Current Status of HIV Continuum of Care Research

Carlos del Rio, MD
Emory University
Center for AIDS Research
Atlanta, USA
• HIV-infected unaware of status
• HIV-infected not in care
  • Not ready for care or do not want care
• HIV-infected in sporadic care
  • They come and go from care/ some have been on ARV’s
• HIV-infected in care and long term treatment
  • In clinic regularly/ virologically suppressed

del Rio C, Green S, Abrams C, Lennox JL, From Diagnosis to Undetectable: The Reality of HIV/AIDS Care in the Inner City. 8th CROI; 2001 (Abstract #S21)
“Pyramid” of HIV/AIDS in the US

5 Million engage in behaviors that put them at high risk (3.5% of US population)\(^1\)

650,000 - 900,000 living with HIV\(^2\)

480,000 - 540,000 know they are infected\(^3\)

292,000 - 372,000 in care\(^3\)

175,000 - 223,000 on HAART\(^3\)

70,000 - 90,000 suppressed\(^4\)

~ 10% of those living with HIV virologically suppressed

---

1. JAIDS 1999; 21:148-156
2. JAMA 1996; 276; 126-31
3. NEJM 1998; 339:1897-904
HRSA Continuum of Engagement in HIV Care

- Unaware of HIV status (not tested or never received results)
- Aware of HIV status (not referred to care; didn’t keep referral)
- May be receiving other medical care but not HIV care
- Entered HIV primary medical care but dropped out (lost to follow-up)
- In and out of HIV care or infrequent user
- Fully engaged in HIV primary medical care

The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection
Edward M. Gardner, Margaret P. McLees, John F. Steiner, Carlos del Rio, and William J. Burman

Clinical Infectious Diseases. 2011;52:793-800
The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection
Edward M. Gardner, Margaret P. McLees, John F. Steiner, Carlos del Rio, and William J. Burman

Clinical Infectious Diseases. 2011;52:793-800

~ 19% of HIV-infected are virologically suppressed
Engagement in HIV care and Treatment US

~ 28% of HIV-infected are virologically suppressed

Cohen et al. MMWR 2011
The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection

Edward M. Gardner,1,3 Margaret P. McLees,1,3 John F. Steiner,2 Carlos del Rio,4,5 and William J. Burman1,3

1Denver Public Health and 2Kaiser Permanente Colorado, Denver, 3University of Colorado Denver, Aurora, Colorado, and 4Rollins School of Public Health of Emory University, and 5Emory Center for AIDS Research, Atlanta, Georgia

37% not suppressed
Cascade presentations at 20th CROI


- Dombrowski J, et al. *An Encouraging HIV Care Cascade: Anomaly, Progress, or Just More Accurate Data?* (Abst 1027)

- Quinn K & Skarbinski J. *Health Insurance Coverage and Type Predict Durable Viral Suppression among HIV+ Adults in Care: US, Medical Monitoring Project, 2009.* (Abst 1028)


- Supervie V & Costagliola D. *The Spectrum of Engagement in HIV Care in France: Strengths and Gaps.* (Abst 1030)

Articles on PubMed

- HIV Cascade – 442 articles (113 since 2011)
- HIV Care continuum – 453 articles (150 since 2011)

However many of these “hits” don’t really have anything to do with the Continuum of Care or the Cascade of Care but rather with other topics such as:

- The CASCADE Collaboration (122 papers)
- Toll-like receptor/interlukin-1R or phospholipase C/protein kinase C signaling cascades
HIV Continuum of Care Research

- **Descriptive/epidemiological studies:**

- **Assessing and modeling the impact of interventions:**
HIV Continuum of Care Research

- **Monitoring quality of care:**
Research Program to improve the Continuum of Care

- Rapid HIV Testing
- ARTAS, HOPE
- CTN 0049, Project RETAIN
Challenges to Interpreting Cascade-Related Data

- Different types of data bases are being used to calculate cascades that are not directly comparable

- Different measures used to calculate cascade steps
  - **Denominators** – infected, diagnosed or living with HIV
  - **Linked to Care** – CD4/VL or visit within 3, 3-4, 6 or 12 months
  - **Retained in Care** - CD4/VL vs. visits, 12 vs. 24 months, frequency
  - **Viral suppression** – undetectable, <200, <400

- Calculation of cascade steps likely under-estimates
  - **Diagnosed** but not reported
  - **Linked or retained** but moved to different jurisdictions or clinical sites
  - **Virally suppressed** with no recent viral load data available
The HIV Care Cascade

Kaiser Permanente Cascade

HIV Spectrum of Engagement Cascade in a Large Integrated Care System by Gender, Age, and Methodologies

US National HIV/AIDS Strategy
Continuum of Care Related Goals

• **Testing** – ↑ percentage of people living with HIV who know their status from **79% to 90%**

• **Linkage** – ↑ proportion of newly diagnosed patients linked to clinical care within 3 mos from **65% to 85%**

• **Retention** – ↑ proportion of Ryan White clients in continuous care from **73% to 80%**

• **Viral Suppression** – ↑ proportion of HIV-diagnosed gay and bisexual men, Blacks and Latinos with undetectable viral load by **20%**

TESTING – Increase HIV serostatus awareness from 79% to 90%

Increase LINKAGE to care w/in 3 months of Dx from 65% to 85%

RETENTION: Increase RW clients in continuous care from 73% to 80%

Increase proportion of HIV Dx’d persons with VIRAL SUPRESSION by 20%
White House Office of National AIDS Policy (ONAP) commissioned the Institute of Medicine (IOM) to convene a committee to:

- recommend data and indicators to assess the impact of the National HIV/AIDS Strategy (NHAS) and the Patient Protection and Affordable Care Act (ACA) on HIV care
- assess available public and private data systems that capture HIV care information
- recommend ways to supplement and to maximize the usefulness of existing data systems
Standardized Cascade-Related Measures

- IOM expert committee recommended standardized cascade-related measures:
  
  - **Linkage** – Proportion of people newly diagnosed with HIV who are linked to care for HIV within 3 mos. of diagnosis
  
  - **Retention in care** – Proportion of people with diagnosed HIV infection who are in continuous care (2 or more visits for routine HIV care in the preceding 12 mos. at least 3 mos. apart)
  
  - **Viral Suppression** – Proportion of people with diagnosed HIV infection who have been on ART for 12 or more mos. and have a viral load below the level of detection

IOM Metrics

**Testing**
- Proportion with CD4+ cell count >200 and without a clinical diagnosis of AIDS

**Diagnosis**
- Proportion linked to care for HIV within 3 months of diagnosis

**Primary Care**
- Proportion in continuous care for 12 or more months with CD4+ cell count ≥350

**Treatment**
- Engagement/Retention

**Virologic Suppression**
- Engagement/Retention

**In the Past 12 Months**
- Proportion who received 2 or more CD4 tests
- Proportion who received 2 or more viral load tests
- Proportion screened for chlamydia, gonorrhea, and syphilis
- Proportion screened for hepatitis B
- Proportion immunized for hepatitis B (if needed)
- Proportion screened for pneumococcal pneumonia
- Proportion who received drug resistance testing prior to ART initiation

**Since Diagnosis**
- Proportion screened for tuberculosis
- Proportion screened for hepatitis B

**Proportion with mental health disorder referred for mental health services who receive these services within 60 days**
- Proportion with substance use disorder referred for substance abuse services who receive these services within 60 days
- Proportion with an unmet need for housing, food or nutrition, transportation
- Proportion screened for mental health disorders at least once in preceding 12 months
- Proportion screened for substance use disorders at least once in preceding 12 months
- Proportion assessed for need for housing, food or nutrition, transportation

**Proportion with a measured CD4+ cell count <500 who are not on ART**
- Proportion with HIV-associated nephropathy, hepatitis B (when treatment is indicated), or active tuberculosis who are not on ART
- Proportion of HIV-infected pregnant women who are not on ART

**Proportion on ART for 12 or more months who have an undetectable viral load**
- All-cause mortality rate
Table 1: Core Indicators for Clinical HIV Care

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion of people newly diagnosed with HIV who are linked to clinical care for HIV within three months of diagnosis</td>
<td>Timely linkage to care improves individual health outcomes and reduces transmission of the virus to others.</td>
</tr>
<tr>
<td>Proportion of people with diagnosed HIV infection who are in continuous care (two or more visits for routine HIV medical care in the preceding 12 months at least three months apart)</td>
<td>Continuous HIV care results in better outcomes, including decreased mortality, and reduced transmission of the virus to others.</td>
</tr>
<tr>
<td>Proportion of people with diagnosed HIV infection who received two or more CD4 tests in the preceding 12 months</td>
<td>Regular CD4 testing permits providers to monitor individuals’ immune function, determine when to start antiretroviral therapy (ART), and assess the need for prophylaxis for opportunistic infections.</td>
</tr>
<tr>
<td>Proportion of people with diagnosed HIV infection who received two or more viral load tests in the preceding 12 months</td>
<td>Regular viral load (plasma HIV RNA) testing is important for monitoring clinical progression of the disease and therapeutic response in individuals on ART.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Measure</th>
<th>Numerator</th>
<th>Denominator</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Positivity</td>
<td># HIV positive tests in 12-month period</td>
<td># HIV tests conducted in 12-mo</td>
</tr>
<tr>
<td>Late HIV Diagnosis</td>
<td># persons with a dx of Stage 3 HIV (AIDS) within 3 mo of dx of HIV infection in 12-mos</td>
<td># persons with an HIV diagnosis in the 12-mos</td>
</tr>
<tr>
<td>Linkage to HIV Medical Care</td>
<td># who attended a routine HIV medical care visit within 3 months of HIV dx</td>
<td># who attended a routine HIV medical care visit within 3 mo of HIV dx</td>
</tr>
<tr>
<td>Retention in HIV Medical Care</td>
<td># with an HIV dx and at least 1 HIV medical care visit in each 6 mo period of the 24 mo measurement period, with a minimum of 60 days between the 1st medical visit in the prior 6 mo period and the last medical visit in the subsequent 6 mo period</td>
<td># with an HIV diagnosis with at least 1 HIV medical care visit in the first 6 mo of the 24-mo measurement period</td>
</tr>
<tr>
<td>Antiretroviral Therapy (ART)</td>
<td># with an HIV dx who are prescribed ART in 12 months</td>
<td># with an HIV diagnosis with ≥ 1 HIV medical care visit in 12 mo</td>
</tr>
<tr>
<td>Viral Load Suppression</td>
<td># with HIV diagnosis with a viral load &lt;200 copies/mL at last test in the 12–month period</td>
<td># with HIV diagnosis who had at least one HIV medical care visit in the 12-months</td>
</tr>
<tr>
<td>Housing Status</td>
<td># with HIV diagnosis who were homeless or unstably housed in the 12-month period</td>
<td># with HIV diagnosis receiving HIV services in the last 12 months</td>
</tr>
</tbody>
</table>
### Ryan White HIV Care Continuum Definitions

<table>
<thead>
<tr>
<th>Numerator</th>
<th>Denominator (for proportion)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RW client</strong></td>
<td></td>
</tr>
<tr>
<td>Client received at least 1 RW-funded service in calendar year</td>
<td></td>
</tr>
<tr>
<td><strong>Received RW-funded medical care or case management and HIV+</strong></td>
<td>RW client</td>
</tr>
<tr>
<td>Client received RW-funded medical care or case management services and was documented to be HIV+</td>
<td></td>
</tr>
<tr>
<td><strong>RW-funded medical care</strong></td>
<td>RW client</td>
</tr>
<tr>
<td>Received RW-funded medical care</td>
<td></td>
</tr>
<tr>
<td><strong>Retained in care</strong></td>
<td>RW-funded medical care and had visit date available</td>
</tr>
<tr>
<td>Attended at least 2 RW-funded medical care visits that were at least 90 days apart</td>
<td></td>
</tr>
<tr>
<td><strong>ART</strong></td>
<td>RW-funded medical care and had ART data and visit date available</td>
</tr>
<tr>
<td>Received ART prescription at any time in the year</td>
<td></td>
</tr>
<tr>
<td><strong>Viral load suppressed</strong></td>
<td>RW-funded medical care and had viral load available</td>
</tr>
<tr>
<td>HIV-1 viral load &lt;200 copies/ml for the most recent value reported</td>
<td></td>
</tr>
</tbody>
</table>

Doshi RK et al. CROI 2013, abstract 1031a.
Viral Load Suppression
Ryan White Services Report 2010 (preliminary)

Viral load suppressed: HIV-1 RNA <200 copies/ml at the most recent check

Doshi RK et al. CROI 2013, abstract 1031a.
**Viral load suppression, Retained vs. not retained**

<table>
<thead>
<tr>
<th>Retention status</th>
<th>Viral load suppressed (&lt;200 copies/ml at most recent test)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retained in medical care</td>
<td>75%</td>
</tr>
<tr>
<td>Not retained in medical care*</td>
<td>50%</td>
</tr>
</tbody>
</table>

*Received at least 1 RW-funded medical visit but not retained in medical care

Doshi RK et al. CROI 2013, abstract 1031a.
Impact of Social Determinants of Health on the Continuum of Care

- Every step is affected by
  - Stigma and discrimination
  - Racism, homophobia
  - Poverty
  - Risk of criminalization
  - High incarceration rates and difficulty with transition
  - Housing instability
  - Employment instability
  - Co-existing conditions: substance use, mental health disorders
  - Cost of medications and co-pays

Adapted from M. Thompson, MD
## Programme component

<table>
<thead>
<tr>
<th>Programme component</th>
<th>Data sources</th>
<th>Key measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with HIV</td>
<td>Estimates and projections (EPP/Spectrum)</td>
<td>Estimated number of PLHIV</td>
</tr>
<tr>
<td>Aware of status</td>
<td>Surveillance data</td>
<td>HIV prevalence estimates (for specific populations and geographical areas)</td>
</tr>
<tr>
<td></td>
<td>Probability surveys</td>
<td>% tested among different groups within past year (men and women aged 15–49 years, young men and women aged 15–24 years, sex workers, MSM and PWID)</td>
</tr>
<tr>
<td></td>
<td>HIV testing and counselling routine monitoring</td>
<td># of diagnosed HIV cases (new and cumulative)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>% positive among those tested from routine HIV testing and counselling data</td>
</tr>
<tr>
<td></td>
<td></td>
<td>% of persons tested for HIV whose regular partner has also been tested</td>
</tr>
<tr>
<td></td>
<td>HIV case reporting formats</td>
<td>Mean CD4 count at time of diagnosis</td>
</tr>
<tr>
<td></td>
<td>PMTCT routine monitoring</td>
<td>% of pregnant women whose regular partner has been tested</td>
</tr>
<tr>
<td>Linked to care</td>
<td>HIV testing and counselling routine monitoring /</td>
<td>% of newly diagnosed cases who have been enrolled in HIV care and treatment services</td>
</tr>
<tr>
<td></td>
<td>Care and treatment registry</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PMTCT routine monitoring</td>
<td>% of pregnant women receiving ARV prophylaxis (if not offered Option B/Option B+)</td>
</tr>
<tr>
<td>Retained in care</td>
<td>Care and treatment registry</td>
<td>Number currently receiving care (e.g., receiving co-trimoxazole prophylaxis, regular clinical monitoring/assessment for ART eligibility)</td>
</tr>
<tr>
<td>On ART</td>
<td>ART register</td>
<td># who initiated ART # currently receiving ART # died, lost to follow up, stopped or switched regimens % retained after 12, 24, 36, 60 months</td>
</tr>
<tr>
<td></td>
<td>EWI for HIV-DR</td>
<td>% of patients with on-time drug pick-up % of clinics with drug supply continuity % of clinics with suboptimal prescribing practices</td>
</tr>
<tr>
<td></td>
<td>Pharmacovigilance monitoring</td>
<td># of patients on ART experiencing adverse drug events</td>
</tr>
<tr>
<td>Virological suppression</td>
<td>EWI for HIV-DR</td>
<td>% virologically suppressed at 12 months</td>
</tr>
<tr>
<td></td>
<td>Routine viral load measures</td>
<td>% virologically suppressed at last viral load measurement in the reporting period</td>
</tr>
<tr>
<td></td>
<td>HIV-DR surveillance survey</td>
<td>% of transmitted DR detected among treatment-naive patients initiating ART % of patients with raised viral load at 12–15 months of ART and 24–26 months of ART. % detected with DR among those with raised viral load</td>
</tr>
</tbody>
</table>
Strengths of Cascade as a Public Health Metric

- Powerful visual tool to monitor engagement in care at the national, state, local and health care system levels

- Provides valuable insights into steps in HIV care continuum where drop-off in engagement occurs that can help target programmatic and research activities

- Can be used to monitor progress of jurisdictions over time, and between jurisdictions if similar definitions and methodologies used
Surveillance Data Used to Track Progress Towards NHAS Goals

Using the HIV Surveillance System to Monitor the National HIV/AIDS Strategy

- 13 jurisdictions with CD4/VL in surveillance system

- **Linkage:** 82% of 4,899 persons diagnosed in 2009 had at least 1 CD4 or VL within 3 mos.

- **Viral Suppression:** 69% of 53,642 PLWH in 2009 had VL<200

- System will become increasingly representative

Gray et al., Am J Public Health 2013
The White House
Office of the Press Secretary

FOR IMMEDIATE RELEASE

JULY 15, 2013

EXECUTIVE ORDER

EXECUTIVE ORDER

ACCELERATING IMPROVEMENTS IN HIV PREVENTION AND CARE IN THE UNITED STATES THROUGH THE HIV CARE CONTINUUM INITIATIVE

By the authority vested in me as President by the Constitution and the laws of the United States of America, and in order to further strengthen the capacity of the Federal Government to effectively respond to the ongoing domestic HIV epidemic, it is hereby ordered as follows:

Section 1. Policy. Addressing the domestic HIV epidemic is a priority of my Administration. In 2010, the White House released the first comprehensive National HIV/AIDS Strategy (Strategy), setting quantitative goals for reducing new HIV infections, improving health outcomes for people living with HIV, and reducing HIV-related health disparities. The Strategy will continue to serve as the blueprint for our national response to the domestic epidemic. It has increased coordination, collaboration, and accountability across executive departments and
Hepatitis C Cascade of Care in United States

RESEARCH RECOMMENDATIONS

- Randomized controlled trials evaluating interventions to improve retention and virologic suppression such as case management, peer-health navigators, contingency management, etc.
- Implementation science research to evaluate scaling up interventions that prove to be effective
- Operational research to optimize / standardize measurements
- Comparative evaluation of monitoring strategies in conjunction with intervention studies
- Comparative evaluation of case management in community settings
- Comparative evaluation and cost effectiveness for best practices for implementation of effective interventions
- Prospective evaluation of pay for performance interventions
- Evaluation of the impact of the ACA on the HIV Care Continuum

Adapted from M. Thompson, MD
Affordable Care Act and HIV

- “Affordable” premiums are not the whole story
- High deductible plans are unaffordable for many
- High co-pays are often unaffordable and may lead to inconsistent drug access
- SU/MH benefits often minimal, if present
- Transportation not covered
- Case management not covered
- Most ART’s are tier 4 drugs with high co-pays
- Many states have refused to expand Medicaid

Adapted from M. Thompson, MD
Acknowledgements

- Alan Greenberg, MD, MPH
- Wendy Armstrong, MD
- Melanie Thompson, MD
- Rupali Doshi, MD, MSCR
- Michael Horberg, MD, MAS

- Funders: NIH/NIAID CFAR (P30 AI050409) & NIH/NIDA (1R01DA032098)