



**NEEDS ASSESSMENT COMMITTEE
ANNOTATED GUIDE TO DATA SOURCES**

Data Resource <i>Created/Collected By</i>	Description	Data Elements	Limitations For Planning
<p>Title I Quality Management Program <i>AIDS Institute- NYS Dept. of Health</i></p>	<p>The goal of this program is to allow providers of HIV-related services in New York City's five boroughs and the Tri-County region to evaluate and improve the quality of services offered. The Title I Quality Management Program works with the Planning Council and service providers to develop quality indicators for Title I programs.</p>	<p><i>Performance Indicators</i></p> <ul style="list-style-type: none"> ▪ Adult and Adolescent Clinical ▪ Pediatric Clinical ▪ Adult Day Treatment Center ▪ Home Health Care ▪ Treatment Education/Adherence ▪ Oral Health ▪ TB DOT/DOPT ▪ Case Management ▪ Food & Nutrition 	<ul style="list-style-type: none"> ▪ Process measures ▪ Sample-based ▪ Representative only of those in care ▪ Does not address issues related to distribution, need for services, etc.
<p>Uniform Reporting System URS <i>MHRA (Client Level Data Project)</i> <i>AIDS Institute Data Collection</i></p>	<p>Client-based tracking system developed by the AIDS Institute in collaboration with Title I to track and report service utilization and demographic data.</p> <p>MHRA is utilizing the URS to implement the collection of de-identified, unduplicated client level data in the NYC EMA. Once fully implemented, client level data will be available for detailed analyses of Ryan White Title I service utilization data by geographic distribution and demographics. This additional analysis will help with planning and tracking service utilization within the NYC EMA and may be used to evaluate programs and plan services that effectively reach and engage people living with HIV/AIDS.</p>	<p><i>Service Utilization</i></p> <ul style="list-style-type: none"> ▪ Provider type ▪ Ownership Status ▪ Funding source ▪ RW Title ▪ Agency description ▪ Funding received <p><i>Demographics</i></p> <ul style="list-style-type: none"> ▪ Gender ▪ Age ▪ Ethnicity/Race ▪ Income ▪ Household data ▪ Insurance status ▪ Zip code ▪ HIV/AIDS status ▪ Co-morbid conditions/Special needs ▪ Enrollment status ▪ Medical information (for providers of primary care) ▪ Counseling and Testing information ▪ Service provision data 	<ul style="list-style-type: none"> ▪ Client level data collected by MHRA will include data provided only by agencies with Title I contracts administered by MHRA or the Westchester County Department of Health.

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C.H.A.I.N. (Community Health Advisory & Information Network) <i>Mailman School of Public Health, Columbia University</i>	CHAIN is a longitudinal study of persons living with HIV disease in New York City and Tri-County conducted on behalf of the Planning Council. The study focuses on the impact of the entire publicly funded HIV service system, not just Title I. Data collected by CHAIN covers a broad spectrum of HIV health and related questions. Research reports have primarily focused on factors related to access to care and maintenance in care, the impact of ancillary services on HIV primary care and HAART utilization, the impact of Title I services on health outcomes, social factors such as poverty and homelessness, and co-morbidities (mental health services, case management services substance abuse, social services, health services, AOD services). See attached list for CHAIN reports available:	Please refer to <i>Appendix A</i> for “Listing of CHAIN Reports”	<ul style="list-style-type: none"> ▪ Information does not include HIV-positive individuals who are either not in the system of care, or are seen only by private medical providers (and either have no social service needs, or do not go to social service agencies).
Program Monitoring Report <i>MHRA</i>	MHRA, as administrative agent for the EMA’s Title I programs, is responsible for the contracting and contract monitoring of the EMA’s Title I programs. The PMR provides service utilization data based on geographic distribution (United Hospital Fund neighborhood) and demographics (provider type, service type, gender, ethnicity/race).	<i>Service Utilization</i> <ul style="list-style-type: none"> ▪ Provider type ▪ HIV service type ▪ Projected/Actual units of service ▪ Projected/Actual clients served <i>Demographic Characteristics</i> <ul style="list-style-type: none"> ▪ Gender ▪ Ethnicity/Race <i>Geographic Distribution</i> <ul style="list-style-type: none"> ▪ UHF neighborhood ▪ Epidemiological data 	<ul style="list-style-type: none"> ▪ Client level data collected by MHRA will include data provided only be agencies with Title I contracts administered by MHRA or the Westchester County Department of Health.
HIV/AIDS Surveillance and Epidemiology <i>NYC Dept. of Health and Mental Hygiene</i>	In addition to case reporting/tracking, the DOHMH HIV/AIDS Surveillance and Epidemiology Program publishes several periodic reports including (most recent edition indicated): <ul style="list-style-type: none"> ▪ <i>HIV Surveillance and Epidemiology Quarterly Reports</i> ▪ <i>Adult Spectrum of HIV Disease, 2004</i> ▪ <i>New York City HIV/AIDS Surveillance Statistics 2002, August 2004.</i> ▪ <i>Pediatric HIV/AIDS Surveillance in New York City: Semiannual Report.</i> 	<i>HIV and/or AIDS Case Data</i> <ul style="list-style-type: none"> ▪ Number of cases (cumulative, living, deaths) ▪ Case rates (incidence, prevalence, mortality) & trends ▪ Transmission/Risk factors ▪ Demographics (gender, race/ethnicity, age at diagnosis) 	<ul style="list-style-type: none"> ▪ HIV data do not reflect all HIV infected persons in NYC. ▪ There are too many persons with no reported risk in recent years to allow conclusions about distribution of risk.

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Mapping Collaborative Project <i>Planning Council Inter-Agency Collaborative</i>	This is an interagency collaborative initiative designed to geographically identify all Ryan White CARE Act-funded and non RWCA-funded HIV/AIDS services in the New York EMA.	<ul style="list-style-type: none"> ▪ Geographic distribution of services ▪ Funding sources for HIV/AIDS services ▪ Service Gaps 	<ul style="list-style-type: none"> ▪ Service utilization does not fully reflect service needs.
Minority AIDS Initiative <i>New York Academy of Medicine</i>	An outcome evaluation of 23 Minority AIDS Initiative Access-To-Care and Maintenance-In-Care Programs that help African Americans, Latinos, and other people of color with HIV to access the care system and stay more consistently connected to it. Clients in the programs are assessed at baseline and then every quarter using a standard quantitative instrument. Clients' service utilization is also tracked using a standard service encounter data collection form.	Functional Health Status <ul style="list-style-type: none"> ▪ General Health Perception ▪ Physical Functioning ▪ Role Functioning ▪ Social Functioning ▪ Cognitive Functioning ▪ Pain ▪ Mental Health ▪ Vitality/Energy ➤ Biological Markers <ul style="list-style-type: none"> ▪ HIV Status ▪ Viral Load ▪ CD4 Count ▪ History of opportunistic infection ➤ Demographic Characteristics <ul style="list-style-type: none"> ▪ Race ▪ Gender ▪ Country of Birth ▪ Education Level ▪ Primary Language ▪ Age (Birth Date) ➤ Barriers to Care ➤ Social Support ➤ Substance Use and Treatment <ul style="list-style-type: none"> ▪ Past and Current Drug Use ▪ Utilization of Harm Reduction Services ▪ Utilization of Drug Treatment Services ➤ Adherence to Treatment <ul style="list-style-type: none"> ▪ Adherence Rate ▪ Reasons for Missing Doses ➤ Housing status ➤ Household composition ➤ Incarceration history ➤ Receipt of HIV Information ➤ Sources of Income ➤ Zip Code 	<ul style="list-style-type: none"> ▪ Not a randomized controlled study design; thus, the ability to establish causal links between program designs and client outcomes is limited.

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Minority AIDS Initiative <i>Laurence A. Pagnoni Associate (LAPA) & Philliber Research Associates</i>	An outcome evaluation of 13 treatment education and/or treatment adherence agencies, 3 scattered site programs, 2 early intervention prevention programs, 1 drop-in center, 1 mental health program, 1 harm reduction program, and 1 HIV dental service program funded by MAI.	<ul style="list-style-type: none"> ➤ Adherence to HIV medication ➤ Barriers to adherence ➤ HIV status ➤ CD4 counts ➤ Viral loads ➤ Housing status ➤ Age ➤ Gender ➤ Zip code of residence ➤ History of substance abuse 	<ul style="list-style-type: none"> ▪ Only reflects outcomes for participants in programs evaluated: not generalized to the entire population of people with HIV/AIDS.
Community Forums/Surveys <i>PC/Office of AIDS Policy Coordination</i>	Throughout the year, the Planning Council and the Office of AIDS Policy Coordination conduct a number of forums and surveys to elicit input from PLWHA advisory groups and HIV/AIDS providers that assists the Planning Council in identifying needs and setting priorities for Ryan White Title I services.	<ul style="list-style-type: none"> ▪ New York City Ryan White Care Act I Consumer Advisory Group Survey Report, May 2004. (OAPC) ▪ Community Forum Report, Spring 2004. (OAPC) ▪ Community Forum Report, Spring 2003. (OAPC) ▪ NAPWA Survey, 2004 (OAPC) 	<ul style="list-style-type: none"> ▪ Anecdotal in nature.
Planning & Evaluation Initiatives <i>Planning Council-Funded Initiatives</i>	Through the years, the Planning Council has funded a number of research projects that focus on specific populations or service gaps/needs.	List of available publications: <ul style="list-style-type: none"> ▪ <i>2004 Monitoring and Evaluation Update of the New York EMA Comprehensive Strategic Plan for HIV/AIDS Services, 2002-2005</i>. September 2004. McClain and Associates, Inc. ▪ <i>Factors Associated with Delayed Care Seeking Among HIV-Infected Individuals in New York City Fact Sheet</i>. Summer 2004. CHAIN. ▪ <i>New York Eligible Metropolitan Area HIV/AIDS Needs Assessment Update 2004</i>. July 2004. McClain and Associates, Inc. ▪ <i>Tri-County HIV/AIDS Needs Assessment Update 2004</i>. July 2004. McClain and Associates, Inc. ▪ <i>Delayed Entry to HIV Care</i>. September 2003. CHAIN. ▪ <i>Manual for Primary Care Providers: Effectively Caring for Active Substance Users</i>. September 2002. New York Academy of Medicine. ▪ <i>New York EMA Comprehensive Strategic Plan for HIV/AIDS Services, 2002-2005</i>. September 2002. McClain and Associates, Inc. 	N/A

		<ul style="list-style-type: none"> ▪ <i>Qualitative Needs Assessment of HIV Services Among Dominicans, Mexicans and Central American Immigrant Populations Living in the New York Eligible Metropolitan Area.</i> March 2002. Sociomedical Resources Associates. ▪ <i>Initial Needs Assessment for New York City, 2002-05.</i> March 2002. McClain and Associates, Inc. ▪ <i>Assessing the Effects of Selected Legislative and Administrative Policies on Ryan White Title I-Funding Programs in the New York Eligible Metropolitan Area.</i> March 2002. McClain and Associates. ▪ <i>Needs Assessment and Service Utilization Study of Dental Care For HIV Infected Persons.</i> December 2001. Montefiore Medical Center, University Hospital for the Albert Einstein College of Medicine, Department Of Dentistry and Social Medicine and Epidemiology. ▪ <i>Needs Assessment of Community Based Organizations Serving Persons Affected by HIV/AIDS in New York City.</i> September 2001. Conservation Company. ▪ <i>Report on the Mental Health Tool Feasibility Study: Implementing The Use of A Standardized Mental Health Screener At Diverse Provider Sites Serving Adults Living with HIV/AIDS in New York City.</i> October 2000. Cikatelli Associates, Inc. ▪ <i>Voices: An Assessment of Needs Among Asian and Pacific Islander Undocumented Non-Citizens Living with HIV Disease in New York City.</i> October 2000. Memorial Sloan-Kettering Cancer Center, Department of Psychiatry and Behavior. ▪ <i>Health Care Accessibility and Acceptability Among People that Inject Drugs or Use Crack Cocaine.</i> March 2000. New York Academy of Medicine. ▪ <i>Senior Needs Assessment Project: The Housing and Service Needs of Older New Yorkers Infected and Affected by HIV/AIDS.</i> May 1999. Columbia University School of Public Health. ▪ <i>The Changing Environment: A Report To the HIV Health and Human Services Planning Council of NYC.</i> September 1997 	
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APPENDIX A: CHAIN Reports

TECHNICAL REPORTS

Tech #1	8/31/94	Sample Design For Staffing Needs And Client Survey Studies
Tech #2	7/5/94	Survey Of Personnel Needs Of HIV/AIDS Agencies: Recruitment & Retention Difficulties And Personnel Incentive Programs
Tech #3	9/27/95	Training For HIV/AIDS Service Agencies
Tech #4	3/1/95	Summary Tables For Client Survey – The First 100 Cases
Tech #5	8/2/95	A Tri-County Survey Of The Personnel Needs Of HIV/AIDS Service Agencies
Tech #6	8/2/95	The Personnel Needs Study Part II Delivery
Tech #7R	12/14/95	Summary Tables For Baseline Client Survey
Tech #8	10/20/95	The Adolescent HIV Study: Needs, Utilization And Barriers For Medical Care, Social Services And Prevention Education
Tech #9	11/17/95	The “Unconnected” – Service Needs Of HIV Positive Persons Who Are Outside Or Marginal To The Service Delivery System
Tech #10	5/10/96	Housing & HIV/AIDS In New York City
Tech #11	5/12/96	HIV Case Management Services In NYC: Quality And Outcomes
Tech #12	5/22/96	Substance Use & HIV/AIDS In New York City
Tech #13	6/3/96	The Infrastructure Work Group Report
Tech #14	6/10/96	HIV Health Care Services In New York City: Utilization And Quality
Tech #15	6/16/96	Accessing Medical And Social Services: Barriers And Strategies For Improving HIV Care Infrastructure
Tech #16	6/18/96	Need For Mental Health Services And Service Utilization In New York City
Tech #17	10/4/96	Summary Tables Time 2 Client Survey
Tech #18	04/24/00	Client Outcomes Rapid Response Reports

RAPID RESPONSE REPORTS

Rap Resp#2	4/21/97	Economic Security & Income Characteristics Of The Baseline Sample
Rap Resp#3	4/14/00	High Risk Behaviors: Unprotected Sex & Needle

BRIEFING PAPER

Briefing Pr#1	4/29/99	The Unconnected Revisited: A Chain Briefing Paper Update Reports
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UPDATE REPORTS

Upd Rep#1	4/21/97	The Introduction Of Combination Therapies
Upd Rep#2	4/21/97	Migration To Services
Upd Rep#3	4/28/97	Family Constellations And Need For Social Services
Upd Rep#4	4/24/97	Managed Care And Health Services For People Living With HIV
Upd Rep#5	5/30/97	Continuity And Change In Housing Problems & Need For Housing Services
Upd Rep#6	5/09/97	Access To Primary And Change In Health Problems & Need For Housing Services
Upd Rep#7	5/30/97	Matching Client Needs And Intensity Of Case Management: A Methodology For Planning And Evaluation
Upd Rep#8	6/17/97	Substance Use And Need For Alcohol & Drug Services
Upd Rep#9	12/97	Need For Mental Health Services And Service Utilization
Upd Rep#11	3/4/98	Understanding Migration To Services
Upd Rep#12	4/15/98	Trends In Use Of HIV Antiretroviral Therapy
Upd Rep#13	4/24/98	Satisfaction And Dissatisfaction With Medical And Social Services
Upd Rep#14	4/27/98	Individual Initiation And Cessation Of Antiretroviral Therapy
Upd Rep#15	2/18/98	Trends In Managed Care Plans And People Living With HIV
Upd Rep#16	5/1/98	Top Client Identified Unmet Needs For Medical An Social Services
Upd Rep#18	4/12/99	Cohort Comparison: Assessing Changes & Trends Between The 1994 And 1998 Chain Cohorts
Upd Rep#19	5/03/99	Trends In Current Use Of HIV Antiretroviral Therapy-1998
Upd Rep#20	5/19/99	Patterns Of Adherence To Antiretroviral Medication
Upd Rep#21	5/12/99	Trends In Health Status
Upd Rep#22	5/18/99	Needs Assessment For Work-Related Services Among Persons Living With HIV/AIDS
Upd Rep#23	5/1/00	Patterns Of Adherence To Antiretroviral Medications, 1995-1999
Upd Rep#24	4/27/00	Comorbidity Conditions: Intersecting Needs Among The Chain Cohort
Upd Rep#25	4/27/00	Factors Influencing Interest In Employment Among Persons Living With HIV
Upd Rep#26	4/28/00	Declining Mortality Rates And Service Interventions
Upd Rep#27	4/27/00	Complementary And Alternative Medicine: Rates Of Utilization Among The Chain Cohort
Upd Rep#28	4/21/00	Women's Need For And Utilization Of Services By Family Types
Upd Rep#29	6/2000	Mental Health Services & Treatment Needs

Upd Rep#30	4/12/00	The Impact Of Ancillary Services On Entry & Retention To HIV Medical Care In New York City
Upd Rep#32	4/17/00	Housing Assistance And Housing Stability Among Persons Living With HIV/ AIDS
Upd Rep#33	3/28/01	Dental Services For HIV+ Individuals In NYC's Chain Cohort
Upd Rep#34	8/16/01	Medication Adherence And Patient Outcomes
Upd Rep#35	5/23/01	Assessing The Impact Of Ryan White Care Acton On Health Outcomes In NYC: Executive Summary
Upd Rp#35a	5/23/01	Ryan White Impact Technical Tables
Upd Rep#36	7/25/01	Pathways To Medical Care
Upd Rep#37	7/25/01	Housing And Medical Care Among Persons Living With AIDS
Upd Rep#38	7/31/01	Ancillary Services And Adherence
Upd Rep#39	7/24/01	Trends In Health Status, Updated
Upd Rep#40	12/01	Pathways To Mental Health Services
Upd Rep#41	11/13/01	Housing Status And Health Outcomes Among Persons Living With HIV/AIDS
Upd Rep#42	12/12/01	Geographic Display Of The Chain Cohort And Service Utilization
Upd Rep#43	12/19/02	Low Threshold AOD Programs
Upd Rep#44	12/19/02	Latinos In The Chain Cohort
Upd Rep#45	2/19/03	Patterns Of Sexual Behaviors And Sexual Risk Among HIV Positive People In New York City
Upd Rep#46	7/25/02	Chronic Diseases And Clinical Comorbidities
Upd Rep#47	1/15/03	Chain Retrospective: 1994-2002 Retrospective: Unmet Need

BRIEF COMMUNICATIONS

2002-1	7/24/02	Trauma & Violence
2002-2	4/16/02	Drug Holidays
2002-3	8/10/02	Food & Nutrition
2002-4	4/16/03	Religion And Spirituality Among Persons Living With HIV

MEMOS

2002-1	7/25/02	Patterns Of Medical Care And Substance Use Providers
2002-2	7/25/02	Partner Notification
2002-3	7/25/02	Medical Care Visits
2002-4	11/20/02	People Over 50 Years Old With HIV/AIDS

TRI-COUNTY REPORTS

2002-1	11/13/02	Cohort Characteristics
2002-2	11/13/02	Health Status & Health Service Utilization
2002-3	11/13/02	Stigma & Social Isolation
2002-4	11/13/02	Field Notes
2002-5	11/13/02	Support Groups
2002-6	11/13/02	Baseline Needs Assessment
2003-1	Jan/Feb 2004	Unmet Needs and Service Utilization in the Continuum of Care
2003-3	March 2004	A Geographic Display of Health and Social Service Agencies in the Tri-County Region
2003-4	Jan. 2004	Partner Notification
2003-5	Sept. 2003	Estimating the Number of HIV/AIDS Infected Individuals in Tri-County
2003-7	June 2004	Strategic Plan Benchmark Report

REPORTS

2003-1		Strategic Plan Program Indicators: Baseline Report
2003-2		Geographical Distribution Of Service Gaps Among The NYC Chain Cohort: A Geomapping Analysis
2003-3		Validation Of Self-Reported Viral Load Levels
2003-4		Client Attributes And Service Intervention Correlation Of Self Reported Viral Loads
2004-1		Services Gaps And Utilization In The Continuum Of Care In New York City
2004-2		Strategic Plan Progress Indicators: New Cohort Update
2004-3		Baseline Summary of NYC II Cohort
2004-4		Field Notes: Recruiting a Longitudinal Cohort