Data to Care: From Start to Finish

Friday, September 11, 2015
United States Conference on AIDS
Session Outline

- NASTAD’s work on Data to Care (D2C)
- Policy and Data to Care
- D2C in Action – Washington State
- Questions and Answers
- Next Steps
Data to Care (D2C)

• *Data to Care* is a public health strategy that aims to use HIV surveillance data to identify HIV-diagnosed individuals not in care, link them to care, and support the HIV Care Continuum.

• NASTAD created a Community of Practice (CoP) to help Health Departments implement D2C.

• CoP Facilitators: Colorado, Hawaii, South Carolina and Washington State
Assessing Health Departments’ Readiness to Implement D2C

• 22 jurisdictions (including cities) responded to a NASTAD survey, indicating they were implementing D2C:
  • Among High Prevalence Jurisdictions: California, Florida, Georgia, Louisiana, Maryland, North Carolina, New York City, Puerto Rico, South Carolina and Texas.
Assessing Readiness, cont.

**COMPLETED**

• Conducted ongoing assessment and monitoring of timeliness and completeness of HIV surveillance data, including laboratory reporting, to ensure minimum data quality standards are met. (70%)

• Assessed internal and external compliance with CDC's NCHHSTP data security and confidentiality guidelines. (70%)

• Met with relevant health department stakeholders (e.g., HIV prevention/care, HIV surveillance, STD surveillance, etc.) and consider ways to strengthen program integration. (57%)
D2C Models being implemented (N=22)

- Combination Health Department/Healthcare Provider Model 61.5%
- Health Department Model 23.1%
- Other, please specify 15.4%
Collaboration between HIV Prevention, Care and Surveillance

- Superior 34.8%
- Good 26.1%
- Sufficient 21.7%
- Needs improvement 17.4%
Policy and D2C
The HIV Care Continuum

- Also known as the “HIV Treatment Cascade”
U.S. HIV Care Continuum, 2011

Example 1: Prevalence-Based HIV Care Continuum, 2011

- Diagnosed: 86%
- Linked to care*: 80% of those diagnosed in 2011
- Engaged in care: 40%
- Prescribed ART: 37%
- Viral suppression: 30%

*Linkage to care measures the percentage of people diagnosed with HIV in a given calendar year who had one or more documented viral load or CD4+ test within three months of diagnosis. Because it is calculated differently from other steps in the continuum, it cannot be directly compared to other steps and is therefore shown in a different color. See Table 1 on page 4 for more details.


National HIV Care Continuum Objectives

Federal Policy

• Federal Funding
  • Ryan White HIV Program
  • High-impact prevention (PS12-1201)

• National HIV/AIDS Strategy: Updated to 2020
  • “Strengthen coordination across data systems, and the use of data to improve health outcomes and monitor use of Federal funds.”
  • “‘Data to care’ strategies may be applied to identify and re-engage persons in care, and have shown to be effective in improving care continuum outcomes.”
State and Local Policy

- HIV disease reporting laws
  - CD4
  - Viral load test
- Health Information
  - Security required
  - Information privacy
  - HIPPA
- Disclosure
Managing the HIV Continuum: Data to Care

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U.S. Conference on AIDS
2015
Data to Care Definitions

“A new public health strategy that aims to use HIV surveillance data to identify HIV-diagnosed individuals not in care, link them to care, and support the HIV Care Continuum.”


A public health strategy that integrates surveillance and other data to identify HIV-diagnosed individuals not in care, engage them in care, and manage the HIV Care Continuum.
Goals for Data to Care in WA

• Improve accuracy of surveillance data—Washington State had approximately 3500 HIV cases in eHARS with ambiguous data when the Data to Care project began in 2012:
  • Residence
  • Provider information
  • Care status
• Locate, contact and re-link out of care PLWH
• Enable use of the HIV Continuum to drive strategies and evaluate outcomes for prevention and care services.
Considerations

- Organization
- People
- Data
- Geography
Organization

The Office of Infectious Disease (OID) reorganized to include adult viral hepatitis and the STD program into a new Infectious Disease Prevention unit (IDPS) and began joint coordination of HIV Continuum services.

Established Linkage and Retention in Care Services (LARCS) team to implement continuum services and develop new data systems for programs that address gaps in the continuum:

- Antiviral Treatment and Access to Services (ARTAS)
- Care and ART Promotion Program (CAPP)
- Locating out of Care system (LOOC)
- Future joint RFP for HIV continuum services
- Integrating data to care into Washington Disease Reporting System (2016)
People

- Disease investigators were assigned to facilitate entry/reentry into medical care
- Epidemiologists and researchers began participating in programming decisions
- Information technologists and program developers struggled with communications challenges
- Community agencies’ new role in care as prevention
  - Accountability for linkage to care.
  - Case managers trained in ARTAS
  - Opportunities for re-linkage and adherence services.
Data

• Existing data systems were developed independently for core surveillance, HIV/STI prevention, and care services
• Incompatible variables and data management standards
• Data systems were not equipped to support action in the field outcome evaluation and timely feedback
• New tools were needed to enable effective use of available data
Geography

• Washington’s prevention resources are limited to areas with greatest HIV burden -- the Puget Sound region and two other metropolitan areas
• PLWH throughout the state need access to medical care, including linkage, engagement and treatment adherence services
• Our D2C approach uses a combination of centralized and local resources to cover the entire state
Blue-shaded counties represent 93% of all new HIV cases

Pink dots represent one person living with HIV (n = 10,447; dots randomized within census tracts).
Tools Developed

• Improved STD/HIV partner services data base
• Preliminary positive reporting for non-clinical testing sites
• Increased HIV testing for MSM diagnosed with STI (with linkage expected)
• Increased HIV / STI testing for all receiving partner services
• Developed the Locating out of Care (LOOC) data system
• Manuals and training for system users
• Plan for both these systems to be incorporated into forthcoming Washington Disease Reporting System (WDRS)
Linkage to Care
## Linkage to Care 2014

### Time between date of HIV diagnosis and date of first CD4 test, among newly diagnosed cases, Washington State, 2014

<table>
<thead>
<tr>
<th>Time interval</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same date</td>
<td>25%</td>
<td>24%</td>
<td>25%</td>
</tr>
<tr>
<td>&lt; 3 months</td>
<td>64%</td>
<td>63%</td>
<td>64%</td>
</tr>
<tr>
<td>3-6 months</td>
<td>4%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>6-12 months</td>
<td>2%</td>
<td>4%</td>
<td>3%</td>
</tr>
<tr>
<td>&gt; 12 months</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Unknown/missing</td>
<td>5%</td>
<td>7%</td>
<td>5%</td>
</tr>
</tbody>
</table>
1. eHARS
2. Lab Tracker
3. ADAP / HADS
4. CareWare
5. Accurint
6. PHIMS STD
7. DOC registry
8. OOS surveillance
RE-LINKAGE / DISPOSITION

- LOOC
- INTERNAL INVESTIGATION
- EXTERNAL (STATE / LOCAL DIS)
- DISPOSITION
- RE-LINK INTERVENTION
- CASE MANAGER
- MEDICAL PROVIDER
### Overview of LOOC Process

<table>
<thead>
<tr>
<th>Step</th>
<th>Who</th>
<th>What</th>
<th>Why</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DOH eHARS Query</strong></td>
<td>DOH epidemiologist</td>
<td>Query statewide HIV surveillance data to identify PLWHA who haven’t had labs during 12-month follow-up period.</td>
<td>Identify potentially OOC cases and make baseline data available for investigation.</td>
</tr>
<tr>
<td><strong>Internal Investigation</strong></td>
<td>DOH disease investigators</td>
<td>Use available resources to investigate and document patient whereabouts and HIV care status.</td>
<td>Reduce investigation burden on local public health, take advantage of DOH-specific data resources, and ensure consistency and efficiency of investigation methods.</td>
</tr>
<tr>
<td><strong>Local Investigation</strong></td>
<td>Local DIS</td>
<td>Use locally-available resources to investigate, verify, and document patient whereabouts and HIV care status.</td>
<td>Take advantage of local data resources; leverage familiarity with local landscape and existing provider relationships.</td>
</tr>
<tr>
<td><strong>Care Assessment</strong></td>
<td>Local DIS or CAPP specialists</td>
<td>Contact and discuss HIV care status directly with patient; use Care Assessment Tool or CAPP interview (KC only).</td>
<td>Take advantage of direct patient proximity to make direct contact, get patient perspective regarding care status and service needs. Identify and document reasons for being out of care.</td>
</tr>
<tr>
<td><strong>Action &amp; Referral</strong></td>
<td>Local DIS or CAPP specialists</td>
<td>Attempt to provide direct assistance or refer patient to re-engagement service(s)</td>
<td>Take advantage of direct patient contact and care assessment data to help patient get (re-) linked to HIV medical care.</td>
</tr>
</tbody>
</table>

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Internal Investigation – Process Flow

- **Automated or manual** checks of available data systems including:
  - eHARS,
  - Lab Tracker,
  - Accurint,
  - HADS,
  - PHIMS STD, and
  - CareWare

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**DOH eHARS Query** → **Internal Investigation** → **Local Investigation**

- **Evidence of WA residency?**
  - Yes → **Assign Final Disposition**
  - No → **Push for Local Investigation**

- **Evidence of HIV care?**
  - Yes → **Assign Final Disposition**
  - No → **Push for Local Investigation**
Local Investigation – Process Flow

DOH eHARS Query → Internal Investigation → Local Investigation → Care Assessment

Evidence of WA residency?
- Yes
- No

Evidence of HIV care?
- Yes
- No

Assign Final Disposition

Needs to be re-pushed?
- Yes
- No

Re-push case to new county

Assign Final Disposition

Contact patient, assess care

Manual checks of available data resources including:
- eHARS
- Accurint
- remote EMR,
- program records,
- prison/jail records,
- provider contact,
- patient contact
Care Assessment—Process Flow

1. Internal Investigation
2. Local Investigation
3. Care Assessment
   - Patient contacted?
     - Yes: Evidence of HIV care?
       - Yes: Assign Final Disposition
       - No: Go to Action & Referral
     - No: Assign Final Disposition
4. Action & Referral

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Referral & Action– Process Flow

Local Investigation → Care Assessment → Action & Referral

Accepts DIS assistance (or doesn't need it)?

- Yes: Assign Final Disposition
- No: Accepts CAPP referral?
  - Yes: Refer to CAPP
  - No: Assign Final Disposition
DISPOSITIONS
2015 THROUGH 9/1

OOC - Visit: 146
Moved/OOS: 126
In Care: 81
Not Located: 19
Other: 14
OOC - Other: 10
OOC - Helped Make Appt: 8
Died: 2
Error: 2
OOC - CAPP: 1

31% of dispositions are OOC - Visit.
56% of dispositions are OOC - Visit and Moved/OOS combined.
HIV Care Continuum, WA State, 2014

Based on HIV surveillance data reported to the Washington State Department of Health as of June 30, 2015

† Limited to newly diagnosed HIV cases linked to care within one month (30 days) of HIV diagnosis
* Includes cases with laboratory evidence of at least one HIV care visit in 2014
** Suppression based on whether the last reported viral load test result in 2014 was ≤ 200 copies/mL
Findings

• Many PLWH sampled from surveillance with unknown care status are engaged in medical care. In WA, 84% of newly diagnosed PLWH linked within 30 days.

• Existing definitions of being engaged in care may erroneously classify PLWH as out of care if their schedule of medical visits is different from the chosen surveillance period.

• Surveillance data in Washington show that engagement in medical care is strongly correlated with viral suppression. 85% of those in care are suppressed.

• More timely and consistent lab reporting could limit the number of PLWH with ambiguous care status.

• For all periods with data available, 20->30% of the sample were no longer in state.

• Only a small group located and contacted needed or received assistance to re-enter care.
Implications

• Existing HIV continua may reflect incomplete/inaccurate data
• D2C can be an effective strategy to improve these estimates
• Out of care status may often be transitory, rather than chronic
• DIS are effective in locating PLWH to determine their status
• Circumstances leading to care gaps are complex
• New D2C strategies are needed to identify and re-link PLWH closer to “real time”
In Progress

• Adopting 18-month surveillance period
• Developing more referral streams for LOOC
  • Case managers
  • ADAP
  • Clinical sites
• Analysis of outcome data from LOOC
• Prioritizing cases for re-investigation
• Developing QA/QI reports for different user levels
Re-investigation

**Priority 1:**
>1 VL reported since 1/1/2010 with last reported VL > 5000 copies/ml OR previous LOOC investigation indicated WA residence and person was either in care or out of care

**Priority 2:** > 1 VL reported since 1/1/2010

**Priority 3:** Not yet investigated in LOOC (includes pending)

**Priority 4:** Previous LOOC investigation with final disposition of Not Located, Data Error, or Other
Lessons Learned

- Complete service modeling and system mapping before building the data system to support it.
- Functional integration of HIV care, prevention, and assessment services enhances data to care system development.
- The experience and work habits of people doing investigations should inform the design of the data system. Involve them throughout your data to care transition.
- Resist the temptation to collect huge amounts of data—stick to an essential data set to support outcome evaluation.
- Don’t underestimate the time needed to get this right.
- Plan for continuous training and quality assurance.
- Attention to relationships and communication pays off.
Tools Needed to Improve D2C

• Standard Continuum definitions and variables
• More realistic definition of engagement in medical care
• Solution to bridge the gap dividing surveillance based data and community services information
• Methods for identifying out of care PLWH (or at risk) more quickly than surveillance initiated investigation
• Access to / analysis of clinical and claims data
Future Challenge—manage data for comprehensive HIV prevention and care services

Surveillance data are not available for the At-Risk cascade
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Washington State Department of Health
Thank You

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