
Report 2004-4



Field Notes:
Recruiting CHAIN's
2002 Longitudinal
NYC Cohort

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C.H.A.I.N. REPORT

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Background

The goal of the Community Health Advisory & Information Network (CHAIN) Project is to provide a comprehensive portrait of persons living with HIV/AIDS in New York City. Understanding the needs of people living with HIV presents a unique challenge. Given privacy concerns and the relative scarcity of the condition, one cannot simply conduct a survey of the general population. Focus groups are useful, particularly in identifying areas of concern, but the views expressed by participants may not represent the views of all HIV+ individuals in an area. Similarly one could survey local area providers as to the needs of their clients, but this too suffers from a lack of comprehensiveness since providers know their own clients well but not necessarily those with other service needs. The “gold standard” of such population research is to conduct a randomized sampling among all HIV+ individuals who live in a particular area in order to construct a representative cohort. This random cohort, if selected properly, will contain a cross-section of all persons living with HIV and will fairly represent the full population of interest.

In 2002, the Planning and Evaluation Subcommittee of the New York HIV Health and Human Services Planning Council authorized the NYC Department of Health and Mental Hygiene and the Medical and Health Research Association of New York City to contract with researchers at the Center for Applied Public Health at Columbia University’s Mailman School of Public Health to recruit a new cohort of 700 HIV+ adults residents of New York City, following the methodology used by the researchers in conducting the original CHAIN cohort recruited in 1994-95. The CHAIN “new cohort” study began enrolling clients in July, 2002 and closed enrollment in December, 2003. The objective of the CHAIN new cohort recruitment was to establish a baseline cohort of 700 HIV+ adults living in the five boroughs of New York City, 650 who were in care or receiving some type of HIV services, and 50 who were ‘unconnected’ to care. At the end of the period of enrollment, 684 individuals in care, and 23 unconnected were recruited and interviewed. This report describes the recruitment and enrollment of the ‘agency’ sample of 684 individuals; a separate report describes the effort to locate, recruit and interview HIV positive persons unconnected to care.

Sample Design

The goal of the study was to assemble a cohort that is broadly representative of all New York City residents living with HIV. To achieve this goal, a multi-stage stratified sampling strategy was developed in which HIV medical or social service agencies were first randomly selected according to specific criteria, and then a random selection of study eligible clients were recruited. To be eligible for the study, a client had to be at least 20 years old, a resident of one of the five boroughs in New York City (although not necessarily a legal citizen), and have been diagnosed with HIV for at least six months. Two client sampling strategies were devised – a list recruitment protocol and a sequential recruitment protocol. The following sections describe the efforts to first engage the HIV service agencies, and then to carry out the client recruitment. Each recruitment strategy will be described in detail. The full recruitment protocol is reprinted in the Appendix.

The first stage in the multi-stage stratified sampling protocol centered upon health and social service agencies serving an HIV-positive clientele. The steps involved within this stage included: (1) identifying a sampling frame composed of eligible agencies, (2) defining the strata

and the random selection process within the strata, (3) determining replacement rules for resampling agencies that were either ineligible or unwilling to participate, and (4) implementing the sampling protocol.

In order to identify the sampling frame we utilized an agency database that was first populated in 1993 with lists of agencies providing health and social services, and that has been continuously updated since then. Generally speaking, the sampling unit was considered to be an agency site of service rather than a single administrative entity that encompassed many sites of service. For example, if an AIDS Service Organization had storefront operations at three locations, all three would be entered in to the sampling frame as distinct units. The rationale was that each site served a different client population, each of whom should have an equal opportunity of being sampled. On the other hand, if the agency housed all of its programs within one site, that single site was considered to be a distinct sampling unit. As much as possible, the decision rule we used to create a distinct sampling unit was that it represent the smallest autonomous unit that might be readily identified by a client. At medical agencies, for example, an infectious disease clinic in a hospital or a satellite clinic would both be considered autonomous units, whereas a treatment adherence program within an HIV clinic would not be considered autonomous (instead, it would be considered part of the HIV clinic).

The list began in 1993 with approximately 450 records. There are currently 3,109 unduplicated records of sites of service in New York state, most of which are located in New York City. The list has been expanded by incorporating data on recipients of Ryan White CARE Act funding across all titles (see CHAIN Update 35, The Ryan White Impact Study, for further details), by constantly reviewing provider lists and resource directories, and by adding providers identified by respondents in the CHAIN cohorts. At each CHAIN interview, a respondent is asked to enumerate all the health and social service providers that he or she has seen in the past 6 months. If a respondent mentions a provider that is not found in the agency database, a new record is created. Respondents identify approximately 20 providers at each interview. Considering that we have conducted over 4,000 interviews since 1993, that means that we have reports of over 80,000 providers, most of whom are duplicates of providers mentioned previously. Still, the process provides for a dynamic means of continuously checking and updating the agency database. While not an exhaustive list of all providers in the city, we are reasonably confident that it represents the most commonly visited ones.

Prior to stratifying the agencies we reduced the list to an unduplicated number of health and social service agencies located in New York City, and further reduced the medical agencies to those providing primary medical care or dental care. The sampling frame thus began with 849 agency sites of service. As with the earlier stratified sampling that we employed in 1994, we identified three strata – borough, provider type (medical or social service), and funding type (Ryan White Title I grant recipient or not). For each borough except Staten Island, which had too few agencies to stratify by Ryan White funding type, we created four strata: Ryan White medical, non-Ryan White medical, Ryan White social service, and non-Ryan White social service. Within each list the agencies were sorted by zip code and by organizational cluster¹; we

¹ Each agency record is assigned a “parent agency” as well as a “health system” if it is part of a vertically-integrated organization. For example, the AIDS Clinic at Columbia University Medical Center (CUMC) is the smallest autonomous unit, CUMC is the “parent agency” and New York Presbyterian Hospital is the “health system.” Health systems are not applied to social service agencies, but if there are multiple locations then each will

used a random starting point within each stratum and interval sampling in order to produce a randomly sampled list of agencies. In Staten Island we sampled one medical and one social service agency, and then within each of the remaining sixteen strata (four strata in four boroughs) we sampled between nine and ten agencies. The initial sampling yielded 40 agencies.

Letters were sent to each sampled agency and follow-up phone calls were made to conform an agency's eligibility (in order to be eligible, an agency had to serve a minimum of 20 HIV-positive clientele). Agencies that were ineligible, could not be located, or who refused to participate were replaced with the next agency on the list (see Appendix for the detailed sampling protocol).

Each of the original forty agencies was replaced (if necessary) until an agency was identified that was eligible and agreed to participate. As many as five replacements were conducted in some cases until an eligible agency was identified. As Table 1 illustrates, in order to yield a minimum number of agencies, a total of 91 agencies were sampled. When agency recruitment was stopped, 34 agencies (37%) were eligible and had agreed to participate, whereas 57 agencies (63%) were "non-participants." Among the non-participating agencies were those that were ineligible (e.g., insufficient client caseloads, no direct service, no longer existing), providers who refused to participate (which included direct refusals, persistent non-response despite repeated phone calls and letters, or IRB issues which were unresolvable), a handful of agencies that re-directed us to a more appropriate unit within their organization, and one agency that agreed but was unable to conduct any recruitment.

Table 1. Agency Sampling and Participation Rates

	n	%
Total # agencies sampled (n=91)	91	
<i>Participating agencies</i>	34	37%
<i>Non-participating agencies</i>	57	63%
Reasons for non-participation (among n=57)		
<i>Ineligible</i>	36	63%
<i>Refused</i>	15	26%
<i>Re-directed to another site within agency</i>	5	9%
<i>Agreed but never recruited</i>	1	2%

There were certain patterns evident among the 57 non-participants. Social service agencies were far more likely than medical agencies to be classified as ineligible (78% versus 22%, data not shown), primarily because they had an insufficient numbers of HIV-positive clients or did not distinguish their clients by HIV serostatus. On the other hand, medical providers were far more likely to either refuse, be non-responsive, or have irreconcilable IRB issues than were social service agencies (80% versus 20%, data not shown).

A total of 651 clients were recruited from these randomly selected agencies. As a check

be grouped within a "parent" agency that serves as the central administrative site.

on the representativeness of the sample, comparisons with NYC surveillance data were conducted periodically and toward the the end of the recruitment effort, it was decided that the subpopulation of white men was under-represented among clients recruited to that point. To address this concern, a multi-service agency with a relatively high proportion of white men living with HIV was selected as a recruitment site, and an additional 33 respondents recruited with their assistance. Thus a total of 684 persons living with HIV represent the agency-recruited sample for the new CHAIN cohort².

Table 2 illustrates the distribution of agencies randomly selected as recruitment sites and the clients recruited from these agencies by two of the sampling strata, organizational type and borough. There was an even split between clients recruited at medical agencies and those recruited at social service agencies. Interestingly, even though the borough level recruitment shows a greater proportion of clients sampled in agencies located in Manhattan, the actual borough of residence often differs from the borough in which the client was sampled. Despite the fact that 44% of all respondents were recruited at Manhattan agencies, only 28% of the cohort actually lives in Manhattan. Thus the overall sampling protocol produced a sample that was reasonably and proportionally distributed by both organizational type and by borough.

Table 2. Agency Participation and Client Recruitment by Strata

	Agencies		Clients by sampling site			Clients by residence	
	n = 34	%	n = 684	%	Avg clients per agency	n = 684	%
By Organization Type							
<i>Medical</i>	15	44%	340	50%	22.7		
<i>Social</i>	19	56%	344	40%	17.2		
By Borough							
<i>Bronx</i>	5	15%	77	11%	15.4	174	25%
<i>Brooklyn</i>	7	21%	146	21%	20.9	195	29%
<i>Manhattan</i>	15	44%	349	51%	23.3	190	28%
<i>Queens</i>	5	15%	84	12%	16.8	94	14%
<i>Staten Island</i>	2	6%	28	4%	14.0	31	5%

Working with HIV Service Agencies

The success of the sampling strategy depended upon the active cooperation of personnel from the medical and social service agencies selected as recruitment sites. An initial introductory packet was sent to the sampled agencies, which included a letter from the NYC CHAIN Study Director and the Field Director. The letter explained the purpose of the study and

² There are presently three CHAIN cohorts: NYC I, which was recruited in 1994-1995 and refreshed in 1998; NYC II, recruited in 2002-2003, and which is the topic of this report; and Tri-County, recruited in 2001-2002.

requested the opportunity to learn more about the key features of the agency's operation. The packet also included a letter of support signed by the Associate Commissioner of Disease Intervention at the NYCDOH, the Governmental Co-Chair of the HIV Health and Human Services Planning Council, the Community Co-Chair of the HIV Health and Human Services Planning Council, and the Co-Chair of the PWA/HIV Advisory Group.

The mailing was followed-up by a phone call to an agency contact. This was a brief 15-minute interview, which included information on the active number of HIV+ clients, sites of HIV services, the amount of different programs providing HIV services and the hours of operation. We also asked about non-clinic based programs, such as mobile units and outstationing at another agency. The purpose of the phone interview was: (1) to assess the agency's willingness to participate; (2) to gather key information about the agency in order to determine eligibility; (3) describe the recruitment protocol; and (4) to determine the best recruitment strategy – list recruitment or sequential enrollment.

Upon determining agency eligibility and interest in participating, site visits were conducted by the Study Director, Senior Project Director and/or the Field Director to meet with key agency personnel. It was important to introduce the study and secure cooperation from the person in the highest position of authority to grant permission to conduct recruitment onsite. Initial meetings were generally conducted with executive directors of social service agencies or medical directors of clinical services. However, it was important that we identified someone who had direct contact with clients to also be a part of these initial meetings - for example, the onsite case manager supervisor, or supervising nurse. If initial permission was granted, CHAIN staff then conducted presentations with all staff members to ensure that everyone who was involved with the clients had some familiarity with the study, had an opportunity to ask questions about the study and the recruitment procedure, and to provide suggestions to the researchers about how best to work effectively and respectfully within their service setting. The support of the full staff was invaluable since staff members who were aware of the study and believed in its usefulness to their clients were extremely helpful with client recruitment.

CHAIN staff worked with agency representatives to determine who would be best to act as a single Agency Coordinator. The Agency Coordinator acted as the liaison between the agency and CHAIN staff researchers. The Agency Coordinator was responsible for introducing the study to eligible clients, to explain what would be expected of study participants, and to be prepared to answer questions about the research - e.g. the purpose of the study, confidentiality provisions, incentives for participation, etc. Agency Coordinators received one-on-one training conducted by the Field Director or Study Director to prepare them to represent the study and to address any of the clients questions or concerns, as well as to implement the recruitment protocol. The Coordinator was most often the point of first contact with a potential study participant, although in some agencies, multiple staff under the Agency Coordinator would introduce the study to potential participants.

Recruitment Strategies

Once an agency agreed to assist with client recruitment, we determined the best recruitment strategy - list recruitment or sequential recruitment. Both strategies were designed to ensure that a random cross-section of agency clients were invited to participate in the CHAIN Project, and to minimize any tendency of agencies to refer their most satisfied, vocal, or

accessible clients.

List Recruitment of clients involved a systematic random sampling of an agency's list of all its active clients, defined as an HIV positive adult who had at least one service contact for any reason in the prior 12 months. A list was prepared by the agency with anonymous ID numbers; no names or other personally-identifying information was used. A proportional sampling design provided for a selection of fewer clients at smaller agencies and greater numbers at larger agencies. For each list a sampling interval was determined based on the total number of clients on the list and the desired number in the sample. Then a random seed number was selected as a starting point and client ID numbers were selected at the sampling interval. Additional ID numbers were selected to serve as replacement numbers in the event that the original client sampled was ineligible (e.g. not resident within the five boroughs; not HIV positive). The list of sampled clients was then returned to the agency.

A designated agency coordinator from the service provider's staff then attempted to contact each sampled client to describe the project to the prospective respondent. A standard "Consent to Contact" script was read to each sampled client. The objective was to enlist the client's agreement to be contacted by someone from the CHAIN project staff. Agency coordinators were trained in ways to respond to the most commonly cited barriers offered by clients (e.g., concerns about confidentiality, time, incentives to participate). Additional documentation used by the agency coordinators included a contact log which described the agency coordinator's effort to reach and persuade the client, and, for clients who agreed to be contacted by CHAIN, detailed contact information. The agency coordinator also provided demographic information on all sampled persons (gender, race/ethnicity, age), regardless of whether or not they agreed to be contacted by CHAIN. This information was crucial in assessing the representativeness of the sample. Periodically, clients sampled off the agency lists had to be replaced due to ineligibility - for example, their residence was outside of New York City, or they were not HIV positive.

The decision to conduct a list recruitment was based on the determination that there were few opportunities to locate a sufficient number of eligible clients in a given period of time, either because of low client caseloads, or because of the nature of the interaction between the agency and its clientele. A variety of agencies comprised this group. List recruitment sites included social service programs where providers might see clients once per month or less often, or where services were provided for clients in their homes. The list recruitment strategy was employed for both medical and social service providers.

The major challenges with this process stemmed from the demands placed on the Agency Coordinator to follow up with contacting sampled clients. Agency staff made numerous attempts to reach clients who were hard to find, and these attempts included phone calls, letters, and identifying when clients were scheduled for appointments with a provider at the agency. The process of locating and contacting clients often proved to be time consuming, and busy, high case load agencies had limited resources to consistently devote staff time to the recruitment effort. Staff turnover and reassignments further complicated the task. Agencies which were most successful in recruiting clients through this process were able to designate a single staff member who was known and trusted by clients, who had extensive client contact, and who could designate a few hours on a daily basis to client recruitment, and maintain regular contact with the CHAIN Project Field Director.

Sequential On-site Enrollment was designed to recruit all eligible clients visiting a site of service on a given day. Agencies involved in this enrollment strategy were primarily busy medical clinics, day treatment programs, or large support groups, where on any given day a minimum of 10-15 HIV+ adult clients might be present. The primary elements of sequential enrollment were to identify possible recruitment periods and to assign an agency coordinator to work with CHAIN staff. Days and hours of operation were ascertained for each potential sequential recruitment site, and with the help of agency staff various recruitment periods were selected. Although we were able to quickly identify potential recruitment periods we did not schedule the site visits much in advance. This was done purposefully, as to assure the greatest possible randomness of clients (and discourage any potential “steering” of clients in to the study if the recruitment period was known sufficiently in advance). In addition, we wanted to make sure we were on site during a time when they agency was not restricted to serving only certain populations. For example, some sites offered special services such as gynecological care on certain days, which meant that there would be more women on site than on other days. Furthermore, if an agency offered services during “off hours” we would also do recruitment during this time as well.

As with the random recruitment, the agency coordinators were instructed to present the study to every eligible client, and to read the “Consent to Contact” verbatim. At a number of sites, a CHAIN invitation describing the study was posted or distributed to all clients entering the clinic area, so that clients had some knowledge of the study prior to being approached by the agency coordinator. At each sequential enrollment site, the agency coordinator was asked to maintain a recruitment roster. This roster was intended to list all eligible clients present during the recruitment period, and each client’s age, gender and race/ethnicity regardless of whether the client agreed to participate. Again, these data were used to assess the representativeness of the final sample. Multiple CHAIN staff were present on site or nearby on recruitment days and if a client agreed to speak with someone from CHAIN, the agency coordinator would facilitate the introduction on the spot. At this point, the CHAIN staff would further explain the project, collect contact information from the client, complete the interview at that time if possible, or schedule the interview for another day.

The major challenge for sequential enrollment was the difficulty of ensuring that all eligible clients were introduced to the study. Again, in busy service settings, the agency coordinator might be called to other duties in the middle of the recruitment period, allowing clients to come and go without being invited to meet with the CHAIN staff. The agencies who were most successful with this strategy were those in which the Agency Coordinator was able to have some contact with all clients who presented for services on a recruitment day, and/or to be in touch with all of the service providers on site that day. In this way, the Agency Coordinator could inform the case manager, medical provider, nutritionist, etc. that clients they saw that day were eligible for the study, and ensure that staff referred their clients to the Agency Coordinator for information about the project. Close communication with the CHAIN staff was also crucial so that clients who were interested in hearing more about the study could be seen immediately. Often times, CHAIN staff could enroll clients and complete the interviews in the same day.

In general, larger facilities, such as medical providers and multi-service organizations, conducted on-site sequential enrollment, while smaller social service agencies, which usually

had small caseloads or few face-to-face client interactions conducted random recruitment off a list. The target number to be recruited per site depended upon the active caseload of the agency. We sampled 15-20 clients from agencies with 20-100 clients, 20-25 clients from agencies with 101-500 clients, and 25-35 clients from agencies with more than 500 clients. Eleven of the thirty-four agencies provided anonymous client lists, and the remaining twenty-three agencies conducted on-site sequential enrollment. Among the agencies that conducted randomized list recruitment only two were medical providers. Both had a relatively small number of active clients and were specialized programs that were connected to a larger medical facility that was not sampled.

Bias Analyses – Is the Cohort Representative of People in Care?

In order to assure that there were no systematic biases in how we recruited individuals into the study, we examined three potential “threats” to sample validity. The first, a *strategy bias* analysis, explored the comparability of the recruitment strategies. In this analysis we were looking to see whether individuals recruited by one strategy (list based or sequential sampling) differed in any systematic way from those recruited through the other strategy. The second analysis explored *recruitment bias* to determine if those individuals who consented to participate were generally similar to those individuals who were eligible but did not consent to participate. The final analysis involved *enrollment bias*, in which we assessed whether the individuals who agreed to participate and who were interviewed were comparable to those who agreed to participate but were not interviewed.

For all the bias analyses we compared group differences among three characteristics – gender, age group, or race/ethnicity. Hypothetically, if there was no bias present the groups would appear to be relatively equivalent. Bias analyses for recruits vs. non-recruits (*recruitment bias*) and interviewed vs. non-interviewed (*enrollment bias*) are based on demographic data available for at least 85% of potential respondents.

Testing for Strategy Bias: Comparing Sequential and Random Client Pools

Table 3 compares the overall composition of the potential respondent pool of HIV positive persons sampled for the study by type of recruitment (list recruitment or sequential recruitment) and by type of agency (medical or social service). The 1,265 individuals who compose the “denominator” for this analysis include all those who were listed by agencies or who were present at an agency for a sequential recruitment. In other words, these represent all the eligible respondents for the study, regardless as to whether they agreed to participate. In comparing the list versus the sequential rosters first by medical and then by social service agency, we found differences by gender and race/ethnicity. Among social service agencies, more women were defined as potential respondents by the sequential recruitment strategy compared to list recruitment; there were no statistically significant gender differences by recruitment strategy at medical agencies. African Americans were more likely to be in the pool of potential participants for both medical and social service agencies when the sequential strategy was used. At social

Table 3. Strategy Bias - Comparing the Potential Respondent Pool by Agency Type

	Medical Service		Social Service		ALL	
	List	Sequential	List	Sequential	List	Sequential
Total eligible (n=1265)	75	611	262	317	337	928
Gender ¹						
Female	33%	44%	25%	34%*	27%	40%***
Male	67%	56%	75%	66%	73%	60%
Age ²						
20-34 years old	19%	11%	12%	9%	13%	10%
35-49 years old	60%	62%	55%	63%	56%	62%
50+ years old	21%	27%	33%	28%	31%	28%
Race/Ethnicity ³						
Black	31%	55%**	44%	56%***	41%	56%***
White	9%	6%	24%	5%	21%	5%
Latino	58%	38%	30%	37%	36%	38%
Asian / Other	2%	1%	3%	2%	3%	1%

* p < .05 ** p < .01 *** p < .001

¹ There are 134 missing values for sex¹ There are 184 missing values for age¹ There are 157 missing values for race/ethnicity

service agencies, a greater proportion of non-Hispanic white clients were defined by list recruitment as compared to sequential recruitment. It is difficult to interpret the reasons as to why higher proportions of women and African Americans were in the potential pool of clients when sequential strategies were used. This may represent the success of extensive HIV/AIDS outreach efforts targeting these groups to bring them into care. It may indicate that women compared to men, and African Americans compared to other race/ethnic groups, have greater service needs and thus make more frequent visits to service providers. Whatever the reason for the disparity, persons with more frequent visits are more likely to be sampled using an onsite, sequential strategy than are those being recruited using a list based strategy where each active client, regardless of frequency of visits, has an equal chance of being sampled.

Testing for Recruitment Bias: Comparing Recruits Versus Non-recruits

Tables 4.1 & 4.2 illustrate findings from the recruitment bias analysis, which compared individuals who were recruited by agency coordinators to eligible individuals who were not recruited by agency coordinators. Table 4.1 examines these comparisons separately for medical and social service recruitment sites. There were no significant differences between the groups being compared, except by age. Within medical facilities, middle aged clients (35-49 yrs old) were somewhat more likely than younger clients (20-34) to agree to be contacted by CHAIN for the study. With this exception, the individuals who were recruited “look the same” as those who

were not recruited.

The analysis of possible recruitment bias was conducted by recruitment strategy as well, comparing list based and sequential recruitment approaches. The only statistically significant difference was again by age. According to this analysis, younger PLWH were under-recruited and middle aged clients were over-recruited in the sequential recruitment effort. For example, the proportion of younger clients who were recruited was 8% whereas the proportion of clients in the same age group who were not recruited at the same sequential enrollment sites was 15% .

Overall, the combined recruitment rate for the project was 64% (806/1265) indicating that almost two-thirds of eligible clients approached by the agency coordinator through either the list or sequential strategies signed a consent to be contacted by the CHAIN Project (see Table 6, below). Our data suggest that the pool of recruited respondents generally represents the population of HIV+ adults in care in the five boroughs of New York City. Although both recruitment strategies were capable of sampling a representative cohort of HIV+ adults, examining the rates for each strategy demonstrates differences in the efficiency of sequential and random enrollment. The recruitment rate for sequential enrollment was 66% whereas the recruitment rate for list based recruitment was considerably lower; only 46% of those sampled from agency rosters were recruited by agency coordinators. Despite these differences in the net yield of clients from their respective pools, the recruitment bias analyses suggest that the individuals who were recruited by the agency coordinators are reasonably equivalent in terms of gender and race/ethnicity to those eligible individuals who were not recruited. The slight under recruitment of younger persons living with HIV would not seem sufficient to warrant major concern about overall sample representativeness.

Testing for Enrollment bias – Comparing interviewed and non-interviewed clients among the recruited

Despite considerable field efforts to contact, enroll, and interview every individual who agreed to be contacted by CHAIN, a certain proportion of these individuals either decided they did not want to participate in the study, were unable to participate due to physical or logistical limitations or continued broken appointments, or could not be found. An examination of differences between the total sample of individuals who were interviewed and those who were recruited but not interviewed found no statistically significant differences by gender, age, or race/ethnicity (Table 5). Although there was a difference in gender composition of those who were interviewed compared to non-interviewees recruited in medical settings, with greater numbers of women among the interviewed compared to the non-interviewed, this difference was offset by the reverse tendency in social service settings. Likewise, in the analysis of possible enrollment bias by recruitment type (list or sequential) we see a similar pattern, with differential enrollment by gender using one modality being offset by gender composition of persons enrolled using the other strategy (data not shown). In addition, any differences in enrollment rates are minimized by the relatively few numbers who declined or otherwise did not complete a baseline interview such that the impact of such compositional differences is negligible.

Table 4-1. Recruitment Bias - Recruits versus Non-Recruits by Agency Type

	Medical		Social Service		ALL	
	Recruited	Not Recruited	Recruited	Not Recruited	Recruited	Not Recruited
Total eligible (n=1265)	397	289	369	210	766	499
Gender ¹						
Female	45%	41%	31%	27%	38%	35%
Male	55%	59%	69%	73%	62%	65%
Age ²						
20-34 years old	9%	16%*	9%	14%	9%	15%**
35-49 years old	64%	57%	59%	60%	62%	58%
50+ years old	26%	27%	33%	25%	29%	26%
Race/Ethnicity ³						
Black	56%	46%	49%	55%	53%	50%
White	5%	7%	12%	15%	8%	11%
Latino	38%	45%	37%	28%	37%	37%
Asian / Other	1%	2%	2%	3%	2%	2%

* p < .05 ** p < .01 *** p < .001

Table 4-2. Recruitment Bias - Recruits versus Non-Recruits by Recruitment Type

	List		Sequential		ALL	
	Recruited	Not Recruited	Recruited	Not Recruited	Recruited	Not Recruited
Total eligible (n=1265)	156	181	610	318	766	499
Gender ¹						
Female	28%	25%	41%	40%	38%	35%
Male	72%	75%	59%	60%	62%	65%
Age ²						
20-34 years old	12%	16%	8%	15%*	9%	15%**
35-49 years old	53%	60%	64%	58%	62%	58%
50+ years old	35%	25%	28%	27%	29%	26%
Race/Ethnicity ³						
Black	42%	40%	56%	55%	53%	50%
White	21%	21%	5%	5%	8%	11%
Latino	37%	34%	37%	39%	37%	37%
Asian / Other	1%	4%	2%	1%	2%	2%

* p < .05 ** p < .01 *** p < .001

¹ There are 134 missing values for sex² There are 184 missing values for age³ There are 157 missing values for race/ethnicity

Table 5. Enrollment Bias – Interviewed versus Non-Interviewed by Agency Type Among Recruited Clients

	Medical		Social Service		ALL	
	Interviewed	Not Interviewed	Interviewed	Not Interviewed	Interviewed	Not Interviewed
Total (n=766)	340	57	344	25	684	82
Gender ¹						
Female	48%	23%***	31%	40%	39%	28%
Male	52%	77%	69%	60%	61%	72%
Age ²						
20-34 years old	10%	2%	9%	5%	10%	3%
35-49 years old	63%	74%	58%	71%	60%	73%
50+ years old	27%	24%	33%	24%	30%	24%
Race/Ethnicity ³						
Black	56%	55%	50%	44%	53%	51%
White	6%	2%	12%	12%	9%	5%
Latino	37%	39%	36%	44%	37%	41%
Asian / Other	<1%	4%	2%	0%	1%	3%

* p < .05 ** p < .01 *** p < .001

¹ There are 1 missing values for sex

² There are 15 missing values for age

³ There are 6 missing values for race/ethnicity

Final Sample Completion and Sample Representativeness.

Table 6 and Table 7 summarize the overall success of the CHAIN field effort. A total of 806 PLWH consented to be contacted by CHAIN from among the 1265 clients identified by agencies as potentially eligible for the study, a recruitment rate of 63.7%. As Table 6 shows, the most common reason for non-recruitment was the inability of the agency coordinator to reach a sampled client to discuss the possibility of study participation.

At the end of the enrollment period we had interviewed 684 of the 806 individuals who consented to be contacted by CHAIN for an enrollment rate of 84.9%. The reasons for non-interview are shown in Table 6. Again, difficulties in locating potential study participants presented the greatest challenge. Addresses given by respondents at initial recruitment included homeless shelters, residential treatment facilities, and other transient living arrangements and address changes subsequent to initial recruitment were not uncommon. Although clients had given their permission to be contacted by CHAIN, with increasing concern for confidentiality of client records under HIPPA regulations, agency personnel were less willing to share discharge or forwarding information than in prior CHAIN study enrollment periods. Ninety-four individuals who were recruited from medical or social service agencies and who had given their consent to be contacted by CHAIN researchers, were lost or otherwise could not be contacted to complete enrollment and conduct a baseline interview.

On the other hand, refusal rates were remarkably low. Only 10% of eligible clients approached by agency coordinators refused to participate in the study. Of the 806 clients who agreed to be contacted by CHAIN, only 26 (2%) declined to be interviewed.

Table 6. Disposition of Cases

Total number of cases identified by agencies		1320	
<i>Total number excluded (deceased, not HIV+, not in area, duplicate)</i>		55	(4%)
Total number of cases not excluded		1265	
Among clients not excluded by agency	<i>Unable to participate (institutionally inaccessible, physically or mentally unable, temporarily out of town)</i>	18	(1%)
	<i>Unable to be reached by agency coordinator</i>	310	(23%)
	<i>Refused to agency coordinator</i>	131	(10%)
Recruited: Consented to contact by CHAIN		806	
Among clients consented to contact by CHAIN	<i>Unable to participate (institutionally inaccessible, physically or mentally unable, out of town)</i>	2	(<1%)
	<i>Unable to be reached by CHAIN</i>	94	(7%)
	<i>Refused to CHAIN</i>	26	(2%)
Enrolled: Interviewed by CHAIN		684 (52%)	

Table 7. Survey Rates

	Definition	Numbers	Rate
Recruitment rate	<i>Total consented / total eligible</i>	806 / 1265	63.7%
Enrollment rate	<i>Total interviewed / total consented</i>	684 / 806	84.9%

Comparison to AIDS Surveillance Data

Our final analysis to examine the representativeness of the CHAIN sample was to compare the newly recruited CHAIN cohort of 684 individuals with NYC surveillance data reporting characteristics of people living with HIV and AIDS. We can also compare the CHAIN sample with information about clients provided by a duplicated count of Ryan White CARE Act-funded encounters. When comparing with HIV surveillance data, the currently constituted cohort appears proportionally different than the population of people living with AIDS with regard to race/ethnicity. In particular, there are fewer white men and women in the new cohort than the AIDS epidemiology, and a greater proportion of black and Latino respondents in the new cohort. What is striking, however, is that the new cohort more closely mirrors the Ryan White encounter data.

There are several possible explanations for this. One consideration is that the

epidemiology of HIV/AIDS is changing in New York City, such that more blacks and Latinos are becoming infected, entering the system of care, and present in greater numbers in many service settings, compared to people who have been living with the virus longer, and who have progressed to an AIDS diagnosis. Another consideration may be that white individuals living with HIV/AIDS in NYC are less likely to seek care at a broad range of health and social service agencies, as they did at earlier recruitment periods for CHAIN, and may be more concentrated in a limited number of service settings. It is also possible that this race/ethnic differential in a manifestation of sampling issues in the CHAIN recruitment and enrollment of the new cohort such that white PLWHA did not have an equal chance of entering the cohort as did black and Latino PLWHAs. There is the possibility that white individuals were more reluctant to participate in the study, or that agency coordinators who helped facilitate the recruitment process were more reluctant to approach white clients.

Table 8. Sample Representativeness, NYC HIV/AIDS Cases and CHAIN Cohort

	NYC Persons Living with AIDS, as of 6/30/03 ¹		NYC Persons Known to be Living with HIV, as of 6/30/03 ¹		Ryan White Encounters, 3/2001 - 2/2002 ²		CHAIN New Cohort 6/2002-6/2004	
	Female	Male	Female	Male	Female	Male	Female	Male ⁴
Total N	15,753 (28%)	39,765 (72%)	10,104 (35%)	18,995 (65%)	10,765 (39%)	16,962 (61%)	268 (39%)	416 (61%)
White	11%	25%	8%	30%	9%	8%	6%	10%
Black	56%	40%	58%	36%	53%	53%	62%	47%
Latino	33%	32%	31%	30%	37%	37%	31%	41%
Other	1%	2%	3%	4%	2%	2%	<1% (1)	2%

¹ Source: Personal correspondence, HIV Epidemiology Program, Department of Health and Mental Hygiene, the City of New York

² Source: HIV CARE Services. Data represent a duplicated count of first time encounters with Ryan White CARE Services in FY11, March 2001 - February 2002.

⁴ Seven transgender cases are included in male category.

Given our tests of recruitment and enrollment bias, this possibility seems least likely. We suspect that the first two explanations – a changing epidemiology, and selective use of services by white PLWHA – are the most likely causes. Persons living with HIV/AIDS who receive their medical care from private physicians and who have no need for social services would not be included in the CHAIN agency based client sampling frame. Given these considerations, it would seem most appropriate to characterize the newly recruited CHAIN Study Cohort as representative of persons living with HIV or AIDS in New York City who are receiving publically-funded services.

APPENDIX: CHAIN Recruitment Protocol

Protocol for Sequential Enrollment into NYC CHAIN Project

1. The Tri-County CHAIN study staff will work with agency executives, managers, and staff to identify optimal times and places for recruiting patients and clients into the CHAIN study. Agencies will identify an Agency Coordinator(s) to serve as liaisons with NYC CHAIN study staff. CHAIN staff and agency personnel will identify one or more potential “recruitment periods” in which to enroll clients in to the study. A recruitment period is defined as a block of time, from several hours to a full day, in which CHAIN staff will be present at a site to enroll clients in to the study.
2. The Agency Coordinator or designee (e.g., social worker, triage nurse, case manager) will enumerate all HIV-positive adults who present at the recruitment site during a recruitment period by completing the **NYC CHAIN Recruitment Roster**. This roster includes such patient or client information as a patient ID, age group, gender, and race/ethnicity.
3. Every patient or client present during a recruitment period will be provided with a **NYC CHAIN Invitation**. This invitation will include a basic introduction to the NYC CHAIN study as well as ways of entering the study.
4. During the individual’s clinical encounter the Agency Coordinator or the provider will briefly introduce the NYC CHAIN Study and read the **Permission to Contact** form. This permission allows CHAIN staff to speak directly with the individual about participating in the study. It does not obligate the individual to participate in any way. The individual will sign the Permission to Contact form. One copy remains with the patient, the other copy is collected by CHAIN staff.
5. After signing the Permission to Contact form, the client will be directed to the CHAIN site coordinator, who will determine the client’s eligibility and assure that the client has not been previously enrolled in the study. In order to be eligible, a client must be: (a) HIV positive for at least 6 months, (b) at least 20 years of age, and (c) a resident of New York City. The CHAIN site coordinator will obtain basic contact and provider information from the client and schedule an interview. If possible, interviews will be scheduled for that day at the clinic or agency (provided space is available). If the client is willing to be interviewed immediately, he or she will be introduced to the interviewer.
6. If the client consents to being contacted but leaves prior to being seen by CHAIN, then CHAIN staff will follow-up with the individual as soon as possible, preferably within 24 hours.
7. At the end of each recruitment period at the site, the CHAIN site coordinator will review the NYC CHAIN Recruitment Roster with the Agency Coordinator to make sure that the roster is complete (i.e., all numbers should be accounted for, in that the total number rostered should match the total number of HIV-positive patients or clients seen that day;

furthermore, all clients who consented to be contacted should be on the roster).

Protocol for Random Enrollment into NYC CHAIN Project

1. Agency will provide a list, either paper-based or electronic, of all Client ID's of individuals who are (a) active clients, (b) diagnosed with HIV at least six months, (c) over 20 years old, and (d) residents of New York City.
2. CHAIN will randomly select a proportional list of clients to be recruited.
3. CHAIN will generate a Recruitment Roster with several additional contact fields (process: Contact attempted, Contact made, Accept/refusal, Contact mode [in person, by phone], Ineligible).
4. Agency Coordinator will contact all sampled clients, report on recruitment progress, replace ineligible or refusals as necessary.
5. CHAIN staff will review status of recruitment and maintain a Recruitment Process Log.
6. If a sampled client consents to contact (using Permission to Contact form, which may have verbal agreement as noted by Agency Coordinator), Agency Coordinator will fax consent and contact information to CHAIN.
7. CHAIN will then process the case – make contact, check for eligibility and duplication, and schedule the interview.