



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

**Division of HIV/AIDS Prevention
Centers for Disease Control and Prevention**

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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 national HIV prevention goals (<https://www.hiv.gov/federal-response/national-hiv-aids-strategy/overview>).

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 currently 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 have begun to 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 PS18-1802, you should include plans to integrate D2C activities as part of your health department's overall HIV prevention program.

D2C approaches may vary and range 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).

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 out of care or not virally suppressed

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

Some state and local health departments have started D2C activities. If your jurisdiction is currently implementing D2C activities, you should describe your current activities and plans to enhance them. 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. 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) 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 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 the local community and key stakeholders throughout the program development, implementation, and evaluation phases. 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.

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. Further information about monitoring and evaluation can be found at:

<https://www.cdc.gov/hiv/pdf/funding/announcements/ps18-1802/CDC-HIV-PS18-1802-AttachmentC-EPMP-1Pager.pdf>.

Data Sharing

A common challenge to D2C programs is the sharing of data – especially sharing of data obtained through HIV surveillance studies. 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.

CDC's Data to Care Toolkit

CDC has developed a D2C [toolkit](#) outlining important considerations and successful approaches and best practices in developing a D2C program. Additionally, the [toolkit](#) provides resources to assist health departments and their partners in developing and implementing a D2C program. Although the toolkit currently focuses on D2C activities aimed at identifying person not in care and linking them to care, it includes useful information that can be applied to other prioritized groups such as people who are not virally suppressed or who are experiencing viral failure to support the HIV care continuum. Additional information on D2C activities related to perinatal services coordination is provided in the Perinatal Program Guidance document and Technical Guidance for Surveillance Program chapter on Pediatric Surveillance (see website for more details: <https://www.cdc.gov/hiv/funding/announcements/ps18-1802>).

The following resources located in the D2C toolkit under [Data to Care Technical Assistance Tools](#) can help in planning and implementing D2C activities:

[Data to Care Assessment Tool for Health Departments](#). One of the first steps in developing a D2C program is assessing your health department's readiness and capacity to conduct D2C. Designing a program that will be manageable, complementary to existing programs, and effective can be a challenge. This tool assists health departments and their partners throughout all phases of developing and implementing a D2C program.

1. [Data to Care Flow Diagram](#). This diagram provides a detailed outline of key operational steps in generating a NIC list and conducting an investigation.
2. [Sketching Your Data to Care Program](#). This tool helps to conceptualize the jurisdiction's D2C program.

3. [Methods for Engaging Stakeholders and Communities](#). These technical assistance tools include an outline for a community engagement plan as well as information on engaging providers in D2C.
4. [Potential Database Fields Used in Tracking Investigations of NIC Persons](#). This data dictionary provides a list of potential fields/measures for tracking D2C outreach and investigation activities. Health departments can use these as examples as they determine their jurisdiction-specific variables of interest (a single jurisdiction is unlikely to collect all of these).
5. [Data Sources](#). Health departments should consider using a number of data sources in addition to HIV surveillance data. A list of potential sources is available in the D2C toolkit. A careful review of data will be key in developing a D2C program.
6. [Data Sharing Agreement Examples and Resources](#). Examples of data sharing agreements and other data sharing resources are also provided.

Technical Assistance

Capacity building assistance (CBA) and technical assistance for implementing D2C programs is available through the Division of HIV/AIDS Prevention (DHAP) and may be requested through the CBA request information system ([CRIS](#)) supported by DHAP's Capacity Building 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 CRIS request to ensure the appropriate assistance is provided.