CNY Regional Group (CNYRG) Kick-Off Meeting

November 16, 2015
Welcome & Opening Remarks

- Dr. Indu Gupta, Onondaga County HD
- Ginger Hall, Jefferson County HD
- Claudia Edwards, Broome County HD
- Steve Sawicki, NY Links Director
- Howard Lavigne, CNYRG Lead
Agenda

- Welcome & Charge for the Day
- Introductions
- Ending the Epidemic by 2020
- Building a System to Link & Retain Patients – Regional Service Map Exercise
- Working Lunch – Building Collaborative Relationships
Agenda (Cont.)

- What is NY Links?
- Epidemiology Data & CNY
- Afternoon Activity
- Break
- Consumers & QI
- AI Initiatives: LRTA, RAP & ExPS
- Wrap-Up:
  - Next Steps
  - Evaluation
Central New York Regional meeting
Ending the HIV Epidemic

Indu Gupta, MD, MPH, MA, FACP
Commissioner of Health
November 16, 2015
National Statistics

- > 1.2 million people in the United States are living with HIV infection.
- Almost 1 in 8 (12.8%) do not know of their infection, a significant public health concern.
- Gay, bisexual, and other men who have sex with men (MSM)
- Blacks/African Americans face the most severe burden of HIV.
- About 50,000 new HIV infections per year.
NYS Statistics

- The number of new cases in NYS has significantly decreased from 14,000 in 1993 to 3000 in 2014.
- Goal is to further decrease to 750 by 2020
Onondaga County

- In Onondaga County, the rate of new HIV infections has increased from 8 per 100,000 in 2008-2010 to 9 per 100,000 in 2010-2012.

- Below NYS Prevention Agenda of 14.7/100,000,

- Significant racial disparity exists in new HIV diagnoses. From 2010-2012 the difference in case rates between black and white populations was 32.1.
Difference in Rates of New HIV Diagnosis (Black and White)

Data Source: Bureau of HIV/AIDS Epidemiology data as of January 2014

NYSDOH: Prevention Agenda

WORSENED

SIGNIFICANTLY
Other Public health concerns

Additional areas of concerns for new HIV infections should address following areas-

- Rising rates of syphilis and other STD
- Rising rates of heroin abuse- with IV use
- Problem of untreated mental health
- Poverty, homelessness
Syphilis Case Rate per 100,000 Men, 2008-2014*

Onondaga County

*Preliminary data; 2014 data not available for NYS
Source: NYSDOH, CDESS
Gonorrhea Case Rate per 100,000 Women (Aged 15-44 yrs)

Data Source: NYS STD Surveillance System data as of January 2015

NYSDOH: Prevention Agenda
THOUGH REMAINS HIGH

IMPROVING
Gonorrhea Case Rate per 100,000 men-
(Aged 15-44 yrs)

Data Source: NYS STD Surveillance System data as of January 2015

NYSDOH: Prevention Agenda
THOUGH REMAINS HIGH

IMPROVING
Chlamydia Case Rate per 100,000 Women (Aged 15-44 yrs)

Data Source: NYS STD Surveillance System data as of January 2015

NYSDOH: Prevention Agenda
THOUGH REMAINS HIGH

IMPROVING
Heroin deaths, Onondaga County, 2010-2014

Source: OCHD Medical Examiner's Office
Heroin mortality rates by sex, Onondaga County, 2010-2014
Regional Approach is Important

These basic facts could be used as an important tool by all of us as we start to strategically align ourselves with our neighboring counties and community partners- who may be already working to address one or more of these issues.
Efforts to Curb the Epidemic

- The first prong: Know the HIV status.
- Encourage everyone in to test for HIV. Rapid HIV test being implemented in OCHD
- OCHD’s STD Center, ACR Health, NYSDOH CNY Regional office, Syracuse Community Health Center, Family planning, Planned Parenthood, Prompt care, emergency rooms
- Primary care provider: A very important role
Efforts to Curb the Epidemic

- **The second prong**: Link and retain people diagnosed with HIV to health care.
- **OCHD**: Re-links people living with infection to a health care provider so that they can get timely treatment and remain healthy and thus prevents further transmission.
- A step in breaking the chain of transmission.
Efforts to Curb the Epidemic

- **Third Prong:** Pre-Exposure Prophylaxis (PreP)
- OCHD refers to Upstate Immune Health Services to refer patient who would benefit from receiving Pre-Exposure Prophylaxis or PrEP.
- OCHD will be initiating such effort early next year
Collaborative Approach of NYLinks

- Local
- Regional
- State
Standardized Practices

- Standard measure will be applied to all the sites/organizations
- Guidance regarding all the measures - whether

  (1) Linkage,
  (2) Retention of new or established patients in clinical care
  (3) Clinical engagement: all supportive Svcs- case management and coordination, substance use, mental health, treatment, Food, nutrition etc
  (4) Viral load Suppression
Benefits of Joint Approach of NYLinks

- Monitor the progress and impact of regional efforts to improve linkage to and retention in HIV clinical care.
- All participating organizations would collect data and report aggregate results through the data reporting @ newyorklinks.org quarterly.
- Data should capture all with the diagnosis of HIV/AIDS, irrespective of age or funding sources.
- These data will help in setting regional priorities and also our improvement efforts.
Thank You!
Jefferson County

November 16, 2015
Jefferson County
Jefferson County

- Population: 116,229
- Rural county
- Adjacent to Lake Ontario and southeast from the Canadian border of Ontario
- Fort Drum-home of the 10th Mountain Division- unique in that the base does not have a hospital or school on the base- integrated within the community
### Jefferson County

<table>
<thead>
<tr>
<th></th>
<th>LIVING HIV (not AIDS) Cases</th>
<th>LIVING AIDS CASES</th>
<th>LIVING HIV AND AIDS CASES</th>
<th>Area population</th>
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</thead>
<tbody>
<tr>
<td>As of Dec 2013</td>
<td>Number COL% Prevalence Rate</td>
<td>Number COL% Prevalence Rate</td>
<td>Number COL% Prevalence Rate</td>
<td></td>
</tr>
<tr>
<td>Total NY excluding NYC</td>
<td>11,758 100.0 104.0</td>
<td>16,418 100.0 139.9</td>
<td>28,176 100.0 243.9</td>
<td>11,245,290</td>
</tr>
<tr>
<td>Sex at birth Male</td>
<td>8,150 69.3 145.4</td>
<td>11,765 71.7 203.5</td>
<td>19,915 70.7 348.9</td>
<td>5,625,820</td>
</tr>
<tr>
<td></td>
<td>3,608 30.7 63.6</td>
<td>4,653 28.3 79.0</td>
<td>8,261 29.3 142.6</td>
<td>5,719,470</td>
</tr>
<tr>
<td>Total Jefferson</td>
<td>33 100.0 27.6</td>
<td>54 100.0 45.2</td>
<td>87 100.0 72.8</td>
<td>119,504</td>
</tr>
<tr>
<td>Sex at birth Male</td>
<td>19 57.6 -</td>
<td>34 63.0 -</td>
<td>53 60.9 -</td>
<td></td>
</tr>
<tr>
<td></td>
<td>14 42.4 -</td>
<td>20 37.0 -</td>
<td>34 39.1 -</td>
<td></td>
</tr>
</tbody>
</table>

Source BHAENYS DOH, 2015
Jefferson County

- Jefferson County Public Health Service
  - Provides a 3 hour STD clinic weekly

<table>
<thead>
<tr>
<th></th>
<th>2013</th>
<th>2014</th>
<th>As of Sept 2015</th>
</tr>
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<tbody>
<tr>
<td>HIV Testing</td>
<td>275</td>
<td>216</td>
<td>235</td>
</tr>
</tbody>
</table>
Jefferson County

- Action Plan to decrease HIV morbidity, increase early access and retention in HIV care includes:
  - Working closely with community partners—especially ACR Health and Dr. Marylene Duah, a board certified infectious disease specialist in Watertown, for early access and treatment
  - Offering navigators on site for immunization clinic to facilitate access to health insurance
  - Offering Health Promotion activities at Jefferson Community College to increase knowledge of community resources
  - Forming a STD coalition to address gaps in services and access barriers
  - Targeting social media to increase awareness of STD testing as well as Hep C
  - Educating CREDO Community Center that provides treatment for addiction via Health Promotion staff activities regarding Hep C and STD testing
Jefferson County

- Example of successful early access via our partnerships:
  - Individual identified as HIV positive at JCPHS
  - Immediate contact made by staff with Dr. Duah-appointment made for same day of HIV positive identification
  - ACR contacted and transported patient to Dr. Duah’s office
  - Identification and access to treatment all in same day
Jefferson County

- Collaboration with community partners is a critical element in our action plan
Introductions
Name, agency, service provided
From Blueprint to Action: Ending the Epidemic in New York State

GET TESTED. TREAT EARLY. STAY SAFE.
End AIDS.

health.ny.gov/etc

NEW YORK STATE OF OPPORTUNITY.
Department of Health
New York State Cascade of HIV Care, 2013
Persons Residing in NYS† at End of 2013

- **Estimated HIV Infected Persons**: 129,000
- **Persons Living w/ Diagnosed HIV Infection**: 112,000 (87% of infected)
- **Cases w/any HIV Care during the year**: 86,000 (67% of infected; 77% of PLWDHI)
- **Cases w/continuous care during the year**: 74,000 (58% of infected; 66% of PLWDHI)
- **Virally suppressed (n.d. or ≤200/ml) at test closest to end-of-year**: 70,000 (55% of infected; 63% of PLWDHI; 82% of cases w/any care)

* Any VL or CD4 test during the year; ** At least 2 tests, at least 3 months apart
†Persons presumed to be residing in NYS 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.
Mark Harrington and Charles King getting arrested at AIDS 2012 protest.

Governor Andrew Cuomo announcing his new initiative to combat the AIDS epidemic before the 2014 NYC Gay Pride Parade.


NYS Ending the Epidemic Task Force Meeting.

Dr. Demetre Daskalakis
Assistant Commissioner, NYCDOHMH
HIV/AIDS Prevention and Control.
Defining the End of AIDS

Goal
Reduce from 3,000 to 750 new HIV infections per year by the end of 2020.

Three Point Plan

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 for persons who engage in high risk behaviors to keep them HIV negative.
ETE Task Force Blueprint Recommendations and Structure

The 30 BP Recommendations include various steps that can be taken now to get New York State to the stated goal of 750 new HIV infections per year by the end of 2020.

The 7 GTZ Recommendations represent additional steps that could accelerate movement towards 0 infections. The Task Force understood this is not currently possible due to fiscal and policy realities. GTZ recommendations are not necessary to get to the goal of 750 new HIV infections per year by the end of 2020.
The Task Force ensured that prioritizing the needs of key populations significantly impacted by HIV and AIDS became a central component of the final ETE Blueprint document.
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
“Several jurisdictions have, through focused efforts, seen decreasing trends in HIV, including the States of New York and Massachusetts and the cities of San Francisco and Los Angeles. In addition, some States and local areas have put forth their own plans to “end AIDS,” such as New York State, Washington State, and San Francisco.” – NHAS 2020 Pg. 17
The Investment

$10 Million towards Ending the Epidemic services and expenses in the 2015-2016 Budget

Article VII
2014 - 2015 Amendments

• Elimination of written consent for HIV testing.
• Expand data sharing between state and local health departments and health care providers for linkage and retention efforts.
• Implementation of a “30% rent cap” affordable housing protection.

Article VII
2015 - 2016 Amendments

• Elimination of written consent for HIV testing in correctional facilities.
• Limiting the admission of condoms in criminal proceedings for misdemeanor prostitution offenses.
• Addressing the legality of syringes obtained through syringe exchange programs.
Ending the Epidemic Marketing Campaign

- Launched on March 16, 2015
- ‘Get Tested. Treat Early. Stay Safe.’
- The campaign is statewide and includes a variety of audio and print media
- health.ny.gov/ete
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
BP6: Incentivize Performance
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.
BP9: Provide enhanced services for patients within correctional and other institutions.
BP10: Maximize opportunities through DSRIP process to support programs.

BP29: Expand & enhance the use of data to track and report progress
New and Expanded Programs

- **NY Links**, improves systems for linking to and retention in care.
- **Expanded Partner Services Program (ExPS)** uses HIV surveillance data to identify and re-engage individuals in medical care.
- The **Linkage, Retention and Treatment Adherence Initiative** facilitates patient entry into treatment, promotes adherence to antiretroviral treatment (ART), and viral suppression.
- **Positive Pathways**, working with HIV-positive incarcerated persons to encourage the initiation of medical care.
- Development of a **Peer Certification** program for persons with HIV/AIDS.
- **Hospital reviews** for HIV testing conducted by IPRO.
- Utilize the **new HIV testing algorithm** to diagnose asymptomatic early HIV infections.
- Use of **surveillance data** for both Medicaid and DOCCS matches.
- **New syringe exchange program sites** and use of peers to work with young injectors.
- Expand **targeted health care services** to young MSM and transgender persons.
- January 1, 2015 start up of **PrEP – AP** to provide reimbursement for necessary primary care services for eligible individuals.
- Use of targeted **social marketing and messaging** efforts to identify persons with HIV.
Current PrEP Initiatives

www.prepforsex.org
Since January the program has received 249 applications for coverage.

Uptake on enrollment has steadily increased and as word of mouth spreads, requests from providers for in-service training are increasing.

52 providers with 107 sites are enrolled, 57 labs are enrolled.

PrEP-AP participant demographics indicate that 81% of enrollees are uninsured, 96% are male, 67% are 35 years of age or younger with 15% younger than 25.

81% of enrollees are from New York City, 34% are white, 41% Latino, 7% African American and 9% Asian.

Most, 92%, are single and most, 74%, have incomes above 100% of the federal poverty level.

PrEP-AP is serving a younger, slightly higher income and predominantly uninsured group of people.
LGBT Health: Beyond the Epidemic

Join the AIDS Institute of the New York State Department of Health and the Empire State Pride Agenda for a two-day health symposium. Day 1 will focus on transgender health and Day 2 on the intersections of LGBT health and human services and HIV prevention.

July 13-15, 2015
Hilton Garden Inn, Troy, New York

Keynotes: Cara Page, Scout, PhD, Carrie Davis, MSW, Kenyon Farrow

Registration is free. A limited number of travel scholarships are available for those who are not AIDS Institute grantees.

To register, please visit prideagenda.org/LGBTHealth
ETE Dashboard – Now Live!

- Key metrics will be systematically tracked at the state and local levels, with publicly available results.
- HIV prevention, HIV incidence, testing, new diagnoses and linkage, prevalence and care, AIDS diagnoses, and deaths compiled from various data sources and presented in one place.

ETEDASHBOARDNY.ORG
### NYS Regional Discussions

- Receive updated information about HIV/AIDS in your region/borough.
- Provide input on identified service gaps in your region/borough.
- Participate in regional/borough discussions about ending the epidemic.

#### NYS Regional Discussion Dates

<table>
<thead>
<tr>
<th>Region</th>
<th>Date</th>
<th>Region</th>
<th>Date</th>
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<tbody>
<tr>
<td>Syracuse</td>
<td>August 3</td>
<td>Manhattan, Lower</td>
<td>September 22</td>
</tr>
<tr>
<td>Buffalo</td>
<td>August 12</td>
<td>Brooklyn</td>
<td>September 24</td>
</tr>
<tr>
<td>Rochester</td>
<td>August 13</td>
<td>Queens</td>
<td>October 13</td>
</tr>
<tr>
<td>Albany</td>
<td>August 18</td>
<td>Staten Island</td>
<td>October 14</td>
</tr>
<tr>
<td>Hudson Valley</td>
<td>August 24</td>
<td>Nassau County</td>
<td>November 12</td>
</tr>
<tr>
<td>Bronx</td>
<td>August 31</td>
<td>Suffolk County</td>
<td>November 13</td>
</tr>
<tr>
<td>Manhattan, Upper</td>
<td>September 21</td>
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Gathering Implementation Strategies

The SurveyMonkey to collect implementation strategies in support of Blueprint Recommendations is currently active until **Tuesday November 24, 2015**.

It will be available on the ETE webpage: [https://health.ny.gov/EndingtheEpidemic](https://health.ny.gov/EndingtheEpidemic)
Karen Hagos  
Karen.Hagos@health.ny.gov  

https://health.ny.gov/EndingtheEpidemic  
https://health.ny.gov/ete  
http://ETEdashboardNY.org
Kick off of NY Links: CNY Regional Group

Howard Lavigne – Regional Lead

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

- Improve Linkage to Care
- Improve Retention in Care
- Improve Viral Load Suppression
Participant Teams
Participant Teams

- Identify a leader who will drive change, support quality improvement activities, direct resources and facilitate communication within the organization in support of the agency specific NY Links activities.
- Form a multidisciplinary team, including expert staff (data and evaluation, quality improvement, clinical providers, consumer(s) involved in QI) to participate as a team in the CNYRG; and
- Members of the Participant Team attend all learning sessions and champion linkage, retention, and VLS activities in the agency.
Roles

- Identify key staff to fill the following potential roles/responsibilities:
  - Senior Leader/Participant Team Lead
  - Point of Contact – person who can move QI projects ahead and coordinate
  - Data Manager – to help with data extraction, accuracy and submission
  - Clinical Provider – someone to inform the project
  - Consumer/PLWHA actively participating in QI
Partnership Meetings
Purpose of Partnership Meetings

- Learn more about your agency and your participation in current HIV activities and coalitions/networks
- Meet with your staff who will be involved in the NY Links Initiative; including representation from agency’s Primary Care, Supportive Service, HIV Testing, and Quality Management Programs
- Strengthen your agency’s understanding of the NY Links CNY Regional Group (CNYRG)
- Components:
  - Complete a Regional Group Assessment
  - Address any questions regarding CNYRG
  - Identify team members for CNYRG participation
  - Discuss pre-work/measures/QI activities for future CNYRG meetings
Partnership Meeting Logistics

- Meeting Duration: 90-120 minutes
- Each visit will be lead by a representative from NYSDOH, Howard Lavigne, and when possible, Steven Sawicki, NY Links Project Director.
- Partner Participation:
  - Executive Leader(s), QI Program Coordinator, Data/IT Coordinator, and/or any other team members
Building a System to Link and Retain Patients: Small Group Work

Howard Lavigne
Table Facilitators
Building a System to Link and Retain

Overview:
To visually create a system and its sub systems that depict organizational relationships that link patients to care within the Central NY region.

The diagrams will illustrate:
• the strength of organizational relationships (none to strong)
• linking and retaining patients in care

Uses: Over time,
• identify strengths, weaknesses, and opportunities for improvement (system, sub-systems)
• peer exchange
• identifying needs for TA and content and methodology for regional workshops
Part 1: Regional Service Map

30 minutes

1. There are four colors:
   - Orange = Supportive Service
   - Yellow = Testing
   - Blue = Clinical
   - Green = Other

2. Each agency writes its name on the appropriately colored circle. If there are several services within an agency, the agency can write its name on each of the designated color circles.

3. Each agency tapes its circle(s) on the flip chart paper.

4. Draw an arrow connecting your agency to those agencies that you have a linkage and retention relationship with (i.e. protocols in place, frequent referrals and follow up, etc.). An arrow in one direction means the communication is essentially in one direction. An arrow that goes in both directions means there is flow both ways.

5. Draw a dotted line to those agencies that you have a more informal relationship with and less frequent referrals.

6. If you work with an agency that is not here, add its name to a circle and tape it to the diagram.
Buffalo (WNY) Regional Group Service Map
Part 2: Present to the Group

10 minutes

1. Present your service diagram to the group.
2. The group makes observations, comments, suggestions.
Part 3: Brief Discussion

5 minutes

Large group exchange:
1. Share your experience and observations in creating the diagram. Were there new insights? To what degree was there agreement?
2. What are some of your system’s strengths? Sub-systems strengths?
3. Are there opportunities to strengthen your system? Sub-system?
4. What can you observe about your strategies for linking or retaining patients?
Who are the DOH staff

- Abigail Baim-Lance
- Barbara Bright-Motelson
- Barbara Westad
- Ben Katz
- Beth Woolston
- Bruce Agins
- Carol-Ann Swain
- Clemens Steinbock
- Dalys Febres
- Dan Belanger
- Dan Tietz
- Denis Nash
- Diane Addison
- February Dauria
- Felicia Schady
- Howard Lavigne
- Jill Dingle
- Jim Tesoriero
- Johanne Morne
- Joy Williams
- Julie Helberg Hirsch
- Karen Hagos
- Kelly Piersanti
- Lauren Suchman
- Linda DiCamillo
- Lyn Stevens
- Mary-Ellen Reo
- Meaghan Abrego
- Megan Johnson
- Nanette Brey-Magnani
- Rachel Malloy
- Stephen Crowe
- Steve Sawicki
- Susan Weigl
- Yanick Eveillard
Contact Information

- Clemens Steinbock, MBA, Quality Initiatives Director
clemens.steinbock@health.ny.gov
- Steven Sawicki, MHSA, NY Links Project Director
  steven.sawicki@health.ny.gov
- Bruce Agins, MD, MPH, Medical Director
  bruce.agins@health.ny.gov
- Howard Lavigne, NY Links CNYRG Lead, 315-477-8479
  howard.lavigne@health.ny.gov
- General Information: info@newyorklinks.org
WORKING LUNCH: Building Collaborative Relationships
What is New York Links?
Overall Objectives

• Improve Linkage to Care
• Improve Retention in Care
• Improve Viral Load Suppression
NYLINKS LONG TERM STRATEGIES

Involves providers and consumers in planning and implementation of regional processes to build networks that improve outcomes along the cascade of care.

Enhance understanding of how facility and local data affect regional and statewide cascade results.

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

Strengthen partnerships and peer learning.

Integrate NYLinks into the Ending of the Epidemic Initiative.
Background Information
HRSA ‘SPNS’ grant received 9/1/11

- NYLinks initiated through HRSA SPNS grant funding as part of a demonstration project which included a strong evaluation component. Funding was awarded to only 6 states.
NYS Links Mission

We will bridge systemic gaps between HIV related services and achieve better outcomes for PLWHA through improving systems for monitoring, recording, accessing, and sharing information about linkage to care, retention in care, and viral load suppression in New York State.
Regional Groups
Existing collaborative locations in New York State
REGIONAL GROUPS:

• Engagement of all medical and non-medical organizations within a geographic area to improve linkage to and retention in HIV care and viral load suppression

• Regional groups involve all levels of organizations—hospitals, community health centers, CBOs, local health departments, NYS staff

• Regional groups involve all levels of individuals—consumers, frontline staff, administrators, data staff, QI staff, CEOs, medical directors, medical providers

• Use data to improve performance

• Use QI strategies to design improvements and assess performance

• Use peer learning to spread innovation

• Develop an individual and a regional approach to improvement
Methods
## Collaborative Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Linkage to care among newly diagnosed persons</strong></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>
Strategies

- Online reporting database to facilitate self-reporting and instantaneous benchmarking
- On-site coaching and TA by recognized improvement experts
- Access to the full range of AIDS Institute resources and training
- Integration of NYS 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
Strategies

- Involve providers and consumers in planning and implementation of regional processes to build regional networks to sustain peer learning
- Consumers are full partners of NYLinks
- Regional approach to improvement
- Utilization of existing structures for support of work
- NYLinks embedded into Ending the Epidemic Initiative
NY Links Website

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 PLWHIV 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 folding 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 Sliney 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

www.NewYorkLinks.org
Playing With Numbers

When you begin a process of change it is important to have a solid understanding of where you are starting. This allows you to begin to think about where you are going to focus your change efforts. A big part of knowing where you are starting is having strong baseline data. You also need to know what you will be measuring and what your expected outcomes might be. For example, when we go on a diet we should know what our starting weight is, we should have some idea of what efforts we are going to undertake—adding in exercise, changing food choices, changing eating habits, etc.—and we should have a goal in mind. Keeping with this we need to decide whether we are going to use weight or inches as our measure. It does not do us a lot of good if our baseline data is in pounds but our hoped for outcome is in inches. Not impossible mind you just hard to connect one to the other and measure our progress.
Cascade of Care
New York State Cascade of HIV Care, 2013

Persons Residing in NYS at End of 2013

- Estimated HIV Infected Persons: 129,000
- Persons Living w/ Diagnosed HIV Infection: 112,000 (87% of infected)
- Cases w/any HIV Care during the year*: 86,000 (67% of infected)
- Cases w/continuous care during the year**: 74,000 (58% of infected)
- Virally suppressed (n.d. or ≤200/ml) at test closest to end-of-year: 70,000 (55% of infected)

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New York State Cascade of HIV Care, 2013

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- Estimated HIV Infected Persons: 129,000
- Persons Living w/ Diagnosed HIV Infection: 112,000 (87% of infected)
- Cases w/any HIV Care during the year*: 86,000 (67% of infected)
- Cases w/continuous care during the year**: 74,000 (58% of infected)
- Virally suppressed (n.d. or ≤200/ml) at test closest to end-of-year: 70,000 (55% of infected)

* Any VL or CD4 test during the year; ** At least 2 tests, at least 3 months apart
†Persons presumed to be residing in NYS 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.

Testing and Prevention
Linkage
Engagement
ART Therapy and Adherence
82% of cases w/any care
Who are the We

- Bruce Agins
- Annelise Hersokowitz
- Cameron Stainken
- Meredith Baumgartner
- Nanette Brey-Magnani
- Susan Weigl
- Johanna Buck
- Inez Jones
- Dan Tietz
- Denis Nash
- Diane Addison
- Rebekkah Robins
- Carol-Ann Watson
- Clemens Steinbock
- Lenee Simon
- Kelly Piersanti
- Steve Sawicki
- Monica Sweeney
- Demetre Daskalaskas
- Graham Harriman
- Andy Doniger
- Byron Kennedy
- Kim Smith
- Gale Burstein
- Cheryl Moore
- Roger Hayes
- Terry Hamilton
- Johanne Morne
- Lou Smith
- Dan Gordon
- John Fuller
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HIV Infection in New York State
Presentation to the NYLinks Central NY Regional Group
Presentation Outline

- Epidemiology of HIV infection
  - New York State
  - Central New York
- HIV care outcomes in Central New York
- Summary
Trends in HIV and AIDS*
New York State, 2002-2013

*Data as of April 2015. New HIV diagnoses include those diagnosed concurrently with AIDS. HIV named reporting began in NYS in 2000.
Newly Diagnosed HIV Cases by County of Residence at Diagnosis
New York State, 2013 (excludes New York City)

Data EXCLUDES prison inmates*

*Prison inmate refers to persons incarcerated in state correctional facilities at the time of diagnosis. The county of residence at diagnosis reflects the county of incarceration at the time of diagnosis.

NYS HIV surveillance data as of April, 2015. Maps created by the NYLinks Evaluation
Number of People Living with Diagnosed HIV/AIDS by County of Residence at Diagnosis New York State, 2013 (excludes New York City)

EXCLUDES prison inmates*

INCLUDES prison inmates*

*Prison inmate refers to persons incarcerated in state correctional facilities at the time of diagnosis (even if they are no longer in prison). The county of residence at diagnosis reflects the county of incarceration at the time of diagnosis or first report, which may be different from the individual's home county and later county of incarceration. NYS HIV surveillance data as of April, 2015. Maps created by the NYLinks Epidemiology Team, May 2015.
HIV Diagnoses and Living Cases
New York State, 2013

New diagnoses
- 3,512 new diagnoses of HIV infection occurred in 2013
  - 79% male
  - 57% MSM transmission risk
  - 25% heterosexual contact transmission risk

Living cases as of 2013
- 133,266 persons were living with diagnosed HIV infection (PLWDHI)
  - 71% male
  - 38% MSM transmission risk
  - 28% heterosexual contact transmission risk

Counties in the Syracuse & Binghamton Ryan White Regions

- Syracuse Ryan White Region (RWR):
  - Cayuga, Cortland, Herkimer, Jefferson, Lewis, Madison,
  - Oneida, Onondaga, Oswego, St. Lawrence, Tompkins

- Binghamton Ryan White Region:
  - Broome, Chenango, Tioga
HIV Diagnoses and Living Cases by Residence at Diagnosis
Syracuse & Binghamton Ryan White Regions, 2013

Newly diagnosed HIV cases, 2013
- 99 new diagnoses
  - 74% male
  - 53% MSM transmission risk
  - 25% heterosexual contact transmission risk

Living cases as of December 2013
- ~2,800 persons were living with diagnosed HIV infection
  - 74% male
  - 47% MSM transmission risk
  - 23% heterosexual contact transmission risk

Cascade of HIV Care: Syracuse Ryan White Region

Persons Residing in the Syracuse Ryan White Region†, at End of 2013 (excludes prisoner cases)

- Estimated HIV Infected Persons: 2,100
- Persons Living w/ Diagnosed HIV Infection: 1,800
- Cases w/any HIV Care during the year*: 1,400
- Cases w/continuous care during the year**: 1,300
- Virally suppressed (n.d. or ≤200/ml) at test closest to...: 1,200

* 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.
Cascade of HIV Care: Binghamton Ryan White Region

Persons Residing in the Binghamton Ryan White Region†, at End of 2013 (excludes prisoner cases)

**Virologically Suppressed**

- 87% of infected
- 69% of infected
- 78% of PLWDHI
- 59% of infected
- 68% of PLWDHI
- 59% of infected
- 68% of PLWDHI
- 87% of cases w/any care

**Persons Living w/ Diagnosed HIV Infection**

- 410
- 470
- 87% of infected
- 69% of infected
- 78% of PLWDHI
- 59% of infected
- 68% of PLWDHI
- 87% of cases w/any care

**Cases w/any HIV Care during the year**

- 320
- 69% of infected
- 78% of PLWDHI
- 59% of infected
- 68% of PLWDHI

**Cases w/continuous care during the year**

- 280
- 59% of infected
- 68% of PLWDHI

**Virally suppressed (n.d. or ≤200/ml) at test closest to...**

- 280
- 59% of infected
- 68% of PLWDHI

* 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.
Linkage to Care within 3 Months of HIV Diagnosis by Region of Diagnosis, 2013 (excludes prisoner cases)

% Linked

- M. Hudson: 88%
- Nassau Suffolk: 87%
- Rochester: 87%
- Syracuse: 86%
- Albany: 81%
- Buffalo: 81%
- Binghamton*: 79%
- L. Hudson: 77%

*Based on less than 20 persons.

NHAS 2015 Goal 85%
Viral Suppression among Persons Living with Diagnosed HIV Infection* in New York State, 2013 (excludes prisoner cases)

% Viral Suppression

- Albany: 73%
- Buffalo: 71%
- Rochester: 70%
- Syracuse: 69%
- Nassau Suffolk: 69%
- Binghamton: 68%
- M. Hudson: 67%
- L. Hudson: 66%

*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
Viral Suppression by Race/Ethnicity
Syracuse and Binghamton RWR, 2013 (excludes prisoner cases)

- White: 72%
- Black: 61%
- Hispanic: 64%
- Asian/Pac Isl: 78%
- Native Am.: 60%
- Multirace: 67%

*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
Viral Suppression by Age
Syracuse and Binghamton RWR, 2013 (excludes prisoner cases)

*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
Viral Suppression by HIV Transmission Risk
Syracuse and Binghamton RWR, 2013 (excludes prisoner cases)

MSM - men who have sex with men; IDU - injection drug use; FPHC - female presumed heterosexual contact

*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...
Summary: Disease Burden in the Population

- Relative to other counties in the region, Onondaga has a high number of new diagnoses and PLWDHI

- Linkage to care exceeds the national target in the Syracuse RWR
  - Small numbers prevent substantive interpretation for Binghamton RWR

- Viral suppression is lowest among
  - Blacks and Hispanics
  - Persons aged 20-39 years
  - Persons with heterosexual contact as their HIV transmission risk
Thank you.

Carol-Ann Swain
carolann.swain@health.ny.gov
518-474-4284

For more data on HIV in New York State, please visit http://www.health.ny.gov/diseases/aids/statistics/

Data requests to:
BHAE@health.ny.gov

*Thank you to the staff of BHAE for their efforts in assuring the quality and completeness of the NYS HIV Surveillance Registry*
Game: Survive on the Moon

Source: July 1999 issue of the NightTimes
Overview

- Introduction to NASA Game Scenario
- Individual Ranking
- Group Discussion and Ranking
- Debriefing
NASA Game Scenario

You are a member of a space crew originally scheduled to rendezvous with a mother ship on the lighted surface of the moon. However, due to mechanical difficulties, your ship was forced to land at a spot some 200 miles from the rendezvous point. During reentry and landing, much of the equipment aboard was damaged and, since survival depends on reaching the mother ship, the most critical items available must be chosen for the 200-mile trip. Below are listed the 15 items left intact and undamaged after landing. Your task is to rank order them in terms of their importance for your crew in allowing them to reach the rendezvous point.
Recovered Items

- Box of matches
- Food concentrate
- 50 feet of nylon rope
- Parachute silk
- Portable heating unit
- Two .45 caliber pistols
- One case of dehydrated milk
- Two 100 lb. tanks of oxygen
- Stellar map
- Self-inflating life raft
- Magnetic compass
- 5 gallons of water
- Signal flares
- First aid kit, including injection needle
- Solar-powered FM receiver-transmitter
Individual Ranking

- What are the most important items?
  - 3 minutes
  - Using the Reporting Form, place the number 1 by the most important item, the number 2 by the second most important, and so on through number 15 for the least important
Group Ranking

- Group Discussion
  - Form Groups: 8-10 individuals
  - Assignment: one facilitator, one observer and a recorder
  - 20 minutes

- Ranking
  - Discuss the ranking of the recovered items in the group and develop one ranking
  - Using the Reporting Form, place the number 1 by the most important item, the number 2 by the second most important, and so on through number 15 for the least important
Scoring

- For each item, mark the number of points that your score differs from the NASA ranking, then add up all the points. Disregard plus or minus differences. The lower the total, the better your score.
  - Example: Box of matches – Individual Ranking 5 and NASA Ranking 10; count 5 points
  - Score the individual and group rankings
## Answers to the Survival on the Moon Exercise

<table>
<thead>
<tr>
<th>Item</th>
<th>NASA Ranking</th>
<th>NASA's Reasoning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Box of matches</td>
<td>15</td>
<td>Virtually worthless -- there's no oxygen on the moon to sustain combustion</td>
</tr>
<tr>
<td>Food concentrate</td>
<td>4</td>
<td>Efficient means of supplying energy requirements</td>
</tr>
<tr>
<td>50 feet of nylon rope</td>
<td>6</td>
<td>Useful in scaling cliffs and tying injured together</td>
</tr>
<tr>
<td>Parachute silk</td>
<td>8</td>
<td>Protection from the sun's rays</td>
</tr>
<tr>
<td>Portable heating unit</td>
<td>13</td>
<td>Not needed unless on the dark side</td>
</tr>
<tr>
<td>Two .45 caliber pistols</td>
<td>11</td>
<td>Possible means of self-propulsion</td>
</tr>
<tr>
<td>One case of dehydrated milk</td>
<td>12</td>
<td>Bulkier duplication of food concentrate</td>
</tr>
<tr>
<td>Two 100 lb. tanks of oxygen</td>
<td>1</td>
<td>Most pressing survival need (weight is not a factor since gravity is one-sixth of the Earth's -- each tank would weigh only about 17 lbs. on the moon)</td>
</tr>
<tr>
<td>Stellar map</td>
<td>3</td>
<td>Primary means of navigation - star patterns appear essentially identical on the moon as on Earth</td>
</tr>
<tr>
<td>Self-inflating life raft</td>
<td>9</td>
<td>CO₂ bottle in military raft may be used for propulsion</td>
</tr>
</tbody>
</table>
# Answers to the Survival on the Moon Exercise

<table>
<thead>
<tr>
<th>Item</th>
<th>Quantity</th>
<th>Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Magnetic compass</td>
<td>14</td>
<td>The magnetic field on the moon is not polarized, so it's worthless for navigation</td>
</tr>
<tr>
<td>5 gallons of water</td>
<td>2</td>
<td>Needed for replacement of tremendous liquid loss on the light side</td>
</tr>
<tr>
<td>Signal flares</td>
<td>10</td>
<td>Use as distress signal when the mother ship is sighted</td>
</tr>
<tr>
<td>First aid kit, including injection needle</td>
<td>7</td>
<td>Needles connected to vials of vitamins, medicines, etc. will fit special aperture in NASA space suit</td>
</tr>
<tr>
<td>Solar-powered FM receiver-transmitter</td>
<td>5</td>
<td>For communication with mother ship (but FM requires line-of-sight transmission and can only be used over short ranges)</td>
</tr>
</tbody>
</table>
Scoring

- 0 - 25 excellent (*true survivor…*)
- 26 - 32 good
- 33 - 45 average
- 46 - 55 fair
- 56 - 70 uh-oh (*suggests use of Earth-bound logic…*)
- 71 - 112 yikes! (*you’re one of the casualties of the space program!*
Debriefing

- Compare individual and group rankings
  - How many are better off? Why did more survive? What were the factors for higher group survival?
- Team dynamics - report from observer
  - How did the group work together? Why did the group work well (or not)? What were the group dynamics that positively contributed to a higher survival?
Reflections

What are the lessons learned from this game? How can a group reach a common goal?

- Teamwork can produce better results than individual work, especially when faced with complex issues
- Healthy team dynamics are critical to team work and development
- The role of the facilitator is extremely important, especially when dealing with time constraints
- It is important to take the time to obtain all team members’ views and perspectives
- A benefit of teamwork is that diversity in culture, opinion, and experience can be addressed positively
BREAK
Consumer Involvement in Quality Management

- Quality improvement (QI) models used in health care grew out of statistical process control models designed for industry.

- Critical dimension of QI is determining consumer needs as well as developing products and services that meet and exceed customer expectations.

- Adapted for use in health care settings, although many medical disciplines are still grappling with how and to what extent they should involve consumers.
Patient Experience

- Focusing on patient experience involves the emotional bonds that are created between ‘patients’ and ‘healthcare providers’

- Patients want 4 psychological elements fulfilled:
  1. Confidence: provider delivers on promises
  2. Integrity: provider treats patients fairly and resolves problems
  3. Pride patient feels good about provider, has commitment to provider
  4. Passion reflects belief that provider is integral part of patient’s life

The Beryl Institute, 2012
Patient-Centered Care:
Care that is respectful of and responsive to individual patient preferences, needs, and values and ensures that patient values guide all clinical decisions. (IOM, 2001)

- **History:** Coined by the Picker Institute in the context of research to document patients’ needs and preferences to understand their definitions of high-quality care.

Self-Management:
Improving self-efficacy and fostering collaborative goal setting and decision making between consumers and providers, allowing consumers to monitor and manage their health. (Bodenheimer, Lorig et al, 2002; Lorig, 2003). A fundamental component of the Chronic Care Model. (Wagner)

- **History:** Most research about self-management has focused on chronic conditions. A key element of the chronic care model.

Consumer Involvement:
Formally soliciting input and recommendations from the diversity of individuals using care delivery services. (NYSDOH AI)

- **History:** Identified as key component of quality management programs for HIV care in New York State to help achieve sustainable outcomes.
<table>
<thead>
<tr>
<th>Patient-Centered Care</th>
<th>Self-Management</th>
<th>Consumer Involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Respect patients' values, preferences &amp; expressed needs, treating them as individuals</td>
<td>▪ Develop education programs that address lifestyle changes, medical management and emotional factors</td>
<td>▪ Include consumers as members on QM committee and QI teams</td>
</tr>
<tr>
<td>▪ Support patient education</td>
<td>▪ Shift clinician's role from professional expert (instruct/decide) to guide (support/advise)</td>
<td>▪ Have consumers review performance data and QI activities</td>
</tr>
<tr>
<td>▪ Focus on communication strategies</td>
<td>▪ Support patient self monitoring</td>
<td>▪ Build consumer skills to join providers in organizational activities to improve outcomes</td>
</tr>
<tr>
<td>▪ Involve family &amp; friends</td>
<td>▪ Support joint decision- making</td>
<td>▪ Assess consumer needs and satisfaction at least annually and integrate findings into QI activities</td>
</tr>
<tr>
<td>▪ Determine patients' preferences for involvement in care</td>
<td>▪ Collaborative goal setting and action planning</td>
<td></td>
</tr>
<tr>
<td>▪ Enhance physical comfort</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The AIDS Institute

Patient-Centered Care Brochure

WHAT IS PATIENT ENGAGEMENT?

Patient engagement is crucial to ensuring that patients are at the center of their own care and the health system as a whole. The diagram below presents concrete examples of patient engagement at various levels along a continuum of engagement. The ultimate goal of these forms of patient engagement is the establishment of partnerships and shared leadership between patients and providers. Capacity building at both the staff and patient level may be necessary to achieve these levels of engagement.

Adapted from Exhibit 1 of Carman, et al. (2013):

CONTINUUM OF ENGAGEMENT

- Direct Care: Patients receive information about a diagnosis
- Communication: Patients are asked about their preferences in treatment plans
- Involvement: Care teams are made up of patient partners and clinical staff

FACTORs INFLUENCING ENGAGEMENT:
- Patient beliefs about patient roles, health literacy, education
- Organization (policies, practices, culture)
- Society (social norms, regulations, policy)
Conceptual framework

PLWHA involvement in QM/QI

- Defines the ways to FORMALLY involve PLWHA in HIV facility-wide QI activities and the mechanisms during each stage of the QI process
A Multidimensional Framework For Patient And Family Engagement In Healthcare

Levels of engagement

Direct care

Consultation

Patients receive information about a diagnosis

Involvement

Patients are asked about their preferences in treatment plan

Partnership and shared leadership

Treatment decisions are made based on patients’ preferences, medical evidence, and clinical judgment

Organizational design and governance

Organization surveys patients about their care experiences

Hospital involves patients as advisers or advisory council members

Policy making

Public agency conducts focus groups with patients to ask opinions about a health care issue

Patients’ recommendations about research priorities are used by public agency to make funding decisions

Patients have equal representation on agency committee that makes decisions about how to allocate resources to health programs

Factors influencing engagement:

- Patient (beliefs about patient role, health literacy, education)
- Organization (policies and practices, culture)
- Society (social norms, regulations, policy)

Carman K L et al. Health Aff 2013;32:223-231

©2013 by Project HOPE - The People-to-People Health Foundation, Inc.
Consumer Involvement in Quality Management

- Quality improvement (QI) models used in health care grew out of statistical process control models designed for industry.

- Critical dimension of QI is determining consumer needs as well as developing products and services that meet and exceed customer expectations.

- Adapted for use in health care settings, although many medical disciplines are still grappling with how and to what extent they should involve consumers.
New York State Model for Consumer Involvement in Quality Improvement
## To what extent are consumers effectively engaged and involved in the HIV quality management program?

<table>
<thead>
<tr>
<th>Stage</th>
<th>Consumer involvement:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning and Initiation</td>
<td>Is occasionally addressed by soliciting consumer feedback, but no formal process is in place for ongoing and systematic participation in quality management program activities.</td>
</tr>
<tr>
<td>Beginning Implementation</td>
<td>Is addressed by soliciting consumer feedback, with development of a formal process for ongoing and systematic participation in quality management program activities.</td>
</tr>
</tbody>
</table>
| Implementation (Meets HAB requirements) | **Includes engagement with consumers to solicit perspectives and experiences related to quality of care.**
- Is formally part of HIV quality management program activities through a formal consumer advisory committee, satisfaction surveys, interviews, focus groups and/or consumer training/skills building. However, the extent to which consumers participate in quality management program activities is not documented or assessed. |
| Progress toward systematic approach to quality | **Includes engagement with consumers to solicit perspectives and experiences related to quality of care.**
- Is part of a formal process for consumers to participate in HIV quality management program activities, including a formal consumer advisory committee, surveys, focus groups and/or consumer training/skills building.  
- In improvement activities includes three or more of the following:
  - sharing performance data and discussing quality during consumer advisory board meetings
  - membership on the internal quality management team or committee
  - training on quality management principles and methodologies
  - engagement to make recommendations based on performance data results
  - increasing documentation of recommendations by consumers to implement quality improvement projects.
- Information gathered through the above noted activities is documented and used to improve the quality of care. However, staff does not review with consumers how their involvement contributes to refinements in quality improvement activities. |
| Full systematic approach to quality management in place | **Includes engagement with consumers to solicit perspectives and experiences related to quality of care.**
- Is part of a formal, well-documented process for consumers to participate in HIV quality management program activities, including a consumer advisory committee with regular meetings, consumer surveys, interviews, focus groups and consumer training/skills building.  
- In quality improvement activities includes four or more of the items bulleted in E2#4.
- Information gathered through the above noted activities is documented, assessed and used to drive QI projects and establish priorities for improvement.
- Includes work with program staff to review changes made based on recommendations received with opportunities to offer refinements for improvements. Information is gathered in this process and used to improve the quality of care.
- Involves at minimum, an annual review by the quality management team/committee of successes and challenges of consumer involvement in quality management program activities to foster and enhance collaboration between consumers and providers engaged in quality improvement. |
Consumer Capacity Building Resource
Consumer Capacity Building Resources
NQC Offerings

NQC Website

HIVQUAL
Regional Groups

in+care
Campaign

Quality Academy

On-Site TA

NQC Trainings
TRAINING OF CONSUMERS ON QUALITY (TCQ)

- To build capacity of consumers to be equal partners in the planning, implementation, and evaluation of QI efforts at both clinical and regional levels

- To increase and prepare people living with HIV/AIDS to be formally engaged in ongoing quality management (QM) programs, internal QI teams and regional QI activities
**TCQ Learning Objectives**

- Increased understanding of expectations and requirements for quality management
- Increased understanding of basic vocabulary for quality improvement tools, methodologies, activities and processes
  - Includes knowledge related to numeracy for better understanding of indicator development and performance measurement data interpretation
- Increased competency to be a consumer champion in local or regional quality management committee activities
- Understanding of the distinction between individual care and the system in which care is delivered
Post 2-day Training Participant Expectations

- Serve on internal QM committees and QI team activities within supporting organization, or regional QI activities
- Attend and actively participate in post-TCQ conference calls and complete post TCQ evaluation assessment tool (4 hours)
Post-TCQ Sponsor Expectations

- Review and offer feedback to participant on personalized action plan developed during TCQ
- Coach/mentor TCQ participant and support active engagement in QI activities for continued capacity development
- Participate in post-training evaluation activities via webinars, focus groups or interviews to assess TCQ program impact on consumer involvement in QI
Contact Information

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(518)473-7542
Objectives

- Understanding of ExPS
- Showcase ExPS as a collaborative model of care
- Discuss the major players in Central New York from the NYSDOH and Onondaga County
- Reinforce the ultimate goal of ExPS
- The unique role of CBOs
Expanded Partner Services (ExPS)

Collaboration between the Division of HIV/STD/HCV Prevention and the Division of Epidemiology, Evaluation & Research
  - Health Department Data-to-Care Model

Utilized HIV surveillance data to identify previously known positive individuals who appear to be out-of-care

ExPS Pilot launched in September 2013
  - PS Staff in Erie, Monroe, Westchester, & Onondaga LHDs, with Coordination by AIDS Institute
  - One year Pilot Period (Sept 13 – Aug 14)

Statewide expansion January 2015
Background and Context

Collaboration & Service Integration

State & Local Health Departments

Community Based Organizations

Health Centers & Medical Providers
Ending the Epidemic

Three Point Plan

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 for high risk persons to keep them HIV negative.

BP7: Use Client-level data to identify and assist patient lost to care or not virally suppressed
Modified from the CDC’s Continuum of Engagement in HIV Medical Care http://www.cdc.gov/hiv/prevention/programs/pwp/linkage.html

Updated 11.9.2015
Expanded Partner Services (ExPS)

**Health Department Model**

HIV surveillance data to identify individuals diagnosed with HIV who **may** be out-of-care

Patients with no recent VL or CD4 labs within New York’s HIV Tracking System for 13-24 months

**High Impact Care and Prevention Project (HICAPP)**

**Combination Model**
Health Department & Healthcare Provider

HIV surveillance data & selected health center’s data to identify individuals diagnosed with HIV who **may** be out-of-care

4 definitions of out-of-care

**ExPS in Department of Corrections and Community Supervision (DOCCS)**

**Health Department Model**

Unique collaboration btw DOH and DOCCS

DOCCS custody data matched with HIV surveillance data to identify individuals diagnosed with HIV who **may** be out-of-care

2 definitions of out-of-care
NYS D2C Timeline

- **2012**
  - Concept Paper
  - Internal AI Workgroup Developed
  - Calls with County Commissioners & Program Staff / Focus Groups

- **2013**
  - Conference Call with Pilot Counties
  - Initial Pilot ExPS Training

- **2014**
  - 1st ExPS Case Assignments
  - Planning for Expansion
  - Data Match
  - Health Center Files Submitted
  - Planning for Assignment Generation

- **2015**
  - Revamped Protocols Issued
  - Internal AI D2C Workgroup Expanded
  - 1st Case Assignments
  - ExPS Training
  - Statewide Expansion Case Assignments
  - ExPS in DOCCS
  - HICAPP/P4C
Expansion of ExPS

**AI Funded Counties**

1. Erie  
2. Monroe  
3. Onondaga  
4. Westchester  
5. Albany  
6. Orange  
7. Dutchess  
8. Nassau  
9. Suffolk  
10. NYC

**Bureau of HIV STD Field Services**

**Western Region**
- **Buffalo** - Allegany, Cattaraugus, Chautauqua, Genesee, Niagara, Orleans, & Wyoming
- **Rochester** - Chemung, Livingston, Ontario, Schuyler County, Steuben, Wayne, & Yates

**Central Region**
- Broome, Cayuga, Chenango, Cortland, Herkimer, Jefferson, Lewis, Madison, Oneida, Oswego, St. Lawrence, Tioga, & Tompkins

**Capital Region**

**Metropolitan Region**
- Putnam, Sullivan, & Ulster

**Long Island Region**
- Nassau & Suffolk
1. Linkage to medical care;
2. Referrals for identified supportive services;
3. Prevention/Risk Reduction Counseling/Discussion of Partners; and
4. Safer sex supplies.
Case Investigation Process

Strategies for Identifying and Locating Out-of-Care Patients

1. Vital Status Verification
2. Department of Corrections and Community Supervision (DOCCS) Inmate Lookup
3. Regional Health Information Organization (RHIO) Search
4. Last Known Medical Provider Check
5. Phone calls to OOC patient
6. Internet Searches
7. Investigation of persons who are incarcerated in a local jail
8. Accurint Search Request – Unable to Locate Individuals

Prioritizing cases for outreach

STD Comorbid Status

- Perform a search to determine whether the ExPS OOC patient has a history of diagnosis, or was a partner to any reportable STD case within the past 12 months

Length of Time OOC and/or Viral load/CD4

- In some cases it may help to further prioritize cases for outreach based on risk status as determined by the OOC patient’s length of time out of care, or their last viral load/CD4
Central New York
Broome, Cayuga, Chenango, Cortland, Herkimer, Jefferson, Lewis, Madison, Oneida, Onondaga, Oswego, St. Lawrence, Tioga, and Tompkins Counties
Case outcomes based on information entered into NYEHMS Tracking System as of 10/29/15. Includes all ExPS cases generated and assigned from September 2014-Present (excluding NYC). Data are subject to change pending lab updates, worker revisions, and/or data QA reclassifications.
EXPS CASE DEMOGRAPHICS – CENTRAL NY (N=465)

**Gender**
- Male: 69.7%
- Female: 29.7%
- Transgender: 0.6%

**Age Distribution**
- <20: 0%
- 20-29: 13%
- 30-39: 18%
- 40-49: 29%
- 50-59: 26%
- >60: 13%
**ExPS Case Demographics – Central NY**
(N=465)

**Risk Factors Upon Transmission**

- **MSM/IDU**: 4%
- **IDU**: 14%
- **MSM**: 39%
- **Heterosexual**: 25%
- **Female Presumed Hetero**: 7%
- **Unknown**: 11%

**Race/Ethnicity**

- White, Non-Hispanic: 48%
- Black, Non-Hispanic: 33%
- Hispanic: 7%
- Asian / Pacific Islander: 2%
- Other / Missing: 10%

**Other Race/Ethnicity**: 10%
REASONS OUT OF CARE, CENTRAL NY (N=56)
What does this mean for me or my agency?

**Medical Provider**
May contact you or your office to inquire about the status of a presumed out-of-care individual to confirm identifying and demographic information.

May also contact you or your office to link a previously known HIV positive individual and/or an identified partner(s) into medical care.

- The Advocate will then contact you or your office the date of or shortly after the patient's scheduled medical appointment to confirm attendance.

**Community Based Organization**
May contact your agency on behalf of an HIV positive individual and/or his or her identified partner(s) in order to link him/her to the services that your agency provides.
Retaining HIV-positive people in medical care: Resources and Information for Providers

- Expand DOH-2557 to at least 2 years & have consent forms on file for every patient to facilitate follow-up with CBOs
- Encourage patients to add your practice’s name to any releases they sign with other organizations they frequent
- Become a member of area Health Home(s)
- Explain to all HIV positive individuals (including those newly identified) that if they appear to have fallen out of HIV medical care, he or she may be contacted by the health department to address barriers to care and to promote engagement in care.
- Use information from the RHIO, if available, to determine if s/he is in care with another provider or if updated personal contact information is available.
- Conduct a health benefits check, if available, on the person to determine if s/he changed insurance or are in care with another provider.
- Try multiple modes of contact (phone, text, letter, email, and social media) at varying times of the day/week to reach the patient.
The Unique Role of a CBO

“Individual, social, structural, ethical, legal, and policy issues shape the lives of persons with HIV and their ability to use HIV prevention and care services and adopt HIV prevention strategies.

CBOs who understand these issues are better prepared to create a sense of shared responsibility and decision making with their clients with HIV.

- motivating clients with HIV to adopt prevention strategies and obtain essential services
- endorsing the strategy of “treatment as prevention” to contribute to community well-being
- communicating in a sensitive, respectful, and culturally competent manner
- promoting the development of community resources to support prevention and care services”

Recommendations for HIV Prevention with Adults and Adolescents with HIV in the United States, 2014 Summary for Nonclinical Providers
Prior to a lapse in care

- Talk with all your HIV+ clients about their medical care status (e.g., Are they in care? With what provider(s)? When was their last CD4/VL test? What was their last VL?)
- Expand DOH-2557 to at least 2 years
- Encourage patients to add your agency’s name to any releases they sign with other organizations they frequent
- Utilize bidirectional linkage agreements with medical care providers and STD clinics to facilitate access to care, retention in services, and the sharing of information.
- Collaborate with local Partner Services staff to better promote partner services to clients and to foster bidirectional referrals.
- Explain to all HIV positive individuals (including those newly identified) that if a person with HIV appears to have fallen out of HIV medical care, he or she will be contacted by the medical provider or health department to address barriers to care and to promote engagement in care.
  - Phone call - Text message - Formal letter
- Other thoughts…
Example out-of-care letter a client/patient may receive

Insert Approved Letterhead for patient mailings

Insert Date

Dear Insert Patient Name,

I have been trying to contact you to provide some health information that is important for you to have. The nature of the information I have for you requires that it be delivered directly to you, rather than sent in a letter. At this point it is urgent that we speak as soon as possible.

Our records indicate that you may not be in care for an ongoing medical condition and may be overdue for a medical appointment. When we connect, I would like to talk about any health needs you may have that are not being met. One of my roles as a Public Health Representative is to link people to the care they need.

Again, it is very important that I speak with you as soon as possible. Please call my office Monday through Friday, 8:30AM to 3:30PM at XXX XXX XXXXX [Insert you may text me at that number if applicable]. If I am not here when you call, please tell the representative that answers the phone that you are responding to a letter from me and someone else will help you. If you call before 8:30AM, or after 3:30 PM please leave a message with the best method (e.g., phone call, text, face-to-face visit, etc.) and time to contact you back.

I look forward to speaking with you soon.

Best Regards,

Insert Worker Name

Public Health Representative
XXX XXX XXXXX
Thank You.

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Additional Slides
Wrap Up: Expectations, Next Steps & Evaluation

Howard Lavigne & Steve Sawicki
To participate agencies should have the following:

- A QI project team with clear roles and responsibilities (includes Senior Leader/Participant Team Lead, Project Lead, Data Lead, Clinical Lead, and a Consumer)
- A performance measurement system that is used to routinely monitor the rate of linkage to and on-going retention in HIV primary care for patients
- Demonstrated experience in applying quality improvement methods to identify and test system changes
- Capacity to collect and submit quarterly process and outcome measures related to the initiative and if an intervention is selected
- Willingness to participate in regular meetings with the NY Links staff assessing intervention fidelity
- Willingness to share learning and adapt interventions
- Commitment to work with the NY Links team
Benefits
GET TESTED.
TREAT EARLY.
STAY SAFE.

End AIDS.

health.ny.gov/ete
NATIONAL HIV/AIDS STRATEGY for the UNITED STATES:

UPDATED TO 2020

JULY 2015
MORE BENEFITS

• Data collection tools, protocols and support to implement interventions known to improve timely access and/or retention in HIV primary care

• Training resources specific to each intervention and for additional recommended strategies that can supplement NY Links interventions

• Technical assistance and coaching that includes assessment of key elements for implementation and ongoing fidelity monitoring for site specific refinement

• Expert input, data reports and tools to assure a sound evaluation plan
EVEN MORE BENEFITS

• Guidance on developing a successful team

• Opportunities to strengthen cross-continuum teams and potentially bridge learning across diseases

• On-going peer exchange and a community of support from colleagues implementing interventions

• Opportunity to highlight your agency's progress and expertise in addressing the key issue of access to and on-going retention in care to funders and key stakeholders

• Access to all of the resources available to NY Links so you can be successful in this endeavor
STILL EVEN MORE BENEFITS

• Opportunity to be part of a very limited, nationally recognized process designed to improve linkage and retention

• Opportunities to be part of any material published related to the process or the particular interventions selected

• Potential national and international recognition
Future Meetings

- Who is not here and should be
- Contact lists
- Remain as one group
  - Frequency of meetings
- Split into northern/southern chapters
  - Chapter meetings/frequency
- Rotation of meeting space
- Webinars
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With Gratitude & Many Thanks

- Johanne Morne
- Steve Sawicki
- Bruce Agins
- Jim Tesoriero
- Karen Hagos
- Nanette Brey-Magnani
- MaryEllen Reo

- Carol-Ann Swain
- Stephen Crowe
- Dan Tietz
- Anna Harris
- Beth Woolston
- Meg Johnson
- And **YOU!!!**
Evaluation & Adjournment!