

Update Report #39



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# Trends in Health Status

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**C.H.A.I.N. Report**

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## **Background**

Documentation of program outcomes is a prominent requirement for Ryan White CARE Act funding. FY'01 guidance specifies that Title I grantees are expected to assemble quantifiable outcomes that document the "overall results achieved by the continuum of HIV/AIDS care in the EMA for PLWH as a group or as sub-groups." Examples of outcomes mentioned in the guidance include "increased access to care, reduced barriers to care, and reduced morbidity and mortality," as well as "health status outcomes and other indicators specific to primary medical care."

The CHAIN data set is an important source of information for the discussion of outcomes specified in the CARE Act guidance. CHAIN interviews collect a wealth of self-reported data on health status and health care for a broadly representative sample of PLWH living in New York City. With these data one is able to construct repeated measures of health outcomes for a period dating back to 1995. Earlier CHAIN reports have often presented findings involving health status measures, but Update Report #21 released on May 12, 1999 was the last comprehensive overview of the CHAIN cohort's health status. That report presented trends in health status through the first five rounds of interviews. It also presented findings from a cross-sectional analysis of individual factors that influenced health outcomes.

The current report extends Update #21 in two important ways. First, the trends in health outcomes are extended for an additional two years. Second, this report presents a focused subgroup analysis of temporal patterns in possible ethnic disparities in health outcomes.

The data presented in this report document the direction of change in health for the CHAIN cohort for multiple dimensions of health status and functioning. We have constructed 19 health status and health care indicators that range from clinical measures of disease progression through health-related limitations on social interactions. Trend data are summarized for seven rounds of interviews covering the critical six year-period between 1995 and 2000 that witnessed the widespread introduction of life extending combination antiretroviral therapies. The trend data presented in this report document the general direction of change in health status for New York City PLWH. These data may also serve as benchmarks against which to compare the results of other outcomes data and studies that examine comparable outcomes from specific CARE Act funded programs. Another study currently underway using CHAIN data is examining more directly how health-related outcomes for people receiving care from agencies that are and are not recipients of CARE Act funding. (See Update Report #35)

We further test for evidence of ethnic disparities in health outcomes and possible change in these disparities over time. This analysis responds to HRSA's agency-wide goal of achieving zero percent health disparities

The findings of this report take the form of a chart book. For each health status measure, we have prepared a table presenting means for each round of interviews and the estimated linear trend coefficient. A graphic display of the fitted trend line accompanies each table. Data are presented for the entire cohort and then separately for African American, Latino, and non-Latino white cohort members. These tables and graphs are contained in the Appendix of this report. The methods section describes the framework for organizing health outcomes measures. A summary of the pattern of trends in health status is presented in the main body of the report.

### **Key Findings**

- With respect to measures of disease progression, the CHAIN cohort has experienced substantial improvements in health between 1995 and 2000. The CHAIN cohort has experienced substantial and sustained reduction in mortality, increases in CD 4 T Cell counts, and declines in viral loads. There has been a corresponding decline in opportunistic infections.
- The improvements in physiologic health have not fully translated into improvements in perceived health status and functioning. Measures of perceived mental health status and functioning increased during the early rounds of the interviews but have leveled-off in recent years. Measures of perceived physical health exhibit an inverted u-shape pattern. After steady improvements in physical health during the first four rounds of interviews, physical health measures have reverted to levels that approach or equal those at baseline.
- The CHAIN cohort's capacity to engage in normal social and economic roles has shown relatively limited drift during the study period. People continue to report health-related limitations in everyday social encounters. Employment has risen slightly, but only 12 percent of the cohort reports employment at round 7.
- The improvement in physiological health is mirrored in the dramatic increased use of HAART and declines in emergency room visits and inpatient stays.
- The data are difficult to interpret with respect to trends in ethnic health disparities. This is in part due to the poorer health of whites at the time of the baseline study. Nonetheless over half the health measures show some evidence of greater health gains among African Americans and Latinos than among whites.

## **Methodology**

The Community Health Advisory and Information Network (CHAIN) Study is a longitudinal study of persons living with HIV, conducted as part of the evaluation activities of New York City's Title I HIV Health and Human Services Planning Council. Its purpose is to provide systematic data from the perspective of HIV+ adults about their needs for health and human services, their encounters with the full continuum of HIV services, and their physical, mental, and social well being.

### **The CHAIN sample design and participant recruitment**

At its inception in 1994, the CHAIN Project pursued a recruitment procedure designed to yield a broadly representative sample of people known to be living with HIV in New York City. Study recruitment was conducted collaboratively with 43 randomly selected agencies, stratified to represent roughly equal numbers of medical care and social service as well as sites that were and were not recipients of Ryan White Title I grants. A total of 648 individuals recruited from participating agencies completed baseline interviews. The agency-based sample was supplemented with 52 interviews conducted with HIV+ individuals with little or no connection to medical and social services.

Since their original interview in 1994-1995, individuals in the study have been re-interviewed six times. The time between the start of successive interviews has ranged between 8 and 12 months. At the request of the HIV Planning Council, the Columbia University research team recruited new participants into the CHAIN study during 1998, which coincided with the fifth round of interviews with the original cohort. In consultation with MHRA, the NYC Department of Health, and the HIV Planning Council, the Columbia researchers returned to the original 43 agencies for assistance in recruiting individuals newly diagnosed with HIV since 1994. Twenty-two agencies participated in the refresher effort. A total of 267 refresher respondents (including 14 individuals unconnected to medical care) were added to the CHAIN cohort, resulting in a total sample of 652 participants for the fifth round of interviews.

### **Sample completion rates**

The CHAIN project has maintained high completion rates over the seven rounds of interviews. For the first four rounds of follow-up interviews, completion rates were above 80 percent (see Table 1). For the two most recent rounds of interviews, the completion rate has fallen slightly to between 70 and 80 percent. The reduced completion rate during partly reflects an increased effort to locate CHAIN members not followed-up at earlier rounds, who were otherwise not known to be dead or to have relocated outside the City.

**Table 1: Sample size and completion rate for interview rounds 1 through 7**

Interview Round	Completed Interviews	Completion Rates*	Reason For Non-completion		
			% Died or moved away	% refusal	% other eligible not interviewed
1	700	NA	NA	NA	NA
2	568	81%	10%	2%	7%
3	480	83%	11%	1%	5%
4	420	86%	8%	1%	5%
5**	562	88%	7%	1%	4%
6	508	78%	5%	3%	14%
7	440	73%	9%	4%	14%

\*Completion rates are based upon the number of people fielded for follow-up interviews at each round. Those fielded, excluded individuals known to be deceased, moved out of New York City or refusals from earlier rounds. The number of individuals fields for interviews at each round of follow-up are Round 2=700 Round 3=580, Round 4=486, Round 5=435 Round 6=654, Round 7=610.

\*\*New participants were added during this round of interviews, completion rate is based upon continuing cohort field for this round of interviews.

The number of completed interviews at round 7,440, corresponds to 45 percent of the 968 individuals composing the original and refresher cohorts. However, death and relocation are the major reasons for long-term loss of cohort members. The round 7 sample constitutes 66 percent of those still alive and residing in New York City. Through the seventh round of interviews, 30 percent of the full cohort has been lost due to death or relocation outside of New York City. In contrast only 5 percent of the cohort has been lost because they refused to participate in follow-up interviews. This leaves 19 percent of the full cohort available but not interviewed at round 7. Despite the substantial cumulative attrition over the six-year span of the study, the ethnic and risk behavior profile of the CHAIN cohort continues to correspond closely to the ethnic composition of AIDS cases in New York City. The cohort at the time of the original interviews and then again at round 6 interviews is generally similar to the composition of living adult AIDS cases in 1994 and 1998, respectively. In 1998, blacks comprise a somewhat greater percentage of the CHAIN cohort than their representation among living NYC AIDS cases; Latinos and whites are under represented.

Information on sampling strategy is described in more detail in earlier Update reports. A comprehensive discussion of sampling and recruitment for the original cohort may be obtained upon request from MHRA (CHAIN Technical Report #1). For further information about the sampling strategy, recruitment, and comparability of the refresher cohort refer to the Cohort Comparison Report (Update Report #18) and the Unconnected Revisited (Briefing Paper #1).

## **Interview**

During the two-hour long interview, CHAIN participants are asked about: (1) their initial encounter with the health care delivery system, (2) their need for services, (3) their access, utilization and satisfaction with health and social services, (4) key sociodemographic characteristics, (5) informal care giving from friends, family and volunteers, and (6) their quality of life with respect to health status, psychological and social functioning. A number of items have been added over the years related to antiretroviral therapies, specific medical care services, viral load levels, adherence, managed care, and other topics of interest to policymakers, planners, providers, and consumers on the Planning Council.

## **Health outcomes**

The interview includes a large battery of questions on current health status. Self-reported information is available on common clinical markers of HIV diseases as well as several more generic quality of life measures. Many of the health-related quality of life scales are derived from the Medical Outcomes Study (MOS), Health Survey instrument<sup>1</sup>. This instrument has been validated in the general populations as well as in samples of PLWH. Table 2 lists the 19 health status measures assembled for this report. The table includes an illustrative question for each measure and Cronbach alpha reliability coefficients for multi-item scales. With one exception, the multi-item scales have Cronbach alpha reliability coefficients in excess of 0.8, a level that is generally deemed as evidence of excellent scale properties. Even the single measure with a reliability below 0.8, barely fell below this level with an alpha of 0.79.

The selection and organization of health status measures used here follows the World Health Organization's definition of health as a "state of complete physical, mental and social

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<sup>1</sup>John Ware, SF-36 Physical and Mental Health Summary Scales: A User's Guide  
Boston: The Health Institute, New England Medical Center, 1994.

well being and not merely the absence of disease or infirmity”<sup>2</sup>. A key insight of this expanded definition of health is the distinction between physiologic status, as “objectively” measured by health practitioners, and patient’s self-assessed experience of physical, mental and social well-being. As HIV disease progresses, as measured by decline in CD4 T-Cells, individuals undoubtedly feel in poorer health and become more disengaged from social life, but changes in feelings of well being need not closely follow changes in CD4 count. Health related quality of life may differ greatly among individuals with similar CD4 counts. The correspondence between physiological health and well-being is likely to be further attenuated among people on combination therapy. Individuals who are showing increased CD4 counts and reduced viral load because of HAART, may not experience comparable improvements in perceived health status for reasons discussed more fully below.

Following a standard organization of health status measures, we have grouped the study measures into four separate health domains and a final health care domain. The first domain includes physiological markers of disease progression: T-Cell count, viral load, opportunistic infections and death. A second domain groups measures of health perceptions. These measures capture generalized feelings of ill health and include a single item general health rating, and three multi-item scales that measure vitality, body pain and mental health.

The third domain includes measures of restrictions in an individual’s ability to function in a manner considered normal for a human being.<sup>3</sup> The scales in this domain measure physical and cognitive functioning. The fourth domain captures restrictions on ones social life and economic livelihood that may arise from impaired physical and mental health functioning. Scales in this domain measure emotionally impaired role performance, social role performance, and employment.

Six of the scales presented above (see Table 2) are combined to form physical and mental health summary scales. Statistical analysis of the six component scales indicate that these scales could be combined to form two scales that measured physical and mental dimensions of health.<sup>4</sup>

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<sup>2</sup>As quoted by John J. Ware. “The Assessment of Health Status” in Social Science Medicine and Policy, edited by Linda H. Aiken and David Mechanic, New Brunswick, NJ: Rutgers (206) 1989.

<sup>3</sup>Statement paraphrased from Ian McDowell and Claire Newell, Measuring Health, New York: Oxford Press, 1987, 25.

<sup>4</sup>John Ware, SF-36 Physical and Mental Health Summary Scales: A User’s Guide Boston: The Health Institute, New England Medical Center, 1994.

The implication of these results is that statistical analysis of the two summary scales captures the salient information present in separate analyses of all six component scales.

The physical and mental health summary scales are norm to have a mean value of 50 and standard deviation of 10 for a general population of healthy American adults. The statistical properties of these two scales in the CHAIN population are similar to those reported for other general populations and those with HIV. The physical health summary scale is strongly correlated with CD4 count and is an independent prognosticator of short-term changes in clinical health measures. As a point of comparison for the CHAIN sample, Table 3 presents mean values on the two summary scales for several samples of persons with chronic health conditions. A two to three point change in scale values is associated with a clinically meaningful change in health status. Benchmark studies have also determined threshold values below which individuals are highly likely to experience reduced physical functioning that restricts ability to work (45 on the physical health summary scale) and high likelihood of a having diagnosed mental illness (37 on the mental health summary scale).

**Table 2: Health Status Measures**

Short Label	Description or Illustrative Measure	# of items	Validity or Reliability*
<b>Physiological Status</b>			
<b>Mortality</b>	Half year death rates (deaths/1,000 person years)	1	death certificate search, web
<b>CD 4 T Cell Count</b>	Most recent CD-4 or T-cell count	1	
<b>Viral Load</b>	Result of the most recent viral load test	1	
<b>Opportunistic Infections</b>	One or more of 24 Opportunistic Infection symptoms in the last six months	24	
<b>Perceived Health Status</b>			
<b>General Health**</b>	In general, would you say your health is?	1	
<b>Mental Health***</b>	Have you felt so down in the dumps that nothing could cheer you up?	5	Alpha=0.85
<b>Vitality***</b>	During the past month, did you felt full of pep (liveliness or enthusiasm)?	4	Alpha=0.83
<b>Body Pain**</b>	During the last month, how much did pain interfere with your normal work or regular daily activities?	2	Alpha=0.87
<b>Functional Health Status</b>			
<b>Physical Functioning**</b>	The kinds or amounts of vigorous activities you can do, like lifting heavy objects, running, or participating in strenuous sports	6	Alpha=0.88
<b>Cognitive Functioning</b>	During the past month, compared to the best your memory has been, how would you describe your memory?	2	Alpha=0.87
<b>Role Performance</b>			
<b>Employment</b>	Currently work as a full time or more?	1	
<b>Social Role Performance*</b>	During the past month how much has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?	2	Alpha=0.81

Short Label	Description or Illustrative Measure	# of items	Validity or Reliability*
<b>Emotional Role*** Performance</b>	During the past month have you had problems with your work or other regular daily activities as a result of any emotional problems?	2	Alpha=0.79
<b>Health Summary Scales</b>			
<b>Physical Health</b>	SF-36 Physical Component Summary Scale	26	Alpha=0.93
<b>Mental Health</b>	SF-36 Mental Component Summary Scale	26	Alpha=0.93
<b>Medical Care Indicators</b>			
<b>Currently on HAART</b>	Combination therapy including a PI or NNRTI	# of meds	
<b>Emergency Room Visit</b>	One or more emergency room visits since last interview	1	
<b>Inpatient Episode</b>	One or more hospital stays since last interview	1	
<b>Inpatient Length of Study</b>	How many days in hospital for the last six months?	1	

\* alpha scores from the most recent, wave 7, interviews

\*\* Subscale components of physical health summary scale

\*\*\*Subscale components of mental health summary scale

The final domain includes four measures of health care: one measure of appropriate health care, (currently taking HAART) and three items that are sensitive to and poor access to primary care: emergency room visits, hospital stays and length of inpatient stays.

### The dynamics of group-level change in health outcomes

Changes in health outcomes are here summarized at the group level, rather than variation across individuals. We use the CHAIN cohort to approximate the average health burden of all HIV infected individuals, who interact with New York City's HIV health care system at successive points in time. Group-level change in health is a result of both individual changes in health and changes due to the shifting composition of HIV infected individuals due to death and the infusion of new individuals who are represented by the refresher cohort.

**Table 3: COMPARISONS OF PHYSICAL SUMMARY COMPONENTS (DSL) and MENTAL COMPONENTS SUMMARY (MCS) SCALES**

Group		PCS		MCS	
		Mean	SD	Mean	SD
<i>Total Sample of General US Population (N=2,474)</i>		50.0	10.0	50.0	10.0
By Sex	<i>Female (N=1,412)</i>	49.07	10.42	49.33	10.32
	<i>Male (N=1,055)</i>	51.05	9.39	50.73	9.57
By Age	<i>Age 18-24 (N=173)</i>	53.44	7.59	49.11	10.16
	<i>Age 25-34 (N=474)</i>	53.72	7.13	48.64	10.22
	<i>Age 35-44 (N=503)</i>	52.15	7.75	49.91	9.26
	<i>Age 45-54 (N=338)</i>	49.64	9.67	50.53	10.02
	<i>Age 55-64 (N=269)</i>	45.90	11.25	51.05	9.69
	<i>Age 65-74 (N=442)</i>	43.33	11.16	52.68	9.29
	<i>Age 75+ (N=264)</i>	37.89	11.16	50.44	11.66
<i>"Healthy" group, no chronic conditions (N=465)</i>		55.26	5.10	53.43	6.33
<i>Cancer patients (N=105)</i>		45.12	11.60	48.82	11.07
<i>Congestive heart failure (N=83)</i>		31.02	10.64	45.65	12.49
<i>Clinical depression, MOS participants (N=502)</i>		44.96	12.05	34.84	12.17

Source: data from NORC GSS 1990. John E Ware, et al. 1994, *SF-36 Physical and mental health Summary Scales: A User's Manual*, p.8:12-29

This report is a descriptive summary of trends in health outcomes. It does not attempt to account directly for the factors that give rise to temporal changes in health status. In particular, it does not attempt to assess the impact of enhancements in medical care and social services in recent years. Nonetheless, it is instructive to list some of the factors that might be expected to influence group-level changes as a basis for beginning to interpret the implication of these trends for policy and planning purposes. Table 4 lists seven explanatory factors and their hypothesized associations with each of the health domains listed in Table 2.

**Table 4: Dynamics of Health Outcomes: Possible factors operating on improvement (↗) and decline (↘) in health outcomes.**

Factor	Health Status Domain				
	Physiological status	Perceived Health	Functional Status	Role Performance	Medical Care
<b>Aging</b>	↘	↘	↘	?	?
<b>Attrition due to Mortality</b>	↗	↗	↗	↗	↗
<b>New HIV Cases</b>	?	?	?	?	?
<b>Access to efficacious medical care</b>	↗	↗	↗	?	↗
<b>Adverse Effects of Medications</b>	?	↘	↘	?	?
<b>Medication Failure</b>	↘	↕	↕	↘	↘
<b>Access to effective supportive services</b>	Indirect	?	↗	↗	↗

?=No hypothesized, No influence

↕=could influence improvement or decline in health.

In the absence of access to efficacious medical therapies and the infusion of more recently infected individuals, HIV is assumed to be a progressively degenerative disease. Therefore the surviving cohort would experience a progressive decline across all health domains. We have identified three broad influences that may reinforce or alter this trend: aging,

compositional changes in the CHAIN cohort, and health systems interventions. The aging of the cohort may both be understood as a proxy for increasing duration of HIV infection as well as the natural aging process that all human beings experience. We hypothesize that poorer health status is associated with both older cohort members as well as the effects of aging over the six years of the study period. For the CHAIN cohort we make no assumption that aging has a systematic impact on either level of social engagement or employment status. Nor do we advance a strong hypothesis to relate use of medical care and social services with age. Age is included as an independent variable in the statistical analyses that complement the graphic and tabular presentations in this report.

The shifting composition of the CHAIN cohort is a second force of change on group-level health outcomes. CHAIN participants are permanently lost from both the cohort and the New York City health care system through mortality and to a much lesser extent because they move out of the City. The consequence of mortality is to remove individuals in poorest health, and consequently to produce a surviving cohort that at the group level, at least temporarily, is in better health. The infusion of a refresher cohort at the time of the fifth round of interviews is the second major factor that alters the composition of the CHAIN cohort. The refresher cohort was fielded for two reasons. One was to augment the diminishing sample size of the original cohort, and the second was to adjust the cohort's composition to include people who became aware of their infection status since the original cohort was fielded. As Table 4 shows, we have refrained from stating hypotheses regarding the affect of the refresher cohort on changes in health outcomes. This is because the new cohort differs from the original cohort in both the recency of HIV infection and its sociodemographic profile. We leave it as an empirical question that we investigate below as to whether the health status of the refresher cohort differs and in what direction from that of the surviving members of the original cohort.

The final source of influences relates to change in access to efficacious medical care and supportive services. The most important care intervention is the widespread introduction of combination antiretroviral therapy beginning in 1996. The impact of these medications should be most clearly evident in improvements in physiological status and health care indicators. Insofar as individuals experience less acute conditions related to HIV infection these should translate into improved health perceptions and functional health status. It is less certain how effective use of these medications will impact role performance, since other intervening psychosocial factors may mediate between the medical interventions and these more causally remote health outcomes.

Even with widespread access to these medications, there is concern that the therapeutic effectiveness of these medications for the general population of PLWH may have peaked and even begun to wane. This is a consequence of both adverse side effects and an increasing

number of patients who experience failure of these medications to suppress viral loads. The first of these factors may not affect physiological status. People may continue to take their medications, but these medications may adversely impact on the various health related quality of life measures. With an increasing number of people on failing therapies, prior improvement in physiological status may begin to decline as well. Consequently we were uncertain about the impact of medication failure on change in perceived and functional health status. People may stop taking these medications because of perceived ill health, and withdrawal of medications may in the short run result in better subjective assessment of health.

Finally, providing access to support services, particularly those related to engagement in medical care and adherence, may produce improvements in health. Supportive services may have an indirect positive impact on physiological status insofar as they facilitate access and adherence to medications. Support services may themselves have direct therapeutic value of improved functional health status and role performance.

The observant reader might note that sample attrition among CHAIN members not known to be dead is another source of compositional differences not represented in Table 4. About a quarter of the CHAIN cohort has been “permanently” lost to follow-up at some time during the six rounds of follow-up interviews. We have not included this source of sample attrition in Table 4, as distinguished from sample loss due to mortality, as it represents a methodological problem rather than a substantive force on change in group-level outcomes. Nonrandom loss to follow-up may result in a retained CHAIN cohort that becomes increasingly less like the population it is intended to represent—PLWH in New York who have contact with health and social service providers. An analysis of sample attrition bias does confirm that those lost to follow-up because of death are at their last interview in much poorer health than survivors. However, the health of those who drop out of the survey for reasons other than death differ little, at time of last interview, from those who continue to be interviewed.

### **Assessing trends in health outcomes**

The trends for each of the health outcomes are presented in these forms. For each health outcome we tabulate the observed mean value at each of the seven rounds of interviews. These means are calculated for all individuals interviewed at each round. No adjustment is made for aging or the changing composition of the cohort. Observed mean values are separately tabulated for African American, White and Latino cohort members.

A statistical analysis is performed that estimates a secular trend line that adjusts for age, the addition of the refresher cohort, and possible deviations from a linear trend line. Two forms of the regression equations were estimated =

$$\text{Health Outcome} = \beta_0 + \beta_1 * \text{DateRound} + \beta_2 * (\text{Round 6 or 7}) + \beta_3 * \text{Age} + \beta_4 * \text{Refresh} \quad (1a)$$

$$\text{Health Outcome} = \beta_0 + \beta_1 * \text{DateRound} + \beta_2 * \text{DateRound}^2 + \beta_3 * \text{Age} + \beta_4 * \text{Refresh} \quad (1b)$$

Regression equations, 1a and 1b differ only with respect to the third term ( $\beta_2$ ) that measures possible deviation from a linear trend. DateRound is the date of the midpoint for each round of interview and is assigned to all individuals completing an interview for that round regardless of when the actual interview was administered. The associated coefficient ( $\beta_1$ ) in both equations measures linear change in outcome and is here reported as change over a year's time. The next term is an estimate of how much the actual trend deviates from the "fitted" linear trend. "Round 6 or 7" is a measure of the average deviation above or below the linear trend line for interviews conducted at either rounds 6 or 7. This parameter is a common sense approach to measuring "recent" change in the long-term linear trend that may have occurred in 1999 or 2000. RoundDate<sup>2</sup> adds the square of the round date to the equation. This fits a gradual nonlinear curvature in the trend line.

"Age" adjusts for both cross sectional differences in age and the aging effect of the cohort. The term "Refresh" measures any net difference in health between the original cohort and the refresher sample.

On a more technical note, regression equations are estimated with ordinary least squares, in which all seven rounds of data for each of the health outcomes are pooled, with the exception of viral loads in which data were first collected during round 4. The standard errors of the estimated coefficients are adjusted for pooling repeated observations on the same individuals at several points in time. Information from equations 1a and 1b is used when summarizing findings.

Graphs display the mean values for each health outcome at each round of interviews and a fitted regression line. Equation 1b was found to be superior to 1a when graphically displaying the trend line. The trend lines also display any systematic differences in health between the original and the refresher cohort.

## Assessing changes in ethnic disparity in health outcomes

Possible trends in ethnic disparities in health outcomes were determined by comparing the mean health outcomes for the three major ethnic groups at baseline and round 7 interviews. We first tested for statistically significant ethnic groups differences in baseline health status between ethnic groups after adjusting for age. We then tested for the age adjusted difference in group means at round 7 interviews. To further confirm conclusions drawn from the comparison between the first and last round of interviews, we visually examined ethnic specific linear trend lines. Combining these pieces of information, we distinguished the following qualitative patterns.

Convergence: Whites were in better health than both blacks and Latinos at baseline and ethnic differences were smaller at round 7.

Constant differences: The qualitative differences in group outcomes were the same at both interviews in which case ethnic disparities if they existed remained constant.

Divergence: The trend for whites was steeper than for one or both of the ethnic groups. Whites may or may not be healthier than minorities at baseline.

Minority Improvement: Minority health status is superior to white health status at baseline. Ethnic differences remain constant or minority groups improve relative to whites

## Findings

### *The historical context for temporal change.*

The study data span three distinct time periods: a pre combination therapy period spanning the first two interviews from 1995 through early 1996: rapid introduction of combination therapy (Rounds 3 and 4 spanning 1996 and 1997); and rounds 5 through 7, 1998-2000 that correspond to the addition of the refresher sample and the stabilization in levels of current use of combination therapies. The graphs in the appendix demarcate these periods to accentuate possible changes in group-level health status that coincide with changes in these periods.

### *Current health status for selected single item outcomes*

Many outcomes in this study are scales that assume numeric values which may not be easy to interpret. To assist readers in understanding what the scales measure, Table 5 presents frequency distributions at round 7 for selected single item measures. The left column indicates the scales from which the items are taken.

The overall pattern of the single item measures suggests that a substantial number of people currently report some health impairment, but only a minority, seldom more than 30 percent, place themselves in the worst response category. For example the round 7 sample is almost evenly divided when asked to rate their overall health on a five-point scale from excellent to poor.

As a point of comparison, the right column represents comparable frequency description for the physical health items reported by a nationally represented sample of people living with HIV in 1996, the HIV Cost and Service Utilization Study (HSCUS). With the possible exception of the item “has your health limited climbing stairs”, the frequency distributions for the four health items are quite similar for the CHAIN cohort and the national HCSUS cohort.

**Table 5: Single Item Health Status Measure - Round 7 Interviews, With Selected National Item Comparisons**

Parent Scale	Item	CHAIN	HCSUS*Cohort
General Health	<i>Would you say your health is</i>		
	Excellent/very good	35%	
	Good	34%	
	Fair or poor	31%	
Vitality	<i>Do you have a lot of energy</i>		
	All or most of the time	40%	
	Good bit or some of the time	40%	
	Little or none	19%	
Cognitive Impairment	<i>Difficulty solving problem</i>		
	All or most of the time	9%	
	Good bit or some of the time	13%	
	Little or none	78%	
Cognitive Impairment	<i>How does your memory compare with the best it has been</i>		
	Much or somewhat worse	30%	
	Same	47%	
	Somewhat better or much better	13%	
Social Role Functioning	<i>How much time does health or emotional problems interfere with normal social activities</i>		
	All or most of the time	17%	
	Some or little	47%	
	None	36%	
Physical Health	<i>Has your health limited doing vigorous activity</i>		
	A Lot	34%	37%
	A Little	34%	27%
	Not at all	32%	36%

Parent Scale	Item	CHAIN	HCSUS*Cohort
Physical Health	<i>Has your health limited climbing stairs</i>		
	A Lot	29%	17%
	A Little	33%	27%
	Not at all	38%	56%
Physical Health	<i>Has your health limited walking one block</i>		
	A lot	10%	8%
	A little	21%	18%
	Not at all	69%	74%
Physical Health	<i>Has your health limited eating, dressing or bathing</i>		
	A lot	5%	4%
	A little	10%	10%
	Not at all	85%	86%
Pain	<i>How much bodily pain have you had in last month</i>		
	None	29%	
	Very mild or mild	33%	
	Moderate severe to very severe	38%	
















See Table 2 for more information on the parent scales.

\*Source: Crystal, Stephen, Fleishman, John, Hays, Ron et al. Physical and role functioning among persons with HIV. Medical Care 38(2000): 1210-1223.

*Trends in health outcomes*

Table 6 summarizes the basic secular trend for each of the health outcome measures. Each row in this table should be examined in conjunction with the corresponding table and graph in the Appendix. Symbols are used in this table as a shorthand notation to describe the qualitative form of the trend. The left column distinguishes three basic trends. The “↗” indicates consistent increasing in the scale mean over the seven rounds of interviews. This pattern generally corresponds to improving health status throughout the study period. For a few measures have downward “↘” sloping curve. In all instances associate this negative health status measures so the downward slope measure improved health as well. The second pattern “↘”

**Table 6: Trends in Health Status For Full CHAIN Cohort**

Health Status Measure*	Basic Trend**	Recent Changes	Recent HIV+ cases	Summary of Ethnic Differences***	
				Baseline Differences	Trends Converge?
<b>Physiological Status</b>					
Mortality					
CD4 T Cell Count		--	--	B>L>W	W>B&L
Undetectable Viral Load****		--	--	None at R 4	B&L>W
Opportunistic Infections		--	--	L>W>B	B&L>W
<b>Perceived Health Status</b>					
General Health		--	↓	W&B>L	No, Diverge
Mental Health (Mood Anxiety)		--	↓	B>W&L	No
Vitality		--	--	B>W&L	B>W&L
Pain (Higher values less pain)		↓	--	None	B&L>W
<b>Functional Health Status</b>					
Physical functioning		↓	↓	W>B&L	Yes
Cognitive Functioning		--	--	None	B&L>W
<b>Role Performance</b>					
Employment		—	↓	W>B&L	Yes
Social Role Performance		↓	↓	B>W&L	No
Emotional Role Performance		↓	--	None	B>W&L

Health Summary Scales					
<b>Physical Health Summary Score</b>	∩	↓	↓	W&B>L	Yes
<b>Mental Health Summary Score</b>	↘	--	--	B>W&L	No
Medical Care Indicators					
<b>1 or more ER Visits</b>	↘	-	--	L>B>W	Yes
<b>1 or more inpatient episodes</b>	↘	-	--	None	No
<b>Inpatient length of stay</b>	↘	--	↑	None	No, Diverge
<b>Currently on HAART</b>	↘	↓	--	W>B&L	Yes

\*Higher values on all items indicate better client outcomes except for opportunistic infection, ER visits, inpatient episodes and inpatient length of stay.

\*\* Trend Symbols

- ↘ Downward linear trend
- ↗ Upward linear trend
- ∩ Curvilinear trend, upward trending followed by downward trend, may return to baseline level
- No trend
- ↘ Downward trend that levels off
- ↗ Upward trend that levels off
- ↓ Downward deviation from linear trend line
- ↑ Upward deviation from linear trend line

\*\*\*Ethnic differences: B=African Americans, L=Latinos, W=NonLatino Whites, "Baseline Differences":

**A > B** indicates that group A has a statistically significant higher mean value than group B.

"Trend Converge?" :

**Yes** indicates minority disparities at baseline are reduced between first and seventh rounds of interviews

**No** indicates that baseline race/ethnic differences, if any, remain largely unchanged during study period

**No, Diverge** indicates that whites improves relative to minorities

**A>B** One or both minority groups show relative improvement to whites in outcome

\*\*\*\* Data only available since round 4.

corresponds to an extended duration of improving health status that levels off during the latter stages of the study period. Finally, some of the health outcomes exhibit an inverted U-shaped pattern “∩”, which indicates that a period of improved health status is followed by a period of decline that at the end of the period is substantially lower than the period of peak health outcome.

The column labeled “recent change” indicates with a “↓” health outcomes in which the combined mean value for rounds 6 and 7 falls significantly below the predicted linear trend line. Combined with the first column, this column highlights group-level health outcomes that have stopped moving upward or are showing absolute declines after improvements in earlier rounds of interviews.

The “Recent HIV+ Cases” column identifies health outcomes in which there is a statistically significant difference between the original and refresher cohort.

#### *Physiological measures*

The CHAIN cohort has experienced a sharp drop in mortality and significant improvements in physiological measures of disease progression (cf Appendix Table and Figure 1). Mortality rates dropped consistently through the 2<sup>nd</sup> half of 1998 and have stayed at low levels through 1999 and the first half of 2000. In line with the reduction in mortality, CD4 Counts have steadily increased throughout the study period, as have the proportion of the cohort reporting undetectable viral loads. The percentage of CHAIN participants reporting an opportunistic infection within six months of the interview has dropped since the start of the study. The trend line (cf Appendix Figure 4) suggests a consistent drop during the first four rounds of interviews, followed by leveling off during the most recent interviews. The statistical models find no evidence for fall off in the improvement in physiological measures during the two most recent interviews or group differences between the original and refresher cohorts.

#### *Perceived health and functional health*

The substantial improvement in physiological health enjoyed by the CHAIN cohort has only partially translated into improvements in other domains of health. Through the first four rounds of interviews, the CHAIN cohort experienced significant improvements in both physical and mental health. However, in more recent periods, trends in physical and mental health measures have tended to diverge. On the one hand, there has been a downward trend across all measures of physical health: general health perception, physical functioning and social role functioning. The nearly three point gain in the physical summary achieved between the baseline and round 4 was

almost entirely lost by round 7 (see Appendix Figure and Table 14 ). On the other hand, the steady gains in mental health during the first half of the study have stopped, but remain at relatively high levels in recent years.

It is important to emphasize that even at their peak the physical and mental health summary scores for the CHAIN cohort (See Appendix Figures and Tables 14 and 15) are below means for similarly aged U.S. populations. From the benchmark statistics in Table 3, we see that there is more than a ten point difference between the PCS and MCS scales for a healthy group of adults and the CHAIN cohort. The mean PCS scores almost never exceeded 45, a level below which deteriorating health status is an important obstacle to gainful employment. Despite the general increase in the mental health summary score, the mean values in recent rounds are below those for cancer patients and similar to individuals with congestive heart failure. The average MCS scores are also 4 to 5 points (approximately a half a standard deviation on the MCS scale) below means for general population between the ages of 18 and 44.

The “Recent Change” column further confirms the declines in physical health status measures for rounds 6 and 7. We find that the refresher cohort reports health deficits on 3 of 6. On no measures is the refresher cohort superior to the original cohort

### *Role performance*

Improvements in physiological status and mental health functioning have not been translated into improvements in social and economic role performance. As evidenced by the rising trend for emotional role performance scale ( cf. Appendix Figure and Table 13), there has been a significant reduction in the extent to which emotional feelings have impaired ability to interact on a normal basis with family and friends. However physical health continues to impair the level of engagement in social relations. The social role performance scale, after peaking during the middle-period interviews has reverted in round five onward to levels similar to the baseline means. (cf. Appendix Figure and Table 12) Although trends in employment are upward, the increase is substantively very small. Employment rate reaches a high of only 12 percent for round 7. The refresher cohort exhibits a lower employment rate and lower social role performance than the original CHAIN cohort.

### *Medical care indicators*

The general trend in the medical care indicators is consistent with the trends in physiological measures. To begin with, current use of HAART therapy (cf Appendix Figure and Table 16)

shows a rapid increase from the second through fifth round of interviews and has been sustained at just above 50 percent through rounds 6 and 7. Meanwhile the CHAIN cohort has exhibited consistent declines across the entire study period in use of emergency rooms and inpatient stays.

### *Trends in ethnic health differences*

There was no evidence for a general pattern of ethnic health disparities as is commonly reported for other health conditions and populations. Part of the reasons is that the typical white participant was at a more advanced stage of HIV disease than either African American or Latino CHAIN participants. This undoubtedly reflects the dynamics of the epidemic with its more recent incursion into communities of color. Examination of the right hand side of Table 6, shows that whites exhibit superior outcomes at baseline for only physical functioning, employment, emergency room visits, and initial use of HAART. For 6 outcomes, there were no statistically significant ethnic baseline differences and for 8 outcomes, mean baseline values for African Americans, Latinos or both were better than those for whites.

As a consequence of these baseline conditions, we find little evidence for the classic pattern of reduced ethnic disparities. However for all four cases where whites reported superior health outcomes at baseline, we found evidence for convergence and hence reduction in ethnic disparities. For seven other outcomes we found evidence that improvements by African Americans or Latinos outpaced those experienced by white participants in the CHAIN cohort. Finally, seven of the health outcomes exhibited either no change in ethnic differences or some evidence for whites improving more than one or both of the minority groups.

## **Discussion**

There is much in the data in the Appendix that have gone unexamined in the above summary and may find its way into other assessments of system level outcomes of health care services in New York City. A few final observations are in order to begin a discussion about how health outcomes are related to program performance.

A central theme of this report is that measures of health should go beyond the skin. The general import of the findings summarized above underscores an important duality when the expanded definition of health developed for this report is applied. While the physiological health of the CHAIN cohort has improved greatly over the six years of the study, measures of health perception, functioning and performance have failed to follow. CHAIN cohort members are living

longer but not necessarily feeling better. The trend data also suggest that people with newer infection as represented by the refresher cohort are not necessary healthier than surviving individuals with longer periods of infection.

Our data underscore the success of the Ryan White programs, Title I in particular, with other state and federal programs in facilitating widespread access to combination antiretroviral therapy. Undoubtedly for the foreseeable future, high priority will continue to be placed on programs that maintain current high levels of access to current and future generations of medications, with an increasing attention to how to support long-term adherence to medical regimens. Our data however also suggest that we have much to learn about how to translate CARE Act success in extending medical care to poorly served populations into programs that promote the broader physical, mental and social well being of persons infected with HIV.

## APPENDIX

These Are the Tables and Figures to See Trend of Health Outcomes

Figure 1, Table 1 ... Trend in Mortality Rate

Figure 2, Table 2 ... Trend in CD4 T-cell Count

Figure 3, Table 3 ... Trend in Undetectable Viral Load

Figure 4, Table 4 ... Trend in Opportunistic Infections

Figure 5, Table 5 ... Trend in General Health

Figure 6, Table 6 ... Trend in Mental Health Functioning (Mood Activity)

Figure 7, Table 7 ... Trend in Vitality

Figure 8, Table 8 ... Trend in Body Pain (Higher Values Less Pain)

Figure 9, Table 9 ... Trend in Physical Functioning

Figure 10, Table 10 ... Trend in Cognitive Functioning

Figure 11, Table 11 ... Trend in Employment Status

Figure 12, Table 12 ... Trend in Social Role Performance

Figure 13, Table 13 ... Trend in Emotional Role Performance

Figure 14, Table 14 ... Trend in Summarized Physical Health Score (PCS)

Figure 15, Table 15 ... Trend in Summarized Mental Health Score (MCS)

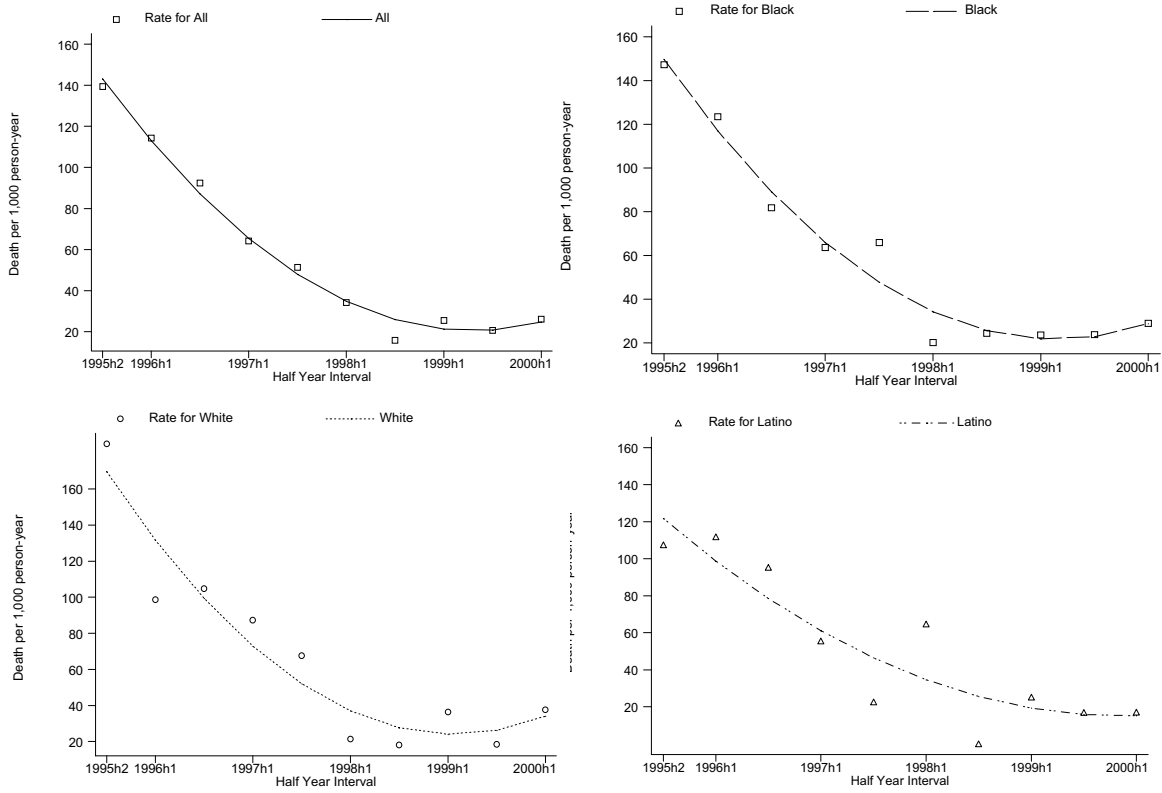
Figure 16, Table 16 ... Trend in HAART Use

Figure 17, Table 17 ... Trend in Emergency Room Visits

Figure 18, Table 18 ... Trend in Inpatient Episodes

Figure 19, Table 19 ... Trend in Total Number of Inpatient Days

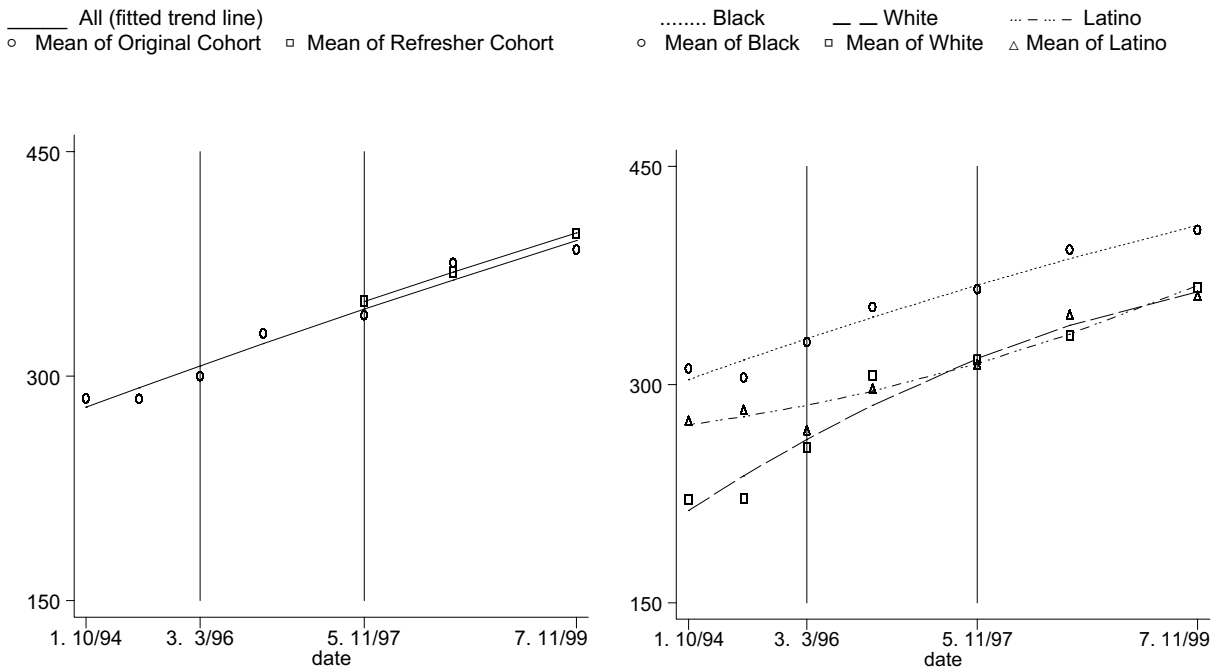
**FIGURE 1. TREND IN MORTALITY RATE**



**Table 1: Trends in Mortality Rate by Ethnic /Racial Groups**

	Total	Non Latino White	African American	Latino
2 <sup>nd</sup> half of 1995	139	185	147	108
1 <sup>st</sup> half of 1996	114	99	124	112
2 <sup>nd</sup> half of 1996	92	105	82	95
1 <sup>st</sup> half of 1997	64	87	64	56
2 <sup>nd</sup> half of 1997	51	67	66	23
1 <sup>st</sup> half of 1998	34	21	20	65
2 <sup>nd</sup> half of 1998	16	18	24	0
1 <sup>st</sup> half of 1999	26	36	23	25
2 <sup>nd</sup> half of 1999	21	18	24	17
1 <sup>st</sup> half of 2000	26	38	29	17

**FIGURE 2. TREND IN CD4 T CELL COUNT**



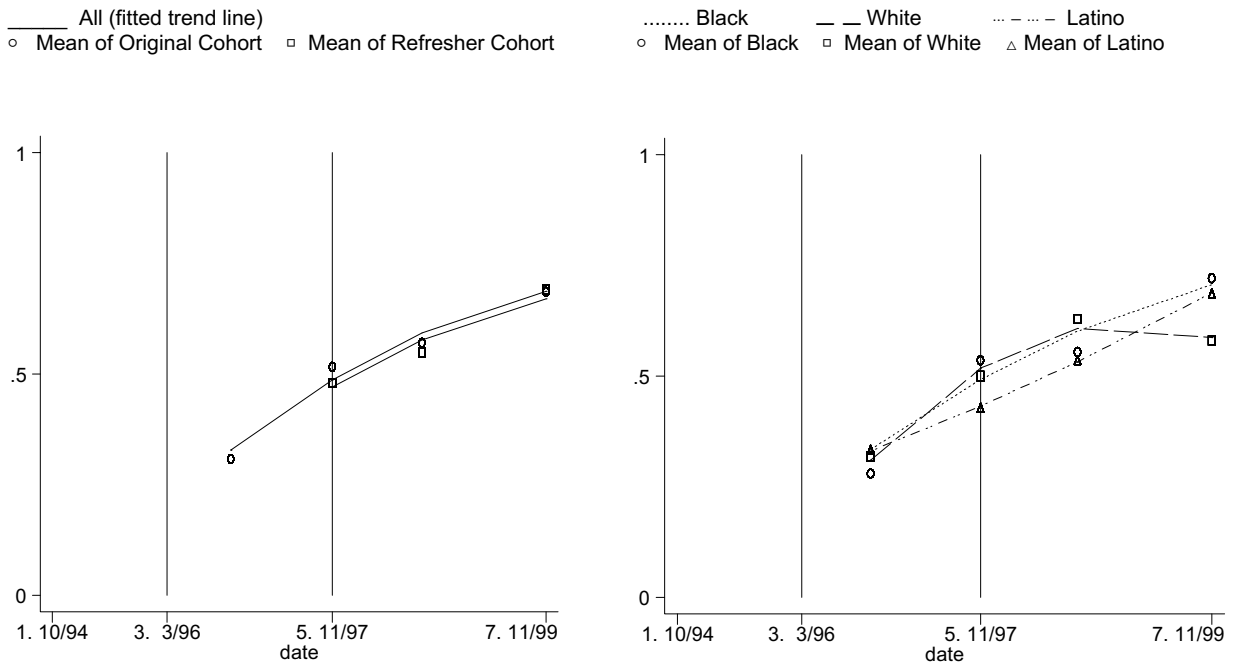
**Table 2: Trends in Mean CD4 T Cell Count by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	285	221	311	275
Round 2 2/95 - 3/96	285	222	305	283
Round 3 3/96 -12/96	300	257	329	269
Round 4 10/96 - 9/97	329	306	353	297
Round 5 11/97 -10/98	345	317	365	314
Round 6 10/98 - 1/00	373	334	393	348
Round 7 11/99 - 3/01	389	366	406	361
<b>Linear Trend Coefficient*</b>	20.586	40.15	22.265	6.935
<b>Intercept**</b>	281.08	217.03	305.62	272.18
<b>P-Value</b>	0.00	0.00	0.00	0.20

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 3. TREND IN UNDETECTABLE VIRAL LOAD**



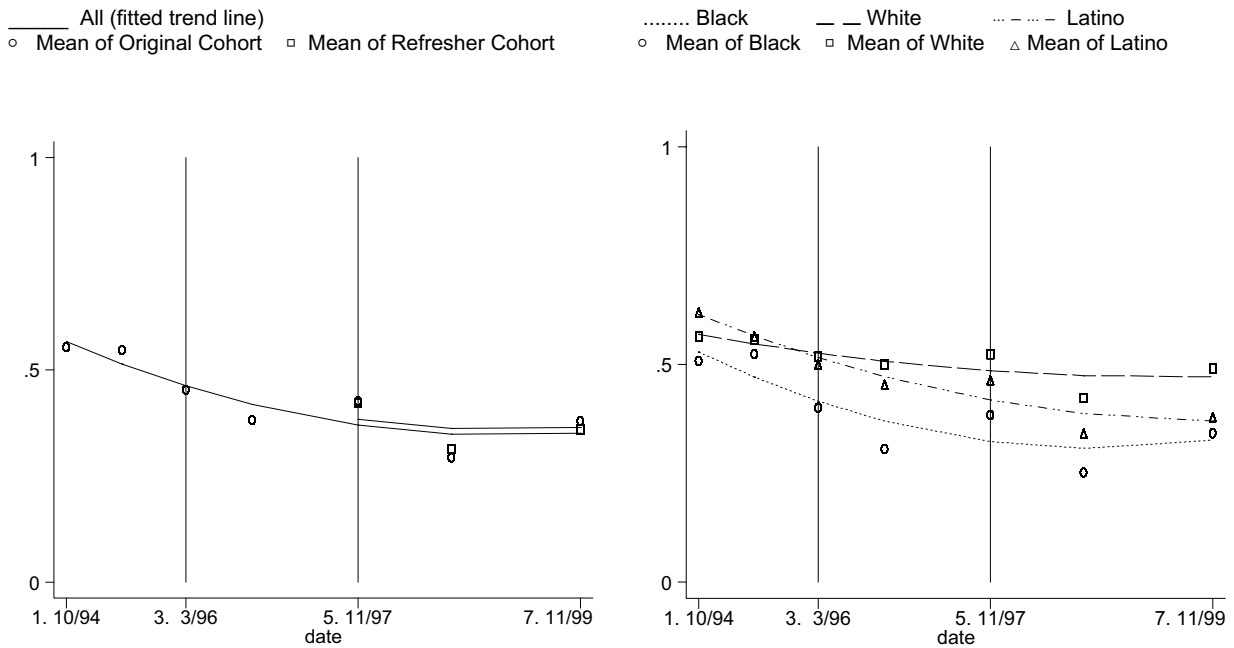
**Table 3: Trends in Undetectable Viral Load by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	-	-	-	-
Round 2 2/95 - 3/96	-	-	-	-
Round 3 3/96 -12/96	-	-	-	-
Round 4 10/96 - 9/97	0.307	0.319	0.279	0.333
Round 5 11/97 -10/98	0.502	0.5	0.535	0.429
Round 6 10/98 - 1/00	0.562	0.629	0.555	0.536
Round 7 11/99 - 3/01	0.688	0.58	0.72	0.687
<b>bn</b>				
<b>Linear Trend Coefficient*</b>	0.1095	0.0365	0.14235	0.1095
<b>Intercept**</b>	0.128	0.321	0.071	0.122
<b>P-Value</b>	0.000	0.399	0.00	0.002

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 4. TREND IN OPPORTUNISTIC INFECTIONS**



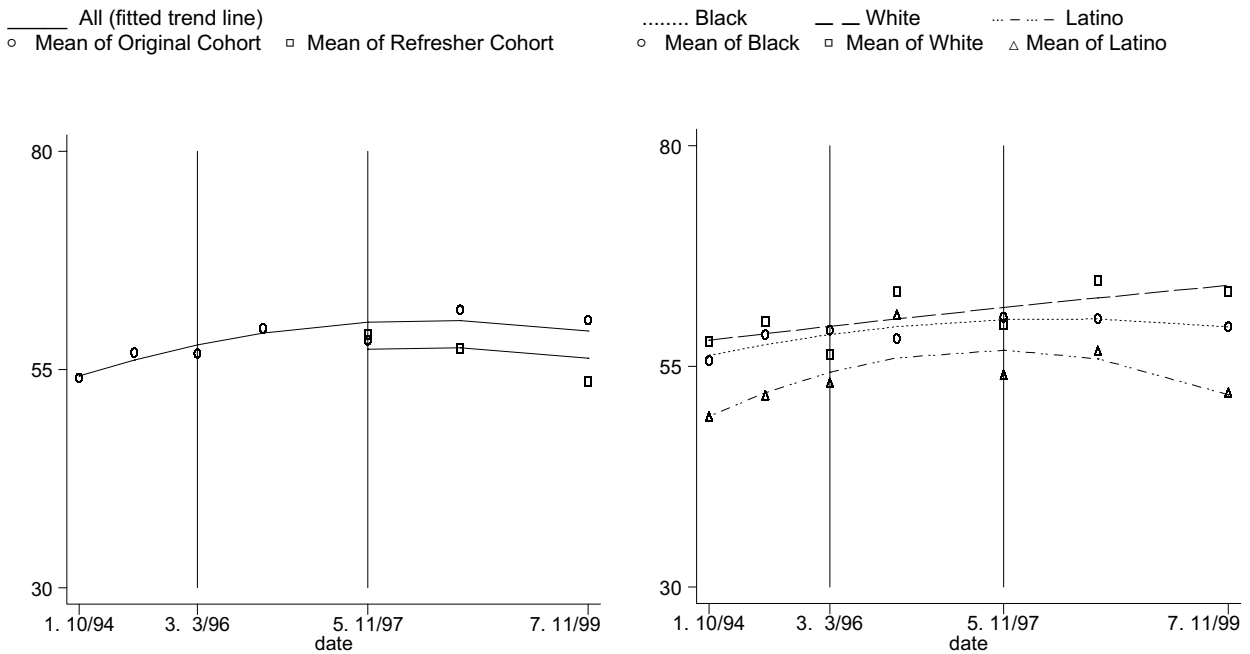
**Table 4: Trends in Opportunistic Infections by Ethnic /Racial Groups**  
 (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	0.553	0.563	0.507	0.619
Round 2 2/95 - 3/96	0.546	0.558	0.524	0.564
Round 3 3/96 -12/96	0.452	0.519	0.4	0.5
Round 4 10/96 - 9/97	0.381	0.5	0.305	0.453
Round 5 11/97 -10/98	0.423	0.523	0.384	0.463
Round 6 10/98 - 1/00	0.301	0.423	0.251	0.341
Round 7 11/99 - 3/01	0.371	0.491	0.341	0.378
<b>Linear Trend Coefficient*</b>	-0.04088	-0.02471	-0.04099	-0.0442
<b>Intercept**</b>	0.532	0.549	0.488	0.589
<b>P-Value</b>	0.0	0.23	0.00	0.005

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 5. TREND IN GENERAL HEALTH**



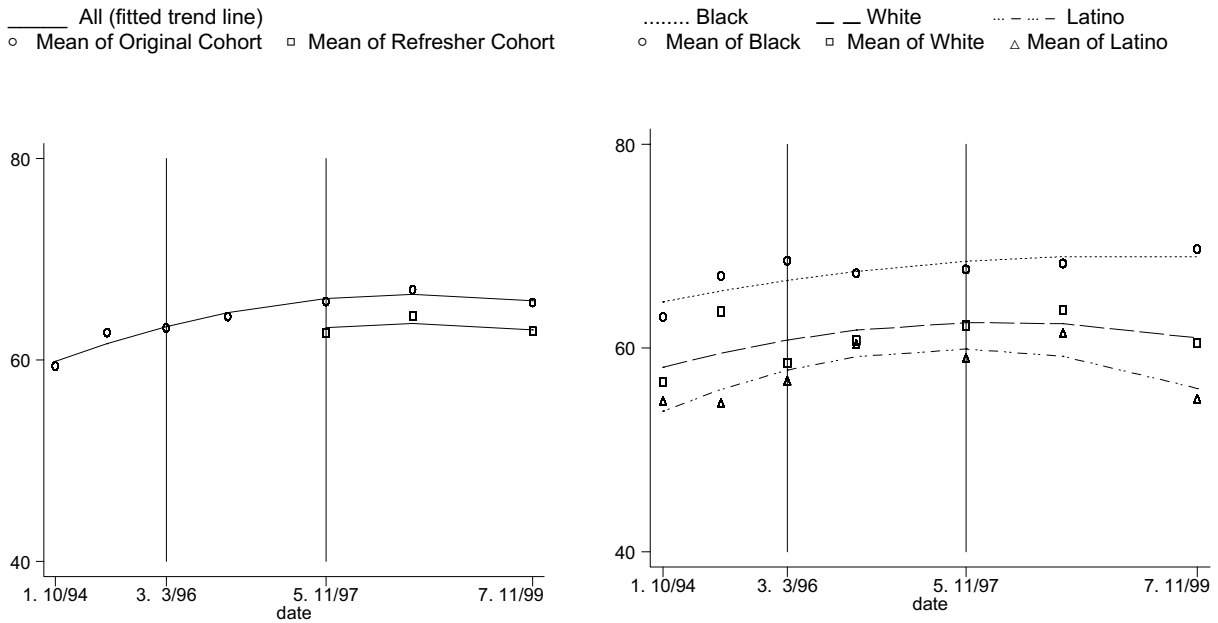
**Table 5: Trends in Mean General Health Scores by Ethnic /Racial Group (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	54.01	57.78	55.62	49.25
Round 2 2/95 - 3/96	56.9	60.11	58.55	51.73
Round 3 3/96 -12/96	56.8	56.28	59.05	53.14
Round 4 10/96 - 9/97	59.67	63.41	58.12	60.84
Round 5 11/97 -10/98	58.61	59.67	60.51	54.03
Round 6 10/98 - 1/00	60.1	64.69	60.36	56.75
Round 7 11/99 - 3/01	57.96	63.47	59.46	51.99
<b>Linear Trend Coefficient*</b>	1.9345	1.1315	1.825	2.555
<b>Intercept**</b>	55.24	58.66	57.20	49.83
<b>P-Value</b>	0.000	0.307	0.001	0.003

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 6 . TREND IN MENTAL HEALTH FUNCTIONING (MOOD ACTIVITY)**



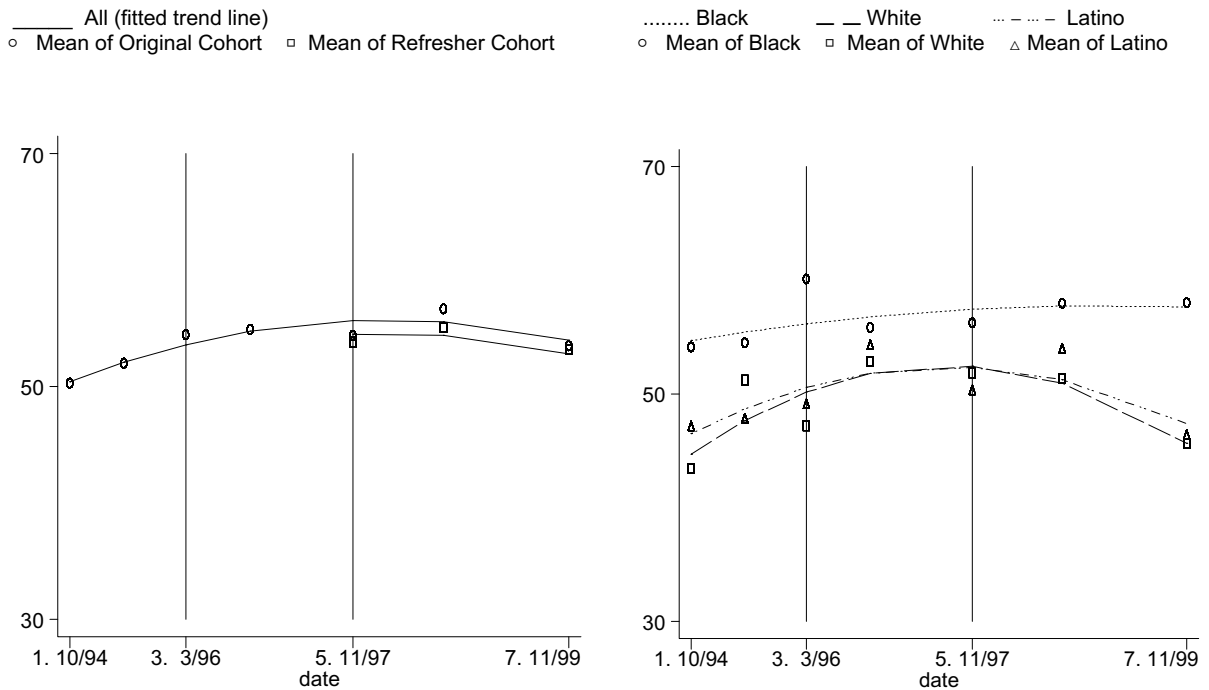
**Table 6: Trends in Mean Mental Health Functioning Scores by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	59.36	56.62	63.01	54.8
Round 2 2/95 - 3/96	62.72	63.58	67.06	54.56
Round 3 3/96 -12/96	63.14	58.53	68.54	56.79
Round 4 10/96 - 9/97	64.27	60.71	67.33	60.67
Round 5 11/97 -10/98	64.52	62.19	67.67	58.97
Round 6 10/98 - 1/00	65.93	63.72	68.29	61.43
Round 7 11/99 - 3/01	64.62	60.44	69.69	55.03
<b>Linear Trend Coefficient*</b>	1.533	0.438	1.971	1.241
<b>Intercept**</b>	60.81	59.21	64.68	55.31
<b>P-Value</b>	0.000	0.596	0.000	0.045

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 7 . TREND IN VITALITY**



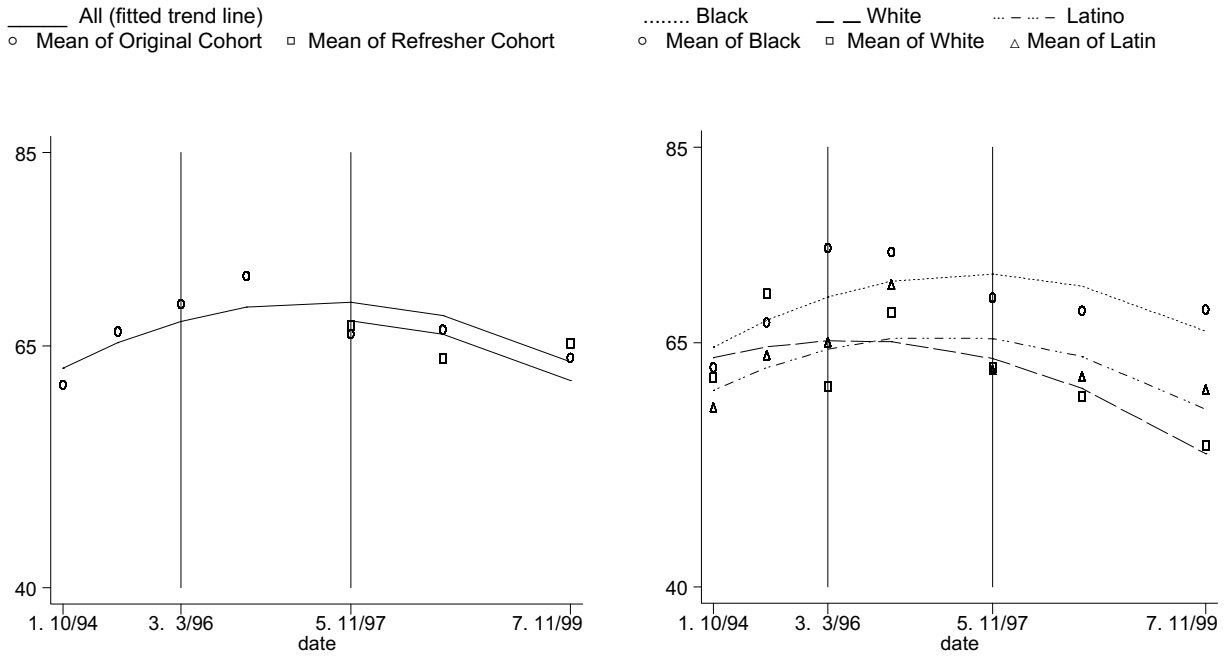
**Table 7: Trends in Mean Vitality Scores by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	50.24	43.43	54.13	47.18
Round 2 2/95 - 3/96	51.99	51.21	54.49	47.88
Round 3 3/96 -12/96	54.41	47.18	60.09	49.12
Round 4 10/96 - 9/97	54.88	52.86	55.83	54.33
Round 5 11/97 -10/98	54.12	51.86	56.26	50.36
Round 6 10/98 - 1/00	56.01	51.34	57.94	54.02
Round 7 11/99 - 3/01	53.36	45.64	57.99	46.43
<b>Linear Trend Coefficient*</b>	1.1534	1.8615	1.2045	1.2045
<b>Intercept**</b>	51.58	46.92	55.16	48.58
<b>P-Value</b>	0.001	0.029	0.013	0.310

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 8 . TREND IN BODY PAIN** (Higher values less pain)



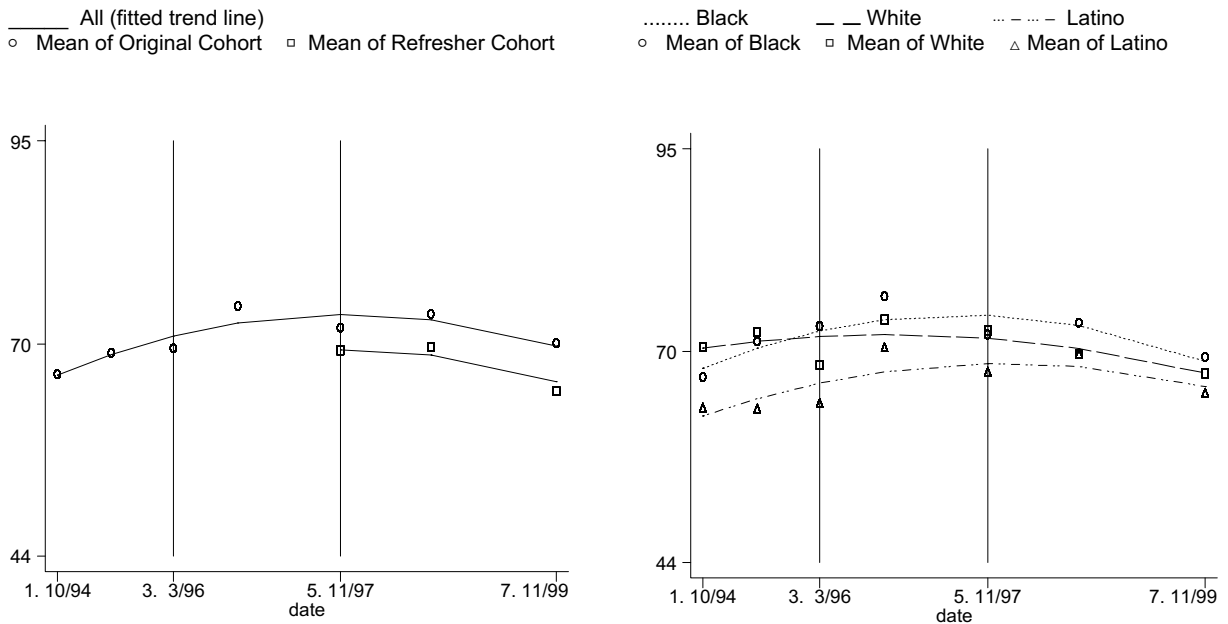
**Table 8: Trends in Mean Body Pain Scores by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	60.95	61.34	62.44	58.36
Round 2 2/95 - 3/96	66.44	70	67.03	63.72
Round 3 3/96 -12/96	69.32	60.47	74.65	65.03
Round 4 10/96 - 9/97	72.2	68.09	74.24	70.96
Round 5 11/97 -10/98	66.58	62.42	69.58	62.2
Round 6 10/98 - 1/00	65.46	59.49	68.24	61.5
Round 7 11/99 - 3/01	64.35	54.44	68.35	60.18
<b>Linear Trend Coefficient*</b>	2.1535	-0.365	2.92	2.19
<b>Intercept**</b>	64.26	65.38	66.20	60.29
<b>P-Value</b>	0.000	0.742	0.000	0.008

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 9. TREND IN PHYSICAL FUNCTIONING**



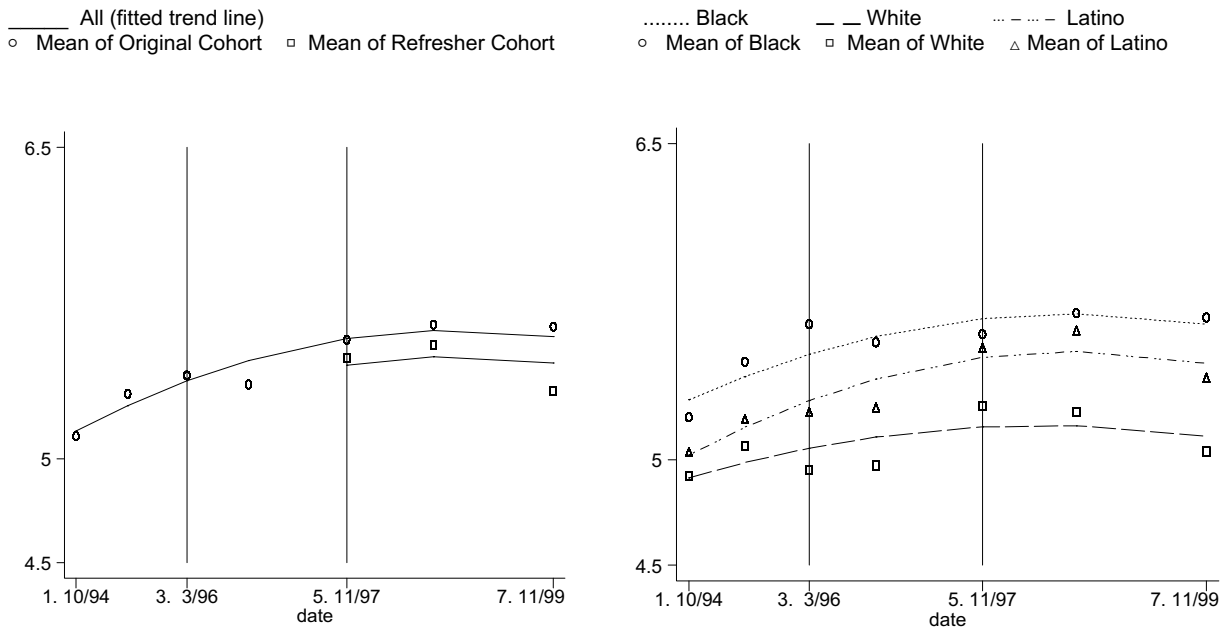
**Table 9: Trends in Mean Physical Functioning Scores by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	66.33	70.55	66.83	63.11
Round 2 2/95 - 3/96	68.9	72.37	71.2	62.98
Round 3 3/96 -12/96	69.5	68.31	73.1	63.67
Round 4 10/96 - 9/97	74.68	73.93	76.84	70.52
Round 5 11/97 -10/98	70.87	72.58	72.09	67.55
Round 6 10/98 - 1/00	72.11	69.72	73.54	69.77
Round 7 11/99 - 3/01	67.87	67.27	69.29	64.92
<b>Linear Trend Coefficient*</b>	2.263	1.2045	2.555	2.0075
<b>Intercept**</b>	67.83	71.51	70.17	62.21
<b>P-Value</b>	0.000	0.191	0.000	0.022

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 10. TREND IN COGNITIVE FUNCTIONING**



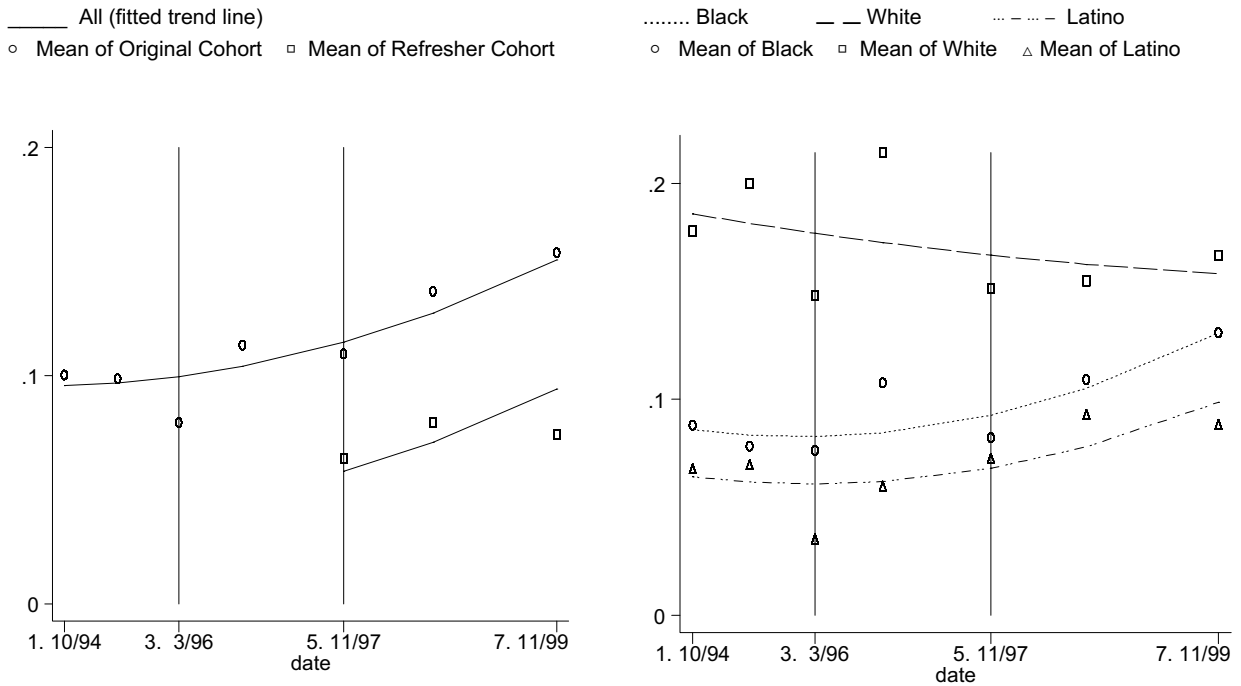
**Table 10: Trends in Mean Cognitive Functioning Scores by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	5.11	4.92	5.2	5.04
Round 2 2/95 - 3/96	5.31	5.06	5.46	5.19
Round 3 3/96 -12/96	5.4	4.95	5.64	5.23
Round 4 10/96 - 9/97	5.36	4.97	5.56	5.25
Round 5 11/97 -10/98	5.54	5.26	5.6	5.53
Round 6 10/98 - 1/00	5.61	5.23	5.69	5.61
Round 7 11/99 - 3/01	5.52	5.04	5.67	5.39
<b>Linear Trend Coefficient*</b>	0.128	0.0584	0.1387	0.146
<b>Intercept**</b>	5.189	4.955	5.343	5.05
<b>P-Value</b>	0.000	0.275	0.000	0.001

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 11 . TREND IN EMPLOYMENT STATUS**



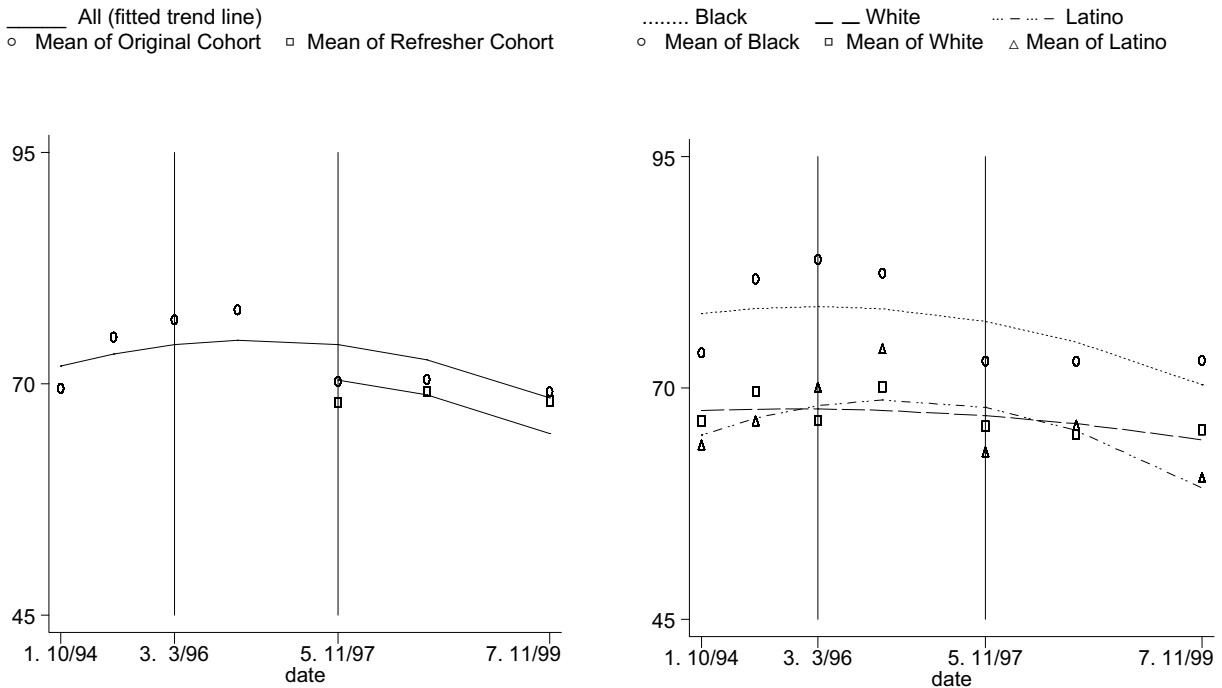
**Table 11: Trends in Mean Employment Status by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	0.1	0.178	0.088	0.068
Round 2 2/95 - 3/96	0.1	0.2	0.078	0.07
Round 3 3/96 -12/96	0.08	0.148	0.076	0.035
Round 4 10/96 - 9/97	0.11	0.214	0.108	0.06
Round 5 11/97 -10/98	0.09	0.151	0.08	0.073
Round 6 10/98 - 1/00	0.11	0.155	0.109	0.093
Round 7 11/99 - 3/01	0.12	0.17	0.13	0.09
<b>Linear Trend Coefficient*</b>	0.0084	0.0064	0.0121	0.0051
<b>Intercept**</b>	0.094	0.185	0.082	0.06
<b>P-Value</b>	0.068	0.652	0.048	0.512

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 12. TREND IN SOCIAL ROLE PERFORMANCE**



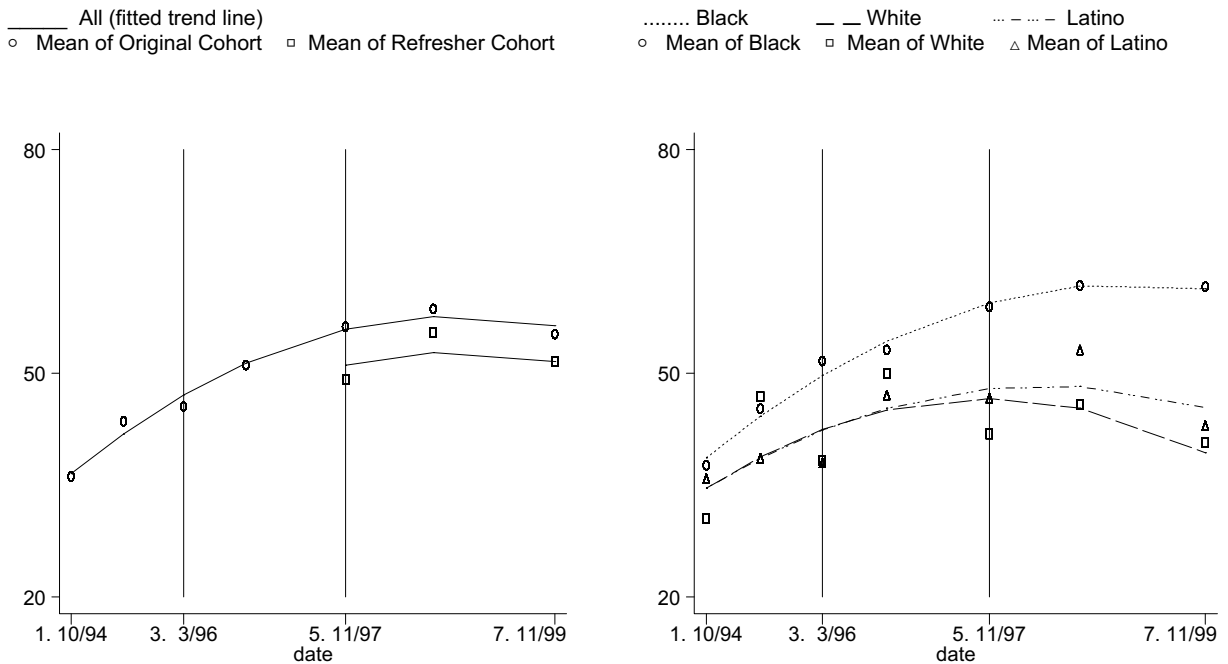
**Table 12: Trends in Mean Social Role Performance Scores by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	69.46	66.45	73.77	63.81
Round 2 2/95 - 3/96	75	69.57	81.77	66.44
Round 3 3/96 -12/96	76.9	66.46	83.84	70.04
Round 4 10/96 - 9/97	78	70.07	82.4	74.22
Round 5 11/97 -10/98	69.29	64.84	72.85	63.06
Round 6 10/98 - 1/00	69.93	64.96	72.9	65.99
Round 7 11/99 - 3/01	68.76	65.45	72.94	60.29
<b>Linear Trend Coefficient*</b>	0.2081	-0.18615	0.09125	0.47085
<b>Intercept**</b>	73.19	67.97	78.74	66.15
<b>P-Value</b>	0.662	0.871	0.882	0.634

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 13. TREND IN EMOTIONAL ROLE PERFORMANCE**



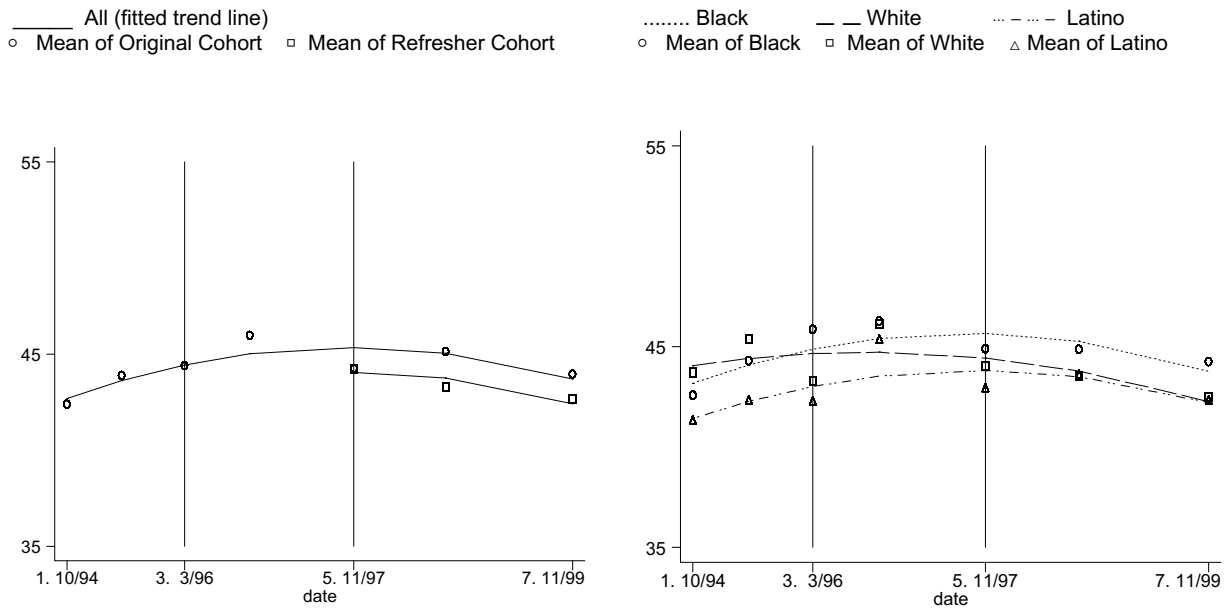
**Table 13: Trends in Mean Emotional Role Performance Scores by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	36.12	30.51	37.61	35.84
Round 2 2/95 - 3/96	43.56	46.84	45.24	38.6
Round 3 3/96 -12/96	45.51	38.27	51.6	37.94
Round 4 10/96 - 9/97	51.07	50	53.1	47.06
Round 5 11/97 -10/98	53.3	41.86	58.86	46.65
Round 6 10/98 - 1/00	57.38	45.77	61.72	53.1
Round 7 11/99 - 3/01	53.8	40.74	61.6	42.98
<b>Linear Trend Coefficient*</b>	5.50	2.19	7.67	3.54
<b>Intercept**</b>	39.06	37.73	40.87	36.07
<b>P-Value</b>	0.000	0.210	0.000	0.013

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 14. TREND IN SUMMARIZED PHYSICAL HEALTH SCORE (PCS)**



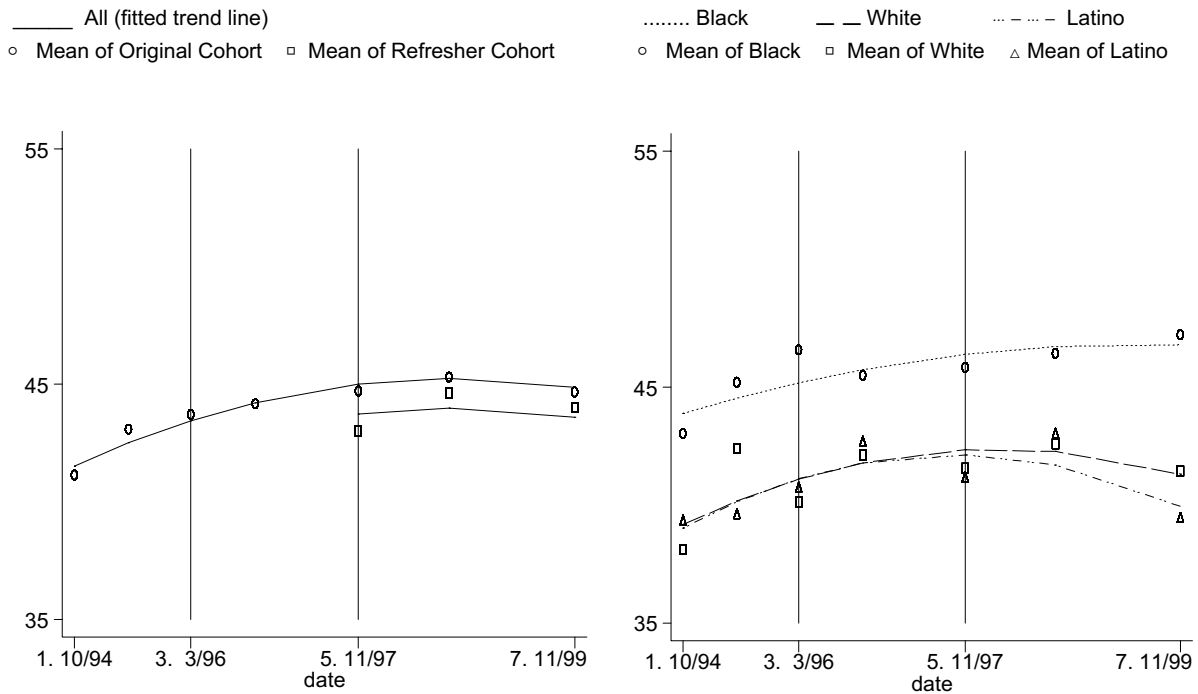
**Table 14: Trends in Mean Summarized Physical Health Score by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	42.39	43.71	42.57	41.34
Round 2 2/95 - 3/96	43.89	45.34	44.28	42.36
Round 3 3/96 -12/96	44.39	43.29	45.85	42.29
Round 4 10/96 - 9/97	45.98	46.12	46.26	45.37
Round 5 11/97 -10/98	44.23	44.01	44.87	42.96
Round 6 10/98 - 1/00	44.4	43.55	44.86	43.61
Round 7 11/99 - 3/01	43.2	42.43	43.87	42.15
<b>Linear Trend Coefficient*</b>	0.791	0.470	1.035	0.560
<b>Intercept**</b>	44.08	39.90	44.01	39.94
<b>P-Value</b>	0.00	0.381	0.00	0.119

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 15. TREND IN SUMMARIZED MENTAL HEALTH SCORE (MCS)**



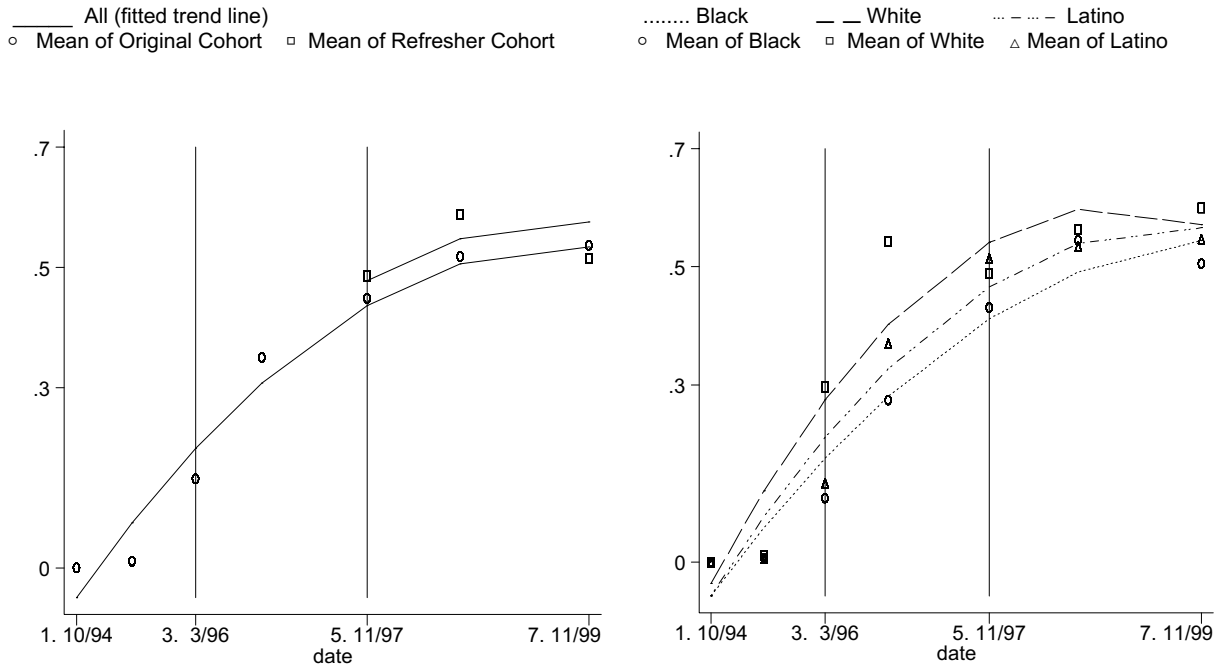
**Table 15: Trends in Mean Summarized Mental Health Scores by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	41.11	38.1	43.04	39.35
Round 2 2/95 - 3/96	43.06	42.4	45.21	39.63
Round 3 3/96 -12/96	43.71	40.13	46.58	40.76
Round 4 10/96 - 9/97	44.15	42.13	45.49	42.7
Round 5 11/97 -10/98	44.01	41.56	45.83	41.2
Round 6 10/98 - 1/00	45.02	42.6	46.43	43.04
Round 7 11/99 - 3/01	44.28	41	47	39.6
<b>Linear Trend Coefficient*</b>	0.896	0.411	1.074	0.840
<b>Intercept**</b>	43.27	44.54	43.97	41.38
<b>P-Value</b>	0.00	0.33	0.000	0.01

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 16. TREND IN HAART USE**



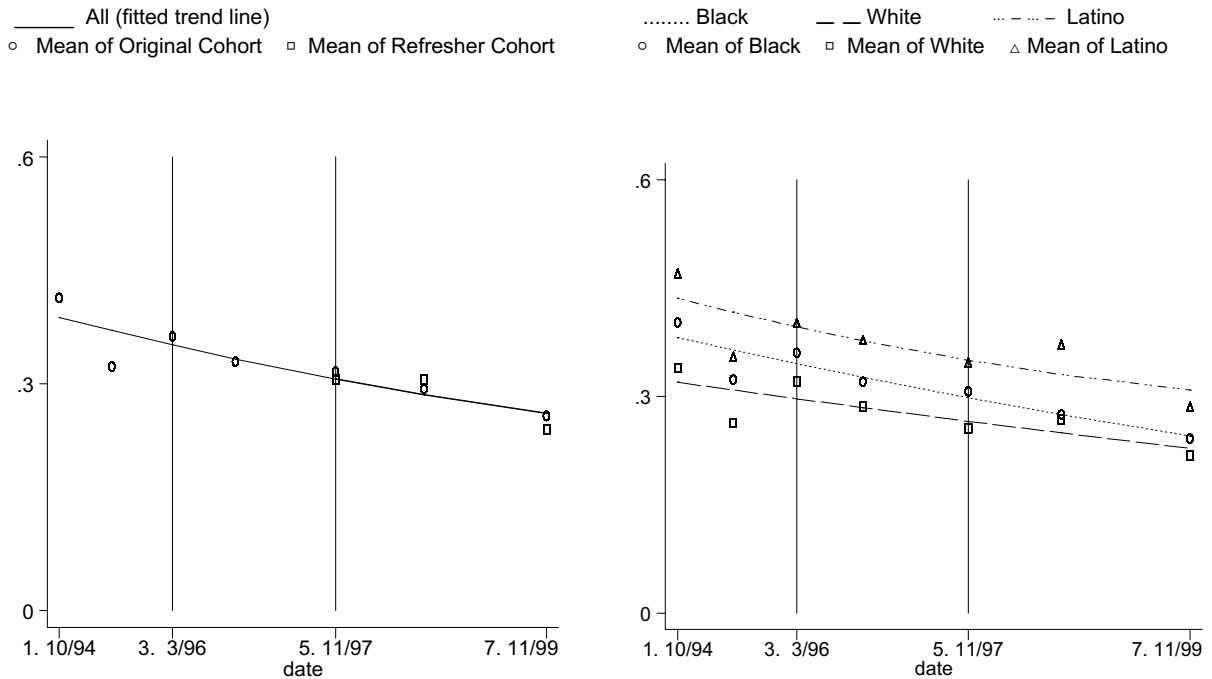
**Table 16: Trends in HAART Use by Ethnic/ Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	-	-	-	-
Round 2 2/95 - 3/96	-	-	-	-
Round 3 3/96 -12/96	0.148	0.296	0.108	0.134
Round 4 10/96 - 9/97	0.35	0.543	0.274	0.37
Round 5 11/97 -10/98	0.463	0.488	0.431	0.514
Round 6 10/98 - 1/00	0.545	0.563	0.545	0.535
Round 7 11/99 - 3/01	0.528	0.6	0.506	0.546
<b>Linear Trend Coefficient*</b>	0.1387	0.1825	0.1168	0.1825
<b>Intercept**</b>	-0.005	0.018	-0.010	-0.017
<b>P-Value</b>	0.000	0.000	0.000	0.000

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 17. TREND IN EMERGENCY ROOM VISITS**



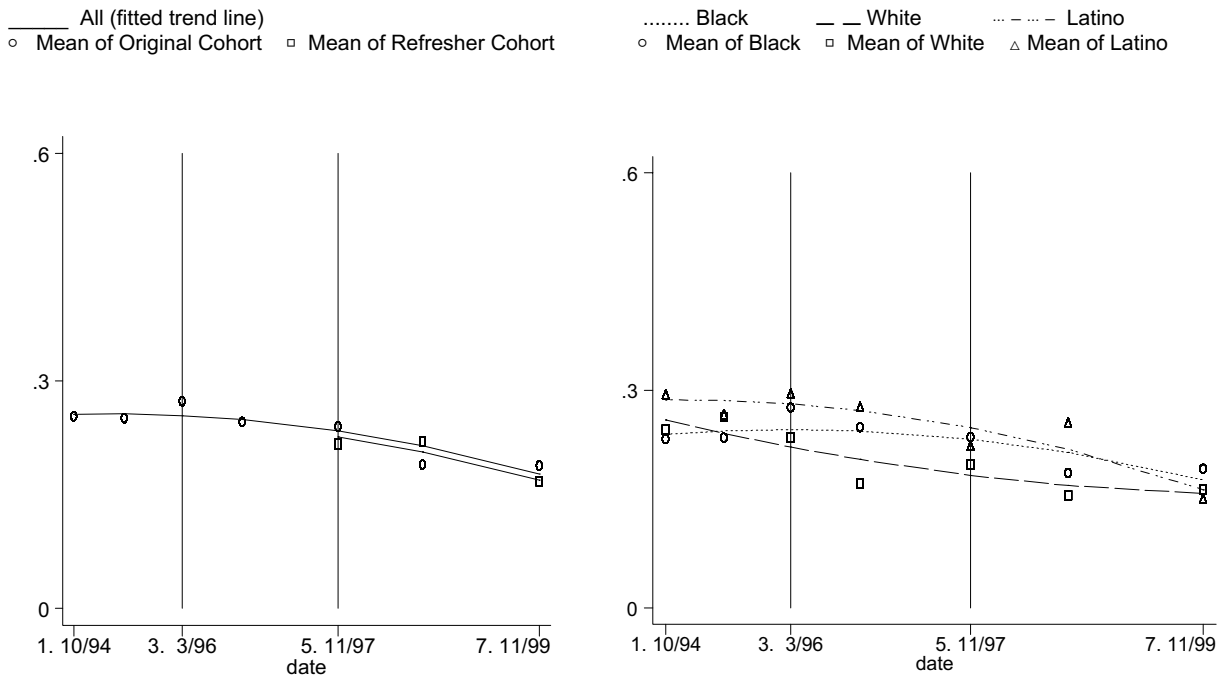
**Table 17: Trends in Emergency Room Visits by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	0.413	0.339	0.402	0.471
Round 2 2/95 - 3/96	0.322	0.263	0.323	0.555
Round 3 3/96 -12/96	0.363	0.321	0.36	0.401
Round 4 10/96 - 9/97	0.329	0.286	0.32	0.378
Round 5 11/97 -10/98	0.311	0.256	0.327	0.346
Round 6 10/98 - 1/00	0.298	0.268	0.275	0.372
Round 7 11/99 - 3/01	0.251	0.218	0.241	0.286
<b>Linear Trend Coefficient*</b>	-0.0277	-0.0210	-0.0317	-0.0364
<b>Intercept**</b>	0.387	0.322	0.378	0.44
<b>P-Value</b>	0.000	0.265	0.008	0.010

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 18. TREND IN INPATIENT EPISODES**



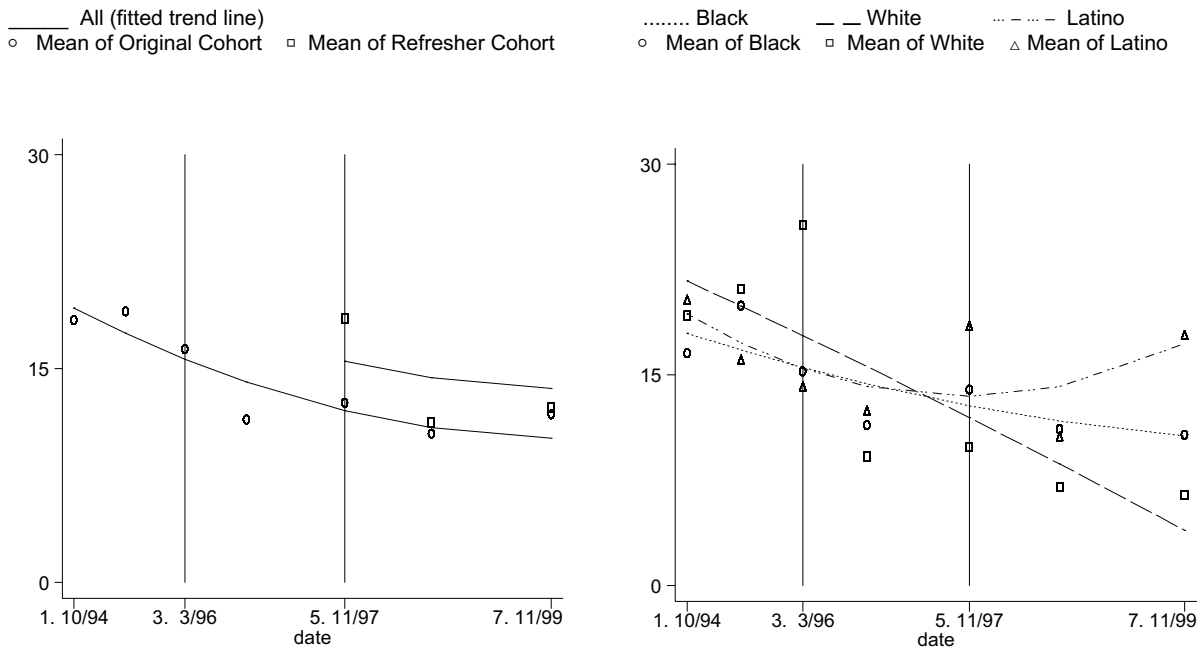
**Table 18: Trends in Inpatient Episodes by Ethnic /Racial Groups**  
 (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	0.253	0.246	0.232	0.294
Round 2 2/95 - 3/96	0.25	0.263	0.235	0.267
Round 3 3/96 -12/96	0.273	0.235	0.276	0.296
Round 4 10/96 - 9/97	0.246	0.171	0.249	0.277
Round 5 11/97 -10/98	0.23	0.198	0.235	0.223
Round 6 10/98 - 1/00	0.201	0.155	0.185	0.256
Round 7 11/99 - 3/01	0.18	0.163	0.192	0.151
<b>Linear Trend Coefficient*</b>	-0.0091	-0.0179	0.0026	-0.0325
<b>Intercept**</b>	0.260	0.252	0.238	0.312
<b>P-Value</b>	0.200	0.293	0.769	0.010

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.

**FIGURE 19. TREND IN TOTAL NUMBER OF INPATIENT DAYS**



**Table 19: Trends in Mean of Total Number In-Patient Days by Ethnic /Racial Groups (Adjusted for age, membership in the refresher cohort and recent deviations from linear trend)**

	Total	Non Latino White	African American	Latino
Round 1 10/94 - 7/95	18.4	19.2	16.53	20.37
Round 2 2/95 - 3/96	19	21.12	19.93	16.07
Round 3 3/96 -12/96	16.34	25.67	15.22	14.19
Round 4 10/96 - 9/97	11.38	9.18	11.39	12.44
Round 5 11/97 -10/98	14.87	9.88	13.94	18.5
Round 6 10/98 - 1/00	10.76	7	11.13	10.61
Round 7 11/99 - 3/01	11.94	6.44	10.72	17.83
<b>Linear Trend Coefficient*</b>	-1.858	-3.285	-1.752	-1.095
<b>Intercept**</b>	18.39	21.84	17.55	17.75
<b>P-Value</b>	0.001	0.023	0.007	0.428

\* Change over a one-year period

\*\* This is the expected value for a 39 year old at baseline interview.