Everything Comes Down to This

Systems Linkages and Access to Care for Populations at High Risk for HIV Infection in New York State

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Program Manager, NYS DOH, AIDS Institute, Office of the Medical Director, SPNS Lead

May, 2013
Cascades
CDC’s National ‘Cascade’ (July, 2012)

OVERALL: Of the 1.1 million Americans living with HIV, only 25 percent are virally suppressed.

- Diagnosed: 82%
- Linked to Care: 66%
- Retained in Care: 37%
- Prescribed ART: 33%
- Virally Suppressed: 25%
Cascade of HIV Care
New York State, 2010

- Estimated HIV Infected Persons: 156,287
- Persons Living w/ Diagnosed HIV Infection: 128,653
- Cases w/any HIV Care during the year*: 84,701
- Cases w/continuous care during the year**: 73,634
- Virally suppressed (n.d. or <200/ml) at test closest to...: 58,337

* Any VL or CD4 test during the year
** At least 2 tests, at least 3 months apart

82% of infected
54% of infected
47% of infected
37% of infected
66% of PLWDHI
57% of PLWDHI
45% of PLWDHI
69% of cases w/any care

BHAIE, NYSDOH January, 2012
NY Links HIV care cascade: all PLWH in NYC and Upper Manhattan, 2011

- Total PLWH: N=126,064
- Diagnosed PLWH: N=108,415

Evidence of care in 2011: 54% among all PLWH, 63% among diagnosed PLWH

Retention in care among PLWH with evidence of recent care: 84%

Viral suppression among PLWH with evidence of recent care: 74%

Sustained viral suppression among PLWH with evidence of recent care: 61%

Viral suppression among all diagnosed PLWH: 47%

Viral suppression among all PLWH: 40%

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1 Presented at the AIDS Institute/Queens and Staten Island Collaborative Learning Session, February 22, 2013
2 The New York City Department of Health and Mental Hygiene, 42-09 28th St. Long Island City, NY 11101

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Footnotes:
1. Persons diagnosed with HIV on or before June 30, 2010 and living as of December 31, 2011. As reported to the New York City HIV Surveillance Registry (NYCHSR) as of September 30, 2012. [PROVISIONAL DATA]
2. Retaining care at an UMRG NY Links provider or at a non-NY Links provider is determined by the ordering provider of the first CD4/VL reported to the NYCHSR January 1, 2011 – December 31, 2011.
4. Evidence of recent care is defined as ≥1 CD4/VL reported to the NYCHSR January 1, 2011 – December 31, 2011.
5. Retained in care is defined as the percentage of PLWH with recent care who had ≥2 CD4/VL tests reported to the NYCHSR January 1, 2011 – December 31, 2011 that were at least 45 days but no more than 183 days apart.
6. Viral load suppression is defined as the % of PLWH with evidence of recent care whose most recent VL reported to the NYCHSR January 1, 2011 – December 31, 2011 was <400 copies/mL.
7. Sustained viral load suppression is defined as the % of PLWH with evidence of recent care whose VL tests reported to the NYCHSR January 1, 2011 – December 31, 2011 were ALL <400 copies/mL.
NY Links HIV care cascade: all PLWH in NYC and Queens/Staten Island, 2011

- Total PLWH: N=126,064
- Diagnosed PLWH: N=108,415
- Evidence of care in 2011: 54% among all PLWH, 63% among diagnosed PLWH
- Retention in care among PLWH with evidence of recent care: 77% among all PLWH, 81% among diagnosed PLWH
- Viral suppression among PLWH with evidence of recent care: 71% among all PLWH, 75% among diagnosed PLWH
- Sustained viral suppression among PLWH with evidence of recent care: 59% among all PLWH, 63% among diagnosed PLWH
- Viral suppression among all diagnosed PLWH: 47%
- Viral suppression among all PLWH: 40%

1 Persons diagnosed with HIV on or before June 30, 2010 and living as of December 31, 2011. As reported to the New York City HIV Surveillance Registry (NYCHSR) as of September 30, 2012 [PROVISIONAL DATA]
2 Receiving care at a Queens/Staten Island (QSI) provider or at a non-QSI provider is determined by the location of the ordering provider of the first CD4/VL reported to the NYCHSR January 1, 2011 - December 31, 2011
4 Evidence of recent care is defined as ≥2 CD4/VL reported to the NYCHSR January 1, 2011 - December 31, 2011
5 Retained in care is defined as the percentage of PLWH with recent care who had ≥2 CD4/VL tests reported to the NYCHSR January 1, 2011 - December 31, 2011 that were at least 45 days but no more than 183 days apart
6 Viral load suppression is defined as the % of PLWH with evidence of recent care whose most recent VL reported to the NYCHSR January 1, 2011 - December 31, 2011 was <400 copies/mL
7 Sustained viral suppression is defined as the % of PLWH with evidence of recent care whose VL tests reported to the NYCHSR January 1, 2011 - December 31, 2011 were ALL <400 copies/mL
Viral Suppression Among All Persons Living with Diagnosed HIV Infection in 2010

NYC: 45%
Rochester: 52%
Buffalo: 45%
Syracuse: 41%
Nassau-Suffolk: 48%
Mid-Hudson: 39%
Lower Hudson: 39%
Binghamton: 46%
Albany: 45%

NYS Total, 45%

NHAS Target, 20% increase above baseline for specific groups

% of living cases with viral load non-detectable or ≤ 200 copies/ml, test closest to mid-year

BHAE, NYSDOH January, 2012
Cascades from Elsewhere

Figure 1. Percentage of estimated number of HIV-infected persons* in stages of continuum of HIV care in four large United States cities through December 2009:

- Chicago (23,799)
- Los Angeles County (47,658)
- Philadelphia (19,691)
- San Francisco (17,665)

*Includes people diagnosed with HIV through 2008 and living with HIV through 2009 and an estimated additional 20% who are unaware of their infection.
What Does This Mean?
CDC’s National ‘Cascade’ (July, 2012)

OVERALL: Of the 1.1 million Americans living with HIV, only 25 percent are virally suppressed.

- 82% Diagnosed
- 66% Linked to Care
- 37% Retained in Care
- 33% Prescribed ART
- 25% Virally Suppressed

Opportunities for Improvement
SPNS Overview
What are ‘SPNS’?

• Special Projects of National Significance
  – Part of the Ryan White HIV/AIDS Program
  – Supports the development of innovative models of HIV care that respond to emerging needs of Ryan White clients
  – Topics for SPNS funding prioritized by HRSA
  – Strong evaluation/research component to assess the effectiveness of models, and then focus on the dissemination and replication of successes at a national level
  – Overall goals are consistent with National HIV/AIDS Strategy
NY Links Overview
NY Links Mission

Together, we

• identify innovative solutions for improving linkage to and retention in HIV care to support the delivery of routine, timely, and effective care for PLWHA in New York State; and

• bridge systemic gaps between HIV related services to achieve better outcomes for PLWHA through improving systems for monitoring, recording, and accessing information about HIV care in NYS.
Existing collaborative locations in New York State

Susan Weigl, Director; Lenee Simon, Co-Director

Nanette Brey-Magnani, Director

Upper Manhattan

Queens and Staten Island

Lenee Simon, Director
Upper Manhattan Regional Group

- Engagement of all medical and non-medical providers in the Upper Manhattan geographic area to improve linkage to and retention in HIV care. Initiated 11/11.

- Current Progress:
  - 5th Learning Session: January 23, 2013, Next Session, June 21
  - Provider driven interventions currently being tested and evaluated.
  - *Patient/Peer Navigation
  - *Notification Systems
  - *Linkage to Care handoffs
  - *System Modification

- **Blue**-Clinical Program Participating in the Upper Manhattan Regional Group
- **Yellow**-Supportive Service Program Participating in Upper Manhattan Regional Group
Western New York State Collaborative (WNYS)

- Engagement of all HIV medical and non-medical providers in the Western NY geographic area (Rochester and Buffalo) to improve linkage to and retention in HIV care. Initiated 6/12

- Current Progress:
  - 4th Learning session scheduled for June 26th
  - Providers working on utilizing data, as a system and individually, to locate areas where interventions would have the most impact.

- Red - Programs Participating in the WNYS Regional Collaborative
Queens-Statens Island Collaborative

Engagement of all HIV medical and non-medical providers in the Queens and Staten Island geographic area to improve linkage to and retention in HIV care. Initiated 2/13

Current progress:

- Introduce providers to the goals and objectives of this Collaborative
- Generate momentum to jointly work on linkage and retention interventions
Mid and Lower Hudson Collaborative

• Working with providers in the 7 counties north of NYC: Westchester, Rockland, Putnam, Orange, Sullivan, Ulster, and Duchess.

• First Learning Session targeted for September, 2013.
NY Links Performance Measures
Because Data Drives Quality
# Brief Overview of NYS Links Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Agency Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linkage</td>
<td>All Programs that Conduct HIV Testing</td>
</tr>
<tr>
<td>Retention</td>
<td>HIV Clinical Care</td>
</tr>
<tr>
<td>New Patient Retention</td>
<td>HIV Clinical Care</td>
</tr>
<tr>
<td>Clinical Engagement</td>
<td>Supportive Services &amp; General Medical Assistance*</td>
</tr>
<tr>
<td>New Client Clinical Engagement</td>
<td>Supportive Services &amp; General Medical Assistance*</td>
</tr>
</tbody>
</table>
QI and QI Project Steps
Quality Improvement Projects Should Look Inside and Out

Internal Processes – Drilled down data, team review, determination of interventions, testing of interventions, results

• Retention
• New Patient
• Clinical Engagement

External Processes – Identification of Gap, Partnering, testing of approach or intervention, results

• Retention
• New Patient
• Clinical engagement
Quality Improvement Project Steps
A Problem Solving Process

Test of process change:
Drilling down Data to identify patients; interventions to address specific patients’ needs; documentation and reporting of results (track individually and group)

Step 1: Review, Collect and Analyze Baseline Data
Step 2: Form a Team, Develop a Work Plan
Step 3: Investigate the Process/Problem
Step 4. Plan and Test Changes – PDSA Cycles
Step 5: Evaluate Results with Key Stakeholders
Step 6: Systematize Change
“Every system is perfectly designed to achieve exactly the results it achieves.”

The System
(Before New York Links)
Interventions

Act locally:

• Linkage and retention activities and improvements are unique in the context of:
  
  • each organization, its patient population and its community

  • each Collaborative, its patient population and its community.
Drilling Down Data
ECMC Patient Retention

1075--# of Patients

118—Excluded (transfers, moves, deceased, incarcerated.

957 pts in pool:
Retained: 823 (86.4%)
Not Retained: 134

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number of Patients</th>
<th>Average VL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Returned to clinic at the end of the reporting period, working with</td>
<td>40</td>
<td>7336</td>
</tr>
<tr>
<td>staff on past barriers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown – can’t reach them due to changed contact information</td>
<td>18</td>
<td>7833</td>
</tr>
<tr>
<td>Medically stable – feel well; doing well on treatment, generally</td>
<td>13</td>
<td>21</td>
</tr>
<tr>
<td>state desire to come in as needed; counseled on continued need for</td>
<td></td>
<td></td>
</tr>
<tr>
<td>monitoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment – cite difficulties coming to appts due to work</td>
<td>6</td>
<td>258</td>
</tr>
<tr>
<td>schedule</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disclosure/confidentiality issues – report difficulty coming to clinic</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>due to concerns about who they will see and who will see them</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ongoing alcohol/substance use-</td>
<td>14</td>
<td>32194</td>
</tr>
<tr>
<td>Continued use creates barrier to attendance to medical and other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>obligations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Health-</td>
<td>8</td>
<td>15044</td>
</tr>
<tr>
<td>Continued mental health issues create a barrier to attendance to</td>
<td></td>
<td></td>
</tr>
<tr>
<td>medical and other obligations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insurance instability</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>Since resolved, created temporary issue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disengaged/lack of buy-in</td>
<td>13</td>
<td>27436</td>
</tr>
<tr>
<td>Staff has successfully contacted the patient but pt does not express</td>
<td></td>
<td></td>
</tr>
<tr>
<td>understanding of importance medical follow up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family obligations</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>Cite obligations to family, generally care of young children and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>elderly patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospitalized off site</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Long admission to another local health facility</td>
<td>2</td>
<td>2210</td>
</tr>
<tr>
<td>Incarcerated &lt;90 days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not incarcerated long enough to meet exclusion criteria, but did</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>miss appointments as result</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refuses treatment</td>
<td>3</td>
<td>4942</td>
</tr>
<tr>
<td>Patient expresses they do not wish to continue treatment/medical</td>
<td></td>
<td></td>
</tr>
<tr>
<td>follow up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dually located:</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>Transportation</td>
<td>1</td>
<td>415211</td>
</tr>
<tr>
<td>Ongoing Utility/financial</td>
<td>1</td>
<td>272</td>
</tr>
<tr>
<td>Other medical issues</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>Plans to relocate/transfer</td>
<td>5</td>
<td>26</td>
</tr>
<tr>
<td>Housing instability</td>
<td>1</td>
<td>20</td>
</tr>
</tbody>
</table>
### June 2011-May 2012 10/13 retained = 77%

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance Issues</td>
<td>2</td>
</tr>
<tr>
<td>Incarcerated &lt;90 days, did not meet exclusion requirement, but did miss appointments</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total Patients:</strong></td>
<td>3</td>
</tr>
</tbody>
</table>

### August 2011-July 2012 8/11 retained = 73%

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance Issues (still in care)</td>
<td>2</td>
</tr>
<tr>
<td>Language Barrier/ Lack of available interpreter (still in care)</td>
<td>1</td>
</tr>
<tr>
<td>Transferred HIV care back to PCP</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total Patients:</strong></td>
<td>4</td>
</tr>
</tbody>
</table>
The American Red Cross

3. Retention and engagement into HIV Primary Care for supportive services and general medical services

3a. Clinical Engagement Measure

Results: May/June – 77.23% of 101 patients

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Could not reach</td>
<td>11</td>
</tr>
<tr>
<td>None scheduled, good health</td>
<td>4</td>
</tr>
<tr>
<td>None scheduled, but should have</td>
<td>2</td>
</tr>
<tr>
<td>No primary visit, but went to a specialist</td>
<td>6</td>
</tr>
</tbody>
</table>
4 Guiding Principles of Improvement

• Understanding work in terms of processes and systems
• Developing solutions by teams of providers and patients
• Focusing on patient needs
• Testing and measuring effects of changes
Most problems are found in processes not in people.
Overview
Why develop a process diagram?

• Rationale:
  – More deeply understand process improvement
    • PDSA – Discern whether change is isolated vs clearly connected to process
  – Promotes better decision making
    • Helps you to see your work as a system, a whole
    • Gathers team thinking
    • Creates buy-in and consensus
    • Functions as a procedure and thus can be used to create protocols and evaluate current ones
    • Promotes wider understanding of process

Resources:  HIVQUAL Workbook – flow chart
            NQC: National Quality Academy Tutorials – flow chart
Model for Improvement

What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?

Act

Plan

Check

Do

Model for Improvement
The System
(Under Improvement)
Erie County Medical Center
Immunodeficiency Services
Buffalo, NY

Retention Process

**Review Process**
- Generate monthly list of patients not seen for medical visit in greater than 90 days
- Review most recent clinic notes (medical and case management) to determine case disposition.
- Create follow up plan as indicated by review of notes.

**Social Work Intervention**
- Assigned case manager contacts patient to discuss visit lapse and to identify present barriers
- Develop plan to address barriers toward returning to regular medical care.
- Refer to outreach if unable to achieve above.

**Pharmacy Intervention**
- When patient retention issue is also impacted by medication adherence, referral is made to pharmacist.
- Pharmacist to discuss with patient current feeling regarding medication toward determining if current regimen is appropriate or should be changed.
- Provide ongoing patient education toward increased barber adherence.

**Outreach Intervention**
- When patient is unable to be reached through standard measure outreach staff checks in person at last known address.
- Last known pharmacy is checked to find if patient has continued to fill medications.
- Review of facility ER records and Medicaid verification for potential new address.

**Patient Returns**
- Upon successful contact patient returns to care and above described interventions are continued toward retention and adherence.
- Patient attendance continues to be assessed in monthly review of patients not seen medically in greater than 90 days.

**Case Closure**
- If above mentioned interventions are unsuccessful case is moved for closure after one year of no successful contact.
- If above mentioned interventions find that patient has transferred care, relocated, become incarcerated, or is not deceased case is closed immediately.
AIDS Care. This is the spreadsheet Community Outreach Specialists use to track referrals for patient follow-up, language barriers, connection to Community Health Initiative programs and progress with re-engagement.
AIDS Care use of EMR log notes to communicate interventions taken by Front Office, Community Outreach and Care Management

- Referral to Community Outreach
- Assistance with barriers
- Front Office documentation

**Frequent CM contact to engage in MH and Substance use treatment**

**Re-engaged with CM**

**Patient returned to care with provider on 1/7/2013 after 6 months**

**Telephone, Log and Prescription Notes**
- 02/20/2013 NO SHOW Truong, Yen
- 02/20/2013 Medical Quinones, Abigail
- 02/13/2013 Face To Face Quinones, Abigail
- 02/06/2013 Face to Face Quinones, Abigail
- 02/05/2013 MHT Quinones, Abigail
- 02/05/2013 Serrano, Alma
- 02/01/2013 Face to Face Quinones, Abigail
- 01/28/2013 Reassessment and Service Quinones, Abigail
- 01/25/2013 R/A and Service Plan Goals Quinones, Abigail
- 01/23/2013 Follow Up Quinones, Abigail
- 01/14/2013 NO SHOW Truong, Yen
- 01/07/2013 Transportation/Bus Passes Brown, Julian
- 01/04/2013 Medical Quinones, Abigail
- 11/30/2012 Medical Quinones, Abigail
- 11/29/2012 Medical Referral Quinones, Abigail
- 11/29/2012 Referral to Outreach Flores, Lily
- 11/15/2012 FOLLOW UP Quinones, Abigail
- 11/14/2012 Medical Quinones, Abigail
- 11/08/2012 NO SHOW Truong, Yen
PI Indicator (Important Function): **No-Show Rate**

Why was this indicator selected? To attain viral load suppression of HIV positive patients through improved retention of patients in HIV care. NYLinks reports have identified that patient retention needs improvement.

**Plan**
- Improve patient retention rates, reduce number of patient “no-shows”.

**Do**
- Nursing and social workers are meeting every other week after case management to review the HIV patient “no show” list from the prior week. The staff discuss reasons why patients are missing appointments and social workers are following up with patients and/or their case managers re these missed appointments. This information is being transferred to an intranet data sharing program.

**Study**
- The HIV Clinic SPNS Committee reviews the intranet data monthly to identify trends and other systemic issues. The SPNS Committee presents this analysis to the monthly HIV Clinic staff meeting.

**Act**
- Staff members discuss results/analyses and provide recommendations to improve outcomes.

**Goal:** New Patient Retention of 65%; Current Patient Retention of 85%
The System
(Initial Results)
Linkage to Care: % of newly diagnosed patients who had their first HIV primary care visit within 30 days of the date of their confirmatory HIV test result.
Retention: % of HIV pts, regardless of age, who had at least one medical visit with a provider with prescribing privileges in each 6-month period of the 24-month measurement period with a minimum of 60 days between medical visits
The Goal