

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

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Information and Resources for Developing a *Data to Care* Program

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.

We have designed this toolkit to share information and resources to assist health departments and their partners in developing and implementing a *Data to Care* program.

A number of jurisdictions are exploring using various methodologies to implement this strategy, including:

- Health Department Model—Health department-initiated linkage and re-engagement outreach
- Healthcare Provider Model—Healthcare provider-initiated linkage and re-engagement outreach
- Combination Health Department/Healthcare Provider Model—A combination of both approaches

Public health officials working in HIV prevention and surveillance are familiar with many of the important considerations and safeguards that they must address when developing a *Data to Care* program. We will continue to add successful approaches and best practices to this Web site as jurisdictions gain more experience implementing *Data to Care* programs.

Descriptions of *Data to Care* programs or models shared on this site are for illustrative purposes only. The methods might not have been evaluated and, thus, statements about their efficacy or effectiveness cannot be made.

To learn more about the important considerations for developing a *Data to Care* program, please refer to the easy-to-navigate links provided along the right side of this page.

Program Introduction and Goals

Part of the growing HIV prevention toolkit is a focus on linking or re-engaging HIV-diagnosed persons to care since HIV treatment confers important individual-level health benefits and population-level prevention benefits. *Data to Care* is one strategy for identifying these individuals, by using HIV surveillance data routinely collected by state and local health departments, and then linking to or re-engaging them in care. Applying the proven public health strategy of using surveillance data to intervene directly in disease control reflects a shift from the more typical use of HIV surveillance data for descriptive and monitoring purposes.

Data to Care programs use laboratory reports received by a health department's HIV surveillance program as markers of HIV care and analyze them to identify individuals who either never linked to care after diagnosis or who did not continue to receive care. The program then offers individuals on this list for outreach by health departments, providers, or both to assist them

with getting into HIV care.

CDC promotes HIV prevention strategies, such as Data to Care, that are consistent with the National HIV/AIDS Strategy goals of decreasing HIV transmission and increasing the number of HIV-diagnosed persons linked to care. Jurisdictions should include use of HIV surveillance data for prevention programming as one part of their comprehensive strategy for linkage and re-engagement in care activities. Such a strategy might include multiple approaches for identifying HIV-diagnosed individuals not in care and linking them to or re-engaging them in care, including expanded HIV screening services, linkage to care interventions such as ARTAS, and other case management and peer-based interventions.

Goals of the *Data to Care* Strategy

- Increase the number of HIV-diagnosed individuals who are engaged in HIV care, and
- Increase the number of HIV-diagnosed persons with an undetectable viral load.

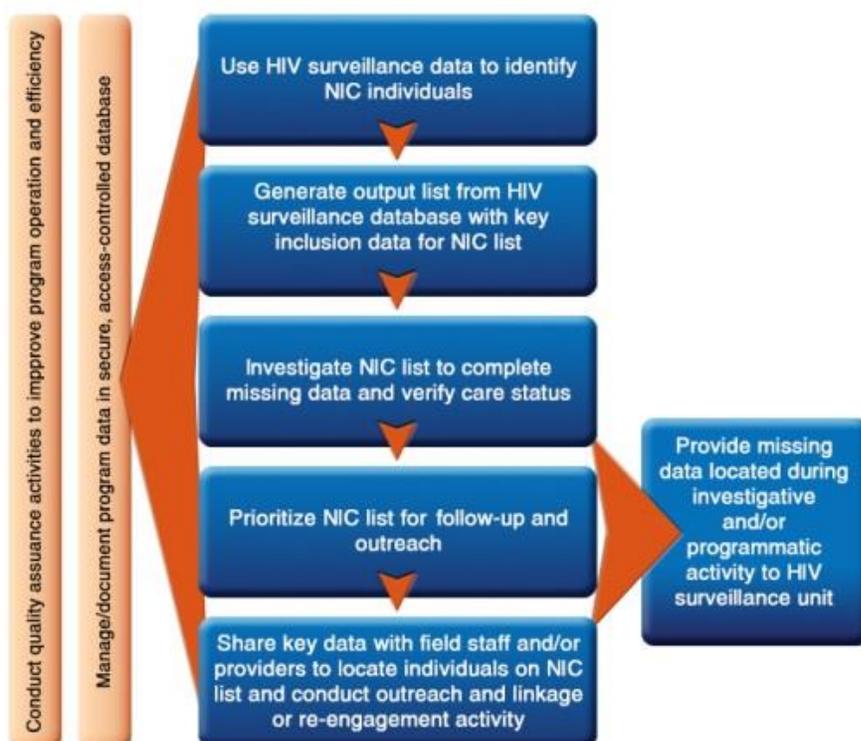
Laboratory reporting to health departments of CD4 and viral load results are a primary data source for identifying individuals who were never linked to care after diagnosis or who did not continue to receive care. By using information from HIV surveillance systems to trigger linkage and re-engagement outreach and assess participation in care, jurisdictions can help ensure improved health outcomes for individuals and reductions in new HIV infections.

Operational Steps and Data Needs for a *Data to Care* Program

Health departments that are considering the use of HIV surveillance data to identify HIV-diagnosed persons “not in care” (NIC) and to ensure linkage to or re-engagement in care will need to make important data-related decisions at each step of *Data to Care* program operation.

To protect confidential patient information, health departments should share the minimal amount of data necessary to accomplish programmatic objectives, and should only share the data with those who need this information in their role with the program.

This diagram outlines basic operational steps for a *Data to Care* program:



Information about each step is listed below:

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

Health department surveillance programs and systems differ in various and important ways. The operational steps presented on this site are one general example of how a *Data to Care* program might conduct this activity. We encourage health departments to consider how this process would work best given their surveillance and prevention programs and tailor it to their situation.

Throughout a *Data to Care* program where HIV surveillance data are used to identify HIV-diagnosed NIC persons and link to or re-engage them in care, health departments might want to:

- Collect and manage program data (i.e., how long it takes to locate a client or whether or not a patient identified as NIC is actually in care) along each step of the program;

- Treat programmatic data with the same level of security and confidentiality as other HIV surveillance data;
- Devise data management processes and systems that will ensure that both HIV surveillance data and ancillary programmatic data are maintained in secure environments; and
- Use program data to conduct quality assurance activities to ensure a highly effective and efficient *Data to Care* program.

Use HIV Surveillance Data to Identify NIC Individuals

The first step is to extract from the health department's HIV surveillance database a list of individuals who are probably not in HIV medical care currently. eHARS software manages the health departments' HIV surveillance databases, which can interface with data management/analysis software such as SAS to extract the list. The most basic data requirements for data extraction are:

- Currently residing in jurisdiction
- HIV diagnosis at or before the end of the specified time period,
- Vital status "Alive," and
- No CD4 (count or %), viral load, or genotype test result during a specified time period.

The Division of HIV/AIDS Prevention's HIV Incidence and Case Surveillance Branch (HICSB) provides a SAS program, called eHARS SAS Program for Identifying Individuals Not in Care, with flexibility to modify the "specified time period," to accomplish this step. The program is available on the HIV Incidence and Case Surveillance Branch's (HIV Incidence and Case Surveillance Branch's (HICSB) SharePoint Web site) SharePoint Web site. HICSB's SharePoint Web site is an access-controlled site only available to HIV surveillance personnel. HIV surveillance staff members who do not currently have access to the SharePoint Web site should consult their assigned HICSB epidemiologist or project officer.

Health departments also might choose to run a locally developed analytic program that performs the same function. Because standards of care, resources, data quality, and the number of "not in care" (NIC) individuals vary significantly across jurisdictions, health departments should establish their own NIC definitions and criteria. This might include decisions about whether to prioritize individuals with no evidence of previous care or individuals who did not continue to receive care, and which criteria to use for determining whether someone is in or out of care (e.g., 3, 6, or 12 months with no CD4 or viral load measure).

In addition to using eHARS to manage HIV surveillance data, many surveillance programs maintain supplemental databases (i.e., laboratory databases) to assist with processing and managing incoming surveillance data. CDC requires that all surveillance programs enter all laboratory data into their eHARS HIV surveillance database as a condition of their funding.

Surveillance programs might consider using their supplemental databases to help create their NIC list if there is a backlog for entering such data into eHARS.

It is important to recognize some limitations when using HIV surveillance algorithms for identifying HIV-diagnosed NIC persons, which might lead to persons being flagged erroneously as NIC when they actually are in care. Examples of why and how this might occur include:

- Delayed laboratory reporting or data entry;
- Incomplete laboratory reporting that can result when a state does not have mandatory reporting of all CD4 and viral load values and an HIV-diagnosed person's results do not meet the reporting threshold;
- Poor-quality laboratory data, such as results missing a patient's date of birth or sex, that preclude matching and entry of the results in the surveillance database; and
- Transience of HIV-diagnosed persons where the lack of laboratory results for an individual could be indicative of them moving to another jurisdiction or getting care in another jurisdiction.

These limitations underscore the importance of HIV surveillance programs working diligently with laboratories, healthcare providers, and internal staff to improve the quality and the timely reporting/entry of all laboratory and case report data. Experience from jurisdictions currently using surveillance data to support linkage and re-engagement in care reinforces the importance of timely and quality laboratory data to achieve best use for *Data to Care* purposes.

Generate Output List from HIV Surveillance Database with Key Inclusion Data for NIC List

The analytic program discussed in Step 1 should extract key data for refining and prioritizing a jurisdiction's "not in care" (NIC) list based upon the operational definition and criteria for "not in care." In addition to basic demographic information for identification purposes, other important data include facility and provider information, laboratory results, and other patient identifiers that might be helpful in investigating whether someone is in care or no longer receiving care.

Because the NIC list contains personally identifying and confidential information reported through surveillance, health departments must keep it in a secure location accessible only to authorized individuals. They also should consider keeping the data file and any back-up copies of the data file encrypted when not using it, as well as limiting any hard copies of these data, securing them when not in use, and destroying them when they are no longer needed. Health departments should develop specific security and confidentiality policies and procedures detailing proper storage and use of these data.

The NIC line listing generated by HICSB's SAS program includes:

- HIV surveillance number (state number)
- Name, including all available names and associated name type (e.g., legal, alias, maiden)
- Date of birth

- Age on the date the line list is generated
- Sex at birth
- Race/ethnicity
- Social Security Number, including alias number(s)
- STD*MIS identification number(s)
- ADAP identification number(s)
- Ryan White identification number(s)
- Medical Monitoring Project participant identification number(s)
- All available address information
- All available telephone numbers
- Date of HIV diagnosis
- Time since initial diagnosis of HIV infection
- State (or country) of residence at initial HIV diagnosis
- County of residence at initial HIV diagnosis
- Date of last care event
- Type(s) of test(s) performed at last care event (if applicable)
- Result(s) of test(s) performed at last care event (if applicable)
- Facility/provider for last care event (if applicable)
- All available facility/provider information (i.e., name, address, telephone number, and whether the facility/provider was a diagnosing, care, or reporting facility/provider)
- All available duplicate review information

Investigate NIC List to Complete Missing Data and Verify Care Status

After generating a “not in care” (NIC) list, health departments should determine if the individuals on the list truly are not in care, to minimize expending resources locating individuals already in care. This step should include turning to other data sources to fill in important information that might be missing from an individual’s record (e.g., current telephone number or address) and to verify the care status.

One step of the investigation process should be checking with the last known care provider to verify care status. Another step of the investigation process should include matching the NIC list to other data sources, which might include databases both internal and external to the health department (e.g., STD Surveillance Database, CAREWare, ADAP, Medicaid, etc.). HICSB provides guidance on conducting data matches in its Technical Guidance for HIV Surveillance Programs. Jurisdictions that do not have the resources to conduct routine electronic matches of the NIC list with other databases might need to conduct matches manually. Health departments should ensure that local law, regulations, and health department policy permit these types of database matches.

Whenever performing matches, compare records to complete data missing from the HIV surveillance database as well as to collect data indicative of care (e.g., laboratory results).

Health departments using Web-based applications or databases as well as conducting electronic data matches should take steps to ensure security and confidentiality of the data. They should

become familiar with how the search function of an application or database will secure the information they use to search for data and whether the application or database will store any information from the search, for how long, and for what purpose. Web-based applications for Internet searches might not be completely secure. Health departments must investigate these applications prior to use and, if they decide to use one: take steps to conduct searches with limited information using secure electronic methods; and ensure IP addresses do not identify the HIV program or its staff directly.

Prioritize NIC List for Follow-up and Outreach

Some health departments might not be able to follow up on every HIV-diagnosed “not in care” (NIC) person on their list. After refining the initial NIC list through investigation, *Data to Care* programs utilizing a Health Department Model might need to prioritize with whom they follow up if it is not possible to contact everyone. For *Data to Care* programs utilizing a Healthcare Provider Model, the health department might find prioritization unnecessary or they might need the healthcare provider to prioritize the information for them. We strongly encourage follow-up with all HIV-diagnosed NIC persons, but programs might not be able to follow up with everyone due to limited resources.

When follow-up with all NIC persons is not possible, *Data to Care* programs might need selection criteria for prioritizing and selecting individuals for follow-up. For example, jurisdictions might prioritize people with more recent diagnoses ahead of older diagnoses, with the intention of increasing the likelihood of locating the individual. Jurisdictions also might choose to prioritize cases that might be recent infections (e.g. acute infection) ahead of those who have more long-standing infection, with the intention of disease interruption among those more likely to transmit infection. In making these decisions, health departments should consider carefully the impact to both the individuals who will not receive follow-up as well as the impact to ongoing HIV transmission in the population.

Examples of other data from the NIC list that *Data to Care* programs might use to prioritize individuals for follow-up include:

- Time from last care visit
- Time since any new information reported to HIV surveillance program
- Most recent unsuppressed viral load
- Geographic area of current residence
- Transmission category
- Race/ethnicity
- Current age

If a health department elects to prioritize cases for follow-up based on geographic areas with high numbers of diagnosed NIC individuals, they might find geospatial mapping a useful tool in identifying these areas. HICSB has guidance for conducting geospatial mapping of HIV surveillance data in its Technical Guidance for HIV Surveillance Programs.

Share Key Data with Field Staff and/or Providers to Locate Individuals on NIC List and Conduct Outreach and Linkage or Re-engagement Activity

Health departments need to determine the minimum data they need to provide to field staff and/or providers responsible for conducting outreach and linkage and re-engagement services. Because these activities have the potential for security or confidentiality breaches, departments should give special attention to using the minimum amount of data needed to ensure adherence to all NCHHSTP security and confidentiality guidelines.

Health departments likely will want to consider including data that will help field staff and/or providers:

- Identify a patient (age, date of birth, gender, race/ethnicity);
- Locate a patient (current home address, most recent care provider and facility, address for most recent care provider); and
- Engage in informed outreach interactions with patient (sufficient information about patient's diagnosis and previous care).

Suggested data for line lists that field staff/providers can use to conduct follow-up with HIV-diagnosed “not in care” (NIC) persons might include:

- Name
- Date of birth
- Gender
- Race/ethnicity
- Age in years
- Most recent known telephone number
- Most recent complete home address
- Medical record number (if giving a list to a provider or going to a provider's office for follow-up)
- Facility of last care event
- Provider of last care event
- Address of last care event
- Last four digits of unique identifier

Jurisdictions might choose to include additional data on the line list depending on the method of follow-up and whether other information is essential to conducting the outreach activities. Jurisdictions should conduct a careful review of the data shared with the healthcare provider to ensure compliance with legal, ethical, and security and confidentiality guidelines on data sharing.

Provide Missing Data Located During Investigative and/or Programmatic Activity to HIV Surveillance Unit for Review and Quality Assurance

During *Data to Care* investigative and/or programmatic activities, health departments that discover information that was missing from the initial “not in care” line list extracted from the HIV surveillance database should provide that information back to the HIV surveillance program so that the program can update individual records. Examples of such information include an individual’s address, telephone number(s), provider name and contact information, or recent laboratory results. The HIV surveillance program should review and verify new data for quality assurance purposes before adding them to the HIV surveillance database.

Data to Care Program Models

Most health departments’ *Data to Care* programs fall into one of three overarching models:

- Health Department Model—Health department-initiated linkage and re-engagement outreach
- Healthcare Provider Model—Healthcare provider-initiated linkage and re-engagement outreach
- Combination Health Department/Healthcare Provider Model—A combination of both approaches

Health Department Model

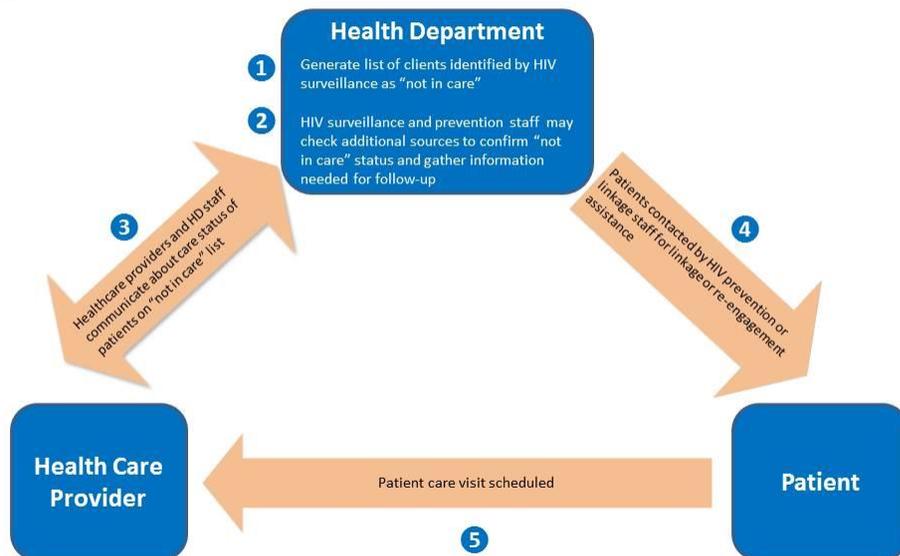
Health departments that conduct HIV surveillance-based outreach to facilitate linkage and re-engagement in care can assign surveillance staff to review CD4 and viral load laboratory tests reported to surveillance to determine preliminarily if an HIV-diagnosed individual has never been in care or is no longer receiving care. By reviewing laboratory tests and dates, surveillance staff can look for missing laboratory tests or a gap in laboratory tests indicating a missed connection or disconnection from care.

Health departments then might assign the list of persons meeting these criteria to field staff, such as disease intervention specialists (DIS) or linkage coordinators, to investigate the care status of those on the list by reviewing other health department records (e.g., CAREWare, ADAP, STD Surveillance, etc.) and contacting the provider each person most recently visited, if any. If field staff can find no evidence or no recent evidence of care, they might attempt to contact the client by telephone, email, or home visit and assist the individual in linking or re-engaging in care.

In jurisdictions that have linked the HIV Partner Services program to HIV surveillance, DIS already might be attempting to facilitate HIV care to fulfill one of the objectives of the program. Contacting all persons who need but are not connected to HIV care will, for many health

departments, represent either an expansion of the scope of the Partner Services program or the addition of a new program to focus on reaching individuals needing linkage or re-engagement in HIV care. Both options typically require additional staff resources.

Data to Care Health Department Model for Linkage and Re-Engagement



Healthcare Provider Model

Some health departments are using HIV surveillance data to inform and assist healthcare providers in contacting patients to facilitate linkage to or re-engagement in care rather than contacting the individuals directly. These collaborations tend to be limited to certain providers or facilities, rather than jurisdiction-wide. For example, health departments might collaborate with providers of Ryan White-funded care by providing lists of patients who do not have laboratory evidence of a recent care visit and encouraging the Ryan White providers to re-engage these patients.

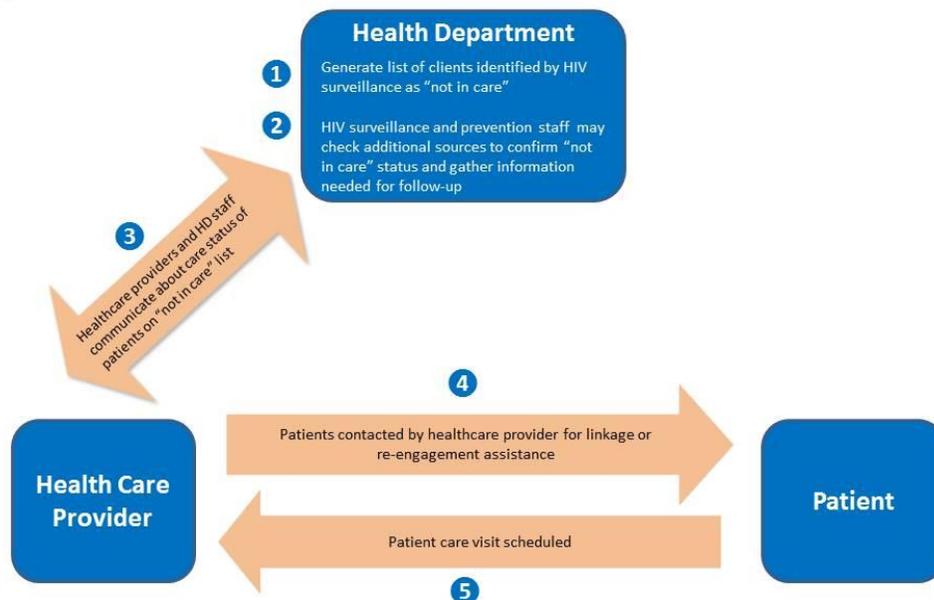
Ryan White providers also might collaborate with HIV surveillance programs by sending a list of patients they have not seen in their clinics for more than 6 months, which the health department matches to HIV surveillance data and other data sources, such as CAREWare and ADAP databases. Then, the health department informs the healthcare providers whether the match does or does not indicate that individual patients are receiving care from another healthcare provider. The healthcare providers then can prioritize contacting people whose last visit was more than 6 months ago and who do not appear to be in care elsewhere (1). This approach also might require varying degrees of effort to build relationships and partnerships focused on implementation, which might be formalized through memoranda of understanding (2, 3).

Health departments might be able to assist healthcare providers who use electronic medical records in conducting linkage and re-engagement activities in a more automated way. This could be accomplished by developing a secure, bidirectional system for exchange of data between the state-wide HIV surveillance database and a facility's electronic medical record system. The bidirectional communication could alert providers that a patient they are seeing for a non-HIV-related care visit potentially has fallen out of HIV care or never entered care. The providers then could offer assistance with re-engagement or linkage to HIV care.

Health departments might use such a system to prompt a healthcare provider accessing the records of an HIV-diagnosed person who has not had a recent care visit to discuss and deliver HIV care to the patient, or to refer the patient to an HIV specialist. Consider this type of approach when it is possible to integrate HIV surveillance and a clinical information system,⁷ but will require resources to operationalize the technical aspects and careful formative work before implementation. This work might include:

- An ethics review,
- A review of legislation to assess the legal environment related to sharing public health information,
- An assessment of physician and patient acceptability (5),
- Solicitation of input from physicians and public health personnel to design the system, and
- Engagement of stakeholders to build consensus and a commitment to protecting patients and public health (4).

Data to Care Health Care Provider Model for Linkage and Re-Engagement



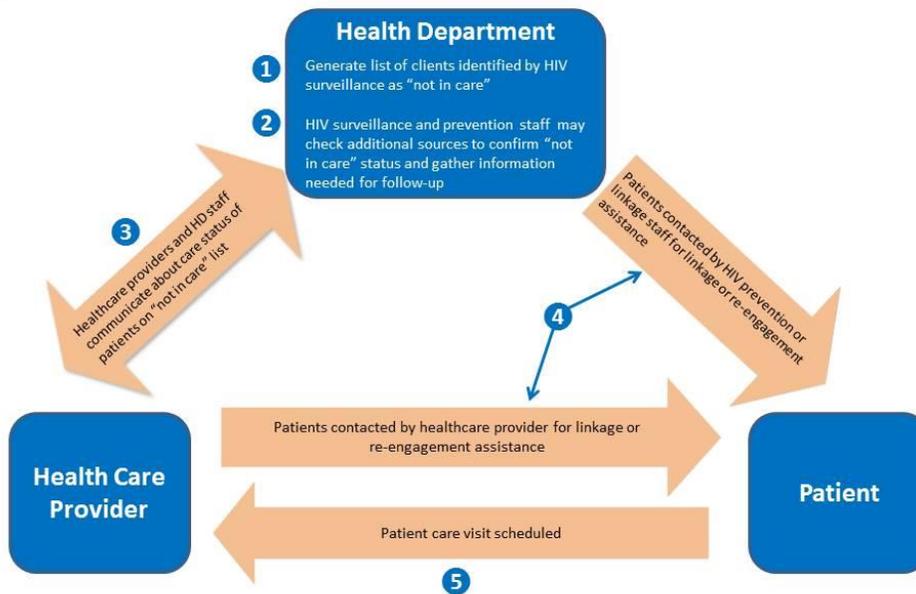
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2. District of Columbia. “Recapture blitz”: Ryan White grantees in Washington, D.C. [PowerPoint presentation]. 2010. Available from: http://nationalqualitycenter.org/download_resource.cfm?fileID=36822, accessed on November 6, 2013.
3. West, T. Strategic information in DC: Uses of public health data for evidence based programming [PowerPoint presentation]. 2011. Available from: http://www.uchaps.org/assets/DC_Strategic_Info_West.pdf, accessed on November 6, 2013.
4. Herwehe, J, Wilbright, W, Abrams, A, Bergson, S, Foxhood, J, Kaiser, M, et al. Implementation of an innovative, integrated electronic medical record (EMR) and public health information exchange for HIV/AIDS. J Am Med Inform Assoc 2012; 19(3):448–52. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3341789/pdf/amiajnl-2011-000412.pdf>, accessed November 7, 2013.
5. Louisiana Office of Public Health. Louisiana Public Health Information Exchange 2012. Available from: <http://www.lsms.org/site/images/stories/LaPhie-Non-technical%20Guide.pdf>, accessed November 6, 2013.

Combination Health Department/Healthcare Provider Model

As described in the Health Department Model and Healthcare Provider Model sections, some health departments are using HIV surveillance data to reach out directly to HIV-diagnosed persons who appear never to have entered or are no longer receiving care, to assist them with connecting or re-connecting to care. Others are using surveillance data to assist providers in reaching out to their patients who appear to no longer be receiving care.

In addition, some health departments are using a combination of these approaches. For example, disease intervention specialists first might confer with providers about contacting persons identified through surveillance, giving the provider the opportunity to opt out of follow-up on behalf of any patient, to initiate follow-up by clinic staff, or to defer follow-up to the health department (1, 2).

Data to Care Combination of Health Department and Health Care Provider Models for Linkage and Re-Engagement



1. Dombrowski, JC. Testing, linkage, and retention in care: Getting control of the cascade in Seattle. Presented at: 2012 National Summit on HIV and Viral Hepatitis Diagnosis, Prevention, and Access to Care; 2012 Nov 26–28, Washington, D.C.
2. Dombrowski JC, Fleming M, Simoni J, Hughes JP, Golden MR. Surveillance-based outreach to promote HIV care engagement and antiretroviral use: Results from the pilot phase of a health department intervention [X-244]. Presented at: Conference on Retroviruses and Opportunistic Infections; 2013 Mar 3–6, Atlanta, GA.

Data Quality for a *Data to Care* Program

Before developing and implementing a *Data to Care* program that uses HIV surveillance data to identify HIV-diagnosed “not in care” (NIC) individuals and link or re-engage them to care, health departments should ensure that the data sources they plan to use are of good quality. By using high quality data, *Data to Care* program staff will spend less time attempting to reach people who are already in care, deceased, or who have left the jurisdiction. The ability to use HIV surveillance data to take public health action and link or re-engage people to care relies heavily on having access to timely and high-quality HIV surveillance data.

As part of the formative process of developing a *Data to Care* program, as well as for ongoing evaluation, HIV surveillance programs should, at a minimum, conduct an assessment of their data quality as recommended and described in CDC’s Technical Guidance for HIV Surveillance Programs. We encourage health departments to conduct additional quality assurance activities

that other agencies already conducting *Data to Care* programs might be using; some of the health department program examples highlighted on this Web site describe such efforts.

Failure to assess HIV surveillance data quality could result in inaccurate information with the following results:

- Missed opportunities for re-engaging HIV-diagnosed NIC individuals, or
- Contacting HIV-diagnosed persons who are currently in care, which could:
 - Waste resources,
 - Lead to poor community and provider support for a *Data to Care* program, and
 - Confuse or irritate the HIV-diagnosed person.

To the extent that health departments use other databases, such as CAREWare and ADAP, to cross-reference and help classify individuals as in or out of care, they should assess the quality of those data sources for the same reasons cited above.

Assessing a Health Department HIV Surveillance System's Performance Using CDC's National HIV Surveillance System Evaluation Standards

Prior to conducting linkage and re-engagement activities, health departments should, at a minimum, assess data quality both for case reporting completeness and timeliness using CDC's National HIV Surveillance System Evaluation Standards. If the data do not meet the standards, health departments should identify areas in which the surveillance system is not performing adequately and develop a plan to address system weaknesses. Assigned CDC HICSB epidemiologists and HIV Prevention Program Branch project officers also can assist health departments in taking corrective action to improve surveillance system performance.

In addition to assessing the overall performance of the local surveillance system, health departments also should assess the quality of specific data elements in the HIV surveillance database that they will use in conducting linkage and re-engagement outreach. Examples of these data elements include:

- Demographic information (home address, telephone number, date of birth), and
- Provider information (name, address, etc.)

If these fields are missing or inaccurate for a substantial number of persons identified, then the health department should improve the completeness and accuracy of these data. Incomplete case reporting indicates that the health department might be missing HIV-diagnosed persons in their surveillance system. If these individuals whose diagnoses are not reported are not in care, the information in the surveillance system will not identify them for linkage or re-engagement outreach.

Improvements might consist of training internal staff to abstract records completely for demographic and provider information as well as educating and training healthcare providers and their staff about the importance of completing the case report form in full.

Health departments also should educate surveillance staff and healthcare providers and their staff about the possible uses and importance of the collected data. For example, explaining to providers and surveillance staff how helpful email or alternative telephone numbers can be when attempting to locate a “not in care” patient might result in more complete and accurate email and telephone number data.

National HIV Surveillance System Evaluation Standards

The following table shows CDC’s national HIV surveillance system evaluation standards. More information on the standards can be found in CDC’s HIV Surveillance Technical Guidance for HIV Surveillance Programs.

National HIV Surveillance System Evaluation Standards	
Process Standard	Definition
Death ascertainment	No less than annual matching of state/local vital statistics, Social Security Death Master File, and National Death Index records (where not prohibited by law) using the most current data year for each of the three sources.
Intrastate duplicate review	No less than monthly resolution of all potential intrastate duplicate pairs.
Interstate duplicate review	No less than semiannual resolution of all potential interstate duplicate pairs.
Outcome Standard	Definition
Completeness	≥70% of the expected number of cases for a diagnosis year are reported by 12 months after the diagnosis year, assessed at 12 months after the diagnosis year.
Timeliness	≥70% of the expected number of cases in a diagnosis year are reported within 6 months after diagnosis, assessed at 12 months after the diagnosis year.
Data quality	≥97% of cases for a diagnosis year pass all standard data edit checks, assessed at 12 months after the diagnosis year.
Outcome Standard	Definition
Risk factor ascertainment	≥70% of cases for a report year have sufficient risk factor information to be classified into a known HIV transmission category, assessed at 12 months after the report year.
Intrastate duplication	≤1% duplicate cases, assessed at 12 months after the report year.
Interstate duplication	≤5% duplicate cases in the NHSS, assessed at 12 months after the report year.
CD4 reporting	≥60% of cases ≥ 13 years old for a diagnosis year have an initial CD4 test result, assessed at 12 months after the diagnosis year.

National HIV Surveillance System Evaluation Standards	
Viral load reporting	≥60% of cases ≥ 13 years old for a diagnosis year have an initial viral load test result, assessed at 12 months after the diagnosis year.
Data reporting and dissemination	Annual HIV infection surveillance report published by the surveillance program.

Assessing Laboratory Data Quality for Use in a *Data to Care* Program

Laboratory reporting laws, which vary from state to state, dictate the specific viral load and CD4 test results that state health departments require for reporting. As of January 2013, 37 state health departments, the city of Philadelphia, Washington D.C., Puerto Rico, and Guam began mandated reporting of all CD4 T-lymphocyte (CD4) and HIV viral load tests to state and/or local public health departments. HIV surveillance programs should conduct periodic assessments of laboratory reporting in their jurisdiction to identify laboratories not reporting HIV test results to the health department and to bring them into compliance with state laws governing HIV reporting. Missing laboratory results could indicate “not in care” (NIC) patients, incomplete laboratory reporting, patient out-migration to another jurisdiction, or death. Therefore, health departments need to develop a *Data to Care* program that draws on multiple data sources to classify cases as in or out of care. Ideally, all laboratory data should be submitted electronically and imported into the HIV surveillance database within timeframes consistent with CDC’s Technical Guidance for HIV Surveillance Programs.

If a state does not receive all laboratory results, (e.g., HIV viral loads >200 copies/ml), then a health department might erroneously designate an HIV-diagnosed person as NIC when really they are in care but have laboratory values that the state does not require be reported. In states where there is restricted laboratory reporting, health departments might find other data sources helpful for determining if a person is in care. Health departments in states that do not require reporting of all CD4 and viral load results should consider carefully if they should implement a *Data to Care* program. Rather, they first might choose to work toward requiring laboratories and healthcare providers to report all CD4 and viral load results.

Data Sources for a *Data to Care* Program

To implement a linkage and re-engagement in care program based on HIV surveillance data, health departments also should consider using a number of data sources in addition to HIV surveillance data. As implied in the name—*Data to Care: Using HIV Surveillance Data to Support the HIV Continuum of Care*—the HIV surveillance database maintained by a jurisdiction’s health department is a necessary data source for conducting this type of program because it contains information on all HIV-diagnosed persons reported to the health department. Laboratory data are necessary for program operation because they contain information about HIV-related laboratory tests conducted on HIV-diagnosed persons in the jurisdiction, which are used as a marker for receipt of care.

Health departments can run a CDC-developed SAS program against the HIV surveillance database, or use a locally developed SAS program, to generate a line list of individuals who appear to be “not in care” (NIC) based upon available HIV surveillance and laboratory data. Once health departments create a line list of HIV-diagnosed NIC persons, they should turn to other sources of information and data that might provide evidence that a person actually is receiving care even if surveillance data suggest otherwise.

Information sources might be a healthcare provider or case manager, and data sources could be one of a number of public health and non-public health databases. For example, a person might appear on a line list extracted from the HIV surveillance database without any evidence of laboratory tests in the past 2 years. However, when a health department matches this list to the ADAP database, they might find that the person is currently in care and receiving medication assistance through the ADAP system and can be removed from the NIC list. This information is not only important for *Data to Care* programs; it also is important information for the HIV surveillance program so that it can investigate why there are missing laboratory tests and can follow up.

Health departments also should turn to other data sources that might complete missing information for persons identified as NIC. For example, if someone is on the NIC line listing and does not have a telephone number in the HIV surveillance database, health departments potentially could use other databases to find a valid telephone number.

The next section describes common data sources that could inform a *Data to Care* program. Health departments routinely use many of these data sources, but perhaps do not typically share them across their program areas. They might need to develop data sharing agreements as *Data to Care* programs look to access multiple data sources. These data sources provide information that could assist in the identification, investigation, and location of NIC clients. The list we provide on this site is not exhaustive and we encourage health departments to explore other or external software systems that might have data that could support these activities. Areas considering using external systems should ensure their use complies with state and local laws and regulations. CDC’s Technical Guidance for HIV Surveillance Programs also provides guidance about conducting electronic database matching.

Potential Data Sources to Help Inform and Run a *Data to Care* Program

- AIDS Drug Assistance Program (ADAP)
- Ancillary HIV Surveillance Laboratory Database
- CAREWare Database
- National HIV Prevention Program Monitoring and Evaluation
- Social Security Death Index
- State Medicaid Database

- State or Local HIV Surveillance Database
- STD Surveillance Database
- Viral Hepatitis and Tuberculosis (TB) Surveillance Databases

AIDS Drug Assistance Program (ADAP)

Each state and local health department that receives funding from the Health Resources and Services Administration maintains the AIDS Drug Assistance Program (ADAP) to provide HIV care and treatment services to individuals with limited or no health insurance coverage. The ADAP database is a potential resource to match against “not in care” line lists generated from the HIV surveillance database to determine if someone is erroneously on this list (e.g., the ADAP database provides evidence of recent laboratory tests or antiretroviral prescription filling). The ADAP database also might be a resource for finding missing information on an individual, such as address, telephone number, or most recent medical provider. An ADAP database often houses laboratory data and health departments might use the information to confirm known laboratory results or to identify previously unreported laboratory test results. The HIV surveillance program should address identifying gaps in laboratory results reporting to ensure more accurate line lists in the future.

Ancillary HIV Surveillance Laboratory Database

Some health departments maintain an ancillary HIV surveillance laboratory database to store, process, and manage laboratory reports they receive prior to importing/entering the data into the HIV surveillance database. Staff should upload all laboratory reports into the HIV surveillance database in a timely manner. Review of the ancillary HIV surveillance laboratory database could be important for determining whether staff have imported all laboratory reports into the HIV surveillance database and for determining if additional laboratory reports are available to designate an individual as in or out of care.

Staff can match line lists extracted from the HIV surveillance database of individuals thought to be “not in care” (NIC) against the laboratory database to determine if such classification is correct. The laboratory database also might be useful for verifying whether the most current locating information for an individual, such as address or most recent provider information, is contained in the line list. The quality of a jurisdiction’s laboratory data is crucial for the success of a *Data to Care* program since poor quality data potentially can lead to misclassification of persons as NIC and inefficient use of resources to locate them. Jurisdictions should place a high priority on ensuring timely reporting and entry of laboratory data into the HIV surveillance database and should conduct continuous and frequent quality assurance evaluations of laboratory reporting and data.

CAREWare Database

CAREWare is a Health Resources and Services Administration-provided software program that health departments can use to manage and monitor HIV clinical and supportive care delivered by Ryan White providers. The CAREWare database includes patient demographic information, medical visits, and laboratory information. Health departments can match CAREWare data against a “not in care” line list extracted from the HIV surveillance database to determine if an individual has evidence of recent HIV care (e.g., recent laboratory or provider visit data), and is another potential resource for obtaining current locating information needed for linkage and re-engagement outreach.

National HIV Prevention Program Monitoring and Evaluation

Health departments are required to collect National HIV Prevention Program Monitoring and Evaluation (NHM&E) data about their CDC-funded HIV prevention activities. NHM&E variables, specifically those related to HIV screening and HIV partner services, might be useful in determining if an individual has been linked to HIV medical care. Information collected on HIV screening events includes HIV test dates and HIV test results. For persons testing positive, data should include referral and linkage to medical care as well as to other prevention services. Health departments might track the patient in question using both the patient’s name and form identification number. Health departments also might use HIV surveillance data in conjunction with HIV screening program data to confirm linkage to care for clients and subsequently update the linkage status.

Another option is that health departments could use the patient’s name and local client identification number collected through partner services to determine linkage to care. As with HIV screening data, patient identifiers are not submitted to CDC; however, these might be available locally at the health department. The HIV partner services variables capture all data related to the HIV partner services process. These include patient demographic information, medical test results, case management process, and notification and testing of partners. The utility of partner services information depends on the quality and completeness of data entered by the health departments.

Social Security Death Index

The Social Security Death Index (SSDI) is created using the U.S. Social Security Administration’s (SSA) “Death Master File” extract. Individuals who had a Social Security Number (SSN) and whose death was reported to SSA are listed in the SSDI. The SSDI contains name, date of birth, last place of residence, SSN, and death information. SSDI is an important data source for HIV surveillance programs to match against prior to commencing linkage and re-engagement work if matching between the HIV surveillance database and the SSDI has not occurred in the last year.

Conducting regular death ascertainment activities and updating vital status in accordance with HIV surveillance standards is an important activity to ensure high-quality “not in care” (NIC) line lists. If the HIV surveillance database identifies an individual as NIC, the health department

can assess vital status using the SSDI prior to beginning linkage and re-engagement activities so that they do not expend resources on providing outreach services to a deceased individual. HIV surveillance programs should conduct death ascertainment activities annually to keep vital status updated in the HIV surveillance database. CDC's HICSB provides the SSDI to their health department grantees free of charge and provides guidance and tools to assist health departments in conducting the SSDI match.

State Medicaid Database

Medicaid is a health and long-term care coverage program that is financially supported by states and the federal government. Each state establishes and administers its own Medicaid program and determines the type, amount, duration, and scope of services covered within broad federal guidelines. Medicaid databases contain patient demographic information, such as address, and medical information, such as antiretroviral use, laboratory results, and medical visits. Health departments might find this information helpful in determining if an individual is in or out of care as well as locating missing locating information that they can use to update the HIV surveillance database.

State or Local HIV Surveillance Database

CDC-funded state and local health departments use eHARS software to manage their HIV surveillance database. Staff enters or imports case report and laboratory data into the HIV surveillance database on a routine basis and analyze surveillance data with SAS programs to generate line lists of persons who might need follow-up because of incomplete information (e.g., missing address or risk factor information). Health departments using HIV surveillance data for linkage and re-engagement in care activities can run locally developed SAS programs or a CDC-developed SAS program to generate a line list of individuals who appear to be "not in care" (NIC). The line list might contain data elements that are needed to conduct linkage and re-engagement outreach to NIC individuals, such as name, date of birth, address, telephone number, gender, race/ethnicity, and healthcare provider.

STD Surveillance Database

Health departments maintain the STD Surveillance Database, which contains demographic and clinical information about persons diagnosed with a sexually transmitted infection (STI). HIV-diagnosed individuals might become co-infected with an STI and, during the course of an STI field interview, provide current locating information such as address, telephone number, email, provider name, and so forth. Additionally, the health department might receive a notifiable disease report of the STI that contains important demographic, locating, or healthcare provider information. Hence, the STD Surveillance Database can serve as a potential resource for obtaining missing locating information for HIV-diagnosed patients who are in need of linkage or re-engagement outreach.

Additionally, this database might provide evidence of HIV care and treatment services for an individual on the HIV surveillance database-generated "not in care" line list, thereby preventing health department staff from spending time providing outreach services to the individual. If the

latter occurs, it is important for the health department to investigate and address why some HIV-related laboratory data are not appearing in the HIV surveillance database and to take steps to ensure more accurate line lists in the future.

Tuberculosis Surveillance Database

Many state health departments maintain a tuberculosis (TB) surveillance database, which may contain demographic as well as clinical information. This database might have information about individuals who also are HIV positive, including information indicating that an individual is receiving HIV care when such information is possibly lacking in the HIV surveillance database. Matching the line list of HIV-diagnosed persons identified as “not in care” to the TB database might result in removing some individuals from the list or might provide locating information that is missing from the HIV surveillance database.

Viral Hepatitis Surveillance Database

Matching the line list of HIV-diagnosed persons identified as “not in care” to the viral hepatitis surveillance database might result in removing some individuals from the list or might provide locating information that is missing from the HIV surveillance database.

Obtaining Access to Data Sources

Gaining access to and utilizing other databases often is resource-intensive. Health departments must weigh the gain of additional data against the amount of effort required to obtain that data. Identifying relevant staff in other areas of the health department with access to data sources, establishing partnerships, and determining necessary security and confidentiality guidelines will help to facilitate data access. Health departments also might consider prioritizing the data sources that they already have access to or to which they could easily gain access.

Security and Confidentiality Considerations

Health departments routinely use personally identifiable and sensitive information as part of their disease prevention and control activities. When following up with HIV-diagnosed individuals who need linkage to or re-engagement in care services, health department staff must be able to access client locating information, client medical and laboratory information, and provider and facility information. Ensuring that all of this information is managed, stored, and used securely and confidentially is crucial for maintaining public trust and successfully implementing HIV-related public health programs.

Having common guiding principles and standards for protecting data that might be shared across public health programs within a health department or within a jurisdiction is necessary to ensure the data are adequately protected. Health departments should ensure that written policies and procedures that cover all aspects of data collection, storage, and use, are in place and that standard approaches are used to increase awareness among staff and support a culture of maintaining privacy, whether data are used in workplace or taken into the field.

Guiding Principles and Standards

CDC's National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) has developed data security and confidentiality guidelines for their health department-funded programs that outline standards to be used as the foundation for developing local policies and procedures while enabling use of data for various public health activities. CDC-funded HIV prevention and HIV surveillance programs (as well as other disease programs) are required to adhere to these standards as a condition of funding. The 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 outlines 10 overarching guiding principles (see Appendix A) that health departments should use as guidance when they develop *Data to Care* procedures for linkage to and re-engagement in care activities.

CDC's guidelines specify standards that support the most desirable practices for enabling secure data use and ensuring comprehensive preventive services, while being broad enough to allow for differences in public health activities by disease program. The standards address areas of program policies and responsibilities, data collection and use, data sharing and release, physical security, and electronic data security. Each section outlines specific standards that health departments should follow.

The 10 guiding principles are intended to guide NCHHSTP-funded programs as they develop data security and confidentiality policies and broadly guide the collection, storage, and use of data for legitimate public health purposes. Legitimate public health purposes can be defined as a population-based activity or individual effort aimed primarily at the prevention of injury, disease, or premature mortality. This term also refers to the promotion of health in the community, including:

- Assessing the health needs and status of the community through public health surveillance and epidemiologic research,
- Developing public health policy, and
- Responding to public health needs and emergencies.

Public health purposes can include analysis and evaluation of conditions of public health importance and evaluation of public health programs (1, 2).

The principles include minimizing access to identifiable and sensitive information to authorized individuals, minimizing the amount of personally identifiable or confidential information collected and stored, and maintaining data in a physically and technically secure environment. The best approach for securing data will involve using both physical and electronic protections whenever possible. Health departments should:

- Limit the number of places data are stored, the duration they are stored, and the means to access the data, whether in paper or electronic form;
- Keep paper copies with identifying or sensitive information to a minimum, accessible only by authorized individuals, and stored in a secured locked cabinet when not in use;

- Encrypt electronic data both when in transit and at rest if possible, as well as use password protection and other electronic access controls for electronic data if possible;
- Physically secure equipment like servers, computers, and laptops;
- Tell staff to avoid faxing and emailing personally identifiable information and never to email personally identifiable data that is not encrypted; and
- Have clear policies and procedures on use of facsimile, email, and portable devices (e.g., mobile phones tablets, PDAs) for public health activities.

The NCHHSTP Data Security and Confidentiality Guidelines (2) outline standards for physical and electronic data security and provide additional guidance.

Health department HIV surveillance and prevention programs should work collaboratively to address data security and confidentiality when developing protocols for implementing linkage and re-engagement activities and ensure procedures are consistent with local policies and NCHHSTP guidelines. When implementing these activities, health departments should be respectful of the rights of individuals and communities and minimize undue burden. For example, protocols for contacting individuals should be respectful of time, setting, privacy, and personal choice. Additionally, data should not be released in a way that might stigmatize an individual or group.

Finally health departments have the responsibility to be active, responsible stewards of public health data; to that end, they should address these issues in policies and procedures, provide annual training for staff, and require individuals to sign confidentiality agreements before they receive access to confidential health data and annually thereafter.

Linkage to and re-engagement in care activities might require sharing of personally identifiable data across health department programs and might require searching of other databases to complete missing or incomplete information. Health departments should follow the same principles to protect data when transmitting and storing data shared across programs and using alternate data sources.

Some health department programs might require data use agreements or memoranda of understanding to ensure standard procedures are used by programs sharing data. Data sharing plans can serve as a basis for these agreements and a starting point for discussion. Plans should include, at a minimum:

- intent of the activity;
- persons authorized to access data,
- minimum data elements needed,
- physical and electronic security protections,
- planned analyses,
- data disposition.

1. Lee, LM, Gostin, LO. Ethical collection, storage, and use of public health data: A proposal for a national privacy protection. JAMA 2009; 302(1):82–4. Available from: <http://jama.jamanetwork.com/article.aspx?articleid=184159>, accessed November 7, 2013.
2. Centers for Disease Control and Prevention. 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. Atlanta (GA): U.S. Department of Health and Human Services, 2011. Available from: <http://www.cdc.gov/nchhstp/programintegration/docs/PCSIDataSecurityGuidelines.pdf>, accessed November 6, 2013.

Legal Considerations for a *Data to Care* Program

Public health law is central to discussions on the use of local HIV surveillance data for linkage and re-engagement in care activities. Laws that require reporting of HIV-related laboratory test results are the foundation for efforts to use HIV surveillance data to identify and provide supportive services to persons who have not been linked to care, who are not currently in care, or who might have sustained high viral load and/or persistently low CD4 counts. Before initiating use of HIV surveillance data to follow up with individuals, health departments should review their HIV disease reporting laws to determine whether healthcare providers and laboratories in their jurisdictions report CD4 t-lymphocyte test results (both counts and percentages) and viral load test results (both detectable and not detectable). Laboratory reports should include test results from patients whose specimens are obtained in the jurisdiction (i.e., the provider who took the specimen is located in the jurisdiction), regardless of where the patient resides, and for patients who are residents of the jurisdiction. This will ensure accurate monitoring of HIV Care Continuum activities in the jurisdiction and correct identification of “not in care” persons who are in need of follow-up.

Public health agencies traditionally have worked with clinicians reporting infectious disease diagnoses to surveillance to implement prevention and control interventions; public health generally has legal authority to follow up with individuals to notify infectious people of their diagnosis, treat them, or take other measures to interrupt transmission. However, prior to the implementation of new linkage and re-engagement in care activities with HIV-positive persons, health departments should review their laws, rules, and regulations to ensure the proposed activity is consistent with their existing public health authority under applicable state and local laws.

Laws applicable to the security of health data, information privacy, and sharing of health information also might affect the implementation of HIV linkage to and re-engagement in care activities that are driven by HIV surveillance data. At the federal level, the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule protects most health records from disclosure but permits healthcare providers to make disclosures to public health officials. The rule does not address protection of information held by public health programs from disclosure,

except in limited circumstances, and does not preempt state laws that might require or allow disclosure of data by public health authorities (1).

Some states have laws that address disclosure or that restrict the use of STD and/or HIV data specifically (2). Because laws vary from state to state, health departments should review applicable state laws and regulations to ensure the new linkage to and re-engagement in care activities both fall within the scope of public health authority and are conducted in a manner consistent with any laws or regulations governing data security, data sharing, confidentiality, and information privacy. This might include consulting with the legal counsel within their health department as well as their HIPAA privacy officer.

1. U.S. Department of Health and Human Services. Health Insurance Portability and Accountability Act of 1996 privacy rules. Available from: <http://www.hhs.gov/ocr/privacy/>, accessed on November 6, 2013.
2. O'Connor, J., Matthews, G. 2011. Informational Privacy, Public Health, and State Laws. *Am J Public Health* 101(10):1845-1850.

Ethical Considerations for a *Data to Care* Program

- Why should programs consider using individual-level HIV surveillance data for public health action now?
- Why should programs consider the unique history of HIV surveillance in their jurisdiction?
- Why review ethical considerations when implementing new uses of HIV surveillance data?
- What is the process for reviewing ethical considerations?
- What are some of the key ethically based questions programs should answer to guide innovative uses of HIV surveillance?

Why should programs consider using individual-level HIV surveillance data for public health action now?

Data collection and use for public health action is a fundamental component of public health practice. Public health officials have a duty to act on evidence they collect for the public good and to ensure health departments carry out public health programs in an ethical and confidential manner.

The timing is right to consider more actively using HIV surveillance data to improve linkage to and re-engagement in care. For years following the discovery of HIV, no treatment was available and fear and stigma surrounded HIV. Today, strong scientific evidence shows that antiretroviral treatment both saves lives (1–3) and prevents transmission (4). However, HIV Care Continuum and other data show deficiencies in linkage and retention in care and unequal access to life-saving treatment, which provides a compelling scientific basis for public health action and use of surveillance data as part of the *Data to Care* strategy (5–12).

HIV surveillance systems have evolved as well, and now robust systems exist to collect essential laboratory data (both CD4 and viral load in most jurisdictions) to use in indicating if a person has been linked to care, retained in care, and ultimately achieved viral suppression. There are potential benefits to both individuals and the population for using these data more actively. Because HIV surveillance data are population-based, using them can facilitate access and linkage to care for potentially all diagnosed persons across a jurisdiction, equalizing opportunities to access services, and importantly, facilitating linkage for those persons who may no longer be receiving care and out of reach of traditional healthcare providers. Furthermore, public health authorities have the ethical obligation to use the data once collected to improve and protect the public's health. While privacy concerns and stigma still exist, the strong scientific evidence and the existence of the infrastructure to carry out these activities shift the risk balance toward using surveillance data to maximize opportunities for care and treatment for HIV-diagnosed individuals.

With a strong justification for the use of surveillance data to support linkage to care and provision of healthcare services, the implementation of *Data to Care* programs also must be guided by ethical principles and based on sound public health practices. Review of ethical considerations before implementing any new public health approach is good public health practice; moreover, because of the unique historical and social context in which health departments have implemented HIV surveillance programs, review of these considerations within the local context of a jurisdiction will be essential for ensuring success.

Why should programs consider the unique history of HIV surveillance in their jurisdiction?

Public health agencies traditionally have worked with practicing clinicians reporting diagnoses to surveillance to implement infectious disease prevention and control interventions. These include notifying infectious people of their diagnosis, treating them or taking other measures to interrupt transmission, as well as notifying exposed persons of their exposure, identifying and treating contacts, and assisting uninfected contacts who have ongoing exposure to avoid infection. For some conditions, such as sexually transmitted diseases and tuberculosis, health departments use surveillance data to facilitate provision of partner services and case management as part of routine infectious disease control strategies. However, the use of HIV surveillance data for case management and referral to care, particularly to patients of private healthcare providers outside of the public health system, has been more controversial and has not been as widely implemented.

Concerns about individual privacy and confidentiality are central to discussions about using public health surveillance data because this information typically is collected without the consent of the individual. With HIV in particular, concerns about stigma, confidentiality, and potential loss of privacy resulted in much controversy around the implementation of name-based HIV surveillance in the 1980s through the early 2000s. As a result, some health departments delayed implementing HIV case surveillance and strictly limited the data it collected.

These concerns, in addition to the lack of available treatment for HIV at the time, resulted in limited implementation of traditional disease control and prevention interventions for HIV in many areas. In some jurisdictions, HIV-affected communities supported name-based reporting of HIV diagnoses for surveillance only if health departments would not use the information to contact individuals for public health follow-up. Although past practices should not preclude the implementation of *Data to Care* programs, health departments should take the unique historical context of their jurisdiction into consideration when implementing new methods and considering using HIV surveillance data in new ways.

The availability of life-saving treatment and the possibility of preventing further HIV infections are compelling reasons to reconsider the use of surveillance data to facilitate linkage and re-engagement through traditional and more contemporary infectious disease control strategies. Implementation of these programs will require addressing privacy concerns and continued engagement with affected communities and healthcare providers to maintain trust and increase acceptability of proposed methods.

Why review ethical considerations when implementing new uses of HIV surveillance data?

Maintaining public trust is central to the mission of all public health activities. Reviewing ethical considerations when implementing new programs can help ensure trust and community support. In the case of HIV surveillance, public health programs engaged communities early on and earned their trust by using approaches that preserved confidentiality while collecting and providing needed data. Programs developed strict security and confidentiality protections to ensure proper protection of personal information reported through surveillance. This provided the important foundation for the high-quality, accurate surveillance data used to monitor the impact of HIV both at the national and local levels today. The same processes are foundational for the continuing evolution of HIV-related public health programs and to ensure the success of these programs going forward.

Some benefits of reviewing ethical considerations include:

- Building and maintaining credibility and public trust,
- Fostering consensus and respectfully resolving values conflicts,
- Making decisions where methods might be new or science might be limited and/or uncertain,
- Justifying choices where diverse opinions prevail, and
- Increasing awareness of stakeholder and community interests regarding public health practices.

What is the process for reviewing ethical considerations?

Several models of ethical decision-making in public health might provide practical guidance for decisions on HIV surveillance data use. The following steps outline a general process (13):

- Begin by identifying the public health ethics issues in the specific situation or proposed activity, including those related to risks and benefits.
- Identify the public health goals, stakeholders and their respective values, and any precedent cases.
- Generate and compare different options or courses of action and the ethical rationale for each. Choose the best option and justify the chosen course of action.
- Evaluate the selected action to determine if the desired outcome was achieved.

Additional training tools developed by CDC for state and local health departments are available to strengthen public health ethics capacity at the local level. The CDC manual *Good Decision Making in Real Time: Public Health Ethics Training for Local Health Departments* includes an introduction to public health ethics; relevant case studies, including a specific case study on new uses of HIV surveillance data; suggestions for integrating ethics into health departments; and additional resources.

What are some of the key ethically based concerns programs should answer to guide innovative uses of HIV surveillance data?

Surveillance data should be collected, held, and used for legitimate public health purposes, including injury prevention, disease mortality, health promotion, needs assessment, policy development, and emergency response. Uses of HIV surveillance data to facilitate linkage to and re-engagement in HIV care should conform to state and local laws. Even where law permits these activities, health departments must engage providers and patients to address concerns and develop arrangements for using HIV surveillance data that stakeholders will find acceptable (14).

Public health ethics frameworks provide concrete principles and values on which to base actions and review new uses of surveillance data (14–17). Principles used in biomedical research—such as beneficence, which includes the obligation to act to maximize benefits and reduce harms; respect for persons, which relates to autonomy and includes giving due consideration to an individual’s ability to make their own decisions and to act upon them; and justice, which includes giving due consideration to how fairly both benefits and burdens are distributed—are particularly useful for considering applications of new uses of HIV surveillance data (14, 16). For example, health departments can enhance autonomy and show respect for persons by implementing program methods that allow individuals to make choices on how and when they will be contacted.

Health departments also can use “justificatory conditions” (16,17) to think through ethical questions and decide on appropriate courses of action as well as consider the effectiveness of the proposed activities. For example, when thinking through methods for following up with

individuals, departments should consider whether the proposed methods will allow them to locate and contact individuals effectively. Additionally, they also should consider if the benefits of the proposed activity outweigh any risks or infringement on individuals (proportionality). A general example is whether the benefit of contacting a patient (e.g., facilitating their access to treatment or re-engaging in care) outweighs any risk to the individual (e.g., inconvenience of being contacted, risk of loss of confidentiality, risk associated with not being on treatment).

Because surveillance data is obtained without consent of individuals, methods for contacting persons should involve the least intrusive methods. For example, some health departments work with providers, obtaining permission to follow up with their patients on their behalf. Upon initial contact, the patient might consent to further contact by the health department and choose the best method for that contact.

Health departments also should consider whether the use of the proposed method is necessary or if there are less risky alternative methods they can use to achieve the same goal or end. Departments should ensure that they conduct new activities with the least infringement on a person's autonomy and privacy. Finally, to ensure public trust and accountability, health departments should take adequate steps to ensure justification by the public, which includes engagement of stakeholders before undertaking changes in activities. Health departments can increase accountability when their policies and procedures are well-documented.

The Ethics Toolbox for New Uses of HIV Surveillance Data (Appendix B) provides a listing of some example principles and values that health departments might find useful for guiding discussions on new uses of HIV surveillance data as well as examples of how to apply these uses in practice. Additionally, Sweeney et al. (17) describe ethical, procedural, and strategic considerations using practical examples of activities conducted by several health departments currently using HIV surveillance data to contact persons identified as needing assistance with initiating or returning to care.

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Community Engagement for a *Data to Care* Program

When developing *Data to Care* programs that use HIV surveillance data to link and re-engage individuals to HIV care, health departments should involve the local community and key stakeholders throughout the program development, implementation, and evaluation phases. Community involvement is an essential element in developing public health programs that respond to local HIV prevention needs and priorities. Representatives of the local community, such as HIV-positive people, public health officials, community-based organizations, and HIV care providers should be engaged on an ongoing basis.

Proactive community engagement methods help to address stakeholders’ needs and concerns in a timely fashion and allow for the community to “buy in” to the process while providing input and feedback from the program’s inception.

Historically, the HIV community has been vocal and engaged in the evolution of HIV surveillance in many jurisdictions, providing input and voicing concerns during the transition from name-based AIDS case reporting to name-based HIV reporting. Central to community and health department concerns was the preservation of privacy and confidentiality for infected individuals and, in many jurisdictions, this concern translated into written or unwritten policies that prevented public health officials from contacting HIV-diagnosed individuals who needed follow-up.

By engaging stakeholders in developing a *Data to Care* program, health departments can honor the important collaborations and relations that have been built over time with community partners about the role of surveillance systems in public health. Engaging the community also is an opportunity to communicate the important ways in which a *Data to Care* program will benefit the public, including increasing the number of people with access to life-saving treatment,

reducing ongoing HIV transmission, and increasing understanding of the health benefits of HIV treatment.

There are shifting views within health departments and the broader HIV community about the value of using individual-level HIV surveillance data for taking public health action such as linkage to and re-engagement in care. Because of the potential benefits to both individual and public health, many now view these benefits as outweighing the concerns and are calling for broader use of HIV surveillance data, though clearly departments must have safeguards in place to protect individual privacy. While there are many considerations to weigh in making this shift, some of which are outlined in the sections on Ethical Considerations and Security and Confidentiality Considerations, there is no question about the importance of involving the local community, from the outset, in discussing and making this shift.

Methods for Engaging Community Partners and Stakeholders in Developing a *Data to Care* Program

Health departments have many approaches for community engagement that include drawing upon existing HIV-focused community groups to provide input and feedback as well as convening new community groups to specifically focus on this issue. Additionally, health departments could circulate a written proposal that describes details of the program early in the development process to generate community discussion and feedback about proposed activities. Examples of existing HIV-focused community groups that health departments could engage include:

- HIV planning groups
- Ryan White planning groups
- Combined care and prevention groups
- Local HIV-focused coalitions
- Community advocacy coalitions for HIV prevention and care services
- Community mobilization groups that represent/target the specific priority populations in the jurisdiction

Additionally, the health department might want to convene a new, special group of community representatives to discuss the core elements of a *Data to Care* program that uses HIV surveillance data for linkage to and re-engagement in care activities and receive feedback and recommendations. Community members might include some of the following:

- HIV-positive consumers
- HIV care providers (physicians, nurses, physician assistants, case managers, patient navigators, etc.)
- Community-based organization staff (case managers, peer educators, peer navigators, linkage-to-care coordinators, counseling and testing staff, etc.)
- HIV advocates
- Legal and ethical experts
- Public and private funders
- Insurers
- General public

- HIV community advisory boards
- HIV prevention and care planning groups
- Medicaid and Medicare service providers
- Key opinion leaders from rural and urban communities, including some non-HIV providers
- Health department groups or other groups in the community that are involved in activities designed to remove barriers to HIV care (e.g., through policy initiatives and structural interventions)

Topical Areas to Discuss with Community Members in Developing a *Data to Care* Program

In engaging the community and relevant stakeholders in developing and implementing a *Data to Care* program, health department staff might include some of the following topics in their discussion:

- Reasons for the proposed program activity
- Description of proposed program activity
- Scientific evidence for test and treat approaches to HIV prevention
- Client and provider acceptability of using HIV surveillance data for linkage and re-engagement in care activities
- Legal and ethical concerns about using HIV surveillance data for linkage and re-engagement in care activities, including weighing benefits and risks of this approach
- Anticipated challenges and barriers, and solutions that could be used to address them
- Security and confidentiality concerns and proposed program's compliance with CDC Security and Confidentiality Guiding Principles and Standards
- Data matching and sharing methods
- Use of multiple data sources (e.g., ADAP, CAREWare, STD Surveillance) for program operation
- Data limitations
- Potential program partners
- Strategies for community engagement
- Client and provider engagement for program development and implementation
- Program monitoring and evaluation

Descriptions of how some jurisdictions have engaged the community and key stakeholders in discussing these topics can be found on the homepage under "Health Department Data to Care Program Examples."

Monitoring and Evaluating a *Data to Care* Program

Monitoring and evaluating a *Data to Care* program are important activities 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 *Data to Care* program. All *Data to Care* M&E activities should adhere to the principles described in this site's ethical considerations section. While it is important to conduct M&E activities because they can improve the performance of a *Data to Care* program, it is equally important to minimize or avoid adverse outcomes; thus, health departments should take into account important ethical considerations.

To get started, there are some basic questions that health departments and their partners should ask as they are designing and developing their *Data to Care* program.

Questions to Answer Before Designing and Developing a *Data to Care* Program

- Do we have a need for program monitoring, program evaluation, or both?
- What information do we need to monitor/evaluate the *Data to Care* program?
- How will we use *Data to Care* M&E findings?

Once health departments have answered these questions, they can proceed with creating a *Data to Care* evaluation plan and interpreting and using program and outcome data.

How will our program benefit from monitoring and evaluation?

The purpose of program monitoring is to determine if the program is implanting *Data to Care* activities as planned and whether it is reaching the right people. For example, does the program, in fact, identify HIV-diagnosed people who need to be linked to or re-engaged in care and provide quality methods to locate them? Is the program adequately funded with the right number of field staff needed to reach program goals within the specified timeline?

Program monitoring also might include gathering information related to successes and barriers experienced by staff that generate the “not in care” (NIC) line list from the surveillance system and/or use the line list in the field to locate people. For example, are there specific strategies that work best to successfully link individuals to care? Health departments should routinely document and share program monitoring with *Data to Care* staff to ensure program success. Departments also should communicate monitoring findings regularly to key staff involved with implementation to improve delivery of services and program implementation.

The purpose of evaluating a *Data to Care* program is to determine whether the program is effective and reaching overall project goals and objectives. For example, of all individuals on the NIC list targeted for linkage or re-engagement services, did the program link 75 percent of them to care? Or, when comparing the *Data to Care* program to traditional methods of linkage and re-engagement, were significantly more HIV-diagnosed individuals linked or re-engaged in HIV

medical care through *Data to Care*? Evaluation findings from a *Data to Care* program also might include “lessons learned” that describe how and why the program worked—or did not work—and what the program can do in the future to improve operation.

What information do we need to monitor and evaluate?

In addition to data elements described in Operational Steps and Data Needs, program staff should consider any quantitative and qualitative data that, when monitored over time, will provide evidence that their program is or is not working while also ensuring that activities are adherent to ethical considerations. An important monitoring and evaluation question that program staff should assess is whether the individuals who appeared on the final NIC list were classified correctly. If a significant number of individuals were found to be “in care” during the course of programmatic activity, then health departments should re-evaluate the quality of key laboratory data, the analytic algorithm they use to extract NIC individuals from the HIV surveillance database, and the methods they use to investigate these individuals prior to conducting linkage or re-engagement services.

Types of data that might be informative include:

1. Viral load and CD4 counts
2. Antiretroviral treatment use
3. Name of staff who initiated contact with patient
4. Reasons patient refused linkage or re-engagement services
5. Procedures/experiences related to following up with client after initial contact
6. Procedures/experiences related to following up with client if he/she gets linked into care but does not remain in care
7. Client and provider acceptability of the program
8. Client- and provider-perceived barriers to linkage and re-engagement
9. Strategies used for getting clients to agree to seek care
10. Time required to complete key program steps to identify areas for improvement (e.g., how long from client identification in surveillance system to location of client? How long from location of client to first medical appointment?)

Health departments should consider how they might integrate STD surveillance, partner services, HIV prevention program, and health service utilization data with HIV surveillance data to inform *Data to Care* monitoring and evaluation. Partnering with other groups within the health department to share information across systems and networks is essential to obtaining complete and quality data. *Data to Care* programs that will be evaluated over time should follow some percentage of HIV-diagnosed individuals identified through the program over a specified time period (with their consent) and collect basic information about their experiences, satisfaction with services, and whether they remain in medical care. Further, if someone the *Data to Care* program identified as NIC is then later linked to care, the health department should continue to use HIV surveillance data to monitor whether the person is retained in care. It also might be informative to assess if clients continue to monitor if the same or different providers are accessed.

Example related studies:

- Dombrowski J. How health departments promote retention in HIV care. Medscape Sep 19, 2012. Available from: <http://www.medscape.com/viewarticle/770953>, accessed November 6, 2013.
- Magnus M, Herwehe J, Gruber D, Wilbright W, Shepard E, Abrams A, et al. Improved HIV-related outcomes associated with implementation of a novel public health information exchange. Int J Med Inform 2012; 81(10):e30–8. Available from: <http://www.sciencedirect.com/science/article/pii/S1386505612001268>, accessed November 7, 2013.
- Proeschold-Bell, RJ, Belden, CM, Parnell, H, Cohen, S, Cromwell, M, Lombard, F. A randomized controlled trial of health information exchange between human immunodeficiency virus institutions J Public Health Manag Pract 2010; 16 (Nov–Dec (6)): 521–8. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/20885182>, accessed November 7, 2013.

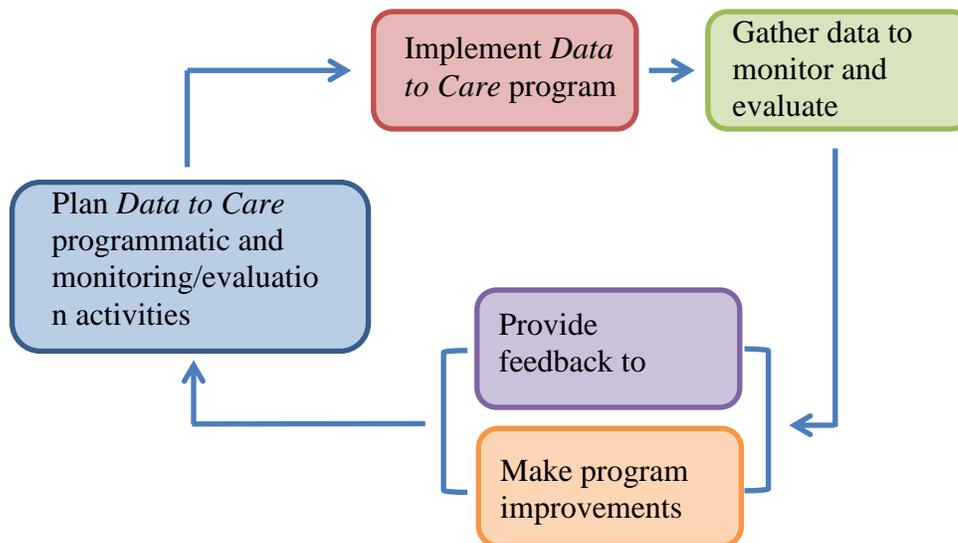
How will we use monitoring and evaluation findings?

It is important to consider early how the program will use the monitoring and evaluation findings results, with whom they will share the results, and how the results will help program improvement. Program planning should include plans for data utilization, including:

- Specific indicators, measures, and data sources that will be used;
- Frequency of data gathering;
- Level of data that will be needed for different purposes (e.g., client-level for some data sources, provider-level for other data sources);
- Potential analytic strategies (e.g., descriptive reporting only or more sophisticated statistical analyses);
- Stakeholders that will be informed of findings and when they will be notified; and
- A feedback loop for improving program performance.

Findings should be fed back into the *Data to Care* program process at different points to make improvements, as depicted in the following schematic:

Feedback Loop for Improving *Data to Care* Program Performance



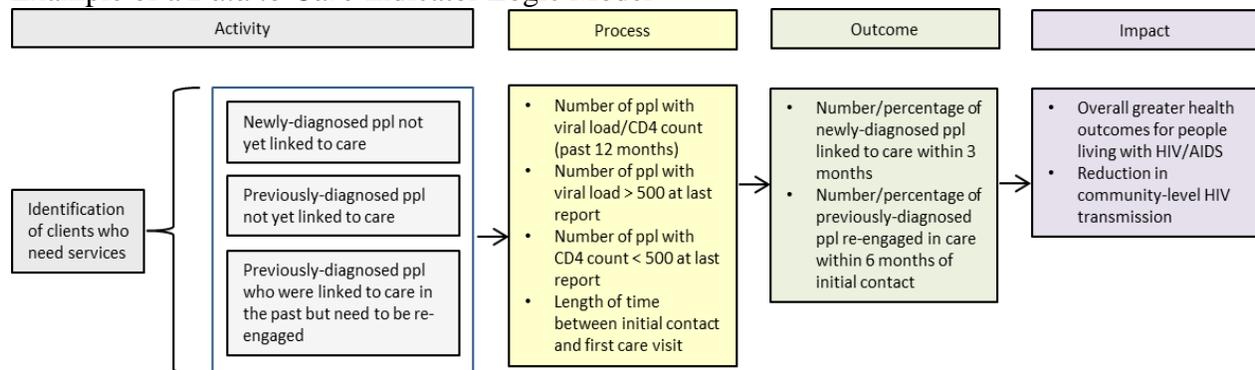
Creating a *Data to Care* Evaluation Plan

Once health departments answer the *Data to Care* “getting started” questions, they should be in a good position to create an evaluation plan. The plan does not have to be long; its purpose is simply to describe the M&E activities that the department will conduct. The plan should include the following information:

- Project goals and objectives
 - Example: Re-engage 75 percent of HIV-diagnosed “not in care” individuals within 4 months of first contact by health department staff
- Questions that M&E activities will address
 - Example: What barriers exist that prevent newly diagnosed individuals from being linked into care?
- Information that the department will use to answer the M&E questions
 - Example: Laboratory data, survey data, healthcare provider data
- Plans for data collection, sources, and analysis
 - Example: What data will the program collect and from which systems? How will the program analyze the data to answer questions and monitor progress toward goals and objectives? Which staff members are responsible?
- Recipients and plans for disseminating findings
 - Example: Monthly presentations to field staff on progress toward objectives, quarterly reports to stakeholders.

Health departments also might find it helpful to create a program logic model or data flow diagram to include in a *Data to Care* evaluation plan. A program logic model is a graphical depiction of the resources going into the program, programmatic activities, and expected outputs and outcomes of the program. A data flow diagram (or indicator logic model) is a graphical depiction of the data that will be collected at different steps of the project, showing the relationships between process, outcome, and impact. These types of diagrams are useful tools for communicating key program and data-related concepts to stakeholders.

Example of a *Data to Care* Indicator Logic Model



Some Logic Model Web sites:

- [W.K. Kellogg Foundation Logic Model Development Guide](#)
- [University of Wisconsin logic model examples and templates](#)
- [Office of Justice Programs – Center for Program Evaluation and Performance Measurement](#)
- [Innovation Network, Inc. Logic Model Workbook](#)

Interpreting and Using Program and Outcome Data

- Integrating data from different sources
- Taking into account influencing factors that are not related to a *Data to Care* program
- Transforming *Data to Care* results into meaningful conclusions for stakeholders
- Future content updates
- Additional program M&E resources

Integrating data from different sources

It is likely that health departments will need to consider data from more than one source when assessing if a *Data to Care* program is having an impact. Integrating programmatic, M&E,

surveillance, and health services data sources can improve staff's understanding of the public health problem (i.e., not all HIV-diagnosed individuals are linked to medical care and stay in medical care) and improve efforts to address the problem (i.e., increase percentage of HIV-diagnosed individuals who are linked to or re-engaged in care).

For example, people may no longer be receiving care for a variety of reasons, such as:

- They relocated to a different town and have not found a new doctor yet;
- They lost or switched jobs, which resulted in changes in health insurance coverage/healthcare providers;
- They lack social support from family, peers, significant others; or
- Other, more immediate, problems that they need to address before being able to access care (e.g., substance abuse, mental health issues).

Thus, health departments might find it helpful to gather qualitative and quantitative data from prevention programs, support services, and healthcare provider data sources that might explain why people are not getting linked to care and/or do not stay in care. Health departments should gather this information throughout program planning and implementation and use it to improve program processes.

Data to Care programs must document referrals and linkages they make in a client's records if the client participates in (or is otherwise reached through) CDC-funded interventions. Specifically, if a client tests positive through a CDC-funded HIV test but is not linked to care successfully until months or years later, program staff should make sure they go back and document on the client's HIV test form that he or she was linked to care successfully (and then resubmit the updated test data to CDC).

Additionally, both local and national program monitoring must document on the test form that they made the linkage because this is the only way that health departments and CDC will know that people testing HIV-positive through CDC-funded screening activities are being linked to care. For example, if a jurisdiction successfully linked 100 people to care in 2013 and half of those individuals tested positive in a publically funded screening program, the HIV screening data for those HIV-positive persons who were tested in the program must be updated to reflect linkage to care and other required referral data.

Additionally, many health departments have established linkage to care activities that are not related directly to their CDC-funded HIV screening programs. Feedback from the *Data to Care* program to those activities should also document successful linkages for local and national prevention program performance monitoring. So, if another quarter of those 100 clients who were successfully linked to care came through a patient navigation program, then the aggregate linkage to care data variables must include those 25 successful linkages. Health departments needing assistance with reporting data related to HIV linkage to and re-engagement in care should contact the National HIV Prevention Program Monitoring and Evaluation Service Center at (855) 374-7310 or NHMEservice@cdc.gov.

Taking into account influencing factors that are not related to a Data to Care program

Factors external to a *Data to Care* program also can affect its results. It is important to identify what these factors could be and track them over time.

Some examples of contextual factors include:

- Changes in state- or national-level policies or legal statutes that can affect health department functioning;
- Shifts in staff resources or funding levels during program implementation;
- Changes in community partnerships that support the program that could affect program results;
- Other programmatic activities that were scaled up at the same time that resulted in more people linked or re-engaged in care; and
- Shifts in data collection/management/reporting that make more, less, or different data available for M&E purposes.

Transforming Data to Care results into meaningful conclusions for stakeholders

Throughout *Data to Care* program planning and implementation, program staff should communicate with stakeholders to report progress toward objectives, challenges encountered, how challenges were addressed, and so forth. See the Community Engagement section for more information about engaging community partners and stakeholders at different points along the way. When reporting program results, health departments will need to design different types of communications and reports accordingly for varied audiences. Consider the best method of communication for each audience or stakeholder type (e.g., PowerPoint presentation for a face-to-face meeting versus an emailed report) and level of detail needed (e.g., data tables and graphs versus narratives and anecdotal information reported from field staff).

Health departments could use a detailed monthly report to communicate to staff how well things are going, including a summary of barriers reported and proposed strategies for addressing the barriers. On the other hand, a high-level quarterly report that shows progress toward objectives and goals might be sufficient for communicating with senior health department managers and community partners.

Regardless of the audience, health departments should present *Data to Care* results in a way that makes the information useful for the program. For example, field staff will need to know about new strategies that work well for approaching people lost to care and approaches they should avoid, so reports and presentations designed for them should include this type of detail. On the other hand, managers need to be kept informed of important indicators that represent program progress and, if progress is slow, why this might be happening so that the department can improve the program. Managers also need information that can help guide their decisions about agency resources (e.g., information to guide if and when agency resources should be shifted to better support key programmatic steps).

Finally, as noted above, all *Data to Care* M&E activities should adhere to the principles described in this site's Ethical Considerations section.

Future content updates

Since *Data to Care* programs are a relatively new public health strategy that health departments only recently began implementing, M&E best practices are still under development. As such practices emerge, this Web site will share information and tools to support continued M&E of *Data to Care* programs.

Additional program monitoring and evaluation resources:

Web sites:

- [CDC's Framework for Program Evaluation](#)
- [CDC's National Center for Chronic Disease Prevention and Health Promotion- Developing an Effective Evaluation Plan](#)
- [National Science Foundation- Online Evaluation Resource Library](#)
- [Point K Learning Center evaluation tools and resources](#)
- [Western Michigan University Evaluation Checklists](#)

Other resources:

- Knowlton, LW, Phillips, C, editors. The logic model guidebook: Better strategies for great results. Thousand Oaks (CA): Sage Publications; 2009.
- Milstein, B, Chapel, T J, Wetterhall, S F, Cotton, D A. Building capacity for program evaluation at the Centers for Disease Control and Prevention. *New Directions for Evaluation* 2002; 93:27–46. Available from: <http://onlinelibrary.wiley.com/doi/10.1002/ev.40/pdf>, accessed November 7, 2013.
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Appendix A

Ten Guiding Principles for Data Collection, Storage, Sharing, and Use to Ensure Security and Confidentiality

1. Public health data should be acquired, used, disclosed, and stored only for legitimate public health purposes.
2. Programs should collect the minimum amount of personally identifiable information necessary to conduct public health activities.
3. Programs should have strong policies to protect the privacy and security of personally identifiable data.
4. Data collection and use policies should reflect respect for the rights of individuals and community groups and minimize undue burden.
5. Programs should have policies and procedures to ensure the quality of any data they collect or use.
6. Programs have the obligation to use and disseminate summary data to relevant stakeholders in a timely manner.
7. Programs should share data for legitimate public health purposes and may establish data-use agreements to facilitate sharing data in a timely manner.
8. Public health data should be maintained in a secure environment and transmitted through secure methods.
9. Minimize the number of persons and entities granted access to identifiable data.
10. Program officials should be active, responsible stewards of public health data.

Adapted from: Lee, LM, Gostin, LO. Ethical collection, storage, and use of public health data: A proposal for a national privacy protection. *JAMA* 2009; 302(1):82–4. Available from: <http://jama.jamanetwork.com/article.aspx?articleid=184159>, accessed November 7, 2013.

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Appendix B

Ethics Toolbox for New Uses of HIV Surveillance Data*

Ethical Principle/Value	General Public Health Application	<i>Data to Care</i> Application
Health	<ul style="list-style-type: none"> – Maximize health benefits to population and the individual – Implement interventions to prevent disease transmission 	<ul style="list-style-type: none"> – 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	<ul style="list-style-type: none"> – 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? 	<ul style="list-style-type: none"> – 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?
Necessity	<ul style="list-style-type: none"> – Ensure that the activity is essential and without better options 	<ul style="list-style-type: none"> – Is it necessary to use HIV surveillance data to identify and link persons who are not in care? – Are there other ways to identify persons not in care that would be less risky?
Least Infringement	<ul style="list-style-type: none"> – Only the least possible infringement is justified – Contact individuals using the least intrusive method 	<ul style="list-style-type: none"> – Will methods used to contact people be acceptable to individuals and their providers? – Do the methods present the least risk of infringement (e.g., are confidential, at no cost, least disruptive to their schedule)

Ethical Principle/Value	General Public Health Application	<i>Data to Care</i> Application
Respect for Persons/Autonomy	<ul style="list-style-type: none"> – Include consent where possible – Use methods that are non-coercive and preserve personal choice 	<ul style="list-style-type: none"> – Do the proposed methods honor individual choice with respect to linkage and re-engagement to care? - Can working through the health care provider help ensure respect for person?
Confidentiality/Privacy	<ul style="list-style-type: none"> – Minimize access to personally identifiable and sensitive data – Minimize access to confidential data to those that need to know – Ensure data security controls are in place 	<ul style="list-style-type: none"> – How will security and confidentiality be maintained? – Has the minimum amount of personally identifiable data been used or shared? – Are proposed methods permitted by state law and consistent with locally agreed-upon conditions for the uses of surveillance data? – Have policies and procedures been developed to honor confidentiality when contacting an individual? – Does the proposed use comply with applicable laws and regulations related to privacy of health data and data sharing?
Effectiveness	<ul style="list-style-type: none"> – Ensure proposed use provides maximal benefits and minimize harms 	<ul style="list-style-type: none"> – Are the proposed activities likely to effectively identify people needing care and/or connect them to care? – Are plans in place to evaluate the effectiveness and risks associated with the program?
Proportionality	<ul style="list-style-type: none"> – Negative effects on individuals should be proportional to the public good – Consequences of interventions should not exceed the potential risk or need 	<ul style="list-style-type: none"> – Have all the risks and benefits been thought through? – How can the risks be minimized?

Ethical Principle/Value	General Public Health Application	<i>Data to Care</i> Application
	in the community	
Social Justice /Equity	<ul style="list-style-type: none"> – Reducing health disparities to achieve health equity – Reducing transmission rates aligns with health equity 	<ul style="list-style-type: none"> – Although the privacy concerns surrounding uses of HIV surveillance data still exist, countervailing ethical concerns arise if HIV surveillance is <u>not</u> used to maximize the available benefits from HIV medical care and ART for all. This is so not only because ART potentially protects the larger population at risk of acquiring HIV infection, but because the use of surveillance data to contact individuals for the purpose of facilitating care could equalize access to HIV care and treatment.
Interdependence, Stewardship, Trust, Public Justification, and Transparency	<ul style="list-style-type: none"> – Plan carefully – Engage stakeholders – Written protocols and procedures – Ensure data confidentiality – Use methods that have been used successfully in other settings – Include evaluation of new activities – Disseminate results in a timely manner to stakeholders 	<ul style="list-style-type: none"> – How will the public be engaged? How will accountability to the public be ensured?

*Not an exhaustive list.