

C. H. A. I. N.

Community Health Advisory & Information Network

The **Community Health Advisory & Information Network** (CHAIN) Project, is an ongoing prospective cohort study of a representative sample of persons living with HIV/AIDS in New York City, conducted by researchers from Mailman School of Public Health at Columbia University as part of the evaluation activities of New York City's Health and Human Services Planning Council. Its purpose is to supply systematic data from the perspective of persons living with HIV 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.

During 1994 and 1995, a two-stage sampling method was used to recruit a cohort that would be representative of HIV-positive adults (age 20+ years) who were aware of their positive HIV serostatus. For the first stage, 50 recruitment sites were randomly selected from a sampling frame of 341 medical and social service agencies known to serve an adult clientele and to have HIV case loads of 20 or more. For the second stage, a sample of HIV positive clients were recruited from 43 of the sites either through random selection from a client list prepared by agency staff, or through onsite, sequential enrollment. To complete the CHAIN longitudinal cohort, HIV-positive persons unconnected to medical care and case management services at the time of the interview were also recruited to supplement the agency-based sampling strategy. These "unconnected" individuals were contacted at outreach sites and through acquaintance sampling from among enrolled CHAIN participants. Baseline interviews were completed with 648 HIV+ individuals from the agency sites and 52 HIV+ individuals unconnected to services.

CHAIN interviews, take approximately two hours to complete, and are conducted in person by trained community interviewers who were matched to respondents as much as possible with regard to gender and race/ethnicity. Approximately 10% of interviews are conducted in Spanish. Several members of the field staff are themselves HIV positive. CHAIN participants receive \$25 in gift cards, transportation or food vouchers for each completed interview. Major interview topic areas include: (1) need for health and social services, (2) access, utilization and satisfaction with health and social services, (3) sociodemographic characteristics, (4) housing and other aspects of living situation; (5) sex and drug risk behaviors; (6) informal care giving from friends, family and volunteers, and (7) their quality of life with respect to health status and 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, and other topics of interest to policymakers, planners, providers, and clients on the HIV Health and Human Services Planning Council.

Follow-up interviews have been conducted at 6-12 month intervals. In 1998, in response to cohort attrition due primarily to mortality, the sample was replenished with 268 individuals using the same sample frame and recruitment strategies. Eight rounds of interviews have been completed with the original cohort and up to four with the refresher cohort. The cohort's ethnic composition and HIV risk factor profile are similar to surviving NYC AIDS cases for the period 1995 and 2000 (for details about sampling and recruitment see Messeri et al., 1995; Messeri et al., 2003).

Cohort attrition has remained low. For the original cohort, among CHAIN participants alive and still living in NYC, survey completion were always higher than 80 % and exceeded 90 percent for 4 of the 7 follow-up rounds of interviews. The single largest reason for loss to follow-up has been death. Individuals lost to follow-up over the course of the study have shown few differences when compared with those who continued to participate, although attrition has been somewhat higher among Hispanics and those reporting unstable housing conditions at baseline.

In 2002, at the direction of the Planning Council, Columbia researchers recruited an entirely new cohort of 707 HIV+ adults residents of New York City, following the same methodology used for the original CHAIN cohort. The CHAIN “new cohort” study began enrolling clients in July, 2002 and closed enrollment in December, 2003. A total of 684 HIV positives in care, and 23 PLWHA aware of their status but unconnected to care were recruited and interviewed. Follow-up interviews have been completed approximately yearly with the fourth round of interviews coming to a close in 2008. The same high rates of continued participation in the CHAIN study have been maintained among new cohort members.

In addition to the New York City cohort studies, the CHAIN program of research was extended to three northern suburban counties, Putnam, Rockland, and Westchester counties. Using the same methodology of sampling, Tri-County CHAIN recruited an original cohort of 398 adults in 2001 and 84 PLWHA as a refresher cohort during 2005 and 2006. Five rounds of interviews were completed by 2007. Recruitment of a new cohort of Tri-County adults living with HIV/AIDS began in 2008. The same core measures are being used in NYC and in the Tri-County Region which allow cross-cohort as well as cross time comparisons.

Each year CHAIN researchers produce a series of reports for the New York HIV Planning Council responding to the questions, interests, and priorities of the Council and its workgroups, the NYC Department of Health and Mental Hygiene (DOHMH) Office of AIDS Policy Coordination, and provider and consumer communities. In addition to the work done on behalf of the Planning Council, CHAIN researchers have conducted several studies under contract to the federal Health Resources and Services Administration (HRSA) HIV/AIDS Bureau. To date, over 100 reports have been written examining a range of topics with focus on unmet health and social service needs, trends in service utilization, and various outcomes among the CHAIN cohort. All CHAIN reports are available at no cost and widely distributed.

A Technical Review Team (TRT) provides oversight for the CHAIN Project in New York City and in the Tri-County. In addition to Peter Messeri, PhD and Angela Aidala, PhD of Columbia University’s Mailman School of Public Health, the TRT includes researchers and policy representatives from Public Health Solutions (formerly MHRA), the NYC Department of Health and Mental Hygiene, the Westchester County Department of Health, and the New York City Office of AIDS Policy.

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Information about CHAIN and copies of reports can be found on the NYC HIV Health and Human Services Planning Council website: http://www.nychiv.com/data_chain.html.