Data Systems Across the Continuum
Locating out of Care (LOOC)

David Heal M.S.W.
Washington State Department of Health
July 30, 2015
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 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.
WA implementation of Data to Care

• Data to Care provided a pathway to achieve these goals.

• The time was ripe to further integrate HIV prevention, care, and assessment programs within the Office of Infectious Disease

• With 12-1201 Category C funding we had the opportunity to develop the human and technical infrastructure to support ongoing work to improve HIV surveillance and support engagement in medical care for PLWH in Washington.
Considerations

- Organizational
- Personnel
- Data
- Lay of the land
The Office of Infectious Disease (OID) reorganized in 2011 to unite HIV and Adult Viral Hepatitis prevention programs, then again in 2012 to include 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
Personnel

- Some disease investigators needed new skills to facilitate entry/reentry into medical care.
- Epidemiologists and researchers were unused to participating in programming decisions.
- Information technologists and program developers faced communications challenges.
- Staff of community-based agencies were uncomfortable with data driven services.
Data

- Our existing data systems were developed independently for core surveillance, HIV prevention, and HIV Care Services.
- Incompatible variables and data management standards
- Data systems were not equipped to support program outcome evaluation.
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).
1. eHARS
2. Lab Tracker
3. ADAP / HADS
4. CareWare
5. Accurint
6. PHIMS STD
7. DOC registry
8. OOS surveillance
Tools Developed

• Improved STD/HIV partner services data base
  Increased HIV testing for MSM diagnosed with STI
  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 the department-wide data system now under development
Overview of LOOC Process

1. **DOH eHARS Query**
   - **Who:** DOH epidemiologist
   - **What:** Query statewide HIV surveillance data to identify PLWHA who haven’t had labs during 12-month follow-up period.
   - **Why:** Identify potentially OOC cases and make baseline data available for investigation.

2. **Internal Investigation**
   - **Who:** DOH disease investigators
   - **What:** Use available resources to investigate and document patient whereabouts and HIV care status.
   - **Why:** Reduce investigation burden on local public health, take advantage of DOH-specific data resources, and ensure consistency and efficiency of investigation methods.

3. **Local Investigation**
   - **Who:** Local DIS
   - **What:** Use locally-available resources to investigate, verify, and document patient whereabouts and HIV care status.
   - **Why:** Take advantage of local data resources; leverage familiarity with local landscape and existing provider relationships.

4. **Care Assessment**
   - **Who:** Local DIS or CAPP specialists
   - **What:** Contact and discuss HIV care status directly with patient; use Care Assessment Tool or CAPP interview (KC only).
   - **Why:** Take advantage of direct patient contact and care assessment data to help patient get (re-) linked to HIV medical care.

5. **Action & Referral**
   - **Who:** Local DIS or CAPP specialists
   - **What:** Attempt to provide direct assistance or refer patient to re-engagement service(s)
   - **Why:** Take advantage of direct patient contact and care assessment data to help patient get (re-) linked to HIV medical care.
Internal Investigation – Process Flow

DOH eHARS Query → Internal Investigation → Local Investigation

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

Automated or manual checks of available data systems including:
- eHARS,
- Lab Tracker,
- Accurint,
- HADS,
- PHIMS STD, and
- CareWare
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
- 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 → Local Investigation → Care Assessment → Action & Referral

2. Patient contacted?
   - Yes → Evidence of HIV care?
     - Yes → Assign Final Disposition
     - No → Go to Action & Referral
   - No → Assign Final Disposition
Referral & Action– Process Flow

1. 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

Assign Final Disposition
### DOH Internal Investigation

1. Internal Investigation Status: **Pending**
   - For tracking purposes, please set to "Open" when internal investigation is started. Once internal investigation is complete, set to "Closed".

2. Internal Investigation Steps (Check when complete):
   - Check eHRS
   - Check STD PHRMS
   - Check HADS (DOH Only)
   - Check Prison/Jail Records
   - Check Death Records
   - Check Account
   - Check LabTracker

3a. Residency and Vital Status: **Pending**
   - 3b. If residency/vital status is "Other", please specify:
     - *Instructions: If residency equals "Located, WA Resident", continue to next question (3c). Otherwise, skip to Final Disposition.*


3c. Evidence of HIV care (confirmed by lab result or doctor visit): **Pending**
   - *Instructions: If evidence of HIV care equals "No", continue to next question (#4). Otherwise, skip to Final Disposition.*

4. Push to County: Thurston Co.

### Local Investigation

5. Local Investigation Status: **Pending**
   - For tracking purposes, please set to "Open" when local investigation is started. Once local investigation is complete, set to "Closed".

6a. Local Investigation Steps (Check when complete):
   - Check eHRS
   - Check STD PHRMS
   - Check HADS (DOH Only)
   - Check Prison/Jail Records
   - Check Death Records
   - Check Account
   - Check LabTracker
   - EMR Review-Other
   - Check Local Record
   - Check Case Management
   - EMR Review-CWW
   - EMR Review-STD/MIS/EPIC
   - Contact Provider
   - Contact Patient

6b. If "EMR Review-Other" is checked, please specify:

6c. Request HADS review by DOH (PHS/KC only)? **No**

6d. Used CAPP system to conduct part of investigation (PHS/KC only)? **No**

7a. Residency and Vital Status: **Pending**
   - 7b. If residency/vital status is "Other", please specify:
     - *Instructions: If residency equals "Located, WA Resident", continue to next question (7c). Otherwise, skip to Final Disposition.*
**Care Assessment Tool**

"I would like to ask you a few questions about your experience getting HIV medical care. " (Interviewer: please read each question out loud).

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>8a. Has not having health insurance prevented you from receiving HIV medical care?</td>
<td>Pending</td>
</tr>
<tr>
<td>8b. Has the high cost of care or medication prevented you from receiving HIV medical care, even if you have health insurance?</td>
<td>Pending</td>
</tr>
<tr>
<td>8c. Have you had trouble finding a doctor to provide HIV medical care?</td>
<td>Pending</td>
</tr>
<tr>
<td>8d. Have you had trouble scheduling appointments with your HIV doctor?</td>
<td>Pending</td>
</tr>
<tr>
<td>8e. Has not having reliable transportation prevented you from receiving HIV medical care?</td>
<td>Pending</td>
</tr>
</tbody>
</table>

| In your own words, please tell me if there are any other reasons why you have not been able to get HIV medical care? | (Check all that apply) |
| Forget appointments                                                      | Too busy/day-to-day responsibilities |
| Inconvenient clinic hours or location                                     | Lack of stable housing/homeless           |
| Don't like/trust my doctor                                              | Incarcerated                            |
| Using alcohol or drugs                                                  | Too depressed/other mental health problems |
| Don't like/trust healthcare workers in general                          | Don't want to think about being HIV-positive |
| Language barriers                                                       | Feel good/don't need a doctor            |

| 9b. If additional reason is "Other", please specify:                     | Other                                   |

| 10a. When was the last time you went to the doctor for HIV medical care? | Please enter a valid date MM/DD/YYYY. If you do not know the month or day, please enter 99 (e.g. 04/09/2011). |
| 10b. The last time you went to the doctor for HIV medical care, did you have blood drawn? | (Blank) |

**Surveillance period for evaluation of care status: July 1, 1960 - June 30, 1961.**

**Instructions:** If patient was out-of-care during surveillance period, continue to Action and Referral. Otherwise, skip to Final Disposition.

**Action and Referral**

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>11a. Initial action by DIS: Pending</td>
<td>Pending</td>
</tr>
<tr>
<td>11b. If local action is &quot;Other&quot;, please specify:</td>
<td>Other</td>
</tr>
<tr>
<td>11c. If local action is &quot;Patient Accepted CAPP Interview&quot;, please indicate CAPP site</td>
<td>(Blank)</td>
</tr>
</tbody>
</table>


Outcomes

Historic Case Breakdown

- **TOTAL**: 6819
- **FINAL DISPO**: 5770
- **NO FINAL DISPO**: 1049

85 %
Outcomes

1st Q 2015 Dispositions N = 50

- In Care: 52%
- Moved/OOS: 22%
- OOC - Visit After Survey: 10%
- OOC - Other: 3
- Not Located: 2
- OOC - Helped Make Appt: 4%
- Error: 1
Findings

• The largest proportion of PLWH selected by sampling surveillance data are engaged in medical care.
• Existing definitions of being engaged in care may erroneously classify PLWH as out of care if their schedule of medical visits does not meet inclusion criteria for sampling.
• Surveillance data in Washington show that engagement in medical care is strongly correlated with viral suppression.
• More timely and consistent lab reporting could limit the number of PLWH selected for LOOC investigations.
• For all periods studied, 20-30% of the sample were no longer in state.
In Progress

• Developing system to deal with initial linkage and establishment of care for 18 months after diagnosis
• Developing more referral streams for LOOC
  • Case managers
  • ADAP
  • Clinical sites
• Analysis of outcome data from LOOC
• Developing QA/QI reports for different user levels
Tools Needed

• Standardization of Continuum definitions and variables
• More nuanced definition of engagement in medical care
• Bi-directional flow of surveillance information to more quickly determine migration in and out of state.
• Solution to bridging 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
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. A dedicated team with responsibility for the system works best.
- The work flow of people doing investigations and analysis should strongly influence 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.
Future Challenge—manage data for comprehensive HIV prevention and care services

Surveillance data are not available for the At-Risk cascade
ACKNOWLEDGEMENTS

Jason Carr, Epidemiologist
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Washington State Department of Health
Thank You

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Data System Integration Across the Continuum

VIRGINIA DEPARTMENT OF HEALTH
Division of Disease Prevention

Anne Rhodes, PhD
Director, HIV Surveillance
Overview

• Improving Care Continuum Data
• Integrated HIV Care/Prevention Data System
• Data to Care Efforts/Pilot Results
• Evaluating Interventions with Care Continuum Data
• Next Steps
Surveillance is the conscience of the epidemic
- Dr. James Curran
National HIV Care Continuum

HIV Care Continuum Shows Where Improvements are Needed

In the US, 1.2 million people are living with HIV. Of those:

- **Diagnosed**: 86%
- **Engaged in Care**: 40%
- **Prescribed ART**: 37%
- **Virally Suppressed**: 30%

**Sources:** CDC National HIV Surveillance System and Medical Monitoring Project, 2011.

DATA and PROGRAM

Labs/care markers not reported consistently

Not all deaths reported
Virginia HIV Continuum of Care

12.7% of persons undiagnosed but living with HIV in Virginia in 2012 (n=3200)

<table>
<thead>
<tr>
<th>Category</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosed with HIV</td>
<td>24,887</td>
<td>25,642</td>
</tr>
<tr>
<td>Linked to Care (newly Dx only)</td>
<td>78%</td>
<td>82%</td>
</tr>
<tr>
<td>Care Marker</td>
<td>737</td>
<td>786</td>
</tr>
<tr>
<td>Retained</td>
<td>50%</td>
<td>51%</td>
</tr>
<tr>
<td>Virally Suppressed</td>
<td>39%</td>
<td>39%</td>
</tr>
<tr>
<td></td>
<td>78%</td>
<td>75%</td>
</tr>
<tr>
<td></td>
<td>75%</td>
<td>65%</td>
</tr>
</tbody>
</table>

12.7% of persons undiagnosed but living with HIV in Virginia in 2012 (n=3200).
Continuum of Care for Ryan White Clients, 2013

- Diagnosed with HIV: 100.0%
- Diagnosed in 2013 and linked to care: 97.4%
- Care marker in 2013: 96.4%
- Retained in care in 2013: 85.2%
- Virally suppressed in 2013: 76.7%

All RW clients living with HIV in Virginia as of 2013

RW clients diagnosed with HIV in 2013 (N=421)

- All RW clients living with HIV in Virginia as of 2013: 7,083
- RW clients diagnosed with HIV in 2013 (N=421): 6,831
Disparities in Care Continuum: 2014

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Linkage (n=783)</th>
<th>Retention (n=25,620)</th>
<th>Suppression (n=25,620)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black Race</td>
<td>5.85 (4.06, 8.43)</td>
<td>0.34 (0.32, 0.35)</td>
<td>0.31 (0.29, 0.32)</td>
</tr>
<tr>
<td>MSM</td>
<td>6.33 (4.18, 9.59)</td>
<td>0.35 (0.33, 0.36)</td>
<td>0.37 (0.35, 0.39)</td>
</tr>
</tbody>
</table>

Adjusted Odds Ratio (95% CI) - Adjusted for Receipt of Ryan White Services

Odds Ratio (95% CI)

| Receipt of RW Services | 32.83 (18.48, 58.31) | 1.88 (1.81, 1.96) | 1.16 (1.11, 1.20) |
Black Box: Real Time HIV Surveillance

- Pilot project from Georgetown, funded by NIH
- Involved DC, MD, and VA Departments of Health
- Utilized privacy technology for sharing surveillance data among jurisdictions where an algorithm for matching was set up in the “black box” and returned matches of varying strengths (Exact to Very Low) to each jurisdiction
## Black Box Results

<table>
<thead>
<tr>
<th>Person matches across jurisdictions:</th>
<th>Exact</th>
<th>Very High</th>
<th>High</th>
<th>Medium High</th>
<th>Medium</th>
<th>Very Low</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>DC-MD*</td>
<td>4,013</td>
<td>5,907</td>
<td>53</td>
<td>268</td>
<td>645</td>
<td>482</td>
<td>11,368</td>
</tr>
<tr>
<td>MD-VA*</td>
<td>856</td>
<td>2,343</td>
<td>11</td>
<td>117</td>
<td>377</td>
<td>865</td>
<td>4,569</td>
</tr>
<tr>
<td>VA-DC*</td>
<td>1,064</td>
<td>3,340</td>
<td>15</td>
<td>149</td>
<td>438</td>
<td>529</td>
<td>5,535</td>
</tr>
<tr>
<td>Total</td>
<td>5,933</td>
<td>11,590</td>
<td>79</td>
<td>534</td>
<td>1,460</td>
<td>1,876</td>
<td>21,472</td>
</tr>
</tbody>
</table>

* DC = District of Columbia  
* MD = Maryland  
* VA = Virginia
Care Markers Database

Each of the databases to the left has monthly data extracts uploaded to the CMDB matched on client name, birth date, gender and race. eHARS serves as the base of cases for the CMDB.
e2Virginia

Ryan White All Parts data

HIV Prevention data (Corrections, CAPUS, Testing)

Patient Navigation Process Data

Out of Care Lists
You have a new data sharing request from ABCD Healthcare.

Please log in to https://demo.rde.org/e2virginia/ to grant or deny this request.

Thanks,
the e2Virginia team.
## Summary of Current Alerts

Click on each alert for details.

<table>
<thead>
<tr>
<th>Type</th>
<th>Upcoming Alerts</th>
<th>Past-Due Alerts</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD4 test not performed within past three months</td>
<td>0</td>
<td>160</td>
<td>Consider scheduling or following-up to conduct CD4 test</td>
</tr>
<tr>
<td>VL test not performed within past three months</td>
<td>0</td>
<td>164</td>
<td>Consider scheduling or following-up to conduct a VL test</td>
</tr>
<tr>
<td>No medical appointment in the past three months</td>
<td>N/A</td>
<td>108</td>
<td>Consider scheduling or following-up to ensure medical appointment</td>
</tr>
<tr>
<td>CD4 results less than 200 but status has not changed to AIDS</td>
<td>N/A</td>
<td>7</td>
<td>Review records and ensure the HIV Status is correct. It may need to be changed to AIDS.</td>
</tr>
<tr>
<td>No TB/TST conducted within 12 months of the last TB/TST</td>
<td>N/A</td>
<td>122</td>
<td>Consider scheduling or following-up to conduct TB/TST</td>
</tr>
<tr>
<td>Active clients who have not received any services in the past 6 months</td>
<td>N/A</td>
<td>178</td>
<td>Review client records and try to reconnect them to services or mark as inactive.</td>
</tr>
</tbody>
</table>

All recommendations assume that you first ensure that the data (e.g., CD4 test date and value) has been entered into eCOMPAS.

If you wish to suggest a new alert click [here](#).
Email Alerts

Hello Serge V,

The following are system alert(s) to which you are subscribed:

System: eCOMPAS (https://www.e-compas.com/)
Contract: Ryan White Grantee

<table>
<thead>
<tr>
<th>Type</th>
<th>Alerts</th>
<th>Warnings</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD4 test performed</td>
<td>125</td>
<td>36</td>
</tr>
<tr>
<td>VL test performed</td>
<td>130</td>
<td>34</td>
</tr>
<tr>
<td>Missed Medical Appointment (last medical visit)</td>
<td>168</td>
<td>N/A</td>
</tr>
<tr>
<td>CD4 results less than 200 and status not AIDS</td>
<td>8</td>
<td>N/A</td>
</tr>
<tr>
<td>TB/TST Eligible but not tested this year</td>
<td>105</td>
<td>N/A</td>
</tr>
<tr>
<td>Inactive Clients</td>
<td>115</td>
<td>N/A</td>
</tr>
</tbody>
</table>

You may manage your subscriptions to alerts and reminders by logging into eCOMPAS, clicking the My Account button, and then by clicking the “Alerts and Reminder” tab.

Thank you,
The eCOMPAS Team
Lost to Care Lists

Protocol
• Time frame
• Additional sources
• VDH processes

Distribution
• DIS
• Medical Sites
• Patient Navigators

Data Collection
• In Care
• Reasons Not in Care
• Linked
• Unable to Locate
Results: Pilot Overall

N = 43

- In Care: 39%
- Out of State: 21%
- Deceased: 19%
- Not In Care: 14%
- Not Found: 7%
Evaluation Example

• Care Coordination (CC) intervention at VDH provides medication access and active referrals to care and other providers as persons living with HIV are released from state and local correctional facilities

• CHARLI program (funded through HIV Prevention) funds community-based organizations to provide pre and post-release case management and support services to correctional population living with HIV

• Some client overlap between CC and CHARLI
Re-engagement/re-linkage in HIV medical care is based on evidence of a CD4 or viral load lab draw, HIV medical care visit, or antiretroviral prescription within 90 days following release.

Continuous engagement (retention) was based on two or more of these markers for care within the 12-month post-release time period that were at least 60 days apart.

Virologic suppression was measured as the last viral load within the 12-month post-release time period that was <200 copies/mL.
Next Steps/Future Directions

- Black Box data from other jurisdictions being utilized to update HIV Surveillance data, will be piloting sharing of care marker data among jurisdictions on a real-time basis using Black Box technology.

- Data to Care Staff hired at VDH to review out of care lists internally (Lexis Nexis, other sources) and work with HIV prevention and HIV care contractors to determine missing/other potential data sources, including EMRs.

- e2Virginia launch statewide in January 2016 to collect RSR, CHARLI, HIV testing, and patient navigation data.
Final Thoughts

• HIV Care Continuum is a framework and tool for examining both data and care issues

• Utilizing data for public health action requires merging of multiple sources of information across systems and funding streams

• Increased alignment of goals and objectives across agencies that fund HIV prevention, care, and surveillance activities