

RECRUITING RARE & HARD TO REACH POPULATIONS: A SAMPLING STRATEGY FOR SURVEYING NYC RESIDENTS LIVING WITH HIV/AIDS, USING AGENCY RECRUITERS.

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Key Words: HIV, Multi-Stage Sampling, Agency Recruitment

Recruitment of a probability sample of people living with HIV/AIDS presents a formidable challenge for survey researchers. This is a disease that has flourished at the margins of society, beyond the reach of conventional sampling techniques. Many individuals living with HIV or AIDS have unstable housing situations, are active substance users, or are disenfranchised or alienated from mainstream society. As a result, standard procedures for screening households or assembling lists of eligible respondents are not feasible. Strict rules governing patient/client confidentiality preclude a survey researcher from making direct contact with an HIV infected client through a medical or social service provider. Initial contact with such a sampled client must be made through an intermediary who has some pre-existing relationship with an eligible respondent. One attractive solution is to use a two-stage sample in which a probability sample of HIV service agencies is drawn, followed by a random sample of eligible clients within an agency; this would be followed by an agency liaison attempting to recruit the sampled client. The drawback to the researcher, of course, is that the success of the fieldwork then depends on organizational actors external to the research team. These agency proxies work under varying organizational constraints, and they vary in their interest, motivation, and autonomous capacity regarding the research. Here we describe our fieldwork experience assembling a broadly representative longitudinal cohort of individuals in New York City living with HIV/AIDS using just such a strategy. The survey's major objective was to learn about individuals' service needs, utilization, access, and satisfaction. A further objective was to chart the impact of a multi-dimensional service system on an individual's physical, mental and social well-being.

The literature relating the experiences of researchers who have relied upon the active assistance of care-providing organizations to recruit probability samples is sparse. The Robert Wood Johnson Foundation's AIDS Health Services Program studied demonstration AIDS service delivery networks in nine cities. Two service delivery sites in each network were identified (one was a hospital clinic and the other was a

community-based organization), and case managers at the sites were used to contact a random sample of cases drawn from agency client lists. The accrual of cases proceeded at a much slower rate than anticipated, and at the completion of the data collection, only 18 percent of the sample had been contacted and interviewed (Fleishman et al., 1992). The federally-funded AIDS Cost and Services Utilization Study (ACSUS) involved recruiting a large national sample of persons living with HIV. A sample of 32 large medical facilities in 10 cities were randomly selected, of which 26 agreed to participate. Rather than use agency-generated client lists for their sampling frame, as the Robert Wood Johnson researchers had done, ACSUS employed 55 specially trained site coordinators to administer screening interviews in order to create their sampling frame. This screening process identified about 6,000 eligible persons, of whom 40 percent were randomly sampled to participate in the study and 88 percent of whom were eventually interviewed (Berk et al. 1993). There is no information, however, relating the number screened to the number of HIV patients at each study site, so estimating a recruitment rate is not possible. ACSUS makes no claims to being a national probability sample and its experiences are likely to be difficult to emulate because of the large amount of resources devoted to recruitment efforts.

Furthermore, these studies present minimal information about the specific mechanics involved in cultivating agency contacts as intermediaries in a rigorous research protocol. This paper presents findings on our fieldwork experiences assembling a representative sample using such agency intermediaries. After describing the planned sampling strategies, we discuss levels of agency participation, the time involved in securing effective agency participation, data on rates of accrual, and strategies employed to proceed with a rigorous recruitment design in the face of individual, situational, and organizational barriers. We also examine how organizational characteristics affected the pace of agency participation. It was our impression, systematically examined here, that organizational complexity was an important factor influencing how long it took us to fully enlist agencies in client recruitment.

SAMPLE DESIGN

A total study sample of 700 respondents was planned for the baseline survey, drawn from several sample frames. This paper reports only on our efforts to recruit a probability sample of 400 individuals using agency-generated client lists (another 250 individuals would be recruited through agency-based convenience samples, and 50 people who were unaffiliated with medical or social service agencies would be recruited by acquaintance sampling and street outreach efforts). The sample frame for this study began with an enumeration of 358 major providers of HIV services in New York City. The enumeration attempted to be reasonably exhaustive of HIV service providers, with the exception of office-based physicians and other small medical practices. Of the listed agencies, 300 with estimated HIV caseloads of 20 or more constituted the sampling frame for this study.

For the first stage of sampling, the agencies were divided into four strata, based upon whether or not the agency received federal funding (specifically, Ryan White Title I funds) and whether or not it was a medical care facility. Within each stratum, the goal was to recruit 10 sites that would be sampled systematically with sampling rates proportionate to the estimated size of their HIV caseload. A sample of 40 sites was drawn in this way and additional sites were identified as substitutes in case a sampled agency proved ineligible or unwilling to participate.

For the second phase of sampling, participating agencies were asked to prepare an anonymous listing of all HIV-positive clients or patients with whom they had one or more contacts within the last 12 months. The research team drew between 15 to 40 persons randomly from these client rosters, stratified by gender and tenure at the agency. The objective was to oversample women in proportion to their true prevalence among the HIV-positive population, and to use the variable of tenure at the agency as a reasonable proxy to achieve a distribution of individuals across the disease spectrum (that is, from those with few or no symptoms of the disease to those with full-blown AIDS). Agencies designated a staff person to act as a coordinator who would locate sampled clients, describe the study, and obtain an initial consent for the research team to contact the client directly for recruitment into the study.

The entire fieldwork operation, from initial contact with agencies to completion of the interviews was to be done in an 8½ month period. Two months were allotted for obtaining agency agreement, training agency coordinators, and having agencies prepare client lists. We assumed that agencies would be able to recruit their quota of clients in a six week period. We planned to approach the 40 sampled agencies in successive monthly waves of ten each in order to stagger the tasks of agency

recruitment, list preparation, coordinator training, and then respondent interviewing. Our time plan allowed for about a 1½ month slippage in this ambitious schedule. The research team achieved its goal of obtaining a broadly representative sample, although the process did take longer than anticipated.

THE AGENCY PROCESS

Agency involvement can be divided into three phases: deliberation, commitment, and recruitment. The **deliberation** phase began with a letter and introductory packet from the research team and its sponsors sent to designated agency contacts. This phase included the internal delegation procedures by which the recipient of the introductory letter -- often an executive director or a program director -- had to decide what organizational rules governed the decision to participate, and which staff members should be involved in the decision. Many agencies were required to pass the proposed research design through an internal review process (formal and informal). Responding to the initial request to participate in the research often required numerous meetings to secure various permissions and engage relevant staff in the research process. The researchers utilized high-profile sponsors of the evaluation research in an effort to persuade agency directors to participate in the study. It is worth noting that at least half of the sampled agencies were dependent on these sponsors for their own funding as well.

The **commitment** phase began once an agency coordinator/recruiter had been designated (occasionally multiple coordinator/recruiters were designated). These coordinators were then trained in the research protocol, which involved educating the coordinators as to the nature of the research, the necessity of maintaining a rigorous sample design, use of a standardized script with which to enroll participants, and the requisite documentation in order to monitor the process and assure that respondents' informed consent to be contacted by the researchers had been obtained. This phase was complete when an agency's client list had been received.

Strategies utilized by the research team to expedite this commitment phase included technical support to create the list, a standardized research protocol training session for agency recruiters, a "Casebook" that explained the study and included instructions on recruitment and documentation, weekly and biweekly follow-up phone calls, and faxes alerting agencies to all upcoming training sessions (also with follow-up phone calls).

The **recruitment** stage commenced once the research team had sampled clients from the lists provided by the agencies. The agency representative was asked to contact the sampled client, secure the client's consent to

be contacted by the research team, and then send the necessary documentation to the research team to enable direct contact of the client. Once agency documentation was received, an interviewer was assigned by the research team, contact was made with the respondent, and the interview was scheduled and completed.

FINDINGS

Participation Rates

Table 1 shows the participation status of sampled agencies. The overwhelming majority of agencies contacted expressed a willingness to participate. We sampled 51 agencies; nine agencies were ineligible because of small or nonexistent caseloads, five elected not to participate, four agreed but could not complete their tasks within the fieldwork time frame, three participated as open enrollment sites, and 30 agencies recruited clients randomly drawn from their enumeration lists.

Table 1. PARTICIPATION STATUS

	<u># of Agencies</u>
Total number sampled	51
Recruited clients from lists	30
Participated in convenience sampling	3
Ineligible	9
Unwilling or unable to participate	9

Table 2 summarizes information on the duration of each phase of fieldwork. Agencies varied considerably in the time it took them to deliberate and commit to recruiting clients, ranging from 2 to 38 weeks between the time we sent out our letter of invitations to the point at which agencies were ready to recruit clients. Half of all agencies took longer than the estimated 8 weeks to complete this phase. The processes involved in this phase are obviously varied and complex. The enumeration was accomplished at some agencies relatively expeditiously. More often, the enumeration was either held up by bureaucratic review processes or the restrictions or non-existence of organized records. Several agencies required between four and seven months in which to complete their lists.

In general, list-making was a problem for one of several reasons:

(1) The person capable of generating such a list was in another division of the agency (such as Management of Information Systems), and the request was accorded low priority;

(2) The agency was physically unable to locate records within a timely fashion, or had a system of record-keeping that made such an endeavor daunting to the list-maker (and often unknown to the executive or program contact who endorsed the agency's participation);

(3) In one case, an agency submitted a list compiled by a part-time volunteer, and when the cases were sampled by the research team the agency was unable to decipher the codes utilized by the volunteer, and was further unable to even reach this volunteer to obtain an explanation of the system;

(4) At the point of sending the research team the enumeration, someone at the agency balked at the idea of sending confidential information out of the agency, an informal review process was reinstated, and the agency had to be reassured that in fact confidential information was not being released.

Another unanticipated element was the extended time it took to arrange coordinator training. Originally we had hoped to be able to quickly identify coordinators and train them in groups of ten. It turned out to be very difficult to arrange a time when a large number of coordinators could be convened. Rather than having four training sessions we ended up arranging eight. The number of participants at each session ranged from three to eight. We eventually found it necessary to visit seven sites for individual training sessions.

Recruitment of clients also took much longer than expected. It took several weeks from the time we sent agencies their lists of sampled clients to the time they sent us back the first name. This ranged from 1 to 15

Table 2. FIELDWORK DURATION, IN WEEKS

Fieldwork Phase	N of Agency	Mean	Range
COMMITMENT			
<i>Weeks from Invitation Letter to...</i>			
Coordinator Training	33	10.0	1-38
List Preparation	32	11.1	2-36
Completion of Phase	31	12.6	2-38
RECRUITMENT			
<i>Weeks from Sampling Client IDs to...</i>			
Recruitment of 1st client	30	5.5	1-15
Recruitment of 10th client	22	16.0	3-42
<i>Weeks from Invitation Letter to 1st Client</i>			
Letter to 1st Client	30	16.4	4-42

weeks with half taking five or more weeks. Achieving 10 recruited clients took even longer and only 22 of 30 agencies even achieved this level. This took anywhere from 3 to 42 weeks, with the agencies averaging 9 weeks. Overall it took anywhere from 4 to 42 weeks from the time an invitation letter was sent to when the first client was interviewed, and half of all agencies required 13 or more weeks.

Table 3. COMPLETION RATES

Percent Recruited from List	Number of Agencies
60%+	10
40-59%	9
20-39%	9
Less than 20%	2

Table 3 presents additional data on the pace of recruitment. Here we show the distribution of agencies by the number of clients successfully recruited as a percent of the total quota they were assigned. During the course of the fieldwork the research team had sampled 850 client IDs from agency lists, which meant that in order to achieve a sample size of 400, agencies had to recruit approximately half the persons on their sample list. Table 3 illustrates that only about a third of the agencies achieved a recruitment rate of 60 percent or more, whereas a third had not managed to even recruit 40 percent off their list.

Table 4 summarizes results for the final phase of the fieldwork progress, conducting the interview. Here a much different picture emerges. Once a name was provided to the research team by an agency, the research team was able to complete most interviews in slightly over one week. Outright refusals after initial agreement was given was quite low, running between 2 and 3 percent.

Table 4. DURATION BETWEEN RECRUITMENT AND COMPLETED INTERVIEW

Number of Completed Interviews	389
<i>Weeks from Interview Assignment to Completed Interview</i>	
Mean	1.8
Median	1.1
5th Percentile	0.1
95th Percentile	5.7

Obstacles within this phase often arose with the agency coordinator's inability to devote time to contacting clients. It should be noted that agencies and agency coordinators were compensated with lump sum disbursements (a little under \$20 per client) in recognition of their efforts. Some of the problems encountered in this phase included:

(1) An agency coordinator who terminated employment at the agency and took the research records with him;

(2) Several agency coordinators who encountered resistance from agency field staff and case workers in attempting to initiate contact with clients;

(3) Agencies with a significant proportion of clientele who were "hard-to-reach," either because the individuals had unstable living situations, rapidly changing addresses, no known phone numbers, were incarcerated, or moved in and out of drug treatment programs (and were considered unreachable while they were in treatment);

(4) Agency coordinators who were ineffective recruiters because their personality, style or approach was not conducive to persuading clients to enroll.

This last may be the most difficult to monitor or chart, since the research team did not have direct control over the designation of agency coordinators or their interaction with clients. It also points to the weakest link in this random probability sample model -- the researchers' absolute dependence on the ability and willingness of complex organizational entities and individuals outside the research team to make all necessary efforts to contact clients, represent the study fairly and appropriately (not to mention enthusiastically), and to secure participation.

Organizational Features

We investigated the effect of several organizational characteristics on the pace of agencies' commitment and recruitment. During the commitment phase, the organizational characteristics associated with a delayed completion of this phase included public sector agencies and agencies where authority to make decisions was divided among personnel located in different units within the parent agency. Interestingly, federally-funded agencies were also significantly slower to complete this commitment phase, even though the study was being sponsored as an evaluation of the impact of the federal program in New York City.

Organizational factors had weaker effects on the recruitment phase, specifically the time it took to recruit the first client. However, delays in beginning recruitment were associated with agencies with several layers of management above our key agency contact and agencies

where other persons besides the trained agency coordinators were involved in recruitment.

Clearly, in those agencies where staff members who had not been trained in the research protocol were utilized in the study, there were other signs of delayed or incomplete recruitment. These agencies showed a sharp drop in the percent that recruited at least 10 clients (32% fewer than agencies using only specially trained agency recruiters). It is also interesting to note that contrary to our expectations, recipients of federal Ryan White funds were generally slower than other agencies during all phases of fieldwork. We had expected that receiving these federal monies would have stimulated recruiting, since this survey was being done as an evaluation of the federal Ryan White Title I program.

DISCUSSION

We found that an unanticipated complication in working with agency intermediaries was the extended "start-up" time necessary to mobilize agencies to complete enumerations and client recruitment. Agencies took between three and four months to move through a complete fieldwork cycle, from the initial letter inviting an agency's participation through recruitment of at least ten sampled clients, and in fact only slightly more than two-thirds of the participating agencies could even reach that plateau. Several agencies took between three to five months deliberating whether to participate, which either slowed down or negated the research team's replacement strategy, and then ultimately declined to participate. This, combined with the inability of agencies sampled in four successive waves to hew to the estimated timeline, suggests two considerations for similar studies: (1) It would have made as much sense to approach all 40 agencies at once, assuming that they would deliberate, commit, and recruit at different paces anyway, and thus not be an undue burden on the research staff, and (2) the "fish or cut bait" period in which an agency could deliberate whether or not to participate should be shorter and more clearly defined. As much time was spent by agencies in internal processes of formal and informal consent to participate and task assignment as was spent on outreach activities to locate and secure cooperation of client respondents.

Our experiences further indicate that with a good training program for agency recruiters, monetary compensation to cover agency time and effort for recruitment, and ongoing assistance and guidance from the survey team, it is possible to implement rigorous sampling procedures. We found that although initial willingness to participate was very high, it was nevertheless very difficult to find ways to shorten the fieldwork cycle when other organizations had to be relied upon to recruit respondents without jeopardizing the

quality of the sample. However, it is possible to identify in advance certain organizational features that will likely slow down the process. Most importantly, efforts to obtain agency approval and time to prepare agencies to recruit clients are impeded when organizational authority is so widely distributed that many persons need to be consulted before formal approval is given.

Notwithstanding some of the institutional, structural or individual impediments inherent in such a sampling and recruitment design, it is evident to us that a careful investment in agency relations at the beginning of such a longitudinal cohort will yield an intact and willing pool of respondents. We attribute a part of the ease with which we are able to contact, secure, and interview respondents to the efforts of the agency recruiters. As demanding as it is using "proxy" recruiters for a random probability sample, these proxies are also necessary and essential collaborators in the research.

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This study was supported under contract # 93-EVL-4645A from the Medical and Health Research Association of New York City, Inc., with funds from the Health Resources and Services Administration under the Ryan White CARE Act, Title I.
