NY-Links

A Community-wide Response, Contributing to End the HIV Epidemic in New York State

¹ A HRSA Funded Special Project of National Significance
Presenters:

Kimberly Smith, MPA
Supervising Public Health Representative, Monroe County Dept. of Public Health

Rebecca Green, LMSW
Regional Director of HIV Programs, Institute for Family Health

Jennifer Knight, FNP, MPH
Nurse Practitioner, New York Presbyterian - Columbia University Medical Center

Dawn Trotter
Retention Support Assistant/Consumer
Evergreen Medical Group

Susan Weigl
NY Links Upper Manhattan Regional Group Quality Improvement Coach
New York State Department of Health, AIDS Institute
Disclosures

Presenters have no financial interest to disclose.

This continuing education activity is managed and accredited by Professional Education Services Group in cooperation with HSRA and LRG. PESG, HSRA, LRG and all accrediting organizations do not support or endorse any product or service mentioned in this activity.

PESG, HRSA, and LRG staff has no financial interest to disclose.
Learning Objectives

At the conclusion of this activity, the participant will be able to:

1) Describe a dynamic structure and approach to create regionally specific systems focused on reducing the gaps found within the HIV care continuum, contributing toward New York State’s goal to end the HIV epidemic by 2020.

2) Specify how regional surveillance data, along with agency specific data and quality improvement methodology is used to inform interventions and collaboration to improve public health and individual health outcomes, inclusive of populations disproportionately impacted by HIV/AIDS.

3) Assess the achievements, benefits and unique strategies used within the NYLinks initiative to mobilize locally led community-wide responses to impact health outcomes towards ending the HIV epidemic.
Obtaining CME/CE Credit

If you would like to receive continuing education credit for this activity, please visit:

http://ryanwhite.cds.pesgce.com
Agenda

- Overview of NYLinks - Regional Groups; Methods & Snapshots
- Provider and Consumer Presentations from Western New York Regional Group and Upper Manhattan Regional Group
- Q & A
- Video: Governor Mario Cuomo’s Public release of New York State’s Ending the HIV Epidemic Blue Print
Overview
Defining the “End of AIDS”

A 3-Point plan announced by the Governor on June 29, 2014

1. Identify all persons with HIV who remain undiagnosed and link them to health care.
2. Link and retain those with HIV in health care, to treat them with anti-HIV therapy to maximize virus suppression so they remain healthy and prevent further transmission.
3. Provide Pre-Exposure Prophylaxis (PrEP) for persons who engage in high-risk behaviors to keep them HIV negative.

Reduce the number of new HIV infections to just 750 [from an estimated 3,000] by 2020.
Public Release of the Blueprint

April 29, 2015

We must add AIDS to the list of diseases conquered by our society, and today we are saying we can, we must and we will end this epidemic.

~Governor Cuomo
NYLinks Background:

- Initiated as a HRSA sponsored Special Project of National Significance demonstration project awarded Sept 2011.

- Four year project focused on improving linkage to and retention in care through the initiation and dissemination of effective improvement strategies.

- **Sustainability** of work was a required part of grant. Integration of NYLinks within Ending the Epidemic is a key element of sustainability.
NYS Links Vision

The number of new HIV infections, HIV-related mortality and corresponding community viral burden will be reduced throughout New York State.

NYS Links Mission

We address community needs and statewide priorities through enhanced collaboration and integration of quality improvement methodology among agencies and programs that provide HIV services to decrease gaps in the HIV care cascade as part of the New York State initiative of Ending the Epidemic.
Overall Objectives of NY Links

- Improve Linkage to Care in NYS
- Improve Retention in Care in NYS
- Improve Viral Load Suppression in NYS
Major Strategies

- Implement **Regional Groups** that mobilize a community-wide response to the HIV epidemic to improve outcomes along the continuum of HIV care in geographic areas.

- **Use NYS surveillance data** to make HIV treatment cascade data accessible to frontline providers for QI efforts and to compare against **facility level reports**.

- Align programs, providers and the community to address the goals of New York State’s Ending the Epidemic through **shared, local leadership with technical support from state and local health departments**.

- Build capacity and use quality improvement in the region, to identify and disseminate **successful interventions within the continuum of HIV services and sustain achieved regional goals**.
The number of new HIV infections, HIV-related mortality and corresponding community viral burden will be reduced throughout New York State.
Regional Groups
New York State Regional Group Locations
Regional Group Composition and Structure

Key Points:

• Aim to involve
  - All medical and non-medical organizations within a geographic area to improve linkage to and retention in HIV care and viral load suppression
  - All organizations across systems of care in a community—hospitals, community health centers, CBOs, local health departments, NYS staff, pharmacists, MCO, DSRIP leads etc. and all levels of individuals

• Infrastructure, composition, goals, plans and interventions are unique to the contextual and epidemiological factors within a given region and its communities

• New York City and State Regional Groups launched on rolling Basis: Upper Manhattan; Western NYS; Queens/SI, Mid-Lower Hudson; North Eastern NY; Bronx; Central NYS; etc.
Stages of Regional Group Development

**Stages of Development**

**Infrastructure**
- Identify stakeholders
- Structure communication and decision making

**Planning**
- Map the region
- Use data to define margins and composition of group

**Community Engagement**
- Initiate community outreach

**Performance Measurement**
- Establish shared measures (indicators and surveillance measures), capacity and systems to track progress
- Analyze baseline data to identify issues/gaps in HIV care

**Quality Improvement**
- Assess organizational and regional capacity for QM/QI; provide TA as needed
- Support QI teams: Which include executive, consumer, data, and clinician leads

**Creation**

**Alignment**
- Create infrastructure
- Administrative and regional partnerships & processes
- Create common agenda
- Regional goals and approach
- Engage community and build community will and strong partnerships
- Routinely analyze and drill down data to highlight trends and disparities in access to and retention in HIV care specific to the region
- Accelerate improvements at individual agencies
- Design mutually reinforcing interventions
- Launch joint QI projects

**Sustain Action and Outcomes**
- Support and refine
- Support implementation (alignment to goal and strategies)
- Continue engagement, build advocacy, sustain strong partnerships, community ownership
- Collect, track and report progress
- Spread and sustain successful interventions and partnerships
- Identify and integrate EBIs
- Share success throughout state.
NYLinks Regional Groups:

- Providers and consumers actively involved in planning and implementation of regional processes to build regional networks, and set regional goals/priorities and plans
- Participating organizations identify QI project teams, submit linkage, retention and VLS data, & share QI project results and expertise
- Collaborative meetings - structured for systems level networking, problem solving, implementation of strategies for key pops and highest level of need (Lost to Care, never Dx and/or linked, & unsuppressed)
- Use of data and QI to assess and improve performance at agencies and across the continuum of HIV care and organizations
- Peer learning to spread innovation
Linking QI with Public Health Outcomes

Bruce Agins, MD, MPH, NYSDOH AIDS Institute, IAPAC Presentation, May 9, 2016.
Quality Improvement Support

- Standard NYLinks Measures – Linkage, Retention and VLS
- Centralized database to facilitate data reporting and instantaneous benchmarking
- Integration of NYS and NYC surveillance data to create state and regional cascades which make data accessible to front line providers for QI efforts and for comparison against facility level data
- On-site coaching by recognized improvement experts
- Access to a range of AIDS Institute resources and training
## Collaborative Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Linkage to care</strong> among newly diagnosed persons</td>
<td>After diagnosis, how many people are linked to care within 30 days?</td>
</tr>
<tr>
<td><strong>Global retention</strong></td>
<td>Over a two year period, how many patients have been seen at least every 6 months by a medical provider?</td>
</tr>
<tr>
<td><strong>New patient retention</strong></td>
<td>If a patient is new to the clinic, are they seen at least once in each 4 month periods of that year as required by HIV care guidelines?</td>
</tr>
<tr>
<td><strong>Clinical engagement</strong></td>
<td>For non-clinical organizations, have clients who have received services in the past two months had a primary care visit during the 6 month period prior?</td>
</tr>
<tr>
<td><strong>Viral Load Suppression</strong></td>
<td>Were patients who were active in the organization over the past year virally suppressed at their last viral load test (&lt;200mm)?</td>
</tr>
</tbody>
</table>
Welcome to NY Links

NY Links focuses on improving linkage to and retention in HIV care to support the delivery of routine, timely, and effective care for Persons living with HIV/AIDS in New York State. We bridge systemic gaps between HIV related services and achieve better outcomes for PLWHA through improving systems for monitoring, recording, and accessing information about HIV care in NYS. Region by region, we utilize the learning collaborative model to fortify the links holding together communities of practice, and the links grounding them in the communities of consumers they serve.

New York Links is supported by the HRSA HIV/AIDS Bureau (HAB)-sponsored Special Projects of National Significance (SPNS) and the NYSDOH AIDS Institute.

New York State Ending the Epidemic Initiative

On June 29, 2014, Governor Andrew M. Cuomo detailed a three-point plan to move us closer to the end of

www.NewYorkLinks.org
Rochester—New patient retention (2b): proportion of new patients retained in care over one year

% of new patients retained

WNYS collaborative begins
June 2012

69%

91%

Measurement period

Jun'11-May'12
Jun'12-May'13
Jun'13-May'14
Apr'14-Mar'15

Eligible patients
95 pts
67 pts
25 pts
33 pts

Sites reporting
3/3 sites
3/3 sites
2/3 sites
2/3 sites

* Each data point represents the aggregate bi-monthly data submission from Aug 2012-Jun 2015
Data Source: NYLinks facility-level measures, updated: June 23, 2015
Example Facility Level “Snapshots”

**Ben’s Health Center’s Linkage, Retention and Viral Load Suppression Data Compared with Upper Manhattan Regional Group and New York State Surveillance Data**

- **Linkage**
  - Patients newly diagnosed and linked w/in 30 days
  - (Feb 2014 - Jul 2014)
  - Ben’s Health Center: 69%
  - UMRG: 71%
  - New York State: 68%

- **2 Year Retention**
  - Patients with at least 1 HIV care visit between Apr 2012 - Jan 2013 and each 6-mo period of the following 18 months
  - (Apr 2012 - Jan 2013)
  - Ben’s Health Center: 82%
  - UMRG: 67%
  - New York State: 77%

- **New Patient Retention**
  - New patients with their 1st HIV care visit between Apr 2013 - Nov 2013 who had at least one visit in each 4-mo period within 12-mo of the first visit
  - (Apr 2013 - Nov 2013)
  - Ben’s Health Center: 48% NY Links n = 46
  - UMRG: 56%
  - New York State: 48% NY Surveillance

- **eHIVQUAL Viral Suppression**
  - Patients on ART for min 12 weeks who were virally suppressed at last VL in first and last 6-mo period of 2011
  - (Jan-Dec 2011)
  - Ben’s Health Center: No data submitted
  - UMRG: 59% eHIVQUAL n = 1064
  - New York State: 68% eHIVQUAL n = 2761

*n = number of eligible patients during review period*
Linkage to care within 30 days, 60 days, 3 months, and 12 months post diagnosis*
Diagnosed by Queens NYLinks provider or Rest of NYC provider

Data Source: NYC HIV/AIDS Registry, updated July 2015 with data reported by March 31, 2015
*Labs (CD4/VL) within 7 days of diagnosis removed.
Interventions Aimed at Linkage
HIV Care Cascade: Newly Diagnosed by NYLinks Upper Manhattan Provider, by year of diagnosis, 2010-2013

Total newly diagnosed¹
Linked timely to care²
Retained in care³
VLS w/in 6 months of diagnosis⁴
VLS w/in 12 months of diagnosis⁴

1 As reported to the New York City HIV Surveillance Registry (NYC HSR) by June 30, 2015. Excludes new diagnoses made by providers outside of NYC.
2 Timely linkage to care is defined as ≥1 CD4/VL reported to the NYC HSR 8 - 91 days post diagnosis.
3 Retention in care is defined as ≥1 CD4/VL test reported to the NYC HSR during each 4 month period in the 12 months immediately following diagnosis.
4 Suppressed viral load is defined as a patient's most recent viral load quantity reported to the NYC HSR within 6 /12 months of diagnosis was ≤200 copies/mL.
### Iris House HIV Care Continuum, Jan-Dec 2013

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV- diagnosed</td>
<td>154 (100%)</td>
</tr>
<tr>
<td>Engaged in Care</td>
<td>149 (97%)</td>
</tr>
<tr>
<td>Retained in Care in 2013</td>
<td>122 (79%)</td>
</tr>
<tr>
<td>Prescribed ART by PCP</td>
<td>146 (95%)</td>
</tr>
<tr>
<td>VL Suppressed</td>
<td>115 (75%)</td>
</tr>
</tbody>
</table>

- **HIV- diagnosed**: Client's chart has proof of HIV status
- **Engaged in Care**: Client's chart holds record of current HIV medical care provider in 2013
- **Retained in Care in 2013**: At least 2 lab tests in 2013, at least 6 months apart
- **Prescribed ART by PCP**: Client's chart holds documentation of prescribed HIV medication in 2013
- **VL Suppressed**: Most recent VL in 2013 was ≤200 copies/mL

Multi-disciplinary teams use MI and comprehensive CM to support patients with adherence.
# Linking to Improvement

## HIV Cascade of Interventions

### Testing

- Universal: Opt-out testing (IAPAC: A) ²⁰
- Active choice testing ²
- Community based testing: Multi-disease prevention community health campaigns (IAPAC: A) ¹, ⁵, ⁶, ⁷, ⁸, ¹³, ¹⁴, ²³, ²⁴, ²⁵
- Partner notification and referral to testing (IAPAC: A) ³
- Self-testing (IAPAC: B) ²¹
- Testing in workplace and institutional settings, including prison, military, police, mining/trucking companies, and educational venues (IAPAC: B III) ³, ⁶, ⁷, ¹³, ¹⁴, ²³

### Linkage

- Universal: Co-locating medical services for onsite testing and medical care (IAPAC: A) ²²

### Domestics

- ARTAS case management (IAPAC: B II) ¹, ⁴, ⁸, ¹³
- HIV clinic based linkage to care team (IAPAC: A) ²²
- Strength-based case management ¹, ⁸, ¹⁰, ¹⁶
- Outreach workers ¹, ⁸, ¹³, ²²
- Youth targeted interventions ¹, ⁸, ¹⁵, ¹⁹, ¹²
- Patient navigation ¹, ⁸, ¹³

### International

- Extended home visit counseling ⁵, ¹⁰
- Food Incentives ²⁰
- Immediate inpatient HIV counseling and testing (IAPAC: A) ⁹, ¹², ¹³, ¹⁵
- Peer home visits post-diagnosis ²⁰

### Retention

- Universal: Reminders (SMS, call, post mail) within 48 hours (IAPAC: B II) ²²

### Domestics

- Clinic-wide messaging (IAPAC: A I) ²⁰
- Enhanced Personal contact ¹, ⁸, ¹³, ²¹
- Computer decision-support systems (Virology Fast Track) ²⁰
- Medical case management ¹, ¹⁴
- Buprenorphine Treatment ²⁰

### International

- Peer support ²⁰

### Adherence & Viral Load Suppression

- Universal: Computer Based Adherence Interventions
- Decentralization of Treatment

### Domestics

- Cognitive Behavioral Therapy for Adherence ¹⁷
- Cognitive Behavioral Therapy & Motivational Interviewing
- Coping Skills & Self Management of Treatment Side Effects ²⁰
- Monetary Reinforcement
- Personalized Cell Phone Reminder System
- Pillboxes

### International

- Community Based ART Programs
- Community Based Adherence Clubs
- Counselling and Alarm Devices
- Counseling and Reminder Text Messages
- Directly Administered Antiretroviral Therapy (DAART)
- Health Workers
- Individually Tailored DOT with economic and psychosocial support ¹⁰
- Online Self-Management Programs
- Phone Calls and Home Visits ²⁹
- Task Shifting and Involvement of Community
- Text Message Reminders

## Glossary

**Active choice testing**

Notifying patients orally or in writing that an HIV test will be performed unless patient declines.

**Multi-disease prevention community health campaigns**

Testing patients in non-facility based settings, eg. mobile vans, in combination with other interventions.

## Population Key

1. African American
2. All high risk
3. All partners of HIV+ individuals
4. ARV naive
5. First-time testers
6. Incarcerated
7. Latina/Latino
8. No low education
9. Low income
10. Marginalized/housed
11. Married
12. Men
13. MSM
14. Newly diagnosed
15. No insurance
16. Poor education
17. People w/depression
18. Pregnant women
19. Substance use
20. Unspecified
21. Women
22. YMSM
23. Youth

## IAPAC Key

<table>
<thead>
<tr>
<th>Strength of the Recommendation</th>
<th>Quality of the Body of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strong (A)</td>
<td>Excellent (I)</td>
</tr>
<tr>
<td>Moderate (B)</td>
<td>High (II)</td>
</tr>
<tr>
<td>Weak (C)</td>
<td>Medium (III)</td>
</tr>
<tr>
<td>Low (IV)</td>
<td></td>
</tr>
</tbody>
</table>

**National Ryan White Conference on HIV Care & Treatment**
Welcome to the Ending the Epidemic Dashboard for New York State!

As recommended by the ETE Task Force, the purpose of this Dashboard is to extend and enhance the use of data to track and report progress on ending the epidemic in New York and broadly disseminate information to stakeholders on the initiative's progress.

NEW INTERACTIVE DATA: Visit the Dashboard's new NYC HIV testing data visualization

Estimated metrics for tracking progress towards Ending the Epidemic in NYS

- **Prevention**: 32% Condom use at last sex in NYC
- **New Infections**: 2,481 New infections in NYS
- **Testing**: 32% recently tested in NYC
“Ending the Epidemic In Monroe County”
Actions influenced by NY Links*

Kimberly Smith, MPA

Monroe County Department of Public Health (MCDPH)
Supervising Public Health Representative

McPEnE (Monroe County Partnering to End The Epidemic)
Initiative Manager

*A HRSA Special Project of National Significance
Sustaining NY Links in Western New York

- **WNY Links initiated in June, 2012**
  - Engagement of Senior and Program Leadership
  - Clinical and supportive service agencies - mostly located in Buffalo and Rochester
  - Erie County DOH, Monroe CDPH
  - Held Collaborative meetings (2-3/year) between Buffalo and Rochester agencies
    - to promote peer learning particularly quality improvement work focused on NY Links measures and VL suppression;
    - to discuss statewide and local issues related to linkage, retention, and VL suppression;
    - to build partnerships across agencies with the goal of building a web of care so that patients are not lost in the system and conducting cross agency quality initiatives.

- **SPNS funding – time limited**
  - Consensus
    - To create sustainability plans to sustain NY Links through Regional Groups
    - To create a shared leadership approach to sustainability
  - Difference in motivation of agencies within Erie County and Monroe County to sustain initiative
    - Monroe County Department of Public Health highly motivated to not only continue NY Links mission, but to broaden it to End the Epidemic in NY
MCDPH QI Internal Project
“Data to Care”

MCDPH QI External Project
Data to Care
“Partnerships (RW Agency)”

Piloted Interventions

- CAPTAIN: 100% of those eligible for linkage
- SWAT: 98% of those eligible for linkage
\( \text{Success} \)

% Linked to Care Within 30 Day of Confirmatory HIV+ Test Results

- Dec. Jan. 2015: 97%
- Feb. Mar. 2015: 92%
- April May 2015: 91%
- June July 2015: 75%
- Aug Sept 2015: 100%
- Oct Nov 2015: 100%
- Dec. 2015: 100%

2 Pos difficult to locate
For Post Test.
1 located, Post tested

NATIONAL RYAN WHITE
CONFERENCE ON HIV CARE & TREATMENT
McPEtE
(Monroe County Partnering to End The Epidemic)

Mission: To end the HIV/AIDS epidemic in Monroe County by 2020 through the development of county wide partnerships of HIV clinical and non-clinical service providers, consumers and networks committed to specific objectives and activities that align with the New York State End the Epidemic (ETE) initiative.
McPEtE Structure

Managing Team
Monroe County Department of Public Health (Nursing Division) (MCDPH)

Technical Advisor
New York State Department of Health AIDS Institute (NYSDOH AI)

Core Team
Consumer, MCDPH, Jordan Health, Catholic Charities Community Services (CCCS), Action for a Better Community (ABC), Trillium Health

Consumer Advisory Council
McPEtE is utilizing RATFA’s (Rochester Area Task Force on AIDS) CAC. A minimum of 4 graduates of the AI sponsored Training of Consumers on Quality (TCQ) program of the National Quality Center will lead the processes.

McPEtE Partners (Collective)

Clinical
Trillium Health, Jordan Health, URMC Rochester Victory Alliance (HIV Vaccine Clinical Research), Strong Memorial Hospital Infectious Disease Clinic, Huther Doyle, Rochester Regional Health, Unity Infectious Disease, National Center for Deaf Health Research

Nonclinical
Consumers, MCDPH, NYSDOH, Catholic Charities (CCCS), ABC, Partners Advocating for Community Change (PACC), BLCA (Black Leadership Commission on AIDS), RATFA (Rochester Area task Force on AIDS)
Agency Commitment Plans
Agency visits to Solidify Commitment to...

McPEtE Objectives

1. Increase by 20% # of Newly Diagnosed (RW Cascade #1)
2. 100% ND Linked To Care within 3 Business days (Cascade #3)
3. Increase Retention from 88% to 95% (Cascade #4)
4. Reengage 95% of clients OOC (Cascade #4)
5. Viral Suppression from 83% to 95% (Cascade #5)
6. Increase PrEP/PEP Referrals
7. Community Involvement in Clinic Trials

Recommendations From the ETE Blueprint

Areas highlighted in Yellow are areas that have not been covered within McPEtE

1. Make routine HIV testing truly routine
2. Expand targeted testing
3. Address acute infection
4. Improve referral and engagement
5. Continuously act to monitor and improve rates of viral suppression
6. Incentivize performance
7. Use client level data to identify and assist patients lost to care or not virally suppressed
8. Enhance and streamline services to support the non-medical needs of all persons with HIV
9. Provide enhanced services for patients within correctional and other institutions and specific programming for patients returning home from corrections or other institutional settings
10. Maximize opportunities through the Delivery System Reform Incentive Payment (DSRIP) process to support programs to achieve goals related to linkage, retention and viral suppression
11. Undertake a statewide education campaign on PrEP and nPEP
12. Include a variety of statewide programs for distribution and increased access to PrEP and nPEP
13. Create a coordinated statewide mechanism for persons to access PrEP and nPEP and prevention-focused care
14. Develop mechanisms to determine PrEP and nPEP usage and adherence statewide
15. Increase momentum in promoting the health of people who use drugs
16. Ensure access to stable housing
17. Reduce new HIV incidence among homeless youth through stable housing and supportive services
18. Ensure and protect health, housing, and human rights for LGBT communities
19. Institute an integrated comprehensive approach to transgender healthcare and human rights
20. Provide expanded Medicaid coverage for sexual and drug related health services to targeted populations
21. Establish mechanisms for an HIV peer workforce
22. Ensure access to care for residents of rural, suburban and other areas of the state
23. Promote comprehensive sexual health education
24. Remove disincentives related to possession of condoms
25. Promote treatment as prevention information and anti-stigma media campaign
26. Provide HCV testing to persons with HIV and remove restrictions to HCV treatment access based on financial considerations for individuals co-infected with HIV and HCV
27. Implement the Compassionate Care Act in a way most likely to improve HIV viral suppression
28. Ensure equitable funding where resources follow the statistics of the epidemic
29. Expand and enhance the use of data to track and report progress
30. Increase access to opportunities for employment and employment/vocational services
McPeteE
Based on the Success of Individual Interventions & Partnerships

Successful Interventions

University of Rochester
- ID Clinic (SWAT) – 98%

Jordan Health Services
- (CAPTAIN) – 100%

Trillium Health
- (Toni2020) – 96%

Catholic Charities
- (CC-CAR) – 98%

Action for a Better Community
- (LERN) 86%

New Partnerships

Rochester Regional Health
- Internal Medicine, ED, Unity ID Clinic

Community For AIDS Research (CFAR)
- Clinical Trials and Research

National Center for Deaf Health Research
- Advocacy for the hearing impaired

Task Force & Coalitions
- Rochester Area task Force on AIDS, National Black Leadership Coalition
NY LINKS:
Upper Manhattan’s Response, Contributing to End the HIV Epidemic in New York State

Rebecca Green, LMSW
Institute for Family Health
Regional Director of HIV Programs
Why NY Links?

• Membership in the Upper Manhattan since 2012 and now Bronx NY Links Regional Groups
• QI support
• Commitment to peer learning and regional success
• Leverage resources
• Steering committee involvement
  • Additional level of commitment
  • Shared leadership with the State for success of group
  • Weigh in on regional goals, meeting structure, etc.
  • Build my own motivation
  • Motivate organizations in the region
UM Regional Group

- Initiated late 2011
- Engagement of all medical, non-medical, and supportive services providers in the Upper Manhattan geographic area
- Consumers actively involved in leadership, at meetings, and on agency QI/QM teams
- Medicaid managed care organizations, DSRIP, local pharmacy, local city council members, pharmacists, city department of health staff
- Participation Involves:
  - Quarterly face-to-face meetings
  - Routine data submission of standardized indicators
  - Implementation of QI interventions to address internal and cross-agency linkage/retention challenges
  - Collaboration across community

- **Blue**—Clinical Program Participating in the Upper Manhattan Regional Group
- **Yellow**—Supportive Service Program Participating in Upper Manhattan Regional Group
- **Green**—Marginally engaged or re-engaging
<table>
<thead>
<tr>
<th>Community Members</th>
<th>HIV Medical and Supportive Service Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ NYC HHC - Harlem Hospital Center</td>
<td>☐ New York Presbyterian Hospital - Comprehensive HIV Program</td>
</tr>
<tr>
<td>☐ Iris House</td>
<td>☐ Center for Special Studies</td>
</tr>
<tr>
<td>☐ Harlem United</td>
<td>☐ Community Health Care Network</td>
</tr>
<tr>
<td>☐ FROST'D @ Harlem United</td>
<td>☐ Lenox Hill Hospital</td>
</tr>
<tr>
<td>☐ Institute for Family Health</td>
<td>☐ Boriken Neighborhood CHC</td>
</tr>
<tr>
<td>☐ Center for Comprehensive Health Practice</td>
<td>☐ Settlement Health and Medical Services</td>
</tr>
<tr>
<td>☐ AIDS Service Center</td>
<td>☐ William F. Ryan CHC (97th St)</td>
</tr>
<tr>
<td>☐ NYC HHC - Metropolitan Hospital Center</td>
<td>☐ William F Ryan Chelsea Clinton</td>
</tr>
<tr>
<td>☐ START - Addiction Research and Treatment Corporation</td>
<td>☐ Citicare, Inc</td>
</tr>
<tr>
<td>☐ African Services Committee</td>
<td>☐ NYC HHC- Renaissance Healthcare</td>
</tr>
<tr>
<td>☐ Harm Reduction Educators</td>
<td>☐ Union Settlement</td>
</tr>
<tr>
<td>☐ Mount Sinai Medical Center</td>
<td>☐ FACES NY</td>
</tr>
<tr>
<td>☐ - Jack Martin Clinic</td>
<td>☐ Bailey House</td>
</tr>
<tr>
<td>☐ - Morningside Clinic</td>
<td>☐ Ali Forney Center</td>
</tr>
<tr>
<td>☐ - Samuels Clinic</td>
<td>☐ Safe Horizon</td>
</tr>
<tr>
<td></td>
<td>☐ Heritage Health and Housing</td>
</tr>
<tr>
<td></td>
<td>☐ Harm Reduction Coalition</td>
</tr>
</tbody>
</table>
Upper Manhattan Steering Committee

- A self-organizing, peer-driven group made up of 8 nominated leaders with various skill sets and roles who participate in the regional group.
- Members are active providers, leaders, public health staff and community members from the region
- Purpose:
  - Maintain leadership at the community level
  - Streamline communication
  - Support and direct the regional group
  - Increase regional group sustainability
  - Hold all participants accountable for participation, goals, and outcomes
  - Plan and Facilitate Meetings
  - Lead the buddy system
- Co-Chairs for Ending the Epidemic Initiative are active members
Day-At-A-Glance
(Typical Regional Group Agenda)

Morning
- Welcome – Introductions
- Recap and Meeting Overview, Regional Goals and Progress
- QI Projects Steps: Process Investigation & Provider Examples
  - Comprehensive VLS and Care Connection to ETE
  - Peer Support Improving New Patient Retention
- Buddy System - Reconvening Our Community Support System
  - QI Project Updates & Next Steps
- Ending the Epidemic – Update and Alignment

Afternoon
- REACH – Ready to End AIDS and Cure Hepatitis C
- Tell It Like It Is – Community Driven Improvement Strategies
  - Panel | Full Group Brainstorming
  - KiKi Ballroom – Keeping It Real!
- Wrap-Up: Community Updates; Action Items & Plan Refinement
- Join Us! Networking & Partnership Development (1:30 – 2:00)
Upper Manhattan “Buddy System”

- For the purposes of our group a buddy system is a support network or a way for members to help each other individually and collectively reach goals.

- Up to four agencies form a “buddy system”, with at least one member from the Steering Committee serving as the lead.

- Ultimately, may be a way to benefit from one another’s strengths, share and practice valuable skills and take greater ownership for the Regional Group.
Upper Manhattan Regional Goals

By January 2017:

• Improve linkage to care from 76% to 81%
• Increase retention in care from 62% to 75%
• Improve new patient retention from 58% to 68%
• Increase the percentage of PLWHA who are virally suppressed from 71% to 81%
• Create equity in outcomes and access to care for priority communities in Upper Manhattan
  ▪ Young MSM of color
  ▪ Transgender
  ▪ Individuals with Mental Health/Substance use issues
  ▪ Women of Color
Upper Manhattan
Linkage, Retention and Viral Load Suppression
2016 Regional Goals

- Linkage to Care: Goal = 81%
- New Patient Retention: Goal = 68%
- Retention in Care: Goal = 75%
- Viral Load Suppression: Goal = 80%
- Clinical Engagement: Goal = 83%

Dec-15 (11 Providers)
16-Mar (8 Providers)
16-Jun (6 Providers)
Upper Manhattan Successes

- Regional Service Directory
- Catalogue of regional interventions and resources for priority populations
- *Tell It Like It Is* – collaborative initiative to improve engagement of YMSM and Trans community in healthcare
- Collaborative linkage, retention and VLS partnerships:
  - Targeted support groups co-facilitated/hosted
  - Care coordination/outreach offered by CBO to clinics
  - Training/visits amongst members
- Regional Cascade Analysis and Intervention Mapping
- Facility level HIV care cascades developed & used for QI
- Twenty+ agencies launched and refined linkage, retention and/or vls projects
Case Conferencing to Viral Load Suppression

Rebecca Green, LMSW

Institute for Family Health
Institute for Family Health

- Federally Qualified Health Center network of 27 full and part-time clinics in Manhattan, the Bronx and the Mid-Hudson region, serving over 90,000 patients annually
- Joint Commission accredited, Level 3 Patient Centered Medical Home
- Primary care, mental health, dental care, case/care management, community programs and more
- Ryan White Part A, C and NYS AIDS Institute funding.
- Serve approximately 1000 patients with HIV/AIDS annually
Continuous Quality Improvement in VLS

2012  Small sample, program specific, tightly monitored

2013  Expanded to all IFH clinics, developed reports to facilitate data, more attention paid to process outcomes

2014  Continued focus on all IFH clinics, more structured intervention, shared responsibility of site leaders to ensure validity of intervention

2015  Intervention becomes best practice, monthly case conferences and, intervention options refined. No longer a CQI project, just what we do

2016  Focus on Chronically Unsuppressed (CU) patients. Patients with 2 or more unsuppressed VLS
VLS Outcomes 2013-2015

- 2013: 76%
- 2014: 79%
- 2015: 81%

% of Pts with Suppressed VL (VL ≤200)
Consumer Involvement

Dawn Trotter

Retention Support Assistant

EVERGREEN Medical Group
Consumer Involvement in NYLinks

My Role:

Region: Western NY Regional Group

Agency: Evergreen Health Center - is a multi-agency non-profit organization, working collectively to address the healthcare and related needs of individuals and families living in the eight counties of Western New York (WNY). The medical group provides comprehensive, medical care and pharmacy with a chronic disease specialty.

Role:
NYLinks
New York State’s Quality Management Program
Evergreen
Consumer Involvement In New York State

• Consumer involvement in HIV service delivery is designed to increase the involvement of consumers in HIV prevention/care/treatment policy and program development, implementation, and evaluation.

• Consumer involvement facilitates direct participation and identification of consumer priorities for healthcare programs.

*The New York State Department of Health AIDS Institute, since its inception, recognizes the important role that peers can play in improving health outcomes and many health and social service programs have a long history of successfully engaging clients in a wide range of activities.*
Forms of Consumer Involvement In New York State

• HIV/AIDS Advocacy (healthcare and research policy, treatment, community, and individual advocacy)
• Consumer Advisory Boards
• Serving as formal members of quality management teams/committees and participation in quality improvement projects at facility, region, state, national and international levels
• Clinical guidelines review
• HIV/AIDS education materials development
• Self-management and patient-centered care
• RW Community planning bodies
Consumer Involvement Structure

- Initially consumers met as sub-groups in regional groups
- The structure was modified to integrate consumers as facility multi-disciplinary team members in each region
- Consumers now serve as active members of regional groups and sub-committees
- Provide leadership within steering committees
- Facilitate meetings
- Deliver presentations
- Participate in regional assessments and goal setting
- Offer input from the patient experience
Consumer Involvement in QI

• Draw from personal experiences and those of other HIV positive persons within network to provide real world examples of success for people when they are in place of hopelessness

• Reflect on personal struggles in fitting medical visits to real life and difficulty accepting need to take medication to help those struggling make connections to medical care in their own life

• Demonstrate from lived experience the way treatment of HIV fits into other aspects of life

• **Attend training to enhance abilities as peer educator**
  - Share learned knowledge with those not yet able to attend training due to availability or readiness to acknowledge HIV+ diagnosis in group setting
Consumer Involvement Capacity Building

• Participation in National Quality Center 2-day training for consumers on quality improvement (TCQ) and TCQPlus
  - to facilitate formal consumer involvement in facility level quality management committees/teams, and NYLINKS regional groups and QI activities
• Development, implementation and evaluation of interventions to improve linkage, retention, and VLS
NYLinks: Moving from Data to Action

Jenny Knight, FNP, MPH

Nurse Practitioner
New York Presbyterian –CUMC
Upper Manhattan Regional Group
Improving New Patient Retention: A Peer Intervention

- A NYLinks Quality Improvement Intervention piloted at NYC HHC’s Harlem Hospital Center 11/2014 – 10/2015

- This project built on Harlem Hospital’s strength in integrating peer support directly into its HIV prevention and treatment work

- The goal of the project was to increase the New Patient Retention rate from a baseline of 55% to 70% within 12 months

- New Patient Retention Measure: % of new patients seen in first 4 months of review period who have a medical visit in each of the 2 subsequent 4-month periods
The Peer Intervention Model

- Two experienced, trained peers were recruited to work with Harlem Hospital’s HIV Linkage specialist
- At the patient’s first visit the peer carried out a 5-part intervention:
  - Introduces him/herself to the new patient
  - Provides a tour of the clinic
  - Introduces key staff,
  - Explains clinic services
  - Gives the patient a clinic information packet
- The peer is also available to meet with patient at subsequent clinic visits, make reminder phone calls and link patient to case management/social work services
Results

• The 12-month retention data is based on the patients seen in the first 4 months of the project. In the first 4 months, 19 new patients were identified and linked with the peers.

• All of these patients received all five parts of the intervention.

• Most of the patients received additional peer outreach and support.

• The 12-month retention data from 10/1/14 – 9/30/15 indicated an increase in the patient retention rate from the baseline of 55% to 86% -- surpassing the set goal of 70%.

![Retention Chart]

<table>
<thead>
<tr>
<th>Retention</th>
<th>2014</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>55%</td>
<td></td>
</tr>
<tr>
<td>2015</td>
<td>86%</td>
<td></td>
</tr>
</tbody>
</table>

Goal 70%
Lessons Learned

• Peers continue to be an effective resource in improving new patient linkage and retention

• Peers who receive education, training and role orientation can work effectively with a staff linkage team

• Integrating peers into a staff team, takes education and support of involved staff to build buy-in

• Supervision and support of peers during the project is also key

• Stipend support for peer services is optimal
Tell It Like It Is:
Creating a two-way conversation with HIV-positive and at-risk youth and young adults

- A collaborative project between several CBO’s and medical providers with the NYLinks Upper Manhattan Regional Group

- An outreach project to include young MSM’s of color and other at risk youth and young adults in the Upper Manhattan Region
Telling It Like It Is . . .
The Tell It Like It is Project:

• An attempt to translate the New York State Blueprint to End the Epidemic into meaningful action at the community level

  Through . . .

• An ongoing series of community-based conversations on engaging at-risk youth and young adults in HIV treatment and prevention.

  Based on . . .

• A commitment to bringing the voices of those we want to serve into the conversation
Events to Date
Organized as a collaboration of NYLinks

Tell It Like It Is: February 2015
A young adult–centered evening event involving food, entertainment, panel discussion and an informal community needs assessment
Attendance: 90 people representing 19 CBO’s and medical providers

Taking Pride in our Health: June 2015
Expanded workshop with Keynote address by Dr. Robert Fullilove, topical workshops, Best Practices from CBO’s. Music and food Attendance (100 people)

Tell It Like It Is: Small strategy forum on working with at risk youth and young adults: February 2016

Going to the Youth: Focus Group at Ali Forney on attitudes towards HIV treatment and Prevention: March 2016

Sharing Lesson learned: Tell It Like It Is and Kiki Ballroom scene presentation to Upper Manhattan Regional Group: June 2016
Key Questions

• What can we do TOGETHER to decrease infection rates among young YMSM’s of color in the communities we serve?

• How do we acknowledge outside barriers without getting shut down by them (Lack of affordable housing, stigma, healthcare disparities, etc)?

• How do we move from laundry lists to action?
What we have learned:

We need to:

- hear real life stories
- reduce stigma and discrimination
- treat clients as people not numbers
- address survival issues (housing, food, jobs)
- continue with peer support/peer-based education
- role models are important
- avoid labeling and categorizing people
  -- age, gender, race, ethnicity, HIV status
- address the tension between medical and social service paradigms
We are challenged by:

- Hidden underserved youth
- Insurance issues
- Limited resources
- Engaging the unengaged
- Referrals
- Undocumented clients
- Agency bureaucracy
- Competition among agencies
- Burn out
- Poor follow through
- Stigma
- Being driven by numbers
- Losing sight of our goals
What makes us successful

Flexible approaches
Consistent availability to clients
Being sex positive
Demonstrating a clear commitment to patients/clients
Empathy
Building linguistic and cultural bridges to the communities we want to reach
Mentorship
Strong regional collaboration and partnership with city and state
Necessary skills/practices

Linkage to Care
Using evidenced-based interventions
Community engagement
Effective HIV Testing Programs
Ongoing Research
Strong skills in comprehensive assessments/sexual health histories
PrEP and PEP outreach programs
Access to medications
What we need:

Stronger Interagency Collaboration
Ongoing Funding
More Data
data supports new treatment options and evidence-based medical and non-medical interventions
Affordable Housing
Mental Health services
LGBT sensitization
Substance use treatment
Next Steps

• 2016 Fall Forum: youth and young adult-friendly with focus on MSM and Transgender youth
• Continue the conversation between at-risk and positive youth and young adults and the CBO’s and medical providers who serve them
• Develop youth-centered concrete action steps that will help decrease new HIV infections in Young MSM’s of color and young people with trans-experience
Special Thanks!

Jeffrey Padilla – Iris House
David Matthews – Bridging Access to Care—Brooklyn Men (K)onnect
Clarence Thorne-Williams -- Whoever We Love Support Group
Travis Harris – Whoever We Love Support Group
Wrap-Up

Q & A
Special Thanks:

• Dawn Trotter
  trotter.dawn@yahoo.com
• Jenny Knight
  jknight155@yahoo.com
• Rebecca Green
  rgreen@institute.org
• Kimberly Smith
  ksmith@monroecounty.gov
Acknowledgements

• Bruce Agins, MD, MPH
• Clemens Steinbock, MBA
• Steve Sawicki, MHA
• Dan Belanger, MSW
• Stephen Crowe, MSW
• Nova West, MPH
• Maryellen Mancinelli
• Nanette Brey-Magnani, MEd
• Inez Jones, MPH
• Dan Tietz
• Diane Addison, PhD
• Ben Katz, MPH
• Carol-Ann Watson, PhD
• Kelly Piersanti, MPH
• Terry Hamilton, MPH
• Demetre Daskalakis, MD Bisrat Abraham, MD & NYCDOHMH HIV CSU
• Graham Harriman, MSW
• Andy Doniger
• Byron Kennedy, MD
• Kim Smith, MHA
• Gale Burstein, MD
• Cheryl Moore, MPH
• Roger Hayes, MA
• Denis Nash, PhD
• Johanne Morne
• Karen Hagos, MPH
• Lou Smith, PhD
• Dan Gordon, PhD
• John Fuller,
• Yamileth Quejada
Contact Information

Steve Sawicki, NYLinks Lead, steven.sawicki@health.state.ny.us

NYSDOH Regional Leads
Upper Manhattan—Susan Weigl, sweigl@yahoo.com
Lower Manhattan—Susan Weigl
Western NY—Nanette Brey Magnani, breymagnan@aol.com
Long Island—Stephen Crowe, stephen.crowe@health.ny.gov
Central NY & Southern Tier—Steve Sawicki
Mid & Lower Hudson—Steve Sawicki
Queens—Nova West, nova.west@health.ny.gov
Brooklyn—Clemens Steinbock, clemens.steinbock@health.ny.gov
Bronx—Dan Belanger, dan.belanger@health.ny.gov
Northeastern NY—Steve Sawicki

If not sure, info@newyorklinks.org
Welcome to NY Links

NY Links focuses on improving linkage to and retention in HIV care to support the delivery of routine, timely, and effective care for Persons living with HIV/AIDS in New York State. We bridge systemic gaps between HIV related services and achieve better outcomes for PLWH through improving systems for monitoring, recording, and accessing information about HIV care in NYS. Region by region, we utilize the learning collaborative model to fortify the links holding together communities of practice, and the links grounding them in the communities of consumers they serve.

New York Links is supported by the HRSA HIV/AIDS Bureau (HAB)-sponsored Special Projects of National Significance (SPNS) and the NYSDOH AIDS Institute.

Dr. Bruce Agins leads a discussion at the January 23, 2013 Upper Manhattan Learning Session.

New York State Ending the Epidemic Initiative

On June 29, 2014, Governor Andrew M. Cuomo detailed a three-point plan to move us closer to the end of
References/Tools for Sustainability of Community Initiatives

- Sustainability Framework and Assessment Tools
  
  *Center for Public Health Systems Science; Washington University, St Louis.*  
  [https://sustaintool.org/understand](https://sustaintool.org/understand)


- Principles of Community Engagement; CDC.1997

  *Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement*  