



CHAIN Report 2004-2

Strategic Plan
Progress Indicators:
New Cohort Update

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C.H.A.I.N. REPORT

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INTRODUCTION:

During 2002 a comprehensive strategic plan for the organization and delivery of HIV/AIDS services was prepared for New York's Title I Planning Council¹. The centerpiece of this plan is a set of goals and objectives developed by each of the planning council's work groups². For each objective, a performance measure was defined to monitor progress towards achieving each objective. For many of the objectives it was possible to construct a progress indicator from CHAIN interview data. This document is a follow-up to CHAIN Report 2003-1, which presented baseline data for these performance measures. In this current report we have compared the performance measures for respondents in the newly-recruited cohort (NYC CHAIN Cohort II) with the performance measures reported at baseline from the earlier cohort (NYC CHAIN Cohort I). This allows a reader to evaluate New York City's system of HIV care from several perspectives:

(1) Has the performance of the system changed over time? By comparing the performance measures between a representative group interviewed in 2002-2003 and a representative group interviewed in 1998-2001, one can begin to estimate whether the performance of the system improved, was static, or declined. There are, of course, other explanations as to differences between the cohorts – respondents in one cohort might have a greater need for services than respondents in the other cohort, or one might be a more “experienced” cohort with greater ability to navigate the city's system of services. Notwithstanding these potential explanatory factors, comparing the performance measures among the two cohorts provides a starting point for further analyses, and we have attempted to control for some of these possible differences in a multi-variate regression analysis.

(2) Are there certain subgroups or populations who fare better or worse than others? A reader can look at the bar graphs in this report and – at a glance – begin to note differences in the performance measurement rates by groups. We have restricted this subgroup analysis to the following group differences: gender, race/ethnicity, HIV risk behavior, T-cell count, and for a number of performance measures we added year diagnosed, borough of residence, and age group.

(3) Do the subgroup differences vary between the two cohorts, or do those groups who fared better in the earlier cohort also fare better in the newer cohort? The regression analysis presented in this report attempted to identify the most significant group differences across the two cohorts.

To assist the reader in navigating through this document, a brief summary of the organization of this report is presented below. A detailed description of the CHAIN survey and its methods of data collection is included as an Appendix to this report. Definitions for each CHAIN measure were developed for the strategic plan³. Each measure is constructed as a

¹ McClain and Associates, Inc. New York EMA Comprehensive Strategic Plan for HIV/AIDS Services 2002-2005.

² Ibid, pp: 58-87.

³ Ibid, pp: 96-123.

dichotomy which illustrates how well CHAIN participants' experiences relate to the stated performance criteria.

The section beginning after the Key Findings summarizes the progress indicators for each cohort by work group, and also presents the subgroups and populations in the new cohort who experienced statistically lower rates among the progress indicators. Following these summary tables is a page detailing the results of the multivariate regression analyses, which examined the most significant factors associated with five of the most common progress indicators (reporting a lower physical health score, being adherent to HIV medications, reporting comprehensive medical care, having an episode of unstable housing in the past 6 months, and experiencing barriers to medical or social services).

The subgroup bar charts follow these summary tables. The objectives are organized by work group goals. The heading of each page identifies the work group, the objective number, and a statement of the objective. The numerical prefix of the objective corresponds to the number of the work group goals. For example, Health Services Work Group Objective 1A is the first objective for Goal 1 of this work group. Readers interested in the wording of work group goals should refer to the Strategic Plan Report. The "progress indicator" for the objective is then defined and an overall baseline value for NYC CHAIN Cohort I is reported as is the value for NYC CHAIN Cohort II, the "new cohort." Two bars for each category (males and females, major ethnic groups, HIV risk categories, T-cell levels, HIV diagnosed year groups, residential borough, and age groups) are presented. The black bar presents baseline values for each group and the red bar presents values for the new cohort. The baseline values for the entire CHAIN sample and the subgroups are based on most recent observation for each CHAIN participant, which may have occurred between the 5th through the 8th rounds of interviews that were conducted between 1998 and 2002, encompassing a sample population of 652 respondents. Data for the new cohort were drawn from baseline interviews with 562 respondents between 2002-2003. Enrollment in the new cohort, which was completed in the summer of 2004, was not complete at the time the analyses were conducted for this report. It is expected that the rates of the progress indicators for the full cohort of 684 individuals will not differ greatly from the 562 reported here. In order to present a graphically "clean" illustration of this very complex data, we have placed the denominator values in a table in the Appendix. Furthermore, we have noted statistically significant differences between subgroups in the new cohort by the presence of an asterisk alongside the group name.

KEY FINDINGS: HEALTH Work Group

Health was measured in three domains: as self reported health status assessment, by use of a clinical marker (T-cell counts), and as a function of health care. The first, health status, was measured in one of two ways. The more subjective measure was a single global question rating current health from excellent to poor. A more objective measure of physical health was calculated by applying the Physical Component Summary Scale (PCS) of the SF36, which is a standardized set of questions that correlate with stage of disease.

An assessment of clinical care was established in one of two ways. In the first, a scale was developed in conjunction with the AIDS Institute, capitalizing on three criteria: the number of visits reported over a period of time, a report of a complete physical exam, and a report of recent blood work. The second strategy for assessing clinical care was drawn from standards of care developed by the World Health Organization. Primary HIV medical care was considered to be “comprehensive” if a provider was available for well-visits, for health advice and information, and was accessible 24 hours a day if needed.

- Overall, a representative group of HIV-positive adults in 2002-2003 reported similar experiences and health characteristics when compared with a representative group of HIV-positive adults in 1998-2001. This suggests that the health system did not change dramatically in New York City – either for the better or for the worse – over this period of time. Among the new CHAIN cohort, approximately one-third reported t-cell counts above 500 (unchanged from the earlier cohort), and 72 percent said they were completely adherent to their HIV medications (representing a slight rise from the 67% adherence rate of the original cohort).
- In looking at their medical care, approximately three-quarters of the new cohort said they had maintained the same primary medical provider for at least a year, reported receiving medical services from their primary medical provider that met the minimal preferred HIV-primary care guidelines, and further responded that their primary care met key elements of comprehensive care (i.e., available for well visits, health advice, and accessible 24 hours a day). Conversely, one-quarter did not meet these care criteria.
- There were subgroup differences on several progress indicators. Problem drug users (that is, individuals who had ever used crack, cocaine, or heroin three or more times a week, for a month or more; or who had ever injected drugs; or who were problem alcoholics) were more likely to report poor health, as were individuals with lower t-cell counts. Black respondents were less likely to report receiving comprehensive medical care, and also less likely to report being completely adherent.
- In a multi-variate analysis that looked at the contribution of the factors associated with increased adherence, men and Latinos were two groups more likely to report being adherent, as were groups reporting comprehensive medical care and groups that did not experience barriers to health or social service care. In the original CHAIN cohort, individuals whose primary care could be considered comprehensive were 68% adherent, compared with a 59% adherence rate among those whose primary care could not be considered comprehensive. This difference grew in the new CHAIN cohort, in which 75% of individuals with comprehensive primary care were adherent, compared to a 59% adherence rate among those whose primary care did not meet the criteria for comprehensive care (data not shown).
- Individuals who reported having experienced barriers to health or social services were more likely to report low physical health scores, and also less likely to be adherent.

KEY FINDINGS: HOUSING Work Group

- The representative group of HIV-positive adults in 2002-2003 was far more likely to have experienced an episode of unstable housing (28% versus 18%) and or homelessness (18% versus 10%) in the prior 6 months than were members of the original CHAIN cohort interviewed in 1998-2001. It is possible to attribute some of this variation to the difference between a new “baseline” cohort and to the group who “survived” in the original CHAIN cohort from their initial recruitment in 1994-1995. Over time, in the original CHAIN cohort, respondents who were unstably housed were more likely to be lost to follow-up.
- Regardless as to which cohort is being measured, men were statistically more likely than women to report unstable housing or homelessness.
- In a multivariate analysis (data not shown), the other factors associated with unstable housing – regardless of which cohort is being considered – is problem drug use and the age group of 20-34 year olds.
- There was a significant increase between the original and the new CHAIN cohorts in the proportion of unstably housed individuals who received housing subsidies, lived in specialized AIDS housing, or who received some other housing services.

KEY FINDINGS: AOD Work Group

- Overall, there were no statistically significant differences in the two AOD progress indicators when the new CHAIN cohort from 2002-2003 was compared with the original CHAIN cohort interviewed in 1998-2001.
- One major sub-group difference did emerge – individuals in the heterosexual HIV risk behavior category with a history of current or former drug use were more likely than individuals in other HIV risk categories to have experienced barriers to health care or social services. This was also true among the heterosexual risk behavior group if drug use history was not taken in to account.

KEY FINDINGS: INFRASTRUCTURE Work Group

- Overall, there were no statistically significant differences in the Infrastructure progress indicator when the new CHAIN cohort from 2002-2003 was compared with the original CHAIN cohort interviewed in 1998-2001.
- One major sub-group difference emerged, in that women were more likely than men to have reported delaying or not getting the service they needed because they didn’t know

where to go for specific medical or social services.

KEY FINDINGS: SOCIAL SERVICES Work Group

- Overall, there were no statistically significant differences in the progress indicators when the new CHAIN cohort from 2002-2003 was compared with the original CHAIN cohort interviewed in 1998-2001.
- The only sub-group difference was among 20-34 year olds, who were more likely to have unresolved problems in legal matters, child care, or food services than were older respondents with similar expressions of need for these services.

KEY FINDINGS: MENTAL HEALTH Work Group

Mental Health was assessed by the Mental Health Component Summary, MCS, of the SF36. Rates of adherence to medication were measured for people with very low mental health both taking into account receipt of mental health services and regardless of whether mental health services were reported.

- Overall, several progress indicators suggested considerable improvement when the new CHAIN cohort from 2002-2003 was compared with the original CHAIN cohort interviewed in 1998-2001. Among individuals with low mental health scores on a standardized scale (less than 37.0 on the SF-36 mental component summary scale), people in the new CHAIN cohort were almost twice as likely to report good physical health scores than were respondents in the original CHAIN cohort. This finding did not vary based on whether the individuals received mental health services or not.
- White respondents with low mental health scores were significantly less likely to be adherent than Latino respondents and less likely to report good physical health than were Black respondents. The reported receipt of professional mental health services among respondents with low mental health scores did not appreciably raise their physical health scores.

Strategic Plan: HEALTH Work Group Objectives

Obj #	Objective	Progress Indicator	% of NYC CHAIN Cohort I with Positive Indicator (1998-2001), n=652	% of NYC CHAIN Cohort II with Positive Indicator (2002-2003), n=562	Groups in New CHAIN cohort with statistically lower progress
1A-1	PLWHA will have improved survival and health outcomes	Self-reported health status score is at or above national average for “good health”	48%	51%	1. Whites 2. Latinos 3. Problem drug users 4. CD4<500
1A-2	PLWHA will have improved survival and health outcomes	Self-reported CD4 count is greater than 500 cells/mm ³	34%	34%	
1B	Persons who receive health services will adhere to treatment	Self-reported adherence to HIV medications	67%	72%	1. Women 2. Blacks 3. Whites
2A	PLWHA will remain connected to services once in the care continuum	Reported same primary doctor as of last interview or within past year	69%	76%*	1. Men 2. MSM
3A-1	PLWHA in care will receive services that meet or exceed AI quality standards	Reported medical care that met minimal preferred practice guidelines	71%	74%	
3A-2	PLWHA in care will receive services that meet or exceed AI quality standards	Primary medical provider is available for well-visits, available for health advice, and available 24 hours/day	75%	77%	1. Blacks
3B	PLWHA report health-related quality of life as good or better	Self-reported health is “good,” “very good,” or “excellent”	66%	65%	1. Problem drug users 2. CD4 below 200

** Percentage reported by new cohort is statistically significantly different than the older cohort*

Strategic Plan: HOUSING Work Group Objectives

Obj #	Objective	Progress Indicator	% of Original CHAIN cohort with Positive Indicator (1998-2001), n=652	% of New CHAIN cohort with Positive Indicator (2002-2003), n=562	Groups in New CHAIN cohort with statistically lower progress
1A-1	Transitional housing will be available to PLWHA who need it	Percent who reported being unstably housed, who had any episode of living on street, in shelter, SRO, or doubled-up with friend or relative in past 6 months	18%	28%*	1. Men
1A-2	Transitional housing will be available to PLWHA who need it	Percent who reported being homeless	10%	18%*	
2A	Housing placement assistance services will be available for PLWHA who need them	Among those who reported any unstable housing, percent who received housing subsidy, lived in specialized AIDS housing, or received housing services	33%	47%*	

** Percentage reported by new cohort is statistically significantly different than the older cohort*

Strategic Plan: AOD Work Group Objectives

Obj #	Objective	Progress Indicator	% of Original CHAIN cohort with Positive Indicator (1998-2001), n=652	% of New CHAIN cohort with Positive Indicator (2002-2003), n=562	Groups in New CHAIN cohort with statistically lower progress
1A	Health care/mental health and other providers will understand AOD culture and provide culturally appropriate and sensitive treatment to AOD users	Among those who reported current or past drug use, the percent who delayed or did not get medical or social services because of barriers experienced	18%	17%	1.Heterosexual HIV risk
1B	Health care, mental health, and other services will be more available and accessible to AOD users	Among those who reported current or past drug use, and who had an objective need for mental health services (a low mental health score on a standardized scale), the percent who reported they received professional or supportive mental health services	50%	60%	

** Percentage reported by new cohort is statistically significantly different than the older cohort*

Strategic Plan: INFRASTRUCTURE Work Group Objectives

Obj #	Objective	Progress Indicator	% of Original CHAIN cohort with Positive Indicator (1998-2001), n=652	% of New CHAIN cohort with Positive Indicator (2002-2003), n=562	Groups in New CHAIN cohort with statistically lower progress
1A	Appropriate information will be available on the type and location of services and on options for choosing services that best meet the needs of PLWHA	Percent who reported they delayed or did not get medical or social services because they did not know where to go for services	11%	11%	1. Women

** Percentage reported by new cohort is statistically significantly different than the older cohort*

Strategic Plan: SOCIAL SERVICES Work Group Objectives

Obj #	Objective	Progress Indicator	% of Original CHAIN cohort with Positive Indicator (1998-2001), n=652	% of New CHAIN cohort with Positive Indicator (2002-2003), n=562	Groups in New CHAIN cohort with statistically lower progress
1B	PLWHA will have access to culturally competent and linguistically appropriate social services	Percent who delayed or did not get medical or social services because staff did not speak their language; were not competent to deal with problem; were not polite, respectful or sensitive; did not understand their problem; or did not listen to their problem or needs	15%	13%	1. Whites
1C	PLWHA will have access to necessary transportation services	Among those who reported needing help with transportation, or who said it was a barrier to receiving, percent who received transportation services	45%	38%	
1D	PLWHA will have access to a broad range of support, advocacy and basic needs programs within their geographic area	Among those who reported needing help with legal matters, child care, or food/ groceries/ meals, percent who said “no change has occurred,” “no progress has been made,” or the “problems have been getting worse”	53%	58%	1. 20-34 year olds
3B	PLWHA will have increased knowledge regarding treatment issues and adherence strategies	Among those who received help with taking meds, percent who reported the advice was “very helpful” or “somewhat helpful”	91%	91%	
4A	Unmet benefit need [add language from Plan]	Among those who had an annual household income below \$10,000 and t-cell count below 200, percent who reported being on Medicaid	98%	96%	

** Percentage reported by new cohort is statistically significantly different than the older cohort*

Strategic Plan: MENTAL HEALTH Work Group Objectives

Obj #	Objective	Progress Indicator	% of Original CHAIN cohort with Positive Indicator (1998-2001), n=652	% of New CHAIN cohort with Positive Indicator (2002-2003), n=562	Groups in New CHAIN cohort with statistically lower progress
1B-1	PLWHA engaged in mental health care will adhere to treatment	Among those with an objective need for mental health services (a very low MH score on a standard scale), percent who reported being fully adherent to HIV meds	61%	66%	1. Women 2. Blacks 3. Whites
1B-2	PLWHA engaged in mental health care will adhere to treatment	Among those with an objective need for mental health services (a very low MH score on a standard scale), and who reported receiving professional or supportive MH services, percent who reported being fully adherent to HIV meds	58%	66%	1. Blacks 2. Whites
1C-1	PLWHA engaged in mental health care will have improved quality of life	Among those with an objective need for mental health services (a very low MH score on a standard scale), percent reporting good physical health (based on high score on standard scale)	28%	48%*	1. Whites
1C-1 (mod)	PLWHA engaged in mental health care will have improved quality of life	Among those with an objective need for mental health services (a very low MH score on a standard scale), and who received professional MH services, percent reporting good physical health (based on high score on standard scale)	39%	44%	1. Men
1C-2	PLWHA engaged in mental health care will have improved quality of life	Among those with an objective need for mental health services (a very low MH score on a standard scale), and who received professional OR supportive MH services, percent reporting good physical health (based on high score on standard scale)	28%	50%*	1. Whites 2. Latinos

** Percentage reported by new cohort is statistically significantly different than the older cohort*

Strategic Plan: Multivariate Analysis

Preface: In considering sub-group differences, readers should consider that certain group characteristics may cluster together, thus making a determination of the most significant effect difficult to establish. For example, if most Latino men in the CHAIN cohort live in the Bronx, and they tend to be healthier with t-cell counts over 500, than when one looks at self-reported health status and sees “men,” “Latinos,” and people living in the Bronx, one cannot tell if all men in the cohort are healthier than women, or if this is being driven by the preponderance of healthier Latino men in the Bronx. In order to estimate the individual effects more accurately, we have conducted a multivariate regression analysis, which looks at all the effects together. What this analysis does is look at each effect as if all the other factors are equal. In our example, the analysis would look at men, controlling for such other effects as being Latino, living in the Bronx, or having a high t-cell count. If after conducting this analysis men are still significantly healthier, this holds regardless as to whether the men are Latinos, live in the Bronx, or have high t-cell counts. The following illustrates the major factors associated with five of the major outcomes or performance measures used by the Work Groups in the Strategic Plan.

<i>Factors most significantly associated with...</i>				
Reporting a lower physical health score	Being adherent to HIV medications	Reporting comprehensive medical care (provider available 24 hours, for well-visit, and for health advice)	Having an episode of unstable housing in the past 6 months	Experiencing barriers to medical or social services care
<ul style="list-style-type: none"> – Original cohort – Problem drug users – T-cell less than 500 – Age over 50 years – Low mental health – Experienced barriers 	<ul style="list-style-type: none"> – Men – Latinos – Reporting comprehensive medical care – Not reporting barriers to health or social service care 	<ul style="list-style-type: none"> – Living in Brooklyn – having continuous medical care – Being white or Latino – Not having low mental health score – Not reporting barriers to health or social service care 	<ul style="list-style-type: none"> – New cohort – Men – Problem drug users – Living in Manhattan – Age 20-34 years – Current or former drug user 	<ul style="list-style-type: none"> – Being white – Not reporting comprehensive medical care – Having a low physical health score

Note: This analysis considered the following potential factors for each outcome – gender, age, race/ethnicity, HIV risk category, borough of residence, drug use history, mental and physical health scores, continuity of medical care, comprehensive medical care, and year of HIV diagnosis.

GLOSSARY OF TERMS

AIDS Institute (AI) criteria for care—AI criteria for appropriate medical care for HIV+ persons consists of: 1) required number of medical care visits (further contingent upon T-cell count and antiretroviral use); 2) self-reported complete physical and blood work; and 3) self-reported T-cell count.

AOD—Alcohol and other drugs.

Barriers to care—Barriers to care (lack of information) were established via questions such as: “Did you ever delay or not get assistance you thought you needed” because “you didn’t know or weren’t sure where to go” for medical or social services?

Comprehensive medical care—Respondents were considered to receive comprehensive medical care if they responded “yes” to the following three questions: Is your routine medical provider someone you can go to for (1) “routine check-ups,” (2) “information or advice about a health concern” and (3) “someone you could call up 24 hours a day in case of a medical emergency?”

Cultural/language barriers to care—Established via the following questions: “Did you ever delay or not get assistance you thought you needed” because the staff “. . . Do not speak your language? . . . Are not competent to deal with your problem? . . . Are often not polite, disrespectful or insensitive to your needs?” Are you not sure that they “. . . would understand your problems?” or are “not good at listening to your problems or needs?”

Help with taking meds—Established via responses to the question: “Has anyone suggested ways to help you take your medicine on time and in the right way?”

Hetero—HIV risk group for persons who risk exposure to the virus via heterosexual contact.

MSM—Men who have sex with men.

Need for benefits—Defined by a self-reported T-cell count of less than 200 and an annual household income of less than \$10,000.

Objective need for mental health services—Established by a score of less than 37.0 on the Mental Health Component Summary score of the SF-36, developed by the MOS.

PCS score—Physical Component Summary score of the SF-36, developed by the MOS. Scores of 45 and above are considered at or above the national norm, particularly for people who feel well enough to work regularly.

PDU—Problem drug users, who have ever used cocaine, crack, or heroin three or more times a week for a month or more, or who have ever injected drugs, or meet the “problem drinking” criteria established by CAGE scale (i.e., others have criticized your drinking, ever needed a drink as an “eye-opener,” etc.).

Professional mental health services—Mental health services provided by a psychiatrist, psychologist, or therapist.

Supportive mental health services—Mental health services such as counseling provided by a case manager, clergy, etc.

Unstable housing—Any episode of living in the street, a shelter, a single-room occupancy, or doubled up with a friend or relative in past 6 months.

Health Service: Objective 1A-1

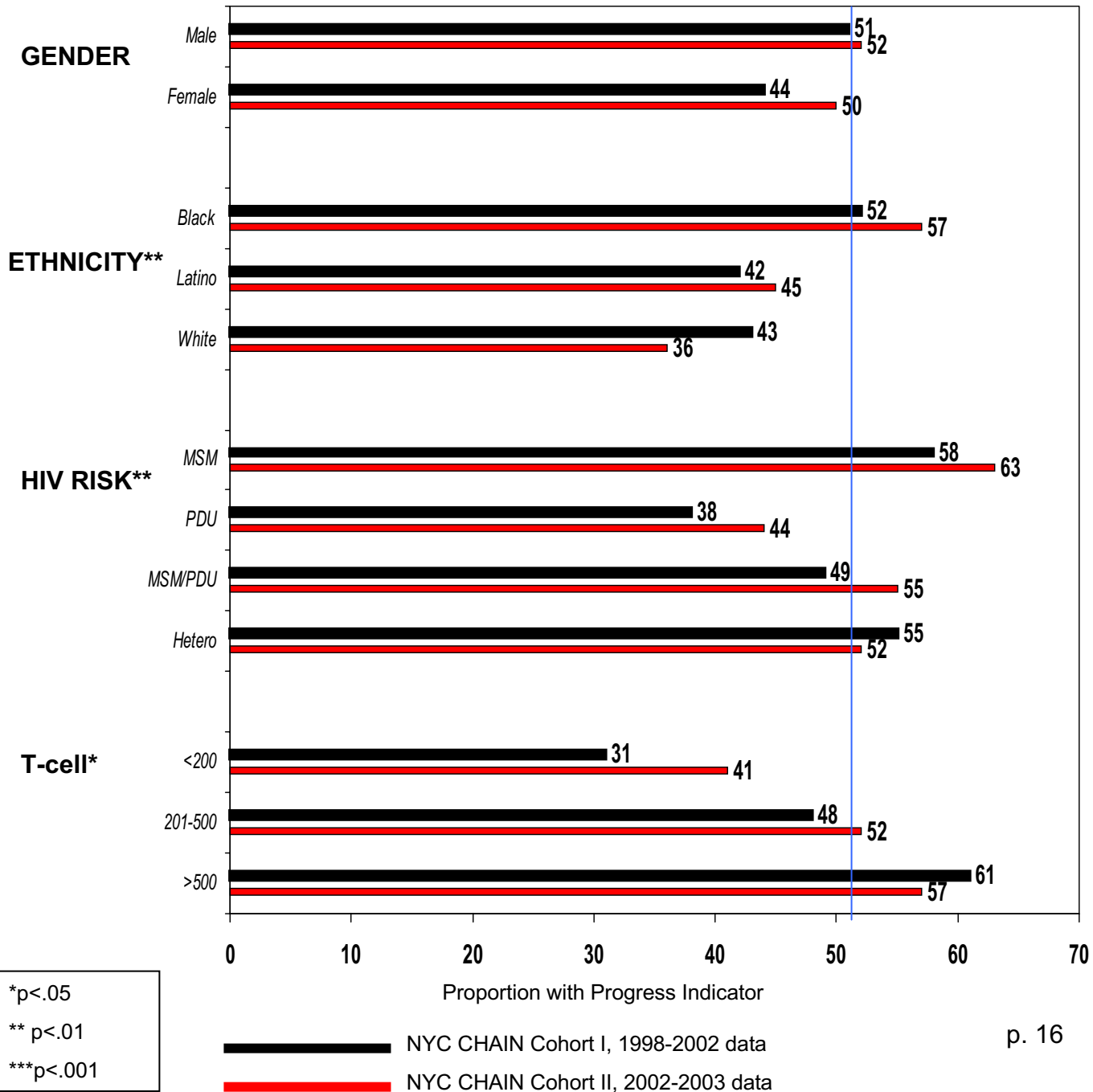
Persons with HIV disease engaged in health care services will have improved survival and health outcomes.

PROGRESS INDICATOR: Good self-reported health status, as measured by a standardized multi-item health scale (the PCS score).

BASELINE: 48 percent with PCS score of 45 or higher

NEW COHORT: 51 percent with PCS score of 45 or higher

Cohort II
Average



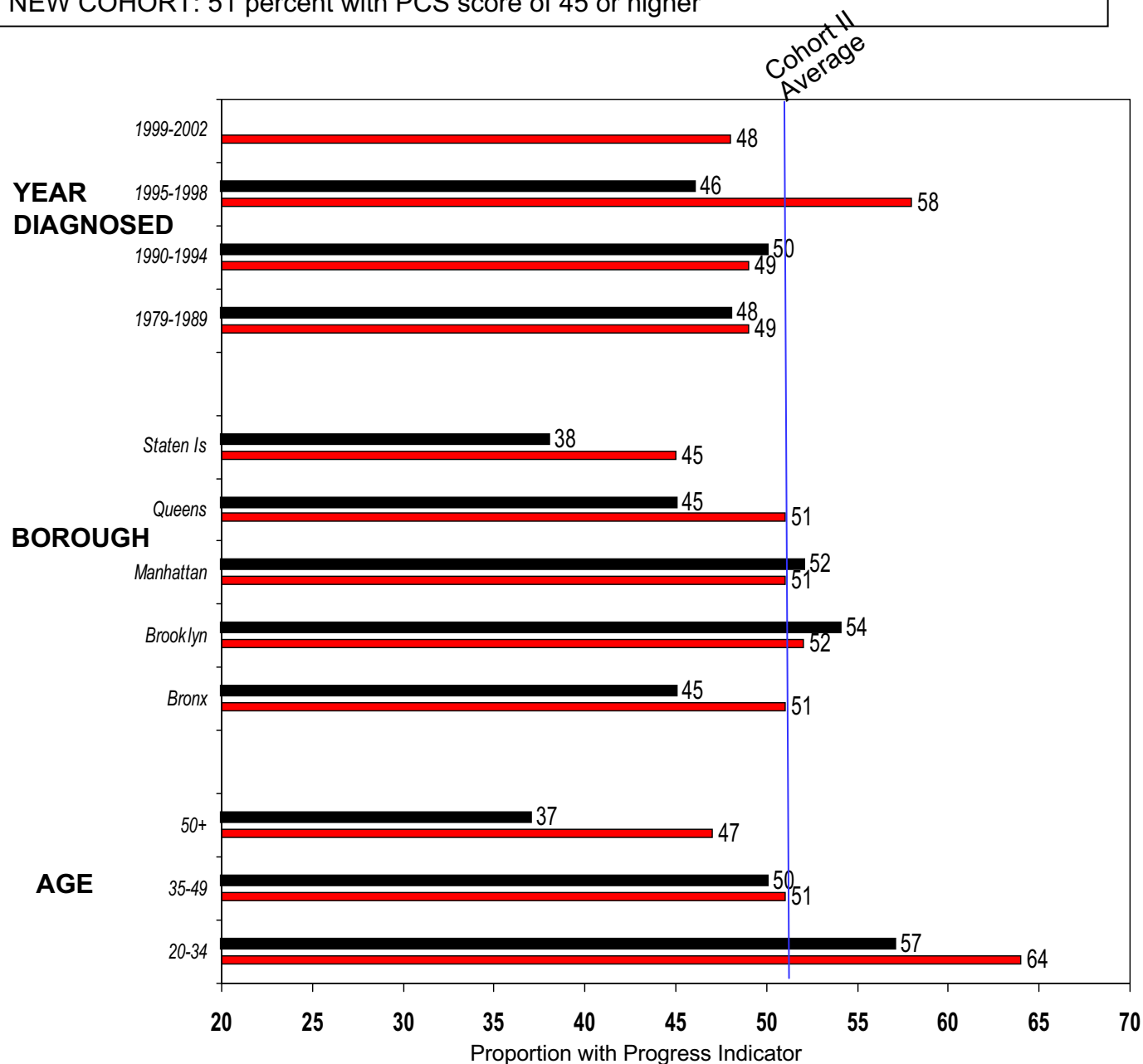
Health Service: Objective 1A-1 (continued)

Persons with HIV disease engaged in health care services will have improved survival and health outcomes.

PROGRESS INDICATOR: Self-reported health status, as measured by a standardized multi-item health scale (the PCS score).

BASELINE: 48 percent with PCS score of 45 or higher

NEW COHORT: 51 percent with PCS score of 45 or higher



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

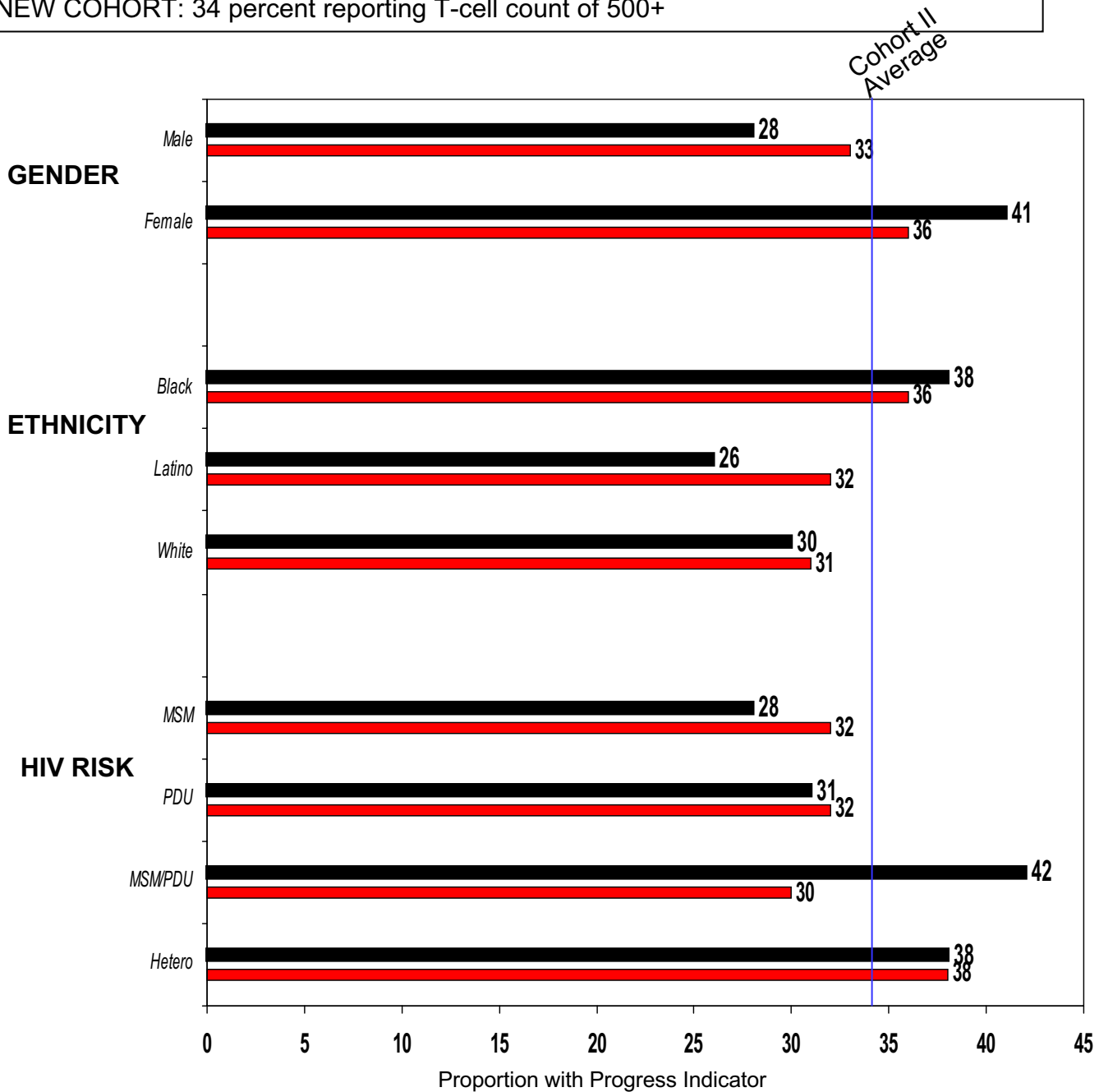
Health Service: Objective 1A-2

Persons with HIV disease engaged in health care services will have improved survival and health outcomes.

PROGRESS INDICATOR: Most recent self-reported T-cell count.

BASELINE: 34 percent reporting T-cell count of 500+

NEW COHORT: 34 percent reporting T-cell count of 500+



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

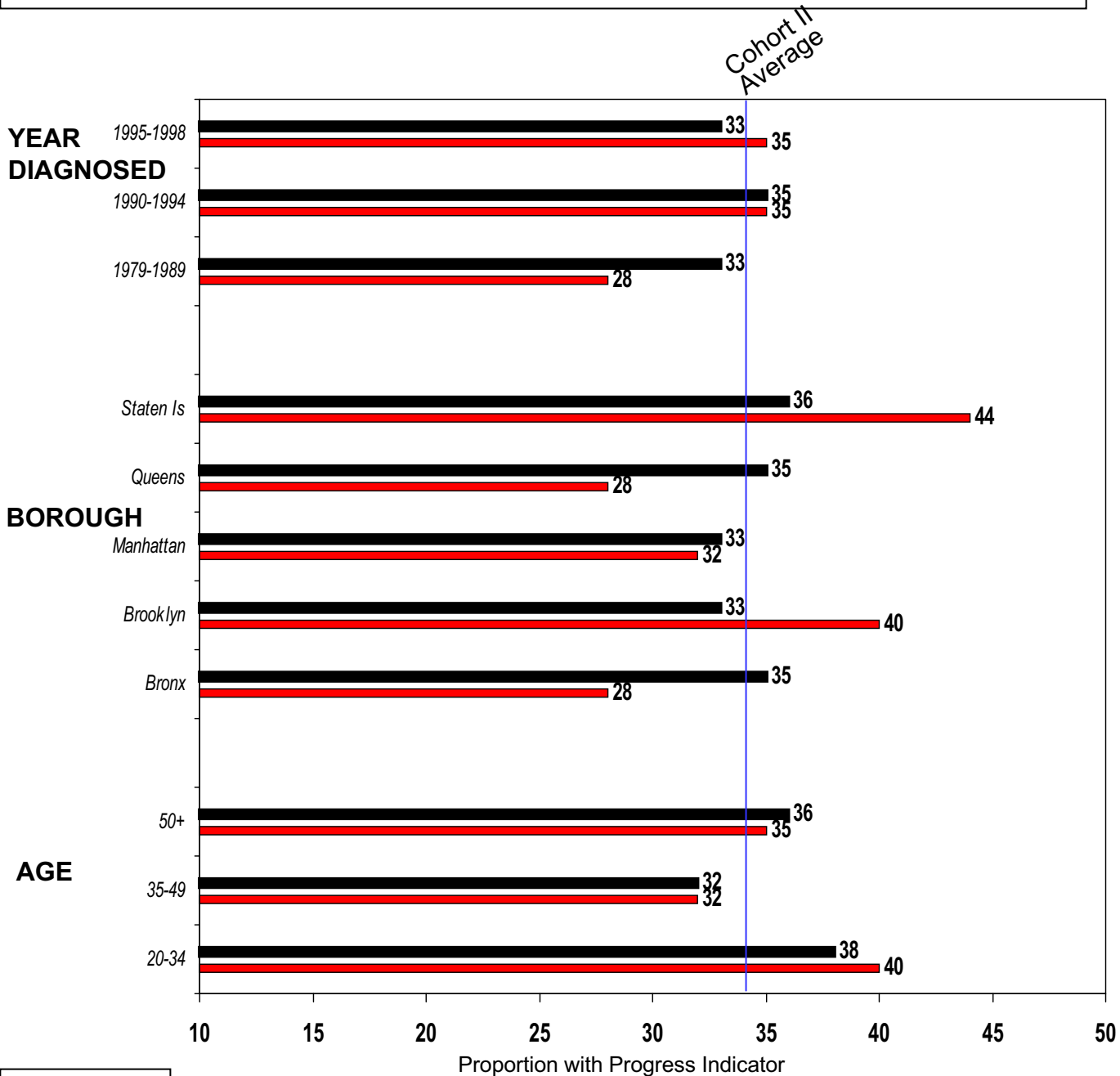
Health Service: Objective 1A-2 (continued)

Persons with HIV disease engaged in health care services will have improved survival and health outcomes.

PROGRESS INDICATOR: Most recent self-reported T-cell count.

BASELINE: 34 percent reporting T-cell count of 500+

NEW COHORT: 34 percent reporting T-cell count of 500+



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

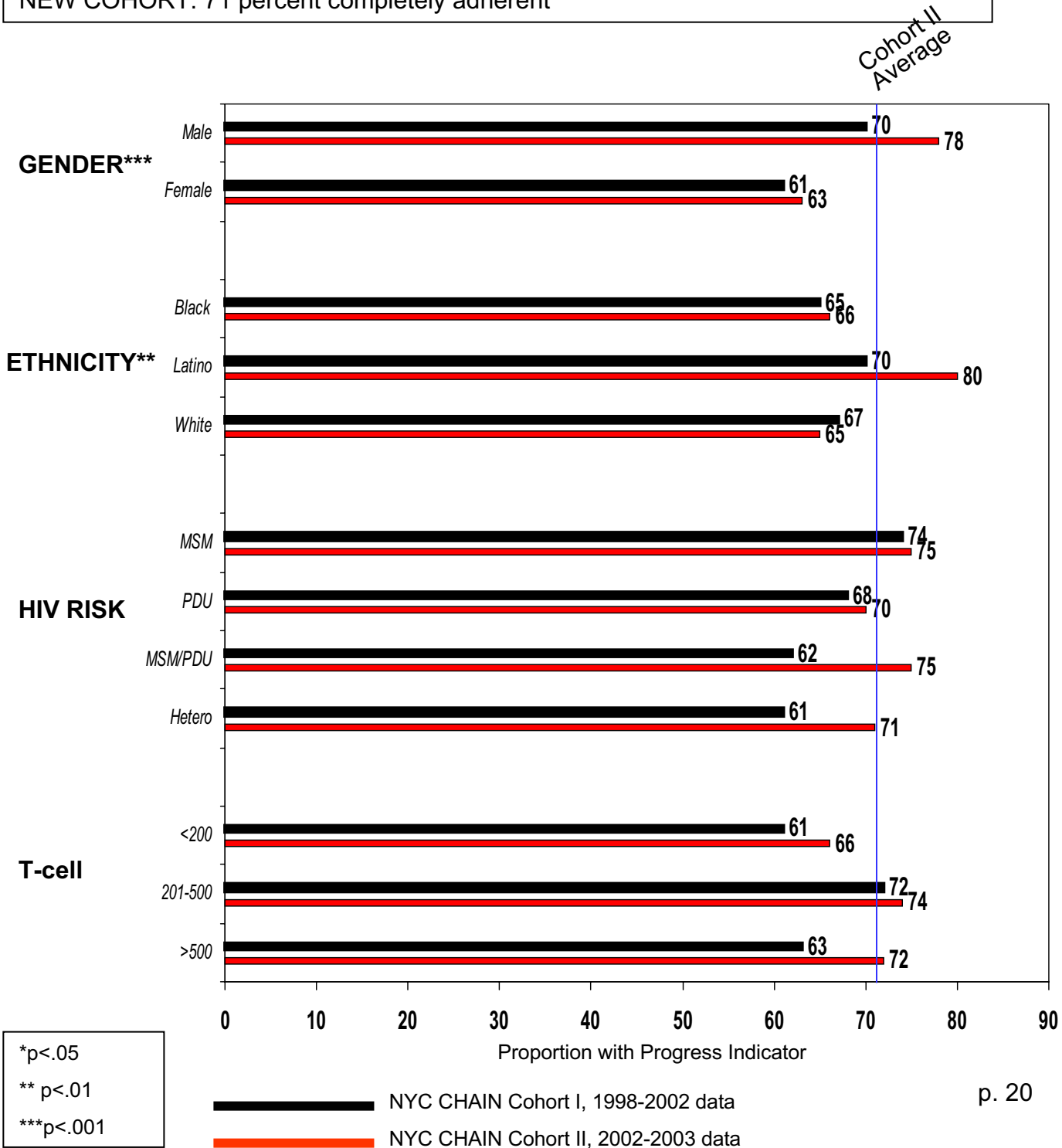
Health Service: Objective 1B

Persons who receive health services will adhere to treatments.

PROGRESS INDICATOR: Self-reported adherence to HIV antiretroviral medication, plus no reported missed pills in the two days prior to interview.

BASELINE: 67 percent completely adherent

NEW COHORT: 71 percent completely adherent



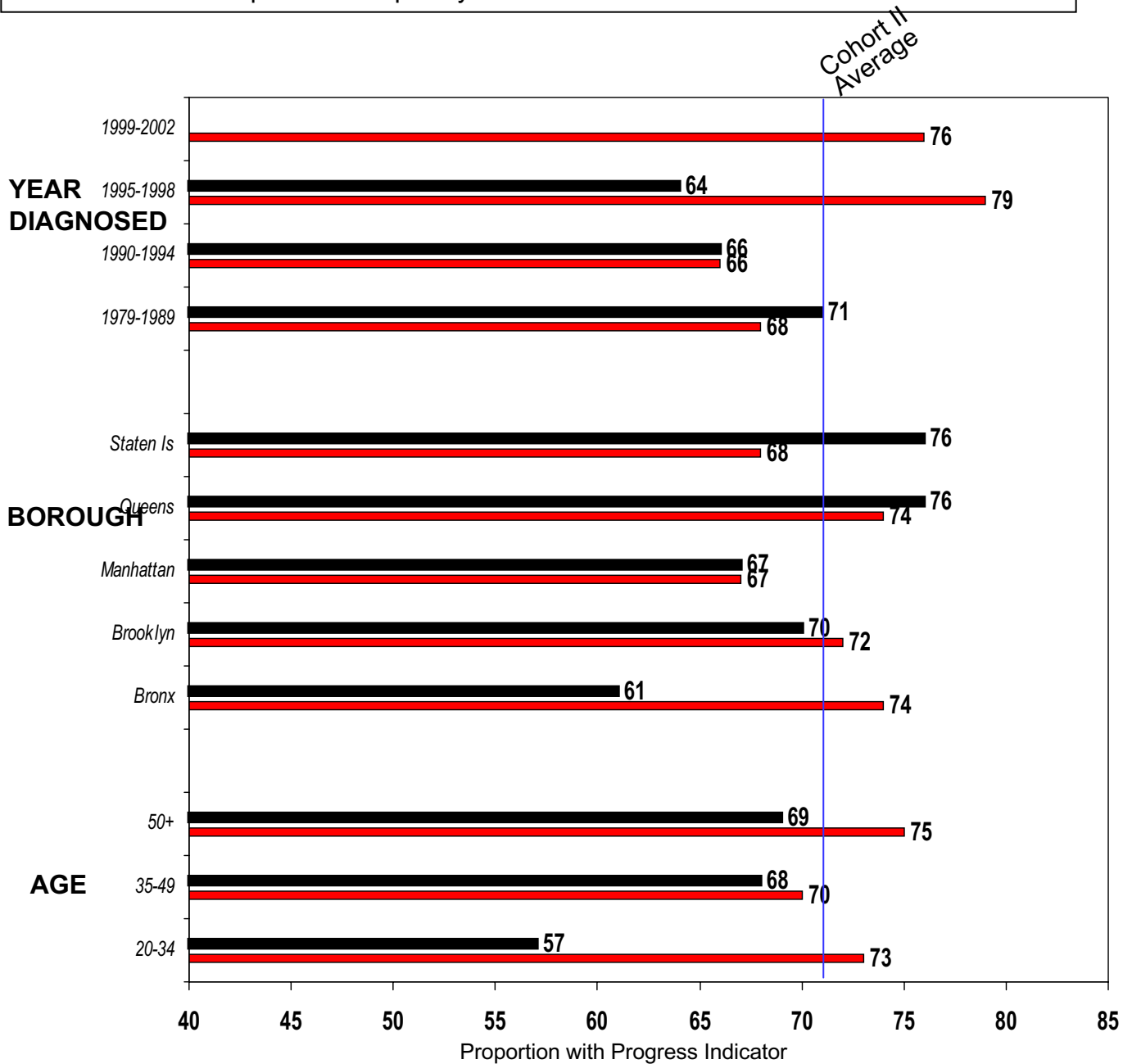
Health Service: Objective 1B (continued)

Persons who receive health services will adhere to treatments.

PROGRESS INDICATOR: Self-reported adherence to HIV antiretroviral medication, plus no reported missed pills in the two days prior to interview.

BASELINE: 67 percent completely adherent

NEW COHORT: 71 percent completely adherent



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

Health Service: Objective 2A

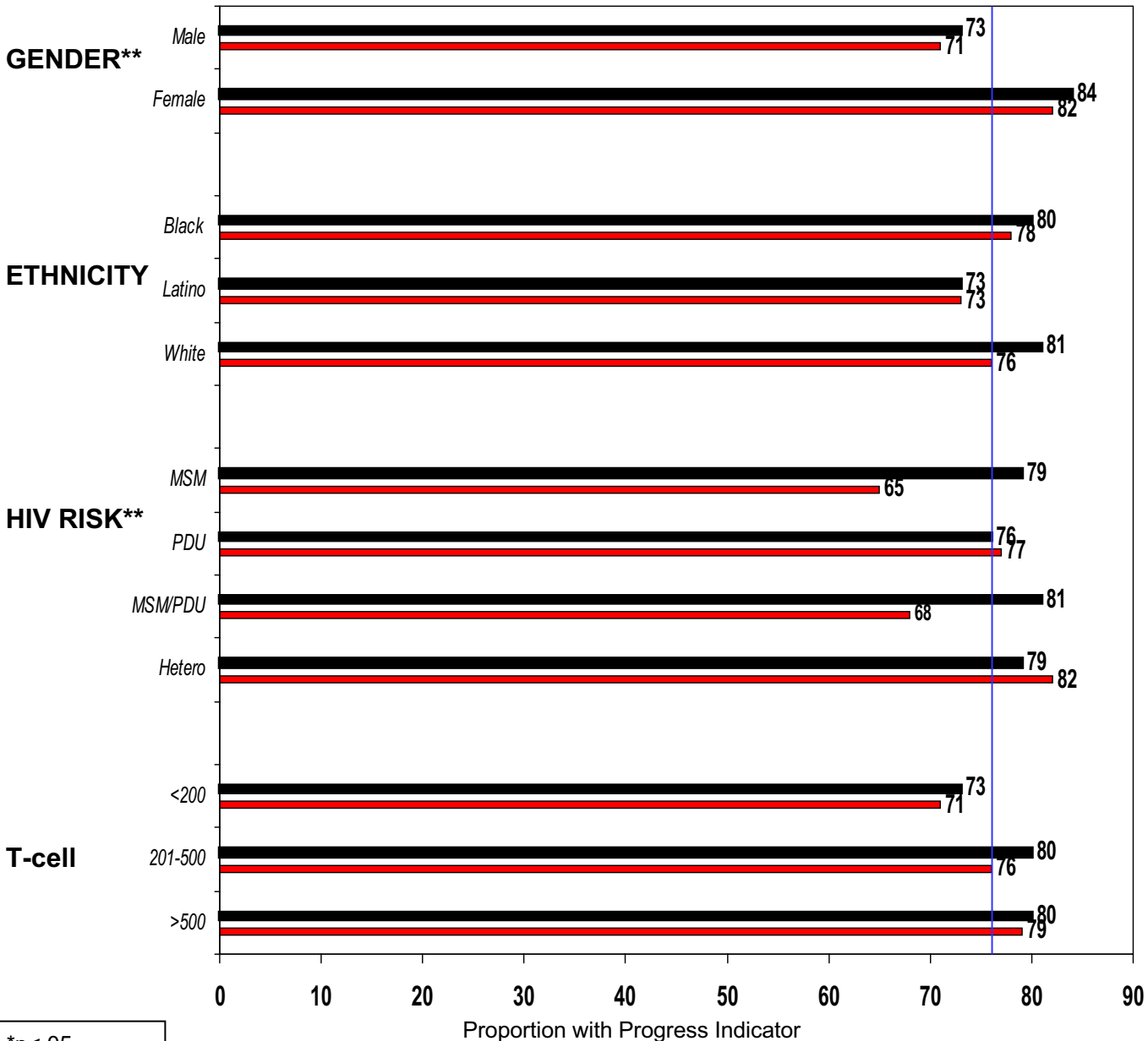
Persons with HIV disease engaged in care will remain connected to services once they have entered the continuum of care.

PROGRESS INDICATOR: Reported primary medical care doctor from same agency as last interview.

BASELINE: 78 percent

NEW COHORT: 76 percent

Cohort II
Average



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data
NYC CHAIN Cohort II, 2002-2003 data

Health Service: Objective 2A (continued)

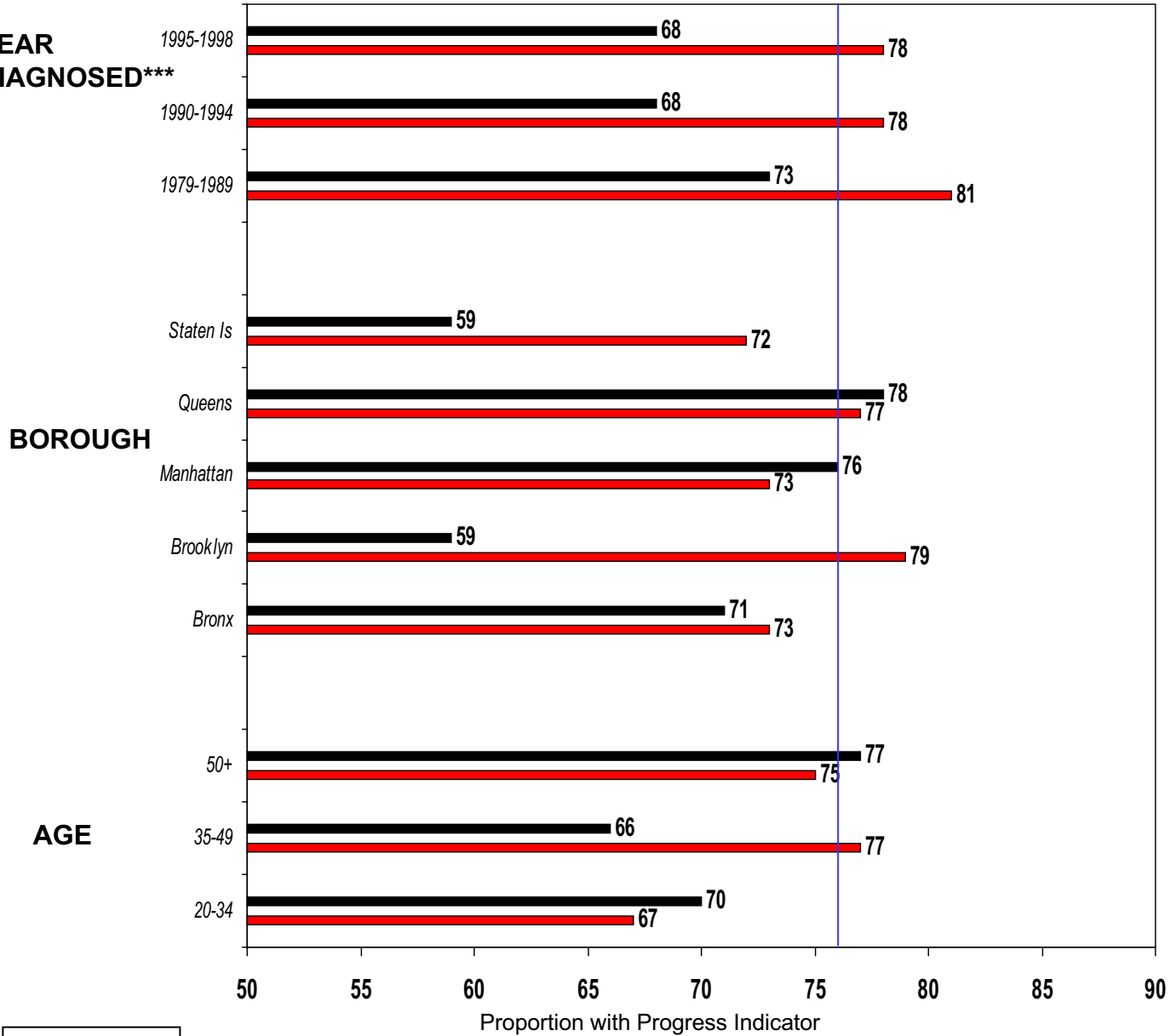
Persons with HIV disease engaged in care will remain connected to services once they have entered the continuum of care.

PROGRESS INDICATOR: Reported primary medical care doctor from same agency as last interview.

BASELINE: 78 percent

NEW COHORT: 76 percent

Cohort II
Average



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

Health Service: Objective 3A

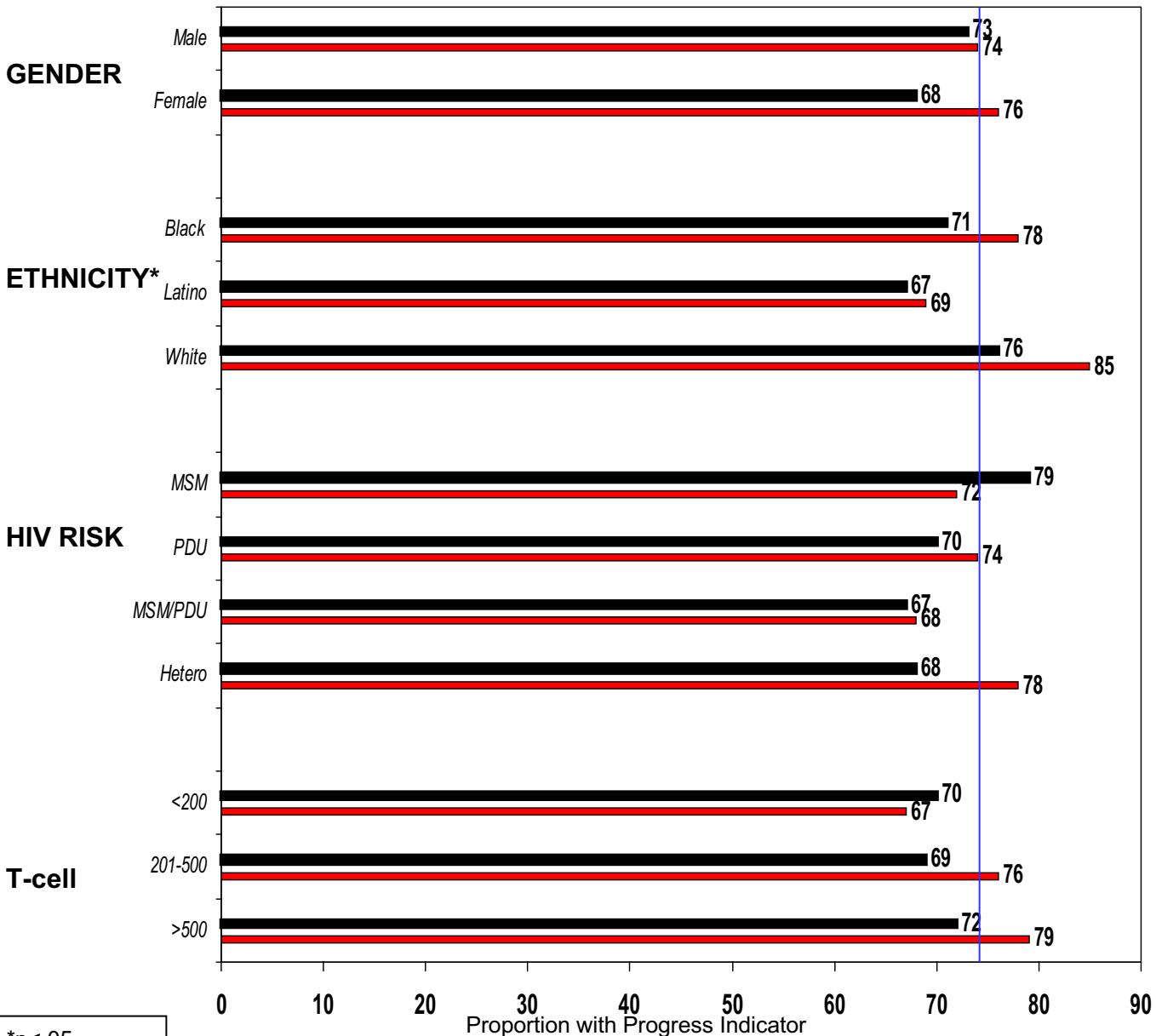
Persons with HIV disease who are in care receive services that meet or exceed the quality standards of the New York State AIDS Institute.

PROGRESS INDICATOR: Met 3 AI criteria for appropriate medical care: minimum number of medical visits, complete physical exam, and a blood workup.

BASELINE: 71 percent

NEW COHORT: 74 percent

Cohort II
Average



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

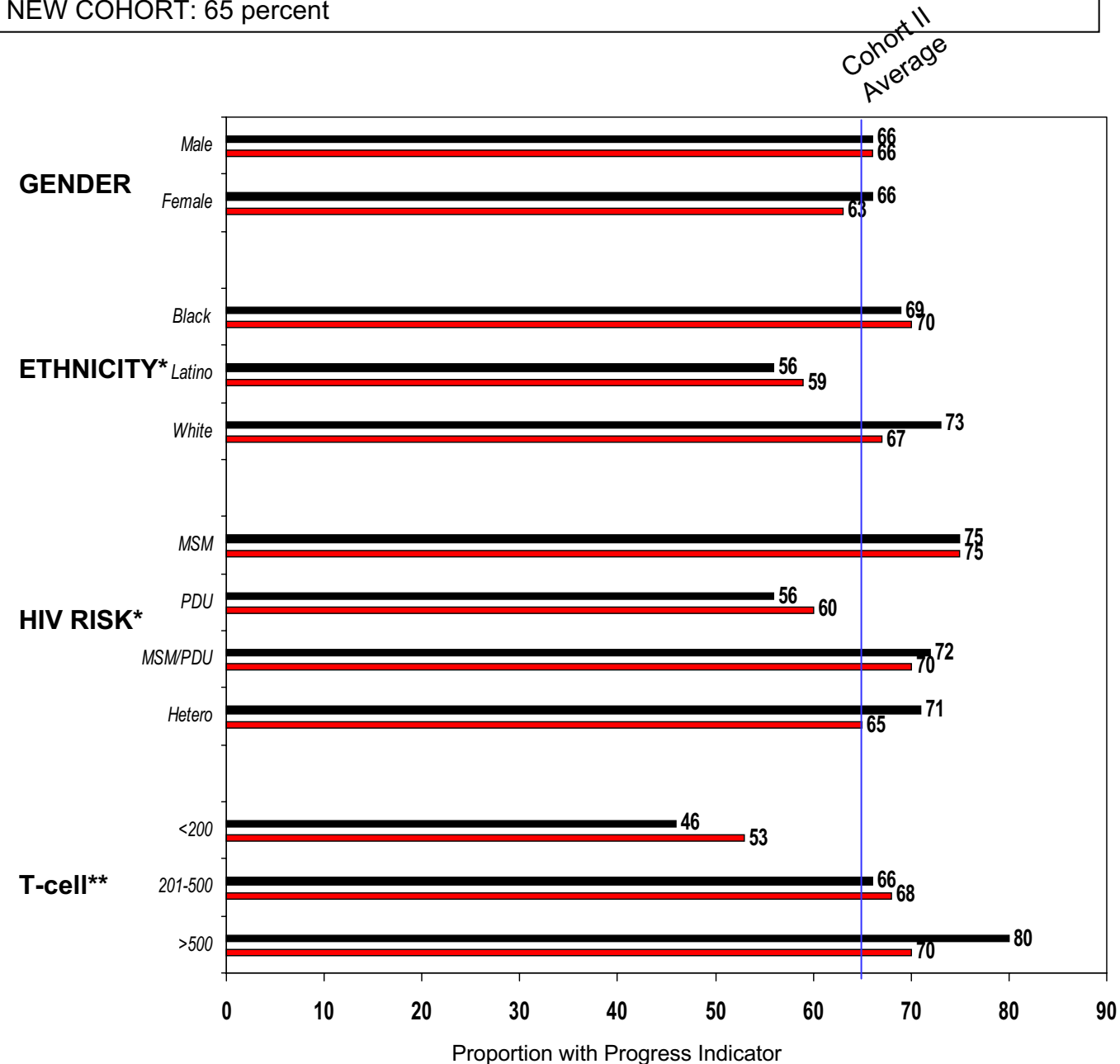
Health Service: Objective 3B

Persons with HIV disease report their health-related quality of life as “good” or better.

PROGRESS INDICATOR: Single global question measuring self-reported health status: “In general, would you say your health is excellent, very good, good, fair or poor?” (reporting “excellent,” “very good,” or “good”)

BASELINE: 66 percent

NEW COHORT: 65 percent



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

Health Service:

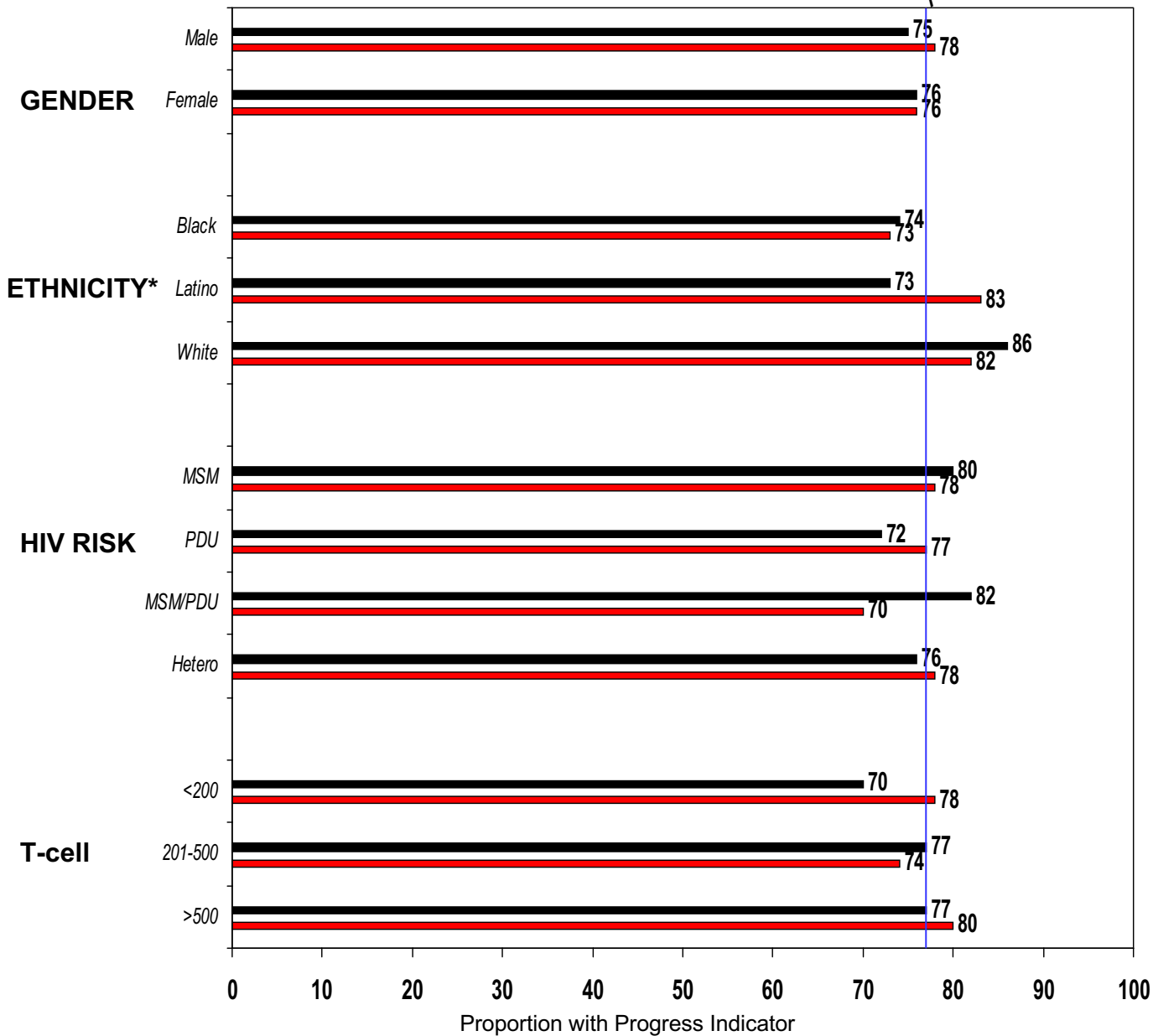
Comprehensive medical care.

PROGRESS INDICATOR: Respondents report receiving comprehensive medical care, defined as a primary medical provider available for well-visits, health advice or information, and accessible 24 hours a day if needed.

BASELINE: 75 percent

NEW COHORT: 77 percent

Cohort II
Average



*p<.05

** p<.01

***p<.001

— NYC CHAIN Cohort I, 1998-2002
 — NYC CHAIN Cohort II, 2002-2003

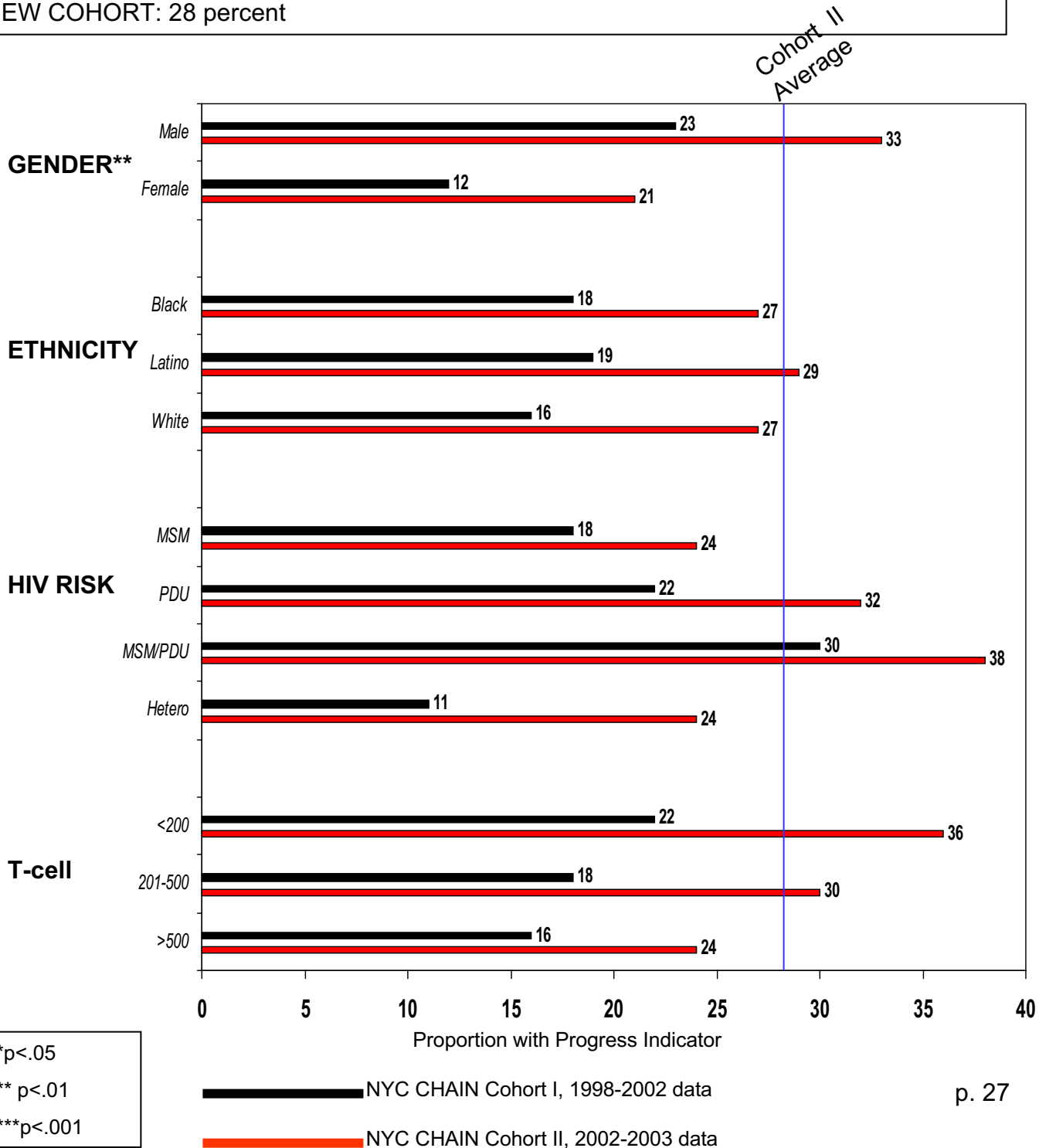
Housing: Objective 1A

Transitional housing will be available to people with HIV/AIDS who need it.

PROGRESS INDICATOR: Reported being unstably housed: any episode of living in street, shelter, single room occupancy, or doubled up with a friend or relative.

BASELINE: 18 percent

NEW COHORT: 28 percent



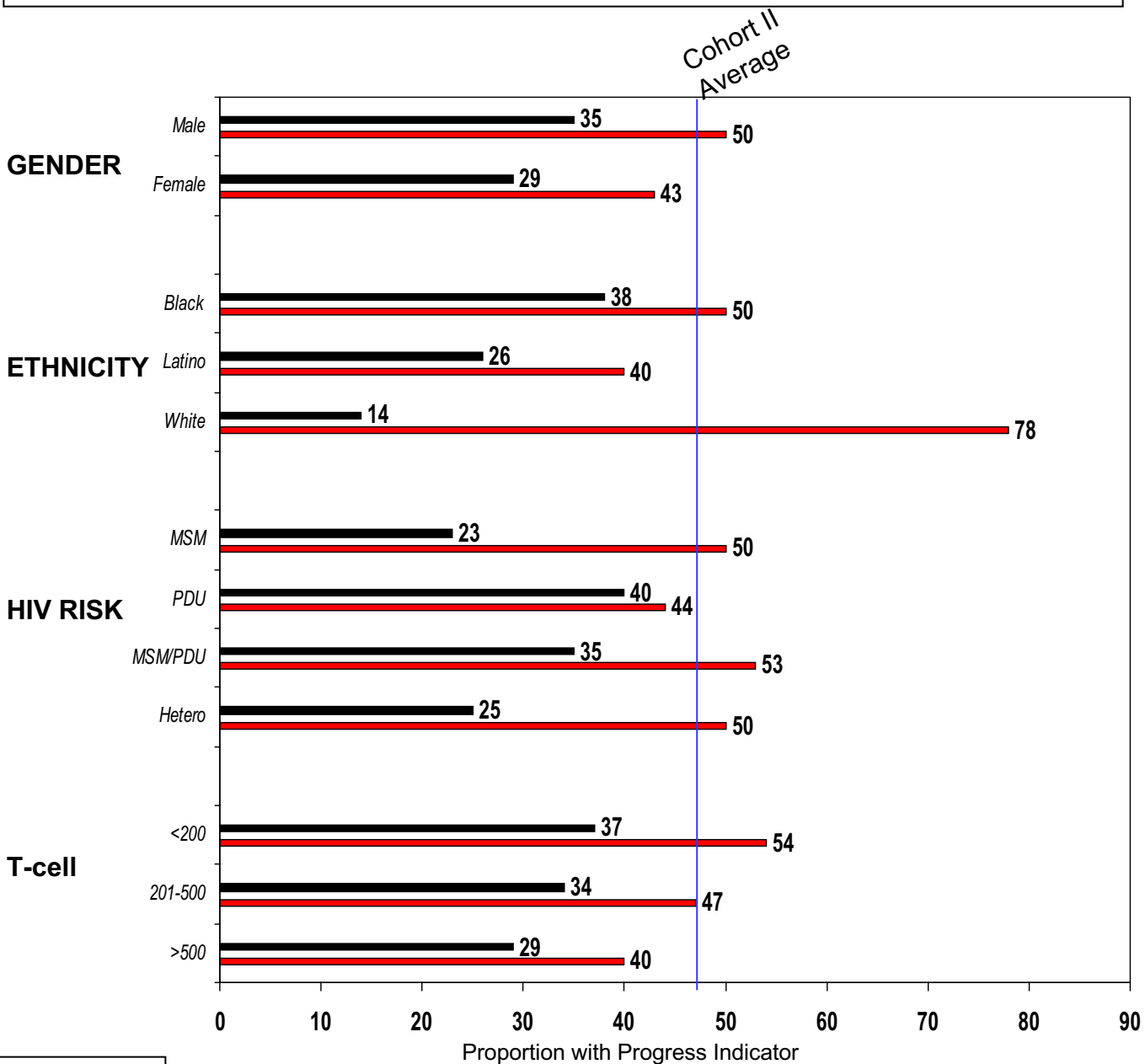
Housing: Objective 2A

Housing placement assistance services will be available for persons with HIV who need them.

PROGRESS INDICATOR: Among those who reported being unstably housed, those who received a housing subsidy, lived in specialized AIDS housing (such as scatter-site housing), or received housing services to assist with house/apartment maintenance, landlord/tenant issues, access, etc.

BASELINE: 33 percent

NEW COHORT: 47 percent



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

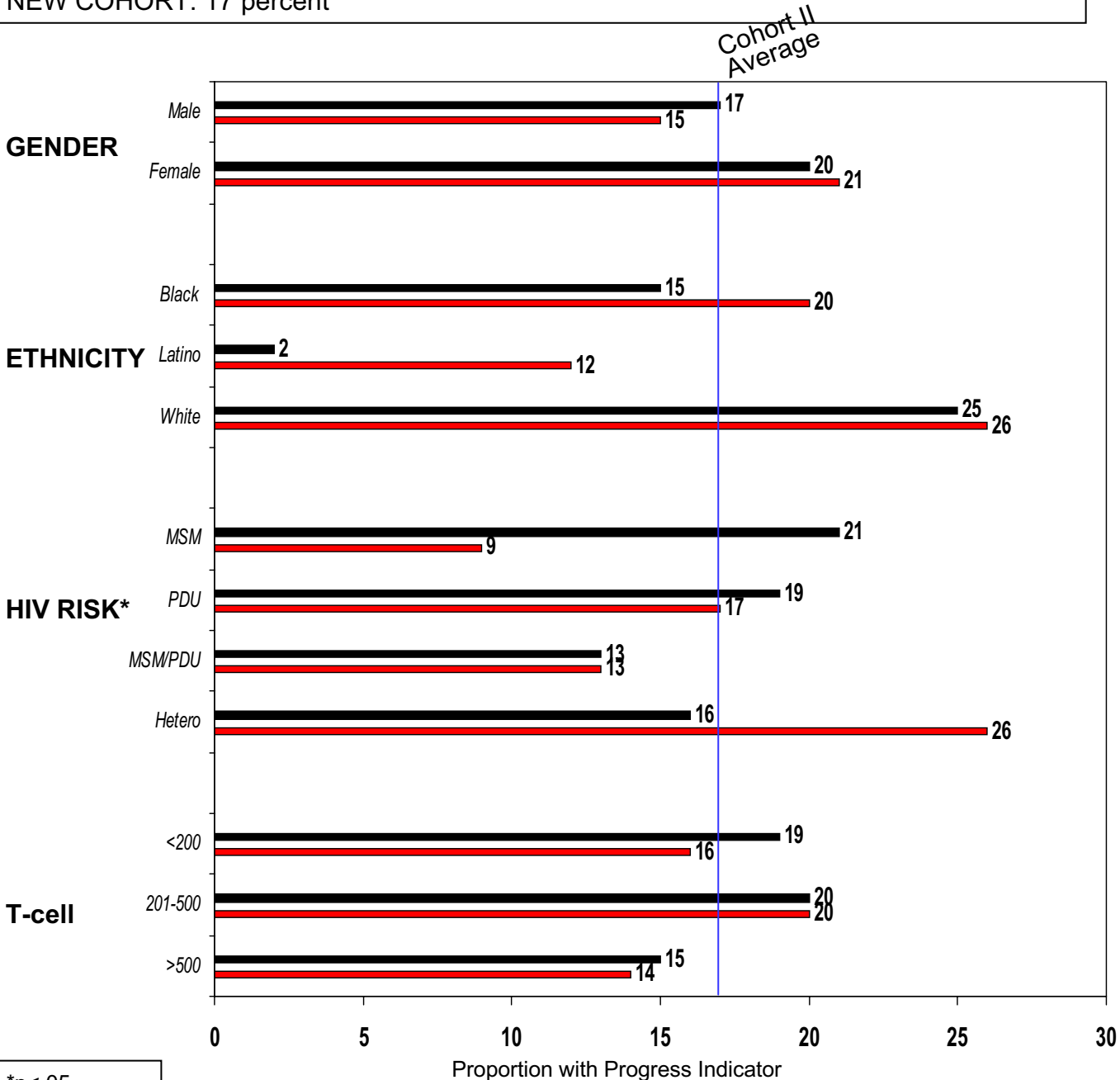
AOD: Objective 1A

Health care/mental health and other providers will understand AOD culture and provide culturally appropriate and sensitive treatment to AOD users.

PROGRESS INDICATOR: Among those who reported current or past drug use, proportion who delayed or did not get medical or social services because staff were insensitive, misunderstood client, or treated client poorly.

BASELINE: 18 percent

NEW COHORT: 17 percent



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

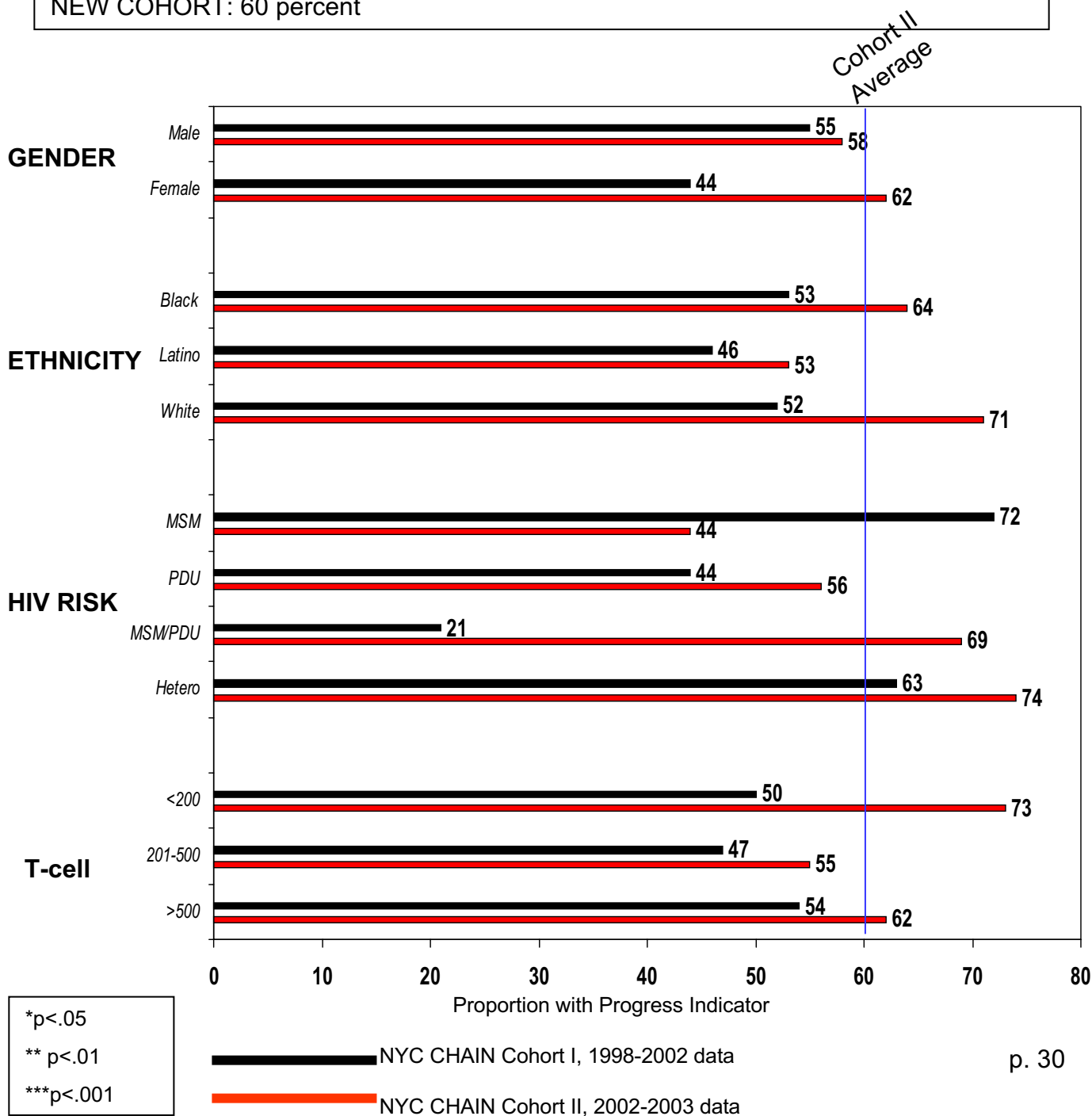
AOD: Objective 1B

Health care, mental health and other services will be more available and accessible to AOD users.

PROGRESS INDICATOR: Among those who reported current or past drug use and had objective need for mental health services, those who reported that they received professional or supportive mental health services.

BASELINE: 50 percent

NEW COHORT: 60 percent



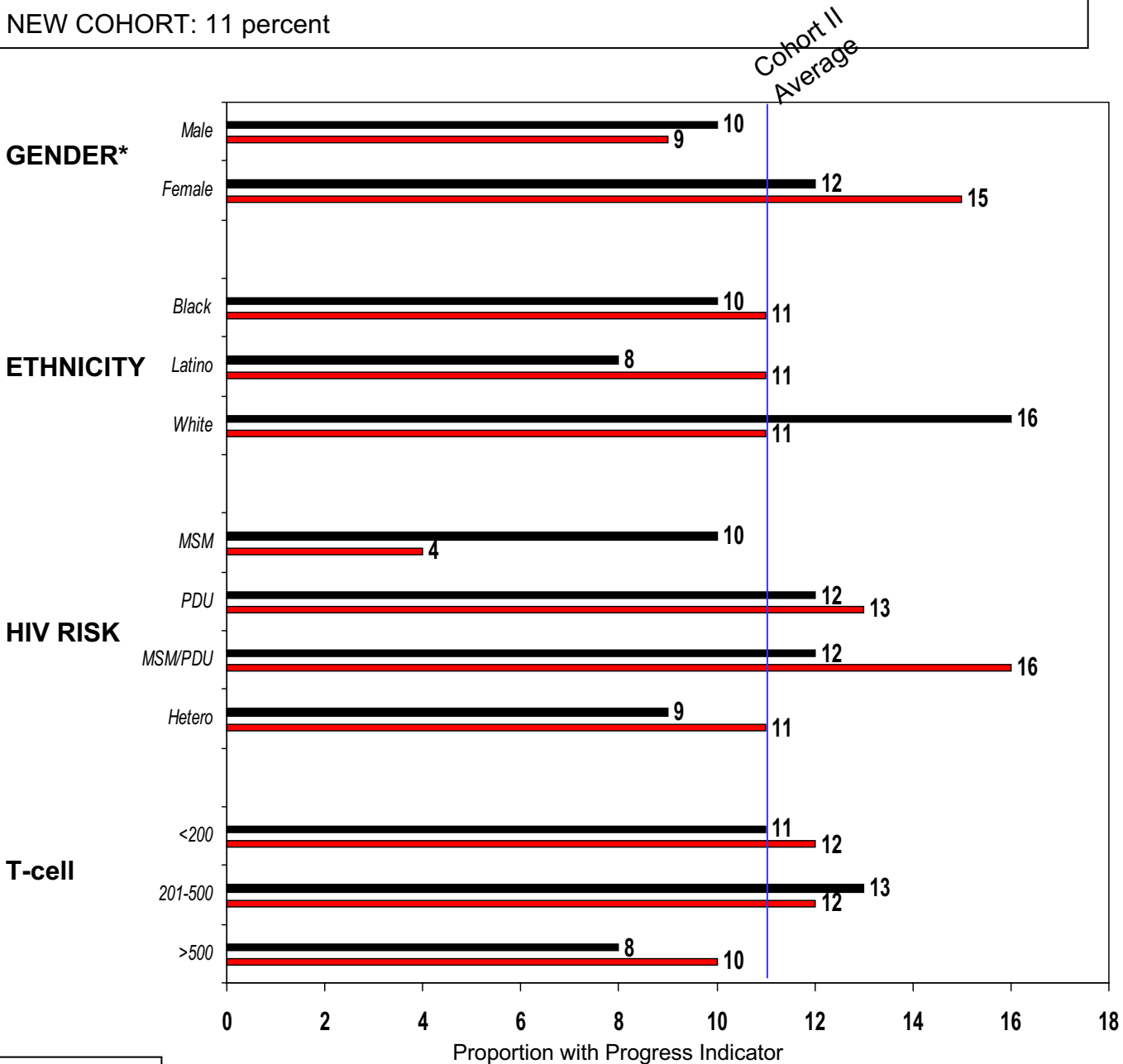
Infrastructure: Objective 1A

Appropriate information will be available on type and location of services and on options for choosing services that best meet the needs of persons with HIV.

PROGRESS INDICATOR: Proportion reporting they delayed or did not get medical or social services because they didn't know or weren't sure where to go for medical or social services.

BASELINE: 11 percent

NEW COHORT: 11 percent



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

Social Services: Objective 1B

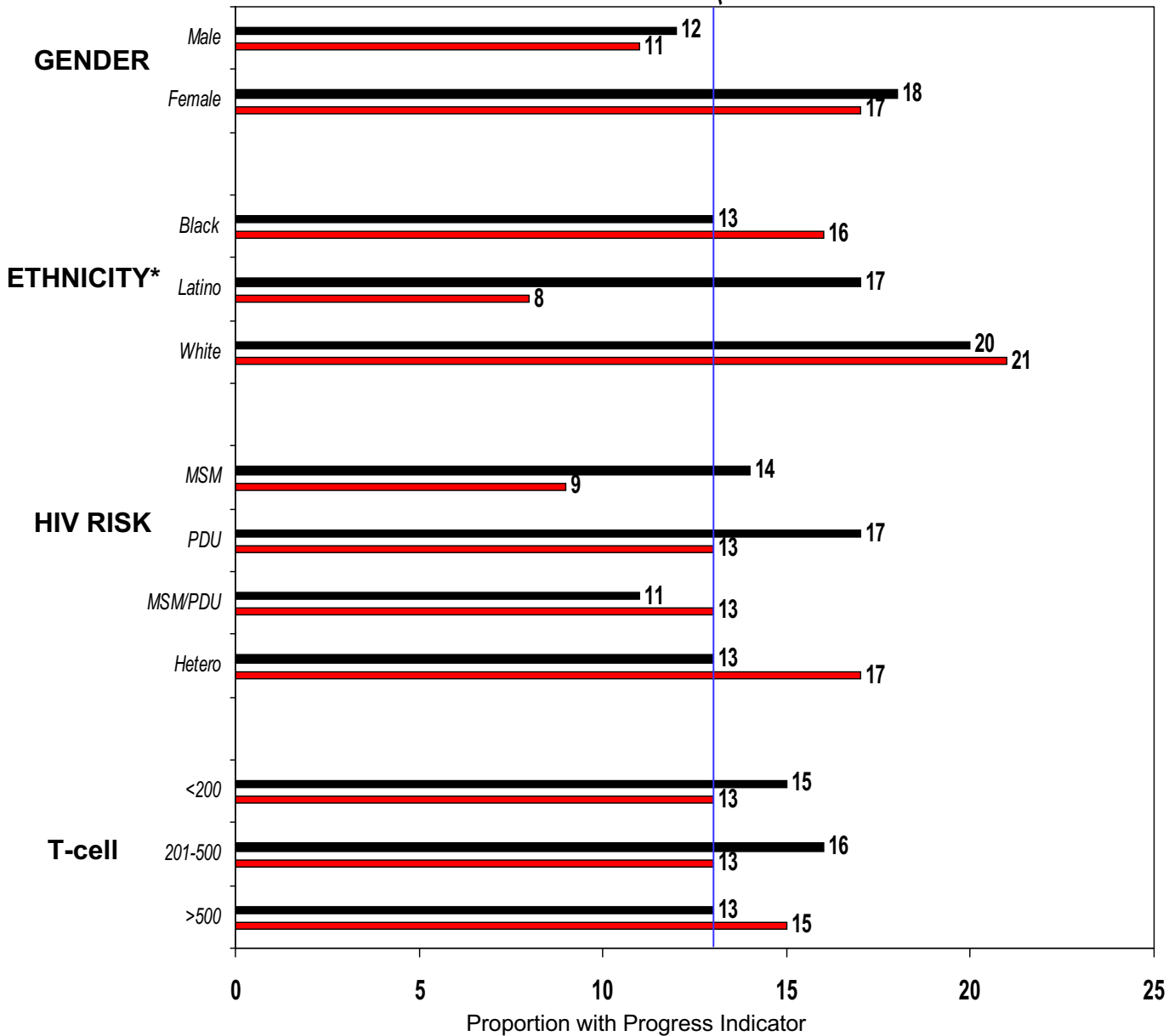
PLWH/A will have access to culturally competent and linguistically appropriate social services

PROGRESS INDICATOR: Proportion reporting they delayed or did not get medical or social services because staff didn't speak their language, were not competent, were disrespectful, didn't understand client's problems, or were not good at listening.

BASELINE: 15 percent

NEW COHORT: 13 percent

Cohort II
Average



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

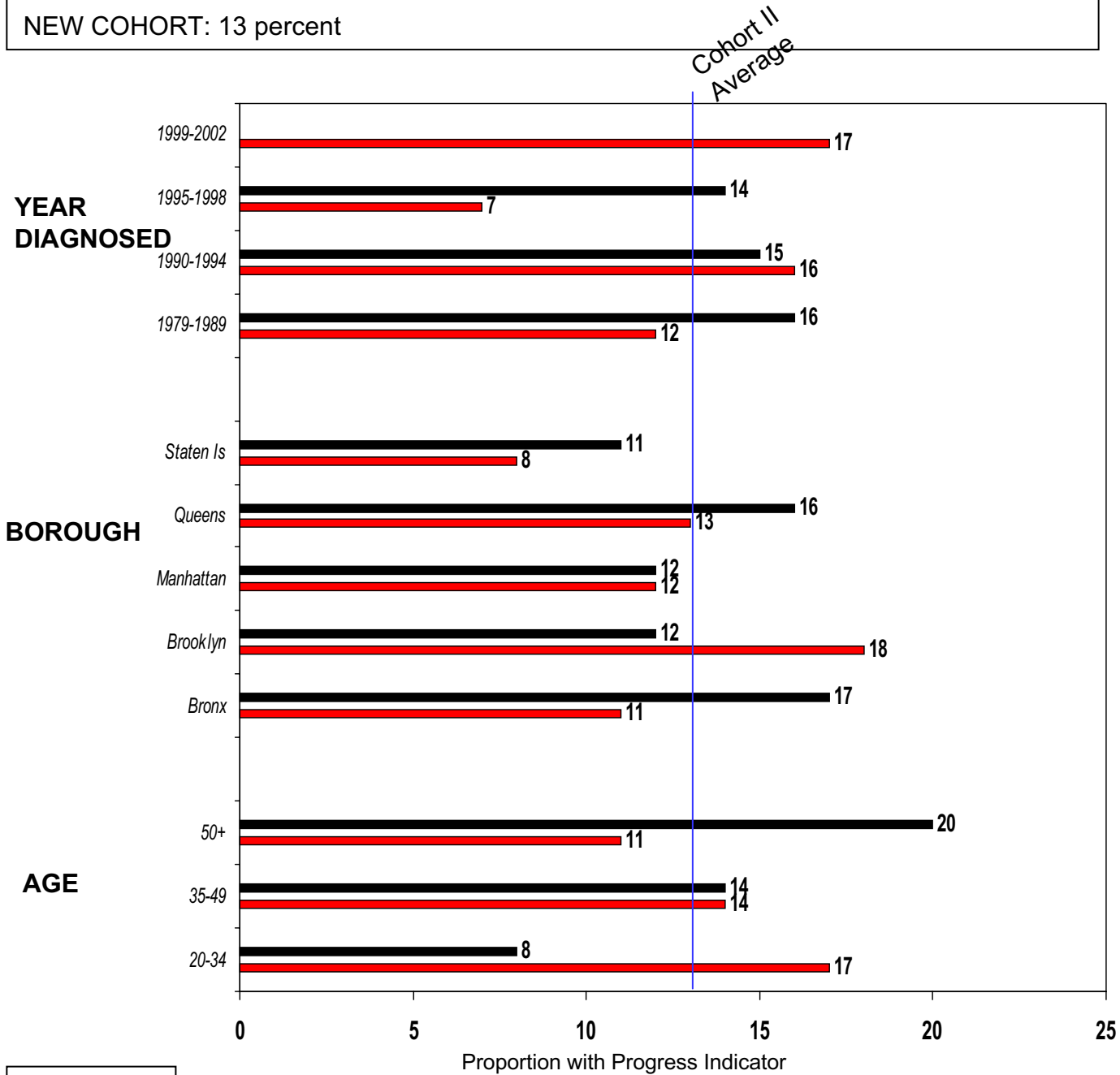
Social Services: Objective 1B (continued)

PLWH/A will have access to culturally competent and linguistically appropriate social services

PROGRESS INDICATOR: Proportion reporting they delayed or did not get medical or social services because staff didn't speak their language, were not competent, were disrespectful, didn't understand client's problems, or were not good at listening.

BASELINE: 15 percent

NEW COHORT: 13 percent



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

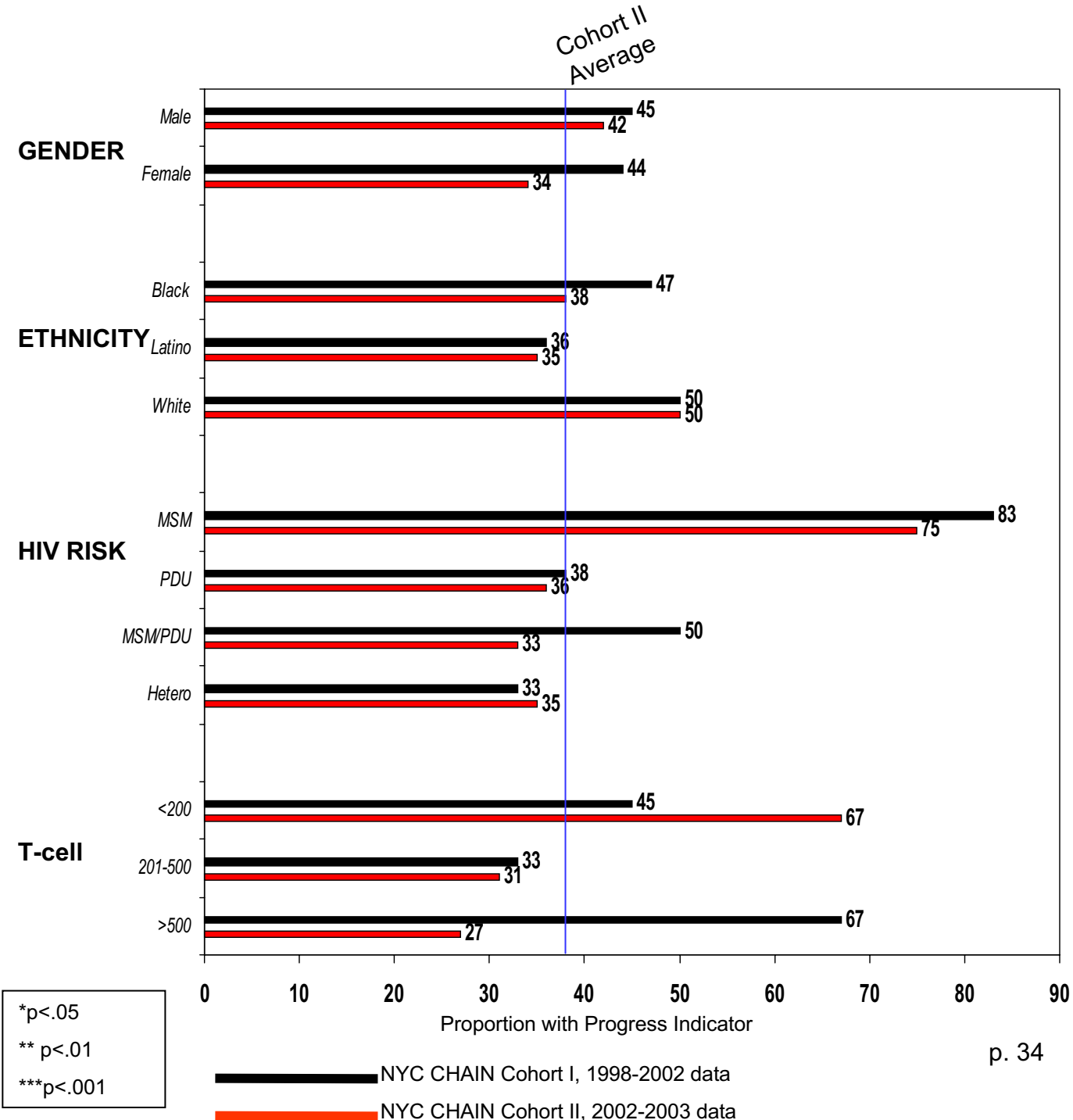
Social Services: Objective 1C

PLWH/A will have access to necessary transportation services.

PROGRESS INDICATOR: Among those who reported needing help with transportation services or that it was a barrier in receiving care in the 6 months prior to interview, those who received transportation services.

BASELINE: 45 percent

NEW COHORT: 38 percent



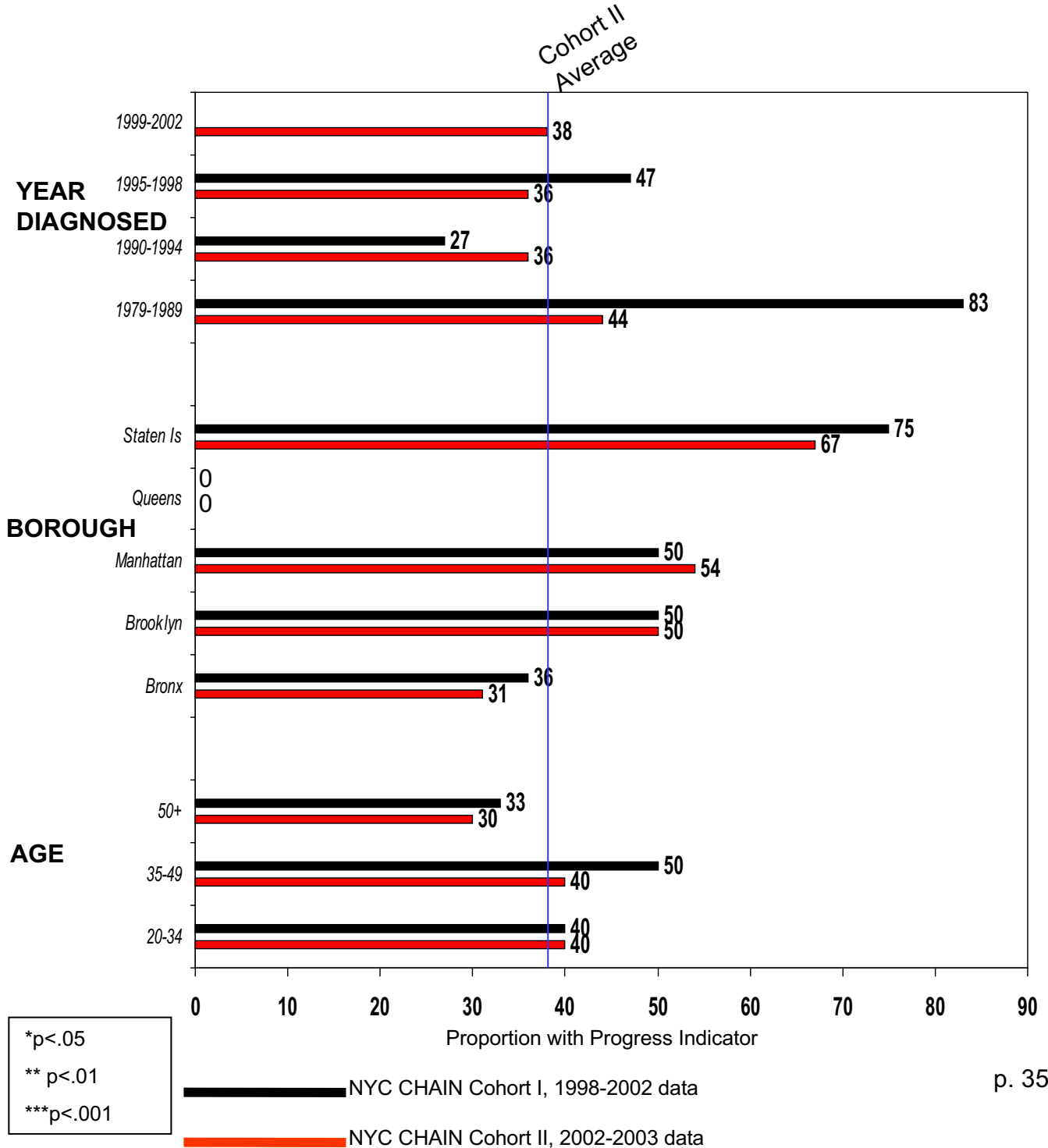
Social Services: Objective 1C (continued)

PLWH/A will have access to necessary transportation services.

PROGRESS INDICATOR: Among those who reported needing help with transportation services or that it was a barrier in receiving care in the 6 months prior to interview, those who received transportation services.

BASELINE: 45 percent

NEW COHORT: 38 percent



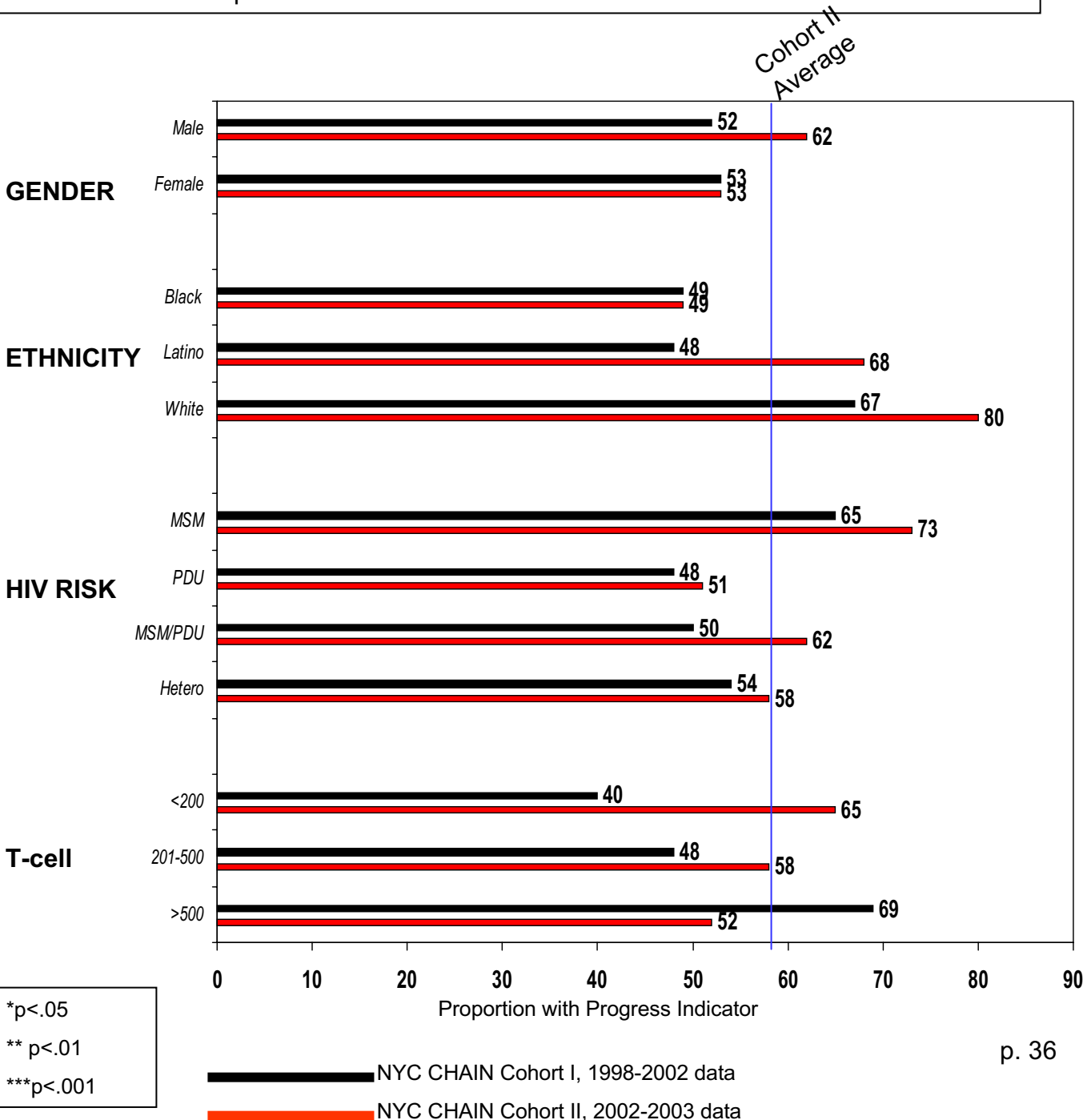
Social Services: Objective 1D

PLWH/A will have access to a broad range of support, advocacy and basic needs programs within their geographic area.

PROGRESS INDICATOR: Among those who expressed needing assistance with legal matters, child care, or food/groceries/meals, those who reported that “no change has occurred in the situation or no progress has been made” or that “the problems have been getting worse” in the respective areas.

BASELINE: 53 percent

NEW COHORT: 58 percent



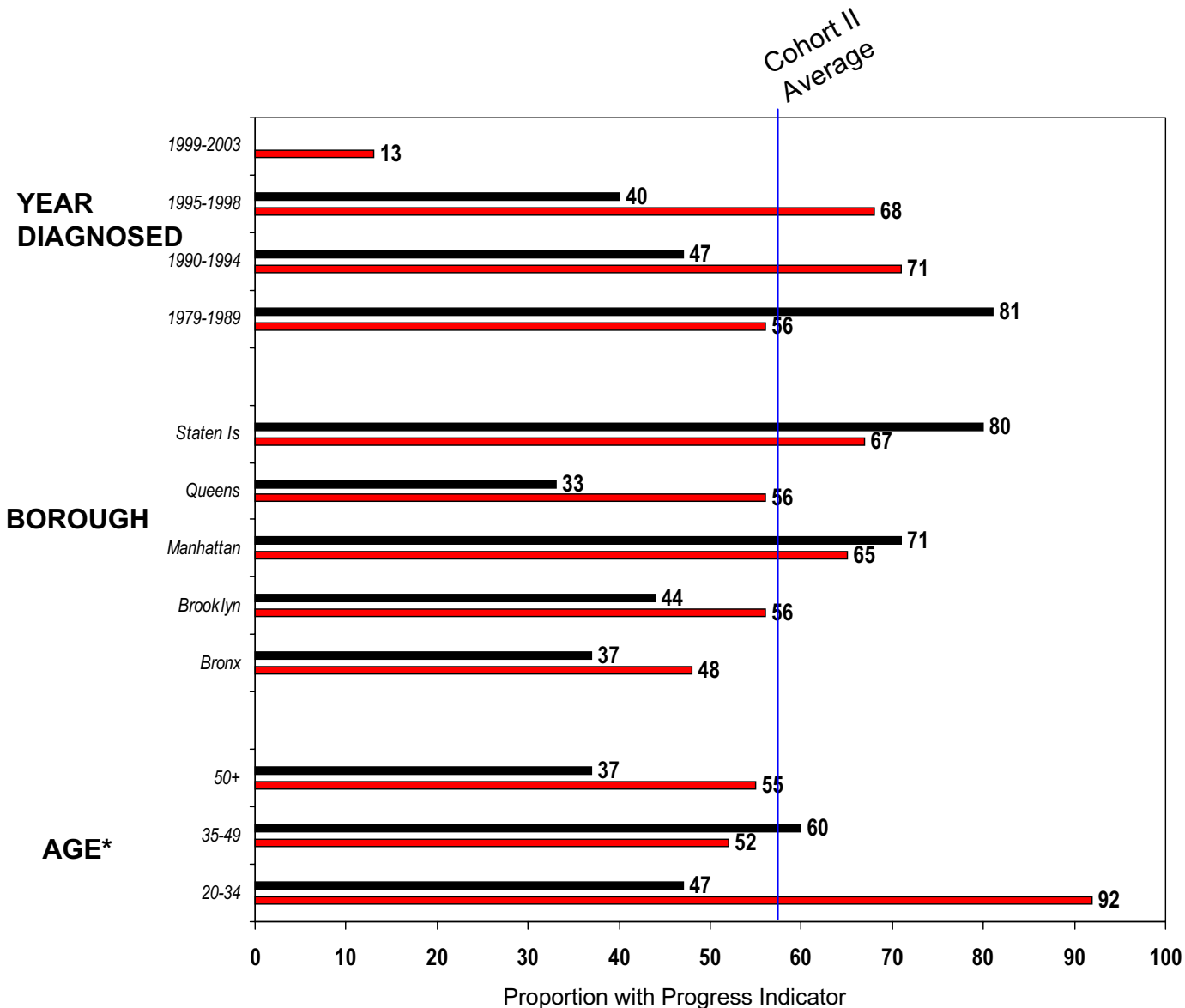
Social Services: Objective 1D (continued)

PLWH/A will have access to a broad range of support, advocacy and basic needs programs within their geographic area.

PROGRESS INDICATOR: Among those who expressed needing assistance with legal matters, child care, or food/groceries/meals, those who reported that “no change has occurred in the situation or no progress has been made” or that “the problems have been getting worse” in the respective areas.

BASELINE: 53 percent

NEW COHORT: 58 percent



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

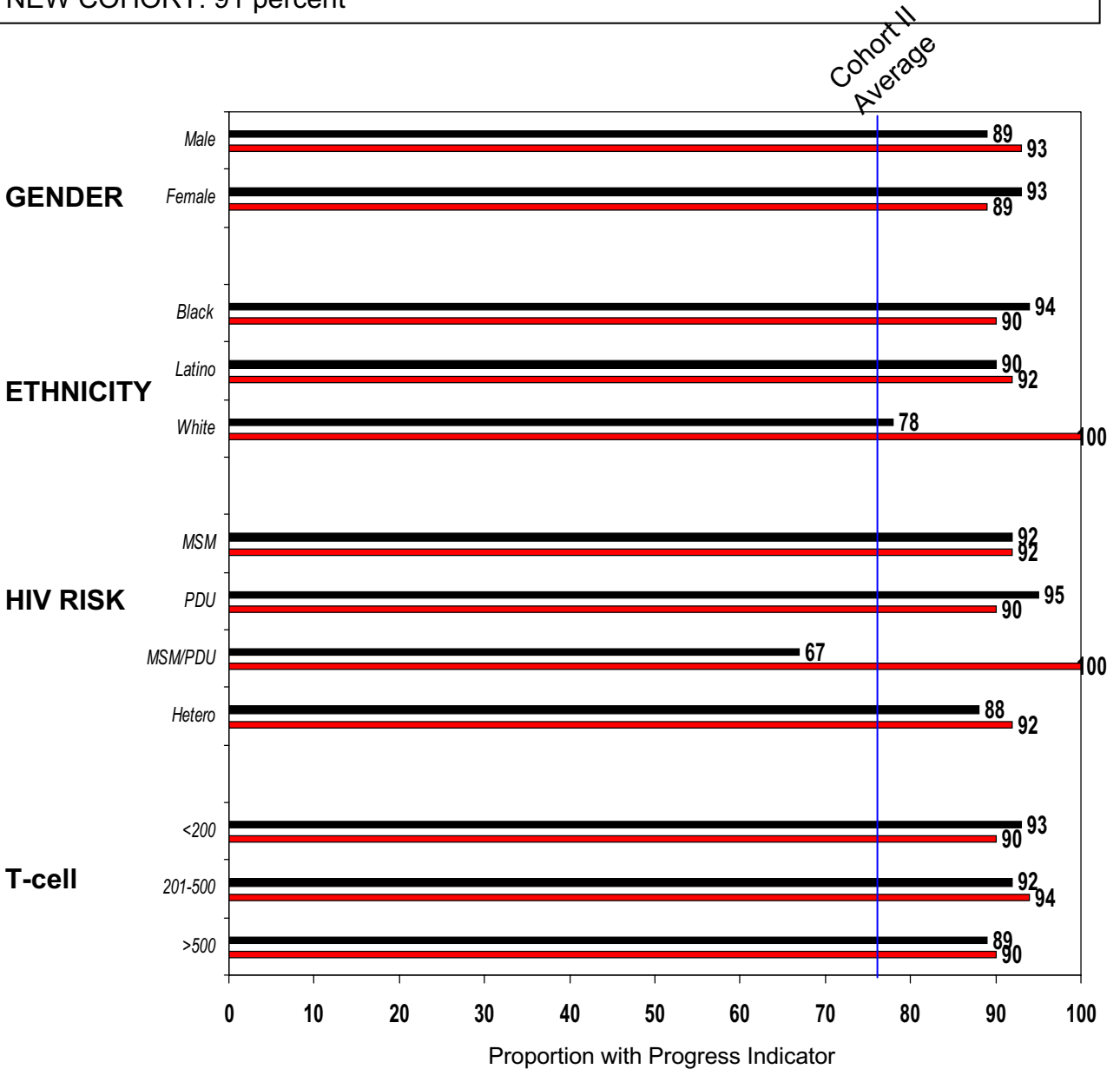
Social Service: Objective 3B

PLWH/A will have increased knowledge regarding treatment issues and adherence strategies

PROGRESS INDICATOR: Among those who received help with taking medication those who reported that the advice was “very helpful” or “somewhat helpful.”

BASELINE: 91 percent

NEW COHORT: 91 percent



*p<.05

** p<.01

***p<.001

— NYC CHAIN Cohort I, 1998-2002 data

— NYC CHAIN Cohort II, 2002-2003 data

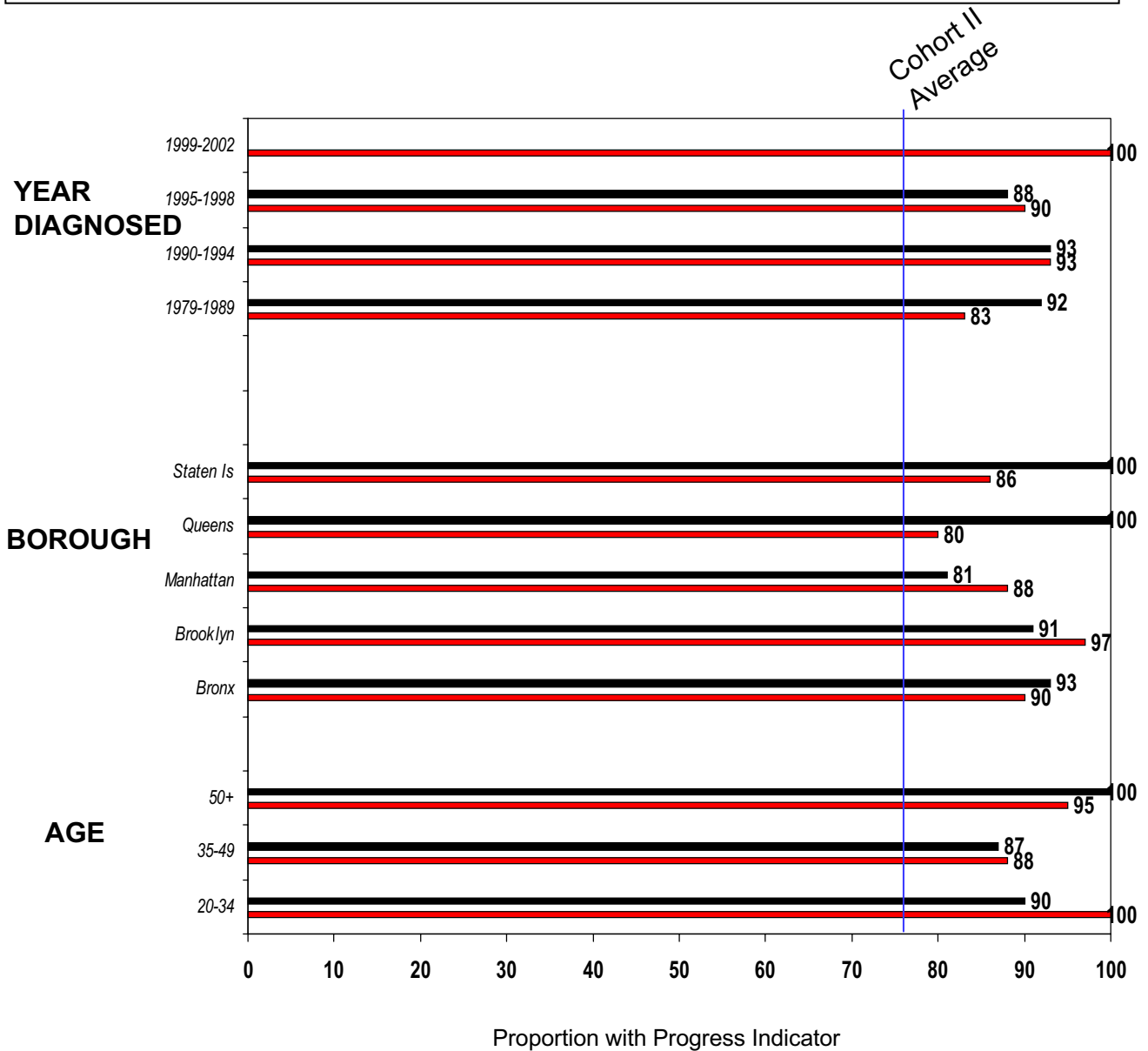
Social Service: Objective 3B (continued)

PLWH/A will have increased knowledge regarding treatment issues and adherence strategies

PROGRESS INDICATOR: Among those who received help with taking medication those who reported that the advice was “very helpful” or “somewhat helpful.”

BASELINE: 91 percent

NEW COHORT: 91 percent



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

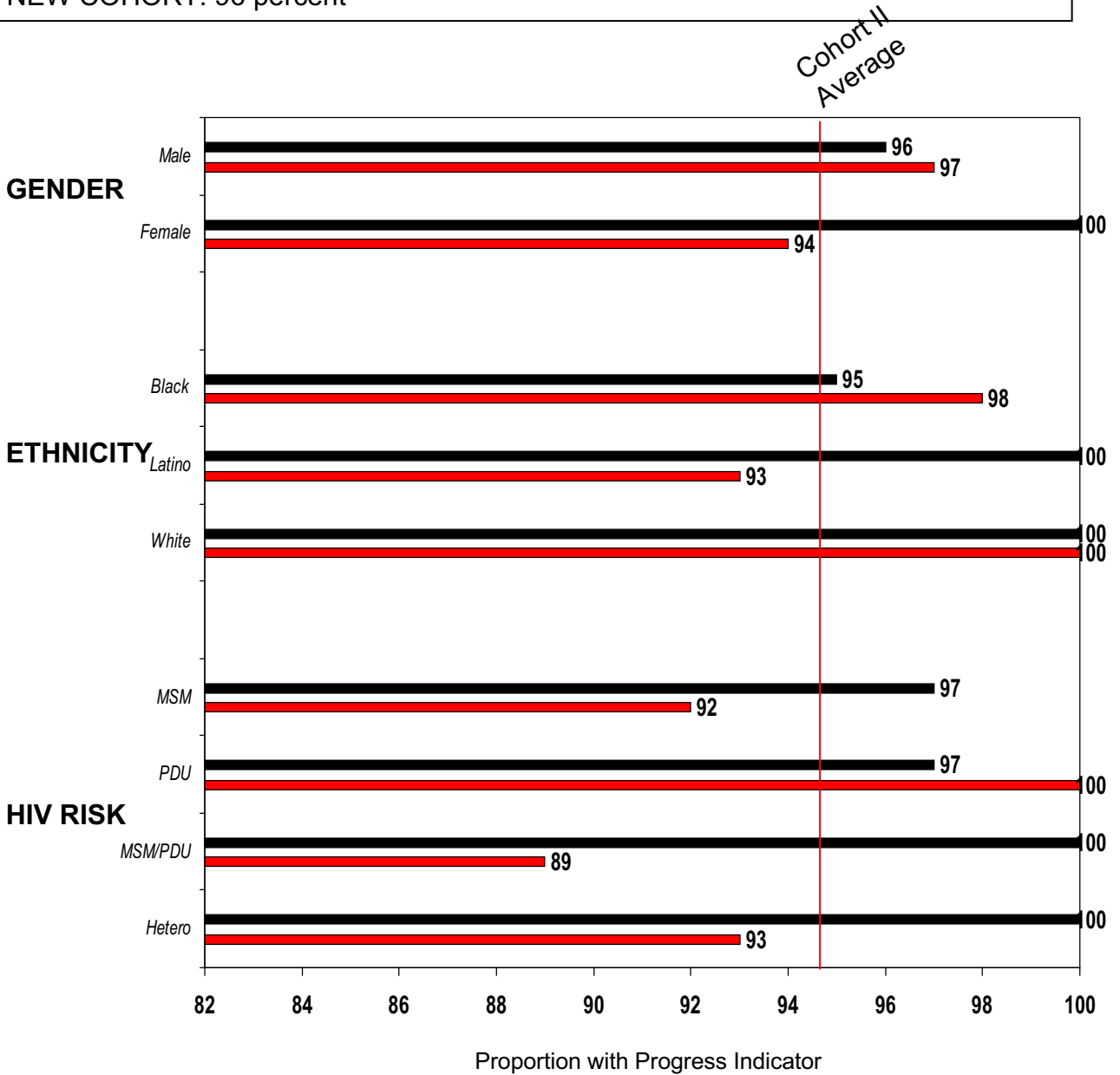
Social Services: Objective 4A

Unmet benefit need.

PROGRESS INDICATOR: Among those who had need for benefits (annual household incomes below \$10,000 and T-cell counts below 200) those who reported being on Medicaid.

BASELINE: 98 percent

NEW COHORT: 96 percent



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

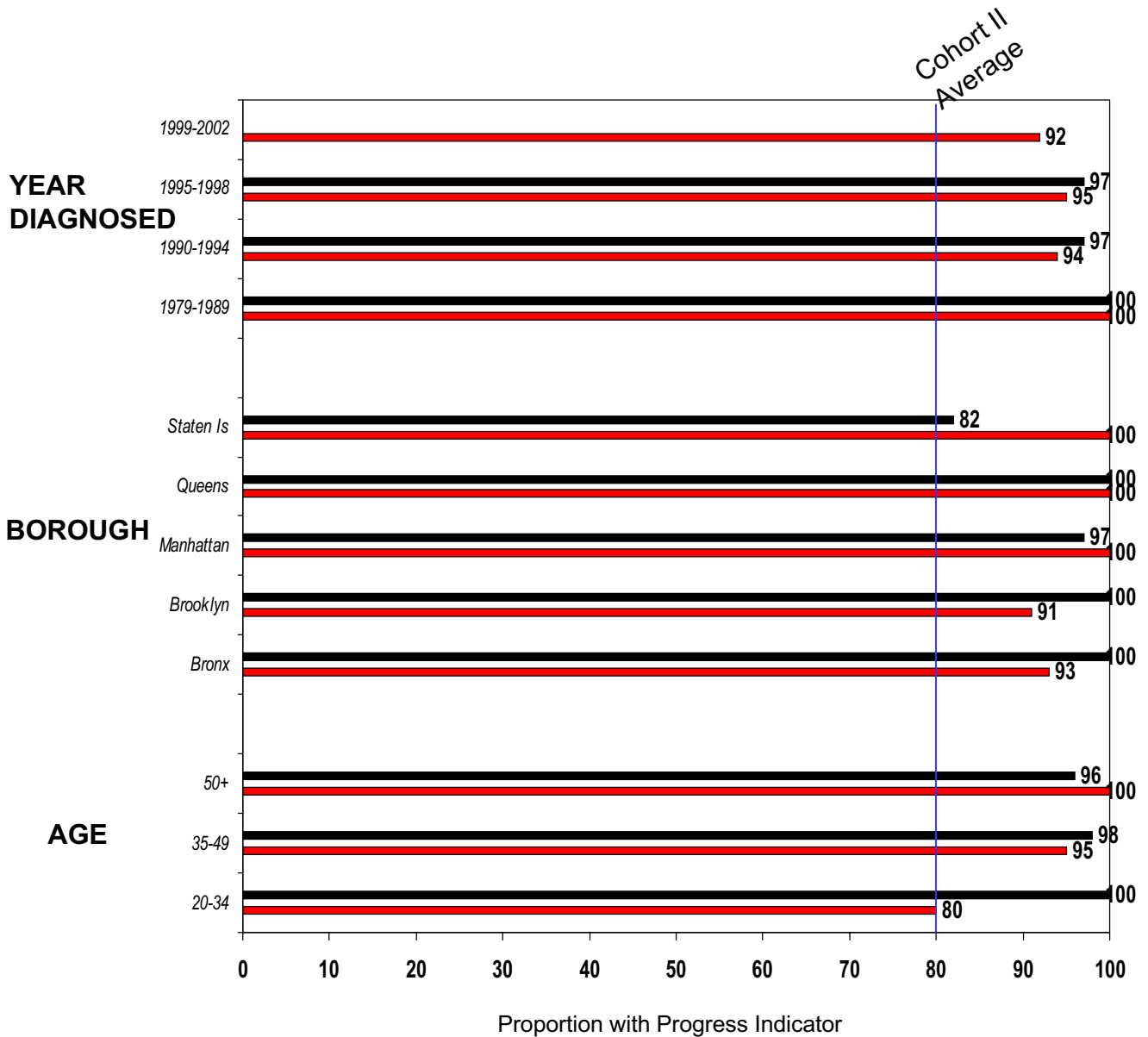
Social Services: Objective 4A (continued)

Unmet benefit need.

PROGRESS INDICATOR: Among those who had need for benefits (annual household incomes below \$10,000 and T-cell counts below 200) those who reported being on Medicaid.

BASELINE: 98 percent

NEW COHORT: 96 percent



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

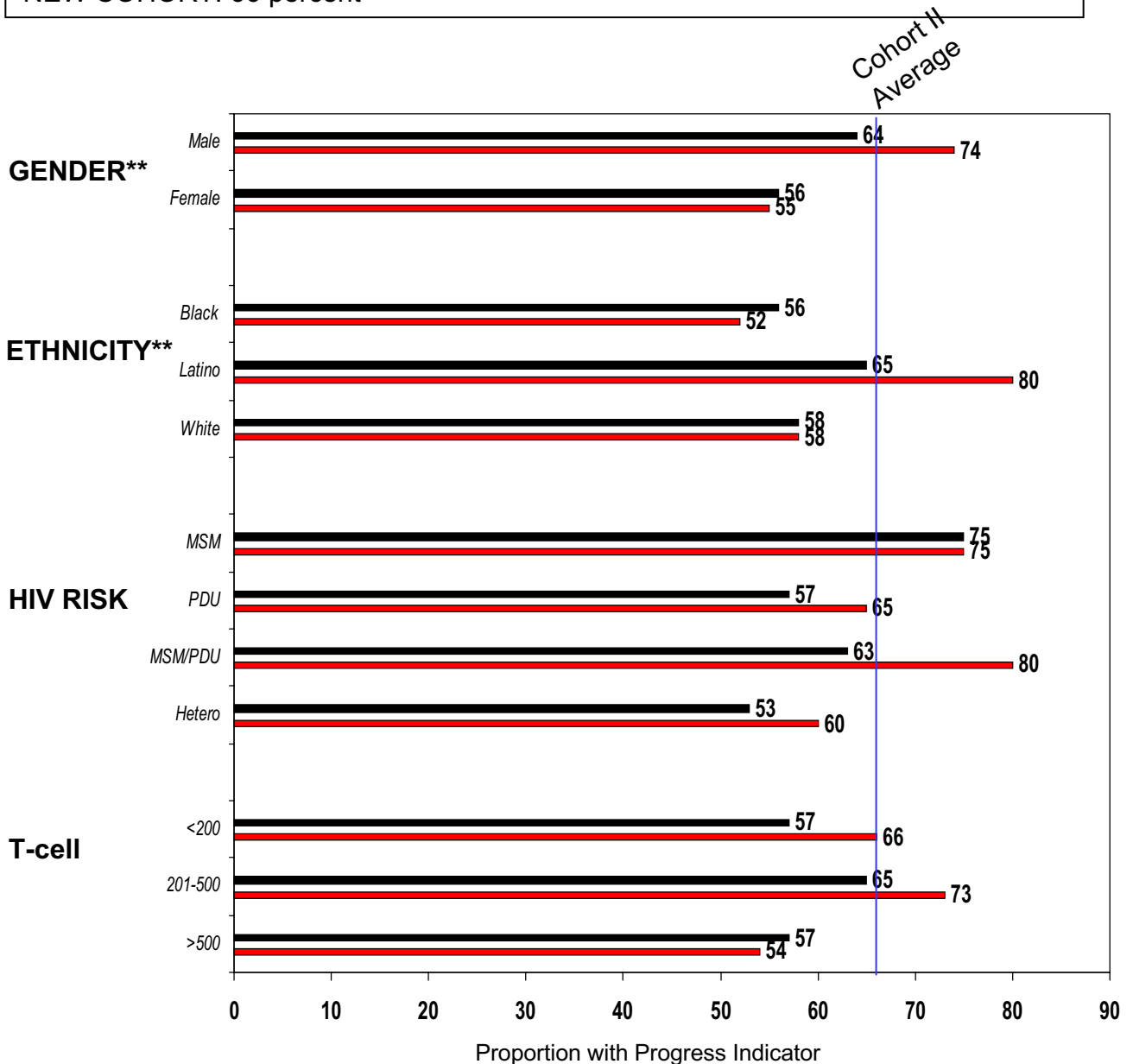
Mental Health: Objective 1B-1

Persons with HIV disease engaged in mental health care and services will adhere to treatment.

PROGRESS INDICATOR: Among those who scored very low on a standardized mental health scale, those who self-reported being adherent to HIV medication and not missing pills in the two days prior to interview.

BASELINE: 61 percent

NEW COHORT: 66 percent



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

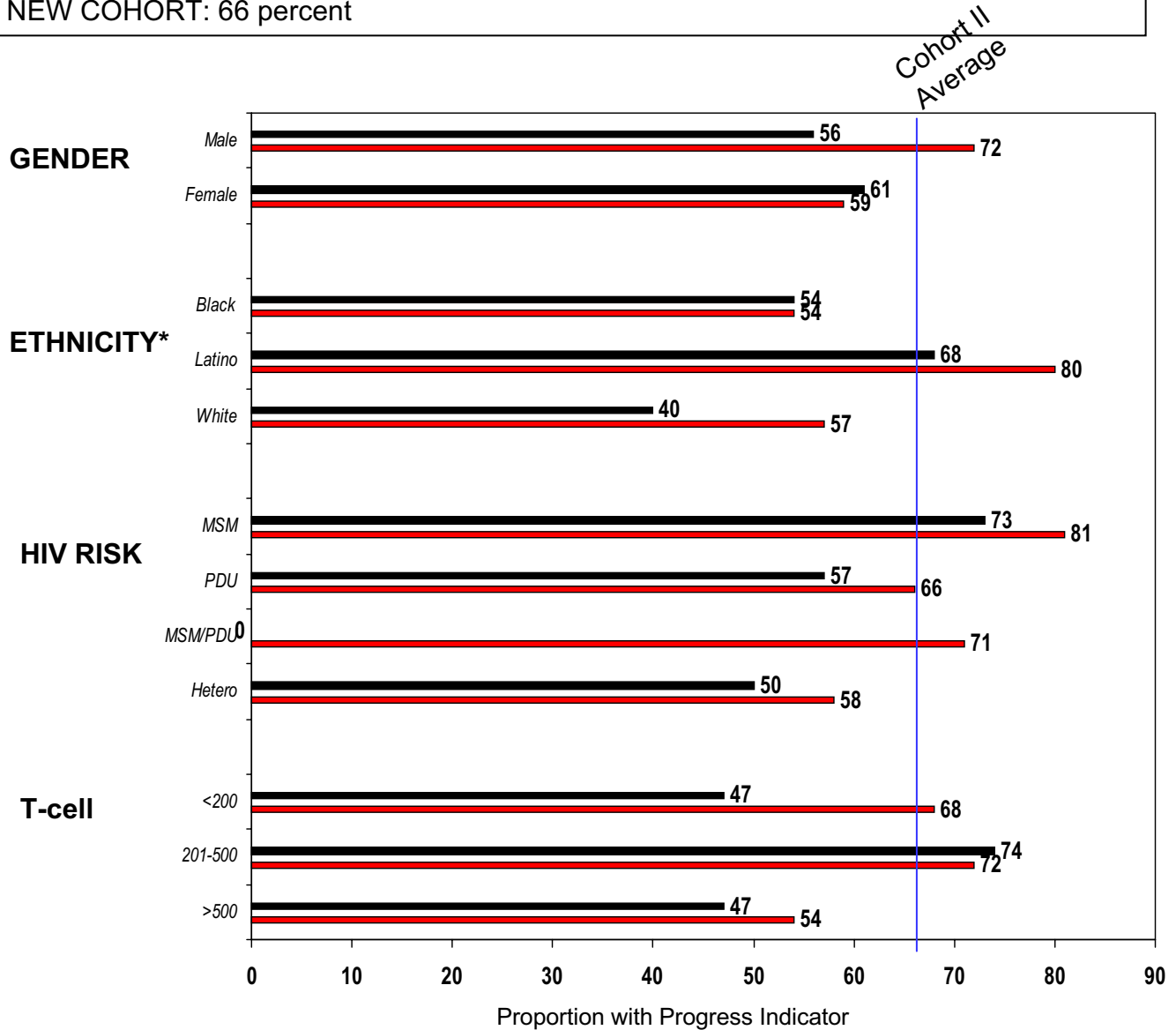
Mental Health: Objective 1B-2

Persons with HIV disease engaged in mental health care and services will adhere to treatment.

PROGRESS INDICATOR: Among those who scored very low on a standardized mental health scale and who reported receiving professional or supportive mental health services, those who self-reported being adherent to HIV medication and not missing pills in the two days prior to interview.

BASELINE: 58 percent

NEW COHORT: 66 percent



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

Mental Health: Objective 1C-1

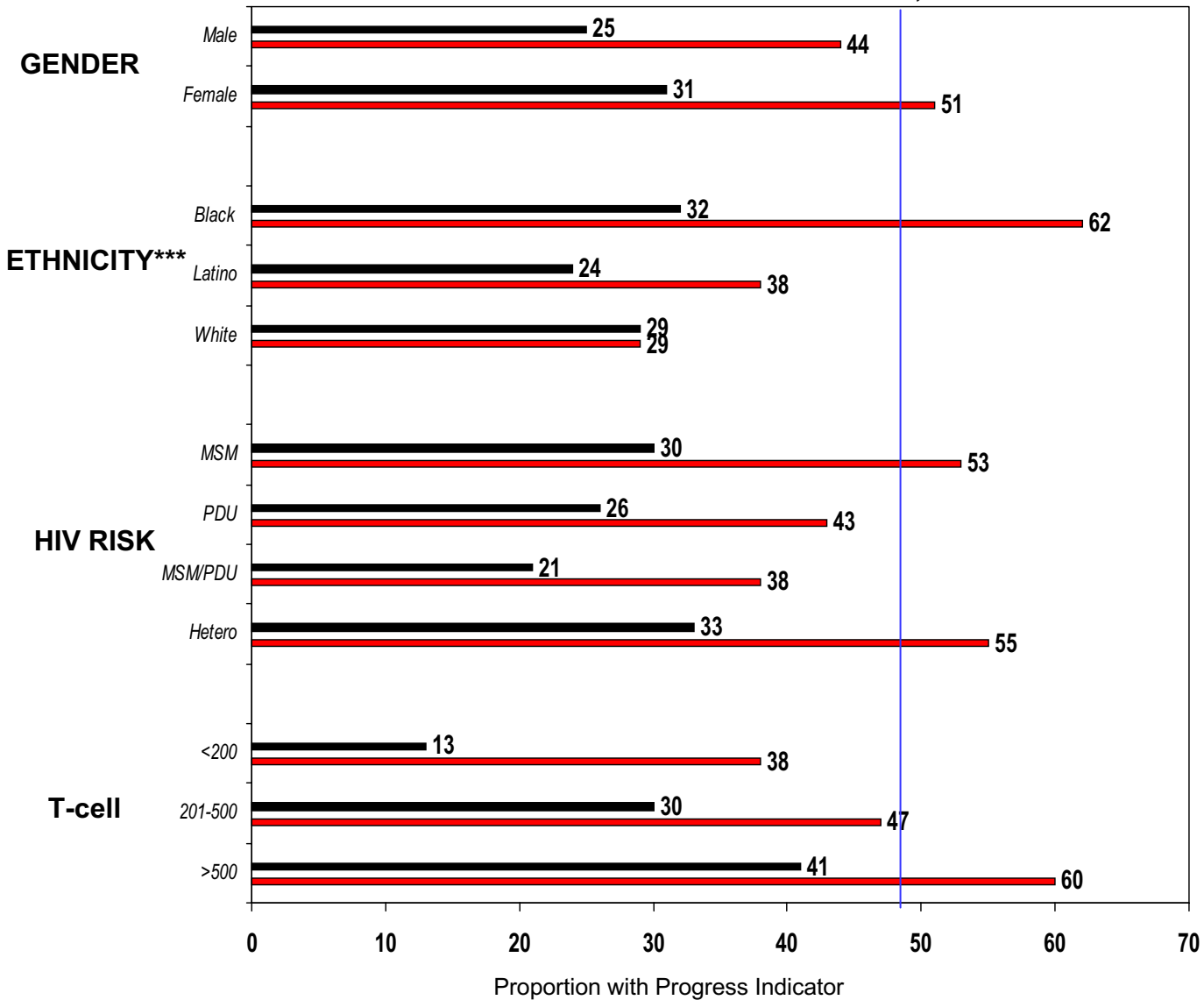
Persons with HIV disease engaged in mental health care and services will have improved quality of life.

PROGRESS INDICATOR: Among those who scored very low on a standardized mental health scale, their self-reported health status, as measured by a standardized multi-item health scale (the PCS score).

BASELINE: 28 percent (PCS scores at or above 45)

NEW COHORT: 48 percent (PCS scores at or above 45)

Cohort II
Average



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

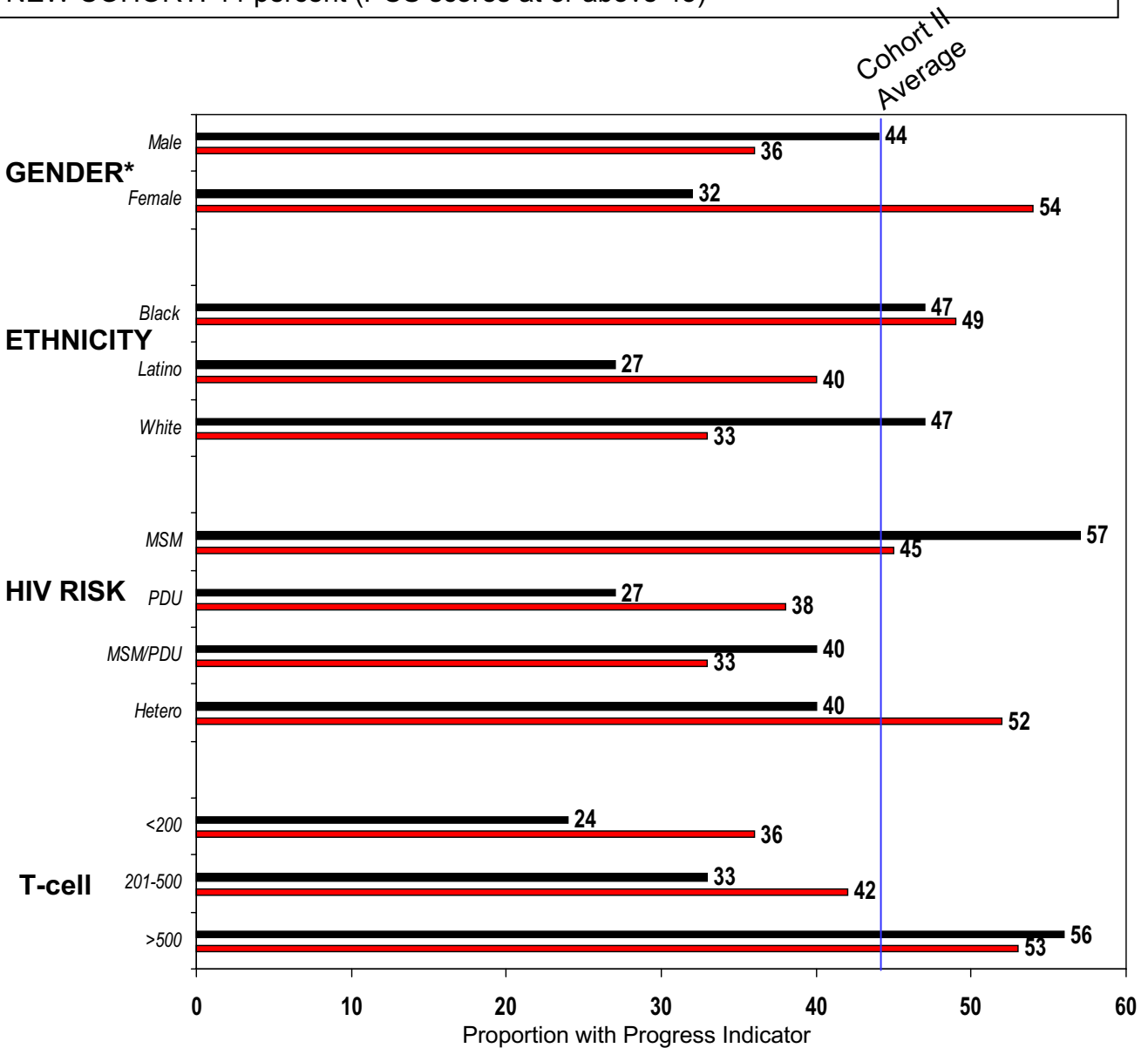
Mental Health: Objective 1C-1 (Modified)

Persons with HIV disease engaged in mental health care and services will have improved quality of life.

PROGRESS INDICATOR: Among those who scored very low on a standardized mental health scale and who received professional mental health services, their self-reported health status, as measured by a standardized multi-item health scale (the PCS score).

BASELINE: 39 percent (PCS scores at or above 45)

NEW COHORT: 44 percent (PCS scores at or above 45)



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

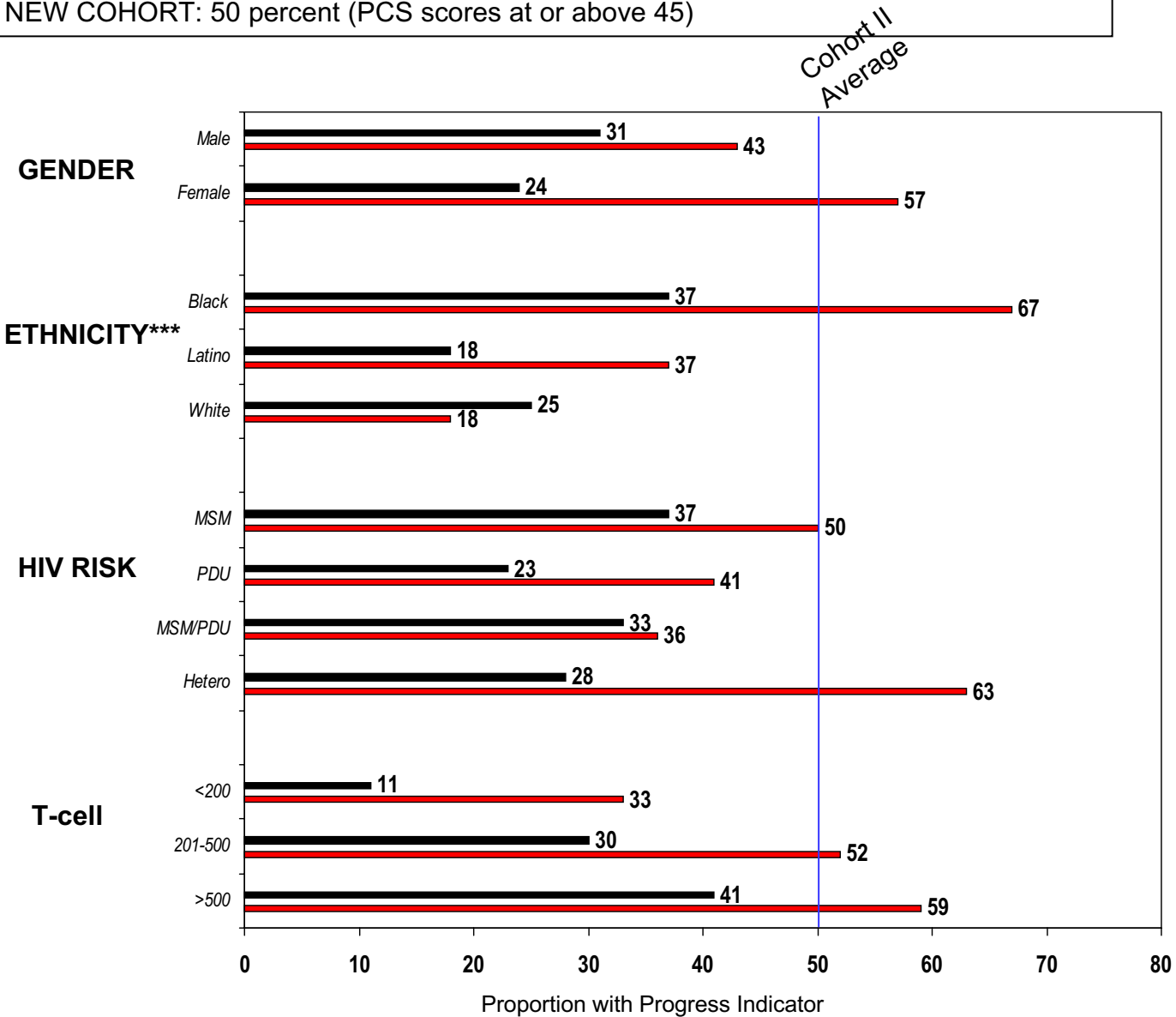
Mental Health: Objective 1C-2

Persons with HIV disease engaged in mental health care and services will have improved quality of life.

PROGRESS INDICATOR: Among those who scored very low on a standardized mental health scale and who reported receiving professional or supportive mental health services, their self-reported health status, as measured by a standardized multi-item health scale (the PCS score).

BASELINE: 28 percent (PCS scores at or above 45)

NEW COHORT: 50 percent (PCS scores at or above 45)



*p<.05

** p<.01

***p<.001

NYC CHAIN Cohort I, 1998-2002 data

NYC CHAIN Cohort II, 2002-2003 data

DATA & METHODOLOGY

Background

The purpose of the CHAIN study is to assess the impact of the full continuum of services delivered to HIV positive persons living in New York City, 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 1993, the Planning and Evaluation Subcommittee of the New York HIV Health and Human Services Planning Council authorized the Medical and health Research Association of New York City, Inc. (MHRA) to develop a longitudinal study of New York City residents living with HIV. The Mailman School of Public Health at Columbia University was contracted by MHRA to conduct the ongoing survey, carry out analyses of survey data, and report its findings.

An initial cohort of 700 HIV+ individuals was recruited in 1994-1995, a refresher cohort of 268 individuals was recruited in 1998, and a new cohort of 700 HIV+ adults is presently being completed.

Sample design

One of the major goals of this study is to assemble a cohort that is broadly representative of all NYC 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 the 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 New York City providing HIV services to at least twenty clients. Medical and social service agencies were independently randomly sampled within each borough and further sampled within Ryan White funded and non-Ryan White funded categories.

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 NYC residents, at least 20 years of age, and HIV+ for at least six 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 to 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, as a minimum), who would be present for such a recruitment. The CHAIN research team 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 topics that was circulated to the Planning and Evaluation Subcommittee, NYC Department of Health and Mental Hygiene, and MHRA. 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+ populations. The interview takes between two and three hours to complete, dependent upon issues relevant to each client's unique service needs. Between 1994 and 2002, 4159 interviews were conducted with the 968 individuals recruited in to the study, over eight rounds of data collection. The new cohort study (NYC CHAIN Cohort II) started in 2002; as of the date of this analysis, data from 562 individuals recruited in to the study between 2002 and 2003 were available. Most interviews were conducted in English, although a number were conducted in Spanish.

Table Denominators 1

	GENDER		RACE/ETHNIC			HIV RISK				T-cell		
	Male	Fem	Wh	Bl	Lat	MSM	PDU	MSM/ PDU	Hetero	<200	201- 500	>500
Health Obj 1A-1												
<i>Cohort I</i>	376	276	86	377	180	123	261	57	211	159	274	219
<i>Cohort II</i>	337	225	33	307	213	100	235	40	187	113	244	183
Health Obj 1A-2												
<i>Cohort I</i>	376	276	86	377	180	123	261	57	211			
<i>Cohort II</i>	329	211	32	295	204	97	225	40	178			
Health Obj 1B												
<i>Cohort I</i>	262	168	66	239	118	95	166	34	135	106	179	145
<i>Cohort II</i>	252	178	26	230	167	71	171	28	160	93	196	126
Health Obj 2A												
<i>Cohort I</i>	285	222	73	301	127	96	204	43	164	123	210	174
<i>Cohort II</i>	337	225	33	307	213	100	235	40	187	113	244	183
Health Obj 3A												
<i>Cohort I</i>	376	276	86	377	180	123	261	57	211	159	274	219
<i>Cohort II</i>	337	225	33	307	213	100	235	40	187	113	244	183
Health Obj 3B												
<i>Cohort I</i>	376	276	86	377	180	123	261	57	211	159	274	219
<i>Cohort II</i>	337	225	33	307	213	100	235	40	187	113	244	183
Health Obj Comprehensive Medical Care												
<i>Cohort I</i>	376	275	86	376	180	123	261	57	210	159	273	219
<i>Cohort II</i>	335	225	33	305	213	99	235	40	186	113	244	182

Table Denominators 2

	GENDER		RACE/ETHNIC			HIV RISK				T-cell		
	Male	Fem	Wh	Bl	Lat	MSM	PDU	MSM/ PDU	Hetero	<200	201- 500	>500
Housing Obj 1A												
<i>Cohort I</i>	376	276	86	377	180	123	261	57	211	159	274	219
<i>Cohort II</i>	337	225	33	307	213	100	235	40	187	113	244	183
Housing Obj 2A												
<i>Cohort I</i>	86	34	14	68	34	22	57	17	24	35	50	35
<i>Cohort II</i>	111	47	9	82	62	24	75	15	44	41	72	43
AOD Obj 1A												
<i>Cohort I</i>	328	222	76	317	151	97	261	56	136	138	225	187
<i>Cohort II</i>	241	140	23	208	146	47	212	38	84	79	177	119
AOD Obj 1B												
<i>Cohort I</i>	87	75	12	70	68	25	91	14	32	52	62	48
<i>Cohort II</i>	90	66	14	72	70	18	88	16	34	37	69	45
Infrastructure Obj 1A												
<i>Cohort I</i>	376	276	86	377	180	123	261	57	211	159	274	219
<i>Cohort II</i>	302	200	28	273	192	91	212	38	161	103	222	165
Social Services Obj 1B												
<i>Cohort I</i>	358	268	81	366	170	115	252	55	204	149	264	213
<i>Cohort II</i>	302	200	28	273	192	91	212	38	161	103	222	165
Social Services Obj 1C												
<i>Cohort I</i>	20	18	6	19	11	6	21	2	9	11	18	9
<i>Cohort II</i>	26	29	6	32	17	4	22	6	23	12	26	15
Social Services Obj 1D												
<i>Cohort I</i>	46	43	15	43	29	17	46	2	24	25	35	29
<i>Cohort II</i>	47	43	5	51	34	11	35	13	31	20	40	29

Table Denominators 3

	GENDER		RACE/ETHNIC			HIV RISK				T-cell		
	Male	Fem	Wh	Bl	Lat	MSM	PDU	MSM/ PDU	Hetero	<200	201- 500	>500
Social Services Obj 3B												
<i>Cohort I</i>	38	41	9	50	20	12	39	3	25	28	24	27
<i>Cohort II</i>	58	56	8	68	37	13	50	3	48	29	51	29
Social Services Obj 4A												
<i>Cohort I</i>	80	47	12	55	59	26	63	9	29	127		
<i>Cohort II</i>	58	34	2	46	42	13	40	9	30	92		
Mental Health Obj 1B-1												
<i>Cohort I</i>	61	48	19	41	49	24	58	8	19	35	46	28
<i>Cohort II</i>	86	64	13	64	71	28	62	10	50	38	70	39
Mental Health Obj 1B-2												
<i>Cohort I</i>	36	23	10	24	25	15	30	2	12	19	23	17
<i>Cohort II</i>	53	41	7	46	41	16	38	7	33	25	43	26
Mental Health Obj 1C-1												
<i>Cohort I</i>	92	83	24	76	74	30	91	14	40	53	71	51
<i>Cohort II</i>	120	88	17	93	94	40	88	16	64	47	90	65
Mental Health Obj 1C-1 (Modified)												
<i>Cohort I</i>	94	59	30	62	59	44	64	15	30	45	51	57
<i>Cohort II</i>	91	80	12	89	70	31	65	12	63	36	79	53
Mental Health Obj 1C-2												
<i>Cohort I</i>	49	38	12	41	33	19	40	3	25	27	33	27
<i>Cohort II</i>	69	54	11	60	52	22	49	11	41	30	52	41

Table Denominators 4

	YEAR DIAGNOSED			BOROUGH					AGE		
	79-89	90-94	95-02	Bx	Bklyn	Man	Qu	SI	20-34	35-49	50+
Health Obj 1A											
<i>Cohort I</i>	143	298	211	215	146	163	64	45	91	408	153
<i>Cohort II</i>	129	189	244	150	159	122	83	29	45	340	177
Health Obj 1A-2											
<i>Cohort I</i>	143	298	211	215	146	163	64	45	91	408	153
<i>Cohort II</i>	125	184	231	141	154	118	81	27	42	330	168
Health Obj 1B											
<i>Cohort I</i>	98	192	140	140	96	108	45	33	58	267	105
<i>Cohort II</i>	90	146	194	103	130	89	69	25	33	256	141
Health Obj 2A											
<i>Cohort I</i>	120	241	146	163	114	132	50	37	56	322	129
<i>Cohort II</i>	129	189	244	150	159	122	83	29	45	340	177
Health Obj 3A											
<i>Cohort I</i>	143	298	211	215	146	163	64	45	91	408	153
<i>Cohort II</i>	129	189	244	150	159	122	83	29	45	340	177
Health Obj 3B											
<i>Cohort I</i>	143	298	211	215	146	163	64	45	91	408	153
<i>Cohort II</i>	129	189	244	150	159	122	83	29	45	340	177
Health Obj Comprehensive Medical Care											
<i>Cohort I</i>	143	298	211	215	146	163	64	45	91	408	153
<i>Cohort II</i>	129	189	244	150	159	122	83	29	45	340	177

Table Denominators 5

	YEAR DIAGNOSED			BOROUGH					AGE		
	79-89	90-94	95-02	Bx	Bklyn	Man	Qu	SI	20-34	35-49	50+
Social Services Obj 1B											
<i>Cohort I</i>	134	287	205	210	140	151	62	44	90	388	148
<i>Cohort II</i>	115	177	210	135	136	112	78	25	42	309	151
Social Services Obj 1C											
<i>Cohort I</i>	6	15	17	14	10	4	2	4	5	24	9
<i>Cohort II</i>	9	22	24	16	16	11	7	3	5	40	10
Social Services Obj 1D											
<i>Cohort I</i>	21	43	25	30	18	21	6	10	15	55	19
<i>Cohort II</i>	16	28	46	21	27	20	17	3	12	56	22
Social Services Obj 3B											
<i>Cohort I</i>	13	41	25	29	23	16	5	5	10	45	24
<i>Cohort II</i>	23	45	46	30	39	24	10	7	10	66	38
Social Services Obj 4A											
<i>Cohort I</i>	26	71	30	49	28	34	4	11	21	83	23
<i>Cohort II</i>	23	36	33	29	22	21	17	2	5	62	25