



Tri-County CHAIN

Memo 2003-5

Estimating the Number of HIV/AIDS Infected Individuals in the Tri-County Region, in Care and Not in Care

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C.H.A.I.N. REPORT

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Tri-County CHAIN Project

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Background

The purpose of this memo is to estimate the total number of people in the Tri-County region living with HIV or AIDS, and to further estimate the numbers in the public and private systems of care as well as the numbers who know their serostatus but who are not in care. Prior to 2000, vital statistics data had been limited in that only individuals with an AIDS diagnosis were reportable. Since June 2000, subsequent to state mandatory HIV reporting laws, all identifiable positive HIV antibody test results and all lab reports of CD4 counts less than 500 per cubic centimeter have also been reported to the state health department by medical providers and laboratories. This has allowed for more refined estimates of the number of HIV-positive individuals living in the area.

A number of sources of data were used to develop the estimates in this report:

1. NYS DOH HIV/AIDS surveillance and HIV registry data;
2. Data on stage of disease and insurance coverage among respondents in the representatively sampled Tri-County CHAIN cohort;
3. Interviews conducted with executive directors and program managers of Tri-County health and social service agencies regarding their active caseloads;
4. New York State SPARCS hospital discharge data;
5. Medicaid/ADAP claims data.

Although the state epidemiologic data have become more comprehensive in the past two years, there are still categories of HIV-positive individuals for whom the data are incomplete. First are the individuals who are HIV-positive but who have never been reported to the state because they have not met the state criteria for reporting, either because they were diagnosed prior to June 2000, or because they have never experienced a reportable condition (i.e., a t-cell count below 500). The second area beyond the reach of state epidemiologic data is the distinction among people in the public and private systems of medical care, and those not in care. In order to extrapolate out from the state surveillance data, this analysis first establishes the number of people in the Tri-County CHAIN cohort who would have been “non-reportable.” Table 1 illustrates the distribution of people in the Tri-County CHAIN cohort, characterized by their stage of infection and their HIV diagnosis date.

Table 1. Tri-County CHAIN cohort stages of infection (*Baseline CHAIN data, 2002*)

HIV Stage	HIV/AIDS Diagnosis prior to June 2000			HIV/AIDS Diagnosis after June 2000	Total
	TOTAL	Non-reportable conditions	Reportable conditions ¹		
Asymptomatic	73	49	24	13	86
Symptomatic	62	25	37	4	66
AIDS	226	0	226	20	246
TOTAL	361	74	287	37	398

¹ Reportable conditions = Latest tcell <500 or recent opportunistic infection (i.e., HIV illness)

Table 2 illustrates the epidemiological data reported by New York State, excluding prisoners but including pediatric and adolescent cases, through November 2002.

Table 2. Living HIV and AIDS reported cases in Tri-County region (NYSDOH data)

HIV Stage	Total, as of Nov 2002
Living with HIV (symp + asymp)	668
Living with AIDS	2,185
TOTAL	2,853

Source: NYS HIV/AIDS Surveillance Semiannual Report, for cases diagnosed through Dec 31, 2001

!!! Important note: The numbers presented below should be treated as *estimates only*, and should not be regarded as absolute numbers. Also, those estimated as “not in care” may not be directly comparable with HRSA’s definition of unmet need.

1. Estimating the total number of HIV+ diagnosed prior to June 2000

One can estimate the total number of people living with HIV in the Tri-County area, in care, who (1) learned their HIV diagnosis prior to the start of mandatory HIV reporting in June 2000, (2) whose clinical laboratory values since June 2000 have remained above the reportable levels of $CD4 < 500$ or a detectable viral load, and (3) who have not had an AIDS diagnosis, using the Tri-County CHAIN cohort. These individuals, presumably, would not be captured in the HIV registry.

These estimates assume that the proportion of Tri-County CHAIN respondents who were diagnosed prior to June 2000 are representative of the general HIV+ population.

1. Let x = total asymptomatic Living HIV+ in Tri-County, who were diagnosed prior to June 2000, and are in care
2. Given that there are 74 HIV+ individuals with “non-reportable” conditions in Tri-County CHAIN who learned their diagnosis prior to June 2000
3. And given that there are 226 AIDS diagnosed individuals in the Tri-County CHAIN cohort who learned their diagnosis prior to June 2000
4. And given that there are 2,185 AIDS reported cases in the Tri-County region

Then, $74/226 = x/2,185$, and $x = 715$.

- 1.1** There are an estimated **715** individuals with HIV, in care, who would not have reported to the state registry since June 2000.

This estimate does not include HIV+ individuals not in care.

2. Estimating the total number of HIV+ diagnosed after June 2000 Not in Care

In order to estimate the number of HIV+ individuals not in the public system of care, one can take the difference between the total number who have been reported, and the total estimated to be in care proportional to the Tri-County CHAIN cohort.

1. Let x = the total number of HIV+ individuals who know their serostatus but who are not in the care system
2. Given that there are 17 individuals in the Tri-County CHAIN cohort (both symptomatic and asymptomatic) who learned their diagnosis after June 2000
3. And given that there are a total of 246 AIDS cases in the Tri-County CHAIN cohort
4. And given that there are 2,185 reported AIDS cases in the Tri-County region
5. And given that there are 668 reported HIV cases in the Tri-County region since June 2000

Then, $(668-x) / 2,185 = 17 / 246$

$$x = 668 - (17 * 2185 / 246)$$

$$x = 517.$$

This may underestimate the total number of HIV+ individuals who are not in the system of care since CHAIN did not sample individuals who had learned their diagnosis in the past 6 months. Since much of the cohort was recruited after May 2002, however, this number would be fairly small.

Also, this number does not estimate the total number who know their HIV serostatus and who have sought private medical care or care outside of the region.

As an estimate of “unmet need,” or those unconnected to care, this might be regarded as an upper bound since it is unknown how many of these individuals are in private or out-of-area care.

- 2.1** There are an **estimated 517** HIV+ individuals living in the Tri-County region who are not in the public system of care, and who were diagnosed after June 2000.
- 2.2** There are an estimated total of **4,085** individuals in the Tri-County region who are HIV-positive and who know their serostatus: the individuals who have been reported to the state registry (2,853, from Table 1) + those individuals diagnosed prior to 2000 and who have non-reportable conditions (estimate 1.1, 715) + those individuals diagnosed after 2000 and who have non-reportable conditions (estimate 2.1, 517).

3. Estimating the total number of HIV+ in the public and private systems of care

This report uses two different strategies to estimate the numbers of individuals in the “public” system of HIV medical care and in the “private” system of care. The public system is

defined as those medical care organizations who are the typical providers of medical care to patients with either public insurance or who are uninsured. In the Tri-County region this includes public and private hospitals – both out-patient departments, satellite clinics, and mobile units – and federally-qualified community health centers, public health clinics, the Veterans Administration, and other neighborhood health clinics. The private system of care is generally considered to be medical care delivered in the private medical offices of solo practitioners or those affiliated as group practices.

The first of the two modeling strategies is based upon a combination of Medicaid and ADAP claims data as well as hospital discharge data. This may be thought of as the “top down” approach, since the numbers are based on administrative data collected at the state level. The second modeling strategy is the “bottom up” approach, in which CHAIN data and key informant interview data with medical providers were combined to establish an estimate.

Top-down approach

The New York State AIDS Institute has estimated that there are 2,577 unduplicated Medicaid and ADAP recipients living in the Tri-County region, based on claims processed between Oct 1, 2000 and Sep 30, 2001 (memo prepared for the Planning Council’s Unmet Need Project, April 2004). These 2,577 individuals may be considered to constitute the “public” system of care, although it is acknowledged that some proportion of these individuals may receive their care in private medical settings, notwithstanding their public insurance coverage. In order to estimate the non-Medicaid population in care, one needs an “adjustment factor.” I have used SPARCS hospital discharge data from 2001 (source: Infoshare proprietary database) to calculate this adjustment factor based on the payor mix of HIV-positive individuals who have been hospitalized. There were a total of 321 hospital admissions in the Tri-County region in 2001 with a disease classification ICD-9 code of 042 through 044 (“HIV infection related”). Of these 321 admissions, 48% were Medicaid payor; 14% were Medicare payor; 34% were Blue Cross Blue Shield, commercial insurance, or an HMO; and 4% were self pay. The split between Medicaid and self-pay (public) and non-Medicaid (private) is thus 52% versus 48%. Given that individuals who have been hospitalized do not necessarily represent the general HIV-positive population, since they are sicker and more likely to have been diagnosed earlier than the general HIV-positive population, one must “discount” the 48% number to arrive at a more representative estimate. Among the Tri-County CHAIN cohort, 14% of the 398 individuals interviewed at baseline indicated they had private insurance. This cohort is both healthier than the individuals in the SPARCS database, and is more likely to be drawn from the public system of care, so the true number in the private payor category may be estimated as a point between 14% and 48%. I have selected an adjustment factor of 35%, a little over half the difference between the two numbers, since the SPARCS data are more complete than the CHAIN data.

Using this adjustment factor, one can estimate the total number of people in the public and private systems of care as $2,577 \times 1.35 = 3,479$. This breaks down as 2,577 in the public system, plus 902 individuals in the private system.

3.1 The “top-down” estimate of the total number of people in care, both in public and private systems, is **3,479**.

Bottom-up approach

Prior to recruiting individuals in to the CHAIN cohort, we conducted brief key informant interviews with executive directors and program managers at 37 health and social service agencies in Tri-County in the summer and fall of 2001. The primary purpose of these telephone interviews was to establish a database of HIV health and social service providers, with sufficient information to develop appropriate sampling procedures. An unintended benefit of these interviews, though, has been our ability to generate an estimate of patient caseloads in the region. Thirteen of the thirty-seven agencies provided primary medical care services. Informants were asked to estimate their current active caseloads. We have assumed that individuals generally have only one primary medical provider, and that aggregating these estimates represents an unduplicated number. The primary medical care agencies included: Greenburgh Neighborhood Health Center, Good Samaritan Hospital, Hudson River Health Care, Hudson Valley Hospital, Jewish Guild for the Blind, Mount Vernon Hospital, Mount Vernon Neighborhood Health Center, Open Door, Rockland DOH, Saint John's Riverside - Yonkers General, Saint Josephs Family Health Center, Sound Shore Medical Center, Westchester Medical Center. The informants estimated a combined total of 1,499 active cases. I have added an additional 10% to cover individuals seen at other public care agencies in the region who were not interviewed. The public care system is assumed to include hospital out-patient departments, clinics, neighborhood health centers, and the Veterans Administration.

3.2 The estimate of individuals in the public system of care is thus $1,499 \times 1.10 = 1,649$.

Combining the estimates

Table 3 illustrates the final model that estimates the distribution of all people in the Tri-County region who know their HIV serostatus. The following page provides the step-by-step approach to filling out the table based on the estimates and reportable cases noted in the report.

Table 3. Estimates of total Tri-County HIV/AIDS cases of known seropositivity

		A	B	C
	System of Care	Living with HIV	Living with AIDS	TOTAL
1	<i>Public system</i>	627	1,022	1,649
2	<i>Private MD</i>	652	1,063	1,715
3	<i>Not in care</i>	621	100	721
4	TOTAL	1,900	2,185	4,085

- Step 1. Cell B-4 is filled in with the number of AIDS cases reported to the state, 2,185, from Table 2 above.
- Step 2. Cell C-1 is filled in with the estimate of individuals in the public system of care, drawn from estimate 3.2 above, 1, 649.
- Step 3. Cells A-1 and B-1 are filled in based on the proportion of individuals in the CHAIN cohort who were AIDS-diagnosed and those who were HIV+ without an AIDS diagnosis, 62% and 38% respectively. These percentages were applied to the total in C-1.
- Step 4. Cell B-3, the number of individuals with full-blown AIDS not presently in care, was estimated to be 100 individuals. It was assumed that only 100 people would be living with AIDS and not in care, given the natural progression of the illness and the natural inclination to seek care once one is sick..
- Step 5. Cell B-2 is derived as the difference between the total number of reported AIDS cases in cell B-4 (2,185) and the combined number of estimated AIDS cases in the public system of care, B-1 (1,022), and those not in care, B-3 (100). Those who remained (1,063) are those estimated to be living with AIDS and in the private system of care.
- Step 6. For cell A-2 , the same ratio used in Step 3 above, of AIDS cases (62%) to HIV, non AIDS (38%), was applied to the numbers of individuals estimated to be in the private system of care [$38/62 : x/1063$, $x=652$]. This further allowed extrapolation to cell C-2 [$A-2 + B-2 = 1,715$].
- Step 7. Cell A-4 is derived as the sum of (1) the total number of HIV+ individuals reported to the state registry after June 2000, 668; plus (2) those estimated to have been diagnosed prior to June 2000 (715, illustrated above in estimate 1.1) who are in the public system of care; plus (3) those estimated to have been diagnosed prior to June 2000 who are not in the public system of care (517, as illustrated above in estimate 2.1), for a total of 1,900.
- Step 8. Cell A-3, the total number of individuals estimated to be living with HIV but not in care, is derived by subtracting the estimated numbers in the public (cell A-1) and private (cell A-2) systems of care from the total (cell A-4).

As a final comment, it is noteworthy that the “top-down” estimate of the total number of people in the public and private systems of care is 3,479 (estimate 2.1), which is reasonably similar to the “bottom-up” estimate of 3,364 (cells C-1 + C-2) derived from Table 3 above.