



Published in final edited form as:

J Acquir Immune Defic Syndr. 2019 September 01; 82(Suppl 1): S1–S5. doi:10.1097/

QAI.0000000000002059.

HIV Data to Care—Using Public Health Data to Improve HIV Care and Prevention

Patricia Sweeney, MPH,
Elizabeth A. DiNenno, PhD,
Stephen A. Flores, PhD,
Samuel Dooley, MD,
R. Luke Shouse, MD,
Stacy Muckleroy, MPH,
Andrew D. Margolis, MPH

Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, Atlanta, GA.

Abstract

Background: “Data to Care” (D2C) is a public health strategy that uses surveillance and other data to improve continuity of HIV care for persons with HIV (PWH) by identifying those who are in need of medical care or other services and facilitating linkage to these services. The primary goal of D2C is to increase the number of PWH who are engaged in care and virally suppressed.

Methods: Data to Care can be implemented using several approaches. Surveillance-based D2C is usually initiated by health departments, using HIV surveillance and other data to identify those not in care. Health care providers may also initiate D2C by identifying patients who may have fallen out of care and working collaboratively with health departments to investigate, locate, and relink the patients to medical care or other needed services.

Results: Although D2C is a relatively new strategy, health department D2C programs have reported both promising results (eg, improved surveillance data quality and successful linkage to or re-engagement in care for PWH) and challenges (eg, incomplete or inaccurate data in surveillance systems, barriers to data sharing, and limitations of existing data systems).

Conclusions: Data to Care is expected to enable health departments to move closer toward achieving national HIV prevention goals. However, additional information on appropriate implementation practices at each step of the D2C process is needed. This *JAIDS* Special Supplement explores how CDC funding to state health departments (eg, technical assistance and demonstration projects), and partnerships across federal agencies, are advancing our knowledge of D2C.

Correspondence to: Patricia Sweeney, MPH, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, 1600 Clifton Road, MS E-47, Atlanta, GA 30329 (psweeney@cdc.gov).

The authors declare no conflicts of interest. This manuscript was developed as part of the authors’ normal work activities at the Centers for Disease Control and Prevention, no external funding was provided.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Keywords

Data to Care; CDC; HIV prevention

BACKGROUND

HIV treatment provides life-saving individual-level health benefits, improves quality of life for persons with HIV (PWH) and produces substantial population-level prevention benefits by reducing the likelihood of onward HIV transmission.^{1,2} However, not all PWH are linked to and retained in continuous care and receive antiretroviral therapy. Therefore, top priorities for HIV prevention programs include: (1) ensuring that persons with diagnosed HIV infection are linked to and remain in HIV medical care, and (2) ensuring that PWH who fall out of care are identified and relinked to care.¹

Health department HIV surveillance and prevention programs are uniquely positioned to facilitate identification of PWH who have never been linked to HIV medical care, or who have fallen out of care, through several approaches (Fig. 1). One such approach is “Data to Care” (D2C)—a public health strategy that uses HIV surveillance and other data to improve continuity of HIV care for PWH by identifying those who are in need of HIV medical care or other services and facilitating linkage to these services.³ The primary goal of D2C is to increase the number of PWH who are engaged in HIV medical care and virally suppressed, which aligns with national HIV prevention goals.¹ Data to Care can be implemented using several approaches. Surveillance-based D2C is usually initiated by HIV surveillance programs in health departments, using HIV surveillance and other data to identify those not in care (NIC). Health care providers may also initiate D2C by identifying patients who may have fallen out of care and working collaboratively with health departments to investigate, locate, and relink their patients to medical care or other required services.

Although D2C is a relatively new strategy, health department D2C programs have reported both promising results (eg, improved surveillance data quality; increased collaboration among surveillance, prevention, and care and treatment staff; and successful linkage to or re-engagement in care for PWH) and challenges (eg, incomplete or inaccurate data in surveillance systems, barriers to data sharing, and limitations of existing data systems).⁴⁻¹¹ Additional information on appropriate implementation practices at each step of the D2C process, including models for efficiently using and sharing data is needed. Here, we describe the basic operational steps for D2C programs, discuss CDC’s efforts to support state and local health departments in the early implementation of D2C, and consider future directions for this potentially important HIV prevention strategy.

OPERATIONAL STEPS

The operational steps and activities for D2C outlined in Figure 2 represent a generic model for how D2C programs may function, but health departments differ in how they operationalize these processes.³ The starting point of the D2C process is identifying PWH who may not be receiving regular HIV medical care, either because they were never

linked to care after their infection was diagnosed, or because they were linked to care but subsequently fell out of care. This is usually accomplished by reviewing HIV-related laboratory test results (eg, CD4 cell count, HIV viral load, and HIV genotype test) reported to the HIV surveillance program and looking for (1) persons with no test results reported after their infection was diagnosed, suggesting that they may never have been linked to care; and (2) persons with tests reported after initial diagnosis, but without recent tests, suggesting that they were linked to care at some time, but may since have fallen out of care. From this review, a list of PWH who are presumptively NIC—a presumptive NIC list—is generated. Operational definitions for determining care status (ie, NIC) can be influenced by multiple factors and vary across jurisdictions and clinic settings. The process of establishing agreed-on definitions is a central aspect of establishing a D2C program and can continue as more partners (eg, HIV medical providers, Ryan White providers, and other federally qualified health centers) participate.

Central to D2C is availability of and access to data sources that can help confirm the care status of PWH. An HIV surveillance database maintained by a jurisdiction's health department is necessary for implementing D2C, because it contains information (eg, date of diagnosis, provider name, CD4 cell count, and HIV viral load test results) on all persons with diagnosed HIV reported to the health department. Laboratory data are necessary for D2C program operation, because they contain information about HIV-related laboratory tests conducted on all such persons in the jurisdiction, and are used as markers for receipt of care. CDC requires that funded health departments enter all HIV-related laboratory data that is reported to health departments as part of mandated disease reporting into their HIV surveillance database.

Health departments routinely access other data sources to obtain care history, vital status, and location information for PWH confirmed to be NIC. Databases and information sources used typically fall into one of 3 categories: (1) those that may help determine care status (eg, Ryan White HIV/AIDS Program services database, Medicaid database, electronic health records, and STD*MIS/PRISM); (2) those that may help determine vital status (eg, state vital statistics registry, Social Security death index, and people search tools); and (3) those that may provide information to help locate persons on the list (eg, people search tools, tax records, drivers' license registries, public service registries, state department of corrections inmate locators, and city or county electronic jail rosters). Health departments continue to explore how best to access and use these and other data sources, such as AIDS Drug Assistance Program and pharmacy data for improving early identification of NIC persons through prescription refill data.

Obtaining, integrating, and interpreting data from multiple data sources can be resource intensive and complex, but necessary for a successful D2C program. Continuously identifying and evaluating external data sources that can improve the efficiency of D2C processes should be ongoing. Designing and building state-level capabilities to automatically integrate multiple data sources (eg, surveillance and laboratory databases, health care provider electronic health records, and hospital databases) may also facilitate more rapid and accurate identification of persons who are truly NIC.^{12,13} Such an automated system could reduce the amount of time needed to identify a person as NIC, to conduct field

investigations and confirm care status, and deliver linkage-to-care and other HIV care and prevention services.¹⁴

The type and quality of data used can enhance or limit the impact of a D2C program. Poor data quality and incomplete information for accurately identifying care status or locating PWH for follow-up present challenges and create inefficiencies that result in wasted staff time and resources.^{11,15} Therefore, optimizing data quality and completeness is essential for D2C programs. Establishing data-sharing agreements so that data can be shared efficiently can greatly improve the quality and use of the D2C strategy.^{16,17} As partners are identified and included in D2C program activities, data-sharing agreements will help ensure clear communications and expectations around data stewardship and assurance of confidentiality, and will formalize commitments for data sharing. Ideally, D2C strategies expand the reach of care providers, health delivery systems, and health departments in supporting PWH.

CDC SUPPORT FOR IMPLEMENTATION OF DATA TO CARE

CDC's Division of HIV/AIDS Prevention (DHAP) has been working with health departments and other stakeholders to develop tools and to identify best practices from surveillance and prevention programs and capacity building partners to help identify PWH who are NIC. The division has developed locally modifiable computer algorithms in SAS program language to use with health department HIV surveillance systems to identify persons who are presumptively NIC. The division has also conducted several large-scale demonstration projects focusing on different aspects of D2C implementation. For example, the Care and Prevention in the United States (*CAPUS*) project focused on building capacity for surveillance systems to support D2C programs in states with large racial and ethnic disparities in HIV.¹⁸ To achieve state-wide scale-up of D2C, and to reach people most in need of services, the project targeted social and structural factors locally identified as barriers to receiving effective HIV care or associated with poor linkage to and retention in care.¹⁹ A key lesson from the *CAPUS* project was that capacity among systems and staff and local tailoring of strategies, are key aspects of D2C success.

The Partnerships for Care (*P4C*) project focused on partnerships between CDC-funded health departments and HRSA-funded federally-qualified health centers that were not funded through the Ryan White mechanism. A central aspect of D2C work in *P4C* was a focus on provider partnerships, including the development of data-sharing agreements. This project demonstrated that bi-directional data-sharing agreements, enhancements to data systems, and effective navigation of state statutes were all keys to success. The *P4C* project also resulted in development of a toolkit, which is available online.²⁰ Project *PrIDE* focused on an MSA-level scale-up of D2C strategies, with emphasis on serving racial/ethnic minority men who have sex with men and transgender persons. To better serve these populations, the project required programs to prioritize men who have sex with men and transgender persons for D2C, and adopted a health equity focus to address major barriers to care experienced by socially marginalized populations. Project *PrIDE* also operated an online learning collaborative for team members, using a peer-to-peer format for interactively sharing information and locally-developed materials. This project has demonstrated that

provider-specific data-sharing agreements, and a focus on environmental and social factors, support reaching marginalized populations in need of services.

In addition, several DHAP-funded research projects are focusing on how best to implement D2C strategies. The Cooperative Re-Engagement Controlled Trial (*CoRECT* study) is designed to rigorously evaluate the ability of different D2C strategies (eg, data sharing and provision of services) to improve HIV outcomes. Study results will also include a cost-effectiveness analysis. Also, the division is examining qualitative data from a variety of stakeholders (ie, health departments, health care providers, and PWH receiving D2C program services) to understand what types of support may be needed to improve health outcomes among people engaged in the D2C process.

Results and lessons learned from these and other projects will be made available for health departments to adapt to their needs. One such project is the CDC-funded Medical Monitoring Project (*MMP*), a surveillance system that collects interview and medical record abstraction data among adults with diagnosed HIV infection in the United States. Many of the tools and processes used for *MMP* can inform D2C activities and provide useful information on promising practices for locating and contacting persons identified as presumptively NIC. Finally, CDC has funded technical assistance providers to support health departments in areas such as confidentiality and data security, community engagement, quality of HIV surveillance data, data sharing, staffing resources, creating NIC lists, and evaluating D2C programs. These direct capacity-building efforts have resulted in development of tools and resources to support D2C program implementation. Taken together, these collective efforts are identifying practices that increase the likelihood that D2C strategies will have broad impact on improving HIV outcomes and will benefit groups disproportionately burdened by HIV.

FUTURE DIRECTIONS

In January 2018, CDC awarded funds to 61 U.S. health department jurisdictions through cooperative agreement PS18-1802: “Integrated HIV Surveillance and Prevention Programs for Health Departments”.²¹ Through this funding, health departments are expected to (1) implement a comprehensive and integrated HIV surveillance and prevention program to prevent new infections; (2) improve health outcomes for PWH infection, including achieving and sustaining viral suppression; and (3) reduce HIV-related health disparities in accordance with national prevention goals and CDC’s High-Impact Prevention approach by using quality, timely, and complete surveillance and program data to guide HIV prevention efforts. Conducting D2C activities is a key strategy required of health departments receiving PS18-1802 funds. This includes establishing data-sharing agreements with partners, sharing client-level data, and using available data sources to identify PWH who have not been reported in the surveillance system. CDC will collaborate with PS18-1802 recipients to evaluate their D2C programs; DHAP has devised an evaluation plan, with input from several health departments, to monitor implementation of D2C programs. Working with health departments, CDC will evaluate 3 outcomes: (1) health departments’ ability to use HIV surveillance and other data to accurately identify PWH who are not in HIV medical care; (2) linkage to HIV medical care among PWH who are confirmed, through D2C activities, not to

be in care; and (3) achievement of HIV viral load suppression among PWH linked to HIV medical care after being identified through D2C activities. CDC will use these evaluation outcomes to assess the effectiveness of D2C strategies, drive continuous program and system improvement; and work with health departments to improve overall project performance.

CONCLUSIONS

Data to Care is a promising HIV prevention and care strategy expected to enable health departments to move closer to achieving national HIV prevention goals.^{1,22} As with many new program efforts, there are relatively few published papers describing the implementation and effectiveness of D2C. This *JAIDS* Special Supplement explores how CDC funding to state health departments, and partnerships with other federal agencies, are advancing our knowledge of D2C. Given that many HIV surveillance and prevention programs in state health departments are just beginning to implement D2C programs, a better understanding of what does and does not work from programs that already have experience implementing D2C activities is of great importance. In addition, local health departments' ability to successfully implement D2C programs lies not only in the ability of HIV surveillance programs to accurately identify PWH in need of services, but also in the availability of dedicated, knowledgeable local staff who can provide culturally sensitive, appropriate outreach and medical services, and acceptance of the program by the community. Successful integration of HIV surveillance and prevention programs holds the promise of making D2C a powerful tool for achieving continuity of care, viral suppression, and improved health outcomes among PWH, with the end goal of no new HIV infections in the United States.

ACKNOWLEDGMENTS

The authors thank our partners at local and state health departments, collaborating HHS agencies, and other stakeholders who have been instrumental in advancing our knowledge of Data to Care. The authors also thank all members of DHAP's Data to Care Workgroup, and teams from the CAPUS, P4C, and PrIDE Demonstration Projects for their important contributions to D2C. In particular, The authors would like to acknowledge: Rakhat Akmatova, Mi Chen, Renata Ellington, Aba Essuon, Robyn C. Neblett Fanfair, Kathleen Green, Kristen Leigh Hess, Mariette Marano, Andrea Moore, Margaret A. Nyaku, Cynthia Prather, Tobey Sapiano, Renee Stein, and Kim Williams.

REFERENCES

1. The White House Office of National AIDS Policy. National HIV/AIDS Strategy for the United States: Updated to 2020; 2015. Available at: <https://www.hiv.gov/federal-response/national-hiv-aids-strategy/nhas-update>. Accessed April 23, 2019.
2. Cohen J. Breakthrough of the year. HIV treatment as prevention. *Science*. 2011;334:1628. [PubMed: 22194547]
3. Centers for Disease Control and Prevention. Effective interventions: HIV prevention that works. 2019. Available at: <https://effectiveinterventions.cdc.gov/en/data-to-care/group-1/data-to-care>. Accessed January 8, 2019.
4. Hart-Malloy R, Brown S, Bogucki K, et al. Implementing data-to-care initiatives for HIV in New York State: assessing the value of community health centers identifying persons out of care for health department follow-up. *AIDS Care*. 2018;30:391–396. [PubMed: 28791877]
5. Tesoriero J, Johnson BL, Hart-Malloy R, et al. Improving retention in HIV care through New York's expanded partner services data-to-care pilot. *J Public Health Manag Pract*. 2017;23:255–263. [PubMed: 27902561]

6. New York State Department of Health AIDS Institute. Partner Services Data to Care Report, New York State (excluding New York City) 2015. Albany, NY: New York State Department of Health. Available at: https://www.health.ny.gov/diseases/aids/general/statistics/docs/partner_services.pdf. Accessed April 22, 2019.
7. Buchacz K, Chen MJ, Parisi MK, et al. Using HIV surveillance registry data to re-link persons to care: the RSVP project in san Francisco. *PLoS One*. 2015;10:e0118923. [PubMed: 25748668]
8. Bove JM, Golden MR, Dhanireddy S, et al. Outcomes of a clinic-based surveillance-informed intervention to relink patients to HIV care. *J Acquir Immune Defic Syndr*. 2015;70:262–268. [PubMed: 26068720]
9. Wohl AR, Dierst-Davies R, Victoroff A, et al. The navigation program: an intervention to reengage lost patients at 7 HIV clinics in los angeles county, 2012-2014. *J Acquir Immune Defic Syndr*. 2016;71:e44–e50. [PubMed: 26484741]
10. Udeagu CC, Webster TR, Bocour A, et al. Lost or just not following up: public health effort to re-engage HIV-infected persons lost to follow-up into HIV medical care. *AIDS*. 2013;27:2271–2279. [PubMed: 23669157]
11. Sweeney P, Hoyte T, Mulatu MS et al. Implementing a data to care strategy to improve health outcomes for people with HIV: a report from the care and prevention in the United States demonstration project. *Public Health Rep*. 2018;133(2 suppl 2):60S–74S. [PubMed: 30457958]
12. Christopoulos KA, Scheer S, Steward WT, et al. Examining clinic-based and public health approaches to ascertainment of HIV care status. *J Acquir Immune Defic Syndr*. 2015;69(Suppl 1):S56–S62. [PubMed: 25867779]
13. Das M, Christopoulos KA, Geckeler D, et al. Linkage to HIV care in San Francisco: implications of measure selection. *J Acquir Immune Defic Syndr*. 2013;64:S27–S32. [PubMed: 24126446]
14. Enns E, Reilly CS, Virnig BA, et al. Potential impact of integrating HIV surveillance and clinic data on retention-in-care estimates and re-engagement efforts. *AIDS Patient Care and STDs*. 2016;30:409–415. [PubMed: 27610462]
15. Padilla M, Mattson CL, Scheer S, et al. Locating people diagnosed with HIV for public health action: utility of HIV case surveillance and other data sources. *Public Health Rep*. 2018;133:147–154. [PubMed: 29486143]
16. Ocampo JMF, Smart JC, Allston A, et al. Improving HIV surveillance data for public health action in Washington, DC: a novel multiorganizational data-sharing method. *JMIR Public Health Surveill*. 2016;2:e3. [PubMed: 27227157]
17. Lubelchek RJ, Finnegan KJ, Hotton AL, et al. Assessing the use of HIV surveillance data to help gauge patient retention-in-care. *J Acquir Immune Defic Syndr*. 2015;69(suppl 1):S25–S30. [PubMed: 25867775]
18. Harrison TP, Williams KM, Mulatu MS, et al. Integrating Federal Collaboration in HIV Programming: The CAPUS Demonstration Project, 2012–2016. *Public Health Rep*. 2018;133 (2 suppl):10S–17S. [PubMed: 30457950]
19. Williams K, Taylor RD, Painter T, et al. Learning by doing: lessons from the care and prevention in the United States demonstration project. *Public Health Rep*. 2018;133:18S–27S. [PubMed: 30457953]
20. U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Primary Health Care. Integrating HIV Care, Treatment & Prevention Services into Primary Care—A Toolkit for Health Centers. Rockville, Maryland: U.S. Department of Health and Human Services, 2017.
21. CDC-RFA-PS-18-1802, Integrated HIV Surveillance and Prevention Programs for Health Departments. Available at: <https://www.cdc.gov/hiv/pdf/funding/announcements/ps18-1802/cdc-hiv-ps18-1802-nofo.pdf>. Accessed January 23, 2019.
22. Fauci AS, Redfield RR, Sigounas G, et al. Ending the HIV epidemic: a plan for the United States. *JAMA*. 2019;321:844–845. [PubMed: 30730529]

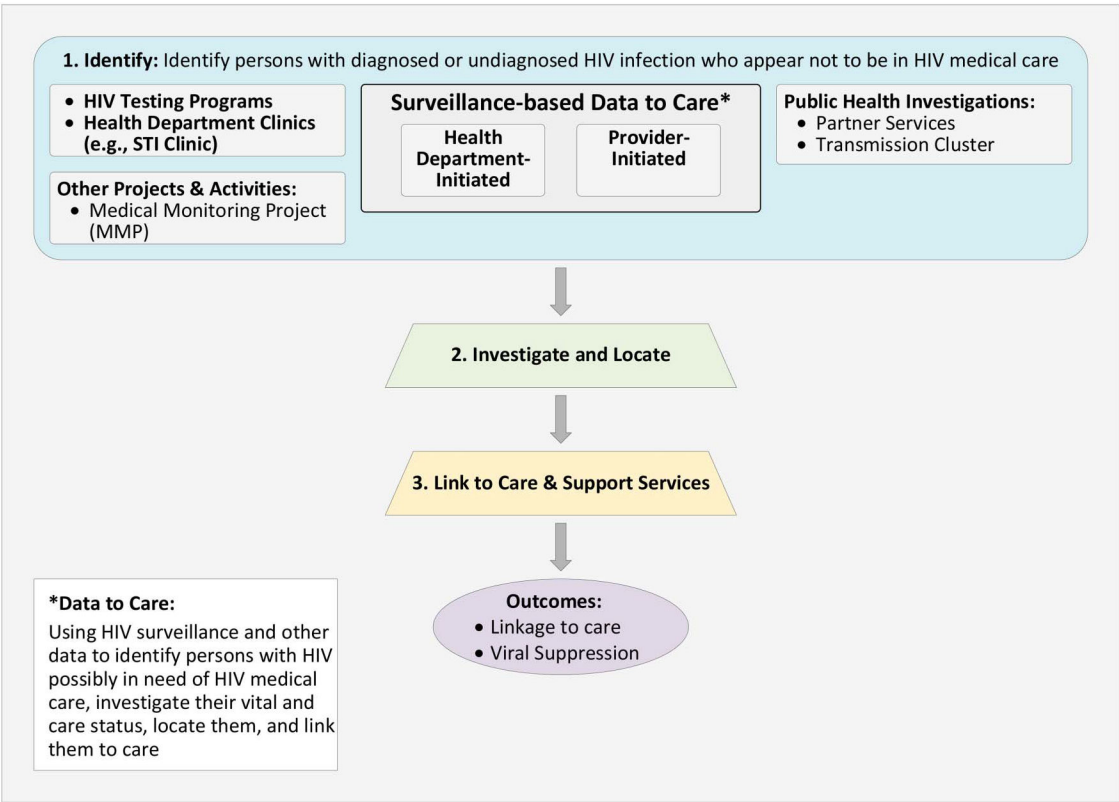


FIGURE 1.
A comprehensive HIV linkage-to-care program.

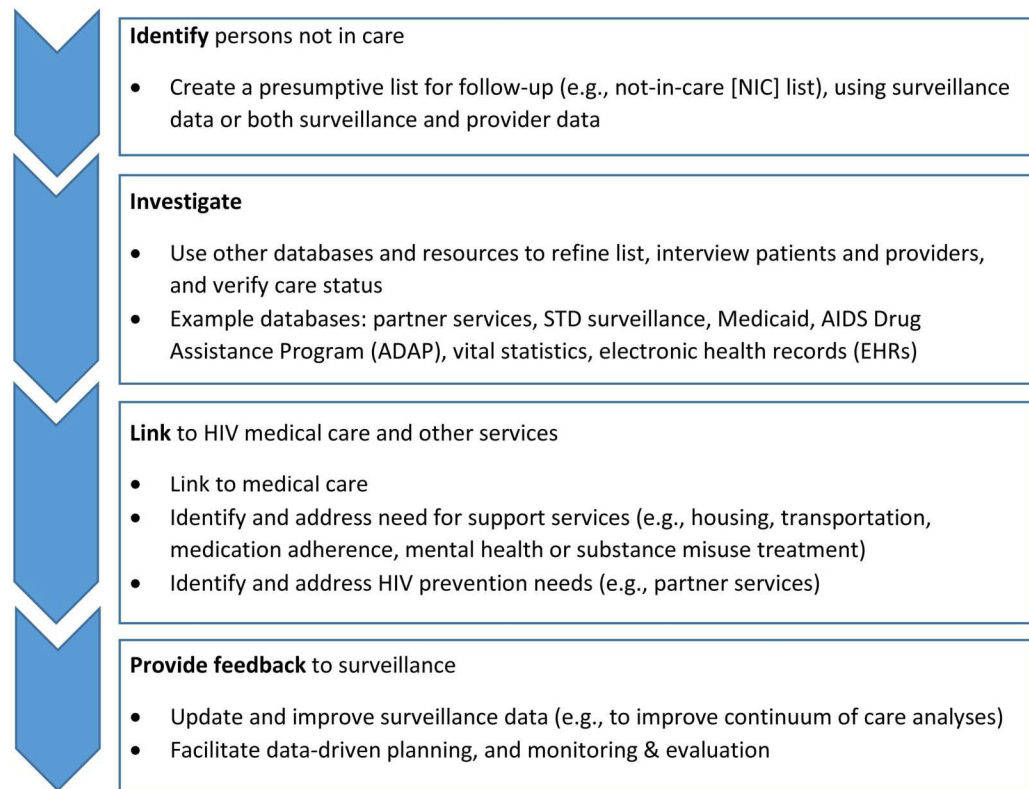


FIGURE 2.
Operational steps in data-to-care not-in-care programs.