C.H.A.I.N. Report

Key Findings from Final 2003-2005 Tri-County CHAIN Data Reports

Columbia University
Mailman School of Public Health
In collaboration with Medical and Health Research Association of New York, the NYC Department of Health and Mental Hygiene, the Westchester Department of Health, and the NY Health & Human Services HIV Planning Council

TRI-COUNTY CHAIN
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We are particularly grateful to all the participants in the Tri-County CHAIN Project who share their time and their experiences with us. We take their trust in us seriously, and hope that our project serves to amplify the voice of the HIV-positive community in Putnam, Rockland, and Westchester counties.

Tri-County CHAIN Project

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Report 2003-1

Service gaps and Utilization

KEY FINDINGS:
1. Many of the needs in Tri-County Cohort are remarkably similar to the NYC Cohort. Among the differences are a greater need in Tri-County for financial housing services and transportation services.

2. Among those with a need for drug or alcohol treatment services, 76% report a service gap. Among those with a need for mental health services, 55% reported a gap.

3. The need for treatment adherence services, comprehensive case management and the need for transportation services has increased.

4. More people with Tcell counts below 200 were on combination therapy in Wave 2 than Wave 1.

5. The three highest areas of service utilization are primary medical care (95%), case management (74%) and dental care (71%).

6. White respondents are more likely than black respondents to report mental health services.

7. Women were more likely to report a need for help with food or groceries and a need for help with emotional issues.
Report 2003-4

Partner Notification

KEY FINDINGS:

1. 18% of respondents reported that their medical provider had asked for the names of sexual or needle sharing partners. 35% of these individuals provided contact names to their doctors.

2. Individuals in Tri-County were twice as likely as NYC respondents to reports having discussed needle-sharing and sexual partners with their providers.

3. White respondents were less likely than either black or Latino respondents to have discussed sexual or needle-sharing partners with their medical providers.

4. Individuals with greater than a high school education were less likely to discuss partners with their doctors.

5. Respondents whose initial HIV diagnosis occurred between 1996-2002 were more likely to have discussed partner notification with their providers than those with an earlier HIV diagnosis.
Housing

KEY FINDINGS:
1. From Wave 1 to Wave 2 the housing arrangements did not vary. Tri-county respondents housing status, i.e., whether renting, or doubled-up, remained stable over time.

2. Women were more likely than men to be living in public housing, and urban residents were more likely to live in AIDS supportive housing than suburban residents. Living in AIDS supportive housing was associated with receiving of mental health services.

3. Fifty percent of respondents reported some type of housing need, either financial or permanent. This need persisted across each wave. Respondents with low MCS scores reported financial housing needs more than those with better MCS scores.

4. Women reported a paying a higher proportion of their income towards rent than men. MSM had the lowest rent burden among the risk groups.

5. Factors associated with seeking agency help with housing were income levels below $5000 per year, and living alone. Compared to men women were more likely to seek agency help with housing.
Report 2003-7

Strategic Plan Progress Indicators

KEY FINDINGS:
1. Black respondents reported poorer health more often than White or Latino respondents over time.
2. MSM tend to report being completely adherent more often than other risk groups.
3. Men were significantly more likely than women to report T-cell counts lower than 500 in Wave 2 which was not noted in Wave 1.
4. In Wave 2 problem drug users reported significantly more difficulties with staff that resulted in delay, or decline of services by respondent.
5. The number of respondents that indicated they experienced a cultural or language barrier within the care system increased substantially between waves.
6. Black and Latino respondents expressing a need for transportation were less likely than white respondents to receive the service.
7. Respondents indicated a decreased awareness in the
Report 2005-1

Haitian Respondents in the Tri-County CHAIN Cohort

KEY FINDINGS:

1. 14/15 of the Haitian have been or are currently married compared with 55% of the overall cohort.

2. Most of the Haitians are stably housed with only 2/15 doubled up. Few live alone (3/15). There is a high degree of employment (10/15).

3. 27% of Haitian respondents did not know their t-cell counts, compared with 11% of the rest of the cohort.

4. All of the Haitian respondents reported themselves heterosexual. The Respondents report very little drug use. Only 1/15 reported serious drug use.

5. Most of the respondents have not disclosed their HIV status to friends or family.

6. Only 2/15 said they had no social problems. This population is more likely to report a need for assistance in housing, financial employment, home care, clothing and childcare.

7.
Report 2005-2

Trends in HAART & Treatment Adherence Programs

KEY FINDINGS:

1. Black respondents and current drug users are least likely to know their T-cell counts. Respondents in specialized AIDS housing are more likely to know their t-cell counts.

2. Women and Latinos are more likely to move from non-adherence to adherence.

3. Poorer respondents, unstably housed individuals, and those not in partnership relationships are more likely to be in treatment adherence programs.

4. MSM are more likely to be adherent in both waves, and more likely to know their t-cell counts.

5. Comprehensive case management is significantly associated with being on HIV medications, being in a treatment adherence program and knowing one’s t-cell count.
Report 2005-3

Prevention for Positives

KEY FINDINGS:

1. Doctors are more likely to counsel men than women about sexual activity and drug use.

2. Doctors are more likely to counsel black and Latinos than white respondents about sexual activity and drug use.

3. Doctors are more likely to counsel individuals in urban Westchester about super-infection.

4. Doctors are more likely to ask less educated respondents about condom use.

5. Doctors are more likely to counsel lower income respondents about safer drug use and super-infections.

6. Respondents with T-cell counts less than 200 are more likely to be counseled about drug treatment.

7. Doctors are more likely to counsel drug users than MSM about safer sex and drug use.
DATA & METHODOLOGY

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

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

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

Agency-based random recruitment

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

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

**Agency-based sequential enrollment**

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

**Interview Schedule**

All interviews are conducted in person by trained interviewers. The major topics covered during the interviews include (1) initial encounter with the health care delivery system, (2) need for services, (3) access, utilization and satisfaction with health and social services, (4) sociodemographic characteristics of respondents, (5) informal caregiving from friends, family and volunteers, and (6) quality of life with respect to health status, psychological and social functioning. The interview schedule was developed based upon a listing of questions under each of these broader tropics that was circulated to the Planning and Evaluation Subcommittee, WDOH and MHRA. Whenever possible, interview questions were taken from earlier surveys administered to persons living with HIV and were designed to match questions asked of participants in the New York City CHAIN study. In particular, information on use of health and social services was obtained using questions developed for a federally funded study of AIDS service utilization. Health status was assessed using survey questions that have well established psychometric properties (such as the Medical Outcomes Survey scale, and indices measuring health locus of control, and self-efficacy) and which have been widely administered to HIV positive populations. The interview takes between two and three hours to complete, dependent upon issues relevant to each client's unique service needs. Most interviews were conducted in English, although fifteen were conducted in Spanish and six in Creole.