Centers for Disease Control and Prevention

NATIONAL CENTER FOR HIV, VIRAL HEPATITIS, STD, AND TB PREVENTION

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

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High-Impact HIV Prevention and Surveillance Programs for Health Departments

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Background

Data to Care (D2C) is a public health strategy that uses HIV surveillance and other data to support the HIV Care Continuum, by identifying persons living with HIV who are in need of HIV medical care or other services and facilitating linkage to these services. The primary goals of D2C are to increase the number of persons with diagnosed HIV who are engaged in HIV medical care and to increase the number of HIV-diagnosed persons who are virally suppressed, which are consistent with achieve national goals outlined in Healthy People 2030, the National HIV/AIDS Strategy (2022–2025), and the Ending the HIV Epidemic in the U.S. (EHE) initiative.

Jurisdictions should include the active use of HIV surveillance data as part of their comprehensive strategy for linkage to and re-engagement in care activities. Programs should review current D2C activities and may choose to continue programs or refocus activities based on lessons learned. Programs implementing D2C have shown improved surveillance data quality, better collaboration among surveillance, prevention and care and treatment staff, and successful linkage to or re-engagement in care for persons living with HIV. Some programs have also found D2C to be an efficient strategy for offering expanded partner services for persons living with HIV not newly diagnosed, and an opportunity to re-interview individuals out of care, conduct partner notification and offer testing and other prevention services. Finally, some programs use D2C methods to identify and follow-up with HIV diagnosed individuals who may be in care, but are not virally suppressed, and may need adherence support or other services. Because D2C activities require collaborative efforts between the health department, HIV medical providers, and essential support service providers, D2C provides important opportunities for enhancing existing collaborations. In preparing your health department's funding application for PS24-0047, you should include plans to integrate new or continue D2C activities as part of your health department's overall HIV prevention program.

D2C approaches may vary in scope and design. Some examples of D2C activities include using HIV surveillance data routinely collected by state and local health departments and other data sources to:

1) Identify persons who are not in care (NIC) and then link or re-engage them in care
2) Identify persons who are in care but are not virally suppressed and work with the clients and their providers to support attaining viral suppression or
3) Identify pregnant women or mothers and their exposed infants who may need coordinated services (perinatal HIV services coordination).
4) Identify persons prescribed HIV prescription medicines who have not filled or renewed their prescriptions (Data to Care Rx).

In each example, the basic steps are similar as outlined in the following figure. Surveillance data are used to identify and create a list of persons in need of follow-up. Persons are identified by using surveillance data or provider data linked to surveillance data. The approach to following up with individuals varies and can be conducted by health departments, providers or a combination of both. Information gained as part of the D2C investigation are then fed back ("feedback loop") to health department surveillance programs to improve data quality and monitor the continuum of care for individuals and

populations in your jurisdiction. These improved data can be used by state and local HIV prevention programs, healthcare facilities or clinical providers, as well as community or state agencies, to conduct data-driven planning, monitoring, and evaluation to continuously enhance HIV surveillance, prevention and care activities.

Basic Steps for Data to Care (D2C)

STEP 1

Identify persons presumptively needing follow-up

- Create a presumptive list for follow-up (e.g., not in care (NIC) list, or not virally suppressed, not receiving prescribed HIV medicines) using:
  - Surveillance data
  - Linked surveillance and provider or pharmacy data

STEP 2

Refine list by matching with available data sources

Examples include (but are not limited to):

- HIV Partner Services, STD Surveillance, State Medicaid, Department of Motor Vehicles (DMV) for locating information
- AIDS Drug Assistance Program (ADAP), Ryan White Care Database or EMR/clinic data for care status and other info
- Vital statistics, Social Security Death Index for death information

STEP 3

Conduct follow-up

- Health Department Model – Health department-initiated linkage and re-engagement outreach (partner services, case management)
- Healthcare Provider Model – Healthcare provider-initiated linkage and re-engagement outreach
- Combination Health Department/Healthcare Provider Model

STEP 4

Monitor continuum of care

- Feedback loop to surveillance
- Surveillance data used for analyses
- Data driven planning, monitoring, and evaluation

If your jurisdiction is currently implementing D2C activities, you should describe your current activities and any plans to enhance them in your application. If you have not started D2C activities, you should lay out your plans to begin using surveillance and other available data to identify persons with diagnosed HIV who need to be linked to or re-engaged in care, or who may need assistance in attaining viral suppression, those who

have been prescribed and not receiving their HIV medicines. D2C methods could be incorporated into existing linkage and retention programs that do not currently use surveillance data to identify cases for follow-up or be a component of new programs.

D2C requires use of data available to the health department on persons with diagnosed HIV. The primary source of these data is the HIV surveillance system. Having good quality surveillance data, conducting initial and ongoing assessments, and monitoring of timeliness and completeness of these data is critical for D2C programs. Having state statutes that require reporting of all CD4 and viral load test results and having complete reporting of those tests from laboratories to surveillance will allow more accurate identification of a person's care status and make D2C activities more efficient. Other databases (e.g., STD surveillance data, CAREWare, ADAP, Medicaid, vital records, pharmacy data) may also provide useful information for D2C, such as vital status or current address updates to supplement surveillance data. A careful review of data will be key in developing your D2C program. Creating D2C processes and procedures for sharing data, completing and updating information obtained from multiple sources and creating a feedback loop to surveillance databases will enhance data quality.

Community Involvement

Community involvement is an essential element in developing public health programs that respond to local HIV prevention needs and priorities. When developing D2C programs health departments should involve and inform the local community and key partners throughout the program development, implementation, and evaluation phases. Communities should be informed about the outcomes of the D2C activities and how they contribute to the goals of ending the HIV epidemic. Representatives of the local community, such as persons living with HIV, public health officials, community-based organizations, and HIV care providers should be engaged on an ongoing basis.

Program Tracking and Data Management

Tracking of activities and outcomes of D2C investigations and follow-up activities is an important part of implementing a D2C program. Local programs may add data fields to eHARS to track D2C activities. Some programs have found it useful to manage information in a database external to eHARS (e.g., Microsoft Excel or Access) and some have incorporated key tracking information into currently existing case management or partner services systems used for case management (e.g., Maven, Prism). Whatever data management system is used should meet all NCHHSTP Data Security and Confidentiality standards and allow for tracking of investigation information (e.g., dates and dispositions) to evaluate D2C. NIC investigation outcomes should be reported to CDC through eHARS according to CDC guidance (see Data to Care Reporting Guidance (cdc.gov)).

Monitoring and Evaluation

Monitoring and evaluating D2C activities are important for optimizing both program performance and outcomes. Health departments should involve individuals with experience in program monitoring and evaluation (M&E) from the inception in the design and implementation of a D2C program. Additional resources for monitoring and evaluation

are available at: Data to Care Reporting Guidance (cdc.gov).

Data Sharing

A common challenge to D2C programs is the sharing of data – especially sharing of data obtained through HIV surveillance statues. Challenges can arise when sharing data with internal programs or external partners. To date, program experience suggests that developing and implementing data sharing agreements for D2C may take time, and therefore health departments should consider starting discussions with clinical and community partners around data sharing as early as possible. A good approach is to outline a written plan or agreement. Data sharing agreements are often helpful in facilitating the sharing of needed information and can serve as a starting point for discussions both between public health programs within a health department and between health departments and care providers. Having common security and confidentiality guidelines for protecting data that might be shared either across public health programs within a health department or within a jurisdiction is necessary to ensure the data are adequately protected. The NCHHSTP Data Security and Confidentiality Guidelines provide an outline of content areas of a data-sharing plan and standards for ensuring data security and confidentiality.

Data to Care Resources

Here are some external resources that recipients may want to consider to inform the strengthening and maintenance of their D2C programs.

Flipbook (nastad.org) – This is the weblink to NASTAD's digibook "Data Points: A Health Department Roadmap for Enhancing Data to Care Programs". This web-based book contains more information about D2C, a 2015 assessment of D2C programs, and some examples from Health Departments. **

Data to Care 2019 (nastad.org) – This is the weblink to NASTAD's D2C site with companion information to the Digibook "Data Points: A Health Department Roadmap for Enhancing Data to Care Programs". Additional guidance and resources exist at this site on funding, staffing, data sharing, prioritizing, managing, monitoring, and evaluating D2C programs. **

** Disclaimer – These weblinks were sponsored by CDC's Division of HIV Prevention and are current as of February 2, 2024. Maintenance of these weblinks is the responsibility of the authorizing agency.

Selection of Journal Articles

JAIDS supplement on Data to Care:
Advancing Data to Care as a prevention strategy to reduce HIV morbidity and mortality in the U.S. *Journal of Acquired Immune Deficiency Syndrome.* 82:S1-S79, September 1, 2019

Carey JW, Roland KB, Bessler PA, Tesfaye CL, Randall LA, Frew PM. Overcoming Challenges to HIV Medical Care-seeking and Treatment Among Data-to-Care Program Clients in Baton

Rouge and New Orleans, Louisiana. J Assoc Nurses AIDS Care. 2022 Dec 16. PMID: 36524875. DOI: 10.1097/JNC.0000000000000375

Mulatu MS, Carter JW, Flores SA, et al. Expanding data to care programs to improve HIV care continuum among men who have sex with men and transgender persons: Key processes and outcomes from Project PrIDE, 2015-2019. *Public Health Rep*. 2023 Jan-Feb; 138(1): 43-53.

Neblett Fanfair R, Khalil G, Williams T, et al. The Cooperative Re-engagement Controlled Rial (CoRECT): A randomized trial to assess a collaborative data to care model to improve HIV care continuum outcomes. *Lancet Reg Health Am*. 2021 Aug 28:3:100057.

Roland KB, Carey JW, Bessler PA, et al. "Take care of their hierarchy of needs first": Strategies used by data-to-care staff to address barriers to HIV care engagement. *AIDS Care*. 2023 May; 35(5):764-771.

Technical Assistance

Capacity building assistance (CBA) through trainings and technical assistance for implementing D2C programs is available through the Division of HIV Prevention (DHP) and may be requested through the CBA Tracking System (CTS) supported by DHP's HIV Prevention Capacity Development Branch. Examples of D2C technical assistance received by jurisdictions include developing D2C protocols and data sharing agreements, prioritizing not in care lists, and improving data quality. CBA is provided using varying methods, such as peer-to- peer mentoring, training, information dissemination and consultation. Other technical assistance may also be available from CDC prevention, surveillance, and evaluation programs. Therefore, it is recommended that programs discuss their technical assistance needs with their CDC surveillance epidemiologist and program consultant and prevention program project officers before submitting a CTS request to ensure the appropriate assistance is provided.