Data to Care:
Using HIV Surveillance Data to Support the HIV Care Continuum

Webinar for Health Department Prevention Programs
May 15, 2014
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Presentation Outline

• Objective
• Workgroup
• Toolkit
• Technical Assistance
Data to Care

• Objective
  • To use HIV surveillance data to identify HIV positive individuals not in care and support them along the HIV care continuum

• Target audiences
  • Health departments
  • Health care providers
  • Community-based organizations
National HIV/AIDS Strategy

• Increasing access to care and optimizing health outcomes for people living with HIV

• Reducing the number of people who become infected with HIV

• Reducing HIV-related health disparities
Data to Care Workgroup

- CDC Division of HIV/AIDS Prevention workgroup
- Membership
  - Internal: CDC Division of HIV/AIDS Prevention staff
  - External: HIV surveillance & program representatives from:
    - D.C.
    - LA
    - NC
    - NY
    - WA
    - Chicago
    - NYC
    - San Francisco
    - Seattle
Toolkit demo
Next Steps

- Toolkit went live April 30th
- [www.effectiveinterventions.org](http://www.effectiveinterventions.org)
- Add additional tools, resources, and examples of jurisdictions’ *Data to Care* programs
- New content on how HIV surveillance data can help support other activities addressing the HIV care continuum (e.g. retention, viral suppression)
Technical Assistance for HDs

- CDC awarded JSI a one-year contract on 9-29-13 to provide T.A. to seven HDs interested in conducting *Data to Care* work
  - Colorado
  - Florida
  - Hawaii
  - Maine
  - Massachusetts
  - South Carolina
  - Virginia

- Data to Care technical assistance to be a regular offering by the Capacity Building Program
Questions?
Organization of Toolkit

- Important Considerations for Developing a *Data to Care* Program
- Health Department *Data to Care* Program Examples
- *Data to Care* Tools and Resources
Important Considerations

- Program Introduction and Goals
- Operational Steps and Data Needs
- Program Models
- Data Quality
- Data Sources
- Security and Confidentiality
- Ethical Considerations
- Community Engagement
- Monitoring and Evaluation
Operational Steps

1. Use HIV surveillance data to identify NIC individuals
2. Generate output list from HIV surveillance database with key inclusion data for NIC list
3. Investigate NIC list to complete missing data and verify care status
4. Prioritize NIC list for follow-up and outreach
5. Share key data with field staff and/or providers to locate individuals on NIC list and conduct outreach and linkage or re-engagement activity
6. Provide missing data located during investigative and/or programmatic activity to HIV surveillance unit
Program Models

- Health Department
- Healthcare Provider
- Combination
Data Quality

- High quality data is essential
  - Poor quality data may lead to contacting HIV-diagnosed persons who are currently in care, which could:
    - Waste resources
    - Lead to poor community and provider support
    - Confuse or irritate patients

- National HIV Surveillance System Evaluation Standards
Data Sources

- ADAP
- Ancillary surveillance databases
- CAREWare
- National HIV Prevention Program Monitoring and Evaluation
- Social Security Death Index
- State Medicaid Database
- STD, Hepatitis, TB Surveillance Database
- Commercially available databases (people finding services)
Security and Confidentiality

- Key tenant for success
- NCHHSTP Guidelines apply
- Data sharing agreements/MOUs
- Training for staff
Legal/Ethical

- CD4/viral load reporting
- Laws regarding use of HIV surveillance data
- Ethics
  - Benefits to individual and population
  - Consider ethics in implementation
<table>
<thead>
<tr>
<th>Ethical Principle/Value</th>
<th>General Public Health Application</th>
<th>Data to Care Application</th>
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| Health                 | • Maximize health benefits to population and the individual  
                        • Implement interventions to prevent disease transmission | • Is it a legitimate public health use?  
                                • Will it lead to fewer cases of HIV?  
                                • Will persons living with HIV have improved health outcomes? |
| Beneficence            | • Minimize harm (e.g. adverse consequences of treatment, drug resistance)  
                        • How can the risks be minimized?  
                        • What are the known benefits and risks?  
                        • Who incurs the benefits and risks? | • Has our program been designed to reduce the risk to clients as much as possible?  
                                • Have we taken measures to reduce the likelihood of disclosure?  
                                • What benefit will our program offer persons that we contact that wouldn’t have been available to them otherwise?  
                                • Will our program reach the people with HIV who potentially have the most need? |
Community Engagement

- Build support and buy-in
- Inform community of program
- Engage stakeholders
- Honor past processes and agreements with community and affected populations
- Potential topics to discuss with community
Monitoring and Evaluation

**Inputs**
- Number of staff/volunteers working on *Data to Care* activities
- Amount of time spent by staff conducting key *Data to Care* activities
- Amount of funding to support *Data to Care* activities

**Activities**
- Identification of clients who need services
- Previously diagnosed individuals not yet linked to care
- Previously diagnosed individuals who were linked to care in the past but need to be re-engaged

**Processes**
- Number of HIV-diagnosed individuals with viral load/CD4 count (past 12 months)
- Number of HIV-diagnosed individuals contacted who are not in medical care (past 12 months)
- Length of time between initial contact and first care visit
- Number/per centage of previously diagnosed individuals re-engaged in care within 6 months of initial contact

**Outcomes**
- Overall greater health outcomes for people living with HIV/AIDS
- Reduction in community-level HIV transmission

**Impacts**

*Data to Care*
Improving health and prevention
Health Department *Data to Care* Program Examples (1)

• Louisiana
  – Presents one aspect of their Data to Care activities
  – “The LaPHIE program, one of Louisiana’s data to care initiatives, uses a healthcare provider model to directly contact patients and facilitate linkage to or re-engagement in care. Providers (physicians, registered nurses, physician assistants, and nurse practitioners) who practice within the participating medical centers are the facilitators of this data to care work.”
Health Department *Data to Care* Program Examples (2)

- Washington
  - Combination Model
  - “Washington State has adopted a statewide ‘treatment as prevention’ model which focuses on ensuring that all people living with HIV are diagnosed, linked to consistent, optimal HIV medical care, receive antiretroviral treatment, and have a suppressed viral load.”
Tools and Resources

- Dear Colleague Letter
- SAS Program
- Assessment Tool for Health Departments
- NCHHSTP Security and Confidentiality Guidelines
- Project Inform Think Tank Report
- References
- Email Sign-Up for Updates
SAS Program

- Customizable
- Produces individual-level dataset of persons ‘not in care’
- User guide
- Available on HICSB’s SharePoint site
Assessment Tool for Health Departments

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<tr>
<th>Activity</th>
<th>Pre-Program Development</th>
<th>Program Development</th>
<th>Implementation</th>
<th>Continuous QI</th>
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<tbody>
<tr>
<td>1. Read background material on <a href="http://www.effectiveinterventions.org">www.effectiveinterventions.org</a> regarding the use of HIV surveillance data for linkage and re-engagement in care activities.</td>
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<td>2. Talk to staff in other health departments about experiences developing a program that uses HIV surveillance data for LTC activities.</td>
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<td>3. Conduct ongoing assessment and monitoring of timeliness and completeness of HIV surveillance data, including laboratory reporting, to ensure minimum data quality standards are met.</td>
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Using Surveillance and Other Data to Improve HIV Care Linkage and Retention

A report from a Think Tank convened by Project Inform, held November 6 & 7, 2012
San Francisco, California

Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs: Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action

National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention

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