Barriers and Facilitators of Linkage to and Engagement in HIV Primary Care in New York City

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New York City Department of Health and Mental Hygiene

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Acknowledgements: The National Institute of Allergy and Infectious Diseases

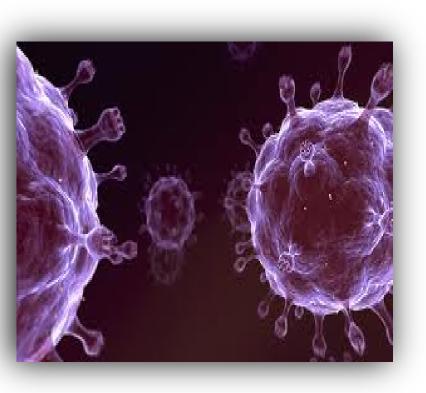
The National Institute of Mental Health







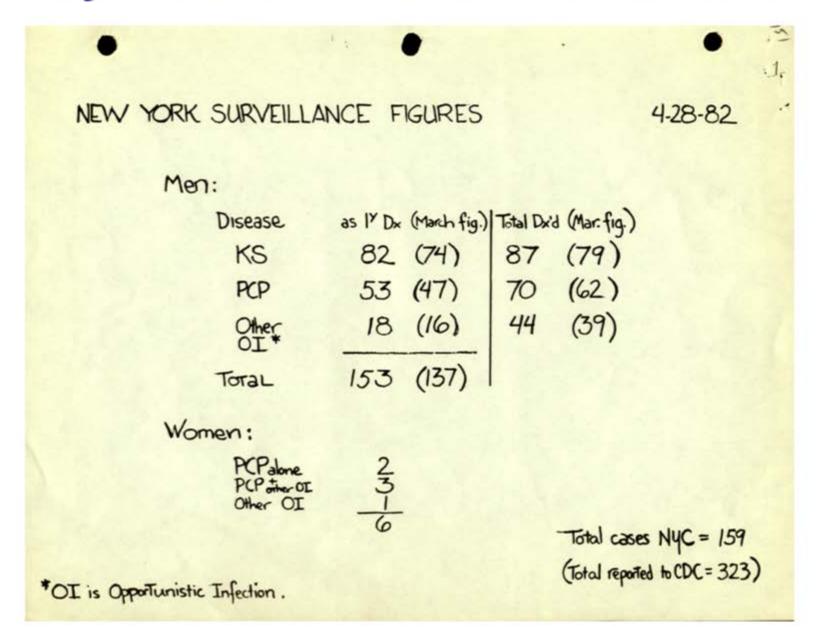
ENHANCING LINKAGE AND ENGAGEMENT IN CARE: THE NYC EXPERIENCE



Blayne Cutler, MD PhD Director, HIV Prevention Bureau of HIV/AIDS Prevention & Control NYC Department of Health & Mental Hygiene

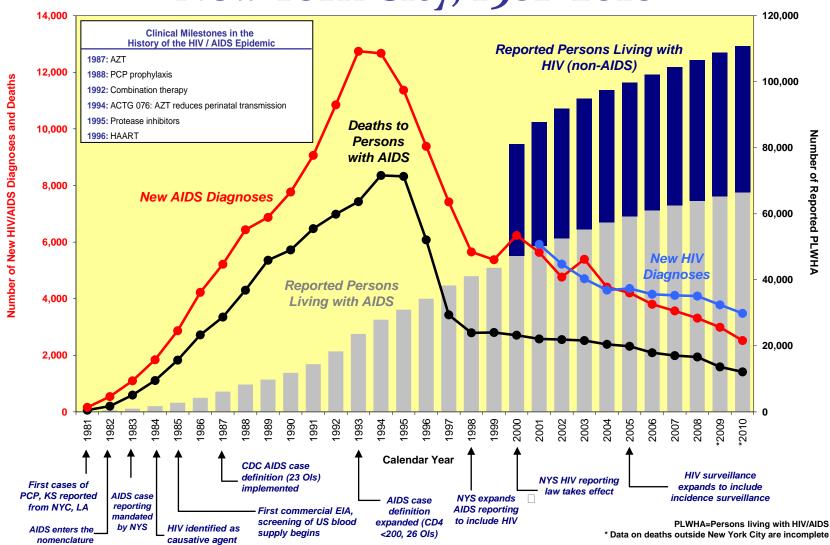


Early HIV/AIDS Surveillance in NYC





Trends in HIV/AIDS New York City, 1981–2010



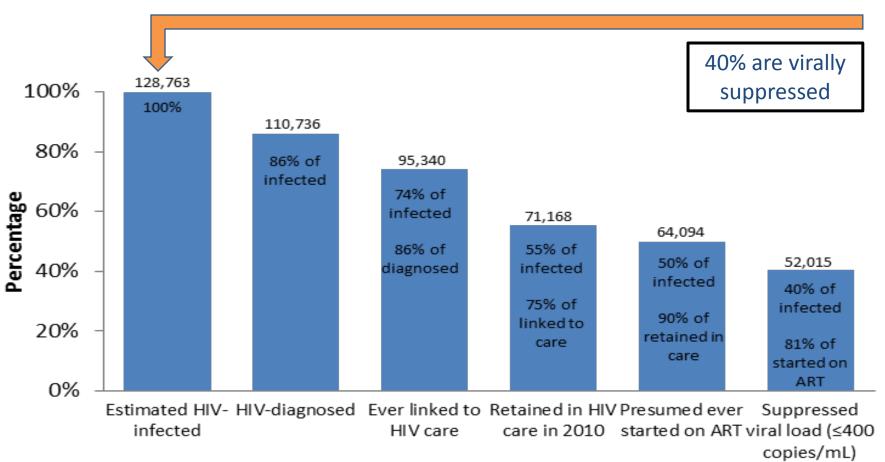


As reported to NYC DOHMH by September 30, 2011.

PLWHA, Persons living with HIV/AIDS.

*Data on deaths outside New York City are incomplete.

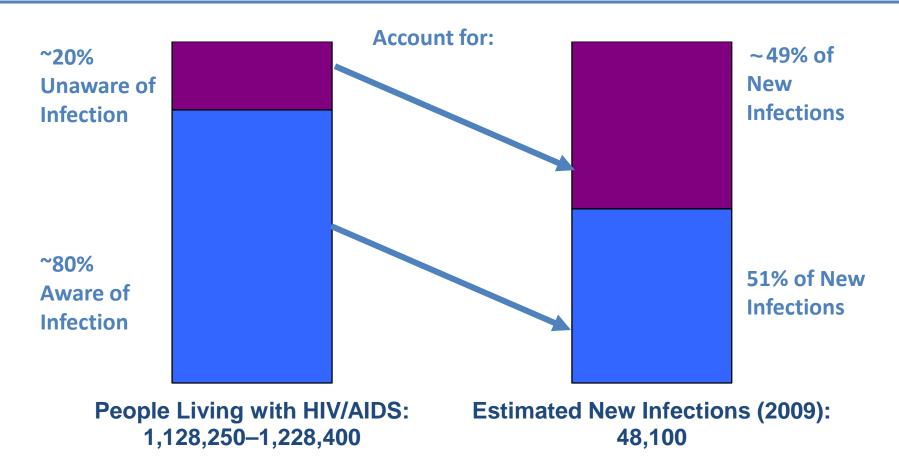
NYC Continuum of Care, 2010



Engagement in HIV care



People With HIV Who Don't Know It Account for Nearly Half of New Infections





Scalable Strategies Deployed in NYC

Changing the Law

- Key provisions: mandatory offer, change in consent, LTC
- Regulations and accountability

- <u>Jurisdictional Scale Up</u>

- Mobilizing all stakeholders within a jurisdictions (Bronx/Brooklyn/NYC Knows)
- Unified social marketing/new social media
- Public/private and academic partnerships

Leveraging Contracts

- Using payment points to achieve programmatic outcomes
- Aligning data reporting with national goals
- Using new solicitations as opportunities to shift technologies



ECHPP Phase I in NYC (2010-2011)

- Situational Analysis (3-4 months)
 - Assessment of current NYC landscape
 - Describe activities underway in each of 24 CDC interventions
 - Comprehensive review of HIV prevention in NYC:
 - priority populations
 - epidemiology/surveillance data
 - prior modeling
 - community advisory plans
 - Development of goals and objectives for project period.

- Preliminary modeling results: maximal infections averted

- Maximize HIV testing and linkage to care
- Condoms, particularly high risk HIV (+) persons
 Social marketing to HIV (+) persons
- Community level interventions
- Screening/treatment of STDS, SU/MH for HIV+
- Partner services



Key Shifts Accelerated by ECHPP/NHAS ECHPP Phase II in NYC (2011-2013)

- Further Scale Up of 'Coefficients' in TLC Strategy:

Testing

- Enhance/Expand Jurisdictional HIV Testing
- Shift in NYS Testing Law (September 2010)
- Rebid of testing portfolio, use of MPAs (2011)

• Linkage to Care

- Contractual incentives for linkage and navigation (2011)
- Required ARTAS training (2011)

Treatment

- Medical case management for engagement/retention (2009)
- Early ART recommendation (December 2011)



Key Shifts Accelerated by ECHPP/NHAS ECHPP Phase II in NYC (2011-2013)

Enhancing Prevention Among HIV (+) Persons

- Clinic-based pilot of three PWP risk reduction models (2012)
- Condom distribution to HIV (+) 'universe' (2011)
- The Positive Life Workshop (September 2011)
- Enhancement of PS for newly diagnosed and AHI cases

Scale back low yield/high cost interventions

- EBIs for <u>low prevalence</u> populations (2012)
- Cofactor screening for <u>low prevalence</u> populations (2012)

Deploy relevant structural interventions

- Ex: change in NYS testing law (2010)
- Clinical EHR prompts to facilitate routine testing offer (2009)
- Early ART (December 2011)



Key Shifts Accelerated by ECHPP/NHAS ECHPP Phase II in NYC (2011-2013)

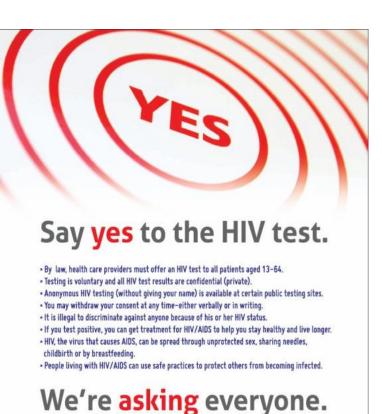
RFP Prevention Rebid

Service categories reflect ECHPP/NHAS goals:

- 1. Integrated sexual/behavioral health for priority pops
- 2. System level/structural change
- 3. CLIs/community mobilization
- 4. Condoms for highly impacted populations
- 5. Demonstration projects in CDC core areas
 - ❖ Biomedical/behavioral interventions that can reduce HIV incidence
 - ❖Innovative HIV testing activities
 - ❖ Enhanced linkage to and retention in care
 - Advanced use of technology



Using Legislation to Expand HIV Screening



It's the law.

health.nv.gov/aids

nyc.gov (Search for 'hiv testing')

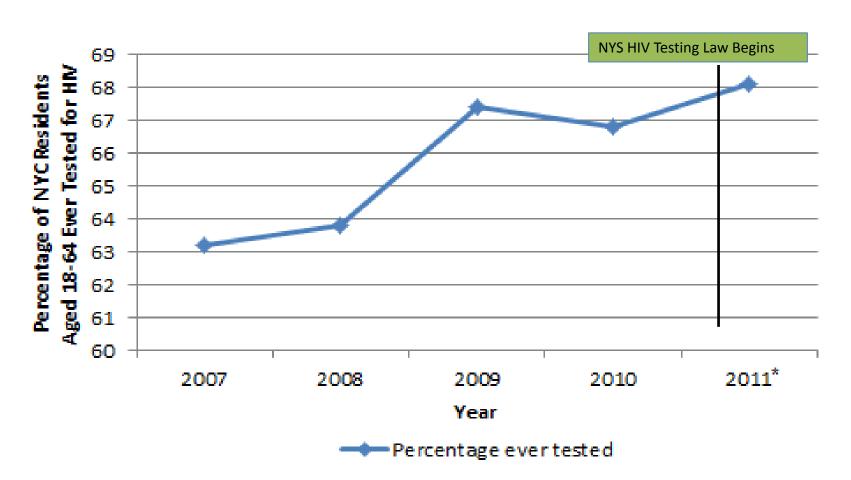
- Chapter 308: Laws of 2010

- MANDATORY OFFER of HIV test to all persons 13-64 most healthcare settings
- Simplified consent
 - Documented oral consent for tests that process in < 60 min
 - Can use general medical consent
 - Consent is now durable
- Simplified lab ordering
- Requires active linkage to care



Early Impact

NYC Residents Aged 18-64 Ever Tested for HIV (2007 to 2011)





Early Impact

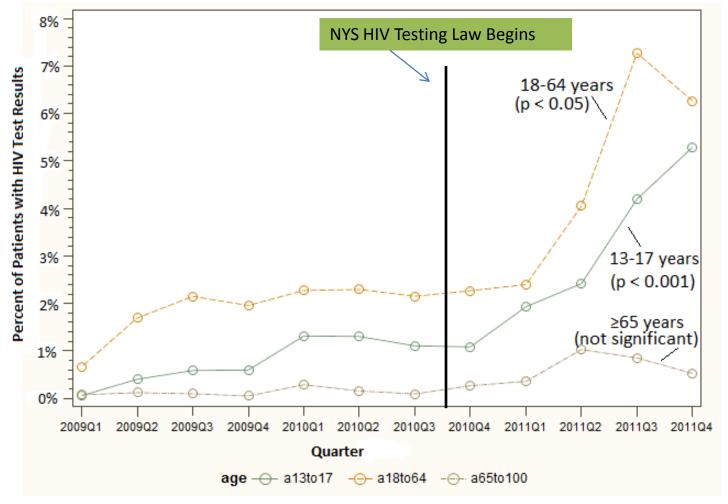
Laboratory Reported HIV Testing 13 Month Before and After NYS Law (n=215)

	Total Tests 9/09-9/10 (Pre 2010 HIV Testing Law)	Total Tests 10/10-10/11 (Post 2010 HIV Testing Law)	% Change
Conventional HIV Screening Tests (Labs=98)	2,023,968	2,198,390	9%
Rapid HIV Screening Tests (Labs=138)	294,764	322,881	9.5%
Total (Number of Labs = 215)	2,324,914	2,531,253	9%



Early Impact

Percent of Patients with HIV Test Results at CHCs and Small Practice Sites – By Age, NYC, 2009-2011 (n=97)





Jurisdictional HIV Testing Scale Up













Results

Sector	HIV Tests	Confirmed Positive
TOTAL	607,570	4,820 (0.8%)
Hospitals	277,391	2,317 (0.8%)
CHCs	275,531	1,690 (0.6%)
CBOs	54,648	813 (1.5%)



% New Pos

positive by self report

Linked[†]

Results

Year 1

# Tested	184,145	207,759	215,666	
Newly Diagnosed	621	611	499	
# New Pos Linked [†]	432	490	401	



Three Year

Grand Total

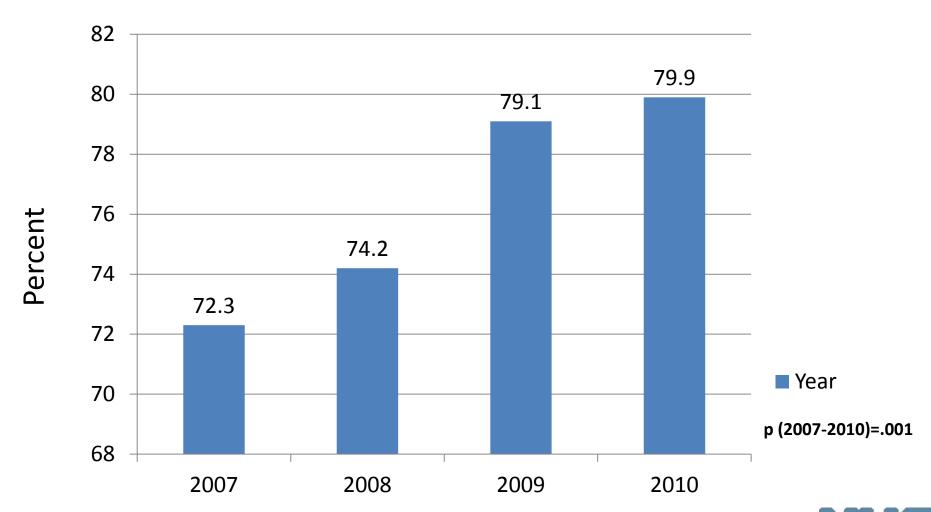
607,570

Year 3

Year 2

Self-Reported HIV Testing in the Bronx

(% Bronx adults, aged 18-64, ever HIV tested, 2007-2010)





Demographics of New Diagnoses April 2008 – March 2011

	New Diagnoses The Bronx Knows Partners N (%)	New Diagnoses Other NYC Boroughs N (%)
Total	1,262 (100.0)	7,845 (100.0)
Sex		
Male	765 (60.6)	6,179 (78.8)
Female	497 (39.4)	1,666 (21.2)
Race/Ethnicity		
Black	638 (50.5)	3,828 (48.8)
Hispanic	575 (45.6)	2,172 (27.7)
White	39 (3.1)	1,533 (19.5)
Asian/Pacific Islander	4 (0.3)	280 (3.6)
Native American	6 (0.5)	23 (0.3)

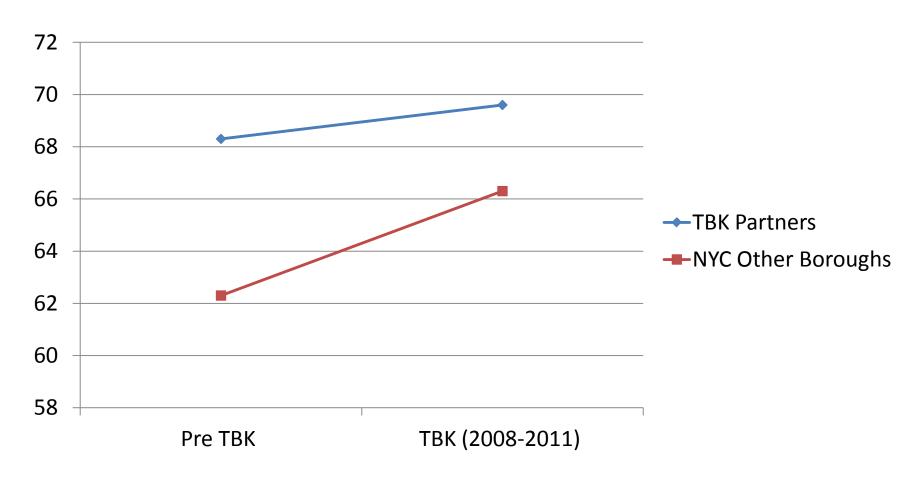


Demographics of New Diagnoses April 2008 – March 2011

Transmission Risk	New Diagnoses The Bronx Knows Partners N (%)	New Diagnoses Other NYC Boroughs N (%)
Men who have Sex with Men	320 (25.4)	3,905 (49.8)
Injection Drug Use History	99 (7.8)	376 (4.8)
Heterosexual	500 (39.6)	1,523 (19.4)
Perinatal	9 (0.7)	20 (0.3)
Unknown	334 (26.5)	2,021 (25.8)



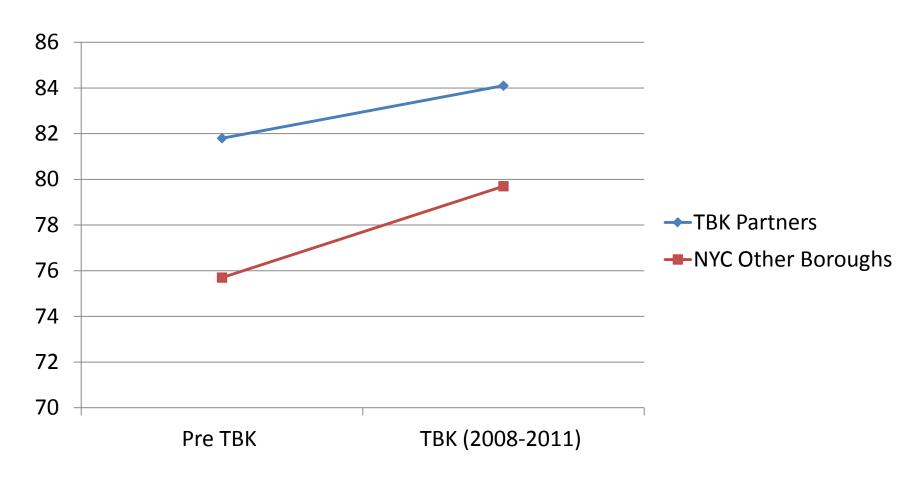
Linkage to Care within 91 Days: TBK Partners vs. Other NYC Boroughs



New York City Department of Health and Mental Hygiene, Bureau of HIV/AIDS Prevention and Control. Events reported to NYC DOHMH by March 31, 2012.* Linkage-to-care was considered to have occurred if any HIV viral load or CD4 test within 3 months (91 days) of HIV diagnosis, following a 7-day lag, was reported to DOHMH.



Linkage to Care within 12 Months: TBK Partners vs. Other NYC Boroughs



New York City Department of Health and Mental Hygiene, Bureau of HIV/AIDS Prevention and Control. Events reported to NYC DOHMH by March 31, 2012.* Linkage-to-care was considered to have occurred if any HIV viral load or CD4 test within 12 months of HIV diagnosis, following a 7-day lag, was reported to DOHMH.



Linkage To Care By Sector Type

Sector	Pre-TBK	Years 1-3
ALL BRONX KNOWS PARTNERS		
Linked to care within 3 months, N (%)	336 (68.9%)	869 (69.9%)
Linked to care within 12 months, N (%)	399 (81.8%)	1048 (84.3%)
Hospitals		
Linked to care within 3 months, N (%)	232 (70.9%)	677 (71.3%)
Linked to care within 12 months, N (%)	277 (84.7%)	816 (86.0%)
Community Health Centers		
Linked to care within 3 months, N (%)	93 (71.0%)	175 (69.2%)
Linked to care within 12 months, N (%)	107 (81.7%)	213 (84.2%)
Community Based Organizations		
Linked to care within 3 months, N (%)	11 (36.7%)	17 (41.5%)
Linked to care within 12 months, N (%)	15 (50.0%)	19 (46.3%)



New York City Department of Health and Mental Hygiene, Bureau of HIV/AIDS Prevention and Control. Events reported to NYC DOHMH by March 31, 2012.* Linkage-to-care was considered to have occurred if any HIV viral load or CD4 test within 3 months or 12 months of HIV diagnosis, following a 7-day lag, was reported to DOHMH (depending on linkage category above).

Jurisdictional Testing Highlights

CLINICAL SCIENCE

Assessing the Impact of a Community-Wide HIV Testing Scale-Up Initiative in a Major Urban Epidemic

Julie E. Myers, MD, MPH,*† Sarah L. Braunstein, PhD, MPH,† Colin W. Shepard, MD,†
Blayne H. Cutler, MD, PhD,† Andrea R. Mantsios, MHS,† Monica M. Sweeney, MD, MPH,†
and Benjamin W. Tsoi, MD, MPH†



DOHMH/CFAR ECHPP Collaboration Year One

- Explore best practices & barriers in linkage to care among partners of The Bronx Knows
 - 1. Use surveillance data to analyze linkage to care in the Bronx(specifically among TBK partners)
 - 2. Conduct qualitative interviews re: linkage practices
 - Explore differences by sector (Hospital, CHC, CBO)
 - 3. Case studies in linkage
 - Highlight 1-2 successful programs in each sector



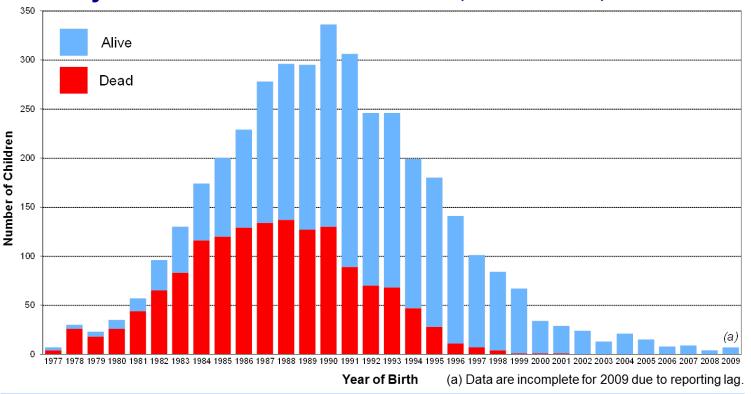
DOHMH/CFAR/HIV Center ECHPP Collaboration: Year Two

- Assess barriers to engagement and/or retention in care among vulnerable populations
 - 1. Young men who have sex with men
 - 2. Transgender women
 - 3. Foreign-born New Yorkers diagnosed with HIV
 - 4. New York City residents recently released from jail



Lessons Learned from Another Era

Figure 1. Perinatally HIV-infected Children (N=3,920), by Year of Birth and Vital Status, 1977–2009, NYC



The number of HIV-infected infants born each year decreased dramatically from the peak in 1990. This coincides with the use of perinatal prevention measures. 92% were born in NYC.



Acknowledgements

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Maureen Malave

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Madeleine Colon

Robin Kassa

Magaly Reid

Lorraine Smith

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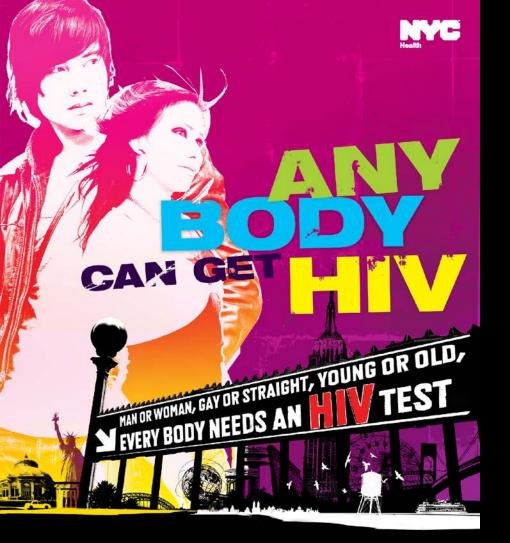
Einstein CFAR

HIV Center for

Clinical & Behavioral

Studies





Thank You

ASK FOR AN HIV TEST TODAY!





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Acknowledgements: The National Institute of Allergy and Infectious Diseases

The National Institute of Mental Health







Qualitative Research

Interviews and Case Studies

Interviews

- 30 testing programs representing all 70 sites in The Bronx Knows
- Interviewed 24 of 28 (86%)
- Conducted by phone
- Mean length = 45 minutes

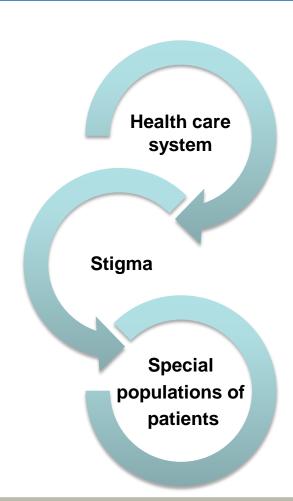




- Selected 9 testing sites
 - 3 each CBOs, CHCs, hospitals
 - exemplary linkage rates
 - ≥10 new HIV positive patients/year
- Interviewed program director on site, plus those responsible for linkage

Problems with Linkage to HIV Care

Intersection of System, Social and Patient Challenges



Linkage to HIV Care

Intersection of Patient, Social and System Challenges

Health care system care **Stigma Special** populations of patients

- 1) Delay from test to
- 2) Health care difficult to navigate
- 3) Care sites not patient friendly

Two reasons for the delay

Confirmatory Test

- Care sites require positive confirmatory test
- Confirmatory test delays linkage by 7-14 days
- CBOs must refer clients out for confirmatory test

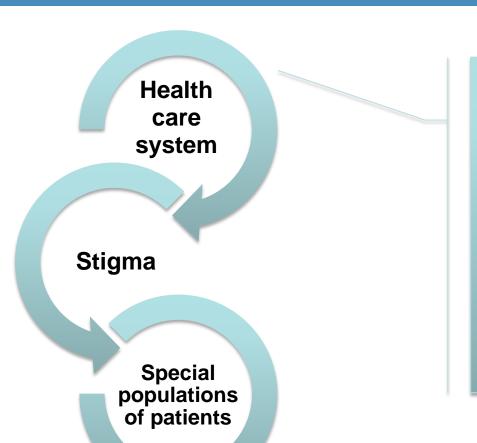
Scheduling appointments

- Average wait is 1-3 weeks
- CBOs wait for preferred site
- Doctors are overbooked
- Clinic hours limited



Problems with Linkage to HIV Care

Intersection of Patient, Social and System Challenges



- Delay from test to care
- 2) Health care difficult to navigate
- 3) Care sites not patient friendly

Patient navigation models

Classic

one point person navigates physically and virtually

Temporary

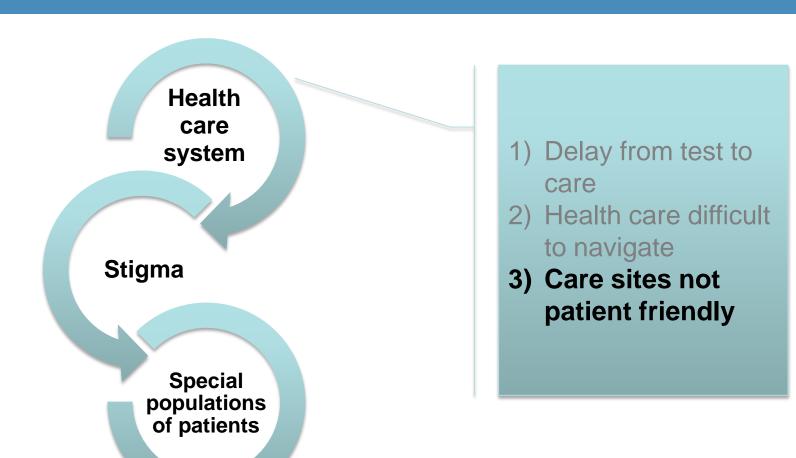
"classic" model but only until patient arrives at first medical appointment

Partial

Multiple people provide idiosyncratic services (e.g., make appointments, maintain contact, remind about appointments, case management)

Problems with Linkage to HIV Care

Intersection of Patient, Social and System Challenges

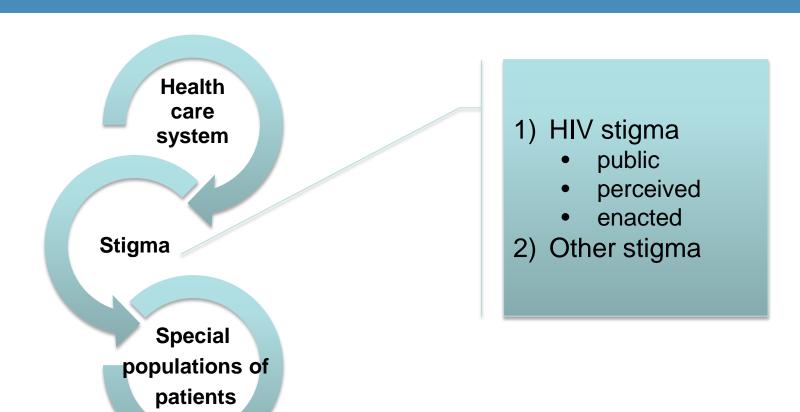


Some care sites not patient friendly

- Clerical, front desk staff frequently mentioned
 - have an "attitude"
 - are not helpful
- Patients are not treated with respect
- Special populations poorly understood

Problems with Linkage to HIV Care

Intersection of System, Social and Patient Challenges



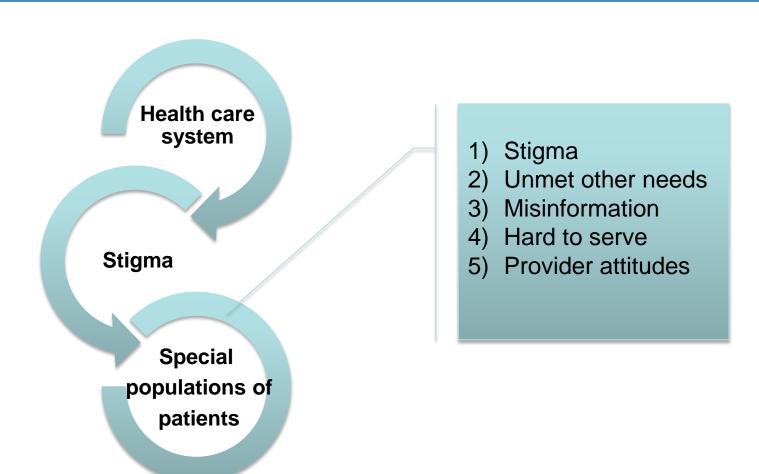
HIV stigma: Barriers to linkage

- Fear of disclosure
- Feel judged by care staff
- Compound stigma



Problems with Linkage

Intersection of System, Social and Patient Challenges



What are special populations?

- Substance users (n=11)
- Mentally ill (n=5)
- Unstably housed, homeless (n=5)
- Transgender (n=5)
- Immigrants and undocumented (n=4)
- Race/Ethnic Groups (Latino n=3, West African n=3)
- MSM and YMSM (n=2)
- Recently released prisoners (n=2)

Why are special populations hard to link?

- Unmet basic needs, high stress
- Patient misinformation
 - care cost
 - deportation/loss of visa
 - no symptoms, denial of illness
- Hard to work with
 - locate, track
 - language barriers
 - low health literacy

Why are special populations hard to link? Stigma

- "What made them HIV positive is why they are hard to link"
- Patients lie; manipulate for benefits, drugs
- Resistance
 - Some people will not go to hospitals
 - Some don't want to be found
 - If patients don't want help, can't force them

Best Practice

Best Practices CBOs organizational practices

- Commitment they champion serving special populations
- Train all staff in cultural competency and in special populations
- Quality assurance
- Network of care sites

Best Practices CBOs linkage practices

- <u>Pro-active</u> individualized, comprehensive assessment of threats to linkage
- <u>Comprehensive</u> interim services (especially social work/case management, non-HIV)
- Build relationship between tester and client
- Facilitate appointment
 - Make appointment and remind them
 - Maintain contact
 - Escort patient to appointment
 - Find patients who missed the appointment

Best Practices

Health Care Sites

- Providers see new positive patients immediately
 - Keep some appointment slots open
 - Assign a covering MD to see new positive patients
 - Evening and weekend hours
- Team approach
- Comprehensive services

Best Practices CBOs and Care Sites: Minimizing HIV stigma

- Integrative approach
- Protect confidentiality
- Specific strategies used
 - physical touch
 - match patients to HIV care site
 - normalizing services (e.g., exercise, yoga groups)

RESEARCH RECOMMENDATIONS

- Evidence-based interventions
- Patient navigation models
- Stigma-reducing practices
- Fit of linkage practices to different special populations

PUBLIC HEALTH RECOMMENDATIONS

- Eliminate delay in linkage from required confirmatory test
- 2. Require timely HIV care appointments
- 3. Define health care system responsibilities to include linkage, retention and patient outcomes

KEY PUBLIC HEALTH RECOMMENDATION

4. Shift focus from quality care for *individual* patients to *public health* need to reduce transmission.

THE EINSTEIN STUDY TEAM

Laurie Bauman, PhD

Dana Watnick, MPH, MSSW

Rosy Chhabra, PsyD

Angelic Rivera, MPH, MCHES

Jamie Sclafane, MS, MCHES

Principal Investigator

Project Director

Case studies

Interviewer

Interviewer

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The National Institute of Mental Health







Goal

To study <u>engagement in HIV medical care</u> among four groups of people living with HIV (PLWHIV) in New York City:

- 1. African immigrants
- 2. Recently released prisoners
- 3. Transgender women (male to female transgender persons)
- 4. Young men who have sex with men (MSM)

Partners

Einstein-Montefiore Center for AIDS Research team

Laurie J. Bauman, Ph.D.; Yvette Calderon, M.D.; Rosy Chhabra, Psy.D.; Dana Watnick, M.P.H., M.S.S.W.

HIV Center for Clinical and Behavioral Studies team

◆ Robert H. Remien, Ph.D.; Joanne Mantell, Ph.D.; Patricia Warne, Ph.D.

NYC Department of Health and Mental Hygiene team

◆ Blayne Cutler, M.D.; Benjamin Tsoi, M.D.

Study Aims

- Aim 1: To use existing NYCDOHMH surveillance data to describe at a population level rates and patterns of insecure HIV care engagement among African immigrants, recently released prisoners, transgender women, and young MSM in New York City.
- Aim 2: Through interviews with (a) community key informants and (b) HIV medical providers, to identify community- and structural-level factors associated with insecure care engagement among African immigrants, recently released prisoners, transgender women, and young MSM in New York City.

Study Aims (cont'd.)

Aim 3: To identify individual-level factors that enhance and interfere with engagement in care among African immigrants, recently released prisoners, transgender women, and young MSM in New York City.

In each subpopulation we will target both PLWHIV who are engaged in regular care and those who are insecurely engaged (i.e.,having never engaged in HIV medical care or having missed 2 or more consecutive HIV care appointments in the past year).

Study Phases

- **Phase 1:** Analysis and interpretation of surveillance data describing the four populations
- Phase 2: A qualitative study focused on PLWHIV (N=80) in the four groups as well as community key informants (N=16) and HIV healthcare providers (N=12) who serve/are knowledgeable about them and/or are potential "influencers" of intervention

Study Participants

Community Key Informants (N=16): Representatives from New York City CBOs, institutions, and churches and other community leaders who represent or work with African immigrants (N=4), recently released prisoners (N=4), transgender women (N=4), and young MSM (N=4).

HIV Healthcare Providers (N=12): Physicians, nurse practitioners, and physician's assistants who provide medical care for HIV+ patients at New York City clinics.

Study Participants (cont'd.)

PLWHIV (**N**=80):

- At least 90 days post-HIV diagnosis (self-report)
- Able to speak English or Spanish
- Aged 18 or older
- No cognitive impairment that would preclude interview

Insecurely engaged in care (N=40, 10 from each group):

 Having missed 2 or more consecutive appointments in the last year (self-report)

Study Participants (cont'd.)

African immigrants:

Black West African immigrant from Anglophone country

Recently released prisoners:

Released from prison or jail in the past 1-6 months

Transgender women:

Assigned male at birth but living in female gender role

Young MSM:

- ◆ Aged 18 28 years
- Has sex with men

Procedures

- **Aim 1:** To use existing NYCDOHMH surveillance data to describe at a population level rates and patterns of insecure care engagement.
 - Examine linkage to and retention in care and viral suppression
 - Compare city-wide estimates examining differences among our four vulnerable population groups

Procedures (cont'd.)

- **Aim 2:** In interviews with community key informants and HIV medical providers, to identify community- and structural-level factors associated with insecure care engagement.
 - ◆ 45 to 60-minute qualitative interviews
 - Patient characteristics: language culture, health beliefs; stigma; access/insurance; drug/alcohol dependence
 - System characteristics: hours of operation; patientfriendliness; care coordination; wrap-around services; prejudice/stigma
 - Recruitment strategies for PLWHIV

Procedures (cont'd.)

- **Aim 3:** To identify individual-level factors that enhance/interfere with engagement in care among African immigrants, recently released prisoners, transgender women, and young MSM.
 - ◆ 45-60-minute qualitative interviews; narrative interviewing
 - ◆ Linkage/non-linkage to HIV medical care: barriers and facilitators (individual- and system-level), social support, and CD4/VL results
 - Engagement/non-engagement in care: barriers and facilitators (individual- and system-level), leaving care, CD4/VL monitoring
 - ARV treatment: initiating treatment, adherence, staying on treatment

Partnerships

PROCEDURE	NYCDOHMH	E-M CFAR	HIV CENTER
Analysis of surveillance data	X		
Interpretation and reporting of surveillance data analyses	X	X	X
Development of interview guides	X	X	X
Community Key Informant interviews African immigrants Recently released prisoners Transgender women Young MSM		X X	X X
HIV Healthcare Provider interviews		Х	Х
PLWH interviews African immigrants Recently released prisoners Transgender women Young MSM		X X	X X
Coding/analysis of qualitative data		Х	Х
Interpretation and reporting of results	Х	Х	Х