CNY NYLinks Group Meeting

January 24, 2018
The Atrium at City Hall Commons
Laura O’Shea, Project Coordinator
Office of the Medical Director- AIDS Institute
Parking lot back of room-questions/concerns/topics that the group can work to address at the end of the meeting.

Lunch

Restrooms
Introductions:

• Name
• Organization
Meeting Outcomes

• Understand Quality Improvement and its’ role in Ending the Epidemic.

• Use this time together to think of the BIG regional picture through several QI activities- *Word Associations* and *Building the Perfect System* to build on our work with the Force Field Analysis

• Use our discussion to develop an agenda for our next CNY NYLINKS meeting.
NYLinks Background
NYLinks

Started September 2011 (HRSA SPNS Project)
11 regions across New York State
261 organizations involved
2,449 distinct individuals involved
89 regional meetings held
11 coaches
5 Interventions developed and disseminated
45 webinars held for 1,849 people
30 blog posts
2,976 visitors in 2016 to the NYLinks Website
In 2016 53,000 patients positively impacted
NYLinks 2017 Review

• 31 regional meetings (13 with ETE and 2 with the HIV Care Network, and 1 with ETE and Knows)
• 2 posters on NYLinks work was presented at the International Association of Providers of AIDS Care (IAPAC) Conference in Miami.
• 2 articles accepted for publication
• 2 presentations at the ETE Summit Meeting which was part of World AIDS Day Activities in Albany this past December.
• The NYLinks team received a Commissioner’s Excellent Award for the work done in 2016.
• 2,445 distinct individuals visited our web page (which is full of information by the way!)
  • There were visitors from 61 different countries and there were 10,768 page views.
Quality Improvement- Why is it important?

Quality Improvement consists of **systematic and continuous actions** that lead **to measurable improvement in health care services and the health status** of targeted patient groups.

If you cannot measure it…
You cannot improve it.
Linking QI with Public Health Outcomes

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

• Start small
• Theory of “1”
• Plan Do Study Act

Start with an idea...

Small continuous improvement - make adjustments as needed
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.
Consumer Involvement

• Consumer involvement in QI is an essential element for HIV QM programs in NYS, helping programs to achieve sustainable health outcomes.

• It is an expectation of all HIV providers, defined explicitly in the QOC Standards, and assessed in the organizational assessment of HIV QM programs.

• The QOC Program offers the following consumer involvement capacity building activities:
  • Training Consumers in Quality (TCQ)
  • Training Consumers in Quality Training-of-Trainer Program (TCQPlus)
  • Consumer Quality Training Academy
  • Health Care Stories Project
  • The Living Cascade
Club Zero- Upstate Medical Immune Health Services
Newly Released Call to action...
Dear Colleague,

Our collective effort to end the AIDS epidemic (ETE) by the end of 2020 is at a critical juncture. As we enter 2018, we have reached the mid-point of our six-year plan. We can celebrate the fact that we have clear evidence of a significant reduction in new HIV diagnoses. This has allowed us to see the first ever "bending of the curve" toward ending of the epidemic. However, we need to redouble our efforts in order to reach our historic goals of:

1. Fewer than 750 incident cases per year by the end of 2020;
2. Elimination of drug-related mortality;
3. Expanded access to HIV prevention and treatment for youth; and,
4. Sustaining the elimination of mother-to-child transmission of HIV.

The End the Epidemic Summit No Population Left Behind, held in Albany on December 5-6, 2017 was a great success, with significant focus on how we can roll out Undetectable=Untransmittable (U=U) messaging as a powerful tool in our support of efforts to end the epidemic. Your feedback on U=U messaging is greatly appreciated, whether you "voted" on examples of messages during the Summit, took part in recent stakeholder calls or were one of over 600 people to complete the AIDS Institute on-line U=U Messaging Survey.

An archive of the ETE Summit plenary sessions on December 6th is available for viewing. During the closing session, I issued a three-point charge which I am disseminating widely through this letter. I am asking all grant-funded programs, clinical programs, health care providers, stakeholders and community partners to take concrete steps to implement this three-point charge and use data, program evaluation and quality improvement strategies to monitor and improve your progress. The three items outlined below represent critical elements that we must all embrace if we are to reach our ETE goals.

1. Facilitate Rapid Access to HIV Treatment with Patient Consent

A critical ETE metric is the duration of time from HIV diagnosis to linkage to care and initiation of treatment. Our data on linkage to care shows that we did not meet our target metric in 2016, the latest year for which data are available. This is especially concerning given that we have seen successful pilots of RapidTX and QuickVHIV and we fully understand that early initiation of treatment with patient consent helps improve health outcomes and prevent HIV transmission. The latest New York State HIV clinical guidelines identify initial ART regimens using one pill once a day, meaning this: HIV treatment is effective, has few or no side effects and is relatively easy to take. I am urging that, at the local level, HIV testing providers, clinical care providers, linkage/engagement/navigators, laboratories, and pharmacies establish systems which strive for the gold standard of same day initiation of HIV treatment with patient consent, even while initial lab work is pending. While same day initiation of treatment may not always be possible, in no case should that day allow minors to enrolment. This removes a critical barrier to care, improving quality, driving progress, and enhancing health access and outcomes. The AIDS Institute supports this initiative and encourages all providers to take advantage of this opportunity.

2. Minimize barriers to HIV care

There is no question that the long-standing stigma, gender identity, and gender expression of care barriers are major challenges. The AIDS Institute is working with carriers to address stigma around HIV and to improve access and outcomes. The NYS DHSS HIV/AIDS LTC facilitators and individuals to care services and The bottom line is this: a focus on every provider who is in treatment with patient retention.

3. Progress

The three-point charge eliminates the possibility to transmit HIV to a person. Quality of care cascades of care.

In 2017, we saw significant progress in care, including:

- Expansion of care, including services that provide access to care, including:
- New York City Department of Health, who can help individuals and families to the fullest extent possible, regardless of gender identity.
- Eligible providers can learn and share their experiences and how to best support individuals to consent to the full continuum of care.

The first state health consensus statement on important steps forward in treatment effectiveness at the 2018 ETE Summit.

4. Prevention

In 2017, we also saw the importance of HIV treatment among individuals from transgender and other marginalized communities. This valuable forum, which is dedicated to addressing long standing issues of the HIV Advisory Body, which I believe reflects.

These recommendations for care, prevention, testing and with your board, executive adopting them.
Three Critical Elements

• Facilitate Rapid Access to HIV Treatment with Patient Consent

• Establish Goals Regarding Viral Suppression Rates and Monitor Progress

• Take Steps to Eliminate the Long-Standing Problem of Stigma
New York State Department of Health AIDS Institute
Recommendations for Improving Language and Establishing Stigma-Free,
Supportive, Service Delivery Environments
January, 2018

- Use person-first language: Use phrases such as "person living with HIV" or "person who uses drugs" and avoid using phrases such as "person infected with HIV," "carrier," "addict," "positives," "injection drug user" or "IDU.

- Use identity-affirming language on public facing documents, websites, etc. Engage consumer advocacy boards or focus groups to help change language used on the agency website, consumer education documents, social media posts and other public communications. Based on this input, use identity-affirming language. For example, refer to men who identify as gay as such, rather than using the term MSM. Be sensitive to guidance from people of transgender experience and people who are gender non-conforming regarding use of gender-based pronouns.

- Establish a welcoming environment: Prominently display "Safe Space" posters and ensure that other posters and artwork displayed is inclusive of all communities served. Since front desk and security staff are often the first people to interact with individuals served, ensure that there are policies and training in place to prepare these important members of the team to demonstrate the agency’s commitment to providing stigma-free services. Ensure that the physical environment of your agency is perceived as safe, welcoming and inclusive.

- Recognize the value of staff being representative of the communities served, including people who are living with HIV: Ensuring that agency staff are representative of the communities being served is a long-standing value of the AIDS Institute and an important step in promoting stigma-free services.

- Provide staff training and address stigma during new staff orientation and supervision: All staff, regardless of their positions, should be provided training on cultural competency and providing stigma-free, affirming services. It is important that all staff be trained on agency expectations, policies and procedures for addressing stigma, including prompt training for new hires. Staff performance around provision of stigma-free services should be addressed as part of staff supervision/performance evaluation.

- Build staff skills to dialogue with clients/patients about language: There is no one-size-fits-all approach to communicating with individuals served in an affirming manner. Language evolves with culture, and people are individuals with distinct feelings and preferences. Staff should be trained on the communication skills needed to: 1) ask individuals served about their preferences regarding language, including acceptable pronouns, 2) demonstrate openness to hearing feedback about these preferences, and 3) adopt verbal and nonverbal communication in a manner that is affirming to each individual client.

- Be on the alert for judgmental language: Referring to substance use treatment as "getting clean" implies that using substances is somehow "dirty." Using terms such as "infectious" also promotes stigma. Attention to the impact of language will bring awareness to words and phrases that promote stigma. Evaluate and assess alternative words and phrases that will serve to create a more affirming environment.

- Establish policies and procedures to provide services to individuals in their preferred language: Agencies should establish and follow a Language Access Plan (LAP) to address the language needs of the individuals being served. The LAP should address all legal requirements that your agency may be subject to, based on agency type, affiliation and services delivered.

- Be prepared to address the needs of people with disabilities: Agencies should be prepared to meet their responsibilities under the Americans With Disabilities Act. Based on agency type, size and other factors, this may include providing wheelchair access, American Sign Language interpreters, auxiliary aids and other accommodations to enable reasonable access for all to the full range of agency programs and services.

- Use quality improvement to dismantle stigma: Conduct quality improvement activities that engage people from all levels of the organization to improve how your agency demonstrates to individuals that it provides stigma-free, affirming services.

- Promote ongoing discussions regarding stigma: Engage staff, consumers, board members and community members in ongoing discussions about providing stigma-free services. Discussions can focus on how to identify stigma, how to be an effective ally, and how well the agency is meeting its goal of providing stigma-free services.

- Document agency policies, practices and progress toward eliminating stigma: Steps to address stigma should be included in the agency’s formal policies and procedures. This is critical to ensuring agency-wide acceptance and full-scale implementation of these efforts. Documenting agency policies and tracking progress toward eliminating stigma will help ensure accountability over time, even if there are changes in agency staff, managers or leadership.
Progress towards EtE in 2020

• Surveillance Data

• ETE Dashboard  http://etedashboardny.org

• Facility level cascade development and sharing with regional partners
  **Etedashboardny.org has posted the methodologies and facility cascades**
### Ending the Epidemic Metrics

<table>
<thead>
<tr>
<th>Category</th>
<th>Metric Description</th>
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<tbody>
<tr>
<td>New HIV Diagnoses</td>
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<tr>
<td>Concurrent AIDS Diagnosis</td>
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<tr>
<td>Receive Any Care</td>
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<tr>
<td>HIV Status Aware</td>
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<tr>
<td>New HIV Infections</td>
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<tr>
<td>Viral Suppression – All Diagnosed</td>
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<tr>
<td>Time to AIDS</td>
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<tr>
<td>Linkage to HIV Medical Care</td>
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<tr>
<td>Viral Suppression – with Any Care</td>
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</table>
By the end of 2020, reduce the number of new HIV diagnoses by 55%.

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<tr>
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<td>3,443</td>
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<td>2,911</td>
<td>2,881</td>
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<tr>
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<td>2,620</td>
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<tr>
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<td>2,253</td>
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</tr>
<tr>
<td>2019</td>
<td>1,870</td>
<td>*</td>
</tr>
<tr>
<td>2020</td>
<td>1,515</td>
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</table>

Measure: Number of newly diagnosed HIV cases reported.

HIV Status Aware

Increase the percentage of people living with HIV who know their serostatus to at least 98%.

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<th>Year</th>
<th>Target</th>
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<tbody>
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<td>92%</td>
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<td>2017</td>
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<tr>
<td><strong>2020</strong></td>
<td><strong>98%</strong></td>
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EXPECT THE TEST
This health care facility follows good medical practice and public health law by offering HIV testing to all patients aged 13 and older.

HERE’S WHAT YOU NEED TO KNOW ABOUT HIV TESTING

- HIV testing is voluntary and all HIV test results are confidential (private).
- HIV can be spread through unprotected sex, sharing needles, childbirth, or breastfeeding.
- Treatment for HIV is effective, has few or no side effects, and may involve taking just one pill a day.
- Partners can keep each other safe by knowing their HIV status and getting HIV treatment or taking HIV pre-exposure prophylaxis (PrEP). Not sharing needles and practicing safer sex will help protect against HIV, hepatitis C and other STDs.
- It is illegal to discriminate against a person because of their HIV status.
- Anonymous HIV testing (without giving your name) is available at certain public testing sites.
- HIV testing is a routine part of health care but you have the right to object or decline an HIV test.
- If you wish to decline HIV testing, inform the health care provider.

Talk to your health care provider about how and when you will learn your HIV results.
Worst HIV status: unknown. Testing puts you in control. HIVtestNY.org
Time to AIDS

By the end of 2020, reduce the rate at which persons newly diagnosed with HIV progress to AIDS by 50%.

<table>
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<th>Target</th>
<th>Actual</th>
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<tr>
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<td>*</td>
<td>10.4%</td>
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<tr>
<td>2013</td>
<td>*</td>
<td>6.8%</td>
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<tr>
<td><strong>2014</strong></td>
<td><strong>8.9%</strong></td>
<td><strong>7.1%</strong></td>
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<tr>
<td>2015</td>
<td>8.2%</td>
<td>*</td>
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<tr>
<td>2016</td>
<td>7.6%</td>
<td>*</td>
</tr>
<tr>
<td>2017</td>
<td>7.0%</td>
<td>*</td>
</tr>
<tr>
<td>2018</td>
<td>6.4%</td>
<td>*</td>
</tr>
<tr>
<td>2019</td>
<td>5.8%</td>
<td>*</td>
</tr>
<tr>
<td><strong>2020</strong></td>
<td><strong>5.1%</strong></td>
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</table>


* Two year lag built into indicator definition.
By the end of 2020, increase the percentage of individuals living with diagnosed HIV infection with suppressed viral load to 85%.

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<th>Year</th>
<th>Target</th>
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<tbody>
<tr>
<td>2013</td>
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<td>66%</td>
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<td>2014</td>
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<td>68%</td>
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<tr>
<td>2015</td>
<td>*</td>
<td>67%</td>
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<tr>
<td>2016</td>
<td>73%</td>
<td>70%</td>
</tr>
<tr>
<td>2017</td>
<td>76%</td>
<td>*</td>
</tr>
<tr>
<td>2018</td>
<td>79%</td>
<td>*</td>
</tr>
<tr>
<td>2019</td>
<td>82%</td>
<td>*</td>
</tr>
<tr>
<td>2020</td>
<td>85%</td>
<td>*</td>
</tr>
</tbody>
</table>

Measure: Last VL test in calendar year is non detectable or <200 copies/ml in NYSDOH HIV Surveillance system.

## Concurrent AIDS Diagnosis

By the end of 2020, reduce the proportion of persons with a diagnosis of AIDS within 30 days of HIV diagnosis to 15%.

<table>
<thead>
<tr>
<th>Year</th>
<th>Target</th>
<th>Actual</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>2013</td>
<td>*</td>
<td>736</td>
</tr>
<tr>
<td>2014</td>
<td>*</td>
<td>674</td>
</tr>
<tr>
<td>2015</td>
<td>*</td>
<td>612</td>
</tr>
<tr>
<td>2016</td>
<td>536</td>
<td>18.4</td>
</tr>
<tr>
<td>2017</td>
<td>461</td>
<td>17.6</td>
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<td>2018</td>
<td>376</td>
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<tr>
<td>2019</td>
<td>295</td>
<td>15.8</td>
</tr>
<tr>
<td>2020</td>
<td>225</td>
<td>15.0</td>
</tr>
</tbody>
</table>

**2016**

**Target | 536 (18.4%)**  
**Actual | 541 (18.8%)**


Measure: CD4 <200 (Stage 3 HIV) w/ in 30 days of dx.
New HIV Infections (Incidence)

By the end of 2020, reduce the number of new HIV infections to 750.

<table>
<thead>
<tr>
<th>Year</th>
<th>Target</th>
<th>Actual</th>
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<tbody>
<tr>
<td>2013</td>
<td>*</td>
<td>2,509</td>
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<tr>
<td>2014</td>
<td>*</td>
<td>2,497</td>
</tr>
<tr>
<td>2015</td>
<td>*</td>
<td>2,436</td>
</tr>
<tr>
<td>2016</td>
<td>2,050</td>
<td>2,115</td>
</tr>
<tr>
<td>2017</td>
<td>1,750</td>
<td>*</td>
</tr>
<tr>
<td>2018</td>
<td>1,410</td>
<td>*</td>
</tr>
<tr>
<td>2019</td>
<td>1,060</td>
<td>*</td>
</tr>
<tr>
<td>2020</td>
<td>750</td>
<td>*</td>
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</tbody>
</table>

2016
Target | 2,050
Actual | 2,115

Measure: Incidence estimates are calculated using CDC statistical methods.

Linkage to Care After Diagnosis

By the end of 2020, increase the percentage of newly diagnosed persons linked to HIV medical care within 30 days of diagnosis to at least 90%

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<tr>
<th>Year</th>
<th>Target</th>
<th>Actual</th>
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<tbody>
<tr>
<td>2013</td>
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<td>69%</td>
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<tr>
<td>2014</td>
<td>*</td>
<td>72%</td>
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<tr>
<td>2015</td>
<td>*</td>
<td>73%</td>
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<tr>
<td>2016</td>
<td>78%</td>
<td>75%</td>
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<td>2017</td>
<td>81%</td>
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<tr>
<td>2018</td>
<td>84%</td>
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<tr>
<td>2019</td>
<td>87%</td>
<td>*</td>
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<tr>
<td>2020</td>
<td>90%</td>
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Measure: Any CD4, VL or genotype test in NYSDOH HIV Surveillance system.

Receiving Any Care

By the end of 2020, increase the percentage of persons living with diagnosed HIV infection who receive any care to 90%.

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<tr>
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<td>2013</td>
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<td>2016</td>
<td>84%</td>
<td>80%</td>
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<tr>
<td>2017</td>
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<tr>
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<td>2019</td>
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<td>2020</td>
<td>90%</td>
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Measure: Any VL, CD4 or genotype test in NYSDOH HIV Surveillance system in calendar year.
**Viral Suppression - PLWDHI**

By the end of 2020, increase the percentage of individuals living with diagnosed HIV infection with suppressed viral load to 85%.

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<td>2013</td>
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<td>2019</td>
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<tr>
<td><strong>2020</strong></td>
<td>85%</td>
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**2016**

**Target | 73%**  
**Actual | 70%**

**Measure:** Last VL test in calendar year is non detectable or <200 copies/ml in NYSDOH HIV Surveillance system.

By the end of 2020, increase the percentage of individuals living with diagnosed HIV infection and receiving any care with suppressed viral load to 95%.

<table>
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<tr>
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<td>2013</td>
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<td>81%</td>
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<tr>
<td>2020</td>
<td>95%</td>
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</table>


Measure: Last VL test in calendar year is non detectable or <200 copies/ml in NYSDOH HIV Surveillance system.
Make the Connection - Developing Fresh Perspectives
Word Connections
Common words used in outlined strategies

- Education
- Resources
- Training
- Navigation
- Collaboration
- Support
- Engaged
- Options
- Awareness
- Networking
- Conversation
- Advocacy
- Transportation
- Access
- Improvement
What did we learn from this activity?
Support Services Program Enrollment at ACR Health Update - CNY HIV Care Network
Force Field Analysis - Kurt Lewin
A Culture is not a painted picture; it is a living process, composed of countless social interactions... The culture pattern of a people at a given time is maintained by a balance of counteracting forces.

– K. Lewin, Social psychologist late 1800’s
Force Field Analysis - Kurt Lewin

Driving Forces

Desired State

Restraining Forces
The Process....

• Define the change you want to see
• Brainstorm the Driving Forces (Those that favor change)
• Brainstorm the Restraining Forces (Those that oppose change)
• Evaluate The forces on a scale of 1(weak)-5(strong) give rating OR you can leave the numbers out and focus holistically on the impact each has.
Locating out of care patients and linking them to care

- Healthier life (readiness)
- Family, friends, loved ones (support system)
- Becoming informed about resources
- Having education (around HIV, stigma and barriers)
- Healthy relationships
- Self-care (readiness)
- Having support team through agencies
- Starting medication
- Maintaining healthy peer support
- Disclosure-linkage of partner to PrEP to reduce transmission
- Transportation

- Locating patient’s stigma
- Fear anxiety
- Confidentiality
- Lack of transportation
- Lack of insurance
- Mental health
- Substance use
- Housing
- Family/Daycare
- Don’t like taking medications
- Cultural diversity
- Avoiding acceptance of status
- Not knowing resources
- No social support
- Insurance
- Resistance to change
- Language barriers
- Health literacy

Strategies
- Being solution based by addressing barriers
- Outreach and peer navigators
- Client focused-client centered
- Education
- Advocacy
- Resources
- Support meetings
- navigation
- Bus passes/star/MA Transportation
- Testing vs calling
- Partners program
- Local case management agency
- Staff trainings
### Driving Forces
Positive Forces for Change
- Taking ARV as Prescribed
- Healthy Lifestyle
- Stable Living Environment
- Positive Behavioral Health
- Having Insurance
- Social support system
- Access to medication
- Transportation
- Desire to not transmit (U=U)
- Good relationship with health care provider
- Failing Health
- Desire to live longer
- Support
- Ability to be present for family
- Fear of Death
- Ensure partners health

### Restrainting Forces
Obstacles to Change
- Depression/Mental Health
- Stigma/fear
- Getting scoffed
- Misinformation/uninformed
- Other life issues
- Lack of transportation
- Lack of insurance
- Not knowing status
- Other chronic issues
- Health literacy
- Embarrassment/stigma/discrimination
- Substance Use/mental health issues
- Homelessness
- Financial barriers
- Accessibility to treatment
- Not having support
- Negative relationship with healthcare
- Treatment fatigue
- Side effects of drugs

### Increasing Viral Load Suppression rates among patients already in care

### Strategies
- Continued community collaborations
- Improve the support system
- Universal healthcare/Insurance Reform
- Stigma lowering education
- More caring and engaged staff and providers
- Having support/more options
- Funding
- Have a connection with behavioral health services
- Improve access to transportation
- More awareness of services
- Networking with providers
- Case management/peer support
- Education in School
- Improving patient centered care
- Expand access to SU Treatment
- Family support
- Keep conversation in media
Designing the Perfect System
Each Team will designate a recorder to draw a process flow map for each step in the cascade

- Teams review the current process steps for linkage, engagement/retention, and viral load suppression, drawing a process flow map for each of these areas.
- Each team identifies ways that these processes can be improved, streamlined or strengthened by eliminating unnecessary steps, adding steps or improving steps.
- Put the improved processes together into a single process flow that begins with testing and culminates with suppression.
- Goals for each step should be linkage to care within 3 days, ART initiation at that visit, people engaged in care as evidenced by 1 visit within 12 months, people are virally suppressed
OR

• Using their current knowledge, teams create from scratch a perfect system of steps for linkage, engagement/retention, and viral load suppression, drawing a process flow map for each of these areas.
• Each team identifies each step of the process, using as many steps as necessary.
• Create a single process flow that begins with testing and culminates with suppression.
• Goals for each step should be linkage to care within 3 days of new diagnosis with ARV initiation at that visit, people engaged in care as evidenced by 1 visit within 12 months, people are virally suppressed.
Presentations From Last Meeting...
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The AIDS LAW PROJECT

LEGAL AID PROVIDED BY LEGAL SERVICES OF CENTRAL NEW YORK
Family Stabilization support services PROVIDED by ACR Health
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Important Follow- Up and Dates

• Periodic Peer Exchange and Coaching webinars
• Third Stigma Submission: Due **January 31st**
• Stay Tuned:
  Guidance for 2017 Quality of Care Review- First week in February; disparity data with Care Cascades.
  Final NYS QM Plan, Program Standards
• Training offerings- TCQ?
Next Meeting - April

• What kind of topics do you want to address?
• Sharing of 2017 cascades and QI Plans
• Agency approaches to call to action on the three critical elements
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