GET TESTED. TREAT EARLY. STAY SAFE.

Let’s End AIDS, Central NY.

NEW YORK STATE Department of Health
Central New York State Regional Group
April 19th, 2017

WELCOME

Ending the Epidemic in New York State
Ending the Epidemic

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
Blueprint Recommendations (BPs)

Link and retain persons diagnosed with HIV in care to maximize virus suppression so they remain healthy and prevent further transmission.

**BP5:** Continuously act to monitor and improve rates of viral suppression

**BP7:** Use client-level data to identify & assist patients lost to care or not virally suppressed

**BP8:** Enhance & streamline services to support the non-medical needs of persons with HIV...

**BP29:** Expand & enhance the use of data to track and report progress
New York State Cascade of HIV Care, 2015

Persons Residing in NYS† at End of 2015

- Estimated HIV-Infected Persons‡: 122,000
- Persons Living w/Diagnosed HIV Infection: 112,000 (92% of infected)
- Cases w/any HIV care during the year*: 90,000 (74% of infected, 81% of PLWDHI)
- Cases w/continuous care during the year**: 74,000 (61% of infected, 66% of PLWDHI)
- Virally suppressed (n.d. or <200 copies/ml) at test closest to end-of-year: 75,000 (62% of infected, 67% of PLWDHI, 83% of cases w/any care)

† Based on most recent address, regardless of where diagnosed. Excludes persons with AIDS with no evidence of care for 5 years and persons with diagnosed HIV (non-AIDS) with no evidence of care for 8 years.
‡ 8% were infected and unaware (CDC estimate)
* Any VL, CD4, genotype test during the year; ** At least 2 tests, at least 91 days apart
The counties that make up the Central NY Region
Cascade of HIV Care: Binghamton Ryan White Region

Persons Residing in the Binghamton Ryan White Region† at End of 2015 (excludes prisoner cases)

- Estimated HIV-Infected Persons‡: 560
- Persons Living w/Diagnosed HIV Infection: 490 (87% of infected)
- Cases w/any HIV care during the year*: 370 (67% of infected, 76% of PLWDHI)
- Cases w/continuous care during the year**: 300 (53% of infected, 61% of PLWDHI)
- Virally suppressed (n.d. or <200 copies/ml) at test closest to end-of-year: 330 (59% of infected, 67% of PLWDHI, 88% of cases w/any care)

†Based on most recent address, regardless of where diagnosed. Excludes persons with AIDS with no evidence of care for 5 years and persons with diagnosed HIV (non-AIDS) with no evidence of care for 8 years.
‡ 13% were infected and unaware (CDC estimate)
* Any VL, CD4, genotype test during the year; ** At least 2 tests, at least 91 days apart

NEW YORK STATE DEPARTMENT OF HEALTH
Cascade of HIV Care: Binghamton Ryan White Region
Persons Residing in the Binghamton Ryan White Region†, at End of 2014 (excludes prisoner cases)

- Estimated HIV Infected Persons: 500
- Persons Living w/ Diagnosed HIV Infection: 500 (87% of infected)
- Cases w/any HIV Care during the year*: 400 (72% of infected, 83% of PLWDHI)
- Cases w/continuous care during the year**: 300 (57% of infected, 66% of PLWDHI)
- Virally suppressed (n.d. or ≤200/ml) at test closest to end-of-year: 300 (62% of infected, 72% of PLWDHI, 87% of cases w/any care)

* Any VL or CD4 test during the year; ** At least 2 tests, at least 3 months apart
†Based on most recent address, regardless of where diagnosed. Excludes persons with AIDS with no evidence of care for 5 years and persons with diagnosed HIV (non-AIDS) with no evidence of care for 8 years.

NEW YORK STATE OF OPPORTUNITY | Department of Health
Cascade of HIV Care: Syracuse Ryan White Region
Persons Residing in the Syracuse Ryan White Region† at End of 2015 (excludes prisoner cases)

- Estimated HIV-Infected Persons‡: 2,490
- Persons Living w/Diagnosed HIV Infection: 2,170 (87% of infected)
- Cases w/any HIV care during the year*: 1,760 (70% of infected, 81% of PLWDHI)
- Cases w/continuous care during the year**: 1,510 (61% of infected, 70% of PLWDHI)
- Virally suppressed (n.d. or <200 copies/ml) at test closest to end-of-year: 1,550 (62% of infected, 71% of PLWDHI, 88% of cases w/any care)

†Based on most recent address, regardless of where diagnosed. Excludes persons with AIDS with no evidence of care for 5 years and persons with diagnosed HIV (non-AIDS) with no evidence of care for 8 years.
‡ 13% were infected and unaware (CDC estimate)
* Any VL, CD4, genotype test during the year; ** At least 2 tests, at least 91 days apart
Cascade of HIV Care: Syracuse Ryan White Region

Persons Residing in the Syracuse Ryan White Region†, at End of 2014 (excludes prisoner cases)

- **Estimated HIV Infected Persons:** 2,400
- **Persons Living w/ Diagnosed HIV Infection:** 2,100 (87% of infected)
- **Cases w/any HIV Care during the year***:** 1,700 (71% of infected, 82% of PLWDH)
- **Cases w/continuous care during the year**:** 1,400 (58% of infected, 66% of PLWDH)
- **Virally suppressed (n.d. or ≤200/ml) at test closest to end-of-year:** 1,500 (63% of infected, 72% of PLWDH, 88% of cases w/any care)

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* Any VL or CD4 test during the year; ** At least 2 tests, at least 3 months apart
†Based on most recent address, regardless of where diagnosed. Excludes persons with AIDS with no evidence of care for 5 years and persons with diagnosed HIV (non-AIDS) with no evidence of care for 8 years.
The Living Cascade
The Living Cascade: Consumer Cascade Journeys

Daniel Tietz, Manager, Consumer Affairs
New York State Department of Health AIDS Institute
Presentation Outline

- Purpose of the cascade
- Build a cascade
- Interpret your cascade
- Setting goals based on your cascade
- Living cascades: The Consumer Experience
The "cascade" is a population-based tool that has been adapted by agencies to show their HIV care outcomes.

OVERALL: Of 1.1 million Americans living with HIV, only 25 percent are virally suppressed.
Purpose of **Organizational HIV Treatment Cascade**

*To show the number of individuals living with HIV infection, the medical care they are receiving, the medical care they need, and the results of that care*

- A visual tool of HIV care and outcome at a point in time
- Monitor the extent and quality of care being delivered to all HIV-positive patients seen at an organization
- Assess key parameters of care for persons living with HIV infection
- Identify gaps in care
- Prompt discussion on steps to improve HIV care outcomes
- Create data-driven plans to assess and improve care through QI activities.
The New HIV Neutral Continuum of Care
Cascade Components
Components of an Effective Cascade

- Information should be:
  - Accurate
  - Consistent
  - Understandable
  - Focused on target audience
  - Reflect usage for QI activities
The Anatomy of an Effective Cascade

A “good” cascade is one that enables organizations to visualize data that are locally relevant, timely, and actionable.
HIV Care Cascade-Patients Linked to Care FY 2016
Southwest Hospital and Clinics

Required: Title specifies patient population being captured (Linked to Care) and year (2016) from which data are drawn
HIV Care Cascade - Patients Linked to Care
FY 2016
Southwest Hospital and Clinics

Axes are clearly labeled.
Legend includes definitions and data sources for all measures featured in the cascade.
Case Load

HIV Care Cascade - Patients Linked to Care
FY 2016
Southwest Hospital and Clinics

- Open: 100%
- Active: 100%
- On ART: 75%
- Virally suppressed: 65%

Case Load Volume is clearly displayed

Newly Diagnosed
HIV Care Cascade-Patients Linked to Care
FY 2016
Southwest Hospital and Clinics

Measures

Newly Diagnosed—All HIV + Patients with any visit in the past 12 months
Linked—Patients who had an HIV medical visit within the required time frame
On ART—Patients prescribed ART in time period
Virally Suppressed—Patients with viral load <200 mL

Measures are presented clearly with easy to read labels.
Numbers

HIV Care Cascade-Patients Linked to Care
FY 2016
Southwest Hospital and Clinics

Newly Diagnosed—All HIV + Patients with any visit in the past 12 months
Linked—Patients who had an HIV medical visit within the required time frame
On ART—Patients prescribed ART in time period
Virally Suppressed—Patients with viral load <200 mL

Proportions and raw figures are presented to specify number of patients impacted by each measure
HIV Care Cascade for Newly Diagnosed
Cascade Measures for Newly Diagnosed

- Number of Patients newly diagnosed with HIV during the measurement year
- Percentage of patients who attended a routine HIV medical visit (within 3 calendar days if linked within and 5 calendar days if linked externally)
- Percentage of patients prescribed ART during measurement year
- Percentage of patients with an HIV viral load less than 200 copies/mL at last HIV viral load test during measurement year

*The measurement year for the initial cascade will be 1/1/2016 through 12/31/2016*
Definition: Number of Patients newly diagnosed with HIV during the measurement year

- **Open**: 100%
- **Active**: 100%
- **On ART**: 75%
- **Virally suppressed**: 65%
- **Undetectable**: 45%

**Newly Diagnosed**
Definition: Percentage of patients who attended a routine HIV medical visit (within 3 calendar days if linked within and 5 calendar days if linked without)

Number of patients who attended a routine medical visit/number of patients who were newly diagnosed
Definition: Percentage of patients newly diagnosed with HIV that were prescribed ART during the measurement year.

Number of patients who were prescribed ART/number of patients who were newly diagnosed.
**Viral Load Suppression**

*Definition:* Percentage of patients who were newly diagnosed with a viral load <200 copies/mL at last viral load testing during the measurement year.

Number of patients with a viral load <200 copies/mL/number of patients who were newly diagnosed.
Building the Cascade for Established Patients

All patients matter—differentiating active and open caseloads

**Open caseload:** HIV+ patients who “touched the facility.”

**Active caseload:** HIV+ patients who received services in the HIV program.

Exclusions: Patients who have died, are incarcerated or who have been confirmed to be in care outside the organization.
**Open Caseload**

*Definition:* Number of patients, regardless of age, with a known diagnosis of HIV who received services anywhere in the organization—whether routine, urgent, or emergent—during the measurement year.
Active Caseload

Definition: Number of patients, regardless of age, with a known diagnosis of HIV who received services in the HIV program of the organization during the measurement year.
Prescription of Antiretroviral Therapy

**Definition:** Percentage of patients from the active caseload that were prescribed ART during the measurement year.

Number of patients that were prescribed ART/Number of patients who were active

<table>
<thead>
<tr>
<th>State</th>
<th>Percentage of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open</td>
<td>100%</td>
</tr>
<tr>
<td>Active</td>
<td>100%</td>
</tr>
<tr>
<td>On ART</td>
<td>75%</td>
</tr>
<tr>
<td>Virally suppressed</td>
<td>65%</td>
</tr>
<tr>
<td>Undetectable</td>
<td>45%</td>
</tr>
</tbody>
</table>
**Viral Load Suppression**

*Definition:* Percentage of patients from the active caseload with a viral load <200 copies/mL at last viral load testing during the measurement year.

*Number of patients with a viral load <200 copies/mL/Number of active patients*
The Living Cascade
The Living Cascade

‘Patient(s) Journey and experiences along the HIV healthcare continuum’

Questions-

• If you improve the steps along the continuum, will there be an increased chance that patients will achieve better sustained health outcomes?

• Each process step along the cascade involves a human interaction. All of the steps together are a journey the consumer takes. Working together, can we improve the consumer journey and help the consumer to arrive at a place of sustained health?

• How can we partner with the community beyond our clinic walls to improve outcomes along the treatment cascade?
Each **Cascade Bar** involves a human interaction.
The Data are made up of real people
How can we help people living with HIV to become engaged in care and to stay healthy?
Analyze Cascade Data & Plan improvement activities based on the Data
What changes can you make to drive improvements?

Driver Diagram
Driver Diagram

• *A driver diagram* is a visual tool to help understand and prioritize factors within a system that drive desired outcomes called the primary outcome.
• Primary drivers are the main factors that drive the primary outcome.
• Secondary factors are subsets of the primary factors, and drive these factors.
• The driver diagram can help you to think strategically about what changes you can make to your current system to achieve your improvement goal.
Driver Diagram Components
Driver Diagram Example: Obtaining Masters Degree

**Primary Outcome**
Attain a Masters Degree

**Primary Drivers**
- Study
- Pay tuition
- Write Thesis
- Complete fieldwork
- Attain all credits

**Secondary Drivers**
- Take notes
- Schedule time to read
- Buy books
- Take out student loan
- Get a part time job
- Research/ talk to the experts
- Develop a theory
- Interview
- Adjust work schedule
- Complete homework
- Pass tests
- Take all classes
Viral Load Suppression

**Primary Drivers**
- Primary Driver: Psycho-Social Support
- Primary Driver: Retention
- Primary Driver: ARV Adherence

**Secondary Drivers**
- Housing
- Substance Use
- Mental Health
- Appointments
- Transportation
- Continuity of care
- Treatment Education
- Health Literacy
- Health Insurance

**Primary Outcome**
To improve and sustain the viral load suppression rate.
Flow Charts

know your flow
Flow Chart

“If you can’t describe what you are doing as a process, you don’t know what you’re doing.”

-W. Edwards Deming
Most Commonly Used Flowchart Symbols

- Activity
- Terminator
- Decision
- Wait symbol

Connecting lines

Page connector
Flow Chart: Is This an Efficient Process?

Patient arrives at front desk → Staff asks name, searches database for file → Patient in system?

- Yes: Staff asks patient to be seated
- No: Staff asks patient to provide information → Patient waits → Nurse takes patient to exam room
## W. Edwards Deming’s System of Profound Knowledge

<table>
<thead>
<tr>
<th>Appreciate the System</th>
<th>Understand Variation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychology</td>
<td>Theory of Knowledge</td>
</tr>
</tbody>
</table>
Method for Change

- What are we trying to accomplish?
- How will we know that a change is an improvement?
- What changes can we make that will result in improvement?

Act

Plan

Study

Do

Model for Improvement
Consumer Cascade Journey

- 100% Gay White Male Diagnosed with Shingles in Emergency Room
- 100% Primary Care Physician (PCP) Orders HIV Test
- 90% Initial visit with Case Manager and HIV Specialist at local Designated AIDS Center
- 85% Patient begins AZT regimen in 1988
- 75% Patient begins taking first generation Protease Inhibitor in 1997
- 65% 1996: Patient CD4 <100 and Viral Load > 1,000,000 copies/ml
- 45% 1997: Viral Suppressed & Undetectable

April 1987: PCP informs patient that he is HIV+ (via telephone call while at work)
Patient informs parents of diagnosis who researched local HIV specialist and scheduled initial medical visit
Patient Attends local HIV+ Gay MSM support groups

1991: Patient begins professional career with New York State Department of Health AIDS Institute
Patient begins taking first generation Protease Inhibitor in 1997
1996: Patient CD4 <100 and Viral Load > 1,000,000 copies/ml
1997: Viral Suppressed & Undetectable

Durable Viral Load Suppression & Undetectable
Conclusion

• Working together, we can all make a difference, improving supportive processes, and helping consumers to become virally suppressed, maintain health and play an important part in ending the epidemic by 2020.
Further Discussion
Thank you!
For further information, please contact us at...

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Dan Tietz  
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What’s in a Name?

**Vision**—A picture of a preferred future—the dream

**Mission**—Overall purpose—What are we doing, why, and for who

**Strategies**—Broad steps to be taken

**Goals**—Expected or desired outcomes

**Objectives**—Detailed statements of measurable results we hope to accomplish

**Action Steps**—Very specific details tied to people, dates, resources, and processes
Applied to HIV

Vision—NY State without HIV
Mission—To end the epidemic by 2020
Strategies—The blueprint
Goals—Everyone virally suppressed, everyone linked to care, everyone on ART. (By December 31, 2017, the Central NY Region will achieve a 90% linkage to care rate for those newly diagnosed)
Objectives—By June 30, 2017 all clinical organizations will agree to provide a medical visit <3 days to any individual newly identified as HIV Positive. All testing organizations will agree to do a warm handoff <24 hours to the clinical organization the newly diagnosed individual has chosen. Progress will be reviewed at the September Warm Handoff Meeting
Action Steps—By May 1, the network chair will convene a meeting at SUNY Upstate to.....
Let’s be SMART about this

Specific (simple, sensible, significant)
Measurable (meaningful, motivating)
Achievable (agreed, attainable, actionable)
Relevant (reasonable, realistic)
Time Bound (time-based, time limited, timely)
Visceral Racing will have great pit stops at Road America
Visceral Racing will have great pit stops at Road America

Visceral Racing will complete all work at every pit stop at Road America in under five minutes
Visceral Racing will have great pit stops at Road America

Visceral Racing will complete all work at every pit stop at Road America in under five minutes

Visceral Racing, during pit stops at the Road America Race will fill the car with gas, change drivers, check tire pressures, check oil, clean windshield, and visually check the car in under five minutes
Visceral Racing will have great pit stops at Road America.

Visceral Racing will complete all work at every pit stop at Road America in under five minutes.

Visceral Racing, during pit stops at the Road America Race will fill the car with gas, change drivers, check tire pressures, check oil, clean windshield, and visually check the car in under five minutes.

Visceral Racing, during each pit stop at the Road America Race on 4/21-22, will fully fill the car with gas, change drivers, check and adjust tire pressures, check and fill oil if needed, clean windshield, and visually check the car so it can be at pit out in under five minutes.
Your Mission

1. Following this slide will be an organizational cascade
2. Using that cascade, identify two opportunities where improvement could happen
3. For each of those opportunities write an improvement plan as a SMART goal

Specific, Measurable, Achievable, Relevant, Time Bound
Anonymous Health Center, Fictitious, NY

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open Cases (anyone HIV+ seen at org)</td>
<td>100%</td>
<td>333</td>
</tr>
<tr>
<td>Active Cases (HIV+ people seen at clinic)</td>
<td>50%</td>
<td>165</td>
</tr>
<tr>
<td>On ART</td>
<td>74%</td>
<td>122</td>
</tr>
<tr>
<td>Virally Suppressed &lt;200</td>
<td>74%</td>
<td>90</td>
</tr>
</tbody>
</table>
SMART Sharing
QOC/Cascade Building Questions
Welcome to NY Links

NY Links focuses on improving linkage to care and retention in care and supports the delivery of routine, timely, and effective care for persons living with HIV/AIDS (PLWHA) in New York State. We also bridge systemic gaps between HIV related services in order to achieve better outcomes for PLWHA through improving systems for monitoring, recording, and accessing information about HIV care in NYS. We use a regional approach, utilizing 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 was created through a HRSA HIV/AIDS Bureau (HAB) sponsored Special Projects of National Significance (SPNS). Since September of 2015 it is under the Governor’s Ending the Epidemic Initiative through the NYSDOH AIDS Institute.

+ New York Links Ryan White Conference Presentations

+ New York Links Poster Presentations at the National Ryan White HIV/AIDS Conference

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 the AIDS epidemic in New York State. The goal is to reduce the number of new HIV infections to just 750 (from an estimated 3,000) by 2020 and achieve the first ever decrease in HIV prevalence in New York State.

The three-point plan:

1. Identifies persons with HIV who remain undiagnosed and link them to health care.

2. Links and retains persons diagnosed with HIV in health care to maximize virus suppression so they remain healthy and prevent further transmission.

3. Facilitates access to Pre-Exposure Prophylaxis (PrEP) for high-risk persons to keep them HIV negative.

Ending the Epidemic (ETE) in New York State will maximize the availability of life-saving, transmission-interrupting treatment for HIV, saving lives and improving the health of New Yorkers. It will move New York from a history of being the most HIV affected in the nation to a future where our infections are
I want to hear from you!

• Interested in hosting a CNY NYLinks meeting in your area?
• Suggestions on future meeting topics?
• Need technical assistance on Quality Improvement?

Laura O’Shea
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315-477-8124
WHAT’S COMING UP?

April 19th, Brooklyn Regional NYLinks meeting

April 19th, Central New York NYLinks meeting

May 12th, Bronx Regional NYLinks meeting

May 19th, Suffolk County Sub-Regional NYLinks meeting (with ETE)

May 25th, McPEtE Collective Meeting

June ??, Long Island NYLinks meeting
Contact Information

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• Blog at http://linkandretain.wordpress.com/
• Website at http://www.newyorklinks.org