



C.H.A.I.N. REPORT

Tri-County CHAIN

Key Findings from Final 2002 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

Originally submitted Nov. 13, 2002
Final report submitted Apr 1, 2003
HRSA Grant # H89 HA 0015-11

ACKNOWLEDGMENTS

A Technical Review Team (TRT) provides oversight for the CHAIN Project in New York City and in the Tri-County area of Putnam, Rockland, and Westchester counties. In addition to Peter Messeri, PhD, Angela Aidala, PhD, and David Abramson, of Columbia University's Mailman School of Public Health, TRT members include Mary Ann Chiasson, DrPH, MHRA (chair); Kevin Garrett, Mayor's Office of AIDS Policy; JoAnn Hilger, NYCDOHMH; Julie Lehane, PhD, Westchester County DOH; Jennifer Nelson, MHRA; and Tom Sentell, PWA Advisory Group. Additionally, the Tri-County CHAIN project regularly consults with Tom Petro, Jan Carl Park, Julie Lehane, and Renee O'Rourke of the Westchester Department of Health.

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

Peter Messeri, PhD	Principal Investigator
David Abramson, MPH MPhil	Study Director
Barbara Bennet	Field Director
Tasha Stehling	Data Manager
Rachel Ferat	Office Manager & Research Assistant
Sandra Smartt & Dave Hunter	Data Editors
Narine Malcolm	Administrator

Interviewers: Deanna Cambell, Sophia Luyando, Rose Rivera, Elizabeth Romero, Kenneth Smith
Office Staff: Karen Earley, Jeanine Moy, Emma Snowden
Graduate Research Assistants: Laura Kozek, Thurka Sangaramoorthy

This research was made possible by grant number H89 HA 0015-11 from the US Health Resources and Services Administration (HRSA) HIV/AIDS Bureau. The CHAIN study is supported by the HIV Health and Human Services Planning Council of New York under a Title I grant of the Ryan White Comprehensive AIDS Resource Emergency Act of 1990 through the New York City Department of Health and Mental Hygiene. It is conducted under the auspices of the Medical and Health Research Association of New York City, Inc, and in Tri-County under the Westchester Department of Health. Its contents are solely the responsibility of the researchers and do not necessarily represent the official views of the U.S. Health Resources and Services Administration; the City of New York; Putnam, Rockland, or Westchester counties; or the Medical and Health Research Association of New York.



Tri-County CHAIN

Report 2002-1

The Tri-County Cohort: Demographics & Other Characteristics

KEY FINDINGS:

1. The Tri-County cohort is reasonably similar to the racial/ethnic composition of People Living With AIDS in the area
2. Very few individuals under 35 years old (12%).
3. High proportion of people who report that fairly often they don't have enough money for clothing (29%), utilities (17%), food (18%) or rent (15%).
4. Approximately 55% of the cohort has been or is currently married, and 35% have children under 18 in the household.
5. A large number of respondents (18%) reported that they had a sibling who was HIV-positive.
6. There are clear socioeconomic and racial/ethnic differences between the urban and suburban respondents. Suburban respondents are more likely to be white, stably housed, and non-drug users than urban respondents.

Tri-County CHAIN



Report 2002-2

Health Status and Health Service Utilization

KEY FINDINGS:

1. Tri-County respondents who have ever had an AIDS diagnosis are less likely to be on HAART than a comparable group of NYC respondents in CHAIN
2. Approximately 1/3 of white respondents are "long-term survivors," having been diagnosed in the 1980's, compared with 19% of black and 21% of Latino respondents.
3. There are subgroup differences in self-reported adherence patterns. Men who have sex with men are far more likely to report adherence (87%) than are problem drug users (54%), MSM/PDU (53%) or heterosexual respondents (65%).
4. Nearly one quarter of all respondents report a recent "drug holiday," or structured treatment interruption. Among those who have taken a drug holiday from their HIV medications, 70% have done so on their own, without consulting their medical providers.

Tri-County CHAIN



Report 2002-3

Stigma & Social Isolation

KEY FINDINGS:

1. Overall, Tri-County respondents report very high rates of felt stigma – 62% report high stigma scores and 27% report moderate HIV-related stigma.
2. Women are more likely than men (70% compared to 55%) to express high levels of perceived stigma.
3. There were few differences in felt stigma, suggesting that it is a relatively universal experience among Tri-County respondents.
4. Most elements of the HIV care system, such as a case manager or recent visits to professional or supportive mental health services, were not associated with reducing rates of stigma. Only recent attendance at support groups was related to higher rates of HIV status disclosure.
5. Among respondents who report that they have never used drugs, 30% have disclosed to only a few close friends and family members or to no one at all, compared to 12% of individuals who report ever having used drugs.



Tri-County CHAIN

Report 2002-4

Field Notes: Recruiting a Longitudinal Cohort

KEY FINDINGS:

1. Building a sampling frame entailed identifying potential sites, screening agencies, and enumerating the project to agency staff.
2. Participating agencies were designated an enrollment strategy depending on the type of service provided and the number of clients at each site.
3. The most productive random or sequential sites provided a variety of medical and social services and used a team approach for recruiting clients.
4. There was no statistically significant difference between the pools of randomly recruited and sequentially recruited respondents.
5. Our data suggest that the pool of recruited respondents generally represents the population of HIV+ adults in care in Westchester, Putnam and Rockland counties.



Tri-County CHAIN

Report 2002-5

Support Groups

KEY FINDINGS:

1. About half (46%) of the respondents said they ever attended a support group.
2. The principal reasons among all the respondents to attend support groups was to receive emotional support or to educate themselves about living with and managing HIV.
3. Women were slightly more likely to report that they attended support groups in order to share experiences with other women, whereas men were more likely to say they attended support groups to obtain information or to receive an incentive.
4. Individuals who had disclosed their HIV status to many friends and family members were 4.4 times more likely to have ever attended a support group than were individuals who had disclosed to only a few friends and family members.

Tri-County CHAIN



Report 2002-6

Baseline Needs Assessment

KEY FINDINGS:

1. Among people not receiving local medical care, approximately one-quarter would prefer such services. When considered among individuals who live in suburban areas and do not have access to a car the issue becomes a predominant one, in that 35-39% of this group would prefer local medical care.
2. In estimating unmet need for mental health services, half of the people with low mental health scores on a national scale were not receiving either professional or supportive mental health services.
3. Among current drug users interested in drug treatment, 69% are not in treatment; among former drug users interested in treatment, 83% are not in treatment.
4. Excluding housing, the most commonly cited problems were finances (42%), food issues (30%), household items (20%), and transportation (19%). Most of the problem areas discussed by respondents either remain unchanged or have worsened.

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. 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 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 topics 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.