



Report 2004-3

Baseline Summary of NYC II Cohort

- I. Demographics & Other Characteristics
- II. Health Status and Health Service Use
- III. Needs Assessment

(N=684)

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Originally submitted July 21, 2004
Final draft submitted Jan 19, 2005
HRSA Grant # H89 HA 0015-13
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C.H.A.I.N. REPORT

ACKNOWLEDGMENTS

A Technical Review Team (TRT) provides oversight for the CHAIN Project in New York City and in the Tri-County area of Putnam, Rockland, and Westchester counties. In addition to Peter Messeri, PhD, Angela Aidala, PhD, and David Abramson, of Columbia University's Mailman School of Public Health, TRT members include Mary Ann Chiasson, DrPH, MHRA (chair); Grace Moon, NYCDOHMH Office of AIDS Policy; Susan Forlenza, MD MPH, NYCDOHMH; JoAnn Hilger, NYCDOHMH; Julie Lehane, PhD, Westchester County DOH; Jennifer Nelson, MHRA; and Ken Butler, PWA Advisory Group.

This research was made possible by grant number H89 HA 0015-13 from the US Health Resources and Services Administration (HRSA) HIV/AIDS Bureau. The CHAIN study is supported by the HIV Health and Human Services Planning Council of New York under a Title I grant of the Ryan White Comprehensive AIDS Resource Emergency Act of 1990 through the New York City Department of Health and Mental Hygiene. It is conducted under the auspices of the Medical and Health Research Association of New York City, Inc, and in Tri-County under the Westchester Department of Health. Its contents are solely the responsibility of the researchers and do not necessarily represent the official views of the U.S. Health Resources and Services Administration; the City of New York; Putnam, Rockland, or Westchester counties; or the Medical and Health Research Association of New York.

Introduction

Assembling a representative cohort of HIV+ adults in New York City presents a number of challenges, many of which are described in our Field Notes (CHAIN Report 2004-4). If the cohort is truly representative, then researchers and readers can view the experiences and opinions of these 684 individuals as an accurate mirror for all HIV+ adults in the public system of care in NYC.

Certainly there are several groups who are, by definition, missing from the cohort. Those individuals living in NYC 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 or who have dropped out from services¹. Lastly, those individuals who go to private medical providers and who may have no need for any other supportive or social services, would likewise not be sampled for this cohort.

What the NYC cohort *does* represent is a picture of the people involved in the “public” system of HIV care in the city. 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 new NYC cohort at baseline with three similar cohorts that we have recruited – the original New York City cohort we recruited in 1994-1995, a refresher NYC cohort recruited in 1998, and the Tri-County cohort recruited in Westchester, Rockland, and Putnam counties in 2001-2002. 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 may be 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.” When the groups being compared, 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 noted those small denominators.

Statistical tests of significance were conducted (generally chi-square analyses) to determine whether the differences between sub-groups were related to chance or were significantly associated with the sub-group characteristic. For example, if 45% of women in the cohort are on HIV medications, compared with 50% of men, the statistical test would determine whether that difference was “real” or merely a result of chance (these figures are for illustration only). If the sampling error was plus or minus 5 percentage points, than the range of women on

¹ See separate Columbia University study, Delayed Entry to HIV Care, Year 2 Final Report, Executive Summary (July 2004), A Aidala et al.

HIV medications would be from 40 - 50% and for men from 45 - 55%. Given the overlap, one could not determine whether the difference was real, or was simply the results of sampling error and a certain amount of randomness. When the data are accompanied by an asterisk in the tables, it means that the differences are significant, at either a .1, .05, .01, or .001 level. If the proportions are statistically significant at a .05 level, that means that there is a 5% chance (a 1-in-20 chance) that the range of proportions overlap. Since this is considered a remote possibility, one can assert that the differences in rates or proportions are “statistically significantly different.” A proportional difference at a .001 level (a 1-in-1000 chance of being within a similar range) would be even more remote.

Finally, because of rounding, some percentages will add up to either 99% or 101%.

A Note on Terminology

All individual characteristics that are used to distinguish people and sort them by sub-group or sub-population are based upon a respondent’s self-report. For example, if a respondent reports that her gender is “female,” that will be the way that individual is characterized, not by an interviewer’s subjective assessment. Within the HIV risk category, which does not attempt to identify the source of HIV transmission but instead to identify risk behaviors, “Problem drug use” is defined as intensive use of cocaine, crack, or heroin for three or more times a week for a period of a month or more. The “Other” category in HIV risk represents the default category, when there is no reported behavior of men having sex with men and no problem drug use behavior. Generally speaking, this represents individuals whose HIV risk may be characterized as heterosexual risk. There have been very few instances of individuals in the cohort who described blood transfusion risks.

Part I. DEMOGRAPHICS AND OTHER CHARACTERISTICS

Epidemiology

Table 1-1 illustrates the comparison of the newly recruited CHAIN cohort of 684 individuals with reported AIDS cases, more recently reported HIV non-AIDS cases, and with a duplicated count of Ryan White CARE Act-funded encounters. Whereas the original NYC cohort of 1994-1995 and the refresher cohort of 1998 tended to “look” more like AIDS epidemiology of New York City, the currently constituted cohort appears proportionally different than the population of people living with AIDS. 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. This suggests several possible explanations:

- (1) the epidemiology of HIV/AIDS is changing in New York City, such that more blacks and Latinos are becoming infected and entering the system of care, particularly when compared with people who have been living with the virus longer and who have progressed to an AIDS diagnosis; or
- (2) white individuals living with HIV/AIDS in NYC are less likely to seek care at the majority of health and social service agencies, as they did at earlier recruitment periods for CHAIN, and may be more selective in the services they need and attend; or
- (3) there are sampling issues in the CHAIN recruitment and enrollment of the new cohort such that white PLWHA do not have an equal probability of entering the cohort as do black and Latino PLWHAs.

Table 1-1. Sample Representativeness, NYC HIV/AIDS Cases and CHAIN Cohort

| | NYC Persons Living with AIDS, as of 6/30/03 ¹ | | NYC Persons 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 ³ |
| Total N | 15,753 (28%) | 39,765 (72%) | 10,104 (35%) | 18,995 (65%) | 10,765 (39%) | 16,962 (61%) | 267 (39%) | 417 (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.

³ Seven transgender cases are included in male category.

This last might include the possibility of a greater reluctance of white individuals to participate in the cohort study, or a greater reluctance to be approached by the agency coordinators who

helped facilitate the recruitment process for CHAIN. Although we do not have definitive answers as to which of these possibilities most closely represents reality, we suspect that the first two explanations – a changing epidemiology, and selective use of services by white PLWHA – are the most likely causes.

Sociodemographics (Table 1-2)

- Fewer 20-34 year old in the new cohort and more respondents over 50.
- Approximately one-quarter of the new cohort are foreign-born, but few (6%) have recently immigrated to this country. Given that AIDS surveillance data have consistently reported that approximately 11% to 12% of all newly diagnosed cases are foreign-born (as per personal correspondence from NYCDOHMH HIV Epidemiology Program), this finding of 24% being foreign-born suggests a greater likelihood among those foreign-born to be in the public system of care rather than the private system of care.

Economic characteristics (Table 1-3)

- Fewer are employed full-time than in 1998, but more are employed part-time. However, overall 84% are unemployed, compared to 76% unemployed among the 1995 cohort.
- Income is similar to 1998 cohort, with almost three-quarters of the cohort reporting an annual household income less than \$10,000.
- As with the 1998 cohort, the new cohort is less likely than the 1995 cohort to report not having enough money for rent utilities, food, medical care, clothing and recreation. Still, one out of five respondents do note that they often do not have enough money for clothing.

Family & Household (Table 1-4)

- The proportion of married and partnered individuals is similar to earlier cohorts, but fewer in the new cohort are living in household with children under 18 years old. This may be a function of the fact that the cohort is proportionally older than the earlier cohorts.
- Over one in four report a recent episode of unstable housing or being homeless at least one night in the prior six months. This does represent a decline from the 1995 cohort, when 35% reported a recent unstable housing episode.

HIV Diagnosis and Early Medical Care (Table 1-5)

- One out of four respondents in the new cohort learned their initial diagnosis in the 1980's. Only 7% have been diagnosed since 2001.
- The proportion delaying initial medical care – 28% – is higher than the 1998 or 1995 cohorts (16% and 22%, respectively).

- The new cohort is more likely than earlier cohorts to have been married at the time of initial diagnosis and to have had adequate medical insurance.
- There is a drop in the proportion of respondents who had a regular partner at the time of their diagnosis (64%) to the proportion who currently have a partner (49%), as reported in Table 1-4. This 15-point “partnership drop” is similar to that experienced by Tri-County respondents (a 17-point partnership drop), but different from the 1998 cohort (a 2-point partnership increase) or the 1995 cohort (a 9-point partnership drop).

Current Health Status (Table 1-6)

- As with 1998 cohort, slightly over half the cohort has been diagnosed with AIDS.
- The proportion of people who don’t know their T-cell counts is lower (2%) than the 1995 or 1998 cohorts (7%).
- Approximately one in five respondents have a spouse or partner living with HIV/AIDS.

Risk Characteristics (Table 1-7)

- The current cohort is composed of 20% Men who have Sex with Men, 39% Problem Drug Users (having ever used cocaine, crack, or heroin three or more times a week for a month or more, or ever injected drugs), 8% are Men who have Sex with Men and are also Problem Drug Users, and 33% fall in to the “other” risk category, which generally suggests heterosexual risk behaviors.
- Approximately half the new cohort have scored low on a standardized mental health score. 35% of the respondents scored “very low” (below 37.0 on the Medical Outcome Study mental health component summary score) and 12 % scored “low” (below 42.0 but above 37.0). These proportions are similar to earlier cohorts. 10% of the new cohort are dually diagnosed with both very low mental health score and current drug use.

Risk by Race and Gender (Table 1-8)

- White respondents are more likely to be in the MSM risk category, whereas black respondents are more likely to be in the Heterosexual/Other risk category.
- White respondents are more likely to live in Manhattan, black respondents to live in Brooklyn, and Latino respondents to live in the Bronx.
- White respondents are more likely than other race/ethnicities in the cohort to be current drug users.
- Men are more likely than women to be unstably housed (31% versus 19%).
- Men are more likely than women to be current drug users (27% versus 19%).

Table 1-2. Sociodemographic Characteristics

| | NYC CHAIN New Baseline 2002-04 | | NYC CHAIN Original Baseline 1994-95 | | NYC CHAIN Refresher Baseline 1998 | | Tri-County CHAIN Baseline 2001-02 | |
|-----------------------------------------------|--------------------------------------|----------|-------------------------------------------|----------|--------------------------------------------|----------|-----------------------------------------|----------|
| Total Sample | n | % | n | % | n | % | n | % |
| Gender | | | | | | | | |
| <i>Male</i> | 417 | 61% | 404 | 62% | 131 | 52% | 204 | 51% |
| <i>Female</i> | 267 | 39% | 244 | 38% | 123 | 48% | 194 | 49% |
| Race/Ethnicity | | | | | | | | |
| <i>White, non-Hispanic</i> | 59 | 9% | 114 | 18% | 25 | 10% | 82 | 21% |
| <i>Black, non-Hispanic</i> | 360 | 53% | 321 | 50% | 159 | 63% | 197 | 50% |
| <i>Hispanic/Latino</i> | 254 | 37% | 206 | 32% | 67 | 26% | 110 | 28% |
| <i>Other</i> | 11 | 2% | 7 | 1% | 3 | 1% | 9 | 2% |
| Age categories | | | | | | | | |
| <i>20-34 years old</i> | 63 | 9% | 207 | 32% | 64 | 25% | 48 | 12% |
| <i>35-49 years old</i> | 405 | 59% | 385 | 59% | 156 | 62% | 249 | 63% |
| <i>50+ years old</i> | 216 | 32% | 56 | 9% | 34 | 13% | 101 | 25% |
| Residential Borough | | | | | | | | |
| <i>Bronx</i> | 174 | 25% | 203 | 31% | 98 | 39% | | |
| <i>Brooklyn</i> | 192 | 28% | 155 | 24% | 53 | 21% | | |
| <i>Manhattan</i> | 193 | 28% | 191 | 30% | 52 | 20% | | |
| <i>Queens</i> | 94 | 14% | 63 | 10% | 28 | 11% | | |
| <i>Staten Island</i> | 31 | 5% | 34 | 5% | 23 | 9% | | |
| Live in High Need Neighborhoods* | | | | | | | | |
| <i>Yes</i> | 368 | 54% | 347 | 54% | 158 | 62% | | |
| <i>No</i> | 315 | 46% | 300 | 46% | 96 | 38% | | |
| Ancestry | | | | | | | | |
| <i>Foreign-Born</i> | 163 | 24% | 123 | 19% | 67 | 26% | 66 | 17% |
| <i>US-Born</i> | 520 | 76% | 525 | 81% | 187 | 74% | 332 | 83% |
| Years in US among foreign-born (n=149) | | | | | | | | |
| <i>Less than 3 years</i> | 9 | 6% | 3 | 3% | 5 | 7% | 1 | 2% |
| <i>3-8years</i> | 7 | 5% | 10 | 9% | 12 | 18% | 15 | 23% |
| <i>> 9 years</i> | 133 | 89% | 93 | 88% | 50 | 74% | 50 | 75% |

* High need neighborhoods have been defined by NYS AIDS Institute based upon cocaine and opioid hospital discharges, sexually transmitted diseases, teen pregnancy, and low birthweight.

Table 1-3. Economic Resources

| | NYC CHAIN New Baseline 2002-04 | | NYC CHAIN Original Baseline 1994-95 | | NYC CHAIN Refresher Baseline 1998 | | Tri-County CHAIN Baseline 2001-02 | |
|-----------------------------------------------------------------------------------------------|--------------------------------------|-------------|-------------------------------------------|-------------|-----------------------------------------|------------|-----------------------------------------|-------------|
| | n | % | n | % | n | % | n | % |
| Total Sample | 684 | 100% | 648 | 100% | 254 | 100 | 398 | 100% |
| Educational attainment | | | | | | | | |
| <i>Less than high school</i> | 258 | 39% | 210 | 32% | 118 | 46% | 140 | 37% |
| <i>High school graduate</i> | 291 | 44% | 328 | 51% | 99 | 39% | 169 | 45% |
| <i>Some college</i> | 24 | 4% | 39 | 6% | 20 | 8% | 33 | 9% |
| <i>College graduate</i> | 47 | 7% | 54 | 8% | 13 | 5% | 26 | 7% |
| <i>Post-graduate</i> | 35 | 5% | 17 | 3% | 4 | 2% | 9 | 2% |
| Employment status | | | | | | | | |
| <i>Employed full-time</i> | 20 | 3% | 67 | 10% | 17 | 7% | 55 | 14% |
| <i>Employed part-time</i> | 85 | 12% | 90 | 14% | 22 | 9% | 50 | 13% |
| <i>Not employed</i> | 573 | 84% | 490 | 76% | 215 | 85% | 289 | 73% |
| <i>Volunteer</i> | 5 | 1% | | | | | 2 | 1% |
| Annual household income | | | | | | | | |
| <i><\$10,000</i> | 486 | 73% | 325 | 50% | 185 | 73% | 201 | 51% |
| <i>\$10,000 - \$14,999</i> | 88 | 13% | 108 | 17% | 30 | 12% | 66 | 17% |
| <i>\$15,000 - \$24,999</i> | 43 | 6% | 92 | 14% | 18 | 7% | 55 | 14% |
| <i>\$25,000 - \$44,999</i> | 32 | 5% | 56 | 9% | 10 | 4% | 47 | 12% |
| <i>\$45,000+</i> | 10 | 2% | 31 | 5% | 7 | 3% | 21 | 5% |
| <i>Refused/Don't Know</i> | 5 | 1% | 36 | 6% | 4 | 2% | 6 | 2% |
| Fairly often/ very often, respondent did not have enough money in the household for... | | | | | | | | |
| <i>Rent</i> | 56 | 9% | 102 | 16% | 21 | 8% | 56 | 15% |
| <i>Utilities</i> | 73 | 12% | 103 | 16% | 22 | 9% | 65 | 17% |
| <i>Food</i> | 80 | 13% | 129 | 20% | 32 | 13% | 67 | 18% |
| <i>Medical care</i> | 13 | 2% | 47 | 7% | 8 | 3% | 21 | 6% |
| <i>Clothing</i> | 133 | 22% | 188 | 29% | 48 | 19% | 111 | 29% |
| <i>Recreational activities</i> | 180 | 29% | 245 | 38% | 50 | 20% | 151 | 40% |

Table 1-4. Family & Household Characteristics

| | NYC CHAIN New Baseline 2002-04 | | NYC CHAIN Original Baseline 1994-95 | | NYC CHAIN Refresher Baseline 1998 | | Tri-County CHAIN Baseline 2001-02 | |
|-------------------------------------------------|--------------------------------------|------|----------------------------------------------|------|--------------------------------------------|-----|-----------------------------------------|------|
| Total Sample | n | % | n | % | n | % | n | % |
| | 684 | 100% | 648 | 100% | 254 | 100 | 398 | 100% |
| Current marital status | | | | | | | | |
| <i>Married</i> | 66 | 10% | 67 | 10% | 42 | 17% | 76 | 19% |
| <i>Separated</i> | 62 | 9% | 66 | 10% | 34 | 13% | 33 | 8% |
| <i>Divorced</i> | 83 | 12% | 85 | 13% | 42 | 17% | 72 | 18% |
| <i>Widowed</i> | 69 | 10% | 37 | 6% | 11 | 4% | 39 | 10% |
| <i>Never married</i> | 403 | 59% | 392 | 61% | 125 | 49% | 178 | 45% |
| Current partner relationship | | | | | | | | |
| <i>Not in partner relationship</i> | 351 | 51% | 336 | 52% | 120 | 47% | 193 | 48% |
| <i>Living with spouse or partner</i> | 138 | 20% | 149 | 23% | 52 | 20% | 119 | 30% |
| <i>Non-coresident partner relationship</i> | 195 | 29% | 163 | 25% | 82 | 32% | 86 | 22% |
| Number of children under 18 in household | | | | | | | | |
| <i>None</i> | 574 | 84% | 497 | 77% | 182 | 72% | 258 | 65% |
| <i>1 - 3</i> | 104 | 15% | 136 | 21% | 66 | 26% | 129 | 32% |
| <i>4 or more</i> | 6 | 1% | 15 | 2% | 6 | 2% | 11 | 3% |
| Current living situation | | | | | | | | |
| <i>Own or rent an apartment or house</i> | 519 | 76% | 513 | 79% | 177 | 70% | 316 | 79% |
| <i>“Doubled up” with friend or relative</i> | 25 | 4% | 39 | 6% | 15 | 6% | 28 | 7% |
| <i>Welfare hotel or motel</i> | 58 | 8% | 41 | 6% | 12 | 5% | 9 | 2% |
| <i>Specialized AIDS housing</i> | 33 | 5% | 16 | 2% | 27 | 11% | 21 | 5% |
| <i>Drug treatment program housing</i> | 14 | 2% | 18 | 3% | 19 | 7% | 4 | 1% |
| <i>Shelter, street, or other public place</i> | 17 | 2% | 11 | 2% | 1 | <1% | 8 | 2% |
| <i>Hospital, nursing home, hospice</i> | 15 | 2% | 6 | 1% | 0 | 0% | 8 | 2% |
| <i>Jail, prison, halfway house</i> | 2 | <1% | 0 | 0% | 0 | 0% | 2 | 1% |
| <i>Other</i> | 0 | 0% | 4 | 1% | 3 | 1% | 2 | 1% |
| Stability of housing in past 6 months | | | | | | | | |
| <i>Stably housed</i> | 502 | 73% | 423 | 65% | 183 | 72% | 328 | 82% |
| <i>Unstably Housed or Doubled-Up</i> | 66 | 10% | 101 | 16% | 49 | 19% | 48 | 12% |
| <i>Homeless at least one night</i> | 116 | 17% | 124 | 19% | 22 | 9% | 22 | 6% |

Table 1-5. HIV Diagnosis & Early Medical Care

| | NYC CHAIN New Baseline 2002-04 | | NYC CHAIN Original Baseline 1994-95 | | NYC CHAIN Refresher Baseline 1998 | | Tri-County CHAIN Baseline 2001-02 | |
|-------------------------------------------------------------------------|--------------------------------------|------|-------------------------------------------|------|-----------------------------------------|-----|-----------------------------------------|------|
| Total Sample | n | % | n | % | n | % | n | % |
| | 684 | 100% | 648 | 100% | 254 | 100 | 398 | 100% |
| Year of HIV or AIDS diagnosis | | | | | | | | |
| <i>1978-1989</i> | 166 | 24% | 217 | 33% | 14 | 6% | 92 | 23% |
| <i>1990-1995</i> | 281 | 41% | 441 | 67% | 117 | 46% | 164 | 41% |
| <i>1996-2000</i> | 191 | 28% | | | 123 | 48% | 115 | 29% |
| <i>2001-2003</i> | 46 | 7% | | | | | 26 | 7% |
| Time between diagnosis and HIV medical care | | | | | | | | |
| <i>Less than 3 months</i> | 491 | 72% | 504 | 78% | 214 | 84% | 302 | 78% |
| <i>Greater than 3 months</i> | 193 | 28% | 144 | 22% | 40 | 16% | 84 | 22% |
| Health at time of initial HIV medical care | | | | | | | | |
| <i>No medical problems</i> | 339 | 50% | 321 | 50% | 113 | 45% | 197 | 51% |
| <i>Minor medical problems</i> | 198 | 29% | 156 | 24% | 67 | 26% | 76 | 20% |
| <i>Major medical problems</i> | 148 | 21% | 165 | 26% | 71 | 28% | 110 | 29% |
| Life circumstances at time of initial HIV diagnosis ¹ | | | | | | | | |
| <i>Married or in a regular relationship</i> | 435 | 64% | 255 | 57% | 123 | 49% | 264 | 69% |
| <i>Drinking a lot</i> | 275 | 40% | 166 | 37% | 60 | 24% | 135 | 35% |
| <i>Using drugs regularly</i> | 366 | 54% | 221 | 49% | 93 | 37% | 171 | 45% |
| <i>Had adequate medical insurance</i> | 485 | 71% | 255 | 57% | 129 | 48% | 264 | 69% |

¹ Questions for original cohort were asked in wave 3 (1997) and N=451.

Table 1-6. Current Health Status

| | NYC CHAIN New Baseline 2002-04 | | NYC CHAIN Original Baseline 1994-95 | | NYC CHAIN Refresher Baseline 1998 | | Tri-County CHAIN Baseline 2001-02 | |
|---------------------------------------------------|--------------------------------------|------|-------------------------------------------|------|--------------------------------------------|-----|--------------------------------------------|------|
| | n | % | n | % | n | % | n | % |
| Total Sample | 684 | 100% | 648 | 100% | 254 | 100 | 398 | 100% |
| Most recent t-cell count | | | | | | | | |
| <i>Greater than 500 copies per mm³</i> | 214 | 31% | 126 | 19% | 71 | 28% | 132 | 33% |
| <i>201-500 copies per mm³</i> | 302 | 44% | 210 | 32% | 102 | 40% | 139 | 35% |
| <i>Less than 200 copies per mm³</i> | 156 | 23% | 269 | 42% | 64 | 25% | 81 | 20% |
| <i>Missing/Don't know</i> | 12 | 2% | 43 | 7% | 17 | 7% | 46 | 12% |
| Stage of HIV infection | | | | | | | | |
| <i>Asymptomatic HIV</i> | 223 | 33% | 128 | 20% | 68 | 27% | 86 | 22% |
| <i>Symptomatic HIV</i> | 85 | 13% | 93 | 14% | 42 | 17% | 66 | 17% |
| <i>Clinically-diagnosed AIDS</i> | 373 | 55% | 427 | 66% | 132 | 57% | 246 | 62% |
| Current use of antiretroviral therapy | | | | | | | | |
| <i>None</i> | 162 | 24% | 586 | 90% | 54 | 21% | 92 | 23% |
| <i>Non-HAART Combination therapy</i> | 82 | 12% | 62 | 10% | 68 | 27% | 254 | 13% |
| <i>HAART</i> | 440 | 64% | 0 | 0% | 132 | 52% | 50 | 64% |
| Family members with HIV | | | | | | | | |
| <i>Live-in spouse/partner</i> | 41 | 6% | 61 | 9% | 21 | 8% | 33 | 8% |
| <i>Non live-in spouse/partner</i> | 103 | 15% | 58 | 9% | 28 | 11% | 31 | 8% |
| <i>Children under 18 years old</i> | 24 | 4% | 59 | 9% | 8 | 3% | - | - |

Table 1-7. Risk Characteristics

| | NYC CHAIN New Baseline 2002-04 | | NYC CHAIN Original Baseline 1994-95 | | NYC CHAIN Refresher Baseline 1998 | | Tri-County CHAIN Baseline 2001-02 | |
|------------------------------------------------------------------------|--------------------------------------|------|-------------------------------------------|------|--------------------------------------------|-----|--------------------------------------------|------|
| Total Sample | n | % | n | % | n | % | n | % |
| | 684 | 100% | 648 | 100% | 254 | 100 | 398 | 100% |
| HIV risk | | | | | | | | |
| <i>MSM</i> | 136 | 20% | 150 | 23% | 36 | 14% | 62 | 16% |
| <i>Problem drug use</i> | 269 | 39% | 275 | 42% | 84 | 33% | 164 | 41% |
| <i>MSM + problem drug use</i> | 53 | 8% | 67 | 10% | 11 | 4% | 19 | 5% |
| <i>Heterosexual and other</i> | 226 | 33% | 156 | 24% | 123 | 48% | 153 | 38% |
| Sexual history | | | | | | | | |
| <i>Exclusively heterosexual</i> | 399 | 61% | 368 | 57% | 186 | 74% | 265 | 67% |
| <i>Men who have ever had sex with men</i> | 192 | 29% | 219 | 34% | 46 | 18% | 81 | 21% |
| <i>Women who ever had sex with women</i> | 61 | 9% | 60 | 9% | 21 | 8% | 47 | 12% |
| Drug use | | | | | | | | |
| <i>Never used drugs</i> | 181 | 26% | 149 | 23% | 85 | 33% | 137 | 34% |
| <i>Former drug use</i> | 340 | 50% | 307 | 47% | 131 | 52% | 196 | 49% |
| <i>Current drug use</i> | 163 | 24% | 192 | 30% | 38 | 15% | 65 | 16% |
| Injection drug use | | | | | | | | |
| <i>Never injected drugs</i> | 450 | 66% | 380 | 59% | 177 | 70% | 254 | 64% |
| <i>Ever injected drugs</i> | 234 | 34% | 268 | 41% | 77 | 30% | 144 | 36% |
| Mental health component summary score (MCS) | | | | | | | | |
| <i><37.0 (very low mental health score)</i> | 260 | 35% | 227 | 35% | 77 | 30% | 131 | 33% |
| <i>37.0 - 42.0 (low mental health score)</i> | 83 | 12% | 95 | 15% | 29 | 11% | 57 | 14% |
| <i>>42.0 (average mental health score)</i> | 351 | 53% | 318 | 50% | 148 | 58% | 210 | 53% |
| Dually-diagnosed individuals (Low mental health & drug use) | | | | | | | | |
| <i><37.0 MCS + current drug use</i> | 69 | 10% | 78 | 12% | 15 | 6% | 28 | 7% |

Table 1-8. Presentation Categories and Risk by Race/Ethnicity & Gender

| Characteristic | Total N | Race/Ethnicity | | | | Gender | |
|----------------------------------------|------------|----------------|-------|--------|--------------------|--------|-------|
| | | White | Black | Latino | Other ¹ | Female | Male |
| Total Sample | 684 | 59 | 360 | 254 | 11 | 267 | 417 |
| HIV Risk | | | | | | | |
| <i>MSM</i> | 20% | 36% | 16% | 21% | (4)** | - | 33% |
| <i>Problem Drug Use</i> | 39% | 34% | 40% | 41% | (3) | 42% | 38% |
| <i>MSM + Problem Drug Use</i> | 8% | 12% | 6% | 9% | (0) | - | 13% |
| <i>Heterosexual & Other</i> | 33% | 19% | 38% | 29% | (4) | 58% | 17% |
| Borough | | | | | | | |
| <i>Bronx</i> | 25% | 15% | 24% | 30% | (3)** | 25% | 26% |
| <i>Brooklyn</i> | 28% | 20% | 34% | 22% | (1) | 32% | 26% |
| <i>Manhattan</i> | 28% | 51% | 25% | 27% | (3) | 25% | 30% |
| <i>Queens</i> | 14% | 10% | 12% | 16% | (4) | 14% | 14% |
| <i>Staten Island</i> | 5% | 3% | 4% | 6% | (0) | 4% | 5% |
| Live in High Need Neighborhoods | | | | | | | |
| <i>Yes</i> | 56% | 40% | 56% | 55% | (6) | 56% | 53% |
| <i>No</i> | 46% | 60% | 44% | 45% | (3) | 44% | 47% |
| Housing Stability | | | | | | | |
| <i>Stably Housed</i> | 73% | 80% | 75% | 70% | (5)* | 80% | 69%** |
| <i>Unstably Housed or Doubled-Up</i> | 10% | 5% | 9% | 12% | (0) | 9% | 10% |
| <i>Homeless at least one night</i> | 17% | 15% | 16% | 18% | (6) | 10% | 21% |
| Substance Abuse | | | | | | | |
| <i>Never used drugs</i> | 26% | 27% | 24% | 28% | (6) | 31% | 23%* |
| <i>Former drug user</i> | 50% | 39% | 53% | 48% | (3) | 50% | 50% |
| <i>Current drug user</i> | 24% | 34% | 22% | 24% | (2) | 19% | 27% |

¹ Numbers are shown due to the small size of sample.

* p < .05

** p < .01

*** p < .001

PART II. HEALTH STATUS and HEALTH SERVICE USE

Self-Reported Health Status (Table 2-1)

- Latinos and Problem Drug Users are more likely to report their health as less than good, and also more likely to have low physical health scores on the standardized Medical Outcome Study physical component summary score.
- 14% of the new cohort says that their health is worse than it had been six months earlier, which is a much smaller proportion than the 1995 cohort, in which 35% said their health was worse than it had been six months earlier.
- Approximately one of three in the new cohort reported a recent opportunistic infection, compared to nearly one of two in the 1995 cohort.

Health services and insurance (Table 2-2)

- Women in the new cohort are more likely than men to report recent in-patient use, recent emergency room use, and are more likely to be on Medicaid.
- Black and Latino respondents are more likely than white respondents to be on Medicaid.
- Very few people in the new cohort report having no insurance (less than 1%), compared to 8% who were uninsured in the 1995 cohort.

Medical care characteristics (Table 2-3)

- Women are less likely than men to report being adherent (61% versus 79%).
- Latinos are more likely than either black or white respondents to report being adherent (80%, compared to 66% and 69%, respectively).
- White respondents are more likely than black or Latino respondents to have been diagnosed in the 1980s (44%, compared to 22% and 23%, respectively).

HAART use and patterns

- There is greater use of HAART, based on either preferred or alternative regimens from DHHS guidelines, in the new cohort than at the last wave of the original cohort (70% versus 63%). (Table 2-4)
- Unlike the older cohort, in the new cohort men are less likely to be on HAART than are women, and those individuals who reported recent bouts of unstable housing, but who were not homeless, were more likely to be on HAART. (Table 2-5)
- As with the last wave of the original cohort, approximately one-quarter of the respondents in the new cohort report having been on a drug holiday in the prior 6 months

(Table 2-6), although respondents in the new cohort were more likely to be on a drug holiday in coordination or consultation with their medical provider (35% versus 24%) (Table 2-7)

- Women are more likely than men to report recent drug holidays, and younger respondents are more likely than older respondents to report recent drug holidays. Although these trends are similar in both the newer and older cohorts, they have reached statistically significant differences in the new cohort.

Table 2-1. Self-reported Health Status by Sociodemographic Differences

| Characteristic | Gender | | Race/ Ethnicity | | | Risk Group | | | | All New cohort 2002-4 (Wave1) | Original Cohort 2000 (Wave8) | Original Cohort 1994-5 (Wave1) |
|----------------------------------------------------------------|------------------|------|-----------------|-------|--------|------------|-----|----------|--------|-------------------------------------|------------------------------------|--------------------------------------|
| | Female | Male | White | Black | Latino | MSM | PDU | MSM /PDU | Other | | | |
| (Total N=684) | 267 | 417 | 59 | 360 | 254 | 136 | 269 | 53 | 226 | 684 | 388 | 700 |
| In general, would you say your health is... | | | | | | | | | | | | |
| <i>Excellent or very good</i> | 31% ¹ | 33% | 32% | 37% | 26%* | 40% | 25% | 34% | 35%** | 32% | 33% | 33% |
| <i>Good</i> | 30% | 33% | 32% | 33% | 31% | 35% | 33% | 36% | 27% | 32% | 36% | 28% |
| <i>Fair or poor</i> | 40% | 34% | 36% | 31% | 43% | 25% | 42% | 30% | 38% | 36% | 31% | 39% |
| Compared to six months ago, is your health generally... | | | | | | | | | | | | |
| <i>Better</i> | 50% | 49% | 42% | 50% | 52%* | 46% | 48% | 56% | 52% | 49% | 35% | 34% |
| <i>Same</i> | 34% | 38% | 49% | 39% | 31% | 41% | 36% | 32% | 35% | 37% | 51% | 32% |
| <i>Worse</i> | 16% | 13% | 9% | 11% | 18% | 13% | 16% | 12% | 13% | 14% | 13% | 35% |
| Physical & Mental Health² | | | | | | | | | | | | |
| <i>Low Physical Health Score (<45)</i> | 63% | 54%* | 58% | 54% | 62%* | 41% | 68% | 51% | 58%*** | 58% | 52% | 57% |
| <i>Low Mental Health Score (<37)</i> | 36% | 35% | 42% | 29% | 42%** | 42% | 33% | 36% | 35% | 35% | 24% | 36% |
| T-cell count | | | | | | | | | | | | |
| <i>>501</i> | 24% | 22% | 19% | 19% | 28% | 18% | 24% | 25% | 23% | 23% | 37% | 19% |
| <i>201-500</i> | 43% | 45% | 47% | 46% | 41% | 48% | 44% | 47% | 42% | 44% | 44% | 31% |
| <i>≤200</i> | 31% | 32% | 31% | 33% | 30% | 32% | 30% | 28% | 33% | 31% | 19% | 40% |
| <i>Missing/Don't know</i> | 2% | 1% | 3% | 2% | 1% | 1% | 3% | 0% | 1% | 2% | 0% | 10% |
| Opportunistic infections (OI) | | | | | | | | | | | | |
| <i>OI in past 6 months</i> | 29% | 35% | 32% | 30% | 37% | 32% | 32% | 51% | 31%* | 33% | 35% | 48% |

¹ Cells represent the percentage of CHAIN participants with each characteristic who report specific clinical outcomes or health status measures, for example, the percentage of men with a t-cell count greater than 500.

² These scores are drawn from a standardized scale, the Short Form 36 of the Medical Outcomes Scale. Mental health scores below 37.0 are highly correlated with clinical psychiatric symptomatology.

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

Table 2-2. Health Services & Insurance by Sociodemographic Differences

| Characteristic ¹ | Gender | | Race/ Ethnicity | | | Risk Group | | | | All New cohort 2002-3 (Wave1) | Original Cohort 2000 (Wave8) | Original Cohort 1994-5 (Wave1) |
|-------------------------------------------------------------------------------|------------|------------|-----------------|------------|------------|------------|------------|-----------|------------|-------------------------------|------------------------------|--------------------------------|
| | Female | Male | White | Black | Latino | MSM | PDU | MSM/ PDU | Other | | | |
| (Total N=684) | 267 | 417 | 59 | 360 | 254 | 136 | 269 | 53 | 226 | 684 | 388 | 700 |
| Hospital & ER Use | | | | | | | | | | | | |
| <i>Any in-patient use</i> | 24% | 16%** | 24% | 19% | 18% | 18% | 19% | 13% | 21% | 19% | 21% | 25% |
| <i>Any ER Use</i> | 40% | 27%*** | 32% | 31% | 33% | 20% | 35% | 23% | 38%*** | 32% | 30% | 41% |
| Medical Care Characteristics | | | | | | | | | | | | |
| <i>Meets preferred practice guideline²</i> | 76% | 73% | 81% | 78% | 68%* | 72% | 72% | 72% | 78% | 74% | 70% | 70% |
| <i>Meets primary care characteristics of access and well-care³</i> | 74% | 78% | 81% | 73% | 82%* | 78% | 77% | 75% | 76% | 76% | 84% | 50% |
| Insurance | | | | | | | | | | | | |
| <i>Private</i> | 1% | 3%** | 14% | 1% | 2%*** | 7% | 1% | 6% | <1%*** | 2% | 9% | 12% |
| <i>Medicaid</i> | 94% | 87% | 76% | 92% | 89% | 79% | 94% | 83% | 92% | 90% | 83% | 74% |
| <i>Other public insurance²</i> | 4% | 9% | 10% | 6% | 8% | 14% | 3% | 11% | 7% | 7% | 8% | 6% |
| <i>None</i> | 0% | 1% | 0% | <1% | <1% | 0% | 1% | 0% | 0% | <1% | 1% | 8% |

¹ Cells represent the percentage of CHAIN participants with each characteristic who report specific clinical outcomes or health status measures, for example, the percentage of urban respondents with Medicaid insurance

² Refers to an index of preferred practice guidelines based on the number of primary care visits within a 6-month period, the report of a complete physical exam and lab work. Number of visits are contingent upon t-cell count and whether respondent is presently on HIV antiretroviral medications.

³ Based on respondents reporting that primary care physician is available for (1) well-visits and vaccinations, (2) health advice or information, (3) after-hours access either directly or through a service.

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

Table 2-3. Medical Characteristics by Sociodemographic Characteristics

| Characteristic ¹ | Gender | | Race/ Ethnicity | | | Risk Group | | | | All New cohort 2002-3 (Wave1) | Original Cohort 2000 (Wave8) | Original Cohort 1994-5 (Wave1) |
|----------------------------------------------|------------|------------|-----------------|------------|------------|------------|------------|-----------|------------|-------------------------------|------------------------------|--------------------------------|
| | Female | Male | White | Black | Latino | MSM | PDU | MSM/PDU | Other | | | |
| (Total N=684) | 267 | 417 | 59 | 360 | 254 | 136 | 269 | 53 | 226 | 684 | 388 | 700 |
| Year of HIV/AIDS Diagnosis | | | | | | | | | | | | |
| <i>Prior to 1989</i> | 22% | 25% | 44% | 22% | 23%** | 21% | 30% | 36% | 16%*** | 24% | 24% | 33% |
| <i>1990-1995</i> | 41% | 41% | 29% | 40% | 45% | 44% | 45% | 30% | 37% | 41% | 57% | 67% |
| <i>1996-2002</i> | 37% | 33% | 27% | 38% | 31% | 35% | 25% | 34% | 47% | 35% | 19% | - |
| HIV Stage | | | | | | | | | | | | |
| <i>Asymptomatic</i> | 35% | 31% | 22% | 36% | 32% | 28% | 34% | 23% | 36% | 32% | 11% | 22% |
| <i>Symptomatic HIV</i> | 13% | 12% | 17% | 14% | 9% | 16% | 11% | 8% | 13% | 13% | 7% | 14% |
| <i>AIDS</i> | 52% | 57% | 61% | 50% | 59% | 56% | 55% | 70% | 51% | 55% | 82% | 63% |
| HIV Combination Therapy | | | | | | | | | | | | |
| <i>None</i> | 23% | 24% | 14% | 25% | 24% | 27% | 28% | 26% | 16%** | 24% | 29% | 63% |
| <i>Non-HAART</i> | 9% | 14% | 12% | 11% | 14% | 15% | 13% | 6% | 10% | 12% | 10% | 37% |
| <i>HAART²</i> | 69% | 62% | 75% | 64% | 62% | 57% | 59% | 68% | 74% | 64% | 61% | - |
| Adherence (on HIV medications, N=522) | | | | | | | | | | (N=274) | | |
| <i>Not completely adherent</i> | 39% | 21%*** | 31% | 34% | 20%** | 24% | 31% | 18% | 30% | 28% | 33% | - |
| <i>Completely adherent</i> | 61% | 79% | 69% | 66% | 80% | 76% | 69% | 82% | 70% | 72% | 67% | - |

¹ Cells represent the percentage of CHAIN participants with each characteristic who report specific clinical outcomes or health status measures, for example, the percentage of Latino respondents on HAART

² HAART is Highly Active Antiretroviral Therapy, which are HIV medications prescribed as per NIH guidelines.

* p < .05

** p < .01

*** p < .001

Table 2-4. Percent on HAART Among AIDS-Diagnosed Original and New Cohorts

| | New Cohort | Original Cohort, 2000 (Wave 8) |
|-----------------------------------------------------------------|------------|--------------------------------|
| Sample (N=375 / 320) | 70% | 63% |
| Gender | | |
| <i>Female (138/ 149)</i> | 72% | 57% + |
| <i>Male (234 / 171)</i> | 68% | 67% |
| Race/Ethnicity | | |
| <i>White, non-Hispanic (35 / 44)</i> | 75%* | 66% |
| <i>Black, non-Hispanic (180/ 181)</i> | 69% | 62% |
| <i>Hispanic/Latino (151/ 91)</i> | 68% | 59% |
| <i>Other (8/ 4)</i> | 88% | 100% |
| Risk characteristic | | |
| <i>MSM (76 / 65)</i> | 64%* | 74%* |
| <i>Problem Drug User (147 / 134)</i> | 63% | 63% |
| <i>MSM + Problem Drug User (37 / 30)</i> | 78% | 43% |
| <i>Heterosexual and other (115 / 91)</i> | 78% | 59% |
| Substance Abuse History | | |
| <i>Never used drugs (99 / 32)</i> | 78% | 66% ** |
| <i>Former drug user(188 / 224)</i> | 66% | 67% |
| <i>Current drug user (88 / 64)</i> | 68% | 45% |
| Household Income | | |
| <i>Less than \$10,000 annual household income (253 / 185)</i> | 70% | 62% |
| <i>Greater than \$10,000 annual household income (108/ 135)</i> | 71% | 64% |
| CD4 count | | |
| <i>CD4 > 500 (156/ 96)</i> | 68% | 56% |
| <i>200< CD4< 500 (145 / 148)</i> | 74% | 65% |
| <i>CD4<200 (58/ 76)</i> | 64% | 66% |
| Education | | |
| <i>Greater than high school (243 / 215)</i> | 68% | 60% |
| <i>Less than high school (132/ 105)</i> | 73% | 68% |
| Age categories | | |
| <i>20-34 years old (34 / 25)</i> | 68% | 56% |
| <i>35-49 years old (217 / 202)</i> | 69% | 65% |
| <i>50+ years old (124 / 93)</i> | 71% | 59% |
| Insurance | | |
| <i>Private (9 / 25)</i> | 67% | 64% |
| <i>Medicaid (334 / 270)</i> | 69% | 62% |
| <i>Other Public – ADAP, Medicare, CHAMPUS (31 / 22)</i> | 77% | 73% |
| <i>None (1/ 3)</i> | (1) | (1) |

† p < .1

* p < .05

** p < .01

*** p < .001

Table 2-5. Factors Associated with Use of Highly Active Antiretroviral Therapy (HAART) Among Individuals Who Have Ever Had an AIDS Diagnosis

| Respondent Characteristics | Odds of Being on HAART | |
|-------------------------------------------------------------------------|------------------------|--------------------------------------------|
| | New Cohorts (n=375) | Original Cohort, 2000 (Wave8, n=320) |
| <i>Age (an increase of one year intervals)</i> | 1.00 | 1.00 |
| <i>Men (versus women)</i> | 0.87 | 2.13** |
| <i>Black (versus non-Black)</i> | 0.57 | 0.88 |
| <i>Latino (versus non-Latino)</i> | 0.48 † | 0.69 |
| <i>Former drug users (versus never drug users)</i> | 0.55 * | 1.21 |
| <i>Current drug users (versus never drug users)</i> | 0.70 | 0.49 |
| <i>Unstably housed (versus stably housed)</i> | 3.87* | 0.33* |
| <i>Homeless in past 6 months (versus not homeless in past 6 months)</i> | 0.54* | 1.21 |
| <i>Household annual income <\$10,000</i> | 1.24 | 0.98 |
| <i>Less than a high school education</i> | 1.43 | 1.90 |

† p < .1

* p < .05

** p < .01

*** p < .001

Table 2-6. Client Characteristics Associated with HIV Medication Interruptions (also known as “Drug Holidays”)¹ in Past 6 Months, (row percentages)

| Client Characteristics | New Cohort | | Original Cohort (Wave 8, 2000) | |
|----------------------------|------------|-------------------|-----------------------------------|-------------------|
| | Total n | % on Drug Holiday | Total n | % on Drug Holiday |
| TOTAL SAMPLE | 661 | 24% | 352 | 28% |
| GENDER | | | | |
| <i>Female</i> | 254 | 30%** | 171 | 30% |
| <i>Male</i> | 407 | 21% | 181 | 25% |
| RACE/ETHNICITY | | | | |
| <i>White, non-Hispanic</i> | 58 | 26% | 42 | 24% |
| <i>Black, non-Hispanic</i> | 350 | 24% | 219 | 29% |
| <i>Hispanic</i> | 242 | 25% | 88 | 25% |
| AGE GROUP | | | | |
| <i>20-34 years old</i> | 59 | 29%*** | 57 | 32% |
| <i>35-49 years old</i> | 394 | 29% | 236 | 28% |
| <i>50+ years old</i> | 208 | 14% | 59 | 22% |
| DRUG USE | | | | |
| <i>Never used</i> | 176 | 20%* | 59 | 25%*** |
| <i>Former user</i> | 324 | 23% | 224 | 23% |
| <i>Current user</i> | 161 | 31% | 69 | 46% |

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

¹ “Drug holidays” are characterized by respondents who answered affirmatively to the following question: “Some people have taken a drug holiday, a structured treatment interruption, or stopped taking their combination therapy. In the past six months, have you taken a drug holiday, had a structured treatment interruption, or stopped taking any of your combination therapy?”

Table 2-7. Client Characteristics Associated with Drug Holiday Decisions (row percentages)

| Client Characteristics | New Cohort | | | Original Cohort (wave8, 2000) | | |
|--------------------------------|-----------------------|---------------------|---------------|-------------------------------|---------------------|---------------|
| | Total on Drug Holiday | Solely respondent's | Together w/MD | Total on Drug Holiday | Solely respondent's | Together w/MD |
| TOTAL | (N=152) | 65% | 35% | (N=98) | 76% | 24% |
| GENDER | | | | | | |
| <i>Female</i> | 72 | 61% | 39% | 52 | 69% | 31% |
| <i>Male</i> | 80 | 69% | 31% | 46 | 84% | 16% |
| RACE/ETHNICITY | | | | | | |
| <i>White</i> | 14 | 57% | 43% | 10 | 78% | 22% |
| <i>Black</i> | 81 | 63% | 38% | 64 | 77% | 23% |
| <i>Hispanic</i> | 57 | 70% | 30% | 22 | 77% | 23% |
| AGE GROUP | | | | | | |
| <i>20-34 years old</i> | 17 | 71% | 29% | 18 | 67% | 33% |
| <i>35-49 years old</i> | 111 | 64% | 37% | 68 | 77% | 23% |
| <i>50+ years old</i> | 24 | 67% | 33% | 13 | 85% | 15% |
| DRUG USE | | | | | | |
| <i>Never used</i> | 34 | 53% | 47% | 15 | 87% | 13% |
| <i>Former user</i> | 73 | 68% | 32% | 52 | 69% | 31% |
| <i>Current user</i> | 45 | 69% | 31% | 31 | 84% | 16% |
| LENGTH of DRUG HOLIDAY | | | | | | |
| <i>less than 1 month</i> | 60 | 70% | 30% | 41 | 80% | 20% |
| <i>1-3 months</i> | 33 | 55% | 45% | 18 | 72% | 28% |
| <i>4-6 months</i> | 24 | 71% | 29% | 16 | 94% | 6% |
| <i>7-12 months</i> | 21 | 62% | 38% | 15 | 60% | 40% |
| <i>more than 1 year</i> | 12 | 75% | 25% | 8 | 50% | 50% |
| FUTURE PLAN | | | | | | |
| <i>Back on medication</i> | 84 | 71% | 29% | 50 | 82% | 18% |
| <i>Intend to return</i> | 52 | 58% | 42% | 31 | 71% | 29% |
| <i>Do not intend to return</i> | 14 | 57% | 43% | 17 | 65% | 35% |

* p < .05

** p < .01

*** p < .001

PART III: NEED ASSESSMENT

Client Satisfaction

- Among the new cohort, 3% do not report a current medical provider, which is similar to earlier cohorts (Table 3-1). People who are unconnected to care are not included in these analyses.
- A great majority of the new cohort report reasonably short waiting times – 71% report waiting less than 30 minutes for their last medical appointment, and an additional 18% report waiting 31-60 minutes. 87% of the new cohort are satisfied with their medical provider, and only 11% would change their provider if they had the opportunity. (Table 3-1)
- The proportion of respondents who report having a case manager increased from the original cohort. In the 1995 cohort, 59% of respondents reported having a case manager. In the new cohort, 74% report having a case manager. The average number of case managers has declined slightly over time. In the 1995 cohort, among people who had a case manager they reported having an average of 1.67 case managers. In the current cohort, among respondents who have a case manager they report an average of 1.48 case managers. (Table 3-2)
- In the new cohort, 66% are satisfied with their case manager, compared to 49% reporting satisfaction with their case managers in 1995. Notwithstanding that approximately one-third are not satisfied with their case managers in the current cohort, only 11% would change their case manager if they could, compared to 15% in the 1995 cohort who would have changed their case manager. (Table 3-2)

Service Gaps

- In terms of service gaps, among respondents who scored very low on a standardized mental health score, 40% of the new cohort reported not receiving professional mental health services in the past six months. This compared to 45% who reported a similar mental health service gap in 1995. (Table 3-3)
- Among current drug users in the new cohort, or those who expressed an interest in drug treatment, 62% reported they are not receiving drug treatment. This compares to a 32% service gap in drug treatment in 1995. (Table 3-3)

Problems & Barriers

- In 1995, respondents listed the following as their top five non-medical problems: financial issues (46%), housing (38%), food (25%), household items (24%), and transportation (22%). Among respondents in the new cohort, the top five non-health problems are: housing (35%), financial issues (24%), legal issues (11%), household items (10%), and job-related issues (8%). These represent an overall decline in the proportion

reporting problems, as well as a shift in the set of problems – except for housing. (Table 3-4)

- The newer cohort represents a compositionally different population than the 1995 cohort – more likely to be minority, to have lower education and income, and less likely to be currently employed. Given such differences, the newer cohort may have different expectations of and interactions with the HIV care system. As Table 3-5 illustrates, the new cohort reports fewer logistical barriers to accessing medical care than the original cohort (12% versus 33%), and fewer logistical barriers to accessing social services (15% versus 30%). Among the largest differences between the two cohorts are the proportions who reported they delayed or didn't get medical services because there were unsure where to go (4% in the current cohort versus 11% in the 1995 cohort), didn't have transportation (6% currently versus 21% in 1995), or who said that it cost too much (4% currently versus 12% in 1995).
- There were similar trends among respondents concerning interpersonal barriers (i.e., providers who did not understand them, were disrespectful, didn't listen, or treated them discriminantly because of their sexual orientation or drug use). In the new cohort, 12% of respondents delayed or did not get medical care because of such provider issues, compared to 29% who delayed or did not get care among the 1995 cohort. Similarly, 15% of the new cohort delayed or didn't get social services, compared to 23% among the 1995 cohort. Across the board, respondents in the current cohort were less likely to report specific barriers than were respondents in the 1995 cohort.

Table 3-1. Access, Waiting time, Satisfaction, and Comprehensiveness of Medical Care Services

| Characteristics | NYC CHAIN New Baseline 2002-4 (N=684) | NYC CHAIN Original Baseline 1994-95 (N=648) | NYC CHAIN Refresher Baseline 1998 (N=254) | Tri-County CHAIN Baseline 2001-02 (N=398) |
|--------------------------------------------------|------------------------------------------------|------------------------------------------------------|----------------------------------------------------|----------------------------------------------------|
| Having a Medical Care Provider | | | | |
| <i>Yes</i> | 97% | 97% | 98% | 100% |
| <i>No</i> | 3% | 3% | 2% | <1% |
| Waiting time to see Medical Care Provider | | | | |
| <i>Less than 30 minutes</i> | 71% | 63% | 60% | 72% |
| <i>31-60 minutes</i> | 18% | 19% | 22% | 19% |
| <i>Over one hour</i> | 11% | 18% | 18% | 8% |
| Satisfaction with Medical Care Provider | | | | |
| <i>Satisfied</i> | 87% | 82% | 88% | 88% |
| <i>Dissatisfied</i> | 13% | 18% | 12% | 12% |
| Comprehensive Medical Care ¹ | | | | |
| <i>Not comprehensive care</i> | 24% | 49% | 37% | 28% |
| <i>Comprehensive care</i> | 76% | 51% | 63% | 72% |
| Want to change Medical Care Provider | | | | |
| <i>Yes</i> | 11% | 16% | 9% | 13% |
| <i>No</i> | 89% | 84% | 91% | 87% |

¹ Comprehensive medical care is based on the respondent reporting that his or her medical provider: (1) provides well-care visits, (2) is available to discuss health issues, (3) is available 24 hours a day, either directly or through a service or beeper

Table 3-2. Access, Waiting time, and Satisfaction of Case Manager Services

| Characteristics | NYC CHAIN New Baseline 2002-4 (N=684) | NYC CHAIN Original Baseline 1994-95 (N=648) | NYC CHAIN Refresher Baseline 1998 (N=254) | Tri-County CHAIN Baseline 2001-02 (N=398) |
|---------------------------------------------------------------|------------------------------------------------|------------------------------------------------------|----------------------------------------------------|----------------------------------------------------|
| Number of Case Manager | | | | |
| 0 | 26% | 41% | 15% | 26% |
| 1 | 46% | 35% | 57% | 40% |
| 2 | 21% | 16% | 22% | 23% |
| 3+ | 7% | 9% | 6% | 10% |
| Mean Number of Case Manager Among Who Has Case Manager | | | | |
| <i>Mean Number</i> | 1.48 | 1.67 | 1.4 | 1.67 |
| Waiting time to see Case Manager | | | | |
| <i>Less than 30 minutes</i> | 93% | 91% | 93% | 94% |
| <i>31-60 minutes</i> | 4% | 5% | 5% | 4% |
| <i>Over one hour</i> | 3% | 4% | 3% | 2% |
| Satisfaction with Case Manager | | | | |
| <i>Satisfied</i> | 66% | 49% | 76% | 35% |
| <i>Dissatisfied</i> | 34% | 51% | 24% | 64% |
| Want to change Case Manager | | | | |
| <i>Yes</i> | 11% | 15% | 10% | 15% |
| <i>No</i> | 89% | 85% | 90% | 85% |

Table 3-3. Need and Service Use for Ancillary Services

| | | NYC CHAIN New Baseline 2002-4 (N=684) | NYC CHAIN Original Baseline 1994-95 (N=648) | NYC CHAIN Refresher Baseline 1998 (N=254) | Tri-County CHAIN Baseline 2001-02 (N=398) |
|----------------------------------------------------------------------------------------------------------------|------------------------------------------------------|------------------------------------------------|---------------------------------------------------------|-------------------------------------------------------|-------------------------------------------------------|
| Mental Health Services | | | | | |
| <i>Mental health score > 37.0 (N=444/413/177/267)</i> | <i>Not currently receiving mental health service</i> | 44% | 46% | 53% | 67% |
| | <i>Currently receiving mental health service</i> | 56% | 54% | 47% | 33% |
| <i>Mental health score <37.0 (N=240/227/77/131)</i> | <i>Not currently receiving mental health service</i> | 40% | 45% | 42% | 51% |
| | <i>Currently receiving mental health service</i> | 60% | 55% | 58% | 49% |
| Drug and Alcohol Treatment Services | | | | | |
| <i>Among former drug users, expressed a need for drug treatment (N=237/307/81/126)</i> | <i>Not currently receiving any drug treatment</i> | 77% | 23% | 32% | 83% |
| | <i>Currently receiving drug treatment</i> | 23% | 77% | 68% | 17% |
| <i>Among current drug users, expressed a need for drug treatment (N=94/192/27/45)</i> | <i>Not currently receiving any drug treatment</i> | 62% | 32% | 37% | 69% |
| | <i>Currently receiving drug treatment</i> | 38% | 68% | 63% | 31% |
| Housing Services | | | | | |
| <i>Among stably housed respondents, expressed a need for housing services (N=120/116/50/112)</i> | <i>Not currently receiving housing service</i> | 36% | 30% | 18% | 65% |
| | <i>Currently receiving housing service</i> | 64% | 70% | 82% | 35% |
| <i>Unstably housed respondents¹ Expressed a need for housing services (N=118/128/40/43)</i> | <i>Not currently receiving housing service</i> | 34% | 22% | 13% | 67% |
| | <i>Currently receiving housing service</i> | 66% | 78% | 88% | 33% |

¹ Any episode of unstable housing, such as a night in shelter or on street, in jail or prison, or temporarily doubled up with friends or family in past 6 months

Table 3-4. Reported Problems and Progress Towards Resolving Problems

| <i>Problem area</i> | NYC CHAIN New Baseline 2002-4 (N=684) | | NYC CHAIN Original Baseline 1994-5 (N=648) | | NYC CHAIN Refresher Baseline 1998 (N=254) | | Tri-County CHAIN Baseline 2001-02 (N=398) | |
|---------------------------|---------------------------------------------|----------------------------------------------------|--------------------------------------------------|----------------------------------------------------|-------------------------------------------------|----------------------------------------------------|-------------------------------------------------|----------------------------------------------------|
| | having a problem | no progress/ problem has gotten worse* | having a problem | no progress/ problem has gotten worse* | having a problem | no progress/ problem has gotten worse* | having a problem | no progress/ problem has gotten worse* |
| <i>Housing</i> | 35% | 49% | 38% | 59% | 36% | 39% | 38% | 78% |
| <i>Financial issues</i> | 24% | 61% | 46% | 60% | 25% | 53% | 45% | 82% |
| <i>Legal issues</i> | 11% | 42% | 21% | 52% | 11% | 56% | 20% | 57% |
| <i>Job-related issues</i> | 8% | 66% | 8% | 65% | 6% | 73% | 9% | 100% |
| <i>Home care</i> | 4% | 41% | 10% | 56% | 2% | 75% | 9% | 67% |
| <i>Household items</i> | 10% | 72% | 24% | 72% | 14% | 60% | 24% | 79% |
| <i>Child care</i> | <1% | 0% | 3% | 57% | 2% | 75% | 3% | 88% |
| <i>Transportation</i> | 9% | 57% | 22% | 68% | 11% | 86% | 22% | 65% |
| <i>Food</i> | 8% | 42% | 25% | 64% | 10% | 68% | 25% | 62% |

Note: Problems were identified by respondents in response to the question: Did you need help or assistance in this area in the last six months?"

* percentages among who have a problem

Table 3-5. Barriers to Medical Care and Social Service

| | NYC CHAIN New Baseline 2002-4 (N=684) | | NYC CHAIN Original Baseline 1994-5 (N=648) | | NYC CHAIN Refresher 1998 (N=254) | | Tri-County CHAIN Baseline 2001-02 (N=398) | |
|------------------------------------------------------------------------------|---------------------------------------------|-------------------|--------------------------------------------------|-------------------|----------------------------------------|-------------------|-------------------------------------------------|-------------------|
| | Medical Care | Social Service | Medical Care | Social Service | Medical Care | Social Service | Medical Care | Social Service |
| LOGISTICAL BARRIERS | | | | | | | | |
| <i>Reported at least one logistical barrier</i> | 12% | 15% | 33% | 30% | 7% | 7% | 23% | 26% |
| <i>Language barriers</i> | 1% | 2% | 3% | 5% | <1% | <1% | 2% | 2% |
| <i>Cost too much</i> | 4% | 1% | 12% | 4% | 2% | <1% | 8% | 2% |
| <i>Unsure where to go for services</i> | 4% | 11% | 11% | 17% | 3% | 6% | 5% | 19% |
| <i>Transportation</i> | 6% | 6% | 21% | 15% | 3% | 2% | 12% | 15% |
| <i>Need for child care</i> | <1% | 1% | 5% | 4% | 0% | 0% | 3% | 4% |
| PROVIDER / STAFF BARRIERS | | | | | | | | |
| <i>Reported at least one staff barrier</i> | 12% | 15% | 29% | 23% | 9% | 9% | 20% | 24% |
| <i>Didn't trust staff to safeguard privacy</i> | 2% | 2% | 6% | 5% | 2% | <1% | 3% | 2% |
| <i>Staff not competent</i> | 5% | 7% | 11% | 11% | 5% | 4% | 7% | 14% |
| <i>Staff disrespectful</i> | 7% | 8% | 11% | 11% | 6% | 4% | 9% | 13% |
| <i>Staff didn't understand the problem</i> | 4% | 9% | 11% | 12% | 5% | 4% | 9% | 15% |
| <i>Staff didn't listen</i> | 7% | 9% | 14% | 15% | 6% | 7% | 9% | 16% |
| <i>Respondents nervous about what provider might say regarding condition</i> | 3% | 3% | 15% | 5% | 4% | 2% | 9% | 7% |
| <i>Felt discriminated because of sexual orientation</i> | 1% | 2% | | | | | 2% | 2% |
| <i>Felt discriminated because of drug use</i> | 2% | 3% | | | | | 3% | 4% |