Data to Care:
Leveraging Public Health Partnerships
Across the HIV Continuum

Adherence 2015
June 29, 2015

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Topics

- Data overview
- Overview of Data to Care (D2C) strategy
- Using surveillance data for D2C
- Program aspects of D2C
- Opportunities, challenges, next steps
Diagnosis and treatment status of persons living with HIV who are not virally suppressed — United States, 2011

- 30% Virally suppressed
- 70% Not virally suppressed
- 66% Diagnosed but not in care
- 4% In care but not on ART
- 10% On ART but not virally suppressed
- 20% Not diagnosed

N = 1,201,100
N = 839,336
Estimated Number and Percentage of Transmissions along the HIV Care Continuum, United States, 2009

- HIV infected but undiagnosed: 30,200 (30.2%)
- HIV diagnosed but not retained in care: 25,000 (61.3%)
- Retained in care by not prescribed ART: 2,700 (2.7%)
- Prescribed ART but not virally suppressed: 3,300 (3.3%)
- Virally suppressed: 2,500 (2.5%)
Data to Care Strategy

- **Basic concept is using surveillance data to identify people who are not engaged in care**
  - Never linked to care
  - Dropped out of care

- **Uses surveillance data to determine care status**
  - CD4 or viral load test result as proxy for care visit

- **Data are used for public health follow up**
  - Continuum of Care = aggregate data for monitoring
  - D2C=individual data for public health action
Goals of the *Data to Care* Strategy

- Increase the number of HIV-diagnosed individuals who are engaged in HIV care
- Increase the number of HIV-diagnosed persons with an undetectable viral load
Data to Care: 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
Data to Care Models

- Health Department Model
- Healthcare Provider Model
- Combination Model
**Data to Care** Health Department Model for Linkage and Re-Engagement

1. **Health Department**
   - Generate list of clients identified by HIV surveillance as “not in care”

2. HIV surveillance and prevention staff may check additional sources to confirm “not in care” status and gather information needed for follow-up

3. Healthcare providers and HIV staff communicate about care status of patients on “not in care” list

4. Patients contacted by HIV prevention or linkage staff for linkage or re-engagement assistance

5. **Health Care Provider**

   Patient care visit scheduled

6. **Patient**
Data to Care Health Care Provider Model for Linkage and Re-Engagement

1. Health Department
   - Generate list of clients identified by HIV surveillance as “not in care”

2. HIV surveillance and prevention staff may check additional sources to confirm “not in care” status and gather information needed for follow-up

3. Health care providers and HD staff communicate about care status of patients on “not in care” list

4. Patients contacted by healthcare provider for linkage or re-engagement assistance

5. Patient care visit scheduled
Data to Care Combination of Health Department and Health Care Provider Models for Linkage and Re-Engagement

1. Health Department
   - Generate list of clients identified by HIV surveillance as “not in care”

2. HIV surveillance and prevention staff may check additional sources to confirm “not in care” status and gather information needed for follow-up

3. Healthcare providers and HD staff communicate about care status of patients on “not in care” list

4. Patients contacted by HIV prevention or linkage staff for linkage or re-engagement assistance

5. Patients contacted by healthcare provider for linkage or re-engagement assistance

Patient care visit scheduled
Using HIV Surveillance Data for D2C

- **Requirements**
  - All values of CD4/VL tests reported to surveillance
    - Policy for reporting all values to HD
    - Laboratory compliance
      - Report the test results
      - Use of ELR facilitates the process
  - SAS code and local program inputs to generate NIC list
Areas with Laws and Regulations for Reporting all CD4 and Viral Load Values, July 2014

- Laboratory reporting (laws and regulations)
- Not all values
- All values, specified
- All values, not specified

Puerto Rico
Virgin Islands
Using HIV Surveillance Data for D2C

- **Challenges**
  - Recent or current address - what’s available, what’s current
  - People Search tools
    - Being used by states, local decision to use, consult local legal counsel; concerns about confidentiality and access by vendors

- **Opportunities**
  - Support for use of HIV surveillance data for this purpose from grantees, advocates
  - Multiple projects = more opportunities to enhance surveillance data and its use and learn new strategies
Program Aspects of D2C

- **Requirements**
  - Data sharing from surveillance to program of NIC list
  - Field staff to find and link people to care
  - Tracking of outcomes

- **Challenges**
  - Locating people is challenging (out migration)
  - Reasons for not engaging in care are multifactorial and complex

- **Opportunities**
  - Brings together HIV surveillance, care, and prevention staff together for the first time in some jurisdictions or, in other jurisdictions, with a common purpose that they all support.
Data to Care Toolkit: Technical Assistance at Your Fingertips!
D2C in DHAP

**Program Funding**
- Prevention with Health Departments

**Surveillance Funding**
- National HIV Surveillance System

**Research and Demonstration Projects**
- CoRECT Study
- CAPUS
- Partnerships for Care (P4C)
- Prevention with Health Departments: Cat C innovative projects
- FOA PS15-1506
- FOA PS15-1509

**Technical Assistance Support**
- Toolkit
- TA contract
- CBA grantees
Evaluating D2C

- Many lessons learned and improvements over time
- Few areas are far enough along to have adequate data for evaluation purposes
- CoRECT Study to quantify effectiveness
Next Steps for D2C

- Ongoing projects will provide information on:
  - How effective D2C methods are (CoRECT)
  - Operational aspects of different D2C models
  - Ways to improve use of surveillance data

- Technical assistance to grantees

- Future efforts may include:
  - HDs creating reports for clinics/providers summarizing their linkage and viral suppression outcomes (feedback reports)
Data to Care – Part of a solution

- Jurisdictions should have a comprehensive program to improve the continuum of care
- Data to Care can be an important component
- Data to Care likely isn’t sufficient by itself
  - May be too slow
  - May not identify all persons not in care
  - May not be able to reach all persons not in care
  - Resource intensive
DHAP

Publications and Resources

Available by visiting the DHAP website:
www.cdc.gov/hiv/dhap/about.html

Or by calling:
1-800-CDC-INFO

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