed there.

If the research assistant suspects that clients are homeless, she can check around to discover where they tend to hang out, such as local food pantries or free meal programs. Go there and ask staff or other homeless persons to deliver a message to call the project. Homeless persons have an amazing communication network, and they appreciate the tangible rewards of research participation.

The following case is an example of a homeless participant who was literally living in a tree house. The case describes the research staff's step-by-step strategy for locating the participant.

> Mike presented at intake with a history of instability in both employment and residence, having lived as a homeless person for extended periods of his life. His characterization of those time periods was "a hobo's life." He had also been imprisoned at one time for a drug offense and received alcohol/drug treatment while incarcerated. He did not have a driver's license, worked for a temporary employment agency, and had no family in the area. He named one person, Leon, as both collateral and locator. During treatment, Mike had difficulty with abstinence, but he completed his treatment and the first two followup interviews without any problem. He was cooperative and seemed to want to be responsible. However, he frequently missed appointments and seemed oblivious to the importance of schedules. When he was

lost to followup, his locator reported he had not spoken to him and did not know of his whereabouts.

Working Hypothesis: Based on his history, it is likely that Mike is experiencing problems. He may or may not be in an institution. However, it is possible that he is simply homeless and in no particular crisis. The most promising plan for relocating him is to use his locator/collateral in the hope that Mike is still in the area and will turn up again. We assume he will cooperate with the interview if we can find him. Travel money may be necessary.

Strategies: (1) Send a letter to Leon asking his help locating Mike. (2) Consider a finder's fee if Leon helps us locate and interview Mike [if the IRB allows this]. (3) Assign a followup worker to call Leon periodically to update the status of the case. (4) Be prepared to canvas a neighborhood, or conduct the interview in the community, if Mike is sighted.

Outcome: Leon agrees to notify us if he sees or hears of Mike. The followup worker places routine calls on a monthly basis. On one occasion, Leon reports that a mutual friend has seen Mike, who is apparently living in the friend's son's tree house. This is likely to be temporary, however, because cold weather is coming, and Mike is likely to move to Florida. A drive-by is arranged in the area where we suspect Mike is living. Two research assistants are prepared to complete the interview if they can find him. Mike is sighted at a local convenience store getting a cup of coffee. The research assistants approach Mike and say, "Mike! We're from Project MATCH. We've been trying to find you to do your last followup. We have the money with us to give you when you complete the interview. How about we buy you breakfast and do the interview right now?" Mike agrees and completes the missing interview. Anticipating that he will move soon, the research assistants give Mike several stamped postcards to update his location, and a card with instructions to call the office collect if he moves.

Comment: In most instances, updated or additional locators would be the preferred strategy to maintain contact with a participant whose living situation is unstable. However, Mike has no enduring relationships and is likely to be lost again if steps are not taken to track his location between interviews. Cash incentives and the personal relationship with the research team are likely to be the best reinforcement for maintaining contact.

Deceased Participants

Large, longitudinal studies are certain to experience some deaths among the people enrolled. Information about the date and cause of death is important for the study as well for the alcohol field in general, because alcohol-related deaths are often underreported, leading to a misrepresentation of the true social costs of alcohol abuse (U.S. Department of Health and Human Services 1993). Notice of a participant's death most often occurs when a routine

letter or telephone call is returned by a family member. Other sources of information about mortality include obituaries and official death records.

When staff has determined that someone in the study has died, they must plan to obtain information for project records about the date and cause of death. Family, friends, or another person who was named by the participant as a collateral are the people most likely to provide the needed information. These individuals may have had previous contact with the research staff and, if so, will likely be happy to answer a few questions about the circumstances surrounding the death. It is important to inform the person that the information related to the death is needed in order to complete your record. Recognize that the family member may be grieving and not feel like talking about the cause of death. Appropriate concern and empathic telephone manners will help. Ask family members if they feel prepared to answer some questions. It is always possible to call again later if the person is emotionally distraught. The following case is an example of a conversation initiated after a letter was returned marked "deceased."

I: Hello, Mrs. Smith. This is Sue Miller from Project MATCH. I have spoken with you in the past. I just heard the sad news that your son Jim died.

L: Yes, he died October 7. I was out of town on vacation, and he was supposed to have dinner with his sisters. When he didn't show up or answer the telephone, they went over to his apartment and found him dead.

I: I'm so sorry. I was surprised at the news. Had he been sick?

L: Well, he had pneumonia and then an infection in his heart. I think it was his drinking. He kept promising me he would go for more treatment, but then he'd put it off.

I: I understand how that is. People with alcohol problems sometimes have such a hard time deciding to get help. How are you doing?

L: Not so good. I'm upset that I didn't get a chance to see him before he died.

I: That's hard, his dying suddenly like this. (Pause) I called mainly to express my condolences for your loss, and to thank you for your past help and your support of Jim while he was involved in the study. It has meant a lot to us. We're very sad to lose him. I need to ask you a few questions about the time and cause of death, but I know this may not be the best time. What do you think? Do you want me to call you back some other time?

L: No. I suppose this is as good as any. Is it going to take a long time?

Comment: This represents a sensitive handling of a difficult situation. The collateral is informed why she is being called and offered a choice about responding now or being called back later. Information obtained should be kept to a minimum, asking only what is needed for the data base. We have found that common courtesies help the grieving family feel that we are interested in more than just the facts. Following up the interview with a sympathy card is a good idea.

Another way to get needed information is to contact the local newspaper and ask for the obituary department. Give them the name of the deceased, and they will give the date of death. If it is known that the death was violent, contact the police department, using the project's letterhead. For a slight fee, they will honor a request and provide last known address and date of death. Another way to confirm the death is through the bureau of vital statistics in the city in which the person died. However, some cities require a relative of the deceased to request a death certificate.

Resistant or Refusing Participants

Once a lost participant is found, the goal is to schedule and complete the necessary interview and to obtain a renewed commitment to continue with the research study. For some individuals, the interaction is straightforward: the staff reminds them of their commitment, emphasizes the importance of their input, and proceeds with the routine protocol. For individuals easily reengaged, it is important that staff reinforce the participant's renewed commitment (such as, "That's great! We're really glad to have you back on board again! This will help us a lot!") and obtain additional information to prevent the participant from being lost again. These positive interactions should be a routine part of the social reinforcement that clients receive for their involvement.

For other individuals, relocation raises the more fundamental problem that they do not want to schedule an interview at this time. Many factors impinge on the participant's decision to cooperate or not with the followup. Staff will probably have to ask about the difficulties they are having in providing the requisite data and attempt to talk through the issues with them. What research assistants uncover may seem trivial or irrelevant, and they may feel annoyed by participants' actions or words. This reaction is normal. However, these actions are probably not directed at the research assistants personally, so they should approach each situation unencumbered by personal biases and avoid arguing or moralizing.

Remind staff that their job is to collect the data, not to provide therapy. They should focus on completing the interview and collecting the necessary data. If not successful in that regard, it is very important that they keep the door open to future contact and continued involvement in the study.

Interactive Strategies

This section is intended as a guide to use as staff negotiates the conditions of continued participation with resistant participants. The interactive strategies describe an attitude as well as a set of concrete steps to follow. They are designed to elicit important information about the participant's beliefs, expectations, and preferences, with the hope of identifying the source of the problem and a possible solution. The style of interaction is person-oriented as opposed to data-oriented.

Interactive Strategies

- Meet resistance with understanding, empathy, and respect
- Normalize or legitimize problems with the study
- Provide a rationale for involvement and a range of possible solutions

In practice, it is impossible to collect data and avoid at least some discussion of current problems or personal concerns (Maisto et al. 1985). However, it is imperative that the research assistant who engages a resistant participant recognize the importance of avoiding giving unnecessary support, advice, or referrals for treatment even when the client is in distress. Attentive listening to the personal experiences of the participant may result in the interviewer being perceived in a helping role. Regular clarification of the roles and responsibilities of research staff helps research assistants adhere to the research protocol.

Meet Resistance With Understanding, Empathy, and Respect

Numerous studies have cited the importance of empathy and understanding in promoting compliance with various health-care regimens (Chafetz et al. 1964; Meichenbaum and Turk 1987; Miller 1985). Robles et al. (1994) indicate that in their longitudinal study, resistant subjects were likely to be depressed, harried, and overwhelmed by recent events in their lives. These factors were associated with noncompliance, and their resolution was contingent on staff taking a posture of support and encouragement until the resistance dropped.

In Project MATCH, we found that acknowledging the difficulty that participants were experiencing was an effective way of communicating respect for their situation. That can be conveyed in a

simple phrase such as, "I understand. That must be hard for you." If the discussion reveals a fundamental problem with the study, it is important to know the nature of the complaint. Understanding the participant's perspective on the problem may provide an opportunity to influence the situation in question.

Normalize or Legitimize Problems

The research assistant should communicate to participants that other people in the study have experienced life problems that interfered with followup or have expressed reservations about continued involvement. In their longitudinal research, Capaldi and Patterson (1987) described the importance of legitimizing the experiences of subjects. They trained their research staff in communication skills, stressed that families are diverse in their lifestyles, and urged staff to communicate a sensitivity to the many problems facing families. This posture allows the research staff to empathize with the participant and avoid an adversarial relationship. It is also important that the staff member communicate that, while problems do occur, they can be resolved by coming to some compromise that meets the participant's needs while obtaining the necessary data.

Provide a Rationale

Providing a rationale for involvement is a highly individualized process that needs to reflect the context of the person's life and values. This represents the element of persuasion in the specialized strategies. The goal is to help the person decide to continue as an active research participant. It helps to know the previously identified motives for participation. For instance, it will make a big difference if participants initially identified "free treatment" as the primary reason for involvement. They may or may not be responsive to appeals to altruism.

People often express the belief that "my data won't help you." Somehow, they come to believe that if they never improved,

Rationale for Continued Participant Involvement

- Participation may not directly benefit the participant, but it will help others with the same problem.
- Dropping out diminishes the quality of information for the study and makes it hard to draw conclusions about the helpfulness of treatment.
- Many participants report some difficulty following the exact protocol. Some adjustments can be made to accommodate the individual's special circumstances.
- It is better to lose some data (i.e., miss an interview) than to have people drop out just because they cannot complete the interview at this time.

dropped out of treatment, or relapsed, they would not be able to provide helpful information. These individuals need encouragement and a reorientation about the value of their contribution. They need to be reminded that a research study learns as much from what does not work as it does from what does work for different individuals.

The following case demonstrates the importance of eliciting data from a man who had been lost and who is clearly discouraged.

> Jim had experienced many problems during the course of the study. He relapsed during the treatment phase and was hospitalized twice during followup. His wife left him and filed for divorce, and for some time we could not locate him. During periods of relative stability, Jim lived with his mother, whom he named as both locator and collateral. She had cooperated with past attempts to contact Jim. This time, however, he is lost and she says that she does not know his whereabouts. The research staff think that Jim's mother is hiding him. This represents a change of behavior on her part and suggests that something about Jim's status has changed. The staff question whether he is really lost, but will accept her statement at face value until new information surfaces.
>
> *Plan*: (1) Call Jim's mother regularly to check on Jim's whereabouts. (2) Send a collateral letter to Jim's mother thanking her for past assistance and asking for her help getting a letter to Jim. Enclose with the collateral letter a letter addressed to Jim. Explain to the mother that participants generally want to be interviewed if we can locate them. (3) In the letter addressed to Jim, offer a plausible guess about why he was lost; remind him of the rewards of participation and reinforce the importance of knowing what happens to people over time. Also inform him of everything that has gone on between us and his mother, explaining that these steps are consistent with the research agreement he had signed at intake.
>
> *Outcome*: Contact is made with Jim's mother. We ask if she has received our letter, and she says yes. We ask if she would be able to help us get in contact with Jim. She says, "Why don't you ask him yourself, he's right here." The staff expresses appreciation to Jim for agreeing to talk to us and reminds him of the importance to the study of complete information on all participants. Jim's telephone demeanor is brusque, gruff, and guarded.
>
> *Working Hypothesis*: Based on Jim's history and his demeanor with the interviewer, it seems that he is not committed to continuation and needs to be persuaded to remain in the study.
>
> *Strategies*: (1) Ask about the noncompliance (assuming he is lost and not resistant or refusing) and explore his thinking about continuation. (2) Offer a rationale for his continued involvement that may address some of his concerns. (3) Use financial incen-

tives or adapt the task demands to fit Jim's current situation. The following is an excerpt from the conversation.

I: So, you received our letter. We appreciate the help your mom has given us in reaching you. Are you able to set an appointment?

P: Yeah, I suppose so, but this is going to have to be the last one.

I: Is there a problem with you continuing after this appointment?

P: I just got out of the hospital, and I'm spending all of my time going to meetings so I don't go back to drinking.

I: It seems like you are busy and you don't have the time to come for an interview. We can make some adjustments to make it less demanding of your time. We can come to you, or even do it over the telephone. What do you think?

P: That's not the point. I just don't have anything new to tell you. I don't know if you know how it is, but it's hell to recover from this disease. I do okay for awhile, but it seems I can't get very far away from my next drink. The only thing I know to do is go to meetings. I don't see any point in coming in and going over the same questions. Anything I have to say, I've already said.

Comment: It is disheartening for Jim to come in repeatedly and tell us of his failures. The research assistant communicates empathy and understanding, while asking for information about his problem. Still, it seems he will need another reason to continue in the followup.

I: You've been through a lot trying to overcome your problem. I understand that you're getting the help and support you need. Other people in the study have had similar experiences, and we've had to work with them so that they can take care of themselves. I hope you will give us a chance to do the same thing with you. We can learn a lot from people like yourself about how hard it is, and to what lengths people have to go to recover. I can understand why you say you don't have anything new to tell us, but from my viewpoint, you still have something important to contribute. We hate to lose you when you are so close to being finished. We could do a short telephone interview now, it would only take us about 5 minutes to answer some basic questions. We still want you to do the last scheduled followup interview in 6 months. That would give you some time to take care of your affairs.

Comment: As the investigator incorporates a number of specialized strategies in this case example, it is hard to say which strategy is successful. Jim's primary need is to be reassured that he is still valued and has something of importance to contribute. It seems that this is accomplished in a straightforward and respectful fashion that persuades Jim to continue despite his discouragement and his own belief that he has failed.

In cases like this, where the risk of attrition is high, it is helpful to educate the participant about the cost of attrition. Many people, like Jim, are not aware of the problems that occur when someone does not complete the followup. The message we give is "dropout diminishes our ability to draw conclusions about the helpfulness of treatment for people like yourself." This by itself may not dissuade an angry or disappointed participant to continue, but it may be enough to encourage a resister to reconsider or to consider another option (such as a call-back at another date) that preserves the research relationship.

Adaptive Strategies

If interactive strategies are unsuccessful, the next step is to attempt adaptive strategies. These can be added incrementally, because each represents a greater deviation from the standard protocol. This might involve removing aversive elements, increasing financial or other incentives to make participation more attractive, or, for cases of persistent refusal, encouraging the participant to delay decisionmaking until later. These steps provide an opportunity for the staff to review the case and influence the participant's decisionmaking about continued involvement. It may also give the client time to resolve the problems that are blocking participation. Identifying a range of options (all of which incorporate a *yes* to participation) and allowing the client to choose, is a highly effective approach to overcoming resistance. For most clients, it is the *perception* of choice that increases cooperation.

Adaptive Strategies

- Offer financial incentives
- Remove aversive elements
- Obtain partial data
- Delay decisionmaking
- Defer to a higher authority
- Accept no as temporary and situational
- When all else fails, accept the decision gracefully

Financial Incentives

While many participants identify altruistic motives for participation, it is clear that tangible rewards, including money, are an important part of the incentive package. We routinely remind clients about the benefits of participation, such as by saying, "I know you're not doing this for the money, but you will receive $25 for doing this followup." We present this as reimbursement for the time, travel, and service (feedback, data, opinions) provided. Institutions' human subjects committees usually have strict rules regarding participant reimbursement, so financial incentives must be in keeping with these.

Remove Aversive Elements

Some individuals object to certain elements of the protocol that they perceive as aversive. These may include giving laboratory specimens, completing the self-report forms, or traveling to a distant research office. Initiating a discussion about such issues may uncover reservations about an aspect of the protocol that, if eliminated, will resolve the problem.

Cooperating with the participant's preference communicates an attitude of respect and responsiveness, which seems to enhance the mutual, reciprocal nature of the research agreement. This interaction can also provide important feedback to the investigator about conditions that impact on the participation of other individuals. For instance, at one MATCH site, we heard complaints about a phlebotomist who was performing the blood specimen draw at the time of enrollment. Several people indicated that they were bruised by this staff member's technique. This problem represented considerable risk to compliance with the study because we were informing participants that we would be collecting blood samples every 3 months. We addressed the problem with the laboratory and then assured these participants that they would not have to worry about a recurrence of the problem. Listening to the complaint and recognizing that giving blood is very aversive for some individuals resulted in effective problem-solving.

Obtain Partial Data

Another option is to obtain only partial data when the participant is unwilling (or unable) to complete the entire interview. For instance, Project MATCH protocol called for a telephone version of the main drinking data interview (FORM 90-T), and a quick version of the daily drinking calendar (90-Q) for use when it was unlikely that the participant would schedule an inperson interview. When it appears that only partial data can be obtained, prioritize the measures for the interview so as to obtain the most critical information first. Sometimes, after participants have provided some basic information, they will feel reengaged with the study and agree to provide more complete data.

Delay Decisionmaking

If talking through the problem or adapting the research protocol does not resolve the compliance problem, it is best to delay the decision about continuation. Support for the technique of delayed commitment to change is well established (Kelman and Hovland 1953; Zweben et al. 1988). A participant who has relapsed may not feel like doing anything, but when sober again is likely to want to cooperate. Removing pressure to decide upon study participation will decrease the likelihood that individuals will drop out of the study as a means of resolving their current discomfort.

Defer to a Higher Authority

Sometimes, despite use of these strategies, a research assistant will be unable to obtain the participant's cooperation and agreement

to continue in the study. If clients refuse to do the interview, research assistants can indicate that they do not have the authority to "dissolve the research agreement" and request that they talk with the Principal Investigator. This emphasizes the importance of the decision and the value of the participant's contribution to the study. It also provides clients with another opportunity to rethink their decision. Also, a person of greater authority may be able to more effectively address the issues that concern the participant. In our experience, the Principal Investigator and Project Coordinator typically have the most success persuading resistant participants to continue.

Accept No as Temporary and Situational

Individuals have the right to decline continued involvement, and this right must be respected by the research team. However, a participant's no may be due to a temporary situation, such as a life crises or heavy drinking, and may not reflect an exact preference. In a sense, the process of engaging participants in a discussion about the problems with the study clarifies their thinking and allows a more careful decision about an important commitment. There is an ethical fine line here, because it may be difficult to determine if the decision to drop out is a current state of mind or a decision arrived at through a more intentional process. The research assistant can set the tone of cooperation by acknowledging the participants' perspective and respecting their choice but still offering another option.

The following statements are examples of adaptive strategies; the word in parentheses after each statement describes the type of adaptive strategy.

- I understand what you're saying about not wanting to continue in the study. (*acknowledgment*)
- This has come up with others, but it often is a matter of being *really* inconvenient to do the interview now. (*normalization*)
- I know that you understand how important it is to the integrity of the research to not lose participants, especially after so much time and energy on your part and ours. I know that the information you have to share may not seem helpful to you, but it will help others like yourself in the future. (*education*)
- I wonder if you would consider skipping this interview and allowing us to call you in 3 months to see if things have changed for you. If you still want to drop out of the study, you can let us know, and we will close your case. (*delaying decisionmaking*)

- If your situation is different and you are willing to do the interview, we can make an appointment. There won't be any problem making up the data we missed. (*providing a rationale*)

- We would pay you for both interviews because we would be covering the two full periods in one interview. (*offering financial incentives*)

The following case describes a surprising turnaround after the staff used several adaptive strategies.

Tori, a 40-year-old woman, participated in Project MATCH but dropped out of treatment, placing her in a high-risk category for research attrition. The research team had difficulty scheduling her for the first research followup, which further reinforced the tenuous nature of the relationship. Tori finally agreed to a home visit, but when the research assistant arrived, Tori refused to allow the interview to take place in the house. She denied any drinking and angrily declined to answer certain questions in the interview. She wrote on one self-report inventory, "NONE OF YOUR BUSINESS." This was interpreted as a clear message that the participant was not interested in continuing. She also declined to have her husband be interviewed as a collateral. Our guess was confirmed at the next scheduled interview. The participant said, "I don't want to continue."

Working Hypothesis: Staff suspect that Tori is drinking and that there is some conflict between her and her husband. A letter is sent, acknowledging her decision.

Strategies: Another letter is sent prior to the due date for the 15-month interview inviting Tori to reconsider her decision (appendix C). Tori responds by calling the investigator and requesting information about the interview. This is an opportunity to reinvolve her in the study. She is told: (1) We understand that she had her reasons for deciding to drop out 12 months ago; (2) she is welcomed back into the study and has a significant contribution to make; and (3) the missing information could be captured without much difficulty. We offered her several options, including another home visit, which she chose.

New Hypothesis: Tori has resolved the unknown obstacle to compliance and wants to complete her commitment and regain her sense of integrity. Providing a rationale for reinvolvement and reinforcement for her decision is critical.

Outcome: Upon arrival, the interviewers are invited in and shown the home Tori and her husband have built. When the discussion about the research agreement begins, Tori volunteers that she refused previously because of her heavy drinking. Her husband had been angry, refusing to allow her to drive because of the risk of an accident. He had refused to participate as collateral because

of her relapse. She had sobered up 8 months after that time and decided "to tell her story in the hope that it might help the alcoholic who is still suffering."

Comment: Respecting the participant's decision without interpreting her no as an absolute decision provided an opportunity for both the client and the researcher to end as winners. The source of her noncompliance was a combination of contextual, individual, and relapse factors: she cannot drive to the office for the interview, feels ashamed about her relapse, and does not want to acknowledge her drinking for fear it might further hurt her marriage. The particular approach used in this instance required the investigator to both respect the client's no and persist in a creative fashion with a variety of compliance strategies.

Accept the Decision Gracefully

It is inevitable in longitudinal research that some participants will not respond to attempts to reinvolve them and will assert their intention to withdraw from the study. This is their right, and it must be respected. When attempts to deter participants from dropping out do not work, it is important to express gratitude for their contribution to the study. We have found it helpful to follow this verbal exchange with a personalized letter from someone in authority (appendix C). This letter acknowledges the decision to quit and thanks the individual for contributing. It also identifies the means for getting reinvolved in case there is a change of heart at a later date. In some instances, this may include a statement informing the participant that there will be a notification of the due date of the last interview to provide an opportunity for reconsideration. This procedure should be cleared by each institution's IRB before using it.

Other Issues

No Treatment

One of the more difficult scenarios for the followup team occurs when a participant is enrolled in the study but receives no treatment. These participants feel less connected to the study and may even think that they are no longer part of it. The two most likely reasons why treatment is not received are (1) the participants are doing worse than expected or (2) they decide that alcohol treatment is not necessary. From the client's perspective, the reason may not matter. The fact remains that they received no treatment as part of their participation in the study, so one condition of the research agreement was not fulfilled.

When clients are doing worse than expected, it is likely that they cannot stop drinking and are in need of detoxification or hospitalization. They may have underreported their drinking at intake or relapsed to heavy drinking once enrolled in the study or the motivation for change may have decreased even though they

initially sought treatment. If participants have changed their minds about wanting treatment, staff is faced with the challenge of engaging them in a meaningful research relationship. It is likely that they will have to work hard throughout followup to reinforce participation and instill a sense of responsibility toward completing the study.

In such cases, staff should start by reviewing the research agreement. The case should be flagged as nonroutine and extra attention given to tracking and monitoring. Often these participants require help with concrete problems (for example, a treatment referral) in order to stabilize their condition. The factors behind the lack of treatment may not emerge for some time into the followup period. We have found the following steps to be helpful when no treatment was received.

- Inform the participants in writing that the decision to drop out of treatment does not invalidate their agreement to participate in followup (appendix C).
- Follow the letter with personal contact. Ask participants what they intend to do about followup appointments. This is best done by the Project Coordinator or Investigator.
- Be prepared to carry out various outreach activities to complete the first followup. Participants who comply with one interview are more likely to comply with others even if their condition deteriorates.

Clinical Deterioration

It is inevitable that some participants will suffer setbacks in their personal or interpersonal functioning. It is imperative that accommodations be made to provide support or referral services for medical, psychological, or substance abuse services when they are needed. Offering referral services when clients express a need is an informal incentive to participation that seems important to some individuals. However, many participants who make requests for additional help may not follow through on the referral given.

Treatment Referrals

Staff training and active involvement in the staffing of noncompliant cases provide vehicles for balancing personal relationships between staff and participants with methodologically sound ways of conducting followup. It is difficult for a research assistant to listen to a client's woes and not offer advice, encouragement, or active support. Thus, initiating treatment referrals is a topic that needs to be addressed in staff training and in the establishment of policies and procedures for all staff involved in the research. These policies and procedures may be influenced by the practices

of the host agency (for example, a VA hospital) or by criteria identified for the protection of human participants (IRB). Establishing clear policies for responding to clinical deterioration will prevent staff from undertaking an active helping role with clients. Several strategies are helpful in this regard.

- Inform participants that a treatment referral is available if required. This should be done at the same time that staff are reviewing roles and responsibilities for study participation.
- Give participants requesting a referral a list of treatment resources so they can call directly. However, research staff should take the initiative on a referral only if there is concern about the participant's personal safety or in another such emergency.
- Identify one staff member, perhaps the Project Coordinator, who is not involved in data collection as the person to contact if a referral is needed.

Mandatory Reporting Laws

Mandatory reporting laws pose a unique and special challenge for the research team. All individuals entering treatment need to be educated about the circumstances in which their confidentiality may be breached. This includes participants in a research study that provides treatment, because the same laws mandate that the therapist report certain crimes or events. In addition, information obtained outside the treatment relationship can create a situation that increases the likelihood of noncompliance because disclosure of some facts may result in unwanted social or legal consequences (for example, reporting suspected child abuse to protective services). Clients should be routinely reminded of the risks of reporting certain behaviors (such as planning to hurt themselves or someone else) and the protections in place for their privacy (such as a blind file, statements of confidentiality). Research assistants should also be required to report any problems or complaints that a participant voices. These should be carefully documented along with what action, if any, was taken.