HIV Care Continuum

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Association of Nurses in AIDS Care

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Conflict of Interest Disclosure Statement

• No financial relationships to disclose
• No off-label discussions in presentation
Objectives

1. To understand the current state of engagement and retention in care for persons living with HIV
2. To discuss the challenges and barriers to engagement in HIV care
3. To review strategies for improving engagement and retention in the U.S.
The HIV Care Continuum
HIV CARE CONTINUUM:

THE SERIES OF STEPS A PERSON WITH HIV TAKES FROM INITIAL DIAGNOSIS THROUGH THEIR SUCCESSFUL TREATMENT WITH HIV MEDICATION

- **Diagnosed with HIV**
- **Engaged or Retained in Care**
- **Linked to Care**
- **Prescribed Antiretroviral Therapy**
- **Achieved Viral Suppression**

![Graph showing stages of HIV care](www.aids.gov)
HIV CARE CONTINUUM:

- Acquire HIV
- Diagnosed with HIV
- Linked to Care
- Engaged or Retained in Care
- Prescribed Antiretroviral Therapy
- Achieved Viral Suppression

[Graph showing the stages of HIV care and the number of individuals at each stage]

www.hiv.gov
The U.S. 2014 HIV Care Continuum

Persons Living with Diagnosed or Undiagnosed HIV Infection

HIV Care Continuum Outcomes, 2014—United States

Note. Receipt of medical care was defined as ≥1 test (CD4 or VL) in 2014. Retained in continuous medical care was defined as ≥2 tests (CD4 or VL) ≥3 months apart in 2014. Viral suppression was defined as <200 copies/mL on the most recent VL test in 2014.
Linkage to HIV Medical Care within 1 Month after HIV Diagnosis during 2015, among Persons Aged ≥13 Years, by Age—37 States and the District of Columbia

Note. Linkage to HIV medical care was defined as having a CD4 or VL test ≤1 month after HIV diagnosis.
Persons Living with Diagnosed or Undiagnosed HIV Infection
HIV Care Continuum Outcomes, by Sex, 2014—United States

Note. Receipt of medical care was defined as ≥1 test (CD4 or VL) in 2014. Retained in continuous medical care was defined as ≥2 tests (CD4 or VL) ≥3 months apart in 2014. Viral suppression was defined as <200 copies/mL on the most recent VL test in 2014.

Persons Living with Diagnosed or Undiagnosed HIV Infection
HIV Care Continuum Outcomes, by Age, 2014—United States

Note. Receipt of medical care was defined as ≥1 test (CD4 or VL) in 2014. Retained in continuous medical care was defined as ≥2 tests (CD4 or VL) ≥3 months apart in 2014. Viral suppression was defined as <200 copies/mL on the most recent VL test in 2014.

Persons Living with Diagnosed or Undiagnosed HIV Infection
HIV Care Continuum Outcomes, by Race/Ethnicity, 2014—United States

Note. Receipt of medical care was defined as ≥1 test (CD4 or VL) in 2014. Retained in continuous medical care was defined as ≥2 tests (CD4 or VL) ≥3 months apart in 2014. Viral suppression was defined as <200 copies/mL on the most recent VL test in 2014. Asian includes Asian/Pacific Islander legacy cases. Hispanics/Latinos can be of any race.

Persons Living with Diagnosed or Undiagnosed HIV Infection
HIV Care Continuum Outcomes, by Transmission Category, 2014—United States

Note. Receipt of medical care was defined as ≥1 test (CD4 or VL) in 2014. Retained in continuous medical care was defined as ≥2 tests (CD4 or VL) ≥3 months apart in 2014. Viral suppression was defined as <200 copies/mL on the most recent VL test in 2014. Heterosexual contact is with a person known to have, or be at high risk for, HIV infection. MSM, male-to-male sexual contact; IDU, injection drug use.

Challenges and Barriers in the HIV Continuum
The Continuum has Helped Change the Way We View HIV Prevention and Care

• It is more readily apparent that prevention and treatment are part of the same spectrum

• Funding is becoming less siloed:
  – CDC – HIV testing and prevention
  – HRSA – HIV treatment and care

• Gives structure to our conversations
  – With funders, HCWs, PLWH, clients

• Allows us to measure and track our efforts
Barriers to Engagement in HIV Care

• Competing life activities
• Feeling sick
• Stigma
• Depression and mental illness
• Transportation
• Access/Health Insurance
• Forgetfulness
• Substance abuse
• Poor patient experience
• Challenges with appointment scheduling
• Poor staff/provider interactions
• Housing

Yehia et al. BMC Infect Dis. 2015;15:246
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Facilitators to Engagement in HIV Care

• Good staff/provider relationship
• Social support
• Patient-friendly clinic services
• Patient initiated reminder strategies
• Flexible schedules
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Who Contributes to Continuum Success?

• PLWH/Clients
• Activists
• Health Care Workers
• Community Based Organizations
• Community members
• Health departments
• Funders
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Strategies to Improve Engagement in HIV Care
How do we improve the Continuum?

- Improving social support for PLWH
- Improve handoffs for new diagnoses
- Outreach and navigation
- Improve messaging on the importance of engagement
- Substance abuse counseling and treatment
- Mental Health diagnosis and care
- Universal Health Care (?)
- Improve housing and decrease homelessness
- Decrease competing needs (food, clothing, etc.)
- Adherence Support
- Improve the system of health care delivery
Linkage to HIV Care
Linkage Basics

• Getting a new diagnosis can be traumatic
• Linkage services have to be sensitive and persistent
• Factors to assess: socioeconomics, insurance, substance use, social support, mental health, stigma, and clinical stage (and others)
• Consideration for same-day HAART
• Monitoring Linkage is everyone’s job including the testing site, public health, and HIV Clinics
• Linkage should be active not passive
Antiretroviral Treatment and Access Study (ARTAS): Linkage to Care Intervention

- Recently HIV-Diagnosed Individuals
- Randomized to
  - Standard of Care = passive referral to HIV Care
    - Received information about HIV and local resources
  - Strengths Based Case Management
    - Up to five case manager contacts over 90 days
    - Relationship building
    - Identifying client resources, needs and barriers to care
    - Help clients identify their strengths and assets
    - If needed, accompany the client to their first appointment

ARTAS: Percentage of Clients Linked to Care by 6 Months and Who Persisted in Care at 12 Months

In Care by 6 Months: 78%
In Care at Both 6 and 12 Months: 64%

Case Management
Simple Referral (SOC)

Other Linkage Strategies

• Outreach and Navigation
• Post-test counselling/education
• Motivational interviewing
• Peer Support
• Engaging the newly diagnosed individual with the clinic prior to the provider visit

• Strategies that have not worked:
  – Financial Incentives
Retention in HIV Care
Retention Basics

• Poor retention is associated with a higher risk of death
• Monitoring retention in the clinic setting should be done routinely
• System level factors are sometimes critically important for promoting retention:
  – Patient-provider relationship
  – Better patient experience
  – Appointment availability
  – Scheduling convenience
Intensive Outreach Improves Retention in HIV Care

• Underserved, recently diagnosed individuals
  – women, youth, substance abuse, mental illness

• Intensive outreach defined as HIV education, addressing stigma, helping individuals access resources, addressing structural barriers to care

• 104 participants:
  – 81% had two visits over the first year
  – 45% undetectable viral load at 12 months
  – 50% of uninsured gained insurance at 12 months
  – 50% reduction in self-reported stigma as barrier

Naar-King et al. AIDS Pat Care STDs 2007;21 (Suppl1): S40-8
HIV Systems Navigation Improves Retention in HIV Care

• Another SPNS publication

• Peer patient Navigation supported:
  – Coaching patients
  – Health system navigation
  – Community linkages

• 437 individuals followed
  – Engagement at 6 months improved 64% to 87%
  – 79% were still engaged at 12 months
  – 50% increase in rates of viral suppression

Bradford et al. AIDS Pat Care STDs 2007;21 (Suppl1): S49-58
Retention Messaging Improves Retention “Stay Connected”

- Clinic-wide (not just nurses/prescribers)
- Low cost, low effort
- Messages were written and verbal
- Clinic staff received formal training on the messaging
- Study included a pre-intervention/post-intervention comparison
- Took place at 6 U.S. clinics

Retention Messaging Improves Retention “Stay Connected”

• The messaging intervention included:
  – Print reminder material including brochures and posters that encouraged staying in care and contained information on:
    • The importance of staying in care
    • Clinic contact numbers
    • Research showing better health with regular care
  – Brief verbal messages used by all clinic staff
    • “Thank you for doing such a good job of keeping your appointments. It makes it easier for all of us to work together to keep you healthy.”

Stay Connected – Clinic Wide Intervention

% Keeping Next 2 Visits

- Pre-Intervention Year (2008 - 2009): 49.3%
- Intervention Year (2009-2010): 52.7%

Proportion of Visits Kept

- Pre-Intervention Year (2008 - 2009): 67.9%
- Intervention Year (2009-2010): 69.9%

p < 0.0001

7% Relative Improvement     3% Relative Improvement

*Data adjusted for baseline variables

Stay Connected – Clinic Wide Intervention

**Keeping 2 appointments was 28% better for individuals new or returning to care and 16% better for those with detectable viremia at baseline.**

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  - Proportion of Visits Kept: 67.9%

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  - Proportion of Visits Kept: 69.9%

*Data adjusted for baseline variables*  
Data to Care (D2C): Surveillance for Engagement

The Division of HIV/AIDS Prevention strongly encourages state and local health departments to use HIV case surveillance data to improve the continuum of care in their communities, including the use of individual-level data to offer linkage and re-engagement to care services when appropriate. The Data to Care toolkit is one resource to assist programs in moving forward with these activities. The Division of HIV/AIDS Prevention will continue to provide resources and technical assistance to assist you in these efforts.

Sincerely,

/Janet C. Cleveland/

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CDC. High impact prevention: data to care.
Using HIV Surveillance Data to Re-engage Out-of-Care HIV-infected individuals

• 229 (33%) with ‘no care’ in 9 months were active and in care
• 409 (60%) were confirmed lost to follow-up with these outcomes:

Many People Re-Engage in Care in the Absence of an Intervention

Time to Viral Suppression According to Intervention vs. Control Period (excluding deaths and relocations, N=822)

Hazard ratio 1.18 (95% CI: 0.83 – 1.68)

Dombrowski JC et al, IAS 2015. Abstract TUAD0105LB.
Clinic-Based Data to Care: Effective, but Effect Size is Small

Madison Clinic, Seattle
Time to first return clinic visit: intervention vs. historical controls (N=1399)

Uganda, Kenya, Tanzania
Time to first return clinic visit in a randomized, controlled trial (N=5781)

HR: 1.7 (95% CI: 1.2 – 2.3)

HR = hazard ratio
What About Incentives? HPTN 065

• Randomized by site, Bronx and D.C.
• Patients (all patients at about 40 clinics)
•Received $70 for a suppressed viral load up to once every quarter
  – 40,000 gift cards were given to 10,000 PLWH at intervention sites
  – About $2.8 Million

HPTN 065: Incentives for Retention In Care

Percent Change in Retention and Suppression in HPTN 065

- Continuity in Care: Incentive Arm 16.5% (p < 0.001) vs. Standard of Care -1.8%
- Viral Suppression Overall: Incentive Arm 11.5% (p = 0.01) vs. Standard of Care 3.7%
- Viral Suppression in Those Not Consistently Suppressed at Baseline: Incentive Arm 22.3% (p = 0.007) vs. Standard of Care 16.1%

HIV Clinic-Based Buprenorphine Improved Clinic Retention Compared to Referral for Buprenorphine

EMR-Based Retention Reminders to Providers Improves Retention (to an extent)

**Barriers to Care among Participants in a Public Health HIV Care Relinkage Program**

<table>
<thead>
<tr>
<th>Barriers to HIV Care (N=247)</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No insurance</td>
<td>124 (50)</td>
</tr>
<tr>
<td>Forget appointments</td>
<td>83 (34)</td>
</tr>
<tr>
<td>Trouble getting appointments</td>
<td>79 (32)</td>
</tr>
<tr>
<td>Costs not covered by insurance are too high</td>
<td>75 (30)</td>
</tr>
<tr>
<td>No transportation</td>
<td>70 (28)</td>
</tr>
<tr>
<td><strong>At least one healthcare organization and delivery barrier</strong></td>
<td>184 (74)</td>
</tr>
<tr>
<td>Homelessness</td>
<td>59 (24)</td>
</tr>
<tr>
<td>Using drugs</td>
<td>56 (23)</td>
</tr>
<tr>
<td>Don’t need a doctor</td>
<td>48 (19)</td>
</tr>
</tbody>
</table>

*69% screened positive for depression, 54% reported substance use*

**Healthcare organization & delivery barriers are the most common “important” barriers**

Sometimes, even if I stand in the middle of the room, no one acknowledges me.
Same Day Visit Expansion

- Difficulties in retaining patients who had competing issues and making appointments
- Developed daily slots reserved for ‘same-day’ visits
  - Started with 4 per day in 2010
  - Increased to 10 per day in 2012
  - Increased to 14 per day in 2014
- Encouraged use for urgent issues at first
  - To avoid ER and Urgent Care visits
- Routine care was quickly added
- Covered by existing clinic providers
  - Each provider has one day of same-day each week which doesn’t change week to week
- Has also been very helpful for our PrEP clients
# High Need, Complex Patients

## The MAX ("MAXimum Assistance") Clinic

<table>
<thead>
<tr>
<th>Low-Threshold Care</th>
<th>Incentives</th>
<th>High Intensity Outreach Support</th>
<th>Coordinated Care &amp; Case Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walk-in access to medical care</td>
<td>Snacks each visit, $10 meal vouchers 1x/wk</td>
<td>Non-medical case managers (Public Health)</td>
<td>Madison Clinic and Public Health – Seattle &amp; King County STD Clinic</td>
</tr>
<tr>
<td>- 5 afternoons/wk</td>
<td>Cell phone</td>
<td>Medical case managers (Madison)</td>
<td>Bailey Boushay Day Program</td>
</tr>
<tr>
<td>- case managers 5 days/wk</td>
<td>Bus pass</td>
<td></td>
<td>Lifelong, DESC, supportive housing facilities</td>
</tr>
<tr>
<td>Direct phone line to MAX case managers (no phone tree)</td>
<td>$25 - visit + blood draw q 2 months</td>
<td></td>
<td>Jail release planners</td>
</tr>
<tr>
<td>Text message communication</td>
<td>$50 – VL&lt;200 q 2 months</td>
<td></td>
<td>HMC Office-Based Opioid Treatment Team</td>
</tr>
<tr>
<td>Harm reduction approach</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Enrolled 95 patients in first 2 years; **80%** achieved **viral suppression at least once**, ~**65%** currently virally suppressed

CDC Compendium of Best Practices in Linkage, Retention, and Re-Engagement in HIV Care

Key Messages

• Streamline linkage to care, handoffs need to be active
• Respond to no-show visits, track retention
• Change clinic structure: open access approach for the hardest to reach patients
• Improve the system of care – remove barriers
• Focus on the patient/client
• Implement low-cost, low-effort interventions, when appropriate (with or without clinical trial data)
• Be pre-emptive, it is easier to find people when they are marginally engaged than when they are not engaged
The U.S. HIV Continuum 90:90:90 Goals

- Diagnosed: 90%
- Receipt of care: 81%
- Retained in care On Therapy: 72%
- Viral suppression: 72%
Estimated annual HIV infections in the U.S. declined **18%**

Between 2008 - 2014 infections fell from 45,700 to 37,600

- **56%** decline among people who inject drugs
- **36%** decline among heterosexuals
- **26%** decline among gay and bisexual men aged 35-44 years
- **18%** decline among gay and bisexual men aged 13-24 years

Gay and bisexual men remain most affected

- Gay and bisexual men: 26,200 infections (70%)
- People who inject drugs: 1,700 infections (5%)
- Gay and bisexual men who inject drugs: 1,100 infections (3%)
- Heterosexuals: 8,600 infections (23%)
Trends in annual Age-Adjusted* Rate of Death Due to HIV Infection by sex, United States, 1987-2014

Note. For comparison with data for 1999 and later years, data for 1987–1998 were modified to account for ICD-10 rules instead of ICD-9 rules.

*Standard: age distribution of 2000 US population
Keep up the great work!
Thank You

Questions?

Contact Email:

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