

*C.H.A.I.N. 101:
An Introduction to
Columbia's
New York City
HIV+ Cohorts*

Center for Applied Public Health
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Overview

- This presentation provides an introduction to Columbia U.'s CHAIN study
- Why do a population study? – the value of a longitudinal cohort study
- The details of producing longitudinal data

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What are sources of data about HIV/AIDS?

- Vital statistics (birth, death, registries)
 - Birth Certificate: Newborn seroprevalence
 - Death Certificate: Cause of death, ICD-9 coding
 - HIV registry
- Service utilization, morbidity, & encounter data
 - SPARCS (hospital discharge data)
 - Medicaid
 - Ryan White
 - Clinic-specific
- Research data
 - Lab
 - Clinical (including Clinical Trials)
 - Population-based – for example, the CHAIN cohort studies

Illustrations of Applied Research Questions

- Incidence/prevalence
 - How many people have been diagnosed with HIV or AIDS?
 - How has HIV/AIDS affected different groups -- by gender, race/ethnicity, risk, age, geography
- Outcomes and Effectiveness research
 - Which treatments or models of care work best?
 - Which are most cost-effective
- Social determinants
 - What factors in a person's life affect his health and use of services?

Illustration of Policymakers' Questions

- What services do HIV+ people need?
- Where do they go for care?
- What are their unmet needs / service gaps?
- What populations are being under-served?
- What works well, what doesn't work?
- What are the barriers and access issues?
- **WHERE SHOULD WE PUT OUR MONEY???**

Matching Studies to Questions

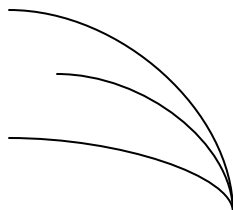
- *Incidence/prevalence* = primarily vital statistics data
- *Outcomes* = clinical and lab data, cohort studies
- *Social determinants* = cohort studies
- *Policy questions* = cohort studies, service data, vital stats, clinical data

History of CHAIN

- Initially developed in 1993 as one of the Planning Council's evaluation resources
- Over time, CHAIN has recruited 3 cohorts: NYC I (1994-2001, 968 people), NYC II (2002-present, 693 people), Tri-County (2001-present, 398 people)
- A Technical Review Team (TRT), with representatives of MHRA, NYCDOHMH, WDOH, and the Planning Council, oversees CHAIN implementation

CHAIN studies

Ancillary Services, 1999
Social Comorbidities, 2000
Ryan White Impact, 2001



Personnel Needs
1995 - 1996

CHAIN Adult Cohort I
1994 – 2002
N=968

The Unconnected
1995 & 1998

Adolescent Study
1995

CHAIN Adult Cohort II
2002 – present
N=693

Tri-County Cohort
Study
2002 – present
N=398

CHAIN's Evaluation Objectives

- To recruit and maintain a representative cohort of HIV positive adults in NY
- To assess the system of HIV care – both health and social services – from the perspective of people living with HIV
- To report on unmet needs, service utilization trends, and outcomes to the Planning Council & its Committees

8 Year Highlights of the Original CHAIN cohort (NYC I, 1994-2002)

- 4,159 interviews with 968 respondents
- 850-item questionnaire
- 94 trained interviewers
- 73% - 95% retention rate
- 65 reports
- Employment and research training opportunities

Steps in the Process

1. Develop a strategy
2. Develop research infrastructure
3. Implement strategy
4. Analyze & report on research findings
5. Re-evaluate strategy
6. Consult with stakeholders

1. Develop a Strategy

- Unit of analysis: individual client
- Sociological construct
- Probability sample
- Quantitative data
- Longitudinal cohort
- Time-series analyses

2. Develop Research Infrastructure

- Staff
 - Field Team – interviewers to collect data
 - Data Team – data programmers & editors
 - Analysts & Writers
- Develop the Survey & IRB protocols
- Data & client tracking systems
- Field & data protocols
- Monitoring the field and data pipelines

3. Implement strategy

- Develop & maintain staff
- Develop & maintain data tools
- Develop research protocols
- Recruit clients
- Interview clients
- Data management & quality assurance

Topics Covered in CHAIN Survey

- Current health status
- Family, housing, work, resources
- Outlook on life
- Risk behaviors – sex & drugs
- History and use of medical services
- History and use of social services
- Needs, satisfaction, barriers

CHAIN Multistage Stratified Sampling

- 1st stage: enumerate all health and social service agencies serving HIV clients. Stratify by...
 - Primary Medical vs Social Service
 - Borough
 - Ryan White Funding
- 2nd stage: recruit clients
 - Random recruitment
 - Sequential enrollment

Collecting Data

- Respondents interviewed annually
- Most often in their homes
- Community-based interviewing team
- \$25 incentive for every interview + referral resource

Comparison of Epidemiological Data with CHAIN Data

| | Cumulative AIDS Cases, NYC | CHAIN Cohort I |
|---------------------------|-----------------------------------|-----------------------|
| | 1995-2000 | 1994-2002 |
| | n | |
| MALE | 40,760 | 968 |
| | 29,046 | 579 |
| <i>Non-Hispanic White</i> | 21% | 21% |
| <i>Non-Hispanic Black</i> | 43% | 48% |
| <i>Hispanic</i> | 34% | 30% |
| <i>Other</i> | 2% | 1% |
| FEMALE | 11,714 | 389 |
| <i>Non-Hispanic White</i> | 9% | 6% |
| <i>Non-Hispanic Black</i> | 57% | 63% |
| <i>Hispanic</i> | 33% | 31% |
| <i>Other</i> | 1% | <1% |

† NYC DOH HIV/ AIDS Surveillance Program, "AIDS Surveillance Update, 4th Quarter 2000"

4. Analyze & Report

- Presentation categories
- Coding rules & conventions
- Descriptive statistics
- Subgroup analyses (i.e., chi square)
- Multi-variate analyses
- Reporting formats & presentation style
- Reporting forums

Presentation categories

- Gender
 - Male / female / transgender
- Race / Ethnicity
 - White / Black / Latino / Other
- HIV risk behavior
 - MSM / Problem Drug Use (PDU) / MSM + PDU / Hetero & Other
- Stage of illness
 - AIDS / HIV symptomatic / HIV asymptomatic

Types of Analyses

- Descriptive (performance measures, distribution by group, trends over time)
- Analytical
 - Are there group differences?
 - Do certain models of care, interventions, or policies make a difference?
- Multi-variate, multi-modal, multi-level

Assessing the System of Care

- Trend data
- Outcome measures
- Individual factors associated with outcomes
- Systemic factors associated with outcomes

Outcome Measures

- Appropriate medical care
- In-patient use & Length of Stay (LOS)
- Recent opportunistic infection (OI)
- T-cell changes
- ARV and HAART utilization & adherence
- Mortality

Individual Factors Measured in the CHAIN Study

- **Sociodemographics:** gender, race/ethnic, age, education, income, poverty area
- **Health:** self-reported physical and mental health status, t-cell, OI, ARV, HAART
- **Risks:** HIV risk behavior, drug use, unstable housing
- **Medical care:** provider type, primary care characteristics, insurance coverage

5. Re-evaluate Strategy

- Is the cohort representative?
- Is there an unusual loss to follow-up?
- Are there sufficient numbers in the cohort to conduct subgroup analyses?
- Are the field and data protocols appropriate and effective?

6. Consult with stakeholders

- Are the research reports responsive to stakeholder needs?
- Is there an ongoing mechanism for stakeholder involvement, oversight, and comment?
- What emerging issues should be evaluated (drug holidays, partner notification, managed care, adherence)

The Value of a Longitudinal Survey Research Project such as CHAIN

- Population-based
- One can collect broad range of evidence in order to establish causal chains in non-experimental settings, including such ecological characteristics as policy-driven funding streams
- Repeated observations over time can control for historical and secular trends