Data to Care is 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.

CDC and John Snow Inc. (JSI) developed a D2C toolkit located on: https://effectiveinterventions.cdc.gov/en/HighImpactPrevention/PublicHealthStrategies/DatatoCare.aspx

Resources include:
- List of important considerations
- Health Department Case Studies
- Tools and Resources
Goal of D2C Community of Practice

- CoPs are working to strengthen public health as members learn, share expertise, and work together on solving common problems in their communities’ domains.

- D2C CoP pilot is a series of interactive conversations between jurisdictions on strategies, challenges and practices.

Desired outcomes:
- Create a comprehensive list of best practices and challenges
- Select an idea, challenge or practice to work on as a team
- Create an active forum to share ideas and develop template for products
March 26, 2015
D2C Case Studies in Implementation (South Carolina and Hawaii)

Today-Webinar #2
Thursday, April 16, 2015
Developing polies and procedures for D2C Implementation (Colorado)

Webinar #3
Thursday, May 14, 2015
Community Engagement: “Necessary Conversations” (Massachusetts)

Webinar #4
Thursday, June 4, 2015
Operationalizing Data: Data and Data Systems used in D2C (Washington state, Colorado, Massachusetts)
Participation in today’s call

- Phones are muted. Please press *7 to unmute your line
- **Today’s call is an interactive discussion forum.** Please ask questions during the presentation via chat box.
- We encourage all participants to respond to questions and share their experience via chat box as we move through the presentation.
- Please participate in polling throughout the call.
Learning Objectives

- Develop policies and procedures to navigate a new system.
- Explore the legalities of data sharing.
- Develop effective communication between programs.
Problem Statement

- Too many people known to be HIV infected have not engaged in HIV care or have fallen out of care.
- We need to develop a process to determine who and where these clients are.
- We need to develop a process to engage and re-engage clients in care.
Why did we implement Data to Care?

- Saw the need for finding people out of care.
- Wanted to learn the barriers keeping people from engaging in care, and how to eliminate these barriers.
- To identify resources available to address this problem.
What challenges to linkage and retention in care has your jurisdiction identified among persons living with HIV in your state?
How did we do it?

- Used what we knew worked (DIS field investigations) as a model for conducting active LTC.
- Began working from referrals DIS provided when interviewing a person newly identified with HIV or had lapsed out of care.
- Initiated FRs with a LTC disease code and created dispositions specific to LTC.
Polling Question

- Who is responsible for loss to care follow up?
  A. Health Department Disease Intervention Specialist
  B. Health Department Dedicated Linkage to Care Coordinators
  C. Staff from Ryan White Funded Clinics
  D. All of the Above
  E. Others, please specify in chat box
How did we do it?

- **Light Bulb Moment:** Our Surveillance colleagues have CD4/VL data. They could cross tab that with persons known to be HIV infected to identify those persons with no CD4/VL reported.

- Employed DIS investigations skills to locate and engage with clients.

- Actively worked with clients thru each step of engagement in care.

- **Sacrifice:** Reassignment of an experienced DIS to this new program.
How do we measure our process?

Helping People Move Through the HIV Continuum of Care

First Diagnosis with HIV

Linked to Care

Retained in Care

Achieve Viral Suppression
Considerations

- Legalities of sharing data.
- Utilize your resources (i.e., discussions with CDC project and privacy officers).
- Program integration; not a concern for Colorado, but could be new territory for other jurisdictions.
- Building relationships; clients and providers to show them the benefits of the program.
- Building understanding of the LTC role both internally and externally.
In Progress

- Data Sharing Task Force.
- Clarification of the Board of Health, CRS 25-4-1404(b).
- Continual education of staff and providers.
- Expansion of LTC to Linkage to Medical Home (LTMH).
- Continuation of the JSI technical assistance by staff to streamline the process across programs.
Tools Developed

- **CDPHE Data to Care: Not in Care Investigation Protocol.**
- Evolving D2C report from surveillance to client based prevention.
- Referral tools for providers to refer to D2C program.
- Initially used DIS D2C model and after JSI TA, developed a D2C collaborative, cross programmatic D2C model.
- Example:
  - DIS passive and active referrals to oversee every new positive in CO
  - Surveillance reports, development of Colorado HIV Care Continuum
Lessons Learned

- What’s next?
  - Ability to change the system; working upstream.
  - Critical Events program to immediately address clients with the highest need to retain or reengage them in care.
  - Integrating up and coming interventions.
    - LTC model has been used for our PrEP program development
    - Program development with ACA changes; enrolling clients in insurance
Colorado Share Screen
Process Maps

- **Before**
  - BOH rule; limited sharing of information
  - LTC Specialist; internal referrals
  - Surveillance reports; internal only

- **After**
  - BOH clarification; expanded process for sharing data for LTC
  - Statewide LTC Coordinator; internal and external referrals
  - Surveillance reports; “continuum of care” data
Investigation Protocol

Figure 1: Summary of NIC Case Investigation Protocol

Databases Used to Update Care Status
- PRISM
- ARIES
- eHARS
- DIS files
- CD4/VL Database
- Ramsell (ADAP medication)
- Medical Records

Databases Used to Update Location Information
- LexisNexis® Accurint®
- Ramsell (ADAP medication)
- ARIES
- OIT (Office of Information Technology) Laboratory Test File
- DMV
- Medical Records
- Post Office Searches
- Social media sites
- Jail searches
- Shelter searches

Contact surveillance authority in jurisdiction of apparent relocation

If evidence of relocation (OOR)

CASE DISPOSITIONS
- Moved
- Died
- In area, successfully contacted
- Presumed in area, contact not successful

If Contacted:
- Currently in care
- Currently in care, other referrals needed
- Previously in care, new LTF
- Not (never?) in care, new LTF case
- LTC self-initiated, f/up in one month
- Outside LTF, not self-initiated
- Located, refused LTF
- Other

Potential NIC Cases
- Contact last known provider
- Contact case to offer re-linkage assistance
  - Call 1 → Letter 1 → Letter 2 → Field Visit
Chat Question

- Colorado uses an extensive network of search engines to update their location information, does your jurisdiction also use these tools?

- What other tools does your state use to update surveillance location information?
Shared Experiences

Louisiana and New York State
Louisiana: Tools to Help Prioritize Investigations

DEBBIE WENDELL, LOUISIANA STD/HIV PROGRAM
Polling Question

Is your jurisdiction considering changing how it prioritizes case investigations (reactor grid) to accommodate data to care activities?

A. Yes we are or have considered changing how cases are prioritized for investigation
B. No, we have not determined there is a need to change how cases are prioritized for investigation
Tools Needed-Colorado

- Legal ability to share surveillance data with prevention programs.
- Data systems to be able to produce reports.
- Skilled staff to extract and create data reports.
- Skilled staff for client interaction and investigation.
- Ability to identify gaps in the system and barriers for clients.
- Develop a network of resources.
Case Study in Developing Policies and Procedures, New York State

MEGAN JOHNSON, DIVISION OF HIV/STD/HCV PREVENTION SERVICES
Data to Care in New York State

A Look at the Evolution of NYSDOH’s ExPanded Partner Services Program

Megan Johnson, MPH, CHES
New York State Department of Health
AIDS Institute
Division of HIV/STD/HCV Prevention Services
Objectives

- Discuss the major players within the NYSDOH, AIDS Institute
- Provide history and context for Data to Care in NYS
- NYSDOHs approach to developing protocols
  - Showcase Data to Care as a collaborative model of care in NYS from inception through service delivery
- Data to Care Job Aids
- Challenges for Data to Care in NYS
- Training Requirements for Linkage Specialist
### Expanded Partner Services (ExPS)

#### Health Department Model
HIV surveillance data to identify individuals diagnosed with HIV who may be out-of-care

Patients with no recent VL or CD4 labs within New York’s HIV Tracking System for 13-24 months

#### High Impact Care and Prevention Project (HICAPP)

**Combination Model**
Health Department & Healthcare Provider

HIV surveillance data & selected health center’s data to identify individuals diagnosed with HIV who may be out-of-care

4 definitions of out-of-care

#### ExPS in Department of Corrections and Community Supervision (DOCCS)

**Health Department Model**
Unique collaboration btw DOH and DOCCS

DOCCS custody data matched with HIV surveillance data to identify individuals diagnosed with HIV who may be out-of-care

2 definitions of out-of-care
NYS D2C TimeLine

2012
- Concept Paper
- Internal AI Workgroup Developed

2013
- Conference Call with Pilot Counties

2014
- 1st ExPS Case Assignments
- Planning for Expansion
- ExPS
- ExPS in DOCCS

2015
- Revamped Protocols Issued
- Internal AI D2C Workgroup Expanded
- 1st Case Assignments

Dec | Jan | Feb | Mar | Apr | May | Jun | July | Aug | Sept | Oct | Nov | Dec | Jan | Feb | Mar | Apr | May | Jun | July

Calls with County Commissioners & Program Staff / Focus Groups
- Initial Pilot ExPS Training
- Pilot Ended
- Health Center Files Submitted
- ExPS Training
- Statewide Expansion Case Assignments
- Data Match
- 1st Case Assignments

Protocol Development & Modification/Enhancements to Systems

Protocol Modifications and System Enhancements
Developing ExPS Protocols

Internal NYSDOH Players

- Surveillance Teams
  - Bureau of HIV/AIDS Epidemiology
  - Bureau of STD Prevention and Epidemiology
- Bureau of HIV/STD Field Services
- Office of the Medical Director
  - Case definition on out-of-care
  - Step-by-step process for working with medical provider

External Players

- Other jurisdictions
  - New York City Department of Health and Mental Hygiene
- Local health departments
Community Engagement

- Focus groups in pilot counties
- Presented at several provider meetings across NYS & NYC
- Sent out ‘Dear Provider’ letters and program summary sheets
- Informed community based organizations (CBOs) & directed funding to support ‘Linkage and Navigation’ services
- Required local health departments to establish collaboration agreements/ MOUs with medical providers & CBOs
Protocol Development
ExPS Job Aids
ExPS Training for Linkage Specialist

Comprehensive Three-Day Training

- Advance partner services skills to ensure staff are prepared to address the needs and challenges associated with re-engagement of individuals along the HIV care continuum
- Key goals and objectives of ExPS and data collection protocols
- Motivation Interviewing & transtheoretical model of behavior change
Challenges

- Monitoring of data quality
- Quality & processing of surveillance data for out-of-care work
- Coordination of initiative
  - Staffing at state level
  - Linkage Specialists
- Access to up-to-date protocols and job aids
Mid-Course Modifications

• Change of assignment basis from last known provider address to last known residence
  – Reduce number of cases classified as out-of-jurisdiction (and, in future, cases transferred)

• Changing date of case assignment “drop” to better coincide with surveillance lab processing schedule
  – Helped reduce cases “pulled back” due to lag in lab result receipt

• Requests for additional information to better match current to care cases
  – Utilize lab accession numbers, dates of last lab draw to “find” lab data

• Pursuit of Lexis Nexis® Accurint® for Unable to Locate Cases
  – Multiple confirmed relinkages as a result of Accurint person search tool
Importance of Flexibility

IX. TIMEFRAMES FOR EXPS CASE CLOSURE

For new diagnoses of HIV/STDs, timely and prompt intervention by PS staff is critical to ensuring patients and partners are tested and treated in order to prevent the spread of infection. While using similar methods, ExPS work for patients living with HIV focuses on a different step in the care continuum, and encourages a more holistic approach to patient preparedness and re-engagement in care.

ExPS Advocates are encouraged to work with patients to comprehensively address barriers to engagement and retention, and to work with medical providers and support services programs to facilitate effective and lasting engagement in HIV care. With this difference in mind, it is expected that ExPS cases may require more intensive work on the part of the ExPS advocate, and may be open for longer time periods than PS investigations for new HIV cases.
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Unfortunately at this point NYSDOH materials are unable to be shared externally.
Thank you!
Questions?
Reminder: Next D2C Webinar
Thursday, May 14, 2015

- 5/14: Massachusetts and Community Engagement.

- Share your experiences: EBascom@NASTAD.org