

Barriers to Care among Adults Newly Diagnosed with HIV in New York City

Results from the Never in Care Study
Formative Research

National HIV Prevention Conference
December 2007

Samuel Jenness, David Hanna, Christopher Murrill

HIV Epidemiology Program
New York City Department of Health and Mental Hygiene

CDC Grant# 5U01PS000108-03

Never in Care Study Formative Research

- Never in Care (NIC) study includes formative research component to:
 - Provide data on NIC population independent of primary data collection phase
 - Support the primary data collection phase in its design and logistics
- NIC formative research conducted May - December 2006

Objectives of Analysis

- Describe the barriers to care faced by the NIC population in NYC
- Compare barriers
 - NIC population members vs. service providers
 - Across formative research methods
- Evaluate formative research activities in meeting NIC study goals

Formative Research Design

- Literature review on barriers to care
- HIV/AIDS case surveillance analysis
- 18 key informant interviews and 2 focus groups with NIC service providers
- 1 focus group with NIC population members

Formative Research Methods

- Literature review
 - Searched PubMed for relevant literature, followed-up on relevant citations, described main outcomes
- HIV/AIDS surveillance analysis
 - Descriptive and analytic statistics, mapping
- Key informant interviews and focus groups
 - Transcribe responses, highlight key themes, select representative quotations

Literature Review: Overview

- Literature on NIC population is sparse
- Many care-related studies focus on high-risk HIV+ groups, but barriers to care not the focus of research
- Research limited by small sample sizes, convenience sampling, and lack of standardized population definitions and outcomes

Barriers to Care Nationally: HIV Cost and Services Utilization Study (HCSUS)

- Barriers^{1,2}
 - Race/Ethnicity
 - Not having a regular source of care
 - No medical insurance
 - No trust in one's care provider
 - Competing caregiver responsibilities
- Limitations of study
 - Participants sampled after entry into care
 - Pre-HAART sample (1996)

Barriers to Care in NYC: Local Research

- CHAIN study (2002-2005)
 - Care delayers more likely to be male, Hispanic, IDU, homeless, poor, mentally ill, and previously incarcerated³
- Other small-scale studies (2002-2006)
 - No use of ancillary support services^{4,5}
 - Drug use and lack of social support⁶
 - Use of crack cocaine⁷
 - Immigration issues⁸

HIV/AIDS Surveillance Data

- NIC analysis population:
 - HIV diagnoses in 2005 who had no evidence of care within 3 months of diagnosis
 - Evidence of care:
 - HIV viral load test...
 - or CD4 test...
 - or AIDS diagnosis...

...in a month following the month of HIV diagnosis
 - Excluded: minors, non-residents, deceased, anonymous testers, non-notified of HIV dx

Demographics of the NYC NIC Population (n=881)

Gender

| | |
|--------|-----|
| Male | 74% |
| Female | 26% |

HIV Transmission Risk

| | |
|--------------|------|
| MSM | 33% |
| IDU | 6%* |
| MSM & IDU | 1% |
| Heterosexual | 19% |
| Undetermined | 41%* |

Race/Ethnicity

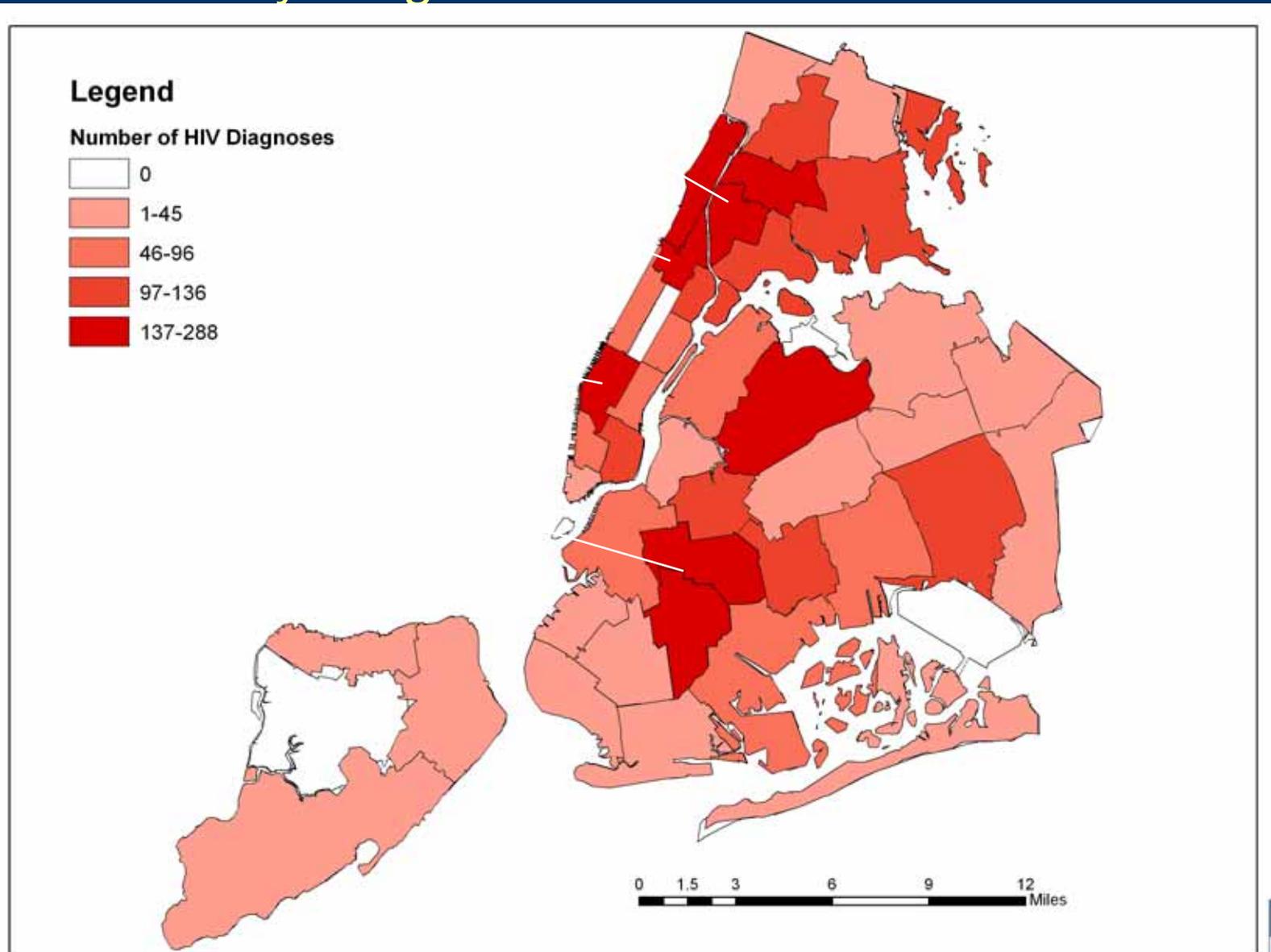
| | |
|----------|------|
| Black | 57%* |
| Hispanic | 27% |
| White | 13% |
| Other | 3% |

Age at HIV Diagnosis

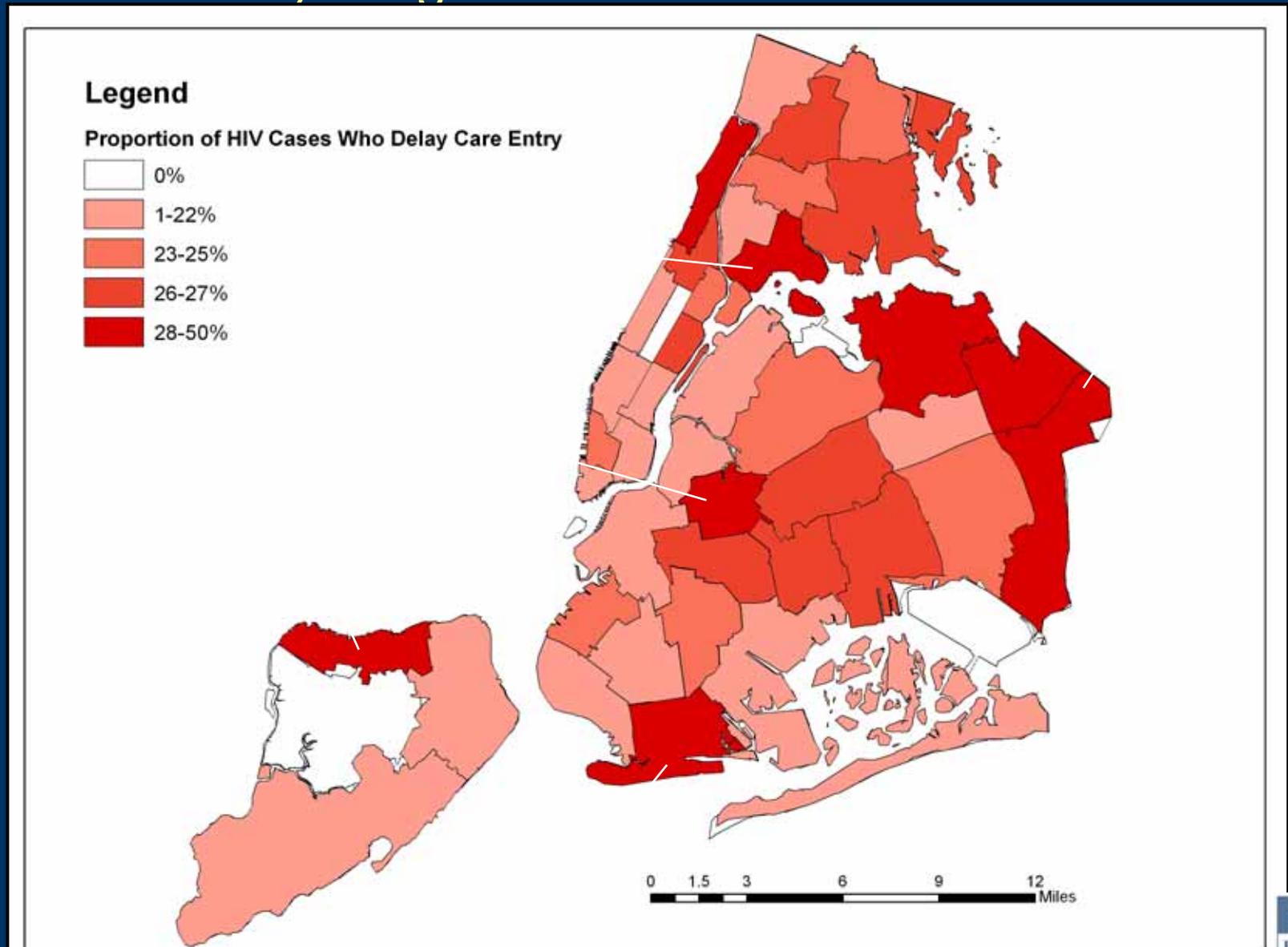
| | |
|-------|------|
| 18-29 | 27%* |
| 30-39 | 29% |
| 40-49 | 28% |
| 50+ | 15% |

* More likely to delay care entry (p<0.01)

Distribution of New HIV Cases in 2005, by Neighborhood of Residence



Proportion of NIC Cases among All New HIV Cases, by Neighborhood of Residence



Interviews and Focus Groups with Providers: Barriers to Care in NYC

- **HIV stigma and denial**

“Testing is one thing, but routine engagement in the care system requires a certain acceptance of HIV.”

- **Concerns about treatment when asymptomatic**

“Clients would tell me, ‘I feel fine now, so why should I go on meds that make me look and feel sicker?’”

- **Drug use, poverty & homelessness**

“When someone is dope sick, homeless, and hungry, there is just not much of a priority to see a doctor for a disease with no symptoms.”

Interviews and Focus Groups with Providers: Barriers to Care in NYC

- **Immigration**

“Some immigrants think entering medical care means being ‘part of the system’, and have concerns about deportation.”

“In many of their native countries, there was no public health care, so it does not automatically register that there is in the U.S.”

- **Incarceration**

“When the jail is under lock-down, inmates have to reschedule HIV appointments. Inmates ask, ‘Is it worth it if it’s all like this?’”

Interviews and Focus Groups with Providers: Barriers to Care in NYC

- **Distance to services**
“In the Bronx, everything is more spread out and it is difficult for some people to access care.”
- **Navigating the system**
“Many people just feel lost after they test positive because then they need to know what HIV really means, and how to navigate the system.”
- **Testing**
“With streamlined HIV counseling and rapid testing, there is less time for the counselor to explain the importance of entering medical care.”

NIC Population Focus Group: Barriers to Care in NYC

- **Competing life priorities**

My biggest priority “would be keeping a roof over my head.”

“I don’t want to just get a job and have to take off to go because I am sick or get an appointment.”

- **Asymptomatic infection & natural remedies**

“I take care of myself. Juice. I take vitamins. You know I work out...I can’t say I would never take medicine, but right now I feel like...I don’t have to.”

“I try to buy some organic food...Changes how it gives me energy and how it makes me feel.”

NIC Population Focus Group: Barriers to Care in NYC

- **Distrust of doctors**

“Sometimes I feel like [doctors] are just experimenting with us.”

“There ain’t but two things a doctor is going to do: Tell you that you need surgery or here is some medication. That’s it.”

- **Aversion to HIV treatment**

“When I first started taking [medications], they made me all sick. So I couldn’t stay...I tried one and I got sick.”

NIC Population Focus Group: Barriers to Care in NYC

- **Fear, denial, stigma**

“Hopelessness...People think that when you get the disease you are dead.”

“Sometimes you are just hoping it [HIV] will go away.”

People treat me like, “You’ve got AIDS. Don’t come near me. You are not clean.”

- **Lack of social support**

“How can I tell a friend to go see a doctor if I don’t go myself to see a doctor?”

Summary of Barriers to Care

- Identified barriers fall into core three areas:
 - **Sociodemographic**
Race/ethnicity, poverty, homelessness, immigration, incarceration
 - **Psychological**
Drug use, fear/stigma/denial, distrust of MDs, lack of perceived need, competing priorities
 - **Institutional/Structural**
Location of care, travel, navigating the system, structure of testing, use of ancillary services

Discussion

- Barriers to care were relatively consistent across methods
- Providers more likely to identify institutional barriers; NIC population more likely to identify psychological barriers
- NIC population mentioned distrust of MDs as barrier more frequently than providers
- Entering care and starting treatment frequently equated

Conclusions

- Providers need to better understand delayers psychological barriers around distrust
- Those at risk for delaying need education around differences between medical monitoring and starting treatment
- Formative research a valuable tool to meet NIC study goals
- Timing of formative research is important
- Consistency across methods is one way to assess validity of findings

Acknowledgments

- Centers for Disease Control & Prevention
- Aeffect, Inc.
- Focus group and interview participants

References

1. Shapiro MF, Morton SC, McCaffrey DF, Senterfitt JW, et al. Variations in the care of HIV-infected adults in the United States: Results from the HIV Cost and Services Utilization Study. *JAMA* 1999;281(24):2305-2315.
2. Turner BJ, Cunningham WE, Duan N, Andersen RM, Shapiro MF, Bozzette SA, et al. Delayed medical care after diagnosis in a U.S. national probability sample of persons infected with human immunodeficiency virus. *Arch Intern Med* 2000;160:2614-22.
3. Aidala A, Waddell E, Sotheran J. Delayers, Drop-Outs, the Unconnected, and "Unmet Need". NYC CHAIN Report. 2005. Published online at: http://www.nyhiv.org/data_chain.html
4. Messeri PA, Abramson DM, Aidala AA, et al. The impact of ancillary HIV services on engagement in medical care in New York City. *AIDS Care*. 2002 Aug;14 Suppl 1:S15-29.
5. Gardner LI, Metsch LR, Anderson-Mahoney P, et al. Efficacy of a brief case management intervention to link recently diagnosed HIV-positive persons to care. *AIDS*. 2005 Mar 4;19(4):423-31.
6. Kang SY, Goldstein MF, and Deren S. Health care utilization and risk behaviors among HIV positive minority drug users. *J Health Care Poor Underserved*. 2006 May;17(2):265-75.
7. Cunningham CO, Sohler NL, Berg KM, et al. Type of substance use and access to HIV-related health care. *AIDS Patient Care STDS*. 2006 Jun;20(6):399-407.
8. Kang E, Rapkin BD, Springer C, et al. The "Demon Plague" and access to care among Asian undocumented immigrants living with HIV disease in New York City. *J Immigr Health*. 2003 Apr;5(2):49-58.