Data to Care and Models for Re-engagement in Care

NASTAD Prevention and Care
Technical Assistance Meeting 2016
The HIV Care Continuum

Source: https://www.aids.gov/federal-resources/policies/care-continuum
Data to Care is a strategy that uses HIV surveillance data for individual-level action to re-link PLWH not in care, and support outcomes across the Care Continuum.
Data to Care in Practice

Provider Model

Combination Model

Health Department Model
Data to Care in Practice

- Use surveillance data to identify out-of-care individuals
- Prioritize out-of-care list
- Locate and conduct linkage/re-engagement outreach
- Track and report disposition back to health department
NASTAD’s Data to Care Work

- Capacity Building Assistance (CBA) provider for individual Data to Care technical assistance for health departments
- Online Community of Practice via NASTAD OnTAP (Online Technical Assistance Platform)
- Digi-Book: Coming summer/fall 2016
Re-engagement and Retention: Successfully Using Surveillance Data in Tennessee

NASTAD TA Meeting    July 28, 2016
Accurint Software

- To improve data accuracy, we used the commercial, person-locating software application Accurint®
- Software package owned by Lexis-Nexis, an information service company
- Direct connection to over 37 billion current public records held within 10,000 databases
- Used to verify identities, obtain current address and telephone information, conduct investigations
- Same software used by police and fire departments, bill collectors, federal, state, and local agencies
- Cost is $160/user/month
Generating Out of Care Lists

- Each year, Surveillance generates a list of living HIV clients who reside in Tennessee and who have been out of care for more than 1 year.

  - Clients with evidence of any HIV care (as evidenced by either a CD4 or VL entry) during the prior 3 years (e.g. January 1, 2010 through December 31, 2012)

  - Clients with evidence of any of the following are then eliminated from the list:
    - i. Death
    - ii. Receipt of HIV care in the last year (e.g. January 1, 2012 through December 31, 2012)
    - iii. No longer living in Tennessee
• September, 2013 - First list generated from eHARS
  3,111 eligible clients
  2,264 (after removing Out-of-State, deceased)
• In Feb 2014, Accurint was applied to the entire eHARS database
  15% of clients were removed due to updated info
• 2014 list generated from eHARS
  1,430 eligible clients after removing OOS & deceased
• 2015 list generated from eHARS
  1465 eligible clients (~25% already appeared on prior list)
• Lists are sorted by Public Health Regions and Metro Areas
15% Out of State!
7% Out of State
Privacy Concerns

- Discussions with community partners at statewide meetings
- Decision to use specially trained DIS for re-engagement
- Addressing ‘Big Brother’ issues with contacting clients out of care
Re-Engagement List
Generated from eHARS (May 2015)

68% Individuals reside in CAPUS DIS jurisdictions

- East: 142, 10%
- Nashville: 357, 24%
- Middle TN: 491, 33%
- Memphis: 140, 10%
- Other: 335, 23%

N=1,465
Re-Engagement in Medical Care

• Develop Out-of-Care Lists for 4 DIS Re-Engagement Specialists
  – Identify known diagnosed PLWH who have been out of care for ≥ 1yr
  – Clients with evidence of any care during prior 3 years (1/1/10 – 12/31/12)
  – Eliminate anyone who...
    • Received care w/in the past 1 year,
    • Moved out of state, or
    • Died
  – Stratify remaining list by geography & distribute monthly to DIS Specialists

• Each year fully implemented
  – > 800 cases / year (200 cases per DIS/year)
    • > 70% cases contacted
      – > 70% contacted cases linked to care ≤ 3 mos (or ≥ 49% of total)
DIS Re-Engagement Specialists

Training

- CDC Passport to Partner Services
  - 106 hours of online modules
  - 5 days of in-person training
- ARTAS (Antiretroviral Treatment and Access to Services)
- EIS/DIS/MCM Shadowing
- Continuing Education by SEATEC

Located in geographically distinct areas

- 2 in Memphis
- 1 in Nashville
- 1 in Middle TN

(Note: These 4 DIS cover the jurisdictions that account for ~70% of all known positives who have been identified as being out of medical care for > 1 year.)
Distribution of Client Names

• Client names from the CAPUS list are distributed by the CAPUS Epi or CAPUS central office staff to the CAPUS DIS

• Distributed via two methods
  ✓ Secure transfer (FileZilla)
  ✓ Secure USB Flash Drive

• 25 client names containing most recent contact information are provided to each CAPUS DIS on a monthly basis
CAPUS DIS Investigation

• Access to various databases
  ✓ eHARS
  ✓ PRISM
  ✓ Ryan White Eligibility Service Database
  ✓ PTBMIS
  ✓ Medical record searches (LHD or medical facility)
  ✓ Accurint searches
  ✓ CAREWare
  ✓ TennCare search
  ✓ Facebook
  ✓ Court documentation/arrest records
  ✓ Other electronic databases

• Assessment of care status and barriers if truly out of care
Re-engagement to Care Process

1. Assigned names
   - Utilizing Accurint© and eHARS

2. Verification of Care Status
   - Investigation by DIS

3. Contact those out of care
   - Phone calls
   - House visits
   - Letters

4. Re-engage persons into medical care & social services

5. Informal follow-up to ensure in care
All CAPUS DIS case work is entered into Excel spreadsheet.

<table>
<thead>
<tr>
<th>Current Status of Case</th>
<th>Demographics</th>
<th>Contact Information</th>
<th>If Client in Care</th>
<th>If Client out of Care</th>
<th>Barrier Information</th>
<th>Resource Information</th>
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<tbody>
<tr>
<td></td>
<td>eHARS Number</td>
<td>PRISM Number</td>
<td>Name (last, first)</td>
<td>DOB (mm/dd/yyyy)</td>
<td>Gender (M/F/T)</td>
<td>Race/Ethnicity (See key below)</td>
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<td>Resources Provided and other Notes</td>
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</tbody>
</table>
Disposition of Clients From OOC List

- Deceased
- Out of Jurisdiction
- Contacted – Already in Care
- Contact attempts in progress
- Contacted – In progress
- Contacted – Pending Appointment
- Contacted – Linked to Care
- Contacted – Prefers no contact
- Unable to Locate
- No Contact Attempted
## Data Management

<table>
<thead>
<tr>
<th>Time Period of Year 4</th>
<th>A - Number of Cases Assigned</th>
<th>B - Verified IN CARE</th>
<th>C - Presumed OUT of CARE</th>
<th>D - Deceased</th>
<th>E - Out-of-State/ Jurisdiction</th>
<th>F - In-state, OUT CARE, Eligible for CAPUS Services</th>
<th>G - Contact Attempts in Progress</th>
<th>H - Unable to Contact/ Locate</th>
<th>I - Refused CAPUS Services</th>
<th>J - Pending Appts for Re-engagement</th>
<th>K - Linked to CARE via CAPUS</th>
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</tbody>
</table>

**Definitions**

- **A - Number of Cases Assigned**: Number of CAPUS cases assigned to CAPUS DIS within an allotted period of time (average is 25/month)
- **B - Verified IN CARE (No need of CAPUS efforts)**: Pts. who are verified by CAPUS DIS to be in medical care within the past year; occurs via CAPUS DIS contact, eHARS record search, or provider call
- **C - OUT of CARE (Total cases for CAPUS Investigation)**: Pts. who are out of care, and will be investigated by CAPUS DIS for HIV re-engagement
- **D - Deceased**: Pts. who are deceased thru investigation; CAPUS DIS verifies thru Office of Vital Statistics where death certificate is obtained
- **E - Out-of-State/ Jurisdiction**: Pts. who live outside CAPUS DIS jurisdiction OR pts. who live outside TN
- **F - In-state, OUT CARE (In need of CAPUS DIS services)**: Remaining CAPUS caseload who are out of care and will be contacted by CAPUS DIS, and eligible for CAPUS DIS re-engagement services
- **G - Contact Attempts in Progress**: Pts. whom the CAPUS DIS is currently locating or contacting
- **H - Unable to Contact/ Locate**: Pts. whose locating information cannot be found and contact attempts are exhausted by CAPUS DIS
- **I - Refused CAPUS Services**: Pts. who are out of care and contacted by CAPUS DIS, yet they refuse re-engagement services at that time
- **J - Pending Appts for Re-engagement**: Pts. who have a pending medical appt. in the near future, and are being re-engaged into care; pts. have an actual appt. scheduled w/ prompting by CAPUS DIS
- **K - Linked to CARE via CAPUS**: Pts. who were re-engaged back into medical care b/c of communication and support from CAPUS DIS; pts. actually attended medical appointment and appt. is verified via EHRs
## TN Data-to-Care Program: Progress
(Oct. ‘14 – Sept. ‘15: 12 months)

<table>
<thead>
<tr>
<th>Time Period of Year 3</th>
<th>A Number of Cases Assigned</th>
<th>B Verified IN CARE</th>
<th>C Presumed OUT of CARE</th>
<th>D Deceased</th>
<th>E Out-of-State/Jurisdiction</th>
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<td><strong>215</strong></td>
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<td><strong>5</strong></td>
<td><strong>90</strong></td>
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### CAPUS Goal (Description)

| % of Clients Investigated/Contacted | \( \frac{(B+G+H+J+K)}{(A - (D+E))} \) | 71.2% | 70.00% |
| % of Clients Verified in Care and Linked to Care | \( \frac{(B+K)}{(B+G+H+J+K)} \) | 75.5% | 70.00% |
Data to Care: Lessons Learned

- eHARS accuracy lacking with respect to location and (to a lesser extent) vital status

- Despite reporting requirements, HIV-1 viral load and CD4 reporting to TDH not comprehensive

- While overall “in-care” rates exceeded original target, these numbers were driven by clients found to already be in care
  - Informative (ID labs that hadn’t been reporting CD4 & VL results)
  - As data reporting improves, future linkage-to-care rates among contacted clients are likely to be lower than originally targeted (45% versus 70%)
Application of Lessons Learned

- Accurint applied to entire eHARS database

- Laboratories previously not reporting have been approached and reporting deficiencies have been reconciled (files back-dated to 1/1/12)

- Cleaner data
  - New CAPUS out of care lists more accurate with respect to location and OOC status
    (70% of names located within jurisdictions covered by CAPUS DIS)
  - HIV Continuum of Care more reflective of true picture
Data to Care (D2C)

Iowa’s Reengagement Efforts

NASTAD Prevention and Care Technical Assistance Meeting
Holly Hanson, MA
July 28, 2016
Population Distribution

Iowa’s unique needs...
Hired D2C Coordinator Nov 2014
- Solicited input/buy-in from Bureau partners and HIV community
- Cleaned up surveillance data
- Choose a data system
- Defined roles & responsibilities
- Wrote policies & procedures
- Piloted program
Data System Limitations

- HIV care, prevention, surveillance, DIS all use specialized systems that met siloed needs and outcomes
- D2C is unique program versus multiple systems, duplicate data entry
- Iowa’s current systems were insufficient for D2C activities
Data System Needs

- Ability to gather information from multiple data sources into one place
- Ability to document activities and progress
- Ability to run reports and look at data in multiple ways
- Easy for non IT or “data” people to create forms and manage data
- Flexible and adaptable as program evolves
EpilInfo

- A system designed by CDC for use by public health professions
- [https://www.cdc.gov/epiinfo/index.html](https://www.cdc.gov/epiinfo/index.html)
Cas Documentation

Pg 1: eHARS Import

Pg 2: Surveillance

Pg 3: Initial Investigation

Pg 4: Outreach & Reengagement Activities
Data 2 Care Overview

1. Out of Care List
   - eHARS Quarterly Updates
   - Address in Iowa, vital status alive
   - No evidence of Viral Load, CD4 in prior 12 months
   - Ryan White Referrals
     - Part B Diligent Search Process and referrals
     - Part C "lost to care"

2. Initial Investigation
   - DATA SOURCES
     - eHARS
     - SourceData
     - CAREWare
     - Accurint
     - Medicaid data
   - Social media
   - Incarceration records
   - IDSS
   - ARTS
   - Last known medical provider
   - Last known case manager

3. Initial Status
   - In care out of jurisdiction
   - In care, labs outside of surveillance period
   - In care, reengaged on own
   - In care lab reporting error
   - Deceased
   - Unable to locate
   - Out of care out of jurisdiction
   - Out of care in Iowa
   - Other

4. OOC in Iowa Prioritization
   - Recent STI
   - Named as a contact in an HIV/STI investigation
   - Never Linked to Care
   - Referral from case manager, medical provider
   - Low CD4, high viral load

5. Case Assignment
   - JD2C Coordinator will make initial contact or refer cases to:
     - Medical provider
     - Case manager
     - State or county DIS

6. Outreach & Reengagement Activities
   - Case Staffing with involved parties
   - Individualized outreach plan
   - Strategies
   - Social Media
   - Texts
   - Home visits

All data and activities documented in Epi Info
Out of Care (OOC) List

1. HIV surveillance staff exports list from eHARS using IDPH SAS program
   a. List is imported into EpilInfo on a quarterly basis
2. Ryan White B & C contractors refer OOC cases before they show up on surveillance list
Maintaining OOC List

It’s just as much an active surveillance program as it is a reengagement program…
Initial list generated 567 people who had no evidence of labs 12 months prior to 12/31/14. Initial investigation results (Jan-June 2015):

- 209 relocated
- 80 had labs the first quarter of 2015
- 14 deceased
- 6 determined to be in Iowa and truly out of care (2 were reengaged)
- 258 still pending investigation
Quarterly Updates

January 2016:
377 persons appeared OOC in Iowa
43 added since the previous quarter

April 2016:
338 persons appeared OOC in Iowa
56 added since the previous quarter

July 2016:
351 persons appeared OOC in Iowa
56 added since the previous quarter
“Active” Surveillance

- RW Part B forwards discharge summaries to HIV surveillance
- Discharge summary created for RW Part C clinics to submit to HIV surveillance
- Residency and vital status changes are confirmed and updated in eHARS by D2C Coordinator
- Clients determined “lost to care” are referred to D2C Program
Referrals from RW Part B

RW Part B Discharge Summaries

- Numerous discharges identified client as "lost to care" when client was actually "lost to case mgmt"
- **Diligent search processes** created to identify client’s true status and guide case mgmt efforts to retain and engage in care
- After case manager has exhausted efforts to locate and engage client, client referred to D2C
D2C Coordinator conducts internal investigation:
  ○ Database searches
  ○ Internet searches
  ○ Interviews with service and medical providers
**Status Definitions**

**In care out of jurisdiction:** Labs and current addresses confirmed via surveillance office in another state or territory

**In care, labs outside of surveillance period:** Labs >12 months apart, VL remains undetectable

**In care, reengaged on own:** Labs > 12 months apart with detectable viral load, back in care but not as result of D2C efforts

**In care lab reporting error:** Recent labs, information not captured in eHARS

**Out of care out of jurisdiction:** All data points to residency outside of Iowa, unable to confirm care status

**Deceased:** Verified by obituary, SSDI

**Out of care in Iowa:** Cases are prioritized for outreach and reengagement services

**Unable to Locate:** Electronic searches and interviews exhausted
Case Prioritization

- Recently diagnosed with an STI
- Named as a contact in an HIV/STD investigation
- Never linked to care after initial diagnosis
- Referral from case manager/medical provider related to high-risk behaviors (substance abuse, mental health, multiple partners, etc.)
- High viral load and/or low CD4 count
- Other
D2C Coordinator will make initial contact or refer cases to:

- Medical provider
- Case manager
- State or county DIS
Outreach/Reengagement

- Currently piloting this phase of the program
- Conducting OOC interviews with clients to inform outreach efforts and strategies
- D2C Coordinator conducts case staffings with involved parties to develop individualized outreach plan for high priority cases
- Cases are not closed unless client requests. Always leave door open, asking client if we can check in again in a few months
- Denial, stigma, and addiction are powerful players
Outcomes

28 people are confirmed OOC in Iowa and were referred for outreach and reengagement services in 2016

- 9 have been reengaged with confirmed labs and medical appts
- 6 are active D2C cases, but have not yet been reengaged
- 8 have been contacted, no response
- 5 still trying to find correct numbers, addresses
Customized Outreach

Training Needed:
• Lifetime management of chronic disease vs. one-time treatment
• More in-depth, complex, multiple barriers
• “Baggage”, history of care
• Individualized outreach plan
• What if unable to reengage?
• How often do we reach out?
• How to handle cases who are frequently in and out of care?
Questions Remaining...

Need for state level intensive and ongoing case management program focused on reengagement for the toughest of the toughest of the toughest cases?

Future role of D2C Coordinator: skill set, data focus vs client outreach
Future Activities

- Evaluate outreach activities and strategies
- Involve additional community partners
  - Medical providers outside of the RW system of care
  - Correctional facilities
  - Parole officers and community-based corrections
Thank you!

Questions, comments, suggestions?

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Data to Care: The Hawai‘i Experience

Tim McCormick
NASTAD Prevention and Care TA Meeting:
Ending New HIV and Hepatitis Infections
July 28, 2016
Background

- Low HIV incidence
  - Incidence, 2014: 9.2*
  - Prevalence, 2013: 205.6*
- Population: 1.2m
- Geography
- HIV-specific confidentiality law
- Lab reporting of HIV tests
- Intensive DtC TA
- Staff with SAS skills

*adults and adolescence; per 100,000

CDC, HIV Surveillance Report, Vol. 26; published November 2015
Engagement in HIV Care - Hawai‘i

The continuum of HIV care among persons with diagnosed HIV infection - Hawai‘i, 2012

- 100% of PLWH
- 88.3% of diagnoses in 2010
- 44.2% of PLWH
- 52.1% of PLWH

Denominators are persons living with diagnosed HIV in the end of 2011 (2,208 persons)

Denominator is newly Hawai‘i Diagnosed in 2010 (94 persons)

Data to Care Model

• Rely on reported labs, *not limited to* eHARS/case reports
  • *Of new diagnoses on which linkage to care or partner follow up was initiated, nearly one third were based on lab report only.*
• All newly diagnosed
• Newly diagnosed with no subsequent lab w/in 92 days
• Prev dx, no lab in >275 days
• Additional data:
  • HIV RNA value; previous value(s)/date(s)
  • Syphilis/gonorrhea co-infection
  • Identify/exclude not new; moved out of state
• Follow up:
  • 1. Case manager (if enrolled in case management)
  • 2. Medical provider who ordered last labs
  • 3. Intervention Specialist (IS)

For background on Data to Care, see:
Implementation

“Phased implementation”

1. Integrate assessment of engagement in care for PLWH in the course of HIV Partner Services and STD case investigations
   - Staff re-alignment: DOH STD DIS, HIV PS, STD and HIV testing/linkage positions became Intervention Specialists
2. NIC List: first diagnosed in prior 12 months
3. Collaboration with medical provider to follow up on patients not virally suppressed
4. ADAP-associated clients
5. Expand NIC List to previously diagnosed: not in care or high viral load
Phase 2: Recently Diagnosed

2015: Four Not in Care (NIC) lists, 98 individuals without labs within 92 days of diagnosis; limited to individuals whom the HIV Surveillance Program could not excluded as old cases or moved

- 36 had labs subsequent to NIC list (*results as of end June 2016*)
  - 25 had a SVL in past 6 months
  - 6 had SVL in past 7-12 months, but no subsequent lab for ≥ 6 months
  - 3 had labs in past 6 months, but had not achieved SVL
  - 2 had labs in past 7-12 months, but had not achieved SVL, and no subsequent lab for ≥ 6 months
Phase 3: Medical Provider

- DtC provided HIV RNA lab data for patients last seen by the provider (N=268).
- List included labs as of Dec 2015; provider follow up report as of May 2016
  - 234 (87%) had HIV RNA <20 copies/mL
  - 14 (5%) had low level viremia (20-100 copies/mL)
  - 20 (7%) had HIV RNA > 100 copies/mL. Of these:
    - all had been prescribed ARVs;
    - follow up could not be done on 5: one believed to have moved out of state; one possibly incarcerated; three lost to follow up.
    - The remaining 15 were well known to clinic and case management staff and there had been ongoing contact. Three had died but follow up information was collected.
- Major barriers:
  - 1: stigma
  - 1: working full-time and unable to get to clinic (resolved)
  - 11: substance abuse issues
  - 10: (poorly defined) mental health issues
  - 3: domestic issues including domestic violence
  - 2: homeless
Phase 4: ADAP-Associated Clients

- ADAP gets lab data match on active ADAP clients
  - Summary of active clients (on 4/1/2015, N=311):
    - 75% had labs ≤ 6 mo
    - 11% had labs in the 6-12 mo prior
    - Remainder had not had labs 1-2 years, but all had SVL on all labs for several previous years
    - ADAP discharges clients when there are no charges (selection bias)
  - 2016, Lab data match for clients who were discharged from ADAP in 2015, excluded those discharged because they had died or moved out of state (N=95); and clients whose ADAP applications were denied in 2015 (N=9)
    - Ten identified for f/u: no labs > 12mo or HIV RNA > 10,000 copies/mL
Lessons Learned

• Start somewhere: move parts forward where it’s feasible and taking advantage of opportunities

• “Brand” the different efforts as Data to Care

• Implement with attention to ways to move from reactive to proactive
  • Identify characteristics (of individuals or situations) associated with greater risk of falling out of care
  • Identify earlier points to intervene
Mahalo & Acknowledgments

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