



C.H.A.I.N. REPORT

Tri-County CHAIN

Report 2002-1

The Tri-County Cohort: Demographics & Other Characteristics

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Introduction

Assembling a representative cohort of HIV+ adults in Westchester, Rockland, and Putnam counties presents a number of challenges, many of which are described in our Field Notes (Tri-County CHAIN Report 2002-4). If the cohort is truly representative, then researchers and readers can view the experiences and opinions of these 398 individuals as an accurate mirror for all HIV+ adults in care who are living in the Tri-County region.

Certainly there are several groups who are, by definition, missing from the cohort. Those individuals living in the three counties who do not know their serostatus are not included, nor are those who know their HIV status but who have not yet engaged any medical care or HIV-related social services. Lastly, those individuals who are in care in New York City or other areas outside of Tri-County, or who go to private medical providers and have no need for any other supportive or social services, would likewise not be sampled for this cohort.

What the Tri-County cohort *does* represent is a picture of the people involved in the HIV care system in the three counties. And since policymakers, providers, consumers, and advocates are generally most interested in the systems of care over which they have influence, then this cohort provides a window in to the lives of people engaging in this system.

For this specific report we have compared the Tri-County cohort at baseline with two similar cohorts that we have recruited – a New York City cohort we recruited in 1994-1995, and a NYC cohort recruited in 1998. The New York City arm of the CHAIN study is presently enrolling a new cohort of 700 individuals in to the project, and comparative data on this group should be available sometime next year. We have been careful to ask a core set of the same questions of all these CHAIN cohorts, so that their responses and individual characteristics can be equitably compared.

This report describes a number of characteristics of the baseline cohort – socio-demographics, economic resources, family & household characteristics, HIV diagnosis and early medical care, current health status, and risks, among others. The two to three hour survey includes over 850 items, and provides a comprehensive quantitative profile of the people who have participated. A word of caution is in order, though, regarding those tables and cells with “small numbers.” Because the population of people living with HIV in these three counties is relatively small (perhaps only 1,500 - 2,000 people in the system of care), the cohort of 398 representative individuals cannot be subdivided endlessly without losing its meaning. When the groups being compared, such as men and women, or people living in urban versus suburban/rural areas, have at least 50 individuals in each group, then the comparisons may be statistically valid. With smaller numbers, the percentages may be skewed and it is difficult to ascertain true group differences. Wherever possible, we have annotated the numbers in the tables with asterisks indicating their statistical significance.

Key Findings

- The Tri-County cohort is reasonably similar to the racial/ethnic composition of People Living With AIDS in the area, when considered by gender. There are some differences, in that black men represent a slightly smaller proportion of the CHAIN cohort than they do in the AIDS epidemiology, and Latino men represent a slightly larger proportion among the CHAIN male respondents than they do in AIDS epidemiology. Based on the analyses we reported on in the Field Notes, though, we recruited people in the same proportions they were represented at the agencies providing care. This suggests that either the epidemiology of AIDS is changing in the region, or that the people most likely to be “unconnected” to care are non-Hispanic African American men.
- Surprisingly, there were very few individuals under 35 years old (12%). Subsequent analyses of individuals in their 20's revealed even smaller numbers than expected. As was observed in the finding above, either the epidemiology is shifting or this particular group is not engaged in care in the Tri-County region.
- High proportion of people who report that fairly often they don't have enough money for clothing (29%), utilities (17%), food (18%) or rent (15%).
- Approximately 55% of the cohort has been or is currently married, and 35% report having children under 18 years old in the household.
- The value of HIV medications may be apparent in the discrepancy between the proportion of the cohort with clinically-diagnosed AIDS (62%) and the proportion with t-cells below 200 (20%), although it should be noted that a large proportion of respondents did not know their t-cell counts (12%).
- A large number of respondents – 18% – reported that they had a sibling who was HIV-positive.
- There are clear socioeconomic and racial/ethnic differences between the urban and suburban / rural respondents. Suburban respondents are more likely to be white, stably housed, and non-drug users than their urban counterparts.
- In many ways, the Tri-County cohort of 2002 resembles the New York City cohort of 1994-1995 rather than the New York City cohort of 1998. The current Tri-County cohort is of slightly higher socioeconomic status, more highly educated, and more likely to be composed of individuals reporting themselves as white race/ethnicity when compared with the New York City cohort of 1998.

Table 1. Sample Representativeness, Tri-County AIDS Cases and CHAIN Cohort

	Tri-County Surviving AIDS Cases, 12/31/00 ¹		Tri-County CHAIN Cohort	
	Male	Female	Male	Female
n	1429	748	204	194
<i>White</i>	27%	18%	27%	14%
<i>Black</i>	50%	60%	43%	57%
<i>Latino</i>	22%	22%	29%	26%
<i>Other</i>	<1%	<1%	1%	3%

¹ Source: New York State Department of Health, Bureau of HIV/AIDS Epidemiology

Table 2. Sociodemographic Characteristics (Tri-County CHAIN data, 2001-2002)

	Tri-County 2001-02		NYC CHAIN, Baseline 1994-95		NYC CHAIN, Refresher 1998	
	n	%	n	%	n	%
FULL COHORT	398	100	700	100%	268	100%
Gender						
<i>Male</i>	204	51%	438	63%	139	52%
<i>Female</i>	194	49%	262	37%	129	48%
Race/Ethnicity						
<i>White, non-Hispanic</i>	82	21%	119	17%	26	10%
<i>Black, non-Hispanic</i>	197	50%	353	50%	168	63%
<i>Hispanic/Latino</i>	110	28%	221	32%	70	26%
<i>Other</i>	9	2%	7	1%	4	1%
Age categories						
<i>20-34 years old</i>	48	12%	224	32%	67	25%
<i>35-49 years old</i>	249	63%	414	59%	165	62%
<i>50+ years old</i>	101	25%	62	9%	36	13%
Residential characteristic						
<i>Urban Westchester</i>	213	54%				
<i>Suburban Westchester & Putnam</i>	112	28%				
<i>Rockland</i>	73	18%				
Ancestry						
<i>Foreign-Born</i>	66	17%	131	19%	74	28%
<i>US-Born</i>	332	83%	569	81%	194	72%
Years in US among foreign-born (n=66)						
<i>Less than 3 years</i>	1	2%	3	3%	5	7%
<i>3-8years</i>	15	23%	12	11%	12	18%
<i>> 9 years</i>	50	75%	99	87%	51	75%

Table 3. Economic Resources, (Tri-County CHAIN data, 2001-2002)

	Tri-County 2001-02		NYC CHAIN, Baseline 1994-95		NYC CHAIN, Refresher 1998	
	n	%	n	%	n	%
FULL COHORT	398	100%	700	100%	268	100
Educational attainment (n=377)						
<i>Less than high school</i>	140	37%	233	33%	125	49%
<i>High school graduate</i>	158	42%	298	43%	104	39%
<i>Some college</i>	44	12%	93	13%	20	7%
<i>College graduate</i>	26	7%	56	8%	14	5%
<i>Post-graduate</i>	9	2%	17	2%	4	2%
Employment status (n=396)						
<i>Employed full-time</i>	55	14%	70	10%	17	6%
<i>Employed part-time</i>	50	13%	100	14%	23	9%
<i>Not employed</i>	289	73%	529	76%	228	85%
<i>Volunteer</i>	2	1%				
Annual household income (n=396)						
<i><\$10,000</i>	201	51%	359	51%	197	74%
<i>\$10,000 - \$14,999</i>	66	17%	111	16%	31	12%
<i>\$15,000 - \$24,999</i>	55	14%	98	14%	19	7%
<i>\$25,000 - \$44,999</i>	47	12%	60	9%	10	4%
<i>\$45,000+</i>	21	5%	32	5%	7	3%
<i>Refused</i>	6	2%	38	5%	4	1%
Fairly often or very often, respondent did not have enough money in the household for... (n=382)						
<i>Rent</i>	56	15%	117	17%	23	9%
<i>Utilities</i>	65	17%	115	17%	25	10%
<i>Food</i>	67	18%	150	22%	39	15%
<i>Medical care</i>	21	6%	67	10%	15	6%
<i>Clothing</i>	111	29%	210	30%	55	21%
<i>Recreational activities</i>	151	40%	265	38%	55	21%

* p < .05

** p < .01

*** p < .001

Table 4. Family & Household Characteristics (Tri-County CHAIN data, 2001-2002)

	Tri-County 2001-02		NYC CHAIN, Baseline 1994-95		NYC CHAIN, Refresher 1998	
	n	%	n	%	n	%
FULL COHORT	398	100%	700	100%	268	100%
Current marital status						
<i>Married</i>	76	19%	71	10%	46	17%
<i>Separated</i>	33	8%	76	11%	36	13%
<i>Divorced</i>	72	18%	92	13%	42	16%
<i>Widowed</i>	39	10%	41	6%	11	4%
<i>Never married</i>	178	45%	418	60%	133	50%
Current partner relationship						
<i>Not in partner relationship</i>	193	48%	374	53%	133	50%
<i>Living with spouse or partner</i>	119	30%	153	22%	58	22%
<i>Non-coresident partner relationship</i>	86	22%	173	25%	77	29%
Number of children under 18 in household						
<i>None</i>	258	65%	545	78%	193	72%
<i>1 - 3</i>	129	32%	138	20%	68	25%
<i>4 or more</i>	11	3%	17	2%	7	3%
Current living situation						
<i>Own or rent an apartment or house</i>	316	79%	540	77%	184	69%
<i>"Doubled up" with friend or relative</i>	28	7%	43	6%	15	6%
<i>Welfare hotel or motel</i>	9	2%	42	6%	12	4%
<i>Specialized AIDS housing</i>	21	5%	17	2%	27	10%
<i>Drug treatment program housing</i>	4	1%	18	3%	19	7%
<i>Shelter, street, or other public place</i>	8	2%	29	4%	8	3%
<i>Hospital, nursing home, hospice</i>	8	2%	6	1%	0	0%
<i>Jail, prison, halfway house</i>	2	1%	0	0%	0	0%
<i>Other</i>	2	1%	4	1%	3	1%
Stability of housing in past 6 months						
<i>Stably housed</i>	328	82%	440	63%	186	69%
<i>Unstably housed at least one night</i>	70	18%	260	37%	82	31%

* p < .05

** p < .01

*** p < .001

Table 5. HIV Diagnosis & Early Medical Care (Tri-County CHAIN data, 2001-2002)

	Tri-County 2001-02		NYC CHAIN, Baseline 1994-95		NYC CHAIN, Refresher 1998	
	n	%	n	%	n	%
FULL COHORT	398	100%	700	100%	268	100%
Year of HIV or AIDS diagnosis (n=397)						
<i>1980-1989</i>	92	23%	228	33%	14	5%
<i>1990-1995</i>	164	41%	472	67%	123	46%
<i>1996-2000</i>	115	29%			131	49%
<i>2001-2002</i>	26	7%				
Time between diagnosis and HIV medical care (n=386)						
<i>Less than 3 months</i>	302	78%	524	77%	219	82%
<i>Greater than 3 months</i>	84	22%	154	23%	49	18%
Health at time of initial HIV medical care (n=383)						
<i>No medical problems</i>	197	51%	335	50%	115	45%
<i>Minor medical problems</i>	76	20%	166	25%	67	26%
<i>Major medical problems</i>	110	29%	173	26%	74	29%
Life circumstances at time of initial HIV diagnosis (n=381)						
<i>Married or in a regular relationship</i>	264	69%			129	48%
<i>Drinking a lot</i>	135	35%			66	25%
<i>Using drugs regularly</i>	171	45%			105	39%
<i>Had adequate medical insurance</i>	264	69%			129	48%

* p < .05

** p < .01

*** p < .001

Table 6. Current Health Status (Tri-County CHAIN data, 2001-2002)

	Tri-County 2001-02		NYC CHAIN, Baseline 1994-95		NYC CHAIN, Refresher 1998	
	n	%	n	%	n	%
FULL COHORT	398	100%	700	100%	268	100%
Most recent t-cell count						
<i>Greater than 500 copies per mm³</i>	132	33%	136	19%	72	27%
<i>201-500 copies per mm³</i>	139	35%	219	31%	105	39%
<i>Less than 200 copies per mm³</i>	81	20%	276	40%	64	24%
<i>Missing/Don't know</i>	46	12%	68	10%	26	10%
Stage of HIV infection						
<i>Asymptomatic HIV</i>	86	22%	157	22%	76	28%
<i>Symptomatic HIV</i>	66	17%	101	14%	46	17%
<i>Clinically-diagnosed AIDS</i>	246	62%	442	63%	146	54%
Current use of antiretroviral therapy						
<i>None</i>	105	26%	638	91%	67	25%
<i>Non-HAART therapy</i>	110	28%	62	9%	71	26%
<i>HAART</i>	183	46%	0	0%	130	49%
Family members with HIV						
<i>Spouse/partner</i>	33	8%	63	9%	22	8%
<i>Non live-in spouse/partner</i>	31	8%	65	10%	29	11%
<i>Siblings</i>	72	18%			38	14%

* p < .05

** p < .01

*** p < .001

Table 7. Risk Characteristics (Tri-County CHAIN data, 2001-2002)

	Tri-County 2001-02		NYC CHAIN, Baseline 1994-95		NYC CHAIN, Refresher 1998	
	n	%	n	%	n	%
FULL COHORT	398	100%	700	100%	268	100%
HIV risk						
<i>MSM</i>	62	16%	156	22%	36	13%
<i>Problem drug use</i>	164	41%	309	44%	95	35%
<i>MSM + problem drug use</i>	19	5%	73	10%	12	5%
<i>Heterosexual and other</i>	153	38%	162	23%	125	47%
Sexual history (n=393)						
<i>Exclusively heterosexual</i>	265	67%	403	58%	198	74%
<i>Men who have ever had sex with men</i>	81	21%	230	33%	47	18%
<i>Women who have ever had sex with women</i>	47	12%	65	9%	22	8%
Drug use						
<i>Never used drugs</i>	137	34%	154	22%	85	32%
<i>Former drug use</i>	196	49%	318	45%	133	50%
<i>Current drug use</i>	65	16%	228	33%	50	19%
Injection drug use						
<i>Never injected drugs</i>	254	64%	401	57%	180	67%
<i>Ever injected drugs</i>	144	36%	297	43%	88	33%
Mental health component summary score (MCS)						
<i><37.0 (very low mental health score_</i>	131	33%	250	36%	86	32%
<i>37.0 - 42.0 (low mental health score)</i>	57	14%	102	15%	30	11%
<i>>42.0 (average mental health score)</i>	210	53%	338	49%	152	57%
Dually-diagnosed individuals (Low mental health & drug use)						
<i><37.0 MCS + current drug use</i>	28	7%	96	14%	22	8%

* p < .05

** p < .01

*** p < .001

Table 8. Presentation Categories and Risk by Race/Ethnicity & Gender
(Tri-County CHAIN data, 2001-2002)

Characteristic ¹	Total	Race/Ethnicity				Gender	
		White	Black	Latino	Other	Male	Female
FULL COHORT	398	82	197	110	9	204	194
HIV Risk							
<i>MSM</i>	16%	38%	8%	14%	0%	30%	na
<i>Problem Drug Use</i>	41%	30%	44%	45%	33%	42%	41%
<i>MSM + Problem Drug Use</i>	5%	2%	4%	7%	22%	9%	na
<i>Heterosexual & Other</i>	38%	29%	45%	34%	44%	19%	59%
Geography							
<i>Urban Westchester</i>	54%	24%***	63%	59%	33%	61%**	46%
<i>Suburban Westchester & Putnam</i>	28%	46%	21%	26%	44%	22%	34%
<i>Rockland</i>	18%	29%	16%	15%	22%	17%	20%
Housing Stability							
<i>Stably Housed</i>	82%	89%	80%	80%	100%	81%	84%
<i>Unstably Housed or Doubled-Up</i>	18%	11%	20%	20%	0%	19%	16%
Substance Abuse							
<i>Never used drugs</i>	34%	39%	31%	35%	44%	29%	40%
<i>Former drug user</i>	49%	52%	51%	44%	44%	53%	45%
<i>Current drug user</i>	16%	9%	17%	21%	11%	18%	15%

* p < .05

** p < .01

*** p < .001

DATA & METHODOLOGY

Background

The purpose of the Tri-County CHAIN Study is to assess the impact of the full continuum of services delivered to HIV positive persons living in Westchester, Rockland, and Putnam counties, and to identify unmet needs for services. The interviews for this study present quantitative profiles of respondents' needs for health and human services, their encounters with health care and social service organizations, their satisfaction with services, and their current health status. The people who participated in the baseline survey are being re-interviewed at approximately annual intervals.

In 2001, the Planning and Evaluation Subcommittee of the New York HIV Health and Human Services Planning Council authorized the Westchester Department of Health (WDOH) and Medical and Health Research Association of New York City, Inc. (MHRA), to develop a longitudinal study of Tri-County residents living with HIV similar to the existing New York City longitudinal project. The Mailman School of Public Health at Columbia University was contracted by MHRA to conduct the survey and carry out analyses of survey data.

Sample Design

One of the major goals of this study is to assemble a cohort that is broadly representative of all Tri-County residents living with HIV. The simplest strategy for achieving this goal, drawing a random household sample, is not feasible because persons with HIV are relatively rare in the population, and many are, for good reason, reluctant to disclose their HIV seropositive status. Therefore, to approximate the ideal sample, several sampling strategies were developed.

Agency-based random recruitment

The first strategy involved sampling clients and patients drawn from rosters of agencies providing medical and social services to persons living with HIV. To achieve a representative sample of clients, a two-step sampling procedure was followed. The first step involved identifying all health and social service agencies in the Tri-County region providing HIV services to at least ten clients. Since there were only 32 agencies or sites of service identified during this procedure it was determined to sample clients from the entire universe of agencies rather than sampling from this list.

The second step involved recruiting a random sample of clients from each participating agency. Random selection of clients was intended to minimize the tendency of agencies to refer their most satisfied and/or easier-to-reach clients. Each agency that agreed to help recruit participants assembled a list containing anonymous identifiers for all persons living with HIV who had contact with the agency within a year of constructing the list, and also designated one of their employees to act as a liaison/coordinator between the Columbia team and the sampled individuals. In order to be eligible for the study, individuals had to be residents of Westchester, Rockland, or Putnam counties, at least 20 years of age, and HIV-positive for at least 6 months. The Columbia team randomly drew between 15 and 25 identifiers from each agency list. The identifiers were returned to the agency coordinators who made initial contact with the sampled clients to explain the purpose of the study and to determine if they were willing to participate.

Only then did the agency coordinator send the names, addresses and telephone numbers of consenting clients to the Columbia field staff to schedule and conduct the interviews.

Agency-based sequential enrollment

In addition the agency-based random recruitment we employed a sequential enrollment strategy, in which all clients present at a given site during a specific time period were invited to participate in the study. Such a strategy could only be used at sites with sufficient numbers of clients (nominally 10-20 clients, at a minimum), who would be present for such a recruitment. The Tri--County CHAIN Field Director would coordinate recruitment with an agency coordinator from the participating agency. The agency would maintain a roster of all eligible clients present during the recruitment period so that a later analysis could be conducted to determine if CHAIN recruited most (or all) eligible clients present, and if those recruited were reasonably representative of all eligible clients present.

Interview Schedule

All interviews are conducted in person by trained interviewers. The major topics covered during the interviews include (1) initial encounter with the health care delivery system, (2) need for services, (3) access, utilization and satisfaction with health and social services, (4) sociodemographic characteristics of respondents, (5) informal caregiving from friends, family and volunteers, and (6) quality of life with respect to health status, psychological and social functioning. The interview schedule was developed based upon a listing of questions under each of these broader tropics that was circulated to the Planning and Evaluation Subcommittee, WDOH and MHRA. Whenever possible, interview questions were taken from earlier surveys administered to persons living with HIV and were designed to match questions asked of participants in the New York City CHAIN study. In particular, information on use of health and social services was obtained using questions developed for a federally funded study of AIDS service utilization. Health status was assessed using survey questions that have well established psychometric properties (such as the Medical Outcomes Survey scale, and indices measuring health locus of control, and self-efficacy) and which have been widely administered to HIV positive populations. The interview takes between two and three hours to complete, dependent upon issues relevant to each client's unique service needs. Most interviews were conducted in English, although fifteen were conducted in Spanish and six in Creole. Sixteen of the three hundred and ninety-eight interviews were conducted on an abbreviated survey (a "short form") that captures most of the variables used in analyses. We have tried to note the appropriate denominator in the tables in which the item being reported was not a part of the abbreviated form. These short forms were primarily used when respondents were physically or mentally unable to complete the entire survey.